FEDERAL MULTI-SITE STUDY FINDS CONSUMER-OPERATED SERVICE PROGRAMS ARE EVIDENCE-BASED PRACTICES

Jean Campbell, PhD

Program in Consumer Studies & Training

Missouri Institute of Mental Health

January, 2009

After a decade of research on eight consumer-operated service programs located across the United States (1998-2008), investigators of a large SAMHSA-funded multi-site research initiative at the Missouri Institute of Mental Health (MIMH) Coordinating Center report that participation in consumer-operated service programs (COSPs) by adults with serious mental illness had positive effects on their psychological well-being.

Analysis of over 1800 participants in the randomized, controlled trial revealed that those offered consumer-operated services as an adjunct to their traditional mental health services showed significant gains in hope, self-efficacy, empowerment, goal attainment and meaning of life in comparison to those who were offered traditional mental health services *only*.

Further, the greatest gains in well-being were found for the group of participants who actually used the peer services the most and variations in well-being effects across sites were unrelated to formal COSP models of peer service delivery.

"Wellness functions as an internal resource, with hope the wellspring of motivation for change. When well-being is combined with the treatment of mental illness and favorable external resources and opportunities, hope can jump-start involvement in new activities and empower consumers to sustain their recovery journey."

--Dr. Jean Campbell
Principle Investigator
COSP Coordinating Center

As the nation's mental health system adopts an integrated, recovery-based approach to providing mental health services and supports, scientific reviews of the effectiveness of peer-run services have encouraged policy efforts to expand peer supports within the continuum of community care. Results of the COSP multi-site study confirm this growing body of evidence that COSPs are an evidence-based practice that supplements

the treatment of mental illness by promoting wellness and the promise of recovery of a life in the community.

- In 2003, *The President's New Freedom Commission on Mental Health* acknowledged the emergence of the COSP evidence-base and further recommended that consumers and families be fully involved in orienting the mental health system towards recovery.

- As part of the federal effort to identify and implement evidence-based practices in real-life settings, SAMHSA is currently developing the *Consumer-Operated Services Program Evidence-Based Practice KIT* for national distribution.

THE PEER-TO-PEER APPROACH TO RECOVERY

COSPs are peer-run self-help organizations or groups that are administratively controlled and operated by mental health consumers. They provide persons with mental illnesses the experience of giving and receiving peer supports. The peer-to-peer approach to recovery encourages consumers to regain a sense of self and purpose through mutual support, community-building, services, and advocacy.

COSPs were organized in the 1970s by mental health consumers in response to the dehumanizing conditions they faced within the community in the wake of de-institutionalization. Over the past three decades, COSPs have matured, diversified and increased in numbers across the United States (Campbell, 2005).

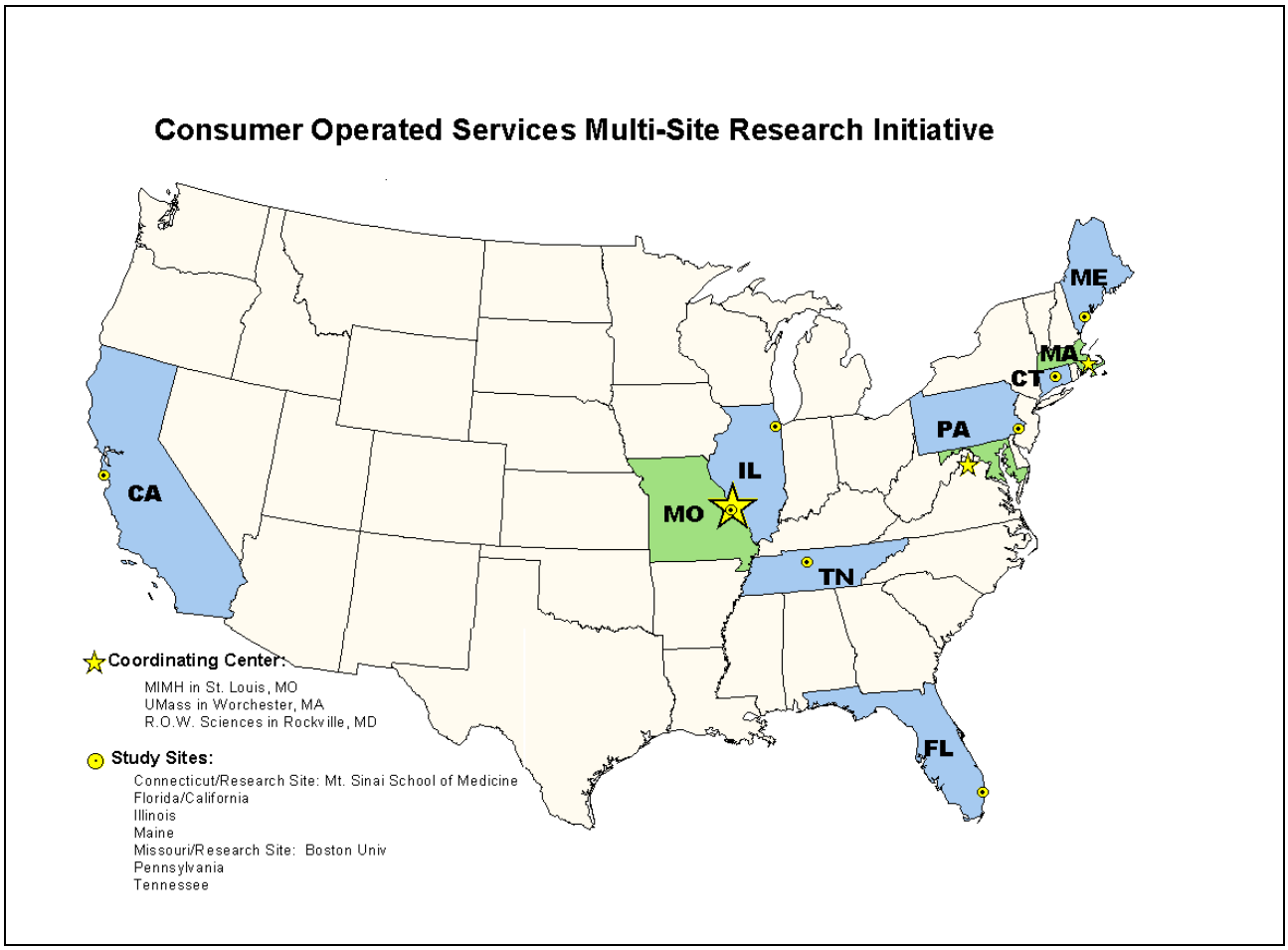
> The authors of a 2002 national survey estimated that there were 3,315 mutual support groups, 3,019 self-help organizations run by and for mental health consumers and/or family members, and 1,133 consumer-operated services in the United States.
>
> --Goldstrom, Campbell, Rogers, Lambert, Blacklow, Henderson & Manderscheid, 2005

Today, there is a broad variety of COSP models, including:

- drop-in centers;
- mutual support groups;
- peer educator and advocacy programs;
- multi-service agencies with benefits counseling and case-management;
- specialized supportive services focusing on crisis respite, employment, housing; and,
- peer phone services (warmlines).

COSP MULTI-SITE OVERVIEW

The COSP Multi-site Research Initiative (Campbell, Lichtenstein, Teague, Johnsen, Yates, Sonnefeld et al., 2006) is the largest and most rigorous study of consumer-operated service programs conducted to date. It included seven study sites composed of traditional mental health service programs and eight program sites representing three COSP general program models: Drop-In (4), Mutual Support (2), and Education/Advocacy (2).



The goals of the project as defined by the federal government were:

1. To establish the extent to which consumer-operated services are effective in improving selected outcomes (empowerment, social inclusion, employment, housing, service satisfaction and cost) for consumers of mental health services;
2. Create strong and productive partnerships among consumers, service providers and service researchers; and,
3. Disseminate the knowledge gained.

The multi-site study developed a common protocol to measure a wide-range of participant characteristics and outcomes. However, since data collection would occur at four points over a year, the study anticipated that only short-term outcomes would exhibit

substantial change. The study was challenged to identify and test a primary but short-term outcome that was sensitive to peer support practices.

This primary outcome needed to be supported by both mental health services research and consumer literature. Well-being was recommended by consumer providers involved in the administration of the study because they had observed that the first and strongest impact of participation in a COSP was the realization that "We are not alone." As early as the mid-1980s the landmark consumer research project, The Well-Being Project (Campbell & Schraiber, 1989), had found that peer support promoted well-being. In the field of positive psychology, well-being has also been identified as a key factor in the resiliency of psychologically vulnerable populations (Ryff & Singer, 1996). Well-being was measured using a composite of established scales that assessed hope, empowerment, meaning of life, self-efficacy, and goal attainment.

Primary Study Hypothesis

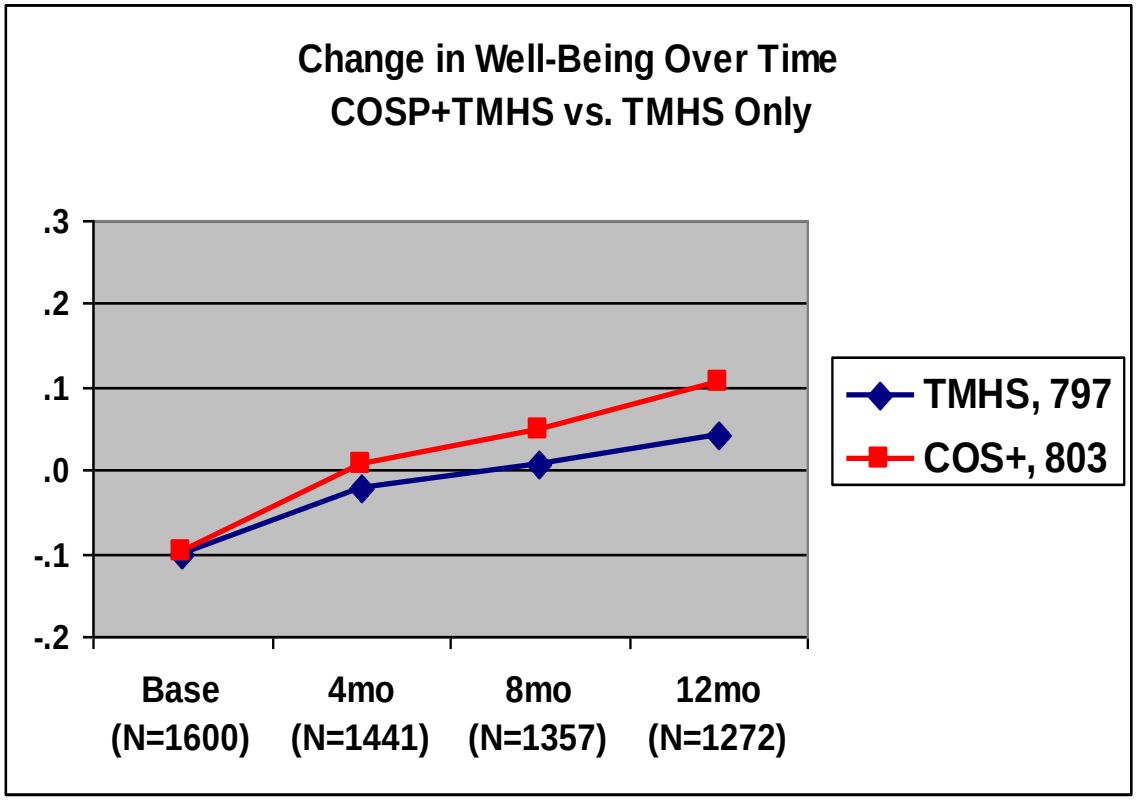
Participants offered both traditional and consumer-operated services would show greater improvement in well-being over time than participants offered only traditional mental health services.

1827 adults with diagnosable mental disorders that used traditional mental health services enrolled in the study, with over 1600 included in the multi-level analysis of the findings. Consumers randomized to the experimental group were offered COSP as an adjunct to traditional mental health services, although adherence to assigned experimental (COSP + TMHS) or control (TMHS *only*) conditions was not mandatory.

COSP MULTISITE STUDY RESULTS

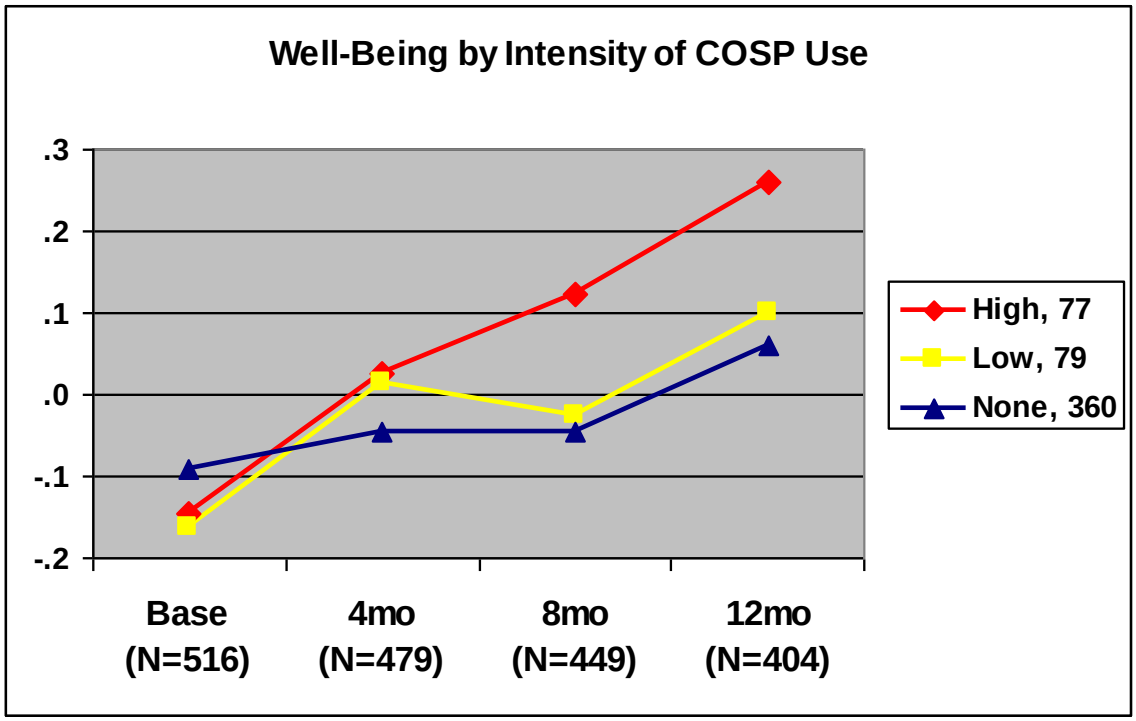
Overall, study participants in both the experimental (COSP +TMHS) and control (TMHS *only*) conditions showed an increase in well-being over time. Although allowing participants choice in selecting desired services throughout the study reduced the strength

of any formal experimental effects, the experimental group (N=803) had a significantly greater increase in well-being ($p < .01$) than the control group (N=797).



Further, trends for a general increase in well-being over time were closely equivalent for all but one COSP study site. Consequently, differences in experimental effects across the sites resulted primarily from differences in associated traditional mental health service programs.

When actual use of COSPs was examined, well-being effects proved even stronger. Participants who used COSP had greater average increases in well-being than those who did not. Those who participated more in COSP had greater average increases than those who participated less.



A subset of empowerment outcomes was also examined and use of COSPs was positively associated with increases in personal empowerment. These results held up without significant variation across the eight COSPs, but gains in empowerment from using COSPs became apparent only with higher levels of use.

There was also evidence of a modest positive effect in reduction in hospitalization and symptoms, and with increased levels of socialization by COSP participants. In particular, there was no evidence of increased risk of harm from participation in a COSP. On the contrary, although experimental evidence for reduction in hospitalization was weak, and symptom reduction could only be discerned on an as-treated basis, the results consistently point away from harm and toward benefits.

Supported by the significant increase in well-being findings from participation in a COSP, it is clear that the positive and inclusive environment of the COSP fulfils a fundamental human need to belong. Therefore, COSPs have the potential to moderate psychological distress, both internally through the development of self-efficacy, and externally through social support.

Intermediate and long-term outcomes such as employment and housing outcomes were computed for participants with three complete follow-up interviews, but it was clear from summary statistics that they had changed very little over the 12 months.

Findings of the COSP Multi-site Research Initiative support the conclusion that adjunctive participation in consumer-operated service programs leads to significant additional increases in subjective aspects of both well-being and empowerment and modest positive effect in clinical outcomes over increases achieved through traditional MH services alone. These effects are not restricted to specific types of peer-run programs but appear to apply to COSPs in general. For these outcomes, the effects also appear to be both additive and compensatory. In addition to a general effect, there are greater relative gains where traditional programs alone show less effect.

RELATIONSHIP OF PARTICIPANT CHARACTERISTICS TO OUTCOMES

There were more females (60%) than males (40%) among multisite participants, and slightly less than half (43%) were minorities or individuals who described themselves using two or more race categories. The average participant age was 43 years old. Only 13% of participants were married at baseline with another 23% having a "significant other" to whom they were not married.

More than half of the study participants had achieved at least a high school diploma, with 42% going beyond high school. Although nearly all participants (97%) had been employed at some point during their life, only about one-third (29%) were working either for pay or as a volunteer at the time of the baseline interview.

In general, outcomes in the COSPs were found to apply equivalently across the range of study participants. However, there were some notably variations based on population characteristics. Well-being, empowerment, socialization, symptom and hospitalization outcomes were assessed in relationship to age, gender, race, marital status, education, and employment. Education had significant interactions with almost all outcomes that were evaluated followed by gender, marital status, age, race, and finally employment.

RELATIONSHIP OF PEER PRACTICES TO OUTCOMES

In order to successfully research COSPs as an adjunct to traditional mental health services, it was necessary for the multi-site study to determine the degree to which all the study sites operated according to a similar set of well-defined peer practices.

Under the leadership of the Consumer Advisory Panel, 46 common ingredients of peer practices at the eight participating COSPs were identified and organized into an objective, structured tool called the Fidelity Assessment Common Ingredients Tool (FACIT). The FACIT was administered to both the COSPs and the traditional mental health programs at each study site to determine the extent that they implemented the COSP model, processes, and values (Johnsen, Teague & McDonel Herr, 2005). It also identified characteristic differences between COSPs and traditional mental health programs and differences between COSP models.

Most important, analyses of FACIT and outcome results established evidence of a strong relationship between key peer practices that support inclusion, peer beliefs and self-expression and an increase in study outcomes.

KEY PEER PRACTICES

Inclusion

- Services free of charge
- Program rules ensure physical safety, developed by consumers
- No hierarchy, sense of freedom and self-expression, warmth among participants and staff
- Sense of community, fellowship, mutual caring, and belonging
- Lack of coerciveness, no threats or unwanted treatment, tolerance of harmless behavior, emphasis on participant choice

Choice & Respect

- Member choices about participation
- Acceptance and respect for diversity

Self-Expression

- Opportunities for telling one's story in visual arts, music, poetry
- Opportunities for sharing life experiences
- Structured groups for listening, empathy, and compassion based on common experience

PUTTING COSP RESULTS INTO PRACTICE

As states adopt an evidence-based practice approach to the delivery of mental health services, there are growing demands for consumer-operated services to examine the fidelity and effectiveness of the peer services they provide. It is doubtful peer programs can continue to expand beyond current operations if they lack valid, reliable tools to evaluate program effectiveness and improve the quality of their workforce. This call for accountability has challenged peer providers to finance and build quality improvement processes and trained personnel that support peer values and the lived experience of program participants.

When results of the FACIT were analyzed, researchers were able to pinpoint program weaknesses, clarify program strengths, and associate various program outcomes to key peer practices. Such capabilities can advance the capacity of researchers, peer providers, and mental health administrators to promote evidence-based practices in developing consumer-operated services, to guide quality improvements in mature COSPs, and to identify and measure "consumer-friendly elements" of traditional mental health programs.

The FACIT is now available to the field in order to be used at the discretion of individual programs through a quality improvement team approach or as part of an external monitoring system. Implementation is based on program choice, and is intended to build skills and be empowering.

STUDY IMPLICATIONS

Studies of peer-to-peer services have enhanced knowledge of peer practice and provided the empirical basis for creating effective partnerships between peer providers, public mental health agencies, and managed care organizations. The COSP multi-site study established the effectiveness of peer-run programs in increasing well-being outcomes beyond the level currently obtained at traditional mental health programs. Traditional mental health programs were also shown to have considerable potential as settings to facilitate these outcomes by incorporating consumer-defined program features associated with positive psychological outcomes. The expanding evidence base of effectiveness of peer-to-peer services to promote and enhance recovery validates efforts to bring mental health consumers into the mental health workforce within peer-run programs and as peer specialists within traditional mental health services.

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For more information contact:

Jean Campbell, PhD
Director
Program in Consumer Studies & Training
Missouri Institute of Mental Health
5400 Arsenal Street
St. Louis, MO 63139
(314) 877-6457
Jean.Campbell@MIMH.edu