

Welcome to the fourth newsletter of the Community Mental Health Evaluation Initiative!

This multi-site study began in 1998 and is following over 800 consumers of mental health services and supports for a period of 18 months. It knits together six individual evaluation studies of intensive case management, assertive community treatment, crisis intervention, consumer and family initiatives. A seventh project is developing a tool to measure the critical ingredients of community support programs. All the programs are collecting a common set of information from participants, providing a unique opportunity to describe and compare consumers of very diverse services and supports. Our goal is to better understand who the programs are serving and their impact, and to compare the Ontario experience with other jurisdictions.

We are pleased that the Initiative has created a network of experienced researchers and community partners in Ontario. Consumers and family members have made valuable contributions in defining research questions, interviewing and assisting in the interpretation of findings. The Initiative is funded by the Ontario Ministry of Health and Long Term Care.

The CMHEI is entering an exciting period because data collection is almost complete and analyses have begun. Initiative researchers and their program partners met recently to share and discuss preliminary findings.

Overall, the evidence is consistent and positive, indicating that the investment in community mental

health programs is paying off for persons with serious and persistent mental illness, including those who are homeless.

Preliminary findings from across projects indicate that:

- Individuals using mental health services and supports are showing improvement in their community functioning, have decreased symptoms and use of substances, and are experiencing fewer crisis episodes and days in hospital.
- Because somewhat different populations are accessing and being helped by the different types of community mental health programs, maintaining a comprehensive range of options is essential for consumer choice.

- Consumers using these programs (both service and peer support) are living in impoverished circumstances. Most lack employment and are managing on inadequate incomes and social support.
- It is important not to underestimate the place of healthy communities and the basics of housing, income, medical and dental care in the well being of people with mental illness living in the community.

This newsletter briefly describes each project's main objective and selected emerging findings. Subsequent newsletters will highlight individual projects, providing more in-depth coverage about study methods and findings. ■

FEATURED INTERVIEW with Dr. Katherine Boydell, Family Study

Dr. Katherine Boydell is leading a project to examine the family member's role in the mental health system – both on a personal level and an organizational level. The team took a unique approach to their study by training and employing family members to be research assistants. Initially the recruitment process was difficult due to family member skepticism. Family members were frustrated that they had been interviewed by other teams so often and yet never saw the results of their work. The team have made knowledge transfer and family inclusion priorities in the study. They are currently involved with developing ideas about how to distribute information effectively to family members.

Dr. Katherine Boydell
Co-Principal Investigator,
"A Longitudinal Evaluation of Family Initiative in Community Mental Health in Ontario"



Dr. Boydell says the involvement of family members as research assistants has been very positive, not only for the study but for the members themselves – helping Katherine's team make sure they are gathering information that will be useful. Often family members give suggestions on how to improve questions, what questions would be more helpful, and what questions they feel are unnecessary. They have a few family members who are over the age of 65 and are excited about the contribution they are making at this stage in their lives.

Dr. Boydell's history with mental health research is extensive. She has covered adult, youth and presently, children's mental health. Her recent work at the Hospital for Sick Children makes her aware of the need for support groups for parents of young children with mental illness. She says that while the adult system has developed a strong support network, it is lacking in the children's system. We wish Dr. Boydell and her team continued success!



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A longitudinal evaluation of family initiatives

Central Ontario

Is participation in self-help/mutual aid organizations beneficial for family members of a relative with a diagnosis of mental illness? What is the experience of empowerment, coping, burden, hope, stigma, and social support for family members involved in a self-help/mutual aid group? These questions are the focus of this study of 279 family member participants. Family members have been a key resource in this project, conducting interviews and helping to shape the qualitative component.

Preliminary results show that families are involved in daily, ongoing supportive roles whether or not their ill relative lives with them. Many are benefiting from the support, education, and advocacy that self-help organizations provide, yet these programs are an unacknowledged and under-funded arm of the mental health system.

PARTICIPANT VOICE

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

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Explaining outcomes: Developing instruments to assess the critical characteristics of community support programs for people with severe mental illness

Provincial

The Explaining Outcomes Project is using both key informant interviews and a comprehensive review of the literature to identify the program elements that make a difference. Resulting feedback has been

incorporated into a series of tools that are being pilot tested in programs across the province. One consistent message is that program success is influenced by the broader system and community context, e.g. availability of jobs and housing. Another is that mental health service providers are eager for reflective self-evaluation tools that relate services provided to consumer outcomes.

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A randomized controlled trial of ACT and intensive case management in a Canadian inner city

Toronto

This study is comparing the impact of assertive community treatment and intensive case management on the lives of 80 individuals with severe and persistent mental illness in downtown Toronto.

Initial findings show that these programs can be implemented in the urban core of a city, and that clients with complex and challenging conditions can be retained in treatment. Both program approaches are showing success. In the first nine months of the study, clients in both programs experienced an improved level of overall functioning and reduced psychiatric symptoms. Hospital admission also dropped significantly.

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A longitudinal study of consumer/survivor initiatives

Central Ontario

This study examines both personal and system level changes resulting from participating in Consumer/Survivor Initiatives (CSIs). CSIs are self-help/mutual aid organizations, developed exclusively by and for people with serious mental illness. The Ontario Peer Development Initiatives is a partner in this study and currently oversees over 60 CSIs across Ontario.

Preliminary findings are positive. Data indicate that a higher number of contacts with CSIs are associated with fewer psychiatric symptoms, significantly greater personal empowerment and increased quality of life. In addition to facilitating individual improvements, CSI members engage in a wide range of system-level activities, including public education and relations, community planning and coordination, political advocacy, and action research. CSI members can point to specific instances in which their participation in systems-level activity led to a significant community change.

PARTICIPANT VOICE

No one else has studied consumer/survivor self help groups before. Our research could have positive consequences if it shows that self help groups are a good use of mental health dollars.

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Evaluation of crisis occurrence and resolution in persons with severe and persistent mental illness

Toronto

Does the intensity and type of community support affect crisis occurrence and resolution in clients with severe and persistent mental illness? This study compares the number of crises experienced and how they are resolved by looking more closely at the clients in the Wasylenki study (see page 2).

Preliminary findings show that clients in both programs experienced a reduction in Emergency Room (ER) visits and hospital admissions between the first and second 9 months of treatment. Their overall level of functioning at the start of the study was predictive of the number of ER visits and crises experienced in the first nine months, but their psychiatric symptoms at baseline were not.

PARTICIPANT VOICE

I like the fact that people listen to you when you talk, and if crises occur, they will be there at any time.

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Variations in assertive community treatment: A study of processes and outcomes of four teams

Southeastern Ontario

With four Assertive Community Treatment (ACT) teams operating in the Kingston area, this project has an opportunity to assess how differences in ACT service delivery affect client experiences and outcomes. Current program clients are being followed for

up to 18 months. This project also includes a participatory component where consumers decide the questions, conduct interviews and assist with analysis.

A particular interest in this study is the employment situation of consumers. Initial analyses show that the majority of clients are unemployed, yet only a small amount of time is devoted by ACT teams to providing vocational assistance. The low rates of employment do not appear to reflect a client's diagnosis, symptoms, length of hospitalization and/or education, suggesting that other community factors also play an important role. Feedback obtained through the qualitative component was very positive, with many clients attributing their ability to live in the community directly to ACT services.

PARTICIPANT VOICE

I really like [my worker]. When I'm down, she's able to pick me up and make me laugh. When I'm unsure, she's able to point out different things to me, whether I should or shouldn't do it.

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Evaluation of intensive case management for people who are homeless and mentally ill

Ottawa

Using a randomized controlled trial, this study defines the key elements and assesses the effectiveness of intensive case management (ICM) for people who are homeless and seriously mentally ill. A costing component is also included.

Initial analyses are showing that ICM is a specific, valid and effective service, even in early stages of treatment, assisting individuals to

improve in many areas. The total cost of maintaining an individual in the community is in the range of \$35,000 per year, with the majority of expenditures going towards medical and psychiatric services. Many clients do not receive education, employment, recreation and/or leisure services, despite the fact that these services would help people better integrate into the community.

PARTICIPANT VOICE

The thing I'd like to change is there should be a group or a program where you can even just hang out with other people in the program. It's hard to find people to talk to or be social with.

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UPCOMING FEATURES

- Research team/program partnerships
- More investigator profiles
- The experiences of consumer researchers

CONTACT INFORMATION

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