Canadian Centre for
Caregiving Excellence

Giving Care

An approach to a better caregiving landscape in Canada

Canadian Centre for Caregiving Excellence

The Canadian Centre for Caregiving Excellence is a new initiative incubated and powered by the Azrieli Foundation. The Foundation has long supported innovative initiatives to improve access to quality care. Following a period of building networks and convening stakeholders, the Centre will become a stand-alone organization.

Fondation Azrieli Foundation

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Land Acknowledgement

The office of the Canadian Centre for Caregiving Excellence (CCCE) is located in Toronto, TKaronto, on the traditional territory of the Anishinaabe, including the Mississaugas of the Credit, Haudenosaunee, and Huron-Wendat. This land has been governed by the Dish With One Spoon Wampum Belt for a thousand years and in recent times by the Williams Treaty and Treaty 13.

All people living in Canada are treaty people; we are all part of a relationship based on respect, co-operation, partnership and recognition of Indigenous rights.

CCCE is committed to equity for Indigenous caregivers and care providers and to learning from and working with Indigenous communities.

Acknowledgements

Caregiving is the next frontier of public policy in Canada. We hope that this whitepaper builds on the important work of caregiving organizations to date and ignites a pan-Canadian conversation about how we can and must do better to support caregivers and care providers from coast to coast to coast.

An offering of this consequence would not be possible without the help of many devoted experts, supporters and allies, including hundreds of caregivers and care providers with lived experience. The text was prepared with the assistance of Jasmine Lee, Adrienne Lipsey, and Alannah Dharamshi of Springboard Policy. Elaine Stam of Universe Design Studio designed the layout and visual identity of this paper. It was copyedited by Susan Hanna and translated by Julie Bourbeau.

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“My time as a caregiver was the most rewarding and harrowing experience of my life. The deep and intimate care I was able to give my father was so important — but I spent so much time and money trying to get help that just wasn’t available. I took hits financially and to my own health. Sometimes I felt lost and completely disconnected. It’s hard when you can’t see over the horizon. I know we can do better for caregivers.”

Caregiver
Lethbridge, Alberta, 2022

Executive summary

Caregivers are the unseen and unacknowledged foundation upon which our health-care, social services and disability supports systems are built. Their labour to support care recipients from every walk of life make our economy tick and our society run. If all caregivers took a week off, every Canadian would experience the collapse of our care systems before noon on the first day.

Unpaid caregivers and paid care providers make up the largest part of Canada's health-care and social supports systems. Research shows that they provide approximately three hours of care for every hour provided through the rest of our systems. They help seniors living in the community or in long-term care settings; children and adults with physical, intellectual, or developmental disabilities; people with medical conditions; people experiencing mental illness; and people with changing support needs related to aging.

The sustainability of Canada's health-care and social systems relies on caregivers and care providers, but they are at a breaking point.

The existing patchwork of provincial, territorial and federal caregiving policies is failing. The systems caregivers, care providers and care recipients rely on are overextended and fraying as they struggle to meet unprecedented demand. As a result, caregivers face significant financial, physical and emotional consequences, due to insufficient support. Care providers are burned out and care recipients suffer from a revolving door of unpredictable care. Every day, we see that our already limited caregiving infrastructure is being further stressed by significant policy and program gaps. For example:

- Services for caregivers and care recipients are insufficient, fragmented and difficult to access
- Financial supports are insufficient and ineffectively designed
- The care provider workforce is in crisis
- Supports for caregivers do not meet their current and future needs
- Leaves and protections for employed caregivers are inadequate

The Canadian Centre for Caregiving Excellence (CCCE) is committed to working with people with lived experience, researchers and experts to help develop policies that will help caregivers and care providers. Federal and provincial governments need to make the reforms necessary to improve outcomes today to ensure a strong caregiving ecosystem for the future.

Canadians are living longer with disabilities and multiple medical conditions. As our population ages, our systems will be further stretched as more people access services not designed for increasing demand. We urgently need a policy regime that meets our current and future needs for caregiving and support. To meet this challenge, we must:

Create a co-ordinated approach to caregiving, through: a common and inclusive definition of caregiving; a national caregiving strategy; provincial caregiving legislation; and international caregiver recognition

Improve, expand and invest in services for care recipients and caregivers, through: home and community care funding; mandatory assessment of caregiver needs; integrated care across services and sectors; and public navigator roles

Develop strategies for supporting employed caregivers, through: expanded leaves and benefits, flexible work legislation and promotion, caregiver-friendly workplaces; and government leadership

Develop financial supports that reflect the value of caregiving, through: inclusive tax credits and benefits; caregiver allowances or income; and increased supports for people with disabilities

Develop the workforce and improve conditions for care providers, through: competitive wages and increased funding; professionalization of care provider roles; support and protection for migrants to fill workforce gaps; and a workforce development strategy.

Caregiving is the next frontier of public policy in Canada. This policy whitepaper aims to ignite a public conversation on the state of caregiving and how we can do better. Over the coming months, CCCE will work with caregivers, care providers, care recipients, policy makers and stakeholders across the country to help shape the caregiving future we need.

Key definitions

Caregiving

Providing help or care to another person, including: people with physical, intellectual, or developmental disabilities; people with medical conditions; people experiencing mental illness; and/or people with changing support needs related to aging.[1]

Caregiver

An unpaid family member, friend, or other support for someone who needs care due to physical, intellectual, or developmental disabilities; medical conditions; mental illness; or needs related to aging. Caregivers provide care because of a relationship, not as a job or a career. This definition does not include parents or guardians providing care to a child without a disability, medical condition or illness.

Care provider

A person who is trained and paid to provide care to people who need it, due to physical, intellectual, or developmental disabilities; medical conditions; mental illness; or needs related to aging. This includes such professionals as Direct Support Professionals (DSPs), Personal Support Workers (PSWs), attendants for people with disabilities and respite workers.

Care recipient

A person with a physical, intellectual, or developmental disability; medical condition; mental illness; and/or changing support needs and frailty related to aging who receives care. Children without a disability, medical condition or illness are not included in this definition.

Double-duty caregiver

A person who provides unpaid care to a family member or friend while also being employed in the health-care field.

What is caregiving?

Caregiving is both a rewarding and challenging experience for caregivers and care providers. It is carried out by people of all ages, races and genders, though disproportionately by racialized women.[2] Providing help to someone who needs it can be fulfilling and bring people closer together. This can be especially true when caregivers and care providers offer emotional support to care recipients. At the same time, caregiving takes time and effort; performing such tasks as changing clothes, providing transportation, managing care networks and preparing food can be mentally and physically exhausting. The consequences of caregiving, including financial and emotional stress, are often associated with a lack of support.

Caregiving is essential for care recipients and Canadian society

Caregivers and care providers play a vital role in the everyday lives of people who receive care and in Canada's broader health, community and social service systems. For every hour of professional care, caregivers provide three hours of care to family and friends.[3] At the same time, care providers are essential, but often undervalued, members of Canada's health and social service workforce. They contribute $97.1 billion annually to Canada's economy.[4] In a recent study, the majority of PSWs in the Greater Toronto Area were considered low income (55 per cent), precariously employed (86 per cent), lacking paid sick days (89 per cent) and without extended health benefits (74 per cent).[5]

Caregiving is done by both unpaid caregivers and paid care providers

Caregivers (care-partners, carers) are unpaid family members, chosen family, friends and other supports of someone who needs care. Caregivers provide care because of a relationship with the person who needs care. Care providers are individuals who are trained and paid to provide care.[6 7 8] Care providers include such professionals as DSPs, PSWs and respite workers.[9]

Caregiving roles and responsibilities are varied and evolving

Care providers and caregivers often fill major gaps in broader health and social systems.[10] For example, support professionals now provide educational support, health care, physical therapy and mental health care.[11] Caregivers also bear a wide range of responsibilities, such as: personal care; food preparation; shopping and housekeeping; transportation and care co-ordination; health-care-related tasks such as dialysis and ventilator management; advocating on behalf of the care recipient; providing care recipients with emotional support; and financial management.[12]

Caregiving is done by individuals with diverse identities and experiences

Caregivers and care providers have unique identities and circumstances that shape their individual experiences in providing care to others. For example, 45 per cent of caregivers were born outside of Canada, or their parents were born outside of Canada.[13] Transnational caregivers face unique challenges providing support and care across distances and borders.[14] Double-duty caregivers provide unpaid care to a family member or friend while also being employed in the health-care field. Some caregivers are young.[15] Siblings of children who are ill or have a disability and children of parents who are ill or have a disability begin their caregiver roles at a young age. There are approximately 1.25 million caregivers aged 15 to 24 in Canada.[16] Care providers are also diverse, with many individuals in the field belonging to racialized groups.[17] In Canada, PSWs are primarily woman-identified and racialized.[18] Moreover, racialized women make up 27 per cent of workers in home health-care services.[19]

Caregiving is often continuous work and can occur across a person's lifetime

Caregivers often support people more than once over the course of their lives.[20] For example, some Canadians take on one caregiving role later in life, while others have taken on multiple episodes of care by the time they reach their late 50s.[21] In other cases, family caregivers spend a significant portion of their adult life providing care.[22] As Canada's population ages, more and more Canadians are balancing elder care responsibilities with child care responsibilities — this group is often referred to as the Sandwich Generation.[23] The Sandwich Generation, typically made up of Canadians aged 45 to 64, includes 28 per cent of all caregivers.[24]

Introduction

To properly support caregivers and care providers, public policy needs to consider caregivers and care providers as relevant partners in health and social services. This will require more than just a shift in perspective; it will require bold public policy solutions to address the problems facing caregivers and care providers.

Introduction

Canada is in the midst of a caregiving crisis, yet caregiving remains largely invisible in public policy across the country. Caregivers and care providers are an afterthought at best in most government planning. Continuing along this path will push already strained health and social safety nets to the brink.

Caregivers and care providers in Canada support people with disabilities, medical conditions and needs related to aging to lead rewarding lives. Our health-care system relies on caregivers. Without them, proper care would not be possible in hospitals, through continuing care (home care, supportive living, long-term care and palliative care) and in longer-term care settings for people with disabilities and complex medical conditions. They make up the largest part of Canada's health-care system and contribute more value to Canada's gross domestic product (GDP) than the agriculture, forestry, fishing and hunting industries combined.[25] In 2018 alone, 7.8 million Canadians provided care to a family member or friend.[26] If caregivers in Canada stopped providing care for one day, Canada's health-care system and economy would immediately grind to a halt.

Families, friends and neighbours have always been central to providing care to people who need support. Over time, this circle of support has expanded to include a professional class of care providers, such as PSWs and DSPs. These critical roles have become even more important as society has transitioned away from institutionalized settings toward community- and home-based supports. Caregivers and care providers have been asked to do more and more at home and in the community, as overtaxed and underfunded support services have been pushed to the breaking point. Across Canada, each province has numerous streams of incoherent and poorly connected services delivered across regions, public and private offerings and pathways to requiring care. Caregivers and care providers are left to navigate an opaque and dysfunctional network of services[27] and undertake the work that previously cost governments billions of dollars to co-ordinate and deliver.

The existing network of provincial, territorial and federal caregiving policies is failing. Canadian caregivers and care providers are being pushed past a breaking point by the lack of supports for themselves and the people for whom they care. There are inadequate services, workplace protections and financial supports for caregivers, as well as poor working conditions, professional supports and compensation for care providers. These gaps have been exacerbated by COVID-19 pandemic, which has made every element of providing care more challenging and will continue to do so. This is not sustainable.

But there is hope. **The solution to this problem is concerted, co-ordinated, and paradigm-changing government action.** To properly support caregivers and care providers, public policy needs to consider caregivers and care providers as relevant partners in health and social services. This will require more than just a shift in perspective; it will require bold public policy solutions to address the problems facing caregivers and care providers.

> CCCE is committed to working with caregivers, care providers, care recipients, researchers, policy makers and people with lived experience from coast to coast to coast. It will renew efforts toward developing a comprehensive and actionable National Caregiver Strategy to bring together disability, aging, health-care and caregiving perspectives and to meet our current and future needs.

This report is the Canadian Centre for Caregiving Excellence's (CCCE's) first contribution to transforming caregiving public policy. CCCE is committed to working with caregivers, care providers, care recipients, researchers, policy makers and people with lived experience from coast to coast to coast. It will renew efforts toward developing a comprehensive and actionable National Caregiver Strategy to bring together disability, aging, health-care and caregiving perspectives and to meet our current and future needs.

With this report, our goal is to highlight critical challenges across the caregiving landscape and introduce concrete, useful policy solutions that could form the basis of overall transformation. While this report does not map every possible policy answer to the caregiving crisis, it pushes the conversation into the realm of real, practical solutions. It draws attention to the glaring gaps in our policy landscape that need to be addressed quickly and decisively. Caregivers, care providers and the sustainability of our health-care system all rely on a stronger caregiving landscape.

About this research

Since early 2022, CCCE has been engaging stakeholders across the caregiving landscape around the need for a new approach to caregiving in Canada. Through our research and engagements, we have investigated existing challenges facing caregivers and care providers and identified opportunities for change.

This report outlines some of these key issues, as well as ideas to help address them. It draws on a review of academic and grey literature (i.e., information published outside of traditional academic and commercial channels) and a jurisdictional scan of best public policy practices for supporting caregiving in Canada and across the globe. It is also grounded in the lived experiences of people who provide care. Our research included three focus group sessions with caregivers, care providers and other key stakeholders within the caregiving landscape. It was further informed by reports from three additional focus group sessions with key stakeholders in the caregiving space.

The report also benefitted from review by leaders in the caregiving field, although it does not necessarily reflect their views.

CCCE is committed to advocating for the needs of both caregivers and care providers. Our research focused on policy issues and solutions that have potential to make an impact across the caregiving landscape. We found that there are more and better models of public policy support for caregivers that could be explored and adapted to the Canadian context.

In preparing this paper, it became clear that the volume, variety and scope of current research and policy work in Canada on caregivers far exceeds that on care providers. To our surprise, much of the existing work on care providers does not include the full breadth of workers in that space (PSWs, DSPs, et al.). This report therefore places a greater emphasis on caregivers than on care providers because that is the reality of our current research and policy landscape. CCCE will work with care providers, stakeholders and experts to address this gap and pursue research and build better policy solutions for care providers. This is especially vital in the light of Canada's ongoing care provider staffing challenges and health-care crisis.

In our ongoing partnership with care providers, we will contribute to research and advocacy work to help develop practical policy solutions to support care providers in their lives and work.

Caregiving is essential to Canadian society

The economic value of caregiving work is immense. Caregivers in Canada spend 5.7 billion hours each year supporting others and are estimated to contribute the equivalent of 4.2 per cent of GDP or $97.1 billion annually to Canada's economy. This represents more than three times the national expenditures on home, community and long-term care.

Caregiving is essential to Canadian society

Caregiving plays an essential role in people's lives and is one of the main support structures in Canadian society. Caregivers and care providers allow people to live within their communities, in their homes and to have a higher quality of life.[28] By supporting people with disabilities, medical conditions and needs related to aging, caregiving is the largest part of Canada's health and social care systems. It bridges the major gap between medical practitioners, social services systems and care recipients. The scale of caregiving in Canada cannot be overstated: one in four Canadians is a caregiver to a family member or a friend and 50 per cent of Canadians will be caregivers at some point in their lives.[29]

The economic value of caregiving work is immense. Caregivers in Canada spend 5.7 billion hours each year supporting others[30] and are estimated to contribute the equivalent of 4.2 per cent of GDP or $97.1 billion annually to Canada's economy.[31] This represents more than three times the national expenditures on home, community and long-term care.[32] By comparison, the agriculture, forestry, fishing and hunting industries combined contributed $39.8 billion to GDP in 2021.[33] These statistics are for caregivers alone. Combined with the contributions of care providers across the country, caregiving contributes enormous value to the Canadian economy and can be described as the work that makes all other work possible.

People in the caregiving sector are at a breaking point

Despite caregivers' contributions, Canada's public policy landscape does not treat caregiving like other important sectors. Caregivers and care providers are not adequately supported or considered. Many are operating past the point of burnout and personal and professional crises.

Caregiving takes a toll on the physical, mental and emotional well-being of people providing care.[34] A 2021 survey found that 87 per cent of caregivers experienced loneliness, 73 per cent experienced moderate to high anxiety and 69 per cent noted a deterioration in their mental health.[35] Over half of caregivers also reported a deterioration in their physical health. Based on an analysis of the NHS (National Health Service) England GP Patient Survey, caregivers are 16 per cent more likely to live with two or more long-term health conditions.[36]

Although just over half of unpaid caregivers self-identified as women,[37] women are often known to provide more caregiving hours. This means that they help with more caregiving tasks and assist with more personal care than their male counterparts. Consequently, women have reported higher rates of burden, depression, poor mental health and deteriorating well-being[38] and are more likely to experience employment and social consequences due to their care work.

While unpaid caregivers are often acting out of love, the truth is that caregiving responsibilities frequently influence their social well-being and the ability to maintain relationships and take care of themselves.[3940] Fifty-nine per cent of caregivers report needing to take breaks from their responsibilities[41] and many others report feeling lonely or isolated.[42] When caregivers are providing assistance, they can't spend that energy elsewhere.[43] These negative impacts do not only affect caregivers. Caregiver distress also affects people receiving care. In a study of physical symptoms among cancer patients receiving palliative care at home, caregiver distress was associated with worsened physical symptoms for care recipients.[44]

> Fifty-nine per cent of caregivers report needing to take breaks from their responsibilities and many others report feeling lonely or isolated. When caregivers are providing assistance, they can't spend that energy elsewhere. These negative impacts do not only affect caregivers. Caregiver distress also affects the person they are caring for.

For many, caregiving also means taking time away from paid work. Caregivers are more likely to take time off, request a leave of absence, require a flexible work schedule, leave the workforce or retire early as a result of their caregiving responsibilities.[45] In a recent study, 46 per cent of caregivers in the workforce reported short-term absenteeism due to caregiving responsibilities in the last year.[46] We also heard in focus groups that many caregivers cannot remain in paid employment at the same time as caring for their loved ones. As a result, many caregivers are in a worsened financial position due to their caregiving responsibilities. Moreover, fewer than half of caregivers in Ontario feel their employers understand their role — more than 30 per cent are worried about losing their job or feel they may have to consider leaving the workforce to take care of their family member or friend.[47]

Moreover, caregiving also introduces new out-of-pocket expenses, such as travel, household-related expenses or home modifications.[48] The average caregiver in Canada reported spending $5,800 each year on care-related expenses[49] and 20 per cent of caregivers in Ontario reported taking out a loan or line of credit to pay for caregiving expenses in 2020.[50] In the United Kingdom, 39 per cent of caregivers were struggling to make ends meet in 2019. Some caregivers feel they are unable to reduce their work hours, given the financial pressures of caregiving.[51] There are few government-funded financial supports directly for caregivers and those that exist do not generally offset the economic consequences of caregiving.[52] In fact, there are few supports or training of any kind for caregivers. Focus group participants highlighted that the limited supports available are inconsistent, inefficient and difficult to navigate.

The picture is different but no better for care providers. The demand for care providers is significantly higher than the supply. The COVID-19 pandemic highlighted and exacerbated critical staffing shortages in long-term care, home care and disability supports across the country. In many well-documented cases, the quality of care in these settings deteriorated as staff were stretched by illness and caregivers were barred from providing direct care for their loved ones due to lockdowns, isolation protocols and infection prevention measures. Many care providers who typically hold part-time positions at multiple workplaces were no longer allowed to work in more than one congregate setting. In 2020, long-term care homes reported being one to two PSWs short on almost all shifts, with the situation worse in rural and northern Ontario.[53]

In time, this situation will only worsen, disproportionally so for rural Canada. In Alberta, particularly rural Alberta, demand for PSWs to support home care is expected to double by 2037.[54] Instead of creating better working conditions, care providers report that this high demand has only increased pressures to work unreasonably long hours, cover additional shifts and work short-staffed. Low rates of entry into the profession and high rates of turnover result from and exacerbate these problems.[55] Despite care providers' importance, low wages persist, often placing these key workers below the living wage mark.

Without immediate intervention, caregivers and care providers will be unable to meet the needs of the people for whom they provide care. If current realities are not enough to put support for caregivers and care providers on federal and provincial government policy agendas, then future realities must be. Canada's population is aging — people are living longer, with multiple disabilities or medical conditions and the population of available family caregivers is shrinking.[56] Between 2014 and 2030, Canada's senior population will grow from six million to more than 9.5 million[57] and projections indicate there will be 30 per cent fewer close family members available to provide care to loved ones.[58] Taken together, these trends mean that the caregiving crisis will only get worse. Canada needs a host of future-thinking policy solutions and innovations to allow Canadians to live and age in the community.[59][60]

Failure to address these issues will have social and economic consequences

Caregivers and care providers cannot sustain their work alone. The Canadian health-care system cannot sustain itself without their contributions.[61] Caregivers provide care equivalent to 2.8 million full-time paid care providers each year. This saves billions of dollars in health-care resources,[62] [63] allowing those funds to be spent elsewhere and enabling care recipients to live at home rather than in costly institutional care.[64]

When caregivers are not sufficiently supported or involved as a part of the care team, care recipients are more likely to be prematurely admitted to a hospital or long-term care institution.[65] The COVID-19 pandemic has underlined something that has long been clear: Canada's hospital and long-term care systems are inadequate, even for current levels of need. Caregivers continue to assist with care when their friends and family enter congregate care settings. While the work of care providers is vital, these institutions would collapse without the additional support of friends and family. Hospitals, long-term care settings and other models of care cannot absorb a surge of people whose caregivers and care providers find themselves at a breaking point.

> When caregivers are not sufficiently supported or involved as a part of the care team, care recipients are more likely to be prematurely admitted to a hospital or long-term care institution. The COVID-19 pandemic has underlined something that has long been clear: Canada's hospital and long-term care systems are inadequate, even for current levels of need.

Beyond the health-care system, relying on this unsustainable model of caregiving also threatens Canada's economy and labour market. Balancing caregiving responsibilities with paid work reduces employee productivity and increases absenteeism and turnover.[66] A lack of support for caregivers leaves lost productivity on the table — the cost of which is estimated to be $1.3 billion per year.[67] When employees are forced to leave their jobs unexpectedly due to caregiving responsibilities, employers spend time and money replacing their knowledge, skills and experience.[68] Canada loses the cost equivalent of 557,698 full-time employees from the workforce every year due to employee absences and departures stemming from conflicting responsibilities of work and care. [69]This is equivalent to more than half of Canada's health-care and social assistance sector[70] — a major loss to the Canadian labour force and economy.[71]

Canada needs to care about caregiving

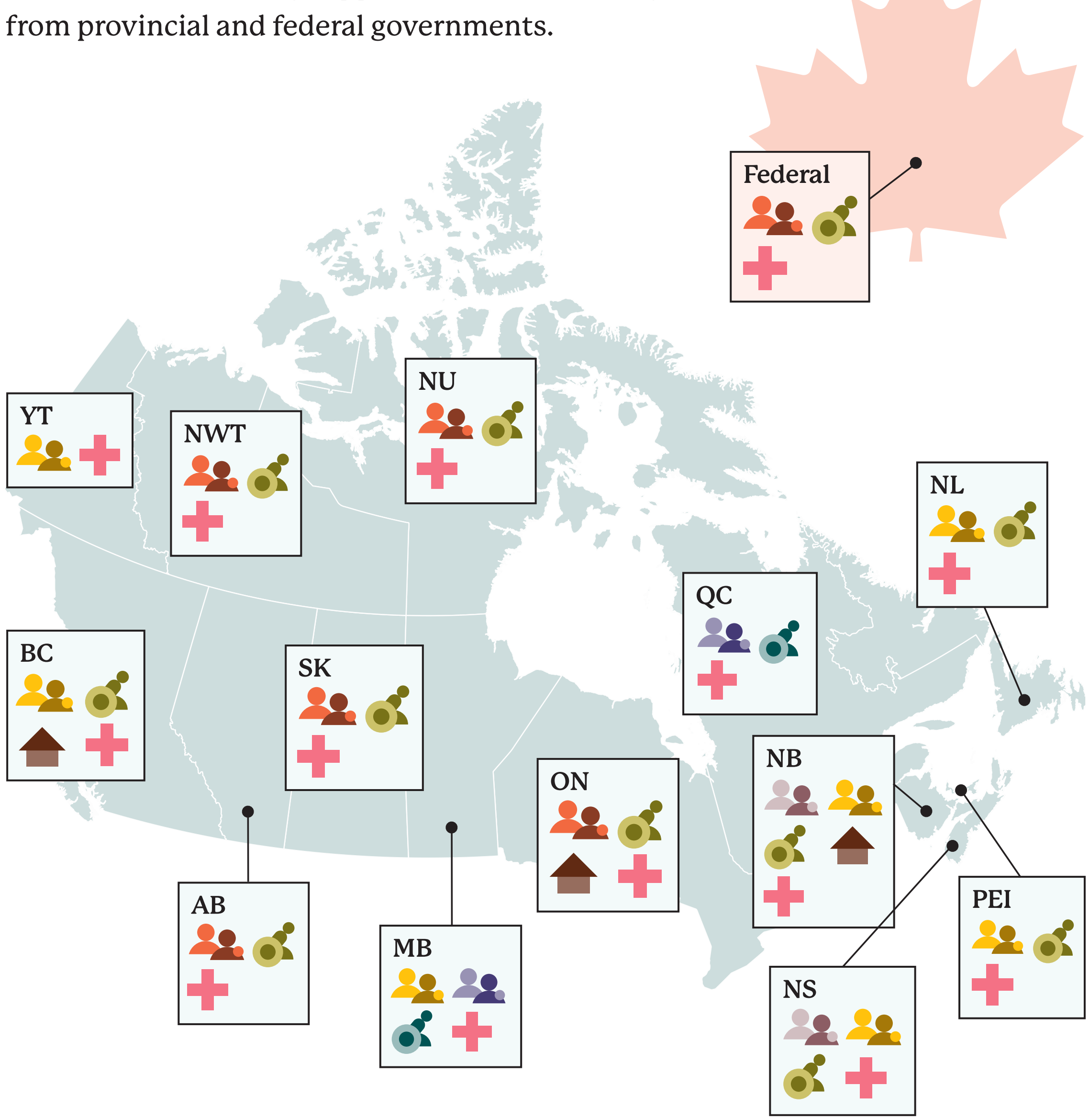
Caregivers and care providers are the hidden bedrock of Canada's health and social systems and are essential to our economic prosperity. Without government support, this sector cannot continue to operate at status quo levels, let alone meet the real needs of the people it serves. This is the time for real policy change to close the gaps that are dragging down our economic potential and leaving caregivers, care providers and care recipients in untenable and unsustainable situations.

Mapping the policy landscape

Policies and programs supporting caregivers vary across provinces and territories. While this is necessary in the Canadian context, the disparity between the quality and availability of support for caregivers from one province or territory to another is alarming.

Income supports, benefits, tax credits & deductions across Canada

Financial supports (tax credits and deductions), benefits, leaves and programs and services for caregivers vary across the provinces and territories in Canada. The map below illustrates the existing supports available to caregivers from provincial and federal governments.



Legend

- Non-Refundable **Caregiver Credit** + OVER $5000
- Refundable **Caregiver Credit**
- Non-Refundable **Disability Credit** + OVER $5000
- Refundable **Home Renovation Credit**
- Non-Refundable **Caregiver Credit** -UNDER $5000
- **Caregiver Benefit**
- Non-Refundable **Disability Credit** -UNDER $5000
- **Medical Expenses**

For more detailed information about the benefits and supports for caregivers by provinces and territories, see the Annex (p. 78).

Mapping the policy landscape

From legislation to programs and services to tax credits, there are several public policy tools that support — or fail to support — caregivers and care providers. These different types of support are diverse and vary significantly across the provinces and territories in Canada. They can be better understood by considering which order(s) of government determines how they work:

Caregiver legislation and recognition

Legislation, regulation and strategies that, among other things, set caregiving terms

Federal and provincial governments can use legislation, regulation and policy strategies to define and support caregivers. Many of the main governance areas relevant to the caregiving sector fall under provincial responsibility.

Care recipient programs and services

Care recipient programs and services designed to support people who receive care

Provincial governments fund home care and other support programs and services for people who receive care and set some criteria, but need is assessed by regional authorities and services are delivered by local agencies.

Caregiver programs and services

Caregiver programs and services designed to support people who provide care

Provincial governments fund respite and other support programs and services for people who provide care and set some criteria, but need is assessed by regional authorities and services are delivered by local agencies.

Supports for caregivers in the workforce

Benefits, rights and leaves, especially to help caregivers to maintain paid employment

Provincial governments govern most workplaces, while the federal government plays a role in establishing benefits, rights and leaves for federally regulated employees. The federal government also provides some other benefits to support caregivers taking time off work, as administered through Employment Insurance (EI).

Financial supports

Tax credits and deductions aimed at improving the financial situation of caregivers

The federal government is responsible for the disability tax credit, Canada caregiver credit, home accessibility tax credit and medical expense tax credit. Provincial governments offer their own versions of these credits, which are available to caregivers on top of those from the federal government.

Care provider training and support

Workforce development and regulation to meet demand and improve care provider outcomes

Most care provider occupations are not regulated professions. Training requirements vary across provincial jurisdictions and according to the provider's work setting.

Note: More information on some of the public policy tools aimed at assisting caregivers by each province and territory can be found in Annex: Supports, benefits and programs for caregivers.

It makes sense for policies and programs supporting caregivers to vary across provinces and territories — Canada is a federation and Nunavut has unique needs compared to Ontario or British Columbia. While this is necessary in the Canadian context, the disparity between the quality and availability of support for caregivers from one province or territory to another is alarming. Examples of provincial and territorial caregiving approaches to date include:

- In Nunavut, needs across the caregiving landscape are not yet fully understood, but it is clear that Nunavummiut with disabilities are vastly under-supported.[72] Accessibility barriers across the territory make it difficult to live with a disability. It is also difficult for care recipients and caregivers to find any programs and services to support them consistently. [73]
- In Ontario, financial support for people with disabilities is so low it leaves many recipients living below the poverty line.[74] The maximum amount a single person can receive through the Ontario Disability Support Program (ODSP) is $1,169 a month or $14,028 a year. Ontario's poverty line is $20,000, putting the annual ODSP amount about 30 per cent below the poverty line.
- In Manitoba, a recent survey of family caregivers during the COVID-19 pandemic indicated that 56 per cent were receiving fewer publicly funded services and 60 per cent of respondents took on more care work during the pandemic.[75] More than half of respondents shared that their mental and physical health had declined. Persistent staffing shortages led to less emotional support and compassion for care recipients and burnout for care providers.[76]
- In Nova Scotia, important financial support for people with cognitive disabilities does not always arrive on time, leaving care recipients and their families to pay for the services out-of-pocket.[77] Closures related to the COVID-19 pandemic have left many families without available respite services for years, with concerns that capacity will never return to pre-pandemic levels.[78] Services and financial support should be able to withstand stressors such as the COVID-19 pandemic.
- In Prince Edward Island, staffing shortages forced Health PEI to make cuts to respite care services across the province. This left primary caregivers of care recipients with dementia without adequate breaks to maintain their own well-being. Without respite care, caregivers can end up in poor health themselves and their loved ones can be forced out of home care.[79] Again, this highlights a failure in funding and support for services available to caregivers.

These policy failures demand attention but should also be viewed as an opportunity for change. Caregiver organizations across the country have risen to the challenge and are trying to offer caregivers more support, resources, education and training to make caregiving easier. For example:

- Family Caregivers of BC offers a support line and support groups where caregivers can share ideas and resources with each other.[80] This helps give caregivers a sense of community support.
- Caregivers Alberta created the COMPASS for the Caregiver program, a multi-session workshop that helps caregivers learn how to balance their well-being with the challenges of caregiving. The workshop covers how to handle guilt and grief, manage stress, improve communication, navigate the system and plan for the future.[81] This program gives caregivers the important resources they need to be able to care for themselves amid their caregiving responsibilities.
- Caregivers Alberta, MatchWork and the University of Alberta are collaborating to connect caregivers to meaningful work. Through the initiative, caregivers complete a survey to create an individual profile that helps connect them to flexible work they can balance with their caregiving responsibilities.[82] This is important work to help caregivers remain in the workforce.
- Proche aidance Québec is a non-profit comprised of 124 community-based organizations throughout the province that work to improve the lives of caregivers and help them understand their rights through advocacy, awareness and research.[83]
- In partnership with the Government of Québec, L'Appui pour les proches aidants supports caregivers and supporting organizations across the province. It helps caregivers take advantage of health and well-being services available to them across the province. It also offers tips to caregivers specific to their circumstances, such as information for caregivers caring for someone with a neurocognitive disorder.

> Caregivers and care providers across all provinces and territories experience unique challenges around the policies and programs supporting them. In addition to these challenges, the overall trend is that public policy in Canada is failing to support caregivers and care providers.

- Ontario Caregiver Organization offers a range of support for caregivers and care providers throughout the province. It has a suite of resources for care providers that aims to help them engage family caregivers and treat them as a part of the care team.[84] It also offers helpful tools for employers to better support caregivers in the workplace, a 24/7 caregiver helpline, webinars and counselling.[85] During the pandemic, it helped to accelerate the implementation of essential caregiver programs in care settings.
- CCCE is conducting a collaborative caregiver needs mapping exercise with the Nunavummi Disabilities Makinnasuiqtiit Society to address the gap in knowledge of the unique needs of caregivers in Nunavut. This work will include Indigenous-led sharing circles in 25 Nunavut communities, a report outlining where services and supports are lacking and practices and services to fill critical gaps with sustainable supports.
- The Canadian Mental Health Association Yukon Division offers information, resources and counselling support to caregivers in the area. It also offers workshops, support groups and a support phone line for all residents, including caregivers.[86]

This is far from a complete list of the work many caregiving organizations are doing to fill the policy gaps that leave caregivers without support. Every province and territory across Canada would benefit from having a local caregiving organization. Over time, CCCE hopes to support this growth and a national network.

Caregivers and care providers across all provinces and territories experience unique challenges around the policies and programs supporting them. In addition to these challenges, the overall trend is that public policy in Canada is failing to support caregivers and care providers. While several provincial and national organizations are working to compensate for those shortcomings, all governments can and should do to ensure the sustainability of Canada's caregiving landscape. Below, we identify the policies failing to support caregivers and critical issue areas that have informed our proposed policy agenda for a better caregiving landscape in Canada.

Caregiver legislation and recognition

THE POLICY:

Legislation, regulation and strategies

Although the federal government has strategies and action plans related to continuing care, dementia and healthy aging, there is no comprehensive federal strategy or legislation to strengthen systems of support for caregivers.[87] Unlike peer jurisdictions such as Australia, the United States or the United Kingdom, Canada lacks a co-ordinated approach to caregiving across the country in the form of a dedicated strategy and/or specific caregiving legislation.[88]

While there is no federal law or strategy dedicated specifically to caregivers, some provinces have enacted their own legislation and action plans to enhance caregiver rights and supports. In Québec, the Act to recognize and support caregivers commits the provincial government to create a policy for caregivers, update a plan every five years and assign responsibilities to various ministries to support caregivers.[89] The Québec government launched its Government action plan for caregivers 2021-2026: Recognizing caregivers to better support them in October 2021.[90] The plan proposes a number of measures to develop an approach that involves collaboration among the health network, community organizations, and caregivers.[91]

In Manitoba, The Caregiver Recognition Act guides the development of a framework of supports for caregivers and recognizes the importance of their role.[92] Under the Act, each department and agency within the government is required to understand the principles of the law and is responsible for developing caregiver supports.[93] Since coming into effect in 2011, the Government of Manitoba has reported: improvements to the accessibility of the provincial Primary Caregiver Tax Credit; efforts to make the health system more patient-focused and efficient; and the introduction of responsibilities related to supporting caregivers within the mandate for the Minister Responsible for Seniors.[94] Similarly, the Ontario Caregiver Recognition Act, 2018 recognizes the role of caregivers and general principles that should be followed when developing, implementing and evaluating caregiver supports.[95]

Some provinces have also enacted policies that clearly define caregivers and provide supports to people who meet that definition. Québec has a home care policy that treats caregivers as partners of the health-care system,[96] meaning that caregivers have access to the services, information and training, financial support and employment accommodations they need.[97] In British Columbia, the Home and Community Care Policy recognizes caregivers as a part of the care team, requiring health-care professionals to collaborate with caregivers when developing care plans. Similarly, the home care policies in Saskatchewan and New Brunswick recognize the importance of caregivers to client care and consider the needs of caregivers in care planning.[98]

THE PROBLEM:

Canada lacks a comprehensive approach to caregiving

Various policies, legislation and strategies in place across the country help to support and recognize caregivers. The problem is that parts of Canada lack these supports, leaving many Canadians without a systemic approach to helping caregivers. A more systemic approach could embed the needs of caregivers into government decision-making. Instead, we have a patchwork of strategies, plans and legislation across jurisdictions, meaning some caregivers get less consideration and support simply because of where they live. All governments need to consider caregivers, recognize their contributions and use the policy tools available to them to ensure the sustainability of their care work.

Governments do not take a considered, systemic approach to supporting caregivers and caregiving work is taken for granted. Under-valuing care work is a policy choice that disproportionately affects caregivers — who are predominantly female — and care providers, who are predominantly racialized females. It places them at a disadvantage and reinforces gendered norms around the division of labour. Further, it reinforces prevailing assumptions around women's assumed roles as "natural" caregivers and the under-valuing of their contributions to society. Caregiving policy is a gendered and racialized issue that propagates inequity across the country.

While some provincial governments have taken steps to enact caregiver legislation recognizing the roles and needs of caregivers, each has come with challenges and disappointments for caregivers. In the case of *The Caregiver Recognition Act* in Manitoba, stakeholders have been disappointed by a lack of action following its

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implementation. Caregivers remain largely invisible in health-care transformation documents. Despite reported efforts to make the Primary Caregiver Tax Credit more accessible, some caregivers find it to be less accessible now than in the past. These challenges highlight the importance of involving impacted stakeholders in evaluating progress following the implementation of caregiver legislation and of ensuring governments will be held accountable for commitments they make.

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Focus on young caregivers

Young caregivers are children, youth and young adults who care for someone with a chronic illness, disability, mental illness, or health issue related to aging.[99] Young caregivers have a range of caregiving responsibilities that they balance with other parts of their lives, such as school, jobs or extracurricular activities.[100] Young caregivers often provide personal care for parents, grandparents, or siblings. They also provide financial and emotional support for care recipients and serve as a point of contact with health-care providers when their parents do not speak English or French. While caregivers across the board are invisible in many circumstances, young caregivers are particularly hidden in their roles.[101]

Young caregivers spend on average 14-27 hours of their week providing care — equivalent to a part-time job.[102] Given the time spent providing care, many young caregivers' responsibilities take away from their focus on school, social development and even future professional development.[103] We heard from one young caregiver who helps his newcomer parents support his brother who has Down syndrome and autism. He is close to his brother and is an integral part of his support team, often providing respite for his parents. He has lived at home during university to continue to help care for his brother and declined an opportunity to travel across the country on a medical school scholarship because he felt he could not leave the region.

Supporting young caregivers early in their caregiving roles can help to mitigate some of the socio-economic and mental consequences of providing care.[104] Organizations such as Young Caregivers Association help empower young caregivers to be resilient in their roles and to be better supported with educational resources, counselling and respite services.[105] For example, Powerhouse is a program developed by Young Caregivers Association that teaches young caregivers important life skills and gives them the opportunity to connect with other young caregivers.[106]

Care recipient programs and services

THE POLICY:

Programs and services for care recipients

Support services for care recipients include everything from medical treatment to homecare, physical and occupational therapy, personal care and household management. The services a person receives varies based on their disability, health condition, or accessibility needs related to aging. For this reason, there is no single snapshot of the public policy landscape for services that impact care recipients. However, they are by and large shaped by provincial policy and delivered by local agencies or practitioners.

THE PROBLEM:

Care services are insufficient and fragmented

The literature and the caregivers we spoke to in focus groups make it clear: the best way to support caregivers is to ensure the people *they* support have the right services in place. However, beyond the vital work of caring for people, caregivers said they spend a tremendous amount of their time navigating many complicated systems and services. Both the quality and quantity of supports are lacking across Canada, and what does exist is too difficult to access.[107]

Services are fragmented and unco-ordinated

Services across health and social care are deeply fragmented and often organized by which sector is providing the care rather than the needs of the care recipient.[108] Services can also be organized based on public or private funding,[109] or the type of service needed. Fragmented programs and services results in frequent reassessments and repetitive explanations for the multitude of disjointed offerings. It also reduces collaboration and communication among various service providers. Focus group participants told us that separate funding envelopes make it difficult for different types of providers to work together across organizational mandates to deliver more integrated care that would better meet people's needs.

Beyond the quantity of support, services often do not meet people's needs. Services often focus on only the basic medical needs of care recipients. This means that other important needs such as dressing, cooking and housekeeping are not addressed. Instead, caregivers must hire private care services or learn to meet the care recipient's needs themselves.

This fragmentation reduces the quality of care and adds a heavy burden of work for caregivers,[110] who must frequently function as system navigators, co-ordinators, advocates and accountants to piece together services for the people they support.[111] This can mean searching for information from multiple sources and relying on their own resourcefulness and time – something not everyone can do.[112] System navigation reduces the time caregivers could be spending on supporting care recipients or themselves.[113] System navigation is especially taxing for racialized caregivers who experience resistance and microaggressions, newcomers to Canada with language barriers and aging caregivers.

Caregivers must also co-ordinate care among different providers, ensuring that care recipient needs are met, that care is continuous and that relevant knowledge is maintained and transferred.[114] Surveys show that most caregivers see themselves as fully or partially responsible for organizing other members of the care team and find this crucial co-ordination work and the work of system navigation to be a serious challenge.[115] While there are some free and paid services that can help caregivers with system navigation and care co-ordination, these supports are difficult to access. Only four per cent of caregivers report that a provider, government agency, or co-ordinator takes on the role of co-ordinating care, and those that do are frequently limited to either institutional care or community care, but not both.[116]

The quantity and quality of services are insufficient

While some long-term care is based in facilities, health and social care has increasingly shifted from institution-based settings to home and community care.[117] This is a positive step, in that it helps deliver autonomy and community connection to care recipients and improves their quality of life.[118] This shift has also benefited provincial governments by reducing the high costs of institutional care.[119] For example, the average cost of a hospital bed in Ontario is $842/day, while care at home costs the government $42/day on average.[120] That recovered cost has not been redirected to providing comparable care in the community and the support services needed for this approach to work have not been sufficiently funded.[121] In fact, funding cuts have led to a reduction of support services for care recipients.[122] The cost and labour of supporting care recipients has essentially been outsourced to caregivers.

These problems are exacerbated by labour force shortages in the public and private care sectors. Staffing and service agencies struggle to fill staffing shortages to meet care needs, resulting in care provider burnout or leaving care recipients without adequate supports. Caregivers have been left to fill in these gaps. A recent study showed that over a third of people receiving home care services had unmet home care needs[123] and some caregivers who theoretically have access to services receive only one or two hours of help a week.[124] The COVID-19 pandemic has made the situation even worse. In Alberta, for example, almost half of people surveyed reported reduced home care services in the wake of the pandemic.[125]

Beyond the quantity of support, services often do not meet people's needs.[126] Services often focus on only the basic medical needs of care recipients.[127] This means that other important needs such as dressing, cooking and housekeeping are not addressed. Instead, caregivers must hire private care services or learn to meet the care recipient's needs themselves.[128]

Eligibility is strict and there is a high administrative burden

Narrow and strict eligibility criteria, long wait times and onerous application processes are also barriers to support services for care recipients.[129] Application processes for services can be overwhelming and intimidating, and eligibility criteria varies from one service to the next. People are increasingly deemed ineligible for publicly funded services for which they have previously qualified without understanding why they are denied.[130] Consequently, they must incur high out-of-pocket costs for private services to meet support needs.

Caregivers are not sufficiently involved as a part of the care team

While caregivers are increasingly referred to as partners in care, in practice they are not valued within the system. Caregivers have unique and valuable expertise that can help health-care workers and care providers make better care decisions.[131] For care recipients who face barriers to care, such as stigma or language barriers, caregivers play an integral role in facilitating person-centred care for the care recipient. Yet, focus group participants highlighted that caregivers, and young caregivers in particular, do not receive respect from health-care professionals and service providers. Often, caregivers' ideas and perspectives are not included in care planning, despite their valuable expertise and enormous contributions to care work.

In Alberta, fewer than a third of caregivers surveyed since the COVID-19 pandemic began had been asked by health-care professionals about their own well-being.[132] This failure to include caregivers and their goals in the design, planning and delivery of health and social care contributes negatively to caregiver and care recipient well-being.[133] In the initial stages of the pandemic, many facilities implemented visitor bans that barred caregivers from seeing care recipients, resulting in negative outcomes for the people receiving care.[134] The important role of caregivers on the care team was made clear over the course of the COVID-19 pandemic, leading to the acknowledgement of caregivers as essential partners in care and to Healthcare Excellence Canada's work to develop policy guidance for decision-makers on the reintegration of caregivers as essential partners.[135] In practice, much more can be done to include caregivers as partners in care.[136]

Services do not adequately accommodate the unique needs of caregivers

Where services are available, they do not often use a person-centred and trauma-informed approach to meet the unique needs of individual caregivers. This is especially true for caregivers in the LGBTQ2S+ community, newcomers or immigrant caregivers, racialized caregivers and female caregivers. Racialized caregivers experience challenges in the health-care system due to systemic racism and discrimination. They may also face barriers to accessing services that are culturally sensitive and are disproportionally impacted by certain illnesses and social determinants of health.[137] Due to factors such as systemic racism, different networks of care and demographics in Indigenous communities, Canada's Indigenous people have different social determinants of health.[138] These unique circumstances should be factored in when assessing caregivers' needs and incorporating them into care planning.

Existing programs and services to support care recipients are falling short. Understanding where care services are lacking is the first step to improving them. There is a way forward: targeted improvements and significant investments in care services can help to better support care recipients.

KB's experience as an unemployed caregiver

KB is a full-time caregiver for her son, who has a disability. Before she started her family, she worked outside the home full-time, but since then she's had to become an expert in co-ordinating care, advocating for her child and providing for his needs. He's now 13 and some aspects of his care are becoming more difficult as he grows up.

KB views her role as a second career. She works all day, every day, meeting her son's direct needs, arranging his medical appointments, advocating for him with his school, ensuring his space is safe for him, helping him connect with his community and just being with him. Dealing with all the different institutions and organizations is exhausting; it seems like she's always duplicating work, or troubleshooting, or following up with care providers who are themselves stretched thin. She sometimes feels that if she weren't constantly on top of things, nothing would happen for her son. She doesn't have days off, except when he is able to access a day program.

KB is glad that she's able to be with her son and give him the love and attention he needs. She feels the choice to leave the workforce to care for her son was the right decision for her and her family. At the same time, she knows that this has changed the course of her family's finances. They now run a household on one income. They worry that they may have to move from the suburb where they live to somewhere less expensive. They chose their current home because it is close to their son's day program. KB hasn't made a Canada Pension Plan (CPP) or EI contribution in years. She wouldn't want to go back to paid work and cannot afford to because paying for a full-time caregiver is out of reach. She wishes her family could have more financial stability.

Focus on LGBTQ2S+ caregivers and care recipients

LGBTQ2S+ care recipients and caregivers are largely understudied in the research literature. Some studies indicate that 250,000 caregivers across Canada are LGBTQ2S+ or care for someone who is.[139] LGBTQ2S+ caregivers and care recipients have unique and often challenging experiences with our health-care and social systems. They face barriers in accessing health care, such as stigma and prejudice, which often have negative consequences for their mental health.[140] This discrimination in the health-care system has only recently received research attention.[141]

LGBTQ2S+ caregivers may be at a greater risk of mental health conditions[142] that can be a direct result of, or exacerbated by, their caregiving responsibilities. Having access to mental health services is paramount for this community.[143] Many caregivers experience a lack of respect or inclusion in care planning, but LGBTQ2S+ caregivers often experience the same challenges to a higher degree due to prejudice, stigma and unconscious bias in the health-care system.[144]

LGBTQ2S+ care recipients have similar challenges with access, respect and visibility in the health-care system. For example, transgender people with dementia can experience cognitive changes that influence their gender identity and create gender confusion.[145] Invisibility of LGBTQ2S+ care recipients in research, policy and practice, as well as consistent data gaps, continue to limit our understanding of the health outcomes of this community.[146] Initiatives such as the development of the 2SLGBTQ+ Canadian Healthcare Bill of Rights for Advanced Illness, Frailty and End of Life (2SLBGTQ+ Bill of Rights) help LGBTQ2S+ care recipients understand their rights in health-care settings, such as the right to identify who will be their advocate or the right to decide who does and does not visit them when they are sick.[147] Recent research also points toward the need to broaden societal notions of caregivers beyond spouses and children to include friends, adult siblings, more distant relatives and other members of the community.[148]

Translating greater knowledge and understanding of the unique challenges experienced by LGBTQ2S+ caregivers and care recipients into practice will enable the government, medical and other professionals to give the LGBTQ2S+ community proper support and care.[149] Much more can be done to make LGBTQ2S+ care recipients and caregivers feel seen, safe and supported,[150] to reduce barriers to access and to reduce stigma throughout the health-care system.

Caregiver programs and services

THE POLICY:

Programs and services for caregivers

Government programs and services for caregivers are typically provided at the provincial or territorial level and are geared toward providing relief or respite care services for the caregiver. These services can be delivered at home, in the community through day programming, or through short-term overnight stays in a residential care facility for the care recipient.

In-home respite is typically accessed as a component of other home care services, although not everyone who qualifies for home care qualifies for respite care. Facility-based respite care services are offered as a short-term visit to existing care facilities. Out- of-home day programs are also offered in some fashion in most jurisdictions. These services vary significantly across jurisdictions, including differences in funding structure, cost, availability to caregivers, availability across regions, eligibility criteria and the type of services available.

In addition, organizations in provinces and territories across Canada offer resources, mental health support, training and education for caregivers. For example, Caregivers Nova Scotia provides caregivers free access to a caregivers' handbook with tools, tips and resources.

THE PROBLEM:

Supports designed specifically for caregivers do not meet their needs

When caregivers take care recipients to routine medical appointments, there is no consistent protocol or practice around checking on the health and well-being of the caregiver.

For many people, caregiving is a 24/7 responsibility.[151] Caregivers need a break from caregiving responsibilities to take care of their own mental, physical and emotional health.[152] Services such as respite care are meant to give caregivers the opportunity to take time away from caregiving and focus on their own health and well-being. They also benefit the care recipient, helping them build a community and develop life skills and independence. Evidence shows that respite care can reduce caregiver stress, reduce burnout and strengthen family interactions.[153] Unfortunately, respite care services in Canada are not meeting caregivers' needs.

In addition to respite care, some training, resources and support groups are available to caregivers who have access to them. However, caregivers who are unaware of this support, ineligible for it, or living where it is unavailable are left to navigate challenging care responsibilities on their own.

Availability of respite care services is patchy and inflexible

Respite care is rarely available in the type or amount needed. While most provinces and territories offer some form of in-home, short-term or day programming for seniors and adults and children with disabilities, publicly funded respite services are generally not adaptable enough to meet the individual needs of caregivers.[154] For example, respite is available in some provinces and territories for seniors' caregivers, but only for those providing end-of-life care. In other cases, day programming may be available for caregivers of children with disabilities but not for adults.[155]

The availability of respite care is also often limited by the capacity of the program and the availability of professional care providers. This is another area of extreme need that became more pronounced during the COVID-19 pandemic. Demand for respite care services is often much higher than the available supply, driving demand for private in-home services.[156]

Respite services are costly and eligibility criteria are restrictive

The criteria for respite services are often based on the needs of care recipients rather than those of the person providing care. Caregiver services are often left out of care planning altogether, and if a caregiver does seek out respite care services on their own, the process can be time consuming and confusing.[157] Respite care is also frequently costly. While some provinces and territories, such as the Yukon and Northwest Territories, have in-home respite available at no cost, others, such as Nova Scotia and Newfoundland and Labrador, use income to assess eligibility for publicly funded services.[158] If a caregiver is not eligible for publicly funded respite care services, they must purchase these services from other health and community service providers.[159]

Training and resources for caregivers are lacking

Caregivers often find themselves in situations where they could use more coaching and support. Sometimes, because of insufficient home care support services, they need to perform such medical tasks as changing bandages or tending wounds. In some cases, caregivers are required to perform more demanding tasks, such as catheterization and dialysis — tasks that should be performed by a health-care professional. When caregivers are not included as a part of the care team, they are not trained or prepared to care for loved ones. This can be especially true for caregivers of care recipients with dementia or trauma, whose care needs can be unpredictable and complicated. Without proper training, caregivers may not know how to respond to trauma responses or how to avoid triggers.[160]

Training and coaching must also reflect the broader complexities of caregiving. Given the patchwork of services, caregivers need help with systems navigation to make sure they have access to and take advantage of the support available to them. Financial literacy and expert advice on how to manage budgets and support contracts would also help caregivers navigate complex income support and benefit programs.

Respite care services are not the only form of support caregivers need. Online counselling and resources are a great starting point for caregivers. However, caregivers would benefit most from training and emotional support that is specific to their needs. Caregiving changes over the course of the care trajectory and skills and training should reflect the evolving nature of caregiving responsibilities and each caregiver's needs. Caregiving is both rewarding and challenging and when caregivers are not supported to navigate and balance the emotionally taxing responsibilities associated with providing care, they are more likely to burn out and need care themselves.

Current support models do not give caregivers the respite and assistance they need to be able to manage their own well-being and that of the care recipients. Fortunately, health-care providers in some jurisdictions are moving toward including caregivers' needs in care planning and building their respite care needs into the care plan. Governments can build on that momentum and work toward guaranteed, quality services and supports for all caregivers.

Supports for caregivers in the workforce

THE POLICY:

Workers' benefits, rights and leaves

A combination of leaves and benefits support caregivers when they need to take time away from work. Compassionate care leave is an unpaid leave available to all employees in Canada. The administration and eligibility criteria for the leave depends on whether an employee's job is regulated under provincial, territorial or federal jurisdiction. If an employee works under federal jurisdiction in Canada, they can be eligible for the federal leave. If an employee is regulated under provincial or territorial jurisdiction, they can be eligible for the equivalent compassionate care leave in that province or territory.

Compassionate care leave allows employees to take time away from work to care for someone who is at a significant risk of death, as certified by a medical practitioner. Eligibility criteria for federal, provincial or territorial compassionate care leave is similar across jurisdictions. Generally, the length of leave is between 26 and 28 weeks. Leaves vary across jurisdictions around the length of time a person must be employed before they take the leave and around the definition of family caregiver.

Family caregiver leave is also available to caregivers in the workforce who need to take time away from work to care for someone who is critically ill or injured. Again, caregivers are eligible for the federal leave or for the provincial or territorial equivalent, depending on which jurisdiction regulates their workplace.

While federal, provincial and territorial leaves guarantee time away from work without losing one's job, two associated federal benefits for caregivers under the Employment Insurance Act help give caregivers income when they are taking such leaves. The Compassionate Caregiver Benefit is available to all Canadian employees who are providing end-of-life care or support and is available for up to 26 weeks. The Family Caregiver Benefit is available to employees caring for someone who is critically ill or injured and can be paid for up to 15 weeks. These are paid as up to 55 per cent of a person's EI-insured earnings, to a maximum of $638 per week. Caregivers are eligible for both benefits during the 52 weeks following certification by a medical practitioner, providing they worked at least 420 insured hours in the 52 weeks prior to the claim.

As of 2019, the Canada Labour Code, which applies to employees in federally regulated workplaces, includes new rights intended to give caregivers more flexibility in the terms and conditions of their paid work, including hours of work, scheduling and work location. The Code now includes a provision for personal leave of up to five days for family emergencies, three days of which must be paid. Businesses that fall under provincial or territorial legislation were not affected by the changes to the Code, but have the option to provide flexible arrangements for employees, providing they meet the requirements of their provincial or territorial labour legislation.

THE PROBLEM:

Leaves and protections for employed caregivers are inadequate

Over six million Canadians are balancing work and caregiving responsibilities.[161] In addition to being necessary for their financial security, work can be a welcome form of respite for some caregivers. Without effective policies and workplace supports, employees often have limited employment options, must reduce their hours or exit the workforce. Of employed caregivers, 15 per cent reduce their work hours, 10 per cent turn down job opportunities and 26 per cent take a leave of absence from their job to provide care.[162] For caregivers who provide care for longer periods of time, the impact on their work responsibilities can be more pronounced. This situation is more dire for some caregivers, depending on their circumstances and the severity of their caregiving responsibilities. Double-duty caregivers are more likely to reduce their work hours or turn down a promotion if they provide four or more hours of care a week.[163]

> It can be extremely difficult for caregivers in the workforce to juggle work and care responsibilities. Often, caregivers experience mental health consequences and other acute health consequences that require them to take disability leave from work.

It can be extremely difficult for caregivers in the workforce to juggle work and care responsibilities. Often, caregivers experience mental health consequences and other acute health consequences that require them to take disability leave from work.[164] [165] [166] Double-duty caregivers in the health-care workforce can experience high levels of stress, anxiety and burnout. Without support, they are more likely to take a leave of absence.[167] Some focus group participants said they were forced to quit their jobs or leave the workforce entirely because it was impossible to balance both paid work and longer-term care. The combined cost of losing skilled employees and increased turnover due to workers leaving the workforce to provide care amounts to over $1 billion in lost productivity per year.[168]

Caregiving leaves are inadequate

Despite the leaves and benefits in place, caregivers often use their sick or vacation days to fulfill caregiving obligations.[169] This is because provincial, territorial and federal leaves available to employed caregivers do not fulfill their long-term needs and short-term provincial and territorial family responsibility leaves allow workers to only take up to two unpaid weeks away from work.[170]

Compassionate care leave and family caregiver leave offer longer-term leaves for caregivers in the workforce but are strictly limited to end-of-life care or a serious medical condition.[171] While compassionate care leave and family caregiver leave provide job-protected time off, the person receiving care must be certified by a medical professional that they are critically ill, injured, or in need of end-of-life care before caregivers can secure the associated EI benefits.[172] In many cases, medical professionals are reluctant to confirm that a patient is nearing the end of their life or critically ill, making it difficult to qualify for federal leaves and benefits. Additionally, the eligibility criteria for both long-term leaves and benefits, combined with the administrative burden required to obtain them, means that many employed caregivers must take time away from work through other means.[173] These benefits also exclude self-employed, part-time and casual workers from financial support.

Flexible work arrangements are up to the employer

The average number of days caregivers need to take away from work to fulfill their typical caregiving obligations exceeds most government leave limits, outside of end-of-life or critical care,.[174] Government leaves and benefits are typically less amenable to sudden, unpredictable episodic care needs. Caregivers in the workforce then rely on the availability of flexible workplace arrangements and supports from their individual employers. Flexible working arrangements — such as remote work or flexible working hours, leave top-ups, and extended benefits from employers — can supplement existing government supports. However, flexible working arrangements must be requested and approved and exist only where employers have the interest or capacity to provide them.[175] Often, in the absence of employersponsored benefits or individual supports, employed caregivers use their own sick or vacation days to fulfill caregiving obligations.[176] Further, workplace policies for caregivers often exclude LGBTQS+ employees if they are caring for someone from their chosen family, i.e., a non-biologically related group of people chosen to provide social support.[177] [178]

Negative impact on future employment and finances

Balancing caregiving with work responsibilities can negatively impact career advancement opportunities and workplace satisfaction. Reducing work hours, taking more days away from work, passing up promotions and requiring more flexibility puts caregivers at a disadvantage. An estimated 45 per cent of caregivers in the workforce are economically impacted by the costs of balancing work, care and other responsibilities.[179] Caregivers lose an estimated $336.8 million in wages each year in Canada. Caregivers in the workforce bear financial costs due to lost income, lost future earnings, reduced benefits, out-of-pocket expenses and time spent on caregiving responsibilities.[180] Caregiving also threatens their future income security, as taking time away from work or exiting the workforce to provide care can reduce a caregiver's future government-sponsored or private pension.[181] While the Canada Pension Plan (CPP) allows contributors to exclude 15 per cent of the month or year of their lowest earnings, more could be done to ensure pensions are not reduced as a result of caregiving responsibilities.[182]

Given that EI supports for caregivers offer a fraction of the earner's regular income during their leave, family members with lower incomes are more likely than their higher-paid spouse or relative to take a leave.[183] Moreover, caregivers with significant caregiving duties throughout their adult lives may not have the opportunity to work at all. These caregivers are unable to make CPP contributions and are therefore ineligible for the CPP and related CPP benefits in their senior years, as well as being ineligible for the EI benefits described earlier. This reality negatively impacts family caregivers who remain out of the workforce to provide care to a family member or friend during their working-age years. Women are more likely to provide care, given the societal pressure for them to "naturally" take on caregiving roles. They are therefore more likely to experience poverty related to gaps in their own employment or a lack of pension income due to their caregiving duties.[184] A general lack of financial support, recognition and value for caregivers leaves many female caregivers without sufficient financial means to support their own retirement and inevitably, their own care to help them age in place.

Gender inequity for caregivers in the workplace

Employers should reflect on gendered experiences and account for them when developing workforce policies to support caregivers.[185] [186] [187] For women caregivers, the pressure of gender expectations and the design of caregiver leaves exacerbate existing gender disadvantages in the workplace.[188] In a 2012 national survey, women in the workforce with caregiving responsibilities reported worse mental health outcomes than men after seeking accommodations for their caregiving role.[189] Women reported more hours dedicated to providing care, more employment adjustments required and more conflict between their competing roles.[190] The study also found that women are more likely to adjust their careers to meet their caregiving duties.[191]

On balance, caregivers in the workplace do not feel they have the support and flexibility to maintain their employment and significant caregiving duties over a long term. However, a growing number of employers are shifting toward flexible workplace accommodations by default and some have improved their workplace policies and benefits to support their employees as they balance multiple responsibilities. This positive trend in workplaces, combined with strengthened leaves and benefits from all orders of government, have the potential to enable caregivers in the workforce to remain fully employed.

> When developing workplace policies to support caregivers, employers should reflect on gendered experiences and account for them in their policies. Further, given that EI supports for caregivers offer a fraction of the caregiver's regular income during their leave, family members with lower incomes are more likely than their higher-paid spouse or relative to take a leave.

PJ’s experience as an employed caregiver

PJ is a caregiver for his sister, who has a degenerative disease. PJ and his sister are in their 50s and their parents have died. His sister doesn’t have a partner or anyone else who can help her.

PJ works full time in an industry that he loves and leaving his job is not financially viable. He often has to take time off work to help his sister get to her appointments or make long phone calls during the day to try and co-ordinate her care. He thinks his work is suffering and that bothers him. In his off hours, he does his sister’s grocery shopping and meal preparation.

PJ has tried to find time to help his sister by using vacation and sick days. His bosses have been understanding, but he feels they are getting impatient. He thinks there may be official leave and benefits available to him, but he can’t take the pay cut of going on EI. He also heard that it’s mostly to care for people who are dying and thankfully his sister is a long way away from that.

PJ has struggled to find a publicly funded or even private care provider to help his sister with personal care. The workers are stretched too thin; sometimes they do not show up or show up at unexpected times and his sister misses them because she is napping.

PJ loves his sister — they’ve always been close. She is his priority. But he never feels like he’s doing enough for her, or enough at his job. He doesn’t know how to sustain this.

Financial supports

THE POLICY:

Tax credits and financial supports

Federal, provincial and territorial governments use the tax system to try to decrease or buffer the costs of caregiving. Federally, tax credits and deductions include:

- The Canada Caregiver Credit (CCC), a non-refundable credit that provides a maximum of $7,348 to caregivers of dependent relatives, or up to $2,295 for the care of a common-law partner, spouse or minor child. Non-refundable credits reduce the amount of tax paid each year, benefitting caregivers with incomes high enough to have significant taxes owed each year.
- The Disability Tax Credit (DTC), a non-refundable tax credit that can be transferred from a dependent with a disability to a caregiver under certain circumstances.
- The Home Accessibility Tax Credit, Medical Expense Tax Credit, the Disability Supports Deduction and the Child Disability Benefit are also relevant to some caregivers.

Tax credits in provinces and territories often mirror those available from the federal government. For example, the Government of Alberta offers a caregiver credit, disability credit and medical expenses credit in addition to the claims available from the Government of Canada. Nova Scotia offers a caregiver benefit each month. As additional financial support, caregivers may also be able to claim portions of federal disability, attendant care and medical expense tax credits that are not used by the person receiving care.

Financial supports may also be available to the person receiving care. People with disabilities are generally financially supported through some form of income support program, depending on where they live. In Ontario, for example, individuals with disabilities receive financial support from the ODSP.

THE PROBLEM:

Financial supports are insufficient and ineffectively designed

Caregivers incur direct and indirect financial costs associated with their caregiving responsibilities. In some cases, providing care prevents caregivers from entering the workforce full-time, if at all, or forces them to leave the workforce to support someone who needs care. An estimated 390,000 workers leave the workforce each year to provide care.[192] The financial burden of caregiving can lead to additional burdens, such as the toll taken on mental and physical well-being.

There is insufficient financial support available

Existing income support schemes leave many people facing financial strain and insecurity because of their caregiving responsibilities.[193] The amount of financial support available rarely offsets the financial consequences of providing care. This is especially true for financial impacts that are difficult to quantify, such as the opportunity cost from time spent providing unpaid care rather than earning an income.

Direct financial supports for individuals with disabilities, such as the ODSP or British Columbia's disability assistance, also fall short. The small amount of financial support a person receives indirectly impacts family or friends providing them with unpaid care, who fill in the gaps with their own time or money. Focus group research with care providers showed that the limited income support families receive reduces the amount of paid care they are able to purchase from care providers.

Existing financial supports are inaccessible

Many caregivers who may be eligible for government support do not take advantage of benefits, credits, or allowances because they do not know they are eligible or find the process confusing or inaccessible.[194] Financial supports are difficult to locate, access and navigate for many Canadians. In 2018, only eight per cent of caregivers received tax credits and six per cent received financial support from the government.[195] Low uptake can result from lack of awareness of available supports, difficulty accessing them and strict eligibility criteria.[196] Income cut-offs for support can also be too low; they include those with a low income but exclude people with higher incomes from receiving support even though they may need it.

Moreover, most caregiver tax credits provided by federal, provincial and territorial governments are non-refundable.[197] This means that non-refundable tax credits only benefit caregivers who have a high enough taxable income to receive them.[198] As a result, most tax credits do not effectively support low-income caregivers.

Eligibility criteria are restrictive

Many caregivers are not eligible for financial support, despite the outsized financial cost of their caregiving responsibilities.[199] For example, federal benefits exclude caregivers who are self-employed, part-time, or casual workers.[200] Medical practitioners may also be hesitant to complete the paperwork required for EI benefits because it involves estimating a person's remaining lifespan. Strict eligibility criteria and administrative challenges are also an issue for some disability supports, such as the DTC. Focus group research with caregivers showed that becoming certified by a medical practitioner to receive the DTC can be extremely difficult. This prevents people from even applying for the DTC and from accessing a range of other financial supports requiring medical certification.

Too much administrative red tape

Caregiver credits and financial support programs each have their own criteria, application process and reporting requirements, which are time consuming and burdensome for caregivers. Most provinces and territories have some sort of direct funding program to help people with disabilities or medical needs hire their own attendant care. Self-managed care programs provide benefits directly to the person with a disability or other need, who can use the financial support to hire their own services, including family caregivers.[201] While this model provides autonomy and flexibility, it assumes there is a ready supply of care providers available to meet demand and places an administrative responsibility on caregivers and people receiving care. It assumes that each care recipient is able, or has a caregiver who is able, to take on the administrative burden of co-ordinating care. The same is true about financial supports for aging care recipients; both models place an administrative burden on caregivers and assume a readily available supply of care providers.

Financial supports for caregivers and care recipients are insufficient. Expanding financial supports, especially supports that already exist in some form, is a promising tactic to better support caregivers in Canada.

Focus on siblings of people with disabilities

Siblings play an important role in the lives of people with disabilities. They have strong connections and emotional bonds.[202] As people with disabilities live longer, siblings are more likely to become their sibling's primary caregiver at some point in the future.[203] [204] The transition of care from parents or guardians to siblings is a source of anxiety for many siblings of people with disabilities.[205]

When it comes to planning for the future and transitioning care responsibilities, there are a number of barriers that prevent families from planning and approaching the topic.[206] In many cases, emotions and fear around the subject, difficult family dynamics and uncertainty are barriers to preparing for the future.[207] Many siblings describe future care planning as a highly emotive and stressful topic, with financial planning often described as the most worrisome issue. In one study of siblings of people with disabilities, only 33 per cent of respondents felt financially prepared for caring for their sibling.[208]

Planning for the future helps siblings feel confident during the transition of care and it also helps to ensure care recipients undergo a smooth transition.[209] While research is limited, the benefits of future planning for families of people with disabilities are clear. In particular, it is important for siblings to be involved in the planning and that planning discussions are comprehensive rather than focused solely on finances.[210] Care recipients could be better supported by integrating their siblings into planning for future care needs.

Siblings Canada, an initiative of CCCE, serves as a source of knowledge and resources for siblings of people with disabilities in Canada. Siblings Canada is focused on creating national awareness of the role siblings play, contributing to research, creating a community for siblings and bolstering the capacity of social service agencies to better support siblings.

Care provider training and support

THE POLICY:

Regulation of paid care providers

Care providers have many different titles and qualifications. They can work through publicly funded agencies or be hired privately. While most people are more familiar with the role of PSWs, there are other types of care providers, such as DSPs, who are front-line disability support workers in the intellectual and developmental services workforce.

Care providers have a wide scope of practice. They help care recipients with such personal care and daily living needs as eating, toileting and dressing; contribute to mental and physical health care; and encourage care recipients to foster relationships and be involved in their communities. The skills and knowledge of care providers range from those required to provide basic needs to a detailed understanding of the clinical supports needed to support care recipients to live in their community.

PSWs provide care to people who require assistance with daily living. PSWs assist with personal care and other activities, such as meal preparation, housekeeping and companionship. They may also complete some clinical tasks. PSWs often provide care to seniors with needs related to aging in their homes, in a retirement residence or in a long-term care facility.

The National Occupation Classification (NOC) also uses such terms as home care aide (HCA), home health-care worker, personal care aide and others to describe the role of professionals providing personal care and companionship for seniors, people with disabilities and others.

DSPs provide care specifically to people with disabilities. While the scope of their care is similar to that of a PSW, such as personal care, mobility or housekeeping, people with disabilities typically require different forms of support due to the nature of their disability. For example, DSPs may monitor a person's behaviour; encourage their independence and participation in the community; and ensure they are safe in their environment. DSPs work in public and private settings, often assisting people with disabilities in their homes, assisted living communities or in schools.

Assisted living communities include group homes for adults and children with disabilities, where care recipients share personal care resources and foster responsibility for their own relationships and household management. They also include private dwellings where adults require supports due to some physical or functional challenges.

Unlike other health-related professions such as doctors and nurses, some of the key job categories for care providers are not regulated and parts of the workforce have not yet been professionalized.

This creates a lack of standardization that results in discrepancies in training, certification and scope of practice. It also means that care providers lack professional bodies to champion their work and advocate for their needs. While some jurisdictions such as Ontario, British Columbia, Nova Scotia, and Alberta have implemented registries for PSWs, these tools focus more on providing an avenue for complaints and connecting workers with employers and are not necessarily a step toward a fully regulated profession. There is also variability within training requirements. For example, in Nova Scotia there are specific education requirements for PSWs but only for those who work in nursing homes and for agencies that provide home care.

THE PROBLEM:

The care provider workforce is in crisis

Care providers are essential to millions and demand for their services is expected to increase across most jurisdictions in Canada.[211] Yet, there is currently a significant shortage of care providers across the country and around the world.[212] The pandemic has made the situation even worse, with Home Care Ontario reporting that providers were only able to fulfil requests for care 56 per cent of the time, as of December 2021.[213] Focus group participants highlighted that these gaps have devastating impacts for caregivers, who have to backfill for care provider shortages and turnover themselves.

The shortage of care providers is tied to workforce development problems. Although some governments have taken steps to fast-track qualification, such as the Ontario government's recent investments in tuition-free training for PSWs,[214] it has become increasingly difficult to attract and retain care providers in the workforce. This is due in part to poor compensation, lack of benefits and poor job quality; lack of recognition and standardized qualifications; and limited education, training and professional development opportunities.[215] Focus group participants shared that sometimes care providers change sectors and move across provinces and territories to take on better opportunities. Taken together, this undermines care provider well-being and the overall sustainability of the care provider sector.[216]

Care providers earn low compensation and endure poor work conditions

Relatively low pay, non-standard employment and poor working conditions make work challenging for care providers.[217] They are increasingly expected to do more with less in their roles. For example, the scope of practice for DSPs has evolved to require a wide range of skills and competencies[218] and 77 per cent of workers in the field have reported an increase in their workloads.[219] Focus group participants underscored this trend, showing that care providers are expected to do an unreasonable amount of work in too little time, to provide care to a large and ever growing number of people and to consistently work overtime due to staffing shortages. They are often unpaid for their travel time between clients. In addition to how this affects their own well-being, care providers frequently say they are worried about the well-being of the people they care for given their working conditions. At times, care recipients are left in bad conditions without care due to staffing shortages. We heard from focus group participants that staffing shortages force care providers to miss shifts or arrive hours behind schedule, ultimately hurting the care recipient and their families who fill in the gaps.

While care providers are expected to do more, compensation for their work remains low.[220] For example, most new PSWs can only find part-time work that pays $16-$18 an hour,[221] which is not a living wage across most of Canada. Many PSWs, DSPs and attendants work part-time because that is all that is available, sometimes working multiple part-time jobs to meet their needs. When comparing the wages of full-time employees in the sector with the national average, social and community service workers made $2 less per hour.[222] Further, after adjusting for inflation, a PSW working full-time-equivalent hours earned almost $2,800 less per year in 2018 than in 2009.[223]

Seventy-eight per cent of social and community service workers are women;[224] in female-dominated sectors, low pay propagates broader gender pay inequities in the workforce.[225] Moreover, women comprise 90 per cent of the PSW workforce and 41 per cent are racialized, making existing workforce issues a gendered and racialized issue.[226]

As mentioned, many care providers must work part-time at multiple workplaces to survive.[227] However, COVID-19 reduced this critical source of income, as many people were no longer allowed to work in more than one congregate setting. What's more, many care providers do not have access to benefits. For example, a survey in Sudbury and Manitoulin found that almost six out of 10 PSWs receive no benefits through work.[228]

These conditions hurt the well-being of care providers and contribute to high rates of turnover and labour shortages. Only 50 per cent of PSWs remain in the sector for more than five years, often citing burnout due to staffing challenges as their main reason for leaving.[229] These issues also discourage potential workers from entering the workforce development pipeline.[230]

There are few educational, training and development opportunities for care providers

Care providers have limited educational opportunities, limited established education prerequisites and inconsistent training requirements across workplaces and jurisdictions. Although some jurisdictions have taken steps to create a common educational standard for professions such as PSWs,[231] there is concern about the variable quality of training programs. Focus group participants said that education programs need to focus more on patient and family-centred care, human rights and teaching from individuals with lived experience.

Care providers rarely receive ongoing training and professional development opportunities through their workplaces. Some service agencies lack the resources to give their employees robust continuing education.[232] This issue has been exacerbated by COVID-19; many employers had to suspend training for new staff during the pandemic due to staffing shortages. Focus group participants shared that training is often passed down from more senior employees to junior care providers. This can be an issue if senior employees train junior employees based on practices that are decades old, rather than guidelines that have been updated recently. These training gaps also exist in management. Front-line DSPs often transition to supervisor and middle management positions without adequate training support in place.[233] Further, many senior leaders in the workforce are close to retirement, which means the sector will have more shoes to fill.

The COVID-19 pandemic shone a light on pre-existing vulnerabilities within the care provider workforce. The care provider sector needs more resources, long-term solutions to staffing crises and respect from all Canadians. CCCE has recently committed to education and leadership development through the Leadership Institute for Developmental Services, which aims to foster leadership development in the workforce. All recent efforts to better support, educate, recruit, retain and train care providers are a steppingstone toward better livelihoods for those in the workforce and those impacted by its shortcomings. In addition, care providers deserve mental health and wellness support. The Ontario-based Cultivating Community Wellness initiative funded by CCCE targets the mental health of care providers while building the capacity for the sector to support long-term wellness.

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LL's experience as a paid care provider

LL is a professional care provider. She immigrated to Canada 15 years ago. She was a nurse in her home country, but her qualifications have not been recognized in Canada. She was able to go to school to become a PSW. She has two kids and a partner and lives in a large urban centre.

LL holds multiple jobs as a PSW for people with difficulties associated with aging. She works part- time for a local publicly-funded agency to provide home care to people who qualify. She is contracted to provide an hour of care to each person, but the people she works with live across the city and she is not paid for travel time. She relies on public transit to get from person to person and there are often delays, meaning she is late. She regularly works past her scheduled hours and isn't home to help her kids with their homework.

LL also sometimes picks up shifts at long-term care homes, although this had to stop during the COVID-19 pandemic. LL lost a lot of her income and was worried about her health and the health of her clients. LL has not received much ongoing training since starting work with the agency, as it seems resources are always stretched too thin. She would like to take the next step in her career, but is unsure if a more senior opportunity exists; she heard from co-workers that more training does not always mean more pay or seniority. She mostly likes her clients and their families, but sometimes she experiences racist and xenophobic comments and even violence on the job. She isn't sure who to complain to about this, or if they would be able to do anything.

LL is proud of her work and finds it personally rewarding to be such an important part of people's lives. She is very tired at the end of most days and it is discouraging doing such intense work without seeing much financial reward. She would like to own her home one day and save more for retirement, but does not see how that will be possible. She often considers switching careers, but she worries about what would happen to the people she supports, since there are so few PSWs available to work right now.

Focus on migrant care workers

Canada relies heavily on female migrant workers to fill labour shortages in the care provider workforce. Temporary residents with an eligible work permit can work as care providers in Canada. Eventually, they can apply for permanent residency if they have worked a certain number of hours in Canada.[234]

Migrant care workers can be vulnerable to abuse and exploitation, given the nature of their work environments in private households and the employment insecurity created by Canada's immigration and labour laws.[235] Home-based care work often creates an imbalance of power in the care provider's relationship with their employer.[236]

Over the course of the pandemic, migrant care workers worked longer (and at times unpaid) hours. [237] In a survey of 201 migrant care workers about their experiences during the pandemic, 40 per cent of workers had increased their work hours without compensation.[238] One in three workers reported being forbidden by their employers to leave the house, even for such essentials as groceries and to meet their families.[239] Increased delays in processing permanent residency applications left many care workers restricted to their work permits and tied to their employer. Many migrant workers make significant sacrifices to obtain permanent residency in Canada, impacting their financial, emotional and personal well-being.[240]

Though the federal government made recent adjustments to create a new pathway to permanent residency for care workers,[241] among others, much more can be done to ensure migrant workers are protected. Further, efforts should be made to ensure that migrant workers are skilled, trained and paid to remain in Canada to do this important work.

A policy agenda for a better caregiving landscape

Federal, provincial and territorial governments have a responsibility to take action to improve outcomes today and ensure a strong caregiving ecosystem for the future. This means acting on policy opportunities across different areas. This section outlines some promising ideas to help drive transformational change.

A policy agenda for a better caregiving landscape

Caregivers and care providers are responsible for the majority of care for people who need it, yet the issues facing these individuals are rarely considered or addressed by governments. Caregivers continuously fill in the gaps where government supports, services and resources fall short and this takes a toll on their own well-being. Care providers are also working hard to support families, but are in short supply and are underrecognized as essential workers in Canada's health and social systems. Caregivers and care providers in focus groups reported often feeling invisible. From an outside perspective, they are invisible in legislation, policies and programs surrounding care.

> Canada's current approach to care is not sustainable. Government supports are lacking and care responsibilities are therefore offloaded onto caregivers. The negative consequences of this approach are felt across the caregiving landscape. Federal, provincial and territorial governments have a responsibility to take action to improve outcomes today and ensure a strong caregiving ecosystem for the future.

Canada's current approach to care is not sustainable. Government supports are lacking and care responsibilities are therefore offloaded onto caregivers. The negative consequences of this approach are felt across the caregiving landscape. Federal, provincial and territorial governments have a responsibility to take action to improve outcomes today and ensure a strong caregiving ecosystem for the future. This means acting on policy opportunities across different areas. This section outlines some promising ideas to help drive transformational change.

Potential policy opportunities, by policy area

A co-ordinated approach to caregiving

- Common caregiving definition
- National strategy
- Provincial and territorial legislation
- International caregiver recognition

Services for care recipients, caregivers and care providers

- Funding for home and community care
- Assessment of caregiver needs
- Trauma-informed person-centred support
- Integrated care
- System navigator roles

Strategies for employed caregivers

- Expanded leaves and benefits
- Rights to flexible work
- Caregiver-friendly workplaces
- Government leadership

Adequate financial supports

- Inclusive tax credits and benefits
- Caregiver allowances
- Support for people with disabilities

Working conditions and workforce development for care providers

- Increase wages and government funding
- Professionalize care provider roles
- Support and protect migrant care workers
- Strategy to develop the workforce

Create a co-ordinated approach to caregiving

Canada needs a comprehensive approach to caregiving in all provinces and territories that respects the contributions of caregivers, provides the supports that they need to succeed and ensures care providers are also recognized and enabled to thrive in their work.[242] [243] Caregivers and care providers need to be visible in our health and social systems and included under policies, programs and legislation across jurisdictions that reflect their value to a functioning society.

A co-ordinated approach to caregiving should include intergovernmental collaboration to improve outcomes and close gaps among the patchwork of supports and policies available to people who provide care. This could involve leveraging different types of policy tools across different program areas — and across federal, provincial, territorial and municipal orders of government — to create an integrated support system for caregivers and care providers.

Potential options to facilitate a co-ordinated approach to caregiving include:

Recognizing a common and inclusive definition of caregiving

Recognizing a common definition of caregiving across orders of government could be a first step toward establishing the rights, recognition and support that people who provide care deserve. Such a definition would need to include both caregivers and care providers and recognize the complexity of their work and their essential role in our health and social systems.[244]

Formalizing a common and inclusive definition would enable further policy change and alignment by making it clear who should be at the centre of a more comprehensive system of supports, services and policy. A common definition would also make it easier to give formal rights to caregivers, such as the right to contribute to care planning and access to respite services, financial support and flexible work arrangements. It also makes caregivers and care providers more visible in the broader social and economic agenda of governments across Canada.

A common and inclusive definition of caregiving would encourage caregivers to be included as a part of the care team. Caregivers have valuable knowledge and ideas to contribute to care planning and decision-making that is too often overlooked by health-care professionals and, at times, care providers. A common definition would pave the way for future policies that mandate the inclusion of caregivers in care planning and establish rights for caregivers that ensure they are able to co-ordinate and advocate for their family member's or friend's person-centred care.

Launching a national caregiving strategy

A national caregiving strategy could increase recognition of the essential role caregiving plays in our society and help to develop a specific policy agenda for improving caregiver and care provider outcomes across Canada. Such a strategy would need to integrate the work of relevant federal departments[245] and create a commitment to working with provincial, territorial and municipal governments to co-ordinate action on addressing the shortcomings and inconsistencies in existing caregiving policies and supports across the country. To be effective, it would also need to address both tactical and systemic factors.

To be truly transformative, a national caregiving strategy needs to be grounded in a meaningful consultation with knowledgeable stakeholders. Caregivers, care providers and caregiving organizations are ready to partner with government to change the paradigm around care.

To be truly transformative, a national caregiving strategy needs to be grounded in a meaningful consultation with knowledgeable stakeholders. Caregivers, care providers and caregiving organizations are ready to partner with government to change the paradigm around care. A pan-Canadian strategy could include several shared priorities to help improve the caregiving landscape. For example, these priorities could include increasing collaboration across jurisdictions, program areas and systems; increasing the availability and quality of support services; creating a workforce development strategy for care providers; and designing new financial supports for caregivers.

There are effective caregiving strategies from other jurisdictions that Canada could draw upon. For example, the United Kingdom has developed *The Carers Action Plan 2018 to 2020*,[246] which builds on its previous *National Carers Strategy*.[247] The *Plan* sets out a number of cross-government actions on devolved matters in England and on reserved matters in the United Kingdom.[248] So far, the *Plan* has achieved quality standards for caregiver-friendly general practitioner practices, best practice guidance for caregiver breaks and respite and grants to organizations supporting caregivers returning to work.[249]

There have also been Canadian efforts to develop a strategy specifically for caregivers that the federal government could adopt and grow. The Canadian Caregiver Coalition, led by Carers Canada, developed *A Canadian Caregiver Strategy*,[250] which includes five priority areas developed in consultation with caregivers and caregiver support groups.[251] Guided by the core values of choice, self-determination and respect, the work of Carers Canada and the Coalition was key to igniting the national conversation about caregiving and painting an accurate picture of the status quo. The release of the strategy in 2013 was an important starting point. A future pan-Canadian strategy can build on this laudable work.

> Together with partners from coast to coast to coast, CCCE is poised to take up this mantle and develop a renewed strategy to encompass both the caregivers and care providers who play a vital role in the care ecosystem.

Together with partners from coast to coast to coast, CCCE is poised to take up this mantle and develop a renewed strategy to encompass both the caregivers and care providers who play a vital role in the care ecosystem. An effective new strategy must address the changing landscape, glaring policy omissions, the impact of the COVID-19 pandemic, changing demographics and increasing workforce shortages. CCCE is committed to working with caregivers, care providers, care recipients, researchers, policy makers and people with lived experience across the country to lead efforts to develop a detailed, practicable and actionable National Caregiver Strategy that brings together disability, aging, health care and caregiving perspectives and meets our current and future needs.

Creating provincial and territorial caregiving legislation

As policies related to caregiving primarily fall under provincial and territorial jurisdictions, these governments could adopt caregiving legislation to further increase the visibility of caregivers and care providers and provide them with specific rights to the supports they need. Combined with a common national understanding or definition of caregiving, provincial and territorial legislation could work in unison with the federal government to achieve the goal of a co-ordinated federal strategy for everyone who provides care across the country.

Some provinces have already enacted this type of legislation. In 2011, Manitoba became the first province to adopt legislation for caregivers with the passage of *The Caregiver Recognition Act*.[252] More recently, Québec adopted the *Act to recognize and support caregivers.*[253] Together with the province's home care policy work, the *Act* aims to ensure that caregivers are treated as partners in the health-care system,[254] with access to the services, information and training they need to carry out their role as caregivers, as well as financial support and employment accommodations.[255] The *Act* committed the Québec government to a number of legal obligations that have led to the development of its *National policy for caregivers — recognizing and supporting with respect for their wishes and ability to commit* and its *Government action plan for caregivers (2021-2026 — Recognize to better support,* describing the actions the government will take in response to the policy.[256] Focus group participants indicated that, as with any new policy or legislation, Québec's approach has room for improvement. That said, choosing to implement legislation has been effective in making the Québec government accountable for taking action to support caregivers through legal obligations.

International caregiver recognition strategies and legislation

Several jurisdictions outside Canada have taken a formal approach to caregiver visibility through strategies supporting caregivers and legislation recognizing their role in society.

Australia's Carer Recognition Act was adopted in 2010[257] and aims to increase recognition of caregivers and acknowledge the valuable contribution they make to society.[258] The *Act* includes a list of principles related to the treatment of caregivers and sets out obligations required of public service agencies to reflect the principles set out in the Statement for Australia's Carers.[259]

The New Zealand Carers' Strategy was launched in 2008[260] and envisions a society that values carers such that they are enabled to participate in family life, social activities, employment and education, and that carers are involved in decision-making that affects them.[261] New Zealand's latest *Carers' Strategy Action Plan* involves actions to support carer recognition, improved system navigation and well-being and balance.[262]

The United Kingdom's Care Act was adopted in 2014,[263] replacing original caregiver recognition legislation from 1995.[264] It requires local authorities to promote individual well-being and provide caregivers with information, advice, assessments and rights to services.[265] It also aims to help improve the services available to carers, ensure that the law focuses on the needs of people and established a consistent route to determining entitlement to support for carers. [266]

Scotland's Carers Act was adopted in 2016[267] and requires authorities to create a carer support plan, implement local carer strategies across Scotland, ensure carers have the support and services they need and involve caregivers while creating plans for the person receiving care.[268] Under the *Act*, carers may request a carer support plan from their local authority.[269] This *Act* is a good example of how legislation enacted by various orders of government can work together.

The United States' Recognize, Assist, Include, Support and Engage Family Caregivers Act was adopted in 2017[270] and directs the Department of Health and Human Services to develop and make publicly available a National Family Caregiving Strategy.[271] It aims to: promote person and family-centered care; involve caregivers and recipients in assessments and planning; ensure respite options; and address financial security and workplace issues.[272] The National Strategy to Support Family Caregivers was released in September 2022. In addition to this *Act* and the National Strategy, states may have their own caregiver legislation, such as the *California Family Rights Act*, which allows Californians to take job-protected leave to provide care.[273]

Improve, expand and invest in services for care recipients and caregivers

Canada needs to improve and invest in services for care recipients, which will also help to support and improve outcomes for caregivers. This means investing in services to enable effective home and community care. It also means working to integrate broader care services, streamline systems navigation and care co-ordination and promote patient and family-centred care. Accomplishing this requires meaningful inclusion of caregivers on care teams, taking proactive action to account for and ensure caregiver needs are met and ensuring caregivers have access to supports that maintain their mental, physical and financial well-being. It also requires a concerted effort to reduce red tape for caregivers where possible. Learning from recent transformation efforts in other jurisdictions, such as the Wigan Deal in the United Kingdom,[274] all orders of government have an opportunity to re-think service delivery across the caregiving landscape.

Potential options to help improve care services include:

Increasing funding for home and community services

Provincial and territorial governments should increase funding for home, continuing care and community support services. As outlined later in this report, this could include allocating more resources toward ensuring there is a ready supply of quality, available and affordable support professionals to assist with home and community care.[275] Recent initiatives, such as the Ontario government's April 2022 commitment to investing an additional $1 billion to expand home care over the next three years, have been a step in the right direction.[276] Ontario has also permanently enhanced wages for all DSPs and PSWs by $3 an hour on top of existing wages.[277] Similarly, the Alberta government has committed an additional $36 million to address home and continuing care staffing challenges and to increase the wages of health-care aides.[278] However, to improve care recipient and care provider experience and outcomes, more and sustained investment is needed to address caregiver and care provider burnout, improve working conditions for care providers and stop the rationing of care.

Mandating assessments for caregivers' needs

Standardized assessment tools could be mandated for care services. These tools could be used to assess caregivers' needs and eligibility for all available services. The results of the assessment could be used to develop a family-centred support and care plan. For example, researchers found they could easily identify caregivers who would benefit from more support after screening their interRAI-based self-reported survey using a Caregiver Wellbeing Index.[279] Using this approach, eligibility criteria and assessment screening tools could be consistent throughout each province and territory and could be transparent and accessible for all publicly-funded services, training and financial supports.[280] In another example, the Carer Support Needs Assessment Tool (CSNAT), co-developed by Dr. Gail Ewing and Dr. Gunn Grande in the United Kingdom, indicates where caregivers need more support to care for their family member or friend and care for themselves.[281] The CSNAT is short, easy to use and involves a five-stage approach from introduction to shared action plan and review.[282]

Some jurisdictions have already taken steps to require caregiving assessments. For example, the United Kingdom's *Care Act* gives caregivers the right to have their own needs assessed and met.[283] However, for caregiving assessments to be effective, focus group participants emphasized that they need to be tied to concrete obligations to act and to properly funded services and supports that address the identified needs.

Providing training and support to meet the unique needs of caregivers

Caregivers consistently find themselves in circumstances where they would benefit from coaching and training. As the needs of a care recipient change, so do the training needs of caregivers. Training and support for caregivers should therefore be available and adaptable to their current situation. Caregivers should be directed toward training and resources that already exist, such as McMaster University's Continuing Education online courses on caregiving essentials.[284] In addition, institutions should invest in more training courses designed for common challenges caregivers face. Beyond training, caregivers should have guaranteed access to personalized coaching from health-care professionals to be able to meet the unique needs of the care recipient.

It can be difficult for health-care providers to identify, engage and support caregivers, but this can be better accomplished with a person-centred and trauma-informed approach. This is especially important for caregivers in the LGBTQ2S+ community, newcomers, racialized caregivers and female caregivers. Researchers from the University of Alberta have collaborated to create training resources and a learning platform for health-care providers on caregiver-centred care.[285] Caregivers have unique circumstances and needs that can be better met through person-centred and trauma-informed care, as well as a guaranteed consistent assessment of their needs as a component of the care plan.

Enabling integrated care across services and sectors

Provincial and territorial governments could work with local health and social care authorities to provide more integrated care, which places the care recipient and their caregivers at the centre of care and organizes services according to their needs.[286] There has been some movement to adopt this approach across governments and organizations. For example, the Ontario Caregiver Organization has been leading efforts to develop greater co-ordination and collaboration across different sectors, including work to embed caregiver strategies into new models of integrated care within Ontario Health Teams.[287] However, more action is needed to enable integrated care. For example, funding arrangements could be better integrated to create shared accountability and incentivize collaboration across different service providers and health-care settings.[288]

Developing and funding public navigator roles

While working to achieve truly integrated care, provincial and territorial governments could develop more public navigator roles. While some system navigation support is offered by case managers and social workers in health and social systems, public navigators would have a primary mandate to help people identify and overcome barriers to accessing care services.[289] For example, Family Navigator is an online directory that connects Canadian Armed Forces families with resources, tools and information to support individuals who have disabilities and needs related to aging.[290] Public navigators are increasingly available across Canada, but development of these roles could be expanded to transform system navigation and care co-ordination into a public responsibility, rather than obligation downloaded onto caregivers and care recipients.[291] To be effective, these navigators should be thoroughly trained in the systems in which they operate and know how to work across silos to achieve results for the people they are supporting. Inevitably, some system navigation will require a fee for caregivers, similar to existing services that help recipients manage individualized funding allocations. Licensing or some other oversight regime would be necessary to ensure ethical conduct by trained systems navigators and prevent conflicts-of-interest between navigators and service organizations. This role could also be an opportunity to engage experienced caregivers to support their peers in navigating complex systems.

Develop strategies for supporting employed caregivers

Many caregivers struggle to balance caregiving and paid employment, often leaving the workforce entirely. Exiting the workforce prematurely, often at a time when caregivers are in their peak earning years, risks their financial stability. Workers lose income and pension credits and the workforce loses experienced, skilled and knowledgeable employees, which impedes economic growth.[292] Supporting more caregivers to remain in the workforce would benefit the economy and Canada as a whole by fostering intergenerational knowledge exchange among workers and maximizing economic productivity.[293]

Caregivers need flexibility and support to maintain full employment and personal well-being while providing care. Public and private sectors alike have roles to play in creating workplace strategies and policies to foster caregiver-friendly workplaces.[294] Full employment for most caregivers is feasible if caregiving duties are not overwhelming and if they are provided with support in the workplace.[295]

Potential policy options to support caregivers in the workforce include:

Expanding federal, provincial and territorial leaves and benefits

While existing leaves and benefits are stronger in Canada than some other countries, federal, provincial and territorial governments can make the lives of employed caregivers easier by expanding leave and benefit options. Most caregivers need to take more than five to 10 days away from the workplace to fulfill caregiving responsibilities. In some cases, these responsibilities are permanent, and they often do not qualify for protected leaves as they are not related to critical illness or end-of-life care.

The federal government could reduce administrative barriers to accessing benefits — such as physicians' certificates — and expand eligibility criteria to include a broad range of caregiving responsibilities.[296] These benefits, or a similar solution, should also be made available to caregivers who are self-employed, casual, or part-time employees, as they are often left out of job-protected leaves and benefits paid through the EI system. These caregivers face the same realities as full-time employees but do not have access to the same financial benefits.[297]

Flexible work legislation and promotion

Some countries have moved toward guaranteeing the right to flexible work arrangements to help caregivers maintain their employment. Flexible work legislation can reduce stress, decrease stigma and discrimination and prevent premature workforce exit among employed caregivers.[298] Belgium, France, Germany and the Netherlands offer all employees the right to flexible work arrangements through legislation.[299]

Non-profit and government-sponsored organizations can act as partners to promote caregiver-inclusive and supportive workplaces. [300] Employers for Carers in the United Kingdom is a non-profit that helps member employers support and retain their employees.[301] In Australia, Carers + Employers is a project that incentivizes employers to meet a set of supportive Carers + Employers Standards. [302]

Caregiver-friendly workplace policies

Individual employers can support caregivers through caregiver-friendly workplace policies (CFWPs), which are organizational changes that support caregivers in the workforce.[303] CFWPs help employers retain their employees, reduce turnover and improve workplace culture. Common components of CFWPs include: paid leave top-ups; employee benefits such as support groups, counselling and workshops; subsidized emergency workplace care; extended leave policies for caregivers; and flexible work arrangements.[304]

The Canadian Standards Association (CSA) partnered with McMaster University — and specifically with Dr. Allison Williams — to create *B701-17: Carer-inclusive and accommodating organizations standard* and an associated handbook, *B701HB: Helping worker-carers in your organization*,[305] which are available in English and French and can be used by organizations to support their caregivers. A wide range of user-friendly associated tools have been created and are available for free download.[306] Forced workplace flexibility that came about because of the COVID-19 pandemic have been helpful for many employed caregivers, who have benefited from greater flexibility in their schedule and work location.[307] [308]

While employers are increasingly paying attention to gender equality and equity, diversity and inclusion issues, there is a push to consider caregivers as a distinct group when developing workplace policies to ensure they are protected from discrimination.[309] Caregivers should feel confident identifying themselves as a caregiver to their employer without concerns that self-identification will impede their chances of employment or progression within the organization. Further, limiting CFWPs to care provided to biological family instead of chosen family may exclude LGBTQ2S+ people from receiving accommodations. CFWPs should apply to any caregiver in the workforce providing care to someone close to them.[310] Finally, CFWPs should accommodate the unique needs of trans-national, double-duty and immigrant caregivers.

Government leadership

Canadian governments can set an example as leading employers and build awareness of the importance and benefits of supporting caregivers at work.[311] For example, the federal government employs hundreds of thousands of people and should adopt best practices, including the CSA Carer-Inclusive Standard and CFWPs. It could promote these practices and raise awareness and uptake of the Compassionate Care Benefit.[312] Further, governments should consider engaging and incentivizing workplaces to provide CFWPs for their employees and study how to support caregivers in sectors where they do not have access to workplace accommodations and flexibility. Caregivers without workplace policies and accommodations are more likely to be lower-income earners and therefore disproportionately impacted by the conflicting responsibilities of care work and paid work.

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Develop financial supports that reflect the value of caregiving

The financial toll that caregiving takes on friends and family is clear. In a recent survey of Canadian caregivers, more than two-thirds of respondents reported financial assistance as one of their most desired supports.[313] It is also clear that, without caregivers, our social and health-care systems would face immediate costs and consequences. We need caregivers to continue providing care to their friends and family, but they should never be forced into financial insecurity as a result.

Governments need to recognize the immense economic value of the work provided by caregivers and care providers, guarantee their financial security and help them maintain their physical, mental and financial well-being. Assessing both federal and provincial and territorial financial supports for their efficacy and accessibility would help to identify areas for improvement and areas where support is lacking entirely. From there, financial support policies could be adapted by all jurisdictions and orders of government. Revised financial support policies for caregivers should be comprehensive and consider both direct and indirect sources of financial support.

Potential policy changes to improve financial supports for caregivers include:

Making tax credits and benefits more inclusive

The current financial support model for caregivers uses the tax system to encourage working while caregiving. But available federal, provincial and territorial tax credits and benefits for caregivers could be far more inclusive. Governments should make changes to available tax credits and benefits to make them easier to access with broader eligibility criteria.

At a minimum, Canada's caregiver benefits should be made available to caregivers who are self-employed, casual or part-time employees.[314] [315] The requirement for a physician's certificate indicating that the person receiving care is at the end of their life could be removed from the criteria, or eligibility for the benefits could be expanded beyond leaves taken to provide care for someone who is near the end of their life, critically ill or injured. Further, tax credits could be made refundable to benefit all taxpaying caregivers, instead of only those with incomes high enough to benefit from non-refundable credits. Caregivers may also benefit from being able to split their income with spouses to make one or both eligible for tax credits.

Supporting caregivers directly through caregiver allowances or income

Outside of the tax system, supporting caregivers directly through allowances or income is another option for ensuring their financial security. Nova Scotia provides direct compensation to caregivers through grants and allowances. The federal government and the other provincial and territorial governments should consider introducing similar income supports for caregivers. This would help to ensure that caregivers have a basic income and demonstrate the value of caregiving to society. It also has the benefit of supporting caregivers who do not have taxable income and therefore do not benefit from non-refundable tax credits.

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Direct compensation programs are a component of caregiving policy in various other jurisdictions, including Australia, the United Kingdom, France, Germany, the Netherlands, Sweden and Norway.[316] For example, the Care Allowance in Germany is offered to caregivers through tong-term care insurance that is paid directly to the care recipient, who can then transfer the payment to their family caregiver.[317] The amount is dependent upon the care recipient's needs and is not considered to be taxable income, meaning caregivers can add the amount to their net income each year.[318] Sweden's Carer Allowance is compensation for family caregivers in households where the family member does the care work. This amount is the same level of compensation that would be given to a person paid to deliver home help.[319] This allowance is in addition to the home care allowance that is available in situations where the care work needs at home are significant.[320]

Carer’s allowances in the United Kingdom and Australia

The United Kingdom and Australia are two jurisdictions among several that use carer’s allowances to recognize the value of caregivers’ work and encourage caregivers to remain in the workforce.

The UK Carer’s Allowance provides £68 ($103) per week to people who spend at least 35 hours a week caring for individuals with a disability.[321] The benefit is directed toward people who are full-time carers and who are unable to obtain a sufficient income as a result.[322] In Scotland, carers now receive an extra lump sum payment twice a year.[323]

Australia’s caregiver policy payment program provides low-income carers with the Carer Payment, a bi-weekly benefit to full-time caregivers who cannot work due to their caregiving responsibilities.[324] Higher-income carers can access the Australian Carer Allowance, which targets caregivers providing up to 20 hours per week of care.[325] The Carer Allowance is income-tested and provided to carers earning less than 250,000 AUD ($222 400) per year. It amounts to A$ 136.50 ($120) every two weeks.[326]

Increasing financial supports for people with disabilities

Caregivers are indirectly influenced by inadequate financial support for care recipients. Focus group participants shared that caregivers often fill in gaps financially or by providing their own care when people with disabilities receive less than they need to cover their basic costs. Moreover, insufficient supports for people with disabilities forces them and their families to stretch their budgets to afford professional care.[327] In turn, paid care providers often provide more care than they are paid for to give the recipient the care they need. Inadequate financial support for people with disabilities has negative consequences for the people receiving care, their caregivers and their paid care providers.[328]

The Government of Canada recently introduced Bill C-22, the *Canada Disability Benefit Act*, which passed first reading on June 2, 2022.[329] The proposed *Act* aims to reduce poverty among working-age Canadians with disabilities — who are twice as likely to live in poverty — through the Canada Disability Benefit.[330] If passed, this new legislation and financial benefit would be an important step toward ensuring that Canadians with disabilities and the people who care for them enjoy a better quality of life. The Government of Canada should prioritize passage of this bill and implementation of the new benefit.

Similarly, provincial and territorial governments could look to increase the amount of support provided and ensure that it increases steadily with inflation. The Government of Ontario's recent increase in ODSP payments by five per cent is welcome, but is only a fraction of what is necessary to ensure people with disabilities live above the poverty line.[331]

Australia's National Disability Insurance Scheme

Australia's National Disability Insurance Scheme (NDIS) was established under the **National Disability Insurance Scheme Act 2013** (NDIS Act). The NDIS is publicly funded by the Australian government and participating state and territory governments and is not means tested. The program funds costs for support related to a person's disability, but there are limitations to what is provided. The funding goes directly to the person with a disability and they or their caregiver then chooses which providers will supply their goods and services.[332]

The program does not pay basic living expenses aside from those directly related to a disability, so there is no set amount of money provided to each individual.[333] Instead, each person receives an individual plan based on their needs.[334] The NDIS helps to connect people with information and services in their communities. The objectives of the NDIS are to support independence and economic participation, provide supports, enable people to exercise their choice and promote the provision of high-quality supports.[335]

Develop the workforce and improve conditions for care providers

Reform is necessary to support and develop the care provider workforce and close critical labour gaps. This means improving work conditions for care providers and making the profession a viable and respected career over the long term. Professionalization would help strengthen the care providing professions through improved structures and career pathways. It also means taking action to attract and develop a pipeline of strong talent to work in the caregiving field.

Potential options to develop the workforce and improve conditions include:

Increasing compensation and funding for care providers

Provinces and territories could work with all staffing, developmental services, home and community care agencies and relevant unions to increase compensation for care providers, including increasing wages, expanding the number of full-time positions available and encouraging the provision of workplace benefits such as drugs and dental care. Some provinces, such as Ontario, have already implemented wage enhancements for DSPs and PSWs in the wake of COVID-19.[336] These increases need to be sustained, increased and adopted across Canada. In the case of wages, provinces and territories may also need to co-ordinate with the federal government, as the ability of agencies and other providers to enhance wages for workers is tied to funding levels and structures.[337]

Supporting the professionalization of care providers

While care provider roles are important and generally understood, this field of work in Canada has yet to be professionalized. Professionalization could provide an avenue to establish certification, set standards for care provision, regulate fair wages, advocate for better working conditions and provide ongoing professional development requirements and resources.[338]

Professionalization is often accomplished through a professional association. This is one way to increase the status of care providers and address some of the other challenges facing the workforce.

Professional associations for care provider roles already exist in other jurisdictions and in some provinces. Ontario, for example, is working toward the development of an Ontario Association for Developmental Services Professionals.[339]

Professional associations and agencies for support professionals

In the United States, **the National Alliance for Direct Support Professionals (NADSP)** provides supports for DSPs. The NADSP supports DSPs by: providing ongoing educational opportunities; certifying workers to incentivize greater compensation; offering continuing education and access to career advancement; ensuring values and ethics can be learned and implemented in front-line work; and enhancing partnerships between DSPs and the caregiving community to strengthen the quality of care.

The **Alliance of Direct Support Professionals of Manitoba** gives DSPs a unified voice. It seeks to: raise awareness of the work DSPs do in Manitoba; promote accountability among the public, government, agencies and DSPs; develop and promote professional standards; and advocate on behalf of DSPs.[340]

In the United Kingdom, the **National Association of Care & Support Workers** (NACAS) helps care and support workers develop their careers through knowledge, skills development and sharing of best practices.[341] NACAS was formed to help professionalize the workforce, bolster its reputation and help care and support workers feel respected.[342] One key feature of NACAS membership is its training options and professional development for care and support workers, such as DSPs and PSWs.[343]

Supporting immigration to fill workforce gaps

Increasing immigration and developing specialized immigration classes for care providers could help fill care provider workforce gaps. Canada is already increasing immigration in the wake of a shortfall caused by COVID-19. The federal 2022-2024 Immigration Levels Plan charts a path toward an immigration rate of one per cent of Canada's population to help fill critical labour market gaps and support our economy.[344] Building on this momentum, the federal government could work with provincial and territorial governments to leverage their existing plans to address workforce challenges through immigration with a co-ordinated strategy to increase the supply of qualified care providers across the country. These plans should include pathways to permanent residency and protections from exploitative working conditions.

Care provider workforce development and staffing strategies in Canada

Some work has been done in Canada to cultivate targeted workforce development strategies to address labour supply issues and the challenges facing care providers. The University Health Network, in partnership with the Future Skills Centre and other partners, is developing resources to support PSWs into the future and to level out inequities they face compared to other health professions.[345] In Ontario's Long-Term Care Staffing Plan, the province plans to: increase staffing levels; recruit, retain, train and support more staff; support ongoing development; improve working conditions; provide more leadership; and measure success.[346]

Other workforce development strategies have focused on the developmental services sector. For example:

The Alberta Persons with Developmental Disabilities program partnered with the Alberta Council of Disability Services in 2004 to launch Workforce 2010, a three-year initiative to investigate the human resources challenges facing Alberta's community disability services sector.[347] Insights from this initiative were used to inform the development of a Human Resource Strategy for Community Disability Services, launched in 2006.[348] The Strategy included nine focus areas: branding and marketing; communicating with non-profit community boards; tracking labour market and human resource measures; promoting the sector as an employer of choice; professionalizing the sector; communicating with employees; creating a qualified workforce; developing leadership; and integrating human resources with accreditation standards. This work has continued in the wake of COVID-19, with a view toward building a skilled and sustainable disability services system.[349]

The Ontario Ministry of Children, Community and Social Services partnered with developmental services agencies in 2008 to launch the Developmental Services Human Resource Strategy (DSHR Strategy). The 10-year DSHR Strategy aimed to support workforce development and enhance human resources in the sector by targeting four key objectives: increasing the pool of professionals; ensuring consistency and congruency in education, workplace learning and professional development; creating opportunity and clarity for career progression; and encouraging competency-based management and leadership.[350] To date, this work has produced a variety of resources to help human resource professionals improve hiring and retention of staff and deliver more effective on-the-job training. A new apprenticeship program has also helped strengthen the talent pipeline between colleges and agencies seeking front-line workers.

Conclusion

> “Indeed, supporting both dementia patients and their caregivers isn’t just a political obligation; it’s a moral imperative. Or to put it differently: A society can be judged, not merely by how it treats its most vulnerable members, but by how it treats those who care for them.”[351]
>
> **~ Toronto Star Editorial**

Conclusion

Canada's patchwork of caregiving supports is failing Canadians. The existing makeshift system of caregiving policies across the country takes the essential work of caregivers and care providers for granted and offers far less support and protection than they need to be able to provide care for others and care for themselves.

Without an immediate public policy response, caregivers and care providers will not be able to provide what Canada demands of them. If this happens, Canada's health-care system will not be able to sustain itself and our economy will run far below our potential. Caregivers and care providers can no longer be an invisible support upon which so many people, and so much of the economy, rely on every day. Caregivers and care providers need to see themselves considered, understood and provided for in public policy, health-care provision and programs across the country.

This change is possible, and it can start with good ideas for how to improve services for people who receive care, develop and value the care provider workforce and provide financial assistance, workplace support and targeted services for caregivers. Caregivers, care providers and care recipients deserve better. With a co-ordinated response from all orders of government, **Canada can become the best place in the world to give and receive care.**

This report is a continuation of the clarion call that caregivers, care providers and organizations have been sounding for decades. It is an attempt to push public policy forward, bringing Canada's caregiving policy needs to the top of provincial, territorial and federal government agendas. Caregivers and care providers have been doing heroic work unsupported for far too long. This can be a hopeful moment defined by collaboration and action toward a better caregiving landscape across the country.

Caregiving is the next frontier of public policy in Canada. CCCE envisions Canada leading the way in quality care, where caregiving is valued, care recipients, caregivers and care providers are central to policy planning and there is a real, working system that supports caregiving.

Annex: Income supports, benefits, tax credits and deductions across Canada

Legend:

R – Refundable

NR – Non-Refundable

Province/ Territory	Benefits, tax credits and deductions [352] [353]	Benefits and leaves [354] [355] [356]	Programs and services [357] [358]
All	▪ Canada Caregiver Credit – NR, $2295-$7348 ▪ Medical expenses ▪ Disability amount – NR, $8662 - $13715	▪ Compassionate Care Benefit and Leave ▪ Family Caregiver Benefit	
British Columbia	▪ Caregiver amount – NR, $4844 ▪ Disability amount – NR, $8303 ▪ Medical expenses ▪ Home renovation – R, up to $10 000	▪ Compassionate Care Leave (27 weeks) ▪ Family Responsibility Leave (five days)	Respite: ▪ In-home ▪ Short-term facility ▪ Day programs (seniors and adults with disabilities)
Alberta	▪ Caregiver amount – NR, $11212 ▪ Disability amount – NR, $14940 ▪ Medical expenses	▪ Compassionate Care Leave (27 weeks) ▪ Critical Illness Leave (16 weeks) ▪ Personal and Family Responsibility Leave (five days)	Respite: ▪ In-home ▪ Short-term facility (seniors) ▪ Day programs (seniors)
Saskatchewan	▪ Caregiver amount – NR, $9559 ▪ Disability amount – NR, $9559 ▪ Medical expenses	▪ Compassionate Care Leave (28 weeks)	Respite: ▪ In-home ▪ Short-term facility (seniors) ▪ Day programs (seniors)

Manitoba	▪ Primary Caregiver credit – R, $1400 ▪ Caregiver amount – NR, $3605 ▪ Disability amount – NR, $6180 ▪ Medical expenses	▪ Compassionate Care Leave (28 weeks) ▪ Family Leave (three days)	Respite: ▪ In-home ▪ Short-term facility (seniors and adults with disabilities) ▪ Day programs (seniors and adults with disabilities)
Ontario	▪ Caregiver amount – NR, $5252 ▪ Disability amount – NR, $8790 ▪ Medical expenses ▪ Seniors' home safety – R, up to $10 000	▪ Family Medical Leave (28 weeks) ▪ Family Caregiver Leave (eight weeks)	Respite: ▪ In-home ▪ Short-term facility (seniors) ▪ Day programs (seniors and people with a brain injury)
Québec	▪ Credit for caregivers - R, $925-$1154 ▪ Amount for other dependents - NR ▪ Disability amount – NR, $3492 ▪ Credit for respite of caregivers – R, $1266-$5200 ▪ Medical expenses	▪ Family or parental obligations (16, 27 or 36 weeks) ▪ Non-work-related accident or illness (26 weeks)	Respite: ▪ In-home ▪ Short-term facility ▪ Day programs Other: ▪ Financial Assistance Program for Domestic Help Services
New Brunswick	▪ Caregiver amount – NR, $4989 ▪ Caregiver benefit ($106.25/month) ▪ Disability amount – NR, $8552 ▪ Medical expenses ▪ Seniors' home renovation – R, $10000	▪ Compassionate Care Leave (28 weeks) ▪ Critically Ill Adult Leave (16 weeks) ▪ Family Responsibility Leave (three days)	Respite: ▪ In-home ▪ Day programs (seniors and adults with disabilities) ▪ Short-term facility (seniors)

Nova Scotia	▪ Caregiver amount - NR, $4898 ▪ Caregiver benefit ($400/month) ▪ Disability amount – NR, $7341 ▪ Medical expenses	▪ Compassionate Care Leave (28 weeks) ▪ Critically Ill Adult Care Leave (16 weeks)	Respite: ▪ In-home (seniors and children with disabilities) ▪ Short-term facility (seniors) ▪ Short-term out-of-home (children with disabilities) ▪ Day programs (adults with disabilities)
Prince Edward Island	▪ Caregiver amount – NR, $2446 ▪ Disability amount – NR, $6890 ▪ Medical expenses	▪ Compassionate Care Leave (28 weeks) ▪ Family Leave (three days)	Respite: ▪ In-home ▪ Short-term facility (seniors) ▪ Day programs (volunteer programs for seniors)
Newfoundland and Labrador	▪ Caregiver amount – NR, $3028 ▪ Disability amount – NR, $6435 ▪ Medical expenses	▪ Compassionate Care Leave (28) ▪ Critical Illness Leave (17 weeks)	Respite: ▪ In-home ▪ Short-term facility (seniors) ▪ Day programs
Yukon	▪ Caregiver amount – NR, $2295 ▪ Medical expenses	▪ Compassionate Care Leave (28 weeks) ▪ Critical Illness and Adult Leave (17 weeks)	Respite: ▪ In-home ▪ Short-term facility ▪ Day programs
Northwest Territories	▪ Caregiver amount – NR, $5052 ▪ Disability amount – NR, $12362 ▪ Medical expenses	▪ Compassionate Care Leave (eight weeks)	Respite: ▪ In-home ▪ Short-term facility ▪ Day programs (seniors)

Nunavut	- Caregiver amount - NR, $5052 - Disability amount – NR, $14016 - Medical expenses	- Compassionate Care Leave (eight weeks)	- Respite: - In-home (no formal service, some homemakers available) - Short-term facility (limited, seniors and children and adults with disabilities) - Day programs (adults with disabilities)

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Notes

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