



EXPANDING CAREGIVER SUPPORT IN ONTARIO

**Advice from Janet Beed
to the Honourable Eric Hoskins
Minister of Health and Long-Term Care**

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June 2017

The Honourable Eric Hoskins
Minister of Health and Long-Term Care
Government of Ontario
Toronto, Ontario

Dear Dr. Hoskins:

I am pleased to submit my report to you on expanding caregiver support which is one of the ten steps in the Ministry of Health and Long-Term Care's "**Roadmap to Strengthen Home and Community Care**". Caregivers provide unpaid care to their family, friends and neighbours of any age who have physical and/or mental health care needs.

I was asked to inform next steps in coordinating and strengthening caregiver supports. This included whether a new provincial caregiver organization could serve Ontario caregivers and, if so, to recommend an organizational structure that would complement and leverage the capacity and expertise of organizations that already help support caregivers.

I listened to over 200 individuals and reviewed relevant documents. My firm belief is that Ontario needs to invest in supporting its caregivers, and that a made-in-Ontario approach would be welcomed and highly beneficial. My advice takes the caregiver's perspective and is reflected in the following three recommendations:

- For truly effective caregiver support, I recommend that the ministry develop initiatives at the individual, organizational and system levels. Initiatives need to be sensitive to the fact that each caregiver brings their own experiences – which are influenced by culture, language, age and other factors – and which evolve over time. The consultations highlighted the need to recognize and provide caregiver supports to our French Language caregivers in French. In addition, the consultations stressed the importance of co-designing and co-developing supports with and for our Indigenous Peoples, as well as working with the LGBTQ community to further understand and develop appropriate caregiver supports.
- Ontario does not have an organization or entity that: focuses solely on caregivers and their multiple diverse needs; reflects the broad culture of caregiving as opposed to caregiving within a focused area(s); and can deliver and coordinate the full-range of supports at each level. I, therefore, recommend that the ministry establish a stand-alone caregiver support organization to achieve these ends. It will be important to respect the critical role played by existing organizations that have a strong track record supporting care recipients and caregivers.
- A tangible commitment to implement is crucial and, thus, I recommend that the ministry appoint an Implementation Lead in the short term to begin this important work.

These recommendations support Ontario's "**Patients First**" commitment which puts people and patients at the centre of the care experience. Caregivers augment our taxpayer-funded services, are an intrinsic part of our health care system, and contribute significantly to the health and well-being of Ontarians. I strongly believe that these recommendations will benefit caregivers, improve the caregiving experience, and enable them to continue their important work.

Minister Hoskins, I would like to thank you for asking me to provide advice on strengthening caregiver supports. It was a privilege to do this important work on behalf of caregivers in Ontario.

Yours sincerely,



Janet Beed

ACKNOWLEDGEMENTS

On behalf of the thousands of caregivers in Ontario, I would like to thank the Minister of Health and Long-Term Care, Dr. Eric Hoskins, for the opportunity to recommend how we can ensure that all caregivers feel supported and valued.

My recommendations were formulated with the assistance of many groups and individuals who contributed their thoughts, experiences, concerns, hopes and dreams. I extend my thanks to:

- The caregivers and members of organizations who support and interact with caregivers for participating in the consultations, for following up with questions and suggestions, and for their ongoing belief that we can make it better.
- The Ministry of Health and Long-Term Care – particularly Nancy Naylor, Amy Olmstead and Ellen Bruce – for their guidance and support. This team was readily available to help gather experiences and brainstorm possible ways forward.
- Cathy Fooks and the Change Foundation for their foundational work and ongoing commitment to explore, through research, ways to enhance the caregiver experience.
- Gail Donner, Chair, Expert Group on Home and Community Care, who helped us remain connected to the “Patients First” agenda and was a source of support and guidance throughout the process.
- Joann Trypuc, who facilitated our consultations and created an environment that allowed us to hear the diverse opinions, stories and experiences that shaped the final advice and recommendations. Joann’s ability to remain focused on the task while relating warmly with everyone we met provided me with tremendous support.

This project has been an honour to undertake and has enhanced my personal experience of, and deep appreciation for, caregiving.

Many thanks.

A handwritten signature in cursive script, appearing to read 'J Beed', written in dark ink.

EXECUTIVE SUMMARY

Caregivers provide unpaid care to their family, friends and neighbours of any age who have physical and/or mental health care needs. Many reports have identified the importance of caregivers, the need to support them, and the challenges they face. Although Ontario is fortunate to have many valuable organizations that help support caregivers, they still face challenges finding and accessing appropriate information and supports.

In early 2017, the Minister of Health and Long-Term Care, Dr. Eric Hoskins, asked me to inform next steps in coordinating and strengthening caregiver supports. This included whether a new provincial caregiver organization could serve Ontario caregivers and, if so, to recommend an organizational structure that would complement and leverage the capacity and expertise of organizations that already help support caregivers. Expanding caregiver support is one of the ten steps in the Ministry of Health and Long-Term Care's "**Roadmap to Strengthen Home and Community Care**".

My observations and recommendations are based on listening to over 200 caregivers, representatives of home and community care organizations, and caregiver support organizations in other jurisdictions, and reviewing relevant documents. My advice and three recommendations take the caregiver's perspective, and are based on my firm belief that Ontario needs to invest in supporting its caregivers, and that a made-in-Ontario approach would be welcomed and highly beneficial.

There was widespread agreement during the consultations that effective caregiver support must include initiatives at the individual, organizational and system levels. My first recommendation is to develop caregiver support initiatives at each of these three levels:

- **Individual level supports** should include one access point where caregivers can receive information and be connected to available services and supports.
- **Organizational level supports** should identify caregiver support gaps within and between the Local Health Integration Networks (LHINs) – as well as among organizations that support caregivers – and advise on opportunities to address gaps, standardize services, make better use of collective resources, expand excellent programs, and improve equitable access to supports.
- **System level supports** should include public education and awareness programs about the value, importance and challenges of caregiving; increased knowledge of health care and other service providers (such as EMS and police) about the role and value of engaging caregivers; opportunities to improve and align caregiver support policies and legislation at the municipal, provincial and federal levels; and opportunities for caregiver and best practices research.

Over the course of the consultations, there was agreement that, currently, Ontario does not have an organization or entity that: focuses solely on caregivers and their multiple diverse needs; reflects the broad culture of caregiving as opposed to caregiving within a focused area(s); and can deliver and coordinate the full range of individual, organizational and system level caregiver supports. There was widespread support from caregivers for the creation of an organization dedicated to meeting their broad needs. After carefully considering various options, my second recommendation is the establishment of a stand-alone caregiver support organization to deliver and coordinate the full range of supports to caregivers. Key characteristics include:

- A volunteer Board of Directors.
- A staff secretariat at a central location and at regional locations – strengthened by local volunteer networks – aligned with, co-located within, and arms-length from the LHINs.
- Staff accountability to a CEO and organizational accountability to the Minister of Health and Long-Term Care or their designate.
- Non-profit charitable status with multi-year government funding.
- Accountability for performance.
- Continuous evaluation and refinement as the health care system evolves.

Initiatives need to be sensitive to the fact that each caregiver brings their own experiences – which are influenced by culture, language, age and other factors – and which evolve over time. The consultations highlighted the need to recognize and provide caregiver supports to our French Language caregivers in French. In addition, the consultations stressed the importance of co-designing and co-developing supports with and for our Indigenous Peoples, as well as working with the LGBTQ community to further understand and develop appropriate caregiver supports.

In addition, it will be important to respect the critical role played by existing organizations that have a strong track record supporting care recipients and caregivers. Their input has been invaluable and, going forward, we need to draw on their experience and expertise, and leave room for their continued support to caregivers.

My third recommendation is the appointment of an Implementation Lead in the short term to begin this important work. This tangible commitment to implement is crucial.

These recommendations support Ontario's "**Patients First**" commitment which puts people and patients at the centre of the care experience. The contribution and value of caregiving are significant and growing. Caregivers augment our taxpayer-funded services, are an intrinsic part of our health care system, and contribute significantly to the health and well-being of Ontarians. I strongly believe that these recommendations will benefit caregivers, improve the caregiving experience, and enable them to continue their important work.

PART A

INTRODUCTION

1 BACKGROUND

THE TASK

In early 2017, the Minister of Health and Long-Term Care, Dr. Eric Hoskins, asked me to inform next steps in coordinating and strengthening caregiver supports. This included whether a new provincial caregiver organization could serve Ontario caregivers and, if so, to recommend an organizational structure that would complement and leverage the capacity and expertise of organizations that already help support caregivers. I was also asked to suggest the organization's vision, mandate and supporting structure that would best meet the needs of caregivers.

STRATEGIES USED

I used two strategies to support this work: consultation and a review of background reports.

- **Consultations:** I conducted consultation sessions with caregivers, a wide range of individuals and organizations in the home and community care sector, individuals and groups that influence caregiver supports, and caregiver support organizations in other jurisdictions. Consultation sessions included committee meetings, group consultations and individual interviews. (Appendix A)
- **Review of background reports:** I reviewed numerous documents related to caregiver needs and supports, as well as the models used by other jurisdictions to support caregivers. (Appendix B)

These activities provided a wealth of information on caregiver needs and ways to provide support, and helped to identify potential directions for the future.

REPORT OVERVIEW

This report presents my observations and recommendations based on listening to over 200 individuals and reviewing relevant documents. The report refers liberally to the experiences of caregivers as heard through the consultation sessions.

The report begins with an assessment of caregivers and caregiver supports both in Ontario and other jurisdictions, followed by my advice on a made-in-Ontario approach to supporting caregivers (Chapters 2 and 3 respectively). Appendices follow which include my interim report submitted to Minister Hoskins on April 21, 2017. (Appendix C)

PART B

OBSERVATIONS AND RECOMMENDATIONS

2 CAREGIVERS AND CAREGIVER SUPPORTS IN ONTARIO

CAREGIVERS

Who Are Ontario's Caregivers?

Caregivers provide unpaid care to their family, friends and neighbours of any age who have physical and/or mental health care needs.¹ The recipients of this care may be living in their own homes or in facilities. In comparison, the term **care providers** refers to people who are hired and paid to provide care, some of which may be similar to what caregivers do and in other instances may be more complex.

Many caregivers attended our consultations. It was abundantly clear that caregivers are not a homogeneous group; rather, each one is unique with unique experiences. For example, I met:

- A young woman who quit work and cares full-time for her older mother.
- A middle-aged parent who provides specialized care for her autistic son.
- A middle-aged man who cares for his aging parents.
- An older man who cares for his wife with dementia.
- An older woman who supported her husband when he was alive and now helps a friend and neighbour who needs support to remain in her own home.

A caregiver is an individual as well as a member of a unit or dyad that includes the care recipient. Some caregivers live with those they care for whereas others routinely travel – sometimes long distances – to provide support. All caregivers are in constant contact with those they support. I was struck by the fact that the caregivers I met are deeply committed to fulfilling their caregiving responsibilities, however stressful and challenging they may be. Some do so willingly and consider it a part of life; whereas others are compelled by family expectations or an inability to find what they consider to be sufficient supports.

A number of caregivers pointed out that their relationship is characterized by an unequal give-and-take. Research has shown that caregiving has major impacts on the lives of caregivers including significant negative impacts on their emotional well-being (Lin et al. 2016), increased levels of stress and distress, financial hardship, an inability to concentrate at work, job instability (such as leaving jobs voluntarily or involuntarily), and so on. (The Change Foundation 2016)

¹Other terms used to describe individuals who provide unpaid care to their family, friends and neighbours include carers and informal caregivers.

I listened to caregivers talk about the high levels of stress they feel. A number of them commented that they cannot quit their roles – and do not want to quit – even though they may feel frustrated, tired, discouraged, resentful, and even afraid of what the future will bring when the person they care for ages, gets sicker, has a health crisis or passes on. Everyone I listened to agreed that caregivers need support to be able to continue caring.

What Contribution Do Caregivers Make?

The Change Foundation estimated that 3.3 million Ontarians – or 29 per cent of the provincial population – provide support and care to a chronically ill, disabled, or aging family member, friend or neighbour (2016).² These supports range from emotional support, transportation and housekeeping to performing clinical tasks such as tube feeding, wound care and giving injections.

It has been further estimated that it would cost upwards of \$26 billion annually to replace the work of Canadians caring for seniors with paid equivalent care (Hollander et al. 2009). This cost would be higher when caring for family, friends and neighbours of all ages.

I believe that caregivers' contributions and their value will continue to increase substantially in the future. Ontarians have benefitted from many significant trends such as higher life expectancies, technological advances that save and prolong lives, effective management of chronic illnesses, and shifts from inpatient to outpatient care and from hospital to home and community-based care, to name a few.

Although these trends are highly positive, they have placed higher expectations on caregivers to support their loved ones who now survive, live longer, experience age-related illnesses, are technology dependent, need ongoing therapies, need help getting to and from medical appointments and procedures, and need help functioning on a daily basis. These trends have also placed higher expectations on children and youth who may be helping to care for their siblings, parents and grandparents.

Societal trends have also exacerbated the pressure on caregivers. The shift from larger extended families to smaller families, increased mobility where adult children may live further from their parents, and greater participation of women in the paid workforce mean that responsibility for family caregiving may fall on fewer adult children who may live at a distance and have workplace and other family obligations.

It is well recognized that our tax-funded health care system and its paid providers make a highly valued and substantial contribution to meeting the care needs of Ontarians. What is less well recognized, valued and, indeed, included in economic equations is the significant contribution that unpaid caregivers make. They augment our taxpayer-funded services, are an intrinsic part of Ontario's health care system, and contribute significantly to the health and well-being of its citizens.

CAREGIVER SUPPORTS IN ONTARIO

Many Organizations Provide Highly Valued Services in Focused Areas of Expertise and With Various Sources of Funding

The consultations highlighted the fact that many organizations provide highly valued caregiver supports in Ontario. These organizations play a critical role and have a strong track record of supporting care recipients and caregivers either directly or indirectly. In the latter instance, for example, organizations may provide services such as respite care which helps support the caregiver while attending to the care recipient's needs.

These organizations – and the services they provide – vary widely in terms of focus and funding.

²The Change Foundation analyzed Statistics Canada's 2012 General Social Survey Data specific to Ontario.

The majority of organizations focus on selected areas of expertise such as:

- A disease, condition or issue (e.g., cancer, heart and stroke, Alzheimer's, multiple sclerosis, schizophrenia, bereaved families, etc.).
- Particular ages (e.g., infants, children, youth, older persons, etc.).
- Type of service (e.g., healthy living, helping people stay in their homes, etc.).

The focus on selected areas of expertise can be very challenging for caregivers. During the consultations, one caregiver noted that their needs did not fall cleanly into any existing disease or age-oriented organizations:

“I just care for my 26 year old son who cannot be left alone.”

An additional challenge is that caregivers may not find supports in certain areas and may become confused about what they can expect and depend upon. One caregiver commented that she was supported very well when her mother was diagnosed with dementia; however, when her father was debilitated with another illness, she found little to no support.

There are commonalities among organizations with a specific focus. Typically they provide caregiver support services such as information and education. Some also help caregivers navigate services, and may engage in research and advocacy on behalf of caregivers.

Funding for caregiver supports varies widely. Organizations and services may be:

- Publicly-funded such as programs through the LHINs, Community Care Access Centres (CCACs), hospitals and primary care.³
- Privately-funded by for-profit or not-for-profit companies such as organizations that offer supplemental home care or home support.
- Funded through charitable donations and foundations.

The funding source tends to influence the caregiver supports that are developed and where they are locally available. For example, a LHIN's priorities will directly influence whether it allocates funds for caregiver supports. As well, for-profit organizations may prefer to develop selected services that have defensible business cases, whereas philanthropic funding may focus on supports that have a personal or emotional connection to donors.

There is Inequitable and Ineffective Access to Caregiver Supports

Ontario has some superb caregiver support initiatives. Regrettably, they tend to exist in pockets or focused areas that may not meet the needs of all caregivers. The result is inequitable and ineffective access to appropriate caregiver supports across the province. Typically, caregivers discover these gaps when they try to find needed supports.

Examples from the consultations include:

- One LHIN participant described a program of caregiver education that they had recently purchased and how positively it was being received, yet participants from other LHINs were either unaware of the program or did not have any plans to adopt such a program.

³The mandate of the LHINs – as the single point of accountability for integrated home and community care – is being expanded to include home care services from the CCACs. The transfer from the CCACs to the LHINs was completed in June 2017.

- A representative of a disease-focused organization believed that their regional model worked very well, with many caregivers in the consultations agreeing; however, other caregivers stated that this support was not available in remote areas where they lived.
- A caregiver commented that the services for her husband were terrific in one area but when they moved to another LHIN, he could not access the same supports or level of support. The expectations and demands on the wife to provide care increased.

Generally, I observed that organizations that focused on diseases or were in selected areas of the province appeared to think they were doing an effective job of meeting caregiver needs. In comparison, caregivers were more likely to identify gaps and limitations in the supports available. For me, this highlighted the importance of validating the caregiver's experience and taking the caregiver's perspective.

CAREGIVER SUPPORTS IN OTHER JURISDICTIONS

It was very useful to examine the experiences and models of other jurisdictions that have more formalized approaches to caregiver support. These included:

- Nova Scotia
- Alberta
- Sweden
- United Kingdom

Additional information on these jurisdictions can be found in Appendix D.

3 A MADE-IN-ONTARIO APPROACH TO SUPPORTING CAREGIVERS

INTRODUCTION

I believe that an appropriate made-in-Ontario approach to supporting caregivers has to articulate clearly what caregivers need. One of my primary focuses was to obtain consensus on what this would be. The review of background documents helped to identify a long list of potential caregiver supports. These documents – along with an assessment of caregiver organizations in other jurisdictions – were also used to identify potential options for a structure.

All this information was presented to those I consulted with for discussion, debate and improvement. This grassroots input was invaluable for guiding and shaping my final advice and recommendations on caregiver supports and a structure to provide these supports.

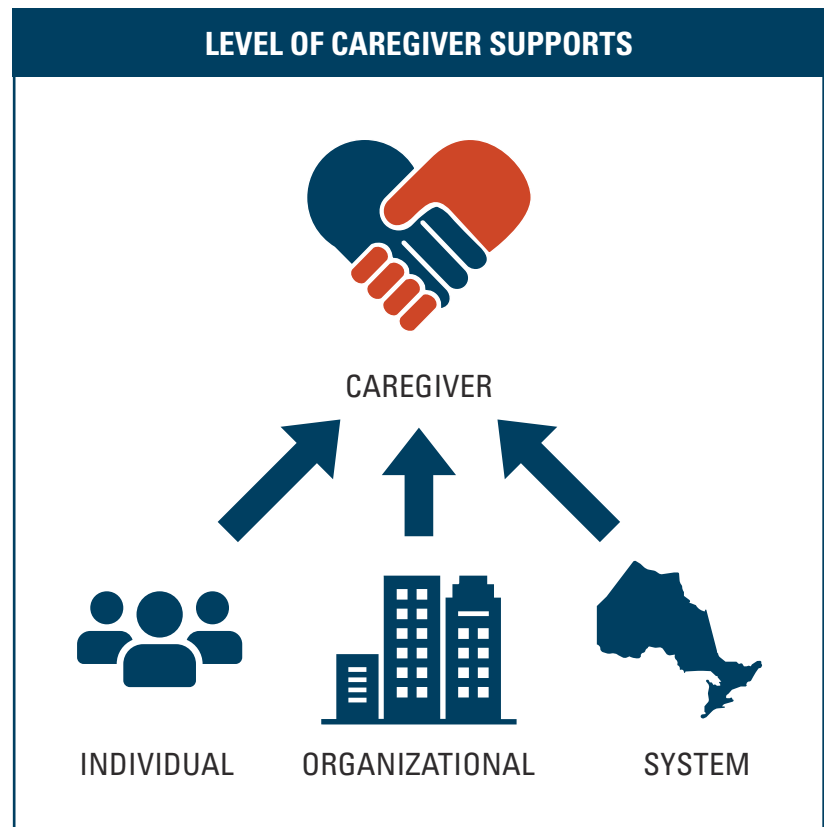
CAREGIVER SUPPORTS

There is a tendency to assume that individual level supports are sufficient to sustain effective caregiving. I believe that effective caregiver support needs to include initiatives at the individual, organizational and system levels. There was very strong agreement on these three levels of support throughout our consultations, along with wide-spread agreement on the specific supports needed at each of these levels.

Individual Level Supports

The consultations highlighted the fact that caregivers struggle trying to access information and supports for various reasons. They:

- Do not know where they are.
- Do not know how to access them.
- Find supports that are too specialized and unable to meet their needs.
- Cannot find general supports relevant to all caregivers.



In addition, caregivers reported having gaps in knowledge and needing information on how to fulfill their caregiving role. A number of caregivers stressed the importance of information that is relevant to the phase of caregiving they are in. The caregiver's role evolves over time in relation to the changing needs of the care recipient.

Caregiver supports at the individual level need to include the following two initiatives:

1. Establish One Access Point

Individual caregivers need one access point to connect to regardless of where they live, the resources they have, or any communication challenges they may face. A number of stakeholders noted that having a one-number-to-call when they faced critical caregiving challenges and needed immediate connection would go a long way towards supporting them and keeping the care recipient at home longer.

One access point should have the capacity to:

- Provide consistent information on caregiving and the services and supports that are available to the caregiver.⁴
- Advise caregivers on the most appropriate services to meet their needs, with sufficient details on the type of service, who provides it, how it can be accessed, and cost.
- Link caregivers to the services and organizations that would meet their needs. This active navigation could include linking caregivers to specific services or programs (such as being a caregiver; giving medications; moving someone without hurting them and yourself; when to call for help or go to the hospital; the trajectory of a disease, illness or impairment; and so on).

There was overwhelming support for a “warm connection to a person and a warm handoff to another person.” There was also widespread agreement that one access point should be equitable for everyone across the province, and that it should be sensitive to the unique needs of caregivers of various cultures, orientations, languages, ages and other factors (e.g., Indigenous Peoples (First Nation, Métis, Inuit), French Language, LGBTQ, and other groups).

2. Offer Education and Support Programs

These programs should focus on meeting the general needs of all caregivers. Examples from the consultations include but are not limited to how to juggle multiple priorities when caregiving, re-entering the workforce after caregiving, and coping with no longer being a caregiver.

INDIVIDUAL LEVEL CAREGIVER SUPPORTS

- Establish One Access Point
- Offer Education and Support Programs



INDIVIDUAL

⁴This could include general information such as the availability of financial programs and relief programs and how to access them.

Organizational Level Supports

The consultations highlighted the fact that although Ontario has many valuable caregiver supports, organizations have different foci and reflect pockets of excellence in selected areas. This leads to variable access depending on where caregivers live and what problems they face. It was also suggested in the consultations that many organizations would benefit from knowing what each other is doing while respecting their competitive advantages from a philanthropic perspective.

There was widespread agreement that caregiver supports at the organizational level need to include the following two initiatives:

1. Address Gaps in Caregiver Services and Supports Within and Between LHINs

This would involve identifying gaps and advising on opportunities to address these gaps, standardize services, expand excellent programs, and improve equitable access to caregiver supports.

2. Facilitate Caregiver Organizations to Collaborate on Addressing Gaps and Maximizing Their Impact

This would involve inviting caregiver organizations to come together to:

- Identify and close service gaps.
- Share ideas and successful approaches.
- Make better use of their collective resources by minimizing duplication.
- Expand excellent programs.
- Improve equitable access to caregiver supports.

ORGANIZATIONAL LEVEL CAREGIVER SUPPORTS

- Address Gaps Within and Between LHINs
- Facilitate Caregiver Organizations to Address Gaps and Maximize Their Impact



ORGANIZATIONAL

System Level Supports

The consultations highlighted the fact that there are broad caregiver support issues that cannot be effectively addressed at an individual or organizational level. These include wider public issues as well as those that involve multiple provincial ministries – such as health, community and social services, education, housing and transportation – and involve various levels of government such as provincial, municipal and federal.

There was widespread agreement that caregiver supports at the system level need to include the following four initiatives:

1. Conduct Public Education and Awareness Programs

These programs should focus on the value, importance and challenges of caregiving. Some key messages that were suggested include: the impact of caregiving on caregivers, and the rights of caregivers to have healthy lives themselves.

2. Increase Knowledge Among Health Care and Other Service Providers About the Role, Value and Active Engagement of Caregivers

Caregivers in the consultations gave examples of being with their families, friends or neighbours, and being ignored or overlooked by service providers (such as physicians, nurses, emergency medical services, police, and others). Typically, caregivers can provide valuable information and assistance in these situations (e.g., calming down an overly anxious child or parent, communicating information that may be hard to understand).

It was suggested that in the short term, organizations – such as hospitals, clinics, emergency service, police – could train their staff. In the longer term, this type of training could be included in the curriculum of education programs.

3. Advise on Improved Caregiver Support Policies and Legislation

This advice may address as well as align policies and legislation at the municipal, provincial and federal levels. For example, caregiver needs must be considered in provincial health system reform such as primary care. Another example is education reform where individuals who leave the workforce to be full-time caregivers could receive educational credits for the skills they have developed.

4. Advise on and Participate in Caregiver Research

This research could focus on caregivers, their needs, and caregiver support best practices. There is increasing interest in studying caregiving from many perspectives. Caregiver research – including design, conduct and implementation – should increase our understanding of, and improve, the caregiving experience. There is a need to avoid research or survey fatigue among caregivers and care recipients.

SYSTEM LEVEL CAREGIVER SUPPORTS

- Conduct Public Education and Awareness Programs
- Increase Knowledge Among Health Care and Other Service Providers About Caregivers
 - Advise on Caregiver Support Policies and Legislation
 - Advise on and Participate in Caregiver Research



SYSTEM

RECOMMENDATION 1

It is recommended that:

The Ministry of Health and Long-Term Care support the development of the following initiatives at the individual, organizational and system levels:

- Individual level supports to include: establish one access point; and offer education and support programs.
- Organizational level supports to include: address gaps in caregiver services and supports within and between LHINs; and facilitate caregiver organizations to address gaps and maximize their impact.
- System level supports to include: conduct public education and awareness programs; increase knowledge among health care and other service providers about the role, value and active engagement of caregivers; advise on improved caregiver support policies and legislation; and advise on and participate in caregiver research.

A STRUCTURE TO PROVIDE SUPPORTS

There was widespread agreement throughout the consultations that existing organizations play a critical role supporting care recipients and caregivers. These include organizations focused on particular diseases, home and community care provider organizations, patient and caregiver associations, and taxpayer-funded health care services. Everyone agreed that this important support needs to continue.

There also appeared to be agreement that currently Ontario has no organization or entity that:

- Focuses solely on caregivers and their multiple diverse needs;
- Reflects the broad culture of caregiving as opposed to caregiving within a focused area(s); and
- Can deliver and coordinate the full-range of caregiver supports set out in Recommendation 1.

In the consultations, caregivers supported creating an organization dedicated to meeting their broad needs. Representatives of existing organizations were generally supportive and could see the value of a caregiver organization. They expressed some concerns about the ability of an organization to catch up to existing systems of support, and wondered where such an organization would fit in the current system. Existing organizations also cautioned against duplicating caregiver services that are already available.

There was general agreement on the underlying principles to guide a caregiver organization; however, opinions varied widely on the best structure to deliver and coordinate caregiver supports.

Underlying Principles for a Caregiver Organization

The following principles emerged through the consultation process. A made-in-Ontario caregiver support organization must:

- Partner with caregivers in designing, creating and governing the organization while avoiding doing this work “on the backs of caregivers.”
- Add value for caregivers by improving their caregiving experiences.
- Focus on general supports that all caregivers may need regardless of the disease, condition and/or age of the care recipient.

- Be able to cross government ministries to support the multiple needs of caregivers – such as education, transportation, housing, employment, social services – as care recipients transition across different levels of care.
- Avoid taking on the responsibilities of other organizations or government (e.g., mediating home care services provided through the LHINs; funding individual services, etc.).
- Partner with existing provincial, regional and local organizations, programs and services to maximize supports, minimize duplication, and expand what currently exists more broadly across the province.
- Recognize and provide caregiver supports to French Language caregivers in French.
- Ensure that the organization's structure and all its activities support diversity, equity, inclusivity and cultural competence (i.e., the ability to understand, communicate and effectively interact with people across cultures). This includes being sensitive and responsive to the unique caregiver support needs of Ontario's population including but not limited to:
 - Indigenous Peoples (First Nation, Inuit, Métis). The unique needs of Indigenous Peoples were not explored in depth. Further engagement to co-design and co-develop appropriate caregiver supports is required.
 - LGBTQ Communities. The consultations identified unique caregiving issues, including caregivers and care recipients who may hide their gender identities to avoid mistreatment, harassment, and refusal of health services and support.
- Be cost responsible and maximize system effectiveness by leveraging current systems and databases that are appropriate and relevant.

Options for a Caregiver Support Organization

Based on previous reports, studies and consultations on the needs of caregivers – as well as additional consultations with over 200 individuals – I believe that caregivers would benefit from a formalized provincial approach to caregiver support. I considered a number of options all of which were suggested in one form or another through the consultations.

One option was to create a caregiver support organization as a provincial government agency. An Ontario agency would be established by and accountable to government but not actually be part of a government ministry. An agency would have the authority and responsibility to perform a public function or service. Generally, government appoints the individuals who sit on the agency or its governing body. Although this option would give the caregiver organization a high provincial profile, it may be seen as being too closely aligned to government to reflect the unique culture of caregiving. As well, a provincial agency may not be perceived as an objective voice of caregivers when it comes to addressing issues that include multiple provincial ministries (such as health, community and social services, education, housing and transportation) and various levels of government (such as provincial, municipal and federal). For these reasons, this option was regarded as unacceptable.

A second option was to make a caregiver support organization a department or program within the Ministry of Health and Long-Term Care. Caregiver support would become a government service which would make it difficult to involve caregivers in governance other than as advisers. Ultimately, government would have the authority to make decisions about the service. Other organizations may perceive the service as getting preferential treatment for funding since it is within government. It would also be difficult for the service to reflect the unique culture of caregiving. Furthermore, since the service would be within the health ministry, it would be difficult to address issues that cross multiple ministries and various levels of government. This option was not accepted.

A third option was to create a caregiver support organization run by the collective group of 14 LHINs. Individual LHINs are knowledgeable about their local populations and local health and community services. They would be able to use this knowledge to provide individual level supports. However, since LHINs are now responsible for providing home care services, caregivers may not regard a LHIN-run organization as an objective voice for caregivers. Although there is merit to LHINs bringing a regional perspective, it could be challenging for LHINs to address organizational and system level supports. Finally, if the caregiver support organization is to succeed, an unrelenting focus on development and implementation is needed now. At this time, LHINs are undergoing significant organizational changes and, by necessity, must focus their efforts on successfully executing these changes. This option was not accepted.

A fourth option – and one which I regard as doable, practical and most appropriate – is to establish a stand-alone caregiver support organization. Such an organization would be able to focus on the full range of individual, organizational and system level supports recommended earlier (Recommendation 1). In addition, it would be perceived as arms-length from government, involve caregivers in governance, embrace a regional caregiver support model under a provincial umbrella, be sensitive and responsive to the unique caregiver support needs of Ontario’s population, and be cost responsible.

The characteristics of this option – which needs to be continuously evaluated and modified, as required with the evolving health care system – should include the following elements:

Governance Leadership

- Governance provided by a volunteer Board of Directors who have the appropriate skills and expertise. The Board would be representative of Ontario’s diverse population, and seek to balance experience in areas such as caregiving, policy, finance, legal, business and other areas.

GOVERNANCE LEADERSHIP
<ul style="list-style-type: none"> • Volunteer Board • Diverse • Skills-based Including Caregiving and Other Skills

Management Leadership

- A staff secretariat at a central location and at regional locations strengthened by local volunteer networks.

CENTRAL LOCATION
<ul style="list-style-type: none"> • CEO • Staff for Central Functions and Administrative Support • Management and Operations (Central functions: 1# to Call; Education; IT; Marketing and Communications; etc.)

Location

- Central and regional locations. Ideally, these regional locations would be aligned with and co-located within each of the 14 LHINs; however, it would be important to have an arms-length relationship from the LHINs to avoid confusion and any disputes related to home care support.

REGIONAL LOCATIONS
<ul style="list-style-type: none"> • Local Area Caregiver Support Lead • Local Volunteer Networks • Community Outreach and Engagement

Staffing

- Staffing at the central location would include a Chief Executive Officer (CEO), administrative support, and selected central staff to oversee key functions (e.g., one-number-to-call, education programs, information systems, marketing and communications, and other functions).
- Staffing at the regional locations would include at least one local area caregiver support lead in each region, augmented by a team of volunteers.

Corporate Status

- The organization would have non-profit charitable status to enable research and other grant opportunities. The organization would not compete in fundraising but could receive donations from grateful participants or foundations.

Funding

- There would be multi-year government funding linked to goals and deliverables. Back office functions could be provided by another organization to minimize overhead costs.

Accountability

- All staff would be accountable to the CEO.
- Organizational accountability would be to the Minister of Health and Long-Term Care or their designate.
- Accountability for performance would include performance indicators that measure both process and outcomes at the individual, organizational and system levels. These could include but not be limited to: caregiver satisfaction with supports; successful links between caregivers and the supports they need (i.e., removal of silos); satisfaction with information and education received; organizational collaborations; etc.

Regional/Local Activities

- Staff would provide management and operational support at the central location with community outreach and engagement at regional locations.
- There would be ongoing two-way communications between the central office and regional locations to identify and address common issues, gaps and duplications, standardize programs, and ensure that programs are delivered and evaluated locally. Issues unique to some regions would benefit from discussions with, and the support of, the other regions.
- Local program delivery would include strategies related to: self-help; caregiver to caregiver outreach; engagement of local teams and individuals (e.g., pharmacists, physiotherapists, lifestyle coaches; local spiritual/religious leaders; etc.); coaching; compassionate community initiatives; virtual support groups; and active partnering with local organizations that currently deliver programs.
- Staff would ensure that French language caregivers are served in French.
- Staff would engage Indigenous Peoples to co-design and co-develop appropriate supports to meet their unique caregiving philosophy.
- Staff would work with members of the LGBTQ communities to further understand and develop appropriate caregiver supports.

RECOMMENDATION 2

It is recommended that:

The Ministry of Health and Long-Term Care establish a stand-alone caregiver support organization to deliver and coordinate the full range of individual, organizational and system level supports (Recommendation 1). The key characteristics of the organization should include but not be limited to the following:

- A volunteer Board of Directors.
- A staff secretariat that provides management and operational support at a central location and at regional locations that are aligned with, co-located within and arms-length from the LHINs.
- Staff accountability to a CEO and organizational accountability to the Minister of Health and Long-Term Care or their designate.
- Non-profit charitable status.
- Multi-year government funding linked to accountabilities for achieving goals and deliverables.
- Continuous evaluation and refinement of the structure and functions, if required, as the health care system evolves.

The following vision and mandate for the organization are proposed for consideration and further development:

Vision: That all caregivers feel supported and valued.

Mandate: To use information, support and respect to enhance the caregiving experience in Ontario.

I believe it will be important to respect the critical role played by existing organizations that have a strong track record supporting care recipients and caregivers, such as those that focus on particular diseases, home and community care provider organizations, patient and caregiver associations, and the other parts of the health care system. Their input has been invaluable and, going forward, we need to draw on their experience and expertise, and leave room for their continued support to caregivers.

See Appendix E for additional details of the recommended model.

A COMMITMENT TO IMPLEMENT

I believe that a strong commitment to implement is needed to ensure success. Given that it will take time and effort to plan, confirm and/or strengthen the proposed characteristics of the model, and begin to develop the organization, the ministry should consider appointing an Implementation Lead in the short term to begin this important work.

RECOMMENDATION 3

It is recommended that:

The Ministry of Health and Long-Term Care appoint an Implementation Lead to oversee the planning and development of the caregiver support organization in its initial stages until the CEO and Board are in place and functioning.

In closing, a great deal will be expected of a made-in-Ontario caregiver organization. It will be essential to pace the implementation which means that some initiatives will be addressed sooner than others. I believe that caregiver engagement, genuine communication at multiple levels, ongoing feedback and patience will help this evolving organization deliver what Ontarians need.

CONSOLIDATED RECOMMENDATIONS

RECOMMENDATION 1: CAREGIVER SUPPORTS

It is recommended that:

The Ministry of Health and Long-Term Care support the development of the following initiatives at the individual, organizational and system levels:

- Individual level supports to include: establish one access point; and offer education and support programs.
- Organizational level supports to include: address gaps in caregiver services and supports within and between LHINs; and facilitate caregiver organizations to address gaps and maximize their impact.
- System level supports to include: conduct public education and awareness programs; increase knowledge among health care and other service providers about the role, value and active engagement of caregivers; advise on improved caregiver support policies and legislation; and advise on and participate in caregiver research.

RECOMMENDATION 2: A STRUCTURE TO PROVIDE SUPPORTS

It is recommended that:

The Ministry of Health and Long-Term Care establish a stand-alone caregiver support organization to deliver and coordinate the full range of individual, organizational and system level supports (Recommendation 1). The key characteristics of the organization should include but not be limited to the following:

- A volunteer Board of Directors.
- A staff secretariat that provides management and operational support at a central location and at regional locations that are aligned with, co-located within and arms-length from the LHINs.
- Staff accountability to a CEO and organizational accountability to the Minister of Health and Long-Term Care or their designate.
- Non-profit charitable status.
- Multi-year government funding linked to accountabilities for achieving goals and deliverables.
- Continuous evaluation and refinement of the structure and functions, if required, as the health care system evolves.

RECOMMENDATION 3: A COMMITMENT TO IMPLEMENT

It is recommended that:

The Ministry of Health and Long-Term Care appoint an Implementation Lead to oversee the planning and development of the caregiver support organization in its initial stages until the CEO and Board are in place and functioning.

APPENDIX A: CONSULTATIONS

Profile of Consultations by Type, Individual/Group and Number of People

MONTH 2017	TYPE OF CONSULTATION	INDIVIDUAL/GROUP	#
January	Individual Interview	Kim Baker, CEO, Central Local Health Integration Network	1
	Individual Interview	Chris Dennis, CEO, Alzheimer Society of Ontario	1
	Individual Interview	Gail Donner, Chair, Expert Group on Home and Community Care	1
	Individual Interview	Cathy Fooks, President and CEO, The Change Foundation	1
	Individual Interview	Lisa Levin, Chair, Ontario Caregiver Coalition	1
	Individual Interview	Anna Mann, Past Executive Director, Caregivers Alberta	1
	Individual Interview	Shirlee Sharkey, President and CEO, Saint Elizabeth	1
February	Advisory Body Consultation	Ministry of Health and Long-Term Care (MOHLTC) Home and Community Care Advisory Table	23
	Advisory Body Consultation	MOHLTC Patient and Caregiver Advisory Table	20
	Advisory Body Consultation	MOHLTC French Language Health Services Advisory Table	7
	Group Consultation	Leaders - Caregiver Stakeholder Organizations	8
March	Workshop Consultation	In-person Workshop of Caregivers and Stakeholders	34
	Individual Consultation	Angus Campbell, Executive Director, Caregivers Nova Scotia	1
	Workshop Consultation	In-person Workshop of Caregivers and Stakeholders	30
	Workshop Consultation	Teleconference Workshop of Caregivers and Stakeholders	38
	Group Consultation	Government Partners: Ministry of Health and Long-Term Care; Ministry of Children and Youth Services; Ministry of Community and Social Services, Ontario Seniors' Secretariat	16
April-May	Individual Consultations	Caregivers Who Personally Reached Out to Janet Beed	25+
TOTAL			209+

APPENDIX A (cont'd)

Organizations Participating in the Consultations

1. Abounding Grace Home Care Services
2. Accueil francophone de Thunder Bay
3. Addictions and Mental Health Ontario
4. Alliance des Réseaux ontariens de santé en français
5. Alzheimer Society of Durham Region
6. Alzheimer Society of Ontario
7. Arnprior Region and Ottawa West Health Link
8. Canadian Association of Retired Persons
9. Canadian Mental Health Association
10. Canadian Mental Health Association - Ontario
11. Canadian Mental Health Association - Toronto
12. Caregivers Alberta
13. Caregivers Nova Scotia
14. CarePartners
15. CBI Home Health / We Care Home Health Services
16. Central East Community Care Access Centre
17. Central East Local Health Integration Network
18. Central East Local Health Integration Network Seniors Care Network
19. Central West Community Care Access Centre
20. Central West Local Health Integration Network
21. Centre de santé communautaire de l'Estrie
22. Centre for Addiction and Mental Health
23. Centre francophone de Toronto
24. Champlain Community Care Access Centre Patient and Caregiver Council
25. Champlain Region Family Council Network
26. Cheshire Homes (Hastings-Prince Edward) Inc.
27. Circle of Care - Sinai Health System
28. Collège Boréal
29. Cornwall Community Hospital - Geriatric Day Hospital
30. Erie St. Clair Community Care Access Centre
31. Families for Addiction Recovery
32. Fédération des aînés et des retraités francophones de l'Ontario
33. Hamilton Niagara Haldimand Brant Community Care Access Centre
34. Hamilton Niagara Haldimand Brant Local Health Integration Network
35. Health and Emergency Services, County of Simcoe
36. Health Quality Ontario
37. Health Shared Services Ontario
38. Holland Bloorview Family Advisory Committee
39. Home Care Ontario
40. Home Instead Senior Care
41. Home on the Hill Supportive Housing
42. Hospice Palliative Care Ontario
43. Institut des sciences de la santé et de la vie
44. Life & Hope Foundation
45. Métis Nation of Ontario
46. Ministry of Children and Youth Services
47. Ministry of Community and Social Services
48. Ministry of Health and Long-Term Care
49. North East Community Care Access Centre
50. North West Community Care Access Centre
51. North West Local Health Integration Network

APPENDIX A (cont'd)

Organizations Participating in the Consultations (cont'd)

52. North West Local Health Integration Network
Regional Palliative Care Program
53. North York Community House
54. North York General Hospital
55. Older Adult Centres' Association of Ontario
56. Ontario Association of Non-Profit Homes and
Services for Seniors
57. Ontario Caregiver Coalition
58. Ontario Community Support Association
59. Ontario Dementia Advisory Group
60. Ontario Family Caregivers' Advisory Network
61. Ontario Hospital Association
62. Ontario Palliative Care Network
63. Ontario Seniors' Secretariat
64. Ontario Society of Senior Citizens Organizations
65. Ottawa Regional Cancer Foundation
66. ParaMed Home Health Care
67. Patient and Caregiver Advisory Table
68. Peterborough Regional Health Centre
69. Queensway Carleton Hospital Patient and
Family Advisory Council
70. Réseau franco-santé du Sud de l'Ontario
71. Saint Elizabeth
72. Seneca College Social Service Worker -
Gerontology Program
73. Senior Pride Network
74. South West Community Care Access Centre
75. Spectrum Health Care
76. St. Paul's L'Amoreaux Centre
77. The Change Foundation
78. The Nation Municipality
79. Toronto Central Community Care Access Centre
80. VHA Home HealthCare
81. West Neighborhood House
82. William Osler Health System
83. Women's College Hospital

APPENDIX B: BACKGROUND REPORTS

Expert Group on Home and Community Care (Gail Donner, Chair). 2015 (January 30). *Bringing Care Home: Report of the Expert Group on Home and Community Care*. Prepared for the Honourable Minister of Health and Long-Term Care (Ontario), Dr. Eric Hoskins. http://health.gov.on.ca/en/public/programs/ccac/docs/hcc_report.pdf

Gori, C., J. Fernandez and R. Wittenberg (editors). 2016. *Long-Term Care Reforms in OECD Countries: Successes and Failures*. Bristol: Policy Press.

Hollander, M.J., G. Liu and N.L. Chappell. 2009. *Who cares and how much? The imputed economic contribution to the Canadian health care system of middle-aged and older unpaid caregivers providing care to the elderly*. *Healthcare Quarterly* 12(2): 42-49. <http://ab-cca.ca/uploads/files/PDF/Who%20Cares%20and%20How%20Much%20-%20Economic%20Contribution%20to%20the%20Canadian%20Health%20care%20System.pdf>

Johansson, L., H. Long and M.G. Parker. 2011 (October). *Informal Caregiving for Elders in Sweden: An Analysis of Current Policy Developments*. *Journal of Aging & Social Policy* 23 (4): 335-353.

Lin, E., J. Durbin, T. Volpe and A. Selick. 2016 (November 15). *Measuring the Family/Friend Caregiver Experience in Ontario: Pilot Study Results*. Health System Performance Research Network (HSPRN), University of Toronto. (Health System Performance Research Network, University of Toronto and the Provincial System Support Program, The Centre for Addiction and Mental Health). http://hsprn.ca/uploads/files/CGStudyPilotResults_HSPRNFInalReport.pdf

Ministry of Health and Long-Term Care. 2015 (February). *Patients First: Action Plan for Health Care*. Toronto: Queen's Printer for Ontario. http://www.health.gov.on.ca/en/ms/ecfa/healthy_change/docs/rep_patientsfirst.pdf

The Change Foundation. 2016. *A Profile of Family Caregivers in Ontario*. Toronto: Author. <http://www.changefoundation.ca/profile-of-family-caregivers-ontario/>

APPENDIX C: INTERIM REPORT FROM JANET BEED TO THE HONOURABLE ERIC HOSKINS

The Honourable Eric Hoskins
Minister of Health and Long-Term Care
Hepburn Block, 10th Floor
80 Grosvenor Street
Toronto ON M7A 2C4

April 21, 2017

Dear Dr. Hoskins:

I am pleased to submit my interim report on expanding caregiver supports which is one of the ten steps in the Ministry of Health and Long-Term Care's "**Roadmap to Strengthen Home and Community Care**". I was asked to examine how to strengthen caregiver supports, particularly whether a new provincial caregiver organization would benefit Ontario's caregivers and, if so, what would it look like. I will be providing a final report in May but wanted to take this opportunity to let you know that I will be recommending a number of enhanced and/or new supports for Ontario's caregivers, as well as the creation of a caregiver organization.

Caregivers provide unpaid care to their family, friends and neighbours of any age who have physical and/or mental health care needs. Caregivers experience high levels of stress and need support to be able to continue caring. Although Ontario is fortunate to have many valuable organizations that help support caregivers, they still face challenges finding and accessing appropriate information and supports.

The contribution and value of caregiving are significant and growing. Caregivers augment our taxpayer-funded services, are an intrinsic part of our health care system, and contribute significantly to the health and wellbeing of Ontarians. I believe that Ontario needs to invest in supporting its caregivers, and that a made-in-Ontario approach would be welcomed and highly beneficial. My advice is based on a solid foundation that includes previous reports, studies and consultations on the needs of caregivers. In addition, I consulted on the supports that caregivers need and how best to provide these. Almost 200 caregivers, representatives of home and community care organizations, and caregiver support organizations elsewhere gave their input.

My recommendations will focus on the supports that caregivers need and a structure for providing these supports. My advice takes the caregiver's perspective and aims to benefit caregivers.

The Supports That Caregivers Need

There was widespread agreement during the consultations that effective caregiver support must include initiatives at the individual, organizational and system levels.

APPENDIX C (cont'd)

- **Individual level supports** should include one access point where caregivers can receive information and be connected to available services and supports. Caregiver education and programs will also address individual level needs.
- **Organizational level supports** should identify caregiver support gaps within and between LHINs – as well as among organizations that support caregivers – and advise on opportunities to address gaps, standardize services, make better use of collective resources, expand excellent programs, and improve equitable access to supports. This will help reduce inequitable access to services.
- **System level supports** should include public education and awareness campaigns about the value, importance and challenges of caregiving; increased knowledge of health care and other service providers (such as EMS and police) about the role and value of engaging caregivers; opportunities to improve and align caregiver support policies and legislation at the municipal, provincial and federal levels; and opportunities for caregiver and best practices research.

Structure for Providing Caregiver Supports

Over the course of the consultations, there was agreement that, currently, Ontario does not have an organization or entity that can deliver the full range of caregiver supports **and** reflect the unique culture of caregiving. There was widespread support from caregivers for the creation of an organization dedicated to meeting their broad needs. Although opinions varied widely on the best structure, it was agreed that the structure should deliver on the supports identified above, and be cost responsible. I believe it will be important to respect the critical role played by existing organizations that have a strong track record supporting care recipients and caregivers, such as those that focus on particular diseases, home and community care provider organizations, patient and caregiver associations, and other parts of the health care system. Their input has been invaluable and, going forward, we need to draw on their experience and expertise, and leave room for their continued support to caregivers.

In closing, I have found widespread agreement about the need for enhanced supports for caregivers and the need for an entity to provide or facilitate access to these supports. Consequently, I will be recommending the creation of a provincial caregiver organization. Currently, I am considering organizational options and anticipate having a proposal for your consideration in May.

Minister Hoskins, it has been a great honour and a humbling experience to explore with caregivers their needs. I look forward to moving forward with you and your government to provide the support that will help caregivers thrive.

Sincerely,



Janet Beed

APPENDIX D: CAREGIVER SUPPORTS IN OTHER JURISDICTIONS

Nova Scotia

Caregivers Nova Scotia is a non-profit organization governed by a Board of Directors, and staffed by an Executive Director, Research and Operations Coordinator, and five Regional Support Coordinators located throughout the province. The main activities of Caregivers Nova Scotia include:

- Providing information and navigating caregivers to the services they need.
- Providing support to caregivers through one-on-one phone conversations, face-to-face support groups and group phone conversations.
- Providing education through workshops that they develop or co-develop with other organizations.
- Advocating for caregivers to government, on committees, to the media, and others.

Founded over 20 years ago by a group of caregivers, Caregivers Nova Scotia now receives annual operational funding from the Nova Scotia Department of Health and Wellness, and project funding from the Nova Scotia Department of Seniors.⁵

Alberta

Caregivers Alberta is a non-profit organization governed by a Board of Directors, and staffed by an Executive Director, three coordinators who oversee education, caregiver navigation and projects, and an office manager. The goals of Caregivers Alberta include:

- Providing programs that meet the information, education, support, networking and advocacy needs of individual caregivers (e.g., one-on-one support and advice over the phone, by email and in person; COMPASS education program; caregiver information sessions).
- Influencing system change at all levels to recognize caregivers and address their needs.
- Raising the profile of and public support for caregivers, their issues and Caregivers Alberta.
- Expanding the reach of Caregivers Alberta to support communities and their caregivers throughout Alberta.

Founded in 2001 by a group of caregivers and focused in Edmonton, Caregivers Alberta has been expanding its reach using partnerships and community collaborations since 2009. In 2013, the organization received a Ministry of Health grant which makes its program available in more than 30 communities across Alberta.⁶

Sweden

In Sweden, caring for elderly people is believed to be a social responsibility. In the 1990s, Sweden promoted policies and legislative changes to support family caregivers (Johansson et al. 2011). In 2009, the Swedish Parliament passed a new law obliging municipalities to offer support to persons caring for people with chronic illnesses, elderly people, or people with functional disabilities. National grants have been made available to stimulate the development of municipal-level caregiver services and supports (Johansson et al. 2011).

⁵Additional information on Caregivers Nova Scotia can be found at: <http://caregiversns.org/> Accessed April 23, 2017.

⁶Additional information on Caregivers Alberta can be found at: <http://www.caregiversalberta.ca/> Accessed April 23, 2017.

APPENDIX D (cont'd)

United Kingdom

Carers UK began as a grassroots movement to make the lives of caregivers better (note: Carers UK uses the term “carer” rather than “caregiver”). As the movement grew, support for caregivers became more formalized. For example, a large group of caregiver organizations compelled government to introduce the **Care Act, 2014** which legislates local health authorities to assess caregivers who appear to need support now or in the future (<http://www.legislation.gov.uk/ukpga/2014/23/section/10>).

The organization, Carers UK, is a national membership charity for caregivers governed by a board of trustees. Staff include a CEO; Directors in the areas of policy and public affairs, business development and innovation, fundraising, finance and resources; and Directors of Carers in Wales, Scotland and Northern Ireland.

Carers UK:

- Provides advice, information and support to caregivers by phone and online.
- Connects caregivers to caregiver groups and volunteers in local communities.
- Advocates for caregivers.
- Works with local authorities and other organizations to improve services for caregivers.⁷

⁷Additional information on Carers UK can be found at: <http://www.carersuk.org/>. Accessed April 23, 2017.

APPENDIX E: ADDITIONAL DETAILS OF THE RECOMMENDED MODEL

Caregiver Supports Ontario (Working Title): A stand-alone organization that delivers and coordinates a full range of individual, organization and system level supports for caregivers in Ontario.

This appendix includes the following for consideration and further development:

- Caregiver Supports Ontario (Working Title): Key Characteristics and Descriptions
- Proposed Implementation Steps
- Funding Requirements
- Accountabilities: Central and Regional Offices

CAREGIVER SUPPORTS ONTARIO (WORKING TITLE): KEY CHARACTERISTICS AND DESCRIPTIONS		
CHARACTERISTICS		DESCRIPTIONS
1	Vision	All caregivers in Ontario feel supported and valued.
2	Mandate	To use information, support and respect to enhance the caregiving experience in Ontario.
3	Governance Leadership	<ul style="list-style-type: none"> • Volunteer Board of Directors. • Representative of Ontario's diverse population. • Directors with appropriate skills and expertise (balance of experience in areas such as caregiving, policy, finance, legal, business and other areas).
4	Management Leadership	Chief Executive Officer.
5	Location	<ul style="list-style-type: none"> • One central location. • Regional locations aligned with, co-located within and arms-length from the LHINs. Final numbers and distribution to be determined based on caregiver needs.
6	Staffing	<ul style="list-style-type: none"> • Central location: CEO, administrative support, and selected central staff to oversee key functions (e.g., one-number-to-call, education programs, information systems, marketing and communications, and other functions). • Regional locations: at least one local area caregiver support lead in each region strengthened by local volunteer networks.
7	Corporate Status	Non-profit organization with charitable status.
8	Funding	Multi-year government funding linked to goals and deliverables.
9	Accountability	<ul style="list-style-type: none"> • CEO accountable to the Board. • Staff accountable to the CEO. • Organization accountable to the Minister of Health and Long-Term Care or the Minister's designate.

APPENDIX E (cont'd)

CAREGIVER SUPPORTS ONTARIO (WORKING TITLE): KEY CHARACTERISTICS AND DESCRIPTIONS		
CHARACTERISTICS		DESCRIPTIONS
10	Back Office	Back office functions may be provided by another organization to minimize overhead costs.
11	Performance and Sustainability	<ul style="list-style-type: none"> • Ongoing accountability for performance. • Effectiveness and efficiency of structure continuously evaluated and modified, if appropriate, as the health care system evolves.

APPENDIX E (cont'd)

PROPOSED IMPLEMENTATION STEPS

The Minister/ministry to select an Implementation Lead (Recommendation 3).

The Implementation Lead – in consultation with the ministry – to establish a small interim advisory group to work with the Lead on the initial stages of implementation.

The Lead to develop a three-year action plan that sets out goals, deliverables and timelines. The potential plan may include:

Year One

- Secure the Board and develop by-laws.
- Recruit a Chief Executive Officer.
- Develop the strategic plan with a supporting implementation plan.
- Develop and begin to implement a communication strategy (e.g., website, newsletters with updates on status and activities, etc.).

Year Two

- Begin to implement the strategic plan.
- Refine the structure and staffing for the central and local offices.
- Recruit staff.
- Establish core programs.
- Identify indicators to evaluate performance.

Year Three

- Continue to implement the strategic plan.
- Develop objectives for the next three years.
- Evaluate the central and local structure and modify, if required.

FUNDING REQUIREMENTS

Incremental Government Funding:

- Year 1: \$ 1.0 M
- Year 2: \$ 2.5 M
- Year 3+: \$ 3.0 M

Ongoing financial evaluation based on operational plans.

Other source of funds may include donations and grants.

APPENDIX E (cont'd)

ACCOUNTABILITIES: CENTRAL AND REGIONAL OFFICES

Central Office: Accountabilities

Establish and maintain:

1. Mission, vision, values
2. Goals and objectives
3. Budget
4. Purchased services
5. French language program (French language caregivers served in French)
6. Indigenous Peoples' (First Nation, Métis, Inuit) services (co-design and co-develop supports)
7. IT platform/search engine
8. Functional Accountabilities, i.e.:
 - Education and support program development
 - Provincial partnerships
 - Transitions across ministries
 - Federal initiatives
 - Public awareness

Regional Offices: Accountabilities

1. Link between and among local area initiatives and centralized programs
2. Secure volunteers and developing local area programs
3. Deliver central/core programs
4. Regional leads to work with but not be owned by the LHINs (independent of home care services)

