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Newsletter of The Royal's Client and Family Advisory Councils

SUMMER 2021



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Mental health worker

by Nancy McLaren Kennedy

My name is Nancy McLaren Kennedy and I work as a Peer Specialist/
Mental Health worker in Women's
Mental Health (WMH). My role is part of a collaboration between WMH and the Ottawa Birth and Wellness
Centre (OBWC). I was hired because I have experience with birth (I have an 18 year old son and identical twin 15 year old daughters) and I have experience with mental illness.

My experience with depression and anxiety started when I was very young. I remember one day feeling that all was good with the word and the next day experiencing the world as a very scary and unsafe place.

I had lost my mother and father before the birth of my son and the lack of support really impacted my mental health.

Mental Health Worker continued...

I had a very long and dangerous birth with my son. Once I brought him home I had a lot of trouble sleeping and I was constantly worried that something bad was going to happen to him. I believed that it was normal for new moms to experience this level of fear and sadness. I could not bear hearing my son cry. I had him sleep with me not out of desire but rather I didn't want him out of my sight.

I went to see a therapist and started a medication but this didn't help. I then became pregnant again, this time with twins. Due to my experience with depression and anxiety I was referred to a perinatal psychologist. I did not understand about medication during pregnancy so I refused to take it.

After the birth of my twin daughters I experienced intense headaches. I found out that my blood pressure was 200/100 and I was rushed to the hospital with postpartum pre-eclampsia (PPPE). I had experienced difficulty breastfeeding my son and now because of hospitalization I was not able to breastfeed my daughters. I felt extreme guilt over this because my image of a "perfect" mom included breastfeeding.

After the hospitalization for PPPE I came home and stopped sleeping. Over the next couple of months I began to experience auditory hallucinations. I ended up being hospitalized for a second time that year.

I would like to say that there was an easy fix to my mental health struggles but there wasn't. I did gradually feel better with the support of my husband, good friends, peer support, medication and a psychiatrist I can trust. I believe that recovery is an active process which will be ongoing for the rest of my life.

In my role as peer specialist I am now able to support women and birthing people who are having some of the same mental health struggles I experienced. I let them know that intense anxiety and depression are not normal parts of motherhood. You should be able to get some rest. I want people to understand that it is possible to mother and parent with a mental illness with support.

Our perinatal wellness groups are on Tuesday morning and Wednesday afternoon. I also host Facebook Lives on the OBWC Facebook page. I have covered topics such as birth trauma, overview of Perinatal Mood and Anxiety Disorder, perinatal gut health. We have over 7,000 views and you can watch these sessions and more anytime. The next Facebook Live is on the topic of breastfeeding grief which may come with not being able to breastfeed either by choice or medical issues.

Here is a quote from Leonard Cohen which I find very inspiring:

"Ring the bells that still can ring. Forget your perfect offering. There is a crack, a crack in everything. That's how the light gets in."



Photo by Alexandria



In October 2019 the Family Advisory Council (FAC) and the Client Advisory Council (CAC) came together to unite their voices on new initiatives designed to enhance the experiences of clients and families at The Royal.

One of the results of their partnership is a new Client and Family Service and Support Vision. These guidelines are designed to ensure that client and family perspectives and experiences are reflected and incorporated across the organization and that client and family voices are always part of the conversation.

Glenda O'Hara, chair of the CAC says: "It is so hopeful that our discussions on peer support a year and a half ago have morphed into this Client and Family Service and Support Vision and caught the attention of senior management at The Royal."

This year, the united FAC and CAC are also laying the groundwork for a Client and Family Resource Hub with peer and navigation support. It will connect service users to resources and bring them together with peer supporters for emotional and practical support. Stay tuned for more information about this exciting initiative.

"There's so much going on and we are so excited to participate and engage in what will be transformational change," says Michèle Langlois, chair of FAC.

Of course, more projects need more hands on deck! The FAC and CAC are currently collaborating on a **recruitment strategy** to bring diverse client and family voices to the table.

"Our goal is change for the better, for the greater good, and factoring the needs of all the players in the ecosystem, including care team members," says Langlois.

For more information about getting involved, contact Juliet Haynes by phone at 613-755-6521, ext. 7573 or email at juliet.haynes@theroyal.ca, or Jackie Desrochers at 613-722-6521 ext. 6710 or jacqueline.desrochers@theroyal.ca.



Delivering outreach to **MENTAL HEALTH CAREGIVERS**



during the COVID-19 pandemic

by Juliet Haynes, MSW, RSW, Family Engagement and Experience Coordinator, The Royal

BACKGROUND

Since 1983, The Royal has offered mental-health family groups open to the public. In March 2020, little was known about Zoom and pivoting in-person groups to a virtual platform was considered innovative. The groups are live and not recorded. All sessions are interactive, supportive and focus on the caregivers' wellness.

METHODOLOGY

Families were invited to groups via email addresses collected from the in-person group attendance sheets.
Between March 23 and June 30, 2020, 202 attendees joined 27 sessions. Nine participants followed from in-person groups whereas 38 were new

joiners. Family Voice
E-Bulletins; 13 sessioncontent summaries
were distributed to
participants. These
co-designed summaries
promoted shared learning
and family engagement.

BARRIERS

Lack of privacy, tech skills, unstable or no internet, accessibility issues linked to visual and hearing impairments were noted. A virtual appointment tip sheet was developed, but no "live" tech support is available. Safeguards requesting video be turned on were implemented as group quidelines, but were not enforceable. Attendance grew rapidly placing increased demand on admin support for registration completed manually.

FINDINGS

In 2020, 105 feedback surveys received indicated 84% of respondents rated sessions as highly to extremely helpful; 89% were likely or extremely likely to recommend the sessions. The success and demand for the groups prompted senior management to set a 2021 performance goal for growing caregiver group attendance.

UPDATES

Between March 2020 and April 2021, there were 638 attendees. Closed Captioning is now live.

Experiential Research at The Royal

by Cynthia Clark, FAC Member

I would like to share a few reflections on the collaborative journey of the caregiver initiated and directed research entitled "Building a Framework for Supporting Meaningful Family Caregiver Engagement" resourced through Canadian Institutes of Health Research (CIHR) and supported by The Royal's Institute for Mental Health Research.

As with many projects, it started with an idea, that was sparked by an email announcing a call for Patient-Oriented Research grant proposals and took root when Florence Dzierszinkski responded favourably to my suggestions for exploring research possibilities in the area of Caregiver Advisor Collaboration.

We agreed that the research topic of caregiver engagement was relevant and timely. Ontario had moved to a model of governance which includes patients and their family members as collaborative partners in all aspects of health care delivery. This welcomed change has resulted in the revamping of organizational stakeholder partnership practices and an increased need to engage volunteer family caregiver advisors. While significant material has been produced on this topic by such organizations as: Health Quality Ontario, The Center of Excellence for Children's Mental Health and The Change Foundation, there is a lack of quantifiable or comparable data particularly in our focus area of mental health and Substance Use and Concurrent Disorder.

As a caregiver advisor to agencies and organizations who provide many levels of service; as a twenty-year advocate for quality mental health/Substance Use Disorder care; and a well-known volunteer at the Royal, I was in a good position to initiate and guide this research project.

With encouragement from Florence and a guarantee for support from the Royal, I accepted the position of Nominated Principal Investigator on the grant proposal, a unique position to be held by a caregiver with lived experience. In January 2020, I received notification of funding approval from CIHR!

Since becoming involved in this endeavour, I have learned a LOT about "processes", technical steps (including grant proposal writing), hiring a research co-ordinator, the requirements of conducting ethical research and of course, how to launch a research project during a pandemic etc.

Most importantly, from conception, the research proposal was constructed in a way that would be in keeping with the principals of collaborative codesign:

For example:

Co-design and collaborative models were applied to all aspects of development, including: project planning, survey design, research team engagement, expert working group consultations and educational materials development.

By assessing the needs and perspectives of seasoned caregiver advisors; other caregivers; service providers who have worked in collaboration with caregivers, as well as those who have not; met the goal of ensuring a broad experience-oriented database.

Built into the plan was a forum for further exploration of some prominent research results. The information gathered from several workgroup deliberations would lay the groundwork for the direction and design of educational products.

This model for consultation with panels of experts added an additional layer for product co-design.

Included in the funding proposal was dedicated resources for the development and dissemination of Knowledge Products that would support meaningful caregiver advisor engagement. This additional step of immediately translating the research results into useful products can be viewed as a motivating factor for participatory research and incentive for supporting research partnerships.

The "Building a Framework for Supporting Meaningful Family Caregiver Engagement "research report contains details about the

research purpose, methodology, survey results and an overview of the various levels of engagement which were built into the fabric of the research process.

I am thankful to have been given the opportunity by The Royal to partner in this research project. There were many lessons learned throughout this collaborative process that I hope will be applied to similar partnerships in the future.

Research Outcomes: publishing research results and translating research into practical information

We will be submitting a research article for publication based on some of our findings and we plan to release a detailed report by the end of February. (which Alexis will send to everyone present)

Useful knowledge products to be shared broadly.

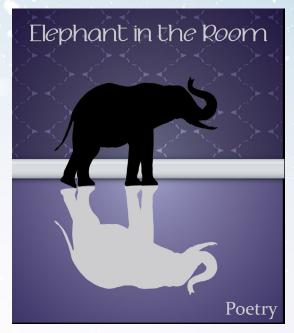
Our pre-COVID plan included a one-day workshop at The Royal to tackle some of aspects of the findings that may present challenges when developing the knowledge products. Plans change! But I am confident that this task can be accomplished within the 3 virtual meetings taking place this week. I really look forward to hearing from you shortly.

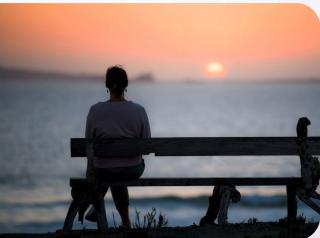
The third phase of this project is the co-designing of a suite of knowledge products which will include a repository of links to supporting resources.

Financial support for developing and disseminating information and helpful teaching tools, came from CIHR and The Royal's Foundation.

TO MAKE A DIFFERENCE IN SOMEONE'S LIFE, YOU DON'T HAVE TO BE BRILLIANT, RICH, BEAUTIFUL, OR PERFECT. YOU JUST HAVE TO CARE







Really Listen

I love the music that travels with me Favourite songs from now and then I stop and sit down on a bench And really listen

To healing songs and ones that bring me back

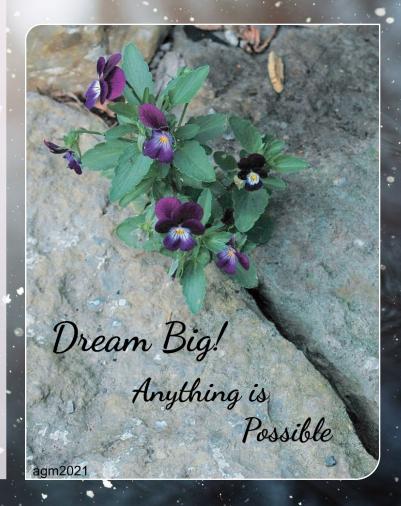
To certain times when I was young and free And more hopeful than now And it makes me feel

Glenda O'Hara

The Mountain.

lessonslearnedinlife.com

If the mountain seems too big today then climb a hill instead. If the morning brings you sadness it's ok to stay in bed. If the day ahead weighs heavy and your plans feel like a curse, there's no shame in rearranging, don't make yourself feel worse. If a shower stings like needles and a bath feels like you'll drown, if you haven't washed your hair for days, don't throw away your crown. A day is not a lifetime a rest is not defeat. don't think of it as failure, just a quiet, kind retreat. It's ok to take a moment from an anxious, fractured mind. the world will not stop turning while you get realigned. The mountain will still be there when you want to try again, you can climb it in your own time, just love yourself til then. - Laura Ding-Edwards



There is always a reason

Why do we meet all of the people we do,
Yet we tend to keep by us only a few.

All the different ways you meet each other, The impact you have, may unknowingly change them forever.

The gesture may be big or small, You can squish them down or help them stand tall.

How you greet those you meet, Could make a difference instantly.

A smile of empathy as you see the strain in their face, May be just enough to hold them in place.

Opening that door for one last guy, Saving him a struggle he is happy to pass by.

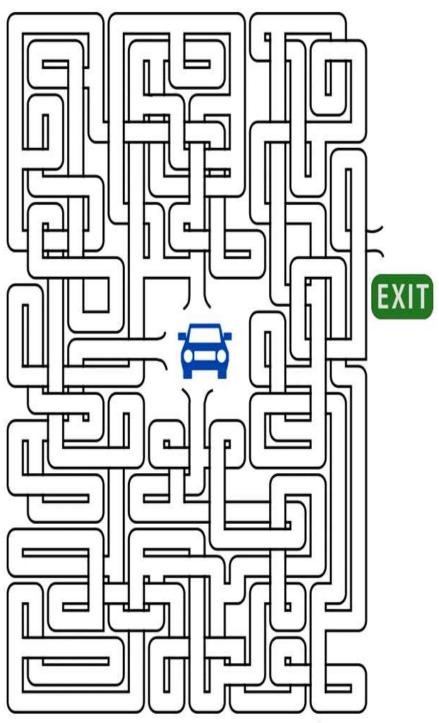
Bending to pick up the fallen book,

Saved her shearing pain, how grateful she looks.

We can never understand the full impact we impose,
Just remember we communicate from our head to our toes.

Brenda Buckley

Can you get out of the parking lot?



o puzzlez-to-printcom

Henri parked his car in the city parking garage, but he can't seem to find his way out. What is the shortest route to the exit?

from you!

Show your artwork
Share your poems
Tell a funny story

Show your photos
Share your wellness journey
Tell us your favourite quote

Contact Us We would love to hear what you have to say about *The Client's Voice* or if you would like to become a member of the Client Advisory Council, feel free to call, write or email your questions and comments to:

Client Advisory Council

The Royal, 1145 Carling Avenue, Room 1349, Ottawa ON K1Z 7K4 613.722.6521, ext. 6767

Email: cac@theroyal.ca

Send your submissions to:

Alexis Milne

alexis.milne@theroyal.ca





Photo by Alexandria