



In-Depth Brief on Priorities and Recommendations Related to Caregivers

Summary

The Ontario Caregiver Coalition (OCC) is fully committed to working with all elected officials in the province to implement policies and programs that best meet the individual needs of caregivers¹ while acknowledging the reality of limited fiscal resources and the many competing demands on these resources. Central to this is ensuring that the “voices”, and unique and diverse circumstances of individual caregivers, inform and drive policy.

This brief highlights OCC’s key priorities and recommendations and is presented in two parts:

Part One focuses on **respite** in light of recent investments and includes examples from OCC members which highlight main concerns. Overall, investment in respite must be targeted to programs that:

- Give caregivers more *flexibility and control* over when and how they use services;
- Respond to the unique needs and circumstances of individual caregivers;
- Build on existing successful and innovative programs;
- Allow caregivers to access supports and services early so they are not put in a position to have to wait until their situation becomes overwhelming before they seek help; and
- Are universally accessible and affordable.

Part two explains why we believe government must urgently address and alleviate the emerging issue of **caregiver financial distress** and provides recommendations for achieving this:

- Caregiver tax credits, when introduced, must be refundable.

OCC is the provincial advocacy body that supports unpaid caregivers in Ontario. We are comprised of over 140 individuals and organizations who actively work together to increase awareness of the important role unpaid caregivers play in the long-term sustainability of Ontario’s health care system, and advocates for improved supports for caregivers.

¹ OCC defines caregiver (sometimes referred to as family caregiver or carer) as anyone who takes on an unpaid caring role for someone who needs help because of a physical, mental or cognitive condition, an injury or chronic life-limiting illness.

- As tax credits do not adequately address the problem of caregiver financial distress, other caregiver financial benefits must be urgently considered.

OCC is very aware that health care dollars are limited. We also recognize that social determinants of health (SDOH), including income security, are well-established indicators of individual and social health outcomes. For these reasons, we urge decision-makers to adopt the principles of equity and empowerment when allocating scarce health care resources, and to work across ministries to meet the needs of the roughly 3.3 million unpaid caregivers in Ontario.

Part One: Respite

Wesway is a respite service provider that takes the approach that families know best when it comes to the frequency, duration and type of break they need.

Respite can occur:

In the family home

Out of the home

Daytime, evenings, weekends (including overnight)

From a few hours a day to much longer periods of time

Through community activities

In an emergency

For short vacations

Respite care can be provided by:

A trusted friend or neighbour

A recognized community recreation group or activity program

Purchasing additional service from another organization which already provides support to the family.

The following are some real-life examples of the respite needs of caregivers in Ontario as described by OCC members. Several of these examples show the success of the Wesway model of self-directed respite that has been funded for a number of years in Thunder Bay. OCC believes that this service delivery model, which takes a person-centred, flexible approach, could be replicated throughout the province for respite services across all disabilities with some of the increased allocation of respite funding announced in Budget 2017.

Example 1:

The Smiths live in a small town in Northern Ontario. Jack is 83 years old and recently had a stroke which resulted in his full dependence on his wife Diane for his day-to-day care. He and Diane also provide 24-hour care for their 51 year old son who has a developmental disability. With Jack's recent stroke, the care of both individuals now solely rests with Diane and although exhausted, she desperately wants to keep her family together. As with most small towns, Diane realized that she has limited options available. Thankfully Diane was able to access Wesway's Family Directed Respite Funding, a flexible funding model designed to support family caregivers where and when they need support.

She is able to use the funding to hire the people she knows and trusts to provide care and support to her family. These flexible respite supports have given Diane the strength to keep her family together.

What this example shows:

- Geography is an important factor. Many respite services like day programs are not economically feasible in small communities due to economy-of-scale considerations. Agency-provided personal support workers may have to travel a long distance and may not be available when needed. The caregiver is often in the best position to identify a trusted and available person to provide care when she most needs it. Self-directed funding options like the model used at Wesway make it possible for the caregiver to tailor the support to their unique circumstances.
- Sometimes, the caregiver has more than one person to care for – it is not surprising they are often “exhausted”.
- Caregivers are highly motivated to keep family members at home – but they also need care to avoid “burn out”.

Example 2:

Joe and Kora are in their 70s and live in a small town in northern Ontario. Due to Joe’s care needs, both have retired. Joe had a massive heart attack 20 years ago and as a result his care is quite medically complex. Joe requires the support of a device that is so rare that he is one in 200,000 people worldwide who relies on this type of device. Kora is the only person north of Sudbury to be trained on such a device. Additionally, Kora has health issues of her own. She has had a kidney transplant and also has lupus. Her health issues and the stress of being the only person who is familiar with Joe’s care and supportive device is taking its toll on her. Through the use of Wesway’s Family Directed Respite Funding and the support of the service coordinator, nurses who live in their area were recruited, hired and trained to provide the specialized care that Joe needs. Because these funds are so flexible, Kora is able to have the support when and where she needs it most and feels very confident in the care that is provided.

What this example shows:

- Caregivers are often caring for someone with medically complex needs for whom it is more difficult to find respite care.
- Caregivers often have their own health issues that only add to their stress and vulnerability.

Example 3:

Carol, a 62 year old single woman, lives in a 3rd story apartment with her 95 year old mother, Audrey. While this living arrangement has suited both women for many years, Audrey's dramatic changes in health have recently made this more difficult. Audrey has rapidly moved through the stages of dementia and is no longer able to walk. Recently Carol was faced with her own medical crisis and with only stairs to reach their 3rd story home, an out-of-home option for Audrey's care was difficult for Carol to consider. Carol required surgery and relied on Wesway to provide care while she was hospitalized. Wesway's respite workers moved into Carol's home and provided 24-hour care during the time that Carol was in the hospital. Once Carol was home, the workers continued providing enhanced care for 10 weeks during Carol's difficult recovery. Without this additional support from Wesway, Audrey would not have been able to remain at home through this period.

What this example shows:

- Out-of-home options for respite are not always suitable, especially when overnight care is required.
- Access to additional respite supports during crisis times or unexpected life events is essential to sustain the health of caregivers.
- The number of hours of respite and when they are provided need to be fluid enough so that you can have more respite services in times of need and less when life is more stable.

See Appendix for additional examples.

We draw from these examples the following recommendations:

- Investment in respite must be implemented in a way that gives caregivers more *flexibility and control* over when and how they use services if such respite is to truly provide a sense of relief and a real break from the stresses of caregiving.
- Respite programs must be flexible and responsive to the unique needs and circumstances of caregivers.
- Respite options should build on successful and innovative programs currently being employed – particularly well designed, self-directed caregiver respite options.
- Eligibility criteria for the provision of respite to a caregiver need to be reviewed so that caregivers have access to supports and services early and are not put in a position to have to wait until their situation becomes overwhelming before they seek help.
- Access to respite must be universally affordable. Many caregivers are not working, working only part-time, or are seniors on low income and even modest charges for

respite care are beyond their means. Costs should not be a barrier to caregivers accessing the help they need.

- The application for self-directed respite or in-home care funding must be as simple, clear, fair and reasonable as possible, with accountability mechanisms that are realistic.

Part Two: Alleviating Caregiver Financial Distress

- Caregiver tax credits, when introduced, must be refundable. When they are non-refundable, the most economically disadvantaged are being treated inequitably.
- Tax credits as a form of financial support for caregivers do not adequately address the problem of caregiver financial distress; other caregiver financial benefits must be considered.

The Importance of *Refundable* Tax Credits

Many caregivers have found that the impact of caregiving is significant in multiple spheres of their lives. For example, a recent survey by CIBC¹ showed that 14% of those with parents over the age of 65 incur care-related, out-of-pocket costs that average \$3,300 a year. Notably, the study found that many of these direct costs are being borne by those with lower incomes – approximately 30% more than those with higher incomes.

The survey also highlighted that “direct costs pale in comparison to labour-related costs, which represent the amount of time Canadians take out of their work week to care for aging parents.” Of course, this study only looked at caregivers of aging parents. Both working and non-employed caregivers are caring for spouses, siblings, children – even friends – and we can assume that they are incurring financial costs that can lead to distress.

A May 2010 report from the Social Assistance Review

Manitoba has a *refundable* Primary Caregiver Tax Credit of up to \$1,400 available to people who act as primary caregivers for spouses, relatives, neighbours or friends who live at home in Manitoba. There are eligibility requirements for this credit related to the level of care needed by the care recipient that would need to be adapted in Ontario for provincial context and to ensure equitable access. The important thing to note is that any caregiver can benefit, even if they are low-income. Non-refundable tax credits tend to most benefit high-income caregivers and thus are inequitable.

¹ Tal, B. & Mendes. R. (2017). *Who Cares: The Economics of Caring for Aging Parents* Retrieved from <https://www.cibc.com/content/dam/pwm-public-assets/documents/pdfs/insights/who-cares-the-economics-of-caring-for-aging-parents-in-focus-en.pdf>

Advisory Council² highlighted that refundable tax credits are a simple, non-stigmatizing way to provide much-needed additional income to assist those in need. For instance, “tax credits account for one third or more of income for single parents on social assistance. Most are child-related tax credits” (pg. 8). Moreover, they can work well with those who are precariously employed. They contribute to “the goal of an income security system which simultaneously provides decent incomes for those not working while ensuring that work is financially rewarding” (pg. 9). Refundable tax credits can help ensure all caregivers are treated fairly and equitably.

The report also noted that “Ontario needs an income security review” (pg. 1). It took six years but in June 2016, Ontario established an Income Security Reform Working Group to help guide the province’s efforts to reduce poverty and move to a more holistic, client-centred approach to supporting people in need.

In a meeting with Ministry of Community and Social Services staff overseeing this work, the Schizophrenia Society of Ontario (SSO), an OCC member, highlighted concerns about the financial challenges experienced by caregivers of people with disabilities. SSO emphasized that caregivers are filling gaps not only for the health budget, but for the social budget as well, often covering housing, food, transportation and other social expenses as well as supplementing income to make up for inadequate social services and benefits. This in turn affects caregivers’ own income security. It is anticipated that the Working Group will be issuing a report in fall 2017.

The Caregiver Allowance/Benefit Model

There are two main reasons why a caregiver financial benefit is needed in addition to caregiver tax credits.

1. The value of existing and proposed caregiver tax credits, both non-refundable and refundable, is so low relative to the overall expenses typically incurred by caregivers that they do not adequately address or alleviate caregiver financial distress. This is especially the case when caregiving responsibilities and demands interrupt employment. In some cases, caregivers even leave their jobs indefinitely in order to care for a family member to enable them to remain at home as long as possible. When the caregiver is in the prime of her/his working career, as is often the case, the loss of income and career advancement prospects that may occur can have an enormous effect on the caregiver and adds significantly to caregiver emotional distress while having a

² Ontario Social Assistance Review Advisory Council. (2010). *Recommendations for an Ontario Income Security Review*. Retrieved from <http://www.mcsc.gov.on.ca/documents/en/mcsc/publications/social/sarac%20report/SARAC%20Report%20-%20FINAL.pdf>

negative effect on society from the perspective of productivity. At the same time, these caregivers contribute to saving public dollars by helping to reduce the use of long-term or community care. OCC believes that this is an unfair burden on caregivers and that, as a society, we should ensure the substantial economic value of caregivers is both acknowledged and fairly compensated.

2. Providing financial support through a caregiver allowance can enable caregivers to continue to provide caregiving in the community without jeopardy to their own financial, emotional and physical health. This has the potential for saving costs in other areas such as long-term care. According to preliminary evaluation of the Caregiver Benefit Program in Nova Scotia, for example, the caregiver benefit reduces the probability that individuals will be admitted to long-term care, suggesting significant savings to government in long-term care costs. With the rapidly advancing demographics of Ontario's aging population, we believe this model deserves urgent consideration.

Although Nova Scotia is the only province in Canada currently offering a caregiver benefit program of its kind, it is evident that many caregivers would welcome the introduction of this in Ontario. Countless enquiries come into the OCC on a weekly basis from caregivers who have visited OCC's website and are asking for more information on this type of financial benefit. It is difficult to explain that, at present, it is not available in Ontario.

If the caregiver and the care recipient both qualify for the Nova Scotia Caregiver Benefit Program, the caregiver will receive the Caregiver Benefit of \$400 per month. This is still a modest reimbursement totalling \$4,800 per year, but offers a more realistic and equitable financial benefit than the currently available tax credits.

This benefit is means-tested (i.e., eligibility criteria include having an annual household income of \$37,004 or less) so it benefits lower-income caregivers most.

Concluding Comments

OCC is very aware that health care dollars are limited. Thus decisions on how best to allocate scarce health care resources have a strong ethical component. We also know that social determinants of health (SDOH), including income security, are well-established indicators of individual and social health outcomes. For this reason, we offer two final comments in support of the recommendations above:

1. When deciding how to allocate scarce health care dollars and resources, government needs to be transparent about the ethical principles upon which their decisions are

based. One critically important ethical principle is that of **equity**– that is, promoting just/fair access to resources by ensuring burdens are not borne disproportionately by any individual, group or institution. Caregivers are frequently bearing a disproportionate burden of care in our system without adequate resources.

It is also ethically important for government to promote stakeholder **empowerment** – that is, making decisions explicitly with stakeholder views in mind and ensuring that those most affected by the decisions have meaningful and effective opportunities to participate in and/or inform the decision-making process. Personal autonomy and dignity should be respected to the greatest extent possible within the constraints of available resources.

Excerpt from the Wellesley Institute’s submission to LCO

Caregivers are an affected group with significant unmet needs related to SDOH, such as employment protections and income security. Supports for caregivers are guided by legislation that crosses policy sectors and levels of government. These include the provincial Employment Standards Act, which governs Family Medical Leave and Personal Emergency Leave, the federal Employment Insurance program, which offers Compassionate Care benefits, and the provincial Ontario Disability Support Program Act, which allows caregivers to access social assistance without employment or job training conditions. These disparate pieces of legislation provide basic supports for caregivers, yet they remain largely uncoordinated. Cross-governmental efforts to expand and harmonize caregiver supports, such as extending supports during bereavement, are needed to support caregivers and reduce caregiving distress which is expected to lead to health inequities. Efforts to expand these supports would likely benefit from more consistency and harmonization across ministries and jurisdictions (pg. 34).

This is similar to the position advanced by the Wellesley Institute in their submission to the Law Commission of Ontario³ in which they support the principle of a health equity approach to planning the allocation of scarce health care resources. They note that Health Quality Ontario (HQO) defines health equity as a state in which “all people living in Ontario are able to reach their full health potential” and “receive quality care that is fair and appropriate to them – regardless of where they live, what their economic or social status, language, culture, gender or religion” (pg. 6). The submission highlights, for instance, that HQO has found that Ontarians with lower income receive different access to palliative home care (pg.

³ Wellesley Institute. (2017). *Submission to the Law Commission of Ontario: Improving the last stages of life*. Retrieved from http://www.wellesleyinstitute.com/wp-content/uploads/2017/09/Wellesley-LCO-LSL-submission_September-11-2017-FINAL-Sept-21-2017.pdf

18). In addition, as part of their new mandates under the Patients First transformation, Local Health Integration Networks have been directed to “promote health equity and recognize the impact of SDOH to reduce or eliminate health disparities and inequities in the planning, design, delivery and evaluation of services” (pg. 7).

2. There must be an effort to enhance **inter-ministerial cooperation** at the government level when addressing many health and community care issues, especially those involving the complexity of families and the diverse range of caregiving challenges they may experience. Only by looking at the “big picture” and the inter-connectedness of our health and social programs can we understand what will be the best use of limited resources.

For instance, OCC recognizes the efforts of the Ontario government to better support Ontario caregivers with the implementation of the *Family Caregiver Leave Act*, giving caregivers eight weeks of job security to provide care without the need for the person they are caring for to be near death or dying. However, currently the Compassionate Care Benefit (CCB) is not as flexible and stipulates that a person “can receive compassionate care benefits for up to a maximum of 26 weeks if you have to be absent from work to provide care or support to a “gravely ill family member at risk of dying within 26 weeks”.

Ontario has shown leadership with the *Family Caregiver Leave Act*, by not adding a “near death or dying” criteria. It is unfortunate that caregivers can be eligible for this time, but not eligible for CCB during their leave unless the person they are caring for is near death. Many caregivers are already challenged financially making the number of caregivers able to access an unpaid job protected leave very low.

Furthermore, there is a disconnect between the weeks of Employment Insurance (EI) funding through the CCB and the current amount of job secured time that is offered in Ontario. As such, OCC continues to call for collaboration between the Ministry of Labour and the Ministry of Finance to work with their federal counterparts to expand the eligibility of the CCB beyond only those caring for someone who is gravely ill and at risk of dying and to make available 26 weeks of job protected and EI covered time.

All caregivers are contributing in so many ways to strengthen society while caring for those individuals who are most vulnerable. They deserve not just recognition for their contributions and role but also fair and equitable treatment when they are financially disadvantaged.

Presented on behalf of the Ontario Caregiver Coalition by: Joanne Bertrand,
jbertrand@alzheimeront.org , 647-351-8088 & Antonella Scali, ascali@schizophrenia.on.ca, 416-449-
6830 Ex. 259