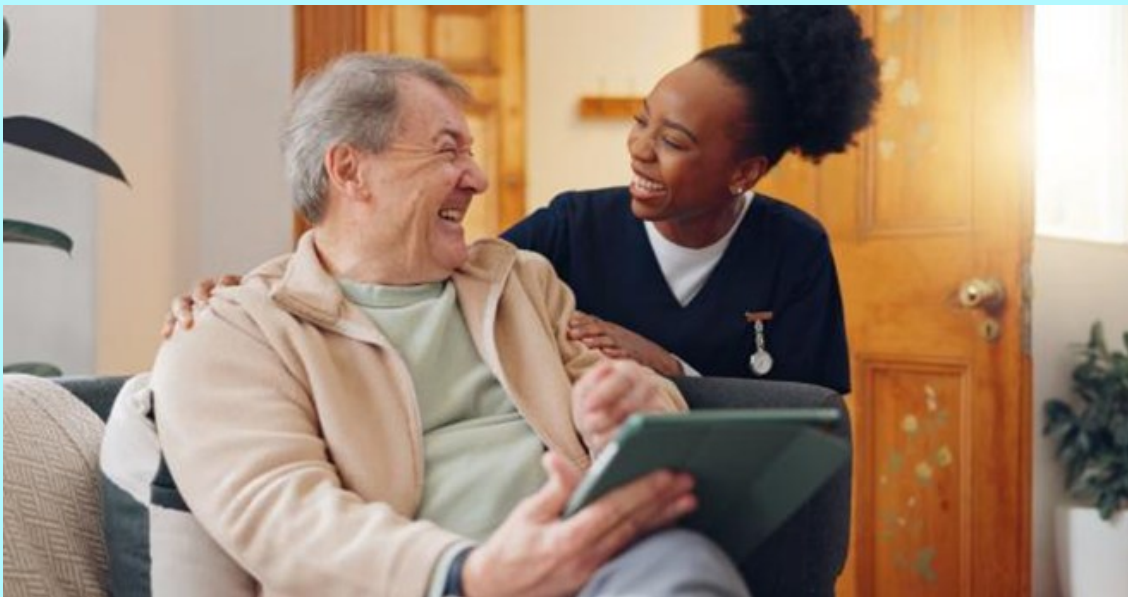




FAMILY MANAGED HOME CARE: THE NEED TO END DISCRIMINATORY CRITERIA AND IMPROVE ACCESSIBILITY



BRIEF TO ONTARIO HEALTH AT HOME

SENIORS FOR SOCIAL ACTION ONTARIO (SSAO)

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BRIEF TO ONTARIO HEALTH AT HOME

INTRODUCTION

Seniors for Social Action Ontario (SSAO) has noted many improvements in Home Care provision over the past several months as well as the willingness of senior Ontario Health at Home managers to respond quickly, sensitively, and effectively to issues raised by individuals and families using home care services.

SSAO also notes the willingness of Ontario Health at Home to fully embrace home care modernization by examining ways that integrated care can be provided to communities with a high percentage of older adults.

With this in mind, this brief identifies an area of home care provision that also requires streamlining and modernization – Family Managed Home Care.

The primary areas that need to be addressed that would optimize access and effective use of this program are:

- Removal of current discriminatory age and disability-based criteria for access and replacement with needs-based criteria;
- Replacement of ‘exceptional circumstances’ criteria with criteria that supports more flexibility in home care provision;
- Streamlining of the currently excessively onerous and bureaucratic application and reporting process.

Addressing these three areas would transform the Family Managed Home Care Program into a much more effective and accessible way to deliver home care services.

FAMILY MANAGED HOME CARE: A GOOD PROGRAM THAT COULD BE EVEN BETTER

Family Managed Home Care is a vital resource for individuals with disabilities and their caregivers in Ontario. Like other direct funding programs across Canada, it “enhances choice and flexibility of home care services, particularly in terms of what gets done and when it gets done, leading to greater satisfaction and a sense of improved care quality among both clients and caregivers.... [it] also reduces caregiver burden” (Kelly, 2020).

Another benefit of this program is that it can help to address the shortage of care workers in that family caregivers are often able to find and employ workers familiar with their loved ones, creating more comfort for both those receiving care and their family caregivers.

SSAO recognizes that direct funding may not be for everyone as the research points out, and that it does not necessarily lead to better health or social outcomes, and it may involve caregivers having to deal with “increased complexity of system navigation” (Kelly et al, 2020).

Having said that, for families willing and able to take on this challenge, it has been a godsend in allowing a more

reliable, relational, and individualized approach to caregiving.

A STATEMENT OF THE PROBLEM

Seniors for Social Action Ontario values the availability of Ontario’s direct funding program, which supports many individuals in need.

Discriminatory Access Criteria

Family Managed Home Care has been a blessing for many older people in Ontario. But for too many others, the current discriminatory criteria prevent access, create health services inequity, and the unnecessarily cumbersome and bureaucratic process prevent those who could benefit from this option from being able to access it.

Older adults in Ontario requiring traditional home care have few options. Most home care is transactional, with workers from private companies or non-profit organizations 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, three years ago, of Seniors for Social Action Ontario members found that 35% of home care recipients were satisfied or very satisfied, while 45% of respondents were dissatisfied or very dissatisfied with home care services (Seniors for Social Action Ontario, 2023).

The current Family Managed Home Care criteria provide unencumbered and unrestricted access to families with children with complex medical needs and to adults with acquired brain injuries. Home-schooled children must also be considered “eligible”. Older adults are not mentioned under the criteria even though they comprise a large proportion of Ontario Health at Home’s clientele.

These criteria essentially allow discrimination in the provision of services to occur based on type of disability grouping and age, not on individuals’ needs. Disability and age are both considered “grounds” and “services” are considered social areas under the Ontario Human Rights Code (Ontario Human Rights Commission, n.d.).

SSAO is proposing that criteria for the Family Managed Home Care program be changed to reflect individuals’ needs rather than to which disability or age group they belong.

Accessibility

Individuals who live in rural areas as well as those requiring more flexibility than the current Home Care Program offers would benefit from the current Family Managed Home Care Program. However, both discriminatory criteria and excessive bureaucratic requirements often prevent them from accessing this program.

Many older people who need home care want choice and flexibility over who and how people come into our homes, and to have trusting relationships with their workers. SSAO believes that Family Managed Home Care upholds important principles like choice, control, flexibility, and relational care, so it should be easier for older people and their caregivers to access.

SSAO is proposing that Ontario Health at Home remove the criteria of ‘exceptional circumstances’ and replace it with ‘individuals and families who require maximum flexibility’.

SSAO is also proposing that Ontario Health at Home streamline the current excessively onerous and bureaucratic application and reporting process, replacing it with an easier, more streamlined and accessible process.

Research Supporting Direct Funding for Family Caregivers

Hiring workers directly from clients' personal networks or from the local community has been shown to achieve positive benefits (Kelly et al, 2020) including better quality, more relational care, greater consistency in care workers, improved access in rural areas, and task shifting – greater flexibility in tasks that workers complete.

Being able to access Family Managed Home Care and, in specific circumstances, also access traditional Home Care has been an important feature of the program (University of British Columbia, 2024:85).

Having the flexibility to self-manage this program or reduce the administrative burden through the use of agency services has also been helpful to family caregivers (Dansereau et al, 2022).

In spite of a dearth of research concerning Family Managed Home Care in Ontario, SSAO does receive feedback from family caregivers concerning the issues they are having with traditional Home Care that Family Managed Home Care would address, as well as the reasons for their inability to access this program.

Issues families identify with traditional home care:

- Home care agencies frequently changing not just the worker, but also the schedule without informing, much less consulting individuals and families, making it difficult for caregivers to manage tasks and create a consistent approach to care;
- Care provided is often transactional without any consideration being given to the genuine individual needs of the person;
- Workers arriving sick, impaired, and/or unprepared or undertrained to provide the needed care;
- Agency care coordinators who appear unaware of skill-related problems with direct care workers and their inability to meet the needs of clients;
- A revolving door of care workers that families need to train and retrain about routines and specific care needs;
- Agencies inadequately compensating care workers, leading to high turnover;
- Agencies being unable to, or avoiding providing the care they are contracted to provide (Lord, 2026).

Issues with accessing and using Family Managed Care

- The criteria are too stringent and difficult to understand. Families are unable to determine whether or not their situation would meet the “extraordinary” criteria.
- The amount of administrative work involved and extensive application process for caregivers who are already stressed because of caregiving demands discourages some from applying.
- Concern that caregivers would be unable to retain current workers who know their loved ones if they switched from traditional home care to Family Managed Home Care.
- Although finding workers can be a challenge, because home care involves close, often intimate interaction, families appreciate being able to hire someone well-suited to the older person’s needs.

- Being unable to carry over unspent funds to the next month is a barrier for families trying to plan things like vacations and other transitions.

IN CONCLUSION

Expanding Family Managed Home Care would allow a greater number of older adults to benefit from the program and enable families who want more flexibility to benefit from direct funding.

Seniors for Social Action Ontario considers Family Managed Home Care to be a vital part of the home support services spectrum. By addressing the recommended changes, more families can benefit, and more older adults are likely to be able to be supported in their own homes and communities.

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