

Growing a **network**
of people who
care



Ontario Family Caregivers' Advisory Network

Annual Report
2016



Coming together is a beginning... keeping together is progress... working together is success.

Henry Ford

Dear Friends,

It has been my honour to be part of a growing network of dedicated advisory councils and community groups that are devoted to supporting family caregivers of people with mental health and addictions issues.

OFCAN's first Annual Report is an opportunity to share with others a story of the "blossoming ideas" that would lead to volunteers working collaboratively to achieve common goals and to strike beneficial partnerships.

Over the past couple of years our members have devoted significant energy towards sharing information, establishing "who we are" and laying the foundation for a strong network.

I am proud of OFCAN's accomplishments and would like to thank our volunteers, members and partners for their support.

OFCAN'S BOARD OF DIRECTORS

Cynthia Clark
Chair

Christine Holland
Vice-Chair

Bruce Popplow
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Christine Cooper
Special Projects

Carol Riddell-Elson
Secretary



Cynthia Clark,
Chair, Board of Directors

The Three Musketeers (L-R):
Carol Riddell-Elson, Secretary;
Cynthia Clark, Chair; Christine
Holland, Vice-Chair.



Our Journey

OUR VISION

An Ontario Mental Health & Addictions healthcare system that values and empowers family caregivers.

In spring 2011 members of the Family Advisory Council of Regional Mental Health Care London decided to pursue the possibility of organizing a provincial Family Advisory Council Network. Contacts were made with other Family Advisory Councils of the Psychiatric hospitals across Ontario whose members quickly saw the benefits of sharing information and supporting each other.

Soon the Family Advisory Council Network (FCAN) was formed with the primary goals of representing the interests of Family Councils of Mental Health Hospitals in Ontario and fostering the growth of family involvement within the hospital systems. For the next couple of years, Family Advisory Council representatives met at different hospitals sites and via OTN to share information about the work of the councils and strengthening caregiver engagement in the hospital setting.

Inaugural Conference

FCAN increased its provincial profile by hosting a highly successful conference in the fall of 2014. Promotional materials now contained our new name: Ontario Family Caregiver Advisory Network (OFCAN)! The conference, entitled “Partnering with Family Caregivers – A Shift in the Recovery Paradigm”, had many highlights including the key note speaker, Ella Amir’s presentation on the “National Guidelines for a Comprehensive Service System to Support Family Caregivers of Adults with Mental Health Problems and Illnesses”. The majority of the participants felt that what they had learned at the conference would have a positive impact on future interactions between their organization and the caregivers that they serve. Many thanks for support from Ontario Shores Centre for Mental Health Sciences and Mental Health Commission of Canada.

WORDS OF HOPE

Two of Ella Amit’s affirmations from the conference that we are on the right road were: “ignoring caregivers is no longer an option” and “caregivers will be the driving force for change.”

A COMMITMENT TO INCLUSIVENESS

Spurred on by the positive responses from conference attendees, many who were represented of family community groups, OFCAN members decided to extend membership to include Ontario community family caregiver groups and organizations with interests in mental health and addictions. The official change in our name from “family councils” to “family caregivers” occurred in the spring 2015, with the incorporation of the Ontario Family Advisory Caregivers’ Network, a non-profit operated organization.

Empowerment Through Engagement

OFCAN member groups and organizations endeavour to support and serve family caregivers in a variety of ways either by providing direct service to caregivers or acting in an advisory capacity in related areas of engagement. Some of the direct benefits of active information sharing are:

- Receiving timely communiqués about opportunities for participating in educational workshops, online surveys, caregiver movements and announcements related to mental health and addictions.
- Learning about the activities of member groups, promising practices and proposed solutions to shared concerns.
- Providing a forum for discussion about common issues facing family caregivers and the caregiver groups/organizations.

Reaching Out to Make a Difference

With increased recognition that caregivers are a valuable resource in the health care system, who need to be respected and supported, as well as, engaged at all levels of service provision (including policy making). Member organizations/ groups are involved in countless hospital and community committees, stakeholder events, task groups and invited to participate in special projects. OFCAN is a member of the Ontario Caregiver Coalition. It is represented at the Excellence Through Quality Improvement Project (for AMHO, CMHA and HQO); Mental Health and Addictions Leadership Advisory Council (for MHLTC); Health Quality Ontario, Mental Health Quality Standards Expert Advisory Panel for Schizophrenia and Implementation Advisory Group and on the editorial advisory board for the Journal of Recovery in Mental Health. OFCAN members are eager to work in partnership with mental health stakeholders to meet the challenges of effecting change.

Shaping our Organization: A Strong Foundation

Healthy networks adhere to the mission and vision of the organization while responding to the needs of its members. The focus of the past 16 months has been to establish the essential structures for going forward such as: incorporation, launching our website (www.ofcan.org), developing Board

policies and procedures, exploring opportunities for partnerships, developing Member Profiles, surveying member satisfaction, expanding our membership and increasing the visibility of OFCAN.

Response to Legislative Change: The Quiet Advocate

MEMBER INVOLVEMENT

Member groups are encouraged to bring forth areas of concern which may resonate with other members across Ontario. The following are examples which help to showcase our work.

In November 2015 Dr. Richard O'Reilly, Director of Research, Parkwood Institute in London, Ontario delivered a presentation to OFCAN members about Bill 122, an Act to amend the Mental Health Act and the Health Care Consent Act of 1996, and the proposed amendments to the Act that were put forth by the OPA, OMA and OHA to allow treatment to start as soon as the Consent and Capacity Board adjudicated that a patient is incapable. All members present were in support of changes to the Mental Health Act which would allow hospitals to use medication while treating patient, while the patients' appeals are going through the courts. OFCAN responded by sharing the pertinent information, which was provided by Dr. O'Reilly, as well as providing a direct email to the Standing Committee reviewing Bill 22 so that family caregivers would have the opportunity to have a voice in this matter while meeting the deadline for submissions.

Absence of Research

One of OFCAN's ongoing areas of concern is the need for a province-wide survey for family carers of people with mental health issues and addictions problems. At the moment, very little research has been undertaken to evaluate caregiver needs and perspectives in this area. OFCAN members conducted a review of the Ontario Perception of Care Tool for Mental Health and Addictions (OPOC-MHA) and determined that the OPOC survey tool which is being used to evaluate client care seemed to be acceptable. However, it was determined that the OPOC "Non-registered Family Member/Significant Other/Supporter Questionnaire" would require revisions in order to adequately reflect the family experience. A report summarizing OFCAN's views of this Tool is available to caregiver groups. It can be used as a reference document when speaking to administration about the shortcomings of the Family OPOC Survey. There will ongoing discussions on the topic with independent researchers.

EVIDENCE EXCHANGE NETWORK

EENet is a mental health and addictions knowledge exchange network that connects stakeholders across Ontario has over 5,000 members. Partners in the Family Caregiver Community of Interest include:

Knowledge Exchange Project

In January 2016, the Evidence Exchange Network (“EENet”) accepted OFCAN’s proposal to be the lead agency for a Family Caregiver Community of Interest (Col). A Col brings together those who share a common interest to develop and spread new knowledge to improve understanding and action around an issue. Cynthia Clark and Christine Holland co-lead the Family Caregiver Col with the assistance of an EENet Knowledge Broker and vested partners, including: Canadian Mental Health Association (Peel); Centre for Addiction and Mental Health; Children’s Mental Health Ontario; Family Outreach and Response; Hopewell Eating Disorders Support Centre; Lanark County Family Support; Mental Health Commission of Canada; Mothers Offering Mutual Support; Ontario Caregiver Coalition; Ontario Family Caregivers’ Advisory Network; Parents’ Lifelines of Eastern Ontario; Schizophrenia Society of Ontario; and The Change Foundation.

Many of the projects and operations of family caregiver organizations across Ontario demonstrate a “best practice” for family partnerships and caregiver engagement. One of the activities of the Col would be to examine these initiatives and determine how to best highlight these models of proven results in a way that will make it easy for others to understand and in turn utilize in their own communities.

Our preliminary focus for knowledge sharing (via a webcast) and the development of knowledge products will feature “Promising Practices” that have worked which are not necessarily science-based but have helped to inform practice.

A Look Towards The Future

There is a growing understanding that partnering with family caregivers will improve service quality and better outcomes for users of the health system. There is also evidence that efforts are being made to better understand, engage and support unpaid caregivers.¹ For example, “how to guides for family engagement” have been developed for hospital staff to use² and mechanisms have been put in place for caregivers to share experiences for the purpose of improving services.³ The work of the Change Foundation is an excellent example that the caregiver voice is being heard and respected.⁴

Changing perspectives, attitudes and way of doing things takes time and ongoing effort on the part of those who are championing these changes. We are aware that traditionally mental health and addiction care has not been well resourced, researched or at the forefront of innovative funding. We know that our family caregivers are presented with **unique** challenges created by stigma, illness complexity and lack of access to the many levels of services that are required to support their loved-ones.

Acknowledging that our network is in a position to foster positive change, OFCAN will aspire to meet its mandate by hosting a second provincial educational conference in 2017, continue member engagement through quarterly video conferences, promote ongoing relationship development with related provincial organizations and government, expand our membership and explore research options.

Together we can make a difference.

1 Report of the Expert Group on Home & Community Care “Bringing Care Home” Ministry of Health and Long-Term Care, March 2015

2 “Engaging Patients and Caregivers: About Patient Relations: A Guide for Hospitals” by Health Quality Ontario. Queen’s Printer for Ontario, 2015 ISBN 978-1-4606-6754-5

3 “We are eager to hear how you have decided to engage patients and their caregivers in efforts to improve patient relations at your hospital, and what additions or modifications you would make to this guide based on your experience. Please reach out—we promise to follow up!”
Contact us: Patient, Caregiver and Public Engagement Health Quality Ontario
engagement@hqontario.ca

4 “Out of the Shadows and Into the Circle: From Listening and Learning to Action”. The Change Foundation, Toronto, ON www.changefoundation.ca

