

**SUPPORTING THE CAREGIVERS OF SENIORS
THROUGH POLICY – THE CAREGIVER POLICY LENS**

Prepared by Penny MacCourt and Marian Krawczyk
for the Caregiver Toolkit
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pennymaccourt@shaw.ca

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“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 can be a rewarding experience but is frequently fraught with challenges.

Caregivers: A Vital Resource

Support for the caregivers of older adults is vital - by sustaining caregivers the health care system will also be sustained

- Seventy-five to eighty-five percent of the care today’s seniors receive is provided by family and friends (“caregivers”)¹, 60% of whom provide care for more than three years.² 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.³ Additionally, the *number* of seniors needing assistance is expected to more than double between 2001 and 2031.⁴
- With the aging population the number of seniors providing care will also grow. One in four caregivers is over age 65⁵, many of whom are likely to experience their own age/ health related challenges,⁶ 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.
- 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 employers⁷, all of which contributes to both immediate and future burdens on society.
- Caregivers provide care to older adults when the recipient is institutionalized⁸, an important consideration with the challenges in staffing long term care facilities that will only grow with the aging workforce.

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 risk⁹. For example, almost one third of those providing care to seniors with a dementia experience depression¹⁰. Low levels of social support have also been associated with negative psychological and health outcomes.¹¹ 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.^{1213 14}. 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 and programs from the perspective of caregivers of older adults. 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., 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 of seniors, both as partners in care and in the development, implementation and evaluation of policies and programs that affect them.

Who Should Use the Caregiver Policy Lens?

The CGPL can be used by policy makers and analysts, program managers, educators, service providers, researchers, caregiver advocates and organizations.

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
- 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.

Educators can use the CGPL to raise students' awareness, sensitivity and knowledge about the concerns and needs of caregivers.

Advocacy groups can use the CGPL to critique policies and programs from the perspectives of caregivers and to frame a response to policies and programs that affect caregivers of older adults.

The CGPL can be used as a process tool to:

- Focus discussion on caregiver 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 of seniors. 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 experience are summarized in Appendix 1. The information derived from focus group and key informant results and from the literature, underpin the principles, values and key concepts that frame the CGPL, described in Appendix 2.

II. SUMMARY OF THE CGPL QUESTIONS

1. Caregiver Involvement

How are caregivers, caregiver advocates and caregiver organizations involved in the design/review of the policy, program or practice?

2. Collaboration

Are relevant organizations, Ministries, interest groups and individuals concerned with caregiving involved?

3. 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 senior?

4. Diversity and Marginalization

Does the policy, program or practice assess whether diverse caregivers are likely to experience inequities or negative impacts resulting from their membership in marginalized groups?

5. Self-Determination and Independence

Does the policy, program or practice promote and support caregivers' self-determination and independence?

6. Accessibility

Does the policy, program or practice facilitate access to the services available to caregivers of seniors and make appropriate adaptations to accommodate diverse needs?

7. Responsiveness

Is the policy, program or practice designed in such a way that crises and excess use of system supports are minimized?

8. Communication

Are there clear lines of communication and responsibility between service providers and caregivers, and between agencies?

9. Resiliency

Does the policy, program, or practice support the caregiver's capacity to cope with stress and adversity?

10. Individuality

Are caregivers assessed for their own needs and addressed separately from the care recipient?

11. Sustaining Caregivers

Does the policy, program, or practice help equip caregivers with knowledge, skills and respite to carry out their role?

12. 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?

13. Fairness and Equity

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

14. Evidence Informed

Is the policy, program, or practice informed by evidence?

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III. CAREGIVER POLICY LENS (CGPL)

INSTRUCTIONS

You may refer to the Appendix 2 for explanations of the questions/concepts. *(Note- Eventually examples of how others have applied them and tips will be included as an appendix in print CGPL and as links in electronic version).*

PREPARATION AND CONTEXT

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)?

Notes: _____

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: _____

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.
- Each of the category/question headings are hyperlinked to further information at the end of this document; click on them to read more about the importance of each category.

Process Factors: Stakeholder Engagement

1. Caregiver Inclusion and Voice

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

Ask:	Yes	No	Not Sure	N/A
Are caregivers affected by the policy/program (directly or indirectly) participants in the policy or program				

review/development?				
Are the general public, caregivers, seniors and their advocates informed in advance about proposed policies and programs (or their review) that affect caregivers?				
Are caregivers and their advocates consulted about proposed policies (e.g., government, organization, program) 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

2. Collaboration

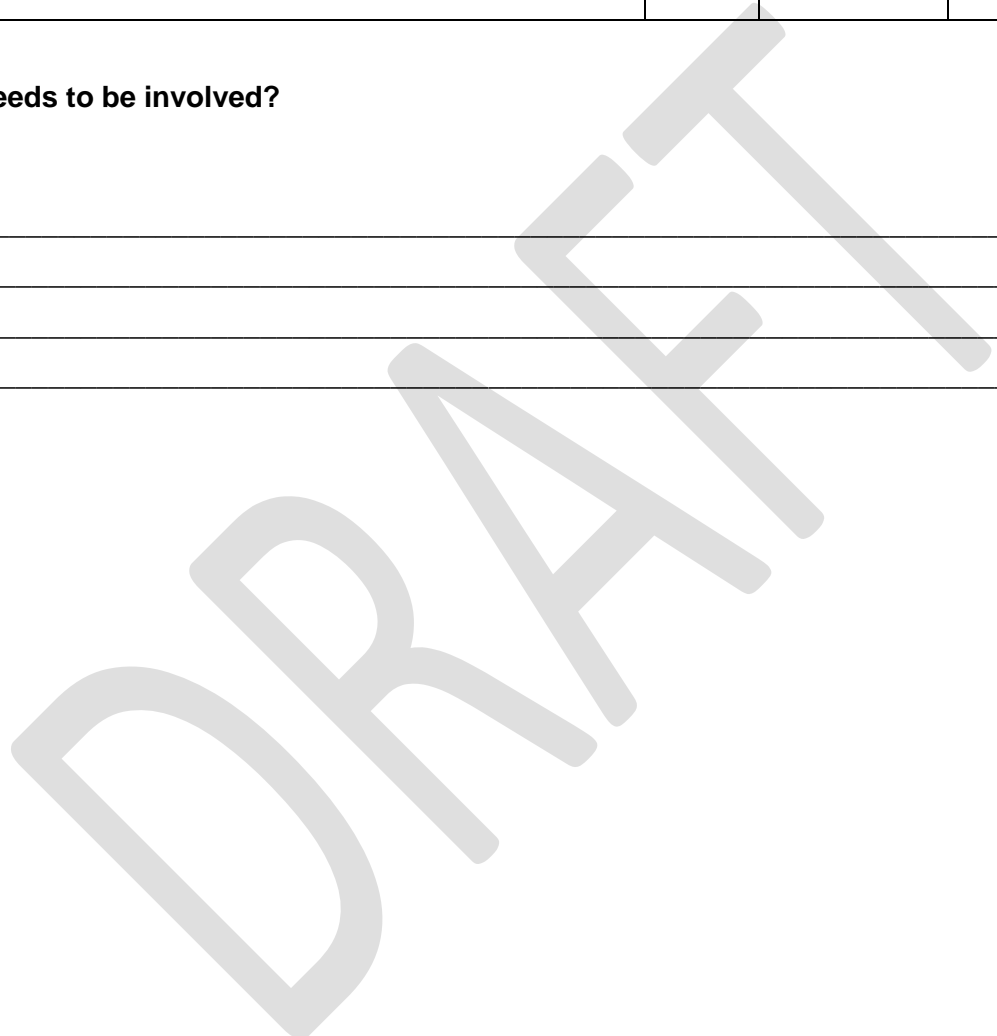
- Relevant organizations providing services affecting caregivers, caregiver advocacy organizations, different levels of government and Ministries, interest groups, and individuals concerned with caregivers must be involved in developing or reviewing the policy or program.

Ask:	Yes	No	Not Sure	N/A
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Has the policy/program been developed in collaboration with organizations, levels of government and programs that are concerned with caregivers of seniors 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?				

Who else needs to be involved?

Notes: _____



Assessing Policy/Program Content

3. Respect

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

Ask:	Yes	No	Not Sure	N/A
Use positive language to portray caregivers and the care				

they provide?				
Formally acknowledge and value the contribution of caregivers?				
Identify the need to respect caregivers' privacy and confidentiality?				
Demonstrate respect for caregivers? (e.g., their time, relationship with the seniors, their preferences).				
Include the caregiver in developing care plans, discharge plans etc. for of the senior for whom they care?				
Recognize the importance of the relationship between the senior and caregiver (e.g. visiting policies in hospital, no "first available bed" policies; "allowable" care in care facilities)?				

Notes:

4. Diversity and Marginalization

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

Does the policy or program demonstrate sensitivity to diversity?	Yes	No	Not Sure	N/A
In the use of language?				

Acknowledge the need to accommodate diverse interests and needs.				
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 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?

Does this policy/program promote the well-being of, or avoid negative effects, for caregivers who are:	Yes	No	Not Sure	N/A
Women				
Men				
Members of an ethnocultural, linguistic, religious, and/or racial minority				
Gay, lesbian, bisexual or transgendered				
Low literacy or limited English or French skills				
Low-income				
Seniors				
Parents of children at home				
First Nations				
Newer Immigrants				
Caring for an immigrant senior				
Living with the senior				
Living In rural or remote regions				
Caring for a senior with challenging behaviours				
Employed (paid or volunteer)				
Other				

Notes: _____

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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5. 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 provide?

Ask:	Yes	No	Not Sure	N/A
Is the right of family members to decline, limit or end caregiving explicitly acknowledged?				
Are caregivers provided with clear information required to make informed choices? (e.g. about care the senior requires, potential challenges, likely duration, and the system support they can expect, including during crises).				

Is the caregiver informed about and offered services available to the senior proactively and prior to crises?				
Is the caregiver's willingness to provide care, the boundaries of their care, and the senior's needs reviewed on a regular basis?				
Are caregivers consulted about any significant changes in service provision including discharges of the senior from community or hospital prior to their occurrence?				
Is there a plan in place if the caregiver chooses to limit or end part or their entire caregiving role?				

Notes: _____



6. Accessibility

- The policy/program facilitates access to the services available to caregivers of seniors and makes appropriate adaptations to accommodate diverse needs.

Ask:	Yes	No	Not Sure	N/A
Is pertinent information readily available about policies and programs that is appropriate to the needs and preference of diverse caregivers? (Taking into account literacy, language, culture, geographic location, etc).				

Are eligibility criteria, application processes and other relevant information about access presented clearly and simply? (including in languages and cultures specific to communities served)				
Is eligibility criteria and other relevant information about access available in a variety of mediums (e.g. print, audio, telephone, web) designed to reach rural and remote caregivers?				
Is an appeal process in place (with assistance as needed) for those who do not meet eligibility requirements?				
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 services required available in a timely manner?				
Is affordability addressed?				
Are any practical barriers (e.g. transportation) addressed?				
Are staff knowledgeable about, and able to refer caregivers to programs for which they are eligible outside of their own agency?				

Notes: _____

7. Responsiveness

- Policies, programs and services to support caregivers, and the seniors they care for, must be designed in such a way that crises and excess use of system supports are minimized.

Ask:	Yes	No	Not Sure	N/A
Are services offered proactively and provided before needs reach crises proportion?				

Is there sufficient flexibility (e.g., in eligibility, implementation and service delivery) to respond to diverse needs?				
Is there sufficient capacity to meet immediate needs identified by caregivers?				
Is there sufficient capacity and flexibility to respond to cries in a timely manner without escalating needs?				

Notes: _____

8. Communication

- Clear lines of communication and responsibility are important between caregivers and service providers, and between agencies.

Ask:	Yes	No	Not Sure	N/A
Is adequate communication between agencies and workers in place such that the caregiver does not have to repeat information over and over?				
Are the roles and responsibilities of each agency and worker providing services to the seniors made clear to the caregiver?				
Are mechanisms in place so that caregivers and workers can exchange information/update each other on changes in the seniors' needs and care?				
Are there processes in place to mediate disputes between caregivers and services, with support for caregivers provided as needed?				

Notes: _____

9. Resiliency

- Does the program or policy support the caregiver's capacity to cope with stress and adversity?

Are the following factors assessed and taken into account/addressed routinely?	Yes	No	Not Sure	N/A
Relationship to the senior cared for/family dynamics				
Social support available (family, friends, community)				

services)				
Competing responsibilities to other family members/friends				
Work responsibilities				
Personal needs for self-care(recreation, learning, exercise, etc.)				
Geographic distance from senior				
Personal health and functioning				
Financial costs (e.g. supplementing seniors' income, travel, supplies, and assistive devices for the senior)				
Emotional and mental health issues/needs				
Knowledge about care management				
Risk factors impacting health and well being (e.g. old age, health conditions, isolation, etc.)				

Notes: _____

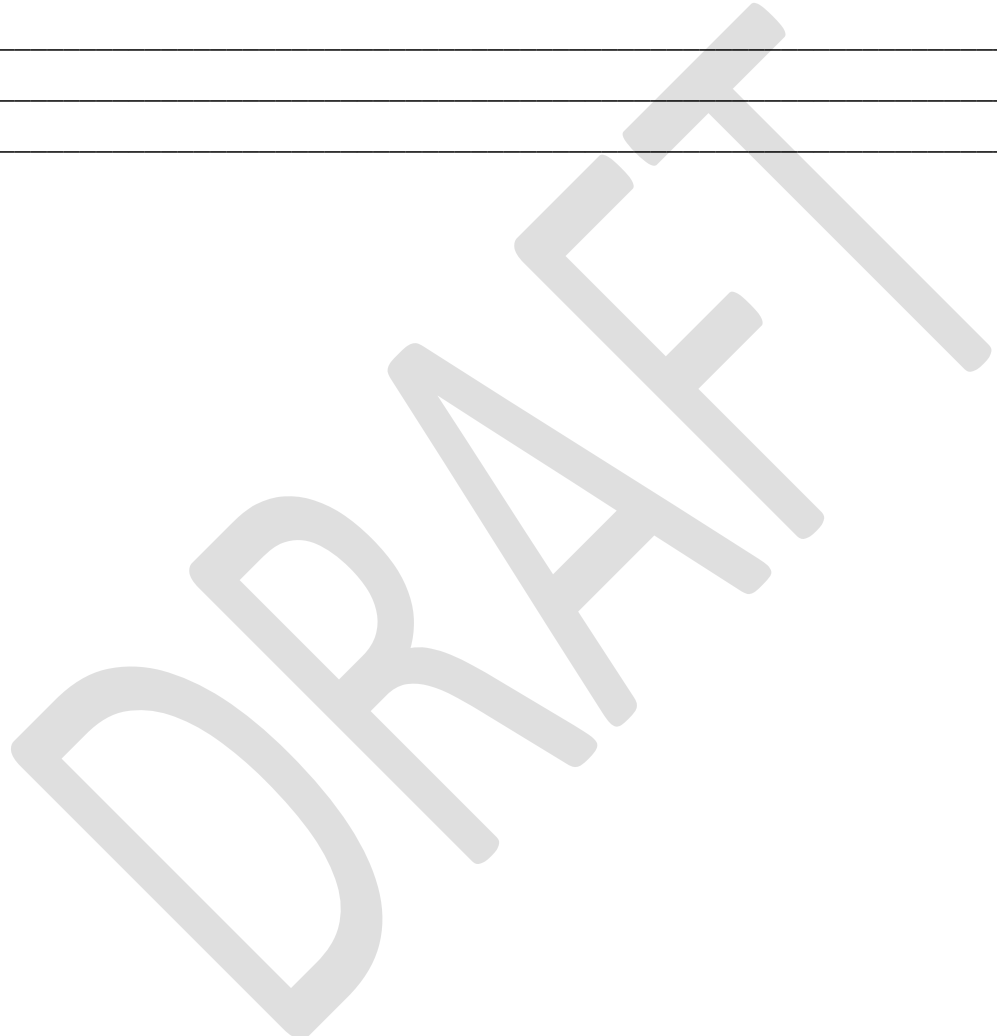
10. Individuality

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

Ask:	Yes	No	Not Sure	N/A
Are caregivers explicitly asked about what support and services they need?				
Are caregivers' needs (separate from those of the senior)				

assessed?				
Does the policy or program meet the stated needs of the caregiver?				
Are caregivers asked to provide input and feedback about how well their needs are assessed and addressed?				
Are caregivers asked to identify changes needed to the support and services they need/use?				
Is personal counselling available for issues related to caregiving (e.g., grief, depressed mood) when needed?				

Notes: _____



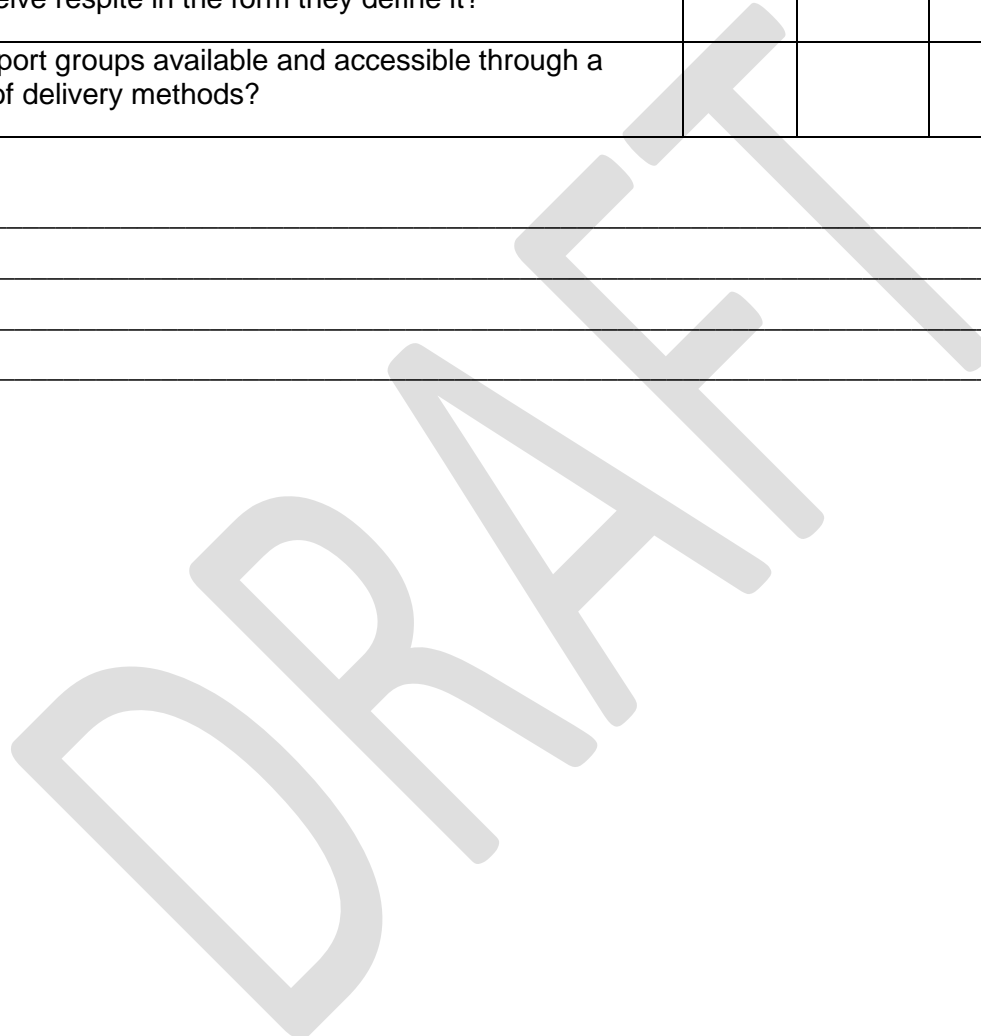
11. Sustaining Caregivers

- Caregivers must be equipped with necessary knowledge, skills and respite to carry out their role.

Ask:	Yes	No	Not Sure	N/A
Is education provided about the practical aspects of caregiving (e.g., transferring)?				
Is information about the medical, cognitive and functional needs of the seniors being cared for, and how to meet				

these, provided?				
Is individualized information and coaching available to address specific issues confronting the caregiver (e.g. paranoid behaviours)?				
Is respite encouraged on a regular basis as a measure to promote caregiver well-being burden?				
Is respite provided when needed?				
Is there sufficient flexibility to allow the caregiver to identify and receive respite in the form they define it?				
Are support groups available and accessible through a variety of delivery methods?				

Notes: _____



12. Sustaining Systems

- Policies and programs for seniors must be sensitive to the needs and concerns of caregivers, and be delivered by knowledgeable staff with sufficient time and skill to develop caring, trusting relationships.

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				

seniors?				
Is the number of different service providers/workers kept to the minimum, encouraging trust, relationship building and continuity of care?				
Do the hours of services provided to the seniors 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 seniors' programs outside of home, appointments etc., and when desired, allow the caregiver to accompany the seniors?				
Are supplies (e.g. incontinence supplies), and assistive devices (e.g. bathroom bars) made available?				

Notes: _____

13. 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 and collective needs?				
Does the effect of the policy/program create economic or social disadvantages for any population group or non-health sector?				

Notes: _____



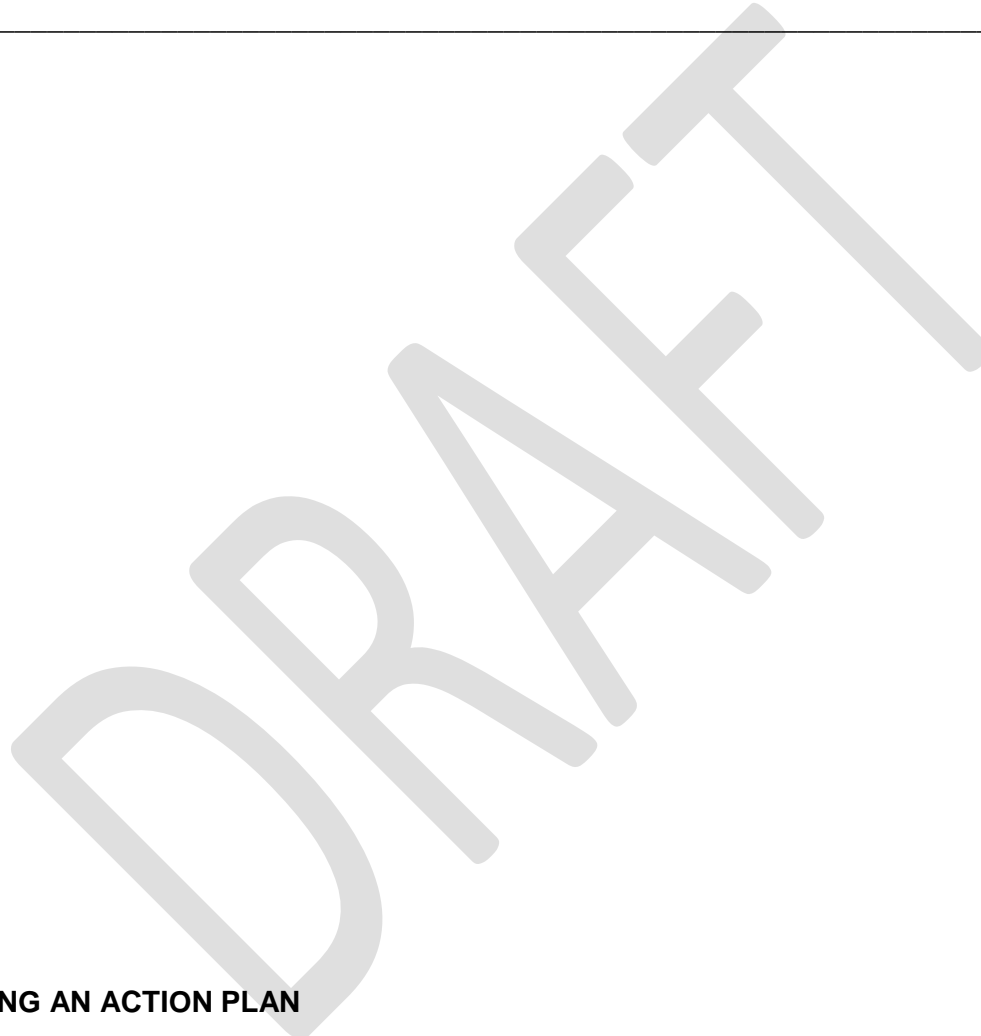
14. Evidence Informed

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

Is the policy/program informed by the best available evidence?	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/program on an ongoing basis?				
Is the policy/program congruent with relevant laws and legislation?				

Notes: _____



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.

3. 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 address this process, and what information needs to be gathered. Set target dates.

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

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.

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 taken from 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 themselves, and gaps in getting their 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 formal health and social services in relation to the seniors for whom care is being provided. The type of care giving required, how much of it and for how long it will be required, is not part of the formal assessment and care planning for the senior. 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 seniors 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 seniors they care for, or in accessing them. This is especially true where seniors have 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 seniors, (e.g. home support, adult day care, volunteer visiting, Handi-dart) 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 senior. Handi-dart services are difficult to arrange, need advance planning and may or may not allow the caregiver to travel with the senior.

“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 they care for, 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 the seniors to whom they provide care 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 senior) often feel overwhelmed by number of services and workers involved. As a result both seniors 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 senior 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 they assume 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.¹⁵

“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 facility¹⁶. 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.¹⁷⁻¹⁸ 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**I. 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 ensuring 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.

In developing policies and programs, inclusion means asking: Are caregivers and caregiver organizations participants in developing the policies and programs that affect them? 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 the making of sound policy.¹⁹

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 for caregivers usually remains in the domain of health services and organizations. Additionally, services, programs and policies often unintentionally affect caregivers' rights and services in other areas.

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?

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?

II. Assessing Policies and Programs

3. Respect

Family caregivers must be acknowledged, respected and valued for their caregiving work (Canadian Caregiver Coalition, 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 filters 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, and facilitating this relationship, denotes respect.

4. 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 – GLBT 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.

5. 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). 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 seniors' care 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.

6. Accessibility

Sustainable caregiving 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 (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.

7. Responsiveness

Policies and programs need to 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 seniors 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?

8. 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. Staff 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.)

9. Communication

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.

The importance of communication is one that transcends the provision of direct support to caregivers; policies, programs and services must be designed to encourage open and innovate 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.

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.

10. Individuality - Supporting Caregivers in Their Own Right

“Family caregivers have the right to express their needs and receive support” (Canadian Caregiver Coalition, www.ccc-ccan.ca). Caregivers have the right to have their own needs assessed, not just in relation to those of the seniors 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”.

Service providers need to ask caregivers explicitly about their own needs, by being proactive and non-judgmental in asking caregivers about their self-care, the challenges they are experiencing, and what might help. Respite should be offered proactively on a regular basis but also be made available when the caregiver expresses the need for it. Support for caregivers in their own right might include, but is not limited to,

- 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, respite, information about the caregiving journey – especially challenges and transitions),
- Healthy aging (supportive community, services supporting non-medical activities of daily living, periodic reassessments during caregiver journey)

11. Sustaining the Caregiver Role (Sustainable Caregiving)

Sustaining the caregiver role is about the policies, programs and services - 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. Sustainability comes from addressing and creating system supports to sustain caregiver 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 seniors 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 the senior for whom they provide care.
- 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 seniors.

12. Sustaining Systems to Support Caregiving

A system that sustains caregiving also ensures that transition crises, premature placement or hospitalization are minimized. 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 are based on best practices, and 3) evaluation and monitoring mechanisms of policies, programs and services 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.

13. 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 elder 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, caregivers pool and the economy. For example, it is possible that a policy that benefits caregivers of seniors may impact workers and their families negatively. Furthermore, while health outcomes may be positive, economic and social effects may be detrimental for one or more groups.

14. 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 both to design an effective policy, program or service. For policies, programs or services that have either a direct or indirect effect on caregivers, you must include mechanisms that include their perspective 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.

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