



Mental Health  
Commission  
of Canada

Commission de  
la santé mentale  
du Canada

# Taking the Caregiver Guidelines Off the Shelf: Mobilization Toolkit

*National Guidelines for a Comprehensive Service  
System to Support Family Caregivers of Adults with  
Mental Health Problems and Illnesses*



*Ce document est disponible en français.*

This document is available at <http://www.mentalhealthcommission.ca>

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This toolkit was developed by the Mental Health Commission of Canada with the help of members of the Former Family Caregivers Advisory Committee.

It is based on the work done by Penny MacCourt, MSW, PhD and the former Family Caregivers Advisory Committee in the *National Guidelines for a Comprehensive Service System to Support Family Caregivers of Adults with Mental Health Problems and Illnesses*.

# 1. Background on the Issue

This toolkit is intended to support individuals, groups, or organizations in their efforts to help others understand and implement the recommendations in *The National Guidelines for a Comprehensive Service System to Support Family Caregivers of Adults with Mental Health Problems and Illnesses (Guidelines)*. The *Guidelines* were published by the Mental Health Commission of Canada (MHCC) in 2013 and provide concrete guidance to system planners, policy makers, and mental health managers in planning, implementing, and evaluating a family-friendly system of care.

The term “family caregiver,” here and in the *Guidelines*, refers to all those in the circle of care, including family members and other significant people who provide unpaid support to an individual living with a mental health problem or illness (hereafter referred to as “caregivers”).

A family-friendly system of mental health care is expected to optimally support caregivers so they can provide the best possible support to their loved ones while sustaining their own wellbeing.

## 1.1 Toolkit Goal and Objectives

The goal of this toolkit is to encourage the implementation of recommendations in the *Guidelines*.

These tools are intended to support any individual or group who wishes to inform and engage those with the influence or decision-making power to implement any or all of its recommendations.

After familiarizing yourself with this toolkit, you will be better prepared to:

- > introduce the *Guidelines* to others and encourage implementation of recommendations;
- > determine the different steps you may take in mobilizing the implementation process;
- > choose appropriate activities and tools (e.g. when to use the slide deck, meeting activities, or a summary document); and
- > understand your role as a facilitator of this process.

## 1.2 *The Mental Health Strategy for Canada*

*Changing Directions, Changing Lives: The Mental Health Strategy for Canada (Strategy)* was released in May 2012. It offers practical recommendations to improve mental health and wellbeing throughout the country. The *Strategy* was designed to establish common priorities and build on federal, provincial, and territorial initiatives. The recommendations address mental health problems and illnesses throughout the lifespan and across the continuum, including promotion and prevention, education, justice, social policy and health care services.

The *Strategy* is a blueprint for change and shows that there can be a role for everyone. It aims to raise the profile of mental health issues, encourage public discussion, and help reduce stigma.

## MHCC'S SIX STRATEGIC DIRECTIONS

The 27 priorities and 109 recommendations in the *Strategy* are anchored on six strategic directions:

1. Promoting mental health and preventing mental illness and suicide wherever possible.
2. Fostering recovery and wellbeing for people living with mental health problems and mental illnesses and upholding their rights.
3. Providing access to the right services, treatments, and supports.
4. Reducing imbalance in risk factors and access to services and addressing diversity.
5. Working with First Nations, Inuit, and Métis.
6. Mobilizing leadership, improving knowledge, and fostering collaboration.

### 1.3 Caregivers and the *Strategy*

Several of the *Strategy's* recommendations directly address the role of the family and the circle of support of individuals living with mental health problems and illnesses.

Caregivers are recognized as important participants in the recovery journey of their loved ones and as effective advocates for care. The *Strategy* recommends a balanced approach to including caregivers in the care trajectory and respecting the autonomy and confidentiality of the person in need of services. The *Strategy* further recommends that family caregivers be better supported and encouraged to take on active roles in governance, accreditation, monitoring, and advisory bodies within the service system to take advantage of their interest, experience, and perspectives.

Finally, the *Strategy* calls for enhanced support for families so that they can provide optimal care while meeting their own needs. This includes more access to respite care and flexible work policies. The *Strategy's* recommendations set the stage for the work that went into the *Guidelines*.

## 1.4 Caregivers and the *Guidelines*

The *National Guidelines for a Comprehensive Service System to Support Family Caregivers of Adults with Mental Health Problems and Illnesses (Guidelines)* were initiated by the former Family Caregivers Advisory Committee of the MHCC. They reflected the Committee's mission "to help create conditions that will promote full and meaningful lives for people diagnosed with mental illness and for their families and friends who often serve as their primary support network."

The *Guidelines* aim to assist planners, policy makers, and service providers in planning, implementing, and evaluating mental health care services that recognize and address the unique needs of family caregivers. They are grounded in the knowledge that:

- > Well-supported family caregivers can play an important role in the recovery journey of their ill relative, in the improvement of their quality of life, and in their inclusion in all aspects of community life.
- > Adequate support can ease the stressors often associated with caregiving. The absence of such supports, on the other hand, can lead to negative effects for family caregivers that jeopardize both their capacity to provide care and their own health and wellbeing.
- > The unpaid care and support provided by family caregivers makes a major contribution to the health and social service system, which would be very costly to replace with paid formal services.

## 1.5 What Is It Like For Caregivers These Days?

Eight million Canadians, aged 15 and over, were caregivers to family members or friends with a long-term health condition, a disability, or problems associated with aging in 2012. That's 3 in10! Approximately seven per cent, or 560,000, of those caregivers provided care to a person living with a mental health problem or illness making mental illness the fourth leading reason for caregiving, after aging, cancer, and cardio-vascular disease. Mental health problems and illnesses, such as depression, bipolar disorder, and schizophrenia, were the most common reasons for a parent to provide care to a child (23 per cent).<sup>1</sup>

Family caregivers of adults with mental illnesses fulfill a distinct and important role by providing support, advocating for their relatives, and contributing to their recovery.

However, the unpredictable nature of many mental illnesses, their longevity, the historical barriers to family involvement within the mental health system, as well as the stigma that is still associated with mental illness, can compromise the health of family caregivers themselves. Many caregivers and service providers continue to face challenges in balancing the individual rights of the person living with a mental health problem or illness with the family caregiver's needs for information and their own support. In some cases, a lack of insight, also referred to as anosognosia, may present an additional challenge.<sup>2</sup>

Inadequate recognition and support for caregivers may generate significant emotional, physical, financial and social burdens. According to the 2013 Statistics Canada report – *Caregiving: What are the consequences?* – caregivers have reported significant psychological, health, and financial consequences of providing care for two hours a week or more. Not surprisingly, the more intense the care required, the greater the impact on the caregiver's own health. Those caring for ill or disabled children or spouses were more likely than other caregivers to sustain an injury, consult a medical professional for health issues related to their tasks, and be prescribed medications to cope with their responsibilities, making them “collateral casualties” of mental illness.

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<sup>1</sup> Family caregiving: What are the consequences?” Insights on Canadian Society. September. (2013) Turcotte, Martin. Statistics Canada.

<sup>2</sup> For more information on anosognosia and how to help someone with mental illness accept treatment visit the LEAP Institute at <http://www.leapinstitute.org/>

The personal financial consequences of caregiving had a significant impact on disposable income and personal savings for some. Nearly half of parents providing care to their children, and 38 per cent of those caring for a spouse, spent \$2000 or more during a 12 month period. Twelve percent had to take out a loan from a financial institution as a result of caregiving responsibilities, while 21 per cent depleted or deferred their savings. This can be devastating not only to the caregiver, but also for the person receiving care.

Caregivers are a very diverse group of people and their experience navigating the system can be affected by many factors, including their age, health, location, employment status, gender, ethnicity, language, and the nature of the relationship with their ill loved one.

## 1.6 What do Caregivers Need?

Through consultations and research conducted by MHCC, caregivers identified **four supports** that would help them fulfil their caregiving responsibilities more effectively and allow the health and social services system to continue to reap the benefits of unpaid caregiving. To feel well supported, caregivers said they need:

- > To know that their relative is receiving appropriate care and has access to the services and supports that will maximize their potential for quality of life;
- > To have their relationships and caregiving roles recognized by mental health service providers and to be meaningfully involved in assessment and treatment planning;
- > To receive information and timely support from knowledgeable mental health service providers, including enhancing their coping skills, so they can effectively provide care to their relative; and
- > To have their personal needs outside of their caregiving role recognized and supported to sustain their own health and emotional wellbeing.

The *Guidelines* address these needs through specific recommendations. Moreover, the *Strategy* makes many recommendations for improving access to appropriate and recovery-oriented care, services, and supports for people living with mental health problems and illnesses.

## 2. Planning Guide

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“Someone’s sitting in the shade today because someone planted a tree a long time ago.”

- Warren Buffet

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This planning guide is designed to help you think through who you will encourage to implement the *Guidelines* and how and when you will provide encouragement. It includes a questionnaire that you can use to prepare your approach for different target audiences – who, what, where, when, and why. With a well-prepared case and your passion for the cause, you will be better able to influence the outcome.

→ **See Resource: Planning Questionnaire**

## 2.1 Getting Started

This section outlines a few steps to help you prepare for an outreach or education effort to get a specific or series of recommendations in the *Guidelines* implemented. It is not a comprehensive guide to planning these types of efforts, but will help get you started!

### HOW WOULD YOU LIKE TO WORK?

Think about how you work best. Ask how much time you or your organization has for this initiative and any restrictions. Do you have more time and energy at a particular time of year? Would you like to create a working group? Form a two-person team? Embark on your own? Is there an existing organization, group or network already in place with whom you could work?

Although you can start the process on your own, consider creating a working group as well as linking with an existing organization that is already playing a leadership role on mental health caregiving issues. Recognized groups or networks add credibility, can help strengthen your pitch, and may have more resources already in place to sustain your efforts.

Working in a group allows you to bounce ideas off others and benefit from multiple perspectives before approaching a potentially interested party to implement a change.

→ **See Section 4.5: Resources – Support Services for Caregivers**

### WHO IS YOUR TARGET AUDIENCE AND WHY?

Be clear about who you wish to engage in the discussion and what you want the outcome to be.

Is there a certain agency, service, organization, or sector with whom you have first-hand experience and in which you want to see a specific change? Is there a specific person or group that might be a strong ally inside an organization to help bring about a change? Or is there a specific recommendation that you think you could help implement? Matching recommendations to the right audience is important for success.

Examples of target audiences for the *Guidelines* include the director of a hospital program or department, the head of human resources in a specific work place, a community service provider, a government policy developer.

To help identify your audience map out your network using a stakeholder analysis tool or by making a list of people and organizations that you already know or know something about and how you know them. Determine which you would like to target first and why; then, add the name of someone who could be your liaison and their contact details, if known.

To map your network, identify target audiences for specific changes, and prioritize who to contact, you could try activities described in this toolkit: Thought Shower, Stakeholder Analysis, Mindmapping, or Dotmocracy.

→ **See Resource: Planning Activities**

### **WHICH RECOMMENDATIONS WOULD BE RELEVANT TO YOUR TARGET AUDIENCE?**

The recommendations are divided into sectors in Appendix 1 - Recommendations - in the *Guidelines*. Review the recommendations for the sector you are targeting and consider which ones your audience might have some influence over. If reaching out to an individual to get your foot in the door, think about which issue is most likely to resonate with them.

### **WHAT WOULD YOU LIKE TO SEE HAPPEN?**

Planning can be the key to successfully engaging others. A well-planned process can also save time. To communicate clearly, identify your objective for each stage of the process and the expected result. Example:

In the first phone call, I will:

- > find out how familiar my contact person is with the *Guidelines*.
- > ask if they have 10 minutes to talk now or schedule a phone call for later.

As a result, I hope to:

- > familiarize them with the relevant recommendations.
- > schedule a 30-minute meeting to present the issues to the department within a month.

### **WHAT IS YOUR KEY MESSAGE?**

You know better than anybody your reason for wanting to mobilize and help implement the *Guidelines*. When communicating with your target audience it is important to have a clear message for them.

This message should speak to why you are reaching out to them, how the *Guidelines* are related and important to their work, and a clear understanding of the benefits of implementing a specific or set of recommendations. Where possible, use stories, research, or data to back up your argument.

→ **See Resources: Sample Letter, Sample Summary Document, Telling Your Personal Story**

### **WHEN WILL YOU APPROACH THEM?**

Consider whether there is a “best” time to approach each target audience, especially those that follow a clear-cut cycle, such as educational institutions and school boards. Examples: When does the school board schedule professional development days? When do they plan for the coming year? Is there a conference coming up that would be a prime time to give a presentation to a wide audience within a particular sector?

### **HOW WILL YOU MAKE THE INITIAL CONTACT?**

How you approach the target group will depend on how well you know your key contact. Some questions to consider may be; is your key contact someone you can speak to casually outside the work environment, over a cup of tea, or at a social gathering? If not, you will probably benefit from thinking through the tone you set from the beginning. Formal or informal? Will you do it by phone, email, or letter? Would it be better to request an introduction to your desired contact person through a mutual friend, family member, or colleague?

### **WHAT ARE THE LOGISTICS?**

List where, when, and what resources you will need for each stage in the process and who will provide or develop them. For example, if providing the target group with a summary document, who will write it and what will be the key message?

## **2.2 Communicating Your Message**

There are many ways to communicate your message, including meetings, telephone calls, presentations, and emails. Your method of communication will often depend on your relationship with your target audience.

In your communication, it is important to include key messages and a clear “ask” – the action you want your target audience to take. Using evidence in the form of research, data, or personal experience can be a powerful way to back up your argument.

### **LETTERS AND SUMMARY DOCUMENTS**

Some audiences may require written communication to help them understand your message and objectives. For example, if you are trying to target decision makers, such as senior leadership in a hospital, a government policy maker, or the board of a community health organization, it is important to communicate in a way that makes sense for them. Letters and summary documents, sometimes called briefing notes or backgrounders, are two ways to do that. They are also good tools to organize your message and help audiences reflect on the topic.

- **See Resource: [Sample Letter](#)**
- **See Resource: [Sample Summary Document](#)**

## MEETINGS AND PRESENTATIONS

Face-to-face meetings and presentations can be very effective for communicating your message and building working relationships. They can ensure engagement, encourage participation and provide the space to clarify meaning. However, they require planning, preparation and follow-up. To plan an effective meeting, organizers need to consider the purpose, logistics, invitations, presenter responsibilities, and more.

- [See Resource: Planning a Meeting for tips and checklists for preparing for a meeting](#)
- [See Resource: Facilitator Guide for tips on how to facilitate a meeting](#)

## POWERPOINTS AND VISUAL AIDS

Oral communication requires focus and structure. In addition to key messages, using compelling stories can help illustrate your point. PowerPoint or a video showing powerful visuals can not only help you communicate your message, but also evoke emotional responses. Having a leave behind is another tool to help your audience reflect on your message.

- [See Resource: Planning Activities on how to build a PowerPoint](#)
- [See Resource: Recommendations Handouts](#)

## TELLING YOUR PERSONAL STORY

Personal stories can go a long way to help illustrate the need for a changed mental health system to support family caregivers. Stories help people connect with their audience who often remember stories better than they do data. Personal experience, and ultimately the stories that follow, are often the 'WHY' of why we are doing this work. In order to be effective, a story should be relevant to your audience, well-thought-out, and link clearly to the change you want to see implemented.

- [See Resource: Telling Your Personal Story](#)

## 2.3 Planning a Meeting

### WHAT IS THE MEETING PURPOSE AND AGENDA?

The purpose of your first meeting might be to simply get to know your contact person and pitch the idea of taking time to review the *Guidelines* or a specific recommendation. Determine in advance whether it is appropriate to give a short PowerPoint presentation; or simply talk and give them a copy of the *Guidelines* and a handout from this toolkit with the relevant sector recommendations.

Your role might end at that point. However, if you are comfortable facilitating processes, you could offer to support the group in future meetings as they identify:

1. which recommendations are a priority for their circumstance;
2. to what extent they are already applying them; and
3. what else they could be doing to meet a particular recommendation.

### WHAT ARE THE MEETING LOGISTICS?

Work with your contact person to set the agenda for meetings together – when to meet, where, how often, who is going to chair the meetings, will there be “homework” between meetings, etc. Give yourself enough time to prepare. Find out how long the first meeting can be and identify the best location. Does the contact person or target group prefer to meet in their office, your office, or would it be a welcome break to go to a coffee shop nearby?

### WHO SHOULD BE INVITED AND BY WHOM?

If your contact person supports the idea of setting up a meeting with a larger group, work together to determine how to proceed. Find out who should be invited and by whom, you or the internal contact? How should the invitation be made, by telephone or email? Should it be a teleconference, face-to-face meeting, video conference call, or Skype call?

### WHAT RESOURCES WILL YOU NEED?

List the materials and audio visual equipment needed. Do you need to bring a presentation projector, screen, and laptop or is the organization equipped for audio/visual display? Do you need flipcharts and markers for participants to jot down their thoughts in a small group? How many copies of the relevant sector recommendations handout will you need and who will arrange the photocopies?

➔ See Resource: [Planning a Meeting for tips and checklists for preparing for a meeting](#)

## HOW WILL YOU START THE MEETING?

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“Beginning a conversation well can make the rest of a conversation more productive.”

- Anne Davidson and Roger Schwarz in *The Skilled Facilitator Fieldbook 1*

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You can set the tone of a discussion or meeting through prior planning, even considering what you will chat about with participants as they arrive. Try to have all materials and equipment ready beforehand, so you can focus on making a connection.

Decide when to give the handout with recommendations for their sector.

- > Will you email it to participants before the meeting along with the agenda?
- > Will you hand it out as people arrive, along with the agenda?
- > Will you hand it out when you reach that item on the agenda?

Think about how to ease into the meeting, giving participants time to gather their thoughts during the first few minutes. Here are a few suggestions:

- > Welcome participants and thank them for making time to meet with you.
- > State the purpose of the meeting and desired outcomes.
- > Read the agenda or give participants the chance to read it themselves. Ask if any adjustments are needed.
- > If there are several people present, check whether they would like to assign a note taker and timekeeper (if not already discussed with your contact person).

## HOW WILL YOU PRESENT THE ISSUE?

Decide how you will introduce the *Guidelines* and present background information.

- > What would immediately capture their attention, a surprising statistic? A question about caregivers that relates to their sector? Briefly sharing the reason the *Guidelines* are important to you? (See slide deck for a few options.)
- > Check participants' existing knowledge prior to the meeting or check early in the meeting. For example, who is already familiar with the *Guidelines*? Could you summarize their purpose? What else do you know about them?
- > Select PowerPoint slides to provide background information on the issue. If not using slides, you might find it helpful to print out the notes page of the PowerPoint presentation as a reminder of key points.

## HOW WILL THE SECTOR RECOMMENDATIONS BE INTRODUCED AND DISCUSSED?

If you are guiding the discussion, plan how you will give everyone an opportunity to share their thoughts whether verbally or in writing. Here are some ideas.

- > (Solo) If participants have not already read the recommendations and recorded thoughts, you could give them about five minutes to do so on their own.
- > (Pairs or small groups) Consider whether there will be greater input from all participants if they have 15-30 minutes to discuss the handout questions in pairs or small groups and jot down their thoughts. You can often get more information when people work in small groups. Some people are more comfortable working in pairs/small groups and will participate more. The amount of time needed will depend on the number of recommendations to be discussed. If this option is chosen, move around the room, checking in with any group that seems confused to offer clarification. Check on the groups again after about 10-15 minutes to see whether more time is needed. When each group is finished, invite them to share their top ideas verbally or on a flipchart.

## HOW WILL THE TARGET GROUP PRIORITIZE THEIR IDEAS AND NEXT STEPS?

The target group will need to determine the criteria for identifying which ideas and actions to seriously consider implementing. Example: What will have the most impact on the most people the quickest? Or what will be most effective and most feasible within a designated time frame? Over what areas does the target group have authority or influence?

→ See Resource: [Planning Activities - Dotmocracy](#).

## CONCLUDING THE MEETING

Plan how you will end the meeting with as much clarity as the beginning. Try to provide a sense of accomplishment. Suggestions:

- > Summarize progress and any decisions made.
- > Review commitments (who will do what and when).
- > Invite suggestions for agenda items for the next meeting.
- > Make a request for action, such as, "Can I contact you in two weeks to discuss the recommendations you consider a priority?"
- > Get feedback on how well the meeting went and suggestions for next time.

## THE IMPORTANCE OF THANK YOU NOTES AND FOLLOW-UPS

Timely follow-up on your commitments from meetings is important for demonstrating professionalism, credibility and building trusting relationships. Be sure to send out meeting notes and "thank you" notes to everyone involved. Building trusting and respectful relationships will help you move the conversation forward and help you reach the desired outcome.

## 3. Case Studies

The following case studies illustrate how one person or group encouraged implementation of the *Guidelines*. They can be used to get ideas for yourself or they can be discussed with the target audience. Select the one that is best suited to the meeting participants, according to sector or stage in the process – for example, making the initial contact, follow-up, introducing the *Guidelines*, facilitating a meeting, etc.

## 3.1 Acute Care Sector

### CASE STUDY: APPROACHING A PSYCHIATRY DEPARTMENT

A family caregiver organization (FCO) put together a committee with the aim of promoting the *Guidelines* and “taking them off the shelf.” They approached a local hospital’s psychiatry department about making a presentation on the *Guidelines* at a grand round. At the end of the presentation the presenter asked if someone would be interested in joining the FCO committee to explore how the recommendations from the *Guidelines* could be further explored. A social worker volunteered and agreed to seek out other interested members from the psychiatry department who might like to join the working group. Meanwhile, the FCO committee reviewed all the *Guidelines’* recommendations and zeroed in on those that may be easier to implement in the hospital.

The two groups – the FCO committee and the hospital’s internal group – then met to get to know one another’s work and to discuss expectations and desired outcomes. Together they have identified some priority recommendations.

The joint working group decided to work on the development of “teaching sheets” for caregivers and other audiences, as well as exploring the possibility of piloting a Family Peer Support program in the hospital. Their approach was to identify two priorities; one that they could start immediately (teaching sheets) and one that they would have to work towards (Family Peer Support). They started with the recommendation that would be easiest to implement and did not carry a high cost. Successful implementation of the first one can lead to a deeper commitment to exploring the longer-term process required for the second recommendation.

- Implement strategies to facilitate system navigation inside hospital-based services such as written guides, designated contact persons, and family peer support workers.

#### Recommendation 20.2

### REFLECTION QUESTIONS

1. Which elements of this case do you see as most central to its success?
2. Who could be part of a planning team in your organization?
3. Which elements of this case do you see as possible for your organization?
4. Are there recommendations in the *Guidelines* that can be implemented right away?
5. Are there recommendations that you would like to see your organization work towards?

## CASE STUDY: A FAMILY CAREGIVER APPROACHES A HOSPITAL

Margaret has a best friend who is in the hospital involuntarily. The patient, Anna, will not talk with her mother or with Margaret. She is in and out of the hospital consistently and released voluntarily.

No doctor will talk with the mother or Margaret, leaving them with many questions. How can she and the family get information to the doctor about Anna making death threats towards others and herself? Has any doctor asked the patient if they can involve the family? What should she and the family do?

Margaret and Anna's mother were eventually able to relay their questions and concerns through various nurses to a doctor, but they left the hospital feeling frustrated, scared, and uninformed. They needed guidance from a designated ER staff member. Anna's mother had heard of the *Guidelines*, so Margaret did an internet search and found them online. She read the recommendations for acute care services and felt that any one of the six recommendations would greatly improve communication with family caregivers in the future. She asked a nurse who to speak to about it and was directed to the hospital ombudsman.

Margaret left a message, requesting an appointment to discuss recommendations in the *Guidelines* for acute care. She wrote down what she wanted to say before calling the hospital. In her voicemail, she clearly and briefly conveyed the purpose and importance of the meeting.

## REFLECTION QUESTIONS

1. Which elements of this case might resonate with you?
2. What would improve Margaret's likelihood for success in her initial discussion with the ombudsman about implementing *Guideline* recommendations for the hospital ER?
3. What information should she provide? Should she go it alone or work with another group, such as a family association?
4. Are there recommendations from the *Guidelines* that your target group might be able to implement right away?
5. Are there recommendations that you would like to see your target audience organization work towards implementing?

## 3.2 Inter-sectoral Partnerships

A family support group did a survey with all of its members, past and present. The survey asked questions about caregivers' experience supporting their loved ones in hospital, educational, and other community settings. From the information that was gathered, the support group found that their members faced significant challenges when it came to working with the local police services. They decided to put together a committee to host a discussion about improving communication and positive interaction between caregivers and the police services.

The committee made a list of possible contacts and found that they knew someone who worked as an administrative assistant at the police department. They decided the best strategy was to make initial contact through this person.

To guide their discussion, the committee set clear communication and meetings objectives, highlighting Recommendation 25 from the *Guidelines*.

After a conversation with their key contact, the committee was put in touch with the community development team at police services. Two officers from the team met with the committee. The officers were receptive to the information provided and were willing to explore ways to improve responses to caregivers, but required approval to commit more of their time to this topic. Following that meeting, the committee put together a briefing note (summary document) that the officers took to their supervisors detailing the issue and their request. Their supervisors asked that they put together a Terms of Reference before moving forward.

### REFLECTION QUESTIONS

1. What methods can be used to help identify potential audiences?
2. Do your local institutions – schools, police services, financial institutions – have community-focused programs that can be engaged?
3. If you are not involved with a caregiver organization, who could you involve in this kind of a project?
4. What are some ways that you can create an ongoing relationship rather than a one-time discussion?

- Develop or enhance mental health training programs for police officers that emphasize working with and responding to a family caregivers.  
**Recommendation 25.2**
- Support police services to develop protocols for offering support to family caregivers who witness their relative being apprehended such as referral to victim services.  
**Recommendation 25.3**
- Strike a multi- and cross-sectoral task force to translate these Guidelines into an action plan to support Canadian family caregivers of adults living with mental illness.  
**Recommendation 41**

## 3.3 Government and Policy Sector

### CASE STUDY - CAREGIVERS IN THE WORKPLACE

Michael is the single parent of an adult child who was recently diagnosed with schizophrenia. Since his daughter's diagnosis, Michael has taken time off work, sometimes on very short notice, which means he can't meet deadlines and leaves him feeling guilty about putting extra work on his team. At first he did not disclose the nature of his daughter's illness. However, the more he understands his role as a caregiver, the more he sees that situations can arise where he will need flexibility with his work in order to provide the best care possible. He's been working with this company for four years.

Michael did his due diligence and looked into all the benefits offered by his company. He found that sick days could also be used in cases where children of parents working for the company were sick, which he could use to take his daughter to appointments. Next Michael contacted his Employment and Family Assistance Plan (EFAP) where he spoke to a counsellor about his new role as a caregiver and discussed other benefits. The EFAP counsellor pointed him to his province's Employment Standards Act where he found that he was eligible for eight weeks of job protected, unpaid leave each calendar year. He was glad to know that he had that option, especially for a time when his daughter required extra help or special treatment. However, unpaid time off was not his first choice financially because of the cost of his daughter's medication. EFAP also suggested that he make time to speak with his manager to discuss workplace accommodations, such as flexible hours and working from home. Michael wasn't sure if his office did that kind of thing, so he researched workplace accommodation for caregivers. He found the *Guide to Balancing Work and Caregiving Obligations* written by the Human Rights Commission of Canada. He understood that caregiving was his right and that he should not lose his job because of his need to care for his daughter. He continued his research and found the *National Standard of Canada for Psychological Health and Safety in the Workplace*, a tool he thought his manager might need to see.

Michael met with his manager and explained his daughter's illness and some of the demands that come with it. He presented the information he had gathered and made a request for accommodation when his daughter needs him most. His manager was open to the idea of accommodation but unsure of the process, so he contacted his Human Resources manager to set up a meeting. Michael provided information from the *Standard* and the *Guide*. Over the course of two meetings Michael, his manager, and HR were able to work out a flexible schedule, a buddy system with his colleague in case he needed to leave on short notice, and ways to use his benefits for his own self-care.

More importantly, as a result of Michael's initiative, the Human Resources Manager came back to Michael a little while later, to get his input on a new company policy to better accommodate caregivers' needs.

- Encourage employers to better address caregiver needs by implementing psychological health and safety policies, such as flexible workplace policies and adopting the *National Standard on Psychological Health and Safety in the Workplace*.

**Recommendation 29**

- **See Resources for Employers for more information.**

**REFLECTION QUESTIONS**

1. What resources are available in your workplace and personal life to help you prepare to speak with your manager?
2. Who else could Michael have involved in his discussion with management? His daughter's doctor, social worker, or a caregiver organization?

## 3.4 Training and Support for Mental Health Service Providers

### **CASE STUDY: FACILITATING SUPPORT FOR CAREGIVERS IN THE HEALTH CARE SYSTEM**

A provincial schizophrenia society was concerned about the many reports from caregivers about their difficulties obtaining the appropriate information on their relatives' mental illness that would enable them to provide adequate care. They said they frequently felt excluded or dismissed by mental health providers who were unaware of – or indifferent to – their needs for information and support. They reported that they were either given no information about community resources or that the information provided was inappropriate or outdated.

The schizophrenia society contacted other organizations concerned with mental illness (e.g. Alzheimer Society, Mood Disorder, Canadian Mental Health Association) and found that they had heard similar concerns from caregivers. At issue seemed to be lack of clarity and consistency among mental health providers about the limits of confidentiality, little awareness/sensitivity to the experience and needs of caregivers, and limited knowledge about community supports for caregivers.

An interagency working group was formed to develop a strategy to address the concerns with the health regions. It was decided that recommendations in the *Guidelines* would be used as a framework for discussion with the health regions and for addressing concerns.

- Support mental health service providers in increasing their knowledge about mental health service provider privacy, confidentiality, access to information legislation, and related institutional and professional policies.  
**Recommendation 14.2**
- Provide training and support to mental health service providers to increase their knowledge of and sensitivity to family caregivers.  
**Recommendation 37.1**
- Assist and train mental health service providers in becoming knowledgeable about and sensitive to the range of relationships and associated challenges, roles, and support needs of all family caregivers.  
**Recommendation 5**
- Facilitate mental health service providers taking more time to share up-to-date information about the range of community, social, and mental health services available for adults with mental illness, including their eligibility requirements, making referrals to other services as needed and supporting family caregivers in accessing these services when and as they are needed.  
**Recommendation 2.3**

The meeting turned out to be timely and productive. The health regions acknowledged the value of caregivers and reported that they were required by the Ministry of Health (MOH) to develop Caregiver Action Plans to support caregivers.

At the close of the meeting it was decided that representatives from the working group would participate in the development of the Caregiver Action Plans; the working group member organizations would provide information about their services to the health regions for distribution; together the health regions and working group would develop a series of webinars, aimed at increasing the awareness of health care providers about the experience of family caregivers and their support needs; and the MOH, health regions, public trustee and working group members would develop a protocol for providing information to caregivers.

### **REFLECTION QUESTIONS**

1. Which elements of this case do you see as most central to its success?
2. Which elements of this case do you see as possible for your organization?
3. Who could be part of a strategy team in your organization?
4. Which recommendations in the *Guidelines* would you want to see implemented right away?
5. Are there recommendations that you would like to see your organization work towards?

### 3.5 Integrating Family Support into Mental Health Services: General

At 19, Moe and Maya's son, Jay, was diagnosed with a severe and persistent mental illness. For the first couple of years following Jay's diagnosis, Moe and Maya felt overwhelmed with information about treatments, medication, and simply trying to manage the day to day; there never seemed to be any time to plan for the future. Eventually Moe and Maya realized that they would need to start planning for their retirement and for Jay's future. They decided to contact Jay's social worker to get advice on where to find help for themselves and how to start planning. Jay's social worker couldn't provide them with direct services, but was able to refer them to a local mental health service organization.

Moe and Maya met with a representative from a local mental health service organization, but they found there was no clear-cut path and the organization's resources to support them were limited. Moe and Maya knew that Jay needed housing and financial support and that there were financial and legal considerations too. The representative referred them to a family caregiver support group. Through the family support group they met other family members who had either been through, or were going through similar experiences. Through group members, they got the name of a good financial planner to help them develop a financial plan and look at life insurance. Then they were referred to a lawyer to help them revisit their will, identify Power of Attorney, and after consultation with Jay and other family members, they decided to set up a Henson Trust. Finally, with Jay, they began looking into supportive housing options.

Moe and Maya saw the value of putting their knowledge and experiences into a shareable resource for other families. Together with members of the support group, they decided to approach the coordinator of the support group to explore the possibility of working with the mental health service organization to develop a resource on personal and financial planning. Specifically they wanted to highlight the best resources in their community.

The group first determined what they needed to ask in a summary document. Then, through the support group coordinator, they set up a meeting with the organization's leadership. After presenting their proposal to leadership they gave the summary document as a leave-behind. Moe and Maya followed up a week later and received good news; the organization would provide their group with a small budget for layout and printing and the support group coordinator would be their liaison for the process.

- Develop information and tools for family caregivers on personal and financial planning. Encourage families to engage in this kind of planning as early as possible and provide them with support to do so at various points of service such as family caregiver organizations and notary offices.

**Recommendation 30**

**REFLECTION QUESTIONS**

1. Where do opportunities exist for you or your organization to share knowledge and experience about future planning for caregivers?
2. Aside from mental health organizations, are there other points of service that could be providing legal, financial, or future planning information to caregivers?
3. Are there other tools that might be useful to caregivers as they start to plan for the future?

- **See Resources for Future Planning**

## 4. Supporting Resources

### 4.1 Research on Caregiving

**“Family caregiving: What are the consequences?”** *Insights on Canadian Society*. September. (2013) Turcotte, Martin. Statistics Canada.

Downloadable PDF: <http://www.statcan.gc.ca/pub/75-006-x/2013001/article/11858-eng.htm>

This study uses new data to shed light on all family caregivers aged 15 and over in Canada. It examines data associated with caregiving responsibilities, exploring whether some types of caregivers are more likely to experience psychological, social, or financial consequences and why.

**Canadian Caregiver Coalition** is a virtual alliance of diverse partner organizations that work collectively, and autonomously, to identify and respond to the needs of caregivers in Canada. They offer research, resources, and supports for caregivers across Canada.

<http://www.ccc-ccan.ca/index.php>

### 4.2 Resources for Employers

**Guide to Balancing Work and Caregiving Obligations:** *Collaborative Approaches for a Supportive and Well-performing Workplace*. (2014). Canadian Human Rights Commission.

Downloadable PDF: <http://www.chrc-ccdp.gc.ca/eng/content/guide-balancing-work-and-caregiving-obligations>

This online guide offers employers and employees practical tips on what to do when an employee’s family caregiving and work responsibilities come into conflict.

**Toolkit for Employers:** *Resources for Supporting Family Caregivers in the Workplace*.

Downloadable PDF: <http://www.fcns-caregiving.org/education/supporting-family-caregivers-in-the-workplace/toolkit-for-employers-resources-for-supporting-family-caregivers-in-the-workplace/>

This toolkit was designed to provide both employers and employees with information and resources to help minimize the impact of caregiving on both the employee and the workplace.

***When Work and Caregiving Collide: How Employers Can Support Their Employees Who Are Caregivers - Employer's Resource Toolbox.*** Employment and Social Development Canada.

To view the Employer's Resource Toolbox visit: [http://www.esdc.gc.ca/eng/seniors/reports/cec.shtml?\\_ga=1.258564745.2085633141.1428432445#h2.10](http://www.esdc.gc.ca/eng/seniors/reports/cec.shtml?_ga=1.258564745.2085633141.1428432445#h2.10)

Following Budget 2014, the Government of Canada launched the Canadian Employers for Caregivers Plan to explore ways to help employee caregivers participate as fully as possible in the workforce. Through this initiative an inventory of employer-led, flexible workplace practices supporting employed caregivers was developed.

***National Standard of Canada for Psychological Health and Safety in the Workplace***

For more information and to download the *Standard* visit: <http://www.mentalhealthcommission.ca/English/node/5346>

Championed by the Mental Health Commission of Canada, and developed by the Canadian Standards Association and the Bureau de normalisation du Québec, the *Standard* is a voluntary set of guidelines, tools, and resources focused on promoting employees' psychological health and preventing psychological harm due to workplace factors.

## 4.3 Resources for Policy Makers

**Caregivers Toolkit – Caregivers Policy Lens.**

Website: <http://caregivertoolkit.ca/>

This website is full of useful resources and information for anyone concerned with the needs of caregivers of older adults. For policy makers, the Caregivers Policy Lens is a user-friendly tool to inform the development of policies and programs that integrate and reflect caregivers' values and concerns. It is an evidence-informed, principle-based, analytical framework for reviewing and developing policies that affect caregivers, from their perspective, and in order to avoid any unintended negative effects on them.

**Mental Health Commission of Canada.** (2012). *Changing Directions, Changing Lives: the Mental Health Strategy for Canada.* Calgary, AB.

This *Strategy* is about improving mental health and wellbeing for everyone and creating, together, a mental health system that can truly meet the needs of people of all ages living with mental health problems and illnesses and their families. The *Strategy* tackles a broad range of issues and presents many recommendation for change.

## 4.4 Facilitation

**Great Meetings! How to facilitate like a pro.** (1997). Kelsey, Dee and Pam Plumb.

A clear, user-friendly resource book on planning and facilitating a great meeting. Much of the information applies to facilitating a training session, as well.

**Great Meetings! Great Results: A Practical Guide for Facilitating Successful, Productive Meetings** (2013). Kelsey, Dee.

A practical, downloadable e-book by the one of the authors of the original *Great Meetings!*

**Participatory Approaches: A facilitator's guide.** (2009). VSO.

Available on many websites: <http://community.eldis.org/.59c6ec19/>

Free downloadable PDF in three parts. Part 1 has valuable tips for new facilitators who wish to ensure that all participants have a voice in a process. Part 2 describes methods of each stage of a project or program and is less relevant to this toolkit. Part 3 offers 47 very useful, clearly written, participatory activities that can be used in meetings or training sessions.

**The Skilled Facilitator Fieldbook.** (2005). Roger Schwarz et al.

Very thick (3cm) reference book full of in-depth information on the authors' *Skilled Facilitator* approach, tools, exercises, models, and stories that will help you respond to challenging situations. Recommended for readers who do a great deal of process facilitation and would like to fine tune their knowledge and skills.

### **Dotmocracy**

Website: <http://dotmocracy.org>

Free downloadable information and cards for decision-making in large groups.

## 4.5 Support Services for Caregivers

This section provides links to a few key caregiver resources by province and territory.\* Many of these organizations provide direct support to caregivers and their loved ones who are living with mental health problems or illnesses. They may also be great starting points for networking and collaboration. This list is illustrative of gateway types of organizations available but not a comprehensive list.

### **ALBERTA:**

Alberta Health Services compiled a list of caregiver resources from across the province. See the Condition-Specific Resources for Caregivers.

<http://www.albertahealthservices.ca/ev/ne-ev-2010-10-4-8-mental-illness-week-caregiver-resource-list.pdf>

### **BRITISH COLUMBIA:**

Mental health care providers across the province partnered to create *Here to Help*. A site that provides information about mental health and substance use and links to partner organizations. Here to Help - <http://www.heretohelp.bc.ca>

Schizophrenia Society of British Columbia is also a gateway to family support groups in the province: <http://www.bcscs.org/category/branches>

### **MANITOBA:**

The province developed a site for healthy living and seniors that identifies mental health services available throughout the province and includes a list of self-help and community support organizations in the province.

<http://www.gov.mb.ca/healthyliving/mh/system.html>

### **NEW BRUNSWICK:**

Capital Region Mental Health and Addictions Services <http://www.crmhaa.ca> offers a gateway to information and resources in the capital region and beyond. It also runs FAMI, a group of friends and family members who have a relative or friend with a mental illness.

### **NEWFOUNDLAND AND LABRADOR:**

*Caregivers Out of Isolation* has a well-developed resource section with links to specific resources for caregivers or people living with mental health problems and illnesses. <http://www.caregiversoutofisolationnl.ca>

The government's mental health web page is also a good source of resource links, including lists of community partners.

[http://www.health.gov.nl.ca/health/mentalhealth/community\\_partners.html](http://www.health.gov.nl.ca/health/mentalhealth/community_partners.html)

### **NORTH WEST TERRITORIES:**

The Government of NWT's Mental Health and Addictions Community Counselling Program is the gateway to services and resources in the Territory. <http://www.hss.gov.nt.ca/social-services/mental-health-and-addictions/addictions-where-get-help/what-community-counselling-program>

See also: <http://www.hss.gov.nt.ca/sites/default/files/mental-health-where-to-get-help.pdf>

### **NOVA SCOTIA:**

Capital District Health Authority developed a guide for family and friends of people living with mental illness. [http://ourhealthyminds.com/family-handbook/Family\\_Handbook.pdf](http://ourhealthyminds.com/family-handbook/Family_Handbook.pdf)

Mental Health Nova Scotia offers links to resources and organizations across the province. <http://novascotia.ca/dhw/mental-health/finding-help.asp>

### **NUNAVUT:**

The government offers an online gateway to information about mental health services at <http://gov.nu.ca/health/programs-services/mental-health>

You can also find resources through the Nunavut Community Information Database. <http://thunderbay.cioc.ca/?UseCICVw=45>

### **ONTARIO:**

eMental Health is an online database of a wide range of mental health resources. [www.ementalhealth.ca](http://www.ementalhealth.ca)

Centre for Addiction and Mental Health operates Portico, which is a network of addiction and mental health sites from across Canada. <https://www.porticonetwork.ca>

Four of the key family caregiver networks and support organizations in Ontario are:

- > The Ontario Family Advisory Council Network which links family advisory councils from psychiatric institutions across Ontario. You can reach them by calling your nearest Psychiatric Hospital (e.g. Ontario Shores, the Royal, etc.).
- > Mental Illness Caregivers Association of Canada. <http://www.micaontario.com>
- > Family Outreach & Response Program is devoted to helping families achieve recovery for their loved ones. <http://familymentalhealthrecovery.org>
- > Canadian Mental Health Association of Ontario provides a list of resources for Caregivers. <http://ontario.cmha.ca/mental-health/services-and-support/support-for-families-and-caregivers/>

#### **PRINCE EDWARD ISLAND:**

PEI Ministry of Health offers a list of provincial and community mental health services and links to community organizations.

<http://www.healthpei.ca/mentalhealth>

#### **QUEBEC:**

Federation of Families and Friends of People Living with Mental Illness (FFAPAMM) provides a membership list to find local members of their largely francophone network of family support organizations.

<http://www.ffapamm.com/associations-membres/nos-membres>

AMI-Quebec is the leading resource for English speaking families in Quebec.

<http://amiquebec.org/family-support/>

#### **SASKATCHEWAN:**

The Saskatchewan Mental Health Coalition brings together health agencies, families and individuals. See their member organizations as a gateway to resources for families in the province.

<http://www.saskmentalhealthcoalition.ca/members.htm>

#### **YUKON:**

Yukon mental health services web site offers links to a number of resources and information about services in the Yukon, including a family caregiver support group.

[http://www.hss.gov.yk.ca/mental\\_health.php](http://www.hss.gov.yk.ca/mental_health.php)

\* This list is not exhaustive but is meant to provide a starting point for caregivers seeking resources and connections.

## 4.6 Resources for Future Planning

Although not specific to mental health or mental illness, the “Special Needs” Planning Group website offers detailed information about financial planning and tax benefit information.

<http://www.specialneedsplanning.ca/index.html>

AMI Quebec has also developed a comprehensive document for financial and legal planning in Quebec:

[http://amiquebec.org/wp-content/uploads/2013/02/Care\\_En.pdf](http://amiquebec.org/wp-content/uploads/2013/02/Care_En.pdf)

Social assistance, employment assistance, income assistance, and disability support programs, are provincially and territorial administered so it is recommended that caregivers visit their provincial or territorial website.



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[in/Mental Health Commission of Canada](https://www.linkedin.com/company/mental-health-commission-of-canada)