Advancing Neurorehabilitation and Recovery in British Columbia

September 2023

BC Rehabilitation+ Recovery

Stroke, Spinal Cord Injury (SCI), and Brain Injury (BI) are life-altering events that require long-term support over what is usually a life-time journey. Unfortunately, our current systems of health, community, and social care do not recognize this reality.

In British Columbia, while emergency response and acute care are prioritized, neurorehabilitation and recovery support receive less attention and significantly fewer resources. The current system is also highly fragmented, with wide gaps in access and minimal coordination between services. The lack of integration places the burden of navigating the complex landscape of health care and social support on people living with stroke, spinal cord injury and brain injury, as well as their care partners.

Inadequate communication and information flows between healthcare providers and clients, as well as between different healthcare providers and organizations, often leads to feelings of isolation and abandonment. These challenges are amplified by an uneven geographical distribution of services, transportation options, and housing conditions faced by those with significant physical challenges and loss in income.

This is not the first time these issues have been raised or recommendations put forward. In 2007, the Physicians Working Group on Rehabilitation pointed out the "fragmented patchwork" through which services were then delivered, in which "access is often based on availability of third-party funding or geography." None of these recommendations were taken up, nor was 2010's BC Stroke Strategy, for the delivery of rehabilitation and community reintegration services. Sixteen years later, the Physicians' Working Group recommendations for change are still waiting to be acted upon. But it doesn't have to stay that way.

Groups collaborating on the BC Rehabilitation and Recovery Strategy are urging the province to designate rehabilitation and recovery as priorities, and develop a comprehensive, and people-centred strategy and action plan.

The Province already funds some elements of such a system (see topic box on current assets), though on a limited basis. For example, the BC Brain Injury Fund supports post-hospital navigation, case management, and peer support in limited locations, delivered through member organizations of the BC Brain Injury Alliance. Interior Health Authority funds March of Dimes Canada for a part-time position for outreach services for people living in the North Okanagan-Shuswap area. The organization is also funded by Island Health to provide support and an adult day program in the Capital Regional District. Finally, the Stroke Recovery Association of British Columbia is funded by the Provincial Health Services Authority to support community recovery groups. Other examples exist but what is missing are integrated elements such as overall vision, strategic planning, coordination, and necessary funding.

As the health care system continues to focus on renewal from a pandemic that highlighted decades of 'belt-tightening', it is imperative to rethink how, when, and where services are delivered.

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WHO WE ARE:

The **BC Rehabilitation and Recovery (R+R) Strategy** is a collaboration between five health-focused community organizations, health professionals, and people with lived experience of stroke, spinal cord injury, and brain injury. The collaborating organizations include:

Heart & Stroke

BC Brain Wellness Program

March of Dimes Canada | After Stroke

Spinal Cord Injury BC

BC Brain Injury Association – The Voice of Brain Injury in BC

We came together to work on this issue as a result of an urgent need for a person-centred, integrated, provincial approach to rehabilitation and recovery services. We are committed to working together to make the case to all levels of provincial decision-makers over the next two years and beyond.

The recommendations below, combined by consultations with people living with these conditions and current evidence, are designed to help achieve that goal. If implemented, they will improve outcomes for all British Columbians. While new investment will be required, BC currently has a range of existing assets that can be mobilized to expedite a comprehensive strategy. Indeed, key elements of an improved system are already in place and could be scaled, integrated, and coordinated without requiring an entirely new system.

The recommendations fall into three categories:

1. **System Access, Coordination, and Infrastructure** identifies key changes that will improve overall coordination and integration of rehabilitation and recovery services and programs, enhancing linkages with communities.

2. **Community Services and Support** offers solutions that will more fully enable community support and peer-driven organizations to improve transition support. In addition, strengthening and coordinating community-based groups will generate consistent channels of communication between health care providers, both in and out of the hospital setting, and individuals.

3. **Supports and Infrastructure for Daily Living** highlights changes which will allow for people living with stroke, SCI, and TBI, and their families, to live with a high degree of control over their own lives.

1. System Access Coordination and Infrastructure Recommendations

1.1 Create a province-wide agency responsible for coordinating neurorehabilitation and recovery services from acute care to the community.

The Ministry of Health should create and fund an agency responsible for coordinating neurorehabilitation and recovery services, spanning the journey from acute care into the community. A single agency with the mandate to oversee renew rehabilitation and recovery services can repair the current state of administrative fragmentation and disparities in services. This agency would work across systemic boundaries with Health Authorities and community organizations to direct resources and promote innovation. This agency should also be responsible for collecting data—a major gap in the rehabilitation and recovery system—and better monitoring and evaluating system effectiveness. It should also coordinate training and mentoring for health professionals, another key gap identified outside the major centres.

1.2 Expand the province-wide mandate, governance, and funding for GF Strong while accelerating its expansion and rebuild.

As the main centre for neurorehabilitation in BC, GF Strong Rehabilitation Centre—originally constructed in 1949—is long overdue for new updates and a renewal of its governance and purpose. Currently, its governance by the Vancouver Coastal Health Authority is in conflict with its mandate to provide province-wide services. At the same time, neither available funding for staff nor the condition of the building itself can support the needs of province-wide service. Not only is the facility short on beds, but staffing shortages and structural challenges have created situations that are not conducive to successful services and support.

1.3 Remove barriers to accessing trained, experienced rehabilitation and recovery professionals and programs for people living in the community and long-term care.

People living with chronic neurological diagnoses, whether at home or in long-term care, face barriers that impede access to health professionals. **BC has a dire shortage of rehabilitation professionals, especially in the public system.** As the province expands placements for health trainees through its Health Human Resources Strategy, it is vital that rehabilitation professionals are included and that increased post-secondary training places includes physiatrists and allied professions such physio- and occupational therapists as well as speech pathologists. Such an expansion would also take advantage of the need for student practicums and placements to enhance low-cost access to rehabilitation programs.

2. Community Services and Support

2.1 Prioritize management and coordination of transitions from acute care to outpatient care to community settings.

Transitions from hospital to home or long-term care, from one set of health care providers to another, from one type of facility or program to another, is difficult, especially for people who are facing an unexpected future. While some programs have transition processes, systemic pressures (including staff shortages) often mean they are not used adequately. In other cases, people and families are left to manage entirely on their own. Health care professionals can also experience difficulty getting adequate information when a person transitions between care providers or regional systems. One solution is a navigation program to support the transition from hospital to community, and to facilitate connections with health and community care services. Navigators would operate at the junction of individuals and their families, community health programs, and organizations, providing linkages as well as facilitating connections to social programs such as income, housing, and transportation support.

2.2 Recognize and provide resources for community organizations that support people with chronic neurological injuries.

BC has a broad network of community groups—often peer-driven—which work directly with clients, as well as their families. **While many of these organizations operate with some provincial and/or federal funding, most of this funding is not permanent, nor is it integrated into a broader strategy for post-hospital care.** A key advantage of community groups is their autonomy and on-the-ground experience, which provides them with far greater flexibility than government programs. Yet the lack of a coordinated strategy means the province is not fully leveraging the opportunities presented by these organizations to improve quality of life for people living with chronic diagnoses.

2.3 Integrate formalized roles, including training opportunities, for peers to work in the rehabilitation and recovery system, from acute care to community services.

Opportunities available through peer experiences can significantly boost a person's recovery. Both the transition management process and community organizations offer channels for providing peer support. Health organizations should explore ways of incorporating peer counsellors into their teams and identify other avenues for their use, up to and including as trained professional who can offer solutions through similar experiences.

HOW MANY PEOPLE **IN BC** ARE LIVING WITH **BRAIN INJURIES?**

22,000
number of **brain injuries** per year in BC

224,000
traumatic brain injury hospitalizations in BC (2002-2018)

HOW MANY PEOPLE **IN BC** ARE LIVING WITH **STROKE?**

Over 15,000
people had a **stroke** in BC (2017-2018)*

136,000
people living with **stroke** in BC (2021)

* Source: Holodinsky, J. K. et al. Can. J. Neurol. Sci. 1–18 (2022) doi:10.1017/cjn.2022.338.

3. Supports and infrastructure for daily living

3.1 Expand transportation options for people with mobility challenges — especially in rural areas and smaller centres.

Most transit services in BC have at least some accessible buses on regular routes. In addition, TransLink and BC Transit support HandyDart services across the province. However, levels of service vary, often with long lead times requiring advance planning. Travel beyond service areas and out-of-region can be very difficult for people living with mobility challenges. Despite major transit improvements over the past 30 years, there are still many barriers faced by people who need support. To support mobility with an aging population, social inclusion will demand ongoing and accelerated improvements to infrastructure.

3.2 Enhance income support for people who are unable to work post-injury.

The economic burden of chronic neurological injuries at the social level is well documented, especially for stroke. Less understood is the household burden. For people of working age data shows clearly that post-stroke income falls dramatically. While some living with SCI or TBI may have income through WorkSafe or ICBC settlements, most people under 65 living with neurological injuries and unable to work must rely on Disability Assistance or Canada Pension–Disability. Provincial support pays less than $1400/month for single people and just over $2100/month for couples with one child. Federal support ranges from $1000/month to just over $1500/month. These are mutually exclusive, i.e., receipt of one precludes receipt of the other. Income available through such programs is much less than minimum wage—highly problematic given that BC's high living costs often increase because of mobility and/or cognitive challenges.

3.3 Develop and expand ongoing supports for essential needs – services, devices and equipment, and supplies vital for daily living and survival.

People living with mobility and other challenges often require a range of resources and support that are necessities for their survival. In many cases, they are required to pay for these items or services. While urinary catheters for people living with spinal cord injury are perhaps the most egregious example, the list ranges from shower/bathtub rails to wheelchairs (manual and electric) and walkers to a plethora of musculo-skeletal and cognitive therapeutic services that are rarely available through MSP. At the same time, availability of home support and services is often limited, increasing the burden of family to provide services that should be covered publicly.

HOW MANY PEOPLE **IN BC** ARE LIVING WITH **SPINAL CORD INJURIES?**

12,000
people living with **spinal cord injuries** in BC (2019/2020)

500
estimated new cases of **SCI** every year (2021)

$1.6 - $3 million
is the estimated lifetime cost of living with an **SCI**

$1.1 billion
Annual increase in the cumulative economic burden of **SCI** in BC

Current Provincial Assets

With significant assets already in place, BC is well positioned to build a coordinated system of post-hospital neurorehabilitation and recovery. The following is a list of these assets:

GOVERNMENT AND HEALTH SYSTEM ASSETS:

- **Funding** – some provincial funding is already provided to a range of community organizations that work with people living with stroke, SCI, and brain injury. However, this funding has been limited and is subject to funding re-alignments due to shifting priorities and/or changes in government. As a result, such funding has never been part of a strategic approach to neurorehabilitation.
- **Health Improvement Networks** – Numerous health improvement networks (HINs) already operate to coordinate province-wide services and work with Health Authorities. Among these HINs, Stroke Services BC and Trauma Services BC have major impact. Among these HINs, Stroke Services BC and Trauma Services BC have major impact on system performance, patient outcomes and patient experiences.
- **Infrastructure** – GF Strong provides neurorehabilitation and offers services that provide support after hospital discharge, as well as providing BC's only SCI rehabilitation program.
- **In-patient rehabilitation programs** – a 2017 Heart & Stroke survey identified 19 adult rehabilitation programs in BC connected to hospitals and health authorities. At the onset of the pandemic, many programs were closed and it is unclear if they have all been restarted or to what level (most locations also referred people to community programs upon discharge; it's also unclear which have now restarted).

COMMUNITY ASSETS:

- **Community-based organizations** – a range of services, from system navigation, peer support, and rehabilitation services to advocacy, housing, and other services – are provided in communities across the province. Currently, there are more than 30 grassroots local groups across BC devoted to supporting people living with stroke and brain injury.
- **Community centres** – there are a small number of community centres that offer stroke rehabilitation classes based on programs such as *Together in Movement and Exercise (TIME)*, and the *Fitness and Mobility Exercise (FAME) Program*.
- **Community focused organizations** – the Rick Hansen Foundation, the Neil Squire Society, CONNECT Communities, and the BC Centre for Ability provide services and support for people living with SCI and/or acquired or traumatic brain injuries often with at least some funding from the province.

POSTSECONDARY ASSETS:

- **Education and research** – the four largest BC universities are, together, the home of a world-class health education and research cluster. The province thus has a solid foundation for managing the supply of health care professionals and supporting program development through evaluation and innovation.