



Submission to the Standing Committee on Health for its study on Canada's Health Workforce

By: Neurological Health Charities Canada
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NHCC Recommendations

That the government:

- Invest in training, support, retention and capacity-building of a non-specialist neurological health-care workforce including family physicians, nurses, and personal support workers;
 - Invest in digital education and online learning programs to accelerate workforce training geared towards caring for those with neurological conditions. This would enhance equitable access to care;
 - Build national capacity to collect, monitor and report on population and health-care system data related to neurological conditions;
 - Support the development of electronic medical records with appropriate access for individuals living with neurological conditions;
 - Create a working group to develop a National Neurological Strategy for Canada.
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Neurological Health Charities Canada (NHCC) is grateful for the opportunity to provide our recommendations to the Committee on its timely study on Canada's health workforce. This issue has long been a concern of our coalition of organizations that represent millions of Canadians living with neurological diseases, disorders and injuries.

Like many health-care stakeholders, we are concerned about access to adequate health-care resources – be it the availability of qualified personal support workers or access to specialists – and would also note the importance of ensuring continuity of care for individuals within both the health and social service sectors. The submission that follows addresses particular issues from the perspective of the stakeholders we serve - those living with neurological diseases, disorders and injuries.

Background

NHCC came together in 2008 because we were concerned that far too little was known about the impact, health service use, scope and risk factors associated with neurological conditions. Through our advocacy, the Government of Canada funded the first-ever population-based study of neurological conditions. We were proud to help lead the study from 2009-2013 along with the Public Health Agency of Canada, the Canadian Institutes of Health Research and Health Canada. It resulted in the seminal report *Mapping Connections: An understanding of neurological conditions in Canada*¹ and is still recognized as the most comprehensive study of neurological conditions in Canada.

The findings in the *Mapping Connections* section on health service use and disparities are as important today as they were when the report was released. In fact, the challenges imposed by the COVID-19 pandemic have exacerbated a number of the service gaps, according to many NHCC member organizations that have had to step in to supplement services since March 2020.

Health services for neurological conditions

Living with a neurological condition is hard. Harder still is being frustrated that health-care providers at times know very little about those conditions and the most up-to-date and best practices to make individuals lives better.

Canadians living with a neurological condition usually use more health-care services than those without a neurological condition or even those with other chronic conditions, whether they are living in the community or in health-care facilities, receiving alternate level of care, or obtaining the services of physicians and other health-care professionalsⁱⁱ. Complicating this is the fact that a wide range of health services is necessary to address the needs of individuals living with a neurological condition and those of their families and caregivers. Sadly, often these services are not available, especially in rural and remote communities.

Other studies have come to similar conclusions. A Canadian study focusing on stroke emphasized that a team approach involving a full range of services is key to successful rehabilitation and recovery. A stroke care team ideally involves specially trained physicians, psychiatrists, neurologists, physiotherapists, occupational therapists, speech-language pathologists, nurses, social workers and dieticians as well as pharmacists, case managers, psychologists, palliative-care specialists and recreation and vocational therapistsⁱⁱⁱ. Unfortunately, this approach is not universally available to the detriment of the stroke survivors^{iv}.

Mental health and cognitive issues complicate care

The *Mapping Connections* study also identified a number of barriers to effective care for people with brain conditions. In some cases, family physicians were unwilling to accept them as patients because of their complex care needs. In addition, self-management, a key feature of chronic-disease management, is difficult to achieve when the individual has significant mental health or cognitive challenges.^v

Some health service providers excluded people with brain conditions from their services if they had a co-existing psychiatric diagnosis, severe behavioural disorder or substance abuse/dependence. Based on results from an online survey completed by administrators of publicly funded acute care hospitals, long-term care facilities, and community outpatient centres from all regions of Canada, 33% of respondents indicated that their facility did not accept patients with psychiatric diagnoses or severe behavioural disorders. Only 9% of these service providers had access to a neuropsychologist, and only 3% had access to a neuropsychiatrist^{vi}.

A Saskatoon man lives with spina bifida and hydrocephalus. He no longer has a family physician since his previous doctor stopped treating him because of the amount of care he requires. His health and mobility have deteriorated and at times he can't leave his home to shop for food. He also has difficulty getting medications for his severe pain renewed. When he has tried to have them renewed at emergency departments; he has been labelled as "looking to get meds." Now, he has stopped trying.^{vii}

Transitioning from child to adult care

Children with neurological conditions face additional obstacles. They may have a crisis in care when they reach age 18 and have to move from pediatric to adult health care. A paediatric clinic setting, where the child received coordinated care from an integrated team of health professionals, is often replaced by an over-worked family physician who may have little knowledge about the child's specific brain condition. The teenager, hopefully supported by a parent or caregiver, must become an expert in his or her care and in navigating a complex system. Unfortunately, the transition is not always successful and can result in delayed and/or inappropriate care, and inferior health outcomes.

Kayeigh has Rett syndrome. Seemingly healthy until she was 23-months-old, she then lost the ability to speak, to use her hands, and eventually to walk. Caring for a child with a

neurodevelopmental disorder like Rett syndrome can consume the life of the entire family. Even worse, when Kayleigh reached 18, she was discharged from five specialists at the local children's hospital and her care switched to the family doctor. He became responsible for the management of her seizures, cardiac and urological issues, gastrostomy tube, osteoporosis, pain and so much more. Leaving the coordinated care at the children's hospital for decentralized medical care has been overwhelming for Kayleigh and her family.^{viii}

In addition, children living with a neurological condition require regular use of health services, but these services are sometimes lacking. One *Mapping Connections* project estimated that a fifth of children with a neurological condition had not seen a general practitioner or pediatrician in the previous year, and only two-thirds had received specialist physician care. Children with newly diagnosed cerebral palsy require a range of rehabilitation services, but services were often not available when a condition was long-standing or if the condition was combined with a cognitive impairment. Overall, as another project found, there were fewer services offered for children (age 0 to 17 years) than those available to adults^{ix}.

First Nations and Métis health- services needs

The health service needs for First Nations and Métis individuals with a neurological condition deserve particular consideration. One project identified a number of challenges faced by First Nations and Métis individuals requiring health-care services for neurological conditions: Lack of accessible specialized health-care and diagnostic services in northern, rural, or remote locations; difficulties navigating the health system in relation to which level of government was responsible; lack of support and training for families with a member affected by a neurological condition; lack of understandable information regarding neurological conditions; and issues of stigma and discrimination^x.

Our solutions

As Canada emerges from the COVID-19 pandemic, it is time to tackle one of the most challenging but ultimately solvable health issues of the twenty-first century: the prevention, treatment, and cure of neurological conditions. The pandemic showed the importance of governments working together with citizens for a common goal. A **National Neurological Strategy for Canada** is an opportunity for collaboration well beyond what we have experienced previously.

One of the key components of the Strategy is for the Government of Canada to invest in capacity building of the neurological health workforce. We suggest that it is important to focus on two key components:

- Investing in training, support, retention and capacity-building of a non-specialist neurological health-care workforce including family physicians, nurses, and personal support workers;
- Investing in digital education and online learning programs to accelerate workforce training geared towards caring for those with neurological conditions. This would enhance equitable access to care.

Related to workforce training is the need to strengthen Canada's health information systems. As the *Mapping Connections* report illustrated, it is not possible to build and improve health-care systems and workforces without appropriate information. To that end, NHCC recommends that the Government of Canada focus on:

- Building national capacity to collect, monitor and report on population and health-care system data related to neurological conditions;
- Supporting the development of electronic medical records with appropriate access for individuals living with neurological conditions.

Finally, the Government of Canada has recognized that national strategies are important to solving health problems, including the National Mental Health Strategy (launched 2012), the National Dementia Strategy (launched 2019) and the National Autism Strategy (launched 2020). In addition, the Canadian Brain Research Strategy^{xi} received funding in 2020 for development work. Building on this important work and the findings in the seminal report *Mapping Connections*, NHCC proposes the creation of a **National Neurological Strategy for Canada** to allow all Canadians to maximize brain health including tackling the challenges and disparities we have identified within Canada’s health workforce. We recommend that the first step should be:

- The creation of a working group to develop a National Neurological Strategy for Canada.

NHCC looks forward to working with the Standing Committee on Health to realize these important goals.

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.

ⁱⁱ *Mapping Connections*, p. 36.

ⁱⁱⁱ Hebert D, Lindsay MP, McIntyre A, Kirton A, Rumney PG, Bagg S, et al. Canadian stroke best practice recommendations: stroke rehabilitation practice guidelines, update 2015. *Int J Stroke*. 2016;11(4):459–84.

^{iv} Hartford, W., Lear, S. & Nimmon, L. Stroke survivors’ experiences of team support along their recovery continuum. *BMC Health Serv Res* 19, 723 (2019). <https://doi.org/10.1186/s12913-019-4533-z>.

^v *Mapping Connections*; p. 41.

^{vi} *Mapping Connections*, p. 38.

^{vii} Provided by Hydrocephalus Canada.

^{viii} Provided by Ontario Rett Syndrome Association

^{ix} *Mapping Connections*, p. 44.

^x *Mapping Connections*, p. 45.

^{xi} The Canadian Brain Research Strategy is a pan-Canadian endeavour which aims to link brain research initiatives and projects, public and private funders, and patient organizations in a uniquely collaborative effort that will push the frontiers of brain science. It coordinates Canada’s participation in the International Brain Initiative. Accessed at <https://canadianbrain.ca/>