A Longitudinal Study of Mental Health Consumer/Survivor Initiatives:

Part I – Literature Review and Overview of the Study

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Abstract

Mental health consumer-run organizations are alternatives to mainstream mental health services and they have the dual focus of supporting members and creating systems change. The existing literature suggests that these organizations have beneficial impacts on social support, community integration, personal empowerment, subjective quality of life, symptom distress, utilization of hospitals, and employment/education. However, much of this research is cross-sectional or retrospective and has not used comparison groups, thus limiting conclusions about the effectiveness of these organizations in improving the lives of members. While many consumer-run organizations also have a focus on social systems change, there has been little research documenting either the nature of these activities or the system changes that result from such activities. We provide an overview of a longitudinal study of four mental health Consumer/Survivor Initiatives. The study examines both individual-level and systems-level activities and impacts using both quantitative and qualitative methods with a participatory action research framework.

A Longitudinal Study of Mental Health Consumer/Survivor Initiatives:

Part I – Literature Review and Overview of the Study

In the mental health field, there has been a growing recognition of the capacity of people with serious mental illness to take action on behalf of themselves and others (Corrigan & Garman, 1997; Davidson, Chinman, Kloos, Weingarten, Stayner, & Tebes, 1999; Salzer, 2002; Solomon, 2004; Solomon & Draine, 2001). This capacity is expressed in a number of ways including: consumer-provided services, in which peers are hired as case managers or members of Assertive Community Treatment (ACT) teams to provide support (Davidson et al., 1999; Solomon & Draine, 2001), self-help/mutual aid groups (Humphreys, 1996; Kyrouz & Humphreys, 1996), consumer-run businesses or employment activities (Trainor & Tremblay, 1992), and consumer-operated organizations (Mowbray & Tan, 1993; Segal, Silverman, & Temkin, 1995). As these various forms of peer support become a more prominent and legitimate part of the mental health landscape, there are increasing calls to examine the nature and effects of these diverse forms of help (Davidson et al., 1999; Solomon, 2004; Solomon & Draine, 2001).

Consumer/Survivor Initiatives (CSIs) are organizations that are operated exclusively by and for people with a history of mental illness. Note that the terms "consumer/survivor" and "Consumer/Survivor Initiatives" were developed by people with mental illness to refer to themselves and their organizations. The Consumer/Survivor Development Initiative in Ontario (now called the Ontario Peer Development Initiative, OPDI) was formally launched in the spring of 1991, when the Ontario Ministry of Health and Long-Term Care provided $3.1 million in funding for consumer-run organizations. There are now more than 60 CSIs in Ontario with a total budget of over $5 million. Each CSI is unique because CSIs are driven by the needs of

members. However, the different CSIs offer one or more of the following program activities: one-to-one peer support, self-help and peer support groups, community-economic development, education and training for the public and mental health professionals, advocacy to create systems-level change, opportunities for consumer/survivors to develop their skills, the creation and distribution of resources based on consumer/survivor knowledge, and artistic and cultural activities (Consumer/Survivor Development Initiative, 1996; Trainor, Shepherd, Boydell, Leff, & Crawford, 1996, 1997).

As an exemplar of consumer-run organizations, CSIs are more comprehensive in their approach than other forms of peer support mentioned above, because CSIs can provide one-to-one peer support, self-help/mutual aid groups, employment activities, and a range of other activities that members create. It is also important to clarify what we mean by the term "self-help." "Self-help" is often used to refer to self-help groups, but it is also used to refer to solitary activities, such as bibliotherapy or self-directed treatment. Consumer-run organizations may utilize print materials to assist members, but their emphasis is clearly on self-help groups, mutual aid, and peer support. Thus, in the context of consumer-run organizations, self-help refers primarily to the social support provided by individual members, self-help/mutual aid groups, and the organization as a whole.

The purpose of this set of papers is to report on a longitudinal study of four consumer-run organizations in Ontario. The papers examine both impacts on individuals and systems, using both quantitative and qualitative methods. In this paper, we first review the literature on consumer-run, self-help organizations. We then provide an overview of the current longitudinal study. The findings of the research are reported in the next three papers (Parts II-IV).

Literature Review

Rooted in the concepts of peer support and recovery (Deegan, 1988; Jacobson &
Greenley, 2001; Mead, Hilton, & Curtis, 2001), consumer-run organizations strive to be different
from the formal mental health system and mainstream professional services, which are often
viewed as bureaucratic and paternalistic (McCubbin, 1994). While mental health agencies focus
on treatment or case management, consumer-run organizations provide activities and supports
that are aimed at fostering socialization, mutual support, empowerment, and systems-level
change (Nelson, Ochocka, Lord, & Griffin, 1998). Moreover, whereas relationships between
consumer/survivors and professionals are typically characterized by an imbalance of power, in
CSIs there is an adjustment of power, so that members share power (Chamberlin, 1990).
Moreover, CSIs strive not only to empower members, but they seek to create social systems
change towards the goal of more supportive communities, services, and policies for
consumer/survivors. In the following sections, we review literature pertinent to both individual
and systems impacts of mental health consumer-run organizations.

Impacts of Consumer-run Self-help Organizations on Members

Outcomes of participation. Over the past decade, there have been a number of
quantitative studies that have evaluated the impacts of different types of peer support programs
for consumer/survivors, and reviews of these studies have suggested positive impacts on a
number of outcome dimensions (Davidson et al., 1999; Kyrouz & Humphreys, 1996). These
dimensions include social support, community integration, personal empowerment, subjective
quality of life, symptom distress, utilization of hospitals, and employment/education.

While reviews of the literature (Kyrouz & Humphreys, 1996; Kyrouz, Humphreys, & Loomis, 2003) have suggested positive impacts of self-help/mutual aid groups on the social support and social networks of consumer/survivors, none of these studies used comparison groups. Thus, it is uncertain whether reported improvements in social support are due to self-help participation. A second important outcome to consider is community integration or the extent to which people meaningfully participate in community activities. Qualitative research (Nelson, Lord, & Ochocka, 2001; Tranior et al., 1996, 1997) has found that participation in CSIs is a springboard for many people to become more active in other community settings. In a study of four consumer-run organizations, Segal and Silverman (2002) found that after controlling for baseline levels of social participation and demographic variables that the degree of organizational empowerment of the four settings was positively related to members' ratings of their social participation six months later.

Third, personal empowerment, which is of considerable importance to CSIs (Trainor et al., 1996, 1997), is a multi-dimensional construct that refers to perceptions of power, feelings of confidence, autonomy, and community activism (Rogers, Chamberlin, Ellison, & Crean, 1997). Again, qualitative research has suggested enhanced personal empowerment of consumer/survivors as a function of their participation in CSIs (Nelson et al., 2001; Tranior et al., 1996, 1997). Also, Segal and Silverman (2002) found that organizational empowerment was positively related to personal empowerment six months later, after controlling for baseline ratings of personal empowerment and demographic variables. Fourth, subjective quality of life (feelings of satisfaction in different areas of life, such as housing and relationships) is another

outcome domain that may be enhanced by participation in consumer-run organizations, but there has yet to be a study that has tested this hypothesis.

Fifth, participation in consumer-run organizations may help to reduce psychiatric symptoms and enhance personal management of an illness. In a study of self-help groups for people with mood disorders, Powell, Yeaton, Hill, and Silk (2001) found that participants' perceptions of involvement in self-help groups were related positively to management of their illness at a one-year follow-up after controlling for baseline levels of illness management, illness severity, demographic variables, social support, and professional treatment. Similarly, in a study of people with substance use disorders (of whom 35% also had a mental health problem), Moos, Schaefer, Andrassy, and Moos (2001) found that the amount of participation in self-help groups was associated with a reduction in psychiatric symptoms and symptom distress.

Participation in consumer-run organizations may reduce the utilization of institutional mental health services. While most consumer/survivors find treatment services to be useful and important, many also recognize their need for reduced dependence on such services. Several studies of self-help/mutual aid groups and consumer-run organizations have found reductions in rates of rehospitalization and use of other mental health services with active participation in a CSI (Edmunson, Bedell, & Gordon, 1984; Kennedy, 1989; Rappaport et al., 1985; Trainor et al., 1996, 1997; Trainor & Tremblay, 1992). However, these studies have not used control or comparison groups. Thus, it is uncertain as to whether participation in CSIs accounts for reduced rates of rehospitalization. Finally, participation in consumer-run organizations may lead to more instrumental role involvement in the community, such as employment (be it for pay or as a volunteer) or education.

While several of the early quantitative studies of consumer-run self-help organizations used longitudinal designs, none used a comparison group. A more recent study coordinated by Dr. Jean Campbell is using a randomized design to examine the impacts of peer support on mental health consumers. More than 1800 participants at 8 different sites were randomly assigned to either traditional mental services or traditional mental health services and peer support. The impacts of this intervention are being studied over a one-year period (http://www.cstprogram.org/consumer%20op/index.html).

In addition to these quantitative studies, some researchers (e.g., Rappaport, 1993) have used a qualitative, narrative approach to the study of consumer-run organizations. For example, Kennedy and Humphreys (1994) found positive changes in the self, relationships with others, the universal order, and personal problems in a qualitative study of 30 members of two 12-step groups (including the GROW organization for people with mental illness). Similarly, in a qualitative study of 46 members of Schizophrenics Anonymous, Weaver Randall, Salem, and Reischl (2001) reported a process of recovery over time, including identity transformation and enhanced well-being and quality of life. Corrigan and colleagues have used qualitative methods to examine recovery processes in the program materials and testimonies (Corrigan et al., 2002) and interviews (Corrigan et al., submitted) of members of the GROW self-help organization. Becoming more reasonable in one's thoughts and actions, becoming more active and involved in the community, and gaining a sense of personal value were seen as important for one's process of recovery.

Helpful processes. In addition to the focus on outcomes, it is also important to understand the qualities of consumer-run organizations that contribute to positive growth in members.

Levine (1988) suggested that self-help organizations provide their members ". . . with an ideology that serves as the basis for re-establishing a sense of community and for coping with recurrent problems of the group's core issue" (p. 167). Other helpful qualities identified by Levine (1988) include a psychological sense of community, confession, catharsis, and criticism in a group context, social role models, the opportunity to learn coping strategies, and a network of supportive relationships. In a study of GROW self-help groups, Roberts et al. (1999) found that giving help to others was associated with positive psychosocial well-being. Research has also found that organizational empowerment (Segal & Silverman, 2002) and identification with the self-help organization (Hatzidimitriadou, 2002) to be related to personal empowerment. In a study of consumer-run organizations, Yanos, Primavera, and Knight (2001) found that the relationship between participation in self-help and positive social functioning was mediated by the use of problem-centered coping strategies. In a qualitative study, Corrigan et al. (submitted) found that peer support was the most important element of the GROW organization for recovery.

Systems-level Activities and Impacts of Consumer-run Organizations

Consumer-run organizations vary according to their political ideology and focus on social change (Emerick, 1990, 1995; Hatzidimitriadou, 2002). Some organizations take a more overtly political posture by locating the causes of members' problems in political and social institutions (Humphreys & Rappaport, 1994). Since the 1970s we have seen the development of mental health consumer/survivor organizations that not only offer mutual support but also have agendas for social and legal change (Chamberlin, 1978; Weitz, 1984). Many of these organizations view themselves as part of a social movement for the liberation of psychiatric survivors (Burstow & Weitz, 1988; Chamberlin, 1978, 1984; Everett, 1994). History has shown

a long history of abuse in psychiatry (Deutsch, 1948; Whitaker, 2001), whether in its crude

physical treatments (Collins, 1998) or forced incarceration (Szasz, 1974). Consumer-run

organizations have recognized that, left to its own devices, the medical/psychiatric/governmental

triad can produce and condone abusive situations. In this sense, consumer-run organizations

view themselves as essential rudders for a mental health system that can run out of control. As a

result, they have strived to change the face of laws and policies and the operations of service

delivery systems, so as to add new dimensions to clinical training; to alter traditional

relationships between mental health professionals and consumer/survivors; and to change the

public perception of mental health challenges (Bassman, 2001; Everett, 1998, 2000; Humphreys,

1997; McLean, 1995; Van Tosh, Ralph, & Campbell, 2000).

Yet despite the existence of consumer-run self-help organizations that engage in

important system-level activities, research has tended to focus primarily on these organizations'

impacts on their individual members (Kyrouz et al., 2003; Trainor et al., 1997). The potential of

consumer-run organizations to achieve system-level impacts has not received as much systematic

attention in the literature (Humphreys & Rappaport, 1994). When system-level impacts are

discussed in the literature, researchers have discussed the impacts of the loosely defined mental

health consumer and survivor movement without documenting the specific role of consumer-run

initiatives within this movement (Katz, 1993; McLean, 2000). Alternatively, researchers have

focused on the outcomes of consumer participation in community planning, without directly

investigating the role of consumer-run organizations in achieving community-level changes,

leaving much of the credit to governments that have recently sponsored partnerships between

services and consumer/survivors (Happell & Roper, 2003; Masters et al., 2002; Milewa,

Dowswell, & Harrison, 2002). Finally, researchers have noted a lack of formal and systematic research evaluating the impact of consumer-run organizations beyond their members (Bowl, 2002). In discussing research on consumer empowerment and discrimination against consumers, Corrigan and Garman (1997) asserted that ". . . researchers must examine not only individuals with schizophrenia but also groups, organizations, service systems, and communities in which psychosocial interventions occur" (p. 349).

Mental health consumer-run organizations are one exemplar of alternative settings, organizations that are created by disadvantaged groups as an alternative to mainstream professional services that are viewed as paternalistic and unhelpful or harmful to people who are disadvantaged. Alternative settings have a strong emphasis on creating a supportive community, recognizing the strengths of members, promoting power-sharing and member control, providing a holistic approach to health and well-being, and advocating for social change (Reinharz, 1984; Riger, 1984). Moreover, alternative settings strive to promote second-order or transformative change, changes in the "rules of the game" or the way business is typically conducted, as opposed to first-order or ameliorative change, which focuses on improving services without addressing the underlying values and assumptions on which those services are based (Nelson & Prilleltensky, 2005).

One of the fundamental changes practised in alternative settings is that of "power reversal" (Weitz, 1984). In mental health consumer-run organizations, self-help and peer support programs eliminate the power differential that exists between professionals and "patients" or "clients" by emphasizing member equality and mutual aid. As we noted earlier, this theme of adjustment in the balance of power can also be implemented to create systemic change, with

members of consumer-run organizations actively participating to challenge the status quo and make the community more welcoming to people with mental health challenges. In contrast to activities to support individual members, that focus on the values of caring and compassion, system-change activities address issues of social justice, such as consumers' access to concrete resources (i.e., housing, employment) and the elimination of discrimination and stigma against people with mental health challenges (Nelson et al., 2001; Nelson & Prilleltensky, 2004).

Overview of the Study

As was noted earlier, the purpose of the study was to examine the activities and impacts of CSIs on both individuals and systems.

Research Context and Participatory Action Research Approach

This study was one of six research projects funded by the Ontario Ministry of Health and Long-Term Care to evaluate four different types of community mental health programs for people with serious mental illness: case management, crisis intervention, family self-help, and CSIs. This Community Mental Health Evaluation Initiative (CMHEI) was coordinated by Health Systems Research and Consulting Unit (HSRCU) of the Centre for Addiction and Mental Health (CAMH) in Toronto (see Dewa et al., 2002 for a description of the overall design of the CMHEI). While each study had its own team of investigators and research staff, all of the studies used some common measures and collected data from participants at the same time periods.

When the call for proposals was announced, we met with the Coordinator of the OPDI to consider applying for a grant to study the CSIs. From the beginning, we used participatory action research (PAR), which can be defined as: "a research approach which consists of the maximum participation of stakeholders, those whose lives who are most affected by the problem under

study, in the systematic collection and analysis of information for the purpose of taking action and making change" (Nelson et al., 1998, p. 885). This approach is particularly well suited to research *with* CSIs. Members of CSIs don't want to be "research subjects," but rather "active partners" in the research process. Moreover, CSIs are member-driven and are interested in participating in something that they believe is meaningful and will be useful for the organizations and their members. We began by holding a series of meetings with representatives of several CSIs and the OPDI Coordinator to develop the proposal. It is important to note that the research team members are not service-providers and that we had no role in providing services or supports within the CSIs or in consulting with the CSIs about their programs. The CSIs operated as autonomous alternative settings throughout the research process, and the role of the research team was to conduct the research. We have reflected on some of the challenges in conducting the research in a previous article (Nelson, Ochocka, Janzen, Trainor, & Lauzon, in press).

Once we obtained funding for the research, we (the researchers and the OPDI Coordinator) selected 4 CSIs for participation in the research. Selection was done using several criteria: (a) the level of interest and the willingness to commit the involvement of the CSI and its members to a major research initiative for at least 5 years, (b) the ability of the CSI to recruit new members into the CSI and the research, and (c) geographic proximity to the researchers. A total of 6 CSIs were visited during the summer of 1998; 3 were invited to participate; and all accepted the invitation. Due to unanticipated difficulties in recruiting an adequate number of participants in one CSI, a second CSI in the same region was approached and agreed to

participate beginning in the year 2000. These sites are not representative of all CSIs in the province, and we do not claim to generalize the findings beyond these particular settings.

The project was managed by staff from the Centre for Research and Education in Human Services, a leader in PAR. There were two main components to our PAR process. First, the research was guided by a Steering Committee, which was composed of the investigators, two senior researchers who manage the project, an OPDI representative, the Executive Directors of the 4 CSIs, and CSI volunteers. This committee was chaired by a consumer/survivor since its inception and met every 2-3 months to discuss, review, and approve all of the research activities that are undertaken. Second, consumer/survivor Research Assistants (RAs) were hired and trained to recruit participants and conduct the interviews. During the main data collection phase of the study, meeting of this Research Team were held monthly or bi-monthly. These meetings were facilitated by the senior researchers and were held to ensure that the data were collected in a timely and appropriate manner, to provide support to the RAs, to trouble shoot problems, and to provide training and supervision. Our experience is that these PAR processes are essential for building trust and enhancing communication and collaboration between the researchers and consumer/survivors who operate and participate in the CSIs (Ochocka, Janzen, & Nelson, 2002; Reeve, Cornell, D'Costa, Janzen & Ochocka, 2002).

As for the action component of PAR, we produced short summary bulletins describing the preliminary findings of the study as they emerged from the analysis. These were presented to senior government policy-makers in the Ontario Ministry of Health and Long-Term Care at meetings of the CMHEI working group, along with oral presentations about the study. These summary bulletins were also distributed to a wide range of government planners across the

province, including the 9 regional Mental Health Task Forces that drafted reports for mental health reform. We also wrote regular updates on the research for the OPDI newsletter, *Around the Loop*, and we presented the findings at annual conferences organized by the OPDI.

At the conclusion of the study, we reported the main findings in a fact sheet and summary bulletin. These summary bulletins, which contained recommendations, were also used by the OPDI and CSIs for various educational and advocacy activities. We also created a project website, held feedback meetings for each of the sites, held meetings in 7 different regions of the province (to which consumers, mental health service-providers, and planners were invited), held a feedback meeting with senior policy-makers in the Ontario Ministry of Health and Long-term Care, and created a DVD on the CSIs and the research entitled "From Madhouse to Our House." We also presented the findings at professional conferences in Ontario and elsewhere, and we are in the process of publishing the main findings of the study.

Description of the CSIs and their Programs

At the beginning of the research, we visited each CSI to learn more about the programs, activities, and desired outcomes at each setting. Through discussions with participating CSI members and staff and a review of CSI documents, a program logic model was developed for each CSI (Rush & Ogborne, 1991). Each logic model divided the activities and outcomes into individual-level and system-level. We also constructed an overall logic model, which consists of three basic components: (a) identification of program components and their objectives, (b) activities associated with each of the program components, and (c) intended outcomes that are expected to result from program activities (see Nelson et al., in press). The creation of the logic model was useful in two ways. First, the model helped us to identify the main program activities

of the CSIs, which included internal activities (e.g., meetings, committees, recreational events), drop-in, self-help groups, and one-to-one peer support. Second, identification of the intended outcomes helped us to select appropriate outcome measures.

The 4 CSIs are all located in southwestern Ontario, and all provide opportunities to become involved in internal, organization development activities (e.g., volunteering within the CSI, attending membership meetings, participating on CSI committees) and external, systems-level activities (e.g., education, advocacy, community planning, action research). Moreover, the 4 CSIs possess many of the qualities that have been identified as critical ingredients of consumer-run organizations (Holter, Mowbray, Bellamy, MacFarlane, & Dukarski, 2004), including: "consumer control, consumer choices and opportunities for decision-making, the voluntary nature of participation (and the absence of coercion), and respect for members by staff" (p. 60).

One of the CSIs serves a broad geographic area, operating several self-help groups in several small to medium-sized cities (largest city is 130,000). Another CSI serves a large urban population (500,000) and concentrates its activities on a drop-in and on one-to-one peer support. The third CSI also serves a large urban population (300,000) and provides a variety of self-help groups but does not operate a drop-in. The final CSI serves a medium-sized urban population (100,000) and operates self-help groups, a drop-in, and a ceramics collective. All of the CSIs have an Executive Director and a small number of other paid staff. The 4 CSIs have a combined budget $640,000 (average budget for each CSI is $160,000 in Canadian dollars) and over 750 members on their mailing lists.

Individual-level Activities and Impacts

Research design. Regarding the questions that are examined and the methods that are used in self-help research, Humphreys and Rappaport (1994) argue that the question "Do self-help groups work better than a 'no-treatment condition'?" (p. 224) is inappropriate. A more fitting question is: What is the impact of level of participation in a CSI on people who have received mental health treatment? Since self-help can be developed to accommodate new members and since CSIs are member-controlled, the very idea of allowing professional researchers to decide who can receive support is anathema to CSIs. Attempting to force CSIs into a true experimental design would change the conditions of these initiatives, which defeats the purpose of examining CSIs as they naturally occur (Humphreys & Rappaport, 1994).

For these reasons, we used a non-equivalent comparison group design (Cook & Campbell, 1979). Two groups of participants are compared: (a) new, active participants of CSIs and (b) people who are eligible for but who do not become involved in a CSI. Data were collected through interviews with each participant at 3 different time periods: baseline (BL) and follow-up interviews 9 and 18 months later. All BL interviews for CSI participants were conducted within 3 months of each new participant's involvement with a CSI. Active CSI participants for the 9 month follow-up interview were defined as those who participated more than 2 hours in a CSI over the first 8 months of their involvement; while active CSI participants for the 18 month follow-up interview were defined as those who participated more than 4 hours in a CSI over the first 16 months of their involvement.

Interviews. Almost all of the BL, 9 and 18 month interviews were completed by consumer/survivor RAs. The interviews were conducted in the participants' homes, at the CSIs, or at other convenient locations chosen by the participants. In addition to conducting the

interviews, the RAs provided all participants with information about the CSIs, and in some cases with information about other services in the communities depending upon the needs of the participant.

Quantitative data were gathered from all participants using a structured interview protocol, which consisted of demographic variables, service utilization, and a number of scales tapping outcome dimensions. A sub-set of the overall sample provided qualitative data through semi-structured interviews at the same time intervals. This mixed-methods approach was used for triangulation of the findings (Patton, 2002). Qualitative data complement the quantitative data by providing much more depth regarding participants' life experiences and changes and by providing insights on the qualities of CSIs that were important for participants' growth. Other researchers have noted the value of using qualitative, naturalistic, and narrative methods for the study of members of self-help groups and organizations for people with mental illness (Kennedy, Humphreys, & Borkman, 1994; Rappaport, 1993). More information on the quantitative and qualitative methods used to examine individual-level impacts is provided in Parts II and III of this set of papers.

Population, recruitment, and sampling. Consumer/survivor RAs developed and implemented a recruitment strategy for the research with each of the 4 CSIs. Depending on the context, participants were recruited through other community agencies or hospitals or through people who learned of the CSI by word of mouth. The inclusion criteria were that participants had no prior participation in the CSI and that they met the OPDI definition of who could become a CSI member - "'Consumer/survivors' are defined as 'people who have a mental health problem and/or people who have used mental health services or programs'" (Trainor et al., 1996, p. 1).

Individuals meeting these criteria were asked if they were interested in participating in a research project, and they were provided with an information letter explaining the nature of the study and their rights as participants. All of the participants met the inclusion criteria of no previous participation in a CSI, having a psychiatric diagnosis, and having used mental health services.

For our BL sample, we found that 31% had been hospitalized for mental health problems within the past 9 months, and more than 90% had received a diagnosis of mood disorder or schizophrenia. Moreover, we found that in comparison with consumer/survivors participating in 4 Assertive Community Treatment Teams (for people with serious mental illness) in eastern Ontario, CSI members and ACT clients are similar on many dimensions at BL, such as Social Support, Personal Empowerment, and Subjective Quality of Life. However, CSI members have higher rates of completing high school, higher rates of current employment, and higher rates of involvement in vocational-educational programs, suggesting higher levels of well-being than ACT clients. On the other hand, CSI members have higher levels of Symptom Distress, higher rates of physical health problems, greater housing instability, and higher rates of emergency room utilization than ACT clients, suggesting that they have more difficulties than ACT clients. Also, CSI participants were more likely to have a diagnosis of mood disorder or anxiety disorder and less likely to have a diagnosis of schizophrenia than ACT clients (Goering et al., in press).

All of the new, active participants in the 4 CSIs consented to participate in the research. Recruitment and BL interviews began in April, 1999 and ended in September, 2001. All participants were given an honorarium of $15 for each interview. Also during the BL interview, the RAs discussed ways of keeping in touch with the participant and asked for the participant's consent to provide names of people who could assist in contacting the person should he/she

move and not leave a forwarding address or phone number. In the time between the BL and the 9 and 18 month interviews, the RAs did a variety of things to keep in touch with participants, including: contacting them by phone every 2 months to ask questions about their participation in the CSIs, sending a thank you card after each interview and a birthday card and season's greetings card once a year, and providing participants with summary bulletins describing the findings of the research. Whenever a participant's phone number changed or mail sent to the person was returned to sender, the RAs began a process of tracking the participant through contact information that participants had provided.

Systems-level Activities and Impacts

A combination of quantitative and qualitative methods was used to examine system-level activities and outcomes of CSIs.

Quantitative system-level tracking tool. We developed a systematic way of keeping track of system-level activities within the CSIs. With regard to system-level activities, we noted four main types of activities: (a) public education and relations (activities that increase awareness or change in public opinions about mental health issues and people who experience mental health issues), (b) political advocacy (activities that work toward changes in social policies and practices), (c) community planning and collaboration (activities that bring about changes in planning practices and existing services, as well as the creation of new supports and services),