



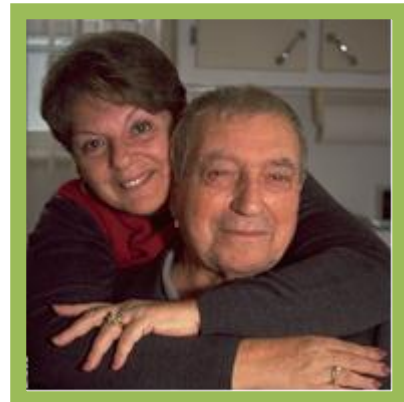
## **Supporting Caregivers through Policy:**

The Caregiver Policy Lens

An evidence-informed practical resource for developing policy, legislation, programs and services that support caregivers.



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for the BC Ppsychogeriatric Association*



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## **Who We Are**

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**Additional Resources:**

Additional information on caregiving resources for service providers, policy analysts, researchers and advocates is available at [www.caregivertoolkit.ca](http://www.caregivertoolkit.ca).

**Disclaimer:**

Every effort has been made to ensure the accuracy of the information provided on this website. The views expressed herein do not necessarily represent the views of the Government of Canada or of the BC Psychogeriatric Association.

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## I - SUPPORTING THE CAREGIVERS THROUGH POLICY – THE CAREGIVER POLICY LENS

“Caregivers” are defined as family members and friends who care for someone to support their health and wellbeing, typically without pay. They are also referred to as “informal caregivers”, “primary caregivers” and “carers.” It is important to note that although these terms are used by health and social service systems, family and friends who provide care may or may not identify themselves as caregivers. Caregiving can be a rewarding experience but is frequently fraught with challenges.

### Caregivers: A Vital Resource

The support that caregivers provide to family and friends is vital to the well being and quality of life of these individuals, and a major contribution to Canadian society. Canada’s population is aging and along with this there is an increased prevalence of multiple chronic health conditions, and a corresponding increase in the complexity of needs.

- There are approximately 4.5 million Canadians providing care for a family member with long-term health problems<sup>1</sup>.
- Seventy-five to eighty-five percent of the care today’s seniors receive is provided by family and friends (“caregivers”)<sup>2</sup>, 60% of whom provide care for more than three years.<sup>3</sup> It is estimated that if all the services provided by informal caregivers in the community were replaced at rates paid to home healthcare providers, the value would be \$25 to \$26 billion.<sup>4</sup> Additionally, the *number* of seniors needing assistance is expected to more than double between 2001 and 2031.<sup>5</sup>
- With the aging population the number of seniors providing care will also grow. One in four caregivers is over age 65<sup>6</sup>, many of whom are likely to experience their own age/ health related challenges,<sup>7</sup> and are at risk of becoming care recipients themselves. Supporting them in their role as caregivers lessens this risk and the additional health care costs this would entail.
- Most care recipients are elderly, although this is not exclusively the case. More than half (57%) are 65 years of age or older, and 17 percent are at least 85. At the same time, one in four are under 45, most of whom are children (minors or adults) being cared for by a parent. Parents being cared for by their children are mostly 75 and older, while spouses/partners range more broadly in age, with most
- between 45 and 84.
- Among caregivers who are employed, one in four faces challenges at work (e.g., increased absenteeism for illness and caregiving responsibilities), with economic implications for their income now and in retirement, and for their employers<sup>8</sup>, all of which contributes to both immediate and future burdens on society.
- Caregivers provide care when the recipient is institutionalized<sup>9</sup>, an important consideration with the challenges in staffing long term care facilities that will only grow with the aging workforce.
- Caregivers often provide care for many years and often care for more than one care receiver at a time.

## Caregivers: In Need of Support

Most public policies have been developed without taking into account the needs that affect caregivers of older adults. Their contribution has been mostly overlooked, largely under-valued, and even undermined. Often these policies have unintentional negative effects on caregivers and their families, potentially increasing the burden on themselves, those they care for and the health care system.

Without (1) recognition of the importance of caregivers to the health and social service systems, (2) their inclusion in policy making, and (3) adequate support for their role, the tremendous social and economic contribution caregivers make will be jeopardized. Caregiving is associated with financial strain, and with physical and psychosocial symptoms, placing the physical and mental health of the caregiver, and their ability to continue to provide care, at risk<sup>10</sup>. For example, almost one third of those providing care to seniors with a dementia experience depression<sup>11 12 13 14</sup>. Low levels of social support have also been associated with negative psychological and health outcomes<sup>15</sup>. In addition, there are immediate and future financial costs related to the provision of unpaid labour; out of pocket expenses incurred through purchasing equipment, supplies, and services; or reduction in employment income through reduced hours or missed time, turning down promotions or training, or even leaving the labour market to provide care.<sup>16 17 18 19 20</sup>. As a result, caregivers may find themselves without immediate and long-term financial security, perhaps requiring social support.

In spite of these risks to caregivers' well-being, and all that this implies, in most Canadian jurisdictions caregivers' needs are not formally acknowledged, assessed, or addressed by health and social services, and often service providers lack evidence-informed tools and resources to do so. Policies, programs and services that value and support caregivers and their role can promote caregivers' well-being and reduce the potential risks to these most valuable individuals.

## Introducing the Caregiver Policy Lens

The Caregiver Policy Lens (CGPL) is a framework for examining policies, programs and services from the perspective of caregivers. Government, organizational, program and service delivery policies can be analyzed for their potential effects (both positive and negative) on caregivers. The CGPL can be used to assess existing policies and programs that may affect caregivers directly (e.g., Caregiver Tax Credit, Caregiver Support Interventions) or indirectly (e.g., home care policies and programs for seniors).

The CGPL is a series of questions intended to (1) increase awareness about caregivers' needs, (2) facilitate the identification of any unintended negative effects of policies on caregivers, and (3) promote the inclusion of the caregivers, both as partners in care and in the development, implementation and evaluation of policies and programs that affect them.

Although the focus of this project is caregivers of older adults the information, tools and resources on this website are relevant to caregivers of younger adults who experience many of the same challenges and issues as caregivers of seniors, and access the same health, social and financial services.

## Who Should Use the Caregiver Policy Lens?

The CGPL is intended to assist policy analysts and program planners and managers to understand and consider the needs of caregivers. It can also be used by caregiver advocates and organizations, educators, service providers and researchers.

## When to Use the Caregiver Policy Lens

The CGPL can be used with policies and programs that affect caregivers directly or indirectly to:

- Frame development of new programs and policies
- Design policies and programs that value and support caregivers of older Canadians
- Critique proposed policies and programs for potential unintended negative effects on caregivers
- Assess whether policies or programs promote caregivers' well-being
- Identify gaps in current policies, programs and activities that affect caregivers
- Guide studies of the impact of programs on caregivers
- Develop a policy response to an issue or need

The CGPL can be used as a process tool to:

- Focus discussion on caregivers' needs and how to support them
- Engage in cross and multi sectoral consideration of policies and programs
- Facilitate multiple perspectives in support of caregivers' needs.

## Benefits of Using the CGPL

- Increased awareness of the value of caregiving.
- Increased awareness of the challenges caregivers' experience.
- Policies and programs that integrate and reflect caregivers' values and concerns.
- Consistent approach to policy development and redevelopment, and critique, that facilitates:
  - an integrated holistic, interdisciplinary, inter-jurisdictional and cross-sectoral approach to policy and programs affecting caregiver
  - information sharing regarding policies and programs that affect caregivers
  - increased sensitivity to issues affecting caregivers
  - partnerships in identifying and meeting the needs of Canadian caregivers
  - less duplication and fewer gaps
  - a society that values and supports caregiving

## Development of the Caregiver Policy Lens

The CGPL is informed by literature about, and extensive consultation with, caregivers. These consultations focused on caregivers' diverse roles, challenges and needs. Particular attention was paid to caregivers' relationships with service providers, their experiences with services, and gaps in having their needs met. Measures were taken to include caregivers from diverse backgrounds and caregivers who are marginalized. A

wide range of service providers, caregiver advocates, program managers and policy analysts were also interviewed about the needs of caregivers and the challenges in meeting these needs. Information was gathered from British Columbia, Manitoba, Ontario, Nova Scotia and Newfoundland, both in rural and urban areas. Information gathered about the optimal design of a policy lens has also been incorporated into the CGPL.

The key challenges that caregivers report they experience in obtaining support are summarized in Appendix 1. The principles, values and key concepts that frame the CGPL (derived from focus group and key informant results and from the literature), are described in Appendix 2.

## II - SUMMARY OF THE CGPL QUESTIONS

The following is a list of overarching questions to consider when creating or reviewing policies to ensure (1) that the perspectives of caregivers and other stakeholders are included, and (2) that caregivers' well being is promoted and negative effects on them are avoided. These questions can be used as a quick scan of a proposed or existing policy. If you are using an e-copy of this document, you can click on each question to link to the full question. **In the CGPL specific questions are posed to sharpen the focus of each overarching question and a scoring matrix is provided.**

### *Assessing Process Factors: Stakeholder Engagement*

1. [Caregiver Inclusion and Voice](#)  
How are caregivers, caregiver advocates and caregiver organizations involved in the design, decision making, implementation, and evaluation of the policy, program or practice?
2. [Collaboration](#)  
Are relevant organizations, Ministries, interest groups and individuals concerned with caregiving involved?
3. [Evidence Informed](#)  
Is the policy, program, or practice informed by evidence?

### *Assessing Policy/Program Content*

4. [Respect and Dignity](#)  
Does the policy, program or practice reflect respect for caregivers and support their dignity through valuing the importance of their contribution and acknowledging their relationship with the care recipient?
5. [Diversity and Marginalization](#)  
Does the policy, program or practice assess whether diverse caregivers and/or care recipients are likely to experience inequities or negative impacts resulting from their membership in marginalized groups?
6. [Choice, Self-Determination and Independence](#)  
Does the policy, program or practice promote and support caregivers' self-determination and independence?
7. [Accessibility](#)  
Does the policy, program or practice facilitate access to the services available to caregivers and make appropriate adaptations to accommodate diverse needs?
8. [Caregiver Assessment](#)  
Are caregivers' needs assessed and addressed separately from those of the care recipient?
9. [Sustaining Caregivers](#)  
Does the policy, program, or practice help equip caregivers with knowledge, skills and appropriate respite and other supports to carry out their role?



**10. Sustaining Systems**

Is the policy or program for seniors sensitive to the needs and concerns of caregivers, and delivered by knowledgeable staff with sufficient time and skill to develop caring, trusting relationships? Is the system appropriately resourced so that crises can be avoided?

**11. Fairness and Equity**

Does the policy, program, or practice ensure fairness to caregivers while not diminishing benefits to others?

### III - CAREGIVER POLICY LENS (CGPL)

**INSTRUCTIONS**

Refer to Appendix 2 *Values and Principles Underpinning the Caregiver Policy Lens* for explanations of the questions/concepts and questions to consider if applying the CGPL at the organizational/program levels.

**PREPARATION AND CONTEXT**

**Describe the context**

- Review and comment on the political or organizational context in which the policy/program is operating.
- Does the organization embrace the concept of caregivers as ‘partners in care’?

**Describe the Policy/Program**

- Review the purpose and objective of the policy/program to which the CGPL is being applied.
- What is the purpose of applying the CGPL (e.g., policy development, program review)?
- What are the interventions being recommended, implemented or evaluated by the CGPL?
- What is the expected outcome of the policy/program?

**Notes:** \_\_\_\_\_  
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\_\_\_\_\_

**Consider the Caregivers Likely to be Affected by the Policy/Program**

- Who are the caregivers likely to be most affected by the policy/program/practice under discussion (e.g., elderly caregivers, employed caregivers)?
- Who are they caring for (e.g., rural seniors, seniors with a dementia)?
- Think about those who are caregivers today as well as future caregivers.

**Notes:** \_\_\_\_\_  
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**Think about these caregivers as you respond to each of the CGPL questions.**

**APPLY THE CAREGIVER POLICY LENS**

- Beside each question in the CGPL check *Yes, No, or Not Sure, NA (Not Applicable)*, according to what you believe your policy or program reflects.
- Be sure to keep notes as you go about areas where you require more information and your plans for obtaining it.
- *In the online or CD versions of the CGPL, each of the question headings is linked to further information at the end of this document; click on them to clarify meaning and for examples of questions to consider in developing/reviewing organizational or program level policies.*

**Process Factors**

*Stakeholder Engagement*

**1. Caregiver Inclusion and Voice**

- Caregivers, caregiver advocates and organizations providing services to caregivers must be engaged in developing, reviewing and evaluating policies and programs that affect them directly or indirectly.

<b>Ask:</b>	<b>Yes</b>	<b>No</b>	<b>Not Sure</b>	<b>N/A</b>
Are caregivers affected by the policy/program (directly or indirectly) participants in the policy or program review/development?				
Are the general public, caregivers, care recipients and their advocates informed in advance about proposed policies and programs (or their review) that affect caregivers?				
Are caregivers and their advocates involved in the implementation of the programs and policies that affect them?				
Are caregivers and their advocates asked to provide evaluative feedback on policies and programs that affect them?				

**Who needs to be involved?**

**Notes**

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Click to link: [Questions to ask on an organizational/program level for caregiver voice and inclusion](#)

## 2. Collaboration

- A diversity of relevant organization, advocates, levels of government, and individuals concerned with caregivers of must be involved in developing or reviewing the policy or program.

Ask:	Yes	No	Not Sure	N/A
Has the policy/program been developed in collaboration with organizations, levels of government and programs that are concerned with caregivers or those that will be affected by the policy/program?				
Does the policy/program emphasize partnership and collaboration?				
Are relevant levels of government, non-government/ voluntary/ private organizations informed of proposed policies and programs (or their review) that may affect them?				
Are linkages made with organizations, community networks and coalitions addressing the needs of caregivers?				

### Who else needs to be involved?

Notes: \_\_\_\_\_

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Click to link: [Questions to ask on an organizational/program level for collaboration](#)

## 3. Evidence Informed

All policies and programs should be based on the best available evidence, including the experiential evidence of caregivers and service providers.

Ask:	Yes	No	Not Sure	N/A
Is it based on current evidence (including experiential) and/or best practices?				
Are measures in place to monitor and evaluate process and outcome?				
Are caregivers invited and supported to provide input and to evaluate the policy or program on an ongoing basis?				
Is the policy or program congruent with relevant laws and legislation?				

**Notes:** \_\_\_\_\_  
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 \_\_\_\_\_  
 \_\_\_\_\_

Click to link to: [Questions to ask on an organizational/program level about informed evidence](#)

**Policy/Program Content**

**4. Respect and Dignity**

- The policy/program must reflect respect for caregivers, value the importance of their contribution, and acknowledge the importance of their relationship with the care recipient.

Ask:	Yes	No	Not Sure	N/A
Is positive language used to portray caregivers and the care they provide?				
Are the contributions of caregivers formally acknowledged and valued?				
Is the need to respect caregivers' privacy and confidentiality identified?				
Is respect for caregivers (e.g., their time, relationship with the care recipient, their preferences and other obligations) demonstrated?				

**Notes:** \_\_\_\_\_  
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Click to link to: [Questions to ask on an organizational/program level about Respect and Dignity](#)

### 5. Diversity and Marginalization

- The policy or program must acknowledge and demonstrate sensitivity to diversity, and particularly to those who are marginalized.

Ask:	Yes	No	Not Sure	N/A
Does the policy or program demonstrate sensitivity to diversity in the use of language?				
Is the need to accommodate diverse interests and needs acknowledged?				
Are diverse caregivers and those who are marginalized engaged in developing, reviewing and evaluating policies and programs that affect them directly or indirectly?				

- Consider the unique needs of diverse caregivers and/or care recipients who may be marginalized.
  - Does the policy/program promote their well-being?
  - Are they likely to experience inequities or negative impacts resulting from their memberships in marginalized groups?
  - More information on each of the categories below can be found in Appendix Three.

Does this policy/program promote the well-being of, or avoid negative effects, for caregivers and/or care recipients who are:	Yes	No	Not Sure	N/A
5a. <a href="#">Women</a>				
5b. <a href="#">Men</a>				
5c. <a href="#">Minorities/Immigrants</a>				
5d. <a href="#">Gay, lesbian, bisexual or transgendered</a>				
5e. <a href="#">Low literacy or limited English or French skills</a>				
5f. <a href="#">Low-income</a>				
5g. <a href="#">Seniors</a>				
5h. <a href="#">Parents of dependent children</a>				
5i. <a href="#">First Nations, Inuit, Metis</a>				
5j. <a href="#">Caregivers of younger adults</a>				
5k. <a href="#">Caring for someone with compromised cognition</a>				
5l. <a href="#">Living with the care recipient</a>				
5m. <a href="#">Living In rural or remote regions</a>				
5n. <a href="#">Caregivers of persons with challenging behaviours</a>				
5o. <a href="#">Employed (paid or volunteer)</a>				

**Discussion Notes:** How can the policy/program be adapted to address the barriers/challenges that may be experienced by the specific populations of caregivers identified? (Consider information, eligibility, implementation).

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Click to link to: [Questions to ask on an organizational/program level about Diversity and Marginalization](#)

## 6. Choice, Self-Determination and Independence

- The choice to take up the role of a caregiver is the right of each individual. Does the policy or program reflect the right of caregivers to determine the parameters of the care they choose to (or not to) provide?

Ask:	Yes	No	Not Sure	N/A
Is the right of family members to decline, limit or end caregiving explicitly acknowledged?				
Are there prescribed points at which the caregiver's willingness and capacity to provide care, and the boundaries of their care, must be reviewed?				

**Notes:** \_\_\_\_\_

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Click to link to: [Questions to ask on an organizational/program level about Choice, Self-Determination and Independence](#)

## 7. Accessibility

- The policy/program facilitates access to programs/services available to caregivers and make appropriate adaptations to accommodate diverse needs.

Ask:	Yes	No	Not Sure	N/A
Is information about the policy readily and easily available in a variety of mediums and formats that reflects the diversity of caregivers (e.g., language, literacy, income, culture, vision, etc.)?				
Is an appeal process in place (with assistance as needed) for those who do not, or no longer, meet eligibility requirements?				
Are sufficient resources attached to the policy/program in order to ensure services are available in a timely manner?				

**Notes:** \_\_\_\_\_

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Click to link to: [Questions to ask at an organizational/program level about Accessibility](#)

## 8. Caregiver Assessment

- Caregivers have the right to have their own needs assessed and addressed, separate from those of the care recipient.

Ask:	Yes	No	Not Sure	N/A
Does the policy or program facilitate family/friends identifying as caregivers?				
Is the policy/program based on the identified needs of caregivers (separate from those of the senior)?				
Are policies/programs based on caregivers' input and feedback about how well their needs are assessed and addressed?				
Does the policy or program meet the stated needs of caregivers?				

Notes: \_\_\_\_\_

Click to link: [Questions to ask at an organizational level about Caregiver Assessment](#)

## 9. Sustaining Caregivers

- Caregivers must be equipped with the necessary information, education, skills, respite and other supports to enable them to carry out their role.

Ask:	Yes	No	Not Sure	N/A
Is education available to support caregiving (e.g., about the practical aspects of caregiving such as transferring, nutritional needs, etc.)?				
Is information about financial supports for caregivers available and is access to these supports facilitated?				
Is legal information and related supports available and accessible?				

Notes: \_\_\_\_\_

Click to link: [Questions to ask at an organizational level about Sustaining Caregivers](#)

## 10. Sustaining Systems

- The system that supports caregivers (directly and indirectly) requires appropriately educated and skilled human resources, and must be organized and resourced to facilitate continuity of care and to avoid crises leading to excess use of services.

Ask:	Yes	No	Not Sure	N/A
Are service providers educated about, and sensitive to, the needs of caregivers and how to support them?				
Do service providers have the appropriate knowledge, skills and supervision to provide sensitive and competent care to caregivers?				
Is there sufficient system capacity to be proactive and to meet both immediate and urgent needs of caregivers?				

**Notes:** \_\_\_\_\_

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Click to link: [Questions to ask at an organizational/program level about Sustaining Systems](#)

## 11. Fairness and Equity

- Policies and programs must be 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.

Ask:	Yes	No	Not Sure	N/A
Are the procedures and criteria inherent in the policy/program fair and reasonable?				
Does the policy ensure that caregivers do not accumulate disadvantages that will later impose individual or public costs (e.g., increased need for health care or financial support due to negative impacts on health; reduced pensions)?				
Does the policy or program consider both individual needs of the caregiver and collective needs (e.g., needs of all caregivers)?				
Does the effect of the policy or program create economic or social disadvantages for any population group inside or outside the health sector?				



**Notes:** \_\_\_\_\_  
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 \_\_\_\_\_

Click to link: [Questions to ask at an organizational/program level about Fairness and Equity](#)

## IV - CREATING AN ACTION PLAN

### 1. Summate the columns- How are we doing? Where can we improve?

**YES>NO?** You are well on your way to a positive policy/program. But look for some ways it could be improved. Go back and determine if there are any changes that will yet increase the number of “Yes” responses.

**NO>YES?** Your policy/program practice should be re-examined for content and overall intent. Many needs, preferences and concerns of caregiver are not being met. A good source of input is from caregiver themselves- ask them!

**NOT SURE> Either YES or NO** You need to gather more information before proceeding with your policy/program practice. This will ensure it more comprehensive and holistic.

**NOT APPLICABLE> Either YES or NO** Go back and critically examine your policy. Are there really this many categories that do not apply to your policy /program? Or does much of the policy/ program not apply to the needs, preferences and concerns of those for whom it is intended?

#### 1. Review

Review your notes and your discussions. Note strengths of the policy/program.

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#### 2. Identify

Identify the individual areas that require improvement and ways that potential negative effects could be addressed or off-set. Note who needs to be involved to make necessary changes, and what information needs to be gathered. Set target dates.

<b>Issues Identified</b>	<b>Actions/Information Needed</b>	<b>Who needs to be involved?</b>	<b>Target date</b>
<b>Issues Identified</b>	<b>Actions/Information Needed</b>	<b>Who needs to be involved?</b>	<b>Target date</b>

#### 4. Make a Recommendation

Answer yes or no to whether the policy should be *accepted*, or *accepted as revised*, whether there is a *need for more information*, or if *revision is required*.

RECOMMENDATION	Yes	No
Accepted		
Accepted as revised		
Need more information to decide from whom, where		
Needs revision		

#### 5. Revise

Revise the policy, and re-apply the lens, starting at the beginning. Repeat until the (revised) policy is recommended for acceptance.

#### 6. Date of next review?

## APPENDIX ONE: Challenges in Obtaining Support Identified by Caregivers

This section summarizes issues and challenges facing caregivers in obtaining the practical and personal support necessary to be resilient caregivers. The following is developed from information provided by more than 250 caregivers, service providers and others across Canada, including British Columbia, Manitoba, Ontario, Nova Scotia and Newfoundland, in both rural and urban areas.

- Caregivers of seniors were asked about their roles, challenges, needs, their relationships with service providers and experiences with services for seniors and for themselves, and gaps in getting needs met.
- Measures were taken to include caregivers from diverse backgrounds and caregivers who are marginalized.
- Service providers, caregiver advocates, educators, researchers, program managers and policy analysts were interviewed about the needs of caregivers and the challenges in meeting these needs.

**There is an assumption that family members will automatically provide some care and support by becoming caregivers.** Within the health and social service systems across Canada the senior in need of care is automatically conceptualized as the client and their family as a source of support and assistance to the senior.

*“There can be a lot of resentment and anger on the part of the caregiver feeling ‘forced’ into the role. Many people don’t want to be caregivers, for a diversity of reasons”. (Caregiver)*

**There is a lack of clarity about the role of caregivers and the role of formal health and social services.** The type of care giving required along with how much and for how long it will be required, is not routinely part of the formal assessment and care planning for the person receiving care. Service providers need to prepare caregivers for their role by informing them about issues such as the care receivers' health condition and legal and financial matters.

*“There are no real goals in service provision about providing care to caregivers, so that leads us to a sticky place where staff are trying to work a balancing act between what they can provide and what they should provide”. (Service provider)*

**The needs of the caregiver in their own right are not formally assessed.** Their capacity to provide care is generally assumed. Caregivers are not formally assessed in terms of their health, social supports, social and emotional needs, financial circumstances, competing obligations, relationship with the care recipient or family dynamics – all factors that could impinge on their willingness or capacity to provide care .

*“Service providers often don’t see the level of help required because all they see is that the work is done (i.e. clean house, clean client) and not the amount of work that goes into it – they think the caregiver doesn’t need help”. (Caregiver)*

**Obtaining appropriate information, knowledge and skills to manage such things as medical procedures, dietary needs, challenging behaviors and psychiatric symptoms is difficult.** Information and

education needs to be provided through a variety of mediums and opportunities for personal consultation made available.

*“As a caregiver, I get frustrated from lack of information about services and what to expect in caregiving role”. (Caregiver)*

**Caregivers may have difficulty discovering services for the care recipient , or in accessing them.** This is especially true where the care recipient has multiple needs that may require the services of a number of different agencies/providers, and when caregivers lack the energy to track down services and apply for them.

*“Frail and/or elderly caregivers are often too tired or stressed out to know how, or to follow through, with directions to accessing services”. (Service Provider)*

**Services available to care recipients, (e.g. home support, adult day care, volunteer visiting, accessible transportation) and how they are delivered, are not designed with the needs of caregivers in mind.**

Caregiving is 24/7 and yet services in the community are largely confined to business hours. For example, it is almost impossible to obtain a quick response to deal with double incontinence at night, or picking up someone who has fallen. Adult day programs often demand that the caregiver deliver and collect the care recipient . Specialized transportation services are difficult to arrange, need advance planning and may or may not allow the caregiver to travel with the care recipient.

*“There’s a real tension between the of scheduling services [based on the organization’s needs] versus the burden of unpredictable care scheduling for the caregiver. But sometimes that’s the only time we can come [for home care]”. (Service Provider)*

**Services intended to support caregivers (e.g., respite care and psycho-educational or support groups) are neither individualized nor flexible enough to meet many caregivers’ needs.** Respite is an outcome and requires an individual approach—for one person it might be a good night’s sleep, for another a massage or a regular poker night with friends. The way in-home and institutional respite are currently provided is very limited and inflexible, and for many caregivers, fails to result in respite.

*“In our community there’s one family that’s been waiting for a respite bed since October and it’s now December. Services need to be flexible otherwise it’s not a useful tool; we need more beds so they are not booked all the time”. (Service provider)*

**The peripheral role assigned to caregivers by the health and social service system often leaves caregivers feeling discounted, devalued and not respected.** They have no formal voice in the policies or programs that affect the seniors the care recipient, and by extension, themselves. Frequently they are not consulted in care planning, discharge planning or treatments.

*“Some service providers don’t give us credit for how much we know, and they assume they know what’s best for [care recipient]. At worst, they don’t even ask you how you feel about what’s going to happen next”. (Caregiver)*

**Caregivers are as diverse as the Canadian population but policies and programs that affect them seldom take into account or address this diversity.** Some caregivers and/or their care recipients may as a result be marginalized.

*“I come from a culturally diverse area – Aboriginals from Innu, Inuit, Metis make up a portion of my region’s population. Culturally there are many barriers still in this day and age that continue to plague people of my community to meet on common ground”. (Service Provider)*

**Caregivers (especially those living with the care recipient ) often feel overwhelmed by number of services and workers involved.** As a result both care recipients and caregivers find it challenging to develop relationships with service providers, jeopardizing their trust in the quality of care provided. Compounding this, caregivers may need to explain the needs of the care recipient and how to meet them over and over again to the different service providers.

*“I have to deal with many different service providers and this is very stressful and disrupting for me and for [care recipient]. I have to tell the same story over again each time a new person gets added and that gets exhausting”. (Caregiver)*

**Recent policy shifts emphasizing reduced stays in hospitals and increased post-acute home care have had negative impacts on caregivers.** First it is assumed that such caregivers are available and able to provide care to the hospital patient who has moved home “sicker and quicker” than in the past. Secondly, the increased emphasis on post-acute home care has deflected resources and the importance of the preventative-maintenance model of home care –one in which supports for the person living with chronic illnesses facilitates their ability to remain in the community and decreases their use of hospital services.<sup>21</sup>

*“In our quest to professionalize services, we have lost focus on the unmet needs of people who don’t need an MRI – they just need a ride to the store”. (Service provider)*

## APPENDIX TWO: VALUES AND PRINCIPLES UNDERPINNING THE CAREGIVER POLICY LENS

### Definition of Terms

#### Family:

For the purpose of this document “family” is defined as relatives, friends and significant others whom the senior defines as family, including same-sex partners.

#### Caregivers:

“Caregivers”, also referred to as “informal caregivers”, “primary caregivers” and “carers”, are defined as family members and friends who care for someone with whom they have a relationship, typically without pay. It is important to note that although these terms are used by health and social service systems, family and friends who provide care to seniors may or may not identify themselves as caregivers.

#### Caregiving:

“Caregiving” is defined as the actions taken to provide care. The kind of assistance and support seniors require is very individual. The nature of needs vary over time, as does their intensity, and they often increase over time. Caregiving may include:

- practical assistance with basic and instrumental daily living activities (e.g., housekeeping, shopping, meal preparation) and personal care ,
- emotional and social support,
- assistance with physical needs (e.g., transferring, incontinence, and/or medical tasks such as IV changes and oxygen monitoring),
- assistance with management of medication,
- assistance with managing financial matters,
- finding and accessing services, making appointments, providing transportation, and/or
- mediation with formal organizations and service providers.

Where there is significant cognitive impairment, caregivers may need to take over the senior’s finances, provide close supervision, devise ways to communicate effectively and to manage behaviours. Overarching all of these tasks is the concern, worry, responsibility and emotional involvement with the seniors for whom care is provided. Caregiving occurs in the community and continues once a person is in a care facility<sup>22</sup>. Caregiving may also be carried out from a distance (e.g., from another province).

### Value and Principle Based Policy

Developing policy is a value-laden process which requires both empirical evidence and an ethical or principle-based framework to guide policy development.<sup>23-24</sup> An ethical framework facilitates a move from approaches based on cost reduction, towards those that also recognize and value caregiving as a worthwhile activity. Such a move positions caregiving as a social or collective responsibility rather than a purely individual or familial one. Employing principle-based frameworks and transparency of values can serve to reveal the realities of caregiving as well as the potential cost of ignoring the limitations of existing policies and programs.

The Caregiver Policy Lens (CGPL) is guided by values and principles derived from more than 250 discussions with the caregivers, caregiver organizations, service providers, program planners and policy makers across Canada who participated in this project. Values and principles of sustaining resilient caregivers were also reviewed from pertinent literature. These values, principles, and key concepts that frame the CGPL are described below and have been “translated” into the set of questions that make up the CGPL.

## **Values and Principle Underpinning the CGPL**

### *1. Process Factors*

#### **1. Caregiver Inclusion and Voice**

A socially inclusive society is one in which all people are recognized as equal and given free voice. No one person is given more value or respect than another. Social inclusion ensures a focus on the needs of every individual and ensures the right conditions and support are in place for each person to achieve their full potential. For caregivers, this means recognizing and valuing them as equally important as those they care for, while realizing that no two caregivers are alike.

Inclusion and diversity go hand in hand. Inclusion requires acknowledging and valuing a range of cultures, genders, ethnicities, sexual orientations, disabilities, capacities, interests, values, beliefs and opinions. To provide inclusive policies, programs and services to caregivers, basic knowledge of your caregiving population and those they are caring for is essential. Otherwise, social exclusion results in economic, social, political and cultural disadvantage. Those who are included have access to valued goods and services in society while those who are excluded do not.

Engaging caregivers and caregiver organizations in the process of developing, implementing, and evaluating policies and programs has the potential to make a positive difference in achieving desired outcomes. Collaborative and participatory approaches permit those affected by new public policy directions the opportunity to be involved in the process that produces inputs, such as research information, used to inform policy. Those engaged in the policy process from the outset inevitably also contribute to creating the policy. Caregivers’ experiential knowledge and reflection of the values and beliefs of their peers contribute to making sound policy.<sup>25</sup>

For caregivers, service provision communication is not just about disseminating information; through communication, we offer the presence of caring, comfort, support, and respect. Good communication has the following components:

- It facilitates comprehensive knowledge transfer, without information or emotional overload
- Uses strategies for active, critical, and empathic listening
- It takes into account diversity: cultural, socio-economic, ability, and literacy
- It breaks down barriers between agencies, services providers, and government and/or organizational departments
- Respects privacy and confidentiality requirements while taking into account the need for information
- Does not assume that the caregiver and care recipient are one entity
- Recognizes the importance of relationships between the caregiver and service providers in building trust and confidence in care/services.



- Creates a voice/space for the caregiver in the care team - involves caregivers in goals of care planning for the care recipient

Policies, programs and services designed for caregivers need to have these components of good communication; ideally they will also contain tools and resources for caregivers to improve their own communication with care recipients.

In developing policies and programs, being inclusive means asking: Are caregivers and caregiver organizations participants in developing the policies and programs that affect them?

At the organizational/program level, consider the following:

- Are caregivers included in developing care plans, discharge plans, etc. for the care recipient?
- Are caregivers consulted about any significant changes in service provision including discharges of the care recipient from community or hospital prior to their occurrence?
- Click [here](#) to return to CGPL category “Caregiver inclusion and voice”

## 2. Collaboration

We live in a society where competition for funding has created growing divisions between professions, agencies and groups representing similar causes. This fragmentation has created ‘silos’ of information and a lack of communication between professions, policy, services, research and practice. Developing policy, programs and services for caregivers requires that non-medical supports are given equal emphasis as medical needs. For caregivers, the needs for support regarding non-medical activities of daily living are as important as a biomedical focus. Unfortunately, caregivers’ needs are all too often ‘lumped in’ with the care recipients’ health concerns. This means that support (or lack of support) for caregivers usually remains in the domain of health services and organizations. Additionally, services, programs and policies can unintentionally affect caregivers’ rights and services in other areas (e.g., time off work can result in decreased pension benefits at retirement).

Sustainable caregiving requires the development of solutions that are broader than any one department, agency or organization. Inter- and intra-jurisdictional communication, networking and capacity building is the only viable way to develop caregiver policies and programs. Through these relationships, those interested in developing supports for caregivers bring their unique challenges and unique approaches to similar issues. The goal is to break down individual ‘silos’ and share expertise on the best way to support caregivers; this connectivity will also ensure that unintended negative impacts on caregivers are minimized or eliminated. For example, where a municipality or health region is designing policies and programs in rural communities (e.g., caregiver support group), are service groups involved that may be able to provide volunteers and transportation?

Policies, programs and services must be designed to encourage open and innovative forms of communication between and among organizations. This is particularly relevant for government departments or organizations that have traditionally organized their work and focus as ‘silos’ from other departments and organizations. Good communication is a cornerstone in developing and delivering programs and services that sustain caregiving. Caregivers should not, as is often the case, need to tell their stories repeatedly or to constantly orient new service providers. Clear lines of communication and responsibility between caregivers and service providers, and between agencies, is crucial. Policies, programs and services need mechanisms to ensure input

and feedback from caregivers, without adding to their responsibilities. Caregivers need to know the processes in place to resolve any concerns about care. Caregivers may feel that complaints about care or services will place the care receiver (or themselves) at risk of retaliation, necessitating support to do so

When developing policies and programs, ask: Are all stakeholders (e.g., different levels of government, health and non-health organizations, voluntary and business sectors) pertinent to the development, implementation and support of the policy or program involved and collaborating effectively with each other and with caregivers?

At the organizational/program levels consider the following:

- Are the roles and responsibilities of each agency and worker providing services to the care recipient made clear to the caregiver?
- Are mechanisms in place so that caregivers and workers can exchange information/update each other on changes in the care recipients' needs and care (with appropriate consents)?
- Is adequate communication between agencies and workers in place such that the caregiver does not have to repeat information over and over?
- Are staff knowledgeable about, and able to refer caregivers to programs for which they are eligible outside of their own agency?
- Click [here](#) to return to CGPL category "Collaboration"

### 3. Evidence Informed

Policies and programs must be informed by the best available evidence found in the peer reviewed literature and the experiential knowledge of those receiving services and those delivering them. The *Service Provider Resource Guide: A Toolkit for Supporting Caregivers of Older Adult* includes a review of caregiver assessment tools, proven caregiver interventions programs and other pertinent resources to inform policies and programs.

Monitoring and evaluation are the processes of collecting and analyzing information about a program, policy or service that tells you whether you are 'on track' in reaching your objectives, and whether or not the program, policy or service achieved what you wanted it to. You cannot know this without monitoring a policy, program or service during its implementation as well as evaluating its impact at specific points. It is necessary to plan for monitoring and evaluation when you design your program, policy or service; this will help you design and maintain an effective policy, program or service. For policies, programs or services that have either a direct or *indirect* effect on caregivers, mechanisms should be in place to ensure inclusion of caregiver perspectives and experiences. By gathering and reviewing this information, you will be able to evaluate effectiveness and impact for caregivers, and develop a better program and service that responds to the specific needs and circumstances of caregivers as they change over time.

At the organizational or program level, consider the following:

- What mechanisms are in place to obtain input and feedback from caregivers in program development, service delivery and evaluation of outcomes?
- How are diverse caregivers engaged and supported to provide input and feedback?

- Click [here](#) to return to CGPL category “Evidence Informed”

## II. Assessing Policies and Programs

### **4. Respect and Dignity**

Family caregivers must be acknowledged, respected and valued for their caregiving work (Canadian Caregiver Coalition, [www.ccc-ccan.ca](http://www.ccc-ccan.ca)). They have the right (but not the obligation) to be active partners both in decisions about service provision and as providers of services to the seniors for whom they provide care. Respect is conveyed through language used to refer to caregivers and caregiving which should portray caregivers positively. This is important as policies and programs create an image of those at whom the policy is directed, filtering down into programs and practices, shaping the social environment. Respect is conveyed when privacy and confidentiality requirements are met. Respect is conveyed when caregivers’ input and feedback on policies, programs and services is solicited and considered. Ensuring that policies and programs recognize the importance of the relationship between the caregiver and the senior they care for, and facilitating this relationship, denotes respect.

At the organization/program level, consider the following:

- Do policies reflect recognition of the importance of the relationship between the care recipient and caregiver (e.g., visiting policies in institutions, no “first available bed” policies, “allowable” care in care facilities)?
- Do policies take into account that caregivers may have other roles and responsibilities outside of their caregiving role (e.g. spouse, mother, employee, friend, etc.)?
- Are protocols in place between agencies and workers so that caregivers do not have to repeat information over and over?
- Click [here](#) to return to CGPL category “Respect and Dignity”

### **5. Diversity and Marginalization**

Caregivers are a diverse group, with diverse needs, desires and abilities. Understanding the diversity of caregivers so that they are not marginalized means being aware of how ethnicity, cultural diversity, faith, income, mental health, and sexual orientation influence a person's experience as a caregiver. Diversity can become marginalization when these differences are not recognized, or worse, discriminated against. Caregivers’ needs and appropriate solutions vary depending on their ethnicity, income, physical and mental health, culture, and gender – and where the care receiver is in their illness journey and/or type of illness. Many caregivers are marginalized for more than one reason. When developing policies, programs and services, necessary concepts in diversity and marginalization include:

- Ethno-cultural – particularly for recent immigrants, First Nations, Métis, and Inuit communities, and Canadian Africans.
- Gender - including gender analysis given that women, as the majority of caregivers, often experience considerable challenges managing caregiving with work and other responsibilities.

- Poverty – economic marginalization can be both a cause and consequence of caregiving. People living on low incomes may face a double burden of marginalization.
- Mental health – of both the caregiver, and the care receiver.
- Addiction issues – of both the caregiver, and the care receiver.
- Challenging behaviours - emotional and behavioral symptoms of an illness, particularly dementia, can cause extreme hardship for caregivers.
- Sexual orientation – GBLT caregivers may face unique issues from other caregivers, due to their sexual orientation.
- Aging/ill health/disability – as the majority of caregivers age, this is an increasingly pressing issue.

Caregivers can be socially and economically marginalized due to their provision of care, including blame or stigma associated with some illnesses. Policies, programs and future research must be responsive to the changing context of caregiving in Canada and the increasing diversity in our society at large. There is further information on specific issues in diversity and marginalization in Appendix Three.

At the organization/program level, consider the following:

- Are eligibility criteria, application processes and other relevant information presented clearly and simply (including in languages and cultures specific to the communities served)?
- Is eligibility criteria and other relevant information available in a variety of mediums (e.g., print, audio, telephone, web) designed to reach caregivers who are isolated or live in rural and remote areas?
- Are staff available to “interpret” policies and programs and assist with applications when needed (e.g., for caregivers with barriers related to language, literacy, or are feeling overwhelmed)?
- Click [here](#) to return to CGPL category “Diversity and Marginalization”

## **6. Choice, Self-Determination and Independence**

“Family caregivers have a choice to become partners in care and have the right to choose the degree of their involvement at every point on the continuum of care” (Canadian Caregiver Coalition, [www.ccc-ccan.ca](http://www.ccc-ccan.ca) ). Willingness or capacity to take on the role of caregiver cannot be assumed. This necessitates that service providers explore this issue at the time of the initial assessment and review on an ongoing basis. In order for there to be genuine choice, information must be provided about what to expect in terms of the care recipient’s needs and what support can be expected from the health and service system (including information about eligibility, wait lists, etc.), and what can be expected if crises occur or if a decision is made to limit or end caregiving at some point.

At the organizational/program level, consider the following:

- Are caregivers provided with clear information required to make informed choices (e.g., about care the required, potential changes, likely duration, and the system support they can expect, including during crises)?
- Is the caregiver informed about and offered services available to the care recipient proactively and prior to crises?

- Is the caregiver’s willingness to provide care, the boundaries of their care, and the care recipient’s needs reviewed on a regular basis, and at critical transition points during the care (e.g., hospital admission or discharge, access home care, moving to long-term care, etc.)?
- Is there a plan in place if the caregiver chooses to limit or end part or their entire caregiving role?
- Are other options to provide care explored with the care recipient and caregiver (e.g., help mobilizing their support networks to provide more care, access additional community services, move to long-term care, etc.)
- Click [here](#) to return to CGPL category “Choice, Self-Determination and Independence”

## 7. Accessibility

Supporting caregivers requires that policies, programs and services are both accessible and responsive to the needs of diverse caregivers. How a program or service is organized, promoted, and delivered has important effects on caregivers. To access services caregivers require education, and information about system requirements and pathways (e.g., wait lists, service elements, eligibility criteria, how to request and use time with healthcare professionals and service providers, identify their needs, and access services), delivered in ways that are appropriate to their needs, circumstances (e.g., vision, literacy, language) and culture.

At the organizational/program level, consider the following:

- Are staff available to “interpret” policies and programs and assist with applications when needed (e.g., for caregivers with barriers related to language, literacy or are feeling overwhelmed)?
- Are any practical barriers addressed (e.g., cost, transportation)?
- Click [here](#) to return to the CGPL category “Accessibility”

## 8. Caregiver Assessment

“Family caregivers have the right to express their needs and receive support” (Canadian Caregiver Coalition, [www.ccc-ccan.ca](http://www.ccc-ccan.ca)). Caregivers have the right to have their own needs assessed, not just in relation to those for whom they are providing care. This is to ensure that the risks to their own health and well being that caregiving presents, are as much as possible, ameliorated so that they do not become “second victims”.

### *Promoting and Supporting Resiliency*

Resiliency is the capacity of a caregiver to cope with stress and adversity. Resiliency is a process, not an inherent trait of an individual. Resilience is the result of individuals interacting with their environments and the processes that either promote well-being or protect them against the overwhelming influence of risk factors. An environment that promotes resiliency includes inclusive services, communities, and social policies.

In the development of policies or provision of services for caregivers, a focus on resiliency requires that we identify the individual, family and community factors that support caregivers’ resiliency and those that place it at risk. Service providers need to be proactive and non-judgmental in asking caregivers about their self-care, the challenges they are experiencing, and what might help. To do this service providers require not only the time

and skills to gather information but sufficient knowledge of their communities to link caregivers to appropriate program and resources (e.g., health promotion, recreation, transportation, income supports, etc.)

At the organizational/program level, consider the following:

- Are caregivers explicitly asked about their own needs and how they might be best addressed?
- Are caregivers asked to identify changes needed to the support and services they need/use?

At the organizational/program level some factors to consider in assessing resiliency are:

- Relationship to the care recipient/family dynamics; social support available (e.g., family, friends, community services);
- Competing responsibilities to other family members/friends; work responsibilities (e.g., impact of taking time off work);
- Personal needs for self-care (recreation, learning, exercise, etc.);
- Geographic distance from senior;
- Personal health and functioning
- Financial costs (e.g. supplementing income, travel, supplies, and assistive devices for the care recipient )
- Emotional and mental health issues/needs;
- Knowledge about care management;
- Risk factors impacting health and well being (e.g., age, health conditions, isolation, etc.)
- Click [here](#) to return to CGPL category “Caregiver Assessment”

## 9. Sustaining Caregivers

Sustaining the caregiver role is about having access to the necessary system supports during the caregiving journey. For caregiving to be sustainable, caregivers need a combination of personal support networks and community-based supports that help create and sustain resiliency. There are two main components to system sustainability: appropriate staffing and education, and appropriate focus of policies, programs and services. In short, it means *the right programs at the right time*.

Even well-developed policies and programs for the care recipient may have unintended negative impacts on the caregiver. For example, many day programs for care recipients do not include transportation, and require caregivers to juggle competing priorities and time constraints. If a program or policy has unintended negative impacts for the caregiver, this translates to negative impacts for the care recipient as well.

Sustainability in developing or evaluating policies, programs and services means asking “What are the tools caregivers need to support their caregiving endeavors?” Necessary tools include:

- Education and information about the services available to themselves and those they provide care for.
- Training (how to provide appropriate care)



- Services (for both caregivers and care recipients)

Caregivers need to feel that they can trust service providers, which necessitates sufficient time and sanction to develop relationships. Continuity of care can be facilitated by keeping the number of different staff to a minimum, perhaps offering services as teams or pods so that shifts and absences can be accommodated while ensuring least disturbance to caregivers and those they care for.

At the organizational/program level, consider the following examples of support for caregivers in their own right:

- Personal relationship building (the development and provision of care, support, trust and encouragement, both within and outside the family),
- Emotional/psychological support (including time to themselves, self-care knowledge and practice),
- Practical support (connection to resources, information about the caregiving journey – especially challenges and transitions),
- Respite (understood as an ‘outcome’ and not just a service?<sup>26</sup>), offered proactively on a regular basis and in form preferred, and also made available when the caregiver expresses the need for it
- Healthy aging (supportive community, services supporting non-medical activities of daily living, periodic reassessments during caregiver journey)
- Personal counselling for issues related to caregiving (e.g., grief, depressed mood) when needed.
- Support groups accessible through a variety of delivery methods.
- Individualized information about the medical, cognitive and functional needs of the care recipient being cared for, and how to meet these, using appropriate health literacy principles?<sup>27</sup>
- Individualized information and coaching to address specific issues confronting the caregiver (e.g., paranoid behaviours) using adult education principles.
- Information about community resources and support to navigate the system.
- Click [here](#) to return to CGPL category “Sustaining Caregivers”

## 10. Sustaining Systems

A system that sustains caregiving also ensures that transition crises, premature placement or hospitalization are minimized. Policies and programs should be flexible enough to respond to individual and immediate needs. Service delivery policies need to take into account the caregivers’ schedule and needs (including those of those being cared for), which may, for example, occur outside business hours. The need to always plan in advance and wait lists for accessing and receiving services should be avoided. Perhaps most importantly, accessibility and flexibility of policies, programs, and services means that they are proactive where the burden of ‘not knowing the right questions to ask’ or what services exist is not placed on the caregiver. This means asking – Does the policy, program, or service support caregivers in such a way that crises and excess use of system supports are likely to be avoided?

Components of a sustainable system of support for caregivers include: 1) front-line staff with appropriate education, training, and relationship skills to support caregivers as well as care receivers; 2) programs, policies

and services based on best practices, and 3) evaluation and monitoring mechanisms of policies, programs and services that include caregivers' perspectives. Health professionals and other service providers often need training on how to better communicate with and involve family caregivers as part of the care team. Additionally, to facilitate sustainable caregiving, caregivers and care receivers should receive support and services that reflect their cultural and linguistic backgrounds. Sustainable caregiving means that programs, policies and services must recognize that initiatives to support care receivers influence the degree of caregiving required, and that initiatives for both populations are mutually supportive.

At the organizational/program levels, consider the following:

- Is there sufficient flexibility in policies (e.g., eligibility, implementation and service delivery) for preventative action?
- Are services offered proactively and provided before needs reach crises proportion?
- Is there sufficient capacity and flexibility to respond to crises in a timely manner without escalating needs?
- Is there a menu of options to provide for the information, support (including financial), and education needs of caregivers?
- Are service providers educated about, and sensitive to, the needs of caregivers and how to support them?
- Do service providers have the appropriate knowledge, skills and supervision to provide sensitive and competent care to care recipients and/or caregivers?
- Is the number of different service providers/workers kept to the minimum, encouraging trust, relationship building and continuity of care?
- Do service providers have the time, skill and support to develop caring, trusting relationships? Do the hours of services provided to the care recipient take into account the caregivers' preferred schedule?
- Are the services for seniors affordable to them (e.g., scaled fees or not requiring caregiver to pay)?
- Is transportation attached to the care recipient' programs outside of home, appointments etc., and when desired, does it allow the caregiver to accompany the care recipient?
- Click [here](#) to return to CGPL category "Sustaining Systems"

## 11. Fairness and Equity

The impacts of policies can be long term, intergenerational and society-wide, and can affect different populations differently- benefitting some and disadvantaging others. In examining and developing caregiver policy, it is important to consider whether the policy is fair not only to today's caregivers but also to those of tomorrow. The provision of informal care can affect private business productivity and profits as well as both the public and private sectors of the economy. Brink (2004) argues that policy development must examine the data on elder care from the perspective of the senior, the caregiver, the worker and the employer as well as the macro view of the labour force, caregiver pool and the economy. For example, it is possible that a policy that benefits caregivers may impact other workers and their families negatively. Furthermore, while health outcomes may be positive, economic and social effects may be detrimental for one or more groups.

At the organizational/program levels, consider the following:

- Are eligibility criteria disclosed with rationale for exclusions and mitigation strategies provided?



- Are individual needs balanced with those of the larger group (e.g., behavioural challenges of individuals in a congregate living setting)
- Click [here](#) to return to CGPL category “Fairness and Equity”

## APPENDIX THREE: FURTHER DISCUSSION OF DIVERSITY AND MARGINALIZATION

### Gender

Health Canada recognizes gender is an important determinant of health. Men and women's experiencing of caregiving, their social relationships, life expectations and economic circumstances are all shaped by gender. Gender influences access to services, interaction within health care systems, and expectations around caregiving.

In our society, women have traditionally provided the majority of care. While this is starting to change, women continue to spend more time caregiving<sup>28</sup>. Canadian statistics indicate that female caregivers provide most of the personal care where male caregivers were responsible for transportation assistance and home maintenance<sup>29</sup>. These, among other studies, continue to highlight that women are significantly likely to provide more time in providing physical care and emotional support<sup>30</sup>.

Depending on the caregiving context, gender differences can be small or large. For example, one study found that caregiving sons experienced more family conflict than caregiving daughters if there was a high level of care recipient impairment<sup>31</sup>. Other research found that women, regardless of the family relationship to the care recipient, continue to carry the majority burden of care, take on the most challenging caregiving tasks and therefore are more likely than men to suffer from extreme stress due to caregiving<sup>32</sup>.

Increasingly, gender-based analysis is used by policy and program planners to better understand the impact of gender on the caregiving experience. Gender-based analysis challenges that women and men are affected in the same way by policies, programs and legislation, and requires thought as to how to reduce disadvantage through creating more equitable, inclusive options.

### Members of an ethno-cultural minority/recent immigrants

Health Canada recognizes culture is an important determinant of health. An ethno-cultural individual or community is defined by having an ethnic heritage that is not British, French, or Aboriginal. Canada now has over 200 ethnic groups consisting of newcomers and those that have been here for several generations. 18% of the population is foreign-born with almost 80% of new immigrants arriving from Asia, Africa, The Middle East, and South and Central America<sup>33</sup>. Ethno-cultural minorities face barriers such as language, higher rates of mental health and substance use, lack of awareness of services, discrimination, isolation, racism, and social and economic disadvantages<sup>34</sup>.

First-generation ethno-cultural minorities immigrating to Canada face uncoordinated policies, including those related to immigration, resettlement, employment, and government funding for health and social services. These present significant barriers to immigrant caregivers, particularly women caregivers. These challenges are compounded by language and separation from family in the home country. Caregivers may then avoid certain formal services for a variety of reasons, including lack of cultural sensitivity<sup>35</sup>. While there is little research on this topic, one study found that female caregivers from ethno-cultural minorities were able to overcome these barriers if they had a strong informal support network and connection with at least one community service<sup>36</sup>. Other studies suggest that caregiving arrangements are more costly in both financial and emotional terms, than in their countries of origin<sup>37</sup>.

Financial concerns may become chronic; the Canadian Council for Social Development stated that "recent immigrants are having greater difficulties in the labour market than did previous immigrants, and that their incomes may never reach the Canadian average". The economic situation of recently-arrived older immigrants is even less secure; the older the age at immigration the more likely one will live in poverty. With

little or no work history in Canada (necessary to qualify for Canada Pension Plans) and a 10-year residency requirement to qualify for the Old Age Security benefit, many immigrant seniors are unlikely to be able to access public pensions<sup>38</sup>.

While culturally diverse caregivers can experience barriers accessing services, it cannot be assumed that every caregiver within these groups have the same experiences. Exclusion that is experienced through membership in an ethno-cultural minority may not be the same across groups of people. A 'culturally competent' system and/or service provider recognizes that: 1) caregivers diverse values, beliefs, and behaviours must be taken into consideration in tailoring policies and programs; 2) has an understanding of the communities being served as well as cultural influences on individual beliefs and behaviours, and 3) devises strategies to identify and address cultural barriers to accessing services (adapted from 'Cultural Competence Guide for Primary Health Care Professionals in Nova Scotia', 2005). VON has a model for culturally-sensitive program development ([www.von.ca/en/special\\_projects/docs/RR\\_manual.pdf](http://www.von.ca/en/special_projects/docs/RR_manual.pdf)). Although it focuses on mental health, the framework can be used for a diversity of program development. The National Centre for Cultural Competence has developed a policy assessment tool specific to ethno-cultural issues ([www.CLCPA\\_clyural\\_competence\\_guide.pdf](http://www.CLCPA_clyural_competence_guide.pdf)).

### Employed

The majority of employed Canadians also have caregiving responsibilities. Most commonly, employed caregivers are middle-aged, single, childless women with lower incomes who combine their paid work with care for an elderly parent who has chronic health problems. Many report these responsibilities negatively impact their work, including scheduling changes, reduction of hours, a reduction in income, and lost opportunity costs such as training, promotion, and overtime<sup>39</sup>. Health Canada reports that more than 25% of caregivers have quit, retired or experienced other job changes as a result of their caregiving obligations<sup>40</sup>. Employed female caregivers are more likely to make workplace adjustments than male caregivers<sup>41</sup>. It is estimated that the Canadian cost of absenteeism due to caregiving responsibilities is between \$1-4 billion.

The demands placed on employed caregivers can be taxing. Employed caregivers of older adults are then at higher risk for a conflict in balancing work and life, resulting in caregiver strain from a decrease in mental and health. Financial strain can also be an issue, either through a decline in income or through an increase in costs. Not only is this a threat to current income, it also penalizes caregivers' ability to generate retirement pension/income. Only 35% of households with caregivers report income over \$45 000<sup>42</sup>.

Studies indicate that there are very few differences in need for employed caregiver supports (i.e. no difference between job sector or type). This is an important finding as it highlights the ability for organizations to put policies and practices in place to address these needs<sup>43</sup>.

### Living in rural/remote regions

Health Canada recognizes geography as an important determinant of health. People in rural and remote communities have poorer health status than Canadians who live in larger centres. For example:

- Life expectancy for people in predominantly rural regions is less than the Canadian average;
- Disability rates are higher in smaller communities;
- Rates for accidents, poisoning and violence are also higher in smaller communities; and
- People living in remote northern communities are the least healthy and have the lowest life and disability-free life expectancies<sup>44</sup>.

In rural Canada, the rates of informal caregiving are increasing due to health care restructuring, moving of health services to urban locations, aging of population, and the desire to age at home. In these geographic

locations, the caregiving role is usually assumed by women<sup>45</sup>. Caregivers living in rural and remote locations may experience different challenges than urban caregivers including transportation challenges and social/geographic isolation. An additional challenge is that it is difficult to recruit and retain home care workers in these areas due to a smaller labour pool and the need to travel long distances. Together, these issues can leave rural caregivers at a higher risk to stress and burnout, with limited resources for support. For more information on the unique challenges facing rural and remote caregivers in Canada, click [here](http://www.rrh.org.au/publishedarticles/article_print_520.pdf) ([http://www.rrh.org.au/publishedarticles/article\\_print\\_520.pdf](http://www.rrh.org.au/publishedarticles/article_print_520.pdf)).

### Lesbian, gay, bisexual and transgendered (LGBT)

Many LGBT caregivers face stigma by their care recipient, their family, and within the health care system. While service providers may want to support LGBT caregivers, their lack of willingness to engage with, or address, issues of identity and sexuality limits their ability to do so<sup>46</sup>. Other service providers may not be so supportive due to personal beliefs that homosexuality is 'wrong'. LGBT caregivers highlight the importance of having support systems that validated their unique experiences, which include higher levels of uncertain physical and emotional health, including disability, depression, addiction and stress<sup>47</sup>.

Unlike the general population, older LGBT individuals tend to care for one another, rather than caregiving being a family member's responsibility. The Family Caregiver Alliance states that this translates to a higher rate of LGBT individuals providing care to an adult friend or relative than the heterosexual population<sup>48</sup>. LGBT care recipients often have a network of caregivers who are friends that may not include traditional biological or legal relationships, thereby increasing the challenge for caregivers who wish to be involved in care planning. Older spousal same-sex caregivers may be forced to 'come out' in order to have a voice in care planning, particularly in hospital and long-term care settings. Within the context of family dynamics, LGBT family members may be expected to be primary caregiver of a parent if they are not married and/or have children, regardless of the historical relationship between the caregiver and care recipient. Those caring for a homophobic parent may be particularly vulnerable to exploitation or abuse. In rural areas, living in smaller homogenous communities may increase the invisibility of LGBT caregivers<sup>49</sup>.

The result is that many of these caregivers may not seek support due to real or perceived homophobia. Collectively, the historical discrimination and invisibility faced by LGBT caregivers (and their care recipients) place them at a higher risk than heterosexual caregivers. Although developed within an American context, the Guide to GLBT Caregiving is a useful resource on how to address specific challenges faced by this caregiving population, including changes in care settings ([http://www.nextstepincare.org/uploads/File/Guides/LGBT/LGBT\\_Guide.pdf](http://www.nextstepincare.org/uploads/File/Guides/LGBT/LGBT_Guide.pdf)).

### Low literacy or limited English or French skills

Four out of ten Canadians struggle with everyday needs due to low levels of literacy<sup>50</sup>. Seniors, as well as those who do not have English or French as their mother tongue, struggle with higher rates of low literacy. Further, cultural insensitivity in health care may worsen issues created by poor fluency in English or French.

General literacy (i.e. the ability to read and write) is one of the most significant barriers to accessing health information and resources. While there are a range of informational resources for caregivers, much of it is inaccessible to the very population that needs it due to writing styles and assumptions of literacy. Therefore many individuals with low levels of literacy may be embarrassed and not ask basic questions about resource and disease management while health care providers may assume that caregivers are informed<sup>51</sup>.

The Canadian Council on Learning advocates the following in design and implementation of information supports for caregivers:

- Write at a Grade 5-7 level
- Quality and clarity in graphic design

- Consulting and collaborating with end users
- Locally produced materials
- Use every day words, real-life example, illustrations, and a narrative style consistent with the cultural beliefs of the community
- In face-to-face communication speak slowly, using non-technical jargon, and present only two or three concepts at a time, while regularly checking for understanding by asking the caregiver to 'teach back' what they have learned<sup>52</sup>.

### Low-income

Health Canada identifies income as one of the most important determinants of overall health and well-being. Caregivers' financial situation is therefore an important predictor of financial and emotional strain in caregiving<sup>53</sup>. Given their greater life span and social roles, women are far more likely to be at risk of experiencing low-income as well as becoming a caregiver.

Caregiving can require either partially or entirely meeting the needs of the care recipient, including basics such as food, heat and shelter. Yet caregivers with modest or low-incomes may not have enough money for their own, much less others', care. If the caregiver has a low or fixed income, this can lead to chronic financial uncertainty, including their own ability to provide themselves basics such as nutritious food, meet household costs, and transportation. Caregiving can also negatively impact potential income earning (see employed caregivers).

For caregivers, the health and social implications of low-income include higher rates of poor health and death, disrupted relationships, and ultimately a higher cost to health care systems through additional physician and emergency room visits<sup>54</sup>. Further, a lack of money can cause social isolation, loneliness and depression, as well as ill health and a shorter lifespan. For older adults caring for a family member, living on a fixed income means they may always be only one 'emergency' away from the threshold of poverty.

### Seniors

The proportion of the population that is over 65 has increased by 68% over the past two decades<sup>55</sup>. As the Canadian population ages, an increasing number of older adults are becoming caregivers. In Canada, one in four caregivers is over age 65, many of whom are likely to experience their own age/health related challenges, and are at risk of becoming care recipients themselves. In 2002, more than 324,000 Canadian seniors provided care to other seniors with long-term health conditions<sup>56</sup>. Research also shows that the number of hours dedicated to caregiving increases with the age of the caregiver<sup>57</sup>.

Many seniors live with modest or low incomes. In 2006, the average after-tax income of senior couples was \$41,400, with the median income for unattached seniors at \$20,800. Single older women in particular may have a low-income. Unlike the general population, among spousal caregivers seniors 75+ both sexes provide equal amounts of care. While many older care recipients experience positive effects from aging in place within their homes, that can also produce strain on their caregiver children who are becoming seniors themselves. On the other side, grandparents may become primarily responsible for the care of their grandchildren, either through formal or informal custodial agreements. This new caring role may be taken on, for example, as a result of parental disability, death, imprisonment, substance abuse and child neglect, abuse or abandonment.

Issues of older caregivers are not well defined in research. Older caregivers are speculated to be at a greater risk for injury and subsequent activity limitations and participation restrictions than younger counterparts. Further, older caregivers may also be dealing with their own health issues. One study found that only 18% of Canadian seniors who are caregivers get any kind of break from their caregiving duties<sup>58</sup>. These older caregivers will be increasingly relied upon in the future, yet they must also safeguard their own health to be able to continue to care for themselves<sup>59</sup>.

## Parents of dependent children

One in four Canadians cares for an elderly parent; almost one in five have responsibilities for both eldercare and childcare – approximately 750,000 individuals<sup>60</sup>. The term ‘sandwich generation’ defines those who provide care both to their children as well as their parents – sandwiched between two caregiving roles. The vast majority (80%) of those with children and caring for an elderly person were employed.

Increasingly women are delaying childbearing and are working more; in North America these changes mean the average married couple may have more living parents than children<sup>61</sup>. Combined with a longer life span of their parents these individuals are then caught between child rearing, caring for their parents, and the demands emerging from employment. This dual caregiving role, while being stressful, can also have significant rewards due to the appropriateness of life cycle role. Recent surveys have shown that most people (82%) who worked while providing both child care and elder care are generally satisfied with the balance they had struck<sup>62</sup>. Other studies find that adult children experience more rewards than do spousal caregivers<sup>63</sup>. However, while parents have seen child-care services evolve, little formal support has been established for the growing number of those caring for seniors. Employed caregivers who are part of the sandwich generation are likely to be older and live in smaller communities, with one in three earning low-income<sup>64</sup>. This ‘sandwich generation’ will have increasing caregiving responsibilities as the baby boom generation ages.

## First nations/Inuit/Metis

Experiences of historical trauma, social marginalization, poverty, cultural disruption and racism all negatively impact the ability and desirability of accessing health and/or caregiving services and resources. Issues that challenge the ability to provide sustainable caregiving include:

- First Nations and Inuit have the lowest life expectancy of all groups in Canada.
- Lack of stable housing with severe shortages, overcrowding, substandard construction, needs for major repair, and lack of basic utilities
- 71% of First Nations seniors did not complete high school, leading to low levels of literacy
- 50% of First Nations adults aged 18-54 have not completed high school

Complicating these issues, First Nations communities offer fewer health services, often at a greater geographical distance, than other communities in Canada. Those living in remote and isolated areas may have substantial barriers to sustainable caregiving including: lack of roads and efficient transportation, high cost of transportation for medical supplies, inability to access rehabilitative services, adequate palliative or respite care and the lack of available health professional requiring frequent travel to urban centres, the incurrence of greater financial expenses, and lengthy wait times<sup>65</sup>.

The First Nations population age 55+ will increase more than 230% over the next several decades. While life expectancy is anticipated to improve, so too will a corresponding rise in chronic illness. First Nations people have higher rates of chronic illness such as diabetes, cardiovascular disease, arthritis and functional/activity limitations. Currently there is a ratio of 1 bed per 99 individuals aged 55 and over for First Nations living in their communities compared to 1 bed per 22 individuals aged 65 and over in the general Canadian population<sup>66</sup>.

On the other end of the scale, approximately 50% of the First Nations population is under the age of 25, compared to Canada’s median age of 37.5 years. Additionally, migration back to First Nation communities will increase the population already living in these communities to increase by 34%. This will impact on existing services and supports needed to provide culturally competent support to for population in rural and/or remote settings, including the demand for continuing care.

Addictions and mental health issues arising from cultural fragmentation can complicate the ability of First Nations individuals to provide appropriate care. As with the broader aging population elder abuse is also



an ongoing concern. While statistics on the abuse of elders are scarce for the general Canadian population, even less information is available for the Aboriginal elder population with respect to the incidence and prevalence rates of abuse that may be occurring in the Aboriginal community. Existing research on the issue of violence and First Nations people indicates higher rates in comparison to the general population in Canada<sup>67</sup>.

However, there are also strong family and community ties embedded within First Nations culture that support caregivers. In designing policy and programs to support these ties, it is important to recognize that Western conceptions of intervention may be different than First Nations ones, and that elements of First Nations culture cannot necessarily be 'extracted' to fit Western care models. This awareness and ability to support First Nations caregivers requires cultural competency. Cultural competence is defined as a set of "congruent behaviours, attitudes, and policies that come together in a system, agency, or among professionals that enables the system or professionals to work effectively in cross-cultural situations"<sup>68</sup>. The Nova Scotia Department of Health has developed a guide on cultural competence for those working in the primary health care system

([http://healthteamnovascotia.ca/cultural\\_competence/Cultural\\_Competence\\_guide\\_for\\_Primary\\_Health\\_Care\\_Professionals.pdf](http://healthteamnovascotia.ca/cultural_competence/Cultural_Competence_guide_for_Primary_Health_Care_Professionals.pdf)).

### Living with the care recipient

Caregivers who live with the care recipient face report increased rates of physical and emotional distress in comparison to caregivers who do not live with the care recipient, including not being able to get enough sleep or engaging in healthy eating patterns<sup>69</sup>. Research indicates that caregivers who live with the care recipient are also much more likely to report experiencing financial problems than caregivers who do not (Thompson, 2004). Employed caregivers who provide dependent care to an older adult are more likely to be unmarried women without any children<sup>70</sup>. Caregivers who live with the care recipient and also providing care to dependent children report higher rates of role stress – competing demands by differing care recipients.

Spousal caregivers often feel extreme rates of stress as they have few, if any, breaks from caregiving. Spousal caregivers may also feel a sense of obligation to care for their spouse well beyond their abilities. Loss of intimacy and role changes within marriage may cause additional emotional distress. Where dementia exists, spousal caregivers are especially vulnerable to loss of their own identity and self-definition<sup>71</sup>. Caregiving spouses, compared to non-spouse caregivers, resist institutional placement of the care recipient for a longer period of time despite level of disability<sup>72</sup>.

### Caregivers of Younger Adults

Some caregivers do not provide care to an aging parent, spouse, or developmentally disabled child. These caregivers may be providing care to a non-senior spouse or adult child with MS, ALS, Huntington's or other chronic/terminal illness. Therefore, their caregiving issues may be different than the general caregiving population. These families often find themselves facing increasing demands while experiencing diminishing resources of health, income, and social support<sup>73</sup>.

For those caring for a non-senior spouse, identity and role changes can be dramatic, including changes in intimacy. Many spousal/partner caregivers state that they do not identify as a caregiver, particularly if the illness is progressive and terminal. Some families may also have to cope with the loss of the care recipient's income. Late middle-aged adults with functional limitations are more likely than older groups to be married and cared for primarily by spouses; however, they may be particularly vulnerable to unmet need for care<sup>74</sup>.

## Caring for someone with compromised cognition

Caregivers may face a range of issues arising from the care recipient's fluctuating, or reduced cognition. Reasons for changes in cognition may include chronic and/or life limiting illnesses, acquired brain injury, dementia, mental illness and addictions, and/or developmental disability. Compromised cognition can be very challenging for caregivers and may create emotional, financial and even physical conflicts with the care recipient, including legal issues (e.g. consent for treatment) and future planning, especially for older caregivers.

Several studies have found that compromised cognitive status is common among informal caregivers of older adults, particularly if the caregiver themselves are older. If a caregiver themselves has cognitive issues, this may place service providers in particularly challenging situations<sup>75</sup>. Issues of caregiver cognition may be increased through experiences of caregiver stress and distress, such as lack of support networks and/or respite. Competency means that caregivers are able to provide care that meets the basic needs of the care recipient, as well as being able to take care of themselves. Service providers can support caregiver competency through validating their knowledge, experience, providing appropriate resources and information. Alternately, service providers can damage caregiver competency by ignoring or minimizing their experience and knowledge thereby eroding confidence. Caregiver competency requires a sustainable system of support, including provision of services and information.

Other issues specific to caregiving to those with mental health and addictions, as well as developmental disabilities, is explored further in the following sections.

### *Mental health/addictions*

Approximately two percent of the population (18 years and over) provides care to a family member, friend, or neighbour diagnosed with a mental illness. This translates into approximately a half a million Canadians. One in five caregivers also care for someone who is ill or disabled in addition to providing care to someone diagnosed with a mental illness. Seven in ten report that they had no other reasonable options when they decided to become the primary caregiver. Approximately half are providing the care because they believe there to be a lack of home care and/or mental health services. Close to half of these caregivers have been providing on-going care for an extended period (5 years or more), and most describe the condition for which care is required as something that is long-term. A sizeable majority of caregivers provide the care in their own home. Almost six in ten caregivers pay out-of-pocket expenses, mainly paying for transportation-related costs and medications, with three in ten are spending over \$300 per month<sup>76</sup>.

Family members caring for those with serious and persistent mental illness tend to find themselves becoming a nurse/counselor/advocate/crisis worker/home-care and income provider all rolled into one. Although a majority of caregivers say they are coping reasonably well, many are experiencing at least some difficulties in other aspects of their life as a result of their caregiving duties. This is most often the case for balancing their personal and family needs, and least likely in terms of their own physical health. Despite the fact that a majority of caregivers are confident they have the necessary skills, almost all would welcome help performing their caregiving tasks. However, when asked what would be most helpful, there is no clear consensus as to what types of assistance would be most beneficial.

What are the issues when the caregiver has mental health concerns? Caregiving can exact both a physical and an emotional toll. Symptoms of depression and mental health problems are much more common among caregivers than among non-caregivers. Proportions of caregivers reporting depressive disorders or symptoms range among studies from 30-59%<sup>77</sup>. According to a 2002 Health Canada Study, caregivers are most likely to feel stressed in terms of their emotional health, with close to eight in ten reporting that caregiving has resulted in significant (29%) or some (48%) emotional difficulties for themselves<sup>78</sup>.

Mental health issues and addiction often go hand-in-hand. Little research has been done on caregiving and addiction. One prominent American clinician-researcher working states that, in particular, caregivers of



chronically ill patients are more vulnerable to addiction as a way to “self-medicate anxiety, depression and fear”<sup>79</sup> If a care recipient is addicted to drugs, alcohol, pharmaceutical medication or a range of illicit/illegal behaviours, caregivers may face challenging behaviours. Stigma also is a problem as caregivers of addicts may not receive the same social sympathy as caring for someone with cancer, or those with chronic illness(es). Addictions and/or mental health issues may also become an issue in receiving services if home service providers feel unsafe, thereby negatively affecting caregiver resiliency.

### *Developmental disabilities*

Canadians with developmental disabilities can now reasonably have a life-expectancy that extends beyond mid-life. Parents are still the primary caregivers for adults with developmental disabilities and are themselves aging. Combined with the de-institutionalization of persons with developmental disabilities have given rise to situations where parents in their eighties or nineties are still the primary caregivers of their developmentally disabled adult child in his/her fifties or sixties. One age-related concern is providing support to the family caregivers who themselves are experiencing diminished capacity<sup>80</sup>. Caregiving parents find it extremely difficult to locate resources to help them plan for the time when they can no longer care for their son or daughter and consequently, adult children may be left at risk and/or homeless when their parents die<sup>81</sup>. Further, some aging parental caregivers may be reluctant to access services if they have had negative experiences (such as being encouraged to place their children in care) early in the care recipient’s life.

### Caring for challenging behaviours

“Challenging behaviour” is a descriptive term, with the meaning changing depending on context, service delivery, and even geography. Challenging behaviours can include: agitation, restlessness, sexual disinhibition, cursing, hallucination/delusion, depression and/or mania. Nearly 80% of long-term care residents have some degree of moderate to severe behavior problems, stemming from mental illness, dementia, difficult personalities, longstanding behavior patterns, or personal distress. Challenging behaviours are particularly common among those with dementia, with studies indicating that anywhere from 60 to 90% of people with dementia develop behavior problems at some point in their disease. These types of behaviours can also be common among those with developmental disabilities. The number one cause of challenging behaviours towards caregivers is intimate care (e.g. bathing, dressing, feeding, toileting).

Studies indicate that caregivers exposed to challenging behaviours leads to increased negative emotional responses. This then means that caregivers under stress are more likely to engage in avoidant behaviours that maintain challenging behaviours<sup>82</sup>. The lack of caregiving knowledge about how to deal with challenging behaviours often results in caregiver stress and anxiety that is projected on the person needing care, thereby increasing negative behavioral reactions. If a caregiver is stressed and/or depressed this means that this contributes to challenging behaviors in the care recipient and challenging behaviors contribute back into increased stress and/or depression in the caregiver. More depressed caregivers report more behavioral issues in the persons for whom they provide care than those who manage the situation well<sup>83</sup>. Therefore, appropriate information and education for caregivers is crucial in order for them to develop the necessary skills to care both for the care recipient, as well as themselves.

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