THE FAMILY CAREGIVING PROJECT



OCTOBER 2021 Mid-project report

This is a mid-project report from the SSHRC-funded research project "United we stand, divided we falter: Advancing a familycentred agenda for research on caregiving".

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THE FAMILY CAREGIVING PROJECT MID-PROJECT REPORT

INTRODUCTION



What is the Family Caregiving Project?

The Family Caregiving Project is a research study exploring the experiences of families affected by mental illness. The project is being conducted in Ontario, Canada. There are three phases: a series of events called "Family Mental Health Cafés", an online survey, and in-depth interviews with families. The research has been funded by the Social Sciences and Humanities Research Council of Canada and the Factor-Inwentash Chair in Health and Mental Health. The title of the funded grant is "United we stand, divided we falter: Advancing a family-centred agenda for research on caregiving." As the project has moved into implementation, it has been renamed "The Family Caregiving Project."

This study has received ethics approval at the University of Toronto under protocol #000034791.

Why was the Family Caregiving Project created?

The plan for this project emerged out of encounters with families in the mental health care system and in our communities who were navigating the challenges created by having someone within the family affected by mental illness. Many of those well-researched challenges were created by lack of services or difficulty accessing them. However, the existing research rarely considered the diversity of family forms, family cultures, and family histories that affected those challenges. In addition, it did not seem to recognize that people diagnosed with mental illness could be both receivers of care and caregivers in their families. Another neglected issue was that people identified as caregivers in their families also needed care, sometimes for their own mental health concerns. The complicated realities of family lives are frequently not reflected in guidelines for practice. Most often, the healthcare system focuses on "family burden" and engages with diagnosed individuals and with caregivers separately, but has very little to offer families as a whole. Further, the overlapping demands of caring for family were often overlooked in thinking about what services, practices, and policies would serve the needs of families affected by mental illness.

The overarching goals of this project are to gather and share information that will lead to more appropriate services for families in the mental health care system. The hope is that this information sharing will also lead to increased understanding of mental illness and its effects on families in our communities. The Family Caregiving Project exists



because we believe that families have stories that need to be heard if we are to build better supports for them in the Ontario health care system. It exists because we believe there are people who have never been heard that need to have their voices included in discussions about what services should be available to families affected by mental illness. It exists because the community-at-large needs to have a better understanding of how families are affected by mental illness and how they can contribute to making our communities more welcoming spaces for those families.

The research questions for the study are:

 What are the meanings that families give to the care (giving, receiving, sharing, exchanging) that is carried out in a family affected by long-term, unpredictable, chronic illness?

- 2. How do those meanings inform family discourses surrounding family identity and the role the family plays in society?
- 3. What can caregiving families teach us about navigating social and institutional spaces as a family, and the impact that has on family stress and resilience?

Planned outputs from the project include:

 Research papers and reports that will be directed at health professionals and health and social service organizations to inform their development of services.



- Policy reports to share with decision makers in relevant provincial and federal government bodies.
- Presentations for academic, professional and public conferences.
- A website (familyguidetomentalhealth.com/family-caregiving-project) that presents project documents, educational materials and videos for the general public.

IMPORTANT CONCEPTS IN THIS PROJECT

Family: a group of individuals (who may be legally or biologically linked) that self-identify as connected to each other, share a mutual commitment to that connection, and expect to care (emotional support, concern, assistance, etc.) for each other over an extended period.

Caregiving: The provision of what is necessary for health, welfare, support and protection of a person with limitations due to illness, injury or disability.

Caregiving Family: A family that manages caregiving for one or more people who need caregiving support, in addition to managing other care needs in the family.

MEMBERS OF THE RESEARCH TEAM

Investigators

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ACKNOWLEDGEMENTS AND THANKS

This project would not have been possible without the contributions of people who shared the vision for this work. These collaborators include:

Staff and faculty at the Factor-Inwentash Faculty of Social Work who assisted in multiple ways and generously shared their time and space for the project.

Stuart Clarfield and the team at the Mission Media Company have documented our work and shared it through the familyguidetomentalhealth.com website.

Staff at Canadian Mental Health Association Toronto (Steve Lurie, Elly Litvack, Gillian Gray), CMHA Ottawa (Dania Versailles, Julie Levesque), CMHA Kenora (Sara Dias, Karla McClain), CMHA Middlesex/London (Christine Sansom, Sabrina Andrews) and CMHA Peel-Dufferin (David Smith, Afreen Chowdhury, Tim Smith) who assisted with recruitment and delivering the Family Mental Health Cafés. There are many other individuals and agencies that assisted with our outreach into communities.

Rachel Cooper and CMBusiness & Transcription Services who transcribed hours of recorded interviews.

Sabrina Baker, whose shared her work and passion for working with families affected by mental illness at multiple stages in the project.

OUTPUTS FROM THE PROJECT

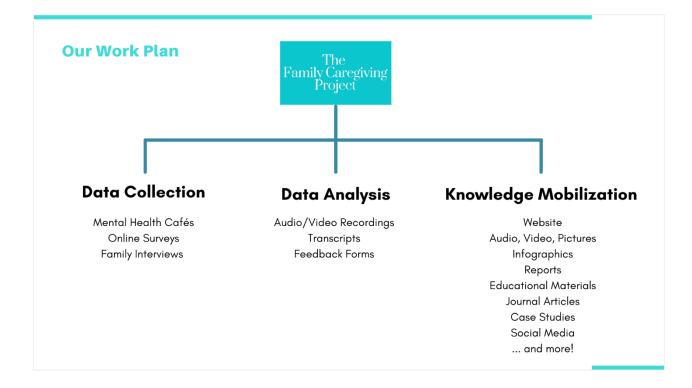


At the time of this report, we are still in the process of processing and analyzing the information that we have gathered in the study. For this mid-project report we are sharing details about the various sections of the study and preliminary impressions from our participation in the various research activities.



The Family Caregiving Project has been designed with a variety of methods for gathering information, each with a slightly different purpose. There are differences between what people share when they are typing into a computer, sitting with people who share similar experiences, or talking with a family member about what has happened in the family. Each platform allows different information to come forward that, together, produce a more comprehensive picture of what families are experiencing. We need these deeper, detailed, and complex experiences to be known if we hope to have policies and services that are responsive to the details and complications of families' lives.

The COVID-19 pandemic forced delays and postponements of activities, resulting in a longer timeline than originally planned. This mid-project report is being produced while research is ongoing. An updated final report is anticipated in early 2022. Information, materials, and results from the study will be shared on an ongoing basis through the project website at www.familyguidetomentalhealth.com/family-caregiving-project.



Part A. The Family Mental Health Cafés

The Family Mental Health Cafés were community gatherings hosted in five cities across Ontario (Toronto, London, Ottawa, Kenora, Brampton) from June 2018 to June 2019. These gatherings invited people who were in families affected by mental illness to come together with others sharing their



experience and discuss the challenges, strategies, and hopes they had for themselves and other families. Participants were recruited by contacting community agencies in each city. In addition, Canadian Mental Health Association (CMHA) organizations were collaborators in the recruitment and hosted the events. An unusual aspect of these cafés was that we included people who were diagnosed with mental illness and people who identified as caregivers in the same gathering so that we could hear multiple perspectives about the family experience. Often people identified with both roles and, in some cases, also had roles as service providers. These cafés generated videotaped presentations, videotaped interviews, and audiotaped group conversations that have been transcribed for analysis.



The cafés were designed based on a method called World Café (www.theworldcafe.com). World Cafés are structured group dialogues in which groups of people with a shared concern are brought together to discuss and share their perspectives on a few carefully chosen questions. The goal of the process is to tap into the

collective wisdom of the group, and to use group energy to generate new ideas for solutions to shared problems. The cafés began with an introduction to issues surrounding families, mental illness, and caregiving, followed by participant discussion. Participants discussed the following prompts and questions:

- When I hear caregiver/care receiver, I think... When I hear caregiving family, I think...
- What makes caring in families affected by mental illness difficult?
- What makes caring in families affected by mental illness work well?
- I think the way we could make caring and caregiving work for families is...

We met with 67 family members at the five sites. The cafés were well-received by participants, many of them remarking on the value of having an opportunity to sit down and hear about the shared concerns and varying perspectives of different family members. They also shared the value of including those who had diagnosed mental disorders. For additional information about the cafés, see the Appendix.

Part B. The Family Caregiving Survey

The Family Caregiving Survey was an online survey launched between November 2019 and May 2020. Outreach for the survey was similar to that used for the Family Mental Health Cafés, however, we reached a broader audience because anyone in the province of Ontario who met the eligibility criteria could participate. The survey was created to allow participation by individuals who would not be able to join a café event or participate in one of the interviews planned for later in the study. It differed from other parts of the project since individuals were able to participate alone, without the involvement of others that might influence a group discussion or a family interview. The survey asked participants to answer questions similar to those used in the family mental health café events:

- What would you say makes caring in families affected by mental illness difficult?
- What would you say makes caring in families affected by mental illness work well?
- How would you complete the following sentence: "I think the way we could make caring and caregiving work for families is..."

• Is there anything specific to your personal experience of family caring and caregiving that you would like to share?

We are pleased to report that we have received 102 completed surveys from people across Ontario who identify as occupying a wide variety of family caregiving roles.

Part C. The Family Interviews

The family interviews began in May 2021. We invited family members to participate in interviews where they could discuss their experiences caring for family members and coping with mental illness. Each interview included at least two family members with at least one individual having a mental illness diagnosis. Family was a broad term used to describe anyone significant for the participants including families of choice. We interviewed partners, parents and adult children, friends, and siblings. As with other parts of the project, it was not unusual for individuals to have multiple roles in the family. These families discussed their definitions of family and caregiving, as well as how their family is affected by mental illness. Families also described how they support one another, how they perceive the mental health care system involves families, and what they would like other families to know from their experiences. Interviews were audio-recorded and transcribed for analysis.

The three components of the project provide a variety of perspectives of family experience in the context of mental illness. There are differences between what people share when they are typing into a computer, sitting with people who share similar experiences, or talking with a family member about what has happened in the family. Each platform allows different pieces of information to come forward that, together, produce a more comprehensive picture of what families are experiencing. We need these deeper, detailed and complex experiences to be known if we hope to have policies and services that are responsive to the depth details and complications of families' lives.

CONCLUSIONS

We have heard from families across Ontario about their commitments to supporting each other and the difficulties they face doing so. Some of these difficulties arise from the complexity of managing family life in a social context that includes economic and social challenges that impact all families. Some difficulties arise from the growing number of families that are managing multiple caregiving demands as children arrive, elders age, and adults are affected by chronic physical or mental health disorders. Some difficulties arise from stigma against mental illness that isolate families and make it hard for them to find support and community. Some difficulties arise from engaging with a mental health care system that does not devote enough attention or resources to supporting families and promoting the mental health of families.

As we move forward into the stage of analyzing and sharing the findings from this study, it is our commitment to take stories that families have shared with us into training for health and social service professionals, public education, and advocacy with health care institutions and policymakers. It is our goal that this work will contribute to caregiving families feeling supported by their communities and by the organizations that provide mental health care services.



APPENDIX

The Family Caregiving Project Team visited five different locations across Ontario:

June 16, 2018: Toronto, hosted at Factor-Inwentash Faculty of Social Work, University of Toronto

September 15, 2018: Ottawa, hosted by CMHA Ottawa

October 13, 2018: Kenora, hosted by CMHA Kenora

May 25, 2019: London, hosted by CMHA Middlesex

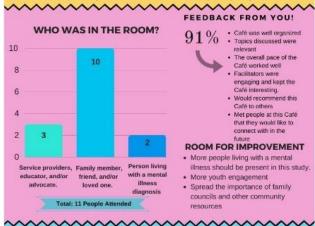
June 22, 2019: Brampton, hosted by CMHA Peel-Dufferin

Below is a summary for each of the five cafés. In these infographics you will learn who participated, main themes that emerged, and feedback provided by participants in each café.

To view a larger version of the infographics online, please visit www.familyguidetomentalhealth.com/familymental-health-cafes/.

TORONTO FAMILY MENTAL HEATH CAFÉ 2018 PROJECT SUMMARY

On June 16, 2018, the Family Mental Health Research Project began the Ontario tour in Toronto. This study is led by Prof. Charmaine Williams. Thank you for joining the conversation



KEY AREAS OF CONVERSATION

'CAREGIVING FAMILIES'

- Caregiver' and 'care receiver' roles are not binary
- . The whole family needs to be educated
- · Can't do it alone
- Navigating services
- · Outside resources and systems are crucial
- Isolating

'CAREGIVER' ROLE

- · Caring is work
- A lot of responsibility
- · Often guestion your abilities
- · Feeling isolated ~~~~~
- · We have no idea how to deal with it.

CHALLENGES

- · Trying to protect family members while dealing with other issues.
- · Harmful assumptions made by healthcare professionals and law enforcement
- · Medical system (i.e. harmful discharge planning, lack of access to services and mental health programs)
- · Feeling a sense of loss and grief
- Stigma
- Strain on family and friend relationships · Hours of operation (mental illness is not
- only between 9:00am and 5:00pm)

WHAT DO FAMILIES NEED?

- · Centralized place to access resources (too
- many siloes of care)
- More funding and resources (i.e. ODSP) · Not just crisis focused help/resources, need
- prevention-based support Empathetic listening of the system
- · Holistic healing (i.e. integrating healing circles and have more knowledge about
- and/or other cultural traditions)
- Supportive housing and employment
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· Concerns with not reaching milestones and meeting expectations Feeling isolated

'CARE RECEIVER' ROLE

- · Redefining relationships in the family

HELPFUL STRATEGIES

- Developing boundarie Being validated – hear that "I am doing a
- good job" · Outside support (i.e. access to a therapist)
- · Open discussions lines of communication
- · More ongoing education and willingness to learn
- Self-care (e.g. reading, walking, therapy)
- · Peer support
- · Connecting with community (i.e. volunteering)

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- Hopest conversations in a safe environment
 Diversion from the criminal/justice system
 - · Respite
 - · Patient-centered care from the
 - Police and healthcare professionals

need to be more kind, compassionate,

- mental health

ch is funded by the Si Sciences and Humanities Research Council of Canada

OTTAWA FAMILY MENTAL HEATH CAFÉ 2018 PROJECT SUMMARY

On Sentember 15, 2018, the Family Mental Health Research Project made its second stop in Otta ON. This study is led by Prof. Charmaine Williams and was hosted by the Canadian Mental Heal a Branch (CMHA Ottawa), Thank

KEY AREAS OF CONVERSATION



- what the general questions may I so we can be prepared.



'CARE RECEIVER' ROLE

- Feelings of guilt
- · Feeling isolated
- · People who "care" can harm

GROUP'S REFLECTION: These traditional terms (i.e. caregiving family, caregiver, and care receiver) sets polarized roles. A better way to address these relationships is the term 'SUPPORTER

HELPFUL STRATEGIES

collaboration

recovery journey

from the hospital.

· Person-centered support

Stable housing

Reduce stigma

professions."

More funding

Peer support

Resp

Mutual understanding, communication a

· Recognize and celebrate moments in the

· Having a plan for when you're discharged

Access to support during and post-crisis

Wellness Recovery Action Plan (WRAP)

· Better understanding of the relationsh

between mental health and gender.

Ree

· More men involved in the "helping

· Prevention-based interventions

· More accessible and culturally

appropriate services.

· Hope and having something to live for.

(i.e. psychologist, GP, distress line)

~ ~ ~ ~ CHALLENGES

Feeling isolated

and care

· Bigger load to support Isolating

Blurred Boundaries

Family is not always available

'CAREGIVER' ROLE

other family members

Feel responsible to educate

· Also need to receive support

- · When you want to give support, but the person does not want to receive that
- support · Limited resources (i.e. lack of psychiatrists
- in Ontario and practical support) Stigma and shame
- Denial in families (i.e. family member(s) who don't believe in mental illness)
- · Lack of communication and follow-up
- between professionals and families · Finances and housing
- · Life goes on...

WHAT DO FAMILIES NEED?

- Educating health profe ls, public institutions, and the police (more general knowledge about mental illness)
- · Education/courses on how to advocate
- · Stable programs in the community
- · Access to flexible paid work that includes benefits
- · Person-centered system navigation and a resource network for families

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This research is funded by Social Sciences and Human

a Sciences and Huma search Council of Car

- systems and institutions

~

ience guilt

'CARE RECEIVER' ROLE May feel like a burden and experience
 Stigmatized by labels

GROUP REFLECTION: Rather than one person

~~~~~

giving care and the other receiving, the relationship is

**HELPFUL STRATEGIES** 

· Communication (open dialogue both within

families and between families and service

· Validation of feelings and support from social

Interdisciplinary approach to treatment

More support accessing social assistance (i.e.

Circles of care that include the person with the diagnosis and the family

· More awareness of mental health and suicide

· Mental health kits, mental health phonebook for

workers, occupational therap

· Celebrating the joys, dark humour

· Self-compassion, Self-care

(i.e. workplaces, schools, co

psychiatrists, peers

practices (i.e. Mental Health First Aid, Applied

uicide Intervention Skills Training] Training)

· Experiences helplessness

providers)

Medication

· Being realistic

OW, ODSP)

nesses)

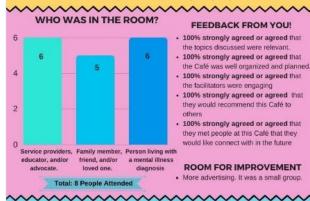
· Can be contributors too

illy be peticial

· Needs to be given space and time

#### KENORA FAMILY MENTAL HEATH CAFÉ 2018 PROJECT SUMMARY

On October 13th, 2018, the Family Mental Health Research Project made its third stop in Kenora, ON. This study is led by Prof. Charmaine Williams and was hosted by the Canadian Mental Health Association, Kenora Branch (CMHA Kenora). Thank you for joining the conversation!



#### **KEY AREAS OF CONVERSATION** 'CAREGIVING FAMILIES'

- · Families may choose not to help for various reasons (e.g. location and relationship)
- · Family members take on multiple roles, sometimes incompatible (parent, pharmacist,
- and counselor). · Service users are like family too

#### CAREGIVER' ROLE

- · Advocate for both the care receiver and themselves
- Feelings of quilt Feeling a sense of loss
- · Feeling isolated

#### ~~~~ CHALLENGES

- Lack of resources in Northwestern
- Ontario throughout the life course · Proximity to care and travel costs (i.e. enduring a 5 hour trip to Thunder Bay for ... Sharing stories with peers, colleagues, and
- Lack of education available for families
- Delaved diagnosis · Clinicians and the overall system not working with families
- · 'Death' of the person's potential, relationships, and expectations.

#### WHAT DO FAMILIES NEED?

- · System navigators who know 'where all the mental illness
- Individuals, families, and the overall society should be educated to fight stigma
- More respite to promote self-care

back doors are'

- · Permanent 24-hour supportive housing
- · More funding for staff (e.g. ACT team and Kenora Association for Community Living)
- More funding for programs
- · Educate children from a young age about mental illness

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- illness..

- LONDON FAMILY MENTAL HEATH CAFÉ **2019 PROJECT UPDATE**
- On May 25, 2019, the Family Mental Health Research Project made its fourth stop in London, ON. Th study is led by Prof. Charmaine Williams and was hosted by the Canadian Mental Health Association, Middlesex Branch (CMHA Middlesex). Thank you for joining the conversation!



~ **KEY AREAS OF CONVERSATION** 

- 'CAREGIVING FAMILIES'
- "Caregiving family" is inclusi
- members and reflects the reality bette
- · Family members are thought to have singular roles as either caregivers or care receivers.
- There is an expectation that women in the family (e.g. mother, sister) will take on roles as the iors and worriers"
- · Families may feel unsupported or experience

#### 'CAREGIVER' ROLE

- but "can't give up"
- · Offers many kinds of support (i.e. financial, emotional)
- · "Takes on the biggest load at the worst time
- Has important knowledge about
- e family member

#### CHALLENGES

- Negative impacts of social media
  Families stories are dismissed
- Loss of trust due to bad experiences. Stigma, secrecy around mental illness
- Lack of resources (i.e. personal finances, community investment, funding)
- · Barriers to involvement because of consent process
- Not educated about illness and resources The illness itself (unpredictability, paranoia,
- fluctuation of symptoms)

  Side effects of medication can be negative
- Illness pushes family/friends away
   Legislative barriers that exclude caregivers

  - WHAT DO FAMILIES NEED?
- Flexible and understanding employers
  Support for caregivers who also experience their own mental health concerns
- · More community spaces with free access to recreational activities
- Respite for caregivers and more peer support
   Better service coordination, more
   comprehensive follow-ups, and centralized
- access point
- · Basic Income, stable housing, employment
- support
  Shorter wait times to access services

This study has been approved by the University of Toronto Research Ethics Board

- · Creating opportunities for people diagnosed with mental illness to connect with each other and ibute to the co
  - This research is funded by the locial Sciences and Humanitie Research Council of Canada

'CARE RECEIVER' ROLE · Feelings of resentment and guilt · Feeling a sense of loss (i.e. grieving over expectations and identity)

· Self-blame GROUP REFLECTION: Caregiver and a care receiver can sometimes be one and the same

#### ~~~~ **HELPFUL STRATEGIES**

- · Diagnosis can trigger reflection (e.g. realizing that other family members may have had an undiagnosed mental illness in the past).
- clinicians · Proactive tools that help with crisis
- planning/relapse, such as the Wellness Recovery Action Plan (WRAP) and Family Recovery Action Plan (FRAP)
- · Humour, friendliness, and self-care
- Promoting independence · Somebody you trust that is non-judgmental and compassionate

- · Meals on Wheels for people living with a
- Acceptance
  - · Holistic mental health services
    - illness
      - supports in the community

This research is funded by th Social Sciences and Humaniti Research Council of Canada

- · Feel comfortable talking about ment
- · Education about formal and informal

- · Need a life that is not just about the

ded by the

#### BRAMPTON FAMILY MENTAL HEATH CAFÉ 2019 PROJECT SUMMARY

On June 22, 2019, the Family Mental Health Research Project made its fifth stop in Brampton, ON. This study is led by Prof. Charmaine Williams and was hosted by the Canadian Mental Health Association, Peel Dufferin Branch (CMHA Peel Dufferin). Thank you for joining the conversation!



This study has been approved by the University of Toronto R esearch Ethics Board

This research is funded by the Social Sciences and Humanitie Research Council of Canada FACTOR-INWENTASH IVERSITY OF TO

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