

A Longitudinal Study of the Consumer/Survivor Initiatives in Ontario



The first independent study of Consumer/Survivor Initiatives done in Canada.

Progress Report

Summer 2001

The Ontario Ministry of Health established a Community Mental Health Evaluation Initiative (CMHEI) to fund research projects related to the following areas of mental health reform: 1) crisis intervention, 2) case management and support coordination, and 3) consumer/survivor and family initiatives. The funding is administered through the Ontario Mental Health Foundation (OMHF) and proposals were to be submitted by October 31, 1997. The study of Consumer/Survivor Initiatives (CSIs) is one of seven projects funded under the CMHEI.

Who are the Partners and How Did the Study Get Started



Marnie Shepherd, Coordinator of the Ontario Peer Development Initiative (formerly the Consumer/Survivor Development Initiative), John Trainor of the Centre for Addiction and Mental Health - Queen Street Division, and the staff of several CSIs met in February, 1997 to consider applying for this research funding when the call for proposals was released. There was agreement that a proposal for research with the CSIs should be developed and that Geoff Nelson of Wilfrid Laurier University and Joanna Ochocka of the Centre for Research and Education in Human Services should be invited to develop such a proposal. Another meeting was held in June, 1997, and it was agreed at that meeting that Marnie Shepherd, Geoff Nelson, Joanna Ochocka, and John Trainor, would take responsibility for developing the proposal with consultation from staff of CSIs. Katherine Boydell, formerly of the Centre for Addiction and Mental Health, and John Trainor developed a somewhat similar proposal for a study of family self-help initiatives.

A meeting with Marnie, Geoff, Joanna and staff

from several CSIs was held in August, 1997. This planning group reviewed the terms of reference of the "call for proposals" and discussed the potential risks and benefits of doing the research, what the focus of the research would be, how the partners would work together, and how the proposal would be developed. It was agreed that Geoff and Joanna would develop a proposal which would be reviewed by this planning group. Three more meetings were held in October with drafts of the proposal being presented. Staff of CSIs gave feedback on the drafts of the proposal and discussed key issues in the research. Letters of support from 17 CSIs were submitted with the final proposal just before the October 31, 1997 deadline.

In February, 1998, the partners heard that the review of the proposal was generally positive, but that a few concerns were raised. After reviewing this feedback, another meeting with CSIs was held regarding proposed responses to the reviews. The partners then submitted these changes to OMHF. After these changes were reviewed, the project was funded.

What is the Research Approach



A participatory and action-oriented approach to the research is used. Three CSIs from southwestern Ontario were initially selected for participation in the research: the Consumer/Survivor Initiative of Niagara, Hamilton Mental Health Rights Coalition, and Waterloo Region Self Help (WRSH). A fourth site, Cambridge Active Self Help (CASH), joined the project in January of 2000 because of difficulty recruiting enough participants from WRSH. CASH and WRSH are both located in Waterloo Region. The project is managed by Joanna Ochocka of the Centre for Research and Education in Human Services in Kitchener.

A Steering Committee composed of members of the participating CSIs (Judy Hoover and Shawn Lauzon from the Consumer/Survivor Initiative of Niagara, Deborah Sherman from Hamilton Mental Health Rights Coalition, Terry Dick and Alex Troeger from WRSH, Beth Shier from CASH, and Marnie Shepherd as Coordinator of the Ontario Peer Development Initiative), and the researchers (Geoff Nelson from Wilfrid Laurier

University, John Trainor from the Centre for Addiction and Mental Health, Joanna Ochocka and Rich Janzen from the Centre for Research and Education in Human Services) guide the research. This committee has met approximately every two months since September of 1998. This committee is chaired by Alex Troeger of WRSH.

Staff from the Centre for Research and Education and each of the CSIs hired consumer/survivor researchers for each of the 4 settings. These researchers are Jean Irish and Leah Sagloski for the Consumer/Survivor Initiative of Niagara, Robert Chapman for Hamilton Mental Health Rights Coalition, and Helmut Braun and Michelle Moziar for WRSH and CASH. The Research Team, which consists of Joanna and Rich from the Centre, Geoff, and the consumer/survivor researchers, meets every month or two months for communication, training, support, review of progress, and problem-solving.

Any time you join a group, you are in a better situation than you are on your own.

Participant

What Is the Focus of the Research



The purpose of the study is to evaluate changes that have occurred as a result of the creation of Consumer/Survivor Initiatives, and their effect on people (individual level) and their communities (systems level). The study focuses on both the personal growth of consumer/survivors and the impacts of the CSIs on social systems. Quantitative data consist of standardized measures of personal empowerment, social support, and quality of life.



Qualitative data are obtained from open-ended interview questions. The chart on page 9 of this report outlines the main components of the proposed research.



Research Focusing on the Personal Growth of Consumer/Survivors

I feel much better after having been through this interview..

Participant

Inviting people to participate

Two groups of consumer/survivors have been invited to participate in the research: new members of CSIs and non-members of CSIs. With their consent, these individuals participate in 3 interviews over a period of one and one-half years (a baseline interview and then follow-up interviews at 9 and 18 months). For new CSI members, the interviews take place within 2 months of them becoming involved in a CSI. All interviews have been conducted by consumer/survivor researchers and are strictly voluntary and confidential. Care has been taken to ensure that the interviews are not too long or burdensome for people, and that they do not appear to be clinical, so that people do not think they are being tested. Both the way the interviews are conducted and the questions asked have been designed to maximize each person's level of comfort. Individuals are reimbursed \$15 for each of the interviews that they complete. In between interviews, the researchers keep in touch with each participant every 2 months and ask them questions about their participation in the CSI.

The participants: People continuing and people who have dropped out

At this point in time, we have reached our goal of 155 participants for the baseline interview. There is a good balance between active and non-active participants (73 people are active in a CSI and 82 non-active). The numbers of

participants across sites are: 62 in Hamilton, 52 in Niagara, and 41 in Waterloo Region. A total of 26 participants who completed the baseline interview have discontinued their participation in the study: 17 from Hamilton, 3 from Niagara, and 6 from Waterloo Region. While the total number of discontinued participants who were active in a CSI (13) and inactive in a CSI (13) is equal across sites, it is notable that all but one of the active participants is from Hamilton. Also, 9 participants from Hamilton and one participant from Waterloo completed the 9-month interview. One reason for the higher rates of discontinuation in Hamilton compared to the other sites is that the Hamilton Mental Health Rights Coalition changed location in the summer of 1999, and 11 of the people who discontinued participation were interviewed in the spring and early summer before the move. Overall, the reasons for discontinuation are: move and/or unable to contact (16), stressful or time consuming issues (2), suspicions about the study (3), partner's disapproval of the study (2), difficulty answering questions (1), death (1), and unknown (1).

Quantitative interviews: Preliminary findings

The 155 participants complete interviews with questions that are answered with fixed-response answers that can be quantified. For example, participants are asked to make ratings about different aspects of social support, such as

...I'm starting to believe that I too can make a difference within myself. Whereas before I thought I was just the victim of circumstance.

Participant

whether they can rely on support from friends on a rating scale (strongly disagree, disagree, agree, or strongly agree). It is expected that participation in the CSIs will have positive impacts on these quantitative measures of consumer/survivors' personal empowerment, utilization of mental health care, social support, community integration, number of friends, access to valued resources (work, education, finances, housing), subjective distress, and life satisfaction. As of December 2000, there were 55 people who had completed both the baseline and 9-month interviews. Using a statistical analysis, there were no significant differences between people who are active in CSIs and people who do not participate in CSIs on any demographic variable (e.g., age) or any of the outcome measures at baseline. This means that the two groups are comparable, which is good. If the groups differed in some way, interpretation of positive findings would be more problematic.

The two groups (active vs. not active in CSIs) were compared on three measures of CSI participation: minutes of participation in the first 8 months, psychological attachment to the CSI (a 9-item questionnaire), and number of events attended. The two groups differ significantly on all three measures. The average amount of participation is 24 hours and 4 events for the active group, but there is wide variation in levels of participation. All of the measures of participation are related to one another, but the relationships are not perfect, indicating that each measure provides a somewhat different dimension of participation.

CSI participation (some or none) predicts symptoms. Symptom scores can range from 15 (low) to 75 (high). For those who are active in the CSIs, symptoms decrease significantly from baseline (35.8) to 9-month follow-up (31.9), while for those who do not participate in CSIs, symptoms increase from baseline (35.6) to 9-month follow-up(38.1).

CSI participation (some or none) is related to days of hospitalization. For those who are active in the CSIs, days of hospitalization decrease significantly from baseline (6.9 days) to 9-month follow-up (.7days), while for those who do not participate in CSIs, days of hospitalization do not decrease significantly from baseline (5.2 days) to 9-month follow-up (4.3 days). Psychological attachment to a CSI is related to number of friends at the 9-month follow-up, although this relationship is not quite statistically significant. For community integration, the number of minutes of CSI participation is inversely related to community integration. That is, the more time spent in a CSI, the less community integration. However, psychological attachment to a CSI is directly related to community integration: the more attachment, the more integration. These findings are not quite statistically significant. With the full sample, these trends which are not yet significant should be significant.

Statistical analysis of the data has thus far shown that CSI participation is not related to personal empowerment, social support, or quality of life at 9 months, after controlling for demographic and baseline levels of these measures.

I'm proud to be part of this project as it became clear that this was a pioneering, ground-breaking research project. No one else has studied consumer/survivor self help groups like this before. Our research could have positive consequences if it shows that self help groups are a good use of mental health dollars.

Participant

Qualitative interviews

To complement this quantitative information, the consumer/survivor researchers are collecting the stories of a sub-group of the larger sample (15 people active in CSIs and 15 people not active in CSIs) through qualitative interviews. The information obtained from qualitative interviews comes from people's words, not numbers.

Interviews are taped, transcribed, and then coded for themes with quotes to illustrate the themes. Qualitative interviews yield information that is deep, rich, and personal. Participants are asked what difference the CSIs or other influences have made in their lives (outcomes) and what factors (processes) contributed to those outcomes. These qualitative interviews are completed at roughly the same time intervals as the quantitative interviews (baseline, 9-month, 18-month). Again, participants are paid \$15 for each interview that they complete. At this point in time, baseline qualitative interviews have been completed with 26 participants (the goal is to have 30 participants) and 9-month and 18-month follow-up interviews are in progress. Analysis of these data is in the beginning stages.



Research Focusing on Systems Level Activities and Changes

Quantitative information on systems level activities and changes: Preliminary findings

A common tracking log for systems level activities and changes has been implemented by each of the CSIs participating in the research. This tracking log is completed on a monthly basis by CSI staff. Systems level activities include: 1) education of the public and professionals, 2) community planning, 3) advocacy, and 4) research. Potential areas of systems level changes include the following: 1) impacts/changes on mainstream mental health service organizations (e.g., more consumer/survivor participation on boards, staff, volunteer positions, changes in services or the way services are provided), 2) impacts/changes on mental health planning and policy (e.g., increased participation on District Health Councils), and 3) impacts/changes on community (e.g., increased involvement of consumer/survivors in community settings).

The most striking finding thus far is that community planning activities dominate in all four CSIs. This was true both in terms of having the most system level activities, as well as involving the most CSI staff and members in those types of activities. CSI of Niagara, in

community planning activities as a way to involve its members in helping to make a change in the local service system. Moreover, there seems to be two types of community planning activities: those that are one-time in nature (e.g., giving one time advice to organizations in how they could be more consumer/survivor sensitive) and, more frequently, ongoing commitments to meetings within a variety of community settings. Also, community planning activities vary in their function. Some activities are mutual information sharing opportunities among service-providers, while in others CSIs had an opportunity to shape, plan, or advise existing or new services. Community planning activities also vary in their content, with some focusing specifically on community mental health services, while in many other cases, CSIs actively provide input into a number of other human service sectors (e.g., employment, poverty, disabilities, youth, homelessness, psychiatric treatment, housing).

...my focus now isn't to hide from the world. It is to participate in the world...In the old days it was like everybody was forcing me out.

Participant

Public education and political advocacy activities were the next most common system level activities and involved the second highest

number of CSI staff and members. While Hamilton and Niagara tend to emphasize public education activities over advocacy, the opposite was true for both WRSH and CASH. There are a number of different types of public education activities, ranging from producing regular newsletters and presenting at community events to participating in annual public education events. Political advocacy activities include circulating petitions, making presentations of reports to local politicians, sitting on provincial policy advisory committees, meeting with local politicians, responding to policy positions of other organizations, and participating in consultations requested by the Ontario Ministry of Health and Long-term Care. Advocacy around Bill 68 was a theme of many advocacy events during this time period, but other issues were addressed as well, including transportation allowance, homelessness and housing, mandatory drug testing, psychiatric programs, and mental health reform.



The least common system level activity was action research. The CSIs in both Hamilton and Niagara are involved in the Therapeutic Relationships Project (or “Connections”). Hamilton has also been involved in a few other research projects (e.g., DHC survey, Employment Ventures, Bridges to Discharge at St. Joseph’s Hospital), while CASH participated in the “Explaining Outcomes” research project, which is one of the other CMHEI projects, and research on transportation access.

There are a small number of concrete outcomes noted by CSI staff when filling out the tracking log. When they were noted, it was not surprising that community planning outcomes are the most commonly reported. The observed

outcomes here are increased awareness of consumer/survivor perspectives in service delivery and planning. Outcomes resulting from political advocacy are similar. While advocacy efforts over the course of the year may not have directly changed legislation, CSI staff reported that policy-makers had an increased awareness of consumer/survivor perspectives on the topics under consideration. A good example of this was the advocacy done around Bill 68. The legislation was ultimately passed but CSIs seized the opportunity to politically mobilize around the bill and to express their positions on important issues facing consumer/survivors.

...because I cope as well as I do, it’s almost like I get penalized for it cause, um, nobody thinks I need any help. I’ve learned to be more...assertive, in saying “I need help.”
Participant

Qualitative interviews regarding systems level activities and changes and organizational stories

Qualitative focus group interviews have recently been completed with staff and members of the four CSIs and the Ontario Peer Development Initiative (the provincial support organization) regarding systems level activities and impacts. Over the summer of 2001, additional qualitative interviews will be conducted with professionals, planners, and policy-makers to inquire about their perceptions of activities and impacts that the CSI has had on the community. Barriers and limitations to systems reform and change will also be ascertained and documented, and recommendations for policy can be generated to overcome those barriers.



Qualitative interviews with key members of the 4 CSIs participating in the research and Ontario Peer Development Initiative will be conducted in the fall of 2001 to trace the growth and development of each CSI from the time each began operating to the present. A document which tells the story of each CSI, chronicling their 10-year (or longer) history, will be completed. Just as individuals have their stories, so too do each of the CSIs. This information will be useful to the settings in terms of providing a historical record of their evolution, as well as being instructive for policy-makers and consumer/survivors who are interested in starting similar settings in other jurisdictions.

...I reached out and went to various supports, therapy, and learned different ways of thinking that helped me to see things in a different light...it helped improve my mental health in that I don't have that real horrible agonizing depression that I did a year ago.

Participant

What is the Coordination Centre, Working Group, and Multi-site Study



As was noted at the beginning of this report, this study is one of several studies being funded under the CMHEI. A Coordination Centre for all funded projects is staffed by the Health Services Research and Consulting Unit of the Centre for Addiction and Mental Health - Clarke Institute Division. This Coordination Centre is processing all of the quantitative information and coordinating the information for a multi-site study. A Working Group of 3 representatives from each of the funded projects meets 2-4 times per year to collaborate with the Coordination Centre with regard to the multi-site study, to communicate information about this initiative to the mental health community, and to provide a forum for problem-solving research issues. Three of the funded projects are evaluating case management programs (in Toronto, Ottawa, and 4 sites in the Kingston-Brockville area): one project is studying family initiatives; one project is evaluating a crisis intervention service; and one study is examining

programs that explain positive outcomes for consumer/survivors. Each of the funded projects is using some common measures (e.g. empowerment, social support, health care utilization) during interviews with people at baseline, 9 months, and 18 months. This information will be used to answer several questions:

- 1) how do the different types of services/supports differ in terms of who they serve?**
- 2) how do the different types of services/supports differ in change over time in outcomes?**
- 3) how do the different types of services/supports differ in terms of costs (program costs, total mental health care costs, total health service costs) ?**
- 4) how does the cost-effectiveness differ among the services/supports?**



They Believe I Have the “Spirit of Mental Illness” Research with Heart

by Robert Chapman, Research Assistant - Hamilton Site

Jane (not her real name) disclosed to me at church that she had recently been diagnosed with bipolar depression. She knew I worked in the mental health field and felt safe to tell me as I had come to know her family over the years. Jane's family, and even I, knew something was wrong with her moods.

Seeking to recruit new participants for the CSI longitudinal study, I recognized there was a candidate before me. What's interesting is what Jane also expressed concern about. She told me that members of her well-intentioned, Christian family held strong religious views about people with mental illness. Having read a very resourceful book written by a consumer who is also involved in my study, I saw an opportunity to assist with some education. The vigilant stigma-buster in me saw a course of action to de-mystify mental illness in a direct personal way.

After Jane consented to be a participant in the study and the baseline protocol done, she gave me permission to give her Mom and Dad some literature. I had a couple of pages from the book in mind I wanted to photocopy. In the book there is a section addressing common myths such as: mental illness is caused by sin, demon possession, and that mental illness is a weakness. I wondered how I could pass these photocopied pages to Jane's Mom in a tactful, nonconfrontative, way.

I arranged to have Jane meet the author of the book at the office. It was a pleasure to see two things occur here - Jane, eager to learn yet scared, begin to find her way with someone who has "been there", and, the author shine as she felt purposeful in connecting and assisting young Jane. Here was peer support on the spot. I backed away without either of them noticing, leaving the rookie and the veteran to share together.

The next Sunday, I gently handed the photocopies to Jane's Mom saying that oftentimes when a member of the family is newly diagnosed the family needs education about what mental illness is and isn't. Receptive to this, she appeared pleased that I was part of this process to understand her daughter. Days later when I bumped into Jane's Mom, she told me she read the pages and thanked me for the information I passed along to her. I felt afterwards a warmth of good feeling that what I did went well. Jane, too, thanked me for helping to begin a change in the beliefs her parents had which until then presented a barrier to them understanding and supporting her. After a participant is involved in the study, it is interesting how, if at all, I may assist him or her. I may introduce the participant to another consumer at the CSI, a staff member, a peer support worker, a brochure, or direction to a community service. This is research with a heart.

Main Components of the Proposed Research

Type of Data	Process vs. Outcome	Level of Analysis	
		Personal	Systems
Quantitative	Process	Participation measures (amount of participation in different CSI activities, psychological attachment to the CSI) gathered through bi-monthly tracking and individual interviews with 2 groups of participants (75 members and 75 non-members of 4 CSIs) over time (baseline, 9-months, 18-months)	Tracking system implemented in 4 CSI organizations to monitor systems level activities and outcomes
	Outcome	Outcome measures (personal empowerment, utilization of mental health care, perceptions of social support and friendship networks, community integration, access to valued resources [work, education, finances, housing], subjective distress, and life satisfaction) gathered through individual interviews with 2 groups of participants (75 members and 75 non-members of 4 CSIs) over time (baseline, 9-months, 18-months)	Tracking system implemented in 4 CSI organizations to monitor systems level activities and outcomes
Qualitative	Process	Open-ended questions about factors that facilitate and inhibit personal growth gathered through individual interviews with 2 groups of participants (15 members and 15 non-members of 4 CSIs) over time (baseline, 9-months, 18-months)	Qualitative interviews with CSI key informants regarding systems-level activities and tasks, processes, systems interactions, and critical issues at different points in the development and evolution of 4 CSI organizations and the Ontario Peer Development Initiative at the provincial level
	Outcome	Open-ended questions about personal growth gathered through individual interviews with 2 groups of participants (15 members and 15 non-members of 3 CSIs) over time (baseline, 9-months, 18 months)	Qualitative interviews with CSI staff and members and other key informants regarding changes in mainstream mental health organizations, community changes, and social policy changes in the context of 4 CSI organizations and the Ontario Peer Development Initiative at the provincial level



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For further information about this project, please contact any of the following people:

Geoff Nelson, Principal Investigator
Psychology Department
Wilfrid Laurier University
Waterloo, ON N2L 3C5
Phone: 519-884-0710 (ext. 3314)
Email: gnelson@wlu.ca

Marnie Shepherd, Community Partner
Ontario Peer Development Initiative
2160 Yonge Street, 3rd Floor
Toronto, ON M4S 2Z3
Phone: 416-484-8785
Email: marnie@scdinit.on.ca

Joanna Ochocka, Project Manager or
Rich Janzen, Senior Researcher
Centre for Research and Education in Human
Services
26 College Street
Kitchener, ON N2G 4R3
Phone: 519-741-1318
Email: joanna@crehs.on.ca or
rich@crehs.on.ca

John Trainor, Co-investigator
Community Support and Research Unit
Centre for Addiction and Mental Health -
Queen Street Division
Administration Building, 2nd Floor
1001 Queen Street West
Toronto, ON M6J 1H4
Phone: 416-535-8501 (ext. 2071)
Email: jtrainor@camh.net

If you are interested in finding out more about Consumer/Survivor Initiatives and this study, we can and will do presentations. So please contact us at the addresses above for details!