

**THE
SURGEON
GENERAL
WORKSHOP ON
SELF-HELP
AND
PUBLIC HEALTH**



Los Angeles, California
September 20-22, 1987

U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES
Public Health Service
Health Resources and Services Administration
Bureau of Maternal and Child Health and Resource Development



I believe in self-help as an effective way of dealing with problems, stress, hardship, and pain ... Mending people, curing them, is no longer enough; it is only part of the total health care that most people require.

C. Everett Koop, M.D., Sc.D.
Surgeon General, U.S. Public Health Service

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Introduction of the Surgeon General

Faye G. Abdellah, Deputy Surgeon General of the U.S. Public Health Service

Keynote Address

C. Everett Koop, M.D., D.Sc., Surgeon General of the U.S. Public Health
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Panel Presentation

Frances J. Dory, Moderator, New York City Self-Help Clearinghouse

Panel Members:

Leonore Miller, President of SHARE, Inc.

Edward J. Madara, Director of the Self-Help Clearinghouse of St. Clares-
Riverside Medical Center

S. Denise Rouse, Member of the Board of Directors of the National Black
Women's Health Project

Irving K. Zola, Professor of Sociology, Brandeis University

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THE SURGEON GENERAL'S WORKSHOP ON
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*University of California
Los Angeles
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INTRODUCTION

Emotional support in times of trouble is a basic need, and human beings have traditionally received it from family and community. But there have been profound changes in the nature of family and community life in our times that have made those sources less available or less reliable for many people. For example, community life can be practically impossible in a society as highly mobile and fragmented as ours. Social changes affecting families and communities, together with the fact that there have always been some problems that simply cannot be shared with either family or the broader community, can create devastating feelings of isolation and hopelessness for people who are ill or in distress.

Many health and other personal problems have no easy remedies, and for some people the problems are lifelong. Increasingly, however, people in need of emotional support for such problems are finding it in groups that are dedicated to helping people help themselves. For literally millions of people, these groups, called self-help or mutual help groups, are providing an effective and rewarding alternative to coping with serious problems all alone. The essence of these groups is that their members help each other cope with or overcome a health or other problem that they all share.

Thousands of such groups have sprung up in communities across the country in recent years, although the history of the self-help movement spans centuries. These

groups deal with a vast range of health and other human problems, such as alcoholism, genetic disorders, chronic disabilities, emotional disorders, and bereavement. Indeed, such groups are so numerous, and they address such a wide range of human problems, that numerous self-help information clearinghouses have sprung up across the country to keep track of them all, so people needing help can be referred appropriately. These clearinghouses are also instrumental in helping new self-help groups get started, and new ones are starting all the time.

It has been estimated that a half million self-help groups are serving some 10 million people in the United States. There are probably several valid ways to classify them. The National Institute of Mental Health has identified three general kinds of self-help groups: groups for people with a physical or mental illness, with groups in existence for practically every disorder; recovery groups for people with problems such as alcoholism, drug addiction, or other compulsions or addictions; and groups for certain minorities such as the handicapped. Many of these groups serve not only their primary members but also their families.

Although emotional support is the central purpose of most self-help groups, many of them also engage in advocacy of changes in policies, laws, attitudes, and practices in the broader communities. It is not uncommon, for example, for groups to work for changes in profes-

sional health care practices, because their members perceive from personal experience that the formal health care system sometimes has serious shortcomings in dealing with patients and their problems.

Despite their diversity, the basic purposes of all self-help groups are the same: to provide mutual aid and emotional support for people who share the same predicament. People who have struggled long and alone to cope with a personal problem or tragedy feel great relief and security when they discover others who know exactly what they are experiencing because they are in the same situation. In this accepting environment, where there is empathy, people can express their feelings and know that they are understood, and through mutual help the members can develop more effective ways to cope with the problem they all share. What people discover in self-help groups is that when they help others they help themselves, and that can be a happy discovery indeed.

Self-help groups share some other features as well. One of the most typical features of self-help groups is a strong desire to be autonomous. Although many successful self-help groups have been initiated by physicians or other health professional who brought people with common problems together, they usually have developed spontaneously out of needs perceived by people in their own lives. In either case, a key element of success is that members see the group as belonging to them, although most self-helpers welcome recognition, support, and cooperation from professionals. The relationship between self-helpers and formal systems for health care delivery can sometimes be strained, however. Many self-helpers consider the established health care systems to be insensitive, resistant to needed

change, and unappreciative of the unique perspectives and contributions that can be provided by individuals who have experiential knowledge of an illness or other condition.

Self-Help and Health

A growing body of research is demonstrating that social support helps healthy people stay well, speeds the recovery of people who are ill, and improves the quality of life for those for whom full recovery is not possible. The following are examples from recent clinical literature:

- Only 20 percent of patients with emphysema, chronic bronchitis, or asthma who participated in a self-help group needed hospitalization over a 6-month period, compared to 64 percent of controls. The self-help participants who did have to be hospitalized spent an average of 0.8 day in the hospital, compared to an average of 5 days for controls. (Jensen, P.S. Risk, protective factors, and supportive interventions in chronic airway obstruction. *Archives of General Psychology* 40(11), 1983.)
- In a randomized prospective study, women with metastatic breast cancer who participated in a weekly support group had significantly lower mood disturbances, fewer maladaptive coping responses, and less phobia than similar patients who did not participate in a support group. (Spiegel, D.; Bloom, J.R.; and Yalom, I. Group support for patients with metastatic cancer: A randomized prospective outcome study. *Archives of General Psychiatry* 38(5), 1981.)
- A randomized study of men and women with rheumatoid arthritis found that patients who participated in a mutual support group showed greater improvement in joint tenderness than a similar group of nonpar-

ticipants. The 105 patients in this study were randomly assigned to one of three conditions: a stress management group, a mutual support group, or a no-treatment group. The stress management and support groups, which were facilitated by a psychologist, met for 10 weekly sessions. (Shearn, M.A. and Fireman, B.H. Stress management and mutual support groups in rheumatoid arthritis. *American Journal of Medicine* 78(5), 1985.)

- Forty patients discharged from a State psychiatric hospital who were randomly assigned to a Community Network Development Program (a type of self-help group) had half the rehospitalization rate of 40 similar patients who did not participate in such a program. They also required one-third as many patient days of rehospitalization (7 days versus 25 days) and fewer contacts with community mental health services agencies (48 percent versus 74 percent). (Gordon, R.E.; Edmunson, E.; and Bedell, J. Reducing hospitalization of state mental patients: Peer management and support. In: A. Jeger and R. Slotnick (eds.) *Community Mental Health*. New York: Plenum Press, 1982.)

In addition to studies aimed at objective measurement of outcomes, there have been a number of surveys of participants in a variety of self-help groups organized around physical, mental, and social health problems. Response rates are typically very high, and the majority of respondents report that their participation in such groups has brought them significant benefits.

Although it may seem paradoxical, modern advances in medical knowledge and technology are making self-help groups increasingly important. There is no real paradox, however:

- People with disabling conditions that would have been quickly fatal a generation ago can now live for many years. As a result, more people face the problem of learning how to live successfully and happily despite chronic disability. Many are learning how in self-help groups.
- Research shows that a growing proportion of health care outlays in our aging population are for diseases related to lifestyle, such as excessive drinking, smoking, and overeating. There are, however, no magic elixirs to change someone's lifestyle. Those changes have to come from the individual, but they are often extremely difficult, if not impossible, to accomplish alone. For this reason, health professionals have become very interested in developing closer relationships and referral patterns with self-help groups devoted to helping their members conquer health-threatening habits or chemical dependencies.
- Though advances in medicine in recent decades have been spectacular—organ transplantation, for example—their cost is also spectacular, and they clearly cannot be regarded as general tools to preserve and improve the public health. Health care financing systems are under great strain and are very much involved in efforts to contain costs by stressing prevention rather than cure. Self-help groups focused on healthy living are being viewed increasingly by employers, health plan administrators, and public health officials as an attractive alternative to the costly formal medical interventions that must be made after disease strikes.

These and related trends in public health suggest that the formal health care system, which is traditionally oriented to

treating sick people case by case, cannot by itself be expected to preserve the health and well-being of our people. There is growing recognition that informal care networks perform unique and valuable health services that can have great impact on public and personal health and well-being. Obviously, self-help groups cannot be substitutes for surgery, pharmaceuticals, and other medical interventions. But their approaches can give a human dimension to health care, help people assume greater responsibility for their own health, and simultaneously address the needs of body, mind, and spirit.

Self-Help and Public Health: Steps Toward Partnership

In May 1986, representatives of self-help clearinghouses, the American Medical Association, and the American Hospital Association met with C. Everett Koop, M.D., Surgeon General of the U.S. Public Health Service, to discuss possible ways in which self-help groups and health care professionals could work together for the benefit of public health.

Dr. Koop expressed great interest because he has long believed that self-help groups can play an extremely useful role in preserving and restoring health, and that the self-help movement ought to be regarded as a valuable partner of the formal health care system. In his long career as a pediatric surgeon he had frequently witnessed, long before the phrase "self-help group" became current, the benefits to patients and their families that resulted when they were brought together with others in the same situation.

Periodically, the Surgeon General convenes workshops to address public health issues and solicit recommendations from participants regarding necessary actions. At the May 1986 meeting Dr. Koop offered to sponsor a Surgeon General's

Workshop on Self-Help and Public Health. After consultation with constituencies and further meetings with Dr. Koop and representatives from the U.S. Public Health Service, the self-help advocates formed a steering committee to begin the planning process for the workshop, including the selection of a planning committee.

The steering committee included representatives from the American Medical Association, American Hospital Association, U.S. Public Health Service, and the International Network of Mutual Support Centers. Actual preparations for the workshop were handled by the 25-member planning committee, which included representatives from a broad range of self-help organizations. Subcommittees addressed selection of participants, resources development, issues development, and postworkshop activities. Seed money for the workshop came from grants from the W. Clement and Jesse V. Stone Foundation. The California Department of Mental Health, the Exxon Corporation, and the U.S. Public Health Service contributed funds for later activities.

The workshop, held in Los Angeles on September 20-22, brought together nearly 200 leaders in the self-help movement to develop specific recommendations aimed at expanding and strengthening the role of self-help groups in protecting and enhancing the Nation's health.

The workshop participants, selected to represent a broad cross-section of self-helpers, academicians, professional health caregivers, and public policymakers, developed and presented 16 recommendations to the Surgeon General for creating a partnership between the self-help movement and the formal health care system.

This document is the product of their deliberations.

CHAPTER 1

**ORGANIZATION OF THE SURGEON GENERAL'S
WORKSHOP ON SELF-HELP AND
PUBLIC HEALTH**

Organization of the Surgeon General's Workshop on Self-Help and Public Health was guided by a planning committee whose membership represented a broad range of self-help and public health activities. The membership included representatives of national and local self-help groups and clearinghouses, health professionals, and researchers.

In planning the workshop, the Committee operated under the following assumptions:

1. As a Surgeon General's workshop on self-help and public health, the primary focus would be on self-help groups as an informal support system whose activities are relevant to public health. Self-help groups dealing explicitly with physical and mental health concerns would therefore be the primary topic of discussion, although it was recognized that many other kinds of informal support systems dealing with issues such as housing, poverty, and unemployment can also have important impacts on public health.
2. For the purposes of the workshop, self-help groups would be defined as self-governing groups whose members share a common health concern and give each other emotional support and material aid, charge either no fee or only a small fee for membership, and place high value on experiential knowledge in the belief that it provides special understanding of a situation. In addition to providing mutual support for their members, such groups may also be involved in information, education, material aid, and social advocacy in their communities.
3. It was recognized that, although self-help groups share many characteristics, they also differ from each other in important ways.
4. Convening the workshop would not imply that self-help groups are in need of enhancement by professionals, governments, or any other outside party.
5. It was recognized that the informal support systems and the formal health care delivery system provide somewhat overlapping functions, but that they have significantly different purposes and neither can substitute for the other.
6. For the purposes of the workshop, partnership would be defined not in the narrow and legalistic contractual sense, but rather as a relationship that is mutually beneficial to people (or organizations) who are interdependent whether they realize it or not. Partnership in this sense can include relationships in which there is friction and challenge as well those where things go smoothly.
7. Exchange of information among self-help groups, health care professionals,

and health care systems was deemed desirable and worthy of encouragement.

The Issue Development Subcommittee, one of four working groups of the planning committee, refined the issues to be discussed at the workshop and collected background information (see Appendix A) to provide a common knowledge base for all participants. Commissioned data collection activities included key informant interviews, surveys of callers to self-help clearinghouses, and surveys of providers in hospitals and health maintenance organizations. Based on the results of the data collection, it was recommended that all eight workshop groups address these two broad questions:

1. How can public health be improved through partnership between self-helpers and the health care delivery system?
2. How can these partnerships be achieved without compromising the essential nature of self-help?

The range of issues addressed at the Surgeon General's Workshop is reflected in a set of specific questions sent to participants before the workshop to stimulate their thinking about the self-help/public health partnership idea:

- How can communication between self-help groups and health care professionals be increased and improved? What are the advantages and disadvantages to the self-help movement in having stronger relationships with the health care professions? Can such relationships be established without violating the traditions and essential characteristics of self-help groups? What are the proper roles of clearinghouses, governments, health care professionals, and researchers in relation to the self-help movement? What things help or

hinder the flow of information among self-help groups and between those groups and professionals?

- How should consumers and service providers learn about and gain access to self-help groups? Should self-help organizations develop a massive informal communication system to disseminate health information? How can clearinghouses for referral and self-help group development services be financed?
- How can self-help enhance the effectiveness of the long-term care delivery system? How do self-help approaches affect the course of chronic illness, recovery, and care utilization? What are the positive and negative outcomes of self-help groups?
- How can self-help become a component of a coordinated health care plan? Will pressure for cost containment compromise the quality of care by letting referrals to self-help groups take the place of referrals to needed professional care? Is there a danger that policymakers will use the existence of self-help groups as an excuse to recommend cuts in vital health care services and entitlement programs?
- What factors help self-help groups develop, and what are the effects of external resources on this process? What kind of training is needed for self-help group leaders and facilitators and for professional service providers? What kind of education for the general public? What research and demonstration programs should be undertaken?

Questions like these were very much on the minds of the participants during the two-and-a-half-day workshop, and their answers to them were reflected in their recommendations to the Surgeon General.

CHAPTER II:

OPENING PLENARY SESSION

Sunday, September 20, 1987

WELCOME AND CHARGE TO THE PARTICIPANTS

C. Everett Koop, M.D.

Surgeon General

United States Public Health Service

I am very pleased to welcome all of you to this Surgeon General's Workshop on Self-Help and Public Health, and I am especially happy to see such a large group of participants representing self-help and mutual help organizations from all over the country.

I know that for many of you, coming to this workshop required a considerable sacrifice of money, time, and energy, but I hope your experiences here will repay you a hundred times over. You won't get your money back, I'm afraid, and the time of course is gone forever, though I'm sure the calories you burn here will all be restored. But what I hope you will get from this workshop is the opportunity to renew old friendships with your colleagues and make new friendships with others who, like you, labor long and hard, a day at a time, to help themselves at the same time they help others.

I had a conversation a while ago with several colleagues in the health field back in Washington. We were talking about the self-help movement and the desirability of having a workshop to explore its potential to contribute to public health. One of them asked, somewhat skeptically, "Dr. Koop, do you think it's wise to invest the power and prestige of your office in the self-help movement?" My answer was an emphatic "Yes," because I believe self-help is an effective way of dealing with problems, stress, hardship, and pain. So, I have called all of you together here to spend the next 2 days dis-

cussing how self-help and public health can work more closely together toward the common goal of personal well-being. By the final session I hope we will be able to shed some light on the potential contribution of government to the self-help movement, especially how the Public Health Service can acknowledge more fully the benefits of self-help in health care delivery.

We in government need your contributions to help us find the answers to two fundamental questions: What do we want to do? What do we have to know in order to do it well? Now those questions sound simple, but don't be fooled. Getting answers to them is a major challenge for health policymakers, health care providers, and everyone else involved in maintaining and improving the health of Americans.

What do we want to do? When I was in medical school, back in the Dark Ages, I learned how to diagnose and treat patients with a variety of disease conditions. What we wanted to do was cure people, repair their hurt and broken bodies, and sometimes their broken minds. Today, that desire alone is not a sufficient basis for a health care system. Mending people, curing them, is no longer enough. It is only part of the total health care that most people require.

For one thing, people who go to doctors these days do not present, as much as they used to, a clear-cut disease that calls for a highly specific treatment.

According to a recent national survey of physicians' practices, the main reason people go to a doctor is for what has been called "a condition without a sickness." The patient does have trouble of some kind, of course, but it does not fit the traditional disease categories. Medical schools and other health profession schools have not quite caught up with the self-help and mutual help groups who have long recognized this reality. I believe that recognition is a key aspect of the valuable work these groups do.

The anguished parents of a mentally or physically impaired child, the sorrowful child who grows up in an alcoholic home, the person grieving over the loss of a spouse, the person disfigured in an auto accident or a fire, the infertile couple—when people like these seek help, are they really sick? No, they are not. But they do need help.

These conditions without sickness by no means constitute the total health picture of Americans, but they are a very significant part of it. Generally, most Americans are in good to excellent health by all the routine technical standards. Life expectancy is at a new record high. The average child born today can look forward to living 74.5 years, and even people my age are doing better on life expectancy. You and I can expect a few more years of life than our parents could at our age, and we can expect several more years than our grandparents could. I think these particular figures are more important to most families than the latest Dow Jones average.

Here is some more good news. The age-adjusted death rate for stroke, the third leading cause of death in this country, continues to decline. Today, the mortality rate for stroke is half what it was only 15 years ago, and it appears to be falling by about 5 percent a year. The

same decline is occurring in heart disease, the leading cause of death in our country, although the change is not as dramatic.

Figures like these tell us that we are making good progress across a broad front of acute and chronic conditions. Yet I must tell you that none of this progress is based on new miracle cures, although some of it, very little actually, is due to new medical technologies such as coronary bypass surgery. No, it is because something else is going on in our society, something outside the domains of formal, traditional medicine. It is not any single thing, but rather a constellation of actions and attitudes that have captured the imagination of the American people. The self-help movement is a big part of it, with people joining together to provide emotional support to each other and to share information about common health concerns.

In light of these developments, I believe we have the answer to the first question, "What do we want to do?" We want to promote good health. We want to prevent acute and chronic diseases from occurring. That is the clear direction in which we are moving today—from almost total reliance on cure after disease starts to keeping it from starting in the first place.

What do we need to know to do it well? Certainly we need to have good biomedical science. That is crucial for both cure and prevention. But we need to know more—a lot more—about many things that are new to medicine. We need to understand more about human behavior; how people interact with each other and their physical environment; how they respond to life-cycle events such as childbirth, family growth, the maturation and departure of the young, and death. We need to understand how people cope with economic, social, and cul-

tural stress; how they perceive the future and how they see themselves as part of it. This kind of knowledge tells us not only about health, it tells us about wholeness.

How will we get this knowledge? From behavioral research? Yes, some of it. From research in medicine and the other life sciences? Yes, some of it will come that way, too. But I believe that a great deal of the new knowledge on health and wellness can come from groups like the ones represented in this workshop—from you.

Therefore my charge to you is to formulate recommendations around the following questions:

- How can we develop partnerships between self-help groups and the health care delivery system that improve the health and well-being of the public?
- How can we educate the public and the health professions on the use and benefits of self-help groups?
- How can we expand the current knowledge of how self-help groups work, their benefits and their limitations, through organized research?
- How can we begin to start and support self-help groups as part of a health care delivery system?

Let me make a suggestion about your responses to my charge. Naturally, I want you to consider issues and make recommendations that a Surgeon General has some chance of accomplishing, but I also urge you not to hesitate in making broader recommendations. The report of this workshop will go far and wide, and it is altogether possible that opportunities will come for me to make a fitting connection for you and your cause in areas

where I have no authority to act directly.

I am delighted that this workshop is taking place. I am also pleased that the Public Health Service has helped make it possible and that a number of my colleagues from the Public Health Service are here to learn and share. I congratulate the planning committee not only for its good sense, but also for its sensitivity. The dynamic and independent nature of self-help movement people is indeed a virtue, but it is not always conducive to tranquil planning and organizing. The committee came through the crucible of planning with even stronger commitment to the goals of partnership.

My special thanks go to Mark Mayeda and his staff at the California Self-Help Center and to Marilyn Ruiz and Annette Nussbaum of the Illinois Self-Help Center for their very significant contributions to the workshop. Throughout the many months leading to this moment they have attended to countless details without losing sight of the overall objective, and they have been excellent coordinators.

Now it is up to the rest of us. Over the next 2 days, let us share our hopes, our knowledge and experience, our courage, and our love for who we are. We are people who know full well how imperfect the human race is but are nevertheless determined to make it better.

Let me leave you with these words by M. Scott Peck, M.D., from his book, *The Different Drum*:

There can be no vulnerability without risk. There can be no community without vulnerability. And there can be no peace, and ultimately no life, without community.

God bless you. Thank you very much for coming. Now let us begin.

**REMARKS OF
THE HONORABLE JAMES R. THOMPSON**

Governor of the State of Illinois

Dear Surgeon General Koop and
Workshop Participants:

My congratulations and best wishes as you embark on the Surgeon General's Workshop on Self-Help and Public Health. I look forward to the results of your important explorations of the partnerships between self-help and public health.

Self-help has long been of interest to me and my administration. Indeed, we are very proud that one of the leaders in advocating for self-help and mutual aid is a well-known Illinoisan, Clement Stone. Stone understood very early how remarkable self-help could be—a voluntary effort through which people can help themselves while helping others—by sharing insights, problems, and support. Another Illinoisan, Leonard Borman, founder of the Evanston Self-Help Center, was one of the first people to sit on the Advisory Council of my Office of Voluntary Action. Borman was an articulate champion of self-help, and under his leadership a directory of self-help groups in the Chicago metropolitan area and a

directory of self-help opportunities for people with developmental disabilities were developed.

It is important for people to know about the availability of self-help groups. In 1983, the Illinois Legislature made a grant available to start an Illinois Self-Help Clearinghouse. That project has included many partnerships—my office, the Clement and Jesse Stone Foundation, the Illinois Hospital Association, the American Medical Association, National Easter Seals, and many others. It is important that health care professionals and citizens be aware of the availability and effectiveness of self-help. Self-help has had tremendous impact in improving individual lives. In addition, it is a voluntary effort and is extraordinarily cost effective.

My best wishes for a successful workshop which will help all of us to help each other.

Sincerely yours,
James R. Thompson, Governor
State of Illinois

¹ Governor Thompson's statement was read to the workshop participants by Ms. Jean Bradner, Director of the Office of Voluntary Action, Office of the Governor, State of Illinois.

**REMARKS OF
THE HONORABLE GEORGE DEUKMEJIAN ²**

Dear Surgeon General Koop and Workshop Participants:

I would like to take this opportunity to welcome Surgeon General Koop and all the participants of this Workshop on Self-Help and Public Health. I am especially pleased that you have chosen the California Self-Help Center, a program initiated by our administration and funded by the California Department of Mental Health, for the site of your conference.

It is becoming increasingly evident that self-help groups are particularly effective in helping people cope with personal and health-related problems. The dramatic increase in the number of groups, both in California and throughout the Nation,

has enabled thousands of individuals to seek the comfort and support of others facing similar concerns.

With representatives from self-help organizations, the media, human services agencies, educational and research programs, business, and labor, this national conference will enable the individuals with varied backgrounds to address the future of self-help in the United States.

I am confident that with your strong support and leadership, Dr. Koop, this workshop will be a success. Please accept my best wishes.

Most cordially,

George Deukmejian, Governor
State of California

² Governor Deukmejian's letter was read to the workshop participants by Mr. Clifford Allenby, Secretary of the California Health and Welfare Agency.

**WELCOMING ADDRESS BY
MARK MAYEDA**

*Workshop Moderator
Deputy Director of the California Self-Help
Center University of California, Los Angeles*

On behalf of the planning committee and the California Self-Help Center, I welcome Dr. Koop, other honored guests, and workshop participants. This Surgeon General's Workshop on Self-Help and Public Health is a historic event. Although it is only one step in gaining national recognition of the self-help movement and acceptance of the vitality of its principles, it is a major step.

All of us here today share an interest in self-help, but my perspective may differ from many of yours. I am a public administrator by profession and for the last 15 years I have been involved in managing not-for-profit organizations providing human services. As I gained experience in my field, I came to understand that an ever-present challenge is how to provide effective, quality services when resources are limited and needs for those services often exceed an organization's capacity to respond. It was only about 2 years ago, a year after I joined the California Self-Help Center, that I fully realized that self-help and mutual support presents an opportunity to meet this challenge. To understand why this is so, let me call your attention to some of the factors that make self-help groups so effective. My esteemed colleague, Dr. Bonnie Burstein, has identified three major things that these groups provide.

First, they eliminate the isolation of their members. When people develop a health or health-threatening problem they usually feel isolated and distant from

those who do not have the same condition. However, groups of people who have a common problem and common experiences can end their isolation by sharing their feelings and giving each other needed emotional support. An example is SHARE, a breast cancer self-help mutual support group in New York. SHARE helps women cope with a highly distressing and physically difficult health situation. Members are able to deal with feelings that they have not been able to share anywhere else.

Second, members of such groups gain perspective by providing information on what can be expected emotionally, physically, financially, and socially, and much of this information is based on the personal experience of the members. Groups can also provide information on effective coping strategies. For example, I CAN COPE, a cancer self-help and mutual support group, helps its members understand what to expect from cancer treatments, such as chemotherapy and its side effects.

Third, self-help and mutual support groups help their members develop a sense of empowerment in situations that usually create feelings of helplessness. The sense of empowerment comes in two ways: seeing others cope with the same concern, and helping oneself by helping others. The California Network of Mental Health Clients and the National Black Women's Health Project are examples. Both use self-help mutual support groups

to develop in their members a sense of empowerment and control of their own well-being.

Fourth, self-help and mutual support groups are able to reach not only those who are directly afflicted but also those who are close to them.

These attributes of self-help and mutual support groups can have important consequences for public health, and in my view they support the validity of seeking partnership between the self-help movement and the health care delivery system.

However, I must also stress the importance of respecting the integrity and autonomy of the groups. The full value of self-help and mutual support groups is possible only because they are self-Governing and serve the needs of their members, not those of outside powers.

There is much that all of us need to learn and understand about self-help and mutual support. We face formidable challenges over the next 2 days and well into the future, but I am confident that we are equal to the task.

WHO WAS INVITED HERE—AND WHY

*Frances Dory
Member of the Selection Subcommittee and
Executive Director of the New York City Self-Help
Clearinghouse*

Hundreds of people were nominated as potential participants in this workshop, and to have invited them all would have made a conference far too large to operate effectively. Though we had selection criteria, it was no easy matter to sift through these nominations. Your presence here means that, in the opinion of both the selection subcommittee and the larger planning committee, you best represent the self-help movement in America today.

You bring a wealth of experience and knowledge that we need, and we respect and appreciate your commitment to apply that experience and knowledge to improving the well-being of the American people. We know how difficult it was for some of you to get here, and we thank all you for coming.

There are 175 of you here from 23 States and the District of Columbia. You

are equally divided between men and women and between human service providers and self-helpers, and 27 percent of you are members of racial minorities. A substantial number of you are people with disabling conditions, and you are a very significant part of the self-help movement. This diversity is essential to the work we will be doing over the next 2 days, and it will be reflected in the composition of each of the smaller topical groups to which all of you will be assigned when we get down to the business of this conference.

Now I want to tell you a little story. It's about a man named Sam who died. On arriving at the gates of Heaven he petitioned St. Peter, who was surrounded by a host of angels, to let him in. St. Peter informed Sam that he would first have to make a brief presentation about his qualifications. Unfortunately, Sam had

not participated in any self-help groups and therefore was not fully prepared to deal with this level of disclosure. He said he would have to think a bit before he could come up with something St. Peter might find acceptable. St. Peter, being a good helper, encouraged Sam to reflect on his life and recall some event that could provide convincing evidence of his eligibility for admission, then left him alone to ponder.

When St. Peter returned after awhile, Sam told him he thought he deserved to be in Heaven because he had survived a great flood in Johnstown, Pennsylvania. St. Peter, bewildered, asked him to explain why that should be a qualification. "Well," said Sam, "that flood came when I was a boy, and it was scary, there was a lot of damage, and a lot of people died. But I survived it, and that's why I think I should go to Heaven." After a long pause, St. Peter motioned toward the band of angels and whispered, "Sam, I think I ought to tell you, Noah is in the audience."

We who organized this workshop understand how Sam must have felt at that moment, because all of you in this audience are Noahs. Yes, we did work hard, but we are mindful that we are building on values and traditions that have been carefully and deliberately thought out by people like you, who have worked hard over many years and know what it's like to be in a real deluge.

The self-help movement is diverse and not especially well organized, but it is not haphazard. Since the founding of Alcoholics Anonymous more than 50 years ago, self-help groups have proliferated at a phenomenal rate. Ten years ago, the President's Commission on Mental Health set the stage for the interface of formal health care systems and informal helping networks by recommending the

development of resource centers to collect and disseminate information on self-help groups. These centers, many of which are now known as self-help clearinghouses, have added immeasurably to the proliferation of support groups in their geographic areas. There are now more than 40 of these clearinghouses in the United States and several in Canada, and linkage between self-helpers in different countries was established just 2 years ago with the formation of the International Network of Mutual Help Centers.

Today we begin another leg of this journey of pulling our movement together, making it better organized and more effective, and becoming clearer about what we want and need. No matter whose figures you use, there are more than 10 million people who regularly participate in mutual aid groups. By any standard, when that many people are doing something in essentially the same way and out of the same belief system, what you are witnessing is a social movement. Like the women's movement and the civil rights movement, we are part of an effort to create social change in America, and like all such movements, our goal is to improve the relationships among people.

What the self-help movement is about is better relationships in the spiritual sense. It is about the changes needed in human services agencies to make them more effective, more accountable, and more meaningful to the people they hope to serve. In this new leg of our journey, we have to do more than look at those whom we serve now. Some of the unmet needs we will be addressing in the next couple of days involve huge numbers of people who are not being served. An estimated 22 million people in this country have hypertension, but not many of them are being served by self-help groups at this

time. It is also estimated that there are 6 million substance abusers, 5 million diabetics, and 18 million arthritics. I am sure Dr. Koop could tell us about the number of people who still smoke, and about the lung diseases and other disorders they risk or have because of it. Self-help groups exist for all of these conditions, but most of the people who have them are not yet participating.

The task we face is enormous, because the number of people who are not being served is enormous and that number keeps growing. For example, 10 years ago acquired immunodeficiency syndrome was unheard of, but today most of our self-help clearinghouses are dealing with the huge task of reaching out to people who test positive for HIV, to those who actually have AIDS or AIDS-related complex, and to those who are struggling to give them care. We believe that self-help has enhanced the services available to all these people.

These tremendous unmet needs can be met if we can tap the tremendous human

potential represented by the very people who are having the problems, yet too often those people are seen as problems, not as resources. You and I know that every person who has arthritis, diabetes, AIDS, or any other condition is a potential caregiver capable of helping others resolve, cope with, and change the conditions of their lives.

This entire society cries out for new definition of the ways people relate to each other. The essence of right relationship is seeing ourselves as part of the solution and recognizing that none of us is safe from tragedy. Levine's phrase, "the soap opera of life," applies to all of us. We are not at this workshop to talk about what we in here can do for them out there, we are here to talk about how all of us in this society can save ourselves by helping each other. That is our hope—that we can begin to see ourselves as a community and as part of a very, very important movement, and perhaps its cutting edge.

WHAT HEALTH PROFESSIONALS CAN LEARN FROM BREAST CANCER PATIENTS

Leonore Miller
Member of the Planning Committee and
President of the SHARE Breast Cancer Group
New York, N.Y.

Twelve years ago, I could not have imagined that anything positive could come from having breast cancer. Now, looking back, I can say that out that frightening and devastating experience some rewarding outcomes did emerge, namely my involvement with SHARE, a self-help group for women with breast cancer.

We began 11 years ago, inspired by Dr. Eugene Thiessen, a concerned physician who felt that breast cancer patients, especially younger women, needed to discuss their concerns with their peers. Though he was a physician who had the sensitivity to see the painful emotional aspects of this disease, Dr. Thiessen was nevertheless a frequent target of anger among the

women, as a symbol of all the surgeons who were perceived as having massacred and disfigured us.

Over the past 11 years I have listened to the experiences of more than 600 women. All of them were unique individuals, but the fear, the anger, the depression, and, yes, the hope they expressed was universal. Through floundering and trial-and-error learning we learned ways to cope with this life-threatening illness and its emotional, social, and practical impacts. We each brought our own history to our illness, so we all reacted differently to it, but always consistently with the core of ourselves.

Hippocrates said he would rather know what sort of person has a disease than what sort of disease the person has. Listening to each other and sharing our differences gave us the ability to appreciate our basic similarities and thus validate ourselves. Watching others nod their heads in affirmation as we spoke was more comforting than a thousand words from someone else who did not truly understand. Sometimes when a new member arrived, tears of relief would flood her eyes because at last she could allow her feelings to surface in an atmosphere of encouragement and warmth.

At that time, radical mastectomies were the order of the day. Breast reconstruction was not on the scene yet, and involving the patient in medical options was still in the distant future. Lumpectomies were considered poor medicine, and power between the women and the medical establishment was very unbalanced. It was not until 1979 that insurance companies stopped classifying breast reconstruction as cosmetic surgery and began to reimburse for it, although they had always reimbursed for testicular implants.

These changes were accomplished by

women who became knowledgeable medical consumers, who began to regard themselves with confidence and trust and to feel their own power. Mutual aid groups were instrumental in fostering this spirit, because when women came together in an atmosphere of trust and acceptance, their collective experience gave flesh and bones to theory, and the subjective become something visceral. This understanding needs to be communicated to health care providers through networking, informal meetings, informational materials, and the personal self-help experience a health care provider might have encountered.

Many women feel shame and guilt because they have cancer. The very word evokes the thought of death. An attentive health care provider can diminish guilt and shame and reinforce the idea that cancer carries with it no moral implications or judgments. The altered body image does create problems regarding desirability and sexuality. But before discussing sexual matters with patients, health professionals should be comfortable both with the subject and the colloquialisms used to discuss it, be prepared for all types of questions, be nonjudgmental and supportive, include the partner whenever possible and without assuming that it is always a male or that there even is a partner, have a quiet private place to talk, and really listen.

Two national surveys indicated that the three main determinants of patient satisfaction are all related to contact with the physician. Most important is the initial contact, then the information conveyed, and finally, the general supportiveness. Physicians are trained to cure. They are used to success and want to be superhuman, but cure is not always possible or certain. Physicians who cannot handle their own feelings in this situation may

withdraw just when the patient is most in need of support. Training in medical schools and hospitals is needed to help physicians deal with their own feelings about death and lack of success.

Health care providers need to keep up with the latest developments in the field, both to diminish their own pessimism and to avoid cutting off hope in their patients. Nurses have the most intimate contact with patients and the greatest opportunity to pick up clues and communicate with warmth and understanding. But being female, as most nurses are, has its own special problems in caring for breast cancer patients. Nurses may be constrained by their identification with the patient and their own fears of illness and death. If a nurse has had breast cancer she must be careful not to react in terms of her own disease, but in terms of the patient's needs. Coping strategies for stress and burnout need to be considered for anyone working with high-risk patients.

The sensitivity of professionals in their relations with patients was a topic that came up many times during group meetings. I can remember lying on a table in a huge chilly lab, waiting for the results of a lung biopsy. The technicians had a few idle moments while the test was being done to see if my cancer had metastasized to my lungs. They began to chat and joke and laugh among themselves while I lay there trembling and waiting for the news. It was Friday afternoon, and as they talked about their plans for the weekend, it made me feel acutely that I might never be part of that normal world again. I was too frightened to speak up and ask them to stop, yet I also understood that they were expressing their own need for release from tension. Fortunately, the results were good, but later, when I knew more and heard similar stories from so many

other women, I was sorry I had not used the opportunity to point out to them how that kind of banter exacerbates a patient's anguish.

One of the women in our group was frightened of her chemotherapist. He seemed impatient when she asked questions and he often engaged in long phone conversations during her treatment. But she also felt that her life depended on him, and she was afraid of retribution if she were to make her needs known. The women in the group tried to encourage her to speak up, and one of them volunteered to accompany her on the next visit and give her support in confronting the physician. The two women did go together on the next visit, and although the SHARE volunteer said nothing, her mere presence improved the situation. The doctor did become more cooperative and his telephone conversations did become shorter.

Trust in the doctor is a prime requisite for creating a receptive environment for treatment, but a trusting relationship implies that patients feel it is safe to criticize. How contradictory it is when a physician responds with professional skill to save a woman by surgical or medical intervention, then denies her the support she needs to form a different lifestyle and adjust to an altered body image, and the woman—frightened and depressed—is unable to say anything about it.

Out of the hundreds of meetings of our group over the past 11 years a body of subjective knowledge has emerged, through groping and pain, trial and error, sharing and laughter. I want to summarize what we have learned, because I think it provides a true grasp of what self-help is all about. Furthermore, I think it can lead to a real partnership with the formal health care system that is built on a bedrock of understanding.

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- Fear, anger, and depression are normal responses to a serious disease.
 - There is solace and validation in sharing with peers.
 - Grieving is healthy because it frees up your energy to get on with your life. But grief comes in layers, and each layer must be worked through or it goes underground and emerges in undesirable ways. One woman told us that after mourning the loss of her breast she was able to grieve about the loss of her father, then her divorce, and finally, the loss of her pet.
 - Facing the possibility of death means losing your feeling of invulnerability. It is much like losing the innocence of childhood. But facing reality can enhance the good times, change your perspective, and establish your priorities. You become able to ask questions like, "If not now, when?" and the social hypocrisy most of us indulge in from time to time seems superfluous.
 - We need to feel in control again, even if we know it is an illusion in the grand scheme of things. We need to feel we can take charge of our own bodies, be informed medical consumers, and participate fully in decisions regarding our health. An uninformed choice is not a real choice.
 - We are more alike than different, but we need to appreciate and respect our differences.
 - There is a difference between enlightened self-interest and selfishness.
 - Living with uncertainty is difficult, but it is possible. Having cancer taught us what was always true, that life is uncertain.
 - There are many kinds of courage, and though we cannot absorb courage from others, we can be inspired by it.
 - Each of us is a person of value, and when we respect our own essential humanness, we can bring that respect to others.
- For me, that is the message of partnership. This workshop is a special moment in time—a time for self-helpers and health professionals to reflect and join hands to fight our common enemies, ignorance and disease.
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WHO WAS INVITED HERE—AND WHY

*Frances Dory
Member of the Selection Subcommittee and
Executive Director of the New York City Self-Help
Clearinghouse*

Self-help clearinghouses represent one of the most exciting and innovative forms of human service today. Over 40 of them have been created across the country in the last decade, and each of them has been finding new and different ways to foster the development of self-help groups

in their communities and increase awareness of their availability by people in need.

These clearinghouses also serve as bridges for increasing collaboration between the self-help and professional communities. Through their work they

demonstrate some of the possibilities that exist for any organization to collaborate with self-help groups in meeting people's health and human needs.

Our experience in New Jersey is just one example. At our medical center, it all began with a simple list containing contacts for some two dozen self help groups. It had been compiled because several hospital staff members had often asked for these hard-to-find resources and were reporting how grateful patients were to learn about them. The more the list was circulated, the more it grew, until it eventually included nearly 70 groups.

As we followed up on leads, we began to come in contact with people who had wanted to start a group but didn't know how to proceed—people like Elinore Neal of Reach to Recovery, who said, "I don't want to start this mastectomy group for myself. I simply want to prevent other women from having to go through the hell I've had to go through alone." We linked people like Elinore with all the related national or model groups we could identify, so they wouldn't have to reinvent the wheel. We eventually published this list as a directory that included national groups that had no local chapters, so people could see what new groups might be started in their community.

We had observed what we refer to as a demonstrational effect, and we saw its power to encourage people to start new self-help groups in their communities by providing evidence that a similar group had been started somewhere else. For example, we had numerous calls requesting information on groups for survivors of suicide. No such groups existed in New Jersey, but we were able to send callers material from a model group in the midwest. One woman called back in tears, explaining that the material had shown her how starting such a group could pro-

vide meaning to a meaningless act.

Hospital staff expressed an interest in helping patients form new groups. A laryngectomy club was started with the help of the speech and hearing clinic staff. The mental health center's phobia program staff assisted in developing an independent phobia self-help group for patient aftercare support.

As time went on, more and more lay people called seeking a group, and if there was no group to refer them to, we would simply ask them if they would be interested in joining with others to form a group. We recorded the names of those who said yes so we could link them with the next caller who might also be interested in developing that particular kind of group. It was like rubbing two sticks together to make a fire. Those linkages often resulted in new groups. We began to realize how, with a little encouragement and support, some of the help-seekers who called us could be readily transformed into resource developers who started groups.

We have found that one of the most appropriate roles we or other professionals can take in helping these groups is that of consultant, giving advice and counsel but not getting involved in actual decisionmaking or leadership. In our view, the professional should remain on tap, not on top.

In 1981 we extended services to the entire State using toll-free phone lines and a computer system that included a local, State, and national directory. Since that time, by providing encouragement and support, we have assisted in the development of over 420 new groups across the State. We have given consultation to people like Nancy Berchtold, who called us 2 years ago to ask about a group for postpartum depression and found that there weren't any. She went on to develop one

of the first such groups in the country, and it has since grown into a national organization helping many more groups get started. Then there are Sally and Jeff Toughill, who founded the Histiocytosis-X Association of America to work with and learn from other parents of children with that condition.

Clearinghouses have helped start many groups across the country that have developed into State or national foundations. We should recognize that many long-standing health foundations, societies, and agencies dealing with specific illnesses began as self-help groups. This form of development continues today as improved medical technology and research increase the survival for previously life-threatening disorders and continue to identify new disorders.

In 1984 a blind caller educated us about the need for special self-help groups for people who were losing their sight. We worked with him and wrote a proposal that provided him with a driver, a staff, and a position at the clearinghouse. His name is John Dehmer, and he and his staff have started over 30 new self-help groups across the State for people who are visually impaired or adjusting to blindness.

In other development work, the clearinghouses use self-help group representatives as paid part-time consultants for education and training. Our clearinghouse currently helps over 10,000 callers a year with referrals; over a third of them are professionals who have no other place to turn. We also publish a State directory each year along with newsletters and various how-to materials, and we assist in conferences and workshops throughout the year that bring professionals and self-help group leaders together to learn from each other. Foundation-funded grants have allowed the creation and distribution

of Tel-Med tapes on self-help for every hospital in New Jersey and the publication of a national directory of groups.

Still there is a great need for learning. It was Marie Killilea, speaking at one of our New Jersey conferences on self-help, who wisely counseled us that the first thing professionals have to learn about self-help groups is that there is something to learn. Although professionals have become increasingly aware of the value of self-help groups, few understand the underlying principles of self-determination and empowerment that are fundamental to their life and success. By understanding these principles, professionals and self-helpers have a better appreciation of how to form partnerships without compromising the essential nature of self-help.

I believe the most important need is to respect self-determination. Several years ago I asked Dr. Agnes Harfield, a researcher who is one of the founders of the National Alliance for the Mentally Ill, what she felt was the most important factor that contributed to the vitality of a successful self-help group. Her reply was one word: "Ownership." A sense of ownership on the part of the members. To the extent that the members recognize that the group is theirs, they will invest their time and effort to make the group work. But if they perceive that the group is owned by someone else, whether a professional or an agency, they tend to step back and let the professionals do the work.

In negotiating any partnership it is important to have a true sense of equality and mutual respect for each other's values and knowledge, whether that knowledge is experiential or professional. A partnership is built between equals. Self-help groups empower their members to regain control of their lives and deal effectively with their condition. They

encourage individuals to assume an active role in restoring and maintaining their health. Some groups are advocacy oriented, reflecting a healthy skepticism of our health care delivery system and helping to make health care more responsive to consumer needs.

Several self-help groups have shown their ability to improve public health on at least three other levels of health care delivery. First, they have demonstrated their ability to prevent some health problems from occurring by reducing stress in general, as well as through educational programs such as laryngectomy clubs, stop smoking campaigns in schools, and certainly the advocacy efforts of Mothers Against Drunk Drivers (MADD). Second, they have shown that they can supplement and humanize treatment services by serving as adjuncts to treatment or providing social support and help that is not available within the professional milieu. Third, they have demonstrated their ability by providing aftercare services that reduce recidivism, reinstitutionalization, and readmission to the health care system.

There are some areas that require development. From our experience, the media clearly have tremendous power to inform people about self-help. We saw that in the case of a woman who called us after seeing a television program about incest. She told us it had been 40 years since she had been abused by her father, and she had never spoken to her husband or her therapist about it. The TV program, which depicted a self-help group, had given her the courage to reach out to someone else. We can do much to maximize media resources, from promoting weekly newspaper listings of groups to developing public service announcements.

Advances in telecommunication provide additional opportunities. Telephone

and computer conferencing systems have permitted an increasing number of self-help groups to meet over great distances. Our clearinghouse has helped host telephonic meetings of people with Ehlers-Danlos syndrome, a connective tissue disorder. It was the first opportunity they had to talk with other people who had their condition, and several of them went on to form a national foundation for the problem.

Health care and other agencies can play a role in making this technology more available to self-help groups, for reaching out to rural areas, and allowing participation by people who are unable to leave their homes or their hospital beds. Electronic communication will surely increase the linkage of people, ideas, and concerns in the years ahead and will provide many innovative ways for people to find and develop the mutual aid and support they need.

Local self-help clearinghouses and resource centers, which now serve almost half the country, have their own stories to tell about the partnerships they have helped create and the ones that remain to be created. The International Network for Mutual Help Centers, an association of centers that was formed in 1985, serves as a forum for the development and exchange of these and other ideas that support the philosophy and practice of self-help. Members of the network may be of service in implementing some of the recommendations that come out of this workshop.

All of us here realize profoundly the immense potential of self-help groups, and we know that more must be done to make health care professionals aware of these resources so more people can find the support and the help they need. We recognize that it would be unethical for a physician to withhold the medication a

patient clearly needs. With the increasing amount of research that indicates the value of social support in restoring and promoting health, we must ask ourselves if professionals do not have a similar obli-

gation to provide patients with referral to self-help groups when they know it can reduce suffering and promote recovery or rehabilitation.

SELF-HELP FOR HEALTH PROFESSIONALS

*S. Denise Rouse
Member, Planning Committee
Board Member of the National Black Women's
Health Project Commissioned Corps, USPHS*

Like many others, I came to the self-help movement seeking an alternative. I was dissatisfied by the lack of progress in improving health in the black community. I knew that most black Americans had some access to health care, but I was also aware that it wasn't making much of a difference. Knowing that the major causes of excess morbidity and mortality are behavioral, I chose to look outside the system.

My search led me to the beginnings of the Black Women's Health Project of the National Women's Health Network, which later became the National Black Women's Health Project, Inc. This is a self-help organization whose purpose is the empowerment of black women around issues of improving their own health status, and its major intervention strategy is the self-help group. Supporting strategies include developing health promotion material oriented to black women—films, videos, brochures, newsletters, and conferences—and developing a body of accurate information about black women for use in forming public policy.

I came into this movement with the notion that I would find a tool that would enable me and others to improve our

health. What I also found was a way to improve my own life. I also learned that, for most people, it is not what is done to them that makes a long-term difference in their lives and in their health, but what they can do for themselves.

Shortly after becoming involved in self-help, I was reassigned to West Alabama Health Services, a rural health care delivery system in Alabama. With the gracious and generous support of Jim Coleman, the executive director, and Sandra Hewlett, the medical director, we began to test self-help as a tool for improving health status, using the self-help model developed by the National Black Women's Health Project.

We started staff groups first as a way to validate the appropriateness of using self-help as a tool for health promotion, with additional goals of improving communication among the staff, enhancing their sensitivity and responsiveness to clients, and improving staff-client communication. The self-help groups for staff were organized in three settings—an ambulatory care center, an infant survival project, and a nursing home. The participants, who self-selected after the project was presented to all staff members, represented all but one of the profes-

sional and nonprofessional staff categories. The only category not represented was dentistry. The staff groups started in November 1984, meeting weekly for six months, then every two weeks. The average membership was 19 and the average attendance was 10. These groups dealt with workplace issues, personal health problems, and family problems.

The long-term care facility was in a state of crisis when we formed a self-help group there. West Alabama Health Services, which is a federally funded primary health care center, was in the process of developing a health maintenance organization for the Medicaid population as a demonstration project. The county hospital and nursing home were on the verge of closing, and since their closure would have ended the development of the health maintenance organization, that organization took over their management. The nursing home was in danger of losing its license because of the quality of the care that was being given to its residents. Self-help group techniques were used in managing the staff during this crisis and in reshaping the staff into an effective long-term care delivery team. The nursing home retained its license and patient care improved dramatically.

The issues addressed in the long-term group were feelings of oppression by management, inability to cope with a rapidly deteriorating and demanding workplace, low morale, perceived racism in work relations and in patient care, dissociation of the staff from the residents, and the problems of coping with disability, dying, and death on a daily basis. The self-help group also supplied motivation for staff in a setting where financial incentives were lacking.

We found that staff members valued the opportunity to have input in decision-

making, to share relevant experience and expertise with management, and to be recognized for the first time as valued and respected members of the health care delivery team.

From our experience with the staff groups, we concluded that the model was indeed appropriate for our clients and proceeded to form a young mothers group. These were first-time mothers, which in that community means teenagers. The participants were also participating in an infant survival project funded by the Ford Foundation. During the group's first year there were no infant deaths. The group, which called itself "Sharing Good Values," began a loan fund to alleviate the shared experience of not having enough money to get through to the end of the month, raising money for the fund by organizing dances and rummage sales. Group members were able to deal openly with such sensitive issues as contraception, teen pregnancy, sexually transmitted diseases, breast cancer, obesity, and family violence. This was possible because the self-help process alleviates feelings of isolation, powerlessness, and hopelessness, which affect behavior profoundly. Sharing occurred in an atmosphere of trust and acceptance that many of these young women had never experienced in their daily lives.

The National Black Women's Health Project has found that self-help groups are very effective in bridging the gap between the public health community and the black community. Felicia Ward, a self-helper in Oakland, California explains that the reason lies in the process of empowerment. Individuals recognize their own need to change and want to share their experiences with others, so they form a group. The group in turn wants to share what it has learned with the entire community. This progression

from the individual to the group to the community is a normal, natural flow of information that has been validated by the leaders in the community.

In Georgia the National Black Women's Health Project uses their model of self-help group development to mobilize women to participate in a series of maternal and child health conferences sponsored by the Georgia Department of Human Resources. In North Carolina five self-help groups formed the bone and sinew of a statewide health planning network that has established a historic linkage between North Carolina A&T College of Nursing, the NAACP, the North Carolina Child Development Institute, and grassroots women. Similar networks now exist in South Carolina and California. In California the South Berkeley Women's Center is using the self-help group as a tool for helping women cope with their health problems.

I believe the beneficial effects of self-help on public health are infinite. I will mention just a few. Self-help breaks down the communication barriers between providers and clients by creating an environment where greater trust is possible, where the client can be viewed and understood as a whole person. It provides a process for translating health information into a usable form, frequently by the clients themselves. It builds bridges between public health and the community and provides a mechanism to get information to hard-to-reach groups, and this is critical for implementing community-based health promotion programs. It offers providers additional tools for coping with an ever-changing and demanding workplace. It offers providers insight into their own frustrations about noncompliant patients. Self-help provides an opportunity for providers to share their knowledge and expertise in a receptive,

nonthreatening atmosphere. It can be a tool for resolving sensitive issues and conflicts in the workplace. It can give providers a tool for coping with their own responses to disability, death, and dying, and this is especially relevant in long-term care settings and in caring for AIDS patients.

In the six years I have been involved with self-help I have learned six lessons:

1. The self-help process is particularly effective in dealing with isolation, powerlessness, and hopelessness.
 2. It is effective in enabling people to cope with many forms of oppression, whether by society, by individuals, or from within.
 3. Health information is more valued when it is delivered by a provider who has experienced a health problem firsthand and can share that personal experience.
 4. Self-help principles are highly adaptable to different sexual, racial, and cultural groups. For example, the National Black Women's Health Project has successfully shared its self-help model with Kenyan, Caribbean, and Latin American women. Each community adopts from the self-help process what they feel will work for them.
- As health professionals we need to respect each group's ability to shape the self-help process for its own needs. This implies acceptance and respect for cultural diversity.
6. It is important to understand one's own health concerns and behaviors before requesting others to change. By going through the self-help process first, professionals gain valuable insights as well as credibility.

I believe that a partnership already exists between self-help and public health.

In some of the federally-funded migrant and community health centers, for example, self-help projects have been implemented for infant mortality prevention, teen pregnancy prevention, diabetes control, and improved nutrition. My favorite example is the "brown bag" program of the Delmarva Ministries Migrant Health Center in Delaware, in which women in seasonal and migratory farmworker communities pool their limited food money to make lower-cost bulk purchases from a local wholesaler.

The self-help process is particularly adaptable to the needs of rural and underserved communities and migrant and seasonal farmworker populations because of its ability to end isolation and its marvelous adaptability to ethnic differences. This is especially relevant for the migrant community, both because it is migratory and because there are at least five differ-

ent ethnic groups harvesting the Nation's crops at any given time. The National Migrant Health Program of the Public Health Service has, for the first time, a national program objective to encourage the development of a self-help component in the health promotion programs of all 122 migrant health centers.

In summary, self-help offers two major benefits to health providers: it helps us cope personally with the work environment, and it helps us serve our clients. In addition, it provides tools for program management and mechanisms for working with hard-to-reach and culturally diverse populations. The self-help movement provides a marvelously adaptable tool for health promotion. I encourage health professionals to take the time to understand the process fully by experiencing it first-hand.

THE POLITICS OF SELF-HELP

Irving K. Zola

*Professor of Sociology, Brandeis University
Co-Founder of the Greenhouse Mental Health Collective
Co-Founder of the Boston Self-Help Center*

There was once a health worker who was standing by the side of a raging river. Suddenly she saw someone floundering desperately in the turbulent water, about to drown, and she jumped in and pulled him to safety. She had no sooner restored the victim's breathing by artificial respiration when she heard another cry of distress coming from the river. Again she jumped in and rescued someone on the verge of drowning. This went on repeatedly. As soon as she would save one life there would be another one to save, and another, and another. The health worker

spent so much time jumping into that raging river, dragging out its victims, and applying artificial respiration that she had no time to see who the hell was upstream pushing all those people in.

I want to talk about certain kinds of self-help activities that are intended to prevent people from being pushed into or falling into that deadly river. For lack of a better term, I call it the self-help movement's political function. That function has always been a major part of the movement. Katz and Bender, in their extraordinarily fine history of the self-help

movement, wrote, "As long ago as the late 18th and 19th centuries, mutual aid organizations served not only to deal with the imminent needs of their members, but served also to politicize them." Or, as we might say today, to raise their consciousness.

Let me briefly articulate some of these political functions that have always been present. When I speak of politicization, I also mean a recognition of the power dimension in self-help. This was brought home to me when I was reading Katz's and Bender's book, but it also was emphasized for me by the responses to the survey that was sent out to the participants in this workshop. Many of the respondents said that a crucial issue to be faced in the provider-patient relationship is who has control and who is making the decisions. What this reveals to me is a strong concern about imbalance of power.

To regain this balance, almost all self-help groups in the health care area have engaged, either implicitly or explicitly, in what might be called a process of demystification—of a particular problem, disease, or disability, of the nature of treatment, and of what care providers can give. What some in the self-help movement call empowerment also has political dimensions. For many mutual support groups, empowerment takes the form of personal advocacy in helping an individual get through the system, whatever that system may be.

For other groups, empowerment goes beyond that and becomes what I would call interactional advocacy, which is based a realization that in dealing with the health care system one should not go it alone because the power imbalance is too great. I got that particular insight from a group called the Black Panthers, who were setting up a group in my home town

of Dorchester around 20 years ago. The Panthers felt that no person, especially if poor, old, and black, should go alone into a situation where there was such an imbalance, so they always sent someone to accompany anyone needing access to the health care system.

A third political aspect of empowerment occurs in groups that are not organized around a single specific category of disease or disability but cut across a number of them. The perspective of these groups is that certain kinds of actions can be accomplished far better if the similarities among members, irrespective of the particular nature of their individual conditions, is recognized. There may also be an unwitting recognition in such groups that specialization according to disease or disability categories can produce fragmentation and insularity, and an attitude of, "my disease is worse than yours."

For some people even this cross-cutting approach is not adequate, however, and one result has been the creation of alternatives to the mainstream health care system itself, all based on the concepts of self-help. In the late 1960's I was part of a group that created one of the first ostomy rehabilitation clinics in the country. Though based in a hospital and headed by a physician, it was run completely by people who had ostomies. Things got even more explicit in the late 1960's and 1970's. Women formed their own self-help clinics when they felt that the predominant health care system could not hear their voices. A number of disability groups followed suit and eventually created not only a movement of the disabled but independent living centers for the disabled.

Yet, for at least these two segments of the self-help movement, these internal gains were still not sufficient. They per-

ceived a need to work for change in the political, legislative, and social arenas. This idea was perhaps first articulated in the book, *Our Bodies, Ourselves*, which came from a group of women engaged in self-help. The thesis of these groups within the women's movement was that it is not enough just to support ourselves, we also have to understand the system that is oppressing us so we can work for changes. Out of this movement arose groups like the Women's Health Network and the National Black Women's Health Project.

The development of the disability rights movement was quite similar. First there were various groups organized along specific disability categories—cerebral palsy, blindness, spinal cord injury, and many other conditions—and quite separated from each other. The 1970's, however, saw the spawning of much broader and more action-oriented organizations such as Disabled in Action and the American Association of Citizens with Disabilities.

I want to discuss a phenomenon occurring in our colleges and universities because it illustrates the fruits of empowerment and proves that even academics can learn. There was a paper in the workshop packet that everyone here received saying, “. . . it is not too far-fetched to predict that mutual support psychology will become a staple in graduate school curricula, just as therapy-related courses are today.” Well, that day has already come; such courses exist. Also, in the footsteps of self-help actions of the civil rights movement that led to black studies on campuses, and similar actions in the women's movement that led to women's studies, there is now a movement on campuses to create disability

studies. The last time I counted, there were around 40 campuses across the country that had started disability studies, and there are now three academic journals for disability studies, as well as a newly scholarly organization called the Society for Disability Studies whose members include social scientists, many with disabilities.

Let me end with a warning. I think it is in the nature of this historical moment that the encounter between health care providers and patients or people with disability in their families may have the elements of confrontation. In previous times, when patients felt disregarded, abandoned, or misunderstood, they always had a recourse but it was a passive one: noncompliance. That is changing, and words that were once used only for rhetorical effect, like negotiation, have become real if not legal parts of some practitioner-patient relationships. People with disabilities, people in the self-help movement, have begun to find their voices, and occasionally those voices may be harsh and strident. If so, it is because the time has been so long in coming, and there is often the feeling that we have to shout to be heard.

J. Katz, a professor of psychiatry and law, has written that the reluctance of health care workers to share information and converse meaningfully with their patients or their families has a 2,000-year history. This surely means that the changes to come will not come overnight, but it does not mean that providers and self-helpers can passively wait for them to happen. For if we do, we will find ourselves living out a 1960's cliché: if we are not part of the solution, we are certainly part of the problem.

CHAPTER III

DELIBERATIONS OF THE WORKSHOP

Overview of the Workshop Process

The Surgeon General's Workshop on Self-Help and Public Health had a number of unique features. It was designed to be highly participatory, with all participants having equal standing, and it was highly task oriented. The goal of the steering and planning committees was to create an open process in which all ideas merited equal consideration in an environment that permitted scholars, human service professionals, and self-help leaders to share their expertise. The deliberative process of the workshop itself embodied the ethos of self-help since it was structured to give theoretical knowledge and experiential knowledge equal value.

The Modified Delphi Technique

The specific process used in the workshop was a modification of the Delphi technique, a method originally developed in defense-oriented "think tanks" to gather the best thinking of experts on a topic in a short amount of time. In the original Delphi model, experts were asked to respond to specific questions and rank their responses according to priority. However, there was no personal interaction among the experts in the original Delphi technique; they worked independently of each other and submitted their responses in writing. In contrast, the modified Delphi technique used in the Surgeon General's Workshop involved direct interaction of participants deliber-

ating in small groups. Thus the workshop used some parts of the original process but combined them with humanistic approaches, particularly those used by self-help groups.

The Delphi process, both in its original form and in this modification, encourages the ranking of ideas to increase the probability that the best ideas will come out on top. Although the process can produce some tension, that tension was regarded by the workshop planners as an essential part of the creative process and capable of bringing forth the best ideas.

Small-Group Deliberations

Workshop participants were assigned to one of eight groups, each of which reflected as much as possible the composition of the entire workshop. These working groups spent the better part of a morning session examining specific areas of the potential partnership of the self-help movement and the health care delivery system and proposing recommendations. Each group was led by a specially trained facilitator responsible for helping organize the work, guiding the group, maintaining a schedule, and managing conflicts. The facilitator was assisted by a recorder who was responsible for keeping a record of the group's deliberations and proposed recommendations.

Each of the eight small-group workshops began with a brainstorming session,

a process whose general guidelines are as follows:

- The sky's the limit, so don't censor your ideas—express them.
- Build on the ideas of others.
- Don't judge or criticize other people's ideas during brainstorming.
- Hold off any discussion until the brainstorming session is over.

The brainstorming session was followed by discussion to refine, expand, or

consolidate the ideas that had been produced.

This process, which occurred in each of the eight working groups, yielded 40 recommendations, 5 from each group. These were presented to the full workshop, which considered and debated them all. After modifying and consolidating several of the recommendations through normal parliamentary procedures and selecting the 16 most favored, the selected recommendations were divided among the small-group workshops for development of possible implementation strategies.

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CHAPTER IV

RECOMMENDATIONS TO THE SURGEON GENERAL

The 16 recommendations of the workshop are listed here in the order in which they were addressed by the Surgeon General in his response (see Chapter V). This ordering does not reflect the relative priorities of the recommendations as suggested by the number of votes each one received. The number in parentheses after each recommendation indicates that recommendation's level of approval by the participants. Recommendations that received the most votes have the lowest numbers. Suggested strategies for implementing these recommendations are in Appendix B.

Recommendation No. 1: Develop, fund, and support a proactive national centralized information center for referral to existing self-help groups and clearing-houses and for assistance in the formation of new groups (Priority: 5). Many self-help groups are small, single-chapter organizations without resources to advertise their services to those who need them. Workshop participants favored creation of a nationwide service to match people with appropriate existing self-help groups, identify areas and conditions where new groups are needed, and support the establishment of new groups.

Recommendation No. 2: Increase the effectiveness of self-help groups by facilitating communication among groups and disseminating successful models for self-help (Priority: 16). There are many variations among groups in application of

the self-help concept, and there is no one best model that is appropriate for all groups. Self-help groups typically examine what is being done elsewhere and select the approaches that seem right for them. The workshop participants saw a need to improve this process by more systematic dissemination of information among groups.

Recommendation No. 3: Incorporate self-help concepts into the policy and practice of governmental and nongovernmental organizations, including health care providers (Priority: 4). This recommendation expresses the workshop participants' conviction that the self-help process is adaptable to a wide range of situations and can be incorporated successfully in many existing programs. The participants felt that this incorporation could bring the benefits of self-help to those being served by existing programs without creating a totally new service delivery system.

Recommendation No. 4: Establish a structure within the Public Health Service for the promotion and development of self-help (Priority: 8). This recommendation expresses the conviction of the workshop participants that a partnership between self-help and public health is both desirable and feasible. It also recognizes that the self-help movement, to realize its full potential as an instrument for protecting and improving public health, needs formal recognition, promotion, and

support within the preeminent Federal public health agency.

Recommendation No. 5: *Develop multimedia campaigns aimed at the public, human services professionals, and self-helpers (Priority: 15).* Members of self-help groups at this time tend to identify themselves in terms of a specific problem that brings them together, for example, as cancer patients or alcoholics. One result is that the term self-help is used in many different ways both by human services professionals and the general public. Workshop participants advocated an educational effort to explain what self-help is in the broader sense, what it can and cannot do, and how people can find or form a group appropriate to their needs.

Recommendation No. 6: *Support collaborative research and demonstration projects using methodologies appropriate to self-help group approaches and values (Priority: 3).* Systematic study of the self-help process is still very limited, especially study of the mechanisms responsible for success. Research in this area has been hindered by the limits of current research methods in studying highly informal associations dedicated to providing full support to all their members. The workshop participants recognized the importance of research on self-help but stressed the need to develop appropriate methodologies.

Recommendation No. 7: *Develop mechanisms for linking self-help resources and the formal services delivery system as equal partners, giving special consideration to programs for special populations (Priority: 7).* The workshop participants endorsed the idea of a partnership between self-help and public health and urged the creation of appropriate mechanisms to facilitate it. They urged

the creation of mechanisms that recognize both equality in the partnership and appreciation of the unique contributions that self-help groups and formal service organizations can each make to public health.

Recommendation No. 8: *Develop, promote, and incorporate mechanisms to educate primary and secondary school children about self-help through education and health care delivery (Priority: 14).* Workshop participants believed that self-help concepts are beneficial for people of all ages, including school children. Children, no less than adults, can feel isolated by their problems and can benefit from mutual caring and sharing.

Recommendation No. 9: *Establish, coordinate, and strengthen self-help clearinghouses and other networking resources at national, State, and local levels, with self-helpers having equal involvement in governance and implementation (Priority: 13).* The workshop participants recognized that self-help clearinghouses are playing a major role in linking the public with groups, creating networks among groups, and educating professionals and the public about self-help. The participants urged support for the further development of these critically important resources.

Recommendation No. 10: *Establish a national center or institute to fund, coordinate, and facilitate research, training, and dissemination of information on self-help (Priority: 6).* This recommendation, like Recommendation No. 1, addresses the current fragmentation of the self-help movement. The workshop participants urged better communication among self-help groups as well as training for leadership in self-help and expansion of knowledge about self-help for the public, the professions, and self-helpers themselves.

Recommendation No. 11: *Channel resources for self-help into underserved areas and populations such as minorities, rural areas, low-income people, the aged, people with disabilities, alternative family groupings, the homeless, and youth (Priority: 10).* Although there is much evidence that the self-help concept is adaptable to serving minorities, low-income, and other special populations, most self-helpers at this time are white, middle-class, and female. The workshop participants saw a clear need to reach underserved populations, who stand to gain much from self-help.

Recommendation No. 12: *Develop and advocate national policies that recognize the validity and role of self-help groups in the full age spectrum of American society (Priority: 12).* The workshop participants felt that the validity of self-help concepts should be reflected in public policy, particularly in the design and implementation of public health programs. A continuing focus on self-help within the U.S. Public Health Service, with participation of self-help representatives in shaping relevant policies and objectives, was considered essential.

Recommendation No. 13: *Increase minority leadership in the self-help movement and enhance the sensitivity of self-help organizers and groups to culturally diverse populations (Priority: 9).* This recommendation, like Recommendation No. 11, recognizes the benefits that self-help can provide for minorities, who are currently underserved. The workshop participants considered the development of self-help leadership within minority populations essential and entirely consistent with the central idea that self-help groups should arise from indigenous needs and should be self governing.

Recommendation No. 14: *Incorporate information and experiential knowledge about self-help in the training and practices of professionals (Priority: 1).* The participants felt that exposure to the concepts and benefits of self-help should be included in the training curriculums of all helping professions. Including this knowledge in the training of health professionals was considered especially important for developing a partnership between self-help and public health.

Recommendation No. 15: *Develop and influence public policy through networking, coalition-building, and advocacy (Priority: 11).* This recommendation, which was mainly directed to the self-help movement itself, reflects a major theme that emerged at the workshop—that self-help groups need to end their isolation and fragmentation and begin working together to achieve common goals. It was evident to many participants that, although self-help groups represent a large constituency, too few of them have worked together to influence public policy on issues that affect their membership and the self-help movement as a whole.

Recommendation No. 16: *Increase Federal, State, local, and private funding for self-help groups and activities (Priority: 2).* Typically, self-help groups are very small, very informal, and unskilled at “grantsmanship” and other kinds of fundraising. Yet collectively they are providing indispensable services that improve health and the quality of life for millions of people in a highly cost-effective manner. The workshop participants believed that with adequate financial assistance the self-help movement could spread its benefits to many more millions of people. They therefore urged increased funding of self-help activities from all levels of government as well as from the private sector.

CHAPTER IV

THE SURGEON GENERAL'S
RESPONSE

*C. Everett Koop, M.D.
Surgeon General
U.S. Public Health Service*

When I became a pediatric surgeon in 1946 there were only five others in the entire country, so many of the procedures I did had never been done before. This new medical specialty allowed many youngsters to survive what were previously considered hopeless diagnoses and be habilitated into our society.

I'm talking about problems such as establishing continence in a 10-year-old child born without a rectum.

I'm talking about spina bifida, which in those days was rarely operated on, and about hydrocephalus, for which there was no cure or prevention.

I'm talking about youngsters born with no esophagus or with an esophageal defect that required years of training in swallowing to prevent choking and asphyxiation.

One way I helped families who had to cope with problems like those was by introducing them to each other. It was for self-help and mutual aid, only I didn't call it that. I was reinventing the wheel and didn't know it.

As time went on, I began to attract a number of children with tumors. I must tell you that this was an era when pediatricians practically denied the existence of cancer in children. It was an era when even the word "cancer" was unspeakable. I remember actually being forbidden to use it when I was on a radio program talking about pediatric surgery.

One of the frequent consequences of childhood cancer was death on the hospi-

tal ward, and I saw that after such a heartbreaking event the student nurse would lean on the staff nurse, and the staff nurse would lean on the supervising nurse. Eventually there was no one to lean on but me. So we started a self-help group, though we didn't call it that, for grieving pediatric care providers. We met regularly but also spontaneously when the pain became overwhelming. To this day in the hospital where I worked there is still a group that meets with the chaplain to talk out their feelings.

I put in the first shunt for hydrocephalus, to drain the excessive cerebrospinal fluid out of the brain ventricles into the peritoneal cavity. When word of this successful surgery spread, children with untreated hydrocephalus came from far and wide. There were days when I would arrive at work to find a trailer parked in the hospital courtyard, and in it would be a family with a hydrocephalic child. The heads of some of those children were huge, as large as the biggest pumpkin you've ever seen. Many of them had heads of such size and weight that they could not be conveniently moved even in a wheelchair. Many of these children were intelligent, but at that late stage the shunt operation couldn't be done. The frustrated families of these youngsters became the focus of another self-help group.

A pediatric surgeon learns early that there are different types of grieving parents. Those who lose their child in an accident have their own kind of grief. Those

whose children die in mid-childhood of chronic diseases like cancer have a special kind of grief, because they lose their children after they have become people, after they have developed personalities. There is special pain in knowing that the future of that child, that small person, will not be permitted to unfold. Some of these parents seem to lose their children twice—first when the hopeless diagnosis is made, and again when the child dies. The real death is sometimes easier to bear, because it brings a sense of release and relief. But sometimes the period between diagnosis and death is long and extraordinarily difficult.

The grief of parents who lose a child after a prolonged illness during the neonatal period is also of a special kind, because it is often compounded by a feeling of unreality. Their child had to be taken from them for intensive care before they could even adjust to the fact that they were parents. They never even had a chance to bond to the child.

So, about 40 years ago I began to bring grieving parents together. I do not mean to imply that excellent groups such as the Compassionate Friends are offshoots of what I began. I only offer my experience to illustrate the fact that a great need will evoke the same kind of response in many places at the same time. I tell you these things to let you know that even 40 years ago I was interested in and concerned about self-help. I tried to address the same problems everyone here is concerned about—isolation, powerlessness, alienation, and the awful feeling that nobody understands.

Before I respond to your recommendations let me say that, although the leadership in previous Surgeon General's workshops has been excellent, none of the other workshops has matched the superb organization of this one. I am most grateful. I have come to admire, respect, and

feel affection for several individuals I have met here during the past few days. I wish I could have gotten to know all of you and heard your personal histories. I thank all of you for being who you are and doing what you do, and I am grateful for the thoughtful and excellent work you have done here at this conference.

Turning now to your recommendations, I think **Recommendation 1**, *establish a national self-help information center*, is right on target. Let me give you an analogy to explain why I think so. I'm sure you all remember the Baby Doe case and the fact that I was the lightning rod in the Administration for that particular issue. It was appropriate for me to be the lightning rod, because when I came to Washington I had probably operated on more Baby Does than anyone else in this hemisphere.

I was convinced that Baby Does existed for two reasons. The first reason was obstetricians or pediatricians making snap judgments in the delivery room about lesions they did not understand and about habilitation processes they had never witnessed. The second reason, and the more important one, was that pediatricians did not know as much as they should about the support systems that existed in the community to help patients and their families go through the difficult times that accompany certain diagnoses.

I knew those things and acted on that knowledge, and now, in various parts of the country, there are computerized data retrieval services available to parents and physicians alike. They can get information tailored to their own understanding and needs. I see no reason why this cannot be done for self-help, and I will investigate how it might be done and report back to you in some fashion.

Recommendation 2—*increase the effectiveness of self-help groups by facilitating communication among them,*

with funding, technical assistance, and dissemination of successful self-help models—is also appropriate. That communication has to be facilitated, and I think some of your other recommendations refer to specific ways that might accomplish it. All these things need funding and technical assistance, and I will investigate how that might be best accomplished. However, I think the dissemination of successful models is up to you, and I will look forward to a Surgeon General's conference as a followup to this one, perhaps 3 years from now, when a planning committee will bring model programs together at a national meeting so people can examine, appreciate, and attempt to replicate them in their own communities.

I think the merits of **Recommendation 3**—*build self-help into public health policy and into the policy and practice of governmental and nongovernmental organizations, including health care providers*—are self-evident. If we are to do anything with any of the other recommendations, self-help must be transformed into policy. I pledge to do all I can to build self-help into public health policy. I can do that best at the governmental level, but the Surgeon General is not without influence in other sectors.

Recommendation 4—*establish a structure within the Public Health Service for promoting and developing self-help*—ties all of the previous recommendations together. I believe such a structure should be established, and I will explore ways to accomplish it. I will present your recommendation to Dr. David Sundwall, Director of the Health Resources and Services Administration. Dr. Sundwall has a sincere interest in self-help, and I will ask him to consider the possibility of establishing such a structure within his agency. I will also speak to Dr. Michael McGinnis, who directs the Office of

Health Promotion and Disease Prevention, to see if some aspects of this recommendation could be carried out by his agency, whose efforts reach far into the community. I will not stop there, however, because self-help cuts across every health-related service provided by government. Almost every cabinet department has some health component, and I will explore the possibilities of creating a focal point for self-help activities with all of them, taking care to avoid overlap and duplication of effort.

The aims of **Recommendation 5**—*sponsor an informational campaign aimed at the general public, human service professionals, and self-helpers*—I think can best be accomplished by producing a book, and I would support that in any way I can. I think it should be produced by a commercial publisher and not be a government publication. I think any commercial publisher who knew that there are 500,000 self-help groups in this country would recognize that such a book would be a best seller. I would like to work with representatives of this group to see how this might be accomplished. One possibility is a multi-authored book with the Surgeon General as editor, which would give the prestige of that office to the endeavor. I am 75 percent certain this could be accomplished. My 25 percent uncertainty comes from awareness of the difficulties a Surgeon General might have in accomplishing this without appearing to endorse specific programs, which is forbidden by the rules of ethics that govern the person holding that office.

Recommendation 6—*support collaborative research and demonstration projects using methodologies appropriate to the self-help approach*—is extremely important. As we all know, the self-help movement, with its estimated 500,000 groups across the country, has had

phenomenal growth and has reached a stage of maturity, so future development should probably be in consolidation and networking. Extension of the self-help initiative in America will require specific information based on research with appropriate methodologies. We realize that self-help groups and scientific investigators may have conflicting purposes and needs, and we will do our best to iron out these difficulties, perhaps in the wording of grant proposal guidelines.

Recommendation 7—*identify mechanisms for linking self-help resources and the formal service delivery system as equal partners, giving special consideration to programs for special populations*—ties in with some of the other recommendations. I think we do need networking, not only at the grassroots level but through self-help clearinghouses. I think creating a partnership between self-help groups and the formal health service delivery system will require a major educational effort, which might culminate in a national conference of self-helpers and health professionals a few years from now. This educational effort is the subject of your next recommendation, number 8.

Recommendation 8—*develop, promote, and incorporate mechanisms to educate primary and secondary school children about self-help through education and health care delivery*. I will encourage the incorporation of knowledge of self-help resources and their value in the education of young physicians, nurses, and other health professionals. They need to know that self-help is an important resource without which their patients will be shortchanged. The Bureau of Health Professions within the Health Resources and Services Administration might be helpful in developing guidelines for this education, and I will bring this recommendation to their attention.

However, regarding the incorporation of self-help education at the primary and secondary school levels, such decisions are made in local communities and States. The Federal Government has no direct role in these decisions. I can promise only to refer your recommendation to the Department of Education for consideration.

Recommendation 9—*establish, coordinate, maintain, and strengthen self-help clearinghouses and other networking resources on national, State, and local levels, involving self-helpers in decisionmaking*—is somewhat covered by your previous recommendations. That self-helpers ought to be involved in decisionmaking goes without saying.

Recommendation 10—*establish a national center or institute to fund, coordinate, and facilitate research, training, and public dissemination of information on self-help and mutual help*—may be premature. I think we first have to convince the professions and the public that we can do what we think we can do, and then the time will come to move in that direction. Let me call your attention to the fact that a national center for nursing research was established only last year, and it took 30 years of effort to do it.

On **Recommendation 11**—*channel resources for self-help into underserved areas and populations such as minorities, rural areas, low-income people, and youth*—I think the Public Health Service can serve you well, because its National Health Service Corps is serving the populations you named in precisely the kinds of areas you named. I will do my part to provide information about self-help to all in the Public Health Service who deal with these areas and populations, including the National Health Service Corps and the Office of Minority Health, and I will direct their attention to any data bases that might develop.

Recommendation 12—*develop and advocate for a national health policy that recognizes the validity and the role of self-help groups and recognizes the full age spectrum of the American society.* I think this is partly answered by the fact that I am here and have given the prestige of my office and the support of the Public Health Service to this meeting. Establishing self-help help in national health policy may be a short or a long way off, but I can assure you that this Surgeon General recognizes the validity and the role of self-help groups, recognizes that they cut across every aspect of health care delivery in the country and across all age groups, and will inform and advocate on self-help for the duration of his term.

Recommendation 13—*increase minority leadership in self-help and enhance the sensitivity of self-help providers to culturally diverse populations*—is consistent with my aims in everything else I attempt to do, whether it is in smoking cessation, AIDS, family violence, or care of aged: to develop leadership in the minority groups, include them in any planning for the future, and enhance the sensitivity of others.

Recommendation 14—*change knowledge, attitudes, and practices of health and human service providers by providing information in formal professional training, through direct personal contact between professionals and self-helpers, and in other ways such as postgraduate training and continuing education, about self-help groups and their benefits; and extend these same principles to other professions who contact people in trouble, such as police, clergy, school counselors, and probation officers.*

This is probably the most far-reaching of your recommendations and certainly the longest, but it covers many of the things I have already promised to address. We have covered the matter of incor-

porating self-help knowledge in the training of health professionals, and I think once that is established, post-graduate studies, on-the-job training, and continuing education will inevitably follow. However, I will bring this recommendation to the attention of people involved in continuing education, and I will do my best to encourage direct personal contact between professionals and self-help groups.

On extending knowledge of self-help to other professions such as law enforcement, it is not always easy for the Surgeon General to step over the boundaries between health and other domains, but it can be done and I am not new to it. My work on violence and sexual abuse of children has crossed the borders between the Department of Health and Human Services and the Department of Justice and has reached down to the level of police and juvenile courts. I will use every opportunity to bring your message to people these other fields.

Recommendation 15—*develop and influence public policy through advocacy, coalition building, and networking*—I think has been covered in everything I have said so far.

Recommendation 16—*increase Federal, State, local, and private funding for self-help groups and activities*—deals with economics. I recognize the need for increased funds, but I must tell you that I have no budgetary authority. However, I do have the power of moral suasion. If that were not so, we would not be meeting here. I will do what I can, but I think increasing the level of funding is based on performance and high visibility over time. I pledge to do everything I can, inside and outside the Federal Government and including the private sector and foundations, to increase funding for self-help groups and their activities.

Those are my responses to your recom-

mendations. Let me add that I will seek to establish a national toll-free number with TDD voice to provide referral information on self-help groups and State and local self-help clearinghouses. I am also willing to help develop and deliver up to three public service announcements on self-help originating from the Office of the Surgeon General during the next year, and I will be looking for you to be helpful in that. And I will promote an awareness of self-help in all my dealings with professional associations, government agencies, and the private sector.

I want you to report progress to me as it develops, through Heddy Hubbard in the Health Resources and Services Administration, and I will see that you are periodically informed of the progress we have at our end. Through the Office of Intergovernmental Affairs, a part of the Department of Health and Human Services, I will see that everything we have discussed here is made available to the State, territorial, and municipal health officers.

A self-help coordinating committee representing appropriate Public Health Service agencies is also on my agenda, and you yourselves may want to seek a way to become a more formal body to meet and deal that group. In the past, I have been able to help groups such as yours find funds to organize and seek a 504C3 tax exemption. Though I cannot promise a positive result, I will do the best I can in the next budgetary year to find funds for you if you decide you want to become a more formal organization, so you out there can have representation with us in here.

In conclusion, I trust that you understand the extraordinary complexity of the proposals and strategies you have recommended. You know where my heart is in this matter. Though I promise you absolutely nothing about eventual outcomes, because I can't, I pledge my best efforts to achieve the worthy goals you seek.

Thank you all for coming.

CLOSING REMARKS

Mark Mayeda

Dr. Koop's words are a great encouragement to all who are involved in self-help and mutual help. It is important for us to realize, however, that the task ahead is mainly our responsibility and that we ourselves must follow up on the recommendations we have made and not simply look for the Surgeon General to do it all for us.

Something else we all need to remem-

ber is that self-help and mutual help are not limited to health issues. It is not just groups of people with particular diseases or disabilities getting together and helping each other. It goes beyond that. It is a many-faceted movement whose central feature is people empowering themselves and each other to deal with all the challenges they encounter throughout their lives.

APPENDIX A

PRE-WORKSHOP ACTIVITIES

*Background Readings Supplied to
Participants*

Before the workshop, the planning committee's subcommittee on issues development sent participants selected background readings to give them a common knowledge base. The materials dealt with a wide range of issues, some of them controversial, that surfaced during a preworkshop survey of key informants, callers to self-help clearinghouses, and care providers. As a service to interested readers, the materials and their sources are listed here.

Executive Summary: Report to the Steering Committee for the Surgeon General's Workshop on Self-Help and Public Health. This summary of the results of the pre-workshop data collection activities is available from the Self-Help Division of Ambulatory Care and Health Promotion, American Hospital Association, 840 N. Lake Shore Drive, Chicago, IL 60611 (\$0.85 and self-addressed 9 x 12 envelope.)

Plain Talk About Mutual Help Groups. Published by the Alcohol, Drug Abuse, and Mental Health Administration, Rockville, MD 20857.

Composite of the Properties of Various Types of Self-Help Organizations. Table A1 from Powell, Thomas J., *Self-Help Organizations and Professional Practice.* Silver Spring, MD: National Association of Social Workers, 1987, pp. 319-323.

Self-Help Mutual Aid Groups: A Different Helping Paradigm? by Borkman, T. Prepared for the Surgeon General's Workshop on Self-Help and Public Health, July 1987. Single copies available from Thomasina Borkman, Department of Sociology, George Mason University, 4400 University Drive, Fairfax, VA 22030 (stamped, self-addressed envelope).

"Explorations in Self-Help and Mutual Aid." Excerpt from *Proceedings of the Self-Help Exploratory Workshop* (Borkman, L., ed.) held in Chicago June 9-12, 1974. Describes a self-helper's experiences in establishing a committee to combat Huntington's disease. Available from the Self-Help Center, 1600 Dodge Ave., Suite S-122, Evanston, IL 60201 (\$0.45 postage and a self-addressed envelope).

"Development of a Bereaved Parents Group," by Davidson, Harriet. In: *Self-Help Groups for Coping with Crisis* (Lieberman, M.A. et al., eds.). Jossey-Bass, 1979, pp. 80-94.

"Self-Help Groups in Western Society: History and Prospects," by Katz, A., and Bender, E., *Journal of Applied Behavioral Science* 12:3, 265-282, 1976 (special issue on self-help groups).

"Selected Highlights of Research on Effectiveness of Self-Help Groups," by Medvene, L. Unpublished paper, 1987,

revised. Available from the California Self-Help Center, 2349 Franz Hall, University of California Los Angeles, 405 Hilgard Avenue, Los Angeles, CA 90024.

“Sharing Caring,” excerpts from a communications kit developed by the American Hospital Association to assist hospitals in their involvement with self-help groups, 187. Ordering information: Division of Ambulatory Care and Health Promotion, American Hospital Association, 840 Lake Shore Drive, Chicago, IL 60611.

A Survey of Self-Help Clearinghouses in North America, Wollert, R. Unpublished paper, 1987. Write to Richard Wollert, Department of Psychology,

University of Saskatchewan, Saskatoon, Saskatchewan S7N 0W0, Canada.

Self-Help Groups: The Next Fifteen Years, Goodman, G. and Jacobs, M. Unpublished paper, 1987. Single copies of the original paper available from the California Self-Help Center, 2349 Franz Hall, University of California Los Angeles, 405 Hilgard Avenue, Los Angeles, CA 90024. A revised version titled “Psychology and Self-Help Groups: Predictions on a Partnership” is in press (*American Psychologist*).

Achieving Health for All—A Framework for Health Promotion. Report published by the Canadian Ministry of National Health and Welfare, 1986.

APPENDIX B

SUGGESTED STRATEGIES FOR IMPLEMENTING

THE WORKSHOP RECOMMENDATIONS

**Development of
Implementation Strategies**

After the 16 most favored recommendations were selected by the workshop, a set of possible strategies for implementing them were developed in small working groups. The goal was to consider steps and tasks that might be appropriate and useful in achieving the aims of each of the recommendations. It is important to note that there was not time for either the implementation work groups or the workshop as a whole to develop consensus on specific strategies. Indeed, many suggested strategies that emerged in the discussions evoked disagreement among workshop participants. It was further recognized that the Surgeon General may not have specific authority to take certain actions. Thus the implementation strategies presented below cannot be regarded as prescriptions, but only as suggestions and ideas that came out of group discussions at the workshop. Finally, many of the suggested strategies were not directed to the Surgeon General but to the self-help movement itself.

Recommendation No. 1: *Develop, fund, and support a proactive national centralized information center for referral to existing self-help groups and clearinghouses and for assistance in the formation of new groups.*

It was suggested that a planning group for this center be appointed and that it

include substantial representation by self-helpers from a broad-based constituency. The planning group would assist in evaluating needs and resources in the self-help area and in developing and implementing a plan for a national self-help information center.

Recommendation No. 2: *Increase the effectiveness of self-help groups by facilitating communication among groups and disseminating successful models for self-help.*

Throughout the workshop there was strong sentiment for developing communication channels among self-help groups as well as developing educational materials on self-help for professionals. A suggestion that came out of one of the strategy groups was a national symposium or a series of regional symposiums on the development of partnerships between self-helpers and professionals. In addition to self-helpers and health professionals, participants would include corporations and health care organizations.

Another suggestion was to encourage the publication of articles on self-help in health professions journals, especially articles written by self-helpers and by professionals involved in self-help activities. Workshops and symposiums for sharing of information among self-help groups, as well as establishment of a self-help journal, were also suggested as ways to facilitate communication among self-helpers.

Several workshop participants emphasized the importance of identifying successful models for self-help and disseminating knowledge of those models to others in the self-help movement. It was suggested that systematic studies, perhaps on a national level, could clarify the processes that determine either success or failure in local self-help groups and national self-help organizations.

Recommendation No. 3: *Incorporate self-help concepts into the policy and practice of governmental and nongovernmental organizations, including health care providers.*

Among the suggestions for implementing this recommendation were (1) a Surgeon General's position paper defining self-help and describing its benefits to public health; (2) encouraging conferences among relevant Federal agencies to consider ways of enhancing the partnership between the self-help movement and the health care delivery system; (3) preparing publications on barriers and facilitators to partnership between self-helpers and health care provider partnership, for dissemination to organizations providing formal health care; (4) giving public recognition to exemplary models of partnership between self-help groups and formal health organizations; (5) increasing awareness about and support for the self-help/public health partnership among selected officials; and (6) including self-help component in appropriate requests for proposals.

Other suggestions included encouraging major associations of health care providers to develop policies to encourage partnership between self-help and public health. It was suggested that the Surgeon General could help in this effort by contacting associations of health care providers, professional schools, foundations, and corporations, as well as elected

officials and State health departments. It was recognized that the Surgeon General would need the support of health professionals, self-help groups, and self-help clearinghouses in such efforts.

Finally, it was suggested that partnership between self-help and public health be included in the formulation of national health goals for the year 2000.

Recommendation No. 4: *Establish a structure within the Public Health Service for the promotion and development of self-help.*

Suggestions for implementing this recommendation included creation of a Federal office, perhaps in the Surgeon General's office, for coordination of self-help activities, with the coordinator chosen with substantial input from self-helpers. Another suggestion was creation of a Federal self-help coordinating committee comprised of representatives from appropriate Public Health Service agencies, with each agency also having its own component for promotion of self-help.

There was also a suggestion that separate self-help coordinating committees be established in the regional offices of the Public Health Service, with nominations for membership to regional committees generated by regional staff and local self-help groups and clearinghouses.

Other suggestions included providing space and support for self-help groups in federally funded buildings, funding of training and research grants in self-help, inclusion of information on self-help groups and clearinghouses in Federal publications pertaining to health, and participation of self-help representatives in future Surgeon General's conferences.

Recommendation No. 5: *Develop multimedia campaigns aimed at the public, human services professionals, and self-helpers.*

There was a suggestion that a mass media campaign on self-help be initiated, focused broadly on self-help rather than on specific problems or groups, and that the campaign be developed in collaboration with an advisory committee of self-help group participants, human services professionals involved with self-help groups, and other interested parties. Among the suggested features of such a campaign were video endorsements of self-help principles and practices by prestigious officeholders such as the President of the United States and the Surgeon General.

Other suggestions included White House sponsorship of an annual awards ceremony to honor outstanding contributors to the field of self-help, production of a multi-authored book about self-help for the general public, development of a speakers bureau, education of media professionals about self-help groups, creation of special telephone directory listings of self-help organizations and clearinghouses, designation of a Day, Week, Month, or Year of Self-Help, and encouraging health maintenance organizations and health insurers to communicate information about self-help services to their members.

There were also suggestions that producers of television shows with a human services theme be encouraged to provide the telephone numbers of self-help groups or clearinghouses that offer services relevant to the theme of the program, that professional health organizations include promotional messages for self-help in their journals, that an audiotape seminar be developed to train self-help groups in public relations skills, and that local libraries collect publications from self-help organizations and maintain reference directories of mutual help groups.

Recommendation No. 6: *Support collaborative research and demonstration projects using methodologies appropriate to self-help group approaches and values.*

There was a suggestion that it might be appropriate to have an organization within the National Institutes of Health, or perhaps in other Federal agencies, to foster and conduct research and demonstration projects on self-help and mutual help. It was felt that review committees for the evaluation of research proposals should include members who understand self-help and mutual help principles. Another suggestion was that conferences be convened involving Federal granting agencies, foundations, other potential funders, self- and mutual help organizations, and individual researchers to develop a research agenda that includes research methodologies appropriate for the study of self-help activities.

Several participants at the workshop recognized that self-help groups themselves need to develop an understanding of the importance of research: what it can do directly for the groups, its usefulness for explaining the self-help philosophy and approach to a wider audience, the ability of involvement in research to influence professionals and develop future support, and the potential of research to provide concrete financial support to groups.

Recommendation No. 7: *Develop mechanisms for linking self-help resources and the formal services delivery system as equal partners, giving special consideration to programs for special populations.*

A suggestion that emerged from discussion was creation of a permanent commission to guide national policy on linkages between self-help groups and formal delivery systems for health and human services. The membership of the national

commission would include members of self-help organizations, professionals in the delivery system, and management personnel.

A suggested mechanism to promote linkages, which some felt might be encouraged by the Surgeon General, was periodic conferences of self-helpers, health professionals, and health system managers. Suggestions included annual regional conferences of representatives of these constituencies in administrative regions of the U.S. Department of Health and Human Services, annual national conferences of these same constituencies, and an international conference to be held every three years.

Another suggestion that emerged from discussion of this recommendation was that the U.S. Department of Health and Human Services establish a toll-free telephone service with TDD voice capability to provide information and referral for individuals seeking self-help information, including consumers, self-help groups, self-help clearinghouses, and professionals. (In his response to the recommendations, Surgeon General Koop said he would endeavor to carry out this suggestion.) It was also suggested that the Department of Health and Human Services provide a focal point for collecting, abstracting, and disseminating self-help research findings and results of demonstration projects, as well as proposals for research in the self-help area.

Suggested incentives for more linkages between self-help groups and the health care delivery system included continuing education credits for professionals at meetings that systematically involve self-helpers in conferences, as well contacts by the Surgeon General with professional organizations to point out the value of linkages between the formal health care delivery system and self-help groups. It

was pointed out, however, that self-helpers themselves should also take the initiative in encouraging linkages between professionals and self-help groups.

Recommendation No. 8: *Develop, promote, and incorporate mechanisms to educate primary and secondary school children about self-help through education and health care delivery.*

This recommendation reflected the workshop's belief that primary and secondary school children need to know about self-help. There was also awareness, however, that a valid self-help program must originate among individuals who share a particular problem or need, and that self-help programs instituted by school authorities as part of a curriculum would contradict the voluntary coming together for mutual assistance that is at the core of the self-help philosophy. It was felt, however, that much can be done to raise awareness about self-help among students, school personnel, and parents.

Several suggested strategies came out of the discussion of this recommendation. One was that the visibility and credibility of self-help at this level could be enhanced by public endorsements by the Surgeon General, the media, celebrities, government agencies, professional organizations, and self-helpers themselves. The aim of such strategies would be to help school personnel and parents understand and appreciate the benefits self-help activities can bring to students from kindergarten through high school. It was recognized, however, that self-help materials directed to children should be sensitive to their diversity. It was felt that materials should emphasize the value of peer support and mutual help, of being good friends and neighbors, and should always be appropriate for the age group being addressed. Suggested avenues for dis-

seminating self-help materials and information included clearinghouses, youth agencies, United Way organizations, libraries, schools, school speaker bureaus, community charitable organizations, parent advocacy groups, and parents and teachers associations.

There was recognition that marketing strategies need to be developed to emphasize the value of self-help in ways that are understandable to school boards, principals, teachers, students, school nurses, vocational and disability counselors. It was also recognized that these efforts would need to be continuous and would require the participation of self-help groups and regional and national self-help clearinghouses.

Recommendation No. 9: *Establish, coordinate, and strengthen self-help clearinghouses and other networking resources at national, State, and local levels, with self-helpers having equal involvement in governance and implementation.*

Many workshop participants saw a need to strengthen self-help clearinghouses and other networking resources at national, state, and local levels. They also felt that guidelines were needed to ensure that self-helpers are involved equally in the governance and implementation of self-help clearinghouse activities, including mission statements, organization, evaluation, accountability, responsibility, ethics, and standards.

Other suggestions included the drafting of a generic grant proposal to guide self-help organizations lacking proposal-writing experience in seeking funds from national, State, and local grant sources, a task that some felt would be appropriate for International Network of Mutual Help Centers.

It was also suggested that appropriations from Congress be sought to provide

matching funds to States for the establishment and perhaps the maintenance of self-help clearinghouses, and that a task force of self-helpers and organizations such as the American Hospital Association be formed to develop financial resources for strengthening self-help networks.

Recommendation No. 10: *Establish a national center or institute to fund, coordinate, and facilitate research, training, and dissemination of information on self-help.*

There was support for the idea of creating a nonprofit organization to develop and implement ideas that emerged from the workshop discussions. There was a suggestion, for example, that the Workshop planning committee appoint a steering committee to explore the feasibility of a national self-help center to continue what had been initiated at the workshop. The center, which might be housed either alone or in a university setting, would have majority representation by persons from self-help organizations. One of its early responsibilities would be raising seed funds to further its future development into an organization that could further the broad aims of the self-help movement. A further responsibility would be coordinating information from existing clearinghouses and promoting the expansion of the self-help clearinghouse system to all States, not competing with existing clearinghouses.

Other suggested functions for the national center included: (1) identifying public and private funding sources for self-help groups across the Nation, promoting self-help through survey mechanisms; (2) identifying models of collaboration between self-help groups and public and private agencies and disseminating information of the factors that

account for their success; (3) developing pilot projects to demonstrate the need and effectiveness of self-help groups; (4) developing policy on issues that affect self-help groups; (5) as capability develops, serving as a funding conduit for basic and applied research on self-help issues that affect all self-help groups; (6) developing networks among self-help groups with similar interests across the Nation; (7) developing training programs for professionals and self-helpers; and (8) urging the inclusion of self-help components in research proposals solicited by Federal and private granting agencies.

Recommendation No. 11: *Channel resources for self-help into underserved areas and populations such as minorities, rural areas, low-income people, the aged, people with disabilities, alternative family groupings, the homeless, and youth.*

Some workshop participants were concerned that existing definitions of underserved areas and populations may be excluding some who need help, and it was suggested that existing Federal definitions of minority and underserved populations be reviewed to identify underserved areas and populations not included in existing definitions. There was sentiment favoring a study to determine the existence of such excluded groups and identify any self-help mechanisms they may have developed. It was also suggested that culturally sensitive self-help components be developed in programs for all underserved populations.

Recommendation No. 12: *Develop and advocate national policies that recognize the validity and role of self-help groups in the full age spectrum of American society.*

Workshop participants strongly felt that self-help should be a public health matter of high priority and that the validity of self-help and mutual help should be

reflected in public policy. There was insistence, however, that the autonomy of self-help groups, which is one of their core features and essential to their success, be respected. Many participants felt that public policy should focus on goals related to the development of a barrier-free society, and that self-help is crucial for achieving that end. A continuing focus within the Office of the Surgeon General on the roles of self-help in public health was considered essential by most participants. They also felt that participation by representatives of self-help organizations in shaping public health policies and objectives is essential.

There was a suggestion that an Office for Self-Help be established in the Department of Health and Human Services to provide liaison with self-help organizations and public health programs, sponsor self-help meetings and conferences, influence funding for research programs, and coordinate access and linkage between self-help groups and public health programs.

It was also suggested that ad hoc interdepartmental and interagency task forces with self-help group representation be established to influence policy, funding, programming, and program evaluation in such health issues as "orphan" diseases, low-incidence diseases, problems of the aged and the homeless, financing, insurance, and third-party reimbursements.

Recommendation No. 13: *Increase minority leadership in the self-help movement and enhance the sensitivity of self-help organizers and groups to culturally diverse populations.*

Workshop participants recognized that self-help groups are not always sufficiently sensitive to the special needs of minority groups and that minorities need greater representation in the leadership of

the self-help movement. It was also felt that many existing Federal programs could be enhanced by the inclusion of minority group leaders from self-help organizations, and that the influence of the Surgeon General might be helpful in achieving this goal.

Suggestions to implement recommendation 13 included holding a national conference to deal with minority self-help issues and enhance the relationships of minorities with human services agencies, self-help organizations, and other voluntary associations. A number of resources in both the public and private sectors were suggested as potential underwriters of such a conference. Other suggestions included establishment of incentives, such as a national fellowship program for minority leaders and a minority technical assistance networks, to promote the concept of self-help within minority communities and identify leaders within those communities.

Development of outreach and education programs on self-help for minorities at the community level was also suggested. It was emphasized that bodies established to carry out these programs should include representatives of the target communities and reflect the composition of those communities.

Recommendation No. 14: *Incorporate information and experiential knowledge about self-help in the training and practices of professionals.*

Workshop participants generally considered this recommendation as one of the most crucial for developing effective partnerships between self-help and mutual help groups and the formal health care delivery system. Many participants felt that the influence of the Surgeon General could be very helpful in increasing awareness of self-help principles in the health

and human services professions, including students preparing for careers in those professions. There was considerable agreement that such training would be greatly enhanced by involving self-helpers who could share experiential knowledge of self-help in relation to their own particular health problems.

It also was felt that people already in the health professions need to know more about the potential of self-help groups to benefit their patients, and again it was suggested that encouragement by the Surgeon General could be helpful in bringing about the needed changes.

Recommendation No. 15: *Develop and influence public policy through networking, coalition-building, and advocacy.*

There was sentiment favoring a study of self-help clearinghouses to understand their activities and to publicize those that may benefit self help groups and their members. Participants felt that such studies could increase the ability of clearinghouses to strengthen self-help groups' ability to organize, develop referral and recruitment systems, form networks, develop advocacy programs, and build coalitions. Such studies were also perceived a helpful for developing better patterns for representation of self-help groups in the operation of these agencies. It was also suggested that international and regional meetings of self-help group leaders and activists be conducted to develop links and networks among groups with similar constituencies, conditions. Some participants also felt that the Surgeon General could be instrumental in arranging meetings of self-help group leaders and national organizations of professionals and human service providers.

Another suggestion was development and funding of an Independent National

Council on Self-Help modeled after the National Center on the Handicapped. This effort, for which Federal funds might be solicited, would involve the efforts of self-help advocates and national self-help groups. Here, too, participants suggested that the Surgeon General's office could play a helpful role.

There were also suggestions favoring ongoing training in advocacy skills for self-help groups, including distribution of information on advocacy skills through newsletters of self-help groups and clearinghouses and convening of local conferences for advocacy training for self-helpers in cooperation with clearinghouses and self-help groups.

A White House Conference on Self-Help was suggested as a fitting way to inaugurate an International Year of Self-Help and creation of a National Council on Self-Help.

Some participants urged doing away with the prohibition of advocacy by some nonprofit organizations, saying that self-help groups and other nonprofit organizations should be allowed to influence public policy.

Other suggestions favored the development of public and private sector alliances in self-help group operations and funding; formation of links between self-help groups and other citizen organizations around specific issues; development of a national newsletter for self-help groups; development of ongoing coalitions among local, State, regional, and national self-help groups; and dissemination of the workshop's recommendations by the Surgeon General, with encouragement of their implementation.

Recommendation No. 16: *Increase Federal, State, local, and private funding for self-help groups and activities.*

Since funding is a chronic problem for

many self-help organizations, several suggestions on how to alleviate it emerged from workshop discussions. One was to train self-help leaders in grantsmanship in order to increase the chances of funding for self-help groups. Another was for appropriate Federal agencies to establish self-help as a generic field for priority funding in order to counter a perceived tendency of current funding sources to favor funding of projects related to specific conditions.

There was also a suggestion that administrative procedures for contracts, requests for proposals, and grants be made compatible with self-help principles to permit compliance by self-help groups. Another suggestion was drafting model legislation to support and enhance self-help as part of the health services delivery system. Participants felt that this was mainly the responsibility of self-help groups, but that help from entities experienced in drafting such legislation would be needed.

Other suggestions included training and technical assistance programs for self-help groups in economic development and self-sufficiency; initiation of a corporate campaign to include self-help in health promotion and disease prevention efforts; modification of third-party payment policies to allow reimbursement for participation in self-help activities; assistance of the Surgeon General in encouraging dissemination of information on potential grant funding sources to self-help organizations; inclusion of self-help linkages in existing and new health delivery and prevention programs; and documentation of the current funding levels for self-help groups by Federal and State governments and private foundations, to facilitate prudent financial planning by self-help organizations.

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