



# ONTARIO CAREGIVER COALITION SUBMISSION – HOME & COMMUNITY CARE REGULATIONS

*July 2021*

## SCOPE OF SERVICES & SERVICE MAXIMUMS

### Financial Support

With regards to the scope of services and service maximums laid out in slides 9-11, the Ontario Caregiver Coalition (OCC) is generally supportive of the additions proposed by the Ministry of Health. In particular, OCC supports the inclusion of Indigenous services as well as the respite services, bereavement services, behavioural supports, and education, prevention, and awareness services included as part of the Community Support Services.

However, the OCC would support the inclusion of additional homemaking services as part of the scope of the home and community care services provided by the Ministry, to help address the challenges faced by caregivers, particularly to assist them with the financial distress they may face as a result of their caregiving duties. According to Statistics Canada, in 2018, one in four Canadians aged 15 and older provide care to a family member or friend, and approximately 21% of them provide 20 hours or more of care per week. Almost half (45%) of caregivers reported receiving support from spouses or coworkers who modified their work arrangements to help provide care. Moreover, though only 14% of caregivers reported receiving financial assistance, of caregivers who reported having unmet needs, 68% said they needed more financial support – this is even true amongst seniors who provide care, 56% of whom said they needed more financial support.

To this end, the OCC suggests the government should include the following services as part of their Homemaking Services:

- 1) Navigation for social assistance programs and employment supports
- 2) Financial and tax planning

The Government of Canada and the Government of Ontario offer several income-based supports for caregivers, including the Employment Insurance Compassionate Care Benefit and the Caregiver Tax Credit, as well as unpaid, job-protected leave for caregivers. However, as reported by Statistics Canada, only 6% of caregivers received funds through government programs and only 8% received the federal tax credit (with the same eligibility requirements existing for the Ontario tax credit). Providing support to help caregivers manage the financial impact of becoming a caregiver, any disruptions to their employment, as well as ensuring they are accessing all the supports to which they are entitled through our tax system would allow caregivers to focus on providing care to loved ones rather than increasing their financial burden and the stress that creates. This could enable more family caregivers, who are

disproportionately likely to be women, to remain in the workforce - and mitigate the long-term impact of taking on caregiving responsibilities on their financial wellbeing by leaving the workforce, such as their career prospects upon re-entering the workforce and on their pension and retirement savings.

The OCC would posit the government already recognizes the need to provide administrative supports like this by offering banking and bill payment services, as well as advance care planning options through its palliative care service offerings. Supporting caregivers to manage the personal financial consequences of providing care at home or in the community makes it easier for them to continue doing so. In this way, expanding the scope of homemaking services to a greater range of financial activities can contribute to delaying or avoiding admission to long-term care.

## **BILL OF RIGHTS**

The OCC is supportive of the changes to the Bill of Rights proposed by the Ministry. In particular, we are enthusiastic the Ministry will enshrine the right of persons to “actively participate, in the presence of whomever they choose, in the assessment of their care needs”. We think enshrining the right of persons to include caregivers in the assessment process is critical because caregivers often are a vital resource for the care team in providing a complete picture of their loved one’s needs.

However, given the concerns raised during the COVID-19 pandemic regarding access to home care services, as well as the conditions of patients in long-term care, the OCC would argue it is more critical than ever to empower caregivers as advocates for their loved one in all settings of care. The OCC recommends the Bill of Rights include explicit provisions to enable caregivers not just to be present, but to participate in assessment and decisions about care when requested by the person receiving care, and for the right of caregivers to raise concerns, recommend changes, or make formal complaints on behalf of their loved one without fear of reprisal regarding their care.

## **SELF-DIRECTED SERVICES**

The mission of the OCC is to improve the lives of caregivers by advocating for fair access to needed supports. Our membership includes people of all ages who provide crucial physical, emotional, financial, social and other supports to their family and friends, together with organizations that advocate for or support caregivers. Caregivers are the backbone of our health care system – something that has become even more clear during the COVID-19 pandemic. However, they themselves need support to continue filling their vital roles. Without adequate supports, caregivers often experience significant mental, emotional and financial distress.

¶Our members have been clear their top priorities are improved access to home care supports and practical measures to address the often extensive financial costs associated with caregiving. Self-directed care services can, for many caregivers, address both of these issues. For this reason, improved access to self-directed services is a key priority for the OCC. We appreciate the government’s commitment to improving self-directed programs and are pleased to support your work by sharing the experiences and perspectives of our members. Our comments on self-directed services are based on extensive consultation with our membership, as well as a survey, focus groups, and interviews with caregivers more broadly.

Caregivers carry out their vital roles in a variety of contexts. Not every family is the same or has the same needs. Some would benefit from traditional home care and respite programs, in which organizations source, organize, and supervise supports, taking on the significant administrative and supervisory responsibilities associated with that. Others would benefit from the choice and flexibility associated with self-directed and family-managed programs. These programs enable caregivers to access supports tailored to their needs and circumstances in their own homes and communities. Individuals and caregivers can choose care providers within their communities, whether urban or rural, that are responsive to their cultural and linguistic needs. In this way, self-directed programs support quality of life and independence for individuals and enable caregivers to continue caring for loved ones at home.

However, access to these programs is currently severely constrained by restrictive eligibility requirements, challenging navigational pathways, and design barriers. The OCC aims to see programs in Ontario build on the proven success in other jurisdictions, and thereby improve the quality and accessibility of supports for caregiving. This will benefit caregivers themselves, their loved ones, and the sustainability of Ontario's health system as a whole.

The OCC appreciates the government's decision to set out the program parameters for self-directed care more in program policy than in regulation or legislation, as this will allow greater flexibility to respond to the evolving needs and the ongoing transformation of our health care system, and to evaluate and improve programs over time. In our view, to ensure self-directed programs achieve their intended effects, the policies guiding self-directed programs should adhere to three core principles:

- **Inclusion:** self-directed programs can be beneficial to many families. Eligibility criteria should focus on need, and the ability of families to benefit from these programs, rather than on specific impairments.
- **Accessibility:** program design and delivery should focus on accessibility so all eligible families can benefit regardless of financial, linguistic, cultural, geographic or other barriers.
- **Person-centred:** program requirements and services should be flexible and responsive to the needs of families.

With these principles in mind, the OCC offers the following six recommendations for the design of self-directed programs.

### **Recommendation 1: Ensure eligibility criteria are based on need rather than impairment**

Currently, regulations limit the availability of self-directed care funding to only certain persons: children with complex medical needs, adults with acquired brain injuries, home-schooled children eligible for school health personal support or professional services, and persons in extraordinary circumstances.

Criteria based on particular impairments or disabilities risk arbitrariness, leaving individuals with equal need unable to access equal supports. Canadian jurisdictions with similar programs instead use need and appropriateness as criteria. For example:

- *Alberta Health Services Self-Managed Care Program:* individuals must have unmet health care needs within AHS provincial home care service guidelines and have stable and predictable care needs. Eligibility is based on assessments.

- *Saskatchewan Individualized Funding Program*: requires the individual to first be eligible for home care support services. Next, they must meet the requirements specific to the Individualized Funding program where the individual requires long term supportive care; is capable of managing the funding successfully; is willing to accept responsibilities; and signs an agreement with the Saskatchewan Health Authority which outlines services, funding level, accountability, and reporting requirements.
- *Manitoba Self and Family Managed Care*: to be eligible, the individual must require health services or assistance with the activities of daily living; require service to remain safely in their homes, and require more assistance than is available from existing supports and community resources. A one-year enrollment on regular home care may be required before the SFMC program if there are any concerns about care or client instability.

The OCC recommends eligibility criteria focused on the nature of individual impairments or disabilities be replaced by a focus on need and appropriateness.

As a related concern, eligibility criteria that appear neutral on their face may in fact embed barriers for persons with cognitive, intellectual or developmental disabilities.

Self-directed programs offered through the LHINs have generally required recipients to be able to self-manage all administrative and supervisory aspects of the program. In effect, this has left individuals with cognitive, intellectual or developmental impairments unable to access these programs, even if they have family members or other caregivers prepared to assist with these aspects. This impacts a significant number of potential program beneficiaries, particularly when one considers that it excludes many of the growing number of seniors who are living with some form of dementia.

Other jurisdictions with self-directed programs do allow substitute decision-makers (or those with supported decision-making arrangements, where these exist) to take responsibility for application and planning for self-directed programs. This includes Alberta Health Services Self-Managed Care Program, Saskatchewan's Individualized Funding Program, Manitoba's Self and Family Managed Care, Quebec's Direct Allowance Program, Nova Scotia's Supportive Care Program, among others. Ontario's approach is an outlier and reflects an outmoded approach to decision-making by and for persons with disabilities that affect their decision-making abilities.

Ensuring self-directed programs in Ontario include substitute decision-makers or supportive arrangements with caregivers in the application process would allow more families to receive the support necessary to arrange the care they need and to remain in their homes for long, thereby delaying unnecessary admissions to long-term care, and improve the quality of life both for care recipients and their caregivers.

**Recommendation 2: Ensure that programs are navigable and accessible to all those eligible**

Many families who would benefit from self-directed services are not able to access them due to navigational barriers. The patchwork of programs, together with a lack of easily accessible information, and complex processes for application and administration, means these programs do not operate as effectively or equitably as they could. For example, there is very limited information available online about the Family Managed Home Care programs, including eligible expenses, funding levels, application processes, administrative requirements. Families are thus largely unaware of the program, and where they are aware, are unable to make meaningful decisions about whether to pursue the application

process. Many caregivers we spoke to were completely unaware of the existence of these programs, even though such programs might be well suited to their family's needs and capacities.

Steps that programs could take to improve access include:

- provide online information that is clear, accessible, plain language and sufficiently comprehensive to ensure families can understand the potential benefits of the program to their situation and to make meaningful decisions about applications
- undertaking proactive informational initiatives to improve awareness, for example by reaching out to family doctors or undertaking a public awareness campaign
- reaching out to cultural, linguistic or other communities who may not be aware of their program, to develop outreach and informational strategies for these communities. This may, for example, include the provision of information in multiple languages.
- providing supports, for example in the form of telephone information or advice, to enable families to understand and effectively navigate complex application or administrative requirements.
- building on the example of *respiteservices.com*, create a central repository of resources for direct funding recipients who are seeking staff.

### **Recommendation 3: Provide services that are flexible to fit the unique needs of families**

Through our consultations with caregivers, including caregivers who are currently receiving self-directed services, we have heard about the central importance, in these programs, of the ability to truly tailor services to the unique needs of their families. This is the true power of self-directed and family-managed programs – the ability to ensure that the services received are addressed to the specific needs of that family. Families must often be very creative to balance the needs of work and care, and the needs of all family members. Rather than relying on restrictive lists of eligible and ineligible supports and services, self-directed programs should support this creativity and flexibility, in order to have maximum impact.

Similarly, self-directed and family-managed programs should allow for the hiring of family members and friends. For both families and the person receiving care, trust, stability and compatibility are essential. With the dearth of personal support workers, high turnover within that profession, and the natural instability of part-time work, it may be difficult to create and maintain the long-term, trusting relationships that are essential to good care. If family members can not trust the person providing care, supports are illusory because family members feel constrained to closely monitor and supervise the provision of supports. As well, enabling the hiring of family and friends can help families to address their particular cultural or linguistic needs.

### **Recommendation 4: Remove income barriers to program access by moving away from reimbursement models**

In self-directed care programs, the Ministry of Health may enter into financial agreements with families and/or their caregivers to support their loved one to live at home. However, there is a lack of consistency across the different programs related to their administration and the methods of flowing the funding. Programs offered through the Ministry of Health (Family Managed Care, Direct Funding) are based on quarterly installments of funding with reimbursements at each quarter. Families waiting for reimbursements for funds already spent jeopardizes their financial stability.

The reimbursement model is not accessible to family caregivers and their loved ones with a low income who do not have the financial buffer to wait for reimbursement. This often further reinforces the financial challenges and stresses for informal caregivers who are unable to work due to their caregiving responsibilities.

To address financial barriers for caregivers and families, and promote equity among families and caregivers, the Ministry of Health should examine funding models for self-directed, direct funding and family-managed care that allow for the administration of funding on a reconciliation basis rather than a reimbursement model.

**Recommendation 5: Transition funding, over time, to self-directed and family-managed families, as they avoid or delay the use of institutional care**

Need for self-directed and family-managed care far outstrips availability. There are currently very lengthy waitlists for established self-directed care programs. Less well-known programs, such as the Family Managed Home Care program appear to support only tiny numbers of families.

Many studies have recommended increased funding for services in the community as an effective means of reducing institutional care. Supporting families to care for their loved ones in the community is considerably less costly than institutional care in settings such as long-term care homes or repeated hospital admissions. Many patients and caregivers also have clearly expressed a desire for more care in the community – particularly during the COVID-19 pandemic – but did not have the option because the services did not exist in a way that was accessible. Increased funding for self-directed or family-managed services should be part of future-oriented strategies for the health of the health care, home care and long-term care sectors.