Potential Contribution of Consumers to an Integrated Health Care System

Based on a theoretical framework and on practical experience in the area of Pennsylvania served by the Mon Valley Health and Welfare Council, the authors have conceptualized the role that the informed consumer can play in today's complex health care delivery system. They conceive of this role as a practical one that can significantly help a modern, rapidly evolving health care system to meet the challenge of change.

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ACTIVE CONSUMER participation in the planning of health care delivery is a relatively recent phenomenon, and the way it operates and the effects it has are not easy to determine and analyze. Consumer input into the planning of health policy and legislation and into the planning and delivery of health care services has greatly increased in recent years. However, because of the conditions under which consumer input has occurred, rational planning and analysis of consumer participation have not generally taken place (*1*). What is needed is a conceptual framework that will facilitate consumer input and permit the realization of its full potential. This essay represents an initial step in the construction of a conceptual model for consumer participation in health services delivery. We have drawn from the history of such participation from organization theory and from a case study, but the considerations presented in this report are only a beginning toward understanding and anticipating the role of the consumer in bringing about changes in the health care system.

Historical Considerations

Health care has been largely a physician-dominated enterprise, in which the medical treatment of disease under a private, fee-for-service system has been emphasized. Many forces, however, have been operating to change both the basic values upon which this system was founded and the structure of the health care delivery system in the United States (*2*). For one thing, the general public during recent years has come to view good quality health care as a right rather than a privilege, and the concept of health care has been broadened to include some social concerns as well as the traditional medical ones (*3,4*).

Some restructuring of the professional-organizational context in which health care is delivered has accompanied this shift in the public's values and conceptualization (*5*). The health care system that

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is evolving can be characterized in part as (*a*) being composed largely of medical care professionals and paraprofessionals, supplemented by increasing numbers of support personnel, such as planners, administrators, and statisticians, (*b*) having a structure that is not adequately described by the typical bureaucratic model of organization because it has elements of collegiality and openness that would not be acceptable in traditional bureaucracies, and (*c*) experiencing a gradual shift of control from the individual health professionals who provide the medical care to community-based management boards, typically consisting of representatives of a variety of special-interest groups, including consumers.

Consumer input, however, generally has not been as effective a mechanism for bringing about progressive and meaningful change in the health care system as its advocates had expected, largely because consumers and their needs have tended to remain outside the organizational network of health professionals (*6–8*). In the usual situation, only the providers of health care — individual professionals and health care organizations—have access to the information needed for planning, evaluation, and rational decision making. The health care consumers are frequently unable to obtain this information, and when they can obtain it, they often cannot interpret it. In some instances, this situation has led to conflict about health system change. In most cases, however, it has led to ineffective, uninformed consumer participation or no consumer participation at all.

Given these historical circumstances, consumer participation needs to be viewed from a new perspective, one from which it can be observed and evaluated. To date, however, the organizational context in which meaningful consumer participation can take place and have an impact upon health care delivery has eluded us, both conceptually and in practice.

Health Experts and Consumers

In a stimulating analysis, Grimes has differentiated between primary and secondary experts in the health care field (*9*). Primary experts include physicians, nurses, and members of the other occupational groups most directly involved in the care of individual patients. Secondary experts are less directly engaged in the provision of services and include, for example, statisticians, health planners, and health services administrators. Grimes' contention is that the growth of the secondary expert category is challenging the dominance of the primary expert and that a conflict over roles and status is the result.

Lack of coordination between the functions of the two groups of experts has hampered the planning of health care delivery. The challenge by the secondary experts to the traditional authority of the primary expert has arisen in part because a major function of the secondary experts is to gather information, and they are therefore often called upon to incorporate that information into the new forms of planning, evaluation, and decision making being carried out in the health care system.

The distinction that Grimes makes between the primary and secondary experts, as well as his analysis of their conflict, is useful. Admittedly, the concept is general, but it can be broadened so that the primary and secondary experts are viewed as elements of two distinct networks, which we refer to here as primary and secondary organizational layers. All complex organizations must have procedures for collecting and processing information if they are to survive and grow (*10*), but in the health care delivery system, the sequence in which the functions of the two layers, or networks, came to be performed historically is different from that of most other organizations. In effect, the secondary organizational layer, composed of the experts who are more indirectly related to patient care, has been superimposed upon the primary one, which is composed of the experts closest to actual patient care and whose status has been reached through successes achieved in such care.

Entities outside the primary health care delivery layer, such as State and Federal governmental units, have promoted this superimposition. Interaction between the two organizational layers generally has been superficial because the primary providers have resented the intrusion of the secondary experts, and the functional integration that was envisioned in comprehensive health planning legislation has not actually occurred.

When consumers try to align themselves with either organizational layer, their effort is usually doomed. Consumers ordinarily cannot be oriented and educated into the functioning of either layer without losing their own vital and unique perspective. Consumer alignment with either the primary or the secondary layer cannot therefore be completely functional because neither coalition solves the problems created by the superimposition of the secondary layer upon the primary.

Although only time may resolve the issues arising from the sequence in which, historically, the functions of the primary and secondary layers have come to be performed, recent national health legislation may help to solidify the position of the consumer of services within the health care delivery system. Strict adherence to the criteria as to what constitutes a consumer may help insure the maintenance of a vital consumer perspective, as opposed to the perspective of a consumer turned into a secondary expert by virtue of information and education.

Certain events have already contributed to a better understanding of the consumer's role, and they also suggest a conceptual framework that can help in future planning. One example can be drawn from the southwestern area of

Pennsylvania served by the Mon Valley Health and Welfare Council, where a special set of circumstances provided a field laboratory in which the ideas presented in this essay were developed. Instead of viewing the consumer as part of either the primary expert layer or the layer of secondary experts, it may be more meaningful to view the consumer's role as that of a special kind of provocative agent operating between the two layers.

Mon Valley Experience

We collected much of the basic data and did most of the analysis for the conceptual approach suggested in this essay through our association with the Mon Valley Health and Welfare Council. We also participated in the establishment of an experimental health services delivery system (EHSDS) project, whose function in part was to conduct planning and evaluative research as a basis for setting up health programs within the Mon Valley health care delivery system. Thus, we have worked from the perspective of participants in, and observers of, this complex system as it has evolved over time. Throughout the evolution of the system, members of the faculty of the Graduate School of Public Health of the University of Pittsburgh provided an outside perspective, which has been helpful in maintaining objectivity in evaluation and documentation.

Early in the EHSDS project, many of the Mon Valley community leaders, including primary experts, secondary experts, and consumers, were disturbed by the strong emphasis that the Federal EHSDS office placed on the concept of community management. They interpreted this emphasis as interference in the autonomy of the local health care providers and in local planning and management functions. Many of the primary and secondary experts were reluctant to acquiesce to any more participation by consumers in decision making than had occurred in the past, since they believed the consumers were not prepared to participate significantly in the establishment of the Mon Valley health care system. Consumers were concerned about the possible loss of control over certain organizations which they had historically dominated. These sensitivities were never overcome, but a sufficiently strong coalition of interests was formed to permit the creation of a community management board. As finally agreed upon, this entity includes political leaders, primary and secondary experts (including presidents of service agencies and institutions), representatives of funding or payor agencies, and representatives of the Mon Valley consumer sector. Consumers are primarily represented on the management board by representatives elected by subarea community councils, each of which is staffed by an EHSDS professional. In addition, at-large members are appointed to represent special groups of consumers, such as those under 25 years of age and those over 65.

Given this board structure, one of the primary ways the Mon Valley Health and Welfare Council has attempted to penetrate the health care system and achieve extensive communitywide participation is through committees. All requests, proposals, and reports received by the council from its own staff or other organizations go to the appropriate committee for evaluation and recommendations. The members of the committees are drawn from the Mon Valley community in general and are selected, for example, for their interest in a particular subject, for their particular perspective, or for their expertise. In this way, many more community members have input into the council and are afforded an opportunity to participate in planning for the health care delivery system than would be possible through membership on the board alone.

In effect, the strength of these committees lies in their being forums in which representatives of all sectors of the community can respond to issues pertaining to the health care delivery system. Depending upon how representative an individual committee is of communitywide attitudes, many issues are resolved within the committee itself.

Planning and evaluation by the committees are attempted through the use of data collected by the council staff and presented to them for review. The final interpretation and implementation of recommendations rest with each committee and the council. The primary responsibility of each committee is to know its subject area well and to become familiar with the data pertaining to needs of the Mon Valley residents. Items that the committees deem need further action are presented to the board.

Despite the consumers' dependence on the council staff (that is, on secondary experts) for data collection and analysis, the consumers have resisted being co-opted by the secondary layer. The Mon Valley consumers are not an arm of the secondary experts. In fact, the consumer sector often takes positions contrary to those taken by both the primary and secondary layers. As consumer input is increasingly sought in the establishment of policy and in the planning of services, it appears that more and more often neither the primary experts who lean toward the status quo, nor the secondary experts who lean toward drastic change, are in control.

For example, the service area of the Mon Valley Health and Welfare Council includes portions of three counties, and the health care needs of the residents of the area do not always conform with the priorities that those counties have established. The funneling in recent years of much of the funding for human services through county governments has placed the Mon Valley area at a disadvantage. Politically, therefore, the council has assumed the role of advocate for its constituency vis-à-vis outside organizations. Such actions have included presentation of petitions to county commissioners by neighborhood groups, submission of recommended changes in State legislation to regional organizations,

provision of documentation in port of local programs to State cials. This advocacy function of e council would be much weaker the management board were dom- ated by either primary or second- y experts or if it lacked consumer pport.

Experiences in the Mon Valley ea have shown that the presence consumer representatives on the nagement board, even though ese representatives account for 51 rcent of the membership, does not itself guarantee meaningful con- mer participation in decision mak- g and planning. The most salient tor in meaningful participation the consumer membership is its eparedness.

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recent situation in the Mon Val- y area illustrates the usefulness of ving informed consumers act as a ovocative agent between the pri- ry and secondary experts of a alth care delivery system. At least ur different blood banks had been llecting blood from the area's resi- nts, but the residents had only rtial coverage for their blood sup- y needs and also had to pay rela- ely expensive service fees. Upon e insistence of consumer represent- ves on the advisory board of one od bank, the Mon Valley Health d Welfare Council entertained guments regarding blood availabil- y and coverage, along with sugges- ns of ways to improve the situa- n. A task force composed of blood nk representatives, health care oviders, council staff, and consum- was formed, and for a year it col- ted data from all four blood nks, analyzed the information, and bsequently considered a number of rnatives to the blood supply ar- gement then in force. Ultimately, plan was devised for using only e public blood collection agency. is decision has enabled the chosen ency and the other three banks wo operated by local hospitals and e other by a private organization) pool the blood they collect so that can be obtained by the public from a single location. Having a single collection organization within the Mon Valley area has lowered costs for the hospitals, while at the same time coverage is now available for all residents.

The Mon Valley's primary and secondary health care experts had not been satisfied with the blood bank services for many years. Yet they had never previously made a concerted effort to implement a better system. The council staff also had recognized the lack of coordination and duplication of effort, but initially had given the problem relatively low priority on the list of changes needed in the Mon Valley area. Informed consumers, however, sitting on the board of the one blood bank and aware of the difficulties, forced the council to recognize the issue and to pursue a solution systematically. By proposing changes in the blood bank system at a community management board meeting, these consumers were able to publicly provoke the primary and secondary experts into action. It is unlikely that the primary and secondary experts, acting either alone or together, would have been able to effect an acceptable solution without the consumers' influence. Having the various blood banks represented on the task force that worked out a solution also avoided imposition of a new system upon unwilling participants.

Analytical Considerations

Our observations have led us to believe that the most productive role for the consumer in bringing about changes in the health care system may be one of provoking issues between the primary and secondary health care layers and using various techniques to move the two layers toward the resolution of these issues. As the consumer role evolves, it may further legitimize the role of the secondary organizational layer by using the information gathering capacity of that layer to provoke changes in the primary organizational layer.

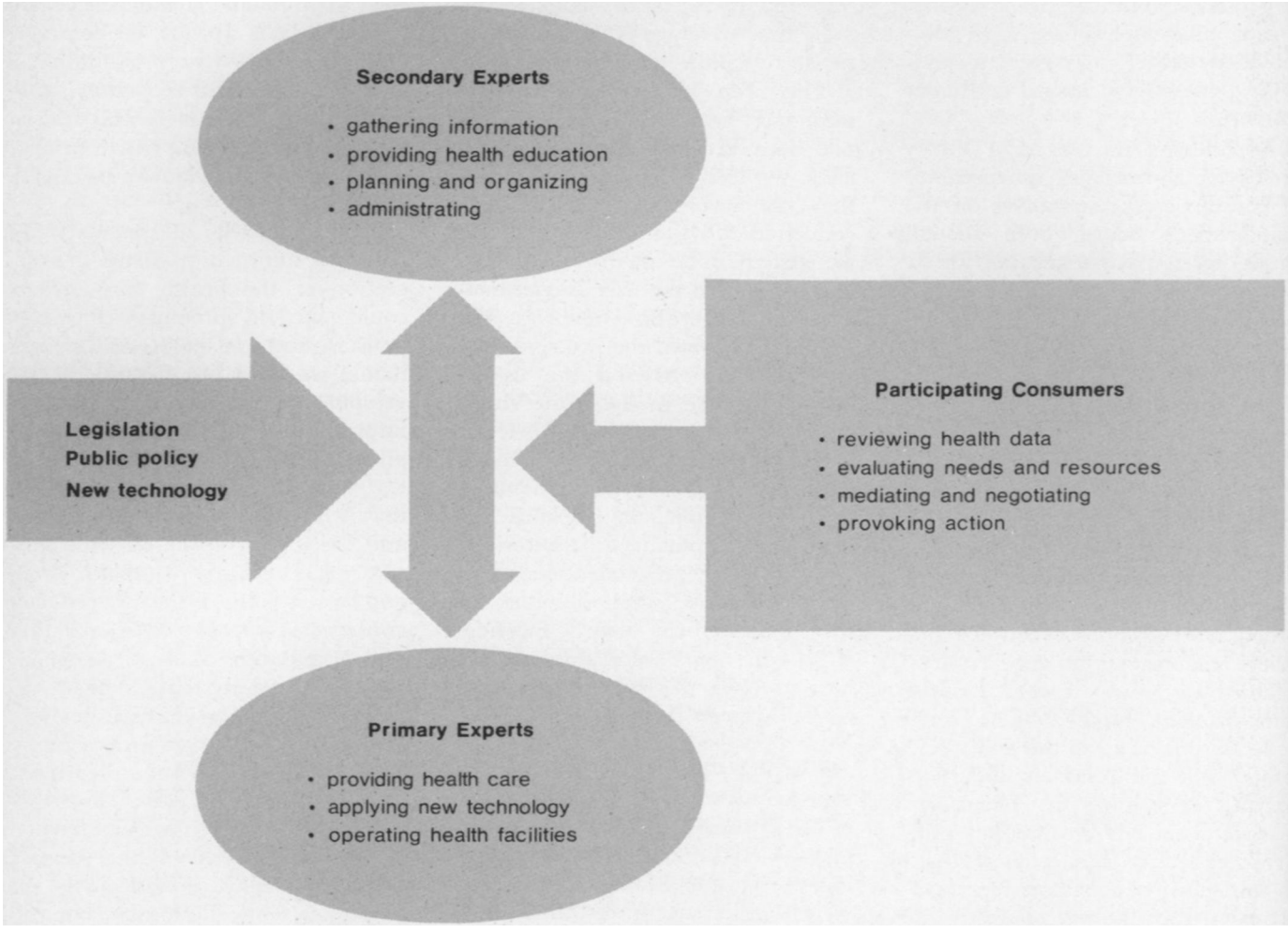
The rationale for this thesis is that consumers are the only participants in health care planning today whose position on issues is consistently dominated by the belief that good health is a right. In contrast, persons in the two organizational layers, primary and secondary, usually see issues within special frames of reference that emphasize professional and organizational goals and interests.

The availability of systematically collected information about the operation of the health care system could further promote consumer participation and help establish the model we have just described. Developing the capacity to obtain such information is the responsibility of all parties, but it is the main task of the secondary experts. We believe that when information is collected and knowledge is shared with consumers concerning the quality, costs, and accessibility of health services, consumers will develop mediating and negotiating skills to augment their role as a provocative agent.

The consumer himself cannot lead the system toward greater accessibility while at the same time moderating health care costs. Nevertheless, given the normal friction between the primary and secondary layers of health professionals, the consumer who is informed but can still maintain his consumer perspective may be the most appropriate mechanism for resolving policy and organizational problems in health care planning and health services delivery. Our analysis suggests that educational programs for consumers, by emphasizing the techniques of mediation and negotiation, may thereby be able to enhance the usefulness of health records and information systems.

The requirements for operation of the consumer participation model suggested in this report are (*a*) the existence of the primary and secondary layers for health care, (*b*) a structure that permits consumer involvement in health care planning, such as a community management board, (*c*) procedures by which information can be transmitted to and

Roles, relationships, and influences operating in the consumer participation model



interpreted by consumers, and (*d*) a process for negotiation and mediation between opposing forces. These four elements and their interrelations are shown in the chart. It is expected that as these elements converge within the community setting, the role of the consumer will evolve, permitting movement toward integrated health care system planning.

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