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Characteristics and Service Use of Long-Term Members of Self-Help Agencies for Mental Health Clients

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Objective: This study examined the characteristics of long-term members of self-help agencies managed and staffed by mental health clients, why they sought help from the agencies, and how they differed from clients of community mental health agencies. Methods: A survey and assessment instruments were used to obtain information on the service utilization of 310 long-term agency members as well as on their resources, history of disability, functional status, psychological disability, health problems, and DSM-III-R diagnosis. Data from management information systems of the self-help and community mental health agencies were used to compare service populations. Results: The self-help agencies served a primarily African-American population (64 percent), many of whom were homeless (46 percent). Eighty-seven percent had confirmed DSM-III-R diagnoses, and 50 percent had dual diagnoses with moderate to severe substance or alcohol abuse or dependence. They had sought help from the self-help agencies primarily for resources such as food or clothing, for "a place to be," or because they were homeless. Obtaining counseling or help for substance or alcohol abuse was a less important reason for coming to the self-help agencies. Conclusions: A high proportion of the persons served by the self-help agencies in the study were homeless and had a dual diagnosis of mental disorder and substance abuse. The self-help agencies provided their clients with material resources while community mental health agencies provided psychotherapeutic and medical care.

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During the past ten years, growth in the number of self-help agencies has constituted a major development in mental health services. Self-help agencies are often incorporated as voluntary organizations and are independently managed and staffed by former patients (1). Clients usually refer to themselves as members of the organization. These organizations are defined as agencies because they provide mutual assistance (euphemistically called self-help) such as help in locating housing and obtaining disability benefits and other entitlements, as well as offer peer support groups. Self-help agencies have established goals and technologies that they and others believe are effective in improving the lives of their members (2). These agencies further claim to serve individuals who are less well served by traditional mental health services.

We know very little about self-help agencies and their place in the mental health service system. Existing research, well summarized by Thomas Powell (3), has concentrated on self-help groups such as Recovery or Emotions Anonymous, which are generally not formal voluntary service organizations. Thus the literature on self-help groups does not address self-help agencies' practices of offering a spectrum of services reputedly comparable in scope to those offered by professional organizations.

Despite a lack of knowledge about the activities of self-help agencies, mental health professionals regard these organizations as service providers. As self-help agencies have proliferated, support for their activities by state legislatures, local mental health systems, and foundations has increased (4,5). A 1993 collaborative survey conducted by the Center for Self-Help Research and the National Association of State Mental Health Program Directors showed that 46 states funded 567 self-help groups and agencies for persons with mental disabilities and their family members (6). Self-help, or more accurately mutual assistance, is a key component of the services system and one of the few components of the system that will grow in the immediate future.

It is thus surprising that there are few empirical data describing the basic characteristics of members of self-help agencies. This paper uses data from a survey of members of four self-help agencies in the San Francisco Bay Area to address four questions. First, what are the demographic, diagnostic, and social characteristics of long-term members of self-help agencies? Second, how do members learn about the self-help agencies and what services do members use? Third, are the characteristics of members of self-help agencies comparable to those of persons who use community mental

health agencies located nearby? Fourth, are the demographic characteristics of members of self-help agencies in the San Francisco Bay Area comparable to those of members of self-help agencies outside of California?

Description of agencies

Self-help agencies run by mental health clients vary widely in program philosophy, mission, and range of activities (5,7–9). The self-help agencies we studied are concerned with improving members' lives and helping them gain skills and resources to achieve stability, but they also place the responsibility to make the necessary changes on the members themselves. At the same time, the agencies believe that societal inequities contribute to members' problems and that these inequities must be changed through collective action.

Zinman (10) developed a typology of self-help organizations based on program activities. The four self-help agencies we studied fit the model of the drop-in or community center. They provide a place for members to socialize, to build a support network, and to receive advocacy and a gamut of services to assist in independent living. Three of the four agencies target their services to individuals who are homeless or at risk of homelessness. The fourth targets services to all seriously mentally disabled individuals and has many homeless individuals among its membership. All provide mutual support groups, drop-in space, resources for survival in the community, and direct services. All have members who are active in state and national consumer-led organizations.

The services provided by the agencies include assistance in getting food and finding temporary shelter and permanent housing, counseling and advocacy concerning financial benefits, job counseling, substance abuse counseling and support groups, counseling about money management, payeeship services, case management, peer counseling, and information and referral. All provide coffee, snacks, clothing, food vouchers, free use of a telephone, and special-interest support groups. All have paid staff and volunteers, but vary in the extent to which staff functions are specialized and their volunteer programs formalized. Finally, staff, volunteers, and members at all agencies are engaged in a variety of ad-hoc political activities, including demonstrating to protest proposed cuts in welfare and mental health funding, testifying at city council hearings, gaining appointments to task forces and local commissions, and holding press conferences.

Methods

In 1992–1993 we surveyed 310 long-term members of four self-help agencies in two counties in the San Francisco Bay Area. The agencies were the only consumer-run organizations in the area that had achieved agency status. Each agency was independently incorporated, had a governing board, and offered a wide spectrum of services.

We attempted to interview all staff and volunteers, who were themselves mental health clients and members of the self-help organization, as well as a sample of other long-term members. Respondents were categorized as staff or volunteers if they worked at least ten hours a week at the self-help agency.

We selected long-term members randomly from people who fit our eligibility criteria and who were present in the drop-in center when an interviewer was available. Persons who had been members of the agency for at least three months and who had attended the agency at least twice a week during that period were eligible to be interviewed. Interviewers went to the self-help agencies at different times and on different days with no consistent schedule. All interviewers were trained by the Center for Self-Help Research. Interviewers included former mental health clients and mental health professionals with experience in interacting with people with serious mental disabilities.

Only three of 25 staff and ten of 236 long-term users who were approached to participate in the survey refused to participate. All active volunteers participated. The total response rate was 96 percent.

Respondents were asked questions about service utilization, resource availability, history of disability, and experiences in the agency. Functional status, psychological disability, and health problems were assessed using the Brief Psychiatric Rating Scale (BPRS) (11); the Langner Scale (12), which screens for psychiatric symptoms indicating impairment; and the Health Problems Checklist (13). The interviewers also administered the Diagnostic Interview Schedule (DIS), excluding modules for diagnoses believed to be either uncommon in this population (for example, bulimia) or to have a less critical effect on daily coping (for example, tobacco dependence).

Data were also drawn from a management information system we developed for one of the four self-help agencies as well as from the management information systems of two community mental health agencies located near two of the self-help agencies. We also used information from one self-help agency's fiscal reports to obtain data on the demographic characteristics of the total client population of that agency.

Results

Findings are presented in four sections: characteristics of respondents, data about referral and services, comparisons of people who use community mental health agencies and self-help agencies, and data about several self-help organizations outside California.

Client characteristics

Demographic characteristics. Table 1 shows data on the demographic characteristics of the 310 survey respondents. The mean age was 37 years, and the median age was 38 years. Particularly noteworthy was the high proportion of African-American and homeless individuals in the survey sample.

Twenty-seven percent of respondents were staff or volunteers (members who worked ten or more hours a week at the agency). There were no significant differences between staff and volunteers and other respondents in gender or ethnicity. Staff and volunteers had more education than other respondents: 18 percent of the staff and volunteers had a

bachelor's degree or more education, compared with 4 percent of other respondents (χ^2=7.27, df=6, p< .0006).

Housing status. Forty-six percent of respondents were literally homeless, that is, they lived on the streets or in a shelter. Many of the remaining respondents were precariously housed: 18.5 percent of them had to vacate their residences within two months, and almost half within two weeks. Of those who had to leave within two months, 62 percent had no idea of where they would live next. If the percentage of precariously housed respondents with no prospects for housing were added to the percentage who are literally homeless, a total of 59 percent of the respondents could be considered homeless.

In addition, 78 percent of respondents had been homeless at least once in the past five years, often for considerable periods of time. The median amount of time they had been homeless was a little more than two years. Ten percent had been homeless for the entire five years.

Staff and volunteers were less likely than other respondents to be literally homeless at the time of the interview (29 percent versus 52 percent; χ^2=12.34, df=1, p=.0004). However, they did not differ from other members in likelihood of being precariously housed or of having been homeless during the past five years.

Disabilities. Respondents had multiple disabilities. Eighty-seven percent had confirmed *DSM-III-R* diagnoses, as indicated by the DIS. Half of the respondents had a dual diagnosis of mental illness and moderate or severe substance abuse or dependence. An additional 20 percent had a diagnosis of only substance abuse or dependence. No differences were found between staff and volunteers and other respondents in diagnostic characteristics, although staff and volunteers were more likely to have a diagnosis of an affective disorder (25 percent versus 16 percent; χ^2=4.80, df=1, p=.028).

Fifty-nine percent had a score of 4 or higher on the Langner Scale, indicating serious psychological disability (12). Staff and volunteers were slightly less likely than other respondents to have a score of 4 or higher, but the difference only approached significance (p=.06).

The BPRS rates respondents on 24 items using a scale from 1 to 7, on which scores of 6 and 7 indicate clinically significant symptoms occurring in the past month (11). Ratings are based on self-report and interviewer observations. BPRS interrater reliabilities were in the .9 range in this study. Twenty-four percent of respondents had at least one clinically significant symptom. Staff and volunteers were less likely than others to have clinically significant symptoms, as measured by the BPRS (16.5 percent versus 27.6 percent; χ^2=4.096, df=1, p=.04).

Taken together, the DIS, Langner, and BPRS scores support the claim that self-help agencies serve a population with severe mental disabilities, which justifies their support by public mental health systems.

Many respondents also had physical disabilities. Respondents were asked about the occurrence of 34 heath problems during the previous six months, including those often found among homeless individuals such as swollen ankles, arthritis and rheumatism, and frequent severe chest colds. Only 10 percent had no health problems; 25 percent listed eight or more problems. Twenty-two percent mentioned arthritis or rheumatism, 7 percent fits or seizures, and 5 percent tuberculosis. No differences in health problems were observed between staff and volunteers and other respondents.

Income and employment. Although 98 percent of respondents had held paid jobs in the past, only 24 percent did so at the time of the interview. Many of those who were employed had low-paying, undependable jobs. Respondents worked a median of 19 hours per week, and 52 percent of those who worked held temporary jobs. Of respondents who were working, 19 percent were unable to find at least some work every week. Median monthly wages were $550. Those who were not employed by the self-help agencies typically performed low-skilled manual labor.

Many respondents received government support. Thirty-six percent received Supplemental Security Income or Social Security Disability Income, and 36 percent received general assistance. Nine percent of respondents had children who stayed with them; 5 percent received Aid to Families With Dependent Children.

A caveat in interpreting these figures is that many respondents made at least some income from panhandling or "hustling"—combinations of legal and illegal activities. Interviewers asked for details from respondents who said they engaged in these activities, but respondents varied in their willingness to discuss them. In many cases, respondents

Table 1
Demographic characteristics of long-term clients (N=310) of four self-help agencies in the San Francisco Bay Area

Characteristic	%
Gender	
Male	72
Female	28
Ethnicity	
African American	64
White	17
Latino or black Latino	7
Native American	5
Asian	1
Other, declined to answer	6
Primary diagnosis	
None	13
Drug or alcohol abuse	20
Antisocial personality disorder	12
Panic disorder, posttraumatic stress disorder, anxiety disorder, dysthymia	24
Affective disorder	19
Schizophrenia	13
Homeless or living in shelter	46
Marital status	
Never married	49
Ever married	51
Never married or lived with partner for more than a year	14
Ever married or lived with partner for more than a year	86
Age (years)	
18 to 24	5
25 to 44	76
45 to 64	19
Over 65	<1
Education	
Less than high school	27
High school	30
Technical	3
Some college	31
Bachelor's degree or more	8

Table 2
Stressful life events in the past year among long-term clients of self-help agencies and samples of community residents and psychiatric outpatients, in percentages

Event	Long-term clients (N=310)	Community sample (N=257)[1]	Out-patients (N=118)[1]
Thrown out of or lost place where staying	44	—	—
Lost job	23	6.3	8.7
Lost other source of income	20	—	—
Separated from spouse or significant other	32	0.8	8.8
Lost or had stolen a valuable possession	47	—	—
Lost or used up money saved	48	—	—
Turned down for entitlements	21	—	—
Spent time in jail or prison	29	—	—
Involuntary hospitalization	8	—	—
Serious accident	15	2.0	4.4
Sick or disabled	18	14.2	16.7
Someone close died	39	15.7	16.7
Someone close very sick or hurt	30	10.7	11.4
Lost custody of child	8	—	—
Beaten, mugged, stabbed, or raped	24	—	—
Attempted suicide	8	—	—

[1] From Dohrenwend and Dohrenwend (14)

did not view hustling as work, and the reimbursement they received for these activities was not in cash.

Life stressors. Eighty-seven percent of respondents had experienced at least one of 16 major stressors shown in Table 2 in the past year, and 60 percent had experienced such stressors in the past month. Given the high percentage who were homeless, the numbers who lost housing or a job is not surprising. However, respondents were also likely to have experienced disruption through separation, death, or illness of significant others and to have themselves been ill or injured. Eight percent attempted suicide in the past year.

For comparison of respondents' life stressors with those of other populations, Table 2 also shows data from earlier studies of life stressors in a community sample and a sample of psychiatric outpatients (14). Although the data for the two comparison groups are old, the large differences between the percentages shown for the comparison groups and those for the respondents are disturbing.

Referral and services

Two raters coded responses to an open-ended question about ways in which respondents had heard about the self-help agency. Responses were classified with a 95 percent rate of agreement into seven categories. Pathways to the agency primarily depended on informal referrals. Most respondents (46.1 percent) were referred by friends or relatives. One-fifth were referred by a mental health or social service agency. Twenty percent heard about the agency by word of mouth on the street, and 10 percent saw the agency when they happened to be walking by.

Responses to an open-ended question about what initially brought respondents to the self-help agency suggested the importance of basic resources. Two raters classified responses to this question with 78 percent agreement into eight categories. Most respondents came to the agency for resources such as food or clothing (31.6 percent). Others came for a "place to be" (22 percent), because they were homeless and needed help (12.8 percent), or because they sought "to be with people" (10.2 percent) or to see what was available (8.1 percent). Obtaining counseling (8.4 percent) or help for substance or alcohol abuse (4.9 percent) or participating in self-help or helping others (4.3 percent) were less important reasons for first coming to the agencies.

During a six-month assessment period, basic resources from the self-help agency were received by the following percentages of respondents: food (26.3 percent), bus pass (28.5 percent), place to shower (21.2 percent), clothing (36.9 percent), mailing address (42.3 percent), personal items (18.6 percent), temporary housing (34.3 percent), storage (23.4 percent), supported employment (22 percent), help in finding a job (24.7 percent), help with rent (17.9 percent), and service information (38.8 percent).

A total of 41.8 percent of respondents received counseling. Forty-five percent of those respondents received counseling only for psychiatric problems, 25 percent only for substance abuse problems, 22 percent for both types of problems, and 8 percent for some other problem. The median duration of counseling was 42 weeks for psychiatric problems and 20 weeks for substance abuse counseling. Psychological counseling was primarily provided by mental health professionals affiliated with the community mental health agency; substance abuse counseling was provided by equal proportions of professionals and nonprofessionals.

Fifty-two percent of respondents had a history of psychiatric hospitalization, and 75 percent of that group had been hospitalized within the past ten years. Of the respondents hospitalized in the past ten years, 71 percent had been held involuntarily at least one time.

The management information system at one of the self-help agencies we studied showed that over a one-year period the agency provided about 239 service hours in an average week. The average daily attendance for drop-in and service activities was 162, with a range from 100 to 283. An individual who was highly active in the agency's activities received about 11 hours of service a week, and a less active individual about 1.5 hours. For persons at both levels of activity, primary services included training in independent living skills, peer counseling, access to telephones, and assistance in obtaining clothing. Both groups of individuals used the drop-in center more than 20 hours a week.

agency is able to reach individuals through informal referral and then to connect those who wish additional services with community mental health agencies.

The *DSM-III-R* diagnoses derived from the DIS may underrepresent the actual number of disorders present in the survey sample. The DIS screening criteria for symptom severity include consultation with professionals, use of medication, and interference with daily life activities. An unknown proportion of the individuals we interviewed avoided professionals, took illegal rather than legal drugs to alleviate symptoms, and denied that psychological problems interfered with their daily activities, even though the interviewer suspected that they were a cause of the respondents' homelessness.

Given selection procedures that traditionally have reduced use of outpatient mental health services by African Americans (16), especially those with dual diagnoses or substance abuse problems, these data are extremely important because they include many individuals from these less-well-served groups. About 64 percent of the persons served by the self-help agencies in our sample are African Americans; at least 50 percent of the members of these agencies have been diagnosed with moderate to severe substance or alcohol abuse or dependence in addition to their mental disorder.

Table 3
Characteristics of clientele at two self-help agencies and two clinics operated by a community mental health agency (CMHA) in the San Francisco Bay Area, in percentages[1]

	Self-help agencies		CMHA clinics	
Characteristic	Agency 1 (N=1,456)	Agency 2 (N=987)	Clinic 1 (N=2,650)	Clinic 2 (N=735)
Gender				
Male	61.0	71	51	51.0
Female	39.0	29	49	49.0
Ethnicity				
African American	76.0	78	57	38.7
White	18.0	17	26	46.5
Latino or black Latino	4.0	1	4	3.7
Native American	1.0	1	1	1.0
Asian	0.5	1	9	1.7
Other, declined to answer	0.5	2	3	1.4
Primary diagnosis[2]				
None	9.0	13	1	na
Drug or alcohol abuse	16.0	21	3	12.5
Antisocial personality disorder	8.0	15	0	na
Panic disorder, posttraumatic stress disorder, anxiety disorder, dysthymia	25.0	27	6	6.1
Affective disorder	24.0	16	21	37.4
Schizophrenia	18.0	8	35	19.0
Other nonorganic disorder	na	na	33	na
Other organic disorder	na	na	2	na
Homeless	55.0	62	11	20.0

[1] Median ages of the four client groups were 40 years at self-help agency 1, 35 years at self-help agency 2, 40 years at CMHA clinic 1, and 38 years at CMHA clinic 2.
[2] Primary diagnoses for clients of the self-help agencies were estimated from data on the sample of long-term members.

Comparing users of two types of agencies

Table 3 shows demographic and clinical characteristics of all members—not just our long-term sample—at two of the self-help agencies we studied and characteristics of clients of two clinics operated by a community mental health agency serving the area in which the self-help agencies are located.

The two self-help agencies are partly funded by the community mental health agency and are intended to serve homeless individuals with mental disabilities. A much higher percentage of persons served by the self-help agencies are homeless compared with those served by the clinics operated by the community mental health agency, even though the clinics are located near the self-help agencies. Thus the self-help agencies are able to attract and retain precisely the individuals they claim to serve and are intended to serve by one of their funding sources.

The extent to which the self-help agencies reach the the homeless mentally disabled population in the area is impossible to determine. However, data gathered by Robertson and associates (15) in the county where this study was done and during the same time period show that the ethnic distribution of homeless individuals with *DSM-III-R* diagnoses exactly matches that among the homeless individuals in our sample.

The populations served by the self-help agencies and by the clinics operated by the community mental health agency overlap—28 percent of respondents to our survey currently received psychiatric counseling, and an additional 26 percent had done so in the past. Eighty-seven percent of the survey respondents had a confirmed *DSM-III-R* diagnosis. Of those who currently received psychiatric counseling, 66 percent began counseling after they became members of the self-help agency. The data suggest that the self-help

A national perspective

To our knowledge, no data on a nationwide sample of clients of self-help agencies exist. However, information on 160 clients of five self-help agencies outside of California were gathered by Judi Chamberlin at the Center for Psychiatric Rehabilitation in Boston (Chamberlin J, personal communication, 1993).

Although no diagnostic data are available for this sample, notable demographic differences were found between the members of the self-help agencies in our study and of those studied by Chamberlin. The agencies in our study served more males (72 percent versus 55 percent) and emphasized services to African Americans (64 percent versus 9 percent) and homeless persons (46 per-

cent versus 15 percent). The agencies in our study also served a higher proportion of persons with at least some college education (39 percent versus 15 percent) and a higher proportion of persons with less than an high school education (27 percent versus 15 percent).

Current information provided by leaders in the self-help movement indicates that programs with high percentages of members who are African American and other people of color are beginning to develop throughout the country (17, D'Asaro A, personal communication, 1995).

Discussions and conclusions

The self-help agencies in the San Francisco Bay Area that we surveyed, along with local community mental health agencies, serve a highly needy population with mental disorders and substance abuse diagnoses. The demographic characteristics of the population served by the self-help agencies were similar to those of mentally disabled homeless people in the San Francisco Bay Area and in other urban areas (15,18,19). The demographic data suggest that self-help agencies, in combination with community mental health agencies, can serve a poor, primarily African-American and often homeless population—subgroups that are traditionally less well served by the mental health system.

The differences between the populations served by self-help agencies and those served by community mental health agencies suggest a division of labor between the two types of agencies that has not yet been formalized or validated. Self-help agencies provide psychosocial and material assistance, while community mental health agencies provide medical and psychotherapeutic care. Evidence for this division of labor includes, first, the importance of self-referrals to self-help agencies among long-term members of such organizations, and, second, the high proportion of long-term clients receiving professional counseling primarily at local community mental health agencies who started such counseling after coming to the self-help agency. How well this division of labor works for clients remains unclear.

The comprehensive social supports, material assistance, and advocacy services required by poor, homeless, and seriously mentally disabled individuals are available in self-help agencies. Members are first attracted to self-help agencies by the material and social assistance offered, less so by counseling services. This finding is consistent with the expressed needs of homeless mentally disabled persons (20,21). Clients' use of counseling services develops with time.

Clients of self-help agencies who become staff and volunteers are in some ways better off than other long-term clients, but not so much so as to make them a separate or unique group. Although staff and volunteers are more educated and are more likely than other members to have an affective disorder, the majority of members filling these positions have neither a bachelor's degree nor an affective disorder. Staff and volunteers may be less symptomatic than other members, but they still show considerable symptoms. They are more likely than other members to have housing, but they are equally as likely to be housed precariously and to have experienced homelessness in the past five years.

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