Self Help Organized Through Mutual Assistance in Helping Communities

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Abstract

Self-help organizations facilitate mutual assistance in helping communities. They offer a vehicle for people with a common problem to gain support and recognition, obtain information on, advocate on behalf of, address issues associated with, and take control of the circumstances that bring about, perpetuate, and provide solutions to their shared concern. Self-help organizations may be small informal groups, confined to interactive support for their members, commonly called self-help groups, or differentiated and structured multiservice agencies, mutual assistance organizations referred to as self-help agencies. Such agencies are generally directed and staffed by "self-helpers" and distinct from professionally-led organizations. In these agencies, self-helpers are well-represented as board members with the right to hire and fire professionals in the organization Self-help groups and agencies empower members through shared example and modeled success. Of late, community-based professionally-led organizations have attempted to integrate self-help principles into their support service offerings, reflecting ongoing financial and ideological dynamics in systems of care. This effort has led to the development of peer professional helpers, known as peer support specialists, whose contribution to the helping professions are defined by their lived experience. Spread throughout the world, self-help groups, agencies and integrated peer support specialists are considered a major community resource for enabling people to help themselves. This chapter looks at the development, the content, and the effectiveness of self-help organizations and peer support specialists within professionally-led community-based systems of care.

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Keywords

Self help
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Empowerment

Self-help is the mantra of American life. In the past fort-five years, "self-help", more accurately described as self-help effort organized or facilitated by mutual assistance in helping communities, has become one of the fastest growing movements and adjuncts to professional helping efforts in the U.S. and around the world (US Department of Health and Human Services 1999; WHO 2001, 2008; SAMHSA 2011).

Helping oneself, and being part of a community of individuals with similar issues who are working together to help themselves, fosters a sense of mastery and is probably one of the most satisfying human experiences. It is hard to replicate the gratification it seems to provide to people with problems who have experienced repeated and significant hardships; gratification evidenced by the changes in facial expressions and posture during such participatory experiences. Participation in a community effort of mutual assistance can thus be a gift made possible by finding a position where one, in concert with a peer, in a group, or in an organization, can make decisions that are respected and implemented; people can participate in a meaningful way that provides a context of self-respect for the result of their decision-making process. It is extraordinary to understand that one's problem in such a context is not only accepted, but a qualification for participation. The achievement of such positive effects—though gratifying and validating to the helper-is owned by the individual. Thus the rule for fidelity of self-help intervention—i.e. whether the intervention is truly self-help—is based upon the extent to which the individual is involved in their own decision-making or the decision-making of a group or organization in which they are involved, and the extent to which that decision-making can contribute to implemented action. Whether the self-help intervention is effective is measured by the extent to which participation in decision-making leads to measures of positive outcome.

19.1. Organizational Forms

Self-help settings seek to invest power in a member to recover from a problem or more importantly live a better life with their ongoing problem. Self-help delivered in the form of mutual assistance in a helping community has developed in three major organizational forms: small groups, service agencies, and via peer assistance within a professional service organization. Self-help organizations facilitate mutual assistance (Alcoholics Anonymous 1976; Low 1950). They offer a vehicle for people with a common problem to gain support and recognition, obtain information on, advocate on behalf of, address issues associated with, and take control of the circumstances that bring about, perpetuate, and provide solutions to their shared concern. It is the shared problem that binds a group together and the belief that having experienced the problem gives one a special understanding of how to address its solution. Such organizations may be small informal self-help groups (SHGs), confined to interactive support for their members, or differentiated and structured multiservice self-help agencies (SHAs). Small SHGs frequently affiliate with national organizations that help promote their philosophy and method and that facilitate the formation of new affiliates by providing support, expertise, and referrals. As SHAs, they may provide drop-in service, social support, vocational assistance, housing help, or access to specialized self-help discussion groups. SHGs and SHAs are run by self-helpers, who are individuals that have "lived experience," and, as such, are distinct from professionally lead support groups, which are a mainstay of professional helping practice. Professionally led organizations addressing particular psycho-social, health, or mental health problems are increasingly hiring people with lived experience, peer helpers/peer-support specialists, to supplement their helping efforts. Peer support specialists (PSSs) have become part of the staffs of professionally led organizations—staffers whose expertise derives from their lived experience. These individuals have become increasingly concerned about their vocational opportunities, their potential for advancement in professional organizations and the limited compensation for their helping efforts.

Various terms are used to describe the self-help organizations and the people with lived experience who participate in, hold volunteer positions in, or are employed in self-help activities. The organizations have been called self- help groups, consumer-run organizations (CROs), consumer-operated service programs (COSPs), consumer operated programs (COPs), and self-help agencies (SHAs). Herein, for consistency, all small informal aggregations of individuals helping each other will be referred to as self-helps groups (SHGs), and multi-function service programs run by self-helpers as self-help agencies (SHAs). Participants with lived experience in such programs and in professionally led organizations have been called: self-helpers, members, consumer-survivors, consumers, consumer-providers, peer educators, prosumers and peer support specialists. Herein, again for consistency, all participants in SHGs and SHAs are referred to as self-helpers or members, those holding positions in professionally led helping organizations as peer-support specialists (PSSs).

19.2. Scope

The American Self Help Group Clearing House provides a key-word-searchable database of over 1100 national, international, model, and online self-help support groups and agencies that cover over four hundred separate problems involving addictions, bereavement, health, mental health, disabilities, abuse, parenting, caregiver concerns, and other stressful life situations. In 2015, the single listing of one of the oldest surviving groups—Alcoholics Anonymous World Services, Inc., which was founded in 1935—alone included 106,202 Alcoholics Anonymous (AA) groups in 180 countries worldwide. Other listings in the mental health area include Recovery, Inc., with over 700 affiliate groups; Schizophrenics Anonymous, Inc., with 130 groups; and Grow, Inc., with 143 groups worldwide. Other online resources focus on particular problem areas, such as the National Mental Health Consumers' Self-Help Clearinghouse, which offers news, training, technical assistance, and listings of consumer-driven services in their area of specialty.

A 2002 national survey of mental health mutual support groups and self-help organizations run by and for mental health consumers and/or family members, and consumer-operated services found 7467 groups and organizations—more than the number of traditional mental health organizations (4546). Mutual support groups reported that 41,363 people attended their last meetings and that approximately 1.5 million members were served in 1 year (Goldstrom et al. 2006). In the U.S. alone, the Center for Self-Help Research's (CSHR's) collaborative survey with the National Association of State Mental Health Program Directors (NASMHPD) showed that in 1993 (Segal 1994), 46 states were funding 567 such organizations; by 2015 a similar survey compiled a sample frame of 895 (Ostrow and Leaf 2014). Directors of 190 self-help mental health programs tended to view their services as alternatives to traditional mental health services (Ostrow and Hayes 2015).

Driven in part by policies, which, to varying degrees, mandate peer support (DOH 2009; Kirby 2006; Surgeon General's Report 1999; New Zealand Ministry of Health 2005; AHMC 2009), peer helpers/peer-support specialists are being employed in Canada, the United States, New Zealand, Australia, and the United Kingdom (Walker and Bryant 2013). In the U.S., peer support workers bill Medicaid (GCPSP 2010) and peer operated services are recognized as best practices (Substance Abuse and Mental Health Services Administration 2011; NASMHPD 1989). In 2008, funding was available for associations of service users or consumers in most of the EU15 countries. In the United Kingdom, a Recovery College has been set up, which trains peer support specialists (Wilson 2010). In Ontario, Canada, community mental health care teams are mandated to hire peer support specialists (White et al. 2003).

19.3. Groups and Self Helper Operated Organizations: Philosophy, Method, and Objectives

SHGs share much with SHAs in terms of philosophy and method, yet vary in the breadth of their functional objectives. Both organization types attempt to empower people to change their own lives and to provide them with an accepting, safe, nonjudgmental place where they can find community, information, and support. Their purpose is to pursue personal growth and change. Everyone is a peer. They typically facilitate sharing or interaction or both among members. Decisions are made in a democratic fashion. Leadership is nonprofessional. Leadership positions in the SHG are shared or rotated, though are more established in the SHA. Each member can become a leader with minimal training. Neither the SHG or the SHA is dependent on a particular person for its continued existence. Each member has a right to due process in disputes within the organization. Dues and fees are nominal, covering group expenses (Share 2016; Alcoholics Anonymous 2016, 1976; Low 1950).

The SHA, which is usually incorporated as a nonprofit with a lay board, looks from the outside very much like a traditional community-based nonprofit multiservice agency. It differs in that it is run by and for the service user. Its director, a majority of its governing board, and its staff are

current or former service users. Like in the SHG, the expertise underlying the recovery or helping process derives from personal experience with the problem. SHAs serving people with mental illness include independent living programs that help members access material resources and gain practical skills, as well as drop-in community centers that provide a place for members to socialize, build a supportive community, and get advocacy and a gamut of independent living services (Zinman 1987).

The program of the free-standing SHG generally is embodied in a written text and constitutes a structured *philosophy of life and a psychology of mental health for the ordinary person*. This document is often born out of the founders' resolve to record and share what worked in their own recovery or the recovery of others they are familiar with. The continued development of the structure and philosophy of the groups are ensured by the leaders and the groups' umbrella organizations over the years.

Many SHGs are modeled on the AA philosophy and method, which is contained in the 12 steps and 12 traditions approach that is discussed in Alcoholics Anonymous, and are adapted in such places as Grow's "Blue Book," or "Dual Recovery Anonymous' The twelve steps and dual disorders". Important elements in these 12-step groups include the recognition that the problem is out of control, and that the member wants to deal with the problem within a spiritual framework. AA describes itself as a fellowship of men and women who share their experience, strength, and hope with each other so that they may solve their common problem and help others to recover from alcoholism. The only requirement for membership is a desire to stop drinking. There are no dues or fees for AA membership; they are self-supporting through their own contributions. AA is not allied with any sect, denomination, politics, organization, or institution; does not wish to engage in any controversy; and neither endorses nor opposes any causes. AA's primary purpose is to stay sober and help other alcoholics to achieve sobriety (http://www.aa.org). Their 12 steps and traditions are included in the following text box.

The 12 steps of alcoholics anonymous	**The 12 traditions of alcoholics anonymous**

The 12 steps of alcoholics anonymous	The 12 traditions of alcoholics anonymous
1. We admitted we were powerless over alcohol—that our lives had become unmanageable 2. Came to believe that a Power greater than ourselves could restore us to sanity 3. Made a decision to turn our will and our lives over to the care of God *as we understood Him* 4. Made a searching and fearless moral inventory of ourselves 5. Admitted to God, to ourselves, and to another human being the exact nature of our wrongs 6. Were entirely ready to have God remove all these defects of character 7. Humbly asked Him to remove our shortcomings 8. Made a list of all persons we had harmed, and became willing to make amends to them all 9. Made direct amends to such people wherever possible, except when to do so would injure them or others 10. Continued to take personal inventory and when we were wrong promptly admitted it 11. Sought through prayer and meditation to improve our conscious contact with God, *as we understood Him*, praying only for knowledge of His will for us and the power to carry that out 12. Having had a spiritual awakening as the result of these steps, we tried to carry this message to alcoholics, and to practice these principles in all our affairs	1. Our common welfare should come first; personal recovery depends upon AA unity 2. For our group purpose there is but one ultimate authority—a loving God as He may express Himself in our group conscience. Our leaders are but trusted servants; they do not govern 3. The only requirement for AA membership is a desire to stop drinking 4. Each group should be autonomous except in matters affecting other groups or AA as a whole 5. Each group has but one primary purpose—to carry its message to the alcoholic who still suffers 6. An AA group ought never endorse, finance, or lend the AA name to any related facility or outside enterprise, lest problems of money, property, and prestige divert us from our primary purpose 7. Every AA group ought to be fully self-supporting, declining outside contributions 8. AA should remain forever nonprofessional, but our service centers may employ special workers 9. AA, as such, ought never be organized; but we may create service boards or committees directly responsible to those they serve 10. AA has no opinion on outside issues; hence the AA name ought never be drawn into public controversy 11. Our public relations policy is based on attraction rather than promotion; we need to always maintain personal anonymity at the level of press, radio, and films 12. Anonymity is the spiritual foundation of all our traditions, ever reminding us to place principles before personalities

19.3.1. Empowerment

Self-help is about empowerment, that is, the investment of power in a member to overcome a problem. According to The Oxford English Dictionary (2012), “to empower” implies a formal investment of power. Power may constitute influence over the inner self so that one may take control of one’s impulses to abuse drugs, food, gambling, or other substances or activities, or it may constitute formal power to cope with one’s inner emotions in grief, in gaining control over one’s internal voices or demons, or it may constitute power over one’s social and political context so as to create accommodation of disability, direct one’s own care, and overcome social stigma, poverty, homelessness, and other structural impediments to solving one’s problem. The SHG, in its written principles and by the examples of its members who have actually taken control of their situations or exercised control over their problem, provides a supportive testing ground for the individual to take control of their own problems—as power is rarely given, but rather is taken. Power can be formally invested but must be exercised. The SHG invests power by structuring participation in the 12-step ceremony of spiritual awakening or other through other ceremonial participation. The SHA provides roles for the exercise of power in organizational and extra organizational activities. The peer support specialist invests power by role modeling coping behavior based on lived experience.

The 12-step SHG legitimizes and supports the member’s appeal to a higher authority to help provide the internal strength to exercise such power (Alcoholics Anonymous 1976; Low 1950). While many SHGs originate to deal with an internal issue and are nonpolitical, others come from dissatisfaction with external conditions and their seeming lack of power to do anything about these conditions—such is the case of those groups

arising from the disability rights movement and the antipsychiatry movement. Disability rights advocates banded together to empower themselves to force society to accommodate their disabilities; similarly, the antipsychiatry movement encourages consumers of mental health services to empower themselves to have a voice in the design and implementation of mental health services and their own care and to stop what many described as patient abuse, as reflected in its motto: "Nothing About Us Without Us!" These newer SHGs and SHAs address issues of personal, organizational, and extra-organizational empowerment of their members through the following related activities:

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.

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 (Segal et al. ~~1995~~1993 & 1995).

People who use the services run them, making all the decisions; service providers and recipients are one and the same. The 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. They are based on choice; they are totally voluntary… And finally, they address the real economic, social, and cultural needs of suffering people (Zinman 1986).

19.3.2. Self-help Activities

Providing 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, "mentally ill", "addict", "fat person" and other disabling conditions create 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 societal and organizational structures unwilling to accommodate the disability, and by political decisions limiting available resources.

For many self-helpers the disabling aspects of their disability cannot be separated from their poverty. SHAs seem to be offering the social and psychological package of services unfunded and missing in mainstream programs. Results of a study of 226 new users of eleven mental health SHAs in the greater San Francisco Bay Area indicate that during a six month assessment period, basic resources from the SHA were received by the following percent of sample members: food (71%), bus pass (31%), place to shower (35%), clothing (33%), mailing address (29%), personal items (28%), housing (23%), storage (16%), employment (10%), help in finding a job (10%), help with rent (10%,), and service information (20%) (Segal et al. 2002).

SHAs 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.

Building 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 (see Rotter 1966 on "locus of control" theory and Dweck 2007 on the impact of "learned helplessness"). A person with a mental disability or an addiction 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 SHAs 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.

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 SHAs. By presenting the client with evidence that a group defined by a mental disability is capable of creating an organization, 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 and Maida 1990; Mowbray et al. 1988).

The SHA 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 (see also Weiner 2000, 2010).

SHAs also deal directly with issues of stigma and self-worth. All strive to 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.

Perhaps the single most important factor established to be empirically associated with enhancing client outcomes in SHAs is organizational empowerment (Segal and Silverman 2002). Clients are given an active role in the running of the agencies. All agencies are controlled by clients. At community 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. Experience with responsible decision making within the organization seems to carryover to more effective decision making in their personal lives and a sense of personal empowerment.

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, self-helpers have worked to attain legitimate power, the normative assumption being that disabled individuals should be involved in policy roles (French and 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. Involvement is intended to create conditions in which the disabled 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 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.

Self-helpers are increasing their representation on the governing boards of nonprofit agencies whose client base may include individuals with similar disabilities. As board members, self-helpers can help these agencies become more responsive to the needs of their 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.

19.3.3. Eleven Self-help Programs

In order to better illustrate self-help agency objectives I describe eleven self-help agencies (Segal et al. 2002). The observations are drawn from several years of structured and informal observations at these agencies. The programs combine unstructured drop-ins with structured meetings and other activities and services. All call themselves self-help because the entire membership, staff, volunteers, and others must fit the self-helper control criteria specified above and because the programs employ an empowering approach directed to helping members gain the resources and capacities to better their lives and self-concept. The programs served people with a mental disability at least two-thirds of whom were homeless or marginally housed.

The programs vary in the services and activities offered. All offer a drop-in space, and coffee and several of the programs offer meals. All run support groups and serve as advocates, helping members to obtain shelter and housing referrals, assistance with securing benefits and negotiating the welfare bureaucracy. All offer peer and job counseling, independent living skills training and general discussion sessions. Four programs schedule weekly movies and organized recreational activities such as excursions to baseball games and roller-skating parties for their membership.

The programs are funded from a variety of sources including federal, state, and county monies and foundation grants. They serve anywhere from 20 to well over 100 people a day. Although there are important differences among the programs, we find fundamental similarities in the way each establishes a viable self-help setting. The following five organizational characteristics seem to be important features of such organizations:

Focus on shared experience.

The self-help agencies differ from regular social service agencies in that the majority or all services are delivered by people who have and continue to struggle with the kinds of disabilities that bring new clients to the agency. Thus, for example, many of the staff and volunteers that we interviewed were literally homeless (street or shelter) at the time of the interview or had been homeless at some point in their lives. People draw on their own experiences in living with disabilities, stigma and racism, and in dealing with the sometimes chaotic and seemingly irrational world of social service agencies. They offer advice, for example, on how best to secure disability benefits or which shelters are most accommodating. They offer peer counseling on living with voices that counsel suicide or on trying to stay clean of illegal drugs in an environment where drug use or alcohol use may be the norm. Their advice to clients and ability to listen resonates perhaps with greater authority since they have been there themselves.

One pattern often observed was for staff to tell clients that they did not need to play the games that were seen as necessary to secure informal and formal assistance in the larger world. Staff told the client that they had played such games themselves to get social service personnel to give them a scarce referral to housing or to maintain a benefit after a rule had been broken. Staff in theory and usually in practice, did not divide clients into the deserving and the undeserving poor as a basis for giving assistance. Staff felt further that when clients did not think they had to spin stories to receive help, they were better able to take fuller responsibility for their actions.

At this point, there is no rigorous evidence on whether staff claims are correct. On the one hand, staff and volunteers do serve as models of what is possible for clients. Yet, those who give help continue to struggle with the problems that brought them to the agencies and sometimes these problems gain a greater hold over them. Some clients interviewed spoke bitterly about how they could be expected to be helped by someone who had their own troubles. Unlike a typical social service agency where there is a greater formal separation between client and staff, the SHA blurs the boundaries. The possible greater identification of the client with staff may lead to a greater set of expectations of how the staff should behave.

Focus on mutual assistance.

Certainly the staff helped the clients but clients who did not have a formal role helped out as well. The agencies themselves did not have sufficient personnel to perform all duties. In result, clients might volunteer to go pick up donated coffee, or to answer phones when a staff member was not available. The agencies formalized this informal helping by creating the role of volunteer. Clients who performed volunteer duties were often rewarded through the provision of bus passes or an addition to their resume. However, most, as the staff, worked far more hours than necessary since their duties gave them a chance to help and to be valued for that help.

Clients also helped each other directly. One client was observed giving another in visible distress the valued and scarce resource of a cigarette. They were not friends he just knew how it felt to be depressed. Another was observed giving information about the best place to obtain free meals or to secure needed services.

Re-evaluation of the meaning of having a disability.

Where elsewhere the problems that bring clients to the agency serve as a source of stigma, at these agencies in addition to a brief period of voluntary attendance they define membership. The agencies work to make that membership have a real positive meaning. It is indicative that only one percent of the long-term self-help members were ashamed of being a client at an agency for homeless and mentally disabled individuals while 51% were proud of being a client at the agency (Segal et al. 2002). Seventy-eight percent disagreed with the statement that, "This (the agency) is just a place I come to, it's not that important to me." (Segal et al. 2002) The agencies provide direct evidence that people with disabilities can govern their own affairs. Even if an individual is not capable at that moment of contributing to the agency, he or she can see that others with similar disabilities can help and be trusted to assume important positions. Several vignettes are indicative: A newcomer to one of the agencies was sitting in a community meeting. He questioned the leader of the meeting about a statement. In listening to the leader's answer, the newcomer began to realize that the leader was just like him struggling with the problems of being homeless and having a mental disability. For a few minutes the newcomer kept questioning the leader, unable to believe that an agency of that size would use people with disabilities in important positions. As he began to understand the agency, he was visibly shaken. In another case an individual talked about truly understanding what it meant to be empowered. Although a relative newcomer to the agency, he had been selected to represent the agency' interests at a city function. He had asked the coordinator what he should say and was told that he would be supported in whatever he proposed. He had been homeless and a client of the mental health system and therefore was an expert on what was really needed.

Accommodation of disability.

While the programs turned what were elsewhere stigmatized attributes into sources of contribution and worth, they also had to deal with the day-to-day realities of members who had mental disabilities, substance abuse problems and general problems from dealing with the frustrations of being homeless. There were ongoing problems of maintaining order and permitting the programs to continue. The agencies evolved a series of strategies to deal with members' difficulties. People who were severely depressed or lost in conversation with their voices would be treated with respect. One man, for example, sat in a chair working on a painting with a brush that had no paint. He was left to his art but also involved in activities or discussions when he turned outward to the meeting. Another man who lost track of his actions and refilled a coffee pot several times so that its water spilled over was not visibly noticed or ostracized but instead calmly permitted to clean up the resulting mess. A very depressed woman who was also screaming obscenities was asked by a staff member if she would help him. The request showing that she had value to the organization was sufficient to cause her to smile and help out. Finally, the agency board interviewed a man who was actively hallucinating for a porter's job the organization was recruiting for along with all other applicants. The man was responsive to questions and was considered like all other applicants on the merits of his application and interview.

Some behavior went beyond what was permitted if the agencies were to continue to function. Violence and theft were recurring problems. Members who broke agency rules were brought up to a rules committee composed of their peers and were able to defend their own position. When behavior went beyond what the organization could reasonably tolerate clients might be suspended but were permitted to reapply for attendance privileges after a reasonable period of time. Even while banned, these individuals could continue to use the SHA as a mailing address so that they would not lose a necessary service.

In this manner the agencies recognized that it would be naive to expect anything close to perfection in the behavior of the membership. However, unlike other agencies that permanently banned individuals, the SHAs gave people second and third chances.

Participatory democracy.

The formal organizational structure of the SHAs supported the above practices by moving much of the important decision-making into the hands of the clients. Boards of directors had a mandate and a large number of client held seats on the board. As mentioned staff positions were largely held by clients. Furthermore, all agencies are at least partially run as participatory democracies where at weekly community meetings members discussed and voted on center policy, staffing, rules, and discipline. Staff were selected by a vote of the membership (membership status usually being achieved after a modest period of attendance) at four agencies and by a committee composed of members and staff at the others. Similarly, members determined center rules and policies such as the timing of service availability, location of non-smoking areas and agency positions on external issues that affected the organization. Policies toward and case by case decisions on those who broke the rules were decided either by an open vote of the membership or by an elected committee.

19.4. Peer-Support of Professional Practice

Throughout the United States there is increasing commitment to actively involving individuals with lived experience in the decision making and service delivery of professionally run organizations. Such individuals are involved either as volunteers or peer employees—i.e. peer support specialists (PSSs) working either alongside professionally trained personnel, as part of a team or independently in assisting clients of a professionally led agency.

In both SHGs and SHAs, the relationships that peers have with each other are valued for their reciprocity; they give an opportunity for sharing experiences, both giving and receiving support and for building up a mutual and synergistic understanding that benefits both parties (Mead et al. 2003). In contrast, where peers are employed to provide support in services, the peer employed in the support role is generally considered to be further along their road to recovery (Davidson et al. 2006). Peers use their own experience of overcoming their own problem to support others who are currently in crisis or struggling. This shift in emphasis from reciprocal relationship to a less symmetrical relationship of 'giver' and 'receiver' of care appears to underpin the differing role of peer support in SHGs and SHAs~~.~~ ~~Verses~~ verses professionally-run organizations (Davidson et al. 1999). This shift in status is perhaps the most difficult issue in justifying the position of the PSS, especially when that person has been in a position of such differential status for an extended period of time and may have had a very limited amount of lived experience. No threshold regarding the nature of the lived experience is rigidly employed. Repper and Carter (2011) and others have attempted to address this issue, perhaps doing summersaults to justify the role, in light of expert status claims made for the PSS. They note that while: "…reciprocity is integral to the process of 'peer-to-peer support' as distinct from 'expert worker support,' this is not to say that peer support is not an 'expert role.'…'Peer support is about being an expert at not being an expert and that takes a lot of expertise'." Peer support could therefore be defined as: 'social emotional support, frequently coupled with instrumental support, that is mutually offered or provided by persons having a mental health condition to others sharing a similar mental health condition to bring about a desired social or personal change' (Solomon 2004, p. 393)." As the similarity of lived experience is unspecified, the extent to which this is a mutual assistance activity is open to significant question. Further the extent to which the helping is hierarchical in its presentation subjects it to the same difficulties often attributable to critiques of professional/client relationships. This said professionals whose expertise derives from their lived experience have become a part of helping organizations. They strive for professional identity and have become increasingly concerned about their vocational opportunities, their roles for advancement in professional organizations and their more limited compensation for their helping efforts.

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19.5. Effectiveness

Studies have demonstrated that if the current members of any SHG are surveyed at any given time, the members will respond positively about the group and say that it helps them. As such, a review of more methodically sound studies, focused primarily on studies that compare self-help participants to non-participants in the areas of addiction related recovery, bereavement, cancer groups, caregiver groups, chronic illnesses, diabetes, groups for elderly people, mental health, and weight loss all report salutary outcomes (Kyrouz et al. 2002).

Self-help delivered as a form of mutual assistance, though, is delivered via diverse organizational forms that have considerable variance within groups and organizations. It is assumed useful for diverse problems with diverse definitions of what is self-help and considerable variance in desired outcomes. When addressing the expertise associated with efforts of PSSs no consistency in the definition of lived experience or its match to clients prevails. It is thus not a surprise that a general finding in multiple meta-analyses and some multisite studies is no or little difference in outcomes attributable to the PSS (Lloyd-Evans et al. 2014), or when focused on RCTs, inconsistent findings (Repper and Carter 2011; Doughty and Tse 2011). In order to address this variance in outcomes, herein the focus is placed on the efficacy of self-help efforts to serve people with mental illness. The starting point for considering the effectiveness of such programs is the assumption that the answer is embedded in the details of the program and the conformity of that program to the primary ideology and outcome objectives of the founders of the self-help mental health services movement.

“Nothing about us without us” is the defining objective of the process activity that defines self-help mental health services. It is the giving of agency to participants. In considering the effectiveness of such self-help activities, intervention fidelity should be defined by the extent to which the process conveys agency. The outcome should be criteria-defined as those discussed among self-helpers, and include empowerment, hope, self-efficacy, functional enhancement, and reduced symptomatology. Interventions calling themselves self-help enable people to help themselves, but most importantly do not do things *for* people that they can do for themselves, thereby stealing agency.

SHAs, though founded on the principles of self-help, are not all self-help services, and their essential components are poorly-defined in the literature. Generally, mental health research has failed to make the distinction between those with fidelity to the self-help approach and those that are simply run by individuals or organizations who employ a former patient/consumer. Even the definition of who is eligible to be a consumer, one with lived experience, has blurred from an original criterion of inpatient hospitalization, to an unspecified outpatient contact, to a member of an underrepresented minority. In the face of vague definitions and funding mandates requiring participation of those with lived experience, organizations define their own version of self-helper led services and peer support with little specification of what self-helper-providers actually do or the model of lived experience they are supposed to represent.

The general finding in multiple meta-analyses and some multisite studies of no or little difference in outcomes attributable to the self-helper service (Lloyd-Evans et al. 2014), or when focused on RCTs, inconsistent findings (Repper and Carter 2011; Doughty and Tse 2011) can result from mixed programmatic efforts, some of which enhance outcomes as they are true self-help programs and some of which degrade outcomes, for in the false claim of providing agency comes disappointment and another failure. The indiscriminate combining of studies produces the average: no effect, or inconsistent effects that support self-helper-run service by relying on failure to report significant differences from usual professionally-delivered care, i.e. inappropriately accepting the null hypothesis.

Self-helper control, while a necessary condition for SHA service, is not a sufficient condition to ensure that the organization’s empowerment ideology and its major contributions to member outcomes will be carried into practice. The most challenging RCTs to date, indicate that organizations with a participant democracy approach succeed by truly empowering their membership with significant decision making responsibility; those organizations with a top-down traditional non-profit agency approach that fails to empower their membership fail as helping agents and may be harmful (Segal et al.

2010, 2011, 2013). A self-helper operated service without its empowering approach may be no more than cheap care at best, not an organization within the conceptual and operational achievement of the mental health self-help movement's founders.

Having emphasized the importance of an empowering approach to SHA recovery-focused service, it must be acknowledged that making such programs work is not a simple task. Empowering members is a strength but also a weakness of the SHA. The organizational functionality of more democratically-oriented organizations is often challenging. The less hierarchical enterprises often appear to be more confusing and disorganized the more democratic their operations tend to get. This is also often accompanied by diffusion of responsibility and accountability—while people are empowered to take action within organizations when activities are enjoyable or self-serving, there may suddenly be fewer empowered people available to help as major organizational challenges arise. This can only be addressed by strong leadership that respects cooperative effort without exerting unidirectional control. Thus, the SHA may seem a contradiction of mutual-support and wise leadership—in fact at its best it is a model of joint governance and needs to be evaluated as such.

As self-helper operated service programs demonstrate their success in serving people with mental health challenges, they become recognized as a source of specialized knowledge; thus, they develop expert power (French and 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. To the extent that self-helper operated program directors fail to appreciate the unique contribution of the empowering approach to their organizational successes and fail to protect it within their organizations, the self-helper-run approach may ultimately join the ranks of previously promising but discredited psychosocial treatment efforts.

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