

# Educator's Guide

## CAREGIVING FAMILIES & MENTAL ILLNESS

Building off of our [Discussion Guide](#), this Educator's Guide was developed to promote discussion of topics relevant to the wellbeing of caregiving families affected by mental illness specifically for healthcare providers and students. Each section has its own video compilation, reflection questions, and summary takeaway points, as well as key concepts and supplemental literature for further reading.



### How to use this Educator's Guide

The videos you will watch are interviews conducted after [Family Mental Health Cafés](#) across Ontario. Each theme contains short sections of video interviews with a variety of people who are part of families affected by mental illness; they could be caregivers, care-receivers, service providers, or any combination of these identities. We recommend using these videos and the guide in training programs for health profession students and people providing support to families in healthcare settings, social services organizations, and other community settings. [Click here to download a PDF](#) of supplemental materials for educators, which includes key family caregiving concepts and readings related to this theme.

Visit the **Integrating Your Learning** page for questions to promote further reflection and integration of the lessons presented by caregiving families.

We hope you find this guide useful. Should you have any questions, please contact us at [fmhproject@gmail.com](mailto:fmhproject@gmail.com).

### Learning Outcomes

- Identify features of a caregiving family, and ways that families negotiate living with mental illness
- Explain family caregiving experiences and interactions on an interpersonal/societal level, and how families navigate experiences of stigma, discrimination, and structural violence
- Describe ways that current healthcare systems and social institutions cause harm, and some emerging practices that are supportive to caregiving families

### Introducing the Themes

The six different themes listed below describe and explore the experiences of caregiving families living with mental illness.

1. **Roles in Caregiving Families** (page 4)
  - Defining Family Caregiving roles
  - Navigating multiple demands in the family
  - Intergenerational family caregiving & mental illness

## 2. Relationships in Caregiving Families (page 6)

- Tensions
- Supportive strategies

## 3. Sustaining Caregiving Families (page 7)

- Maintaining hope
- Caring for self
- Whole Family Mental Health

## 4. Structural and Social Issues Affecting Caregiving Families (page 9)

- Discrimination
- Stigma and isolation
- Advice from families

## 5. Healthcare System Interactions for Caregiving Families (page 11)

- Harmful practices
- Helpful practices
- Peer support

## 6. Systemic Issues affecting Caregiving Families (page 13)

- Social Determinants of Mental Health
- Promoting change

## Introducing the Caregiving Families

These 14 people generously provided their time to share issues that were top of mind for them when it comes to family caregiving and mental health. Some are caregivers to loved ones diagnosed with mental illness, and others have diagnoses themselves; sometimes they occupy both roles. We are grateful for the time they took to share difficult memories, helpful experiences, and hope for change on the horizon.

Lana



Ken



Paula



Heidi



Sally



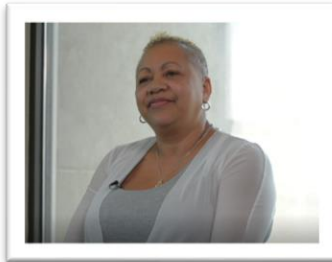
Brenda



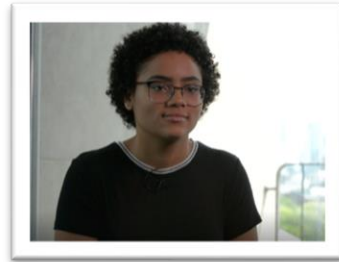
Kira



Anna



Iyanna



Nicole



Kathleen



Karla



Marilyn



Reece



# THEME 1: Roles in Caregiving Families

## Introduction to the Theme

We hear from our interviewees about the ways in which they deal with and work through issues associated with mental illness in the context of their family roles. Interviewees discuss caring for and receiving care from their family members despite life's many other challenges, and how families have been dealing with mental illness across generations.

Interviewees talked about the roles in their caregiving families in three main areas:

### Defining Family Caregiving roles



Interviewees talk about their roles within their caregiving families as caregivers and care-receivers, and how they navigate these roles with other members of their family.

YouTube: [Clip 1.1 – Defining Family Caregiving Roles](#)

**Q1.** Compare and contrast the family caregiving roles you have heard discussed in the videos. How do these roles differ depending on things like their relation to the person diagnosed with mental illness (e.g., mother, sister, spouse), their identity (e.g., age, gender), and others?

**Q2.** What were some of the challenges that interviewees mentioned that can impact the process of giving and receiving care? What do you think are some important qualities of caregiving families that promote mutual support and caring?

### Navigating multiple demands in the family



Interviewees describe their responsibilities, both within and outside of their caregiving families, as well as strategies they use to cope with the multiple demands.

YouTube: [Clip 1.2 – Navigating Demands in the Family](#)

**Q1.** What roles other than caregiver/care-receiver do interviewees occupy, both inside and outside of their caregiving families? How might this influence their caregiving responsibilities?

**Q2.** List some of the strategies the interviewees employed to support their family member and help themselves cope with the roles they play in their family. How have they adapted to their caregiving/care-receiving roles?

## Intergenerational family caregiving and mental illness



Interviewees discuss their families' experiences of mental illness and caregiving across generations, and insights they have gained as a result.

YouTube: [Clip 1.3 – Intergenerational Family Caregiving](#)

**Q1.** Interviewees talk about their experiences with mental illness and providing/receiving care in their families. What happens when care is absent or becomes more difficult? Discuss factors and experiences that can influence these shifts in the provision of care in families?

**Q2.** Thinking about families as systems can provide a more comprehensive picture of a person (and family)'s mental illness experience. Discuss why it would be important to factor intergenerational mental illness into a person's care?

## THEME 2: Relationships in Caregiving Families

### Introduction to the Theme

This section explores relationship dynamics within families, including ways of communicating with each other and the factors that shape those interactions. Issues tended to come up in places where family members get stuck, and interviewees also explored ways they successfully navigate the dynamics within their family.

Interviewees talked about the relationships in their caregiving families in the form of:

**Tensions**, or the things that do not go well



Interviewees talk about difficult interactions they have had with family members in the context of discussing their experiences of providing and receiving care, and ways they have come to terms with these tensions.

YouTube: [Clip 2.1 – Tensions](#)

**Q1.** What qualities of family relationships make caregiving and receiving care harder? How have the interviewees dealt with these challenges?

**Q2.** Interviewees discuss how experiences with mental illness are hard to share with others, especially with those who have preconceived notions or may not understand. What are some consequences of sharing, or not sharing, that interviewees speak about?

**Supportive strategies**, or the facilitators that promote helpful interactions



Interviewees describe the strategies they have found useful while navigating relationships with other members of their caregiving families.

YouTube: [Clip 2.2 – Supportive Strategies](#)

**Q1.** What qualities of family relationships make caregiving and receiving care easier?

**Q2.** How do themes of transparency and open communication come into interviewees' stories? How has this influenced their family relationships?

**Q3.** Describe how acceptance and unconditional support play a role in some of the interviewees' family caregiving experiences. What experiences and processes do you think they had to go through for them to embrace these perspectives?

## THEME 3: Sustaining Caregiving Families

### Introduction to the Theme

Interviewees were very open about ways in which they cope with mental illness as a caregiving family, and how they wish to share these strategies with others in similar circumstances. These range from daily practices and activities, ways they prepare for the future, and how they hold hope for broader system change.

Interviewees talked about the things that sustain their caregiving families in three main areas:

#### Maintaining hope



Interviewees share their thoughts about maintaining and promoting hope for caregiving families living with mental illness, and signals of change they are seeing that promotes this.

YouTube: [Clip 3.1 – Maintaining Hope](#)

**Q1.** Interviewees wanted to impart the importance of hope to other caregiving families. Why do you think holding onto hope is so important to facilitate coping with mental illness as a caregiving family?

**Q2.** Discuss how healthcare settings and providers can be more supportive of this and contribute to keeping hope alive for families they work with.

#### Caring for self



Interviewees discuss the vital ways in which they prioritize caring for themselves and promote healthier ways of coping with mental illness.

YouTube: [Clip 3.2 – Caring For Self](#)

**Q1.** List some of the practical ways in which interviewees sustain themselves and their families on a daily basis.

**Q2.** We receive insight into the process of how interviewees developed their own practices that sustain them and their families. How do you think they arrived at a place that prioritizes care and hopefulness, and who or what aided them in their process?

## **Whole Family Mental Health**



Interviewees share their thoughts about why whole families must be included in the treatment and support process of a person diagnosed with mental illness.

YouTube: [Clip 3.3 – Whole Family Mental Health](#)

**Q1.** How do interviewees describe why families should be included in an individual's care? How does Family Systems Theory help to explain these perspectives?

**Q2.** Caring about Whole Family Mental Health means also considering the emotional health and well-being of family members who do not have a diagnosis. How can the concept of Whole Family Mental Health be applied more within the healthcare system? Think of specific contexts and ways that Whole Family Mental Health would improve outcomes for caregiving families.



## THEME 4: Structural & Social Issues Affecting Caregiving Families

### Introduction to the Theme

This section explores the ways in which interviewees and their families have come up against structures and social harms that have negatively impacted their experiences with mental illness and family caregiving. Stigma and discrimination are individual, interpersonal and institutional phenomena which lead to experiences of self-stigmatization, isolation, and institutional marginalization, ultimately resulting in poor health and care outcomes for the whole family.

Interviewees talked about the interpersonal issues affecting their caregiving families in the form of:

#### Discrimination



Interviewees recall painful experiences of discrimination from their own families or from families they have supported.

YouTube: [Clip 4.1 – Discrimination](#)

**Q1.** How and where does discrimination and structural violence show up in the stories told by interviewees? How can we work to dismantle this harm for caregiving families living with mental illness? Where would you start?

**Q2.** Consider how Intersectionality and Feminist Family Theory can be applied when working with caregiving families, and in wider policy and service development. How would working from these lenses improve outcomes for caregiving families?

#### Stigma and isolation



Interviewees share their experiences of stigma and the harmful ways that it shows up across a variety of social settings for caregiving families.

YouTube: [Clip 4.2 – Stigma & Isolation](#)

**Q1.** How does stigma place additional burden on caregiving families, and what repercussions does it have for families trying to access and receive care?

**Q2.** Interviewees describe some factors that can heighten the stigmatization of people and families living with mental illness. How can experiences of isolation and fear lead to internalized negative attitudes and self-stigmatization?

**Advice from families**, which covers strategies, ideas for increased support for families, and hope for structural change



Interviewees discuss their thoughts and suggestions for ways that we can better support caregiving families living with mental illness as a society.

YouTube: [Clip 4.3 – Advice From Families](#)

**Q1.** What advice did interviewees have for settings and systems to improve outcomes for caregiving families affected by mental illness?

**Q2.** To what extent do healthcare practitioners and settings already integrate this advice from caregiving families to reduce experiences of stigma and discrimination? What areas of practice and/or policy do you think have the biggest opportunity for change?

## THEME 5: Healthcare System Interactions for Caregiving Families

### Introduction to the Theme

Interviewees recount painful experiences of their interactions within healthcare settings and systems, as well as types of interventions and practices that have potential to support and affect positive change for families.

These interactions included:

#### Harmful practices



Interviewees recount difficult and painful interactions their caregiving families have had with healthcare practices and settings.

YouTube: [Clip 5.1 – Harmful Practices](#)

**Q1.** What went wrong for interviewees and their families in these situations?

**Q2.** In what ways does the healthcare system devalue perspectives of caregiving family members?

**Q3.** How do harmful practices in healthcare settings put a toll on family caregiving relationships? How do they perpetuate and exacerbate stigma and discrimination?

#### Helpful practices



Interviewees share the practices and systems that helped promote family mental health when their caregiving family was seeking support through the healthcare system.

YouTube: [Clip 5.2 – Helpful Practices](#)

**Q1.** What resources or strategies were helpful for interviewees? What resources or strategies could have been helpful if interviewees had them at their disposal? At what stages of care would you implement these resources?

**Q2.** Interviewees discuss the importance of healthcare practitioners collaborating with caregiving families to improve care experiences and outcomes. Discuss ways to integrate this philosophy more effectively throughout healthcare settings, and any barriers you foresee to doing this.

## **Peer support**



Interviewees discuss their thoughts on peer support and why this type of intervention is so important for caregiving families.

YouTube: [Clip 5.3 – Peer Support](#)

**Q1.** What are some of the characteristics of peer support services and environments that interviewees found important and helpful?

**Q2.** What different types of peer support were explored and discussed by interviewees? How can all members of caregiving families benefit from this type of support?

## THEME 6: Systemic Issues Affecting Caregiving Families

### Introduction to the Theme

In this section we hear from interviewees about the systems and social institutions that their families have interacted with, and the ways in which they have experienced harm. Interviewees discussed examining and tackling the root causes of systemic inequities to promote the possibility of prevention and better recovery. Many interviewees also expressed a wish to participate in advocacy efforts and contribute to solutions for caregiving families. Interviewees talked about their experiences with:

#### **Social Determinants of Mental Health**



Interviewees share painful experiences their caregiving families have had with social institutions and their thoughts on why change must happen.

YouTube: [Clip 6.1 – Social Determinants of Mental Health](#)

**Q1.** Discuss how the Social and Structural Determinants of Health and Mental Health show up in interviewees' stories.

**Q2.** Interviewees share how supports and social services are either not in place, or are stripped away, when people become ill. How does this contribute to persistent illness and difficulties with staying well?

**Q3.** List the social institutions interviewees discuss interacting with, and the ways in which each one perpetuates experiences of marginalization.

#### **Promoting change for caregiving families**



Interviewees share signals of change, hopes for the future, and reasons to include caregiving families in transforming mental health care.

YouTube: [Clip 6.2 – Promoting Change](#)

**Q1.** What signals of change for caregiving families living with mental illness do interviewees discuss? What excites you the most from this list?

**Q2.** How can healthcare providers use their power to help drive change, and what could that look like from a practice, policy, advocacy, or other standpoint?

**Q3.** How would services and systems differ if they were co-developed with caregiving families? How can we integrate more family-driven care and support programs into our healthcare system?

## INTEGRATING YOUR LEARNING

After working your way through this Educator's Guide, we encourage you to reflect on how the lessons from caregiving families has impacted you personally and professionally. What has changed for you after hearing these stories? How will you change your professional practices now and in the future?

**Take a moment to answer these questions and those listed below to integrate your learning about caregiving families and mental illness:**

- What were the main issues that you identified as affecting the wellbeing of families affected by mental illness?
- What practice guidelines or theories explain the experiences of these families and their impact?
- Where do you see gaps between existing practice models or theories and the needs identified by these family members?
- What practices or policies could you see implemented in your role or setting that would support caregiving families more effectively?
- What changes will you commit to making as you move forward in your work with caregiving families?

### Looking for more Family Caregiving Resources?

Thank you for participating in our Educator's Guide! Visit [www.familyguidetomentalhealth.com/family-caregiving-project](http://www.familyguidetomentalhealth.com/family-caregiving-project) for a wide range of other materials including education, support, and advocacy resources for families, communities, and clinicians.

### Inspired to do More?

Consider facilitating a [Family Mental Health Café](#) in your community. We have a facilitators' guide and additional materials that walk through every step of the process.

For questions and additional information, please get in touch with us at [fmhproject@gmail.com](mailto:fmhproject@gmail.com).