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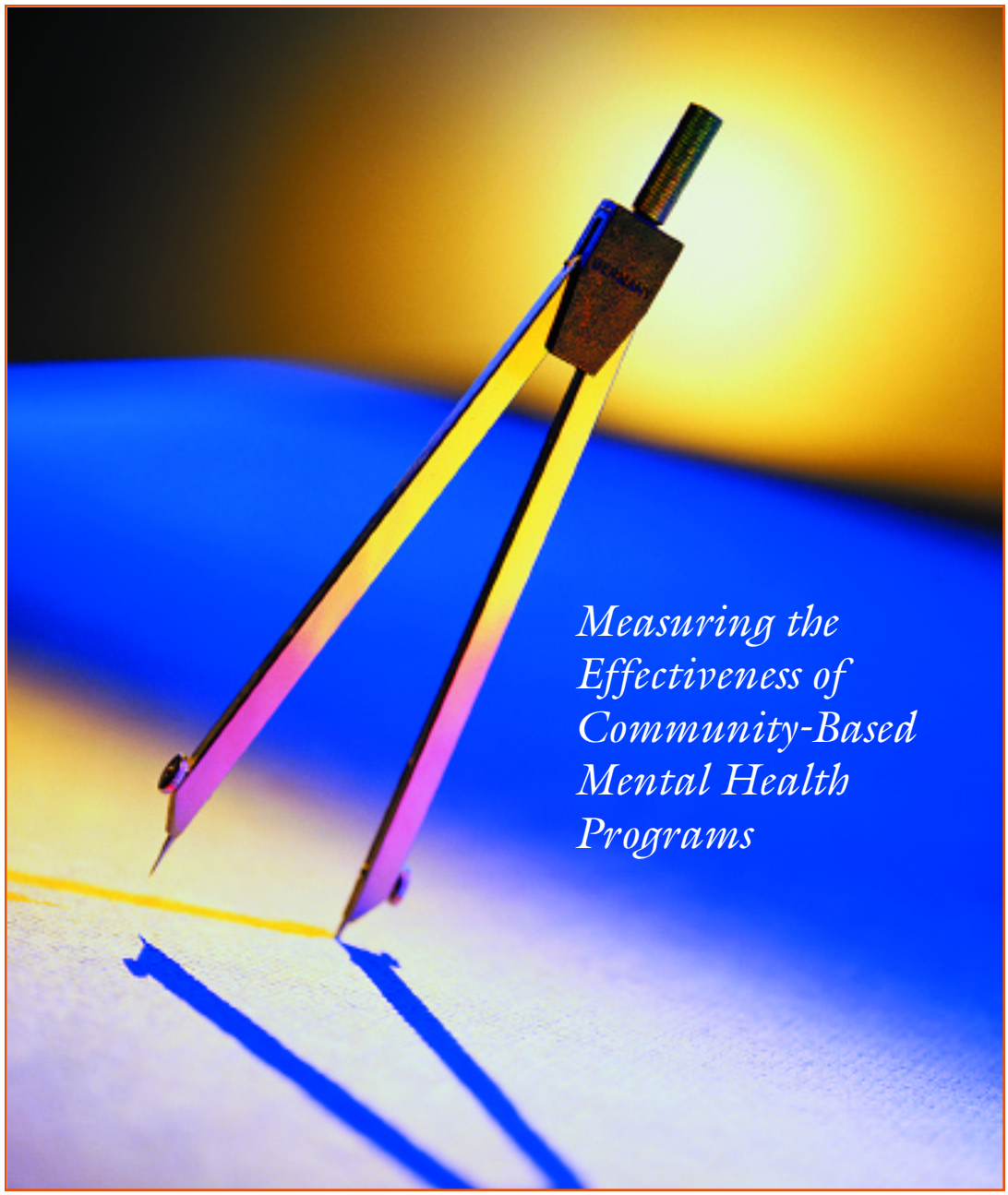

CANADIAN MENTAL HEALTH ASSOCIATION
L'ASSOCIATION CANADIENNE POUR LA SANTÉ MENTALE
Canadian Mental Health Association, ONTARIO

IN THIS ISSUE:

COMMUNITY MENTAL HEALTH EVALUATION INITIATIVE:

Researching the effectiveness of, and advocating best practices for, community-based mental health programs

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Vol. 19 No. 2 FALL 2003

CANADIAN MENTAL HEALTH ASSOCIATION
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Canadian Mental Health Association, ONTARIO

OUR MISSION:
To provide leadership in advocacy and service delivery for people with mental disorders, and to enhance, maintain and promote the mental health of all individuals and communities in Ontario.

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A symbol of resilience and recovery for people who care about mental illness and health.

How do we know that the services we provide work?

BARBARA EVERETT, PH.D.
Chief Executive Officer

The many hundreds of staff who work in community mental health agencies in Ontario know intuitively that the help they provide makes a difference in the lives of people living with mental illness and their families. We often hear from people how much it means when we help them find a home that is both safe and affordable. They also tell us that offering understanding when they speak of their suffering helps. And we know that people feel more secure because we're available to offer support in times of trouble. Consumers and family members who participate in self-help initiatives also know that the message they give to others, "you're not alone," and the support and information they share help people not just to cope with, but to overcome the challenges they face.

So, in the community mental health sector, our day-to-day experience of making a difference in people's lives gives us confidence that the services we provide are working. We support people as they learn how to manage their lives and their symptoms in an effective way so they maintain their housing, make friends, find work and reduce their dependence on institutions.

Community mental health agencies, as part of good management, routinely collect confidential statistics on who they serve, what sorts of problems clients are dealing with, and how long people stay in programs. We also conduct "customer satisfaction" surveys to ensure that the people who use the programs find them useful. However, in a climate of scarce health care dollars and threatened reductions in services, this kind of information is no longer enough.

Believing that our services are cost-efficient and effective – and proving it to funders – are two different things. More and more, funders ask for independent scientific research as evidence that programs work.

This is a reasonable expectation. Taxpayers' dollars are not endless and they must be invested in the types of help that are proven to be effective.

The Community Mental Health Evaluation Initiative (CMHEI) described in this issue of *Network* was designed to research a number of community mental health programs across the province to see if they produce positive outcomes for people. Given that we already believed that our services work, we are not surprised that preliminary research findings show that people do better on a variety of scientific measures when they receive community mental health services than when they do not.

The surprise is how very much better they do. For example, intensive case management services reduce emergency room visits by 60% and hospitalizations by 86%. Services that find housing for homeless people show that 91% are still in those homes 9 months later. In addition, community mental health services are remarkably cost-effective – it costs $35,000 per year to support a person in the community and $170,820 per year to keep them in hospital. With health care dollars becoming increasingly scarce, it only makes sense to spend them in the most efficient manner.

As a final note, it is important that we understand that community mental health services are only one part – and many would say only a small part – of the journey towards recovery and sustained wellness. Friends, family, a caring community and meaningful work are today, and will forever be, the most important ingredients in living a healthy life.

The Role of Community-Based Mental Health Services

Over the last two decades, Ontario has been laying the groundwork for the fundamental reform of mental health care – a move away from traditional, institution-based treatment for people with serious mental illness toward client-centered, community based help.

This change is at the leading edge of the Ontario vision for "advancing healthcare, and enhancing physical and mental health in all life's stages, through a high-quality system that is easily accessible for all Ontarians."

As part of mental health reform, some new services and supports for consumer-survivors and their families have been put in place including assertive community treatment, intensive case management, crisis response, consumer/survivor initiatives and family initiatives.

The Community Mental Health Evaluation Initiative (CMHEI) was launched in 1997 to examine these services and explore a number of questions including: Who are they serving? How well are they working? What is working best for whom and in which situations? Are changes needed? Are the programs producing good value for the money invested in them? The Community Mental Health Evaluation Initiative is the first broad-scale, systematic assessment of the effectiveness of community-based mental health services in Ontario. The CMHEI has been designed to provide a fact base that supports decisions about future service delivery. Its development and funding are rooted in the Ministry of Health and Long-Term Care's commitment to evidence-based policy making. The CMHEI also creates a new pool of experienced researchers in various parts of the province and a new set of research tools and partnerships that give Ontario the capacity to assess and measure, scientifically, the effectiveness of community mental health services and supports.

Funded entirely by the Ministry of Health and Long-Term Care ($3.54 million over six years), the Community Mental Health Evaluation Initiative consists of eight projects in four Ontario centres – Kingston, Kitchener-Waterloo, Ottawa and Toronto. Six projects are evaluating specific services in specific communities over nine- and 18-month intervals; one is integrating information generated by each local study to draw broader conclusions, and one is assessing factors critical to the success of community-based programs. Data collection on all of the projects has now been completed and although the final analysis has yet to be presented, all of the indicators point to the importance of community-based services and the need to expand these services in communities across Ontario.

The CMHEI project has substantially increased the capacity of the system to conduct relevant research on community mental health programs, resulting in a network of experienced researchers and community partners poised for future research and evaluation. Consumers and family members have made valuable contributions in defining research questions, interviewing and assisting in interpretation of findings."

Community Mental Health Evaluation Initiative: Multi-site Study Project Summary, March 26, 2002

"The people served by community mental health services are among the most vulnerable citizens of our province."
CMHA, ONTARIO

Emerging findings of the Community Mental Health Evaluation Initiative show that:

- *The investment in community mental health programs is paying off for persons with serious and persistent mental illness. They are showing improvement in their community functioning, symptoms, use of substances, and experience fewer crisis episodes and days in hospital.*

- *It is important not to underestimate the contribution of healthy communities and the basics of housing, income, medical and dental care to the well-being of people with mental illness living in the community. Many lack employment and are managing on inadequate incomes and social support.*

- *Two approaches to providing intensive community supports – ACT teams and intensive case management – are both serving very disabled client groups. In preliminary results, both show promise to help people to decrease their reliance on institutional care and to improve their quality of life.*

- *In developing program models it is important to investigate the program elements and caregiver characteristics that are most beneficial to consumers and families.*

- *Peer support programs are beneficial to consumers and to their family members, and also have a positive impact on communities and the care system. However these programs currently receive less than 1% of the provincial mental health budget.*

Measuring the Effectiveness of Community-Based Mental Health Programs

The Community Mental Health Evaluation Initiative (CMHEI) is a provincial evaluation project conceived by the Mental Health Policy Research Group, which is a consortium including the Ontario Mental Health Foundation, the Centre for Addiction and Mental Health, and the Canadian Mental Health Association, Ontario. The purpose of the consortium is to research and advocate solutions for major issues and problems in the mental health arena, with funding support from the Ministry of Health and Long-Term Care.

DR. PAULA GOERING, RN, PHD, IS AN EXPERIENCED CLINICIAN, CONSULTANT, EDUCATOR AND RESEARCHER. SHE IS DIRECTOR OF THE HEALTH SYSTEMS RESEARCH AND CONSULTING UNIT AT THE CENTRE FOR ADDICTION AND MENTAL HEALTH AND PROFESSOR IN THE DEPARTMENT OF PSYCHIATRY WITH CROSS APPOINTMENTS TO THE FACULTY OF NURSING, INSTITUTE OF MEDICAL SCIENCE AND DEPARTMENT OF HEALTH, POLICY MANAGEMENT AND EVALUATION AT THE UNIVERSITY OF TORONTO. DR. GOERING IS RECOGNIZED AS A LEADER IN THE FIELD OF MENTAL HEALTH POLICY.

What triggered the development of the CMHEI?

PAULA GOERING: The seeds of this came from a project we did on Best Practices and Mental Health Reform for Health Canada. An important part of that project was a comprehensive review of what the research literature had to tell us about best practices in community mental health. It was very difficult to find Canadian studies to focus on for that review. We ended up relying on literature that came primarily from the United States, Britain and Australia, and it really raised the question of why we weren't doing more of this kind of research in Canada. When I began exploring that question with my colleagues and people in the field, it became evident that there were two major problems: one was that we did not have that many individuals who were trained and interested in doing research in this area, and the second was that the typical funding streams were not very well suited and didn't match well with what would be required for this type of research. That then led to a discussion with funding bodies and with the government to see whether there would be any vehicle for funding a special initiative in community mental health research that would use a different kind of format. The response I got at that time from the Ministry of Health and Long-Term Care was that it would be possible but that they would like to see this proposal coming from a coalition of organizations that represented various perspectives. That led to the creation of the Mental Health Policy Research Group which was composed of the Centre for Addiction and Mental Health, the Ontario Mental Health Foundation, which was our local research funding body, and CMHA, Ontario which was the best representative of the providers in the field. Together we worked with the Ministry of

Health and Long-Term Care to see whether we had enough in common and could put together a group who would advocate on behalf of this agenda. The four partners were very interested and enthusiastic from the beginning. Initially the group had a number of different functions, one of which was to get some special funding dedicated to new investigator awards.

How did this funding work?

PAULA GOERING: It was funding that was set aside for investigators who wanted to do research in community mental health. Behind all of this was the idea that in order to encourage this kind of research we had to do it somewhat differently. We had to invest in people and try to build the number of people in the province who were interested and available and capable of doing this research. The Mental Health Policy Research Group agreed that it would make sense to try to fund a multi-site project. The Ministry's agenda was that they asked us to look at the kinds of services they were investing resources in as part of mental health reform so that they would then have some evidence that they had made a good investment. We saw the project as being one that would be a collaboration between researchers and policy makers in the field right from the beginning. We invited people from across the province to come to a one-day workshop to help us figure out what made sense, what would work, and how to actually shape the project.

Were the people who attended this workshop all coming from the research perspective?

PAULA GOERING: No. Although we did have researchers there who we thought might be interested in applying, we also had consumer groups, providers, agencies and ministry policy people. They were the ones who were helping to design this project. After the workshop we sent out a call for proposals for researchers for three kinds of services. The first was case management, the second was crisis and the third was family and consumer self-help. A peer review process was then set up to look at the applications. The projects were selected and funded, with my unit as a coordinating centre that tied them all together.

The Community Mental Health Evaluation Initiative consists of six evaluation projects and one methods study. The three priority areas are: case management including housing support; crisis response; and consumer/survivor and family initiatives.

Was there an overall method of doing this research that all of the projects used, or was that left to each individual researcher?

PAULA GOERING: It's really a bit of a combination. Every project is a unique project in and of itself, addressing the questions that were of interest and importance to them, but all the projects use a common data protocol. Because people were aware of this from the beginning, they designed their projects knowing that some of the crucial decisions about how we were going to measure outcomes, or what we were going to have to measure, would have to be decided collectively.

A Multi-Site Evaluation of Community Mental Health Programs in Ontario

The multi-site project joins six separate evaluation studies through use of a common data collection protocol. The goal is to examine the roles played by different forms of community support in helping individuals with serious mental illness to improve their living conditions and quality of life.

Investigators are examining how program types differ in whom they serve, their impact on users over time, their approach to delivery of service and support, their costs and cost-effectiveness.

One of the preliminary findings of the project is that the investment in community mental health programs is paying off for persons with serious and persistent mental illness, including those who are homeless. They are showing improvement in their community functioning, symptoms and use of substances, and are experiencing fewer crisis episodes and days in hospital.

Community Mental Health Evaluation Initiative: Multi-site Study Project Summary, March 26, 2002

Measuring the Effectiveness of Community-Based Mental Health Programs

So there are some questions that are common to all groups but some that are unique to each project?

PAULA GOERING: That's correct. After we got started, the Mental Health Policy Research Group dissolved as a formal organization. CMHA, Ontario took on the responsibility for the communication function because we wanted to be communicating with the field all along, not just waiting until everything was finished. They have been very helpful to us in terms of newsletters, websites and strategies for getting the word out to people about who we are and what we are doing. OMHF has continued to be involved as a funder and has made sure that the accountability has been in place. We have had to make some adjustments as we've gone along for unexpected contingencies, so they've been involved in trying to figure out what made sense in terms of the changes to some of the projects. At the Ministry of Health and Long-Term Care, Darryl Sturtevant, Director, Mental Health and Rehabilitation Reform, has also been very encouraging and facilitative in terms of how to get the word out about the project to the appropriate audience.

Are all the projects now complete?

PAULA GOERING: Everyone has finished data collection but we are just now beginning to do the analysis and summarize what we've learnt.

So it is yet to be determined how well community programs are working and what changes are needed?

PAULA GOERING: I think it's fair to say that based on the preliminary findings we are confident that we are going to be able to give a positive message back about the investment. We can see from even the initial follow-up findings how much improvement there is in people's lives and in their functioning. There was also an interim external review of the multi-site project that was done for the Ontario Mental Health Research Foundation which was submitted to them in August 2000 which said that "considering the complexity of the initiative, the most salient conclusion from the Interim Review is that 'it works pretty well!'". This external review was conducted by Celine Mercier, PhD, McGill University and Douglas Hospital Research Centre, and Heather Stuart, PhD, Queen's University.

"Based on the preliminary findings we are confident that we are going to be able to give a positive message back about the investment. We can see from even the initial follow-up findings how much improvement there is in people's lives and in their functioning."

Would you say that the four partners went into this with a firm belief that community mental health programs and services are the way to go and that is where new funding should be directed?

PAULA GOERING: Certainly the CMHA has always supported that. I don't know that the OMHF or even the Ministry of Health and Long-Term Care necessarily thought that. What they knew was that they needed more evaluation. There was definitely objectivity going into this project. In addition to providing credible data about the effectiveness of community-based mental health programs, another thing we wanted to do was build capacity to do this kind of research. Many students have written their theses on these projects. We now have a whole new generation of students who have been exposed to these kinds of methods and this kind of subject matter. Across the projects I believe we have also hired about 45 consumer and family members. We have trained them to help us with research and interviews, and given them jobs that have been very satisfying to them. We have trained almost as many students, as well as project coordinators and research assistants. For me the human capacity element has been as important as the information we have gained.

For more detailed information on each of the Community Mental Health Evaluation Initiative projects visit the website at: www.ontario.cmha.ca/cmhei. You will find project descriptions and proposals, the complete list of names and addresses of all individuals involved and a copy of press releases and newsletters. Questionnaires that have been used in the multisite project can also be downloaded. You can also subscribe to the CMHEI newsletter on-line.

Intensive Case Management

Using a randomized controlled trial, the Evaluation of Intensive Case Management for Persons With Severe Mental Illness Who Are Homeless study, defines the key elements and assesses the effectiveness of intensive case management for people who are homeless and seriously mentally ill. Marnie Smith, Acting Executive Director of the CMHA, Ottawa Branch, has been one of the partners involved in this project. Preliminary findings show that intensive case management helps mentally ill homeless people to live in the community, with early results showing that people experience fewer symptoms, lower rates of drug abuse and better overall functioning, even in the early stages of treatment.

One of the CMHEI projects was based on the community support services program you offer at the CMHA, Ottawa Branch. What does your program consist of and how was the research and the evaluation of this program conducted?

MARNIE SMITH: At the CMHA, Ottawa Branch, we deliver both outreach and intensive case management services to individuals who are either homeless or at risk of being homeless along with other complex needs. Our particular model for intensive case management is a strengths-based model that has very strong components of psychosocial rehabilitation connected to it. There are other locations in Ontario that have similar programs but there has not been any research to indicate whether there were important outcomes for this client group. When I heard there was going to be a possibility of funding to conduct research into community mental health programs I really wanted our agency to be able to partner with one of the researchers so that they could look at our intensive case management model because we really do feel it makes a difference. We were also concerned because we didn't believe that across the province there was the recognition and understanding by our funder, the Ministry of Health and Long Term-Care, that this was indeed an important component of the community mental health system.

Community mental health programs save the healthcare system money. It costs $95.89 per day or $35,000 per year to provide services to a person with a mental illness in the community. It costs $468 per day or $170,820 per year to keep a person in hospital.

So you were really looking for evidence-based proof?

MARNIE SMITH: That's right. As an agency, because we also coordinate a whole area-wide case management program where there are nine other partner agencies connected to delivering case management and where referrals come centrally from

Intensive Case Management

CMHA, Ottawa, we already were somewhat of a 'hub' for case management. We had developed a central way of collecting information and data. The opportunity to be involved with this research project allowed us, as an agency, to increase our ability to collect data, monitor services and properly evaluate them.

I understand you had two groups: one receiving case management services and one receiving outreach services. What is the difference?

MARNIE SMITH: The control group, which we used as the point of referral to our study, was from the outreach workers of CMHA, Ottawa Branch, who worked with the homeless sector. We did a random identification of who would go into the experimental group and who would go into the control group. Because the funding is very much geared to outcomes, the mandate for our outreach services is that when somebody is housed and stabilized, and their broad needs are met, the outreach worker will usually pull out. After two or three years of our study, some of the people in the control group may not have a case worker involved with them. Some might be receiving quasi-like case management services just to keep them from spiralling back.

"Intensive case management is a specific, valid and effective service, and we now have the technology to reproduce it in other communities where needed."*

So the difference with the intensive case management would be that even after someone's needs have been identified and met and they have stabilized they would still continue to have contact with their case manager?

MARNIE SMITH: That's right. The criteria of who we are funded to serve under the Ministry of Health and Long Term-Care is people who have a serious and persistent mental illness, a high degree of disability and who require a significant amount of help in order to live independently in the community.

"Housing outreach services are successful at housing people who are homeless and mentally ill; 91% were in permanent housing after nine months."*

Is it your belief that some people drop through the cracks when there is not the funding for intensive case management?

MARNIE SMITH: Yes, we do believe that is true for a lot of people. There is somewhere in the range of about 5,000 people we have identified who might need intensive case management services in Ottawa but who are not receiving help because there aren't enough services.

What role did consumers play as you undertook this project?

MARNIE SMITH: We had several consumers as well as family members on the Advisory Committee to the project. We also had consumers who were involved as interviewers and one as a co-investigator. The Advisory Committee consumer members helped with pre-testing the interview questions. We had introduced a number of extra open-ended questions that we added into the common protocol that all of the projects used. We felt that it was important to give clients more opportunities to give their impressions of things. Sometimes it was too depressing for them to explain why they didn't have the housing they wanted, or why they weren't doing the things they would like to do with their life, so we countered that by developing more open-ended questions.

Can you give me an example?

MARNIE SMITH: The quality of life interview is fairly standardized, but we gave clients the opportunity to express a little more by asking them what kinds of things they would like to do if they had the opportunity – we gave them the chance to dream a little, and express some of their hopes and feelings. Without those types of questions we found that people felt even worse about their life by the end of the interview. We

tried to make the interviews user-friendly for our clients. The coordinator of the project, Heather Smith Fowler, was located at our office and she developed a good rapport with our staff at the agency. She was able to match the interviewers with the description we gave of a client thus ensuring a higher degree of 'comfort' within the interview itself. Heather and I did the training of all of the interviewers, making sure that these were people who were good at listening, good at understanding that they couldn't necessarily do the interview in one shot. The interviews were paced to the needs of the individual client. For instance, because we are interviewing homeless people, people who have had disadvantaged lives, interviewers might have to think about offering a client lunch if they hadn't eaten so that they could think properly. We also tried to get feedback from the client along the way to make sure the process made sense to them and to find out if there was anything that would make the interview easier for them. The interviewers were very good at giving us feedback, and we tried to modify some of what we did based on this feedback.

"Intensive case management in Ottawa is serving people with complex needs, including homelessness and addictions. Overall, however, resources in health and social services do not appear to be allocated on the basis of client needs. Better ways of allocating resources across the system are clearly required."*

What are the results that you are seeing from the project?

MARNIE SMITH: After collecting baseline data we followed up at 9, 18 and 24 months and we are seeing changes across certain dimensions. In the past we haven't had good random control designs to prove the outcomes, even though the literature on the strengths model of case management suggests that it has good outcomes. It takes a number of years of service delivery before you see changes, particularly if you are working with very marginalized people. However, the data we have collected certainly seems to be suggesting the importance of intensive case management. Outside of this project we also do ongoing data collection on all the other case management positions at CMHA, Ottawa Branch. In the CMHEI project we have approximately 100 clients, but our agency serves between 600 and 900 clients in outreach case management, and that doesn't include those clients served by other agencies in the area. Our data does show that there is a statistically significant decrease in, for example, hospitalization as the number of years of case management service is increased. There is a correlation between those two things. The great thing about the CMHEI project is that although it will only just be starting to show those trends, because we've only followed people for two years, it is a random control designed study so whatever comes out of it is considered to be more credible both by the funders and researchers. It's proving the importance of this service – describing the components of the service delivery and the importance of it to client outcomes.

COSTING STRATEGY IN THE MULTI-SITE STUDY

At the very heart of the CMHEI project is the recognition that the mental health system cannot adequately meet the needs of the population with one type of program alone, but requires a mix of different types of services. The goal of the cost-effectiveness analysis being conducted is to understand how, within the context of a constrained budget, these different types of services and supports meet different needs and fit together to form a comprehensive picture.

**Community Mental Health Evaluation Initiative: Multi-site Study Project Summary, March 26, 2002*

Consumer/Survivor Initiatives

Consumer/survivor initiatives (CSIs) are self-help/mutual aid organizations 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. Geoffrey Nelson, principal investigator of the CMHEI Longitudinal Study of the Consumer/Survivor Initiatives in Community Mental Health in Ontario, expects that participation in the consumer/survivor initiatives will have a positive impact on personal empowerment, social support, community integration, work, education and subjective quality of life. The goals of the project include examining the personal changes that are experienced by new members of CSIs as they participate in these self-help consumer-directed initiatives (less need to utilize health services, more social support and personal empowerment), and the role that CSIs play in helping to make changes in systems relating to housing, employment opportunities, public education, community planning, advocacy and action research.

Robert Chapman experienced a serious major mental illness in the early 80s and went on to take a course in psychosocial rehabilitation at college because of his desire to work in the mental health field. Mr. Chapman has been involved in this CMHEI project since the beginning. He has interviewed consumers for the research study, had input into the design of the questions, and also made several presentations along with the principal investigators.

What is the kind of response you have been getting from consumers as you have conducted interviews?

Robert Chapman: I think first of all that consumers have had a sense that their input is valuable. They are hoping that they are a part of something that may play a significant role in seeing increased funding for CSIs in Ontario. I think it was really important that the Centre for Addiction and Mental Health hired consumers to conduct these interviews because there has been a decreased guardedness on the part of the participants in the study. They feel more comfortable in sharing information that they might otherwise be reluctant to open up about if a non-consumer was conducting the interview. Because they trust me, because they know that I have a vested interest in the outcome of this project just like they do, they understand the need to give me precise information.

How has being involved in this project affected you personally?

Robert Chapman: It has definitely increased my feelings of self-worth and empowerment. I was working part time before I got this job, and having a job that pays a decent wage, and one which is personally significant and meaningful to me has helped me a lot. It's also

helped me to network with the community and become more connected with the staff and participants here within the CSI. It's given me a sense of purpose.

Do you feel that the role you have played in this project has given you marketable skills for the next job you go to?

ROBERT CHAPMAN: Definitely. It's actually given me more appreciation for peer support. I know that's a different topic, but there have been times when I have been interviewing a consumer and their life is so upside down that they have broken down and I've found myself wanting to do more than just offer them a tissue. Because of this I became interested in the peer support course that was offered here at the CSI. I took that and now I am a peer support volunteer. I would never have taken that step had it not been for my involvement in this CMHEI project.

"I'm proud to be part of this project as it became clear that this was a pioneering, ground-breaking research project. No one else has studied consumer/survivor self-help groups like this before. Our research could have positive consequences if it shows that self-help groups are a good use of mental health dollars."

CONSUMER/SURVIVOR RESEARCHER

Were you part of a consumer organization before you became an interviewer for this project?

ROBERT CHAPMAN: No. I was aware of CSIs but didn't really know what they were all about or what they offered. I think if more consumers knew about CSIs there would have to be increased funding because there would be such a demand for them. There already is a high demand because it is a crucial connection for consumers to come to a CSI within their community. They can talk freely and comfortably about their illness if they want to without fear of judgment or condemnation. That is a huge thing for consumers with so much unnecessary stigma surrounding mental illness. To be able to meet with other people, to take part in activities and feel connected in the sense of belonging to a community is very valuable.

What do you feel are the expectations that consumers have that will come out of this study?

ROBERT CHAPMAN: They've said that they want a bigger place to meet, a better presence in the community with more activities to do but also that they want to have some meaningful activity in their life. The CSI is a place that can facilitate that.

Are you, as a consumer, satisfied with the credibility of this project, the way in which it has been conducted?

ROBERT CHAPMAN: Very much so. It has impressed me that they value the role of the consumer in being involved in this. It shows the Centre's integrity, and the integrity of the information that has been shared with us as consumers because of the trust that is placed in us by those we have interviewed. I think the consumers we have interviewed have seen a passion in us because this means so much to us on a personal level.

"Preliminary findings show that the amount of utilization of emergency room services drops in half for people who are involved in a consumer/survivor initiative as compared to actually going up a little for people who aren't involved."

DR. GEOFFREY NELSON

"Participation in peer support is beneficial to consumers and to family members of ill relatives. Peer support programs are also having a positive impact on communities and systems serving the seriously and persistently mentally ill. However these programs currently receive less than 1% of the provincial mental health budget."
CMHEI PROJECT NEWSLETTER – EMERGING FINDINGS

Dr. Geoffrey Nelson is Professor of Psychology at Wilfrid Laurier University. His research with psychiatric consumer/survivors has focussed on housing, community mental health programs and self-help/mutual aid. For six years he served as the Senior Editor of the Canadian Journal of Community Mental Health.

Evaluation of Family Initiatives

Families represent the largest group of community caregivers for those with serious and persistent mental illness. The Longitudinal Evaluation of Family Initiatives in Community Mental Health in Ontario study, led by Dr. Katherine Boydell and John Trainor, is examining family self-help/mutual aid initiatives from both an individual and systems level.

KATHERINE BOYDELL IS A SOCIOLOGIST AND HEALTH SYSTEMS RESEARCH SCIENTIST WHO HOLDS AN APPOINTMENT AS ASSISTANT PROFESSOR IN THE DEPARTMENTS OF PSYCHIATRY AND PUBLIC HEALTH SCIENCES AT THE UNIVERSITY OF TORONTO. DR. BOYDELL RECEIVED HER MASTER OF HEALTH SCIENCE DEGREE IN COMMUNITY HEALTH AND EPIDEMIOLOGY AT THE UNIVERSITY OF TORONTO AND HER DOCTORATE IN SOCIOLOGY AT YORK UNIVERSITY. SHE SPENT MANY YEARS CONDUCTING SOCIAL AND COMMUNITY PSYCHIATRIC RESEARCH IN THE ADULT MENTAL HEALTH SYSTEM PRIOR TO HER APPOINTMENT AT THE HOSPITAL FOR SICK CHILDREN. HER RESEARCH HAS FOCUSED ON THE USE OF BOTH QUANTITATIVE AND QUALITATIVE METHODS TO EXAMINE KEY ISSUES IN HEALTH AND MENTAL HEALTH. HER RESEARCH INTERESTS INCLUDE PARTICIPATORY RESEARCH, HOMELESSNESS, SOCIAL HOUSING FOR MARGINALIZED GROUPS, PREDICTORS OF REHOSPITALIZATION, YOUTH IN CRISIS, THE FAMILY EXPERIENCE, EVALUATION OF HOSPITAL-COMMUNITY PARTNERSHIPS, AND RESEARCH ON MODEL HEALTH AND MENTAL HEALTH PROGRAMS IN THE COMMUNITY. SHE HAS PUBLISHED NUMEROUS ARTICLES IN PEER-REVIEWED JOURNALS AND HAS PRESENTED WIDELY TO INTERNATIONAL CONFERENCES.

How do you measure the impact of family self-help and advocacy groups on family members?

KATHERINE BOYDELL: In the project we've been involved with we have looked at this from two levels: the impact that self-help/mutual aid organizations have at the individual level – what impact they have on family coping strategies, a family's feeling of empowerment, burden and social support – and then also at the systemic level – the impact these organizations have in terms of the education and advocacy that they do. Within each of these two levels we are using a qualitative and quantitative approach. For example, at the individual level we have done some intensive in-depth interviews with about 20 family members asking about their experience, how they came to be involved in the family support group and what it has meant to them in their lives. The qualitative piece of the project comes from the interviews with family members where we find out exactly what is being done in terms of advocacy, education, support, community activities etc. We've also been involved in conducting focus groups with people who have been involved with the organization since its outset to get the organizational story, finding out how family members can be more involved in the planning, policy making, sitting on boards, that kind of thing. We have interviewed 270 people and are just now coming to the end of our five-year study.

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.

From this study are you able to determine the difference that participation has on family members who get involved at this kind of organizational level and those who don't?

KATHERINE BOYDELL: We have concentrated our study on family members who are involved at one level or another. That means that although everyone we have interviewed is a member of a family self-help group, it could range from merely receiving the organization's newsletter, to spending many hours involved in advocacy or education. There's a huge range of involvement, and we have begun to look at high-level involvement versus low. There certainly is a difference between the two groups in terms of some of our variables, but we don't have a group that has absolutely no involvement. One of the problems with the study in terms of not being able to have a randomized group is that you can't really randomize some families to a support group and not others. In the current literature it is acknowledged that family members who choose to become involved are likely different from family members who don't.

"After I had finished completing my interview and was no longer employed on the project, I continued to stay in touch with one of the people I had interviewed who had become a friend. Her ill relative is now a friend of my ill relative and they provide friendship and support to each other. That was an unexpected benefit of being part of this project."
FAMILY MEMBER/RESEARCHER

What were your goals with this project?

KATHERINE BOYDELL: I guess one of the main ones at the individual level was to assess and understand the pathways to self-help: how do family members come to be involved in self-help organizations? What is their pathway in, and then following that, what has been the impact of this involvement from their own perspective? At the systems level our goal has been to find out what impact these groups have had in the areas of advocacy, education and support.

"Families often provide daily support to seriously mentally ill relatives (whether or not they are living together), yet the extent of their contribution is not formally acknowledged."
COMMUNITY MENTAL HEALTH EVALUATION INITIATIVE: MULTI-SITE STUDY SUMMARY, MARCH 26, 2002

Who did the interviewing of family members to gather this information?

KATHERINE BOYDELL: Over the course of the study we hired nine family members and took them through an intensive two-day training period to enable them to conduct the interviews. They were also involved on a monthly basis in our advisory group. Our goal was not only to develop the expertise in family members to carry out the interviews, but also to work with the research team, sharing strategies and information. The family members we worked with often talked about the impact it had on them as they worked closely with other family members, building relationships and connecting with each other as they conducted the interviews. Many of the interviewers said that talking to other family members really helped in terms of how they dealt with their own ill relative. A couple of the women who were over 65 expressed what it meant to them to have paid employment at that stage of their lives. Another woman mentioned the fact that by being involved in the study her own feelings of being stigmatized had changed and she had a different perspective.

"I think the level of the research conducted is much higher when the person doing the interview also has a relative with a mental illness. It's like any other project that you do - if you have a better understanding of that topic you are a better researcher. You know what to ask and what to expect. You know the interview cannot be rushed through. Sometimes things come up and you have to sit there and listen and I considered that to be part of the job. People are sharing something very personal, very emotional and sensitive. You can't just show up at somebody's door and start asking for all this personal information that will bring up a lot of emotion in people. You need to build a rapport before asking the questions."
FAMILY MEMBER/RESEARCHER

Did the family members help determine what some of the questions should be in the interview process?

Evaluation of Family Initiatives

KATHERINE BOYDELL: It's interesting that you ask that because when we first submitted our proposal one of the comments that the external reviewer made was that the proposal itself was very ambitious. They recommended that we take out some of the sections that we had proposed looking at, specifically hope and stigma. It was family members who said no, these two issues are really important to us, put them back in, so we did. We now have two students, one of whom is doing her dissertation on the experience of stigma and the other on hope.

"I hope that through this project family members will be heard; that their input will be appreciated, listened to and acted on."
FAMILY MEMBER/RESEARCHER

What do you think are some of the major findings that will come out of this study that will show the importance of family self-help/ mutual aid organizations?

KATHERINE BOYDELL: I think without question we are seeing that these kinds of groups give people the comfort of knowing they are not alone. Family members can talk to someone who has a shared experience and not only gain support and assistance but also give it. Also our study shows that these kind of groups help family members in becoming advocates, it helps them to manoeuvre the system. A sense of community has been a huge theme. The fact that there is this sense of community within the group, that they are not so isolated. And again the reduction of stigma and self-blame is a really important outcome.

All these things are obviously beneficial for family members. What is the benefit to the ill relative?

KATHERINE BOYDELL: I would say that in the relationship with the ill relative, expectations change. There is more understanding of the illness itself, and family members have made that link to say that their relationship with their ill relative has changed for the better as a result of their increasing coping capacity or increased understanding of the illness and how to handle it. Very definitely the impact is not only on the family member but also on their relative.

Quite a few students are basing their theses on the CMHEI projects – is this the start of a whole new database of credible information as to what is needed in the community to meet the needs of both those who suffer from a mental illness and family members who act as a caregiver?

KATHERINE BOYDELL: I think so. Prior to this whole initiative Paula Goering and I had done a complete literature review and there was very little in terms of a Canadian database. Now, as a result of this initiative, for the first time we have a credible, burgeoning Canadian database that is well documented.

"Family members need to receive more support from community services and from self-help groups so definitely there is room to expand these. I think it's important when somebody is sitting down and designing those programs and services to get the input of family members because we are dealing with the situation on a daily basis. They may be professionals who are trained in the area of mental illness, but when it comes to the practical aspects family members understand it on a personal level. They definitely need to be involved in the design of community programs."
FAMILY MEMBER/RESEARCHER

"The health care system in Ontario is operating under severe fiscal constraints. Hospitals and other institutional services for the mentally ill have been reduced, resulting in a greater demand for community-based services. But funding 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."
CMHEI NEWSLETTER, WINTER 2003, NO. 6

Investment in Community Mental Health Programs Pays off

THE PRELIMINARY FINDINGS OF THE COMMUNITY MENTAL HEALTH EVALUATION INITIATIVE ARE CLEAR: COMMUNITY MENTAL HEALTH SERVICES ARE A COST-EFFECTIVE WAY TO HELP PEOPLE WITH SERIOUS MENTAL ILLNESS.

Broad findings across all sites include:
1. Where it has occurred, investment in community mental health programs is paying off for persons with serious and persistent mental illness, including those who are homeless. They are showing improvement in their day-to-day functioning, a reduction in symptoms and use of substances, and are experiencing fewer crisis episodes and days in hospital.
2. Maintaining a broad range of services for diverse populations is essential for consumer choice.
3. While it is obvious that community mental health programs are helpful, it can't be forgotten that most people with serious mental illness live in poverty without access to employment opportunities.

CMHEI's findings can help produce the best possible value from tax dollars invested in mental health care.

Assertive Community Treatment (ACT) Teams in Kingston:
Clients experience decreased hospitalization rates.
Clients feel that the service helps them stay in their own homes, in their own communities.

Intensive Case Management in Ottawa:
Clients experience fewer symptoms, lower rates of drug abuse and better overall life functioning as a result of these services.
Housing outreach services are successful in finding homes for the homeless and after 9 months, 91% had maintained their tenancy.
Community mental health programs save the healthcare system money. It costs $35,000 per year to provide services in the community compared to $170,820 per year to keep a person in hospital.

Assertive Community Treatment Teams and Intensive Case Management in Toronto's inner city:
Clients' overall functioning improved 20% after only 9 months of service.
ACT Teams reduced emergency room visits by 33%. Intensive Case Management reduced emergency room visits by 60%.
ACT Teams reduced hospitalization by 43%. Intensive Case Management reduced hospitalization by 86%.
Both programs reduced crisis events by 34%.

Community mental health services have not had an increase to their base budgets for over a decade. Under-funding community mental health services leads to three consequences: overuse of more expensive health services, inappropriate use of services that were never meant to serve the mentally ill, and to the tragedies of homelessness, victimization and suicide.

Family Self-Help Groups in Toronto:
Families are often the only caregivers for people with mental illness.
Families benefit from self-help groups.
Self-help is unacknowledged and under-funded in Ontario.

Consumer/Survivor Initiatives (self-help and employment projects) in Kitchener-Waterloo:
People involved in these programs experienced a reduction in symptoms and felt a greater sense of mastery over their lives.
Participants in the study reported an improved quality of life.
People were hospitalized fewer times.

Mental Health Facts

It affects all of us:
Health Canada (2002) indicates that:
20% of Canadians will personally experience a mental illness in their lifetime, and the 80% remaining will be indirectly affected by its impact upon a family member, friend or colleague.
Suicide accounts for 24% of all deaths among 15-24 year olds and 16% among those aged 25-44.
It's a growing problem:
Mental health disorders are one of the three leading causes of disability in the world today.
Since 1994, depressive disorders have grown 100% as a percentage of short-term and long-term disability claims, 40% as a percentage of Workers' Safety and Insurance Board claims and 55% across all categories of disability-related absences from work.
Stress and mental health-related problems currently represent 40-50% of the short-term disability claims among employees of some of Canada's largest corporations.
Over the next 20 years, Harvard University and the World Bank foresee depression becoming the leading source of workdays lost through disability and premature death. Heart disease will be second.
Psychiatric claims are now the fastest growing category of long-term disability in Canada. *(Manulife Financial Group)*
It's an expensive problem:
In Canada, the cost of mental illness represents nearly 14% of all corporate income.
Households with a disabled family member consume on average 40% less in goods and services than the average household.
The Canadian economy loses an estimated $30 billion a year in productivity due to mental illness and addiction problems. *(Global Business and Economic Roundtable on Addiction and Mental Health)*

Community mental health programs support people in their own homes and in their own communities. Community services take the pressure off of more expensive services such as hospitals, emergency rooms and ambulance services. They also help reduce the number of calls to police for nuisance offences and ensure that the mentally ill are offered help instead of a jail term.

MENTAL HEALTH WORKS

- **The World Health Organization has predicted that by the year 2020 depression will be second only to heart disease as the leading contributor to the global burden of disease.**
- **Psychiatric claims are now the fastest growing category of long-term disability in Canada.**
- **Canada's economy loses an estimated $21.4 billion annually due to lost productivity caused by mental health problems.**

How we deal with mental health in the workplace is a problem that we can no longer afford to ignore. ***Mental Health Works*** *helps organizations and individuals become part of the solution by:*

- Developing networks to exchange strategies and knowledge to address mental health issues in the workplace
- Providing access to the latest information for employers, employees and mental health professionals about mental health in the workplace
- Providing information on early identification, prevention, and accommodation
- Developing and distributing training materials and information kits for employers and employees
- Collaborating with organizations to design and pilot training initiatives

If you are interested in learning more about Mental Health Works – or about how you or your organization can get involved, contact:
Patti Bregman c/o Canadian Mental Health Association, Ontario, 180 Dundas Street West, Suite 2301, Toronto, ON M5G 1Z8
Ph: 416-977-5580
Fax: 416-977-2813
Email: info@mentalhealthworks.ca

Mental Health Works *is an initiative of the Canadian Mental Health Association, Ontario.*

OCTOBER 5 – 11, 2003

Mental Illness Awareness Week (MIAW). Mental Illness and the Family – Resources for Recovery. MIAW is led by the Canadian Psychiatric Association with the support of allied mental health care organizations and volunteers. The theme of this year's Mental Illness Awareness Week campaign focuses on the tapestry of families associated with the recovery process of mental illness.
For more information: www.cpa-apc.org.

OCTOBER 10, 2003

World Mental Health Day. Emotional & Behavioral Disorders of Children and Adolescents. The theme for World Mental Health Day 2003, the World Federation for Mental Health's global mental health education project, will focus worldwide attention and concern on the identification, treatment, and prevention of emotional and behavioral disorders in children and adolescents.
For more information: www.wmhday.net.

OCTOBER 22, 2003

Marketing Madness: How Pharmaceutical Companies Shape the Way We Think. Dr. David Healy will discuss the changing nature of mental health – from mental illness services to mental health services to mental risk services. A panel discussion, moderated by Elizabeth Gray (former host of CBC radio's As It Happens and Cross Country Check-Up) will follow.
Registration: $85.00 (before Sept. 15), $100 (after Sept. 15), lunch is provided. 9:00 am – 3:00 pm, George Brown College, 290 Adelaide St. E., 4th Floor auditorium, Toronto.
For more information:
Rosalind Gilbert, Tel: 416-415-5000 ext. 2641.

NOVEMBER 2 – 5, 2003

54th Annual Ontario Public Health Association Conference: Public Health in Motion. OPHA's Annual Conference is the single largest forum for public and community health workers in the province of Ontario. The Cleary International Centre, 201 Riverside Drive, Windsor ON.
For more information: www.wechealtthunit.org.

NOVEMBER 3, 4, & 5, 2003

Today's Choices…Tomorrow's Care – Ontario Hospital Association Convention and Exhibition 2003. The largest and most comprehensive health care convention and exhibition of its kind in North America. Metro Toronto Convention Centre, North Building.
For more information: www.oha.com.
E-mail: convention@oha.com.
Tel: 416-205-1362.

NOVEMBER 16 – 18, 2003

INPUT '03 – The 15th Biennial Symposium on Employee and Family Assistance Programs in the Workplace. Over 500 EAP/EFAP professionals from across the country will be attending INPUT '03. Fairmont Chateau Laurier, Ottawa.
For more information: Neala Puran, Humber College, Corporate & Continuing Education, Tel: 416-675-6622 ext. 4020, Fax: 416-675-0135, E-mail: neala.puran@humber.ca, Web: www.humberc.on.ca/~input.

DECEMBER 5, 2003

Current Legal Issues – What Mental Health Professionals Need to Know. Led by Torkin Manes Group. In this fast-paced and information-filled seminar, four leading practitioners from Toronto's prestigious Torkin Manes Cohen Arbus law firm will teach you what you need to know about recent developments in four key areas – Records, Confidentiality and Reporting; Avoiding Lawsuits and Professional Discipline; The Role of the Therapist in Sexual Assault; and Recent Developments in Family Law.
For more information: Leading Edge Seminars, Tel: 416-964-1133, Fax: 416-964-7172, Web: www.leadingedgeseminars.org.

JANUARY 20, 2004

Community Information Forum: Exploring Recovery in Mental Health. This forum will explore what recovery means in mental health.
For more information contact: Barbara Steep, Tel: 416-535-8501 ext. 4553, E-mail: Barbara_steep@camh.net.

Mental Health Works Launches Web Site

Want to know how to tell your manager that you have a mental health problem? Wondering what your rights and responsibilities are if you have an employee with a mental health problem? Take a browse through our new web site. You'll find the latest information about mental health in the workplace for employers and employees, answers to frequently asked questions, links, breaking news stories, and much more. ***www.mentalhealthworks.ca*** *– your first stop for information about mental health and the workplace.*

Planning a Gift

TO CMHA, ONTARIO

Mental illness affects one in five Canadians at some time in their lives.

Through a planned gift to CMHA, Ontario, you can make a significant contribution, tailored to your personal and financial circumstances, and have a positive impact on untold lives.

A planned gift:

- Is made, after careful consideration, from assets not income
- Enables you to achieve your charitable goals as well as realize tax savings

Through a bequest in your will or a gift while you are alive, through life insurance or appreciated stock, or through other types of appreciated property, you can help to ensure CMHA Ontario's life-changing work continues.

More than ever before, CMHA, Ontario is relying on public support to provide the programs and services that are so desperately needed by people in mental distress. Over the years, these programs have become even more essential as a result of the many changes to our public health care system, and especially to mental health care.

There is no question that these programs help save lives.

When you consider making a gift to CMHA, Ontario, you become a partner in the fight to protect the mental health of all Ontarians.

If you would like more information, please call Mary Jane Wood at:
416-977-5580 Ext. 4159 or e-mail mjwood@ontario.cmha.ca.

Thank you for understanding that mental health matters.

Network
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CANADIAN MENTAL HEALTH ASSOCIATION
L'ASSOCIATION CANADIENNE POUR LA SANTÉ MENTALE
Canadian Mental Health Association, ONTARIO

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