

**CONTRIBUTING TO CANADA'S FUTURE
THROUGH ACTION ON BRAIN HEALTH**

SUBMISSION TO THE HOUSE OF COMMONS STANDING COMMITTEE ON FINANCE
FOR THE 2020 PRE-BUDGET CONSULTATIONS

Neurological Health Charities Canada

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RECOMMENDATIONS

- **Recommendation 1:** Work with Neurological Health Charities Canada (NHCC) and its member organizations representing millions of Canadians, to establish a Canadian Brain Council to lead unprecedented collaboration in brain health research and patient care services.
- **Recommendation 2:** Support Canadians living with brain conditions, as well as their families and caregivers, by improving and expanding existing income support programs and tax credits.
- **Recommendation 3:** Utilize federal leadership to test an expanded chronic care model for neurological conditions that integrates health and support care services to deliver better and more coordinated care.

The Costs of Inadequately Addressing Brain Health in Canada

Brain health is vital and critical to the lives of all Canadians. Neurological Health Charities Canada (NHCC) believes a basic right of Canadians living with brain conditions is unrestricted access to the best treatments, community and patient care supports. This right can only be fulfilled by governments committing to investing in both high quality brain health research and health and community supports.

One-in-three Canadians live with a brain condition. It is far too big an issue to leave unaddressed.

- ❖ Brain conditions make it harder to work, succeed academically and participate in everyday activities, resulting in lost income, financial hardshipⁱ and lost productivity for Canada as a whole;
- ❖ Neurological and mental health disorders cost the Canadian economy \$61 billion annuallyⁱⁱ – more than cancer and cardiovascular disease combined;
- ❖ Working-age Canadians with brain conditions are five times more likely to be permanently unemployed than Canadians without brain conditionsⁱⁱⁱ;
- ❖ Between now and 2031, indirect costs due to working-age premature death and disability related to brain conditions will increase^{iv} and total health care costs for Parkinson disease and dementia will double^v.

Build on existing evidence

NHCC's recommendations build on Canada's investment of \$15 million in 2009 which forged a better understanding of the impact of brain conditions through the Government of Canada-funded [National Population Health Study of Neurological Conditions](#), the most comprehensive examination of brain illnesses, disorders and injuries ever undertaken in Canada. The 2014 report, [Mapping Connections](#), provided information important to improving the lives of people living with brain conditions. However, five years have gone by since the report was released and much of the work needed to improve lives has still to be done.

The critical knowledge obtained through this research was the government's first step in assessing the scope of needed government support. Now it is time for phase two – **to provide that support**.

Critical areas that still need addressing, as identified in *Mapping Connections* includes:

1. Lack of information about how brain conditions affect various communities and socio-economic groups differently including:
 - ✓ Indigenous populations;
 - ✓ less prevalent brain conditions;
 - ✓ socio-economically-disadvantaged communities who have limited access to resources;

- ✓ women who disproportionately develop certain brain conditions, or, if not affected personally, more often tend to take on the role of caregivers to those who are.
- 2. Stigma which can result in inconsistency of health services, especially when individuals live with more than one condition, such as a neurological disease and a mental health condition.
- 3. Income insecurity – life with a brain condition often means high costs but low incomes, including for the families who provide day-to-day care.

Who We Are

Neurological Health Charities Canada (NHCC) is a coalition of 12 organizations that represent over two million Canadians living with brain diseases, disorders and injuries (brain conditions). NHCC was an integral partner in the government-funded study and its report, *Mapping Connections*. See more information at: www.mybrainmatters.ca or www.moncerveaumavie.ca.

The Brain Health Action Plan: Recommendations Explained

It's time to systematically build on the knowledge in *Mapping Connections*. NHCC believes our recommendations are the basis of a much-needed **Canadian Action Plan for Brain Health**. Putting these recommendations into practice would make a significant difference in the lives of individuals affected by brain conditions – those living with brain conditions, their families and caregivers.

Recommendation 1: Work with Neurological Health Charities Canada (NHCC) and its member organizations representing millions of Canadians, to establish a Canadian Brain Council to lead unprecedented collaboration in brain health research and patient care services.

It is time for Canada to establish a Brain Council to lead unprecedented collaboration within the brain health community. NHCC is ready to help lead this exciting collaborative approach to drive knowledge to action. We know excellent research is being done at universities and hospitals on potential treatments, better diagnoses and possible preventions. We know innovative health care services are helping people affected by brain conditions have healthier lives. What we don't know is whether all of this knowledge and innovation is reaching the people it is intended to help.

We envision a Canadian Brain Council that would pull the brain health community together and coordinate efforts to move forward. We recommend it be comprised of Canadians living with brain conditions, families and caregivers, brain health charities, health-care professionals, social services experts, brain health researchers, the federal health portfolio, representatives of provincial and provincial governments and the pharmaceutical industry.

It could serve as a critical knowledge hub to bring together existing resources, consider and provide advice about emerging trends and gap areas, and disseminate information and engage more partners in finding solutions. It would also serve as a bridge bringing together neurological

and mental health sectors. The European Brain Council^{vi} provides an excellent model for how such a network could be structured, and for how it can lead to tangible results for real people.

What would this mean for Canadians?

The Canadian Brain Council would:

- ✓ Assess progress that has been made in filling gaps identified in the seminal report *Mapping Connections*;
- ✓ Determine the steps needed to fill those gaps including recommendations for further brain condition data collection and risk factor research;
- ✓ Assess information needs of Canadians affected by brain conditions and how brain health charities and others can better serve them;
- ✓ Promote ongoing dialogue and collaboration between brain health researchers, industry, governments and the larger brain health community;
- ✓ Assess awareness and education needs and foster strategies for prevention, early detection, diagnosis and treatment;
- ✓ Examine other disability income security and support models to Canada's needs, for example, guaranteed income models and Australia's National Disability Insurance scheme.

Estimated cost: \$3.5 million

Recommendation 2: Support Canadians living with brain conditions, as well as their families and caregivers, by improving and expanding existing income support programs and tax credits

Brain conditions often lead to disability. That means leaving a job prematurely, not being able to work at all, or requiring access to mobility equipment, expensive medications, therapies, adaptations to homes or specialized transportation.

Income insecurity also affects caregivers, as documented in *Mapping Connections*. Nearly a quarter of parents whose children have a brain condition reported financial problems such as pay cuts, demotions and/or the ability to work outside the home.

NHCC believes it is time for Canadians affected by brain conditions to be explicitly included in existing federal government programs. It is also time for the Government of Canada to officially examine disability income security models that have proven successful in other jurisdictions and commit to putting into effect the model that would best suit Canada.

What would this mean for Canadians?

They would have better financial security through:

- ✓ Increasing the Caregiver Amount (tax credit) and the Family Caregiver Amount (tax credit) by 10 per cent in 2019 and another 10 per cent in 2020; **\$22.1 million^{vii}**
- ✓ Making both caregiver tax credits refundable to help families whose incomes are so low they do not benefit from the credit; **Information on cost not publicly available.**
- ✓ Increasing EI sickness benefits to 26 weeks with expanded flexibility for partial work and partial benefits; **\$50 to \$100 million annually^{viii}**

- ✓ Ensuring eligibility for Disability Tax Credit and Canada Pension Plan Disability Benefits includes individuals living with brain conditions that are episodic in nature; **Information on cost not publicly available.**
- ✓ Creating a National Pharmacare Program to ensure that Canadians living with brain conditions have access to the medications they need. **Up to \$20 billion^{ix}**
- ✓ Examining disability income security models that have proven successful in other jurisdictions and commit to putting best model into effect. **Costing not available.**

Recommendation 3: Utilize federal leadership to test an expanded chronic care model for neurological conditions that integrates health and support care services to deliver better and more coordinated care.

Individuals with brain conditions face disjointed, fragmented care across multiple settings and care providers. *Mapping Connections* documents a lack of knowledge or awareness of brain conditions among health service providers and limited availability and/or accessibility of necessary services, particularly for people living in rural areas.

Mapping Connections also provides substantial evidence that when individuals experience both neurological and mental health conditions, their health outcomes are more negative. When psychiatric diagnoses or severe behavioural disorders are concurrent with a neurological condition, access to health care services becomes limited^x. Furthermore, individuals with neurological conditions are often denied services if they also have a mental health condition.

NHCC is looking for a commitment from the Government of Canada to work with NHCC, the provinces and territories to test an **Expanded Chronic Care Model for Neurological Conditions**. A project in the National Population Health Study of Neurological Conditions provided a model emphasizing caregiver support and supported transitions, acceptance and openness to overcome stigma associated with brain conditions, and ensuring increased knowledge of brain conditions reaches across all services and programs – not just health care.

What would this mean for Canadians?

- ✓ Reduced stigma – the proposed model emphasizes caregiver support and supported transitions, acceptance and openness within health care to overcome the stigma and bias experienced by individuals who have both a neurological and mental health condition;
- ✓ Reduction in urban-rural differences in accessing health care and support services resulting in more equitable access;
- ✓ Reduced isolation of individuals living with brain conditions and caregivers.

Estimated Cost: \$10 million over two years

Brain Conditions Continue to Impact Millions of Canadians

NHCC strongly believes that implementing our recommendations will improve the lives, productivity and prosperity of the millions of Canadians living with brain conditions and their families. *Mapping Connections* has shown that brain conditions impact every demographic and every region in Canada, and specifically affect Indigenous peoples, women and socio-economically disadvantaged communities more profoundly.

Unemployment among Canadians living with brain conditions remains 12 times higher than the general population. The number of Canadians with brain conditions is increasing: *Mapping Connections* documented by 2031 the number of people with Alzheimer's disease and other dementias, Parkinson's disease and traumatic brain injury is expected to double.

Supporting Canadians with brain conditions is not solely about improving health and social policy, it is vital to the future of our economy.

We look forward to working with the Government of Canada and other important partners to tackle these important issues and to establish a **Canadian Action Plan for Brain Health**.

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ⁱ Public Health Agency of Canada. *Mapping Connections: An understanding of neurological conditions in Canada*. Ottawa (ON): Public Health Agency of Canada; 2014. 98 p. Report No.: ISBN 978-1-100-24442-6, p. 24.

ⁱⁱ 2016 Report of INMHA Evaluation Panel from the CIHR Institute of Neurosciences, Mental Health and Addiction

ⁱⁱⁱ *Mapping Connections*, p. 24.

^{iv} *Mapping Connections*, p. 30.

^v *Mapping Connections*, p. 46.

^{vi} European Brain Council. Accessed at <https://www.braincouncil.eu/>

^{vii} Based on 10% increase of projected cost of both programs 2017-2018, Parliamentary Budget Officer. Federal Support for Low Income Individuals and Families. November 2017. Accessed at: https://www.pbo-dpb.gc.ca/web/default/files/Documents/Reports/2017/Fed%20Support%20for%20Low%20Income%20Families/Federal%20Support%20for%20Low%20Income%20Individuals%20and%20Families_EN.pdf

^{viii} Prince, Michael. Testimony at Standing Committee on Human Resources, Skills and Social Development and the Status of Persons with Disabilities. Dec. 4, 2018.

^{ix} Standing Committee on Health. *Pharmacare Now: Prescription Medicine Coverage for All Canadians*. April 2018.

^x *Mapping Connections*, p. 41.