

Executive summary

One in three (10 million) Canadians will be affected by a neurological or psychiatric disease, disorder or injury at some point in their lives. This figure will increase as the population ages due to degenerative brain diseases associated with agingⁱ. Diseases, disorders and injuries of the brain, spinal cord and nervous system, such as Alzheimer's disease, stroke, schizophrenia, multiple sclerosis, spinal cord injury, depression, sense organ diseasesⁱⁱ and traumatic brain injury afflict Canadians of all ages and backgrounds, and can strike anyone at anytime. These conditions are often chronic, leading to a profound deterioration of a person's quality of life. Brain disordersⁱⁱⁱ are a result of a complex interplay of genetic and environmental factors. Research is the key to unraveling the intricacies of the brain and nervous system. It is the only hope for finding therapies and cures.

The brain is the most critical and mysterious organ, and is what makes us human. It is the "last frontier" of human biology. Ninety per cent of what we have learned about the brain has been in the past fifteen years, but researchers still have far to go toward fully understanding brain function. There is a currently an explosion in brain research with unlimited potential for growth in knowledge based societies, with benefits for both Canada and the world.

The following report prepared by NeuroScience Canada presents the case for Canada's increased investment in neuroscience research. The first part of this report establishes the need: the enormous burden that neurological and psychiatric diseases, disorders and injuries place on the Canadian healthcare system. The second part of the case establishes the excellence and capacity of Canadian neuroscience research, and calls for governments to increase funding available for neuroscience research, so that our world-class researchers can fully utilize the investments already made in infrastructure and salaries.

When looking at Health Canada data, there is no single class of disease associated with the range of neurological, psychiatric and sense organ diseases, disorders and injuries that encompass the range of the conditions included in the neurosciences. The absence of a single recognized category for all brain and nervous system disorders exacerbates the difficulty to obtain precise figures for the burden of this disease group, as existing information and surveys have been compiled using different parameters. Therefore, in an effort to determine an accurate burden of brain, spinal cord and nervous system disorders for the creation of this report, data had to be culled from several sources. A number of stakeholder groups who share NeuroScience Canada's concern about the absence of reliable data on the incidence, prevalence, and economic and social impact of brain, spinal cord and nerve-related conditions in Canada, supported and aided the process^{iv}.

Health Canada estimated the total economic burden of illness in 1998 to be \$159.4 billion^v. Of this, neurological and psychiatric conditions accounted for \$22.7 billion or 14% of the total burden of illness. In comparison, cardiovascular diseases accounted for \$18.5 billion or

12% of the total burden of illness; cancer accounted for \$14.2 billion or 9% of the total burden of illness. However, Health Canada used mortality data as the basis for calculating burden of illness statistics in that study, and this is not considered adequate as this practice fails to consider disability, which results in a reduction of quality of life. The leading causes of disability are substantially different from the leading causes of death. There should be a relation between investment and burden of disease, and therefore, there is a need to reframe health care investment in services and research to morbidity data.

The Global Burden of Disease (GBD) 1990 study conducted by The Harvard School of Public Health, the World Health Organization, and the World Bank, created a new metric using a disability component for determining burden of disease that is becoming universally accepted. The Disability Adjusted Life year (DALY) is a measure that expresses years of life lost to premature death and years lived with a disability of specified severity and duration. The DALY combines years of life lost (YLLs) with years lived with disabilities (YLDs) into a single indicator and allows for a comparison of the burden of illness. Based on the GBD 2002 study, neurological and psychiatric conditions account for 38.3% of DALYs, compared with 12.7% for cancer and 11.8% for cardiovascular disease. In addition, six of the top 10 leading causes of burden in established market economies can be attributed to neurological and psychiatric conditions, with unipolar depressive disorders second only to ischemic heart disease.

Health Canada's *Economic Burden of Illness in Canada (EBIC)* report and the GBD study aims to examine the economic impact of long-term disability costs attributed to neurological and psychiatric diseases, disorders and injuries, most significantly for mental disorders. Independent reports by stakeholders in Canada and the US recognize the shift in the global burden of disease from infectious to non-communicable disorders, and are unanimous in their message that neuropsychiatric disorders, specifically those pertaining to mental health, have been seriously underestimated and impose a far greater burden in terms of lost productivity and costs to society than was originally believed. In addition to this enormous burden, there is considerable stigma surrounding neuropsychiatric^{vi} diseases and only recently has there been public recognition that these conditions have a physiological basis.

Canada has a critical role in addressing the enormous burden of neuropsychiatric conditions. Canada is a leader in neuroscience research and is home to a number of important discoveries in the neurosciences. This country has leading laboratories in the areas of neurodegenerative disease, neurotrauma, neuroimaging, tissue engineering and biomaterials, regeneration, protection and functional recovery and genetics.

The Canadian government has recognized the need to invest in research and has created successful programs such as the Canada Research Chairs program to recruit top talent, Canadian Foundation for Innovation to fund infrastructure, and Genome Canada, which

provides funding for large-scale genomics and proteomics research. Private donors have also aided in providing infrastructure, including establishing a number of neuroscience research centres across Canada. However, physical infrastructure and salaries are not sufficient; there must be increased investment in operating funding to enable researchers to run their labs and provide training environments for doctoral students and postdoctoral fellows.

The Canadian Institutes of Health Research is currently the major source of public funding for health research, but at \$662 million in 2004 (the budget will be almost \$700 million by 2006), it is still short of the \$1-billion target it had established to provide adequate funding to Canadian researchers, including those involved in neuroscience research. Even when private funding is included, the current allocation of funding to the neurosciences is disproportionate to the burden of disease, and is disproportionate in comparison to the funding other disease groups are receiving. Through the CIHR's open competition, an estimated \$81 million was allocated to neuroscience research in 2003/2004, compared with \$94 million for cancer and \$109 million for cardiovascular. However, cancer receives an additional \$64 million^{vii} per year from the Canadian Cancer Society and the National Cancer Institute of Canada, and cardiovascular receives an additional \$51 million^{viii} per year from the Heart and Stroke Foundation of Canada. There is no similar source of major funding from private donors or foundations for neuroscience research, and the combined research funding from neuroscience-focused Voluntary Health Organizations is estimated at only \$15 million (Please see Appendix 4 for a Table depicting research and public awareness expenditures for Canadian Voluntary Health Organizations).

Canadian researchers are increasingly having to turn to American institutes such as the National Institutes of Health and the Howard Hughes Medical Institute for funding. Although there are a number of Voluntary Health Organizations that raise money for public awareness and research into specific conditions, NeuroScience Canada is the only Canadian, national non-profit, non-governmental organization devoted to raising funds for research into the full range of diseases, disorders and injuries that encompass the neurosciences. However, the current funding capacity of NeuroScience Canada is modest in comparison to the umbrella organizations for the other disease groups. Increases in neuroscience operating research funds, in tandem with the government programs already established, will help Canada remain a leader in neuroscience research, but more importantly, will help in the global effort to alleviate the tremendous burden of neurological and psychiatric diseases, disorders and injuries.

NeuroScience Canada recommends the following steps be taken:

- The neuroscience community should develop a public awareness campaign about the true burden of brain disorders to help stimulate increased private and public investment. NeuroScience Canada intends to take the leadership in organizing such a campaign, but this would require an initial investment and the appropriate support from other stakeholders in this area.
- The federal government should immediately invest \$5 million per year for five years, for a total of \$25 million to support large-scale neuroscience research projects. These funds would be leveraged by NeuroScience Canada to attract and stimulate additional private funding, at a ratio of \$1 from private sources for every \$2 in government funding.
- Finally, the neuroscience community should seek an increase in the Canadian Institutes of Health Research's (CIHR) allocation to the Institute of Neuroscience, Mental Health and Addiction (INMHA), to support both individual investigators and team grants. In order not to divert funds from other areas, this would mean increasing the CIHR budget to its \$1 billion target.