CONSUMER PARTICIPATION

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Health affairs have been moving rather rapidly from a largely private affair to a matter of public policy. Accompanying that movement has been an emerging consumerism still largely without a defined role and function, largely without the acceptance and support of health professionals, and also lacking a base in the larger consumer body. In order to fulfill the potential of consumerism for changing and improving the health care system, it needs nurturing and developing by consumers themselves; but it also needs the support and encouragement of health professionals. Consumer input at all levels in all agencies is needed to develop a more effective and responsive health care system.

If one considers the mandates of various government health programs, they all depend upon a large pool of informed citizens in health affairs. It would seem logical, therefore, that an office of consumer health affairs be established at an appropriate level in government health activities. Comprehensive health planning, in fulfilling its mandate for a majority of consumers at the State level and for areawide agency boards to be similarly constructed, seems to have an especially high level of need for an informed consumer health constituency. Comprehensive health planning might, therefore, be encouraged to increase and broaden the thrust of its activities in consumer participation.

A multitude of factors are responsible for the rapidly emerging prominence of consumers in the health care system—higher educational levels of the general population, greater expectations derived from improved communication, a somewhat higher standard of living (or expectation of a higher level of living), and frustrations which develop when the demand and ability to purchase health services do not equal the ability of the system to supply services and frequently not the quality of service desired. Additionally, the slow growth in the development of new

ideas and programs to meet increasing needs, the general cultural acceptability of "militancy," and the more political nature of health services today are all important factors in the emergence of the consumer role in health.

Consumer participation, especially in ghetto communities, has become an important force for change. In some cases, it is even perceived as a serious problem to professionals in the health field. The ghetto consumer has sought power within the very structure of the medical care system and demands a substantial role in policy development and a role in governing health care institutions. Because of the strength of these demands, sometimes backed by Federal money, and his insistence on change, the consumer on the one hand poses serious threats to the health professional and on the other hand provides the potential for improvements of health care in a relatively short time.

What is Consumerism?

Consumer participation is citizen involvement. Citizen involvement in health is neither a new concept nor does it have a single objective. In the past, well-to-do members of a community gave their time, usually as members of boards or trustees of hospitals, to insure that the community had health care. Some ethnic groups provided institutions for care of their own people. In other related parts of the health system, such as health planning agencies and insurance plans, the "participating" consumers were, and still are in some cases, from the middle and upper classes of the community. They were chosen because of their position, money, and business knowledge. More recently, in some areas of the country the upper class businessman and the union leader have also been encouraged to participate.

Up to now, citizen board members have largely not encroached on the planning for the delivery of health services but have participated mostly in areas of lay expertise, such as fund raising. The health professional has largely dominated health-related decision making. Thus, who shall get health services, where they shall come from, and how they shall be provided rarely rests in the hands of the consumer. Professional satisfaction with a program rather than consumer satisfaction has been the measure of success.

Even in the neighborhood health centers of the Office of Economic Opportunity, where maximum feasible participation was mandated, an appraisal by Sparer and co-workers (*1*) showed that consumer involvement varied. Seven neighborhood centers were rated high in the degree of involvement (actual participation of the consumer group in policies, practices, and operational decisions), nine rated moderate, and 11 rated low.

Demand for consumer participation is arising mostly in ghetto areas and somewhat in middle-class areas and is devoted almost exclusively to gaps in health care and to dissatisfaction with service and with the manner in which service is rendered. Heretofore, these have been solely professional decisions. This involvement is both strong and frankly political. Whereas the fundraising role is almost dead, the new ghetto consumer has the potential to influence the direction of Federal and State moneys.

Early in 1969, President Nixon requested that the Secretary of the Department of Health, Education, and Welfare study the problems of Medicaid and related programs and make recommendations to improve these programs. By July of that year, a task force (*2*) was in operation.

It was determined very early that the problems of Medicaid or Medicare, or both, lay beyond the walls of such specific programs. Rather the problems existed within the current health system, and significant changes in our system of delivering care were required.

It was noted by the task force that "not only do millions of consumers get care on a hit and miss basis or lack access to care except in medical crises, but virtually all consumers lack access to the decision making machinery that can bring about change. Few institutions and programs include representatives of every day users of their services on policy-making or governing boards in spite of their non-profit and presumedly community character" (*2*).

A basic tenet of the report (and of this paper) is that "greater consumer involvement in decision making is required to overcome deficiencies in the health system . . . and to achieve better management of resources . . . without substantial consumer input, health institutions can become excessively self serving and, in fact, tangential to even fundamental community health problems. Also, without consumer input, user identity with service can deteriorate and inappropriate use can occur. Perhaps it should be added that, as in the management of other community institutions, for example, education, the fact that the consumer 'wants in' is a valid reason for involvement in its own right" (*2*).

Yet staff research in this area demonstrated no national means of providing the consumer the assistance he needs to become a positive force for the improvement of national health care services and no means for bringing the consumer and provider together to work jointly. This observation should not be interpreted to mean that in individual cases and in special instances consumers have not been in roles of power in the health system or that the consumer does not take part in health system decisions, but these instances are rare in the national picture.

Who is a Consumer?

"Who is a consumer" is frequently a cloudy issue. In recent deliberations of the Task Force on Medicaid and Related Programs, the consumer was defined as "any user of the health care system." Since users reflect certain social, economic, racial, and geographic characteristics, the task force recommended that a "participating" consumer must also reflect these characteristics. (*2*).

In ghetto areas, as is true in other communities, not every person participates directly in programs affecting his community. The ghetto consumer is frequently represented by an organization whose leaders and most of whose staff originate from the immediate community. There may also be various volunteers (VISTA, and so forth) from outside the community as well as other part-time or full-time salaried staff and consultants from outside the community who act as advisers and who, in many cases, guide the community organization to action.

Consumer groups usually state that they are supported by the community and feel that they voice their discontent. In most instances, motives are good. They seek to improve health care in the community and, in many cases, they know what's wrong with a facility. They come, however, usually with little or no organizational capability and very little knowledge of health. These consumer groups are usually distrustful of the health establishment and in turn are usually not trusted by the establishment (*3*).

Change

A variety of factors are moving us toward a greater role for consumers. The consumer role in three government programs—the Juvenile Delinquency Program of the Department of Health, Education, and Welfare; O.E.O.'s Community Action Program; and more recently, the Model Cities Program of the Department of Housing and Urban Development—offers interesting comparisons.

Consumerism has evolved from a minor role in the public-private policy-shaping function of the Juvenile Delinquency Program's community leadership coalition to more significant participation in policy formulation in Community Action Program activities—and it has further progressed to a more dominant position in the Model Cities Program. This program sometimes places city government and black neighborhoods in adversary relationships, with each having a degree of independent authority over planning and program development.

The Juvenile Delinquency Program offered the "previously unheard" consumer what might be labeled token participation. O.E.O. programs were encouraged to achieve "maximum feasible participation." The Model Cities Program represents an evolution of the consumer role to a "must be heard" status both within organized neighborhoods and in its claims on the attention of city government.

More important, and specifically in the health area, comprehensive health planning requires at least a majority of consumer representatives on comprehensive health planning councils. In most cases, however, there is little evidence that mandating consumer participation has truly achieved the participation of consumers, especially the "previously unheard" consumer.

There are increasing attempts to permit consumers to participate in policy making at all levels. Even though not entirely successful, in many cases it has been realized that a board of trustees of a hospital made up entirely of persons who no longer live in a community usually cannot voice the needs and desires of that community. In his inaugural address as President of the American Hospital Association, Dr. Mark Berke said (*4*): "For all of us, the question now is how to involve consumers in a meaningful way. We need to get some input from such groups, and to gain from them knowledge and understanding of our problems for these problems are, in the final analysis, the problems of the consumers."

In line with Berke's comments, the Catholic Hospital Association has recently issued a "Board of Trustees Guide" which stresses community representation as a desirable element in trustee membership (*5*).

Opportunities for Participation

The Urban Coalition in its "R_x for Action" (*6*) has recommended "that information about the community, the various bodies in the community in which the people can participate *as members,* and the nature of organized efforts be catalogued and made available to all citizens, particularly neighborhood groups representing the poor." The Coalition has further suggested that this function could best be performed by the comprehensive health planning agency.

Opportunities for consumer participation in varying organizational settings with varying needs for policy determination, advice, technical assistance, monitoring, and evaluation postulate the need for consumers of varying sophistication and varying experience.

Figure 1 suggests that the experience needed to make appropriate inputs into a local hospital board, community consumer services committee, neighborhood health center, or voluntary agency differs from that needed to plan or advise on State or national programs; more important, perhaps the reverse is true. Hence, the Medicaid task force recommended that "organizations and institutions involved in planning, purchasing, and delivering health services should provide for major-

Figure 1. Theoretical opportunities for consumer participation at local, State, and Federal levels

Local	State	Federal
	Planning and Coordination Functions	
Areawide comprehensive health planning	State comprehensive health planning	National Advisory Council on Comprehensive Health Planning Programs
Hospital planning	Hill-Burton	Hill-Burton
Other planning councils	Other planning councils	Other Federal advisory councils
	Financing Functions	
Medicaid	Medicaid Advisory Committee	Medical assistance advisory committee
Medicare	Medicare Advisory Committee (some States)	Health insurance benefits Advisory Council
Private insurance	.....	Health Insurance Council
Prepaid group practices	.....	Group Health Association of America
	Organization and Delivery Functions	
Hospital boards	Hospital associations	American Hospital Association
Nursing homes	Nursing home associations	American Nursing Home Association
Home health care	.....	(Proposed)
Neighborhood health centers	.....	Office of Economic Opportunity
Prepaid group practices	.....	Group Health Association of America
.....	.....	Veterans Administration
Indian health	.....	Indian Health Service
Migrant health	.....	Migrant health program
	Regulatory Functions	
.....	Facility and personnel licensure	.....
Environmental health	Environmental health	Environmental health
	Voluntary and Professional Health Agencies	
Health and welfare councils	State councils	United Health Foundations, Inc. (non-Federal)
Medical society	State associations	American Medical Association (non-Federal)
Hospital association	State association	American Hospital Association (non-Federal)
Public health society	State association	American Public Health Association (non-Federal)
Voluntary health agencies	State association	National associations

ity consumer participation in deliberations on the nature of those services, and at least one-third of that majority should be made up of users of the health care program or facility involved" (2).

From this statement, it would follow that there are both broad and particular consumer interests to be considered; for example, the American Hospital Association's "consumers" would be both broadly representative of potential hospital users and might also include some recent actual users.

Opportunities for consumer participation might be looked at in the light of a "Chinese box" in which the most effective consumers emerge from a system which fosters their development.

Prewitt (7) uses the Chinese box to describe the process by which our political leaders are chosen, but his box might be adapted to a health-political system. Such a system would require that certain consumer functions be performed in behalf of those who receive health care at local, State, and national levels.

Figure 2 postulates a planned system of producing informed consumers chosen from all those who are served, phased through a series of experiences on varying levels, from which those who have the most to contribute and who have personal charisma would emerge.

The figure also postulates that each program will have its own consumer selection criteria based on functions as defined legally, by charter or bylaws. Also operating would be other selection criteria such as socioeconomic representation and the selective effect of personality and skill. As the opportunities for participation grow fewer, many are called but few are chosen.

Achievement of the status of health consumer leader or of top spokesman for health consumers at the national level could not happen without the experience, desire, and significant personal effort on the part of consumers.

Until consumer participation in health affairs is a more frequent

Figure 2. The Chinese box -- a pool of consumers

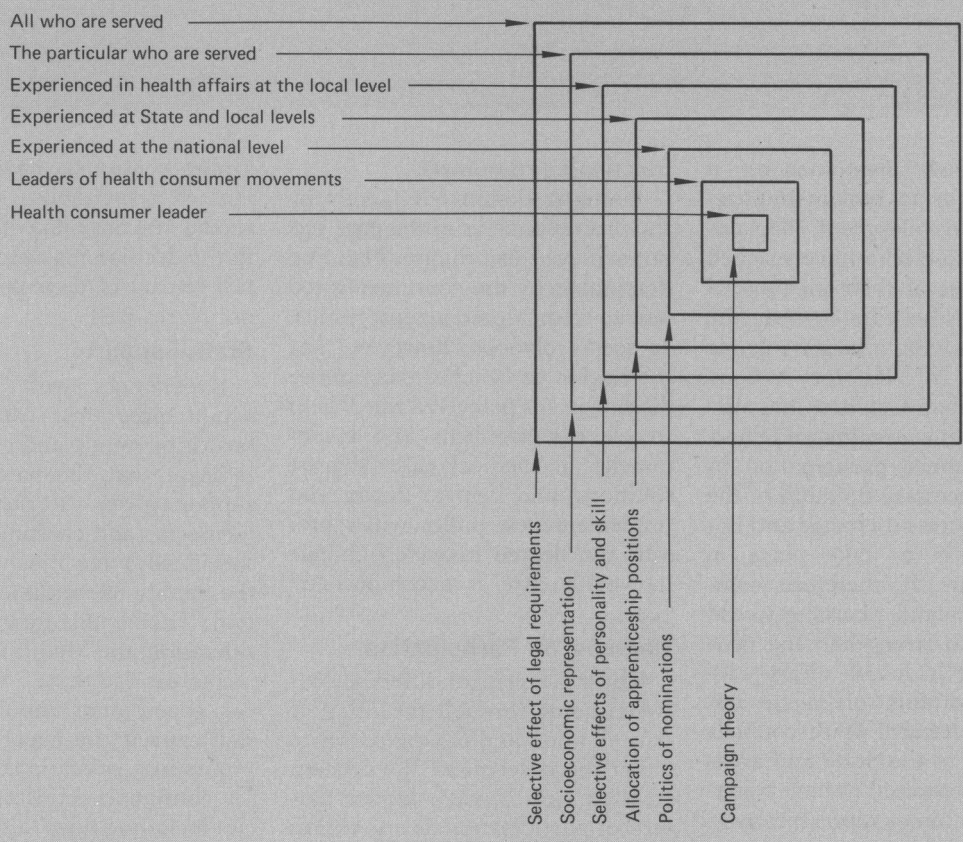
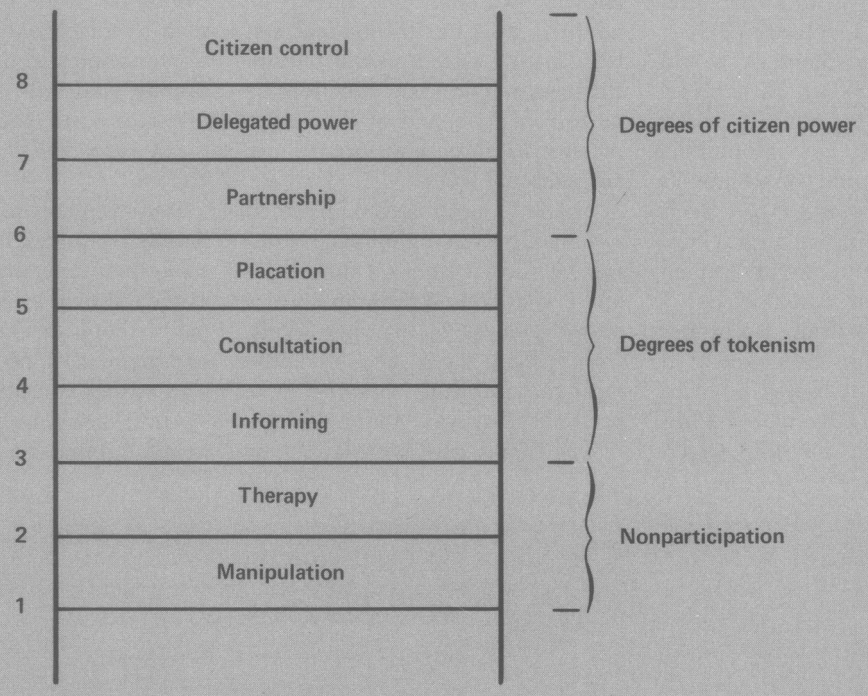


Figure 3. Arnstein's ladder of participation



and planned phenomenon, it would appear to remain haphazard in its development, depending upon those who have reached an awareness of their inequity of access to health care to bear the brunt of evolving a larger role for consumers. In "R_X for Action" (*6*), the Urban Coalition has suggested that encouraging and cherishing consumer participation in total is a necessary function of the planning process if change and improvement is to take place in health affairs. If, therefore, comprehensive health planning would undertake to strengthen the consumer's role in health affairs, development of this role might not remain haphazard. With councils and boards at the State and areawide levels required to have a majority of consumer representatives, comprehensive health planning agencies—more than any others—need experienced and effectively functioning consumers.

Planning dominated largely by the professional, as in the past, has not achieved its promise. Planning dominated by the consumer is too new to be measured against results. It seems obvious, however, that the degree to which the consumer discharges his perceived role, "help to identify problems and inadequacies in medical care, suggest solutions, and help to design and implement new policy will represent the degree to which change in health care is accomplished" (*2*).

Degrees of Participation

There is a critical difference between going through the ritual of participation and having power to affect the outcome of the process. Arnstein (*8*) poses a ladder pattern of participation as one means of sorting out what is meant by participation (fig. 3). The ladder postulates degrees of responsibility. Unless consumers have been designated responsibility or have assumed responsibility for outcomes in the decision making process, the full impact of their potential may not be realized.

Staff Support

Experiences with community action programs, comprehensive health planning, and other groups indicate that the nature of staff support given to orienting board members (and consumer members specifically) has much to do with the quality of consumer participation. Taking this factor into consideration, the Medicaid task force recommended that: "State and local government should establish staff capacity for inaugurating and promoting educational programs for consumers. Health care agencies including hospitals should also be encouraged to undertake similar activities. Licensing organizations that are working closely with

health care institutions on other matters should assist these institutions in providing for consumer participation in policy matters relating to service" (*2*).

Consumer Training

Many voluntary agencies have provided orientation programs for new board members with varying degrees of success. Since the development of programs requiring consumer participation, such as the neighborhood health center, Model Cities, and comprehensive health planning, more consumers are being given training. Such training has brought into focus a "new" consumer, not the familiar typical volunteer or yesterday's board member of the health agency. The low-income consumer appears characterized by a direct approach to problems, speaking out on issues, a lack of tolerance with professionals' methods of doing business, and intensely strong and personal involvement with the issues at stake.

The degree of feeling and hostility which can be generated was reported in a study of the training program for consumers in policy-making roles in health care projects (*9*). "Some felt that medical professionals unnecessarily asserted the sanctity of the medical professional. One board member quoted a doctor as saying to him, 'You better remember you are working with doctors, not a bunch of carpenters.' "

Professionals, generally, were criticized for using complicated, technical language to express simple points: "Professionals rattle off this hogwash; half the time I don't know what's going on." Or in the words of other board members, "Doctors can rattle on for hours; if you try to ask a simple question, they just take it and go on and on. We asked our director to stop using long words because we just don't understand" (*9*).

Moreover, "an effective representative board will always be involving new groups and its activities and the issues facing the boards are constantly changing." Training should not be viewed as a "one-shot stabilizing device but an ongoing process" (*9*).

Extent of Consumerism

Thus far, the thrust for greater community participation has had its major impact on the public school system. The community is asking for an unfreezing of that lethargic system administratively and politically and for a shift from peer accountability to community accountability. It has been suggested that the demand for accountability should lead to new methods of evaluation and quality control, integrating in a comprehensive way a variety of approaches. A further effect could be demand for active participation within the school system by teachers, students, and paraprofessionals. The major goals are to make institutions more relevant to the needs of the neighborhood and to make agencies more accessible and service more available.

A major hypothesis is that a strong community voice will sensitize the various human service institutions to potential neighborhood reactions, bringing about anticipatory reaction to community demand and producing a new and more responsive atmosphere and tone in the agencies. Whether this will really happen remains to be seen. What is clear is that consumers are seeking ways to change human services.

While pointing out the impact that a community voice may have on the human services system, Reissman and Gartner (*10*) suggest that "bringing soul to the system does not necessarily improve its efficiency, though it may change its atmosphere and character; that the unfreezing of the equilibrium of human service does not guarantee improvement; it provides an opening for such improvement." The test remains ahead. To avoid many of the basic dangers, Reissman and Gartner call for specific policy changes at the national level, suggesting that local community interests must be connected clearly to larger national and international issues because the basic problems of our society originate and the basic control of resources lies at the national and centralized level.

Provider Training

Most, if not all, persons who see the need for shifts or changes in health care systems—aside from the problem of learning to work with consumers—suggest that there is a need for training professionals on policy-making and advisory boards. Parker, co-author of a report on training consumers in policy-making roles, states that professionals "have as much, if not more, need for training as the low-income consumer representatives" (*9*).

Little information exists with respect to the training of professionals to participate on policy-making and advisory boards. In many organizations, such as comprehensive health planning agencies at the State and area-wide levels, orientation or board member training appears to be subsumed as part of an ongoing operation rather than an area which requires specific planning.

There is a wealth of material available on how to get a group to work together effectively. The degree to which such information is being used in specific situations when there has been no major thrust nationally to orient boards, neighborhood health centers, and comprehensive health planning groups is not documented. There are some clues, however.

In a series of informal interviews with CHP board members, one chairman of a CHP council indicated that, as the new chairman, he intended to seek out those members of the council least known to him and least vocal in the activities of the council and determine their interests and relevant experiences.

If these interests are not expressed voluntarily, he plans to make an attempt to draw them out by providing an atmosphere in which they can express their views.

Another areawide CHP council first organized a consumer group, which in turn was given the responsibility for developing criteria for selection of provider members and orienting such provider members to perceived health needs. An advisory committee charged with reviewing grant applications recently suggested that all CHP agencies be required to submit annual reports on their orientation activities.

Potential for Change

In some of its deliberations, the Medicaid task force panel concerned with consumer participation perceived the unique role of the consumer as being (*a*) to assure that decisions of policy-making health bodies are based on awareness of the needs and interests of consumers, (*b*) to provide a continuing liaison with the population served, and (*c*) to monitor the delivery of health services from the point of view of the consumer as to effectiveness and cost. It is essential to spell out the role of the consumer, both to enable him to fulfill his responsibility and function and to enable the providers to accept the consumers' input. (*11*).

It is also essential to define precisely the unique role of the health professional in providing technical expertise. Similarly, it would seem useful to spell out those areas of joint responsibility for policy development and advisory activities. Furthermore, it would seem useful to differentiate clearly, in charges to boards and committees, their roles in decision making or their advisory activities.

Effective decision making by boards or committees does not come about by accident. Consumer participation is but one aspect of a board's effectiveness. It can only happen if roles are clearly defined, if orientation to function is a continuing process, if staff have clearly defined roles to nurture it, and if the process is traceable in the activities of the agency at whatever level. What needs to be done to make consumer participation fulfill its potential seems clear. Whether it will get done remains to be seen.

Accomplishment

It is too early to measure what the new consumerism is accomplishing in health affairs. Some impact is traceable but the lack of a clearly defined responsibility for consumer affairs in health by any agency hampers a full accounting. Some impacts are reported with irritation, other impacts with satisfaction. The interviews with comprehensive health planning agencies reported previously indicate that in certain councils consumers have been successful in moving consumer health problems to a higher priority. The National Welfare Rights Organization has recently been in dialog with the Joint Commission on Accreditation of Hospitals, pointing to a consumer role in hospital affairs. Advisory committee members of O.E.O. neighborhood health centers have formed a National Patient Rights Organization which has announced and is promoting a consumer manifesto. Medicaid task force staff members report that most organizations and agencies in the health field are talking about consumer participation. Consumer organizations have been formed to undertake functions which existing organizations would not.

Whether consumer participation in health will remain a spotty, little known entity or whether it will become a full-fledged element of a changing political and organizational scene which is more responsive and relevant in all human services remains to unfold. What is clear is that the health professional needs the consumer to achieve a relevant and responsive health care system.

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