EVIDENCE-BASED PRACTICES

KIT

Knowledge Informing Transformation

Building

Your Program

Consumer-Operated Services

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Substance Abuse and Mental Health Services Administration
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EVIDENCE-BASED PRACTICES

KiT

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Building Your Program

What Are Consumer-Operated Services?

Consumers are called many things

Mental Health Consumers

Consumers/Survivors

Psychiatrically Labeled

Ex-patients

Clients

Peers

All of these terms refer to individuals who have experienced or been diagnosed with a psychiatric disorder. Most have received treatment by public or private providers. There is no consensus on which term is preferred. Consumers, consumer/survivors, and peers are most frequently used in this material.

Consumer-operated services are peer-run service programs that are owned, administratively controlled, and operated by mental health consumers and emphasize self-help as their operational approach.

Consumer-operated services may be called by other names such as *consumer-operated service programs*, *consumer-run organizations*, *peer support programs*, *peer services*, or *peer service agencies*.

Consumer-operated services help individuals see what is possible for themselves and for others. People see that recovery is real and possible. They can see it in the people surrounding them.

State mental health policymaker

"Consumer-operated" means—

- Independent—the entity is administratively controlled and operated by mental health consumers.
- Autonomous—decisions about governance, fiscal, personnel, policy, and operational issues are made by the program.
- Accountable—responsibility for decisions rests with the program.
- Consumer controlled—the governance board is at least 51 percent mental health consumers.
- Peer workers— staff and management are individuals who have received mental health services.

Consumer-operated services often collaborate with other mental health service providers but retain autonomy and an identity distinct from other providers.

What are possible functions of consumer-operated services?

Consumer-operated services have diverse sets of practices, but research has recognized four basic types of functions: mutual support, community building, providing services, and advocacy. Some consumer-operated services assume all four of these functions; others emphasize only some of them.

Mutual support

People with common life experiences have a unique capacity to help each other because they share a deep understanding that might not exist in other relationships. Mutual support exemplifies the "helper's principle" which means that both parties benefit from the process. When peers support each other in this way, there is no need to designate who is the "helper" and who is the "helpee." They might switch back and forth in these roles or act simultaneously.

The willingness to offer a hand up to someone who is considering a new way of life is the very basis of who the staff are and what they do. It is wholeheartedly believed that recovery from addiction and mental illness is possible because staff have lived it.

Consumer-operated service director

Community building

Consumer-operated services offer opportunities for participants to develop new social and interpersonal networks, to experience membership in an inclusive and accepting community, to think about themselves in new ways, and to learn better ways to handle problems.

Providing services

The services offered by consumer-operated services vary considerably. They might reflect the needs of a community, the expectations of a funder, and/or the interests or talents of group members. Concrete services might include the following:

- Drop-in centers;
- Peer counseling;
- Assistance with basic needs or benefits;
- Help with housing, employment, or education;
- Linkage to services or resources;
- Social and recreational opportunities;
- Arts and expression;
- Structured educational or support groups;
- Crisis response and respite;
- Information and education; and
- Outreach to community and institutions.

Some consumer-operated services are also involved in providing technical assistance, evaluation and research, training, or public education. Some even serve as healthcare purchasing cooperatives.

For many participants, consumer-operated services augment their traditional provider services. They may also serve as alternatives to traditional services, especially for those who will not accept, or who do not choose to participate in, traditional services.

What is peer support?

- Peer support is a mutually supportive relationship based on two or more people's shared experiences.
- In consumer-operated services, peer connections often revolve around experiences with treatment, the service system, life problems, and social stigma, not just the shared experience of psychiatric difficulty.
- Peer support may occur in formal groups or structured services and programs. Most often it occurs in day-to-day interactions and informal conversations.

Advocacy

Advocacy and social action to promote system change and social justice has been a core element of the consumer self-help movement from its inception. Consumers now participate at local, state, and federal levels to help plan services, shape policy, and promote change.

What makes consumer-operated services unique?

Consumer-operated services are not simply mental health services delivered by consumers. They have a different world view, structure, and approach to "helping" than traditional treatment services.

This uniqueness emerges from values and ideas born in the experience of living with a psychiatric difficulty and experiencing its impact on every aspect of a person's life: identity and sense of self, relationships, opportunities, acceptance by others, and even beliefs about the future. It comes from the conviction of many who have used traditional services that "there has to be another way."

There are different kinds of consumer-operated services. Some focus on peer support groups and some on educational programs. Others primarily provide a specific service such as housing and still others operate drop-in centers with a spectrum of services.

Studies on consumer-operated services from around the United States have identified some common ingredients that bind these different models together and distinguish them from other kinds of mental health services. These common ingredients are found in aspects of program structure, guiding values, and operational processes.

Program Structure

Program Structure refers to how programs are organized and operated. A consumer-operated service includes the following structural attributes:

It is controlled by consumers – the people who use the service.

It is run by its membership.

Leadership is participatory.

Participation is voluntary.

The structure is planned with both physical and emotional safety in mind.

Values

Consumer-operated services share some core belief systems and offer an alternative worldview, incorporating the following:

Empowerment and responsibility;

Choice;

Acceptance and respect for diversity;

Reciprocity and mutuality in relationships;

Social action; and

Recovery from psychiatric difficulties.

Operational Process

Operational Process refers to the services offered and the methods of providing those services, including these:

Peer support through relationships and informal and structured interactions;

Meaningful roles and opportunities for everyone;

Interactive decisionmaking; and

Peer mentoring and teaching.

Frequently asked questions about consumer-operated services

Q: Who really runs a consumer-operated service?

The essential element of consumer-operated services programs is that they are run by the people who use them—"by us and for us." The governance boards of consumer-operated services must be no less than 51 percent identified mental health consumers. The operation of a consumer-operated service cannot be assumed or directed by any outside group or organization.

Q: Can anyone who has received counseling, for example, marriage counseling, be considered a consumer and operate a consumer-operated service?

By definition, peer support happens among individuals who share common experiences. If you are designing a peer support service for people going through marital difficulties, then yes, that person could be considered a peer or consumer.

However, if you are establishing a consumer-operated service for persons who have experienced problems with serious mental illnesses, then a person with marital counseling experience only would not be the right person to run it.

Q: Why is autonomy and peer leadership so important?

Consumer-operated services may position themselves as alternatives, adjuncts, or enhancements to the traditional mental health service system, but they cannot structurally be an arm or extension of it. This is necessary so that consumer-operated services can do the following:

Promote equity and reciprocity in relationships. Consumer-operated services try to minimize or eliminate power differentials inherent in relationships between the workers and clients in traditional mental health services;

Reduce pressure to conform to standards, practices, and values that are not consumer driven, and sometimes not even consumer centered; and

Function as centers of opportunity for empowerment and leadership development.

Q: Can a mental health center or clubhouse hire a consumer manager for a program and call it a consumer-operated service?

No. Some mental health providers believe they provide many of the benefits of consumer-operated services outlined above through their treatment programs. However, consumer-operated services must be fully controlled by the people who use the service. They are organizationally separate and distinct from provider organizations such as hospitals, mental health centers, or rehabilitation agencies. Programs run by traditional providers are subject to the policies and mandates of those organizations. Consumer-operated services are responsible for making their own organizational and management decisions and policies. They assume both the responsibility and the risks of their decisions.

Q: Are there roles for nonconsumers or outside supporters?

Yes. There are a number of necessary and valuable roles for nonconsumer supporters and partners. In addition to being friends, allies, advocates, and champions, specific roles are the following:

Funder/contractor;

Sponsor/fiscal agent;

Mentor; and

Collaborator.

The role of a sponsor/fiscal agent is a temporary startup accommodation sometimes used for new programs. See *Tips for Mental Health Authorities* for a broader discussion of fiscal agency.

Q: My agency hires peer specialists. Isn't that a consumer-operated service?

A number of states and organizations have developed peer specialist training programs. These programs provide a standardized training curriculum and a certificate of successful training completion. This certificate may qualify graduates for particular employment opportunities or enable them to provide Medicaid-reimbursable services. Mental health agencies are increasingly hiring certified peer specialists to provide a variety of services under the supervision of mental health professionals. They are often members of clinical programs or teams or may run a peer support program within the agency.

Peer specialists can richly benefit the organizations that employ them. But, when the governance of the organization is not fully consumer controlled, employing peer specialists does not designate an agency or a program as "consumer-operated." Other aspects of best practice fidelity must also be considered.

Some consumer-operated services also employ certified peer specialists, and the trend is growing.

The majority of people who currently work in consumer-operated services have attained their positions through active involvement and investment in the program over time, rather than through formal peer specialist training or certification. As more consumer-operated services consider Medicaid as a source of funding, there is increasing attention to staff qualifications and certifications as required by Medicaid guidelines. Some of the pros and cons of using Medicaid to finance consumer-operated services are discussed later in this chapter.

Some consumers and nonconsumers share the concern that when peers become "specialists" or "billable" under the supervision of traditional service providers, they risk losing many of the values and characteristics that comprise their unique voice and contribution to the system of care. All agencies hiring peer specialists should be mindful to help them retain the distinctive qualities and experience they bring to the organization.

For more information on peer specialists in traditional agency settings, see the following references included in *The Evidence* booklet of this KIT: Substance Abuse and Mental Health Services Administration, 2005 and Townsend and Griffin, 2005.

Recovery is more than symptom management:

- To consumers, recovery implies having hope for the future, living a self-determined life, maintaining self-esteem, and achieving a meaningful role in society. All of these things can be accomplished with or without psychiatric symptoms.
- Who can I become, and why should I say "Yes" to life?

What is the history of consumer-operated services?

The roots of consumer-operated services are deeply embedded in the tradition of self-help, in the civil and human rights movements, and in the vision and experience of recovery among persons with psychiatric difficulties. *The Evidence* booklet of this KIT provides a more extensive discussion of this rich legacy.

Recovery

Individuals have spoken about recovery from psychiatric disorders and have occasionally written about recovery for many years. These anecdotal reports were largely discounted by professionals until recent research supported these personal experiences of recovery. Two core beliefs form the bedrock of consumer-operated service philosophy:

People with psychiatric difficulties can and do recover, living meaningful lives and

Peers can help each other with the recovery process in ways that professionals cannot.

Recovery must be the common, recognized outcome of the services we support.

Charles Curie, SAMHSA Administrator, 2006

Self-help

Self-help and peer support are the oldest and most traditional forms of mental health services. A friend lends a hand to a friend. A neighbor assists a neighbor in distress.

There is a natural tendency for people to seek others with similar problems and concerns in order to make sense of their experiences and to be validated, comforted, and empowered by that knowledge.

In the mid-20th century, peer support was formalized in a variety of ways, including the development of self-help groups such as Alcoholics Anonymous, GROW, and the Depression and Bipolar Support Alliance (DBSA), formerly the Depression/Manic Depression Association. In virtually every community, there are now self-help and peer support resources to help people cope with scores of health concerns and difficult life experiences.

Civil and human rights

The civil and human rights movements of the 1960s, and particularly the disability rights movement, were influential. Early mental health consumer leaders saw commonality between their own experiences of stigma and disenfranchisement and those of other oppressed groups.

The disability rights movement focused on promoting rights of people with disabilities, developing a different way of viewing the experience of disability, and establishing alternative service centers.

Similarly, a mental health patients' rights movement began to emerge, and mental health peers began to create self-help services in the form of consumer-run drop-in centers and other programs.

Growing policy support

Government agencies, researchers, and some professionals began to recognize the importance and potential of consumer-operated service initiatives. The Community Support Program (CSP), now part of SAMHSA, funded the first national consumer Alternatives Conference in 1985. From 1988 to 1992 SAMHSA funded 14 Consumer-Operated Services Demonstration Projects. Consumer-run technical assistance and self-help research centers were also established through federal grants.

Acceptance and inclusion within the service system

While consumer-operated services operate as independent entities, they are increasingly considered a core element in an effective system of care for adults with psychiatric problems.

Recovery-oriented services and supports are often successfully provided by consumers through consumer-run organizations and by consumers who work as providers in a variety of settings, such as peer support and psychosocial rehabilitation programs.

New Freedom Commission on Mental Health Final Report, 2003

In 1989, the National Association of State Mental Health Program Directors (NASMHPD) issued a position statement on consumer contributions to the mental health system. In addition to promoting consumer participation in all aspects of policy and practice, the statement calls for client-operated self-help and mutual support services to be "available in each locality as alternatives and adjuncts to existing mental health service delivery systems. State financial support should be provided to ensure their viability and independence" (Leaver & Campbell, 2003).

In 1999, the Surgeon General's report on mental health firmly established the concept of recovery as a guiding principle for mental health service systems and promoted self-help and consumer-operated services as important elements of recovery-oriented comprehensive mental health service systems (U.S. Department of Health and Human Services, 1999).

The 2003 President's New Freedom Commission on Mental Health Final Report acknowledges that many Americans are not receiving services oriented toward the hope of recovery. It presents consumer-operated, peer-delivered services as an emerging best practice (New Freedom Commission on Mental Health, 2003).

The National Council on Disability report (2000) and the Institute of Medicine report (2006) also advocate for a shift toward more recovery-oriented and more consumer-driven mental health systems. Consumer-operated services are part of this shift.

In 2006, SAMHSA issued a Consensus Statement on Mental Health Recovery. Developed by 110 expert panelists representing many stakeholder groups, the statement presents 10 fundamental components of recovery, one of which is peer support. It states, "Consumers encourage and engage other consumers in recovery and provide each other with a sense of belonging, supportive relationships, valued roles, and community." The bedrock philosophy of consumer-operated services supports mental health recovery and the value of peers helping peers with the process.

We're looking at consumer-operated services as more than just a "good thing." We see them as a critical core component of the continuum of care. There are strategic advantages to other parts of the system because effective consumer-operated services provide role modeling, natural support systems, and clearly help individuals with their personal recovery. They can work in ways that traditional services cannot.

State mental health commissioner

There are numerous examples of state, regional, and local mental health authorities incorporating peer-operated services into their systems of care. Some states have established significant statewide networks of consumer-operated services, while others are considering how to best develop and implement these services.

Are consumer-operated services effective?

Many studies support the value and effectiveness of peer support services in helping individuals to address problems in their lives. Other studies give credence to specific elements of peer support such as positive relationships, meaningful activity, sense of community and belonging, and so forth.

Until recently, research on consumer-operated services as a program model has been limited, albeit promising. In the past decade, however, an increasing number of controlled studies on consumer-operated services have demonstrated their effectiveness.

A study of the 14 SAMHSA-funded Consumer Operated Services Demonstration Projects 1988-1992 concluded that "as a result of these initiatives, consumers/survivors had achieved greater levels of independence, empowerment, and self esteem. Individuals had an improved sense that they could make their own decisions, solve problems, and help others." Participant quality of life improved and there were noted increases in social supports, employment skills, and education.

In 2003, Charles Curie, then Administrator of SAMHSA, reported on interviews he had with people about to be discharged from a state psychiatric hospital:

I asked them what they needed to make their transition successful. They didn't say they needed a psychiatrist, a psychologist, or a social worker. They didn't say they needed a comprehensive service delivery system or evidence-based practices. They said they need a job, a home, and meaningful personal relationships, or to use a direct quote..."I need a life—a real life. I need a job, a home, and a date on weekends."

cited in Clay, 2005

In 2001, researchers compared a group who participated in consumer-operated self-help programs with another matched group who did not use self-help groups. The self-help group showed higher use of problem-centered coping skills, used more coping strategies, achieved more years of education, and scored higher in social functioning on a standardized scale. The higher ratings of hopefulness and self-efficacy found in the self-help group positively affected coping strategies.

The Consumer-Operated Services Program (COSP) Multisite Research Initiative (1998-2006), funded by SAMHSA, is the largest and most rigorous study of consumer-operated services programs conducted to date. It looked at several models of peer-operated services around the country to determine whether consumer-operated services are effective as an adjunct to traditional mental health services in improving the outcomes of adults with serious mental illness.

This study found that consumer-operated services are effective, pointing specifically to the following:

- An overall increase in well-being among study participants and a greater average increase in well-being among those who used consumer-operated services the most;
- A significant effect on well-being for users of drop-in type services;
- An increase in most measures of empowerment correlated with the extent to which consumers used consumer-operated services.

These positive findings were not limited to one program model but encompassed all the consumer-operated service models studied.

A 2006 study by Corrigan similarly found positive correlations between participation in consumer-operated services and core factors associated with recovery and empowerment such as personal confidence and hope; willingness to ask for help; goal and success oriented; self-esteem/self-efficacy; sense of personal power; autonomy; optimism and control over the future.

How are consumer-operated services funded?

Consumer-operated services are best practices and should be funded as part of the mental health service system. Some mental health authorities (MHAs) are creating permanent carveouts (i.e. setting aside specific funds) for consumer-operated services. Others are using statutory mandates and other mechanisms to define consumer-operated services as a required core service, thereby including them in funding formulas.

Consumer-operated services are currently funded in a number of ways, each with advantages and disadvantages, and with specific accountability and reporting requirements. The text box lists the most common mechanisms for funding consumer-operated services. See *Tips for Mental Health Authorities* in this booklet for a broader discussion of funding.

As with other nonprofit services, funding is a perennial challenge for consumer-operated services. They are often seen as pilot or innovative program initiatives without permanent funding streams or are the first to see cuts in lean fiscal times. They must typically reapply for funds annually and are often first to have funding cut during periods of retrenchment or cutback. Applying for funding is complex and is an area where consumer-operated services often need and desire technical assistance.

Like other human services, consumer-operated services ideally need a diverse funding mix to ensure sustainability and to weather vagaries in the funding environment. However, some consumer-operated services—especially less established groups—find it overwhelming to navigate multiple funders. Attaining long-term sustainability remains a key challenge.

Primary sources of funding for consumer-operated services

- Federal Mental Health Block Grant
- Other federal sources, including SAMHSA, National Institute of Disability and Rehabilitation Research (NIDRR), and Departments of Veterans Affairs (VA) and Housing and Urban Development (HUD)
- State or county general funds and county tax levies
- Other state funds such as vocational rehabilitation, social and substance abuse services, and reallocations from state psychiatric hospital downsizing
- Community reinvestment and community redevelopment initiatives
- Medicaid
- Grants from national, regional, and community foundations for specific projects or initiatives
- Managed care organizations and behavioral health care networks
- Charity groups, faith-based organizations, and nonprofit organizations
- Fundraising activities
- Entrepreneurial ventures and businesses run by consumer-operated services or programs

For more information about the effectiveness of consumer-operated services, see *The Evidence* booklet of this KIT.