Final Report

A Study of Consumer-Operated Service Programs

Submitted to the
Center for Mental Health Services of the
Substance Abuse & Mental Health Services Administration
(SAMHSA)

by

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Executive Summary

Funding for this SAMHSA-funded study of consumer operated programs began in September, 1998 with several consumer-operated programs that partnered with universities. The study was overseen by a Coordinating Center at the Missouri Institute for Mental Health. During the first year of the study, extensive cross-site consultations resulted in the development of a logic model, depicting various inputs and outcomes that were expected in the study. Based on that logic model, an interview and assessment document was developed, pilot-tested, and revised and an interviewers' manual with question-by-question instructions was developed, piloted, and standardized. A database for collecting data from all sites was developed and a cost study developed. A Follow-up Protocol was designed, containing a subset of the baseline Common Protocol items. Sites all received approval from their Institutional Review Boards (IRB's) for the conduct of the study. Data collection began in January, 2000 with the Tennessee site and all other sites followed suite within approximately 4 months.

The Boston University research team found it necessary to terminate our relationship with our original consumer partner in January, 2000, when it became clear that the consumer program in Iowa, with whom we had partnered, could not meet the requirements to participate in the study. After extensive consultation with CMHS and consumer advisers, the team proposed to continue the study in partnership with the St. Louis Empowerment Center in St. Louis, Missouri. Following extensive consultations with those providers as well as CMHS and Coordinating Center staff, a new research plan was proposed and approved by SAMHSA. This new plan proposed a partnership with the St. Louis Empowerment Center (SLEC); BJC Behavioral Health; Places for People, Inc.; and Southern Illinois University at Edwardsville.

The St. Louis Empowerment Center is a consumer-operated drop-in center consisting of four components: a peer-run Drop-In Center, Community- and Facility-Based Self-Help Groups, Individual Peer Support and the Friendship Line. It is a joint program of the Depressive and Manic-Depressive Association (DMDA) and the Mental Health Association of Greater St. Louis. BJC Behavioral Health (one of the traditional providers) is a large community mental health agency that provides psychiatric services, employment services, case management, money management, and housing assistance for consumers in the greater St. Louis area. Places for People (the second traditional provider), is a not-for-profit traditional mental health provider in the City of St. Louis. They provide case management services, services to individuals who are homeless, group home residential services and a clubhouse. Southern Illinois University at Edwardsville (SIUE) was chosen as the sub-contractor to hire and house the on-site researcher and the part-time interviewers.

The multi-site study was designed as a classical experimental design (Campbell & Stanley, 1966) with random assignment within each site to each of two conditions: traditional mental health services combined with consumer operated services (the experimental (E) condition) or traditional mental health services alone (the control (C) condition). The common assessment tool for the study was designed to measure the following: demographics, employment, finances and entitlements, housing, satisfaction with services, lifetime service use, subjective side effects from medication, substance use, empowerment, service utilization, program activities, social inclusion, social acceptance,

discrimination, quality of life, symptoms, recovery, meaning of life, religion/spirituality and hope. Standardized instruments were used whenever feasible. All study directors/coordinators participated in extensive training in interview methods and data collection procedures. The baseline version of the Common Protocol (CP) was administered to all consenting participants and at 4 months, 8 and 12 months after the baseline date of administration.

We hypothesized that participants receiving consumer operated services in addition to traditional mental health services would experience greater levels of empowerment, greater social inclusion, achieve greater gains in vocational functioning, achieve greater residential stability, report greater satisfaction with services, be more likely to remain in the intervention, report better subjective quality of life, and report greater hopefulness for recovery. Recruitment in the Missouri site began in the spring of 2000 with baseline data collection beginning on May 26, 2000. Enrollment in the study continued until September 19, 2001 and follow-up data collection continued until August 22, 2002.

The final participant count was 243, randomly assigned to the control condition (TMHS only, n=122) or the experimental condition (TMHS plus consumer operated services n=121). However, the study showed that only approximately 15% to 20% of those in the experimental group referred to the COS program actually engaged in and attended the program. At baseline there were no significant differences in the demographic characteristics between the E and C groups except for receipt of SSDI (p=0.030), with individuals in the control condition more likely to be recipients. These analyses suggested that the randomization was reasonably successful in balancing the two groups.

At follow-up, results suggested that the E group was performing better in terms of full time work (more individuals were working full time at the 8-month follow-up), and more individuals in the experimental group were working part time at the 12-month follow-up. There were significant differences between the E and C groups in terms of personal empowerment at the 4-month follow-up and a trend for a significant difference at the 12-month follow-up. There were differences in social inclusion with those in the E group expressing a greater sense of social inclusion than those in the C group.

In addition to the randomized experiment conducted in the multi-site study, the Missouri site engaged in a variety of other site-specific research activities. First, we used the Respect Scale and the Rosenberg Self Esteem Scale for both the E and the C participants at baseline, 4, 8, 12 month interviews. Secondly, we conducted a qualitative study intended to compliment the multi-site quantitative study with an investigation of the empowerment processes within the COSP. Finally, because of the low engagement rate after randomization to the experimental group, we conducted a quasi-experimental study. The purpose of the quasi-experimental study was to maximize the likelihood that we would learn about the effects of consumer-operated services for the individuals who use them. We recruited new attendees to the Empowerment Center at the "front door" rather than through the TMHS providers and then randomly assigning them. In almost all ways this quasi-experimental study was identical to the larger multi-site randomized study. Analyses of site-specific data are not yet complete.