

Latest Suggestions to Improve Services for Care Recipients and Caregivers

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Looking at the news can be overwhelming. With each day that goes by, there seem to be more and more problems, and nobody seems to have any solutions.

To an extent, we need to talk about problems before we come up with a solution. If we act before we fully understand the complex factors behind a problem, our response can be more of a reaction than a solution.

Although we rarely see solutions in the news, many people are committed to researching and thinking about lasting solutions for the healthcare problems that we're facing. This article will feature just one group: the Canadian Centre for Caregiving Excellence (the CCCE).

The COVID-19 pandemic shone a light on pre-existing vulnerabilities within the caregiving field, and the CCCE has come up with a number of possible solutions ([p. 51](#)).

Who is Proposing Solutions for the State of Caregiving in Canada?

The CCCE is a group of diverse people across Canada with a variety of educational and professional backgrounds ([source](#)). They are committed to supporting and empowering caregivers and care providers, as well as advancing the knowledge and capacity of the caregiving field and advocating for effective and visionary social policy ([source](#)). They approach all of this important work with an understanding of disability ([source](#)).

A few weeks ago, the CCCE published their first policy whitepaper ([source](#)). Click [here](#) to read a 7-page summary, and click [here](#) to read the 100-page document.

Their whitepaper offers potential solutions to address the many challenges and systemic issues experienced by more than 8 million caregivers and care providers across the country ([source](#)). Their goal is to ignite a public conversation on the state of caregiving ([source](#)).

I hope that this short preview of the original, longer document sparks your curiosity and inspires you to join the conversation! Your experience as a care recipient and/or caregiver is extremely valuable. Your input can be part of the solution by helping the CCCE advocate for better policies that improve services for care recipients and caregivers/care providers.

There will be more information about next steps in the Final Thoughts section of this article.

Definitions

You might be wondering if this conversation applies to you. These definitions should make it clear and address any doubts you may have!

A **care recipient** is 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 ([page 3](#)).

This does not include children without a disability, medical condition or illness ([page 3](#)).

Caregiving refers to providing help or care to another person, such as: people with physical, intellectual, or developmental disabilities; people with medical conditions; those experiencing mental illness; and/or people with changing support needs related to aging ([page 3](#)).

Caregiving is done by both unpaid caregivers and paid care providers ([page 4](#)). Care providers and caregivers often fill major gaps in broader health and social systems ([page 4](#)).

A **care provider** is 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 ([page 3](#)). This includes Direct Support Professionals (DSPs), Personal Support Workers (PSWs), attendants for people with disabilities, and respite workers ([page 3](#)). Support professionals now provide educational support, health care, physical therapy and mental health care.

A **caregiver** is an unpaid family member, friend, or other support for someone who needs care due to physical, intellectual, or developmental disabilities; medical conditions; mental illness; or needs related to aging ([page 3](#)). Caregivers provide care because of a relationship, not as a job or a career ([page 3](#)). This definition does not include parents or guardians providing care to a child without a disability, medical condition or illness ([page 3](#)).

Caregivers also bear a wide range of responsibilities, such as: personal care; food preparation; shopping and housekeeping; transportation and care co-ordination; health-care-related tasks such as dialysis and ventilator management; advocating on behalf of the care recipient; providing care recipients with emotional support; and financial management ([pages 4-5](#)).

A **double-duty caregiver** is a person who provides unpaid care to a family member or friend while also being employed in the health-care field ([page 4](#)).

What challenges do Canadian caregivers and care providers experience?

Most Canadians will be a caregiver or need a caregiver at some point in their lives, but providing care can come at great emotional, physical, and financial cost ([source](#)). Policy solutions are urgently needed to support caregivers and care providers across the country ([source](#)).

- In Canada, 1 in 4 people identify as a caregiver and 1 in 2 will become one in their lifetime ([source](#)).

- Caregivers spend 5.7 billion hours supporting others every year, valued at \$97.1 billion ([source](#)).
- Caregivers provide the equivalent support of 2.8 million full-time paid care providers each year ([source](#)). Caregivers provide 3 hours of care for every 1 hour in healthcare and social support systems ([source](#)).
- Many caregivers struggle with lost economic productivity. The total amount of caregivers' lost economic productivity due to care responsibilities is valued at \$1.3 billion per year ([source](#)).
- The fact that 69% of caregivers reported worsening mental health shows that the cost is more than financial ([source](#)).

During COVID-19, the high demand and shortage of care providers has increased pressures for them to work unreasonably long hours, cover additional shifts, and work short-staffed ([source](#)). In 2020, Long-Term Care facilities were 1 to 2 staff short every shift ([source](#)). Research shows that only 50% of PSWs remain in the sector for more than five years ([source](#)).

What are the CCCE's solutions?

The CCCE offers multiple solutions in its 100-page whitepaper!

This part of the article will share a simplified summary of the solutions within the section called "Improve, expand and invest in services for care recipients and caregivers", which can be found on pages 63 to 65 of their whitepaper.

I highly recommend you read the table of contents and read other sections that are relevant to you! Click [here](#) to read the full document.

Potential options to help improve care services:

1. Provincial and territorial governments should increase funding for home, continuing care, and community support services

In April 2022, the Ontario government committed to investing \$1 billion to expand home care over the next three years, and it has permanently enhanced wages for all DSPs and PSWs by \$3 an hour on top of existing wages ([page 63](#)).

These are steps in the right direction, however, the CCCE states that we need more investment, and more sustained investment ([page 63](#)). This would address caregiver and care provider burnout, improve working conditions for care providers, and prevent care recipients from not getting the care that they need ([page 63](#)).

2. Making it mandatory to assess caregivers' needs

Too often, caregivers have not received enough support. This led to the creation of standardized assessment tools that measure caregivers' needs and eligibility for services

([page 63](#)). Two examples are the interRAI-based self-reported survey using a Caregiver Wellbeing Index and the Carer Support Needs Assessment Tool (CSNAT) ([page 64](#)).

These tools could be consistently used throughout each province and territory ([page 64](#)). Also, these tools could be transparent and accessible for all publicly-funded services, training and financial supports that are available for caregivers ([page 64](#)).

If it were mandatory to do these caregiving assessments, it would be easier for caregivers to receive the support that they need. However, according to focus group participants, assessments need to be tied to healthcare workers' concrete obligations to act, and the services and supports that they are being referred to need to be properly funded ([page 64](#)).

3. Providing training and support to meet the unique needs of caregivers

Caregivers often deal with difficult circumstances when they would have appreciated some coaching and training ([page 64](#))! As the needs of a care recipient change, so do the training needs of caregivers ([page 64](#)).

Training and support for caregivers should be available and adaptable to their current situation ([page 64](#)). In addition, institutions should invest in more training courses designed for common challenges caregivers face ([page 64](#)).

One resource already exists: McMaster University's Continuing Education online courses on caregiving essentials ([page 64](#)). These courses are free and self-paced, meaning that you don't need to follow a schedule to complete them ([source](#)). Click [here](#) to learn more.

Beyond training, caregivers should have guaranteed access to personalized coaching from healthcare professionals to make sure they can meet the unique needs of the care recipient ([page 64](#)).

It can be difficult for health-care providers to identify, engage and support caregivers ([page 64](#)). Caregivers' unique circumstances and needs would be better met through person-centred and trauma-informed care from healthcare providers ([page 64](#)). Also, a guaranteed and consistent assessment of a caregiver's needs should be a component of the care recipient's care plan ([page 64](#)).

4. Provincial and territorial governments could work with local health and social care authorities to provide more integrated care

This has already begun to happen in Ontario: The Ontario Caregiver Organization has been leading efforts to develop greater co-ordination and collaboration across different sectors so that care recipients and caregivers are at the centre of care ([page 65](#)).

This effort includes working on including caregiver strategies into new models of integrated care within Ontario Health Teams ([page 65](#)).

However, more action is needed for integrated care to happen ([page 65](#)). Funding arrangements could be better integrated to create shared accountability and incentivize collaboration across different service providers and health-care settings ([page 65](#)).

5. Develop and fund Public Navigators

While the sector is working towards truly integrated care, provincial and territorial governments could develop more public navigator roles ([page 65](#)). While case managers and social workers offer system navigation support, it's only one component of their role ([page 65](#)). The difference with public navigators is that their main purpose would be helping people identify and overcome barriers to accessing care services ([page 65](#)).

The CCCE recommends that these navigators are thoroughly trained in the systems they will be working within, and they should know how to work across silos to achieve results for the people they are supporting ([page 65](#)). This service will require a fee for caregivers because licensing or some other process of overseeing their work would be required to make sure that it is ethical and there are no conflicts-of-interest ([page 65](#)). This role could also be an opportunity to engage experienced caregivers to support their peers in navigating complex systems ([page 65](#)).

Public navigators already exist for specific groups, such as Canadian Armed Forces families ([page 65](#)). If we expanded public navigators' role, it would help solve the problem of caregivers and care recipients struggling to navigate the complex healthcare system by themselves. This responsibility would be shifted from private to public ([page 65](#)).

Final Thoughts

What do you think about these possible solutions? You're invited to join the conversation on social media by using the hashtag #CdnCaregiving. You're welcome to share an image that the CCCE created (click [here](#) and scroll down) and/or write a personal statement about why giving care is important to you and your future.

The CCCE's whitepaper is the first in their series of actions to rally support behind creating policies that will establish a coordinated approach to caregiving ([source](#)).

Over the course of 2023, the CCCE plans on hosting a national caregiving summit with stakeholders from across the country ([source](#)). This includes organizational partners and people with lived experience from coast to coast to coast ([source](#)). This summit will lead to the development of a national caregiver strategy ([source](#)).

To contact the CCCE and/or sign up for their newsletter for more information, click [here](#).

If you think you may be experiencing symptoms of COVID-19, take the self-assessment at www.ontario.ca/coronavirus. Follow all directions from your medical provider or your local health unit at the following phone numbers:

Telehealth Ontario: 1-866-797-0000

Toronto Public Health: 416-338-7600

Peel Public Health: 905-799-7700

Durham Region Health Department: 905-668-7711

York Region Public Health: 1-877-464-9675