

**ASSESSING THE NEEDS AND STRENGTHS
OF SELF-HELP GROUPS: OPPORTUNITIES TO
MEET HEALTH CARE NEEDS**

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ABSTRACT

Over 15 years ago the Self-Help Network, a statewide clearinghouse for self-help groups, conducted a needs assessment of groups. Findings from that needs assessment provided direction for the activities of the Self-Help Network and insights for health and human service professionals. Health care has changed dramatically over the past 15 years, including interest in alternative treatments, higher costs, managed care, and greater use of Web-based information. It is difficult to determine what impact, if any, these changes have had on the needs of self-help groups. Consequently, the Self-Help Network conducted another assessment and needs assessment of groups. Findings show that groups primarily need public awareness and referrals. Groups struggle with organizational issues such as finding meeting locations and shared leadership. The primary benefits of groups are the sharing between members, followed by information and education. Implications for health and human service professionals are discussed, including insights on how they can provide referrals and technical assistance to groups.

Over the past half century, self-help groups have become a prominent component of healthcare systems across the world. Yet because of their grassroots nature, the existence of self-help groups was frequently only known through word of mouth.

To improve access to these groups, self-help clearinghouses formed to provide referrals and other types of support to these groups. In an effort as a self-help clearinghouse to be maximally helpful, the Self-Help Network (SHN) conducted a needs assessment of self-help groups (Meissen, Gleason, & Embree, 1991) to provide direction and guidance for the SHN's own activities, but to also inform health and human service professionals interested in assisting self-help groups. Over the past 15 years the self-help movement and the American healthcare system have changed in a number of ways (i.e., managed care, expansion of alternative healthcare, growth of the Internet). It is unclear how these and other changes have impacted the assets and needs of self-help groups. Therefore, the purposes of this research were to determine the current strengths and needs of self-help groups, thereby providing insights for health and human service professionals, self-help clearinghouses, self-help group leaders, and others interested in assisting self-help groups.

SELF-HELP GROUP MOVEMENT

As self-help groups have gained popularity, they have increasingly come to be recognized as an "emerging social movement" (Borkman, 1990). This movement began to formalize through (a) the rise in the number of self-help groups, (b) the expansion of self-help clearinghouses, and (c) the growing complexity of self-help groups into self-help organizations. In addition, a growing body of research and literature suggested that self-help groups were an effective and efficient complement to traditional health and human services. Finally, health and mental health professionals who were traditionally reluctant to provide referrals to self-help groups were beginning to recognize the benefits of self-help groups for their clients and patients.

Self-help groups have increasingly come to be viewed as dynamic and complex social groups (Humphreys & Rappaport, 1994). While the 12-steps of Alcoholics Anonymous continue to be the most widely recognized model, self-help groups are growing in their diversity, with differences in their structure, mission, and focus. Many groups meet in churches, hospitals, or individual member's homes with little external support or prescribed structure. Other groups have developed into nationally recognized nonprofits with sophisticated structures and political power (e.g., National Alliance for the Mentally Ill). Schubert and Borkman (1991) developed a classification system that recognized this diversity, highlighting groups that were affiliated, unaffiliated, and federated. Self-help clearinghouses have also grown in number and visibility. They have made thousands of referrals to self-help groups and assisted group leaders in starting and maintaining groups. Healthy People 2000 included the establishment of statewide self-help clearinghouses in at least 25 states as one of its year 2000 goals (Institute of Medicine, 1990).

Professional Interest and Involvement in Self-Help

The growth, formalization, and empirical evaluation of self-help groups has fostered support for and interest of self-help groups from health and human service professionals. Traditionally, professionals' interest in self-help groups has been perceived as low among self-help participants and advocates, although these views have never been widely documented. Some professionals view self-help groups at best as "alternative" or at worst harmful to clients. In addition, the self-help literature has seen much debate about the differences between peer-led and professionally-led groups, especially around issues of professionalization and co-optation of groups (e.g., Emerick, 1990; Toro, Reischl, Zimmerman, & Rappaport, 1988). As professional support of self-help groups has increased, skepticism toward professionals has subsided.

These and other generalizations were reviewed by Jacobs and Goodman (1989), who offered their insights about the state of the self-help group movement. Their article provided a critique of the characteristics of self-help groups, reasons for their dramatic rise in utilization, and dilemmas when trying to understand the effectiveness of self-help groups. Jacobs and Goodman's article concluded with three predictions regarding the self-help movement in relation to health care in the United States: 1) self-help mutual support groups will flourish under corporately controlled healthcare; 2) groups will be seen as an effective, economical, and legitimate modality for mental health promotion and treatment; and 3) professionals will have greater involvement with them, producing tailor-made formats to enhance their effectiveness for specific populations.

THE NEEDS OF SELF-HELP GROUPS DURING THE LATE 1980s

The SHN conducted a needs assessment of self-help groups in the late 1980s and published the findings in 1991 (Meissen et al., 1991). Prior to the needs assessment, it was largely assumed that the primary concerns of group leaders were problem members and over-involvement of professionals. It was believed that self-help group leaders would be interested in workshops and trainings to help address these and other topics to improve their group's functioning.

Surveying a random sample of 90 Wichita area self-help groups, the results ran counter to assumptions. Rather than problem members or the over involvement of professionals, survey results found that the recruitment of members and a lack of public awareness were the top two problems facing self-help groups. Almost 75% of respondents rated them as either important or extremely important. Furthermore, an open ended question found that improving public awareness of the group was the most frequently cited need of groups, with 61% of respondents mentioning it. Likert scaled results reflect this, with referrals to groups and the publishing of a self-help group directory ranking as the top two

needs of groups. Over 85% of respondents considered these two needs as important or extremely important.

Recent Changes in Healthcare

The healthcare system looks very different today than it did 15 years ago when the Self-Help Network conducted its first needs assessment (Keigher, 2001). To some degree Jacobs and Goodman's predictions have come to be realized. Yet, they likely did not materialize in the manner Jacobs and Goodman (1989) had imagined. Managed care has changed the way healthcare decisions are made and financed. Health and human service professionals are having to position themselves in light of these changes (Schneider, Hyer, & Luptak, 2000). These changes have decreased hospital stays from an average of 7.8 days in 1970 to 4.9 days in 2001 (Kozak, Owings, & Hall, 2005). Despite managed care's attempts to control rising healthcare costs, premiums for family coverage have increased by 59% between 2000 and 2004, compared with inflation growth of 9.7% and wage growth of 12.3% (Kaiser Family Foundation and Health Research and Educational Trust, 2004). Along with rising healthcare costs are a rising number of uninsured Americans.

Trust in traditional healthcare has also decreased. In 2002, 44% of Americans said someone in their immediate family had encountered at least one problem with access to healthcare, paying medical bills, or perceived quality of care in the past year (National Public Radio (NPR)/The Kaiser Family Foundation and Harvard's Kennedy School of Government, 2002). Vast differences remain in the quality of health care received by Americans (Gorin, 2000). Between 1987 and 2003 the number of uninsured Americans rose 45% from 31 million to 45 million (DeNavas-Walt, Proctor, & Mills, 2004). Consequently, a growing number of Americans are concerned about their health insurance and health care coverage.

E-mail and the Internet have drastically changed the way Americans access information about their health concerns. A study by the NFO Worldgroup and Forrester Research (2003) found that 61% of Americans go online at least once a month, with 50% of Americans going online at least several times a week. Recent healthcare polls show that eight out of ten adult Internet users seek healthcare information when they are online, and one in three e-mail users have exchanged health-related information with their friends, family, or healthcare professionals (Pew Internet and American Life Project, 2005).

Given these social and healthcare changes, it is time to revisit the needs of self-help groups to better understand the challenges they face and the strengths and/or assets they possess. By having a better understanding of the needs and strengths of self-help groups, health and human service professionals and self-help clearinghouses can be in a position to assist and partner with self-help groups. More specifically, this research will examine current needs, challenges, and strengths of self-help groups in Kansas.

METHOD

Procedure and Participants

The Self-Help Network Center for Community Support and Research at Wichita State University maintains one of the most comprehensive statewide computerized databases of self-help groups in the United States. To be listed in the database, groups have to meet the following criteria: 1) be composed of members who share a common situation or problem, 2) have a mutual assistance orientation—members helping members—as the primary form of assistance, 3) have meetings and activities available to anyone sharing the problem that defines the group with no time limit as to how long someone can attend, and 4) must be cost-free or low-cost. Twelve-step anonymous groups (i.e., Alcoholics Anonymous (AA), Narcotics Anonymous (NA), Overeaters Anonymous (OA), etc.) were not included in the current study because of the amount of research already conducted with these groups and to respect their anonymity, independence, and formal structure.

The SHN's self-help group database contains approximately 1500 Kansas groups. The entire database is updated bi-annually. From the 1500 Kansas self-help groups, 250 groups were randomly selected using a computer-based random number generator. Each group listed in the database includes a minimum of one contact telephone number, and the great majority of entries include a contact name as well. In most cases the contact name is that of the group leader. Seven trained research assistants called the contact telephone number to identify the group leader or the most appropriate person to complete the survey. The research assistants then contacted group leaders via telephone to schedule a time to complete the survey. Interviewers explained the goals of the survey to participants, and verbal informed consent was obtained. Participants were assured their responses would remain confidential, their participation was voluntary, and their responses would not be reported individually.

Sixty-four groups were unable to be contacted despite multiple efforts to contact them during the day and evening. Our experience as a clearinghouse indicates that a majority of these 64 groups had likely disbanded. We documented that an additional 31 had disbanded in the previous year, and 14 no longer met the criteria of a self-help group. Fourteen people were the leaders of multiple groups and were asked only to complete one survey for one of their groups. Five people refused to participate, resulting in a 4% refusal rate and 122 completed surveys.

Consistent with the Self-Help Network's database, many of the groups surveyed focused on physical illnesses (48%). Other types of groups included those for parenting and/or caregiving (14%), death of a loved one (14%), living with disabilities (6%), mental health (5%), abuse (5%), relationships (5%), and alcohol and or drug addiction (3%). Groups were peer-led (39%), professionally-facilitated (23%), or had shared leadership between peers and professionals

(38%). Of those who said their group was peer-led, 41% indicated the leadership of the group was the responsibility of one individual as opposed to being shared among group members.

SURVEY INSTRUMENT

The goal of the survey was to get a better sense of leaders' experiences in their self-help groups and to assess the strengths and challenges of groups. Another goal was to understand how self-help clearinghouses (i.e., the Self-Help Network) and other helping professionals can assist self-help groups.

Benefits and Challenges of Self-Help Groups

In an open-ended format, participants were first asked to identify three things that have made their group effective and then identify the three greatest challenges their group faced. Following was a series of 13 Likert items related to tasks or topics which may be challenging to self-help groups. Participants were asked to rate the difficulty of each particular task or topic on a 6-point scale ranging from (1) "extremely difficult" to (6) "extremely easy." The Likert items were based on the first needs assessment conducted by the Self-Help Network (Meissen et al., 1991), experience working with self-help groups, and focus groups conducted with self-help group leaders. Those items, along with their means, can be found in Table 1.

Needs for Self-Help Group Clearinghouse

Participants were asked an open-ended question about what services they needed. They were then asked seven Likert items related to services provided by the Self-Help Network. They were asked to indicate how likely they would be to use these services within the next year by rating them on a 6-point scale with (1) being "extremely unlikely" and (6) being "extremely likely." The Likert items and their means can be found in Table 2. Following the Likert items, participants were asked to identify which of the Self-Help Network's referral means is most useful to them (Website, directory or toll-free phone number). In addition, participants were asked two Likert items, with responses ranging from "none" to "all" regarding how many group members supported each other via the Internet (i.e., e-mail or chatrooms) between meetings and how many group members located information about the group's concern on the Internet.

RESULTS

Strengths of Groups

When asked an open-ended question about what made their group effective, the primary strength identified by respondents was members supporting each other

Table 1. Problems Faced by Self-Help Groups

Items	<i>M</i>
Raising community or public awareness about the group	3.2
Recruiting people to come to the group (new members)	3.2
Locating sufficient funding	3.4
Getting members to regularly come to meetings	3.7
Keeping leaders from becoming overworked and tired	3.7
Getting members to share the work	3.9
Finding solutions to members who are posing a problem to the group	4.0
Obtaining support from professionals	4.2
Knowing what to do when difficulties arise	4.2
Keeping meetings interesting	4.5
Knowing who to turn to when difficulties arise	4.8
Keeping professionals from becoming over-involved	4.9

Note: Based on 6-point Likert scale from 1 to 6 with 1 = "extremely difficult"; 2 = "difficult"; 3 = "somewhat difficult"; 4 = "somewhat easy"; 5 = "easy"; and 6 = "extremely easy."

Table 2. Needs of Self-Help Groups

Items	<i>M</i>
Reading a quarterly newsletter containing information specific to self-help groups	5.3
Accessing the Self-Help Network Website	4.3
Accessing materials regarding the operation of self-help groups	4.2
Calling the Self-Help Network's toll-free number for assistance	4.1
Attending workshops on special self-help group topics	3.9
Meeting with other group leaders in person to discuss self-help group issues	3.6
Meeting with other group leaders via an Internet discussion group	3.1

Note: Based on 6-point Likert scale from 1 to 6 with 1 = "extremely unlikely"; 2 = "unlikely"; 3 = "somewhat unlikely"; 4 = "somewhat likely"; 5 = "likely"; and 6 = "extremely likely."

(79%; see Table 3). One participant mentioned “Cohesiveness. People get to come to our group and discuss their problems and solutions with each other. They really develop a set of personal acquaintances unlike others.” Participants emphasized the unique, supportive nature of their groups when members shared past experiences with others in similar situations. One participant said, “All members (of the group) share a common bond.” Similarly, another suggested that members “sharing experiences (helps them) know they’re not alone.” An additional question asked participants about group members’ use of the Internet and e-mail between meetings. Nearly 50% of participants stated that at least some of their members provide support to one another via e-mail or the Internet between group meetings. By providing a supportive, non-judgmental atmosphere, groups provide an opportunity for members to build trusting relationships by mutually supporting one another.

Group structure was another important attribute that contributed to the effectiveness of groups (56% of respondents). At a fundamental level, participants emphasized the need to provide a consistent meeting time and convenient location. These logistical aspects helped prospective members easily access group meetings. Beyond these logistical aspects, groups were structured in very different ways. Some groups followed a specific set of guidelines or procedures for conducting meetings. For example, one group started each meeting with a speaker, followed by small group time where members broke into smaller groups to discuss concerns. Conversely, other groups were much more informally structured. These groups, while having specific meeting times and locations, had minimal group guidelines or discussion topics. Regardless of how the group was structured, it

Table 3. Strengths and Challenges of Self-Help Groups Identified by Group Leaders

	Percent
Most commonly mentioned strengths:	
Members supporting each other	79
Group structure	56
Source of useful information	49
Leadership	38
Acceptance of others	20
Most commonly mentioned challenges:	
Group logistics	68
Attendance at group meetings	50
Public awareness difficulties	33

Note: Based on responses to an open-ended questions asking participants about the strengths and challenges associated with their group.

was an asset of groups in that it contributed to a safe and comfortable environment to discuss concerns.

Another common strength was that groups were a source of useful information for members (49% of respondents). Self-help groups were often a source of practical information that members may not always get from other health care professionals. The types of information included referrals to other sources of support and information, information about new treatments or medicines, and simple techniques and activities that may help reduce stress and burden. Some self-help groups occasionally had social workers, nurses, doctors, or other health care professionals visit to answer questions and provide members with information and educational materials. An additional question asked participants about group members finding information regarding the group's concern. Forty percent of participants said at least a few group members found information related to the group's concern over the Internet. This information was occasionally formally or informally shared with group members.

Leadership structure also contributed to positive outcomes (38% of respondents), but as with group structure, it varied considerably across groups. While there was variation in how groups approached leadership (i.e., peer-led, professionally-facilitated, or shared between peers and professionals), respondents emphasized that their group had a leadership structure that was consistent with the needs of their group and was beneficial to group members.

Finally, just over 20% of respondents stated that the group's acceptance of others was a positive and beneficial aspect of their group. One participant said that it is good to let everyone know they are important to the group. Another participant said that members of the group are very open and accepting and are also willing to help other members when they need it. Other participants also said that the members of their groups are very welcoming to new members.

Challenges Groups Face

Participants were asked in an open-ended format to list their three greatest problems or challenges related to their group. Sixty-eight percent of participants mentioned problems related to logistics, such as transportation, meeting location/time, childcare, and funding (see Table 3). Nearly 50% of participants mentioned that attendance at group meetings was a problem. Finally, difficulties related to public awareness were mentioned by 33% of participants.

Following the open-ended question, participants were asked to rate, using a Likert scale with (1) being "very difficult" and (6) being "very easy" the ten potential problems faced by groups. Lack of public awareness ($m = 3.2$) and difficulties in recruiting new people to the group ($m = 3.2$) were the two most commonly cited challenges or difficulties. More than 60% of participants rated each of these items as at least somewhat difficult. Several items were rated fairly easy, including keeping professionals from becoming over-involved ($m = 4.9$),

knowing who to turn to when problems arise in the group ($m = 4.8$), and keeping meetings interesting ($m = 4.5$). More than 60% of participants rated each of these items as at least somewhat easy. Table 1 provides an overview of all the challenges faced by self-help groups and the extent to which they were viewed as easy or difficult.

Needs of Groups

Participants were asked in an open-ended format their needs regarding what a self-help clearinghouse could provide. Over 50% mentioned needing help with public awareness. When asked a follow-up question about the Self-Help Network's best approach for referring people to self-help groups, 35% mentioned the SHN's statewide directory of self-help groups, 35% of participants stated through SHN's Website, and 30% mentioned the SHN's toll-free phone number. Forty percent of participants mentioned a need in helping to start and maintain a group. Finally, 22% mentioned the need to locate guest speakers and other community resources.

Following the open-ended question, participants were asked to rate, using a Likert scale with (1) being "extremely unlikely" and (6) being "extremely likely" how likely they would be to use assistance from the SHN (see Table 2). The assistance participants most likely would use was a quarterly newsletter containing information specific to self-help groups ($m = 5.3$). This type of assistance was followed by access to the SHN's Website ($m = 4.3$), materials from the SHN regarding the operation of groups ($m = 4.2$), and access to the SHN's toll-free information line ($m = 4.1$). Table 2 provides a complete list of items related to the SHN's assistance.

DISCUSSION

Findings from the current needs assessment both confirm and expand upon the previous needs assessment of self-help groups conducted in the late 1980s by the Self-Help Network. While changes in health care and technology have likely impacted self-help groups over the past two decades, four of the five top needs of self-help groups were the same as in the previous needs assessment, including raising community awareness, recruiting new members, getting members to regularly attend meetings, and keeping leaders from becoming overworked. Groups continue to seek approaches and strategies to recruit participants and generate shared leadership within their groups. Self-help group members use e-mail and the Internet to support each other and find out about their concern or problem. In addition, greater professional involvement is not a concern among self-help groups, as they are more interested in getting professionals involved in various ways. Self-help groups share some similarities in that they are inwardly focused on helping members, providing opportunities for members to share

information, concerns, and experiences. At the same time, self-help groups are differently structured and have different approaches to leadership making each group distinct. These findings have a number of implications for the partnerships that can exist between self-help groups, health and human service professionals, and self-help group clearinghouses.

Implications for Self-Help Groups

Self-help groups offer many unique strengths and assets, especially in light of changes to health and human services that increasingly emphasize cost-containment, prevention, and alternative methods to treatment. Self-help groups offer no-cost support and information about particular concerns and problems. There are hundreds of different types of groups available, structured and organized in different ways to meet member needs. Collectively, self-help groups represent a practical and valuable resource for health and human service professionals. At the same time, self-help groups are in need of group members. Without new members, self-help groups are at-risk of becoming stagnant and even disband. With little or no budget for public awareness, self-help groups look to community gatekeepers to provide referrals and support. Most groups simply want others who share the concern to know that they are available. Some self-help group leaders look for assistance with the organizational aspects of starting and maintaining self-help groups, including finding meeting locations, maintaining mailing lists, and locating guest speakers.

Implications for Health and Human Service Professionals

Health and human service professionals can be key community gatekeepers for self-help groups as they are in a position to refer clients and patients. There are a number of ways in which health and human service professionals can be helpful to self-help groups. As a first step, health and human service professionals can become more aware and knowledgeable of groups in their area. Health and human service professionals can also share their knowledge of self-help groups with other colleagues and professionals. Once they refer their clients and patients to groups, health and human service professionals can follow-up after they have attended a group to ask about their experiences and emphasize the importance of continued participation. Health and human service professionals can help self-help groups find new members by helping them locate low- to no-cost ways to publicize in local churches, directories, newspapers, etc. Finally, health and human service professionals often have the technical expertise and knowledge about community resources that could be shared with self-help groups.

Health and human service professionals can also help self-help group leaders in structuring groups, developing group guidelines, and creating shared leadership opportunities so that members can get involved. Health and human service

professionals can emphasize the need to have a small group of interested individuals who can share responsibilities. Such an approach to group leadership can help decrease the likelihood of burnout among group leaders and provides new opportunities for others to become invested in the group.

Self-Help Group Clearinghouses

Self-help group clearinghouses are located in some states and larger metropolitan areas. Self-help group clearinghouses can be instrumental in developing and strengthening the relationship between self-help groups and health and human service professionals as they often have background and experiences with both. Self-help clearinghouses can play an intermediary role between self-help groups and health and human service providers helping connect resources for both. At a fundamental level, self-help clearinghouses have information about local self-help groups so health and human service providers have an access point for current information and meetings of self-help groups. Such assistance is also useful to self-help groups as it addresses one of their primary needs of needing new members. Self-help clearinghouses can promote the use of self-help groups by educating health and human service professionals about groups in their area. While some self-help groups are highly recognized (e.g., Alcoholics Anonymous), most remain hidden from the public eye contributing to their need for referrals. By raising the awareness and educating health and human service professionals about the diversity of self-help groups, clearinghouses can help more groups gain exposure to those in need. Clearinghouses can also educate health and human service professionals about the roles that they might play within self-help groups and ways in which to be helpful to groups without becoming overly dependent upon. Clearinghouses can also serve self-help groups by educating group leaders about ways in which they can connect with local health and human service professionals. Self-help clearinghouses can serve an important intermediary role between health and human service professionals and self-help groups meeting the needs of both. Additional support, policies, and expansion of self-help clearinghouses are needed to help build the infrastructure of self-help clearinghouses across the United States.

CONCLUSION

Self-help groups have become part of the continuum of health care in the United States, providing additional and much needed support and information to millions of Americans facing life difficulties. They are a natural community resource that health and human service professionals can use for their clients and patients. Health and human service professionals are in a position to assist self-help groups in many ways, ranging from referrals to becoming an advisor. Finally, self-help clearinghouses can be an important connector between self-help

groups and health and human service professionals, meeting the needs of both. Attention is needed toward these partnerships and how best to support them. Such attention will help continue to build and strengthen the self-help movement for years to come.

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