

CMHEI community mental health

EVALUATION INITIATIVE

Family Members Matter

Families make up the largest group of community caregivers for people with serious and persistent mental illness. They play an essential role in the community mental health system, yet very little research has been done to fully understand the nature and importance of their contribution. A Longitudinal Evaluation of Family Initiatives in Community Mental Health in Ontario is a five-year study that aims to fill part of this gap. Now in its final year, the study examines the impact of self-help/mutual aid organizations on families of people with mental illness and on the mental health system.

The study involves three partner organizations with a combined membership of approximately 1,800 people — Family Association for Mental Health Everywhere (FAME), Schizophrenia Society of Ontario (SSO Toronto), and Mood Disorders Association of Ontario (MDAO). Principal investigators are Katherine Boydell, Hospital for Sick Children (HSC), and John Trainor, Centre for Addiction and Mental Health (CAMH). The research coordinator is Darryle Jadaa, HSC and CAMH.

What are family self-help/mutual aid organizations?

Family self-help/mutual aid organizations provide a caring environment for people who have a relative diagnosed with a mental illness. They are established and administered by and for family members, to provide mutual support, education, and advocacy. Family members are encouraged to participate at all levels of the organization through positions such as executive director, board member, support group facilitator, and/or crisis line volunteer.

Why study support groups for family members who do not have a mental illness themselves?

The health care system in Ontario is operating under severe fiscal constraints. Hospital and other institutional services for the mentally ill have been reduced, resulting in a greater demand for community-based services. But funding



A Longitudinal Evaluation of Family Initiatives researchers (l-r): Katherine Boydell (Co-principal Investigator) and Darryle Jadaa (Research Coordinator)

for community mental health services has not grown to meet the demand.

Increasingly, families are relied upon to act as caregivers to their ill relatives. Research has shown that the role of caregiver places great emotional and psychological strain on family members. This burden can be especially great for caregivers of people with severe mental illness.

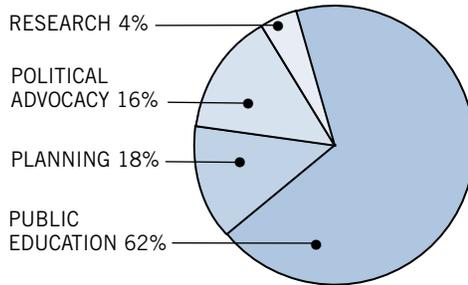
Studies such as the Longitudinal Evaluation of Family Initiatives are important because we need to learn more about ways to reduce the burden on family members. Understanding the needs and experiences of these essential caregivers, and recognizing the valuable part they play in planning services and advocating for the family, will ensure that their role is recognized and supported adequately. The health care system has begun to contribute limited funding to support family members, and research provides the evidence to assess how effective those funding dollars can be.



What do family self-help groups do in the community?

Family members interviewed for this study identify research and advocacy as important activities. Preliminary findings, however, indicate that more time is spent on public education and activities such as community planning.

The three participating family organizations were



Main activities of family self-help groups

tracked over a one-year period to measure their involvement with four main activities — public education, political advocacy, community planning, and research. Preliminary results are available for one organization, illustrated by the pie chart. Public education was the most frequent activity, with 71 events. There were also 20 community planning events, 18 political advocacy events, and 4 research events.

How often do people use family self-help groups?

A preliminary focus group indicated that patterns of use vary greatly among individual members. Many family members are very involved, attending their support groups regularly and providing support to the organization and its members on a daily basis. Others say that just knowing such a group exists helps them to feel better, even though they may not attend very often. Some family members use the group only when they are in crisis, while others, when in crisis, may feel overwhelmed and unable to reach out to the group for help. More research is being conducted on this topic.

How important are family self-help groups?

Family self-help groups rely on volunteer labour. One method of measuring the importance of these groups is by estimating the financial cost to the health care system if professionals were hired to do what family members are doing. Carolyn Dewa, a health economist at CAMH, is using this method to evaluate the contribution these self-help groups are making, in terms of cost-savings for the Ministry of Health and Long-Term Care.

Preliminary data show that a majority of active family members participate in providing education and community support, as well as performing many administrative tasks associated with that support. An early cost analysis indicates that the Ministry's modest investment in family self-help initiatives has reaped a significantly greater reward than the equivalent dollars would earn by funding professional services.

Enhancing family members' capacity

Research was an integral part of this study. The majority (75%) of the research assistants (RAs) were family members, recruited through ads and referrals from family organizations. They conducted extensive quantitative interviews with 279 family members at three points in time — baseline, 9 months, and 18 months. These structured interviews aimed to measure the subjects' experiences of coping, social support, burden, empowerment, and participation in the family organization.

Did research have any effect on research assistants?

In addition to conducting interviews, the RAs actively recruited subjects for the study by speaking at various support group meetings and seminars. The RAs reported that this employment opportunity had a profoundly positive effect on them. Working on the study gave them a reason to get out of the house and participate in the broader community. Learning how to successfully interview people instilled a sense of empowerment, and they felt less stigma by speaking out and recognizing that many people are dealing with the same issues. The experience altered their perception of themselves in relation to other family members, and they became more active with their own support group.

Working as paid researchers provided some financial support, but the experience also opened the door to future employment. Preliminary findings indicate that at least three or four RAs became employed full-time afterward.

A separate paper is being written about the impact of their involvement with the study. It will explore how the experience changed their worldview and influenced the way they interact with the system, with their support group, and with their relative who has a mental illness.

What other research has this project encouraged?

The Longitudinal Evaluation of Family Initiatives study has spawned several sub-studies. One examines stigma, using a quantitative scale to measure its extent, as well as qualitative methods (more in-depth interviews) to gather information from families about their experiences with stigma. Another sub-study is investigating the concept of hope, and how a family member's personal sense of hope can help to alleviate burden and improve coping. Further research will be needed to understand how the results might be generalized to include all participants in mental health self-help initiatives.

About CMHEI

The Community Mental Health Evaluation Initiative (CMHEI) is a provincial evaluation project conceived by the Ontario Mental Health Foundation, the Centre for Addiction and Mental Health, and the Canadian Mental Health Association, Ontario Division. 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. To subscribe online, visit www.ontario.cmha.ca/cmhei.