

Submission to the Standing Committee on General Government

Bill 21, An Act to amend the Employment Standards Act, 2000 in respect of family caregiver, critically ill child care and crime-related child death or disappearance leaves of absence.

THE ISSUE

The role of family caregivers has become increasingly important in society as the population ages and more people with chronic diseases and/or conditions related to aging choose to receive care at home. Family caregiving responsibilities can interfere with the typical life course of a family and too often, families must reduce their contributions in other areas, including employment. Ontarians will typically choose to care for a family member in need and without support will make the difficult decision to leave the workforce or reduce their employment. In Ontario, where 29% of residents are typically engaged in caregivingⁱ, the impact can be significant to the goal of a healthy and prosperous province.

OHCA RECOMMENDATIONS

The Ontario Home Care Association (OHCA) supports Bill 21 and believes that it is an important step to acknowledging the importance of family caregivers in Ontario. OHCA recommends that in advancing this legislation, a commitment be made to strengthen the support of family caregivers. The following recommendations will contribute to improved recognition of the important contribution of family caregivers:

1. **Increase the investment in home care** in order to better support family members who provide the majority of the care.
2. **Enable the family contribution** through financial levers to support family caregivers to manage their costs.
3. **Improve access to support** by providing more flexible leave periods and clarifying the terminology so families know if they qualify for a leave.

Background

The health care system relies on family to support individuals to manage their health care needs. This is particularly evident within home care where publicly funded services are designed to

A fundamental component of home care is that family and/or friends will provide care to supplement the publicly funded service.

complement and supplement, but not replace, the efforts of individuals to care for themselves with the assistance of family, friends and community.

Family members are called upon to perform tasks such as wound dressings and injections, delegated by the health care professional; personal care such as bathing, dressing, eating or toileting; support activities such as preparing meals, household

management, managing medication or attending to finances; and, activities such as coordinating the myriad of services that care recipients may require.

An estimated 80% of care that is provided to the ill, frail and dying at home is assumed by family and friends.ⁱⁱ In 2006–2008, more than half (57%) of palliative care clients in Ontario were cared for primarily by their spouses or partners, while a third (29%) received most of their primary informal caregiving from their children or children-in-law.ⁱⁱⁱ

According to the 2012 General Social Survey on Caregiving and Care Receiving, 29% of Ontarians were actively engaged in providing care to a family member with a long-term health condition, disability or aging needs.^{iv} Caring for family is not new; however the context for caring has changed. Nuclear families are decreasing; families are smaller and more dispersed; there are more women in the formal workforce; childbearing occurs later in life; and, retirement is delayed. The result is a family life course that includes juggling child rearing, working, and caring for an elder family member.

Traditional support networks are disappearing.

The impact too often is that caregivers have to miss work, or reduce hours and possibly forgo job opportunities in order to fulfill their responsibilities. In addition to lost income related to a reduction in employment, many family caregivers face long-term financial pressures. For those who either temporarily or permanently leave employment to provide care, work-related losses include a loss or reduction of employer-sponsored benefits, CPP credits, training opportunities, experience in one's field and opportunities for promotion. Employers lose valued and skilled workers.

Families face long term financial pressures and employers experience the consequences of work interruptions and reduced productivity.

While caregiving is a positive experience for many, more than one in four (22%) showed signs of distress, including anger, depression, being overwhelmed and unable to continue providing care.^v

Families with the means may retain home care service provider organizations (SPOs) to deliver additional hours that supplement publicly funded care. This care may be paid by privately-insured plans and/or direct private purchase. The OHCA estimates that 150,000 Ontarians purchase an additional 20 million visits/hours of home care services annually in order to remain at home.^{vi}

It has been calculated that it would cost \$25B to replace the contribution of families to the health care system in Canada.^{vii} All things being equal, Ontario, with 38.9% of the country's population, would incur an additional cost of \$9.7B if family and friends were reimbursed as employees. Families typically want to care for loved ones and would not expect this level of compensation. However, acknowledgement for the financial, emotional and physical challenges that family caregivers sometimes experience is important to avoiding negative outcomes such as caregiver exhaustion, illness or shortage of funds, that would compound the health issues facing the province.

Recommendation 1 - Invest in Home Care.

The growth of home care programs and services must be accelerated to address client need and preference, and to better support family members who provide the majority of the care. The OHCA commends the government for funding increases in home care over the past decade. These commitments have begun to shift the system, but as is well known, the need is rising faster than capacity. There is a large cohort of seniors (the boomers) who will need support to remain at home. By 2036 the numbers of seniors in Ontario will more than double from 1.9 million to 4.1.^{viii} The oldest age groups, and typically those that are most frail and in need of the most support from families, are increasing most rapidly with the 75 plus group projected to grow by approximately 144 percent by 2036 and the 90plus group to triple in size.^{ix} The ballooning dependency ratio will challenge the ability of both the health system and families to respond.

OHCA believes that it is vital that the home care sector be exempt from cost containment strategies in order not to place at risk the services on which the future of the health system in Ontario rests. A schedule of investment increases in home care service needs to be established so that as the population ages, the amount of publicly funded home care rises. OHCA recommends that a funding formula be created that defines that which the public system will provide and that Ontarians can anticipate as they plan for the care of aging family members.

Investments in home care must include funding for testing and adoption of new technologies and innovative practices. Innovation labs within home care need to be created so that ways of leveraging technology to support individuals to continue to live their lives at home can be developed. Examples include incentives for individuals to install components of “smart homes”; support for providers to conduct virtual visits; establishment of the electronic health record. These solutions are needed so that individuals and their families can feel confident that they are supported at home and can access the health provider to resolve care needs in a timely and effective manner. This will be increasingly important in order to meet the demand within a shrinking health human resource pool.

Specific actions for the government to take include:

- Establish an acceptable funding formula that informs Ontarians as to the amount of home care provided through the public system.
- Establish home-based respite programs in order to minimize the disruption to family caregivers and care recipients who need relief in order to sustain their ongoing caregiving obligations.
- Implement a schedule of funding investments that is linked to population projections and aligns to approved funding levels for home care.
- Institute multi-year funding formulae in order to flatten the current annual cycles that can diminish confidence in home care’s ability to meet demand.
- Allocate funding specifically for testing and adoption of new technologies and innovative practices that are designed to improve the ability to provide home-based care.

Recommendation 2 - Enable the Family Contribution

All home care systems are dependent on the support of families and loved ones. In a 24-hour day, paid staff gives only a small amount of care. In Ontario, family caregivers contribute to more than 70% of total caregiving needs.^x The caregiving responsibilities are often intense and lengthy in duration. In 2009 the government undertook long-range scenario planning for family caregiving. The following statistics reflect the needs:

- 27% of Ontario families have been providing constant care for over two years.
- 1 in 6 Ontarians reports that constant care requirements have a major impact on the ability to earn family income.
- 1 in 4 caregivers has no help; 1 in 4 has paid help; 61% need more help.
- The average family caregiver spends twenty hours per week caring for duration of four years; one quarter spends forty hours per week.
- 32% of family caregivers also have children less than 18 years of age living at home.
- 15% of caregivers describe their quality of life as poor.^{xi}

The responsibility of caregiving is a social one, with deep connections and dependencies with community, government and business.

Jane Jensen, Canadian Policy
Research Network, 2009

The Healthy Homes Renovation Tax Credit and Bill 21 are important measures to support families. Additional tax-exempt savings vehicles that are designed to address family caregiving would serve to offset financial strain and to highlight this important activity within society. Government also has a role in establishing programs to incent family caregiving friendly policy and behaviours.

Supporting family caregiving as a social norm will be enhanced if families are provided greater support to maintain their natural and desired caregiving role including access to quality privately purchased care. Without the financial acknowledgement of the fundamental reliance of the home and community care system on the dedication and presence of the family, institutionalization may be the only option for many individuals.

Specific actions for the government to take include:

- Establish savings vehicles that incent Ontarians to set aside funds to meet their needs for care at home as they age.
- Introduce financial incentives such as HST exemptions, and tax credits for privately purchased home care.
- Engage in dialogue with business to develop incentives that support a caregiving culture.
- Waive any fee associated with obtaining a certificate stating that the care recipient meets the criteria for the provisions in the Act.

Recommendation 3 – Improve Access to Support

One of the most significant and least desirable outcomes for families is to have to make a decision to place a family member in an institution because of the lack of home and community care based health and social support options. Most often, family caregivers need flexible leave provisions. A full week and one that is defined as Sunday to Saturday is too restrictive for most caregiving situations.

Ontarians need to know that an assessment and service is guaranteed; and that full disclosure of service and support options will be made. Too often, good programs are under utilized because of inadequate dissemination, confusing language, and/or restrictive criteria. Families will be more confident and better supported when the supports are readily accessible and appropriately responsive.

Specific actions for the government to take include:

- Allow more flexibility in the leave periods that working family members can access. Leaves as short as a half-day should be permitted.
- Allow working caregivers to accrue unused time.
- Clarify the definition of a “serious medical condition” and increase the eligibility to those with chronic and/or episodic conditions.
- Expand the definition of a qualified practitioner who can determine eligibility for family caregiver leave.

Conclusion

Bill 21 is tangible evidence of the Ontario government’s awareness of family caregivers and the challenges that many families face. OHCA believes that the measures within the Bill can be strengthened through the recommendations provided and in so doing the provincial government can more effectively respond to those who are experiencing the challenges of balancing caregiving responsibilities with paid employment in the regular workforce.

About the Ontario Home Care Association

The Ontario Home Care Association (OHCA), *the voice of home care in Ontario™*, is a member-based organization with a mandate to promote growth and development of the home care sector through advocacy, knowledge transfer, and member service. OHCA members include those engaged in and/or supportive of home-based health care. In Ontario, service provider organizations are responsible for providing nursing care, home support services, personal care, physiotherapy, occupational therapy, social work, dietetics, speech language therapy and medical equipment and supplies in the home to individuals of all ages. An estimated 54 million hours of publicly and privately purchased home care service is provided annually across the province.

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For the latest in news and information about the home care sector in Ontario, subscribe to the Ontario Home Care Association’s “House Call” at www.homecareontario.ca or follow us on [Twitter](#)

ENDNOTES

- ⁱ Sinha, Marie (2013) Portrait of caregivers, 2012. Statistics Canada, Social and Aboriginal Statistics Division.
- ⁱⁱ Fast, J., Niehaus, L., Eales, J., & Keating, N. (2002a) *A profile of Canadian chronic care providers*, submitted to Human Resources & Development Canada
- ⁱⁱⁱ Change Foundation (2011) Facing the Facts.
- ^{iv} Sinha, Marie (2013) Portrait of caregivers, 2012. Statistics Canada, Social and Aboriginal Statistics Division.
- ^v Change Foundation (2011) Facing the Facts.
- ^{vi} Ontario Home Care Association, (2009) *Creating an Ontario Home Care Rebate to Prevent Additional Costs to the Frail and Vulnerable*. Retrieved from <http://www.homecareontario.ca/public/about/publications-presentations.cfm>. The findings are based on results of an OHCA membership survey and polling data from OHCA members conducted in 2009. Reasonableness was affirmed as follows:
- 1) The Health Council of Canada estimates that 500,000 people across Canada purchase home care privately (Health Council of Canada, 2008, Fixing the Foundation: An Update on Primary Health Care and Home Care Renewal in Canada. Toronto: Health Council. www.healthcouncilcanada.ca/http://secure.cihi.ca/cihiweb/products/trends_home_care_mar_2007_e.pdf, p8) and as Ontario represents approximately 39% of Canada's population, 150,000 is a conservative estimate
 - 2) In an unpublished study, André Grenon from Health Canada estimated private home care spending in Canada at \$963.1 million in 2002-2003 (CIHI 2007- Public-Sector Expenditures and Utilization of Home Care Services in Canada: Exploring the Data , p3). OHCA assumed a growth rate on private home care spending from 2002 to 2010 and an average consumer cost of \$23.00 per hour, recognizing that approximately two thirds of purchased care is for home support.
- ^{vii} Hollander, M., Liu, G., Chappelle, N. (2009) *Who Cares and How Much? The imputed economic contribution to the Canadian healthcare system of middle-aged and older unpaid caregivers providing care to the elderly*. Healthcare Quarterly, Vol 12 No 2.
- ^{viii} Ontario's Seniors' Secretariat (2013) *Independence, Activity and Good Health Ontario's Action Plan for Seniors*. Queen's Printer for Ontario, p5
- ^{ix} Ibid.
- ^x Stobert, S. And K. Cranswick, "Looking After Seniors: Who Does What for Whom", Canadian Social Trends, Autumn 2004
- ^{xi} Deloitte Inc. 2009 Survey of Health Care Consumers - A comprehensive assessment of consumer attitudes, behaviors and unmet needs. Deloitte Center for Health Solutions.; Available from: pmacmillan@deloitte.ca