Friend or Foe: The Impact of Managed Care on Self-Help

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The expansion of managed care throughout the health-care industry brings with it both promise and peril. There is the potential to create exciting new opportunities for the growth of the self-help movement. At the same time, managed care has the potential to co-opt, exploit, or marginalize self-help.

At this point in the spread of managed care, few industry decision-makers seem to be aware of the potential value of self-help as an adjunct to or substitute for medical treatment, or as a crucial part of rehabilitation. There doesn't appear to be much awareness of the beneficial role self-help can play in promoting healing and preventing or ameliorating health-care problems, and in fostering recovery. The managed-care industry needs to be introduced to the philosophy of self-help and shown how it will benefit their companies' bottom line and the well-being of their enrollees.

To use the vocabulary of the industry, we need to learn how to "market" self-help in the new health-care environment. In order to do this successfully, we first need to demystify managed care by learning something about its underlying assumptions and practices. While many people are somewhat intimidated by the technical jargon surrounding managed-care organizations (MCOs), it is based on a few concepts that are easily grasped.

- Managed care is primarily a health-care financing strategy to ensure cost-containment. This is generally accomplished by reducing access to the most expensive types of care and substituting less expensive interventions. This means that managed-care plans are less wedded to any particular treatment

philosophy than are traditional fee-for-service systems. If they can be shown that something works well and is less expensive, MCOs have few ideological or guild barriers that prevent them from trying something new.

- Most managed-care plans are based on a capitated rate. This means that the plan receives a set amount per month per enrollee, whether that enrollee uses services or not. It is to the managed-care plan's advantage to keep healthy people healthy and to help ill and disabled people recover as much functioning as possible with as little expense as possible—something the managed-care industry refers to as "managing risk." Self-help in its many forms would be an ideal risk-reduction strategy.
- The entity that pays the bills calls the shots. The managed-care benefit package to be offered is determined not by the managed-care company or the HMO, but by the entity that contracts with the managed-care company. This could be a private employer or, in the case of Medicaid managed care, the government. If we want to ensure that self-help is part of the benefit package, we need to convince the company or government body who hires the managed-care company that self-help needs to be part of their benefit package.

Advocating for Self-Help

In all our advocacy, we must remember that the health-care industry—whether privately or publicly funded—is, first and foremost, primarily concerned with its own financial well-being. The managed-care decision-makers will not embrace self-help because it empowers people, teaches coping and self-care skills, or is the right and humane thing to do. If they are to be convinced that self-help needs to be promoted within managed care, it will be because they believe it will save them money. And while many of us are not comfortable with this worldview, we must take full advantage of it by using every means at our disposal to prove to this industry that promoting self-help will be to their economic benefit.

It is up to those who know the value of self-help to bring the message to the people who determine how managed care is structured, practiced, and paid for. This includes the executives and stockholders of managed-care organizations, managers and staff of HMOs, health-care providers who belong to managed-care networks, and government officials. In order to be effective with this audience, we will have to go beyond personal testimonials and heart-warming anecdotes. If we are going to persuade these business people that self-help is, in their lexicon, a "good investment," we will need to learn how to speak their language. We will have to talk knowledgeably about outcome data, cost-containment and cost-avoidance; we will need to support our beliefs and opinions with facts, scientific studies, and proof of cost-effectiveness.

Although many in the movement have decried the relative lack of rigorous outcome studies about self-help programs, there are some good data that demonstrate the effectiveness of self-help among people with a wide variety of medical conditions, and we need to become conversant with this literature. For example, women with metastasized breast

cancer who participated in a weekly support group for one year survived an average of 1 1/2 years longer than women who received medical treatment alone. The women in the support group also had fewer mood disturbances, fewer maladaptive coping responses, and were less phobic. In another study, people with chronic respiratory conditions who participated in self-help groups were much less likely to be hospitalized and to have shorter hospital stays than a control group. Another study found that people discharged from state psychiatric hospitals who were randomly assigned to participate in self-help groups were rehospitalized 50 percent less frequently than a control group, and used only one-third as many hospital days.

These kinds of data make an impression on managed-care companies because hospitalization is obviously the most expensive type of care, and these companies are always looking for ways to avoid paying for hospital days. There are numerous other studies that can be used to demonstrate the effectiveness of self-help for people with long-term disabilities and chronic medical conditions. We need to gather and summarize these studies and get the information into the hands of the managed-care decision-makers.

Trends in Health-Care Practice

In addition to the cost-containment arguments, we have a number of reasons to be guardedly optimistic about the possibilities for self-help under managed care. Several changes in the health-care environment in recent years have created a climate that may be conducive to the growth of self-help in the medical arena. Frank Riessman and David Carroll, in *Redefining Self-Help: Policy and Practice,* note the following trends in health-care practice.

- Increased focus on chronic health problems; longer life expectancies and improvements in the treatment of acute illnesses have resulted in the vast majority of medical care going toward treatment of chronic conditions. People with chronic illnesses are most likely to benefit from self-help.
- Changing attitudes toward doctors, combined with increasing costs and less personalized service, have resulted in many people being more skeptical about the medical profession and more willing to question conventional medical practice.
- Increased interest in alternative healing systems and alternative medicine is at an all-time high: herbal medicine, acupuncture, massage, homeopathy, and more. People willing to seek out new healing regimens are likely to be the kind of self-motivated people who will embrace self-help.
- A new emphasis on preventive medicine is attracting many individuals, yet few medical professionals have state-of-the-art knowledge about prevention strategies. Self-help can fill this void.
- People frustrated by high cost and overprofessionalism in the health-care field increasingly are turning to self-care for many types of problems that can easily be dealt with at home. About 75 percent of health care is undertaken without professional intervention.
- As Riessmann and Carroll point out, self-help is not necessarily either a conservative

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or a liberal philosophy—aspects of it appeal to both political persuasions. The recent emphasis on personal responsibility, empowerment, and less government intervention are all conducive to the growth of self-help.

All of these factors bode well for the increased attractiveness of self-help to both individuals with medical problems and to the organizations that provide and regulate health care. If we are successful in educating the managed-care decision-makers, there will be new opportunities to benefit the self-help movement.

To understand how we might explain the benefits of self-help to the managed-care industry, let's consider two possible scenarios for the implementation of managed care for people receiving Medicaid.

Best Case Scenario

In the first version, the managed-care organization with whom the state Medicaid agency contracts understands that self-help in its many forms will both improve the health of Medicaid enrollees and help contain or even lower medical costs. In this system, the MCO has reached out to existing local self-help groups for people with a wide-range of physical and mental-health problems. It provides these groups with needed supplies and equipment, transportation expenses, space, and other costs in exchange for access and referral agreements between the groups and the managed-care plan.

The MCO also has a staff liaison responsible for promoting access to self-help for enrollees, maintaining up-to-date information and referral capacity, gathering and disseminating self-help materials, educating health-care providers about the benefits of self-help, and a host of other related duties. The MCO lets its enrollees know that it values and encourages self-help, mutual support, and self-care activities. It makes resources available to enrollees who want to start new self-help groups, and it encourages its providers to work in partnership with the self-help movement. The MCO does not direct or control the self-help groups, does not mandate curricula or methods, and actively supports the independence of self-help groups.

If I am a single mother on disability who receives medical benefits through this MCO, I have the opportunity to improve my use of medical services. Not only does my young daughter have a pediatrician to provide treatment for her asthma, I also have access to a peer-run support group for mothers of children with asthma. The group not only provides me with emotional support, but I learn new skills to help me manage my daughter's illness so that she needs less frequent emergency medical intervention. My daughter is healthier and more active, I am more confident because I can help manage her illness, and

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significantly less money is spent on my daughter's medical care.

Self-help plays a role in my own health care as well. In addition to medication and/or psychotherapy for my psychiatric disability, I have a choice of several self-help organizations of individuals with psychiatric diagnoses. If my experience with mental health self-help is typical, I reduce my use of inpatient hospitalization by at least 50 percent, and have much shorter lengths of stay if I am hospitalized. I have an expanded social network of people who share common experiences with me. I see myself in the socially valued role of helper, which leads to improved self-esteem, which in turn provides a buffer from anxiety. I learn coping skills and self-care techniques that improve my ability to deal with my disability. I begin to recognize that I can and must play a major role in my own healing and recovery. I'm happier and more satisfied with my life, and the managed-care organization saves money it otherwise would have spent on emergency room or inpatient treatment.

My elderly mother who has a heart condition takes classes with other seniors on diet, exercise, and life-style changes they can make to help to reduce the risk of heart attacks. She has access to free yoga classes at the senior center paid for by the MCO, and can join a peer-directed stop-smoking group. She loses weight, lowers her blood pressure, has her medication titrated, and doesn't have a second heart attack.

Worse Case Scenario

The second possibility is that the MCO and the state Medicaid do not take the time to learn about the benefits of self-help, dismiss it as unscientific, or just think it can save even more money by not spending a few dollars on self-help. Or, perhaps even more unfortunately, the MCO knows very little about the philosophy and practices of self-help, but thinks it sounds like a good marketing tool, and implements a bogus version of self-help that is controlled by professionals, does not empower people, and leaves them dissatisfied or cynical. In this case, if I am the same woman on disability discussed above, my daughter now has an assigned pediatrician but there is no mothers' group available. I find the doctor somewhat intimidating and am afraid to ask questions when I'm not clear about his instructions. I feel overwhelmed by my daughter's condition and may panic if she has an asthma attack. My daughter too frequently ends up in the emergency room, which is anxiety-producing for her and for me, and expensive for the MCO.

Instead of an independent self-help group for people with psychiatric disabilities, I am offered a monthly "medication management" group led by a professional. The professional talks down to the members. She stresses the importance of taking medication but dismisses concerns about serious side effects. We are taught that we are "chronically mentally ill"

and will never recover, but can merely hope to exist in the community between hospitalizations. I learn no new skills, make no social contacts, despair about the seeming hopelessness of my condition, and get re-hospitalized. Meanwhile, my mother who unsuccessfully tries to modify her eating and exercise patterns totally on her own requires increased medication, is often bedridden and in pain. The burden of caring for my daughter while I am hospitalized falls to my mother, who is not well enough to do so. All three of us are in poor health, under stress, and feel hopeless. At the same time, the MCO has spent more on our care than it might have under the first scenario.

Which of these scenarios comes closest to reality will be determined in part by how effectively we in the self-help movement communicate with the appropriate decision-makers. It is up to those of us who have personally experienced the power of self-help or those of us who have seen its benefits for family, friends, and clients or those of us who know it works to persuade the managed-care sector that access to self-help needs to be an integral part of any health-care benefit package, and to see to it that self-help is incorporated in a way that preserves its integrity and meets the needs of individuals.

Some Cautionary Notes

Knowing that managed care is primarily about controlling costs, we need to be vigilant that self-help is not used as a strategy by MCOs to avoid legal responsibilities to provide adequate medical care. As mentioned earlier, we need to be concerned about the potential for MCOs to exploit or co-opt the idea of self-help by using it solely as a marketing tool, and implementing bogus versions of self-help that are controlled by professionals, do not empower people, and leave them dissatisfied or cynical.

There are other issues that will need to be resolved if self-help is going to relate successfully to the managed-care system. One of the most controversial will be if (and how) self-help is funded under a capitated system. Earlier, I advocated that managed-care entities develop agreements with self-help organizations that would ensure access for plan enrollees in exchange for some minimal funding for mailing and copying expenses, transportation, refreshments, and the like. Some people in the movement may feel that even such small payments violate some of the fundamental tenets of self-help. Others might feel that self-help will be a tool by which managed-care companies will make a profit, and that therefore self-help groups should receive more than token reimbursement. Still others might believe that patient empowerment and self-care instruction require that peers be paid as providers. This same idea would undoubtedly draw protests from many self-helpers.

These and other complex issues will need to be addressed thoughtfully by self-help advocates as we plan how to get the most benefit for self-help in the managed- care environment. But we need to remember that we are in a good position; we have something beneficial and cost-effective to offer. The opportunities are there for us—it's up to us to make them work.