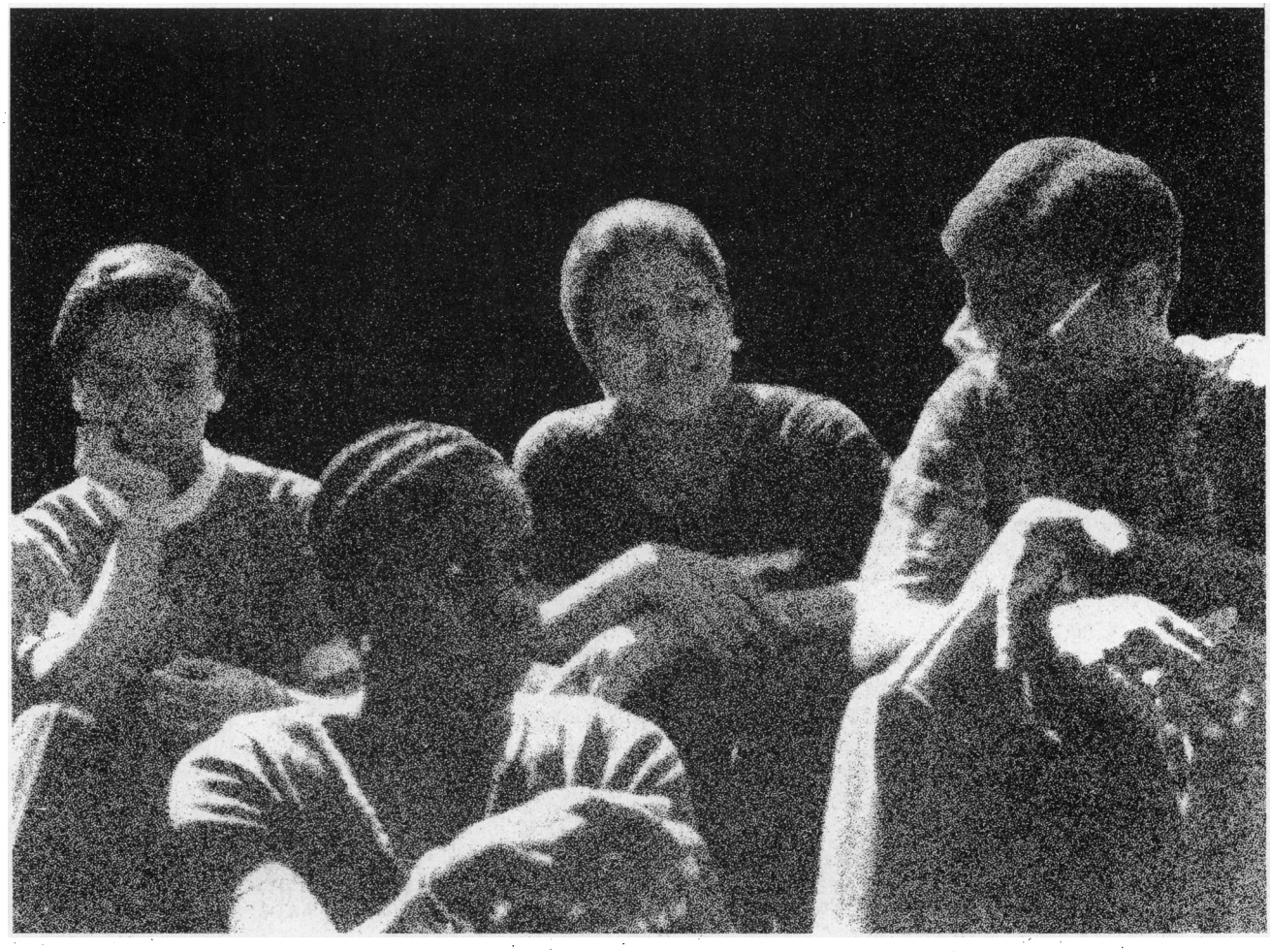
An Approach to Consumer-Patient Activation In Health Maintenance

A report of the Maryland 1-year health education demonstration project

VIRGINIA LI WANG, MPH, PhD, HAYDEN REITER, MPH, GEORGE A. LENTZ, Jr., MD, and GENE C. WHAPLES, PhD

MEDICAL CARE is only one aspect of health care—there is a need for a broader health focus that emphasizes health maintenance and disease prevention. It has been suggested that the greatest single untapped manpower resource is the individual consumer who can take the initiative to preserve personal health. When sufficiently motivated or "activated," the educated consumer will take positive steps to prevent the occurrence of illness, the progression of minor illnesses, or the onset of personal dependency. This consumer will understand the changing delivery system and how to gain entry to it. Moreover, he will learn what he can accomplish by self-help before calling on the formal health care delivery system. Thus, consumer-patient activation can help to



alleviate the pressures bearing on service delivery, scarce manpower resources, and health facilities (*1, 2*)).

As the demand for health education increases, new configurations in the delivery of health education services become essential. The Maryland Consumer Health Education Demonstration Project, carried out in 1972, was a major effort to unite the resources of the Extension Service of the University of Maryland and the university medical center. State universities and land grant colleges have a system of service delivery through their extension services. Traditionally, the Maryland Extension Service has employed educational outreach to bring the resources of the university to the local community. Its strength lies in the ability to identify problems and needs, organize groups, and work with and through existing local resources and power structures in generating programs that meet the recognized needs of the people.

The Maryland demonstration program sought to transfer and adapt extension education methods and processes in community development to an urban health center in order to support health services delivery. In this paper we describe the program, present the objectives in nine functional areas that were identified for consumer-patient activation, and discuss some general observations on the question of partnership between the extension service and the health center and between providers and consumers.

The Maryland Program

Community Pediatric Center and target population. The Community Pediatric Center of the University of Maryland is an outpatient, walk-in facility that provides free, comprehensive medical and dental services to approximately 10,000 inner-city, newborn to age 19 patients in southwest Baltimore. The center also provides training for students in the health professions and hospital staffs, and it conducts research in health care delivery.

The center's services are organized to blanket the target population with a wide range of preventive services; to screen the target population for treatable, common illness in its early stages; and to provide facilities for curative and episodic care that are geared to the needs of preschool, school age, and adolescent patients.

For the demonstration program, youth ages 10-19 were selected as the target population because this was the age group that was the least affected by the existing services at the center. Because an obvious communication gap existed between the center and the adolescent community, there was a need to develop mechanisms to reach and influence this group to use the center's services. Furthermore, this age group constituted a most promising population because health-maintenance knowledge, attitudes, and behavior acquired during adolescence tend to have a positive effect later in life.

Of the major health problems identified by the Community Pediatric Center, teenage pregnancy, premature births, venereal disease, drug use, dental caries, and malnutrition were found to be particularly prevalent among adolescents. Poverty and lack of knowledge, coupled with a lack of role models for achievement and career goals, added to identity problems for these youth. The health problems of adolescence reflect a combination of stresses resulting from rapid social and physical development in a sometimes turbulent and unsympathetic society.

The total population within the area is approximately 55 percent black and 45 percent white. Generally, the families are in the lowest 10th of the economic level. The educational level of the heads of households is 8 or 9 years. Many homes have only one parent and are matriarchal centered. The majority live in cramped rowhouses or walkup tenements that often are poorly heated, without adequate bathroom facilities, and infested with roaches and rats.

Objectives. The overall objective of the demonstration program was to influence the adolescents toward preventive health behavior through positive individual and group experiences. It was hypothesized that a modified program in 4-H and youth work and home economics under the urban Maryland Cooperative Extension Service would favorably affect health knowledge, attitudes, and behavior in relation to the services provided by the Community Pediatric Center. The parents of the adolescents constitued a subtarget population, because inherent in the 4-H philosophy is leadership training and development which involves both youth and adults. The program was therefore aimed at enabling the youth to (*a*) engage in decision making for healthful individual, family, and community living, (*b*) practice healthful living, including constructive use of leisure time, (*c*) strengthen personal standards and citizenship ideals, (*d*) cultivate desire and ability to cooperate with others, (*e*) develop leadership talents, and (*f*) explore career opportunities and continue needed education. A related objective was to develop a closer relationship between health

---

□ *Dr. Wang, now associate professor, Department of Public Health Administration, Johns Hopkins University School of Hygiene and Public Health, and associate director, Office of Continuing Education, John Hopkins Medical Institutions, was formerly health education specialist in the Cooperative Extension Service, University of Maryland at College Park. Mr. Reiter was extension health educator in the Consumer Health Education Demonstration. Dr. Lentz is director of the Community Pediatric Center, University of Maryland Medical School in Baltimore, and Dr. Whaples is 4-H and youth program leader in the Cooperative Extension Service. Dr. Wang and Dr. Lentz were project co-directors in the Maryland Consumer Health Education Demonstration Project.* *This paper was based on a project supported by a grant, HSM-99-72-9, from the National Institute of Mental Health.*

Tearsheet requests to Dr. Virginia Li Wang, Johns Hopkins University School of Hygiene and Public Health, 615 N. Wolfe St., Baltimore, Md. 21205.

professionals and consumers, while sensitizing the professionals to community needs and the planning of programs to meet those needs.

Conceptual base. It has been shown that efficiency of delivery, although very important, is not the only essential to assure full medical use of the clinic. In a community where food, housing, employment, and education are more pressing needs than medical care, a broad, social approach to health must be adopted. As Hilleboe *(3)* pointed out, "Health no longer is an end in itself. . . but a means for attaining optimum social well-being within the constraints of the physical, social and biological environment in which man finds himself. Health care can no longer be viewed out of context of the social and economic aspects of daily living."

Health education is concerned with people and their health behavior. It is an educational process through which people increase their understanding or change their ways of thinking or actions as a result of exposure to new experiences. Obviously, health education cannot attempt to refashion the society by imposing the values of those originating the program. Decisions must be reached in collaboration with informed consumers, who should have a major voice in decisions of how and what to change. In a clinic where the socioeconomic gap between providers and consumers is wide, the gap can be narrowed by engaging people in such learning experiences and decision making as defining the relationship between a center and the community it serves.

The rationale has been that through learning by doing, in skill development and in learning responsible actions through involvement with others, people in the community can be guided to launch an aggressive attack on a host of health problems. Program emphasis was on learning experiences which led to greater individual and group effectiveness in decision making in health-related matters. A program may begin with recreation and craft skills, but it will lead ultimately to learning experiences in, for example, clinic utilization, the use of prophylactics, nutrition, or hygiene.

Project team development. The demonstration team included a health educator, a home economist, a 4-H agent, and five program assistants who served as outreach workers. The program assistants were selected from more than 60 applicants from the community. After an initial interview, 30 applicants were invited to the group-interview phase of the selection process. By means of a modified nominal-group approach *(4)*, candidates were brought together in one sitting at which each applicant, functioning as a member of a group, responded to the study question: "What are the physical, mental, and social problems confronting the youth in the community?" Self-selection listings, obtained by peer ratings and ratings by the professionals present, were compiled. Initial interview records and references were also considered in the screening process. An important byproduct of the nominal-group process was the documentation of perceived needs by the 30 applicants. The most frequently listed needs were health (for example, drugs, venereal disease, and alcoholism), lack of education and motivation, unemployment, crime, racism, school drop out, and family problems (for example, child abuse), broken homes, and the generation gap. A further examination of the southwest Baltimore area revealed that polarization existed between blacks and whites, and that youth socialization was largely confined to one city block.

A focus of the demonstration was the retraining of extension personnel in health education methods and processes. Inservice training for the professional staff consisted of consultation with the project co-directors, extension service personnel, service chiefs of the Community Pediatric Center, visits to community agencies, and consumer interviews. Community resource assessment further served the staff in determining needs and problems of the target area and building baseline data.

The program assistants participated in a 5-week intensive induction training program immediately following their employment. The training was oriented to enable the staff to acquire understanding and skills in identifying community needs, community organization, interpersonal relationship and communication, and health service organization.

Center staff provided information about their respective service areas and assisted in staff development. Their participation as resource persons during training also facilitated communication and coordination of services. Cooperation in planning efforts during the initial period further helped the center staff to become acquainted with health education methods and processes and extension outreach education.

Community contacts. At the community level, nearly 60 social, educational service, and consumer action agencies were contacted. Contacts were also made with community leaders and lay groups to seek their support in problem identification, program planning, and implementation.

Active entry into the community began for the program assistants during induction training. Goals for the team included acquiring knowledge of the community and designating target areas. The staff concentrated on facilitating cooperative efforts with other agencies in the area and determining consumer needs and interests in program coordination. In addition to the Community Pediatric Center, the project obtained the use of three area facilities in which to conduct educational programs.

The staff went into the neighborhoods and contacted teenagers on street corners, in homes, and at popular gathering places. Teenagers and parents were included in planning and developmental activities that focused on the expressed needs of adolescents. During the first 8 months, more than 3,500 persons participated in the program. Group activities featured discussions on sex

education, drug abuse, nutrition, home economics, recreation, and community improvement.

Program assistants worked across the board in community organization and in support of the services provided by the Community Pediatric Center. Flexibility in scheduling was an important element in programing. Many activities were held in the evening and on weekends at hours convenient to the clientele. While the initial contact was usually on a person-to-person basis, all outreach activities and program efforts were organized into group work.

The following brief descriptions of several activities illustrate extension outreach in health education in the Maryland program.

The game concept of health carnivals was introduced at a community fair. Games were devised to promote Community Pediatric Center services and encourage audience involvement. Staffing of health carnival booths by center employees helped to advance community relations.

Through a roller skating program, youths learned to work together, planned their schedules, organized transportation and raised the fare, and mingled socially on an interracial basis. Parents and older teenagers functioned as leaders and supervised the younger children. A first-aid course was introduced as a precaution against possible accidents at the rink, as well as to provide a lesson in access and entry to the health care system.

In a 6-week drug education series, professionals in health and community services, neighborhood leaders, and rehabilitated addicts were used as instructors. The final meeting featured a fashion show—complete with orchestra comprised of rehabilitated addicts—that was attended by families and friends of the participants.

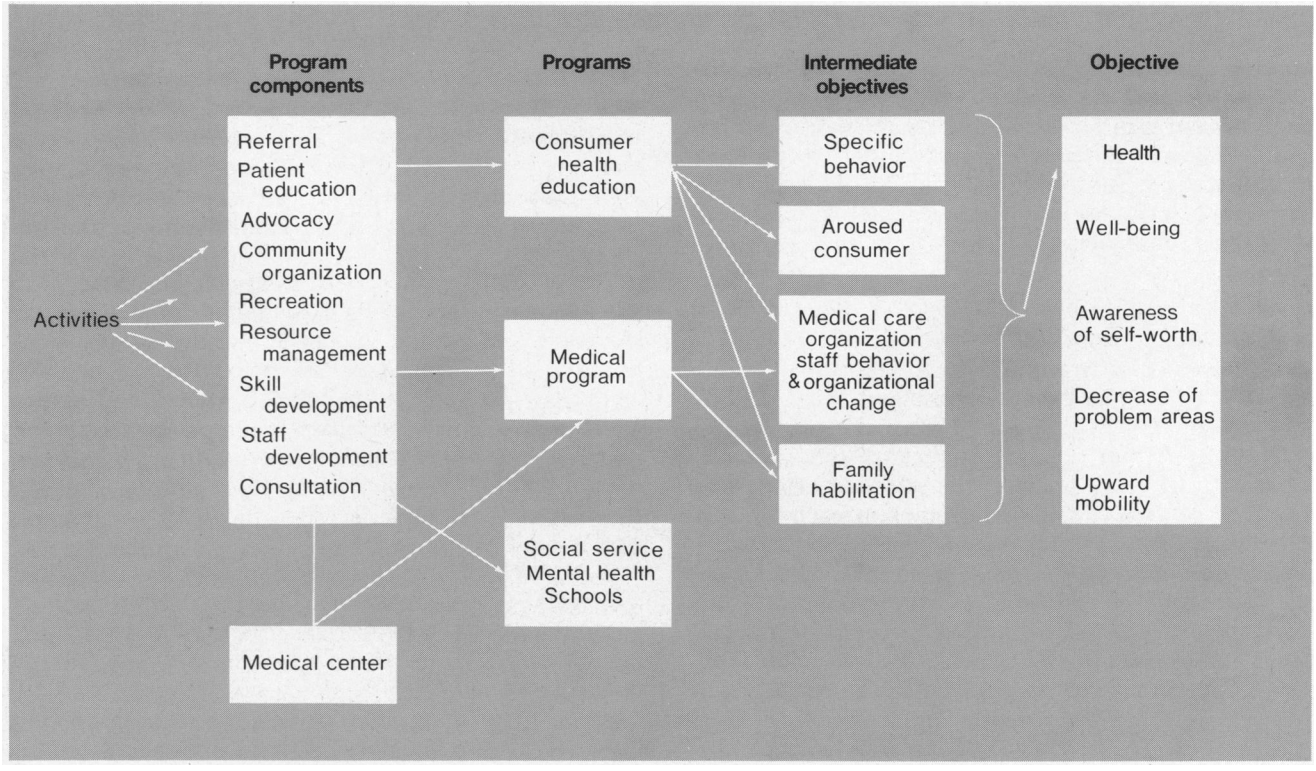
"Tot Lot" for preschool children was one result of organized community efforts. Through person-to-person contact, a group was organized to convert a garbage dump on a vacant block into a playground. Guided by a program assistant, concerned citizens organized a task force and negotiated with city agencies for funds to construct the playground. Residents agreed to supervise the park when playground equipment is installed. The lighting of a 20-foot Christmas tree, donated by merchants, brought out 200 local residents for a holiday festival. The decorated tree stood on the site for 2 weeks; no vandalism occurred.

In an effort to develop a dental education program for primary school children, 40 sixth graders were recruited and trained as "mini-dentists" to conduct dental screening in schools and in the Community Pediatric Center for 500 first- and second-grade pupils.

As program outreach expanded, the project demonstrated that health education is a process of people involvement and community organization. Program planning and coordination, as well as training professionals, aides, volunteers, and related workers in health education methods and processes were included.

The project services were integrated into the Community Pediatric Center's program. These services included recruitment of staff for a nutrition program, referrals ranging from psychological assistance to vocational rehabilitation, project staff working with social workers to strengthen the citizens council, and home visit followup. Volunteer teenagers were recruited and trained as tutors in a patient-education program for adolescents at the university hospital.

Schema for Maryland Consumer Health Education Demonstration Project



Conceptual Objectives

After a 6-month testing period, the demonstration project staff designated nine main program components—referral, patient education, advocacy, community organization, recreation, resource management, skill development, staff development, and consultation—as salient features of extension educational work that complement and support the delivery and use of health services. The nine components and the conceptual objectives of the program (see schema) can be combined in any manner to meet the needs of a specific population. Although referral, advocacy, patient education, community organization, training, and consultation should be inherent in any health education program for any audience, recreation, resource management, and skill development are essential for a disadvantaged clientele or teenage groups. Conceptually, the functional objectives are defined as follows:

REFERRALS OF CONSUMERS will be conducted to maximize exposure to and visibility by as many direct-service facilities as possible within the legitimate bounds of the project service area. Increased referrals will encourage providers to *(a)* use the team approach when dealing with consumers either as groups or individually, *(b)* maintain open avenues of communication for effective and efficient delivery of services, *(c)* use resources outside the direct medical service sphere where necessary—for example, food stamps, social services, and schooling counseling, and *(d)* explore existing support systems for the widest range of assistance available. Consumers will gain from the referral process by learning of the most appropriate and effective sources of assistance in both the medical care delivery system and the community at large.

PATIENT EDUCATION will be conducted to provide experience in determining personal and family health care, medical care needs, and appropriate behavior for better physical, mental, and social well-being. Activities in this area will be designed so that consumers can develop skills to *(a)* identify their specific health needs, *(b)* become aware of the different roles of practitioners within the delivery system and to seek out appropriate medical care services at proper times in the most efficient manner, *(c)* practice preventive health care, *(d)* relate to the professional needs of staff delivering care so that a more efficient system can evolve, and *(e)* use the telephone as the first line of inquiry about minor symptoms.

ADVOCACY OF CONSUMER DIRECTION in planning, modifying, and maintaining the medical and social service delivery systems will be conducted in light of developing the "activated consumer." Providers will *(a)* increase parent involvement in determination of optimum delivery of services, *(b)* improve use of present systems, *(c)* maintain avenues for feedback as a "check" on present systems of delivery and interaction with them, and *(d)* recruit and train consumers to become legitimate workers or volunteers within present service systems.

COMMUNITY ORGANIZATION ACTIVITIES will be conducted to maximize support from community groups and engagement of parents in project activities, development, and utilization. Staff will conduct activities to achieve a unified community of consumers and providers toward bridging service gaps. Further, consumers will develop skills to *(a)* develop leadership within their own neighborhood and social groups and *(b)* delegate tasks and responsibilities to other residents of the area toward achieving community improvement.

RECREATIONAL PURSUITS will be offered in an effort to organize youth and parents and to provide structured experiences. Experience in structured recreational pursuits will enable parents and children to *(a)* recognize their status as members of their respective social groups, *(b)* develop leadership skills in planning individual and group activities, and *(c)* determine optimum use of leisure time based on resources available in the community.

RESOURCE MANAGEMENT will be reflected through skill development in the determination of day-to-day living habits and household organization. As an educational function, the project will prepare consumers to *(a)* assess their quality of living in relation to available personal resources, *(b)* practice decision making to alleviate frustration in conducting activities of daily living, and *(c)* plan use of time in regard to the use of existing medical, social, and community services.

SKILL DEVELOPMENT PROGRAMS will focus on individual development as consumers. Determination of programing in this area will be largely in response to the expressed needs of the consumers. Training programs will afford participants the skills to *(a)* recognize their present skill levels and assess potential through self-growth, *(b)* develop a sense of self-worth through accomplishment of tasks, *(c)* determine social as well as vocational opportunities relative to personal ability, and *(d)* plan for and seek improvement of personal skills by exploration and use of community resources.

STAFF DEVELOPMENT OF PROVIDERS will increase their potential to *(a)* understand the consumer's orientation toward the medical care organization system, *(b)* seek out consumer input to planning and decision making, *(c)* develop efficient mechanisms in meeting the consumer needs, *(d)* deal with change while minimizing conflict, *(e)* become involved in an increasing number of community activities, external to the medical center and established delivery system, and *(f)* decrease "emergent" and crisis-oriented delivery of medical care.

CONSULTATION will be provided to both providers and consumers to enhance their abilities in program planning and decision making. Consultants will be drawn from the Community Pediatric Center, the university and the community at large in order to *(a)* provide solutions to problem areas, *(b)* bridge possible communication gaps between providers and consumers, and *(c)* draw out the potentials already existing within providers and consumer groups.

Discussion and Conclusion

Mobilization of resources of community, school, health, and other services is essential if a project is to meet its stated objectives and relate to health education of the citizenry. Eventually, professionals and lay leaders—regardless of their specialties and interests—must recognize that they share vital functions in disease prevention and health maintenance and the promotion of physical, social, and mental well-being.

The 1-year demonstration did not allow sufficient time to conduct a systematic evaluation. While we cannot claim with certainty that the project achieved its objectives, there are manifestations that information transferred by the change agents has affected *(a)* development of understanding of the Community Pediatric Center by consumers, *(b)* development of skills for movement through that system by consumers, and *(c)* establishment of behavior patterns necessary to maintain optimum health by consumers.

The joining of the Cooperative Extension Service and the Community Pediatric Center in outreach health education probably would not have occurred had it not been stimulated by Federal financial support. The extension service's staff specialist, who had been trained in public health, and its program base for health education provided a bridge to the health center and facilitated the formation of a partnership.

If organizations are to work effectively together, all parties must respect the competencies and understand

the needs and limitations of each other. In our demonstration program, the extension service and the Community Pediatric Center personnel had diverse backgrounds and capabilities; however, dedicated people committed to the project overcame what could have been insurmountable obstacles. A basic problem lies with the common notion that health care is a domain of the health professionals. Undoubtedly, this is related to the disease concept of health care. That health is often a byproduct of the quality of life strongly influenced by lifestyle is frequently overlooked.

When it is essential for persons to assume responsibility for their own health care, extension outreach in health education can enhance medical service delivery and complement health care. The thrust of this program has been to influence consumers to understand and react positively to medical care delivery and other social factors infringing on their health and lifestyles.

While the extension service has long professed a commitment to better health, and the pediatrics center has been committed to patient care, neither has regarded health education as a priority in the allocation of resources. To unite permanently the resources of both facilities, incentives must be provided continuously in order to cultivate that kind of partnership. A change in organizational behavior requires time for redirection.

Consumer participation in decision making attracted nationwide attention in the mid-1960s with the Office of Economic Opportunity's pronouncement of "maximum feasible participation." After a decade of steadily mounting appropriations and increased attention to comprehensive health planning, there is little evidence today that mandated consumer participation has been truly achieved *(5)*. It has been observed that one reason for the inability to achieve results is that consumer participation has grown out of political rather than educational concerns *(6)*.

Much has been said about the relevance or irrelevance of education. Unless health education is made relevant to people's needs, they are not likely to be motivated to learn more about health care. Health and sickness are relative concepts that vary among cultures and groups. There is a tremendous gap between what the consumer knows and what the professional knows about health and disease. Most consumers are not concerned about health unless stricken with illness. But they are concerned with living and the amenities in life. The Maryland Consumer Health Education Demonstration Project was made attractive to people by relating it to their activities of daily living. Thus, the people in the community responded quickly and enthusiastically with their support.

We were willing to seek out the clientele, help them identify felt and unfelt needs, and then expose them to experiences that satisfied those needs through active participation. This called for sensitivity and keen observation on the part of providers. Response of the people in the community went beyond acceptance of the services they desired. They generated program activities as well as learning experiences for themselves and for their community.

Involvement of volunteers in program services deserves emphasis. It is often said that the poor seldom volunteer their services, and that the concept of volunteerism is almost nonexistent in poverty areas. We found that this hypothesis is not tenable. The Consumer Health Education Demonstration included more than 300 adult and teenage volunteers who worked in many capacities to serve some 3,500 teenagers. The project's commitment to volunteer leadership development was an important factor. In keeping with the philosophy of extension education, the staff was trained to identify, recruit, support, and provide training for volunteers.

The project demonstrated that a concerted health education effort in support of a medical delivery unit can effectively promote a bona fide provider-consumer partnership in health care. By assimilating the project into the center staffing, the providers developed a greater appreciation of the multi-dimensional factors influencing consumer reaction to service delivery. The demonstration brought together consumers and providers on a mutual plane and made them more sensitive to each other's needs. It enabled each group to understand better the other's role in the partnership for health, as well as their mutual responsibilities.

We wish to emphasize that outreach is a task usually assigned a second- or third-order priority to primary medical care delivery. If health education is merely an adjunct to service rather than a specific program effort, it will fall short of accomplishing the objective of educating consumers in self-help. When a program does not receive strong endorsement and fiscal support, there is a spontaneous lack of commitment by the staff. Health education as practiced in the Maryland Consumer Health Education Demonstration served the double role of consumer-patient activation and provider sensitization. It holds the potential to serve as a model for the broader development of true consumer participation in comprehensive health planning.

References

1. The University of Wisconsin: Interim report of project-planning proposal for consumer health education. University Extension, Professional and Human Development Division, Health Science Unit, Madison, 1971, mimeographed.
2. Wilson, V. E.: Rural health care systems. JAMA 216: 1623–1626, June 1971.
3. Hilleboe, H. E.: Public health in the United States in the 1970's. Am J Public Health 58: 1588–1610 (1589), September 1968.
4. Van de Ven, A. H., and Delbecq, A. L.: The nominal group process as a research instrument for exploratory health studies. Am J Public Health 62: 337–342, March 1972.
5. Galiher, C. B., Needleman, J., and Rolfe, A. J.: Consumer participation. HSMHA Health Rep 86: 99–106, February 1971.
6. Hochbaum, G. M.: Consumer participation in health planning: toward conceptual clarification. Am J Public Health 59: 1698–1705, September 1969.