EDITORIAL...

CERTAIN INALIENABLE RIGHTS

“HEALTH CARE IS A PRIVILEGE, NOT A RIGHT,” SAID A RECENT AMA PRESIDENT. AND HE WAS RIGHT. DESPITE ALL THE CONGRESSIONAL RHETORIC WRITTEN INTO HEALTH “NEW DEAL” LEGISLATION SUCH AS COMPREHENSIVE HEALTH PLANNING AND MEDICARE, HEALTH CARE REMAINS A PRIVILEGE TO BE EARNED THROUGH PAYMENTS OR OTHER SACRIFICES. IN FACT, AS THE RHETORIC OF HEALTH RIGHTS ESCALATES, MANY PEOPLE’S ACCESS TO HEALTH SERVICES IS DECREASING. SHRINKING BLUE CROSS COVERAGE [SEE BULLETIN, SEPTEMBER, 1969] AND TOUGHER MEDICAID eligibility limits [see BULLETIN, June, 1969] means that access to care is becoming financially out of reach for middle-income people as well as the poor. Accelerating specialization of health professional training means that there are fewer and fewer general practitioners to serve white neighborhoods, let alone black and Puerto Rican slums. The increasing numbers of people who can’t pay for care with money, must pay with their dignity—as training and research material in hospital wards and clinics.

The basic “health right” of access to care is a fiction. Even more nebulous are the rights of patients as individuals within the health care system. In theory there are laws which protect the patient’s privacy and give him a measure of control over what is done to his body. But these “patients’ rights” are so limited and untested that they have no significant effect on medical practice. Full explanations, even when the patient’s “informed” consent is required, are rare. Medical records are kept more confidential from the patient than the police. “Patients’ rights” provide no bulwark against growing medical repression in the form of stricter enforcement of drug abuse laws among young people or looser commitment proceedings for mental patients. Prisoners in jail can be labeled pathological for resistance. The police can intrude into emergency rooms to question injured suspects.

We live in a time of repressive reform: National reform programs, heralded as great leaps forward, are coupled with intensification of local repression of individuals. Such reforms as Medicaid, Medicare and comprehensive health planning are announced as the arrival of a new era of health rights. Yet, patients’ individual rights are violated more glaringly than before. With the increasing institutionalization of medicine into hospital-centered complexes, the possibility of personal medical care becomes more remote and the ability of individuals to hold professionals accountable becomes nearly impossible. Marginal increases in availability of medical care occur. But the old people and poor people who gained access to the medical system under these national reforms have often been disappointed with what they found. The concept of health rights without patients’ rights is vacuous.

Conversely, patients’ rights can mean nothing without full health rights for all. As long as health is not a right, as long as barriers to care can be raised or lowered at institutional or local legislative whim, who would dare press to make his paper “patient’s rights” real? The poor, non-paying patient would know better than to demand his rights as a patient from a doctor or a facility which could simply exclude him as a troublemaker. The paying patient would hesitate to shatter his fragile, fee-based, doctor-patient relationship with the threat of litigation. People’s rights as patients will mean nothing until people have the right to be patients—to enter the health care system.

The struggle for patients’ rights and health rights converge in the demand for consumer control of health services. The energy for this movement is largely derived from the denial of health as a right, although the specific issues are often violations of patients’ rights. The real issue is who controls health services. Will it be doctors with their research and teaching emphasis? Will it be hospitals with their costs and financing concerns? Will it be the police with their “law and order” medicine? As long as these forces have the power to define health and patients’ rights, the inequities and indignities of the present system will persist. Only consumer participation and control will result in medical services consistent with individual patients’ rights and full health rights for all.
The Health Rights Defenders

ALL POWER TO THE PATIENTS

HEALTH CONSUMERS ARE DEMANDING enforcement procedures to guarantee their rights as patients. The enforcement devices vary from community to community and institution to institution, ranging from informal patients' advocate personnel to formalized grievance procedures and special health councils. But the basic pattern is the same—efforts by health consumers or their representatives to enforce basic health rights by scrutinizing the daily functioning of medical providers and by trying to change the organization and policy decisions of health institutions.

These watch-dog efforts emphasize non-judicial (out-of-court) processes as opposed to traditional legal approaches. They acknowledge that the courts may be able to end some discriminatory practices or administrative abuses, but such matters as the proper allocation of medical resources (for example, between preventive and curative medicine) will ultimately depend on swaying consumer muscle. For instance, litigation may contribute to a legal definition of "informal consent," but the ideal of the professional as consultant rather than omnipotent witch-doctor will never become reality until the deliverers of medical services are pressed, on a daily basis, to recognize patients' rights within the doctor-patient relationship.

One of the first experiments in this new health rights movement was the 1967 summer Student Health Organization (SHO) project, which stationed medical students as patients' advocates at Morrisania Hospital in the Bronx. The medical students, with little knowledge of or access to the hospital, and even less familiarity with the patients and their problems, were given the task of enforcing amorphous standards of health rights through totally undefined channels. The students' effectiveness was further restricted by their inability to follow-up patients' rights violations during their short (two month) program. Descriptive reports by the students disclosed numerous cases of callousness, bureaucratic inefficiency and abuse of human dignity, but little could be done at the time to grapple with these problems. As a result, the project has been branded by one observer as a "good learning experience" for the students, but of little benefit to the patients. Both Dixwell Legal Rights organization in New Haven and The Martin Luther King Health Center (MLK) in the Bronx have subsequently avoided using medical students as patients' advocates.

A more successful patients' advocate program has been conducted for the past 9 months at Yale-New Haven Hospital by the Dixwell Legal Rights organization. Dixwell hired and trained Mrs. Celeste Williams to serve as a patients' advocate within the hospital. Mrs. Williams was eminently qualified for her task since she lived in the community and had 13 years of medical experience as a practical nurse as well as 10 months of legal advocacy training from Dixwell.

Mrs. Williams has, up to now, been serving in less than ideal circumstances. At the outset she faced the overwhelming task of covering over 700 inpatients at Yale-New Haven Hospital. Initially the hospital provided only a small office, inaccessible to patients and subject to considerable noise and staff intrusion. No efforts were made to publicize Mrs. Williams' presence or her potential usefulness to patients. More importantly, the hospital failed to acknowledge or establish any standards of patients' rights to which it could be held; nor did it institute any standard procedures or channels by which Mrs. Williams could officially press patients' claims. (The standards problem should be alleviated by publication of a patients' rights manual prepared by students taking part in a 1969 summer VISTA project at Yale-New Haven.)

Despite these barriers, Mrs. Williams has assisted numerous patients and obtained meaningful results on an individual case, if not institutional, basis. She has reached her clients by circulating through the wards and communicating directly with patients. Cases are handled on an ad hoc basis, but usually simple consultation with the physician or other staff personnel involved, or a conference between the patient (assisted by Mrs. Williams) and staff person, is sufficient to straighten things out. Most of the complaints concern problems of informed consent and privacy [see "Violations," Page 7]. Patients are often baffled by cursory explanations of medical terminology, such as "hysterectomy," or are intimidated when a doctor is trailed into the room by a herd of students or interns whose identity or function is never revealed. In these areas Mrs. Williams has achieved satisfactory results by approaching the physicians involved, even without the support of an official enforcement mechanism or threat of sanctions. But her advocacy procedure alone is not likely to accomplish change on an institutional level and Mrs. Williams has not attempted to operate on that plane.

The Missing Link

One of the missing links in the Dixwell program is an active patients' organization. Coler hospital in New York City provides three examples of patient groups which represent a spectrum of health rights activities. The Patient's Committee chaired by Mr. John Whitten is the most cautious and conservative group. It operates largely as a "group patient advocate" for individual patient grievances. The Patient's Committee "sees that patients are taken care of right," says Mr. Whitten, and "that they have enough clothes, warm food, and visits outside during the summertime." The group has taken on this conservative contour partly because it draws from the most handicapped patients and partly because it relies heavily on the Social Service Department of the hospital. It is no coincidence that the least mobile patients represented heavily on the Social Service Department of the hospital. It is no coincidence that the least mobile patients represented...
Patients Raise Issues

However, it is the Patients’ Service Corp that really acts on this premise. Admittedly the most activist-oriented patients’ organization at Coler, the Patients’ Service Corp is willing to take stands which are not popular with the hospital administration. This posture was evident when the Patients’ Service Corp went to court over the issue of Social Security checks. The Catalano Case, as yet unsettled in court, challenges the assumption that patient groups can take. But the limitations of each group are apparent. Without an explicit code of patients’ rights is difficult. Without a role in policy-making process through collective action. Of course, the hospital administration has tried to co-opt this small group of resisters by offering to increase the personal allowance to $45

"consumer councils,” and the health system has a good deal more public accountability than the faceless American non-system.

Easy to Complain

The grievance form is a simple one-page document which explains that Mr. Wynn is available to serve as a patient’s advocate. It is accompanied by an explanation of the grievance procedure. Mr. Wynn will follow, which consists of a three-stage process (reminiscent of innumerable labor contracts) calling for meetings at three levels—with any staff person involved, with the employee’s supervisor, and finally with the project director, if prior satisfaction is not obtained. There is a fourth provision in the procedure which enables Mr. Wynn to go directly to the project director to seek changes in the overall system when several patients have voiced similar complaints.

An obvious question is what happens when the administration (i.e. the project director) simply refuses to offer satisfactory redress, whether the issue be an individual complaint or a change in the system. Since the patients’ advocate program is primarily the work of Liery Wynn, a community resident who is a member of the Health Advocacy Department of the Bronx neighborhood health center. Mr. Wynn had a year’s training and experience covering both medical and legal problems, which prepared him for his role as patients’ advocate.

As first steps in his program, Mr. Wynn has drafted a patients’ rights manual, a grievance form and a grievance procedure, all designed for mass distribution to MLK registrants. The rights manual covers the normal spectrum of patients’ rights including privacy, confidentiality, and consents, but makes extraordinary efforts to define them in concrete terms. For example, “confidentiality” includes the right to approve in advance letters which contain information about the patient, and “consent” means that the patient may decline to participate in medical or social research. In addition, certain rights peculiar to MLK, such as the right to have assistance in dealing with Medicaid and the right of incapacitated patients to receive transportation to the facility, are outlined.

Beyond The Fog

From a small office in the north of London, a dynamic woman named Helen Hodgson guides a consumer council for health called the Patients Association. Acting as a clearing house for patients’ complaints about doctors or hospitals in the National Health Service, the group helps sue teaching hospitals, helps patients change doctors or lodge complaints, writes letters to the Lancet (a medical journal) and to the London Times championing patients’ rights.

One outcome of the Association’s activities has been the requirement that all hospitals give out a leaflet outlining patients’ rights and the further requirement that no patients be used as teaching material without their specific consent.

The English Health Service makes such a group’s activities easier than in the US. There are many precedents for “consumer councils,” and the health system has a good deal more public accountability than the faceless American non-system.

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East Harlem's Health

On September 16, 1969, the Young Lords Organization, a revolutionary Puerto Rican youth group, presented the following 10-point program to the East Harlem Health Council. After discussion of the points the Council voted unanimously to adopt and work for the implementation of the program:

1. We want total self-determination of all health services in East Harlem (El Barrio) through an incorporated Community-Staff Governing Board for Metropolitan Hospital. (Staff is . . . everyone working at Metropolitan.)
2. We want immediate replacement of all Lindsay and Terenzio administrators by community and staff-appointed people whose practice has demonstrated their commitment to serve our poor community.
3. We want an immediate end to construction of the new emergency room until the Metropolitan Hospital Community-Staff Governing Board inspects and approves or authorizes new plans.
4. We want employment for our people. All jobs filled in El Barrio must be filled by residents first, using on-the-job training and other educational opportunities as bases for service and promotion.
5. We want free publicly supported health care for treatment and prevention; WE WANT AN END TO ALL FEES.
6. We want total decentralization of health — block health officers responsible to the Community-Staff Board should be instituted.
7. We want "door-to-door" preventive health services emphasizing environment and sanitation control, nutrition, drug addiction, maternal and child care, and senior citizen's services.
8. We want education programs for all the people to expose health problems—sanitation, rats, poor housing, malnutrition, police brutality, pollution, and other forms of oppression.
9. We want total control by the Metropolitan Hospital Community-Staff Governing Board of: budget allocations, medical policy along the above points, hiring, firing, and salaries of employees, construction, and health code enforcement.
10. Any community, union or workers organization must support all the points of this program and work and fight for them or be shown as what they are—enemies of the poor people of East Harlem.

POWER

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and ultimately to the patient population. Presently Mr. Wynn has been meeting with MLK personnel, including the acting project director, to explain and secure commitment to the rights articulated within the manual. The theory is that personnel consulted in advance are more likely to cooperate, to act as ultimate arbiter in the grievance mechanism. If the lay members resisted domination by the professional forces, this structure would be adequate to deal with individual complaints of professional or institutional abuse of rights.

But many aspects of health care delivery are affected by the initial policy decisions of the interests which control health institutions. The scope of medical services, the hours of operation, and the delineation of the service area all depend on policy decisions. Moreover, such intangible aspects of health rights as respect for patients' dignity may be influenced tremendously by the attitude of administrative forces. In light of these facts, consumer impact on policy-making looms as an important immediate goal of the health rights movement.

Consumers Find Openings

Perhaps the most accessible openings for consumer impact, and ones which have already received some attention, are the OEO and Public Health Service-funded neighborhood health centers which dot the country. OEO guidelines dictate that such institutions form either governing boards or advisory committees composed of at least one-third "democratically selected representatives of the poor." Most of these centers do have "advisory" bodies composed of better than 50 percent community people; many, such as NENA, Martin Luther King, and Red Hook in New York City, have boards entirely made up of health consumers.

The difficulties experienced by such boards in influencing the institutional structure of health derive less from the board composition than from the complex power relationships between the board, the project director and the sponsoring institution. Usually government funds go to a "sponsor" hospital or medical school which, after extracting a sizeable chunk for overhead, funnels the money to the neighborhood health center. The sponsor helps assemble the medical staff and provides back-up services, including in-patient facilities. Through control of the purse strings the sponsoring institution retains ultimate control over the neighborhood health center. Some sponsors may be content to assume a benevolently passive role, allowing the health center to appear autonomous. Yet the institution always stands as a sword of Damocles ready to descend upon any center which strays from a traditional course. As long as the sponsor has the power to hire and fire the project director its presence is constantly felt. And because a comprehensive health care center is generally dependent on back-up services and emergency funds, it is tough to operate without a sponsor. Only in a few instances (notably NENA on the Lower East Side and Hunt's Point in the Bronx) have funding grants for neighborhood centers gone directly to community bodies.

Even where there is no formal sponsor, or where the sponsor accepts a passive role, community boards may be impeded in exercising control by confusion over the allocation of authority between the board and the project director. Customarily, the project director assumes responsibility for "administrative" matters while "policy" decisions are left to the board. The term "administrative" decision is fuzzily defined, if defined at all. And it is the project director who determines in the first instance what constitutes an administrative decision which does not require consultation with the advisory board. As a practical matter, then, broad discretion is vested in the project director; as a matter of good faith he may choose to "consult" with the board on many occasions. However, any effort by the board to be assertive
IN YALE-NEW HAVEN HOSPITAL a woman waited in a clinic two and a half hours to see a doctor. She complained of being tired and believed it was because of a blood deficiency since previous tests had indicated that she had such a problem. The doctor took some blood to be tested. She sat and waited an hour for the results. When the results finally came, the doctor told her there was nothing wrong and gave her some pills. After she had left, the doctor told the student-observers what he had failed to tell the patient: that the tests indicated an overdose of tranquilizers, which probably explained her tired feeling.

In A New York City Hospital emergency room, a woman dressed in a hospital gown sat in bed, with her husband sitting on a chair next to her. The draperies which could be pulled around the four beds in the ward remained open. Diagonally across from and in full view of the couple was a man in his undershorts being examined by a doctor. Behind closed drapes, but fully audible to the couple, a doctor was examining another patient. The doctor’s voice could be clearly heard as he asked, “Where does it hurt? How are your bowels? When did you have intercourse last?” Next to the couple, a male patient was being asked by a nurse, “Who can come and pick you up? Do you have a social worker? What about your family?”

In The Record Room of another New York City hospital a policeman asked for information from a patient’s record. One of the record room attendants presented the record to the policeman without requesting a written consent from the patient.

At The Jewish Chronic Disease Hospital of Brooklyn, two doctors injected live cancer cells into 22 debilitated patients without the patients’ voluntary and informed consent. The experiment was financed by the US Public Health Service and the American Cancer Society and was part of a project aimed at discovering ways to build up immunity against cancer.

Modern medical care occurs increasingly in institutions. Even for middle class whites, hospitals have become the physician of last resort, particularly at night time. For most inner-city poor people outpatient clinics and emergency rooms are “the family doctor.” Institutionalization has meant impersonal and non-individualized medical care: that is, increasing violations of the patients’ rights of both middle and low income patients. Patients are often treated as objects of the learning or research process rather than as people needing individualized care. In some hospitals and health care settings, patients and patients’ advocates have made some headway against the growing monolith [see “Power to the Patients;” Page 2] but for most patients, definition of rights is still a first step to be taken.

Through legal research, interviews with various medical and legal professionals, and discussion groups, HEALTH-PAC has been exploring the concept of patients’ rights by focusing on the hospital ambulatory care setting. A broad set of rights which patients can and should demand has been identified. Some of these rights are based on legal precedent. Others, as yet relatively untested in the courts, are only now being recognized as rights.

HEALTH-PAC is preparing to publish a patients’ rights manual for the hospital ambulatory care setting—for use by community and patient organizations and as a guideline for house staff. The manual will deal with such issues as informed consent, confidentiality, privacy, and the patient’s right to complain. Their effectiveness is limited, however, by lack of clearcut procedures and by the fact that the community board members have little time to devote to investigation of complaints and surveillance of practices. The impact of such boards on patients’ rights has primarily come through efforts to ensure responsive personnel and comprehensive medical care. By asserting a more active role in defining and deciding “policy” matters, these boards can hope to set institutional policies which will affect such patients’ rights matters as confidentiality and privacy. And they can certainly govern the allocation of resources within an institution to promote responsiveness to community wishes.

Assertion of patients’ rights, even if accompanied by consumer control of institutions, will not end the dual system of health care or resurrect national priorities to solve the health underfinancing problem. Yet the health rights movement must continue to press for non-judicial enforcement mechanisms under a consumer controlled system. This will bring short run benefits to individual patients, and more importantly, will generate community energy for the long run task of reconstructing the health system around the patient rather than the institution.

—Oliver Fein, M.D.
—Norman Cantor
Attorney, Advocacy Division, MLK Health Center

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information concerning his illness.

The right of a patient to have nothing done to him without his informed consent is one of the most basic patient's rights. To most people, consent means only a signature giving permission for a procedure to be performed. The requirement that consent be informed consent, however, is crucial. It was most sharply articulated in the code adopted by the United States Military Tribunal at Nuremburg as a standard against which to judge German scientists accused of committing medical atrocities. The same standard has been adopted by American courts with respect to experimentation on human beings. The code states that only a freely given consent by a legally competent person, or in some cases his legal representative, based on comprehensive knowledge of the "nature, duration, purpose, methods and means . . . all inconveniences and hazards reasonably to be expected, and effects which may possibly occur" would be proper consent in experimentation.

Generally the patient has the right to receive sufficient information regarding the proposed treatment to enable him to determine intelligently whether to consent to the treatment or exercise his right not to be treated. The physician has the duty to provide that information. If he fails to provide it, consent obtained from the patient will not be informed consent and the doctor or hospital can be sued. The concept of informed consent is central to all legal regulation of research on human beings. The two doctors who injected live cancer cells were punished not because they conducted an experiment that harmed their patients but because they failed to obtain informed consent before injecting their patients with live cancer cells.

Experimentation, however, is only one area in which informed consent is required, and is perhaps the area which is least violated. Informed consent must also be obtained from patients for the following: all major and minor operations, any procedure requiring anesthesia; anything that involves more than a slight risk of harm or a risk of changing the body structure; any time cobalt or X-ray therapy is used; and any time electroshock therapy is used.

Though all of these situations require informed consent, courts in different jurisdictions disagree as to exactly what and how much information must be given in order for the consent to be "informed." It is therefore always advisable for a patient to ask his doctor questions and demand clear answers. Only if the patient understands completely what is going to be done, will his consent be "informed" consent.

The doctor-patient trust is perhaps even more often casually breached in the realm of "confidentiality." The oldest of all medical vows, the Hippocratic Oath, binds the doctor to confidentiality: "I respect the privacy of people I serve. I use in a reasonable manner information gained in professional relationships." But the confidentiality of communications between the patient and the doctor is even more rigorously protected by law. Thirty-three of the States have enacted laws to protect the patient in this area. New York's statute reads as follows: "Confidential information is privileged. Unless the patient waives the privilege, a person authorized to practice medicine or dentistry, or a registered professional or licensed practical nurse, shall not be allowed to disclose any information which he acquired in attending a patient in a professional capacity, and which was necessary to enable him to act in that capacity." Statutes of this nature are intended to enable the doctor to obtain the greatest possible information from the patient, so as to be able to properly treat him, and to assure the patient that the intimate details he brings to his physician will not be disclosed to others. Such confidentiality is usually respected with regard to verbal communications. Hospital records present another problem. Frequently, the patient's record is made available to police and to insurance companies without adequate safeguarding of the patient's privacy and the confidential nature of the communications in the record. This, however, is as much a violation of confidentiality as if the doctor told the police or the insurance company what had transpired. A patient's record in a hospital is legally the property of the hospital rather than the patient. This often results in the curious situation that patients have trouble seeing their own records. Thus they have no way to check that the doctor recorded what they said; they have no way to check if the doctor left out of the record what they wanted left out, and they have no way of determining whether it would help or harm them to allow the police or insurance companies to see the record. For although the hospital owns the record, the patient has the right to approve, through formal consent, any attempt by a third party such as the police to examine the record. If the hospital does release a record without the patient's express consent, and if the patient's interests are harmed because of it, the patient can sue. The limitations of this legal protection of confidentiality are revealed in Section 9 of the AMA Medical Ethics: "A physician may not reveal the confidence entrusted to him in the course of medical attendance, or the deficiencies he may observe in the character of patients, unless he is required to do so by law or unless it becomes necessary in order to protect the welfare of the individual or of the community." Therefore, when the Medical Committee for Human Rights' medical records were subpoenaed by the House Un-American Activities Committee after the Chicago 1968 protest, confidentiality was no legal bar to their release.

The right of privacy is closely related to that of confidentiality. As it is recognized in law, privacy is the right to be protected from mass dissemination of information pertaining to one's personal or private affairs. The right exists either by statute or common law, but not in all states. To be a basis for a legal suit, the invasion of privacy must be done in such a manner as to cause outrage or mental suffering, shame or humiliation to a person of ordinary sensibilities. Doctors and hospitals can be held liable under this law, if they are responsible for the unwarranted intrusion into the private affairs of a patient. Therefore, an individual patient's medical problems should not be discussed in the presence of other patients nor should the patient's body be unduly exposed to others. During medical examinations a patient may request that third persons be excluded from the examination. Third persons include police and anyone else not necessary to help

HEALTH-PAC now has a legal arm. Through the NYU Vista Lawyers program, Ken Kimberling has joined the HEALTH-PAC staff. A 1969 graduate of Columbia Law School, Ken will be working on a masters degree at NYU and spending the rest of his time developing the HEALTH-PAC patients' rights project and investigating environmental health hazards in New York City.
Under the Law:

CHARTING THE UNCHARTED

WHAT ARE THE "LEGAL RIGHTS" of the citizen who seeks health benefits? The answer to this question will determine, in large measure, the quantity and quality of life for the majority of Americans. Yet there has been virtually no serious, sustained legal work to develop clear answers. Most socially-aware lawyers do not even know the issues that arise from health-related statutes and regulations. What little legal work has been done has been largely unrelated to the newly budding organizational and political work in the health area.

In short, we are on a long way from being able to define health rights. But we are able to discern the main legal-social issues upon which the development of health right rests, and project the kind of approaches and work through which legal professionals and others can help create health rights. We are, with regard to health law, about where we were with regard to welfare law four years ago. The basis for creative legal work exists, but the work remains to be done.

Three overall kinds of “rights” in the health area can be distinguished: (1) the right to medical benefits and services; (2) the right to equal treatment within medical facilities and equal protection under health law; (3) the right of the health consumer to control the nature of the services given to him. Each of these issues is clearly inter-related with the others. A legal or social breakthrough on any one of them advances the possibilities for breakthrough on the others.

In the statutes there are a wide variety of health benefits laws, two leading examples of which are the Medicaid and Medicare titles of the Social Security Act. If one takes the statutory and regulatory language of these laws plus the health policy statements that have been issued from the President’s office over the years, it is not an exaggeration to say that American “public policy” purports to safeguard the health of all citizens. But, of course, this policy is rendered almost meaningless by enormous gaps in statutory coverage and arbitrary local administration of the laws. The scattered legal activity now taking place around the country, indicates some of the problems and possibilities.

For example, in the case of Loredo v. Sierra View District Hospital (California), where the hospital imposed a quota system on Medicaid patients (fearing a “flood” of poor patients), a State court held that the quota violated the Equal Protection Clause. Another suit, Reilly v. Wyman, has resulted in a temporary restraining order from a Federal court, halting a Medicaid income computation procedure which might have disentitled thousands of New Yorkers [See Box, Page 8]. In Washington, D. C., there was little private hospital participation in Medicaid until issues regarding the nonconformity of the D. C. Medicaid plan with the Federal requirements (coupled with a political campaign) were raised with HEW.

There has been little attempt to apply the results of these cases to other locales in the country. In fact, in no state do Medicaid or Medicare applicants get a clear, written statement of their rights under the program. Nor has there been analysis of most of the larger statutory issues. For example, we are now undergoing a period of cut-backs in the level and scope of eligibility for Medicaid in many states. How consistent are such cut-backs with the Federal requirement that the States proceed with the development of “comprehensive care and services” as a condition of Federal aid? We need to stop assuming that the decisions of State Legislatures in this area are “legal.” Lawyers stopped assuming that in welfare law some time back, and benefited greatly.

What about the “right,” under Federal law, of Medicaid patients to the use of a doctor or facility of their own choice? In some cities, there is good reason to believe that, through a type of “gentleman’s” agreement, Medicaid patients are referred only to certain public institutions while other institutions, also the recipients of public money, are “spared.” Insofar as the local government and public hospitals cooperate in such agreement, are they circumventing the right of the patient to choose his own facility? In any event, how different is this situation from the Loredo case mentioned above?

What about medical institutions which refuse to extend emergency services to sick people? Hospitals built with Federal (Hill-Burton Act) funds are among those guilty of such practices. Hill-Burton hospitals are not free to accept or reject patients, without restraint. But lawyers have not yet begun to seriously examine the potential use of the Hill-Burton Act in preventing discrimination in emergency—and maybe even nonemergency—services. How about the tax exemptions which such institutions (whether built with Hill-Burton funds or not) receive? Are they really carrying out their “charitable” missions?

The list of practices legally questionable under our present statutes will grow as lawyers and law students begin to engage themselves in the right to health. Consider some of the issues raised by Larry Silver, director of the newly established National Legal Program on Health Problems of the Poor (at UCLA in Los Angeles):

“Almost totally unexplored are the legal remedies available to the indigent against health hazards in the environment which peculiarly

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affect the poor, or concerning which groups of poor individuals have an identifiable and real interest. For example, migrant workers are exposed to health hazards by virtue of the excess of use of pesticides. Do the Federal standards established under the Federal Rodenticide, Pesticide, and Pesticide Act—for the violation of which there are criminal remedies—give rise to civil acts? What rights might be conferred upon poor people who because of patterns of zoning, etc., might be exposed to conditions of environmental pollution which violate Federal standards or state compacts? Inadequate in administration as our present statutory health benefit programs are, their worst consequence flows from the total exclusion of whole groups of people who are as needy and as ill as the individuals who are covered. Consider, for example, the plight of an ill, impoverished, and unemployed 60-year old woman who—as is the case in many states—is eligible for no benefits whatsoever under the Medicaid program. Yet her 65-year old sister will get benefits under Medicaid. She is eligible for no benefits whatsoever under the Medicaid program. Yet her 65-year old sister will get benefits under Medicaid. Suppose the local hospital will not admit the patient because it has absorbed its quota of non-paying patients. Is she to simply lie down and die? In the area of welfare, exclusions from aid for various narrow, arbitrary reasons have been struck down on the basis of the Equal Protection Clause of the Constitution. The Federal courts are subjecting "crazy-quilt" patterns of inclusion and exclusion to an increasingly careful scrutiny. For example, a three-judge Federal court recently held that a statutory differential of $5 in welfare aid between needy people in Nassau County and New York City was patentely arbitrary and violative of equal protection. The court, in Rothstein v. Wyman (August 4, 1969) noted that:

Receipt of welfare benefits may not at the present time constitute the exercise of a constitutional right. But among our Constitution's expressed purposes was the desire to "insure domestic tranquility" and "promote the general welfare." Implicit in those phrases are certain basic concepts of humanity and decency. One of these . . . is the desire to insure that indigent, unemployed citizens will have at least the bare minimums required for existence, without which our expressed fundamental constitutional rights and liberties frequently cannot be exercised and therefore become meaningless.

Medical treatment for a sick person is surely among the bare minimums required for existence. It is time to start an equal protection assault on the crazy-quilt exclusions from medical benefits. Such an assault should be by no means be limited to the courts. Legislatures also have a duty to enforce the Constitution. Equal protection by the health laws—and equal opportunities for all citizens to live—should be a political rallying cry.

Equal protection should apply not only to exclusionary patterns in benefit programs, but to unequal methods and kinds of treatment within our health facilities. Consider the "dual system" of medical care that exists in so many of our hospitals. The comfortable private pavilion for the rich. The ward or quasi-ward for the poor. The extra long waiting periods—whether for x-rays or what-have-you (usually the poor patient is not even told what he is waiting for). The committed, personal doctor for the well-to-do. The changing staff "committee," including students, for the poor. Duff and Hollingshead's Sickness and Society (Harper and Row, 1968) provides a first-rate sociological description of the "dual system" in one major medical center (Yale-New Haven Medical Center).

The Equal Protection Clause applies to major hospitals today, even those labeled "voluntary." A well-documented court action in a northern city directed against a hospital system similar to Yale-New Haven might deeply shake the entire medical delivery system. Almost inviting such an action are the requirements of the Medicaid program. As stated in the Federal regulations:

The Congress has made very clear its intent that the medical and remedial care and services made available to recipients under Title XIX be of high quality and in no way inferior to that of the rest of the population.

Lawyers are only beginning to seek out, define, and protect the patient's status vis-a-vis his doctor or hospital. [See "Patient Power," Page 2.] The patients' right to know his diagnosis and control what is done to his body is fundamental to a proper professional-citizen relationship. Medical theorists frame objections to patient knowledge and control in some situations, usually based on paternalistic concepts of the "best interest" of the patient. But callousness and bureaucracy explain many more situations. The right of the patient to confidentiality in regard to his medical files is recognized by medical ethics (subject again to "best interest" exceptions), and some statutory and case law. But, even in the prestigious Yale-New Haven Medical Center, as recently as July, 1968, in the Center's written rules, record room personnel were directed to disclose records to uniformed policemen upon their request. Concepts of privacy, budding anew in the law and our society, are recognized at times by individual doctors or hospital administrations as a concession.

Cutback and Cutoff

Surprisingly, in this summer of cutback and cutoff, the consumers' right to medical care received a small boost from the Federal District court.

At issue is the "co-insurance" provision of the Medicaid cutbacks, a particularly vicious cutback that means that medically indigent people will now have to pay the first 20 percent of their outpatient expenses themselves. For those medically indigent people who have chronic medical problems and thus frequent medical expenses, this cutback is a major disaster.

On June 26, four days before the new law was to take effect, the Columbia Center on Social Welfare Policy and Law went to court. Representing several plaintiffs who have chronic medical problems, they argued that the new law would force these people to use up all their money and thus drive them onto welfare. They also argued that by denying previously available services to some people but not to others, the new provision violated the legal doctrine of "equal protection under law." On July 2, the Court granted a temporary restraining order prohibiting the State Department of Social Services from implementing the co-insurance provision.

There are still several stages of legal battle before the end of the case, and the final outcome is not clear. Meanwhile, however, the temporary restraining order is still in effect and the co-insurance provision has not been implemented so that patients are still receiving full coverage under Medicaid.
Voluntary Hospitals Plead Bankruptcy

LAST SPRING IT WAS THE MUNICIPAL HOSPITALS. Now it's the voluntary (private, nonprofit) hospitals' turn for a fiscal crisis. Thirteen voluntary hospitals serving low-income areas are threatening serious cutbacks in service and even closings—if funds aren't found fast to make up for vanishing Medicaid revenues. Like many other "private" hospitals, these 13 had gotten hooked on Medicaid. Philanthropy, the traditional solace of hospitals in distress, was no help this time. It can no longer be counted on to pay for more than about 2 percent of the average "private" hospital's operating costs. In early September, the United Hospital Fund, the voluntary hospitals' "Christmas Club," which dispenses philanthropy and policy to its 78 member hospitals, demanded an "immediate emergency infusion" of City money. (The United Hospital Fund, which had watched silently while Medicaid and the City hospitals' budget were cut last spring, did not offer to redistribute its own funds to help out the 13 hard-pressed ghetto-based hospitals.)

Two months before the mayoral election is as good a time as any to announce a crisis, but the crisis itself was guaranteed six months ago when the State legislature (1) cut 200,000 people off the Medicaid rolls, and (2) froze Medicaid reimbursement rates to hospitals at their 1968 levels. The effect of the cutbacks in people—over a million since 1968—has been to make hospitals leery of the city's estimated two million "gray zone" people, who are too "rich" for Medicaid, too young for Medicare, and too poor to pay for their own care. The effect of the rate freeze has been to make Medicaid patients almost as unattractive to hospitals as the non-Medicaid poor, because 1968 Medicaid rates don't cover 1969 costs for care. Many voluntary hospitals report that they are losing up to $30 a day per Medicaid inpatient.

No one called it a "crisis" at the time, but many voluntaries started cutting back on services even before the Medicaid cutbacks were signed into law. One tactic that savings-minded voluntaries have employed is to gerrymander their outpatient catchment area—the area from which they will accept clinic patients—to cut out high-poverty neighborhoods. This amounts to de facto patient dumping to Municipal hospitals. A second, perhaps more widespread measure, has been job freezes, since the turnover of hospital workers is notoriously high, a prolonged job freeze is just a slow way of closing a hospital.

Quiet retrenchments, like gerrymandering and job-freezing, are not aimed at solving anybody's problems except those of the hospitals themselves. Only recently have the voluntary hospitals taken any dramatic, publicly visible measures, aimed at actually winning new funds. Knickerbocker Hospital in Harlem, St. Mary's in Bedford-Stuyvesant and several other hospitals announced that they have been literally living on borrowed time since last spring and will close unless funds are found to meet their bank debts as well as operating expenses. Bronx-Lebanon Hospital has already closed down its Concourse clinic. Gouverneur Ambulatory Care Unit, a Beth Israel affiliate on the Lower East Side, faces the lay-off of 96 employees, which could mean a 25-30 percent reduction in services.

The voluntary hospitals may have what they call "a sacred trust," but they have no legal commitment to serve the poor or anyone else. If they threaten to close, they can follow up by closing. In fact, for many of the ghetto-based voluntaries, drained by years of underfinancing, the present fiscal crisis may provide a long-awaited excuse to close up shop for good. In the past 15 years, the original white constituencies of the voluntaries have migrated out from under them, leaving the hospitals with black and brown patients ethnically unrelated to the hospitals' founders. For instance, the Federation (Continued Page 10)

We have yet to place a legal road block between the patient's living body and its needless exposure or its constant handling and poking for "teaching" purposes.

Going beyond the individual consumer, the entire community's relationship to the medical facility needs to be re-defined. Lay boards are legally vested with policy-making powers in most hospitals. Few such lay boards include representatives of the slum communities which surround many of our largest hospitals. Basic decisions on social policy—for example, whether to extend emergency room service or develop certain new research efforts—are made without any input from the community. Legal handles to open hospital boards to the local consumer barely exist. (They depend on social pressures on the hospital, aimed at concessions through negotiations. Handles thus developed become a weapon for further pressure.) Legal ways of ensuring participation in OEO neighborhood health facilities are easier to find, but lawyers and organizers have usually failed to exploit them.

Equally important in the long run, is the right of organized consumer groups to enter into and control health planning programs, as such control will determine whether planning programs serve democratic or narrowly defined professional interests. Comprehensive Health Planning statutes have barely been implemented. Yet, they could be of far-reaching importance. Under the statutes and HEW regulations, there are provisions for consumer participation which may provide significant handles—if utilized.

What part can legal action—and lawyers generally—play in the struggle for health rights and patients' rights? In the first place, the development of health "rights" cannot be segregated into "legal" versus "social" or "political" efforts. "Test cases" have an important role to play in providing support for social action and political efforts, of some impact, affect the outcome of "test cases." Second, the lawyer has an extremely important role to play in aiding the development of health consumer groups. He can supply, among other things, the technical openings through which such groups can win initial victories and around which—in some instances—they can organize. Third, the rhetoric of health rights as laid out in Federal legislation—the right to decent medical treatment, the right to equal protection, etc.—is fundamental to the creation of legally enforceable health rights. Finally, the possibilities for combined legal and social movement in the health area exist now. Indeed, such forward possibilities may well be more ripe today in health than in any other major social area.

—Edward V. Sparer

EDITOR'S NOTE: Mr. Sparer, Associate Professor of Law, Univ. of Penna., conducts a seminar on the health system for law and medical students. One of the developers of welfare rights law, he founded Columbia's Center on Social Welfare Policy and Law.
Voluntary

(From Page 9)

of Jewish Philanthropies might be just as happy to lose Bronx-Lebanon and concentrate its funds elsewhere. Catholic Charities may have no further interest in maintaining St. Mary’s in all-black Bedford-Stuyvesant.

The present threats, then, have to be taken seriously. And if they’re carried out, New York City would face a major health crisis, instead of just a paper fiscal “crisis.” Cutbacks by the ghetto-based voluntaries, which represent 20 percent of the city’s voluntary general care beds, would have to be made up for by the Municipal hospital system, which is still reeling from City budget cutbacks, as well as Medicaid cutbacks. Hundreds of thousands of people would simply have no place to turn.

Public and private leaders who could conceivably do something about the crisis have been eerily quiet. The Mayor has done little more than request a special legislative session to deal with New York City’s health and welfare cuts. Governor Rockefeller denied Lindsay’s request, claiming designation at the State level, but later cloyly revealed an unexpected $35 million surplus in State revenues. One guess is that ex-liberal Rockefeller, a Marchi man, is saving up any bonuses for the City until after Lindsay’s expected defeat in November. Drug and Hospital Workers Local 1199, the bargaining agent for many of the City’s voluntary hospital workers, has taken the position that neither worker lay-offs nor service cutbacks are acceptable. But since the union’s only familiar weapon, a strike, would seem to be a self-defeating way of dealing with lay-offs and closures, 1199 has been uncharacteristically subdued. So far no one—hospitals, government officials or union—has thought of joining with the communities which would be affected by the cutbacks to take common action.

If there hasn’t yet been a militant response to the crisis, it may be because many people have been getting used to the idea of a perpetual hospital crisis. The underlying causes blur out into problems which are endemic to the entire US health system: unstable, fragmented financing; uncontrolled costs which include a growing profit component for doctors, drug and supply companies, etc.; an irrational distribution of facilities; absent or inadequate preventive and ambulatory services; and so on. In this system hospitals may be, as one harassed administrator suggested, fiscal hemophiliacs, which will not be cured by any number of budgetary transfusions. But the problem facing the city now is on the level of first aid—finding funds to keep the hospitals functioning, however poorly. To many concerned hospital workers and community groups, the logical starting place is New York’s billionaire Governor, the single person most responsible for last spring’s genocidal health and welfare cuts. The next target for a community-worker “treasure hunt” for hospital funds is likely to be banks such as First National City which are profiting (at the rate of 8 or 9 percent) from loans to failing hospitals.

No sooner had the State Insurance Department granted New York Blue Cross a “modest” 43.6 percent rate hike than City mayoral candidates Lindsay and Procaccino almost tripped over each other in bringing suits against the increase. (Conservative Republican candidate Marchi reportedly favored the boost.) In his ruling on the Lindsay/Procaccino suits, State Supreme Court Justice Brust denounced the State Insurance Department’s 43.6 percent gift to Blue Cross as “arbitrary, capricious and ill-advised.” He went on to condemn the August 4 public hearings on the rate increase as “merely an abortive exercise in fishbowl group therapy”—just what the dissidents who disrupted the hearings had said. [See September HEALTH-PAC BULLETIN.]

Ordered by Justice Brust to give Blue Cross a temporary emergency increase “in the absolute minimum amount necessary to keep Blue Cross solvent,” the State Insurance Department grudgingly hiked the rate hike down to a mere 33 percent. Even this bare-bone increase will gross Blue Cross an estimated additional $60 million-year—well beyond Blue Cross’s reported deficit of about $11 million/year. Abandoning its already-cracked public service image, Blue Cross is girding up for a no-holds-barred fight for higher rates. In late September it appeals the State Supreme Court’s decision. And, in case the appeal fails, Blue Cross head Coleman is hinting darkly that Blue Cross will try to cut benefits—so subscribers will get less as they pay more.

—Barbara Ehrenreich

NEWS BRIEFS

Knowles: Two-Time Loser

The Columbia Empire is looking for a new director of its medical center. They plan to combine the positions of dean of the medical school and director of the hospital. In an attempt at pacification of increasingly restive medical students, Columbia included students on its search committee. After interviewing AMA-reject John Knowles of Massachusetts General Hospital, the students rejected him. Aside from problems of personal style, they found him “no liberal.”

All Choked Up

The tunnel officers of the American Federation of State, County and Municipal Employees Local 1396 have decided not to strike over the air pollution hazards they face in their daily work. At a press conference in July, they revealed that for five years the Triborough Bridge and Tunnel Authority (TBTA) had sat on a study showing serious health effects from the high levels of carbon monoxide in tunnels. Two months after the press conference, the tunnel workers had succeeded in transferring responsibility for monitoring the quality of the air in the tunnels from the TBTA to the City Department of Air Resources; had forced an agreement providing for outside medical experts chosen by both the TBTA and the Union to develop programs for maintaining the tunnel air quality and for monitoring the tunnel officers’ health; and had the TBTA on record as planning to comply with State standards dealing with air quality.

Look Mom, No Hands

All the promotional campaigns for the new enzyme detergents have left out the rather appalling health statistics coming in from Britain and more recently from the United States. It is fairly well known that workers and consumers have developed rashes and skin irritations; other health effects are just being explored. Perhaps the most damaging statement, however, comes from a recent in-house memo at a major soap company. Discussing the safety precautions for workers handling the company’s enzyme detergent, the memo urges that workers not spill detergent on their clothes.