Expanding the self-help group movement to improve

community health and well-being

A briefing paper for

The California Wellness Foundation and The California Endowment

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Purpose

The purposes of this briefing paper are to review the nature and status of the self-help group movement, evaluate its potential for improving health and well-being, and stimulate support for self-help groups and "self-help friendly" policies in government, health care, and community service organizations. Although this paper was developed for private foundations, it should also be of interest to other health funders, health care and social service organizations, and government health officials. This paper focuses on The State of California, but most if not all of the information and recommendations here will be relevant to other areas of the country.

Definitions

The terms **self-help group** and **mutual help group** are synonyms, and will be used interchangeably in this paper. Surgeon General C. Everett Koop's Workshop on Self-Help and Public Health¹ defined self-helps group 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 a 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." Most self-help groups meet face-to-face, but a significant number have meetings using new technologies such as the internet and teleconferencing.

Support groups organized and led by helping professionals are <u>not</u> considered self-help groups unless the helping professional personally shares the problem/concern of the group (e.g., a social worker who has cancer could lead a cancer self-help group) and relates as a peer with group members (i.e., both gives and receives help and does not charge members a fee). Finally, it is important to note that in this paper, "self-help" refers

only to community and internet-based group activities and not to self-help books read in isolation by individuals.

Basis of this briefing paper

Preparation of this briefing paper was supported by grants from The California Endowment and The California Wellness Foundation that enabled the authors to gather and assimilate information from three sources:

- (1) Review of scholarly literature on the prevalence of mutual help groups, the characteristics of participants, and the effects of group participation on the health of members. Mutual help group research has a more than twenty year history and has been carefully reviewed in the past;²⁻⁵ the present document highlights selected examples of work from the field.
- (2) Deliberations of a working group of 20 experts who met for one day in San Francisco to discuss the status of the self-help group movement and provide guidance on how it could be expanded. This diverse group was primarily composed of Californians, and included self-help clearinghouse directors, self-help group members and founders, academics, clinicians, government health officials and foundation staff (many attendees fell into more than one of these categories).
- (3) Consultation with a national panel of expert advisors. Panel members included mutualhelp researchers, clearinghouse directors, and activists.

Although the advice of the working group and advisory panel members (see Appendix) was invaluable for the preparation of this document, the authors are fully responsible for all statements and recommendations made herein.

The Status and Scope of the Mutual Help Group Movement

Nationwide, there are over 800 self-help organizations that address a plethora of health and social problems.⁶ For example, mutual help organizations exist for almost every major chronic condition and leading cause of mortality⁷ in the United States (see Table 1).

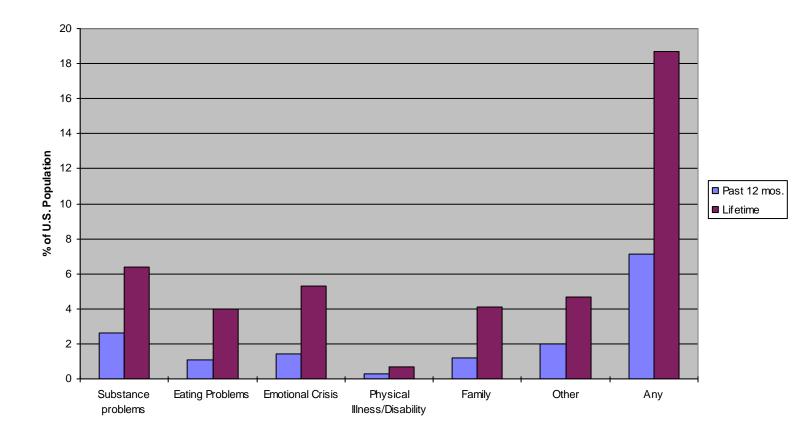
Table 1. Mutual help groups addressing prevalent chronic conditions and leading causes of mortality

| Prevalent Chronic Condition | Example Group |
|-----------------------------|--|
| Arthritis | Young et Heart |
| Visual Impairment | Council of Citizens with Low Vision Support Groups |
| Hearing Impairment | Self-Help for Hard of Hearing People |
| Ischemic Heart Disease | Mended Hearts |
| Diabetes Mellitus | Diabetics Anonymous |
| Malignant Neoplasms | Make Today Count |
| Psychiatric Disabilities | Recovery Inc. |
| | |
| Leading Cause of Mortality | Example Group |
| Tobacco | Nicotine Anonymous |
| Diet/Activity Patterns | Overeaters Anonymous |
| Alcohol | Women for Sobriety |
| Microbial Agents | Hepatitis B Foundation Support Groups |
| Toxic Agents | Parents Against Lead |
| Firearms | Parents of Murdered Children |
| Sexual Behavior | Blacks Educating Blacks About Sexual Health Issues |
| Motor Vehicles | Mothers Against Drunk Driving |
| Illicit Drug Use | Narcotics Anonymous |

A recent national survey by Harvard University researchers indicated that a large number of Americans participate in mutual help groups for a variety of health concerns.⁸

As shown in Figure 1, approximately 7% of American adults (about 11 million people) participated in a mutual help group in the past year, and 18% have done so at some point in their lifetime.

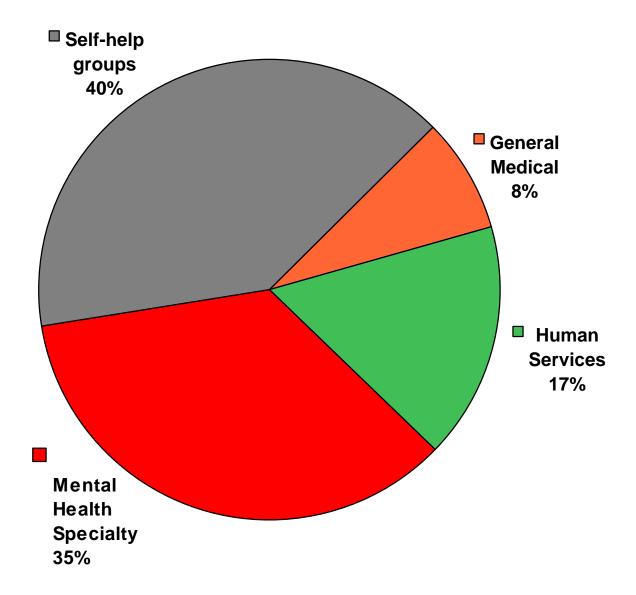
Figure 1: Lifetime and past 12 months participation in self-help groups



The most common type of participation identified in the Harvard survey was for mutual help groups that address substance abuse and emotional problems. A key reason for this is that the largest and most attended mutual help organization is Alcoholics Anonymous (AA),⁹ which has approximately one million members in the U.S. The importance of AA, other addiction groups (e.g., Women for Sobriety, Moderation Management), and mental health-related groups (e.g., Manic Depressive and Depressive Association) to the nation's *de facto* system of care has been well documented.^{10,11} Figure

2 illustrates this point, using data from a national study of help-seeking for substance abuse and psychiatric problems that was recently published in the <u>New England Journal of Medicine</u>. ¹⁰ Impressively, Americans make more visits to mutual help groups for addiction and psychiatric problems than they do to the entire mental health specialty care sector (i.e., psychiatrists, psychologists, social workers etc.).

Figure 2: Help-seeking visits for addiction and psychiatric problems by U.S. Adults



Because they are so widely attended, addiction and mental health self-help groups are the best known. However, the self-help group movement is by no means limited to

these sorts of groups. As was shown in Figure 1, millions of Americans participate in groups focused on chronic physical illnesses, disabilities, stigmatized statuses, and family problems. Further, new self-help organizations are constantly coming into being in response to new health and social concerns, including latex allergies, post-terrorist attack trauma (e.g., groups were formed after the World Trade Center and Oklahoma City bombings), and adverse reactions to anti-depressant medication (e.g., Prozac).

The Harvard survey revealed some important facts about the characteristics of self-help group participants. First, with the exception of groups for eating problems (whose membership is composed almost entirely of Caucasian women), African-Americans and Whites are equally likely to attend all types of self-help groups. Further, individuals with low incomes (0-\$20,000/year) are more likely to participate than are middle class and affluent individuals. Finally, individuals who are divorced or separated and have less social support are more likely to attend groups than are married individuals and individuals with extensive social support. Given these data, we may conclude that **efforts to expand self-help groups have significant potential to benefit diverse racial groups, and individuals with low financial and social resources**.

The benefits of self-help groups to community health and well-being

Self-help organizations can contribute to health and well-being in California and across the nation through three main avenues:

(1) Independent, community-based self-help organizations can serve as an accessible, low cost resource for managing illness and promoting health

Increasing access to health-promoting resources and reducing health disparities between individuals from different socioeconomic strata are key goals of public health, as reflected in the <u>Healthy People 2000</u> initiative, ¹² and in the mission statements of many health-related foundations. Because self-help groups are typically free or nearly free of charge, they have significant potential to help society

meet these goals. Despite their low cost, community-based self-help groups can produce impressive health outcomes.

For example, a prospective study of 201 alcohol-abusing individuals indicated that, over a 3-year period, individuals who attended AA decreased their daily alcohol intake by 75% and decreased their alcohol dependence symptoms (e.g., blackouts) by 71%. These positive outcomes were comparable to those of a comparison group who had sought treatment from a professional outpatient service provider. Importantly, AA participants in this study consumed 45% less alcohol-related health care resources (almost \$2000 less per person) over time than did individuals who initially sought professional outpatient treatment.

Turning to a different type of self-help group, Marmar and colleagues¹⁴ found evidence supporting the effectiveness of self-help groups for complicated conjugal bereavement. Treatment-seeking widows who had shown no evidence of spontaneous improvement within four months of bereavement (n = 61) were randomly assigned to either a bereavement self-help group or twelve sessions of professional psychotherapy. At 4-month follow-up, self-help group participants improved on a variety of psychiatric (e.g., depression, anxiety), social adjustment, and work functioning outcomes. Across outcome measures, the average degree of improvement experienced by self-help group participants was 21%, which was comparable to that experienced by the widows who had received professional psychotherapy.

Mutual help groups also appear to be helpful in promoting weight loss, which is of tremendous importance given the alarming statistic that one-third of the U.S. population is now overweight.¹⁵ A study of weight-loss mutual help groups in Norway found that participants lost an average of 14 pounds over eight weeks, and, that 85% of this weight loss was maintained a year later.¹⁶ The "staying power" of

the effects of weight-loss mutual help groups stands in sharp contrast to the transient benefits of most diets undertaken in isolation by overweight individuals.

Although the number of longitudinal studies examining the effects of mutual help group participation on health is currently small, the studies that have been done suggest that free, member-run self-help groups can produce positive health and social outcomes. From a policy point of view, this suggests that access to effective, low-cost health interventions could be enhanced significantly if some public health promotion resources were devoted to facilitating the growth of self-help groups. Moreover, this support would be leveraged as groups became self-sustaining, free providers of help to their communities.

(2) Self-help groups can enhance the quality of professionally-run health promotion and health care programs

Self-help groups that are integrated into professionally-operated health interventions are different from independent, community-based groups in that they lose some of their grassroots flavor and self-direction. Nevertheless, several studies suggest that self-help groups can be successfully incorporated into professional programs in a fashion that enhances outcomes with little additional cost. For example, Jason and colleagues ¹⁷ implemented a worksite smoking cessation program composed of a manual and a related television program. Twenty-one out of 43 companies were randomly assigned to have this intervention supplemented by employee-led self-help groups. Companies that had employee-led groups achieved average post-intervention quit rates of 41% compared to 21% in companies without groups.

Turning from health promotion to health care, a controlled evaluation of selfhelp groups for parents of premature infants also reported positive results. Twentyeight parents were randomly assigned to participate in a group co-led by a nurse and a mother who had successfully raised a premature infant. Parents in the experimental condition visited their infants more often (4.5 versus 3.1 times per week), and spent about 20% more time touching, talking to, and gazing at their infants during hospital visits than did controls (n=29). Three months after the babies were discharged, self-help group participants also showed more involvement with their infant during feeding and reported greater confidence in raising their infant than did parents in the control condition.¹⁸

Similarly impressive outcomes have been found with discharged psychiatric inpatients. Patients randomly assigned to participate in a patient-operated mutual help network were half as likely to be rehospitalized within 10 months as were controls. ¹⁹ In addition, when patients assigned to the mutual help network were rehospitalized, their stays averaged only 7 days, compared to 25 days for controls. Findings from these projects converge with those of studies of community-based self-help groups ^{13,20} demonstrating that self-help groups not only promote positive outcomes, but also may take a significant burden off of the formal health care system.

(3) Self-help groups can enrich community life and build a constituency for public health advocacy

Self-help groups are not just health interventions; they are also grassroots civic organizations. In a society where many citizens feel isolated in 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 nonetheless can be considered a valuable contribution if one takes a broader view of health that includes quality of life and social well-being.²¹

A more direct contribution of mutual help organizations to public health can be seen in their 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, The Association of Retarded Citizens developed from a small self-help group for parents into an advocacy organization with national impact. Mothers Against Drunk Driving, a catalyst for legislation intended to reduce alcohol-involved auto fatalities, also began as an informal mutual support group. The National Black Women's Health Project and The California Network of Mental Health are further examples of organizations that combine grassroots self-help groups with health-related political advocacy.

In addition to enhancing civil society by advocating directly for changes in existing institutions and laws, self-help organizations can be a force for reform by creating new, alternative settings that challenge existing conceptions of how to care for our citizens. For example, a project currently being conducted in Sacramento County has successfully demonstrated that an unlocked residential facility based on self-help principles and staffed by former psychiatric patients can care effectively for severely psychiatrically disabled citizens who otherwise would be committed to a locked inpatient ward.²³ Simply by providing an innovative alternative for people in severe distress, this facility expands "the range of the possible" and raises awareness of the limitations of widely-accepted methods of attempting to help troubled individuals.

Priorities and how to pursue them

Self-help groups are by no means a panacea for the health and social problems of communities. However, the evidence reviewed here demonstrates that:

 Self-help groups are a low cost helping resource accessed by a diverse group of over ten million Americans.

- Self-help group participation produces positive health outcomes, and also may lower health care expenditures.
- Professionally-operated health care and health promotion programs can be improved by integrating self-help approaches.
- Self-helps groups are an energizing force in civil society.

Given these benefits of self-help groups, expanding and supporting the self-help group movement is clearly an important mechanism for improving community health and well-being. We now turn to recommendations for how this expansion and support could be accomplished.

General considerations in supporting and expanding mutual help groups

One of the most famous stories in the mutual help group movement concerns a 1940 meeting between the Rockefeller family and the early members of AA. John D. Rockefeller admired AA's work, but asked "won't money ruin this thing?". Rockefeller's concern is still pertinent today. External resources can benefit the mutual help group movement, but also carry the risk of damaging mutual help groups' independent, non-bureaucratic, and voluntary character. A grant to a group to pay for developing, photocopying and mailing a newsletter could be a valuable support. In contrast, if an external funder provided professional training, credentialing, and salaries to the leaders of mutual help groups, the groups might lose their grassroots spirit. Rockefeller ended up providing legitimation and limited financial support to AA, but never in a way that undermined AA's autonomy and spirit. Philanthropists of the current era will need a similar degree of discernment to effectively nourish the mutual help group movement.

The mutual help group movement's diversity also deserves comment. Some mutual help organizations (e.g., AA) have many stable groups and are fully self-supporting whereas others have few groups and are struggling to survive. Further, different racial and

ethnic communities may define self-help in diverse ways and therefore disagree on how best to promote it. Lastly, like all other social phenomena, the mutual help group movement will continue to change over time, and some strategies that are helpful to it at one point may be ineffective at others. Consequently, carefully evaluated demonstration projects in defined areas must precede any efforts to support mutual help groups on a national scale. By virtue of its diversity and its role as a cultural bellwether, California is an ideal place to implement such projects.

In summary, using external resources to support mutual help groups is not as simple or straightforward as supporting professionally-operated programs. This reality suggests two important principles. First, the individuals and organizations that implement the strategies put forward below should have a long-term commitment to and understanding of mutual help groups that extends beyond the limits of any given grant or project. Second, a guiding assumption of mutual help group support/expansion efforts should be that there is no universal "magic bullet" that will work for every group, in every community, at every time. Rather, a variety of strategies will be needed, each sensitive to time, context, and place.

Goals and strategies for expanding self-help

We break down efforts to support and expand the mutual help group movement into four goals. The goals are listed in order of priority, as assessed by the collective judgments of the working group and advisory council. Below each goal is a list of potential strategies for implementation. Foundations, health care and social service organizations, and government bodies could implement the strategies directly or fund other organizations (e.g., self-help clearinghouses) to implement them. The overall organization of goals and strategies employed here is for ease of

comprehension only, and does not imply that strategies under one area do not serve other goals, or that the four goals are not related to each other.

Goal #1: Build a constituency and a coordinating organization to support and expand self-help groups: Individuals and organizations that value self-help are diverse, scattered, and often unaware of how their own activities relate to those of others. As a result, there is no clear, organized community of interest that can advocate for self-help and give it a familiar public face comparable to, for example, what General Colin Powell's organization provides for volunteerism. Some strategies that could help increase the organization and coordination of self-help related efforts are:

- Identify, and bring together on an ongoing basis, potential committed members of a statewide "self-help friendly" constituency. This constituency would include self-help group leaders (many of whom currently have little interchange), as well as supportive political representatives and staffers, hospital and HMO directors, clergy, educators, business leaders, and ethnic association presidents. Implementing this strategy through ongoing face-to-face meetings and teleconferences has the potential to build a network of well-informed, well-placed individuals who would identify with and advocate for self-help groups as a broad public health interest not tied exclusively to the provincial concerns of any one organization or individual. Assuming common ground were achieved, building this constituency would serve to energize and inform self-help group leadership in California, and bring significant resources (particularly information and access to important stakeholders) to the self-help group movement.
- Initiate planning for the development of a coordinating center that could provide a consistent public profile and advocacy/support for self-help groups. Planning

for this organization would be a democratic process involving the "self-help friendly constituency" identified above. The planning phase would be used to determine the coordinating center's nature (e.g., an office in the state health department, an independent institute, a statewide clearinghouse, a university-based center) and functions (e.g., policy analysis, referrals and technical support for groups, scholarship, advocacy). Establishing a long-term funding base — preferably an endowment that would free the center from dependence on short-term grants — would also of course be critical. In addition, planning would have to be directed toward how the coordinating organization would have statewide visibility and focus and statewide leadership, but also do justice to the local conditions that shape the needs and views of the state's diverse communities (cf. Hock's concept of a "chaordic" organization²⁴).

Goal #2: Support existing self-help clearinghouses and groups: California currently has several small self-help clearinghouses. Clearinghouses are nonprofit agencies or programs that refer individuals to self-help groups, give technical consultation to existing self-help groups, and help new self-help groups get started. California also has many self-help organizations, which vary widely in their degree of stability and strength. The following strategies could help support the clearinghouses and groups already in existence in California and beyond:

- Fund the revival and maintenance of those self-help clearinghouses that were defunded by the state during the recession.
- Conduct a statewide survey of all self-help groups to assess their needs for assistance from and collaboration with health funders, health professionals, and policy makers.

- Develop self-help resource exchange networks²⁵ within defined geographical regions of the state. To build such networks, diverse self-help group members from around each area would be invited to a series of informal meetings. These meetings would allow group members to develop relationships to other groups and members with which they could exchange their valuable experience and wisdom on dealing with difficult members, publicizing groups, attracting new members, etc.
- Convene statewide meetings of all self-help clearinghouses on an annual basis to promote sharing of resources and information. If possible, such meetings should co-occur with meetings of the National Network of Mutual Help Centers, an organization of clearinghouses in the U.S. and Canada.
- Develop a microgrant program (e.g., up to \$1000) with extremely simple application guidelines for groups wishing to do defined projects such as launching a newsletter, conducting a membership drive, or developing a community education program.
- Create an annual award for self-help groups that contribute exceptionally to the well-being of their communities.
- In collaboration with a California-based internet companies, train groups to develop their own world wide web pages and to hold on-line meetings. The latter type of meeting may be particularly useful for drawing participation from individuals who may be less likely to participate in face-to-face groups, such as physically disabled people, men, and Japanese-Americans.
- Establish a statewide toll-free number (e.g., 1-800-slf-help) that can provide referrals and information about groups. For such a service to be implemented, regular statewide surveys of groups will be required, so that referral information can be updated and logged in an accessible database.

- Create policy briefs for legislators on why groups and clearinghouses are valuable, and advocate for policies that will help support groups. Potential goals for advocacy include obtaining consistent funding for clearinghouses through general health-related funding streams (rather than relying exclusively on mental health funds), inclusion of self-help in health policy goal statements (e.g., Healthy People 2010), and inclusion of self-help group members on health commissions and hospital boards.
- Develop a tool kit for individuals wishing to form mutual help groups, and for mutual help groups wishing to become 501(c)3 non-profit organizations.

Goal #3: Raise public awareness of self-help groups: Many Californians are not aware of groups that would be relevant to them, do not know how to access groups, or are aware of groups but have a negative image of them (e.g., that they are for trivial concerns or that attending them will be depressing or disturbing). Increasing the visibility and positive image of self-help groups could help ameliorate this situation. Potential strategies for accomplishing this task include:

- Launch a public service announcement campaign on radio/TV that emphasizes the benefits of participating in self-help groups and their role in promoting wellness. The campaign should include endorsements from opinion leaders and celebrities, and emphasize the positive features of self-help groups rather than negative stereotypes.
- Increase advertising of self-help groups in "everyday settings" such as YMCAs, workplaces, senior centers, churches/synagogues/mosques, laundromats, and schools.

- Produce a radio show on self-help groups featuring live group meetings and the opportunity for listeners sharing the problem of interest to telephone in.
- Partner with organizations and individuals who regularly organize mass mailings (e.g., legislative offices, Kaiser HMO, university cooperative extension services) to include information on self-help in their mailings.
- Disseminate self-help group directories, readable summaries of research on the benefits of self-help groups, and descriptions of groups to teachers, clergy, journalists, business and opinion leaders and other key influentials in California. These materials could include videotapes of actual groups, CD-ROMs about self-help, documents on the world wide web, as well as printed materials.

Goal #4: Expand interconnections between mutual help groups, health care and health promotion: Some mutual help organizations are critical of how professionals provide health care and therefore wish to remain fully autonomous alternative service providers. Similarly, some health professionals are skeptical of any health intervention not under their control and therefore do not wish to cooperate or consult with mutual help groups. In contrast, other members of mutual help groups and the health professions desire a mutually rewarding collaboration. Where such good will exists, the research discussed earlier indicates that professionally-operated health care and health promotion efforts could be enhanced through partnerships with mutual help organizations. Some strategies to build such interconnections include:

Develop educational materials on self-help groups (e.g., CD-ROMs, presentations, videos) for patients, hospitals, associations of health professionals, nursing homes, hospices, and managed care administrators. In order to keep resources and control within the self-help movement, the best mechanism to accomplish this would be to fund self-help groups and clearinghouses to design

- and administer the materials, rather than fund professionals directly to educate themselves.
- Develop a program on self-help groups to be presented at national conferences on the education of nurses, physicians, psychologists, social workers and other health professionals.
- Develop and mail out a brief informational letter on self-help to all California health care providers, and attempt to get the essence of the letter published in a major medical or nursing journal.
- Organize a presentation on self-help for the Council on Foundations,
 Grantmakers in Health, Grantmakers for children, youth and family, and other affinity groups.
- Work with practice oversight groups (e.g., JCAHO, AHCPR clinical practice guidelines committees) to create and publicize a "degree of self-help friendliness" report card system for HMOs. The report card could be used in order to build the perception in the health care community that self-help groups should be an essential part of care rather than an occasional or esoteric adjunct.
- Convene a conference to bring together health professionals, health care administrators and leaders of self-help groups to discuss avenues of collaboration that will be mutually beneficial and not result in the co-optation of groups by professionals.

Evaluation research will be essential across all goals and strategies

It is never wise to assume that good intentions guarantee positive results. Hence, external support for any of the strategies described above will have to include funds directed specifically at evaluating the effects of the effort. Evaluation research is the only way we can learn which strategies move us toward our goals,

and which do not. This is particularly important if California is to serve as a "laboratory" for self-help group enhancement efforts that will be replicated (or not) elsewhere in the nation depending on whether they were effective.

In addition to evaluating the effects of the above strategies, evaluation of selfhelp groups is an important activity in its own right for funders to support. For example, the evaluation studies mentioned here demonstrating the positive effects of self-help groups for various conditions help build the credibility of self-help in the eyes of the general public and health professionals.

Among other issues, evaluation research in this area should address the health and health care utilization effects of group participation, the current location and prevalence of different types of groups, the needs of self-help groups, the effects of external assistance on groups, and the interplay of self-help groups and formal health care systems. In order for the utility of evaluation results to be maximized, a variety of stakeholders (e.g., self-help group members, foundation staff, policy makers academics) should be involved in defining the nature, process, and purposes of self-help group evaluation research projects.

Conclusion

Mutual help groups are already an important part of how citizens take care of each other in California and across the nation. Yet the full potential of the movement to become a major force in health care, health promotion, and civil society remains unrealized, due in part to a lack of external legitimation and support. A potential next step for organizations and individuals wishing to support and expand self-help groups would be to convene a working group to plan the implementation of some or all of the strategies offered in this briefing paper. We hope that foundations and other funders will support such an effort

and thereby take advantage of a tremendous opportunity to promote health and well-being in California, and ultimately, across the nation.

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Appendix

The following individuals attended the meeting of the working group, served on the national advisory

committee, and/or commented on earlier versions of this document.

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