VIEWPOINT

ON SELF-HELP GROUPS

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The Case for a Partnership with Self-Help Groups

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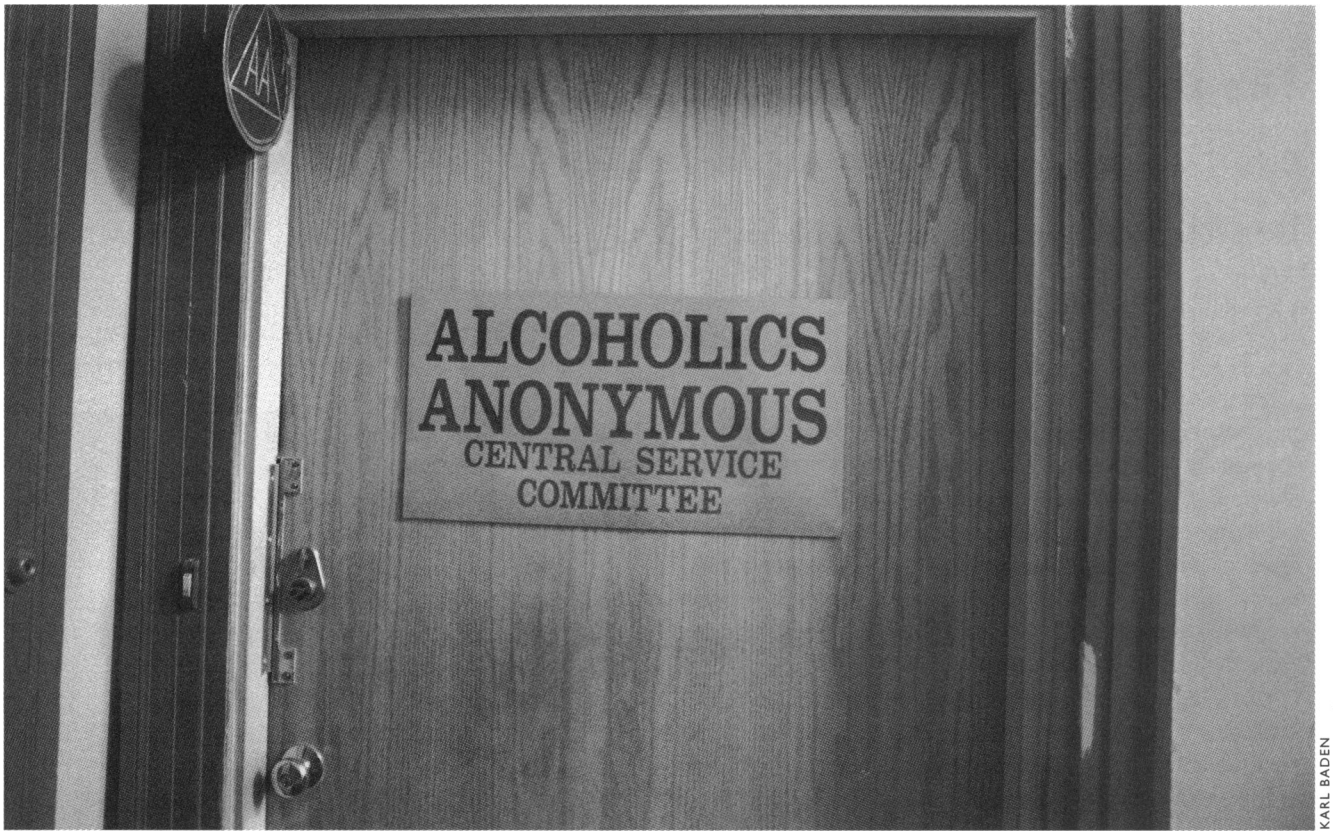
THE SELF-HELP GROUP MOVEMENT IS ARGUABLY BOTH THE MOST exciting and least recognized resource for improving public health in the United States. Approximately 10 million Americans participate in self-help groups (also known as mutual help groups) each year, and 25 million have done so in their lifetimes.[1] These groups address virtually every problem known to clinical medicine and public health. There are self-help groups for diabetes (for example, Diabetics Anonymous), ischemic heart disease (for example, Mended Hearts), cancer (for example, Candlelighters and Man-to-Man), violence (for example, Parents of Murdered Children), and every other leading cause of morbidity and mortality in the US.

Research reports and policy discussions about self-help groups have become fairly common in the psychiatric, psychology, social work, and nursing literatures,[2–6] yet very little has been written about grassroots self-help groups in the public health literature. While there is a substantial public health literature on the effects of peer-led groups on health behaviors,[2] most of these reports describe health promotion programs in which nonprofessional peer helpers were trained and supervised by professionals.[2]

Although a handful of US states include self-help clearinghouses in their networks of public services and many clinicians and researchers are aware of and collaborate with self-help groups, there is currently little systematic collaboration between the public health community and self-help organizations. In what follows, we argue for greater collaboration between public health professionals and these grassroots organizations to meet the goal of improving the public's health.

In 1990, Surgeon General C. Everett Koop sponsored a Workshop on Self-Help and Public Health.[7] The steering committee for the workshop—which drew nearly 200 self-help leaders—included representatives of the American Medical Association, the American Hospital Association, the US Public Health Service, and the International Network of Self-Help Clearinghouses. The steering committee defined self-help groups as "as self-governing groups whose members share a common



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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."[7] Their grassroots origin and minimal costs to members make self-help groups distinct from professionally operated group psychotherapy and support groups, and the mutual aid inherent in group settings differentiates self-help groups from self-help books and manuals.

The mechanisms through which self-help groups can promote health have been discussed extensively elsewhere.[2–6] Commonly cited factors include the social support that results from members sharing the same problem or life situation, the behavioral learning and sense of hope resulting from exposure to positive role models, the specific technologies or programs of change that groups offer (for example, the 12 steps of Alcoholics Anonymous [AA] and similar groups), and in some cases the politicization of members into advocates for changes in society at large. *(See pages 326-7.)*

ADDRESSING PUBLIC HEALTH PROBLEMS

Self-help groups can be effective in addressing public health issues in three main ways:

1. *By offering accessible and effective interventions for specific problems.* Increasing access to health services and reducing health disparities between individuals from different socioeconomic strata are key public health goals.[8] Because self-help meetings are typically free of charge or very inexpensive, they can be a useful partner in pursuit of these goals.

The available research suggests that self-help groups can produce positive social and health-related outcomes in participants. For example, longitudinal studies have provided evidence of the effectiveness of the AA model,[9,10] and a three-year naturalistic prospective study of individuals who abused alcohol showed that those who participated in AA meetings and those who received outpatient psychotherapy experienced comparable decreases in daily ethanol intake and in symptoms of alcohol dependence.[11]

Marmar and colleagues found evidence supporting the effectiveness of self-help groups for complicated conjugal bereavement.[12] Widows who sought treatment were randomly assigned to either 12 sessions of professional

The self-help group movement is arguably both the most exciting and least recognized resource for improving public health in the United States.

psychotherapy or to a bereavement self-help group. At four-month follow-up, self-help group participants showed improvement on a variety of psychiatric, social adjustment, and work functioning outcomes, including level of depression and anxiety. Across outcome measures, self-help group participants and those who received professional psychotherapy experienced comparable degrees of improvement.

Self-help groups are now the largest sector of the de facto US system of care for mental and addictive disorders, accounting for the majority of help-seeking visits.[1,13] It is important to keep in mind that a free or inexpensive intervention that reaches large numbers of people may not need to have a large individual effect to have a significant population effect.[14] Using population data from each of the 50 states, Mann and colleagues found that increases in AA membership were the second largest correlate of a declining incidence of chronic liver disease and cirrhosis, after reductions in alcohol consumption.[15] From 1974 to 1983, population cirrhosis death rates, adjusted for changes in alcohol consumption, declined by 0.06% for each 1% increase in AA membership (AA membership nationwide doubled over this period). These correlations are clearly not definitive evidence of a causal link,[16] but they do suggest that the potential impact on population health of large self-help organizations merits serious discussion and further evaluation.

2. *By enhancing professionally run health promotion and health care programs.* Collaboration with self-help organizations can be an attractive way to enhance the quality of health promotion programs and extend the reach of health care services in an era of tightened fiscal resources. Research findings have shown that self-help groups not only promote positive outcomes but may also take a significant burden off the formal health care system.[11,17]

Self-help groups that are integrated into professionally operated health interventions lack the grassroots flavor and self-direction of community-based groups. Nevertheless, several studies suggest that self-help groups can be successfully incorporated into professional programs to enhance outcomes with little additional cost. For example, Jason and colleagues found that a worksite smoking cessation program was more successful when the intervention was supplemented by employee-led self-help groups.[18] Companies with employee-led groups achieved average post-intervention quit rates of 41%, compared with 21% in companies without groups. At three month follow-up, quit rates were still higher at companies with self-help groups (22%) than at companies without them (12%).


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A controlled evaluation of self-help groups for parents of premature infants also reported positive results. Twenty-eight parents were randomly assigned to participate in a self-help group co-led by a nurse and a "veteran" mother who had successfully raised a premature infant. Parents in the experimental condition visited their infants more often and spent about 20% more time touching,

talking to, and gazing at their infants during visits than did controls. Three months after the babies were discharged, group participants also showed more involvement with their infants during feeding and reported greater confidence in raising their infants than parents in the control condition.[19]

3. *By enriching community life and building a base for public health advocacy.* Organizing and empowering communities and enhancing their quality of life has a long history within public health, particularly in the field of community health education. As grassroots civic organizations, self-help organizations can be a powerful ally in such efforts. As Banks has argued,[20] in a society in which many citizens feel isolated and alienated from their communities, a grassroots movement of millions of citizens meeting in supportive small groups may enhance the quality and connectedness of community life. Enriching civil society may not necessarily affect morbidity and mortality, but it can be considered a valuable contribution from the standpoint of a broad view of health that takes into account quality of life and social well-being.[21]

In addition, a subset of mutual help organizations contribute directly to public health through their political advocacy efforts, which are frequently focused on benefiting marginalized and vulnerable members of society. A number of powerful organizations that have influenced public health policy and the health care system began as self-help groups. For example, Mothers Against Drunk Driving grew from an informal support group for parents whose children had been killed by drunk drivers into a major catalyst for legislative efforts to reduce alcohol-related auto fatalities.[22] The Association for Retarded Citizens also expanded from a parent self-help group to a powerful advocacy organization.[22] Other examples of organizations that combine grassroots self-help groups with health-related political advocacy are the National Black Women's Health Project and the National Alliance for the Mentally Ill.

Whether working on a local, state, or national level, public health professionals engaged in community organizing and political advocacy efforts could potentially further their goals by contacting relevant self-help organizations and initiating a dialogue about cooperative efforts.

Policy advocacy might also increase public funding for self-help clearinghouses, which are professionally operated organizations that provide information, referrals, and training related to self-help groups. Given the retrenchment of support for such clearinghouses, it appears unlikely that the US will meet the Healthy People 2000 goal of 25 statewide self-help clearinghouses.[8]

A COLLABORATIVE EFFORT

Medical and public health professionals can play important roles in connecting potential members to existing groups, in strengthening existing groups, and in helping new ones get started. The *Self-Help Sourcebook*[23] of the American Self-Help Clearinghouse provides extensive practical advice to professionals wishing to strengthen existing groups or start new ones. The *Sourcebook* includes a national compendium of self-help groups, which is also available on the Web at **www.cmhc.com/selfhelp**. Many groups can also now be reached on the Web, which increases the opportunities for professionals to find partners for collaborative efforts and advocacy.

Professionals desiring to integrate self-help groups with formal health promotion and health care programs have several options. One is to contact an existing group and determine if they would be willing to enter into a cooperative arrangement; for example, a hospital may donate meeting space to cancer self-help groups in exchange for groups sending invitations to patients undergoing chemotherapy. Cooperation may involve exchange of information: professionals may offer to speak to groups about health-related issues, and groups may send members to speak to providers about their activities and encourage referrals.[23]

Starting new groups, like involving local residents in community health education efforts,[24] requires careful role structuring so that the professional facilitates the creation of the group but does not ultimately control it. Although the work of identifying potential participants and helping them initiate self-help groups can initially be significant, this effort is rewarded by groups becoming self-sustaining providers of services to their communities.

THE BENEFITS OF COLLABORATION

Why should public health and medical professionals be interested in collaborating with a grassroots movement of untrained citizens? First, fiscal resources for health care are currently contracting and are likely to continue to do so in the future. Second, as former Surgeon General Koop noted, self-help groups can provide benefits that the best health care often does not: identification with other sufferers, long-term support and companionship, and a sense of competence and empowerment.[7] Third, professionally operated community intervention programs have the liability of depending on professionals to operate them. When professionals move on to new problems or new communi-

APPALACHIAN COAL MIN
MUTUAL HELP AND ADVO

Central Appalachia is a region of storytellers, and coal miners tell some of the best. In my 11 years with the Virginia Black Lung Association (VBLA), the pay has usually been terrible, but the on-the-job education has been outstanding.

I've heard about the pick and shovel days, when miners got paid by the ton or by the railroad cars they loaded. All of our members sing Ernie Ford's "Sixteen Tons" with more passion than melody. They elaborate in detail on the literally back-breaking hard work and of owing their souls to the company store.

Miners talk of watching the ever-present rats to know if there was danger of a roof fall: "When the rats start swarming out, you better leave."

I've heard miners describe what it was like to crawl in and out of the blades of a massive mining plow trying to find the source of a malfunction in total darkness—unable to see their buddies through the thick dust.

As VBLA has assisted with individual disability claims, we've recorded the work histories of sick men. Retired miners who could no longer breathe without medication and oxygen talked about dust so thick they could not see more than a foot in front of them. They could not, however, win their black lung benefits, available under a special Department of Labor program to miners who prove disability due to occupationally caused lung disease.

Black lung disease (pneumoconiosis) is an occupationally caused progressive, incurable disease that continues its debilitation of the miner even after employment ends. The most telling symptom is extreme shortness of breath. Former miners sleep on three pillows at night, but still wake in the middle of the night gasping for air. I've lived my whole life in coal mining communities and have never known of a coal miner older than age 55 who did not have the disease.

Founding of the VBLA. VBLA began in January 1988 with a meeting of 32 disabled coal miners and family members, including adult children, who were frustrated by federal regulations enacted in 1981 that had resulted in only a 3% approval rate for black lung benefits. Most of the miners whose disability claims were rejected had failed the mining companies' pulmonary exams because of their lung disease.

Within two weeks of the initial meeting, retired miners and their family members were anxiously calling our chairperson at home for membership cards. Individual recruitment led us to 200 members within six months. In three years, we covered a 7500-square-mile area—the five coal mining counties of Virginia—and today have about 2100 members.

Gaining strength and power. At first, VBLA looked like a therapy group. Mining is dangerous work; esprit de corps and pride are important. Men who were used to thinking of themselves as valued by the coal companies were wondering what they had done to deserve rejection. By telling their individual stories, the members learned that all had experienced the same kind of rejection when their occupationally caused illnesses became obvious.

Members of VBLA expressed frustration and a sense of worthlessness because they had so little formal education. This lack of education was hardly an accident in a one-industry region where education and involvement in the political structure were discouraged. Being "uneducated and dumb" got to be such a refrain in meetings that finally one of the miners' wives raised her hand and said, "I make a motion that there are no dumb miners in this organization." The motion carried with laughter, and the refrain ceased.

Members soon began to look at their strengths. They could talk well. No one in the country understands mining conditions like miners and their family members. And there is one strength that grows out of living in a one-industry region that is the equivalent of a political science post-graduate education: every individual understands the industry's global connections. For example, a no-nonsense grandmother living in a remote ridge an hour from the nearest town explained to me

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how the oil companies' ownership of coal corporations meant that they could manipulate prices all over the world. She used examples from Australia and Turkey.

Mutual help. VBLA members draw heavily on the principle of mutual self-help in educating and organizing themselves. Semi-literate miners who quit school in the second and third grades for work taught themselves to read by filling membership cards while they recruited. Women and men have learned to speak to other organizations and to master sound bites for local TV. At membership meetings, we offered "Lobbying 101" training; in groups of three, members then talked with Congresspeople, took notes, and reported findings to a committee. Now VBLA members do all their own recruitment, grassroots fundraising, media work (including their own newsletter), and legislative advocacy.

The heart of our association is the membership meeting, held at four sites each month. Both health education and advocacy are on the agenda at every meeting, which are forums for asking questions and for educating each other. Members also offer one-on-one support to miners filing claims for black lung benefits. We know that our efforts improve the chances of individual claims being approved and that our public education efforts prepare other disabled miners to fight more effectively for benefits. Currently, the national approval rate for black lung claims is 7%; VBLA's approval rate runs at 65%.

—Marilyn Carroll

A longer version of this text appeared in the April 1999 *Resist Newsletter*.

Marilyn Carroll grew up in east Tennessee, has worked for 12 years as a paralegal representing miners filing for black lung disability benefits, and has served as Director of the Virginia Black Lung Association since 1988.

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ties, the programs they have initiated often fade away.[25] In contrast, if community-based self-help groups are involved in the design and administration of a public health intervention, this provides a potential basis for sustainability.[26]

Finally, because they are local and democratic, self-help groups provide more diverse solutions to health problems than one-size-fits-all interventions that implement a single solution for a whole community or population.[26] Specifically focused or tailored self-help groups develop by a natural evolutionary process. Thus people with drinking problems can choose between self-help groups that emphasize abstinence (for example, AA) or moderate drinking (for example, Moderation Management), that are for women only (for example, Women for Sobriety), that have an atheistic philosophy (for example, Rational Recovery), or that are steeped in fundamentalist Christian thought (for example, Alcoholics Victorious). There are groups focusing on the alcohol-related problems of Native Americans, Latinos, gays and lesbians, Jews, Catholics, people with "dual (psychiatric and substance abuse) diagnoses," academics, artists, lawyers, health care professionals, and even real estate agents.[23] Tailoring professionally led interventions for all of these constituencies would be a significant challenge.

It is not a slight to professionals to say that they can benefit from a productive collaboration with the self-help group movement. Other nations, such as Canada, have shown that partnerships between health and social welfare professionals and grassroots self-help groups can be mutually beneficial.[27] We close with an imagined example of what might be gained by such a connection in the US.

A Vision for the Future

How might self-help groups and professionals work together to make a major impact on a prevalent public health problem? As a hypothetical example, let us consider the alarming rise in the prevalence of obesity in the US.[28] Addressing this problem using professionally administered programs and services is a daunting task in terms of both human and fiscal resources. Yet a coalition of professionals and self-help organizations could potentially have the resources to make a significant impact on this serious public health problem.

Norway's "Grete Roede Slim Clubs" provide an excellent example of the potential of self-help groups focused on weight loss. A prospective study conducted in 1981 found that more than 80,000 Norwegians had participated in weight loss self-help groups, an impressive 2% of the national population at the time.[29] The groups were led by formerly obese individuals and emphasized the importance of a low-calorie diet and physical exercise. Because the groups were inexpensive (dues were about $5 per meeting), they were highly accessible. The average member lost approximately 15 pounds over eight weeks of participation. Four years after participating, 35% of participants maintained all of their weight loss or continued to lose weight, 50% maintained some of their weight loss, and only 15% regained all of their lost weight or more.[29]

Self-help groups such as Take Off Pounds Sensibly (TOPS) and Overeaters Anonymous (OA) reach a relatively small proportion of the US population.[23] However, their range might be expanded considerably if more clinicians and public health professionals drew attention to these groups and encouraged individuals to use them.

The activities of community-based groups could be complemented by incorporating peer-led weight loss support groups into the workplace, where they can serve as a cost-effective method of health promotion.[30] Clinicians and other professionals could contribute to the effectiveness and credibility of self-help weight loss groups by providing information on effective weight loss techniques,[31] on the benefits of physical activity, on accessing health care services, and on deciphering food labels.[32] Researchers could work with groups to evaluate the costs and benefits of participation and the factors that differentiate effective and ineffective groups. Collaborative research could also identify ways in which groups can address problematic issues such as member attrition and leader burnout.

Equally important, by allying with a grassroots self-help group movement focused on obesity and weight loss, public health advocates may gain what they frequently lack

when they confront vested interests that promote obesity (for example, aggressive marketing of unhealthy foods by fast food restaurant chains and junk food manufacturers): a connection to a vibrant grassroots movement of ordinary citizens whose lives have been adversely affected by being overweight. This potential base for political advocacy, combined with millions of individuals gaining access to free or inexpensive weight loss self-help groups, could have a significant impact on obesity in the US.

Like any collaboration, cooperation between public health professionals and self-help groups will at times raise differences in philosophy and approach as well as control issues that will need to be addressed. However, the potential benefits of such an alliance, we contend, far outweigh the potential challenges.

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