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Self help programs: A description of their characteristics and their members

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USER-RUN PROGRAMS HAVE PROLIFERATED IN THE PAST 10 YEARS, YET THERE ARE FEW EMPIRICALLY-BASED STUDIES ABOUT THEM. A SURVEY OF SELF-HELP PROGRAMS WAS UNDERTAKEN TO INCREASE OUR UNDERSTANDING ABOUT THE USERS OF SUCH PROGRAMS, THEIR DEMOGRAPHICS, AND THEIR PERCEPTIONS OF HOW SUCH PROGRAMS HAVE AFFECTED THE QUALITY OF THEIR LIVES. RESPONDENTS WERE ALSO ASKED ABOUT THEIR SATISFACTION WITH USER-RUN PROGRAMS. THE STUDY WAS CONDUCTED USING A PARTICIPATORY ACTION RESEARCH PARADIGM (WHYTE, 1991), USING AN ADVISORY COMMITTEE OF PERSONS WHO HAVE USED SUCH PROGRAMS, AND WITH THE INTENTION OF DEVELOPING AN EVALUATION METHODOLOGY THAT COULD BE REPLICATED IN FUTURE STUDIES OF USER-RUN PROGRAMS. DESPITE LIMITATIONS IN REPRESENTATIVENESS, THESE SURVEY RESULTS ARE USEFUL IN UNDERSTANDING THE PERCEPTIONS OF SELF-HELP MEMBERS. RESULTS OF THE SURVEY AND THE METHODOLOGY ARE DISCUSSED.

INTRODUCTION

THE VALUE OF SELF-HELP GROUPS IS BEING DISCUSSED WITH INCREASING FREQUENCY, AND AS MORE CLIENT-RUN PROGRAMS ARE FUNDED BY STATE, LOCAL, AND NATIONAL MENTAL HEALTH AUTHORITIES, IT BECOMES INCREASINGLY MORE IMPORTANT TO ACQUIRE RELIABLE INFORMATION ABOUT THEM. WHILE SOME DESCRIPTIVE INFORMATION ABOUT USER-RUN PROGRAMS DOES EXIST (CHAMBERLIN, ROGERS, & SNEED, 1991; CHESTER, 1991; EMERICK, 1988; KAUFMAN, FREUND & WILSON, 1989; MOWBRAY, CHAMBERLAIN, JENNINGS, & REED, 1988; MOWBRAY, WELLMOOD, & CHAMBERLAIN, 1988; ROBERTS, SALEM, STEIN, & ZIMMERMAN, 1985; ZINMAN, 1982; ZINMAN, HARP, & BUDD, 1987), THERE ARE FEW STUDIES EXAMINING THE EFFECT OF SUCH PROGRAMS. ONE EXCEPTION IS THE WORK OF RAPPAPORT AND HIS COLLEAGUES WHO HAVE STUDIED SELF AND MUTUAL HELP ORGANIZATIONS RATHER EXTENSIVELY, INCLUDING BOTH DESCRIPTIVE AND THEORETICAL EX-
Self-help programs were defined as having to meet the following criteria: 1) Groups are local and grass roots (although they may be affiliated regionally, statewide, nationally. Three research plans for potential self-help programs nationally were developed and letters were sent to these programs requesting their participation. From that initial recruitment letter, 64 programs expressed interest and met the criteria of being a consumer-run program, as defined by the Research Advisory Board. For example, programs had to be run by consumers who had control of their own budget, staff, and activities.

The advisory board reviewed all 64 programs in the final group during the summer of 1991 and decided to select programs that afforded diversity in geography, racial and ethnic makeup, and program type. Because many advisory board members were familiar with the various programs, they had available a great deal of information about the programs under consideration. After several hours of discussion, six programs were selected that were thought to represent the broad scope of consumer

### Methodology

This study was designed with the assistance of a consumer research advisory board, under the direction of the senior author. At the onset of the project, the senior author selected ten individuals whom she believed could represent the diverse opinions of the self-help movement nationally. Three research plannings meetings were held with this research advisory board to design and plan the study and to develop survey questions. The use of a research advisory committee such as this is encouraged by proponents of Participatory Action Research (Whyte, 1991; Rogers & Palmer-erbs, 1994), who assert that for evaluation to be meaningful and credible, constituents of that research must be involved.

### Subjects

The Research Advisory Board decided to sample members of six self-help programs in various parts of the country. Six programs were chosen primarily because of the limited fiscal resources of the study. With the assistance of the Research Advisory Board, a list of potential self-help programs nationally was developed and letters were sent to these programs requesting their participation. From that initial recruitment letter, 64 programs expressed interest and met the criteria of being a consumer-run program, as defined by the Research Advisory Board. For example, programs had to be run by consumers who had control of their own budget, staff, and activities.

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run self-help programs. The six self-help programs were in the following states: New Hampshire, New Jersey, Indiana, Arkansas, Washington, and California. The senior author visited all but one site to discuss the project further, to discuss the logistics of project implementation, to meet members, and to secure final agreement for participation.

Instrumentation
Instruments for the study were also developed in conjunction with the advisory board. Instruments were developed to collect information about the members’ demographics, including the length of time they had been involved in self-help programs; their perceived quality of life, self-esteem, and social supports since participating in self-help; and their satisfaction with their current program. Standard guidelines for developing paper and pencil survey instruments were followed (Dillman, 1978; Fink & Kosecoff, 1985).

Questions were developed using concepts from existing scales (e.g. quality of life and self-esteem); however, the Research Advisory Board decided to avoid standardized, psychological instruments in favor of survey questions that were potentially less threatening to members. All ratings of quality of life, self-esteem, social supports, and demographics were based upon self-report. A separate survey instrument was developed to obtain descriptive information about the programs themselves. This nine-page questionnaire described the mission, funding, structure, activities, and physical facilities of the program. Additional questions were used to verify that the program met the definition of a self-help organization described earlier.

The final instruments were pilot tested during the winter of 1991 with a local self-help program that was not scheduled to participate in the study to ensure that the instruments were unambiguous and formatted in an easy-to-use manner.2

Survey Implementation
Data collection with the six selected programs began in March 1992 and concluded in August 1992. Detailed written instructions about member recruitment and data collection were provided to each site liaison requesting that they attempt to get as many members as possible to complete the survey. Each site was receiving a small stipend for participation ($250) and liaisons were advised to inform members that their program would benefit as a result of their participation in the survey.

The senior author had frequent contact with the sites to monitor the data collection. A total of 271 usable questionnaires (California, n = 111; New Jersey, n = 77; Arkansas, n = 36; Indiana, n = 21; Washington, n = 14; New Hampshire, n = 12) were returned.

Response rates were calculated using each site’s number of active members; they ranged from a low of 10% in New Jersey to a high of 55% in Arkansas. However, no attempt was made to have each site monitor refusals (or the reasons for members’ refusal) nor is it possible to calculate what the exact number of active users is, given the way that self-help programs operate. Therefore a more precise response rate cannot be calculated.

RESULTS
Program Description
Descriptive data from each of the self-help programs were synthesized to gain an understanding of the operation of the self-help programs participating in this study.

Mission, funding, and staffing. As part of the survey, we asked each site liaison to provide us with information about the program’s mission statement and how that mission statement was developed. All programs reported that their mission statement was developed solely by members of their organization, without collaboration with professionals or input from funding bodies. Keywords in the mission statements were content analyzed, and, not surprisingly, the programs seek to: promote empowerment and independence among members, promote choice and self-determination, provide peer support, provide education, information, advocacy, and assistance to access services. Other mission statements referred to improving the quality of life of members, eliminating stigma and promoting respect for persons with mental illness.

Several of the programs have received support from the National Institute of Mental Health, the Center for Mental Health Services, their state Department of Mental Health, or their Office of Vocational Rehabilitation. County health or government boards were the source of support for two programs, and charitable foundations provided support for several programs as well. One program mentioned the receipt of funds from the U. S. Department of Housing and Urban Development. Total operating budgets range from a low of $47 thousand dollars per year, to a high of $2.9 million dollars per year. Programs reported a fair amount of autonomy in how they expend their operating funds.

Programs were asked about their staffing patterns: the number of full-time equivalent staff ranged from a low of 1.5 to a high of 12.5. Several programs reported having a significant contingent of volunteers to supplement their paid staff. The most common job

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2 Copies of the instruments are available from the senior author.
titles reported by the programs were: advocates, peer support persons, resource coordinators, employment and education specialists, and residential support persons. Programs also report having administrative, managerial, and business support staff (i.e., clerical workers, managers and directors, bookkeepers, and the like).

**Activities.** Table 1 contains a checklist of services that each program provides. Programs were asked to indicate whether each activity was an official and routine service of their organization. The only service provided by all programs participating in this study was assistance with legal problems. Assistance with employment and general advocacy efforts were next most common. Social/recreational services and temporary shelter were provided by only half the responding programs. The “other activities” provided by the programs included services such as an emergency hotline, peer counselor training, technical assistance to start other self-help groups, publishing a newsletter, educating the community about mental illness, developing permanent housing, and so forth.

**Membership information.** Programs were asked about the procedures that prospective members must follow to participate in their program. Only one of the responding programs indicated that members must provide evidence that they had received mental health services in order to attend the program. Programs identified their services as being open to “ex-patients,” “consumers of mental health services,” and “psychiatric survivors.” One program followed a more traditional approach and required that the individual have a “diagnosis of mental illness;” one program required that potential members have “experienced mental illness.” Programs indicated that they had from 40 to 750 “active users,” with a mean of 199. The one program having 750 active users greatly skewed the mean. The median number of active users was 65.

Programs were asked whether participation in their self-help program is ever required by treatment professionals, to which two of the six programs responded affirmatively. All programs stated that they give members an opportunity to choose to participate in some activities and not in others. Finally, programs were asked whether they were involved in monitoring the treatment or services of individual members. Only one program responded yes to that question, stating that they provide consumer case management services, and peer support for participants of certain mental health programs.

**Demographics of Self-help Members**

**Gender, age, race, and marital status.** There was a greater percentage of male respondents (59.8%) than female (40.2%). The average age was 40.4 years. Racially, the sample consisted of 56.4% whites, 36% African-Americans, and 7.6% others. Most participants reported being either single (54.1%) or divorced/separated (31.3%). Only 14.6% reported that they were married. More than half of the participants reported having children (52.8%).

**Psychiatric involvement.** Respondents were asked a number of questions about their psychiatric history and involvement. (A decision was made not to ask about psychiatric diagnosis, since we believed that many people either did not know their diagnosis, or had multiple diagnoses and would not know which to report. The Research Advisory Board also expressed concern about the implicit labeling such a question would connote.) The average age at first reported psychiatric contact was 23 years. Fifty percent of respondents reported currently taking psychiatric medication and, on average, respondents took psychiatric medication for 8.8 years. The majority of respondents (67.5%) reported having been hospitalized for psychiatric reasons at least once in their lifetime. The average total number of psychiatric hospitalizations was 4.8; the average number of years spent as an inpatient was 1.2.

### Table 1—Type of Activities and Services Provided by Programs

<table>
<thead>
<tr>
<th>TYPE OF ACTIVITIES AND SERVICES</th>
<th>PERCENT OF PROGRAMS PROVIDING SERVICES</th>
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</thead>
<tbody>
<tr>
<td>Social/Recreational Activities</td>
<td>50%</td>
</tr>
<tr>
<td>Protection or Advocacy for Individual Members</td>
<td>66%</td>
</tr>
<tr>
<td>Advocacy Efforts on Behalf of all Persons with Psychiatric Disabilities</td>
<td>83%</td>
</tr>
<tr>
<td>Assistance with Housing</td>
<td>66%</td>
</tr>
<tr>
<td>Assistance with Legal Problems</td>
<td>100%</td>
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<tr>
<td>Assistance with Employment</td>
<td>83%</td>
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<tr>
<td>Transportation</td>
<td>50%</td>
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<tr>
<td>Food Assistance</td>
<td>66%</td>
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<tr>
<td>Temporary Shelter</td>
<td>50%</td>
</tr>
<tr>
<td>Assistance with Activities of Daily Living</td>
<td>66%</td>
</tr>
<tr>
<td>Other</td>
<td>100%</td>
</tr>
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</table>
**Education, employment, and income.** The sample group was fairly well educated with the majority having a high school degree (46.2%) or higher educational attainment, (19.7% associates/technical degree; 11.4% college degree; and 8.3% graduate degree). However, most respondents were not competitively employed. A “regular job” was held by 16.2% of respondents; 34.5% of respondents were currently unemployed; 12.6% reported having a “sheltered/supported job.” Others held “volunteer jobs” or reported being “in school, not working” or classified themselves as “housewife/husband.” Those working averaged 24.5 hours per week.

The median monthly income for respondents was $575 (range $0 to $4,500; the median is reported because a few high monthly incomes appeared to skew the mean). Sources of income reported were Social Security (55.7%); employment income (22.1%); welfare (22.1%); other sources (18.8%); vocational program (4.1%); and “no income” (5.9%).

**Housing.** In terms of living arrangements, most respondents lived in private homes or apartments (48.1%), and the next most frequent response was homelessness (15.2%). Some respondents lived in a “rooming house/apartment” (12.9%), in “other supervised living” (11.7%), or “other” arrangements (12.1%). When asked about whom they reside: 38.7% reported living alone; 26.9% reported living with other non-related persons; 16.2% of respondents stated they lived with a spouse or live-in partner; 9.2% live with their children; 5.2% live with parents; and 4.4% report living with “other family members.”

**Demographics of self-help sample members and other populations with mental illness.** Contrasting the demographics of the self-help sample with data from a national sample of community support clients surveyed in 1984 (Mulkern & Manderscheid, 1989), we found some consistencies and some disparities. The self-help sample has a higher proportion of males (59.8% versus 51% of community support clients), a much higher proportion of African-Americans (36% versus 11%); and the self-help sample had much higher educational attainment (14.4% had less than a high school diploma versus 46% for the community support sample). The two groups were close in age (average of 40.4 years versus 44 years respectively) and had similar rates of marriage with 54.1% of the self-help group reporting being single in contrast with 53% of the community support group.

Data on psychiatric involvement showed a much lower proportion of people who had ever been psychiatrically hospitalized in the self-help sample (67.5% versus 91%) and a much lower average number of months hospitalized (12 months versus 46 months). However, these data should be read keeping the nearly 10-year discrepancy in mind and the concurrent social policy to reduce hospital admissions and lengths of stay. Half of the self-help sample reported currently using medication, whereas 87% of the community support sample did so.

The above data could support contentions that self-help groups tend to reach people who are less psychiatrically involved. However, further elucidation of the self-help sample is necessary prior to drawing conclusions. Although all six program sites varied in some significant ways from one another, one of the sites is consistently different from the others. The California site, which comprises 41% of the whole sample, includes a drop-in center that largely serves the homeless population of Oakland. This particular group, when separated from the rest of the sample shows a characteristically different population than those served by the other five sites. The following demographics are statistically different for the California site versus the other five sites. California has significantly more males, far greater numbers of African-Americans, more unmarried people, greater numbers of unemployed people, less receipt of Social Security income, greater homelessness; fewer people using medications, fewer ever hospitalized, fewer total number of psychiatric hospitalizations, and a lower average number of months spent as an inpatient. These findings are similar to Segal and his colleagues (1995).

Excluding the California sample, we found that the psychiatric involvement of the remaining subjects in this sample were similar to the community support sample. For the remaining five sites, 87% had ever been psychiatrically hospitalized; they had been hospitalized on average 6.6 times; 67.5% were currently taking psychotropic medication, and they were taking medications on average for 11.7 years. Racially, the other five sites also resembled the community support sample (87% white, 9% African-American). The difference in educational attainment remains consistent whether or not the California site is excluded.

**Service Utilization**

Respondents were queried about the number and types of mental health services they used in the past year. From a list of 22 possible services, respondents had used, on average, 7 services in the past year. The most frequently used services were: counseling (71.7%), medication (61.5%), general support (54.7%), transportation (45.7%), emergency services (44.5%), day activities (40.0%), and psychiatric hospital (38.5%). The California site did not differ significantly from the other sites regarding service utilization.
Involvement in Program
Respondents were very involved in their user-run programs spending an average of 15.3 hours a week at the program. A sizeable minority (39.5%) held a formal position or title within the program. Of these positions, 63% were paid positions and the average number of hours worked per week was 16.4. The average amount of time participants had been involved with their current self-help program was 2.9 years. The average amount of time participants had been involved with any self-help program was 4.7 years.

Quality of Life, Self-Esteem, and Social Supports
Respondents were queried about their perceived quality of life, particularly satisfaction with their housing, finances, social situation, work, and physical well-being. More respondents were satisfied with their housing (59%); social situation (61.4%); and physical well-being (66.2%) than dissatisfied. Conversely members were dissatisfied or very dissatisfied with their work (58.0%) and their finances (59.8%). Other items on this instrument asked respondents to rate the effect of participation in the self-help program on their quality of life. Respondents reported positive or highly positive effects of self-help on their general satisfaction with life (78.4%) and on how successful their life has been (72.1%). Self-help participation increased positive feelings by “a fair amount” or “a great deal” for 88.1% of respondents and it helped 88.1% of respondents “get the things they want out of life” by a “fair amount or great deal.” When asked what effect self-help had on their housing, financial and social situations, 77% of participants said it had some or highly positive effect.

There was a significant difference among the six sites with respect to quality of life scores. \(F(5,266) = 6.8, p < .00009\). The California site showed lower quality of life scores. This was attributed to the population served who were more likely to be homeless and had lower incomes.

In regard to self-esteem, respondents were asked how self-help involvement had affected their feelings about themselves. Respondents reported feeling more positive about themselves as a result of self-help involvement (92%), having more respect for themselves (87.5%), feeling more productive and capable (86.8%), feeling better about themselves and able to recognize their strengths (89.4%). Furthermore, 87.5% reported that being involved in self-help provided the opportunity to help others.

Finally, respondents were asked about the impact self-help involvement has had on their social life. Respondents were asked to indicate whether the quality and the frequency of contact with family and friends has: “Changed in a way I like”; “Changed in a way I do not like”; or “Not changed.” Forty-six percent of participants indicated that self-help involvement had changed the amount of contact they had with their family in a way they liked. Forty-three percent of respondents indicated no change in the amount of contact, and 11% stated that the amount of contact they had changed in a way they did not like. Fifty percent of respondents indicated that self-help involvement had changed the quality of their family contact in a way they liked and 41% stated their contact had not changed qualitatively. Similar results were found on the questions regarding contact with friends: 53% indicated the amount of contact had changed in a way that they liked; 38% reported no change. Fifty-eight percent of respondents reported that the quality of their contact with friends had changed in a way that they liked and 34% reported no change.

When respondents were asked, overall, whether self-help involvement affected the number of family, friends, or others with whom they had regular contact, 60% stated it had, in a way that they liked. Thirty-two percent reported no change in frequency of regular contact with family and friends. Sites differed with respect to their reports of how self-help had affected their self-esteem and quality of life (see Table 2).

Satisfaction with Participation in Program
A 19-item questionnaire using a four-point Likert scale was administered to respondents to gather information.
about their satisfaction with their self-help program. Overall, programs received very positive ratings of satisfaction. For example, the majority of respondents found that participation helped them to solve problems (59.4%), and helped them to feel more in control of their lives (64.2%). The majority found that the self-help program was easy to get to, had convenient hours, and was in a comfortable building. Most felt treated as an equal by other members (81.2%) and that they were treated with courtesy and respect (82.3%). Nearly all (91.5%) would recommend the program to a friend. Most find that they get the kind of help they are looking for (69.7%). Nearly all respondents rated the overall quality of their program as good or excellent (48.7% and 35.3% respectively). There were no significant differences in satisfaction with program across the six sites.

Satisfaction with program also varied significantly with two demographic variables. Using an analysis of variance, there was an overall significant difference in satisfaction by educational attainment ($F(4, 267) = 2.5, p = .02$), with those having the lowest educational attainment and those having the highest educational attainment showing the highest satisfaction scores. Another significant difference arose when satisfaction was analyzed by living arrangement for the respondent ($F(4, 267) = 3.1, p = .01$). Satisfaction scores were highest for people living in various kinds of supervised arrangements, for those living in private domiciles, or in unsupervised co-operative apartments. Homeless people and people living in rooms or other arrangements had relatively lower scores. One might speculate whether individuals who are homeless were less satisfied because they expected the program to assist them to obtain suitable housing and did not receive that assistance. Analyses by all other demographic variables showed no significant differences in relation to satisfaction with self-help including extent of psychiatric involvement and extent of involvement in this or other self-help program, age, race, sex, or employment status.

### Community Activity

Respondents were given a checklist of community activities (Rappaport, 1985) and asked to indicate which of these activities they had engaged in during the last year. Activities included items such as voting in an election, writing to a political official, boycotting a product, and so forth. Table 3 contains the percentages of individuals stating they performed each activity. Over 90% of the respondents indicated they participated in at least one of those community activities; almost 40% indicated they participated in five or more community activities.

Prior to a discussion of the findings, it is important to note that these results must be interpreted cautiously for two reasons. First, they represent only 6 out of 64 self-help programs that expressed a willingness to participate in this study. The programs chosen for this study were selected deliberately, and with the intention of getting geographical representativeness and organizational variety. Secondly, the researchers did not have the ability to systematically track response rates within each of the six programs. That level of monitoring was considered too burdensome for the sites and very difficult given the informal “drop-in” structure of all the programs surveyed. It is possible that the data presented here is therefore biased, and not representative of all self-help programs.
members. On the other hand, all members were encouraged to respond to the survey, and we received no reports from the site liaisons that obvious selection biases occurred. Given the dearth of information available on self-help programs, we believe that these data have value in understanding self-help programs and their members despite these methodological limitations. Aside from selection or sampling bias, it is also important to note that these results are all based upon self-report. No attempts were made to verify or validate the effects of self-help on members’ lives through other source of information.

The self-help programs that participated in this study receive support from traditional funding sources such as the Center for Mental Health Services, state and local mental health authorities, and the Department of Housing and Urban Development. Despite this, the programs do not appear to be beholden to those sources, and are able to develop their missions and operate their programs quite autonomously. In contrast to traditional mental health programs, these user-run programs describe themselves as interested in advocating for empowerment, choice, and self-determination for their members. Two of the programs we surveyed operated with a very significant budget and paid staff, suggesting that while self-help programs may have started as small, informal organizations who survived on a “shoestring,” they are growing into formidable operations. Programs report offering assistance with residential, employment, and education services; service coordination; legal help; general advocacy; and social and recreational services. Results suggest that, at least to some extent, the role of the self-help programs has been both to fill gaps in the present system of care and to help members get what they need from existing services. However, some self-help programs actually provide what might be considered traditional mental health services.

Results of the analyses of demographic characteristics of self-help members was somewhat confounded by the California site. It might be concluded that some self-help programs, particularly those in poor, urban areas serve individuals who are less involved in the traditional mental health system than do other similar programs. The California site serves far more individuals who are homeless, African-American, and with proportionately fewer having a history of being hospitalized for psychiatric reasons. Given the lack of resources for poor, urban individuals, self-help programs may be appealing to them whether or not they strongly identify with the mission of the self-help movement. These findings are consistent with those of Segal and his colleagues who surveyed two self-help programs in the San Francisco area and found demographics similar to ours, and that members were attracted to the social supports and material assistance offered by self-help programs.

Results of data on service utilization suggest that respondents do not rely only upon services available to them through their self-help organization, but also on services that might be considered traditional, such as counseling, day services, and inpatient hospitals. Respondents seem able to meld services from traditional sources with those offered by the self-help program.

Judging by the amount of time respondents spend in their programs (an average of 15 hours per week), these organizations seem to fill various gaps for respondents and thus possibly reducing the need for other, more costly services. It appears from the data regarding the number of holding positions within their program, that members belong to self-help programs not only to receive help, but also to give help, which is the essence of a mutual help organization. These respondents were also fairly seasoned users of self-help, having spent an average of almost 5 years involved in such programs. When the data were compared to the national UCDI data, it would appear that users of the programs we surveyed are more educated on average than those surveyed in the UCDI study. This finding was apparent when the data were analyzed with and without the California sample. The possibility of self-selection needs to be investigated further. It is possible that individuals with higher levels of education feel more comfortable in self-help organizations, or perhaps that individuals with higher levels of education were more willing to participate in this survey.

Overall, respondents indicated that being involved in self-help had a salutary effect on their quality of life, including their general life satisfaction.
fied with their work and financial situation than their housing, social situation, and physical health, a not surprising finding given the low employment rates and the abysmally low incomes reported. California respondents reported a lower perceived quality of life, also not surprising given the high degree of homelessness and the low incomes among that group. Self-help involvement also positively affected members’ self-esteem and social lives, according to their self-reports. It might be concluded from the satisfaction with self-help programs that the programs surveyed are achieving their mission: members overwhelmingly reported being satisfied with the services and personal interactions within the self-help programs.

These results are consistent with the findings of Mowbray and Tan (1992) and Carpinello, Knight, and Jatulis (1992), both of whom evaluated consumer drop-in centers. In the Mowbray and Tan study, members expressed satisfaction with their program and positive effects as a result of participation. Carpinello and associates discussed the positive effects afforded by self-help involvement in the areas of self-concept, well-being, social functioning, decision-making, and achieving educational and career goals.

Though this study has made an attempt to answer questions about who uses self-help programs, much investigation remains to be done. First the methodological limitations of this study limit the certainty with which conclusions can be drawn. However, for a variety of reasons, it is doubtful that a truly representative survey of self-help members can be conducted. Furthermore, there are questions that require a prospective, longitudinal research design, or an in-depth sociological perspective, such as whether participation in self-help positively affects hospitalization and rehabilitation outcomes, the structure of self-help programs and how they operate, or how self-help programs differ from traditional mental health services. Obviously, questions such as these were beyond the scope of the current study, and suggest the need for further research. Because this study did not involve systematic, representative sampling methods, the results must be interpreted cautiously. For example, it is difficult to generalize these results with certainty to all user-run programs, or more broadly to self-help programs in general. However, our deliberate selection of a geographic and organizational range of programs allows us to generalize with some confidence.

The level of community involvement for respondents deserves further investigation. For example, community involvement appears very high (e.g., 19.6% reported writing a letter to a public official within the last year; 55% reported having voted in a city, state, or national election) that they raise questions about the reputation for apathy and lack of affiliation frequently attributed to persons with severe mental illness. Are these respondents a unique group, or does membership in such programs raise the political conscience of its participants? These data give reason to believe that at least some consumers are more like the general public in terms of their community or political activism, and less like the popular stereotypes, than many investigators would lead us to believe.

As self-help groups and programs continue to proliferate, and as they affect larger and larger segments of the community mental health population, it becomes increasingly important to learn more about them. In order to best study this population, a participatory approach is essential, since many such programs will simply refuse to be studied otherwise. As we learn more about self-help programs and their participants, we may learn about different and non-traditional ways that quality of life and community tenure can be improved.

References


