Community Treatment of the Mentally Ill: The Promise of Mutual-Help Organizations

TWO DECADES after its humanitarian conception, both critics and supporters recognize that deinstitutionalization of the mentally ill has failed as a national mental health policy. Deinstitutionalization was intended to decrease use of traditional institutional settings and expand so-called community-based alternatives, and supporters anticipated an improvement in quality of life and an increase in effectiveness of care. Unfortunately, reduction in the chronic resident population of public mental institutions appears to have been accomplished by moving patients to alternate custodial and residential settings and by releasing marginally prepared patients into communities with inadequate support services. Institutional horror stories have been replaced with tales of revolving door hospitalizations, dehumanizing board and care homes, and increasing numbers of people with prolonged mental illness among the homeless and in the judicial system. If deinstitutionalization is to succeed, then positive alternatives to avoid hospitalization must be designed. The alternatives must be acceptable and feasible given current societal barriers.

The research literature on alternatives to hospitalization indicates that the necessary ingredients of community care can be reliably identified. Research is consistent enough across studies to conclude that successful programs must, above all, provide ongoing, long-term support. Ideally, programs should be individually tailored to provide the particular skills and supports each person requires. Programs must find a balance between care that is assertive enough to reach clients who typically fall between the cracks in the system and care that is flexible enough so that individuals can develop their own resources without counterproductive overdependence on the mental health system.

Mutual-help organizations are an alternative consistent with the research

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The failure of deinstitutionalization is less a problem of what is known and more a problem of what is done. The literature on alternatives to hospitalization suggests that successful programs involve individually tailored, assertive, long-term support. Mutual-help organizations, which have the above-mentioned characteristics, are promising community treatment alternatives consistent with the original goals of deinstitutionalization and with current political and economic realities. One such organization, observed by a research team over a period of 5 years, is presented as an example.

findings, the original goals of deinstitutionalization, and current political and economic realities. A research team observed one such organization over a period of 5 years that illustrates the promise of such organizations.

Effective Community Care

Although deinstitutionalization has failed as a national policy, the research literature demonstrates that the problem is one of implementation rather than "treatment" effects. When positive alternatives to hospitalization are provided, there is good reason to believe that they can be useful.

Alternative care for patients who otherwise would be hospitalized takes the form of day hospital programs, halfway houses, home care, foster care, supervised apartment living, board and care homes, community families, and other variations on semiindependent living. A growing literature indicates that when time, money, and care have been invested in positive programs, they can be equally as effective or more effective than hospitalization. This is true for programs that serve patients who have been released from the hospital and those intended as alternatives to hospitalization.

Fairweather and his colleagues developed one of the most well-known examples of an alternative to traditional care (Fairweather, Sanders, Cressler, & Maynard, 1969). They found that in group living, patients with prolonged mental illness were able to stay in the community for a longer period than were those who were assigned to traditional outpatient care.

Several reviewers compared hospitalization to alternative care programs and concluded that levels of symptomatology, recidivism rates, social adjustment, community living skills, and general quality of life are as good or better for patients in alternative programs. These programs are equally as effective or more effective than hospitalization while they are in operation, but once patients lose contact with the program, their gains disappear.

Test and Stein (1978) found that symptom reduction and social role functioning were as good or better for patients treated in day hospital programs or in the community as they were for hospitalized patients, while the programs are in operation or 3 to 6 months thereafter. Rates of hospitalization (number of admissions, length of stay, or length of time until next hospitalization) were better in alternative programs for 3 to 6 months after treatment, but by 1 to 2 years later, after the treatment program had ended, these gains had disappeared. Even in their own highly successful program of community care, once treatment had ceased there was a rapid decline in the outcome of the experimental group (Stein, Test, & Marx, 1975).

Fenton, Tessier, & Struening (1979) found similar results for the 1-year follow-up of a home treatment program.

They also reviewed three long-term follow-up studies that they viewed as methodologically sound and concluded that although community treatment is more effective in certain areas, when community treatment stops, and both community and hospital groups have access to the same aftercare facilities, clinical gains of the community group are lost.

Dellario and Anthony (1981) reviewed research that compared day hospitalization, in-home care and community clinics, and hospitalization. They also concluded that although community treatments are superior while they are ongoing, once treatment is withdrawn there is no significant difference in symptom reduction, psychosocial functioning, interpersonal functioning, or personal adjustment. Gains seen in the community groups' recidivism rates and employment status fell off after approximately 18 months.

Other programs, such as Soteria House and Pasamanick and colleague's home treatment program, have clearly shown a similar decline in positive treatment effects once the programs ended (Davis, Dinitz, & Pasamanick, 1972; Mathews, Roper, Mosher, & Menn, 1979). On closer scrutiny, even programs that appear to have long-lasting effectiveness do not contradict this finding. For example, Weinman and Kleiner (1978) compared two community treatment groups with two hospital control groups. Patients in the experimental groups were assigned community "enablers" to help them with daily tasks and adjustment programs. Patients lived either in the enabler's home or they lived in an apartment with one or two other patients and received regular visits from an enabler. In the 24 months following treatment, those in the traditional hospital control group were significantly more likely to be readmitted to the hospital than those in the community group (41 percent and 16 percent respectively). The community group maintained a lower admissions rate 2 years after the termination of treatment. Although these findings appear to contradict the assumption that treatment effects will decline, the maintenance of gains may be attributable to the fact that 67 percent of the patients who remained in the community con-

tinued to live with their enablers for 24 months following treatment. Thus, although the official program had ended, patients had an ongoing source of support.

Kiesler (1982) reviewed the experimental literature on alternatives to hospitalization for relevance to policy decisions. He argued that it is likely that too many people are being institutionalized and that the amount of hospital care provided could be significantly reduced if adequate initial community care were available. He also concluded that although there are a variety of potentially effective alternative treatments, they do not collectively offer insight for national policy because each program tested its own method of care.

Braun et al. (1981) reviewed a similar set of studies and generally agreed that selected patients in alternative treatment programs do no worse than those who are hospitalized. However, they concluded that "whatever general value can be obtained from studies of deinstitutionalization with defined programs of community care must necessarily be applied only for comparable patients in situations where similar conditions prevail" (p. 748).

In general, reviewers are correct in asserting that there is no single best treatment program. However, given the fact that the studies reviewed by several different authors show tremendous diversity in patient populations, treatment modality, duration and location of treatment, and outcome measurement, their consensus on one basic issue is striking: Community-based treatments are viable alternatives to hospitalization when they provide ongoing, rather than time-limited, care and support. This is consistent with the recognition that although there is great diversity in individual outcome (Harding, Zubin, & Strauss, 1987), for many mental illness is a long-term problem that requires ongoing support or care (Lamb, 1986).

Close scrutiny of the success of individual programs reveals that effective alternatives to hospitalization also are characterized by assertive, individualized treatment programs that provide emotional and instrumental support. Care must be assertive to reach this more chronic group of community-based pa-

tients (Test, 1981). On their own, they may not aggressively seek out mental health services and therefore will remain unserved. Lamb (1979), for example, found that 63 percent of the residents of a board and care home were in contact with a mental health professional. He found that 5 percent never left the confines of the home; only 15 percent made more than minimal use of community services. Fifty-one percent of the residents participated in a social rehabilitation program located on the same block. When it moved and transportation was provided, 27 percent continued to attend the program. When the van was sold and only public bus transportation was available, attendance dropped to 3 percent.

Care must be individually tailored to provide the particular skill training and support each individual requires. The program must be flexible so that individuals can develop their own resources without counterproductive overdependence on the mental health system (Estroff, 1981). There is a subtle balance between providing ongoing services and encouraging maximum feasible independence. Individualized programs that are located in the community, rather than in a hospital, and that remain available, rather than time limited, appear to provide such a balance.

Barriers to Effective Community Care

Use of the current knowledge on alternative community treatments has been hindered by inadequate development of a positive theory and philosophy of community care and by a lack of political and economic support for alternative programs.

Inadequate Positive Philosophy

Reduction in the rate of long-term hospitalization has not been obtained by means of a "cure" for the problems of major mental illness or by establishment of an adequate number of community-based treatment programs. Deinstitutionalization is itself merely an administrative decision. Bachrach (1978) noted that society has focused policies on movement of patients out of the hospital and back to the community. There remains

a need for positive inputs, often ongoing, in the lives of many people. Deinstitutionalization must include an exchange of resources as well as clients, and requires the expansion of community-based services that will act as functional alternatives to the hospital.

One barrier to expansion of community services has been the failure to adapt them to a changing community-based clientele. The inpatient hospital care system and the outpatient community care system traditionally have served distinct populations (Price & Smith, 1983). Outpatients have sought short-term, voluntary care for personal or situational crises. Inpatients, in contrast, typically have been more severely disturbed and in need of long-term care. When inpatients were shifted to the outpatient system, a corresponding change in services and resources failed to materialize. These patients provide a new challenge to the mental health professions. Working with such clients day-to-day is both difficult and unglamorous. Although there is a fair amount of prestige in providing in-the-office therapeutic services, and a good deal of control in the hospital, neither prestige nor control is characteristic of ongoing community services for formerly hospitalized patients.

Outpatient clinical services generally remain oriented toward the short-term user, despite the fact that many patients released from hospital care need long-term support such as housing and educational and vocational assistance, in addition to traditional medical and psychological services. Although adequate community-based services have not yet been developed, many writers point out that there still is momentum for improved community care (James, 1987; Torrey, 1986).

Lack of Political and Economic Support

Although deinstitutionalization ostensibly remains national policy, hospitalization still is a major form of treatment for the mentally ill in the United States. Although the resident population in public mental institutions dropped by 57 percent between 1955 and 1974 and state and county hospitalization episodes decreased by 35 percent (Felton & Shinn, 1981), the number of inpatient psychiatric admissions to other hospitals (general, community mental health centers, Veterans Administration, and private psychiatric hospitals) increased during this period from 477,000 to 1.2 million (Kiesler, 1982). Although community care also increased from 379,000 episodes in 1955 to 4,600,000 in 1975, Kiesler (1980) estimated that 70 percent of the funds spent on mental health care are spent for hospitalization. This apparent contradiction can be explained in part by the fact that three federal programs continue to provide economic incentives for hospitalization of the mentally ill. Medicare, Medicaid, and the Supplemental Security Income Program provide financial support for brief hospitalizations and "community-based" custodial care. These incentives have led to a policy of revolving door hospital admissions and alternative forms of physical care with no genuine psychological and social services. Patients have been moved out of state-funded hospitals into federally reimbursable custodial facilities. Treatment in these facilities typically is substandard or nonexistent, and replaces the state hospital system with one that provides little more than shelter, the only requirement for receipt of funds.

The availability of federal funds for custodial and hospital care is a disincentive for states to develop their own positive community care programs. In addition, the general political shift away from support for human welfare services has left community mental health providers with neither the funds nor the mandate to develop and expand genuine services. Most centers are only marginally able to serve their traditional outpatient populations, let alone aggressively pursue a new, more difficult to reach clientele.

Although a policy of ongoing, long-term community support should be encouraged, it may not be a realistic option, given the current mental health delivery system. Experimental alternative programs, although effective, tend to be relatively short-lived. They often are research oriented or of a demonstration nature. They eventually lose funding or the support of the institution with which they are affiliated. Given the current political and economic climate, it is not clear whether resources for the development of community services and training or retraining of a different type of mental health worker will be forthcoming from federal, state, or local governments. These traditional sources of support will not necessarily aggressively fund expansion of ongoing, positive services identified as necessary for realistic community care of individuals with prolonged mental illness.

Mutual-Help Organizations

Because the present system of mental health service delivery has not provided several basic components of effective community care for people with prolonged mental illness, other options must be considered. One possibility is to look toward grass-roots mental health alternatives, in particular, mutual-help organizations.

The past 2 decades have seen a surge in the development of self- or mutual-help groups and organizations (Zimmerman, 1987). These groups are based on the idea of individuals with similar problems helping one another. To date, there has been only limited systematic evaluation of such organizations; nevertheless, those evaluations that have been undertaken have found participants to be satisfied with the services they receive (Gartner & Reissman, 1984).

Although the terms often are used interchangeably, it is important to distinguish between self- (or mutual-) help groups and mutual-help organizations. Self-help groups tend to focus on a particular shared problem or concern. They offer a weekly meeting, a shared cognitive perspective, and some amount of ongoing support, but typically do not become an integral part of the member's broader social context. In contrast, mutual-help organizations are composed of more than group meetings. Rather, they are well-developed organizational structures that include leadership positions, formal roles, and extragroup as well as intragroup contacts, roles, and activities. They can offer an entire social network, consisting of mutual relationships and a consistent, ongoing structure. They also may provide members

with a sense that they are connected to something larger than their individual group experience.

Mutual-help organizations provide a source of community support that is consistent with many of the original goals of deinstitutionalization. First, they offer a positive alternative to hospitalization that may fill the gap left by other community services. They do not eliminate the need for other psychological, residential, skill development, and financial services. They may, however, provide a supportive context within which individuals can mobilize and manage other resources.

Second, rather than creating smaller institutions, in the form of nursing homes, board and care homes, and halfway houses, mutual-help organizations draw on and create genuine community support systems (Levine & Perkins, 1987). They do not necessarily depend on professionals or on public funding sources. They arise from and are part of the community.

Third, mutual-help organizations may provide a mechanism for cooperation and collaboration among mental health professionals and other community members and organizations. Although they can exist independently, they may benefit from professional support and state or federal funding. In return they add to the community's mental health resources.

Finally, mutual-help organizations provide support, while they increase members' personal independence and discourage overdependence on the mental health system. They encompass the positive goals of rehabilitation by working toward building and using each individual's strengths, rather than focusing solely on eliminating deficits. They seek to convert problems or needs into resources. Gartner and Riessman (1982) pointed out that, because those helped also are the helpers, mutual-help organizations can expand indefinitely to respond to an ever-increasing need. Because they are run by their members, the organizations escape the dehumanizing effects of bureaucratic or institutional structure. They take seriously the goals of increasing community adjustment and improving quality of life by focusing on day-to-day issues and problems and by

providing a social context, which often is lacking in the lives of people with prolonged mental illness.

Mutual-help organizations seem well suited to meet the varied needs of individuals with prolonged mental illness. GROW, a long-standing mutual-help organization, illustrates such organizations' role in providing long-term community support.

GROW: A Case Study

This case study is based on 5 years of close contact with the GROW organization (Rappaport et al., 1985). GROW initiated contact, which developed into a collaborative, longitudinal program of research. The researchers acted as participant–observers in the organization. The research team attended more

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than 1,000 GROW meetings and conducted between one and six extensive interviews with approximately 300 GROW members and leaders. In addition, participant–observers analyzed the organization's literature and attended leadership and training functions, meetings between the GROW organization and other mental health professionals, and formal and informal social functions.

GROW was founded in Australia in 1957 by a group of expatients, who were led by a priest who was recovering from mental breakdown. In 1978, a GROW group was established in Illinois, and since that time it has established close to 100 groups in the state.

GROW has a small paid staff, but most positions are filled by member–volunteers. GROW usually does not depend on professional leadership. Leadership positions at all levels typically are filled by individuals who move up through the organization. GROW's rapid expansion in Illinois has been facilitated by the use of professionals who lead groups until natural leaders emerge from the membership. When professional leaders are used, it is explicitly stated that leadership should be shifted from professionals to group members within 6 months of the establishment of the group.

GROW has three program components: (1) group meetings held weekly, (2) literature, and (3) what GROW refers to as "the sharing and caring community." As in most mutual-help groups, the meetings focus on group problem solving and support, and the literature provides cognitive guidance. The unique aspect of GROW is that it extends beyond weekly meetings to form a community for living. Through formal structures (social gatherings, assignments to call and see each other throughout the week, and a drop-in center) and informal social contacts, ongoing friendships and supportive relationships form. GROW becomes an integral part of the individual's life. There is a strong emphasis on development of friendship networks, and each person is expected to both be a helper and receive help, relying on the well-known "helper therapy principle" (Reissman, 1965). Members are encouraged to go beyond "help" per se and to share their lives in more diverse ways, including the positive as well as the difficult experiences of living.

Although an intensive summative evaluation is not complete, the data gathered suggest that GROW both maintains and implements a positive philosophy of community care. It is also congruent with current political and fiscal opportunities for implementation.

Therapeutic Characteristics

GROW uses many of the therapeutic characteristics identified as effective ingredients of alternative care. First, the organization is ongoing, rather than time limited. It is not experimental and its continuation is not subject to changing

mental health trends or policies. The GROW organization has been a stable link in the Australian mental health system for more than 30 years. Although there have been instances of groups folding as a result of lack of membership, in the majority of cases once GROW enters a community it provides an ongoing source of support. GROW has been successful in maintaining at least one group in 41 of the 51 Illinois communities it has entered.

In addition to long-term availability, GROW provides varied, continual sources of support, on a 24-hour basis, because the organization becomes part of the members' lives. Members are encouraged to call on one another for support in times of crisis and for friendship and entertainment during less stressful times. When newcomers attend their first GROW meeting, they are encouraged to exchange phone numbers. Informal contacts are supplemented through a formal process by which arrangements are made for members to exchange phone calls and meet socially. In a study of 15 GROW groups (based on a sample of 527 meetings, with an average of approximately eight attendees per meeting), an average of 54 percent of those present reported that they had been in contact with another GROW member at least once since the last meeting. Contact also is encouraged through monthly social events scheduled for all of the groups in a region.

Second, GROW takes an assertive approach. Members chart their progress in the GROW program according to what they call "the 12 steps towards personal growth." The last of these steps reads as follows "We carried the GROW message to others in need" (GROW, 1982). This commitment is taken seriously. Members, of whom approximately 75 percent are themselves former mental patients, go into hospitals to visit patients and introduce them to the organization before they are released. GROW meetings often are held in hospitals to involve patients in the organization and provide a smoother transition to community involvement. One of GROW's explicit goals and expansion strategies is to start groups in and around cities with hospitals, so patients will have community support upon release. Once an individual comes into

contact with GROW, other members make an aggressive personal effort to involve them in the organization through telephone calls, visits, and assistance in getting to meetings.

Third, involvement in a mutual-help organization can be individualized to meet changing needs. For example, members can maintain whatever degree of involvement they find useful. Members' attendance and leadership pattern often will change radically throughout their involvement with GROW. At times they may attend several meetings a week and many social events. As their needs change, they may attend less regularly. Although some members become involved in the organization's leadership and become life-long participants, others move on. There also is great role flexibility in GROW. Members give and receive help as they are able. The GROW literature states that leadership is not a position in GROW, it is a responsibility that members take more or less of, dependent on their capabilities and interests. Members are able to take on leadership responsibilities gradually, which allows them to receive support and build competence simultaneously.

Involvement in a mutual-help organization can help to build members' self-esteem and motivation to stay out of the hospital. The organization provides an opportunity to help others, to experience a sense of ownership, and to take on leadership and responsibility. Rather than becoming overly dependent on mental health services, individuals are able to build friendship networks that provide support and meaningful relationships.

Economic Feasibility

Compared with traditional mental health services, mutual-help organizations are cost efficient. Rather than hiring caregivers, they develop leadership through the organization. Rather than viewing the mentally ill as a drain on society, these organizations view them as potential resources for helping one another. The operating budget for such an organization can be modest. In central Illinois in 1986, GROW had approximately 800 members. The only paid employees were 20 fieldworkers, an administrative secretary, a director, and

a bookkeeper/accountant. All other group leaders were volunteers who emerged from the membership. There were 99 GROW groups in Illinois, offering approximately 200 hours of meeting time each week. The organization also ran eight drop-in centers, offering 24-hour availability. GROW provided this extensive community support system on a budget of approximately $500,000. This money was a combination of state funding, church funding, and private donations.

Political Support and Successful Implementation

Mutual-help organizations such as GROW are grass-roots organizations. They originated in reaction to traditional mental health services and more recently have thrived and grown as traditional services have deteriorated. They are not subject to political whim, current mental health policy, or changing professional ideas about effective care. They were formulated from the bottom up, rather than from the top down, and are grounded in the wisdom of grass-roots individuals and organizations. This context provides a critical sense of ownership and empowerment to those affected.

Mutual-help organizations hold considerable promise in their philosophy and techniques of community care, economic viability, and grass-roots support; however, widespread implementation requires political and societal support as well. Federal and state policy must facilitate access to resources (technical, financial, and psychological) and contain incentives for the compliance or cooperation of disinterested or hostile parties.

Role of Professionals

Professionals can support mutual-help organizations in many ways, including referring clients, serving as a link between these organizations and more traditional service agencies, providing material resources such as clerical help or meeting space, serving as a consultant, and helping to initiate mutual-help groups (Hermalin, 1986; Toseland & Hacker, 1982, 1985). Professionals also can act as advocates for these organizations by helping them to secure resources

and legitimacy within the mental health community. Lastly, researchers can turn their attention to the phenomena of self-help (Riessman, 1987).

Katz (1970) pointed out that the long history of self-help groups in America is contrasted with a relatively sparse literature of empirical study or theoretical analysis. The recent increase in writing about mutual help has not changed this fact. The implementation of policy must go hand in hand with the systematic investigation of mutual-help organizations, including evaluation of their efficacy, the process of their meetings, the content of their literature, their expansion strategies and goals, and their organizational structure.

Ultimately, the success or failure of efforts in community care will depend less on mental health professionals' ability to create supportive environments or to teach specific skills and more on the ability to find and encourage naturally occurring niches. These niches are where people find meaning in life; mutual, rather than unidirectional, relationships; and consistent ongoing structures on which to depend. These are the settings that those who experience serious psychopathology often are unable to find. Mutual-help organizations may provide naturally occurring (that is, not professionally developed) settings that are available to people who are left to maintain themselves in the world when the professionals, the aftercare workers, and the volunteers have gone home.

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