

**A Longitudinal Study of the Consumer/Survivor Initiatives  
in Community Mental Health in Ontario**

Revised Proposal - November, 2000

Geoffrey Nelson, Principal Investigator    John Trainor, Co-investigator

Department of Psychology, Wilfrid Laurier    Centre for Addiction and Mental Health - Queen

University, Waterloo, ON    Street Division, Toronto, ON

Marnie Shepherd, Community Partner    Joanna Ochocka, Project Manager

Consumer/survivor Development Initiative,    Centre for Research and Education in Human

Toronto, ON    Services, Kitchener, ON

## Background

As consumer/survivor initiatives (CSIs) become a more prominent and legitimate part of the landscape of the mental health field, there are increasing calls to examine the nature and effects of these diverse organizations. The purpose of this project is to conduct a longitudinal evaluation of CSIs that have been funded and implemented in the province of Ontario (Trainor, Shepherd, Boydell, Leff, & Crawford, 1996, 1997). Throughout this proposal, we use the term “consumer/survivor,” rather than terms like patient or client, because that is the term that currently enjoys the most widespread acceptance by individuals who have received mental health services and the groups and organizations that represent them in Ontario.

### Descriptions of the Programs or Interventions to be Evaluated

The Consumer/Survivor Development Initiative (CSDI) was formally launched in the spring of 1991, when the Ontario Ministry of Health announced \$3.1 million in funding for non-service initiatives to be operated by consumer/survivors. A CSDI staff team was organized and reviewed 266 applications, and 42 projects from across the province were funded. As of early 1997, 36 projects (34 local/regional and 2 provincial) have remained active, and recently another 15 projects have been funded through the Ontario Ministry of Health Community Investment Fund. The CSIs are described in two documents (CSDI Project Descriptions, 1996; Trainor et al., 1996). There are now more than 50 CSIs, with a total budget of over \$5 million, which offer one or more of the following program activities: a) self-help and peer support groups, b) community-economic development, c) education, sensitization, and training for the public and mental health professionals, d) advocacy to create systems-level change, e) opportunities for consumer/ survivors to develop further their skills, f) the creation and distribution of

resources based on consumer/survivor knowledge, and g) artistic and cultural activities (CSDI Project Descriptions, 1996). CSIs also provide opportunities for leadership and organization development.

The CSDI in Ontario is a major innovation in community mental health. No other province, state, or other jurisdiction that we are aware of has created and funded CSIs on such a wide scale. The innovative nature of CSIs is described in more detail in the following section, as is the issue of systems-level change. The proposed research builds on a previous cross-sectional evaluation of 16 CSIs carried out between 1992 and 1995 (Trainor et al., 1996), which identified several areas of personal and community impacts that CSI members reported.

#### Summary of the State of Knowledge Relevant to the Proposal

There are three underlying assumptions about CSIs that guide this proposed research: a) CSIs are based on a fundamentally different world view or paradigm than professionally-delivered community mental health programs; b) due to their unique nature, CSIs require a research approach that is compatible with their world view; and c) CSIs can be a significant resource in the personal empowerment, community integration, and quality of life of psychiatric consumer/ survivors and in effecting change in the broader community and in mainstream mental health services.

#### Consumer/Survivor Initiatives as a Unique Alternative

Regarding the first assumption, we believe that CSIs should be viewed as something unique, an alternative to, not an extension of, professional services (Borkman, 1990; Rappaport, 1993). In fact, some CSIs define themselves in opposition to mental health services, which consumer/survivors view as paternalistic or even abusive (Burstow & Weitz, 1984; Emerick, 1990; Everett, 2000). CSIs view themselves as having a different ethos from mental health services (Chamberlin, 1978). For the

purposes of this proposal, we define CSIs as settings in which people who have received mental health services come together on a voluntary and equal basis to share their experiential knowledge and to provide and receive peer support.

There are four values which we believe capture the ethos of CSIs (Nelson, Ochocka, Griffin, & Lord, 1998). First, there is a strong emphasis on consumer/survivor empowerment (Salzer, 1997). Whereas relationships between survivors and professionals are characterized by a number of different power imbalances, in CSIs there is a power reversal, in which members share power (Weitz, 1984). People who have received mental health treatment are seen as having valuable experiential knowledge which can be shared with others in a process of mutual aid and peer support. The notion of survivor “voice and choice” refers to the importance of self-determination and participation in consumer/survivor initiatives (Nelson, Walsh-Bowers, & Hall, 1998). Second, because fellow consumer/survivors are on a relatively equal footing, there is a strong sense of kinship, a special bond between people who have gone through similar experiences (Chamberlin & Rogers, 1990; Everett, 2000). While there is pervasive stigmatization of people who have received mental health treatment through professional labelling, segregated services, and public prejudice, people can become a valued part of community in CSIs (McKnight, 1995). There is a focus on the whole person and his/her strengths and potential to contribute in CSIs, not the person’s perceived problems or deficiencies.

Third, many CSIs strive to create change in the mental health system and the broader community through education and advocacy. While CSIs are quite diverse with respect to their politics and relationships with mental health services, many CSIs have a strong social change orientation (Church, 1993; Everett, 2000). Fourth, many CSIs have a focus on learning as an ongoing process,

which is consistent with Senge and colleagues (Senge, 1990; Kofman & Senge, 1993) notion of a “learning organization.” Learning organizations are committed to “a new way of thinking, feeling, and being,” or a culture of learning, change, growth, and community building (Kofman & Senge, 1993, p. 6). Rappaport (1993) has suggested that CSIs have their own world views and a community narrative which expresses that view.

### Consumer/Survivor Initiatives and Participatory Action Research

Given these four predominant values which we believe characterize CSIs, several writers have argued that research *with* these organizations needs to use methods that are consistent with these values (Borkman & Schubert, 1994; Chesler, 1991; Nelson et al., 1998; Rapp, Shera, & Kisthardt, 1993). Specifically related to this second assumption of our proposal, we believe that participatory action research is best suited to research with CSIs. Participatory action research 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). Moreover, the values of CSIs, described in the previous section, are compatible with the values underlying participatory action research (Nelson et al., 1998).

Participatory action research differs from mainstream research in the questions that are posed, the types of methods that are used, the way the research is conducted, and the use to which the information is put. 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. Rather, a more fitting question might be

“What is the impact of level of participation in a CSI on people who have received mental health treatment?” The latter question makes more sense in the context of CSIs, while the former question is inconsistent with the self-help ethos of choice and support. Randomly assigning people to a wait-list control, as is often used with professional services because the demand for service exceeds the supply, is not appropriate in CSIs. In CSIs, new peer support groups can be developed to accommodate new members. 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). We believe that naturalistic experiments or quasi-experiments, combined with qualitative methods, are more suitable to CSIs (Rappaport, Seidman, Toro, McFadden, Reischl, Roberts, Salem, Stein, & Zimmerman, 1985). Such methods can preserve the integrity of CSIs and can capture the richness of the self-help experience, as Rappaport and his colleagues have demonstrated (1993; Rappaport et al., 1985).

The way research with CSIs is conducted is at least as important as the substantive focus of the research (Nelson et al., 1998). Self-help/mutual aid researchers have argued that a collaborative, participatory style of research between the researchers and the host organizations is critical for the successful implementation of the research (Borkman & Schubert, 1994; Chesler, 1991; Rappaport et al., 1985). Members of CSIs don't want to be “research subjects,” but rather “active partners” in the research process. Moreover, CSIs are membership-driven and are interested in participating in something that will be immediately useful for the organization and members. Thus, the action component is an integral part of participatory action research with CSIs.

## Consumer/Survivor Initiatives as Resources to Individuals and the Community

Many self/help mutual aid organizations have the dual goals of personal growth of members and social and community change (Humphreys & Rappaport, 1994). CSIs can be an important resource both to individual consumer/survivors and to the community. Many researchers (e.g., Goering, Wasylenki, Lancee, & Freeman, 1984; Mechanic & Rochefort, 1990) and consumer/survivors (e.g., Capponi, 1992) have observed and/or experienced the woeful inadequacies in the community support of consumer/survivors after discharge from psychiatric hospitals or the psychiatric units of general hospitals. This research and personal experience has shown that psychiatric consumer/survivors face significant barriers in their attempts to reintegrate into the community and to achieve a decent quality of life. Services, supports, and housing that consumer/survivors identify as important for their quality of life are often unavailable to aid people in the transition from hospital to community (e.g., Capponi, 1992; Goering et al., 1984).

Personal impacts. To help meet the challenges faced following discharge from hospital, Salem, Seidman, and Rappaport (1988) have argued that CSIs can be a significant resource to individuals. Over the past decade, there have been a number of studies which have examined a variety of different types of peer support programs for psychiatric consumer/survivors (for reviews, see Davidson, Chinman, Kloos, Weingarten, Stayner, & Tebes, 1997; Humphreys, 1996; Kyrouz & Humphreys, 1996). Several different areas of personal impact which might be affected by participation in CSIs are: a) the availability of social support and friendship networks, b) personal empowerment, c) subjective quality of life, d) symptom distress, e) access to valued resources, f) utilization of institutional mental health services, g) community integration, and h) coping.

CSIs can potentially impact on consumer/survivors' perceptions of the availability of social support and social networks. Several studies have suggested that social support contributes to the well-being of psychiatric consumer/survivors (e.g., Hall & Nelson, 1996). Consumer/survivors have provided testimonials about the tremendous solidarity and kinship that they experience in self-help organizations (Burstow & Weitz, 1988; Chamberlin, 1978; Everett, 2000). There are also several studies reviewed by Kyrouz and Humphreys (1996) which suggest such impacts on social support and social networks, but few of these studies have used longitudinal designs and/or comparison groups.

Personal empowerment is of considerable importance to CSIs (Trainor et al., 1996, 1997). Personal or psychological empowerment is a multi-dimensional construct which refers to perceptions of power, feelings of confidence, autonomy, and community activism (Rogers, Chamberlin, Ellison, & Crean, 1997). Several studies which have used qualitative methods have suggested enhanced personal empowerment of consumer/survivors as a function of their participation in CSIs (Kennedy & Humphreys, 1994; Nelson, Lord, & Ochocka, 2001; Trainor et al., 1996, 1997).

Subjective quality of life, symptom distress, and access to valued resources may also be impacted by CSIs (Kyrouz & Humphreys, 1996). Subjective quality of life refers to feelings of satisfaction in a number of areas of life, such as housing and relationships (Nelson, Wiltshire, Hall, Pearson, & Walsh-Bowers, 1995), whereas symptom distress refers to feelings of anxiety and Access to valued resources means that individuals are able to gain basic resources, such as work, education, housing, and income (Nelson et al., 2001; Nelson, Walsh-Bowers, & Hall, 1998).

Another area of personal impact is utilization of institutional mental health services. While many consumer/survivors find treatment services to be useful and important, consumer/survivors also

recognize their need for reduced dependence on such services. Several studies of CSIs have found reductions in rates of rehospitalization and use of other mental health services with active participation in these initiatives (Edmunson, Bedell, & Gordon, 1984; Kennedy, 1989; Trainor et al., 1996, 1997; Trainor & Tremblay, 1992).

Community integration, which refers to meaningful participation in community settings, and coping, or how one responds to life's challenges, could improve as a result of participation in CSIs. Trainor et al. (1996, 1997) reported that participation in CSIs was a springboard for many people to become more active in other community settings. Self-help organizations also provide a setting in which individuals can share coping strategies that they have found to be effective in dealing with problems that they face (Levine & Perkins, 1997). Luke (1989) followed up 115 new members of the GROW self-help organization over a period of 10 months and found that those who dropped out of GROW showed more negative impacts on measures of psychological, interpersonal, and community adaptation than those who stayed involved. Of those who stayed involved, more active participants showed more positive impacts on these dimensions than those who attended less than once per month.

Zimmerman (1995) has distinguished between empowering processes and outcomes. It is important to understand the key processes of CSIs that contribute to empowerment outcomes for members. In this regard, Levy, Derby, and Martinkowski (1993) have found that feelings of psychological attachment to self-help groups and fellow members to be related to bereaved persons' experience of psychological well-being. Similarly, Segal, Silverman, and Temkin (1995) have developed measures of empowering organizational processes, such as participation in and contributions to the organization, in CSIs and have found such processes to be related to consumer/survivors'

personal empowerment. In addition to opportunities for influence and contribution, a psychological sense of community is another important ingredient of self-help/mutual aid organizations (Levine & Perkins, 1997). However, longitudinal studies of attachment to the self-help organization, empowering organizational processes, and psychological sense of community processes are lacking.

Systems impacts. As Humphreys and Rappaport (1994) noted in their review, most of the research on self-help/mutual aid has been concerned with the interpersonal support and personal growth aspects of these groups and organizations. However, many consumer/survivor initiatives have an advocacy and social change focus (Chamberlin, 1990; Everett, 1994, 2000). The initial evaluation of the CSIs documented a range of systems activities (e.g., education and advocacy) and involvement in different community settings. Church (1993, 1995, 1996) studied the impact of consumer/survivor participation on community mental health legislation in Ontario.

Social change can be aimed at several different levels of analysis, including organization, community, and social policy. Organizational change might focus on changing mental health services to make them more responsive to survivors' needs. Changes at the community and social policy level often focus on increasing survivors' access to valued resources, including housing, income, employment, and education (Nelson et al., 2000). Supported housing, employment, and education, community economic development, and housing cooperatives are alternatives which can increase consumer/survivors' access to such basic resources (Carling, 1995; Church & Reville, 1989; Trainor & Tremblay, 1992). Since many governments have initiated "mental health reform," it is important to note how the presence or

absence of CSIs has had an impact on such systems. This focus is consistent with one of the goals of the RFP (“to monitor the progress of mental health reform”). Also, we have much to learn from consumer/survivors who have started their own businesses and other community economic development initiatives (Church, 1997).

Rappaport (1993) has argued that CSIs have their own “community narratives,” and that these narratives play an important role in the lives of individual members. To date, there has been little research regarding the narratives of such settings. One exception is the study of the creation of a CSI by Bargal (1992). The stories of how such alternative settings are created and develop over time would be very instructive, since such organizations usually operate with little external support and often face opposition from mainstream mental health settings. Powell and Nelson (1997) have articulated a model to understand the life cycle of grassroots neighbourhood organizations which can be applied to CSIs. Their model suggests that organizational tasks, processes, systems interactions, and critical issues are the central components which need to be examined over different stages (initiating, building, stabilizing) of an organization’s life cycle.

### Hypotheses/Research Questions

#### Personal Impacts

The first objective of this research is to examine personal impacts (outcomes) experienced by consumer/survivors and factors which contribute to those impacts (processes). Both quantitative and qualitative data will be gathered within the context of a non-equivalent comparison group design (Cook & Campbell, 1979). Data will be collected from each participant at 3 different time periods (baseline, 9, and 18 months). Two groups of participants

will be compared: a) active new members of a CSI, and b) people who do not become involved in a CSI.

### Quantitative Data

1. We expect that, after controlling for demographic variables and baseline levels of the outcome measures, level of participation in the CSIs will be related to the following outcome measures at the 9 and 18 month follow-up periods: a) the availability of social support and friendship networks, b) personal empowerment, c) subjective quality of life (life satisfaction), d) symptom distress, e) access to valued resources (work, education, housing, income), f) utilization of institutional mental health services (number of hospitalizations, days of hospitalization, number of uses of emergency or crisis services), g) community integration (meaningful involvement and participation in the community), and h) coping.

2. We expect that process measures of consumer/survivors' social environments (attachment to the CSI, empowering organizational processes, psychological sense of community) will be related to the outcome indicators (e.g., social support, personal empowerment) at the 9 and 18 month follow-up periods after controlling for demographic variables and baseline levels of the outcome measures.

3. At the 9 and 18 month follow-up periods, we expect that the members of CSIs will report higher scores than non-members on the following process measures of consumer/survivors' social environments: a) psychological attachment to the CSI, b) empowering organizational processes, and c) psychological sense of community within an organization.

### Qualitative Data

4. We expect that active members of CSIs will show more positive impacts than non-members in response to open-ended questions about how they have changed as a person since the last interview at the 9 and 18 month follow-up periods.

5. We also expect that there will be different themes in the responses of active members and non-members of CSIs in response to open-ended questions about processes that facilitated or inhibited the personal changes that they report.

### Systems Impacts

The second objective of this research is to examine systems impacts (outcomes) reported by consumer/survivors and factors which contribute to those systems impacts (processes). A longitudinal design will be used to track program activities and processes designed to create change (e.g., education, advocacy) and actual systems impacts (e.g., changes in policies or practices of mainstream organizations). In contrast to the previous section on personal changes, the focus on systems impacts is more exploratory and descriptive. Hence, research questions are posed, but specific hypotheses are not advanced.

### Quantitative Data

6. What is the nature and amount of activity over time in which CSIs engage in attempting to effect organizational, community, planning, and policy changes?

7. What is the nature and amount of organizational, community, planning, and policy impacts over time that occur in the context of CSI activities?

### Qualitative Data

8. What are the tasks, processes, systems interactions, and critical issues at different points in time in the development and evolution of CSIs?

9. What changes have key informants observed in mainstream mental health organizations, the community, regional planning, and social policy in the context of CSI activities?

### Methods

This is a longitudinal study of 4 CSIs which employs a non-equivalent comparison group design and utilizes both quantitative and qualitative data to examine personal and systems impacts. Our overall approach strives to combine scientific rigour with sensitivity to the research participants and settings.

#### Longitudinal Study Involving Four CSIs

##### Site Selection

Four CSIs were selected for participation in this part of the research. All 36 CSIs that have been in operation since before 1997 were invited to indicate their interest in being one of the research sites. The selection of the settings was done by the Investigators, the Project Manager, and the CSDI Coordinator. Selection was done via purposive sampling, 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 the next 5 years, b) the ability of the CSI to recruit members into the CSI and the research, c) the major activities of the CSIs, and d) geographic considerations (location in the southwestern part of the province). A total of 6 CSIs were visited during the summer of 1998 and 3 were invited to participate. All 3 accepted the invitation to participate. Due to unanticipated difficulties in one CSI, a second CSI in the same region was approached and agreed to participate, joining the study in the year 2000.

##### Program Description

At the beginning of the research, we will visit each participating CSI and try to learn more about the programs that they offer. For each CSI, we will construct a program logic model (Rush & Ogbourne, 1991). A program logic model consists of three basic components: a) a description of program activities, b) intended outcomes that are expected to result from program activities, and c) a rationale which links activities and outcomes (i.e., a plausible theory of program change). This program description should help us to understand which outcome measures are most likely to be impacted by participation in the CSIs.

#### Research Approach to Examine Personal Impacts

Research design. As stated earlier, the basic design for this component of the research is a non-equivalent comparison group design (Cook & Campbell, 1979). Data will be collected from each participant at 3 different time periods (baseline, 9, and 18 months). Two groups of participants will be compared: a) new, active members of CSIs and b) people who do not become involved in a CSI. Site is another factor. All baseline interviews will be conducted within three months of each new member's involvement with the CSI. Follow-up interviews will be conducted 9 and 18 months after the baseline interviews.

The 2 groups will be constructed according to their level of involvement in the CSI. Humphreys and Noke (1997) have suggested that the construct of involvement in self-help/mutual aid should tap both attendance and perceptions of involvement. Like Levy et al. (1993), we define members as people who attend 2 or more CSI meetings or activities, whereas non-members are those who never attend or attend only once. Participation in a CSI will also be treated as a continuous variable. The number of activities attended will be recorded for 2 month intervals throughout the 18-month period of the study.

Population, recruitment, and sampling. Consumer/survivor Research Assistants from each of the 4 CSIs will work with their CSIs to develop and implement a recruitment strategy for the research and for participation in the CSIs. The actual recruitment approach will be decided on a site-by-site basis. Depending on the context, participants may be recruited through other community agencies or hospitals or through people who learn of the CSI by word of mouth. The criteria for selection are that participants have no prior participation in the CSI and that they meet the CSDI definition of who can 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). The CSIs do not believe that it is useful to collect information which could be used to determine if a member meets the criteria of serious mental illness (diagnosis, disability, duration). However, it is the experience of CSIs that the majority of CSI members have met these criteria of serious mental illness. In the earlier evaluation report, Trainor et al. (1996) reported that participants averaged 48 days of hospitalization for mental health problems in the year prior to joining the CSI. Individuals meeting these criteria will be asked if they are interested in participating in a research project. Research Assistants will take note of the number of people who refuse participation, so that consent rates across sites can be determined.

The total sample size will be 150 participants (75 active members and 75 non-members). Having a final sample size of 67 per group (assuming a 10% attrition rate over the 18 months of the study) will provide sufficient statistical power (.80) to detect what has been referred to as a medium effect size ( $T^2 = .06$ ) (Keppel, 1991). The recruitment goals are to have 30 active members and 30 non-members from one CSI site, 25 active members and 25 non-members in

another CSI site, and 20 active members and 20 non-members in the two CSIs from the same region. The actual numbers at each site may vary from these estimates depending upon the availability of new members at each CSI.

Demographic variables. We will be using a Common Protocol for the baseline, 9, and 18 month follow-up interviews that was developed collaboratively by the Working Group for the Community Mental Health Evaluation Initiative (CMHEI). The Working Group consists of investigators, staff, and community partners for the 6 CMHEI funded projects and staff of the CMHEI Coordinating Centre from the Health Systems Research Unit of the Centre for Addiction and Mental Health - Clarke Division. Demographic information from the Common Protocol that will be collected includes gender, age, preferred language, racial background, born in Canada or elsewhere, education, marital status, diagnosis, and employment with the highest level of responsibility. This information is collected from participants through interviews.

Outcome measures. Different outcome measures will be used to tap the outcome dimensions discussed earlier. The following outcome measures are a part of the Common Protocol (see Appendix A for the Common Protocols for the Baseline, 9, and 18 month interviews).

1. Social Support - Seven items from Cutrona and Russell's (1987) Social Provisions Scale will be used to assess participants' perceptions of the availability of social support. These items are rated on a 4-point scale from "strongly agree" to "strongly disagree." In the Better Beginnings, Better Futures research in Ontario (Peters, 1994), this shortened scale has been found to have excellent reliability ( $r = .80$ ) and validity (it correlates positively with other

measures of social support). Questions from Humphreys and Noke's (1997) measure will be used to tap the person's support network. Participants will be asked to report the number of people (family members, friends, spiritual leader, care providers, boyfriend, girlfriend, and partner) "with whom they feel at ease and can talk to about personal matters," and how often they were in contact with these people (on a 4-point scale from "not at all" to "several times a week"). Friendship networks have been shown to change following participation in self-help (Humphreys & Noke, 1997), and other research has pointed to the importance of friendships for the well-being of consumer/ survivors (Goering, Durbin, Foster, Boyles, Babiak, & Lancee, 1992).

2. Personal Empowerment - Items from Rosenberg's (1965) Self-esteem Scale and three subscales (Power/powerlessness, Community Activism, Autonomy) of Rogers et al.'s (1994) consumer/survivor-constructed measure of empowerment will be used to tap personal empowerment. There are 23 items, which are rated on a 4-point scale from "strongly agree" to "strongly disagree."

3. Subjective Quality of Life - An 11-item measure of subjective quality of life was taken from Lehman's (1988) measure. Individuals will be asked to rate different dimensions of their lives on a 7-point scale from "terrible" to "delighted."

4. Symptom Distress - The Symptom Distress Scale will be used to measure the intensity of participants' feelings of anxiety and depression during the past week. The 15 items, which are rated on a 5-point scale from "not at all" to "extremely," were taken from the Symptom Checklist (SCL-10; Nguyen, Attkisson, & Stegner, 1983), with 5 additional items from the anxiety dimensions of the SCL-90 (Derogatis & Cleary, 1977).

5. Access to Valued Resources - At each interview, participants will answer a number of questions related to education, employment, finances, and housing for the previous 9-month time period.

6. Utilization of Mental Health Care - At each interview, participants will be asked about a number of different mental health services that they have used in the previous 9 months, including hospitalization, psychiatrist visits, non-psychiatrist health professional visits, emergency room visits, use of community outpatient services, and use of psychotropic medications.

In addition to these Common Protocol measures, we also included two measures for this study, which the Investigators and Partners thought were important outcome goals of CSIs (see Appendix B for the Unique Protocols for the Baseline, 9, and 18 month interviews).

7. Community Integration - Maton's (1990) 4-item measure of Meaningful Activity will be used as an index of community integration. This measure has adequate reliability (" estimates range from .59 to .82) and validity (it correlates with measures of social support and subjective well-being) (Nelson, Hall, & Walsh-Bowers, 1997). Each item is rated on a 5-point scale from "not at all" to "very often." An additional 6 items which tap community participation will be used and rated on the same scale. These items are taken from the Better Beginnings, Better Futures research (Peters, 1994), and they show adequate internal consistency (" = .76). The reliability for the 10-item scale will be examined using coefficient alpha.

7. Coping - A 17-item coping scale, with each item rated on a 4-point scale regarding frequency of use from "not at all" to "often," will be used to assess coping strategies used by

consumer/survivors. The items were adopted from Folkman and Lazarus' (1988) coping scale. There are four sub-scales for the coping measure: distancing (the sum of items 1, 5, 9, and 12), planful problem-solving (the sum of items 2, 6, and 13), seeking social support (the sum of items 3, 7, 10, and 14), and escape-avoidance (the sum of items 4, 8, 11, 15, and 16).

Process measures. The following process measures are unique to this study. They reflect dimensions of self-help organizations which are believed to be important to the process of personal change on the outcome measures.

1. Participation in a CSI - As suggested by Levy et al. (1993), both attendance and perceptions of involvement will be used to measure CSI participation. Every two months, participants will be asked how many events and activities they have attended at the CSI, yielding a measure of attendance at CSI activities (see Appendix C for the Participant Tracking Form). This participation will assess both the number of events attended and the number of minutes in which the person participated in CSI activities. Also, as part of the 9 and 18 month interviews (see the 9 and 18 month Common Protocols), participants will be asked to complete a 9-item measure which assesses their perceptions of involvement in and attachment to the CSI. The 9 items are answered "yes" or "no," and Levy et al. (1993) reported excellent reliability for this measure ( $r = .82$ ).

2. Empowering Organizational Processes - Segal et al.'s (1995) measure of Organizational Empowerment, which was developed for use with CSIs, will be used. Based on a review by the project's Steering Committee, some items were modified, while others were added, yielding an 18-item measure. Items are answer on a "yes" or "no" basis. Participants will be asked to complete this measure in reference to some self-help, health, mental health, or

social service organization in which they have recently participated. In this way, both CSI members and those in the comparison group can respond to the questions. Segal et al. have reported excellent reliability ( $\alpha = .87$ ) and validity (it correlates with measures of personal empowerment). See the 9 and 18 month Unique Protocols in Appendix B for this measure.

3. Psychological Sense of Community - We will use a modified version of Buckner's (1988) Neighborhood Cohesion scale. We want to assess sense of community in whatever context (consumer/survivor community, mental health organization, neighbourhood, work setting, club, church, etc.) participants feel provides them with the greatest sense of community. Since Buckner's items refer to sense of community within the context of one's neighborhood, we have found it necessary to delete 2 items and modify the remaining 15 items. Buckner reported high reliability for the scale ( $\alpha = .95$ ), which we will need to retest, given the modifications we have made. Items are rated on a 5-point scale from "strongly agree" to "strongly disagree." See the 9 and 18 month Unique Protocols in Appendix B for this measure.

Qualitative data. Qualitative data regarding personal impacts, factors which facilitate or inhibit those personal impacts, and experiences with the CSI (if applicable) will be gathered from 15 active members and 15 non-members. Participants will be purposively selected from those who have completed the quantitative interviews. Selection criteria include the following: interest in the study and willingness to talk about personal experiences (i.e., information-rich cases), gender, age, history of involvement with the mental health system, and time in Canada. We want to have a balance of men and women, younger and older participants, people with short and long histories of involvement with the mental health system, and new Canadians and people born in Canada. We will select 5 active member and 5 non-members from each of the three CSI

regions.

An interview guide will be used (see Appendix D), and the interviews will be tape-recorded and transcribed. The qualitative data will be gathered three times, shortly after each of the quantitative interviews. These sample sizes should be sufficient to provide saturation of the codes and themes that emerge from the data (Patton, 1990). Saturation occurs when little or no new information is obtained which pertain to codes and themes.

Interview process. At the baseline interview, the Research Assistant will begin by discussing the ways of keeping in touch and will ask for the person to consent to provide names of people who can assist the Research Assistant in contacting the person should he/she move and not leave a forwarding address or phone number (see Appendix E). In the time between the 3 interviews, the Research Assistants will do a variety of things to keep in touch with participants, as described in Appendix E. The strategies that we will use are borrowed from the Better Beginning, Better Futures longitudinal study (Peters, 1994) and are designed to minimize attrition of the sample over time (our goal is to keep attrition to 10% or less), which is a critical issue in this type of longitudinal research. The main method of keeping in touch is the bi-monthly phone contacts to gather information for the participant tracking form.

Data analysis. Humphreys and colleagues (Humphreys, Finney, & Moos, 1994; Humphreys & Noke, 1997) have developed a general analytic model to examine process-outcome linkages in self-help/mutual aid organizations. Consistent with this approach, we will use multiple regression analyses to determine the relationship between the participation and process measures and the outcome measures, after controlling for earlier levels of adaptation on the outcome measures. To examine the impact of extent of participation and the three process

measures (attachment to the self-help organization, empowering organizational processes, psychological sense of community within an organization) on the outcome measures, we will perform the following stepwise, hierarchical multiple regression analyses. Separate regression models will be calculated for each of the outcome measures (e.g., social support, personal empowerment). On the first block, we will see if any of the baseline demographic variables (age, gender, education, income) enter the equation to predict the outcome measures at the 9 month interview. On the second block, we will determine if baseline levels of the specific outcome measure and number of days hospitalized in the nine months prior to the baseline interview enter the equation. Then, on block three we will examine whether or not frequency of CSI participation, psychological attachment to the CSI, and CSI site (dummy coded into two variables for the three CSI site regions) add to the prediction of the outcome measures at 9 months. Finally, we will determine if the process measures of organizational empowerment and psychological sense of community enter the equation on block four.

Entering demographic variables, initial levels of the outcome measures, and days of hospitalization on the first two blocks of the analysis controls for any potential selection factors. Similar data analytic strategies have been used in other recent quasi-experimental studies of self-help interventions (Humphreys et al., 1994; Levy et al., 1993). These same analyses can be repeated to predict the outcome measures at the 18 month interviews. The only change in the analysis is that participation in the CSI for the entire 18 month period and the process measures at the 18 month interview will be the predictor variables for the third and fourth blocks. These two sets of analyses will be used to examine the first two hypotheses.

To examine the third hypothesis that CSI members will differ from non-members on the

process measures, multivariate analyses of variance will be used to examine the differences between these two groups on the following variables: frequency of participation in the CSI, psychological attachment to the CSI, empowering organizational processes, and psychological sense of community within an organization.

To analyse the qualitative data pertinent to hypotheses 4 and 5, we will begin by transcribing all the interviews and feeding them back to interview participants for their verification and editing. Next, all of the data will be inputted into the NUDIST qualitative data analysis software package. Analysis of the data will begin with a process of open coding of the interview transcripts to develop a set of codes that capture the main responses to each of the questions (Strauss & Corbin, 1990). Matrix displays will also be used to examine the codes by group and by time (Miles & Huberman, 1994). Next, axial, or second-order, coding will be used to determine broader themes which link process and outcome over time (Strauss & Corbin, 1990). The overall goal of the qualitative data analysis is to come up with a grounded theory of the personal changes experienced by consumer/survivors and the role that the CSI and other factors play in the change process (Strauss & Corbin, 1990).

In addition to the themes, we plan to provide a 3-5 page narrative of each person's experiences to provide rich examples of the process of personal growth. Various techniques, described by Lincoln and Guba (1985), will be used to verify the trustworthiness of the qualitative data (e.g., having more than one researcher code the data, having participants check the accuracy of the transcripts, comparing the qualitative findings with the quantitative findings, consistency with the findings of the earlier CSI evaluation, implementation of quality control procedures).

## Research Approach to Examine Systems Impacts

Quantitative measures. In each of the 4 CSIs, we plan to implement a system to track activities that are designed to create change and changes that have been made at the systems-level. We will adapt the tracking system developed by Francisco, Paine, and Fawcett (1990), which has been used to track processes and outcomes in community health coalitions (Francisco et al., 1990; Goodman, Wandersman, Chinman, Imm, & Morrissey, 1996). Francisco et al.'s tracking systems includes several measures of process (members recruited, planning products, financial resources generated, dollars obtained, volunteers recruited) and outcome (services provided, community actions, community changes). Francisco et al. (1990) have reported inter-observer reliabilities ranging from 70% to 95% for the different measures. We will consult with the 4 CSIs to adapt this system to their settings and to come up with a common system. We will identify activities designed to create systems level change (e.g., obtaining funding, public education, advocacy) and outcomes in different systems (e.g., within the CSI, mainstream mental health organizations, community, regional planning, government policy). An event log will be kept by the Research Assistant or some other member of each of the 4 CSIs. See Appendix F for a copy of the Systems Tracking Log.

Qualitative inquiry. While the quantitative data described in the previous section provide an indication of the volume and types of activities and outcomes regarding systems change, qualitative inquiry can provide more depth and richness about the development of the organization, social change activities, and systems-level changes. In each site, a focus group will be held with a small group of key informants. People who can provide a historical perspective on the development of the CSI will be purposefully selected (see Appendix G for

the interview guide regarding each CSI's story). Using the framework for organizational life cycles used by Powell and Nelson (1997), the interview guide will ask key informants to describe their experiences at several different stages of development of the CSI (initiating, building, and stabilizing stages) with regard to tasks undertaken (the work of the CSI), processes involved (how people worked together), systems interaction (experiences with other agencies, government, and the community), and critical issues faced. The interview data may be supplemented with CSI documents that are relevant to the history of the organization. We also plan to conduct a focus group interview with key people who have been involved in the development of the provincial CSDI office to learn about the life cycle of this organization and the role that it has played in the province. These systems-level activities and changes refer to the organizational level of analysis.

In a separate focus group interview, CSI key informants will be asked about activities designed to effect social systems changes (within the CSI organization, mainstream mental health agencies, community settings, regional planning [e.g., District Health Council], government policy). In each locale, a second focus group will be held with a small group of people from mental health agencies, District Health Council, and other community settings. These people will be purposefully sampled according to their knowledge of each CSI, its activities, and impacts (see Appendix H for the interview guide regarding each CSI's systems-level activities and impacts).

Data analysis. To analyse the data collected from the tracking system that are relevant to research questions 6 and 7, we will plot the number of occurrences of each of the process and outcome indicators by month. This will yield a cumulative record of activities and outcomes for

each of the 4 sites over the course of the study (see Francisco et al., 1990 for an example).

The procedures to analyse the qualitative data relevant to systems changes will be similar to those used to examine personal changes. For the life cycle data on the CSIs, we will start with open coding and then proceed to see how well the data fit Powell and Nelson's (1997) life cycle model. Also, a 3-5 page summary of each CSI's narrative will be constructed from the data. For the data on systems-level activities and impacts, we will use open coding for each area of change (e.g., government policy) and factors influencing those impacts. The end goal is to come up with a grounded model of social change activities and outcomes for the CSIs. We realize that we will not be able to make any causal inferences from these qualitative data. Techniques to determine the trustworthiness of the data will be employed (e.g., triangulation of sources and data analysts, having participants review the transcripts and summaries).

#### Communication with Other CSIs

We also plan to communicate with other CSIs about this research project with the 4 CSIs in southwestern Ontario. This will be done in several ways. First, information about the research will be shared via the CMHEI newsletter and the CSDI newsletter, [Around the Loop](#). The Investigators, consumer/survivor Research Assistants, and Partners will write about various aspects of the research for these newsletters. Second, we will provide information about the study at the CSDI annual conference. Since this conference is primarily for consumer/survivors, presentations will likely be made by Partners and the consumer/survivor Research Assistants. Third, we will attempt to offer workshops about the research at provincial conferences and at regional meetings of the CSI initiatives. There are networks for different

geographic areas of the province that we will approach to see if they would be interested in having a workshop on the project.

## Project Work Plan

### Year 1 (April, 1998-March, 1999)

The first 6 months of the study will focus on building a structure and preparing participants for the 5-year study. First, the Investigators, CSDI Coordinator, and Project Manager will select the 4 sites. Second, the Steering Committee (which is described in a subsequent section) will be formed and 2 consumer/survivor Research Assistants from each of the 4 sites will be hired and trained. In participatory action research, it is of critical importance to establish a positive climate for the research early in the process and to develop clear communication among all partners. The Steering Committee will: a) decide on the values and principles of the research, b) refine the research objectives, c) review and approve the research instruments in consultation with the Coordinating Centre and Working Group, d) organize the process for hiring and training Research Assistants, e) develop a plan for recruitment of participants, f) review ethical issues, g) maintain communication with all CSIs, and h) define roles and responsibilities for all participants.

The Research Team, which includes the Research Assistants, the Coordinator and staff from the Centre for Research, and the Investigators, will meet on a regular basis and will be responsible for collecting the research data. During the latter half of the first year, the Research Team will begin to identify and recruit participants into the research, conduct baseline quantitative and qualitative interviews, keep in touch with participants, clean-up, code, input, and begin the analysis of the data. Communication will occur through the CSDI newsletter

(Around the Loop), and a conference presentation, in which we will present an overview of the research. Finally, we will hold 2 meetings of all key stakeholders (Investigators, Project Manager, Site Research Assistants, and Steering Committee members) to review how the research is progressing.

#### Year 2 (April, 1999-March, 2000)

There will be 4-5 meetings of the Steering Committee (for the purposes of guiding the research process, planning new activities, reflecting on activities in progress, reviewing reports, etc.), 4-5 meetings of the Research Team (for the purposes of planning, reflecting, training, and supervising), and 2 meetings of these 2 groups together. Baseline interviews will continue; 9 month follow-up interviews will start; activities to keep in touch with participants will occur; and data cleaning, coding, inputting, and analysis will continue. Quality control procedures for the quantitative and qualitative interviews related to personal impacts will be developed and implemented in each site for each interviewer.

The tracking system for systems-level activities and impacts will be developed by the Steering Committee and piloted by the Research Team (this will include site visits and training in the system by the Investigators and Project Manager). Newsletter communications and a workshop focused on qualitative research and personal impacts at the CSDI conference will be used for communication with all CSIs.

#### Year 3 (April, 2000-March, 2001)

The Steering Committee and the Research Team will continue to meet 4-5 times per year, with the combined group meeting twice. Follow-up quantitative and qualitative (9 and 18 month) interviews related to personal impacts will be conducted; activities to keep in touch will

be done on a regular basis; and quality control procedures will be used. Data for the tracking system for systems-level activities and impacts will be collected, analysed, and reported. Quality control procedures for the tracking system data will be developed and implemented.

Two types of focus groups will be conducted within each of the 4 sites: one with selected CSI members to collect organizational stories and another with CSI members and key informants from community organizations (e.g., mental health professionals, planners) to describe and understand systems-level activities and impacts. Quantitative and qualitative data will be cleaned, organized, coded, inputted, and analysed. Workshops will be offered to regional CSI networks and articles will be written for the CSDI newsletter.

#### Year 4 (April, 2001-March, 2002)

The Steering Committee and the Research Team will continue to meet 4-5 times per year, with the combined group meeting twice. Follow-up quantitative and qualitative interviews (9 and 18 month) related to personal impacts will be conducted; activities to keep in touch will be done on a regular basis; and quality control procedures used. Data for the tracking system for systems-level activities and impacts will be collected, analysed, subjected to reliability checks, and reported. Quantitative and qualitative data will be organized, coded, inputted, and analysed. In addition to the routine communication strategies with all sites described for the previous 3 years, a workshop will be held at the annual CSDI conference on qualitative research regarding systems-level activities and impacts for all CSI organizations.

#### Year 5 (April, 2002-March, 2003)

The Steering Committee and the Research Team will continue to meet 4-5 times per year, with the combined group meeting twice. All quantitative and qualitative follow-up

interviews will be completed, along with keeping in touch activities. These data will be cleaned, coded, inputted, and analysed. A major portion of this year will be devoted to final analyses of the data and writing up the findings. Data from the tracking system will continue to be collected and analysed. The annual CSDI workshop will focus on results, recommendations, and the future. Workshop participants and Steering Committee members will be encouraged to discuss the implications of the findings and to make recommendations for practice, organizational change, policy, and further research.

### Proposed Staffing Plan

The Research Team consists of the Investigators (Geoffrey Nelson, Principal Investigator, John Trainor, Co-Investigator), the Project Manager (Joanna Ochocka), and the Community Partner (Ms. Marnie Shepherd, Coordinator of the CSDI). The Centre for Research and Education in Human Services, which has been a leader in participatory action research in community mental health for 15 years, will manage the project under the direction of Dr. Ochocka. Additional staff from the Centre and students from the M. A. Program in Community Psychology at Wilfrid Laurier University will assist Dr. Ochocka in implementing the research. The Centre has a network of micro-computers with Internet access and a variety of software for word processing (Word and WordPerfect), quantitative data analysis (SPSS for Windows), and qualitative data analysis (NUDIST).

The Investigators will be primarily responsible for overseeing all research activities and guiding the implementation of the research methods, data analysis, and write-up of findings. Two consumer/survivor Research Assistants from each of the 4 CSI sites will be hired and trained. They will be primarily responsible for data collection in each of the 4 sites, but will be

assisted by Centre staff and the Investigators. The Investigators have experience in hiring, training, and supervising consumer/survivor Research Assistants, and have found that these assistants make substantial contributions to the research, in addition to gaining valuable research skills.

### Involvement of Key Stakeholders

This study is a partnership between the CSDI office in Toronto, CSI sites, the Centre for Research and Education in Human Services, and the project Investigators. The development of this proposal was guided by a Planning Committee of staff members from 7 CSIs. We plan to continue with this arrangement if the project is funded. We are committed to and experienced in the participatory action research approach described earlier (Boydell, Trainor, & Intagliata, 1986; Constantino & Nelson, 1995; Nelson et al., 1998).

A project Steering Committee will be composed of 2 representatives from the 4 CSI sites and the CSDI Coordinator. This committee will have a mandate of planning, reviewing, and approving all research activities and will meet 4-5 times per year. We will also hold 10 meetings during the course of the project in which the Research Team and the Steering Committee share experiences and reflect on what we have collectively learned about the research process and findings from the study. As has been previously noted, communication with and the involvement of other CSI sites will also occur through newsletter information, workshops, and conference presentations. It is our experience that these participatory and consultative processes are critical to the successful implementation of research with CSIs.

## References

Bargal, D. (1992). The early stage in the creation of two self-help organizations: An exploratory study. Administration in Social Work, 16(3/4), 81-98.

Borkman, T. J. (1990). Experiential, professional, and lay frames of reference. In T. J. Powell (Ed.), Working with self-help (pp. 3-30). Silver Spring, MD: National Association of Social Workers.

Borkman, T. J., & Schubert, M. (1994). Participatory action research as a strategy for studying self-help groups internationally. Prevention in Human Services, 11, 45-68.

Boydell, K., Trainor, J., & Intagliata, J. (1986). A participatory approach to the evaluation design of a case management program for the long-term mentally ill. Canada's Mental Health, 34(1), 11-13.

Buckner, J. C. (1988). The development of an instrument to measure neighborhood cohesion. American Journal of Community Psychology, 16, 771-791.

Burstow, B., & Weitz, D. (Eds.).(1988). Shrink resistant: The struggle against psychiatry in Canada. Vancouver, B.C.: New Star Books.

Capponi, P. (1992). Upstairs in the crazy house: The life of a psychiatric survivor. Toronto: Viking.

Carling, P. J. (1995). Return to community: Building support systems for people with psychiatric disabilities. New York: The Guilford Press.

Chamberlin, J. (1978). On our own: Patient-controlled alternatives to the mental health system. New York: McGraw-Hill.

Chamberlin, J. (1990). The ex-psychiatric patients' movement: Where we've been and where

we're going. The Journal of Mind and Behavior, 11, 323-336.

Chamberlin, J., & Rogers, J. A. (1990). Planning a community-based of service recipients. American Psychologist, 45, 1241-1244.

Chesler, M. A. (1991). Participatory action research with self-help groups: An alternative paradigm for inquiry and action. American Journal of Community Psychology, 19, 757-768.

Church, K. (1993). Breaking down/breaking through: Multi-voiced narratives on psychiatric survivor participation in Ontario's community mental health system. Unpublished doctoral dissertation, University of Toronto, Toronto.

Church, K. (1995). Forbidden narratives: Critical autobiography as social science. Amsterdam: Gordon and Breach Publishers.

Church, K. (1996). Beyond "bad manners": The power relations of "consumer participation" in Ontario's community mental health system. Canadian Journal of Community Mental Health, 15(2), 27-44.

Church, K. (1997). Because of where we've been: The business behind the business of psychiatric survivor economic development. Available from 761 Community Development Corporation, 761 Queen Street West, 3rd Floor, Toronto, Ontario, M6J 1G1.

Church, K., & Reville, D. (1989). User involvement in the mental health field in Canada. Canada's Mental Health, 37(2), 22-25.

Constantino, V., & Nelson, G. (1995). Changing relationships between self-help groups and mental health professionals: Shifting ideology and power. Canadian Journal of Community Mental Health, 14(2), 55-70.

Consumer/Survivor Development Initiative (1996). Consumer/Survivor Development Initiative Project Descriptions: "All 36 of the Consumer/Survivor Initiatives described in their own words". Toronto: Consumer/Survivor Development Initiative.

Cook, T. D., & Campbell, D. T. (1979). Quasi-experimentation: Design and analysis issues for field settings. Chicago: Rand McNally.

Cutrona, C. E., & Russell, D. (1987). The provisions of social relationships and adaptation to stress. In W. H. Jones & D. Perlman (Eds.), Advances in personal relationships (Vol. 1, pp. 37-68). Greenwich, CT: JAI Press.

Davidson, L., Chinman, M., Kloos, B., Weingarten, R., Stayner, D., & Tebes, J. K. (1997, May). Peer support among individuals with severe mental illness: History, roadblocks, and a review of the evidence. Invited paper presented at the Self-Help Research Pre-Conference, Biennial Conference of the Society for Community Research and Action, Columbia, South Carolina.

Derogatis, L. R., & Cleary, P. A. (1977). Confirmation of the dimensional structure of the SCL-90: A study in construct validation. Journal of Clinical Psychology, *33*, 981-989.

Edmunson, E. D., Bedell, J. R., & Gordon, R. E. (1984). The Community Network Development Project: Bridging the gap between professional aftercare and self-help. In A. Gartner & F. Riessman (Eds.), The self-help revolution (pp. 195-203). New York: Human Sciences Press.

Emerick, R. E. (1990). Self-help groups for former patients: Relations with mental health professionals. Hospital and Community Psychiatry, *41*, 401-407.

Everett, B. (1994). Something is happening: The contemporary consumer and psychiatric survivor movement in historical context. Journal of Mind and Behavior, *15*, 55-69.

Everett, B. (2000). A fragile revolution: Consumers and psychiatric survivors confront the power of the mental health system. Waterloo, ON: Wilfrid Laurier University Press.

Folkman, S., Lazarus, R. (1988). The relationship between coping and emotion: Implications for theory and research. Social Science and Medicine, 26, 306-317.

Francisco, V. T., Paine, A. L., & Fawcett, S. B. (1990). A methodology for monitoring and evaluating community health coalitions. Health Education Research: Theory and Practice, 8, 403-416.

Goering, P., Durbin J., Foster R., Boyles S., Babiak T., & Lancee, B. (1992). Social networks of residents in supportive housing. Community Mental Health Journal, 28, 199-214.

Goering, P., Wasylenki, D., Lancee, W., & Freeman, S. J. J. (1984). From hospital to community: Six-month and two-year outcomes for 505 patients. The Journal of Nervous and Mental Disease, 172, 667-673.

Goodman, R. M., Wandersman, A., Chinman, M., Imm, P., & Morrissey, E. (1996). An ecological assessment of community-based interventions for prevention and health promotion: Approaches to measuring community coalitions. American Journal of Community Psychology, 24, 33-61.

Hall, G. B., & Nelson, G. (1996). Social networks, social support, personal empowerment, and the adaptation of psychiatric consumer/survivors: Path-analytic models. Social Science and Medicine, 43, 1743-1754.

Humphreys, K. (Ed.). (1996). Self-help/mutual aid initiatives by people with psychiatric disabilities [Special section]. The Community Psychologist, 29, 9-25.

Humphreys, K., Finney, J. W., & Moos, R. H. (1994). Applying a stress and coping

framework to research on mutual help organizations. Journal of Community Psychology, 22, 312-327.

Humphreys, K., & Noke, J. M. (1997). The influence of posttreatment mutual help group participation on the friendship networks of substance abuse patients. American Journal of Community Psychology, 25, 1-16.

Humphreys, K., & Rappaport, J. (1994). Researching self-help/mutual aid groups and organizations: Many roads, one journey. Applied and Preventive Psychology, 3, 217-231.

Kennedy, M. (1989). Psychiatric rehospitalization of GROWers. Paper presented at the Biennial Conference of the Society for Community Research and Action, East Lansing, Michigan.

Kennedy, M., & Humphreys, K. (1994). Understanding worldview transformation in members of mutual help groups. Prevention in Human Services, 11, 181-198.

Keppel, G. (1991). Design and analysis: A researcher's handbook (3rd ed.). Englewood Cliffs, N. J.: Prentice-Hall.

Kofman, F., & Senge, P. M. (1993). Communities of commitment: The heart of learning organizations. Organizational Dynamics, 22, 5-23.

Kyrouz, E., & Humphreys, K. (1996). Do psychiatrically disabled people benefit from participation in self-help/mutual aid organizations? A research review. The Community Psychologist, 29(3), 21-25.

Lehman, A. F. (1988). A quality of life interview for the chronically mentally ill. Evaluation and Program Planning, 11, 51-62.

Levine, M., & Perkins, D. V. (1997). Principles of community psychology: Perspectives and

applications (2nd edition). New York: Oxford University Press.

Levy, L. H., Derby, J. F., & Martinkowski, K. S. (1993). Effects of membership in bereavement support groups on adaptation to conjugal bereavement. American Journal of Community Psychology, 21, 361-381.

Lincoln, Y. S., & Guba, E. (1985). Naturalistic inquiry. Beverly Hills: Sage.

Luke, D. A. (1989). The measurement of change in a self-help context. Unpublished doctoral dissertation, University of Illinois, Urbana-Champaign.

Maton, K. I. (1990). Meaningful involvement in instrumental activity and well-being: Studies of older adolescents and at-risk urban teenagers. American Journal of Community Psychology, 18, 297-320.

McKnight, J. (1995). The careless society: Community and its counterfeits. New York: Basic Books.

Mechanic, D., & Rochefort, D. A. (1990). Deinstitutionalization: An appraisal of reform. Annual Review of Sociology, 16, 301-327.

Miles, M. B., & Huberman, A. M. (1994). Qualitative data analysis: An expanded sourcebook. Newbury Park, CA: Sage.

Nelson, G., Hall, G. B., & Walsh-Bowers, R. (1997). A comparative evaluation of supportive apartments, group homes, and board-and-care homes for psychiatric consumer/ survivors. Journal of Community Psychology, 25, 167-188.

Nelson, G., Lord, J., & Ochocka, J. (2001). Shifting the paradigm in community mental health: Towards empowerment and community. Toronto: University of Toronto Press.

Nelson, G., Ochocka, J., Griffin, K., & Lord, J. (1998). "Nothing about me, without me": Participatory action research with self-help/mutual aid organizations for psychiatric consumer/survivors. American Journal of Community Psychology, 26, 881-912.

Nelson, G., Walsh-Bowers, R., & Hall, G. B. (1998). Housing for psychiatric survivors: Values, policy, and research. Administration and Policy in Mental Health, 25, 55-62.

Nelson, G., Wiltshire, C., Hall, G. B., Pearson, L., & Walsh-Bowers, R. consumer/survivors' quality of life: Quantitative and qualitative Psychology, 23, 216-233.

Nguyen, T. D., Attkisson, C. C., & Stegner, B. L. (1983). Assessment of patient satisfaction: Development and refinement of a service evaluation questionnaire. Evaluation and Program Planning, 6, 299-313.

Patton, M. Q. (1990). Qualitative evaluation and research methods (2nd ed.). Newbury Park, CA: Sage.

Peters, R. DeV. (1994). Better Beginnings, Better Futures: A community-based approach to primary prevention. Canadian Journal of Community Mental Health, 13(2), 183-188.

Powell, B., & Nelson, G. (1997). The cultivation of neighbourhood Journal for the Community Development Society, 28, 25-42.

Rapp, C. A., Shera, W., & Kisthardt, W. (1993). Research strategies for consumer empowerment of people with severe mental illness. Social Work, 38, 727-735.

Rappaport, J. (1993). Narrative studies, personal stories, and identity transformation in the mutual help context. Journal of Applied Behavioral Science, 29, 239-256.

Rappaport, J., Seidman, E., Toro, P. A., McFadden, L. S., Reischl, T. M., Roberts, L. J., Salem, D. A., Stein, C. H., & Zimmerman, M. A. (1985). Finishing the unfinished business: Collaborative research with a mutual help organization. Social Policy, 16, 12-24.

Rogers, E. S., Chamberlin, J., Ellison, M. L., & Crean, T. (1997). A consumer-constructed scale to measure empowerment of users of mental health services. Psychiatric Services, 48, 914-918.

Rosenberg, M (1965). Society and the adolescent self-image. Princeton, NJ: Princeton University Press.

Rush, B., & Ogborne, A. (1991). Program logic models: Expanding their role and structure for program planning and evaluation. Canadian Journal of Program Evaluation, 6, 93-105.

Salem, D. A., Seidman, E., & Rappaport, J. (1988). Community treatment of the mentally ill: The promise of mutual help organizations. Social Work, 33, 403-408.

Salzer, M. S. (1997). Consumer empowerment in mental health organizations: Concept, benefits, and impediments. Administration and Policy in Mental Health, 24, 425-434.

Segal, S. P., Silverman, C., & Temkin, T. (1995). Measuring empowerment in client-run self-help agencies. Community Mental Health Journal, 31, 215-227.

Senge, P. (1990). The fifth discipline: The art and practice of the learning organization. New York: Doubleday Currency.

Strauss, A., & Corbin, J. (1990). Basics of qualitative research: Grounded theory procedures and techniques. Newbury Park, CA: Sage.

Trainor, J., Shepherd, M., Boydell, K., Leff, A., & Crawford, E. (1996).

Consumer/Survivor Development Initiative: Evaluation report. Toronto: Consumer/Survivor Development Initiative.

Trainor, J., Shepherd, M., Boydell, K. M., Leff, A., & Crawford, E. (1997). Beyond the service paradigm: The impact and implications of consumer/survivor initiatives. Psychiatric Rehabilitation Journal, 21, 132-140.

Trainor, J., & Tremblay, J. (1992). Consumer/survivor businesses in Ontario: Challenging the rehabilitation model. Canadian Journal of Community Mental Health, 11(2), 65-71.

Weitz, D. (1984). "On Our Own": A self-help model. In D. P. Lumsden (Ed.), Community mental health action: Primary prevention programming in Canada (pp. 312-320). Ottawa: Canadian Public Health Association.

Zimmerman, M. A. (1995). Psychological empowerment: Issues and illustrations. American Journal of Community Psychology, 23, 581-599.

# **Appendix A**

## **Common Protocols**



# CMHEI - Baseline Information

(Please print using BLOCK letters or numbers inside boxes)

STATUS  
CSI  
pg 1/6

ID:

Date (mm/dd/yy):  /  /

Person Completing Form:

Length of Program Participation:  months

Not a CSI participant

## Illness Information:

Were you ever hospitalized for a psychiatric illness? If yes, how old were you the first time?  (Enter "98" if never hospitalized)

Were you ever given a psychiatric diagnosis? What was it? (Probe when necessary. Select one or more.)

- Mood disorder
- Anxiety disorder
- Schizophrenic disorder
- Personality disorder
- Developmental handicap
- Substance-related disorder
- Mental disorders due to a medical condition
- Delirium, dementia, amnesic, other cognitive disorders
- Specific disorder of childhood/ adolescence
- Other
- Unknown

**All work is considered important, regardless of whether it is completed in or outside of the home. The following questions are about your most responsible job held outside the home.**

Have you ever been employed outside the home?  Yes  No If no, go to next page

For the job with highest level of responsibility you ever had, please indicate:

<p><b>Job status:</b></p> <p><input type="radio"/> Full-time</p> <p><input type="radio"/> Part-time regular</p> <p><input type="radio"/> Part-time casual</p>	<p><b>Hourly wage or annual salary:</b></p> <p>hourly wage \$ <input type="text"/><input type="text"/><input type="text"/> . <input type="text"/><input type="text"/></p> <p>-- OR --</p> <p>annual salary \$ <input type="text"/><input type="text"/><input type="text"/> , <input type="text"/><input type="text"/><input type="text"/><input type="text"/></p>	<p><b>Payment:</b></p> <p><input type="radio"/> Paid</p> <p><input type="radio"/> Volunteer</p>	<p><b>Job support:</b></p> <p><input type="radio"/> Sheltered workshop</p> <p><input type="radio"/> Other supported approach</p> <p><input type="radio"/> Independent</p>
---	---	---	---

Indicate the number of months you held your most responsible job:

What year did you hold your most responsible job?





23559

# CMHEI - Health, Education and Legal Issues

(Please print using BLOCK letters or numbers inside boxes)

STATUS  
CSI  
pg 2/6

ID:

Date (mm/dd/yy):  /  /

Person Completing Form:

Indicate Period:  Baseline  Follow-up 3  
 Follow-up 1  Follow-up 4  
 Follow-up 2

If no follow-up data collected, fill in circle and return form to CC:  No follow-up

### Health and Issues (in the past 9 MONTHS):

In the last **9 MONTHS** have you had any kind of physical health problem. If yes, what kind of health problems did you have? How much did these problems restrict your activities or keep you from doing things?

No physical health problem.  
 Minor health problems (e.g. cold, non-serious fall, etc.).  
 Physical health problem imposes mild restriction on mobility and activity.  
 Moderate degree of restriction on activity due to physical health problem.  
 Severe or complete incapacity due to physical health problem.

Do you have a primary therapist, case manager or social worker?  Yes  No  
If yes, how often do you have contact with your primary therapist, case manager or social worker?  
 Daily  At least weekly  At least monthly  Less than monthly  Not at all

Have you been prescribed medications for emotions, nerves or abuse of alcohol or drugs?  Yes  No  
If yes, how often do you take these medications as prescribed?  
 Most of the time  About half of the time  Less than half of the time  Unknown

### Education:

Are you currently enrolled as a student (in the past week)?  Yes  No  
Have you been enrolled as a student during the past **9 MONTHS**?  Yes  No  
What is the most recent school?:  Secondary (High School)  Vocational/Technical / Trade School  
 Adult Education  University  
 Community College  Other  
Were you a full-time or part-time student?  Full-time  Part-time  
How regularly did you attend classes?  Most of the time  Less than half of the time  
 About half of the time  Unknown

Go to "Legal Issues" section

**Legal Issues:** Traditionally, some consumers/ survivors have had experiences with the legal system. There is a belief that many of these experiences may have been avoided if the individual had better support from the community. We want to ask you about your types of experiences with the legal system.

Please answer the following questions for the period beginning **9 MONTHS** ago and ending today. Have you..

... been arrested?  No  Yes If yes, # of arrests:   
... been arrested under the mental health act?  No  Yes If yes, # of arrests:   
... spent any nights in prison/ jail?  No  Yes If yes, # of nights:   
How many separate times did you spend in prison/jail last **9 MONTHS**:   
How many times were you in prison/jails for offences committed in **last 9 MONTHS**:   
... been on parole/probation?  No  Yes If yes, # of episodes:   
How many times were you put on parole/ probation for offences committed in **last 9 MONTHS**:   
... been violently victimized?  No  Yes If yes, # of times:   
... been otherwise victimized?  No  Yes If yes, # of times:

23559









23559

# CMHEI - Hospitalization Log

(Please print using BLOCK letters or numbers inside boxes)

STATUS  
CSI  
pg 5/6

ID:

Date (mm/dd/yy):  /  /

Person Completing Form:

Indicate Period:  
 Baseline     Follow-up 3  
 Follow-up 1     Follow-up 4  
 Follow-up 2

The following are questions about any type of hospitalization you may have had in the past 9 MONTHS. This project is interested in seeing if there are changes in your use of hospitalization over time.

Have you stayed overnight in a hospital during the past 9 MONTHS?

Yes     No

If no, go to next page

If yes, how many different times were in hospital? In which hospitals did you stay? Please tell me something about each time you were hospitalized.

Hospital	Province (if not ON)	Reason* (check all that apply)	Hospital code**	Voluntary	Days in Hospital	Admission date also in last 9 months?
	<input type="text"/> <input type="text"/>	<input type="radio"/> Psy <input type="radio"/> SA <input type="radio"/> Med	<input type="radio"/> Sp <input type="radio"/> PPH <input type="radio"/> GH <input type="radio"/> GH1 <input type="radio"/> GH2 <input type="radio"/> Other	<input type="radio"/> Yes <input type="radio"/> No	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="radio"/> Yes <input type="radio"/> No
	<input type="text"/> <input type="text"/>	<input type="radio"/> Psy <input type="radio"/> SA <input type="radio"/> Med	<input type="radio"/> Sp <input type="radio"/> PPH <input type="radio"/> GH <input type="radio"/> GH1 <input type="radio"/> GH2 <input type="radio"/> Other	<input type="radio"/> Yes <input type="radio"/> No	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="radio"/> Yes <input type="radio"/> No
	<input type="text"/> <input type="text"/>	<input type="radio"/> Psy <input type="radio"/> SA <input type="radio"/> Med	<input type="radio"/> Sp <input type="radio"/> PPH <input type="radio"/> GH <input type="radio"/> GH1 <input type="radio"/> GH2 <input type="radio"/> Other	<input type="radio"/> Yes <input type="radio"/> No	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="radio"/> Yes <input type="radio"/> No
	<input type="text"/> <input type="text"/>	<input type="radio"/> Psy <input type="radio"/> SA <input type="radio"/> Med	<input type="radio"/> Sp <input type="radio"/> PPH <input type="radio"/> GH <input type="radio"/> GH1 <input type="radio"/> GH2 <input type="radio"/> Other	<input type="radio"/> Yes <input type="radio"/> No	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="radio"/> Yes <input type="radio"/> No
	<input type="text"/> <input type="text"/>	<input type="radio"/> Psy <input type="radio"/> SA <input type="radio"/> Med	<input type="radio"/> Sp <input type="radio"/> PPH <input type="radio"/> GH <input type="radio"/> GH1 <input type="radio"/> GH2 <input type="radio"/> Other	<input type="radio"/> Yes <input type="radio"/> No	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="radio"/> Yes <input type="radio"/> No
	<input type="text"/> <input type="text"/>	<input type="radio"/> Psy <input type="radio"/> SA <input type="radio"/> Med	<input type="radio"/> Sp <input type="radio"/> PPH <input type="radio"/> GH <input type="radio"/> GH1 <input type="radio"/> GH2 <input type="radio"/> Other	<input type="radio"/> Yes <input type="radio"/> No	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="radio"/> Yes <input type="radio"/> No
	<input type="text"/> <input type="text"/>	<input type="radio"/> Psy <input type="radio"/> SA <input type="radio"/> Med	<input type="radio"/> Sp <input type="radio"/> PPH <input type="radio"/> GH <input type="radio"/> GH1 <input type="radio"/> GH2 <input type="radio"/> Other	<input type="radio"/> Yes <input type="radio"/> No	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="radio"/> Yes <input type="radio"/> No
	<input type="text"/> <input type="text"/>	<input type="radio"/> Psy <input type="radio"/> SA <input type="radio"/> Med	<input type="radio"/> Sp <input type="radio"/> PPH <input type="radio"/> GH <input type="radio"/> GH1 <input type="radio"/> GH2 <input type="radio"/> Other	<input type="radio"/> Yes <input type="radio"/> No	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="radio"/> Yes <input type="radio"/> No

\*: Reason:    Psy: Psychiatric    SA: Substance Abuse    Med: Medical

\*\*: Type Codes:    PPH: Provincial Psychiatric Hospital    SP: Specialty Hospital  
GH: General hospital without psychiatric ward (non-schedule 1)  
GH1: General hospital with psychiatric ward (schedule 1) on psychiatry ward  
GH2: General hospital with psychiatric ward (schedule 1) not on psychiatry ward

23559





# CMHEI - Baseline Self-Report

(Please print using BLOCK letters and numbers inside boxes)

SR  
CSI  
pg. 1/5

6138

ID:

Date (mm/dd/yy):  /  /

Person Completing Form:

Gender:  Female  
 Male

What is your date of birth (mm/dd/yy)?  /  /

What is your preferred language? Only one should be indicated.  
 English  
 French  
 Other, specify:

How would you describe your racial background?  
 Aboriginal  White  
 Asian  Mixed  
 Black  Other, specify:

Were you born in Canada?  Yes  No  
If no, indicate your country of birth.

If not Canada, approximately when did you come to Canada?

How many years of school did you complete? Please circle one.

0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20+  
Primary Secondary Post-secondary

What is your marital status?  
 Single, Never Married  Separated  
 Married  Divorced  
 Cohabiting with Significant Other  Widowed

Shade circles like this:   
Not like this:

6138



# CMHEI - Social Support

(Please print using BLOCK letters and numbers inside boxes)

SR  
CSI  
pg. 2/5

6138

ID:

Date (mm/dd/yy):  /  /

Person Completing Form:

Indicate Period:  
 Baseline     Follow-up 3  
 Follow-up 1     Follow-up 4  
 Follow-up 2

**HAND CONSUMER ANSWER KEY CARD. I'm going to read you some statements about your relationships with others. For each, could you please tell me whether you strongly disagree, disagree, agree, or strongly agree. FILL THE APPROPRIATE CIRCLE.**

	strongly agree	agree	disagree	strongly disagree	N/A
1. If something went wrong, no one would help me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. I have family and friends who help me feel safe, secure and happy.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. There is someone I trust whom I could turn to for advice if I were having problems.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. There is no one I feel comfortable talking about problems with.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. I lack a feeling of intimacy with another person.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. There are people I can count on in an emergency.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. I provide support to my friends and/ or my family.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. I have a lot of serious disagreements and arguments with my family.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Now, I'm going to ask you some questions about the people you are close to.**

9. Are there any people with whom you feel at ease and can talk to about personal issues?  Yes  No  No answer

If no or no answer, then skip to question 13

10. Among these people, how many are:

family members (including spouse)

friends

spiritual leader

care providers

boyfriend, girlfriend or partner

other (specify):

11. How many of these people have also received mental health treatment?

12. How many of these people are CSI members?

13. During the past month, how often have you been in contact with close friends?

- Not at all
- Once or twice
- Once a week
- Several times a week
- No answer

14. During the past month, how often have you been in contact with anyone in your family (include spouses/ partners)?

- Not at all
- Once or twice
- Once a week
- Several times a week
- No answer

15. Do you have a family member involved in a family self help initiative?

- Yes
- No
- No answer

Shade circles like this:

Not like this:

6138



# CMHEI - Empowerment Scale

(Please print using BLOCK letters and numbers inside boxes)

SR  
CSI  
pg. 3/5

6138

ID:

Date (mm/dd/yy):  /  /

Person Completing Form:

Indicate Period:  
 Baseline       Follow-up 3  
 Follow-up 1       Follow-up 4  
 Follow-up 2

**HAND CONSUMER ANSWER KEY CARD.  
FILL THE APPROPRIATE CIRCLE.**

	strongly agree	agree	disagree	strongly disagree	N/A
1. I am usually confident about the decisions I make.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Most of the misfortunes in my life were due to bad luck.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. People working together can have an effect on their community.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Making waves never gets you anywhere.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. When I make plans, I am almost certain to make them work.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Usually, I feel alone.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Experts are in the best position to decide what people should do or learn.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. I generally accomplish what I set out to do.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. People should try to live their lives the way they want to.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. You can't fight the government.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. I feel powerless most of the time.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. When I am unsure about something, I usually go along with the group.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. People have a right to make their own decisions, even if they are bad ones.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. On the whole, I am satisfied with myself.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. At times, I think that I am no good at all.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. I feel that I have a number of good qualities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. I am able to do things as well as most other people.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. I feel I do not have much to be proud of.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. I certainly feel useless at times.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. I feel that I'm a person of worth, at least on an equal basis with others.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. I wish I could have more respect for myself.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. All in all, I am inclined to feel that I am a failure.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. I have a positive attitude toward myself.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Shade circles like this:   
Not like this:

6138



# CMHEI - Quality of Life Scale

(Please print using BLOCK letters and numbers inside boxes)

SR  
CSI  
pg. 4/5

6138

ID:

Date (mm/dd/yy):  /  /

Person Completing Form:

Indicate Period:  Baseline  Follow-up 3  
 Follow-up 1  Follow-up 4  
 Follow-up 2

Now I am going to ask you a series of questions about different areas of your life and your satisfaction with them. **HAND CONSUMER ANSWER KEY CARD.** This is called the "Delighted-Terrible Scale". For each item, please tell me which point on the scale best describes how you feel. **FILL THE APPROPRIATE CIRCLE.**

terrible   unhappy   mostly dissatisfied   mixed   mostly satisfied   pleased   delighted   N/A

1. How do you feel about your life as a whole?
2. How do you feel about how safe you are on the streets in your neighbourhood?
3. How do you feel about how safe you are where you live?
4. How do you feel about the protection you have against being robbed or attacked?
5. How do you feel about the living arrangements where you live?
6. How do you feel about the privacy that you have there?
7. How do you feel about the idea of staying where you live for a long time?
8. How do you feel about the way that you spend your spare time?
9. How do you feel about the chances you have to enjoy pleasant or beautiful things?
10. How do you feel about the amount of fun you have?
11. How do you feel about the amount of relaxation in your life?

Shade circles like this:   
Not like this:

6138





6138

# CMHEI - Symptom Distress

(Please print using BLOCK letters and numbers inside boxes)

SR  
CSI  
pg. 5/5

ID:

Date (mm/dd/yy):   /   /

Person Completing Form:

Indicate Period:  Baseline  Follow-up 3  
 Follow-up 1  Follow-up 4  
 Follow-up 2

**HAND CONSUMER ANSWER KEY CARD.** I am going to ask you some questions about how much you were distressed or bothered by some things during the PAST 7 DAYS. I'd like you to tell me which of the answers on the card best describes how you feel. **FILL THE APPROPRIATE CIRCLE.**

During the PAST 7 DAYS about how much were you distressed or bothered by:

	not at all	a little bit	moderately	quite a bit	extremely	N/A
1. Nervousness or shakiness inside?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Being suddenly scared for no reason?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Feeling fearful?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Feeling tense or keyed up?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Spells of terror or panic?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Feeling so restless you couldn't sit still?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Heavy feelings in your arms or legs?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Feeling afraid to go out of your home alone?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Feelings of worthlessness?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. Feeling lonely even when you are with other people?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. Feeling weak in parts of your body?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. Feeling blue?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. Feeling lonely?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. Feeling no interest in things?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. Feeling afraid in open spaces or on the streets?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Shade circles like this:

Not like this:

6138



6374

# CMHEI - Service/ Resource Use Form

## Psychiatrist Visits Log

(Please print using BLOCK letters and numbers inside boxes)

**SU**  
 CSI  
 pg 1/5

**ID:**

**Date (mm/dd/yy):**  /  /

**Person Completing Form:**

**Indicate Period:**

Baseline       Follow-up 3  
 Follow-up 1       Follow-up 4  
 Follow-up 2

The following are questions about different services consumer/ survivors and other people use. This project is interested in seeing if there are changes in how you use these services over time.

In the PAST 30 DAYS did you consult a psychiatrist?

- No    If no, go to next page.  
 Yes    If yes, complete one line for each visit:

Location	Province (if not ON)	Group, individual or family therapy ?	Length of visit
<input type="radio"/> Prov. Psych. Hosp. <input type="radio"/> All other sites	<input type="text"/> <input type="text"/>	<input type="radio"/> Group <input type="radio"/> Individual <input type="radio"/> Family	<input type="radio"/> <20 min. <input type="radio"/> 30-59 min. <input type="radio"/> 20-29 min. <input type="radio"/> 60+ min.
<input type="radio"/> Prov. Psych. Hosp. <input type="radio"/> All other sites	<input type="text"/> <input type="text"/>	<input type="radio"/> Group <input type="radio"/> Individual <input type="radio"/> Family	<input type="radio"/> <20 min. <input type="radio"/> 30-59 min. <input type="radio"/> 20-29 min. <input type="radio"/> 60+ min.
<input type="radio"/> Prov. Psych. Hosp. <input type="radio"/> All other sites	<input type="text"/> <input type="text"/>	<input type="radio"/> Group <input type="radio"/> Individual <input type="radio"/> Family	<input type="radio"/> <20 min. <input type="radio"/> 30-59 min. <input type="radio"/> 20-29 min. <input type="radio"/> 60+ min.
<input type="radio"/> Prov. Psych. Hosp. <input type="radio"/> All other sites	<input type="text"/> <input type="text"/>	<input type="radio"/> Group <input type="radio"/> Individual <input type="radio"/> Family	<input type="radio"/> <20 min. <input type="radio"/> 30-59 min. <input type="radio"/> 20-29 min. <input type="radio"/> 60+ min.
<input type="radio"/> Prov. Psych. Hosp. <input type="radio"/> All other sites	<input type="text"/> <input type="text"/>	<input type="radio"/> Group <input type="radio"/> Individual <input type="radio"/> Family	<input type="radio"/> <20 min. <input type="radio"/> 30-59 min. <input type="radio"/> 20-29 min. <input type="radio"/> 60+ min.
<input type="radio"/> Prov. Psych. Hosp. <input type="radio"/> All other sites	<input type="text"/> <input type="text"/>	<input type="radio"/> Group <input type="radio"/> Individual <input type="radio"/> Family	<input type="radio"/> <20 min. <input type="radio"/> 30-59 min. <input type="radio"/> 20-29 min. <input type="radio"/> 60+ min.
<input type="radio"/> Prov. Psych. Hosp. <input type="radio"/> All other sites	<input type="text"/> <input type="text"/>	<input type="radio"/> Group <input type="radio"/> Individual <input type="radio"/> Family	<input type="radio"/> <20 min. <input type="radio"/> 30-59 min. <input type="radio"/> 20-29 min. <input type="radio"/> 60+ min.
<input type="radio"/> Prov. Psych. Hosp. <input type="radio"/> All other sites	<input type="text"/> <input type="text"/>	<input type="radio"/> Group <input type="radio"/> Individual <input type="radio"/> Family	<input type="radio"/> <20 min. <input type="radio"/> 30-59 min. <input type="radio"/> 20-29 min. <input type="radio"/> 60+ min.
<input type="radio"/> Prov. Psych. Hosp. <input type="radio"/> All other sites	<input type="text"/> <input type="text"/>	<input type="radio"/> Group <input type="radio"/> Individual <input type="radio"/> Family	<input type="radio"/> <20 min. <input type="radio"/> 30-59 min. <input type="radio"/> 20-29 min. <input type="radio"/> 60+ min.
<input type="radio"/> Prov. Psych. Hosp. <input type="radio"/> All other sites	<input type="text"/> <input type="text"/>	<input type="radio"/> Group <input type="radio"/> Individual <input type="radio"/> Family	<input type="radio"/> <20 min. <input type="radio"/> 30-59 min. <input type="radio"/> 20-29 min. <input type="radio"/> 60+ min.

Shade circles like this:   
 Not like this:





6374

# CMHEI - Service/ Resource Use Form

## Non-psychiatrist Health Professional Visits Log

(Please print using BLOCK letters and numbers inside boxes)

SU  
CSI  
pg 2/5

ID:

Date (mm/dd/yy):  /  /

Person Completing Form:

Indicate Period:

Baseline       Follow-up 3

Follow-up 1     Follow-up 4

Follow-up 2

In the **PAST 30 DAYS** did you visit a physician (non-psychiatrist) in any setting or another health professional in an office-based practice?

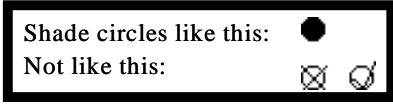
No    If no, go to next page.

Yes    If yes, complete one line for each type of service:

Type of visit*	Provider	Location	Province (if not ON)	Average length of visit	Number of visits
<input type="checkbox"/>	<input type="radio"/> Physician <input type="radio"/> Other (e.g., dentist, podiatrist, social worker)	<input type="radio"/> Prov. Psych. Hosp <input type="radio"/> All other sites	<input type="text"/> <input type="text"/>	<input type="radio"/> <20 mins <input type="radio"/> 30-59 mins <input type="radio"/> 20-29 mins <input type="radio"/> 60+ mins	<input type="text"/> <input type="text"/>
<input type="checkbox"/>	<input type="radio"/> Physician <input type="radio"/> Other (e.g., dentist, podiatrist, social worker)	<input type="radio"/> Prov. Psych. Hosp <input type="radio"/> All other sites	<input type="text"/> <input type="text"/>	<input type="radio"/> <20 mins <input type="radio"/> 30-59 mins <input type="radio"/> 20-29 mins <input type="radio"/> 60+ mins	<input type="text"/> <input type="text"/>
<input type="checkbox"/>	<input type="radio"/> Physician <input type="radio"/> Other (e.g., dentist, podiatrist, social worker)	<input type="radio"/> Prov. Psych. Hosp <input type="radio"/> All other sites	<input type="text"/> <input type="text"/>	<input type="radio"/> <20 mins <input type="radio"/> 30-59 mins <input type="radio"/> 20-29 mins <input type="radio"/> 60+ mins	<input type="text"/> <input type="text"/>
<input type="checkbox"/>	<input type="radio"/> Physician <input type="radio"/> Other (e.g., dentist, podiatrist, social worker)	<input type="radio"/> Prov. Psych. Hosp <input type="radio"/> All other sites	<input type="text"/> <input type="text"/>	<input type="radio"/> <20 mins <input type="radio"/> 30-59 mins <input type="radio"/> 20-29 mins <input type="radio"/> 60+ mins	<input type="text"/> <input type="text"/>
<input type="checkbox"/>	<input type="radio"/> Physician <input type="radio"/> Other (e.g., dentist, podiatrist, social worker)	<input type="radio"/> Prov. Psych. Hosp <input type="radio"/> All other sites	<input type="text"/> <input type="text"/>	<input type="radio"/> <20 mins <input type="radio"/> 30-59 mins <input type="radio"/> 20-29 mins <input type="radio"/> 60+ mins	<input type="text"/> <input type="text"/>
<input type="checkbox"/>	<input type="radio"/> Physician <input type="radio"/> Other (e.g., dentist, podiatrist, social worker)	<input type="radio"/> Prov. Psych. Hosp <input type="radio"/> All other sites	<input type="text"/> <input type="text"/>	<input type="radio"/> <20 mins <input type="radio"/> 30-59 mins <input type="radio"/> 20-29 mins <input type="radio"/> 60+ mins	<input type="text"/> <input type="text"/>
<input type="checkbox"/>	<input type="radio"/> Physician <input type="radio"/> Other (e.g., dentist, podiatrist, social worker)	<input type="radio"/> Prov. Psych. Hosp <input type="radio"/> All other sites	<input type="text"/> <input type="text"/>	<input type="radio"/> <20 mins <input type="radio"/> 30-59 mins <input type="radio"/> 20-29 mins <input type="radio"/> 60+ mins	<input type="text"/> <input type="text"/>
<input type="checkbox"/>	<input type="radio"/> Physician <input type="radio"/> Other (e.g., dentist, podiatrist, social worker)	<input type="radio"/> Prov. Psych. Hosp <input type="radio"/> All other sites	<input type="text"/> <input type="text"/>	<input type="radio"/> <20 mins <input type="radio"/> 30-59 mins <input type="radio"/> 20-29 mins <input type="radio"/> 60+ mins	<input type="text"/> <input type="text"/>
<input type="checkbox"/>	<input type="radio"/> Physician <input type="radio"/> Other (e.g., dentist, podiatrist, social worker)	<input type="radio"/> Prov. Psych. Hosp <input type="radio"/> All other sites	<input type="text"/> <input type="text"/>	<input type="radio"/> <20 mins <input type="radio"/> 30-59 mins <input type="radio"/> 20-29 mins <input type="radio"/> 60+ mins	<input type="text"/> <input type="text"/>

**Type\*:**

1= mental health	5= foot care
2= eye care	6= lab tests
3= dental care	7= other physical health
4= ear care	8= other



6374





6374

# CMHEI - Service/ Resource Use Form

## Community Services and Support Programs Log

(Please print using BLOCK letters and numbers inside boxes)

SU  
 CSI  
 pg 3/5

ID:

Date (mm/dd/yy):   /   /

Person Completing Form:

Indicate Period:  Baseline  Follow-up 3  
 Follow-up 1  Follow-up 4  
 Follow-up 2

Have you used community services and support programs during the **PAST 30 DAYS**?

- No If no, go to next page.  
 Yes If yes, complete the following for each program:

Name of Program/ Agency	City	Province (if not ON)	Program Type*	Total contacts in past 30 days	Contacts in past 30 days which were in a group	Contacts in past 30 days which were on the phone	Total # weeks attended in past 30 days	Average hours per week
		<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> . <input style="width: 20px; height: 20px;" type="text"/>
		<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> . <input style="width: 20px; height: 20px;" type="text"/>
		<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> . <input style="width: 20px; height: 20px;" type="text"/>
		<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> . <input style="width: 20px; height: 20px;" type="text"/>
		<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> . <input style="width: 20px; height: 20px;" type="text"/>
		<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> . <input style="width: 20px; height: 20px;" type="text"/>
		<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> . <input style="width: 20px; height: 20px;" type="text"/>
		<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> . <input style="width: 20px; height: 20px;" type="text"/>
		<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> . <input style="width: 20px; height: 20px;" type="text"/>
		<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> . <input style="width: 20px; height: 20px;" type="text"/>
		<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> . <input style="width: 20px; height: 20px;" type="text"/>
		<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> . <input style="width: 20px; height: 20px;" type="text"/>
		<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> . <input style="width: 20px; height: 20px;" type="text"/>
		<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> . <input style="width: 20px; height: 20px;" type="text"/>

<b>Program Type*:</b>	1 = Social/ recreational	6 = Case management
	2 = Vocational/ educational	7 = Self-help/ consumer initiative
	3 = Crisis	8 = Legal advocacy
	4 = Housing	9 = Other
	5 = Medical/ therapeutic	



6374

# CMHEI - Service/ Resource Use Form Emergency Room Visits Log

(Please print using BLOCK letters and numbers inside boxes)

SU  
CSI  
pg 4/5

ID:

Date (mm/dd/yy):  /  /

Person Completing Form:

Indicate Period:  Baseline  Follow-up 3  
 Follow-up 1  Follow-up 4  
 Follow-up 2

Did you go to an emergency room during the PAST 3 MONTHS?

- No If no, go to next page.
- Yes If yes, complete the following for each ER visit:

Name of Hospital for ER visit	City	Province (if not ON)	Purpose* (check all that apply)	Stayed overnight in holding bed?	Led to a hospital admission?
		<input type="text"/> <input type="text"/>	<input type="radio"/> Psy <input type="radio"/> Med <input type="radio"/> SA <input type="radio"/> Oth	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No
		<input type="text"/> <input type="text"/>	<input type="radio"/> Psy <input type="radio"/> Med <input type="radio"/> SA <input type="radio"/> Oth	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No
		<input type="text"/> <input type="text"/>	<input type="radio"/> Psy <input type="radio"/> Med <input type="radio"/> SA <input type="radio"/> Oth	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No
		<input type="text"/> <input type="text"/>	<input type="radio"/> Psy <input type="radio"/> Med <input type="radio"/> SA <input type="radio"/> Oth	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No
		<input type="text"/> <input type="text"/>	<input type="radio"/> Psy <input type="radio"/> Med <input type="radio"/> SA <input type="radio"/> Oth	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No
		<input type="text"/> <input type="text"/>	<input type="radio"/> Psy <input type="radio"/> Med <input type="radio"/> SA <input type="radio"/> Oth	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No
		<input type="text"/> <input type="text"/>	<input type="radio"/> Psy <input type="radio"/> Med <input type="radio"/> SA <input type="radio"/> Oth	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No
		<input type="text"/> <input type="text"/>	<input type="radio"/> Psy <input type="radio"/> Med <input type="radio"/> SA <input type="radio"/> Oth	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No
		<input type="text"/> <input type="text"/>	<input type="radio"/> Psy <input type="radio"/> Med <input type="radio"/> SA <input type="radio"/> Oth	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No

**Purpose\*:** Psy = Psychiatric  
SA = Substance Abuse  
Med = Medical  
Oth = Other

Shade circles like this: ●  
Not like this: ⊗ ⊕

6374





6374

# CMHEI - Service/ Resource Use Form

## Prescribed Psychotropic Medication Log

(Please print using BLOCK letters and numbers inside boxes)

SU  
CSI  
pg 5/5

ID:

Date (mm/dd/yy):   /   /

Person Completing Form:

Indicate Period:  Baseline  Follow-up 3  
 Follow-up 1  Follow-up 4  
 Follow-up 2

Did you take prescribed medications for psychiatric/ substance abuse problems during the **PAST 30 DAYS?**

No **If no, go to next page.**  
 Yes **If yes, complete the following for each medication:**

Prescription Name	Type*	Prescribed Dose (mg) <i>(or number of pills/ injections taken at one time)</i>	# doses in 24 hour period prescribed <i>(if injection, PRN*, see below)</i>	During past month, # days medication or injection prescribed/ taken
	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> mg OR <input style="width: 20px; height: 20px;" type="text"/> # pills/ injections	<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>
	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> mg OR <input style="width: 20px; height: 20px;" type="text"/> # pills/ injections	<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>
	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> mg OR <input style="width: 20px; height: 20px;" type="text"/> # pills/ injections	<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>
	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> mg OR <input style="width: 20px; height: 20px;" type="text"/> # pills/ injections	<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>
	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> mg OR <input style="width: 20px; height: 20px;" type="text"/> # pills/ injections	<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>
	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> mg OR <input style="width: 20px; height: 20px;" type="text"/> # pills/ injections	<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>
	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> mg OR <input style="width: 20px; height: 20px;" type="text"/> # pills/ injections	<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>
	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> mg OR <input style="width: 20px; height: 20px;" type="text"/> # pills/ injections	<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>
	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> mg OR <input style="width: 20px; height: 20px;" type="text"/> # pills/ injections	<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>

**Type\*:** 1 = Sleeping pills or other sedatives (e.g. Halcion, Dalmane)  
2 = Antidepressant or mood stabilizing medications (e.g. Prozac, Elavil, Lithium)  
3 = Tranquillizers (e.g. Ativan, Valium)  
4 = Analgesics or painkillers (e.g. Demerol, Darvon)  
5 = Anti-psychotics (e.g. Haldol, Modecate)  
6 = Substance abuse treatment (e.g. Methadone, Antabuse)  
7 = Other

**Indicate:**  
97 = PRN  
98 = Injection  
99 = Unknown

6374



# **Appendix B**

## **Unique Protocols**

# Unique Protocol for the Study of Consumer/Survivor Initiatives 9 & 18 Month Interview

---

ID: 

--	--	--	--	--	--	--	--	--	--

Date (mm/dd/yy): 

		/			/		
--	--	---	--	--	---	--	--

Person Completing Form: 

--	--	--	--	--

Indicate Period:  Baseline  Follow-up 3  
 Follow-up 1  Follow-up 4  
 Follow-up 2

What groups or organizations (e.g., self-help, mental health, recreation, etc.) have you been involved in during the past 9 months?

---

---

Of these groups or organizations, which one have you been the most involved in?

---

---

I would like you to think of that group or organization in answering the following questions.

If the person cannot think of a group or organization, skip to section on Participation in a Consumer/Survivor Initiative.

# CMHEI - Organizational Empowerment

ID: 

--	--	--	--	--	--	--	--	--	--

Date (mm/dd/yy): 

		/			/		
--	--	---	--	--	---	--	--

Person Completing Form: 

--	--	--	--	--

Indicate Period:  Baseline       Follow-up 3  
 Follow-up 1       Follow-up 4  
 Follow-up 2

Yes	No	NA	R		
1	0	9	9	1.	Have you helped set up a meeting at [name of group/organization]?
1	0	9	9	2.	Have you had the opportunity to help set up a meeting at [name of group/organization]?
1	0	9	9	3.	Have you been responsible for preparing food or bringing refreshments to [name of group/organization]?
1	0	9	9	4.	Have you had the opportunity to be responsible for preparing food or bringing refreshments to [name of group/organization]?
1	0	9	9	5.	Have you become a volunteer on a regular basis in [name of group/organization]?
1	0	9	9	6.	Have you had the opportunity to become a volunteer on a regular basis in [name of group/organization]?
1	0	9	9	7.	Have you led or helped to lead a group in [name of group/organization]?
1	0	9	9	8.	Have you had the opportunity to lead or help to lead a group in [name of group/organization]?
1	0	9	9	9.	Have you taken part in deciding what activities will be held in [name of group/organization]?
1	0	9	9	10.	Have you had the opportunity to take part in deciding what activities will be held in [name of group/organization]?
1	0	9	9	11.	Have you taken part in deciding how often a group of people will meet in [name of group/organization]?
1	0	9	9	12.	Have you had the opportunity to take part in deciding how often a group of people will meet in [name of group/organization]?
1	0	9	9	13.	Have you participated on the board of directors in [name of group/organization]?
1	0	9	9	14.	Have you had the opportunity to participate on the board of directors in [name of group/organization]?
1	0	9	9	15.	Have you suggested to staff of [name of group/organization] as to what you think might be changed or improved there?
1	0	9	9	16.	Have you had the opportunity to suggest to staff of [name of group/organization] as to what you think might be changed or improved there?
1	0	9	9	17.	Have you contributed in other ways in [name of group/organization]?
1	0	9	9	18.	Have you had the opportunity to contribute in other ways in [name of group/organization]?



## CMHEI - Sense of Community Within the Organization

ID: 

--	--	--	--	--	--	--	--	--	--

Date (mm/dd/yy): 

		/			/		
--	--	---	--	--	---	--	--

Person Completing Form: 

--	--	--	--	--

Indicate Period:  Baseline  Follow-up 3  
 Follow-up 1  Follow-up 4  
 Follow-up 2

Now I am going to ask you some questions about your sense of community or belonging within the organization in which you have been the most involved.

	Strongly Disagree 1	Disagree 2	Neither Agree, nor Disagree 3	Agree 4	Strongly Agree 5	NA 9	R 9
1. I feel like I belong to this organization.	1	2	3	4	5	9	9
2. I visit with people from this organization in their homes.	1	2	3	4	5	9	9
3. The friendships and associations I have with other people in this organization mean a lot to me.	1	2	3	4	5	9	9
4. If the people in this organization were planning something, I'd think of it as something we were doing rather than they were doing.	1	2	3	4	5	9	9
5. If I needed advice about something, I could go to someone in this organization.	1	2	3	4	5	9	9
6. I think I agree with most people in this organization about what is important in life.	1	2	3	4	5	9	9
7. I believe people in this organization would help me in an emergency.	1	2	3	4	5	9	9
8. I feel loyal to the people in this organization.	1	2	3	4	5	9	9
9. I borrow things and exchange favours with members of this organization.	1	2	3	4	5	9	9
10. I would be willing to work together with others on something to improve this organization.	1	2	3	4	5	9	9
11. I plan to remain a member of this organization for a number of years.	1	2	3	4	5	9	9
12. I like to think of myself as similar to members of this organization.	1	2	3	4	5	9	9
13. I rarely have members of this organization over to my house to visit.	1	2	3	4	5	9	9
14. A feeling of fellowship runs deep between me and other members of this organization.	1	2	3	4	5	9	9
15. I regularly talk with people in this organization.	1	2	3	4	5	9	9



## CMHEI - Participation in a Consumer/Survivor Initiative

ID: 

--	--	--	--	--	--	--	--	--	--

Date (mm/dd/yy): 

		/			/		
--	--	---	--	--	---	--	--

Person Completing Form: 

--	--	--	--	--

Indicate Period:  Baseline  Follow-up 3  
 Follow-up 1  Follow-up 4  
 Follow-up 2

1. During the past 9 months, have you participated in a consumer/survivor initiative?

Yes(1) \_\_\_\_\_ No (0) \_\_\_\_\_ Refused (9) \_\_\_\_\_

If no, skip to section .

2. Has your level of involvement in the consumer/survivor initiative increased or decreased since the last interview?

Increased (1) \_\_\_\_\_ Decreased (2) \_\_\_\_\_ Stayed the same (3) \_\_\_\_\_

If it has increased or decreased, why has your involvement changed?

---

---

---

## CMHEI - Community Integration

---

ID: 

--	--	--	--	--	--	--	--	--	--

Date (mm/dd/yy): 

		/			/		
--	--	---	--	--	---	--	--

Person Completing Form: 

--	--	--	--

Indicate Period:  Baseline       Follow-up 3  
 Follow-up 1       Follow-up 4  
 Follow-up 2

Now for the next few questions, I would like you to think back over the last 9 months. **In the last 9 months, how often did you...**

	Not at All	Rarely	Sometimes	Often
1. Attend or take part in a recreational event in the community (e.g., a sporting event or a concert)?	1	2	3	4
2. Work with a group, club or team?	1	2	3	4
3. Help with a neighbourhood or community social event (e.g., by organizing or making food for it)?	1	2	3	4
4. Help out a neighbour (e.g., by looking after a child, giving a ride, or helping around the house or garden)?	1	2	3	4
5. Go to meetings dealing with community concerns (e.g., meetings of a committee you serve)?	1	2	3	4
6. Go to neighbourhood events (e.g., picnics, meals)?	1	2	3	4
7. Take part in activities that help you achieve important education, job, or career goals?	1	2	3	4
8. Take part in activities that help you achieve an important personal goal?	1	2	3	4
9. Take part in activities in which you use skills or talents that are important to you?	1	2	3	4
10. Take part in activities that contribute to the goals of a group in which you believe?	1	2	3	4

## CMHEI - Coping Questions

ID: 

--	--	--	--	--	--	--	--	--	--

Date (mm/dd/yy): 

		/			/		
--	--	---	--	--	---	--	--

Person Completing Form: 

--	--	--	--	--

Indicate Period:  Baseline  Follow-up 3  
 Follow-up 1  Follow-up 4  
 Follow-up 2

People often experience things in their life that are upsetting or stressful. I'd like to ask you a few questions about what you do to try to feel better or handle situations in your life which are upsetting. **In the past month, how often have you used each of the following strategies in helping you deal with upsetting situations?**

	not at all 1	rarely 2	sometimes 3	often 4
1. I went on as if nothing had happened.				
2. I just concentrated on what I had to do next - the next step.				
3. I talked to someone to find out more about the situation.				
4. I tried to make myself feel better by eating, drinking, smoking, using drugs or medication, or that sort of thing.				
5. I tried to forget the whole thing.				
6. I made a plan of action and followed it.				
7. I talked to someone who could do something concrete about the problem.				
8. I avoided being with people in general.				
9. I didn't let it get to me; I refused to think too much about it.				
10. I asked a relative or friend I respected for advice.				
11. I wished that the situation would go away or somehow be over with.				
12. I made light of the situation. I refused to get too serious about it.				
13. I changed something so that things would turn out alright.				
14. I talked to someone about how I was feeling.				
15. I fantasized or wished about how things could turn out.				
16. I tried to make myself feel better by taking natural medications.				
17. I used other strategies _____ (describe)				

**How well are you coping with life's problems?**

0            1            2            3            4            5            6            7            8

Not  
at all

A  
little

Somewhat

Very  
well

Extremely  
well

## CMHEI – Ending the Interview

ID: 

--	--	--	--	--	--	--	--	--	--

Date (mm/dd/yy): 

		/			/		
--	--	---	--	--	---	--	--

Person Completing  
Form: 

--	--	--	--	--

Indicate Period:  Baseline  Follow-up 3  
 Follow-up 1  Follow-up 4  
 Follow-up 2

1. What did you think about the interview?

---

---

---

2. Did you feel comfortable doing this interview?

---

---

---

3. Is there anything we can do to improve the interview?

---

---

---

4. Is there anything that we have not covered that you think is important for me to know about how you have been feeling or getting along in the community?

---

---

---

5. Do you have any questions of me?

---

---

---

**Thanks very much for participating in this interview. I appreciate your willingness to participate in this interview.**

# **Appendix C**

## **Participant Tracking Form**

# CMHEI - Bi-Monthly Participant Tracking Form

Contact  
CSI  
pg 1/1

ID: 

--	--	--	--	--	--	--	--	--	--

From: (mm/dd/yy): 

--	--

 / 

--	--

 / 

--	--

To: (mm/dd/yy): 

--	--

 / 

--	--

 / 

--	--

Site/Researcher Code: 

--	--	--	--	--	--

During the last 2 months, how much time in total did you spend doing CSI activities (*in minutes*)? 

--	--	--	--

Total number of times attended in the *past 2 months*. 

--	--	--

33727



CSI Activity Area - During the last 2 months	Fill in all circles that apply	How much time ( <i>in minutes</i> )?	How many times?	CSI Activity Area - During the last 2 months	Fill in all circles that apply	How much time ( <i>in minutes</i> )?	How many times?								
<b>Membership/Volunteer/ Staff Development</b>	Attended general membership meetings	<input type="radio"/>	<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>					<b>Public Education</b>	Organized/attended a CSI public education event	<input type="radio"/>	<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>				
	Dropped in to the resource centre	<input type="radio"/>	<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>						Helped with the latest Newsletter issue	<input type="radio"/>	<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>				
	Participated on internal CSI committee(s)	<input type="radio"/>	<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>						Volunteered at resource centre	<input type="radio"/>	<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>				
Participated in volunteer/staff training	<input type="radio"/>	<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>					Made media presentations/wrote media articles	<input type="radio"/>	<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>						
Attended a CSI discussion group or forum	<input type="radio"/>	<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>					<b>Political Advocacy</b>	Organized/attended a CSI political advocacy initiative	<input type="radio"/>	<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>					
Attended an educational conference organized for CSI members	<input type="radio"/>	<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>					Attended CSI advocacy committee meetings	<input type="radio"/>	<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>						
Attended an external conference/event supported by the CSI	<input type="radio"/>	<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>					Collected policy information	<input type="radio"/>	<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>						
Carried out other volunteer work within the CSI	<input type="radio"/>	<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>					<b>Community Planning</b>	Represented CSI on community board/committee	<input type="radio"/>	<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>					
Attended volunteer recognition event	<input type="radio"/>	<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>					Made CSI presentation to local service providers	<input type="radio"/>	<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>						
<b>Social and Recreational</b>	Organized/attended CSI event	<input type="radio"/>	<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>					<b>Research</b>	Involved as a participant in another CSI internal research project	<input type="radio"/>	<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>				
<b>Self-Help Support Groups</b>	Facilitated CSI support group(s)	<input type="radio"/>	<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>						Received training as a volunteer researcher	<input type="radio"/>	<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>				
Attended CSI support group(s)	<input type="radio"/>	<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>					Gathered information in a CSI internal research project	<input type="radio"/>	<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>						
<b>Alternative/Complimentary Practices</b>	Attended music therapy, art therapy	<input type="radio"/>	<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>					Helped write/present research findings	<input type="radio"/>	<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>					
Participated in community kitchen	<input type="radio"/>	<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>					<b>One-to-One Peer Support</b>	Received staff peer support	<input type="radio"/>	<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>					
<b>Economic Development</b>	Received employment support	<input type="radio"/>	<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>					Attended volunteer peer support training group	<input type="radio"/>	<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>					
Received self-employment support	<input type="radio"/>	<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>					Offered in-office peer support to another CSI member	<input type="radio"/>	<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>						
<b>Other activities (please specify)</b>			<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>					Supported another CSI member in hospital or community setting	<input type="radio"/>	<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>					
		<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>							<table border="1" style="width: 40px; height: 20px;"><tr><td></td><td></td><td></td><td></td></tr></table>						

Enter 9's in boxes if value is unknown

Enter 9's in boxes if value is unknown

Shade circles like this:   
Not like this:

33727



## **Appendix D**

# **Qualitative Interview Guides for Personal Changes**

## **Baseline Qualitative Interview Guide for Personal Impacts**

The purpose of this interview is for you to tell your story about your personal growth and what has affected your personal growth. The interview should not last more than 90 minutes. We can take a break if you wish. With your permission, I will be tape-recording the interview. Please be aware that your participation in the study is completely voluntary. You are free not to participate, to withdraw your participation at any time, and to not answer any questions which you do not wish to answer. Furthermore, your decision to participate or not participate will not affect the services or support you receive. We will hold everything that you say in confidence.

After the interview is completed, we will provide you with a typed copy of the interview transcript and a short summary which you can correct or edit and return to me. The transcription of the interview will be identified by code number and stored in a locked filing cabinet to protect the confidentiality of your responses. Please note that your name will not be associated in any way with your responses. You will receive a written summary about the research findings when the research is completed. Do you have any questions before we get started?

1. What was your life like when you first experienced mental health problems?
2. What experiences have you had with services supporting you regarding mental health issues?
3. Thinking back to the time of your baseline interview (indicate month of interview), what was a typical day in your life like?
4. I am now going to ask you a number of questions about personal changes that you have experienced in a number of areas and things that helped or hindered such changes. I want you to focus on the nine-month time period prior to your baseline interview. For you, this would be the time period starting in (give month and year) and ending (give month and year). Please try to focus on this time period in your answers. What changes happened in your personal life during this time period?
  - A. What changes, if any, did you experience in terms of power and control over your life during this time period? What helped to bring about these changes? What hindered change?
  - B. What changes, if any, did you experience in terms of your health and/or mental health during this time period? What helped to bring about these changes? What hindered change?
  - C. What changes, if any, did you experience in terms of your relationships with other people during this time period? What helped to bring about these changes? What hindered change?
  - D. What changes, if any, did you experience in terms of your participation in community settings (e.g., church, clubs, recreation) during this time period? What helped to bring about these

changes? What hindered change?

E. What changes, if any, did you experience in terms of work (volunteer and/or paid employment) during this time period? What helped to bring about these changes? What hindered change?

F. What changes, if any, did you experience in terms of education and training during this time period? What helped to bring about these changes? What hindered change?

G. What changes, if any, did you experience in terms of your housing during this time period? What helped to bring about these changes? What hindered change?

H. What changes, if any, did you experience in terms of income during this time period? What helped to bring about these changes? What hindered change?

I. What other changes, either positive or negative, did you experience during this time period? What helped to bring about these changes? What hindered change?

5. Is there anything that we have not covered that you think is important for me to know about how you have experienced this research?

6. What did you think about the interview?

7. Did you feel comfortable doing this interview?

8. Is there anything we can do to improve the interview?

9. Do you have any questions about the study?

Thank you very much for participating in this interview. I appreciate your willingness to take part in this interview.

## **Qualitative Interview Guide for Personal Impacts 9 Month and 18 Month Interviews**

The purpose of this interview is for you to tell your story about your personal growth and what has affected your personal growth. The interview should last about 90 minutes. We can take a break if you wish. With your permission, I will be tape-recording the interview. Please be aware that your participation in the study is completely voluntary. You are free not to participate, to withdraw your participation at any time, and to not answer any questions which you do not wish to answer. Furthermore, your decision to participate or not participate will not affect the services or support you receive. We will hold everything that you say in confidence.

After the interview is completed, we will provide you with a typed copy of the interview transcript and a short summary which you can correct or edit and return to me. The transcription of the interview will be identified by code number and stored in a locked filing cabinet to protect the confidentiality of your responses. Please note that your name will not be associated in any way with your responses. You will receive a written summary about the research findings when the research is completed. Are there any questions before we get started?

### A. Initial Involvement with CSI (to be asked of CSI members only at 9 month follow-up interview)

1. When and how did you first hear about this CSI (Consumer/Survivor Initiative of Niagara, Hamilton Mental Health Rights Coalition, or Waterloo Region Self Help)?
2. What was it like when you first got involved with this CSI (Consumer/Survivor Initiative of Niagara, Hamilton Mental Health Rights Coalition, or Waterloo Region Self Help)? (to be asked of CSI members only)
3. Why did you decide not to get involved or not to participate regularly in the CSI (Consumer/Survivor Initiative of Niagara, Hamilton Mental Health Rights Coalition, or Waterloo Region Self Help)? (to be asked of CSI non-members only)

### B. Types of Involvement, Relationships, Satisfying Experiences, and Challenges with the CSI (to be asked of CSI members only at 9 and 18 month follow-up interviews)

1. What kinds of things have you done with this CSI (Consumer/Survivor Initiative of Niagara, Hamilton Mental Health Rights Coalition, or Waterloo Region Self Help)?
2. What have your relationships been like with people (staff, volunteers, peers) in this CSI (Consumer/Survivor Initiative of Niagara, Hamilton Mental Health Rights Coalition, or Waterloo Region Self Help)?

3. What kinds of things have been particularly satisfying, meaningful, or rewarding for you about your participation in this CSI (Consumer/Survivor Initiative of Niagara, Hamilton Mental Health Rights Coalition, or Waterloo Region Self Help)?

4. What kinds of things have been personally difficult and/or challenging about your participation in this CSI (Consumer/Survivor Initiative of Niagara, Hamilton Mental Health Rights Coalition, or Waterloo Region Self Help)?

C. Personal Impacts Associated with Participation in a CSI (to be asked at 9 and 18 month follow-up interviews)

1. In general in the past month, what is a typical day in your life like?

2. What difference has this CSI (Consumer/Survivor Initiative of Niagara, Hamilton Mental Health Rights Coalition, or Waterloo Region Self Help) made in your life? (How do you think your life would be different if you had not gotten involved with this organization?) If you have experienced changes, what do you think helped to bring about these changes? (to be asked of CSI members only at 9 and 18 month follow-up interviews)

3. I am now going to ask you a number of questions about personal changes that you have experienced in a number of areas and things that helped or hindered such changes. I want you to focus on the nine-months since your last interview. For you, this would be the time period starting in (give month and year) and ending (give month and year). Please try to focus your answers to that time. What changes happened in your personal life during this time period?

A. What changes, if any, did you experience in terms of power and control over your life during this time period? What helped to bring about these changes? What hindered change?

B. What changes, if any, did you experience in terms of your health and/or mental health during this time period? What helped to bring about these changes? What hindered change?

C. What changes, if any, did you experience in terms of your relationships with other people during this time period? What helped to bring about these changes? What hindered change?

D. What changes, if any, did you experience in terms of your participation in community settings (e.g., church, clubs, recreation) during this time period? What helped to bring about these changes? What hindered change?

E. What changes, if any, did you experience in terms of work (volunteer and/or paid employment) during this time period? What helped to bring about these changes? What hindered change?

F. What changes, if any, did you experience in terms of education and training during this

time period? What helped to bring about these changes? What hindered change?

G. What changes, if any, did you experience in terms of your housing during this time period? What helped to bring about these changes? What hindered change?

H. What changes, if any, did you experience in terms of income during this time period? What helped to bring about these changes? What hindered change?

I. What other changes, either positive or negative, did you experience during this time period? What helped to bring about these changes? What hindered change?

#### D. Ending the Interview

1. Do you have anything else to say about this CSI (Consumer/Survivor Initiative of Niagara, Hamilton Mental Health Rights Coalition, or Waterloo Region Self Help) that you have not already said? (to be asked of CSI members only at the 9 and 18 month follow-up interviews)

2. Is there anything that we have not covered that you think is important for me to know about how you have been feeling or getting along in the community?

3. What did you think about the interview?

4. Did you feel comfortable doing this interview?

5. Is there anything we can do to improve the interview?

6. Do you have any questions of me?

Thank you very much for participating in this interview. I appreciate your willingness to take part in this interview.

# **Appendix E**

## **Keeping in Touch**

**INFORMATION SHEET:  
IMPORTANCE OF KEEPING IN TOUCH**

This research involves interviews with people every 6-months over a period of 2-years. By following people who have received treatment for mental health problems for 2 years, we will see how well consumer/survivor initiatives and other community supports are working. Therefore it is important that we keep in touch with you over the next 2 years to see if you are still willing to continue with your participation in the research.

One of the ways that would really help us stay in touch if you move or change your phone number, is that you could let us know. So here is a fridge magnet with the telephone number (519-741-1318) of the Centre for Research and Education in Human Services on it. If you know you are moving or change your telephone number, I would really appreciate you giving the Centre a call. Or you can use this prepaid change of address card if you move. Some people find it handy to keep this card on their fridge with our magnet.

Another way for us to find you if you move and we haven't heard from you is to contact a close friend or relative. So I will be asking you for some people that we could contact if you move. You have the right to decide which people we can contact. We will not contact anyone without your permission. Here are magnets and change of address cards for those who are your additional contacts.

Because your participation is important to our research and change of address cards will help us keep in touch, we plan to thank you for mailing the card to us. The card will let us know your new address and phone number.

Again, all the information you provide will be kept confidential and will be stored in a locked cabinet. Only the research staff will have access to this stored information and nothing you say will be passed on to anyone outside the research staff. If you change your mind about who we can contact, please give us a call at the Centre for Research and Education in Human Services.

## Consent to Contact

I have received a copy of the **INFORMATION SHEET: IMPORTANCE OF KEEPING IN TOUCH**. I have read it or had it read to me and understand it. I understand that a researcher will want to contact me on a regular basis over the next 2 years to see if I would be willing to continue my participation in this research. In order to help the researcher find me if I do move, I agree that s/he can contact the following:

	Yes	No	N/A
- friend (Q.#5 on information sheet)	+), )-	+), )-	+), )-
- relative (Q.#6 on family information sheet)	+), )-	+), )-	+), )-
- partner (Q.#5 on family information sheet)	+), )-	+), )-	+), )-
- consumer/survivor initiative or other program staff (Q. # 11 on family information sheet)	+), )-	+), )-	+), )-

I understand that the researcher will not share my new address or telephone number with anyone outside of the research team.

Date: \_\_\_\_\_

Name: \_\_\_\_\_  
(please print name)

\_\_\_\_\_  
(signature)

I have discussed the **INFORMATION SHEET: IMPORTANCE OF KEEPING IN TOUCH** and this **Consent to Contact** form with this participant and believe that s/he understands the purpose of these documents and the information contained in them.

Interviewer: \_\_\_\_\_  
(please print name)

\_\_\_\_\_

\_\_\_\_\_  
(signature)

### Keeping in Touch Information Sheet

**Note to Interviewer:** Only ask for information that Respondent has agreed to let us use in "Consent to Contact" form.

1. What is your full name? Just to make sure that I have the correct spelling, would you mind spelling it out for me?

\_\_\_\_\_  
first name

\_\_\_\_\_  
middle name

\_\_\_\_\_  
last name

2. What name do you usually go by?

\_\_\_ same as name in Q.1

or different name \_\_\_\_\_

3. What is your home address?  
(Note to interviewer: only ask the R this question if you do not know his/her home address. If you do know, record this information and go to Q.4)

\_\_\_\_\_  
apt #/ street name

\_\_\_\_\_  
city

\_\_\_\_\_  
province

\_\_\_\_\_  
postal code

4. What is your home telephone number (if applicable)? \_\_\_\_\_

What is the best time of day to reach you?  
\_\_\_\_\_

**Keeping in Touch Information Sheet**

5. **What is a name, address and phone number of a friend we could contact if you moved? This friend should not be currently living with you because if you move they might move with you, and we couldn't contact you or your friend. Please spell the name and give an initial.**

\_\_\_\_\_

**friend's first/last name**

\_\_\_\_\_

**home address**

\_\_\_\_\_

**telephone no.**

\_\_\_\_\_

**best time of day to reach this person**

6. **What is a name, address and phone number of a relative we could contact if you moved? Again, this person should not be currently living with you.**

\_\_\_\_\_

**relative's first/last name**

\_\_\_\_\_

**home address**

\_\_\_\_\_

**telephone no.**

\_\_\_\_\_

**relationship to respondent (e.g., mother, aunt, cousin, child [18 years of age of older])**

\_\_\_\_\_

**best time of day to reach this person**

**Note to Interviewer: PLEASE SAY THE FOLLOWING TO R:**

***Could you please let (name of friend) and (name of relative) know that you have given me their names and that I may be contacting them if you move to find out your new address. Here is a card and fridge magnet for you to give (name of friend) and (name of relative).***

**Note to Interviewer: Skip Questions 8 to 11 if R does not currently have a partner.**

7. **What is your partner's full name? Just to make sure that I have the correct spelling, would you mind spelling it out for me?**

\_\_\_\_\_

**first name**

\_\_\_\_\_

**middle name**

\_\_\_\_\_

**last name**

**Keeping in Touch Information Sheet**

**8. What name does your partner usually go by?**

same as name in Q.7

or different name \_\_\_\_\_

**9. What is your partner's home address?**

same as Respondent's

or different home address:

\_\_\_\_\_

apt #/ street name

\_\_\_\_\_

city

\_\_\_\_\_

province

\_\_\_\_\_

postal code

**10. What is your partner's home telephone number (if applicable)?**

same as Respondent's

or different home phone: \_\_\_\_\_

**11. What is a name, address and phone number of a staff member from the consumer/survivor initiative or another program in which you participate that we could contact if you moved? Please spell the name and give an initial.**

\_\_\_\_\_

person's first/last name

\_\_\_\_\_

home address

\_\_\_\_\_

telephone no.

\_\_\_\_\_

best time of day to reach this person

**12. Would it be alright if I phoned you every 2 months to keep in touch with you to see how you are getting along?**

no

yes

**Keeping in Touch Information Sheet**

**13. Do you have any plans to move in the next year?**

\_\_\_ no

\_\_\_ yes

**If yes, where will you be moving? (if R not sure, try to get at least the name of the city)**

\_\_\_\_\_

**street address**

**city**

**province**

**14. Do you have plans to change your name in the next year?**

\_\_\_ no

\_\_\_ yes, if yes

**What will your new name be? \_\_\_\_\_**

**first**

**middle**

**last**

## **METHODS FOR KEEPING IN TOUCH WITH RESEARCH PARTICIPANTS: A REVIEW OF STRATEGIES**

The research has two major challenges: 1) to maintain the participation of individuals who have agreed to participate in the baseline interview and 2) to find participants who have moved.

### **Strategies for Keeping Individuals Involved in the Research**

- ! Whenever possible, use the same interviewer (Research Assistant) from one interview to the next in order to build and maintain a relationship with the individual.
- ! Individuals are paid \$10 for each interview he/she completes.
- ! After each interview, the Research Assistant sends the participant a Thank You card.
- ! Provide each participant with a fridge magnet with the name and phone number of the Centre for Research and Education in Human Services. Ask each participant to phone the Research Assistant to notify him/her if he/she moves.
- ! The Research Assistants send each participant a birthday card each year.
- ! The Research Assistants send each participant a season's greeting card each year.
- ! At every contact, the Research Assistants provides each participant with a prepaid change of address card to mail in case he/she moves.
- ! At the end of the baseline interview, ask each participant a series of questions about who we can contact in case he/she moves and we can't find him/her. Also, ask if the participant plans to move and where that might be or change their name and what the name will be in the near future
- ! Research Assistants are to phone each participant every 2 months to keep in touch, if the participant agrees to this.
- ! The Research Assistants are to provide each participant with the annual progress report on the research, which summarizes the main findings.

### **Strategies for Finding Individuals Involved in the Research Who Have Moved**

- ! Research Assistants are to complete the Keeping in Touch Information Sheet at the end of the baseline interview.
- ! At follow-up interviews, Research Assistants should check to see that all the information on the Keeping in Touch Information Sheet is accurate and up-to-date.

- ! During the baseline interview, Research Assistants are to ask the participant to give fridge magnets to each person on their Consent to Contact sheet.
  
- ! Whenever a card (birthday, season's greeting) is sent back because the person no longer lives there, Research Assistants are to start using these procedures to locate the person immediately. It may be easier to find people a couple of months after they have moved, instead of 6 months.

# **Appendix F**

## **Systems Tracking Log**

# Consumer/Survivor Initiative Log

## Systems-Level Activities and Outcomes

Name of CSI \_\_\_\_\_ Completed for the month of \_\_\_\_\_

Complete one row of the log for each activity (use back of page if needed)

Type of activity (Check one option for each row)	Date of activity	Action (what was done?)	To whom was the activity directed?	# of staff involved	# of CSI members involved	Where was activity held?	What outcomes, if any, were observed as a result of the activity?
<input type="checkbox"/> Public education  <input type="checkbox"/> Political advocacy  <input type="checkbox"/> Community planning  <input type="checkbox"/> Action research							
<input type="checkbox"/> Public education  <input type="checkbox"/> Political advocacy  <input type="checkbox"/> Community planning  <input type="checkbox"/> Action research							
<input type="checkbox"/> Public education  <input type="checkbox"/> Political advocacy  <input type="checkbox"/> Community planning  <input type="checkbox"/> Action research							



Centre for Research & Education in Human Services

**Appendix G**

**Interview Guide for**

**Organizational Stories**

## Qualitative Interview Guide for Organizational Stories

The purpose of this interview is to find out about how this Consumer/Survivor Initiative has developed over time. The interview should last about \_\_\_\_\_ minutes. We can take a break if you wish. With your permission, I will be tape-recording the interview. Please be aware that your participation in the study is completely voluntary. You are free not to participate, to withdraw your participation at any time, and to not answer any questions which you do not wish to answer. Furthermore, your decision to participate or not participate will not affect the services or support you receive. We will hold everything that you say in confidence.

After the interview is completed, we will provide you with a typed copy of the interview transcript and a short summary which you can correct or edit and return to me. The transcription of the interview will be identified by code number and stored in a locked filing cabinet to protect the confidentiality of your responses. Please note that your name will not be associated in any way with your responses. You will receive a written summary about the research findings when the research is completed. Are there any questions before we get started?

### A. Planning the CSI

1. Please describe what it was like when the plans for the CSI were first made. When did the planning happen?
2. What were some of the important work tasks during the planning of the CSI?
3. What values guided the work? What were the key processes or relationships among consumer/survivors that were important during the planning of the CSI?
4. What other systems were you involved with in planning the CSI (e.g., Ministry of Health, local mental health agencies, District Health Council)? What were your interactions and relationships like with these systems?
5. What kinds of things were particularly satisfying, meaningful, or rewarding during the planning of the CSI?
6. What kinds of things were particularly difficult or challenging during the planning of the CSI?
7. What were the critical issues during the planning of the CSI?

### B. Building the CSI

1. Please describe what it was like after the funding for the CSI was announced.

2. What were some of the important work tasks during the early building of the CSI?
3. What values guided the work? What were the key processes or relationships among consumer/survivors that were important during the early building of the CSI?
4. What other systems were you involved with in the early building of the CSI (e.g., Ministry of Health, local mental health agencies, District Health Council)? What were your interactions and relationships like with these systems?
5. What kinds of things were particularly satisfying, meaningful, or rewarding during the early building of the CSI?
6. What kinds of things were particularly difficult or challenging during the early building of the CSI?
7. What were the critical issues during the early building of the CSI?

### C. Stabilizing the CSI

1. Please describe what it has been like in more recent years at the CSI.
2. What have been some of the important work tasks in more recent years at the CSI?
3. What values have guided the more recent work of the CSI? What are some of the key processes or relationships among consumer/survivors that have been important in more recent years at the CSI?
4. What other systems have you been involved with in more recent years at the CSI (e.g., Ministry of Health, local mental health agencies, District Health Council)? What have your interactions and relationships been like with these systems?
5. What kinds of things have been particularly satisfying, meaningful, or rewarding during recent years of the CSI?
6. What kinds of things have been particularly difficult or challenging during recent years of this CSI?
5. What have been the critical issues during more recent years at the CSI?

Are there any other important aspects about the history or development of the CSI that we have not touched on in this interview? If so, please describe these.

Thank you very much for participating in this interview. I appreciate your willingness to take

part in this interview.

**Appendix H**

**Interview Guide for**

**Systems-Level Impacts**

**and Activities**

## **Qualitative Interview Guide for Systems-Level Activities and Impacts**

The purpose of this interview is to find out about how the systems-level activities and impacts in which this Consumer/Survivor Initiative has been involved. The interview should last about \_\_\_\_\_ minutes. We can take a break if you wish. With your permission, I will be tape-recording the interview. Please be aware that your participation in the study is completely voluntary. You are free not to participate, to withdraw your participation at any time, and to not answer any questions which you do not wish to answer. We will hold everything that you say in confidence.

After the interview is completed, we will provide you with a typed copy of the interview transcript and a short summary which you can correct or edit and return to me. The transcription of the interview will be identified by code number and stored in a locked filing cabinet to protect the confidentiality of your responses. Please note that your name will not be associated in any way with your responses. You will receive a written summary about the research findings when the research is completed. Are there any questions before we get started?

### **A. Systems-Level Activities**

1. Please describe some of the activities in which the local consumer/survivor initiative has been involved in the community and in the province since its inception.
2. What are some of the educational activities that the local consumer/survivor initiative has undertaken?
3. What are some of the advocacy activities that the local consumer/survivor initiative has undertaken?
4. What are some of the ways in which the local consumer/survivor initiative has participated in the mental health community in this region?
5. What are some of the ways in which the local consumer/survivor initiative has participated in the mental health community at the provincial level? the national level?
6. How has the consumer/survivor initiative participated in the process of mental health reform in the province?

### **B. Systems-Level Impacts**

1. In your experience, what are some of the impacts or changes that you have seen resulting from the presence and activity of the local consumer/survivor initiative?
2. In your experience, what are some of the impacts of the local consumer/survivor initiative on

mainstream mental health agencies in the community?

3. In your experience, what are some of the impacts that the local consumer/survivor initiative has had on regional planning in mental health (e.g., District Health Council)

4. In your experience, what are some of the impacts that the local consumer/survivor initiative has had on the community of psychiatric consumer/survivors?

5. In your experience, what are some of the impacts that the local consumer/survivor initiative has had on the community at large?

6. In your experience, what are some of the impacts that the local consumer/survivor initiative has had on mental health policy reform at the provincial level? at the national level?

Are there any other important aspects about the systems-level activities and impacts of the local consumer/survivor initiative that we have not touched on in this interview? If so, please describe these.

Thank you very much for participating in this interview. I appreciate your willingness to take part in this interview.