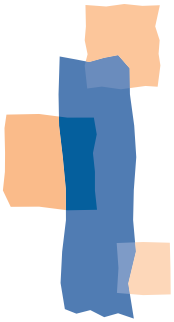

EVIDENCE-BASED PRACTICES KIT

Knowledge Informing Transformation

The Evidence

Consumer-Operated Services

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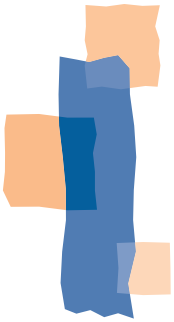

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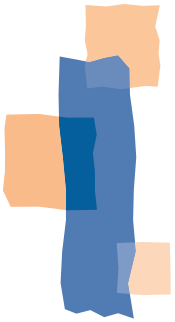


EVIDENCE-BASED PRACTICES

KIT

Knowledge Informing Transformation

The Evidence

The Evidence introduces all stakeholders to the research literature and other resources on consumer-operated services. This booklet includes the following:

- A review of research literature;
- A detailed bibliography for further reading; and
- References for the citations presented throughout the KIT.

Consumer-Operated Services

This KIT is part of a series of Evidence-Based Practices KITs created by the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services.

This booklet is part of the Consumer-Operated Services KIT, which includes seven booklets:

How to Use the Evidence-Based Practices KITs

Getting Started with Evidence-Based Practices

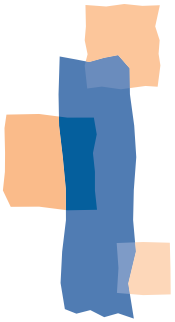
Building Your Program

Training Frontline Staff

Evaluating Your Program

The Evidence

Using Multimedia to Introduce Consumer-Operated Services



EVIDENCE-BASED PRACTICES

KIT

Knowledge Informing Transformation

What's in *The Evidence*

Consumer-Operated Services

EVIDENCE-BASED PRACTICES

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Knowledge Informing Transformation

The Evidence

Consumer-Operated Services: A Review of the Research Literature

Introduction

Throughout history, peer support has helped people achieve health and wellness. The consumer-operated service model of peer support is now being recognized nationally and internationally. As noted in the New Freedom Commission on Mental Health's final report *Achieving the Promise: Transforming Mental Health Care in America* (2003): "Recovery-oriented services and supports are often successfully provided by consumers through consumer-run organizations … Studies show that consumer-run services and consumer-providers can broaden access to peer support, engage more individuals in traditional mental health services, and serve as a resource in the recovery of people with a psychiatric diagnosis" (p. 37).

Funders are increasingly demanding evidence that program models work. In response, consumer-operated programs must continue to demonstrate their role in supporting people's recovery.

This paper reviews the literature on consumer-operated services. It explores the history, principles, and program types as well as relevant research studies of effectiveness. In this review, a consumer-operated service is defined as "a peer-run program or service that is administratively controlled and operated by the mental health consumers and emphasizes self-help as its operational approach" (U.S. Department of Health and Human Services, 1998).

Consumer-operated services are fully independent, separate, and autonomous from other mental health agencies, with the authority and responsibility for all oversight and decision-making on governance, financial, personnel, policy, and program issues (Zinman, 1987; Solomon, 2004; Van Tosh & del Vecchio, 2001; Holter, Mowbray, Bellamy, MacFarlane, & Dukarski, 2004).

To a large degree, consumer-operated programs are staffed by individuals who have received mental health services (Mowbray & Moxley, 1997; Goldstrom et al., 2004, 2006). In this literature review, the term "consumer" is defined simply as an individual who identifies as having been diagnosed with a psychiatric disorder and/or who uses or has used mental health services (Solomon, 2004).

Methodology

A comprehensive list of 144 published studies of consumer-operated services and supplemental materials was developed based on the thorough search of key databases and the collection of other pertinent materials by project participants. However, the methodological rigor used to identify and categorize citations was limited by the many possible source locations, the replication of articles in multiple electronic databases, and the inclusion of many inappropriate articles in preliminary literature searches due to inconsistent study labeling.

Through an initial computerized library search, 201 articles, book chapters, and reports were identified in the published literature. Seven social science databases were searched for the years 1970-2005. Each search involved cross-referencing "mental health," "research," and "evaluation" with peer," "consumer program services," and "mutual support." A second search, crossing "research" and "evaluation" with "self-help," produced 606 citations. A working literature review database with 115 entries was developed and subdivided into the following categories: research (38), theory (10), description (23), historical (19), supplemental (17), and general (8).

In addition, 66 publications were suggested for inclusion by core group members and colleagues after hand searches of private files, conference presentations, and a variety of reports and documents from multiple sources. These were vetted for relevance, appropriateness, and quality and included as appropriate.

History: The development of consumer-operated services

The story of consumer-operated services begins with people: their lives, their psychiatric disabilities, their coping, and their recovery. It starts with what they did to get along, to get better, to help, or be helped by others. From a past of often coercive and dehumanizing treatment, peer-run services emerged based on the insight that the "dynamics of recovery are grounded in a person's mind and body—in his or her hopes, needs, preferences, and choices" (Campbell, 2005).

The legacy of peer support

The legacy of peer support rests on written and oral accounts by former patients and on the record of their accomplishments establishing self-help organizations and other groups promoting empowerment.

There are more than 300 first person accounts of madness published in the English language (Hornstein, 2002). These accounts are truly witness testimony by experts—the people who experience mental illness. They are an important part of the legacy of peer support (Deegan, 2004).

The earliest accounts by former inmates urging reform originated in the United Kingdom in the early 18th century (Defoe, 1728). In America, early first person accounts included those by Elizabeth Stone (1842), Isaac Hunt (1851), Elizabeth Packard (1879), and Clifford Beers (1907). Most of these accounts reached beyond individual concerns and mobilized former patients, the general public,

legislatures, policymakers and even the professions to improve services for all people diagnosed with mental disorders. These examples demonstrate that even in its earliest manifestations, peer support has always been rooted in the belief that helping oneself involves helping others.

Oral traditions have been critical in keeping alive the legacy of peer support. For example, consider the story of Jenni Fulgham, an African American woman living in the small town of Zuni, Virginia. In 1947, she was admitted to the racially segregated Central State Hospital in Petersburgh, Virginia, and diagnosed with paranoid schizophrenia. After discharge, "Miss Jenni" worked for the New York City phone company for 20 years, where her former status as a mental patient went unremarked. In 1961, she and another former patient secured a van and began to visit and encourage patients at the city's mental institutions. In 1978, Miss Jenni returned home to Virginia to establish the Zuni Federation for Mental Health. She cleared three acres of land with a shovel and wheelbarrow and created a retreat where former patients were welcome at no cost.

Miss Jenni's story is not in newspapers or professional journals. We know her story because ex-patients collected oral histories of people of color in mental health systems (Jackson, 2003). Hers is a story similar to those of perhaps hundreds—or even thousands—of other patients from all ethnic and racial groups.

This unwritten legacy must be woven together from bits and fragments of evidence: artifacts left in patients' suitcases and found a century later by ex-patients (Gonnerman, 2004); oral history projects; ex-patient publications such as Madness Network News Third World Issue (Teish, 1976; Sen, 1976); patient comments in clinical records (Reaume, 2000); and ex-patient radio broadcasts (Dain, 1989). Through these artifacts we glimpse the informal, unregulated, compassionate, and spontaneous spirit that is part of the legacy of≈peer support.

The history of ex-patients organizing to support each other and speak for themselves began in England in 1838. Following his confinement in a madhouse, Richard Paternoster placed an advertisement in the London Times for ex-inmates to join in a campaign to reform the madhouse system. He was joined by four former inmates who in 1845 named their fledgling organization the Alleged Lunatics' Friend Society. The group remained active for nearly 20 years and boasted 60 members at its height. The organization's mission was to visit individual inmates, advocate for their needs, press for basic rights and due process of law, and lobby Parliament to reform the madhouse system (Hervey, 1986). Former patients made up the vast majority of the membership, but lawyers and family members were welcome as partners.

Organized peer support in the United States developed in fits and starts and incorporated various ideas and movements, some of which occurred simultaneously. Peer support practitioners continue to capture new ideas and experiences that have proven effective in the field, ensuring that the movement evolves over time to respond to ongoing research discoveries and to changes in the society and culture.

One of the many strands braided together to create organized peer support was developed by ex-patient Clifford Beers. During the first decade of the 20th century, Beers conceived of what would become the Mental Hygiene Movement. However, Beers distrusted ex-patients' capacity to speak for themselves and looked to progressive professionals and citizens to spearhead reforms on behalf of people in mental institutions (Dain, 1980).

In 1937, a group of 30 ex-patients in Chicago formed an organization called Recovery, Inc., at the suggestion of Dr. A. A. Low of the Illinois Psychiatric Institute. With Dr. Low as the president, Recovery, Inc., set about changing discriminatory state civil service applications and commitment proceedings. By 1939 the group had 200 members who attended community meetings

and spoke on radio shows. The group also had its own newsletter with a distribution of 1,500. However, by 1940 the group lost its ties to the state hospital and ceased its activism (Dain, 1980). Although it was spearheaded by a medical professional, Recovery, Inc., was an important first step on the road to peer support.

In the late 1960s some ex-patients joined therapists in radical collectives to achieve therapeutic goals. However, the collectives often dissolved into separate movements reflecting the tensions between the two groups. This creative tension between collaboration with professionals and the creation of alternatives is part of the peer support legacy.

Discovering the power of self-help

The modern self-help movement began during the Depression when one alcoholic helped another get and stay sober. Together they launched Alcoholics Anonymous. AA members recover by sharing their "experience, strength and hope." The success of this basic recipe has spurred the broader self-help movement to grow to an estimated 500,000 groups with 7.5 million members in the U.S. (Lieberman & Snowden, 1994). The self-help groups help people cope with and heal from scores of illnesses, disabilities, and conditions.

Within the mental health movement, consumers increasingly began forming groups to meet their needs and those of their peers who were returning to the community. For example, ex-patients formed the clubhouse movement in the 1950s to provide peer support (Beard, Propst & Malamud, 1982; Beard, 1976). Research shows that many people, including those with mental illnesses, can improve their lives significantly by participating in self-help efforts. Policymakers are acknowledging the benefits of peer support by developing and funding new programs within the system of care (Medvene, 1986; Grusky et al., 1985; Gartner & Riessman, 1982).

Professional psychiatric rehabilitation programs offer socialization

Realizing the need for autonomy and social association among ex-patients and others who had experienced serious mental illnesses, and drawing on the early lessons of self-help, mental health agencies began to teach and evaluate socialization as part of rehabilitation (Campbell, 2005).

At least indirectly, the professionals followed the examples of the ex-patients who had developed a clubhouse model. Like the clubhouses, these rehabilitation programs offered participants opportunities to foster relationships and develop the confidence they needed to live more independent lives (Breier & Strauss, 1984).

Rise of patients' rights groups

Beginning in the 1960s, consumers insisted on an idea that was new to many outsiders: they had rights just like everyone else. What had been considered clinical issues were reframed by reformers as basic self-determination. This campaign benefited from the lessons of the civil rights, feminist, and other movements seeking to empower disenfranchised groups (Chamberlin, 1979, 1997; Van Tosh, Ralph, & Campbell, 2000).

Local patients' rights groups emerged in New York city, Portland (Oregon), and elsewhere, and groups formed loose networks with each other.

Addressing the needs of deinstitutionalized psychiatric patients

The various movements for empowering the disenfranchised continued to energize each other and, during the 1970s, these groups helped set the stage for the deinstitutionalization of psychiatric care. Waves of people left the wards on their own initiative or due to lawsuits and legislative and other reforms (Chamberlin, 1997). Other people, such as those with physical or developmental impairments, were also leaving institutions at that time.

After leaving the institutions, many ex-patients experienced a radical culture shock, often created by conditions beyond their control. For instance, they often entered communities where, thanks to suburbanization and other changes, they no longer had next-door neighbors, stores, and services within walking distance, nor did they have easy access to bus and train lines running to and from schools, offices, and medical facilities.

Furthermore, not only did ex-patients find themselves in new locations where it was difficult to establish independent lives, they also had to grapple with social prejudice and internalized feelings of worthlessness. As a result, many ex-patients felt stigmatized, lonely, and rejected (Baker & Intagliata, 1984; Campbell & Schraiber, 1989; Reidy, 1994; Zinman, 1987).

In 1971, peers in Vancouver, Canada responded to the challenges by creating self-help services in the form of a consumer-operated drop-in center and residence. Ex-patients in the United States followed suit. An array of self-help services was created that could be used exclusively or combined with traditional services (Chamberlin, 1997; Chamberlin, Rogers & Sneed, 1989).

The impetus for change

The patients' rights and self-help movements encouraged consumers to make informed decisions and take active roles in their treatment (Chamberlin, 1997). As one consumer told the Well-Being Project (Campbell & Schraiber, 1989), "We believe in the freedom to be able to choose the kind of services that are going to make us feel like worthwhile adults in the community and feel like we're contributing members to society. We feel the best way to do that is to allow us to make our own choices."

Over time, Federal agencies and, to some extent, professionals in the field recognized and accepted the importance of consumer decisionmaking. In 1977, the National Institute of Mental Health (NIMH) launched the Community Support Program (CSP) to focus on the needs of persons with long-term mental illnesses. Now an arm of the Substance Abuse and Mental Health Services Administration (SAMHSA), CSP funded the first National Consumer Alternatives Conferences in 1985 and sponsored 14 federal demonstration projects in communities across the country from 1988–91. CSP also funded consumer-operated centers for self-help research and consulting in≈Philadelphia, Lawrence (Massachusetts), and other locales.

From alternative programs to inclusion within the continuum of care

Once organized in their local communities, groups of ex-patients began to visit institutions to help patients recover and prepare for life outside. A surviving example is the Peer Bridger program, which operates around the country. In 1969, ex-patient and highly respected consumer rights activist "Howie the Harp" developed the first model for supported housing, one that heralded the right to "housing first" (Howie the Harp, 1993). This philosophy states that consumers have a right to safe housing; it builds on the concept that individuals make more progress in treatment when their basic need for security has been met.

As consumer self-help programs grew in numbers and competence, they received greater recognition. Gradually, they were included as options in mainstream planning efforts, notably the state and local Continuum of Care projects. Consumers also began to develop models and outcomes, evaluate services, and ensure that peer programs were offered by agencies and governments. These activities became particularly important because peer programs were becoming increasingly popular as complements to mainstream services (Van Tosh, Ralph & Campbell, 2000; McCabe and Unzicker, 1995; Chamberlin, Rogers & Ellison, 1996).

Beginning in the 1990s, consumers organized for empowerment, under the motto "Nothing About Us Without Us" (Chamberlin, 1997). They demanded and achieved new roles in mental health services and found an unexpected opportunity as customers in the then-new managed care systems (McCabe & Unzicker, 1995; Beisecker & Beisecker, 1993).

In response to the managed care opportunities, traditional providers hired consumers or worked with peer groups to provide services such as case management or crisis intervention (Solomon & Draine, 2001). Patients and ex-patients initiated conferences and workgroups and staffed consumer offices at the federal and state levels.

Expansion and differentiation of peer services

The vision of recovery articulated by consumers began to help shape rehabilitation across the nation. The vision was based on these realizations:

- People could and did recover even from severe mental illness; and
- Recovery should build on a person's strengths ((DeSisto et al., 1995; Harding et al., 1987; Rapp, 1998).

Peer programs developed common goals: (1) providing a safe and supportive environment, acceptance, and education and (2) encouraging the sharing of personal stories using the model established by twelve-step groups. Self-help among equals is the method generally used to achieve these goals, although peers may need to take formal roles as staff, mentors, and trainers to sustain and expand the groups' accomplishments (Salzer & Liptzin-Shear, 2002). Peer programs are "a work in progress" and continue to evolve based on participants' experiences and assessments of their accomplishments.

Self-determination and peer support across disabilities

The movement for empowerment for individuals with mental illnesses occurred as part of a broader context. In the 19th and 20th centuries, hundreds of thousands of people with all types of disabilities were swept up in the social policy of institutionalization and found themselves confined, some for life, in state hospitals, state "schools" and other segregated settings. In time, some individuals among this diverse group of people with physical, sensory, cognitive, and/or mental impairments recognized what they had in common.

Eventually, groups organized, no longer allowing themselves to be separated by diagnoses. Together they learned that they were impaired less by disability than by the lack of affordable housing, employment, transportation, education, and community living. They protested the medicalization of their lives and sought to become self-determining.

In the 1970s, as the self-help movement gained steam across disabilities, groups of people with various disabling conditions established peer-run, cross-disability organizations called Independent Living Centers. Eventually they reached every state. Peer support, skill building, and advocacy were the foundations of these centers, which have historically included people with psychiatric disabilities (DeJong, 1979; Deegan, 1992).

People with disabilities, including psychiatric disabilities, were appointed to serve on the National Council on Disability (2000), and organized at local, statewide, and national levels. In the 1980s, the cross-disability rights movement began to change the landscape of America to be more inclusive of people with disabilities.

Landmark victories were the 1990 passage of the Americans With Disabilities Act (ADA) guaranteeing civil rights to people with disabilities and the Supreme Court's *Olmstead* decision of 1999, guaranteeing people with disabilities the right to live and receive services in the community rather than being confined to institutions (Fleischer & Zarnes, 2001). This decision has been used to promote community living and the inclusion of individuals with mental illnesses under ADA protection (Bazelon, n.d.).

The cross-disability rights movement continues to encourage the evolution of service models such as self-directed care. In this strategy, people with disabilities control the funds for the supports they determine they need in the community (Center for Mental Health Services, 2005).

What are possible functions of consumer-operated service programs?

Consumer-operated programs may include the following:

- Providing mutual support;
- Building the community;
- Offering services; and
- Conducting advocacy activities.

These efforts may be undertaken separately or in any combination.

Mutual support

People who have common life experiences also have a unique capacity to help each other based on a shared affiliation and a deep understanding that may go beyond what exists in their other relationships (Carpinello, Knight, & Jantulis, 1992; Zinman, 1987). Peers often can help each other in an egalitarian manner, without designating who is the "helper" and who is the "helpee" (Constantino & Nelson, 1995; Riessman, 1990).

Further, the roles may shift back and forth within a relationship or occur simultaneously, with both parties benefiting from the process (Roberts et al., 1999; Mowbray & Moxley, 1997; Solomon, 2004; Clay, 2005). In self-help and mutual support, people offer their experience, strength, and hope to their peers, which allows for natural evolution of personal growth, wellness promotion, and recovery (Carpinello et al., 1992; Schubert & Borkman, 1994).

Community building

Consumer-operated services programs provide participants with opportunities to develop new social and interpersonal networks and to become full members of an inclusive and accepting community (Hardiman & Segal, 2003; Hardiman, 2004; Yanos, Primavera, & Knight, 2001).

These alternative communities or reference groups provide new ways of thinking about one's experience and practical ways to handle problems (Mead, Hilton, & Curtis, 2001; Campbell, 2005; Carpinello et al., 1991).

Providing services

Many consumer-operated programs provide concrete services such as safe shelters and assistance with other basic needs, such as housing and employment or education. The programs also may provide crisis response services, links to resources, social and recreational opportunities, information/education, and outreach (Clay, 2005; Goldstrom et al., 2006; Campbell & Leaver, 2003; Zinman, 1987).

In addition to direct services, the programs may be involved in providing technical assistance, evaluation and research, training, public education, and even healthcare purchasing cooperatives (Potter & Mulkern, 2004; Van Tosh & del Vecchio, 2001).

Advocacy

Consumer-operated organizations also may provide advocacy services in two levels. They may advocate for individuals by helping them to know and exercise their rights, access resources within the traditional service system or broader community, and address grievances.

Another purpose of consumers helping consumers is to form advocacy coalitions that amplify members' voices to promote system change and social justice (Zinman, 1987; Chamberlin, 1988; Harp & Zinman, 1994; Roberts & Rappaport, 1989). This social action agenda has been a fundamental element of the consumer self-help movement from its inception.

Consumers now actively and effectively participate in shaping mental health policy and services on the federal, state, and local levels (New Freedom Commission on Mental Health, 2003; U.S. Department of Health and Human Services, 1999).

Common ingredients

Consumer-operated organizations may take different approaches to providing services, but they do share certain essential ingredients. Various research studies are identifying and categorizing these elements (Solomon, 2004; Holter et al., 2004; Mowbray et al., 2005; Clay, 2005; Johnsen, Teague, & MocDonnel-Herr, 2005), and are delineating best practices, outcomes, and standards (MacNeil & Mead, 2005; Salzer, 2002).

The structures, processes, and values that distinguish consumer-operated programs from other kinds of services and supports are becoming better understood as common ingredients are identified. These elements and supports also provide important benchmarks for developing, managing, funding, replicating, evaluating, and defining quality (Hardiman, 2005; *Infusing Recovery*, 2002; Davidson, 1999).

Holter et al. (2004) divides the essential ingredients into two categories, structure and process. These are discussed below.

Structure

Structure refers to how programs are organized and operated. Structural elements that are essential for effective consumer-operated programs include consumer control, membership-run activities, participatory leadership, and voluntary participation.

Consumer control

True consumer-operated organizations are autonomous and fully consumer controlled. Consumers have majority (at least 51 percent) control of the governing board and have full authority for program administration and operation; this includes making policy, fiscal/budget, personnel, and programming decisions.

Typically, consumer-operated programs either function as independent nonprofit 501(c)3 organizations or exist under the fiscal umbrella of a supportive entity while they go through the steps of establishing this status (Mowbray et al., 2005; Clay, 2005; Van Tosh & del Vecchio, 2001; Davidson et al., 1999).

Although they are structurally autonomous, consumer-operated programs commonly build relationships with other agencies, supports, and resources in the community (Johnsen, Teague, & McDonel-Herr, 2005).

Member-run activities

Consumer-operated programs provide opportunities for members to perform different roles within the organization, including serving as paid or volunteer staff and as board members and officers (Johnson, Teague, & McDonel-Herr, 2005; Mowbray et al., 2005).

Many of the programs rely heavily on members for basic operations. This creates opportunities for participants to learn and practice new skills, exercise choice and decisionmaking responsibility, and assume leadership roles. Mental health consumers, many of whom are former program members, generally take any paid positions created by the organization (Mowbray & Tan, 1992).

Participatory leadership

Leadership styles within programs may be as diverse as those found in organizations not operated by consumers (Van Tosh & del Vecchio, 2001). Each style has its advantages and challenges, and shapes the character of the program itself.

Consumer-operated programs often try to establish participatory, nonhierarchical, and shared leadership structures. This provides for a fluidity and permeability of power within the organization among management, staff, and members (Mowbray et al., 2005; Zinman, 1987; MacNeil & Mead, 2005).

Programs respond to the needs and preferences of participants in various ways. This includes implementing democratic procedures, putting processes in place that enable consumers to indicate their satisfaction or dissatisfaction, and encouraging managers to make changes based on participant preferences, needs, and concerns (Clay, 2005; Mowbray et al., 2005).

Voluntary participation

Participation in consumer-operated services is voluntary. Members choose the amount and kind of program participation that fits their personal needs or preferences (Holter et al., 2004; Mowbray et al., 2005; Van Tosh & del Vecchio, 2000; Carpinello, Knight, & Jatulis, 1991).

The Consumer-Operated Service Program Multisite Study (1998–2002) identified this quality as a kind of "emotional safety" within the environment, which to mental health consumers means "a non-coercive milieu that soothes fears resulting from past trauma or trauma induced by the mental health service system," without "threat of commitment, clinical diagnosis, or unwanted treatment except in cases of suicide attempt or of physical danger to other participants" (Clay, 2005, p. 10).

Process

Process refers to the methods of delivering services within an organization. Solomon (2004) identified five basic process elements of consumer-operated programs that differ from traditional mental health services: control by consumers, voluntary participation, mutual benefit, natural (i.e. peer) support, and experiential learning.

Holter et al. (2004) present a set of critical process ingredients that directly parallel the principles and philosophies discussed below:

- Belief systems that include empowerment, recovery beliefs, recovery practices.
- Role structures that emphasize opportunity through group empowerment, advocacy, equal relationships, member activity, member participation, choice and decisionmaking opportunities, practice in improved skills, and positive role modeling.
- Social activities that include reciprocal relationships, social networks and opportunities, a sense of community, self-help, peer role models, and a sense of one's inherent strengths and value.

Fidelity

Can these common ingredients be measured or studied? Fidelity is a systemic effort to identify critical operational components of programs and to determine how well practitioners adhere to them. It is key to producing desired outcomes.

Studies have been conducted to identify common structure and process characteristics of consumer-operated services. For example, Mowbray et al. (2005) evaluated 31 consumer-operated drop-in programs to identify key ingredients. The researchers developed the Fidelity Rating Criteria for Consumer-Run Drop-In Centers (FRC-CRDI) to study and evaluate these services.

A seminal study was conducted between 1998 and 2002 by the SAMHSA Center for Mental Health Services. The Consumer-Operated Services and Programs (COSP) Multisite Study identified common ingredients across the seven consumer-operated multiservice agencies participating in the study. These elements were organized into five distinct categories:

- Program structure;
- Program environment;
- Belief systems;
- Peer support; and
- Education/advocacy.

These elements and categories formed the basis for the Fidelity Assessment Common Ingredients Tool (FACIT) further discussed later in this section (Johnsen, Teague, & McDonel-Herr, 2005).

In both of these formulations, belief systems or values emerge as primary common elements of consumer-operated organizations. These beliefs form the philosophy and principles that make peer support programs unique.

Principles and philosophy of consumer-operated services

Consumer-operated services are grounded in values and traditions inherent in the history of self-help in general and, more recently, the mental health consumer self-help movement.

Basic principles include belief in "peer-based support and assistance; non-reliance on professionals; voluntary membership; egalitarian, non-bureaucratic, and informal structure; affordability; confidentiality; and nonjudgmental support" (Van Tosh & del Vecchio, 2001, p. 11). Other core values include empowerment, independence, responsibility, choice, respect and dignity, and social action (Zinman, 1987; Chamberlin et al., 1996).

These principles have been organized into two broad domains: emancipatory (empowerment) and caring functions (Campbell, 2005).

Emancipatory functions

Emancipatory functions enable participants in consumer-operated programs to make choices guiding their own recovery. These include personal and organizational empowerment, the empowerment that comes from social action, consciousness-raising, and voluntariness.

Empowerment on personal, program, and system or political levels drives program development and management and is a definable and measurable outcome (Chamberlin, 1997; Rogers, Chamberlin, Ellison, & Crean, 1997; Segal, Silverman, & Tempkin, 1995a).

Personal empowerment

Personal empowerment and the related concepts of choice and self-determination are commonly heard terms among consumer-operated service programs (Mowbray, Holter, & Stark, 2005). Mental health consumers consistently state that their need for respect, dignity, and choice is most significant to their well-being and recovery (Campbell & Schraiber, 1989).

The working definition of personal empowerment developed by Chamberlin (1997) includes "decision-making power, access to information, choice from a range of options, assertiveness, feeling like one can make a difference, thinking critically, learning about and expressing anger, feeling a sense of belonging, knowing one's rights, effecting change, learning skills that one feels are important, changing other's perceptions, coming out of the closet, growth and change, and increasing one's positive self-image "(p. 44)."

These qualities can lead to independence and recovery, and are integrated into most consumer-operated programs and services.

Organizational empowerment

While empowerment can be thought of as a personal quality, it is also a characteristic of the structure and operation of successful consumer-operated programs. Attributes of an empowered organization include shared decisionmaking and mutual responsibility (MacNeil & Mead, 2005; Carley, 1994; Segal et al., 1993).

Empowerment through social action

Empowerment also occurs through social action. Because of the social justice and civil rights roots of the mental health consumer movement, consumer-operated programs often have a stronger political frame of reference than other self-help groups or initiatives (Mead & MacNeil, 2005; Zinman, 1987; Chamberlin, 1979; McLean, 1995).

In 1990, Riessman suggested that empowerment is both a personal and a politicization process through which an individual grows in self-awareness and then develops an awareness of broader social issues that affect both him/herself and other consumers.

Consciousness-raising

For personal choice or empowerment to have meaning, individuals must know the options and opportunities available to them, including options for interpreting their experiences. This requires consciousness-raising and its prerequisites: education, exploration, and the generation of alternatives.

Voluntariness

Voluntariness reflects the extent that attendance or participation in the service is truly a choice as opposed to required, mandated, or coerced. In consumer-operated organizations, "participation is completely voluntary, and. . . [occurs only when] the consumer decides to participate, which aspects of the program to take advantage of, and what other types of services to participate in" (Strouhl, 1986, p. 50).

Consumer-operated programs often serve individuals who are underserved by traditional agencies or who have "dropped out" of the formal treatment system. The lack of formal attendance requirements may promote trust and honest participation (Segal, Hardiman, & Hodges, 2002).

Caring functions

Caring functions ensure that individuals find appropriate support when they participate in consumer-operated services. Caring functions include these:

- A recovery orientation;
- Friendly, empathetic peer support that puts the helper and peer principles into action;
- A validating community that builds interdependence and mutual responsibility;
- Safe nonjudgmental service;
- Cultural competence;
- Experiential knowledge, including the "right to fail"; and
- Personhood.

A recovery orientation

A recovery orientation is based on the belief that each individual is capable of personal recovery and of living well (Clay, 2005). This belief in people's abilities creates the context for relationships that focus on wellness, health, life, and choice (Mead et al., 2001; Ralph, 2000; Diehl & Baxter, 1999).

The commitment to recovery helps members define "what works," including the use of supports outside the traditional mental health service system (Copeland and Mead, 2004).

Friendly empathetic peer support that puts the helper principle into action

Consumer-operated programs establish informal environments where relationships can grow among equals and each partner is valued for her or his inherent worth (Mowbray & Tan, 1992; Clay, 2005). These peer relationships involve not only common or shared experiences but also equal, accepting, and reciprocal relationships (Clay).

Peer support is empathetic and friendly, but should not be confused with therapy. Budd (1987) notes, "In support, the goal is to comfort, to be available as a caring friend, to listen, and to share the knowledge of common experiences. In any natural relationship, it is common for friends to make suggestions of multiple options, to listen to another's troubles, to offer encouragement, to comfort by expressing empathy, and to have common experiences and knowledge about available resources" (p. 43). Peers understand and offer each other the healing value of "being with" or "walking beside."

Peer support relationships have been repeatedly found to positively affect individual recovery (Breier & Strauss, 1984; Neighbors & Jackson, 1984; Powell, 1988; Davidson et al., 1999).

Communication, concern, and personal contact are consistently identified as important factors in helping relationships (Campbell, 2005; Asay & Lambert, 1999; Seligman, 1995).

The quantifiable positive outcomes in therapy can be largely attributed to the client's perception of the helping relationship and the strength of the connection—a sense that both parties are cooperating on a common goal. This applies across studies, programs, service approaches, and client groups (Kozart, 2002; Bachelor & Horvath, 1999; Horvath & Luborsky, 1993; Hartley & Strupp, 1983).

Peer support relationships embody the peer and helper principles (Gartner and Riessman, 1984; Carpinello, Knight, & Jatulis, 1991). The peer principle states that, "Members of [a peer] group understand each other as no one else can (Riessman, undated).

The helper principle acknowledges that "the healing effect and understanding of being helped by, and helping, someone else with the same problem is one of the key strengths of self-help" (Riessman, undated).

A validating community that builds interdependence and mutual responsibility

A unique aspect of consumer-operated organizations is the opportunity to create and experience an accepting and validating community. Being part of a network of caring individuals translates into feeling part of a greater whole and a sense of acceptance based on one's inherent value (Hardiman, 2005; Lieberman, Gowdy, & Knutson, 1991).

Community participation, peer support, and shared decisionmaking help participants develop a sense of mutual responsibility (Zinman, 1987) for the well-being of the group and helps participants overcome their isolation (Mead & MacNeil, 2005; Lieberman, Gowdy, & Knutson, 1991; Kurtz, 1988).

Safe, nonjudgmental service

Consumer-operated services provide the safe, nonjudgmental settings required for personal development. "Safety" in consumer-operated programs depends on people feeling comfortable "being themselves." With this unconditional acceptance come the strength and sense of security necessary for making major changes in thinking, beliefs, and behaviors (Clay, 2005).

Cultural competence

Cultural competence is an essential component of any kind of helping relationship. To be aware and knowledgeable about different cultural experiences with help and support is to respect people's different needs. As with other evidence-based practices, adaptation to environment, circumstances, and culture enable consumer-operated services to maintain fidelity to values and remain sensitive to each situation.

It is not enough, however, to think about cultural competence solely in terms of ethnicity and culture, but also in terms of how people have "come to know what they know" (Mead & MacNeil, 2005). People who have become acculturated to the language of mental health may, not surprisingly, prefer medical interpretations of experience. This phenomenon has often blinded us to the effects of trauma and abuse (Jennings, 1994).

A large percentage of people receiving services in the mental health system have histories of trauma and abuse (Jennings, 2004; Mueser et al.. 1998). Trauma-informed services are beginning to appear in the traditional service delivery system to respond to people's specific needs in a culturally competent manner (Harris & Fallot, 2001).

Consumer-operated services have perhaps an even greater challenge as we see the extent to which trauma has influenced people as individuals, their relationships, and even their organizations. Issues of leadership, conflict, role, boundaries, and safety must be addressed and evaluated with special attention to peer values and principles as well as with a deep awareness of the effects of trauma and abuse.

Experiential knowledge, including the "right to fail"

Consumer-operated services value experiential knowledge (Schubert & Borkman, 1994). Members believe that they can learn practical and alternative solutions for their problems and challenges by sharing their experiences, including their failures. In fact, members reserve the "right to fail" as a valued part of the learning experience.

For many people with mental illnesses, taking risks has been discouraged. Individuals have learned to think of themselves as fragile and dependent. Participants in consumer-operated programs recognize that taking risks can involve failing as well as succeeding. Regardless, risk-taking is seen as a learning experience, facilitating the journey of growth and opportunities (Chamberlin, 1979; DeJong, 1979).

Personhood

By promoting all of the caring and emancipatory factors, consumer-operated services help members develop a sense of personhood (Copeland & Mead, 2004; Mowbray & Tan 1992). Members have a range of roles, choices, and opportunities and relate to each other through their strengths, wellness, and recovery.

Who attends: The people who use consumer-operated services

Who participates in consumer-operated services?

Demographic information is incomplete but demonstrates that large numbers of people are attending consumer-operated services. Goldstrom et al. (2005), in a federal study of mutual support groups and self-help organizations run for and by mental health consumers, shows that these have surpassed the number of traditional mental health organizations nationwide. The support groups reported a total of over a million members, and the consumer-operated services reported serving over 534,000 persons in the previous year.

In 1996, Chamberlin and associates surveyed six representative consumer-operated services from across the United States. The membership demographics from the self-help sample were compared with data from a national sample of federal Community Support Program clients from traditional agencies. While the two groups were close in age and had similar rates of marriage, the self-help sample had more males, a larger proportion of African Americans, higher educational achievement, and fewer psychiatric hospitalizations. The authors noted that one urban peer-run program accounted for the majority of the variance in the samples.

A study by Segal et al. (1995b) on long-term members of self-help agencies in an urban area found that a high proportion were homeless and had co-occurring mental health and substance abuse disorders. "The demographic data suggest that self-help agencies, in combination with community

mental health agencies, can serve a poor, primarily African American and often homeless population—subgroups that are traditionally less well served by the mental health system" (p. 274). More recently, Holter & Mowbray (2005) studied 32 drop-in centers in Michigan. Their findings were similar: the majority of the users were male, with African Americans overrepresented in urban areas. They also found that 80 percent of the members were also clients of other mental health programs.

Why do people choose to use consumer-operated services?

Mowbray and Tan (1992) found that people went to consumer-operated services in large part for social reasons: they had friends there, they enjoyed the sense of family and community, and they liked having something to do and the opportunity to exchange ideas and assistance. Getting meals and snacks and having a place to go were also cited.

A recent study by Segal et al. (2002) looked at the factors driving decisions to seek help from self-help agencies or from traditional agencies and found "the primary reasons for going to the [self-help agency] are to seek self-help services and socialization opportunities. The major reasons for going to the community mental health agency are "to receive medication and counseling" (p. 246). They noted that perceptions of need, perceived helpfulness, fear of coercion, and ease of access to services are factors that form a complex and dynamic backdrop to these decisions.

What are some models for consumer-operated services?

Though consumer-operated services share some common elements, there are a variety of program types with varying functions. These models include mutual support groups, multiservice agencies, independent living centers, peer-run drop-in programs, as well as specialized supportive services (Campbell & Leaver, 2003).

Mutual support groups

Contemporary self-help groups, also described as mutual aid or mutual support/help groups, differ from traditional, naturally occurring support in that they are more intentional and structured, rely on specific processes or routines, and may have specific approaches for addressing problems and issues (Davidson et al., 1999). In recent years, self-help groups focused on mental health concerns have proliferated (Budd, 1987; Carpinello et al., 1992; Goldstrom et al., 2005).

Mutual aid groups generally emphasize anonymity, voluntary membership, member leadership and facilitation of the group, and the lack of a profit orientation (Mowbray & Tan, 1992; Budd, 1987; Chamberlin et al., 1996; Mead et al., 2001; MacNeil & Mead, 2005; Kennedy & Humphreys, 1994).

Members "help each other manage a range of personal concerns, including those associated with their psychiatric symptoms, prejudice and discrimination, work, housing, health, and personal relationships" (Campbell, 2005, p. 29).

The goal is to foster self-esteem, learn and teach practical skills for dealing with various mental health concerns, and to provide a safe nonjudgmental environment in which to share one's story (Clay, 2005; Ridgway, 2001; Whitecraft et al., 2005).

Reported outcomes of participating in mutual help groups include increased self-esteem, hopefulness, exposure to people who are further along in the recovery process (role models), a sense of empowerment, a renewed sense of one's strengths, value and identity, and an increased awareness of rights and social justice issues (Chamberlin, 1995; Van Tosh & del Vecchio, 2001).

Further, because of the shifts between help giver and receiver, members of such groups practice reciprocal support which can diminish overdependence on the traditional service system (Roberts et al., 1999). Self-help groups may be small, grass-roots groups within various communities or part of a structured network such as GROW (Keck & Mussey, 2005).

Multiservice agencies

Although peer support is typical of all program types, multiservice agencies also provide other services and programs. The range of potential services and programs is vast and may include mutual help groups, drop-in programs, housing services, employment or education support, and crisis response or respite. These agencies also may provide outreach to those who are underserved or who are in need (Leiberman et al., 1991), case management (Nikkel et al., 1992), trained peer advocates (Trainor et al., 1997), and help using community resources (Campbell, 2005).

Independent living centers

Independent living centers include programs and services for people across disabilities and are not limited to people who have psychiatric diagnoses. These programs may offer different services, but they always have a strong focus on advocacy, personal assistance, and self-help (DeJong, 1979).

Peer-run drop-in programs

Drop-in centers provide a central location, have no requirement for attendance, and provide a community place where people participate at will and each individual is invited to "just be yourself" (Kaufmann, Ward-Colasante, & Farmer, 1993; LeDoux, 1997; Meek, 1994; Silverman, 1997). They may be open when other services are closed.

Drop-in centers often appeal to people who have been disenfranchised or avoid the traditional mental health system. The centers are accessible; provide safe, nonjudgmental, and informal environments; and put few demands on clients (Chamberlin, 1979, Zinman, 1987).

Many drop-in centers also function as multiservice agencies, providing a venue for people to receive a range of needed services (Holter & Mowbray, 2005). Among these are support and activity groups, telephone and computer access, shower and laundry facilities, help with entitlements or housing, transportation passes, mail and address services, clothing, meals, and art and creative expression sessions (Chamberlin et al., 1996; Clay, 2005; Campbell, 2005; Schell, 2005).

Consumers also have access to libraries of self-help resources (Elkanich, 2005), as well as structured educational programs on coping and problem-solving skills, recovery, and wellness (Copeland, 1997); health and medication; and substance abuse (Vogel et al., 1998). Educational programs also cover consumer rights, self-advocacy, leadership development (Silverman, 1997), and financial management and tenancy skills.

Despite the fact that peer-run drop-in centers vary widely in the number and types of services offered, they share the common elements of socialization, empowerment, and advocacy (Mowbray, Wellwood, & Chamberlin, 1988).

Specialized supportive services

Some consumer-operated services organize themselves around one particular helping service such as housing, employment, supported education, or crisis response and respite.

Housing

These services range from helping people find housing to addressing homelessness, developing and operating housing, and creating housing cooperatives (Swarbrick & Duffy, 2000; Campbell & Leaver, 2003). All of these consumer-operated housing options support people in community life (Besio & Mahler, 1993) and encourage participants to access other components of consumer-operated services.

Supported employment

Supported employment programs help individuals develop the skills and confidence they need to compete in the job market. Services may be offered through a free-standing supported employment agency (Miller & Miller, 1997) or consumer-controlled business initiatives (Trainor et al., 1997).

More often, supported employment services are informally woven into the fabric of consumer-operated services, as members assume responsibility for specific tasks and then take on larger roles as volunteers, staff members, and leaders (Minth, 2005; Schell & Erwin, 2005). The training, education, and support available within the program can function as an avenue to employment and education in the larger community.

Crisis response and respite

Consumer-operated crisis programs emerged as alternatives to the coercive or abusive practices experienced by some people in traditional crisis services and psychiatric hospitals. The consumer-operated services offer an informal, nonclinical approach that relies on peer counseling.

The programs may be designed to prevent emergency hospitalization, provide alternative support throughout a crisis, or serve as a step-down program for individuals recently released from psychiatric hospitals.

Research indicates that these programs are associated with significantly decreased hospitalizations (Mead & Hilton, 2003; Dumont & Jones, 2002; Burns-Lynch & Salzer, 2001).

Substance abuse

Substance abuse is a co-occurring challenge for a number of consumers. Studies have found that peer support, especially when offered in tandem with traditional mental health treatment, improves outcomes and the individual quality of life (Klein et al., 1998; Whitecraft et al., 2005; Magura et al., 2002; Campbell & Leaver, 2003).

People with co-occurring disorders often respond better to peers who understand and share their experiences and can help them engage in substance-free and productive social activities. For example, Double Trouble in Recovery (DTR) is a mutual aid, self-help program for adults who have been dually diagnosed with mental illness and a substance use disorder that has been researched (Vogel et al., 1998), and as of 2008 it is listed in SAMHSA's National Registry of Evidence-Based Programs and Practices (NREPP).

Programs for specific groups

While all consumer-operated programs try to be sensitive to individual needs and experiences, more specialized strategies are emerging to meet the needs and preferences of specific groups. These groups include people with histories of trauma and abuse (MacNeil & Mead, 2005), as well as people from different cultural backgrounds (Harp & Zinman, 1994). Tailored programs are becoming increasingly important as consumer-operated services become more widely used and accepted.

Education and advocacy

Consumer-operated education and advocacy programs offer a structured curriculum in classroom format. While curricula may vary, the programs all stress 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 and psychiatric services, as well as strategies to support wellness" (Campbell, 2005, p. 30).

Advocacy programs offer training about service options, navigating the system and self-advocacy, working within the traditional system, and working effectively with social policy (Sangster, 2005). Education curricula include systematic wellness recovery plans (Copeland, 1997; Diehl & Baxter, 1999), information on treatment and recovery options (Hix, 2005), and other courses that provide people with skills and choices for their own recovery.

The emergence of an evidence base for consumer-operated services

Mental illness ranks high among illnesses that cause disability in the United States, Canada, and Western Europe. However, far too many Americans fail to receive services oriented to the single most important goal of people experiencing mental illnesses—the hope of recovery. Since the deinstitutionalization of mental health services in the 1970s, consumer-operated services have matured, diversified, and increased in numbers.

Formal integration of consumer-operated services into the continuum of community mental health care should improve treatment outcomes, promote wellness, and expand system capacity. These programs offer much-needed peer-directed practices to our nation's mental health infrastructure as we move to a recovery-based system.

Until recently research on consumer-operated services was largely limited to studies without scientific controls, demonstrations of feasibility, and preliminary findings. These suggested that consumer-operated services were effective across a variety of domains (Davidson et al., 1999; Solomon & Draine, 2001), but did not provide the more definitive findings associated with randomized clinical trials.

Since the inclusion of a discussion of the benefits of self-help for consumers in *Mental Health: A Report of the Surgeon General* (1999), the mental health field has observed the growth of a research base of controlled studies that demonstrate the effectiveness of peer practices in consumer-operated programs.

In 2003, *Achieving the Promise: Transforming Mental Health Care in America* (New Freedom Commission on Mental Health) acknowledged that consumers have "a key role in expanding the mental healthcare delivery workforce and creating a system that focuses on recovery" (p. 37). The report goes on to recommend that "consumers should be involved in a variety of appropriate service and support settings. In particular, consumer-operated services for which an evidence base is emerging should be promoted" (p. 37).

Ranking the evidence

Mental health care policy increasingly relies on evidence from empirical studies rather than on expert opinion or clinical experience alone (West et al., 2002).

Policymakers must understand both study results and the scientific quality of these findings to determine which models of consumer-operated services are most effective for different populations and to identify the costs associated with various outcomes. Research grading systems have been developed that help policymakers understand the quality of the scientific evidence presented in various studies.

This literature review uses the evidence grading system that was developed by the Agency for Healthcare Policy and Research (AHCPR, 1992; Leff, Conley, & Elmore, 2005; West et al., 2002) to determine "the extent to which a study's design, conduct and analysis have minimized selection, measurement, and confounding biases" (West et al., p. 1), and to establish the effectiveness and quality of the evidence base for consumer-operated services. This review includes findings from 25 studies conducted over the past 27 years that received level I (the highest) through level III rankings. The review also includes results from numerous reports meeting the lowest rank of evidence quality (level IV).

The following sections summarize all of the findings from the lowest to the highest rank of evidence quality.

Expert reports – Level IV evidence

The lowest rank of evidence quality (Level IV) is assigned to reports from expert committees and respected authorities with significant experience in the field. Level IV findings include the following:

- In his 1986 review of community support service models, Stroul reported, "Self-help is rapidly becoming an important force in the mental health arena, with increasing numbers of consumers coming together to share their pain, problems, and solutions. As with other types of self-help groups, mental health consumers can help each other because of their similar experiences and problems. . . Self-help groups can counter these feelings of loneliness, rejection, discrimination, and frustration by offering mutual support, companionship, empathy and sharing" (p. 49).
- In 1989, the National Association of State Mental Health Program Directors (NASMHPD) approved a position paper that recognized that former mental health patients/mental health consumers have unique contributions to make in the provision of direct services.

The bulk of expert knowledge on consumer-operated services is found in early publications on peer support services written by persons with mental illness (Zinman, 1986; Zinman, Harp, & Budd, 1987; Chamberlin, 1979; Campbell & Schraiber, 1989). These include some of the first-person accounts discussed earlier in the paper. In this literature, consumer-valued processes and outcomes of wellness promotion are documented, laying the groundwork for future quantitative studies of well-being, hope, empowerment, and recovery.

Zinman (1987) writes, "Self-help groups demystify our emotional life, giving back to us the knowledge and tools to help ourselves. Our emotional life is no longer somebody else's, the medical profession's specialty. We are the experts" (p.11). Budd (1987) describes mutual support groups as "a place to give as well as receive, a place to feel useful and to affirm your self-respect. A mutual support group can, thus, help you to explore your self-identification and to be a role model for your peers. This can be very empowering" (p. 43).

In the oral histories conducted as part of the Well-Being Project (Campbell & Schraiber, 1989), many consumer leaders discussed the value of peer-run programs in reducing psychiatric problems and in building empowerment, personhood, and social connectedness. Comments included the following:

- "I've pretty much been able to stay out of the hospital with the help of self-help groups" (Harp, p. 43).
- "The biggest thing that has brought me a sense of empowerment is to be a member of [the consumer-operated service] CAPABLE (Pierce, p. 51).
- "I've seen people grow tremendously while they been at Spiritmenders [a client self-help center]. They come and find peers; they find friends. . . Here they feel like they're human beings. . ." (Kaplan, p. 45).
- "It's in the right direction… People don't believe us, that we're capable of doing anything. . . But the trouble is, self-help works" (Price, p. 53).

Descriptive studies – Level III evidence

Level III evidence is obtained from well-designed nonexperimental descriptive studies, such as comparative, correlation, and case control studies.

In general, most of the research at this level was undertaken in the early development of consumer-operated services to ascertain the characteristics of people who choose to participate in these services, the processes that lead to change, and member perspectives on benefits of program participation in drop-in centers and organized mutual support groups.

Positive impacts reported by program members included improvements in quality of life (Chamberlin, Rogers, & Ellison, 1996), problem solving, satisfaction, social support, and coping skills (Silverman, Blank & Taylor, 1997; Lewis, 2001).

In addition, reductions were reported in hospitalizations (Mowbray & Tan, 1993), manic depressive symptomology, and use of traditional mental health treatment services ((Lewis, 2001).

This literature review includes 13 descriptive studies of drop-in centers and mutual support groups. These studies include Raiff (1984); Mowbray, Wellwood, & Chamberlain (1988); Kurtz (1988); Mowbray & Tan (1993); and Kaufmann, Ward-Colasante, & Farmer (1993. Also included are Luke, Roberts, & Rappaport (1994); Chamberlin, Rogers, & Ellison (1996); Carpinello, Knight, Videka-Sherman, Sofka, & Markowitz (1996); and Trainor, Shepherd, Boydell, Leff, & Crawford (1997).

In addition, the studies included DeMasi, Carpinello, Knight, Videka-Sherman, Solka, & Markowitz (1997); Van Tosh & del Vecchio (2001); Lewis (2001); and Segal, Hardiman, & Hodges (2002).

Drop-in centers

In a statewide initiative to promote consumer involvement, the Pennsylvania Office of Mental Health funded the development and evaluation of nine drop-in centers (Kaufmann, Ward-Colasante, & Farmer, 1993).

During the 6-month survey period, a total of 478 consumers used the drop-in services with a daily average attendance at 28 for each center. Although consumers were highly satisfied with the drop-in centers, they desired improvements in the number of paid staff, hours of operation, management, and transportation. The researchers concluded that consumer-operated centers "needed adequate funding and technical assistance to become viable components of community support services" (p. 678).

In Michigan, Mowbray & Tan (1993) evaluated six drop-in centers that had been open for at least 2 years, serving a total of 1,445 consumers. Structured interviews of 120 participants collected over a 6-month period indicated that the programs were meeting their funding goals: (1) serving people with severe mental illness and (2) creating an environment that promoted social support and shared problem-solving.

Social support emerged as the dominant reason consumers used the drop-in centers, with the majority of respondents (53.3 percent) reporting that they came to the center for people-related reasons such as having friends there, a sense of family, or the chance to socialize, converse, and exchange ideas. Other reasons consumers attended included something to do (25 percent), a place to go (23.3 percent), responsibility as a volunteer or worker at the center (19.1 percent), relaxation (14.2 percent), for coffee and doughnuts (13.3 percent), and for help and encouragement (6.7 percent).

When asked how the center has changed their lives, respondents noted positive effects. Seventy-nine percent reported gaining more friends, and 53 percent reported being more confident in making decisions in employment, education, living conditions, relationships, treatment, or other life changes. Most respondents (72 percent) attributed the increase in confidence to factors related to the center; 68 percent believed the center had helped them stay out of the hospital. Levels of satisfaction were uniformly high across the centers.

The centers were perceived by 77 percent of the respondents to differ positively from other mental health programs they had experienced. The major differences cited were more freedom (29.2 percent), more support and caring (21.7 percent), and less structure (11.7 percent).

Chamberlin, Rogers, & Ellison (1996) collected survey data from 171 members attending six consumer-operated drop-in programs located throughout the United States to increase understanding about membership demographics, program satisfaction, and perceptions of how these programs had affected quality of life.

The authors reported, "Overall, respondents indicated that being involved in self-help had a salutary effect on their quality of life, including their general life satisfaction" (p. 40). Nearly all (92 percent) respondents felt more positive about themselves as a result of self-help involvement, and 87.5 percent felt more productive and capable. In terms of social life, 50 percent indicated that the quality of their family contact had changed in a way they liked, and 53 percent reported that their contact with friends had similarly improved. When asked what effect self-help had on their housing, financial and social situation, 77 percent reported some or a highly positive effect.

According to Segal, Hardiman, & Hodges (2002), "cost-conscious mental health governing bodies are delegating socially based interventions to self-help agencies, leaving community mental health agencies to focus primarily on clinical interventions" (p. 1146). In order to determine how this division of labor affects who seeks help from these organizations, the researchers compared the demographic, clinical, and social characteristics as well as the service use histories of 673 new clients at 10 pairs of self-help and community mental health agencies serving the same geographic areas.

The researchers found that clients of community mental health agencies had more acute symptoms, lower levels of social functioning, and more life stressors in the previous 30 days than clients of self-help agencies. At the same time, clients of self-help agencies evidenced a greater self-esteem, locus of control, and hope about the future. Based on these findings, the researchers suggested that clients who came to the community mental health agencies were more likely to be in the acute phase of their conditions, whereas those coming to the self-help agency primarily were seeking psychosocial assistance.

Accordingly, the researchers recommended that (1) community mental health agencies focus on addressing acute problems from a multi-service perspective and (2) self-help agencies provide ongoing support services and advocacy for clients with a long history of mental health problems. They added that mental health agencies should strengthen the role of self-help agencies through more formalized referral networks.

Mutual support groups

Raiff (1984) investigated health-related outcomes of self-help participation, using Recovery, Inc., an international mutual support organization with formally structured group meetings, as a case example.

An anonymous 23-page questionnaire was mailed to 520 Recovery, Inc., leaders who had been stratified according to their degree of self-help experience and/or administrative responsibility using a combination of randomization procedures and information chaining.

The study sample consistently displayed improvements in medical utilization rates. Although 199 sample members had at some time been hospitalized, only 17.6 percent had been hospitalized after joining the organization. In addition, although 125 persons in the sample had experience with electroconvulsive therapy (ECT), only 3.3 percent had ECT after affiliation.

The entire sample also reported gains on the indicators describing reduction in physician utilization and medication regimens. The sample appeared to rank high on self-assessments of health satisfaction and lack of worry; they also were satisfied with their overall mental health. Ninety-two percent of the respondents also replied positively to questions about relative happiness and satisfaction. Lower positive ratings appeared to be associated with less than 2 years' membership in the organization.

In a survey of 188 participants in the founding chapter of the National Depressive and Manic Depressive Association, respondents reported that since participation they were better able to accept their illness, cope with symptoms, and comply with medication regimens.

In addition, they reported reduced hospitalizations (Kurtz, 1988). These findings were replicated in a more recent evaluation of more than 1,000 members participating in the Depression and Bipolar Support Alliance (DBSA). Members described participation in their consumer-operated mutual support groups as helping with communication with their doctors, motivation to follow instructions, willingness to take medication, and improved ability to cope with side effects of these medications. In addition, fewer manic depressive symptoms and decreased hospitalization were associated with length of attendance at the consumer-operated program (Lewis, 2001).

Quasi-experimental studies – Level II evidence

A level II rank is assigned to well-designed controlled studies without randomization and other types of well-designed quasi-experimental studies.

Seven studies that used nonrandomized control groups or pretest scores as comparisons were located. These included studies by Nelson, Ochocka, Janzen, Trainor, Goering, & Lomotey (2007); Galanter (1988); Hodges & Segal (2002); and Kennedy (1990). Also included are studies by Magura, Laudet, Mahmood, Rosenblum, & Knight (2002); Roberts, Salem, Rappaport, Toro, Luke, & Seidman (1999); and Yanos, Primavera, & Knight, 2001).

The studies showed that participation in consumer-operated services reduces psychiatric symptoms and hospitalization (Kennedy, 1990; Galanter, 1988), improves psychological and social adjustment (Roberts et al., 1999; Yanos et al., 2001), and encourages goal advancement (Hodges & Segal, 2002).

A study of participation in a 12-step self-help organization specifically designed for persons with both chronic mental illness and substance use disorders found that consistent attendance at meetings was associated with better adherence to psychiatric medication (Magura et al., 2002).

Another study of long-term benefits of consumer-operated services (Nelson et al., 2007) discovered that improvements in outcomes occurred only for those who remained actively involved. As a result, researchers suggested that when participants no longer are active, the positive benefits (e.g., quality of life, involvement in employment and education) diminish because the individuals are no longer in a supportive environment.

Increases in the understanding of consumer-operated program processes and the mediating factors associated with recovery outcomes have been developed based on investigations of (1) the relationships of peers in giving and receiving help, (2) the psychological impact of interacting with recovering peers, and (3) longitudinal studies following participants for more than 2 years.

Interpersonal transactions in giving and receiving help

Investigators have theorized that the interpersonal helping transactions that occur in group meetings may be important therapeutic processes within self-help groups. Roberts and colleagues (1999) hypothesized a link between giving and receiving help and psychosocial adjustment in GROW, a mutual help group for individuals with serious mental illness.

During a 27-month period, the psychosocial adjustment of 186 participants from 15 ongoing GROW groups in central Illinois was assessed at two time points using self-report instruments as well as interviewer ratings of participant functioning; helping behaviors were measured with observational coding of 527 weekly group interactions during the period between assessments. Frequencies of helping behaviors were used to predict Time 2 adjustments after controlling for initial adjustment.

Consistent with the helper therapy principle, giving help to others predicted improvements in psychosocial adjustment. While total amount of help received was not associated with social adjustment, receiving help that provided cognitive reframing was associated with better social adjustment. A predicted interaction suggested that receiving help was related to better functioning when members experienced high levels of group integration.

Impact of relationships with recovering peers

The psychological impact of interacting with recovering peers was examined by Yanos et al. (2001) in a study of the relationship between participation in consumer-operated services and recovery of social functioning among people diagnosed as having serious mental illnesses. The researchers also examined the role of self-efficacy, hopefulness, and informal learning of adaptive coping strategies in mediating this relationship. Sixty participants with a past or present psychiatric diagnosis and at least one past psychiatric hospitalization were recruited from a community mental health center and two consumer-operated programs.

The researchers found that (1) participants involved in consumer-operated services had better social functioning than those involved only in traditional mental health services; (2) psychological variables were significantly associated with social functioning; and (3) the relationship between involvement in consumer-operated services and social functioning was partly mediated by the use of more problem-centered coping strategies. Premorbid and demographic factors did not account for the relationship between psychosocial variables and social functioning, although education was a significant predictor of social functioning.

Long-term study of the impact of consumer-operated services on participant functioning

The Consumer/Survivor Initiatives (CSIs) study in Ontario, Canada conducted by Nelson et al. (2007) is one of few studies of self-help groups using longitudinal designs and comparison groups. In addition, the study is the first to follow participants for more than 2 years.

To evaluate the impacts of long-term participation in CSIs, researchers used a non-equivalent control group design to compare 25 active CSI participants with 77 inactive participants at baseline, at 9- and 18-month intervals, and at 36-month followup.

The two groups were comparable at baseline on a wide range of demographic variables, self-reported psychiatric diagnoses, service use, and outcome measures. However, at 36 months the active CSI participants scored significantly higher than the non-active participants on measures of community integration, quality of life, and instrumental role involvement (such as employment and education).

In addition, active participants scored significantly lower on measures of symptom distress. The study results also indicated a significant reduction in days of psychiatric hospitalization for both active and inactive study participants. These findings suggest that consumer-operated services need to find ways to continue to engage members for long periods of time.

Randomized controlled trials (RCTs) – Level I evidence

Policymakers are committed to transforming mental health care by implementing practices with proven effectiveness. As a result, researchers are increasingly focused on developing the evidence base for consumer-operated services. This literature review summarizes five RCTs of both treatment and wellness outcomes and service costs. These include studies conducted by Campbell et al. (2006); Dumont & Jones (2002); Gordon, Edmundson, Bedell, & Goldstein (1979); Kaufmann, Schulberg, & Schooler (1994); and Kaufmann (1995).

The RCTs are successfully improving the quality of evidence for the effectiveness of consumer-operated services, but they also introduce methodological problems and analytical complexity to some study protocols. Issues under discussion include low participant engagement, selection bias (Campbell et al., 2006; Kaufmann et al., 1994), and the need for multi-level modeling.

However, at least one successful RCT study has been completed, enabling scientists to rank the evidence-base for consumer-operated services at level I.b, the second highest level a service or intervention can achieve. Meta-analysis of multiple RCTs is required to attain the highest rank, I.a.

The effects of participant choice on the study of self-help participation

Kaufmann et al. (1994) developed an experimental design to test the effectiveness of self-help group participation using a sample of 90 participants randomized to either experimental or control groups. Because choice is valued in peer service participation, people randomized to the experimental group were invited, not assigned, to join self-help groups and were given outreach to encourage their participation. Results, however, showed low rates of 17 percent participation in the self-help groups for both experimental and control subjects, yielding a sample too small for statistical analysis. Therefore, the study was terminated.

Post hoc analyses of the 15 persons who participated in self-help, 75 persons who did not participate, and a comparison group of 90 existing self-help members showed that study participants had more severe psychiatric symptoms than either nonparticipants or members. The researchers concluded that the results pointed to the need for multisite studies of self-help groups.

Integrating skill building and peer support in mental health treatment

In a preliminary evaluation of a Florida Community Network Development project, the researchers (Gordon et al., 1979) hypothesized that clients' tenure and independence in the community would increase when they were provided with skill enhancements coupled with supportive environmental changes.

The investigators randomized 80 clients at the point of discharge from the Early Intervention Project (EIP) to either the Community Network Development (CND) project or to a control group. EIP was a program designed to introduce intensive skill training early in clients' residential treatment to increase their personal coping skills and independence.

The CND fostered a peer support system composed of mental health clients who resided in the community and provided each other with emotional, instrumental, and recreational support in their daily lives. Both groups received equivalent discharge planning, including referral to their local mental health center.

At the 10-month followup, 17.5 percent of the participants assigned to the CND project required rehospitalization, compared with 35 percent of the control group. In addition, the average total days of hospitalization was lower for the CND participants (7.0 days) than for the control group (24.6 days).

Furthermore, a significantly greater percentage of CND members were able to function without contact with the mental health system (52.5 percent for CND participants compared to 26 percent of the control group).

The researchers cited anecdotal reports indicating that the most direct measure of the CND project effectiveness was the increase in social and instrumental support available to participants. They concluded that, through the development of friendships, members of the CND were able to interact and to help each other in ways that typically would not be practical in other aftercare programs. By capitalizing on consumers' desire to help each other, it was possible to increase the amount of support and services available to members without additional programmatic costs.

The Self-Help Employment Center

The Self-Help Employment Center project (Kaufmann, 1995) was an early study of the operations of a specialized self-help service focused on employment outcomes.

This National Research Demonstration Grant project was funded by the SAMHSA Center for Mental Health Services (CMHS) to test the effects on employment of mutual support in conjunction with professional vocational rehabilitation services.

The researchers randomly assigned 161 persons with serious mental illnesses to either an experimental group which received services at the Self-Help Employment Center or to a control group receiving customary community service.

Although the Peoples Oakland Self-Help Employment Center selected for the study was not a consumer-operated agency, it was strongly influenced by consumer interests and demands. The Center encouraged and depended upon consumer input and management in daily operations. Together, both staff and consumers actively shaped the programs, assessed their quality, and identified areas needing improvement.

Researchers conducted a first year followup assessment using the Mann-Whitney U-test to measure rank order differences between the groups. They found significant improvements among consumers in the experimental group. Only 16 percent of the Self-Help Employment Center group remained unemployed compared to 25 percent of those in the control group.

Furthermore, 22 percent of the consumers in the Center group had paid work for 16 hours a week or more, but only 15 percent of the control group was employed at this level. In addition, 19 percent of consumers in the experimental group, compared to only 7 percent of the control group, had paid work for less than 16 hours a week.

The Crisis Hostel Project

Another CMHS-funded National Research Demonstration Grant investigated the effectiveness of specialized self-help services in psychiatric crisis management (Dumont & Jones, 2002). Investigators developed and operated the Crisis Hostel, a five-bed residence alternative to psychiatric hospitalization, located in Tompkins County, New York.

Researchers hypothesized that access to consumer-operated, voluntary, nonmedical crisis services based on peer support would result in less frequent and shorter durations of crisis service use in either the hostel or a psychiatric hospital. They predicted that persons with access to Crisis Hostel services would experience a movement toward healing/recovery, and a greater sense of empowerment and satisfaction with services than persons who did not have access to the hostel. They further predicted that the reduction in use of inpatient crisis services would lower total mental health treatment costs when compared to the usual treatment system.

The hostel operated for 2 years. Analysis of the findings showed that the experimental group had better healing outcomes at the 6-month interval and from baseline to 12 months. The experimental group had greater levels of empowerment than the comparison group at the 12-month interval and from baseline to 12 months. However, both groups reported the same number of hours spent in paid or volunteer employment over the entire study period.

Not surprisingly, the experimental group members reported that the Crisis Hostel offered crisis services that were more timely and useful (performed by more competent staff who respected the consumer's rights) than the usual crisis services. The experimental group experienced greater levels of healing and self-care promotion and reported higher levels of service satisfaction than the control group.

In the 6 months prior to entry into the study, a greater proportion of study group participants were admitted to the hospital (24.7 percent vs. 17.5 percent). Despite this, the proportion of hospital admissions was similar for the experimental and control groups during the first 6 months (11. 9 percent vs. 12.6 percent). During the second 6 months, the admission rate for the experimental group dropped to 7.7 percent, compared with 13.2 percent for the control group; however, this change was not statistically significant.

Participants in the experimental group who were hospitalized had shorter lengths of stay than similar members of the control group. Over the year, the average stay was 10.7 days for the test group and 15.15 days for the control group. Due to the small size of the sample, this difference could not be shown to be statistically significant. However, a repeated measure approach that took into account the entire sample did find a significant difference in mean hospital stay.

Cost comparisons found that the experimental group had lower psychiatric hospitalization, crisis service, and total specialty mental health costs. Psychiatric hospital costs (measured as inpatient and emergency room costs) averaged $1,057 for the experimental group and $3,187 for the control group. When Crisis Hostel costs were combined with the other crisis service costs, the experimental group's average costs trended lower than the control groups. When all specialty mental health services were included—the crisis services costs as well as the expenditures on community mental health services and supportive housing programs—the experimental group again had lower treatment costs.

In nearly all areas, people assigned access to the Chrisis Hostel arm of the study had both better outcomes as well as lower costs. Participating in the experimental group was associated with greater levels of healing, empowerment, and satisfaction. This group also experienced less disruption in their work life.

The Consumer-Operated Services Programs Multisite Research Initiative

With urging by consumer researchers and providers, CMHS initiated a study of consumer-operated services using a multisite approach, which accumulates evidence in a standardized, efficient, and rigorous way. After considerable planning and stakeholder input, CMHS published a request for grant applications in 1997.

The Consumer-Operated Services Programs (COSP) Multisite Research Initiative (1998–2006) advanced the field of study design by bringing together individuals with mental illnesses and researchers to deepen the understanding of the programs and services that consumers operate to promote their wellness.

The study (Campbell et al., 2006) is the largest and most rigorous study of consumer-operated services conducted to date, with 1,827 individuals participating at eight sites nationwide—four drop-in centers, two mutual support programs, and two educational/ advocacy programs—and the respective control programs in traditional mental health service organizations. Study participants were all established users of traditional services.

Members of the experimental group were offered consumer-operated services as an adjunct to traditional services, although adherence to a randomly assigned condition was not mandatory.

The primary hypothesis was that persons offered consumer-operated services in addition to traditional services would experience a greater gain in well-being than those expected to use traditional services alone. However, significant differences in group results were not anticipated because outcomes were assessed over the relatively brief followup period of 1 year.

Actual participation in consumer-operated services was relatively low, and some persons assigned to the traditional services-only condition used consumer-operated services, thus potentially reducing the strength of any formal experimental effects. Nonetheless, the experimental group showed a greater overall increase in well-being.

After controlling for actual service use, researchers found that participants who made any use of consumer-operated services had greater average increases in well-being than those who did not, and those who participated more in these services had greater average increases than those who were less active.

General, subjective, and objective empowerment outcomes were examined. Researchers found statistically significant differences using a general measure of empowerment to compare the two groups of study participants. Measures of objective changes in behavior had varied outcomes across the sites.

Participants assigned to consumer-operated services showed significantly greater gains overall in subjective outcomes than those involved only in traditional services. Further, greater use of the consumer-operated services was significantly related to greater gains on most measures of empowerment. The variations in strength of effect across sites were related to levels of participation rather than to types of consumer-operated services.

In summary, findings from the COSP Multisite Research Initiative support the conclusion that participation in consumer-operated services leads to significant increases in both well-being and subjective aspects of empowerment, when compared with results achieved through participation in traditional mental health services alone.

These effects do not appear to be restricted to specific types of consumer-operated services. The effects also appear to be both additive and compensatory: greater relative gains occur where traditional programs alone show less effect.

To better understand these effectiveness findings, the researchers probed for links between specific program characteristics and increases in well-being. FACIT scores analyses indicated that all consumer-operated services scored higher than traditional programs in the Belief System Domain (Johnsen, Teague, & McDonel-Herr, 2005). Items in this domain included the peer and helper's principles, empowerment, choice, recovery, acceptance and respect for diversity, and spiritual growth.

Items included in the Environmental Domain also correlated at significant levels with changes in well-being. These items include services provided free of charge, sense of community, and lack of coerciveness. Other Environmental Domain items are program rules developed by consumers that ensure physical safety and no hierarchy, but rather a sense of freedom and warmth among members and staff.

Self-expression items in the Peer Support Domain also were significantly associated with improvements in well-being. These items include artistic expression, opportunities for sharing life experiences or telling one's story, and formal peer support activities.

When the FACIT scale scores were adjusted to control for condition, all the items in the Structure Domain, as well as the peer ideology and choice/respect items in the Belief System Domain, correlated with well-being change to produce an overall significant correlation of FACIT domain scores with well-being change.

The FACIT findings indicated that the identified ingredients were critical to the delivery of effective consumer-operated services.

From promising practices to evidence-based practices

The following section highlights milestones in the emergence of consumer-operated services as evidence-based practices. The chapter concludes with suggestions about areas in which further research would be especially helpful in solidifying the general understanding of effective practices.

Out of the shadows: Consumer-operated services emerge as an evidence-based practice

The evidence base for consumer-operated services spans a 30-year period, but until recently the identification of evidence-based practices has focused primarily on the effectiveness of traditional mental health programs, neglecting to consider the consumer-operated service elements and outcomes valued by individuals in selecting treatment and services. This has had a profound effect on the quality, amount, and content of the research conducted on consumer-operated services, and consequently, on the development of the evidence base.

In the 1970s and 1980s, mental health administrators used measures of output and volume to make judgments about the value or quality of a service and to make funding decisions regarding these services. Effectiveness studies were seldom funded, and researchers developed and validated outcome indicators that they considered desirable (Campbell, 1998).

Studies of outcomes such as hope, recovery, or the capacity of persons to sustain themselves in the community as independent citizens were absent in the scientific literature. Within this context, there was scant interest or support for rigorous studies of the effectiveness of consumer-operated services or measurement of positive psychological functioning in mental health services research.

The few studies of consumer-operated services tended to assess improvements in clinical outcomes such as medication compliance, and reduction in symptomology and hospitalization (Edmundson, Bedell, Archer, & Gordon, 1982; Galanter, 1988; Kurtz, 1988).

In 1993 CMHS funded a series of focus group sessions of national consumer leaders to begin the systematic articulation of valued treatment outcomes from service recipients' perspectives. According to participants, traditional mental health systems "pathologized" problems of daily life, held low expectations of consumer achievement, were paternalistic, offered a limited range of options, and defined anger as an indicator of pathology or disease. In contrast, the focus groups identified recovery, personhood, well-being, and choice as the most relevant outcomes for mental health programs (Trochim, Dumont, & Campbell, 1993).

The CMHS focus groups and subsequent development of the federal Mental Health Statistics Improvement Program (MHSIP) Consumer-Oriented Report Card established consumer values as a key factor in determining program effectiveness (Teague, Ganju, Hornik, Johnson & McKinney, 1997).

Consumers in dialogue with mental health professionals advocated for the addition of measures of recovery and empowerment, more funding for studies of peer support, and the inclusion of consumers in the research process (Campbell & Johnson, 1995; Loder & Glover, 1992). In New York, a forum was organized for psychiatrists and consumers to exchange perspectives, develop a shared vision of recovery, and consider ways in which treatment relationships could be more collaborative (Blanch, Fisher, Tucker, Walsh, & Chassman, 1993).

As many members of the mental health community began recognizing the value of the experience and perspective of persons who had been institutionalized, the role of recipients of mental health services as partners in the design, delivery, and research of services was reconceptualized (Campbell, 1996; McCabe & Unzicker, 1995; NASMHPD, 1989).

In particular, the growing emphasis on consumer values and broadened measurements of outcomes led to the adoption of participatory styles of research and evaluation (Leff, Campbell, Gagne, & Woocher, 1997). Consumers who were trained researchers joined with consumer administrators and providers to apply sophisticated data and health informatics strategies to public policy debates, peer services, and the conduct of research itself (Campbell, 1997b; Scott, 1993).

The key to the development of the consumer-operated services evidence base was the continued support of the federal government, which began to promote self-help as part of a broader effort to reform psychiatry through patient self-advocacy.

Consumer involvement in mental health services was mandated by federal law and actively promoted by projects at the federal and state levels (Parrish, 1989; National Institute of Mental Health, 1991).

Most notably, the CMHS Community Support Program (CSP) funded 14 projects designed to implement and evaluate consumer-operated services during 1988–91. The projects included Furlong-Norman (1988); Galanter (1988); Heine, Hasemann, Mangine, Dearborn-Morris, & Royse (1993); and Kaufmann, Ward-Colasante, & Farmer (1993). Also funded were: Lieberman, Gowdy, & Knutson (1991); Mowbray & Tan (1992); and Nikkel, Smith, & Edwards (1992).

The projects included drop-in centers, outreach programs, businesses, employment and housing programs, and crisis services (Van Tosh & del Vecchio, 2001; Long & Van Tosh, 1988). Other CSP initiatives included support for centers for self-help research and self-help technical assistance centers, as well as an annual "alternatives" conference.

With federal and state support through block grants and other federal funding such as research demonstration initiatives, the number of consumer-operated services expanded during the 1990s, and multiple models of consumer self-help service provision were offered (Campbell & Leaver, 2003).

Evaluation of these efforts produced a wealth of descriptive and quasi-experimental data on peer-run programs. Since consumer advocates regarded empowerment as the principle underlying self-help goals, scales were developed to measure empowerment in consumer-operated services (Rogers, Chamberlin, Ellison, & Crean, 1997; Segal, Silverman, & Temkin, 1995b).

Building on earlier research and capacity-building initiatives, investigators began to conduct more rigorous studies of consumer-operated services that included measures of empowerment, hope, self-esteem, well-being, and healing/recovery, among others.

Investigation of the relationship of positive psychological functioning and participation in mutual support groups and drop-in centers suggested that consumer-operated services improved perceptions of self, social functioning, and decisionmaking (Roberts et al., 1999; Yanos et al., 2001). Dumont and Jones (2002) showed that access to a crisis hostel program produced healing/recovery and a greater sense of empowerment than traditional hospital-based services.

The link between the service elements of consumer-operated services and positive psychological functioning found in the COSP Multisite Study (Campbell et al., 2006) further validated consumer-provider claims to an important voice in transforming the content and character of community mental health services to a recovery-based system that promotes mental wellness.

Recommendations for further research and practice

Evidence shows that consumer-operated services are supporting people in their wellness and recovery while also contributing to the entire mental health service system. Moving the field forward requires considering the philosophy and values of consumer-operated services, developing more rigorous standards of practice and competencies to help programs achieve these values and principles, and designing and conducting research that will further substantiate the evidence base for consumer-operated services (Fixsen, Naoom, Blase, Friedman, & Wallace, 2005). These studies also should achieve the following:

- Assess the ability of consumer-operated services to improve long-term outcomes such as improved employment and housing stability; and
- Link program ingredients and member characteristics to a wide range of desired outcomes.

Taken together, the results of studies will enhance knowledge of consumer service practices and provide the empirical basis for creating effective partnerships among consumer-operated services, public mental health agencies, and managed care organizations. Findings will also be of great value to consumer-operated services in the early stages of organization or program development, as well as to those involved in workforce certification, evaluation, and other quality improvement efforts.

Establishing standards and competencies

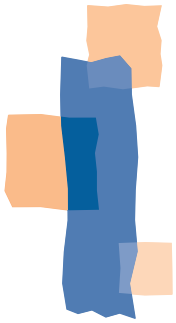
Additional research focused on establishing standards and competencies also will build the field and increase the evidence base. As consumer-operated services become more established and funding more competitive, there is a need to identify specific attitudes, knowledge, and skills that are essential for peer support and effective operation of these services and programs. Articulation and explication of these competencies enhances the ability of consumer-operated service providers to teach and practice the core skills, and ensures the provision of high quality, values-driven services (Curtis et al. 2002).

Several states, associations, and academic institutions are establishing certification programs to ensure a qualified and ethical consumer workforce (Center for Mental Health Serivces, Fricks, 2005; Sabin & Daniels, 2003). In addition, clarification of the competencies and standards unique in peer support can help

programs avoid the "values drift" whereby they assume characteristics of traditional services (Harp & Zinman, 1994, Campbell, Dumont & Einspahr, 1999; Salzer, 2002; MacNeil & Mead, 2005).

However, it is equally important to maintain the flexibility to allow for program adaptation and evolution. While the COSP Multisite Study and other research have identified critical ingredients, new initiatives are developing all the time. As consumer-operated services take on a larger role in the service delivery system, practices will expand and grow, providing new insight into possible outcomes.

In order to capture these changing nuances, evaluation and research strategies may take a more qualitative approach to understanding the unique and growing contribution consumer-operated services are making.



EVIDENCE-BASED PRACTICES

KIT

Knowledge Informing Transformation

The Evidence

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Easy-to understand book about starting and running nonprofit organizations, including information about creating a vision, forming and working with a board of directors, promoting the organization's mission, and working with government officials.

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Copeland, M. E., & Mead, S. (2004). *Wellness recovery action plan and peer support: Personal, group and program development*. West Dummerston, VT: Peach Press.

Offers guidance for integrating Wellness Recovery Action Plan (WRAP) methods and peer support.

Videos

Deegan, P. E., & Sea Rose Productions. (Producer). (2004). [DVD and video]. *The politics of memory*. Available from **http://www.patdeegan.com/**

Explores the history of mental health services from the viewpoint of the people who have received them.

Deegan, P. and Strecker, T. (Producers). (2004). *Inside/outside: Building a meaningful life outside the hospital* [DVD and video]. Available from **http://nmhicstore.samhsa.gov/publications.ordering.aspx or www.pagdeegan.com/shop**

Follows the lives of people who have been institutionalized but now live successfully in the community.

Web sites

- Judge David J. Bazelon Center for Mental Health Law: **http://www.bazelon.org** (Listed under "B" in the references that follow.)
- Boston University Center for Psychiatric Rehabilitation: **http://www.bu.edu/cpr**
- Center for an Accessible Society: **http:///www.accessiblesociety.org**
- Community Consortium: **http://www.community-consortium.org**
- CompassPoint Nonprofit Services: **http://www.compasspoint.org**
- Coordinating Center, COSP Multisite Research Initiative: **http://www.mimh.edu/cstprogramarchive**
- Craigslist: **http://www.craigslist.org**
- E-Grants Initiative: **http://www.grants.gov**
- Foundation Center: **http://www.foundationcenter.org**
- Georgia Certified Peer Specialists: **http://www.gacps.org**
- Mental Health America: **http://www.nmha.org** and **http://www.ncstac.org**
- Mental Health Recovery: **http://www.mentalhealthrecovery.com**
- Mental Health Statistics Improvement Project: **http://www.mhsip.org**
- Mindfreedom International: **http://www.mindfreedom.org**
- National Alliance on Mental Illness (NAMI): **http://www.nami.org**
- National Association of Consumer/Survivor Mental Health Administrators (NAC/SMHA) **http://www.nasmhpd.org/nac_smha.cfm**
- National Association for Rights Protection and Advocacy: **http://www.narpa.org**
- National Coalition of Mental Health Consumer/Survivor Organizations: **http://www.ncmhcso.org**
- National Empowerment Center: **http://www.power2u.org**
- National Mental Health Consumers' Self-Help Clearinghouse: **http://www.mhselfhelp.org**
- National Research and Training Center on Psychiatric Disability, University of Illinois at Chicago: **http://www.cmhsrp.uic.edu/nrtc**
- Nonprofit Genie: **http://www.compasspoint.org/askgenie/**
- Pat Deegan and Associates: **http://www.patdeegan.com**
- Peer-to-Peer Resource Center: **http://www.peersupport.org**
- Psychrights: **http://psychrights.org**
- Resource Center to Promote Acceptance, Dignity, and Social Inclusion Associated with Mental Health (ADS Center): **http://stopstigma.samhsa.gov**
- SCORE® Counselors to America's Small Business: **http://www.score.org/**
- Service Locator (One-Stop Career Centers): **http://www.servicelocator.org**
- Shery Mead Consulting: **http://www.mentalhealthpeers.com**
- Social Security Administration Work Site: **http://www.ssa.gov/work**
- UPenn Collaborative on Community Integration: **http://www.upennrrtc.org**
- Tennessee Mental Health Consumers Association [BRIDGES curriculum]: **http://www.tmhca-tn.org/**
- Virginia Organization of Consumers Asserting Leadership (VOCAL): **http://www.vocalvirginia.org**
- World Network of Users and Survivors of Psychiatry: **http://www.wnusp.org**

The Evidence

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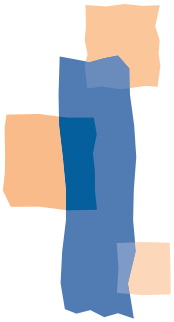

EVIDENCE-BASED PRACTICES

KIT

Knowledge Informing Transformation

The Evidence

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