



Ontario Caregiver Coalition (OCC) Pre-Budget Submission 2018

The Ontario Caregiver Coalition (OCC) is pleased to provide the Standing Committee on Finance and Economic Affairs our suggested priorities and recommendations for the 2018 Ontario Budget on behalf of Ontario's caregivers.

In October 2017, OCC submitted an *In-Depth Brief on Priorities and Recommendations Related to Caregivers* (see attached) to all provincial political parties. This pre-budget submission reiterates two of the key priorities that are of most concern to the majority of OCC members and are of most relevance to the budget process:

- the need to address **caregiver financial distress**
- the need for increased, **flexible respite options** for caregivers

Background:

OCC is a provincial advocacy body that was established in 2009 to bring together organizations with a mandate that includes serving caregivers¹ and individuals who are caregivers to identify and advance common caregiver priorities with policy-makers and government.

We currently have 150 members which includes many organizations with substantial outreach and knowledge of the individual caregivers they serve; for example, Ontario Community Support Services (OCSA), Homecare Ontario, and Saint Elizabeth Health Care. We also have members who represent a very broad range of caregiver ages and care-recipient conditions: Schizophrenia Society of Ontario (mental illness); Ontario Brain Injury Association (OBIA); MS Society of Canada, Ontario & Nunavut Division; Alzheimer Society of Ontario; Powerhouse Project (young carers). We are also a culturally and geographically diverse group with members such as Woodgreen Community Services and the Yee Hong Centre as well as Wesway in

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 a chronic, life-limiting illness.

Thunder Bay, Community & Primary Health Care in Ottawa and Community Care, City of Kawartha Lakes. We offer these examples to show that over the past 8 years, as our membership has grown, we believe we have become a fairly representative group in Ontario that is familiar with caregiver priorities and, thus, can express the views in this *Submission* with a high degree of confidence.

Since our OCC website was introduced in 2016, we are now even more frequently contacted by individual caregivers who are not affiliated with any particular organizations but are seeking assistance with a caregiving matter. There are some recurring themes that caregivers are expressing but none is more common than the financial distress experienced when a caregiver is faced with the risk of losing employment due to the demands of caregiving.

Signs of Progress:

In OCC's 2017 pre-budget submission, our priorities included the following:

1. That the **Compassionate Care Benefit** be expanded to ensure that Ontarians can access not only **unpaid** job-protection for 26 weeks when they have a family member gravely ill but that they can also receive compassionate care benefits during this leave. Otherwise, many caregivers who are financially challenged cannot afford to take this time off.

Sign of Progress: It is encouraging that Bill 182, Compassionate Care act has passed 2nd reading in the Legislature and has now been sent to the Standing Committee on General Government for review and consideration.

2. That the government invest \$20 million dollars over two years to **improve respite services** and delivery of these services for Ontario caregivers.

Signs of progress: An additional 600,000 hours of respite services for caregivers was announced in October 2017 as part of the increased funding for Home and Community Care. It has also been proposed that new, innovative **self-directed care models** that provide more control for eligible clients and their caregivers over their care will be introduced.

3. That additional funding will be provided to support the Ontario Dementia Strategy.

Sign of progress: On November 28, 2017, it was announced that the Ontario Government is investing \$8.15 million dollars over three years to enhance the *First Link* program as part of its overall commitment to the Ontario Dementia Strategy. Early help for caregivers has proven critically important in the process of caring for someone with dementia and this is a positive development. *First Link* is a model that would be of interest to many of our member

organizations as a way to effectively reach caregivers at an early stage in the diagnosis of many chronic and life-limiting illnesses in order to provide much-needed education and support.

Areas of remaining concern:

Caregiver Financial Distress:

OCC believes there are grounds for stating that the degree and widespread nature of financial distress experienced by caregivers is insufficiently recognized or addressed by some of the above signs of progress.

As mentioned previously, although anecdotal, the most common reason for individual caregivers contacting us via our website is to ask if there is any assistance available when the caregiver has had to give up a job to care for a family member. Some of the stories they share are heart-rending. The lost productivity to the workforce of many caregivers who cannot find adequate community support in order to continue both caregiving and working is an important issue especially as the population continues to age. In addition to the economic loss to society, and the financial distress for the caregiver, there is a significant emotional toll for someone who gives up a career. Years of caregiving are not uncommon and this can severely compromise the individual's ability to return to work – and take an emotional toll on the individual.

It is often very difficult to know where to direct these caregivers for help. In Ontario, there is a new Ontario Caregiver Tax Credit but it is **non-refundable** and does not help low-income individuals. In Nova Scotia, there is a monthly caregiver benefit that is means-tested and OCC would like to see this model considered for Ontario.

On January 5, 2018, the Schizophrenia Society of Ontario (SSO), a long-term OCC member organization, responded to the report "*Income Security: A Roadmap for Change*". See link below:

<https://www.ontario.ca/page/income-security-roadmap-change>

SSO offered the following comment and recommendations: "Family members who provide informal, unpaid caregiving support to people with mental health disabilities are at risk of financial stress. They often compensate for inadequate social assistance incomes for the person living with the disability, inadequate housing, other necessities for social participation and additional cost of living with a disability. They also experience barriers to participation in the workforce because of absenteeism related to their caring role. As a result, some carers may risk sharing the poverty of the person living with the mental health disability. At the same time, these carers help to save costs to hospitals, community services and long-term care. This is particularly relevant for carers of adults with schizophrenia, which represents the largest

hospital, physician, prescription medication and psychiatric costs compared to other mental health disabilities. To help alleviate this burden, the Ontario Caregiver Coalition (OCC) has called for making applicable tax credits, such as the new Ontario Caregiver Tax Credit, refundable as non-refundable tax credits do not help the most economically disadvantaged carers. As the value of both non-refundable and refundable tax credits would still not adequately address or alleviate financial distress, especially in cases where caregiving responsibilities and demands interrupt employment, OCC has also called for the consideration of other means-tested financial benefits for caregivers.”

One of the strengths of the **Income Security Report** is that it **does** acknowledge that poverty is a **family** issue. On pg. 35, it states: “People are facing greater labour market instability, less job security, and more non-standard or precarious work, all of which make it harder to achieve an adequate standard of living.” Interestingly, however, not much attention is paid to the diversity of caregivers and they are mentioned only briefly in the context of caring for children with complex medical issues.

OCC Recommendation #1:

That Ontario move forward quickly with the adoption of a financial benefit for caregivers that will allow them to remain in a caregiving role. This could be most easily accomplished through a form of caregiver tax credit that is refundable – or through the introduction of a caregiver benefit allowance that is means-tested.

Flexible Respite Options:

For many years, OCC has been advocating on behalf of caregivers for increased and more flexible respite options.

High quality day programs are an important aspect of providing respite care in the community. The Alzheimer Society of Ontario, another long-term OCC member, has identified the need for “greater access to high quality day programs that offer choice and are flexible and responsive to the unique needs of the care partner and the person living with dementia.” They have noted that many families do not have access to the day programs they need in their communities and there are often long wait times of up to 6 months or more²for existing programs.

Adult Day Programs are not the only solution, however, to improving respite care. They create some barriers for those in remote/rural areas due to transportation difficulties and they may not be financially viable due to economies of scale. As well, the care recipient may pose complex challenges that make an **in-home respite option** more beneficial for both the person receiving care and the caregiver.

² Alzheimer Society of Ontario – oral presentation to the Standing Committee on General Government, January 18, 2018.

In the In-Depth Brief we have attached, OCC presented a variety of examples of real-life situations described by our members that demonstrate how different respite options are needed that are guided by the unique circumstances of individual caregivers and their family members. Many of these examples describe the value of **self-directed respite** care.

At a very recent update on *Patients First: A Roadmap to Strengthen Home and Community Care* given to OCC members by the Ministry of Health and Long Term Care, in which almost 40 OCC members participated, we were told about Ministry plans to create new, innovative self-directed care models. Under the proposed Self-Directed Care Program, LHINs will have authority to offer self-directed care to four client groups: children with medical complexity, clients in extraordinary circumstances, adults with an acquired brain injury and home-schooled children. There will be a new provincial agency that will provide employer-related functions for personal support workers that are selected by the caregiver.

This does appear to offer to caregivers a benefit in being able, potentially, to select a personal support worker (PSW) who best meets their needs and who can accommodate more easily caregiver schedules. At the same time, the caregiver would be relieved of the administrative burdens of such tasks as submitting payroll withholding amounts. The number of hours respite available to the caregiver would be assessed in the same way as those clients served under a more traditional model where the agency determines the PSW's availability.

OCC is unclear at this point if this model will, in fact, increase the availability or flexibility of respite for caregivers.

OCC Recommendation #2:

That there be an emphasis in the rollout of the Self-Directed Care Program by the Ministry of Health and Long Term Care on evaluating the impact, both benefits and disadvantages, on caregivers of implementing this model. In particular, it should be determined, through continuing consultation with caregivers, whether the model is achieving desired results in improving the flexibility of respite options in the community.

The client groups mentioned above are limited and although we appreciate that this is the first stage of implementing this new program, it will be important to expand this program to other client groups whose caregivers face equally difficult challenges.

In conclusion, OCC is eager to remain engaged with Government to promote the values articulated as part of *Patients First: A Roadmap to Strengthen Home and Community Care*. We want to emphasize that these values include care that is **reliable, accessible, respectful,**

integrated and accountable. This means, in part, budget allocations that are ***equitable and responsive*** to the different levels of need of all individuals in Ontario.³

³ Submitted on behalf of the Research & Advocacy Committee, Ontario Caregiver Coalition, by Joanne Bertrand – jbertrand@alzheimeront.org – 416-500-5308