



Mental Health
Commission
of Canada

Commission de
la santé mentale
du Canada



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

SUMMARY

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The Guidelines are available at www.mentalhealthcommission.ca

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INTRODUCTION


These *National Guidelines for a Comprehensive Service System to Support Family Caregivers of Adults with Mental Health Problems and Illnesses* present a comprehensive, principle-based and evidence-informed system of care that supports family caregivers so they can provide the best possible care to adults living with mental illness while maintaining their own well-being.

The Guidelines are intended to advise system 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.

Please note that while these recommendations are applicable to family caregivers of anyone with a mental illness, the focus is on those who care for adults; issues specific to seniors or children and youth are discussed within other documents that are available at www.mentalhealthcommission.ca. This document also does not examine specific issues related to family caregivers of adults with acquired brain injury or living with addictions, but many of the recommendations may be relevant to them.



BACKGROUND AND DEVELOPMENT OF THE GUIDELINES



Caregivers fulfill a distinct and important role by providing support and advocating for persons living with a mental illness, 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 the family caregivers themselves. Inadequate recognition and support for caregivers may generate significant emotional, physical, financial and social burdens. When these situations create chronic stress for family caregivers, they too often become “collateral casualties” of mental illness. These Guidelines acknowledge many of the concerns family caregivers face and offer recommendations for supports that can mitigate the stressors often associated with caregiving.

The development of these Guidelines was overseen by a steering committee that included members of the Mental Health Commission of Canada’s Family Caregivers Advisory Committee, other stakeholder representatives and Commission staff. In June and July 2012, focus groups were held in six cities across Canada with family caregivers, adults living with mental illness, service providers and representatives from not-for-profit mental health organizations. Participants met to discuss their own caregiving experiences and share feedback about an early proposed draft of these Guidelines; their feedback is an integral component of the Guidelines and quotations from participants have been included. A literature scan was also performed on Canadian academic journals, grey literature and policy documents, as well as literature from Australia, New Zealand, the United Kingdom and the United States, with relevant national and international examples included in the Guidelines.



GUIDELINE CONTENT

The full document has been organized into two separate sections:

SECTION I: BACKGROUND AND CONTEXT

Section I explains the purpose and organization of the Guidelines as well as the process used to develop the document. It also explores caregiving in the context of mental illness, outlining who family caregivers are, what they provide, how well their needs have been met and why they should be supported.

SECTION II: COMPREHENSIVE APPROACH FOR FAMILY CAREGIVER SUPPORT

Section II lists the principles and values that need to inform policies that affect family caregivers, contextual issues to consider when planning services, and what supports need to be in place for family caregivers both within and outside of the mental health system. This section also includes all recommendations (in blue boxes) and promising national and international examples (in green boxes).

RECOMMENDATIONS

The Guidelines include 41 recommendations, found throughout the second section of the document. To support readers in locating the recommendations most relevant to their interests, they have been grouped here and in the Appendix of the full document in five broad categories in the tables that follow:

- Integrating Family Support into Mental Health Services (General, Acute Care Services, Community/Ongoing Care)
- Training and Support for Mental Health Service Providers
- Government and Policy
- Intersectoral Partnerships
- Public Awareness

To read the recommendations in context, the page numbers can be found to the left of each recommendation.

INTEGRATING FAMILY SUPPORT INTO MENTAL HEALTH SERVICES: GENERAL

- R 7 (p.18):** At each contact with the mental health system, require service providers to assess the needs of family caregivers and encourage them to become appropriately engaged in their relative's care.
- R 8 (p.20):** Provide family caregivers with timely access to appropriate education that responds to their needs at different stages in the illness and caregiving trajectories.
- R 9 (p.20):** Make evidence-based family psycho-education programs that are delivered by skilled facilitators widely available. Inform family caregivers about these programs and encourage them to participate.
- R 11 (p.21):** Expand access to evidence-based family therapy from certified and regulated clinicians when needed.
- R 12 (p.22):** Make access to family caregiver associations available in all communities and ensure that they receive funding that reflects their role as a key source of support for family caregivers.
- R 13 (p.23):** Require service providers to include family caregivers in treatment planning where appropriate.
- R 16 (p.25):** Assist family caregivers by routinely using validated instruments to identify and assess their needs and help them to develop self-care plans based on this assessment.
- R 21 (p.29):** At the time of initial diagnosis by a mental health service provider, provide timely information relevant to each stage of the mental illness to caregivers and include information about the illness trajectory, evidence-based treatment options, privacy laws, services available and guidance on supporting recovery. Emphasize self-care for the caregivers.
- R 22 (p.29):** Require mental health inpatient and outpatient services to improve the provision of information about the availability of psycho-education programs and encourage family members to participate in these programs.
- R 30 (p.36):** 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.
- R 38 (p.41):** Develop a dedicated family coordinator role, within or outside of the hospital system, to plan, develop and coordinate family support services where possible, and build the capacity of mental health services to recognize and meet family caregivers' needs.

INTEGRATING FAMILY SUPPORT INTO MENTAL HEALTH SERVICES: ACUTE CARE SERVICES

- R 19.1 (p.28):** 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.
- R 19.2 (p.28):** Provide up-to-date information in all emergency rooms in various formats describing support resources for both the person living with mental illness and their family caregivers.
- R 20.1 (p.29):** Create and assign family peer navigator positions for admission and emergency areas with the role of providing direct guidance and information to family caregivers.
- R 20.2 (p.29):** Implement strategies to facilitate system navigation inside hospital-based services such as written guides, designated contact persons and family peer support workers.
- R 24 (p.30):** Establish protocols in hospitals for a clear process of involving family caregivers in discharge and follow-up care plans, including guidance about relapse, crisis prevention, and a recovery plan for both the person with the mental illness and the family caregiver(s).
- R 25.1 (p.32):** Engage families, where applicable, in the discussion around using a Community Treatment Order.

INTEGRATING FAMILY SUPPORT INTO MENTAL HEALTH SERVICES: COMMUNITY/ONGOING CARE

- R 4 (p.16):** Provide telephone and online services to support family caregivers in rural and remote geographic areas, or wherever local service capacity is limited.
- R 15 (p.25):** Encourage and facilitate the development and use of advance directives by the person living with mental illness, in collaboration wherever possible with their family caregivers.
- R 26 (p.33):** Provide a variety of respite options in the community that can be tailored to family caregiver preferences.

TRAINING AND SUPPORT FOR MENTAL HEALTH SERVICE PROVIDERS

- R 2.2 (p.14):** Make current information related to mental illness available in a range of formats (e.g., online, print, face-to-face) that takes into account diversity (e.g., level of education, mental health literacy, geographic location, language, culture).
- R 2.3 (p.14):** 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.
- R 3 (p.15):** Provide education and tools to support mental health clinicians in practicing culturally competent care, and provide access to cultural consultations when assessing or providing support to family caregivers in other ethno-cultural groups.
- R 5 (p.17):** 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.
- R 10 (p.21):** Make expert consultation available to mental health service providers when required.
- R 14.1 (p.24):** Develop and implement clear protocols for providing necessary information to family caregivers and require mental health service providers to follow them.

- R 14.2 (p.24):** 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.
- R 14.3 (p.24):** Require mental health service providers to routinely encourage the involvement of families, while respecting the confidentiality and privacy of the relative living with mental illness.
- R 14.4 (p.24):** Where a relative chooses not to involve family caregivers, ensure that the reasons are explored, discussed and documented, and service providers provide general information about the trajectory of the illness, common symptoms and management of symptoms so that the caregiver has the basic information required to support the family member without compromising confidentiality.
- R 17.1 (p.27):** Provide more support and training to family physicians in screening, early identification of mental illness and linking their clients living with mental illness and their family caregivers to appropriate services.
- R 18 (p.28):** Develop standards and procedures that include protocols for mental health service providers on reaching out to family caregivers to assess their needs and to offer options for support and care.
- R 36 (p.40):** Develop practice guidelines on working with family caregivers and incorporate them into mental health service provider training.
- R 37.1 (p.41):** Provide training and support to mental health service providers to increase their knowledge of and sensitivity to family caregivers.

GOVERNMENT AND POLICY

- R 1 (p.12):** Design policies and programs that encompass the values and needs of family caregivers with the help of available tools such as the Caregiver Policy Lens.
- R 28 (p.35):** Undertake a systematic review of all existing government financial supports across jurisdictions to assess gaps for caregivers and to develop policy options for closing these gaps in consultation with family caregivers.
- R 29 (p.36):** 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.
- R 31 (p.37):** Invite family caregivers to participate in reviewing existing mental health services, identifying gaps and designing plans to address these gaps with policy designers and mental health service administrators.
- R 32 (p.37):** Facilitate the meaningful participation of family caregivers in planning and evaluating services by providing orientation, education and encouragement as needed.
- R 33 (p.38):** Develop caregiver recognition legislation in all provinces and territories
- R 34 (p.39):** Allocate appropriate resources through governmental and non-governmental organizations and agencies to allow family caregivers to participate in the planning of policies related to the development of mental health practice standards and programs.
- R 35 (p.39):** Explicitly recognize the value of caregiving in provincial, territorial and regional mental health services through strategic plans and adequate resource allocations to family caregiver support programs.

INTERSECTORAL PARTNERSHIPS

- R 2.3 (p.14):** 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.
- R 6 (p.17):** Put in place partnerships between mental health service providers, and school and child welfare agencies to determine and coordinate the support needs of young carers and the adult living with mental illness.
- R 23 (p.30):** Increase the availability of prevention and early intervention programs that recognize and appropriately involve families.
- R 25.2 (p.32):** Develop or enhance mental health training programs for police officers that emphasize working with and responding to family caregivers.
- R 25.3 (p.32):** Support police services to develop protocols for offering support to family caregivers who witness their relative being apprehended such as referral to victim services.
- R 27 (p.34):** Increase awareness about financial support programs, eligibility criteria and appeal processes provided by government agencies through public education aimed specifically at caregivers and health care providers.
- R 37.2 (p.41):** Increase community capacity to support family caregivers by sharing knowledge, skills and educational opportunities among family caregiver organizations and community organizations that serve those living with mental illness.
- R 39 (p.42):** Routinely refer family caregivers to family caregiver organizations and partner with them in coordinating care to maximize the potential benefits of all available support services.
- R 40 (p.43):** Develop partnerships with academic and research centres and collaborate in the development of a research agenda that can generate further evidence on the effectiveness of family caregiver support and services.
- R 41 (p.43):** 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.

PUBLIC AWARENESS

- R 2.1 (p.14):** Improve the availability of current information related to mental illness in physicians' offices, emergency departments, counseling offices, work-places and community service organizations, including information about specific mental illnesses, how to provide care and resources for both those living with mental illness and their family caregivers.
- R 17.2 (p.27):** Make information about the signs and symptoms of mental illness and what to do when people are showing signs of distress widely available in schools and universities and incorporate discussion about mental illness into school curricula.

CONCLUSION

The National Guidelines for a Comprehensive Service System to Support Family Caregivers of Adults with Mental Health Problems and Illnesses present a comprehensive, principled and evidence-based set of recommendations for addressing the needs of family caregivers.

With caregivers facing challenges that can lead to chronic stress, which further burdens the health care system, the need to support family caregivers is urgent and immediate action is required. Supporting family caregivers benefits all stakeholders, including people living with mental illness, family caregivers themselves, the mental health system and society as a whole.



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