

# Community Mental Health Evaluation Initiative Project Newsletter

No.1, July 15, 1999

## Welcome from Paula Goering

Hello and welcome to this first edition of our newsletter. The Community Mental Health Evaluation Initiative (CMHEI) wants to keep the field informed about what we are doing and what we are learning as the five year project proceeds. This is one of the forms of communication we will be using to let you know what we are about.

Our project is unique in many ways. It is the first multi-site evaluation of community mental health programs in Canada. It was planned and is being conducted with the involvement of a wide range of players, including government, community providers, family and consumers. It is designed to provide information relevant to policy. The funding was provided by the Ministry of Health to the Mental Health Policy Group, which is a coalition of three agencies: Ontario Mental Health Foundation (OMHF), Canadian Mental Health Association, Ontario Division (CMHA) and Health Systems Research Unit (HSRU). The project was designed to evaluate the types of services and supports that were funded by the Community Reinvestment Fund, i.e. case management, self-help, crisis.

It includes a coordination centre, located in the HSRU, to oversee the development of the project and to conduct a multi-site study. Using a common protocol across projects allows us to address questions that pool data from the separate studies.

A request for proposals was developed through a wide consultation process, which included a one day planning workshop with thirty participants and Dee Roth, a consultant from Ohio. It was circulated throughout the province and proposals were submitted to the OMHF for external and internal peer review. We were pleased with the number and variety of proposals that were received. It was exciting to pioneer at OMHF a grant review process that included non-researchers as active participants in the decision making and the opportunity for selected teams to respond to reviewers' concerns as a part of the funding process.

Getting the projects up and running has taken considerable skill and work on the part of all concerned, but we now are in a position to tell you about what has been accomplished in the first year and what your appetite about the results that will soon be available from the baseline measurement. We are hoping that reading this newsletter will be informative and encourage you to contact any of the various project teams that are relevant to your own interests.

---

*"This interview reminded me of how I feel about my life situation. It was a reality check and a positive experience for me."*

---

participant

---

## Initiative Description

The CMHEI is comprised of seven projects funded to evaluate community mental health programs. These projects have come together to create a common set of measures so that the data can be compared from one program type to the next.

Below is a list of the individual projects and the principal investigator(s) which make up the multisite study. Descriptions, proposals and contacts for each of these projects are available at the CMHEI's website ([www.ontario.cmha.ca/cmhei/index.html](http://www.ontario.cmha.ca/cmhei/index.html)).

### Multisite Study

*Multisite Comparison of Case Management, Crisis Intervention and Self-Help.* - Paula Goering

### Case Management / Assertive Community Treatment

*An Evaluation of Intensive Case Management for Persons with Severe Mental Illness Who are Homeless.* - Tim Aubry

*Variations on Assertive Community Treatment: A Study of Approaches and Client Outcomes of Four Teams in South Eastern Ontario.* - Terry Krupa & Shirley Eastabrook

*A Randomized Controlled Trial of Assertive Community Treatment in a Canadian Inner City Setting.* - Donald Wasylenki

### Consumer/survivor & Family Initiatives

*A Longitudinal Study of the Consumer/Survivor Initiatives in Community Mental Health in Ontario.* - Geoffrey Nelson

*A Longitudinal Evaluation of Family Initiatives in Ontario.*

Katherine Boydell & John Trainor

### Crisis Response / Emergency Services

*An Evaluation of Two Community Mobile Crisis Units for the Chronically Mentally Ill.* - Lorraine Ferris & Kenneth Shulman

### Explaining Outcomes

*Developing Instruments to Assess the Critical Characteristics of Community Support Programs for People with Severe Mental Illness.*

Brian Rush & Ross Norman

---

## Website

[www.ontario.cmha.ca/cmhei/index.html](http://www.ontario.cmha.ca/cmhei/index.html)

For more information regarding the Community Mental Health Evaluation Initiative (CMHEI) visit the website. You will find project descriptions and proposals, the complete list of names and address of all individuals involved, and a copy of our press release and newsletter. From here, you can also download all of the questionnaires that we are using in this multisite project and the manuals to assist you in understanding and using these forms. If you are interested in a particular project or the multisite study you will find much of the information you need on this website. Whether you are a consumer/survivor or family member interested in finding out more about research in community mental health, or if you are a practitioner, student or researcher interested in developing your own evaluation you will find this website very useful.

---

# Featured Project

## Multisite Comparison of Case Management, Crisis Intervention & Self-Help

### Brief Project Description

This multisite evaluation study involves all funded projects. This study is unusual in that each funded project has agreed to collect the same information from program users. This provides us with a "common language" for describing and comparing very different program types (ie., case management, self help). Our goal is to expand understanding about how programs are implemented and about their roles in assisting individuals with serious mental illness to recover and achieve a better quality of life. The common data set also provides an opportunity to test measures and information strategies that have relevance to the wider field.

The Coordination Centre for the multisite study is housed in the Health Systems Research Unit at CAMH. There is a team of six researchers, including a Project Director, Janet Durbin, and a Communications Coordinator, Marie-Anik Gagné. Responsibilities of the CC include:

- C defining the common data collection protocol and instruments (in collaboration with each of the projects);
- C developing a computerized, across-site data management system;
- C analyzing and disseminating findings.

### Research Questions

Approximately 1,200 consumer/survivors will be interviewed three times, at nine month intervals (e.g., start, 9 and 18 months). These data will ultimately increase our understanding of which programs are best for whom by answering these four general questions:

1. How do program types differ in whom they serve?
2. How do program types differ in impact on users over time?
3. How do program, mental health system, and total health system costs differ by program type?
4. How do program cost to outcome effectiveness ratios compare among program types?

### Sub-studies

Each project in the CMHEI has generated a number of sub-studies led by senior researchers and students. Substudies being conducted in the Multisite Study include:

A) *A reliability study of case manager and consumer recall of the consumer's experience with health service use, legal system encounters, housing history and substance use* is being conducted by Carolyn Dewa and Janet Durbin in collaboration with Nicole Kirwan, team leader of the Community Connections Case Management Program (Donald Wasylenki's project).

B) *The Impact of Personality Factors on Community Treatment Outcome: Among Persons with Major Mental Illness.* Conducted by George Tolomiczenko in collaboration with Donald Wasylenki.

C) *Evaluating Assertive community Treatment Teams from an Ecological Perspective: Adapting ACT teams in Canadian Cities.* Conducted by Marie-Anik Gagné in collaboration with Donald Wasylenki, Terry Krupa & Shirley Eastabrook.

### Contact Information

- , Janet Durbin (416) 979-4747 x 2437, jdurbin@hsru.clarke-inst.on.ca
- , Marie-Anik Gagné (416) 979-4747 x 2311, manik@hsru.clarke-inst.on.ca

Health System Research Unit Staff



Back Row: Linda Challenger, Marie-Anik Gagné, George Tolomiczenko, Stephanie Ali, Dianne Macfarlane, Janet Durbin, Tess Sheldon, Dale Butterill, Front Row: Carolyn Dewa, Paula Goering, Jeannette Cochrane, Betty Lin.

### Developing the Common Protocol

The CMHEI working group is made up of three representatives of each evaluation project, including consumer/survivors and family members, and the Coordination Centre. The CMHEI working group met for the first time May 11<sup>th</sup> and 12<sup>th</sup>, 1998. At that time the working group selected the instruments for the common protocol. These were piloted and revised over the next few months, and manuals were developed so that projects would use a similar approach for collecting data.

### Costing Mental Health Services

Much of the information about the costs of community mental health programs comes from abroad (i.e., the U.S. or U.K.). Unfortunately, many of the studies do not give enough detail to help us understand how costs are estimated. As a result, it is not possible to identify where adjustments can be made to better reflect the Canadian system of care. Carolyn Dewa, Health Economist for the multisite study, is working with each project in the initiative to carefully define units of services and costs associated with those services. Because all projects are adopting similar definitions and methods, we can compare costs across program types and attribute them to components of services. In addition, all studies are collecting the same consumer outcome data, making it possible to compare cost effectiveness.

### Processing the Data

A close look at the forms used to collect multisite data may make you curious about the blocks and cross-word type boxes in the corners. Tess Sheldon, Data Analyst, designed these forms to allow for accurate and automated scanning of the data. What's written on the forms is actually "read" by our computers — with some human editing here and there by Stephanie Ali, Research Assistant. This system can handle hundreds of sheets per day and saves data in a format ready for review and analysis. Just the same, neat printing always helps according to George Tolomiczenko, Information System Designer.

## What the CMHEI has done so far!

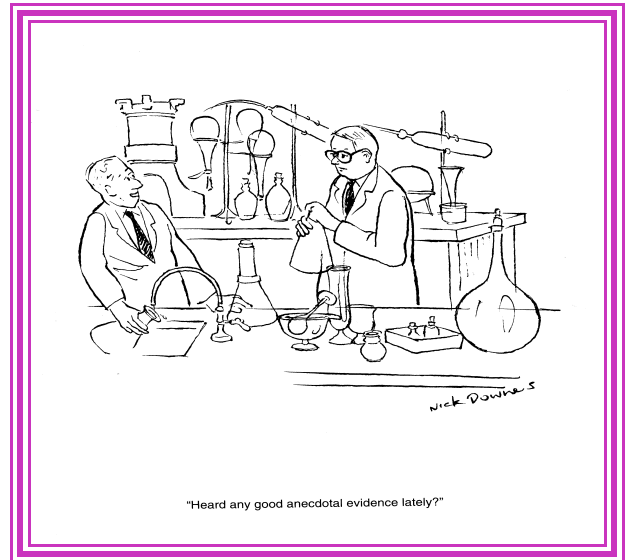
- Data collection at each of the projects is well underway. All are at least part way through the baseline data collection and some have started their 9 month follow-ups.
- We plan to start analyzing baseline data during the fall and will share findings about who uses the programs as soon as we can.
- We created a website and issued our first press release.
- Additional training for the BPRS, MCAS, AUS, DUS, SATS scales in Kingston on June 23, 1999.

## Upcoming Activities

- Planning the third CMHEI- Working Group meeting in the fall.
- Completing site visits to each site participating in the multisite study. These visits will assist us when interpreting the data and describing the programs.

## In our next issue

Watch for our next issue in 6 months! It will report some of the results from the first data collection period, feature two more projects in the initiative and another tool.



## Featured Tool Empowerment Scale

A group of participants at Waterloo Regional Self Help are quite clear about their view of recovery. You're getting better when you can take more control over your life, build an identity that doesn't revolve around being a client or patient, and become involved in the broader community. The term "empowerment" is often used to describe this set of outcomes and is becoming an important part of outcome evaluation. Yet measuring empowerment is a challenge.

Sally Rogers from the Centre for Psychiatric Rehabilitation at Boston University took on this task several years ago, partnering with a number of consumer activists to define empowerment and develop an appropriate measure. The result of their work is "Making Decisions", a 28 item scale measuring five broad areas - self esteem, power, community activism, control of future, righteous anger. Tests of the scale showed that the items are measuring a common concept and can distinguish among consumers in different settings. A number of states have included Making Decisions in their mental health information systems.

In our study, we are using 16 items from Making Decisions combined with items from the Rosenberg scale, a commonly used measure of self esteem, for a total of 23 questions. Consumers are comfortable completing our scale which only takes a few minutes. How program participation affects empowerment remains to be seen. We'll keep you posted.

The items that make up the CMHEI Empowerment scale are listed here. The complete scale can also be downloaded from the CMHEI website.

### CMHEI - Empowerment Scale

Please indicate whether you strongly agree, agree, disagree or strongly disagree with the following statements:

1. I am usually confident about the decisions I make.
2. Most of the misfortunes in my life were due to bad luck.
3. People working together can have an effect on their community.
4. Making waves never gets you anywhere.
5. When I make plans, I am almost certain to make them work.
6. Usually, I feel alone.
7. Experts are in the best position to decide what people should do or learn.
8. I generally accomplish what I set out to do.
9. People should try to live their lives the way they want to.
10. You can't fight the government.
11. I feel powerless most of the time.
12. When I am unsure about something, I usually go along with the group.
13. People have a right to make their own decisions, even if they are bad ones.
14. On the whole, I am satisfied with myself.
15. At times, I think that I am no good at all.
16. I feel that I have a number of good qualities.
17. I am able to do things as well as most other people.
18. I feel I do not have much to be proud of.
19. I certainly feel useless at times.
20. I feel that I'm a person of worth, at least on an equal basis with others.
21. I wish I could have more respect for myself.
22. All in all, I am inclined to feel that I am a failure.
23. I have a positive attitude toward myself.

**Contact information** The CMHEI newsletter is a biannual publication. If you have any questions/comments regarding the content, have an idea for future issues, or would like to receive a copy of our next issue, please contact: Marie-Anik Gagné (416) 979-4747 ext. 2311 / manik@hsru.clarke-inst.on.ca or Lisa Joyce (416) 977-5580 ext. 4146.

# Featured Project

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

### Brief Project Description

Geoffrey Nelson, Principal Investigator of this study, expects that participation in the consumer/survivor initiatives (CSI) will have a positive impact on personal empowerment, social support, community integration, work, education, and subjective quality of life. The greater the amount of participation in the CSI, the larger the positive impact is expected to be. This research will also study the experiences of CSI participants that are believed to have a positive impact - for example: the opportunity to contribute to and have a say in the consumer/survivor organization, a psychological sense of community, and peer support.

Because of the interest expressed by many CSIs, the research team and the CSIs participating in the primary study will share research approaches and findings with all interested CSIs. This will take the form of workshops on several of the different research methods being used.



Back row: Geoff Nelson, Jean Irish, Meaghan Johnson, Robert Chapman, Joanna Ochocka, Front row: Helmut Braun, Yolisa Nongauza, Rich Janzen, Heather Irvine

### Project Structure

Let me, Joanna Ochocka, Project Coordinator, introduce our project structure. Of the 59 CSIs in Ontario, three have been selected for this study: Waterloo Region Self Help (WRSH) in Kitchener, Mental Health Rights Coalition in Hamilton (MHRC) and the CSI of Niagara Region, in Welland (CSIN). This study is guided by a Steering Committee composed of two members from each of these three participating CSIs (Terry Dick & Alex Troger from WRSH, Fiona Wilson & Mark Davies from MHRC, and Judy Hoover & Shawn Lauzon from CSIN), the researchers, and the Coordinator of the Consumer/Survivor Development Initiative.

We have hired and trained six consumer/survivor researchers to help us carry out the project. The researchers work out of offices located in the local CSIs (two researchers for each of the three sites). We meet together as an entire research team about every month, rotating our meeting locations. These meetings are an opportunity for us to learn from each other, and to plan our next steps in the 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

---

### Research Participants

The consumer research assistants are in a process of interviewing a total of 150 people across the three regions. About half the people are new members of CSI's (who joined in 1999), and the other half are people not active in CSI's. With their consent, these individuals will participate in three interviews over an 18-month period (a baseline interview and then follow-up interviews at 9 and 18 months).

The interviews are conducted according to the multisite protocol, with four additional pages of unique questions related to our project only. To supplement this quantitative information (answers to this type of question are recorded as categories, e.g., yes & no), 15 active members and 15 non-members will be asked some open-ended questions about their personal growth (outcomes) and what factors (processes) contributed to their growth. These qualitative interviews will be done three months after the quantitative interviews.

Also, qualitative interviews will be conducted with key CSI members, mental health professionals, planners, and policy-makers to inquire about the impact that the CSIs have had on the community, and barriers and limitations to systems reform. The study will make recommendations for policies to overcome those barriers. Interviews with key members of the three CSIs participating in the research will be used to trace the growth and development of each CSI.

### Preliminary Data

To date we have interviewed eight people in Waterloo Region, 23 in Hamilton and 38 in Niagara Region. Our researchers keep in touch with participants already interviewed, every 2 months (face-to-face or by phone), and ask questions about their participation in CSIs. Soon we will begin the qualitative interviews.

---

*"I feel much better after having been through this interview."*  
Participant

---

### Contact Information

, Joanna Ochocka (519) 741-1318, cfre@kw.igs.net  
, Geoffrey Nelson (519) 884-0710 x 3314, gnelson@mach1.wlu.ca