FAMILY CAREGIVING PROJECT

2024

End-of-project report

Final report from the SSHRC-funded research project "United we stand, divided we falter: Advancing a family-centred agenda for research on caregiving"
(Grant# 435-2017-0237).

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OPENING WORDS FROM FAMILY MEMBERS

This report begins with reflections shared by family members during our Family Mental Health Café events:

"There's a family which is given and there's a ***family by choice, the community of support****. And in that,* ***every caregiver is also a care receiver****, and in the short term things are different, in the long term things are very different. And the way we view giving or receiving impacts our mental health also, whether we are a receiver or giver, so we thought we should use the term '****care sharing****'."*

"There's a ***lot of services that need to be addressed****, that need to be brought forth. Dealing with something like this is a* ***journey for everyone****, and it was especially for my parents. But I think having the humility and the strength to be* ***open and honest*** *and be true to what this was, in the end it was good, and in the end we have a great relationship because of it."*

"Over the years I've met family members, mothers and fathers, and they go, "you know, I go to the community and I listen to my friends, and they're talking about "oh my son's doing so well in high school, he's an honour student," "oh my daughter's in ballet and she's just brilliant," and you're going I've got three kids and they're all mentally ill, how can I talk about my children? ***Why do I feel guilty? Why is the burden on me in the community?****" The community doesn't understand that not only does that mother* ***need respect****, but they* ***need support****. So I think we have to reach out a hand, not only as a person seeking help, but I think the* ***community has to reach out a hand to the people that need the support****."*

*"****Peer support*** *is a huge one, knowing that you don't have to go through it alone is a big affirmation for people... Being the caregiver, knowing that there's* ***resources out there that you can go and talk to other people*** *that are also doing it, looking to make sure that there's not that burnout aspect in regards to helping people going through it, and then also being on the other side of it and* ***knowing that there's other people out there that feel the same way****."*

Thank you to all of the family members who contributed their time, experiences, and recommendations to this project.

To hear more from the family members that participated, please visit our YouTube channel: **www.youtube.com/@thefamilycaregivingproject1114**

Family Caregiving Project

END-OF-PROJECT REPORT

INTRODUCTION

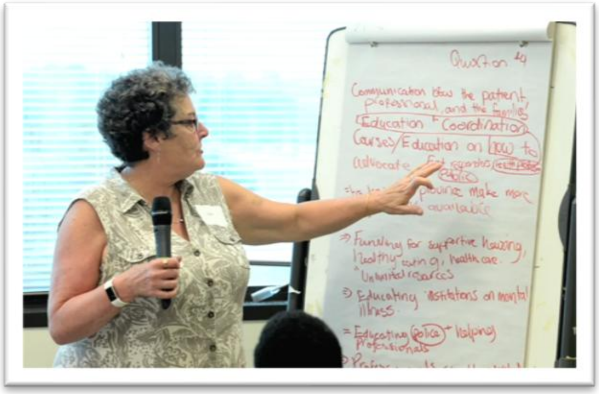
What is the Family Caregiving Project?

The Family Caregiving Project is a research study exploring the experiences of families affected by mental illness. The 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. We also believe that the community-at-large needs to have a better understanding of how families are affected by mental illness and how we all can contribute to making our communities more welcoming spaces for those families.

This study aimed to explore the experiences of Ontario families affected by mental illness through a comprehensive, multi-phase approach. This initiative was unique in its focus on whole-family health, bringing together individuals diagnosed with mental illness, other family members, and service providers as active participants. The research was conducted in three phases: (1) multigroup interviews called "Family Mental Health Cafés," where family members shared their experiences in a supportive group setting; (2) an online survey designed to capture a broader range of perspectives; and (3) dyadic family interviews, which allowed for in-depth exploration of the dynamics between family members.

The research was funded by the Social Sciences and Humanities Research Council of Canada (SSHRC) 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 knowledge mobilization, it has been renamed to "The Family Caregiving Project." For additional information about the Project, please visit https://familyguidetomentalhealth.com/family-caregiving-project/. This study received ethics approval at the University of Toronto under protocol #000034791.

What did the Family Caregiving Project aim to accomplish?

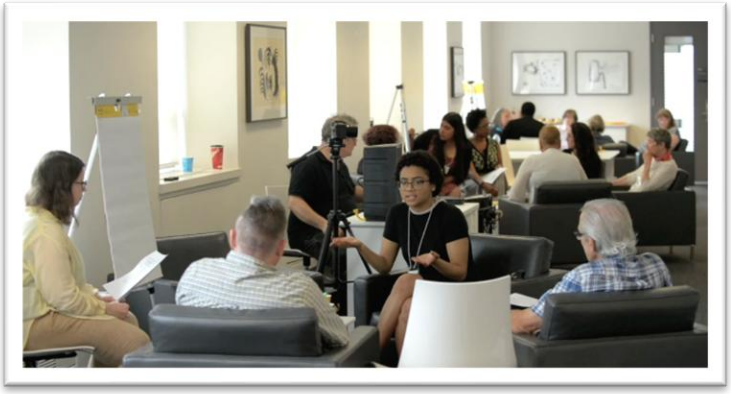


The goal of the project was to bring attention to the experiences of caregiving families managing mental illness by gathering their perspectives on what the public and the healthcare system needed to know about their lives. This work aimed to promote the development of more appropriate services for families and to enhance understanding of mental illness and its impact on families in our communities.

The research questions for the study were:

1. 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?

We have been transforming the stories shared by families into training materials for health and social service professionals, public education communications, and advocacy efforts with health care institutions and policymakers. This ongoing work aims to ensure that caregiving families feel supported by their communities and the organizations that provide mental health care services.



The research produced several significant outcomes aimed at supporting families affected by mental illness, including:

- Knowledge to contribute to evidence for practice
- Enhanced professional practice models
- Enriched public discourse
- New or enhanced collaborations/partnerships

We believe multiple audiences will benefit from the project's outputs, including:

- Academic sector
- General public
- Provincial government
- Not-for-profit/community organizations
- Postsecondary institutions and students
- Practitioner/professional/service networks

The project's planned and completed outputs are detailed further below.

What were the project's overall findings?

We learned that families in the mental health care system and in our communities face significant challenges, many of which are caused or worsened by a lack of services or barriers accessing them. We also learned that existing models of care often did not fit the experiences of families. Research informing care often overlooks the diversity of family structures, cultures, and histories that exist in our society. In addition, it tends to ignore the dual roles that individuals can play – those diagnosed with mental illness may be both care recipients and caregivers within families, while family members identified as caregivers may also need support, including for their own mental health concerns.

The study's findings highlight the need for a more inclusive definition of "caregiving families." Rather than viewing caregiving as a one-way process, families described their relationships as interdependent, involving both giving and receiving care over time. These relationships were marked by periods of heightened caregiving demand, particularly during crises, transitions, or when any family member experienced diminished capacity due to mental illness or other factors.

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, with 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.

Additionally, many families reported that stigma surrounding mental illness increased their sense of isolation, further straining their ability to provide care. They expressed a strong desire for greater institutional, legislative, and community support to help them fulfill their caring roles. Families emphasized their commitment to the health and well-being of both diagnosed and undiagnosed members but noted that they often lacked adequate resources. The study underscores the importance of recognizing the complex needs of caregiving families and calls for systemic changes to better support them in managing the long-term challenges associated with mental illness.

IMPORTANT CONCEPTS IN THIS PROJECT

Family refers to a group of individuals who may be legally or biologically linked, but who primarily self-identify as connected to each other. They share a mutual commitment to this connection and provide care – such as emotional support, concern, and daily assistance – to one another over an extended period.

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

Terms like "**caregiver**" and "**care-receiver**" are often used to distinguish between those providing care (e.g., primary caregivers) and those receiving it (e.g., patients). However, this project uses these terms selectively, recognizing that family members often both give and receive care, and these roles frequently overlap in meeting a family's care and support needs.

Stigma against mental illness refers to negative attitudes, unfair treatment, and discrimination that people with mental health conditions often face. This is fueled by stereotypes and misunderstandings about mental illness. Internalizing such beliefs can lead to feelings of shame for individuals and families affected by mental illness. Stigma experienced in interpersonal relationships can expose individuals and families to judgement, exclusion and hurtful behaviours. Systemic stigma can produce rules, laws and systems that make it harder for people affected by mental illness to get help and to be fully included in society.

In this project **caregiving family** refers to a family that manages caregiving for one or more people who need support, in addition to managing other care needs in the family.

MEMBERS OF THE RESEARCH TEAM

Investigators

Charmaine C. Williams

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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 on video 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. We are also grateful for the 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, who shared her work and passion for working with families affected by mental illness at multiple stages in the project.

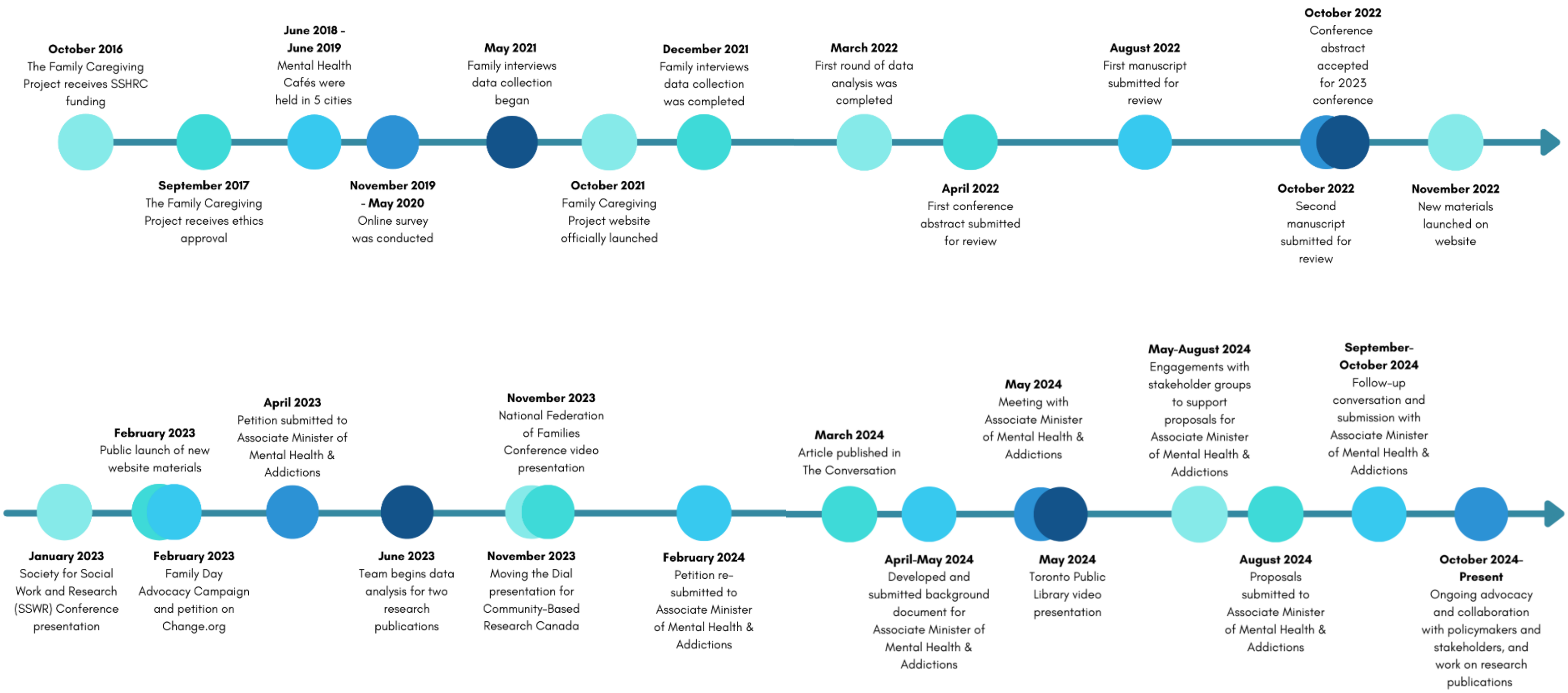
- Staff and members of advocacy and service organizations who have generously shared about their experiences doing vital work to support caregiving families, including Mothers for Mental Health Care Reform, Home on the Hill, and Mental Illness Caregivers Association.

KNOWLEDGE MOBILIZATION & OUTPUTS

Across the Family Caregiving Project

We have completed the collection and analysis of the information that was gathered in the study. In this end-of-project report, we share details about outputs and activities we have carried out to communicate our findings to the public, policymakers, and other stakeholders. *Note: the timeline of the project was extended due to disruptions of the Covid-19 pandemic.*

Our Timeline



October 2016 The Family Caregiving Project receives SSHRC funding

September 2017 The Family Caregiving Project receives ethics approval

June 2018 - June 2019 Mental Health Cafés were held in 5 cities

November 2019 - May 2020 Online survey was conducted

May 2021 Family interviews data collection began

October 2021 Family Caregiving Project website officially launched

December 2021 Family interviews data collection was completed

March 2022 First round of data analysis was completed

April 2022 First conference abstract submitted for review

August 2022 First manuscript submitted for review

October 2022 Conference abstract accepted for 2023 conference

October 2022 Second manuscript submitted for review

November 2022 New materials launched on website

January 2023 Society for Social Work and Research (SSWR) Conference presentation

February 2023 Public launch of new website materials

February 2023 Family Day Advocacy Campaign and petition on Change.org

April 2023 Petition submitted to Associate Minister of Mental Health & Addictions

June 2023 Team begins data analysis for two research publications

November 2023 National Federation of Families Conference video presentation

November 2023 Moving the Dial presentation for Community-Based Research Canada

February 2024 Petition re-submitted to Associate Minister of Mental Health & Addictions

March 2024 Article published in The Conversation

April-May 2024 Developed and submitted background document for Associate Minister of Mental Health & Addictions

May 2024 Meeting with Associate Minister of Mental Health & Addictions

May 2024 Toronto Public Library video presentation

May-August 2024 Engagements with stakeholder groups to support proposals for Associate Minister of Mental Health & Addictions

August 2024 Proposals submitted to Associate Minister of Mental Health & Addictions

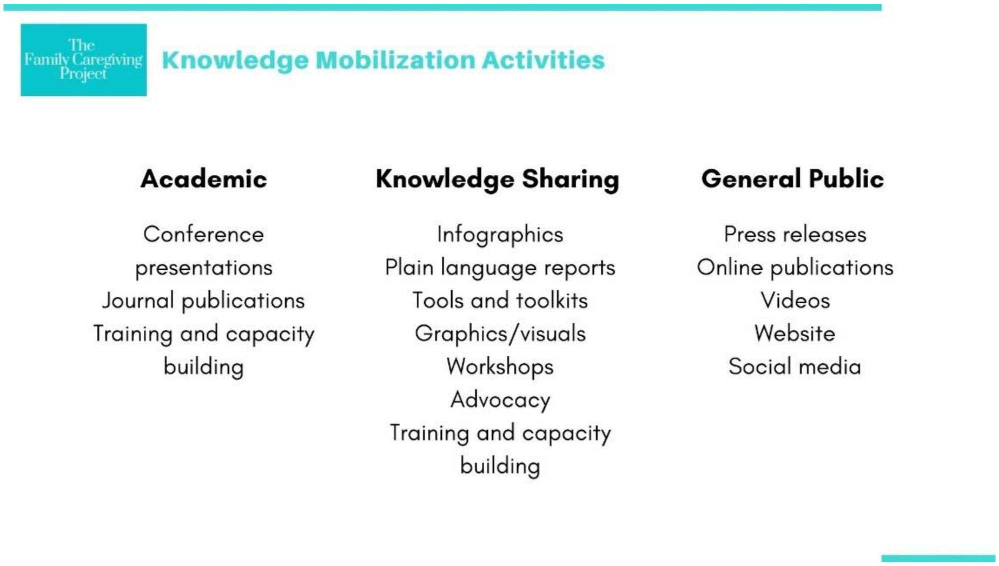
September-October 2024 Follow-up conversation and submission with Associate Minister of Mental Health & Addictions

October 2024-Present Ongoing advocacy and collaboration with policymakers and stakeholders, and work on research publications

The planned outputs from the project included:

- Research papers and reports 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 and meetings.
- A website (https://familyguidetomentalhealth.com/family-caregiving-project/) that presents project documents, educational materials and videos for the general public.

The figure below outlines the key categories of knowledge mobilization activities that have been prioritized for the Family Caregiving Project.



The Family Caregiving Project

Knowledge Mobilization Activities

Academic	Knowledge Sharing	General Public
Conference presentations	Infographics	Press releases
Journal publications	Plain language reports	Online publications
Training and capacity building	Tools and toolkits	Videos
	Graphics/visuals	Website
	Workshops	Social media
	Advocacy	
	Training and capacity building	

Our strategy has been to prioritize knowledge mobilization materials for the public, healthcare professionals, and policymakers, with publications in academic journals as a second phase of mobilization. We are pleased to share the following list of project outputs to date:

Presentations at conferences and educational events:

- The Family Mental Health Cafés: A psychoeducation intervention to diminish stigma and isolation for families living with mental illness by Dr. Charmaine Williams at the 33rd European Congress of Psychiatry (upcoming, April 2025)
- What's suffering got do with it? Some thoughts on MAiD, mental illness and social justice in an unjust world by Dr. Charmaine Williams for the Rehabilitation Sciences Institute Leadership Rehab Rounds, University of Toronto (May 2024)
- Finding Our Way: Family Experiences in Mental Health Recovery by Stuart Clarfield at Toronto Public Library, North York Branch (May 2024)
- Moving the Dial On: Support for Families Affected by Mental Illness by Dr. Charmaine Williams and Joelleann Forbes for Community-Based Research Canada (November 2023)
- Family Caregiving supports, peer activities and recovery resources by Stuart Clarfield at National Federation of Families Conference (November 2023)
- Social Justice and Family Social Work Practice by Dr. Charmaine Williams at the Canadian Association for Social Work Education Annual Conference (June 2019)
- Family mental health: An overlooked public health issue by Dr. Charmaine Williams and Joelleann Forbes at Mental Health for All (MH4A) – CMHA National Conference (October 2018)
- An Argument for Critical Social Work Practice with Families by Dr. Charmaine Williams at St. Thomas University's Connecting for Canada's 150th: Canadian Visionaries of Critical Social Work (November 2017)

Media and press releases:

- MAID and mental health: Does ending the suffering of mental illness mean supporting death or supporting better lives?, posted on The Conversation by Dr. Charmaine Williams (March 2024)
- Toolkit and other Resources: Family Caregiving Project, shared by Community-Based Research Canada (October 2023)
- Families affected by mental health need our help: Learn how the Family Caregiving Project is creating resources and advocating for stronger support, posted by Factor-Inwentash Faculty of Social Work, University of Toronto (February 2023)
- Rethinking family caregiving: Q&A with Charmaine Williams, director of the Family Caregiving Project, posted by Factor-Inwentash Faculty of Social Work, University of Toronto (April 2022)
- New resources to support families in mental health system, posted by Canadian Mental Health Association (October 2021)

- The Family Caregiving Project shares online resources to improve mental health care for families, posted by Factor-Inwentash Faculty of Social Work, University of Toronto (October 2021)
- New video series from The Family Caregiving Project provides insight on how families navigate mental illness, posted by Factor-Inwentash Faculty of Social Work, University of Toronto (May 2021)
- Charmaine Williams talks to Breakfast Television about the disproportionate mental health and health impacts of Ontario's Stay at Home orders, posted by Factor-Inwentash Faculty of Social Work, University of Toronto (January 2021)
- Dr. Charmaine Williams interviewed for Toronto Star article: COVID-19's impact on women's mental health is on the rise, CAMH study says (October 2020)
- Dr. Charmaine Williams: Racism, Mental Health Stigma & Intersectionality, podcast interview on Everybody Hates Me: Let's Talk About Stigma (May 2020)

Social Media & Website:

Since the project's inception, the team has employed social media as an advocacy and engagement tool to distribute information and resources to the public. This included the following main platforms hosted:

- Facebook (The Family Caregiving Project – closed)
    - Engagement highlight: 48+ posts in 2021
    - Over 3000 people reached
- Twitter/X
    - Engagement highlights: 2023 Caregiver Day & World Mental Health Day campaigns, website launch and resource sharing campaigns
    - Featured regularly on Factor-Inwentash Faculty of Social Work feed (@UofT_FIFSW)
- Website (www.familyguidetomentalhealth.com/family-caregiving-project)
    - Engagement highlight: 130 views on home page in November 2024
- YouTube (The Family Caregiving Project) – as of Nov 15, 2024
    - 1723 total views so far
    - 87+ hours of content watched
    - Over 7200 impressions

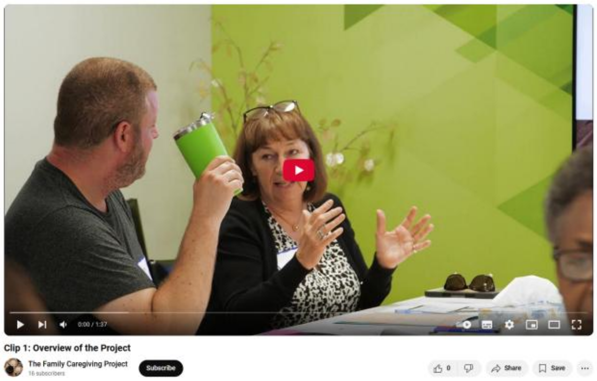
- Engagement highlights: Top videos watched include the following:

468 views:

2018 Family Mental Health Café Highlights

220 views:

Overview of the Project



143 views:

Harmful Healthcare Practices

With the support of our collaborators – including the Canadian Mental Health Association (CMHA), the University of Toronto Factor-Inwentash Faculty of Social Work, the Mission Media Company/Family Guide to Mental Health, and other organizations and individuals who have shared our social media content – we have successfully reached a wide audience with messages and education materials from the project.

Outreach & Advocacy:

We met with numerous stakeholder groups to support the project's goals, including family caregiving advocacy groups, legal professionals and advocates, service providers, academics, and more.

The project sparked significant advocacy efforts, including the development of our advocacy toolkit and our 2023 Family Day petition calling for policy change. A surge in petition signatories around 2023's World Mental Health Day enabled us to engage directly with the Associate Minister of Mental Health & Addictions, the Honourable Michael Tibollo. This has led to a series of meetings with the Associate Minister, alongside family caregiving stakeholder groups. Those engagements have led to the development of one policy brief, two proposals, and collaborations with healthcare system stakeholders to develop their own proposals aimed at securing enhanced funding for family services. Additionally, we are collaborating on a proposal to develop a high school curriculum focused on family mental health education. This curriculum is intended for use in Ontario high schools and in health networks serving Ontario's youth.

Educational Materials & Resources:

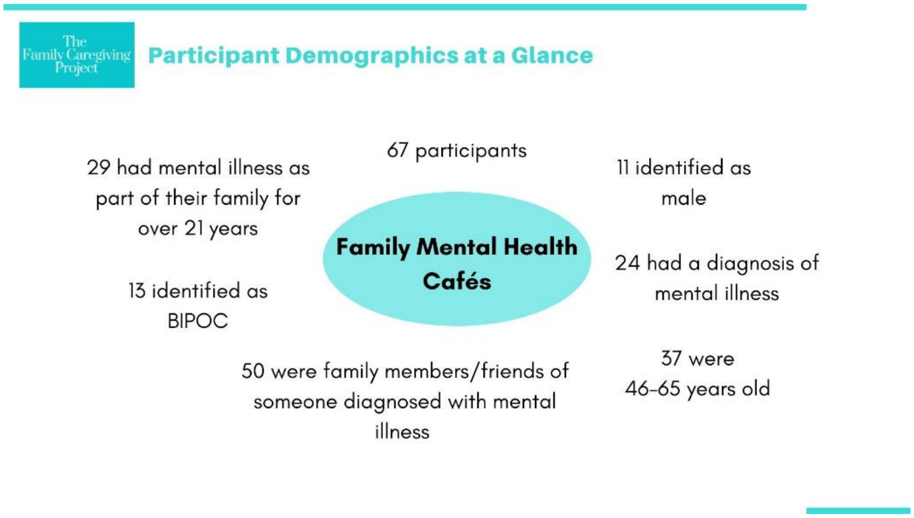
We developed practical resources for academic, professional, and public settings for educators to further disseminate findings and support teaching on family mental health. These resources are included among the educational materials posted on the project website at www.familyguidetomentalhealth.com/family-caregiving-project. Some highlights from these materials include:

- Academic journal publication by Dr. Charmaine Williams: Caregiving Under Siege: An Argument for Critical Social Work Practice with Families (2018)
- Caregiving family workbook for care planning
- PowerPoint decks for external use on: 1) Social Issues affecting Caregiving Families, and 2) The Family System
- Reading and references list (last updated Oct 2022)

We are pleased to share that materials are actively being used in classrooms to educate health sciences students. We look forward to partnering with interested educators to further expand their reach and inspire positive change within the healthcare system.

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. We collected information from 67 participants across the five Café sites. Local branches of the Canadian Mental Health Association (CMHA) collaborated in the recruitment process and hosted the events.



The Family Caregiving Project

Participant Demographics at a Glance

Family Mental Health Cafés

67 participants

29 had mental illness as part of their family for over 21 years

11 identified as male

13 identified as BIPOC

24 had a diagnosis of mental illness

50 were family members/friends of someone diagnosed with mental illness

37 were 46-65 years old

For additional information about how the Cafés were designed and run, please visit http://familyguidetomentalhealth.com/family-mental-health-cafes/

Outputs to date:

Key outputs include a manualized family support and education intervention called "Family Mental Health Cafés," which is available online for use by health and social service organizations. Additionally, the team developed a health professional curriculum, complete with written and video learning materials, designed for use by educational institutions. Please visit the following links to explore materials further:

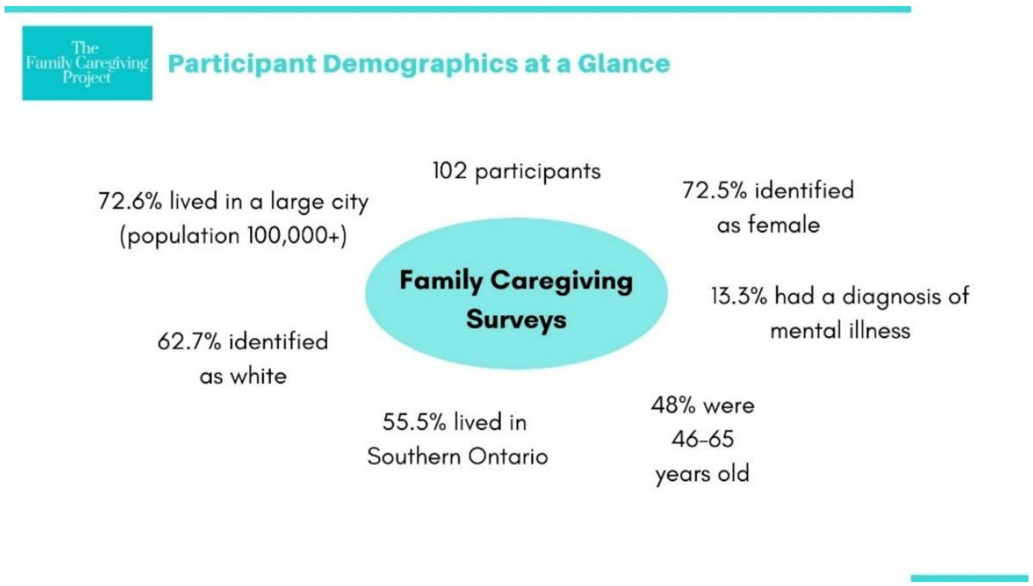
- Family Caregiving Project YouTube Playlists and Videos:
    - Educator's Guide Video Gallery
    - Mental Health Café Video Gallery
    - Mental Health Café Promo Videos
- Family Mental Health Café How-To Toolkit, including an editable PowerPoint deck to facilitate your own Café
- 5 Infographics on each Mental Health Café
- Discussion Guide
- Educator's Guide
- 3 academic journal publications in progress

The Family Caregiving Survey

The Family Caregiving Survey was an online survey launched between November 2019 and May 2020. 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. This part of the project was unique, as it allowed individuals to participate independently, without the presence of others who might influence what they chose to share. 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 received 102 completed surveys from individuals across Ontario.



The following quotations provide a snapshot of the range of recommendations shared in the online survey:

System Level Recommendations: *"We need more resources, more staff, more funding. This would alleviate the jails, police courts, frontline workers, ambulance, hospital emergency rooms. The real reality is we have a pandemic, and it is only going to triple the burden on the healthcare system."*

Service/Organization Level Recommendations: *"There often isn't enough resources or time for the clinician to support loved ones - their goal is to treat the patient (which of course is right), but there needs to be more support for clinicians to better support caregivers as well."*

Family System Level Recommendations: *"Peer relationships are how I heal and learn new ways of being. They allow me to experiment with self-respect, sobriety, etc… but professional relationships tend not to last as long or be as flexible as healthy peer relationships."*

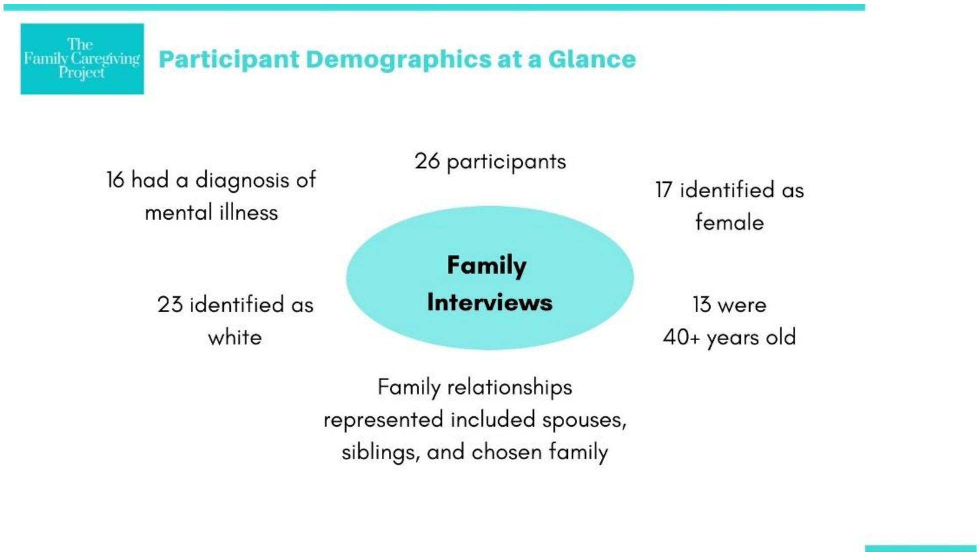
Outputs to date:

Outputs for the survey findings are ongoing. Key outputs to date include:

- Empowerment for Caregiving Families Impacted By Mental Illness: Recommendations from Caregivers and People Diagnosed with Mental Illness by Joelleann Forbes et al. at Society for Social Work and Research (SSWR) Conference (January 2023)
- 1 academic journal publication in draft

The Family Interviews

The Family Interviews were completed between May 2021 and December 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 two family members with at least one having a mental illness diagnosis. We interviewed partners, parents and adult children, friends, and siblings. Similar to other parts of the project, many individuals had experiences both as caregivers and as recipients of care for mental illness. During the interviews, families discussed their definitions of family and caregiving, as well as the impact of mental illness on their family relationships. They also described how they support one another, their perspectives on how the mental health care system involves families, and the insights they would like to share with other families based on their experiences.



The Family Caregiving Project

Participant Demographics at a Glance

26 participants

16 had a diagnosis of mental illness

17 identified as female

Family Interviews

23 identified as white

13 were 40+ years old

Family relationships represented included spouses, siblings, and chosen family

The following quotations offer a glimpse into the perspectives shared during the Family Interviews:

*“**There's a definite disconnect** between mental health, brain health, whatever you want to say, and physical health. I mean, when you get your hip replaced, you come out with a walker, you get physiotherapy. When someone is in for mental health, brain health, addictions, they basically are **often discharged with very little resources**. And I don't know if society's **expecting the families to pick up the slack**, I don't know.”*

*“I do think a lot of it's **swept under the rug** too by individuals with mental illness because **it's such a shameful thing**. It's not something, I mean, as much as sometimes people try to say that it's okay to have a mental illness and it's normal, at the same time, it's not. So, I think that a big part of it is the shame that comes with having it, you sweep it under the rug yourself, you know? So, if someone asks you if you're okay, you're going to say yes, **you're not going to admit that you're struggling** and you have these thoughts that aren't appropriate, or whatever the case may be.”*

*"**You have to be very adaptable**, and you have to learn to, you know, accept people's lack of understanding and their ignorance because it's not the kind of illness that doesn't require you to **fight***

***every day**. And you have to be a warrior to survive. And you have to **pull your family into that** and **sometimes they're not as willing or able** to do that. So, it makes it difficult.”*

*“I just learned to realize nobody's going to do anything for us. **It's going to fall on me until I die**. And that's the pathetic thing. **What happens when I die?**”*

*“Yes, I also think **communication's the biggest thing**, and we've really worked through that over the years, and just, me, I struggled initially voicing when he was struggling, like not necessarily pointing it out but asking those questions, to kind of - **what do you need?** And all of those things. So, we've really learned, I don't know that answers it the way I want it to, but just **being upfront, being honest**, recognizing if we don't want to talk about it, to maybe step back and give some space.”*

*“Yeah. And I would say to another family, like, **definitely seek out support for yourselves**. So, of course you want the loved one to get support, but definitely seek out help for yourself. Talk to a professional, someone in the field. You know, maybe a support group is your thing, maybe it's not, but **definitely talk to somebody** about what you're experiencing. **Create opportunities for breaks and respite** for yourself, for sure. It would be important. I think those would be the big things, but yeah, that talking about what you're going through, don't keep it inside. And then trying to come to a radical acceptance, the sooner the better.”*

Outputs to date:

Outputs for the Family Interview findings are ongoing. Team members are actively working on producing an academic journal publication.

BEYOND THE PROJECT

What comes next?

Although this is the final report on the project, the work of mobilizing knowledge from the project will carry on. Our team will continue to collaborate with policymakers and stakeholders to promote the perspectives shared by families and the materials we have developed. We will also continue to work on academic journal publications.

Moving forward, for resources and information about the Family Caregiving Project and Family Mental Health Cafés, please visit the Family Guide to Mental Health Recovery website at www.familyguidetomentalhealth.com/family-caregiving-project and the Factor-Inwentash Faculty of Social Work's news page at www.socialwork.utoronto.ca/about-us/news. You can also reach out to the Principal Investigator for the project, Dr. Charmaine Williams at charmaine.williams@utoronto.ca.

We hope our videos and resources can continue to be shared in support of families living with mental illness.

Project Recommendations

For those interested in advancing supports for families managing mental illness in Ontario, we will leave you with some overall recommendations:

General:

- Family is defined by the people within it, based on their feelings of connection to each other, and their expectation that they will care for each other over the long term, based on that connection. Families come in many forms and can be created in many ways. Taking this expanded and more inclusive idea of family is vital to respecting the values and realities of the families we serve.
- It is helpful to think about a family as a system: a group of individuals who, together, develop shared identities, histories, and cultures. Individuals within the family play

different roles in maintaining the family system. All are participants in the shared giving and receiving of care within the family.

- Individuals diagnosed with mental illness are not just stressors on the family system; they are part of the family system and also often provide vital care within the family. They should be included in discussions and interventions to support families and family caregiving.
- There is no single model of effective family caregiving. The models of family and caregiving that inform our policies, services and practices may not translate well to many cultures and family life realities. At the extreme, models and approaches based on a single set of expectations for families can create barriers, increase stigma, disrupt functional family support systems, and contribute to the harm that marginalized families experience as they try to access support and services. By prioritizing adaptability and cultural competence, service providers can reduce harm and better support families in accessing the care and resources they need.

In practice:

Healthcare providers must receive specialized training in family mental health and learn ways to support families that build on their unique makeups and strengths. Healthcare providers can play an important role in supporting and advocating for families in the mental health care system.

- Think about Family Mental Health. Check in with people you are providing services to about the health and well-being of the whole family and encourage seeking resources and supports that will promote everyone's well-being.
- Social attitudes and healthcare services all need updating to reflect contemporary, destigmatizing views of mental health and caregiving experiences across different family forms and diverse cultures. Ask people in your care about who should be included in important discussions and decisions.

- Instead of assuming what a particular family should do or how they should function, a more important focus is seeking their perspectives on how to support family functioning in ways that promote the safety, security, and well-being of all family members.

In policy:

Ontario policymakers need to have family caregiving on their agenda. Please contact your MPP to discuss the importance of supporting family mental health.

- Healthcare policy needs to reflect the diverse ways that people create families. Current policies are built on assumptions that one person is always a caregiver and another person is always a care-receiver.
- Policies should be created to support the family system instead of just individual caregivers and 'dependents'. Policies also need to reflect the fact that needs change as families change. Responsive policies would recognize the changes in caring roles within the family system over the family life cycle.
- Healthcare systems must actively work to remove existing barriers that make some families less likely to seek care or make it difficult for them to receive care. Social determinants, regional scarcities, and stigma and discrimination against many groups create systemic inequities that create additional challenges for family experiences of mental illness. These inequities need to be acknowledged and addressed.
- Bolster the equitable distribution of resources to combat disproportionate barriers and stigma. Families need services that are culturally responsive and trusted as safe places in their communities. Increase access to mental health care by channeling more funding to community-based services that will address the diversity of family experiences represented in Ontario and target root causes of health inequities and disparities.
- Create a strategy that increases family-centred services and enhances support for the whole family. This will reduce caregiver stress, prevent family breakdown, and empower family members to care for each other.

- Involve family members, including those diagnosed with mental illness, in designing appropriate and responsive family services.
- Increase targeted solutions for families impacted by serious and persistent mental illness and support equitable distribution of funding to organizations supporting these families.

For families:

Living with mental illness is a long-term, unpredictable journey but it is possible to work together to plan and prepare for potential crises. This preparation may include fostering a deeper understanding of each family member's experiences and priorities, creating advance plans to guide family members during a time of crisis, sharing contacts for important support people, and building support systems for everyone in the family. Some things to consider:

- Brainstorming strategies to manage tasks in the family during times of disruption
- Establishing a practice of checking in with each other regularly
- Identifying signs of family members becoming overwhelmed and planning ahead about how to intervene
- Identifying wellness needs and reliable sources of support in your social network or service provider network
- Creating a care plan and discussing preferences when it comes to treatment and receiving care
- Reviewing our Caregiving Family Workbook for more ideas and information

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APPENDIX

Resource List

Please see below to learn more about some prominent organizations and resources available for caregiving families managing mental illness:

Information on mental illness and mental health:

- Canadian Mental Health Association (CMHA): www.cmha.ca
- Centre for Addiction and Mental Health (CAMH): www.camh.ca
- Mental Health Commission of Canada: www.mentalhealthcommission.ca
- Mood Disorders Society of Canada: www.mdsc.ca
- Schizophrenia Society of Canada: www.schizophrenia.ca
- Anxiety Canada: www.anxietycanada.com
- Youth Mental Health Canada (YMHC): www.ymhc.ngo
- Canadian Centre on Substance Use and Addiction: www.ccsa.ca
- Addictions and Mental Health Ontario: www.amho.ca
- ConnexOntario: www.connexontario.ca
- Institute for Advancements in Mental Health (IAM): www.iamentalhealth.ca

Information on caregiving:

- Family Guide to Mental Health Recovery: www.familyguidetomentalhealth.com
- Caregiver Action Network: www.caregiveraction.org
- Ontario Caregiver Organization: www.ontariocaregiver.ca
- Caregiver Centered-Care: www.caregivercare.ca

Advocacy:

- Find your Member of Parliament (MP): www.ourcommons.ca/members/
- Find your Member of Provincial Parliament (MPP): www.ola.org/en/members/current
- Canadian Alliance on Mental Illness and Mental Health (CAMIMH): www.camimh.ca
- Mothers for Mental Health Care Reform: www.reformmentalhealth.ca
- Mental Illness Caregivers Association of Canada (MICA): www.micaontario.com
- Ontario Caregiver Coalition: www.ontariocaregivercoalition.ca
- Carers Canada: www.carerscanada.ca

Crisis:

- Suicide Crisis Helpline: Call or text 988. More info at www.988.ca
- Kids Help Phone: Call 1-800-668-6868 (toll-free) or text CONNECT to 686868. More info at www.kidshelpphone.ca
- Hope for Wellness Help Line: Available to all Indigenous peoples across Canada. Call 1-855-242-3310 (toll-free). Chat counselling also available at www.hopeforwellness.ca