



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Substance Abuse and Mental Health Services Administration

Center for Mental Health Services

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Emerging New Practices in Organized Peer Support

2003

***Report from NTAC's National Experts Meeting on
Emerging New Practices in Organized Peer Support
March 17-18, 2003, Alexandria, VA***

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Prepared for:

National Technical Assistance Center

for State Mental Health Planning (NTAC),

National Association of State Mental Health Program Directors (NASMHPD),

under contract with the Center for Mental Health Services (CMHS), Substance Abuse and Mental Health Services Administration (SAMHSA),

U.S. Department of Health and Human Services (HHS)

This report was produced by the National Association of State Mental Health Program Directors (NASMHPD) and the National Technical Assistance Center for State Mental Health Planning (NTAC) and is supported under a Contract between the Division of State and Community Systems Development, Center for Mental Health Services (CMHS), Substance Abuse and Mental Health Services Administration (SAMHSA), and the National Association of State Mental Health Program Directors. Its content is solely the responsibility of the author(s) and does not necessarily represent the position of SAMHSA or its centers.

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Acknowledgements

The National Technical Assistance Center for State Mental Health Planning (NTAC) wishes to thank Jean Campbell, Ph.D., director of the Program in Consumer Studies and Training at the Missouri Institute of Mental Health, and Larry Fricks, director of the Office of Consumer Relations for the Georgia Division of Mental Health, Developmental Disabilities and Addictive Diseases for their coordination and facilitation of the *Emerging New Practices in Organized Peer Support* experts meeting held in Alexandria, VA, March 17-18, 2003. Thanks are also due to the meeting sponsors: the Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration and the National Association of State Mental Health Program Directors.

The vision and encouragement of Dr. Campbell and Mr. Fricks as national leaders in the consumer/survivor movement inspired 26 participants (*Editor's note: See Appendix B for a complete meeting participants list*) to represent the best in contemporary peer support and consumer empowerment and recovery. As the lead writer, Dr. Campbell utilized the substance of the experts meeting and her extensive research on peer support to infuse this report with state-of-the-art information and innovation regarding the central role of consumers/survivors in support, treatment, and recovery from mental illnesses.

NTAC extends its appreciation to Judy Leaver, M.A., for her work as the content editor and contributing writer for this report. She was instrumental in ensuring the report's comprehensive and substantive material remained concise and informative.

Thanks also to NTAC staff members who helped to produce this report, including Sarah R. Callahan, M.H.S.A., deputy director; Robert Hennessy, editor and publications coordinator; and Catherine Q. Huynh, M.S.W., former assistant director.

This document is intended to provide guidance and concrete recommendations for how our nation's mental health systems can foster viable peer support programs and advance the recovery movement—now recognized as key elements of change and reform in existing mental health service systems. With your support and facilitation of the ideals and practices presented herein, this task can be accomplished to the betterment of those we serve in public mental health.

— *Kevin Ann Huckshorn, R.N., M.S.N., I.C.A.D.C., Director,
NASMHPD Office of Technical Assistance*

Preface

In the past decade, consumer-operated peer-support services have matured, diversified, and increased their numbers across the United States. As traditional mental health programs are strained by demands for services at a time of limited fiscal resources, the inclusion of consumer-operated/peer-support services within the continuum of community care is expanding the capacity of the mental health delivery system and promoting recovery in cost effective ways.

In this process, some peer-support programs have developed management information systems to track utilization, performance and member outcomes. Others have certified staff, created peer specialist positions, produced training manuals, sought accreditation standards, and developed peer support as a Medicaid-billable service. However, progress has been uneven, and the dissemination of advances in peer-program models, organization, and technologies is limited.

The National Technical Assistance Center for State Mental Health Planning (NTAC) within the National Association of State Mental Health Program Directors (NASMHPD) in collaboration with Jean Campbell, Ph.D., director of the Program in Consumer Studies and Training at the Missouri Institute of Mental Health, and Larry Fricks, director of the Office of Consumer Relations for the Georgia Division of Mental Health, Developmental Disabilities and Addictive Diseases, organized a two-day meeting of peer-support service providers in March 2003 to share emerging new practices in peer-support services. More than 40 people representing leading peer-support programs were invited to apply for participation. Twenty-six were selected based on responses to the short application form, as well as geographic, gender, and racial diversity considerations.

This meeting provided an opportunity to share new practices for delivery, staffing, evaluation, funding, and administration of peer-support programs and to build a network of seasoned peer support service providers.

**Quotations on the wall
at the Georgia Peer Specialist Certification Training...**

“Relate to a person’s potential and you call forth greatness.”

— Ike Powell

“At the heart of the recovery movement is the idea that instead of focusing on the illness, emphasis is placed on the potential for growth in the individual.”

— William Anthony

“Empowerment happens when a person who is seen as the problem begins to see him or herself as part of the solution.”

— Saul Alinsky

“The most important thing you can do for a person who is having a difficult time is to listen.”

— Parker J. Palmer

Introduction

Mental Health: A Report of the Surgeon General (U.S. Department of Health and Human Services, 1999) recognized self-help as an important adjunct to traditional mental health services and concluded that self-help activities serve as powerful agents for change in service programs and policy. *Emerging New Practices in Organized Peer Support* provides an overview of peer support services in the United States in order to guide and promote understanding and integration of peer-run support within the continuum of community mental healthcare. It traces the remarkable history of peer support programs and illuminates the beliefs, values, and customs that bind consumers in an evolving “empowerment culture of recovery” (Ahern & Fisher, 2001b). It reviews studies of effectiveness of peer support approaches, and examines the operating principles of peer-run support services. Looking to the future, it concludes with a discussion of the tensions present when peer-run support programs partner with, or are embedded in, traditional mental health service systems, and also details the benefits and dangers of professionalizing peer-run services.

The emergence of peer-run support services holds promise for improved outcomes for a public mental health system that is under-funded, fails to reach the majority of those with mental illnesses, and often delivers services that are ineffective. *The Interim Report to the President* by the President’s New Freedom Commission on Mental Health, released in the fall of 2002, describes “a mental health system in shambles—more like a maze than a coordinated system of care...Adults with serious mental illness, one of our Nation’s most vulnerable groups, suffer greatly from the fragmentation and failings of the system.”

In light of such a scattered array of efforts to serve individuals with mental illness, it is both inspirational and amazing that a strong consumer/survivor movement has developed and organized to speak out, influence policy development, and deliver peer support services. Perhaps it will be the energy, determination, and vision of consumers/survivors that will bring greater focus and effectiveness to mental health services in the future. The hope instilled in people recovering from mental illnesses through the dynamic exchange of peer support has the potential to foster hope and change for the mental health system.

Current Trends and Issues

Within the sobering context described in the President's New Freedom Commission's *Final Report: Achieving the Promise: Transforming Mental Health Care in America* (2003, July 22), several trends are emerging that will impact the future of peer-run support services as well as the entire mental health delivery system in this country.

Budget Woes in Most States

The NASMHPD Research Institute, Inc. (NRI) reported in *State Mental Health Budget Shortage: FY '03 & '04* (2003) that 38 states are experiencing budget cuts due to state revenue shortfalls in fiscal year 2003, with those cuts reaching into the pockets of 32 state mental health agencies (SMHAs). Because of current economic conditions, further cuts are expected in fiscal year 2004. State agency belt tightening will reduce staffs, services, and numbers of people served in agencies that have historically been under-funded (NRI, 2003).

The movement of managed health care into the behavioral health sector in combination with the economic downturn has resulted in reorganizations in many states, with public mental health funding becoming a smaller part of the state budget. The future of state mental health agencies themselves is uncertain, with many of them reporting floundering leadership of systems that are too diffuse and unfocused to be effective. Unfortunately, sluggish bureaucracies are in some cases still reimbursing for approaches that have been proven ineffective while creating barriers for newer, more effective care. Considering the increasing role Medicaid plays in funding mental health services, it has become apparent that this change is undercutting many state mental health agencies' roles in guiding public mental health policy.

The *State Mental Health Budget Shortage: FY '03 & 04* report indicates that some administrators believe the current reforms in public mental health care may inadvertently be jeopardizing the financial future of these public systems. Since de-institutionalization in the 1950s, state hospitals have been closing and/or consolidating and community-based services have been struggling to reduce overall costs of providing mental health services and develop more relevant programs. Newer, more effective medications have also made inpatient treatment less necessary. Today, reduced levels of hospital services have led to reduced overall funding for public mental health—which in turn tightens the purse strings of community-based services. As James Stone, former commissioner of the New York State Office of Mental Health, warned his colleagues, "Erosion of funding is the consequence of not being viewed as relevant" (NRI, 2003).

Continued Stigma and Lack of Public Awareness

The lives of consumers are frequently set apart by angry or indifferent communities that reject, shun, and sometimes attack them. Stereotypes of persons with mental illness as dangerous, unpredictable, or incompetent are pervasive. The belief that people with mental illness do not know what is in their own best interests persists in popular culture,

while social isolation due to such discrimination and stigma erodes hope and diminishes individual dignity.

The level of public support for mental health services is grounded in stigma due to misunderstanding of mental illnesses, inaccurate portrayals in movies and other media, and media excess when people with mental illness are involved in violent incidents. The consequences of stigma and misunderstanding are reflected in unresponsive public policies and increasing criminalization of individuals with mental illnesses. California's Little Hoover Commission, an organization "dedicated to promoting economy and efficiency in California state government" states that "we don't know what to expect of our mental health system, so we expect very little, and that is what millions of individuals and families receive" (Bell & Shern, 2002).

Evidence Based Practices (EBPs)

On the other hand, there are positive changes occurring daily in the delivery of increasingly effective mental health services. The *Surgeon General's Report* emphasizes the strong science behind services defined as evidence-based. The Substance Abuse and Mental Health Services Administration (SAMHSA) has identified selected interventions as evidence-based and provides funding, toolkits, and technical assistance to implement these services. They include assertive community treatment, illness self-management, supported employment, family support and psycho-education services, integrated dual diagnosis treatment, and a medication algorithm project. Achieving fidelity to the program design of these identified practices is a complex undertaking for mental health systems dealing with the politics of budget deficits and organizational realignments within state government.

Yet, consumer leaders have found that such evidence-based practices often lack relevance to their everyday struggles for a quality of life and are not entirely consistent with a recovery-based philosophy of treatment and service choice, mutual support, and self-determination (Frese, Stanley, Kress, & Vogel-Scibilia, 2001). Limiting funding to select practices could also stifle innovation and narrow the range of available services (International Association of Psychosocial Rehabilitation Services [IAPSRS], 1998). By focusing on EBPs, other factors such as the kindness, respect, and cooperation experienced by consumers, and overall comfort with the program may be neglected (Anthony, 2001; Frese et al., 2001).

In recent years, consumer/survivor knowledge has been translated into a growing understanding that people can recover from mental illness and that peer support has an important role in the process. As policymakers look to science as a means to rationalize mental health care, consumer/survivor involvement in the mental health system as research partners and peer providers has enhanced the quality and relevance of the evidence produced.

The increasing proliferation of peer support services and the evolution of the recovery movement may represent the brightest stars in the future of mental health treatment

systems. The lived experience of people with mental illnesses is having a major impact on the shape of contemporary mental health services.

For instance, self-help has exploded on the Internet. It can be seen in listservs, chat rooms, bulletin boards, and other Internet communities devoted to peer support regarding mental health issues. Mark S. Salzer, Ph.D., in his work with the Mental Health Association of Southeastern Pennsylvania Best Practices Team, reports that research on mental health self-help groups indicates that they are associated with decreased symptoms, increased coping skills, and increased life satisfaction among long-term versus short-term members (2002).

The discrimination mental health consumers often experience has profound effects not only on their well-being, but also on their capacity to live self-determined lives. In contrast, supportive social relationships can positively affect people with mental illness. Both research and anecdotal reports acknowledge the central importance of acceptance and understanding to consumers' validation and recovery.

The Value of Peer-to-Peer Connections

For over thirty years, personal contact, communication, and concern have been identified by persons receiving all types of medical care as most important to the doctor-patient relationship (Cartwright, 1964; Roth, 1963; Skipper, Taglacoza & Mauksch, 1964). The affective component consists of "behavior directed by the physician toward the patient as a person rather than as a case" (Ben-Sira, 1980, p. 173). Within mental health services, the quality of the therapeutic relationship has also been acknowledged as an essential and influential component of mental health treatment (Gelso & Carter, 1985; Greenberg & Pinsof, 1986; Gurman, 1977; Rogers, 1957).

"Many of us who have used mental health services have been told what we "have", how "it" will be treated and how we must think about arranging our lives around this "thing."

We have then begun to see our lives as a series of problems or "symptoms" and we have forgotten that there might be other ways to interpret our experiences."

— Sherry Mead, *Peer Support Training and Evaluation: A Narrative Approach*

The power of hope and self-determination

It is not surprising that many peer-run programs serve persons who will not accept, or who do not choose to participate in, traditional services (Segal, Silverman, & Temkin, 1995a). By responding and empathizing with the experiences of people with mental illness, peer providers have found that recovery does not spring from outside factors, but rather, is grounded in an individual's mind and body—in each person's hopes, needs, preferences, and choices. Peer providers believe each person is capable of entering communities of his or her choice (Ahern & Fisher, 2001b). They are promoting recovery

from mental illness through voluntary forms of assistance directed by individuals who have had similar experiences. According to Ahern and Fisher (2001a, p.4), “The cornerstone of this assistance is the development of trusting relationships, which in turn allows people to (re)capture their dreams and enables them to (re)gain a valued social role.”

Moving from disability to meaningful choices

Peer providers believe that a supported environment based on self-determination, empowering relationships, and full participation of mental health consumers in the work and social life of society needs to be cultivated for people to recover from mental illness and participate in the community in a meaningful way. Peer-run services actively support persons with mental illness in making meaningful choices about their treatment, housing, education, employment and social activities. Because consumers are motivated by the hope that it will be possible one day to lead an independent life, peer support programs foster self-determination by focusing on teaching skills needed to direct one’s own life. This emphasis on self-management in peer support encourages people to take responsibility for their life and illness in an affirming manner. By exercising self-determination, program members become active partners in their efforts to lead productive lives and make significant contributions to the communities in which they live.

Members are assisted to gain meaningful roles in society through housing, jobs, and social supports for truly independent living. Consumer-delivered services (CDS) provide opportunities for consumers to benefit from helping others. This mechanism, referred to as the helper-therapy principle, acknowledges help-giving as extremely beneficial (Riessman, 1965). When persons who have recovered are hired to work in significant roles as mental health providers, they acquire a sense of identity that is acceptable to themselves and to others. Indeed, it is being modeled right before their very eyes. And, many peer providers have stated that when they feel they are making a difference to improve the lives of others, their own recovery progresses. Furthermore, the participation of consumers in peer program decision-making helps transition people into taking responsibility in the broader community.

Peer-run programs also emphasize empowering relationships by teaching the principles of recovery to everyone involved in assisting a member. The skills of listening and collaborating become crucial. Peer support allows adequate time to get to know the person. Consumers repeatedly state that it is critical to their recovery that peers believe in them, stressing the importance of connecting emotionally with the peer provider.

The Recovery Movement

The recovery model of service delivery suggests that “adjuncts and alternatives to formal treatment, involvement in self-help groups, and social opportunities at local drop-in centers foster empowerment and provide opportunities for a more meaningful life” (Forquer & Knight, 2001, p. 25). When peer support services are included within the

continuum of community care, the mental health system expands quantitatively, by reaching more people, and qualitatively, by helping people become more independent and interdependent (Gartner & Reissman, 1982). As a result, mental health administrators are increasingly open to shifting resources to a recovery-based model of community services (President's New Freedom Commission on Mental Health, 2002). Such a shift represents a maturing of relationships between traditional mental health providers and peer providers, and a growing interest to include peer support programs as partners in community systems of mental health service and support.

The Consumer Issues Subcommittee report to the *President's New Freedom Commission* in March 2003 indicated that a recovery-oriented mental health system embraces the following values:

- ◆ self-determination;
- ◆ empowering relationships;
- ◆ meaningful roles in society; and
- ◆ eliminating stigma and discrimination.

The Subcommittee stressed that “to build a recovery-based system, the mental health community must draw upon the resources of people with mental illness in their communities. It is widely recognized that changing the mental health system to be more responsive to consumer needs requires the participation of consumers at all levels of policy planning and program development, implementation, and evaluation. Meaningful involvement can ensure that consumers lead a self-determined life in the community, rather than remaining dependent on the mental health system for a lifetime.”

The Evolution of Peer Support Services

Four significant forces have converged over the past century to foster peer-run support programs as they exist today for people with psychiatric problems: 1) the growth of self-help groups to address a wide range of conditions; 2) the movement of people with special needs from institutions to communities; 3) the mobilization of the consumer/survivor movement; and 4) the growing support of consumer inclusion and concepts of recovery.

1) The Growth of Self-help

Over the past thirty years, participation in self-help groups has become an important way for people to help each other cope with various problems and life crises. Such groups are so common that they have joined the lexicon of American humor. Approximately 7.5 million Americans belong to as many as 500,000 self-help groups, addressing a range of illnesses, addictions, disabilities, and conditions (Lieberman & Snowden, 1994). Members come together to share experiences, feelings, and practical ways of handling problems, and the two-way interaction of giving and receiving help is therapeutic in itself (Mental Health Policy Resource Center, 1991). Durman (1976) found that most self-help groups developed in response to the need for human interaction, quick availability in crisis, and a focus that did not seek to make basic changes in outlook or personality, but to sustain the ability of members to cope with difficult situations. Numerous studies have shown that participation in self-help groups can significantly help people improve the quality of their lives and reduce the need for medical care and hospitalization.

2) Moving from Institutions to the Community

Paralleling the rise of self-help in the 1970s, large numbers of patients were discharged from psychiatric hospitals only to find themselves adrift in uncaring communities: isolated, lonely, and lacking meaningful relationships (Campbell & Schraiber, 1989; Baker & Intagliata, 1984). Limited financial resources restricted their social activity. The media's frequent portrayals of persons with mental illness as dangerous validated community rejection. Prejudice and discrimination polluted public and private spaces. Community and mental health professional stereotyping altered the quality and spontaneity of interpersonal relationships as negative attitudes were internalized (Reidy, 1994; Campbell & Schraiber, 1989). Zinman wrote, "For us as people, we have internalized the dehumanizing stereotypical images propagated by our families, the mental health system, and society at large" (1987, p. 8).

As some consumers/survivors reacted with dissatisfaction to professional mental health treatments and services, they began to seek the company of their peers for validation and support. Lack of understanding, respect, and trust between mental health consumers and professionals prompted some consumers/survivors to reject both clinical and rehabilitation programs and to develop peer-run alternatives. Small groups of people with mental illness began meeting in larger East and West Coast cities. Like other self-help

movements, they shared a 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 (Van Tosh, Ralph & Campbell, 2000). It was often the first opportunity for individuals with mental illness to gather by themselves to provide each other with social support, validation, knowledge exchange, and to provide a forum for community organizing.

3) Organization of the Consumer/Survivor Movement

Early attempts at peer support were followed by the organization of patients' rights groups like the Insane Liberation Front in Portland, WA, and the Mental Patient's Liberation Project in New York City. These were civil rights activist groups (Van Tosh, Ralph & Campbell, 2000; Chamberlin, 1988, 1990) following the tradition of the movements of Blacks, women, and gays in the 1960s and the 1970s. "We are like colonized people, struggling to be free, to reclaim from psychiatry ownership of our lives. We are fighting for autonomy," explained Zinman (1987, p. 7). Activities included organizing support groups, advocating for hospitalized patients, lobbying for changes in laws, public speaking, publishing newsletters, and developing creative and artistic ways of dealing with the mental patient experience (Chamberlin, 1990).

SAMHSA provides impetus to the movement

In 1977, the Community Support Program (CSP), now located within SAMHSA's Center for Mental Health Services (CMHS), provided further impetus to the growing consumer/survivor movement through a variety of initiatives. In the mid-1980s, CSP provided resources for the publication of technical assistance materials and for information on consumer/survivor self-help. In 1985, CSP sponsored the first national conference of consumers, entitled *Alternatives* in Baltimore, MD. It was the beginning of an annual gathering that has attracted a large number of individuals coming together to share information, discuss important issues and provide technical assistance.

From 1988 to 1991, CMHS supported 14 service demonstration projects designed to implement and evaluate consumer-operated peer support services including drop-in centers, outreach programs, businesses, employment and housing programs, and crisis services (Van Tosh & del Vecchio, 2000; Kaufmann, Ward-Colasante, & Farmer, 1993; Mowbray & Tan, 1992; Lieberman, Gowdy, & Knutson, 1991).

In a study of 104 self-help groups, Emerick (1990) classified groups based on structure, affiliation, and service model along an ideological continuum—from radical separatist groups such as The National Alliance of Psychiatric Survivors, to conservative groups that allowed professionals to act as leaders in partnership with consumers/survivors such as Recovery Inc. and Emotions Anonymous. Social movement and individual therapy were found to be the two major service models. The social movement groups offered legal advocacy, public education, technical assistance, and information-referral networking. Individual therapy groups offered more "inner-focused" individual change through group support meetings.

Nothing About Us Without Us

Throughout the 1990s, people with mental illness began to organize on a national level. Consumer voices had become empowered and strengthened by championing the South African disability motto “Nothing About Us, Without Us” (Chamberlin, 1990). Groups opposed traditional mental health system treatments such as day treatment, involuntary commitment, forced drugging, and the use of seclusion and restraints, but they also began to emphasize concepts such as “service recipient,” choice, and treatment “partnerships” of clinicians and clients within the mental health system. Some consumer/survivor leaders started to advocate for consumer inclusion in the administration, provision, and evaluation of mental health services as a tool of system reform (Campbell, 1996, 1997b; Campbell & Johnson, 1995; Campbell, Ralph & Glover, 1993; Scott, 1993).

The transformation of the healthcare delivery system to a managed care environment during this period also produced unintended opportunities for mental health consumers to gain responsibility for making decisions in the medical marketplace as customers/consumers.

4) Growing Support of Consumer Inclusion and Concepts of Recovery

In 1989, the National Association of State Mental Health Program Directors (NASMHPD) approved a position paper that “recognizes that former mental patients/mental health consumers have a unique contribution to make to the improvement of the quality of mental health services in many areas of the service delivery system.” It recommended that consumer contributions be valued and sought in areas of program development, policy formation, program evaluation, quality assurance, system designs, education of mental health service providers, and provision of direct services.

Over the past two decades, mental health consumers/survivors have built a national presence within the public mental health sector, with growing numbers now participating in research and evaluation (Van Tosh, Ralph, & Campbell, 2000) and taking leadership roles in policy and administration of public mental health services (McCabe & Unzicker, 1995). Some professionals and policymakers responded to consumer inclusion by redesigning professional roles and creating opportunities for people who receive services to provide input and perspective. For instance, in 1993 consumer-practitioners and psychiatrists engaged in a dialogue in New York regarding coping strategies and recovery from mental illness (Blanch, Fisher, Tucker, Walsh, & Chassman, 1993).

A vibrant collaboration between consumers and providers

Expanding peer support services on the local, state, and national levels indicates the blossoming of a vibrant culture of collaboration between consumers and the traditional mental health service delivery system. The proliferation of offices of consumer affairs has brought the vision of recovery and the recognition of the important role of peer support to state mental health agencies. An office of consumer affairs is a department

within a state mental health agency that ensures consumer and family views are included in policy making, while also ensuring that client rights are respected and protected. In addition, statewide consumer networks such as Peer Recovery Network of West Virginia, Iowa P.E.E.R.S. Network, California Network of Mental Health Clients, and the Vermont Psychiatric Survivors, Inc. are building peer support within their memberships by developing local groups, conducting assessment, service planning, linkage and referral, skills training, and education, crisis prevention, and advocacy.

To further the development of consumer involvement and self-help programs, in 1992 CSP provided funding to launch the National Mental Health Consumer Self-help Clearinghouse (NMHCSC) in Philadelphia, and the National Empowerment Center (NEC) in Lawrence, MA—the first national self-help technical assistance centers directed by and for mental health consumers. In 1998, CSP expanded to include the Consumer Organization and Networking Technical Assistance Center (CONTAC) in Charleston, WV.

The Clearinghouse

The Clearinghouse in Philadelphia helps consumers organize coalitions, self-help groups, advocate for mental health reform and fight stigma. It has a library of publications and materials available to send to consumers including information on self-help and advocacy, fund raising, peer counseling, involuntary treatment, patient rights, and working with the media. The center also provides referral services and counseling for consumer groups.

National Empowerment Center

NEC provides information on recovery, advance directives, shock treatment, schizophrenia, self-help groups, legal services, meditation, and other topics of interest to consumers. The organization features a toll-free line and has a Spanish-speaking specialist available to make referrals.

CONTAC

The Consumer Organization and Networking Technical Assistance Center (CONTAC) was developed utilizing research on ideal consumer self-help programs, successful consumer-run programs, community support philosophy about service delivery, descriptions of mature mental health systems, and management and leadership skills. CONTAC has been structured to provide four levels of technical assistance to: 1) peer support groups; 2) peer outcome orientation; 3) training for statewide networks; and 4) information sharing. CONTAC also established CONTAC del Oeste, a bilingual center, to meet the needs of populations in the western United States and to focus on Hispanic consumers.

During the past thirty years, peer support programs have been transformed from alternatives with little or no connections to traditional mental health services to service partnerships with multiple and varied relationships with mental health professionals. Today, mental health agencies employ consumers in designated positions to provide peer services such as case management or crisis intervention (Arntsen, Greenfield, Harris, & Sundby, 1995). Peer support services are also offered as part of an array of services designed and delivered through a traditional mental health agency, and staffed with mental health consumer/survivors who share administrative and fiscal authority with non-consumers (Solomon & Draine, 2001).

Most peer support programs still remain autonomous from professionally run organizations and are solely staffed by mental health recipients with decision-making and service delivery responsibility shared among the membership. However, they do enter into collaborative service relationships within the continuum of community care. In most instances, the partnering of peer-run support programs and professional services has not been formalized, but is maintained through ad hoc or informal relationships. For example, peer group members appear to make notable use of the mental health system, receiving approximately seven mental health services in a year with about half taking psychiatric medications (Chamberlin, Rogers, & Ellison, 1996).

Peer Support Member Characteristics

Although there is little empirical data describing the basic characteristics of people who use peer-run support groups, Segal, Silverman, and Temkin (1995a) surveyed 310 long-term members of four peer-run support programs in the San Francisco Bay area on their characteristics and service use. These programs were found to serve a primarily African American population (64%), many who were homeless (46%). Fifty percent of the persons served had a dual diagnosis with moderate to severe substance or alcohol abuse. They reported seeking help for resources such as food and clothing and “a place to be.” Chamberlin, Rogers, and Ellison (1996) found that the peer-run support programs they surveyed served a largely middle-aged, single or divorced, male, white population, with over a third of the membership African American. Most had a high school diploma, were unemployed and/or had a monthly income of less than \$600, and lived in a private home or apartment. They participated in self-help more than 15 hours a week, and had been involved in self-help almost five years.

Peer Support Program Characteristics

Although the goals of most groups are to: 1) provide a safe, supportive community environment; 2) provide an atmosphere of acceptance; 3) promote self-worth, dignity, and respect; and, 4) increase knowledge by learning from one another (Tan, Mowbray, & Foster, 1990), not all peer support groups and organizations offer the same programs, structure, philosophy, or cater to a homogenous consumer or family membership. Zinman (1987, p. 13) observed that “a self-help group can take many different forms; its parameters are limited only by the desires, energy, and possibilities of its members.”

Some groups or organizations receive their support from charitable foundations, private donations, and membership fees, while others are funded through federal agencies such as SAMHSA, state departments of mental health, offices of vocational rehabilitation, or county health boards. Total operating budgets range from a few thousand dollars per year, to several million dollars. Staffing also ranges from a single person to organizations with hundreds of employees. Most consumer-run programs have a significant contingent of volunteers to supplement the work of paid staff.

Peer support involves a wide range of services and there are many program models of service delivery. Within this diversity of peer support services, common elements can be found. They include: 1) a focus on recovery and empowerment; 2) opportunities for members to tell their stories to other peers and to wider audiences; 3) belief that recovery is possible; and 4) the support of peers who believe in recovery (which then fuels the process of intentionally living life on one's own terms).

The Central Importance of Empowerment

Since the beginnings of peer support, consumer providers have asserted that help is best received when the receiver has direct control over the help and there is reciprocity

“I have found a new me. I now make all my decisions and do not depend on any one person for much of anything anymore.”
— Linda J.

between help givers and receivers (Chamberlin, 1988; Zinman, 1987). When studied in peer-run self-help agencies (Segal, Silverman, & Temkin, 1995b), empowerment connotes a process of gaining control over one's life and influencing the organizational and societal structures

in which one lives. It may include gaining new resources or competencies such as the capacity to help others, group leadership skills, and organizational leadership abilities (Rappaport, Reischl, & Zimmerman, 1992).

However, empowerment in any context cannot be bestowed by those with greater power upon those with less. Peer programs empower people because their practice facilitates a grass-roots process (Chamberlin, 1990; Zinman, 1987; Segal, Silverman, & Temkin, 1993) of self-efficacy, self-esteem, and the belief that positive personal change can come about through one's own efforts. Through personal narrative, consumers also combat societal stereotypes and rebuild a sense of identity (Mead, Hilton, & Curtis, 2001; Skillman-Campbell, 1991). Consumers learn to act on their own behalf, and to advocate for the rights of others (McLean, 1995). Peer programs have formalized this process by creating mentoring roles for staff to speak openly about their personal struggles and use their own experience to provide encouragement and technical assistance to other members (Salzer & Liptzin-Shear, 2002). Peer support programs exist in a variety of forms:

- ◆ **Mutual support groups**, such as the Depression and Bipolar Support Alliance, have chapters located throughout the United States that typically consist of

individual or group-based assistance and encouragement organized around empowerment and recovery. Some groups offer peer support to a heterogeneous membership, while others reach out to particular consumers based on a specific diagnosis or ethnicity. For example, Double Trouble in Recovery, Inc. offers mentoring and fellowship based on the 12-Step philosophy of Alcoholics Anonymous for dually-diagnosed people with addictive substance use problems as well as mental disorders. Friends Connection, located in Philadelphia and Norristown, PA, provides friendship, counseling and meaningful leisure activities for this population. In general, they are based on small group dynamics (one person talking *with*, never *down to*, another) with members helping each other manage a range of personal concerns such as psychiatric symptoms, prejudice and discrimination, work, housing, health, and personal relationships.

Such groups differ from naturally occurring social support since the process is intentional and includes “standard procedures, routines, and prescriptions for addressing problems and issues of everyday life” (Davidson, Chinman, Kloos, Weingarten, Stayner & Tebes, 1999, p. 168). Mutual support groups expose members to successful role models and offer information on coping strategies and survival skills (Kaufmann, Freund, & Wilson, 1989; Keogh, 1975; Rootes & Aanes, 1992; Stewart, 1990), and present an alternative worldview to assist persons in making sense of their experiences (Chamberlin, 1988; Kennedy & Humphreys, 1994). Reissman (1965, 1990) identified this shift in roles as the “helper therapy principle.” Through structured social interaction, people provide feedback and assistance to others and receive support for their own efforts to address problems. By assuming socially valued identities, they are no longer restricted to passive patient roles relying solely on mental health professionals for direction and advice (Roberts, Luke, Rappaport, Seidman, Toro, & Reischl, 1991).

- ◆ ***Peer-run multi-service agencies***, such as CHOICE of New Rochelle, Inc. in New York, encourage and support persons with mental illness who have been underserved and who require assistance to obtain vital services through peer advocacy (Trainor, Shepherd, Boydell, Leff, & Crawford, 1997; Chamberlin, Rogers, & Ellison, 1996), outreach (Lieberman, Gowdy, & Knutson, 1991), case management (Nikkel, Smith, & Edwards, 1992) and related services. Such agencies function as an open door to the mental health system—they pose few pre-requisites for service, and usually charge no fees. Each service has a different focus, but they all complement each other by having the same basic goal of teaching people how to find and use community resources.
- ◆ ***Peer-run drop-in programs*** (LeDoux, 1997; Silverman, 1997; Meek, 1994; Mowbray, Wellwood, & Chamberlain, 1988), such as the Mental Health Client Action Network in Santa Cruz, CA and the St. Louis (MO) Empowerment Center, are also multi-service agencies that provide an open venue for consumers to receive a variety of services within a centralized location. Individuals participate in activities on a voluntary, non-coercive basis. Service components may include

support and activity groups, access to telephones, laundry facilities, and computers, as well as assistance with entitlements, medication education, clothing, bus or transportation passes, and assistance with moving. Many have an educational component that teaches members problem-solving skills (Silverman, 1997), coping skills, wellness, available services, consumer rights and other advocacy issues, leadership skills, and the nature of mental illness itself (Copeland, 1997; Diehl & Baxter, 1999).

- ◆ ***Specialized Supportive Services*** tend to focus on a single issue. The Collaborative Support Programs of New Jersey, Inc. addresses the problem of inadequate housing and homelessness (Silverman, 1997; Besio & Mahler, 1993; Long & Van Tosh, 1988). Stepping Stone, in Claremont, NH, provides crisis management (Dumont & Jones, 2002; Mead & Hilton, 2001; Prout, 1997). Unemployment issues (Kaufmann, 1995) are the focus at the Advocacy Consumer Training for New Opportunities to Work (ACT NOW) in Philadelphia and Darby, PA.

Supportive housing programs link affordable housing to supportive services, assisting people to live stable and independent lives in community settings. Groups of consumers/survivors may form an organization to purchase and maintain safe, affordable housing. Others may help individual recipients of mental health services choose and maintain independent housing by working with the recipient and their traditional service provider to offer flexible personalized assistance.

Supportive employment programs emphasize competitive employment and provide a place for consumers to gain skill and confidence, educate themselves about work and disability, and get help over the course of a career. Supportive education encourages people with psychiatric problems to enter or re-enter college or technical school programs. Services include academic and career counseling, assistance obtaining financial aid, study skills, stress control, and tutoring/coaching. Crisis intervention is provided in an informal, non-clinical environment where people can stabilize with the help of peer counselors (Dumont & Jones, 2002; Burns-Lynch, & Salzer, 2001).

- ◆ ***Peer-run education and advocacy programs***, such as BRIDGES in Tennessee; PEOPLE, Inc., in Poughkeepsie, NY; and the Recovery Education Center in Phoenix, AZ, are based on the belief that consumers are best able to address their own recovery needs and to advocate for change within the mental health system when they have accurate and comprehensive knowledge about mental illness, psychiatric services, and strategies to support wellness. Education and advocacy programs use well-defined curricula, sometimes in short-term classroom settings. Participants have commented that this knowledge enables them to make choices and begin to regain control over their lives (Trainor, Shepherd, Boydell, Leff, & Crawford, 1997). In addition, these programs often provide mutual support, supported housing, supported employment, and respite services.

Some consumers have become independent educators who have developed training curriculum on recovery. Mary Ellen Copeland of Vermont offers the Wellness Recovery Action Plan (WRAP), and New Hampshire's Shery Mead has developed the Crisis Respite Training Program for trauma-informed peer supports. They both provide technical assistance, manuals, consultation, and training classes for peer support programs throughout the United States.

Research Evidence Supports Peer-Run Services

Two recent reviews of the literature (Davidson, Chinman et al., 1999; Solomon & Draine, 2001) identified preliminary evidence to support the effectiveness of peer-run support services. Most studies have been descriptive or qualitative, seeking to identify the characteristics of people who choose to participate in these programs, the processes that lead to change, and the service recipient's perspective on benefits of program participation (Chamberlin, Rogers, & Ellison, 1996; Segal, Silverman, & Tempkin, 1995a; Kaufmann, Schulberg, & Schooler, 1994; Mowbray & Tan, 1993).

Social support trumps isolation

There are many reasons why people with mental illness seek out peer-run support services. Campbell and Schraiber (1989) found that 38% of mental health recipients surveyed in California (N=331) felt safe talking about personal matters or their innermost feelings to peer counselors and people in self-help groups. Thirty-two percent reported that they call or see a self-help group if they are having emotional or psychological problems. In research on six peer-run drop-in centers in Michigan, Mowbray and Tan (1992) identified social support as the dominant reason consumers attended.

Mental health improves and symptoms decrease

Studies on the perceived benefits of peer-run support services use pre-post and quasi-experimental group designs. For example, research using nonrandomized control groups or pretest scores as comparisons has shown that participation in these services yields improvement in psychiatric symptoms and decreased hospitalization (Galanter, 1988; Kennedy, 1990; Kurtz, 1988), larger social support networks (Carpinello, Knight, & Janis, 1991; Rappaport, Seidman, Paul, McFadden, Reischl, Roberts, Salem, Stein, & Zimmerman, 1985), and enhanced self-esteem and social functioning (Markowitz, DeMassi, Knight, & Solka, 1996; Kaufmann, Schulberg, & Schooler, 1994). In studies of persons dually diagnosed with serious mental illness and substance abuse, Double Trouble in Recovery was found to significantly reduce substance abuse, mental illness symptoms, and crisis (Magura, Laudet, Rosenblum, Vogel, & Knight, in press; Magura, Laudet, Rosenblum, & Knight, 2002).

Communication with providers improves

In an evaluation of over 1,000 members participating in the Depression and Bipolar Support Alliance (DBSA), 95% of those surveyed described their groups as helping with

communicating with their doctor, being motivated to follow instructions, and being willing to take medication and cope with side effects. There was a statistically significant tendency for people who had been attending DBSA groups longer to report experiencing fewer depressive and manic symptoms. Those who had been attending for more than a year were less likely to have been hospitalized in the same period (Lewis, 2001).

The evidence base continues to expand

Researchers have begun to conduct randomized, controlled studies on outcomes and service costs in order to expand the evidence base for peer-run programs.

Crisis Hostel Project. A National Research Demonstration Grant funded by the Center for Mental Health Services developed and operated the Crisis Hostel, a five-bed residence operated as an alternative to psychiatric hospitalization, and evaluated the outcomes for 265 study participants having or not having access (Dumont & Jones, 2002). Those with access had better healing outcomes and greater levels of empowerment than the comparison group. The researchers reported that those who used the Crisis Hostel felt that crisis services were more timely and useful than did persons receiving traditional mental health crisis services. Hospital stays were also shorter which resulted in lower service costs overall when compared to the control group.

Consumer-Operated Services Program. In 1998, CMHS funded the Consumer-Operated Services Program (COSP) Multisite Research Initiative to study the cost effectiveness of existing consumer-operated service programs for adults with serious and persistent mental illness when offered as an adjunct to traditional mental health services. The four-year, randomized, controlled trial of 1,827 participants from eight peer programs is currently analyzing their baseline characteristics and longitudinal changes in well-being, recovery, empowerment, housing, employment, social inclusion, and satisfaction with services, as well as costs and cost offsets. In addition, the study developed and implemented a fidelity assessment tool (FACIT) to identify and evaluate the implementation of peer service components.

Research further suggests that healthcare is most likely to improve when interventions change organizational structure and/or activate and empower consumers (Stone, Morton, Hulscher, Maglionne, Roth et al., 2002). However, staff often have negative attitudes about adopting behavioral innovations for their programs (Corrigan, McCracken, Edwards, Kommana, & Simpatico, 1997). Consumers and researchers have identified the need to improve provider knowledge and behaviors in areas such as empowerment and recovery in order to encourage a shift toward rehabilitation strategies. Drake et al. (1996) attributed the success at converting treatment programs to individual job placement and support programs to the development of a peer support center and to the training of the staff in recovery-based practices. To further test this outcome, a two-pronged intervention was designed to increase the use of self-help programs and mental health empowerment competencies. The interventions were implemented on a system-wide level in a managed care setting through provider education and consultation. A series of five trainings for staff—plus support and technical assistance to facilitate the formation of self-help

agencies—was provided in one state, with another state serving as a comparison (Chinman, Forquer, Knight, Miller, Vogel, & Young, 2002). Both quantitative and qualitative data show that staff attitudes and behaviors in the experimental group were changed in 8 of the 15 provider competencies assessed. Data also suggested that consumers assumed more responsibility for treatment, management was more supportive of rehabilitation, more support existed for self-help groups among providers, and more consumers attended self-help groups.

Emerging New Practices in Peer Support

It is critical that the role community-based peer support systems play in the rehabilitation of persons with psychiatric disorders be rigorously defined and the functions and competencies of peer providers be established. Consumer-operated service providers have just begun to address the fact that people who provide peer services are not uniformly trained to meet certain performance standards. They are not evaluated on their mastery of peer-support skills and, most important, they do not receive professional certification. Valid, reliable skill assessment tools and training protocols that are both appropriate and flexible are essential if peer support programs are to continue to grow beyond current operations through partnerships with traditional mental health provider agencies.

The lack of certification programs and accreditation agencies for peer providers, combined with a scarcity of resources and tools for management information system evaluation, places peer providers at a disadvantage when competing for funding or billing under Medicaid. The support and adoption of emerging new practices in peer support services like the ones described below enables peer providers to systematically improve the quality of their workforce and the programmatic elements of their services. It aids them to stabilize funding and become more effective peer support providers as they reach out to build an ever-expanding culture of recovery through peer support.

Innovative Consumer-Developed Training Programs

A.) Wellness Recovery Action Plan (WRAP)

Utilizing standardized curricula and facilitated by peer support specialists, recovery training developed by Mary Ellen Copeland is being offered in many peer support programs. In August 1995, the Vermont commissioner of the Department of Developmental and Mental Health Services (DDMHS) established a programmatic priority for the development of recovery-oriented services in the adult mental health service system. One of the major strategies of this programmatic priority was the establishment of a Recovery Education Project based on Copeland's work and modeled after a New Hampshire program. After one year of piloting recovery education activities, Vermont Psychiatric Survivors (VPS), with the assistance of DDMHS, received a grant from the Henry van Ameringen Foundation to teach recovery skills and practices to citizens with psychiatric disabilities, their family members, and professional support providers. Recovery in this context means finding hope, developing a personal understanding of the experience of mental illness, developing the skills and knowledge to support one's own wellness, and—in some cases—full recovery.

Eight-day recovery programs were held in three areas of the state. Using three educational formats (Recovery Education Cycles, Recovery Education Events, and Training of Recovery Educators), this project provided a statewide focus on hope,

personal responsibility, self-advocacy, education, and support. The educational program was designed to:

- ◆ Teach individuals who experience psychiatric symptoms, their family members, supporters, and health care professionals how to reduce or eliminate psychiatric symptoms safely, simply, and effectively on a daily basis, and how to get well and stay well. These skills are taught complementary to, and not exclusive of, other treatments, including medication and rehabilitation supports.
- ◆ Teach peers (others who have experienced mental illness) who have attended a Recovery Education Cycle to become Recovery Educators using a variety of formats to network and teach recovery skills intensively to people in their geographic region.

Core concepts of the recovery curriculum

Having a crisis plan. The Recovery curriculum teaches that disabling symptoms of mental illness can be anticipated and avoided or alleviated using specific skills, tools, and support. In some instances, this can lead to a full recovery from one's illness. In traditional mental health services, consumers have typically been placed in a passive stance of receiving treatment for their symptoms from professionals. In the Recovery cycles, participants begin to take an active part in managing their mental illness. They learn how to recognize their own early warning signs/symptoms; identify specific skills and tools to cope with symptoms; and create a crisis plan that lists their supporters, expresses their needs and wishes, explains their symptoms and early warning signs, and incorporates daily routine tools for staying well.

Through the development of an individualized Wellness Recovery Action Plan, participants develop an understanding of the entire spectrum of illness, identify potential skills to maintain wellness and manage symptoms, and begin to incorporate these wellness tools into a daily routine. This process enables participants to take responsibility for their own recovery process.

Education and Self-advocacy. The Recovery Education curriculum stresses the central importance of education and self-advocacy in recovery. By learning about mental illness and the services, supports, and treatment alternatives that are available, individuals can make better decisions about how to manage their illness. As individuals gain confidence in their ability to advocate for themselves, learn about their rights, and understand the types of treatment and support that are available, they are more capable of expressing and receiving the support they need.

A Strong Support System. Developing and using a strong support system is another key component of the Recovery curriculum. It stresses that support from family, friends, and healthcare professionals is essential, and that effective support can help to prevent or relieve symptoms. In addition, supporters can also be utilized when individuals feel their symptoms are severe enough that someone else needs to make decisions or follow

predetermined plans on their behalf. In this manner, individuals are proactively planning a support system in the event they become acutely ill.

Transformation in the Vermont mental health system

The Recovery Education Project has caused a major shift in how people think about mental illness in Vermont. A significant number of participants reported feeling more hopeful about their own recovery process. In the past, providers were so busy trying to eliminate symptoms with medication and professional support that people with a mental illness passively received treatment. Despite an ideological commitment to empowerment over the past decade, Recovery Education was one of the first hands-on models in which consumers could actually take an active role in their own recovery process. This represented a major shift in how professionals thought about their role as well. Instead of applying treatment to their clients, their clients actually learned the skills and knowledge to understand and manage their own symptoms and make decisions about the supports they receive. With the development of WRAP, consumers could make proactive decisions about their care and support in advance of times when they might not be able to make those decisions for themselves. With these changes, consumers are now becoming equal participants in managing their own recovery process.

Within the provider system, many professionals have shifted their thinking on mental illness, no longer seeing it as a chronic disease that will last a lifetime. Providers are attending Recovery Cycles, public presentations, and conference workshops taught by people who are living proof of the ability to manage and even recover from mental illness. This has helped providers learn new ways to assist clients and gain a fresh sense of hope about the scope of recovery possibilities for their clients.

Both Vermont Psychiatric Survivors and the Department of Developmental and Mental Health Services are committed to continuing and expanding the Vermont Recovery Education Project. WRAP has been replicated in Kentucky, Oklahoma, Kansas, Arizona, and in many regional centers. Several other states are developing similar plans. In addition, 50 trainers from across the country are now teaching in hospitals, mental health centers, community support programs, peer support centers, support groups, and at public forums.

B.) PACE (Personal Assistance in Community Existence)/Recovery Program

The PACE/Recovery Program is based on the principles of recovery, peer support, empowerment, and self-help. It offers an approach centered in the Empowerment Model of recovery. This model is based on research carried out at the National Empowerment Center (NEC) to establish 13 principles of recovery. Many of these principles highlight the importance of provider attitude change. Individual PACE workshops and curricula are designed to shift the culture of mental health care from maintenance, to recovery and hope (Ahern & Fisher, 2001a; Ahern & Fisher, 2001b). The PACE/Recovery Program and WRAP are complementary. For example, WRAP focuses on steps that the individual labeled with mental illness can take, while the PACE/Recovery program shifts the thinking of all stakeholders by creating a recovery culture. The developers of

PACE/Recovery have found that in order for individuals to take a more active role in their recovery through a program such as WRAP, they and the people helping them need to first believe that they can recover. Most people with mental illness have been told that their condition is life-long and that only professionals can maintain their care. Accordingly, PACE/Recovery presents evidence that mental illness is not a permanent condition and in so doing shifts the culture of care to the hope of recovery.

The model stresses that it is critical that helpers believe in the whole person. They must be able to establish trust, encourage self-determination, and find meaning in a person's expressions of distress. Research has shown that 66% of people who have learned the PACE/Recovery program have become more hopeful that they and/or the person they are helping will recover. This research has shown that PACE/Recovery encourages participants to start new peer support programs that assist in consumers' integration into the community (Zahniser & McGuirk, 2002).

C.) B.R.I.D.G.E.S.—Building Recovery of Individual Dreams and Goals through Education and Support

A program of the Tennessee Mental Health Consumers' Association, B.R.I.D.G.E.S. maintains that participants are empowered through psychoeducation and peer support to recover a structured sense of self, and to find new meaning in their lives. In the process of learning about mental illness, participants are able to put symptoms into the background, work toward life roles of their choosing, and begin to make changes in their social environment. The philosophy of B.R.I.D.G.E.S. is based on three major constructs: empowerment, recovery, and psychoeducation.

The BRIDGES program consists of a 15-week course on dual recovery that is taught by consumers and an ongoing support group. There are three components to the course including: 1) the concept of recovery; 2) technical information on mental illness (along with best practices and treatments so consumers are knowledgeable about these and can approach providers); and 3) self-help skills.

D.) SC SHARE: Recovery for Life Program

Established in 1985, SC SHARE (Self Help Association Regarding Emotions) is a statewide, non-profit, consumer-run organization committed to helping people help themselves through advocacy, education, recovery programs, and support groups. Its mission is to offer recovery support by developing and maintaining a network of self-help groups for people with mental illness. In 2000, SC SHARE developed a workbook entitled *Recovery for Life* with ten lessons on defining recovery, overcoming obstacles, setting boundaries, goal setting, managing stress, preventing relapse and fine-tuning one's recovery program. With federal support, the organization introduced the book to 45 consumers in a three-day workshop. Participants were provided the opportunity to take what they had learned back to their community and to introduce the workbook. SC SHARE also trained clinical staff in 17 mental health centers and four psychiatric hospitals. Consumers could then lead groups, have clinicians sign off on the groups, and bill Medicaid. Currently, SC SHARE has 63 support groups and has paid out

approximately \$17,000 in recovery group leader fees. After completing the workbook, groups receive a Group Journaling Book to assist in the continuation of support groups.

E.) The Leadership Academy: Training Consumers/Survivors for Positive Advocacy (CONTAC)

Significantly involving people who use mental health services in policymaking, service provision and research is essential to the development of a recovery-based system of services. Though many consumers/survivors have the skills to identify their needs and express opinions in a clear, positive and assertive manner, they may benefit from assistance in assuming positions of strong leadership and advocacy participation. As consumers become proficient with advocacy skills, they are better able to make an impact in planning and provision of mental health and support services.

As initiated and evaluated in Idaho and further developed in West Virginia, the Leadership Academy is structured to build skills, honor strengths, and encourage positive advocacy. It is tailored for and delivered by consumers. It is an ongoing results-oriented program that supports recovery for individuals. It consists of two basic elements—structured 3-4 day training events, and follow-up networking activities designed to reinforce learning and support application (Sabin & Daniels, 2002). Leadership and advocacy skills are taught through discussion, the use of workbooks, small group exercises, and role-playing. Participants actively practice leadership skills by leading mock meetings, writing action plans, writing letters, and making group presentations.

Hess, Clapper, Hoekstra, and Gibson (2001) reported that effectiveness of the Leadership Academy was measured according to the number of mental health advocacy actions and outcomes accomplished by Academy participants. Over a 27-month period, participants initiated 1,345 advocacy actions, and achieved 400 advocacy outcomes ranging from the establishment of a speakers bureau to starting a respite facility. The highest level of work occurred in the areas of community education and improving services.

Over the past four years, CONTAC has conducted Leadership Academies in Colorado, Florida, Kentucky, Maine, Massachusetts, Nebraska, Nevada, New Jersey, New Mexico, North Carolina, Oklahoma, Pennsylvania, Texas, Virginia, and West Virginia.

F.) Peer Support and Crisis Respite Training

Shery Mead Consulting provides on-going training for many organizations on peer support and crisis respite by providing personal and relational tools that take context, meaning and power into consideration. Her training begins by building an understanding of culture and the development of a worldview to enable participants to think critically about support and listening as processes that must be mutually transforming. The impact of trauma and abuse on self-concept and relationships is introduced through an exploration of patienthood. One day is devoted to proactive training that provides respite workers with the skills to help potential guests design a crisis plan. The plan is then used to guide their respite stay at the program. Emphasis is placed on first contact as a time to model alternative behaviors, and to start conversations around recovery and mutual

responsibility. Finally, the notion of conflict as a learning process is introduced through a discussion about specific types of situations that often cause people discomfort, and the use of examples to point out how one's own discomfort often leads to taking power and control. The final training activities teach participants to be reflective about what constitutes knowledge as they build a common understanding of what works. Aside from standard evaluation reporting formats, participants are invited to use video, poetry, plays, and stories to make the information accessible on both academic and emotional levels.

Using Program Manuals to Disseminate Promising Models

Program materials that provide sufficient information for practice replication are often called manuals and they evolved to improve the internal validity of psychotherapy outcomes studies. There is evidence that adherence to certain empirically supported, manual-based treatments can be associated with positive outcomes (Addis & Krasnow, 2000). Besides enabling replication, manuals specify treatment components and facilitate the monitoring of treatment fidelity and integrity. Developing manuals for peer support program models has also played an important role in facilitating consumer advocacy for peer support services and guiding the establishment of such services. For example, the Tennessee program, B.R.I.D.G.E.S., has an extensive manual that has enabled the program to be replicated in eight states and Vancouver, British Columbia.

New Thinking about Financing

Unfortunately, peer support services are often funded through time-limited special project grants. The lack of solid, ongoing funding for such programs deters stability and the development and testing of evidence-based practices. One approach to support peer-run programs is through partnership with a behavioral managed care company in which self-help processes are integrated into the routine of care to fulfill cost containment and improved outcomes goals (Forquer & Knight, 2001).

Another way to fund the array of community-based peer support services is to use federal dollars available through the Medicaid rehabilitation option. In the past, states have sometimes missed opportunities to support flexible, individualized, consumer-driven services, resulting in less-than-optimal care for people on Medicaid and additional expense for the state (Koyanagi & Semansky, 2001). Consumer-run peer programs can offer Medicaid-covered rehabilitation services if they meet certain standards while providing skill-building, assistance with problems, or other services beyond simply sponsoring social events.

Some states such as Georgia have begun to cover peer-support services for adults under the Medicaid community-based optional services for rehabilitation (Sabin & Daniels, 2003). However, some peer support programs are encountering eligibility barriers because they lack the administrative infrastructure for peer staff certification, program accreditation, training manual development, and program evaluation.

Curtis et al. (1991) have suggested that mental health systems set a target percentage of total mental health system funding for peer-support programs. In Wisconsin, a portion of the block grant was permanently earmarked for consumer/survivor and family peer support activities. In the past few years, a broad-based stakeholder panel supported in part by the Center for Mental Health Services has recommended establishing a 5% carve-out of state mental health funds for peer support programs by 2005 and is currently developing materials to advance this proposal.

Colorado Health Networks

In 1995, as part of the implementation of the Colorado Health Networks, an equal partnership between ValueOptions—a national behavioral health managed care company—and eight community mental health centers, recovery, and self-help programs was integrated into the continuum of community care through the introduction of self-help tools and techniques. Colorado Health Networks created more than 70 self-help groups and four consumer-operated drop-in centers. In an evaluation of the impact of the Colorado managed care capitation project, researchers found that suicide rates and substance abuse decreased significantly with a corresponding increase in participants' ability to carry out activities of daily living (Forquer & Knight, 2001, p. 26). According to the former executive director of Colorado Health Networks, and Dr. Ed Knight, consultant with ValueOptions, "self-help and recovery represent the best utilization management strategies we have today."

Georgia Peer Supports as a Medicaid rehabilitation option service

In 1999, the Georgia Medicaid authority approached the Georgia Division of Mental Health, Developmental Disabilities, and Addictive Diseases (DMHDDAD) with concerns about accountability in service delivery. They were unhappy with the stagnation of services and encouraged the DMHDDAD to work with them to restructure services and other design aspects of the delivery system. Among the many recommendations agreed upon by the two agencies was a proposal to redesign traditional day treatment services for adults with mental illness.

At that point, almost 7,000 consumers were receiving day treatment services without a mandate for the use of recovery and rehabilitative principles. The DMHDDAD had the benefit of persuasive input from the Georgia Mental Health Consumer Network working in conjunction with DMHDDAD's Office of Consumer Relations. The group proposed an idea for peer-led services, and the DMHDDAD formulated a plan for services that would be led by professional consumers, and yet would meet all the parameters of a Medicaid-financed service. In discussions with the Medicaid authority, it was determined that the state should shift its delivery practices from the Medicaid Clinic Option to the Rehabilitation Option in order to better facilitate the promotion of rehabilitation principles. Negotiations through the state plan process with the federal Medicaid agency yielded results, and in July 1999 service delivery began with a new Peer Supports service as well as other more recovery-focused day services. Georgia has the distinction of being the first state to gain approval from the Centers for Medicaid and Medicare Services

(CMS) to offer Peer Supports as a billable service in the state plan for Medicaid Mental Health Services.

In July 2001, the governor's office approached the DMHDDAD again about a system redesign to maximize state dollars devoted to services, but did not have a compatible Medicaid mental health code. As a part of that redesign, the DMHDDAD took the opportunity to raise the bar higher on the credentialing and certification of professional peer specialists.

Medicaid-reimbursable, peer-led support services provide structured, scheduled activities that promote socialization, recovery, self-advocacy, development of natural supports, and maintenance of community living skills under the direct supervision of a mental health professional. A Consumer Peer Support Center maintains adequate staff to foster a safe, structured environment in which consumers can meet and provide mutual encouragement.

The objective of a Peer Support Center—which is more comprehensive and includes additional funding mechanisms other than Medicaid—is to provide supports for consumers with mental illness or co-occurring mental illness and addictive disease to develop employment and life skills to enhance their efforts toward recovery. Skills are taught to increase consumers' resilience, illness management, and reduce the need to use more intense levels of service. Through Peer Support centers, consumers develop skills to go to work and the peer supports needed to help them retain their jobs. Consumers actively participate in decision-making and the operation of program supports. Scheduled activities include: meals and snacks, art and other recreational/leisure activities, educational seminars, informal and formal peer support meetings, and planning/feedback committees. Services promote socialization, recovery, self-sufficiency, self-advocacy, the development of natural supports, and maintaining skills learned in other support services.

Providers of peer support services must be accredited by a national accrediting body or be certified by the state through the DMHDDAD Office of Consumer Relations. Certified Peer Specialists are the professionals of choice providing this service, under the supervision of a mental health professional (MHP). Agencies are encouraged to employ a MHP who is a self-identified consumer in recovery. Across the state, peer support services are being provided in many locations, either as part of a core service, or within one of eight Peer centers. There are also 26 peer support programs that are operating as a part of a comprehensive mental health service provider agency.

Approval by CMS to bill Medicaid for peer support paved the way for a recovery-based system of care in Georgia. In the first three years, \$10 million was billed to Medicaid for peer support services with 3,000 consumers receiving those services annually. There are now more than 150 Certified Peer Specialists working for mental health providers statewide.

Certification and Accreditation

Certification fosters the growth of a qualified, ethical, and culturally diverse workforce through a test-based certification and/or licensing program and the enforcement of a code of ethics. States, Medicaid, Medicare and insurance companies are now requiring workers who practice rehabilitation functions in the community to be certified based on a comprehensive set of workforce competencies. The need for peer support to be recognized as a professional discipline is clear if the programs that employ consumers in helping roles are to be funded and the peer workforce is to be eligible for career benefits. Respect from within the mental health service community could also be a de facto result of certification.

Founded in 2001 by the International Association of Psychosocial Rehabilitation Services (IAPSRs), the Psychiatric Rehabilitation Certification Program is providing certification services for psychiatric rehabilitation professionals, including peer support providers. Applicants for the certification program must meet initial eligibility standards, submit an application, and pass a standardized written examination in order to earn the credential Certified Psychiatric Rehabilitation Practitioner (CPRP). This credential implies continued professional growth through education and adherence to the Practitioner Code of Ethics. There are a number of states such as Pennsylvania, Georgia, Maine, and Virginia that have incorporated the CPRP into their program and/or practitioner standards for providing psychiatric rehabilitation services.

While peer support providers are considered part of the rehabilitation workforce, the knowledge and skills needed to be a competent psychiatric rehabilitation professional could significantly vary from peer role delineation and, therefore, may not be a valid tool for assessing peer support competencies. Therefore, the Georgia Peer Specialist Certification Project is receiving increased attention nationwide.

Georgia Peer Specialist Certification Project

When Georgia was approved by CMS to bill Medicaid for peer support under the Mental Health Rehabilitation Option, a strong foundation for identifying the core competencies of peer providers, developing a training curriculum, conducting training, and certifying the peer workforce became a critical imperative for success. Georgia made an uncompromising commitment to train and certify a new wave of recovery agents called Certified Peer Specialists (CPS).

The CPS performs a wide range of tasks to assist consumers in regaining control over their lives and recovery process. Under supervision ranging from immediate to general, the CPS role models recovery, provides peer support services, teaches skills for coping and self-directed recovery, links consumers with natural supports in the community, and helps consumers determine personal recovery goals. The CPS then documents those goals and recovery progress in individual service plans. Also, the specialist provides consumer information and peer support for consumers in an emergency—in outpatient or inpatient settings.

The Georgia Peer Specialist Certification Project operating under the DMHDDAD Office of Consumer Relations identifies, trains, certifies, and provides ongoing support and education to consumers of mental health services to provide peer supports as part of the Georgia mental health service system, and to promote self-determination, personal responsibility, and empowerment inherent in self-directed recovery.

To date, Georgia has more than 150 CPS that have gone through an eight-day program to become more competent in the principles of recovery, self-help, and peer support, and to learn how to adapt those principles to Medicaid-billable services. Working in partnership with the Georgia Mental Health Consumer Network (approximately 3,000 members), the state also secured a CMHS networking grant to help fund ongoing training and continuing education of CPS. A bulletin board has been created on the Internet so that CPS can exchange knowledge and request information from each other via computer. Currently, they also meet face-to-face every three months to exchange knowledge.

Accreditation is a “seal of excellence” that a healthcare program has demonstrated quality, value, and optimal outcomes of service centering on enhancing the recovery of service recipients. Accredited programs receive a qualified endorsement by an objective third party organization such as the Commission on Accreditation of Rehabilitation Facilities or the Joint Commission on Accreditation of Healthcare Organizations based on an in-depth review of services. The accrediting body determines if a program conforms to nationally recognized service standards and is focused on delivering the best outcomes for consumers. Accreditation enables programs to continually enhance the quality of their services and programs, ensure the safety of service recipients, and promote consumer satisfaction. Therefore, accreditation can be a powerful tool of system accountability and reform. It strengthens grant applications and is important to eligibility for Medicaid reimbursement.

Since peer-run programs have different values and service options from traditional mental health services, accreditation bodies have not developed standards for programs that provide peer support or that routinely include peer-run program accreditation in their portfolio. Lack of an appropriate accrediting body has worked to the disadvantage of peer services that choose to participate in quality improvement and funding opportunities. In response to the need for an organization that can accredit peer-run programs, the Peer Accreditation Association in New York State has developed a peer accrediting initiative for use with peer support programs in the state.

The Peer Accreditation Association

In 1997, a workgroup consisting of approximately 20 members was convened by the New York Bureau of Recipient Affairs Advisory Committee to develop a set of guidelines for a voluntary association that would recognize and accredit peer-run organizations in New York State. This initial effort was presented as a workshop at rehabilitation conferences and regional meetings throughout the state to review and provide input into the draft principles. The Center for Mental Health Services funded the project for three years and a

full-time coordinator was hired, standards for accreditation and an application process were completed, and the organization was incorporated.

The purpose of the Peer Accreditation Association is to support the development and growth of peer-operated organizations by: 1) recognizing and accrediting peer-governed and peer-run programs and services; 2) ensuring the development of genuine alternatives to traditional mental health treatment; 3) ensuring the quality of services; 4) strengthening peer support; 5) guarding against co-optation; 6) maintaining the integrity of genuine peer support; and 7) recognizing and acknowledging the contributions of demonstrated quality peer services. The accreditation process is voluntary, independent, peer-governed, and decisions are made by consensus.

Every effort is made to make the process as friendly and simple as possible, every step of the way. As soon as a program has submitted an application, they are assigned a mentor with expertise in running consumer alternatives and acquainted with the criteria for accreditation. The mentor helps the applicant complete the application packet and gather requested documents. At the time of accreditation, a team of two reviewers makes a two-day site visit to conduct interviews and review documents. Where essential criteria have not been fully met, significant progress toward meeting goals may be acknowledged through Provisional, rather than Full Member designation.

Benefits of peer accreditation include a link from the association's Web site, listing in the Peer Accreditation Association's directory of peer-run organizations in New York State, access and visibility to managed care companies, organization-to-organization support and mentoring, subscription to an association newsletter, and assistance with evaluation tools and reporting.

Management Information Systems and Program Evaluation

How are peer programs performing in relationship to their goals? What are peer programs doing to meet the needs of service recipients? How are peer programs impacting their members? Only the consumer community can truly develop information systems and evaluation protocols that recognize the role of human values and incorporate consumers' experiences and points of view. It is clear that peer support programs need to examine the cost, effectiveness, quality, utilization and appropriateness of the services they provide in order to be more accountable to their funders and service recipients. However, the use of management information systems and outcome protocols in the measurement of service use and effectiveness poses a challenge for peer providers. There is concern among consumers about whether outcomes management and decision support technology may dilute the essential value of community-based peer support programs.

Indeed, some consumers believe that professionalization and the adoption of new practices essential for partnering with traditional mental health systems present a threat to the future of peer-run programs in general. Can and should peer-run support programs be classified, evaluated, and understood by the same measures that govern services provided in the traditional mental health system? Are the important aspects of peer support

programs related more to *how* something is done and *by whom*, than by *what services* are offered? Would standardization of services supplant the healing bond of peer-to-peer relationships as units of time become billable hours, and empathy is certified through training and testing?

There is concern in consumer circles that professionalizing peer services and establishing partnerships with traditional mental health systems will undermine both the emancipatory and caring functions of peer support programs. By becoming part of a continuum of mental health services, consumer leaders caution that peer support could be linked to involuntary hospitalization and treatments and, therefore, would no longer be totally voluntary. Consumer leaders also worry that partnerships with traditional providers would be inherently unequal—with peer providers having little real power or responsibility.

In the groundbreaking book *On Our Own* (1988), Chamberlin argued that mental health consumers who are working with professionals would not be in control of their program due to the uneven power relationship between professionals and the recipients of services. Control can be identified by such indicators as membership on the board of directors and authority over the group budget and staff. This unevenness of power may include organizational linkages with other formal community-based organizations with hierarchies based on expertise and economic resources such as large volunteer organizations (e.g., American Red Cross, Salvation Army, etc.) and church organizations.

Considering these factors, it is not clear whether peer programs could reach their full potential if they lack valid, reliable skill assessment tools, training protocols, and management information systems to measure program outcomes. Therefore, program functions and staff competencies need to be systematically identified. Information necessary to assess the qualifications of peer providers would enable programs to improve the quality of their workforce, and understanding program effectiveness would allow for better design of programmatic elements to meet participant needs and improve service outcomes. As mentioned earlier, however, this is no simple task.

In order to collect and process data, peer programs have to finance and build a data support infrastructure without destroying the fundamental strengths of self-help agencies. In a national survey of data needs of peer support programs, Campbell (1997a) found that almost 40% of the programs surveyed felt that data collection of member information would discourage people from using the services, and 43% felt that it would financially burden the organization. There are also multiple requirements at the personal and organizational level that must be addressed in order for peer support programs to develop appropriate management information systems, including technical readiness, protections such as the rights of privacy and confidentiality, data infrastructure requirements, and data utilization strategies. Such concerns and information system demands raise questions about the ability of peer programs to find the resources, skills, tools, and the will to move forward in adopting useful data technologies.

Ultimately, evaluation can have an instrumental role in helping peer programs adapt to and/or build their future if they use the tools of science to respond to the pressing social and environmental problems facing people with mental illness. Peer providers can learn the basic skills of evaluation to foster improvement and self-determination within a context of social justice and, therefore, add intrinsic value to services. In addition to monitoring and improving the quality of services, data systems can also reduce expenses for services, generate income, increase program efficiency, and increase service demand by enhancing member satisfaction.

CHOICE Outcomes Tracking Data System

CHOICE of New Rochelle, Inc. is a 501(c)(3) corporation located in New Rochelle, NY that provides services to adults with mental illness living in Westchester County, NY. Their mission is helping, encouraging and supporting persons who, like themselves, have used mental health services. CHOICE offers peer advocacy, homeless outreach, case management and related services in a friendly environment. They bring programs to people who have been underserved and require assistance to obtain vital services. Through such efforts they help people become fully empowered, independent, and integrated into the wider community. Believing that anecdotes are nice, but don't prove a thing, CHOICE is developing custom software that conforms to service and agency requirements to allow real time entry of information by staff on the progress of their clients. The software will also provide detailed and meaningful analysis of the impact of services on changes in client status, overall program performance, services rendered, and cost.

Program in Consumer Studies and Training (PCS&T)

The Program in Consumer Studies and Training (PCS&T) is located in St. Louis and is part of the Behavioral Health Division of the Missouri Institute of Mental Health (MIMH), University of Missouri School of Medicine. The program is an outgrowth of the many years of commitment by Jean Campbell, Ph.D., a consumer researcher at MIMH, to the development of a strong and informed consumer voice in all aspects of mental health policy, research and services. Together with the faculty at MIMH, Dr. Campbell has championed the beliefs that mental health consumers have a critical role to play in research and evaluation, and that the involvement of informed consumers in services research brings integrity to the overall process.

Over the past six years, PCS&T has been a clearinghouse for consumer-directed research and evaluation, provided consultation on state and federal data projects, assisted peer programs, and produced several technical assistance manuals such as: 1) *Dressed-down Glossary of Research Terms for Non-Researchers*; 2) *How to Conduct Culturally Competent Research*; 3) an interviewer training manual; and 4) *A Practical Guide for Conducting Consumer Satisfaction Studies in Mental Health*. It also facilitated the development of a consumer/survivor research platform in collaboration with the National Mental Health Consumers' Self-help Clearing House for use at the first National Summit of Mental Health Consumers and Survivors held in Portland, OR in 1999. Most

important, PCS&T has conducted numerous state-of-the-art research efforts that are supporting the peer support provider community in program improvement and advocacy for continued support. Most of the documentation, tools, and support materials developed by PCS&T are available on the program Web site at www.cstprogram.org

The Center for Mental Health Policy and Services Research at the University of Pennsylvania funded PCS&T to convene a consumer panel to investigate core competencies of providers of consumer-operated services. PCS&T compiled an extensive annotated bibliography on peer-run programs, produced a review of consumer-operated services literature, identified exemplary models of peer-run services, and prioritized and grouped core competencies of peer providers using a focus group technology called concept-mapping in collaboration with fifteen consumer participants.

Under contract from the Survey and Analysis Branch of the Center for Mental Health Services, PCS&T directed the creation of a mental health consumer information component for the State Mental Health Agency Profiling System. The Profiling System was developed by the NASMHPD Research Institute, Inc. (NRI) to provide the states with a national computer-based compilation of descriptive information about mental health organizations, funding, operation, services, policies, statutes, staffing, and service recipients for each state. The Consumer Component provides data that is relevant to mental health consumers involved in public policy, research and evaluation, planning, program development, and advocacy. Analysis of the data was completed with support from the National Technical Assistance Center for State Mental Health Planning (NTAC) within NASMHPD, and ultimately *Identifying the Technical Assistance Needs of Consumer/Survivor and Family Stakeholder Groups within State Mental Health Agencies* (Campbell, 1998) was published with support from NTAC.

Under a subcontract from the National Research and Training Center on Psychiatric Disability, University of Illinois-Chicago, PCS&T completed the Peer Support Outcomes Protocol Project (1996-2000). This project developed, validated, and field-tested a modularized peer outcomes protocol (POP) that measures the effectiveness of peer support services for persons with mental illness. The POP is comprised of seven separate modules that can be administered individually or in combination to reflect the information needs of the program. Topics include: demographics, service use, employment, community life, quality of life, well-being, and program satisfaction.

The POP was developed through a comprehensive review of consumer outcomes instruments. Indicators were compiled and several focus groups were held using concept-mapping to rank and cluster domains and indicators. Field-testing and psychometric testing of the protocol involved extensive participation of service recipients from the St. Louis Empowerment Center, a consumer-run drop-in center, and Independence Center, a community-based peer support clubhouse. A survey of the data needs of community-based peer support programs was also conducted with over 30 consumer-run organizations as part of this project. The development of the POP was guided by a vision for an outcomes protocol that would be highly adaptable and responsive in order to produce value-added information that achieves the following objectives:

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- ◆ ***Adaptive Utility:*** There are many models of community-based peer support programs that impact a number of different areas of peoples' lives. Change in one outcome module may or may not coincide with change in another. Each module may be presented as a separate module and programs may choose to collect data on a subset of domains.
 - ◆ ***Simplicity:*** The measures included are accessible to and easily collected by any community-based peer support program, regardless of sophistication in program evaluation or computer technology.
 - ◆ ***Flexibility:*** The protocol offers multiple methods of data collection and management. It also provides guidelines on how to choose the system that best fits the resources, infrastructure, and information needs of a particular agency/program.
 - ◆ ***Face Validity:*** The protocol uses measures that are relevant to community-based peer support programs, and readily understood by non-researchers.
 - ◆ ***Responsiveness & Sensitivity:*** The protocol was developed by and for persons with psychiatric disabilities. It not only collects information on such factors as recovery, personhood, empowerment, well-being, employment, and community life, but at all times promotes these outcomes as values of the protocol itself.
 - ◆ ***Human Subjects Protections:*** The protocol places top priority on the rights of people from whom data is being collected. These rights outweigh any need for information, including privacy, confidentiality, informed consent, voluntary participation, and easy access to one's own data as well as all aggregate data reports.
 - ◆ ***Collaboration:*** The protocol recommends methods for the inclusion of service recipients in all aspects of data collection, analysis, distribution, quality assurance, planning, and program applications.

A toolkit is available that includes the POP, interviewer training manual, question-by-question guide, psychometric report, and implementation guide.

As the Coordinating Center for the Consumer-Operated Services Program (COSP) Multisite Research Initiative, PCS&T helped to develop and test the Fidelity Assessment Common Ingredients Tool (FACIT) in order to measure the frequency and intensity of identified common program ingredients of the consumer-operated and traditional mental health service programs in the study. Common Ingredients (CIs) of consumer-operated programs were derived from consumer literature on peer support and the work of the Consumer Advisory Panel. Descriptive items such as consumer-operated, participant responsiveness, consciousness-raising, peer support, telling our story, peer advocacy, choice, empowerment, recovery, and safety were identified, defined, and organized into

five domains: 1) structure; 2) peer support; 3) belief systems; 4) environment; and 5) education/advocacy. A measurement tool was then developed, scaled, and tested. During two rounds of site visits, teams from the Coordinating Center collected objective and subjective data during program tours, interviews, and focus groups with directors, staff, and consumers. For each program, site visitors independently rated each dimension of the FACIT. This was followed by a conciliation process involving the site visitors discussing the evidence used in making each rating and arriving at a common rating.

The CIs measured in the FACIT are commonly found in peer-run services, but each individual program will have more of some ingredients, and less of others. In fact, a program may be missing some of these ingredients entirely and still be a viable, helpful peer support program. The only common ingredient that will be seen across all programs is that each one is consumer-operated. Therefore, the FACIT is not a checklist to see how programs measure up to a standard and should not be used in that way. Rather, it is a relatively inexpensive way for peer programs to understand differences in style between equally valid approaches and to use that information in conjunction with an outcome protocol to better interpret variation in program effectiveness.

Additional considerations regarding consumer-delivered services

Mark Salzer, Ph.D., and the Mental Health Association of Southeastern Pennsylvania Best Practices Team recommend several points (excerpted below) in their report *Best Practice Guidelines for Consumer-Delivered Services* (2002).

The researchers are emphatic that a program or agency where consumers serve only as advisors or on a board is not a consumer-delivered service (CDS). They go on to differentiate a diversity of services. “Consumer-operated services” are planned, managed, and provided by consumers. “Consumer partnership services” are delivered by consumers, but the control of the program is shared with non-consumers. “Consumers as employees” refers to organizations that employ consumers and non-consumers alike.

The researchers caution that consumer-delivered services that depend too heavily on professional involvement and financing as well as stringent personnel requirements are at risk of losing their unique qualities and benefits. In a viable CDS, good supervision and monitoring is essential, including frequent team meetings and individual supervision. A CDS should be particularly sensitive to providing accommodations consistent with the Americans with Disabilities Act. Supervisors should provide an environment that fosters open discussion about personal and professional issues that might interfere with work.

Past or current relationships between the consumer-provider and the employing organization or non-consumer staff are examples of dual relationships that can create especially complex issues for a CDS. Sexual or dating relationships are generally prohibited in more formal CDS and are not part of the mission of one-to-one peer support programs. Role conflicts and confusion are highly likely when an individual combines experience as a consumer with the role of a provider. There are no established rules on how to handle these issues.

The researchers emphasize the importance of non-consumers receiving training on the unique benefits associated with CDS. They also believe that non-consumers should be provided with opportunities to observe and participate in CDS programs as much as possible (Salzer, 2002).

Recommendations for Moving Forward

Programs developed and administered by mental health consumers/survivors have built a self-help service infrastructure that is helping people recover from psychiatric problems, in addition to providing supports for housing, employment and education. Peer providers have created community linkages with traditional mental health providers through service

“I’ve learned that while I have a mental illness, I can still have a life full of fun, fulfillment, productivity, and meaning.”

— Harvey M.

referrals. They have also educated mental health professionals about the experience of living with a psychiatric diagnosis, and about the struggle to live a quality life in the face of prejudice, discrimination, isolation, and/or poverty. Further, peer-run support services have been shown to positively impact recovery, increase the

empowerment of participants, instill hopefulness, and provide informal learning of adaptive coping strategies for people diagnosed with serious mental illness.

To foster the budding success of peer support programs across the country, the participants at the *Emerging New Practices* meeting developed six overarching recommendations deemed important for the continued development of the peer support field overall, but also for increasing the role of peer support specifically within public mental health. Those recommendations are listed below.

- ◆ Continue providing networking opportunities for peer-specialists and use those opportunities to continue and refine:
 - definitions of peer support,
 - how peer support differs from mutual support,
 - training, certification, and accreditation,
 - whether to bill Medicaid, and
 - resources on how to manage and promote a peer support system.
- ◆ Promote peer support and recovery work as cost-effective with good outcomes.
 - Managed care audits can be an ally in this because they monitor who is and isn’t doing recovery focused work
 - Spread the word about peer support via journal articles and workshops
- ◆ Continue the development of evaluation instruments, competency assessments, and provider recovery skills.
- ◆ Approach NIMH about funding a national research initiative on peer support.
 - Increase the number of consumer researchers
- ◆ Take the consumer/survivor movement to the next level with a national consumer/survivor/ex-patient (C/S/X) coalition to act as a clearinghouse for information, especially on innovative peer support services.

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- ◆ Push inclusion of recovery principles as part of systems reform at the local, state, and national levels.

Subcommittee on Consumer Issues recommendations as a framework for future directions in peer support

In order to facilitate recovery from mental illness, the Subcommittee on Consumer Issues, in its report to the President's New Freedom Commission on Mental Health (2003, March 5), urged federal, state, and local governments to unite to develop a national recovery initiative with two major policy options supported by several key elements:

Policy Option 1 - Promote Collective Self-Determination

- ◆ Employ consumer leadership in a national recovery initiative.
- ◆ Involve consumers and promote recovery in all aspects of research design, activity, and evaluation.
- ◆ Campaign to increase awareness of recovery and reduce stigma and discrimination.

Policy Option 2 - Promote Individual Self-Determination

- ◆ Integrate peer support services into the continuum of community care.
- ◆ Promote inter-agency collaboration to better inform consumer choice.

Both policy options of the Subcommittee acknowledge and address core values of peer support. Policy Option 2, in particular, contains a mandate regarding peer support.

Conclusion

The *Emerging New Practices in Organized Peer Support* experts meeting was a thoughtful first step in considering both the promise and the potential hazards that partnerships with the mental health system may offer peer support programs. The lessons of past struggles for empowerment and recovery and the values and goals that have sustained consumer providers through the years will certainly guide future dialogue, creativity, and calls for leadership in the future. The evidence is now clear that the peer support movement is in a position to infuse hope in mental health systems that have fostered a culture of low expectations in the past. That hope will change mental health systems and the lives they touch.

References

- Addis, M., & Krasnow, A. (2000). A national survey of practicing psychologists' attitudes toward psychotherapy treatment manuals. *Journal of Consulting and Clinical Psychology, 68*(2), 331-339.
- Ahern, L., & Fisher, D. (2001a). *PACE Curriculum* (pp. 1-35). Lawrence, MA: National Empowerment Center.
- Ahern, L., & Fisher, D. (2001b). Recovery at your own PACE. *Journal of Psychological Nursing and Mental Health Services, 39*(4), 22-31.
- Anthony, W. (2001, November 5). Need for recovery-compatible evidence-based practices. *Mental Health Weekly*.
- Arntsen, B., Greenfield, T., Harris, A., & Sundby, E. (1995). CRF: Early experiences at Sacramento's consumer run crisis residential program. *The CAMI Journal, 6*(3), 35.
- Baker, F., & Intagliata, J. (1984). A comparative analysis of the young adult chronic patient in New York State's community support system. *Hospital and Community Psychiatry, 35*(1), 45-50.
- Bell, N., & Shern, D. (2002). *State Mental Health Commissions: Recommendations for Change and Future Directions*. Alexandria, VA: National Technical Assistance Center for State Mental Health Planning, National Association of State Mental Health Program Directors.
- Ben-Sira, Z. (1980). Affective and instrumental components in the physician-patient relationship: An additional dimension of interaction theory. *Journal of Health and Social Behavior, 21*, 170.
- Besio, S., & Mahler, J. (1993). Benefits and challenges of using consumer staff in supported housing services. *Hospital and Community Psychiatry, 44*(5), 490-491.
- Blanch, A., Fisher, D., Tucker, W., Walsh, D., & Chassman, J. (1993). Consumer-practitioners and psychiatrists share insights about recovery and coping. *Disability Studies Quarterly, 13*(2), 17-20.
- Burns-Lynch, B., & Salzer, M. (2001). Adopting innovations: Lessons learned from a peer-based hospital diversion program. *Community Mental Health Journal, 511-521*.
- Campbell, J. (1996). Towards collaborative mental health outcomes systems. *New Directions for Mental Health Services, 71*, 69-68. San Francisco, CA: Jossey-Bass Publishers.
- Campbell, J. (1997a). *The data needs of peer support programs: A national survey*. Saint Louis, MO: Missouri Institute of Mental Health.
- Campbell, J. (1997b). How consumers/survivors are evaluating the quality of psychiatric care. *Evaluation Review, 21*(3), 357-363.

-
- Campbell, J. (1998). *Identifying the technical assistance needs of consumer/survivor and family stakeholder groups within state mental health agencies*. Alexandria, VA: National Technical Assistance Center for State Mental Health Planning, National Association of State Mental Health Program Directors.
- Campbell, J. (2000). MIMH coordinates multi-site consumer studies research initiative. *The Mental Health American, 11*.
- Campbell, J., & Johnson, J. R. (1995). Struggling to reach common ground. *Behavioral Healthcare Tomorrow, 4*(3), 40, 45-46.
- Campbell, J., Ralph, R., & Glover, R. (1993). *From lab rat to researcher: The history, models and policy implications of consumer/survivor involvement in research* (138-157). Proceedings: Fourth Annual National Conference on State Mental Health Agency Services Research and Program Evaluation. Alexandria, VA: National Association of State Mental Health Program Directors.
- Campbell, J., & Schraiber, R. (1989). *In pursuit of wellness: The well-being project*. Sacramento, CA: California Department of Mental Health.
- Carpinello, S. E., Knight, E. L., & Janis, L. (1991, unpublished report). *A qualitative study of the perceptions of the meaning of self-help, self-help group processes and outcomes by self-help group leaders, members, and significant others*. New York State Office of Mental Health.
- Cartwright, A. (1964). *Human relations and hospital care*. London: Routledge and Keegan.
- Chamberlin, J. (1988). *On our own: Patient-controlled alternatives to the mental health system*. England: Mind.
- Chamberlin, J. (1990). The ex-patients movement: Where we've been and where we're going. *The Journal of Mind and Behavior, 11*(4), 323-336.
- Chamberlin, J., Rogers, E. S., & Ellison, M. (1996). Self-help programs: A description of their characteristics and their members. *Psychiatric Rehabilitation Journal, 19*, 33-42.
- Chinman, M., Forquer, S., Knight, E., Miller, A., Vogel, H., & Young, A. (2002, unpublished report). *Increasing the use of self-help programs and mental health empowerment competencies. Final report*. Center for Health Care Strategies, Robert Wood Johnson Foundation.
- Copeland, M. E. (1997). *Wellness recovery action plan* (1-81). W. Dummerston, VT: Peach Press.
- Corrigan, P., McCracken, S., Edwards, M., Kommana, S., & Simpatico, T. (1997). Staff training to improve implementation and impact of behavioral rehabilitation programs. *Psychiatric Services, 48*, 1336-1338.
- Curtis, L., McCabe, S., Montague, W., Caron, D., & Harp, H. (1991). Strategies for increasing and supporting consumer involvement in mental health policy/planning, management, and service delivery. Burlington, VT: Center for Community Change through Housing and Support.

-
- Davidson, L., Chinman, M., Kloos, B., Weingarten, R., Stayner, D., & Tebes, J. (1999). Peer support among individuals with severe mental illness: A review of the evidence. *Clinical Psychology: Science and Practice* 9(2), 165-187.
- Diehl, S., & Baxter, E. (1999). BRIDGES: A journey of hope, a peer-taught curriculum on mental illness, mental health treatment and self-help skills. Knoxville, TN: Tennessee Alliance for the Mentally Ill.
- Drake, R., Becker, D., Wyzik, P., & Torrey, W. (1996). Day treatment versus supported employment for persons with severe and persistent mental illness: A replication study. *Psychiatric Services*, 47(10), 1125-1127.
- Dumont, J., & Jones, K. (2002, spring). Findings from a consumer/survivor defined alternative to psychiatric hospitalization. *Outlook*, 4-6.
- Durman, E. (1976). The role of self-help in service provision. *Journal of Applied Behavioral Science*, 12, 433-443.
- Emerick, R. (1990). Self-help groups for former patients: Relations with mental health professionals. *Hospital and Community Psychiatry*, 41, 401-407.
- Forquer, S., & Knight, E. (2001). Managed care: Recovery enhancer or inhibitor? *Psychiatric Services*, 52(1), 25-26.
- Frese, F. J., Stanley, J., Kress, K., & Vogel-Scibilia, S. (2001). Integrating evidence-based practices and the recovery model. *Psychiatric Services*, 52(11), 1462-1468.
- Galanter, M. (1988). Research on social supports and mental illness. *American Journal of Psychiatry*, 145(10), 1270-1272.
- Gartner, A., & Riessman, F. (1982). Self-help and mental health. *Hospital and Community Psychiatry*, 33(8), 631-635.
- Gelso, C., & Carter, J. (1985). The relationship in counseling and psychotherapy: Components, consequence, and theoretical antecedents. *Counseling Psychologist*, 2, 155-243.
- Greenberg, L., & Pinsof, W. (1986). Process research: Current trends and perspectives. In L. Greenberg, & W. Pinsof, (Eds.), *The psychotherapeutic process: A research handbook*. New York: Guilford.
- Gurman, A. (1977). The patient's perception of the therapeutic relationship. In A. Gurman, & A. Razin (Eds.), *Effective psychotherapy: A handbook of research*. New York.
- Hess, R., Clapper, C., Hoekstra, K., & Gibson, F. (2001). Empowerment effects of teaching leadership skills to adults with a severe mental illness and their families. *Psychiatric Rehabilitation Journal*, 24(3), 257-265.
- International Association of Psychosocial Rehabilitation Services (1998). *IAPSRS position statement: The single model trap*. Columbia, MD: International Association of Psychosocial Rehabilitation Services.
- Kaufmann, C. (1995). The self-help employment center: Some outcomes from the first year. *Psychosocial Rehabilitation Journal*, 18, 145-162.

-
- Kaufmann, C., Freund, P., & Wilson, J. (1989). Self-help in the mental health system: A model for consumer-provider collaboration. *Psychiatric Rehabilitation Journal*, *13*, 520.
- Kaufmann, C., Schulberg, H., & Schooler, N. (1994). Self help group participation among people with severe mental illness. *Prevention in Human Services*, *11*, 315-331.
- Kaufmann, C., Ward-Colesante, M., & Farmer, M. (1993). Development and evaluation of drop-in centers operated by mental health consumers. *Hospital and Community Psychiatry*, *44*(7), 675-678.
- Kennedy, M. (1990). *Psychiatric hospitalization of GROWers*. Paper presented at the Second Biennial Conference on Community Research and Action. East Lansing, MI.
- Kennedy, M., & Humphreys, K. (1994). Understanding worldview transformation in mutual help groups. *Prevention in Human Services*, *11*, 181-189.
- Keogh, C. (1975). *Readings for mental health*. Sydney: GROW.
- Koyanagi, C., & Semansky, S. (2001). *Recovery in the community: Funding mental health rehabilitative approaches under Medicaid*. Washington, DC: Bazelon Center for Mental Health Law.
- Kurtz, L. (1988). Mutual aid for affective disorders: The Manic-Depressive and Depressive Association. *American Journal of Orthopsychiatry*, *58*, 152-155.
- LeDoux, E. (1997). Revitalizing a consumer-controlled alternative. In C. Mowbray, D. Moxley, C. Jasper, & L. Howel (Eds.), *Consumers as providers in psychiatric rehabilitation* (142-147). Columbia, MD: International Association of Psychosocial Rehabilitation Services.
- Lewis, L. (2001). Role of mental health patient organizations in disease management. *Practical Disease Management*, *9*(11), 604-617.
- Lieberman, A., Gowdy, E., & Knutson, L. (1991). The mental health outreach project: A case study in self-help. *Psychosocial Rehabilitation Journal*, *14*(3), 100-105.
- Lieberman, M., & Snowden, L. (1994). Problems in assessing prevalence and membership characteristics of self-help group participants. In T. Powel (Ed.), *Understanding the self-help organization: Frameworks and findings* (32-49). Thousand Oaks, CA: Sage Publications.
- Long, L., & Van Tosh, L. (1988, June). *Program descriptions of consumer-run programs for homeless people: Volume II of three parts*. (Contract No. 304666). Rockville, MD: Division of Education and Service Systems Liaison, National Institute of Mental Health.
- Magura, S., Laudet, A., Mahmood, D., Rosenblum, A., Vogel, H., & Knight, E. (In press). Role of self-help processes in achieving abstinence among dually-diagnosed persons. *Addictive Behaviors*.

-
- Magura, S., Laudet, A., Mahmood, D., Rosenblum, A., & Knight, E. (2002). Medication adherence and participation in self-help groups designed for dually-diagnosed persons. *Psychiatric Services, 53*(3), 310-316.
- Markowitz, F., DeMasi, M., Knight, E., & Solka, L. (1996). *The role of self-help in the recovery process*. Paper presented at the 6th Annual Conference on State Mental Health Agency Research and Program Evaluation, Arlington, VA.
- McCabe, S., & Unzicker, R. (1995). Changing roles of consumer/survivors in mature mental health systems. *New Directions for Mental Health Services (66)*61-73. San Francisco, CA: Jossey Bass Publishers.
- McLean, A. (1995). Empowerment and the psychiatric consumer/ ex-patient movement in the United States: Contradictions, crisis and change. *Social Science Medicine, 40*, 1053-1071.
- Mead, S., Hilton, D., & Curtis, L. (2001). Peer support: A theoretical perspective. *Psychiatric Rehabilitation Journal, 25*(2) 136.
- Meek, C. (1994). Consumer-run drop-in centers as alternatives to mental health system services. *PRO/CON, 3*(1), 49-51.
- Mental Health Policy Resource Center (1991, May). The growing mental health self-help movement. *Policy in Perspective*. Washington, D.C.: Author.
- Mowbray, C., Wellwood, R., & Chamberlain, P. (1988). Project stay: A consumer-run support service. *Psychosocial Rehabilitation Journal, 12*, 33-42.
- Mowbray, C., & Tan, C. (1992). Evaluation of an innovative consumer-run service model: The drop-in center. *Innovations and Research, 1*(2), 19-23.
- Mowbray, C., & Tan, C. (1993). Consumer-operated drop-in centers: evaluation of operations and impact. *Journal of Mental Health Administration, 20*(1), 8-19.
- NASMHPD Research Institute, Inc. (2003, May). *State Mental Health Budget Shortage: FY '03 & '04*. Retrieved May 2003 from <http://nri.rdmc.org>
- Nikkel, R., Smith, G., & Edwards, D. (1992). A consumer-operated case management project. *Hospital and Community Psychiatry, 43*, 577-579.
- Onken, S., Dumont, J., Ridgway, P., Dornan, D., & Ralph, R. (2002). *Mental health recovery: What helps and what hinders? A national research project for the development of recovery facilitating system performance indicators*. Alexandria, VA: National Technical Assistance Center for State Mental Health Planning, National Association of State Mental Health Program Directors.
- President's New Freedom Commission on Mental Health. (2002, October 29). *Interim report*. Washington, D.C.: Office of the President.
- President's New Freedom Commission on Mental Health. (2003, March 5). *Report of the Subcommittee on Consumer Issues: Shifting to a Recovery-Based Continuum of Community Care*. Washington, D.C.: Office of the President.
- President's New Freedom Commission on Mental Health. (2003, July 22). *Final report: Achieving the promise: Transforming mental health care in America*. Washington,

D.C.: Office of the President. Retrieved August 13, 2003 from www.mentalhealthcommission.gov

- Prout, N. (1997). Offering sanctuary and safety: Rainbow House, a peer support facility. In C. Mowbray, D. Moxley, C. Jasper, & L. Howel (Eds.), *Consumers as providers in psychiatric rehabilitation* (148-154). Columbia, MD: International Association of Psychosocial Rehabilitation Services.
- Rappaport, J., Seidman, E., Paul, T. A., McFadden, L., Reischl, T., Roberts, L. J., Salem, D., Stein, C., & Zimmerman, M. (1985). Collaborative research with a self-help organization. *Social Policy*, *15*, 12-24.
- Rappaport, J., Reischl, T., & Zimmerman, M. (1992). Mutual help mechanisms in the empowerment of former mental patients. In D. Saleebey (Ed.), *The strengths perspective in social work practice* (84-97). White Plains, NY: Longman.
- Reidy, D. (1994). Recovering from treatment: The mental health system as an agent of stigma. *Resources*, *6*, 3-10.
- Riessman, F. (1965). The helper-therapy principle. *Social Work*, *10*, 27-32.
- Riessman, F. (1990). Restructuring help: A human services paradigm for the 1990s. *American Journal of Community Psychology*, *18*, 221-230.
- Roberts, L., Luke, D., Rappaport, J., Seidman, E., Toro, P., & Reischl, T. (1991). Charting uncharted terrain: A behavioral observation system for mutual help groups. *American Journal of Community Psychology*, *19*, 715-737.
- Rogers, C. (1957). The necessary and sufficient condition of therapeutic personality change. *Journal of Consulting and Clinical Psychology*, *22*, 95-103.
- Rogers, S. (1994). Help wanted, available consumer/survivor services are helping with job training, placement and hope. *The Key*, *2*(2), 5-16.
- Rootes, L., & Aanes, D. (1992). A conceptual framework for understanding self-help groups. *Hospital and Community Psychiatry*, *43*, 379-381.
- Roth, J. A. (1963). *Timetables*. Indianapolis: Bobbs-Merrill.
- Sabin, J., & Daniels, N. (2002). Strengthening the consumer voice in managed care: The Leadership Academy Program. *Psychiatric Services*, *53*(4), 405-411.
- Sabin, J., & Daniels, N. (2003). Strengthening the consumer voice in managed care: The Georgia peer specialist program. *Psychiatric Services*, 497-498.
- Salzer, M., & Liptzin-Shear, S. (2002). Identifying consumer-provider benefits in evaluation of consumer-delivered services. *Psychiatric Rehabilitation Journal*, *25*(3), 281.
- Salzer, M. S. et al. (2002). *Best practice guidelines for consumer-delivered services*. Prepared for Behavioral Health Recovery Management Project: an Initiative of Fayette Companies, Peoria, IL; Chestnut Health Systems, Bloomington, IL; and the University of Chicago Center for Psychiatric Rehabilitation. Retrieved from www.bhrm.org/guidelines/salzer.pdf on August 5, 2003.

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- Scott, A. (1993). Consumers/survivors reform the system, bringing a “human face” to research. *Resources*, 5(1), 3-6.
- Segal, S., Silverman, C., & Temkin, T. (1993). Empowerment in self-help agency practice. *Social Work*, 38(6), 705-712.
- Segal, S., Silverman, C., & Temkin, T. (1995a). Characteristics and service use of long-term members of self-help agencies for mental health clients, *Psychiatric Services*, 46(3), 269-274.
- Segal, S., Silverman, C., & Temkin, T. (1995b). Measuring empowerment in client-run self-help agencies. *Community Mental Health Journal*, 31(3), 215-227.
- Silverman, S. (1997). Recovery through partnership: On our own, Charlottesville, Virginia. In C. Mowbray, D. Moxley, C. Jasper, & L. Howel (Eds.), *Consumers as providers in psychiatric rehabilitation* (126-141). Columbia, MD: International Association of Psychosocial Rehabilitation Services.
- Skillman-Campbell, J. (1991). *Towards undiscovered country: Mental health clients speak for themselves*. Ann Arbor, MI: UMI.
- Skipper, J., Tagliacozzo, D., & Mauksch, H. (1964). Some possible consequences of limited communication between patients and hospital functionaries. *Journal of Health and Human Behavior*, 6(10), 34.
- Solomon, P., & Draine, J. (2001). The state of knowledge of the effectiveness of consumer provided services. *Psychiatric Rehabilitation Journal*, 25(1), 20-27.
- Stewart, M. (1990). Expanding theoretical conceptualizations of self-help groups. *Social Science and Medicine*, 31, 1057-1066.
- Stone, E., Morton, S., Hulscher, M., Maglionne, M., Roth, E., Grimshaw, J., Mittman, B. et al. (2002). Interventions that increase use of adult immunization and cancer screening services: A meta-analysis. *Annals of Internal Medicine*, 136, 641-651.
- Tan, C., Mowbray, C., & Foster, J. (1990). *Consumer-run drop-in center study: Technical report, executive summary*. Detroit, MI: Michigan State University.
- Trainor, J., Shepherd, M., Boydell, K., Leff, A., & Crawford, E. (1997). Beyond the services paradigm: The impact of consumer/survivor initiatives. *Psychiatric Rehabilitation Journal*, 21(2), 132-140.
- U.S. Department of Health and Human Services. (1999). *Mental health: A report of the Surgeon General*. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institute of Mental Health.
- Van Tosh, L., & del Vecchio, P. (2000). Consumer-operated self-help programs: A technical report. Rockville, MD: Center for Mental Health Services.
- Van Tosh, L., Ralph, R., & Campbell, J. (2000). The rise of consumerism. *Psychiatric Rehabilitation Skills*, 4(3), 383-409.
- Zahniser, J., & McGuirk, F. (2002). *National Empowerment Center survey on PACE: Summary of survey results*. Lawrence, MA: National Empowerment Center.

Zinman, S. (1987). Definition of self-help groups. In S. Zinman, H. Harp, & S. Budd (Eds.), *Reaching across: Mental health clients helping each other* (7-15). Riverside, CA: California Network of Mental Health Clients.

Appendix A: Definitions

Editor's note: The following definitions are intended to assist readers of this report to better understand the language used in describing and discussing peer support practices. These definitions may or may not have relevance outside of the content of this report.

Accreditation is a “seal of excellence” that a healthcare program has demonstrated quality, value, and optimal outcomes of services.

Assessment is a test or other way of measuring something, such as a person’s mental health, or goals, or needs; often the first test in a series of tests, or a test given before treatment starts.

Center for Mental Health Services (CMHS) is part of the Substance Abuse and Mental Health Services Administration in the U.S. Department of Health and Human Services. CMHS works with state and local mental health authorities, service providers, consumers and their families to improve and increase the quality and range of mental health treatment and support services.

Certification is a workforce assessment process that fosters the growth of a qualified, ethical, and culturally diverse workforce through test-based certification and/or a licensing program and the enforcement of a code of ethics.

Concept mapping describes a method of grouping ideas or results based on how similar they are, and then showing the groups in picture form.

Consumer-operated programs are peer-to-peer services that are administratively controlled and operated by consumers and that emphasize self-help as their operational approach.

Continuum of care describes the entire service array including institutional and community mental health services, social supports groups, and volunteer services.

Control group describes the participants being studied who are not receiving the “intervention”/change that the participants in the “experimental” group are receiving.

Data collection is the gathering of information through surveys, tests, interviews, experiments, library records, etc.

Data is information compiled from study records, questionnaires, interviews, etc.

Data processing is the process of recording, storing, and analyzing information with a computer program.

Databases are groups of information recorded in a standardized method.

Drop-in center is a peer-run program model of peer services that are housed at a central location and focus on social skills development and support within an informal setting.

Empowerment occurs when a person gains rights and authority in addition to feeling a sense of personal independence and competence.

Evaluation research is a study to see whether a program or a project is achieving its goals.

Evidence-based practices are interventions for which there is consistent scientific evidence showing that they improve client outcomes.

Experimental group describes the participants who receive the intervention being studied. This group is compared with the *control group*, in which participants are as much like the experimental group as possible, except that the control group participants do not receive the treatment.

Face validity is the measure of whether a study's results are understandable.

Feedback describes the comments, reviews, ratings, or other responses from the study participants or from the people who will receive/review the results of the study.

Fidelity measures are tools to assess the adequacy of implementation of program models. Specifically, fidelity measures quantify the degree to which the elements in a program model have been adequately implemented.

Instruments are ways to gather and measure information (e.g., surveys, tests, scales, or ratings).

International Association of Psychosocial Rehabilitation Services (IAPSR) is a professional organization of providers, consumers, and researchers.

Management Information System (MIS) is a computer network for storing, accessing, and managing data in electronic form; also the database of that information.

Manual and/or workbooks are materials that provide sufficient detail to allow trained personnel to replicate practices.

Medicaid Rehab Option is a model that allows for certain services that support recovery to be billed and reimbursed through the Centers for Medicaid and Medicare Services.

Mental health client is a term used by mental health professionals referring to a person with whom they have a clinical relationship.

Mental health consumer is a term referring to a person who is receiving mental health services.

Mental health survivor is a term referring to a person who has survived the mental health system and/or mental illness.

National Association of State Mental Health Program Directors (NASMHPD) is the national organization that represents the policy interests of state departments of mental health.

Peer service is a generic reference to any service that is provided by a consumer.

Practices are a collection of services designed to improve service recipient outcomes.

Protocol describes the correct way a study should be implemented or how it was implemented. This term can also refer to the test or other measurement used.

Recovery is a value that reinforces the concept of mental illness as a temporary condition.

Services research describes studies of places or groups, like a mental health center, that offer services to people. The research usually focuses on effectiveness of services.

Substance Abuse and Mental Health Services Administration (SAMHSA) is an organization of the federal government, within the U.S. Department of Health and Human Services, which focuses on substance abuse (issues related to drug or alcohol dependence) and on mental health.

Technical assistance is a term to describe manuals, instructions, consultations, etc. that give information or support for learning a technical task or method.

Appendix B:
Participant List from NTAC Experts Meeting



National Technical Assistance Center for State Mental Health Planning

**EMERGING NEW PRACTICES IN ORGANIZED PEER SUPPORT
NETWORKING MEETING**

March 17-18, 2003

Alexandria, VA

Sponsored by:

Center for Mental Health Services,
Substance Abuse and Mental Health Services Administration
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