

SAMHSA Responds to Growth of the Consumer Movement

Within the last 30 years, a new movement has grown among people who use mental health services, based on the philosophy of self-help and the goal of improving the lives of people affected by mental illnesses. Called the "consumer movement," it has already had a profound effect on both service recipients and service providers.

What are its origins and in what ways has SAMHSA responded to the important issues mental health consumers* have raised? This article attempts to provide an introduction and to suggest additional sources of information for those who are interested in learning more.

According to statistics published by the Interagency Council on the Homeless in 1992, as many as 4 million Americans are estimated to have a severe mental illness. Throughout history, these individuals often have been shunned, mistreated, and ignored. The stigma and myths surrounding mental illness have resulted in discrimination in housing, employment, education, and other areas.

"In the past, people who needed mental health services had little or no opportunity to participate or to make choices in their individual treatments," says Paolo del Vecchio, the Consumer Affairs Specialist within SAMHSA's Center for Mental Health Services (CMHS). Mr. del Vecchio

is a self-identified consumer of mental health services. "People also didn't have opportunities to provide feedback to the system designed to provide services or to help plan specific services. Often, they were falsely perceived as not having the intellectual capacity to provide such input."



Photograph by Catherine Brown

Two employees (right) at the Upscale Resale Shop in Rockville, MD, wrap and ring up purchases for a satisfied customer, Anthony Stokes (left). The Upscale Resale Shop is a project of Jobs Unlimited, Inc., a nonprofit organization that promotes vocational opportunities for people with mental illnesses.

Today, consumers are viewed as a valuable resource in the provision of mental health services and consumer-operated self-help services are seen as an essential component of the service system for persons with psychiatric disabilities.

The overwhelming success has resulted in an increase in consumer-generated activities. There are an estimated 6,000 consumer initiatives across the Nation. Growing from the local level, consumer self-help groups have developed into State, national, and even international organizations. An estimated 30 States currently have developed these organizations to coordinate activities and to

conduct advocacy on a statewide level.

Origins of the Self-Help Philosophy

Self-help, in general, is not new. Individuals have been organizing to help themselves throughout history.

Self-help in the traditional human services or treatment arena, however, is a fairly recent development. Historically, provision of such services has been viewed as the domain solely of a professionally educated segment of society. The emergence of Alcoholics Anonymous in 1935 was one of the first efforts to promote the view that people could help themselves and help others to recover even though they were not professionally trained. Since that time, millions of individuals have participated in self-help groups of one form or another.

Individuals participate in self-help for a number of reasons: to receive support, learn coping strategies, gain role models, lower treatment costs, obtain information about issues and services, advocate for changes in the service system, fight stigma, and receive help in a setting they may experience as less judgmental or discriminatory. Participants also benefit from the "helper's principle," in which by helping others, one helps oneself.

"The simple reason self-help is attractive is that it works," says Mr. del Vecchio. "On an individual level, the benefits of self-help include increased independence, self-reliance, self-esteem, coping skills, personal empowerment, and knowledge about services and rights."

*Some individuals use the terms "patient," "survivor," "client," or "recipient." For brevity, the term "consumer" is used here. SAMHSA respects that individuals may choose to identify themselves otherwise.

Growth of the Consumer Movement

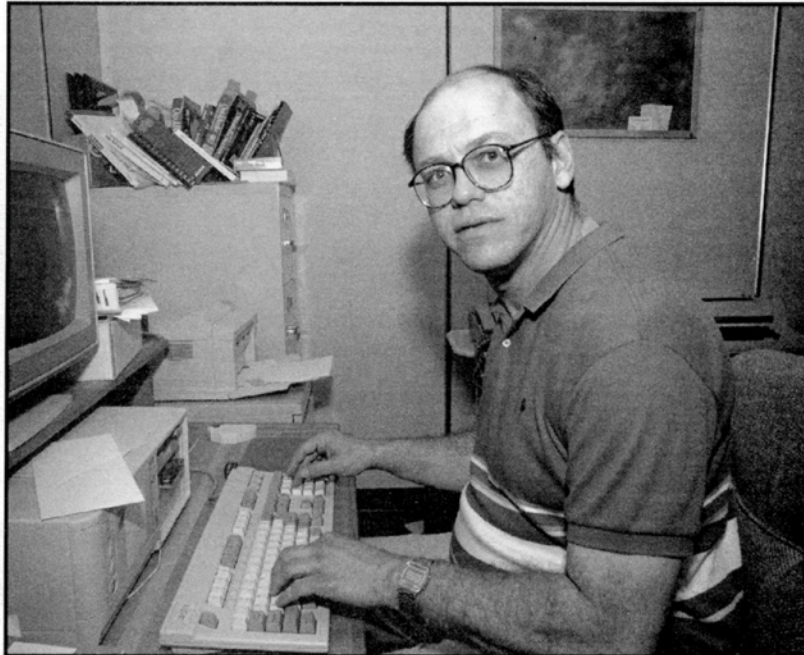
Around the turn of the century, there were a few self-help efforts by former mental patients, most notably, Clifford Beers, founder of the Mental Health Association, and author of *A Mind that Found Itself*.

But the self-help and advocacy movement of people with psychiatric histories was launched in its modern form nearly 60 years later. Beginning in the 1960s, coalitions such as civil rights organizations, feminist groups, Mothers Against Drunk Driving, and ACT UP formed in America not only to improve the lives of their members and promote public education, but also to change policy within the public and private sectors by taking their concerns into the political arena. Some of this momentum fueled a similar movement for change in the area of mental health.

In the late 1960s and early 1970s, small groups of people who had experienced psychiatric hospitalization began meeting in some of the larger cities on the east and west coasts. These groups were small in size and few in number and took a distinctively militant view, evidenced by their names such as the "Alliance for the Liberation of Mental Patients" and "Project Release." The groups were reacting to a mental health system they saw as abusive and unresponsive to their needs.

They provided their members with peer support, education about the problems they were facing and services in the community, and advocacy. These early groups met in members' homes and in churches and enabled participants to share their experiences and obtain positive reinforcement and acceptance. Some of these groups published their own newspapers and magazines (such as *Madness Network News* and *Phoenix Rising*) to provide education and information to their members. They organized an annual conference called the International Conference on Human Rights and Against Psychiatric Oppression.

Allegations of physical and/or sexual abuse at several hospitals and a sense of exclusion from professional groups led some advocates to picket selected institutions and hold protests at professional



Photograph by Catherine Brown

Mental health service consumers may choose from a wide range of paid positions at the Upscale Resale Shop, including cashier, sales clerk, merchandise sorter/pricer, signboard walker, truck driver and truck assistant, assistant manager, bookkeeper/payroll clerk, and clerical assistant/word processor. "Often, their newfound self-confidence helps them to try a new vocation or re-enter a previous field," says Jobs Unlimited Executive Director Tillie Kane.

conventions to demand their right to be treated with dignity and respect and to be involved in the determination of appropriate services for themselves.

On Our Own, a book published by Judi Chamberlin in 1978, was a milestone: for the first time, a book had been published by the mainstream press about the movement of people with psychiatric histories.

During the last two decades, others became involved who believed that psychiatric services were necessary but needed to be reformed.

Still others formed groups that focused more on peer support and less on advocacy. Among these were Emotions Anonymous; Recovery, Inc.; and GROW.

A significant result has been the development of alternative mental health services established and run by and for consumers. The consumer movement has developed and established a variety of models of consumer-run services and has made an enormous impact on mental health policy.

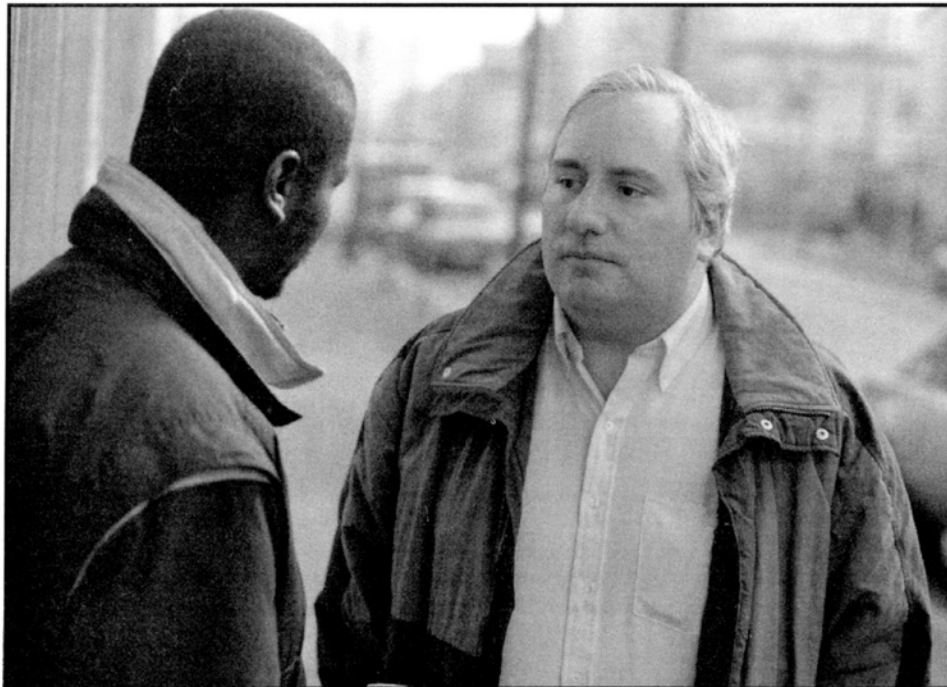
SAMHSA's Response

SAMHSA has had, and continues to

play, an important role in supporting the consumer movement. In the late 1970s, the Agency's Community Support Program (CSP)—then part of the National Institute of Mental Health—developed its Community Support System approach. This approach was characterized by the view that services should be "consumer driven," and that the rights, wishes, and needs of consumers are central in planning and delivering services. The CSP—now located administratively within CMHS—is still mandated to work with States and communities as well as consumers and their families today to improve the effectiveness of the systems of care essential to those whose lives are affected by mental health problems.

In the early 1980s, CSP supported a national teleconference to enable consumers active in the self-help movement to network and identify effective strategies. Support was also provided for technical assistance, including the development of a manual in 1987 on how to organize self-help and advocacy efforts, titled *Reaching*

Consumer Movement continued on Page 4



Photograph by Lawrence W. Jackson, Jr.

William Hartman (right) is employed as a consumer advocate in the Baltimore Assertive Community Treatment Team, a project for homeless people with mental illnesses. Mr. Hartman, who has bipolar disorder, previously experienced both hospitalization and homelessness firsthand. "They can relate to me," he says of the consumers with whom he works. At the same time, he acknowledges, "The practice of consumers working as service providers is new. . . . This can be stressful sometimes. I feel the future of the consumer movement depends on my success and that of other consumers working as providers right now."

Across, available through the California Network of Mental Health Clients, and publications produced by the National Mental Health Consumers' Self-Help Clearinghouse in Philadelphia, PA.

In 1985, CSP funded the first national conference of consumers in Baltimore, MD. The conference, titled "Alternatives '85," drew approximately 400 individuals from across the country and launched an annual gathering that has grown to nearly 2,000 participants from virtually every State and from a number of other countries. Its purpose is to provide information to assist consumers in developing self-help and advocacy programs.

In the late 1980s, CSP funded 13 consumer-operated programs to demonstrate the effectiveness of such activities. Consumer-operated services have multiplied to include drop-in centers, housing programs, peer counseling, monitoring of services and quality improvement, case

management, case and systems advocacy, crisis response, benefits acquisition, research, technical assistance, employment, and other services. In effect, consumers are changing their role from simply being recipients of services to actually providing care themselves.

Since 1992, CMHS has funded two self-help clearinghouses. Last December, the Philadelphia-based National Mental Health Consumers' Self-Help Clearinghouse organized the annual Alternatives '97 conference in Orlando, FL. The Boston-based National Empowerment Center sponsored the "Learning From Us" Conference in March to teach mental health program administrators, policymakers, and professionals about consumer-oriented approaches to empowerment, health, and recovery.

CMHS launched the National Mental Health Services Knowledge Exchange Network (KEN) in 1996 to provide a

clearinghouse to distribute timely information about mental health. In addition to offering free publications and subject bibliographies, KEN—which is accessible by phone, mail, fax, and the Internet—operates an electronic bulletin board to enable users to download information and join news groups on various mental health subjects. A searchable database of mental health consumer consultants is maintained on KEN to enable individuals and organizations to find consumer resource persons on 68 different topics, ranging from advance directives to women's issues. More than 300 people have agreed to be listed in the public database.

A CMHS booklet, *Managed Mental Health Care: What to Look For, What to Ask*, highlights what every consumer needs to know about a growing approach to mental health service delivery. CMHS also has encouraged the first dialogue between consumers and managed care organizations by convening a meeting between representatives of the Consumer Managed Care Network and the American Managed Behavioral Healthcare Association.

In addition to supporting the development of numerous statewide consumer organizations as well as more consumer-operated programs, CMHS hired two consumer affairs staff members to ensure consumer involvement in CMHS activities. (See sidebar on next page for more information on SAMHSA resources.)

Impact of the Consumer Movement

Consumers have been involved increasingly in all aspects of the planning, delivery, and evaluation of mental health services as well as in the protection of rights. For example, Federal legislation for State mental health planning councils and protection and advocacy agencies now mandates consumer involvement.

In addition, consumers are being hired as employees in the traditional mental health system, in much the same way that people recovering from substance abuse work in substance abuse treatment programs. As recognition grows of the benefits of using these individuals as staff, consumers are being hired in many

different capacities at all levels, from case manager aides in treatment and assistance programs to management-level positions in State mental health authorities. Consumers are entering into leadership positions, decreasing stigma, and advocating for needed services.

The consumer self-help movement continues to grow and its importance cannot be underestimated. In the words of consumer and advocate Esso Leete, speaking at the 12th Mary Switzer Memorial Seminar on Rehabilitation in Washington, DC, "I owe my survival in large part to the consumer movement. . . . For, unlike what we so often hear, most of us are able to speak for ourselves and to represent our own needs. Mental health clients are now making choices both individually and collectively, and we are controlling our own lives. We are becoming empowered." ■

Where To Turn: SAMHSA-Funded Consumer Resources

CMHS Consumer Affairs

Paolo del Vecchio
Iris Hyman
Center for Mental Health Services
5600 Fishers Lane, Room 13-103
Rockville, MD 20857
(301) 443-2619/9824 (voice)
(301) 443-4449 (TTY)
(800) 345-0981
(leave messages at ext. 32619)
E-mail: pdelvecc@samhsa.gov
ihyman@samhsa.gov

National Mental Health Services Knowledge Exchange Network (KEN)

P.O. Box 42490
Washington, DC 20015
(800) 789-2647 (voice)
(800) 790-2647 (bulletin board)
Internet: [<http://www.mentalhealth.org>]

National Empowerment Center

20 Ballard Road
Lawrence, MA 01843
(800) POWER-2-U (voice)
(800) TTY-POWER (TTY)
(508) 681-6426 (fax)
E-mail: POWERTWOU@aol.com

National Mental Health Consumers' Self-Help Clearinghouse

1211 Chestnut Street, Suite 1000
Philadelphia, PA 19107
(800) 553-4539 (voice)
(215) 636-6310 (fax)
(215) 751-9655 (TTY)
E-mail: THEKEY@delphi.com
Internet: [http://www.libertynet.org/~mha/cl_house.html]

National Association of State Mental Health Program Directors National Technical Assistance Center (NTAC)

66 Canal Center Plaza, Suite 302
Alexandria, VA 22314
(703) 739-9333 (voice)
(703) 548-9517 (fax)
Internet: [<http://www.nasmhpd.org/ntac>]