

Multiple Sclerosis Society of Canada, Ontario Division Pre-Budget Submission, December 2009

The Multiple Sclerosis Society of Canada, Ontario Division, is pleased to provide its perspective and recommendations on the 2010 Ontario Budget.

Multiple sclerosis (MS) is a disease of the brain and spinal cord. MS is most often diagnosed in young adults – individuals who are finishing school, starting careers and beginning families. A diagnosis of MS impacts the entire family, and society as a whole. Canada has one of the highest rates of MS in the world. There are between 55,000 – 75,000 Canadians who have been diagnosed with MS; 21,000 – 29,000 of these individuals reside in Ontario.

Living with MS is often a struggle. While the disease is highly variable and unpredictable, over time, most people with MS find it difficult to maintain fulltime employment and need increased medical care and supports such as home care. Some – fortunately a relative few – will no longer be able to remain in their own homes and will have to seek institutional care.

Our approach to budgetary issues considers the current fiscal challenges that Ontario faces and focuses on ways in which individuals and families living with MS can participate actively – economically and socially - despite the obstacles and isolation MS can create.

Our recommendations do not require substantial new investments. If implemented, these recommendations will have a profound impact on the lives of Ontarians with MS and those in the broader disability community, those who are often among the hardest hit by challenging financial times. These recommendations are summarized below:

- Continue to implement the accessibility standards under the *Accessibility for Ontarians with Disabilities Act*.
- Continue to develop affordable, accessible, and supportive housing for people with disabilities.
- Earmark a portion of the Long-Term Care Renewal Strategy for the development of age-appropriate long-term care.
- Develop a task force of employer, government, and caregiver representatives to develop and test work place policies and income supports for caregivers.
- Remove the provincial portion of the HST from *all* medically necessary devices, goods, and services and work with the Government of Canada to develop appropriate exemptions.

Making Ontario Accessible

With the introduction of the *Accessibility for Ontarians with Disabilities Act* (AODA) in 2005, the Government of Ontario committed to make the province accessible by 2025. Since the introduction of the AODA, accessibility standards have been developed in five important areas: customer service, information and communications, employment, transportation, and the built environment. The development and implementation of these standards, and potentially others in the areas of retrofit and housing, are critical to moving Ontario's accessibility agenda forward.

While there is great excitement about Ontario's leadership with respect to accessibility, there is also concern that the Accessibility Directorate of Ontario is not well resourced to implement and enforce the accessibility standards. There is also concern that, without guidance and support from the Directorate, the ability of businesses and organizations to implement the standards will be compromised, thus compromising the Government of Ontario's vision for - and commitment to - developing an accessible Ontario.

Recommendations

Specifically, we call on the province to:

- Continue to implement the accessibility standards under the Accessibility for Ontarians with Disabilities Act.

Helping People Remain in their Communities

Access to supportive housing in Ontario is extremely limited. Waitlists of between 3 to 10 years have been reported in communities across Ontario. This is simply too long for individuals who face housing and care crises.

In Budget 2009, the Government of Ontario announced more than \$360 million to help create new affordable housing for low-income seniors and persons with disabilities. In 2009, the federal government also committed to providing \$75 million over two years for the construction of social housing units for persons with disabilities. These funds have not only helped to improve access to housing, but have also helped to secure the jobs of many developers, builders, contractors, and others.

The MS Society applauds these initiatives and encourages both levels of governments to continue to invest in affordable housing. However, these dollars must not only create affordable housing, but also affordable *supportive* and *accessible* housing to help people with disabilities remain active and engaged in their communities by providing the care and support they need in their homes, thus reducing the likelihood of health crises and the need for emergency care in hospitals. These are wise and necessary investments.

Even with future improvements to supportive housing, some young adults with MS may still require institutional care. Right now, far too many young Ontarians end

up in long term care facilities or nursing homes that were designed for frail elderly residents, which do not have the services and activities that would benefit younger disabled people.

According to the Canadian Institute on Health Information (CIHI), in 2005–2006, just over one in six patients (17%) who received treatment in Ontario complex continuing care hospital beds was between 19 and 64 years old, and 56% (2,276 individuals) of this group had neurological conditions. Young adults with MS made up 10% (228 individuals) of the neurological group.

This is of particular concern to the MS Society because of the early age of onset for MS. An individual with MS who enters a long-term care facility designed for the frail and elderly at 35 years of age may remain there for 40 years or more. Age-inappropriate living conditions often result in anxiety, depression, and longer-term mental health issues that increase the already complex health needs of these individuals.

There are existing programs and initiatives that can be leveraged to assist people who require supportive housing or age-appropriate care. The Canada-Ontario Affordable Housing Agreement is a vehicle through which to provide more stable funding for supportive housing for people with disabilities. The Agreement provides longer-term funding security for housing projects than do year-by-year budget announcements.

As well, the Ministry of Municipal Affairs and Housing is developing a 10 Year Affordable Housing Strategy. The development of supportive and accessible affordable housing is within the scope of this strategy.

In addition, through the Long-Term Care Renewal Strategy, the Ministry of Health and Long-Term Care (MOHLTC) will redevelop 35,000 long-term care beds – 3,500 beds annually - over 10 years to ensure equitable access to quality long-term care home accommodation.

Recommendations

We encourage the Government of Ontario to:

- Continue to invest in supportive housing for people with disabilities and utilize the Canada-Ontario Affordable Housing Agreement to provide longer-term funding.
- Prioritize the development of supportive and accessible housing through Ontario's 10 Year Affordable Housing Strategy.
- Immediately allocate a portion of the Long-Term Care Renewal Strategy to create additional age-appropriate spaces for younger people who require long-term care.

These recommendations fall within existing government priorities and, as such, do not require new money in the short-term.

Caring about Caregivers

In *Caring about Caregivers: Caregiving for the future of Ontario*, the Ministry of Health and Long-Term Care notes:

One in five Ontarians is a family caregiver, contributing to more than 70% of total caregiving needsⁱ. In 2011, there will be 1.4 million women in Ontario aged 25-44 of whom 4 in 10 will become caregivers at an age when they have to juggle work, family, and social lifeⁱⁱ. These caregivers are our invisible health partners. They are tired and hurting. Without family caregivers and other informal caregivers Ontario's health care system will not be sustainable.

Current research indicates that declines in informal caregiving contributions result in either heightened spending on formal community care services or in costly and unnecessary institutionalizationⁱⁱⁱ. Yet, besides these known costs, there are other social and economic considerations. These considerations include the direct implications on the social, health, and economic status of caregivers themselves, all of which are potentially affected by the caregiving role. For example, informal caregiving also affects the right to participate in the workforce. Without protection and support, informal caregiving may represent a significant leakage of skills and talent from the labour market – a labour pool which is projected to decrease in the coming decades.

Families and friends who provide caregiving do so often out of necessity, but also out of love. Despite their tremendous contributions, many caregivers face hardship.

Researchers at the University of Alberta^{iv} found that 12% of people who provide care to older adults with disabilities experienced negative employment consequences such as changed work patterns, reduced hours of work, declined promotions, and quitting a job. Among caregivers who care for younger adults with disabilities, approximately 30% declined a promotion while 50% quit work to provide care. As Ontario works to rebuild its economy, the productivity and economic impact of informal caregiving should not be underestimated.

From a collective perspective it is estimated that “informal” or “family” caregivers who care for seniors save Canada's health care system between \$24 billion to \$31 billion annually^v. These figures do not include the contributions of those individuals who care for children or adults under the age of 65 who have health related caregiving needs. It is time to better support these caregivers, to recognize and value the significant contributions that they make to the well-being of our society.

The MS Society is a member of the Ontario Caregiver Coalition (OCC), which has been working in partnership with the Ministry of Health and Long-Term Care to develop policy options to support caregivers. While several of the policy options being explored are longer-term solutions, there are low-cost to no-cost foundational

pieces, such as creating a policy definition of informal caregiver, that should be implemented now.

Supporting caregivers goes beyond those supports that government can provide: it requires leadership, commitment, and vision from employers, large and small, community agencies, and other key stakeholders. While the Ministry of Health and Long-Term Care has taken a leadership role in examining caregiver supports, the supports that caregivers require go beyond health.

As such, and as a starting point of improved caregiver support, the MS Society believes that the Government of Ontario should engage employers and encourage cross-ministerial collaboration to benefit caregivers.

Recommendations

Specifically, we ask the Government of Ontario to:

- Convene a task force of employer, government, and caregiver representatives develop and test work place policies and income supports to benefit caregivers.

Reducing HST Impact on People with Disabilities

The MS Society appreciates the measures that the Government of Ontario has taken to reduce the impact that the HST has on Ontarians, particularly for those with low-incomes. Reductions in personal income tax, provisions of transition payments, the creation a permanent sales tax credit of up to \$260 for low-income adult and child per year, and rebates and exemptions should help mitigate the impact of the HST.

Despite these measures, the extent to which the HST will be felt by people affected by MS and those with other chronic conditions or disabilities is not well understood. Many of these individuals live on limited or fixed incomes, yet they often incur significant costs associated with medically necessary goods and services, such as mobility devices, vehicle conversions, massage and physiotherapy, home care and home cleaning services. The cost of these goods and services on their own are often difficult for people with chronic illness or disabilities to manage, and an additional tax burden will make it more challenging. While some medical devices will be exempt, some medical devices, goods, and services will not.

Recommendation

To help further reduce the impact that the HST will have on people with disabilities, the Government of Ontario should:

- Remove the provincial portion of the HST from *all* medically necessary devices, goods, and services and work with the Government of Canada to develop appropriate exemptions.

Summary

The MS Society recognizes the challenging economic times that our province faces. We have very carefully considered our recommendations for Budget 2010 with these challenges in mind.

The recommendations above require little-to-no short-term investment of new funds, but do require the Government of Ontario to make commitments within existing programs and initiatives that will improve the social, financial, physical and mental health status of people affected by MS, and other Ontarians with disabilities or chronic illness.

In turn, the outcomes of our recommendations – such as reduced wait times and improved financial position and societal participation of people with disabilities and their caregivers - will do much to improve the long-term economic position of our province and its people.

Thank you for your time and interest. We will be pleased to answer any questions.

For more information please contact:

Kim Steele
Senior Coordinator, Government Relations
MS Society of Canada, Ontario Division
175 Bloor Street East, Suite 700, North Tower
Toronto, Ontario
M4W 3R8

Phone: (416) 922-6600 ext. 2243
Fax: (416) 922-7538
E-mail: kim.steele@mssociety.ca
Web address: www.mssociety.ca

ⁱ Stobert, S. and K. Cranswick, "Looking after Seniors: Who does What for Whom", Canadian Social Trends. Autumn 2004.

ⁱⁱ Statistics Canada. 2006 Census. Available from: <http://www.12.statcan.ca/census-recensement/2006/rt-td/index-eng.cfm>

ⁱⁱⁱ Wilkins, K and M.P. Beaudet. "Changes in Social Support in Relation to Seniors Use of Home Care", Health Reports, Spring 2000, 11, 4; Trottier, H., Martel, L., Houle, C., Berthelot, J.M. and J. Légaré, "Living at Home or in an Institution: What Makes the Difference for Seniors?", Health Reports, Spring, 2000, 11, 4.

^{iv} Comparing Consequences of Supporting Older & Younger Adults with Disabilities

^v Hollander, M.J, Lui, G., Chappell, N.L., "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 [Internet]. 12(2):42-49. Available from: <http://www.longwoods.com/product.php?productid=20660>