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

Participatory Action Research in Community Mental Health

Joanna Ochocka
Rich Janzen
Nadia Hausfather
Centre for Research and Education in Human Services

* Action Research
* Program Evaluation
* Proposal Development

* Community Consultations
* Educational Workshops
* Research Training

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Overview of Presentation

• Background on Consumer/Survivor Initiatives
• Background to Research Study
• Research Approach -- Participatory Action Research
• Research Methodology
• Dissemination and Action Strategies
CSIs as a Unique Part of the Mental Health System

- CSIs are self help/mutual aid organizations that have been developed exclusively by and for people with serious mental illness.

- First funded in 1991 by the Ontario Ministry of Health and Long-Term Care, there are now more than 70 CSIs in Ontario with a budget of over $5 million.
CSIs as an Alternative Support

- CSI activities include: self-help groups, peer mentoring, support, and friendship, participation in community planning, education and advocacy

- CSI ethos - sense of community, solidarity, empowerment, mutual learning, social justice and social change
Background to Research Study

• First, independent evaluation of Consumer/Survivor Initiatives in Canada

• Study funded by OMHF and CIHR, 1998-2004

• Research partners: Wilfrid Laurier University, Centre for Research and Education in Human Services, Centre for Addiction and Mental Health, Ontario Peer Development Initiative
Study Context

Part of Ontario Community Mental Health Evaluation Initiative (CMHEI)

Ontario’s first broad, systematic assessment of effectiveness of community-based mental health services and support:

- Crisis intervention
- Case management
- Consumer/survivor and family initiatives

CMHEI projects aim to help show whether community initiatives are on right track
Study Purpose

To examine the activities and impacts of CSI on new members (individual level) and the communities within which they exist (systems level)
Study Partners

60 Consumer/ Survivor Initiatives

- Hamilton: Mental Health Rights Coalition
- Cambridge: Active Self Help
- Kitchener: Waterloo Region Self Help
- Welland: Consumer/ Survivor Initiative of Niagara
- Research Team
- Steering Committee
Study History

- **Proposal Development - 1997**
  **Partners:** Wilfrid Laurier University, Centre for Research and Education, Centre for Addiction and Mental Health, CSDI and CSIs
  **Submission:** letter of support from 17 CSIs, funding Announcement - February 1998

- **Start - April 1998**

- **Site Selection – July/August 1998**

- **First Steering Committee Meeting - September 1998**

- **Research Team Hired and Trained - January 1999**
Participatory Action Research Approach (PAR)

*Value-driven* approach to research that is consonant with the values of CSIs:

- supportive relationships
- empowerment
- learning as an ongoing process
- social change
Participatory Action Research Approach (PAR)

*Principle-driven* approach to research that is consonant with the values of CSIs:

- accommodation
- data for advocacy
- training and mentoring
- opportunity of meaningful involvement
Definition of PAR

PAR is a research approach that involves active participation of stakeholders, those whose lives are affected by the issue being studied, in all phases of research for the purpose of producing useful results to make positive changes (Nelson, Ochocka, Griffin & Lord, 1998)
Mechanisms to Implement PAR

1) Stakeholder steering committee
2) Consumer/survivor researchers
3) Research team meetings (training, support, relationship, participation)
4) Ongoing communication and information sharing
Study Steering Committee

- Composition (stakeholder representation)
- Purpose (to guide all aspects of the research process)
- Process (how often, locations, typical meeting, personal experience)
- Challenges (participation over long period of time, making decisions about measurement tools)
Study Research Team

- Composition (professional and consumer/survivor)
- Purpose (training, tracking, communicating, reflecting, learning, trouble shooting, supporting)
- Process (how often, locations, typical meeting, personal experience)
- Challenges (people’s health, distance, turnover)
Research Methodology

- Individual Quantitative
- Individual Qualitative
- Systems Quantitative
- Systems Qualitative
Methods: Individual Quantitative

• Baseline, 9, 18, 36 month follow-up interviews

• Bi-monthly tracking of CSI participation (amount of time, number of activities, psychological attachment to CSI)

• 160 quantitative interviews (80 new members and 80 non-members)

• Multiple outcome measures (e.g., symptom distress, empowerment, quality of life)
Methods: Individual Qualitative

- Baseline, 9, 18, 36 month follow-up interviews
- 30 qualitative interviews (14 new members and 16 non-members)
- Open-ended interviews - asked about changes in past 9 months, factors facilitating and inhibiting changes, typical day in the life
- Interviews transcribed and coded
Methods: System Quantitative

- Collected 25 months of data on systems activities of the four CSIs using a tracking tool
- The main systems activities are education of the public and professionals, community planning, advocacy, and action research
Methods: System Qualitative

Interviewed staff and board members of each CSI and OPDI regarding systems activities and outcome, as well as other professionals in the community knowledgeable about the CSI.
Dissemination and Action Strategies

- Interim reports and fact sheet summaries circulated to four participating organizations, other mental health organizations across Canada, Mental Health Task Forces and Ministry of Health and Long-Term Care

- Summaries used by CSIs and OPDI for education and advocacy

- Project website and video

- Regular updates and actions within Community Mental Health Evaluation Initiative, including to senior policy-makers in Ontario Ministry of Health and Long-Term Care
Future Contact

**Dr. Joanna Ochocka, Project Coordinator**  
**Rich Janzen, Senior Researcher**  
Centre for Research & Education in Human Services  
73 King Street West, Suite 202  
Kitchener, ON, Canada N2G 1A7  
Phone: (519) 741-1318 Fax: (519) 741-8262  
E-mail: joanna@crehs.on.ca  
Website: www.crehs.on.ca

**Dr. Geoffrey Nelson, Principal Investigator**  
Wilfrid Laurier University, Department of Psychology  
Waterloo, ON, Canada, N2L 3C5  
Phone: 519-884-0710, ext. 3314, Fax: 519-746-7605  
Email: gnelson@wlu.ca