



HEALTH PERSPECTIVES

A NON-PROFIT TAX
EXEMPT ORGANIZATION

Vol. IV, No. 4 & No. 5 PUBLISHED BY THE CONSUMER COMMISSION ON THE ACCREDITATION OF HEALTH SERVICES, INC.

July-Oct. 1977

Pub. 1/78

THE DEVELOPMENT OF A CONSUMER HEALTH NETWORK

— DOUBLE ISSUE —

The Consumer Commission reproduces in its entirety The Development of a Consumer Health Network. This position paper was prepared with assistance from the Health Resources Administration, DHEW, under contract PLD-05592-77TB. In summary, the position paper concerns the need for a national network of health consumer organizations to provide technical assistance and constituency feedback to consumer representatives on health planning bodies.

Consumers of health care are mandated to participate in policy-making activities of the health planning bodies created by the National Health Planning and Development Act of 1974 (PL 93-641). However, the disparity between the resources available to consumer and provider board members, which led to significant failures in the predecessor agencies of the Comprehensive Health Planning Act (PL 89-741), have not yet been addressed or alleviated. Health planning agencies today are little more than a guise for the perpetuation of traditional provider

dominance over health planning decision-making. This position paper documents this resource disparity and presents its effects as viewed by consumer members of Health Systems Agencies, State Health Coordinating Councils, the National Health Planning Council, and members of consumer groups around the country.

To become responsible and responsive representatives consumers need the technical and political support of an organized consumer health constituency. In this paper the Commission identifies the necessary goals and objectives of a national health consumer network, discusses the advantages and obstacles to its formation and develops a feasible and effective organizational structure. Several interim programs which could be independently implemented and later consolidated into a national consumer health network are also suggested.

The Consumer Commission's series on a National Health Service will be continued in 1978.

INTRODUCTION

The purpose of this position paper is to discuss the opportunities, obstacles, and organizational approaches to develop and implement an organized national health planning consumer constituency. This constituency organized into a network will provide information and feedback to the members of the National Health Planning Council (NHPC), the State Health Coordinating Councils (SHCC), and Health Systems Agencies (HSAs) which have been created by PL 93-641, the National Health Planning and Resources Development Act of 1974. To develop an organizational model which would be feasible and best serve the stated purposes, it was necessary to examine the goals and specific objectives of this network, and to explore the particular advantages and obstacles, as well as, to delineate the general environment in which the network would operate. As a result the Consumer Commission (CCAHS) met with consumers and consumer groups across the country; held conferences in three cities—Chicago, Birmingham and Los Angeles—and developed, implemented and analyzed the responses to two questionnaires designed to survey the attitudes and needs of health consumers. Questionnaires were completed by those invited to the conferences, and, in New York City, by individuals identified as representing the range of New York grass roots health consumer groups.

Commission staff also studied several theoretical organizational possibilities to determine how these structures might accomplish the network's goals and objectives within the current milieu.

This paper represents the outcome of the didactic and experiential phases of the Commission's study. It presents the necessary goals and objectives of an organization which could effectively accomplish the following:

1. Develop a national consumer constituency to provide information and feedback to and from health care consumer groups throughout the country, the National Advisory Council and governing body members of local health planning agencies.

2. Explore alternative ways to retrieve, aggregate, analyze and/or distribute consumer oriented health care information, policy alternatives and consumer perspectives.

3. Foster informed consumerism which complements and balances provider knowledge and credibility in health care decision making.

4. Develop consumer proposals for health policy actions to improve the nation's health.

— Additionally the pertinent aspects of the current interaction between health care consumers, government and providers are examined. As a means of highlighting and pinpointing issues and needs as perceived by health care consumers, relevant quotes taken from the questionnaires of those surveyed are included throughout the paper.

THE CURRENT MILIEU

The lack of knowledge among consumer representatives on governing bodies and committees of health planning agencies is a result of the failure of government to support effective consumer education in the areas of health system organization, legislation, regulation, policy formation, etc., and the lack of sufficient resources within the consumer movement to independently and effectively educate and disseminate information.

To accomplish the goal of effective consumer participation in health planning, the inequity between providers and consumers in the distribution of health care resources must be alleviated.

Consumers are expected to participate in the health planning organizations established under PL 93-641. Health Systems Agency governing bodies are mandated to be composed of a majority of consumer representatives. At the present time several thousand people who do not earn their living in health care sit on State Health Coordinating Councils (SHCCs), the National Health Planning Council (NHPC) and on Health Systems Agencies (HSAs).

Unfortunately, numerical representation alone cannot provide consumers with the background to formulate

plans, evaluate ideas and effect changes. Indeed, many consumers, even those within the system, seem to be uninformed concerning the planning structure and goals itself. This was amply demonstrated in the results of our survey. Thirty-seven percent (37%) of those responding were HSA board members. Of these:

- $\frac{2}{3}$ indicated that they neither knew nor understood the role and function of the State Health Coordinating Council;
- $\frac{1}{3}$ were not aware of the ten national health priorities set down in PL 93-641;
- $\frac{3}{4}$ said they did not know and understand the role and function of the National Health Planning Council;
- $\frac{1}{4}$ indicated they considered themselves neither well informed on health issues nor did they have a working knowledge of PL 93-641—the very legislation under which they act as policy and decision-makers;
- some said they did not understand the concepts of review and comment, certificate of need, and the definition and purpose of the Health System Plan and the Annual Implementation Plan.

The extent of this inequity of power and resources between providers and consumers can not be exaggerated. Providers are organized in powerful associations, societies, affiliations, etc. on local, state, regional and national levels. As a political force and as a technical arm of providers these associations concentrate the effectiveness of their representatives on boards and commissions which determine and implement health planning policies, standards, programs, and finances.

Provider representatives of well organized institutional or professional associations have access to most source information; technical staff to accumulate and analyze data; and professional staff to shape policy and program proposals. There are existing mechanisms for them to poll and/or educate their constituencies on proposals under consideration; they have the financial resources to hire statisticians, computer specialists, economists, health planners and any other experts required to further their interests. When a provider representative suggests a course of action, comments or votes on a proposal, it is in the language of the specialists and supported by quantified data; the probable outcomes have been considered, recon- sidered, analyzed, dissected and projected by multiple experts each working for the goals of providers.

Provider representatives also speak as the voice of a well-organized political force. On boards and committees, such as the HSAs and SHCCs, providers have constituencies whose interests they represent and to whom they are accountable. Further concentrating their political effectiveness, providers recognize their mutual interests and often vote together to assure the attainment of their objectives. In the face of consumer opposition, providers are prone to close ranks and coordinate their efforts to stifle any action not in their interests.

Providers seek to shape public attitudes in the media, through educational programs, and by powerful lobbying at all levels of government.

The irony of this situation is that providers use public funds and government subsidies to enhance their position. Indeed, the provider point of view is omnipresent.

In contrast, health care consumers are neither organized nor subsidized. They are represented on planning bodies by a varied array of economic, ethnic, community and job-related groups. Although consumer representatives on health planning bodies may be sharply sensitive to community needs and provider shortcomings, they have been able to do little more than react to provider-initiated proposals. Several facts are apparent:

- consumers do not have access to relevant data*
“...Consumers have been systematically denied access to health and patient/consumer information by most doctors and ancillary health professionals.”
(Birmingham consumer)
- consumers do not have the tools to analyze information presented to them*
“...Problem is the volume of material.”
(New York HSA member)

“...National data serves no purpose if in fact it is not understood...”

(California consumer)

“...Explanation of statistical and financial analyses are needed...”

(Illinois consumer)

“...If I could be briefed on certain issues before meeting(s). I review the materials with someone on staff. We get too much to read before meeting(s) and some of it I do not understand.”

(Alabama HSA member)

—*consumers do not have a means to consult with and share viewpoints with other consumers or their constituents*

“...In so many cases there is lack of intra-communication and one group does not have access or lines of communication to know what another group is doing.”

(Alabama HSA member)

Unlike their provider counterparts, consumer representatives have neither technical expertise nor the power of political force. They lack the resources to thoroughly analyze—sometimes even understand—proposals or to develop alternative ones of their own. Consumers often fail to see their mutual interest; many know little of negotiating techniques. Most perceive themselves as alone, without a constituency and without a need to be accountable; most feel powerless.

On HSA and SHCC boards and committees, consumers feel the provider presence and know of provider expertise. They are required to respond to provider proposals and, lacking knowledge and staff, feel pressured to endorse programs without understanding their content or intent.

Consumer representatives presenting their own health planning ideas and opinions are often challenged by providers. Frequently the success of such challenges is not based on the merits of consumer ideas, but rather on the inability of consumers to understand and express themselves in provider “shop” terminology—

“I feel insecure in making suggestions to HSA in board meetings. Person(s) on the board that are (of) professional background speak in such an overhead language that I feel out of place.”

(Alabama HSA member)

Consumers feel compelled to present their ideas garbed in the weighty cloak of acceptable research and documentation—

“I have a lot of ideas, but I think the board won't take them seriously unless I can point to some studies that have been done to back up what I'm saying.”

(New York consumer)

Consumers must withstand the pressure exerted by the providers' united front—

“...[the] consumers' point of view should be represented in the health planning decision-making process; and not circumvented, by-passed or 'tolerated' because the law says it should be represented but 'we' [providers] know better.”

(Chicago HSA member)

For providers the expense of maintaining associations that further their own interests—through political and technical support activities—is rarely borne by them. Rather, consumer and public dollars (via direct payment for services, reimbursement formulas, tax breaks, contributions, etc.) pay for these perquisites. Travel to professional meetings, association dues, subscriptions to journals—in brief, the costs of organizing and supporting the provider viewpoint—are considered legitimate business expenses passed along to all taxpayers, consumers, patients and subscribers.

Unfortunately, there is no such thing as a legitimate “consumer-business” expense. While no public funds are earmarked to advance the interests of health care consumers, public tax dollars are used to consolidate the political, technical and financial resources of the private, provider sector.

Current inequities have resulted in considerable ire and pessimism among health care consumers:

"At the present time consumers are not recognized by the established provider groups or regulatory groups in HEW. Consequently many costly programs of little value from a consumer's point of view are paid for with our taxes, while worthy...programs are shelved if they affect the providers' pocketbook."

(Alabama HSA member)

And from a New York PSRO staffperson:

"...The ultimate battle over health quality vs. profit, prestige and control is at the root of the problem."

In summary, consumers, though numerically dominant, lack the resources to fulfill their legislated mandate to participate in health planning activities as a responsible majority. This paper specifically addresses the lack of resources of consumers as the major issue facing health planning and consumerism. The proposed network of health consumers and consumer groups focuses on increasing the effectiveness—the breadth and depth—of the consumer voice.

A CONSUMER HEALTH NETWORK: GOALS, OBJECTIVES AND ENVIRONMENT

GOALS OF A CONSUMER NETWORK

The ultimate purpose in developing a national network of consumer organizations is to create an institutional means for consumers to participate in health planning at parity with providers. As a Chicago HSA member aptly stated:

"...decision-making is either in a professional or political context, either of which appears to be inaccessible to all but the most determined consumers."

Consumer representatives on health planning boards are expected to participate in the activities of the governing body and various committees. Since consumers have neither political nor technical support, their ability to be effective is severely hampered. Their ideas are independent of visible constituency support and often based on limited access and data. Their proposals are often challenged and infrequently affect decision-making. As so frequently occurred in Comprehensive Health Planning Agencies, consumers become frustrated and eventually many drop out of the process further undermining their ability to have a continuity in purpose.

Thus, in order to redress present inequities and to ensure effective consumer participation in health planning, a consumer network must seek to achieve goals in two areas: *political and technical*.

Political credibility and political accountability

Political credibility comes as a consequence of representing an organized visible constituency whose interest in the issues are sufficiently concentrated to cause them to support the organization's efforts and decisions. To be credible a board member must represent a definable interest group with political power. *Accountability* is a result of representing the interests of an organization. Representatives are accountable to their constituencies for the decisions they make.

Consumer participation in health planning began in 1966 with the passage of the Comprehensive Health Planning Act (PL 89-741), and was broadened in 1974 by the National Health Planning and Development Act (PL 93-641). Both Acts reflect the notion that the health sector can act as a replica of an ideal democratic-pluralistic model in which consumers and providers vie, struggle, log-roll and compromise in order to arrive at a socially responsive and economically viable health care system. However, the ability of consumer representatives on HSAs to bargain, compromise and press for their interests assumes the existence and backing of a powerful and articulate constituency. Without constituency, consumer presence on governing boards is, at best, advisory and, at worst, cosmetic.

The diffuseness of consumer interest in health matters and the lack of sufficient financial resources are the underlying reasons for the failure of a consumer consti-

tuency to spontaneously coalesce. These two factors are closely intertwined and mutually reinforcing.

Providers have continuous contact with, and interest in, the health care system. They are dependent upon it for their livelihood, personal and professional prestige. They organize to protect their rights and interests. Provider representatives on HSA boards have organized constituencies and they are politically credible and accountable. When, for example, an American Hospital Association representative speaks at an HSA board meeting, that person is speaking for, and with the weight of many of the country's inpatient acute care health facilities.

In contrast, most consumers have but intermittent contact with the health delivery system and thus they can not act effectively to ensure their stake in health care legislation, policies or plans. With the many other financial, familial, work and political claims on the time and resources of citizens, health care issues receive less attention than most other issues. Under these circumstances, the extent of consumer organizing around health matters is impressive. Still, the lack of resources in the consumer movement severely hampers effective organizing and concentrated political action.

Whether HSA and SHCC consumer board members represent the interests of, or are responsive or accountable to, an identifiable constituency is often questioned, by providers and by other consumers. Although HSA consumer representatives are legally required to be broadly representative of the demographic characteristics of the population (i.e. the social, economic, linguistic and racial groups and the geographic areas of each health service area) there is often no other relationship between HSA consumer board members and the community they represent.

Existing consumer groups have little direct connection or liaison with the federally mandated health planning structure. Consumer representatives on the HSAs boards have very little connection with one another or with their counterparts in other HSAs. The organizational structure and goals of consumer groups are also affected by the general public's diffused sense of the importance of health care issues and the concomitant lack of resources in the health consumer movement. Without a reliable funding source consumer groups are dependent on volunteer effort and thus characterized by lack of continuity and single issue concentration.

"Many groups...[have] many interests and changing chairmen so that it is difficult to keep in touch from one issue of interest to another. Specific problems cause [the] group [to organize] and then they tend to lose contact."

(Alabama HSA member)

Operating with subsistent budgets or dependent on volunteer effort, consumer groups must direct most of their energy toward organizational survival. Consumer groups, often structureless, and operating as ad-hoc committees concentrating intensely on a single issue have to settle for the attainment of modest objectives. This fact weighs heavily against their having significant impact on the HSA decision-making process.

Without communication, resources or structured organization there can be no political credibility or accountability. The goal of having a meaningful consumer influence in health planning decision-making cannot be achieved. The national network must provide the vehicle and resources to interrelate consumer groups and consumer representatives on HSA boards. This will create a political constituency and ensure the credibility and accountability of consumer HSA board members.

Technical capability

A network of consumer organizations must also provide technical assistance to HSA consumers and local consumer groups.

"...It is essential to provide technical assistance for a consumer voice which will provide meaningful consumer participation in health planning rather than more token involvement."

(Alabama HSA member)

Where access to resources is concerned, the magnitude of the gap between consumers and providers cannot be overstated. Provider interest groups have the capacity to

purchase consultant services, commission studies and spend money to influence the political process. Providers exercise virtually exclusive control over the collection, analysis and distribution of the most important health care data. Provider associations have managed to perpetuate professional domination over consumers and government health agencies. Institutional review procedures and provider-run PSROs stymie consumer efforts to retrieve, much less to evaluate, quality-of-care data. Where access to information is available, the data is difficult to interpret or analyze. Some data distributed under the guise of patient-provider relationship becomes unusable after deletions are made. (For example, financial statements are prepared without full disclosure statements, etc.)

Consumers need a technical arm to conduct research, gather and interpret data and develop policies and proposals. Just as providers can knowledgeably review HSA proposals, consumers also need this capability. The availability of a consumer-oriented technical resource will make consumer points of view and presentations viable alternatives to those of providers; they will be more factual, more acceptable and, in fact, more responsible. Only an independent technical staff, accountable to network groups and HSA consumer representatives, can accomplish the goal of technically empowering consumers so that they can develop their own health planning priorities, goals, objectives and programs.

NETWORK OBJECTIVES

To bring about the goals of technical and political equity for consumers in the health planning process, the CCAHS recommends that the following specific objectives be set for a national network of consumer organizations:

The Achievement of Political Credibility and Accountability

The network should foster and consolidate an organized consumer constituency that is tied into the HSAs. The network, as voice for that constituency, would help HSA consumer board representatives express consumer goals and positions, and would provide an organized presence of consumers at all health planning levels—a voice comparable to that of providers. Politically, the network should

“...provide [a] power base/constituency for consumers serving on HSAs and SHCCs. Be responsive to issues at all levels of planning.”

(Illinois HSA and SHCC member)

Specific objectives to bring this goal about would be the:

—*linking of already existing groups* with a communication system whereby consumers on the national level might know the concerns of consumers on local and state levels; and consumers on local levels be informed of national policy direction. About 80% of respondents ranked publishing a newsletter informing them of issues under consideration by the National Health Planning Council (NHPC) as very important. This network function ranked highest among the ten possibilities presented in the CCAHS questionnaire.

—*fostering of consumer organizing* in areas where consumer groups are weak or non-existent; develop and support consumer organizations on all levels. Respondents thought it important for the network to:

—“develop state and local units and provide them with support...”

(Alabama HSA member)

—“[be involved in] specific outreach and organizing...”

(California consumer)

—“coordinate national fund-raising activities for health consumer groups...”

(California HSA member)

—“provide knowledge of grant monies, help prepare proposals and help to secure funds”

(Chicago HSA member)

—“help local groups obtain necessary supplementary funding to expand membership and program”

(Chicago consumer)

—“...solicit the interest and then participation of consumers not now members of HSAs. It should make extensive use of press and other media to make known the work of the network and its primary constituency [present HSA consumer members]...”

(New York HSA member)

—“organize consumers”

(Illinois HSA staffperson)

—*speaking as an authoritative voice for health consumers*

—“An organized, well supported consumer advocate agency is absolutely necessary if any change can be expected in our system.”

(New York HSA member)

—“There is an extreme need for a consumer advocacy group expressing consumer viewpoints...”

(New York consumer)

Ninety-seven percent of CCAHS questionnaire respondents answered yes to the question “Should the network have the function of determining and advocating a consumer perspective on issues under discussion by the NHPC?”. To be effective, the network must act analogously to similar provider organizations (i.e. take public positions, present testimony as endorsed by the network, disseminate consumer health policy proposals to the press and legislators, etc.).

The network should:

—“develop positions for local action.”

(Alabama consumer)

—“lobby national (non-federal) organizations for support”

(Alabama consumer)

—“identify a network of “key” individuals between states that have political clout and who are supportive to consumerism, i.e. legislative figures, judicial figures. Also help local groups see *how* to use these people and how to approach them to develop a formal and informal power base”

(Alabama consumer)

—“leverage points, etc. I would rather see seminars etc. devoted to development of political sophistication and the realities of these influences in the health care system.”

(Alabama consumer)

—“lobby”

(two Illinois consumers)

—“identify public and political figures affiliated with health legislation; local and state levels”

(Illinois consumer)

—“lobby at all levels”

(Illinois HSA and SHCC member)

—“represent the consumer interest in HEW proceedings; provide consumer testimony in health planning legislative hearings; ensure circulation of information to local HSA and state consumer councils; provide legal support to consumer challenges if hearings are required.”

(New York consumer)

The Achievement of Independent Technical Capability

The network should ensure that consumers have independent information systems and technical expertise, to bring into being consumer-oriented and consumer-initiated policy-making:

“Finding consumer-oriented staff...and providing financial and educational resources to consumers are the two most important needs, if consumers are to be able to participate fully and effectively as decision-makers.”

(Illinois consumer)

On the questionnaire of the ten suggested services of a national health consumer network, “provide technical assistance” ranked second—after “publish a newsletter”—as an area considered very important by respondents. The goal of independent technical capability would be achieved by:

Providing Technical Staff. The network would provide or contract for consumer-oriented technical staff for re-

search, policy development, and consultation on health issues of concern to consumers. It would

"provide a resource file of consumer-oriented trainers, consultants, and other sources of technical assistance. Identify major consumer health issues and catalyze independent policy oriented research."

(Illinois consumer)

These services should be available to consumer members of HSAs, SHCCs and the NHPC. Within resource limitations these services should also be made widely available to network consumer groups.

Educating Consumers and Consumer Representatives. The network would support and develop courses, seminars, literature, newsletters, etc. on health planning and related subjects, thereby ensuring more effective consumer representation on HSAs, SHCCs and the NHPC.

Fighting For Access To Information. The network would act to make data on hospitals, costs, utilization, quality review, etc. available to HSA consumer members and network groups.

In the words of questionnaire respondents, to responsibly affect the health planning process, consumers need a technical arm to:

—prepare "*educational and explanatory materials*"
(Chicago consumer)

—"To point out *issues and alternatives in each project or plan* to be better able to see the implications and consequences or alternative actions"

(Alabama HSA member)

—to "*clarify the technical nature of the material [and point out] the emphasis and slant in the presentation of the material...*" (New York consumer)

—and prepare "*brief summaries of long papers...to explain implications*" (New York HSA member)

—to provide..."*an objective consulting source and access to evaluations to relate to requests of health care institutions...*" (Illinois consumer)

—to provide "*interpretation and implication of legislation and regulations...*" (an Illinois consumer)

—and "*explanation of statistical and financial analyses...*" (California consumer)

—to provide "*more background material when needed*" (New York HSA member)

—to conduct "*independent policy-oriented research*" (Illinois consumer)

—to "*prepare alternative suggestions...*" (Illinois consumer)*

The need for technical assistance is pervasive throughout the consumer movement and among consumer representatives. From education to consultation, from clarification to summation, consumers need technical help.

THE ENVIRONMENT FOR A CONSUMER NETWORK

Opportunities and Resources

The social and political climate bodes well for successfully achieving effective and responsible consumer involvement in a national health consumer network. The activism of the 1960s resulted in widespread skepticism concerning the intrinsic benevolence of entrenched institutions and an increased willingness on the part of many to take personal responsibility for matters affecting the public welfare. Accompanying these changes was an increased tendency to focus organizing efforts on the local, grassroots level.

Individual consciousness of health issues is particularly high now due to the growing concern with the highly publicized issues of rising hospital costs, environmental pollution, occupational health hazards and the health needs of categorical populations (i.e. the poor, women, the aged, and the other underserved groups). The women's movement has been especially active in health; community groups are also beginning to put health needs higher among their local priorities. In short, activism, skepticism and grassroots organizing have laid much of the groundwork for interested and active participation in a network of consumer health groups.

Within the current milieu there exist consumer-oriented health care groups—The Health Research Group, Washington, D.C., the Consumer Commission on the Accreditation of Health Services, New York City, the Social

Security Department of the UAW and the Social Security Department of the AFL-CIO are some of the better known—which are in communication with consumers, are sensitive to consumer needs and problems, possess the ability to apply their perspective to highly technical data, and are knowledgeable about and capable of entering the public arena to press for policy actions determined to be in the public interest.

These groups fill the unofficial role of public watchdog, initiators of independent research, consumer representatives at public hearings and to the media, analyzers and publishers of consumer-oriented health news, and developers of alternative policy proposals and model legislation. In general they have acquired much of the expertise necessary to organize and sustain a consumer health network.

However, these groups operate on a limited scale, and it is unclear how widely their work is read or understood by local consumer groups or by representatives serving on HSAs and SHCCs. These consumer projects are nonetheless exemplary of the consumers' potential for developing their own technical and informational sources; they constitute a repository of knowledge which could form the nucleus of a national health consumer network. Through the network, the studies, information and proposals of these groups would receive wider public exposure and might eventually be channeled to consumer participants in the HSA planning process as the policies of the network itself.

Local consumer groups such as the Health Education and Action League (HEAL) in Birmingham, the Association of Health Care Consumers in Chicago and Rhode Island Advocates in Providence possess considerable expertise in discerning local health problems and evaluating the effectiveness of the health delivery system at the community level.

Among consumers in general, a category which includes virtually every sort of person, there exists every kind of technical, legal, scientific and practical skill. All of these are potentially available to the network.

Finally, the recent formation of the national Consumer Coalition for Health is demonstrative of the present consciousness of the need for some larger expression of the consumer point of view than has heretofore existed. To take advantage of this level of involvement and channel it into the HSA process is the goal of the proposed network.

Obstacles

There are a few obstacles, some major, to the formation and effective functioning of a national network of health consumers. When asked to assess the importance of various areas as problem sources the respondents to our questionnaires ranked the following *very important*:

1. access to information—86%
2. finding consumer-oriented staff—81%
3. communication among consumer groups and individuals—80%
4. access to consumer decision-makers—80%
access to government decision-makers—77%
access to provider decision-makers—73%
5. obtaining funding—73%

Access to information. Health care providers have and continue to exercise strict control over many kinds of information—especially in the areas of utilization of resources and the measurement of quality in health care—which are of considerable importance to the network. HSA staff control access to the vast data which they collect to develop Health Systems Plans (HSP) and Annual Implementation Plans (AIP). They act as a filter of the data collected, compiled and analyzed, and, even more importantly, they now decide what data is to be collected. Information that does not support the provider's point of view is often not brought forth for review by consumers. In cases where this information must be included in lengthy documentation, its importance is not emphasized. It is possible that legislation will be required to loosen the provider grip on essential planning information. However, it can be expected that consumer organizations with vocal constituencies, national visibility and technical expertise can have greater success at obtaining data than has been experienced by disorganized, underfinanced and less knowledgeable groups and individuals. Although through the HSAs providers could make information gathering more difficult for

*emphasis added

the consumer network, the network would have the resources to independently collect and analyze data. Active consumer organizations using the network resources will be more successful in making HSA consumer representatives more credible, knowledgeable and productive.

Difficulty in finding consumer-oriented technical staff. In the current environment most experienced health planners make their living in the health care industry. Provider points of view in health care are so prevalent that consumers may have difficulty in finding professionals who identify with the perspective and sense of priorities held by lay persons involved in health. Nevertheless it can be reasonably expected that with sufficient resources a consumer organization will be able to compete with providers for experienced staff. Since many HSA personnel are sympathetic to the needs of consumers, some would probably choose to work for a consumer network as it would meet their professional and social, in addition to their economic needs.

Communication among consumer groups and individuals. Currently, interpersonal and group communication among consumers is hampered by insufficient resources, conflicting crisis and issue-oriented organizations and transient volunteer staff. Consumers need adequate finances and a stable organization, the creation of which may lead to organizational problems.

One problem of a network may be the difficulty in maintaining the organization so that it can accommodate the multiple views of consumers. A New York consumer put it this way:

"[An additional problem area may be] overall coordination of consumer interests with room for individual constituency interests and consortiums."

Actually, this surmountable problem has three aspects:

Diversity In The Consumer Population. As with other groups, there is no single "consumer" viewpoint. According to the legislative definition, a consumer is anyone who does not earn his or her living in health related services. The president of a local Chamber of Commerce, a city councilperson, a union member and a welfare mother are all consumers. Consumer groups range from labor unions to associations of parents of retarded children to neighborhood organizations. The interests, ideologies, organizational structures and constituencies of such groups are widely divergent. As a result, the effectiveness and comprehensiveness of a network could be threatened if the respective interests of constituent groups are not accommodated and focused within the larger organization. Assuming that these groups—however different from one another—do have some common purposes and needs as consumers, the network must be organized to enable consumer representatives on HSA planning bodies to receive a wide range of input from their constituencies and set priorities that a significant number can support. The lack of a stable, funded network allows this democratic diversity to weaken health consumerism because there is no organization to develop and put forth a credible consumer program. The network cannot operate on the assumption of consumer unanimity or of the uniformity of consumer needs for its services in different localities. Although all branches of the network will be directed by the established priorities and provide feedback on information requested at national and state levels, the task each local network unit sets for itself will vary according to local needs.

Resistance by Autonomous Groups. Community and advocate groups may fear being absorbed by a larger organization with a specific health planning orientation. In spite of the great need of such groups for support, they may fear that accepting assistance from a government funded organization will compromise their ability to take critical, adversary positions to defend the public interest. Further, they may anticipate that their affiliation with a well-funded network might put greater distance between them and their constituency due to the requirements made by an outside bureaucracy.

It is the goal of the proposed network to support and foster already developed health care consumer groups, not to subsume them. This will be done by making available to those groups the resources necessary to develop effective constituency participation in health care planning at every level.

In order to determine what areas of potential input are considered important by consumers and to determine the amount of receptiveness and support for a national network, CCAHS arranged to meet with people involved in health planning in four cities: Birmingham (South), Chicago (Midwest), Los Angeles (West) and New York (East).

It was the intent of the Commission that consumers from a variety of organizations and HSAs participate in these meetings. To make this possible a list of potential health care consumer groups and individuals in the four geographical areas was compiled. Written and telephone communications were established with:

1. The Health Education and Action League (HEAL) and the Center for Urban Affairs in Birmingham, Alabama;
2. The Association of Health Care Consumers (AHCC) in Chicago, Illinois;
3. The National Health Law Project in Los Angeles, California.

These groups were selected as liaisons for each area. Lists of health care consumers potentially interested in this project were developed and sent to these organizations to be contacted. Those consumers (or groups) listed were selected because of their interest in and ability to discuss the need, organization and possible functions of a national network of health care consumers.

In New York City meetings with representatives of health consumer groups were arranged with the assistance of the New York City Coalition for Community Health.

Conference dates were established and two questionnaires were developed. The first questionnaire was distributed before the meetings. Its purpose was to ascertain the general level of knowledge of consumers concerning the agencies, issues and functions of PL 93-641; their relationship with planning agencies and personnel; and areas considered to be potential problem sources. The second questionnaire was distributed at the conclusion of each meeting. Its intent was to gauge whether consumers favored the establishment of a nationwide communication network of consumer groups; how they believed this network ought to be organized and funded; and what functions it should perform. In sections reserved for comment, consumers were asked to identify their needs; discuss to what extent they believe they are effective in their present roles; offer their opinions on the need for a consumer network; and add to the list of the network's possible functions. Some of these responses have been quoted in the text of this position paper.

All but one respondent favored the establishment of a national network and 77% went so far as to say they would give some measure of financial support to its operation;

Resistance of Consumer Representatives. Consumer representatives on HSAs, SHCCs and the NHPC may not initially accept the network as a resource, especially when network conclusions differ from those which have grown out of the existing working relationships between consumer and provider representatives. Because of the range of backgrounds and ideologies of consumers on HSA boards, the activities of the network may be viewed with suspicion and hostility by some. Internal consumer differences may also initially hamper network credibility with the general public, health care providers and other consumers.

Access to decision-makers. The fact that questionnaire respondents perceived that their biggest problem was access to consumer decision-makers, as opposed to government and provider representatives, is clearly related to the general problem of consumer communication. It is symptomatic of the lack of an organized health consumer constituency. An organized consumer network would facilitate communication between the constituents and representatives. To the extent that the network achieves this goal its creation will be justified.

Obtaining access to government and provider decision-makers presents a related, but different, problem. Decision-makers are more responsive to the needs and desires of those who represent an organized, visible, politically potent force than they are to disorganized and diffused in-

94% said that they would like to actively participate in the functions of such a network.

Ninety-seven percent said the network should have the function of determining and advocating a consumer perspective on issues under discussion by the NHPC and 94% favored the establishment of a permanent national staff based in Washington, D.C. to provide assistance to the consumer members of the NHPC and to act as an independent consumer voice to DHEW.

Ninety-nine percent of the respondents were in favor of representatives of nationally-oriented consumer organizations serving on the network's governing board. Eighty-three percent thought that consumer members of the NHPC should also be board members. The suggestion that representatives of state and local consumer groups, and organized labor also serve on the governing board was frequently written in.

Over two-thirds believed that government should provide more than half of the network's financial support. More than a third believed that government should fully finance the activities of the network.

Of the respondents who are HSA members, 82% answered that they thought that finding a consumer-oriented staff was a major problem affecting their ability to function. Only access to information ranked as a more important problem—87%—in this group.

The same two problem areas—finding consumer-oriented staff and access to information—ranked highest with all respondents although the percentages were reversed with information being more important—84%—and staff second—81%. *Information* and *staff* are almost universally viewed as crucial to consumers in health planning.

Having a separate technical component is of great importance to consumer groups and consumer representatives in the planning process. Producing a newsletter to inform consumers of issues under consideration by the NHPC was considered very important, by 80% of the questionnaire respondents. Providing technical assistance and consultant services ranked as the next most important function. A majority favored retrieval of consumer opinion through circulation and analysis of questionnaires, independent monographs and position papers.

In summary, responding consumers favored the establishment of a national organization, a permanent staff based in Washington, D.C. and a governing board composed of representatives of nationally-oriented, state and local health consumer groups, the consumer members of the NHPC, and organized labor. Specific functions deemed most important were providing technical assistance and determining and advocating a consumer perspective on health planning issues.

terests. Thus, the limited political credibility of the health consumer movement impedes the ability of consumers to gain access to and effectively convince provider and government decision-makers. This situation should be changed by the proposed national network. Its aim is to develop and support the credibility of health care consumers involved in health planning. Its existence will make access to local and state health decision-makers by local consumer organizations easier; ensure more productive relationships; and identify for the planning agencies a recognized and credible consumer program.

Funding. In comparison to providers, consumers are entering the health planning arena with little or no public support. Health providers have built a constituency over the last 50 years—mostly with public funds, tax incentives, and tax exemptions. Consumers are beginning that process now. When adequately funded, the consumer network can be instrumental in closing the resource gap between providers and consumers and can be the vehicle for continuous, informed consumer input into health planning. Funding is needed to hire staff, collect data, publish newsletters, reviews and summaries, develop and implement feedback mechanisms, provide effective education and consultative services, and engage in other activities needed to shape the sporadic surfacing of consumer outrage into knowledgeable, continuous and responsible participation.

ORGANIZATIONAL POSSIBILITIES FOR A NATIONAL NETWORK

In seeking to determine the optimal organizational structure for the administration of a nationwide network of health care consumer organizations, CCAHS staff examined and discussed several alternative possibilities. This section will concisely explain the advantages and disadvantages of these alternatives.

THE NETWORK AS A FUNCTION OF CURRENT PLANNING AGENCIES

The first question to be examined is whether or not existing HSA or Regional Health Planning Center staffs can be used to perform the functions we have postulated for the national health consumer organization.

Initially, the idea of using existing staff offers several attractive advantages. Health planning agencies and centers are already organized, have expert staff, access to data and decision-makers, and are recognized as legitimate sources and centers of health planning activities. If it were possible to achieve network goals and objectives by assigning one or several current staff members to consumers, it would probably cost less than establishing, staffing and operating a new, independent organization.

However, there are significant reasons why it would be impossible for HSA or planning center staff to act as the administrative and technical component of a national network of HSA consumer representatives and health consumer organizations. First, these functions would be in conflict with the intent of the law and the practical necessity that agency staff remain independent of special interests and take an objective view of policies and proposals. Consumers need staff who can evaluate data and proposals and suggest policies and alternatives with the intention of representing the particular need of their constituencies.

"The network needs to help consumers to feel independent from the staff of [the] HSA and to understand their role in being responsive for consumer constituency. To educate and publicize for consumers the politics involved in the health care system and the need for a political strategy to counter balance [it]."

(New York HSA member)

Just as providers independently review proposals made by HSAs and regional centers in light of their interests, consumers also need to have an independent review capability. Agency staff are tied into the planning process in a manner that prevents them from working for consumers exclusively. The function of staff is to implement policy formulated jointly by providers and consumers—in fact, just those consumers whose effectiveness the independent network seeks to augment. Staff cannot and should not be expected to take a special, consumerist point of view. HSA and planning center personnel often identify with provider goals, ideals and objectives because of their professional background and training. Additionally, in sheer numbers alone, agency staff delegated to assist consumers can in no way hope to match the high technical and administrative capability of the provider sector.

The network also has political goals. To facilitate credibility the network seeks to organize a knowledgeable consumer constituency. This organizing is outside the scope of expertise of agency staff and contradictory to the definition of staff as objective advisors.

It is a necessary conclusion that planning agency staff cannot be utilized to achieve the goals and objectives of a national network of health care consumers which is primarily concerned with the health planning process. Rather a separate structure, comparable to the independent provider organizations, with its own staff, is critically important to the realization of effective consumer participation in health planning.

THEORETICAL MODELS AND POSSIBLE APPLICATION

Professor Hyman in *Health Planning: A Systematic Approach*¹ identifies four generic organizational models: the systems, partnership, alliance and individual action models. They are distinguished by the degree of their abil-

¹Herbert Harvey Hyman, *Health Planning: A Systematic Approach*, Aspen Systems Corporation (Germantown, Maryland), 1975.

ity to achieve goal, objective, and program development and integration; and the amount of control each has over the resources necessary to implement its policies. As most organizational forms fall within the spectrum created by these ideal types, they were employed as conceptual models to direct our effort to devise the structure best able to achieve the network's stated goals. The advantages and disadvantages of these theoretical models are presented below.

The Systems Model

The greatest control over the resources necessary to plan and implement goals is assumed in the systems model. The basic authority structure is unitary, i.e., decision-making power rests within itself. The board of such an organization will be composed of likeminded people who share similar organizational goals. Goals are expected to be highly articulated, and integrated linkages between goals, objectives and programs are expected to exist; goals are likely to be achieved. Program approval is determined on the basis of its fitting into the goal-oriented plan.

The explication of this model leads one to envision a rather classical bureaucracy with hierarchical structures of authority, responsibility and accountability. The organization's ability to achieve its goals is based on the technical expertise of its component parts and individual members. The model assumes that primary identification of board and staff members would be with organizational goals. Most modern corporations are based on a model similar to this one.

To accomplish the tasks delineated for the proposed national organization of health care consumers this model, if chosen, would require the establishment of a three-tiered hierarchical bureaucracy organized in parallel to the existing structure of health planning agencies on the local, state and national levels. A national board would be composed of individuals who primarily identify with the network rather than constituent groups; a full time executive director would be delegated considerable authority in carrying out the board's policies. Staff would also be full time, hired for their expertise and accountable to their superiors within the organization. Each organization level would be accountable to and monitored by the next higher one.

Such an organization would, to a considerable degree, be independent of local consumer groups and local politics. Programs which require marshalling internal technical capability can be expected to be achieved. Communication within the organization would follow established patterns designed to maximize efficiency and accuracy. Internal supervision and lines of responsibility could be delineated with predetermined standards and criteria.

Although the systems model appears likely to be efficient and effective in achieving the technical goals of the consumer network, two of its most vital characteristics—autonomy from clientele groups and dependence on expertise—might well work against the achievement of the organizational goal of creating a consumer constituency. It is doubtful that a new quasi-governmental bureaucracy which did not directly assist consumer groups in their own search for resources sufficient to assure continuity and enable them to direct their efforts away from organizational survival and into more positive activity, would gain the support of the consumer movement.

The Partnership Model

The partnership model is structurally a federation, although some power is delegated to the partnership itself. Authority primarily resides in the independent organizations whose representatives sit on the governing board. In this type of organization it is likely that general goals will be established but unlikely that more than a few general objectives can be agreed upon. In a partnership, coordination is normally achieved through compromise, bargaining, and persuasion. It is unlikely that many specific programs would be identified since such identification would immediately disturb the balance of power—giving it to one group and taking it away from another; program approval can be expected to be based on the influence of supporting groups rather than on conformance to systematic criteria developed to determine program impact on the achievement of organizational objectives.

If modeled as a partnership, a national health consumer network would probably consist of a central office with limited independent power, a governing board made up of individuals representing other organizations with whose goals they are primarily identified—such as HEAL, AHCC and CCAHS—and a politicized bureaucracy probably as accountable to their governing board allies as to their hierarchical superiors. Policy-makers are likely to agree on long range goals, but disagree on the means to achieving such goals. In the past—as experienced in CHP “b” agencies—maintaining the status quo has often been the primary achievement of such organizations.

A consumer network organized as a partnership might exacerbate the problem of conflicting ideologies within the health consumer movement by institutionalizing representation by self interest group. It may also have difficulty in achieving consensus on what political stand to take or program to implement. Yet, this type of organization is viewed as that which most nearly reflects democratic pluralistic goals. Neither in word nor in writing did any consumer interviewed during the CCAHS survey suggest any policy-making structure other than a partnership. It appears that only in the federation environment will consumer groups feel that they can continue to control their own policies and disposition of resources while supporting and having a say in the actions of a viable national organization.

Although in the partnership type organization decision-making is carried on in a federation atmosphere, implementation of policies is still the responsibility of the administrative bureaucracy. As in an organization structured after the systems model, this bureaucracy would be independent of local consumer groups—although probably more attentive than a systems-type staff to the desires of the currently powerful group or coalition. Thus a partnership style network would not solve the problem of directly assisting consumer groups and, on the local level, might well be perceived as equally formidable and quasi-governmental as the units of a systems-type organization.

The Alliance Model

The alliance model is based on the concept of goal-oriented volunteerism. Each sub-unit retains its autonomy giving over none to the central organization and only agreeing to act in concert on issues of mutual interest. If the organization has any independent goals at all, privately, each member group hopes to gain something different from the outcome. Neither a long range course of action nor a central coordinating board with authority to act independently is likely to be accepted. Objectives can be expected to be developed in an ad hoc, arbitrary fashion, often as a result of a crisis which calls for a position to be taken by the organization. Programs will be determined in committees by the controlling alliance. Although motivation may be high, concurrence on any particular issue probably cannot be transferred to another issue. Therefore, an alliance is not likely to be an enduring organization; it exists issue to issue.

An alliance composed of consumer groups chosen by DHEW, funded and charged with the responsibility of carrying out network objectives would be one way of overcoming the previously stated objection to the establishment of a separate, quasi-governmental bureaucracy without intimate connection to the consumer movement. Through an alliance resources would flow into consumer groups enabling them to hire expert staff, expand their constituency and develop a communication network with other groups and individuals in their area.

Nevertheless an alliance probably could not achieve, in a continuous fashion, the coordination necessary to provide timely feedback of information and ideas to consumer representatives at the state and national levels. Nor would such an alliance be likely to develop specific statewide or nationwide objectives and programs. It is possible that DHEW staff could monitor the actions of alliance members who would be required to coordinate their activities as a contractual obligation. However, this structure leads once again, inevitably, to consumers' objections to be directed by or accountable to a government agency.

Additionally, the requirement that the network integrate the various, often divergent, views of consumer groups and present a well thought out broad range of ideas to con-

sumer health decision-makers, is unlikely to be within the scope of the arbitrary and independent decision-making processes which normally occur in alliances. Clearly consumers would object to DHEW, as the central office of the alliance, performing such functions and making such decisions.

The Individual Action Model

The individual action model assumes a narrow, homogeneous, action-oriented group, composed of individuals, each acting in his or her self-interest. There is no one place where decision-making can be said to take place; authority remains with each individual. The organization can be expected to focus on the program level with little concern for integration and no pretense at setting goals or objectives. The internal decision-making apparatus is usually so fragmented that only program proposals submitted by external groups are approved and these programs relate primarily to the interests of the program initiators. The individual action organization is basically adaptive in nature; it is more likely to respond to outside initiative than take positive actions on its own.

It is apparent that the individual action model is not suited to developing and achieving the broad long range goals and objectives of a coordinated networks of health consumers at the national, state and local levels.

RECOMMENDATIONS

The recommendation section of this paper will be divided into two sub-sections.

The first will explicate the structure which as been determined to be an acceptable compromise of the various organizational models. This hybrid model will maximize the network's ability to achieve stated goals and objectives.

The second section presents several of the network's component parts, each of which can be separately implemented. The purpose of this section is to address the practical problems of establishing an organization of the proposed scope, i.e. the possible need for legislative approval and the required level of funding that may have to be attained over several fiscal periods. Meanwhile, individual sub-units of the network, and other supportive activities can reasonably and systematically be implemented.

THE NETWORK

The proposed national network would be a private, not-for-profit corporation with a structure combining features of the partnership and alliance models. Through a series of contracts, network affiliates corresponding to each local and state health planning agency would be established. Consumer groups meeting established criteria would be eligible to become fully affiliated with the network. Individuals, organizations and institutions wishing to support the network could become members by making a contribution or by paying established member fees. Regional offices of the central corporate body would be developed to provide expert assistance to affiliates and to foster consumer awareness and organizing.

At a national level the governing board would be organized based on the partnership, pluralistic model—composed of representatives of nationally-oriented consumer organizations with an active involvement in health care issues, state and local level consumer groups, labor and management associations and the consumer members of the National Health Planning Council. This body would be charged with policy-making duties and would be responsible to the government for the disbursement of funds in accordance with the corporation's charter and applicable laws.

A system similar to the current government Request for Proposal (RFP) program would be employed to select consumer groups for affiliation. The national governing board would establish eligibility criteria and minimum standards and functions which consumer groups must meet before being considered and approved. The final selection of network affiliates will be the responsibility of the board.

Central office staff would be established in Washington, D. C., a national (chief) executive officer would be hired and a staff of experts hired or retained as needed. The executive and staff would be directly accountable to the governing board for their decisions and actions.

The national staff would be responsible to:

- provide technical and educational assistance to the consumer members of the National Health Planning Council;
- develop a mechanism to distribute and retrieve consumer-oriented health information and consumer-derived policy alternatives and perspectives;
- create and implement a system to provide timely feedback on specific issues to the consumer members of the NHPC from consumer constituents (to obtain nationwide feedback the national staff would interface with the state affiliates who would develop their own communications mechanisms within their states);
- monitor the performance of state and local affiliates;
- assist groups requesting designation as network affiliates;
- evaluate and make recommendations to the governing board concerning affiliation requests;
- supervise and provide technical expertise to the staff of the regional offices;
- develop policy statements as needed on important health planning issues; and
- publish a regular newsletter on health matters.

At the state and local levels network sub-units would be recognized consumer groups whose functions within the network would be governed by specified contractual obligations. The network will thus become linked to the affiliate's constituency and take advantage of its need to be accountable to consumer interests. The network will enhance the group's credibility with local consumers, providers and government.

Theoretically, state and local network components would relate to each other and the central organization much as do members of an alliance—as autonomous units acting primarily in their own interest. However, while working to accomplish their own objectives, these consumer groups would simultaneously be achieving network goals—expanding their constituency, increasing their credibility, hiring technical staff, and expanding their knowledge of and impact on the health system. Thus the motivation and enthusiasm usually associated with the activities of an alliance member whose own interests are in concert with those of the larger organization would be channeled into network activities.

The disadvantages of an alliance—arbitrary decision-making and lack of mutuality and continuity—would be minimized since basic policy decisions would be made at the national level where state and local groups would be represented but not have unilateral authority. Contracts will be competitive, monitored and re-negotiable; to maintain their network affiliation consumer groups will be required to further network objectives. Mutual interest and contractual obligation will combine to make state and local network affiliates dedicated and accountable to the goals of the national organization.

In those states which have only one Health Systems Agency, one group will be sufficient to handle state and local network functions.

At the state level the network affiliate will be responsible to:

- provide technical and educational assistance to the consumer members of the State Health Coordinating Council;
- coordinate data and information from local network affiliates;
- cooperate with the national staff to gather and distribute information, create and disseminate consumer-oriented policies and alternatives and provide feedback to the NHPC concerning consumer's views on specific national health planning issues;
- create a feedback mechanism to the consumer members of the State Health Coordinating Council on the ideas and alternative suggestions of their statewide constituency on issues under discussion;

- open up channels of communication between established health care decision-makers—providers and government—and local consumer groups; and
- create and implement programs specific to the informational and educational needs of consumers in their state.

At the local HSA level, network affiliates will have the following similar functions:

- provide technical assistance to the consumer members of the Health Systems Agency;
- cooperate with the state group in achieving national and state objectives;
- act as an intermediary between consumers and decision-makers;
- develop and implement programs specific to local needs; and
- organize consumers and support local health consumer groups. (The expansion of an identifiable health consumer constituency will primarily occur in local areas.)

Regional offices of the network will be established to provide specialized assistance to the affiliated groups. The purpose of these offices will be to parallel the functions of the current regional health planning centers of PL 93-641. It can be expected that many local consumer groups will not be able to initially recruit consumer-oriented health planning experts to provide consumer representatives with a wide range of technical assistance. The regional centers will be available to provide such assistance as it is required. Where consumers are not organized, regional staff will seek to foster their organization.

The staff of the regional offices will be hired for their expertise. They will be accountable to the national staff through direct lines of organizational responsibility. Insulated from local politics they can be expected to exercise a coordinating influence—based on national policy objectives—on the actions of network affiliates throughout the country.

In a letter of endorsement written after reviewing this position paper and the proposed organization for a national consumer network, Frank Giarrizzo, President of the Association of Health Care Consumers, Inc. (AHCC) in Chicago, Illinois, stated the following:

“The model you recommend is similar to the one AHCC has been developing in Illinois. We consider this approach to be the only logical one since it very closely parallels the present HSA network established under PL 93-641.

It is imperative that consumer groups receive public funding so that they can participate fully in health planning... [The] future [of AHCC] is uncertain unless new sources of funding develop. Without public funding I believe our job is politically impossible.”

Funding—There are three possible funding mechanisms for a national organization of health care consumer groups of the scope outlined above. The first method would be direct government appropriation channeled through DHEW to the national office of the consumer network. An important disadvantage of this method is that it would link network financing to a highly political process in which providers could exercise their considerable influence against assuring sufficient or continuous funding to consumers. Consumers cannot now be expected to lobby effectively enough to counteract the influence of provider political clout. Indeed, it is the very inequity in the distribution of political and technical resources between health care consumers and providers which has created the need for a national consumer network. For this reason, direct disbursement is not the preferred funding mechanism.

The second possible funding method requires that an equitable percentage of all government payments for institutional health care be directed to the consumer network. The advantage of this method is that it spreads the costs across the community—as does direct appropria-

tions—and it links the amount of money allotted to consumers to government expenditures not to the exigencies of the political process. An amendment to the Social Security Act concerning the rate of reimbursement to facilities participating in government programs would be required to implement this method. The amendment would allow the reimbursement formula to include a percentage for consumer support in proportion to that allowed for support of provider-oriented activities. For example, in 1974 \$40.9 billion was spent for hospital care in the United States; of this amount 52.9%—\$21.628 billion—was paid by government agencies. With an annual budget of just one-tenth of one percent of this amount—\$21.6 million—a national network of health care consumer groups of the scope outlined in this paper could already be a reality. (Figures taken from *Medical Care Expenditures, Prices, and Costs: Background Book*, DHEW, Social Security Administration, Office of Research and Statistics, September, 1975.) A like amount would be deducted from provider expenditures allowed for professional and institutional organization fees, JCAH charges, and provider political and legislative expenses so that in the aggregate health care costs would not rise.

The third method for funding the network would require the amount of government reimbursement spent by institutional providers be identified for some period—e.g. 1976—and, in the future, a proportion of that amount be channeled to consumers. The remaining portion would go to providers. The base year amount would be updated annually. *This method would also not increase health care costs* and it would make funding of a consumer network significantly independent of political processes. This method is the most preferred of the three possible funding mechanisms identified.

Regardless of the funding method chosen, government policies should be amended so that expenses incurred while participating in network activities or by purchasing network or other health consumer goods and services—e.g. the costs of attending meetings and conferences, purchasing journals, hiring consultants—be recognized as legitimate tax deductible items.

Through these combined mechanisms the consumer health care network can be assured continuous funding at levels sufficient to attain its objectives.

The CCAHS recommends that further study be done on the development of methods and formulae for funding a national health consumer network.

NETWORK COMPONENTS

The proposed national network would be composed of several sub-units which could function independently. Although the achievement of the goals and objectives outlined in this paper requires the establishment of a total, integrated national consumer network, the implementation of each network component will further the fair proportioning of resources between consumers and providers of health care and the formation of an organized, informed consumer constituency.

The following are several proposals for the independent establishment of various network components:

Technical Assistance for Consumers on the National Health Planning Council. The purpose of this proposal would be to provide technical assistance to the consumer members of the National Health Planning Council. The multi-disciplinary project staff would assist consumer representatives on the NHPC to better understand the background and implications of issues raised at council meetings. At the request of consumer council members the project staff would engage in independent policy-oriented research and the development of independent proposals for planning guidelines and national goals, objectives and program criteria.

Technical Assistance for HSAs and SHCCs. The purpose of this proposal would be to create pilot projects to provide technical assistance to the consumer members of several Health Systems Agencies and State Health Coordinating Councils. Project staff would assist consumer representatives to make informed decisions when evaluating pro-

posals and plans and deciding on the disposition of health development grant monies. Specifically the project staff would prepare summaries of proposed projects; clarify the meaning of technical data; explain the subtler issues and their implications; and point out possible alternate methods of achieving goals. The staff could also prepare educational, explanatory and background material for consumers. In addition, the project staff would, at the direction of the consumer board members, conduct policy-oriented research and develop independent proposals to be submitted to the agency by consumer representatives.

Statewide Network of Health Consumer Organizations. This proposal would create a program to organize statewide networks of consumer groups with an interest in health care planning issues. The function of project staff would be to identify consumer groups in each of the state's HSA areas and to facilitate communication between and among them and with the State Health Planning and Development Agency (SHPDA) and the State Health Coordinating Council (SHCC); develop mechanisms—written or phone questionnaires for example—to determine the views of consumer groups on health planning issues and pass this information on to consumer representatives at the state level; hold statewide conferences at which consumer group representatives could meet each other and share ideas, experiences and information; act as a point of interconnection between groups by accumulating and disseminating information concerning the expertise and interests of specific groups; and act as a central focus for organizing activities.

Organizing Health Consumers. This proposal would create projects throughout the country to organize consumers around health care planning issues in those health system areas in which such groups do not now exist. In the process of organization the staff would also educate and provide technical assistance to these groups such that they might begin to make their presence felt both to their representatives on the HSA board and independently at public meetings and hearings.

Health Advocacy Project. The purpose of this proposal would be to fund a project to provide representation for community groups, consumers, and patients in hearings before and meetings of several local Health Systems Agencies, State Health Planning and Development Agencies, and State Health Coordinating Councils. The multidisciplinary project staff would represent consumers in Certificate of Need and Section 1122 proceedings, health plan development meetings and in hearings concerning the dispersal of areawide health development grants.

By giving consumer interests the benefit of skilled advocates and technical expertise, such as is regularly depended upon by providers, the project's activities would help to insure that agency decision-making is based on a balanced input of views.

Regional Consumer Resource Centers. The purpose of this proposal would be to fund the establishment of regional centers—on the model of current regional health planning centers—specifically concerned with assisting consumer representatives on Health Systems Agencies and State Health Coordinating Councils. The Centers would perform multiple functions such as providing technical assistance to consumers; developing training projects and conducting seminars and classes specifically geared to the needs of consumer representatives; acting as a clearing house for consumer-oriented information; developing and making available resource lists of consultants and relevant professionals by their field of expertise and consumer groups and individuals and their areas of interest and expertise; publishing a newsletter oriented to regional health planning issues; preparing and disseminating information clarifying highly technical health planning issues; and analyzing the implication to consumers of various national and state laws, rules, regulations and administrative practices.

A National Health Planning Newsletter. The purpose of this proposal would be to organize a newsletter with national circulation geared to publicizing and providing background data and consumer oriented analysis of health planning issues under discussion by the National Health Planning Council; planning rules, regulations, standards,

guidelines, etc. as they are discussed and decided by DHEW; and relevant legislative developments. The primary target audience of this newsletter would be the consumer members of local Health Systems Agencies and State Health Coordinating Councils. This newsletter would increase the information level and sense of national involvement and purpose of consumer board members. Through attached questionnaires and a column featuring letters on relevant issues, the newsletter could become an important resource for the consumer members of the NHPC in providing access to and feedback from their counterparts on other agencies who presumably are in closer contact with the needs and views of consumers throughout the country.

A National Consumer Information and Educational Service. This proposal would fund the establishment of an organization to publish a national health newsletter and develop educational materials specifically designed for consumer representatives on HSA's and SHCC's. The newsletter would serve as a chronicle of consumer activities and a disseminator of consumer expertise. The education service would focus on materials explaining the health system and certain currently topical issues.

This newsletter would not be limited to issues under consideration by the NHPC as would the National Health Planning newsletter. Rather, broadly relevant local HSA activities would be featured, e.g. how consumers have dealt with such problems as overbedding, hospital costs, review of provider applications, evaluation of Health System Plans, Annual Implementation Plans and the like. The issues, problems and experiences of consumers in organizing around health issues would also be addressed. Besides being responsible for reporting from all regions, the newsletter would feature in-depth, informative articles on planning-related topics, chart current federal developments, and print resource lists and bibliographies of use to consumers on HSAs and SHCCs. The newsletter staff would establish a liaison with consumer representatives in each state and HSA district who would feed local news to the central editorial staff.

The consumer education service would have functions similar to the regional resource centers but would be centrally located and thus more geared to issues of general concern and less able to focus on particular regional interests. The service would produce and distribute—perhaps in conjunction with the HSAs, SHCCs and Health Planning Centers—consumer-oriented educational materials for those who have taken on unaccustomed roles in the planning process. Of particular concern would be materials which summarize, in language understandable to lay persons, the various aspects of the health delivery sector; health legislation; the roles of regulatory commissions and other bodies; review and accreditation procedures; the current state of knowledge on such nationally important and controversial technical subjects as the efficacy of computerized axial tomography or the cost efficiency of hospital-based renal dialysis; and the like. In addition, the educational materials would be developed addressing the problem of how to organize consumers around health issues.

A national editorial board—consisting of recognized consumer leaders—would be created to oversee all educational activities and guarantee editorial accountability to consumers.

Planning and Developing New Health Services. Section 1513 (c) (3) of PL 93-641 creates Area Health Services Development Funds (AHSDF) to be financed with grants made under Section 1640. The purpose of these monies is to enable HSAs to make grants and enter into contracts with individuals and public and non-profit private entities "to assist them in planning and developing projects and programs which the agency determines are necessary for the achievement of the health system described in the HSP." AHSDF funds are earmarked for new services needed by and designed for the community. We propose that as a means of supporting the creation of responsible consumer proposals in health planning preference be given to local health consumer groups as recipients of such grants and contracts. Also, any grants channeled through other than consumer groups, should require the review, and, where appropriate, approval of local HSA consumer representatives and designed local health consumer organizations.

CONCLUSION

The overwhelming need for the establishment of a consumer health planning network with the goals of technically and politically educating and empowering health care consumers and linking this organized, informed consumer constituency to the planning agencies of PL 93-641 has been presented. The goals, objectives and environment of such an organization has been discussed; an organizational structure has been developed and several of its components have been suggested for immediate, independent funding.

The existing need makes the establishment of a national health consumer network imperative. The potential cost

savings from constructive consumer-derived health plans will more than offset the costs of establishing this network. In any case, the preferred funding proposal would not increase health care costs.

The success of many current legislative suggestions for the future organization of the American health care system may well depend on the previous existence of organized, knowledgeable health consumers to act as responsible participants and overseers on behalf of the public interest. An informed citizenry will improve health planning now and the health system in the future.

SHELLEY B. FROST—RESEARCH DIRECTOR AND ASSOCIATE EDITOR

The Consumer Commission's Board of Directors

Donald Rubin, President & Editor Edward Gluckmann, Exec. V.P. & Editor Richard Asche, Secretary T. Roland Berner Lillian Bloom Alan Brownstein Jay Dobkin, M.D. Marshall England Alice Fordyce Florence Galkin Frank Goldsmith John Hoh Herbert Hyman	Gail Gordon Sidney Lew Hugh Pickett Inder Persaud Rosina Reilova Lillian Roberts Joan Saltzman Bernard Shiffman Sol Silverman Joseph Tarantola Milton Tarris, M.D. Eleanor Tilson Benjamin Wainfeld, M.D. Judy Wessler
---	---

Consumer Commission on the Accreditation of Health Services, Inc.
 377 Park Ave. South, New York, N.Y. 10016

- \$25.00 Organization Subscription
 \$10.00 Individual Subscription

ORGANIZATION _____

ADDRESS _____

CITY _____ STATE _____ ZIP _____

Back issues of HEALTH PERSPECTIVES and CCAHS QUARTERLYs are available at \$1.00 each.

HEALTH PERSPECTIVES

VOL. I #1 April 1973 VOL. I #2 Sept.-Oct. 1973 VOL. I #3 Nov. 1973 Jan. 1974 VOL. I #4 Feb.-April 1974 VOL. I #5 May-June 1974 VOL. I #6 July-Aug. 1974 VOL. I #7 Sept.-Oct. 1974 VOL. I #8 Nov.-Dec. 1974 VOL. II #1 Jan.-Feb. 1975 VOL. II #2 Mar.-April 1975 VOL. II #3 May-June 1975	The Commissions Program Hospital Profile #1 Hospital Reimbursement Rates Blue Cross, Medicaid, Workmen's Comp. Profile of Governing Bodies of the New York City Voluntary Hospitals Profile of Patients' Rights and Hospital/ Patient Representatives Open Heart Surgical Facilities in New York City area Freedom of Information— The Right of the Public To Know Hospital Inspection—Its Importance to the Consumer Health Dept. Reports on HIP Importance to Consumers Ambulatory Care Program: A Role for the Consumer Hospital Accreditation: Where Do We Go from Here? Malpractice! Consumers' View	VOL. II #4 July-Aug. 1975 VOL. II #5 Sept.-Oct. 1975 VOL. II #6 Nov.-Dec. 1975 VOL. III #2 Mar.-April 1976 VOL. III #3 May-June 1976 VOL. III #4 July-Aug. 1976 VOL. III #5 Sept.-Oct. 1976 VOL. III #6 Nov.-Dec. 1976 VOL. IV #1 Jan.-Feb. 1977 VOL. IV #2 Mar.-April 1977 VOL. IV #3 May-June 1977 VOL. IV #4 July-Aug. 1977 VOL. IV #5 Sept.-Oct. 1977	National Health Care Quality Control: The Alternatives Hospital Reimbursement: Importance to Consumers Clinical Labs: Importance to the Consumer Health Planning: A Consumer View Full and Equal Participation: A Consumer Objective Health Planning and Reimbursement Surgery: Consumers Beware Hospital Social Work: Consumers' Critique National Health Service I National Health Service II National Health Service III The Development of A Consumer Health Network (\$2.00 per copy)
---	--	---	--

CCAHS QUARTERLY

1. Fall 1973 2. Winter 1974 3. Spring 1974 4. Summer 1974 5. Fall 1974 6. Winter 1975 7. Spring 1975 8. Summer 1975	Hospital Accreditation and the Role of the Consumer A Comparison of Hospital Surveyors in New York State Consumer Experiences in Hospital Accreditation Joint Commission on Accreditation of Hospitals (JCAH)—The Lincoln Hospital Experience Occupational Safety & Health (OSHA)— A Means To Improve the Health of Americans: Part I OSHA and the Health System: Part II Nursing Home Transfer Trauma— The Public Interest Cancer and Jobs	9. Fall 1975 10. Winter 1976 11. Spring 1976 12. Summer 1976 13. Fall 1976 14. Winter 1977, Spring 1977 15. Summer 1977 16. Fall 1977	OSHA Guides I and II Nursing Home Transfer Trauma— Part II Health Planning Systems Agencies— Planning for OSHA Hill-Burton Free Care Provisions— A First Step HSA and Hospital Governing Bodies— Conflict or Complement An Occupational Safety and Health Workbook (\$4.00 per copy) Hospital Licensure by Private Accreditation Occupational Illness—Workers' Compensation Doesn't Work
--	--	---	--

PUBLISHED BY CONSUMER COMMISSION ON
 THE ACCREDITATION OF HEALTH SERVICES INC.
 377 PARK AVE. SO., NEW YORK, N.Y. 10016
 TELEPHONE: 689-8959



Non-Profit Org.
U. S. POSTAGE
PAID
New York, N. Y.
Permit No. 7681