

The Family Advisory Council (FAC) of St- Joseph's Mental Health Care Program is pleased to share our fourth report. It highlights some of our successes, accomplishments and the continued advocacy objectives that are important for the well-being of our loved one and families in the mental health care system.

The FAC has been able to achieve several important goals due to partnerships we have formed. St. Joseph's Health Care London has been listening to families to determine what the needs are and influencing and incorporating changes to better meet the needs of families and their loved ones. This is evident in the new Corporate Strategic Plan that has just been released for 2018-2021, which incorporated the voices of families, patients, caregivers, and many other stakeholders.

St. Joseph's new Strategic Plan aligns with the goals and values of the FAC, which were advocated for since its inception. We are proud to have participated in shaping the overall plan and are committed to achieving our goals of family inclusion in mental health care.

"As we often say, there are really only eight kinds of people affected by mental disorder. It's a very small list, but we all know someone on it: someone's mother, daughter, sister or wife; someone's father, brother, husband or son."

Julia Nunes and Scott Simmie

Beyond Crazy, Journeys through Mental Illness

FAMILY ADVISORY COUNCIL
PARKWOOD INSTITUTE MENTAL HEALTH CARE
and
SOUTHWEST CENTRE FOR FORENSIC MENTAL HEALTH CARE

BRIEF HISTORY
and
4th REPORT ON
MAJOR ACCOMPLISHMENTS

Published May, 2018

THE EARLY YEARS

The Family Advisory Council was initiated at the invitation of the administration of the former London and St. Thomas Psychiatric Hospitals in June of 1997 with the purpose of assisting staff to more clearly identify ways in which the delivery of care could be more sensitive and responsive to patient and family needs. The invitation occurred at a time of cultural change, when psychiatric hospitals were being divested from the Ontario Government and some services were being moved from hospital to community. A group of social workers gathered family members of both campuses, and the family members organized a working executive to define the council's structure, membership, and goals.

Membership was, and continues to be, individuals who have a relative or close friend with a mental health concern. The role of the council was to ensure a cooperative, mutually supportive and caring environment from which people with mental illness would benefit. This was to be done through (1) family education and empowerment, (2) obtaining a resource centre that could provide a physical space for family support, information, and credibility, (3) paid staff (4) community links, and (5) in-hospital committee participation.

The first ***Information Booklet for Family Members*** was written in 2001 to answer the many questions families had surrounding their loved ones' admission to the hospital. This booklet has been modified and become part of the present ***Patient and Family Handbook***.

Also in 2001, the **Family Education Course** was developed, organized, and taught by a family member in order to educate and empower other family members. Offered twice a year, this free 12-week course continues today at Parkwood Institute and includes guest speakers on topics such as schizophrenia, mood disorders, treatment, working with mental health providers, family coping strategies, financial planning, legal issues, and advocacy. Attendance is capped at twenty people in order to encourage class discussion, but there is always a long waiting list. The concept was adopted by other mental health providers in London.

The Family Resource Centre was opened in 2003 with funding from the Tillmann Foundation, supplemented and later replaced by the hospital itself. It houses the largest and most current collection of books, magazines and pamphlets in London about mental illness and its treatment, written by and for those living with mental illness and their caregivers. Information about community services, legal and financial issues, public policy and advocacy initiatives are also available.

One-on-one Support for family members in crisis, or just needing some personal information, advice, or understanding from somebody who "had been there", continues to be provided by family members in the privacy of the resource centre.

A **Family Support Group** was initiated and led by a council member experienced in group facilitation in order to provide an opportunity for family members and friends of people with a mental illness to share their experiences, coping strategies, and successes.

The Family Forum, the newsletter of the Family Advisory Council, was first introduced in January 2004. Produced approximately six times a year, it addresses relevant topics such as the decision that the hospital would become smoke-free.

Formal **links with administration** were established early. Representatives were participants in the council's monthly meetings, and quarterly meetings between council leaders and the Vice President of Mental Health Services for St. Joseph's were implemented.

Additional key achievements by council members during the early years consisted of the writing of a series of schizophrenia pamphlets published by Schizophrenia Society of Ontario and requested across Canada; responding to questions on radio and television call-in and interview programs; a presentation to Personal Health Information Protection Act at Queens Park regarding the needs for a change to privacy laws and to parliament regarding reforming the Mental Health Act; membership and executive leadership in the local, provincial, and national schizophrenia societies; creation of a family bulletin board in the main hall of the hospital; membership on numerous government committees such as the South West Mental Health Implementation Task Force; panel and public speaking engagements; presentations to schools (secondary, Fanshawe, UWO); sponsoring talks open to the community; input on hospital policies and procedures; membership on the London Community Justice and Human Services Committee and on the hospital Ethics Committee to name a few.

In January 2006, the **family liaison** position for which the council had advocated was approved. Although initially a part-time position, the initiative proved so successful that it became full time in 2008. This position was instrumental in establishing a network of co-operative community links with other mental health agencies in the community, in establishing a mutually supportive relationship with the Patients' Council Facilitator, and in integrating family needs and input into the hospital system.

The following is a list of the endeavours in which members of the council have been involved over the past few years. It indicates the extensive representation by family members at all levels within the organization.

A comprehensive list of key accomplishments and recommended endeavours can be found in the three Family Advisory Council Reports dated September 2003, June 2006, and January 2011.

PROJECTS INITIATED BY THE COUNCIL

- **Meaningful Activities Proposal** first presented to program managers and clinical Leaders in December 2007 stressed the importance of meaningful activity (which promotes socially appropriate behaviour, cognitive abilities, and skill development) for individuals on the inpatient units and its proven relationship to achieving recovery. A survey was conducted among patients to ascertain activities which they would enjoy. Strategies, resources, and challenges for forming the committee were discussed. With the move to Parkwood Institute, the vision embodied by this committee is beginning to be realized.
- **Family Charter of Rights**, previously written, then revised in July 2016, has been mounted on **plaques** and posted on all units and areas frequented by patients and family members. It has been requested by the Mental Health Commission of Canada.
- **Family Inclusion Project** began in 2012. It is a best practice model for involving families in care and addressing their needs through sharing their stories and the impact of mental illness on the family. It arose from a family survey that revealed only 8% of families with loved ones in Parkwood Institute were aware of the Family Resource Centre and its services. The **Family Inclusion Booklet** was launched in 2015 to all units in both mental health facilities, to the Quality and Recovery Advisory Council, and to the Operational Stress Injury Clinic with the request that they discuss it with others. Booklets are distributed to all new staff when they attend orientation. Ongoing efforts continue to advocate on the importance of family inclusion in mental health care. Ontario Family Caregivers' Advisory Network is hoping to take this model and philosophy to their respective organizations; in fact, Cornwall has been successful in receiving a grant for the development of a family inclusion model using this project as a template.
- **OFCAN (Ontario Family Caregivers' Advisory Network)** is a provincial organization comprised of mental health and addiction family councils with the mandate of building a strong network of family groups who have the shared goal of enhancing mental health care and addiction service, fostering relationships and the exchange of information, and educating and encouraging communication and partnerships between family caregiver groups.

- **London Health Sciences Centre (LHSC) Outreach** conducted a meeting with Security Staff; presented to the Joint Improvement Team regarding procuring an emergency entrance for Mental Health patients; participated on the LHSC Transition Team for Mental Health; and secured CMHA emergency beds.

PRESENTATIONS BY COUNCIL MEMBERS

- **Quality Committee of the Board** – addressed the history, key accomplishments, and future directions of the Family Advisory Council. (April 2014)
- **Webinar for the Mental Health Commission of Canada: Incorporating the Family Voice into Recovery-Oriented Care** – requested a brief history of the Family Advisory Council, accomplishments, partnerships, and the path to the future, followed by a question and answer session. (Feb.2017)
- **Family and Patient Engagement Project** – an opportunity under the South West Local Health Integration Network for patients, family members and caregivers to share details of their health care journey with health care professionals in order to co-create principles for effective patient and family engagement. (Feb. 2017)
- **Orientation for new staff and now including physicians** at Parkwood Institute (on-going)
- **Fundamental Nursing** (on-going)
- **Change Foundation** – made several presentation both public and within St. Joseph's, as well as at the *Provincial Caregivers Conference* and, in Baltimore, June 2018, at *The 8th International Conference on Patient and Family-Centered Care*. (on-going)

COMMITTEE PARTICIPATION BY MEMBERS OF THE Family Advisory Council

- **Safewards Program** includes a series of interventions designed, tested and proven to decrease incidents of conflict and containment on mental health inpatient units by teaching staff and patients new skills and tools to strengthen relationships. Each intervention is meant to improve the patient experience, increase patient engagement, staff confidence and safety for all.

- **Improving Care Together Initiative** has as its current goal “to improve the experience of family caregivers in their interactions with the healthcare system and its providers” by co-design techniques that incorporates a strong caregiver voice in programs and organizational planning. This partnership will feature a number of activities and mechanisms designed to make an impact, including creating communication resource toolkits, formal caregiver assessments, and new education and support initiatives. The tools developed will be shared with all of St. Joseph’s five sites.
- **Quality Standards Committee** is sponsored by Health Quality Ontario and produced ***Care for Adults Living in the Community with Schizophrenia***. Health Quality Ontario has also produced many other Quality Standards for various conditions.
- **Quality Committee of the Board of St. Joseph’s Hospital** is an advisory group composed of hospital leadership and community members whose mandate is to ask questions, provide advice, and monitor the various disciplines within the hospital.
- **Quality and Recovery Advisory Council** oversees and assists with quality improvement initiatives within Parkwood.
- **Research Committee** had its first family member representative fifteen years ago. His contributions were acknowledged by naming the keynote speaker’s address for the Annual Research Half Day in his honour.
- **Seclusion and Restraints Committee** works to set standards, to determine alternatives to restraint, to train staff in those strategies, and to monitor implementation of protocols.
- **Human Service and Justice Coordinating Committee** had as its first family representative a member of the council
- **Mental Health Promotions Committee – has been disbanded**
- **Accessibility Advisory Committee** the FAC has a family council representative on this committee

Meaningful Activities Committee is an outgrowth of the project begun by the council in 2007. A major undertaking was the Leisure Expo organized in October 2016 which incorporated numerous community agencies and a Housing Fair that was held in May 2018.

- **Zero Suicide Implementation Committee** –The model of care of Zero Suicide as a bold goal and an aspirational challenge to prevent suicide within hospital and after discharge

has been embraced by the organization. The model of care has been adopted by the Adult Ambulatory Program at Parkwood Institute and is being rolled out in the inpatient units this year. The training will ensure that inpatient staff is extensively and completely/comprehensively trained in such areas such as early recognition of signs of (early) suicide symptoms, thoughts and behavior(s) and their prevention and that no one staff faces the challenge alone. The inclusion of the family and patient perspectives have been incorporated into the project.

- **Parkwood Institute Research Steering Committee** – A member of the Family Advisory Council sits on this committee which is comprised of research and clinical staff from Parkwood Institute Mental Health Care, Southwest Centre for Forensic Mental Health Care and Parkwood Institute Main, Western University and the Lawson Health Research Institute. The member's role is to offer a family perspective in the strategic planning of research projects for the next few years.
- **Fundamental Nursing** – A Family Advisory Council member is invited to participate in the orientation of new nursing staff at Parkwood Institute and Southwest Centre by offering a family perspective on care. They tell staff about the family resources available and ask them to encourage families to avail themselves of these supports. They shared their lived experience as a caregiver and highlight ways they can help family members heal and become part of the recovery process with their loved one.
- **Feasibility Study** consisted of a series of focus groups with clinical, patient, and family representation and outside facilitation in order to address some of the coordination gaps between mental health services at Parkwood Institute and LHSC and to promote a system more responsive to the needs of patients and families.

TRAINING AND EDUCATIONAL OPPORTUNITIES

- **The Toyota Method** was a training program offered by LHSC
- **Crucial Conversations**, this very beneficial training has been available for FAC members for a number of years. The course focuses on providing skills and tools to have conversations when the emotions and the stakes are high. This training has been offered to staff for many years and it is empowering that FAC members are able to attend the course.
- **Mental Illness & Addiction Course for Families** is a spin-off of the Family Education Course. The course is 12 weeks in duration and is offered by an educator from Organizational Development and Learning Services who has an expertise in the area

addictions. The course is open to any family member who has a loved one with addiction and mental health issues.

- **Family Connections Training** is a program that teaches skills to family members who have a loved one who has emotional dysregulation. The next phase will be for the family members who received the training to teach the course to other family members.

PRESENTATIONS TO THE FAMILY ADVISORY COUNCIL: 2017-2018 (for information and feedback)

- **Addictions and Mental Health** by Kelly Simpson, System Design & Integration Lead for Mental Health & Addictions, LHIN – a formal presentation jointly to Family and Patient Councils, followed by a facilitated discussion resulting in an extensive list of recommendations from the Council (Nov. 2016)
- **Patient Partnerships** by Susan Grieg, Project Lead – asked the questions, “How do clinical staff involve patients and family members in personal health care decisions, in hospital and program initiatives or decisions related to quality of care, quality of services, and patient safety, in policy and advocacy?” The FAC provided feedback from the family perspective which translated to fundamental changes in the Care Partnership framework.
- **Changes with the ACCT Teams** (Feb 2017)
- **Five Questions to Ask About Medications**, a pamphlet presented by pharmacy representatives
- **No Fixed Address**, this project was instrumental in bringing onsite, a person to address housing issues for people who do not have a place to go to upon discharge and for individuals who could potentially become homeless
- **Homes for Special Care**, plans to modernize the model within the province

ON-GOING AREAS OF ADVOCACY

- Meaningful activities in the hospital and community
- Increasing awareness by all employees and family members at Parkwood of the services available for families
- Need for supportive housing
- Family inclusion in care
- Comprehensive care plans during hospitalization and upon discharge
- Building of hospital and community partnerships
- Confidentiality and privacy advocacy/laws
- Sufficient tools and resources clinicians require to provide evidence based treatment
- Provision for province-wide family feedback on mental health needs
- Funding for mental health research

ADDITIONAL REFERENCES

- ***Terms of Reference*** for the Family Advisory Council
- ***Family Charter of Rights***
- ***Assistance for Families***, the Family Advisory Council pamphlet