

The Rise of Consumerism

A Contribution to the Surgeon General's Report on Mental Health

Laura Van Tosh, Ruth O. Ralph, Ph.D., & Jean Campbell, Ph.D.

Published in *Psychiatric Rehabilitation Skills*, Volume 4, Number 3, Winter 2000. pages 383-409

Abstract

Consumerism in mental health began in protest against inhuman treatment received in psychiatric hospitals. It continues today in consumer involvement in a wide array of venues. Consumers are still involved in advocating against inhuman and harmful treatment and in advocating for effective mental health services that are provided with dignity and respect. Consumers are also involved in providing support and sustenance for each other in both informal and formal ways: in mutual self-help and in the provision of consumer-operated services. They are also involved in designing, conducting, and participating in research; and in participating in policy making bodies at the local, state and federal levels. This paper outlines the many ways in which consumers have been and continue to be involved in impacting mental health treatment, research, and policy.

History of the Mental Health Consumer Movement

The mental health consumer movement began when people who had been psychiatrically hospitalized and/or their families protested against the inhuman treatment received. As early as 1845, the Alleged Lunatic's Friend Society was established in England (Frese & Davis, 1997). In the United States, shortly after the Civil War, Elizabeth Packard wrote pamphlets describing her forced commitment by her husband, and founded the Anti-Insane Asylum Society in Illinois (Chamberlin, 1990). Elizabeth Stone organized similar activities in Massachusetts during this same period (Geller & Harris, 1994). In the early 1900's Clifford Beers was hospitalized after experiencing confused thinking and agitation. Through his book, A

Mind That Found Itself (1923), he described the terrible treatment received by people with mental illness. He was also instrumental in the founding of the National Committee for Mental Hygiene, which later became the National Mental Health Association (Grob, 1994).

In the late 1940s a self-help group was formed by patients in Rockland State Hospital in New York called We Are Not Alone (WANA). They continued to meet in New York City after being discharged from the hospital and attracted the attention of some volunteers, who found them a place to meet. Members raised their own money (by holding bazaars, for example) and voted in new members. This was the beginning of Fountain House, which is the founder of the clubhouse movement. However, professional staff were hired, and the self-help club became a new kind of psychiatric facility (Chamberlin, 1978).

The mental health consumer movement (called the psychiatric patients' liberation) began in its modern form in the early 1970s without knowledge of any historical roots (Chamberlin, 1990). Frese and Davis (1997) comment:

...individuals in different parts of the country who had been hospitalized for mental illness began to realize that former patients, like members of other marginalized groups, had been legally denied basic rights. They saw that they, too, were regularly described by insulting and devaluating language, and that society discriminated against people who were stigmatized as *the mentally ill*. Sensing the possibility for change, former mental patients began to gather periodically to plan strategies to regain their rights and renounce the imposed role of powerless victims (pp. 243-244).

These early groups were few in size and number and took a decidedly militant viewpoint against psychiatry and the established mental health system which involuntarily committed individuals to psychiatric hospitalization. Groups with names like the "Alliance for the Liberation of Mental Patients", "The Insane Liberation Front", and "Project Release" met in homes and churches and first drew their membership from the ranks of those with first-hand knowledge of negative experiences with the mental health system (*Madness Network News Reader*, 1974). However, they sustained their membership by providing: peer support, education about services

in the community and about the problems consumers were facing, and advocacy to help members access services as well as to change an often oppressive system (Furlong-Norman, 1988).

The Roots of the Mental Health Self-Help Movement. In the late 1960's and early 1970's, the increasing popularity of self-help movements in general, coupled with the greater awareness of the abuses that consumers experienced (partly as a result of media exposés and the film version of the book *One Flew Over the Cuckoo's Nest*), prompted small groups of mental health consumers to begin organizing in the larger East and West Coast cities (*Madness Network News Reader*, 1974).

The movement toward the development of alternative, consumer run (self-help) services began with groups of ex-patients who began to share their stories of demoralization by the mental health system, particularly in psychiatric hospitals, and found that (1) their stories had many similarities, (2) they were angry about these debilitating experiences, and wanted to share this anger, and (3) they wanted to share emotional support with and from others (Chamberlin, 1978). Examples demonstrate the strength of the protest and the determination to develop alternatives to this system. In Vancouver, people receiving treatment in a day hospital were not allowed to exchange telephone numbers, nor to talk to each other outside of the treatment program. One morning they learned one of their members had committed suicide. The immediate result was the clandestine circulation of a patients' phone list and reliance more on communication with each other than on the therapy received. A public meeting to discuss dissatisfaction with the psychiatric system was attended by over 75 people who came to share their stories and to find support. They decided to provide services they had been unable to find, became the Mental Patients' Association, eventually operating a seven-day/week drop-in center and five cooperative residences. Another group of ex-patients in New York City began meeting together with similar experiences and outlook. Calling themselves the Mental Patients' Liberation Project, in the first few weeks of their existence they wrote a Mental Patients' Bill of Rights. In Boston, Massachusetts, the Mental Patient's Liberation Front (MPLF) was founded

by two ex-patients who focused on consciousness-raising, which brought people to feel self-respect, which they never had before. A small group of MPLF members wrote a patients' rights handbook, researching the mental health laws in Massachusetts with the help of a lawyer consultant. They solicited donations from activist groups and had it printed at the New England Free Press. The resulting publication, *Your Rights as a Mental Patient in Massachusetts*, a 56 page document, includes laws concerning commitment, voluntary and involuntary hospitalization, patients' civil rights and treatment, and a bill of rights – similar to the one developed in New York City (Chamberlin, 1978).

Over time, the numbers and types of groups began to grow, and more moderate viewpoints came to be represented. Groups such as Emotions Anonymous; Recovery, Inc.; and GROW focused more on peer support and far less—if at all—on advocacy, while others even welcomed the involvement of professionals in their activities (Kaufmann and Freund, 1988; Emerick, 1990; Roberts and Rappaport, 1989).

In 1979 the National Alliance for the Mentally Ill (NAMI) was founded primarily by and for the families of individuals with serious mental illness. In 1985 this group formed a subgroup for consumers that was initially called the NAMI Client Council. Later its name was changed to the NAMI Consumer Council (Culwell, 1992; Frese & Davis, 1997).

Communication Among Consumers. The publication of *On Our Own* by Judi Chamberlin (1978) was a milestone in the history of the movement. Consumers and others now could read in the “mainstream” press what it was like to have experienced the mental health system. *On Our Own* also provided details about the mental health consumer self-help movement and discussed the extension of this concept into the development of consumer-run services. For many consumers, reading this book was the beginning of their involvement in the consumer movement (Van Tosh & del Vecchio, in press). The voices of these early consumer groups began to be heard in 1972 with the initial publication of the *Madness Network News*, which continued publication until 1986, and with the establishment of the Conference on Human Rights and Against Psychiatric Oppression which met annually from 1973 through 1985. In

1976, a 20 member President's Commission on Mental Health acknowledged that "groups composed of individuals with mental or emotional problems are being formed all over the United States." (President's Commission on Mental Health, 1978, pp. 14-15).

In 1985, with funding from NIMH/CSP, the first national conference of consumers was held in Baltimore, Maryland, to provide technical assistance and opportunities for networking and information exchange (replacing the former Conference on Human Rights and Against Psychiatric Oppression). This meeting, called "Alternatives '85", was attended by approximately 400 people and proved so popular that it became an annual event. By 1991, the "Alternatives" conference held in Berkeley, California, drew close to 2,000 participants from virtually every State in the Union and a number of foreign countries (Acker, 1990; Twedt, 1990). Since that time, the conferences have continued to be held with similar attendance. Consumers have planned each of the conferences utilizing the skills of national and local consumer organizations.

Other methods of communication are newsletters, conference calls, and more recently the internet, where a proliferation of listserv groups and websites can be found.

Impact of the Consumer Movement

On a systems level, the consumer movement has substantially contributed to the increased involvement of consumers in all aspects of the planning, delivery, and evaluation of mental health services as well as in the protection of individual rights. Specific examples of the positive outcomes achieved as a result of their involvement include: Public Law 102-321 (formerly P.L. 99-660), which established mental health planning councils in every State, and the development of Protection and Advocacy agencies for patients' rights in every State (Chamberlin and Rogers, 1990). Both of these laws also include a requirement for substantive consumer involvement in planning and implementing mandated activities.

The consumer movement also has had a substantial influence on increasing the utilization of consumers as employees in the traditional mental health system as well as in other areas (Specht, 1988; U.S. Department of Education, 1990; Schlageter, 1990; Interagency

Council on the Homeless, 1991). Consumers are being hired at all levels in the mental health system, ranging from case manager aides to management positions in national advocacy organizations as well as state and federal governmental agencies. As consumers enter into leadership positions, many leaders in the field are also disclosing their own mental health histories (Furlong-Norman, 1991 and 1988).

A significant development has been the establishment of Offices of Consumer Affairs (OCAs) in nearly 40 State Mental Health Authorities. OCAs are generally staffed by consumers to support consumer empowerment and self-help in their particular States. In 1995, CMHS hired its first Consumer Affairs Specialist. In the analysis of data on the involvement of consumers collected by the National Association of State Mental Health Program Directors 1995-1996 State Mental Health Agency (SMHA) Profiling System, Campbell (1998) noted that these Offices of Consumer Affairs serve as system change agents. The scope of work of these offices is to bring consumer perspective into areas of policy making, perceptions, and practices of the SMHA, and to encourage consumer and family involvement and empowerment in government. Using chi-square statistics to examine the independence of the presence or absence of OCAs, significant relationships were found in the provision of SMHA resources for conference support ($p < .001$) and technical assistance ($p < .023$); consumer involvement in SMHA boards ($p < .037$) and local boards ($p < .006$); consumer involvement in Internal Review Board (IRB) membership ($p < .001$); and consumer involvement in direct hire of consumers/survivors for services evaluation activities ($p < .001$) (Campbell, 1998).

With the passage of the Americans with Disabilities Act (ADA) in 1990, employment in fields outside the mental health sphere has become a more achievable goal for consumers. This landmark legislation not only makes it possible for persons with disabilities to more easily obtain employment, but also it may assist people with disabilities to maintain a job. In addition, the ADA makes provisions for training consumers to use the legislation appropriately. In the process, employers who otherwise would not be aware of this important legislation will also be educated about the rights of Americans with disabilities and their responsibilities as employers to accommodate special needs in the workplace (Furlong-Norman, 1991).

Self-Help

One of the greatest contributions of the mental health consumerism movement has been the organization and proliferation of self-help groups and the impact they have had on the lives of thousands of consumers of mental health services.

What is Self-Help in Mental Health? Approximately 7.5 million Americans participate in as many as 500,000 self help groups each year, addressing a range of illnesses, addictions, disabilities and conditions (Lieberman & Snowden, 1994). It is estimated that 12 to 15 million people participate during their lifetime. A 1988 survey found an 8% annual increase in membership in mental health self-help groups (Harvard Mental Health Letter, 1993). In 1993, a collaborative survey found that 46 state mental health departments funded 567 self-help groups and agencies for persons with mental disabilities and their family members (National Association of State Mental Health Program Directors, 1993). In the *National Directory of Mental Health Consumer and Ex-patient Organizations and Resources*, (SC SHARE, 1995), all 50 states and the District of Columbia are represented with 235 different consumer organizations. There are also 19 national sources from which to obtain self-help information and referral.

Self-help is based on the principle that people with a shared condition come together to help themselves and each other to cope. The two-way interaction of giving and receiving help is seen as therapeutic in itself. Mutual sharing of experiences, feelings, and practical ways of handling problems assists individuals to get well and function better by validating their feelings

and empowering them (Mental Health Policy Resource Center, 1991). Self-help has gained such notoriety and acceptance that the former Surgeon General of the United States, Dr. C. Everett Koop observed, "...the benefits of mutual aid are experienced by millions of people who turn to others with a similar problem to attempt to deal with their isolation, powerlessness, and alienation..." (Katz, et al. 1992). In a review of self-help research studies, Medvene (1986) found that "...numerous research studies show that participation in self-help groups can help people improve the quality of their lives significantly. Studies also show that support groups can reduce the need for medical care and hospitalization."

According to perspectives from mental health self-help leaders, participants, and significant others, self-help contains seven elements: (1) the common bond, i.e. collective experience related to being diagnosed with a mental illness and receiving mental health services, and individual experiences associated with having survived this process; (2) helping one's self and other people: a mutual process; (3) voluntary and not mandated, forced, or charity; (4) trusting, open, supportive environment; (5) ability to reach out, share experiences and learn; (6) no dichotomy between the helper and the helpee; and (7) decision making rests in group members' hands (Carpinello & Knight, 1991; Zinman, Harp, & Budd, 1987).

Who uses self-help? Studies in a variety of settings show a diverse group of people use self-help. A study of participants in four self-help agencies in San Francisco, (Segal, Silverman, and Tempkin 1995a) found that 46 percent of the respondents were homeless, with an additional 13% in precarious housing (having to move in two months or less). And 78% had been homeless at least once in the past five years. There were more males (72%), and African Americans (64%) and they had an average age of 38. They experienced multiple disabilities (mental illness, substance abuse, health problems). Fifty-two percent of the respondents had a history of psychiatric hospitalization, with 75% hospitalized within the past ten years. Information from participants of six different self-help organizations across the United States showed a greater number of male respondents (60%), an average age of 40, and 56% whites, 36% African Americans, and 8% other (Chamberlin, Rogers, and Ellison 1996). Nearly 15% were

married, and more than half reported they have children (53%). Most respondents lived in private homes or apartments (48%) with 15% homeless, and the remainder in rooming house, supervised living arrangements or “other”. There appears to be notable use of the mental health system suggesting that people use self-help in concert with traditional services rather than as an alternative. Respondents used about 7 mental health services in the past year, and about half were currently taking psychiatric medications. They participated in self-help an average of 15 hours a week, and had been involved in self-help about 5 years. In an area in New York state, which has a high degree of self-help activity, Carpinello et al (1995) examined similarities and differences of participants and non-participants of mental health self-help groups. Respondents choosing to participate in mental health self-help groups were slightly older, more likely to be white, married, and have higher levels of education. They were also more likely to be living in a private residence as opposed to community, group, or public housing. Self-help participants were less likely to have been hospitalized in the past 5 years for mental health problems. Higher confidence in their ability to advocate for themselves and others was reported by the self-help participants.

The Benefits of Consumer Participation in Self-Help People participate in consumer self-help for the same reasons that they participate in other self-help groups; for peer-based support, assistance in developing coping strategies, exposure to relevant role models, affordability, pertinent information about issues and services, advocacy for systems change, the opportunity to interact without stigma, and the sense of well-being and self-esteem that derives from helping others (Borck, 1983; Fleming, 1983; Van Tosh, 1990; Roberts and Rappaport, 1989).

The values and philosophies that guide consumer self-help are the driving forces behind its development and its success. With other self-help movements, it shares the belief in: peer-based support and assistance; non-reliance on professionals; voluntary membership; egalitarian, non-bureaucratic, and informal structure; affordability; confidentiality; and non-judgmental support. Although they share these features in common with other self-help groups,

mental health consumer organizations place an extraordinary value on peer support, hope, and recovery (Van Tosh & del Vecchio, in press).

Self-Help Outcomes. The effectiveness of self-help groups is grossly under-researched. Humphreys and Rappaport (1990) comment: "Although the practice of mutual help is as old as civilization (Kropotkin, 1972), the field of mutual help research is clearly young and has not found a comfortable home or set of habits (p. 221)" One of the reasons for this is that self-help groups are voluntary and non-hierarchical and therefore do not fit into the concept of "treatment". Because of this, the study of self-help does not lend itself to the traditional controlled studies of services research. Zinman (1988) asserts that in order to study self-help groups, members must be involved in the development of the evaluation methodology, with professionals serving as technical experts or consultants. Evaluation might differ if planned and implemented by consumers, because the questions themselves may differ from what professionals would ask (Hatfield, 1988).

Still, within the limitations of appropriate research methodology, a number of studies have been done to demonstrate the value and effectiveness of self-help for consumers. In following 115 former mental patients, Luke (1989) found that those who continued to attend self-help meetings at least once per month over a period of 10 months were more likely to show improvement on psychological, interpersonal, or community adjustment measures than those who attended less frequently.

In a retrospective study of 393 leaders of Recovery, Inc, a self-help organization for mental health recipients, participants reported fewer doctor visits, hospitalizations, and medication use after they began participating in Recovery, Inc. than before they had joined (Raiff, 1984).

In a long-term evaluation study of GROW, another self-help organization for persons with mental illness, GROW members were matched to nonmembers who had been hospitalized an equivalent number of days prior to the member joining GROW. They were also matched on race, sex, age, marital status, diagnosis, religion, community tenure, discharge region, and

number of hospitalizations over a period of 32 months prior to the member joining GROW. Over the 32 month study period, GROW participants spent an average of 49 days in the hospital compared to 123 days for their matched controls (Kennedy, 1989).

Results from a survey of mental health self-help group leaders in New York State (Carpinello & Knight, 1993) provide some further insights about the effectiveness of self-help groups. Respondents identified three positive outcomes that were directly related to self-help group membership: greater self-esteem, more hopefulness about the future, and a greater sense of well-being. Ninety percent of the leaders reported they witnessed the following changes in members: getting along better with others, assuming responsibility, more connected to peers, more assertive, empowered to make own decisions, living more independently, better listening skills, and better problem solving. Eighty percent felt members were also more skillful in speaking in front of a group, were holding a job, and were able to stay out of the hospital longer. In another study, using focus groups and key informant interviews, Carpinello and Knight (1991) delineated the positive effects of self-help. Several participants declared: "Self-help has given my whole life meaning.. it has normalized my life." Participants also talked about how they moved from dependency, self-destruction, or hopelessness to positive social identity. Common themes emerged as participants talked about what self-help had done for them. They saw themselves in a more positive light, experienced a heightened sense of personal well-being, and were more able to make decisions by themselves. They felt they were able to function better in society, and were less dependent on alcohol and drugs. Many were motivated to pursue educational goals and employment opportunities. All of these positive changes led to their having to return to the hospital less often.

Powell and Knight (1994) summarize: "Self-help works because it helps reduce the symptoms of mental illness as people come together to discuss their common concerns. This helps overcome the isolation that is so prevalent. Self-help also helps people move from the role of always being helped to the role of helping others. This gives a sense that they have something worthwhile to contribute. Members share and learn from one another as equals who

have had common experiences. Those who cope successfully serve as role models for people who cope less successfully. Self-help provides meaningful structure for people - not structure imposed from the outside by professionals, but one that is generated from the members themselves.”

Consumer-Operated Programs One of the most significant outcomes of the consumer self-help movement has been the development of mental health consumer-operated programs, which are services that are planned, delivered, and evaluated by consumers themselves. Some programs incorporate the use of professionals in certain areas of planning, implementation, and evaluation (Fleming, 1983; Stroul, 1986). It was an appreciation for the potential value of peer support, as a principal form of social support, that stimulated the Community Support Program (CSP) of the National Institute of Mental Health to fund local consumer-operated Services Demonstration Projects from 1988-1991. These demonstration projects also resulted in the increasing involvement of mental health consumers in the development and provision of peer support, involvement in traditional service roles, evaluation of services, and the articulation of policy. A variety of consumer-operated programs were developed, staffed and evaluated (Furlong-Norman, 1988; Nikkel, Smith & Edwards, 1992) as states began to fund locally-based initiatives. These included drop-in centers, outreach programs, businesses, employment and housing programs, and crisis services, among others (Long & Van Tosh, 1988; National Resource Center on Homelessness and Mental Illness, 1989; Penny, 1992; Van Tosh & del Vecchio, in press). Other independently developed self-help programs or state supported consumer operated services were also evaluated in a variety of ways (Galanter, 1988; Kaufmann, Ward-Colasante, & Farmer, 1993; Heine et al, 1993; Lieberman, Gowdy, & Knutson, 1991; Mowbray & Tan, 1992) More recently, the Center for Mental Health Services has funded a cooperative agreement with 8 sites and a coordinating center to study the effects of consumer operated services added to traditional services (GFA 98-04, 1998)

Consumer Involvement in Research

Consumers have been involved in research in a number of ways: as subjects, which were observed in terms of changes in reactions or functioning as a result of some “treatment”; as respondents who are asked questions about conditions in their life; as the partner, where consumers are involved in some aspect of the planning, designing, and conducting of the research project with professional researchers in control; and as the independent researcher, where consumers design, conduct, analyze the data, and publish the results of the research project (Campbell, Ralph & Glover, 1993).

Advocates of peer support services believe that consumers have an insider’s understanding of the expectations that consumers have of services and the ways in which traditional providers meet and fail to meet these expectations (Campbell, 1996). Likewise, evaluation research with consumer participation can take advantage of consumer perspective to increase meaningfulness and usefulness of investigations. Methods utilizing a participatory style of research where groups being studied are consulted at every stage of the process and encouraged and helped to carry out research themselves have been shown to enrich and validate the knowledge that is produced (Chesler, 1991). Participatory models have the capacity to go beyond the statistics that record numbers to include meaningful interactions with those living with a psychiatric diagnosis. As a result, new questions, methods, and ways of interpreting data have emerged (Ralph & Campbell, 1995; Ralph, 1996).

The last decade has witnessed the blossoming of a vibrant consumer research agenda and the growing belief that consumer involvement in research and evaluation holds great promise for system reform, quality improvement, and outcome measurement. (Campbell, Ralph & Glover, 1993; Campbell, 1997).

Some of the early efforts to involve consumers in research were the People First study in California (1984) and the Hill House Project in Ohio. By using audiotaped meetings, People First (statewide organization of adults with mental retardation) got direct input from disabled people about services they needed, and developed a methodology to utilize the work of these

consumers. In Cleveland, Hill House completed a study with people who were psychiatrically labeled. The process of using clients to design the research instruments proved to be reliable and valid, and demonstrated that consumer members had the expertise to identify and classify their feelings (Prager & Tanaka, 1979; Smith & Ford, 1986).

The Well-Being Project (Campbell & Schraiber, 1989, Campbell, 1992) made a substantial contribution to understanding the concept of quality of life from the perspective of consumers. Results indicate the validation of personhood, a recognition of common humanity, and a tolerance for individual differences are essential to well-being.

One of the areas in which consumers have been most widely involved is in the development and conducting of needs and preferences studies, particularly in the area of housing. Results have shown that people want to live in "their own place", i.e. an apartment or house, and want to choose the people with whom they live - including their children. Privacy, safety, and being able to contact family and staff are considered important issues to consumers. (Ralph & Campbell, 1995; Eastman & Ralph, 1993; Tanzman, 1993).

In all of the research and evaluation work in which consumers have been involved, outcomes valued by consumers have been articulated. In a series of meetings supported by the Center for Mental Health Services, the Consumer/Survivor Mental Health Research and Policy Work Group began a systematic articulation and exploration of consumer values and desired outcomes of mental health services and supports. Recovery, personhood, well-being and liberty were identified as valued outcomes that are seldom measured or operationalized in traditional mental health research or program evaluation (Consumer/Survivor Mental Health Research and Policy Work Group Task Force Reports, June, 1992; July, 1992; September, 1992). The role of recovery is being defined and measures are in process of being developed by consumer researchers (Deegan, 1988; Ralph, Lambric & Steele, 1996; Ralph, 1996; Campbell, 1997).

Empowerment is especially important in the area of self-help in mental health.

Rappaport, (1985) in a keynote address to the third annual meeting of the New York City Self Help Clearinghouse defined empowerment:

Anyone who has experienced joining a group to look for help and discovers that he or she helps others as well knows something of what it feels like to begin a journey toward what I call empowerment. They know what it is like to gain psychological control over one's self, and to extend a positive influence to others, and ultimately to reach out to influence the larger community. (p. 15)

In a study of empowerment in mental health consumer-run agencies, Segal, Silverman & Temkin (1995b) developed a definition of empowerment from writings and practice theories of leaders in the self-help mental health movement and theoretical constructs in community psychology, developed an instrument based upon this definition and construct, and tested it with 310 members of four self-help organizations. They concluded that (1) they measured two components of the empowerment construct: personal empowerment and organizationally/extra-organizationally derived empowerment; (2) dimensions of empowerment are related to different functional outcome domains - quality of life and independent social functioning are most likely to be related to personal empowerment, while organizational empowerment is more related to involvement in work, both paid and volunteer; and (3) self-efficacy proves to be the bridging construct between the two dimensions of empowerment. The two dimensions of empowerment look at the control the individual has over his or her material situation and his or her experiences in exercising control within and outside of the self-help organization (Segal, Silverman, and Temkin, 1995b).

Consumer Involvement in Policy

The mental health field has seen great change in the way in which policy is being developed. Consumers are increasingly becoming equal partners in this process often reserved for seasoned policy analysts and others. With the establishment of state mental health planning councils and local mental health advisory boards and committees, consumers are key players in

these settings, offering input and expertise to the overall development of policy at the state and local levels. In addition, consumers are active participants in the process to reform health and mental health care. They are engaged in dialogues and discussion-making bodies with other stakeholders; e.g. Medicaid departments as states and locales explore the creation of privately operated managed care systems. In addition, consumers have entered the halls of many bureaucracies, serving in leadership roles in Offices of Consumer Affairs and interfacing with other government departments. What was once believed to be the last bastion for consumer integration, consumers are now seen as critical stakeholders.

Regardless of the setting consumers participate in to develop or shape policy, they are also advocates in the communities where they live and work. Advocacy from outside the traditional system provides consumer groups with the opportunity to shape policy with other advocacy organizations. Coalition-building with other stakeholder groups has proven to be an effective method to influence and shape policy. The National Mental Health Association and the National Mental Health Consumer Self-Help Clearinghouse hosted one such conference where two advocacy organizations' memberships came together to form coalitions at the state and local levels (The Key, Vol. 4, No. 2).

In the arena of managed care, The Managed Care Consortium (MCC) formed in 1995 to create educational opportunities for a host of advocacy organizations across the United States. The MCC, with funding support from the federal Center for Mental Health Services, encouraged teams to form in each state to impact the development of managed care programs.

Consumer involvement in policy was initially encouraged by federal laws mandating substantial involvement by consumers in planning, oversight, and advocacy activities at the state level (Chamberlin and Rogers, 1990; Van Tosh and del Vecchio, in press). Even with these major advances, consumers today still struggle to have their voices heard and respected.

The Future of Consumerism

The future of consumerism is being built by the creativity and forward thinking of today's consumers. Deegan, among others, is making an effort to document and guard against repetition of poor mental health treatment through collecting artifacts and taking photos of historical interest in mental health treatment facilities. Included are the efforts of consumers in Georgia to clean up and restore the graveyard in the grounds of the ----- Psychiatric Hospital where patient graves were marked only with metal numbered markers, and many of them had been pulled up and thrown aside. Deegan's dream is to have a museum of these pictures and artifacts - "so that we never forget and never let it happen again." (Personal Communication, spring, 1998).

In the future, consumer self-help groups and organizations will be developed by and for all cultures to respond to their cultural needs and heritage. Other consumer groups will be cross-cultural, with members learning from each other, and a better understanding and appreciation will develop among consumers and families about their diversity and their commonality. Consumers in rural areas will be able to communicate, give and get support from other consumers from their area and the nation through virtual self-help groups in the electronic media.

Two centers for consumer research and training have been instituted in 1998 - one in the Kentucky Department of Mental Health and one at the Missouri Institute of Mental Health in St. Louis. It is expected that others will be initiated. Consumer research is being valued by being funded by state and federal initiatives, and as it continues to contribute, will impact upon the methodology and outcomes of conventional research. Libraries of published and unpublished consumer written literature will be housed at these centers and at other locations in the country. In the near future these will be available on the internet.

Consumers will continue to have a voice and to provide leadership on local, state, and national boards, committees and projects, to provide experienced (in the mental health system) information for decision and policy making.

Consumers have a major stake and role in ensuring their voices are heard in the future. With healthcare reform underway in virtually every state and community, consumers are becoming change agents - looking ahead to protect and preserve valuable services and rights. The role of the consumer is as important today as in the foreseeable future. Today, consumers are laying the framework for generations to come.

The power of the consumer perspective is having an impact on the overall healthcare industry. With the emphasis on “bottom line” economics and policies driven by both the public and private healthcare sectors, the voice of consumers is somewhat dimmed by concerns for the financial health of managed care companies. Yet, there is an increasingly loud call for accountability by consumers themselves, policy makers, and governments. In addition, calls for quality and consumer protections in healthcare are being heard and heeded (Office of the Press Secretary, March 26, 1997 – Remarks by the President during Health Care Quality Commission Announcement, President’s Advisory Commission on Consumer Protection and Quality in the Health Care Industry, 1998). Consumers play a pivotal role in setting the priorities for a healthcare agenda. As a result of these calls by consumers for better quality and accountability, the consumer is far and above the most important stakeholder.

Consumers will continue to “vote with their feet” as healthcare systems are developed and implemented. - Empowerment will give consumers the influence, courage, and respect needed to develop responsive systems for the consumers of tomorrow.

Consumerism Bibliography

- Acker, C. (1990, July 16). Conference gives hope to patients. Philadelphia Inquirer, 1B.
- Beers, C. (1923). A mind that found itself. Garden City, NY: Doubleday.
- Borck, L. (1983). The enhancing of social support for mental health patients through the development of a self-help group. In D. Pelta (ed.) Community support in mental health 3. Columbus, OH: Ohio Department of Mental Health.
- Campbell, J. (1997, June) How consumers/survivors are evaluating the quality of psychiatric care. Evaluation Review, 21 (3), 357-363.
- Campbell, J. (1998) The technical assistance needs of consumer/survivor and family stakeholder groups within state mental health agencies. Prepared for: National Technical Assistance Center for State Mental Health Planning. St, Louis, MO: Missouri Institute of Mental Health.
- Campbell, J. (1992). The Well-Being Project: Mental health clients speak for themselves. In Third annual conference proceedings on state mental health agency research. Alexandria, VA: National Association for State Mental Health Program Directors Research Institute.
- Campbell, J. (1996, Fall). Toward collaborative mental health outcomes systems. New Directions for Mental Health Services 71, 68-69.
- Campbell, J., Ralph, R., & Glover, R. (1993). From lab rat to researcher: The history, models, and policy implications of consumer/survivor involvement in research. Proceedings: Fourth annual national conference on state mental health agency services research and program evaluation, NASMHPD, Alexandria, VA, 138-157.
- Campbell, J. & Schraiber, R. (1989). In pursuit of wellness: The Well-Being Project. Sacramento, CA: California Department of Mental Health.
- Carpinello, S.E. & Knight, E. (1991). A qualitative study of the perceptions of the meaning of self-help, self-help group processes and outcomes. Albany, NY: New York State Office of Mental Health.

- Carpinello, S.E. & Knight, E.L. (1993). A survey of mental health self-help groups in New York state: Summary results. Albany, NY: New York State Office of Mental Health.
- Carpinello, S.E., Knight, E.L., Videka-Sherman, L. Sofka, C., Blanch, A., & Markowitz, F. (1995). A contrasting profile: Participants and nonparticipants of mental health self-help groups. Alexandria, VA, Proceedings, The Fifth Annual National Conference on State Mental Health Agency Services Research and Program Evaluation.
- Chamberlin, J. (1978). On our own: Patient-controlled alternatives to the mental health system. New York: McGraw-Hill Co.
- Chamberlin, J. (1990). The ex-patient's movement: Where we've been and where we're going. Journal of Mind and Behavior 11, 323-36.
- Chamberlin, J. (1995) Rehabilitating ourselves: The psychiatric survivor movement. International Journal of Mental Health 24 (1) 39-46.
- Chamberlin, J. & Rogers, J. (1990). Planning a community-based mental health system. American Psychologist 45 (11), 1241-1244.
- Chamberlin, J., Rogers, E.S. & Ellison, M.L. (1996). Self-help programs: A description of their characteristics and their members. Psychiatric Rehabilitation Journal 19 (3), 33-42.
- Chesler, M.A. (1991). Participatory action research with self-help groups: An alternative paradigm for inquiry and action. American Journal of Community Psychology 19 (5), 757-768.
- Consumer/Survivor Mental Health Research and Policy Work Group Task Force. (1992, unpublished). Focus groups on outcome measures/client outcomes. Fort Lauderdale, FL: Author.
- Culwell, D.H. (1992). The national mental health consumer scene. The Journal of the California Alliance for the Mentally Ill 3 (2), 40-42.
- Deegan, P.E. (1988). Recovery: The lived experience of rehabilitation. Psychosocial Rehabilitation Journal 11 (4), 11-19.

- Eastman, L.A. & Ralph, R.O. (1992) Consumer housing preference survey. Presentation to the Housing Work Group, Brunswick, ME. Shoreline Mental Health Center.
- Emerick, R. (1990). Self-help groups for former patients: Relations with mental health professionals. Hospital and Community Psychiatry 41 (4a), 401-407.
- Fleming, B. (1983). Consumer-operated services. In D. Pelta (ed.), Community support in mental health 3. Columbus, OH: Ohio Department of Mental Health.
- Frese, F.J. & Davis, W.W. (1997). The consumer-survivor movement, recovery, and consumer professionals. Professional Psychiatry, Research and Practice 28 (3), 243-245.
- Furlong-Norman, K. (ed.). (1988, November). Community Support Network News 5 (2).
- Furlong-Norman, K. (ed.). (1991, March). Community Support Network News 7 (3).
- Galanter, M. (1988). Zealous self-help groups as adjuncts to psychiatric treatment: A study of Recovery, Inc. American Journal of Psychiatry 145 (10), 1248-1253.
- Geller, J.L. & Harris, M. (1994). Women of the Asylum. New York: Anchor.
- Hatfield, A. (May 1998). Report of research meeting on community support and rehabilitation services. Presentation at the Joint NIMH/CSP-NIDRR Conference, Bethesda, MD.
- Heine, R., Hasemann, D., Mangine, S., Dearborn-Morris, E., & Royse, D. (1993). Consumer providers in crisis response systems. Proceedings of the fourth annual NASMHPD Research Institute, Inc. conference on state mental health agency services research and program evaluation.
- Humphreys, K. & Rapport, J. (1994) Researching self-help/mutual aid groups and organizations: Many roads, one journey. Applied and Preventive Psychology (3), 217-231.
- Interagency Council on the Homeless. (1991). Reaching out: A guide for service providers. National Institute of Mental Health. Rockville, MD: The National Resource Center on Homelessness and Mental Health.
- Katz, A., Isenberg, D., Goodrich, T., Hedrick, H., Thompson, L., & Kutscher, A. (eds.) (1992). Self help concepts and applications. Philadelphia, PA: The Charles Press.

- Kaufmann, C. & Freund, P. (1988). Self-help and peer mutual support in community mental health: A model for peer-professional collaboration. Pittsburgh, PA: Author.
- Kaufmann, C.L., Ward-Colasante, C. & Farmer, J. (1993). Development and evaluation of drop-in centers operated by mental health consumers. Hospital and Community Psychiatry 44, 675-678.
- Kennedy, M. (1989, June) Psychiatric hospitalizations of growers. Paper presented at the Second Biennial Conference of Community Research and Action. East Lansing, MI.
- Kropotkin, P. (1972). Mutual aid: A factor of evolution. New York: New York University Press. (Original work published 1902).
- Lieberman, A.A., Gowdy, E.A., & Knutson, L.C. (1991). The mental health outreach project: A case study in self-help. Psychosocial Rehabilitation Journal 14 (3), 100-105.
- Lieberman, M.A. & Snowden, L.R. (1994). Problems in assessing prevalence and membership characteristics of self-help group participants. In T.J. Powel (ed.) Understanding the self-help organization: Frameworks and findings. Thousand Oaks, CA: Sage Publications.
- Long, L. & Van Tosh, L. (1988). Program descriptions of consumer-run programs for homeless people with mental illness. Rockville, MD: National Institute for Mental Health.
- Luke, D.A. (1989). The measurement of change in a self-help context. Unpublished doctoral dissertation, University of Illinois, Urbana-Champaign.
- Madness Network News Reader. (1974). San Francisco, CA: Glide Publications.
- Mental Health Policy Resource Center (1991, May) Policy in Perspective.
- Mowbray, C.T. & Tan, C. (1992). Evaluation of an innovative consumer-run service model: The drop-in center. Innovations & Research 1 (2), 19-23.
- National Association of State Mental Health Program Directors. (1993). Putting their money where their mouths are: SMHA support of consumer and family-run programs. Arlington, VA National Association of State Mental Health Program Directors.

- National Resource Center on Homelessness and Mental Illness. (1989). Self-help programs for persons who are homeless and mentally ill. Delmar, NY: Policy Research Associates.
- Nikkel, R.E., Smith, G., & Edwards, D. (1992). A consumer-operated case management project. Hospital and Community Psychiatry 43, 577-579.
- Parrish, J. (1989). The long journey home: Accomplishing the mission of the community support movement. Psychosocial Rehabilitation Journal 12, 107-124.
- Penny, D. (1992) Client/Practitioners offer both insights. OMH News, New York State 4 (4), 16.
- Powell, I.G. & Knight, E. (1994) Empowering the disempowered. New York, Mental Health Recipient Empowerment Project.
- Powell, T. (1987). Self-help organizations and professional practice. Silver Springs, MD: National Association of Social Workers.
- Prager, E. & Tanaka, H. (1979). New research in mental health. Columbus, OH: Ohio Department of Mental Health.
- President's Commission on Mental Health. (1978). Report to the President 1. Washington, DC: U.S. Government Printing Office.
- Public Law 99-660. (1986). Title V - State Comprehensive Mental Health Services Plans.
- Raiff, N.R. (1984). Some health related outcomes of self-help participation: Recovery, Inc. as a case example of a self-help organization in mental health. In A. Gartner & F. Riessman (eds.) The self-help revolution. New York: Human Sciences Press.
- Ralph, R.O. (1996, May) Participatory research and stakeholder involvement in community mental health evaluation and research. Plenary presentation at the Ohio Program Evaluators' Group Spring Conference, Columbus, OH.
- Ralph, R.O. (1996, Sept.) Recovery. Plenary Presentation at the 38th Annual Southern Regional Conference on Mental Health Statistics, New Orleans, LA
- Ralph, R.O. & Campbell, J. (1995). Using a consumer developed housing/supports preference survey as a continuous outcome survey. In Proceedings: Fifth annual national conference

- on state mental health agency services research and program evaluation. San Antonio, TX: National Association of State Mental Health Program Directors Research Institute.
- Ralph, R.O., Lambric, T.M., & Steele, R.B. (1996) Recovery issues in a consumer developed evaluation of the mental health system. In Proceedings: Sixth annual national conference on state mental health agency services research and program evaluation. Alexandria, VA: National Association of State Mental Health Program Directors Research Institute.
- Rappaport, J. (1985) The power of empowerment language. Social Policy, 16 (2) 15-22.
- Roberts, L. & Rappaport, J. (1989). Empowerment in the mutual help context: An empirical analysis of the value of helping others. Lansing, MI: Author.
- SC Share. (1995). National directory of mental health consumer and ex-patient organizations and resources. Charlotte, SC: South Carolina Share.
- Schlageter, C. (ed.). (1990, March). OMH News II (1).
- Segal, S.P., Silverman, C. & Temkin, T. (1995a). Characteristics and service use of long-term members of self-help agencies for mental health clients. Psychiatric Services 46 (3), 269-274.
- Segal, S.P., Silverman, C. & Temkin, T. (1995b). Measuring empowerment in client-run self-help agencies. Community Mental Health Journal 31 (3), 215-227.
- Smith, M.K. & Ford, J. (1986). Client involvement: Practical advice for professionals. Psychosocial Rehabilitation Journal 9 (3),
- Specht, D. (ed.). (1998). Highlights of the findings of a national survey on state support of consumer/ex-patients activities. Holyoke, MA: Human Resource Association of the Northeast.
- Stroul, B. (1986). Models of community support services. Boston, MA: National Institute of Mental Health.
- Tanzman, B. An overview of mental health consumers' preferences for housing and support services. Hospital and Community Psychiatry 44 (5) 450-455.

- The Harvard Mental Health Letter. (1993). Self Help Groups. 9 (9),
- Twedt, S. (1990, July 15). Mental patients rally in search of a fair chance and fewer labels. Pittsburgh Press, A6.
- U.S. Department of Education. (1990, Winter). Training students with learning disabilities for careers in the human services. OSERS News in Print! III (3).
- Van Tosh, L. (1990). Final report and evaluation of Project OATS. Philadelphia, PA: Mental Health Association of Southeastern Pennsylvania.
- Van Tosh, Laura & del Vecchio, Paolo. (In press). Consumer/Survivor-operated self-help programs: A technical report. Washington, DC: U.S. Department of Health and Human Services.
- Zinman, S. (1987) Definition of self-help groups. In S. Budd, H.T. Harp & S. Zinman (eds.) Reaching across: Mental health clients helping each other. Riverside, CA: California Network of Mental Health Clients.
- Zinman, S. (1988, May). Report of research meeting on community support and rehabilitation services. Presentation at the Joint NIMH/CSP-NIDRR Conference. Bethesda, MD.
- Zinman, S., Harp, H.T., & Budd, S. (1987) Reaching Across. Sacramento, CA: California Network of Mental Health Clients.