

# MAKING A DIFFERENCE

Ontario's Community Mental Health  
Evaluation Initiative

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A KEY GOAL OF THE  
CMHEI PROJECT IS  
TO COMMUNICATE  
FINDINGS BEYOND  
THE RESEARCH  
COMMUNITY TO  
SERVICE PROVIDERS,  
CONSUMERS, AND  
FAMILIES; REGIONAL  
AND PROVINCIAL  
DECISION-MAKERS;  
AND POLICY  
DEVELOPERS.

# PRINCIPAL INVESTIGATOR'S MESSAGE

## Community Mental Health Provides Results

On behalf of all CMHEI investigators, research partners, and study participants, I am pleased to present *Making a Difference: Ontario's Community Mental Health Evaluation Initiative*.

The report describes some of the key findings of the Community Mental Health Evaluation Initiative (CMHEI), the first-ever multisite assessment of community mental health programs in Ontario. The CMHEI is a partnership of the Ontario Mental Health Foundation; the Centre for Addiction and Mental Health; the Canadian Mental Health Association, Ontario; and the Ontario Ministry of Health and Long-Term Care, which provided more than \$3.5 million over six years to fund the project. Further analysis of the project data are ongoing, and this report will be followed by more findings and results over the coming months and years.

The research provides new, Ontario-based data on how community mental health is working. Project findings point to the effectiveness, value, and importance of community mental health; but there remain many opportunities for improvement and future research, and work is continuing in a number of areas. The report also reflects the project's strong commitment to developing knowledge that will build the capacity of Ontario's community mental health system and support informed, evidence-based decisions on programs, services, and policies.

A key goal of the CMHEI project is to communicate findings beyond the research community to service providers, consumers, and families; regional and provincial decision-makers; and policy developers. We hope that this report will help to inform and promote increased knowledge and awareness of community mental health. In addition, CMHEI project research findings have been, and will continue to be, published in scientific journal articles, presentations, and reports. The CMHEI website [www.ontario.cmha.ca/cmhei](http://www.ontario.cmha.ca/cmhei) is the best source of updated information about these communications products and vehicles.

I would like to thank all the project partners, principal investigators, researchers, study participants, and others for their contributions. The CMHEI has taken a large step in building the capacity and effectiveness of community mental health in Ontario.

Dr. Paula Goering  
Principal Investigator

# 1

## THE COMMUNITY MENTAL HEALTH EVALUATION INITIATIVE – KEY FINDINGS

## The CMHEI assessed the effectiveness of community-based mental health services and supports, providing evidence to support future decisions about programs and service delivery. Its key findings are:

The Ontario government's investment in community-based services and supports is producing positive results. Community mental health is making a difference in people's lives.

- Community-based services and supports can increase the ability of people with serious mental illness to live in the community.
- It is possible for people with serious mental illness to recover and lead fulfilling lives, as recent work in mental health reform has asserted.

The CMHEI has generated knowledge about the people being served by Ontario's community mental health programs.

- Many people with serious mental illness rate their quality of life as poor. They live in disadvantaged or impoverished circumstances, are marginalized in the community, endure the dual stigma of mental illness and poverty, and suffer from high levels of distress. For some individuals, substance use, physical health problems, and criminal justice involvement further complicate their lives.
- Few study participants work for pay, and most spend considerable time at home, watching TV, and sleeping.
- People with serious mental illness who engage in productive activity report multiple benefits, such as income, freedom, increased self-esteem, and a sense of contributing to and being a part of a community.
- Clients use a variety of strategies for dealing with crises, including managing on their own, getting help from family or friends, and formal services.

People are benefiting from using various kinds of community mental health services.

- Community mental health programs serve a wide range of people who require different types and combinations of services and supports.
- Intensive Case Management (ICM) programs have many components in common with Assertive Community Treatment (ACT) programs. Both ICM and ACT are helping clients to decrease their reliance on institutional care and improve their quality of life.
- People using ACT and ICM services experience fewer crises.
- ACT clients are more likely to remain in treatment.
- Consumer self-help initiatives benefit their members. Participants had fewer symptoms and fewer hospitalizations and reported more satisfaction with quality of life than did those individuals who did not use self-help.
- Members of consumer and family self-help programs contribute to Ontario's mental health system through their involvement in education, community planning, research, and advocacy.
- Family members who participate in self-help programs experience less burden and stigma.

### People need more than community mental health services.

- Housing, employment, income and health care supports are essential to maintaining the health and well-being of people with serious mental illness.

### Community mental health provides value for money.

- Community mental health services and supports save money. For example, it can cost up to five times less to provide services to a person in the community than it would to keep that person in hospital for the same amount of time.
- Consumer and family participants in self-help programs provide thousands of hours of volunteer time each year. When the value of that volume of time is estimated, the findings show that the provincial investment in self-help is multiplied five-fold.

### Implications of the CMHEI for the Mental Health System.

- In order to meet the different needs of people with serious mental illness, it is important to maintain a comprehensive range of programs and services.
- Self-help, ICM, and ACT programs and services are serving somewhat different populations; all should be maintained.
- Community mental health services need better links to primary care, the justice system, and social services.
- Given the benefits of self-help programs, greater investment in these programs is merited.
- The mental health system should recognize the valuable contributions of family members and adequately support their needs.
- To reduce discrimination against people with mental illness, programs should do more to facilitate the involvement of clients in their communities.
- Ongoing process and outcome monitoring is needed to promote program improvement.
- More research is needed to understand the relative strengths of ICM and ACT.

### Implications of the CMHEI for Service Provision.

- All community mental health programs should screen and assess clients for concurrent disorders as a first step in determining the services and supports they require.
- Programs should emphasize supported employment and other strategies that facilitate client engagement in work.
- Programs can serve clients better if providers consider individual needs for both formal and peer support services and refer to both types of programs. Even for clients with serious mental illness, self-help can be a useful complement to other services.
- ACT and ICM programs need to provide a better balance between medical-therapeutic and rehabilitation-recovery services.

### Implications of the CMHEI for Research.

- The CMHEI has increased Ontario's capacity to conduct community mental health research.
- The CMHEI has provided training for a new generation of researchers. It has created a network of experienced scientists, researchers, and community partners – including consumers, family members, and service providers whose knowledge and experience can contribute to future research.
- By engaging community mental health services in evaluation research, the CMHEI has promoted a culture of ongoing, systematic evaluation that will inform evidence-based practice and service delivery.
- The CMHEI has created research momentum, with each project generating a number of new sub-studies led by senior researchers and students.

# 2

## CMHEI OVERVIEW

The Community Mental Health Evaluation Initiative is a provincial evaluation project conceived by four partners: the Ontario Mental Health Foundation; the Centre for Addiction and Mental Health; the Canadian Mental Health Association, Ontario; and the Ontario Ministry of Health and Long-Term Care, which provided all funding for the project, a total of \$3.54 million over six years.

Over the last two decades, Ontario has been undergoing a fundamental reform of mental health care. This includes establishing a community-based system of services and supports for people with severe and persistent mental illnesses so they can receive treatment and live in the community, rather than in hospitals and institutions. These reforms are part of the Ontario government's vision for advancing health care and enhancing physical and mental health in all life stages through a high-quality system that is easily accessible for all Ontarians.

Today in Ontario, community mental health is attempting to help people with serious mental illness to cope more effectively with their illness and live more independently. Greater numbers of people with serious mental illness are being served in the community through a range of services and supports, including ACT, ICM, crisis response, and consumer/survivor and family initiatives.

As community mental health services began to grow in the province, a need emerged for Ontario-based research to support frontline service providers and program managers, as well as policy-makers and system planners. There is a body of community mental health research in Ontario, but studies have used diverse tools and methods. To generate the evidence base that can support planning, managing, and delivering an integrated community-based mental health system, an evaluation of diverse services and supports using a common approach was needed.

The CMHEI was a response to this need, the first of its kind in Canada: an evaluation project with studies involving multiple sites and program types over a six-year period.

The CMHEI research studies involved a diverse range of organizations and individuals, including government, community providers, families, and consumers. This research has generated evidence to support sound decision-making about future programs and service delivery. Findings are also helping to define what constitutes effective practice in the areas studied.

## CMHEI Partners

The **Canadian Mental Health Association, Ontario**, advocates on behalf of people with mental illness and their families and works to raise awareness of mental health issues and to ensure that community-based mental health services are available, accessible, and well funded.

The **Centre for Addiction and Mental Health (CAMH)** is a public hospital providing direct patient care for people with mental health and addiction problems. The Centre is also a research facility, an education and training institute, and a community-based organization providing health promotion and prevention services across Ontario and Canada. CAMH's Health Systems Research and Consulting Unit led the overall initiative and acted as the coordinating centre.

The **Ontario Mental Health Foundation** aims to promote the mental health of people living in Ontario; to prevent mental illness; and to improve diagnosis, treatment, and rehabilitation. It does this by supporting the professional development of researchers and by funding excellent mental health research. The Foundation looks to people with mental disorders, providers, and the research community to identify innovative areas of research.

The **Ontario Ministry of Health and Long-Term Care** is responsible for administering the health care system and providing services to the Ontario public through such programs as health insurance, drug benefits, assistive devices, care for the mentally ill, long-term care, home care, community and public health, and health promotion and disease prevention. It also regulates hospitals and nursing homes, operates psychiatric hospitals and medical laboratories, and co-ordinates emergency health services.

The Ontario government funds research to support the development of effective programs to help people with serious mental illness and their families. The CMHEI was funded entirely by the Ministry of Health and Long-Term Care, which provided \$3.54 million over six years.

# PROVIDING VALUE FOR MONEY

The CMHEI indicates that community-based programs save money for the mental health system. Data from the Ottawa ICM study indicate that, on average, it costs about \$68 per day to provide community-based services to a person with mental illness. To treat that same person in hospital, however, would cost about \$481 per day.

\*Costs are based on 2001 service costs

3

A COMMON METHODOLOGY

The CMHEI consisted of six core research studies that evaluated community mental health services and supports; a comparative multisite study; and a complementary project, Explaining Outcomes, which focused on the data collection tools that can be useful across a wide range of community support models, practices, and community settings.

The six core research studies assessed a range of community-based services and supports, including ACT teams, ICM, crisis response, Consumer/Survivor Initiatives (CSI), and family support organizations.

The project's design linked the six core studies through a common data protocol. Data were collected about more than 800 users of community mental health services and supports in communities across Southern and Eastern Ontario, including Toronto, Ottawa, Kingston, Brockville, Kitchener-Waterloo, Hamilton, and the Niagara Region. Participants included new and existing users of community mental health programs, as well as members of family and consumer self-help groups.

Data were collected through a comprehensive client assessment, which included measures of symptoms, functioning, and service use from the perspective of both the participant and independent raters. Clients were assessed at entry to the study and after nine and 18 months, which enabled CMHEI researchers to assess the rate and areas of client change. It also allowed for comparisons of cost and cost-effectiveness. Finally, the diversity of participating programs enabled the CMHEI to examine how different types of services can work together to meet client needs.

Data were managed by the project's coordinating centre, located in the Health Systems Research and Consulting Unit at the Centre for Addiction and Mental Health in Toronto. Cross-project training of researchers helped to ensure comparable approaches to data collection across the core CMHEI projects. All data were submitted to the project's coordinating centre, where they were checked and merged into a single database to support multisite analysis.

# PARTICIPATORY ACTION RESEARCH

The participatory action research method (PAR) involves individuals in researching their own situations and developing their own solutions. The goal of PAR is to empower people who are traditionally the subjects of research to help achieve positive social change. PAR can also lead to much more accurate research and evaluation results.

PAR was used to expand the role of consumers and family members beyond that of the traditional research subject. This approach reflects a growing awareness that the relationships among mental health consumers, providers, caregivers, researchers, and decision-makers are stronger and more beneficial when they are two-way, based on exchange and collaboration.

In most projects, qualitative data complemented the quantitative findings by providing more information about the experiences of consumers, service providers, and family members. Qualitative interviews played a useful role in the instrument development (Explaining Outcomes) project, identifying characteristics of programs that consumers had found helpful for keeping them out of hospital and improving their quality of life.

Consumers were hired as research assistants in a number of studies, with many benefits. Individuals obtained job experience and training they would not otherwise have received and, subsequent to the CMHEI project, some have successfully moved on to other employment. The consumer research assistants learned new skills and were paid for their efforts, and many said they gained confidence as a result. Many study participants also reported that their interviews were personally fulfilling. They appreciated being heard and they felt respected, knowing that their opinions were valued and had the potential to help others.

Similarly, family member researchers were part of the Family study's team of 11 research assistants. These individuals reported many positive benefits from this employment opportunity. The experience altered their perception of themselves in relation to other family members and, for some, it led to future employment in the research field. As a result of the CMHEI study, family research assistants became more active with their own support groups. Several said the experience had helped them to become more self-sufficient and confident. Others, however, noted that conducting the interviews was also a sad experience, reminding them of how mental illness had affected them, their family, and other families.

# 4

WHO IS USING  
COMMUNITY MENTAL  
HEALTH PROGRAMS

## A Who is being served in programs for individuals with serious mental illness

The CMHEI has provided a picture of individuals using intensive community supports and consumer initiatives, as well as the ill relatives of those using family support. Tables 1 and 2 describe these individuals when they started the study, grouped into three categories: those enrolled in ACT and ICM, members of CSIs, and ill relatives of members of family self-help programs.

These data indicate that community mental health programs are providing care to individuals with diverse needs and are serving the populations they were intended to serve. As table 1 indicates, most individuals in the study were suffering from severe, long-term mental disorders:

- The average age was 41 years, and the average length of illness was about 18 years.
- The majority had a major mental illness: a diagnosis of schizophrenia, mood disorder, or depressive disorder.
- About one-third had two or more psychiatric diagnoses, and one-third were also experiencing physical health conditions.
- Almost all had been prescribed psychotropic medications in the previous nine months.

Table 1: Client illness characteristics on program entry

CLIENT DEMOGRAPHIC AND ILLNESS CHARACTERISTICS	USERS OF ACT/ICM <sup>1</sup>	CSI <sup>2</sup> MEMBERS	ILL RELATIVES OF FAMILY MEMBERS	ALL PROGRAM USERS
SAMPLE SIZE	245	61	216	522
Mean age (years)	41.0	39.5	40.9	40.8
% Male	61.2	45.9	62.5	60.0
% Schizophrenia disorder	66.8	31.1	54.2	57.4
% Mood disorder	33.6	62.3	50.5	44.0
% Two or more psychiatric diagnoses	39.8	37.7	24.1	33.0
Median age at first psychiatric admission (years)	23	23	22	23
% Physical health problems in past nine months	36.7	47.5	30.7	35.5
% Prescribed psychotropic medications in past nine months	94.3	90.0	88.8	91.6

<sup>1</sup> Assertive Community Treatment and Intensive Case Management.

<sup>2</sup> Consumer/Survivor Initiatives.

As table 2 indicates, study clients were living in disadvantaged circumstances, with many experiencing hospitalization and expressing dissatisfaction with their quality of life and level of symptom distress.

- Many people were isolated, living alone, or with unrelated adults. Only 18 per cent were married or lived with a partner, compared with 53 per cent for the Ontario adult population.
- About one-third had not completed high school, compared with 24 per cent for the Ontario adult population.
- Most individuals did not have jobs and lived on very low incomes (the average monthly income was about \$1,000 per month, with income mainly from the Ontario Disability Support Program or other disability pensions).
- About four in 10 individuals had been admitted to hospital for psychiatric reasons at least once during the previous nine months. One in four had visited a hospital emergency room during the same period.

Table 2: Client community functioning on program entry

CLIENT COMMUNITY FUNCTIONING	USERS OF ACT/ICM <sup>1</sup>	CSI <sup>2</sup> MEMBERS	ILL RELATIVES OF FAMILY MEMBERS	ALL PROGRAM USERS
SAMPLE SIZE	245	61	216	522
% Married/living together	8.6	23.0	26.9	17.8
% Less than high school education	43.9	31.1	21.8	33.2
% Unstable housing	35.5	29.5	7.5	23.3
Average monthly income (\$)	868.80	1,096.60	1,206.50	1,005.80
% Any paid employment in past nine months	15.8	43.1	31.8	25.4
% Any legal system involvement past nine months	20.8	9.8	8.3	14.4
% Hospitalized in past nine months	49.8	29.5	30.0	39.3
% Emergency visit in past 90 days	34.3	19.7	12.3	23.8
% Satisfied with quality of life	39.4	37.7	N/A*	39.1
% Reporting moderate or higher symptom distress	26.5	24.6	N/A*	26.1

<sup>1</sup> Assertive Community Treatment and Intensive Case Management.

<sup>2</sup> Consumer/Survivor Initiatives.

\* These data were not collected for this part of the study.

The nature of the serious mental illness and community living challenges varied among users of different services and supports at the start of the study.

Compared with clients of ICM and ACT programs, the CSI members were more likely to have a mood disorder and less likely to have schizophrenia. They were also less likely to have been admitted to hospital or visited a hospital emergency room during the previous nine months. However, there was also notable overlap between both groups:

- Both had high rates of physical health problems and unstable housing.
- Both groups were prescribed psychotropic medication and both had similar rates of co-morbidity.
- Despite higher rates of working for pay among those in self-help, both groups were living on very low incomes.
- Self-report measures indicated similar levels of symptom distress and low personal ratings of quality of life in both groups.

Compared with clients of ICM and ACT programs, the ill relatives of the family self-help members were more stable – fewer were in living in unstable housing, more were married and working, fewer had legal involvements, and rates of hospital admission and emergency room use were lower. However, there was some overlap between the two groups: both were suffering from chronic psychiatric disorders and physical health challenges, and incomes were low.

There were many areas of similarity between the ill relatives of family self-help members and CSI members; i.e., in rates of hospital admission, emergency service use and legal involvements, rates of marriage, and education and income levels.

## B Who is using family self-help

The CMHEI has provided information about members of family self-help programs:

- Most are female (75 per cent) and are older (the average age of members is 59 years).
- Regarding their relationship to their ill relative, 60 per cent are parents, 19 per cent are spouses, 11 per cent are siblings, and 4 per cent are children.
- Forty-three per cent live with their ill relative; of the 57 per cent who do not, 71 per cent have daily or weekly contact.

At study entry, the level of burden and coping of family self-help group members was assessed, showing:

- Spouses reported significantly more burden than siblings.
- Parents reported significantly better coping than spouses.
- Females reported significantly better coping than males.

A comparison between those who lived with an ill relative and those who did not showed that those living with an ill relative experienced significantly more burden and reported higher levels of perceived stigma. No difference, however, was found between the two groups in terms of the amount of social support given and received and the sense of empowerment and hope.

5

HOW CONSUMERS  
ARE DOING

In order to examine the outcomes of people using the community mental health programs studied by the CMHEI, program users were combined into larger groups based on the program model or approach and the length of participation of the program users. The study groups included:

**ICM – new clients.** This group included clients who were new admissions to two ICM programs located in Ottawa and Toronto (enrolled in the program for less than nine months).

**ACT – new clients.** This group included clients who were new admissions to ACT teams in Toronto and Kingston (enrolled in the program for less than nine months).

**ACT – ongoing clients.** This group included clients enrolled in four ACT teams in the Kingston area who had been receiving services for at least nine months when they started the study.

**CSIs – new members.** This group included new members of four CSIs located in central Ontario who had a minimum of four hours of contact with these programs during the first 16 months of the study.

Over an 18-month period, consumers in each study group were examined for changes based on six key outcome measures:

- the percentage who had experienced one or more admissions to hospital for psychiatric reasons (“psychiatric admissions”) during the past nine months;
- the percentage who had one or more visits to a hospital emergency department during the past nine months;
- the percentage with an unstable housing situation (i.e., three or more moves during the past nine months or currently living in hostels, on the street or in some other temporary situation);
- the percentage who worked for pay during the past nine months (full-time, regular part-time, or part-time casual);
- the percentage who were mostly satisfied with their quality of life at the time of assessment; and
- the percentage who reported moderate to extreme symptom distress.

For each of these areas, the study assessed how the consumers in the programs were doing when they started the study and then after nine and 18 months in the program. Some outcome measures pertained to their present situation (e.g., the consumer’s current view of his or her quality of life), whereas others referred to the consumer’s experiences during the preceding nine months (e.g., whether the individual had experienced a psychiatric admission during that time).

The following sections describe outcomes for clients of the individual programs and make some comparisons with control conditions. Future analysis of the data will continue to compare the relative performance of the programs for similar groups of clients.

## A What was learned about new ACT clients

“You feel safe knowing the staff will recognize the symptoms before you do and help keep you out of hospital by giving you treatment.” – ACT study participant

Clients in this study group were receiving service from the Toronto study ACT team or Kingston study ACT teams and had been in the program for less than nine months. Most were very new to the programs.

As figure 1 indicates, community living was very challenging for these clients when they started the programs. Almost all had been hospitalized during the past nine months, and many had visited a hospital emergency department. Half had unstable housing, and few reported satisfaction with their quality of life.

After 18 months, there was significant improvement in every area. Particularly noteworthy was the improvement in paid employment. These ACT teams differed from the ICM programs in having a vocational specialist on staff, and it appears that, consistent with results of other studies, this approach makes a difference. The ACT clients also reported significant improvement in quality of life, although half still reported being mainly dissatisfied or unhappy. Symptom distress declined, but not significantly.

Figure 1: New ACT clients – Changes over 18 months (N=66)



These findings are positive and consistent with the existing evidence base for ACT. With five ACT teams in the study, further CMHEI analyses are planned to explore the relative effect on client outcomes of variations in implementation of this model. Another question of interest is how the effectiveness of ICM, a different form of intensive community support, compares with ACT. Results of a CMHEI analysis to address this question are reported in Section 6.

## B What was learned about clients using ICM

Clients in this study group were receiving service from ICM programs located in Ottawa and Toronto. Both programs provided intensive, individualized community support to clients, using an individual rather than team approach. Caseload ratios in the programs were similar, at about 15 clients per staff member.

The ICM approach is not articulated in as much detail as the ACT approach, and implementation varies, depending on local conditions. The Toronto ICM program differed from the Ottawa program in several ways. It developed a unique partnership with the Toronto Community Care Access Centre and was able to enhance the case management support with nursing and personal support services. Frequency and intensity of support were therefore increased and provided seven days per week as necessary, compared with weekday support provided to clients in the Ottawa program. Also, the Toronto program had more control over access to hospital beds through its hospital sponsorship.

As figure 2 indicates, many clients came into these two programs with high past rates of hospital and emergency room use and unstable housing situations. Very few were working for pay, and only about one-third were satisfied with their current quality of life. After 18 months in the two programs, there were significant improvements. The percentage of consumers admitted to hospital for psychiatric reasons declined, as did visits to hospital emergency departments. Many people moved into stable housing, and those experiencing medium or high levels of symptom distress declined. However, there was little improvement in employment activity, with very few individuals (18 per cent) working for pay, even after 18 months. As well, there was little increase in the number of consumers who were satisfied with their quality of life.

Figure 2: New ICM clients – Changes over 18 months (N=90)



The Ottawa study compared outcomes for the ICM clients to a comparison group of clients who received time-limited housing outreach and other mental health services. Participants in both study groups showed significant improvement over time in housing stability, community functioning, hospitalizations, and substance abuse. They also reported increased levels of satisfaction with their circumstances in the areas of family relations, finances, living situation, and daily activities.

Contrary to what might be expected, there were no significant differences between the groups in rates of improvement. This finding needs further study. One possible explanation is that the early stabilization of housing for clients in the comparison group provided a base for major improvements in other areas. Another explanation relates to the level of support received by individuals in the comparison condition. At nine months, more than half of these clients were receiving at least weekly support from medical or rehabilitation services, and one-third had two or more contacts with providers per week. With broad-based improvement in the quality of community support occurring in many jurisdictions, it is not uncommon for distinctions between experimental and control conditions in research studies to decrease. Further research will examine in more detail the differences in intensity and type of support received by clients in ICM and comparison groups and how this may affect outcomes.

A multisite sub-study compared client outcomes achieved by the two ICM programs (located in Toronto and Ottawa) and the Toronto ACT program. Across the three programs, clients achieved similar rates of decline in emergency room use and similar improvement in housing stability. However, some differences emerged. ACT clients achieved better vocational outcomes (perhaps due to the vocational specialist on staff), and Ottawa ICM program clients were less likely to be admitted to hospital and spent fewer days in hospital, even after taking into account for different rates of hospitalization at baseline.

One aim of intensive community support programs is to engage clients who have a history of instability and difficulty remaining in care. While both programs emphasized proactive outreach, about one-quarter of ICM study clients dropped out of the programs during the study period, compared with only 3 per cent for the Toronto ACT clients. Compared with those who continued, the individuals who dropped out had lower medication adherence when they started the program and less stable housing at nine months. Clients dropped out for many reasons, some of which were beyond the control of program staff. Nevertheless, the findings suggest a need for further research to assess what factors promote continuation in treatment or program retention. There may be other characteristics that distinguish the dropout group that were not measured in the CMHEI study. Future studies can also determine whether this finding holds in other ACT and ICM programs.

Overall, these results indicate that, like ACT, ICM can benefit people with serious mental illness and make a valuable contribution to the continuum of care. Future research can assess the critical ingredients that make both models effective. It can also examine the impact on client outcomes of variations in implementation of ICM. Another question to pursue is whether similar results would be achieved in smaller urban and rural settings.

## C What was learned about ongoing users of ACT

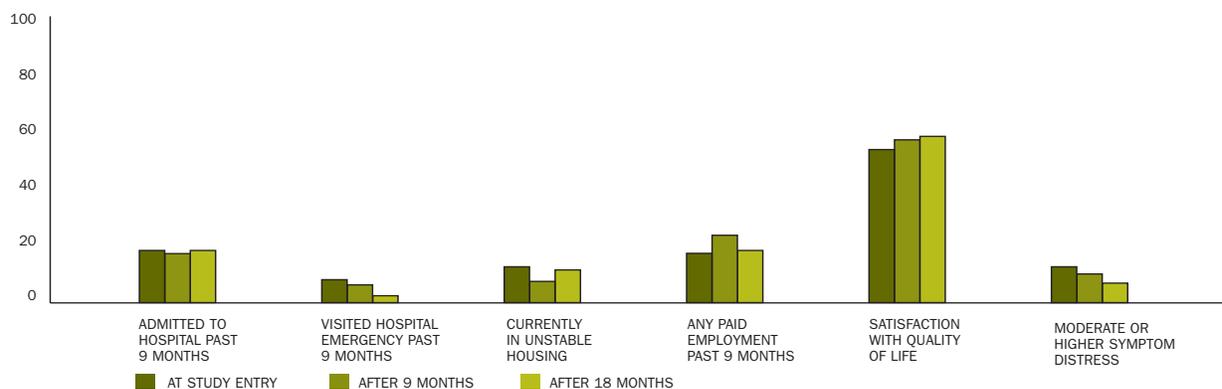
Members of this study group consisted of individuals enrolled in one of the Kingston-area ACT teams who had been receiving service for nine months or more. In fact, most were long-term users. One-half had been in the programs for more than four years.

As indicated in figure 3, this group were higher-functioning than new ACT or new ICM study clients (i.e., more likely to be in stable housing, less likely to visit hospital emergency services or be admitted, with lower rates of symptom distress, and more satisfied with quality of life), yet there was no indication of improvement in outcomes during the study period. After 18 months, a number of problems persisted, with almost 20 per cent having experienced a hospitalization in the past nine months, 11 per cent living in unstable housing situations, and very few individuals working for pay.

These findings raise the question of whether more can be done to support recovery in these individuals. The challenge of integrating treatment and rehabilitation in ACT programs was examined in a sub-study of ACT staff perspectives on service delivery. The staff indicated that their daily activities with clients often focused on immediate issues (e.g., related to crisis management and maintaining housing) rather than rehabilitation and that hiring freezes often resulted in a lack of rehabilitation personnel. Some staff also noted a need for their programs to develop more organized options for socialization and recreation, a suggestion that was echoed in another CMHEI sub-study of client satisfaction with ACT.

Another interpretation of the study findings is that these individuals no longer need the anchoring support of ACT and could benefit from other community services and supports.

Figure 3: Ongoing ACT clients – Changes over 18 months (N=88)



## D What was learned about crisis occurrence and recovery among ICM and ACT users

“[It is] overwhelming... You seem to lose a grip on things. Everything seems to be too much.” – Crisis study participant

The study examined the natural history of crisis events of 80 people, each randomly assigned to either an ICM or ACT program. The investigators looked at the timing and frequency of crisis events; the events leading up to them; and the people, supports, and interventions that were instrumental in helping resolve the crises.

The preliminary analysis showed that the number of crises declined during the study period (18 months). During the first nine months, there were 236 crisis events that required intervention, experienced by two-thirds of the clients. During the second nine months, there were 186 crisis events, a reduction of 21 per cent. Emergency room visits fell by 30 per cent during the same period. For those experiencing psychiatric crises (e.g., psychosis), the rate of decline was 30 per cent and for those experiencing substance-use or psychosocial crisis (e.g., housing or job crises) – the rate of decline was 10 per cent.

In-depth interviews with 14 participants about their experience of crisis were also conducted. These individuals associated their crises with the exacerbation of illness symptoms and employed various strategies to alleviate their crises, including medication, sleeping, walking, seeking help, attending organized activities, and contact with caring individuals. Frequently, a third party sought help on behalf of the individual in crisis. These qualitative accounts differ somewhat from the more traditional model of crisis, which assumes that the crisis is caused by an external event.

“That’s why attending these programs [Assertive Community Treatment and drug rehabilitation] and stuff and getting active and doing things [helps] instead of sitting at home in my home brooding and pouting, and that’s when I start hearing voices and start seeing things.” – ACT client

More in-depth information about the experience of crisis was collected over a nine-month period from a sub-group of clients using ACT, ICM, and a hospital psychiatric emergency service and will be used to further examine factors related to the occurrence and resolution of crisis events. Various ways to define “crisis” – by symptoms, setting, and perspective – are being considered. Based on the literature and interviews, the team is developing a fidelity scale for hospital-based psychiatric emergency services.

# ACT: FROM THE SERVICE PROVIDERS' PERSPECTIVE

A CMHEI qualitative study examined ACT delivery from the perspective of the service providers of four ACT teams in Kingston, Brockville, and rural Southeastern Ontario.

The study was among the first to focus on the experiences of frontline service providers and the particular challenges faced by providers in implementing the ACT model within the Ontario context. It also provided valuable insights about those areas of the ACT model that are working well and those that require further development, assessment, or modification to serve the needs of Ontario clients.

Over all, the providers were largely positive about their involvement with ACT. They identified several features of ACT as particularly satisfying and pointed to low staff turnover as evidence of their belief in and commitment to the ACT model. Seeing clients achieve positive life changes reinforced the hopefulness engendered by the ACT model's philosophy and contributed to the providers' belief that they are doing good work.

Providers also identified a number of distinct challenges related to the larger ACT structures and the province's community mental health system. Findings indicated several areas where providers are experiencing challenges in the delivery of services, as well as aspects of the ACT model that require some attention and development to address the needs of Ontario people using these services.

## E What was learned about members of CSIs

“I felt isolated. I didn’t have any contact with peers who were going through the same situation... It does make quite a difference for an individual to contact his peers and go through what they have gone through and give each other support.” – CSI member

“Overall, I just feel better. I don’t feel hopeless and unsure of what to do now. Before it felt like I had no options and that I’m trapped.” – CSI member

“I have more power in terms of taking control of my own life and I think that [CSI] put that step forward.” – CSI member

Four CSIs participated in the CMHEI study. These programs offered educational, social, and advocacy opportunities, as well as peer support. They were not peer-run businesses.

The study group consisted of 61 new CSI members, with new members defined as persons who had at least a minimum of four hours of contact with their CSI group during the first 16 months of the study. These individuals averaged about one event and two hours of participation a week. These new self-help participants were experiencing many challenges when they joined the CSI: almost 40 per cent were in unstable housing, almost one-third had been admitted to hospital in the past nine months, and one-quarter reported moderate or high symptom distress.

After 18 months in the program, there was significant improvement in a number of areas. These individuals were more likely to be living in stable housing and were less likely to be hospitalized or visit a hospital emergency room. They also reported improvements in quality of life and symptom distress. Only paid employment levels showed no improvement. In qualitative interviews, participants reported improvements in their mental health and more independence in housing and finances and they felt more empowered and supported by their peers. They also valued the programs as a place safe from community perceptions and stigma.

“Participation in CSI helped a lot. In other parts of my life there is nothing there. I am not working. I don’t have a family on my own or anything like that. I was very isolated at the time, so it helped me socialize. Having things to do and places to go and meeting people [started to be] a part of my daily schedule.” – CSI member

Figure 4: CSI members – Changes over 18 months (N=61)



The CSI study compared outcomes over 18 months for new CSI users with a control group who were eligible to participate in the CSIs but were not active. Over 18 months, the CSI members had fewer hospital admissions, less symptom distress, and improved social support and quality of life relating to daily activities. In contrast, there was no change among the inactive group. Employment and education activity also dropped significantly among inactive participants during the study period, while there was no change for those in the active group.

An interesting question that will be examined using these data is the relative benefit of CSIs and of intensive formal services for individuals with similar severity of illness. The study also examined how and to what extent CSI members took part in activities such as public education, political advocacy, community planning, and action research. Feedback from CSI staff, service providers, and health planners pointed to a number of areas of positive impact. Some specific examples were:

- One local hospital saw the effectiveness of CSI peer support and began hiring peer support workers to work within the hospital.
- CSI members lobbied a local municipality to reinstate bus pass subsidies for people living in residential care facilities, many of whom were consumers. Their efforts were so successful that the subsidy was not only brought back, but increased to a full 100 per cent.
- A local hospital increased referrals to one CSI based on findings from this study.

“Usually you appear at something [i.e., a public education event] and you speak and the next thing you know you’re invited to sit on some committee. I guess that’s a good outcome.” – CSI member

## F How family members using community-based self-help programs are doing

“We were just at our wits end... We didn't know what to do. It enables you to take things in stride a lot more.”  
– Family self-help group member

The CMHEI Family study followed 279 family members involved in self-help organizations over 18 months to examine the impact of self-help on coping ability and the perceived burden of caring for an ill relative. Specifically, the researchers examined the relationship between participation, social support, and sense of empowerment (e.g., having a sense of control over events in one's life) and the effect of these elements on coping and burden. Both quantitative and qualitative data were used to assess impact.

Some of the study participants were new to self-help at the start of the study, but most were current members, and about 40 per cent had been members for five years or more. In-depth qualitative interviews with families revealed that the pathway to self-help was often through a crisis experience. The existence of family self-help frequently came to the attention of family members through a crisis episode.

“I was so desperate. I couldn't postpone it [joining self-help] any longer.” – Family self-help group member

At the start of the study, those who reported more years of membership in self-help and more hours of participation in the preceding three months also reported higher levels of social support and a greater sense of empowerment. Over the 18-month study period, perceived stigma and burden decreased. Empowerment was associated with better coping and reduced burden at nine and 18 months, but the amount of participation and social support were not associated with change in these areas. However, many members indicated that the simple act of belonging and knowing that there was a place to call upon when in need was beneficial. Receiving the organizational newsletter provided a critical link for many to the news and information about what was going on in the family organization.

“It brings mental health to the surface... The more people talk about it, the stigma is a lot less. It's a lifeline.”  
– Family self-help group member

During the in-depth interviews, family members linked their involvement with self-help with increased social support, reduced stigma and blame, enhanced capacity for coping, and increased ability to manoeuvre the system through advocacy. They indicated that their participation resulted in increased knowledge about mental illness, which resulted in reframing their relative's illnesses more positively. This may account for the reduction in perceived stigma over time.

“In my own little way, I've become a kind of advocate.” – Family self-help group member

As in the CSI study, the Family study examined the activities that family self-help groups engaged in on a day-to-day basis. Over a one-year period, hundreds of family members were actively involved in public education, political advocacy, community social activities, and social support, contributing an enormous amount of volunteer time in these areas. Key decision-makers interviewed as part of the study (e.g., from mental health agencies and the Ministry of Health and Long-Term Care) generally valued participation by family self-help members in mental health planning groups, forums, and workshops. Many family self-help members, however, felt that their organizations did not have a major impact at the system level. Some spoke of smaller steps made in terms of connecting with local physicians and psychiatrists in the field, but felt they were not yet being heard at the larger system level.

# 6

A METHODS STUDY:  
EXPLAINING OUTCOMES

The Explaining Outcomes study sought to improve understanding of the aspects of community support programs that are effective for people with serious mental illness. The study's approach was distinct in that it developed a package of instruments for measuring "critical" characteristics of community support programs in contrast to measuring, for example, fidelity to a specific model. The intent was to develop tools that can be used to assess the link between program characteristics and client outcomes. The tools can also be used for program planning, monitoring, and quality improvement; and have the potential to be useful at a regional level for systems monitoring.

Investigators conducted 42 qualitative interviews to draw on the experiences of consumers, family members, and service providers across 17 different Ontario communities. Respondents were asked for their perspectives on the aspects of community support programs that, in their opinion, had been effective (or ineffective) in improving their quality of life and in reducing their need for hospitalization. Consumers, family members, and service providers identified a broad range of services or aspects of service that were important in assisting consumers to live in the community. The perspectives were grouped into the categories of basic needs, meaningful activity, personal and social supports, services (e.g., assessment and counselling), service climate, organizational functioning, and systems issues. Participant comments indicated both the breadth and depth of program services and support they had received and emphasized ways that the services were effective and helpful. Many of the comments spoke to how programs offered individualized support and addressed unique circumstances or community contexts. Systems issues such as low income and lack of affordable and quality housing were recurrent themes that had presented challenges for consumers and service providers.

The results of the interview process were combined with an extensive literature review and were incorporated into a draft instrument for field testing. Over 200 consumers then completed the draft tools and provided feedback, the majority noting that it had been a positive learning experience despite the time involved. Service providers (120 from 15 programs) also participated in the field-testing and also found the process helpful. For example, they liked how the experience had prompted discussion within their program regarding what they might do differently and how they might address service gaps. Testing of the materials then proceeded to the next reliability testing phase.

In conducting the research project, investigators found considerable variation in the program structures and the services provided, even within the same program models. Furthermore, many programs appear to be using a mixture of models or modified models such as ACT and case management. These findings highlight the difficulty in studying program models without detailed information as to what services are actually being provided. They also identify the need for instruments to be sensitive to the unique features of community support programs, rather than hypothetical characteristics of a program model that may bear little resemblance to their actual implementation in the community.

The investigators are currently developing a revision of the instrument for use by programs for internal quality-improvement purposes that could complement other evaluative and self-reflective tools such as the Psychosocial Rehabilitation Toolkit. The consumer perspective will be a critical and innovative aspect of these quality-improvement initiatives. Investigators are also in discussion with other researchers about the possibility of future research that would build upon the groundwork laid in this study. Specifically, they are discussing the development of a comprehensive, multilevel outcome study to help to further refine the instrument by identifying ways to reduce the list of characteristics to be assessed, including a link to outcomes measured over time in a large community sample. Such a study might best focus on one or more regional systems of mental health services to capture services received from the full range of programs available, as well as from informal sources of support such as family and friends.



7

USING CMHEI RESEARCH  
TO IMPROVE PRACTICE

This section describes selected CMHEI findings and their implications for the delivery of community mental health programs in four areas:

- Helping clients to lead meaningful and productive lives;
- Understanding co-occurring mental health and substance-abuse disorders;
- The role of self-help; and
- Understanding investments in community mental health.

Service providers, program managers, decision-makers, and scientists may want to consider these areas for future program, policy, or research development to ensure that community mental health services and supports evolve to meet the needs of people with serious mental illness.

## A Helping clients to lead meaningful and productive lives

A major goal of community mental health is to help people with serious mental illness to recover and lead meaningful, productive lives in the community. A series of CMHEI studies on what clients do with their time, work, and productivity provides information about how services and supports currently address this need and how they can better help consumers in this area.

The Explaining Outcomes study used qualitative research methods to explore consumer perspectives on how community support programs do or do not promote “productive activity.” Productive activity in this context included volunteer work, parenting, homemaking, and education, as well as gainful employment. Fourteen consumers using ACT, case management, housing support, self-help programs, and clubhouses were interviewed.

The findings indicated that consumers want programs to adopt a specific focus on productivity and make a concerted effort to link them with productive activities such as a paid job, volunteer committee work, and college courses.

“I mean, if these people are disabled and they want to get out in the community and produce, why aren’t you doing something about that instead of sitting around, taking them out for coffee? Why don’t you do something about it?”  
– Consumer

At the same time, some consumers wanted help from programs to develop skills to prepare them for productive activity such as courses in typing and computers. Having control over what they chose to do was considered to be very important.

“And she said, ‘Well, I’ll put you out there when I think you’re ready.’ And my response is, ‘I think I’m ready now.’ She said, ‘Well, I don’t feel that way.’” – Consumer

Also important was having the ongoing support of service providers, peers, and others to pursue and persevere in productive activity.

“I just really felt like they believed in me, like they knew that I could do it, and that was very important because I had a lot of doubts about myself...” – Consumer

Despite the interest these consumers expressed in productive activity, the CMHEI quantitative data paint a different picture about what consumers are receiving from programs and their involvement in productive activity.

A descriptive study examined the daily time use of ACT clients as a measure of their community adjustment and well-being. Study participants (27 clients of two ACT teams in Southeastern Ontario) recorded their actual daily time use in four categories: personal care, productive activity, leisure, and sleep. The findings were then compared with Canadian population norms.

On average, the ACT clients in the study group spent 14.5 hours a day in passive leisure (such as watching television) or sleeping, which is significantly higher than in the general population. Participants were involved in very few hours of productive activity, and only a small percentage of these productive hours involved paid work or unpaid work activities such as volunteering, going to school, or attending day programs. Instead, 70 per cent of these hours were spent on housework.

CMHEI data also assessed participation in paid work for all participants and found that fewer than three out of 10 were working. Data indicated that staff in the ICM and ACT programs spent very little time on employment activities. However, rates of employment were higher when there was a dedicated vocational specialist on staff. For example, the Toronto ACT team included a vocational specialist who established connections with local businesses to provide employment opportunities for clients. This team was most successful in finding work for clients

# STIGMA AND CONSUMER EXPECTATIONS

Qualitative data from the CMHEI suggest that many community mental health clients expect to be rejected by the community at large because of the stigma attached to mental illness.

A CMHEI sub-study examined the relationships between perceived stigma and community integration in the clients of four ACT teams in the Kingston/Brockville areas. Results indicate that despite living in the community and receiving intensive support, study participants believed other community members would reject them. This perception appears to interfere with the sense of belonging they experience in their communities, particularly among those who receive less social support and have greater psychosocial skill deficits.

These findings suggest that ACT programs should take into account individual expectations of devaluation and discrimination from the community at large. Failure to address these concerns will likely only perpetuate the exclusion of ACT clients from full and equal partnership in their communities. Researchers also proposed an “assertive community integration” approach that would engage ACT clients as full community participants.

Ontario’s mental health policy supports this objective in a policy framework, *Making It Work*. While there is a strong evidence base showing the effectiveness of supported employment programs in helping people to obtain and keep paid employment, those running programs in this study found it challenging to devote time to this.

These findings suggest the need for further discussion about implementing program practices that promote mental health through activity. They also suggest a need for future research to address the relationship between activity participation, mental illness, community adjustment, and models of service delivery. Furthermore, daily time use, rather than work status alone, may be a more useful outcome measure of community adjustment for clients.

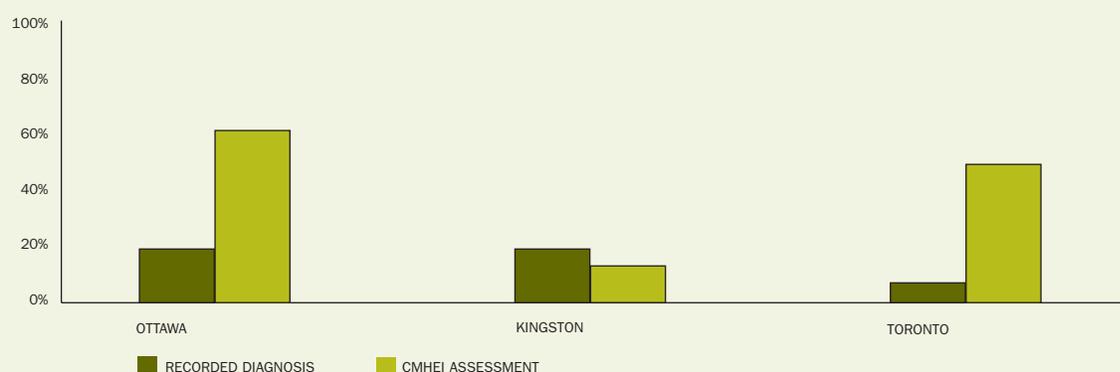
## B Understanding clients with co-occurring substance abuse and mental disorders

The CMHEI project offers a unique opportunity to examine the prevalence and impact of co-occurring disorders in people using community mental health services. Previous research suggests that the co-occurrence of mental health and substance abuse problems is a factor in influencing outcomes. People with concurrent disorders are likely to have poorer service utilization rates, higher readmission rates, lower compliance with medication, and poorer community functioning and quality of life. However, identifying this group is a challenge, and program staff often have difficulty rating substance abuse in clients who are new to their services.

To answer several questions concerning this group, a CMHEI sub-study reviewed how substance abuse was assessed in three of the projects in order to identify more effective approaches for recognizing the problem, estimate the rate of substance abuse, and examine outcomes.

Most programs used the referral diagnosis or conducted a brief admission assessment to establish the presence of a substance abuse problem. The study researchers used additional information sources – including client self-report measures, clinician rating scales, and case conferences – to identify those with co-occurring substance abuse disorder. Analysis compared changes in problem recognition when more time was spent and more data sources were used. As indicated in figure 5, in two study sites the rate of co-occurring problems was significantly higher when using a combination of information sources. The rates rise significantly – from 7 per cent to 49 per cent in the Toronto programs and from 19 per cent to 61 per cent in the Ottawa programs. In Kingston the rate unexpectedly declined from 19 per cent to 13 per cent. Given that the Kingston study participants were ongoing program users, it is possible that the chart diagnosis had not been updated recently to reflect client change. The generally lower rate in Kingston may reflect differences in community context (e.g., a more rural area of the province) and client group served by the ACT teams.

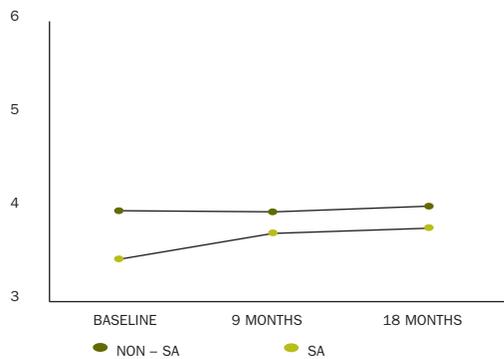
Figure 5: Prevalence of substance abuse/dependence



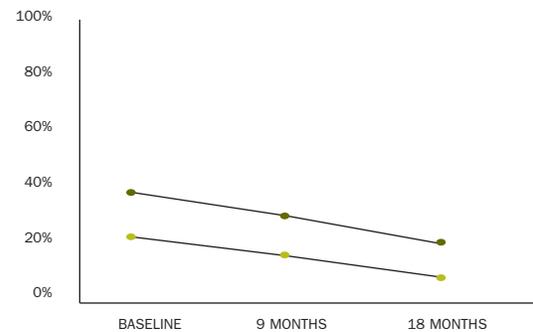
The sub-study also compared profiles of consumers with and without substance abuse at baseline. The substance abuse group was found to be more socially disadvantaged and demonstrated poorer functioning in the community; e.g., more involvement in the criminal justice system (arrested, jailed, or on probation or parole) and poorer community adjustment and quality of life. Importantly, the two groups did not differ with respect to social support, self-esteem, and years of education.

Over time, the substance abuse group improved on primary outcome variables (e.g., hospital and emergency service use, quality of life, and community functioning) (see figures 6 and 7); but at the conclusion of the study, outcomes for the substance abuse group were still below the baseline level for the non-substance abuse group. Thus, there was still considerable room for improvement.

**Figure 6: Quality of Life – Global Rating**



**Figure 7: % Visited ER in Past 90 Days**



These preliminary findings are helpful in considering how community mental health services and supports should address the needs of this group, while also raising important questions for further research. While the prevalence of substance abuse/dependence was very high among consumers in two of the three programs, it was also variable, as seen by the differences between Kingston and the other two sites. This shows the importance of systematic screening and assessment for substance abuse within specific programs of interest. This is consistent with recent recommendations by Health Canada for universal screening for substance abuse/dependence in mental health services. The findings also suggest that resources should be dedicated to substance abuse interventions in community mental health services on the basis of demonstrated need, and it may not be a one-size-fits-all approach.

Results also show that substance abuse/dependence does change over time, with people moving both in and out of “problem categories” with variation across study sites. This suggests that the impact of substance abuse may well be both population- and site-specific. Use of brief outcome-monitoring measures would allow programs to track these changes more effectively.

The comparatively poor community functioning of clients with substance abuse/dependence at baseline and throughout the course of the study suggests that mental health service providers need to be attentive to these problems and their potential impact on individual clients. However, areas of relative strength to draw upon in planning treatment and support would be social support networks, self-esteem, and perhaps education and overall employability. A strengths-based approach building on these areas would be an important topic for future research.

At a system level, the comparatively poorer status of people with substance abuse/dependence and the extent to which this is reflected in the use of high-cost health services such as emergency care and psychiatric hospital beds suggest that decision-makers should ensure that both mental health and addictions services have the capacity to fully address the needs of these clients with co-occurring problems.

Future research with CMHEI data will cost out differential rates of service use that could be attributable to substance abuse/dependence. It will also provide more economic evaluation data to support government’s investment in this sub-population.

## C The role of self-help

*A Canadian Review of Best Practices in Mental Health* (Health Canada, 1997) identified self-help and peer support as significant components of the continuum of care but noted the lack of an evidence base to clarify the nature of these programs and their impact on users. In this context, the CMHEI studies of peer support make an important contribution to the knowledge base. These studies demonstrate that rigorous research about these programs is possible. The participatory action research approach that both the Family and CSI studies used is consistent with the values of these programs and proved to be very successful. Participants developed skills that can support continued research and also appreciated the value of producing tangible evidence about the benefits of their programs to heighten their credibility.

The CMHEI findings indicate that self-help programs can benefit participants in many areas. Furthermore, at the community level, positive changes were demonstrated in service provider perceptions about mental illness and in specific practices, policies, and funding. One noted benefit was increased referrals from hospitals to CSIs. This result is hopeful, as it illustrates the positive change resulting from the CSIs. The CMHEI sub-study that compared members of CSIs and ACT clients found that use of self-help by ACT clients is very low. Similarly, the rate of formal service use by CSI members is low to moderate. For example, 30 per cent of CSI members were living in unstable housing at study entry, yet only 4 per cent used housing programs during the next nine months. Consumers in each program type might benefit from the other, suggesting a need for more effort to make users aware of both types of supports.

Self-help organizations operate on very modest budgets and rely mainly on the contributions of volunteers. A CMHEI sub-study examined CSI and family support programs in an attempt to quantify the value of their volunteer activities. It found that CSI and family member volunteers made a significant volunteer contribution, both at the individual and systems levels, with more than 14,000 hours of activity contributed through these programs over a nine-month period. While individuals both give and receive help, over time the balance shifts, with longer-term members spending more time providing than receiving support.

Both projects, however, noted that the contribution of self-help is not appropriately recognized and it remains underfunded despite its importance in a balanced system of care. One of the basic notions of a recovery-oriented system is that people need supports and resources, not just professional mental health services. Yet a recent report from the Ontario Ministry of Health and Long-Term Care estimated that CSIs receive about 3 per cent of community mental health expenditures and less than 0.2 per cent of the total mental health budget. In part due to low levels of funding, consumer and family support are not consistently available in jurisdictions throughout the province. Moreover, existing programs receive limited funds to organize activities and maintain and renew their organizations.

## D Understanding investments in community mental health

At the very heart of the CMHEI 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. One of the initiative's goals was to understand how, within the context of a constrained budget, resources are used to support individuals with serious mental illness living in the community. Several analysis were conducted using CMHEI data to address this question.

Up until now, we have not been able to answer the basic question of the total costs incurred by clients in the community. Data from clients enrolled in Toronto's ICM and ACT programs were used to examine the costs incurred by these clients in community. An estimated average cost of \$25,849 was incurred during the first nine months in the study. Figure 8 shows how these costs are distributed. The study programs represent a relatively small proportion of total incurred costs. A larger piece of the pie can be attributed to housing. Hospital costs remain substantial, reinforcing the need to continue seeking ways to help individuals maintain their tenure in the community.

One of the most precious resources that community mental health programs and supports have is time. This raises the question of "How are the time costs of the two programs distributed?" Clinical databases were examined to understand how ACT and ICM staff spend time with clients. As figure 9 indicates, the largest proportion of the ACT staff time was focused on one-on-one activities such as symptom management, including medication management, and in activities related to living arrangements. The higher proportion of time spent in symptom management reflects the presence of psychiatrists on the team. In addition, ACT teams spend about an hour each day in team meetings.

In contrast, a smaller proportion of ICM staff time was spent on direct medical care. Consistent with findings reported earlier from other CMHEI analysis, neither of the programs spent a significant proportion of time in activities related to vocation/education, substance use, or physical health. ICM was able to address the physical health needs through partnerships with other community agencies. Programs need to explore how to increase the support provided to clients to address vocational/educational needs.

Using time as a common currency, it is also possible to examine the contributions of family self-help initiatives. The majority of family members participate in support and educational activities (see figure 10). What is the return on investment for these supports? One way to answer this question is to look at what it would take if community program staff were required to perform these activities. This assumes that, in the absence of volunteerism, communities and individuals would rely on community programs for these functions. Based on these assumptions, the Ministry's investment of about \$300,000 in these self-help groups is increased up to five-fold by families' volunteer investment of their time over a year.

Figure 8: Distribution of average monthly costs incurred for clients enrolled in Toronto ICM and ACT for the first nine months

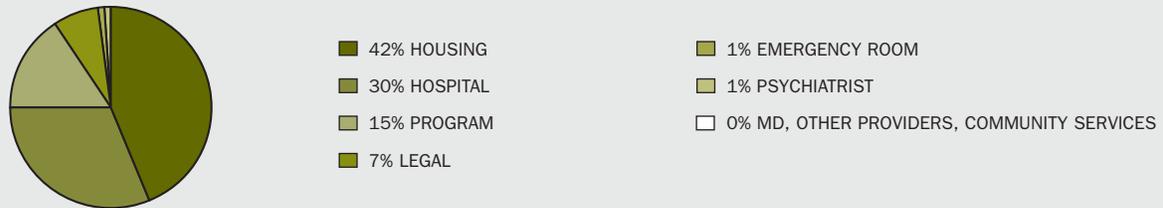
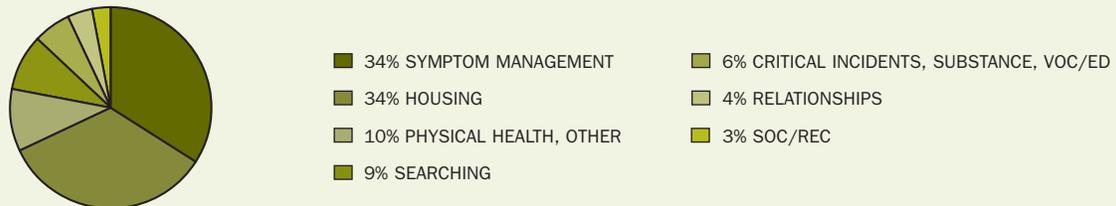


Figure 9: Distribution of time spent in direct client activities by program type

Toronto ACT



Toronto ICM

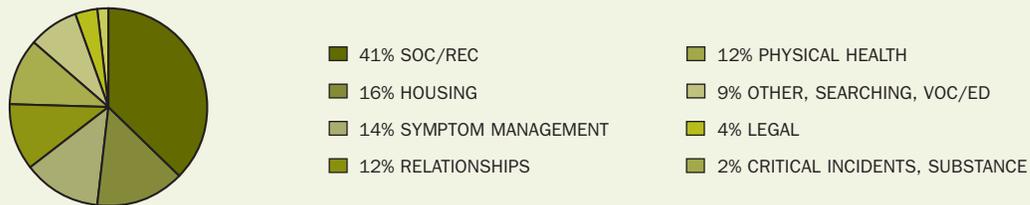
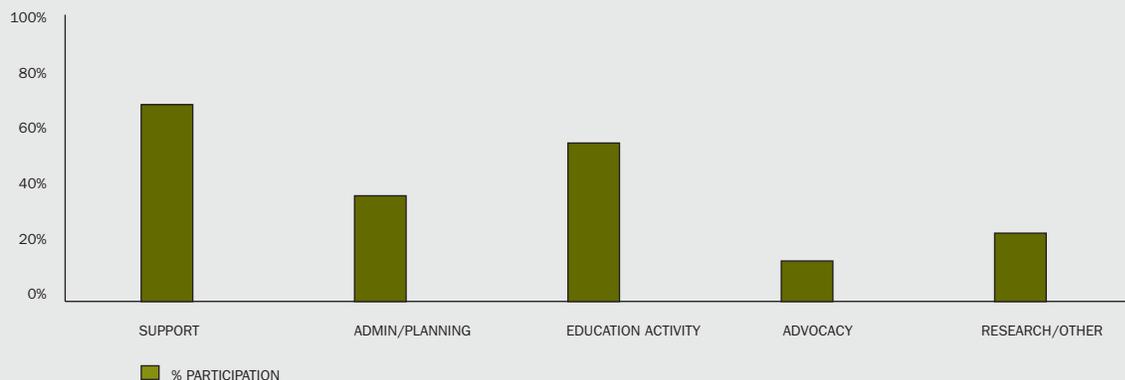


Figure 10: Distribution of activities for family self-help members





8

TOOLS AND METHODS  
FOR MONITORING AND  
QUALITY IMPROVEMENT

CMHEI methodologies emphasized collaboration with program staff, consumers, and family members. PAR, an approach that provided opportunities for meaningful participation from consumers and family members, was particularly valued. Several researchers have written about this approach, including the experience and benefits of consumers and family members working as research assistants.

The CMHEI studies afforded an opportunity to test a variety of outcomes tools. Many were found to have potential for use in routine program monitoring. Also developed were tools for tracking how staff and clients spend their time in the programs. A computer program to help CSI programs keep an inventory of activities was particularly welcomed, as CSIs typically have no way of mapping this information. Now they can continue to use this tool and the information gleaned from it for their own advantage.

The CMHEI also demonstrated that program operators can learn to incorporate data collection into their practice and that they find these data useful for program monitoring and improvement. As a result, programs in other communities throughout the province have adopted some of the tools used in the CMHEI for routine outcome monitoring. These emerging practices are likely to increase the accountability of programs in the community mental health sector.

#### Specific contributions include:

- Testing a suite of tools to consider for outcomes monitoring, including assistance re their use (training, assessment frequency, sensitivity to change);
- Producing data that can provide benchmarks for understanding the level of disability in clients of other programs;
- Introducing research into consumer organizations using participatory action research; and
- Developing tools for program management (e.g., a CSI consumer participation log, an ACT staff activity log, program fidelity tools).

CMHEI researchers are preparing a series of articles for a special issue of the *Canadian Journal of Program Evaluation*, which is scheduled to be published in early 2005. The issue will outline some of these tools and methods in more detail.

#### Examples of article topics include:

- The role of family members as research assistants;
- Creating affirmative employment opportunities for consumers of mental health services in evaluation research;
- Critical considerations for conducting research with marginalized populations; and
- A standardized measure for assessing delivery of case management.

9

CONCLUSION

## The CMHEI study was designed to assess the effectiveness of community-based mental health programs and to provide findings that can support decisions about future service delivery.

Findings from the CMHEI projects clearly show that community mental health is making a difference in the lives of people with serious mental illness, their families, and caregivers. Data indicate that community-based services and supports can help reduce symptoms and increase the ability of people with serious mental illness to live in the community, rather than in hospitals and institutions. Many clients are showing improvement in their daily lives, community functioning, symptoms, and abuse of substances. They also are experiencing fewer crisis episodes and days in hospital.

The CMHEI has significantly increased the system's capacity to conduct relevant community mental health research and to scientifically assess and measure the effectiveness of community mental health services and supports; the project created a network of experienced scientists, researchers, and community partners who will contribute their knowledge and experience to future community mental health research in Ontario; and it has served as a training ground for the development of future researchers in community mental health.

The CMHEI project has benefited from the positive effect of participatory approaches on program staff. The research studies involved community mental health program workers, as well as consumers and families, many of whom had not participated in research studies before. Consumers and family members have made valuable contributions by defining research questions, providing their unique perspectives, conducting interviews, and assisting in the interpretation of findings.

The CMHEI is helping to establish a new set of research tools and partnerships that will build the capacity to assess community mental health services and supports on a scientific basis. A number of unique methods and tools developed specifically for CMHEI studies are contributing to quality improvement, monitoring, and future research. For example, the template of program characteristics resulting from the project raises questions for service and program managers about what services they are providing in relation to consumer needs.

The CMHEI project demonstrates that programs can incorporate data collection into their practice and that program staff are interested in using data for program management and improvement. These experiences can contribute to program and provincial efforts to implement monitoring for improvement and accountability.

The CMHEI has communicated new knowledge to service providers, consumers, and their families; regional and provincial decision-makers; and policy developers to promote actions that improve the effectiveness of Ontario's community mental health system.

# APPENDIX 1

Table 3: CMHEI research studies

CMHEI RESEARCH STUDY	PRINCIPAL INVESTIGATORS AND OTHERS	PARTNER ORGANIZATION
<p><i>An Evaluation of ICM for Persons With Serious Mental Illness Who Are Homeless</i></p> <p>This study evaluated ICM services being provided by the Ottawa branch of the Canadian Mental Health Association to persons with serious mental illness living in the community who are homeless or at risk of being homeless, relative to the standard care in the community.</p>	<p>Dr. Tim Aubry, School of Psychology, Centre for Research on Community Services, University of Ottawa, Ottawa</p> <p>PROJECT COORDINATOR Heather Smith Fowler, MA, Centre for Research on Community Services, University of Ottawa, Ottawa</p>	<p>Canadian Mental Health Association, Ottawa Branch</p>
<p><i>Variations on ACT: A Study of Approaches and Client Outcomes of Four Teams in Southeastern Ontario</i></p> <p>This study examined four community mental health programs in the Kingston and Brockville area that had adapted critical features of the ACT model for local needs. The purpose of the study was to determine whether the ACT model could be modified and still be effective.</p>	<p>Dr. Terry Krupa, School of Rehabilitation Therapy, Queen's University, Kingston</p> <p>Dr. Shirley Eastabrook, School of Nursing, Queen's University, Kingston</p> <p>PROJECT COORDINATOR Salinda Horgan, MA, Queen's University, Kingston</p>	<p>Assertive Community Care Team</p> <p>Assertive Community Rehabilitation Program</p> <p>Community Integration Program</p> <p>Psychosocial Rehabilitation Program</p>
<p><i>A Randomized Controlled Trial of ACT in a Canadian Inner City Setting</i></p> <p>This study evaluated two case management models in downtown Toronto. An ACT program and an ICM program partnered with home care were assessed to determine if they could meet the needs of people with serious mental illness living in a Canadian inner city. The study also compared program costs and evaluated how program participation affected clients and staff.</p>	<p>Dr. Donald Wasylenki, Psychiatrist-in-Chief, St. Michael's Hospital, Toronto</p> <p>PROJECT COORDINATOR Margaret Gehrs, MSc, St. Michael's Hospital, Toronto</p>	<p>CONTACT Mental Health Outreach Service, Toronto</p> <p>Community Connections, Toronto</p>

CMHEI RESEARCH STUDY	PRINCIPAL INVESTIGATORS AND OTHERS	PARTNER ORGANIZATION
<p><i>A Longitudinal Study of the CSIs in Community Mental Health in Ontario</i></p> <p>This study evaluated the impact of CSIs (CSIs) on their members and communities. The researchers gathered both quantitative and qualitative data to examine individual-level activities and impacts on new members, and system-level activities and impacts related to systemic change.</p>	<p>Dr. Geoffrey Nelson, Department of Psychology, Wilfrid Laurier University, Waterloo</p> <p>PROJECT COORDINATOR Dr. Joanna Ochocka, Centre for Research and Education in Human Services, Wilfrid Laurier University, Waterloo</p>	<p>Cambridge Active Self-Help Consumer/Survivor Initiative of Niagara</p> <p>Mental Health Rights Coalition of Hamilton</p> <p>Waterloo Region Self-Help Ontario Peer Development Initiative</p>
<p><i>A Longitudinal Evaluation of Family Initiatives in Ontario</i></p> <p>This study examined the impact of self-help and mutual aid organizations on families of people with mental illness and on the mental health system, in terms of their experiences of such things as coping, empowerment, care-giving burden, and support. It also examined the impacts of family initiatives and systems-level activities such as education, advocacy, and outreach.</p>	<p>Dr. Katherine Boydell, Hospital for Sick Children, Toronto</p> <p>John Trainor, MSW, Centre for Addiction and Mental Health, Toronto</p> <p>RESEARCH COORDINATOR Darryle Jadaa, Hospital for Sick Children and Centre for Addiction and Mental Health, Toronto</p>	<p>Family Association for Mental Health Everywhere</p> <p>Schizophrenia Society of Ontario</p> <p>Mood Disorders Association of Ontario</p>
<p><i>Evaluation of Crisis Occurrence and Resolution in Patients With Severe and Persistent Mental Illness</i></p> <p>The study examined crisis occurrence and resolution in individuals with SPMI and the effectiveness of ICM in preventing crises. The influence of ongoing support in predicting crisis occurrence was studied, and the essential elements of the hospital-based psychiatric emergency service as part of the crisis response system were articulated.</p>	<p>Dr. Paul Links, Arthur Sommer Rotenberg Chair in Suicide Studies, St. Michael's Hospital, Toronto</p> <p>Dr. Sean Rourke, MH Service, Director of Research, St. Michael's Hospital, Toronto</p> <p>PROJECT COORDINATOR Rahel Eynan, MA, St. Michael's Hospital, Toronto</p>	<p>Crisis Intervention Team, St. Michael's Hospital, Toronto</p>
<p><i>Multisite Comparison of Case Management, Crisis, and Self-Help</i></p> <p>All CMHEI individual studies provided data for this project, which included a multisite analysis to compare community mental health services and supports on a number of dimensions. The study also assessed whether the types of programs differed in the populations they served and in their effectiveness, and compared program costs and cost-effectiveness across program types.</p>	<p>COORDINATING CENTRE Health Systems Research and Consulting Unit, CAMH, and University of Toronto, Toronto</p> <p>PRINCIPLE INVESTIGATOR Dr. Paula Goering</p> <p>PROJECT COORDINATOR Dr. Janet Durbin</p> <p>SENIOR SCIENTIST Dr. Carolyn Dewa</p> <p>MANAGER, KNOWLEDGE TRANSFER Dale Butterill, MSW, MPA</p>	<p>All CMHEI local studies</p>
<p><i>Explaining Outcomes: Developing Instruments to Assess the Clinical Characteristics of Community Support Programs for People With Serious Mental Illness</i></p> <p>This complementary project focused on understanding what aspects of community support programs are effective for people with a serious mental illness. The project has worked to develop data collection tools that would be useful across a wide range of community support models and practices and that could identify and evaluate critical ingredients of community support programs.</p>	<p>Dr. Brian Rush, Health Systems Research and Consulting Unit, CAMH, University of Toronto, Toronto</p> <p>Dr. Ross Norman, London Health Sciences Centre, Victoria Campus, London</p> <p>PROJECT COORDINATOR Ellen Tate, MA, Health Systems Research and Consulting Unit, CAMH, Toronto</p>	<p>Ontario Federation of Community Mental Health and Addictions Programs</p> <p>Centre for Addiction and Mental Health</p>

## APPENDIX 2

### THE TYPES OF PROGRAMS EVALUATED

## The various types of community mental health programs assessed by the CMHEI evaluation studies are described below.

**ACT** is a widely implemented model for delivering mental health services in the community. ACT was developed as an alternative to hospitalization for people with serious mental illness. It provides ongoing, individualized, intensive support and helps clients develop the skills they need to live in the community. In the ACT model, a multidisciplinary team provides a full range of services to a roster of clients (about 80 to 100), with each team member contributing his or her professional skills according to need. ACT team services are available 24 hours per day, seven days per week; and the services provided to the clients are ongoing and unlimited in duration.

The ACT model is one of the more widely studied forms of community support, although the bulk of studies have been conducted in the United States. In Ontario, with the move to community mental health care, closing of long-term psychiatric hospitals, and downsizing of general hospitals, ACT has become an important model for service delivery and has been endorsed by the Ontario Ministry of Health and Long-Term Care.

The CMHEI project studied the effectiveness of ACT teams under varying conditions. The multisite analysis also compared ACT with other types of community support to better understand the roles different programs can play in an effective system of mental health care.

**ICM** is another model for providing people with serious mental illness with intensive services and long-term support in the community. ICM helps clients to achieve personal goals, build informal supports, and access community resources. Individual case managers provide assessment, counselling, and advocacy; and link clients with other treatment and rehabilitation services such as social recreation, employment programs, and supportive housing. Unlike ACT, ICM does not typically provide round-the-clock services, although some ICM programs in Ontario offer extended hours of service on evenings and weekends.

### The CMHEI project studied two ICM programs:

- The Ottawa program is a strengths-based, recovery-oriented case management program with strong psychosocial rehabilitation underpinnings. The roles and functions of case managers include assessments, goal-setting/planning of services, supportive counselling, skills teaching, health teaching and monitoring, crisis prevention and early interventions planning, advocacy, supports to community services, liaison with community services, and coordination of services and resources.
- The Toronto ICM program linked clients with community-based treatment and rehabilitation services, including social recreational programming, work programs, supportive housing, and volunteer companions. It developed a unique partnership with the Toronto Community Care Access Centre and was able to enhance the case management support with nursing and personal support services. Frequency and intensity of support were therefore increased and provided seven days per week, as necessary. The Toronto program also had some control over access to hospital beds through its hospital sponsorship.

CSIs are self-help/mutual-aid organizations funded by the Ministry of Health and Long-Term Care. Developed by and for people with serious mental illness, CSIs can include self-help and peer support groups, member-run businesses, and social recreational opportunities.

CSIs are guided by a set of values that include member empowerment and participation, social justice, a sense of community and peer support, and mutual learning. Activities of members can include education and training for mental health professionals and the public, advocacy and political action, community planning, and participatory action research.

The Consumer/Survivor Development Initiative, now called the Ontario Peer Development Initiative, began in 1991 with funding from the Ontario Ministry of Health and Long-Term Care. Currently there are more than 50 funded CSIs across Ontario.

Family self-help/mutual aid organizations provide a caring environment for people who have a relative with a diagnosis of serious mental illness. The organizations 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, or crisis line volunteer.

Families make up the largest group of community caregivers for people with serious and persistent mental illness. Families and caregivers 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. The CMHEI study was designed to fill this gap, in part, by examining the impact of self-help and mutual-aid organizations on the families of people with mental illness and on the mental health system.

FINDINGS FROM  
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