Pre-Budget Submission To The 2017 Select Standing Committee On Finance And Government Services

NJURY

Brain Injury: A Personal Challenge A Community Response



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The Brain Injury Alliance is grateful for this opportunity to address the Committee. Our purpose is to request the establishment of a \$4 million British Columbia Brain Injury Fund to facilitate the efficient, professional and competent delivery of services to the BC brain injury community.

The reason for this request is that acquired brain injury devastates lives. A lot of lives. Government has already demonstrated remarkable leadership through innovative initiatives that have positively influenced the health of the population. The three million dollars invested into enhanced community brain injury associations, and one million dollars to establish the Dr. Gur Singh memorial endowment fund to provide education and employment training, are prime examples that are already reaping substantial dividends.

The outpouring of gratitude by British Columbia's brain injury community for the former Committee's decision has simply been overwhelming. The funding has made, and continues to make, a huge difference in lives all over the province, helping British Columbians get the support and care they need, when and where they need it.

However, the funds provided will be depleted in the year 2018, but the needs of brain injury survivors and their families will continue for the rest of their lives. It is therefore with optimism that we put our request before you, asking for your recommendation to Government to establish an annual Brain Injury Fund.

There is an significant opportunity to further meet the needs of the large and under-served brain injury population, and your recommendation may well be a deciding factor in the future of long-term community brain injury service and program funding. With sustainable and secure funding, community non-profit brain injury organizations can increase their support services and community rehabilitation, provide assistance with managing chronic conditions, and help prevent further injuries.



How Much Is Being Requested?



In order to meet current needs of brain injured persons in British Columbia, and increasing needs going forward, the Alliance asks the Select Standing Committee on Finance and Government Services to recommend Government establishes the "British Columbia Brain Injury Fund Act" (the Fund) to meet the needs of people with brain injuries and their families. As the need for brain injury services and programs currently exceeds funds available, the Alliance requests that the Fund receive \$4 million per year, to be administered by the Brain Injury Alliance.

How Will Funds Be Spent?

The \$4 million annual Fund would be utilized in the following ways:

1. \$2 million will be used annually to continue the work that the Brain Injury Alliance began in 2015, and to expand to areas of the province not currently served by brain injury organizations.

2. \$2 million will be used annually to address emerging brain injury issues, such as; domestic violence, battlefield injuries, housing supports, family resources, services for children, services for seniors, assessments and education.



Why Designate The Alliance Administrator?



The Brain Injury Alliance requests that it be the administrator of further funding because the Alliance has proven itself to be fair, equitable and fiscally accountable.

The Alliance has kept administration costs to an absolute minimum to ensure that every possible dollar of funding provides programs and services goes to improve the lives of persons living with a brain injury.

Our Motto is: Brain Injury; A Personal Challenge, A Community Response

Our Vision is: for all persons with a brain injury in British Columbia thrive in their community.

Our Mission is: to advocate for help, healing and lifelong growth and rehabilitation for British Columbians affected by an injury to the brain.

Our Values are: Professional, Accountable, Collaborative and Transparent.

Community non-profit brain injury associations are safe places for the injured to heal and reach their full potential for growth and development, both as individuals, and as part of their community.

Why More Funding?

The Alliance is asking for an increase in annual brain injury funding because 50while the annual numbers of brain injury have remained relatively stable despite an increase in population, the advent of new emergency medical strategies has dramatically increased the rate of survival. The result is that today an ever increasing number of individuals survive to now live the remainder of their lives with complex cognitive challenges.

Unfortunately, support services have not been developed at the same rate as the life saving procedures. Perhaps even more concerning, is that in the year 2000 there were 45 active charitable non-profit brain injury associations operating in BC.^{*1} By 2014, there were only 21, and by 2015 only 13 remained, leaving a large percentage of the brain injured population unserved.

"Good works are like stones cast into the pool of time; though the stones themselves may disappear, their ripples extend to eternity." ~ Unknown British Columbia community non-profit brain injury associations are becoming recognized as leaders in collaborative care for brain injury, and adequate annual funding will ensure their efforts continues. There is so much more that can be done with a minimal investment, and so many willing to help, that an exciting opportunity exists for Government to forge a progressive future.



Brain Injury Association

Current Funding Disparities

100%

35%

0%



Needs Analysis Survey Results

In a recent needs assessment, the Alliance surveyed members regarding the demand and capacity for their services and programs. The results revealed a 35% increase in referrals to agencies in just a 9 month period, with all members expressing a dire need for additional funding. The most pressing needs were:

- Provision of additional one-to-one supports and services, affordable housing, and housing supports.
- Additional group services, rent, administrative costs, and accounting services.
- Additional family services, injury prevention, and employment services.



Who Is The Brain Injury Alliance?



The Brain Injury Alliance is province wide, and composed of organizations working together to improve the quality of life for people living with a brain injury, and their families.

The Alliance was established in the year 2014 to acquire funding, and to disburse these funds to community charitable non-profit brain injury societies in a fair and equitable manner.

The Alliance first submitted a funding request to the Select Standing Committee on Finance and Government Services that fall.

What Is Brain Injury?

An acquired brain injury is defined as: "Damage to the brain, which occurs after birth and is not related to a congenital or a degenerative disease. These impairments may be temporary or permanent, and cause partial or functional disability, or psychosocial maladjustment."^{*13}

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Brain injury is a significant issue everywhere in Canada, with an estimated 1.3 million Canadians living with an acquired brain injury, taking a massive toll on the lives of individuals, families and communities. A significant incidence of missed cases, misdiagnoses, or misattribution has been reported in the literature*⁵, making already staggering estimates truly epidemic in proportion.

Trauma is one of the six primary causes of acquired brain injury; the others are Stroke, Anoxia, Infection, Tumor and Surgery.^{*16} Data also demonstrates an underestimation of the incidence of concussion, and an underestimation of gender differences, predisposing females to a greater rate of injury.^{*14} For instance, there is a demonstrated need to increase our awareness of domestic violence as a cause of traumatic brain injury, and to understand the cumulative and total effects of violence on both the person victimized, and their family unit.

Victims of domestic violence are exposed to ongoing risk for severe brain injury, and psychological problems stemming from trauma such as PTSD; and yet social stigma continues to make victims feel they must minimize the harm done, and often inhibits them from reporting their injuries.^{*14}

- 60-82% of the current prison population in BC live with disability as a result of at least one serious brain injury. Most will never receive treatment for their injury, and are likely to reoffend.*7
- 53% of homeless individuals live with brain injury, with the vast majority (77%) brain injured prior to becoming homeless.*³
- Up to 10% of all children have an undiagnosed brain injury, affecting learning abilities.*4
- 20% of children diagnosed with emotional disabilities, and 30% classified as 'Learning Disabled' have a brain injury.*⁵
- Approximately half of patients recovering from a brain injury are likely to have some type of long term disability, with cognitive, emotional and/or behavioral problems.*9
- People are up to seven times more likely to develop mental illness after brain injury.*3

Life After Brain Injury

If there is one word that best describes life after brain injury, it is "unimaginable". The reality of brain injury is nothing like it is portrayed on TV. You don't just "wake up" from a brain injury and carry on with life where you left off. One moment it's life as you've always known it, and the next moment, it's totally different. As the brain heals, it does so very slowly, and very differently than a cut, burn, or broken limb.



Recovery is different for every injury, and for every person. Those who receive a brain injury currently enjoy superb acute medical services, however once they leave hospital or facility, they often don't receive further rehabilitative assistance, which can be vital to optimum outcomes.

Healing is slow, inconsistent, and at best, unpredictable. Survivors of a brain injury suddenly find themselves strangers in a strange land; quickly becoming poor, hurt, homeless, depressed, angry, scared, and very, very confused.

Without the supports and services they need, many survivors lose jobs, friends,

The only place that some survivors have left to live, is "in the moment". spouses, families and even homes. This leaves them vulnerable, trying to survive in a world that is quick to take advantage of the disadvantaged. Without help, their lives quickly spiral out of control.

Compared with other health conditions, the incidence of brain injury is simply staggering. And, while acute care (life-saving) services assist ever more persons to survive brain injuries, post acute services and programs for brain injury are extremely limited, and are virtually non-existent in parts of the province.

- Data shows that youth who experience a concussion or mild brain injury have an increased risk of:
- psychiatric inpatient hospitalization (18%–52%)
- premature mortality
- low educational attainment
- dependence on social assistance/disability pensions *14

Data demonstrates that the lack of assistance to help cope with the changes faced after brain injury can be devastating, leading to attempted, and sadly often successful suicide.

Stable funding for community non-profit brain injury organizations helps ensure that the ever increasing needs of BC's brain injury community are met, reducing demands for social and justice resources, and subsequent government costs, while drastically improving the quality of life for tens of thousands of British Columbians.

"Start by doing what's necessary; then do what's possible; and suddenly you are doing the impossible." ~ Francis of Assisi



The Cost Of Brain Injury

The estimated lifetime cost for each survivor of a severe brain injury exceeds \$4 million.*² Current estimates put the annual cost of acute brain injury care in Canada at over \$3.1 billion.*¹¹ Less severe brain injuries may not be as expensive initially, but when the injured receive little to no post-acute assistance, the cost of brain injury to taxpayers in health care, lost wages, increased reliance on social welfare, justice costs, as well as the devastating impact on families and communities, is nearly incalculable.

Living with brain injury is often extremely complex and difficult, both for the injured, and for the loved ones. To compound matters, traditional service strategies based on motivational or behavioral management, are ineffective for people living with cognitive disabilities from an acquired brain injury.^{*3} Their needs, which are frequently life-long, cannot be adequately met by the limited resources and lack of brain injury training offered by generic programs and case management services. For optimal recovery, trained brain injury staff are required.



According to Brain Canada, the economic burden of neurological and psychiatric disorders of the brain combined to an amount of \$22.7 billion a year in Canada.*¹² The need for an innovative community care plan is critical to ensure that British Columbians living with a brain injury receive the levels of care and service they need to heal and reach their full potential. Experience has proven that integrated planning must occur at the local level, and requires established and sustainable broader partnerships across all social policy ministries, as well as with community partners. Brain injury associations have established social and professional networks, and provide trained staff, supports and services specifically designed to assist persons living with a brain injury.

These supports and services dramatically reduce costs to taxpayers by reducing demand for public services by survivors and their families. From strictly an investment point of view, prevention and treatment of brain injury is one of the most cost effective strategies, dramatically reducing the use of health, social service and criminal justice resources, and reaps substantial fiscal and social dividends.

22,000 new brain injuries occur each year in British Columbia.^{*6} However, a significant incidence of missed cases, misdiagnoses, or misattribution is reported in brain injury literature, making the already staggering estimates truly epidemic in proportion.^{*5}



- Brain injury is the greatest cause of loss of life from ages 1 to 45, is the greatest disabler of persons under the age of 44, and causes more loss of life of persons under the age of 20 than all other causes combined.*³

- 20% of children diagnosed with emotional disabilities, and 30% classified as 'Learning Disabled', have a brain injury.*4

- The full impact of a childhood brain injury can be difficult to quantify, since a child's brain is still developing.*¹⁵

Government's Return On Investment



A 2013 Health and Housing in Transition study found 69% of the homeless surveyed in Vancouver had suffered a traumatic brain injury. Research also found homeless brain injury survivors are more likely to visit emergency rooms, be arrested or jailed, or be victims of physical assault. Human suffering needs also be considered.

Given the high costs of emergency department visits, and the burden of crime on society, these findings indicate that adequate investment in brain injury services at the community level will dramatically reduce demand for government resources.

It is estimated that 60-80% of all inmates have suffered at least one brain injury, and most have never received help to rehabilitate and cope with their injury(ies).*⁷ The current estimated cost of provincial incarceration in BC is around \$1.19 billion per year. If treatment and assistance were made available, a conservative 5% reduction of inmates would result, saving just under \$25 million per year; not including the resulting significant reduction in the number of victims of crime.





During 1998, preventable injuries cost the people of British Columbia \$2.1 billion, or \$513.00 for every citizen.*¹¹ The amount has since increased by a minimum of 20%. By helping to reduce preventable injuries by just 1%, hundreds of families will avoid tragedy, and \$20 million per year will be saved.

Properly funded brain injury services, education and prevention will result in an enormous reduction of government expense, and will improve the quality of life for thousands of British Columbians.

The complex needs of persons with brain injury, the regional disparity of resources, lack of a comprehensive database to reflect the actual incidence of brain injury in the regions, absence of community awareness of the varying and usually life-long needs of this population, and geographic moves between regions present many challenges.

Increased regional services and sharing of programs and services will provide a degree of service continuity that currently does not exist, and allow consistent evaluation of the quality and quantity of brain injury programs and services to insure the injured receive provincially consistent levels of service.



Additional Positive Outcomes Anticipated From The British Columbia Brain Injury Fund:

- Increased public awareness about brain injury prevention;
- A reduction in the incidence of brain injury;
- Province wide instant access to user-friendly information about brain injury, how to support a family member with brain injury, and how to live with a family member who has a brain injury;
- Meaningful inclusion of Aboriginal peoples and other ethnic/cultural groups' values, beliefs and healing practices, and specific supports to address diversity and other special needs of persons with brain injury, and their families;
- Evidence-based services and supports designed for positive health outcomes, delivered in a cost effective manner;
- Services providers will be knowledgeable about the complexities of brain injury, and trained to support persons with brain injury and their families;
- Services will maximize the recovery of independence, and functional capacities and skills of persons with brain injury;
- Persons with brain injury will have access to appropriate needs-based services and supports within the community where possible, and specialized services as close to home as possible;
- Brain injury services and supports delivered in a timely manner in order to prevent further complications;
- Community brain injury awareness and involvement, with evidence of direct and in-kind community support for prevention activities;
- A reduction in the duplication of services and supports at several levels;
- Increased quality and quantity of services to survivors of brain injury and their families resulting in decreased costs to Government;
- Brain injury survivors and their families will be supported in decision-making through the provision of accurate and timely information to enable informed choices;
- Families will be supported in their choice of role as care givers;
- Persons with brain injury and their families will be supported in managing transitions effectively;
- Collaborative planning will be enhanced at all levels; processes will support a seamless flow of information among all partners;
- Persons with brain injury and their families will experience satisfaction with services and supports received. However, these shall be provision of a complaint resolution process at the local level, to ensure quick, effective and satisfactory resolution of issues.

Moving Forward



Brain injury awareness has risen sharply over the last decade, due in part to sport superstar and celebrity injuries. Millions of brain injuries have been prevented, or minimized, by helmet use as a result. Unfortunately, the move from considering a mild to moderate trauma to the brain as "getting your bell rung", to understanding the potential harm that may have been done, has been very slow. This is in part to social perceptions of brain injury, which need to change in order to facilitate the earliest possible intervention and rehabilitative strategies. There appears to be growing communal concern that the term 'concussion' may trivialize brain injury, and result in less than thorough investigative methodologies and possible inadequate post-injury treatment, which has been known to lead to death.*¹⁷



In order to effectively serve the brain injury community, there needs to be a greater emphasis on creating collaborative partnerships, and networking with all partners to build capacity and reduce costs. Research shows that health care is best understood and most effectively managed at the community level.^{*1} Community nonprofit brain injury associations reduce cost of service by providing outstanding value, and their established relationships provide many excellent partnership and networking opportunities for collaborative care.

Collaborative community care creates efficiencies in service delivery, improves population health, and helps Government achieve its goals. Secure funding of community brain injury associations is already making a significant difference, saving Government money, and addressing concerns before they require emergency medical, social and/or justice interventions.

Individually, each member of the Committee is remarkable in your own ways. Collectively, you're an engine of change, in a world desperate for change. Please help us usher in an era of greater awareness and understanding of brain injury, and provide necessary community based resources for those with brain injuries to lead happy, productive lives. Continuing fiscal support of brain injury services and programs will ensure that BC families have the supports they need to face the changes and challenges of brain injury.



Funding Eligibility Requirements

The following service provider principles are required in order to receive funding from the Brain Injury Alliance:

~ Respect and Dignity ~

Persons with brain injury and their families will be treated with respect and dignity regarding life choices, access to services, and programming. Every person with brain injury is unique, and the recovery path will be different for each person. Services and supports will be needs based, and targeted to take into account culture and beliefs, developmental stage, special needs, and gender-specific concerns.

~ Prevention Awareness ~

Brain injury is forever, so prevention and public education are paramount, and must occur within communities across the province to reduce help the incidence of brain injuries. A small reduction in brain injury incidence will result in large cost savings, and reduced pain and suffering.

Consumer Focused ~

Services will be developed, delivered, and evaluated in collaboration with persons with brain injury, and their families, and will respect the cost and impact to all British Columbians. Services will focus on the rebuilding of skills, cognitive enhancements, family education and enhancing quality of life.

~ Participation ~

Persons with brain injury and their families will participate in the evaluation of services and supports. Families of persons with brain injury will receive support and education in order to remain actively, and positively, involved in the care and support of their loved ones.

~ Planning ~

Coordination with agencies and government ministries is required. Collaborative planning at all levels supports the seamless flow of information between government, health authorities, support agencies, brain injury associations, survivors, families and other stakeholders.

~ Acceptability ~

Long-term care institutions and extended care units are often inappropriate for the needs of younger persons with brain injury. Wherever possible, community integration and inclusion must be the goal.

Conflict and Resolution ~

Each funded organization will have a conflict resolution process and procedure so service recipients will be informed of, and assisted with, the complaint resolution process in order to ensure quick, effective and respectful resolution of issues.

~ Equity ~

Funding for services and supports will be delivered in a manner that respects diverse geographical and cultural needs, with a focus on decreasing disparity in service levels among all population groups.

~ Shared Responsibility ~

The Brain Injury Alliance, with equitable provincial representation and participation by brain injury survivors, stakeholders, and community service organizations and societies, will ensure shared responsibility in managing and distributing the Fund.

~ Access ~

Services and supports will be accessible within a reasonable travelling distance of place of residence. Persons with brain injury may require post-acute resources several years post-injury, or at transition points in recovery. Acute care and hospital-based rehabilitation services for persons who have brain injuries are reasonably accessible in British Columbia. However, persons with brain injuries often experience difficulties in obtaining community services.

~ Effectiveness ~

Services and supports will be managed and delivered to provide the best possible outcomes for all British Columbians. Survivors of brain injury deserve the opportunity to recover and develop intellectually, physically, emotionally and socially. Services and supports need to provide opportunities to maximize the recovery of independence and functional potential.

~ Continuity ~

The Fund will provide the necessary security for agencies to ensure future planning and continued coordination of long term objectives, and effective data collection. Secured funding allows community organizations to achieve adequate and stable staffing levels, which directly translates to improved services for persons living with a brain injury.

~ Efficiency ~

Timely and responsive services and supports will be available, managed and delivered in a costeffective manner, consistent with quality, evidence-based services. Service provided is based on brain injury best practices and relevant research; Standardized data collection and reports will be mandatory.

~ Appropriateness ~

Services and supports will remain flexible, needs based, and will take into account culture, beliefs, developmental stage, special needs, and gender-specific concerns, and be provided in the least restrictive manner possible.

Advancement ~

The Fund will support association staff training, and the development of new and innovative resources to better serve brain injury survivors, their families, and the public at large. Continued education will insure brain injury associations provide the most progressive levels of service possible.

~ Accountability ~

Standard reports have been designed to monitor services, and to evaluate outcomes. Standard reports provide methodical ways to determine service and support effectiveness.

~ Functions ~

All funded services and supports will be required to include the following elements, to varying degrees:

Coordination – community development, linking to resources, risk management, case management, regular reports, reviews, and a seamless flow of information.

Collaborative Planning – inclusion of survivors, their families and other stakeholders in the planning of individual programs and resource use.

Inclusion - appropriate and anticipatory planning to ensure that individuals in crisis are given priority without jeopardizing the access of others not in crisis.

Transition Management – persons with brain injury and their families will be supported so they can manage transitions effectively. Once a person has been identified as having an acquired brain injury, specific mechanisms will facilitate the person receives coordinated and appropriate care, at all stages of recovery and life.

Crisis Response – services and supports, including risk management, immediate crisis intervention, and follow-up will form part of crisis response.

Complaint Resolution – written processes and procedures to resolve complaints, as well as easily accessible information about use of the processes.

Sources

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- *14 http://www.traumaticbraininjury.net/domestic-violence-brain-injury-and-psychological-trauma/
- *15 http://braininjurycanada.ca/2010/06/16/children-and-brain-injury/
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- *17 http://news.nationalpost.com/features/rowans-law

~ IN CONCLUSION ~

Whereas of all types of injury around the world, injuries to the brain are among the most likely to result in death, or, permanent disability;

Whereas brain injury is the number one cause of seizures in the world;

Whereas brain injury in British Columbia occurs at a rate greater than that of all known cases of Multiple Sclerosis, Spinal Cord Injury, HIV/AIDS and Breast Cancer per year combined;

Whereas brain injury is the leading cause of death and disability among children, with 50 per cent of all fatalities the result of injury to the brain;

Whereas motor vehicle crashes are the number one cause of brain injury in British Columbia;

Whereas violence against persons is a major cause of brain injury in British Columbia;

Whereas sport accidents, strokes, surgery, disease and tumors are a major cause of brain injury in British Columbia;

Whereas addressing the complex needs of brain injury survivors and their families is fundamental to the future of British Columbia;

Whereas a fair, non-partisan and equitable provincial brain injury funding and distribution mechanism has been established to meet the complex needs of brain injury survivors and their families;

Whereas there is great need for comprehensive, coordinated, post-medical rehabilitative and case management services for brain injury survivors and their families;

Whereas the development of innovative research, brain injury educational materials and rehabilitative programs are restoring British Columbia as a world leader in brain injury research, treatment and services;

Whereas the British Columbia Neurotrauma Contribution Funding Act is non-specific and poorly worded;

Whereas community brain injury associations and societies do not share in the funding provided by the British Columbia Neurotrauma Contribution Funding Act;

The brain injury alliance respectfully requests the establishment of the British Columbia Brain Injury Fund to provide a fair, efficient, and sufficient financial resource to meet the needs of brain injury survivors and their families, currently, and into the future.



BRAIN INJURY

A PERSONAL CHALLENGE - A COMMUNITY RESPONSE



