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## **Multiple Sclerosis Society of Canada, Ontario Division Pre-Budget Submission, November 2008**

The Multiple Sclerosis Society of Canada, Ontario Division, is pleased to provide its perspective and recommendations on the 2009 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 financial investment, but will have a profound impact on the lives of Ontarians with MS and those in the broader disability community. These recommendations are summarized below:

- Exempt RDSPs from the income and asset tests used to determine benefits under the Ontario Disability Supports Program and the Ontario Works Program.
- Allocate a portion of the Long-Term Care Renewal Strategy to create additional age-appropriate spaces for younger people who require long-term care.
- Develop regulations and policies regarding the placement of younger adults with MS and other disabilities to ensure they receive care in age-appropriate settings.
- Commit to the development of an Ontario Brain Strategy in Budget 2009 and in the Budget speech.
- Direct ministries that serve Ontarians with neurological conditions to work with the Ministry of Health and Long-Term Care, the NHCC, LHINs, community service providers, and other key stakeholders over the next 3-5 years to develop and cost the strategy.

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

## Registered Disability Savings Program

Later this year, Canada's financial institutions will make Registered Disability Savings Plans (RDSPs) available to Canadians who qualify. The RDSP is a new savings vehicle that will assist families in planning for the long-term financial security of their loved ones with disabilities.

Over time, it is expected that RDSPs will provide "billions of dollars to supplement income, enable home ownership, and enhance quality of life for as many as 700,000 Canadians with disabilities".<sup>1</sup> In other words, RDSPs will be important pieces of broader strategies to help to ensure that people with disabilities have "the same kind of opportunities as everyone else"<sup>2</sup>, a widely-supported goal of the Government of Ontario.

However, current income security policies of the Government of Ontario will serve as some of the biggest challenges that RDSP beneficiaries will face in realizing these opportunities. The way in which income and assets are calculated under the Ontario Disability Support Program (ODSP) and the Ontario Works Program may result in a "clawback" of funds from RDSP beneficiaries, which will limit the ability of these individuals to get further ahead in life.

The federal government has exempted the RDSP from calculations that determine eligibility for and the amount of benefits people with disabilities receive under the Guaranteed Income Supplement (GIS), Old Age Security (OAS), and the Canadian Pension Plan (CPP). As well, British Columbia, the Yukon, Saskatchewan, and Newfoundland have exempted the RDSP as an asset and/or income in benefit calculations under their existing disability support programs.

In her announcement earlier this fall, Saskatchewan's minister of Social Services noted:

*The exemption of RDSP assets and income from social assistance calculations makes sense for a number of reasons. Most importantly, it will encourage individuals with disabilities and parents of children with disabilities to create RDSPs without having to worry that the assets will be clawed back when withdrawals are made on behalf of the beneficiaries.*

The MS Society believes that RDSPs hold promise to help some people with disabilities benefit from greater financial security, which will ultimately help these individuals to have the same kind of opportunities as everyone else.

### Recommendations

In this spirit, the MS Society encourages the Government of Ontario to:

- Exempt RDSPs from the income and asset tests used to determine benefits under the Ontario Disability Supports Program and the Ontario Works Program.

This recommendation requires investment from the Government of Ontario.

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<sup>1</sup> As provided by the Planned Lifetime Advocacy Network (PLAN) at <http://rdsp.files.wordpress.com/2008/04/rdsp-brochure-2008.pdf> on October 10, 2008.

<sup>2</sup> As noted on the Ministry of Community and Social Services website at <http://www.mcsc.gov.on.ca/mcss/english/pillars/accessibilityOntario/> on October 10, 2008.

## **Age-appropriate Long-Term Care**

Some young adults with MS require institutional care. It is vital for their quality of life that their housing and care are appropriate for their age. However, far too many 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.

A 2006 Canadian Institute for Health Information study found that 20% of residents in Ontario hospital-based continuing care facilities were younger than 65, and the Canadian Healthcare Association reported in 2005 that approximately 40% of residents in Ontario's complex care facilities were younger than 65.

This is of particular concern to the MS Society because of the early age of onset for MS. For example, an individual with MS who enters a long-term care facility designed for the frail and elderly at the age of 35 years of age may remain in that facility for 40 years or more. Not surprisingly, 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.

We urge the Ontario government to take specific action to address the long-term care needs of younger adults who live with MS and other disabilities or chronic illnesses. While the Aging at Home Strategy is not designed to address the needs of younger Ontarians with disabilities or chronic illnesses, two existing initiatives provide excellent opportunities to help address the long-term care challenges these individuals face.

### **Long-Term Care Renewal Strategy**

This Ministry of Health and Long-Term Care initiative 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”<sup>3</sup>.

The Ministry will work with Local Health Integration Networks (LHINs) to prioritize renewal projects. MOHLTC is currently considering a number of policy and program design decisions, and the MS Society asks that they incorporate the needs of young people in long-term care into their province-wide planning activities.

### **Long-Term Care Regulations**

The Ministry of Health and Long-Term Care is creating new long-term care regulations. To date, the new regulations have not addressed the issue of age.

For example, very recently the Government of Ontario announced that it was working to improve quality of life in long-term care homes by developing regulations that will allow residents in different homes to switch places if the move is mutually desirable. Under these new regulations, highest priority will be given to people seeking to be reunited with a partner, while secondary priority will be given to residents who are seeking a home that best serves their “religious, ethnicity, or language” needs.

The Ministry of Health and Long-Term Care anticipates that the potential for individual choice that these new regulations offer may improve the flow of patients through hospitals and may reduce wait-times, thereby reducing overall system costs. No mention of age has been included in these regulations or in some of the other regulations that have been developed.

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<sup>3</sup> As taken from [http://www.health.gov.on.ca/english/providers/program/ltc\\_redev/redev\\_mn.html](http://www.health.gov.on.ca/english/providers/program/ltc_redev/redev_mn.html), October 10, 2008.

Inclusion of age-related concerns in the development of long-term care regulations would not only help younger people access long-term care homes that better support their individual medical care needs, but also to access homes that better support the social and psychological needs that impact their well-being and, in many cases, the complexity of their care needs.

### **Recommendations**

Specifically, we call on the province to:

- Allocate a portion of the Long-Term Care Renewal Strategy to create additional age-appropriate spaces for younger people who require long-term care.
- Develop regulations and policies regarding the placement of younger adults with MS and other disabilities to ensure they receive care in age-appropriate settings.

As noted earlier, these recommendations fall within existing government priorities and, as such, do not require new money; they simply require the Government of Ontario to make the decision to address the needs of younger people with disabilities or chronic illnesses in their long-term care planning initiatives.

## **Ontario Brain Strategy**

The estimated annual total cost of MS to Canada's economy is \$1 billion, more than all infectious diseases combined. During their lifetime, on average, each Ontarian with MS will need \$1.6 million in care and support to deal with their illness.<sup>4</sup>

The number of visits to emergency departments in Ontario by patients with MS increased 15.7% from 2002-2003 to 2005-06 (from 1,519 to 1,758). Almost 30% of patients with multiple sclerosis visiting emergency departments in Ontario in 2005-06 were admitted to acute care hospitals. In 2004-05, the median length of stay in Canadian acute care hospitals for patients with MS was six days, compared with four days for all patients in acute care aged 19 years and older.<sup>5</sup>

However, MS is just one of over 1,000 neurological conditions. One in three (10 million) Canadians will be affected by a neurological or psychiatric disease, disorder or injury at some point in their lives. In fact, when death AND disability is considered, the current burden of brain conditions outweighs that of cancer and cardiovascular disease *combined*.<sup>6</sup>

Specifically, in 1998 Health Canada estimated the total economic burden of illness to be \$159.4 billion. Of this, neurological and psychiatric conditions accounted for \$22.7 billion or 14% of the total burden of illness, while cardiovascular diseases accounted for \$18.5 billion (12%) and cancer accounted for \$14.2 billion (9%).

According to a 2006 report conducted by the World Health Organization, "a large body of evidence shows that policy-makers and health-care providers may be unprepared to cope with the predicted rise in the prevalence of neurological and other chronic disorders and the disability resulting from the extensions of life expectancy and aging populations globally."<sup>7</sup>

To address these challenges, a group of 18 neurological health charities came together in early 2008 to form Neurological Health Charities Canada (NHCC). The NHCC is partnering with the

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<sup>4</sup> NeuroScience Canada. *The Case for Increased Investment in Neuroscience Research*. Ottawa, 2004.

<sup>5</sup> *Ibid.*

<sup>6</sup> NeuroScience Canada. *The Case for Increased Investment in Neuroscience Research*. Ottawa, 2004.

<sup>7</sup> Harvard School of Public Health, the World Health Organization, and the World Bank. *Global Burden of Disease*. Washington, 2002.

Ministry of Health and Long-Term Care to create an Ontario Brain Strategy to improve the social, health and economic quality of life for Ontarians who have been diagnosed with a neurological disease through Ontario's *Chronic Disease Prevention and Management Framework*.

While in its early days, key components of the proposed Brain Strategy include strategic initiatives in the areas of diagnosis and treatment, community living and housing, and continuing and long-term care. Strategy development will require the support of other ministries such as Community and Social Services, Municipal Affairs and Housing, and Children and Youth Services, among others.

It is therefore important that development of an Ontario Brain Strategy not simply be a priority of the Ministry of Health and Long-Term Care, but that it is made a broader-based priority of the Government of Ontario.

### **Recommendations**

With this in mind, the MS Society recommends that:

- The Government of Ontario commit to the development of an Ontario Brain Strategy in Budget 2009 and in the Budget speech.
- That representatives from ministries that directly serve Ontarians with neurological conditions work with the Ministry of Health and Long-Term Care, the NHCC, LHINs, community service providers, and other key stakeholders over the next 3-5 years to develop and cost the strategy.

Because this is a longer-term planning initiative, it requires very little in terms of immediate financial investment but does require the Government of Ontario to support our vision and to ensure that the strategy is adequately resourced in the future.

### **Summary**

The MS Society's recommendations 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, and physical and mental health status of Ontarians with disabilities or chronic illness for the long-term.

In turn, the outcomes of our recommendations – such as reduced wait times and improved financial position and societal participation of people with disabilities - 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.

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