

## Benefiting from Consumer/Survivor Participation

For the team of researchers conducting a five-year study of consumer/survivor initiatives (CSIs) in Ontario, the research method is inseparable from the aims of their study. Designed to evaluate the impact of CSIs on their members and their communities, A Longitudinal Study of the Consumer/Survivor Initiatives in Ontario involved psychiatric consumer/survivors both as research assistants and as members of the project steering committee.

The method is known as participatory action research (PAR), and the goal is to empower people who are traditionally the subjects of research. PAR involves people in researching their own situation and developing their own solutions. In so doing, PAR can help to achieve positive social change. PAR can also lead to much more accurate research results.

The study is a collaborative effort between four CSIs in the Central West region of Ontario — Cambridge Active Self Help, Consumer/Survivor Initiative of Niagara, Hamilton Mental Health Rights Coalition, Waterloo Region Self Help — and researchers at Wilfrid Laurier University (principal investigator, Dr. Geoff Nelson), the Centre for Research and Education in Human Services (project manager, Dr. Joanna Ochocka), the Centre for Addiction and Mental Health, and the Ontario Peer Development Initiative. Consumer/survivor representatives are also members of the steering committee that guides the project.

### What are consumer/survivor initiatives and how do they help?

CSIs are self-help/mutual aid organizations developed exclusively by and for people with serious mental illness. Activities include self-help and peer support, skill development, and artistic and cultural pursuits. When people participate in a CSI, their psychiatric symptoms are



Members of the CSI study team (l-r): Geoff Nelson, Deborah Sherman, Rich Janzen, and Alex Troeger

often reduced, according to preliminary findings from this study. Their quality of life improves, and they spend fewer days in hospital.

Participants also report more control over their mental health and more independence in terms of housing, finances, and employment. They report feeling more empowered and feeling supported by their CSI. On being a member of a CSI, one study participant commented, "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."

Beyond the individual improvements to health and well-being, CSIs benefit the system. Participants educate

the public and professionals about mental illness, get involved in community planning, and advocate for organizational, community and social change.

**Why should consumer/survivors participate in the research?**

Deeply entrenched stigma about mental illness contributes to low community integration, difficulty accessing housing, and high unemployment among consumer/survivors. PAR was designed for the study of oppressed communities, and so the researchers consider it to be well suited to the study of CSIs. Self-help/mutual aid organizations and PAR share core values

“ People don’t want to be research subjects or objects. They want research done with them, not on or to them.”

**DR. GEOFF NELSON,  
PRINCIPAL INVESTIGATOR**

— consumer empowerment, socially supportive relationships, inclusion, social justice, and a commitment to learning processes — and this commonality builds trust and creates a strong foundation for positive working relationships.

“People don’t want to be research subjects or objects,” explains Dr. Nelson. “They want research done *with* them, not *on* or *to* them.” PAR is a

model of research that gives participants ownership over the research, providing a sense of control and comfort. This is consistent with the general philosophy of CSIs, and makes participation in research more appealing. Consumers are sometimes wary of the motives of professionals. By fully involving participants in the process, however, their doubts can be overcome and they are more likely to respond openly to the researchers.

**What are the challenges of participatory action research?**

Several consumer/survivor research assistants in this study had social, personal, and health issues that sometimes interfered with their ability to work on the study, and investigators had to build a strong system of communication and support. In some cases, health issues resulted in hospitalization. Extra personal support, in the way of hospital visits, for example, became necessary to maintain the relationship between investigators and research assistants. Rather than being a hindrance to the research, this blurring of the line between work and personal life contributed to the close relationships that were essential to the participatory research process.

**How has the research community benefited from this study?**

Investigators in the CSI study have demonstrated that focusing on trust, honesty, respect, inclusion and participation is an effective approach. It serves the research, the researcher, and the community being studied. Trusting relationships were built among all involved — researchers, assistants, and participants — and as a result, participants were open and honest. Using PAR enabled the investigators to elicit better information and thus, better study results.

**How have these CSIs benefited from their participation?**

The four CSIs involved in this study have learned about the research process, raised awareness of their initiatives within their local communities, and gained new knowledge about their own organizations. For example, researchers developed a system tracking tool, a computer program to keep an inventory of CSI activities. Prior to this study, the participating CSIs had no way of mapping this information. Now, however, they can continue to use this tool and the information gleaned from it for their own advantage.

There were a number of benefits to the consumers who were hired as research assistants. Individuals obtained job experience and training they would not otherwise have received, and some have successfully moved on to other employment.

Their self-esteem improved, they learned new skills, and they were paid for their efforts. Study participants also reported that their interviews were personally fulfilling — they appreciated being heard and they felt respected, knowing that their opinions were valued.

Finally, this study is demonstrating that CSIs are of great value to consumer/survivors. These findings will help policymakers to determine how best to meet the needs of this population group, and will ultimately benefit CSIs and their members.

*For more information about this and other CMHEI studies, visit [www.ontario.cmha.ca/cmhei](http://www.ontario.cmha.ca/cmhei)*

“ Focusing on trust, honesty, respect, inclusion and participation is an effective approach. It serves the research, the researcher, and the community being studied.”

CMHEI

**About CMHEI**

Conceived by four partners – the Canadian Mental Health Association, Ontario, the Centre for Addiction and Mental Health, the Ministry of Health and Long-Term Care, and the Ontario Mental Health Foundation – the Community Mental Health Evaluation Initiative (CMHEI) is the first broad-scale, systematic assessment of the effectiveness of community-based mental health services in Ontario. The goal of the initiative is to research and advocate solutions for major issues and problems in the mental health arena. Funding support provided by the Ministry of Health and Long-Term Care is gratefully appreciated.

**Contact Information**

If you have questions or comments regarding this newsletter, or you would like to receive a copy of our next issue, please contact Susan Macartney at 416-977-5580 ext. 4122 or [smacartney@ontario.cmha.ca](mailto:smacartney@ontario.cmha.ca). To subscribe online, visit [www.ontario.cmha.ca/cmhei](http://www.ontario.cmha.ca/cmhei).