

INFORMATION ALERT: ALTERNATIVES TO INSTITUTIONS

A PAID FAMILY CAREGIVER PROGRAM FOR ONTARIO (PFCP)

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February 25, 2021

Preamble

Ontario needs a paid family caregiver program. This report explains why.

There it is – that gut wrenching decision right before you. Mom is failing. She cannot take care of herself anymore. But you have to work to support your family. You can't afford to take an unpaid leave to care for your mom in the final months or years of her life. The guilt is terrible and so is the stress. What to do? The few home care hours available will not come close to meeting her needs and home care has been shown to be terribly unreliable. You can't afford enough hours of expensive private home care to supplement what publicly funded Home Care provides. What happens if a worker doesn't show up to work? What happens to mom if I have to go to work? What if there are not enough home care workers available in my rural area?

This is a common scenario today in Ontario. Sons and daughters wracked with guilt desperately trying to figure out how to keep mom or dad at home as they become frail and unable to care for themselves. Most have to work to keep food on the table and a roof over their own and their family's heads.

The Ontario Caregiver Alliance¹ says that "there are 3.3 million or 29% of Ontarians who are unpaid family caregivers" including 500,000 caregivers between 15 and 24 years of age who provide between 14 to 27 hours of care per week. Family caregivers lose jobs and suffer significant financial distress as well as illness and death as a result of their caregiving responsibilities. Canada saves between 30 and 40 billion dollars in the free labour provided by family caregivers. It is the families that bear the brunt of what Canada saves at their expense.

Benefits Currently Available

What help is currently available to a family who may want to care for mom or dad at home?

Not much.

Certainly not on a par with what long term care institutions are paid to provide what has been documented in press reports to be substandard and dangerous "care" (Mancini et al, 2020).

¹ Ontario Family Caregiver Alliance – The Facts - https://www.ontariocaregivercoalition.ca/the-work-we-do

The Canadian government, through the Employment Insurance program will provide financial assistance of up to 55% of someone's earning to a maximum of \$595.00 a week. These benefits are available for up to 15 weeks to care for someone who is critically ill or injured, and up to 26 weeks for someone of any age that requires end of life care (Government of Canada, 2021).

People Follow the Money...Right Into Institutions

If you are willing, or forced for lack of other options, to place mom or dad in a nursing home, that facility, often operated by a for-profit multinational corporation, will be paid \$182.23 per day to provide 2.5 hours of care or less (Ontario Ministry of Health and Long Term Care, 2019).

So predominantly for-profit institutions get at least \$1275.61 per week to provide assembly line care on anywhere from a 1:12 to 1:18 staff to resident ratio, while families providing much higher levels of daily personalized care to loved ones only get up to \$595.00 per week.

What is wrong with this picture?

Imagine how many families could keep loved ones at home if they were paid \$1275.61 per week to care for them? Imagine how much that waiting list for long term care institutions would shrink if family caregiving was paid the same as funding provided to institutions, and was actually available?

There are many families in Ontario who, given the opportunity and financial support, would choose to keep loved ones at home rather than have them enter a long term care institution. This has been especially true during the COVID-19 pandemic. Family members who have to work, but who might consider an unpaid leave of absence if they were sure of regular income, might choose to become full-time caregivers for family members needing assistance.

Even those requiring significant levels of complex medical care can now be maintained at home by family caregivers assisted by specialized services provided through Home Care and the Community Paramedicine Program². These include: specialized nursing care, physiotherapy,

² The Community Paramedicine Program provides "access to health services 24-7 through in-home and remote methods such as online or virtual supports; non-emergency home visits and in-home testing procedures; ongoing monitoring of changing and escalating conditions to prevent or reduce emergency incidents; additional education about healthy living and managing chronic diseases; and connections for participants and their families to home care and community supports"

https://news.ontario.ca/en/release/59381/ontario-expanding-existing-community-paramedicine-programs-to-long-term-care

occupational therapy, social work and other services (Ontario, n.d.). A robust Home Care program combined with paid family caregivers would go a long way to taking the pressure off waiting lists for long term care.

By providing payment to family caregivers to facilitate them staying home to care for loved ones, families can become part of a care team that includes specialized supports provided by the programs mentioned.

A paid family caregiver model launched as a pilot project in Ontario with a cap on daily payment at the current rate of payment to a long term care facility is an option to help ease the staffing shortage, and provide assistance to those currently on waiting lists for a long term care bed.

And it would still be cheaper because no expensive funding would be required for infrastructure, bed redevelopment or the funding of new institutional beds.

A Made In Canada Solution: The Newfoundland/Labrador Paid Family Caregiver Program

In 2015, the governments of Newfoundland and Labrador introduced a paid family caregiver program (Newfoundland Labrador Health and Community Services, 2015) intended to enhance community support to allow people to remain in their own homes and communities.

It began as 250 subsidies for seniors and individuals with disabilities allowing them to pay a family member for approved home support through direct, individualized funding. This provided flexibility for individuals receiving the assistance and reduced the administrative burden.

The Paid Family Caregiving Option was so successful that it is now an approved permanent option for delivery of services with no fixed number of subsidies.

It is available to those who need a longer term home support subsidy and meet eligibility requirements for any publicly funded home support services such as the Adults with Disability or Seniors Home Support Programs.

Individuals may receive 4-5 hours of assistance per day for personal services plus additional funding for homemaking and respite services. They must meet clinical and financial assessment criteria to receive services, as well as need personal care and behavioral support that can be provided by a family member. A co-payment may be indicated depending upon the financial assessment.

In Conclusion

Ontario currently relies on predominantly for-profit long term care institutions and a seriously flawed Home Care program to provide assistance to older individuals and people with disabilities. Neither has been shown to be reliable or even safe.

It is long past time for Ontario to recognize the people who care the most, often at great personal and financial cost, lighten their load, and pay them to provide assistance to their loved ones so that they can stay in their own homes or in family member's homes where they are most comfortable.

It is time to stop throwing money at large multinational corporations, and instead re-direct funding to individuals and families where it will do the most good.

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