

OFCAN Conference Summary

“Partnering With Family Caregivers – A Shift in the Recovery Paradigm”

October 10th, 2014 - Hosted by the Ontario Family Council Advisory Network
Ontario Shores Centre for Mental Health Sciences, Whitby, Ontario

The day began with welcoming words from OFCAN Conference Planning Committee Chair, Christine Holland. Christine thanked our sponsors The Mental Health Commission of Canada and Ontario Shores Centre for Mental Health Sciences. She also introduced Karim Mamdani President & CEO, Ontario Shores Centre for Mental Health Sciences who gave a warm welcome to the participants of the inaugural conference of the Ontario Family Council Advisory Network.

Cynthia Clark, OFCAN Chair, provided a brief history of OFCAN and discussed how it has grown since its conception in the fall of 2012. She was pleased to announce that Ontario had been geographically well represented at this conference and OFCAN had reached its target audience. Out of the 116 people in attendance 24 % were clinical staff, professionals from a variety of fields of interest represented 47% of those present and 28 % were family members (including OFCAN members).

Conference Highlights

Opening Comments:

Greetings from the Mental Health Commission of Canada and A Personal Family Caregiver’s Perspective - by Patrick Dion

Patrick launched the conference by stating that “OFCAN is a unique network in Canada, but not surprised given my knowledge of the organizers ...creative, forward-thinkers who do not accept the status quo.” Patrick talked about his family’s personal experience with the mental health system and what progress has been made in putting “greater value on the role that family caregivers play in a loved one’s journey to recovery from mental illness”. Patrick’s sincere and heartfelt words nicely set the tone for the day.



Ella Amir and Patrick Dion

Taking the National Caregiver Guidelines “OFF THE SHELF” by Ella Amir

Ella shared with the attendees the history of the caregiver committee’s partnership with the MHCC and their work in the development of the National Caregiver Guidelines. She emphasised the importance of unpaid and informal caregiving. Ella pointed out that the estimated economic contribution in Canada by caregivers in 2009 was greater than \$25 billion! Ella’s message was that going forward mental health services need to be founded on a “family based approach not a patient based approach”. Although mental health administration and service providers are the target audience for the guidelines, families have an important role to play in ensuring that this document will be the foundation of service provider and family interaction in hospitals and the community. She stated that “ignoring caregivers is no longer an option and that “caregivers will be the driving force for change”.

Panel of Stakeholders: “Families as Partners” by the Grand River Hospital, Family Navigator Program

The members of the panel discussed their experiences as part of the Grand River Hospital Mental Health and Addictions Program. Andrew Palmer, Director of Specialized Dynamic; Jones Amoako, Social Worker; and Elaine Paton, Family Navigator; all outstanding individuals in their own right, provided an example of team work at its best. The hospital staff demonstrated a willingness to listen to families and respond to their needs. The family navigator spoke about lesson learned when working within a hospital setting, a few hurdles that were tackled and adjustments that she made to her role supporting families. All of this was accomplished with respect, flexibility and a sense of humour. This dynamic and innovative program has benefited many families. One thankful mom told her story about the high quality of care that her family received from the program and how she benefited from being part of FACE (Family for Awareness, Change and Education) support group. Her son spoke about his positive experience throughout his recovery and how thankful he was for his mom’s support. This was a powerful presentation of a best practice in mental health care.

“Community Connections” - PLEO Parents’ Lifelines of Eastern Ontario by Phyllis Grant-Parker



Parent’s Lifelines is a community based, bilingual peer support program serving parents who have children (under 25) with mental health issues. For 12 years this non-profit volunteer driven organization had been limited by their inability to secure resources. Two years ago PLEO was offered the long awaited funds needed for capacity building and the PLEO Lifelines program was developed. Through the PLEO telephone help line and support groups, parents are helped to navigate the mental health system, they are empowered to be advocates for their loved-ones and are provided support throughout their journey with a focus on suicide

prevention. This is a story of the community (50 members including hospitals, educators, police officers, agencies, United Way etc) responding to the need to prevent youth suicide by coming together in 2010 to establish the Ottawa established the Community Suicide Prevention Network. The network recognized that families needed to be better supported. PLEO who was already a member of the network executive table and was known as a reliable family support organization, were asked to enhance their services to families. To this end, the network members helped secure base funding, consulted on program design and facilitated the funding stream through the hospital. Through this partnership arrangement PLEO has surpassed all of their target projections for service deliveries and continues to grow the program into the outer regions. As well as, set an example of how working with families has resulted in huge returns to the community.

Ontario Shores Centre for Mental Health Sciences: Family Council/ Family Resource Centre:

The three presenters from Ontario Shores Centre for Mental Health Sciences, Sheila Nueburger, Executive Vice President of Clinical Services; Caroline Tykoliz, Administrative Director and Liaison to Family Council and Christine Holland, Family Council Member, each shared their perspective on the importance of a “shared vision” for the development and implementation of the Family Resource Centre project at Ontario Shores. The partnership created a great deal of change and with that came challenges and successes. Sheila commented that a well-researched and presented proposal was the impetus to the hospital’s senior leadership team in supporting the council’s vision for a Family Resource Centre, paving the way to partnership that allowed the hospital to take a leap in faith to trust the process and embrace change in the way they work with families. Christine explored some of the many changes that council experienced resulting from the partnership and the undertaking of such a large project for a relatively young council – communication, operation, reporting and evaluation were some. Christine identified key personnel to support the Family Council Executive – Family Resource Centre Coordinator, Administrative Director level Liaison with a direct line to Senior Management as well as good collaboration with Social Work Council, Patient Council, Communications department to mention a few. Caroline identified some of the key success factors that helped facilitate the change that allowed successful partnering. She noted a shared vision, passion and commitment allowed each group to recognize and work around the different ways in which the two partners communicate, organize, plan, measure outcomes and share knowledge. Caroline noted that the essential components to building a model of success are honesty, transparency, trust, open dialogue and working together to recognize each other’s strengths and skills in order to build sustainability of programs and services that support family caregivers at Ontario Shores and in the community.

Mental Health Commission of Canada: Pan Canadian Recovery Initiative

Howard Chodos, Director of Mental Health Strategy and Recovery Project, Mental Health Commission of Canada made this presentation: "Advancing Recovery-Oriented Programs, Policies and Practices".



Howard Chodos

The presentation was broken into three components:

- Mental Health Strategy and Caregiving
- Caregiving and Recovery
- Guideline review and group discussion

1) Mental Health Strategy and Caregiving

Howard reviewed "Changing Directions, Changing Lives: Canada's first Mental Health Strategy" released May 2012. He spoke to the Six Strategic Directions and the impact of actually changing directions. "Families- whether relatives or people drawn from broader circles of support- are critical partner's in the recovery journey. Families often provide the bulk of support and care, and can be overtaken by stress and grief from the impact of mental illness and suicide. It is critical that they have access to the information and resources they need to sustain themselves, and that their voices be heard in the mental health system. Failure to support families undermines mental health across the population, leads to poorer outcomes for people living with mental health problems and illnesses, and increases costs to the system."

2) Caregiving and Recovery

The focus of this section was highlighting the benefits of shifting policies and practices toward recovery and well-being for people of all ages living with mental health problems and illnesses and their families. "Recovery in mental health refers to living a satisfying, hopeful, and contributing life, even when there are on-going limitations caused by mental health problems and illness." Recovery is person-driven, grounded in hope and based on self-determination. It is an ongoing, non-linear journey. Recovery is supported by relationships, enhanced by supportive communities and strengthened by family, friends and peers.

3) Guideline Review

There were a number of key messages to note during this part of the presentation. For example: Well-supported caregivers can play a facilitative role in recovery journey of a loved one."

- Adequate support can mitigate stressors often associated with caregiving.

- Recovery is about the context of one's life
- The whole family is in recovery not just the member with a mental illness.

During the ensuing discussion a number of concerns were raised by attendees, for example: The ongoing lack of adequate funding for mental health services; the critical need for treatment before tragedy; and the need for changes to the Mental Health Act which currently gives patients the rights and parents/caregivers the responsibilities.

This was an excellent presentation and positive in its content. If we could all take the guidelines off the shelf, professionals and family members, and use them to work together, things would begin to change! This was an excellent presentation and positive in its content. If we could all take the guidelines off the shelf, professionals and family members, and use them to work together, things would begin to change!

Exhibitors Provided Valuable Information



Purple Yip,
Schizophrenia Society of Ontario

Conference participants benefited from knowledge sharing and lively discussions with the conference's eighteen exhibitors. Many of the day's attendees took advantage of this excellent opportunity to connect with caregiver organizations from across Ontario and to network with volunteers and staff who are dedicated to helping families. We are grateful to all of the exhibitors and to their respective organizations or agencies for participating.

Exhibitor List:

- The Family Navigation Project, Sunnybrook Health Sciences
- Family Advisory Committee of the Addictions and Mental Health Network of Champlain
- Family Support Programs, Toronto East General Hospital
- Krasman Centre
- CAMH-Ryerson Collaborative for Client Centred and Family Sensitive Care
- Minds in Motion; Schizophrenia Society of Ontario
- CAMH, The Family Council
- Ontario Shores Family Council
- Mood Disorders Association of Ontario
- University Health Network
- The Toronto General Hospital Dalglish Family Hearts and Minds Clinic

- Mental Health Commission of Canada
- Evidence Exchange Network (EENet)
- Grand River Hospital
- F.A.C.E.
- PLEO Parents' Lifelines of Eastern Ontario

Conference Evaluation:

The OFCAN Planning Committee is grateful to the sixty percent of the participants who responded to the conference survey! We are pleased that the majority of the respondents (89%) rated the overall conference either good or excellent. Similarly, 94% felt that the conference was well organised while 89% found the topics to be relevant. Further, many participant comments indicated that what they learned at the conference would have a positive impact on future interactions between their organization and the caregivers that they serve.

A significant number of participants offered insightful and helpful ideas for going forward. Many thought that it would be beneficial to have a two-day conference format; increased opportunities for networking; as well as a forum that encouraged more open discussion. A variety of very interesting topics were suggested for a future OFCAN conference.

Sponsors Acknowledgement

OFKAN members would like to extend a heart-felt thank you to our sponsors for their generous financial and in-kind contributions which were essential to making our inaugural event a huge success. It is only through such valuable partnership and support that we are able to achieve our vision for caregivers.

