CONSUMER HEALTH PERSPECTIVES

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HEALTH NEEDS ASSESSMENT

ASSESSING HEALTH CARE NEEDS IN THE COMMUNITY

by Zita Fearon

The Consumer Commission received a grant from the National Science Foundation in October 1980, to establish a Consumer Health Information and Resource Center. The purpose of the Center is to provide grassroots consumers and community and city-wide organizations in New York City with technical and scientific information in plain language, so they will be able to educate and mobilize their communities to impact on public policy in health and environmental matters.

As part of its program, the Center has held a series of small group seminars on technical matters that community and city-wide organizations consider important to their work. The first seminar was held on November 8, 1980 on the topic, "Unmet Needs: Approaches to Community Health Needs Assessment." Some very interesting issues and questions were raised by the seminar, which we would like to share with our readers.

The Meaning of Health

The World Health Organization provides us with an ideal definition of health as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity." A nation's or a community's state of health (health status) is an indication of its level of total resource development (not only medical technology, but also housing, jobs, education, safe environment, etc.) and the complete and democratic access of the population to these resources.

The Measurement of Health

We have not made it our priority as a nation to measure complete physical, mental, and social well-being. There is much disease and infirmity, and that is what we measure to obtain a sense of our health status or, more precisely, the lack of it. Historically, health status has been determined by measuring mortality (death) and morbidity (disease and disability).

Mortality is expressed in terms of the number of deaths per thousand persons in a given year. The number of deaths, and their causes, are established by local health departments based on the information contained on official death certificates filled out by either the Medical Examiner or the physician in attendance at the patient's death. There are problems with the accuracy of the stated cause of death on the

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death certificate. Results of autopsies are seldom used to correct information on the death certificate. Even when the patient dies in the hospital, the information on the death certificate is frequently at variance with the information in the medical record and is based on the physician's opinion or style of reporting. For example, at the seminar, one participant said that her aunt had frozen to death in her apartment in Harlem, but that the doctor had written "heart failure" on the death certificate as the cause of death.

"Epidemology is the study of the distribution and determinants of disease and frequency in man." (MacMahon and Pugh) Local health departments are responsible for carrying out the epidemiological studies. The diseases included in their studies are limited to the infectious, reportable diseases which so greatly decimated populations until this century. Until recently, there was a direct link between the death rate and the infectious disease rate (which is expressed in terms of incidence per 100,000 persons). Since about the turn of the century, health departments have required doctors to report infectious diseases so that their cause could be determined before many people died, and a remedy applied. But before this reporting procedure was required, the problems of death and disease were so horrendous, and the powers and functioning of the Health Department in New York City were so deficient, as to cause a group of citizens to organize and pay for a door to door survey of all the dwellings and inhabitants. In this way, all the known causes of diseases were identified on maps of each city block developed by the surveyors, and a program developed for the removal of filth, and the draining of cellars and outhouses, with the expenses being charged to the landlords.

Today the major causes of death are the chronic, non-infectious diseases, which are not reportable. These include diseases of the heart, cancer, cerebrovascular diseases and accidents, etc. The reportable diseases, on the other hand, are venereal diseases, tuberculosis, measles, meningitis, etc., from which very few people die, comparatively speaking. Nonetheless, measures are still made of these diseases, because their incidence in even small numbers is a proxy measure, an indicator somewhat like an iceberg, not only of conditions which cause ill health, but also of inadequate resources to meet health care needs.

Why Measure Health Status?

The reasons for measuring health status are the desire to reduce/eliminate unnecessary death, disease and disability, the need to plan and develop the total range of health resources to achieve that goal, and the need to evaluate, to learn whether the resources we provide do, in fact, achieve that goal.

Given the change in the nature of the largest causes of death, epidemiological studies should be done, not only of the infectious diseases as is currently done, but also of the non-infectious, chronic diseases, many of which are asymptomatic in their earlier stages. This would also impact on other non-infectious problems which cause disability, such as glaucoma, dental caries, depression, and the rheumatoid diseases. Since it is not possible to determine the extent of these conditions through reporting requirements, measurement methods similar to these undertaken by the Citizens Association in New York City in 1864 at a cost of $22,000 should be utilized.

One very good method developed for the Merharry Study in Nashville, Tennessee in 1970 could be used or adapted for the purpose of determining health status, health problems or deficits, and health risks (such as smoking or unemployment) either in a whole population/community, or in a representative sample of a population/community. The purpose of the Meharry Study was to determine the impact of different forms of health care in reducing unmet health needs. Therefore, they had to measure unmet health needs at the beginning of the study. This was done through the use of a door to door survey questionnaire. Since they wanted to include asymptomatic health problems in the category of unmet needs, they also selected a sample of those surveyed for a clinical examination. One important finding from the Meharry Study was that health needs are limited and finite and that, therefore, meeting health needs will not require unlimited resources. Wolfe, Carr, Neser and Revo of the Meharry Study recommend that this method be adapted for the National Health Survey by the National Center for Health Statistics of the Department of Health and Human Services. They further recommend that the results be broken down by locality and be made available to localities for planning purposes.

Another very good method was developed in 1970 by the Departments of Clinical Epidemiology and Biostatistics, and of Family Medicine at McMaster University Medical School for the purpose of evaluating, through comparison, over time, the effects of access and different kinds of medical care programs on health status.

They decided that for their study to be credible both to clinicians and to administrators, it would have to meet seven prerequisites:

1. Comprehensiveness: It would have to include social and emotional health and function, as well as physical function.

2. Positive-orientation: It would have to identify good or excellent function as well as symptoms, illnesses and catastrophes.

3. General Applicability: It would have to be applicable to free-living populations and could not require prior use or access to health services.

4. Sensitivity: It would have to be able to detect important changes in health status or function.

5. Simplicity, Acceptability and Cost: It would have to be made quickly, at reasonable cost, without embarrassment or offense to those being interviewed, and the interviews would have to be done by non-clinicians.

6. Precision: If the survey was repeated at short intervals, the results for both individuals and groups

should be the same, so that true changes could be observed if they occurred.

7. Amenability to Index Construction: Responses to the questionnaire would have to permit rapid combination into composite indices. For example, answers should be: yes, no, don't know, no answer, rather than essay type answers requiring an analysis of content. It should also be possible to break down the answers by age, sex, ethnicity, etc. To be credible, the questions must also be valid indicators for health and function. There must be face validity (i.e., appropriateness of question), biologic validity and clinical validity.

While it has been possible for a least the last ten years for university based people to develop usable, useful, replicable methods for accurately measuring the health status of a given population, for identifying health needs and unmet health needs, and even the impact of different kinds of health care on health status, these methods have not been developed or adopted by the federal government for use by the state and local planning agencies. Nor does there seem to be a move by local Health Systems Agencies to develop and utilize these methods for their own areas.

Instead, all manner of substitutes are being employed and labeled "Health Needs Assessment." Some examples of these fake articles are:

Utilization studies: these measure the use of, or "demand" for certain facilities or services. This is a market concept which is appropriate for companies interested in selling cars or shoes, but not for a community or agency concerned with identifying and meeting the health care needs of people regardless of their ability to pay, etc.

Screening: an example of this method is where an agency sends out a mobile van or puts up a table at a health fair to do blood pressure screening, and as a result of this, indicates that there is, or is not, a hypertension problem in the community. This is a misuse of screening. The Commission on Chronic Illnesses defined screening as: "the presumptive identification of unrecognized disease or defect by the application of tests, examinations, or other procedures which can be applied rapidly to sort out apparently well persons who probably have a disease from those who probably do not. A screening test is not intended to be diagnostic. Persons with positive or suspicious findings must be referred to their physicians for diagnosis and necessary treatment." Unless screening is combined with easy and sure access to diagnosis and treatment, it should not be done. It is cruel and misleading to pretend that it is the same as diagnosis, treatment or measuring health status.

"Perceived needs assessment": These are merely very poorly structured public opinion polls. The sample base is unscientific, the questions lack validity and usually cannot be tabulated, and certainly cannot be verified for accuracy of response. "Perceived needs" assessments are a hoax to make community people believe they have been "involved in community health needs assessment and the planning process," or put "in control of their own destiny," etc., when they have not.

Community Involvement

Community people and organizations should be involved in community studies. They should be consulted from the start as to the **kind** of study they want done, which is related to its **purpose.** Kinds of health studies, ranging from the most limited to the most inclusive purpose, are described as follows:

1 Determine the **health status** of a clearly defined community. (Social, biological and emotional function, as well as clinical diesease.) Purpose: data collection.

2. **Assessing** or identifying the **health needs** based on (1) above, and distinguishing those which are **met** from those which are **not met.** Purpose: problem identification.

3. Determine **why** health needs, identified in (2) above, have not been met and develop **strategy for meeting need.** Purpose: problem correction.

4. **Start over** with (1) again to see if it (1-3) worked. Purpose: evaluate the efficacy of the corrective action.

It is possible to do only (1), or (1) and (2), or (1), (2) and (3) or all four, but not to do any of them without the preceding ones.

After the community has decided what kind of study it wants, community people should be trained to carry out as much of the interviewing as possible. Technically skilled people can randomly select a sample of the population to be interviewed, if the population is too large to interview everyone. The interview forms already tested and used in university based groups could be utilized. Health facilities can provide the same personnel they would use for a health fair, skip the health fair one year, and donate their services to do the clinical examinations, etc.

When the study results have been tabulated and analyzed by the technical people, they should be presented to the community for its responses, priority setting, and planning. In this way, the community has been involved in 1) deciding what kind of study should be done, 2) interviewing and 3) planning based on the results of a scientific study and their own priorities.

While it is true that this kind of activity costs money and effort, the results are clearly worth it and will save us money in the not very long run. Herman Biggs, in the 1911 issues of the New York City Health Department's *Monthly Bulletin,* said it best:

> *Disease is largely a removable evil. It continues to afflict humanity, not only because of incomplete knowledge of its causes and lack of adequate individual and public hygiene, but also because it is extensively fostered by harsh economic and industrial conditions and by*

wretched housing in congested communities. These conditions and consequently the diseases which spring from them can be removed by better social organization. ***No duty of society acting through its governmental agencies, is paramount to this obligation to attack the removable causes of disease.*** *The duty of leading this attack and bringing home to public opinion the fact that the community can buy its own health protection is laid upon all health officers, organizations and individuals interested in public health movements. For* ***the provision of more and better facilities for the protection of the public health must come in the last analysis through the education of public opinion so that the community shall vividly realize both its needs and powers.*** *The modern spirit of social religion, dealing with the concrete facts of life, demands the reduction of the death rate as the first result of its activity. The reduction of the death rate is the principal statistical expression and the index of human and social progress. It means the saving and lengthening of the lives of thousands of citizens, the extension of the vigorous working period well into old age, and the prevention of inefficiency, misery and suffering. These advances can be made by organized social effort. Public health is purchasable.* (Emphasis added)

SUMMARY: COMMUNITY HEALTH NEEDS ASSESSMENT SEMINAR

The Consumer Health Information and Resource Center held its first seminar on November 8, 1980. The topic was Community Health Needs Assessment. We were fortunate in having three very qualified speakers. Ebun Adelona, the first speaker, is an advocate of community participation in health planning and worked with community members in Central Harlem in performing a community needs assessment. The other two speakers were Willine Carr and Melanie Dreher, both of whom are on the faculty of the Columbia University School of Public Health, and have had extensive experience working in the area of health needs assessment.

The speakers noted that a health needs assessment involves a whole host of variables, and is not simply based on existing medical resources and utilization patterns. One must take into account a variety of factors starting with a comprehensive definition of need. Willine Carr described need as "the situation or condition of an individual or a community that requires some kind of service. Need is not what facilities or resources there are in the community; it's not how often people use the services; it's about people—individuals—what is their state of health? Needs lead to a requirement for services. . . and these services require resources: hospitals, physicians, ambulatory care facilities, and other things..The starting point for planning for services is. . . at the needs end, with a community based focus, rather than a resource based or a utilization based focus."

Ebun Adelona stressed the importance of understanding the historical process that contributes in large part to the health status of a community. This includes such factors as the adequacy of housing, the proportion of employed and unemployed in the community, the political structure and its affect on community resources, living standards, and available health services. Ms. Adelona noted that, in contrast to this broad perspective, the current, dominant definition of need seems to reflect the pervasive influence of the biomedical model, which emphasizes curative medicine and technology over preventive programs.

In the bio-medical model need is defined in relation to medical resources and is based primarily on utilization rates. Ms. Adelona explained that this focus has precluded a more holistic approach to the definition of need and thus the provision of health care services. The emphasis on utilization and demand for services has obscured the larger perspective of community need by confusing the marketing concept of demand with actual community need as measured by a community based survey.

Assessment of community need from the holistic perspective presented by seminar participants would be based on the integration of data routinely collected by the Health Department and data that can be collected by community groups. The Health Department regularly collects and reports mortality and morbidity statistics. These data are essential to the development of a community health profile and have limited value in determining health needs. In this country, mortality data are a good indicator of the need for health services which could affect infant mortality and other types of death from preventable causes. Mortality data can be used to identify areas where it would be most useful to establish preventive health and screening programs, and to provide services that could eliminate unnecessary death. On the other hand, as the speakers pointed out, deaths from communicable disease have decreased dramatically and people are living longer. Mortality data do not reflect how effective the health care system is in dealing with the degenerative and chronic health conditions common in the United States today. Other problems in using mortality data are that such data are gathered from death certificates which often do not reflect the true, underlying cause of a person's death, and that such data are not always broken down from small geographic areas like a neighborhood. If small area data is available, the cost of obtaining it, which can be several hundred dollars, may be prohibitive for community groups.

Melanie Dreher discussed population based planning, which looks at community health needs, ignoring the existing health structure. Population based planning utilizes an epidemiological approach to determining which risk factors associated with various health conditions are identified and what attempts are then made to eliminate them or reduce them to a minimum. The programs called for are usually preventive in nature and utilize both medical and non-medical interventions such as reducing air and water pollution, or implementing a vaccination program. Dr. Dreher also discussed one of the major problems of population based planning: the tendency to place health problems in discrete categories ignoring their inter-relationships and to then develop programs which treat these conditions as separate, unrelated problems.

Dr. Dreher expressed her belief that a better understanding of the concept of community would facilitate more integrated health planning. She defined community as "those humans [who] are related to one another in certain identifiable ways [which] may differ from community to community." A community can be identified by its ethnic, racial, social and economic composition, its political and social structure, and the other dynamics that help determine living conditions and health needs. It is essential to the success of a health plan, according to Dr. Dreher, that it integrate the concept of community.

There was a continuity of approach among all three presentations with an emphasis on some basic themes. The speakers pointed out the necessity of looking at data other than that which is usually relied upon for a needs assessment. To collect this data the community must be observed and people questioned so that the conditions contributing to the health status of the population are determined. For example, one condition known to highly correlate with morbidity and mortality rates is economic status—the more severe the poverty, the higher the morbidity and mortality rate.

All the speakers agreed that a thorough and broad assessment of needs should be used in setting goals for the health care system. The tone of the seminar was perhaps best summed up by Willie Carr when she said that "needs and health status are pretty much the same; needs and demands are not the same; unmet needs are situations which go untreated or unaddressed and suggests an inequity in the system; redressing that inequity should be a goal of health planning in a society that says health care is a right."

EDITOR ...CON'T FROM P. 6

Finally, *Consumer Health Perspectives* will from time to time carry reviews of significant books. These reviews will focus on the implications of the author's point of view for consumers. For example, Alain Enthoven's *Health Plan* emphasizes the need for competition among health providers. What impact will this call for competition have on consumers? Will they be better off in their medical treatment or have less influence over the kind of care they receive?

Herbert H. Hyman, Ph.D.

THE EDITOR SPEAKS.....

With this issue *Consumer Health Perspectives* will be broadening its coverage of health policy issues. There will be the usual main article that speaks to a major health issue, emphasizing the implications of policy decisions for consumers, and identifying alternative methods consumers might use in dealing with them. In this issue, consumer involvement in community health needs assessment is the major topic of discussion. What role can consumers play? How should the assessments be carried out? Are there are models of relevant assessments? What is meant by need? The article addresses these questions and others like them.

A second feature of the *Consumer Health Perspectives* will deal with the findings of seminars funded by the Science for Citizens program of the National Science Foundation. These seminars, which the Consumer Commission has been holding for the past year, have dealt with such topics as toxic waste transportation, prescription drugs, emergency medical services, and community health needs assessment. Future seminars will address such issues as how the community deals with discharged mental patients, how the federal government determines whether a community is medically underserved, and breast cancer treatment. Past and future seminars will be summarized to insure that our readers are kept current with the latest knowledge about health policy issues.

This special feature will also include the findings of studies done by the Science for Citizens Project staff as part of their role of providing technical assistance requested by various community health groups. Reports to date have been completed on such topics as development of a model hypertension program, the importance of hospital interpretators, the role of crisis intervention advocates serving sexually assaulted persons, and development of a brochure on occupational health. We are certain our readers will have reactions to these articles, and we welcome your letters and comments.

Beginning in 1982, we will be devoting our lead article to national health issues that we believe will become major health controversies during the 1980s. Among the issues to be discussed will be national health insurance, health regulation, profitization of the health care system, mental health and health personpower. We will be inviting leading thinkers in these fields to contribute their ideas to these topics. It is hoped that dissenting points of views will be submitted either as alternative articles or as letters to the editor.

CON'T ON P. 5

SUMMARY OF TRANSPORT OF TOXIC WASTE AND RADIOACTIVE AND HAZARDOUS MATERIALS SEMINAR JANUARY 24, 1981

The transport of toxic and hazardous waste is a serious community health issue because of the risks of accidents associated with such transportation. Industry, government and citizen groups disagree about the scope of the problem and the potential solutions to it. Unfortunately, there is an insufficient understanding of nuclear, chemical and other waste-generating issues among community residents. Community education in matters such as risks, regulations and industry and government motives and activities is a necessity if we are to work towards a realistic solution to the problem. This seminar seeks to address this need.

Risks and Regulations in Hazardous Materials Transportation

Nick Freudenberg's presentation focused on the risks involved in the transportation of hazardous materials and currently existing regulations. The National Safety Transportation Act defines "hazardous materials" as follows: *"a substance or material in a quantity or form which may pose an unreasonable risk to health and safety or property."* The definition illustrates the problematic aspects of the hazardous materials transportation issue, e.g., the phrase *"unreasonable risk to health and safety,"* is ambiguous and subject to various interpretations.

The recent data on hazardous materials transportation incidents reveal some of the reasons for the Department of Transportation (DOT)'s hesitancy to commit itself to a more concrete definition: 1) officials fear alarming the public of the real dangers; 2) there are regulatory violations which should be corrected through inspections; 3) there are mistakes in dealing with chemicals, e.g., shipping two antagonistic chemicals together in the same truck. The risk involved in this inaction will only be compounded if left unresolved, judg-

ing by the twofold increase in reported hazardous material incidents nationwide, the increased volume of traffic on the routes taken and the increasing number of chemicals being marketed. Although there has yet to be a documented case of a disaster involving a major loss of life resulting from an incident, the possibility persists. A study done by the Port Authority, which regulates traffic on the George Washington Bridge (GWB) and the NY/NJ tunnels, clearly reveals the health dangers of such an incident on the George Washington Bridge Expressway (GWBE).

This study, as well as the propane gas leak on the GWB in August 1980, alerted the Washington Heights community to the problem, since over one thousand trucks carrying dangerous amounts of hazardous materials are routed daily from the GWBE through two residential streets in Washington Heights. The research of the Washington Heights Health Action Project (WHHAP) exposed the lack of studies on the long-term effects on populations of the transportation of these materials through heavily populated neighborhoods. There is, in addition, little knowledge of, specifically, what materials were being transported to what locations. Without this knowledge Washington Heights residents could not determine whether the transport was, in fact, illegal.

There are several levels of regulations concerning hazardous materials. The federal level is represented by DOT. Among its responsibilities are the following: 1) to set requirements for the classification of hazardous materials according to the kind of hazard (explosive, corrosive), and the degree of hazard; 2) to set standards for container requirements, shipping papers, container labels, vehicle placards, and for procedures for handling and storing during transportation. The DOT's responsibility includes enforcement of these regulations, although there are only 108 federal inspectors nationwide. Spot checks reveal that 30% of the trucks fail to meet federal safety regulations. The problem of lack of enforcement of regulations exists at the state and local levels too. The N.Y. State Dept. of Motor Vehicles does not have the manpower to monitor inspections. At the regional level, the Port Authority must comply with federal regulations, although it is not required to inspect vehicles or cargoes. Within the City of New York, the Fire Department, along with the Dept. of Environmental Protection and the Police Department have jurisdiction over these regulations.

Lack of compliance and enforcement is accompanied by many problems concerning evacuation plans. A study of emergency preparadness response plans for evacuation, conducted by the Disaster Research Center of Ohio State University, exposed a lack of understanding on the part of municipalities concerning the designation of responsibilities. Research done by the WHHAP revealed a similar problem in the Port Authority, the Fire Department and the Police Department. It confirmed the fact that evacuation plans are often made with little consideration given to the nature of a community's population, e.g., the Washington Heights community has residents who speak English as a second language.

An Example of Toxic Waste Problems

In the final part of the seminar Warren Liebold focused on the most hazardous of radioactive materials, spent fuel from nuclear power reactors and research reactors. As spent reactor fuel pools fill, the problem of transportation to away-from-reactor sites arises. This problem has not been successfully resolved for several reasons. Originally, spent fuel pools were designed to hold fuel for nine months to one year; then it was assumed that it would be taken to a reprocessing plant or a waste depository. Reprocessing plants for nuclear fuel have been unsuccessful throughout the world and a permanent disposal site for high level radioactive wastes does not exist. As a result, the waste will continue to pile up in spent fuel pools at individual reactor sites until one of the following decisions is made: 1) devise a means to store spent fuel on site; 2) transport the spent fuel off site; or 3) shut down the nuclear power plant.

The enormous shipments of spent fuel that will soon begin to travel on our nation's highways leads many of us to ask serious questions about the safety of spent fuel transportation. The position of the nuclear power industry is that such transportation is safe, without regard to the fact that there has been little spent fuel transportation to date. The nuclear industry has developed a film that seemingly justifies its position on transportation and cask safety. The film is an "educational" publicity ploy and is shown to state legislators, town councils, etc., around the country to dissuade regional efforts to regulate or ban spent fuel transportation through communities. The film contains deceptions: e.g., there is no spent fuel in the casks used in the film. This avoids the real issue of leaks of radioactive waste, and a fire resulting from the impact, combined with the huge amounts of heat generated by the spent fuel in the cask.

The discussion period was preceded by a summation of crucial policy issues and a warning note about the importance of settling these issues now, because of the continuing assault of these hazards on public health and safety.

The first issue discussed was the recent conflict over the right of the Department of Transportation to pass legislation and regulations that supercede local ordinances banning the transport of radioactive material through their communities. Recently, the DOT published regulations that will pre-empt ex-

isting state and local ordinances that ban, restrict and regulate the shipment of nuclear waste and other radioactive materials. These regulations are due to take effect on February 1, 1982, unless nationwide litigation cases by many municipalities with transportation bans are resolved soon in the Supreme Court.

In an attempt to attack and solve these problems several perspectives have developed. The goal of the public health perspective is to expose the least population to the least risk. Another perspective is to examine alternative transportation systems, such as safe waterways and barge transport. Industrial planners would like to dispose of the waste in sparsely populated areas to reduce the risk of an accident. Others believe that transportation should be permitted in the city if the materials are based there. Enforcement programs, evacuation plans and improved transport vehicles are crucial factors in any proposed solution to these problems.

Finally, there is the long-term perspective, which seeks to build broad coalitions to examine the issues. When attempting to make long-term goals and objectives the key question is how to broaden the more common, limited perspective of individual communities, which are concerned mainly with their own problems and must develop a unified understanding and consensus to treat the issue as it affects the entire country. Movement in this direction could involve developing a coalition between environmentalists and unions that work with these hazardous materials. A citywide conference could provide a meeting ground for community groups, public service workers, environmental groups, workers in industry and industry representatives. By these and other means, it was suggested that community action could have true policy implications by instigating a move from a parochial frame of reference to a more regional perspective.

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