

# A Longitudinal Study of Consumer/Survivor Initiatives (CSIs) in Community Mental Health in Ontario: Individual-level and System-level Activities and Impacts – Fact Sheet

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## Consumer/Survivor Initiatives in Ontario: A Unique Component of the Mental Health System

- Consumer/Survivor Initiatives are self-help/mutual aid organizations that have been developed exclusively by and for people with mental health issues
- Consumer/Survivor Initiatives are not services, but rather supportive settings in which members create and operate self-help groups, one to one peer support, and a variety of other activities
- Consumer/Survivor Initiatives are guided by a set of values that include member empowerment, participation, social justice, and community
- First funded in 1991 by the province of Ontario, there are now over 50 Consumer/Survivor Initiatives in Ontario

## A Participatory Action Research Study with Four Consumer/Survivor Initiatives

- A collaborative study between 4 Consumer/Survivor Initiatives in southwestern Ontario (Cambridge Active Self Help, the Consumer/Survivor Initiative of Niagara, Mental Health Rights Coalition of Hamilton, Waterloo Region Self Help), the Ontario Peer Development Initiative (OPDI) and a group of researchers was conducted under the auspices of the Community Mental Health Evaluation Initiative (CMHEI)
- This research is funded by the Ontario Ministry of Health and Long-term Care (through the Ontario Mental Health Foundation) and the Canadian Institutes of Health Research from 1998-2004 and is managed by the Centre for Research and Education in Human Services
- The project is guided by a Steering Committee, which is composed of the research investigators, representatives of the 4 Consumer/Survivor Initiatives, and a representative from the Ontario Peer Development Initiative
- The Research Team included consumer/survivor researchers from each of the 4 Consumer/Survivor Initiative
- *The purpose of the research was to examine:*
  - (a) individual-level activities and impacts of the Consumer/Survivor Initiatives on new members and
  - (b) system-level activities and impacts related to systemic change

## Individual-level Activities and Impacts

- Participants who were active in the 4 Consumer/Survivor Initiatives had an average age of 39 years, 13 years of education, and an average monthly income of \$1400
- There were equal numbers of men and women; 80% were white; 79% were single, separated, divorced, or widowed; and the most frequent diagnoses were mood disorder (64%) and schizophrenia (33%)
- Most participants were taking psychotropic medication (90%); 75% had a therapist/case-worker; and 49% were involved with some other community mental health agency
- Consumer/Survivor Initiative participants averaged about 1 event and 2 hours of participation in a Consumer/Survivor Initiative per week
- Consumer/Survivor Initiative members participated in a number of ways: internal activities (32%), one to one peer support (25%), drop-in (20%), self-help groups (13%), and external activities (10%)
- 61 new Consumer/Survivor Initiative members and a comparison group of 57 people who were eligible to participate in but who were not active in Consumer/Survivor Initiatives were interviewed at baseline, 9, and 18 months
- The two groups were comparable at baseline on demographic variables, self-reported diagnosis, service use, and the outcome measures
- Relative to the comparison group, Consumer/Survivor Initiative members showed significantly greater reductions hospitalizations and symptom distress and significantly greater improvements in social support, quality of life (daily activities), and employment/education
- Qualitative data were gathered through in-depth, semi-structured interviews with 15 active Consumer/Survivor Initiative participants and a comparison group of 12 participants at baseline, 9, and 18-months
- The qualitative data showed that relative to the comparison group, active participants showed improved mental health, more social support and fewer relationship difficulties, and higher levels of employment, education, and income



## System-level Activities and Impacts

- Consumer/Survivor Initiatives also engage in activities to change communities and systems
- There are four main ways that Consumer/Survivor Initiatives do this: 1) public education, 2) political advocacy, 3) community planning, and 4) action research
- A quantitative tracking log showed that Consumer/Survivor Initiatives participated in a high number system-level activities over a 25-month period—665 events across 3 sites, involving 887 staff and 949 members
- Community planning was consistently the most common activity category across all sites
- However, sites did differ in the number of system level activities they were involved in, and how they balanced activities across the four main categories
- Qualitative data showed that there were two main types of impacts associated with system level activities: 1) changes in perceptions about mental health issues by service-providers, policy makers and the general public, and 2) concrete, tangible changes in service delivery practice, service planning, public policy or funding allocations
- Overall these findings demonstrate that Consumer/Survivor Initiatives are active participants in a variety of community partnerships
- Consequently, many benefits were seen as resulting from consumer/survivors from Consumer/Survivor Initiatives being “at the table” to plan and advocate for community services and supports
- The challenge lies in the minimal resources Consumer/Survivor Initiatives have to carry out these system level activities

## Recommendations

- There is a need for increased funding for Consumer/Survivor Initiatives within the overall mental health budget
- The capacities of Consumer/Survivor Initiatives needs to be strengthened through provincial and regional network building for Consumer/Survivor Initiatives
- Consumer/Survivor Initiatives should be enhanced and expanded
- Further research with Consumer/Survivor Initiatives is needed



*Steering Committee Members. Front Row (from left to right): Joanna Ochocka, Kristen Roderick, Rich Janzen, Lisa Gammage and Shawn Lauzon. Back row (left to right): Deborah Sherman, Geoff Nelson, John Trainor and Alex Troeger*

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