National
Caregiving
Strategy

A National Caregiving Strategy for Canada

Canadian Centre for
Caregiving Excellence

Canadian Centre for Caregiving Excellence

The Canadian Centre for Caregiving Excellence is an initiative powered by the Azrieli Foundation. The Foundation has long supported innovative initiatives to improve access to quality care. The Canadian Centre for Caregiving Excellence supports and empowers family caregivers and care providers, advances the knowledge and capacity of the caregiving field and advocates for effective and visionary social policy with a disability-informed approach.

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Land Acknowledgement

The office of the Canadian Centre for Caregiving Excellence (CCCE) is located in Toronto 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

This document would not have been possible without the support and guidance of thousands of experts, allies, caregivers and care providers. Thank you to every person who took the time to provide their input and share their stories as a part of CCCE's consultation process. Thank you to our partner organizations who hosted online webinars to share this process with their stakeholders and audiences. The National Care Champions Table played a key role in shaping the recommendations in this document. Thank you for your time and expertise as we crafted this strategy together.

This report was prepared by Adrienne Lipsey, Jasmine Lee, and other members of the Springboard Policy team. It was copy-edited by Patricia Karounos, designed by Bex McKnight at McKnight Inclusive Design and translated by Julie Bourbeau.

Terminology

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 parent, 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), disability support workers (DSWs), personal support workers (PSWs), attendants for people with disabilities, home health aides 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.

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Executive summary

The case for a National Caregiving Strategy

Canada is facing a caregiving crisis at a massive scale.

Caregivers and care providers are not sufficiently supported, and they are struggling. Our population is aging, with every year bringing more people needing care, and fewer people available to provide that care. People, including those with disabilities, are living longer and have more complex care needs, but caregivers and care providers are already stretched to a breaking point. The status quo is unsustainable and will only get worse without policy reform.

Caregivers are everywhere, and without them, Canada's health and social systems would collapse.

Caregivers are the people caring for aging parents, children with disabilities, sick friends and neighbours. One in four Canadians are currently caregivers and at least half will be a caregiver at some point in their lives. Caregivers hold healthcare systems together, making sure medical directives are followed, appointments are kept and that care recipients have their needs met.

Caregiving is meaningful to caregivers and their loved ones, and invaluable to the Canadian economy.

Caregivers often act out of love. Care relationships can bring families closer and lead to profound moments of connection. Caregiving is also crucial to the Canadian economy: replacing care from unpaid caregivers would cost the federal government an estimated $97.1 billion annually.

Caregivers cannot continue this vital work without help.

In CCCE's *Caring in Canada* report, 56% of caregivers providing more than five hours of care per week experienced financial stress. In the same report, half of caregivers found accessing supports difficult and 58% of caregivers reported feeling tired because of caregiving.[2]

Care recipients need better financial supports to thrive and live with dignity.

In 2023, 37% of caregivers experienced financial hardship due to their care duties and half of caregivers experienced at least one financial stressor from caregiving in the past year. These supports also make caregiving possible for caregivers. Otherwise, caregivers are left trying to fill every gap—an impossible task for most.

Canada needs more paid care providers, and they need to be treated with the respect they deserve.

Canada's care systems rely on paid care providers. These are rewarding but difficult jobs with high rates of burnout, and not enough people entering or staying in the profession. CCCE's *Caring in Canada* report showed that 80% of care providers considered leaving the field in the 12 months prior to the survey. Paid care providers need protection from abuse, adequate pay and better working conditions to carry on.

Caregivers, care providers and care recipients all need bold leadership and immediate action.

Canada needs a strategy, and the federal government must take the lead on key issues to ensure that caregivers and care providers across Canada can thrive.

Recommendations for a National Caregiving Strategy

The federal government committed to developing a National Caregiving Strategy in Budget 2024. Working in partnership with caregivers, care providers, experts and leaders, CCCE created this strategy with five key areas of action:

Improving supports, programs and services for caregivers	So they can maintain their own well-being while fulfilling caregiving responsibilities.
Supporting caregivers in the workforce and education	So they can better manage the responsibilities of providing care and their work.
Supporting care recipients	So their care needs do not subject them to a lower quality of life.
Building a sustainable care provider workforce	By valuing care providers with higher wages, better training and clear pathways to permanent residency for migrant carers.
Showing leadership and recognition	So Canadians know caregiving is a priority, and provinces, territories, businesses, and others can follow in the federal government's footsteps.

PILLAR ONE

Supports, programs and services for caregivers

Caregiving takes a significant toll on caregivers' physical, mental and financial well-being: caregivers in Canada are past their breaking points, just as care needs are increasing across the country.

SOLUTIONS

Provide caregivers with financial support when and how they need it

- Make the Canada Caregiver Credit refundable
- Introduce a caregiver allowance
- Introduce public care insurance

Improve caregivers' well-being through targeted programs and services

- Fund tailored programs supporting caregivers' mental health and well-being
- Fund respite and home care services for caregivers

PILLAR TWO

Supports for caregivers in work and education

Many caregivers hold jobs in addition to their care responsibilities, and, too often, their employment conditions make it impossible to do both well. Some caregiving responsibilities take people away from paid work, either in the short term or permanently, but this comes at a great cost to their financial well-being. Balancing providing care and education is also a challenge for caregivers who are in school: they miss out on opportunities for their own growth when they are not supported in their caregiving duties.

SOLUTIONS

Make leaves and benefits work for working caregivers

- Make caregiver leaves and benefits more suitable and accessible

Provide caregivers in work and school with greater financial security

- Introduce Canada Pension Plan (CPP) provisions for caregivers with years of low earnings due to caregiving responsibilities
- Make the federal component of student loans more flexible to meet the needs of caregivers

Give caregivers the flexibility to stay in the workforce as they provide care

- Become a leading employer by implementing caregiver-friendly workplace policies
- Give federally regulated employees paid care days
- Introduce incentives for caregiver-friendly workplace policies

PILLAR THREE

Financial supports for care recipients

Care recipients with disabilities are too often pushed to poverty by the high costs of having a disability and the lack of support. When care recipients lack financial support and services, caregivers often try to fill the gaps. This is unsustainable in the long term.

SOLUTIONS

Reduce administrative barriers for care recipients and their families

- Expand Disability Tax Credit eligibility and make it more accessible
- Make improvements to the Registered Disability Savings Plan

Increase the scale of other financial supports for care recipients

- Implement and amend the Canada Disability Benefit
- Make improvements to the Medical Expense Tax Credit

PILLAR FOUR

Build a sustainable care provider workforce

Care providers are essential to the lives of many care recipients; they are mission-critical members of Canada's health and social service workforce. Despite their importance, care providers are significantly undervalued. Poor working conditions and low pay drive many care providers to leave the profession. There are not enough pathways to support newcomers to Canada in doing this meaningful work.

SOLUTIONS

Value paid care providers

- Pay care providers a living wage

Protect and encourage migrant care providers

- Enhance protections for migrant care workers
- Improve pathways to permanent residency for migrant care workers

PILLAR FIVE

Leadership and recognition

Canada lacks a coordinated approach to supporting caregivers, care providers and care recipients across the country. This is a policy issue that cuts across portfolios, but the problems it poses cannot be solved by working in silos. A true coordinated strategy, with built-in advice from caregivers, is necessary to make a difference. The federal government also has an integral role in shaping healthcare across Canada and supporting military families.

SOLUTIONS

Make caregiving a government priority

- Develop caregiver legislation that establishes the National Caregiving Strategy and creates an Advisory Council

Show federal leadership in healthcare

- Prioritize caregiving in healthcare conversations with provinces and territories
- Direct key national research bodies to collaborate on a full research agenda on caregiving

Ensure veterans and military families get the support they deserve

- Ensure interoperability between Canadian Forces Health Services and civilian systems
- Ensure interprovincial mobility of services such as automatic eligibility for autism services
- Assign a case manager to families with complex needs with relocating to new communities
- Expand eligibility of Veterans Affairs Canada Caregiver Recognition Benefit to more families

About this document

In Budget 2024, the federal government made a commitment to develop a National Caregiving Strategy. This document is a compilation of specific, practical and tangible ideas that must be included in the National Caregiving Strategy. It contains actionable recommendations for the federal government to take to better support caregivers, care recipients and care providers across Canada.

This document was developed from the ideas and guidance of the caregiving community. As the federal government develops a National Caregiving Strategy, it is crucial that the experiences of caregivers, care providers and care recipients are incorporated at the centre of the policies and programs that come out of the Strategy.

This document builds on CCCE's previous work. This work includes a policy whitepaper, G*iving care: An approach to a better caregiving landscape in Canada*, which highlights policy gaps and potential solutions for the caregiving landscape across the country, and a national caregiving survey, *Caring in Canada: Survey insights from caregivers and care providers across Canada*, which gathered input from more than 3,000 caregivers and care providers across the country.

Values and principles guiding this strategy

Throughout 2024, CCCE engaged in a broad-based consultation process focused on specific policy suggestions that can be introduced to improve the lives of caregivers, care providers and recipients of care. This conversation and the work presented in these pages have been guided by values and principles that underpin all of our work on the National Caregiving Strategy:

Co-design

CCCE worked with caregivers, care providers, researchers, leaders and service providers to develop and test every one of the ideas included in this Strategy. The voices of lived and living experience have been at the centre of every step of our work.

Practicality

Our goal from the beginning has been to develop a coherent list of ideas that could be taken up by the federal government. As such, we have ensured that the contents of the strategy are practical, tangible and ready for action.

Focus on the federal government

Only the federal government has the jurisdiction to impact all caregivers and care providers with practical policy reform. Moreover, history has shown that federal government reform today brings provincial and territorial reform tomorrow.

Urgency

We are living the beginning of a care crisis in Canada. This crisis will only get worse without urgent action from the federal government to support caregivers and care providers to do their work. It is therefore important to get these good ideas out into the public domain today rather than continue to engage in further conversation to develop more ideas.

Broad application

While every care situation is unique, the broad basket of necessary reforms and supports that caregivers and care providers need are similar regardless of how one becomes a caregiver or care provider. The ideas contained in this Strategy are meant to help as many caregivers and care providers as possible. Broad application is the first step to making Canada the best place in the world to give and receive care.

Just the beginning

While comprehensive, this Strategy remains incomplete. No one policy document can cover the entire panoply of reforms that are needed to build the caregiving future we all deserve. The work will continue well after the publication of this document. The next step is to better address the unique needs of particular populations, starting with Indigenous, Metis and Inuit caregiving.

Inclusion

The lives of people with disabilities (intellectual, physical, etc.) should unfold as fully as those without disabilities. This includes immersion together with peers without a disability in the same pathways and experiences of life common to everyone. Caregivers and care providers have a critical role to play in making this possible.

Quality of life

At its heart, this Strategy prioritizes quality of life for care recipients, caregivers and care providers.

Note on federal and provincial domains in Canada

Readers of this document will note that the policy recommendations included in the National Caregiving Strategy are almost exclusively targeted at the federal government.

Government in Canada is divided into three orders of government: federal, provincial/territorial and municipal. Our system of parliamentary federalism denotes some policy domains exclusively under the jurisdiction of the federal government and others for provincial and territorial governments. While some policy areas are a shared responsibility, many are the exclusive domain of one order of government or another.

The National Caregiving Strategy is intentionally focused on actions only the federal government can take to make Canada the best place in the world to give and receive care. This is not meant to suggest that the 13 provinces and territories across Canada do not need to undertake substantive and urgent reforms. Rather, this federal approach is meant to begin a Canada-wide conversation and achieve broad reform from the one government that touches all Canadians.

Further work from CCCE will focus on the provincial and territorial orders of government, including critically important reforms to health care, social care, respite services and home care.

How we developed these recommendations

This document reflects the invaluable advice offered by the caregiving community. The recommendations in this document were informed by many different inputs, including:

- **Consultations and collaboration** with caregivers, care providers, experts and representatives from provincial caregiving organizations and other key organizations across the country.
- **A National Care Champions Table** comprised of experts convened by CCCE. This included leaders across disability, aging and healthcare organizations, as well as caregivers and care providers.
- **A pan-Canadian co-design consultation process** to help CCCE prioritize what caregivers and care providers need the most. CCCE offered virtual consultation sessions throughout National Caregiver Month and through various national and provincial organizations.
- **CCCE published an online consultation form**, allowing thousands of caregivers and other community members to provide real-time input into this strategy.
- **CCCE's 2023 Canadian Caregiving Summit**, which united 350 stakeholders in person and 150 online from across caregiving communities, including the care workforce, to work together on solutions for a National Caregiving Strategy.
- **CCCE's previous work**, including the policy whitepaper and national survey listed above, which served as a starting point for the recommendations in this document.
- **Research including a literature review and jurisdictional scan** of best practices from other jurisdictions that can have an impact in Canada.

The need for federal action

Caregiving is everywhere.

One in four Canadians is a caregiver to a family member or a friend, and **50% of Canadians will be caregivers** at some point in their lives.[3] Caregivers provide the essential supports that allow healthcare, home and community care and social services to function.

Without caregivers, Canada's health and social systems would collapse.

Canada is facing a caregiving crisis on a massive scale.

The demand for care is growing, with people living longer and with more complex needs, including rising rates of disability and mental health issues. At the same time, there are fewer caregivers available to provide care as caregivers themselves are growing older and families are smaller on average than they used to be. Canada's strained healthcare system and the sustainability of the care economy are at a breaking point.

Caregivers and care providers are not sufficiently supported, and they are struggling.

Without adequate support, caregiving takes a significant toll on caregivers' well-being and financial security.[4] [5] Further, when caregivers suffer, care recipients suffer too. The well-being of caregivers influences the health outcomes of care recipients.

The status quo is unsustainable and needs urgent policy intervention.

Four in five care providers have considered changing careers; half of caregivers reported financial strain; and nearly half reported mental health consequences related to their caregiving responsibilities.[6]

Canada needs a caregiving strategy that will meet our needs today and in the future.

Our aging population is putting unsustainable pressure on all generations to parent, provide care and remain in the workforce. People with disabilities are finally living full lives, often with complex needs that change as they age. Mental illness and addictions have also become a part of too many lives in Canada. This is a systems-level problem that requires a systems-level set of solutions.

The federal government needs to lead.

While some of the most pressing issues caregivers face, like health and social care, are under provincial and territorial jurisdiction, the federal government holds much of the power to solve many of the day-to-day caregiving problems. This includes supporting caregivers directly, stabilizing the finances of care recipients and creating pathways for new care providers to come to Canada.

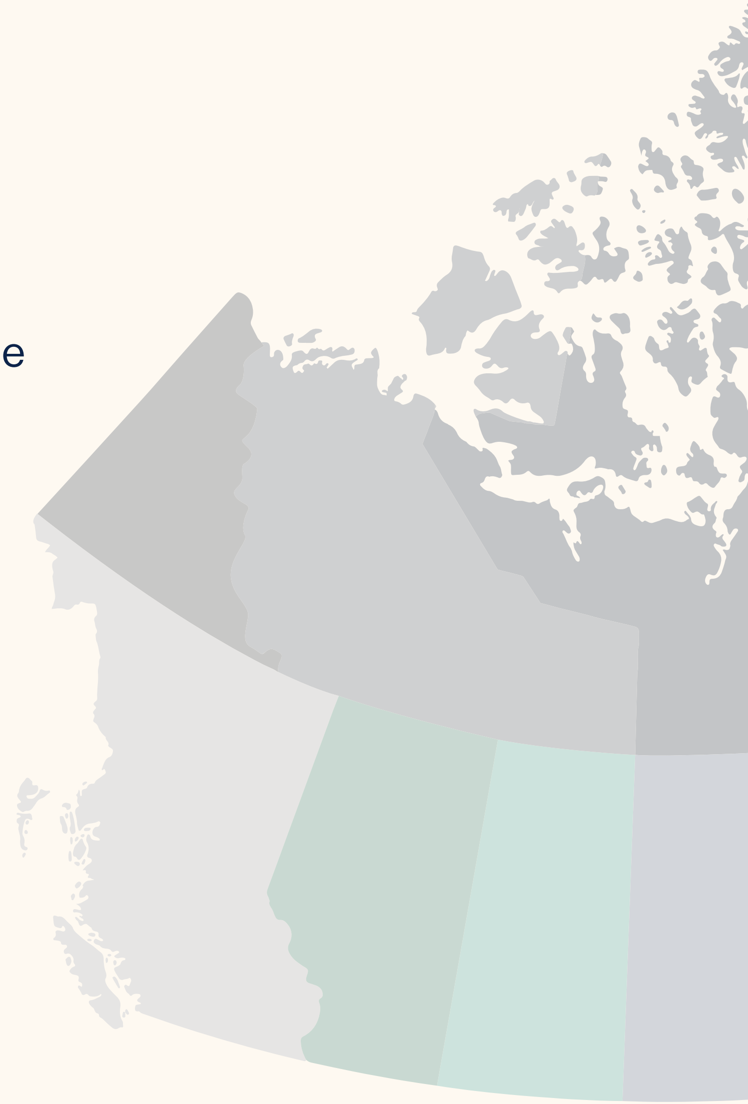
The future of care that Canada needs and deserves will not be possible without federal leadership.

Of course, there are also key roles for other orders of government, and CCCE is working with caregivers and the people they care for to articulate what those governments can do. That work is ongoing and outside the scope of this strategy document.

Snapshot of caregivers

Data from CCCE's National Caregiving Survey highlighted who caregivers and care providers are and the reality of their experiences.[7]

Profile of caregivers in Canada



1 in 4

- caregivers is racialized
- caregivers speak French at home
- caregivers have a household income <$40K

1 in 5

- caregivers lives in a rural area
- caregivers is single
- caregivers were born outside of Canada

1 in 10

- caregivers are LGBTQ2S+
- caregivers are 18 to 24 years old

Caregiving is a constant in caregivers' lives

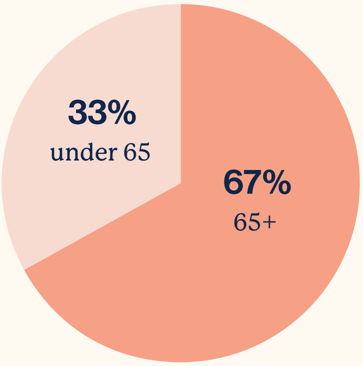
4.6 average years
of caring for main care recipient

5.1 average hours
of active care per day

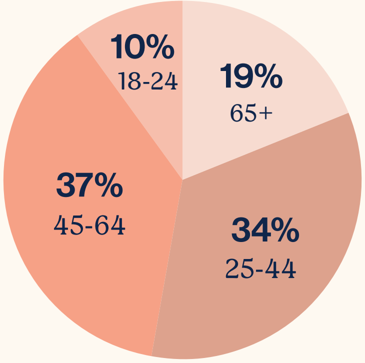
41% of caregivers
live with main care recipient

Caregivers are more likely to be women - and most likely middle-aged women - caring for their parents

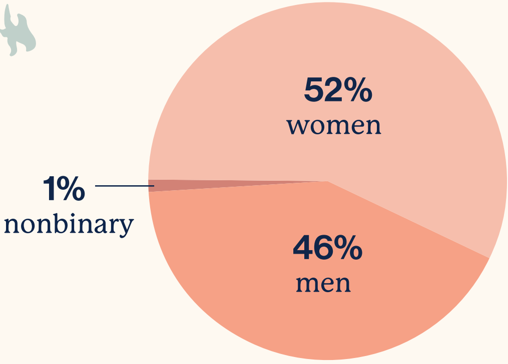
Care recipient age



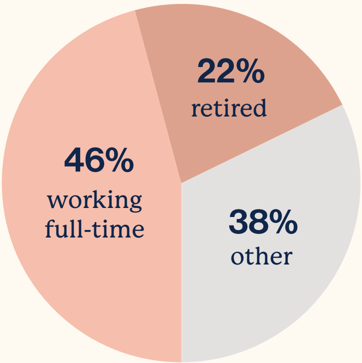
Caregiver age



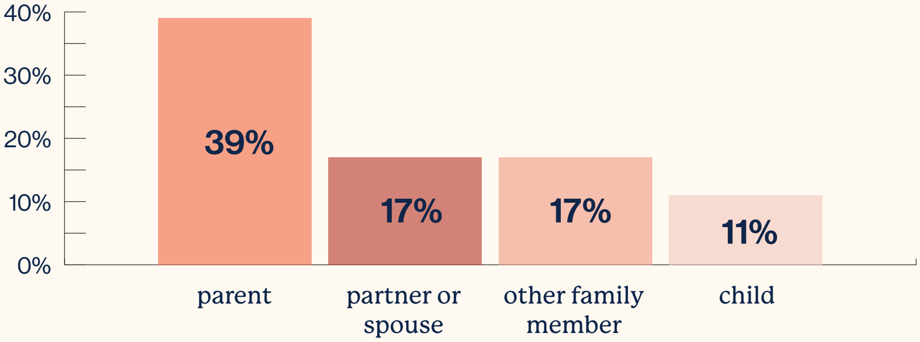
Caregiver gender



More than half of caregivers are employed. 1 in 5 are retired.



My main care recipient is my...



Caregivers have diverse identities and experiences

Sibling caregivers care for a sibling, often with a disability, starting from a young age.

Sibling caregivers are most commonly caring for siblings with disabilities (34%), and 28% of the people they care for are under 18 years old.[8]

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.

Young caregivers are more likely to be caring for a family member who is not a partner, parent, child or sibling compared to other age groups.[9]

Rural caregivers live in smaller communities outside of urban areas.

One in five caregivers in Canada live in a rural area.[10] Caregivers in rural areas are significantly more likely to have not used services like home modifications, healthcare provider assessments or transportation or respite services.[11]

Indigenous caregivers navigate complex cultural, historical and systemic factors that stem from ongoing impacts of colonization as they provide care

Three in four Indigenous caregivers stressed the importance of caregiving supports that are delivered in a culturally sensitive manner. [12]

Women caregivers make up more than half of caregivers in Canada.

Women with higher caregiving demands are 50% more likely to retire early compared to women without caregiving responsibilities.[13] Reduced working hours and years in the workforce impact women's retirement income. Women retire with 18% less retirement income than men on average.[14]

LGBTQ2S+ caregivers make up 10% of caregivers.

LGBTQ2S+ caregivers are significantly more likely than heterosexual caregivers to be caring for someone with a mental health condition.[15]

Double-duty caregivers provide care to a family member or friend and also provide care in the workplace as a care provider.

Double-duty caregivers may face the worst financial impacts. Double-duty caregivers are significantly more likely to have higher out-of-pocket caregiving expenses compared to other caregivers, with 42% spending $1,000 or more each month, despite low wages.[16]

Racialized caregivers are categorized based on perceived racial characteristics, often leading to their marginalization or unequal treatment, representing a large proportion of all caregivers in Canada.

Racialized caregivers are also significantly more likely to be caring for a family member who is not a partner, parent, child or sibling compared to non-racialized caregivers.[17]

National Caregiving Strategy at a glance

1

PILLAR ONE

Supports, programs and services for caregivers

Provide caregivers with financial supports when and how they need it

- Make Canada Caregiver Credit refundable
- Introduce caregiver allowance
- Introduce public care insurance

PILLAR TWO

Support working caregivers

Make leaves and benefits work for working caregivers

- Change Employment Insurance caregiving benefits

PILLAR THREE

Financial supports for care recipients

Reduce administrative barriers for care recipients and their families

- Expand Disability Tax Credit eligibility and make it more accessible
- Improve the Registered Disability Savings Program

PILLAR FOUR

Build a sustainable care provider workforce

Value paid care providers

- Provide care workers with a living wage

PILLAR FIVE

Federal leadership and recognition

Make caregiving a government priority

- Legislate Strategy and Advisory Council

②

Improve caregivers well-being through programs & services

- Fund & develop mental health fund
- Fund respite and home care services

Provide caregivers in work and school with financial security

- Create new Canada Pension Plan provisions to support caregivers
- Make federal component of student loans more flexible

Increase the scale of other financial supports for care recipients

- Implement and amend the Canada Disability Benefit
- Make improvements to the Medical Expense Tax Credit

Protect and encourage migrant care providers

- Enhance protections for migrant care providers
- Improve pathways to permanent residency

Show leadership in healthcare

- Prioritize caregiving in healthcare negotiations
- Direct research bodies to collaborate on caregiving research agenda

③

Give caregivers the flexibility to stay in the workforce as they provide care

- Become a leading employer by implementing caregiver-friendly workplace policies
- Give federally regulated caregivers paid care days
- Incentivize caregiver-friendly workplace policies

Ensure veteran and military families get the support they deserve

- Interoperability between Canadian Forces Health Services and civilian systems
- Ensure interprovincial mobility of autism services
- Assign a case manager when relocating
- Expand eligibility of Veterans Affairs Canada Caregiver Recognition Benefit to more families

Pillar One

Improve supports, programs and services for caregivers

Caregiving can be deeply rewarding and meaningful, but it is also deeply challenging.

Caregiving hurts the physical, mental and financial well-being of millions of Canadians. In CCCE's National Caregiving Survey, **one in four caregivers reported fair or poor mental health.** As caregivers provide more care or care for longer periods of time, the likelihood of experiencing poor mental and physical health grows. More than one in four caregivers providing more than six years of care reported poor physical health.[18] **Caregivers are tired (47%), worried or anxious (44%) or overwhelmed (37%) because of their caregiving responsibilities.[19]**

Caregiving is costly. Half of caregivers have experienced financial stress in the past year due to caregiving.[20] One in five caregivers spends at least $1,000 per month out-of-pocket on caregiving expenses.[21]

Caregiving is time consuming and can lead to burnout. CCCE's National Caregiving Survey revealed that caregivers spend **an average of 5.2 hours providing care daily. The more time a caregiver spends providing care, the more likely they are to report negative impacts on their well-being.[22]**

These pressures transform caregiving from something hard but manageable to something unsustainable and often harmful. **In order to continue providing care, caregivers need better supports from the government**. Where supports do exist, the government should ensure caregivers are aware of and genuinely benefit from them.

How to improve supports and services for caregivers

Provide caregivers with financial supports when and how they need it

- Make the Canada Caregiver Credit refundable
- Introduce caregiver allowance
- Introduce a public care insurance

Improve caregivers' well-being through programs & services

- Fund & develop mental health fund
- Fund respite and home care services

Provide caregivers with financial support when and how they need it

Caregiving can be immensely expensive, and this strain undermines caregivers' well-being and financial outlook. Many caregivers pay for care expenses out of pocket, and many also take time away from paid work. Low-income caregivers are at the highest risk of falling into poverty because of the out-of-pocket costs and responsibilities associated with caregiving.

The harms of financial strain are long-lasting. Even when care responsibilities end, lost earning years cannot be made up, leaving irreparable harm to caregivers' savings, ability to invest for the future and retirement. Women feel this impact particularly acutely.

There is a clear role for the federal government in protecting caregivers' financial well-being and retirement. In 2018, 68% of caregivers said they need financial supports and tax credits. This is a job for the federal government.[23]

The financial cost of caregiving also pushes families to make impossible choices about their loved ones. When care recipients need support for activities of daily living (ADLs), families are forced to choose between trying to provide care at home, which can mean someone leaving paid employment, or receiving care at a facility. For many families, these decisions come down to what they can afford rather than what they know is best.

To address these issues, the federal government must:

- **Make the Canada Caregiver Credit refundable**
- **Introduce a caregiver allowance**
- **Introduce public care insurance**

Make the Canada Caregiver Credit refundable

> ***Convert the Canada Caregiver Credit to a refundable credit by amending the Income Tax Act***
>
> - *Caregivers, especially low-income caregivers, should receive much-needed money in their pockets to help offset the cost of caregiving.*

The Canada Caregiver Credit (CCC) is a non-refundable tax credit. It is available to people who support a spouse, common-law partner or dependant with a physical or mental impairment.[24] **The CCC currently does not do enough to help caregivers who would benefit from it most—in particular low-income caregivers.**

Because the CCC is non-refundable, it can only lower the tax a person pays rather than placing money in the pockets of all caregivers. It does not benefit caregivers with a lower income who do not pay income tax or do not owe tax at the end of the year because there is no tax payment to lower.[25]

The federal government committed to making the CCC a refundable tax credit in 2021. In Minister Freeland's 2021 mandate letter she was instructed to "Convert the Canada Caregiver Credit into a refundable tax-free benefit, allowing caregivers to receive up to $1,250 a year."[26] At time of printing, this has not yet happened.

How to do it

The federal government should convert the Canada Caregiver Credit to a refundable credit by amending the Income Tax Act.

With this change, eligible caregivers would receive up to $1,250 per year through the refundable tax credit. This would help to alleviate some of caregivers' financial stress by providing a little bit of extra help.

This change would help approximately 94,000 Canadians who do not owe on their income taxes and could benefit from the CCC. In 2021, 552,000 Canadians were entitled to receive the CCC.[27] Currently that entitlement only benefits people with taxes owing—approximately 17% of Canadians who file.[28] The CCC should reach all caregivers.

The government should ensure that all caregivers know about the CCC so that people who do not usually file taxes do not lose out on much-needed support.

Introduce a caregiver allowance

> ***Create a caregiver allowance of $600 per month for high-intensity caregivers***
>
> - *The caregivers who provide the most care should receive some compensation for their work and face less financial jeopardy.*

While some financial supports exist for caregivers, they do not provide nearly enough support for caregivers with high-intensity caregiving responsibilities—and the low incomes that often come with those responsibilities. For instance, the CCC provides modest support for caregivers to offset some of the costs associated with caregiving. It does not begin to compensate high-intensity caregivers for the hours they contribute providing care nor does it mitigate the risk of poverty faced by low-income caregivers. The reforms listed above would help.

High-intensity caregivers—people who spend over 35 hours a week providing care—provide a vital service that would otherwise have to be paid for by the public purse through home care or care in a facility. They deserve compensation that reflects the value of their work, and they should not be driven to poverty because of their care work. This is especially true given that many caregivers providing over 35 hours a week of care are likely doing it at the expense of staying in paid employment with full-time jobs.

Within Canada, Nova Scotia, Prince Edward Island and Newfoundland have implemented a monthly caregiver allowance for caregivers with high responsibilities. [29] [30] [31] Caregiver allowance programs targeting low-income caregivers with significant responsibilities are already in place in peer countries, such as the United Kingdom and Australia.[32] In the United Kingdom, the Carer's Allowance provides £81.90 per week to caregiver who provide more than 35 hours of care per week and earning less than £151 after tax[33] – soon to be to £181 per week.[34]

How to do it

A federal caregiver allowance should supplement the CCC with a monthly benefit to caregivers with high care responsibilities. This allowance should be structured similarly to the Guaranteed Income Supplement (GIS) and other programs that are paired with an existing supplement.

The base amount for a caregiver allowance should start at $600 per month ($7,200 per year) and be phased out based on a caregivers' income. This amount aligns with jurisdictions like Australia and the United Kingdom, where caregiver allowances amount to approximately $280 to $500+ per month (£81.90 a week in the UK and $153.50 fortnightly in Australia).[35] It is significantly less than the alternative option of providing this care through public funding for professional care providers, at home or in a facility. Even if those care providers received unacceptably low compensation—for example, the $17.30 federal minimum wage, which would be both immoral and impossible given labour market pressures—the cost of paid care work for the same 35 hours a week would total about $2,600 monthly.

Similar to the Canada Child Benefit, the caregiver allowance should be phased out at a low rate with stepped reductions to ensure the minimum benefit reaches caregivers with an adjusted family net income of $90,000+.

Introduce public care insurance

> ***Create a public care insurance program to provide Canadians with financial security to meet their care needs***
>
> - *The choice between care at home or care at a facility should be made freely, not based on what a family can afford.*

When Canadians need help with daily living, they face a choice between staying at home or receiving care at a care facility. This choice should be made based on what is best for the care recipient and their family. No one should be in a facility because they cannot afford paid or unpaid care at home or receive care at home because they cannot afford a spot in an appropriate facility. In practice, many families make these decisions based on the cost and what unpaid caregivers can practically handle, rather than what they know is best for them. Canadians need new tools to provide them with autonomy over their future care plans.

Home care and care in public and private facilities are partially covered by government funding, but, in practice, families have to fill the gaps with unpaid caregiving or professional care providers. For example, a person may be eligible for three government-funded hours of Personal Support Worker (PSW) care a day at home, leaving families to cover the remaining 21 hours. Alternatively, a government-funded facility may provide basic support, but not the one-on-one attention a person needs.

The calculus of where a person receives care therefore comes down to questions like whether a family member can leave paid employment to become a full-time caregiver, or whether a family can afford to pay for help above a care facility's basic level of service.

Public care insurance would be a way of paying for some of the cost of receiving care at home or in a facility. It could be used to pay for care services that support people with ADLs and instrumental activities of daily living (IADLs), which may be needed because of a disability, illness, physical impairment, mental impairment, or any needs related to aging. Care services can be provided in different places and ways, including:

- Home- and community-care services from public health authorities/health teams (e.g., care provider hours provided in-home).
- Supportive housing services.
- Public and private long-term homes.
- Retirement homes/communities and seniors' communities (non-medical supports with daily living).
- Private care providers.
- Unpaid family/friend caregivers.

Public care insurance would allow Canadians to make genuine choices about how and where to receive help with ADLs. Public care insurance provides funds to hire the help a person needs. Many of Canada's peers on the world stage have public care insurance plans, including Japan, Germany, South Korea, Taiwan, the Netherlands and Washington state in the U.S. While private care insurance is available in Canada, it is not widely used as it is broadly unaffordable and not many people qualify.

How to do it

The design for a Canadian public care insurance system should learn from best-in-class models in Germany and South Korea. A successful public care insurance plan will follow these principles:

Eligibility: Eligibility for care insurance payments should be based on a person's needs rather than age or reason for needing care. Anyone who needs support ADLs, including people with disabilities and people with issues related to aging, should qualify.

Payment type: Benefits should be delivered as cash payments directly to the recipient, allowing them to purchase the services they need when and where they need them. This option will support a care recipient's autonomy and allow families the flexibility to do what is best for them.

Coverage: With a cash benefit, rather than paying directly for public or private care services, the public care insurance program would not need to determine billing levels for specific services.

Funding: Care insurance should be funded though social contributions. It should be modelled on the care insurance program in Germany, where employers and employees contribute an equal amount each year to a national pool of money similar to other insurance plans, like EI and provincial health insurance. There must also be an option for people without an employer (i.e., are self-employed, in gig-work), who are unemployed or cannot work to contribute both amounts (i.e., employee and employer amounts). This ensures all Canadians can access public care insurance—in particular, Canadians with a disability that is incompatible with full-time paid work.

Administration: By structuring the plan around cash benefits, the federal government would be able to administer care insurance directly rather than having it implemented by provinces and territories.

Improve caregivers' well-being through programs and services

Caregiving takes a toll on caregivers' health. Caregivers, especially women, experience impaired physical health, greater acute care use and even increased mortality.[36] Caregivers' mental health suffers when they face substantial care responsibilities without adequate support.[37] Caregivers experience psychological stress, fatigue, anxiety, depression, isolation and loneliness. Many caregivers are going it alone, without any days off or respite opportunities to take time away from caregiving. This deepens mental health challenges and burnout.

Caregivers need to be doing well to take care of others; good mental health and well-being support help to safeguard caregiver well-being, prevent burnout and ensure caregivers can care for their care recipients. Additionally, when caregivers suffer, care recipients' health outcomes follow a similar pattern. An increase in caregiver responsibility and decline in caregiver well-being not only deteriorates caregivers' health, but also leads to worse health outcomes for care recipients.[38]

Caregivers need easier access to mental health supports that are trauma-informed and attuned to their specific needs. In CCCE's consultations, caregivers told us that they need mental health supports like coaching and counselling.

Mental health programs and services are helpful and necessary, but self-care alone cannot prevent burnout among caregivers. Caregivers also need the other recommendations in this document in order to be well, as well as services provided at the provincial and territorial level, like home care services and respite.

To address these issues, the federal government must:

- **Fund programs specifically designed to support caregivers' mental health and well-being**
- **Fund respite and home care services for caregivers**

Caring as an LGBTQ2S+ caregiver

LGBTQ2S+ caregivers navigating the healthcare system face barriers such as stigma and prejudice, which damage their mental health.[39] In CCCE's National Caregiving Survey, 40% of LGBTQ2S+ caregivers rated their mental health as fair or poor, significantly higher than other caregivers at 22%. Similarly, compared to their counterparts, LGBTQ2S+ caregivers had significantly higher rates of being overwhelmed (45% vs. 36%), depressed (29% vs. 22%), lonely (22% vs. 15%) and isolated (22% vs. 14%) because of caregiving.

Many caregivers feel disrespected or excluded in care planning, but LGBTQ2S+ caregivers experience this to a higher degree.[40] LGBTQ2S+ caregivers are more likely to be providing care to a close friend or more distant relative rather than biological family members. Programs and supports need to be designed to recognize this way of forming community and providing care.

Fund programs specifically designed to support caregivers' mental health and well-being

> ***Create a new Caregiver Mental Health Fund for programs and services***
>
> - *Caregivers should have targeted supports to stay mentally well because caregiving can be extremely challenging.*

Caregivers' mental health suffers when they have significant care responsibilities without adequate support.[41] Mental health supports are hard to access for everyone, but this is especially true for caregivers who tend to have very little, if any, time to care for themselves, and fewer financial resources than other Canadians. Caregivers' needs are also specific, with unique experiences of stress, guilt, grief and trauma.

Mental health programs for caregivers exist at the provincial or territorial level, where they exist at all; the strength of support available varies across jurisdictions, but it is uniformly inadequate.[42] For example, in Ontario, the Ontario Caregiver Organization (OCO) offers dedicated supports including a helpline, live chat, online group or individual counselling, peer support, courses and other tools for caregivers.[43] Yet other jurisdictions, like Newfoundland and Labrador, the Northwest Territories and Nunavut have no specific programs or services dedicated to supporting caregivers' mental health and well-being.[44]

The federal government does not fund programs and services specifically to support caregiver mental health and well-being, but provides support to other groups of Canadians (e.g., the Youth Mental Health Fund).

How to do it

A Federal Caregiver Mental Health Fund should support caregivers so they can stay mentally well as they provide care. The goal of the Fund should be to create enough mental health services for all caregivers, and the right mix of delivery models to serve them well. This must include options like virtual care, one-on-one counselling, group sessions, peer support networks and coaching.

All services under the Fund should be trauma-informed, high quality and attuned to each caregivers' unique circumstances. The Fund should place mental health in context, coupling mental health services with warm referrals to complementary services in the community.

Fund respite and home care services for caregivers

> ***Caregivers should have access to respite care to be able to have a break from caregiving and prevent burnout***
>
> - *Home care services must be available and accessible when and where they are needed.*

Too many caregivers lack access to reliable and high-quality respite services. This results in caregivers having no days off and no way to tend to their own needs and goals, such as exercise, education, socializing or simply being able to rest.

Home care is meant to provide support when needed. In practice, there is not enough home care to go around: public support is unavailable and private support is prohibitively expensive for many.

While both respite and home care are primarily under provincial jurisdiction, the federal government can and must show leadership in the following concrete ways:

- Working with provinces and territories to fund respite programs that provide temporary relief to caregivers by offering short-term care for care recipients either at home or in the community.
- Ensuring that the full range of respite and home care expenses are tax-deductible and streamlining the process for accessing those tax benefits.
- Ensuring there are enough care providers in the job market to meet current and future demand for home care services.

Credit: CIRA

Caregiving as an Indigenous caregiver

Indigenous caregivers face realities that stem from a legacy of intergenerational trauma and the ongoing impacts of colonization.[45] They often experience discrimination in the healthcare system, with service providers making assumptions about them based on stigma and biases.[46] This means Indigenous care recipients and caregivers often lack access to culturally safe healthcare: care that does not profile or discriminate against them and respects their culture and traditional healing practices.

Indigenous caregivers are also more likely to experience poverty than non-Indigenous caregivers.[47] Where many caregivers experience financial strain, Indigenous caregivers are more likely to fall into poverty because of their caregiving responsibilities. Indigenous caregivers also face strong cultural expectations to provide care to their family and friends, which can impact their well-being.

SPOTLIGHT

Indigenous caregiving and the Indigenous Caregiving Collective

The ideas presented in this document will benefit millions of caregivers across Canada. Many will need specific supports that meet the historic and ongoing challenges they face every day due to colonization, racism and intergenerational trauma. Indigenous, Metis and Inuit caregivers, care providers and recipients of care have unique needs that need to be met by co-designed and culturally responsive policy responses. This Strategy does not fully address those unique needs.

To better support Indigenous caregivers across the country, CCCE is investing in the creation of a national Indigenous Caregiving Collective (ICC), led by Dr. Grant Bruno, a caregiver, registered member of Nipisihkopahk (Samson Cree Nation) and an assistant professor in pediatrics at the University of Alberta. The ICC will support Indigenous caregivers locally and nationally through research, support services and advocacy.

The goals of the three-year initiative include:

1. Bringing together the institutional support and research-to-practice learnings of the University of Alberta's Women and Children's Health Research Institute, and the clinical services and community engagement of the Nipisihkopahk Pediatric Clinic and Maskwacîs Parents Place within the four nations of Maskwacîs.

2. Building an Indigenous network of researchers and supports for Indigenous caregivers and a pan-Canadian network of Indigenous Elders, organizations, health practitioners and researchers to share knowledge, scale practices, identify research priorities and advocate for better caregiving policy.

The ICC is the first Indigenous-focused caregiving initiative of its kind in Canada. Through the initiative, the collective will identify barriers to culturally appropriate support for care recipients and their caregivers. The ICC will also establish a national advisory circle to guide the work ahead.

The research, policy and advocacy work the ICC will undertake will guide CCCE's next efforts on supporting Indigenous, Metis and Inuit caregivers and care providers.

Credit: CIRA

Pillar Two

Support caregivers in work and education

Balancing work and school commitments with caregiving responsibilities is difficult. Stigma, lack of employer flexibility and ineffective leave options make it difficult and often impossible for caregivers to stay in paid work while caregiving. Likewise, care responsibilities can crowd out education, pushing caregivers out of education temporarily or permanently.

Many caregivers are trying to balance paid work with caregiving. People who have the heaviest caregiving duties often balance them against paid work. In CCCE's National Caregiving Survey, 62% of caregivers reported working in some capacity, and **the more time a person spent providing care, the more likely they were to work longer hours.**[48]

When barriers like employer policies or inadequate leaves make caregiving incompatible with paid work, caregivers are pushed to exit the labour force either for a short period or permanently. **Sometimes this is a genuine and personal choice. Often, however, it is a forced choice because it becomes unsustainable to hold paid employment while providing care. This choice can seriously damage caregivers' long-term financial well-being, as well as their career progression and retirement savings.**

Caregivers have significant value to add to the economy, and their forced exit from the labour force undercuts Canadian productivity. Canada is facing a dangerous productivity slowdown—in absolute terms and relative to our peer economies.[49] Skills shortages are a substantial driver hampering Canada's productivity growth.[50] Caregivers are talented, dedicated workers: 84% of adult caregivers who contributed to CCCE's National Caregiving Survey are working age, each one having built years of human capital and skills. Canada cannot afford to lose caregivers from the workforce. By removing barriers to their participation in paid employment, the federal government can equip caregivers to stay in the labour market, stabilize their financial future and help keep the Canadian economy productive.

How to support caregivers in work and education

Make leaves and benefits work for working caregivers

- Make changes to EI caregiving benefits to make them easier to access, longer in duration, and based on changes in caregiving need

Provide caregivers in work and school with greater financial security

- Introduce CPP provisions for caregivers with years of low to zero earnings as a result of caregiving responsibilities
- Make the federal component of student loans more flexible to meet the needs of caregivers

Give caregivers the flexibility to stay in the workforce as they provide care

- Become a leading employer by implementing caregiver- friendly workplace policies
- Give federally regulated employees paid care days
- Introduce incentives for caregiver-friendly workplace policies

Caregiving as a young caregiver

Young caregivers are people who take on caregiving responsibilities at a young age, often for a sibling, parent, or grandparent. This includes typical caregiving tasks, as well as some special duties—for instance, serving as a point of contact with healthcare providers when the care recipient does not speak English or French.

Being a young caregiver can mean taking time away from a job or extracurriculars, impeding their personal growth. Young caregivers in school often have to take time away from their studies to provide care. This creates setbacks for young caregivers and influences their future, especially if they are never able to go back and complete their schooling.

In CCCE's National Caregiving Survey, young caregivers, who may have less financial stability and face more difficulty with the rising cost of living, experience serious financial strain. About one in four young caregivers (aged 18 to 24) had to work more hours due to the costs of caregiving, while 14% had to use personal short-term savings and 13% had to stop saving altogether.[51]

In the Survey, CCCE also learned that young caregivers spend, on average, 14 to 27 hours of their week providing care—equivalent to a part-time job.[52]

SPOTLIGHT

Young Caregiver Assessments

In the United Kingdom, young carers have an enshrined right to a needs assessment within the healthcare system. This means that the National Health Service and adult and children's social care are obligated to determine the amount, nature and type of care that a child is providing, whether that care is effective for the person being cared for, whether it's sustainable and safe for the child and note actions for follow-up. Similar assessments within provincial and territorial health systems would help address many of the unique and significant challenges young caregivers face.

Make leaves and benefits work for caregivers

Working caregivers need to be able to take time away from paid employment in order to provide care without damaging their financial futures or career trajectories. **The current system for funding time away from work—EI benefits—is disconnected from the realities of caregiving and not fit for purpose.**

Leaves and benefits for caregivers are difficult to qualify for and hard to access. They require caregivers to take on a significant administrative burden and are not designed for the often sudden and episodic nature of caregiving. Caregiving can happen in both short bursts and longer periods, and both these scenarios merit support. EI benefits should be available based on whether caregiving becomes incompatible with work. Instead, they are currently only available where there is a risk the person receiving care will soon die.

Existing benefits for caregivers are rarely used—not because they are not needed, but because of how they are designed. In the month of February 2024, a mere 1,470 caregivers in all of Canada received Compassionate Care Benefits, and only 90 received Family Caregiver Benefits for adults.[53] Few caregivers seem to know about these benefits and they are cumbersome to access, imposing an administrative burden exactly when caregivers are least able to handle government forms and medical assessments.

To address these issues, the federal government must:

- **Make changes to EI caregiving benefits to make them easier to access, longer in duration and based on changes in caregiving need**
- **Improve caregiving benefits for caregivers who are self-employed, casual or part-time employees**

Make changes to EI caregiving benefits to make them easier to access, longer in duration and based on changes in caregiving needs

> ***Change EI caregiving benefit eligibility criteria, duration and application process***
>
> - *Caregivers should be able to get EI benefits—benefits they pay for with each paycheque—when they truly need them.*

Canada's EI system is meant to provide EI benefits to support caregivers in taking a step away from paid employment when a care recipient needs them most. Unfortunately, caregivers can only receive EI benefits and associated job-protected leaves under limited circumstances, such as at the end of life or when a care recipient is at risk of death.

Instead, EI caregiver benefits should be available for the many circumstances where the care a person needs to provide is incompatible with working in their paid job. This should include times when:

- The existing caregiving situation changes (i.e., home-support worker quits).
- A care recipient's situation changes (i.e., a person needing to take time off work to transition a sibling with a disability to residential care upon the death of a parent).
- A new, acute caregiving need emerges (i.e., immediate caregiving needs after hospitalization, or a child with a disability needs surgery).

None of these circumstances are captured by the existing EI caregiver benefits.

One benefit—the **Compassionate Caregiver Benefit**—is available when the person receiving care is at significant risk of death within 26 weeks, as established by a medical certificate. That benefit runs for 26 weeks. The other, the **Family Caregiver Benefit,** is only available with a medical certificate saying the care recipient's life is at risk. It can run for 35 weeks if the person with the critical illness is a child, or 15 weeks for an adult. Both benefits can provide people with 55% income replacement, up to a maximum of about $690 a week.

Tying EI caregiving benefits to risk of death simply does not reflect when and why caregivers need to take paid time off work. One problem is that doctors, caregivers and care recipients find it difficult to say when there is a significant risk of death. It is not reasonable to expect people in the middle of a caregiving crisis to fill out paperwork spelling out exactly how likely it is that their loved one will die. As a result, few people claim these benefits—benefits that they pay for with every EI payroll deduction.

The way these benefits are set up makes them unhelpful and inaccessible. Even though estimates show that 8 million Canadians provide unpaid care to a family or friend, there were only 25,746 new claims for all caregiver benefits in 2022-2023.[54] [55]

How to do it

Benefits should be available based on changes in caregiving need rather than risk of death.

All caregiver EI benefits must be expanded to run up to 50 weeks. The federal government needs to value and support caregivers who take time away from paid work to care for loved ones. In fact, the federal government already uses EI to do just that, supporting people caring for new babies with "standard option" EI benefits for up to 50 weeks in the form of parental and maternity leave. Caring for a person with a disability, health issue or issues related to aging is no less important, meaningful or incompatible with paid employment than caring for an infant.

The government should also create an **additional six weeks of benefits for caregivers providing end of life care after the care recipient dies.** This would allow caregivers to take time away from work to grieve and address the substantial administrative burdens associated with the death of a care recipient (e.g., legal duties, funeral arrangements, family and service provider coordination).

These improvements to EI caregiving benefits should come with **changes to the Employment Insurance Act and the Canada Labour Code to make the same changes to job-protected leaves for caregivers.** The federal government should work with provinces and territories to ensure that leaves for workers across Canada match the improved EI benefits.

The federal government should **increase awareness of caregiver benefits.** This means making information about the benefits easier to use and understand, and undertaking outreach to find caregivers. This should include sharing educational materials with hospitals, doctors' offices, social workers and with employers, including HR professionals, Employee Assistance Plan providers and financial advisors. This work needs to include ensuring caregivers understand that EI caregiving benefits can be broken up and started and stopped over a period of time. [56]

The application process for caregiving benefits should be made simpler and more accessible. There are some key steps the government can take to do this:

- Eliminating the one-week waiting period between the start of a caregiver leave and the receipt of the associated benefit.
- Allowing benefits to start before medical certificates have been filed, a step some governments, like Ontario, have already taken in respect of caregiving leaves.
- Allowing a wider range of healthcare professionals to certify that a caregiver meets the requirements of the caregiving benefits.
- Providing resources and working with professional associations and schools to ensure that medical practitioners understand these EI benefits and their roles in helping caregivers receive them.

Improve caregiving benefits for caregivers who are self-employed, casual or part-time employees

> ***Explore options to make caregiving benefits available and more beneficial for all working caregivers***
>
> - *Working caregivers in part-time, contract, gig-work and self-employment should be able to have paid time off work for caregiving.*

EI caregiver benefits are only available to full-time employees who contribute to EI. Unfortunately, a growing number of Canadians do not qualify for EI benefits because they engage in gig work, contract work, part-time work or are self-employed. In CCCE's National Caregiving Survey, 16% of respondents work part-time, do freelance work or are self-employed.[57] Caregivers may be more likely to be in these forms of employment specifically because they offer the flexibility needed to balance work with care. Even these caregivers, however, sometimes need to move past flexibility and take a paid leave.

The federal government needs to choose options to improve caregiving benefits for all working caregivers. These options include:

- Making changes to the EI benefit program for self-employed people by reducing the requirement for people to contribute for 12 months prior to receiving premiums.
- Introducing a higher replacement rate or higher maximum insurable earnings for caregiving benefits and parental benefits.
- Pulling special benefits, including caregiving benefits, out of EI altogether, and introducing a new federal insurance plan instead.

Provide caregivers in work and school with financial security

The demands of caregiving can require caregivers to take long periods of time away from work. Over the long-term, these years with low to no earnings can hurt a caregiver's CPP retirement benefits. Fewer and lower-paid years paying into CPP means lower pension payments upon retirement and a de facto punishment for giving care that lasts well into retirement years.[58]

Caregiving responsibilities also pull students away from their studies. Caregivers in education have to take time off of school to care for family and friends. Time off impacts caregivers' growth and future earnings, and it also negatively impacts students financially.

To address these issues, the federal government must:

- **Make changes to the CPP to account for years spent caregiving**
- **Make the federal component of student loans more flexible to meet the needs of caregivers**

Caregiving as a woman

Over half of women in Canada are caregivers. Among all unpaid caregivers, women provide more hours of care than men.[59] This makes women more likely to experience the harms associated with caregiving, like stress, poor mental health and well-being, financial strain and pressure to leave the workforce. Women's caregiving duties are not highly valued due to gendered expectations that women should just "naturally" be caregivers. Stigma and stereotypes around caregiving and gender are wide reaching, impacting women's career progression, social status and wage equity.

In CCCE's National Caregiving Survey, 28% of women caregivers reported fair or poor mental health, vs. 20% of men who reported the same. Compared to men, women were significantly more likely to report feeling tired (51% vs. 41%), worried (50% vs. 34%) or overwhelmed (42% vs. 29%). Women were more likely than men to say they would benefit from income tax credits, monthly allowances and a program to pay caregivers.[60]

Introduce CPP provisions to account for years spent caregiving

> ***Introduce drop-out and drop-in provisions for base and enhanced CPP amounts, respectively, when calculating the amount of CPP retirement benefits a person will receive***
>
> - *Caregiving should not mean sacrificing future CPP payments and a dignified retirement.*

Like most Canadians, caregivers generally rely on CPP payments as a key part of their plan for retirement. However, many are uniquely disadvantaged by virtue of taking longer periods of time away from paid employment. The very caregivers whose labour and dedication our health and social service systems depend on are left in poverty and struggling in their old age.

The current CPP system fails to make provisions for caregiving years. The amount of money a person receives through CPP retirement benefits depends on their CPP contributions over their lifetime and when they start taking their pension. The CPP system accounts for years when people make low to no contributions because they had low to no earning years.[61] The aim is to ignore anomalously low-income years when calculating earnings so that people can receive higher pension payments.

This is achieved through "dropping" some years from the calculations and "dropping in" credits for CPP enhancement calculations. For example, general drop-out provisions "drop" up to eight years of a person's lowest earnings between ages 18 to 65 from their CPP calculation. Child-rearing provisions "drop" years people spend with low to no earnings due to caring for a child seven years or younger and "drop in" credits for the CPP enhancement during those years.

There are currently no special drop-out and drop-in provisions to protect caregivers from lower pensions payments on retirement, but this must change.

How to do it

The government should model changes to the CPP on existing child-rearing provisions. Years of low to no earnings should be “dropped” from a caregiver’s CPP calculation and “credits” should be “dropped in” to the enhanced portion of a caregivers’ CPP component.[62] This would be like raising a person’s yearly earnings and total CPP contributions, leading to a higher CPP benefit upon retirement.

These new caregiving provisions should apply for up to five years of time spent away from work due to care responsibilities, meaning caregivers should be granted five years that cannot count against them in calculating their CPP benefit levels. On average, according to CCCE’s National Caregiving Survey, Canadians spend 4.6 years providing care to someone who needs it.[63] These years often mean reduced income because of reduced working hours, adjusted work schedules or even leaving the workforce to retire early. All of these are special risks for “sandwich” caregivers—caregivers providing care to an adult and a child at the same time.[64]

These CPP provisions should be designed to be as inclusive, accessible and as favourable as possible to caregivers. In particular, they should be triggered by information already on file with the CRA. For example, caregivers should be presumed to qualify for the CPP caregiving provisions for years where CRA records show they received the Canada Caregiver Credit and had lower than normal income.

Make the federal component of student loans more flexible to meet the needs of caregivers

> ***Allow caregivers in post-secondary education to delay repayment of the federal component of their student loan if they shift to part-time studies or take time off school to provide care***
>
> - *The government should not financially punish student caregivers for taking time away from school to provide care.*

Caregivers in post-secondary education are often forced to reduce their courseload to part-time or pause their studies altogether due to caregiving duties. When this happens, these students are required to begin repaying the federal component of their student loans within six months. This federal policy treats the circumstances of caregiving students as though they have stepped away from school out of choice or to take on paid employment, and that they can therefore be expected to raise the money to repay loans. In reality, caregivers pause their education to provide care. They use the extra time for caregiving responsibilities, not paid work.

Student caregivers should receive the same flexibility in loan repayment offered to students taking a leave for medical or parental reasons.[65] The federal government should encourage its provincial counterparts to take the same approach with their share of student loans.

Caring for siblings with disabilities

Siblings of people with a disability often take on caregiving duties at a young age. When young sibling caregivers take on adult caregiving duties, it can impact their growth, education and independence. Caring for siblings with disabilities can mean taking time away from school, work and extracurricular activities—with long-term implications for a caregiver's growth and development, and their own well-being.

As their parents grow older and as people with disabilities live longer, siblings are more likely to become primary caregivers at some point in their lives. Transitioning to take on care responsibilities for a sibling as an adult is a source of anxiety for many siblings of people with disabilities.[66]

Give caregivers the flexibility to stay in the workforce as they provide care

Many caregivers want to stay in paid employment while providing care. Too often, employers' policies get in the way.

Caregiver-friendly workplace policies (CFWPs) are steps that employers take to support employees who are also caregivers: "intentional organizational changes, whether in practices, policies or the workplace culture, which relieve work-family conflict."[67] In general, this means being flexible, where possible, on choices like remote work and time-shifted hours.

Caregiver-friendly workplace policies are key to keeping caregivers in the workplace. With policies like flexible hours, time shifting, dedicated days off and the option to work from home, many caregivers can work their full slate of hours while also providing care. Without these policies, caregivers are forced to use sick days, vacation days and unpaid time off to accommodate their caregiving responsibilities.[68] They often face dismissal or feel they must quit when care duties run up against inflexible employers.

Absent flexibility, caregiving reduces work productivity by an estimated $5,600 per employee, or about one-third on average.[69] Employers failing to support employees who provide care results in higher rates of absenteeism, decreased employee retention and a less productive workforce.[70] In a 2023 study, 23.3% of caregivers reported absenteeism or presenteeism over a one-month period due to caregiving responsibilities.[71] **It does not have to be this way. Inflexible, all-or-nothing approaches to workplace policies leave potential productivity from these caregivers on the table.**

Supporting caregivers' ability to work is particularly important now, as Canadian productivity has been stagnant since the COVID-19 pandemic.[72] There is a growing consensus that solving the productivity crisis will require supporting workers to do their jobs more efficiently.[73] Further, as Canada faces a skills gap, the economy needs to retain workers with experience and years of accumulated human capital—workers like the 62% of caregivers who are working age. Canada cannot afford to push caregivers out of the workforce because of an attachment to mid-century norms around working hours and the stigma around caregiving.[74]

To address these issues, the federal government must:

- **Become a leading employer by implementing caregiver-friendly workplace policies**
- **Give federally regulated employees paid care days**
- **Introduce incentives for caregiver-friendly workplace policies**

Become a leading employer by implementing caregiver-friendly workplace policies for federal government employees

> ***Act as a leading employer and grant federal government employees flexible work arrangements to accommodate caregiving responsibilities***
>
> - *If the federal government takes caregivers seriously, it should support the 92,000 caregivers it employs to bring their best to care and work.*

Caregiving can make it difficult to work standard hours. Sometimes this is simply a question of taking a few minutes out of a workday to administer medicine or prepare a meal. Other times, it means shifting working hours to trade off with paid care providers or taking full or half days off to accompany care recipients to medical appointments.

There are 367,000 federal government employees.[75] Given that about 1 in 4 Canadians are caregivers, the federal government has an opportunity to **improve the lives of about 92,000 caregiving Canadians, and the tens of thousands of people they care for,** by becoming a leading employer.[76]

The federal government has the power to raise the bar for valuing caregivers by giving them the tools to be both caregivers and effective workers, and this can push other employers to follow suit.

How to do it

The federal government should give **caregiver-tailored support through Employee Assistance Programs** including advice or information on navigating caregiving benefits, financial planning for caregiving, counselling and caregiving skills.

Leadership in this space also means **improving existing leave and benefits options for caregivers in the federal workplace.** This includes **expanding EI top-ups to caregiving benefits to match what is available for parental leave.** Employees on family caregiver or compassionate care leaves should receive up to 93% of their earnings, equivalent to the top-up for parental leave. This level of top-up will not only leave caregivers in a better financial position, but it will also combat the gendered dynamics and stigma associated with taking time off work for caregiving. In general, women are more likely to take leaves for family illness, but men become increasingly likely to take leaves when wage replacements reach about 80%.[77]

Give federally regulated employees paid care days

> ***Make amendments to the Canada Labour Code to include five days of paid leave for all federally regulated employees***
>
> - *Caregiving is not a vacation: caregivers should be able to take days away from work to provide care without being penalized.*

Under the Canada Labour Code, federally regulated employees are entitled to five personal leave days—three paid and two unpaid.

This is far from enough time for most caregivers to meet their caregiving duties. In practice, caregivers use vacation days and sick days to piece together paid time off to balance work and care. This leaves caregivers with much less time off work for their own needs than other workers, contributing to caregiver burnout and causing many to leave the workforce.[78]

How to do it

The federal government should establish five paid days off for caregiving for all federally regulated workers, including federal employees, by amending the Canada Labour Code. This amounts to one week's work of time off for caregiving every year, and should be available as full days or half days.[79]

There are approximately 910,000 federally regulated private-sector employees. Given that about 1 in 4 Canadians is a caregiver, **this change would provide direct support to about 227,500 Canadians and will also benefit hundreds of thousands of care recipients.** Leadership matters: setting this standard would set the stage for provinces and territories making similar changes to let caregivers thrive in the workplace.

Introduce incentives for caregiver-friendly workplace policies

> ***Caregivers should not be responsible for demonstrating their value to the workforce***

The federal government should set a bar for what caregiver-friendly workplaces look like and encourage federally regulated employers on the path to get there. This means offering rebates, tax incentives and awards and recognition for employers that implement caregiver-friendly workplace policies. The federal government regularly uses these kinds of tools to influence business activities when something important is on the line—for instance, creating incentives for scientific research and development, clean energy investments and incentives for expanding business internationally. Caregiving belongs in the group of issues that need to matter to businesses.

Pillar Three

Improve financial support for care recipients

The financial outlooks of care recipients and caregivers are intertwined. When a care recipient experiences financial hardship or poverty, their caregivers generally try to fill the gap and become financially unstable as well.

This means that poverty for care recipients often means poverty for caregivers. It is well-established that the expenses associated with having a disability in particular push people into poverty. Almost one million people in Canada with a disability live below the poverty line, and people with disabilities represent over 40% of all people living in poverty in the country.[80] Over 73% of people with an intellectual disability who live alone live in poverty.[81]

The federal system of financial supports for people with disabilities is inadequate, inaccessible and pushes people into poverty. This harms people with disabilities and harms the caregivers in their lives.

How to financially support care recipients

Reduce administrative barriers and expand eligibility for two key supports

- Expand Disability Tax Credit eligibility and make it more accessible
- Make improvements to the Registered Disability Savings Plan

Increase the scale of other financial supports for care recipients

- Implement and amend the Canada Disability Benefit
- Make improvements to the Medical Expense Tax Credit

Reduce administrative barriers and expand eligibility for two key supports

The Disability Tax Credit (DTC) is both a vital financial support and the gateway to many other forms of support and services. Yet fewer than 40% of qualifying people claim the DTC.[82] This mismatch of policy intention and policy outcome is a tremendous failure in government service delivery.

Unnecessary administrative barriers and red tape make it difficult for many people to claim the DTC. Qualifying for the DTC requires tax forms, certificates, receipts, doctors' approvals and regular requalifications. The process is opaque and demoralizing. **This administrative red tape has a real-life impact on people who cannot cut through to access supports.** This problem is not exclusive to the DTC, but spreads across financial programs for people with disabilities. Almost half of the people eligible for the Registered Disability Savings Program (RDSP) are not aware of it, and fewer than one-third of eligible people actually have an RDSP account.[83]

Beyond the application process, the rules undergirding both the DTC and the RDSP exclude people who should be supported. For example, to qualify for the DTC, a person's disability needs to be present 90% of the time, but disability can actually be episodic. There are strict rules around how limiting a person's cognitive disability should be for them to receive support. **Eligibility should map onto actual experiences of disability rather than the difficult status quo.**

To address these issues, the federal government must:

- **Expand Disability Tax Credit eligibility and make it more accessible**
- **Introduce a caregiver allowance**
- **Make improvements to the RDSP**

Expand Disability Tax Credit eligibility and make it more accessible

> ***Improve access to the DTC by expanding eligibility criteria to include more people, making it easier to apply and keep certification and increasing awareness of the DTC***
>
> - *The main gateway to disability supports in Canada should be redesigned to actually reflect how disability works, and to reach more people.*

The DTC is both an important tax credit for people with disabilities and a gateway to a range of other government supports and services. As a stand-alone benefit and as a gateway to other supports, **the DTC is a "make-or-break" feature of the federal government's ability to support caregivers in Canada.**

The Disability Tax Credit Certificate is a gateway to access other supports

A DTC Certificate is required to access:

- **Registered Disability Savings Plan**
- **Certain Medical Expense Tax Credit expenses**
- **Child Disability Benefit**
- **Disability supplement for the Canada Workers Benefit**
- **Home accessibility expenses**
- **Canadian Dental Care Plan**
- **Canada Disability Benefit**

A DTC certificate simplifies access to:

- **Provincial/territorial income assistance and tax credits**
- **Canada Caregiver Credit**

Despite its importance, it is hard to access and qualify for the DTC. Applying for the DTC is complicated. Applicants must have forms signed by a medical professional, who will often charge a fee.[84] Fewer than 40% of people who qualify for the DTC claim it because many are not aware that it exists and the application process is unduly complex.[85]

The restrictive **eligibility criteria** for the DTC also exclude too many Canadians with disabilities. Eligibility is based on being "markedly restricted" in carrying out the "basic activity of daily living," but this does not reflect many of the most severe forms of disability.[86] For example, a person with fibromyalgia may experience deep chronic pain and unbeatable fatigue daily, but would be excluded from claiming the DTC based on the strict eligibility criteria. It is especially difficult to establish marked restriction in basic ADLs for many cognitive disabilities.[87] [88] **People who are eligible for the DTC represent fewer than 40% of people in Canada with severe disabilities.[89]**

Worse, the DTC eligibility criteria are applied inconsistently and unfairly. **The CRA's decision-making process for DTC eligibility lacks transparency.[90]** The CRA does not provide guidelines on how determinations are made, and does not provide consistent feedback on applications.[91] In Budget 2024, **the federal government committed to "find ways to increase take-up and lower the administrative burden of obtaining" the DTC.[92]** The CRA has taken some modest steps in the right direction, such as no longer requiring printed forms and enabling people to track the status of their applications. This is a step in the right direction, but the federal government needs to go further and move faster to overtake this problem.

How to do it

The federal government must expand and change eligibility criteria for the DTC, and do so in partnership with people with disabilities, disability policy experts and advocates and the CRA's Disability Advisory Committee. The definition of disability needs to move from the medical model to the biopsychosocial model, meaning it should focus on abilities and not body function, and that it should account for the role that psychological, social and environmental factors play in disability. This is eminently possible. The World Health Organization's WHODAS 2.0 assessment provides an example of how to operationalize the biopsychosocial model.[93]

The government must simplify the application process for the DTC and benefits that flow from it. Re-application creates unnecessary red tape for people with disabilities and caregivers, and the government must waive the requirement to re-apply for the DTC in all but most necessary cases. For example, when a person has a lifelong disability that will not change, they should not have to re-apply. Likewise, when a person was receiving the Child Disability Benefit, they should not have to make a new application for the DTC simply because they “age out” of that program.

The government should also cut other administrative red tape in the application process by:

- Allowing applicants to re-use existing applications, as long as they are newly reviewed by medical professionals.
- Creating dedicated virtual supports, call lines and accessible online formats (e.g., DAISY, e- text, MP3) to assist with applications.
- Developing new and better resources to help medical professionals understand DTC applications and how they are assessed, including working with professional schools and associations.

Receiving the DTC should automatically result in enrollment in the benefits that flow from the DTC. The DTC alone or combined with information that is already in government hands should be the only preconditions to receiving a host of other benefits. Right now, however, people with disabilities or their caregivers need to seek those out one by one and apply for them—if they know about them at all. It is unacceptable for people to lose out on important programs simply because they do not know about them. Changing this should be a top priority for the government.

For example, when someone is approved to receive the DTC, the government should automatically open a government-held Registered Disability Savings Plan (RDSP) account on their behalf and provide them with the Canada Disability Benefit, subject to their income (see also pages 47-50).

It is important to **raise awareness of the DTC and its connection to other benefits, including the forthcoming Canada Disability Benefit.** It is unfair for people to be deprived of vital supports because they are unfamiliar with tax policy. The government should raise awareness of the DTC and all the supports it can unlock by partnering with caregiver and disability support and service organizations, providing them with educational resources about the DTC. The government should also hold itself accountable by publishing annual data on numbers of DTC applications, approvals and reasons for rejections to have a more transparent system.

Make improvements to the Registered Disability Savings Plan

> ***Improve awareness of the RDSP, make it easier to access and make it more flexible with higher contribution limits***
>
> - *The main policy lever to help people with disabilities save for the long-term should work better for people with disabilities.*

The RDSP is a type of registered savings account meant to encourage savings by and for people with disabilities. It is available to people with a DTC certificate and **comes with matching grants** of $3,500 annually (up to a $70,000 lifetime maximum). **Low-income families can also receive bonds** of up to $1,000 annually, and these do not require a matching contribution. (Up to a $20,000 lifetime maximum.)[94]

The lifetime maximum a person or their loved ones can put into an RDSP is currently $200,000. Contributions can only be made until the person with a disability reaches age 59, and grants and bonds cannot be withdrawn without penalty for 10 years.

Established in 2008, the RDSP has not been successful: **the uptake of the RDSPs, matching grants and bonds is extremely low.** Fewer than one-third of eligible people have an RDSP, in part because it is difficult to enrol.[95] Nearly half of people eligible for the RDSP do not know it exists.[96]

The RDSP should be re-designed to provide more benefit to more people.

How to do it

The government must make enrollment in the RDSP easier and, eventually automatic. The government must also redesign the RDSP to make it more useful to people with disabilities.

In the longer term, **the government should automatically open an RDSP for people who qualify,** if they have not done so within four years of qualifying (e.g., gaining a DTC certificate). The government has already committed to this kind of approach by announcing plans to open Registered Education Savings Plans, with associated grants, for people who do not have them by age four.[97] It is vital to make this change to shift the administrative burden away from individuals and their caregivers and back to the government. The government, staffed by service professionals, already holds all the relevant data about eligibility for RDSPs. It is time to move past a model that asks over-burdened Canadians with disabilities and their caregivers to tell the government what it already knows.

In the short term, when a person is approved for the DTC, they should automatically receive information about RDSPs, emphasizing that there are free, government-matching funds available in the form of grants and bonds. All information about the RDSP should be made available in accessible formats.

Beyond the application process, the design of the RDSP itself should be improved. Contributing to RDSPs and withdrawing money should be **easier and more flexible to better meet the needs and realities of people with disabilities.** This means:

- Increasing the age range in which people can contribute to RDSPs from 59 to 71—the same cut off as RRSPs.
- Reducing the waiting period for making withdrawals without paying back grants and bonds from 10 years to five years.
- Increasing the lifetime contribution limit from $200,000 to $400,000 and indexing it annually to inflation going forward to make it easier for people to save more.
- Working with financial institutions to ensure that it is straightforward for friends and family to put inheritances and gifts directly into an RDSP.[98]
- Allowing siblings and other support people—not just parents or partners—to act as the RDSP holder for a loved one who cannot make decisions about their property.[99]
- Ensuring that RDSP grants, bonds and interest are non-taxable, like original contributions.
- Partnering with caregiver support organizations, disability advocates, healthcare providers, tax clinics and other community organizations to raise awareness of RDSPs and how they work; for example, by providing them with targeted, accessible materials that explain RDSPs.
- Using behavioural insights, design information campaigns telling taxpayers that they are eligible for the RDSP in a way that maximizes uptake.

Increase the scale of other financial supports for care recipients

Living with disabilities should not condemn people to poverty. Yet almost one-third of working-age adults with severe disabilities lives in poverty.[100] This number rises to 73% for people with an intellectual disability who live alone.[101] People living with a disability represent 41% of all people living in poverty.[102] By contrast, only about 7% of people without disabilities in Canada live in poverty.[103]

Living with a disability is expensive, with costs related to medical expenses, assistive devices and reduced earning potential. It is costly to be forced to adapt to an environment and a society not built to be accessible to all people. The federal government has a role and responsibility to safeguard the financial health and quality of life of people with disabilities.

Announced in the federal Budget 2024, the CDB is an opportunity to help lift people with disabilities out of poverty. The proposed design for the CDB, however, is completely insufficient and will not meet the mark. People with disabilities and caregivers desperately need and deserve better.

To address these issues, the federal government must:

- **Implement and amend the Canada Disability Benefit**
- **Make improvements to the Medical Expense Tax Credit**

Implement and amend the Canada Disability Benefit

> ***Raise the annual amount payable under the CDB to at least $12,000***
>
> - *The CDB should be fit for its purpose: safeguarding people with disabilities from poverty.*

The federal government passed the Canada Disability Benefit Act in June 2023 in order to create a benefit for low-income people with disabilities aged 18 to 64.[104] To qualify for the CDB a person must have a valid DTC certificate and have a maximum annual income of $23,000 for an individual or $32,500 for a couple.[105] The maximum amount a person can receive from the proposed benefit is $2,400 a year, paid monthly. The federal government has plans to finalize CDB's design and launch it in 2025.

The proposed $2,400 per year falls far short of keeping people with disabilities out of poverty. People with severe disabilities have median incomes 44% lower than people without disabilities and experience much greater costs than others in Canada.[106] The proposed CDB is inadequate to deal with these realities. It is a policy doomed to fail before it begins. It can, however, be remade into a transformative support for people with disabilities.

How to do it

The maximum amount payable under the CDB should be **raised to at least $12,000, indexed to inflation.** It must be non-taxable, and the federal government must ensure that it is **not clawed-back against provincial benefits.** This means that people should receive the full CDB and the provincial benefits for which they currently qualify instead of having their provincial amount reduced because they get new 'income' from the CDB.

The goal of the CDB should be to ensure that **no one with a disability in Canada lives below the poverty line.** When combined with the least generous provincial disability benefits, a $12,000 federal CDB will bring most people to or above the poverty line, measured by the Market Basket Measure or the Statistics Canada Low Income Cutoff in urban areas. Application for the CDB should be **automatic when a person receives a DTC certificate,** provided the CRA has the necessary information about their income.

Make improvements to the Medical Expense Tax Credit

> ***Address insufficient coverage and reduce administrative burden of the Medical Expense Tax Credit and Refundable Medical Expense Supplement***
>
> - *People with disabilities should be able to claim their medical expenses on their taxes through a straightforward, simple process that saves them money.*

The Medical Expense Tax Credit (METC) is a non-refundable tax credit for eligible medical expenses that are not covered by public or private health insurance. The METC only benefits taxpayers with high out-of-pocket expenses. In 2023, people could only benefit from the METC once they had spent the lesser of $2,635, or 3%, of the claimant's or their dependent's income.[107]

The METC has two major shortcomings. First, it **does not provide meaningful tax relief** to reduce the impact of exceptional expenses. For example, a Canadian who earns $60,000 annually and spends $6,000 on medical expenses will only receive a tax credit of $630. The tax credit only reduces the burden of out-of-pocket expenses from 10% to 9% of their pre-tax income.

Second, the METC carries a **high administrative burden,** lowering take-up and imposing unnecessary costs on Canadians.

The METC is paired with a supplement for Canadians with lower incomes—the **Refundable Medical Expense Supplement (RMES).** The RMES provides additional financial support for medical expenses, effectively reimbursing 25% of medical expenses up to a maximum of $1,399.[108] Eligibility for the RMES is limited to working Canadians who earn at least $4,083, but whose adjusted family net income is less than $58,944.

How to do it

The federal government should support caregivers by improving the METC and RMES through the following changes:

- **Double the credit rate for the Medical Expense Tax Credit, bringing it from 15% to 30%.** For example, the same Canadian earning $60,000 with $6,000 of medical expenses would receive a tax credit of $1,260 using the 30% credit rate, compared to only $630 using the 15% credit rate.
- **Decrease the minimum threshold, meaning people can claim the METC when they have paid the lesser of $2,635 or 1.5%, of their income on medical expenses, rather than 3%.** This will expand the reach of the tax credit and make it more impactful and helpful for those who qualify, better achieving the policy goal of off-setting exceptional medical expenses.
- **Simplify the application process for the METC and RMES** by developing a more user-friendly database so Canadians can understand what qualifies as eligible medical expenses and who is eligible. For example, there should be clearer pathways to claiming respite and home care expenses under the METC.
- **Increase the maximum benefit within the RMES from $1,399 to $5,000.** This would benefit low-income Canadians as they would be more likely to receive the full amount of their medical expenses (i.e., Canadians with medical costs at or below $20,000 would receive the full 25% credit).

Pillar Four

Build a sustainable care provider workforce

Care providers—paid professionals that support care recipients—are essential members of Canada's health and social services workforce.

However, care providers are underpaid, undervalued and poorly treated. For example, the majority of PSWs in the Greater Toronto Area are considered low income (55%) and precariously employed (86%), and lack paid sick days (89%) and extended health benefits (74%).[109]

Care providers are burnt out and leaving the profession. Eighty per cent of care providers in CCCE's National Caregiving Survey had considered leaving the profession.[110] Care providers earn low pay, work long hours and work shifts that are consistently short-staffed. They struggle to care for themselves, let alone care for others. **Many care providers love their work, but they need better pay, benefits and working conditions to do it well.** Care recipients deserve care providers who can bring their best to their work.

Many care providers are newcomers to Canada, and the workforce badly needs these workers. Yet migrant care providers too often face poor workplace conditions, poor workplace protection and limited pathways to stay in Canada doing their important work.

The demand for care providers is significantly higher than the supply. Canada has seen critical staffing shortages in long-term care, home care and disability support across the country in recent years. Staffing shortages decrease the quality of care for care recipients, and place unsustainable burdens on workers.

Demand for care providers will continue to rise. High demand without added support puts pressure on care providers to work unreasonably long hours, cover additional shifts and work short- staffed. These conditions are driving high turnover for care providers, leading to insufficient support for the people who need it most.

Building a sustainable care provider workforce is essential to improving the lives of care providers, caregivers and care recipients. Canada needs more care providers to join the workforce and needs those already working to stay in the profession doing their critical work. When paid care providers are not available, it is up to unpaid family and friend caregivers to fill the gap. This pushes caregivers past their limits.

How to build a sustainable care provider workforce

Value paid care providers

- Pay care providers a living wage

Protect and encourage migrant care providers

- Enhance protections for migrant care workers
- Improve pathways to permanent residency for migrant care workers

Value paid care providers

Care providers are significantly underpaid. Despite care providers' importance, low wages persist, often placing these key workers below a living wage.

Care providers' working conditions are unsustainable. Low pay and poor working conditions, like insufficient staffing and precarious work, contribute to burnout for care providers, who are increasingly expected to do more with less in their roles.

To address these issues, the federal government must:

- **Provide care providers with a living wage**

Providing care as racialized caregivers and care providers

Racialized caregivers face more and different barriers, including systemic racism and discrimination in the healthcare system and a lack of culturally relevant services. When racialized caregivers are newcomers, they are even more likely to face challenges, often because of language barriers or a lack of familiarity with Canada's complex and fragmented health and social support systems. According to CCCE's National Caregiving Survey, racialized caregivers spend more time navigating supports compared to non-racialized caregivers.

The survey also showed that 46% of racialized caregivers are under financial strain.[111] They often have a different relationship with care recipients. Racialized caregivers are more likely to provide care to an extended family member, for example an aunt or a cousin, than a non-racialized caregiver.

In Canada, the majority of PSWs are racialized women,[112] and **the problems facing the care provider workforce cannot be understood without appreciating how race, gender, and newcomer status intersect in paid care work.**

Pay care providers a living wage

> ***Work with provinces and territories to increase wages for publicly funded care providers to a minimum wage of at least $25 per hour, indexed to inflation***
>
> - *The professionals who do vital care work must be paid a living wage.*

Care providers are professionals who work across the different places where people need care: in care recipients' homes, in group homes, in long-term care facilities and beyond. Providers have different titles and qualifications. PSWs and disability support workers (DSWs) earn anywhere between $15 to $26 per hour; PSWs in long-term care facilities tend to earn higher salaries than PSWs providing home care.[113]

Care providers all have something in common: their work is essential. There is, however, significant variation in how different kinds of care providers operate across Canada. Care provider professions are not all regulated, and some do not have professional colleges or regulatory bodies to bolster professional development and maintain professional standards. Each province sets its own educational and training requirements for PSWs, for example. Care provider wages typically fall under provincial legislation, and some care provider roles are unionized at the provincial and territorial level (e.g., the Canadian Union of Public Employees or the Ontario Council of Hospital Unions).

There has recently been movement to raise and standardize wages for some care providers in Canada. The 2023 bi-lateral federal-provincial-territorial health agreements planned to distribute "$1.7 billion over five years to support hourly wage increases for personal support workers and related professions, as federal, provincial and territorial governments work together on how best to support recruitment and retention."[114] Earlier, the COVID-19 pandemic motivated wage top-ups for care providers: the Ontario government initiated temporary wage top-ups that were later made permanent for publicly employed PSWs and DSWs.[115] The Liberal Party's 2021 platform committed to raising wages for personal support workers, "including a guaranteed minimum wage of at least $25 per hour."[116]

How to do it

The federal government should work with the provinces and territories to implement a minimum wage of at least $25 per hour for all publicly funded care providers, and maintain this commitment to a reasonable wage by indexing to inflation. This requires the federal government to negotiate under existing bilateral agreements. The federal government would need to increase federal funding transfers for home and community care to cover enhanced wages over time.

Protect migrant care providers

Canada faces a serious shortage of care providers.[117] Canada encourages migrants to come to Canada to work as care providers to help address this shortage. These are invaluable professionals who are helping meet a tremendous and growing need for paid care. They should be supported to come to Canada, and protected and valued when they are here.

The current system exposes migrant care workers to abuse. Many migrant care providers work in private households. This, combined with the employment insecurity created by Canada's immigration and labour laws, leave migrant care workers vulnerable to abuse and exploitation. For example, in a survey of 201 migrant care workers about their experiences during the pandemic, 40% of workers had worked more hours without compensation.[118]

Home-based care work creates an imbalance of power. There is no HR to appeal to when the employer is a care recipient (or a member of their family). More than this, many migrant care providers live with the families they care for, meaning they risk losing their homes if they are in conflict with their employers. Living with employers can also contribute to very low wages, as "room and board" is considered part of compensation. Without sufficiently high wages to allow for saving, however, room and board does nothing for care providers' long-term financial well-being or ability to exit bad employment relationships.

This power imbalance is not limited to home-based work. Care workers on temporary closed work permits can only work for the employer that sponsored them. They risk losing their work permits if they leave their job.

The Canadian caregiving ecosystem cannot function without migrant care providers, but we make it difficult for them to gain permanent residency to do their vital work over the long term. In June 2024, the federal government announced improvements to the Home Support Worker Pilot, including a better pathway to permanent residency.[119] While this is promising, more can be done to better protect migrant care workers. Without pathways to permanent residency, migrant care workers face poor incentives to come to Canada, higher rates of exploitation if they do come and shorter tenures contributing to the Canadian care economy.

To address these issues, the federal government must:

- **Improve pathways to permanent residency for migrant care workers**
- **Enhance protections for migrant care workers**

Providing care as a migrant care worker

Canada relies heavily on female migrant workers to fill labour shortages in the care provider workforce. Often entering Canada with temporary work permits, migrant care workers are vulnerable to abuse and exploitation. The nature of their work in private households and the employment insecurity they face creates an imbalance of power in the care worker's relationship with their employer.[120] They lack social and employment protections afforded to citizens working in Canada, and their residency in Canada is often tied to their employer. This vulnerability worsened during the pandemic, during which many were pressured to work longer and often unpaid hours, and, in some cases, forbidden to leave the private residence where they worked.[121] Migrant care workers face cultural and language barriers, and can lack the support of a community if they have been separated from their families.

Improve pathways to permanent residency for migrant care providers

> ***Make the Home Support Worker Pilot permanent and follow through on recently announced improvements***
>
> - *Canada should invite more care providers to live, work and stay in Canada for the long term.*

Canada desperately needs more care providers. Permanent residency (PR) is the best incentive to attract care providers to Canada, and one of the best ways to ensure they are safeguarded from abuse and exploitation when they are here.

The main pathway to PR for migrant care providers is the Home Support Worker Pilot. Introduced in 2018, it is meant to give migrant care providers pathways to permanent residency.

Recently announced improvements to the Home Support Worker Pilot include: reducing the mandatory work experience from 12 month to six months, accepting eligible work experience from inside or outside of Canada and adding the option to work for more types of organizations. These changes will allow many care providers the opportunity to begin the application process to permanent residency upon arrival to Canada, but **they have not yet been implemented.**

How to do it

The Home Support Worker Pilot should be expanded and made into a permanent program, processing times should be cut and improvements that have already been announced should be enacted quickly.

The federal government should raise the cap on the number of applicants eligible to apply to the Home Support Worker Pilot each year from **2,750 to 3,500.** To get more workers on the path to permanent residency, Immigration, Refugees and Citizenship Canada should take steps to reduce the processing time for permanent residency applications through this pilot to the target goal of **12 months.** Taken together, this can add 750 net-new care providers with permanent residency to the caregiving ecosystem every year.

The government should **enact the improvements announced in June 2024 immediately** in order to support more newcomer care providers working to strengthen the caregiving ecosystem in Canada.

The government should also **recognize the skilled work and training of care providers in the immigration points system** to open further pathways to permanent residency. Canada's point system is a world-leading approach, designed to attract the talent we need—and we need care providers desperately. The point system, or, more formally, the Comprehensive Ranking System, needs to be adapted to reflect this need. Currently, most care providers do not score highly in the ranking system because it emphasizes certain kinds of education.

Enhance protections for migrant care workers

> ***Protect migrant care providers' rights and give them greater stability through occupation-specific work permits***
>
> - *Migrant care providers should be better protected from exploitation.*

Newcomer care providers often work in people's homes without clear boundaries or practical ways to enforce their employment rights. In some cases, they work as temporary foreign workers whose legal status to be in Canada is directly related to their employer, exposing them to exploitation.

How to do it

The federal government should grant all migrant care providers occupation specific (rather than employer-specific) work permits so they can change employers without losing their legal status. Specifically, this includes work in a role that fits under National Occupation Classification (NOC) code 44101 – home support workers, caregivers and related occupations, NOC code 42201 – developmental service worker, group home worker, and related occupations, and NOC code 33102 - nurse aides, orderlies and patient service associates. The scope of this work should be expanded to care providers who work with people with disabilities. This would allow care providers to leave abusive or exploitative employers without fear of being forced to leave Canada.

The government should provide supports and education to protect migrant care providers' rights. This can include language courses, career advancement programs, and information about their rights and employment relationships, as well as immigrant settlement and legal aid services. The federal government should also collect data about migrant care provider experiences, including race and demographic data, to monitor outcomes and inform policy decisions.[122] All of this should be done in direct consultation with migrant care providers.

These changes would make it easier for migrant care providers to make career progress, settle in Canada, and understand their rights. They would also increase the appeal of working in Canada and increase the number of migrant care providers that stay in Canada, thereby filling labour gaps in a more sustainable, long-term way.

Pillar Five

Show leadership and recognition

Canada lacks a coordinated approach to caregiving across the country. While the federal government has made efforts to address aspects of continuing care, disability, dementia and healthy aging, there is no overarching federal strategy or legislation dedicated to strengthening support systems for caregivers.[123] This puts Canada out of step with peer countries like Australia, the United States and the United Kingdom, which recognize that a clear national vision and plan are necessary to avoid a caregiving crisis.

When the federal government makes caregiving a priority on the federal agenda, provinces and territories are more likely to do the same. Policy solutions span all orders of government for the care economy. While healthcare and home care are primarily under provincial jurisdiction, the federal government can use its influence to set caregiving as a priority.

How to show leadership and recognition

Make caregiving a priority in government

- Develop caregiver legislation that establishes the National Caregiving Strategy and creates an Advisory Council

Show federal leadership in healthcare

- Prioritize caregiving in healthcare conversations with provinces and territories
- Direct key national research bodies to collaborate on a full research agenda on caregiving

Ensure military and veteran families get the support they deserve

- Ensure interoperability between Canadian Forces Health Services, and civilian systems
- Ensure interprovincial mobility of services, such as automatic eligibility for autism services
- Assign a case manager to families with complex needs related to relocation

Make caregiving a priority in government

Caregiving should be a top priority for government, with built-in **accountability, measurements and caregiver voices ensuring success.** This moment is also an opportunity to **define and recognize caregivers as part of the care team.**

To address these issues, the federal government must:

- **Develop caregiver legislation that recognizes caregivers, establishes the National Caregiving Strategy and creates an Advisory Council**

Develop caregiver legislation that establishes the National Caregiving Strategy and creates an Advisory Council

> *The National Caregiving Strategy needs to come with legislative accountability mechanisms, and elevate caregivers' lived experience*

Federal Budget 2024 committed to developing a National Caregiving Strategy.[124] As of Fall 2024, the Strategy has not been created, including legislation to establish accountability. Some provinces have created their own legislation and action plans to enhance caregiver rights and supports. In Quebec, 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.[125]

How to do it

National caregiving legislation should establish the National Caregiving Strategy and mandate the development of an Advisory Council to provide advice related to the Strategy. This legislation should be developed through collaboration with the ministers of Health, Labour, Seniors, Diversity, Inclusion and Persons with Disabilities and Families, Children and Social Development, and in consultation with caregivers, care providers and expert stakeholders.

To support caregivers' rights in various settings, national caregiving legislation should include a caregiver definition. For instance, a caregiver designation would help to give caregivers rights as consumers in federally regulated industries, and give rights to caregivers in federal healthcare settings, such as healthcare services for the military. Establishing rights for caregivers at the federal level would provide a model for provinces and territories to do the same in provincially governed settings, such as healthcare.

To ensure the National Caregiving Strategy is implemented successfully with measurable targets, national caregiving legislation **should define roles and responsibilities related to the Strategy and mandate periodic reviews of the Strategy's impact.**

National caregiving legislation should define the mandate of a caregiving Advisory Council and its role in the development and implementation of a National Caregiving Strategy. The Council's role should also extend beyond the Strategy to providing ongoing advice to the federal government on the needs of caregivers, such as tax reform and military and veteran issues.

Show federal leadership in healthcare

Caregiving must be a federal health priority. While healthcare is largely under provincial and territorial jurisdiction, the federal government should play a role by prioritizing caregiving in healthcare negotiations with provinces and territories.

The federal government periodically negotiates bi-lateral agreements with provinces and territories about healthcare priorities and funding amounts. Done properly, this mechanism can dramatically impact the caregiving landscape. For instance, the most recent federal-provincial-territorial (FPT) agreement, the 2023 Working Together to Improve Health Care for Canadians Plan, included funding to support hourly wage increases for personal support workers and related professions.[126] The federal government can also tie funding to specific outcomes, as with the $2 billion transfer to provinces and territories in 2022 to clear backlogs in surgeries for procedures, like hip and knee replacements and cataracts, and in 2004 to reduce wait times in priority areas, like joint replacements and sight restoration.[127] [128]

Caregivers' needs—including their well-being, skills and challenges—should be on the agenda when care recipients meet with healthcare professionals, and this should be a priority for all orders of government. In CCCE's National Caregiving Survey, more than three-quarters of caregivers reported that having healthcare practitioners to ask about these needs and their well-being would be an important step forward. Such assessments are one example of the kind of change that can be advanced through federal-provincial healthcare negotiations.

To address these issues, the federal government must:

- **Prioritize caregiving in healthcare funding negotiations with provinces and territories**
- **Direct key national research bodies to collaborate on a full research agenda on caregiving**

Prioritize caregiving in healthcare funding negotiations with provinces and territories

> ***Prioritize the needs of caregivers in the next health agreement with provinces and territories***
>
> - *The federal government should use its negotiating power to shape provincial support for caregivers.*

The next round of healthcare negotiations with provinces and territories should **include specific funding tied to caregiving priorities, and shared health indicators monitoring caregivers' well-being.**

There is strong precedent for building priority issues into healthcare negotiations. As mentioned, the 2022 negotiations addressed the consequences of the COVID-19 pandemic, like surgery backlogs.[129] The 2023 bi-lateral health negotiations included agreements on measuring pan-Canadian progress on a set of common health indicators, prioritizing mental health and addictions and improving the safety of long-term care. The bilateral agreements also included targeted spending, with funding improvements for long-term care and home and community care, respite care and increases to the wages of PSWs and related professions.[130]

How to do it

The next round of federal-provincial-territorial health agreements **should target caregivers' well-being through a focus on respite services, home care and caregiver check-ins and assessments at healthcare appointments.** The agreements should also prioritize paid care providers with a focus on workforce stabilization.

To directly support caregivers, the federal government should negotiate changes to healthcare billing practices to **allow professionals to provide services to caregivers** alongside care recipients (e.g., well-being checks and referrals to counselling), and pay for extended healthcare professionals to give caregivers **practical training in caregiving skills.** Changes should also include **caregiver recognition and data collection** to inform health policies supporting caregivers.

The federal government should also use its power to improve circumstances for care recipients. These changes should include **additional support for home- and community-care services and respite for caregivers.**

The federal government should work with the pan-Canadian health organizations to set the conditions for better services at the provincial and territorial level. For example, the federal government should work with the Canadian Institute for Health Information to develop more **detailed health indicators that help to monitor the impact of provincial investments on caregiver well-being.**[131] Combined with caregiver well-being assessments, health indicators for caregivers would create accountability to track the impact of targeted caregiver funding in the next round of health agreements.

Direct key national research bodies to collaborate on a full research agenda on caregiving

> ***Canada's leading researchers should be tackling Canada's caregiving crisis***

The federal government should work with Public Health Agency of Canada, the Canadian Institutes of Health Research, and Social Sciences and Humanities Research Council to fund a comprehensive caregiving and care economy research agenda. This should include research on systems of care, the care economy, and best practices in integrative care. Together the agencies should collaborate on a comprehensive research agenda that will move the needle on implementation-ready solutions to improve the conditions of caregiving in Canada.

The role of caregiving as a social determinant of health should be a key research area. Understanding the impacts of caregiving on a caregiver's health is vital to crafting further supports for caregivers' quality of life. In other jurisdictions, like the United Kingdom, health authorities have designated caregiving as a social determinant of health.[132]

Ensure veteran and military families get the support they deserve

According to data from the Department of National Defence, in 2023, there were 52,707 Regular Force members of the Canadian Armed Forces—with 28,579 in the Army; 15,553 in the Air Force, 8,575 in the Navy; and an additional 28,500 in the Reserve Force. There are 461,240 veterans in Canada, and approximately 150,000 veterans from countries around the world currently residing in Canada.

When someone serves in the Canadian Armed Forces for a year or two—or several decades— their family serves beside them. Every military member and veteran possess many identities, diverse perspectives and unique experiences, and they share a deep commitment to service and sacrifice. For the most part, military members, veterans and their families are courageous, resilient, strong, capable and resourceful. To remain so, they require access to resources and supports to thrive and flourish. Military and veteran families experience the same challenges of finding a family doctor, long waits for specialized care, parenting, caregiving and sustaining a healthy relationship with their partner as their civilian counterparts. However, they may be moved to a new community with little notice, deployed to a conflict zone or assigned to study in another community for long periods of time. It is challenging enough when you are on a waiting list to see a specialist for two years, but it is extra hard when you move every two years.

Military and veteran caregiving mirrors civilian caregiving in many ways, but with additional complexities and stressors related to life in the military, military culture, the nature of the work and the challenges associated with inherent mobility, logistic management and risk. The challenges of military and veteran caregiving are magnified and amplified as military service presents unique caregiving challenges due to the nature of the work and life experiences, such as managing ever- changing logistics, mobility (frequent moves with no autonomy over where or when a move takes place) and risk as the work can be demanding and dangerous.

While military service affects military and veteran caregiving, so does the distance from family and friends who may otherwise provide additional caregiving support. Military members, veterans, their families and caregivers may be isolated in new communities, adjusting to disrupted routines and disconnected social networks. Military and veteran caregiving occurs in cities, towns and rural communities across Canada, emphasizing the need to expand the perspective and build awareness and competency to support the well-being and quality of life of all military and veteran caregivers, military and veteran family caregivers, care providers and care receivers.

To support military and veteran caregivers, the federal government should:

- **Ensure the seamless transition of healthcare records to improve the continuity and coordination of healthcare services for military families when they relocate**
- **Ensure interprovincial mobility of services such as automatic eligibility for Autism services**
- **Assign a case manager to military families with complex needs**
- **Expand eligibility of Veterans Affairs Canada Caregiver Recognition Benefit to more families**

Ensure the seamless transition of healthcare records to improve the continuity and coordination of healthcare services for military families when they relocate to new communities

> ***Military families should not go to the back of the line for support services when they are redeployed to new locations in Canada***

Military families are supported by the Canadian Forces and Health Services (CFHS). Operated by the DND, CFHS provides basic healthcare services, like medical, dental, mental health and other specialized services to military members and their families. CFHS collaborates with civilian healthcare providers and systems to ensure Canadian Armed Forces (CAF) members and their families have access to all of the care services they need, including services that are not covered by the military healthcare system. This means working with provincial and territorial healthcare authorities to coordinate care for military families during relocation and deployment. The transition of health records between CFHS and civilian healthcare providers is largely a manual process.

Canada's Defence Policy recognizes that high mobility has a strong impact on military families. The Policy commits to stabilization as a goal and funds support programs for families through Military Family Resource Centres.[133] DND has also committed to working with governments and industry to improve coordination of services across provinces. CFHS modernization is addressing problems like outdated infrastructure and integrating digital health systems.[134] Seamless Canada was established in 2018 to improve access to supports and services when members and their families relocate in Canada.[135]

How to do it

The federal government should work to enhance coordination and interoperability between CHFS and civilian healthcare services in order to ensure records and diagnostic results can be seamlessly transitioned when families relocate. This needs to include making it easy to exchange medical records, diagnostic results, and other health information between CFHS facilities and civilian healthcare organizations when necessary (e.g., during relocation and deployment).

The DND, in collaboration with civilian healthcare services, should launch an initiative committed to modernizing CFHS's systems and pursuing opportunities to improve interoperability. This initiative should be included as a component of other existing modernization initiatives within the DND. Options to improve the continuity and coordination of healthcare services for military families include:

- Interoperability between CFHS's health information systems and those used by civilian healthcare providers.
- Digitization and electronic health records to help ease transitions when families relocate.
- Expedited electronic medical record transfer, and enabling the transfer of records across Canada.
- Better information sharing specifically for families with children who have special needs.
- Exemptions from residency requirements, allowing families to qualify for services in a different province at the time they learn of redeployment instead of the time they move to a new location.

These changes would impact all military members and their families when they relocate.

For families with an Autistic child, these changes would ensure families are able to obtain and maintain important services for their child when they relocate. There are approximately 60,000 dependent children in military families in Canada.[136] Estimating that 8.2% of those military families have a child with special needs, such as Autism, these changes would have a substantial impact on 4,920 children with special needs, as well as their parents.

Ensure interprovincial mobility of services, such as automatic eligibility for autism services

The federal government should explore opportunities to ensure that when a military family is re-located, an agreement between CFHS and provincial health services enables families with an Autistic child to automatically qualify for autism services when they arrive.

Assign a case manager to military families with complex needs when relocating to a different province or territory

The DND and Veterans Affairs Canada should also consider options to leverage existing processes for case management to support families with complex needs when they relocate. Case managers would help to facilitate the seamless exchange of medical records, diagnostic results, and other health information between CFHS facilities and civilian healthcare as soon as a family is notified of redeployment or relocation.

These changes would implicate the DND and should be modelled after case management for veterans in Canada.[137] Alternatively, CFHS should employ more nurse case managers to support military families in addition to military members with complex needs.

Expand eligibility of Veterans Affairs Canada Caregiver Recognition Benefit to more families

Eligibility for the Veterans Affairs Canada Caregiver Recognition Benefit must expand to recognize the diversity of individuals providing care to military members and veterans, including partners, former partners, extended family, close friends, chosen family and young caregivers. This will ensure that spouses and children of veterans have independent access to programs and benefits based on their individual needs, including, but not limited to, financial support and mental health services.

Conclusion

Caregiving in Canada is at a crisis point, but there is hope if the federal government takes action now. The commitment to a National Caregiving Strategy in April 2024 is a historic opportunity for the federal government to set Canada on the right path, allowing caregivers, care providers and care recipients to thrive now and into the future.

This document is the product of CCCE's work with the caregiving community to articulate what is needed right now to stabilize and grow capacity among caregivers. Taken together, these federal actions can make all the difference in the lives of millions of Canadians.

There is work to be done together. The design and implementation of these actions need to be undertaken in collaboration with caregivers, care provider and care recipients. At the same time, the federal government needs to act quickly.

CCCE is also working to engage provincial and territorial governments on key issues like healthcare, home care and social services to complete the other part of the picture and change how caregiving works in Canada.

This is the moment to act. With a clear path forward, the federal government, caregivers, care recipients and care providers can build a future that works for all Canadians.

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