

***Evaluation, Resilience, and
Sustainability in Family Mental Health
& Addiction Peer Support***

~A Research and Innovation Symposium~

**Monday, May 2, 2016
Hôtel-Dieu Grace Healthcare
Windsor, Ontario**

Symposium Proceedings

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ISBN Print Version: 978-0-7714-3130-2

ISBN Online Version: 978-0-7714-3131-9

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**Published by the SouthWestern Academic Health Network (SWAHN), December 2016.
(c/o Schulich School of Medicine & Dentistry, Western University
Clinical Skills Building, Room 3720, London, ON N6A 5C1)**

OVERVIEW

In October 2015, the Mental Health and Addiction Working Group (MHAWG), a Working Group of SWAHN's Community Engagement Committee, hosted a half day event, "*Exploring Models of Mental Health Peer Support*" at Parkwood Institute in London, Ontario. The purpose of this event was to review and discuss the principles of mental health peer support models currently in operation across southwestern Ontario. The desired outcomes for this event included an increased awareness and understanding of various mental health peer support models.

This half-day event included presentations on mental health peer support perspectives and initiatives existing at the local, provincial, and national levels. Through presentations, group discussions, feedback, and post-event meetings, the importance and relatively solid and well-established position occupied by mental health peer support within the larger mental health system, was made apparent.

That said, it was also apparent to the MHAWG that the majority of peer support efforts are dedicated to serving the needs of those who identify as service users of mental health and addiction treatments, programs, and services. And, while the family members of individuals with mental health and addiction concerns are quite significant in their numbers, and in what has been referred to as the 'burden of care' they experience, the attention they receive and the access to peer support that is specific to their needs, is lacking significantly.

It is this area of need that exists within the larger realm of mental health peer support that informed the theme of the SWAHN's May 2016 research and innovation symposium entitled "*Evaluation, Resilience, and Sustainability in Family Mental Health & Addiction Peer Support.*"

Primary goal of the symposium

The primary goal of the symposium was to identify cross-sector (academia and community/hospital) collaborative research projects focused on family mental health and addiction peer support. While a call for abstract submissions was offered across Southwestern Ontario for the symposium, it became clear that research in family peer support is a significantly limited area of focus. It was for this reason that in addition to two research presentations and an experience shared by a family member, a "call to action" to encourage future collaboration and research was offered by the MHAWG Co-Chairs, Dr. Marnie Wedlake and Mr. Robert Moroz.

Symposium objectives

1. To increase knowledge about family/informal caregiver mental health and addiction peer support initiatives in Southwestern Ontario;
2. To facilitate research networking and collaborations between community and academia;
3. To increase research effectiveness and outcomes through partnerships between community and academia;
4. To encourage knowledge transfer through collaboration between researchers and knowledge users.

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SYMPOSIUM AGENDA: MONDAY, MAY 2, 2016

- 9:30 – 10:00 a.m.** **Registration – remained open throughout the day**
- 10:00 – 10:10 a.m. Greetings:
Dr. Ken Blanchette, Co-Chair, SWAHN Steering Committee
Ms. Janice Kaffer, CEO, Hotel-Dieu Grace Healthcare
- 10:10 – 10:20 a.m. Overview of SWAHN and the day’s agenda, and introduction of key
note speaker:
Dr. Margaret Steele, Co-Chair, SWAHN Operations Committee
- 10:20 – 11:00 a.m. **Keynote address: “*Coming Home: The Place of Family in
Treatment*”**
Dr. Rick Csiernik, School of Social Work, King’s University College,
Western University
- 11:00 – 11:15 a.m. Audience Q&A
Moderator: Dr. Sandra Fisman, Member, SWAHN Mental Health &
Addiction Working Group
- 11:15 – 11:20 a.m. Introduction of first presentation
Moderator: Dr. Sandra Fisman, Member, SWAHN Mental Health &
Addiction Working Group
- 11:20 – 11:35 a.m. **“*Having a Voice: The Ethics of Research on Family Mental Health
& Addiction Peer Support*”**
Principal author: Dr. Pierre Boulos
- 11:35 – 11:40 a.m. Audience Q&A
Moderator: Dr. Sandra Fisman, Member, SWAHN Mental Health &
Addiction Working Group
- 11:40 – 12:50 p.m. Lunch and Networking Exercise
- 12:50 – 12:55 p.m. Bingo Card Draw
- 12:55 – 1:00 p.m. Introduction of second presentation
Moderator: Dr. Marnie Wedlake, Co-Chair, SWAHN Mental Health &
Addiction Working Group
- 1:00 – 1:15 p.m. **“*The Unique Role of Student as Facilitator for Family Peer
Support Initiatives for Informal Caregivers of Individuals with
Severe and Chronic Mental Illness*”**
Principal author: Dr. Saadia Ahmad
- 1:15 – 1:20 p.m. Audience Q&A
Moderator: Dr. Marnie Wedlake, Co-Chair, SWAHN Mental Health &
Addiction Working Group
- 1:20 – 1:25 p.m. Introduction of third presentation

- Moderator: Dr. Marnie Wedlake, Co-Chair, SWAHN Mental Health & Addiction Working Group
- 1:25 – 1:40 p.m. ***“The Family Perspective”***
Ms. Joy Lang, Family Support for Caregivers, CMHA Middlesex
- 1:40 – 1:45 p.m. Audience Q&A
Moderator: Dr. Marnie Wedlake, Co-Chair, SWAHN Mental Health & Addiction Working Group
- 1:45 – 2:00 p.m. BREAK
- 2:00 – 2:15 p.m. ***“Research in Family Peer Support: A Call to Action”***
Dr. Marnie Wedlake and Mr. Robert Moroz, Co-Chairs, SWAHN Mental Health & Addition Working Group
- 2:15 – 2:20 p.m. Audience Q&A
Moderator: Dr. Sandra Fisman, Member, SWAHN Mental Health & Addiction Working Group
- 2:20 – 2:25 p.m. Instructions for audience breakout groups
Ms. Catherine Joyes, SWAHN Manager
- 2:25 – 2:35 p.m. Set-up for breakout group discussions
- 2:35 – 3:35 p.m. Breakout group discussions
- 3:35 – 4:15 p.m. Breakout group report-backs
Moderator: Mr. Robert Moroz, Co-Chair, SWAHN Mental Health & Addition Working Group
- 4:15 – 4:25 p.m. Evaluation, next steps Moderator: Mr. Robert Moroz, Co-Chair, SWAHN Mental Health & Addition Working Group
- 4:25 – 4:30 p.m. Wrap up
Dr. Sonja Grbevski, SWAHN Member, Mental Health & Addiction Working Group

SYMPOSIUM HIGHLIGHTS

- SWAHN was delighted to hold the Evaluation, Resilience, and Sustainability in Family Mental Health & Addiction Peer Support Research & Innovation Symposium at Hôtel-Dieu Grace Healthcare, the Network's first event in Windsor, Ontario. (Hôtel-Dieu Grace Healthcare is one of SWAHN's financial contributors.) Special thanks to Janice Kaffer, President & CEO and her staff (especially Sonja Grbevski, Robert Moroz, Barbara Sebben, Shirley Fields, Erica Colovic, and Costin Beliciu) for handling registration, set-up, technology, catering, and promotion of the event.
- SWAHN engages students as Committee and Working Group members across the Network and encourages student involvement in its projects. Jonathan Martin, a student volunteer from St. Clair College in Windsor, provided his time and expertise to videotape the symposium. The videos that capture our speaker presentations throughout the symposium, along with speaker slide decks, are available on the Network's website. Dorian Murariu, a recent graduate in Epidemiology & Biostatistics from Western University, provided assistance in compiling this proceedings document. We thank both Jonathan and Dorian for their efforts.
- The symposium had 65 registrants and 53 attendees from 14 organizations across the SWAHN region.
- Abstract submissions were requested for electronic submission by March 21, 2016 via the Network's website (www.swahn.ca). Submissions were welcomed for research projects that originated in the community or academic sectors that explored one or more of the following concepts:
 - Family/informal caregiver mental health/addiction peer support process or program evaluation;
 - Resilience as an element of family/informal caregiver mental health/addiction peer support;
 - Building sustainability for family/informal caregiver mental health/addiction peer support programs;
 - Applying research into practice with respect to family/informal caregiver mental health/addiction peer support;
 - Strengthening relationships across systems with respect to family/informal caregiver mental health/addiction peer support programs.
- Abstracts were judged according to the following criteria:
 - Projects that are focused on process or program evaluation, resilience, or sustainability, or a combination of these concepts as per the list above.
 - A clear description of the proposed initiative/research program.
 - Identification of proposed research and evaluation questions.
 - Innovation and program development details where applicable.
 - A clear indication of the project's potential for collaboration (mandatory for oral presentations; preferred for posters) beyond your discipline or sector, for example, a community project's engagement of academia or vice versa.
- As noted in the overview above, the call for submissions revealed that little research has been done in the area of mental health and addiction family peer support – at least in the

SWAHN region. This information led the MHAWG to adjust its original symposium agenda to explore this research gap in more detail.

- The first part of the symposium was devoted to oral presentations from Dr. Rick Csiernik (keynote), Dr. Pierre Boulos, Dr. Saadia Ahmad and Ms. Joy Lang. SWAHN's Mental Health & Addiction Working Group Co-Chairs, Dr. Marnie Wedlake and Mr. Robert Moroz, then lead a discussion focused on a "call to action" concerning the importance of research in the area of family peer support.
- The lunch break provided an opportunity for symposium attendees to engage in a networking "bingo" exercise. Dr. Csiernik kindly offered three of his publications in a draw for successfully completed bingo cards.
- The second component of the symposium was focused on attendee participation in breakout group discussions according to group assignments arranged during registration. The groups were assembled for approximately one hour to discuss research, education and sustainability in the area of family peer support.
- After the breakout group discussions, there was a report-back period to the larger group of attendees where various ideas for SWAHN's "next steps" were shared.

KEYNOTE ADDRESS

Coming Home: The Place of Family in Treatment

Dr. Rick Csiernik, School of Social Work, King's University College, Western University

Dr. Csiernik began his presentation explaining that researchers and clinicians work through various lenses that are rooted in different fields of training. As an example, Dr. Csiernik described his background in social work and how he came to conduct research related to families and addiction. Despite the interprofessional nature of peer support, which draws on work from a variety of fields, relatively little research has been done to date on the subject. Throughout the presentation, Dr. Csiernik reminded the audience to consider how other perspectives (not just the ones we are trained in) can contribute to our understanding of mental health and addiction research and its application to clinical practice.

Dr. Csiernik then addressed several conceptual issues that present challenges in peer support research. The first issue concerns the order of events that lead to addiction. A key question is whether an addiction leads to a mental health issue or whether a mental health issue initially exists and in response to that the individual turns to substances and forms an addiction. The second issue raised was 'parent-child' concerns. There is a two-way street in parent-child relationships, where in some cases a child's mental health issues can affect his or her parents (i.e. bottom-up effects), while in other cases a parent's mental health issues can affect children (i.e. top-down effects). For this presentation, Dr. Csiernik would focus on the impact of parents' mental health issues on their children.

Another key conceptual challenge in mental health peer support is the kind of interactions that are being considered and their impact on the individual. The *ecological model* suggests that research on families should consider both *intra-personal factors* (i.e. the individual-level factors) and *inter-personal* interactions between individuals. For example, it is important to consider the positive impact of peer support (an inter-personal factor) on an individual as well as the individual's ability to cope with a mental health or addiction (an intra-personal factor). Inter-personal interactions may be especially important for individuals with complex families, such as a child with multiple step-parents and siblings. Without considering multiple perspectives in studying families, important factors that affect the child's mental health may be overlooked. Yet, families have traditionally been studied in terms of a biology, or psychology, or social perspective, which has resulted in silos of research. Dr. Csiernik emphasized that in clinical practice one cannot treat complex patients by thinking of these different domains in silos. It is particularly important to manage all three domains because relapses in mental health and addiction often happen when the combination of these domains (biological-psychological-social) are not addressed in clinical practice.

Next, Dr. Csiernik addressed ethical issues in treating the patient under limits that exist in real-world settings. Although peer support group meetings may offer great benefits for those with a mental health or an addiction problem, individuals who cannot overcome personal fears about participating in a peer group would not have access to treatment or to support services. Thus, at times it may be necessary to break the traditional bounds of practice in order to meet the needs of clients who would not otherwise be able to seek help for themselves. Dr. Csiernik also emphasized that personal changes can only happen when a problem is first acknowledged. This is also why it is sometimes necessary to take someone by the hand and show them the options because they may not be in a place to fully comprehend their problem or to see the potential solutions.

Ultimately, in order for peer support services to be effective they must consist of a network of people dedicated to mental health and addiction. There must also be a means of ensuring that clients attend the meetings. Many of the existing networks for mental health and addiction started as peer support groups throughout the self-help movement of the 20th century. However, these networks have largely worked in silos to address specific mental health issues (e.g., depression, schizophrenia) while leaving out the role of the family as the primary caretakers.

In response to an audience member's question during the question and answer period, Dr. Csiernik made an observation that pertains to the current state of research in the field of peer support. One of the differences between today and the early 1980's (when he began his career as a social worker) is that there has been a shift in focus from developing and starting new programs, to a growing need to evaluate the impact of these programs. Dr. Csiernik also encouraged program evaluators to consider both outcomes and processes of change in peer support work.

PRESENTATION #1

Title: *Having a Voice: The Ethics of Research on Family Mental Health & Addiction Peer Support*

Principle Author: Dr. Pierre Boulos

Co-Author(s): Suzanne McMurphy

Abstract

“Justice refers to the obligation to treat people fairly and equitably. Fairness entails treating all people with respect and concern.” And so begins the explanation of the third and last research ethics principle in the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans. The goals of this presentation will be twofold. On the one hand, the presentation will surface issues and concepts when conducting research on Family Mental Health & Addictions Peer Support. On the other hand, collaborative research projects focused on peer support for families and/or informal caregivers who are supportive individuals living with mental health and/or addiction-related concerns, to be effective, must respect the rights of research participants. In this case, we will explore the ethical implications for research participants (e.g., those tasked with the burden of care), those affected by the research (e.g., individuals living with mental health and/or addiction issues), and researchers. For research to be implemented into practice, it is incumbent on the collaborative community to ensure that the best possible evidence informs the practice. This presentation aim to show that the ethically inspired research is one and the same as the research that gets the right sort of evidence to inform best practices.

By the end of the presentation, audience members will be able to:

1. Outline general research ethics principles;
2. Apply research ethics principles to projects in family mental health and addiction peer support;
3. Explain the requirement for good mental health research to be synchronous with research ethics principles.

The presentation will aim to be interactive by using discussion as a way to surface topics of interest.

Overview

Dr. Boulos discussed principles of research ethics as they apply to family mental health and addiction peer support research. As a member of a research ethics board, Dr. Boulos' primary concern is to protect the rights of research participants, which, at times, may conflict with the interests of researchers. On a principles basis, both clinical practice and research should have a 'bottom line' of ensuring equity and fairness. However, it is also understood that other factors may be at play which could place practical limitations on the way in which research is conducted.

Dr. Boulos outlined the three basic ethical principles as stated in the Tri-Council Policy Statement for the conduct of research involving human participants. One key ethical consideration for the conduct of research concerns whether there is respect for persons. Potential participants must be seen as autonomous, that is, have the ability to choose for themselves whether or not to participate. Even in cases where an individual does not have the capacity to make an informed decision (i.e. to consent) they still deserve the protection of this principle.

Respect for autonomy in decision making is the key principle underlying the consent process in which an individual learns about a study and its implications before deciding to participate. The consent process is essential because it is meant to ensure that by participating in research, one is not left vulnerable to the risks associated with participating. Vulnerable populations, such as young children and individuals suffering from dementia, do not have the capacity to provide fully informed consent and hence would need to be considered more carefully in order to ensure fair treatment.

The second principle is that we ought to be concerned with the welfare of individuals. A key consideration when a research ethics board reviews a research proposal is whether the benefits of doing research outweigh the risks (or costs). If the potential benefits to participants and to society do not outweigh the costs, then the research should not take place. Stated another way, this principle concerns both beneficence (doing “good”) and non-maleficence (avoiding doing harm).

The final principle is that of justice – whether all individuals who are approached to participate and those who become participants are treated fairly and equitably. For example, it is important to consider how participants are chosen. For example, it would be a cause of concern if experiments were conducted on individuals who were chosen because of a particular disadvantage. According to this principle, the risks of participating in research should be distributed evenly across participants or groups of interest.

Another important ethical consideration in conducting peer support research is that of bystander issues. In family peer support research, the participants are actually the bystanders, so we would have to address how the research impacts family members. It is important to ask what roles each individual plays – are they participants or peer supporters? Would they benefit from participating in research? Presumably, there is also a benefit to the individual suffering from the mental health problem or the addiction who is not the research participant.

There are also privacy considerations in conducting peer support research. Dr. Boulos pointed to two: records retention and custodianship over data. For instance, whose data is it and how is it managed? Is the research record separate from the medical record? Is there a duty of disclosure? The requirements for data retention are different in a research setting versus in a health professional setting, and even among clinical settings (e.g., a social worker’s office versus operating room).

A final note regarding ethical principles of conducting peer support research was that ethical research tends to breed good quality data. Conversely, if participants have ethical misgivings about your research this will also prevent good data collection. Thus, ethically sound research is a staple of quality research.

Dr. Boulos proposed the following questions to ask when conducting family peer support research:

- Who are the participants?
- How do you approach them/how do you get them to participate with you?
- How do you cross the boundary to recruit them?
- How do you know who they are? (Are you their psychiatrist, psychologist, social worker, some other therapist?)
- What role do you play in their lives? Are you a researcher or a psychiatrist?

PRESENTATION #2

Title: *The Unique Role of Student as Facilitator for Family Peer Support Initiatives for Informal Caregivers of Individuals with Severe and Chronic Mental Illness*

Principle Author: Dr. Saadia Ahmad

Co-Author(s): Dr. Leonardo Cortese, Nicole Dube, Amy Goulet, Susan Aussant, Dirusha Moodley

Abstract: There has been a growing body of evidence to suggest the value of peer support programming as beneficial to providing comprehensive mental health services. However, some evidence has demonstrated that for adults with severe mental illness, peer support has yet to yield equivalent outcomes. There are inherent challenges for patients and their family members to understanding severe and chronic mental illness that pose difficulties for meaningful family and peer support efforts. These factors may include a fundamental need for information and education on complex and difficult to treat mental illness, symptoms such as paranoia preventing family inclusion, limits to confidentiality, and caregiver burden. Often times, families are only welcome when crises occur. Many of these limitations to family involvement prevent the development of family support programs.

Hôtel-Dieu Grace Healthcare (HDGH) is a premium healthcare centre offering Specialized Mental Health & Addictions services on an outpatient basis. The Wellness Program for Extended Psychosis is an HDGH community treatment program that serves individuals in Windsor-Essex ages 18 years and older who suffer from extended psychosis (usually defined as greater than two years). The program goal is to assist individuals to achieve independent living through individual and group sessions, avoid hospital admissions or presentation to the Emergency Room.

The W-PEP program team at HDGH has, through naturalistic and clinical observation, observed the value of family members as informal caregivers for their loved ones in the program. The current project seeks to identify a method of peer support that is sustainable for informal family caregivers for program clients with Severe and Chronic Mental Illness. Innovative and unique strategies to recruit family peer support participants that maintain the highest standards of respect and confidentiality for clients, ensure a balance for both education and peer support is maintained, and facilitate the reduction of caregiver burden are proposed in the current presentation. In order to overcome the influence of a power differential and the risk of focus on specific patient information (as opposed to general supportive information), the utilization of a "Student as Peer Support Assistant" will be initiated. This structure also provides an opportunity to further enhance academic/clinical collaborative models of care which is an inherent feature of HDGH service delivery.

Overview:

Dr. Ahmad introduced a program in which she and her colleagues at Hôtel-Dieu Grace Healthcare plan to use students to facilitate education-focused peer support groups for caregivers of individuals with chronic and life-long psychotic disorders. The program recognizes that although treatment of these individuals involves an interprofessional team of nurses, social workers, and psychiatrists, it is the family members who shoulder the greatest burden in providing care throughout the "lifecourse" of the individual. Dr. Ahmad explained that through program evaluations they have discovered that an increase in stress and caregiver burden occurs when a family member falls mentally ill. Often it is more distressing to the loved ones than to the individuals with the illness. Thus, the inspiration for this program came from addressing the question of how to invest in family members as means to help the sick individual.

The program faced several initial challenges. The first step was to create awareness about the purpose of the program by educating patients and building connections with representatives of the program. Another obstacle that arose concerned how to obtain consent to participate in this program, particularly among children. They explored options for using the internet to provide individuals with information, an approach that also provided an avenue for reaching family members who may often be left out of the treatment plan. However, it was not clear whether patients were actually using the website, or accessing the helpline through the information on the website, or otherwise viewing the content and information on the website.

Throughout the presentation Dr. Ahmad stressed that education alone is not enough to draw family members to seek help from peer support groups. In addition, there is no “behavioural pathway” for family members to develop and cultivate the role of primary caregiver. Thus, it is necessary to go beyond simply educating family members and to facilitate such a behavioural pathway, whenever possible and appropriate, for the individual’s particular situation.

Additional challenges to establishing peer support programs include confidentiality, power differentials, and maintaining standards of justice. Dr. Ahmad provided the example of a nurse as a facilitator of a peer group where participants may feel frightened to think that the nurse who is taking care of their loved one is now giving a presentation to a group. She posed the question, “How do you overcome this while also maintaining ethical principles and standards of research and clinical practice?” “How do you maintain professional boundaries?” One solution is to involve students as group facilitators. However, students require additional training in order to be competent in educating family members of complex patients about complex topics, while also moderating the peer support structure. Conversely the benefits of this approach include the lack of a power differential that would be in place with a healthcare worker, and training for these students can be done effectively.

Beyond providing education to family members there is a question of how to actually implement peer support programs in a scalable and effective way, and how to strengthen the relationship between family members and their loved ones with mental health or addiction concerns. In particular, it may become vital to establish effective behavioural pathways for family members so that they may fully endorse the role of primary caregivers.

Finally, another important consideration for developing peer support programs is the ‘ecological component’ i.e., factors such as modes of transportation and economic needs that may limit accessibility to events as well as demographics and ethnic diversity that may influence willingness to participate in the events. Thus, it may be necessary to adjust peer groups in order to meet the needs of individuals based on what may be unique circumstances.

PRESENTATION #3

Title: The Family Perspective

Presentation by: Ms. Joy Lang, Family Support for Caregivers, CMHA Middlesex

Overview:

Ms. Lang gave a narrative account of her experience as a peer support group facilitator. She has over 30 years of experience as a peer support group facilitator, co-facilitator, or as a member. Ms. Lang spent much of her time working with abused women. This presentation was also a personal account of her experiences while in the support groups.

This presentation outlined the format of the groups which evolved depending upon the needs of the group members. The main goal of this group was to support one another, but also to be available to help other families in need.

The members of Ms. Lang's early group recognized that they were not experts in the field of peer support or mental health. However, they believed that their years of experience in living with and caring for family members has earned them a permanent role in maintaining the health of their loved ones.

Ms. Lang recalled that there were obstacles in family members' lives that needed to be overcome. In her experience working within peer support groups she found that some mental health professionals did not understand the role of family members in patient's lives, and in some cases it seemed that providers did not understand what mental illness was. It also became evident that there was no consistent access to services or treatment for mentally ill individuals. She described the flow of patients as getting shuffled through the mental healthcare system with very little follow-up. Families are thus left to pick up the pieces alone at every step. Despite bearing the greatest burden of care, family members often find that they are unable to access the doctors or services they need for the ones they love, and are left in the dark.

In one of the earliest groups that Ms. Lang participated in the facilitator was Dr. Marnie Wedlake (now Co-Chair of SWAHN's Mental Health & Addiction Working Group). Ms. Lang commented that this was a great group because it provided important information about the continuum of mental illness; signs and symptoms; invited speakers; videos; and references to relevant books. A key lesson Ms. Lang learned is that taking on the role of peer supporter is a very complicated task, and it is experienced differently by every member of the family. The most significant takeaway for Ms. Lang from Marnie's group was that you have to take care of yourself because if you do not do this, then you won't be able to take care of others.

Ms. Lang described other obstacles and difficulties that she and her peers faced while in the support groups. When Ms. Lang first joined a peer support group the members had no idea what mental illness was, and many were in denial and had been so for years. What brought them together was that they all sought help in desperation because they had watched their loved ones slip into depression, anxiety, and psychotic episodes for example. The members also considered themselves to be frontline workers, further uniting their group.

Over time this group later continued with eight consistent members. It became a safe place where family members could talk about the difficulties of caring for their mentally ill loved ones. One of the advantages of this sort of group is that people may feel that they are not being judged by their peers or by the facilitator, and they will see that they are not alone, and they feel understood. In addition, Ms. Lang found that the support groups gave the members important

solutions to their complex problems while providing overall support. These peer support groups are also a place where family members can celebrate small successes and those of their loved ones.

As the peer group became more established it was evident that in order to achieve its goals the group required a permanent location. The members approached the Canadian Mental Health Association (CMHA) Middlesex and have since worked with CMHA to ensure its services are ongoing. In addition, CMHA has offered speakers at times when the group has felt stuck or has needed more expertise on a topic.

Finally, Ms. Lang summarized several points that she believes are the key elements of success for support groups:

- The opportunity for family members to participate in a psychosocial educational support group; these individuals provide the information needed to create a peer support group by providing the signs and symptoms that are experienced by peer supporters.
- A central location, set date and time for monthly meetings.
- A referral process from a community partner such as the CMHA, as well as a mechanism for revisiting the referral process when it's not working.
- Some training for informal facilitators who will play a key role in ensuring that everyone in the group has a chance to speak.
- The group has to set guidelines for confidentiality, length of sessions, membership numbers.
- A link to a community mental healthcare provider such as CMHA particularly for those in crisis.
- It's also important to keep family member informed of community programs.
- Need to encourage new and innovative approaches for advocacy and support for family members.
It's also important to acknowledge the frustration of family members with respect to mental health professionals such as psychiatrists around the input from family members in their loved one's care. Some doctors will not even listen to family members, despite them being essentially 'front line' workers in their loved one's lives.
- Need and educational process to help mental health professionals view family members as a valuable part in the ongoing process of helping their patients.

PRESENTATION #4

Title: *Research in Family Peer Support: A Call to Action*

Principle Authors: Dr. Marnie Wedlake and Mr. Robert Moroz, Co-Chairs, SWAHN Mental Health & Addiction Working Group

Overview:

Dr. Wedlake and Mr. Moroz offered an overview of research and statistics related to family peer support. The overall aim of the presentation was twofold:

- To provide a snapshot of the experience of family caregivers who are supporting loved ones who live with mental health challenges; and,
- To encourage research, knowledge transfer and exchange (KTE) in family peer support, where the disparity between need and dedicated interest is quite significant.

The presenters covered several topics:

- An overview aimed at profiling the family caregiver, including demographic content collected from sources like The Mental Health Commission of Canada and Statistics Canada.
- An overview of service provision and economic matters relevant to family caregivers, including the family caregiver burden of care, the economic impact on family caregivers and the economic savings realized by the health care system, services and functions as a result of family caregivers.
- An overview of how family caregivers are coping with their caregiving responsibilities and how they are being impacted by their burdens of care, including psychological distress and consequences to their personal health.
- A snapshot of some of the gaps in the research literature regarding family caregiver peer support, and a brief comparison to research attention given to service user peer support.

The presenters concluded with their rationale for making a call to action for increased research interest in family peer support. It was noted that one of the largest gaps related to peer support is the lack of services that are available to assist family members and informal caregivers. Related to this, is the lack of research that has been published in the area of family peer support.

This presentation was supported by a brief review of the recommendations that resulted from SWAHN's October 2015 event that focused on models of peer support, including:

- SWAHN as a liaison to enable centralized access to resources - bringing people together to do peer group research.
- Advocate for integration of peer support into clinical practice.
- Data management - get data on peer support out there for academics to do their work.
- Create a repository for research information beyond a library.
- Facilitate communication of shared visions.
- Education of front line providers and leaderships.
- Bridge gaps between the paradigms.
- Look at outcomes and evaluations of peer support programs to generate a body of evidence and to compare to existing knowledge.
- Standardized education resources.

BREAKOUT GROUP DISCUSSIONS

In the afternoon, attendees participated in breakout group discussions according to group assignments arranged during registration. The groups were assembled for approximately one hour to discuss one of the following topics, considering the content of the five presentations that were offered in the morning.

Research – How can new research be encouraged in the area of family peer support? What research questions need to be investigated? What do researchers need to consider?

Education – In what ways can students be involved in family peer support? What experiences, skills, knowledge, and education would students require prior to their engagement in this work?

Sustainability – How can sustainability be encouraged and maintained for family peer support initiatives? What are the necessary elements to ensure sustainability?

All groups were also asked to answer the following question:

In five years, envision what SWAHN stakeholders across Southwestern Ontario could achieve in the area of family peer support. What do these stakeholders need in order to be successful?

Before the breakout group discussions took place, the groups were asked to elect a note taker and a presenter for the 40-minute report-back period following the exercise. Verbatim responses from each group have been noted in the appendix below.

NEXT STEPS

Potential next steps for SWAHN identified through breakout group discussions and participant evaluations include:

Research:

- Encourage research in the area of family peer support for those whose loved ones are living with mental health and/or addiction-related concerns
- Review existing research in the area
- Develop a survey to assess research needs

Education:

- Encourage students to take Mental Health First Aid course and/or other related training
- Encourage job shadowing / mentorships for students
- Highlight family stories for students to build their awareness

Sustainability:

- Outcomes/evaluation of programming impact needed
- Engage family peers in program planning
- Build awareness of service availability / promote access to programming
- Develop guidelines/reference guides/standardized programming

Other themes throughout the breakout group discussions and participant evaluations:

- Accessibility – more family peer support groups are needed
- Awareness – need to collect and disseminate information for caregivers re: available family peer support groups
- Standardization/Information – need to build a resource for caregivers re: standardizing groups and sharing information
 - Develop a toolkit or other communication vehicle for caregivers and for service providers
 - Develop a Community of Practice
 - Share information about Peer Support Accreditation and Certification Canada's (PSACC) certification process for family peer supporters and mentors

Other suggestions:

- Consult speakers for feedback/suggestions/assistance re: proposed initiatives
- Reach out to symposium attendees for volunteers for particular initiatives
- Connect with hospital foundations re: funding for family peer support programming
- Connect with the South West and Erie St. Clair Local Health Integration Networks regarding funding for family peer support programming and for assistance/guidance with service promotion
- Work with PSACC on promotion

SWAHN's Mental Health & Addiction Working Group will review the above suggestions to determine how it can make a contribution towards improving the current state of family peer support in terms of information and resources. SWAHN will follow up with the symposium participants concerning its future initiatives.

APPENDICES

APPENDIX 1: OVERVIEW OF THE SOUTHWESTERN ACADEMIC HEALTH NETWORK (SWAHN)

The SouthWestern Academic Health Network's vision is to transform health in Southwestern Ontario through integrated excellence in research, education and clinical practice. Its mission is to improve population health and be a national leader in health care, education, and research by:

- Leading the development of innovative and value-added education, research, evaluation, and knowledge;
- Accelerating the dissemination of research-based evidence and leading practices into clinical practice to enhance patient and population health outcomes, quality, accessibility and affordability of health care;
- Integrate innovative collaborative models of education within health care delivery and research;
- Engaging community partners, patients and families to inform the academic service integration;
- Identifying appropriate performance measures to monitor progress and performance;
- Enhancing and advancing synergy and the sharing of resources between our organizations for mutual benefit in integrated patient care, education and research.

SWAHN is guided by a Steering Committee of leaders from its member organizations and is Co-Chaired by Dr. Gillian Kernaghan, President and Chief Executive Officer of St. Joseph's Health Care London, and Dr. Ken Blanchette, Chair of the School of Health Sciences at St. Clair College in Windsor.

St. Joseph's Health Care London, St. Clair College, and other organizations provide financial support to the Network and include area hospitals in London, Windsor, Sarnia, Chatham, Strathroy, Stratford and Owen Sound; universities and colleges (including Western University, University of Windsor, University of Waterloo, Fanshawe College, St. Clair College, and Lambton College); community and research organizations (Erie St. Clair Hospice Palliative Care Network and Lawson Health Research Institute); and Local Health Integration Networks (LHINs) in the South West and Erie St. Clair regions.

The Operations Committee is co-chaired by Dr. Robin Walker, Integrated Vice President Medical Affairs and Medical Education, London Health Sciences Centre and St. Joseph's Health Care London, and Dr. Doug Jones*, Vice Dean, Basic Medical Sciences, Schulich School of Medicine & Dentistry at Western University. Through its committee structure, SWAHN is engaged in projects that align to its three areas of focus: community, education and research. These projects address priorities for the region including: palliative care, simulation, interprofessional education, research ethics, nutrition and mental health.

*Note: Dr. Margaret Steele was an inaugural Co-Chair of SWAHN's Operations Committee with Dr. Robin Walker until her departure from London, Ontario in August 2016 to lead the Faculty of Medicine at Memorial University in Newfoundland.

APPENDIX 2: SWAHN MENTAL HEALTH & ADDICTION WORKING GROUP MEMBERSHIP

The following individuals contributed their expertise, ideas, and countless hours of effort in the preparations leading up to the May 2, 2016 symposium. SWAHN is grateful for their ongoing support and commitment.

Dr. Marnie Wedlake, Co-Chair (SW LHIN); Knowledge Transfer & Exchange Specialist, Canadian Mental Health Association Middlesex

Mr. Robert Moroz, Co-Chair (ESC LHIN); Integrated Director, Outpatient & Community Services, Hotel-Dieu Grace Hospital / CMHA Windsor Essex County

Dr. Sonja Grbevski, 2nd Co-Chair (ESC LHIN); Vice President, Clinical Operations, Hotel-Dieu Grace Hospital

Prof. Sharon Berry-Ross; Program Advisory Committee, Community Mental Health Multidiscipline Graduate Certificate, Lambton College

Prof. Pat Bethune-Davies; Professor, School of Nursing, Fanshawe College

Ms. Suzanne Book; Senior Manager, Counselling & Accessibility Services, Fanshawe College

Dr. Laurie Carty; Professor, Faculty of Nursing, University of Windsor

Dr. Tamison Doey; Chair, Professional Advisory Council, Hotel Dieu Grace Healthcare

Ms. Cassie Fisher; Mental Health Team Lead, London InterCommunity Health Centre

Dr. Sandra Fisman; Professor/Chair, Division of Child & Adolescent Psychiatry, London Health Sciences Centre – Victoria Hospital

Dr. Melanie Katsivo; Research Officer & Director, Office of Global Health, Schulich School of Medicine & Dentistry, Western University

Mr. Dorian Murariu; MSc Student, Epidemiology & Biostatistics, Schulich School of Medicine & Dentistry, Western University

Ms. Michele Pardo; Manager, Outpatient Mental Health, Huron Perth Health Alliance

Mr. Robert Owens; Coordinator, Social Service Worker Program, School of Human Services, Fanshawe College

Dr. Margaret Steele; Vice Dean, Hospital & Interfaculty Relations, Schulich School of Medicine and Dentistry

Ms. Catherine Joyes; Manager, SWAHN

Ms. Jennie Brown; Work Study Student, Western University

APPENDIX 3: SPEAKER BIOGRAPHIES *(in alphabetical order)*

Dr. Saadia Ahmad, Manager, Outpatient Mental Health Programs, Hôtel-Dieu Grace Healthcare



research awards and grants for her work in the area of neuropsychology.

Dr. Saadia Ahmad has worked for Hotel-Dieu Grace Healthcare for approximately 11 years. She is currently Manager of a number of Outpatient Mental Health programs at Hotel-Dieu Grace health care transitioning to a position as Mental Health and Addictions Clinical Research Lead. Prior to her current position, she served as Clinical Neuropsychologist overseeing all Psychological and Neuropsychological services at the HDGH Ouellette site. Dr. Ahmad is an adjunct faculty member for the University of Western Ontario's Schulich School of Medicine and Dentistry providing lectures on clinical techniques for undifferentiated physicians to the Windsor medical students rotating through Psychiatry. She has also taught approximately 20 courses at the University of Windsor in the Department of Psychology. She has a number of peer review publications and has received a number of provincial and national

Dr. Ken Blanchette, Chair, School of Health Sciences, St. Clair College



Dr. Ken Blanchette is the Chair for the School of Health Sciences at St. Clair College. He received his undergraduate degree from the University of Windsor and completed his Doctor of Chiropractic from National Institute of Health Sciences in Chicago Illinois. He practiced for 12 years in the United States specializing in breach birth complications, epileptic case management and advancing spinal decompression within the region as well as creating an integrated health model between disciplines. In 2010, he joined St. Clair College and was involved in the building of a 32 million dollar state of the art simulation center. Following the completion of the capital project, he has created an opportunity for professional training within our region and internationally for Health Care Disciplines and organizations in gaining continuing education. Dr. Blanchette is a current member of the board of directors for Hotel Dieu Grace Hospital and the Windsor Essex county Health Unit, as well as the Chair for the Heads of Health Sciences for Ontario Colleges.

Dr. Pierre Boulos, Special Advisor, Research Ethics Education & Internationalization, University of Windsor



Pierre Boulos, PhD is the Special Advisor, Research Ethics Education and Internationalization at the University of Windsor, where he has been a faculty member since 2001. Pierre has taught in Computer Science, Education, Physics, and Philosophy. He is a Research Fellow in the Centre for Research in Argumentation, Reasoning, and Rhetoric and a graduate faculty in the new doctoral program in Argumentation Studies. Pierre has presented and published widely on science and logic, computer ethics, and research ethics. His book, *Understanding Cyber Ethics in a Cyber World*, was published in 2008. More recently, Pierre has been appointed to the National Tri-Agency Panel on Research Ethics — the country's highest body setting research ethics policy for all of Canada — a first for someone from the Windsor area.

Dr. Rick Csiernik (Keynote Speaker), Professor, School of Social Work, King's University College, Western University



Rick Csiernik BSc, MSW, PhD, CCAC, RSW, Professor, School of Social Work, King's University College at Western University has written and edited fourteen books, including *Just Say Know*; *A Counsellor's Guide to Psychoactive Drugs*, *Homeless, Housing and Mental Health*, *Substance Use and Abuse: Everything Matters*, and *Responding to the Oppression of Addiction*. He has authored over 150 peer reviewed articles and book chapters and has presented at over 200 national and international conferences, workshops and seminars. He has been part of research teams that have received over three million dollars in funding and has been on the King's University College Honor Role of teaching 16 consecutive times. Rick

was the co-developer of the McMaster University Addiction Studies Program where he has taught for over 25 years and was inaugural recipient of the McMaster University Instructor Appreciation award.

Dr. Sandra Fisman, Professor and Chair, Division of Child and Adolescent Psychiatry, Department of Psychiatry, Schulich School of Medicine & Dentistry, Western University



Dr. Sandra Fisman is presently Professor and Chair of the Division of Child and Adolescent Psychiatry in the Department of Psychiatry at Schulich School of Medicine & Dentistry at Western University. She was previously Chair of the Department of Psychiatry and Chief of the London Mental Hospital Services from 2001-2011. In 2010/2011 she completed the OMA Schulich Physician Leadership Development Program as a member of Cohort 1. She recently completed and published, in the Canadian College of Physician Executives, with her co-authors, a quantitative and qualitative study of the outcome for the first four graduated cohorts of the program. These experiences have fostered for her a strong interest in Healthcare Transformation.

Dr. Fisman has long been engaged in the provision of acute care as well as tertiary care mental health services for children and youth. This interest brought together the respective ministries funding these services (Ministry of Child and Youth Services and Ministry of Health) in a collaborative relationship to develop an access pathway to emergency services in Southwestern Ontario. Her present research is focused on development of a brief Adolescent Screening Instrument to assess suicide risk with predictive validity, the use of an electronic personal health record to facilitate care for adolescents and evaluation of DBT group training skills in reduction of self-harm and suicidal behaviour.

However, most of all, she is the proud parent of four adult children and grandmother to several grandchildren. These experiences have served to educate her more than any professional degrees and have been a reminder of the importance of remaining humble.

Dr. Sonja Grbevski, Vice President, Clinical Operations, Hôtel-Dieu Grace Healthcare



Dr. Sonja Grbevski has her Ph.D. in Counselor Education, with cognates in Rehabilitation Counseling and Educational Psychology from Wayne State University in Detroit, Michigan. She is a Registered Social Worker, in addition, she is certified as a critical incident stress management trainer. Sonja has been with Hotel Dieu Grace Healthcare nee Hospital for over 10 years now in various leadership positions. She is currently the Vice President of Clinical Operations. Sonja is also an Adjunct Professor in the Rehabilitation Counseling program at Wayne State University. Her research includes treatment of individuals with severe mental illness and co-occurring disorders; and trauma informed care. She has presented at numerous conferences throughout North America and has trained professionals through Eli Lilly and Canadian Mental Health Association, and ESC LHIN to name a few.

Ms. Catherine Joyes, Manager, SouthWestern Academic Health Network (SWAHN)



Catherine Joyes holds an HBA (History) from Brescia University College, a Master of Library and Information Science from Western University, and an MBA from the Ivey School of Business. From 1997-2002, Catherine was a member of the Prospect Research team in Advancement Services, part of the External Relations Department at Western. After leaving Western, Catherine spent twelve years working for two local nonprofit funding organizations managing community grantmaking programs. She joined the SouthWestern Academic Health Network as Manager in January 2015. A life-long Londoner, Catherine has an affinity for continuous learning and development and enjoys her involvement in various book clubs and volunteer committees.

Ms. Janice Kaffer, CEO, Hôtel-Dieu Grace Healthcare



As a skilled communicator and systems leader; Janice has been recognized by peers, government and professional colleagues as a successful and engaging leader of strategic change and organizational development. Janice delivers value based leadership that is inclusive of the principles of patient and family centered care, staff development and physician engagement and is focused on individual accountability for results within a strong team based structure.

Janice has been serving in executive roles for many years – most recently as the Chief Executive Officer and President of Hotel Dieu Grace Healthcare, in Windsor. Janice’s role previously at Hotel Dieu Grace Healthcare was as the VP Clinical Programs and CNE. Prior to this role, Janice was the VP and CNE at a district health authority in Nova Scotia where she had leadership accountability for many of the programs now delivered at HDGH.

Janice draws her strength and inspiration from her friends, her colleagues and particularly from her family. Her husband of 35 years Bernie, her children Kate and Matt, as well as her son-in-law Jason all keep Janice focused on the importance of family and community. Janice is an exceptionally proud Amma to her grandchildren, Allison, Nathan and Courtney who are the light of her life.

Ms. Joy Lang, Member, Family Support for Caregivers, CMHA Middlesex; Community Research Associate, Centre for Research & Education on Violence Against Women and Children



Ms. Joy Lang was the founding Director of the Chatham Kent Women's Centre Inc. for 21 years (1979-2000). She was actively involved in enhancing services and training related to woman abuse in her county and across the province of Ontario. Ms. Lang was a founding Director of the Chatham-Kent County Task Force on Family Violence and the Chatham-Kent County Child Abuse Co-ordinating Committee. She has continued to be involved in the areas of woman abuse, sexual harassment, homelessness and domestic violence through her participation in research and clinical services at The Centre for Children and Families in the Justice System of the London Family Court Clinic, The Centre for Research & Education on Violence against Women & Children at Western University, the London Homeless Coalition and The London Co-ordinating Committee to End Woman Abuse. Ms. Lang is currently a Community Research

Associate with The Centre for Research & Education on Violence against Women & Children.

Mr. Robert Moroz, Integrated Director, Canadian Mental Health Association – Windsor-Essex County Branch and Hôtel-Dieu Grace Healthcare



Robert Moroz completed his undergraduate degree at the University of Windsor, and received a Masters of Social Work from Wayne State University in Detroit. For the past 25 years, Rob has held positions in community and emergency mental health services in Essex and Kent counties. Windsor's recent realignment of hospital services has resulted in Rob serving in leadership positions for inpatient and outpatient mental health care in both acute and sub-acute settings.

Rob has led staff, physicians, community partners and clients in redesigning mental health services processes throughout the patient care stream, which has resulted in improved treatment planning, greater staff efficiency and reduced wait times for patient transfers of care.

Additionally, for two years Rob served as HDGH's Safe Workplace Advocate – in this role he was responsible for conflict resolution, development of safe work plans, leadership coaching and conduct of formal investigations. CMHA and HDGH entered a formal collaborative agreement two years ago, and since then HDGH has been designated as the mental health service provider for subacute and acute care within the upcoming Windsor-Essex Health System. Together both partners will have key responsibilities for much of mental health service delivery within this new system, and work has already commenced to integrate clinical processes, maximize staff talents and improve the client experience within the collaborative.

Dr. Margaret Steele, Vice Dean, Hospital & Interfaculty Relations, Schulich School of Medicine & Dentistry



Dr. Margaret Steele is currently the Vice Dean, Hospital & Interfaculty Relations, Schulich School of Medicine & Dentistry. Margaret is a Professor in the Departments of Psychiatry, Pediatrics and Family Medicine. In her current role, she is co-facilitating the development of the Academic Health Sciences Network in Southwestern Ontario (SWAHN).

She earned her Honours degree in Microbiology and Immunology at Western University in 1983 and completed her MD in 1987. She obtained her Fellowship in Psychiatry in 1992, and in 1993, completed the requirements for the Child and Adolescent Psychiatry Diploma. Margaret earned a Masters of Higher Education from the Ontario Institute of

Studies in Education\University of Toronto and became a Fellow of the Hedwig van Ameringen Executive Leadership in Academic Medicine at Drexel University in Philadelphia, Pennsylvania in 2008. In 2012, Margaret became a Distinguished Fellow of the Canadian Psychiatric Association and in 2013 she became a Canadian Certified Physician Executive.

Dr. Marnie Wedlake, Knowledge Transfer & Exchange Specialist, CMHA Middlesex; Adjunct Research Professor/Sessional Assistant Professor, Faculty of Health Sciences, Western University



Marnie has worked in community-based mental health care since 1986, and at CMHA Middlesex since 1997. Her current position at CMHA is Knowledge Transfer & Exchange Specialist. She has a Hons BA in Psychology (Waterloo), a MEd in Educational Psychology (Western), and a PhD in Health Professional Education (Western). As a Registered Psychotherapist, Marnie is a Member of the College of Registered Psychotherapists of Ontario. She has a part-time psychotherapy practice. She is an Adjunct Research Professor and a Sessional Assistant Professor in the Faculty of Health Sciences, at Western University.

As a qualitative researcher and a person who tends to be quite practical, Marnie delights in finding varied and creative ways of applying philosophy and theory to real life. In her spare time Marnie enjoys reading, photography, writing poetry, watching movies, and being active outdoors.

APPENDIX 4: BREAKOUT GROUP EXERCISE



**Evaluation, Resilience, and Sustainability in Family
Mental Health & Addiction Peer Support**
~A Research and Innovation Symposium~
May 2, 2016

We have approximately one hour for this exercise after the groups are assembled. The questions below are assigned for discussion **based on the number of your breakout group**. Before the discussion begins, each breakout group will need to elect a note taker and a presenter for the 40-minute report-back period following this exercise.

Considering all five presentations that we have heard today, please discuss the following questions as per your breakout group number and record your discussion points on the poster paper provided.

Breakout groups #1 and #2 –

1. Research – How can new research be encouraged in the area of family peer support? What research questions need to be investigated? What do researchers need to consider?
2. In five years, envision what SWAHN stakeholders across Southwestern Ontario could achieve in the area of family peer support. What do these stakeholders need in order to be successful?

Breakout groups #3 and #4 –

1. Education – In what ways can students be involved in family peer support? What experiences, skills, knowledge, and education would students require prior to their engagement in this work?
2. In five years, envision what SWAHN stakeholders across Southwestern Ontario could achieve in the area of family peer support. What do these stakeholders need in order to be successful?

Breakout groups #5 and #6 –

1. Sustainability – How can sustainability be encouraged and maintained for family peer support initiatives? What are the necessary elements to ensure sustainability?
2. In five years, envision what SWAHN stakeholders across Southwestern Ontario could achieve in the area of family peer support. What do these stakeholders need in order to be successful?

APPENDIX 5: BREAKOUT GROUP DISCUSSIONS (verbatim transcription of notes)

Breakout Groups 1 & 2 – Research

1. How can new research be encouraged in the area of family peer support? What research questions need to be investigated? What do researchers need to consider?	
Group #1	Group #2
<p>1a) collecting data in timely fashion when caregivers are available:</p> <ul style="list-style-type: none"> • engaging the community, e.g., 211 “crisis services” • standardized tool, e.g., experience based design (questionnaire) • uniformity of language within agencies across the board 	<ul style="list-style-type: none"> • Research questions <ul style="list-style-type: none"> ○ first step needs assessment + use existing studies, e.g. CAMH ○ environmental scan • Considerations: <ul style="list-style-type: none"> ○ incentives, accessibility, consent ○ preventing overlap – increase awareness existing programs, time; meaningful client and stakeholder “buy-in”, facilitate adult learning ○ genuine service/support ○ who collects data • Does the quality of life of the caregiver increase with proper supports? • With proper supports how does this alleviate cost of care (re: health care system) • What is the role of peer support on family involvement in overall wellbeing of the family
<p>1b) ask families where there is a gap:</p> <ul style="list-style-type: none"> • ask families if a system navigator is required • what research is already being done, e.g., (OFCAN) – Ontario Family Caregiver Advisory Network – www.ofcan.org • do caregivers feel safe/confident asking questions? 	
<p>1c)</p> <ul style="list-style-type: none"> • Layman’s terminology • confidentiality vs. being anonymous • trust – safe environment • disseminate date – “close the feedback loop” • value & time • validate the contribution • consider different demographics • what are the benefits to doing this research, e.g., policy changes for: <ul style="list-style-type: none"> ○ them (caregiver) ○ their loved one (outcomes) ○ community 	

Breakout Groups 1 & 2 – Research (continued)

2. In five years, envision what SWAHN stakeholders across Southwestern Ontario could achieve in the area of family peer support. What do these stakeholders need in order to be successful?

Group #1	Group #2
<ul style="list-style-type: none"> • awareness of best practices • opportunities to share • communication • well-articulated program/project information • “Patience” - “but show me the outcomes” • common tools • standardized family support group • database of resources – making this accessible • accessible to provide data & obtain data for the families and services that support families <ul style="list-style-type: none"> ○ education ○ support ○ window of hope • funding • resources • No wrong door 	<ul style="list-style-type: none"> • family members reviewed as primary stakeholders • education re: stigma • program model/curriculum/standardized resources • lunch & learn • hidden vulnerabilities • experienced vs. inexperienced/train-trainer • central resources repository • aftercare • first point of contact (“prime”) • continuity of care • long term study • family system navigator • hotline? • email?

Breakout Groups 3 & 4 – Education

1. In what ways can students be involved in family peer support? What experiences, skills, knowledge, and education would students require prior to their engagement in this work?

Group #3	Group #4
<p>How students are involved:</p> <ul style="list-style-type: none"> • resource • educators – to group, school, community • provide “loose” structures • flexible • offer validation, normalization 	<ul style="list-style-type: none"> • Practical skills based mental health seminars (e.g., mental health first aid) mandatory for students in related fields and voluntary for others – skills necessary: communication, empathy, validation, active listening • Peer support included in mental health education curriculum – family member class presentations, student-family shadowing experiences • Engaging students early (high school) – social media, presentations, celebrity • Increase clinician-student collaboration (shadowing, family community events and presentations) – co-facilitation of groups

2. In five years, envision what SWAHN stakeholders across Southwestern Ontario could achieve in the area of family peer support. What do these stakeholders need in order to be successful?

Group #3	Group #4
<p>In five years, stakeholders need:</p> <ul style="list-style-type: none"> • standardization of funding to peer led groups • research to involve families/peer in meaningful role in decision making/planning • advocate for legislative changes • role clarity • clearly defined goals/outcomes of groups • clear boundaries • theoretical knowledge • interprofessional model of care (OT, nursing, social work, medicine, etc.) • previous exposure to clinical experience • communication skills 	<ul style="list-style-type: none"> • Define role/framework of a family support peer worker – what do they actually do!? • Increase family peer support groups available across SWAHN network – a group for each location • Facilitate curriculum i.e., mental health field and peer support education • Design peer support conference - involvement beyond mental health professionals • Connect website (SWAHN) to social media/YouTube to advertise peer support groups/events and other website links to group events • Development of a family tool kit – fact sheets, student tools, resources available

Breakout Groups 5 & 6 – Sustainability

1. How can sustainability be encouraged and maintained for family peer support initiatives? What are the necessary elements to ensure sustainability?

Group #5	Group #6
<ul style="list-style-type: none"> • Demographics – aging population • Buy-in from stakeholders • Don't overthink it, support groups have worked well throughout history • Members MUST feel: not alone, won't be judged • Evaluate to have outcomes/ proof for funders OR does funding formula need to change? • Brief check in • In crisis? - yes, more time • Members create agenda • Is there a timeline? What connects people? • Orientation importance • Active vs. passive referral • Central liaison role – familiar face • Improve family engagement in treatment in general • How – it came from a need, sense of obligation - it needs to feel like a safe space • No exclusion criteria • Educate staff to promote • Facilitator needs some training to keep group loosely focused and awareness of other community resources 	<ul style="list-style-type: none"> • increased advertisement – “visual”, increased awareness • place – accessibility, both private and public • “promoting” anti-stigma initiatives with starting groups: commitment and regular dates and accessible time and places and mentorship • Accessibility to professionals and support and guidance/education, navigate clear channels to have immediate access • accessibility to a scope of access to all stakeholders • sustainability - *funding* • “safe” environment – maintained • guidelines, validation, respect • “a go to” – group when “disfunctioning” • “Patient experience Partner” – lived through - being active, positive influence • Co-location of multiple mental health services with like-minded goal • “Family Support Centre” • Education!! – at all levels • family/peer supports educating • maintaining “Code of Conduct” • “like” sponsors in AA – “the go-to person” • up to date current information and all services – information, quick reference guide, “hub” on internet • keep engaged/connected “safe location”

2. In five years, envision what SWAHN stakeholders across Southwestern Ontario could achieve in the area of family peer support. What do these stakeholders need in order to be successful?

Group #5	Group #6
<ul style="list-style-type: none"> • research – qualitative, participatory • beyond psycho-education – educate professionals re: valuable role of families • explore research opportunities with existing groups – proof it works! • Awareness campaigns – advertise outside of mental health agencies • Public awareness 	<ul style="list-style-type: none"> • **funding** and documentation to support that the need is being met • feedback – family, patients, healthcare • evaluation (qualitative) at a measured time after meetings • fundraising, community partners • unrestricted pharmacy dollars • facility location, accessibility • having a rep during public events

APPENDIX 6: EVENT EVALUATION FORM



Evaluation, Resilience, and Sustainability in Family Mental Health & Addiction Peer Support
Monday, May 2, 2016

EVENT EVALUATION

SWAHN would like to receive direct feedback and constructive recommendations from you in order to improve events like this one in the future. Please be as specific as possible in your ratings and comments. Thank you.

The desired outcomes for this event include:

- To increase knowledge about family/caregiver mental health/addiction peer support initiatives in Southwestern Ontario;
- To facilitate research networking and collaborations between community and academia;
- To increase research effectiveness and outcomes through partnerships between community and academia;
- To encourage knowledge transfer through collaboration between researchers and knowledge users.

In your opinion how would you rate this event on the following factors? (Please circle the appropriate number)

Please use the scale: 5 = strongly agree to 1 = strongly disagree					
a) The event's contents were relevant to me.	5	4	3	2	1
b) The event satisfied my personal expectations.	5	4	3	2	1
c) The event allowed me to network with people from other organizations.	5	4	3	2	1
d) The event increased my awareness and understanding of various mental health peer support models.	5	4	3	2	1
e) The speakers helped to frame perspectives and demonstrate different family mental health peer support initiatives.	5	4	3	2	1
f) The small group discussions were effective in uncovering possible ways in which SWAHN can contribute to advancement and/or further exploration regarding family mental health peer support.	5	4	3	2	1
g) I was able to make a meaningful/significant contribution to today's discussions.	5	4	3	2	1
h) Overall, the event was an effective learning experience.	5	4	3	2	1
i) I will seek to attend future SWAHN events based on my experience today.	5	4	3	2	1
j) Commercial influence did not bias today's event.	5	4	3	2	1

1. What was the most important thing that you learned today?

2. Describe at least one thing that you will do differently based on what you learned today.

3. Specify any changes that you think would have made this SWAHN event more effective.

4. What advice do you have for SWAHN regarding its role in helping to advance the topic of family mental health peer support across Southwestern Ontario? (If you would like to be engaged with SWAHN in this work, please let us know.)

5. What topics would you like addressed at future SWAHN events?

6. Please provide any general comments that you may have about today's program:

**Thank you for completing this evaluation form!
Your responses will help SWAHN make improvements to its future events.**

APPENDIX 7: EVENT EVALUATION FORM RESPONSES

Responses to Likert Scale Questions: Using the following scale (5=strongly agree to 1=strongly disagree), participants responded as follows. (Percentages have been rounded.)

Statement	Scale	# Responses	% Response
a) The event's contents were relevant to me	1	0	0
	2	1	4%
	3	2	7%
	4	12	43%
	5	13	46%
Total responses:		28	100%
b) The event satisfied my personal expectations	1	1	4%
	2	0	0
	3	6	21%
	4	12	43%
	5	9	32%
Total responses:		28	100%
c) The event allowed me to network with people from other organizations	1	0	0
	2	0	0
	3	2	7%
	4	7	25%
	5	19	68%
Total responses:		28	100%
d) The event increased my awareness and understanding of various family/caregiver mental health and addiction peer support initiatives	1	0	0
	2	2	7%
	3	8	29%
	4	11	39%
	5	7	25%
Total responses:		28	100%
e) The content delivered by the speakers enabled me to have a greater understanding of some of the perspectives, issues, and concerns that impact, and are relevant to, family mental health/addiction peer support initiatives	1	0	0
	2	2	7%
	3	3	11%
	4	12	43%
	5	11	39%
Total responses:		28	100%
f) The small group discussions were effective in uncovering possible ways in which SWAHN can contribute to advancement and/or further exploration regarding family mental health/addiction peer support initiatives and research.	1	0	0
	2	2	7.4%
	3	2	7.4%
	4	10	37%
	5	13	48.1%
Total responses:		27	99.9%

g) I was able to make a meaningful/significant contribution to today's discussions.	1	0	0
	2	0	0
	3	4	14.3%
	4	13	46.4%
	5	11	39.3%
Total responses:		28	100%

h) Overall, the event was an effective learning experience.	1	1	4%
	2	0	0
	3	4	14.3%
	4	14	50%
	5	9	32%
Total responses:		28	100%

i) I hope to attend future SWAHN events based on my experience today.	1	0	0
	2	0	0
	3	4	14.3%
	4	11	39.3%
	5	13	46.4%
Total responses:		28	100%

j) Commercial influence did not bias today's event.	1	1	4%
	2	0	0
	3	1	4%
	4	5	19%
	5	20	74%
Total responses:		27	101%

Verbatim Responses to Narrative Questions:

1. What was the most important thing you learned today?

- I was not aware that there is limited/no support for patients/individuals suffering for addiction and mental health and the integration of that individual back into their family
- Wasn't as focused on the topic?
- There is a tremendous amount of research on peer support groups. However, family peer support group research (in mental health) is sparse
- Learning about SWAHN itself. To begin the conversation together in order to make change for families
- We are so limited due to funding
- Who and what SWAHN is
- The importance of family support is increasingly important. Did not realize how underutilized it was in a formal setting
- Awareness of existing programs
- That stakeholders are appreciating the impact of peer/family support and seem to be realistically addressing related issues via action

- Interesting discussion in the first presentation - parent and step parent - children and their children (from 6 different partners) and effects on grandchildren
- Limited resources in local community - more people moving to area with same amount of resources
- Family perspective as peer support
- Recognizing the contributions of caregivers
- New ways to sustain peer support/family groups in the community
- The suggestions from Joy Lang to make family peer support groups sustainable
- The door has been opened for action/discussion and the lack of family support/peer support
- Exercise and discussion with peers
- The vast “need for family peer support” in our communities when dealing with mental health
- Mental health and addiction go hand in hand and the careful involvement of family and education of treatment options is critical in recovering along with the biological needs, sociological needs, psychological needs of patient
- That many people are interested and motivated to make peer support groups happen
- Adding network resources to support family programs
- Importance of family peer support and the need for research

2. Describe at least one thing that you will do differently based on what you learned today.

- Advocate for students and family members in academia that needs support – perhaps develop a peer support group or “sponsor” that can help individuals obtain help and support
- My appreciation and understanding of living with uncertainty. I will utilize this model.
- Promote more “family support groups” to the families involved
- Reach out to more community resources
- Question family involvement/support with clients
- Knowledge of existing programs
- Address caregiver stress more proactively with my clients
- Passive referral vs. active referral - having a clear definition for what is already done
- Make one’s self available as a psycho-education resource for families
- Refer to the research on the impact to caregivers in order to promote and advocate for more services for family caregivers
- I will make more effort to engage family in considering the limited resources of our program
- Ensure when teaching students to stress importance of family peer support
- Working with family – see what they would like
- Network more
- I will be in contact with a worker in London (who I met) about resources for families and more particulars about her role
- Try to do something more in the realm of self-care. Continue to speak out LOUD about mental health
- Engage more with families

- Bring in peer support speaker to existing program design
- Encourage our family group in my community to continue. Engage outpatient and inpatient in more conversations to streamline family/peer support

3. Specify any changes that you think would have made this SWAHN event more effective.

- Advertise the event earlier and annually to bring information forward
- Let's actually implement
- Opportunities for involvement in SWAHN should be made clear
- Increase interaction and movement. Very uncomfortable seating
- The first speaker was incredible. If he could have spoken longer it would have been great
- None that I can think of at this time
- Knowing agenda well in advance
- I think it was well planned and went well
- Invite people who can provide funding or make policy changes
- Possibly more time to talk with presenters
- Have more academic representation about the same as community participation
- All went well, impressive
- Fruit/veggies 😊

4. What advice do you have for SWAHN regarding its role in helping to advance the topic of family mental health and addiction peer support across Southwestern Ontario in terms of research, knowledge generation, and/or other related areas?

- Network with other organizations (cities) to develop a process to access peer support for individuals and families
- Be more focused
- Provide learning opportunities on site for colleges and university to further engage students (future healthcare workers)
- Put the research into practice
- The key is maintaining sustainability and promoting through advertisements and personal referrals word of mouth
- Put an open call to service providers to give input to topics – more awareness to service providers about SWAHN
- Continue to have workshops/dialogue
- Collaboration between hospital foundations and family peer support to improve resource base
- Include “caregivers”/peer supports
- Promote the absolute value/need to provide treatment/support involving service users and their family
- Follow up by MHAWG on proposed action plans discussed – pick 1-2 top priorities and move forward
- Connect with organizations that already exist – don't reinvent the wheel
- It would be great if we could have a standardized peer family group format to be shared across the area

- Communication/advertising between and within communities of all supports available so that networking not need be only annually at the SWAHN symposium, i.e., London groups today duplication services and both facilitators were unaware – perhaps a chapter of SWAHN regions communicating online
- Social media engagement
- Terrific work that is being done. Talk to families and ensure they are included in decision making

5. What topics would you like addressed at future SWAHN events?

- Cultural / religious barriers and its barrier to receiving support
- Let's decide on a vision of peer support – using evidence - Forchuk
- Mental health on campus
- Perhaps demonstrating a few “true story” family opinion/involvements in the future how SWAHN has changed people's lives
- Funding is always an issue. Safe environments. A need to talk. Respect
- Trauma
- Compassion fatigue vs. burnout, collaborative practice
- Partnerships with healthcare and education
- Seniors and people with intellectual disabilities and aging care
- Further work on collaborative system development
- Outcomes of the symposium – tangible results
- Community participatory research in mental health
- Discussion of residential and outpatient successes and hurdles for addiction recovery – not just stats but best practices
- Integrated mental health – breaking down the silos
- Support for families with addictions

6. Please provide any additional comments about today's program.

- Would like to see SWAHN website set up and be a part of the hospital/school and university/college network; providing a hub of information for easy access for individuals/family members/counsellors/teachers/etc. to provide a process to get support/help. Pre-book the following symposium during preceding symposium so that dates are solidified beforehand.
- I really think the SWAHN is great but throughput, clarity on the work is not quite there
- The Bingo game was a great way to meet others
- Loved the networking exercise
- Wonderful group of people working together to help patients and families. Nice to network with everyone!
- The caregiver at the end of our SWAHN day is still home doing 24hr care loaded with stress.
- Great day – thank you
- Great speakers; knowledgeable; very interesting breakout groups; very educational and helpful; very collaborate approach
- Really enjoyed the day. Perhaps keynote could be stronger
- Great opportunity to meet various people and peers, researchers, clinicians!

- Overall effective collaborative engaging community event
- Well organized; Pierre Boulos, Joy Lang, Marnie & Rob's presentation, breakout group discussions – excellent
- This symposium was a great way to educate the professionals working in the related field but perhaps more caregivers could benefit from similar symposiums and may have been incorporated in the events of the day
- Great event!
- Very educational and well organized event!

APPENDIX 8: SYMPOSIUM ATTENDEE LIST

SWAHN would like to thank the following individuals who attended the symposium. Any errors or omissions are unintended. In recognizing these individuals, please note that the content and analysis of these proceedings should in no way be interpreted as a reflection of their individual opinions or those of their organizations.

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