

# **Consumer-Operated Services Program**

## **(COSP) Multisite Research Initiative**

### **Overview and Preliminary Findings**

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#### **Introduction**

The Final Report of the President's New Freedom Commission on Mental Health (July, 2003) recommends that consumers and families are fully involved in orienting the mental health system toward recovery. The formal integration of peer support programs into the continuum of community mental health services promises to improve service outcomes related to recovery and to expand service system capacity. The Final Report states, "The direct participation of consumers and families in developing a range of community-based, recovery-oriented treatment and support services is a priority" (p. 37). In particular, it urges that consumer-operated services "for which an evidence base is emerging" be promoted.

In the past 30 years, consumer-operated service programs (COSPs) for persons with mental illness have matured, diversified, and increased their numbers across the United States (Davidson et al., 1999; Emerick, 1990; Solomon & Draine, 2001). The profoundly human tendency to seek others with similar problems to make sense of one's experience has fostered a broad range of peer support programs and services. While COSPs operate independently, they often provide services to people who attend both consumer-run as well as traditional mental health programs (Kessler, Mickelson, & Zhao, 1997). In fact, Chamberlin, Rogers, and Ellison (1996) found that members of mental health consumer self-help groups used about seven mental health services in the past year, and about half took psychiatric medications.

Research suggesting that peer support reduces symptoms, enlarges social networks, and enhances quality of life has been largely limited to surveys, uncontrolled studies and demonstrations of feasibility (Davidson et al., 1999). Now nearing completion, the Consumer-Operated Services Program Multisite Research Initiative (1998-2004), a randomized controlled study funded by the Center for Mental Health Services, offers new evidence of the effectiveness of consumer-operated service programs for selected outcomes. The following report provides the

rationale, methods, participant baseline characteristics, and preliminary findings to help guide Veterans Administration planning efforts regarding the introduction of peer-run support programs.

**This preliminary report provides the rationale, methods, participant baseline characteristics, and selected outcome findings of the Consumer-Operated Services Program Multisite Research Initiative (1998-2004), a randomized controlled study funded by the Center for Mental Health Services. Design features include:**

- The multisite study investigated the cost-effectiveness of eight consumer-operated support programs for adults with serious mental illness when offered as an adjunct to traditional mental health services.
- Program models included four drop-in centers, two mutual support programs, and two educational/advocacy programs.
- The research team was composed of seven geographically diverse research sites across the United States, a Coordinating Center and a federal team (CMHS/SAMHSA). Multisite research decisions were made collaboratively through a Steering Committee with a Consumer Advisory Panel.
- 1,827 study participants were assessed at baseline, four, eight, and twelve months using a common assessment protocol that measured outcomes such as employment, empowerment, housing, social inclusion, well-being, and satisfaction.
- A fidelity assessment tool measured program characteristics, and program cost data were also collected.

## **Methodology**

***Interventions.*** The experimental conditions consisted of consumer-operated service programs (COSPs) offered as an adjunct to traditional mental health services (TMHS), and the control condition consisted of traditional mental health services only.

☒ COSPs included in this study were administratively controlled and operated by consumers, emphasized self-help as their operational approach, and had been in operation for at least two years at the beginning of the project.

☒ The TMHS programs included in this study offered services in community-based settings, were operated by appropriately credentialed mental health professionals, and explicitly ascribed to the value and goals of the Community Support System of Care (McDonel Herr, English and Brown, 2003; Stroul, 1986).

**Participant Inclusion Criteria.** Persons with severe and persistent mental illness were recruited for the study with an Axis I or II diagnosis, such as a diagnosis of schizophrenia, schizoaffective disorder, or major affective disorder (American Psychiatric Association APA, 1994).

- ☒ It was necessary for participants to be 18 years of age or older;
- ☒ Be able to provide full and knowing consent;
- ☒ Be actively involved with a traditional mental health provider in the past 12 months (defined as having received at least 4 mental health services in the past year with at least one of those services in the 4 months prior to entry into the study).
- ☒ Consumers who had more than minimal involvement in the COSP under study or COSPs similar to ones in the study within the past 6 months (that is, more than 3 visits to or meetings in a COSP) were not eligible.

**Enrollment procedures.** Study sites recruited from traditional mental health providers, named as partners at each study site, using a variety of methods and materials.

- ☒ Following a common induction process, participants went through an informed consent procedure and then a baseline assessment.
- ☒ To complete enrollment, they were randomized to the experimental or control condition.

**Common Assessment Protocol.** Baseline and follow-up versions of a Common Assessment Protocol composed of 27 scales were administered at baseline, four-month, eight-month, and twelve-month (See Table 1).

- ☒ To assure that the selected scales would yield reliable data, wherever available, validated scales with published data on the COSP target population were selected.
  - A task force of racially and ethnically diverse researchers and consumers also conducted a review for culturally competent language and sensitivity.
- ☒ Two rounds of pilot testing of the Common Assessment Protocol provided opportunities for refinement of items and feedback about ambiguous items or items potentially distressing to participants, as well as interview length and ease.
- ☒ To ensure correct administration, all interviewers participated in extensive training in interview methods and procedures.
  - Additionally, the interviewers received detailed instructions and interpretive guidelines for each item through an accompanying manual, and followed a well-defined script for administration of each interview item.

**Assuring Data Quality.** For the collection and management of data, the Coordinating Center developed a detailed data quality assurance plan early in the project.

- ☒ To minimize data entry errors, an automated data entry system was provided to each site.
  - Key system features included built-in consistency checks, lock out of out-of-range responses, verification of data through double entry, and the ability to build queries for cleaning data.
- ☒ Data entered by sites were forwarded quarterly to the data repository, and merged into a multisite dataset.
- ☒ While Rosenthal (1978) suggests a data error rate of no more than 1%, error rates in quality checks of protocols conducted by the Center were <.01%.

**Baseline Dataset Description.** The COSP baseline dataset contains face-to-face interview data collected from

participants at all eight program sites using the Common Assessment Protocol. ***The final baseline dataset consisted of 1,827 interviews.*** All baseline participant characteristics are based on that final dataset.

- ☒ Across all program sites, 2,267 individuals consented to be contacted about the COSP study and were invited to participate.
  - 232 (10%) refused consent for study participation.
- ☒ Of the 2,035 individuals who consented to participate, baseline interviews were actually completed and entered into the dataset for 1,935 (95%) participants.
  - 108 (6%) were subsequently deleted from the dataset.
    - 18 individuals had no DSM-IV diagnosis as required; five persons failed to meet other eligibility criteria; and 85 individuals were eliminated due to data integrity problems at one program site.
- ☒ Other than non-applicable items, there was a minimum of missing data in the final baseline data set.
  - The item-specific missing value count ranged from 0 (for first DSM-IV, Axis 1 diagnosis, which was required for all participants, and for some other variables such as gender and age), to 166 for “income received from Social Security.”
    - For most items with missing data, other than “not applicable” responses, the number of missing cases was much lower (e.g., 9 for racial/ethnic identification, and 11 for current housing status).

### **Participant Baseline Characteristics**

Overall, COSP research participants present a mixture of demographic and diagnostic characteristics (See Table 2 for a comprehensive description ). Some of those characteristics are associated with positive mental health treatment outcomes such as being female and having more education (Wieselgren & Lindstrom, 1996), while others are associated with a poorer prognosis such as not being married, younger age of first hospitalization or onset of illness, and serious diagnoses (Pfeiffer, O’Malley & Shott, 1996; Yanos, Primavera & Knight, 2001). Rate of serious diagnoses were comparable to those reported in other large mental health services studies (EIDP, 2001). Participants also had extensive histories of psychiatric treatment including hospitalization at rates comparable to those found in other studies (Segal, S. P., Silverman, C., & Temkin, T., 1995; Chamberlin, J., Rogers, E. S., & Ellison, M. L., 1996).

#### ***Demographics.***

- ☒ There were more females (60%) than males (40%) among multisite participants.
- ☒ 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.
- ☒ 53% reported having children, averaging one child per parent; approximately half of the parents indicated their children were under the age of 18 years.

#### ***Diagnosis.***

Nearly half of the participants were diagnosed with Schizophrenia and Schizoaffective Disorder (47%; 31% Schizophrenia, 16% Schizoaffective Disorder). Depression was diagnosed for 25% of the participants, and Bipolar Disorder for 18%.

- ☒ Other major diagnostic categories represented among COSP participants included Anxiety Disorders, Dysthymia, and Psychotic Disorders other than Schizophrenia.
- ☒ Secondary diagnoses on Axis I were found in a small number (11%) of participants with 76% of those with more than one diagnosis having substance-related disorders.
  - The majority of these substance-related, secondary diagnoses were reported for participants in one study site that specifically provides services to a dually-diagnosed population.

### ***Education, Employment, and Benefits.***

- ☒ More than half of the 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, and 77% said that having a paying job was important to them, only about one-third (29%) were working either for pay or as a volunteer at the time of the baseline interview. Whereas 19% received income from paid employment (including a sheltered workshop), a substantial proportion of participants received income from non-employment sources, including Social Security (84%) income, other social welfare benefits (40%), and rent supplements (24%).
  - In addition, most participants (79%) were receiving benefits that covered their psychiatric care, although only 59% reported that their benefits covered all the services they needed.

***Housing.*** In general, the housing situation of participants as reported at baseline was positive, especially as compared to the fairly high rate of past homelessness reported by these same individuals.

- ☒ Although about half of the participants had been homeless at some time in their lives (51%), most participants' living situations at baseline were fairly stable. 85% reported that there was no time limit on how long they could stay at their current place of residence. (Note: This percentage does not indicate how many individuals may have *wished* to move from their current housing situation but were unable to do so; data were not collected on desire to change current housing).
- ☒ More than half of the participants lived in their own residences at the time of the baseline interview (58%), 16% lived in someone else's residence, 19% lived in temporary housing; and only 2% were currently homeless. In addition, about one-third of participants were living alone (36%).
- ☒ Of the two-thirds of participants who lived with someone else, 41% lived with another mental health consumer, 29% lived with a spouse or other live-in partner, 15% lived with their parents, 28% lived with their children, 14% lived with other family members, and 27% lived with a non-related person.

### **Multisite Analytic Plan**

The multisite analytic plan featured two broad approaches: an intent-to-treat and an as-treated approach.

- ☒ The randomized design employed by all sites allowed for a traditional randomized clinical trial (RCT) approach to data analysis. The plan for initial analyses therefore included an intent-to-treat analysis that tested an *a priori* primary hypothesis using data from all sites. Researchers hypothesized that the greatest effect would be seen

by deriving a more general outcome construct, “well-being,” developed from validated scales which measured recovery, quality of life, meaning of life, hope, empowerment, and social inclusion.

➤ Such a construct was theoretically justified by a review of the general literature on well-being and the research on peer support programs and consumer/survivor recovery (Campbell & Schraiber, 1989; Bracke, 2001).

➤ Baseline data were used to examine the distributional properties of potential variables that might contribute to the composite well-being measure (including ceiling and floor effects), as well as their interrelationships (through a factor analysis).

➤ Baseline well-being values for participants who reported having been involved in consumer-operated programs in the past four months were compared with participants reporting no such involvement; ***those reporting some prior involvement had a significantly higher level of well-being at baseline.***

☒ However, because participation in the COSPs was voluntary – study participants assigned to the experimental condition were merely invited and encouraged to use the COSPs, not required – and the COSPs were potentially available to those study participants who had been randomized to the ‘control’ (TMHS-only) condition, random assignment to COSP was accurately predicted to show only a modest correlation with participants’ actual engagement. Consequently, an as-treated analytical approach was also planned to produce estimates of the effects of actual participation in the COSPs.

### **Preliminary Findings**

Preliminary intent-to-treat findings are available from analyses based on interviews at baseline and at follow-up at 4, 8, and 12 months. The primary hypothesis tested can be stated as:

***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.***

Multilevel modeling was used to assess the relationship between the change over time in well-being and random assignment group to account for the nesting of multiple time point observations within participant and of participants within study site. Sites are further nested within clusters of similar program type. Findings are:

There is a significant effect of time ( $p = .0001$ ), indicating that both groups show improved well-being over time; the two-way interaction of time and random assignment group is not significant (Figure 1).

The three-way interaction of time, random assignment group, and site is significant:  $p = .0097$ . At the cluster level there is a significant two-way interaction of time and random assignment group for the drop-in center cluster of programs,  $p = .0017$  (Figure 2), without significant interaction by site.

The results indicate that ***participants randomly assigned to consumer-operated services programs of the drop-in type*** in addition to their traditional mental health services showed ***greater improvement*** in well-being over the course of the study than ***participants randomly assigned to only traditional mental health services*** at those sites.

These findings reflect only the first set of analyses conducted to test intervention effect using a single hypothesized

measure within an intent-to-treat model, i.e., one that for this study contrasts study participants who were *offered* services, whether or not they actually used those services, with those who were *not offered* those services, whether or not they refrained from using them. In this study the experimental group included a substantial number of persons who never participated in the consumer-operated services, and the control group included some who did use the services. Strictly speaking, the experimental design evaluates the effect of *offering* consumer-operated services.

Consequently, as-treated analyses are currently being implemented in order to evaluate the impact of consumer-operated service programs for those who actually receive the interventions. By focusing on service recipients, such analyses typically yield higher estimates of intervention effect. Key research questions are whether study participants who were engaged (i.e., participated in the service programs) showed greater improvement in well-being than those who were not engaged, and whether the degree and timing of engagement are related to the degree of improvement in well-being. As a follow-up to the preliminary intent-to-treat findings, outcomes in additional domains will be examined in relation to participant and program characteristics, allowing among other things a retrospective assessment of whether the *a priori* well-being hypothesis might have been better suited to drop-in programs than to the others. Additional analyses will also evaluate both costs and cost-effectiveness of services and to what degree fidelity to a preliminary general model of consumer-operated services is related to outcomes.

## **Conclusion**

Preliminary findings from this 12-month follow-up study using the most stringent test of effectiveness – intent-to-treat analysis of an *a priori* hypothesis – suggest conservatively that at minimum some types of consumer-operated service programs, when offered as an adjunct to traditional mental health services, can significantly improve the well-being (a composite construct reflecting recovery, social inclusion, empowerment, quality of life, meaning of life, and hope) of adults with serious mental illness. Further analyses will examine both well-being and a wider range of intervention impacts for persons who actually participated in those programs, addressing among others the questions of the degree to which partial engagement may have suppressed estimates of positive effect in consumer-operated service programs other than drop-in centers, and whether alternative outcomes may be emphasized to a greater degree in these other service models.

The results of this multisite study will provide a substantial contribution to an empirical evidence base for creating effective partnerships between peer-run support programs, public mental health agencies, and managed care organizations, as well as offering much practical information for such peer-run support programs in early stages of organization. By expanding the continuum of community mental healthcare to include peer-run support services, the promise of the New Freedom Commission for system transformation and a future when persons with a mental illness can recover and participate fully in the community can begin to be realized.

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**Table 1. Common Assessment Protocol**

<b>Domain</b>	<b>Scale</b>	<b>Number of Items</b>	<b>Reference</b>
Demographics	COSP-MRI	32	
Employment	Adapted from the SAMHSA Supported Employment Intervention Demonstration Program	22	Cook, J. University of Illinois-Chicago; EIDP Web Site, <a href="http://www.psych.uic.edu/eidp/">http://www.psych.uic.edu/eidp/</a>
Finances and Entitlements	Adapted from the SAMHSA Supported Employment Intervention Demonstration Program	44	Cook, J. University of Illinois-Chicago; EIDP Web Site, <a href="http://www.psych.uic.edu/eidp/">http://www.psych.uic.edu/eidp/</a>
Housing	Adapted from the New Hampshire State Outcome Measure	34	
Satisfaction with Traditional Mental Health Services	Adapted from CMHS Mental Health Statistics Improvement Program Report Card	12	Teague, Ganju, Hornik, Johnson, & McKinney (1997)
Outcomes of Traditional Mental Health Services	Adapted from CMHS Mental Health Statistics Improvement Program Report Card	14	Teague, Ganju, Hornik, Johnson, & McKinney (1997)
Satisfaction with Consumer-Operated Services	Adapted from CMHS Mental Health Statistics Improvement Program Report Card	12	Teague, Ganju, Hornik, Johnson, & McKinney (1997)
Outcomes with Consumer-Operated Services	Adapted from CMHS Mental Health Statistics Improvement Program Report Card	14	Teague, Ganju, Hornik, Johnson, & McKinney (1997)
Lifetime Service Use	COSP-MRI	16	

Recent Service Use	COSP-MRI	6	
Subjective Side Effects from Medication	Subjective Side Effects Rating Scale	24 for females; 22 for males	Weiden & Zygmunt (1999)
Substance Use	Adapted from the Addiction Severity Scale	31	McLellan (2002)
Empowerment	Empowerment Making Decisions	28	Chamberlin, Rogers, Ellison, & Crean (1997)
	Personal Empowerment	20	Segal, Silverman, & Temkin (1993)
	Organizationally Mediated Empowerment	272	Segal, Silverman, & Temkin (1995)
Service Utilization	Adapted from the Uniform Client Data Instrument	96	
Program Activities	COSP-MRI	102	
Social Inclusion	Quality of Life Interview Subscale	11	Lehman (1988)
	Well-Being Project Questionnaire Subscale	8	Campbell & Schraiber (1989)
	Adapted from Schedule of Racist Events	34	Landrine & Klonoff (1996)
Quality of Life	Excerpt from the Quality of Life Interview	6	Lehman (1988)
Symptoms	Hopkins symptoms Checklist-25	25	Mattsson, Williams, Rickels, Lipman, & Uhlenhuth (1969); Shern, Wilson, & Coen (1994)
	Colorado Symptom Index-Psychoticism Subscale	10	Shern, Wilson, & Coen (1994)
Physical Health	Health Problems Checklist	17	Segal, Gomory, & Silverman (1998)
Well-Being	Recovery Assessment Scale	41	Corrigan, Giffort, Rashid, Leary, & Okeke (1999)
	Meaning of Life Framework Subscale from Life Regard Index	14	Battista & Almond (1973)
	Herth Hope Index	12	Herth (1992)
Religion/Spirituality		4	Zinnbauer, et al. (1997)

**Table 2. Baseline Characteristics of COSP Participants**

Baseline Characteristic	Multi-site		Program Models		Significance Test
	All Programs (N = 1,827)	Drop-In (N = 771)	Education/ Advocacy (N = 749)	Mutual Support (N = 307)	
Primary Axis I diagnosis					$\chi^2(6) = 33.4^*$
Mood Disorders	44.4%	40.0%	46.9%	49.8%	
Anxiety Disorders	3.7%	3.2%	4.7%	2.6%	
Schizophrenia/Psychotic disorders	50.4%	55.9%	47.4%	43.7%	
Other	1.5%	0.9%	1.1%	3.9%	
Gender: % Male	39.9%	47.7%	28.3%	48.5%	$\chi^2(2) = 71.3^{**}$
Racial/ethnic identification <sup>a</sup>					$\chi^2(2) = 25.8^{**}$
White	57.2%	56.9%	62.3%	45.3%	
African American	16.6%	21.4%	9.2%	22.6%	
Hispanic	1.2%	2.0%	0.7%	0.7%	
Other	2.5%	3.0%	2.3%	2.0%	
Biracial/multi-racial	22.5%	16.8%	25.6%	29.5%	
Average age	42.7	43.0	43.3	40.3	$F(2,1824) = 10.0^{**}$
Currently married	12.6%	6.5%	20.1%	9.5%	$\chi^2(8) = 166.2^{**}$
Have significant other (non-spouse)	23.4%	22.5%	21.5%	30.2%	$\chi^2(2) = 9.7$
Have any children	53.1%	42.4%	64.3%	52.5%	$\chi^2(2) = 72.9^{**}$
Currently employed for pay or volunteer	29.4%	30.9%	28.5%	27.7%	$\chi^2(2) = 1.6$
Having a paying job is important	76.9%	77.3%	76.2%	77.6%	$\chi^2(2) = 0.34$
Educational attainment					$\chi^2(8) = 18.5$
Less than high school	9.3%	8.0%	11.8%	6.2%	
9-12 years	23.6%	21.5%	24.2%	27.7%	
HS graduation	25.3%	25.2%	25.2%	25.7%	
Any college/vocational training	38.8%	41.9%	35.7%	38.4%	

Any post-graduate work	3.0%	3.4%	3.1%	2.0%	
Reporting a physical disability	51.7%	52.5%	52.5%	47.9%	$\chi^2(2) = 2.2$
Social Security income in past 30 days	83.6%	90.1%	78.2%	80.7%	$\chi^2(2) = 38.1^{**}$
Currently live in own residence	58.0%	51.3%	69.6%	46.6%	$\chi^2(12) = 218.6^{**}$
Currently homeless	10.2%	14.0%	4.8%	14.0%	$\chi^2(12) = 218.6^{**}$
Do <u>not</u> have to move from current housing	85.2%	85.7%	88.2%	76.7%	$\chi^2(2) = 22.6^{**}$
Ever homeless during life	51.0%	59.5%	37.9%	61.9%	$\chi^2(2) = 87.4^{**}$
Average age at first psychiatric contact (hospitalization or outpatient treatment)	23.2	23.0	24.4	21.3	$F(2,1376) = 8.6^*$
Any psychiatric hospitalization in life	82.6%	89.5%	73.1%	88.3%	$\chi^2(2) = 79.1^{**}$
More than 5 psychiatric hospitalizations (of those reporting <u>any</u> hospitalization)	44.4%	47.9%	36.7%	51.1%	$\chi^2(2) = 21.4^{**}$
Recent psychiatric hospitalization	16.0%	16.2%	12.6%	23.9%	$\chi^2(2) = 20.3^{**}$
Taking a prescribed psychiatric medication in past 4 months	96.2%	95.7%	96.1%	96.1%	$\chi^2(2) = 0.02$
Experiencing side-effects (of those taking psychiatric medication)	94.9%	93.6%	95.6%	96.5%	$\chi^2(2) = 4.7$
Baseline symptom scores: HSCL (multi-site range=25-98) CSIP (multi-site range=10-50)	49.9 24.2	46.7 23.1	53.4 24.9	49.6 25.0	$F(2,1805) = 34.8^{**}$ $F(2,1806) = 8.7^*$

Note. Total N's are given for the multi-site and for each Program Model. However, denominators for some percentages may vary slightly from the total N, due to missing values.

<sup>a</sup>For ease of interpretation, and because there were very few participants in several of the Race categories, the Chi-square test compared percentages of white versus non-white participants across Program Models (a 2 X 3 cross-tabulation). Therefore, df = 2.

\*  $p < .01$                       \*\*  $p < .001$

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