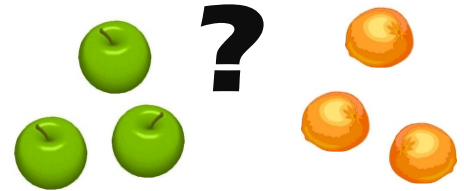


A Longitudinal Study of **Consumer/Survivor Initiatives** in **Community Mental Health** in Ontario

Summary Bulletin

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Consumer/Survivor Initiatives in Ontario **A Unique **Alternative** to the Mental Health System:**

Consumer/Survivor Initiatives (CSIs) are self-help/mutual aid organizations, and some small businesses, that have been developed exclusively by and for people with serious mental illness. CSIs are not services, but rather supportive settings that offer one or more of the following program activities: self-help and peer support groups, community-economic development, education and training for the public and mental health professionals, advocacy to create systems-level change, opportunities for consumer/survivors to develop their skills, the creation and distribution of resources based on consumer/survivor knowledge, and artistic and cultural activities. CSIs are guided by a set of values that include member empowerment and participation, social justice, sense of community and peer support, and mutual learning.

The Consumer/Survivor Development Initiative (CSDI), now called the Ontario Peer Development Initiative (OPDI), began in 1991 with funding from the Ontario Ministry of Health. Currently there are 74 funded CSIs across Ontario sharing a total budget of over \$5 million. CSIs have a distinct voice and provide a unique perspective on mental health and social issues.



A Participatory Action Research **Study with Four Consumer/Survivor Initiatives:**

A collaborative study between four CSIs (Cambridge Active Self Help, the Consumer/Survivor Initiative of Niagara, Hamilton Mental Health Rights Coalition, Waterloo Region Self Help), O.P.D.I. as the community partner, and a group of researchers is being conducted under the auspices of the Community Mental Health Evaluation Initiative. The purpose of this study is to evaluate the impacts of Consumer/Survivor Initiatives in Ontario on CSI members and communities. This research is funded by the Ontario Mental Health Foundation from 1998 to 2003 and is being 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, Board and staff representatives of the 4 CSIs, and the Coordinator from OPDI. The Research Team includes consumer/survivor researchers from each of the 4 CSIs. The four CSIs have a combined budget of \$640,000 and serve over 750 members.

Preliminary **Findings:**



The research examines both personal changes experienced by new CSI members and systems level change. At this point we have reached the goal of over 155 participants for the study. Both qualitative and quantitative data indicate that CSIs have positive impacts on members and the community. Preliminary analysis of the data from 66 participants who have completed baseline and 9-month follow-up interviews has shown that the number of contacts with a CSI is associated with fewer psychiatric symptoms, significantly greater personal empowerment and increased quality of life. Both CSI members and non-members experienced significantly fewer days in hospital from baseline to 9 months. These findings are echoed in the comments of CSI members who completed qualitative interviews. As one participant stated, "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."



Preliminary Findings Continued:

We have also found that in addition to providing supports to individuals, each of the 4 CSIs engages in a wide range of systems-level activities, including public education and relations, community planning and coordination, political advocacy, and action research. CSI members regularly combat stigma and negative media messages about people with mental illness and bring to attention employment and housing issues by speaking out on these issues in newspapers, on television and radio, and through other public presentations. More and more, CSIs are called upon to provide a "consumer/survivor voice" and perspective, not just on mental health issues, but on a variety of issues affecting marginalized people. CSI members can point to specific instances in which their participation in systems-level activity led to a significant change. One example is a CSI that successfully advocated for the allocation of new supportive housing units to be distributed to one part of a region that was underserved and lacking in supportive housing.

Cost-Effectiveness:



Compared to other institutional and community-based mental health services operated by professionals, CSIs are very inexpensive. As part of our study, we are collecting data on the costs of all health and social services used by CSI participants and non-participants. These cost data, along with the outcome data, will provide an estimate of the cost-effectiveness of CSIs.

Recommendations:

The importance of CSIs in a balanced mental health system has been underscored in provincial policy documents, including Putting People First (1993) and Making It Happen (1999). Moreover, the preliminary findings from this research suggest that CSIs have positive impacts on both individuals with serious mental illness and the communities and systems that serve people with serious mental illness. While CSIs are valuable, they are seriously under-resourced. Mental health services consume more than 99% of the mental health budget with less than 1 % going to CSIs. We recommend that the Mental Health Task Forces highlight the value of CSIs by calling for the Ontario Ministry of Health and Long-Term Care to allocate 5% of its mental health budget to CSI initiatives.

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