

***GUIDELINES FOR PLANNING
BRAIN INJURY SERVICES AND SUPPORTS
IN
BRITISH COLUMBIA***

Ministry of Health Services and Ministry of Health Planning

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The collective well-being of all British Columbians is reflected in the well-being of each of us. Our collective well-being is diminished because of physical or mental impairment that can affect any of us.



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GUIDELINES FOR PLANNING BRAIN INJURY SERVICES AND SUPPORTS IN BRITISH COLUMBIA

EXECUTIVE SUMMARY

The purpose of the *Guidelines for Planning Brain Injury Services and Supports in British Columbia* is to guide the development of services and supports in a comprehensive, cohesive and co-ordinated way. The planning guidelines are intended to build on the strengths of the current health service delivery structure and to continue to make progress in providing quality services and supports to persons with brain injury and their families.

Health authorities have the responsibility for delivering of health services to their overall populations, including acute care, continuing care, public health and mental health. The challenges faced in the health sector are many, including the recent change in governance structure of the health authorities; core services review; expectations for health authorities to operate within limited funding; and the responsibility for ensuring cost-effective and efficacious, evidence-based and outcome-driven services.

Considering the complex needs of persons with brain injury, the regional disparity in current resources, lack of a comprehensive database to reflect the true incidence of brain injury in the regions, lack of acute awareness in the communities of the varying and sometimes life-long needs of this population, and geographic moves by persons with brain injury between regions, health authorities have a challenging task ahead. However, providing services within an integrated regionalized structure will assist in providing more effective access to the various health services for this population. Integrated planning must occur at the local level and will require establishing and sustaining broader partnerships across all social policy ministries as well as with community partners. Health authorities will be required to place a greater emphasis on creating collaborative partnerships and networking with all partners to build capacity and effective services within their regions.

Brain injury is forever. A major emphasis must be placed on prevention activities. Brain injury prevention must be one of the provincial injury prevention priorities. Public awareness and education must emphasize safety and the reduction of risk factors for injury, and these activities must be promoted to support the health and safety of all British Columbians.

The planning guidelines outline the goal, anticipated outcomes and principles that will guide planning, delivery and evaluation of services and supports. A range of services and supports (including prevention activities), roles and responsibilities of various partners and accountabilities and outcomes are also identified.

The focus of the planning guidelines is adult services and supports since the responsibility for children and youth services is within the mandate of the Ministry of Children and Family Development. However, the Ministry of Health Services, the Ministry of Health Planning, the Ministry of Children and Family Development, and other ministries and agencies, including health authorities, need to collaborate in order to ensure effective transitions for youth with brain injury into the adult system of care, as well as assisting children and youth who have a parent with brain injury.

1. INTRODUCTION

The *Guidelines for Planning Brain Injury Services and Supports in British Columbia* provides a rationale and philosophy to guide policy and program development. It is a visionary document written for a broad sector. It is consistent with ministry priorities, goals and objectives and is in keeping with governing legislation.

The purpose of the *Guidelines for Planning Brain Injury Services and Supports in British Columbia* is to guide the development of services and supports in a comprehensive, cohesive and co-ordinated way and to continue to support progress in providing quality services and supports to persons with brain injury and their families. In order to ensure cost-effective and efficacious, evidence-based and outcome-driven services, and considering the complex needs of persons with brain injury, a variety of sources for services and supports must exist at the local level. This will require integrated planning and establishing and sustaining broader partnerships across all social policy Ministries as well as with other partners in the communities.

Definition:

The World Health Organization's definition of acquired brain injury has been adopted in British Columbia:

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 (Geneva 1996)

Possible causes of acquired brain injury include, but are not limited to, the following: trauma to the brain, cerebral vascular accidents, tumour, infections of the brain, toxic exposure and lack of oxygen to the brain due to a variety of causes. The severity and type of brain injury will influence the services and supports required by the person with brain injury and his or her family.

The specific data on the number of women, men and children who incur a brain injury is difficult to determine because of the many ways one can acquire a brain injury, as well as the delay and complexity in diagnosis and the lack of adequate information systems to capture this data.

In Canada, estimates for brain injuries are usually extrapolated from United States studies. The estimates of incidence of people who acquire brain injury after birth range from 195/100,000 to 350/100,000. Therefore, with a population in British Columbia of about four million people, the province would have an incidence rate of acquired brain injury of between 7,800 and 14,000.

The estimates for traumatic brain injury (an injury to the brain resulting from a blunt instrument or other cause) range from 100/100,000 to 200/100,000. Using a rate of 150/100,000, this translates into about 6,000 traumatic brain injuries. Based on US statistics, about 20% of individuals will die as a result of a traumatic brain injury before reaching a hospital, which translates into a surviving 4,800 individuals with traumatic brain injuries in the province. Of these remaining 4,800 individuals, the following has been observed, based on US statistics:

- 3,840 will acquire a mild brain injury, requiring services in 10% to 18% of the cases (384 to 691);
- 480 will acquire a moderate brain injury and 7% (34) of these will die. Of the remaining 446, one-third (47) will have no disability and two-thirds (399) will have a disability; and,
- 480 will acquire a severe brain injury - 50% (240) will die. All the remaining 240 will have a disability.

This leaves 1,023 to 1,330 people of all ages requiring rehabilitation every year as a result of a traumatic brain injury. There is minimal data to determine exactly how many require services as a result of a non-traumatic brain injury. An estimate in Alberta places the number at 40% of the total number of individuals who receive a traumatic brain injury (409 to 532). Extrapolating this to the population in British Columbia, this brings the total to between 1,432 to 1,862 British Columbians requiring rehabilitation services per year.

The 1999/2000 data from the British Columbia Injury Prevention Registry reports 2,734 cases of brain injury¹. However, it should be noted that current epidemiological research has demonstrated that utilizing hospital admissions data severely underestimates the true incidence of injury by as much as 20% (Thornhill et al, 2000). In this study, almost 20% of people presenting at an emergency department who were diagnosed as having an acquired brain injury did not show as brain-injured in admission records. This is in addition to the fact that many people with an acquired brain injury may not present to emergency departments. As such, without accurate data, it is difficult to estimate with specificity the number of British Columbians requiring rehabilitation and ongoing services and supports.

¹ Data are based on the Morbidity database, Information Support, and the Health Data Warehouse, BC Ministry of Health Planning and BC Ministry of Health Services. Data include all reported injuries with primary codes 800 Fracture of Vault of Skull, 801 Fracture of Base of Skull, 802 Fracture of Face Bones, 803 Other and Unqualified Skull Fractures, 804 Multiple Fractures Involving Skull or Face with Other Bones, 850 Concussion, 851 Cerebral Laceration and Contusion, 852 Subarachnoid, Subdural and Extradural Haemorrhage Following Injury, 853 Other and Unspecified Intracranial Haemorrhage Following Injury and 854 Intracranial Injury of Other and Unspecified Nature.

A major emphasis must be placed on prevention activities. Prevention and public education must occur within communities and across the province to reduce the incidence of brain injuries. A small reduction in brain injury will result in health care cost savings and reduce the pain and suffering experienced by persons with brain injury and their families. Public awareness and education must emphasize safety and the reduction of risk factors for injury, and these activities must be promoted to support the health and safety of all British Columbians. In addition, critical to assisting persons with brain injury and their families is ensuring that emphasis is also placed on minimizing risks of further injury. Services and supports must be designed to mitigate further health complications following the initial injury and to prevent subsequent brain injury.

Brain injury affects a person's cognitive, physical, psychological and social well-being. Consequences of brain injury typically include difficulties with memory, slowed ability to process information, difficulty in concentrating, seizures, double vision, headaches, fatigue, increased need for sleep, difficulty in completing tasks without reminders, increased anxiety, depression and mood swings, impulsive behaviour, difficulty making decisions and behaviours that may result in harm to self or others. In addition, the personal cost of reorienting to a new identity and of rebuilding on the day-to-day functioning lost due to the brain injury affects the person's current and future quality of life.

For families and significant others, the effects are equally devastating. There is a struggle to understand the full impact of the brain injury on the loved one, issues of grief, loss and intimacy, reorientation of roles and responsibilities within the family and the impact on one's own coping skills and resourcefulness. The costs to society are enormous, not only for care, treatment and rehabilitation but also in lost productivity, the personal contribution to society and the generational impact on the community.

Persons with brain injury receive a range of services from acute care to institutional rehabilitation and community-based support services. 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 the community services many of them subsequently require.

There are a number of outstanding questions that require additional research and specific information to assist in the development of services and supports for persons with brain injury and their families. In particular, these planning guidelines do not utilize a gendered approach to planning for brain injury services and supports, and therefore specific consideration will need to be made in program planning and the delivery of services and supports to better meet the needs of women and men. In addition, as new research and information becomes available, this must inform the planning of brain injury services and supports in the province.

2. GOAL

To strengthen and improve brain injury services and supports in British Columbia.

3. ANTICIPATED OUTCOMES

The following positive outcomes are anticipated:

- The public is informed about ways to prevent brain injury;
- There is a reduction in the incident rate of brain injury. Targets are set at the health authority and provincial planning levels;
- Persons with brain injury and their families have ready access to user-friendly information about brain injury and how to support a family member with brain injury;
- Services and supports are evidence-based and delivered in a cost-effective manner;
- Services providers are knowledgeable in supporting persons with brain injury and their families;
- Persons with brain injury have access to appropriate needs-based services and supports within the community and specialized services as close to home as possible;
- Services and supports are delivered in a timely manner to mitigate potential further complications;
- Duplication of services and supports is reduced;
- Persons with brain injury are receiving timely and appropriate assessments, and services and supports will be needs-based and targeted to take into account culture and beliefs, developmental stage, special needs, and gender-specific concerns;
- Persons with brain injury and their families are supported in decision-making through the provision of accurate and timely information for informed choices;
- Families are supported in their choice of role as caregivers;
- Persons with brain injury and their families are supported in managing transitions effectively;
- Collaborative planning is enhanced at all levels and processes support a seamless flow of information among all partners; and,
- Persons with brain injury and their families express satisfaction with services and supports received, and are informed of the complaint resolution processes at the local level in order to ensure effective resolution of issues.

4. PRINCIPLES

The following principles guide the planning, delivery and evaluation of services and supports at the provincial, regional and local community levels in British Columbia.

Respect and dignity

Persons with brain injury and their families will be treated with respect and dignity. Every person with brain injury is a unique individual 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.

Safety

Brain injury is forever. Services and supports to prevent brain injury will focus on minimizing risks to the health and safety of British Columbians.

Prevention awareness

Public awareness and education to encourage safety and reduce risk factors to prevent brain injury will be promoted.

Prevention of further injury

Services and supports will be delivered in a timely manner to mitigate potential further complications.

Consumer focus

Services and supports will be developed, delivered, and evaluated in collaboration with persons with brain injury and their families and will respect the diversity of all British Columbians. Services and supports should focus on the enhancement of quality of life, thereby promoting a sense of purpose, satisfying relationships, community participation, personal empowerment, safety and well-being, and social inclusion.

Participation

Persons with brain injury and their families will be supported in decision-making through the provision of accurate and timely information for informed choices, and will participate in the evaluation of services and supports. Families of persons with brain injury will require support and education in order to remain actively and positively involved in the care and support of their loved ones.

Better coordination between all agencies and government ministries is required if services to persons with brain injury and their families are to improve. Collaborative planning will be enhanced at all levels, and processes will support a seamless flow of information among all partners. Partnerships will be fostered between various partners - health authorities, agencies, brain injury associations and other stakeholders.

Acceptability

Services and supports will be needs-based. Long-term care institutions and extended care units are not appropriate to the developmental life stage, age or rehabilitation and service needs of persons with brain injury.

Service recipients will be informed of the complaint resolution processes at the local level in order to ensure effective resolution of issues.

Equity

Services and supports will focus on decreasing the disparity in health status among population groups.

Shared responsibility

Persons with brain injury, their families, community groups, agencies, brain injury associations, health authorities, ministries and others have a shared responsibility to ensure that prevention occurs, and that services and supports exist for persons with brain injury and their families.

Access

Services and supports will be readily accessible within a reasonable travelling distance of place of residence. Capacity will be developed based on adequate volume. Specialized services and supports will be accessible to all British Columbians. People with brain injury are entitled to the same dignity and respect afforded to all individuals regarding life choices and access to services and programming.

The recovery path is not linear, and persons with brain injury may require some post-acute resources several years post-injury or at transition points in recovery. Thus, persons may need access to a continuum of services at various points, revisiting some services previously obtained.

Effectiveness

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

Early intervention

Timely assessments and early intervention, including linkages with services and supports, will occur.

Continuity

Services and supports will be effectively co-ordinated and integrated with a focus on managing transitions effectively.

Efficiency

Timely and responsive services and supports will be available, managed and delivered in a cost-effective manner consistent with quality, evidence-based services. Health care professionals and other service providers will provide services and supports based on standards and knowledge. Research and evidence-based practices will be promoted.

Appropriateness

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

5. RANGE OF SERVICES AND SUPPORTS

Health authorities have the responsibility for delivering health services for their overall populations, including acute, continuing care, public health and mental health. Some services and supports will be provided within the community, and others may be provided outside the region because of the expertise and capital costs required to host such services and supports within a health authority. Where appropriate, health authorities must ensure inter-regional access for services and supports that are not readily available in all regions. Health authorities must be familiar with inter-provincial protocols for access to services and supports outside British Columbia.

Some services and supports are provided through other Ministries and agencies. Health authorities are expected to ensure that co-ordination, collaborative planning and complaint resolution processes exist and that persons with brain injury and their families are meaningfully involved.

Rehabilitation and recovery from injury is a life-long effort and is not limited only to a critical period following injury. Extended-care and long-term-care beds are generally not appropriate placements for people recovering from a brain injury.

Even though the range of services and supports is presented in a linear manner in the following chart, services and supports must match the needs of persons with brain injury and their families. As such, persons accessing services and supports will move back and forth through the system based on their needs at any given time.

| PREVENTION | SERVICES AND SUPPORTS FOLLOWING BRAIN INJURY | | |
|--|---|---|--|
| Primary Prevention | Acute care services and supports | Rehabilitation | Ongoing services and supports |
| <p>Public education on prevention of brain injury & reduction of risk factors</p> <p>Public awareness of brain injury and its effects</p> <p>Knowledge and skill development of individuals involved with the range of services and supports</p> | <p>Early intervention</p> <p>Emergency & trauma services</p> <p>Intensive Care Unit</p> <p>Medical/Surgical services</p> <p>In-home monitoring</p> <p>Detoxification Services</p> <p>Case management services</p> | <p>Counselling (grief, relationship, sexuality)</p> <p>Hospital/facility-based post-acute rehabilitation</p> <p>Physical/Activities of daily living therapy</p> <p>Psychosocial rehabilitation</p> <p>Neuropsychological assessment</p> <p>Cognitive-behavioural therapy</p> <p>Communication/ Speech therapy</p> <p>Vocational rehabilitation/ employment/ supported employment</p> <p>Non-vocational support/ leisure & recreation rehabilitation</p> <p>Outpatient/Day programs</p> <p>Addiction recovery services</p> <p>Secondary prevention of further brain injuries</p> <p>Case management services</p> | <p>Individualized community service programming</p> <p>On-going rehabilitation</p> <p>Housing</p> <p>Continuing Care/Home support</p> <p>Family education & counselling</p> <p>Respite services</p> <p>Disability benefits</p> <p>Equipment, supplies and other benefits</p> <p>Mental health services</p> <p>Addictions recovery</p> <p>Secondary prevention of further brain injuries</p> <p>Case management services</p> <p>Adult Community Living Services (MCFD) for individuals whose IQ is below 70</p> |

Functions

All services and supports are required to include the following functions, to varying degrees.

Coordination – functions include community development, linking to resources, risk management, case management*², regular reviews and a seamless flow of information.

Collaborative planning – functions include involving others in the planning of resources.

Complaint resolution – functions include informing and providing processes to resolve complaints.

Managing transitions – functions include ensuring that persons with brain injury and their families are supported to manage transitions effectively. This may include:

- transition from child and youth services and supports to adult services and supports;
- transition between services and supports in a health authority;
- transition between phases of services and supports for persons with brain injury and their families;
- transition and continuity of services and supports from one health authority to another; and,
- transition between funding sources.

Once a person has been identified to the system, mechanisms must be in place to ensure that the person with brain injury and his or her family receive co-ordinated and appropriate care.

Crisis response – Crisis response services and supports may be required, including crisis lines, risk management, immediate crisis intervention and follow-up.

6. ROLES AND RESPONSIBILITIES

Within the regionalized system of health care in the province, the Ministry of Health Services is responsible for the requirements, conditions and policies within which health authorities manage their services and supports. Health authorities are responsible for determining how best to provide a range of services and supports while addressing unique factors within their communities. Health authorities are accountable for outcomes.

There are many others involved in the planning, delivery and evaluation of services and supports for persons with brain injury and their families. Within this context, the following outline of roles and responsibilities is provided and organized under two levels of responsibility: provincial level and regional level.

² Case management services have a positive impact in supporting persons with brain injury and their families, and thus, need to be an integral part of the range of services.

| <i>PROVINCIAL LEVEL</i> | |
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| ORGANIZATION | ROLES AND RESPONSIBILITIES |
| <p>All Ministries, Brain Injury Association of BC (BIABC), agencies and other partners (health authorities in partnership, Insurance Corporation of BC (ICBC), Workers' Compensation Board (WCB), sports and recreation organizations)</p> | <ul style="list-style-type: none"> • Participate in a multi-faceted and effective injury prevention effort that includes education and appropriate enforcement and engineering standards • Participate in public awareness and education on safety and risk factors associated with brain injury |
| <p>Ministry of Health Services and Ministry of Health Planning</p> | <ul style="list-style-type: none"> • Disseminate and interpret the <i>Guidelines for Planning Brain Injury Services and Supports in BC</i>, including any legislative requirements, to health authorities and other partners • Ensure consistency in policy development within the Ministry of Health Services and the Ministry of Health Planning • Create, in collaboration with other ministries, agencies and health authorities, targeted public awareness and education on safety and risk factors associated with brain injury • Assist health authorities with tools to assist in assuming complete responsibility for planning and delivery of brain injury services and supports in an integrated service system • Review and approve health service plans submitted by health authorities through the lens of strengthening and improving prevention efforts and services and supports to persons with brain injury and their families • Review and approve provincial and tertiary health service plans • Monitor the provision of services and supports consistent with the <i>Guidelines for Planning Brain Injury Services and Supports in BC</i>, service agreements, and the <i>BC Accountability Framework for Health Authorities</i> • Promote efforts in education and promotion of research and scholarship related to prevention and evidence-based practices for brain injury services and supports |

| <i>PROVINCIAL LEVEL</i> | |
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| ORGANIZATION | ROLES AND RESPONSIBILITIES |
| BC Neuropsychiatry Program (University of British Columbia Hospital, Riverview Hospital, Skeleem Recovery Centre); G.F. Strong Centre; The Gorge Road Hospital; and neuro-trauma and tertiary specialized services | <ul style="list-style-type: none"> • Develop neuro-trauma, neuro-psychiatry and tertiary services with other partners based on the <i>Guidelines for Planning Brain Injury Services and Supports in BC</i> and evidence-based practices • Develop/enhance neuro-rehabilitation services • Review priorities for enhancement of services to the Ministry of Health Services and the Ministry of Health Planning, based on the provincial tertiary policy and accountability requirements • Develop, with health authorities and other partners discharge planning protocols to facilitate safe and appropriate transitions of persons with brain injury to their home communities • Share knowledge and expertise, including outreach, throughout British Columbia and be a resource outside the province • Monitor the provision of specialized services consistent with the <i>Guidelines for Planning Brain Injury Services and Supports in BC</i>, the <i>BC Accountability Framework for Health Authorities</i> and the provincial tertiary policy and accountability requirements |
| Ministry of Advanced Education | <ul style="list-style-type: none"> • Collaborate with Universities, colleges and educational institutions in the planning and evaluation of specific educational programs related to brain injury • Promote co-ordination of education initiatives and collaborate with educational institutions to promote education, research and scholarship related to brain injury prevention and best practices for service providers |
| Ministry of Attorney General and Treaty Negotiations/ Ministry of Public Safety and Solicitor General | <ul style="list-style-type: none"> • Collaborate with Forensic Psychiatric Services, Ministry of Health Services, in the planning, delivery and evaluation of appropriate services and supports in the correctional/ forensic setting and community re-integration programs, such as the court diversion programs |
| Ministry of Community, Aboriginal and Women's Services | <ul style="list-style-type: none"> • Provide leadership and influence policy development in ensuring that services and supports address the unique needs of Aboriginal people and women of all ages |

| <i>PROVINCIAL LEVEL</i> | |
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| ORGANIZATION | ROLES AND RESPONSIBILITIES |
| Ministry of Children and Family Development | <ul style="list-style-type: none"> • Develop community-based services and supporting policy to address the needs of children and youth with brain injury and their families • Provide services and supports to children and youth who have a brain injury and their families • Collaborate with other ministries, health authorities and community partners to ensure effective transition from hospital to community and from youth to adult services • Provide leadership and influence policy development in ensuring that services and supports address the needs of children and youth with brain injury and their families, as well as children and youth who have a parent or a family member with brain injury, and that transitions are managed effectively |
| Ministry of Education | <ul style="list-style-type: none"> • Promote curriculum development of education initiatives within school districts of educational initiatives related to prevention of brain injury • Participate and collaborate with other partners in awareness and skill development for school district personnel in recognizing brain injury and in supporting and maximizing potential of children and youth with brain injury |
| Ministry of Human Resources | <ul style="list-style-type: none"> • Provide leadership and develop supporting policy in ensuring that supports and benefits address the needs of persons with brain injury and their families • Develop policies and procedures related to income supports and benefits that are user-friendly for persons with brain injury and their families |
| Ministry of Skills, Development and Training | <ul style="list-style-type: none"> • Provide leadership and develop supporting policy that ensures persons with brain injury receive appropriate re-training and supports so they may participate at their optimum as residents within their community |
| Forensic Psychiatric Services | <ul style="list-style-type: none"> • Collaborate with the Ministry of Health Services, Ministry of Health Planning, Ministry of Attorney General and Treaty Negotiations, Ministry of Public Safety and Solicitor General, health authorities and other partners in the planning, delivery and evaluation of specific services and supports for persons with brain injury in: a) forensic settings and, b) community re-integration |

| <i>PROVINCIAL LEVEL</i> | |
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| ORGANIZATION | ROLES AND RESPONSIBILITIES |
| Brain Injury Association of British Columbia (BIABC) | <ul style="list-style-type: none"> • Engage in public awareness and prevention activities in collaboration with the Ministry of Health Services, the Ministry of Children and Family Development, other ministries, Workers' Compensation Board, Insurance Corporation of BC, health authorities, sports governing bodies and other partners • Provide provincial leadership and share information to assist local brain injury associations/societies in community development, and provide technical support and training to local brain injury associations/ societies • Monitor trends, identify priorities and provide information to persons with brain injury, their families and others |
| BC Housing Management Commission | <ul style="list-style-type: none"> • Collaborate with health authorities and others in the planning and development of a range of housing options • Develop supporting policy and share information with health authorities and others on safe, secure and affordable housing options • Provide leadership in creating opportunities in the various housing sectors • Provide resources for housing |
| Insurance Corporation of British Columbia (ICBC) | <ul style="list-style-type: none"> • Provide leadership in creating public awareness and education on safety and risk factors associated with brain injury specific to motor vehicle accidents, in collaboration with other partners • Develop policies, procedures and mechanisms that are user-friendly • Collaborate with other partners in the planning, delivery and evaluation of specific services and supports, and participate in managing transitions effectively • Promote, with other partners, education, research and scholarship related to the prevention of motor vehicle accidents and related injuries |

| <i>PROVINCIAL LEVEL</i> | |
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| ORGANIZATION | ROLES AND RESPONSIBILITIES |
| Workers' Compensation Board (WCB) | <ul style="list-style-type: none"> • Provide leadership in creating employer awareness and education on safety and risk factors associated with brain injury specific to workers, in collaboration with businesses, employers and other partners • Develop policies, procedures and mechanisms that are user-friendly • Collaborate with other partners in the planning, delivery and evaluation of specific services and supports, and participate in managing transitions effectively • Assist workers with brain injury and employers with consultation and support for appropriate rehabilitation that allows for supported and graduated return-to-work plans • Promote, with other partners, education, research and scholarship related to the prevention of workplace accidents and safe practices in the workplace |
| Sports and recreation organizations | <ul style="list-style-type: none"> • Participate with the various ministries and partners (health authorities, ICBC, WCB and BIABC) in a multifaceted injury prevention effort, including education and meeting appropriate safety standards. |
| Professional associations | <ul style="list-style-type: none"> • Provide leadership in developing standards and ensuring that professionals are informed and provide services within the established standards and the scope of practice • Participate in professional development activities • Promote, with other partners, education, research and scholarship |
| Universities and other educational institutions (colleges and schools) | <ul style="list-style-type: none"> • Collaborate with the Ministry of Advanced Education and the Ministry of Education, professional associations and other partners in the development of specific educational programs, research and scholarship related to brain injury prevention and best practices for service providers, school teachers and counselors |
| Non-governmental organizations | <ul style="list-style-type: none"> • Provide leadership and share information to assist others in community development • Monitor trends and provide information to others to assist in the planning and development of shared resources, services and supports |

| <i>REGIONAL LEVEL</i> | |
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| ORGANIZATION | ROLES AND RESPONSIBILITIES |
| Health authorities, ICBC (regional offices and consultants), WCB (regional offices and consultants), sports and recreation organizations (sports governing bodies and associations of providers of recreation), municipalities, business sector/employers and individuals at the community level | <ul style="list-style-type: none"> • Participate in a multi-faceted and effective injury prevention effort that includes education and appropriate enforcement and engineering standards • Participate in prevention activities, public awareness and education on safety and risk factors associated with brain injury |
| Persons with brain injury | <ul style="list-style-type: none"> • With support, participate with health authorities and other partners in the planning and evaluation of services and supports required • With support, present needs and desires in accessing services and supports for oneself • With support, articulate the support needs of their children and other family members • As much as possible, acknowledge and accept the existence of brain injury and its consequent deficits for oneself • Actively engage in recovery • Undertake and demonstrate willingness to adopt the necessary life-style changes or other required adjustments necessary to achieve rehabilitation |
| Families | <ul style="list-style-type: none"> • As much as possible, acknowledge/accept the existence of brain injury and consequent deficits of family member • With support, advocate on behalf of family member with brain injury • Articulate support needs of adult family members, children and youth with brain injury and those who have a parent with brain injury • Participate with health authorities/others in public education, education of professionals and peers • With support, participate with health authorities and other partners in planning for home-care and respite services • With support, participate with health authorities and other partners in the planning and evaluation of services and supports in the community |

| <i>REGIONAL LEVEL</i> | |
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| ORGANIZATION | ROLES AND RESPONSIBILITIES |
| Health authorities | <ul style="list-style-type: none"> • Involve persons with brain injury, their families, local brain injury association/society and other partners in the planning and evaluation of services and supports, using a community development model approach • Engage in prevention activities and target strategies to high-risk groups • Provide access for persons with brain injury and their families to a range of services and supports, based on volume, capacity and identified need • Develop health service plans based on need and consistent with the <i>Guidelines for Planning Brain Injury Services and Supports in BC</i> • Create an environment that enhances the knowledge and skills of physicians and staff about brain injury and the prevention of subsequent complications • Develop, with other health authorities and partners, inter-regional protocols for the delivery of and access to services and supports, including management of transitions • Work with the Ministry of Children and Family Development and other partners to ensure that services and supports address the needs of children and youth with brain injury and their families, as well as children and youth who have a parent or a family member with brain injury, and that transitions are managed effectively • Develop, with the Ministry of Children and Family Development and other partners, protocols to ensure effective transition of youth with brain injury from hospital to community and from youth services to adult services • Monitor, evaluate and report on the delivery of services and supports within the health authority, consistent with the service agreements and the <i>BC Accountability Framework for Health Authorities</i> and other monitoring mechanisms |
| Local brain injury association/society | <ul style="list-style-type: none"> • Advocate on behalf of persons with brain injury and their families to health authorities and other partners • Participate in the planning, delivery and evaluation of services and supports • Provide community leadership, share information to assist in community development and provide technical support and training to persons with brain injury, their families and service providers • Monitor trends, provide information and identify priorities within the community |

| <i>REGIONAL LEVEL</i> | |
|-----------------------------------|--|
| ORGANIZATION | ROLES AND RESPONSIBILITIES |
| Private/Fee-for-service providers | <ul style="list-style-type: none"> • Participate with health authorities and other partners in the planning, delivery and evaluation of services and supports • Deliver services and supports based on standards of practice and treatment guidelines |
| Forensic Psychiatric Services | <ul style="list-style-type: none"> • Collaborate with health authorities, justice personnel and other partners in the planning, delivery and evaluation of specific services and supports for persons with brain injury in forensic settings and assist with discharge planning to facilitate safe and appropriate transitions and re-integration from the institution into the home community • Monitor the provision of services and supports consistent with the planning guidelines and the accountability requirements of the Ministry of Health Services, the Forensic Psychiatric Services Commission and the British Columbia Review Board |
| Business sector/ Employers | <ul style="list-style-type: none"> • Engage in practices that accommodate persons with brain injury in the workforce • Provide resources, directly or in-kind, to support community development for services and supports for persons with brain injury and their families |
| Other community organizations | <ul style="list-style-type: none"> • Provide resources, directly or in-kind to support community development for services and supports for persons with brain injury and their families • Create user-friendly, flexible and accessible environments and opportunities to maximize involvement of persons with brain injury and their families in the community |

7. ACCOUNTABILITIES AND OUTCOMES

Monitoring of services and supports and outcome evaluation are methodical ways to determine whether services and supports are effective, and if so, to what extent. There are many ways to measure outcomes. Health authorities will be expected to monitor outcomes consistent with the *BC Accountability Framework for Health Authorities*. Ministry partners, brain injury associations, care providers and others are expected to monitor the provision of their services and supports consistent with standards and policy that exist or that will be developed.

Measurement of outcomes can occur at the individual and system-wide levels. Through the use of individual planning, ongoing reviews can be conducted to determine that the individual's needs have been met. This includes determining the involvement of the individual in the planning of services, the types of services and supports received, the individual's progress, the involvement of the family and other factors. Through the use of system wide outcomes, assessments can be done to determine the quality, efficiency and effectiveness of the services and supports provided.

| DOMAIN | OUTCOMES |
|---|---|
| <p>EFFECTIVENESS Services and supports will be managed and delivered to provide the best possible health outcomes for British Columbians</p> | <ul style="list-style-type: none"> • Prevalence and incidence of brain injury within the province and by health authority is reduced • Services and supports are needs-based and targeted to take into account culture and beliefs, developmental stage, special needs, and gender-specific concerns • Services and supports are provided based on evidence that they will work and have positive health outcomes • Partnerships exist at the provincial level and within communities to ensure effective planning, delivery and evaluation of services and supports • Collaborative planning within each health authority and between health authorities is evident and protocols exist to ensure inter-regional access and ensure that transitions are managed effectively • Access to services and supports, such as safe, affordable and secure housing, home supports and crisis response services, is available regardless of place of residence or diversity of background and lifestyle, and within a reasonable travelling distance of a person's community • Families have access to supports, including training and respite services • Evidence reflects 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 • Processes are in place to determine recipients' satisfaction with services and the effective resolution of complaints • Opportunities exist to maintain and maximize the recovery of independence and functional potential capacities and skills of persons with brain injury in the community |

| <i>DOMAIN</i> | <i>OUTCOMES</i> |
|--|--|
| <p>EFFICIENCY Services and supports will be managed and delivered such that they are cost-effective, needs and evidence based quality services.</p> | <ul style="list-style-type: none"> • Evidence of direct and in-kind community support for prevention activities exists • Services and supports for persons with brain injury and their families are available within a reasonable time-frame based on standards, knowledge and positive health outcomes • Spending for services and supports within the community is evident in relation to the incidence, type and severity of brain injury • Evaluation indicates that services and supports are available within regions, cross regionally and managed and delivered in a cost-effective manner consistent with quality evidence-based information • Evidence exists regarding processes to facilitate a seamless flow of information between service providers and other partners within the community and between health authorities consistent with the <i>Freedom of Information and Protection of Privacy Act</i> and other legislative requirements • Information systems facilitate the collection of data to assist in the planning, delivery and evaluation of services and supports for persons with brain injury and their families • Partners are participating in education and research activities |

8. CONCLUSION

The *Guidelines for Planning Brain Injury Services and Supports in British Columbia* are intended to provide direction to those involved in the care and support of persons with brain injury and their families. This goal is impossible to achieve without the meaningful participation, critical input, and involvement of persons with brain injury and their families in the planning, delivery and evaluation of services and supports. The planning guidelines addresses the elements of public awareness and prevention, collaborative partnerships and the importance of including all relevant parties in carrying out the mandate of reducing the incidence of brain injuries and strengthening and improving brain injury services and supports in British Columbia.

The geography of the province presents extraordinary challenges in rural and remote communities that add complicating factors such as social isolation and longer distance to service provision and make it difficult to provide many community based services. In addition, British Columbia has a mosaic of Aboriginal and diverse ethnic communities which requires planning guidelines to ensure services and supports address the unique needs of all of its citizens.

The planning guidelines respect the ability of persons with brain injury and their families to make informed choices and decisions, with assistance as required, regarding the types of services and supports they require to assist them to live productive, quality lives.

GLOSSARY

Aboriginal people

Refers to registered “status” First Nations, non-registered “status” First Nations, Metis and Inuit persons as well as persons who are of Aboriginal ancestry.

Acquired Brain Injury

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 (World Health Organization, Geneva, 1996). Acquired brain injury is injury to the brain with disruption of neurological function such as confusion, alteration in consciousness, amnesia or headaches. There can be physical, cognitive and/or psychosocial impairment of a temporary or permanent nature that may or may not result in functional changes for the person.

Case management

The coordination of a person’s health care, housing, employment, training and/or rehabilitation services, usually by one person (the case manager) operating in a team environment who liaises with all others providing services and supports to the person. Case management provides active outreach, coordination of personalized care plans, advocating, linking to appropriate resources and monitoring progress towards the achievement of goals and health outcomes.

Client centred care

Based on the needs and beliefs of the client and ensuring informed decision-making and choices.

Community development

The process of involving a community in the identification and reinforcement of those aspects of community life, culture and political activity that are conducive to health and well-being of its citizens.

Disability benefits

Includes Disability I, Disability II, Canada Pension Plan and other forms of financial compensation provided by the federal or provincial governments.

Evidence-based

A process that takes facts, data and evidence into account. Practice that integrates evidence measured through a variety of ways and that integrates up-to-date knowledge available in the field.

Families

Intended to reflect diverse family structures, supporters to individuals and includes a broader vision than that of the historic nuclear family.

Family centred wholistic care

Services and supports provided that assist families through needs-based assessments of all aspects of the family structure and roles.

Freedom of Information and Protection of Privacy Policy Act (FOIPPA)

Provincial legislation governing the way information, including personal information, is collected by public bodies, and the way personal information is shared between service providers and others. Personal privacy is protected through a comprehensive set of rules for the management of personal information, from its collection, use, retention and protection through to its release. The *Act* provides that decisions by public bodies can be reviewed by an independent Commissioner of Information and Privacy.

Integration

Access to health care services and supports within the region delivered in a seamless manner and ensuring collaboration between partners and reduction of duplication. It emphasizes breaking down silos in the funding and management of services and supports, allowing for a broader review of issues and addressing the needs of individuals and families.

Mental health services

Includes all levels of primary, secondary, tertiary and community-based mental health services.

Needs-based

Refers to services and supports based on the needs of the individual and their families as assessed through integrated assessment of the various factors.

Non-vocational support

Includes activities and aids within the community in a variety of settings not captured under gainful employment and vocational programs.

Prevention activities

Initiatives that assist in raising awareness and understanding of the risk factors of various activities that may lead to incidents causing brain injury.

Service providers

Individuals who provide services and support to assist persons with brain injury and their families. Assistance may be in the form of information, referral consultation, facilitation or direct service. Service providers may be staff from provincial facilities, regional or community staff, contracted staff, local brain injury associations or informal family supports such as volunteers.

APPENDIX A: BACKGROUND

Prior to 1982, very little was known and developed around the services and supports required for persons with brain injury and their families. Acute care services were provided through hospitals, such as emergency and acute stabilization, short-term hospital-based rehabilitation provided through institutions such as the G.F. Strong Centre and Gorge Hospital. In addition, some private sector services were provided through third party sources such as the Worker's Compensation Board (WCB) and the Insurance Corporation of British Columbia (ICBC).

The private sector industry had arisen primarily through ICBC's no-fault superior coverage for medical and rehabilitation services and encouragement of high liability insurance policies. As a result of these arrangements, the majority of British Columbians with brain injury through motor vehicle accidents had the resources to purchase the often very expensive therapeutic services offered through the private sector. The WCB is another important purchaser of these private services.

In 1982, the British Columbia Brain Injury Association (BCBIA) was formed by concerned families and caring professionals wanting to advocate, provide information and support for persons with brain injury and family members. In 2000, the Association was restructured and amended its name to the Brain Injury Associations of BC (BIABC).

In the mid-eighties, the Ministry of Health was concerned about the best strategies that would improve rehabilitation services due to weaknesses within the existing rehabilitation system, such as lack of long-term inpatient rehabilitation, residential care options, community re-entry options and highly specialized professionals to deliver services and specialized clinical programs.

In 1987, persons with brain injury and family members associated with the British Columbia Brain Injury Association also requested the Ministry of Health to examine and improve its service system for persons with brain injury and their families. Persons with brain injury needed specialized rehabilitative services or were inappropriately placed without supports in existing long-term care facilities, mental health boarding homes or extended care units and a high profile number of ambulatory adults who had poor coping and social skills, were poorly served. Priorities identified in the report included developing a more comprehensive range of specialized services, improving access to the existing range of services, and promoting accountability and cost effectiveness.

The report titled the *Program Review: Rehabilitation Services for Persons with a Traumatic Head Injury*, was released by the Ministry of Health in 1988. The Head Injury Program was officially created in the following year, and established through the Services for Community Living Branch of the Ministry of Health, with the support of the BCBIA and in co-operation with existing local brain injury associations, families and service providers.

The Royal Commission on Health Care and Costs, released in 1992, identified the need for improved provincial services and programs for brain injury. In 1993, the Ministry of Health put together a strategic plan in the report *Restoring Hope* that recognized the major service needs of persons with brain injury and their families and suggested building on strengths of the existing provincial system of services. It must be noted that during this time several private service providers began to develop services and supports for persons with brain injury and their families in various communities.

In 1997, the Head Injury Program which was renamed in 1999 the Provincial Brain Injury Program was formally transferred from the Ministry of Health to the Vancouver/Richmond Health Board and managed through the Vancouver Hospitals and Health Sciences Centre. This shift in governance and administration paralleled changes in the evolution of the Provincial Brain Injury Program and its focus and roles.

In April 1997, Acorn and Higenbottam examined partnerships among brain-injured survivors, their families, researchers and community service providers and recommended regionally based solutions to identified needs, discussed examples of community based research and identified key research areas of evaluating the efficiency and existing services. Of note is that some of the needs identified included case management for brain injury survivors, cohesion among brain injury associations, better data on the incidence and prevalence of brain injury and education and training of health professionals.

In the year 2000, Higenbottam was requested by Ministry of Health Services staff to provide follow-up recommendations around brain injury services and supports. The document, *Strategic Directions for Brain Injury Services in British Columbia*, addressed specific planning principles and recommendations to guide the future development of brain injury services and supports.

In February 2001, the Ministry of Health Services embarked on the development of the Brain Injury Services and Supports Policy Framework that would strengthen and improve brain injury services in the province and allow health authorities to assume complete responsibility for the provision of services and supports to persons with brain injury and their families within an integrated and regionalized service delivery system. The existing community-based services and supports provided through the Provincial Brain Injury Program will be transferred to health authorities by March 2002. This transfer is congruent with and a continuation of the process of transferring programs to health authorities, who are, directly responsible for providing the full range of community services for their residents including for persons with brain injury and their families.

APPENDIX B: CURRENT SERVICES AND SUPPORTS

Acute Care Hospitals

Most immediate care for brain injury, whether traumatic injury or associated with disease, is provided in acute care hospitals. Severe brain injury often requires critical care. Some hospitals provide specialized post-acute rehabilitation services.

Complex care including trauma care and neurosurgery is usually provided in trauma centres. Thus, a majority of brain injured individuals requiring complex care are transferred to the hospitals providing trauma and tertiary services such as Vancouver Hospital and Health Sciences Centre, Royal Columbian Hospital, Greater Victoria Hospital and Kelowna General Hospital.

G.F. Strong Centre

The Acquired Brain Injury (ABI) Program at the G.F. Strong Centre located in Vancouver specializes in providing rehabilitation services for people who have had a stroke or traumatic brain injury.

Comprehensive rehabilitation services are supported by an experienced interdisciplinary team who provide individually designed programs for persons with brain injury. The program offers rehabilitation services at the GF Strong Centre (Inpatient and Outpatient Services), community services (Outpatient and Outreach Services) as well as consultative services and educational opportunities for survivors of an acquired brain injury, family and friends, service providers, and caregivers.

The Gorge Road Hospital

The Gorge Road Hospital located in Victoria provides a variety of rehabilitation services through an inter-disciplinary team. These include Inpatient and Outpatient Services as well as community outreach services for assessments and consultation including re-integration into the community. These services are predominantly for the residents of Vancouver Island.

British Columbia Neuropsychiatry Program (BCNP)

University of British Columbia Hospital

The Neuropsychiatry Program – UBC Hospital is a component of the Vancouver Health Sciences Centre located on campus of the University of British Columbia in Vancouver. The program consists of a ten-bed inpatient unit supported by an outpatient clinic. The program consists of an interdisciplinary team that provides comprehensive psychiatric, neurological and psychometric assessments as well as brain imaging and other neurodiagnostic procedures when appropriate. In addition to assessments and treatments in the inpatient unit, the clinic provides outpatient assessment and treatment, as well as second opinions for referring sources across the province.

Riverview Hospital

The Neuropsychiatry Units at Riverview Hospital located in Port Coquitlam provides care to 85 patients in three units. The Neuropsychiatric Assessment and Rehabilitation Unit is a 25-bed integrated unit that provides care to the higher functioning ambulatory patients. In addition, a 30-bed integrated unit provides total care to non-ambulatory or semi-ambulatory patients many of who are unable to communicate verbally and have minimal ability to communicate nonverbally. As well, a 30-bed integrated unit provides care ranging from total assistance with self-care to minimal supervision of activities of daily living to patients who have severe cognitive problems, but generally are higher functioning. Not all patients in this unit have acquired brain injury but rather may have neuropsychiatric problems as a result of dementia or mental disorder due to a general medical condition.

Skeleem Recovery Centre

The Skeleem Recovery Centre located on forty acres in the rural community of Cobble Hill, south of Duncan on Vancouver Island is a residential rehabilitation program consisting of 21 beds divided between three cottages. The program has a mix of short and long-term residents with the majority of residents having neurobehavioral disorders with significant behaviour problems secondary to traumatic brain injuries. In addition to providing a variety of rehabilitative services, Skeleem Recovery Centre has an on-site vocational rehabilitation program. The Skeleem Recovery Centre accesses neuropsychiatric services through the UBC Hospital.

Provincial Brain Injury Program (PBIP)

The Provincial Brain Injury Program administered by Vancouver Hospital and Health Sciences Centre has provided for a variety of community services for persons with brain injury throughout the regions of the province. Funding has been provided for community rehabilitation and other clinical services and residential living. The program has also provided funding to brain injury associations within the regions to support advocacy, education and development including delivery of community services for persons with brain injury and their families. This program will be regionalized as of March 2002.

Brain Injury Associations of British Columbia (BIABC)

The Brain Injury Associations of BC is the primary support and advocacy group in British Columbia at the provincial level for persons who have experienced brain injury and their families. This non-profit organization advocates for survivors with government, insurance companies and other funding sources to provide needed services. The mission of the BIABC is *to coordinate the provision of support services to and on behalf of brain injured people in the province of British Columbia in such a way as to improve their overall quality of life.*

Local brain injury associations/societies

There are more than 45 local brain injury associations/societies who provide information on services and supports, advocacy and have support groups around the province. These associations/societies provide a network of community based support services to assist persons with brain injury and their families.

Community-based organizations and agencies

Community based organizations and agencies provide many services to persons with brain injury and their families within the geographic areas that they live. These services may include case management, post-acute transition care, rehabilitation and grief counseling, family support and education, cognitive rehabilitation, behavioural consultation, residential options, vocational rehabilitation and return to work services including social and recreational support services.

Workers' Compensation Board (WCB)

The Workers' Compensation Board serves workers with a brain injury. The WCB operates an interdisciplinary Brain Injury Assessment Clinic, which provides comprehensive assessments, including neuropsychological assessment of cognitive impairment.

The WCB funds treatment and rehabilitation services for workers in accordance with assessed needs. Services are typically funded through community providers.

Insurance Corporation of British Columbia (ICBC)

Most cases of traumatic brain injury result from motor vehicle accidents. Accordingly, the Insurance Corporation of BC is a major funder of services for brain injury survivors.

The ICBC cases fall into two major categories: a) tort cases involving civil litigation, and b) no fault settlements with a funding limit of \$150,000.

While tort settlements may be very large, a major disadvantage is the legal process which is expensive, time consuming and adversarial. Additionally, brain injured clients are discouraged from participating in active rehabilitation until the court settlement has occurred. This is in the interests of maximizing the disability and the associated award.

The legal process may stretch over months and years and limit the opportunity to benefit from rehabilitation. Inevitably, a large percentage of the final court settlement is absorbed by legal costs. With no fault settlements, funding is more immediately available to provide care and rehabilitation. However, the present limit is \$150,000. This is a relatively small amount of money to purchase services for brain injured clients with significant care and rehabilitation needs. No fault funding is usually rapidly exhausted.

APPENDIX C: PROCESS FOR DEVELOPMENT OF GUIDELINES FOR PLANNING BRAIN INJURY SERVICES AND SUPPORTS IN BRITISH COLUMBIA

Between April and September 2001, Ministry of Health Services staff undertook a review of current services and supports, best practices in the field, issues, challenges and gaps including the strategic environment and current realities in British Columbia.

Some of the key questions that were asked during the consultations included:

- What are the health priorities for persons with brain injury and their families?
- Are there opportunities for concerns of ethnic/culturally specific groups and Aboriginal peoples to be addressed?
- How can the service partnerships between health authorities and brain injury associations/societies at the regional level, be enhanced?
- What should be the role of major partners in developing, delivering and evaluating services and supports?
- How can policy, guidelines, best practices be implemented most effectively?
- What cross-jurisdictional issues need to be defined?
- How can initiatives around risk management, prevention and harm reduction be improved or enhanced?

The multi-pronged approach included direct consultation, focus groups across the province, feedback through questionnaires, and feedback received through letters to the Ministry of Health Services. Literature searches and discussions with other jurisdictions and experts in the field informed the development of the framework.

The consultation process was inclusive of persons with brain injury, families, health authorities, brain injury associations, Provincial Brain Injury Program (PBIP) staff, other Ministries, agencies and stakeholders.

The activities completed to inform the planning guidelines included the following:

1. Establishment of an Advisory Committee in April 2001 with the mandate to guide the consultation process and provide advice, feedback and input on the development of the framework;
2. Pre-consultation meetings with a selected group of stakeholders identified by the Brain Injury Associations of British Columbia (BIABC) to receive advice on the consultation process identified and field-test the interview questions for clarity and inclusiveness;
3. Consultations with representatives from program areas of policy development within the Ministry of Health and other Ministries;
4. Review of relevant British Columbia documents and reports, reports from other jurisdictions and a selective literature review on recommended and emerging practices in the care and support of persons with brain injury and their families;

5. Analysis of responses received through questionnaires and letters to the Ministry of Health Services;
6. Focus groups conducted in various communities across the province regarding existing services and supports, including identification of challenges in the various communities and opportunities to strengthen services and supports;
7. Specific feedback obtained from Health Authorities that currently provide few services and supports, regarding the current strengths in their communities and supports for persons with brain injury and their families, issues and challenges posing barriers to community development, and future opportunities;
8. Site visits to a variety of services and supports for persons with brain injury and their families in the province;
9. Focused consultation with experts to ensure the content in the planning guidelines reflects respectful language, is relevant, accurate and understood by persons with brain injury, their families, health care professionals, other Ministries and other service providers;
10. Discussions with representatives of other Canadian provinces on the strategic directions they are undertaking to support the development of services and supports for persons with brain injury and their families, including their structure and governance, funding and accountability mechanisms;
11. Processes identified to facilitate the review and revisions to the Draft *Guidelines for Planning Brain Injury Services and Supports in BC*; and,
12. Steps identified to seek final approval and dissemination of the *Guidelines for Planning Brain Injury Services and Supports in BC*.

The review has provided the opportunity to raise awareness of the importance of adequate, effective and quality services for persons with brain injury and their families, identify current gaps in services, gather information on current services and successes, including opportunities to improve upon those successes and suggest future directions.

**APPENDIX D: PROVINCIAL, NATIONAL AND INTERNATIONAL
BRAIN INJURY RESOURCES**

| BRITISH COLUMBIA RESOURCES | | | |
|---|--|--|--|
| Organization | Mandate/Role | Website | Contact Info |
| Ministry of Health Services, Government of British Columbia | Supports British Columbians in their efforts to maintain and improve their health. The ministry provides funding, strategic direction and leadership to support the delivery of health care, education and prevention programs and services in British Columbia. | www.gov.bc.ca/hlth | David Babiuk Associate Deputy Minister Performance Management and Improvement Ministry of Health Services Phone: 250-952-1297 Email: david.babiuk@moh.hnet.bc.ca |
| Ministry of Health Planning Government of British Columbia | Supports the development of the long-term planning necessary to sustain British Columbia's public health care system in the years ahead. In consultation with health care providers, health administrators and the people of British Columbia, the ministry is developing a strategic plan for health care to ensure the delivery of timely, affordable, accessible health care for British Columbians when they need it, where they live. | www.gov.bc.ca/hlth/ | Geoff Rowlands Assistant Deputy Minister Strategic Change Initiatives Ministry of Health Planning Phone: 250-952-1116 Email: geoff.rowlands@moh.hnet.bc.ca |
| Ministry of Children and Family Development Government of British Columbia | Supports a range of services and supports for children and families. | www.gov.bc.ca/mcf/ | David MacPherson Director, Child and Youth with Special Needs, Early Childhood Development and Community Living Services Division Phone: 250-356-6022 Fax: 250-356-7878 Email: david.macpherson@gems6.gov.bc.ca |
| Brain Injury Associations of British Columbia | Advocate for people with brain injuries and their families. The Association encourages, promotes and co-ordinates the development of appropriate services, opportunities, rehabilitation and training for all survivors of acquired or traumatic brain injury in British Columbia. | www.biabc.org | Mitch Loreth Executive Director 1207 Quadra Street Victoria, British Columbia V8W 2K6 Phone: 250-380-0500 Fax: 250-380-0600 Toll free 1-800-510-3221 Email: mloreth@biabc.org |

BRITISH COLUMBIA RESOURCES

| Organization | Mandate/Role | Website | Contact Info |
|--|--|--|--|
| Insurance Corporation of British Columbia (ICBC) | The ICBC's mission statement is "to help British Columbians take the risk out of road transportation." ICBC is fully engaged in reducing crashes and their heavy costs. | www.icbc.com | Mavis Johnson, Manager, Road Improvement Strategies (Injury Prevention) 151-West Esplanade (171 ESPW), North Vancouver, BC V7M 3H9 Phone: 604-661-6426 Email: mavis.johnson@icbc.com |
| Worker's Compensation Board (WCB) | The Workers' Compensation Board of BC is dedicated to promoting workplace health and safety for the workers and employers of this province. The WCB regulates, monitors workplaces, educates, and consults with employers and workers on workplace health and safety issues. In the event of work-related injuries or diseases, the WCB works with the affected parties to provide return-to-work rehabilitation, compensation, health care benefits, and a range of other services. | www.worksafebc.com | Ed McCormick Assistant Director, Industry Services, Prevention Division P.O. Box 5350, Vancouver, BC V6B 5L5 Phone: 604-233-4055 Email: emccorm1@wcb.bc.ca |

OTHER CANADIAN RESOURCES

| Organization | Mandate/Role | Website | Contact Info |
|---|--|--|---|
| Alberta Ministry of Community Development, Community Support Services | Currently undertaking review of the province's brain injury programs and preparing a Brain Injury Action Plan. | www.cd.gov.ab.ca | Susan Clay, Director, Community Support Services, Ministry of Community Development Phone: 780-427-8012 susan_clay@gov.ab.ca |
| Alberta Hospital, Ponoka | Operates a provincial Brain Injury Rehabilitation Program, based around multi-disciplinary rehabilitation teams. The program works collaboratively with brain injury associations, Regional Health Authorities and community stakeholders. | www.amhb.ab.ca/programs/prochab.html | Chris Richards Administrative Director Brain Injury Rehabilitation Program Box 1000 Ponoka, Alberta T4J 1R8 Phone: 403-783-7600 Chris.richards@amhb.ab.ca |

OTHER CANADIAN RESOURCES

| Organization | Mandate/Role | Website | Contact Info |
|--|---|--|--|
| Brain Injury Association of Alberta | A provincial advocacy group “dedicated to improving the quality of life for individuals with the effects of acquired brain injury.” | www.biaa.net | 136-17th Avenue N.E. Calgary, Alberta T2E-1L6 Phone: 403-207-5606 Fax: 403-207- 3444 E-mail biaa@cadvision |
| Saskatchewan Brain Injury Association | A non-profit charitable association formed by head injured persons, their families, interested friends and caregivers to provide support, information sharing, public information and awareness. | www.sfn.saskatoon.sk.ca/health/ia/ | SBIA 2310 Louise Avenue, Saskatoon Saskatchewan S7J 2C7 Phone: 306- 373-1555 Fax: 306- 373-5655 |
| Ontario Brain Injury Association | A charity dedicated to preventing traumatic brain injuries and to improving the quality of life for survivors of acquired brain injury, their families and the community with which they interact. | Www.obia.on.ca | PO Box 2338, St. Catherine’s, Ontario L2R 7R9 Phone: 905- 641-8877 Fax: 905- 641-0323 E-mail: obia@obia.on.ca |
| Community Care Access Centres, Ontario | Forty-three “Community Care Access Centres” provide support at home. A complete listing of CCACs, including their websites, is available. | www.gov.on.ca/MOH/english/cac/ccac/ccacloc_mn.html | See website |
| Ministry of Health and Long Term Care, Ontario | Long Term Care Program | www.gov.on.ca/MOH/english/program/lc/brain.html | See website |
| Brainhelper.com | “The online brain-injury resource” provides information on brain injury to individuals with known or suspected brain injury and their families, and to healthcare and other professionals working with persons who may have brain injuries. | www.brainhelper.com | Dr. Lorie Saxby Suite 120 279 Weber St. N. Waterloo, ON, N2J 3H8 Phone: 519-746-8515 Fax: 519-747-8125 Email: saxby@golden.net |

OTHER JURISDICTION RESOURCES

| Organization | Mandate/Role | Website | Contact Info |
|---|--|---|--|
| Brain Injury Association (USA) | Its mandate includes brain injury prevention, research, education and advocacy. | www.biausa.org www.biausa.org/contents.htm provides hundreds to internal and external links to resources and information | 105 North Alfred St Alexandria, VA 22314 Phone: 703-236-6000 Fax: 703-236-6001 |
| Brain Injury Centre (USA) | Operated by Brain Injury Association of Kentucky, and acts as a centralized, plain-language source of information and resources on acquired brain injury. | www.braincenter.org | #330 - 4229 Bardstown Rd Louisville, Kentucky 40218 Phone: 502-493-0609 Fax: 502-499-8995 |
| National Resource Center for Traumatic Brain Injury (USA) | Operated by Virginia Commonwealth University's Medical College of Virginia, its mission is "to provide relevant, practical information for professionals, persons with brain injury, and family members... They have more than 20 years of experience developing intervention programs, assessment tools, and investigating the special needs and problems of persons with brain injury and their families. | www.neuro.pmr.vcu.edu | See website |
| Traumatic Brain Injury Model Systems of Care (USA) | TBIMS is an American, federally funded program created to develop and demonstrate a model system of care for persons with TBI, stressing continuity and comprehensiveness of care; and to maintain a standardized national database for innovative analyses of TBI treatment and outcomes. Each center provides a coordinated system of emergency care, acute neurotrauma management, comprehensive inpatient rehabilitation and long-term interdisciplinary follow-up services. The website contains a wealth of information and links to associated centres and the programs they offer. | www.tbims.org | E-mail: tbisci@tbi-sci.org |

| OTHER JURISDICTION RESOURCES | | | |
|--|--|--|--|
| Organization | Mandate/Role | Website | Contact Info |
| Brain Injury Resource Centre (USA) | Describes itself as “a non-profit clearinghouse founded and operated by head injury activist since 1985.” It maintains many links and resources, primarily from a patient advocacy perspective. It is highly critical of the “brain injury rehabilitation industry.” | www.headinjury.com | See website |
| International Brain Injury Association (International) | Dedicated to the development and support of multidisciplinary medical and clinical professionals, advocates, policy makers, consumers and others who work to improve outcomes and opportunities for persons with brain injury. The organization strives to provide international leadership for creative solutions to the issues associated with brain injury. | www.internationalbrain.org | 505 Wythe St Alexandria, VA 22314 Phone: 703-683-8400 Fax: 703-683-8996 info@internationalbrain.org |

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