



Mental Health
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Commission de
la santé mentale
du Canada

Summary

Building on a Strong Foundation: A Review and Environmental Scan of the Uptake of the *National Guidelines for a Comprehensive Service System to Support Family Caregivers of Adults in Mental Health and Addiction*

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Table of Contents

INTRODUCTION	2
WHO ARE CANADA’S MENTAL HEALTH & ADDICTIONS CAREGIVERS?.....	2
RISKS ASSOCIATED WITH FAMILY CAREGIVING	4
COPING AND CAPACITY	4
INTERVENTIONS AND BEST PRACTICES	4
HOW ARE THE GUIDELINES HELPING FAMILY CAREGIVERS?	5
<i>Implementation of Guidelines</i>	6
<i>Promising Practices</i>	6
THEMES EMERGING FROM THE SURVEY RESPONSES.....	7
BUILDING ON OUR STRONG FOUNDATION: RECOMMENDATIONS TO INCREASE THE GUIDELINES’ IMPACT.....	8



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Introduction

Families play a critical role in supporting people living with mental health problems and illnesses. The emotional support and physical care they provide saves the health system millions of dollars annually. However, their contribution can come at a high personal cost. Family caregivers, sometimes referred to as carers or caregivers, are defined as all those in the circle of care, including family members and other significant people who provide unpaid support to a person living with a mental health problem or illness¹. Caregivers often experience high rates of depression, financial burden, and social isolation². For every person living with a mental health problem or illness, there is a family member who may be living with a burden of chronic stress. Simply put, caregiving can be all-consuming. Family caregivers need support.

In 2013, the Mental Health Commission of Canada (MHCC) issued the [National Guidelines for a Comprehensive Service System to Support Family Caregivers of Adults with Mental Health Problems and Illnesses \(The Guidelines\)](#). The Guidelines include 41 recommendations that fall into 5 distinct categories, describing the many different supports, services, and policies caregivers need at different stages of their loved one's illness, and at different stages of their own lives.

In 2017, the MHCC asked a research team made of Dr. Simon Coloumbe from Sir Wilfred Laurier and Shaleen Jones from Peer Support Canada and Michelle Hebert Boyd from Eating Disorders Nova Scotia and independent researcher, to undertake an environmental scan of and assessment of stakeholder experiences implementing recommendations from the Guidelines. MHCC wanted to know how the Guidelines were being used, to identify barriers to their implementation, and to suggest recommendations to move the work forward. The review was conducted between August and October 2017 and included a survey of stakeholders, an environmental scan, and a literature review. This document summarizes the findings of the team's review.

¹ MacCourt P., Family Caregivers Advisory Committee, Mental Health Commission of Canada. (2013). National Guidelines for a Comprehensive Service System to Support Family Caregivers of Adults with Mental Health Problems and Illnesses. Calgary, AB: Mental Health Commission of Canada.

² Sinha, M. Portrait of Family Caregivers. (2012). Statistics Canada.

Who Are Canada’s Mental Health & Addictions Caregivers?

An estimated 550,000 Canadians care for persons living with mental health problems, and 30,000 assist someone living with an addiction.

Caregivers in mental health and addictions are:	
Female	Women feel pressure to take on caregiving roles, especially for more complex care. Male carers are more likely to feel they had a choice, and have a sense of pride or accomplishment for taking on the role. Perhaps as a result, male caregivers report fewer depressive symptoms and less distress than female caregivers ³ .
Family members	18% of caregivers are sons or daughters, and 13% are siblings. 24% are friends or neighbours.
Young	<p>Compared to caregivers for other health concerns, caregivers of persons living with mental health or addictions issues are relatively young. They are likely to be balancing caregiving with school and/or employment, while also caring for other family members.</p> <p>The people they are caring for are also relatively young – 47% are under the age of 44, compared to just 10% of people receiving care for other health issues.</p> <p>Canada is expected to see an increase in young caregivers due to an aging population, an increasing proportion of children born to older parents, increasing numbers of multi-generational homes, and a growing tendency for long-term care to be provided in the home by family caregivers. Despite this, the literature review found only three programs dedicated to young caregivers in Canada.</p>
Diverse (but we need to hear their stories and support them better)	There is a need for more study and support of culturally sensitive and appropriate caregiver services. Being part of historically marginalized groups can lead caregivers to distrust and avoid “mainstream” services. More investigation is needed into supports for refugee caregivers, who may be extremely isolated due to culture-bound stigma and trauma. There was a significant lack of attention to the needs and experiences of Black or African Canadian caregivers, and none of the literature reviewed considered the experiences or needs of LGBTQ caregivers.

³ Sinha, M. Portrait of Family Caregivers. (2012). Statistics Canada.

Risks Associated with Family Caregiving

Caregiving, in general, increases the risk of emotional difficulties and physical, psychological, and financial stress⁴. Mental health and addiction caregivers are more likely to report depression compared to caregivers of other conditions. They are also more likely to report that they feel tired; worried or anxious; overwhelmed; lonely or isolated; short-tempered or irritable; resentful; and that they experienced loss of appetite or disturbed sleep because of their caregiving responsibilities. A longitudinal study from the Netherlands found that about 40% of caregivers showed symptoms of depression within a two-year period, and about one-eighth of participants reported suicidal thoughts⁵.

The level of stress, and the supports available to caregivers, may vary according to the diagnosis of the person for whom they're providing care. The majority of research into family caregivers, particularly in Canada, focuses on caregivers of people living with dementia. More research is needed into the risks associated with caregiving in other mental health and addiction contexts.

Abuse toward caregivers of people living mental health and addiction problems is likely an under-reported and under-addressed issue in Canada, in part likely due to stigma. Women caring for men are at greater risk of physical or sexual assault by their male spousal care recipient.⁶

Coping and Capacity

Certain protective factors, coping skills, and supports may help family caregivers manage the stress of their role. Higher emotional intelligence and a stronger sense of connection to community are two factors that help caregivers cope with stress better. Caregivers' personality characteristics, emotional intelligence, and history of childhood maltreatment should be assessed in order to tailor support programs to their needs⁷.

Interventions and Best Practices

Some intervention is likely to be better than no intervention, and different interventions are more or less effective for particular outcomes. However, the literature does not indicate that there is one "best" intervention to support caregivers. The literature focussing on interventions

⁴ Sinha, M. Portrait of Family Caregivers. (2012). Statistics Canada.

⁵ Joling, K. J., O'Dwyer, S. T., Hertogh, C. M. P. M., & Hout, H. P. J. (2017). The occurrence and persistence of thoughts of suicide, self-harm and death in family caregivers of people with dementia: A longitudinal data analysis over 2 years. *International Journal of Geriatric Psychiatry*. <https://doi.org/10.1002/gps.4708>

⁶ Band-Winterstein, T., Avieli, H., & Smeloy, Y. (2015). Harmed? Harmful? Experiencing Abusive Adult Children With Mental Disorder Over the Life Course. *Journal of Interpersonal Violence*, *31*(15), 2598–2621. <https://doi.org/10.1177/0886260515579505>

⁷ Weaving, J., Orgeta, V., Orrell, M., & Petrides, K. V. (2014). Predicting anxiety in carers of people with dementia: the role of trait emotional intelligence. *International Psychogeriatrics*, *26*(7), 1201–1209. <https://doi.org/10.1017/S1041610214000404>

skews heavily towards interventions for caregivers of people living with dementia and seldom considers differences in culture, gender or sexual orientation, even though the majority of caregivers are women. Given that Canada's population is among the most diverse in the world, interventions to support family caregivers in Canada need to take cultural and linguistic diversity into consideration.

In general, mental health and addiction caregivers are more likely to need emotional support, such as professional counselling, than caregivers for individuals living with other health issues. In addition to traditional counselling techniques, the literature identified other promising caregiver interventions and supports which include:

- Support groups that provide space for caregivers to share their experience and practical information with others who may be experiencing a similar situation;
- Online and telehealth options that can increase access (especially for rural caregivers), decrease cost, and combat social isolation – these are particularly popular among younger caregivers;
- Photo-based materials which can be useful for caregivers with low literacy;
- Mindfulness, meditation, and yoga as stress relief interventions are growing in popularity

It should be noted that this literature review only turned up 14 Canadian articles published between 2013 and 2017 that looked at interventions that were not related to dementia. Furthermore, to the knowledge of the research team and MHCC staff, there are many interventions currently used to support family caregivers that did not show up in the recent literature. This may indicate that research activity in this area is limited and may warrant further exploration.

How are the Guidelines being used?

An online survey was sent to 3500 stakeholder agencies, groups and agencies who provide mental health services and /or family caregiver services across Canada between September 14-30, 2017. 209 responses were received. Respondents represented 11 provinces and territories. Ontario had the most responses. No responses were received from Yukon or Nunavut.

Even though the response rate was relatively low, the responses provide some insight into the uptake of the Guidelines to date. 38% of respondents indicated they were aware of the Guidelines prior to receiving the online survey. Over one-third of respondents indicated they work in community or unspecified settings. 25% worked in clinical settings. Only 2% worked in a policy setting.

Some respondents identified themselves as champions of the Guidelines. They spoke of advocating for their implementation and working to make peers aware of them. However, individuals and community organizations often feel they are met with resistance when they advocate to health system partners for implementation of recommendations from the

Guidelines. Those working within the system also expressed frustration that their colleagues do not seem to want to implement, or in some cases even hear about, the Guidelines.

Implementation of Guidelines

Respondents were asked to review the 41 recommendations, and indicate for each whether it had been implemented, not implemented, or would be implemented in the future.

Implementation rates were highest for recommendations in the General category, which apply to multiple settings and types of work. For example, the most implemented recommendation was:

Provide family caregivers with timely access to appropriate education that responds to their needs at different stages in the illness and caregiving trajectories. (implemented by 30% of respondents)

Implementation rates were lowest for recommendations that require system-level change and cross-sector collaboration. The least-implemented recommendation was:

Designate, and make available at all times, an emergency room-based staff member who can assess the person who may have a mental illness and provide guidance to family caregivers. (implemented by 3% of respondents)

Guidelines in the **Government & Policy** and **Acute Care** categories had the lowest implementation rates. The low implementation rates, and the lower survey participation rates from people working in these settings, indicate that more needs to be done to connect with policy and acute care settings.

Promising Practices

Survey respondents were asked to describe the practical, innovative and cost-effective work they are doing to support family caregivers, including:

- Supporting the mental health of family caregivers;
- Engaging families, and;
- Supporting access to information for families.

In general, promising practices related to **supporting the mental health of family caregivers** fell into four themes:

Conferences/workshops: *[We host an] annual regional consumer and family conference that offers a variety of workshops which include self-care topics and educational sessions and provides a social evening event; transportation, meals, accommodations are provided.*

Creative & self-care tools and events: *[We host a] "night of celebration" which showcases the successes of families and individuals.*

Online services: *Our Online Educational Speakers Series has been very well received and we have had family members who live in other countries take part to get information in order to better assist their loved one here.*

Walk-in services: *One of our many little programs is the "EAT" (Extending a Tummy) which is partnered with a local restaurant who provides food during their operating hours into the night and allows people to sit inside, this helps reduce stigma and creates another branch of trust without walking in to a service provider as some refuse.*

Promising practices related to **family engagement** were harder to define. While a few respondents (7%) mentioned family advisory committees as a way to include and engage family caregivers, most respondents interpreted 'engagement' to mean activities meant to support caregivers. Work could be done to more clearly articulate core elements of family engagement.

Examples of promising practices that **support access to information and support for family caregivers** focused on system and resource navigation, or distribution of information.

Themes Emerging from the Survey Responses

There is tension over roles in implementing the Guidelines.

Many respondents expressed concern that the bulk of the work to implement recommendations from the Guidelines seems to be falling on community and family, and that there is only so much they can do to influence change.

Change management and consultation are key.

Respondents felt that too often, decisions about how and when to involve and support family caregivers are made from the top down, with little consultation. People involved in all aspects of the system (leadership, front line, and service users) have a great deal to learn from each other. There are positive examples to build on.

Family caregivers should be respected and integrated as part of the care team.

There is a disconnect between the desire to involve family caregivers, and how that actually happens in practice. System-level respondents state they find it challenging to engage families and incorporate them in service planning or as part of the care team. Family caregivers stated they should be included as partners from early stages of planning, and not simply asked to sit at a table once decisions have been made.

We need to define what we mean by "meaningful engagement" of family caregivers.

The survey showed that "family engagement" is a poorly understood concept.

Groups are challenged to identify and offer appropriate respite services.

One of the recommendations with the lowest implementation rate pertained to creating and offering a variety of respite options to meet the varied needs of family caregivers. Providers and caregivers need more coordinated dialogue about what types of respite are helpful and accessible.

Ongoing dialogue is needed to better understand the caregiver experience.

The diversity of lived experience and the needs of diverse groups of caregivers (e.g. racialized, LGBTQ, Indigenous, etc.) must be better reflected and shared.

Building on our Strong Foundation: Research Team Recommendations to Increase impact of the Guidelines'

The Guidelines were developed through extensive consultation, and helped to create a picture of what caregivers felt they needed to provide optimal support to their loved one while minimizing the risk to their own wellbeing. Full implementation of the Guidelines is a tall order, yet they provide a roadmap for a more responsive mental health system of the future. A comprehensive service system that supports family caregivers would value the role of caregivers, support them to have a greater voice, and include them as key partners in planning and service delivery. The shift is underway, but more can be done across sectors and through partnership with stakeholders to increase the Guidelines' reach and impact. Based on the findings in the literature review and the results of the survey, the research team compiled a list of recommendations to increase the uptake and impact of the Guidelines.

Celebrate the successes.

Sharing highlights of how the Guidelines are being used is a great way to increase awareness of the guidelines, to promote their implementation and educate stakeholders about good practices.

Identify champions across sectors, regions and setting.

Identifying and supporting individuals or groups to step up as champions could help people see themselves in the work. Peer to peer knowledge sharing can be very effective, so identifying champions in across the country could improve uptake regionally.

Identify and support 'bridge people'.

Some people have experience and skills working across different sectors and with different parts of the public policy process. These are the "bridge people" who can help to build the link between family/community experience and policy makers. Bridge people help communities and policy makers to access each other and to find common ground.

Reach out to policy-makers to identify their needs and perceived obstacles.

Key policy and government sector partners should be identified and interviewed to gather experiences and ideas around working with inter-sectoral partners to implement the Guidelines.

Create and support mechanisms to help partners listen to each other.

While the Guidelines provide a useful map to describe where we need to go, partners need a vehicle to get them to the final destination. Creating opportunities to bring partners from all sectors together is important.

Reframe the idea of 'engagement' to 'partnership'.

Because 'engagement' means different things to different people, it may be helpful to reframe the concept in clearer terms. Partnership with family caregivers.