



SENIORS FOR SOCIAL ACTION (ONTARIO)

Editorial

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Time for Ontario to Rethink Direct Funding for Older Adults

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In recent years I have needed home care from the province of Ontario to assist with the caregiving for my partner with Huntington's Disease. Our home care support also provides respite for me, so that I can continue my senior's advocacy and pursue my personal interests. Despite these meaningful breaks for self-care, my life as a caregiver requires my full attention day in and day out. It can be wearing and challenging. For me to manage my daily life, I require robust home care and supportive relationships with family, friends, and neighbours.

Older adults who require home care have few options in Ontario. Most home care in the province is transactional, with workers from private companies coming into people's homes for a specified number of hours and designated tasks, such as showering, dressing, eating, and other personal care. Although respite for the caregiver is part of traditional home care, many families report that it is difficult to obtain those hours. A [survey by Seniors for Social Action Ontario](#) found that 35% of home care recipients were satisfied or very satisfied, while 45% of respondents were dissatisfied or very dissatisfied.

There are many reasons why a family might be dissatisfied with their home care. For some people, it is simply that they do not have adequate hours of care. Although there has been \$2 billion added to home care in recent months, compared to the billions spent on long-term care institutions the home care sector is underfunded and under-valued by the Ontario government.

For many home care recipients, it is the lack of flexibility and consistent care, with workers constantly changing within the insecurity of the care system. For our family, we experienced all these issues, and, like many families, traditional home care simply did not meet our needs.

My partner and I need choice, control, and flexibility over who and how people come into our home and to have trusting relationships with our workers. We believe that ***high quality home care must pay attention to these critical values – choice, control, flexibility, and relational care.***

Our family has had direct funded home care under the Family Managed Home Care Program for almost two years. From this lived experience and from research, we believe that direct funding is the only way for these values to be fully achieved.

[Family Managed Home Care in Ontario](#) is a direct funding program that provides “clients or substitute decision-makers with considerable independence and responsibility.” People that have Family Managed Home Care must be able to hire, manage and pay service providers, and be accountable for their spending. The program is available to families that have children with complex needs or to people with brain injuries. For older adults, the program is only available for clients in extraordinary circumstances.

“Extraordinary circumstances” includes a broad array of criteria, including a) The nature, frequency and intensity of care required (e.g., complex medical needs requiring extensive training or unique/challenging behaviours), b) Unique scheduling issues, c) Cultural considerations which may include customs, traditions, cultural values and/or beliefs that affect client care, rural or remote/isolated location (e.g., geographical distance and accessibility of care location), d) Lack of available contracted service providers.

What is missing from these criteria is the need which many people have for consistent relationships. Some vulnerable older adults do not do well with strangers, inconsistent care, or different workers in and out of the home. Direct funding allows for a relationship-based approach with dependable workers. With the same workers spending up to twelve hours a week in our home, they come to understand routines, but also our family values, my partner’s preferences, and gentle approaches that minimize agitation and vulnerabilities.

Issues with Direct Funding Family Managed Home Care

The biggest limitation of the Family Managed Home Care program is the fact that it is only available to older adults who are experiencing “exceptional circumstances.” Many families want more flexibility in the way that their home care is provided. Since direct funding provides much more flexibility than traditional home care, it makes sense that it be available to anyone who wants this kind of flexibility. Being able to hire your own workers is a feature that is very attractive to many families. Since much home care work is intimate between the worker and the recipient, families feel grateful when they can hire someone who is a good fit with the older person’s needs. For example, we hire women who are open-hearted and compassionate, with strong personalities. We want our workers to understand relational care and our need for flexibility, but to also understand the value of personal boundaries. As described by Joan Tronto, this is “caring with,” (as opposed to “caring for”) as the relationships are based on deep respect and trust.¹

Ontario needs to end the discriminatory criteria currently used to assess eligibility for Family Managed Home Care for it to be an option for anyone who requires home care.

Our recommendation to Ontario Health at Home is that they remove the criteria of ‘exceptional circumstances’ and replace it with ‘families who desire maximum flexibility.’

Second, the application process for Family Managed Home Care is quite cumbersome. In comparison to other provincial direct funding programs for people with disabilities, the guidelines are much more complicated and onerous. Families must be able to navigate an on-line system that involves insurance for workers, hiring a bookkeeper, police checks, and several other guidelines. I recently recommended Family Managed Home Care to another family, and after reviewing the guidelines, the older woman in the family said to me. “It is almost as if they do not trust families.” Whenever programs are overly bureaucratic or complicated, it limits who can access the program.

Professor Christine Kelly’s work on direct funding programs across Canada shows that they are used most frequently by higher-income families.ⁱⁱ Simplifying the application process can broaden the appeal of direct funding.

Our recommendation to Ontario Health at Home is that the application process be simplified and that more support be provided to families that are applying.

In response to the demand from families for increased access to Family Managed Home Care, Ontario Health at Home recently hired coordinators in each region of the province. We are grateful for this change and have found it to be very beneficial, as the local coordinators provide more guidance and support for families.

Flexibility and Security in Direct Funding Programs

Direct funding programs do provide a large degree of flexibility. Individuals and families oversee the guidelines for workers, and they can schedule workers at their convenience. They can pay workers with a very reasonable pay scale. At the individual-worker level, much flexibility can lie with the person in terms of how care is provided.

The only direct funding program in Canada that offers more flexibility than Family Managed Home Care is the Newfoundland/ Labrador program, Self-Managed Home Support.ⁱⁱⁱ This is a direct funding program that enables family members to be paid for caregiving if they must leave a job to support a spouse at home. With thousands of Canadians leaving employment every year to become caregivers, this program is an exemplary approach to home care.

Direct funding programs, while providing flexibility for families and individuals, often find it difficult to provide security for workers. Cynthia Cranford, in her book *Home Care Fault Lines*, describes this as “flexibility-security tension” in home care.^{iv} While families rightly want flexibility, workers have a strong desire for security, with regular hours, decent wages, and full-time opportunities.

We have hired neighbours and women looking for part-time work. For workers looking for full-time work, especially immigrant women, direct funding programs cannot address their employment goals.

As direct funding programs expand, we may see a remedy to this flexibility-security tension. In 2021, two women from the Peterborough area of Ontario founded *Home Care Cooperative, Inc.* With 17 personal support workers as co-owners, the Co-op provides home care support to many families with direct funding. As much as possible, they provide flexibility to families, while giving workers security. Co-founder Danielle Turpin emphasizes that co-op workers make decisions together and spend as much time as they need to get to know their clients.

Direct funded home care is not a comprehensive solution to health and aging challenges. Yet, it is an important part of the puzzle that families need when one family member needs care and support. We know that integrated community services, naturally occurring retirement communities (NORC), and strong informal supports from family, friends, and neighbours are also part of a meaningful system of care.

In our family, we always think of self-determination *and* community. How can the person with disabilities experience choice, participation, contribution, and the right supports? Who in the community can be engaged as paid workers, volunteers, and friends? How can self-determination and community enhance quality of life?

As I explore more fully in my book, [*Aging and Elder Care: Time for Transformation*](#), the adage, “it takes a village,” becomes possible when direct funding is available, easily accessible, and manageable for families, alongside other community-based supports that enable older adults to feel they matter and that they belong.

John Lord is a researcher, writer, elder, and leader with SSAO. He was the founding director of the Centre for Community-Based Research and is the author of several books, including Aging and Elder Care: Time for Transformation. John lives in Kitchener-Waterloo, Ontario.

End Notes

ⁱ Tronto, Joan (2013). *Caring Democracy: Markets, Equality and Justice*. New York: New York University Press.

ⁱⁱ Kelly, Christine, et al (2020). *Directly Funded Home Care Programs in Canada*. Winnipeg, MB: Centre on Aging, University of Manitoba.

ⁱⁱⁱ Home Support Services Program Paid Family Caregiving Option, Newfoundland/Labrador: Department of Health and Community Services. [Provincial Home Support Services Program Paid Family Caregiving Option - Health and Community Services \(gov.nl.ca\)](https://www.gov.nl.ca/health/home-support-services-program-paid-family-caregiving-option/)

^{iv} Cynthia J. Cranford (2020). *Home Care Fault Lines: Understanding Tensions and Creating Alliances*. Ithica, New York: Cornell University Press.