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Empowerment and Self-help Agency Practice for People with Mental Disabilities

Steven P. Segal, Carol Silverman, and Tanya Temkin

During the past 15 years, there has been tremendous growth in the number of self-help groups and agencies for mental health clients. This article examines the self-help perspective in relation to problems with traditional mental health services and the need for client-run services. Self-help agencies see their goal as empowerment on an individual, organizational, and societal level. They strive to accomplish this by helping members obtain needed resources and develop coping skills; providing means of enhancing members' self-concept and lessening the stigma of perceived mental disability; giving members control in the agencies' governance, administration, and service delivery; and furthering member involvement in social policy-making. The goal of this article is not to endorse the self-help perspective but to use it as the basis for raising research questions that will further the mental health practitioner's understanding of this service modality.

Key Words: *empowerment; mental health care; mentally ill clients; self-help*

Self-help is an attempt by people with a mutual problem to take control over the circumstances of their lives. Founded on the principle that people who share a disability have something to offer each other that professionals cannot provide, self-help efforts take many forms. Formal self-help efforts involve participation in organized groups for individuals with similar problems or in more differentiated and structured multiservice agencies. Over the past several decades, there has been tremendous growth in the number of such self-help agencies and groups for people with mental disabilities.

Self-helpers and traditional mental health service providers share the primary goal of enabling people to live better lives. However, self-helpers, particularly those in multifunction service agen-

cies, argue there are fundamental differences between their practices, which they believe empower people, and those of traditional helpers, which they regard as disempowering.

In this article, we take the self-help perspective and place it within the social sciences literature to more precisely spell out the mechanisms by which self-help practice might work. This article must be read as a theory of self-help rather than a validation of it. It is intended to serve as the theoretical statement for necessary empirical work. The article is based on readings in the self-help literature and two years of observations, interviews, and meetings with self-help agencies and personnel. In addition, one of the authors has been active in the patients' rights movement for 15 years.

Client Critiques of Traditional Models of Care

The client-run movement has focused its critique on existing models of mental illness, on the practices of professionals who use these models, and on the lack of responsiveness of the larger environment to the needs of people with disabilities. The critique is directly indebted to the independent living movement.

Independent Living Paradigm

The independent living movement is based on a belief in severely disabled people's potential for self-determination, provided that they have access to support services, barrier-free environments, and appropriate information and skills (Frieden, 1978). It is also grounded on a commitment to major consumer involvement in planning and delivering these services. DeJong (1979) maintained that the independent living movement constitutes an analytic paradigm that has redirected the course of disability policy, practice, and research away from the rehabilitation paradigm.

DeJong (1979) noted that whereas the rehabilitation paradigm defines the physically disabled individual's problem in terms of impairment and lack of vocational skills, the independent living paradigm finds the rehabilitation process itself to be problematic. The focus of the problem, according to the rehabilitation paradigm, is in the individual; the solution rests with professionals; the proper role of the disabled individual is as a patient or client deferring to the control of the professional; and the desired outcome is maximum activities of daily living or gainful employment.

In contrast, the independent living paradigm locates the problem in the environment and the rehabilitation process. The solution to the problem is in peer counseling, advocacy, self-help, consumer control, and removal of environmental barriers. The social role of the disabled person is as consumer, with consumer control of services, and the desired outcome is independent living.

The mental health client movement draws from the independent living movement in finding the services of many professionals to be problematic rather than helpful but expands the critique to deal with special difficulties that the mental health client

movement perceives to accompany mental health care. The critique parallels that of others such as Rosehan (1973) or Goffman (1961) and in some cases draws explicitly from them. It broadens existing critiques by focusing on client empowerment as the sine qua non of client-operated services as well as the central theme of the critique of mental health services.

Self-help View of Empowerment

As Rappaport (1985) noted, the absence of empowerment is easy to notice, but its presence is difficult to define as it takes various forms in different contexts (see, for example, Kahn & Bender, 1985; Pinderhughes, 1983; Rappaport, Swift, & Hess, 1981). Self-helpers ascribe empowering functions to self-help agencies by tacitly and expressly comparing them with professionally run services, which they

regard as disempowering. In describing how the common principles of client-run services distinguish them from traditional mental health services, Zinman (1986) noted that

First, people who use the services run them, making all the decisions; service providers and recipients are one and the same. Second, these

groups strive to share power, responsibility, and skills and seek a nonhierarchical structure in which people reach across to each other, rather than up and down. Third, client-run programs are based on choice; they are totally voluntary and are not part of the continuum of mental health services that involuntarily commit people. And finally, they are based on a nonmedical approach to disturbing behavior and therefore see and address the real economic, social, and cultural needs of suffering people. (p. 213)

The issue of empowerment, then, underlies self-helpers' understanding of the nature of the problems with which they contend and under whose control such problems should be addressed, the goal of efforts to deal with them, and appropriate strategies for doing so. Self-helpers believe that the entire conceptual framework that guides their theory and practice differs from that under which professionally based services have been developed.

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Self-help Understanding of the Nature of the Disability

Traditional mental health models treat the disability as an illness or internal problem that requires the services of a professional. Client-run agencies have not developed a uniform approach to mental disability, but some self-helpers have applied the concept of disability developed by the independent living movement to the phenomenon of mental disability (Harp, 1987). In this concept, the individual's mental disability is regarded as a condition that may impede the person's ability to function in certain areas but that need not prevent the person from functioning as he or she wants to function if the appropriate social and environmental accommodations are provided.

Self-help Critique of Traditional Practice

Initially, the client-run movement focused its critique of mental health services on the coercive nature of hospitalization and therapy. Former patients who became activists focused their efforts on restricting involuntary commitment and treatment (Brandt, 1975; Legal Project/Mental Patients Liberation Front, 1975), the most extreme forms of personal disempowerment. They noted that these interventions, done ostensibly in the best interests of mentally disabled people, failed to respect the expressed interests of those individuals to be free of such coercion (Chamberlin, 1979; Jones, 1953). Furthermore, treatment may be in direct conflict with the desires of the patient (Kittrie, 1973; Segal, 1978). Instead, said these critics, mental hospitals, psychiatric drugs, and electroshock were used to punish those who failed to adhere to societal norms (Goffman, 1961; Hirsch et al., 1974; Insane Liberation Front, 1971).

Activists then turned their critique to the therapeutic process itself, including the iatrogenic effects of this process. Many such effects are well known. Medications do not cure mental disabilities, and side effects are often major. Furthermore, as medication or treatment side effects appear, the individual is not sure whether symptoms are a part of the problem or a result of the medication (Gotkin & Gotkin, 1975; Van Putten & Marder, 1987).

Self-helpers also looked at how the therapeutic interaction fostered dependency and anger (Chamberlin, 1978; Gotkin & Gotkin, 1975). Often in therapy the patient is not offered a direct cure, an answer to the question of what is wrong with him or her, or sufficient information to deal with the problem. He or she also is usually not told the actual di-

agnosis or the criteria used to establish the diagnosis. Because treatment is usually based on diagnosis, the patient's understanding of the relationship between the treatment and the problem is very limited.

Therapy can also occur through a problem-solving process. Here the therapist ideally enables clients to make maximum use of their personal resources, guides them to new resources, and informs them of the nature of their situation in terms of its limitations for successful results and its potential for therapeutic success. But when clients lack the resources and enough control over their personal situations to make use of these new insights, the problem-solving process may lead to dependency on the therapist for resources and for intervention into the situation.

The problem-solving process can also create anger. The individual who asks the mental health practitioner, "What is wrong with me?" does not wish to hear, "What do you think is wrong with you?" Thus, clients can become angry as the therapist works to help them help themselves. In this process, the therapist often does not give clients the necessary resources to help themselves and restricts the clients' participation in determining which resources are delivered. This action often breeds resentment and hostility directed to what clients may perceive as the deliberate withholding of agency help. Having no control over the extent of resources available to them and no knowledge of what is available, they are dependent on what the agency offers them.

Following their notion of mental problems as disabilities, not illnesses, self-helpers also question the power of the professional to define them, that is, to give them an identity or "master status" (a status affecting all other statuses one holds) (Scheff, 1966) through the assessment and diagnostic process. The mental health professional reinterprets the individual's behaviors and experiences through a diagnostic framework that attaches such behaviors and experiences to a label rather than to a person. Furthermore, mental health professionals require acceptance of their interpretation of the patients' problem as a criterion for improvement (Goffman, 1961). Although it may well be that a person must first acknowledge a problem to deal with it, there is a major difference between accepting that one has a disease and acknowledging a disability. The former comes with greater stigma and less outcome-specific value and is not necessary for dealing with the disabling behavior.

Dependency and anger are often consequences of treatment for many physical conditions but are particularly important when associated with the treatment of psychological disturbance. In this condition, such emotions and actions have the potential not only to interact with the core problem to exacerbate the condition, but also to be misinterpreted by the clinician as being part of the condition. For these reasons, activists eschewed community mental health outpatient treatment, regarding such services as part of a system that treated clients as incompetent, encouraged them to be dependent, and coerced them into accepting unwanted treatment or other interventions. Self-helpers noted that these attitudes and practices prevented professionals from helping their clients achieve independence and self-sufficiency, despite the claims of providers to the contrary (Chamberlin, 1978).

Psychiatry in general was seen by many self-helpers as an institution that maintained the societal status quo and prevented disempowered people from effecting social change. A national conference of mental health clients adopted the following position:

We oppose the psychiatric system . . . because it uses the trappings of medicine and science to mask the social control function it serves; because it feeds on the poor and powerless: the elderly, women, children, sexual minorities, Third World people . . . because it invalidates the real needs of poor people by offering social welfare under the guise of psychiatric "care and treatment." (Fourth Annual North American Conference on Human Rights and Psychiatric Oppression, 1976, p. 7)

Alternative approaches to traditional mental health care such as the psychosocial rehabilitation model for people with long-term mental disability were also criticized. Superficially, the values and methods of psychiatric rehabilitation and those of client-run agencies seem very similar, or at least compatible. The services of both support the enhancement of clients' competencies and enable them to gain resources needed to reach their desired goals; both espouse involving clients as active agents in the services they receive (Anthony,

Cohen, & Cohen, 1984; Citizens Advisory Council, 1982). However, self-helpers have responded to the psychiatric rehabilitation model with distrust, asserting that it fails to provide true client empowerment on the personal and organizational level. For example, in describing two well-known such programs, Chamberlin (1978) commented,

The staff of these "alternatives" keep records on members, consult with others about members, and make decisions members have to abide by. Members, on the other hand, can participate in only the most limited kinds of decision making. They can vote to schedule a bowling night instead of a swimming night, but they cannot vote to fire the director or point out to a staff member that his or her behavior is "abnormal." A member dissatisfied with the basic structure of these "alternatives" has little recourse. The kinds of changes that are within membership control cannot achieve fundamental changes in the way the service is run. (p. 92)

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For self-helpers, psychiatric rehabilitation programs have failed to empower clients in at least three ways: (1) The decision-making power granted to clients is defined by nonclient administrators; (2) staff-client hierarchies are perpetuated; and (3) the potential for coercion—for example, sending a client back to the hospital or expelling him or her from the program—is ever present.

As community psychologists Gruber and Trickett (1987) noted, the act of service providers empowering service recipients is flawed by the "paradox of empowerment" (p. 363). The inherent inequality of power between professionals and their clients prevents the former from empowering the latter, because "The very institutional structure that puts one group in a position to empower others also works to undermine the act of empowerment" (p. 370). If empowerment in the social services environment is a process that can be initiated and sustained only by those who seek power and self-determination (Simon, 1990), then it cannot legitimately be conferred by others who can define the parameters of such power. Thus, mere consumer participation

allowed in professionally run services must be seen as distinct from true consumer control as practiced in self-help agencies.

Self-help Agency Practice and Empowerment

The mental health client self-help movement promotes the role of mentally disabled people as active consumers who determine which services will best meet their needs (Budd, 1987; Center for Rehabilitation Research and Training in Mental Health, 1984). The desired outcomes are the same as those of the independent living movement—personal independence in accordance with one's self-defined goals, as long as these goals do not infringe on the rights of others. Empowerment, for self-help, is both a systems and an individual phenomenon. Self-help agency efforts, geared toward forcing the larger environment to accommodate disabilities, are designed to work in tandem with efforts directed at and with the individual consumer. Hasenfeld (1987), in discussing empowerment in social work practice, made a distinction that is also relevant to self-help agencies. He talked about how empowerment must occur on at least three levels: (1) on the individual level, through resource improvement; (2) at the organizational level, through actions directed toward "harnessing the agency's power advantage to increasingly serve the needs of the client" (p. 479); and (3) at the policy level, where people become involved in the formation and enactment of policy that affects them. Similarly, the self-help agency's goal is to empower its clients through the following related activities at three levels of organization:

1. Individuals are directly provided or helped to gain access to resources and skills necessary to reach desired goals, and alternative models are provided to counter stigma.
2. Organizations are structured to give clients access to roles that permit them to take responsibility for and exercise discretion over policies that affect them collectively within the agencies (Silverman, Segal, & Anello, 1987).
3. Changes are sought in the larger society that both better the condition of people with disabilities as a class and empower them to participate in making decisions concerning policies that affect them.

Self-help Activities

Resources and Skills. Any discussion of empowerment and self-concept runs the risk of blaming the

victim and of ignoring the very large disempowering structures faced by the person with the disability. As a master status a mental disability creates a real barrier to a person's ability to marshal necessary and desired resources. A mentally disabled person's control of life circumstances is often limited by decisions that view his or her competence as more limited than the actual disability would make it, by general societal and specific organizational structures unwilling to accommodate the disability, and by political decisions limiting the resources available.

For many self-helpers the disabling aspects of their disability cannot be separated from their poverty. As with traditional service providers, agencies either directly furnish or provide access to services and necessities such as benefits counseling, housing assistance, clothing, lockers, showers, and food. Self-help representatives would argue that they differ from traditional providers in that the client, rather than the professional, determines what services are needed and all participation is voluntary. The program philosophies and service activities of self-help agencies parallel those of user-controlled independent living centers founded by people with severe physical and sensory disabilities (Zinman, 1987).

Self-help agencies also attempt to provide their clients with necessary skills. For example, many such agencies employ clients on either a paid or volunteer basis, thus giving them a work history and references. Many offer independent living classes taught from the perspective of someone who has experienced disability and poverty.

Self-concept. For empowerment to occur, the person with the disability must command the necessary skills and resources to secure desired outcomes. However, even commanding the necessary skills and resources is insufficient when the environment is unresponsive or the individual does not believe in the possibility of success and therefore does not exercise power. A person with a mental disability is given an overriding basis for self-identification: He or she is largely defined by that status; it organizes others' expectations about a large range of behaviors unrelated to the disability and leads to negative evaluations based on these expectations. For self-help agencies one of the aspects of empowerment is to alter the meaning of the disability for the member-clients. Of particular importance is altering all the negative stereotypes that attack the person's identity and create an expectation of rejection.

To alter the meaning of the disability, the self-help agency first provides the individual with concrete proof that he or she is not alone and that there are others who share and effectively cope with the same problems. The agency then provides a community that accepts and values the person (Silverman et al., 1987).

Rosenberg (1979) discussed how self-concept is formed by social comparison with others. This concept, with a slight revision, can be applied to the work of self-help groups. By presenting the client with evidence that a group defined by a mental disability is capable of creating an agency, staffing its services, and governing its own behavior, the self-help community redefines the implications of the disability. In effect, the group rather than the individual serves as the basis of comparison with other groups. In particular, to the extent that the agency expands the work of social services agencies, it shows that people with disabilities can be as competent, if not more so, than the professionals who serve them (Katz & Maida, 1990; Mowbray, Wellwood, & Chamberlain, 1988).

The self-help agency can also serve as a local frame of reference (Gecas, 1982). Some client-members are given controlling power in the organization as well as the possibility of filling positions of importance and trust. By directly empowering its members in this manner, the agency provides them with direct evidence of competence and worth to the group. Following Bem's (1972) notion of self-attribution, individuals are able to observe their own behavior and make positive inferences about themselves.

Self-help agencies also deal directly with issues of stigma and self-worth. All provide a setting in which individuals are accepted for who they are and for their contributions to the organization, rather than for their disability. All run some form of discussion group and provide peer counseling. Furthermore, the self-help community has worked to develop understandings of mental illness that avoid the stigmatizing implications of the term, and these writings and concepts are available to clients through written sources as well as discussion.

Organizational Empowerment. Clients are given an active role in the running of the agencies. All agencies are controlled by clients. At commu-

nity meetings, the entire membership is given authority over important policy decisions, including such things as staffing, services offered, and center rules. Governing boards are elected by members and contain a majority of member seats. Staff positions, both paid and unpaid, are largely or totally filled by members. When members break center rules, decisions about what should be done are made either by elected committees or by the entire center membership. Furthermore, the membership attempts to minimize hierarchy within the organization, despite the exigencies of maintaining corporate structures (Zinman, 1987). As result, members are empowered within the organization through exercising control over their collective experiences.

Empowerment Efforts Directed at the Larger Society and Systems Change. As noted earlier, empowerment in the social services context must occur at the policy level as well as in the spheres of the organization and worker-client interaction. Such power in policy formation translates, in turn, into increased influence at the local, state, and national levels. In general, consumers have worked to attain legitimate power, the normative

assumption being that former patients should be involved in policy roles (French & Raven, 1960). Strategies to attain power include advocacy work to influence policy development; input into systems planning, including needs assessments, program design, program management, and evaluation; allocation of existing resources; development of new resources; governance of other agencies; research direction; and community education. Client involvement is intended to create conditions in which clients can gain greater control over their environments and realize their aspirations.

Self-helpers have influenced legislative and regulatory policy decisions at the national, state, and local levels; in turn, these reforms have led to greater consumer involvement in other spheres of systems change. Mentally disabled self-helpers have been an increasingly visible presence on local and state systems planning boards. The Anti-Drug Abuse Act of 1988 (P.L. 100-690) and the ADAMHA [Alcohol, Drug Abuse, and Mental Health Administration] Reorganization Act of 1992 (P.L. 102-321) mandated the inclusion of mental health clients and family members in planning councils.

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Self-helpers are increasing their representation on the governing boards of nonprofit agencies whose client base may include mental health clients. As board members self-helpers can help these agencies become more responsive to the needs of mental health clients. The impact goes beyond the ability of individual organizations to meet those needs; the aggregate effect is to increase the resources in the community clients can use to improve their lives.

As client-run agencies demonstrate their success in serving mentally disabled people, they become recognized as a source of specialized knowledge; thus, they develop expert power (French & Raven, 1960). Providers of mental health services and other social services have invited self-helpers to assist them in making their services more responsive to the needs of their clientele.

Conclusion

We have outlined what is meant by empowerment through self-help agencies, the reasons why these agencies see their activities as necessary, and the types of activities undertaken to achieve their goals. What needs to be done is to document the actual practices of self-help and the effectiveness of those practices. What do self-helpers actually do to empower their clients? To date, the basic services provided by self-help organizations remain poorly documented and poorly understood, at least for those not directly involved in the agencies. Whom do these agencies reach? Is their population, as is often claimed, those who are not willing to use or who are poorly served by the traditional mental health services systems? In what ways and for whom is the self-help model most beneficial? How might it most successfully make use of the traditional mental health services system? A great deal of work needs to be done to understand how these organizations might best contribute to the amelioration of problems associated with psychological disabilities. ■

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