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National Estimates for Mental Health Mutual Support Groups, Self-Help Organizations, and Consumer-Operated Services

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The authors report on a 2002 national survey of mental health mutual support groups (MSG) and self-help organizations (SHO) run by and for mental health consumers and/or family members, and consumer-operated services (COS). They found 7467 of these groups and organizations—3315 MSGs, 3019 SHOs, and 1133 COSs—greatly eclipsing the number of traditional mental health organizations (4546). MSGs reported that 41,363 people attended their last meetings. SHOs reported a total of 1,005,400 members. COSs reported serving 534,551 clients/members in 1 year. The array of services and supports provided within each of these types (MSG, SHO, COS) is reported, and implications for the President's New Freedom Commission on Mental Health recommendations are explicated.

KEY WORDS: CMHS; consumer-operated services; mental health; mutual support groups; self-help organizations.

INTRODUCTION

A shift has occurred in thinking about how to best serve adults with serious mental illnesses and children and youth with serious emotional disturbances. The most recent public policy manifestations of this change are found in the 1999 U.S. Supreme Court *Olmstead* decision (Olmstead, 1999), which legally affirmed the right of individuals with disabilities to community over institutional care; the recommendations from the President's New Freedom Commission on Mental Health (New Freedom Commission on Mental Health [NFCMH], 2003), which called for a transformation in mental health care; and the Institute of Medicine's Crossing the Quality Chasm report (Institute of Medicine [IOM], 2001), which designed a strategy to improve the quality of health care for the 21st century and is developing a blueprint for action for mental health in 2004. Reminiscent of the deinstiutionalization and

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community care movement of the late 1970's and 1980's (Turner & TenHoor, 1978), the emphasis on community-based services is not new. However, the beliefs, that recovery is possible, and that mental health consumers[1] and families must be the drivers of decisions about what they need, are new. The ultimate goal of a transformed mental health system of care, then, is to provide community-based, resiliency-building and recovery-oriented treatment and support services. The success of this transformation rests on the principle that services and treatments must be consumer and family centered, geared toward giving consumers real and meaningful choices about treatment options and providers (NHCMH, 2003, p. 5), also at the essence of the IOM's vision for the future of health care, articulated as ''person-centeredness,'' (Daniels & Adams, 2003).

Consumer- and family driven services and supports that complement those provided by mental health professionals are fundamental to bringing transformation to fruition. Some of these complementary services and supports are found within what is broadly called the ''mental health self-help sector'' and provided within a variety of venues, including, but not limited to, mental health mutual support groups, self-help organizations, and consumer-operated services. The significance of just one of these venues, mental health mutual support groups, is demonstrated through a recent national survey finding that 17.5% of people with serious mental illnesses attended a self-help group (not run by a health care professional) for a mental or emotional problem in the 12-months prior to the survey (Wang, Berglund, & Kessler, 2000). This finding, however, underestimates the full impact of the mental health self-help sector as it is only addresses one venue and is limited to adult mental health consumers.

The evolution of the mental health self-help sector is well documented (Briggs, 1996; Campbell, in press; Davidson et al., 1999; Emerick, 1996; National Mental Health Consumers' Self-Help Clearinghouse, 1999; Riessman & Carroll, 1995; U.S. Department of Health, 1999a). Although a dearth of research on the effects of self-help groups, in particular, has been cited (Kessler, Mickelson, & Zhao, 1997), there is a growing body of literature on outcomes associated with participation in mutual support groups, self-help organizations, and consumer-operated services (Davidson et al., 1999; Hall, Graf, Fitzpatrick, Lane, & Birkel, 2003; Kyrouz & Humphreys, 1997; Solomon & Draine, 2001; Sommers, Campbell, & Ritttenhouse, 1999) and some descriptive studies on their characteristics and the characteristics of the people using them (Briggs, 1996; Chamberlin, Rogers, & Ellison, 1996; Emerick, 1989; Friesen, 1991; Hall et al., 2003; Kaufmann, Schulberg, & Schooler, 1994; Segal, Silverman, & Temkin, 1995; Segal, Hardiman, & Hodges, 2002; Trainor, Shepherd, Boydell, Leff, & Crawford, 1997; VanTosh & del Vecchio, 2000). Models for classifying mental health self-help services and supports also exist for both consumer (Emerick, 1989; Mowbray & Moxley, 1997; Trainor et al., 1997) and family groups and organizations (Briggs & Koroloff, 1995; Davidson et al., 1999; Freisen, 1991; Koroloff & Briggs, 1996).

However, there are significant methodological challenges in conducting research in the mental health self-help arena (Davidson et al., 1999; Humphreys & Rappaport, 1994; Levy, 1984; Lieberman & Snowden, 1993; Powell, 1994; Riessman & Carroll, 1995) and consequent gaps in the knowledge base. Many of the studies referenced above have limited generalizability due to their small sample size and/or variability in definitions. Although it was estimated that there are approximately 500,000 self-help groups in America in (Katz & Bender, 1976) and more than 700 distinct national and international groups (Madara, 1999), the number of mental health self-help groups is unknown. There have been numerous national surveys of the use of mental health mutual support groups by adults with serious mental illnesses (Kessler et al., 1997; Narrow, Regier, Rae, Manderscheid, & Locke, 1993; Regier et al., 1993; Snowden & Lieberman, 1993; Wang et al., 2000), yet only one focusing on the groups, rather than individual mental health consumers, as the unit of analysis (Emerick, 1989). This was a 1987–1988 national study of 104 mental health mutual support groups composed of and run exclusively by consumers. From this study, described by the author as exploratory, it was estimated that there were 1000 such groups nationwide.

The goal of the survey reported here was to close some of these gaps in knowledge by developing a standardized methodology in order to produce the first empirically based national estimates of the number of mental health mutual support groups,

[1]Although persons who use or have used mental health services refer to themselves in various terms (e.g., mental health consumer, psychiatric survivor, ex-patient, client, and recipient), for consistency throughout this paper, the term ''consumer'' will be used.

self-help organizations, and consumer-operated services run by and for consumers and/or family members of adults with serious mental illnesses and/or families of children and youth with serious emotional disturbances. The survey was designed to describe their organizational characteristics, including the services and supports provided within them.

METHODS

The data reported here are from the 2002 Survey of Organized Consumer Self-Help Entities (subsequently referred to as the CMHS Survey), a national survey conducted by the Survey and Analysis Branch, Center for Mental Health Services, Substance Abuse and Mental Health Administration (SAMHSA), as part of its National Reporting Program (NRP). The NRP is congressionally authorized to provide descriptive information and policy analyses about the state of and trends in the delivery of services to mental health consumers and families.

This was the NRP's first national survey of the mental health self-help sector. In line with the NRP commitment to including consumers and families in each stage of the survey research process—conceptualization, implementation, analysis, and reporting—more than 30 self-identified consumers and family members were employed as consultants for the present survey to collaborate in the development of the survey methodology, design and review survey instruments, conduct the pretest, develop the universe, train telephone interviewers, and carry out data analysis. Data were collected under contract to CMHS by TNS, Horsham, Pennsylvania, which subcontracted to the National Mental Health Consumers' Self-Help Clearinghouse, Philadelphia, PA, and Jean Campbell, Ph.D., Missouri Institute of Mental Health, University of Missouri, St. Louis, MO.

Survey Definitions

The diversity among groups, organizations and services in the mental health self-help arena, the fact that they really exist on a continuum with amorphous boundaries rather than represent mutually exclusive types, the evolution of older types and the rapid creation of new types create huge challenges to researchers seeking to conduct empirical studies at the organizational level of analysis. For the CMHS Survey it was first necessary to define the mental health self-help sector universe.

The initial step in the development of the universe was to determine the scope of organizational entities to be included. Determinations had to be made about:

- whether to include entities that had any involvement of professional mental health providers;
- whether to include entities addressing substance use disorders;
- whether to focus solely on entities serving primary consumers or to also include entities serving family members;
- whether to include entities serving only adult mental health consumers or to also include entities that addressed the needs of children and adolescents;
- whether to include entities addressing any mental health condition, problem, or life situation, or to narrow the focus to include entities addressing a more limited range of mental health problems.

For the CMHS survey, these decisions were made in an iterative process by which consensus was reached among consultants, and were further dependent on the level of resources available for the survey, as well as previous research. Based upon these considerations, then, the following inclusion and exclusion criteria were established:

- Entities organized and led by psychiatrists, therapists, religious and spiritual leaders were excluded unless these people participated as peers and not in their professional roles, and,
- Based upon the above, entities associated with lodges and clubhouses were excluded;
- Entities that addressed only mental health or both mental health and substance use (co-occurring) conditions, problems, or life situations were included. Those that addressed substance use without addressing mental health conditions were excluded;
- Entities run by and for mental health consumers and/or their families were included;
- Entities addressing the needs of both adult mental health consumers and families of children and adolescents with serious emotional disturbances were included;
- Entities addressing life crises such as bereavement, transitions, victimization, family problems (Riessman & Carroll, 1995), and

addictions, anger management, developmental disabilities, and Alzheimer's disease were excluded.

In the most general sense, it is helpful to think of the universe as the groups, organizations, and services most likely to have as participants the 5.4% of adults with serious mental illnesses (U.S. Department of Health and Human Services, 1999b), their families, and the families of the 9–13% of children and youth with serious emotional disturbances (U.S. Department of Health and Human Services, 1998).

Meaningful classification of the entities within the universe was also fraught with difficulties; however, there is relative consistency in the literature about the existence of and definitions for a number of types—mutual support groups, self-help organizations, and consumer-operated services. For the purpose of the initial analysis in this paper, we selected these three types and operationally defined them in the broadest sense possible. Groups, organizations, and services were included in the universe if the people within them, and/or their family members, self-identified as having received mental health services and met the operational definitions below.

Since mental health mutual support groups historically laid the foundation for the evolution of other types (Mowbray & Moxley, 1997), these were defined first, as follows.

> *Mental Health Mutual Support Group*. A group of people who get together regularly on the basis of a common experience or goal to help or support one another. Membership in a group must be voluntary and free. Groups organized and led by psychiatrists and therapists do not qualify unless these people are there as group members and not in their professional roles. The primary purpose of the group is to attend mutual support group meetings.

Mental health self-help organizations, which often evolved from coalitions of local mutual support groups into a single network, sometimes called advocacy organizations (Koroloff & Briggs, 1996; Watkins & Callicut, 1997), were operationally defined as follows:

> *Mental Health Self-help Organization*. An organization run by and for consumers and/or family members, which undertakes activities to educate them or their community about mental health issues and/or engages in or undertakes political or legal advocacy and/or provides services to consumers or family members. Some mental health self-help organizations sponsor and/or support mutual support groups.

Consumer-operated services, which have been variously called user-run or client-run programs (Chamberlin et al., 1996) or consumer run alternatives (Mowbray & Moxley, 1997), were operationally defined as follows:

> *Mental Health Consumer-Operated Service*. These are programs, businesses, or services controlled and operated by people who have received mental health services. With limited exceptions, staff also consists of people who have received mental health services.

Survey Procedures

The CMHS Survey was carried out in three phases: universe frame development, telephone screening, and a telephone survey.

Frame Development. Because the number of groups, organizations, and services was unknown, but known to be too large to conduct a national census, a limited set of geographical areas was chosen. These geographical areas were the same as those covered by the National Comorbidity Survey and consisted of 172 counties in 34 States, selected by the Survey Research Center at the University of Michigan with probability proportional to size (Kessler, 1994). Each of these counties was scoured for all potentially relevant groups, organizations, and services using key informants, existing lists from self-help clearinghouses, local public and private mental health agencies, hospitals, social service agencies, United Ways, and mental health associations, and new lists developed through Internet searches, local newspapers, and libraries. Snowball sampling (asking each contact for referrals to other groups, organizations and services) was conducted. Contact information was obtained for 6496 groups, organizations, and services. The first of several attempts to remove duplicates, out-of-scope, and nonexistent entities was undertaken, leaving a total of 3403 eligible for telephone screening.

Telephone Screening. Of the 3403 groups, organizations, and services, 2128 were screened by

telephone. [Among the 1275 that were not screened, approximately 13.2% (n=168) were refusals. The majority of those remaining (77.8%) could not be contacted after up to 20 attempts for such reasons as no answers, answering machines, and busy signals.] During screening, snowballing was again conducted. After screening, 376 were found to be duplicates. Based upon a specific set of criteria, each of the remaining 1752 was classified as either a mental health mutual support group, self-help organization, or consumer-operated service; however, 431 did not fit the eligibility criteria for the main interview and were removed from consideration. It was finally determined that 1321 respondent entities were eligible for the main interview.

Main Telephone Interview. Each of the 1321 in-scope respondent entities received a letter explaining the purpose of the survey prior to telephone contact. The letter also contained a toll-free telephone number for respondents to call at any time, including nights and weekends, to conduct the interview. Computer-assisted telephone interviews were conducted using a slightly different version for mental health mutual support groups, self-help organizations, and consumer-operated services. (The structured interview instrument was constructed by adapting Maton's work (1993) which identified variables for self-help group level analyses. Data were collected on over 120 variables, including but not limited to, questions about the history of the group, organization or service, its governance, funding sources, demographic characteristics of participants, and activities undertaken.) Of the 1321 identified as in-scope, 954 main interviews were completed and 367 either could not be re-contacted or refused to take part in the main interview. Of the 954 completed interviews, 27 were found to be duplicates, resulting in a final sample of 927, consisting of 390 mental health mutual support groups, 413 mental health self-help organizations, and 124 consumer-operated services.

Weighting. Following cleaning and review of the final data, a non-response weight was calculated by region (Northeast, South, Mid-West, West) and type (mutual support group, self-help organization, consumer-operated service) to produce estimated totals for the 172 counties sampled. Sampled counties were then combined into geographic clusters (Primary Sampling Units) and weighted to represent the entire United States using stage one weights originally developed for the National Comorbidity Survey.

RESULTS

Number of Groups, Organizations, and Services

It is estimated that in September, 2002, there were 7467 groups, organizations, and services run by and for mental health consumers and/or families in the United States. Of these, 3315 (44.4%) classify themselves as *mental health mutual support groups*, 3019 (40.4%) as *mental health self-help organizations*, and 1133 (15.2%) as *consumer-operated services*. In comparison, NRP data for 2000 (U.S. Department of Health and Human Services, 2004, p. 245) demonstrated that there were 4546 traditional mental health organizations in the U.S. (State and county mental hospitals, private psychiatric hospitals, non-Federal general hospitals with separate psychiatric units, Veterans Administration medical centers, multiservice mental health organizations, outpatient clinics, and residential treatment centers for children with emotional disturbances).

Volume of Participation in Groups, Organizations, and Services

In order to measure the volume of participation in groups, organizations, and services and not burden respondents with having to institute a special count for CMHS Survey purposes, a different question was asked of each of the three types. It is important to note when interpreting these findings that any one individual could participate in each of the three types of groups, organizations, and services multiple times, so that the numbers cannot simply be added together to get national totals.

Mental health mutual support groups were asked, ''How many people attended your last support group meeting?'' Ninety-three percent (93%) of them responded. The imputed total, corrected for non-response, is that 41,363 people attended, with a mean of 12 attendees per group meeting. The median length of time in existence for mental health mutual support groups is 10 years.

Mental health self-help organizations were asked, ''How many people belong to your organization?'' Ninety-one percent (91%) of them responded. The imputed total, corrected for non-response, is that 1,005,400 people belong to their organizations, with a mean of 319 people per organization. The median length of time in existence for mental health self-help organizations is 16 years.

Consumer-operated services were asked, ''Approximately how many clients or members do you have, however you keep count?'' Findings here must be interpreted very cautiously. Each consumer-operated service chose only one method of count (day, week, month, year, or total); therefore, while each consumer-operated service is counted only once, any one person can be a member of and make numerous visits to multiple services and, any 1 day, week, or month might not be representative. Given these caveats, in the eighty-seven percent (87%) of consumer-operated services reporting, the imputed total of clients/members in the survey year, corrected for non-response, is 534,551. The median length of time in existence for consumer-operated services is 9 years.

Linkages to Traditional Mental Health System

Considerable literature exists addressing the relationship between self-help groups and mental health professionals (Emerick, 1990; Gartner, 1997; Lotery & Jacobs, 1994; Stewart, Banks, Crossman, & Poel, 1994; Watkins & Callicut, 1997). Despite the fact that many mental health mutual support groups, self-help organizations, and consumer-operated services historically arose as alternatives to traditional mental health services, the CMHS Survey demonstrates their evolution into partners with the traditional system. Fewer than 1% report that participants view the activities of their groups, organizations, and services as substituting for services received from mental health professionals. Further, 94% report that they get referrals from psychiatrists, therapists, hospitals or mental health agencies. These findings are consistent with findings from a survey of psychologists (Norcoss, 2000) that found 82% recommended self-help groups to their psychotherapy clients and from another (Kessler et al., 1997) that 76% of people who use self-help groups for emotional problems also see a professional for the same problems.

Supports and Services Provided in Groups, Organizations, and Services

Table 1 presents the proportion of mental health mutual support groups, self-help organizations and consumer-operated services providing a wide range of specific services and supports. In addition to face-to-face meetings, over one-half of *mutual support groups* report that they distribute information produced by others (76%); provide

Table 1. Proportion of Groups, Organizations, and Services Providing Specified Services and Supports, by Service and Support, and by Type of Group, Organization, and Service

	Total	Mutual support groups	Self help organizations	Consumer-operated services
Operates a drop-in center	34%	0%	24%	63%
Face-to-face mentoring/buddy system (in addition to mutual support)	38	25	43	60
Telephone support	68	61	76	71
Social/recreational opportunities	69	58	76	79
Arts activities	35	17	42	74
Spiritual/faith based activities	12	9	15	14
Outreach to members	40	29	46	59
Babysitting or child care	7	3	13	0
Respite care	8	5	12	7
Listserv/website	40	29	50	46
Helps people get jobs	21	5	31	39
Formal training/classes (not job related)	48	22	63	81
Helps people with housing difficulties	34	12	48	58
Write/produces written information	61	42	76	73
Distributes others information	78	76	86	66
Public and community education	66	44	84	81
Advocacy/rights protection	57	33	76	76
Helps people get services they want or to which they are entitled	49	34	63	51
Research activities	39	26	50	47

telephone support such as a hotline, warm line, or information and referral line (61%); and provide opportunities to participate in social/recreational activities (58%). Approximately three-quarters (76%) of *self-help organizations* provide telephone support, social/recreational opportunities, write or produce material or information, and engage in advocacy or rights protection; their most frequently cited services are distributing material or information written or produced by others (86%) and public and community education and other outreach to non-members (84%). Approximately three-quarters of *consumer-operated services* provide social/recreational opportunities (79%), and advocacy or rights protection (76%). About four-fifths (81%) of consumer-operated services provide training or classes in areas that are not job related, as well as public and community education and other outreach activities.

Despite their similarities in some areas, such as providing social/recreational opportunities, public and community education and outreach, advocacy or rights protections and producing material, mental health self-help organizations and consumer-operated services differ in other respects. By way of comparison, *consumer-operated services* are much more likely than self-help organizations to operate drop-in centers (63% of consumer-operated services compared with 24% of self-help organizations), provide face-to-face mentoring or buddy systems in addition to mutual support (60% compared with 43%), engage in creative or performing arts activities (74% compared with 42%), and provide training in areas that are not job related (81% compared with 63%). *Self-help organizations* are much more likely than consumer-operated services to distribute material produced by others (86% of self-help organizations compared with 66% of consumer-operated services).

Relevancy of Findings to the Recommendations of the President's New Freedom Commission on Mental Health (NFCMH) and other National Efforts

A number of the findings from the CMHS Survey have particular relevance to recent recommendations put forth at the national level and highlight the role currently played by the mental health self-help sector in achieving them.

The NFCMH report (2003, p. 29) states that the array of community-based options must be expanded. Table 1 demonstrates the breadth of existing services and supports provided through the mental health self-help sector. According to the NFCMH (2003, p. 16), not knowing where or how to get care is one of the six reasons people face barriers to recovery. Mental health mutual support groups, self-help organizations, and consumer-operated services can help to overcome this barrier by providing central locations (''one stop shops'') where people can learn about the array of community-based services and supports.

Public and community education, particularly as it relates to reducing and eliminating stigma and discrimination, and rights protection are of particular concern to the NFCMH. The report recommended the advancement and implementation of a national campaign to reduce the stigma of seeking care. As CMHS moves forward with its national campaign to reduce stigma and discrimination through the Self-determination Initiative and its Resource Center to Address Discrimination and Stigma (ADS) and the Elimination of Barriers Initiative, the CMHS Survey data demonstrate that efforts to reduce stigma and discrimination already constitute a role played by a large proportion of the groups, organizations and services that make up the mental health self-help sector. More than four out of five mental health self-help organizations (84%) and consumer-operated services (81%) currently engage in public and community education or other outreach to people who are not members. In fact, these stigma-reducing activities are among the most frequently cited activities of these organizations and services.

The NFCMH strongly endorses protecting and enhancing the rights of people with serious mental illnesses and children with serious emotional disturbances (NFCMH, 2003, p. 45). The CMHS Survey data demonstrate that slightly more than three-quarters (76%) of self-help organizations and consumer-operated services report engaging in advocacy or rights protection. More than two-thirds of the mental health self-help organizations (63%) and one-half of the consumer-operated services (51%) report that they provide help to people in obtaining the services they want or to which they are entitled.

Other areas of concern raised by the NFCMH, and critical to the SAMHSA mission, are the importance of jobs, housing, and social relationships for recovery. The report (NFCMH, 2003, p. 29) cites as ''alarming'' the low rate of employment for adults

with mental illnesses and states that consumers need employment and income supports. According to the CMHS Survey, approximately one-third of mental health self-help organizations (31%) and consumer-operated services (39%) report that they currently provide help to people to obtain jobs. In the housing arena, the report acknowledges a shortage of affordable housing and recommends making housing with supports widely available (NFCMH, 2003, p. 42). The CMHS Survey found that nearly one-half of mental health self-help organizations (48%) and more than one-half of consumer-operated services (58%) report helping people face these and other housing difficulties. Further, social and recreational opportunities are reported in nearly 70% of all groups, organizations, and services in the mental health self-help sector.

Limitations

Before discussing the implications of these findings, several caveats need to be identified. First, the CMHS Survey likely provides an *underestimate* of the true number of groups, organizations, and services, particularly mutual support groups. For example: there were groups that did not want to be found; there were frequent changes in leadership of some mutual support groups, resulting in changes in phone numbers lost to searchers; some respondents involved in leadership positions with multiple groups and organizations had difficulty responding for each one separately; and it is not clear whether all of the mutual support groups subsumed under self-help organizations and consumer-operated services were surveyed. Second, although the Internet and the increased availability of self-help clearinghouses and their listings (Madara, 1990, 1997; Rogers, 1996) helped move us beyond many earlier problems associated with producing national estimates, the issue of duplication in the universe was formidable, as described in the methods section above. Third, while this survey provides estimates of the volume of participation in groups, organizations, and services, the numerous caveats associated these estimates must be considered, as discussed in detail in the results section above. Fourth, for the purposes of this paper, the authors classified all entities into three loosely defined types, and respondent groups classified themselves into one of the three types. As noted earlier, a limitation of research in this area is the difficulty in defining mutually exclusive types. However, because of the large number of variables and the level of detail in the CMHS Survey dataset, future researchers have the option of creating classification schemes of their choosing, or analyzing the dataset without categorization. Currently, for example, analyses are being conducted by operationally defining consumer-operated services as those with a board composed of greater than 50% consumers, regardless of the type into which they self-classified. Fifth, since this was the first time these data have been collected and analyzed, they only represent a baseline from which to look at future trends. Although it may be tempting to compare the CMHS Survey findings with studies reported elsewhere, the reader is cautioned to make certain that the definitions and types of groups included are comparable. For example, some surveys of mental health mutual support groups include the very large number of groups that primarily exist to address substance use issues, like Alcoholics Anonymous, and/or groups for people with dementia, excluded from the CMHS Survey. Sixth, limited resources forced difficult decisions about how to define the groups, organizations, and services to be included in the survey. The CMHS Survey only examined a few of the venues that make up the mental health self-help sector, and therefore significantly underestimates the total impact of consumers and families in providing services and supports. The CMHS Survey did not account for the growing role of individual mental health consumers employed as providers in a range of settings within the traditional mental health and social services delivery systems (Mowbray, Moxley, Jasper, & Howell, 1997), variously called peer mentors or bridgers (Knight, 1997), peer specialists, and peer educators. Nor does it capture the role of the Internet in providing support (Madara, 1997). Finally, the exclusion of groups, organizations, and services run by religious and spiritual leaders, sometimes referred to as self-help, and particularly important to African American, Native American, Latino, and other ethnic and cultural groups, points to work that needs to be done to refine definitions of ''mental health self-help'' and develop even better typologies for future research.

CONCLUSIONS

The mental health ''self-help revolution'' (Gartner & Riessman, 1984; Norcross, 2000) has taken root. Mental health self-help has evolved from

its de facto status into the mainstream of the mental health service delivery system. Mutual support groups and consumer-operated services, once viewed as alternatives to formal mental health services, have entered into a phase of partnership and collaboration (Davidson et al., 1999).

The mental health service delivery system has been reconceptualized to accommodate the vision of mental health consumers and families in control of their own care, deemed essential in a quality health care delivery system (IOM, 2001). A transformed system will provide a range of community-based, resiliency- and recovery-oriented treatment and supports that go beyond what was traditionally provided through hospitalization, medication, and rehabilitation. It is recognized that recovery is possible and that, in addition to traditional mental health services, a home, a job, and meaningful social relationships are critical. Mental health self-help services and supports are key to realizing this vision, as they provide other real and meaningful choices in the array of treatment options and providers, upon which the success of transformation rests.

Mental health self-help, which began as an alternative to services in the mental health system, is now rapidly evolving into new forms and into an expanding variety of venues. Further evidence of the revolution is that the language is changing to reflect changes in our thinking and practice. The very terms ''mental health service delivery system'' and, more specifically, ''mental health self-help,'' no longer capture the totality of the way mental health care is provided. Since we expect the softening of distinctions between mental health care and general health care and their further integration (Surgeon General Report on Healthcare and Primary Care, 2001), we may, in the future, be discussing a transformed ''health services and supports system.''

The importance of mental health self-help is heightened by current realities. Only one of two people with a serious mental illness seeks treatment (NFCMH, 2003, p. 19). Contemporary trends point to increasingly limited resources in the public mental health sector, ''unfair treatment limitations and financial requirements placed on mental health benefits in private health insurance'' (NFCMH, 2003, p. 1), the declining role of extended families and neighborhoods to provide social support and practical information (Madara, 1999), and the desire of many Americans to be actively engaged in decisions about their own health care. There are ''severe shortages of practitioners in the mental health workforce'' (NFCMH, 2003, p. 75), particularly in the public sector, and much of the workforce lacks the education and training to provide services and supports within a consumer- and family driven recovery framework. It is evident, then, that the mental health self-help sector will continue to play a role in filling gaps in the present system of care, helping consumers and families receive what they need from existing services, providing some of what might be considered traditional mental health services (Chamberlin et al., 1996), preventing additional mental health and other problems, and promoting recovery.

Nationally, there is discussion regarding the incorporation of self-help groups into the continuum of care through managed care (Meissen, Wituk, Warren, & Shepherd, 2000; Rogers, 1996), and the development of uniform training and certification of peer providers (Campbell & Leaver, 2003). Emerging new practices in peer support have been documented, including innovative consumer-developed and implemented training programs for recovery and peer support, and creative approaches to financing, such as the approval from the Centers for Medicaid and Medicare Services to offer peer supports as a billable service in Georgia for Medicaid mental health services (Campbell & Leaver, 2003; Sabin & Daniels, 2003). At the Federal level, the CMHS Self-Determination Initiative and new Statewide Family Network and Statewide Consumer Network grants represent continuing efforts toward moving family and consumer services and supports further into the mainstream. States, through their State mental health agencies, continue to fund consumer and family initiatives.

With this recent widespread promotion of consumer- and family driven services, particularly prominent in the NFCMH and IOM reports, comes the recognition of the responsibility to empirically describe mental health self-help services and supports. This is necessary in order to move the successful services and supports from anecdotal evidence to emerging or promising practices, and eventually into the best or evidence-based practices meant to form the basis of a transformed ''mental health services and supports system.'' The CMHS Survey of Organized Consumer Self-Help Entities represents a step in this direction by providing a snapshot of the number and use, and a description of the services and supports provided in several segments of the mental health self-help sector. The CMHS survey data demonstrate that many of these

groups, organizations, and services possess the infrastructure required to provide a vast array of free services and supports to mental health consumers and families.

The CMHS Survey findings have implications for mental health consumers and families, researchers, and policy makers. For consumers and families, the data systematically document what they have been saying for a long time, that the mental health self-help sector provides a depth and breadth of critical services and supports, in an atmosphere of mutual support and respect, where they can focus on recovery and resilience unencumbered by stigma and discrimination. The importance of the consumer and family ''workforce'' operating within the mental health self-help sector as ''frontline-staff'' has been acknowledged (Morris & Stuart, 2002). Their presence as providers of services and supports serves to alleviate mental health professional staff shortages. Over time it is expected that they will be increasingly involved in curriculum design and education and training critical to the transformation in mental health (Morris & Stuart, 2002).

For researchers, the CMHS Survey provides insights that can lead to the improvement of methodologies required to undertake further mental health self-help research. It provides benchmark data useful in the design of future studies that have the potential to move consumer-operated services, for example, from promising to best practices. It has produced a data set with greater than 120 variables from which to generate further analyses.

For policy makers seeking to implement the recommendations of the NFCMH, data from this survey describe some of the services and supports fundamental to the transformation of care, both at the societal level, with regard to stigma and discrimination, and at the personal level, with regard to jobs, housing and meaningful social relationships. At the Federal level, these data will enable us to objectively measure national trends over time as we seek to implement the transformation called for by the NFCMH.

It is no longer worthwhile to consider whether what we now call the mental health self-help sector is part of the mental health delivery system and should be included in national, State and local surveys, but only how to overcome the methodological obstacles so that it can be included. The CMHS Survey has surmounted many of the challenges, produced benchmark data, and provided a rich database for the entire mental health field.

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