

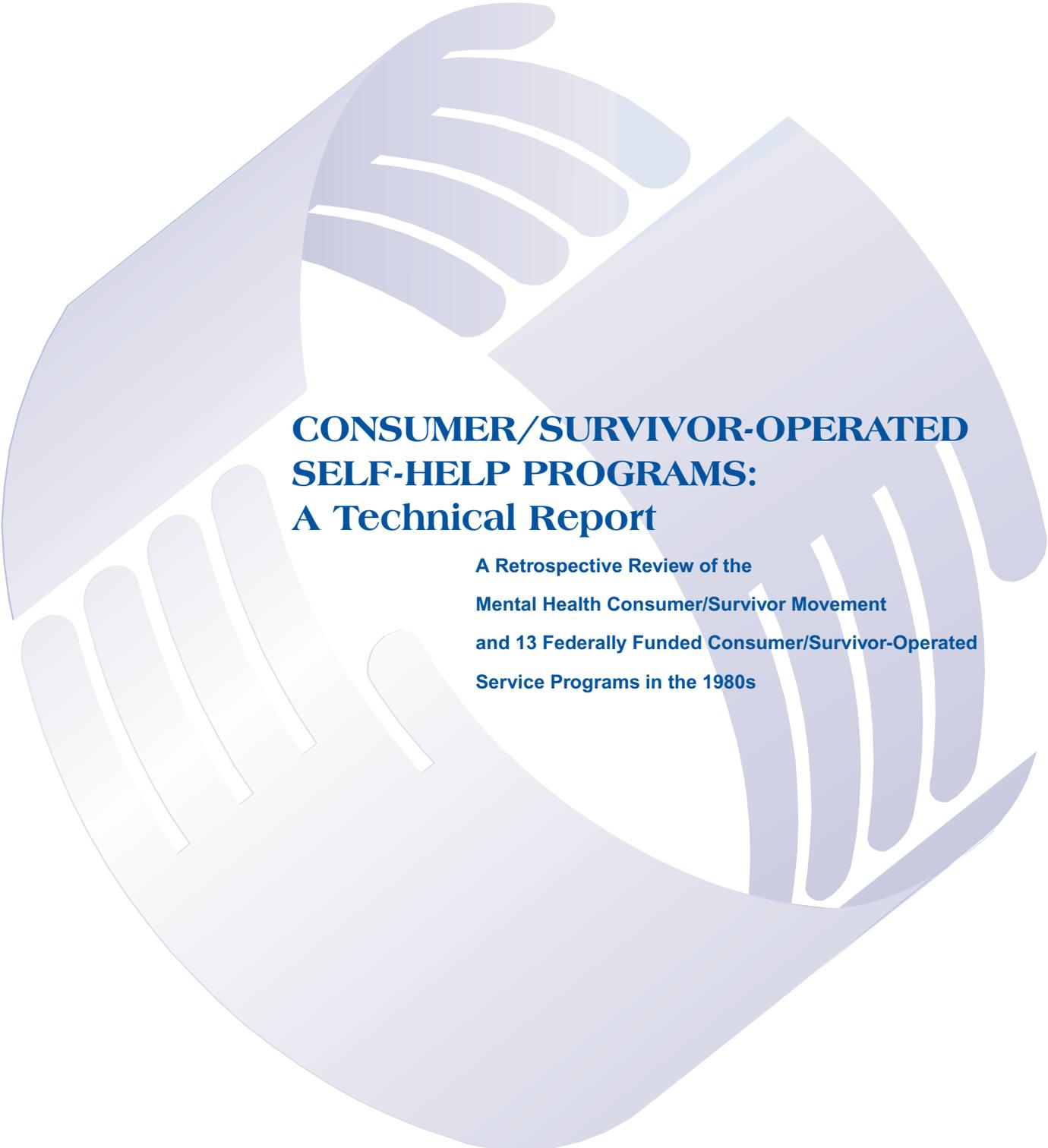


CONSUMER/SURVIVOR-OPERATED SELF-HELP PROGRAMS: A Technical Report

**A Retrospective Review of the
Mental Health Consumer/Survivor Movement
and 13 Federally Funded Consumer/Survivor-Operated
Service Programs in the 1980s**



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Substance Abuse and Mental Health Services Administration
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Disclaimer

The content of this publication does not necessarily reflect the views or policies of the Center for Mental Health Services (CMHS), Substance Abuse and Mental Health Services Administration (SAMHSA), or the Department of Health and Human Services.

Note on Language

Emerging concepts in mental health require a vocabulary that accommodates change. The goal of this guide is language that is flexible and accessible to the general public.

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INTRODUCTION

The mental health consumer/survivor self-help movement has experienced remarkable growth over the last two decades. The impact of this movement on mental health systems nationwide has been dramatic. No longer are people who use these services seen simply as passive recipients but as active participants at all levels in planning, providing, and evaluating services.

The Substance Abuse and Mental Health Services Administration (SAMHSA), Center for Mental Health Services (CMHS) has played a key role in supporting these important developments. Beginning in the early 1980s, the Community Support Program (CSP), which is located within CMHS/SAMHSA, initiated various technical assistance activities to promote self-help, peer support, and client-directed approaches.

In 1988, CSP issued a new grant program to demonstrate and evaluate services run by and for individuals with psychiatric disabilities. Fourteen projects were awarded funding for over \$1.2 million, the first such projects to be supported by a Federal agency.

This document is a retrospective review of the mental health consumer/survivor self-help movement and, specifically, the findings and recommendations from these innovative demonstration projects. *Consumer/Survivor-Operated Self-help Programs*, is the first comprehensive documentation of the experiences of consumers/survivors in designing and operating their own self-help programs. The lessons from these past efforts are invaluable in assisting us to improve mental health services today and in the future.

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THE CONSUMER/SURVIVOR SELF-HELP MOVEMENT: A LITERATURE-BASED REVIEW

In 1987–1992, the National Institute of Mental Health’s (and later the Center for Mental Health Services’) Community Support Program (CSP) launched a unique program to fund community-based consumer/survivor demonstration grants. Through this effort, grants totaling nearly \$5 million were awarded to 14 States to implement and evaluate an array of services to Americans with severe mental illness provided by mental health consumers/survivors. The goals of this effort were to:

- Address a critical shortage in the number and type of self-help services available to mental health consumers in the community;
- Demonstrate the feasibility and effectiveness of consumer-operated programs;
- Analyze, synthesize, and package findings from these grants so that other consumers/survivors could replicate these services in their local communities;
- Generate a series of recommendations useful to policymakers with responsibilities for funding community-based mental health services; and
- Foster support for sustaining existing programs and increasing the number of consumer/survivor self-help initiatives so that effective services will be available to those who need them.

Methodology

This document summarizes an examination of the findings of these innovative grant projects focusing on their accomplishments, implementation, operation, and evaluation. A cross-project analysis was used to determine similarities, differences, generalizable observations, and recommendations for implementing, operating, and evaluating consumer/survivor-run programs.

This report is unique in that it is based on research techniques and has been guided by persons with an understanding of consumer/survivor self-help issues.

The initial method implemented was the identification and summarization of published and unpublished literature on self-help and programs operated by and for consumers/survivors. Project staff completed a literature search with key informants in the consumer/survivor self-help movement, self-help technical assistance centers, national consumer/survivor organizations, self-help researchers, CMHS documents, and other sources. In addition, notices were placed in national consumer/survivor newsletters requesting literature on this topic.

As a result, over 80 pieces of literature were located. These materials have been reviewed while examining such issues as:

- How is “self-help” generally defined? What are the essential characteristics of “self-help”? What is the history and rationale for its use? How has it been instituted in different service fields?
- What is “mental health consumer/survivor self-help”? What is its history and the rationale for its use? What are its major philosophies, goals, values, and outcomes?
- What are consumer/survivor-operated self-help programs? What are the topologies of services delivered? How do the programs differ and how are they similar?
- How are consumer/survivor-operated self-help programs organized to achieve their aims? How are these efforts funded? How are they managed and administered? What sort of staffing patterns exist? What is the population that is served by these efforts? How are these efforts governed? What is the extent of program evaluation and research conducted with these programs? How do they interact with traditional, professional-run organizations, each other, and the external environment?

The second major activity focused on review and analysis of information from each of the CSP demonstration grant projects contained in their original proposals, progress reports, evaluation studies, and final reports.

To accomplish this task, a detailed, qualitative, descriptive analysis was conducted for each project which examined the following domains:

- Project goals and objectives;
- Services provided;
- Individuals served;
- Organization and administration;

- Implementation issues and barriers;
- Successes and evaluation findings; and
- Project recommendations.

The final activity centered on conducting analyses across the projects to determine similarities, differences, generalizable knowledge gains, and recommendations for implementing, operating, and evaluating consumer/survivor-run programs.

A comparative analysis of the qualitative findings of each project enabled a synthesis of information about the projects’ similarities as well as differences in approaches and services, and it contrasted problems encountered and results achieved. In so doing, a matrix analysis was employed to complete this task. Generalizable observations were extracted from the information in the above domains, and conclusions and recommendations were then drawn from this analysis.

Limitations of Methodology

A number of factors affect the validity and reliability of the methodology employed. An important issue is the age of the data. Most of the projects reviewed were initiated approximately 6-8 years before the completion of this report. There are a number of factors which contributed to this, including when the grant for the report was awarded and the time necessary to complete data analyses. While this may, in fact, impact upon some variables (e.g., environmental changes), the results are likely to be relevant and transferable to the present time.

In reviewing literature, it is difficult to complete a comprehensive overview of all sources in this area in that materials are published at a rapid pace. In addition, many pieces of consumer/survivor literature are “fugitive” (e.g., not published in traditional, peer-reviewed professional journals). With over 80 citations, however, this review does approach a significant overview of this field.

The qualitative analysis of the 13 projects also brings significant limitations. These include the examination of self-reports from the projects themselves and the incomplete data which these reports contain. These issues are explored in greater detail at the beginning of Chapter 2. This factor also impacts upon the matrix analysis conducted to determine cross-site findings and recommendations, because this matrix analysis was based on the project findings themselves.

While the above do produce limitations in the methodology, it is believed that this report does offer a valuable—albeit descriptive—analysis of consumer/survivor-operated programs. As such, it should be a useful tool as consumer/survivor-operated programs further develop.

Organization of This Report

This report presents a snapshot of the experiences of 13 of the 14 National Institute of Mental Health/Community Support Program (NIMH/CSP) Consumer-Operated Services Demonstration Projects funded during 1988-1989 (one grant was terminated due to unresolvable implementation problems).

The report opens with a brief overview of the literature on the evolution of the consumer/survivor movement to provide a context within which to understand the achievements of the

13 grantees. Chapter 1 continues with an exploration of the benefits, characteristics, and values of consumer/survivor self-help; reviews program typologies and services; and concludes with a description of how consumer/survivor self-help programs have been organized and administered to achieve their objectives.

Chapter 2 provides a detailed overview of each demonstration project funded and examines: project goals and objectives; program description; implementation issues and barriers; and successes and evaluation findings. This will include a review of the services provided, clients served, and issues surrounding project organization and implementation. Project outcomes, recommendations, and continuation efforts are also discussed.

Chapter 3 offers overall findings based on a cross-site analysis of the project narratives. Specifically, this was conducted using a matrix analysis of the key outcomes associated with each project. Generalizable similarities and differences were extracted and are presented.

The report concludes with a set of broad policy recommendations for public officials, researchers, managed care organizations, State mental health programs, local communities, and consumers/survivors for implementing, operating, and evaluating future, community-based consumer/survivor self-help programs.

SELF-HELP: A HISTORY & DESCRIPTION OF THE GENERAL CONCEPT

In 1992, an estimated 4 million Americans experience “severe mental illness”, a category that loosely encompasses people suffering from schizophrenia, major depression, and bipolar disorder (Interagency Council on the Homeless, 1992).

Historically, society has shunned, mistreated, and ignored those with serious mental health problems, viewing them as incapable of making decisions and thinking for themselves. Not only have the myths and stigmas surrounding mental illness resulted in numerous instances of discrimination in housing, employment, and education, but they have also produced a class of people who have been systematically disempowered and dependent on what they perceive as a largely unresponsive mental health system (Chamberlin, 1978).

Recently, however, consumers/survivors* have begun to change their status both in their own eyes and in those of the public. They have become increasingly vocal and active as participants in planning, delivering, and evaluating mental health services that better meet their needs for appropriate treatment, respect personal dignity, and promote independence (Canadian Mental Health Association, 1988; Chamberlin, Rogers, and Sneed, 1989; Specht, 1988; Chamberlin and Rogers, 1990).

As a result of this positive action, there is a growing acceptance of the role of consumers/survivors in the provision of mental health services as well as increasing support for consumer/survivor-operated self-help services (Interagency Council on the Homeless, 1992).

* Although a number of terms identify people who use or have used mental health services (e.g., mental health consumer, psychiatric survivor, ex-patient, client, inmate, psychiatrically labeled, user, recipient), for consistency throughout this report, the term “consumers/survivors” will be used.

Background

Consumer/survivor-operated self-help programs are a relatively recent phenomenon, and the paucity of information in the literature reflects a field that is still in its infancy. Despite this limitation, a literature review was undertaken of both published and unpublished sources of information in order to discover the basic foundations of consumer/survivor-operated self-help programs. A computerized literature search was completed at the University of Maryland at Baltimore; key researchers and representatives of the consumer/survivor self-help movement were contacted to obtain materials; and notices were placed in national consumer/survivor as well as professional mental health journals. An Editorial Review Committee composed of consumers/survivors as well as traditional mental health researchers provided guidance in interpreting the information contained in the documents identified through the search.

Definition of Self-help

Webster's Dictionary defines self-help as “the act or an instance of providing for or helping oneself without dependence on others” (Webster's, 1974). In more general terms, it is the process whereby individuals who share a common condition or interest assist themselves rather than relying on the assistance of others.

Over the past 25 years, American society (and the world in general) has witnessed a revolution in the way people access and receive help. The self-help movement has grown so dramatically that self-help and support groups now exist for everything from dream sharing to women's health. Self-help has gained such acceptance that the former Surgeon General of the United States, Dr. C. Everett Koop, observed that “. . . 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, alienation . . .” (Katz, et al., 1992).

History of Self-help

Self-help is not a new idea. People have been organizing to help themselves throughout history. Religious institutions have frequently played this role by offering support for common values, meeting basic material needs, and providing opportunities for socialization to their members. In the political arena, the National Association for the Advancement of Colored People (NAACP), the National Organization for Women (NOW), Mothers Against Drunk Driving (MADD), ACT UP, and countless others form self-help coalitions to redress civil and social wrongs, change policy in the public/private sectors, and promote education (Gartner and Riessman, 1984; Zinman, et al., 1987).

Self-help in the traditional human services arena, however, is a fairly recent development. For decades, service providers have been a highly educated and elite segment of society (Riessman, 1989). The “professionalization” of social work—whereby practitioners are educated in university settings and licensure is becoming a standard requirement for employment—is one example of this practice.

Alcoholics Anonymous

The modern self-help movement traces its roots to Alcoholics Anonymous. Founded in 1935 by two recovering alcoholics, Alcoholics Anonymous, or “A.A.” as it is commonly called, is a fellowship of men and women (and, more recently, adolescents) who share their experiences and strength with each other in a group setting, hoping that together they can solve their common problems (Alcoholics Anonymous, 1994; Nace, 1992).

In A.A., alcoholism creates a profound bond between members, all of whom are equal. The line between patient and doctor, professional and amateur does not exist in A.A. Anonymity, the primacy of both the common welfare and group unity, and the absence of hierarchical governance are some of the other notable hallmarks of Alcoholics Anonymous (Nace, 1992).

While the A.A. program is deceptively simple—focusing on the “12 steps” or principles that members follow to maintain sobriety—it has attracted an enormous following: approximately 50,000 A.A. groups exist in North America today.

The work and message of Bill W. and other pioneers of A.A. were the impetus for an entirely new philosophy that held that people do not have to rely on “experts” in order to improve their condition (Bufe, 1991; W., Bill, 1955). A.A.’s success has prompted, in turn, a fundamental shift in ideas about the provision of “help” which has resulted in the blossoming of self-help that is seen today.

The contemporary self-help movement exploded during the late 1960’s and 1970’s as people began to question the status quo of traditional society and began to explore a wide range of “alternative” ideas and behaviors from political philosophies, to sexual mores, to methods of assisting and empowering one another. A.A.’s 12-step model has spawned self-help and peer support groups for virtually every health issue of concern to present-day society. These include such offspring as Narcotics Anonymous, Fundamentalists Anonymous, and many non-12-step model programs for people with mental retardation, as well as those with developmental and physical disabilities (White and Madera, 1992).

Benefits of General Self-help

Millions of individuals have participated in self-help groups of one type or another (Mental Health Policy Resource Center, 1991), and

numerous Statewide, national, and even international information clearinghouses on self-help groups have been organized in response (White and Madera, 1992; Gartner and Riessman, 1984). Clearly, there is something about self-help which attracts adherents and produces positive benefits for its members (Stroul, 1986).

Many tangible benefits are cited by self-help group members as promoting their continued participation:

- **Peer Support.** The ability of group members to be empathic and compassionate based on a common experience assists participants in feeling better by helping them to realize that they are not alone. Self-help actualizes the concept of “strength in numbers”. The sense of solidarity, encouragement, and power derived from the group imbues participants with the sense that they can persevere. Being a member of a group or community also instills a sense of belonging and of being accepted for whom one is (Riessman, 1989).
- **Coping Strategies.** Self-help group members share information and insights developed as a result of their own experiences to help each other “get through tough times” (Gartner and Riessman, 1984).
- **Role Models.** Self-help group members serve a positive role models to one another. Group members who see that others are able to overcome problems and conditions like their own have a renewed sense of hope and energy that “if they can do it, so can I” (Gartner and Riessman, 1984).
- **Affordability.** Self-help is often free or inexpensive, which makes it a very attractive alternative to high-cost and frequently time-limited “professional” services (Riessman, 1989; Chamberlin, Rogers, and Sneed, 1989).
- **Education.** Self-help groups serve as a valuable forum for not only exchanging information about members’ common concerns, but also for learning about other resources available in the community. For example, self-help groups often invite speakers to discuss issues of special relevance to their membership such as the Social Security Administration’s SSI/SSDI benefits (Rogers, J., 1988).
- **Advocacy.** Case and systems-change advocacy are other attractive features of self-help programs. Through group advocacy efforts, many group members are able to access previously unavailable resources. In addition, members gain intrinsic rewards from joining together to change systems or external environmental conditions that are negatively affecting the self-help community (Zinman, et al., 1987).
- **Non-Stigmatizing.** Self-help avoids the stigma and negative connotations that are often associated with seeking traditional, professional support (i.e., those who seek professional services are somehow weak in mind or body). This may be related to self-help’s emphasis on rugged individualism and self-reliance, traits that the larger society seems to value (Riessman, 1989).
- **“Helper’s Principle”.** Proponents of self-help believe that those who are able to provide some support or assistance to others experience a heightened sense of self-worth and self-esteem themselves. This belief is known in the consumer/survivor community as the “helper’s principle”, and, in various forms, is a mainstay of the self-help movement (Gartner and Riessman, 1984; Roberts and Rappaport, 1989).

Characteristics and Values of General Self-help

In addition to the benefits attributed to self-help by its members, it also possesses a number of other features that distinguish it from traditional forms of professional services:

- **Non-Reliance on Professionals.** While some self-help groups take on a decidedly anti-professional stance based on negative personal experiences (i.e., one group is entitled “Victims of Professionals”), the emphasis in the majority of self-help groups is on the practice of self-determination and empowerment. In self-help groups, individuals are encouraged to make the choices and decisions that affect their lives rather than having these decisions made for them (Riessman, 1989; Stroul, 1986).
- **Voluntary.** Traditionally, self-help services are voluntary in nature. There is no coercion or requirements that individuals participate in the group. Most individuals attend the self-help function based on their choice and of their own volition (Gartner and Riessman, 1984; Zinman, et al., 1987).
- **Equality.** Self-help is egalitarian and peer-based. The concept is rooted in a non-hierarchical principle whereby every member has equal status. Leadership is often shared, and facilitation of group discussion is rotated among the members (Zinman, et al., 1987).
- **Non-Judgmental.** Self-help is based on peer support that is provided in a non-judgmental atmosphere where individuals can share their feelings and thoughts openly. Respect for a person’s confidentiality is emphasized, as well.
- **Informality.** Informality is generally the norm with self-help groups (Gartner and Riessman, 1984). Boundaries between

“professional” and “patient” do not exist, nor do the cumbersome administrative arrangements frequently associated with professional services.

Use of General Self-help

Self-help programs have been instituted in a number of different fields including substance abuse treatment, education, housing, corrections, and physical and mental disabilities.

Alcohol and other drug abuse treatment and recovery services are certainly the most obvious areas where self-help has prospered. Virtually all drug and alcohol treatment programs today include or espouse participation in some form of self-help (e.g., Alcoholics Anonymous, Narcotics Anonymous, Cocaine Anonymous). Recovering individuals are employed in many treatment settings and have been found to be highly effective counselors. The experience of having “been there” enables recovering substance abusers to establish a rapport with clients that other counselors cannot. They are also able to serve as both effective role models and educators, transmitting “reality-based” coping strategies, information, and relapse prevention techniques that other treatment personnel either do not know or cannot convey in quite the same way (Riessman, 1989).

In the field of education, peer counselors and peer tutors have been successful in improving the academic performance and in-school behavior of students at risk for failure or dropping out. Informal study groups also are routinely utilized by students at all levels as a form of self-help (Riessman, 1989).

Self-help strategies have been particularly effective in the area of housing development. Self-help organizations such as the National Union of the Homeless and its local chapters and affiliates (including the Oakland Independence Support Center and the Philadelphia-based Committee for Dignity and Fairness for the Homeless) have operated

their own shelters for their members and have devised a number of innovative methods for developing and obtaining permanent housing. Additionally, these groups have produced employment opportunities for their members through such business enterprises as the publication of free community newspapers (National Association of State Mental Health Program Directors, 1992; National Resource Center on Homelessness and Mental Illness, 1989; Long with Van Tosh, 1988a).

Following the lead of the education field, the correctional system has incorporated the concept of peer support into its counseling programs for young offenders. This form of self-help assists its members to improve their life skills with the goal of preventing criminal recidivism and ongoing incarceration (Riessman, 1989).

Physical and mental disabilities are another major area where principles of self-help have been applied effectively (Riessman, 1989; White and Madera, 1992). People who are

deaf or hard-of-hearing, for example, have formed self-help support groups such as SHHH (Self-help for the Hard-of-Hearing) and have mobilized to initiate systems change activities (e.g., insisting on the appointment of an educator with a hearing impairment as President of Gallaudet University). As another example, during the past 20 years, consumer-run Centers for Independent Living have developed for individuals with an array of physical and mental disabilities through the Independent Living movement. Services provided through these self-help oriented centers include information on accessing resources, locating housing, peer counseling, and advocacy services, among others. Independent Living Centers also are opening their doors to mental health consumers/survivors through such programs as the National Empowerment Center (a Federally funded consumer/survivor self-help technical assistance effort based at the Northeast Independent Living Center in Lawrence, Mass.) (DeJong, 1979).

THE MENTAL HEALTH CONSUMER/ SURVIVOR MOVEMENT

“Mental health consumer/survivor self-help” is the process by which mental health consumers/survivors provide assistance to one another based, to a large extent, on the tenets of the self-help paradigm described in the preceding section of this report.

History of the Consumer/ Survivor Self-help Movement

The mental health consumer/survivor self-help movement began in its modern form approximately 25 years ago. Prior to that, a scattering of consumer/survivor self-help efforts were initiated (Zinman, et al., 1987), including the work of Clifford Beers—a consumer/survivor advocate, author of *A Mind That Found Itself*, and founder of the Mental Health Association.

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/survivors 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 consumers/survivors to begin organizing in the larger East and West Coast cities (*Madness Network News Reader*, 1974).

These groups were few in size and number and took a decidedly militant viewpoint against psychiatry and the established mental health system. Groups with names like the “Alliance for the Liberation of Mental Patients” 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; education about services in the community and about the problems consumers/survivors were facing; and advocacy

to help members access services as well as to change an often oppressive system (Furlong-Norman, 1988).

Some of these groups published their own, often impressive, newspapers and magazines (e.g., *Madness Network News*, *Phoenix Rising*) to provide education and information to their members. Others conducted advocacy through such direct actions as protests and pickets both at hospitals accused of being abusive and at conventions of the American Psychiatric Association (*Madness Network News Reader*, 1974).

Members of these East and West Coast self-help groups met at the International Conference on Human Rights and Against Psychiatric Oppression and later at the National Institute of Mental Health’s Learning Community Conferences where they would informally network to share information on what they were doing in their local areas.

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).

The publication of Judi Chamberlin’s seminal work, *On Our Own*, was a milestone in the history of the movement. Consumers/survivors 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/survivor self-help movement and discussed the extension of this concept into the development of consumer/survivor-run services. For many consumers/survivors, reading this book was the beginning of their involve-

ment in the consumer/survivor movement (Chamberlin, 1978).

External Support for the Consumer/Survivor Self-help Movement

In the 1980's, the National Institute of Mental Health (NIMH) began to support technical assistance to further develop the self-help model. Through its Community Support Program (CSP), NIMH (and later, CMHS) funded a monthly teleconference out of Boston University's Center for Psychiatric Rehabilitation (Furlong-Norman, 1988). During these calls, consumers/survivors from around the nation could talk with one another about issues of mutual concern as well as discuss what was happening in their local communities. In addition, funds were provided for the publication of a technical assistance manual by the California Network of Mental Health Clients entitled *Reaching Across* (Zinman, 1987). The Mental Health Association of Southeastern Pennsylvania also received NIMH funds to provide information on consumer/survivor self-help (Furlong-Norman, 1988).

In 1985, again with funding from NIMH/CSP, the first national conference of consumers/survivors was held in Baltimore, Maryland, to provide technical assistance and opportunities for networking and information exchange. 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.

During this period, the number of consumer/survivor self-help groups expanded rapidly. Today, there are an estimated 3,000

consumer/survivor self-help organizations functioning at the local, State, national, and even international levels (O'Hagan, 1991; European Client Unions Network, 1992; World Federation of Psychiatric Users, 1992). Consumer/survivor self-help groups coordinate activities and conduct advocacy on a Statewide level in approximately 30 States. Various national organizations—for example, the National Alliance of Psychiatric Survivors and the National Mental Health Consumers' Association—have evolved. In 1992, the World Federation of Psychiatric Users—the first international consumer/survivor organization—was initiated.

The NIMH/CSP also funded two research centers to examine the phenomenon of consumer/survivor self-help. These centers, located in Michigan and California, have undertaken research that is now producing useful results (Segal, et al., 1991; Boltz, 1992). In 1992, NIMH/CSP expanded its support to fund two technical assistance centers in Massachusetts and Pennsylvania.

In addition to these Government-sponsored initiatives, a number of national publications by consumers/survivors, including *Dendron* and *NAPS News*, also have provided information about the growing consumer/survivor movement (Oaks, 1992; Unzicker, 1992).

Benefits of Consumer/Survivor Self-help

People participate in consumer/survivor self-help for the same reasons that they participate in other self-help groups; namely, 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).

In addition to these factors, consumer/survivor self-help enjoys broad support because it works. Studies are currently being completed that document the value of consumer/survivor self-help as a tool in helping people cope with and overcome their individual and collective problems as well as the stigma and discrimination encountered in the external environment. Recently, CMHS has begun planning a study examining the types of services provided by consumer/survivor self-help efforts. This “inventory” will begin to document the significant contributions that these projects provide.

Value of Consumer/Survivor Self-help

The values and philosophies that guide consumer/survivor 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. However, mental health consumer/survivor self-help also holds specific values and beliefs.

Empowerment

The concept of “empowerment” is central to the belief system of the consumer/survivor self-help. For mental health consumers/survivors, empowerment means acquiring the ability to make those decisions that directly affect their lives. Specifically, this translates into the ability to make decisions about housing, jobs, and services where consumers/survivors have typically had little input (Zinman, 1987; Ridgway, 1988b).

Empowerment on an individual level also translates into control over one’s life. Traditionally, consumers/survivors have been falsely deemed “incapable” of playing this role. Empowerment infuses individuals with a sense

of self-worth and belief in their capacity to “do for themselves” (Ridgway, 1988b).

On the group level, empowerment refers to the capacity to impact the systems that affect members’ lives. True representation, as opposed to tokenism on such decision-making bodies as county mental health services boards, is an example of a form of empowerment that has been put into action (Ridgway, 1988b).

Independence

The concept of independence is another central value of consumer/survivor self-help. Historically, consumers/survivors have been dependent on others (particularly in the mental health system) to meet their basic needs and for support. In contrast, the consumer/survivor self-help movement stresses the importance of striving for independence, self-reliance, and the opportunity to function as productive citizens (Zinman, 1987).

Responsibility

The consumer/survivor self-help movement emphasizes the responsibility that individuals must take for themselves and others (National Mental Health Consumers’ Association, 1987a). In addition, behaving in a responsible way with respect to one’s community is encouraged. For example, when other consumers/survivors are discriminated against in housing or employment, self-help group members are expected to respond and take action to redress those wrongs.

Choice

Choice in services and opportunities is also a value of consumer/survivor self-help (Stroul, 1986; Van Tosh, 1989a). In the past, consumers/survivors had little choice in the kinds of services and supports they received. In some instances, such as involuntary treatment, choice was completely eliminated. One goal of the self-help movement is to create an environment in which consumers/

survivors can make informed choices about treatment, housing, and other needed services (Ridgway, 1988a).

Respect and Dignity

A key value of this movement is that everyone should be treated with respect and dignity regardless of his or her situation, income, education, or status. The consumer/survivor self-help movement is committed to the idea that all individuals are valuable and have skills and strengths to offer society. The movement also stresses that everyone has rights that should be protected at all times (National Mental Health Consumers' Association, 1987a).

Social Action

Many segments of the consumer/survivor self-help movement (although not all), value social action as a mechanism for social change. Advocating for changes in how consumers/survivors are treated by the mental health system and society at large is a core activity for many in the consumer/survivor movement (although other segments of the larger self-help movement, particularly Alcoholics Anonymous, take a firm non-advocacy stance). Within consumer/survivor self-help groups, fostering change takes various forms from individual advocacy (e.g., assisting individuals with accessing benefits) to direct action and civil disobedience campaigns (Van Tosh, 1990; National Mental Health Consumer Self-help Clearinghouse, 1988b; Rogers, 1990; Andre, 1992; Zinman, 1987).

Unique Features of Consumer/Survivor Self-help

Although they share these features in common with other self-help groups, mental health consumer/survivor organizations place an extraordinary value on peer support, hope, and recovery.

Given the history and structure of the prevailing mental health system, consumer/survivor self-help groups view as crucial the capacity to provide emotional support and counseling on a peer level without the power differentials inherent in professional treatment. Developing a peer support network takes on a special importance for people who have mental health problems and have become socially isolated due to attendant stigma and discrimination (Leete, 1988).

Hope and recovery, likewise, are fervently embraced core values. The consumer/survivor self-help movement promotes and reaffirms the fact that people can recover from their often traumatic experiences. In so doing, the movement also fosters the understanding that when systems, communities, and individuals dispense with stereotypes, everyone benefits. As system changes begin to open the doors to improving the quality of life for consumers/survivors, the movement is increasing its focus on the values of hope and recovery and their power to transform attitudes and behavior (Deegan, 1988; Anthony, 1993).

Consumer/Survivor Self-help Classifications

While there is considerable agreement on an acceptance of the majority of values just described, there is a diversity of philosophies in the consumer/survivor self-help movement relating to the professional mental health system. These differences enabled both Chamberlin and Emerick to distinguish consumer/survivor self-help groups from one another and classify them into three categories according to their position on this issue (Chamberlin, 1978; Emerick, 1990).

In the first category are those groups who take an exclusively anti-psychiatric stance towards the mental health system (which they regard as oppressive) and refuse to work with it. Groups in this category rarely include non-consumers/survivors in leadership roles and

view self-help activities as an alternative model to the mental health system. For these groups, which some label “radical”, the self-help movement is a liberation struggle (Chamberlin, 1978; Zinman et al., 1987; Emerick, 1990).

The second category consists of those groups that work with the system, despite being critical of it. While these groups may include non-consumers/survivors within their general membership, consumers/survivors constitute the majority and maintain leadership positions. These groups, sometimes referred to as “moderate”, see the system as needing improvement. However, they also see it as providing some benefits to others (Chamberlin, 1978; Emerick, 1990).

In the third category are those groups who work very closely with the professional system, involve professionals in their activities and commonly share leadership between professionals and consumers/survivors. Self-help groups in this category, sometimes referred to as the “partnership” model, believe that the mental health system is a source of positive help for people with mental health problems and see self-help activities as an adjunct—and not an alternative—to the professional system (Chamberlin, 1978; Emerick, 1990).

There is a great mix of beliefs within consumer/survivor self-help groups that cross the boundaries between categories; neither groups nor individual group members fit neatly into “little boxes”. Since a major goal of the consumer/survivor movement is to reduce the use of “labels” by fostering the recognition that diversity should be respected, classification schemes are only one approach to understanding self-help groups and should be interpreted cautiously.

Funding

Accepting government funding for alternative self-help projects as well as participating in collaborative projects with the mental health

system has been a subject of ongoing debate within the consumer/survivor movement. Those opposed to “taking government money” fear being co-opted, while those accepting funds view it as a pragmatic step that allows their groups to implement needed services for consumers/survivors.

Impact of the Consumer/Survivor Self-help Movement

The two Federally funded research centers and a cadre of independent researchers are in the process of evaluating the impact of the mental health consumer/survivor self-help movement on both individual members and on the larger mental health system.

On an individual level, preliminary research suggests that the benefits of participation in consumer/survivor self-help include: increased independence and self-reliance; improved self-esteem; enhanced coping skills and feelings of personal empowerment; and increased knowledge of services/rights, housing, employment, and other issues of special concern to mental health consumers/survivors. In addition, as a result of their involvement in the movement, a growing number of consumers/survivors are “going public” about their problems and are speaking out against societal stigma (Roberts and Rappaport, 1989; Borck, 1983; Leete, 1988; Van Tosh, 1990).

On a systems level, the movement has substantially contributed to the increased involvement of consumers/survivors 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 substan-

tive consumer/survivor involvement in planning and implementing mandated activities.

Consumers/Survivors as Colleagues

The consumer/survivor self-help movement also has had a substantial influence on increasing the utilization of consumers/survivors 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/survivors are being hired at all levels in the mental health system, ranging from case manager aides to management positions. As consumers/survivors 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 30 State Mental Health Authorities. OCAs are generally staffed by consumers/survivors to support consumer/survivor empowerment and self-help in their particular States. In 1995, CMHS hired its first Consumer Affairs Specialist.

With the passage of the Americans with Disabilities Act (ADA) in 1990, employment in fields outside the mental health sphere has become, for the first time, an achievable goal for consumers/survivors. This landmark legislation not only makes it possible for persons with disabilities to obtain employment, but also it may assist people with disabilities to maintain a job. In addition, the ADA makes provisions for training consumers/survivors 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).

EVOLUTION OF MENTAL HEALTH CONSUMER/SURVIVOR-OPERATED SELF-HELP PROGRAMS

One of the most significant outcomes of the consumer/survivor self-help movement has been the development of mental health consumer/survivor-operated programs.

Consumer/survivor-operated self-help programs are services that are planned, delivered, and evaluated by consumers/survivors themselves, although some programs incorporate the use of professionals in certain areas of planning, implementation, and evaluation (Fleming, 1983; Stroul, 1986).

The majority of consumer/survivor-operated self-help programs are characterized by the values and goals delineated in the discussion of the consumer/survivor self-help movement and, as such, are quite different from those ascribed to traditional professional mental health services. As its name implies, in consumer/survivor-operated programs, the role of consumers/survivors is changed from service recipients to service providers, or what Frank Riessman terms “prosumers” (Riessman, 1989).

History of Consumer/Survivor-Operated Programs

Consumer/survivor-operated services (other than self-help/support groups) are relatively new. One of the earliest consumer/survivor-operated services is Fountainhouse in New York City. Founded by a consumer/survivor in the 1950's, it has become the world-renowned leader of the “clubhouse” movement that provides psychosocial and vocational rehabilitation. Today, however, Fountainhouse is no longer consumer/survivor-operated. Although consumers/survivors are still involved, professional staff assist the program's “members” (Chamberlin, 1978).

Another early consumer/survivor-operated self-help program, the Mental Patients

Association (MPA) of Vancouver, met a similar fate. MPA began as a drop-in center where consumers/survivors could socialize, participate in self-help groups, conduct advocacy, and obtain assistance in accessing other services, among other activities (Chamberlin, 1978). In consumer/survivor-operated drop-in centers, the participants plan and administer its programs and serve as staff. Drop-in centers frequently operate during evening, weekend, and holiday hours when traditional programs are closed (Long with Van Tosh, 1988a).

MPA expanded its operations to include a housing program for consumers/survivors. Originally a decidedly “radical” organization, over time, MPA became increasingly professionalized and hired professionally educated staff.

Not all consumer/survivor-operated self-help programs have followed this path, however. Some have maintained their original values and their principles and have thrived in the process. One of the oldest programs of this kind is the Ruby Rogers Advocacy and Drop-In Center in Cambridge, Massachusetts. Founded in the early 1970's, it remains a consumer/survivor-operated program today. Another drop-in center, On Our Own, is a fixture among consumers/survivors in Baltimore, Maryland, where it has been steadily providing alternative services for more than 10 years (Stroul, 1986).

Type of Services Offered

The range of services that consumers/survivors are now operating is diverse and continues to grow (Barry, 1991; Furlong-Norman, 1988; Ohio Department of Mental Health, 1990). Brief descriptions of 12 of the most common forms of services follow.

Drop-In Centers

Programs based on the drop-in center model now operate in many States in a variety of settings ranging from small church basements to over 5,000 square-foot properties. Some drop-in centers operated on a “shoe string” budget. Consumers/survivors serve as volunteer staff and programs operate one night per week. Others have budgets of over \$150,000, employ fulltime staff, and operate seven days a week. Some drop-in centers are established solely to provide opportunities for social interaction, while others offer a wide variety of different activities (Long with Van Tosh, 1988a).

Housing Programs

Housing programs are another service being operated increasingly by consumers/survivors. Housing options available under these programs range from various kinds of group housing (including a low-demand residential program) to supported independent living arrangements. Collaborative Support Programs of New Jersey has sponsored the development of a unique partnership between a nonprofit housing rehabilitation/development corporation and a local Mental Health Association to provide housing alternatives to consumers/survivors (National Association of State Mental Health Program Directors, 1992). Counter Point in Salt Lake City, Utah, is also collaborating with the local public housing authority to locate housing for some of its members, while Safe Harbor Housing of Rhode Island is both developing and operating housing services by and for consumers/survivors (National Association of State Mental Health Program Directors, 1992).

Homeless Services

Consumers/survivors are also developing services geared towards consumers/survivors experiencing homelessness. Examples include: Project Acceptance, a drop-in center located in Lawrenceville, Kansas, that provides housing services for persons who are

homeless; Project OATS, a street outreach and advocacy program operating in Philadelphia, Pennsylvania; and the Oakland Independence Support Center, a multiservice center in Oakland, California (National Association of State Mental Health Program Directors, 1992; Long with Van Tosh, 1988a; Interagency Council on the Homeless, 1991).

Case Management

Consumers/survivors are now operating their own case management programs (Furlong-Norman, 1991). An NIMH CSP-funded research demonstration project in Philadelphia investigated the effectiveness of consumers/survivors as intensive case managers (Solomon, 1992). It found that consumers/survivors were as effective as non-consumers/survivors in providing case management services. In New York, the Bronx Psychiatric Center has incorporated consumer/survivor peer specialists into case management teams, while in Sacramento, California, consumer/survivor community support services coordinators are employed to assist “clients” in accessing non-traditional case management services (Furlong-Norman, 1991). To prepare consumers/survivors to work as case management aides, Colorado offers a special training program in case management for consumers/survivors.

Crisis Response

Consumers/survivors also are operating respite programs for those in emotional crisis (Stroul, 1986). These programs provide a safe, supportive, and comfortable setting where individuals can obtain some relief from their problems without the stress, coercion, and often public shame associated with traditional, professional crisis response services. Telephone hotlines, as well as temporary shelter during crises, are key features of these services. Project Acceptance has begun to provide these services for its members, as does the

Next Step Respite Center in Ohio (Ohio Department of Mental Health, 1990).

Benefits Acquisition

Consumer/survivor-operated benefits acquisition projects like BACUP in Los Angeles assist their peers in accessing benefits and services to which they are entitled (e.g., Social Security, housing). Consumers/survivors report trusting and feeling comfortable with peers who have experienced problems similar to their own (Long with Van Tosh, 1988a). Some benefits acquisition programs also provide assistance with case advocacy in order to protect the rights of consumers/survivors.

Anti-Stigma Services

Consumers/survivors operate many types of anti-stigma services including repertory companies (Project Return Players), speakers bureaus (Project Overcome), slide presentations (PCPL), and video productions (White Light Communications) (Rogers, S., 1988; Lovejoy, 1988; Schlageter, 1990).

Advocacy

Many consumer/survivor-operated self-help programs also provide advocacy services to their members in an effort to provoke fundamental change. The Alliance of Syracuse, New York, for example, has sponsored educational training for consumers/survivors across the country who wish to learn more about advocacy skills. The Alliance has also been an ardent supporter of individual patients' rights and has provided support to persons in need of advocacy (The Alliance, 1993).

Research

Consumer/survivor-operated research programs are a very new development. Currently, Well-Being Programs, Inc., and the Consumer/Survivor Work Group on Policy and Research have pioneered consumer/

survivor involvement in research, evaluation, and data issues.

Technical Assistance

The consumer/survivor-operated National Empowerment Center in Massachusetts and the National Mental Health Consumers' Self-help Clearinghouse in Pennsylvania are funded to provide technical assistance to help other consumers/survivors implement self-help programs and address other issues. In addition, a number of consumer/survivor-operated organizations sponsor training workshops, conferences, and seminars to transmit needed information and techniques to other consumers/survivors.

Employment

Consumers/survivors have also conducted employment programs that include job training/placement efforts (the former group ACT NOW in Pennsylvania) and job support groups (I CAN in Lancaster, Pennsylvania). In addition, there are a growing number of consumer/survivor-operated businesses, especially in Ohio, which include such enterprises as a jewelry cooperative (Jewelry Plus Craft Cooperative); a tea house (Shining Reflections); and a landscaping business (Your Personal Landscaping and Cleaning Company) (Ohio Department of Mental Health, 1990).

Managed Care

With the recent development of Medicaid managed mental health care, consumers/survivors have begun to respond by organizing and educating themselves on how this will affect their services and their lives. A notable effort has been the Consumer Managed Care Network which has developed a "Platform for Action", indicating, from a consumer perspective, qualities of a responsive managed care system (Consumer Managed Care Network, 1996).

Structure and Organization of Consumer/Survivor-Operated Self-help Programs

Mental health consumer/survivor-operated self-help programs are organized in a variety of ways to achieve their aims. While the type of service dictates organizational specifics, the literature suggests that there are similarities among programs. As mentioned earlier, consumer/survivor-operated efforts are based on the values and guiding principles of the consumer/survivor self-help movement. Thus, egalitarianism is fostered as well as a non-hierarchical approach. Peer support, empowerment, and respect for individuals are also promoted (Zinman, et al., 1987; Segal, et al., 1991).

The differences come into play when these values are operationalized. While some programs take a firm line in adhering to egalitarian and non-hierarchical values, others do not. The question then becomes: does a consumer/survivor-operated self-help organization cease to exist when it no longer practices its stated values (Zinman, et al., 1987; O'Hagan, 1991)? The CSP Consumer/Survivor-Operated Services Demonstration Projects described in Chapter 2 provide some preliminary information that will be useful in answering this question.

Funding

Funding for consumer/survivor-operated self-help programs originated from a mix of sources, including: grants from Federal, State, and local Mental Health Authorities, foundation and corporate grants, membership dues, and private donations. The majority of programs receive a relatively small amount of money for operations (Zinman, et al., 1987; National Mental Health Consumer Self-help Clearinghouse, 1991; Yaskin, 1992a).

Some organizations have objected to the use of Government funds because of the

potential for co-optation. Others view them as funds that consumers/survivors have earned through paying taxes and to which they are entitled. The few organizations with large budgets (over \$500,000/year) have relied primarily on governmental funding. It is clear, however, that the majority of consumer/survivor organizations have difficulty raising the resources necessary to accomplish their aims due to the current economic health of the Nation, the lack of focus on human services, and the persistent stigma that is attached to "mental illness" and consumers/survivors (Furlong-Norman, 1988a).

Program Administration and Leadership

Although consumer/survivor self-help organizations strive to manage and administer their programs in accordance with the values of the movement, a number of different leadership patterns have developed. Ideally, there would be no formal leadership or leadership would be shared among all the project's members or staff. A few programs adhere to this strategy and also attempt to use a consensus model, whereby everyone must agree on a particular course of action before it is implemented. At the other end of the spectrum are organizations that have become hierarchical and bureaucratic as they have grown larger. In these programs, leadership is clearly defined. In the middle, where most projects probably lie, there is a mix of leadership and decisionmaking styles. For example, while a program may have formally defined leaders, democratic participatory management practices are also employed (Zinman, et al., 1987; Emerick, 1989).

Staffing

Staffing patterns also vary greatly from organization to organization. Since most consumer/survivor self-help programs have insufficient

funding to support paid staff, volunteers often comprise the majority of the workforce. In some programs, job responsibilities are shared and staff work part-time (Zinman, et al., 1987; Yaskin, 1992a).

It appears that the availability of support on the job (a feature that appears to be inherent in consumer/survivor organizations) is very important for consumers/survivors to succeed in the work place. In keeping with the Americans with Disabilities Act, consumer/survivor-operated services provide greater “reasonable accommodations” (e.g., “flextime”, additional breaks, time off for appointments) to their staff members than more traditional organizations do and are more sensitive to the issues their employees face.

Populations Served

Given that research and evaluation have not yet become standard activities for these consumer/survivor-operated programs, it is difficult to accurately define the population that they serve. From the literature, it appears that they serve people who are hesitant to utilize existing traditional professional services for a number of reasons, including: the past treatment they have received; the cost of traditional services; the amount of support provided at consumer/survivor programs versus traditional programs; and the stigma associated with seeking professional services. Depending upon their location, some mental health consumer/survivor-operated self-help programs may serve only a few individuals a week, while others in heavily populated urban areas may serve hundreds in the same time period (Gartner and Riessman, 1984).

Program Governance

Governance of consumer/survivor-operated programs tends to follow the values of the

movement. In most programs, Boards of Directors are composed entirely of consumers/survivors. Those that depart from this practice usually have a majority representation of consumers/survivors. Of these programs, some deliberately offer a Board position to a high-profile community member or attorney in order to obtain expertise in a particular area. These consumer/survivor-operated programs believe that this practice is permissible, as long as consumers/survivors constitute the clear majority on the board (Zinman, et al., 1987).

Research and Evaluation

Research and evaluation on consumer/survivor-operated programs is sparse; the findings presented in this report comprise the most comprehensive examination of its kind to date. However, some individual programs (e.g., Project OATS in Philadelphia) have completed evaluation studies that demonstrate that consumers/survivors are successful in providing services to their peers (Van Tosh, 1990). The two Federally funded research centers mentioned earlier are pursuing research into the issue of consumer/survivor self-help and a number of independent researchers (e.g., Phyllis Solomon, Julian Rappaport, Caroline Kauffman, and Athena MacLean) are also beginning to investigate this phenomenon further. Recently, for example, Solomon released findings indicating that consumer/survivor case managers are as effective as non-consumer/survivor case managers in providing services (Solomon, 1992).

In addition, consumers/survivors have begun conducting research themselves. Among their initiatives are an evaluation project directed by Judi Chamberlin at the Boston University Center for Psychiatric Rehabilitation and the newly emerging Consumer/Survivor Work Group on Policy and Research.

Interaction with Other Agencies

Mental health consumer/survivor-operated self-help programs interact with the traditional professional system in a variety of different ways (Emerick, 1990; Boltz, 1992; National Association of State Mental Health Program Directors, 1989; Kaufmann and Freund., 1988). Some self-help programs form partnerships with other agencies, while others retain an independent stance and so do not participate in outside collaboration. The Center for Self-help Research is investigating this area to raise the specific issues involved in forging interorganizational relationships (Hasenfeld and Gidron, 1992).

Consumer/survivor organizations are also increasing their efforts to work with one another. The development of national and, in particular, Statewide organizations have played a role in encouraging consumer/survivor-operated programs to develop linkages with each other. However, on the national level, political differences have created divisiveness among different factions of the movement.

While some observers have argued that this is the type of healthy political discourse found in any movement, others have seen these divisions as destructive to the sense of unity needed to accomplish common goals. Statewide organizations, on the other hand, have made great strides in bringing various independent consumer/survivor-operated programs together to work collectively for positive change and for the further development of consumer/survivor services.

From this overview of the literature, it is clear that there is much more to be learned about the phenomenon of mental health consumer/survivor-operated self-help services. The following chapters of this report examine the results of the 13 CSP Consumer/Survivor-Operated Services Demonstration Projects as the first step in enlarging understanding about the consumer/survivor-operated program model. The descriptions of all 13 individual projects presented in Chapter 2 illuminate project similarities and differences. Chapter 3 offers a cross-site analysis as well as practical, program-level suggestions and policy recommendations based on those findings.

DESCRIPTIONS OF THE 13 DEMONSTRATION GRANT PROJECTS

Project materials from each of the CSP Consumer/Survivor-Operated Services Demonstration Projects were examined in order to provide an in-depth, cross-program examination of each individual initiative. Documents that were reviewed included: original applications, annual continuation applications, relevant correspondence from NIMH, final project reports, and evaluation findings. A variety of program elements were explored: project goals and objectives; services and supports provided; client population served; organizational structure; board development; staff size, characteristics, and training provided; reasonable accommodation practices; program materials developed; implementation issues; inter-organizational coordination; existence of other self-help programs before and after the demonstration grant; project budget; evaluation strategies and findings; and program continuation plans. These domains have been collapsed into four groupings—Project Goals and Objectives, Program Description, Implementation Issues and Problems, and Evaluation Findings—which are presented in this chapter for each of the thirteen programs which were funded.

There are limitations to this analytic strategy which may affect the objectivity of the findings. The majority of materials reviewed were self-reports created by the projects themselves. Other materials were often prepared by State mental health authority personnel, which further complicates validity, as it is possible that such staff were less familiar with a particular program's day-to-day operations than a program coordinator or director would be. The information within these documents was often incomplete, which further limits the usefulness of the documents. Other strategies (such as key informant surveys and site visits) may have been able to capture a broader spectrum of information, and perhaps enhanced the validity of the "information" or "findings" presented. However, resource constraints prevented the use of those methodologies.

The above limitations notwithstanding, these analyses do offer a valuable, albeit descriptive, examination of each demonstration site. The individual project findings indicate a variety of project approaches and successful outcomes. Although there was variation from site to site, an overall conclusion can be drawn that these efforts demonstrated efficacy in meeting consumer/survivor needs.

CALIFORNIA

Alameda County Network of Mental Health Clients

Berkeley Drop-In Center

Berkeley, CA

Oakland Independence Support Center

Oakland, CA

“...Since I’ve been working here...I have felt worthwhile because I’ve been able to help people. Knowing that I’m contributing to society makes me feel like I’m worth something. I also feel safe and confident to be me and work to help people in an environment of people who are like me.”

—Project staffer (OISC)

PROJECT GOALS AND OBJECTIVES

The grant funded the Alameda County Network of Mental Health Clients (ACNMHC) to expand the Oakland Independence Support Center (OISC) and the Berkeley Drop-In Center (BDIC). Grant funds were used to enable these programs to expand client services to better meet their service recipients’ demonstrated need. This was to be accomplished via a “Coordinated Self-help System” (CSHS), which was designed to centralize shared resources, including administrative services, storage space, bookkeeping, statistics, insurance costs, and medical coverage. CSHS was also designed to enable the hiring and assignment of additional staff, develop a volunteer resource bank, and conduct coordinated outreach, evaluation, and fundraising. CSHS was conceptualized as a self-help/mutual support approach to peers helping one another—a “self-help program for self-help programs.” It was hoped that the expanded activities resulting from the grant would lead to the development of a model which could be replicated elsewhere.

PROGRAM DESCRIPTION

Services Provided

The BDIC offered direct services (a drop-in center, support groups, case advocacy, generalized advocacy, information and referral, instructional groups, free food, phone, books, magazines, transportation assistance, and clothing) and recreational activities (socialization and art activities).

The OISC offered a community **drop-in center** (free coffee, food, support groups, and peer counseling), **independent living services** and **independent living skills training** (mailing address, bathroom and shower facilities), and **information and referral** (advocacy, housing search assistance, money management assistance, and outreach to other programs).

As a result of this funding effort, the programs were able to increase their operating hours, increase the number of instructional groups and support groups offered, and offer additional advocacy, socialization, and substance abuse counseling services. Guidelines

for volunteer recruitment were developed, and a brochure and mailing list were created to assist in project outreach. Successful fundraising enabled the ACNMHC to obtain a contract with the Alameda County Mental Health Department to provide tenant support services to consumers/survivors living in the Aztec Hotel, a large, nonprofit, consumer/survivor-operated, single-room occupancy hotel.

Individuals Served

Service recipients were defined as individuals who had a history of psychiatric disability. The Final Report indicated that BDIC estimated the total unduplicated number of individuals served for the entire project was 1,600, while OISC served approximately 1,900 different individuals. Service recipients had the following characteristics: 95% were homeless or at risk of being so; over 98% were very low-income; the majority were African American males; most were between the ages of 22 and 44; 26% had no high school diploma, 53% graduated high school, 16% had some college, and 5% were college graduates; and nearly 30% were veterans.

Organization and Administration

The grant was provided to the California Department of Mental Health (DMH), which initially passed the funds through Berkeley-Oakland Support Services (BOSS). BOSS, in turn, provided the funding to the Alameda County Network of Mental Health Clients (ACNMHC), which then funded the separate BDIC and OISC projects. Later in the grant, both centers as well as the ACNMHC attained nonprofit status and were able to directly receive the grant funds.

A Coordinating Committee reported to the ACNMHC Board and was composed of three at-large members of the ACNMHC Board and three members from each center, including the

Program Coordinator/Director of each. Over time, a decision was made to eliminate the Coordinating Committee, as its function was duplicative of the ACNMHC Board. Both projects had a shared staff and administration.

Shared paid staff consisted of an Administrator; an Administrative Assistant; a Field Advocate who advocated for entitlements, housing, and rights protection; an Independent Living Specialist who conducted skills workshops, assisted service recipients in obtaining housing, and provided benefits counseling, information and referral, and case advocacy; an Activities Coordinator; and a Substance Abuse Peer Counselor. Paid consultants were utilized for program evaluation, fundraising, bookkeeping, and graphics. Unpaid staff consisted of a Program Coordinator and an Activities Coordinator at BDIC, and a Program Developer, a Program Services Coordinator, an Administrative Assistant, and Information and Referral Specialist, a Housing Counselor, an Independent Living Skills Trainer, an Intake Worker, and a Peer Counselor at OISC.

Volunteers averaged 225 hours per month at each center to assist with structured socialization activities, food preparation, facilitating support groups, and site maintenance. The Final Report estimated that over 350 consumers/survivors volunteered during the grant period in a wide variety of tasks.

Most staff were African American men; all were disabled, all were low-income when hired; all had experienced homelessness; and all were consumers/survivors. The ACNMHC has an affirmative action plan that emphasizes ethnic minorities, women, and disabled individuals in all roles within their programming: as participants, as staff, and serving on governing bodies.

Employee orientation and as-needed, on-the-job training were provided. Group training was also provided for the staff, volunteers, and service users on such topics as peer counseling, benefits advocacy, community resources, substance abuse, HIV/AIDS, TB and other

public health issues, civic involvement, defusing potentially violent situations, performing intakes, and chairing meetings.

A number of administrative and program materials were developed, including personnel policies, financial/accounting forms, and client forms. ACNMHC, BDIC, and OISC coordinated their activities with a wide number of other organizations and entities, including community service agencies, advocacy agencies, State consumer/survivor organizations, local mental health and homelessness committees, providers of services to the homeless, mental health providers, State and local mental health authorities, churches, foundations, researchers, legal centers, and neighborhood associations.

A total of \$390,742 was spent on this effort over the three years of project funding. Of this amount, \$376,238 came from Federal funds and \$14,504 came from miscellaneous sources.

IMPLEMENTATION ISSUES AND BARRIERS

Grant Startup Delays and Cashflow Problems

The project startup was delayed for nine months, which affected hiring, procurement of office space, equipment, furnishings and property insurance. This delay was due, in part, to the 1989 San Francisco Bay Area earthquake. State and Federal officials agreed to roll over the first-year funds. This delay, however, caused cashflow problems, and ACNMHC was initially forced to borrow funds to cover payroll. Cashflow problems also prevented the project from conducting outreach in the South County area, but full caseloads made outreach less of a priority.

Heavy Workload and Staff Turnover

During the early phase of the grant, there was some staff turnover. In addition to the staff turnover, it was reported in Year 2 that the individual projects believed that the CSHS administrative office and staff were unable to carry out both the functions of ACNMHC and the functions of the two centers. Eventually, some shared administrative support, such as bookkeeping and statistics, was dropped.

SUCCESSSES AND EVALUATION FINDINGS

Evaluation data were collected from a variety of sources, including observations, interviews, discussions, and the use of program documents, records, and quantitative data.

The Final Report noted that the demonstration project essentially looked as planned. ACNMHC became an effective “umbrella” organization with shared resources, staffing, and administrative assistance. It was agreed that some of the administrative functions for the two centers were not needed and would have been logistically difficult to provide.

Overall, it was noted that both centers succeeded in further developing their programs (focusing on social and survival needs), improving administration and operations (sharing of information), and improving recordkeeping and computer capacity. The local centers were successful in gaining their own foundation grants. In Year 3, a funding consultant was hired, resulting in successful grants and loans.

Boston University conducted an outcome evaluation that examined program participants’ self-esteem, quality of life, satisfaction with the self-help program, service use, and demographics.

Approximately 18% of the individuals served were screened and intaked by CSHS staff at both sites, with interviewers recording various data. The services used by the most people were: hot meals (100%), transportation assistance (100%), social/recreational activities (93%), telephone services (88%), food referrals (84%), peer counseling (76%), independent living skills training (60%), and peer support groups (60%).

A correlational analysis revealed the following:

- Individuals who participated at a higher level in the program had higher levels of program satisfaction and had increased self-esteem and quality of life.
- Findings suggested that persons with long psychiatric histories (including frequent and long hospitalizations) benefited at the same levels as other participants in terms of the program's impact on self-esteem.
- There was no difference between members of different races or individuals with homeless status in terms of self-help program impact on self-esteem, satisfaction, or quality of life.
- No significant correlation was found between taking or not taking medications and self-esteem, satisfaction, or quality of life. However, there was a relationship approaching significance between satisfaction with the program and taking medications (those who do not take medications reported being more satisfied with the program).

The Final Report recommended that additional and more comprehensive technical

assistance and training be provided on the topics of board development, fundraising, recordkeeping, computer technology, and personnel policies and procedures (including laws and regulations governing employment practices). It was also recommended that when Federal funding is temporary, there should be formal and concrete agreements with State and local mental health funding agencies to continue funds past the grant period. Lastly, it was recommended that funds should not be channeled through the State mental health system, as this causes additional delays in project startup. Funds should be provided, instead, directly to the recipient organizations.

The Final Report suggested several interesting hypotheses for further evaluation:

- Outreach to ethnic minorities is best accomplished when a program is situated in that community.
- Both services and social activities are needed for a viable program.
- Programs such as these attract people who are distrustful and resistant to traditional mental health services.
- An umbrella organization is essential for cooperation, communication, and coordination for client-run programs in the same geographic area.

BDIC and OISC both obtained city funds to continue two positions until ACNMHC could obtain ongoing funds. Eventually, ACNMHC obtained county mental health funds to continue operations.

COLORADO

The Phoenix Project Denver, CO

“I feel [it] was a success and made a success by empowered consumers...I can honestly say I learned to use my brain, my knowledge, instincts, wisdom, courage, personal beliefs, education and experience in life...I learned the real meaning of team work...”

—Project staffer

PROJECT GOALS AND OBJECTIVES

The overall goal of The Phoenix Project was to develop a consumer/survivor-controlled and -operated “superstructure” for the development, creation, and sustenance of nonprofit and forprofit consumer/survivor-managed affiliate business enterprises. These affiliate enterprises would employ consumers/survivors and would provide various direct services and alternatives to traditionally based mental health services to other consumers/survivors. It was hoped that the grant would provide initial funds for startup costs and that later each affiliate and the “superstructure” would be self-sufficient from sales and funding support from other agencies and foundations.

Specific objectives included developing at least seven affiliate businesses (of which five would provide mental health services, such as case management, drop-in centers, respite programs, job coaches, companion programs, housing support staff, and vocational case management). Other suggested business ideas included: property management and maintenance, bulletin board services, car detailing, photo finishing, messenger service, phone marketing, wholesale handcraft and art, catering/box lunches, and temporary employee services. It was hoped

that these efforts would employ 50 consumers/survivors serving 500 consumers/survivors in the community.

The parent corporation provided initial support (startup funding), administrative and management services as needed (e.g., training, accounting, marketing, and data processing), and access to, and coordination of, community resources on a cooperative model. The superstructure of the corporation provided a common job center for all affiliates, public relations, technical assistance, and fundraising. There were also plans to disseminate project results throughout the State and nationally.

The Final Report indicated that over time, it became clear that the objectives were too ambitious, so they were revised, with NIMH approval, as follows: to develop seven businesses, of which at least three would provide alternative mental health services. These businesses would provide alternative services to 200 consumers/survivors.

PROGRAM DESCRIPTION

Services Provided

After a lengthy RFP process, seven consumer/survivor-managed businesses were selected for startup funding, with six

being successfully established. These included an auto repair service, Leopard Automotive; a telephone help line, The Helping Ear; a desktop publishing firm, Phoenix Publishing; an auto repair referral service, AutoMedic; a rental management project, Phoenix Property Management; and a benefits assistance project, Professional Benefits Assistance.

The Helping Ear provided information and advocacy, peer counseling, benefits acquisition assistance, and crisis intervention. Grant funding also enabled The Phoenix Project to provide technical assistance to consumers/survivors. This technical assistance was focused on specific skills such as cash register operation; interpersonal skills such as conflict management; and business development, management, and other administrative skills such as bookkeeping, purchasing, payroll, board development, and fundraising. Lastly, the funding enabled The Phoenix Project to disseminate project results through presentations at international, national, Statewide, and local conferences, as well as through providing information to over 300 contacts and through coverage in newspaper articles and newsletters.

Individuals Served

The project focused on serving individuals designated as having a psychiatric disability. The Final Report indicated that a total of 500 individuals received services from the affiliated telephone information service, The Helping Ear. Characteristics on the clients served by the other affiliate businesses are unavailable.

Organization and Administration

The grant was provided to the Colorado Division of Mental Health, which provided the funds to The Phoenix Project. The Phoenix Project's structure consisted of a Board of Directors and a central office staff. It was origi-

nally intended that each affiliate business would have its own Board and staff, although further information was not reported.

Initially, a Board of Directors was to be composed of both consumers/survivors and non-consumers/survivors, as well as minority representation proportional to the State's makeup. After a lengthy process (which included nominations, written evaluations, and in-person interviews), seven consumers/survivors and four non-consumers/survivors were chosen for the Board in late 1989. The Final Report indicated that a total of 31 consumers/survivors and 6 non-consumers/survivors had participated on the Board over the length of the project.

Paid staff consisted of an Executive Director, an Assistant Director, a Consumer Project Coordinator, an Administrative Assistant, and a Bookkeeper. The State also provided in-kind staff support through a Community Support Program Director and a Human Resources Development Assistant. The Final Report indicated that other part-time staff and consultants were hired to assist with administrative tasks including help from a Business Manager and an Operations Manager. The Report also indicated that 100 consumers/survivors over the entire project period participated as staff, consultants, board members, or volunteers. Nearly all paid staff were consumers/survivors; consultants were generally non-consumers/survivors.

Staff were provided with training on non-profit organization development, business management, specific employment-related skills, and interpersonal skills. In Year 2, the project determined that it would encourage its affiliate businesses to offer low-stress, flexible, supportive above-minimum-wage jobs (with time off for doctors' appointments, if needed), career advancement, and assistance to staff in achieving financial independence. It also decided to offer case management to those who were transitioning back to work and

regular support groups for employees to see if their needs were being met.

A number of pertinent materials were developed as a result of this effort, including a personnel handbook, a Request for Proposals, and Board application forms. The project was coordinated with a number of organizations and entities, including retired business executives, training centers, mental health providers, and colleges. In terms of the project's impact on the region, prior to the grant, there was a consumer case management program in Denver and a few self-help groups in the area. After the effort, The Helping Ear and the Statewide consumer/survivor organization Survivors and Consumers of Colorado Organized for Rights and Empowerment (SCCORE) had been developed.

The Final Report indicated that the total Federal funding for the project was \$450,000.

IMPLEMENTATION ISSUES AND BARRIERS

Several issues were encountered in the implementation of this initiative. Delays in startup occurred, due to some State-level staff turnover; as a result, a project extension was granted. Turnover in the Executive Director position and Board members also contributed some difficulties. Tensions over control developed on the Board between consumers/survivors and those who were not consumers/survivors. Eventually, at the end of the project, the Board was composed of all consumers/survivors, except for one member. The amount of resources needed to accomplish the original goals was underestimated, and limited financial resources hindered the program's success. Superstructure delays in providing subgrants to the affiliate businesses resulted in the State threatening to withhold funds for the entire project.

Board and staff members both felt that there was a lack of expertise in marketing approaches, financial management knowledge,

technical assistance, priority setting, and overall direction, which was ultimately detrimental. The affiliate businesses were initiated in an artificial environment. The Board and staff had to train others on how to develop a Board and organization at the same time they were learning to do it themselves, and this contributed to the difficulties. It was recommended that more time should have been allocated to these organizational development tasks. Additional problems mentioned were expediency of decision making (too many decisions were made in times of crisis), and the isolation of Board members from one another.

SUCCESSSES AND EVALUATION FINDINGS

The project evaluation was originally conducted by an independent consultant; this was later contracted to the Center for Technical Assistance and Training at the University of Northern Colorado. Project document analyses and key informant surveys were the principal sources of data.

The Final Report stated that Board members experienced positive impacts, including: more knowledge of services available, knowledge of consumer/survivor needs, knowledge of business and legal issues, and a growing sense of empowerment.

Overall, it was found that the number of consumers/survivors employed was considerably lower than that expected and that self-supporting businesses are a difficult undertaking under even the best circumstances. The project did appear to enable people to develop skills to seek employment elsewhere. Some comments provided by the Board and the staff: “. . . Consumers were motivated to consider themselves as positive members of society . . .”, and “. . . It was highly successful in empowering the consumer participants and in providing them with a variety of interpersonal, leadership, and employment-related skills.”

Some overall recommendations were offered by the evaluation:

- Ongoing training should be provided for staff on mission, policy and procedures, orientation, team building, communication, best business practices, and management issues, and for the Board on such areas as communication, problem solving, decision making, and leadership development;
- Effective communication needs to be improved between the Board and staff;
- Minority representation needs to be increased throughout the program;
- A business advisory committee should be established to direct and advise the businesses proposed;
- The search for additional funding to maintain the project's financial viability should be continued;
- Career planning for consumers/survivors for long-term employment goals should be implemented;
- Ongoing outreach to consumers/survivors who might not be a part of the formal mental health system should be continued;
- Realistic expectations regarding the project should have been established so that participating consumers/survivors were not set up for disappointment;

- Longer-term funding should be secured (e.g., a five-year grant, which would allow for greater success, given that most startup businesses take three to five years to establish themselves);
- The necessity of being proactive and taking a planned, systematic approach to completing the project should be emphasized; and
- There is a need for effective team decision making, values clarification, community linkages, and sound management philosophy.

Additional recommendations were made regarding rewards and incentives. The project should:

- Find ways to concretely celebrate each success, no matter how small (thank-you notes, extra break times, congratulation phone calls);
- Recognize work done well (employee-of-the-month, newsletter mention, letters of recognition);
- Develop incentive programs based upon employee choice and personal values; and
- Treat people with unconditional respect and use rewards strategically but often.

After the grant, attempts were made to locate ongoing funding, but these were ultimately unsuccessful. The Phoenix Project ceased operation in April, 1993.

INDIANA

Knowledge Empowers You Indianapolis, IN

“KEY has helped me to be more motivated and more independent and also it has made me think of myself as a useful person for a change, and not just someone with an illness...”

—Project participant

PROJECT GOALS AND OBJECTIVES

The overall mission of this effort, as stated in the original application, was to empower consumers/survivors by creating opportunities to increase self-esteem, self-reliance, and independence through strengthening support networks and advocacy efforts. Specifically, this was to be accomplished by developing and setting up an Office of Consumer Affairs (OCA) within the Indiana Department of Mental Health, via the Mental Health Association of Indiana. The OCA would establish links with consumers/survivors, family members, providers, and others. It was proposed that this effort would develop a telephone tree for legislative alerts, distribute monthly bulletins, publish a quarterly newsletter, and sponsor quarterly meetings of State and regional councils.

Additionally, the project would work towards developing a structure for the consumer/survivor movement and provide training on starting self-help projects. One component of this training was to develop a model for self-help groups known as KEY (Knowledge Empowers You) groups. The project also hoped to develop a mailing list of consumers/survivors.

A training package for use in public speaking was to be developed as part of a speakers bureau. Other plans included organizing a Statewide conference, information dissemina-

tion, assisting in developing a coalition of consumers, family members, and providers, promoting consumer/survivor representation on boards, and organizing an improvisational theater group and a media anti-stigma campaign.

PROGRAM DESCRIPTION

Services Provided

Grant funding enabled the project to provide the following services:

- **Organizational Development.** The project established the KEY Consumer Organization, a Statewide consumer/survivor organization. A Statewide Consumer Advisory Council and two regional Councils were also developed. A development professional was hired to initiate fundraising activities, and preparations were made for writing several grant proposals.
- **Technical Assistance.** Onsite technical assistance was provided throughout the State. Eight KEY self-help groups were developed, and a leadership training retreat was held. Training was organized on serving on boards and committees, peer support group leadership and facilitation, and communication skills. A peer counseling training program was started,

which provided 28 hours of initial training for those interested in being case aides. The Statewide network was expanded to over 750 consumers/survivors. Two Statewide conferences for consumers/survivors were held. Scholarships were provided to over 80 consumers/survivors to attend conferences and meetings.

- **Advocacy.** Various advocacy efforts were conducted around the State, including obtaining consumer/survivor representation on patients' rights committees, holding sessions for the purpose of meeting legislators, and holding meetings to discuss consumer/survivor rights.
- **Information Dissemination.** *KEYNOTES*, a newsletter, was published and disseminated to over 1,000 individuals. A speakers bureau was organized and provided over 125 educational presentations and workshops. A toll-free hotline was established and provided information and referral services to consumers/survivors. Improvisational theater groups were established, and these conducted a number of educational performances.

Individuals Served

The following criteria were designated for individuals who were to be served by the program:

- Persons with a psychiatric disability;
- Former or current patients or service recipients of the mental health treatment system; or
- "Concerned others" who want help or referrals for mental health or consumer/survivor services.

No specific client characteristics were reported, but the following general characteristics were observed: service recipients? ages

ranged from 15 to 80; more women were served than men; service recipients were mostly low-income; and there was an increase in minority service recipients being served, over time.

Organization and Administration

The grant was provided to the Indiana Department of Mental Health, which provided the funding to the Mental Health Association (MHA) of Indiana. Initially, a Consumer Advisory Council (CAC) was established and composed of representatives from across the State. During the second year of the project, an all-consumer/survivor Board of Directors was formed, formal bylaws were established, and the project was formally incorporated. By the project's end, the KEY Consumer Organization was directly receiving the grant from the State.

Paid staff consisted of a Consumer Affairs Director, an Assistant Director, an Administrative Assistant, an Evaluator Assistant, and a Newsletter and Filing Assistant. Paid staff were primarily Caucasian, middle-aged women. Over 100 volunteers assisted in many different areas. Staff training was provided on computer technology, sign language, and newsletter development. "Flexitime" was provided to staff.

A large number of service-related program and administrative materials were developed during the course of the project, including legislative training information and a support group model description. This project interacted with a number of public and private groups, including family groups, other consumer/survivor groups, mental health providers, vocational rehabilitation offices, and protection and advocacy agencies.

The reported total costs for this effort were \$166,198, with approximately \$161,000 in Federal funding.

IMPLEMENTATION ISSUES AND BARRIERS

Reorganization of Fiscal Agent

In Year 2, the KEY Consumer Organization was established as a nonprofit with bylaws, etc. It was felt that some of the problems experienced by the project were related to the original fiscal agent's lack of understanding regarding the autonomy of KEY. KEY subsequently moved out of the agent's offices and opened an independent office that was provided by the State at no cost.

Regional Councils Were Not Developed

It was originally planned that regional advisory councils would be developed throughout the State. These councils were ultimately not developed due to support groups not being stable and geographic distance.

Obtaining Representation on Patient Advocacy Committees in State Hospitals

Delays were experienced in realizing this objective due to the lengthy processes State hospitals used in appointing representatives to these committees.

Lack of Involvement of People of Color

Staff reported that ". . . members of KEY feel they have tried and failed at attracting the minority populations and they are unsure of what else to do . . .".

Other Issues

Staff noted that the most critical problem, by far, has been the lack of money. Other problems included limited staff resources and interpersonal conflicts among staff.

SUCCESSSES AND EVALUATION FINDINGS

Although formal program evaluations were not completed (according to the Final Report), an informal evaluation was conducted with recipients of KEY services. Results were generally positive. Some of the comments included: "KEY has created a greater awareness of consumer needs and issues especially in the provider community...the main success of KEY has been the empowerment of the consumers . . .," ". . . The KEY Consumer Organization has been a blessing to many people who suffer from mental illness. People who have been empowered by KEY have gone on to live very productive lives."; "Thanks to KEY I can stand up for my rights and do many other things I never could before I came to be involved with them . . . I now have confidence and can do much better than I ever have before."; and "It's made a difference in my life."

During the project period, a new Department of Mental Health Commissioner was appointed. He was considered progressive and supportive of consumer/survivor initiatives and mandated more consumer/survivor involvement. It was reported that KEY received a portion of an NIMH/CMHS Services System Improvement Grant to provide continued services to consumers/survivors.

MAINE

Portland Coalition for the Psychiatrically Labeled Portland, ME

“...We are on the cutting edge of the mental health system—being a consumer organization. We’re working together to make it fly. We have something we can prove. We can make a difference.”

—Project staffer

PROJECT GOALS AND OBJECTIVES

The goals of this effort were “...to empower and enable persons who are psychiatrically labeled to help themselves and other psychiatrically labeled persons [and] to enable consumers to assume and maintain equal status as partners in the mental health system.” Specific objectives included funding the Portland Coalition for the Psychiatrically Labeled (PCPL) to: develop the necessary infrastructure and breadth of competency to operate effectively; refocus PCPL on in-house member activities; turn volunteer service into paid employment; and create a model for consumer/survivor-operated peer support, advocacy, education, and training services.

PROGRAM DESCRIPTION

Services Provided

Grant funding enabled PCPL to provide the following services:

- **Administration.** The project developed an in-house financial system, conducted fundraising, developed a Board, and wrote bylaws and personnel policies.

- **Drop-In Center.** The Drop-In Center provided social and informational activities to benefit members, developed a membership list, held monthly membership meetings, and distributed a monthly update of activities.
- **Peer Support.** The project held frequent and regular peer support meetings, conducted outreach and peer support for individuals in nursing homes and schools, offered informal support to those discharged after long-term institutionalization, provided one-on-one counseling for support on independent living skills, and conducted specialized peer support groups for alcoholism, homelessness, and posttraumatic stress disorder.
- **Respite/Crisis Assistance.** PCPL provided assistance on a limited basis by referring individuals to other services and working with staff of a crisis stabilization project to monitor and evaluate their program.
- **Empowerment.** The project empowered consumers/survivors through greatly increasing the membership and enabling PCPL to conduct special outreach to minority groups.

- **Independent Living Programs.** The project established a stipend program which assisted individuals in developing job skills and provided information and referral services.
- **Public Education.** PCPL published a newsletter three times per year and distributed it to over 1,500 people and produced a slide show on stigma.
- **Advocacy.** The project conducted regular monitoring visits to institutions, testified to State legislators, and filed a class action lawsuit against the Augusta Mental Health Institute regarding patient deaths. PCPL members participated on various mental health committees and task forces Statewide.

Individuals Served

All individuals who were psychiatrically labeled or psychiatrically disabled were eligible to receive project services. It was reported that PCPL experienced a fourfold increase in the number of individuals served during the grant period. Little data were provided on characteristics of service recipients who used services. A drop-in center evaluation found: a slight majority of the participants were male; their ages ranged from 32 to 55; all were psychiatrically labeled; all were living in the community, and a slight majority lived alone; the vast majority were currently receiving mental health services; and all had been previously hospitalized.

Organization and Administration

The grant was awarded to the Maine Department of Mental Health, Office of Community Support Systems. The State then provided the funding to the Portland Coalition for the Psychiatrically Labeled (PCPL).

The PCPL administrative structure was composed of a Board of Directors, staff, and members. The PCPL Board existed prior to the grant and was composed entirely of consumers/survivors. The Board was elected annually and was provided with training. Paid staff included an Executive Director, an Assistant Executive Director, a Consultant/Planner, an Office/Work Skills Manager, a Peer Support Program Coordinator, a House Advocate, a Clerical Supervisor, and Stipend Workers. The State also provided three in-kind positions, serving in the roles of Community Support Program Director, Mental Health Program Coordinator, and Management Analyst II. PCPL staff characteristics were not provided in detail, but it was noted that all were consumers/survivors.

It was reported that staff attended training sessions in management skills and desktop publishing. In addition, stipend workers received group and individual training, and advocacy training was provided to members and staff. "Flextime" was available to staff by prior agreement with the Executive Director. Leaves of absence due to illness could be granted for up to six months.

A number of materials were developed over the course of the project, including newsletters, a poetry book, a Board training notebook, a monthly update, bylaws, personnel policies, and job descriptions. It was noted that the use of documentation (e.g., memos, bimonthly update reports) helped to alleviate personnel issues and stabilized the organization.

PCPL collaborated with a wide array of other organizations in achieving its goals and objectives, including: other disability groups, the State protection and advocacy agency, mental health providers, nonprofit management consultants, advocacy groups, and family groups, and universities.

During the grant period, a total of \$540,500 was expended for this effort. Of this amount, approximately \$469,500 was Federal funding, \$66,000 was State funding and \$5,000 was local funding.

IMPLEMENTATION ISSUES AND BARRIERS

Listed below are the issues which developed during the project's implementation. A retreat at the start of Year 3 developed a strategic plan for improving internal communication in order to solicit input from all members, staff, and Board regarding these issues and other internal and external affairs of PCPL.

Delay in Project Startup

It was reported that this was due to the Executive Director resigning and the time needed to hire a replacement. A reorganization occurred after the change in Executive Director, including other personnel changes and a revision of the bylaws, personnel policies, and job descriptions. The hiring process for several staffers took longer than anticipated, and there was ongoing staff turnover.

Cancellation of Statewide Expansion

A decision was made not to attempt to expand within Maine (as originally planned) and instead to focus programming locally on the Portland area.

Lack of Equipment

A lack of typewriters, word processors, and other equipment hampered the job training stipend program.

Personal Conflicts and Tension

The reports indicated that interpersonal conflicts developed between staff and members. This was a major problem encountered during the project. It affected the entire staff and membership. This resulted because some members obtained employment, while others did not.

Unclear Priorities

This resulted in problems of resource allocation and staff burnout, and was due to a lack of organizational planning.

SUCCESSSES AND EVALUATION FINDINGS

A descriptive, summary evaluation of PCPL's drop-in center was completed and was based on interviews with members who used the drop-in center and observation of drop-in center activities. This evaluation found that a majority of participants reported that the center has helped them stay out of the hospital; a majority felt more confident since coming to the center; almost all would recommend the center to others; and a majority said that coming to the center has helped them cope better with their problems.

The overall evaluation focused on the need for continued development of PCPL organizational features, and the following recommendations were offered by the evaluators:

- PCPL should do planning with an expert facilitator to clarify priorities, specify objectives, create an action plan, and build cohesiveness.
- Training on conflict resolution should be provided to Board, staff, and membership to defuse the tensions that developed during organizational change and growth and employment of certain members.

Chapter 2. Descriptions of the 13 Demonstration Grant Projects

- Experts in group process and team building should be used to provide training to staff and Board and serve as facilitators during Board meetings.
 - Board training should be provided annually, along with a packet of written materials.
 - Board terms should be overlapping, and provisions should be made for alternates.
 - Leadership training should be provided to members.
 - Training and technical assistance should be provided to the Board and Executive Director on hiring practices to address staff turnover as well as on strengthening interpersonal relations.
- PCPL should clarify and enforce policies and procedures, including preparing up-to-date policy manuals and offering training to groups and individuals on policy implementation.
- A final comment within the evaluation indicated the overall success of this effort: “. . . the project has demonstrated, without a doubt, that consumers can plan and run their own organization . . .”
- PCPL was successful in obtaining funding for continued operations.

MISSOURI

The Self-help Center Kirkwood, MO

“Overall, The Self-help Center stands out as a quite successful program.”

—Project participant

PROJECT GOALS AND OBJECTIVES

This project developed The Self-help Center, a drop-in center in Kirkwood, MO, for self-help and advocacy services. Specifically, the Center was set up to offer self-help group meetings, peer case management, a drop-in center (offering recreational activities, socialization, respite care for families, a game room, and a reading room), and a self-help and advocacy clearinghouse (providing hotline services, information on advocacy, legislature visits, position paper development, and publication of a rights information pamphlet).

ences, published newsletters, distributed 1,000 pamphlets, and developed a clearinghouse library.

- **Drop-In Center.** The center operated 30 hours per week, with 20 people served per day. Weekly membership meetings, exercise classes, and biweekly volunteer training meetings were held.
- **Support Groups.** The center sponsored support group meetings of national model self-help programs such as Recovery, Inc., Project SHARE, Overeaters Anonymous, and the Missouri Mental Health Consumer Network, among others.

PROGRAM DESCRIPTION

Services Provided

Grant funding enabled The Self-help Center to offer the following services:

- **Advocacy.** The center assisted in filing a lawsuit on patients' rights, obtained representation on various boards and committees, collected information on consumer/survivor grievances, and advocated that all publicly contracted agencies be required to have consumers/survivors on their Boards of Directors.
- **Dissemination and Public Education.** The center presented at various confer-

Individuals Served

All individuals with a psychiatric disability were eligible for services. A total of 220 members were served, of whom 125 had frequent contact. The average attendance was 16 persons per day. Most of those served were Caucasian and under age 50.

Organization and Administration

Initially, the grant was provided to the Missouri Department of Mental Health, which then provided the funding to the Mental Health Association (MHA) of St. Louis. The MHA served as the fiduciary agent for The Self-

help Center. The Center's members elected representatives to a Board of Directors, as well as officers who functioned in a member/staff role in running the center. The day-to-day decisions were made by a majority vote of the participants at weekly membership meetings. The project eventually received its incorporation and no longer worked through the MHA, as it was able to provide its own accounting services.

The Board consisted of six consumers/survivors, a family member, and one additional interested individual. Factionalism within the Board presented some obstacles, as did ongoing struggles between the Board and the Director.

Paid staff included an Executive Director, an Assistant Director, a Drop-In Center Manager, two Clerical Workers, a Homeless Coordinator, a Benefits Acquisition Specialist, a Case Management Supervisor, a Clearinghouse Manager/Director of Advocacy, a Maintenance Worker, and a Technical Advisor (from the MHA). These positions were primarily part-time positions. All staff were current or former consumers/survivors, with the exception of the Technical Advisor. Attempts were made to use a Transitional Employment worker from a nearby psychosocial program to fill some of the clerical positions. Some members were also provided with stipends (\$75 per month) to work approximately one day per week performing various tasks (outreach, recreation, food services). These workers were elected by the membership to fulfill these roles.

The staff were mostly Caucasian; there was an equal balance between men and women; and there was one physically disabled individual and five former SSI/SSDI recipients. A number of volunteers assisted, including five parents. Training was provided to staff on counseling skills and orientation to case management. Staff were initially permitted to attend self-help group meetings during paid time for their own mental health.

A variety of program and administrative materials were developed, including: drop-in center rules and regulations, weekly drop-in center attendance summary, monthly financial reports, and financial procedures. The project interacted with a number of organizations and entities, including advocacy groups, family groups, mental health providers, State and local mental health authorities, and other consumer/survivor self-help projects.

The project documents reported that a total of \$490,239 was spent on this effort, of which \$461,116 was Federal funding and \$29,123 was from other sources.

IMPLEMENTATION ISSUES AND BARRIERS

The following issues were encountered during the implementation of this project:

- **Staff Turnover and Other Personnel Matters.** A major problem was staff instability, as four employees left. Another problem was the lack of affordable health insurance coverage. Staff were provided with \$100 per month for this purpose, but it did not cover this cost. Another problem identified was the difficulty that members had in setting boundaries in staff and member relationships. The two way nature of these relationships (sharing problems as well as listening to service recipients and being "advice givers") made this difficult. A great deal of time was spent in staff meetings on these issues.
- **Heavy Paperwork Load.** The Executive Director reported being overwhelmed with paperwork and accounting.
- **Site Selection/Renovations.** A site was selected, renovations were completed four months later, and donated office equipment was received. However, delays occurred when the Fire

Marshal required extensive modifications, and during a long negotiation with the State regarding day program licensure requirements.

- **Community Resistance.**

Implementation was difficult because of the “NIMBY” (“Not In My Back Yard”) phenomenon during site selection and development.

SUCCESSSES AND EVALUATION FINDINGS

Overall evaluation findings indicated that the project met most of its stated objectives. A large majority of participants reported that “People who come here are learning to depend on themselves more,” and “People are encouraged to make their own decisions.” A majority of participants felt more confident about making their own decisions, and many agreed with the statement “everyone pitches in.” An impressive 90% said that people are proud of the drop-in center. All staff and Board said their work has made them more confident to help others.

Other findings included: a majority considered the center a good place to “be yourself”

and a place to talk about hopes and dreams; a majority stated that “it’s true that it’s a place to share feelings without being put down”. A large majority said that they felt accepted at the center and that they now have more friends.

Respondents’ impressions regarding what contributes to the longevity and success of a self-help program such as this one were also reported, including:

- Operational effectiveness;
- Member satisfaction;
- The attractiveness of the self-help philosophy, with its emphasis on empowerment and experiential knowledge;
- Strong organizational leadership;
- Strong administrative backing from the Department of Mental Health and NIMH; and
- Interpersonal interaction and social support.

Despite repeated and varied attempts, the project was unsuccessful in obtaining continuation funding and ultimately had to cease operations.

NEW HAMPSHIRE

A Way to Better Living
Manchester, NH

Do Drop-In Center
Concord, NH

“I would like to add that I am grateful for these services, for without them, I would no longer live.”

—Project participant

PROJECT GOALS AND OBJECTIVES

The overall project goal was to enhance consumer/survivor involvement in service planning, service provision, and evaluation in order to overcome obstacles presented by geographic isolation and to address the need for more opportunities for consumers/survivors to actively participate in providing peer self-help, social and educational opportunities, education and information dissemination activities, and community support services. Two projects were proposed and are described below. A special effort was made to increase minority participation and to emphasize services for individuals experiencing homelessness, substance abuse problems, and developmental disabilities.

A Way to Better Living, Inc. (AWBL) of Manchester, NH, sought to provide peer support for consumers/survivors released from NH State Hospital and others in re-integrating into mainstream society. The program would accomplish this by demonstrating how peers might reach their best potential and helping to lessen stigma.

The Merrimack County Drop-In Center in Concord, NH (later named the Do Drop-In Center), developed a drop-in center and a telephone support line to address socialization and support.

PROGRAM DESCRIPTION

Services Provided

AWBL provided the following services:

- **Outreach.** Friendly Companions, an outreach program, used peer volunteers to help facilitate delivery of community-based services.
- **Information Dissemination.** A Speakers Bureau provided monthly talks to increase consumer/survivor knowledge and skills. A newsletter was created and distributed monthly, and a manual of information on community services, laws, regulations, rights and responsibilities was developed.
- **Financial Assistance and Food Services.** A revolving security deposit loan fund provided limited loans for peers to acquire independent, private housing and a food bank assisted in providing food supplies.

The Do Drop-In Center provided a drop-in center in the lower level of a clubhouse program which operated 5:00 p.m.–9:30 p.m. weekdays and 10:00 a.m.–9:30 p.m. on weekends. The program offered an organized activity each night, support groups two nights

per week, and a telephone support line staffed by volunteers.

Individuals Served

A total of 230 individuals were served by the two programs, 140 at AWBL and 90 at the Do Drop-In Center. The largest proportion of service recipients lived in group homes, subsidized housing, and supervised apartments. A minority lived in individual homes or with family.

At AWBL, the majority of service recipients were female, Caucasian, and age 30-40. Unemployment and psychiatric history data were not reported.

At the Do Drop-In Center, the majority of service recipients were male, Caucasian, and age 36-45. Sixty-one percent were unemployed, and only seven percent had full-time employment.

Organization and Administration

Funds were provided to the NH Division of Mental Health, which then provided funds to the two programs. AWBL eventually obtained independent, nonprofit status. Each project had its own Board of Directors, Project Directors, and staff. The overall project had a Statewide Advisory Council of consumers/survivors and family members which met regularly with the Director of the NH Division of Mental Health. AWBL requested a local church to act as its Board of Directors and provided its services through the church, prior to gaining independent nonprofit status. The Do Drop-In Center elected its own Board of consumers/survivors.

Paid staff at AWBL included a Project Director, a Project Manager, a Secretary, and a Treasurer. Volunteers at AWBL, called "Friendly Companions" provided peer support services. Paid staff at the Do Drop-In Center included a Program Director, an Activities Coordinator, an Outreach Coordinator, a

Program Manager, an Operation Supervisor, and Administrative Assistants. Most of the positions at the Do Drop-In Center were part-time, in order to allow flexibility in hiring (based on differing project needs and skills of individuals) and to allow for flexible accommodation of the needs of consumers/survivors. The State provided additional in-kind staff support.

AWBL reported that all paid staff were female consumers/survivors, and most were ages 50-60. The Do Drop-In Center reported that all staff were consumers/survivors from the local county.

The Friendly Companions at AWBL were given specialized training. At the Do Drop-In Center, training was provided to telephone support line volunteers in listening skills, dealing with threats of harm to self or others, and accessing available resources. Project Directors provided additional training to staff depending upon need, and State Division of Mental Health staff provided ongoing consultation.

Program materials developed by the two projects included newsletters, organizational bylaws, job descriptions, and an information sheet for Food Bank recipients at AWBL, and a telephone log sheet to record hotline information at the Do Drop-In Center.

The two projects coordinated their activities with several other groups, including: community service agencies, mental health providers, family groups, hospitals, churches, and mental health providers.

Prior to this project, at least three self-help projects were known to exist in New Hampshire. After the initiative, it was reported that at least 12 new self-help efforts had been developed, including: a satellite program out of the Do Drop-In Center, a social club established at AWBL, a Statewide consumer/survivor council, a Statewide network of regional councils, and consumer/survivor-operated services in six regions of the State. Two of the services which were developed were a consumer/survivor-operated discount retail store and the Wyman

Way Co-op (a consumer/survivor-run consortium of businesses).

The total budget for the three years of the demonstration project was \$254,666, of which \$229,250 was Federal funding and \$25,416 was State funding.

IMPLEMENTATION ISSUES AND BARRIERS

The following issues were encountered during the implementation of this project:

- **Startup Delays.** Delays in passing funds to the projects (which were caused, in part, by State funding regulations and grantee inexperience) caused some service delivery delays at AWBL and resulted in an initial lowering of consumer/survivor interest in the project at the Do Drop-In Center.
- **Transportation.** AWBL was unable to provide transportation services to service recipients due to insurance constraints.
- **Lack of Organized Activities.** A lack of organized activities in the first year at the Do Drop-In Center was later addressed, and the Center began to offer food, dances, bowling trips, field trips and a pool table.

SUCCESSSES AND EVALUATION FINDINGS

A limited process evaluation was conducted on both programs, using questionnaires to collect data on participant demographics and ratings of services.

AWBL's "Friendly Visitor" outreach program served five to ten service recipients per month; the Speakers Bureau conducted approximately 10 engagements per month; and 400 copies of the newsletter were distributed each month. The food service was the most popular service, particularly at the end of the month, due to

economic conditions in New Hampshire. The evaluator stated: "Many consumers told us that they depended on the food supplies to make it through the month, that without this service, they would go hungry."

The Evaluator also found that AWBL was "...blessed with an incredibly devoted staff, with a very low rate of turnover . . . [The] program offers a comprehensive, varied approach to consumer needs . . . which work together to provide consumers with economic, educational, and emotional support when they need it most."

The Evaluator found the Do Drop-In Center was most successful, as it had ". . . grown from a rather small, underutilized social club to a popular, well attended social center for area consumers . . . [it] provides a safe place...[and] fulfills an important role. ...Social bonds are created, maintained and strengthened. As consumers' social networks expand, demand on emergency services and mental health supports [drops]. . . . [Participants] had a place to call their own." For those employed by the Do Drop-In Center, it provided an ". . . important stepping stone to further employment opportunities [and] provided consumers with an opportunity to prove that they can handle the responsibilities of a job."

Recommendations, based upon the evaluation, included:

- All key persons and organizations should be involved from the beginning to build a constituency, generate support, clarify expectations, and enhance the capacity of the system to support these projects.
- Future projects should focus on assisting consumers/survivors in developing natural support systems. This will require a sufficient level of funding for adequate service and meaningful evaluation research.
- Future evaluations should focus on the most effective methods of increasing rates of employment for consumers/survivors and assisting them in obtaining

high school diplomas or GED's. This will also require a sufficient level of funding.

- While the continuation status of these programs was not reported, the following quote was taken from the Final Report: "...[the] Division [is] exploring [the] finan-

cial viability of continuation with general fund dollars [at a] time of financial uncertainty in New Hampshire; nonetheless, the Division is committed to continuing the funding of these projects."

NEW YORK

Share Your Bounty/Friends of the Homeless New York, NY

“...There is also a tremendous increase in self-esteem that comes with going from being a hospital patient who is dependent to working independently and doing something important.”

—Project staffer

PROJECT GOALS AND OBJECTIVES

The overall goal of this effort, which was titled Friends of the Homeless and later renamed Share Your Bounty/Friends of the Homeless (SYB), was to expand the activities of a consumer/survivor-operated food bank and outreach program which had been in operation since 1984, serving people who were experiencing homelessness, primarily in the Bronx and Manhattan. The project's activities included raising food donations from local suppliers and distributing them directly to homeless persons on the streets, in shelters, or through other community agencies.

Specific objectives for this initiative were: establishing an independent organizational base in order to assure consumer/survivor control (by obtaining office space and nonprofit status); expanding and diversifying the project's workforce; and increasing the project's efficiency, number of shelters reached, and number of clients served (by purchasing a van and driver to pick up and deliver food). The project also planned to offer job placement assistance through a vocational rehabilitation counselor; to disseminate results through presentations at conferences and at meetings of national consumer/survivor organizations; and to meet with consumer/survivor groups at all adult State hospitals to develop interest in

replicating the project, including holding a Statewide conference and providing technical assistance to those interested. The project also hoped to develop additional funding resources by creating relationships with the New York State Office of Mental Health, municipal agencies serving homeless individuals, and corporate donors.

PROGRAM DESCRIPTION

Services/Supports Provided

Funding enabled Share Your Bounty/Friends of the Homeless to provide the following services:

- **Sandwich Delivery and Basic Food Supplies.** Until new policies forced homeless individuals out of the building, SYB provided sandwich delivery to this population at Grand Central Station. SYB also provided basic food supply to shelters and other delivery points in the city.
- **Technical Assistance and Training.** SYB conducted workshops throughout the State, which contributed to the development of four other consumer/survivor-run projects, including a consumer/survivor-operated food bank called “Harlem Dollar Stretchers,” an outreach

effort to homebound elderly persons in the Bronx, an “adopt-a-family” donation effort at a hospital, an “adopt-a-shelter” program, and a consumer/survivor-run coffee stand at several mental health residences. Consumer/survivor staff input also directly stimulated the development of a consumer/survivor-run case management program.

- **Committee Work and Housing Advocacy.** Staff served on various task forces, committees, and workshops. Staff assisted the New York City Department of Mental Health in initiating an Integrated Neighborhood Housing Project (INHP). INHP was an effort to promote community acceptance of people with mental illness living in the community in various New York City neighborhoods.
- **Information Dissemination.** A videotape of SYB was developed and distributed widely and shown on White Light Communications (a consumer/survivor-run video production project in Vermont, discussed elsewhere in this chapter), and several articles were accepted for publication in *Hospital & Community Psychiatry* and the monthly bulletin of the New York State Office of Mental Health.
- **Other Services.** SYB acted as fiduciary for a Consumer/Survivor Resource and Information Center at Bronx Psychiatric Center. In the last year of the project, as an increasingly larger number of people in need of help came to the project’s offices, SYB began to offer crisis intervention, referral to social services, and peer support.

Individuals Served

Little specific information was reported on the consumers/survivors who were served by the project. It was estimated that approximately 100 homeless individuals per day were receiv-

ing food at Grand Central Station, during the period when the project provided street food distribution. Most of these individuals were African American and Latino males, ages 18 to 40.

Organization and Administration

Initially, the grant was provided to the New York State Office of Mental Health, which provided the funds to the Bronx Psychiatric Center. Bronx Psychiatric Center acted as the fiscal agent for SYB until the project attained independent nonprofit status. It was proposed that if a conflict developed between the project workers and the hospital, the issue would be sent to an outside committee composed of two consumer/survivor consultants, a provider, and staff of the State Office of Mental Health.

During its first year of operation, SYB became a separate organization. SYB developed a management team composed of the Executive Director, Treasurer/Secretary, Resource Manager, Outreach Manager, and Operations Manager. A bookkeeper, business accountant, project evaluator, and a consumer/survivor evaluator were later added to the team. Three employees served as the Board of Directors. An Advisory Council of providers was also developed. This organizational model was described as a “supportive to separatist” self-help project (see description of Chamberlin’s and Emerick’s typologies in the literature review in Chapter 1). Professional involvement diminished as the program handled its own financial matters and retained its own lawyer.

Paid staff consisted of: an Executive Director, a Treasurer/Secretary, an Outreach Manager, a Resource Manager, an Operations Manager, Food Distributors, Drivers, an Office Manager, a Senior Research Assistant/Field Trainer, Consumer Consultants, a Consumer Evaluator, and a Business Accountant. In-kind staff, funded elsewhere, included: an Assistant

Director, Project Workers, a Custodian, a Bookkeeper, a Secretary, a Research Supervisor, Bronx Psychiatric Center Consultants, a Principal Consultant, and a Senior Research Advisor.

The Project Workers were all consumers/survivors from the Bronx Psychiatric Center. One-half were formerly homeless, 72% were African American or Latino, 18% were Caucasian. Some were still hospitalized, and some had extensive work histories. Education levels ranged from ninth grade to law school graduate; the majority had a high school diploma. Two of the staff had previous self-help movement experience. A total of 46 people participated as paid staff during the life of the project.

Staff attended and presented at various conferences and trainings. Some staff received training on organizational management and fiscal accounting. The Office Manager and the Bookkeeper obtained training in computerized bookkeeping.

At the start of the project, it was determined that there would be no staff stratification based on level of disability. Staff could decide to reduce work activities or take temporary leave, if needed. By Year 2, the Office Manager had been providing peer counseling to staff, and there was interest in developing a drop-in center at the SYB offices. In the following year, all staff including the Executive and Assistant Directors rotated jobs so that all staffers would have familiarity with all positions and so that staff could trade jobs if they disliked what they were doing.

The project collaborated with a number of organizations, including: hospitals, research organizations, homeless service providers, advocacy organizations, food banks, universities, supermarkets, churches, soup kitchens, and State and local mental health authorities.

Total Federal funding for the project was \$378,420.

IMPLEMENTATION ISSUES AND BARRIERS

The following issues were encountered during the implementation of this effort:

- **Office Space.** Originally, the project was established at a temporary space at the Bronx Psychiatric Center. The project later obtained its own space, which greatly facilitated a sense of independence.
- **Delay in Receiving Project Funding.** It was reported that this was due to delays in achieving nonprofit status.
- **New Homeless Policy at Grand Central Station.** SYB was forced to stop food distribution at Grand Central Station, due to a new policy against food distribution and against homeless people congregating at the station.
- **Leadership Gaps.** The resignation of the Executive Director and the unexpected death of a board member left a gap in leadership.
- **Provider vs. Consumer/Survivor Issues.** Differing perceptions by consumers/survivors and professionals regarding what direction the organization should be taking created friction and distrust. These problems were exacerbated at the end of the grant, when non-consumer/survivor outsiders' ideas regarding how SYB could be continued resulted in tense communications.
- **Decisionmaking Hierarchy.** The Final Report indicated that the board and the management team were often the sole individuals involved in decision making. This hierarchical structure prevented some participants from learning to take responsibility and learning how the organization functioned.

- **Drug Abuse Among the Homeless.**
This contributed to the decision to stop street food distribution, as some SYB members felt at-risk as a result of their own substance abuse histories.

SUCCESSSES AND EVALUATION FINDINGS

The evaluation consisted of a qualitative study, using participant-observation, individual interviews, focus groups, and documentation of activities.

Overall findings indicated that the project, by becoming consumer/survivor-run, had “self-deinstitutionalized” itself and its members. SYB members felt they had learned much about the work world from their positions, learned work skills transferrable to other jobs, took great pride in helping others, and found their work to be flexible, enjoyable, and meaningful.

Statements from the staff included:

- “Now I’ve realized how we need people, others need me and I need others.”
- “[At SYB],...no one judges you.”
- “. . . [The] program has contributed to the emotional, spiritual and financial transition from the hospital.”

Members stated that they learned to get along with one another, problem solve together, air out their feelings, and encourage one another. Members supported one another to be drug-free and to act responsibly. They developed a sense of independence, autonomy, and self-confidence that many said they had not felt before. One participant stated: “What’s empowering for us is to do our own thing now.”

It was noted that staff provided peer support/self-help to one another and to other peers. SYB had become a “. . . family center where members socialized, played music, and discussed their problems with one another . . .

birthdays were celebrated . . . [it] took on the aspect of a ‘home’ . . . members referred to each other as ‘family’. Members provided crisis management for one another. At least five members were hospitalized briefly; members would visit and phone regularly, and sometimes people got day passes to come to work. All returned to work after their hospitalizations.”

According to the evaluation, one of the principal benefits of the project was that it “. . . demonstrated that consumers can form an autonomous organization which aided them in transition from [a] long-term, institutionalized [setting] to successful community integration; [it] demonstrated that such an organization can provide its members with a number of essential functions (i.e., socialization) without professional service providers; [and it] demonstrated that SYB members remained committed to [the task] for the duration of the grant, despite occasional setbacks.”

The impact was also felt on the community, where “former mental patients were seen as capable and motivated to provide much-needed outreach and goods to those who are even more destitute. SYB contributed to a destigmatization of formerly institutionalized people, [and] a considerable number of empowerment efforts across the State were begun in the wake of SYB.”

Many professionals, administrators, and State officials, in informal conversation, expressed positive changes in attitudes towards consumers as a result of their contact with SYB. It should also be noted that SYB received Honorable Mention for the 1989 *Hospital & Community Psychiatry Achievement Award*, presented by the American Psychiatric Association.

Some concerns were raised that the grant’s implementation imposed “structural and bureaucratic constraints” on SYB. The quick and large growth of the organization was a positive in terms of the organization’s ability to disseminate information, but it also produced

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self-management growing pains, along with a lack of appropriate technical assistance and education. The “use of outside professionals [rather than consumers] made SYB members wary and uncomfortable with the ‘outside’ world of non-consumers.” This highlighted some differences between participating members and professionals and contributed to tensions.

A series of recommendations were offered, based on the evaluation:

- The State Office of Mental Health should develop technical assistance programs to help consumer/survivor-run programs develop or expand in the areas of incorporation, bylaw development, organizational structure, legal consultation, budgeting, grants management, reporting requirements, and payroll. Wherever possible, this assistance should be provided by other consumers/survivors.
- The New York State Office of Mental Health and the New York City Department of Mental Health should develop a policy concerning the support and devel-

opment of consumer/survivor initiatives, and this policy should be linked to longer-term planning for financing consumer/survivor initiatives. They should identify staff points of contact and funding sources and mechanisms.

- Staff should include at least one bilingual individual.
- Consumer/survivor organizations may want to develop a “Friends of . . .” group, consisting of non-consumers/survivors or consumers/survivors who are not members, for the purpose of networking and fundraising.

Attempts were made to secure continued State funding, city homeless funding, and corporate support, but these efforts to continue the program’s funding were ultimately unsuccessful.

OREGON

Mind Empowered, Inc./Spreading Empowerment, Enlightenment, and Dignity Portland, OR

“MEI [Mind Empowered, Inc.] has made a big difference in my life . . . I don’t know what would have happened to me without these people . . .”

—Project participant

PROJECT GOALS AND OBJECTIVES

The purpose of this effort was to establish, via Mind Empowered, Incorporated (MEI), in Portland, Oregon, outreach services to help consumers/survivors achieve coping and community living skills and a better quality of life and to provide an array of services which assist, support, and empower psychiatrically disabled persons. Activities were organized around three main program elements: training, which focused on developing a cadre of peer outreach counselors, support services which utilized peer counselors and volunteers, and public education/advocacy, which worked to combat stigma through public education and policy advocacy efforts. Specific goals included: developing an existing nonprofit consumer/survivor-operated corporation into a well-organized entity based on sound operating principles; establishing a curriculum and training peer outreach counselors on a quarterly basis; providing stipend-supported and volunteer placements; establishing effective peer support and advocacy services; and pursuing public education and advocacy efforts to combat the stigma of mental illness.

The Final Report indicated that the project had been renamed SEEDS (Spreading Empowerment, Enlightenment, and Dignity).

PROGRAM DESCRIPTION

Services Provided

Funding enabled MEI to provide the following services:

- **Training.** Core trainings were organized and held weekly on topics such as: mental illness, medication and side effects, accessing community resources, psychosocial rehabilitation, dual diagnosis assessment and referral, personality disorders, suicide intervention, and violence.
- **Public Education, Advocacy, and Information Dissemination.** A clearinghouse was developed, numerous public information and interagency presentations were made by project staff, and members participated on a variety of committees.
- **Drop-In Center and Support Groups.** A drop-in center, open Monday–Saturday, 10 a.m.–7 p.m., was started. Holiday dinners were prepared and served on Thanksgiving and Christmas, and monthly dances and cookouts were held. Three time-limited peer support groups met weekly on a variety of issues.
- **Outreach Services.** Outreach was conducted at a homeless shelter and a State hospital.

Individuals Served

Services were open to individuals, 18 years of age and older, who had a psychiatric disability. The program further targeted: people who were in hospitals preparing for discharge, who cannot access mental health services due to long waiting lists; those homeless or at-risk of becoming so; those labeled “hard-to-treat”, who don’t want to be identified with the formal system; and those who wished to supplement their involvement with professional mental health service providers. Recipients of services were primarily male, age 30–50, and Caucasian.

Organization and Administration

The grant was provided to the Oregon Mental Health Division (MHD), which provided the funding to MEI. Initially, MEI used the Mental Health Association of Oregon as its fiscal agent until it attained nonprofit status and became sufficiently established to do its own fiscal books and payroll.

The Board of Directors already existed at the time of the grant application. It required a majority of its membership to be consumers/survivors. Paid staff included an Executive Director, an Outreach Manager, a Socialization Team Leader/Coffee House Manager, a Skill Trainer, an Information and Referral Team Leader, a Volunteer Team Leader, a Secretarial Team Leader, and several Stipend Positions. The State provided several in-kind positions, including: a Manager of Community Programs, a Coordinator of Community Programs, and several Consultants.

MEI policy required that a majority of staff have a history of serious mental illness as well as the capability to perform duties. Where qualified consumers/survivors could not be found for positions requiring an essential type of expertise, non consumers/survivors could be employed, but in such cases they were to

be screened carefully to insure compatible values and a commitment and understanding of consumer/survivor empowerment. Efforts were also made to recruit minority individuals. The Final Report stated that all paid staff were consumers/survivors, and the total number employed throughout the project was 22.

The project’s personnel policies specifically addressed the issue of providing reasonable accommodations. This included paid time off, at the discretion of the Executive Director, to permit stabilization of acute illness and reallocation of duties when necessary.

A number of materials were developed over the course of the project, including: a program flyer; job descriptions; a client intake form; a daily contact log; member’s weekly contacts; a daily time record for staff; an expense summary form; an employment application; an evaluation intake form; progress notes; a goal setting form; an informed consent form; and policies regarding personnel, the drop-in center, outreach, and information and referral services.

The project coordinated its efforts with a number of other organizations, including: mental health providers, hospitals, the National Association for Rights, Protection, and Advocacy, universities, County Commissioners, Social Security offices, homeless service providers, Parks Department special programs, churches, and Oregon Public Radio.

A total of \$480,353 was spent on this effort, of which \$399,196 were Federal funds and \$81,157 were State funds.

IMPLEMENTATION ISSUES AND BARRIERS

The following issues were encountered during the implementation of this project:

- **Systems Change.** Oregon’s mental health system experienced broad operational and philosophical changes which impacted upon this project, including the

implementation of Public Law 99-660. This legislation mandated consumer/survivor involvement in State mental health planning councils. As a result, consumers/survivors were more accepted and included as valued participants.

- **Staff Turnover.** There were reports that staff turnover created some delays in the implementation of certain project activities.
- **Funding.** A ten percent reduction in funding by NIMH across all projects resulted in the project needing to cancel publication of the MEI newsletter.

SUCCESSSES AND EVALUATION FINDINGS

A member satisfaction survey revealed that a majority felt that the center was a major factor in providing them with socialization opportunities and money management skills. Participants valued it as a place to learn about mental illness, low-cost housing, and employment opportunities and many stated the project played a central role in their social lives. Other findings included: a majority felt they had found help for their problems at the center (primarily housing, Social Security, or other practical information); and that the center was a place where hopes and dreams could be discussed. Most said they were encouraged to make their own decisions and that a lot of day-to-day problems were solved through involvement with the center. Overall conclusions found that: members value MEI in the community; many would feel an extreme loss if the center were to close; and MEI assists individuals in linking with community services which enable them to live independently.

An analysis of staff contact logs revealed that housing was the most requested service, followed by money management assistance and interagency referrals.

A process evaluation noted that the greatest strengths and successes of the effort were that consumers/survivors can develop an organization, overcome difficulties, make contact with other consumers/survivors, and deliver needed services. MEI maintained a continuity of vision and philosophy and developed extraordinarily helpful and beneficial relations with other grassroots and consumer/survivor empowerment interests. MEI demonstrated that consumers/survivors can move through the stages of interest, opportunity, learning, and service to others.

Some unanticipated benefits were reported, as well. The project provided a training and proving ground for consumers/survivors' efforts in mental health work, as a number are now working with other agencies. The relationship between the State and the project was especially important during the application and preparation process.

Several recommendations resulted from this evaluation:

- Training sessions should offer a mix of exploration and problem solving.
- The evaluation would have been more successful if a State/project cooperative system of recordkeeping that reported more useful program information had been created. With appropriate opportunities for incorporating feedback, such information would have contributed greatly to decision making, clarifying focus, and documenting changes.
- The theory and practice of self-help and its impact on staff learning, development, and self-esteem should be examined. There is a need for further examination of the model of "becoming interested, volunteering, learning, and moving into staff positions."

It was noted that in 1991, MEI received the Small Employer (of handicapped individuals) of the Year Award by the Oregon Disabilities

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Commission and the Excellence Award by the Oregon Division of Mental Health and Developmental Disability Services.

The State Division of Mental Health and Developmental Disability Services remained

committed to ongoing funding of this project. Continued State funding for SEEDS and for a new program entitled CSP, the Community Survival Program, was awarded.

TENNESSEE

Friends Helping Friends

Nashville, TN

“Through participating in Friends Helping Friends, members achieve greater confidence in decision making, are better able to cope with their problems, have more friends, participate in healthier activities, and are better able to avoid psychiatric hospitalization.”

—Project evaluator

PROJECT GOALS AND OBJECTIVES

The overall objective of this project was to develop and operate a drop-in center and related services, called Friends Helping Friends, to meet the socialization and support needs of consumers/survivors in Nashville, Tennessee. The goals of the project were: to empower consumers/survivors by helping them to gain control over their lives and the services they receive (by developing self-confidence and self-esteem and by rotating leadership positions and responsibilities); to provide emotional support to consumers/survivors (through a support group, friendship networks, and drop-in activities); to combat stigma (through a speakers bureau); and to promote consumer/survivor independence through consumer/survivor-run services (a housing loan program, a crisis intervention/respite care program, job placement services, and roommate matching services).

PROGRAM DESCRIPTION

Services Provided

Grant funding enabled the project to provide the following services and supports:

- **Drop-In Center.** The center offered crisis intervention, peer counseling, hospital visits, an information bureau, referral services, recreation and socialization activities, meals, and holiday gatherings. The center was open seven days per week, including holidays and evening hours.
- **Speakers Bureau.** Ten consumers/survivors were trained and then sent out to speak to groups on a variety of topics, ranging from housing to advocacy to blood pressure to first aid. Consumers/survivors gave an average of four presentations per month.
- **Job Placement Service.** Staff located employers who had temporary jobs and matched consumers/survivors with available jobs. Park Center (a psychosocial program which served as this project's fiscal agent) provided an onsite Job Coach daily.
- **Roommate Matching Service.** The project provided assistance with locating apartments, moving, and followup visits.
- **Crisis Intervention/Housing Respite.** This service was created to offer an alternative to hospitalization, when appropriate. The service was coordi-

nated by Park Center, which placed an onsite Housing Specialist at Friends Helping Friends.

- **Newsletter.** The project published a bimonthly newsletter, which included a schedule of events, creative submissions, information on pending legislation, drop-in center statistics, and consumer/survivor concerns. The newsletter was distributed to over 400 people.
- **Self-help Group.** The project sponsored a weekly group which focused on support, education, and advocacy regarding physical abuse, overmedication, and boarding home abuses.
- **Loan Fund.** A fund which made small, interest-free loans for housing and employment needs was set up. The maximum loan was \$25, and a committee reviewed all requests, which included security deposits, furniture, eyeglasses, and car repairs.

Individuals Served

Criteria for membership stated that individuals served must have a major “mental illness”, be able to travel independently, and abuse no substances at the drop-in center. The definition was later broadened to include former consumers/survivors and homeless consumers/survivors. The definition was broadened in order to respond to concerns that people in need would be denied services.

A total of 300 individuals were served by the project. Fifty individuals, mostly homeless, were referred to other programs. A majority of service recipients were Caucasian males; the average age was 52. Thirty-six percent were African American, 60% had a high school education, 93% had been previously hospitalized, and 98% had previously used community mental health services.

Organization and Administration

The grant was awarded to the Tennessee Department of Mental Health/Mental Retardation, which provided the funds to a psychosocial program, House of Friendship/Park Center Association. Park Center acted as the project’s fiscal agent. Initially, a Planning Group composed of consumers/survivors and providers was formed to help direct the program. This Planning Group later became more formalized, and members held elections for a President, Vice President, and Secretary. By Year Two, this Board had hired a Director, who, in turn, hired staff. Paid staff included the Director, two Peer Counselors, a Secretary, and an additional On-Call Peer Counselor.

A total of \$237,000 was spent on this effort, of which \$234,000 were Federal funds and \$3,000 were individual donations.

IMPLEMENTATION ISSUES AND BARRIERS

The following issues were encountered during the implementation of this effort:

- **Project Development.** Initially, it was planned that two support groups would form the Nashville Consumer Consortium, which would then become incorporated and develop a board. This would enable them to contract directly for services. This apparently never happened, although the reasons are unclear from project materials.
- **Project Location.** The drop-in center was ultimately located within Park Center, as three other independent sites which were explored were deemed unsuitable due to high rent or crime.
- **Project Autonomy.** There were indications that the project did not have a sense of being consumer-run, due to its close affiliation with the Park Center.

Sharing space and staff with this program contributed to this concern. In addition, with Park Center being the fiscal agent, this furthered the impression of excessive professional involvement with this project.

SUCCESSSES AND EVALUATION FINDINGS

The project evaluation was conducted by the State Department of Mental Health and |Mental Retardation. Program aspects to be examined included the number served in various project activities vs. projections and member satisfaction.

Respondents reported that they were proud of the center, and reported that they felt that the center: encouraged people to make their own decisions, helped people learn about resources, and encouraged people to share

feelings without being put down. During the grant period, a Statewide consumer/survivor group, the Tennessee Mental Health Consumers' Association, was formed.

The evaluation found that a sizeable number of people thought that the center was owned by Park Center, and as a result, an interim recommendation was made that the drop-in center try to obtain its own space. The evaluators also recommended more social activities, more outreach to mental health centers, staff training and recognition within the mental health community, a new location for the drop-in center, and efforts to increase minority participation and enhance the cohesion of consumers/survivors, family members, and professionals.

The Final Report indicated that the project received \$90,000 per year in continuation funding from the Tennessee Department of Mental Health/Mental Retardation.

VERMONT

White Light Communications

Burlington, VT

“ . . . [It has] opened up a whole new avenue for communication, for building support networks for fostering empowerment, and for developing a sense of belonging among consumers.”

—Project staffer

PROJECT GOALS AND OBJECTIVES

The original objective of this effort, called White Light Communications, was to use a portable satellite uplink vehicle for transmission of live public education productions to remote regions of Vermont. The project was originally set up to be financially self-sufficient by making its portable uplink available for rental fees to commercial users. Productions were distributed live, via satellite, on a weekly basis to 60,000 cable television subscribers in VT, and included public affairs items, public-interest stories, and entertainment produced by, and featuring, consumers/survivors. This effort provided opportunities for consumers/survivors to communicate directly to the public about their experience of being a psychiatric patient.

Project goals consisted of: public education to change attitudes and misinformation about mental illness; outreach to organize consumers/survivors by conducting State, regional, and national networking; and development of professional employment opportunities for consumers/survivors, including technical and managerial roles not usually available to such individuals.

The project focus was later changed from satellite uplink to direct video production, due to the price of purchasing equipment. The project developed several broadcast-quality productions for distribution on national cable systems; duplicated and sold videos of its pro-

ductions; and worked on co-producing, directing, and staffing two interactive, live, national satellite broadcasts of consumer/survivor panels discussing major issues.

PROGRAM DESCRIPTION

Services Provided

The following services were provided:

- **Weekly Productions.** Half-hour weekly productions were distributed via cable networks in VT's three largest cities and in Syracuse, NY. Throughout the project, nearly 80 half-hour productions on a variety of consumer/survivor issues were made for a monthly cable show.
- **Broadcast-Quality Productions.** Three documentaries on consumer/survivor activities and perspectives were produced for national distribution during the project.
- **Consumer/Survivor Involvement.** Representation was obtained on several mental health boards and committees at the State and local levels.
- **Networking.** A relationship was established with a major video production and distribution company, and contacts were begun with national cable channels for broadcasting a production on *Alternatives*

'90, the fifth annual national mental health consumer/survivor conference, sponsored by NIMH and held in Pittsburgh.

- **Interactive Satellite Conferencing.** A concept for a national, interactive, live satellite television network production was developed and implemented, and the first broadcast of "Self-help Live" took place in 1991. This broadcast focused on highlighting a number of consumer/survivor leaders.
- **Videotape Marketing.** A list of 35 available educational videotapes, all produced by the project, was compiled. The project distributed copies of these tapes. The videotapes were used to promote consumer/survivor education and provide professionals with education and training regarding consumers/survivors and their issues. The best productions were duplicated and a marketing brochure was developed and mailed to 15,000 potential customers. Sales of videos accounted for a percentage of the project's 1992 budget.

Individuals Served

It was estimated that the project reached an estimated 1.6 million homes in the Boston, Seattle, New York City, upstate New York, and Vermont areas via public access cable television stations. A total of 38 states participated in the broadcast of "Self-help Live", with nearly 200 viewing sites.

Organization and Administration

The grant was awarded to the Vermont Department of Mental Health, which provided the funds to the Vermont Liberation Organization to operate the project.

Initially, the Vermont Liberation Organization (VLO) had an existing board which included eight consumers/survivors, one family member

and two mental health professionals. The Board expanded to include business and communications experts, and periodically other constituent group representatives (i.e., other consumer/survivor groups, family groups, etc.) were asked to attend meetings to provide suggestions and feedback.

The staff of the project consisted of an Executive Director, an Office Manager, a Production Coordinator, and 30 part-time production assistants over the life of the project. Several communications professionals and business consultants assisted the project in creating a business plan, bookkeeping, project evaluation, and technical aspects of television production. All staff received two months of training at Adelphia Cable in Burlington.

All staff were consumers/survivors. The staff was all Caucasian, mostly New Englanders, 2/3 were female, and their ages ranged from 30–43. All staff were college graduates, and the mean income was \$21,250.

Materials that were developed during the project included job descriptions, a brochure, videotapes and television productions, and a listing of videotapes available. The project interacted with several other entities, including local, state, and national cable and video production organizations, mental health technical assistance agencies, state mental health authorities, and universities.

A total of \$529,475 was spent on this effort, of which \$517,475 came from Federal funding.

IMPLEMENTATION ISSUES AND BARRIERS

The following issues were encountered during the implementation of this project:

- **Purchase of Equipment Not Feasible.** The original plan to purchase a portable satellite uplink and to lease it in order to generate revenues was not feasible due to cost. The project instead decided to establish a television production busi-

ness and to distribute productions through existing networks.

- **Struggles Regarding Commercial vs. Nonprofit Status.** Originally, the project was set up to evolve into a viable commercial enterprise. The advisory committee urged it to maintain its nonprofit status and to maintain its focus on promoting the consumer/survivor movement.

SUCCESSSES AND EVALUATION FINDINGS

A staff survey was conducted, which found that all staff had high job satisfaction throughout the three years of the project. This survey also found that a wide array of employment activities were offered for participants, there was a high level of acquisition of job skills, staff communication/relationship satisfaction was good, and employees felt high levels of social competence.

Four focus groups were organized, and a process evaluation of two television productions was completed. Findings indicated that the issues and problems portrayed in the productions were important and relevant, but they found that the informational content of the program could be enhanced by through the use of greater visual stimulation and narrative explanation of the content and background of people presented in the show.

Other evaluation activities included a survey of the cable audience, a telephone survey to study the impact and effectiveness of marketing the videotapes, an evaluation of the satellite teleconference broadcast, and a content analysis of the videotapes.

The telephone survey of the cable production audience revealed that, of those who watched the program, they liked it and found it easy to understand and informative about mental health issues. It also revealed that public attitudes towards individuals who are mentally disabled were not very positive; however,

those who viewed the show had more positive attitudes about the mentally disabled on each dimension as compared to non-viewers.

The telephone survey studying the impact of the marketing of video productions revealed that videotape customers represented a broad range of audience groups, with the largest percentage consisting of mental health professionals in private practice and individuals associated with self-help agencies.

A survey of "Self-help Live", the satellite teleconference broadcast, collected data from a total of 977 respondents. Findings included: 85% of respondents were satisfied with the production; 89% learned something new; participants were 72% Caucasian, 13% Native American, 12% African American, 2% Asian, and 1% Latino. Topics suggested for future broadcasts were: employment (42%), housing/homelessness (35%), and abuse of consumers/survivors (27%).

The content analysis of the productions revealed that 86% of the interviewees on the tapes were consumers/survivors, and 63% of the tapes examined involuntary treatment and hospitalization as a major informational focus. The evaluation report stated: "Clearly, the results indicate that involuntary treatment and hospitalization appear to be important issues from the perspective of ex-patients, consumers and mental health consumer advocates." A total of 83% of the tapes had information on public education, and 7% had information on women's issues in the mental health system. The report went on to indicate that, with respect to the latter finding, women's issues were not explored in a significant way.

Overall conclusions, based on the above results, were as follows:

- Broadcast of the weekly program should be continued. The evaluation report stated: "It is evident that the availability of free public access cable channels provides an excellent medium that consumer groups . . . can utilize to

promote consumer education and support networks.”

- There is a strong market for materials produced by consumer/survivor-operated video production organizations. If the production quality and visual content are able to be improved, then the market is likely to grow.
- Employees were able to attain a wide range of job experiences and skills. However, turnover and other satisfaction ratings suggest the need to provide training, orientation, and job enrichment experiences for all employees, in order to foster personal and professional growth.

The final report also stated that the project's greatest strengths were its “ability to stay focused and maintain its clear vision as a communication source for the movement. Using many of the principles of the consumer and ex-patient movement, in the workplace, the staff was able to work [out] its difficulties, support one another, and work toward a common goal...The opportunity of having a non-stigmatized image in the business world played a major role in providing true community integration for mental health consumers and former patients...It affords a bridge across which people from both sides can work together as equals.”

Overall recommendations based on this project included:

- Support for consumer/survivor public education efforts should be continued at the State and Federal levels. It is important for funding support to be provided for consumer-run business demonstration projects in order to promote community integration.
- Participation of State agencies and consumer/survivor service organizations in using the potential of satellite-interactive telecasts should be encouraged and increased.

- Preventive measures should be taken to foster personal and professional growth in the workplace (i.e., building a human environment in the workplace that is supportive and enhances communication, trust, self-esteem, and empowerment among the employees).
- Live video teleconference broadcasts should be continued by asking for State subscriptions. Participation in live teleconferences should be studied, including differences (if any) between levels of participation by consumers/survivors and non-consumers/survivors and the reasons people choose to participate or not participate.
- Research is needed to investigate the impact of teleconference broadcast programs such as “Self-help Live” on the consumer/survivor movement, networking, and State consumer/survivor services in subscribing vs. non-subscribing States.
- There is a critical need to conduct process and outcome research on the use and application of communication technology in promoting public education, consumer/survivor networking, and prevention.

Though it had initially been hoped that the project could continue via the rental of uplink equipment, purchase costs prevented this from being a viable option. The project found that it was able to generate significant revenues through sales of tapes, and with a successful marketing campaign, it planned to generate a significant part of its future funding through tape sales and national commercial broadcasts. There were plans to continue the project after Federal funds expired; a number of contracts for production of public education materials were bid upon, and grant support was applied for from the van Ameringen Foundation and [the John D. and Catherine T. MacArthur

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Foundation. The project also reported that it had obtained subscriptions from 18 states for “Self-help Live”. Ultimately, however, White

Light was unable to generate confirmed funding and was forced to cease operations.

WASHINGTON

Capital Clubhouse Olympia, WA

“ . . . [It was] unique, enjoyable and effective.”

—Project participant

PROJECT GOALS AND OBJECTIVES

The overall goal of this effort was to develop a consumer/survivor designed, managed, and operated clubhouse program with a majority of consumers/survivors on the Board of Directors. The Clubhouse, named Capital Clubhouse, was situated in Olympia, Washington, and served a two-county area, with transportation provided to members.

Objectives included: starting three pre-vocational day programs; publishing a newsletter; providing social and recreational activities for participants; and starting a transitional employment program (TEP).

PROGRAM DESCRIPTION

Services/Supports Provided

The following services were provided by the project: two slots in the Transitional Employment Program; a clerical unit, including production of a newsletter; a kitchen unit, called Capital Cafe; and an outreach unit. Other activities included transportation, advocacy, drop-in center functions, and social/recreational activities. The Final Report indicated that other indirect services were offered, including information/referral, conference coordination, meal catering, provision of meeting space, anti-stigma programs, and dissemination of information

about the project via speaking engagements and news and video releases.

Individuals Served

The original eligibility requirements for service recipients were restricted to those deemed as having a serious mental illness. This was relaxed somewhat in later years, with an emphasis on those not receiving other services.

The project designated three categories of membership: “Regular Participation” (periodic attendance); “Daily Attendance”; and “Applications for Membership on File” (participant initiated contact and completed membership form, but participated very infrequently or not at all). The process for becoming a member included attending an initial meeting, participating in orientation, engaging in an interview with advocacy staff, and submitting a completed application form.

The Final Report indicated that the project served 101 participants. Characteristics included: 64% were female; almost all were Caucasian; and the average age was 40. Fifty-seven percent were single, 11% were married, and 32% were divorced; 57% lived alone, and 40% lived with a roommate or family. Eighty-two percent were unemployed and 14% had part-time work; 22% had less than a high school education, 21% had a high school diploma, 21% were college graduates, and 11% had completed postgraduate work. Ninety-three percent had prior hospitalizations and had a wide variety of diagnoses.

Organization and Administration

The grant was awarded to the Washington Division of Mental Health, which provided the funds to the Thurston-Mason County Regional Support Network. The Network then provided the funds to the Capital Clubhouse, which obtained its nonprofit status and began receiving funding directly from the State during the course of the project.

A Mental Health Consumers' Coalition (MHCC), composed of different area consumers/survivors, helped to develop a Board. The MHCC Board hired the Clubhouse staff and developed job descriptions for Board member duties and expectations. During Year Two, the Clubhouse developed its own ten-member Board. Eighty percent of the members were consumers/survivors. The Board met monthly, and had five committees: finance, fundraising/public relations, program, personnel, and nominations. Over time, an ad hoc Advisory Group was formed to assist the Clubhouse Director. This group was composed of the State Community Support Programs Director, the MHCC Board Chair, a local mental health center manager, and the County Mental Health Coordinator.

Paid staff included an Executive Director, a Clubhouse Manager, two Consumer Clubhouse Staff Workers, and a Social/Recreational Program Staffer.

The Final Report indicated that there was some staff turnover experienced, including the Executive Director's position. Staff characteristics were not provided in detail, although it was noted that all were consumers/survivors.

Training occurred "on the job", and staff met together weekly for peer support and training. Training was also provided for volunteer recruitment, food handling, the Transitional Employment Program, and general organizational development topics, including: marketing a nonprofit, applying for nonprofit status, team building, board training, and Clubhouse orien-

tation. Staff participated in *Alternatives* conferences, the Western Regional Clubhouse conference, and other consumer/survivor conferences.

The total reported expenditures for this project were \$316,074, of which \$277,073 were Federal funds.

IMPLEMENTATION ISSUES AND BARRIERS

The following issues were encountered during the implementation of this effort:

- **Delay in Receiving Funds.** Some delays in the distribution of grant funds were experienced, due to changes in the State Community Support Programs Director and because the county wanted the State to contract directly with the Clubhouse rather than through the county. Eventually, the State did accept this change.
- **Lack of Advance Planning.** It was reported that the decision to open the Clubhouse immediately was detrimental in the short run, as policies and procedures were not yet in place.
- **Peer/Member/Staff Tensions and Internal Conflicts.** It was reported that there was a period of time during which staff and members experienced prolonged conflict. Staff development grew into a priority, with a wide range of issues being discussed, including: role clarification (peer vs. paid staff); how does a member complete the transition into becoming a staffer; how does the program justify paying some members who are staffers, when all members in the program volunteer; staff training on being proactive vs. responding to immediate needs; what kind of "special accommodations" can be made for consumers/survivors; the risks and benefits of getting

off of SSI/SSDI; operating in an equal, non-hierarchical fashion; how can the program integrate into the current mental health system as an alternative to traditional modes of treatment; and how can staffers justify gaining expertise and training when so few consumers/survivors have had the opportunity to do so. It was reported that some of the struggles and tensions arising from these issues resulted in resignations and terminations of staff.

SUCCESSSES AND EVALUATION FINDINGS

A process evaluation, which was conducted by an outside evaluator, focused on membership characteristics, demographics, changes in status with respect to membership and community adjustment, and quality of life. Data were collected through surveys of staff and members, participant observation, and group and individual interviews. The interviews focused on who were the members, what did they like or not like about the program, and in what other mental health services did they participate. Interviews had 189 questions and each respondent was paid for participating.

Interviews revealed the following findings: 39% reported being hospitalized since joining; 85% were involved in more than two other mental health services; more than 67% said that they had insufficient funds for social activities and transportation; and 30% had been victims of nonviolent crimes over the past year. Other findings indicated that: nearly half reported moderate or serious problems in maintaining an adequate diet; 54% said they stayed at home prior to going to club; 54% said they stayed at home when not at the Clubhouse; and time spent in day treatment fell from 25% to 7% after participants began going to the Clubhouse. Still other findings indicated that: 57% heard about the Clubhouse from a professional; 25% from

friend or family; 64% liked the friendship, people, support, and good atmosphere of the club; and 43% liked the lack of stigma and acceptance. While 30% said they would like the Clubhouse to conduct more community involvement/outreach activities, 93% were generally very satisfied with the Clubhouse; 68% said they had more friends since coming to the Club; 93% said they would recommend it to their friends; and 88% of the respondents said that coming to the Clubhouse helped them cope better with their problems.

Recommendations based on this demonstration project were as follows:

- The purpose of the Clubhouse should be clearly defined (e.g., work-ordered day participation vs. drop-in, etc.);
- The service population should be clearly defined, and policy should state who is and is not a candidate for membership;
- Objectives should be stated in measurable terms and reviewed periodically;
- A local project steering/oversight committee should be developed for startup activities, composed of members: who are willing to make a three-year commitment; who understand consumer/survivor empowerment and psychosocial rehabilitation (PSR); and who understand the personal contribution necessary to participate in one's own recovery.
- The Board should be in place prior to hiring an Executive Director, Board members should have expertise in many areas, and the majority should be consumers/survivors;
- Clubhouse activities should include food, clerical, advocacy and outreach services;
- Funding should be sought from additional sources by the Board and the Director;
- Clear personnel policies should be developed, including job descriptions, hiring

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procedures, reasonable accommodations, performance evaluation procedures, termination policies, and ethical standards regarding staff/member relationships;

- Staff should create functional job descriptions, be paid the same as non-consumers for the same work, possess the ability to work with peers and other professionals, and model desired behaviors;
- Staff grievance procedures need to be developed with specific time frames for responses;
- The Clubhouse Director should be the sole staff supervisor, staff should be told of expectations upon hiring, and should be placed upon probationary status followed by an evaluation;
- Staff should be trained on the Clubhouse model, meeting facilitation, food handling, the Americans with Disabilities Act, diver-

sity issues, crisis intervention, emergency management, sexual harassment and safe sex, conducting meetings, public speaking, Board membership, continuous quality improvement and accountability practices, working with “difficult” people, stress management, and setting personal limits;

- The Clubhouse Program Manager should be onsite at all times, should be conversant with all units, and should be able to work with many different types of people; and
- Ethnic/cultural minority outreach and involvement should continue to be a goal.

The Final Report indicated that the Capital Clubhouse received continued grant funding from the Thurston-Mason County Regional Support Network.

WEST VIRGINIA

West Virginia Office of Consumer Affairs
Huntington, WV

“Now for the first time, consumers have a forum in which to voice their opinions, and an organization to provide the support to make that voice heard.”

—Project participant

PROJECT GOALS AND OBJECTIVES

The overall objective of this project was to establish a Consumer/Survivor Affairs Office within the West Virginia Department of Health, Office of Behavioral Health Services.

Specific goals included:

- Empowering consumers/survivors so that they may have an impact on mental health services development, by developing an Office of Consumer Affairs, working with the West Virginia Mental Health Consumers' Association (WVMHCA), becoming involved in policy and planning, developing a consumer/survivor review of mental health services, training staff, reviewing and responding to service grievances and complaints, and developing a consumer/survivor-oriented plan for supportive residential services;
- Improving the communications and interactive networks of consumers/survivors throughout the State by providing assistance to WVMHCA and other consumer/survivor groups, developing Statewide teleconferencing and/or bulletin board services to facilitate communication, and assisting WVMHCA in production of a newsletter;
- Reducing stigma by developing a speakers bureau, developing and distributing informational brochures, and implementing an advertising campaign; and
- Demonstrating that mental health programs can be run effectively and efficiently by and for consumers/survivors, by employing and training consumers/survivors to conduct peer counseling focused on crisis stabilization and by establishing three locally based peer counseling/support services.

Other planned activities included monitoring and disseminating information about State and Federal legislation; facilitating communication and coordinated efforts between all organizations and individuals involved in mental health planning and service; disseminating project information via articles and papers in newsletters, in journals, and at conferences, publishing a consumer/survivor peer counseling resource directory and handbook, and coordinating training opportunities for Board members.

PROGRAM DESCRIPTION

Services Provided

Grant funding enabled the following services to be provided:

- **Education and Training.** Twenty consumers/survivors attended *Alternatives '89* and thirteen attended *Alternatives '90*; two issues of a newsletter were published and distributed Statewide to over 500 individuals; the project started operation of an electronic bulletin board; planning and operation of the speakers bureau began; project staff participated in staff orientations for the State Department of Health; a training curriculum was developed for use with Community Coordinating Councils; and consumers/survivors received training on public speaking from Department staff.
- **Support Groups.** A training and organizing curriculum for peer counseling group development was created. Eight Prescriptive Peer Counseling (PPC) groups were active on a weekly basis, with an average of 50 consumers/survivors participating weekly, and a PPC Handbook was published. A Community Coordinating Council was developed in each local area (consisting of a Peer Counseling Coordinator, a representative of a local Community Behavioral Health Center, a Consumer Affairs Board member, and a local consumer/survivor) to address issues of support group site location, transportation, child care, and referral. A trained volunteer at each site served as advisor and attended meetings. Groups elected a chairperson, who submitted monthly reports on attendance and activities to the State Consumer Affairs Office and maintained contact at least once a month with the Peer Counselor Coordinator. The Peer Counselor Coordinator conducted monitoring and periodic visits. Two hundred copies of the Peer Counseling Resource Directory and Handbook were published and given to each member of the groups as well as to mental health staff, as requested.
- **WVMHCA Support.** The project worked to expand membership in WVMHCA and to strengthen relationships between WVMHCA and community mental health center boards of directors and professional associations. During the course of the project, membership in WVMHCA tripled and ten chapters were organized.
- **Advocacy.** Consumers/survivors were active in various advocacy efforts (including mental health boards and committees), and the Executive Director addressed the State Legislature.
- **Information and Referral Helpline.** A helpline was established and received an average of 19 calls per month.
- **Information Dissemination.** Staff spoke at three *Alternatives* conferences, presented at the International Association of Psycho-Social Rehabilitation Services (IAPSRS) conference, trained the Milwaukee Planning Council on conducting a housing preference survey, presented at the Statewide consumer/survivor conference in South Carolina, conducted a six-hour consumer empowerment training workshop for the South Carolina Mental Health Association, and wrote an article for *Community Support Network News* on grassroots organization of consumers/survivors.
- **Fighting Stigma.** The project participated twice yearly in mental health fairs, and utilized 13 hours of free airtime on public television during May—Mental Health Month.

Individuals Served

The project originally planned to serve adults with severe mental illness. It was estimated that there were 29,000 people in West Virginia who met this criterion. The criteria were later

revised to include all persons who have received any form of mental health treatment.

The “Prescriptive Peer Counseling” groups had members with the following characteristics: each had a severe mental illness; the average age was 40 years; 68% were female; 19% were married, 23% were divorced, 41% were single, and 17% were widowed; 87% were Caucasian, 5% were Native American, and 9% were African American; all were living in the community; 18% were meaningfully employed; 67% received governmental assistance; and the average annual income was \$5,000.

Organization and Administration

The grant was awarded to the West Virginia Department of Health, Office of Behavioral Health Services. The project funds were provided to WVMHCA, which administered the grant activities. No Board information was reported for this effort.

Paid staff included the Project Coordinator/Executive Director, a Clerical Staffer, a Consultant, and a Peer Counseling Program Coordinator. The State provided, in kind, the Mental Health/Community Support Program Director, the Behavioral Health Coordinator, and a Project Evaluator/Consultant.

All staff were required to be consumers/survivors. Staff were interviewed by a committee of State behavioral health services staff and consumers/survivors from WVMHCA. Attempts were also made to recruit minority candidates and individuals who knew American Sign Language.

Staff were primarily female and Caucasian. Volunteers provided over 150 hours per month of service, including leading peer counseling groups and newsletter production. Volunteer contributions were estimated at \$20,000 per year. Staff were provided with training on implementing a housing preference survey, on public speaking, and on creating a speakers bureau.

A number of materials were developed during the course of the project, including newsletters, the PPC Handbook, a housing preference survey, and a training curriculum. The project interacted with a number of other organizations including local mental health providers, family groups, advocacy organizations, hospitals, and other consumer/survivor organizations.

The total expenditure of Federal funds for this effort was \$214,057.

IMPLEMENTATION ISSUES AND BARRIERS

The following issues were encountered during the implementation of this effort:

- **Autonomy.** The office was moved during the second year from the State to rented office space elsewhere, as staff wanted this for privacy, autonomy, and self-empowerment.
- **Bulletin Board System.** This was never fully realized due to the inability of consumers/survivors across the State to access this technology.

SUCCESSSES AND EVALUATION FINDINGS

The evaluation focused on objectives achieved and recipient characteristics and empowerment. It was reported that staff contributed to the development of data collection instruments. Data on empowerment were collected on four sets of empowerment descriptors (personal, emotional, social, and political). The process evaluation was conducted by the WVMHCA Board by reviewing project results on an objective-by-objective basis.

Findings revealed that the project engaged in a wide variety of activities including: recipient involvement on local mental health boards; advocacy for expanded residential services via the housing preference survey; establishment of 10 new chapters of WVMHCA; and increas-

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ing membership from 45 to 200 individuals. It was found that Community Behavioral Health Center staff were aware of WVMHCA chapters, but were slow to make referrals.

The outcome evaluation surveyed 50 consumers/survivors (who were members of four peer counseling groups) twice over a two year period. The following findings were revealed: 85% of respondents had been hospitalized, and 40% had voluntary admissions. Attendance on boards of community programs showed an increase. The number of consumers/survivors who openly voiced opinions on mental health issues showed the greatest increase. Conclusions indicated that project members were more empowered by becoming more involved; the majority of project members had been in the system all of their adult lives; and

change comes slowly with knowledge, training and support.

Recommendations as a result of the project included:

- It was suggested that training on self-help and empowerment should be conducted first, and then training on the organization of the Peer Counseling Groups at selected locales, rather than the reverse (which had been the case).
- Grassroots organization is the most cost-effective method of effecting change.
- Mental health consumers/survivors' natural support systems are each other.

The Final Report stated that the project did continue with West Virginia State funding.

WISCONSIN

Wisconsin Network of Mental Health Consumers Madison, WI

“ . . . Both State and local groups have benefitted from the struggle and learning, and both have flourished.”

—Project participant

PROJECT GOALS AND OBJECTIVES

The objective of this project was to strengthen and formalize the State's fledgling consumer/survivor movement by hiring a consumer specialist within the State Office of Mental Health, establishing a Statewide consumer/survivor Steering Committee to link and support local groups, developing and supporting local consumer/survivor-run programs, and developing the Wisconsin Network of Mental Health Consumers (WINMHC). The Specialist identified and helped communities organize local self-help groups, provided technical assistance, and helped to fight stigma through public education. In addition, the project provided funding for ongoing evaluation which compared different self-help models and for obtaining training and technical assistance via consultation with other States and consumer/survivor attendance at State and national conferences.

PROGRAM DESCRIPTION

Services Provided

Grant funding enabled this project to provide:

- **Technical Assistance.** Thirteen self-help groups, as well as a telephone network of groups throughout the State, were established, and the project maintained a collection of resource materials. Technical

assistance was also provided in State consumer/survivor conference organizing.

- **Newsletter.** The project published and distributed the WINMHC newsletter to over 1,000 individuals.
- **Advocacy.** The project obtained consumer/survivor representation on approximately ten committees. Staff spoke at *Alternatives* conferences, the National Association for Rights, Protection, and Advocacy (NARPA) conference, and various State conferences.
- **Training.** Training was provided to staff on mental health issues, advocacy, leadership training, psychotropic medications, and fundraising strategies. Scholarships were provided to 27 consumers/survivors to attend State and national conferences.
- **Mini-Grant Funding.** Sixteen groups received a total of \$65,000 for self-help groups, drop-in centers, peer counseling, and video production in eleven counties. Technical assistance meetings were held with all grantees, and grants ranged from \$500 to \$6,000.

Individuals Served

Recipients of services were all current consumers/survivors or those with a history of severe and persistent mental illness or emotional disorders. No information was provided regarding client characteristics.

Organization and Administration

In Year 1, grant funds were awarded to the Wisconsin Department of Mental Health. In Year 2, this was changed and funds were awarded from the State to the Wisconsin Coalition for Advocacy (a protection and advocacy agency), which acted as an umbrella for funding and project administration. In Year 3, the grant was directly awarded from the State to WINMHC, which administered and coordinated the grant activities directly.

Initially, a Steering Committee was developed with representatives from six regions of the State. Meetings were held on a periodic basis. In 1991, the Steering Committee merged with the WINMHC Board.

Paid project staff included an Administrative Project Specialist and a Technical Assistance Project Specialist. In-kind staff provided by the State included the Office of Mental Health Director and the State Community Support Program Director.

A number of program materials were developed over the course of the project, including job descriptions, a technical assistance request form, written roles and responsibilities of committee members and staff, and a Request for Proposals. The project collaborated with a number of organizations and entities, including advocacy organizations, the media, family groups, national consumer/survivor groups, NARPA, and the local Mental Health Association.

A total of \$364,359 was expended during the grant period, with \$327,882 in Federal funding.

IMPLEMENTATION ISSUES AND BARRIERS

The following issues were being experienced during the implementation of the grant:

- **Initial Administrative Change.** During Year 2, the State decided to operate the

project through the Wisconsin Coalition for Advocacy (WCA), as it was claimed that they had the administrative capability and the flexibility necessary to complete tasks more quickly than a State agency. It was also stated that this was done to reduce perceptions of disempowerment. However, this new project plan unfortunately resulted in fewer funds being available for local initiatives, due to new operational costs that were previously provided on an in-kind basis by the State.

- **WINMHC Development.** The grant was transferred in order to increase consumer/survivor control over operations and expenditures. During Year 3, it was proposed to transfer the grant to WINMHC in order to increase the autonomy and decisionmaking power of the consumer/survivor staff. Major problems were experienced in this transition as a result of the lack of infrastructure at WINMHC and poor communication between OMH and WINMHC.
- **Delay in Mini-Grant Payments.** This was a significant problem, and it was felt that it was caused by bureaucracy and overregulation. Local projects felt that their efforts were put in serious jeopardy.

SUCCESSSES AND EVALUATION FINDINGS

The Final Report highlighted the following benefits of the mini-grants that were distributed:

- The consumer/survivor movement was strengthened on the local and State levels;
- Education and information were provided;
- New self-help groups and projects were initiated;

- People became motivated;
- There was a reduction of stigma because people “came out” of the closet regarding their diagnosis;
- Administrative tasks were learned; and
- The importance of communication, negotiation, and democratic decision making were learned.

The Final Report indicated that the administration of the project had problems in terms of growing pains, structure, administration, and accountability: “WINMHC [experienced] growing pains . . . [WINMHC and the] consumer movement [were] not mature enough to carry a unified agenda and consequently [were] too ambitious given the time frame of the grant . . . [they also] needed more grassroots support . . .”

An outside evaluator added the following comments: “Many local projects were remarkably successful in assisting people towards empowerment . . . much of the administrative

difficulties resulted from an externally imposed bureaucratic structure.”

The evaluator’s major recommendations were:

- Organizations funded with State or federal dollars should have a clear mission, philosophy, and organizational structure in place; and
- Levels of financial, policy, and administrative structure should be minimized, perhaps through a direct RFP process, rather than through State governments.

WINMHC received continued support from a CMHS Service Systems Improvement Grant. Many local groups continued with the support of county mental health funds, Mental Health Association funds, United Way agencies, and private grants. An increase in the CMHS mental health block grant allocation for Wisconsin provided additional funds for ongoing consumer and family initiatives at the State and local levels.

CROSS-SITE FINDINGS AND RECOMMENDATIONS

An overall cross-site analysis was conducted with the findings from the qualitative analysis of the thirteen demonstration projects. In completing this task, a matrix was developed to compare and contrast the significant findings between each site in each of the seven domains examined (see Appendix A). The significant similarities and differences in the following domains are presented below:

- Project Goals and Objectives;
- Services Provided;
- Individuals Served;
- Organization and Administration;
- Implementation Issues and Barriers;
- Successes and Evaluation Findings; and
- Recommendations.

It is important to note that there are methodological weaknesses with this approach. As different service models were developed in

vastly different environments, there is the potential for many extraneous variables which could impact upon the site—and, therefore, cross-site—findings. Also, as discussed previously, the data are limited in their comprehensiveness and validity. Nonetheless, given that this is a “natural” laboratory, these findings do offer impressions and indications associated with and across these sites.

The last section consists of overall suggestions and recommendations based on the cross-site findings. It is hoped that these will offer guidance for consumers/survivors, State and local mental health authorities, policy makers, managed care organizations, and others involved in the planning, policy development, operation, and evaluation of consumer/survivor-operated services.

PROJECT GOALS AND OBJECTIVES

“[It] appears that these efforts focus on priority needs as identified by consumers/survivors which are often not addressed by traditional mental health service providers.”

In examining the findings from the individual projects, a number of similar themes, goals, and objectives were apparent and are discussed below. Please note that goals stated in project materials may differ from the operational goals that actually existed.

Mutual Support

In keeping with a major tenet of the consumer/survivor self-help movement, over 75% of the sites indicated that the provision of **mutual** or **peer support** was a major goal. This ranged from drop-in center programs in New Hampshire to the shared resource system in California. An array of needs was addressed through the provision of mutual support, including socialization, limited resources, employment, and peer counseling.

Basic Human Needs

The provision of **direct services** to meet critical human needs was also cited by 85% of the projects. The needs included housing, employment, food, independent living skills, protection against discrimination, access to services, socialization, crisis respite care, and outreach. Research has shown that these needs are often cited as priorities by consumers/survivors across the Nation (Ridgeway, 1988b).

Empowerment

Over 50% of the projects noted the general goal of **empowering consumers/survivors** as a major focus. Again, this is a major philosophical tenet of the consumer/survivor self-help movement. This took the form of increasing both personal as well as collective empowerment via leadership development training, community organizing, technical assistance, and obtaining representation on boards and committees.

Public Education

The most frequently cited goal (over 90% of the sites) was **public education and information dissemination**. This ranged from speakers bureaus, to publishing newsletters, to presenting at conferences. Two major foci seemed to be addressing stigma/discrimination and disseminating information about the projects.

Rights Protection

Over 75% of the sites noted that **rights protection** was a project goal. This included both individual case advocacy and systems advocacy and ranged from helping people to access services, to coalition building, to effect needed change. Sites participated in legal and legislative advocacy, as well as hospital monitoring and developing policy and planning initiatives.

Summary

Approximately 70% of the sites indicated similar goals. Four of the sites indicated—in one form or another—all of the above five goals within their stated goals or objectives, with five additional sites indicating four of the goals.

Three sites that were unique in their approach were California (with a focus on shared administration and resources among different self-help initiatives), Colorado (developing a “superstructure” to develop businesses), and Vermont (focusing on video production and distribution). While their approaches may have differed from the other alternative service providers, they did share a number of similar goals (e.g., public education, basic needs) with the other sites.

In reviewing the five significant goals/objectives (mutual support, basic human needs, empowerment, public education, and rights protection), it does seem apparent that the philosophy and values of the consumer/survivor self-help movement have a significant impact upon the focus of these projects. In addition, it appears that these efforts focus on priority needs (as identified by consumers/survivors) which are often not addressed by traditional mental health service providers with a focus on professionally driven mental health treatment. Consumer/survivor-operated services are addressing and striving to meet the critical, self-identified concerns of consumers/survivors that are often overlooked in other models.

Services Provided

“It is clear that consumers/survivors can provide a broad and diverse range of services.”

A range of services were provided via the projects. Documented below are the major categories of services that were provided by these efforts.

Drop-In Centers

More than half of the projects operated **drop-in center** programs that provided socialization/recreation and other services. This is a model that has gained great popularity as an effective consumer/survivor-operated program. Since the implementation of these projects, drop-in centers have continued to flourish with the development of this model in most States across the Nation.

Support Groups

Over 75% of the projects organized **support groups** or **peer counseling** efforts for consumers/survivors. This is indicative of the origins and basis for the consumer/survivor self-help movement—grass-roots self-help groups. A few of the projects were specifically designed to assist in the organizing of local support groups in their region or State. These models help to address the needs for peer support, socialization, and recovery-based approaches that emphasize self-determination, consumer/survivor strengths, encouragement, and hope.

Information and Referral

About 40% of the sites provided **information and referral services** to consumers/survivors to address human and social service needs. These services help consumers/survivors to understand and access services and benefits which may be available to them.

Information Dissemination

All of the sites indicated that they provided **information and education** to the public about their projects, mental health issues, etc. A number indicated that they focused on addressing the topic of stigma. One project (Vermont), focused exclusively on public information/education and communications through video production and dissemination.

Advocacy

As mentioned above, **advocacy for rights protection and service access** was a significant activity by over 75% of the sites. While a variety of advocacy strategies were employed, the facilitation of consumer/survivor representation on boards and committees was a major accomplishment of many of the projects.

Outreach

Outreach activities were conducted by approximately 40% of the sites. This included outreach to individuals in hospitals, in-home outreach to provide support services to people released from such settings, and street and shelter outreach to consumers/survivors experiencing homelessness.

Technical Assistance and Training

Nearly half of the sites provided **technical assistance and training activities** to other consumers/survivors. This ranged from providing training on medication issues to providing technical assistance in other communities to help them replicate these projects.

Independent Living

Direct services to assist persons in independent living were offered by almost 50% of the projects. This ranged from shower facilities, to roommate matching services, to small loan funds for housing or employment expenses.

Employment

A complementary, yet significant, finding was that **all of the projects employed consumers/survivors** in various capacities in their activities. This employment provided valuable experience for the individuals involved. Often, it enabled individuals to cease receiving Social Security and other benefits and become fully employed, tax-paying citizens. It was noted that some of the staff used these positions as “stepping stones” to obtain other employment. Many other individuals participated in non-paid, volunteer employment

positions. While the data were incomplete, sites that reported findings indicated that over 260 consumers/survivors participated in employment capacities within these projects.

Summary

All of the projects offered multiple services. Five of the sites offered seven of the service categories mentioned above. An additional four sites provided services in six of the categories. Therefore, approximately 70% of the projects provided a minimum of six different services. It is clear that consumers/survivors can provide a broad and diverse range of services. Two of the projects were unique in their focus on select activities: the development of consumer-run businesses and a video production enterprise (Colorado and Vermont).

Individuals Served

“Consumer/survivor-operated projects can serve large numbers of low-income individuals with significant mental health concerns who have diverse backgrounds.”

The total number of service recipients reported was 5,701 individuals. This does not include the projected 1.6 million homes that were reached via cable television broadcasts by one of the sites. The number of persons served was probably higher as some of the sites did not provide detailed information on the number or characteristics of those persons who were served. Excluding the video project, the number of reported persons served by individual sites ranged from 101 to 3,500.

Demographic findings across the sites are discussed below.

Persons With Psychiatric Disabilities

All of the projects indicated that they served individuals with psychiatric disabilities. Interestingly, some had initially developed fairly detailed criteria of who was to be served. Over time, this

was found to be cumbersome and broader criteria were employed. As a whole, all of the projects indicated that they served persons with serious mental health problems including persons in hospitals or recently discharged.

Impoverished

Projects that reported the income of participants served (over 30%) indicated that they served persons who were in poverty, including individuals experiencing homelessness. One site indicated that 82% of those served were unemployed, and another reported that the average annual income of service recipients was \$5,000 per year.

Gender Balance

It seems that both genders were attracted to this service model. Four (4) sites reported the majority of members served were men, while three (3) sites reported a higher percentage of members were women.

Cultural Diversity

The reported racial characteristics of members were diverse—however, of those reporting, 70% indicated that a majority of service recipients was Caucasian. Two sites which indicated that a majority of people of color were served were also in highly urbanized areas: the California Bay Area and New York City. A number of projects specifically targeted outreach to people of color communities with varying results.

Young- to Middle-Aged Adults

The range of ages served was from 15 to 80 years old. The average age range seemed to be between **18 and 55 years old**, with over 80% of the sites indicating this range.

Veterans

The one site that reported on this characteristic (CA) indicated that approximately 30% of its recipients were military veterans.

Summary

The above data indicate that consumer/survivor-operated projects can serve large numbers of low-income individuals with significant mental health concerns who have diverse backgrounds.

ORGANIZATION AND ADMINISTRATION

“Consumers/survivors can develop service organizations with moderate costs that are autonomous and, yet, collaborate with a myriad of different sectors to meet consumer/survivor needs.”

Project organization and administration were significant factors that impacted upon the development, operation, and ultimately, outcomes of these initiatives. Only two of the projects operated as bona fide non-profit organizations upon receipt of their funding. Many of the projects learned (and at times struggled) to successfully manage such a structure. Some of the findings in this area are discussed below.

Autonomy

Over the life of the projects, over 90% of the initiatives obtained **autonomous non-profit status** with Boards of Directors. Initially, most of the sites operated via a “pass-through” non-profit organization for administrative supports and services, such as financial management. By the end of these grants, almost all had developed the capacity to conduct these functions on their own.

Training and Technical Assistance

It was reported that over 60% of the sites received **some training and technical assistance** in organizational and staff development. This ranged from training on marketing, to peer counseling skills, to bookkeeping. There was, however, a lack of a coordinated approach to training and technical assistance as is now generally provided in CMHS-funded multisite evaluation demonstration projects.

Project Materials

Over 75% of the sites reported that they developed **project materials** to assist with the administration of their organization. This included personnel policies, financial accounting forms, job descriptions, informed consent forms, intake materials, and others. The development of these materials depicts the growth of these organizations.

Increased Collaboration

Approximately 85% of the sites reported increased **collaboration** with other organizations in the course of their activities. Collaboration to address consumer/survivor needs occurred with many different entities, including: mental health providers, advocates, social services, churches, businesses, universities, and governmental entities.

Funding

The total costs for all thirteen projects for their grant years totaled **\$4.81 million**. The amount of funding for project activities (as \$167,000 to \$540,000 in total costs, with a mean of \$370,000 per site for the average three-year period of these efforts. This large variation significantly impacts upon the comparability of these projects. In general, however, each project had a very modest average budget of approximately \$124,000 per year. As will be noted later, access to adequate resources was reported as a crucial element in project success.

Summary

In reviewing the above, it is apparent that consumers/survivors can develop service organizations with moderate costs that are autonomous and yet collaborate with a myriad of different sectors to meet consumer/survivor needs. In addition, training and technical assistance, along with adequate resources, appear to be key factors in the successful organization and administration of these efforts.

IMPLEMENTATION ISSUES AND BARRIERS

“To avoid these pitfalls, consumers/survivors need adequate resources, training, and development as well as mutually respectful collaborations with public and private sectors.”

Some of the best lessons are realized by the problems we encounter. These demonstration projects experienced implementation issues and barriers which offer useful learning experiences for those who are replicating such models.

Startup Delays

More than half of the projects reported **delays in project implementation** which were primarily due to the length of time it took funding to move from the Federal Government to State Governments and, finally, to the projects. As mentioned earlier, in the early phase of most of these efforts, there were additional organizations which acted as fiduciary agents for the consumer/survivor projects which created another layer of bureaucracy affecting funds transfer. In some cases, the startup delays resulted in lowered consumer/survivor interest and participation as well as increased potential for alienation from State and Federal bureaucracies.

Limited Resources

Almost 50% of the sites reported that a **lack of resources** impeded their ability to adequately carry out their activities. In a number of the projects, consumer/survivor need outpaced the available funds to address them. This resulted in fewer personnel, as well as a lack of necessary equipment for some sites (e.g., typewriters, computers, and video equipment). Many projects believed that more could have been accomplished, given adequate resources.

Staff Turnover

Changes in personnel were reported by almost half of the sites. This was due to a number of factors, including individuals seeking other employment, lack of training, interpersonal conflicts, and health reasons. A number of sites actively pursued staff development training, formal personnel policies, and reasonable accommodation practices to address these issues.

Lack of Organizational Expertise

Approximately one-third of the sites indicated that a **lack of necessary training on organizational issues** (e.g., financial management) was a significant barrier. As indicated elsewhere, most of the organizations undertaking these ventures were new themselves and experienced rapid growth. The vast majority of staff had limited knowledge or expertise in nonprofit organizational management issues. The training that was offered on management skills was reported to be helpful, but comprehensive and coordinated training was missing.

Working with Bureaucracies

Approximately 30% of the projects reported **difficulties working with State bureaucracies** due primarily to value differences between consumer/survivor efforts and State systems. This resulted in issues surrounding paperwork, evaluation requirements, etc.

Interpersonal Conflict

Conflicts between consumer staff and/or board members were reported as barriers by about one-third of the sites. These took the nature of political and philosophical differences, personality and ego clashes, jealousies, and power struggles. These conflicts are not unique to these specific projects, nor are they unique to consumers/survivors. One confounding factor may be the principle of egalitarianism in the consumer/survivor movement, which can be compromised with the introduction of paid staff into such projects.

Unclear Focus

In several of the sites, it was noted that the project **lacked a clearly articulated series of priorities** or foci. This was due, in part, to a lack of experience in strategic planning and is related to the organizational expertise mentioned above.

Autonomy

Approximately one-third of the sites also indicated that consumers operating their own programs created **tensions with professionals**. In a few projects, this took the form of issues of control, paternalism, and “turfism”, as professionals were uncertain in their dealings or responded in traditional fashion with these new models, and, at the same time, consumers/survivors, in pursuit of empowerment and self-determination, resisted these responses.

Summary

While the above issues will be explored in greater detail in the final part of this chapter, it can be stated in summary that in order to avoid these pitfalls, consumers/survivors need adequate resources, training and development, and mutually respectful collaborations with public and private sectors.

It is also interesting to note that a few of the sites had unique issues which they confronted. This included State geographic distances, community resistance to program location, transportation issues, and philosophical debates over having a commercial enterprise orientation versus maintaining an advocacy-based, non-profit status.

SUCCESSES AND EVALUATION FINDINGS

“Consumer/survivor-operated services are successful in increasing the overall quality of life, independence, employment, social supports, and education of consumers/survivors.”

There were wide and varied successes documented within the evaluations of these projects. Overall, the hypothesis that consumers/survivors can successfully develop and operate autonomous service organization was validated.

Perhaps the greatest measure of success is that over 70% of these initiatives were continued with the assistance of other funding sources. These projects demonstrated that they were successful in capturing ongoing financial support. Other significant, cross-site findings, with a focus on person-centered outcome measures, are discussed below.

Increased Recipient Self-Efficacy

All of the projects reported that as a result of these initiatives, consumers/survivors had achieved **greater levels of independence, empowerment, and self-esteem**. Individuals had an improved sense that they could make their own decisions, solve problems, and help others. This helped people to become more confident and to cope better.

All of the projects reported that consumer/survivor **quality of life was increased** in various aspects. This included better income, housing, and friendships. For some individuals, it meant better knowledge of rights and services. These efforts helped people to stay out of hospital settings and contribute positively to their communities.

Increased Social Supports

The **development of social supports** was a key success reported by over 60% of the projects. People felt more accepted and had greater numbers of friends. For some individuals, these efforts played a central role in their social lives. These social supports and acceptance helped people to combat the social ostracism and loneliness which often accompanies mental health problems.

Enhanced Employment

As mentioned elsewhere, all of the projects recorded an increase in **employment skills** and experience among those consumers/survivors participating in these efforts. As poverty and unemployment are other major factors in the lives of consumers/survivors, this success cannot be overlooked.

Expanded Education and Knowledge

More than half of the projects reported success in **increasing the knowledge of consumers/survivors** in various areas such as rights, available services, communication, negotiations, working in a team, and organizational operations. These efforts also played an important role in educating the community about the positive abilities of consumers/survivors, to counter the often negative, stigmatizing portrayals.

Based on these results, it can be said that consumer/survivor-operated services are successful in increasing the overall quality of life, independence, employment, social supports, and education of consumers/survivors.

Other successes cited include that consumers/survivors can be extremely devoted staff members to assist their peers, and that consumers/survivors can overcome difficulties to deliver needed services.

OVERALL RECOMMENDATIONS

“Efforts to develop consumer/survivor-operated services should include adequate technical assistance, strategic planning, funding, and cooperation with a need to increase people of color participation.”

Many of the individual projects offered recommendations on how to improve these efforts. The following represents overall recommendations that were mentioned by the greatest number of sites.

Increased Technical Assistance and Training

Approximately 70% of the sites indicated that **more training and technical assistance** would have contributed to increased successes. This training was needed in organizational development as well as staff development. Participants revealed that they felt hindered by this lack of knowledge and that coordinated, comprehensive approaches to meeting technical assistance needs would have been of benefit.

Better Planning

More than one-third of the projects reported that they needed **better preparation and planning** prior to starting these initiatives. This includes the development of a clear mission, philosophy, and operational structure before implementation. There was a need for a more “proactive” strategic approach to planning.

Adequate Funding and Continuation

About 40% of the sites indicated a need for **increased resources** to adequately accomplish project activities, as well as firm assurances of **continuation funding**. Regarding

the latter, this was a source of substantial distress for a number of the projects in their last grant years, resulting in distractions from project activities.

Enhanced Cooperation

Approximately one-third of the projects reported the need for **improved cooperation** with governmental entities, providers, family members, and advocates. In addition, there was a need for increased cooperation amongst consumers as well.

Expanded People of Color Representation

Approximately one-third of the projects reported the need for **expanded representation of people of color** in consumer/survivor self-help activities. Greater outreach to these communities was cited as a need.

More Research

Approximately 40% also indicated the need for **more research** into consumer/survivor-operated services. This included enhanced research into who is attracted to self-help, as well as rigorous process and outcome evaluations of these ventures.

Fund Projects Directly

As a result of the startup delays mentioned earlier, about 20% of the sites suggested that future **funding** for these initiatives **be provided directly to the recipient organization**, rather than via State Mental Health Authorities.

Summary

The above findings indicate that efforts to develop consumer/survivor-operated services

Chapter 4. Overall Recommendations

should include adequate technical assistance, strategic planning, funding, and cooperation, with a need to increase participation by people of color. Future research is needed to examine the process as well as the outcomes associated with this model.

It is important to note that since the implementation of these projects, a large number of additional consumer/survivor-operated services have been developed, including: case management, housing, employment assistance, “hi-tech” computer networks, a pharmacy, higher education assistance, commercial enterprises, and many others. Also, these and other initiatives have demonstrated similar findings, including the ability to reach large numbers of diverse individuals. One example is an organization in a southeastern State that provides leadership training and development at annual conferences with over 1,500 consumers/survivors at each gathering.

Finally, in addition to the above project-based recommendations, the following overall recommendations are offered:

- **Research.** There is a clearly defined need for more rigorous **research** of consumer/survivor-operated services. Suggested research designs include a multisite, multiyear effort with common data collection and measures. A coordination center should be established to assist with data collection and related technical assistance matters. The determination of the research design and specific measures and methodology to be employed should be directed by consumers/survivors. Consumers/survivors should be meaningfully involved in every stage of this process from conceptualization to data analysis to publication.

Specific outcomes and other measures that could be examined include:

- Cost/benefit analyses;

- Independence (including eliminating people’s need for Social Security and welfare benefits);
- The impact of self-help on specific sub-populations (e.g., racial and ethnic minorities and women);
- Recipient satisfaction with services;
- Empowerment; and
- Examining whether these programs serve those whose needs would not otherwise be met.

Training and Technical Assistance

There is an ongoing need for targeted training and technical assistance in the development of consumer/survivor-operated services. This should be focused on all areas of non-profit organization management, including board development, fiscal management, staff supervision, conflict resolution, strategic planning, fundraising, managed care, and cultural diversity/competency. Training and technical assistance also needs to be given to States and providers to demonstrate how they can support consumers/survivors developing their own service programs. Efforts to provide training and technical assistance should use continuous quality improvement strategies to adapt the training to the needs of consumer/survivor-operated services.

Funding

Financial support for the operation of consumer/survivor-run services should expand and originate from a variety of sources: State governments (possibly through a setaside of block grant funds), managed care organizations, private foundations, and other Federal entities (e.g., HCFA, HRSA, NIMH, RSA, SAMHSA). Also, other financing mechanisms, such as fee-for-service and capitation within managed care arrangements, should be explored.

Public Education

The benefits of consumer/survivor-operated services also need to be marketed. This should be targeted to specific audiences—including funding entities and other policy-determining bodies. This could entail the use of traditional dissemination strategies (e.g., journal articles, conference presentations) as well as other marketing tools (e.g., direct mail, print ads, Internet, and other technologies).

Managed Care

The development of managed care for publicly financed mental health services may drastically alter the landscape for consumer/survivor-operated services. Managed care organizations need to become better educated on these models. There also is the need to integrate consumer/survivor-operated services within managed care settings, through the development of:

- Practice guidelines;
- Best practices;
- Staff competency evaluation and credentialing; and
- Staff training curricula.

These should be developed with the direct and meaningful involvement of consumers/survivors. In addition, draft “boilerplate” language needs to be developed for States to insert in bidding and contracting processes which mandate consumer/survivor services in benefit plans and service system designs.

The future of consumer/survivor self-help services appears to be bright. As the benefits of this model—both on individual and systems levels—become better known throughout the Nation, the growth of self-help efforts will hopefully continue, unabated.

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