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The Consumer-Operated Services Program Multisite Research Initiative (COSP-MRI):  
Overview, Participant Characteristics, and Lessons Learned

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## Abstract

This paper provides the rationale, methods, and baseline study population characteristics for the Consumer-Operated Services Program Multisite Research Initiative (1998-2006), a randomized controlled study funded by the Center for Mental Health Services. Subsequent papers will review cost and outcome results. Composed of seven study sites, a Coordinating Center and a federal team, the multisite study investigated the cost-effectiveness of selected consumer-run programs (8) for people with serious mental illness when offered as an adjunct to traditional mental health services. Program models included drop-in centers, peer support groups, and educational/advocacy programs. 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. Concluding remarks offer some observations about lessons learned and implications of the research for behavioral health evidence-based practices.

In the past 20 years, consumer-operated service programs to serve persons with mental illness (COSPs) 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.

The formal integration of peer support programs into the continuum of community mental health services promises to improve service outcomes and expand system capacity, but little formal evaluation has tested these assumptions or explored the feasibility of sustaining partnerships between consumer-run and traditional mental health programs. Evidence suggesting that peer support reduces symptoms, enlarges social networks, and enhances quality of life is largely limited to uncontrolled studies, demonstrations of feasibility, and preliminary findings (Davidson et al., 1999).

In 1998, the Substance Abuse and Mental Health Services Administration's (SAMHSA) Center for Mental Health Services (CMHS) initiated the Consumer-Operated Services Program Multisite Research Initiative (COSP-MRI) to evaluate existing consumer-run peer support programs for adults with serious and persistent mental illness when offered as an adjunct to traditional mental health services. The goals of this paper are to establish the rationale for the COSP-MRI in terms of the history of consumer-operated programs and previous research, to detail the study methods, to describe the baseline study population characteristics, and to

comment on lessons learned from the collaborative study context.

### **Development of Programs By and For Consumers**

Alternatives to traditional mental health services offered by and for people with severe mental illness emerged in the 1970s in response to service inadequacies experienced by persons moving from large psychiatric hospitals into community treatment (Van Tosh, Ralph, & Campbell, 2000; Zinman, 1986). To many professionals and policy-makers, a revolving-door pattern of care signaled system distress (Geller, 1992), and critics questioned the ability of professionals to successfully provide housing and social supports (Carling, 1990; Tanzman, 1993). Others criticized traditional services' use of coercion to assure treatment compliance (Chamberlin, 1978; Leete, 1988; Susko, 1991).

Ridgway's (1988) review of studies of consumer and professional attitudes concerning mental health service delivery highlighted the differences between professional and consumer perspectives related to the relative importance of treatment goals, the identification of problems, and barriers to community services. The experience of stigma and discrimination coupled with the lack of understanding, respect, and trust between some consumers and mental health professionals prompted individuals with psychiatric disabilities to seek out the company of peers for validation and support (Campbell & Schraiber, 1989). Self-help groups formed to provide reassurance to people with mental illness, reducing anxiety, restoring hope, and reinforcing a sense of belonging (Breier & Strauss, 1984). Early attempts at mutual aid among people with mental illness were followed by survivor and activist groups like the Insane Liberation Front in Portland, Oregon and the Mental Patient's Liberation Project in New York City which addressed issues of social justice (Chamberlin, 1978; 1990; 1995; Van Tosh, Ralph, & Campbell, 2000).

First within the National Institute of Mental Health (NIMH) starting in the late 1970's, and then moving to SAMHSA/CMHS in 1992, the Community Support Program (CSP) has been an ongoing federal initiative to improve community-based services for persons with severe and persistent mental illness (McDonel Herr, English, & Brown, 2003). From 1988-96 the CSP funded 14 projects involving consumers as providers (Linkins et al., 2003) to evaluate consumer-run service models (Furlong-Norman, 1988; Galanter, 1988; Heine, Hasemann, Mangine, Dearborn-Morris, & Royse, 1993; Kaufmann, Ward-Colasante, & Farmer, 1993; Lieberman, Gowdy, & Knutson, 1991; Mowbray & Tan, 1992; Nikkel, Smith, & Edwards, 1992). These included drop-in centers, outreach programs, businesses, employment and housing programs, and crisis services (Long & Van Tosh, 1988; Penny, 1992; Van Tosh & del Vecchio, 2000). Other CSP initiatives included support for centers for self-help research and self-help technical assistance centers, and an annual "Alternatives" conference. Growing collaboration between consumer professionals and SAMHSA representatives also led to greater consumer involvement in the grant review and award process and recognition of the value of peer support programs in mental health reform efforts (Campbell, 1998; Fisher, 1994; Leff, Campbell, Gagne, & Woocher, 1997; Trochim, Dumont, & Campbell, 1993).

### **Research on Peer Support Services**

Most studies of peer support services have been descriptive or qualitative, seeking to identify participant characteristics, processes that lead to change, or consumer perspectives on the benefits of program participation (Chamberlin et al., 1996; Kaufman, Schuldberg, & Schooler, 1994; Luke, Rappaport, & Seidman, 1991; Mowbray, Chamberlain, Jennings, & Reed, 1988; Mowbray & Tan, 1993; Segal, Silverman, & Temkin, 1995; Van Tosh & del Vecchio, 2000). Such research has generally sought to assess program benefits using pre-post or quasi-

experimental designs. Studies using non-randomized control groups or pretest scores as comparisons have found that participation in peer support reduces psychiatric symptoms, decreases hospitalization (Galanter, 1988; Kennedy, 1990), enlarges social networks (Carpinello, Knight, & Janis, 1991; Rappaport et al., 1985), and enhances self-esteem and social functioning (Kaufmann et al., 1994; Markowitz, DeMasi, Knight, & Solka, 1996).

Research focusing on cost-savings and benefits involving participants similar to those who use peer support services (Chamberlin et al., 1996; cf. Newman & Tejada, 1996; Dumont & Jones, 2002) has found that such individuals receive a considerable portion of available health and social services (Buck, Teich, Bae, & Dilonardo, 2001; Larson et al., 1998; Pomerantz, 2001). On the other hand, when mental health consumers with substance abuse problems participated in both mental health services and programs with a 12-Step Recovery Model, Behavioral Skills Model, or Intensive Case Management, medical and criminal justice costs (Jerrell, Jeanette, & Hu, 1996) were reduced, although family costs increased (Franks, 1987; cf. Cardin, McGill, & Falloon, 1985).

Two reviews of peer support programs (Davidson et al., 1999; Solomon & Draine, 2001) make clear that preliminary evidence supports their effectiveness across a variety of domains. However, despite considerable research, the evidence lacks the kind of internally valid studies that randomized clinical trials offer. Also, most peer support programs have not included comprehensive measures of relevant outcome variables in program evaluation. Therefore, policy-makers have lacked a solid research base that would drive widespread funding for peer-run programs across the country. A multisite study such as the COSP-MRI addresses this need for larger sample size and replications of findings, and examines the generalizability of findings to diverse programs, settings, and participant populations.

## **Multisite Study Organization**

SAMHSA/CMHS funded a Coordinating Center (Center) at the Missouri Institute of Mental Health and seven research sites located around the United States (Connecticut, Florida/California, Illinois, Missouri, Maine, Pennsylvania, and Tennessee) to study eight consumer-operated peer support programs. The Center was charged with coordinating multisite data management and analysis, as well as conducting the multisite cost study. It created and maintains a centralized data repository, and is responsible for preparation of the final study database for public domain. Multisite decisions regarding study design, protocol development, and analysis plans were made through a consensus building process by a Steering Committee (SC) composed of principal investigators (PI) and a consumer representative from each site, the Center PI, and a SAMHSA/CMHS representative. In turn, the SC created multiple subcommittees to accomplish much of its work.

Because of the importance of understanding peer support from a consumer perspective (Campbell, Ralph, & Glover, 1993; Kaufmann, Freund, & Wilson, 1989; Rappaport et al., 1985), consumer involvement in every aspect of the project was a defining characteristic of the COSP-MRI. In addition to SC membership, consumers served on every subcommittee throughout the study, were members of a national Consumer Advisory Panel (CAP), and organized local study site CAPs. Consumer-researchers also held prominent positions within the Center and at the site level, including roles as principle investigators, site visitors, interviewers, and coordinators.

In addition, SAMHSA/CMHS representatives provided oversight and guidance for multisite activities. Funded through cooperative agreements, the COSP-MRI had considerable federal involvement to assure that study implementation reflected the intent of the original plan.

## **Study 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. In all, three COSP program models were included: four drop-in centers, two mutual support programs, and two educational/advocacy programs.

The control condition consisted of study participants who used TMHS only. 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). A diagnosis of substance abuse alone was insufficient for inclusion, but was acceptable as a secondary diagnosis. It was also 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. Sites were allowed to impose additional inclusion and exclusion

criteria as long as they adhered to the COSP-MRI inclusion and exclusion criteria for study participation.

***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.*** The SC developed baseline and follow-up versions of a Common Assessment Protocol composed of 27 scales administered at baseline and 4-, 8- and 12-month follow-ups. 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.

**[Insert--Table 1. COSP Common Assessment Protocol--Here]**

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 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%.

***Multisite Analytic Plan.*** The multisite analytic plan features 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 initial analyses therefore include an intent-to-treat analysis that tests an a priori primary hypothesis using data from all sites. However, because participation in the COSPs was voluntary and the COSPs were potentially available to those study participants who had been randomized to the ‘control’ (TMHS-only) condition, random assignment to COSP resulted in a less-than-perfect correlation with participants’ actual engagement. Consequently, an as-treated analytical approach will also be taken to produce estimates of the effects of actual participation in the COSPs.

Analyses of five outcomes (empowerment, employment, housing, social inclusion and satisfaction with services) was federally mandated, as well as determination of cost savings for such services as inpatient hospitalizations and cost offsets for decreases in criminal justice, income support, and related items. However, SC discussions led to the hypothesis that the greatest effect would be seen by deriving a more general construct, “well-being” from the set of five distinct outcome classes specified by the original grant announcement. Such a construct is 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 analyzed to determine general study population characteristics with particular emphasis on demographic characteristics and severity of illness, as well as the relationships among these characteristics. By assessing the relationships among such factors as race, gender, service use, and diagnosis, it was possible to identify major participant subgroups. Another set of analyses explored heterogeneity in participant characteristics across program types and across the eight peer programs. Researchers also relied on analyses of the baseline data to assess the psychometric properties and relationships among all outcome scales, as well as their relationships to proposed covariates. As a preliminary test of the association between COSP experience and outcome, baseline data were used to examine the relationship between the composite well-being measure and baseline measures of prior participation in consumer programs. The distributional properties of potential variables that may contribute to the composite well-being measure (including ceiling and floor effects) were examined, as well as their interrelationships (through a factor analysis) and correlations with self-reported level of prior engagement in consumer-operated programs.

Since the multisite design included eight program sites representing three program models which could be associated with differences in participant characteristics, the heterogeneity of program characteristics and outcomes is to be examined before pooling data from sites (Kraemer, 2000) for the purposes of generalizing across programs to increase statistical power (Lipsey, 1990). Incorporating recent advances in statistical methods appropriate to the nested nature of multisite longitudinal data (Hedeker & Gibbons, 1997; Raudenbush & Bryk, 2002), the analysis plan also specified complementary preliminary, supportive, and ancillary analyses intended to enhance the validity of conclusions drawn about the effects of participating in the COSPs.

Longitudinal multisite analyses of outcomes builds from characteristics of the data and populations, adding characteristics of programs and context (Seltzer, 1994), and integrating these into statistical tests and summaries of comparative outcomes, while supporting and probing these conclusions as threats to validity are encountered (Reichardt & Mark, 1998; Shadish, Cook, & Campbell, 2002). In that randomization could fail to balance experimental and control groups on important baseline variables, and differential attrition or loss to follow-up may also occur across conditions, the pooled dataset of COSP participants with follow-ups is to be examined for evidence of imbalance between two groups by calculating differential attrition rates (by site) over such covariates as gender, racial/ethnic background, whether physical disability affects daily activity, diagnosis, educational attainment, current employment status, housing, whether ever homeless, and current living situation.

Comparison of means and distributions on selected covariates and outcomes in the pooled data is to be followed by modeling of differences between COSP and TMHS participants, controlling for baseline values and covariates determined important in the preliminary analyses. While hierarchical linear models are to be used to assess main effects and site effects concurrently, the COSP analysis plan will focus on defensible estimation of the contribution of COSPs to outcomes within sites and clusters (Rosenthal, 1994; Vacha-Haase, Nilsson, Reetz, Lance, & Thompson, 2000).

In the as-treated analyses, the appropriate comparisons are, first, the members of the TMHS-only group who are as similar as possible on the list of baseline variables previously defined as important, but who did not attend the COSP because they were in the control group. However, one of the core values of the consumer movement is self-determination—consumers should be free to choose what treatments they receive. In the RCT approach, participants

randomized to the experimental condition that never attended the COSP and never received the treatment pose an analytic dilemma.

Extending the value of consumer choice in consumer-operated programs from design to analysis suggests the importance of exploring the effects of the COSP intervention as actually utilized *by individual consumers*. A key analytic question is ‘Does the COSP work for those who attended?’ which may yield a different answer than the policy question of ‘Does the COSP work for those who were randomized to the program?’ In these analyses, the ‘as-treated’ group includes anyone who chose to attend the COSP program in sufficient frequency to be considered ‘treated’ in the initial set of analyses. However, the task is now to distinguish the experimental participants who chose to attend from other experimental participants who chose not to attend. In other words, analysis will account for both the processes through which study participants selected themselves into the COSP programs and the differences between those in the TMHS-only group who chose to attend the COSP and those who did not. Finally, a general concern associated with as-treated analyses is that if the analytic strategy only compares those individuals who actually receive the intervention (however that may be defined) to those who do not receive the intervention, an overestimate of the true treatment effect may be produced. The COSP analyses will, therefore, include several strategies that attempt to control for possible selection bias.

***Measuring Program Implementation and Model Fidelity.*** The growing emphases on controlled studies that have been replicated as a basis for integrating a program into existing systems of care requires careful definition of program(s) under study (Bond, 2000; Bond, Evans, Salyers, Williams, & Won-Kim, 2000; Botvin, Baker, Dusenbury, Tortu, & Botvin, 1990; McDonel, Bond, Salyers, Fekete, Chen, & McGrew, 1997). This is essential if providers are to

identify and adhere to critical elements of evidence-based practice, and achieve the positive outcomes identified in the original research. On the other hand, the presence of diverse conditions in the COSP-MRI presented challenges both in defining the programs and in identifying “core components” likely to account for positive outcomes (CSAP, 2001).

Tan, Mowbray and Foster (1990) described the goals of peer support services as providing a safe, supportive and normalizing community environment, providing an atmosphere of acceptance, helping consumers feel needed and helping to promote their self-worth, dignity and respect, and increasing knowledge about the community by learning from one another. Consumer literature (Chamberlin, 1978; Zinman, 1987) has defined their essential characteristics as self-definition of needs, equal power of members, mutual respect, voluntary participation by members, autonomy, and responsivity to other “special populations.”

Building on previous research and the experience of the COSP consumer-providers, researchers defined the COSPs under study by comparing them to one another, and to the traditional mental health service programs utilized by study participants. The four *consumer-run drop-in programs* in the study provided an open venue for consumers to receive a variety of services as needed in a specific location. Individuals participated in drop-in activities on a voluntary and non-coercive basis. Service components varied but paralleled the range of traditional mental health and social services, including support and activity groups, access to telephones, laundry facilities, and computers, assistance with entitlements, medication education, clothing, and bus or transportation passes. Both *mutual support programs* had a systematic approach consistent with the principals of empowerment and recovery, one offering individual-based support for people with problems associated with substance abuse and mental illness, and the other group-based assistance. Like drop-in centers, the peer support programs frequently

helped consumers to manage a range of personal concerns including those associated with work, recreation, housing, health, and personal relationships. The two *education and advocacy programs* were organized around the belief that consumers are best able to manage their own disabilities and to address what is wrong with the mental health system when they have accurate and comprehensive knowledge about mental illness and psychiatric services. These education and advocacy programs used well-defined curricula to impart this kind of information, usually in short-term classroom settings.

Two approaches were employed to understand cross-site variation. First, to inform cross-site comparisons, a service matrix elaborating the range of discrete services available at each site was prepared annually by the Center for both COSPs and traditional mental health services programs. Second, because of methodological concerns related to pooling multisite data, a committee of consumers and researchers identified common ingredients (CIs) present to some degree in all participating COSPs. These CIs were then utilized to develop the Fidelity Assessment/Common Ingredient Tool (FACIT), designed to assess the extent to which each ingredient is present at each site. The FACIT was used both in COSPs and traditional mental health services to assess differences in the “consumer-orientation” of the services offered in the experimental and the control conditions. During two rounds of site visits, teams from the Center collected objective and subjective data during program tours, interviews and focus groups with directors, staff and consumers. For each program, site visitors independently rated each dimension of the FACIT, followed by a conciliation process involving the site visitors discussing the evidence used in making each rating and arriving at a common rating.

There were several stages in FACIT data analysis: (1) analyses of psychometric properties of the FACIT including inter-rater reliability and internal reliability; (2) use of

information from the MRI to assist in empirical refinement of CIs of consumer operated services; (3) comparison of experimental and control conditions using the FACIT; and, (4) identification of “core components” of COSPs related to one or more favorable outcomes among participants through analyses that include both program level and individual level outcome data (Blasinsky et al., 1998; Johnsen, Teague, & McDonel; 2003).

***Measuring Service Utilization and Costs.*** Costs of the traditional mental health services and COSPs, as well as potential cost-savings and benefits produced by those services in both conditions, were collected, and the data are being analyzed to determine the extent to which COSP participation affects the costs of inpatient hospitalization, crisis intervention, and emergency room utilization, as well as offsetting costs in housing, criminal justice, vocational rehabilitation, physical health care, and income support. Statistical analyses of input and outcome costs, and program activity participation data, collected for individual consumers in the experimental and control conditions, will help determine if participation in COSP activities affect service costs of mental health consumers, and if monetary and non-monetary outcomes (including cost-savings benefits and direct benefits) are affected.

Cost study components include (1) data about service use, employment, housing, vocational rehabilitation and receipt of benefits from respondents at baseline and three follow-up points as part of the common assessment protocol; (2) detailed information about program costs from COSPs for each participant, including cost per visit and number of visits; and, (3) administrative data on mental health and health care costs and utilization. Utilizing the Cost-Procedure-Process-Outcomes Analysis (CPPOA) model (Yates, 1980, 1996, 1999), data on costs and outcomes are integrated with information on program participation and changes in outcome variables to examine possible linkages between program costs, participation in specific program

activities, and changes in participant outcomes (cf. Yates, Delany, & Lockwood Dillard, 2001). Cost-effectiveness and cost-benefit ratios between study conditions, in addition to net benefit (benefits minus costs), are being compared.

***Baseline Dataset Description.*** The COSP-MRI baseline dataset contains face-to-face interview data collected from participants at all eight program sites using the Common Assessment Protocol. Across all program sites, 232 individuals who were directly contacted and invited to participate refused consent. Consent was obtained, and baseline interviews completed and entered into the dataset for 1,935 participants. Of the completed baselines, 108 participants were 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. After removal of these 108 cases, the final baseline dataset consisted of 1,827 interviews (All baseline characteristics in this paper are based on that final dataset).

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).

### **MRI Study Population Characteristics**

Overall, COSP research participants present a mixture of demographic and diagnostic characteristics. 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). COSP-MRI participants had to be adults diagnosed with a serious and persistent mental illness and should experience "...functional impairment which substantially interferes with or limits one or more major life activities" to avoid recruiting the most high-functioning of psychiatric clients, or those with minimal penetration into the mental health care system. Baseline descriptive statistics on diagnosis, treatment history, symptom severity, and medication side effects indicate that enrollment was successful in meeting selection criteria for study participants.

**[Insert--Table 2. Baseline Characteristics of COSP MRI Participants--Here]**

*Demographics.* 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. On the other hand, 53% reported having children, averaging one child per parent; approximately half of the parents indicated their children were under the age of 18 years.

*Education and Employment.* More than half of the MRI 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. 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.** 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 with 85% reporting that there was no time limit on how long they could stay at their current place of residence. 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.

**Diagnosis.** As recorded on Axis I of the DSM-IV, the most common primary psychiatric diagnosis across all participants was Schizophrenia (31%). Depression was diagnosed for 25% of the participants, followed by Bipolar Disorder (18%) and Schizoaffective Disorder (16%). 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% 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.

**Psychiatric Treatment History and Symptoms.** Items such as psychiatric hospitalization and age of first contact within the mental health system, self-reports of recent psychiatric

symptoms, and medication side effects were used to assess severity and persistence of mental illness of study participants. Most participants had been hospitalized for psychiatric/emotional problems at some point in their lives (82%) with 25.8 years old being the average age at first psychiatric hospitalization. Although 85% of these participants had been hospitalized more than once, and 62% had from 2-10 hospitalizations, relatively few participants reported any hospitalization for only a psychiatric reason within the four months prior to baseline (16%). Almost all participants reported that they had been taking prescribed psychiatric medications within the past four months (96%), and/or had seen a psychiatrist in the past four months (89%), with 91% engaging in both treatment activities. In addition, 95% reported experiencing side effects from psychiatric medications. These percentages reflect a high level of participant involvement in the traditional mental health service delivery system.

Participants tended overall to report a moderate level of symptoms – with the average rating falling near the middle of each symptom rating scale – on both measures of psychosis and mood-related symptoms. However, examination of variability on the two symptom measures indicates that score distributions were skewed somewhat toward the low end of each scale. Specifically, on the CSI-Psychosis scale, the mean score was 24.2 and scores ranged from 10 to 50, with a score of 17 falling at the 25<sup>th</sup> percentile (25% of respondents scored 17 or lower), and a score of 31 falling at the 75<sup>th</sup> percentile (75% of respondents scored 31 or lower). On the Hopkins SCL-Total scale, the mean score was 49.9, with scores ranging from 25 to 98; a score of 37 fell at the 25<sup>th</sup> percentile, and a score of 60 fell at the 75<sup>th</sup> percentile.

### **Program Model Study Population Characteristics**

Many of the characteristics of participants were significantly different across the study site program models. The percentage of men in the study was lower for the education/advocacy

programs than for the drop-in centers and peer support programs (chi-square=71.3,  $p < .0001$ ), and the percentage of white participants was lower for the peer support programs (chi-square=25.8,  $p < .0001$ ), as was the average age ( $F(2,1824) = 10.0$ ,  $p < .0001$ ). Finally, the percentage of study participants who had ever married was considerably greater for those in the education/advocacy programs (chi-square=166.2,  $p < .0001$ ).

Other characteristics that varied by program model include receiving Social Security income, housing status and history, and illness severity (see Table 2). A higher percentage of drop-in center participants had received some Social Security income in the 30 days previous to the baseline interview (chi-square=38.1,  $p < .0001$ ). However, these participants did not appear to have the most severe illness as indicated by age at first psychiatric contact and lifetime history of hospitalization. The study participants in the peer support programs had the youngest age of first psychiatric contact ( $F(2, 1376)=8.6$ ,  $p < .001$ ), and the greatest number of lifetime hospitalizations for psychiatric/emotional problems (chi-square=33.3,  $p < .001$ ). However, the Hopkins Symptom Checklist (HSCL) indicated that participants of drop-in centers exhibited the lowest degree of symptoms ( $F(2, 1805) = 34.8$ ,  $p < .0001$ ), as did the Colorado Symptom Index Psychosis Subscale (CSIP) ( $F(2, 1806) = 8.7$ ,  $p < .001$ ). Regarding housing history, study participants in the education/advocacy programs were more likely to live in their own residence (chi-square=218.6,  $p < .0001$ ), and less likely ever to have been homeless (chi-square=87.4,  $p < .0001$ ). On the other hand, study participants in the peer support programs felt they were more likely to have to move from their current housing within the near future (chi-square=22.6,  $p < .0001$ ).

Variability also existed in the distribution of diagnoses across program models, (chi-square=33.4,  $p < .001$ ). As shown in Table 2, participants at both the peer support and

education/advocacy sites were somewhat evenly divided between Mood and Anxiety Disorders versus Schizophrenia and Psychotic disorders. At the drop-in center sites, on the other hand, more study participants were diagnosed with Psychotic Disorders and fewer with Mood Disorders.

### **Study Site Population Characteristics**

There was substantial variability in demographic characteristics of participants at the eight study sites. The variation across sites in participants' gender (chi-square=100.9,  $p < .0001$ ), racial/ethnic identification (chi-square=417.9,  $p < .0001$ ), and marital status (chi-square=239.6,  $p < .0001$ ) was statistically significant. In addition, educational attainment (chi-square=224.0,  $p < .0001$ ) and current employment status at baseline (i.e., whether the participant was currently employed for pay or volunteering) (chi-square=95.7,  $p < .0001$ ) displayed statistically significant heterogeneity across sites, as did the perception of participants that their medical benefits covered all the services they needed and wanted (chi-square=86.3,  $p < .0001$ ). The current housing situation of participants varied considerably across sites (chi-square=1246.5,  $p < .0001$ ), as well as their history of homelessness (chi-square=132.3,  $p < .0001$ ). Lifetime use of psychiatric services also varied across sites, particularly participants' hospitalizations for psychiatric or emotional problems (chi-square=85.7,  $p < .0001$ ) and ER visits (chi-square=161.6,  $p < .0001$ ). Similarly, the percentages of participants visiting an ER for psychiatric reasons (chi-square=43.3,  $p < .0001$ ) or using other emergency mental health services (chi-square=63.1,  $p < .0001$ ) in the 4 months prior to the baseline interview varied considerably across sites, as did the percentages of participants being hospitalized for psychiatric reasons (chi-square=29.9,  $p < .0001$ ). In addition, the percentages of participants seeing a psychiatrist in the 4 months prior to the baseline interview varied across sites (chi-square=27.9,  $p < .001$ ), as did the percentages

seeing a doctor or other health professional for physical health problems (chi-square=45.1,  $p < .0001$ ).

The relationship between diagnosis and site was statistically significant (chi-square = 202.3,  $p < .001$ ). The eight sites differed primarily in percentage of participants with Schizophrenia/Psychosis versus Mood Disorder diagnoses. The largest contrast was between one of the peer support programs, where 67% of participants were diagnosed with Schizophrenia/Psychosis and 32% with Mood Disorders, and one of the Education/Advocacy programs, where 25% were diagnosed with Schizophrenia/Psychosis and 73% with Mood Disorders.

### **Lessons Learned: The Collaborative Context of the Multisite Study**

It is important to note that this study was conducted within a collaborative structure and context that shaped many of the choices and actions taken. As such, it is important to discuss some of the process issues surrounding the collaboration as it directly relates to the scientific enterprise and to achieving the goals of the study. The COSP-MRI can provide lessons to others interested in studying the effectiveness of consumer-operated services and to those engaged in multisite studies employing disparate groups of stakeholders as partners. Many of these lessons are similar to those that might be drawn from other multisite studies: the importance of communication among study partners, advantages of involving consumers in various aspects of the study, and difficulties of carrying out a randomized experiment in the “real world” (Herril & Straw, 2002). Lessons specific to this multisite were the recognition of the fragility of some consumer-operated programs, and the need for careful attention to integration of consumer and researcher cultures throughout the study. For example, a major methodological challenge of the study was the randomization of participants since consumer providers at some program sites felt

that it challenged the basic principle of consumer choice. Furthermore, the substantial responsibilities of being in a large study was burdensome and, at times, interfered with the delivery of services and supports to program members..

Since the collaborative nature of COSP operations and the national distribution of sites required a communication infrastructure that would allow an almost constant flow of information and dialogue among study partners, the MRI communication infrastructure was extensive and featured an array of state-of-the-art mechanisms for assuring reliable and rapid interactions. To facilitate decision-making, manage data transmission, monitor study progress and quality controls, and to share scheduling information, documents in process, and reference information, the Center built a network of telephonic and web-based communications. It supported numerous teleconferences, listservs for the SC and each standing committee, and several intranet and internet sites to store public and confidential documents for reference and retrieval. While this communication infrastructure solved many organizational challenges, it led to others. Study partners learned that e-mail is open to certain kinds of predictable problems. Sometimes e-mails sent in response to particular study wide postings were inadvertently sent to all study partners, leading to occasional embarrassment or ill feeling. Humor and sarcasm best understood in direct face-to-face interactions may be easily misunderstood in e-mails, and may engender blistering reactions. Similarly, while listservs allowed responses to information to be immediate and unrestricted, sometimes an e-mail written in the heat of the moment would have benefited from an opportunity to think again about the ramifications of the response. In addition, the availability of a study-wide forum occasionally led site-specific issues to receive multisite attention in ways that may have been inappropriate. In response to these kinds of issues, the Center developed a guide to etiquette on the net and asked study partners to monitor their use of listservs. In SC

face-to-face meetings, personal and group dynamics improved when a set of “Basic Principles” of collaboration were adopted by the COSP-MRI: (1) Focus on the situation, issue, or behavior, not on the person; (2) Maintain the self-confidence and self-esteem of others; (3) Maintain constructive relationships; (4) Take the initiative to make things better; and, (5) Lead by example.

In general, the broad involvement of mental health consumers in the administration, design, implementation, and analysis activities had an extremely positive effect on the quality of the research protocol. It provided study leaders with rapid and iterative feedback in the selection and development of instruments, led to a deeper understanding of the mechanisms that may be associated with COSP participation, and led to the identification of critical study issues. However, it was clear that initially many researchers did not fully understand consumer perspectives, nor did consumers fully understand the requirements of scientific research at the beginning of the study. No common language or set of experiences naturally brought these constituencies together. The values and goals that arose from culturally dissimilar experiences at times polarized discussion and necessitated that consumers, consumer researchers, consumer providers, and non-consumer researchers involved in the project to reach common ground regarding issues of authority, expertise, and language (Campbell, 1996). Consumer-led sessions on the history of the consumer movement and individual experiences with the mental health system were held at SC face-to-face meetings. Researchers also shared their life stories at another meeting. To help consumers without research experience participate fully in research discussions, the Center familiarized consumers with research terms through publication of a glossary for non-researchers (Rittenhouse, Culter, & Campbell, 2001) and hosting technical assistance workshops about the nature and conduct of research. While these efforts did not

resolve all the tensions between consumers and researchers, a dialogue began bridging consumer and researcher cultures.

The COSP-MRI also found that “consumer” meant many different things within the study. It embraced participants both within TMHS and consumer operated services. However, mental health consumers (present and former) also served as staff or program directors within all COSPs and some of the traditional mental health programs. Thus, in addition to being consumers, they were also, in a strict sense, providers. To further complicate the issue, a number of consumer researchers were serving in roles from interviewers to principal investigators. It became clear that the major source of tension in the multisite was not between consumers and researchers as originally attributed, but rather was located within the relations of research production. For example, each study site had initially proposed its own study, with its own procedures and instruments, and the necessity to change these proposals in order to develop a common interview protocol with common study procedures met with resistance. Similarly, as in many other randomized clinical trials, programs—both consumer-operated and traditional—bristled in the beginning of the study as difficult issues associated with actually implementing random assignment became apparent. Efforts to standardize procedures by the Center were sometimes seen as criticism at the study site level and challenged the authority of site investigators.

One area of concern expressed at key points within the study involved what one might term fragility of some consumer-operated service programs. Consumer-providers recognized from the outset that research involvement might stress these programs and distort program operations, goals and outcomes. They encouraged a commitment within the COSP-MRI to “first, do no harm,” and at the midway point in the study, the SC engaged in self-examination to assess

the potentially negative effects of study participation on programs. In some cases, a slower than expected start-up resulted in fewer study participants assigned to the COSP, potentially elevating costs, and leading to some staff turnover and additional training costs. Within some programs, turnover among program directors led to uncertainty and periods of turmoil. Although turnover itself is not necessarily an indicator of greater fragility, the organizational structures that allow for the orderly succession of administrators were strained. It is of some note, however, that except for the withdrawal of one program site (which was replaced by another), and the reorganization of two study sites into one research effort, all of the consumer-operated services within this study were still functioning at the end of the study.

Due to the scope, complexity, decentralization, and collaborative decision-making process of the multisite study, organizational mechanisms to resolve conflict were not clearly developed and lines of authority sometimes blurred. Therefore, the study leaders found it useful to engage formal facilitation and consultation to help the COSP-MRI remain sensitive to program and participant values and thereby achieve research objectives. At three points, the multisite turned to organizational consultants or facilitators to study difficulties, to allow all parties within the process to have a voice in discussions, and to explore tensions. In one case, interviews by an organizational psychologist allowed for development of a clearer set of expectations that the various parties in this study (the federal representatives, the coordinating center, and study sites) had of one another, and produced a strategic response to better manage these expectations. In another case, a facilitator helped the SC identify some of the potentially negative consequences of consumer-operated program participation in the multisite study, and attempted to play a role in bridging a perceived gap in the perspectives of consumers, providers and researchers. In a third case, facilitators initiated a dialogue among SC members that led to

the adoption of recommendations that enhanced the tone and content of communications. The COSP-MRI experience suggests that skilled organizational consultants and facilitators can play a useful role within multisite studies in providing a safe forum for all parties to share mutual concerns and engage in collaborative problem-solving.

### **Implications for Behavioral Health**

The application of the evidence-based practice (EBP) paradigm to mental health services has received growing attention in recent years, and this emphasis has generated hopes and concerns from multiple stakeholder groups (Essock, Goldman, Van Tosh, et al., in press). One concern is that EBPs will limit consumer program choices. Although most theoretically agree that increasing availability of services with demonstrated effectiveness should be a priority, some suggest that limiting funding to select practices will stifle innovation and narrow the range of available services (International Association of Psychosocial Rehabilitation Services [IAPSRs], 1998). Others worry that by focusing on EBPs other factors important to consumers in the selection of treatments and services will be neglected (Anthony, 2001; Frese, Stanley, Kress, & Vogel-Scibilia, 2001). These factors include how well program and consumer goals coincide: the kindness, respect, and cooperation experienced by the consumer, and overall comfort with the program. Still others question the consistency of EBP with recovery-oriented or consumer-focused practice (Frese et al., 2001). Advocates of peer support services believe that consumers have insider knowledge of the expectations that recipients have of services and the ways providers meet or fail to meet these expectations (Campbell, 1996). For these reasons, a vibrant consumer research agenda has blossomed, spawning the conviction that consumer involvement in evaluation is critical to system improvement (Campbell et al., 1993; Campbell, 1997).

Providing service choice under EBP requires systematic development of the evidence

base. The timing of the COSP-MRI is opportune for advancing knowledge about peer support programs and converting this knowledge into new services. The project simultaneously addresses widely held concerns laid out in the mental health consumer agenda and the EBP philosophy, which at times have been at odds. By determining what works for whom and at what cost, the mental health community can use this research as an opportunity to rethink the current array of mental health services, identifying services for people not easily engaged in the mental health system. A better understanding of COSPs can provide an empirical basis for creating effective partnerships between peer support programs, public mental health agencies, and managed care organizations, as well as offering much practical information for COSPs in early stages of organization. In other words, peer support services offer the mental health system the possibility to expand the continuum of community care by reaching more people, and by helping people become both more independent and interdependent.

C. Wright Mills (1959) recommended the use of sociological imagination to “grasp what is going on in the world, and to understand what is happening in [ourselves] as minute points of the intersections of biography and history within society” (p. 7). Now is a historic opportunity for mental health consumers, traditional and peer support service providers, researchers, and policymakers to enter into dialogue about values, goals, and outcomes of peer support programs. Within the COSP-MRI, the complexity of such collaborations often required people to pause, to support and encourage critical discourse, and to incubate new relationships and ideas. The understanding deepened by the shared experiences of the researchers, consumers and providers reflects this. However, attention to the demands of scientific objectivity remained paramount in the COSP-MRI. Throughout the course of this study, it became evident that the validity of evidence-based practice depends on clarity in evaluation design, persistent attention to data

quality, and a deep and abiding respect for the power that diverse perspectives bring to the production of knowledge.

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Table 1

COSP Common Assessment Protocol

Domain	Scale	Number of Items	Reference
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	Adapted from CMHS Mental Health Statistics Improvement	14	Teague, Ganju, Hornik, Johnson, &

Health Services	Program Report Card		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	14	Battista & Almond (1973)

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Index		
Herth Hope Index	12	Herth (1992)
Religion/Spirituality	4	Zinnbauer, et al. (1997)

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Table 2

Baseline Characteristics of COSP MRI Participants

Baseline Variable Characteristic	Multi-site		Program Models	
	All Programs ( <u>N</u> = 1,827)	Drop-In ( <u>N</u> = 771)	Education/ Advocacy ( <u>N</u> = 749)	Mutual Support ( <u>N</u> = 307)
<b>Primary Axis I diagnosis</b>				
Mood Disorders	44.4%	39.9%	46.9%	49.8%
Anxiety Disorders	3.7%	3.2%	4.7%	2.6%
Schizophrenia/Psychotic disorders	50.4%	55.9%	47.4%	43.6%
Other	1.5%	0.9%	1.1%	3.9%
<b>Gender: % Female</b>				
	60.1%	52.3%	71.7%	51.5%
<b>Racial/ethnic identification</b>				
White	56.9%	56.8%	61.8%	45.0%
African American	16.5%	21.4%	9.1%	22.5%
Hispanic	1.2%	1.9%	0.7%	0.7%
Other	2.5%	3.0%	2.3%	2.1%
Biracial/multi-racial	22.4%	16.8%	25.4%	29.3%
<b>Average age</b>				
	42.7	43.0	43.3	40.3
<b>Currently married</b>				
	12.6%	6.5%	20.0%	9.5%

Have significant other (non-spouse)	22.8%	22.2%	20.6%	30.0%
Have any children	52.8%	42.3%	64.0%	52.1%
Currently employed for pay or volunteer	29.3%	30.7%	28.4%	27.7%
Educational attainment				
Less than high school	9.3%	8.0%	11.8%	6.2%
9-12 years	23.7%	21.5%	24.2%	27.7%
HS graduation	25.3%	25.2%	25.2%	25.7%
Any college/vocational training	38.7%	42.0%	35.4%	38.4%
Any post-graduate work	3.0%	3.4%	3.1%	1.9%
Reporting a physical disability	51.7%	52.4%	52.5%	47.9%
Social Security income in past 30 days	83.6%	90.1%	78.2%	80.7%
Currently live in own residence	57.9%	51.3%	69.6%	46.6%
Currently homeless	10.2%	14.0%	4.8%	14.0%
Do <u>not</u> have to move from current housing	83.3%	85.7%	88.2%	76.7%
Ever homeless during life	51.0%	59.5%	37.9%	61.9%
Average age at first psychiatric contact (hospitalization or outpatient treatment)	23.2	23.0	24.4	21.3

Any psychiatric hospitalization in life	82.1%	88.8%	72.6%	88.3%
More than 5 psychiatric hospitalizations	36.3%	42.2%	26.5%	44.9%
Recent Psychiatric Hospitalization	16.0%	16.1%	12.6%	23.8%
Taking a prescribed psychiatric medication in past 4 months	96.2%	95.7%	96.1%	96.1%
Experiencing side-effects (of those taking psychiatric medication)	90.5%	91.5%	88.3%	96.1%
Baseline symptom scores:				
HSCL (multi-site range=25-98)	49.9	46.7	53.4	49.6
CSIP (multi-site range=10-50)	24.2	23.1	24.9	25.0

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