



Wired for Success: Toward an Ontario Brain Strategy

FINAL REPORT – *Executive Summary*

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Wired for Success: Toward an Ontario Brain Strategy is the product of work undertaken by Neurological Health Charities Canada, with advice and support from the Health System Strategy Division, Ontario Ministry of Health and Long-Term Care.

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NHCC

NEUROLOGICAL HEALTH CHARITIES CANADA

Executive Summary

The human brain is the control centre of the human body. Its' tasks range from the mundane chores of keeping us alive and responsive to our environment – making sure our heart pumps, lungs breathe, eyes see – to the most defining aspects of the human experience including language, science, artistic expression, love, anger, and compassion.

Whether awake or asleep, everything we do, think, and feel is made possible by one's brain. The diversity of roles is astonishing but one thing is clear – if one's brain doesn't work properly, every aspect of daily life can be compromised.

More than two million Ontarians live with a neurological disease, disorder or injury today¹ – one of a thousand brain disorders for which there are limited treatments and no cures. They affect Ontarians at every age and stage of life, and members of every community across this province. Regardless of diagnosis, these individuals and their families face remarkably similar issues and common needs.

As our population ages, and society becomes more educated about recognizing brain conditions, experts predict that the prevalence of neurological conditions and related impact will rise significantly. For most affected, their condition will impact their friendships, family relationships, education, income, employment, housing and social participation.

In 2006, the World Health Organization reported “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 disability resulting from the extension of life expectancy and ageing of populations globally.”²

With such serious health, social and economic implications, for individuals and for society overall, brain health needs to be one of our highest priorities. For this reason, ***Wired for Success: Toward an Ontario Brain Strategy*** is an important first step in developing collaborative approaches and solutions to address this critical issue facing Ontario.

¹ Society for Neuroscience, Brain Facts: a primer on the brain and nervous system (Washington, DC, 2008) - in 2008, the Society for Neuroscience reported that 55 million Americans were living with a neurological condition and 44 million with mental illness. Applied to the Canadian population, the prevalence is approximately 5.5 million Canadians with a neurological condition and 4.9 million with mental illness. Applied to the population of Ontario, the prevalence is approximately 2.2 million Ontarians with a neurological condition and 1.96 million with a mental illness for a total of 4.16 million Ontarians with a brain condition.

² World Health Organization, Neurological Disorders: Public Health Challenges (Switzerland: WHO Press, 2006).

Background

Health charities committed to serving individuals and families living with neurological conditions have been an active part of life in Ontario for the past 60 years. Traditionally, these organizations have advocated to government about condition-specific issues, but with limited success. Individual conditions have presented themselves in isolation, not as parts of a much larger category of illness.

As a result, brain conditions have been overshadowed by illnesses that are perceived to have much greater impact. In January 2008, a group of neurological charities came together as a new coalition, Neurological Health Charities Canada (NHCC). Armed with the 2002 World Health Organization's Global Burden of Disease findings that the impact of brain conditions is greater than that of cardiovascular disease and cancer combined, the NHCC set out to position the brain as a priority issue for governments at all levels.

This marked the first time that policy makers were asked to consider brain conditions as one category with common challenges, and potential common solutions. In April 2009, the Government of Canada announced \$15 million to fund a 4-year population-based study of neurological conditions across Canada. At the same time, several Ontario-based NHCC members agreed to work at the provincial level to address the many common issues facing Ontarians with neurological conditions.

Strategic Framework

In January 2009, a focus group of over 50 NHCC representatives (with advice from government staff) formed a Working Group (WG) to develop options to frame an Ontario Brain Strategy. The WG began its work in February 2009, seeing input from NHCC member organizations and their stakeholders about the present-day priority issues facing Ontarians with neurological issues and their families. This consultation evolved into a formal long-range scenario planning exercise, taking place over six months and garnering input from over 250 individuals and organizations. This process allowed stakeholders to identify key trends, which could either delay progress or act as a catalyst.

Five dominant themes emerged from this consultative work. People expressed a need for having:

- Personal choice
 - Direct control for decisions regarding medical care, social supports and shaping their living environment
- An inclusive culture
 - An Ontario that has a focus on health over illness
 - Reduced stigma achieved by shifting public values and attitudes
 - Employment opportunities and flexible work arrangement
- Enabling technology
 - Assisted living technologies to enable better living
 - Smart homes, accessible education and workplaces
 - Flexible transportation systems
- Supported caregivers
 - Whose role is valued
 - Supported sufficiently to maintain their own health and financial stability

- Shared knowledge
 - Commitment to research and to moving evidence into practice
 - Reliable medical and decision support information
 - Engaged online community

Secondary themes emerged including integrating systems, designing the built environment, engaging the private sector, and taxing and funding.

Living well with a brain condition in Ontario is much more than a 'health' issue. It requires the active engagement of the private sector, non-profit sector and key government ministries including Education, Research and Innovation, Community and Social Service, Finance, Health Promotion, Child and Youth Services, Municipal Affairs and Housing, Labour, Transportation, and through them, the broader public sector.

In short, it requires a thoughtful response from government, industry and the non-profit sector that addresses all aspects of an individual's life: family relationships, education, income, employment, housing and social participation.

Next Steps

We know that there are great opportunities for knowledge and technology to advance in many areas of brain research, clinical insight and in aids for social inclusion and support. The challenge is to find the commonality in our unique interests, to share our key competencies, to broaden the circle of those who might help, and to leverage our collective will to drive these changes faster; farther; and in such a way that timely and effective intervention is no longer a question for those who are in need.

With primary and secondary elements of an Ontario Brain Strategy endorsed by Ontarians living with neurological conditions, next steps involve identifying the full range of system design elements and strategic options available, prioritizing issues and opportunities, and ultimately implementing the strategy.

Additional consultation is required to engage a wider representation of educators, health care professionals, community service providers, stakeholders living with brain conditions not presently represented by the NHCC, members of the private sector (including investors and innovators), and government staff across many ministries.

New thinking is already underway, including the Ontario government's initiative to develop the Ontario Brain Institute, representing one aspect of a multi-faceted strategic need. Significant work has also been done to highlight a range of options that would better support caregivers across the province and the broad array of health care needs that they must address daily. Ontario's long-term affordable housing strategy is another area that needs continued attention in the area of accessibility. Our aim is to build upon these initiatives to ensure that they deliver maximum benefit to Ontarians living with a brain conditions.

For a copy of the full report with appendices, please visit www.mybrainmatters.ca and look under the Ontario Brain Strategy tab of the Public Policy section.