**Attachment 1**

Mental Health Community Coalition ACT response to:

Inquiry into Appropriate Housing for People Living with Mental Illness

# Consumer Operated Services Discussion Paper developed for the National Mental Health Working Group

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"*The consumer movement has increased the involvement of individuals with mental disorders and their families in mutual support services, consumer-run services, and advocacy. They are powerful agents for changes in service programs and policy.*

*The notion of recovery reflects renewed optimism about the outcomes of mental illness, including that achieved through an individual's own self-care efforts, and the opportunities open to persons with mental illness to participate to the full extent of their interests in the community of their choice.*"

*Mental Health: A Report of the Surgeon General Executive Summary – 1999*

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

The Consumer Issues Subcommittee report to the *President's New Freedom Commission* in March 2003

"*There is a revolution brewing in the field of severe mental illness…. [It is] a revolution that is beginning to occur right now. It is a vision – in what is believed to be possible for people with severe mental illness…. It appears that it will be up to consumers and their family members to lead this revolution in vision – to guide or drag professionals toward the 21st century.*"

William A. Anthony, Executive Director Center for Psychiatric Rehabilitation at Boston University

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

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

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

## Introduction

As governments struggle with finding efficient and effective ways of meeting the mental health needs of their citizens, one option is to fund a variety of "consumer-operated programs" or mental health programs run by and for other consumers particularly in this time of significant mental health workforce issues. While there are many ways of talking about and defining consumers, the working definition used in this discussion paper is "people who receive mental health services." Consumer-operated programs are increasingly recognised as a vital resource by such notable authorities as the U.S. Surgeon General (1999) and, more recently, President Bush's New Freedom Commission on Mental Health which has advocated that "peer support services be integrated into the continuum of community care..."

People participate in consumer self-help for the same reasons that they participate in other self-help groups; namely, for peer based support, assistance in developing coping strategies, exposure to relevant role models, affordability, pertinent information about issues and services, advocacy for systems change, the opportunity to interact without stigma, and the sense of well-being and self-esteem that derives from helping others (Borck, 1983; Fleming, 1983; Van Tosh, 1990; Roberts and Rappaport, 1989).

Consumer-Operated Services (COS) have become increasingly integrated into formal mental health systems in the United States and are viewed as an important approach to expanding the continuum of services available to persons with mental illness, including those with serious mental illness. Consumer-operated services are those services where identified consumers interact with other identified consumers in services that are uniquely consumer-operated (e.g., self-help groups) or as part of services that involve both consumer and non-consumer staff (e.g., case management). The sharing of personal experience is a critical element of consumer-operated services and is part of what makes them beneficial. It is recognized that many professionals have personal experiences with mental illnesses but choose not to identify as mental health consumers and do not share their personal experiences as consumers. Services delivered by persons who do not identify as consumers or share their personal experiences as consumers are not consumer-operated services. A program or agency where consumers serve only as advisors or on a board is not a consumer-operated service.

Many different consumer-operated services types have developed over the years, the following typology is useful in appreciating the diversity of these services (Solomon & Draine, 2001). *Consumer operated services* are those that are planned, managed, and provided by consumers. *Consumer partnership services* are those in which consumers deliver the services, but the control of the program is shared with non-consumers. *Consumers as employees* reflect services that employ consumers and non-consumers alike. The aforementioned program types can involve paid and unpaid/volunteer consumer roles.

Consumer-operated services vary greatly in format and focus. While drop-in centres may be the most common form of peer-led programs, and self-help groups may come most readily to mind when consumer-operated services are mentioned, many other types of programs now exist. A number of other types of consumer-operated services have been developed in local communities and mental health systems. For example, there are a growing number of case management services that are wholly consumer-operated or where consumers are one of several members of a larger case management team. Consumer staff have also been added to crisis and respite services, vocational services, one-to-one peer support programs, psycho educational programs, advocacy, residential

services, and supported education. References to articles describing the various consumer-operated services can be found in the bibliography and some of the most common are outlined in Table A.

This paper describes some of the evidence behind consumer-operated services and how consumers and mental health staff can work together to develop and expand such services. It also provides case studies of several successful programs.

## The evidence base behind consumer-operated services

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

By the late 1980's, despite the proliferation and growing acceptance of peer-delivered services, there was little research which had been done on the effectiveness of consumer-operated services. In response, The Center for Mental Health Services (CMHS) in the United States funded a multi-site evaluation study of 13 varied programs across the country, beginning in 1988. The 3-year projects produced evidence that peer-led services increased the social skills, decreased inpatient services, and improved the self-confidence of consumers. This evaluation demonstrated the potential power of the consumer model. By the late 1990's, a small body of literature had accumulated, much of which was derived from uncontrolled studies, which show positive outcomes related to consumer-operated services (See Appendix B for an annotated bibliography on consumer-operated services). More recent studies have shown that the consumer staff members provide care as good as or, in some cases, better than non-consumers.

Government and health professionals have identified selected interventions as evidence-based and provides funding, toolkits, and technical assistance to implement these services. They include assertive community treatment, illness self-management, supported employment, family support and psycho-education services, and integrated dual diagnosis treatment. Achieving fidelity to the program design of these identified practices is a complex undertaking for mental health systems dealing with the politics of budget deficits and organisational realignments within government.

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

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

The increasing proliferation of peer support services and the evolution of the recovery movement may represent the brightest stars in the future of mental health treatment systems. The lived experience of people with mental illness is having a major impact on the shape of contemporary mental health services. Peer support is a unique and

essential element of recovery-oriented mental health systems. Peer support programs provide an opportunity for consumers to direct their own recovery and advocacy process, and to teach one another the skills necessary to lead meaningful lives in the community (Sabin J E, and Daniels N, 2002). Peer support services have demonstrated effective outcomes such as reduced isolation and increased empathic responses to consumers (Powell, 1994, Kurtz, 1997, Mowbray, et al., 1996). Research has also shown that outcomes improve when consumers serve as peer specialists on case management teams (Fenton et al., 1995). Other peer support programs have demonstrated reductions in hospitalisations.

Recently, the Consumer-Operated Services Program (COSP), funded by CMHS in the United States, has begun to rigorously examine the effectiveness of a wide range of peer programs in order to identify best practices within the field. In addition to the Friends Connection, described on page 6, other best practices are being documented in the COSP initiative and as data analysis continues, the project will likely yield other examples of consumer-operated programs with demonstrable results.

Many other consumer-operated programs have not been scientifically demonstrated to be "best practices," yet they have garnered widespread recognition, including community and professional awards, and show potential as exemplary practices. Increasingly, research is also being directed toward these programs to assess whether and to what extent they provide benefit to consumers. PACE, (see page 7) is a widely cited model which has been developed by one of the three National Technical Assistance Centres (NTACS), the National Empowerment Centre in Lawrence, Massachusetts.

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

Table A – Types of Consumer-Operated Services

| Type of Service | Examples |
|---|---|
| Warm Lines | West Virginia Mental Health Consumers Association www.contac.org/WVMHCA/services.htm |
| Drop-in Centres | On Our Own of Charlottesville: www.avenue.org/onourown/ The St Louis Empowerment Center: www.dbsastlouis.com/center.html |
| Independent Living Programs | Independent Living Resource Center of San Francisco; www.ilrcsf.org Main Street Housing: www.onourownmd.org/msh.htm |
| Peer-led Case Management | The Friends Connection www.mhasp.org/friends/ |
| Crisis Support/Respite | Stepping Stone www.m-power.org/Alrespite.htm |
| Technical Assistance | CONTAC www.contac.org/default.htm |
| Benefits Acquisition | Georgia's Certified Peer Specialist Program www.gacps.org |
| Research | Recovery Project www.nasmhpd.org/ntac/reports/index.html |
| Anti-stigma Programs | The Anti-Stigma Project ww.onourownmd.org/asp.htm |
| Advocacy & Advocacy Training programs | Mental Health Consumer Concerns: www.sonic.net/~mhcc The Leadership Academy: www.contac.org/WVMHCA TEAM Tool Kit from: www.mhselfhelp.org |
| Political Action Groups | NARPA www.narpa.org |
| Other Allied Programs | Laura Mitchell Employment Center in Fairfax, Virginia: www.lmec.org Collaborative Support Programs of New Jersey: wwwcspnj.org |

## Example: The Friends Connection

The Friends Connection *www.mhasp.org/friends/*, is a peer-led mobile psychiatric rehabilitation program for those with co-occurring disorders (mental health and substance abuse) and is operated through the Mental Health Association of South eastern Pennsylvania, a non-profit advocacy, service, and education organisation. The program is designed to bridge gaps between the historically separate treatment systems for mental health and substance abuse. Originally funded with community monies when Philadelphia State Hospital (also known as Byberry) closed in 1990, the program now has expanded into surrounding Montgomery County and county level funding has been added to that supplied by the city of Philadelphia. All participating County service providers may use the Friends Connection. Up until 2004, only those people who are in the state mental health system have access to the Friends Connection through a case manager or Resource Coordinator. The Friends Connection uses a multi-disciplinary team approach to Intensive Case Management (ICM).

Consumers are referred from case managers and from other mental health treatment and rehabilitation programs and professionals. After an orientation and assessment, the consumer is matched with a Peer Support Counsellor (who has a program supervisor who in turn is supervised by the Clinical Manager). While staff may receive services elsewhere, they do not currently receive services at the Friends Connection.

Friends Connection staff must meet position-specific credentialing standards. Peer Counsellors act as positive role models and provide one-on-one support to individuals as they work on their individual goals. In developing a personal goal plan, consumers select from among many community based social, education and leisure activities as well as more traditional 12-step programs. The plan is reviewed every 3 months and is used as a basis to determine the medical necessity for the individual to continue receiving services.

The Friends Connection uses a continuous quality improvement model to strive for excellence and exceed the expectations of consumers/survivors using the program. A quality improvement committee, composed of staff and participants, monitor outcomes (including hospitalisation, substance use, and consumer satisfaction).

Through the COSP initiative, the program has secured research funding in partnership with the University of Pennsylvania and in collaboration with the Philadelphia Office of Mental Health. Participants in the Friends Connection (which uses ICM) are being compared with others who receive only ICM. Results from a pilot study7 suggest that the Friends Connection is effective in making a significant, positive change for participants in several dimensions of quality of life (such as perceived physical and emotional well-being, and financial stability). In addition, those who participated in the Friends Connection required less hospitalization than those who did not participate in the peer program.

### Example: PACE - An alternative to PACT

The National Empowerment Center (NEC) has developed a program, Personalized Assistance in Community Existence (PACE), as a non-coercive alternative to the medicalised illness-based model of Programs in Assertive Community Treatment (PACT). Before designing PACE, NEC conducted research into factors that were most important in enabling people to recover from mental illness. Dr. Dan Fisher and Laurie Ahern (then co-directors of NEC) developed PACE which emphasizes recovery and self-determination.

While PACT was designed initially as an alternative to hospitalization, many consumers/survivors including the developers of PACE, believe that it has become focused on compliance with medication, relies on coercion, assumes life-long illness, and has been linked with outpatient commitment.

In contrast, PACE is based on an Empowerment Model of Recovery which values "voluntary forms of assistance directed by the individuals themselves" which may or may not include medication. Developing trusting relationships, which permit people to (again) dream and have valued social roles, is at the center of the Empowerment Model. Both Fisher and Ahern have travelled extensively and trained others in the PACE model. NEC has published results, *8* documenting that after the program, 66% of those in PACE report they are more hopeful (either that they will recover or that the person they are helping will.)

## Steps to consider in moving towards consumer operated services

> *"[It] appears that these efforts focus on priority needs as identified by consumers which are often not addressed by traditional mental health service providers."*

### Phase 1: Issues to consider before states and consumers work together

There are distinct issues for government, as well as consumers, to consider before offering or applying for funding for peer-led programs.

#### Issues for consumers

Perhaps the very first issue that consumers must resolve is whether to accept government funding and other support.

In making that decision, consumers might want to consider the following questions:

- Is the grant program consistent with the orientation and goals of the peer-led program?
- Is there broad-based support for the particular program AND for state funding?
- What changes in basic operations (e.g. hiring, training, certification) might be expected as part of the state program?
- What are the reporting requirements and will such requirements conflict with existing policies or procedures?
- How ready will staff/volunteers be to accept the new program? Or the new fiduciary relationship with the state?
- Finally, what model of government involvement will the program use?

Although there are no "right" or "wrong" choices, the choice of model does affect the type of working relationship the program has with government and vice versa.

One model is for the program to be a stand-alone consumer operated program which receives funding from government and perhaps to incorporate itself as a non-profit

organisation. Another option is for the program to align itself with an existing non-profit organisation and receive government funding indirectly, through the partner as auspice. A third model involves partnering directly with government.

Example: Stepping Stone - Emergency Respite Care

Stepping Stone is one of 15 peer support agencies (PSAs) in New Hampshire, funded through the Division of Behavioural Health via the Federal Block Grant. While the foundation of Stepping Stone is its peer support center, the organisation also operates an innovative two-bed respite program. The Respite Program is free to all New Hampshire residents, but is available at $299/day for out of state residents. Begun in 1997, the Respite Program has 24 hour on-site peer support and is currently staffed by 8 peer-workers. Staff participate in a comprehensive training program. The philosophy of the program is that crisis "is not defined as a negative experience, but rather, as an opportunity for growth: even in the midst of overwhelming situations." While the average length of stay in the Respite Program is three days, the maximum permitted is seven due to an ongoing waiting list.

Applicants to the Respite Care program must fill out a 48 hour crisis plan before being admitted. The Respite Care Program is based upon the Relational Model of Peer Support. Staff and guests are expected to participate as equal partners in the day-to-day tasks of the program, including preparing meals and doing chores.

Respite staff conduct exit interviews to see if guests would like additional care after leaving Stepping Stone and for those who are interested, the peer support center is offered as one option. In addition, the Respite Program is collecting satisfaction data from the guests (for example, asking them to compare the Respite Program with any previous experience with hospitalisation) *www.m-power.org/AIrespite.htm*

### Issues for government

Government, too, should consider several issues as they seek to support the development of consumer-operated services.

- Which of the programmatic models are they willing to support? Under a consumer-operated model, the control of the programs rests with consumers and states serve more of a supporting role. Other models in which the state and consumers act as partners might also fit the state mental health agenda but should be explicitly differentiated from the more strictly defined "consumer-operated" model.
- Next, in choosing among the rather extensive menu of services (such as those outlined in Table A), government might want to weigh the following considerations:
    - *Service Gap*: Which type of consumer-operated program fills an existing service need in the community?
    - *Level of "Science"*: Will the state limit funding to "evidence-based practices" or consider other exemplary or developing programs?
    - *Culture of the Funding Body*: To find the best fit, states must consider, for example, which program has the potential for adhering to state guidelines and policies? Will the state require credentialing or certification which may be at odds with the peer-led program?

- Are there additional *non-state funding* sources (such as philanthropic trusts) which could augment direct state support and supplement vital program operations (such as staff supervision)?
- What level and type of *technical support* is necessary to ensure that the programs are successful? Incorporating appropriate technical assistance can make the difference between successful and unsuccessful consumer-operated programs. Areas in which the state may want to consider providing assistance include:
    - *General Business Management*: In order for a program to be sustainable, it must have sound business practices and engage in strategic planning.
    - *Non-profit Organisational Management*: While not all peer-led programs are delivered through non-profit organisations, those which are may need help in areas such as filing for charitable status, developing the board, or fundraising.
    - *Financial Management and Accounting*: Some peer programs may find it especially challenging to develop and maintain standard financial procedures. For example, what financial accounting forms will the peer program use and will these be sufficient for the program to be funded?
    - *Human Resource Management*: This area includes staff hiring and supervision, conflict resolution, and cultural diversity.
    - *Legal and Regulatory Compliance*: Similar to other new grantees, peer-led programs may need to be oriented to complex state and commonwealth policies.

**Phase 2: Issues to consider as government and consumers work together**

If consumers decide to work with the government, there are a number of ways that they can partner to promote the development or expansion of consumer-operated services. Government and consumers can work together to build the organisational capacity of the consumer organisation, finance the peer-supported services, and monitor the ongoing effectiveness and sustainability of the program.

**Building capacity**

As with any organisation that either initiates or expands its operations, consumers face a daunting series of tasks, including building the capacity of their organisation. Some of the many tasks which consumers might undertake include:

- Conducting needs assessments and identifying service gaps that could be filled by consumer-operated services;
- Developing short-term and long-range strategic plans;
- Diversifying funding to maximize sustainability of the program;
- Organisational development, including:
    - Developing policies and procedures for staff and users of the program;
    - Deciding whether to operate as a stand alone program or to align with another program/agency;

  - Incorporating as a business or remaining an unincorporated association (with the members having legal responsibility and liability for the program);
  - Incorporating either as a for-profit or non-profit entity.
- Hiring, training, and supervising staff;
- Offering and administering employee benefits;
- Locating space;
- Conducting outreach in the community;
- Complying with local, state, and federal regulations.

If the program decides to incorporate as a non-profit organisation, other tasks then follow, such as:

- Preparing Articles of Incorporation and filing with their state incorporation body;
- Filing, at the both the commonwealth and state levels, for tax exempt charitable status as a non-profit organisation;
- Recruiting and managing a Board;
- Maintaining corporate records (including budgets and board minutes)

Fortunately, there are numerous resources available that can be helpful. Several examples below illustrate the types of resources available:

**Financing services:**

Like any other business, consumer-operated services need continued funding to survive.

A range of funding opportunities and structures may be appropriate for states and peer-led programs to consider. In the United States, for example, the federal Medicaid "Rehab Option" is available to support peer services. In several states, the departments of mental health have sought to include peer-operated services within their Medicaid state plans. Nine of these states have woven the peer support into other programs but two states (Georgia and South Carolina) have a separate peer support program under the Rehab Option.

Consumer organisations may have to "think outside the box" and implement innovative business and service structures. Two examples, on page 8 and below, include a 24-hour peer-led emergency respite program and a TEAM Tool Kit.

**Example: TEAM Tool Kit - Training in self-advocacy and business skills**

A more recently developed training program is operated through The National Mental Health Consumers' Self-Help Clearinghouse. The Clearinghouse offers a 3-day training program at both the local and state levels, through which it distributes its TEAM Tool Kit. Using a train-the- trainers approach, Clearinghouse staff helps other consumer/survivor participants build their skills. While similar in some ways to the Leadership Academy, the TEAM Tool Kit specifically targets areas of self-advocacy, and business aspects of consumer-run services (including planning, fundraising, budgeting, and board development). Participants then go on to train other consumers.

## Monitoring effectiveness and sustainability

As with other government-supported programs, consumer-operated services will need to document effectiveness of their program. As funders, government will need to consider what forms of technical assistance and support consumer-operated programs will need to meet monitoring requirements and to develop the sustainability of the program. Some consumer-operated programs may already have procedures in place, while others will need to consider the following tasks:

- Obtaining buy-in across the organisation for the need to monitor program effectiveness (this also includes identifying and responding to barriers to collecting information);
- Charging peer-leaders with deciding which program outcomes are most appropriate to monitor;
- Selecting indicators to use in monitoring these outcomes;
- Designing and implementing record keeping systems to monitor the program;
- Orienting program staff/volunteers to new data procedures;

Example: The Leadership Academy - Training in advocacy skills

The Leadership Academy, offered through the Consumer Organization and Networking Technical Assistance Center (CONTAC), has developed into a program for building consumer advocacy skills through peer-led trainings and follow-up networking at the local level *www.contac.org/WVMHCA*

In addition, CONTAC operates the African American Women's Leadership Academy. The program receives CMHS funding and is operated by WVMHCA. Community organisations and other groups invite the Leadership Academy to train participants selected by the host organisation. Using a train the trainers approach, the Academy offers beginning and advanced seminars in consumer advocacy and has trained over 1,000 consumers from 15 states. Trainees who are interested and able may go on to become trainers at other "Academies" which CONTAC offers. Therefore subsequent trainees will be taught by their peers who are members of the host community. The Academy uses a skills-based curriculum; topics include "etiquette of consumer involvement, identifying issues, gathering information and making reports, conducting effective meetings and forming advocacy organisations". CONTAC also has provided technical assistance in four states as consumers have formed state-wide networks in Massachusetts, Maine, Virginia, and Illinois. The Academy sponsors an annual conference which offers workshops presented by both graduates and expert guests.

As with all of its programs, CONTAC uses continuous quality improvement to refine how it implements its services.

Reported outcomes of the Leadership Academy training have included "an increase in empowerment and networking, better understanding of the workings of the systems, development of individual and organisational advocacy skills, and an improvement in leadership skills of individuals and organisations involved in behavioral health." In addition, a basic pre-post evaluation of this program has demonstrated the effect the program had on empowering participants to write letters, raise funds, and join oversight groups. Other research has supported the work of the Academy.

- Designing continuous quality improvement systems to provide feedback to the program;

- Developing internal mechanisms to use data on program effectiveness to expand the funding base of the consumer program.

Resources, both from within the consumer community and from among other community groups facing similar challenges, exist to guide consumer-led programs in monitoring effectiveness and ensuring sustainability. Some of these resources include:

- *Evaluation guidelines:* Mark S. Salzer (Center for Mental Health Policy and Services Research at the Univ. of Pennsylvania) has proposed guidelines for evaluating effective programs www.bhrm.org/guidelines/salzer.pdf.
- *Indicators for assessing peer support*: Some consumers, as well as evaluators, have asked how peer-led efforts differ from mainstream services, and then have used qualitative research to begin identifying standards of peer support with specified indicators for each standard.
- *Multi-stakeholder models*: Since consumers of mental health services often work in collaboration with non-consumer providers and policy-makers, there will likely be disagreements about what constitutes an effective program. Therefore, a multistakeholder model that can assess the viability and effectiveness of peer-led programs, taking into account these different perspectives, has been suggested.
- *Sustainability toolkit*: The Center for Civic Partnerships, a California-based non-profit organisation providing technical assistance and consultation to community groups, has developed a toolkit for guiding civic and community groups toward sustainability www.civicpartnerships.org/files/SustainabilityToolkit.pdf

**Phase 3: Implementation issues and barriers to be considered**

> *"To avoid these pitfalls, consumers need adequate resources, training, and development as well as mutually respectful collaborations with public and private sectors."*

Some of the best lessons are realized by the problems we encounter. The demonstration projects evaluated in the United States experienced implementation issues and barriers which offer useful learning experiences for those who are replicating such models. (Van Tosh L and Del Vecchio P, 2000)

**Start-up delays**

**Delays in project implementation** often due to the length of time it took funding to move from Government to the projects. In some cases, the start-up delays may result in lowered consumer interest and participation as well as increased potential for alienation from bureaucracies.

**Limited resources**

A **lack of resources** for community based organisations impedes their ability to adequately carry out their activities. Consumer need usually outpaces the availability of funds to address them. This results in fewer personnel, as well as a lack of necessary equipment (e.g., computers, and video equipment). Most services believe that more could be accomplished, given adequate resources.

### Staff turnover

*Changes in personnel* are frequent in community services This is due to a number of factors, including individuals seeking other employment, lack of training, interpersonal conflicts, and health reasons. It is important for organisations to actively pursue staff development training, formal personnel policies, and reasonable accommodation practices to address these issues.

### Lack of organisational expertise

Community organisations indicate that a *lack of necessary training on organisational issues* (e.g. financial management) is a significant barrier. As indicated elsewhere, most of the organisations undertaking these ventures are new themselves and experience rapid growth. The vast majority of staff have limited knowledge or expertise in non-profit organisational management issues. It is imperative to offer training on management skills, and ensure comprehensive and coordinated training.

### Working with bureaucracies

Consumer-operated services are likely to have *difficulties working with bureaucracies* due primarily to value differences between consumer efforts and government systems. This is usually around issues surrounding paperwork, evaluation requirements, etc.

### Interpersonal conflict

*Conflicts* between consumer staff and/or board members are possible barriers. These may take the nature of political and philosophical differences, personality and ego clashes, jealousies, and power struggles. These conflicts are not unique to community based services, nor are they unique to consumers. One confounding factor may be the principle of egalitarianism in the consumer movement, which can be compromised with the introduction of paid staff into such projects.

### Unclear focus

The project may *lack a clearly articulated series of priorities* or foci. This may be due, in part, to a lack of experience in strategic planning and is related to the organisational expertise mentioned above.

### Autonomy

It may be that consumers operating their own programs create *tensions with professionals*. This may take the form of issues of control, paternalism, and "turfism", as professionals may be uncertain in their dealings or respond in traditional fashion with these new models, and, at the same time, consumers, in pursuit of empowerment and self-determination, resist these responses.

## Issues specifically for consumer-providers

### Role conflicts and confusion

This refers to issues that arise for the consumer-provider as a result of assuming an identity that combines their experiences as a consumer with the role of a provider of services. Conflicts with non-consumer staff may arise if consumer-providers are treated as if they are of lesser importance or have less to offer in terms of providing a beneficial service. Non-consumer staff may also treat consumer-providers as if they are "junior staff" or less than equal in terms of skills and ability. Non-consumer staff may even assume the role of "therapist" with consumer staff. These relationships are obviously harmful to all persons involved and can undermine the success of consumer-operated

services. Consumer-providers are also challenged by the need to balance their consumer and provider identities. That is, they may not be accepted within the provider community as full-fledged providers and no longer accepted as consumers among peers. (Carlson, L.S., Rapp, C.A., & McDiarmid, D. 2001)

One solution to role conflicts and confusion includes the clear specification of roles and responsibilities of consumer and non-consumer positions. This will assist the consumer-provider in clearly understanding their roles and duties and highlight to other staff that the consumer provider role is an integral and valued part of the service being provided. Consumer-providers may also experience difficulties in regard to advocating for a consumer participant's needs that are in conflict with the agency or program or with other non-consumer staff. These situations should be closely monitored by a respectful and open-minded supervisor to ensure that the consumer-provider feels comfortable expressing their perspective - a potential goal of the agency in hiring the consumer-provider in the first place - and that non-consumer staff are not threatened or respond in a hostile way. Conflict resolution strategies should be considered in extreme cases and both parties should be encouraged to respect the team decision-making process and conclusions. Other solutions include:

1. Creating an atmosphere within the agency and programs that respects the contributions made by consumer-providers and encouraging dialogue with those who have concerns about consumer-providers;
2. Providing supervision where these issues are respectfully addressed; and
3. Respecting the right of consumer-providers to disclose as much or as little information about their personal experience with other staff and not publicly requesting that they share personal experiences with others or to provide the "consumer perspective" on issues.

**Dual relationships**

This refers to the existence of more than one relationship, professional, social, personal, business, or financial, between an individual and another individual or organisation. Dual relationships are a concern for both consumer and non-consumer providers. Multiple relationships are a fact of life. Specific concerns related to consumer-providers are the existence of past or current relationships between the consumer-provider and the employing organisation or non-consumer staff, and consumer-provider relationships with other consumers participating in the consumer-operated service. There are no hard and fast rules for how to deal with dual relationships. The following alternatives might be used to address this issue:

1. In large urban areas consumer-providers could be hired from outside a particular agency; and
2. It could require that care be sought from another agency.

The former strategy is problematic because it prevents persons from within a particular agency from working in that agency's consumer-operated service.

The latter solution may be particularly challenging because it disrupts already established care relationships. These solutions are nearly impossible for persons residing and receiving treatment in rural areas. The most promising and acceptable strategy may be that supervision and persons with whom the consumer-provider does not have a dual relationship should conduct personnel matters.

Dual relationships with consumer participants are also a concern. Consumer-providers should not be required to sever ties with consumer participants who have become an important part of their social network. However, a number of strategies can be used to diminish potential conflicts that might occur:

1. Those programs that match consumer-providers with a specific consumer participant should avoid matches when a dual relationship involving close, personal contacts has been established;
2. Matches should be avoided with persons who reside in the same housing situation or program; and
3. Supervision should include monitoring of dual relationship issues that might arise over time and steps should be taken to actively address these issues.

The existence of sexual or dating relationships is a particularly important issue to address. Again, these issues are not unique to consumer-providers, as all mental health disciplines struggle with the establishment of professional rules of conduct for effectively dealing with these potentially harmful relationships in service delivery situations. Active sexual or dating relationships are prohibited in more formal consumer-operated services, and past relationships prevent the consumer provider from offering direct services to a person with whom he or she had such a relationship.

Consumer-operated services that are less formal and involve voluntary participation, such as self-help groups, sometimes overtly discourage sexual relationships or dating among members, while others allow discreet romantic relationships. Most recognize that romantic relationships may overly complicate the peer support that is provided and increase the chances that negative or harmful interactions will occur. Sexual relationships are a natural part of healthy interpersonal relationships, but are not part of the mission of one-to-one peer support programs or self-help. (Carlson, L.S., Rapp, C.A., & McDiarmid D., 2001)

## In conclusion

Consumer-operated programs have had a significant impact on the delivery of mental health services in the United States. The central values of consumer-operated services (empowerment, choice, and to a growing extent, self-determination) are now recognised within the traditional mental health system there. At a systems level, consumers have a formal and recognised voice in planning, implementation, and research. There is an established consumer presence on national policy boards/organisations (e.g. National Advisory Board at CMHS) and a mandated presence of consumers in planning, delivery and evaluation of mental health programs. Consumers also have a recognised role, not only in participating in research, but also in designing, conducting, and publishing from research.

Many states in the United States have established offices of consumer affairs within their mental health authority/agency. As a result, not only do consumers run their own programs, but there has been an increase in the number of consumers hired as employees within traditional mental health programs and agencies.

The inclusion of consumer-operated services into the continuum of care challenges beliefs about who can provide services and what services are beneficial and important to persons in recovery. Research indicates that non-consumer staff generally believe that self-help groups, and likely other consumer-operated services, can be helpful. However,

there is a substantial minority who do not feel this way and who may create a hostile, non-collaborative environment.

In addition, even among the vast majority who do believe that consumer-operated services are helpful, many still perceive non-consumer-delivered services to be more helpful, which leads to consumer-operated services being viewed as less important or ancillary to the promotion of mental health. Non-consumers should receive training on the unique benefits associated with consumer-operated services and should be provided with opportunities to observe and participate in consumer-operated service programs as much as possible. This could include attendance at self-help groups or drop-in centres, as well as joining consumer-providers for a day as they provide services. Agency administration and staff need to be respectful to all employees regardless of level of training, discipline, or consumer status, and should be encouraged to discuss issues that might disrupt full support for consumer-operated services. Such concerns may include perceptions that consumer-providers may somehow harm program participants or divulge confidential information, as well as fears that consumer staff might someday replace non-consumer staff.

A positive environment for consumer-providers must also be created to combat the challenges and barriers discussed earlier. Supervisors should create opportunities for issues and concerns to be openly discussed as part of the supervision process as well as in teams. The agency should promote acceptance and provide education about consumer staff and their unique contributions without breaching or requiring loss of privacy. Additional agency support for consumer-providers might include special support, assistance, and mentoring from an agency staff person not affiliated with the specific consumer-operated services. This may be particularly helpful to a consumer provider who has justifiable concerns about expressing problems, especially with their program supervisor. Finally, an agency might consider providing opportunities for consumer-providers to get together and provide support to one another as peers.

## What this means for Australia

At a systems level, consumers have a formal and recognised voice in planning, implementation, and increasingly in research in Australia. There is also an established consumer presence on national policy committees/organisations. However, currently there is not support for consumer-operated services in Australia.

It is critical that the role community-based peer support systems play in the rehabilitation of persons with psychiatric disorders be rigorously defined and the functions and competencies of peer providers be established. Consumer-operated service providers elsewhere have just begun to address the fact that people who provide peer services are not uniformly trained to meet certain performance standards. They are not evaluated on their mastery of peer-support skills and, most important; they do not receive professional certification. Valid, reliable skill assessment tools and training protocols that are both appropriate and flexible are essential if peer support programs are to continue to grow beyond current operations through partnerships with traditional mental health provider agencies. Peer training programs, such as the Georgia Peer Specialists Program and Shery Mead's Peer Support Training, are available in the United States and Australia would do well to investigate these and similar training programs while considering consumer operated services here.

Finally, a range of policy issues and best practices designed to address these issues have been presented here and governments are urged to consider these and other

developments within the field of consumer-operated mental health services as potential options in supporting the work of the consumer communities.