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SELF-HELP GROUPS AND MANAGED CARE: OBSTACLES AND OPPORTUNITIES*†

GREG MEISSEN, PH.D.

SCOTT WITUK, M.A.

MARY L. WARREN, M.A.

MATTHEW D. SHEPHERD, PH.D.

Self-Help Network of Kansas, Wichita State University

ABSTRACT

Managed health care has changed the way health care services are provided in the United States. Although there are several obstacles between self-help groups and managed health care, it appears there is an opportunity for self-help groups to become incorporated into the continuum of health care through managed care. A two-year project was designed to more fully include self-help groups in the health care system. Several insights regarding how to incorporate self-help groups were provided by health care representatives, including 1) broadening health care providers' understanding of self-help groups, 2) researching and documenting the benefits of self-help groups, 3) promoting self-help groups, and 4) carefully selecting points of entry in the health care system. Representatives' insights are described and discussed within the context of this initiative.

In their widely read article, "Psychology and self-help groups: Predictions on a partnership," Jacobs and Goodman (1989) predicted that self-help groups would "flourish under corporately controlled health care" and strongly encouraged

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professionals to engage in research, training and action related to self-help groups. Since Jacobs and Goodman's predictions managed care has become the dominant corporate model of health care delivery in the United States. More specifically, it is estimated that over 90 percent of those privately insured in the United States will receive health care services through a managed care structure early in the twenty-first century (Stapleton, 1997). While Goodman and Jacobs predictions regarding changes in the formal health care system have, for the most part, come true, the self-help movement remains largely unchanged in that it has preserved its autonomy and grassroots nature, but unfortunately is still underutilized by providers and those they serve. With this in mind, the purposes of this article are to explore potential obstacles and opportunities and discuss our experiences with implementing a project to include self-help groups in the continuum of Kansas managed health care.

OBSTACLES

A common concern among self-help researchers and advocates is that health care professionals, particularly those operating in a managed care system, may inadvertently and negatively impact self-help groups (e.g., Borkman, 1990; Jacobs & Goodman, 1989; Meissen & Warren, 1993; Penney, 1997). They cautioned that health care companies may overwhelm self-help groups with referrals, reduce the intimacy of the groups through increased size and turnover, increase conflict in established groups, and "dump" clients and patients inappropriately into groups without providing needed professional care. There is concern that managed care will increase professional "encroachment" in member run self-help groups and will precipitate the creation of more professionally run "support groups" (Jacobs & Goodman, 1989; Penney, 1997; Schubert & Borkman, 1991). Other concerns revolve around the unique nature and culture of self-help groups (i.e., voluntary, on-going, peer-led) that appear to be in direct contrast to the incentives of health care companies that are used to moving fast, acquiring new services if deemed necessary or requested by their corporate clients, especially if they are thought to be cost-efficient (Penney, 1997). Managed care organizations are likely to have little regard for the traditions and ideologies established by self-help groups, as their primary concerns are providing institutionalized health services at lower costs.

OPPORTUNITIES

Any discussion of the potential opportunities between the formal health care system and self-help groups requires a brief review of the historical context of this relationship or what might better be described as a non-relationship. For decades insurance companies paid providers under a fee for service model based on the treatment of acute illnesses (Fox, 1996). Insurance would pay a fee for the treatment the provider considered appropriate for as many visits as the provider

thought prudent. Referrals to specialists were routine and they were also paid a fee for their service. A cautious "test and treat if in doubt" approach was not only medically and legally prudent but was also financially lucrative. Coupled with an emphasis that for every health problem there was a discrete cure and a biomedical model that gave little support to the notion of nonprofessional forms of care, this highly professionalized approach did not encourage the use of self-care practices and self-help groups which were not see as an effective "cure." Further, a patient who opted for a self-help group over professional services might become a revenue loss.

QUALITY HEALTH CARE AT LOWER COSTS

Managed health care has changed the way dollars are distributed for services provided. Managed health care outlines an array of services for a group of people for a prearranged total dollar amount. This "capitation" approach has reoriented medicine to a general practice or primary care focus using specialists and special procedures only when the primary care physician judges specialized treatment is needed and the managed care company pre-approves that treatment. If services provided to that group of individuals cost less than the prearranged contract, the remaining dollars are "profit" to be shared by the managed care company and the providers. If the costs exceed the prearranged contract there is a potential for loss, sometimes called "shared risk." Since delivery of all necessary services to everyone identified in the contract is required, managed care companies have developed many strategies to provide quality health care at lower costs. The development of large and complex health care systems, which at times includes the managed care organization itself, have emerged to provide virtually all services from birthing centers to hospice care. Similarly, one of the primary strengths of self-help groups is that they are available for nearly every concern and there is no charge to attend.

SATISFACTION WITH CARE

The concept of managed care has been controversial from the beginning, and considerable public and political pressure has mounted in response to dissatisfied patients and providers. In May of 1996 the Health Resources and Services Administration (HRSA) established the Center for Managed Care. The mission of the Center is to assure that undeserved and vulnerable populations served through the HRSA's programs are knowledgeable and active within the managed care system. As the easily predicted stories of victims of this system begin to appear regularly, managed care organizations have intensified their efforts to increase customer satisfaction at the corporate and individual level. The creation of the President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry is charged, in part, with examining and making recommendations to reduce such incidents. The National Committee on Quality Assurance (NCQA)

now accredits HMOs, a credential important to corporate clients as they review the yearly bids for group health care plans from rival managed care companies. The NCQA accreditation procedures include criteria on patient satisfaction and patient assessments of quality of care. Consequently, managed care companies are increasingly becoming more sensitive to consumer and provider concerns because they can influence their ability to secure health care contracts, especially those from large corporations. These factors contribute to an environment in which referral to self-help groups could be viewed as a useful, cost-effective service of managed care organizations that have the potential to increase consumer satisfaction.

PREVIOUS RESEARCH WITH SELF-HELP GROUPS

In addition to the system level changes in the health care system, previous research that we have conducted with self-help groups indicates a possibility for greater utilization of self-help groups in the health care system. In a previous needs assessment of a representative sample of groups in Kansas, we found that recruiting and keeping new members, getting members to attend meetings regularly and share the work of the group, and lack of public awareness were considered the most important problems faced by self-help groups (Meissen, Gleason, & Embree, 1991). In a comparison of over 200 active and 100 disbanded groups, similar factors contributing to the survival of self-help groups were also found (Wituk, Shepherd, Warren, & Meissen, 1999). In focus groups with self-help group leaders and members, response was very positive to the idea that health care providers would routinely encourage their clients and patients to attend group meetings. Participants reported not being concerned about having too many members when asked about the possibility of a substantial increase in the number of referrals to their groups from managed care. At the same time, participants were concerned about inappropriate referrals, most notably persons without the core issue of the group or individuals who were so acutely ill that they could not adequately participate in the group and/or be a disruption.

Another long-term issue among self-help researchers has been the differences between self-help and support groups. Although many convincingly argue that professionally led support groups have an essentially different approach than peer-led self-help groups that results in different types of therapeutic settings (Schubert & Borkman, 1991; Toro, 1990), it is not surprising that most health care organizations do not distinguish between the two. After operating a statewide self-help group clearinghouse for over a decade our own experiences indicate that most people seeking groups have little concern about the extent of professional involvement that exists in group meetings. We also have found that professional involvement is really more of a continuum than an easily determined distinction and that the majority of groups have some type of professional involvement (Shepherd et al., 1999).

LESSONS LEARNED FROM A PROJECT TO INCORPORATE GROUPS INTO THE HEALTH CARE SYSTEM

Taking into account these obstacles and opportunities, expanding the interconnections between self-help groups and the health care system would have the potential to increase membership in self-help groups, provide another "service" for managed care companies, and most importantly improve patient outcomes, quality of life, and satisfaction (Kyrouz & Humphreys, 1999; Meissen, Gleason, & Embree, 1991). Recognizing this potential, the Self-Help Network of Kansas mounted a two-year project with the goal of increasing access to groups through health care and managed care organizations. This two-year project included a variety of techniques to increase access to groups, including 1) a statewide roundtable with all the major managed care organizations, who were represented primarily by medical directors, provider service coordinators, and health care consultants; 2) presentations at family physician and other provider conferences to classes in medical nursing schools; and 3) articles in hospital newsletters. In addition, we developed relationships with key individuals in the health care system through a "snowballing" technique of contacting individuals who were referred to us by our existing board members and roundtable participants. Despite these efforts, only two health care organizations made even modest efforts to include self-help groups more routinely in their services, by allowing presentations to their staff and purchasing directories of self-help groups. None of the health care organizations changed recommended procedures or made system-level interventions that would have incorporated self-help groups into their services. For example, one roundtable participant stated he thought self-help groups were a terrific idea, especially with a lack of health care dollars, but that incorporation into the larger health care system would take additional time, resources and most of all persistence and patience. The lasting impact we did have was through building relationships with a number of individual providers. Our conversations and interactions with health care professionals did reveal several key insights for future efforts, including the following.

1. Broaden Health Care Providers' Understanding of Self-Help Groups

Previous research indicates that health care professionals recognize only those groups that are most widely known such as Alcoholics Anonymous or groups related to their speciality (Fridinger, Goodwin, & Chng, 1992). We also found that providers and administers knew little to nothing about the hundreds of groups available throughout the state or that thousands of people utilized self-help groups. In fact, they were quite surprised so many groups existed for their patients. Some thought their organization was already working to include self-help groups in their services as their nurses or social workers had identified or developed a handful of groups for their patients (e.g., cancer, diabetes), but after a brief introduction to the

Self-Help Network they realized that their knowledge and utilization of self-help groups was quite limited.

2. Continue to Research and Document the Benefits of Self-Help Groups

Related to increasing health care providers knowledge of self-help groups is the need to conduct research that enhances the credibility of self-help and support groups. Several lines of research could help in increasing health care providers appreciation of self-help groups.

Group Member Satisfaction and Perception of Effectiveness

The self-help research community has not recently undertaken this type of research for two major reasons. First, despite the unique methodological problems inherent in self-help group research (Powell, 1994), there is a strong encouragement for researchers to "move forward" to methodologically rigorous studies to determine effectiveness. Second, the research done on member satisfaction and perception of effectiveness, coupled with anecdotal information, convinced most self-help researchers and advocates that the routinely positive findings were likely to persist. Based on our conversations with health care representatives, we believe that if providers knew and understood this previous research it would likely increase the credibility and referrals to self-help and support groups. In fact, because they are unaware of this research, their first inclination is to worry that patients will have negative experiences in self-help groups. We also believe that health care organizations would be interested in assessing satisfaction with group experiences as part of overall satisfaction of services the managed care organization provides.

Outcome and Cost-Effectiveness Research

The outcome studies abstracted by Kyrouz and Humphreys (1999) provide a base of research that will allow the health care system to respond with data to providers who express concerns about the effectiveness of self-help and support groups. Although there are methodological limitations to some of the studies conducted with self-help groups, there is a growing body of literature that demonstrates the effectiveness of many self-help groups, including Alcoholics Anonymous, Parents Anonymous, Adult Children of Alcoholics, and GROW. In a study of substance abuse-related health care costs, Humphreys and Moos (1996) found that people who attended AA had health care costs that were about half of those who received outpatient treatment. Taken as a whole, these studies suggest that self-help groups provide low-cost, effective support that can be useful to people dealing with a wide range of issues. At the same time, more well designed outcome studies, particularly cost-benefit research, is needed to further and strengthen this

emerging set of self-help group outcome studies. Dissemination of these outcome studies warrants attention, as health care providers frequently learn about new services through attractive pamphlets and fact sheets, rather than lengthy research articles in academic journals.

Access to Self-Help Groups

One of the most neglected areas of research related to self-help groups involves how individuals initially gain access to a group, and how a subset of those individuals become active members. Findings from such research could lead to further action to increase participation for those who wish to become involved in groups, help groups understand how to engage new members, and promote the utilization among people who might not initially think of a self-help group for their concern. Most managed care companies have some level of "clinical pathway" documentation in place because it is important for them to know where patients and dollars flow through complicated health care systems. Including self-help groups in clinical path documentation would be helpful. This type of research could also positively address some of the issues regarding inappropriate referrals to groups. As we move into an environment of medical "case management" especially for chronic conditions, research on how people find their ways to groups and if they attend a group on the advice of their provider are important questions for both self-help groups and health care organizations. Research on access and referral patterns represents the next major research advance in the area of self-help groups.

3. Find Innovative Ways to Promote Self-Help Groups

Throughout our project, health care representatives suggested that, to reach health care providers, the Self-Help Network would need to promote groups by using institutional incentives or public awareness activities. The former process focuses on systemic changes, including developing professional training programs, particularly medical school curriculum and Continuing Medical Education (CME) models and workshops through hospitals and medical schools or changes in health care regulations to "incentivize" referral to self-help groups. It is worth noting that some managed care companies are beginning to actively encourage their providers to use existing self-help and support groups especially for aftercare or relapse prevention. Value Behavioral Health, one of the largest mental health managed care companies, includes referral to a "self-help support group" within their post-treatment planning document required for every client. Public awareness activities (i.e., advertising campaigns, TV commercials, celebrity endorsements) might be accomplished through reaching out to the general public and encouraging them to ask their health care provider about self-help groups. The proliferation of self-help groups via the world wide web also provides a new outlet for public awareness, especially when a growing number of self-help groups meet on-line. Representatives mentioned that public awareness activities have been

extremely successful among the pharmaceutical companies, as they spend a significant amount of resources encouraging the public to "ask their doctor about their product." On the other hand, the whole notion of "marketing" self-help groups goes against the grain of the self-help ethos and actually violates some groups' traditions and guidelines. For example, the 11th tradition of A.A.'s 12 Traditions states that their "public relations policy is based on attraction rather than promotion . . ." (AA World Services, 1952).

4. Carefully Select Points of Entry in the Health Care System

There are many points of entry into the health care system. Throughout our project, health care representatives encouraged us to look beyond physicians and tap other entry points within the health care system because physicians are often unavailable, hard to reach, and skeptical of non-medical interventions. For example, due to new federal Medicaid regulations, states are in a position to determine which benefits competing managed care companies should provide. States are finding themselves as the large-scale purchasers of health care for their Medicaid recipients, giving them tremendous leverage in purchasing decisions and contract requirements (Epstein, 1997). Several states have taken advantage of these guidelines and have started to require various "enabling services" for their Medicaid population, including transportation networks, preventive strategies, and peer support programs (Gold, Sparer, & Chu, 1996). Similarly, Employee Assistance Programs (EAP), which already make many referrals to self-help groups because many of their clients have addictions, are being used for referral by managed behavioral health care organizations. EAPs are increasingly making referrals to groups, especially those for depression, anxiety, and eating disorders. Interest in the development of an infrastructure to provide reliable access to self-help and support groups is also illustrated by Janssen Pharmacutica, makers of the anti-psychotic medication, Resperdal. They offer a cost-free Person to Person Service which includes referral to a local support group at the request of the patient, family or provider with the explicit motive of medication maintenance and prevention of hospitalization.

CONCLUSION

Many of the changes in the health care system that Jacobs and Goodman (1989) predicted have occurred much sooner than most would have predicted. While self-help and support groups are being recognized by some parts of the larger health care system, including a handful of progressive managed care companies, hospitals, pharmaceutical companies, and state health care programs, the interactions between self-help groups and the health care system at this time primarily remains limited, as it always has been, to front-line health care professionals who

recognize the value of self-help groups for their patients. The dangers that self-help advocates and researchers have articulated are real and pose threats to what we know as the "self-help" movement. At the same time, it is easy to underestimate the collective strength of self-help groups. Members are generally not aware they are part of a "movement" as they focus on the issue that brought them to the group. The health care system only sees the "tip of the iceberg" as well. Who would have thought that the 12-Steps and Traditions that Dr. Bob and Bill W. created to save their lives would become the dominant model in addictions? Twenty years ago when the National Alliance for the Mentally III (NAMI) was formed, who would have imagined the revolution in the mental health field fueled by consumer and family self-help groups and organizations? Is it so impossible to imagine a similar revolution within our larger health care system if self-help groups become a more established part of that continuum of care?

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Direct reprint requests to:

Greg Meissen, Ph.D.
Self-Help Network of Kansas
Wichita State University
Box 34
Wichita, KS 67260-0034