



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



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

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# Foreword from Project Chair

These *Guidelines* are long overdue!

Providing care and support to someone with a mental illness can be a daunting task. The often unpredictable and lengthy course of mental illness is compounded by stigma and by historical barriers to family involvement in the mental health system. This can create a significant burden that can compromise the health of the caregivers themselves.

People with mental illness are starting to receive the attention and respect they deserve. There is a growing recognition that recovery is possible, and that with access to the right treatments and supports, people with mental illness and their communities can often flourish. This same level of attention and respect, however, is not consistently provided to their families! Support for families to help fulfill their caregiving responsibilities and sustain the integrity of their own well-being is hardly integrated into the health care system. With supports spotty and inconsistent at best (and often non-existent), families are left to fend for themselves as they try to help their loved ones recover from mental illness and at the same time keep themselves afloat.

These *Guidelines* attempt to correct this. They offer a template for the many types of supports and services that caregivers need at different stages of their loved one's illness, and at different stages of their own lives. They are primarily aimed at service providers and policy makers, who are often in the best position to change the reality of families for the better.

These *Guidelines* were conceived and advocated for by the Mental Health Commission of Canada's former Family Caregivers Advisory Committee. The Commission then provided the resources so that this initiative could be transformed into concrete guidelines. It is our belief that these *Guidelines* provide the tools that could lead to improved services for family caregivers.

We thank the members of the former Family Caregivers Advisory Committee and the Steering Committee, as well as Commission staff who have been involved in different stages in the creation of the *Guidelines*. Most importantly, we thank the many family caregivers, people living with mental health problems and illnesses, service providers, administrators and other stakeholders who shared their expertise and time with us. Without your courage and commitment, these *Guidelines* would not exist.

It has been a gratifying journey; our real work starts now!

A handwritten signature in black ink, appearing to read 'Ella Amir', with a stylized flourish at the end.

**Ella Amir, PhD, MBA**

Chair, Family Caregivers Advisory Committee, Mental Health Commission of Canada

# Executive Summary

This document, *National Guidelines for a Comprehensive Service System to Support Family Caregivers of Adults with Mental Health Problems and Illnesses (Guidelines)*, was spearheaded by the Family Caregivers Advisory Committee (FCAC) of the Mental Health Commission of Canada (MHCC). Its purpose is to guide 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. The *Guidelines* are aligned with the mission of the MHCC's former Family Caregivers Advisory Committee, "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."<sup>1</sup>

These *Guidelines* describe the needs of family caregivers<sup>2</sup> of adults living with mental illness in Canada. Caregivers fulfill a distinct and important role by providing support and advocating for their ill 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 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. This document gives voice to many of the major concerns and needs of Canadian family caregivers. It makes recommendations for comprehensive support services and policies to better support effective caregiving and mitigate the associated challenges.

Family caregivers need ongoing access to information, guidance and support to fulfill their caregiving responsibilities effectively and to minimize the risk to their own well-being:

- Well-supported family caregivers can play a facilitative 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 mitigate 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 well-being.
- 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.

To provide the best possible care to an adult living with mental illness while sustaining their own well-being, family caregivers usually 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 in enhancing their coping skills, so they can effectively provide care to their relative.
- to have their personal needs outside of their caregiving role recognized and supported to sustain their own health and emotional well-being.

The *Guidelines* propose an evidence-informed, comprehensive approach to meeting the needs of family caregivers. Their adoption, first and foremost, requires a cultural shift to occur within and without the formal mental health system. Strong and committed leadership is needed to achieve a transformed mental health system where recovery-oriented programs and services acknowledge the importance of family caregivers, support them in their caregiving role and recognize and respond to their needs. This leadership is not the sole responsibility of those working within the formal mental health system, but also requires action on the part of other professionals within provincial, territorial and federal governments, as well as a range of other organizations.

The need for family caregiver support is urgent. Failure to recognize, acknowledge and support family caregivers heightens their risk of becoming “collateral casualties” of mental illness, compromises their health and quality of life, reduces the efficacy of the help they can provide to their relatives and increases costs to the health and social service systems. Well-supported family caregivers are likely to provide better care for relatives, generate savings in the system and enhance the benefits of caregiving.



## Section I: Background and Context

## 1 INTRODUCTION

These *Guidelines* focus on family caregivers of adults living with mental illness. The term family caregiver here refers to all those in the circle of care, including family members and other significant people, who provide unpaid support to the person living with a mental illness.<sup>3</sup>

Families often share a unique history and investment in their relationships, caring for each other and promoting the welfare of family members. This can be especially true when a family member is faced with a serious challenge such as mental illness, which often results in family members becoming caregivers. The caregiving role can be very challenging; the episodic and sometimes unpredictable nature of many mental illnesses, their longevity – which may become chronic – and historical barriers to family involvement within the mental health system can present obstacles for family caregivers. Compounding these challenges, caregivers often have to deal with the stigma associated with mental illness. Despite these obstacles, many family caregivers persist in attempting to fulfill a distinct and important role by providing support, advocating on behalf of the person and contributing to his or her recovery.

Family caregivers need ongoing access to information, guidance and support to fulfill their caregiving responsibilities effectively and to minimize the risk to their own well-being.

- Well-supported family caregivers can play a facilitative role in the recovery journey of their ill relative and in the improvement of their quality of life.
- Adequate support can mitigate 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 well-being.
- 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.

## 2 PURPOSE

The purpose of these *Guidelines* is to advise system planners, policy makers and mental health managers in planning, implementing and evaluating a family-friendly system of care. The system described is comprehensive, principle-based and evidence-informed, and is intended to support family caregivers so that they can provide the best possible care to adults living with mental illness while maintaining their own well-being. These *Guidelines* give voice to the concerns and needs of Canadian family caregivers and make recommendations for addressing them. Although the recommendations are applicable to the family caregivers of anyone with a mental illness, the focus is on those who care for adults.<sup>4</sup> Readers interested in issues specific to seniors or to children and youth should refer to the *Guidelines for Comprehensive Mental Health Services for Older Adults in Canada*<sup>5</sup> or to *Evergreen: A child and youth mental health framework for Canada*,<sup>6</sup> respectively.

This document acknowledges the potentially significant distress that family caregivers experience when the needs of the person they care for are not adequately addressed.<sup>7</sup> The focus, however, remains on the supports required by the family caregivers themselves. For an in-depth description of the needs and services that people with mental illness require, please refer to the MHCC's *Mental Health Strategy for Canada*.<sup>8</sup>

The *Guidelines* aim to inform policy makers and service providers who work with or are concerned about family caregivers of adults living with mental illness. However, family caregivers themselves, as well as persons living with mental illness and community organizations that support both groups may also find these guidelines useful. This document does not, however, provide clinical recommendations.

The *Guidelines* are aligned with the mission of the MHCC's Family Caregivers Advisory Committee (FCAC), "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."<sup>9</sup> The *Guidelines* build on the *Mental Health Strategy for Canada*, which acknowledges the value of family caregivers and the challenges they face, and makes recommendations to facilitate a greater voice, participation and support for family caregivers in a transformed mental health system.

### 3 PROCESS TO DEVELOP THE GUIDELINES DOCUMENT

This project was developed by the MHCC's FCAC and overseen by a steering committee that included FCAC members, other stakeholder representatives and MHCC staff. The development of the *Guidelines* consisted of a three-part process:

- A review of literature
- Development of an outline of proposed content that was critiqued and validated by family caregivers, persons living with mental illness and service providers in focus groups
- The development of the *Guidelines*, which incorporate focus group perspectives and suggestions made by FCAC, MHCC and key stakeholders in different mental health areas (see Appendix 1 for a full description of the process)

### 4 ORGANIZATION OF THE GUIDELINES DOCUMENT

To provide context, the *Guidelines* begin by explaining why family caregiver support is so important. A description of the family caregiver role follows, along with its effect on the lives of adults living with mental illness, and the impact of caregiving on the health care system and on the well-being of caregivers (5.2). Next, the needs of family caregivers are discussed, framed by issues related to both the caregiving and illness trajectories (5.3). A comprehensive approach to planning, implementing and evaluating services for family caregivers, underpinned by principles and values, is described in Section II. The support services described are able to help caregivers fulfill their caregiving responsibilities while sustaining their own health and well-being.

The *Guidelines* document includes brief descriptions of evidence-informed and promising practices and programs, which are presented in green boxes. Please note that these examples are not intended to provide a complete list of the many excellent practices and programs available throughout the country but were recommended by participants in the focus groups, other stakeholders, or emerged during the literature review and *Guidelines* development. Illustrative quotes from family caregivers who contributed to the *Guidelines* are set in italics.<sup>10</sup> Recommendations for action are presented throughout the document in blue boxes.

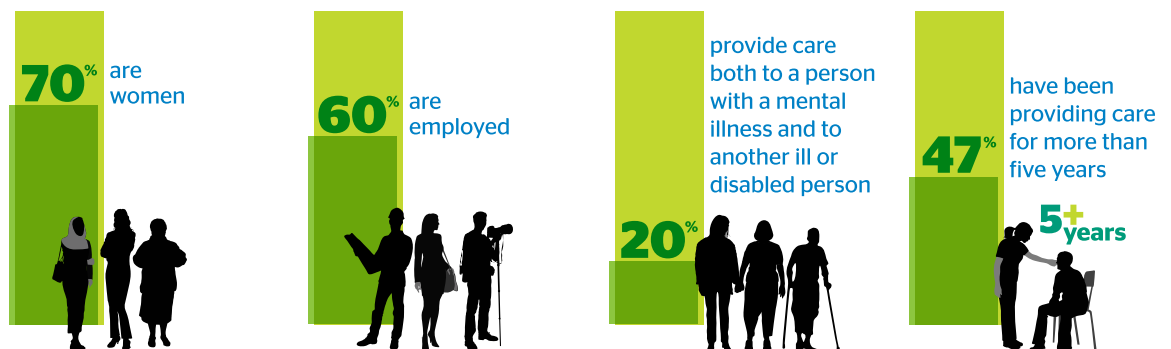
## 5 CAREGIVING IN THE CONTEXT OF MENTAL ILLNESS

### 5.1 WHO ARE FAMILY CAREGIVERS?

A national survey of family caregivers conducted in 2002, which included those caring for adults with mental illness, found that approximately two per cent of the adult population (or about half a million Canadians) provides care to a family member, friend or neighbour living with a serious illness.<sup>11</sup> Other results from the study revealed that 70 per cent of all caregivers are women, 60 per cent of caregivers are employed, 20 per cent provide care both to a person with a mental illness and to another ill or disabled person and 47 per cent have been providing care for more than five years. Family caregivers for people with any type of illness were found to feel a sense of responsibility; 72 per cent felt that there was no other option but to provide care; half felt that there was a lack of home care or mental health services; and most expected to be providing care for many years to come.<sup>12</sup>



### 5.2 WHAT DO FAMILY CAREGIVERS PROVIDE?



It is important to note that the support that family caregivers provide, as well as their own support needs, often change over time. The nature and intensity of caregiving varies, and is based on many factors, such as the illness trajectory, the preferences of the person living with mental illness, competing needs, and availability of resources and support for the family caregiver.

Caregiving takes time, energy, and financial, emotional and other resources. Results from a national study that included family caregivers of adults living with mental illness<sup>13</sup> found that family caregivers may assist with organizing, supervising or carrying out shopping, banking, bill payment, meal preparation and housekeeping; they monitor symptoms, manage problematic behaviours, situations and crises; and provide companionship, and emotional and financial support.

The family caregivers who participated in focus groups for this project recognized the above-mentioned tasks but added that caregivers often do much more, such as providing housing and transportation; educating others about the illness; providing guidance around community resources, money management, personal safety, and hygiene; as well as encouraging and motivating their ill relative in many ways. Some caregivers look after

their grandchildren as another form of support for a relative living with mental illness. Caregivers often have to find services and get their ill relatives into care, advocate on their behalf, and navigate the system and provide continuity, coordination of care and “case management”. They may facilitate access to alternative forms of treatment and share their observations with service providers about the individual’s history and strengths.

Family members providing care for someone with a mental illness report a level of burden<sup>14</sup> comparable to that of dementia caregivers, who are considered to have highly challenging responsibilities.<sup>15</sup> This high level of burden can put caregivers at risk for developing physical and mental health problems of their own.

### 5.3 HOW WELL HAVE THE NEEDS OF FAMILY CAREGIVERS BEEN MET?

Historically, many family members have felt blamed for their loved one’s mental health problems and illnesses. While this phenomenon is gradually diminishing, family caregivers are not yet consistently recognized as potential partners in the person’s recovery journey, or as individuals deserving support and recognition in their own right. As a result, many family caregivers still feel marginalized and their role is neither properly acknowledged nor is it adequately supported.

The need to balance the rights of the person living with mental illness with the family caregiver’s needs for information and support may be a challenge for mental health service providers. Families report that it is difficult to obtain the services, support and information they require to provide support and to maintain their own well-being. Often more than one family caregiver is involved in caregiving, each with their own perspective and need for information. Requests from health care providers to designate a single family member as the primary family contact, therefore, may be frustrating.

When asked about what would most support them in their caregiving roles, the family caregivers who participated in the focus groups said that they needed:

- to know that the person they care for is receiving adequate care and services, and is able to achieve a reasonable quality of life.
- to have their relationships and caregiving role recognized by mental health service providers and to be meaningfully involved in assessment and treatment planning.
- to receive information, skills, support and services from knowledgeable mental health service providers to enable them to effectively provide care to the person living with mental illness.
- to receive support and services for the family and its individual members to sustain their health and emotional well-being.

Other needs identified by participants and noted in the research literature are recognition, validation and support from other family members, the community, employers, government and health care providers. Participants also identified the need for help with daily caregiving activities, along with emotional and financial support.<sup>16</sup>

### 5.4 WHY SUPPORT FAMILY CAREGIVERS?

Timely and adequate support for caregivers is likely to be associated with three main benefits: benefit to the person living with a mental health problem or illness, to the caregivers themselves and to the health and social service system.

**Benefit to the person living with a mental health problem or illness:** Well-supported family caregivers can facilitate the recovery of their ill relatives, increase their quality of

life and support their inclusion in society.<sup>17</sup> Research suggests that enhancing caregiving capacity has a clinically significant impact on the course of their relative's mental illness,<sup>18</sup> on the relationships with the ill relative<sup>19</sup> and on adherence to medications.<sup>20</sup> Adults living with schizophrenia experienced fewer relapses and fewer hospitalizations when their family caregivers participated in psycho-education programs.<sup>21</sup>

**Benefit to the caregiver:** Timely and appropriate support can offset the often negative impact of the caregiving experience. The impact of long-term caregiving for an adult with mental illness on all family members is being increasingly understood and validated. Compared with the general population, family caregivers report higher levels of burden,<sup>22,23</sup> distress,<sup>24</sup> stress,<sup>25</sup> physical and mental health problems,<sup>26</sup> anxiety,<sup>27</sup> depression<sup>28</sup> and lower levels of life satisfaction.<sup>29</sup> The stigma associated with mental illness, the financial strain, the lack of adequate services for the person with the illness and the need for respite, are common factors adding to a caregiver's challenges.<sup>30</sup> An additional stressor is the recognition of and subsequent dealing with the often profound transformations in the person with the mental illness and in the family caregiver's relationship with them.<sup>31</sup>

Additionally, good support can enhance the benefits of caregiving for the caregivers, such as strengthening family bonds and acquiring a sense of pride and gratification for overcoming adversities.<sup>32</sup>

**Benefit to the health and social services system:** The care and support family caregivers provide to people with mental illness represents a major contribution to the health and social service system, which would be very costly to replace with paid formal services.

To date, no accurate estimate has been calculated as to how much family caregivers



**\$50,000,000,000**

save the health and social service system. The MHCC reports that, overall, "\$50 billion [per year] is a conservative estimate of the economic costs of mental illness" (p. 2).<sup>33</sup> A 1999 estimate of the dollar value of the contribution of family caregivers, including those caring for someone living with mental illness, was "5 billion dollars per year, which could be worth as much as 12.3 billion dollars per year [2008] today" (p. 2).<sup>34</sup> At the same time, caregivers assume many of the costs of caregiving themselves. One research study suggests that "lifetime employment-related costs for caregivers of persons with mental illness may be higher than for caregivers of the elderly because of the longer duration and unpredictable nature of care. Based on these findings, these researchers estimated that in 2006, caregiving costs for persons with mental illness were \$3.9 billion in Canada" (p. 18).<sup>35</sup>

Failure to recognize, acknowledge and support family caregivers heightens their risk of becoming "collateral casualties" of mental illness, compromises their health, reduces the efficacy of the help they can provide to their relatives and increases costs to the health and social service systems. Well-supported family caregivers are likely to provide better care for relatives, generate savings in the system and enhance the benefits of caregiving.



## Section II: Comprehensive Approach for Family Caregiver Support

The following section presents the key principles and values for a comprehensive system along with important considerations for the planning, implementation and evaluation of family caregiver services.

## 6 PRINCIPLES AND VALUES

Values, explicit or not, lay beneath the policies that shape the system in which caregiving takes place. Policies help determine what resources, services and goods are distributed, and to whom.<sup>36</sup> The following individual and system-level values and principles are intended to guide the development of a service system “where caregiving is deemed a worthwhile activity and supporting caregivers is recognized as a social responsibility.”<sup>37</sup> The principles and values used in this section are based on a review of literature and key informant interviews. They build on the vision and principles in the MHCC’s *Toward Recovery and Wellbeing: A Framework for a Mental Health Strategy for Canada*, and are grounded in the lived experience of diverse family caregivers across Canada.<sup>38</sup> This section concludes with the presentation of the *Caregiver Policy Lens*.

### 6.1 INDIVIDUAL LEVEL PRINCIPLES AND VALUES

**Family Engagement** – Family caregivers are engaged and encouraged to participate in the diagnosis, treatment and recovery process of the adult with mental illness, with due regard for the rights of the person living with mental illness and for their confidentiality and privacy.

**Respect and Dignity** – Policies, programs and practice reflect respect for the diversity of family caregivers, value their contribution and acknowledge the importance of their relationship with the person living with mental illness, balanced with the rights of the person living with mental illness, including privacy and confidentiality.

**Choice, Self-Determination and Independence** – Policies and programs acknowledge that it is the individual’s right to choose to take up the role of caregiver (or not) and to determine the parameters of care they will provide. Similarly, the person living with mental illness has the right to choose whom to involve and how much they will be involved.

**Family Caregivers’ Distinct Needs** – Family caregivers’ needs are assessed and addressed within a holistic recovery framework and are separate from those of the care recipient.

**Family Caregiver Sustainability** – Family caregivers are provided with the necessary information, education, skills, respite and other supports to enable them to carry out their role.

### 6.2 SYSTEM LEVEL PRINCIPLES AND VALUES

**Family Caregiver Inclusion and Voice**<sup>39</sup> – Family caregivers, advocates and organizations providing services to family caregivers are engaged in developing, reviewing and evaluating policies and programs that affect family caregivers directly or indirectly.

**Accessibility** – Policies and programs facilitate access to the services available to family caregivers and make appropriate adaptations to accommodate diverse needs.

**Diversity** – Family caregivers, as well as those for whom they provide care, hold varied beliefs about caring as well as diverse life goals and histories.<sup>40</sup> Policies and programs acknowledge and demonstrate sensitivity to diversity, particularly to those who are marginalized. Mental health service providers are culturally competent and practice cultural safety.<sup>41</sup>

**System Sustainability** – The system that supports family caregivers (directly and indirectly) is made up of appropriately educated and skilled staff, and is organized and resourced to facilitate continuity of care and to avoid crises leading to excess use of services.

**Collaboration** – Promoting and supporting the health and well-being of family caregivers requires the attention and efforts of the private sector, all levels of government and the public at large. Relevant organizations, advocates, levels of government and individuals concerned with family caregivers are involved in developing and reviewing policies and programs.

**Evidence-Informed** – Policies, programs and practices are based on the best available evidence, including scientific, traditional and cultural knowledge and the experiential evidence of family caregivers, persons living with mental illness and service providers. Those living with mental illness and their family caregivers are fully informed about treatment choices and about the level of evidence that supports them.

**Fairness and Equity** – Fairness is achieved by treating individual needs equitably. Policies and programs are fair, ethical and equitable, taking into account the current and future health and economic risks of caregiving, and consider the competing needs of other populations in a context of finite resources.

**Recovery-Focused** – Family caregivers are supported in their own recovery process and as critical partners in the recovery journey of those for whom they care. “A recovery-oriented system strives to encourage partnerships with service providers, families and friends to support people on their journey toward recovery and well-being”<sup>42</sup>. Such a system is built on the principles of hope, empowerment, self-determination and responsibility.<sup>43</sup>

**Mental Health Promotion** – Systems include strategies to promote mental health for all, including those living with mental illness and their caregivers, through multi-level and multi-sectoral interventions to (1) reduce risk factors for poor mental health and to enhance protective factors, and (2) engage with people and empower them to improve their health.<sup>44</sup>

### 6.3 CAREGIVER POLICY LENS

The *Caregiver Policy Lens* is a practical analytical framework for assessing policies and programs from the perspective of family caregivers, built on the values stated above, all of which are validated by the experience of Canadian family caregivers.<sup>45</sup> The *Lens* can be used in planning new, or critiquing existing programs and policies to ensure they are congruent with the values and preferences of family caregivers, and that they do not have any unintended negative effects.

**Recommendation 1:** 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*.

## 7 CONTEXTUAL ISSUES TO CONSIDER IN PLANNING SERVICES

There are a number of issues that need to be considered when planning a comprehensive system for family caregivers of people living with mental illness. Considering how these issues will be recognized and addressed within the system at the planning stage is important to ensure that they are built into the resulting services and supports. The creation of clear pathways between mental health services and social services can be most easily incorporated into each type of service at the planning stage.

### 7.1 ACCESS TO SERVICES FOR PERSONS LIVING WITH MENTAL ILLNESS

Family caregivers participating in focus groups for this project (and congruent with the literature) reported that a crucial component in supporting their well-being as caregivers is ensuring that the adult for whom they are caring has access to the medical services and social services they need. These social services include housing, income assistance, and legal and employment support, and are important underpinnings of recovery.

To access services for those they care for, family caregivers first need to be aware of such services. Information about resources and how to access them is often difficult to obtain. In addition, the information is rarely available in a range of formats that accommodates the requirements of different caregivers (e.g., online, print), their level of education, geographic location and mental health literacy. Mental health service providers and family caregiver organizations can both play an important role in providing family caregivers with relevant information in an appropriate format.

» Guidelines to help family caregivers of adults with bipolar disorder become informed and minimize risk to their own well-being have been developed by international expert panels of family caregivers, clinicians and persons with mental illness. The guidelines provide information on the illness and its treatment, give suggestions on ways that caregivers can provide support while taking care of themselves in the different phases of illness and wellness, and give information on dealing with specific real-life challenges and other resources.<sup>46</sup>

» Alberta's Mental Health Help Line is staffed 24 hours a day, seven days a week by health professionals. The Mental Health Help Line provides crisis intervention, information on mental health programs and services, and referral to other agencies where appropriate. This confidential, anonymous service is provided by Health Link Alberta and is available to all Albertans.<sup>47</sup>

» Quebec has a practical reference guide<sup>48</sup> for families who are providing care to a relative living with mental illness that includes a description of provincial services, information on confidentiality issues and practical advice for caregivers, as well as a list of useful websites and organizations.

## Recommendation 2:

- 2.1: Improve the availability of current information related to mental illness in physicians' offices, emergency departments, counseling offices, workplaces 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.
- 2.2: 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).
- 2.2: 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.
- 2.3: Set up clear pathways that caregivers can easily navigate between mental health and social services for adults living with mental illness through effective multi and cross-sector collaborations at all service levels.

## 7.2 STIGMA

The stigma<sup>49</sup> associated with mental health problems and illnesses often extends to the families of those who are living with mental illness. Stigma may delay how quickly family caregivers seek help, and often worsens the challenges families are already dealing with. Family caregivers, through their relationship with the person living with mental illness, are affected by negative stereotypes held by the general population (public stigma), including some service providers. Family caregivers may hold some of these beliefs themselves (self-stigma) and struggle with self-esteem and self-efficacy.<sup>50</sup>

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*We went a long time without telling anyone what was going on partly because our son didn't want anyone to know and it would have freaked my family out.*

Family Caregiver

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To fight stigma, family caregivers who were consulted by the MHCC suggested:

- a mandatory mental health curriculum in the education systems of all jurisdictions.
- anti-stigma campaigns using mass media.
- a mandatory mental health curriculum in health and social service provider education and training curricula.
- mental health services available at the primary level (e.g., walk-in clinics, GPs) and psychotherapy and psychologists' services available in schools.<sup>51</sup>

The *Mental Health Strategy for Canada* identifies the promotion of mental health, prevention of mental illness and the reduction of stigma as a priority for the country. The *Strategy* also includes a number of recommendations related to increasing public awareness of mental illness and reducing stigma.

### 7.3 DIVERSITY OF FAMILIES

Family caregivers are as diverse as the Canadian population. Diversity is important to consider as an influence on a person's experience as a family caregiver and includes ethnicity, cultural diversity, faith, gender, income, language and sexual orientation. Diversity can become marginalization when these differences are not recognized, or worse, lead to discrimination against a particular individual or group. Additionally, the influences that social disparities and power imbalances can have on individuals need to be acknowledged in planning and delivering services.<sup>52</sup>

Family member characteristics (e.g., phase of life or age, gender, relationship to the ill relative, ethnicity and experiences of stigma) and characteristics of the person living with mental illness (e.g., contact with family, diagnosis, duration of mental illness and severity of mental illness) have been identified as factors influencing family needs.<sup>53</sup> Education and income are also factors that must be taken into account when exploring a family member's needs.

There are also different family types (e.g., blended, extended, single parent, LGBT) that need to be recognized.<sup>54</sup> In many instances, family members are the primary caregivers, although not always, and the circle of support can include unrelated individuals who have taken on family roles.

### 7.4 CULTURE

The culture and ethnicity of individuals can play a profound role in their well-being. Not all family caregivers share the same understanding about mental illness, and some may experience tension between their own beliefs and those embedded in mental health practices and services. In an Australian study, for example, indigenous families indicated that lack of cultural knowledge and understanding on the part of mental health service providers actually contributed further to their stress.<sup>55</sup>

» The Nova Scotia Department of Health has developed a *Cultural Competency Guide for Health Care Professionals*<sup>56</sup> that includes respectful and effective tools and resources to assist health care professionals in providing culturally competent<sup>57</sup> health care, highlighting issues related to race, ethnicity and language.

» In Ontario, the Hong Fook Mental Health Association was established in 1982 to address the mental health concerns in East and Southeast Asian communities. The Association aims to help people with linguistic and cultural barriers to gain access to mental health services. The Association also provides counselling, case management, assessment, consultation, advocacy, psycho-educational workshops and self-help and mutual support groups, special English as a second language classes, and housing services to community members with mental health problems and their families.<sup>58</sup>

**Recommendation 3:** 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.

## 7.5 GEOGRAPHIC LOCATION

Living in a rural or remote area that has few or limited mental health service providers or services can be isolating for those living with mental illness. They may not be able to access optimal treatment, and their family caregivers may lack access to appropriate support as well. Additionally, in small communities where people may have difficulty in maintaining their privacy, stigma may be an even bigger barrier to seeking or receiving services.

- » Telephone Support Groups (TSGs) for adult children of parents with dementia have proven effective in facilitating problem-solving and coping strategies through education and support. Those who participated in a 12-week TSG, compared to those who did not, felt less distressed, less burdened and had more knowledge about the illness and about services and how to access them.<sup>59</sup>
- » Web-based self-help groups are a promising vehicle for non-face-to-face support for family caregivers. Following participation in a 10-session, professionally facilitated support group, web-based self-help groups were formed and evaluated after six months of operation.<sup>60</sup> Family caregivers who participated reported that they increased their knowledge, bonded with group members and were better able to cope with the stresses of caregiving.
- » Alberta Health Services offers a visiting psychiatrist service that brings psychiatrists to rural communities. These services are provided through referral and mental health clinics.<sup>61</sup>
- » AMI-Québec has been offering telephone-based workshops for remote communities across Quebec on a variety of mental health-related issues.<sup>62</sup> Uptake has been increasing every year.

**Recommendation 4:** Provide telephone and online services to support family caregivers in rural and remote geographic areas, or wherever local service capacity is limited.

## 7.6 IMPACT OF FAMILY LIFE COURSE AND RELATIONSHIPS

Generally, family experience suggests that “as social units, families hold common timetables for the movement of members through certain roles and the formation of particular family structures” (p. 430).<sup>63</sup> For adults who developed a mental illness in youth or young adulthood, challenges in completing schooling, entering the workforce, finding a life partner or becoming a parent can delay or even prohibit the adult from reaching independence or other “ordinary” milestones. This can be a source of grief for family caregivers, especially parents, that is seldom recognized.

Everyone in the family of a person living with mental illness is affected by the illness. While some experiences are common to all, other experiences differ by relationship. Parents of those with schizophrenia have identified feeling burdened by a sense of responsibility for the illness and by the prospect of living with a dependent child for the rest of their lives.<sup>64</sup> The adult child’s need for social, financial and emotional support may divert the parents’ resources and change their expectations about “life after children.” As

they age, parents may face health issues themselves and become increasingly concerned about future planning and who will take over their caregiving role.<sup>65</sup>

Spouses of partners with schizophrenia have identified challenges around marital intimacy and plans for a shared life. Spouses must often take on roles originally performed by the ill partner. Frustration with the mentally ill partner can engender hostile and angry feelings in the other partner, contributing to high divorce rates among such couples.<sup>66</sup> Spouses of adults with bipolar disorder have reported that their relationship with the ill partner affects their own employment, legal matters, finances, and social relationships (including relationships with children), especially during crises.<sup>67</sup>

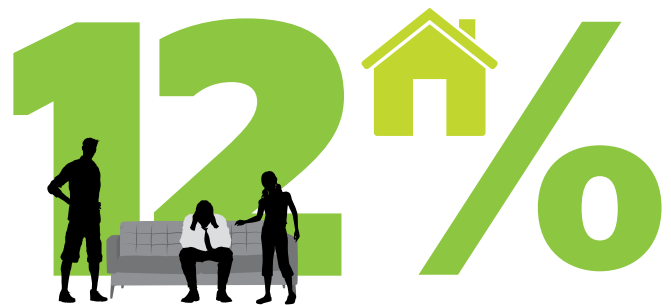
Having a sibling with mental illness affects the relationships, roles and health of other siblings. Siblings who were consulted on this issue were asked to name their most important needs. They identified seeking satisfactory services for their ill relative, working through their feelings about the illness, skills for coping and receiving personal support.<sup>68</sup> Their greatest concern (82 per cent of participants) was about who would take care of their ill sibling when their parents no longer could.

» The Canadian Mental Health Association has a downloadable guide for siblings, *A Sibling's Guide to Psychosis*.<sup>69</sup>

**Recommendation 5:** 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.

When a loved one is diagnosed with mental illness, family caregivers often need to adjust their expectations and goals – both for themselves and for their loved one. This includes disengaging from goals no longer attainable and exploring new attainable goals. A strong ability to adjust goals is associated with better well-being.<sup>70</sup>

“Young carers”<sup>71</sup> who provide care to adult family members living with mental illness face unique challenges. A British Columbia study found that 12 per cent of students age 12-17 surveyed are in a caregiving role.<sup>73</sup> Young carers may experience feelings of stigmatization and social isolation. Those caring for a parent living with a mental illness may experience high levels of anxiety due to the unpredictability of their lives and the potentially unstable nature of the parent’s illness.<sup>74</sup>



**Recommendation 6:** 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.

## 8 SYSTEM OF SUPPORT FOR FAMILY CAREGIVERS

### 8.1 MENTAL HEALTH SERVICE SYSTEM

Implementing a comprehensive mental health system that supports family caregivers requires that service providers proactively engage family caregivers with due respect for the rights to confidentiality and privacy of the person with mental illness. A transformed mental health system requires recovery-oriented programs and services that acknowledge the importance of family caregivers, supports them in their caregiving role and responds to their needs.

#### 8.1.1 THE PYRAMID OF CARE - AN ORGANIZING FRAMEWORK

The *Pyramid of Family Care*<sup>75</sup> was designed in Australia to provide a framework for implementing integrated and coordinated care and support for family caregivers. The Pyramid is based on two premises: (1) if all family caregivers have their basic needs met, then only a small proportion will require more specialized services, and (2) it is within the scope and competence of generalist mental health service providers to engage, assess and address the basic needs of most family caregivers.<sup>76</sup> This is similar to the tiered approach that frames the recommendations for services in the *Mental Health Strategy for Canada*.

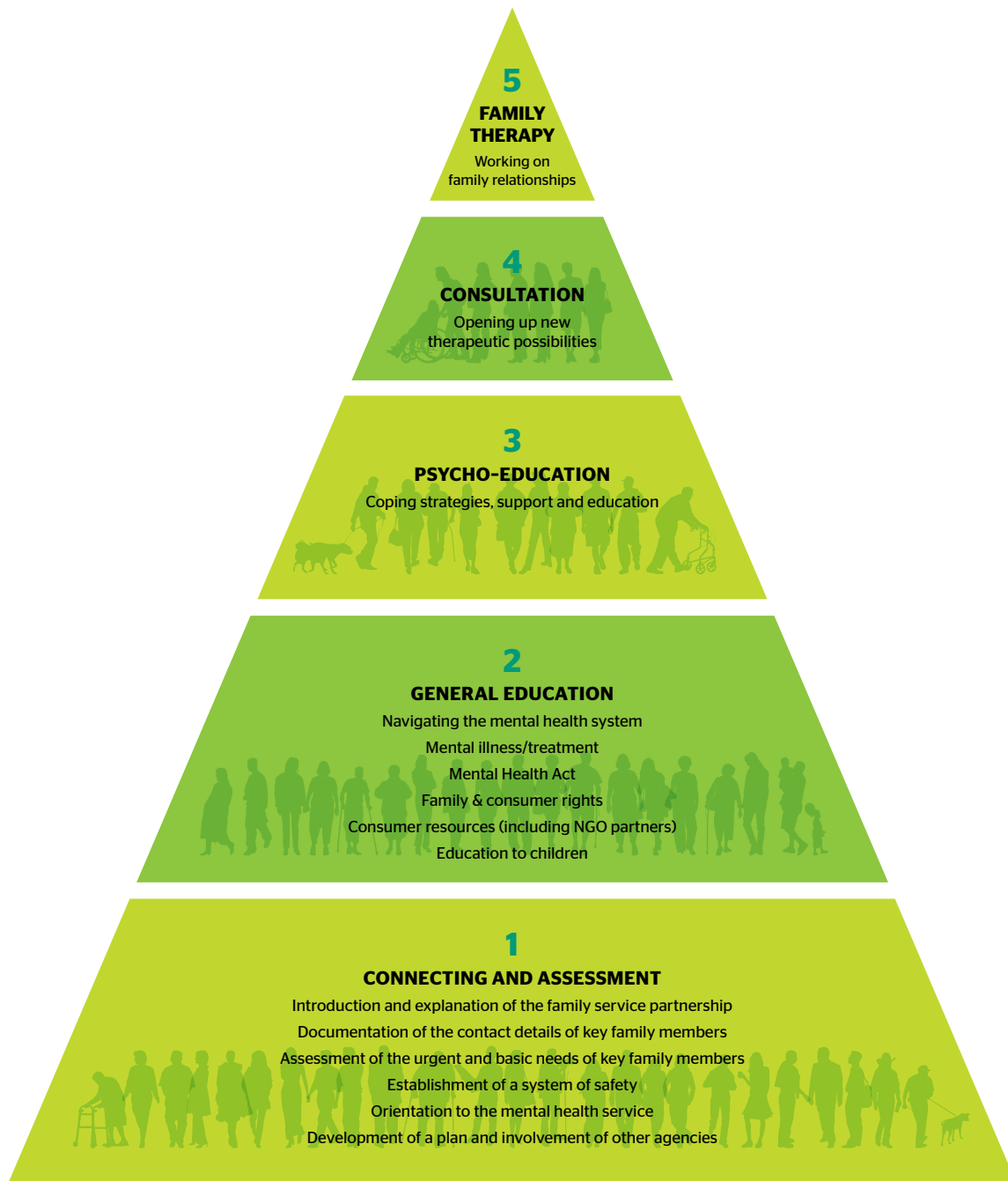
##### 8.1.1.A CONNECTION AND ASSESSMENT

Family caregivers are likely to come into contact with mental health service providers in the community, hospitals and emergency rooms on numerous occasions during their caregiving journey. On each of these occasions, mental health service providers can respectfully encourage family caregivers' involvement in the circle of care in keeping with the desires of the person receiving care, orient them to mental health services, as well as assess their caregiving-related safety, support and service needs, and collaborate in developing a plan for addressing these needs.<sup>80</sup> These actions should be carried out on an ongoing basis since the family caregiver's needs may vary with each particular encounter. These needs are based on the stage of their family member's illness and on the resources available for the family at that time.

**Recommendation 7:** 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.

##### 8.1.1.B GENERAL EDUCATION

The family caregiver's need for education will vary over the illness trajectory and with the different situations they encounter. For example, at the early stages of a loved one's illness (before, during and after the diagnosis), families may require more information and education than at a later stage. General education may include information about resources found both inside and outside the mental health system, for both the person living with mental illness and for the family caregivers. It may also include information about the illness, treatment options, relevant legislation, family and client's rights, as well as community organizations that assist family caregivers.<sup>81</sup> General education needs require assessment at each encounter and can be provided in the community, hospital or emergency room, individually or in groups. Family caregiver organizations are often the primary resource for general education.



**FIGURE 1 THE PYRAMID OF FAMILY CARE FRAMEWORK<sup>77</sup>**

The Pyramid features five hierarchical levels of tasks for meeting the support needs of family caregivers. As one moves up the pyramid, the *intensity* of intervention increases while the *number* of family caregivers who are likely to require the intervention decreases. At the bottom of the pyramid, Levels 1 (connection and assessment) and 2 (general education) indicate the minimum level of service that should be available to all family caregivers. These services could be provided by mental health service providers in the formal system and by family caregiver organizations whose primary clients are family caregivers.<sup>78</sup> The need for Level 1 and 2 interventions should be reassessed at each point of contact.

Level 3 (family psycho-education [FPE]) refers to interventions in which the family caregivers are offered coping strategies or specific ways of dealing with the challenges of mental illness.<sup>79</sup> Many family caregivers benefit from such programs. Level 4 (consultation) may be required by family caregivers with significant challenges in effectively supporting an adult living with mental illness. Level 5 (family therapy) refers to interventions aimed at creating change in the family interactional system. Few family caregivers require Level 4 or 5.

» On Prince Edward Island, “With Hope in Mind” is a comprehensive education and support program designed specifically for family members of persons with mental illness. “With Hope in Mind” offers information on different illnesses, self-care strategies, coping strategies and emotional support for its participants and is provided free of charge by the Canadian Mental Health Association PEI Division in partnership with Health PEI.<sup>82</sup>

**Recommendation 8:** Provide family caregivers with timely access to appropriate education that responds to their needs at different stages in the illness and caregiving trajectories.

#### 8.1.1.C FAMILY PSYCHO-EDUCATION

Family psycho-education (FPE) benefits many families and requires trained facilitators. Family psycho-education refers to interventions in which the family caregivers (in single or multiple family groups) are offered coping strategies or specific ways of dealing with the challenges of mental illness.<sup>83</sup>

» FPE is one of six evidence-based practices endorsed by the United States-based Center for Mental Health Services for individuals suffering from chronic mental illnesses.<sup>84</sup> Family members who receive such interventions for six to nine months (or at least four sessions if less than six months), have been found to have lower levels of burden and distress, along with improved family relationships. Key elements of effective family interventions include illness education, crisis intervention, emotional support and training in how to cope with illness symptoms and related problems. It is suggested that the specific family intervention should be chosen through collaborative decision making among the client, family and clinician.<sup>85</sup>

» The Schizophrenia Patient Outcomes Research Team (PORT), based on the best available evidence, recommends that families and significant others of persons with schizophrenia who have ongoing contact with the person should be offered a family intervention that emphasizes education about the illness, information about services, emotional support and strategies for coping.<sup>86</sup>

» “Strengthening Families Together,” developed by the Schizophrenia Society of Canada, is a 10-week psycho-educational course for family members. It has a strong interactive support component and is delivered by trained family facilitators. This course covers a variety of topics including symptoms, treatment, recovery, coping skills and navigating the mental health system. At the completion of the program, families are referred to local support groups operated by community agencies in Canada by local branches of the Schizophrenia Society and the Mood Disorder Association.

**Recommendation 9:** 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.

#### 8.1.1.D CONSULTATION

Consultation services may be required by frontline mental health service providers working with family caregivers who are highly distressed or having significant challenges in supporting an adult living with mental illness effectively. That is, the mental health service provider may need to consult closely with a highly skilled family clinician or team.

The mental health service provider then applies what they learn to their work with the family, who may or may not be present for the consultation. These services are likely to be needed for only a small proportion of families.

**Recommendation 10:** Make expert consultation available to mental health service providers when required.

#### 8.1.1.E FAMILY THERAPY

Family therapy (interventions aimed at creating change in the family interactional system) is provided by family therapists. Few family caregivers will require family therapy. Research has demonstrated that family therapy is most likely to be helpful if the basic task of engagement (as outlined in Levels 1 and 2) is first successfully carried out.<sup>87</sup>

**Recommendation 11:** Expand access to evidence-based family therapy from certified and regulated clinicians when needed.

#### 8.1.2 FAMILY CAREGIVER ORGANIZATIONS

In Canada, much of the information about services for adults with mental illness and for family caregivers (Level 1), and general education (Level 2) are provided not only by mental health service providers in the formal system but also by family caregiver organizations. Level 3 (family psycho-education) is provided by mental health or family association clinicians with appropriate training. If family caregivers have received effective and timely Level 1, Level 2 and Level 3 services, they are less likely to require additional services. Level 4 (consultation) and Level 5 (family therapy) are usually required by a small proportion of family caregivers, and are provided by specialized clinicians trained in family interventions.

» In the Greater Toronto Area and Peel Region, the Family Association for Mental Health Everywhere (FAME) works at the community level, offering families empathy, support, knowledge and a compass for navigating the health care system as an advocate for a loved one living with mental illness.<sup>88</sup>

#### *THE ROLE OF FAMILY CAREGIVER ORGANIZATIONS IN SUPPORTING FAMILY CAREGIVERS*

Family caregiver organizations provide the bulk of support to family caregivers in many communities. These associations can take different forms, and may include local chapters supported by a national organization. Family caregiver organizations are often developed and run by family caregivers in a particular community or region, may have mental health professionals on staff, and are not-for-profit organizations that often rely heavily on volunteer support. They typically provide information and education sessions, skill development workshops, guidance, advocacy, peer-led support groups and sometimes counseling. Programs are aimed at providing a safe and non-judgmental place to share feelings, experiences and strategies for managing the illness. Central to family caregiver organizations, peer support is often offered in the form of self-help groups and provides a cost-effective way to inform, educate and support family caregivers. It could be expanded to include peer counseling, mentoring and strategies for bridging cultural gaps.<sup>89</sup>

A systematic review of literature about the benefits of peer support found that participants in support groups increased their knowledge about mental illness, developed better coping skills, and experienced an increase in social support and a decrease in burden and distress.<sup>90</sup> Family caregivers reported becoming better able to navigate the mental health system and deal with stigma and discrimination as well as experiencing

less self-stigma.<sup>91</sup> Caregivers are usually welcomed into these informal, peer-led settings at any time of need, which is often not the case with many formal, often hospital-based services that offer some support to families while their relatives are receiving treatment.<sup>92</sup>



To ensure that family caregivers get the information, education and support they need, and that service delivery is optimized, a collaboration between service providers both in the formal system and in the community should be encouraged, including mutual referrals with due respect for the confidentiality and privacy of the person living with mental illness.<sup>93</sup>

» Quebec is a leader in family support with more than 40 family caregiver organizations in the province linked by the *Fédération des familles et amis de la personne atteinte de maladie mentale (FFAPAMM)*. AMI-Québec<sup>94</sup> is the first family association of its kind in Quebec. It offers a broad menu of support services that include all the traditional services, as well as counselling and family peer support at one of Montreal's hospital emergency units.

» The Family-to-Family Education Program developed by the National Alliance on Mental Illness (NAMI) is a 12-week program that provides information about mental illness, medication and rehabilitation. Caregivers learn self-care, mutual assistance and communication skills, as well as problem-solving strategies, advocacy skills and ways to develop emotional insight into their responses to mental illness. Evidence indicates that family caregivers who attend the program, conducted by trained peers, experience significant improvements in their coping and sense of empowerment, knowledge and self-care. They also experience less worry about their ill relative and less subjective burden.<sup>95</sup>

**Recommendation 12:** 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.

### 8.1.3 CLINICAL CONSIDERATIONS

#### 8.1.3.A FAMILIES AS PARTNERS IN THE TREATMENT TEAM

Family caregivers have a unique and critical role in fostering recovery and well-being in those living with mental illness.<sup>96</sup> They often have important information that could be useful for clinicians who assess and treat their relatives, such as knowledge about the onset, symptoms and impact of the mental illness. They are also likely to be the first to observe signs of relapse and to seek help. In a fragmented system, they may be best positioned to ensure continuity of information and coordination of services, especially during transition periods, with or on behalf of the person living with mental illness. To make the best use of such information, family caregivers should be invited and encouraged to share their observations. Meetings with the treatment team, especially around discharge planning, could help family caregivers in their efforts to support their relative effectively. Maintaining working relations with family caregivers does not need to compromise confidentiality and privacy, and reassurance about this should be provided to the person living with mental illness.

**Recommendation 13:** Require service providers to include family caregivers in treatment planning where appropriate.

Family caregivers have ranked communication with health providers as one of their greatest needs.<sup>97</sup> However, many feel excluded by health providers from the process of care.<sup>98</sup> Although there are no restrictions on the information that family caregivers can share with service providers, this information is not always solicited.

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*We felt totally helpless when our son was hospitalized. I've worked in institutions and I get the privacy laws but there are also ways to communicate. You just have to go into Safeway [grocery store] to see that you can be welcoming and make people comfortable without disclosing information.*

Family Caregiver

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One study found that in a community mental health centre where 10 per cent of clients refused consent to share information with family caregivers, the 36 clinicians surveyed made contact with only 48 per cent of the family caregivers. The reason given for not contacting other clients' family caregivers was that the clinician did not believe that such contact would benefit the client.<sup>99</sup>

» In Australia, practice guidelines for family participation have been formulated. These guidelines acknowledge and provide guidance for situations in which health care providers feel that providing information to a nominated caregiver might not be in the best interest of the person under care.<sup>100</sup> They also address instances where the person with the illness refuses consent for family caregiver involvement. In such a case, family caregivers would, at minimum, receive general information about mental illness and about agencies that might support the caregiver.

### 8.1.3.B CONFIDENTIALITY

Many family caregivers who participated in focus groups for this project thought that confidentiality and legal issues related to the sharing of information was a barrier to effective care. They said that in some jurisdictions, relevant information is not provided to family caregivers, even when the individual resides in the family caregiver's home. Some family caregivers described situations where they were not informed about their family member's hospital admission or discharge, and when they called the hospital they were told that the information was confidential.

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*It's as though they start from the presumption that families are harmful! You end up feeling the weight of the system against you while you're trying to care for your loved one. It's wrong.*

Family Caregiver

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» In British Columbia, under its Mental Health Act, notification of a designated family member in the case of an involuntary admission to hospital is mandated.<sup>101</sup>

Policies for the release of information leave room for ambiguity and clinician discretion; this means they are applied differently at different services and organizations and in different jurisdictions. Knowing when and to whom to release confidential information is challenging for clinicians when the person with the illness does not provide explicit consent to do so.

» In British Columbia, “continuity of care” guidelines allow health care providers to release information to “care providers” without consent (qualifications are not explicitly defined).<sup>102</sup> The BC government’s Best Practices in Family Support and Involvement states: “Families must be informed and aware of the treatment plan, and discharge planning should focus not only on the individual personal functioning but also on the family’s ability to care for the client” (p. 2).<sup>103</sup>

Based on a review of research literature, the Centre for Addiction and Mental Health has recommended specific strategies to facilitate the timely and appropriate sharing of information. These include:

- having a clear procedure for obtaining consent to share information
- providing training so that staff are clear about what information can be shared and under what circumstances
- having reasonable time limits that specify the nature of the information that the client is agreeing to share and with whom
- answering questions of families in a general way so as not to violate confidentiality (p 5).<sup>104</sup>
- providing written information to the family about what type of information can be shared with them

#### Recommendation 14:

- 14.1:** Develop and implement clear protocols for providing necessary information to family caregivers and require mental health service providers to follow them.
- 14.2:** 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.
- 14.3:** 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.
- 14.4:** Where a relative chooses not to involve family caregivers, ensure that the reasons are explored, discussed and documented, and that 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.

» Psychiatric advance directives (PADs), widely used in the United States, allow competent persons to request or refuse specific types of treatment and to designate a decision maker in advance of a mental health crisis in which they may lose capacity to make health care decisions. There is no specific legislation about PADs in Canada, but many jurisdictions have general “advance directive” laws that can be used like a PAD. Advance directives are intended to authorize the substitute decision maker “to act in accordance with an incapacitated person’s previously-expressed wishes, known values, or to act in the person’s best interest if the person’s preferences are unknown” (p. 73).<sup>105</sup> More research is needed in Canada to understand the use of PADs and related legislation.<sup>106</sup>

**Recommendation 15:** 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.

### 8.1.3.C ASSESSMENT OF FAMILY CAREGIVER NEEDS

It is important to assess the needs of family caregivers (individually and/or as a family) in their own right, not solely in terms of the services required by the person for whom care is provided. Ideally this assessment should be carried out by skilled clinicians. Areas of assessment could include family relationships (including with the person living with mental illness), risk factors for excess burden, available social supports, competing responsibilities and specific stressors. Following assessment, a plan that includes a self-care component with referrals to appropriate caregiving resources should be developed with the family caregiver. A formal assessment can help determine the effectiveness of supports and how to reduce caregiver burden.

- » The United Kingdom has enshrined the right of family caregivers to obtain a professional assessment of their needs. Such assessment is conducted at the local social services level and is followed by a referral to appropriate services.<sup>107</sup> Based on a three-year study of family caregiver assessment, principles for good practice have been suggested that can guide mental health professionals.<sup>108</sup>
- » The Victorian Order of Nurses (VON) Best Practices Team routinely uses the CARE Tool and Caregiver Risk Screen, a psychosocial assessment tool that treats caregiver needs as equally significant to those of the care receiver, and ensures that the needs of both parties are assessed with equal weight.<sup>109</sup>
- » The Service Provider Resource Guide developed in Canada includes a review of practical, validated caregiver assessment tools for various forms of burden that can be used by clinicians.<sup>110</sup>

**Recommendation 16:** 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.

#### 8.1.3.D FAMILY CAREGIVERS' NEEDS THROUGHOUT THE ILLNESS STAGES

In the following section, family caregivers' needs are described as they move through the different stages of their relative's illness. While there are often early signs that suggest a possible problem, many families begin their learning only when a crisis erupts and the relative is being brought to the hospital. Families, therefore, often embark on their new caregiving role unprepared and uninformed.

The trajectory of mental illness often includes cycles of relapses and remissions, and the illness sometimes evolves in unpredictable ways. Coping with the cyclical, sometimes erratic and often long-term nature of mental illness presents ongoing challenges to family caregivers.

Throughout their journey, most family caregivers would benefit from receiving information, education, guidance and support. The intensity of the needs may change as the illness progresses from one stage to the next, and will also depend on other factors such as individual characteristics of the caregiver, their social networks and personal resources.

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*This illness totally dominates our lives. He stopped taking his meds and was scaring the other kids – the doctor said to kick him out – we called the police – he got treatment – he stopped his meds and got in trouble – we kicked him out – called the police – he stabilized, then the downward spiral again, lost his ID, couldn't get welfare – home again. You get the picture. It's like a roller coaster and no one can get off.*

Family Caregiver

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This stage is often characterized by uncertainty and confusion as caregivers are confronted by unexplained and perplexing behaviours in a family member.<sup>111</sup> Parents who participated in focus groups for this project spoke of feeling guilty for not having accessed services for the person living with mental illness earlier. Others did not feel that their family physicians were knowledgeable about mental illness. However, identification and intervention at the earliest possible stage of mental illness, and psychosis in particular, contribute to earlier remission of negative symptoms, delay and reduction in relapses and prevention of psychosocial deterioration.<sup>112</sup> Failure to intervene is likely to exacerbate the illness. Families who do seek help at an early stage often consult their family doctors. It is important, therefore, that family doctors be sufficiently familiar with mental health problems so that they can provide the necessary help or refer to specialists.

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*We didn't know what was going on. We went to the doctor and he said it was nothing to be concerned with, but we knew he was wrong. It ended up that a friend gave me a pamphlet that described his psychosis to a "t". But by this time J. was worse. It was months before we stumbled onto the First Place program.*

Family Caregiver

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#### Recommendation 17:

- 17.1:** 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.
- 17.2:** 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.

#### IN THE HOSPITAL

Families are likely to access psychiatric care in the hospital only in crisis situations because of a gradual shift of psychiatric care from hospital to community. The hospital, therefore, is often the first opportunity for family caregivers to interface with the mental health system, usually during a crisis. Prior to a crisis, despite some warning signs, families may not seek help, either because they do not know where to turn, their family doctors do not refer them for help or they hope that the situation will resolve itself.

Once in the hospital, many families are overwhelmed by the unknown and devastated by the prospects of mental illness. This foreign and confusing world can seem intimidating and unfriendly. Here, recognition of the family situation and the availability of initial support can be invaluable. The first encounter is important as it sets the tone for the ongoing relationship with the mental health system.

- » Vancouver Coastal Health has developed a *Hospital Guide for Family Members of People with Mental Illness*.<sup>113</sup> It is intended to prepare family caregivers for the hospitalization of an ill relative, providing information about what to expect and how to access services. This resource is recovery-oriented and was developed with the input of family caregivers, persons living with mental illness and service providers.
- » Family Connections: A Program for First Time Admissions<sup>114</sup> is an Australian program that creates a partnership among a teaching hospital, a research centre and a consumer organization. The primary intent of the program is to assist persons living with mental illness and their families to successfully work through the crisis associated with an initial hospital admission for mental illness.

**Recommendation 18:** 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.

Many family caregivers who participated in focus groups for this project spoke of negative experiences in taking a loved one to the emergency room. They spoke of long waits in surroundings that were noisy, crowded and confusing. There was a lack of general information that could help at the time of crisis, and they felt that the staff knew little about mental health issues. Admission to the hospital, especially if done against the choice of the person being admitted, is a difficult experience for many family caregivers and those for whom they care. Sensitivity is required in addressing such trying situations.

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*There we were in the emergency room – my son started yelling that we abused him and a security guard came for him and one for me; then they shut me in some little meeting room and just left us sitting there crying. Twenty minutes later a psychiatrist came in for five minutes tops and said he had schizophrenia but never told us what it all meant or what to do next.*

Family Caregiver

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**Recommendation 19:**

- 19.1:** 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.
- 19.2:** 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.

In addition to mental health service providers in the hospital and emergency room, a family peer support worker could make a significant difference for caregivers facing a crisis, especially for the first time. The peer could provide initial support and referrals to relevant resources and help to navigate the system.

» Family peer support is available in the emergency ward of Ontario's Grey Bruce Health Services (Schedule One Hospital) that serves the Grey-Bruce district residents. The service has proven to be a valuable source of support and information for family caregivers, and is highly regarded by the hospital practitioners.<sup>115</sup>

#### Recommendation 20:

- 20.1: Create and assign family peer navigator positions for admission and emergency areas with the role of providing direct guidance and information to family caregivers.
- 20.2: Implement strategies to facilitate system navigation inside hospital-based services such as written guides, designated contact persons and family peer support workers.

#### *DIAGNOSIS AND BEYOND*

Diagnosis is a “pivotal moment when a potential explanation becomes available, even if given in medical terms. At this point family caregivers crave information and actively work to learn about the illness. This is a period in which caregivers usually embrace their role in the belief that they can ‘save’ or ‘cure’ their loved one. At the same time they may find it difficult to fully empathize with their relatives, and can feel frustration when there is little apparent reciprocity in the relationship.” (p.35)<sup>116</sup>

As suggested in the Pyramid of Family Care Framework (Levels 1 and 2), families would benefit during this period from information and education about the illness and illness-related issues, and an assessment of their needs.

**Recommendation 21:** 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.

As caregivers continue to face the challenges of mental illness, their coping and resilience can be enhanced through mutual support groups and psycho-education programs (Level 3 in the Pyramid of Family Care) provided by skilled mental health or family association clinicians. Such programs provide opportunities for acquiring coping skills and strategies that help caregivers face the ongoing challenges of mental illness.

**Recommendation 22:** 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.

Early intervention in psychosis is a relatively new concept in mental health. In recent years, however, an increasing number of early identification and intervention programs have sprung up in different locations – some in the hospital, others in the community. Early intervention is designed to improve outcomes in schizophrenia and other psychoses through earlier detection of untreated psychosis and effective treatments tailored to the specific phases of the disorder. These programs usually recognize the important role of families and encourage their active involvement.

- » First Place Clinic and Regional Resource Centre (CMHA Thunder Bay)<sup>117</sup> offers community-based consultation and treatment for individuals who are experiencing a first episode of psychosis. They recognize the important role of families and encourage their active involvement. The ultimate goal of the service is to facilitate early identification of psychosis and promote optimal treatment interventions that lead to the maintenance of meaningful functional recovery from psychosis. They apply an interdisciplinary team approach in all aspects of care by including disciplines such as psychiatry, nursing, social work, psychology and rehabilitation specialties.
- » Prevention and Early Intervention Program for Psychosis (PEPP-Montréal)<sup>118</sup> is a program for young people who are experiencing an untreated first episode of psychosis. Its goal is to foster hope for full recovery in adolescents and young people suffering from psychosis. Families are involved and supported.

**Recommendation 23:** Increase the availability of prevention and early intervention programs that recognize and appropriately involve families.

#### *DISCHARGE FROM THE HOSPITAL*

Discharge from the hospital is an important transition point for both the person being discharged and the caregivers. It is important that family caregivers participate in the discharge and the care plan process that follows. Some family caregivers who participated in focus groups for this project reported that they were not informed about discharge – in some cases, even when their relative was returning to their home.

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*They just threw him out on the street without calling anyone. He phoned me to pick him up so he hadn't said not to call me, so why didn't they? Where did they think he was going to go? When I picked him up, he had no coat and no shoes and it was cold! Tell me, what kind of care is that?*

Family Caregiver

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Unless the person living with mental illness has prohibited staff from involving the family caregiver, it is vital that they be involved in the discharge plan and be aware of the discharge date. The involvement of well-informed caregivers is likely to enhance the recovery process of their ill relative and reduce their own stress.

**Recommendation 24:** 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).

As described in the Pyramid of Family Care, the best outcomes for both the person living with mental illness and family caregivers are likely to be achieved if the needs of the family caregiver are routinely assessed throughout the illness trajectory. Such assessments can be done by mental health service providers in the hospital or in the community. Families struggling to cope may require further help in addition to the support services described earlier, including consultation or family therapy (Levels 4 and 5, respectively, in the Pyramid of Family Care).

### 8.1.3.E POLICE, THE LEGAL SYSTEM AND EMERGENCY SERVICES

A particularly devastating experience for family caregivers is when their ill relative comes into contact with the police or the legal system as a result of their illness. This can occur, for example, when they must admit their relative to the hospital involuntarily. It is equally distressing when family caregivers call on emergency services for help, but are met with little sensitivity and often an abrupt attitude. This leaves the family feeling guilty and traumatized.

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*It was the worst day of our family's life – we never thought calling for help would end up in a take-down and handcuffs – we were all crying. We needed help by then but there was none.*

Family Caregiver

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The decision to call the police is always challenging and can jeopardize the relationship with the person living with mental illness and with other family members. Although progress is being made, training of police officers about mental illness remains limited in many communities and may lead to an insensitive or inappropriate response.

- » An innovative “after hours” mobile crisis outreach program in Vancouver, Car 87, staffed by a nurse and a police constable with some mental health training, provides emergency on-site assessment for persons thought to be in psychiatric or psychosocial crisis. Most individuals are stabilized and able to remain in the community.<sup>119</sup>
- » The Mobile Crisis Team in Fredericton is a team of mental health professionals who respond to persons in the community who are experiencing a mental health crisis and require assessment or intervention. Staff provide a range of services including emergency mental health and crisis management to clients and families on evenings and weekends. The team will respond to clients by visiting them at home or making contact at other locations in their community. These services are voluntary and are provided with the consent of the client.<sup>120</sup>

- » *Urgence psychosocial-Justice (UPS-J)* in Montreal responds to cases involving adults with a mental health problem who have performed or are about to perform a criminal act. The goal is to avoid or reduce the incarceration of individuals with severe and persistent mental health problems and promote their integration in the community.<sup>121</sup>
- » Crisis centres across Quebec are open to adults in a state of psychological or psychosocial distress, and to their relatives. The goal is to help them cope with stressful situations and prevent hospitalization whenever possible. 24/7 services include consultation, evaluation, referral, follow-up and temporary accommodation.<sup>122</sup>
- » Community Treatment Orders (CTO)<sup>123</sup> require compulsory treatment to ensure that ill people receive treatment when they are not willing to seek it and when it has been determined that the absence of treatment would compromise their health. In some provinces and territories, family caregivers are encouraged to be formally involved in developing and carrying out the treatment plan. The 2012 Ontario *Legislated Review of Community Treatment Orders Final Report* states: “The family and friends we were able to engage with were almost uniformly positive about CTOs. They commented on the improvements they observed in their loved-one’s quality of life and improvements in their own well-being as they worried less about them” (p. iii).<sup>124</sup>

## Recommendation 25:

- 25.1: Engage families, where applicable, in the discussion around using a Community Treatment Order.
- 25.2: Develop or enhance mental health training programs for police officers that emphasize working with and responding to family caregivers.
- 25.3: Support police services to develop protocols for offering support to family caregivers who witness their relative being apprehended such as referral to victim services.

## 8.2 SUPPORT FOR FAMILY CAREGIVERS OUTSIDE THE MENTAL HEALTH SERVICE SYSTEM

The *Mental Health Strategy for Canada* recommends more help for family caregivers through better financial supports, increased access to respite care and more flexible workplaces. Planning a comprehensive approach to meeting the needs of family caregivers is not the sole responsibility of the mental health system and requires action on the part of many other system stakeholders, including governments and other organizations.

### 8.2.1 RESPITE

Respite means different things to different people. Respite that provides a break from caregiving duties can be helpful and is most effective when the family caregiver identifies what they need to achieve respite and when the services are flexible enough to meet these needs. There are few studies that look at the effects of respite care on family caregivers of those living with mental illness.<sup>125</sup> Findings from studies asking family caregivers about their satisfaction with respite care suggest that respite care services must be targeted, flexible and accessible.<sup>126</sup> Older family caregivers who reported negative experiences with respite care said that the service was too short, of poor quality or that the person they were supporting refused to take part in the respite service.<sup>127</sup> Where family caregivers reported a positive experience, they credited respite care with helping both them and the person living with mental illness to cope better.

» Australia has a National Respite for Carers Program that “makes funds directly available to family caregivers for respite services, respite centres, resource centres and a caregiver-counseling program” (p. 24).<sup>128</sup>

**Recommendation 26:** Provide a variety of respite options in the community that can be tailored to family caregiver preferences.

### 8.2.2 FINANCIAL SUPPORT

To cope effectively with their caregiving responsibilities, many family caregivers require financial support. Results from a national survey of Canadian family caregivers (including those caring for adults living with mental illness) found that about 60 per cent of family caregivers pay out-of-pocket expenses (primarily transportation and medication-related costs), with 30 per cent spending over \$300 per month (p. 7).<sup>129</sup> In large part, these expenditures are due to the family caregiver compensating for inadequate social assistance incomes for the person living with mental illness, along with insufficient and frequently inadequate housing and other necessities for social participation. Some family caregivers may risk sharing the poverty of the person living with mental illness.

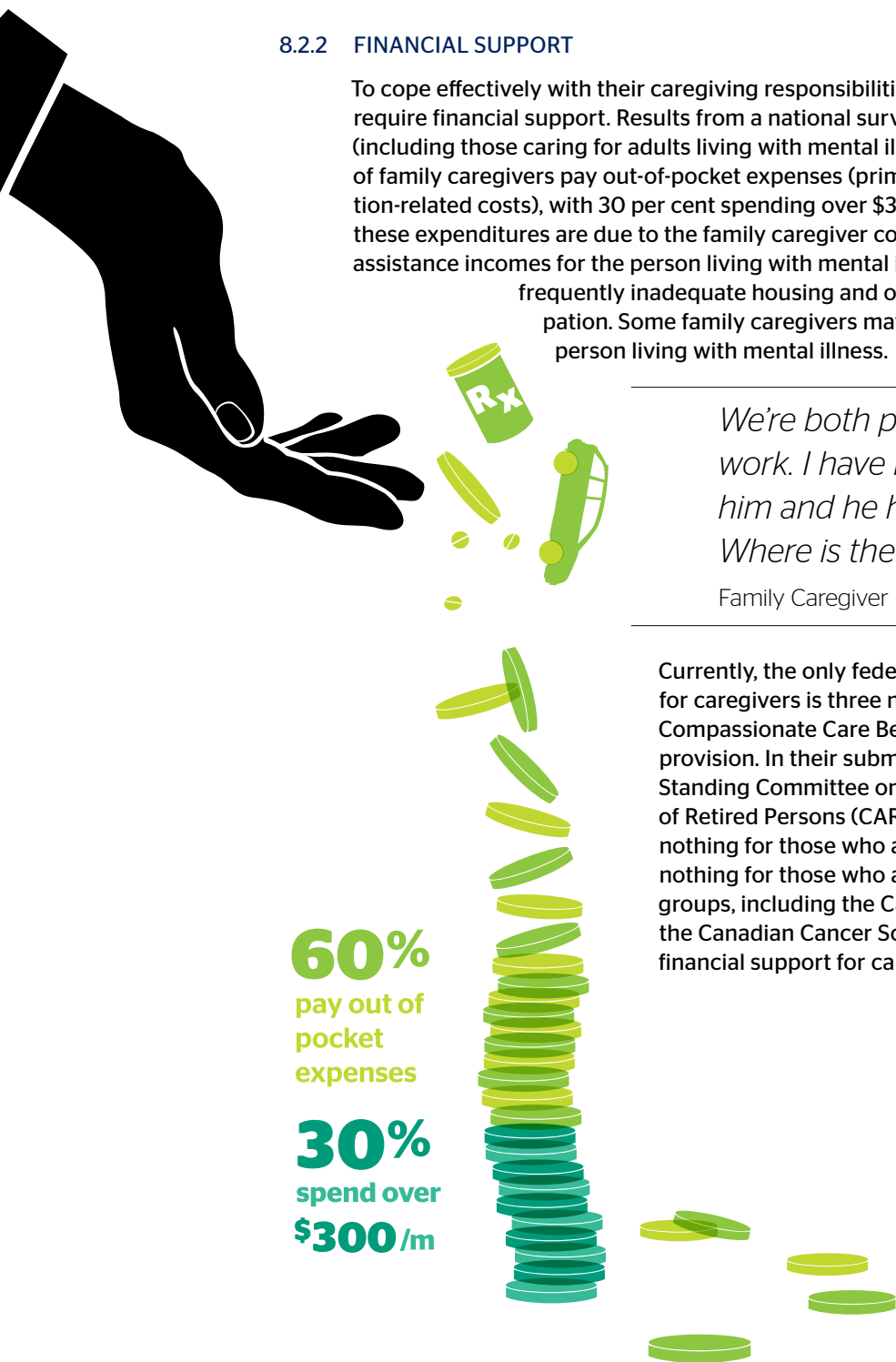
*We're both poor. He can't work. I have nothing to give him and he has nothing. Where is the justice?*

Family Caregiver

Currently, the only federal government financial support for caregivers is three non-refundable tax credits, the Compassionate Care Benefit and the CPP dropout provision. In their submission to the House of Commons Standing Committee on Finance, the Canadian Association of Retired Persons (CARP) noted that “these do virtually nothing for those who are low-income and absolutely nothing for those who are unemployed” (p. 2).<sup>130</sup> Many groups, including the Canadian Caregiver Coalition and the Canadian Cancer Society, are advocating to improve financial support for caregivers.<sup>131</sup>

**60%**  
pay out of  
pocket  
expenses

**30%**  
spend over  
\$300 /m



There have been a number of proposals arguing specifically for a caregiver allowance for Canadian family caregivers (see CARP<sup>132</sup>). Such an allowance would:

- be paid to caregivers to sustain the caregiving relationship and to reduce the need for or avoid delays in institutionalization of the care recipient.
- correspond to a more internationally common form of direct assistance.
- consist of a monthly or biweekly payment or grant.
- be considered to be a financial contribution to a caregiving situation rather than direct compensation to the caregiver for time involved (Keefe & Fancey, 29) (p.2).<sup>133</sup>

» In Australia, financial support policies for family caregivers have been in place for some time. This includes a “carer allowance”, a cash benefit to family caregivers providing at-home care, and a “care payment” for caregivers whose caregiving responsibilities limit their ability to participate in the workforce.<sup>134</sup> Similar supports are available in Norway, Sweden and the United Kingdom.

» Nova Scotia has a *Caregiver Benefit Program* that targets “low income care recipients who have a high level of disability or impairment as determined by a home care assessment. If the caregiver and the care recipient both qualify for the program, the caregiver will receive the Caregiver Benefit of \$400 per month.”<sup>135</sup>

» The *Registered Disability Savings Plan (RDSP)*<sup>136</sup> helps Canadians with disabilities and their families save for the future. Canadian residents under age 60 who are eligible for the Disability Tax Credit (Disability Amount) may be eligible for an RDSP. Earnings accumulate tax-free until the money is taken out of the RDSP. Parents or guardians may open an RDSP for a minor. With written permission from the holder, anyone can contribute to the RDSP.

**Recommendation 27:** 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.

Employed family caregivers are faced with additional financial challenges. Having to leave the workforce may leave some without insurance coverage or pension protection, and risks their long-term economic security. Without employment, family caregivers can no longer make contributions to the Canada Pension Plan (CPP), jeopardizing their financial security in retirement.<sup>137</sup> The federal government has several financial support programs for employed Canadians that, with some adaptation, could be made more caregiver friendly. The following three suggestions for policy changes that would take into account the needs of family caregivers are based on Maytree’s *Policy in Focus* newsletter, Issue 11:

**Expand EI compassionate care leave** – The federal government should expand EI compassionate care leave provisions to allow special leave for the care of persons with chronic conditions. Current provisions limit support to those caring for terminally ill relatives.

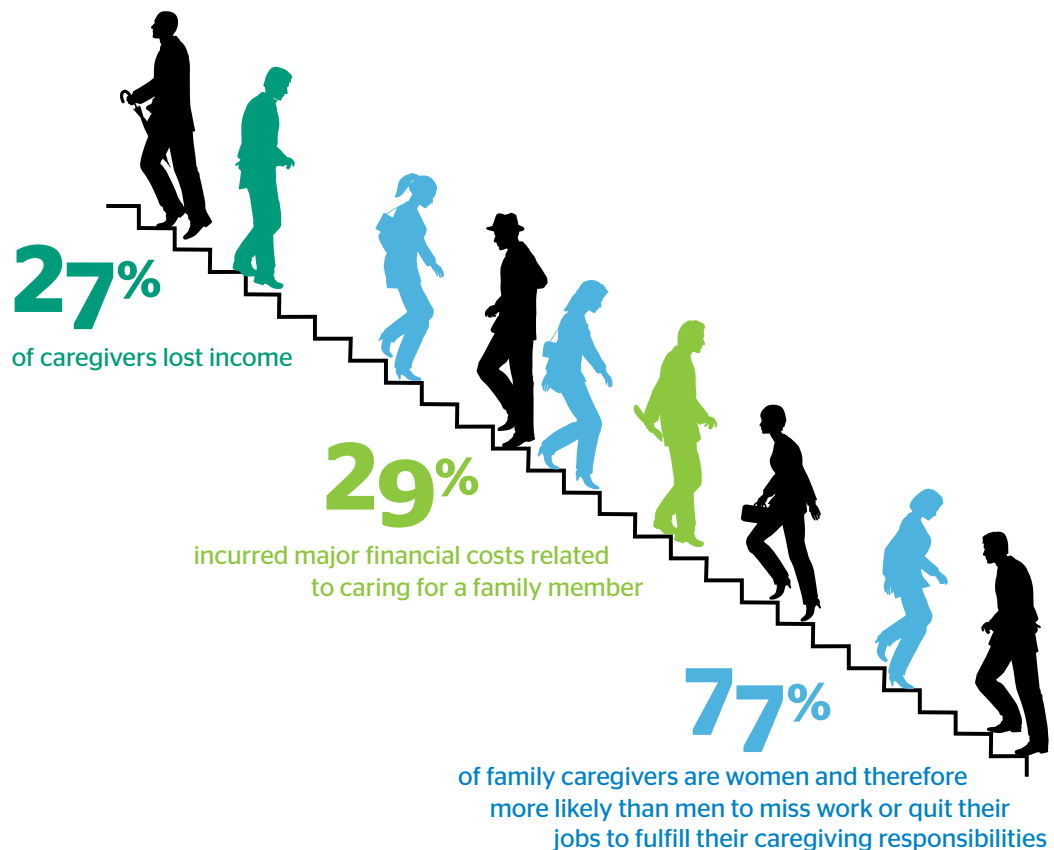
**Extend CPP provisions** – The CPP currently permits workers to exclude from the calculation of pensionable earnings the years when they stopped work or had lower earnings while they had a child under age seven. The federal government should extend this provision to protect the retirement earnings of caregivers who temporarily leave the workforce to care for a person living with a mental illness.

**Make current tax credits for caregivers refundable** – This means that households too poor to pay income tax would actually receive some money from the government to help offset their caregiving costs. Alternatively, the tax credits could be turned into a modest caregiver allowance that would assist all caregiving households. The UK and Australia, for example, pay a small cash benefit to the family caregiver of individuals requiring chronic at-home care (p.3).<sup>138</sup>

**Recommendation 28:** 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.

### 8.2.3 WORKPLACE ACCOMMODATION

Caregivers in the workforce may need to reduce hours or adjust responsibilities as a result of their caregiving role. Such adjustments may result in some cost to themselves and other family members, and in other negative consequences.<sup>139</sup> The *Mental Health Strategy for Canada* notes that caregiving can hinder participation in the workforce and cause caregivers serious economic hardship. One study reported that “27% of caregivers lost income and 29% incurred major financial costs related to caring for a family member” (p 74).<sup>140</sup> Women especially are affected as 77 per cent of family caregivers are women and therefore more likely than men to miss work or quit their jobs to fulfill their caregiving responsibilities.<sup>141</sup>



The *Mental Health Strategy for Canada* asserts that family caregivers require family-friendly workplace policies (e.g., caregiver leaves, flexible hours) to reduce the likelihood of loss of income due to caregiving responsibilities.<sup>142</sup> Family caregiver-friendly policies would benefit not only family caregivers but also employers and society at large.

**Recommendation 29:** 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.

#### 8.2.4 FUTURE PLANNING

Caregiving may be a longstanding commitment and a life-long preoccupation for caregivers, and particularly for parents of persons living with mental illness. As they age, this preoccupation often increases when parents wonder who will take over their caregiving role once they are not available.<sup>143</sup> Siblings worry about who will take care of the ill sibling when parents no longer can and, although they are frequently considered to be the logical replacements for aging parents, some siblings may not wish or be able to take on this role.<sup>144</sup>

Planning for the future of an ill family member includes two main components: *financial* planning and *personal care* planning. Financial planning refers to the financial arrangements caregivers need to make to secure financial safety and security for their ill relative. The needs of the ill relative should be considered in terms of their financial interests, and the income he or she receives from all sources must be reviewed. Government assistance may require that certain criteria be fulfilled, and so for the person's income not to be compromised, caregivers need to be familiar with such conditions and factor them in when forecasting the future financial needs of their relative. Wills and estate planning can help caregivers address this concern.

Securing the personal care of an ill relative may be more challenging, especially for individuals who require support to meet their own needs. It is important to address these issues in a timely fashion to minimize the difficulties the person living with mental illness may experience once his/her parents are gone. Both financial and personal care planning should be done with the participation of the person living with mental illness, as well as with other family members, to the extent possible. Providing relevant information through workshops and written guides could help people living with a mental illness and their caregivers to prepare for the future.

» *Sharing the Care: financial and legal considerations in planning for people with mental disabilities in Quebec*, is a guide to assist family caregivers in their plans to secure the future of an ill relative.<sup>145</sup>

**Recommendation 30:** 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.

## 9 FACTORS FACILITATING SYSTEM TRANSFORMATION

This section outlines some important changes that need to take place within the mental health system and within some service delivery organizations. These changes will facilitate a culture in which family caregivers are supported in their caregiving role and can sustain their own well-being.

### 9.1 FAMILY CAREGIVER ENGAGEMENT IN SERVICE PLANNING AND EVALUATION

Family caregivers are well-positioned to assist in planning and evaluating the programs and services intended to support them in their caregiving role. The MHCC has stressed the importance of hearing family caregivers' voices in the development of a national mental health strategy for Canada and has reinforced this in one of its recommendations.<sup>146</sup> The *Caregiver Policy Lens (Lens)*<sup>147</sup> can be used to engage family caregivers in planning and reviewing policies and programs. The *Lens* stresses the importance of having family caregivers at the table in planning and evaluating services and programs in a meaningful way. It provides a process to facilitate family caregivers' active participation, beyond the merely symbolic. Results from applying the *Lens* can be used to develop an action plan to address any unintended negative effects of policies and programs on family caregivers.

**Recommendation 31:** 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.

Family caregiver involvement needs to be meaningful. The World Health Organization<sup>148</sup> suggests that family caregivers can make important contributions to the mental health system by being involved in system-level roles, such as strategic planning for the organization, service planning, implementation, delivery and evaluation (e.g., satisfaction surveys, accreditation), as well as health policy decision-making and resource allocation and development.

To facilitate their effective participation, family caregivers may require orientation to the organization's operations and to the mental health system, as well as training in participation and encouragement to express their views. They may also require services or resources to support attendance, such as transportation costs and care for their relative while away from home.

**Recommendation 32:** Facilitate the meaningful participation of family caregivers in planning and evaluating services by providing orientation, education and encouragement as needed.

Government policies can support family caregiver engagement in planning and evaluating mental health plans and services at all levels.

- » In British Columbia, the Ministry of Health's *Best Practices in Family Support and Involvement* recommends that families be involved in the planning and evaluation of services.<sup>149</sup>
- » In Quebec, the "Commissioner for health and well-being" released the *Rapport d'appréciation de la performance du système de santé et de services sociaux 2012*, which includes acknowledgement of the important role that families play within the mental health system.<sup>150</sup>
- » In Manitoba, as a result of the provincial Caregiver Recognition Act, a Caregiver Advisory Committee has been formed to advise the Minister of Healthy Living, Youth and Seniors on caregiver issues and family caregiver policy.<sup>151</sup>
- » In New Zealand, at least 50 per cent of the membership of their Mental Health Planning and Advisory Councils must be service users and family caregiver members. These groups review community mental health plans, monitor and evaluate mental health services and advocate for adults and children with mental illnesses.<sup>152</sup>
- » In the United States there is a national body called the *National Association of Mental Health Planning and Advisory Councils* that provides state councils with technical support, information sharing and a national voice on mental health planning issues.<sup>153</sup>
- » In Australia, mental health services are required to involve family caregivers and service users in the delivery and development of mental health services. To ensure this occurs, practice standards have been developed that provide clear guidance to mental health service providers regarding family involvement.<sup>154</sup>

### Recommendation 33: Develop caregiver recognition legislation in all provinces and territories.

Within organizations, practice standards for involving and supporting family caregivers are an important instrument for facilitating family engagement and inclusion. Practice standards are measurable and can increase mental health service providers' accountability, especially when incorporated into accreditation standards. Within organizations, practice guidelines would need input from management, coordinators and frontline staff, in consultation with the family caregiver and consumer groups.

- » Psychosocial Rehabilitation (PSR) Canada has developed practice standards for recovery-oriented care that support family caregiver involvement at the organizational level.

#### **Standard 4 - Individual, Family and Community Participation**

*Individuals, family as defined by the individual and the community, where appropriate, are involved in the planning, implementation and evaluation of the psychosocial rehabilitation support service.*

- 4.1 Policies and procedures relating to the participation of individuals, defined family and the community in planning, evaluation and service delivery are comprehensive and inclusive. Evidence of this may include:
  - Policies and procedures guide the participation of individuals, defined family and the community at every level of the service.
  - Procedures are in place to support individuals and defined family in expressing their views.<sup>155</sup>

**Recommendation 34:** 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.

## 9.2 LEADERSHIP AND ORGANIZATIONAL SUPPORT

Achieving a comprehensive mental health system that promotes and supports the well-being of family caregivers will require strong leadership at all levels to shift organizational culture towards a person and family-centred model. Commitment to change can be expressed in organizations' missions, programs, mandates and strategy documents, and be evident in the organizational goals and priorities for which managers are responsible. Leadership from the top can inspire action in others, leading to culture change throughout the mental health system.

» In British Columbia, a commitment to family engagement has been made at the provincial level, as evidenced in the Best Practices for Family Support and Involvement, and the Family Charter of Rights (developed by the Provincial Mental Health Family Advisory Council, Adult Mental Health Division, Ministry of Health). Provincial and territorial leadership has resulted in strategic plans in all Health Authorities to support family caregivers.

**Recommendation 35:** 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.

At the organizational level, policies and programs need to reflect the importance of family caregivers, the value of caregiving and should lay the groundwork for collaborating with family caregivers and addressing their needs. To accomplish this, mental health organizations need to establish “recovery-oriented system standards” that are linked to policies and procedures, able to monitor progress, establish indicators and track outcomes.<sup>156</sup> For example, including family caregiver support in mental health service providers' job descriptions, practice standards, performance appraisals, program descriptions and strategic plans is vital to supporting mental health service providers' roles with family caregivers.

» Fraser Health Authority *Mental Health and Addictions Strategic Plan 2007 - 2012* formally acknowledges the value and needs of family caregivers, and has developed a strategy to include family caregivers called *Families Are Part of The Solution: A Strategic Direction for Family Support & Inclusion*.<sup>157</sup> They also have a policy on family inclusion to guide mental health staff.

Implementation of family support and inclusion can also be facilitated by clinical practice guidelines that provide explicit detail about how clinicians can carry out their roles.

Significant evidence and international consensus among mental health service provider groups has resulted in evidence-based practice guidelines for clinicians working with families. For example, in the case of psycho-education interventions among families of individuals with schizophrenia, clinicians need to:

- coordinate all elements of treatment and rehabilitation to ensure that everyone is working towards the same goals in a collaborative, supportive relationship.

- pay attention to the social, as well as the clinical needs of the person.
- provide optimum medication management.
- listen to families and treat them as equal partners in treatment planning and delivery.
- explore family members' expectations of the treatment program and for the person.



- assess the family's strengths and limitations in their ability to support the person.
- help resolve family conflict through sensitive response to emotional distress.
- address feelings of loss.
- provide relevant information for the person and family at appropriate times.
- provide an explicit crisis plan and professional response.
- help improve communication among family members.
- provide training for the family in structured problem-solving techniques.
- encourage the family to expand their social support networks (e.g., participation in multi-family groups and/or family support organizations such as the National Alliance for the Mentally Ill).
- be flexible in meeting the needs of the family.
- provide the family with easy access to a professional in case of need if work with the family ceases (p. 225).<sup>158</sup>

**Recommendation 36:** Develop practice guidelines on working with family caregivers and incorporate them into mental health service provider training.

### 9.3 DEVELOPMENT OF A KNOWLEDGEABLE AND SKILLED MENTAL HEALTH WORKFORCE

A knowledgeable and skilled workforce is needed to make the shift to a person- and family-centred model and to effectively engage and support family caregivers. This may not come from standard professional education where many mental health clinical training programs continue to use textbooks, terms and concepts that focus on family pathology rather than family coping, adaptation and competence.<sup>159</sup> Further, most mental health service providers have been trained in, and their work has demanded, a focus on the individual living with mental illness. Although most do not have formal training to work with family, the "... tasks of engaging, providing education and collaborating with most families are well within the scope of an adult mental health worker; with minimal extra training provided the clinician has a general framework for incorporating family work in their everyday practice (p. 2)."<sup>160</sup>

Orientation for new staff needs to include content about the recovery model and family-centred care. For those already in the workforce, a framework for education to facilitate competency in working with family caregivers, implemented in segments over time and tailored to participants' roles and responsibilities, is suggested.<sup>161</sup>

» BC Best Practices in Family Support and Involvement recognizes that a more comprehensive professional education program for mental health service providers will promote a greater understanding of the effects of mental illness on family, facilitate a change in attitude and enhance support for family caregivers. It recommends:

- including skills and competencies in working with families as part of the training provided for mental health service providers.
- providing ongoing mandatory in-service training for working with families.
- providing sessions about partnerships, where family members are included as presenters.
- providing training and information about Freedom of Information Guidelines regarding confidentiality.
- educating staff about the “Family Charter of Rights” (p. 14).<sup>162</sup>

Mental health services can use hiring practices and performance appraisals that focus on competencies to facilitate a knowledgeable and skilled workforce.

Desirable competencies for engaging and supporting family caregivers (Marsh 1998) include: assist family members to clarify needs; utilize rehabilitation/educational approaches to encourage skill development; focus on family strengths; acknowledge limitations and work as a team; help family members learn how to take care of themselves; provide practical and useful advice and support for families with dually diagnosed relatives (Mueser & Fox 2002); remain current about psychiatric illness and medications; and acknowledge and respect diverse cultures and beliefs. (p. 7)<sup>163</sup>

#### Recommendation 37:

- 37.1:** Provide training and support to mental health service providers to increase their knowledge of and sensitivity to family caregivers.
- 37.2:** 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.

#### 9.4 DEVELOPMENT AND PROVISION OF APPROPRIATE RESOURCES

How resources are allocated reflects the value of specific services and importance of those they are meant to serve. Sufficient resources and supports must be available to enable mental health service providers to provide services to family caregivers.

The creation of a family coordinator role, responsible for planning, developing and coordinating family support and services, and integrating them into the routine range of service options, has occurred in some jurisdictions, freeing mental health service providers for direct services.<sup>164</sup> A family coordinator could also be responsible for ensuring that information about family needs is widely distributed to those caring for adults living with mental illness, in and outside of the mental health system.

**Recommendation 38:** 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.

## 9.5 PARTNERSHIPS

Caregiver advocacy groups (e.g., Canadian Caregiver Coalition and provincial or territorial family caregiver associations) and family caregiver organizations are natural partners in efforts to build a comprehensive mental health system that supports and involves family caregivers.

Family caregiver organizations are currently the backbone of support and education for many family caregivers. They provide significant public education about mental illness with the goal of reducing stigma and promoting recovery. Family caregiver organizations provide a broad range of direct services to families, often including peer-led support groups, information and education sessions, skill development workshops, guidance, advocacy and sometimes counseling. These services would be extremely costly to replace in the formal mental health service system.

Despite the existence of many family caregiver organizations across the country, referrals by mental health service providers are usually not made as a matter of routine, and real partnerships seldom occur.

The range and amount of service that community service organizations can provide is often hampered by the struggle to secure funding. Collaborations between community service organizations and the formal mental health service system would maximize the benefits to the family and enhance service capacity.

**Recommendation 39:** 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.

Partnerships between organizations representing people with lived experience of mental illness, caregivers, the mental health service system, government, and academic and research centres can help to establish a research agenda that is grounded in practice and that builds on the existing evidence that family caregivers have a significant impact on the mental health system and on outcomes for people living with mental illnesses.

**Recommendation 40:** 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.

Partnerships with organizations outside the formal mental health service system can strengthen efforts to develop a comprehensive mental health service system that supports family caregivers. In Canada, there is a growing call for a strategy to support all family caregivers from the Canadian Caregiver Coalition<sup>165</sup>, the Alzheimer Society of Canada and other community organizations. A strategy to support family caregivers can help to identify what actions are needed to ensure that caregivers are valued and recognized for their vital contributions. New Zealand and Australia have successfully developed national strategies that accomplish this goal. Canada should follow their example.

**Recommendation 41:** 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.

## 10 CONCLUSION

Family caregivers make significant contributions to the well-being and recovery of people with mental illness, as well as to society at large. However, the challenges that family caregivers shoulder – emotionally, physically, financially and socially, as a result of inadequate recognition and support for their caregiving role – are significant, and can lead to chronic stress, compromise the caregiver’s quality of life and the efficacy of the help they provide, and increase costs to health and social service systems. There is ample evidence that supporting family caregivers benefits all stakeholders, including people living with mental illness, family caregivers themselves and both the mental health system and society as a whole. The voices of family caregivers embedded in this document underline the immediate need for a transformed system that recognizes their role and offers appropriate support.

The *Mental Health Strategy for Canada* asserts that the failure to support family caregivers “undermines mental health across the population, leads to poorer outcomes for people living with mental health problems and illnesses, and increases costs to the system.”(p. 29)<sup>166</sup>

To address the needs of family caregivers, a comprehensive, principled and evidence-based approach has been proposed in this document. A number of recommendations focus on how to better engage and support family caregivers and how to build system capacity. Examples are offered of leading practices and programs that can be replicated or used as inspiration for innovations to meet local needs.

Support for family caregivers of adults living with mental illness is an integral and vital part of the transformed mental health system envisioned in the *Mental Health Strategy for Canada*. To move forward, political will and grassroots action by all stakeholders is needed. Following the lead of Australia, the United Kingdom, New Zealand and others, Canada has the opportunity to enshrine the role of Canadian family caregivers within a comprehensive mental health system that provides the necessary leadership, structures and resources that support and involve family caregivers effectively and authentically. The need to support family caregivers is urgent and immediate action is required.

# Endnotes

1. <http://www.mentalhealthcommission.ca/English/issues/caregiving>
2. The term *family caregiver* denotes those in the circle of care, including family members and other significant people identified by the person living with mental illness, who provide unpaid support to that person. Family caregiving ranges in intensity and in the amount of time, care and support required, depending on the person's illness and on their family's capacity. The adult living with mental illness may live apart from family caregivers and still receive support.
3. Family caregiving ranges in intensity and in the amount of time, care and support required, depending on the person's illness and on their family's capacity. The adult living with mental illness may live apart from family caregivers and still receive support.
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# Appendix 1

## RECOMMENDATIONS

The *Guidelines* include 41 recommendations, found throughout the document. They have been grouped into five broad categories in the tables that follow to support readers in locating the recommendations they may find most relevant to their interests:

- Integrating Family Support into Mental Health Services
- Training and Support for Mental Health Service Providers
- Government and Policy
- Intersectoral Partnerships
- Public Awareness

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.42): 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, workplaces 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.

# Appendix 2

## PROCESS TO DEVELOP THE GUIDELINES

### LITERATURE SCAN

The literature searched for this paper included both peer-reviewed academic journals as well as grey literature and policy documents. Canadian sources were of primary interest; however literature from Australia, New Zealand, the United Kingdom and the United States was also included.

Keyword searches of the academic literature were conducted in online databases such as CINAHL, Medline and PsychInfo, for literature published between 2002 and 2012. The population of interest was caregivers of adults (18-65) with mental illness. In addition to the above-mentioned databases, searches using Google and Google Scholar, and hand searching of key references and caregiver association websites yielded additional sources. Given the focus on evidence-informed practices, review articles (including meta-analyses) were sought over and above single study sources. Searches were conducted using the following keywords: caregiver(s) or caregiving, family caregivers, caregiver burden, severe mental illness, psychosis, schizophrenia, bipolar disorder, “major depression” or suicide AND services or interventions or programs or “evidence-based” or “evidence-informed” or evaluation. Additional terms, such as review and meta-analysis, were also included to identify sources.

### FOCUS GROUPS

Six locations (Victoria, Calgary, Thunder Bay, Toronto, Quebec City and Fredericton) were identified by the steering committee for the focus groups in June and July 2012. One focus group was held in French and the others in English. Family caregivers and adults living with mental illness were most commonly (or usually) recruited through local hospitals, local or provincial chapters of non-profit mental health organizations and multicultural mental health support groups. The organizations received a brief description of the project from the MHCC and were asked to recommend active family caregivers of adults with mental illness. MHCC staff then contacted the family caregivers to learn more about their experience, share the proposed content draft, review confidentiality issues and provide more information on the project and the focus group purpose.

The researcher met first with the family caregivers for approximately 60 to 90 minutes, following which adults living with mental illness and service providers joined the group for a further two hours. The purpose of meeting first with only family caregivers was to provide a safe space for them and to optimize their opportunity to share their experiences.

Nearly 50 family caregivers caring for adults living with mental illness, most frequently with schizophrenia or another psychotic disorder, attended the focus groups. Of these, a significant majority were women, most were caring for an adult child, and about a fifth of the caregivers were providing care for a spouse, a sibling, or a parent, sometimes in addition to an adult child. Each focus group also included people with lived experience of mental illness, as well as service providers from different disciplines and sectors within the mental health system. Representatives from not-for-profit mental health organizations were also involved.

Following a brief overview of the project and answering any questions, confidentiality was discussed and consent forms completed by all participants. A semi-structured conversation was then led by the researcher and audiotaped for future reference. Participants were first asked to provide a brief overview of their caregiving experience, and then asked the following questions, (referring to the outline of intended *Guidelines* content):

- Are there any areas in the draft that need to be highlighted or further elaborated?
  - Are there issues that have not been addressed at all?
  - What, if anything, is missing in the present continuum of support and
- services for family caregivers of adults with mental health problems, in the draft?
  - Can you give us examples of positive programs/services that promote or support the well-being of family caregivers?

Overall the outline was well-received by focus group participants and generated valuable discussion about challenging issues family caregivers had experienced, along with their ideas about how their needs could best be met. Their feedback is an integral component of the *Guidelines* and in some places has been incorporated into the *Guidelines* in their own voices as italicized quotations.





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