



Pre-Budget Submission 2024

January 2024



ABOUT THE ONTARIO CAREGIVER COALITION

The Ontario Caregiver Coalition (OCC) is the voice of caregivers in Ontario. We advocate for recognition and support for the family, friends, and neighbours whose unpaid care is the hidden backbone of Ontario's health system. Our members include both caregivers from across Ontario and organizations that support them.

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THE ISSUE

Caregiver financial distress is an urgent problem in Ontario. Ontario caregivers are the backbone of our health care system, providing an estimated \$28.5 billion per year worth of care.

However, their value to the Ontario health care system comes at a personal cost. Our caregiver members have told us time and time again that their top policy priority is to address the financial impact of caregiving. Considerable out of pocket costs are incurred by caregivers for transportation, prescriptions, medical supplies, home renovations, and supplementary home care, respite services, and occupational and other therapies. Caregiving is also time-consuming, many caregivers must reduce their labour force participation, thereby cutting into their income and savings. As a result, many caregivers experience significant financial distress.

KEY FACTS

- 45% of Ontario's caregivers are experiencing hardship because of their caregiving responsibilities
- 20% have taken a loan or line of credit to pay for the expenses.

(Ontario Caregiver Organization, Spotlight Report 2021)

Where caregivers are unable to care for their loved ones, it substantially impacts the health and long-term care (LTC) systems: caregiver financial distress is a significant cause of collapsed community caregiving arrangements, leading to admission to acute or institutionalized care. This has significant government cost implications.

"I think it's very troubling and surprising that caregivers are not given any financial assistance. Caregivers are not only helping the ones they care for but also helping the government save a world of healthcare costs by taking care of their loved one." (OCC Caregiver Member)

"We dip into our savings and our investments and our lines of credits to pay these things, to get the support and care that not only they need, but that they deserve. (OCC Caregiver Member)

OUR RECOMMENDATIONS

1. Provide direct financial support to unpaid caregivers

Financial distress among unpaid caregivers is a persistent and growing problem. The Canadian Centre for Caregiving Excellence recently reported that two-thirds of unpaid caregivers report financial hardship related to their caregiving responsibilities.* Caregivers are taking out loans and lines of credit, eating into their savings, and cutting back on employment so they can provide care for their loved ones.

* Canadian Centre for Caregiving Excellence, *National Caregiving Survey: Summary of Findings* (November 2023).

Caregiver financial distress and burnout is a major cause of the collapse of community caring arrangements and premature or unnecessary reliance on expensive institutional care.

Unpaid caregivers have access to very limited financial supports. Because of its restrictive requirements and lack of refundability, only 9% of caregivers are currently accessing the Canada Caregiver Credit, which itself provides only minimal support. Ontario's Caregiver Amount tax credit is similarly minimal, complex, and non-refundable and as such does not meet caregiver needs.

A new approach for Ontario's caregivers is needed; one which will ensure that those who need care can continue to receive it in the community as they desire, that unpaid caregivers are not forced to choose between providing care and living in financial distress, and that the limited resources of the health, long-term care and development services systems are effectively allocated.

Nova Scotia's Caregiver Allowance provides an excellent case study. By providing direct financial support to caregivers, it has proven to be a cost-effective way of delaying or avoiding the use of costly institutional care. A Cost-Benefit Analysis developed for the OCC estimated that a Nova Scotia style allowance would result in a net saving for the government of Ontario which would increase over time, by replacing 7.8% of Ontario's long-term care beds. In a conservative scenario, this would represent net yearly savings to government of \$307mn per year, escalating to \$390mn per year in 2040.

The Ontario Caregiver Coalition recommends the creation of an Ontario Caregiver Support Benefit that would:

- *Be available to caregivers providing care to a care recipient enrolled, approved to be enrolled, or waitlisted in programs illustrating a need for care, such as Passport, Special Services at Home, or respite services through Home and Community Care,*
- *Provide support through a monthly allowance, to allow caregivers to budget and meet ongoing expenses,*
- *Provide a maximum of \$1,000 per month, to be scaled based on severity of caregiving needs.*

2. Strengthen Home and Community Care

Unpaid caregiving is part of a web of services allowing individuals and families to receive and provide the essential care they need to remain at home and in their communities. But they can't do it alone - robust home, community, and respite services are vital to maintaining our connection to home and to Ontario's healthcare system overall.

There are more individuals than ever returning home and living in the community who require ongoing assistance. As the Ontario Community Support Association notes, "Between 2003 and 2018 the proportion of home care and community support service clients who are high risk or very high risk of an adverse event has almost doubled" with "most providers [saying] their programs would need to expand a minimum of 25% to meet community needs"[†].

[†] OCSA, 20224 Pre-Budget Consultation Submission, <https://www.ocsa.on.ca/2024-pre-budget-recommendations>

And it is no secret that Ontario is facing a health human resource crisis. As the government focuses on addressing the crisis in acute and long-term care (LTC) settings, the crisis in home and community care human resources continues to worsen. As skilled workers seek out better compensation, benefits, and support, the wage disparity between professionals in the home and community care sector and the hospital and LTC exacerbates the health human resources problem.

As a result, unpaid caregivers are left to fill in the gaps. They increasingly find themselves called upon to provide the kind of care traditionally provided by health professionals, worsening the financial distress and burnout they face ultimately leading to the collapse of community care arrangements.

Ontario can take concrete steps to relieve the pressure and build a more robust system. Investing in the home and community care workforce by removing the wage disparity between it and hospital and LTC will allow providers to recruit, train, and retain the qualified healthcare workers they need.

The Ontario Caregiver Coalition recommends increased investment in home and community care, by investing in a retroactive pay increase and closing the wage and benefits gap with those in comparable positions in hospital and long-term care settings.

3. Improve access to direct funding programs

The needs of individuals and their caregivers are diverse. That's why direct funding programs, including the Passport, Special Services at Home, the CILT Direct Funding Program, and Family Managed Home Care, play a vital role in the quality of life experienced by individuals with disabilities and their caregivers.

However, the skyrocketing cost of living has put an immense financial strain on the most vulnerable among us. Many families have to make impossible choices; between keeping the heat on, feeding their families, or getting the proper care their loved ones need.

No one should be forced to make these choices.

The current disbursement model for programs administered by the Ministry of Children, Community and Social Services such as the Passport and Special Services at Home programs, work on a reimbursement basis, with some having to wait up to eight weeks before being repaid. While there are options for families who cannot wait for reimbursement, such as engaging with a Transfer

Payment Agency to provide direct support, these agencies may claim up to 10% of the client's funds that could otherwise be used for care purposes.

Direct Funding programs managed by the Ministry of Health use the much more accessible reconciliation model. By adjusting the disbursement method, the Province of Ontario can take real action to help ease the financial strain on persons living with disabilities and their caregivers while also ensuring that the funds directly support their intended beneficiary.

These recommendations aim to not only remove barriers for specific populations but also streamline and improve the overall effectiveness of Direct Funding programs. By implementing these changes, the government can contribute to a more accessible and equitable support system for individuals living with disabilities and their caregivers across Ontario.

The Ontario Caregiver Coalition recommends strengthening Direct Funding programs by moving all Direct Funding to a reconciliation rather than reimbursement model.