

ACQUIRED BRAIN INJURY  
A STRATEGY FOR SERVICES

September 25, 1995  
Acquired Brain Injury Working Group

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# EXECUTIVE SUMMARY

Over the past few years, throughout the province of Saskatchewan, persons interested in the services provided to individuals with acquired brain injury (ABI) have been coming together to discuss mutual concerns and problems. This fervour of activity is evidenced by the many forums, surveys, reports and proposals that have been submitted to the Department of Health and District Health Boards since 1992 outlining the service needs of these unique individuals. The frustrations shared by all of these groups emerged as repeated themes. Post-acute services were lacking and among the services in existence, little coordination or integration was evident. ABI survivors, their families and professionals alike were in need of education and support. Rehabilitation, in many cases, ceased when the individual left the hospital setting. The isolation felt by ABI survivors and their families was but one measure of the compromised quality of life experienced by these individuals.

As a result of recommendations from the Rehabilitation Advisory Board instituted by Saskatchewan Government Insurance (SGI), Saskatchewan Health and SGI established a unique partnership in late 1994. Through this partnership, SGI committed to providing 9.3 million dollars for a three year provincial pilot project intended to contribute to a comprehensive, integrated system of supports, resources and services that will enhance the rehabilitation outcomes and improve the quality of life for individuals with acquired brain injury and their families. Saskatchewan Health committed to providing coordinated management and administration of the project. Once operationalized, the project will create a system that promotes the self-determination of individuals with ABI, as well as participation and integration into community life. Further, the system will provide education and support to those individuals, professionals or otherwise, who care for people with ABI.

In the spring of 1995 a multidisciplinary Acquired Brain Injury Working Group was formed. The purpose of the working group was to develop a provincial strategy for an integrated, community-based rehabilitation pilot program for people with ABI, linking existing resources with new program developments. Through a series of meetings between March and August 1995, this purpose was met. The ABI working group identified the population to be served, the needs of this population and gaps in current service provision. In reviewing available information, the working group decided on specific recommendations, priorities and a strategy for services, which are explained in detail in the body of this document, and summarized here.

In addition to province-wide coordination and the establishment of an ongoing Advisory Group, the strategy calls for province-wide education and research support that will allow generic community services to accommodate individuals with ABI. This support will provide much needed education and supportive services for ABI survivors and their families in a timely manner. An annual conference will be an integral part of this service. Recognizing that Saskatchewan's population is fragmented and spread out over a large geographic area, and that all services cannot be present in all communities, the strategy outlines the development of three multidisciplinary outreach teams to provide services to all health districts. Community-based programs that facilitate community reintegration as well as appropriate residential services for individuals with ABI will be enhanced. Lastly, appropriate evaluation mechanisms will be developed and utilized to measure outcomes of the strategy as a whole and each program developed therein.

SGI and Saskatchewan Health have accepted this strategy and are committed to its operationalization and continued development.

# INTRODUCTION

Across North America it is acknowledged that advances in immediate response, emergency procedures and medical care have meant that more people survive severe brain injuries. Regardless of severity, persons who have acquired a brain injury, almost without exception, experience a wide array of physical, cognitive and behavioural impairments. Some recover quickly, but many more of these individuals require complex rehabilitation programs and, sometimes, life long supportive care.

Two reports submitted to Saskatchewan Health since 1992 document the concerns of individuals with acquired brain injury (ABI), family members and health care professionals. The first report was commissioned by Saskatchewan Health (*Planning For the Needs of People With Acquired Brain Injury in Saskatchewan*) and the second was authored by the Saskatchewan Head Injury Association (*Acquired Brain Injury - A Proposal for Services in Saskatchewan*). These documents clearly identify the needs of individuals with ABI and their families as well as the gaps in services and supports to this population. Some of the recommendations and information from these two reports have been incorporated in the body of this document. As such, certain concepts and services are not fully explained herein.

Saskatchewan Government Insurance (SGI) introduced no-fault insurance through the Personal Injury Protection Plan (PIPP) in January 1995. To assist with the implementation of PIPP, SGI formed a Rehabilitation Advisory Board to recommend program developments that would support the timely rehabilitation of individuals injured in motor vehicle crashes. The Board recommended that SGI invest in two areas: 1) enhanced rehabilitation services for people with acquired brain injury; and 2) early intervention programming for individuals with soft tissue injuries. A unique opportunity developed, allowing Saskatchewan Health to collaborate with SGI in working towards enhanced services for people with acquired brain injury.

Saskatchewan Health and SGI agreed on two conditions at the onset of the project. First, this process was to be informed by work already completed so as not to waste time and money redoing that which was already done and relevant. Secondly, it was vital that a working group of stakeholders be invited to participate in the development of the service strategy to ensure its accountability to individuals with ABI, family members and other caregivers. A framework and terms of reference were developed for both the partnership between Saskatchewan Health and SGI and the formation of the Acquired Brain Injury Working Group.

# SECTION A--THE PARTNERSHIP

SGI and Saskatchewan Health have established a partnership to address the growing concerns of survivors of Acquired Brain Injuries (ABI), their families, professionals and other caregivers. Through this association, a three year provincial pilot was developed which will enhance services and supports for people with acquired brain injuries.

## Composition of the Working Group

The first step of the project was to develop a working group to define the issues and subsequently the programs, services and supports necessary to address those issues. Members of the working group were recruited from several areas, thereby bringing a cross-section of expertise to the project. The members come from diverse working backgrounds, including:

- ⌚ physical therapy;
- ⌚ case management;
- ⌚ occupational therapy;
- ⌚ neuropsychology;
- ⌚ Saskatchewan Health;
- ⌚ Saskatchewan Abilities Council;
- ⌚ Saskatchewan Head Injury Association (SHIA);
- ⌚ Saskatchewan Education, Training and Employment; and
- ⌚ Saskatchewan Government Insurance (SGI).
- ⌚ home care;
- ⌚ community services;
- ⌚ physical medicine and rehabilitation;
- ⌚ recreational therapy;
- ⌚ mental health;

The group also included consumers and family members of individuals with ABI. Further, it embraced representation from different geographical areas of the province including rural, urban, north and south. The intersectoral and interdisciplinary approach within the working group ensured that different perspectives and ideas were explored in as unbiased a manner as possible. This broad range of representation further ensured that the interests of many groups, including service providers, funding agencies, and, in particular, families and consumers, were considered.

In addition to drawing on the valuable resources within the working group, further information and expertise has been collected and speakers on diverse topics have presented to this committee. The working group recognizes that it has not consulted with the First Nations and Métis communities in writing the strategy.

**RECOMMENDATION #1: The working group recommends that there be an ongoing Advisory Council that will provide direction to the project and will review the progress of the pilot project.**

**RECOMMENDATION #2: The working group recommends actively pursuing First Nations and Métis consultation as well as membership on the Advisory Council.**

# **SECTION B--THE VISION AND MISSION**

## **The Vision**

Saskatchewan will have a comprehensive, integrated system of supports, resources and services that will enhance the rehabilitation outcomes and improve the quality of life for individuals with acquired brain injury and their families. This system will promote the self-determination of individuals, as well as participation and (re)integration into community life.

## **The Mission**

The broad mission of the working group is the development of a provincial strategy with provision for enhanced training opportunities for service providers, outreach assessment and case management, and community-based rehabilitation program enhancement. The strategy is to link existing resources with program development.

This document outlines the proposed strategy and follows the order of the strategy's objectives (see Section C). Although the strategy is structured around adult rehabilitation, children and adolescents have not been ignored. Issues, needs, gaps and service strategies that are particularly pertinent to children and/or adolescents will be identified in this paper with the following symbol: ☺. Some issues apply to adults as well as children and adolescents. These may or may not be flagged with the symbol.

The distinct developmental needs of children, adolescents and their families are acknowledged and a discussion of these unique needs, taken from throughout the strategy, is appended. It is further recognized that the needs of older adults may differ from those of younger adults. There is a noted lack of research on the process of aging with an ABI, and as such, this concept should be identified as an area in need of further research. However, the working group recognized that persons with ABI at each developmental stage, including childhood, youth, adolescence, early, middle and late adulthood, will have particular and unique developmental needs that must be considered.

# SECTION C--THE OBJECTIVES

Objectives of the strategy are listed below and detailed in the following pages.

1. The population targeted for service enhancement will be identified and defined.
2. Existing resources for people with acquired brain injury will be identified and linked.
3. New program developments will address gaps and meet identified needs.
4. After program implementation, rehabilitation outcomes and quality of life will be improved for people with acquired brain injury and their families.

## **Objective 1: The Population Targeted for Service Enhancement will be Identified and Defined.**

### **1.1 Definition of Acquired Brain Injury**

Acquired brain injury (ABI) is a generic term referring to damage to the brain. This damage occurs as a result of traumatic, chronic or pathological injury and is not related to a congenital disorder or a degenerative disease such as Alzheimer's disease or multiple sclerosis.

**Traumatic brain injury** is an insult to the brain that may occur from any of several causes including, but not limited to, motor vehicle crashes, falls, sports injuries, assaults or job-related accidents.

**Chronic brain injuries** occur as a result of substance abuse including inhalation of toxic substances or chronic alcoholism.

**Pathological brain injury** may involve a viral infection (e.g., encephalitis), cerebral vascular disease (e.g., stroke), tumours, cysts or metabolic disorders (e.g., liver or kidney disease).

In all cases, injury to the brain results from bruising, tearing, or bleeding into soft brain tissues, or, as in "non-traumatic" brain injuries (e.g., near-drowning, choking or strangulation), chronic, and pathological injury, from interference with the oxygen supply to the brain.

### **1.2 Causes of Acquired Brain Injury**

The main categories of causes of traumatic brain injuries are:

- 1) motor vehicle accidents<sup>9</sup> (including All Terrain Vehicles and snowmobiles); and
- 2) assaults (especially in inner cities) including child abuse (e.g., Shaken Baby Syndrome); and falls (especially in the elderly and in alcoholics).

The main causes of non-traumatic brain injuries are:

- 1) cerebral vascular disease (stroke) and tumours.

The relationship between alcohol and brain injuries, particularly traumatic brain injuries, deserves special mention. Alcohol is involved in a great number of motor vehicle accidents causing brain injury. For example, in Rimel, Giordani and Barth's 1982<sup>10</sup> study, they found that alcohol was involved in 78% of moderate brain injuries and in 53% of mild brain injuries. In the majority of these cases, the individual's

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<sup>9</sup> SP Research Associates, 1992.

<sup>10</sup> cited in Kreutzer, Wehman, Harris, Burns & Young, 1991, p.178.



blood alcohol level was over the "legal limit". Alcohol further contributes to the incidence brain injuries in the form of Wernicke-Korsakoff syndrome, an illness which causes damage to brain cells and which can result from chronic alcoholism.

## 1.3 Population Data

### 1.3.1 Incidence

In Saskatchewan, hospital records identify the population treated in acute care facilities where the primary diagnosis using ICD 9 codes indicates traumatic or non-traumatic brain injury. We are not, however, able to easily or accurately identify the needs of, or the services used by, these individuals following the acute phase of hospitalization. We are also unable to accurately account for other brain injuries not documented because the brain injury occurs with another injury that was the primary focus of treatment. This is further compounded that in cases of multiple injuries the individual may be treated on wards other than neurosurgery (e.g., plastic surgery, orthopaedics, general surgery).

As identified in the literature, the three most significant factors that skew the incidence rates are:

- 1) hospital admission data are incomplete because acquired brain injury is often not recognized or recorded when it is part of multiple injuries;
- 2) apart from the diagnostic codes which indicate a traumatic head injury there are many other codes which may or may not indicate brain damage; and
- 3) many people with brain injuries either do not go to the hospital at the time of injury or are not admitted.<sup>11</sup>

Saskatchewan is not alone in this dilemma. No reliable estimates of brain injury incidence and prevalence exist in North America. This has been a deterrent to effective planning for this population.

Extrapolation from available statistics indicates an estimated incidence of approximately 2.2 traumatic head injuries per 1,000 individuals per year. According to this formula, Saskatchewan will have at least 2,200 TBIs occur each year<sup>12</sup>. In addition to this one must include the incidence of non-traumatic brain injuries which, although occurring in much smaller numbers, contribute to the overall numbers of individuals requiring services.

As shown above, there are a variety of factors which lower the recorded incidence rate of ABI. It is important to note, however, that present Saskatchewan data may include and record individuals who incur a cut forehead and those who are admitted for overnight observation as having a head injury. Such data is also misleading as it raises the incidence beyond what might reasonably be expected.

Based on data from Royal University Hospital in Saskatoon and from the Plains Health Centre in Regina it is reasonable to extrapolate that approximately 150 individuals each year will be at risk for incurring a brain injury requiring **multiple services** and **long-term (lifetime) supports**; in other words, there will be 150 new cases of moderate to severe brain injury each year, as well as perhaps 2000 others with "mild" brain injury who may also require short or long-term rehabilitation services. This number includes those adults and children who have a primary diagnosis of a brain injury as well as those who are missed due to being treated on wards other than neurosurgery.

### 1.3.2 Prevalence

Based on research into other populations with disabilities, it seems that the life expectancy of individuals

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<sup>11</sup> SP Research Associates, 1992, p.4.

<sup>12</sup> Ibid, p.5-6.

with ABI is probably reduced by about 10-15%. Moreover, given the long-term nature of the effects of brain injuries, one could reasonably assume there is a growing cumulative need for services. However, it is difficult to estimate how many individuals with residual effects from ABIs are currently in the Saskatchewan general population as there are no longitudinal studies available. Research is needed in this area.

## 1.4 Characteristics of the Brain Injured Population

Brain injuries can happen to anyone although most brain injuries occur in the 16-25 year old age range. A disproportionate number of brain injuries are incurred by young males. Available statistics show that about twice as many males as females acquire brain injuries<sup>13</sup>. Further, when females are injured, they are usually in the company of young males (e.g., the females are passengers in automobile accidents). Most traumatic ABIs occur in rural locations. Further, although ABIs can happen to an individual of any age, socioeconomic status or family background, a disproportionate number of brain injuries occur in individuals who: are from lower socioeconomic backgrounds; are from a disrupted family; have a premorbid history of learning and/or attention deficits; have a substance abuse history; or were drinking before the injury (e.g., drinking and driving). Further, aboriginal people are overrepresented in the population with ABI. These factors are important to note when designing prevention activities targeted to particular groups. A further fact to note is that individuals who incur one head injury have a 40% chance of incurring a second.

- ☺ Most paediatric brain injuries occur as a result of pedestrian or other accidents, and occur before the age of ten years<sup>14</sup>. Aboriginal children are over-represented in paediatric brain injuries.

## 1.5 Effects of Acquired Brain Injury

Injury to the brain, depending on its extent, location, nature and severity, may cause varying degrees of disability. Brain injury can also result in the disturbance of behaviour or emotional functioning. Damages range from minimal to severe. Impairments may be temporary or permanent and may cause partial or total functional disability or psychosocial maladjustment. Brain injury is not something which the individual "gets over". Rather, resulting deficits may need attention at intervals which may be frequent for many. For others, it may be more infrequent, and for some perhaps only occasionally. The following deficits may be short or long term in nature, or may even require lifetime monitoring.

**Physical** problems may include:

- 🕒 decreased fine and gross motor coordination;
- 🕒 sensory impairment; and/or
- 🕒 seizures may develop sometime after the initial injury.

**Behaviour** difficulties may include:

- 🕒 disinhibited or socially inappropriate behaviour
- 🕒 aggression, anger and emotional outbursts; and/or
- 🕒 impulsivity.

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<sup>13</sup> Saskatchewan Head Injury Association, 1993.

<sup>14</sup> Ibid.

**Cognitive** disabilities may involve:

- 🕒 deterioration of receptive and/or expressive language;
- 🕒 loss of short-term memory;
- 🕒 attention deficits and problems with concentration;
- 🕒 lack of motivation;
- 🕒 difficulty processing abstract information; and/or
- 🕒 problem solving deficits.

**Psychosocial** difficulties may include:

- 🕒 anxiety or depression related problems;
- 🕒 poor emotional control; and/or
- 🕒 decreased social interaction skills<sup>15</sup>.

Any combination of the above problems may occur due to an ABI, or, alternately, there may be no overt difficulties. Deficits may not be readily apparent and may be cumulative in nature. Many adults with head injuries, particularly "mild" injuries, appear normal once physical recovery is complete, however, they frequently suffer from residual effects that go almost unnoticed (the "invisibly injured") but impede or prevent a return to a high quality of living. Because of the multiple difficulties which may occur, some of which are not apparent initially (immediately after injury), there must be a mechanism for regular follow-up of the individual.

☺ Paediatric and adolescent brain injury survivors usually achieve good physical recovery but have significant cognitive and behavioural deficits. Many children with "mild" brain injuries often show up in classrooms with emotional or learning disabilities. In a sample of 1500 students in special education classes, it was found that 20% of children with learning disabilities and 40% of children with emotional disabilities had a history of head injury. An unresearched number struggle through the educational system unaided. Paediatric and adolescent brain injury survivors may also be more prone to alcohol or drug abuse following their injury.

In older adults with ABI, it seems as though some of the "normal" aging processes are exaggerated or hastened. Older adults with prior cognitive dysfunction due to an ABI may have increased difficulties in areas such as attention span, memory or problem-solving. Further, there may be functional decline in other areas where deficits are already present. The individual, then, must readjust to accommodate and compensate for the enhanced or new deficits.

The most easily and frequently **recognized** deficits resulting from brain injuries, in order, are physical, cognitive and personality/behaviour. The latter are the most difficult to recognize, measure and assess. The most **prevalent, persisting, perplexing and "painful"** deficits, in order, are personality/behaviour, cognitive and physical. The exception is the physical problem of increased or permanent mental and physical "fatigueability" (i.e., this problem is often difficult to recognize, yet causes a great deal of stress in survivors and families).

Related to the above, some studies have shown that a large proportion (perhaps as high as 80%) of prison populations have had a brain injury in the past, usually untreated. Characteristics of these individuals include: they were injured as children; they had poor school records, and were likely to have been "pushed" through the school system; and in adolescence, due to low self-image and possibly impaired judgment and

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<sup>15</sup> SHIA, 1993.

impulsivity, they turned to drugs, alcohol and/or criminal activities. Again, this points to the need for prevention and early intervention, not only to minimize the effects of the injury and negative outcomes on the individual, but also to offset the high costs to the system, particularly in the realm of institutional care.

## **1.6 Classification of Brain Injuries**

### **1.6.1 Methods of Classification**

Severity of an injury can be measured in several ways: initial status (using the Glasgow Coma Scale), the rate of progress (Post-Traumatic Amnesia) or outcome (Glasgow Outcome Scale).

#### **Glasgow Coma Scale (GCS)**

The GCS describes the individual's level of consciousness after injury and is rated on a scale of 3-15. A rating of 13-15 indicates a mild injury, 9-12 is moderate and 3-8 predicts a severe injury. GCS scores correlate with return to work 12 months post-injury as follows:

- trauma controls (injury, but not to the brain) = 88%
- GCS 9-12 = 56%
- GCS 13-15 = 80%
- GCS 3-8 = 26%

#### **Post-Traumatic Amnesia (PTA)**

Although difficult to assess, PTA refers to the length of time until an individual can form new memories. People with PTA greater than 13 days tend to have persisting deficits as a result of their injury. With PTA under 13 days, individuals are more likely to have a better recovery.

#### **Glasgow Outcome Scales**

This scale has only five ratings as follows: Death; Persistent Vegetative State; Severe Disability; Moderate Disability; and "Good" Recovery. One difficulty with this measure is that in the "good recovery" category, individuals may still exhibit significant impairments.

### **1.6.2 Mild Brain Injury**

Most ABIs are classified as being "mild" (GCS score of 13-15). Although individuals with mild ABI may experience some of the disabilities as individuals with a more severe injury they do not require multiple services as often. They report problems that are physical, cognitive and emotional, including: fatigue, headaches, and dizziness as well as "a decrease in ability to concentrate and perform more intellectual tasks; and feelings of anxiety" (The Continuum of Opportunity Task Force, 1994, p.12). The term "mild", however, is misleading. Without early intervention and education a mild injury can have serious impacts on an individual's return to school, work, the community and family. As many individuals with mild injuries are never diagnosed with ABI and indeed typically do not even seek medical care and assessment, they often receive no education or intervention at all. For the ABI survivor, the experience of any deficits as outlined above, no matter how mild, can be devastating.

Of particular note with regards to individuals with mild brain injuries, although they may seem to be functioning "normally" in most respects, it is often only with the utmost effort that they make it through the school or work day. They frequently report being exhausted at the end of the day from the effort of "keeping up" with their expected productivity. Often, due to the cognitive difficulties experienced by the individual, they may lose their employment.

### **1.6.3 Moderate/Severe Brain Injury**

Individuals with more serious brain injuries are likely to experience multiple deficits depending on the

nature of the injury. Such individuals usually use multiple services, often for a long period - even a lifetime. Many are unable to return to work due to long-lasting deficits. The percentage of injured individuals who have severe disabilities may require slow-paced, long-term or lifetime rehabilitation.

Regardless of the severity of injury, the goal of medical care and rehabilitation is the restoration of as much functional ability and quality of life as possible. Individuals who will never be returned to their original functional capacities must somehow assimilate the changes in themselves and face the challenges of "lifelong living". Most individuals with an ABI will require some assistance with certain aspects of their lives and they must be assisted towards an acceptance of their abilities and deficits. It is the adjustment to residual deficits by compensating with remaining abilities and assets which characterizes the process of lifelong living. This is a process that will continue throughout the individual's life.

Social effects of all brain injuries include family disruption, which may lead to family violence or a breakdown in the family's structure. Cognitive and emotional deficits often include fatigue, difficulties in concentration, memory problems, emotional outbursts, depression and anxiety.

**RECOMMENDATION #3: The working group recognizes that each person with acquired brain injury is unique and requires an individualized service response. The group recommends that appropriate services and resources be available to all individuals with ABI on the basis of need, regardless of age, the severity of injury or other characteristics.**

## **Objective 2. Existing Resources for People with Acquired Brain Injury will be Identified and Linked.**

There are currently limited specialized services for individuals with ABI in Saskatchewan. As indicated above, these individuals may have a variety of physical, cognitive, mental, emotional and behavioural deficits. As such, there is often difficulty placing them in rehabilitation or other programs with other persons with disabilities. Because of the variety of needs that an individual with ABI may have, they typically need services from a several different agencies. A full continuum or menu of care is required. This continuum should include prevention and health promotion activities as well as services and supports that begin at the point of injury and continue through the different stages of healing and recovery. The process of healing follows the following stages:

1. Emergency, crisis intervention, stabilization;
2. Acute care - hospitalization;
3. Acute rehabilitation - hospital based;
4. Acute rehabilitation - community based - involves coordination, case management comprehensive integrated assessment and treatment planning, program delivery, community re-entry;
5. Long-term slower paced individualized rehabilitation - involves day programming, educational/vocational upgrading opportunities, social skill training, independent living skill training, long-term follow-up and support; and
6. Support for the challenges of "lifelong living".

Most professionals and families agree that the first three steps are adequately provided in Saskatchewan, but there is a definite lack of community based and long-term rehabilitation services and supports, as well as supports for lifelong living. The Saskatchewan Head Injury Association has further identified concerns about a shortage of expert personnel within acute care facilities.

## 2.1 Services Available in Saskatchewan

**When looking at the services available to individuals with ABI there appears to be a continuum that could, to some extent, span the range of needs. However, most of these services, even those mandated to be accessible to individuals with ABI, are not specifically targeted to them and may be inappropriate. Although there are services available in the urban areas of the province, rural areas are often lacking them. Further, although services are available, there is often difficulty in gaining access to them due to underresourcing. In some cases, service agencies do not have staff members who are skilled and knowledgeable about ABI. As a result, the services are not provided appropriately for the client. Often, these agencies are unable to take individuals with ABI due to challenging behaviours or other characteristics of the individual. Further, the mandates of some organizations inhibit program delivery to individuals with ABI. This points to the need for upgrading the resources of some programs and services and also to the need for ongoing education and training of individuals who may work with those with ABI.**

In the following summary of services, specific locations of services available in Saskatchewan have been identified, while recognizing that all health services are now delivered by District Health Boards.

**Prevention** activities are provided through a variety of sources including the Saskatchewan Institute for the Prevention of Handicaps (e.g., Bicycle Safety Coalition) and SGI (e.g., the use of seatbelts).

ABI individuals may require services from **several different professionals**, including, but not limited to: behaviour therapists/psychologists, neurosurgeons, neurologists, urologists, ophthalmologists, psychiatrists, nurses, physical therapists, occupational therapists, prosthetists, orthotists, speech language pathologists, dieticians, neuropsychologists, social workers, vocational evaluators, vocational counsellors, lifeskills coaches, addictions counsellors and recreational therapists.

Most moderate to severe brain injuries are initially treated in an **acute care hospital**. They may then be transferred to a **hospital-based rehabilitation program** (including both physical and cognitive rehabilitation), either at the Wascana Rehabilitation Centre or Saskatoon City Hospital for example. Individuals with mild ABI are often not treated in hospital at all.

Some **community and hospital programs** (such as Saskatchewan Hospital North Battleford)<sup>16</sup>, provide rehabilitation to individuals with brain injury, including physical therapy, occupational therapy, speech therapy, social work support, and vocational rehabilitation. These programs are typically provided by several different agencies and volunteers. In general, there is a lack of coordination between existing treatment and rehabilitation services and service delivery agents, which can make service delivery and access complex and inconvenient.

**Financial resources** for brain injured adults are varied such that the individual may receive financial support from Unemployment Insurance, Canada Pension Plan disability benefits, other insurance benefits,

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<sup>16</sup> Admission requirements for SHNB include the presence of an active mental disorder, not just an acquired brain injury.

Saskatchewan Government Insurance disability benefits, Workers Compensation, Social Assistance, or the Federal Government, for aboriginals with Treaty status. (☺ Financial resources for children with ABI are limited unless the child was injured in an automobile accident.)

**Vocational counselling and/or rehabilitation** are available through district health boards or other agencies. In Saskatoon, it is available through the Saskatchewan Abilities Council and University of Saskatchewan Student Services. Programs available in the Regina area include Employment Access and the Career Planning and Development Unit at the Wascana Rehabilitation Centre. Other agencies are: Human Resources Development Canada; Canada Employment and Immigration Commission (CEIC); SIAST; Canadian Paraplegic Association; Mental Health; and Vocational Rehabilitation of Disabled Persons (VRDP). Other agencies also provide psychological and intellectual assessment for vocational rehabilitation. These include the psychology department at the University of Saskatchewan, private and school psychologists, and the Saskatchewan Abilities Council, which not only offers vocational assessments but also Employment Preparation Programs and Supported Employment Programs. The Regional Employment Preparation Program (R.E.D.) is another vocational resource that is specifically geared to individuals receiving Social Service assistance (i.e., not specific to disabled clients). Finally, there are Work Preparation Centres offered through Social Services.

**Addictions services** are available throughout the province through district health board programs which include programs formerly identified as "non-governmental". There are, however, no specialized addictions programs for survivors of brain injuries.

- ☺ Children with ABIs may receive assessment and rehabilitation through the paediatric brain injury program offered at the Kinsmen Children's Centre in Saskatoon.
- ☺ Wascana Rehabilitation Centre's program in Regina also offers services to children with acquired brain injuries. However, these services are not specialized for brain injury.
- ☺ Saskatchewan Abilities Council offers Camp Easter Seal, a wheelchair accessible resort for children, to help meet their social and recreational needs.

**Environmental resources** for ABI individuals include the Saskatchewan Hospital Services Plan (SHSP) (providing regular medical and hospital benefits) and Saskatchewan Aids to Independent Living (SAIL) which provides some physical equipment and aids necessary for independent living (for example, wheelchairs). Home Care Programs (accessed through district health boards) offer assessment, care coordination, nursing services, homemaking, Meals-on-Wheels, home maintenance and in some areas, community therapy and social work services.

**Residential service options** for head injured clients are few. They may reside in long-term care facilities, special care homes or live with their own family. There are also group homes (subsidized or not), and private Personal Care Homes (not subsidized). Problems arise due to, for example, waiting lists for entrance to extended care homes as well as the fact that many private nursing homes are not wheelchair accessible or do not take people with severe behaviour problems. In rural areas, due to a lack of residential service options, many ABI individuals are inappropriately placed or remain in the hospital for long periods.

**Transportation** for physically disabled persons is a joint responsibility of the Department of Community Services and individual municipal governments. Community Services provides grants which the local municipalities can then use to provide transportation services either directly or through contract. For example, the Saskatchewan Abilities Council is contracted in Saskatoon, Swift Current and Yorkton; in

Prince Albert, transportation is provided by Special Needs Transportation. Moreover, there are some volunteer programs in place to assist in transportation (driving disabled persons to medical appointments etc.). There are also private agencies which provide special modifications to cars and vans for private use. Smaller rural areas, in particular, may use service clubs to provided transportation.

**Legal assistance** is provided to low income persons through Legal Aid. The Saskatchewan Human Rights Commission helps people with problems of discrimination (physical disability is included in the Saskatchewan Human Rights Code).

**Other services to individuals with head injuries include:** SARBI (Saskatchewan Association for the Rehabilitation of Brain Injuries) which provides a slow-stream program that is staffed mainly by volunteers; the Saskatchewan Head Injury Association (SHIA) provides advocacy for head injured clients and their families, educates the public, provides a clearing house of ABI information, initiates prevention programs, and provides peer support and socializing opportunities through local chapters.

**RECOMMENDATION #4: A comprehensive inventory of services broken down by health districts be developed and maintained on a regular basis. The inventory must be available to individuals with ABI, their families, professionals and other caregivers.**

## 2.2 Gaps in Service

Most services are present in some form although there is common agreement that services do not adequately meet the needs of the brain injured population. Moreover, as shown above, few of the services available are specialized for individuals with ABI.

- ☺ There are significant gaps in services for children and adolescents with ABI. As discussed above, these two groups have unique needs which are not addressed by the services geared for adults.

Gaps have been identified almost unanimously as being greatest after the acute phase of rehabilitation for persons who have incurred a moderate to severe brain injury. Internal planning documents, documents submitted from SHIA, information supplied by the working group and other concerned stakeholders identify common gaps. These are outlined on the following pages.

### **Prevention, Education and Training**

- ☺ There is no coordinated effort for prevention of traumatic brain injuries (TBIs), and since most TBIs occur in individuals under 35 years of age and the 16 to 25 year age range is most at risk, there is a definite need for age appropriate prevention activities targeted to children, youth<sup>17</sup> and adults. Such prevention activities should also address issues of substance abuse, including drinking and driving and its contribution to ABI.

There is a lack of specific coordinated education and training for all caregivers, including professionals

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<sup>17</sup> There may be an opportunity to link with Saskatchewan's Child Action Plan to coordinate prevention activities for children and youth.



and families, particularly with regard to behavioural issues. Many physicians and other individuals who work with individuals with brain injuries have no specialized training in ABI.

- ☺ Parents and families of children with ABI find it difficult to obtain ongoing and timely education about brain injury. There is also a lack of parent resource materials.

### **Supportive Services for Families**

Many families act as caregivers for their family member with an ABI. These families may require supports such as planned and emergency respite care, education on brain injuries (e.g., what to expect, what not to expect), counselling services and financial aid. Families are not often aware of available resources, or the resources are not flexible enough to meet the needs of the individual and family.

- ☺ There is a lack of ongoing counselling and support available to parents and families of children and adolescents with ABI. This is a crucial aspect of support, as the developmental needs of youth and families change over time. There is also a lack of appropriate respite options available for children and adolescents with ABI. Parents and families must have the opportunity for relief from the burden of care and responsibility at appropriate times.

### **Coordination of Services**

The system of services and supports for individuals with ABIs must be coordinated to facilitate access. Currently, services are fragmented and difficult to obtain. When individuals leave the acute rehabilitation facilities there is not always follow-up to facilitate their adjustment and return to the community.

- ☺ There is a lack of coordination and information sharing between educational services and rehabilitation services for children and adolescents with ABI.

One barrier to service coordination is poor communication between care providers, particularly at the transition from an inpatient treatment centre to community-based programs.

### **Lifeskills, Avocational and Vocational Activities**

As part of the process of lifelong living, the individual with ABI may require supports and rehabilitation to facilitate returning to work or school, participating in meaningful activities and performing the activities of daily living as well as regaining appropriate interpersonal skills. Assessments available are not provided consistently, nor are they always sensitive to changes in the individual's functioning which may be occurring. There is no comprehensive system of determining the individual's need for certain services or supports, and subsequently matching the services to those needs.

- ☺ For children and adolescents (whose work is school) there is a lack of short and long term supports for them to return to school or, once there, to stay in school.

### **Social, Recreational and Leisure Options**

The changes in the social, physical and mental status of individuals with ABI often creates a greater number of leisure hours which must be constructively filled. Further, some studies have shown that individuals show increased loneliness and depression due to a lack of access to appropriate activities and subsequent isolation from social environments.

- ☺ Finances may be a barrier to receiving appropriate social, recreational and leisure options.

- ☺ Many recreation and social activities will not accept children and adolescents with ABI due to a lack of staff training coupled with the often high needs and behaviour issues of the individual.

### **Residential Service Options**

There is a lack of variety of appropriate residential service options. Some individuals with ABI (particularly those with challenging behaviours) may require structured or supervised living arrangements other than a special care home, but this type of residential service option is not easily accessible for individuals with brain injuries.

- ☺ There are few residential service options that meet the needs of children and adolescents.

The most frequently identified gaps among those outlined above are the lack of adequate training for the caregivers of people with ABI and the lack of service coordination to formulate plans for services and supports in the individual's home community after hospital release.

## **Objective 3. Program Developments will Address Gaps and Meet Identified Needs.**

Considering the above identified existing services and gaps, there is an obvious need to develop or enhance programs that reflect the persisting gaps and meet the identified needs of the population with ABI. Guidelines for developing these supports and services are:

- 🕒 Supports and services for people with ABI will be planned with the understanding that the individual will use generic resources available in the community whenever possible and appropriate;
- 🕒 Service enhancements will remove barriers and have the flexibility to adapt existing services to enable people with brain injuries to gain access to them;
- 🕒 Specialized programs and services for people with brain injuries will be recommended for development when the current system cannot meet the needs of people with brain injuries; and
- 🕒 A continuum of connected, transdisciplinary services will be recommended for development, linking provincial resources with regionally and locally delivered programs from which a menu of client-focused services can be accessed for each person with a brain injury.

### **3.1 Prevention, Education and Training Activities**

The working group unanimously agreed that an effective province wide strategy aimed at the prevention of brain injury is a priority and should have designated resources. Most brain injuries are preventable and so efforts must be geared towards changing high risk behaviours that increase the likelihood of incurring a brain injury. This includes campaigns against drinking and driving. The prevention effort would be more effective if undertaken through a partnership of concerned stakeholders. Secondary prevention is also important. For example, current research involving individuals who have had a mild brain injury shows that timely, accurate information about the effects of the injury is crucial to early recovery. Further, secondary prevention should address issues such as prevention of another injury or prevention of drug or alcohol abuse. Tertiary prevention may include the provision of information and training to caregivers and others to prevent further disability in the injured individual.

ABI education, as discussed by the working group, has two primary purposes;

- to raise awareness of ABI and its effects on individuals and their families; and
- to impart specific knowledge and skills to individuals with ABI, their families and caregivers.

The activities to achieve these ends must involve both the development of general information resources to raise awareness as well as specific educational and training materials to upgrade the knowledge and skills of those individuals providing care and support to individuals with ABI.

## PRIORITIES

- ☺ Provide ongoing education for those working with individuals with ABI including family members, social workers, employers, corrections workers, recreation staff, medical personnel, home care workers, education personnel and others.
- ☺ Designate a provincial education and prevention coordinator to identify specific needs, develop information and education packages and promote education, training, workshops and prevention activities with all Districts.
- » Initiate an annual Provincial Conference to: a) promote networking among care providers; b) identify program and research issues; c) raise awareness of issues; and d) identify current community-based rehabilitation models.

The working group had the following directions for ongoing prevention, education and training activities:

- ☺ ⌚ designate resources for prevention;
- ☺ ⌚ develop a central clearinghouse of information on ABI that is readily accessible;
- ☺ ⌚ develop specific education and training targeted to particular groups, including consumers, families, social workers, teachers, emergency room nurses, doctors, employers and others;
- ☺ ⌚ develop and update resource material for parents and families;
- ⌚ develop material for education and awareness targeted to the public;
- ⌚ individuals with expertise on ABI should have designated time to provide training and support to others;
- ⌚ provide hands-on training at provincial and district levels; and
- ⌚ take advantage of technologies such as Internet and Teleconferencing.

### 3.2 Supportive Services for Families

Supportive services for families are resources to be used by the survivor and/or family to create or maintain a strong family unit. Supportive services should recognize and support the strengths in the family, help to reduce stress and provide early intervention to the family to prevent family breakdown. It is also imperative that the developmental stages of individuals with ABI and their families be considered when planning supportive services. ☺ In all instances, parents must be respected as the final authority regarding their child. ***Being supportive of families as a principle of service delivery should be an integral part of all resource development.***

The working group has identified the following as priorities to providing enhanced support for families:

## PRIORITIES

- »☺ Develop and enhance long-term/lifetime counselling services for families.
  - » Recruit, train and support local care providers.
- »☺ Support a problem solving approach to service provision.
- »☺ Provide appropriate planned and emergency/crisis respite care.

The most important support to provide is education. Families and individuals with brain injuries must be educated about how to obtain services, as well as to whom they should appeal when they are dissatisfied with the service plan or the service provision itself.

### 3.3 Coordination of Services

The working group identified the need for coordination at the following six levels:

- Individual and Community; (☺ At the individual level, note that the role of case coordination is different for children and youth with ABI, as the family often acts as the primary case manager, while the formal case manager should be available to provide information, support and assistance.)
- District (services offered in the district);
- Service area (services offered in the service area);
- Provincially (interdepartmental coordination) and centres of expertise;
- Nationally (coordination of education, prevention, research and service activities); and
- Internationally (trends, research, networking).

In the first stages of the project, the focus will be on the first four levels of coordination.

## PRIORITIES

- 🕒 Develop a structure that will identify and assign responsibility for individual service coordination. This responsibility includes coordinating services and supports and providing advocacy in the individual's home community as well as ensuring appropriate assessments and recommendations are completed and timely follow-up is provided.
- 🕒 Assign responsibility in districts, service areas and the province for the identification and coordination of services and supports.
- 🕒 Leadership should be provided by Saskatchewan Health and SGI in developing a provincial task force composed of representatives from consumer groups, Health, Social Services, Education, Municipal Government, Justice, Labour, WCB and SGI. This working group will coordinate policy and program development for the population with ABI.

The following directions will support the coordination of services:

- 🕒 link with the developing systems of case management to enhance integration, coordination, provision of services and advocacy based on mutually agreed upon goals (please see Appendix 3:

- ⌚ Systems-Based Conceptual Model for Case Management);
- ⌚ develop district, service area and provincial service directories;
- ☺ ⌚ develop partnerships with Saskatchewan Education around the Integrated School-Linked Services project; and
- ⌚ encourage inter-governmental cooperation at provincial level to break down current barriers.

### 3.4 Lifeskills, Avocational and Vocational Activities

**Lifeskills** are the skills needed to appropriately and safely carry out activities of daily living and interaction with one's environment, including interaction with other people. These must be integrated into all aspects of an individual's program.

**Avocational** refers to meaningful activities that enrich a person's quality of life and provide a sense of purpose and belonging, with perhaps minimal financial compensation.

**Vocational** activities and services are those that assist the individual to enter or re-enter the workforce and will provide the individual with a source of income or a supplement to their existing income.

<b>PRIORITIES</b>	
	<ul style="list-style-type: none"> <li>⌚ Develop transdisciplinary teams that have the capacity to provide outreach program support to rural communities.</li> <li>⌚ Initiate coordinated transdisciplinary assessments using professionals specifically trained in the assessment of individuals with ABI. The assessments should look at functional ability, job interests and existing supports. There should be ongoing support, training and follow-up to brain injured individuals until mutually agreed upon goals are achieved.</li> <li>⌚ Develop a transdisciplinary community program which integrates lifeskills training into all aspects of community re-entry.</li> <li>⌚ ☺ Provide support to the individual whenever possible to integrate into existing vocational/avocational opportunities. This support should be ongoing with the capacity to follow-up individuals and provide crisis intervention if needed.</li> <li>⌚ Lobby disability insurers to remove (on a trial basis) the financial disincentives for employment (including temporary and part-time).</li> </ul>

The working group has highlighted the following directions as important elements to consider in planning vocational/avocational and lifeskill services:

- ⌚ develop a coordinated transdisciplinary assessment procedure that will look at lifeskill, avocational and vocational needs;
- ⌚ provide "pre-vocational" training for individuals entering vocational placements;
- ⌚ integrate vocational and avocational activities into "real life" placements where possible. This can be done by:
  - developing work site supports such as job coaches and wage subsidies;
  - providing education for employers, co-workers/personnel and communities;

- developing volunteering opportunities in the community that may need to be supported by coaches; and
- providing ongoing support and regular follow-up;
- ☺ ⌚ provide supports and services to assist adolescents and young adults in making the transition to University/College or other educational settings, job training or work placements.
- ☺ ⌚ recognize that children's work is school, and as such ensure that funding is available to provide educational services and support to children and adolescents as they re-enter the educational setting;
  - ⌚ teach and reinforce coping skills for "real life" experiences in the most appropriate settings and provide technical supports as needed; and
- ☺ ⌚ provide one-on-one support, particularly where challenging behaviours are an issue.

### 3.5 Social, Recreational and Leisure Programs

Social, recreational and leisure activities help to keep individuals physically able as well as contributing to their overall social well-being. After a brain injury individuals may not be able to participate in their chosen activities. As well, friendships are often lost as interests and abilities change. Loneliness, isolation and depression are significant problems and challenges for these individuals.

<b>PRIORITIES</b>
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| <ul style="list-style-type: none"> <li>⌚ ☺ Inclusion of assessment, planning and support for leisure activities in the overall assessment and planning with brain injured individuals. This is often overlooked in rehabilitation planning and is a significant feature in improving the quality of life for injured individuals and their families.</li> <li>⌚ ☺ Coordinate with appropriate social, recreational and leisure staff in the provision of social/recreational activities and programs for individuals with ABI.</li> </ul> |
|---|

The working group had the following suggestion for activities:

- ⌚ provide support and training to the individual for leisure options;
- ⌚ develop district directories of activities;
- ⌚ sensitize leisure staff, recreation workers and others involved in social, recreational and leisure activities;
- ⌚ develop a manual which defines how programs and activities can be modified to meet the needs of individuals with ABI (i.e., a resource for families, consumers and personnel);
- ☺ ⌚ modify and fund existing recreation and social activities so that they can accept children and adolescents with ABI;
- ⌚ explore existing leisure assessment tools; and
- ⌚ initiate/enhance peer support groups.

### 3.6 Residential Service Options

Residential needs of individuals will vary depending on age, gender, cultural background, severity of injury

and existing support system of the injured individual.

### PRIORITIES

- 🕒 Develop and implement a community residential program model based on District/Service Area needs assessment.
- 🕒 Designate residential resources for individuals who display challenging behaviour.

When designing or enhancing residential service options one should consider the following directions:

- 🕒 providing support and services to individuals and their families which allows them to live as close to home as possible;
- 😊 🕒 resources that are socially, developmentally and culturally appropriate; and
- 🕒 flexible, person-centred and supportive residential service options to allow individuals to live as independently as possible.

Supportive residential services should include:

- 🕒 support to individuals and families to allow them to stay in their own homes; and
- 🕒 alternative living arrangements which could include group home living, transitional rehabilitation residences, supportive apartment programs and appropriate institutional care when necessary.

## **Objective 4: After Program Implementation, both Rehabilitation Outcomes and Quality of Life will be Improved for People with Acquired Brain Injury and their Families.**

Programs and services must be dually accountable; to the public for spending and policies and to individuals receiving services for quality and continuity of care. Accountability is ensured through program evaluation. Evaluation determines if the delivery of services meets the needs of consumers, families and communities effectively and as intended. Evaluation provides information about how to strengthen programs and identify areas where the program is meeting or exceeding objectives and where it should be changed. Evaluation allows the system and service providers to be accountable and so depends on objectivity in process as well as in the reporting of information. Evaluation processes must be identified and developed to assess new or enhanced programs, services and supports. To do this clear expectations and specifications must be developed through policy and service agreements.

Outcome measures must be based on real life and on the desired goals of the individual with ABI. In addition, both short and long term goals need to be specific, measurable, achievable and compatible with the philosophy and mission of the rehab program. From these client-centred goals, individualized outcome measures in the following three categories can be derived: functional independence, productive activity and community reintegration. The degree to which the families of ABI individuals feel supported and able to adapt should also be measured. Current outcome and evaluation measures do not provide this kind of information, especially when the rehab program is delivered in a community setting.

Quantitative measures must be objective, stable and must be statistically valid. They must have valid correlations with the individuals with ABI's life satisfaction, disability and handicap. Qualitative measures are also needed so that programs can be individualized, and the perspectives of individuals with ABI and their families remain central. The individual with ABI and their family's goals should be included in measures of outcome. Outcome indicators and measures related to both quality of life and functional abilities (including physical, cognitive and behavioural functions) must be developed<sup>18</sup>.

That said we acknowledge that program evaluation and outcome measures for ABI are in the developmental stages. This developing field must link local research with National and International developments. There is a relatively small number of individuals with ABI in each province, which makes the development of a national data system important so that there are adequate numbers to identify homogenous groups for evaluation of outcomes. Uniform database, common terms and assessment tools are needed so that realistic comparisons between programs can be made. Currently Saskatchewan Health is developing an Information Technology Framework for health districts and should play a key role in providing the following:

- ⌚ confidentiality (especially for the individual);
- ⌚ data of quality and integrity;
- ⌚ comparability to other programs; and
- ⌚ a research base;
- ⌚ cost-related measures;
- ⌚ statistical capability.

The common database will contribute to the development of outcome indicators. Indicators are "benchmarks" which are used to assess performance, provide warning as to potential problems and identify areas of system performance or consumer care for further evaluation. What is measured is further reviewed in the context of the expectations and both the province's and the district's priorities. Development of outcome measures allows an examination as to whether expectations have been met, thus ensuring that the system is accountable.

There must be a link to clinical work to ensure that research is of practical use. Research must be done to determine what interventions are effective in the prevention of ABI and what treatment modalities are effective with which groups. Research should also continue to explore new or different therapies, rehabilitation models, methods of education and residential options. Research should use Saskatchewan data, where possible, although it is important to follow activities both nationally and internationally.

**RECOMMENDATION #5: Outcome and quality of life indicators for individuals with ABI should be reviewed and appropriate tools incorporated for program evaluation. Evaluation tools should be consistent with National and International recommendations.**

<sup>18</sup> Indicators other than functional status can include: living arrangements at discharge from a program; employment and productivity; client/family satisfaction; cost/charges; and level of assistance required.



**RECOMMENDATION #6: Evaluation tools consistent with National and International recommendations should be adopted.**

## **SECTION D--STRATEGIES AND ACTIONS**

### **Issues and Principles**

There are several key issues which must be addressed at all stages of strategy development.

- 1) Efforts must be made to integrate new development with existing resources to continue to remove barriers, promote community reintegration and maximize the efficient use of scarce resources. Program enhancements should always complement rather than replace existing resources where possible. However, there may be occasions to develop new services within the province, or, where this is not reasonable, to facilitate the use of out-of-province services.
- 2) There must be commitment to coordination of services and resources across the province. As individuals with head injuries may require services and programs offered through different sectors, there must be an effort made to coordinate across those different sectors. There must be coordination at all levels to allow resources to be used efficiently as well as to ensure that all individuals receive services and supports in a timely, easily accessible manner.
- 3) In striving for a comprehensive continuum of services for individuals with ABI cross-sectoral partnerships should be encouraged wherever possible. Partnership means shared commitment to pursue agree upon goals, jointly and in a coordinated manner. Cost-sharing must be explored where possible to increase available funding for enhanced services and supports. Although SGI has provided the means to initiate the process of developing a comprehensive system of care for individuals with ABI, partners are needed to expand upon this "first step".

### **The Action Plan**

#### **Step 1 - Provincial ABI Coordinator**

(Proposed Budget Allocation - \$65,000 for salary, benefits and travel [office and clerical support will be provided by Saskatchewan Health])

**Role:** This position will be responsible for coordinating programs and services for ABI across Saskatchewan in cooperation with district health boards. Initially the position will be designated for operationalizing the steps of the strategy.

**Functions:** Participate actively in policy and planning and assume a leadership role in the overall program development and advancement;  
Develop partnerships with other jurisdictions and among all agencies involved in supporting individuals with ABI;  
Facilitate the coordination of inter-district services;  
Propose directions for research;  
Network with Alberta and Manitoba regarding interprovincial discharges;

Assist in the development of a provincial database on ABI; and  
Develop a strategic plan and flexible budget for the distribution of SGI funding over the next three years.

The Provincial Coordinator will initially report to Saskatchewan Health and receive ongoing direction from a provincial advisory group (made up of some members of the present working group and others).

## **Step 2 - Prevention, Education, Training and Research**

1) Educational and Research Resource Person (Proposed Budget Allocation - \$400,000 [includes salary of resource person, development of educational materials, development and delivery of training programs and prevention activities])

Role: Coordinating prevention, education and training activities with district health boards throughout Saskatchewan.

Functions: Coordinating and distributing educational materials for families, caregivers and others;  
Collaborate in the development and presentation of brain injury education and training to staff;  
Provide support for the identification of appropriate methods and models of programming;  
Assist in identifying appropriate outcome measures for ABI;  
Propose directions for research;  
Promote ongoing knowledge of professional literature and its practical applications;  
Coordinating training activities and professional development;  
Responsible for public education events and materials;  
Development of a clearinghouse of information on ABI; and  
Responsible for collaboration with other organizations in identifying and contributing to an effective prevention program.

2) Provincial Conference (Proposed Budget Allocation - \$20,000)

Role: This annual conference will promote professional development and training, as well as facilitate access to research and program and service trends.

Functions: Will be jointly planned with SHIA, Social Services, Health, Justice, Municipal Government, SGI and Saskatchewan Education, Training and Employment;  
Will support existing provincial expertise;  
Promote ongoing training of caregivers;  
Disseminate information to consumers, families and caregivers;  
Facilitate networking among agencies; and  
Provide information on research and development of programs.

3) Supportive Services for Families (Proposed Budget Allocation - \$75,000)

Role: Providing supportive services for families in the form of support groups and other resources.

Functions: Development of family support groups;  
Provide a means of interacting with individuals with similar issues and problems;  
Decrease the social isolation which families sometimes face after a family member incurs a brain injury;  
Serve as an information resource that aids in coping and adaptation;  
Offer social support during crisis periods; and  
Assist families and individuals with lifestyle modifications.

NOTE: The provision of emergency/crisis and planned respite care (as a supportive service) must be addressed in several different ways. It may be done through coordination, education and training and as part of a residential program. This issue will be followed for program development.

### **Step 3 - Community-Based Programs and Services**

#### 1) Outreach-Program Support Teams (Proposed Budget Allocations: \$1,200,000 [staff and expenses])

**Role:** These transdisciplinary teams will participate in assessment and will provide service planning and coordination, treatment and outreach program support.

**Functions:** Provide coordination and program support to communities planning for the return of an individual with ABI;

Provide training to local community caregivers;

Provide rehabilitation planning and treatment support;

Promote integration of individuals with ABI into their home communities;

Provide individual case coordination services;

Link with discharge planners in the acute care setting;

Serve as a resource for community caregivers (including formal and informal) by maintaining contact and being accessible to respond to issues as they arise;

The teams will be multidisciplinary and will vary depending on distinct needs and ability to recruit. Some of the outreach services may be provided through contracts with workers in the above fields.

Two transdisciplinary teams will operate through the Regina and Saskatoon district health boards but will provide services to all health districts. The satellite team will likely operate from a location convenient to providing services to Northern Saskatchewan, but with professional support from Saskatoon. The satellite team should also, if possible, include aboriginal caregivers.

☺ One position each from Regina and Saskatoon will be dedicated to providing program support to children with ABI. These may be linked to the Kinsmen Children's Centre but will have the capacity to provide outreach support. ABI services for children must be supported and facilitated through collaborative efforts between Health, Education and Social Services where possible. Further, a full-time paediatric behaviour therapist will be funded to provide outreach services.

#### 2) Community-Based Programs (Proposed Budget Allocation: \$800,000)

**Role:** Programs will provide or enhance community-based services and supports which facilitate community reintegration for the individual with ABI.

**Functions:** Specific functions will depend on the programs focus and goals. Programs may be social, recreational, leisure, vocational, avocational or other rehabilitative.

Program proposals supported by district health boards will be solicited by the provincial coordinator and reviewed by the provincial coordinator, the Advisory Group, Saskatchewan Health and SGI. Appropriate programs will be supported for funding. A large component of this step will be the modification of existing programs (through specialized education and training) to accommodate individuals with ABI. Partnerships should be explored wherever possible (e.g., with Education, Training and Employment, Labour, Social Services and other appropriate agencies).

## ☺Step 4 - Residential Programs

(Proposed Budget Allocation: \$500,000)

Role: To provide necessary and appropriate residential services for individuals with ABI.

Functions: As above. These programs may include appropriate residential supports and services for adolescents and adults with ABI.

After completion of needs assessment appropriate residential service options will be identified and funded. Preference will be given to residential service options that enhance partnerships with other agencies (e.g., Social Services, Municipal Government, etc.).

## Step 5 - Program Evaluation

(Proposed Budget Allocation: \$40,000)

Role: To support the development of appropriate evaluation tools for ABI services and supports and other related activities.

Functions: Assist in identifying appropriate outcome measures for ABI;  
Facilitate the evaluation of existing and developing programs;  
Propose directions for research;  
Provide clerical support; and  
Assist in the development of a provincial database on ABI.

(Please see Appendix 2 - Proposed Budget Allocations)

**RECOMMENDATION #7: The working group recommends that, in keeping with the priorities and directions identified by the group, the strategy and action plan be adopted and implemented by the SGI and Saskatchewan Health partnership.**

# SECTION E--APPENDICES

## APPENDIX 1 - GLOSSARY OF TERMINOLOGY

**Accessible:** Refers to services that can be accessed by residents of a health district even if they are not provided within the district. Such services may be provided by a district board, directly by Saskatchewan Health or be made available on a referral basis (e.g., some specialized services not available in Saskatchewan). Such services may be provided by Non-Government Organizations (NGOs) or others.

**Acquired Brain Injury (ABI):** Acquired brain injury (ABI) is a generic term referring to damage to the brain which occurs as a result of traumatic, chronic or pathological injury and which is not related to a congenital disorder or a degenerative disease such as Alzheimer's disease or multiple sclerosis. In all cases, injury to the brain results from bruising, tearing, or bleeding into soft brain tissues, or, as in "non-traumatic" brain injuries (e.g., near-drowning, choking or strangulation), chronic, and pathological injury, from interference with the oxygen supply to the brain or from exposure to toxins or infections.

**Activities of Daily Living (ADL):** The self-care activities carried out on a daily basis including feeding, dressing, grooming, toileting, bathing, domestic chores, etc<sup>19</sup>. ADL also includes planning, organizing and safely performing such activities as accessing public transportation. (see also **Instrumental Activities of Daily Living**)

**Acute Care:** Care involving 24 hour medical and nursing supervision for diagnosis and treatment.

**Acute Rehabilitation:** A system of rehabilitative care based in an acute care facility such as a hospital. The primary emphasis is on the early phases of rehabilitation beginning as soon as the individual is medically stable. Treatment focuses on intensive physical and cognitive restorative services in early months after injury.

**Adult Day Programs:** Such programs usually stress basic living, socialization and recreation skills. The programs seek to develop sufficient social competence and tolerance to maximize the individual's potential in a community setting.

**Advocacy Organization:** Any organization which provides resource information, support services and/or educational opportunities for individuals or families in need and makes those needs known to professional caregivers as well as to the general public.

**Amnesia:** A loss or impairment of memory<sup>20</sup>

**Avocational Rehabilitation:** A process involving activities which contribute to the individual's ability to participate in occupations other than their employment (i.e., hobbies).

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<sup>19</sup> Roy, D. (1990). *You Are Not Alone. Head Injury: Facts for the Family.*

<sup>20</sup> Ibid.

**Case Management/Case Coordination:** A collaborative, client-centred process that is continuous across provider and agency lines. Case management promotes quality care and cost effective outcomes while addressing the health and well-being of clients. Case management includes assessment, planning, coordinating, implementing, monitoring and evaluating health-related services.

**Chronic Brain Injury:** Chronic brain injuries occur as a result of substance abuse including inhalation of toxic substances or chronic alcoholism.

**Cognitive Function:** The brain's ability to orientate a person to his or her surroundings and to develop insight, knowledge, judgment, problem solving, memory, empathy, language and social skills<sup>21</sup>

**Community-Based Programs/Services:** Programs and services which are available in the community, excluding treatment services provided in hospitals and special care homes.

**Crisis Intervention:** Intervention at a critical moment (e.g., removal of individual(s) from an unsafe or high stress environment).

**Deficit:** A limitation or reduction in functioning. For example, a memory deficit would mean a limitation in one's ability to remember<sup>22</sup>.

**District/Health District:** A health district established or deemed to have been established pursuant to section 3 of The Health Districts Act (HDA).

- Health Districts are the primary organizational units for the planning, management and delivery of health services.
- the affairs of each Health District are managed by a District Health Board established pursuant to provisions contained in the HDA.

**District Health Board:** An elected board which manages the affairs of a health district. Each District Health Board elects a chairperson and may employ chief executive officers who assume responsibility for day-to-day operations.

**Group Home:** A home or homelike facility which provides lodging, supervisory and personal care to individuals who have ongoing service needs.

**High Need Individual:** An individual who requires a large number of services and interventions.

**Holistic Approach to Health:** An approach which involves the interconnectedness of all elements of daily living, including physical, mental, emotional, spiritual and social well-being. Holistic approaches to care place more emphasis on holistic, continuous and preventive care, including health promotion, rather than on curative and episodic approaches.

**Home Based Services:** Services which are provided in the individual's home.

**Incidence:** The number of new cases, episodes or events (of a health problem or disease) occurring over a defined period of time, commonly one year. Incidence is the most basic measure of frequency and is the best indicator of whether a condition is decreasing, increasing or remaining static.

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<sup>21</sup> Ibid.

<sup>22</sup> Ibid.

**Instrumental Activities of Daily Living (IADL):** Goes beyond individual activities and the person's ability to physically perform them, to social adjustment. IADL includes social integration into the community, not just physical integration.

**Integration:** The elimination of administrative and procedural barriers between health services.

**Interdisciplinary:** an approach to care in which persons from two or more disciplines (a multidisciplinary team) cooperatively assume the responsibility for the formulation, provision and review of an integrated care plan responsive to the needs of the client.

**Intersectoral:** Refers to the inter-relationship among all sectors or parts of society. An intersectoral approach means involving representatives from a wide variety of groups such as governments, business, labour, health, education, environment, agriculture and other agencies and interests.

**Lifelong Living:** The process of accommodation to residual deficits of an illness or injury by compensating with remaining abilities and assets. It is a process that will continue throughout the individual's life<sup>23</sup>.

**Lifeskills:** Those competencies that allow a person to live an independent and fulfilling life in the community, including communication and interpersonal skills, work readiness and job search skills, personal skills, problem solving skills, self esteem and academic learning skills.

**Lifestyle:** The set of habits and customs that is influenced, modified, encouraged or constrained by the lifelong process of socialization. The habits and customs include use of substances such as alcohol, tobacco, tea, coffee; dietary habits, exercise, etc. which have important implications for health.

**Multidisciplinary:** An adjective applied to a group or team when the participants come from two or more disciplines.

**Neurology:** A branch of medicine concerned with the nervous system and its disorders.

**Neuropsychiatry:** A branch of medicine concerned with both neurology and psychiatry<sup>24</sup>.

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<sup>23</sup> Jacobs, Blatnick & Sandhorst. (1990). "What is lifelong living and how does it relate to quality of life?", *Journal of Head Trauma Rehabilitation*, 5(1): 1-8.

<sup>24</sup> Webster's Ninth New Collegiate Dictionary. (1985). Markham, Ontario: Thomas Allen & Son Limited.

**Neuropsychology:** A science that seeks to integrate psychological observations on behaviour and the mind with neurological observations on the brain and nervous system<sup>25</sup>; the study and assessment of cognitive, emotional and behavioural performances of an individual as a result of brain dysfunction<sup>26</sup>.

**Occupational Therapy:** A therapy concerned with the client's ability to perform a variety of occupations throughout the lifespan<sup>27</sup>. Occupation includes any task or activity that adds to the individual, family, or community and is paid or unpaid.

**Outcome:** A result; a visible effect; a final consequence.

**Outreach:** The extending of services or activities beyond current or usual limits<sup>28</sup>; providing services and supports outside the usual venue.

**Pathological Brain Injury:** Pathological brain injury may involve a viral infection (e.g., encephalitis), cerebral vascular disease (stroke), tumours, cysts or metabolic disorders (e.g., liver and kidney disease).

**Persistent Vegetative State:** A condition where the individual is awake but unaware.

**Personal Care Home:** A facility, established under The Personal Care Homes Act, which provides accommodation, meals, supervision and assistance with personal care to an adult who is not a relative of the person who operates the facility.

**Physical Rehabilitation:** A process aimed at minimizing the physical effects of an injury.

**Prevalence:** Measures the total number of existing cases, episodes or events occurring at one point in time or during a defined period of time.

**Prevention:** Services designed to prevent disease and illness. Forms of prevention include:

**Primary:** involves measures aimed at promoting and maintaining health by such interventions as improving nutritional status, promoting vehicle safety, and promoting "safe" risk-taking.

**Secondary:** comprises measures aimed at ensuring the early detection and treatment of diseases, infections and injuries.

**Tertiary:** concerned with reducing symptomatic illness and disability.

**Quality of Life:** "the degree to which one perceives that life's quality is good, that life is satisfying, that the individual has physical and material well-being, good relations with others, and the ability to participate in social/community/civic activities, and that the individual has personal development, fulfilment, and recreation" (Padill & Grant, 1985). Health is one of the most important contributors to quality of life.

**Recreation Therapy:** Enhances individuals' quality of life by improving or maintaining the physical, mental, emotional and social skills through recreational and leisure pursuits.

**Rehabilitation:** an individualized array of coordinated services aimed primarily at forestalling, minimizing or reversing the occurrence of handicap, disability or impairment (Fuhrer, 1987, cited in Reynolds). The goal of rehabilitation is for the client to reach their optimum level of functioning.

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<sup>25</sup> Op cit.

<sup>26</sup> *You Are Not Alone*. (1990).

<sup>27</sup> *Position paper on Occupational Therapist's Role in Work Related Therapy*. (1988).

<sup>28</sup> *Ibid*.



**Respite:** An interval of rest or relief extended to the caregiver who is maintaining an ABI individual in his or her own residence or in the residence of a relative or friend. The timing of these intervals of rest will vary according to the situation and the needs of the caregiver. Respite may be needed during the day, evenings, on weekends, during the night or any combination of these. In other cases, an extended period of relief is needed (ie: 1 or 2 weeks), rather than the ongoing relief described above. Respite care may be provided anywhere appropriate care is available. A substitute caregiver can assume the duties of the usual caregiver in the individual's usual place of residence. At times it is necessary to provide respite in a facility such as a special care home or an acute care hospital.

**Service Areas:** Groupings of districts within areas that will work together to provide a fuller range of health services than can be provided by smaller districts by themselves.

**Supportive Care:** Services required on an indefinite basis in order to enable individuals to live independently in the community; may also include respite services for an individual's caregivers.

**Transdisciplinary:** Characterized by sharing or transferring of information and skills across traditional disciplinary boundaries. This is a particularly valuable model for individuals with multiple problems/diagnoses. This approach maximizes efficiency through effective resource utilization and elimination of duplication and overlaps, while facilitating multiskilling and enhancing the proficiencies of professional staff<sup>29</sup>.

**Traumatic Brain Injury:** Traumatic brain injury is an insult to the brain that may occur from any of a number of causes including traffic accidents, falls, sports injuries, assaults or job-related accidents.

**Vocational Rehabilitation:** a continuous and coordinated process of rehabilitation which involves provision of those vocational services, e.g., vocational guidance, vocational training, and selective placement, designed to enable a disabled person to secure and retain suitable employment<sup>30</sup>.

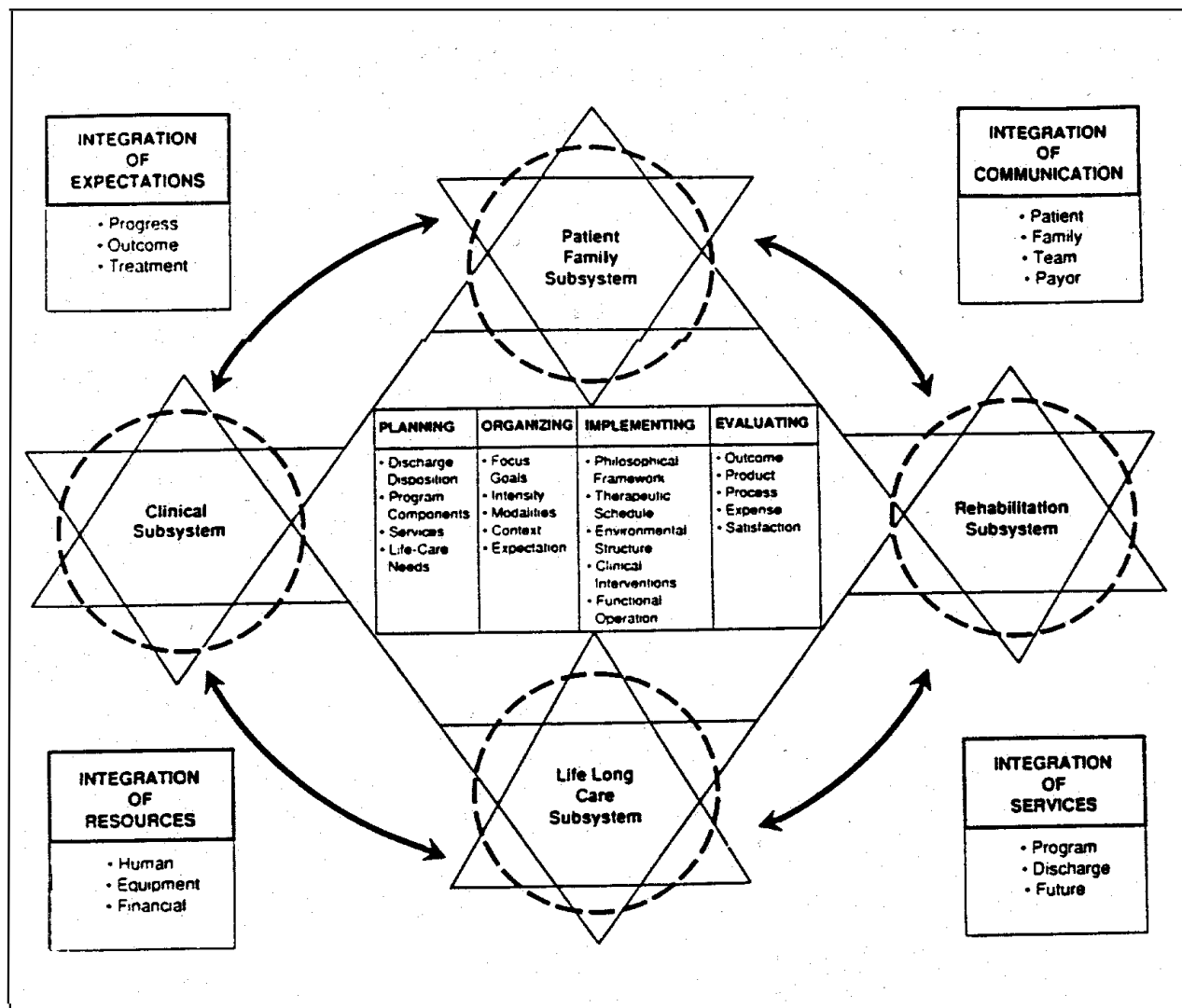
**\*\* Except where specifically noted, all definitions come from the Saskatchewan Health Glossary (1994) or were developed by members of the working group.**

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<sup>29</sup> Reynolds, N. (Unpublished). *Discussion Document - Rehabilitative Services - A Conceptual Framework for Integration*.

<sup>30</sup> Maki, D., McCracken, N., Pape, D. & Scofield, M. (1979). *Journal of Rehabilitation*, 45:48-51.

## APPENDIX 2 - A SYSTEMS-BASED CONCEPTUAL MODEL FOR CASE MANAGEMENT



Whitman, M. (1991). "Case Management in Head Injury Rehabilitation", *Rehabilitation Nursing*. 16(1), p.21.

## **APPENDIX 3 - PROPOSED ANNUAL BUDGET ALLOCATIONS FOR THE THREE YEAR PILOT**

Provincial Coordinator	65,000
Prevention, Education, Training	400,000
Provincial Conference	20,000
Supportive Services for Families	75,000
Outreach Teams and Pediatric Behaviour Therapist	1,200,000
Community-Based Rehabilitation	800,000
Residential Services Options	500,000
Research, Program Evaluation, etc.	40,000
	<b>Total \$3,100,000</b>
	<b>(3.1 million dollars<sup>31</sup>)</b>

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<sup>31</sup> SGI has pledged a total of \$9.3 million over 3 years. If the full \$3.1 million is not spent in one year, it may be carried over to the next year. Further, budget lines are flexible, allowing money to be "transferred" between strategy areas.

## APPENDIX 4 - REFERENCES

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# **APPENDIX 5 - SUMMARY OF ISSUES FOR CHILDREN AND ADOLESCENTS**

Most paediatric brain injuries occur as a result of pedestrian or other accidents, and occur before the age of ten years. One third of children's brain injuries occur below the age of three years, with the largest number of these happening under one year of age. Aboriginal children are over-represented in paediatric brain injuries.

Paediatric and adolescent brain injury survivors tend to achieve good physical recovery but have significant cognitive and behavioural deficits. Many children with "mild" brain injuries show up in classrooms with emotional or learning disabilities. In a sample of 1500 students in special education classes, it was found that 20% of children with learning disabilities and 40% of children with emotional disabilities had a history of head injury.

The issue of substance abuse must be examined further, not only in terms of its role in contributing to ABI, but also in terms of the risk of abuse after injury. Individuals with ABI who were injured as children or adolescents may be more at risk for developing a substance abuse problem.

Children and adolescents with ABIs may receive assessment and rehabilitation through the paediatric brain injury program offered at the Kinsmen Children's Centre in Saskatoon.

## **Prevention, Education and Training**

There is no coordinated effort for prevention of traumatic brain injuries (TBIs), and given that most TBIs occur in individuals under 35 years of age, and that the 16 to 25 year age range seems to be most at risk, there is a definite need for age appropriate prevention activities targeted to children, youth and adults.

Parents and families of children with ABI find it difficult to access ongoing education about brain injury. There is further a lack of parent resource materials.

### **Directions:**

- 🕒 designate resources for prevention;
- 🕒 develop a central clearinghouse of information on ABI that is readily accessible;
- 🕒 develop specific education and training targeted to particular groups, including consumers, families, social workers, teachers, emergency room nurses, doctors, employers and others; and
- 🕒 develop and update resource material for parents and families.

## **Supportive Services for Families**

There is a lack of ongoing counselling and support available to parents and families of children with ABI. This is a crucial aspect of support, as the developmental needs of children and families change over time. There is further a lack of respite available for children and adolescents with ABI. Parents and families must have the opportunity for relief from the burden of care and responsibility at appropriate times.

## **Coordination of Services**

In all instances, parents must be respected as the final authority regarding their child. At the individual

level, it is important to note that the role of case coordination is different for children and adolescents with ABI, as the family acts as the primary case manager, while the formal case manager should be available to provide information and support.

### **Lifeskills, Avocational and Vocational Activities**

There is a lack of coordination between educational services and rehabilitation services for children and adolescents with ABI.

For children and adolescents (whose work is school) there is a lack of supports for them to successfully return to school.

Directions:

- 🕒 develop partnerships with Saskatchewan Education around the Integrated School-Linked Services project; and
- 🕒 recognize that children's work is school, and as such ensure that funding is available to provide educational services and support to children and adolescents as they re-enter the educational setting.

### **Social, Recreational and Leisure Activities**

Saskatchewan Abilities Council offers Camp Easter Seal, a wheelchair accessible resort for children, to help meet their social and recreational needs. However, many recreation and social activities will not accept children and adolescents with ABI due to a lack of staff training coupled with the often high needs of the individual.

Directions:

- 🕒 modify and fund existing recreation and social activities so that they are able to accept children and adolescents with ABI.

### **Residential Service Options**

There are currently few available residential service options that are available to meet the needs of children and adolescents.

Directions:

- 🕒 resources that are socially, developmentally and culturally appropriate.

## **APPENDIX 6 - SUMMARY OF RECOMMENDATIONS**

**RECOMMENDATION #1:** The working group recommends that there be an ongoing Advisory Council that will provide direction to the project and will review the progress of the pilot project.

**RECOMMENDATION #2:** The working group recommends actively pursuing First Nations and Métis consultation as well as membership on the Advisory Council.

**RECOMMENDATION #3:** The working group recognizes that each person with acquired brain injury is unique and requires an individualized service response. The group recommends that appropriate services and resources be available to all individuals with ABI on the basis of need, regardless of age, the severity of injury or other characteristics.

**RECOMMENDATION #4:** A comprehensive inventory of services broken down by health districts be developed and maintained on a regular basis. The inventory must be available to individuals with ABI, their families, professionals and other caregivers.

**RECOMMENDATION #5:** Outcome and quality of life indicators for individuals with ABI should be reviewed and appropriate tools incorporated for program evaluation. Evaluation tools should be consistent with National and International recommendations.

**RECOMMENDATION #6:** Evaluation tools consistent with National and International recommendations should be adopted.

**RECOMMENDATION #7:** The working group recommends that, in keeping with the priorities and directions identified by the group, the strategy and action plan be adopted and implemented by the SGI and Saskatchewan Health partnership.

## APPENDIX 7 - SUMMARY OF PRIORITY ACTIVITIES AND DIRECTIONS

### PRIORITIES

- ⌚ ☺ Provide ongoing education for those working with individuals with ABI including family members, social workers, employers, corrections workers, recreation staff, medical personnel, home care workers, education personnel and others.
- ⌚ ☺ Designate a provincial education and prevention coordinator to identify specific needs, develop information and education packages and promote education, training, workshops and prevention activities with all Districts.
- ⌚ ☺ Initiate an annual Provincial Conference to: a) promote networking among care providers; b) identify program and research issues; c) raise awareness of issues; and d) identify current community-based rehabilitation models.

### PRIORITIES

- ⌚ ☺ Develop and enhance long-term/lifetime counselling services for families.
- ⌚ ☺ Recruit, train and support local care providers.
- ⌚ ☺ Support a problem solving approach to service provision.
- ⌚ ☺ Provide appropriate planned and emergency/crisis respite care.

### PRIORITIES

- ⌚ ☺ Develop a structure that will identify and assign responsibility for individual service coordination. This responsibility includes coordinating services and supports and providing advocacy in the individual's home community as well as ensuring appropriate assessments and recommendations are completed and timely follow-up is provided.
- ⌚ ☺ Assign responsibility in districts, service areas and the province for the identification and coordination of services and supports.
- ⌚ ☺ Leadership should be provided by Saskatchewan Health and SGI in developing a provincial task force composed of representatives from consumer groups, Health, Social Services, Education, Municipal Government, Justice, Labour, WCB and SGI. This working group will coordinate policy and program development for the population with ABI.



### PRIORITIES

- 🕒 Develop transdisciplinary teams that have the capacity to provide outreach program support to rural communities.
- 🕒 Initiate coordinated transdisciplinary assessments using professionals specifically trained in the assessment of individuals with ABI. The assessments should look at functional ability, job interests and existing supports. There should be ongoing support, training and follow-up to brain injured individuals until mutually agreed upon goals are achieved.
- 🕒 Develop a transdisciplinary community program which integrates lifeskills training into all aspects of community re-entry.
- 🕒 ☺ Provide support to the individual whenever possible to integrate into existing vocational/avocational opportunities. This support should be ongoing with the capacity to follow-up individuals and provide crisis intervention if needed.
- 🕒 Lobby disability insurers to remove (on a trial basis) the financial disincentives for employment (including temporary and part-time).

### PRIORITIES

- 🕒 Develop and implement a community residential program model based on District/Service Area needs assessment.
- 🕒 Designate residential resources for individuals who display challenging behaviour.

### PRIORITIES

- 🕒 ☺ Inclusion of assessment, planning and support for leisure activities in the overall assessment and planning with brain injured individuals. This is often overlooked in rehabilitation planning and is a significant feature in improving the quality of life for injured individuals and their families.
- 🕒 ☺ Coordinate with appropriate social, recreational and leisure staff in the provision of social/recreational activities and programs for individuals with ABI.