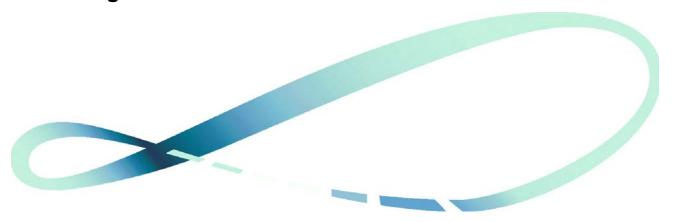




# Acquired Brain Injury Partnership Project: Program Evaluation 2004-2006



## **Acknowledgements**

We would like to extend our thanks to the clients, family members, service providers, and program staff who were involved in this evaluation. In particular we would like to thank the Outreach Teams, Darlene Bessey, Shannon Ellis and Karen Lawson for their contributions and support of the evaluation process.

Heather Murray ABI Evaluator

Michele Cairns Provincial Coordinator

Kelly Froehlich Education and Prevention Coordinator

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## **Executive Summary**

Since 1996, SGI has provided \$38.51 million in funding to the ABI Partnership Project. Over the past eleven years more than 2,600 individuals with ABI have received services from the Partnership.

In this contract period global, in-kind contributions averaged \$1.3M annually for 2004-05 and 2005-06 fiscal years. These contributions have therefore augmented the annual resources available for ABI Partnership Project programming by an average of 34%.

This evaluation focused on four core areas: clients, families, service providers, and education and prevention services. This report covers the period of April 1, 2004 to March 31, 2006. A number of evaluation methods informed this process. Methods ranged from surveys to focus groups and representative case studies.

During this evaluation period, 1,225 individuals with ABI received service; 639 of those were new clients. Of the total discrete clients 65% were male and 35% were female. The most common cause of injury was related to a motor vehicle collision (all types) at 31%.

Overall, it appears that clients maintain a very good level of function during their involvement with the ABI Partnership Project. There were also a number of gains reported in their productivity and level of independence. A decrease in the severity of some client difficulties was also reported. The ABI Partnership is providing services that address the identified needs of individuals with ABI and appears to be meeting most of these needs.

From the information obtained through the focus groups and Family Needs Questionnaire, it is apparent that improvements in services for families are needed. This is an area that should be addressed as soon as possible.

Referral patterns suggest a strong link with other health and human services. The Partnership assists clients with ABI in navigating the system and locates appropriate services/resources, as 87% of referrals made by the ABI Partnership programs are to services outside of the Partnership funded programs.

There appears to be a general level of satisfaction with the ABI Partnership Project programs. Most community partners indicated a willingness to collaborate with ABI Partnership Project programs and would continue that working relationship, as when asked if they would collaborate again, 87% indicated that they would.

From the staff survey, it appears that staff feel that the ABI Partnership Project programs are functioning well. A number of service gaps were reported, however. Overall, respondents seemed to report a general level of satisfaction with how programs are working and they report that the programs excel in a number of areas.

A total of 3,737 Community group and Education and Prevention activities were recorded this period for a total of 8,471 hours of service. A total of 60,412 individuals

attended the various events. Most of the people attending were children, youth, and students (24,059 = 40%).

The Community Grant Program has been in existence since 1997. Since that time, 1,228 projects have been funded across the province, totaling \$1,065,499. SGI and Saskatchewan Health, through the ABI Partnership Project, each provide \$50,000 annually toward this program. In the 2005-06 grant cycle SGI contributed an additional \$50,000 targeted toward bicycle helmet and booster seat use.

The ABI Partnership Project continued providing high caliber educational events this contract period. Dr. Roberta DePompei and Dr. Tim Feeney were the keynote speakers at the 2004 and 2005 *Brain Trust* conferences, respectively.

Feedback regarding the services provided by the Education and Prevention programs was extremely positive indicating community satisfaction with the services.

A number of recommendations regarding program improvements were made across the four core areas evaluated (see pp. 61-63 for the full listing).

## Introduction and Background

In 1995, Saskatchewan Government Insurance (SGI) and Saskatchewan Health developed a unique partnership to establish 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" [1, p.5]. This partnership was established in conjunction with SGI's introduction of No Fault insurance, and resulted in the development of the document Acquired Brain Injury: A Strategy for Services, upon which a community-based ABI service continuum was conceptualized.

In January 1996 a three-year pilot project began with a \$9.3 million funding commitment from SGI over three years from 1996 to 1998. Saskatchewan Health provided project management and coordination of the project and a Provincial Advisory Group comprised of professionals, survivors and families was formed to provide ongoing consultation.

After completing a process evaluation of the pilot project, SGI renewed their commitment for another five years (\$17.83 million from 1999 to 2003). As the program was no longer in a pilot phase, the name of the program was changed from the ABI Pilot Project to the ABI Partnership Project.

At the end of the five-year contract, another evaluation was completed. This evaluation examined program and client outcomes. Upon completion, SGI once again renewed funding for another three years. A total of \$11.36 million dollars was committed for the current contract period of 2004 to 2006. SGI has provided the Partnership with a total of \$38.51 million in funding to date.

#### **In-kind Contributions**

In order to obtain an accurate picture of the additional inputs that assist in the delivery of ABI programming, ABI Partnership agencies have been asked to submit information regarding their in-kind contributions. These contributions demonstrate the degree to which our programs supplement their operations outside of the SGI grant dollars.

Such in-kind contributions include: additional grants or fundraising efforts, human resources (administrative, clinical, information technology, volunteer and practicum students), building occupancy, travel, program and office supplies, training, and fees.

As part of their evaluation report, in the last contract period, programs were asked to include an estimate of in-kind contributions made to their annual operating budgets. At that time, annual in-kind contributions were estimated at \$1.194M.

This practice has continued in the current contract period. A template was developed in order to simplify the reporting process and programs submitted annual in-kind contributions in the 2004-05 and 2005-06 fiscal years.

In this contract period global, in-kind contributions averaged \$1.3M annually for the 2004-05 and 2005-06 fiscal years. These contributions have therefore augmented the annual resources available for ABI Partnership Project programming by an average of 34%.

These in-kind contributions represent a value-added component of ABI programming. Without these, the programs' capacity to deliver effective ABI services would be much diminished and therefore demonstrates the funded agencies' commitment to partnering to improve the scope and quality of ABI programming.

## The Partnership

The Partnership currently consists of 32 community-based and 7 education and prevention programs. Theses programs are located throughout the province and provide a range of services to individuals with ABI, their families, and communities. The Partnership has the unique ability to bring together multiple service providers to address client need in an integrated manner. The range of services are summarized as follows: assessment; case management; consultation; support; education for individuals, families and service providers; rehabilitation (direct therapy and therapeutic aid/assistance); life enrichment programming; vocational and avocational programming; and crisis management services.

While a continuum of services has been established under the ABI Partnership Project umbrella, the Partnership was established to augment and not to duplicate or replace existing health or other social services (e.g., home care, mental health and addiction services). ABI Partnership service providers partner with other human service providers to assist clients in successful community integration.

A total of 68.17 FTEs are funded by the Partnership, in addition to 2 FTEs dedicated to project management and 1 FTE dedicated to education and prevention coordination. The following table displays the distribution of FTEs by health region and program category.

Table 1: Acquired Brain Partnership Injury FTEs

Region	Out	each Ce	dans bro	and Religion	idate dir.	on dina	id /	dildred Co	Prograf	Problide Reside	Intial O	dione lining
Cypress				1								1
Five Hills				1							1	2
Heartland												0
Keewatin Yatthé		0.65										0.65
Kelsey Trail		2.44										2.44
Mamawetan		0.5	0.65									1.15
Prairie North				0.75	0.63				1.92			3.3
Prince Albert Parkland	5.3		1							3		9.3
Regina	10.1	1.5	1		1	1		0.5		8.85		23.95
Saskatoon	8.5	1.5	2.75	1	2	0.5	2.1	0.64	0.69			19.68
Sun Country				1							1.5	2.5
Sunrise				0.8		0.5					0.9	2.15
Athabasca												0
Total	23.9	6.59	5.4	5.55	3.63	2	2.1	1.14	2.61	11.85	3.4	68.17

A total of 11 program categories have been established, excluding project management. Appendix 1 contains graphs of the proportion of funding by program category and service type. See Appendix 2 for a map that details funding and active clients per region (i.e., south, central, and north).

## **Outreach Teams (3)**

The Partnership funds three regional Outreach Teams based in Prince Albert, Regina, and Saskatoon. These teams coordinate services on a province-wide basis. While at times providing direct client services, the primary functions of the Outreach Teams are to provide multidisciplinary assessment, case management/coordination, and consultation services within their respective portions of the province. These teams assist the clients and their families in navigating the system of services and supports for individuals with ABI. A key impact of these teams is the ability to work with clients over the long term. The overall goal of these programs is successful community integration and improved quality of life.

## **Regional Coordinators (6)**

There are six ABI Regional Coordinator positions within the province located in Humboldt, Moose Jaw, North Battleford, Swift Current, Weyburn, and Yorkton. The goal of the Regional Coordinators is to assist clients to reintegrate into their home

community and bridge the gap in services between acute care/rehabilitation and the community. Like the Outreach Teams, they provide case management/coordination and consultation services in their region to promote the community integration and improved quality of life of the individual with ABI.

## **Independent Living Worker Programs (4)**

There are four Independent Living Worker Programs (ILWPs) operating out of SMILE Services (Estevan), Weyburn Group Homes Society (Weyburn), SIGN (Yorkton), and VON (Moose Jaw). The ILWPs participate in the coordination of services for clients with ABI and provide individualized direct care and support. Services include, but are not limited to, life skills, rehabilitation, recreational activities, and a/vocational support.

## Residential Options (2)

There are two Residential programs dedicated to serving the needs of survivors. Phoenix Residential Society – PEARL Manor is situated in Regina and is mandated to act as a provincial resource, and Prince Albert Residential Services, that serves the northern region. The goal of these programs is to enable individuals with ABI to live more independently in the community with improved quality of life by assisting in the restoration of as much functional ability as possible.

## Rehabilitation Programs (6)

These services include the three regionally placed branches of the Saskatchewan Association for the Rehabilitation of the Brain Injured (SARBI) located in Regina, Saskatoon, and Kelvington. These services also include the Speech and Language Pathologist (SLP) located in Melfort and the two Rehabilitation Assistants who serve the Keewatin Yatthé and Mamawetan Chuchill River Health Regions.

The SARBI programs provide volunteer—delivered services focused on increasing independence through slow-stream rehabilitation. The SLP provides assessments and works to improve communication skills of individuals within the Kelsey Trail Health Region. The two Rehabilitation Assistants' goal is to restore, maintain, and enhance function and quality of life. These positions were created to provide services to the most remote areas of the province.

## **Children's Program (1)**

Radius Community Centre, located in Saskatoon, is the only program within the Partnership that offers programming exclusively for children and adolescents. The goal of the Community Integration Program is to facilitate age-appropriate integration opportunities for children and youth with acquired brain injury in their own community.

## **Vocational Programs (3)**

Partners in Employment, a branch of the Saskatchewan Abilities Council, in Regina and Saskatoon, along with Multiworks in Meadow Lake provide individualized support and

training/rehabilitation to individuals with ABI who are interested in obtaining or maintaining employment. The goal of the vocational programs is to improve the quality of life of survivors by enhancing community integration and increasing functional productivity.

#### **Life Enrichment Programs (3)**

There are three ABI Life Enrichment Programs operating out of the Regina, Saskatoon, and Yorkton branches of the Saskatchewan Abilities Council. These programs promote and facilitate personal and social rehabilitation, through recreation and leisure activities, for those that may or may not be capable of returning to the competitive workforce. Based on client interests, activities are organized individually or for a group. These programs assist clients in developing social skills, as well as exposing clients to new experiences.

## **Crisis Management Services (2)**

Mobile Crisis Services located in Regina and Crisis Intervention Services located in Saskatoon, both provide crisis management services for survivors of ABI. These programs provide case management services when mainstream services have been unsuccessful. They also provide crisis intervention services on a 24-hour availability.

## Day Program (2)

Lloydminster Acquired Brain Injury Society (LABIS) and Sherbrooke Community Centre "Moving On" program (Saskatoon) are the two day programs funded by the Partnership. These programs both offer programming two days a week. The programming includes physical and cognitive exercises and life skills with an overall goal to promote independence and community integration.

#### **Education and Prevention (7)**

This program category includes four Regional Education and Prevention Coordinators (Regina, Saskatoon, Prince Albert and La Ronge), the Saskatchewan Prevention Institute (SPI), Saskatchewan Brain Injury Association (SBIA) and the Provincial Education and Prevention Coordinator.

The Regional Education and Prevention Coordinators assist communities in developing effective injury prevention strategies and work on raising the awareness of the effects of ABI through ongoing education initiatives.

SPI, a provincial program located in Saskatoon, develops user-friendly, accessible resources to professionals and the public to prevent injuries in children.

SBIA is a provincial grassroots organization that receives funding to provide support to survivors and families through support groups, education events and resource development.

## **Update on 1999-2003 Evaluation Recommendations**

A number of recommendations arose from the last evaluation phase. During that evaluation 196 recommendations were made in the site-level reports. From these 196 recommendations, specific recommendations regarding education and prevention, evaluation and reporting, program development, intersectoral coordination and funding were developed. Since the last evaluation work has been completed on many levels to address these recommendations.

## **Evaluation and Reporting**

## <u>Improve monitoring and evaluation functions through the Acquired Brain Injury Information System (ABIIS)</u>

Beginning in late 2004, upgrades to the ABIIS system began. The purpose of these upgrades was to increase the functionality of the system and enable the programs and the provincial office to have more confidence in the accuracy of the data. With the changes, a number of system-generated reports were created to increase the ease with which the programs could report their data. Another change that occurred was the introduction of a report that would track the changes in client's functional status.

An ABIIS User Group was created and met in the fall of 2004. Regular correspondence occurred with the members of the user group during the 18 months of upgrades to the system. Many of the members also assisted with testing the system once it was ready for production. Since the system upgrades, programs have been reporting increased satisfaction with the ease of use and the system utility. Overall, programs seem satisfied with the upgrades made.

## Streamline site-level reporting requirements

During this contract period, the Partnership created a number of reporting templates to make reporting less labour-intensive. Programs are required to submit reports at the end of each quarter. With the changes to the ABIIS, the statistical portion of this report requires much less time to complete. The report can be generated by the system for the quarter and includes all the necessary statistical information. A financial template was also created to ensure the necessary information was returned.

## **Develop and streamline evaluation tools**

Three specific tasks associated with this recommendation were initiated. One of these tasks was to develop a standard tracking tool to measure client goal attainment. A Goal Attainment Template was created and implemented on April 1, 2005. Every program began tracking goal attainment as of this date and reported the results at the end of April 2006. The results are presented later in this report.

The second task was to reconvene the Outcomes Working Group to revisit client outcomes. This group met a number of times over the course of the contract period. It was determined that the current outcomes package being used consists of measures frequently used in the area of ABI and should continue to be used. A number of alternate outcome measures were explored but did not appear to meet the evaluation needs of the Partnership. Following the current evaluation, the Outcomes Working Group will reconvene to review the survey administration protocol.

The third task was to develop an evaluation tool to be used with children and youth. Following a comprehensive literature search, a potential survey was located and the program manager of the sole children's program was put in contact with the author to explore the option of using this measure.

## **Ongoing Program Development**

#### **Family services**

It was recommended that services for families be explored more closely. Services for families can be recorded in the ABIIS, however, this rarely occurs. In addition it was suggested that the family focus group feedback be revisited and a questionnaire should be developed to assess family needs. Family focus groups were included in this evaluation and recommendations have been derived from this feedback. In addition, the Family Needs Questionnaire [2] was distributed to family members/caregivers for this evaluation and the analysis elicited a number of recommendations.

#### **Residential Options**

A Residential Options working group was convened during this contract period to determine issues to address.

An intersectoral working group has been struck to look at drafting a supportive housing strategy. The group began meeting in spring 2005. Group involvement includes Community Resources, Health, Saskatchewan Housing Corporation and membership expansion is planned to include other appropriate provincial and federal departments.

A draft strategy is looking at documenting:

- o service descriptions (what sectors deliver what programs for what populations)
- o existing system capacity (service and housing units to support independent living)
- o local innovations/successful partnerships for possible replication elsewhere in the province
- o service challenges, barriers and gaps
- o support needs of a high need client (what we do and what we do not do in support of this client group)

## **Support Groups**

In the last evaluation, support groups and networks were identified by various service providers as a continued need. As one of the Partnership funded projects, the Saskatchewan Brain Injury Association (SBIA) continues to play a role in support group development. Further, local responses to this need have been met by local service providers, families and survivors on an ad hoc basis. A combination of support group formats have been utilized (e.g., self/mutual-help, professionally-run) depending on the preferences of the individuals involved in their formation.

## **Continue to Foster Intersectoral Coordination and Integration**

#### **General Program Pressures**

Through regular formal (reporting) and informal (verbal feedback) communication with line staff in funded programs, the ABI Provincial Office continues to monitor program pressures. Funded agencies have been provided with the opportunity to bring program pressures forward for consideration and the ABI Provincial Office regularly updates the ABI Advisory Group on program pressures. Where demonstrated and urgent need has arisen, program pressures have been addressed (on an ad hoc basis).

## **Continue to seek other funding partners**

A fee for service contract was established with WCB and the three ABI Outreach Teams in 2004. These contracts are intended to be ongoing and have provided a mechanism for the ABI Outreach Teams to bill for the consultative, educational and case management services that they provide to WCB clients.

#### Continue to seek program partners

It is recognized that the ABI Partnership Project requires strong and positive collaborative partnerships across multiple sectors in order to meet the diverse needs of ABI survivors and their families. For this reason it is necessary to continue to promote ABI Partnership Project services to other sectors. This will clarify the role and mandate of our service umbrella, as well as various other sectors and will achieve a better understanding of how the needs of the ABI population are met.

To this end we continue to build intersectoral partnerships and expand intra-Partnership support and collaboration in order to meet client need.

The Residential Options Working Group has met on an ad hoc basis for need and issue identification.

In 2005 information on ABI services was presented to the Regional Executive Directors responsible for Mental Health and Alcohol and Drug Services. ABI Partnership Project service utilization and trends are included as part of Saskatchewan Health, Community

Care Branch's annual program review. This information is disseminated within the health system to aid in program planning and improvement.

A Long Term Care (LTC) survey was initiated to ascertain the prevalence and needs of ABI residents in this institutional setting. Follow-up will occur with the LTC sector.

First Nations partnerships have been established at the local level through our front-line service providers' shared case management with clients' tribal council and bands. As well, several First Nations communities have partnered with us through the Injury Prevention Community Grant program to deliver injury prevention programming tailored to the specific needs of their communities.

#### **Education and Prevention**

One of the key recommendations arising from the last evaluation was the implementation of the draft Injury Prevention and Control strategy. The work done by the ABI Partnership in the development of the draft strategy is being used as the groundwork for the Safe Saskatchewan strategy. Saskatchewan Health is a founding partner of Safe Saskatchewan and commits \$25,000 annually in funding. The Provincial Education and Prevention Coordinator represents Saskatchewan Health on the Safe Saskatchewan Steering Committee. Safe Saskatchewan is currently finalizing their strategic and operational plan. The Safe Saskatchewan Injury Prevention and Control strategy will complement the National Injury Prevention strategy.

Another recommendation was to continue advocacy efforts in the area of bicycle and ATV helmet legislation. Since 2004, the ABI Partnership Project staff have been working with communities to enact their own municipal bylaws. SGI does not anticipate any legislative changes in 2007.

The final recommendation from the May 2004 evaluation report in regards to education and prevention was to ensure provincial service coordination and reach of activities to remote areas. In response to this recommendation, the ABI Partnership Project has continued to fund four Regional Education and Prevention Coordinators, along with two provincial education and prevention services. In addition, the ABI Partnership Project continues to participate and contribute funds to the Community Grant Program, along with SGI. To date, 1,228 projects have been funded across the province totaling \$1,065,499. The funding from the Community Grants Program has been equally distributed between rural and urban communities. Approximately 10% of the total funding has also been distributed to Aboriginal/First Nations organizations.

## **Summary**

Since the last evaluation work has been completed on many levels to address these recommendations and a number of key activities have been accomplished. In the next contract period, work will continue to address these recommendations along with the recommendations arising out of the current evaluation.

## 2004 – 2006 Evaluation Methodology

Two previous evaluations have been conducted on the ABI Partnership. One examined the implementation of the pilot project (1998), and the second explored client and program outcomes (2004). During the second evaluation, each funded program was required to submit a site-level evaluation report. For the current evaluation it was decided the Provincial ABI Office would complete the evaluation and programs would only be required to participate in specific activities that would contribute to the results.

The current evaluation explores four core areas of the Partnership: clients, families, service providers and education and prevention programs. A number of methods were used during this evaluation in order to evaluate services and programs within each of these four core areas. The Outcomes Working Group and Provincial Advisory Group approved the evaluation plan and questions. For all areas a combination of qualitative and quantitative methods was utilized. See Appendix 3 for evaluation tools and questions.

#### Clients

It was determined that examining client needs and outcomes was important for this evaluation. In order to evaluate client needs a number of instruments were used. These included: Goal Attainment Template, ABIIS service event information, journal articles, representative case studies, and focus groups. To evaluate client outcomes, the following tools and methods were used: Community Integration Measure [3], Problem Checklist [4], Sense of Coherence Questionnaire [5], Mayo Portland Adaptability Inventory [6], Quality of Life Questionnaire [7], Goal Attainment Template, Change in Functional Status Report (ABIIS), and representative case studies. Analysis from each of these methods will be presented in the Results section.

## **Families**

Families and caregivers were not focused on during the last evaluation. Because families and caregivers play an integral role in the rehabilitation of individuals with ABI, it was decided to focus attention on the needs of these individuals during this evaluation. In order to assess the needs of family members/caregivers and the degree to which the Partnership is addressing these needs, the Family Needs Questionnaire [2] was distributed to family members/caregivers throughout the province. To supplement the information obtained through the FNQ, three family focus groups were also conducted.

## **Service Providers**

For the purposes of this section service providers included staff of Partnership programs and community partners who staff of the Partnership frequently work with. A staff survey was distributed early in November 2005 to all front-line staff of the Partnership in order for them to provide their perceptions and feedback on how the Partnership is functioning. Programs also distributed a survey to individuals they identified as

community partners. This survey evaluated satisfaction of community partners with the ABI programs. A survey was also distributed by the Provincial Office to the Personal Injury Representatives of SGI.

#### **Education and Prevention**

It is very difficult to directly attribute reductions in injuries to education and prevention activities. For this section, the programs involved were asked to report on the various initiatives they have been involved in and where outcomes were available to report on them. For example, for the Brain Walk and PARTY programs, changes in knowledge and attitudes are evaluated following the program and this will be presented. Rationales and intended outcomes of other activities will also be presented.

## Results

The results section will be divided into the four core areas examined, along with detailed results from the various tools and methods utilized.

## **Clients**

The consequences of ABI are wide-ranging and can include cognitive [8-17], emotional/psychosocial [13,15,16,18-20] and physical [12, 21] symptoms.

The most common cognitive changes that occur following an ABI are: impaired attention and concentration, memory deficits, slowed information processing, communication impairments, visual-spatial difficulties and impaired executive functions [8,10,14,16,17]. The pattern of impairments are specific to the type, severity, and persistence of the deficits and are extremely individual [14].

Emotional/psychosocial consequences include impairments in interpersonal skills, social comprehension and judgment, emotional self-regulation, as well as a lack of insight into the impact of the deficits [15,19,22]. There are also emotional reactions to the injury and disability, but are not directly related to the damage to the brain [15,22]. Common examples of these emotional reactions include: depression, anxiety, frustration, and decreased self-esteem [15,17,19,22].

Physical changes tend to be the least problematic [23]. These changes can include various motor problems that affect movement and coordination, sensory problems including hearing, taste and smell deficits, and other physical changes such as fatigue, pain, and seizures [12].

The consequences of ABI can lead to unemployment, financial problems, social isolation and a narrow support network [24]. Individuals also often suffer with these difficulties in all areas of their lives permanently [24]. Considering this, Hoofien et al. [24], Baguley et al. [25], and Powell et al. [26] suggest it is essential to provide long term,

multidisciplinary outreach support and community-based programs, which focus on assisting the individual with ABI to re-engage with life as fully as possible.

The ABI Partnership Project funds: three multidisciplinary regional Outreach Teams, six Regional Coordinators, four Independent Living Worker programs, two Residential Options programs, six Rehabilitation programs, one Children's program, three Vocational programs, two Crisis Intervention programs, and two Day programs. These services are funded to provide a continuum of services across the province to meet the needs of individuals with ABI.

Since 1996, the ABI Partnership Project has provided service to over 2,600 individuals with ABI. During the 2004-2006 period a total of 1,225 individuals received service. There were 639 new clients receiving service in this period. Of the total discrete clients, 798 (65%) were male and 427 (35%) were female. The most common cause of injury was related to a motor vehicle collision (all types) at (401 = 31%). A Glasgow Coma Scale (GCS) score was recorded for only 75 individuals during this period. Scores between 3 and 8 indicate a severe injury, scores between 9 and 12 indicate a moderate injury, and scores between 13 and 15 indicate a mild injury. A total of 41 clients had a score indicating a severe injury, 12 clients had a score indicating a moderate injury, and 22 clients had a score indicating a mild injury. Table 2 summarizes the demographic characteristics of the clients.

Table 2: Discrete Client Demographics (April 1, 2004 to March 31, 2006)

Demographic Variable	Total (N = 1225)
Client Gender	
Male	798 (65%)
Female	427 (35%)
Client Age (Years)	
17 and under	106 (9%)
18 to 24	151 (12%)
25 to 29	87 (7%)
30 to 39	170 (14%)
40 to 59	477 (39%)
60 to 79	194 (16%)
80 and over	30 (2%)
Not reported	10 (1%)
Cause of Injury*	
Motor Vehicle (all types)	401 (31%)
Stroke	225 (17%)
Fall	102 (8%)
Tumor	86 (7%)
Assault	85 (7%)
Other (Not TBI)	168 (13%)
Other (TBI)	146 (11%)
Glasgow Coma Scale Score**	
3 to 8	41 (55%)
9 to 12	12 (16%)
13 to 15	22 (29%)
Home Health Region*	
Regina Qu'Appelle	336 (27%)
Saskatoon	292 (24%)
PA Parkland	101 (8%)
Five Hills	91 (7%)
Cypress	55 (5%)
Kelsey Trail	91 (7%)
Sunrise	79 (7%)
Sun Country	76 (6%)
Prairie North	71 (6%)
Mamawetan Churchill River	28 (2%)
Heartland	23 (2%)
Keewatin Yatthé	17 (1%)
Athabasca	8 (0.6%)

Table 2: Discrete Client Demographics (April 1, 2004 to March 31, 2006) Continued

Demographic Variable	Total ( $N = 1225$ )					
Ethnicity						
Ethnicity Non Aborioinal	022 (750)					
Non-Aboriginal	922 (75%)					
Status Indian	211 (17%)					
Unknown	86 (7%)					
Other	6 (1%)					
Employment*						
Unemployable	402 (27%)					
Unemployed	309 (21%)					
Student	207 (14%)					
Retired	123 (8%)					
Full Time	105 (7%)					
Supported	46 (3%)					
Other	290 (20%)					
Education Level*						
Secondary	736 (54%)					
Elementary	296 (22%)					
Post-Secondary	266 (20%)					
Pre-School/Kindergarten	39 (3%)					
None	19 (1%)					
Living Situation*						
Supported in own/family home	630 (45%)					
Independent in own/family home	563 (40%)					
Long Term Care Facility	86 (6%)					
Personal Care Home	51 (3%)					
Group Home	22 (2%)					
Other	57 (4%)					

<sup>\*</sup> Note: Due to coding in the information system, these variables do not total the total discrete client count.

Source: ABI Information System

Program types in the ABI Information System are divided into two categories, Outreach and Funded programs. The category of "outreach" represents the three Outreach Teams and "funded" represents all other programs. Figure 1 provides a summary of the discrete clients registered with an outreach team or funded program only or both an outreach team and funded program. Since the last evaluation, there has been a slight reduction in the number of clients seen solely by the outreach teams and this appears to be a continuing trend. There was also about a 10 to 15% increase in the number of clients seen by a funded program only. This could be a result of differences in admission criteria and priorities. There was also a decrease in the number of clients seen by funded programs and outreach teams together. This could imply that client service delivery may be becoming more sequential in nature rather than concurrent. That is, programs may refer to other programs and no longer remain involved following the referral.

<sup>\*\*</sup> Note: Only 75 clients had GCS scores recorded.

450 409 - 45% 400 367-39% 359-38% 350 316 - 34% 300 □ Discrete Clients 2004-2005 □ Discrete Clients 2005-2006 250 215-23% 94 - 21% 200 150 100 50 O

Outreach Teams & Funded Programs

Figure 1: Clients Seen by Funded Programs and Outreach Teams

April 1, 2004 to March 31, 2006

Source: ABI Information System, Corporate Information Technology Branch (CITB) reports

Outreach Teams

The literature reports a number of service needs for individuals with ABI. Some of the frequently reported needs are: assistance with improving cognition [27-29], vocational assistance [27-29], assistance with improving psychological well being (e.g., managing stress, anger and mood) [27-29], increasing social and recreational opportunities [27-29], increasing independence in instrumental activities of daily living (e.g., homemaking, cooking, and shopping) [27-29], and coordination of services [27-29].

Funded Programs

The continuum of services provided by the ABI Partnership is designed to address many of these identified needs. Client service events are recorded in the ABI Information System. The service type, recipient, and time are all recorded. Client service types are divided into nine categories. They are as follows:

- Case Management This category includes assessment, reassessment, care planning, client reviews, service coordination, and discipline-specific assessment. It also includes crisis management services.
- Therapeutic Activities This category represents services that are provided directly to the client. These direct services are divided further into: behavioural interventions, cognitive interventions and training, educational (school) services, exercise and physical interventions, nursing interventions, including medication management, psycho-social services (including counseling and client support), recreation and leisure activities, and speech language interventions.

- **Administration** This category documents client related administration, such as report preparation and funding applications.
- **Community Development** This category includes networking with community resources, education in the school system, education to the community, advocacy, and organizing and preparing workshops.
- **Consultation** This includes providing information to other service providers, agencies or persons in regards to client care and specific professional expertise.
- Life Skills Training This service category includes training in instrumental
  activities of daily living, homemaking, community living skills, social and
  communication skills.
- **Residential Services** This category includes providing assistance with independent living skills, search for accommodations, home management, respite care, and making housing accessible (financially and physically).
- Client Specific Education This includes educating and training other providers to provide service to a particular client and sharing client information to make service provision possible.
- **Vocational Training** All activities relating to vocational services, including job coaching, return to work programs, work trials, job development, supported employment and vocational counseling are recorded in this category.

A total of 96,905 service events for a total of 98,709 hours of service were provided during the 2004-2006 period. The three outreach teams accounted for 28% of the total service events. Total service events and service time by cause of injury were calculated. Individuals whose cause of injury was as a result of a motor vehicle collision (all types) received 33% of the total service events accounting for 33% of total service time. This service event time is 15% higher than any other individual cause of injury. This could be a result of the constellation of needs of individuals whose injuries are a result of a motor vehicle collision, thus they require more services and service time. Figure 2 summarizes service events and time by cause of injury. Figure 3 provides a summary of the pattern of service events and Figure 4 provides a summary of the different types of Therapeutic Activities provided over the period.

35000 30000 25000 20000 ■Total Service Events ☐Total Service Time (hours) 15000 10000 5000 Fall (102) Bicycle (7) Aneurysm (93) Anoxia (35) Blow to Head (assault) (85) Blow to Head (not assault) (46) Blow to Head (Sports Related) (18) Encephalitis/Meningitis (38) Other (Not TBI) (95) Penetrating (missile wounds) (8) Shaken Baby Syndrome (6) Snowmobile Crash (10) TBI (other) (51) **Cause of Injury (Discrete Clients)** 

Figure 2: Total service events and service time by cause of injury

Source: ABI Information System, Corporate Information Technology Branch (CITB) reports

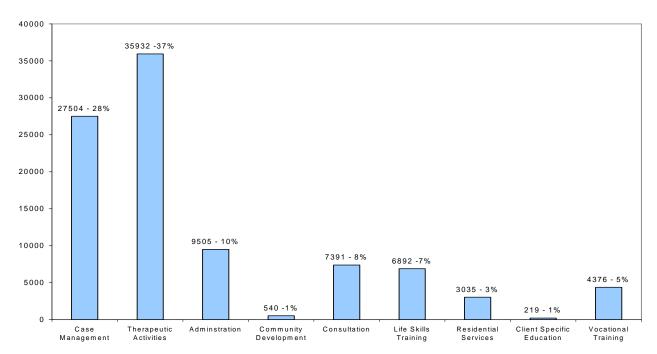


Figure 3: Client Service Events (April 1, 2004 to March 31, 2006)

Source: ABI Information System

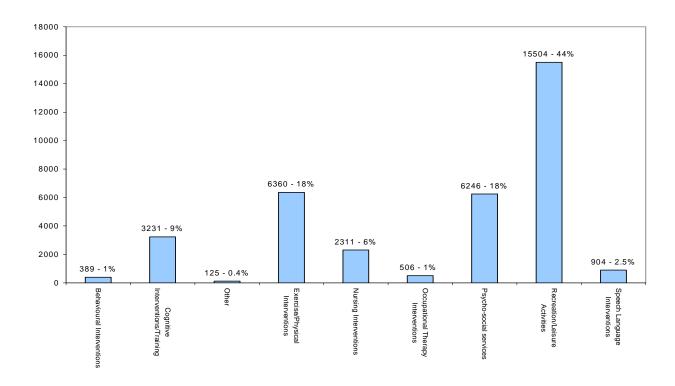


Figure 4: Client Therapeutic Events (April 1, 2004 to March 31, 2006)

Source: ABI Information System

## Client Representative Case Study

The goal of the Client Representative Case Study component was to examine the perceptions that clients, families and services providers involved in the ABI Partnership hold regarding:

- 1) The appropriate matching of services with client needs;
- 2) The linkages and referral patterns between partnering services;
- 3) The effectiveness of the services in addressing the needs of the clients;
- 4) The extent to which the services enabled clients to realize their goals; and
- 5) The improvement in ABI clients' condition as a result of participating in the Partnership services.

Data collection involved personal interviews with:

- ➤ One representative client from each of the three service delivery regions in Saskatchewan (South, Central and North)
- ➤ A family member/members or caregiver for each target client
- ➤ All the relevant ABI service delivery providers involved in the rehabilitation of each target client

The Client Representative Case Study provided feedback on the clients, families and services provider's perceptions. The goal of this process was two-fold. The first part

examined the appropriateness of services provided, the degree of referral effectiveness, and the responsiveness of the services in addressing the needs of the clients and their families. The second part focused on the extent to which the services provided assisted clients in meeting their rehabilitation goals, and whether there was improvement in the clients' condition as a result of participating in the ABI Partnership services.

## Service Appropriateness and Responsiveness

The results indicate that all the key stakeholders for each region believe that the services provided to each representative client, and his/her family, were appropriate, responsive, and demonstrated a high degree of referral effectiveness. When asked how effective/responsive the services were in addressing the needs of the client and their family, the main point one client expressed about the service providers involved with the ABI Partnership Project was that they "want" to help him, in particular they listen to his needs:

"They really listened to me and that is what I like about it...I can call people at ABI and they will help me...they help me get information when I need it...I can talk to them. I stop by and they will talk to me when I need to talk. If I asked about a service they would find it out and get me into it. They were responsible and wanted to help me."

## Meeting Goals

There was a general consensus, among each region's key stakeholders, that the representative clients were able to meet the majority of their goals while being involved in the ABI program, and that the quality of life for the clients and their families was significantly enhanced. Although credit for a client's recovery could not be attributed to one facet of the rehabilitation process, it was stressed that the ABI Partnership was the key underlining factor that improved and enhanced their quality of life. The parents of one client seem to succinctly reflect these sentiments:

"Without this program I don't think he would have half the quality of life that he now has. For the fact that they are more than willing to find any information or any answers to any questions that you could have. If they don't have the answers they would find them. Trust me, our son threw a lot of things their way. I don't think they have ever skipped a beat. I don't think they have ever said to our son it's not achievable. They have always encouraged him. Whether between them and us they have had to maybe guide him in a different direction, which you can do with our son if you do the right way, without him realizing that the direction has been changed. They're always eager to help him. They helped him in a way that encouraged his autonomy; they empowered him. Looked at pros and cons of the situation, always letting him make the decisions so that he has the feeling that 'I did this, it's my decision,' but he also knows where the help comes from to make those decisions. He has a lot of respect for everyone here so it makes it easier for him to ask for help. He feels very comfortable around the team. He will pop in and say hello, which tells me, because we know our boy, that he really likes and respects them. We definitely feel comfortable coming to ask them for

help or ask questions. I can't think of service that we have seen or been through in the last five years that would have given him what he got there."

Although the overall results demonstrated favourable results and outcomes, key stakeholders offered some recommendations for service improvement and enhancement. The more global suggestions offered on how to improve and expand the current services to reach a broader population include:

- Improve communication amongst ABI Partnership Project service providers, and between the ABI Partnership programs and community services.
- ➤ Increase information sharing with minority groups in Saskatchewan (e.g., Aboriginal communities).
- ➤ Broaden the scope of education initiatives.

#### **Client Outcomes**

Evaluation of service delivery and outcomes is particularly problematic as clients reintegrate into the community, due to difficulties with documenting outcome and linking it to interventions of multiple service providers [30]. A number of methods or tools have been implemented by the ABI Partnership Project in attempt to measure and evaluate client outcomes.

## **Outcomes Questionnaire Package**

Since February 2002, an Outcomes Questionnaire Package has been administered to new clients at intake and their 1-year anniversary date in the program or at time of their inactivation. This package includes the Mayo-Portland Adaptability Inventory [6], Problem Checklist [4], Community Integration Measure [3], Sense of Coherence Measure [5], and Quality of Life Measure [7].

To date, a total of 71 complete (intake and anniversary) packages have been returned and used for analysis. Of those that responded, the age at time of injury ranged from 1-98 years (M=38.87; SD=20.83). The gender of respondents was identified as primarily male (59.29%). The most common cause of ABI was a result of a Motor Vehicle Collision (29.6%). Forty-eight percent of respondents had no insurance and 30% were insured under SGI No Fault. Most of the respondents had been registered in at least two programs (62%). And most of the respondents had a Home Health Region of Regina Qu'Appelle (32.4%).

#### Mayo Portland Adaptability Inventory (MPAI)

The MPAI is a measure of long-term (post-acute) outcome following ABI. It provides an indication of challenges in terms of impairments, activity, and participation of the client [6].

The MPAI consists of 6 subscales. A paired sample t-test was conducted on the available data (see data tables in Appendix 4). A lower score indicates the individual has less severe difficulties as a result of an ABI.

A significant improvement in score was not noted on any of the subscales indicating improvement in outcome. This implies that clients were reporting relatively the same level of difficulties at intake and at 1 year.

Improvement was noted in the Physical/Medical and Daily Activities subscales. This improvement was not statistically significant. However, the mean rating went from 3.73 to 3.54 and 4.43 to 3.66, respectively. Overall, it appears that the clients were able to maintain their level of functioning over the time period.

## Problem Checklist (PCL)

The PCL consists of 43 items and 3 subscales. The subscales are: Affective/Behavioural (14-items), Cognitive (9 items), and Physical/Dependency (8 items). Not all of the 43 items are represented in the subscales.

Each subscale has two components, the problem experience and problem severity components. The experience component is a calculation of the yes/no responses to the "Do you experience…" question. If the respondent indicates "yes", they are asked to rate the severity of the problem. This rating is what is used to calculate the severity component on each subscale.

A significant difference was not found on any of the subscales (see data tables in Appendix 4). However, the sample size was relatively small and thus not large enough to find significance.

Mean scores were lower at the one-year anniversary for the Affective/Behavioural severity scale and the Physical severity scales. This could indicate that although the problems are still experienced, the severity of these problems has decreased.

## Community Integration Measure (CIM)

The CIM consists of 10 items. A lower score indicates a client is more integrated into the community [3]. A significant difference was not found on this measure (Appendix 4). However, the mean score for time 1 (intake) was relatively low indicating the clients' perception of being adequately integrated into the community in the early stages of recovery. This measure may not be sensitive enough to measure the change associated with program interventions considering the relatively low scores at time 1.

## Quality of Life (QOL)

The QOL measure consists of 13 items. A lower score implies the perception of a better quality of life [7]. A significant difference was not found on this measure (Appendix 4). As with the CIM, this measure may not be sensitive enough to measure change.

#### Sense of Coherence

The Sense of Coherence questionnaire consists of 29 items. The results are broken down into 3 subscales: Manageability, Meaningfulness, and Comprehensibility. A higher score indicates a stronger sense of coherence, or ability to cope [5].

A significant difference was not found on any of the subscales or the total scale scores that reflect improvement (Appendix 4).

Although a statistically significant difference, indicating improvement, was not found, a number of subscales appeared to have remained relatively the same or showed slight improvements in scores. This would indicate that at the very least the clients involved with the Partnership are able to maintain a relatively good level of function over the year period. Where scores appeared to decrease, implying worse outcomes, this could be as a result of clients becoming more aware of their difficulties over the year and becoming more able to identify these difficulties, implying an increase in awareness. In addition, it is suggested that recovery from ABI may occur several years following the initial trauma [31]. This could indicate that improvement or program impacts may not be measured using the current administration protocol and that the current protocol is inadequate to capture the long-term effects of the ABI Partnership Project.

### **Goal Attainment**

Arising out of the last evaluation was the recommendation to develop a standard tracking tool that could be used to measure goal attainment. Beginning April 1, 2004, all programs were instructed to begin tracking goal attainment and report this information at the end of the fiscal year using the Goal Attainment Template (Appendix 3).

The ABI Partnership provides client-centred services. Goal setting, which involves the client, family and staff member is fundamental to and directs the services provided. At the individual client level, goals are the foundation to identifying and working toward potential outcomes [30]. At a system level, the content of goals may be "seen as a window into service delivery" [30, p.155].

Goal attainment information was collected on 777 clients. A total of 5,690 goals were recorded. Sixty-one percent of total goals were recorded as achieved, 30% were partially achieved, and 9% were recorded as not achieved (see Figure 5). The most common goal area recorded as achieved was in the area of employment (72% achieved). This would indicate that the ABI Partnership Project programs are able to meet this need of the clients. The second most common goal area recorded as achieved was in the area of leisure activities (59% achieved).

The goal areas are divided into five areas: Cognitive, Functional Independence, Psychosocial/Emotional, Community Activities, and Other. Table 3 summarizes the goals achieved, partially achieved, not achieved, and withdrawn within each category.

Figure 5: Client Goal Attainment

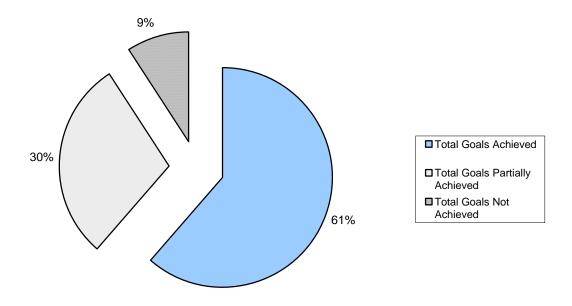


Table 3: Goal Attainment by Category

Goal Area	Achieved	Partially	Not Achieved	Withdrawn	Total
		Achieved			
Cognitive	160	123	18	17	318
Functional	953	480	130	110	1673
Independence					
Psycho-	537	446	84	103	1170
social/Emotional					
Community	1341	384	232	193	2150
Activities					
Other	227	121	14	17	379
Total *	3218 (61%)	1554 (30%)	478 (9%)	440	5690

<sup>\*</sup> Percentage excludes withdrawn column

## **Change in Functional Status**

Also arising out of recommendations made in the last evaluation, was the formulation of a report within the data system to track changes in client functional status. This includes,

education status, living situation and employment status. Beginning in November 2005, programs were asked to ensure they updated client registration records in regards to these three domains. In order to capture the necessary data, the report was run with the date range of April 1, 2004 – March 31, 2006. As can be seen in Table 4, about 7% (n=43) of individuals were reported to have an increase in their level of productivity. Twenty-nine percent (n=187) remained at the same level of productivity, ranging from full time employment to homemaking or attending school. Forty-two percent (n=272) remained unemployed or unemployable.

Table 4: Change in Functional Outcome

Original	Total	Reported Change	
Employment Status			
Unemployable	174	14 (8%) entered some level of productive activity. Ranging	
		from full time employment to homemaking.	
Unemployed	153	18 (12%) became involved in some level of productive	
		activity. Ranging from full time employment to sheltered	
		employment.	
Volunteer Work	5	1 (20%) entered the workforce.	
Supported	29	6 (21%) increased level of independence in employment.	
Employment		Ranging from full time to part time employment.	
Student	84	3 (4%) entered the work force. Ranging from supported	
		employment to full time employment. 77 (92%) remained	
		in school during this reporting period.	
Sheltered	10	1 (10%) increased their level of independence in the area of	
		employment.	

Three percent (n=18) of the clients had a recorded increase in education level. One percent (n=9) increased their education level from elementary school to secondary school. Ninety-four percent (n=614) remained at the same level of education.

In regards to living situation, 77% remained independent or supported in own or family home. Nine percent (n=58) had a reported increase in their level of independence in regard to their living situation.

It must be kept in mind when reviewing these results that this tracking system is relatively new and therefore it will take some time to show the changes in functional status of clients. Overall, there appears to be some positive gains being made by the clients, particularly with employment.

## **Family**

Medical and rehabilitation literature suggests that one of the most difficult tasks that a family can possibly face is attempting to cope with the impact of ABI [11, 32]. In fact, family members are often the other victims, albeit silent and neglected, of ABI [11, 33,34].

The impact on the family can be substantial, in that families often fulfill the vital role of caring for the injured person following the injury [35]. Additionally, over the long-term, the major responsibilities of caring for persons with ABI fall predominantly on informal caregivers such as spouses and parents [36].

The consequences for a family member/caregiver are largely negative [9, 37]. Caring for an individual who has suffered an ABI can result in a variety of difficulties for the family member/caregiver. Family members report an increased number of unfulfilled needs as time since injury increases. These needs also closely correspond to family reports of increased burden and emotional distress. Unfortunately, as time since injury increases, families become less involved with rehabilitation professionals and programs and, therefore, they have fewer options to have these needs met or receive assistance to meet them.

The Vision statement of the Partnership states, "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" [1, p.5]. It was apparent in 1995, when the Strategy was written, that family members/caregivers had service needs that were going unmet.

In the last evaluation phase, the focus was on client outcomes and the area of family needs and satisfaction was not examined. During this phase, it was determined that this area should be focused on. In order to accomplish this, the Family Needs Questionnaire was distributed to family members recruited by the three Outreach Teams. This information was also going to be supplemented by information obtained from three family focus groups. These focus groups took place between February and March 2006 in Regina, Saskatoon, and Prince Albert.

For the purposes of this evaluation a family member/caregiver can include a parent, child, extended family members (e.g., aunt, uncle, etc.), spouse, close friend, lovers, etc. [38]. Basically, the family member/caregiver was self-identified, including the type of relationship.

## Family Needs Questionnaire Results

The purpose of administering this questionnaire was to evaluate and describe the expressed needs of family members of an individual with ABI, and more specifically address the two following objectives:

- (1) To determine the needs of family members/caregivers of survivors of ABI in Saskatchewan.
- (2) To determine to what degree the needs of these people are being met.

Since the development of the FNQ [2], it has been consistently used in the area of family needs and ABI. The FNQ is a 40-item questionnaire designed to assess family members/caregivers' perceived needs following an ABI. The instrument provides information about the extent to which various needs are perceived as important (i.e., not important, slightly important, important, very important). It also provides information on how well these needs have been met (i.e., yes, no, partly).

Items for inclusion were selected based on a review of the literature on family reactions to brain injury and other disabilities [39], as well as from frequently expressed needs during interviews with family members. A factor analysis of the interrelations among the survey items suggested six scales [40]. These are: (1) health information; (2) emotional support; (3) instrumental support; (4) professional support; (5) community services; and (6) involvement with care.

The Outreach Teams distributed a total of 297 questionnaires. A total of 74 questionnaires were returned, for a return rate of 25%. Demographic data was compiled summarizing the respondents and their responses regarding the ABI survivors they care for.

The age of respondents ranged from 21-91 years (M =49.05, SD = 11.13). Most of these family members/caregivers were women (74.5%) and most reside with the individual with an ABI (74.3%). Of the caregivers, 44.6% were parents of an ABI survivor and 36.5% were spouses. Most of the caregivers reside within the Regina Qu'Appelle (29.7%) and the Saskatoon (27.5%) Health Regions. (See Appendix 5 for data tables)

The demographic data of the individuals with ABI was also compiled. The ages of the ABI survivor at the time of injury ranged from 1 to 75 years of age (M = 31.26; SD = 18.74). The range for months since time of injury was quite large, with the most recent injury occurring 5 months prior to the survey completion to a maximum of 364 months (33.3 years) prior to the survey completion. The most common cause of injury was as a result of a motor vehicle/cycle collision (39.2%). (See Appendix 5)

Family members were also asked to identify the services/service providers they had accessed since the survivor had been discharged from the acute or rehabilitation hospital. They were asked to identify services/service providers the survivor and themselves had accessed. Interestingly, 42 of the 74 (57%) family members/caregivers indicated they had not accessed any of the available services. The most common services accessed by family members/caregivers were from the Saskatchewan Central ABI Outreach Team. The most common service accessed by the ABI survivor was the Saskatchewan South ABI Outreach Team. A table summarizing the responses can be found in Appendix 5.

## Analysis of Importance Ratings

Based on the methodology of previous studies (e.g., 41-43), responses to the Family Needs Questionnaire were classified as 'important' if participants responded by circling either "important" or "very important" for an item. Using this classification and similar analysis approach as Armstrong [41], respondents on average rated 29.58 of 40 items as important.

The Health Information scale had the highest mean importance rating (M = 3.73, SD = .37), and the Emotional Support scale had the lowest (M = 3.23, SD = .75). Mean importance ratings for the Instrumental Support, Professional Support, Community Support Network, and Involvement with Care scales were 3.24 (SD = .87), 3.53 (SD = .68), 3.52 (SD = .66), and 3.26 (SD = .75), respectively. These scores are similar to those reported in Murray, Maslany, & Jeffery [44] and Serio et al. [40]. There are slight differences between the mean scores of the current study and the others mentioned. Although, these differences are nominal, they could be accounted for by differences in the sample composition. For example, Murray et al. [44] focused their research on the southern portion of the province, whereas in this study, the focus was provincial.

Mean importance ratings for each of the 40 items were calculated, and values ranged from 2.30 to 3.82. The items were then ranked on the basis of mean importance ratings. Table 4 shows the top needs rated by family members as most important (Range 3.47 to 3.82); 9 items were from the Health Information scale, 2 were from the Involvement with Care scale, 1 was from the Community Support Network scale. In addition 10 of the 12 needs were also rated as important in Murray et al. [44]. These results are consistent with previous research where receiving honest accurate information is ranked as important [41-45]. This demonstrates that despite differences in sample and locations family members/caregivers generally report consistent needs as important.

The needs with the lowest ratings ranged from 2.30 to 2.95 (see table 5). Five of the items were from the Instrumental Support scale. The remaining 5 were from the Health Information, Community Support Network and Emotional Support scales.

Table 5: Family needs with the highest importance ratings

I need	M	Scale
To have my questions answered honestly.	3.82	Health Information
To be assured that the best possible medical care is being given to the patient.	3.78	Health Information
To have complete information on the patient's problems with <a href="mailto:thinking">thinking</a> (e.g., confusion, memory, or communication).	3.74	Health Information
To have complete information on the patient's physical problems (e.g., weakness, headaches, dizziness, problems with vision or walking).	3.73	Health Information
To have explanations from professionals given in terms I can understand.	3.68	Health Information
To be told about all the changes in the patient's medical status.	3.64	Health Information
To have complete information on the medical care of traumatic injuries (e.g., medications, injections, or surgery).	3.62	Health Information
To have a professional to turn to for advice or Network services when the patient needs help.	3.59	Community Support
To be shown that my opinions are used in planning the patient's treatment, rehabilitation, or education.	3.54	Involvement with Care
To have enough <u>resources for the patient</u> (e.g. rehabilitation programs, physical therapy, counseling, job counseling).	3.47	Professional Support
To be shown that medical educational or rehabilitation staff respect the patient's needs or wishes.	3.47	Health Information
To have information on the patient's rehabilitative or educational progress.	3.47	Health Information

## Analysis of met needs

The number of 'important' needs met was also calculated. Similar to Armstrong [41] and Murray et al. [44], the mean percentage of needs rated as 'met' for the sample was 45%. Items were ranked on the basis of the extent to which needs were rated as met. The highest being 62.2% the lowest being 50% (see Table 6). Seven of the ten items rated as met most often were from the Health Information scale. Similar to the importance ratings, many of the items identified as met were similar to Armstrong [41], Kreutzer et al. [42], and Murray et al. [44].

## Analysis of unmet needs

Methods of analyzing met and unmet needs were also adapted from the approach used in previous research [45]. For each participant, only responses endorsed as 'important' or 'very important' were assessed. Needs were then categorized as 'unmet' if the items were endorsed as 'partly met' or 'unmet'. Most of the needs noted as unmet fall within the Emotional Support and Professional Support scales (see Appendix 5). This demonstrated that the expressed needs for understanding, support and reassurance from the social support network, including the community, and resources for information and training on how best to manage difficulties, are not being met.

Table 6: Family needs most frequently rated as 'met'

I need	Endorsement (%)	Scale
To have my questions answered honestly.	62.2	Health Information
To have explanations from professionals given in terms I can understand.	58.1	Health Information
To be shown that my opinions are used in planning patient's treatment, rehabilitation, or education.	ng the 55.4	Involvement with Care
To have complete information on the patient's physical problems (e.g., weakness, headaches, dizziness, problems with vision or walking.	55.4	Health Information
To be told about all the changes in the patient's medical status.	54.1	Health Information
To have information on the patient's rehabilitative ducational progress.	e or 54.1	Health Information
To be assured that the best possible medical care is being given to the patient.	52.7	Health Information
To have a professional to turn to for advice or services when the patient needs help.	52.7	Community Support
To be told why the patient acts different, difficult or strange.	51.4	Not part of scales
To be shown that medical, educational or rehabilitation staff respect the patient's needs or wishes.	50.0	Health Information

Overall, respondents indicated that having honest, accurate information regarding the survivor's physical, medical and cognitive concerns and prospects of improvement are important. Respondents also indicated that almost one-half of the needs indicated as important have gone unmet or only partly met. This would indicate the current service continuum in the province struggles with assisting family members/caregivers with their needs. However, of note, when asked to indicate services accessed 42 of 74 respondents indicated they had not accessed any services. This may indicate that programs need to be more explicit when working with family members/caregivers. In addition, programs may want to consider altering the way in which they work with this group. These results suggest family members/caregivers require support/counseling for themselves throughout the recovery process. For example, many of the items rated as unmet are from the Emotional and Professional Support scales. In order for these needs to be more readily met. ABI Partnership program staff need to make themselves available for the individual family members/caregivers, apart from the individual with the ABI, to allow for open discussion of their concerns. In addition, important items rated as unmet from the Emotional Support scale could be met by providing structured support groups or by having staff members within programs dedicated to family support.

As an initial step, ABI Partnership program staff could assess the family members' needs by using the FNQ or some other method and incorporate this information into their service plans. The FNQ could also be used to evaluate the effectiveness of the services provided to families and/or help provide direction for future service improvement or modifications for family members/caregivers.

## Family Focus Groups

In order to supplement and enhance the information obtained through the FNQ, three regional family focus groups were conducted. The purpose of these was to further explore family needs and satisfaction with the existing services for families and clients. A series of 8 identical questions were presented to focus group participants (Appendix 3).

Twenty-two family members participated in the 3 sessions representing 17 individual families. Participants included: 5 spouses, 15 parents, and 2 siblings. Eight (47%) of the families reside in rural communities of less than 5,000 residents with 9 (93%) residing in communities with a population greater than 5,000 people. Six (35%) have the individual with the ABI residing with them with 11 (65%) living in a different residence.

Responses to the questions can largely be grouped into two categories: 1) ways in which the ABI Partnership Program Services are meeting needs of survivors and family members which are considered strengths of the program and 2) identification of needs not being met by the programs and services or areas in need of improvement.

## **Identified Strengths**

These can be categorized into three key areas: A) Coordination of Services/Access to Services; B) Meaningful Life Activity; and C) Employment and Residential Support.

#### A) Coordination of Services

Families expressed overwhelming appreciation for the outreach teams and other service providers, especially for the role they play in coordination of services. Several of the rural families indicated that being able to receive services close to home made it easier for them to balance their family and work responsibilities. Also indicated as valuable were the referrals for assessments and other resources and assisting with other professionals and service providers.

# B) Meaningful Life Activity

Where employment is not an option, programs that provide life skills training, leisure, and recreational support to survivors were identified as valuable options. These programs not only help the survivor develop new skills and lessen their social isolation, they also provide needed respite for family members.

# C) Employment and Residential Support

Programs that provide these services were highly regarded by family members. Family members indicated that skills training met the needs of the survivor and also relieved the family members of some of the stress and anxiety they are experiencing, as they knew the ABI survivor was involved with a program.

# <u>Identified areas for Improvement</u>

These can be captured by four primary areas: A) More Support/Respite for Families; B) Specialized Resources; C) Access to Resources; and D) Social/Recreational Opportunities/Meaningful Life Activity.

### A) More Support/Respite for Families

Family members indicated that their needs and those of the survivor are being adequately met by the ABI Partnership Project services. However, while services for the survivor provide a great deal of support to the family, they feel there remains a general lack of specialized support for the family itself. This supports the findings of the FNQ. The comment of a spouse of a survivor clearly illustrates this need:

"As a spouse I face huge challenges I am still grieving the loss of the person my husband was prior to his injury. I live now with a totally different individual who is unhappy with his life situation, very impatient and often extremely angry. Our financial situation has changed dramatically as my husband cannot work and his disability benefits certainly do not provide the kind of income he used to earn. I want my children to still have the same opportunities they enjoyed prior to this change in our lives so I am now working outside of the home more than I did before. We have received a great deal of support for my husband's needs and the outreach team has helped me to understand ABI and why my husband behaves the way he does. I still however feel very alone. I feel all the attention is given to the

survivors and not enough to family members whose lives have also been changed. We need help too."

Also of note in this area was family members indicated that the focus group itself was an important opportunity for them to obtain support. This further indicates the need for formal support provided to family members of survivors of ABI.

#### B) Specialized Resources

Many family members expressed concerns with the ability to access Mental Health services for themselves and the ABI survivor. They were also concerned with the ability to access Addiction Services for the ABI survivor. Some had the resources to access private counseling, but this was not an option for others.

Another area of need identified was a structured living environment for the survivor of ABI that included access to appropriate Mental Health and Addiction Services in the community.

#### C) Access to Resources

Access to services in rural areas was an area of concern raised, particularly access to therapy services. In some cases it was felt that the ABI survivor was not receiving adequate physiotherapy and occupational therapy and that neither they nor the ABI survivor could access counseling.

#### D) Social/Recreational Opportunities/Meaningful Life Activity

The lack of a comprehensive program including life skills training, psychological, social, and recreational support and employment support was an area of concern raised by family members.

# What more can be done?

Family members indicated that the provision of information and educational resources was essential in assisting them in understanding the needs to the ABI survivor and the family. The *Tool Kit* [46] and *Survival Guide* [21] were referred to as being excellent resources, however, not all family members were aware of these resources. Suggestions were made to have more information available via Internet and that the information be kept up to date. Information regarding the services of the Saskatchewan Brain Injury Association was also indicated as potentially being useful to all families.

# Family Service Events

A total of 1,200 service events for a total of 800 hours of service were provided to family members during the 2004-2006 period. The most common type of service was Family Case Management, which accounted for 27% of the total family service events. Figure 6 provides a summary of the pattern of service events.

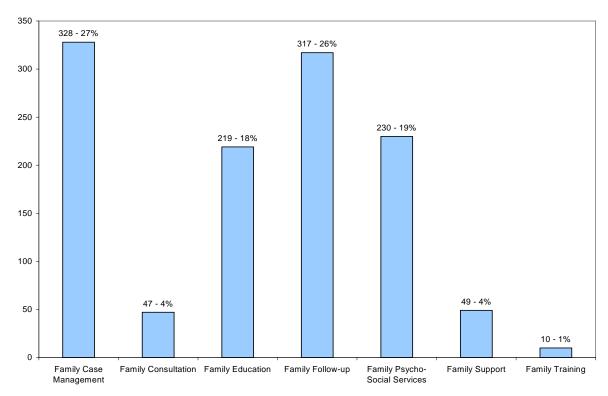


Figure 6: Family Service Events (April 1, 2004 to March 31, 2006)

Source: ABI Information System

From the information provided through the focus groups and Family Needs Questionnaire, it appears that the services being provided to families is an area in need of improvement. Most of the services provided to families are in regards to the individual with ABI and only about 4% of service events are directed to family needs apart from the individual with ABI.

# **Service Providers**

The focus of this section of the evaluation was two-pronged. The first was to report the referral patterns to and from the ABI Partnership Project. The second was to evaluate the working relationship between the Partnership programs and other health and human services, by means of a survey to the Personal Injury Representatives of Saskatchewan Government Insurance and the front-line staff employed with ABI Partnership programs.

# Referral Patterns

A total of 1,738 referrals to the Partnership Programs were recorded during this contract period. Most referrals to the ABI Partnership Project programs predominately come from programs funded under the ABI Partnership (515 = 30%) and acute care and rehabilitation services (497 = 29%).

A core function of the ABI Partnership programs is to augment existing services and provide case coordination. Individual ABI programs within the ABI Partnership Project also make many referrals to other programs. The programs made a total of 4,428 referrals. Most referrals were made primarily with other health and human services (1,165=26%). A number of referrals were also made between programs within the ABI Partnership Project (558=13%). Figure 7 summarizes the referral patterns to the ABI Partnership Project and Figure 8 summarizes the referrals made by ABI Partnership Project programs.

350 296 - 17% 300 266 - 15% 250 231 - 13% 225 - 13% 219 - 13% 200 167 - 10% 150 124 - 7% 102 - 6% 100 67 - 4% 41 - 2% 50 Client Self Referrals Acute Care Services Other Health Care Professionals Outreach Team Other Health Service

Figure 7: Referrals to ABI Partnership Project Programs

Source: ABI Information System

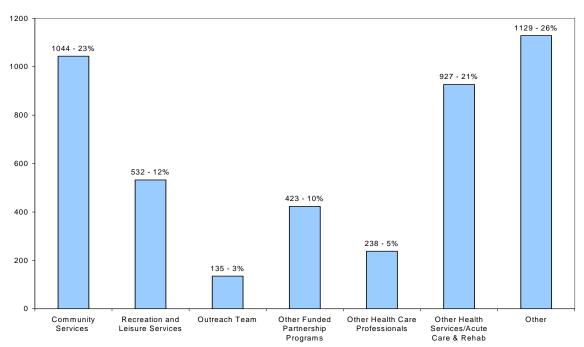


Figure 8: Referrals Made by ABI Partnership Project Programs

Source: ABI Information System

# Service Provider Surveys

A total of 4 different surveys were distributed, as follows: Staff Survey of Partnership programs, Direct client service providers' survey, Education and prevention community partners' survey, and Personal Injury Representatives – Specialists (PIRS) survey (see Appendix 3).

The service delivery philosophy outlined in *Acquired Brain Injury: A Strategy for Services* [1] stated that ABI Partnership services should not duplicate existing services, but augment them. Given this philosophy, the perceptions and opinions of our community partners within these existing services and programs are extremely important.

#### Community Partners Survey

Community partners who work with the client and education and prevention services, including SGI Personal Injury Representatives were surveyed. The purpose was to measure satisfaction with communication, collaboration, and meeting service expectations.

A total of 455 surveys were distributed (320 – direct client services, 125 – education and prevention services, 10 – PIRS). A total of 187 surveys were returned representing a 41% return rate (43% - direct client, 34% - education and prevention, 60% - PIRS).

All surveys used consisted of a 5-point Likert scales. A higher score indicates greater satisfaction. Overall, there appears to be a general level of satisfaction with ABI Partnership programs (mean total rating 4.0/5 = 80%). The mean total scores of the three surveys ranged from 3.12/5 (PIRS) to 4.71/5 (education and prevention). Respondents were also provided with the opportunity to submit comments. One respondent, in regards to a direct client program, indicated that:

"ABI Services are a valuable link for families/clients and the community."

In regards to the education and prevention programs, one respondent indicated:

"I feel that the partnership (with Coordinators/programs) has been vital to our success and promotion of safety in Saskatchewan."

The qualitative information from the PIRS Survey was somewhat difficult to interpret as it was unclear which program was specifically being referred to in some of the comments and if the program is even funded by the Partnership. Based on some of the qualitative comments, it appeared that there has been some discord between the PIRS and some of the programs on particular cases. In addition, there appeared to be some misperceptions on the role, function, and service philosophy of the ABI programs as well as their influence on other services outside the ABI Partnership.

The combined survey results indicate that most programs, which collaborate with ABI Partnership programs, would continue that working relationship, as when asked if they would collaborate again, 87% indicated that they would.

Key areas identified for improvement are communication and reporting by the ABI Partnership programs, particularly to the PIRS. Another area for improvement would be in the area of meeting service expectations. This could be initially addressed by ensuring that service functions are explicitly provided to clients, family members, and other service providers upon initial contact, verbally and in writing. There appears to be some confusion on the part of community partners with regards to the service functions of ABI Partnership programs. It would also be beneficial for ABI Partnership programs to communicate their service functions more frequently to programs outside the ABI Partnership as part of their public relations activities.

Considering some community partners were not able to identify service expectations and roles, and some were not aware of any of the ABI services available (even though an ABI Partnership program identified them as a partner), public relations activities need to be increased if ABI Partnership services are to become more integrated into other health and human services.

### Staff Survey

The Staff Survey consisted of questions eliciting qualitative information in regards to the staff's perceptions of what is working well and what needs improvement, within their individual program and the ABI Partnership as a whole. A total of 72 surveys were distributed and 35 were returned, representing a 49% return rate.

In general, it appears that staff feel that the Partnership programs are functioning well. A number of perceived gaps were reported throughout the responses. Some of these gaps could potentially be addressed by the Partnership, if deemed necessary, whereas, other gaps/difficulties affect many sectors and therefore cannot be addressed by the Partnership alone. Areas that were identified as working well were case management and coordination of services, and education and support of clients, families, and the public. General areas in need of improvement were:

- Assisting high need individuals (e.g., individuals with addictions or other concurrent difficulties);
- More residential and housing options; and
- Better communication between programs.

Overall, respondents seemed to report a general level of satisfaction with the ABI Partnership service continuum and they report that these programs excel in a number of areas. There appears to be a need to work on communication between programs. Areas also reported needing improvement/enhancement are increased vocational services and residential services for higher need individuals.

# **Education and Prevention**

When compared to other Canadian provinces, Saskatchewan has a high unintentional injury rate. The province's injury hospitalization rate is twice the national average, its death rate is 1.4 times higher and its workplace injury rate is one of the highest in Canada [47]. The number of unintentional injuries that occur in Saskatchewan represents approximately 7% of all injuries that occur in Canada, yet its population represents only 3% [47]. Unintentional injuries may well be Saskatchewan's number one health problem. The human cost of pain and suffering is immeasurable. The economic cost is \$1 billion annually [47].

In order to address these concerns, the ABI Partnership Project funds 4 Regional Education and Prevention Coordinators and 2 provincial education and prevention programs (Saskatchewan Brain Injury Association and Saskatchewan Prevention Institute). In addition, the Partnership funds a Provincial Education and Prevention Coordinator.

It is very difficult to directly attribute reductions in injuries to education and prevention activities. For this reason, this section will include reports on various initiatives that have occurred and where outcomes were available they will be reported.

# **Provincial Education and Prevention Coordinator**

In August of 1996 a Provincial ABI Education and Prevention Coordinator position was awarded to the former Moose Jaw Thunder Creek Health District. The original document developed to guide the Acquired Brain Injury (ABI) Project, *Acquired Brain Injury: A Strategy for Services* [1], called for the appointment of an educational, injury prevention and research person for the province. The primary role of this position is to coordinate prevention, education and research activities, related to ABI, with regional health boards, community agencies, survivors and family members throughout Saskatchewan.

Over this contract period, the Provincial Education and Prevention Coordinator has been involved in a number of projects and activities.

#### **Provincial Conference**

*Brain Trust* is the annual provincial conference hosted by the ABI Partnership Project. The goal of the conference is to provide affordable, world-class clinical training to the staff of the funded projects, cross-training opportunities to other human service sectors, and information and education to survivors and their family members.

The topic for *Brain Trust* in 2004 was "Community Partnerships: Developing Collaborative Supports for Individuals with Brain Injury." This conference focused on working with individuals with brain injuries and co-existing disorders including mental health and substance abuse. The keynote speaker for this conference was Dr. Tim Feeney. Dr. Feeney is a world-renowned psychologist. He has authored over 40 scholarly journal articles and book chapters and travels the world over speaking to

audiences about collaborative supports for individuals with brain injury, especially those with complex needs.

In addition to Dr. Feeney, Carole Eaton of Phoenix Residential Society, a funded agency of the Partnership, presented on the psychosocial rehabilitation approach to working with individuals with ABI and mental health issues. This approach is utilized by the PEARL Manor supported apartment program.

For *Brain Trust* in 2005 the topic was "Life Transitions." This conference focused on assisting individuals with brain injury through the transitions in life and school. The keynote speaker was Roberta DePompei. Dr. DePompei is one of the foremost lecturers in the area of brain injury, with a primary interest in the areas of cognitive-communicative disorders with children. In addition to presenting at *Brain Trust*, Dr. DePompei held a special half-day session particularly for teachers.

Other speakers at *Brain Trust* in 2005 included an ABI survivor, Megan Patterson, who spoke of her journey through recovery. Della Ferguson, a social worker, presented on the grief process for families and the ABI survivor following an ABI. Kate McBride, of GF Strong Rehabilitation Centre in British Columbia, presented on sexuality and relationship changes following ABI.

The Brain Trust conference will continue to be organized annually in the next contract period, with equally high-caliber presenters, and with topics that are responsive to the needs identified by the Partnership's services providers.

#### Introduction to Acquired Brain Injury (ABI)

The Provincial Education and Prevention Coordinator, in partnership with various Partnership staff, provide an introductory course on the basics of ABI. The Introduction to Acquired Brain Injury course provides a basic level of knowledge in the following areas:

- Anatomy and function of the brain
- Mechanics of brain injury and indicators of impairment
- Neuropsychological testing
- Stages of recovery
- The brain and behaviour
- Return to work/school
- Addictions and ABI
- Survivor and family perspective
- Cognitive interventions and communication
- · Seizures and medication

The original purpose of this course was to provide introductory information to new staff of the Partnership Project. It now includes individuals from other sectors. This is another example of the cross-training provided by the ABI Partnership Project. To date, 602 participants have attended from across the province. The most recent courses occurred in May 2004 and June 2005. The next course will occur in 2007.

# **Education Days/Support**

The Provincial Education and Prevention Coordinator also organizes smaller education days on specific topics when necessary. During this contract period, Joan McCusker facilitated a session on "Building Successful Teams." This was a one day session for all Partnership programs.

Dr. Feeney also returned to Saskatchewan in September 2005 and met with the ABI Outreach Teams and community organizations for case and system consultation. Dr. Feeney shared his wealth of knowledge and experience with the Partnership on specific challenging cases. Dr. Feeney's two half day sessions were well received by all who attended.

The Provincial Education and Prevention budget supports other educational opportunities. In 2004-2005, grants were provided to Partnership funded agencies for conference registrations to a maximum of \$500. This assisted programs with limited education budgets to attend courses or conferences that would meet their educational needs. In addition, four registrations were sponsored for the ABI Partnership staff to attend the conference "Evaluation and Treatment of Visual Perceptual Dysfunction in Adult Brain Injury: Part 1." This conference was designed for Occupational Therapists, Physiotherapists and Speech Language Therapists.

# Safe Saskatchewan

Safe Saskatchewan is a public/private sector coalition with the objective of achieving a continuous reduction in the number of unintentional injuries in Saskatchewan. The ABI Provincial Education and Prevention coordinator represents Saskatchewan Health on the Safe Saskatchewan steering committee. The Regional Education and Prevention Coordinators and members of the Saskatchewan Prevention Institute also participate with Safe Saskatchewan activities.

A three-step strategy has been instituted by Safe Saskatchewan:

Awareness: Many Saskatchewan people are unaware that they are at a greater

risk of unintentional injury than other Canadians.

Attitude: Many Saskatchewan people believe that unintentional injuries are

random acts of fate. Safe Saskatchewan will endeavour to replace

this thinking with "Injuries are predictable and preventable."

<u>Safe Lifestyle</u>: Many injury prevention programs and services exist in

Saskatchewan. Safe Saskatchewan will offer support to these

initiatives in the form of coordination and resources.

Safe Saskatchewan is led by the Saskatchewan Safety Council. Public and private sector founding partners to date are: IPSCO Inc., Mosaic Potash, Prairie Mines & Royalty Ltd., Saskatchewan Government Insurance, Sask Power, Saskatchewan Health, SaskFerco Products Inc, and WorkSafe Saskatchewan, the workplace injury prevention partnership

between the Saskatchewan Workers' Compensation Board and Saskatchewan Labour. Each founding partner has contributed a minimum of \$25,000 to assist in effecting the Safe Saskatchewan strategy and have committed to subsequent annual contributions over the next three to five years. Endorsements have also been received by many other organizations across a variety of sectors.

#### **Community Grants**

The ABI Partnership Project and Saskatchewan Government Insurance have been involved in a joint program to provide community grants for traffic safety and ABI prevention programs since 1997. The goal of the Community Grants program is to enable community groups to establish, enhance, and deliver programs that address safety issues in their communities.

Since 1997, 1,228 projects have been funded across the province, totaling \$1,065,499. Both SGI and Saskatchewan Health, through the ABI Partnership Project, each provide \$50,000 annually, toward this program. In recent grant cycles SGI has provided an additional \$50,000 toward bicycle helmet and booster seat use.

The funded projects have been categorized using the following fifteen categories:

- Alcohol/Drug/Impaired Driving
- ATV/Motorcycle Safety
- Bike/Skateboard/Inline Skating Safety (including helmet use)
- Child Passenger Restraint
- Falls in Seniors Prevention
- Farm Safety
- First Aid CPR
- General Injury Prevention
- Other Traffic Safety
- Playground Safety
- Shaken Baby Prevention
- Snowmobile Safety
- Sport and Recreation Safety (including helmet use, other than those included above)
- Water Safety
- Workplace Safety

Funding has been distributed throughout the province for various injury prevention projects. The funding from the Community Grants Program also appears to have been equally distributed between Rural and Urban communities. For the purposes of this report, rural is defined as a community with a population of less than 5,000 and urban is a population of greater than 5,000. A total of \$533,510 has been distributed to rural communities and \$531,989 to urban. Table 7 summarizes funding by project category.

Table 7: Community Grant Funding by Project Category

Project Category	Funding
Alcohol/Drug/Impaired Driving	\$187,550.41
ATV/Motorcycle Safety	\$23,217.48
Bike/Skateboard/Inline Skating Safety	\$149,823.74
Child Passenger Restraint	\$135,385
Falls in Seniors	\$34,082
Farm Safety	\$1,025
First Aid - CPR	\$8,923.30
General Injury Prevention	\$208,442.25
Other Traffic Safety	\$140,394.45
Pedestrian Safety	\$17,671.35
Playground Safety	\$7,032
Shaken Baby Prevention	\$2,200
Snowmobile Safety	\$93,273.26
Sport and Recreation Safety	\$24,473.28
Water Safety	\$19,804.5
Workplace Safety	\$3,200
Total	\$1,065,499

The top-five funded project categories account for 78% of total funding. Table 8 summarizes the top five project categories funded and the corresponding percentage of funding received.

Table 8: Top Five Funded Project Categories

Project Category	Funding	Percentage
General Injury Prevention	\$208,442.25	20%
Alcohol/Drug/Impaired Driving	\$187,550.41	18%
Bike/Skateboard/Inline Skating Safety	\$149,823.74	14%
Other Traffic Safety	\$140,394.45	13%
Child Passenger Restraint	\$135,385	13%

# Falls Consortium

Arising out of the document *Fall Injuries Among Saskatchewan Seniors* [48], the Saskatchewan Coalition for Fall Prevention among Older Persons was formed. The Coalition had representatives from across the province. Following this, in September 2002, the Saskatoon Falls Prevention Consortium was formed with growing and varied representatives from many sectors, including the Provincial Education and Prevention Coordinator. This Consortium meets four to six times per year with the vision of "Prevention of injuries related to falls in seniors."

The Consortium received two grants from the Community Grant Program. They received \$4,000 to develop a CD: *Seniors Falls Risk Assessment and Referral Tool*, a tool for health care practitioners for screening and referrals. The second grant was for \$2,500 to cover the cost of a keynote speaker at an upcoming conference to be held in September 2006.

In October 2006 a "Search Conference" will be held with key stakeholders in the area of Falls and Seniors. The conference is a result of a partnership between the ABI Partnership Project and Safe Saskatchewan. The purpose of this search conference will be to develop a Seniors' Falls Injury Prevention Strategy (SFIPS) specific to the needs of Saskatchewan seniors and their families.

# **Regional Education and Prevention Coordinators**

Four Regional Education and Prevention Coordinators are located in Regina, Saskatoon, Prince Albert and La Ronge. The Regional ABI Education & Prevention Coordinators support community-based injury prevention initiatives. The goals of the coordinators include:

- To promote the need for injury prevention and ABI education initiatives in communities.
- To engage communities to become involved in injury prevention.
- To assist communities to plan, implement, and evaluate injury prevention initiatives.

In general, the ABI Education & Prevention Coordinators provide research, education, promotion, community development, and resources to communities on the following topics:

- Acquired Brain Injury
- All-Terrain Vehicle Safety
- Bicycle Safety
- The Brain
- Child Passenger Safety
- Fall Prevention
- Farm Safety
- Helmet Usage
- Home Safety
- Impaired Driving Prevention
- Mild Brain Injury
- Playground Safety
- Snowmobile Safety
- Sports & Recreation Safety
- Traffic Safety (pedestrian, bus)
- Water & Boating Safety

The primary activities of the ABI Education & Prevention Coordinators are to:

- Coordinate and participate in the delivery of the Brain Walk and the PARTY programs;
- Organize and implement injury prevention initiatives;
- Initiate and maintain partnerships with other agencies, community members, other health professionals, and other ABI funded projects;
- Assist communities to develop or maintain injury prevention initiatives; and
- Research, develop, and distribute information and resources about the brain, brain injury, and injury prevention.

# Prevent Alcohol and Risk Related Trauma in Youth (PARTY)

In response to a high annual rate of impaired driving-related crashes in young drivers as well as other high-risk behaviour, the Regional Coordinators obtained and began implementing a new program in the province in the 2004-05 school year to address alcohol and risk-related injuries in youth.

The PARTY Program is a dynamic, interactive injury prevention, health promotion program for teenagers. PARTY was developed in 1986 at Sunnybrook & Women's College Health Sciences Centre in Toronto, Ontario, through a request made by teenagers. Currently fifty-five programs operate nationally, spanning seven provinces and one territory, with expansion into the U.S.

The greatest incidence of death and injury occurs in the 15–24 year age group. PARTY was created to educate teens to the perils of risk-taking behaviour and the tragic consequences that can occur. This program is a vital component in the growing community effort to reduce death and injury from alcohol and risk-related incidents.

Students 14–19 years old experience a full day session that involves following the path of an injury survivor and meeting the professionals that would care for them in a trauma situation. Paramedics, police, nurses and therapists describe the painful journey of a trauma patient. Facts are presented about head and spinal cord injury, and the students have hands-on experience with the equipment used in trauma care and rehabilitation.

The most powerful part of the day is the injury survivor presentation. Young people talk frankly about their injuries, the events that lead to the injury, and what their lives are like now. Students have the opportunity to ask questions of these speakers and learn what life is really like after an injury.

The students, teachers, and volunteers evaluate each session. In addition, a questionnaire is administered to the students, pre- and post- presentation that measures knowledge and attitudes about risk-taking behaviour, past behaviours, and satisfaction with the program. The ABI Provincial Office has conducted an analysis of the completed surveys as of November 2005.

Surveys are distributed at all sessions organized by the Regional Coordinators. The mean scores students received, prior to and following attendance at the PARTY program, were calculated for 133 students. The mean scores on both of these subscales were compared using a paired sample t-test. It is thought that attendance at the PARTY program would increase knowledge and positive attitudes in students. The results of this analysis determined that there was a significant increase in knowledge scores (t = -7.349, SD = 2.06, df = 132, p=.000). It was also determined that there was a significant increase in attitude scores (t = -2.486, SD = 5.55, df = 132, p = .014). The Table 9 summarizes the results.

Table 9: Comparison of mean scores on knowledge and attitude subscales

Subscale	Pre-test Mean	Post-test Mean	SD	t	p <u>&lt;</u> .05
Knowledge	5.09	6.41	2.06	-7.35	.000*
Attitudes	29.23	30.43	5.55	-2.49	.014*

<sup>\*</sup>Significant at p≤.05

It is anticipated that this program will continue to be quite popular within the education system and the Regional Coordinators will be taking a community development approach to service delivery. Health regions currently delivering PARTY programs include: Regina, Saskatoon, PA Parkland, Mamawetan Churchill and Sunrise health regions.

# Brain Walk

Brain Walk is based on the "Body Walk" model that was developed by the Saskatchewan Northern Health Services Branch (Mamawetan Churchill River and Keewatin Yatthé Health Regions). Brain Walk is an interactive walk through of the brain, which helps students learn about the brain's functions and about keeping the brain safe. It is targeted at students from kindergarten to grade 6, but is easily adapted for audiences of all ages.

Brain Walk sends students through 10 different stations highlighting the different areas of the brain and its functions. It also includes stations that demonstrate how to protect the brain, how alcohol and drugs affect the brain, and what it would be like if you hurt your brain. Each station involves demonstrations, activities, displays, and questions. The students travel around the stations in groups of 5 or 6, and have 5 or 6 minutes at each station. Each station is managed by a volunteer facilitator.

The students, teachers, and volunteers evaluate each session. In addition, a questionnaire is administered to the students, pre- and post-presentation that measures change in knowledge.

As part of the feedback form, students were asked to identify two ways to keep the brain safe. A total of 381 options were provided and the results are as follows:

- Wear a helmet = 194 = 51%
- Wear a seatbelt = 91 = 24%
- Don't drink or use drugs = 62 = 16%
- Take care of it = 19 = 5%
- Wear a life jacket = 8 = 2.1%
- Don't drink and drive = 7 = 1.8%

Figure 9 illustrates the change in knowledge scores pre- and post-attendance at Brain Walk by grade level. It appears that the children's level of knowledge regarding the brain increased immediately following attendance at Brain Walk.

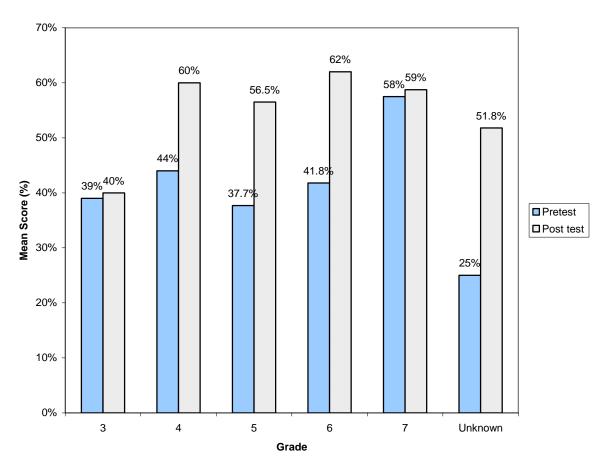


Figure 9: Pre and Post Comparison by grade

#### Safety Resource Kits

Teachers, public health nurses and other community members are regularly seeking out and requesting resources, information, presentations and agency linkages on a variety of injury prevention and safety topics. Many of these requests were of a similar nature in terms of either topic area (e.g., bicycle safety), resource requested (e.g., examples of different helmets), agency information, or presentation requests.

The ABI Education and Prevention Safety Resource Kits provide educators within the province with demonstration equipment and interactive activities to assist in the delivery of injury prevention initiatives. Borrowers within each health region have timely access, at no cost, to a variety of resource kits that include, but are not limited to topics such as: Bicycle Safety, Blade/Board/Scooter Safety, The Brain, Playground Safety, School Bus and Pedestrian Safety, Water and Boating Safety, Winter Sport Safety, Helmet Usage, Home Safety (for children, adults, and seniors), Farm and ATV Safety, General Injury Prevention, Child Passenger Restraint, and Impaired Driving.

The Resource Kits are a collection of established and readily available resources, such as videos, posters, fact sheets, and safety equipment. These kits provide communities with access to resources and alleviate pressure on the ABI Education & Prevention Coordinators to prepare a presentation, travel to a community, and deliver a presentation. This saves time and resources. It also gives the community members ownership of the information and puts responsibility on the community to follow up with the issue.

Each Regional Coordinator has developed one complete set of 15 different safety resource kits. A total of 205 requests have been made for the kits between April 2004 and April 2006 across the province. Comments returned using the feedback forms were very positive. These kits will continue to be a valuable resource to the province.

# **Saskatchewan Prevention Institute**

The Saskatchewan Prevention Institute is a provincial non-profit organization located in Saskatoon that is funded to raise awareness and deliver education about the prevention of acquired brain injury in children.

The focus areas of the child injury prevention program were determined based on the evidence and supporting research on the main causes of acquired brain injury among children as well as what interventions are most effective in reducing these types of injury. Injury prevention interventions include education, legislation, and engineering techniques and the Saskatchewan Prevention Institute strives to implement multifaceted strategies combining these three strategies whenever possible in order to successfully reduce acquired brain injuries among children in Saskatchewan.

Some of the key target areas focused on by the Prevention Institute include:

- Child Passenger Safety, including technician training, car seat clinics, and continuing education.
- Bicycle Safety, including involvement with the Saskatchewan Coalition on Bicycle Safety, conducting helmet usage surveys, and participation in Bicycle Safety Week.
- Million Messages The Million Messages program is the development of a comprehensive plan to standardize messages given to parents about injury by public health nurses and community health nurses.

- Playground Safety, including the development of the Playground Safety Workshop Resource Manual and other resources.
- Home Safety, including presentations and distribution of resource materials and checklists.
- Resource Development the Prevention Institute distributed 88,452 prevention resources during this contract period to date, covering the three broad topic areas of Bicycle Safety, Child Passenger Safety and General Injury Prevention.

#### Child Passenger Safety

When a vehicle is involved in a collision, the occupants keep moving towards the point of impact. If the occupants are not restrained, they will continue to move until they hit a stable object, or are ejected from the vehicle. The occupants need to be restrained in the vehicle in order to decrease the risk of injury or death [49]. A child that is not restrained in a crash at fifty kilometers/hour will sustain the same type of injuries as if they were dropped from a third story window [49]. Children are not able to use the same restraints as adults and must use car seats in order to be protected. Appropriate use of car seats and restraints reduces the likelihood of injury and fatality [49].

Unfortunately, not all seats are properly installed. In 2004, 2,150 car seats were checked in Saskatchewan and 81.4% of seats were not used correctly. Considering this high rate of misuse, the Saskatchewan Prevention Institute and the Regional Education and Prevention Coordinators provide a number of services to the communities of Saskatchewan to address this issue. The expected outcome of Child Passenger Safety activities is an increase in awareness and knowledge of child restraints leading to an increase in the proper usage of them.

The Saskatchewan Prevention Institute organizes Child Passenger Safety Technician training throughout the province. Once trained, the participants are able to return to their communities and provide education to parents and caregivers on how to use their car seats properly. At present, there are 2 Instructor Trainers, 21 Instructors, and 201 Technicians in 65 communities in Saskatchewan. The Child Injury Prevention Program Coordinator is designated as an Instructor Trainer and the South Saskatchewan Education and Prevention Coordinator is an Instructor. There were 12 Technician trainings held in 2005. The participants completed evaluations and rated their satisfaction with the training as 4.4/5 (1 = not satisfied and 5 = very satisfied). The participants were also asked to rate their perceived knowledge of car seats before and after the training on a scale of 1 to 10. Before the training, the average response was 4.5 and after the training it had increased to 8.6.

As part of this training, the Saskatchewan Prevention Institute provides continuing education to everyone certified in Child Passenger Safety by distributing newsletters three times per year and holding a yearly Update course. The newsletters provide any new technical information, refreshers, information on new seats, recalls, and information about the people who have been trained. The yearly Update is held in Saskatoon and

consists of speakers who provide new information, a networking opportunity and has a hands-on component.

Another component of Child Passenger Safety is Car Seat Clinics. Car seat clinics consist of an educator teaching parents/caregivers how to properly install their child's car seat, how to properly restrain their child in the car seat, and what car seat is appropriate for their child. In 2005, there were 2,799 seats checked in 129 clinics and by appointment in 64 communities.

The Saskatchewan Prevention Institute conducted a phone survey in 2004 that determined that this type of education leads to an increased number of parents/caregivers using car seats correctly. The survey measured the perceived usefulness, knowledge change, and changes in behaviours after one year due to attending a car seat clinic in Saskatchewan. The average response of those surveyed regarding the usefulness of the clinic was 4.7/5 (1 = not useful and 5 = very useful). An increase in knowledge of car seats was also reported. Average pre-clinic knowledge was 6.03 and the average response regarding post-clinic knowledge was 8.58. This was a statistically significant change in perceived knowledge.

The participants were also asked if, as result of attending the clinic, they changed how they were installing the seat and/or securing their child in the seat. Sixty- two percent indicated they had changed how they were installing the seat and 42.7% changed how they were securing the child.

Child Passenger Safety continues to be a successful initiative and partnership in terms of satisfaction from participants and continued requests for resources. This initiative will be continued in the future.

#### Bicycle Safety and Helmet Usage

Cycling is an activity that requires skills and behaviours gained through training and practice. The vast majority of cycling-related injuries can be prevented by practicing safe cycling behaviour, following the rules of the road and wearing a bicycle helmet. During the last decade (1994/95 to 2003/04) hospitalizations related to cycling incidents represented 2% of all hospitalized injuries [50]. In addition, 61% of cycling related brain injuries occurred among those between the ages of 5 to 19 years [50].

A number of activities have been undertaken to address this issue since 1991. The expected outcome of these activities is an increase in awareness and knowledge of bicycle safety leading to an increase in the use of helmets and sage cycling behaviour.

The Saskatchewan Prevention Institute has been the lead for the Saskatchewan Coalition on Bicycle Safety agency since 1991 and the Regional Education and Prevention Coordinators are also active members with the Coalition. The goal of the Coalition is safe cycling and the prevention of bicycle-related injuries. They also work in the areas of bicycle safety education and promoting legislation both provincially and municipally.

Another activity of the Coalition, including Partnership programs, is encouraging local groups and communities to promote awareness of bicycle safety during Bicycle Safety Week. A number of agencies are sent information packages, including: RCMP, EMS, Police, health regions, schools, and First Nation communities. Participation varies from distributing information to organizing a community event or activity.

In 2005, 79 agencies participated in Bicycle Safety Week in 58 communities. The planned activities reached an estimated 22,825 children throughout the province. There were 31,615 resources, such as, media guides, bike rodeo guides, helmet observation survey guides, temporary tattoos, activity books, reflective stickers, and colouring page distributed. The participants were surveyed regarding the usefulness of these resources. On a scale of 1 to 5 average ratings ranged from 3.6 to 4.6. The survey also showed that the Coalition was able to increase bicycle safety activities. Of the respondents, 46% of the activities reported were new.

# Saskatchewan Brain Injury Association (SBIA)

SBIA is a provincial organization that works in partnership with other community organizations to create and enhance services and programs for people with ABI and their families. SBIA offers education and support services to ABI survivors and their families.

SBIA provides assistance to the various survivor and/or family Support Groups located throughout the province. Active support groups, that have expressed a desire for SBIA involvement, are currently located in Regina, Saskatoon, Prince Albert, North Battleford, Kelvington, Alida and Kamsack. These Support Groups utilize the self-help/mutual aid model. Other support groups, facilitated by Partnership Program staff, are held at various locations throughout the province. There are also a number of support groups that have been identified throughout the province that are not formally involved with the Partnership, but Partnership clients/families attend.

SBIA also provides three major educational/support events each year. The Survivor and Family Camp is held every spring/summer and provides survivors and their families an opportunity to meet with other people who have shared a similar experience. Based on the 2005 evaluation questionnaire, survivors and family felt the camp helps them deal with the challenges they experience and assists with stress reduction.

In the fall of 2005, SBIA hosted a Personal Development Conference that coincided with the Annual SBIA Walk-a-thon. The Personal Development Conference provides individuals with an opportunity to meet and share with other ABI survivors as well as gain a sense of belonging. From the evaluation questionnaire, it was indicated that the presenter also provided ABI survivors with inspiration and motivation.

The third annual educational event is the Caregiver's Reprieve. This event provides caregivers with the opportunity and strategies to reduce their levels of stress. The comments shared with the organizers were very positive and reflect how important it is for caregivers to take time for themselves.

SBIA also provides telephone support by providing information and referral services. This could be providing basic information on ABI or directing individuals to appropriate services. SBIA maintains a Resource Library that is utilized by survivors, health care professionals and students. SBIA also conducts presentations on brain injury awareness and education.

# **Service Events**

A total of 3,737 Community Group and Education and Prevention activities were recorded in the ABI Information System for the 2004/05 to 2005/06 period for a total of 8,471 hours of service. A total of 60,412 individuals attended the various events. Most of those that attended were children, youth, and students (24,059 = 40%). A variety of services or activities were provided. Table 10 summarizes these activities by event topic.

Table 10: Education, Prevention and Community Activities

Activity/Event Topic	Number of Events
Education on Brain Injury/the Brain	681
General Injury Prevention	622
Support Group/Family Support	552
Education on ABI Partnership	484
Brain Walk	369
PARTY/Impaired Driving Prevention	361
Other Prevention Activities	325
Car Seat/Child Passenger Safety	107
Bicycle Safety/Helmet Use	102
Fall Prevention	94
Mild Brain Injury	40
Total	3,737

Overall, in the area of education and prevention, a number of new initiatives have begun during this contract phase. In the upcoming years the focus will be continued work toward reducing the number of ABIs in the province and to improve the abilities of service providers, community, clients, and their families to better cope with the impacts of ABIs.

# **Conclusions**

In drawing conclusions about the meaning of these results, certain limitations must be addressed. For a number of the surveys, the sample size was limited, as such it may not be representative of the groups being surveyed. Return rates ranged from 34% to 60%. The outcome surveys distributed to clients, also has a limited sample size (n = 71). Due to difficulties with the administration protocol it is difficult to draw many definitive conclusions from these results.

Information from the ABI Information System may not be completely accurate, given inconsistent data reporting practices by front-line staff. With the improvements made to the data system over the past 2 years this data is much more accurate than the data used in previous evaluations of the ABI Partnership Project.

And finally, as the authors of this evaluation are employed to project manage the ABI Partnership Project, this may have biased the interpretation and conclusions drawn from the data. Given these limitations, a number of conclusions can still be drawn regarding each of the four core areas evaluated.

# Clients

The ABI Partnership Project continues to be a valuable service to individuals with ABI and their families. A total of 1,225 individuals received services during this contract period, of those 639 (52%) were new clients.

Over the past contract period there has been a change in the pattern of client registrations. There has been a decrease in the number of clients seen solely by the outreach teams and an increase in the number of clients seen only by a funded program. This could be a result of differences in admission criteria between the programs and priorities. There was also a decrease in the number of clients seen concurrently by funded programs and outreach teams. This could imply that client access to Partnership services may be more sequential in nature. That is, programs may refer to other programs and no longer remain involved with the client following the referral.

Client service event patterns have also changed from the last evaluation. In the 2004 evaluation the most common service event was case management. It is now therapeutic activities, of which 44% of service events are recreation/leisure activities. This reflects an increase in direct service to clients versus case coordination. This is also reflective of the needs of the current population being served. In addition, it supports that programs are working toward the Vision of the ABI Partnership Project, "to improve the quality of life for individuals with acquired brain injuries" [1, p.5].

Total service events and service time by cause of injury were calculated. Individuals whose cause of injury was as a result of a motor vehicle collision (all types) received 33% of the total service events, accounting for 33% of total service time. This is 15%

higher than any other individual cause of injury. This could be a result of the constellation of needs of individuals whose injuries are a result of a motor vehicle collision, thus they require more services and service time.

A number of outcome measures were administered to the clients of the ABI Partnership Project. These include: Mayo Portland Adaptability Inventory, Problem Checklist, Community Integration Measure, Quality of Life, and Sense of Coherence measures. To date, a total of 71 complete (intake and one-year anniversary/inactivation) packages have been returned. A statistically significant difference, that would indicate improvement, was not found. However, a number of subscales appeared to have remained relatively the same or showed slight improvements in scores. This would indicate that at the very least the clients involved with the Partnership are able to maintain a relatively good level of function over a one-year period. The sample size continues to be relatively small and therefore generalizability of the results is limited.

In addition, it is suggested that recovery from ABI may occur several years following the initial trauma [31]. This could indicate that improvement or program impacts may not be seen over the timeframe (i.e., one year after program intake) therefore the current administration protocol and the current array of measures may be inadequate to capture the long-term effects of the ABI Partnership Project.

Many of the current measures are consistently used throughout the research literature to measure outcome and therefore the absence of positive outcomes could be as a result of the current administration protocol. It is apparent that the current administration protocol needs to be reviewed. The time period between the intake and anniversary date is quite short and therefore statistically significant changes may not be observed in this period. In addition, the distribution process may be contributing to the small sample size.

Beginning in this contract period tracking of client goal attainment began. This arose out of recommendations from the 2004 evaluation. Goal attainment can be used to measure client outcome and it is also reflective of the service needs of the clients. A total of 3,218 (61%) goals were recorded as achieved. The most common goal area recorded as achieved was in the area of employment (764 = 72%), indicating that the ABI Partnership Project programs are able to address this service need fairly well. As this is a relatively new tracking tool, there were some inconsistencies with the methodology of reporting this information within and between programs. If continued use of this tool is planned, a review of the protocols would be necessary to ensure accuracy.

Another addition arising from the last evaluation was the development of a tracking system to measure change in client functional status such as employment, education, or living situation. This system was instituted in November 2005 therefore the data was limited. However, it showed that 20% of clients remained at the same level of productivity or had an increase in productivity. It also showed that 97% of clients maintained their educational level or increased it. In addition, 86% of clients maintained their current level of independence with their living situation or increased their independence. With continued use of the tracking system and increased data further gains in functional status could be reported.

Overall, it appears that at the very least clients maintain their level of function during their involvement with Partnership programs. There were also a number of gains in productivity and function reported.

The ABI Partnership Project also appears to be meeting most of the needs of individuals with ABI and is providing services that address the identified needs of individuals with ABI. Specifically, the Partnership programs seem to be responsive to the needs of individuals in the area of service coordination, recreation and social opportunities, and assistance with vocational goals.

### Family

The Vision statement of the Partnership states, "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" [1, p.5]. It was apparent in 1995, when the Strategy was written that family members/caregivers had service needs that were going unmet.

During this evaluation phase, it was determined that family needs and satisfaction should be focused on. In order to accomplish this, the Family Needs Questionnaire was distributed to family members recruited by the three outreach teams. This information was also supplemented by information obtained from three family focus groups.

Overall, family members indicate that having honest, accurate information regarding the ABI survivor's physical, medical and cognitive concerns and prospects of improvement are important. Family members also indicate that almost one-half of the needs they indicated as important have gone unmet or only partly met. This would indicate that the current service continuum in the province struggles with assisting family members/caregivers with their needs. However, of note, when asked to indicate services accessed, 42 of 74 family members indicated they had not accessed any services. This may indicate that programs need to be more explicit when working with family members/caregivers. In addition, programs may want to consider altering the way in which they work with this group.

These results also suggest family members/caregivers require support/counseling for themselves throughout the recovery process. For example, many of the items rated as unmet are from the Emotional and Professional Support scales of the FNQ. It was also stated during the focus groups that there was a general lack of specialized support for the family itself. In order for these needs to be more readily met, staff need to make themselves available for individual family members/caregivers, apart from the individual with the ABI, to allow for open discussion of their concerns. In addition, needs related to emotional support could be met by providing structured support groups or by having some staff time within programs dedicated to family support.

Four suggested areas of improvement to services for families and survivors of ABI arose out of the focus groups. These areas are: More Support/Respite for families; More Access to Specialized services (e.g., Mental Health and Addiction services); More Access to Resources in rural areas; and Social and Recreational Opportunities.

From the information provided through the focus groups and Family Needs Questionnaire, it appears that the services being provided to families is an area in need of improvement. Most of the services provided to families are in regards to the individual with ABI and only about 4% of recorded service events are directed to family needs apart from the individual with ABI.

As an initial step to address some of these issues, program staff could assess the family members' needs by using the Family Needs Questionnaire or some other method and incorporate this information into their service plans. The Family Needs Questionnaire could also be used to evaluate the effectiveness of the services provided to families and/or help provide direction for future service requirements for family members. As well, the development of some form of support services for families would be beneficial.

# Service Providers

The focus of this section was to examine referral patterns and to evaluate the working relationship between ABI Partnership Project programs and other service providers as well as to survey front line staff employed with the programs.

Most referrals to the ABI Partnership Project are from programs funded under the ABI Partnership Project and acute and rehabilitation services. This would suggest that many new Partnership clients come from acute and rehabilitation services and that ABI Partnership Project programs rely on other Partnership programs for some of their referrals. When examining the referral patterns made by the ABI Partnership Project programs, it appears that 87% of referrals made by programs are made to other community services or health and human services, outside the Partnership. This would suggest that the programs are assisting clients with ABI to navigate the system and locate appropriate resources/services.

A number of different surveys were also distributed to community partners and program staff. A total of 455 surveys were distributed to various community partners. There appears to be a general level of satisfaction with the ABI Partnership Project programs. Most community partners indicated a willingness to collaborate with ABI Partnership Project programs and would continue that working relationship, as when asked if they would collaborate again, 87% indicated that they would. Areas indicated for improvement would be communication and reporting by the ABI Partnership Project programs. There is also a need to improve/increase public relation activities, as many community partners could not identify service functions and roles of the various Partnership programs.

From the staff survey, it appears that staff feel that the ABI Partnership Project programs are functioning well. A number of service gaps were reported, as well. Overall, respondents seemed to report a general level of satisfaction with how programs are working and they report that these programs excel in a number of areas. There appears to be a need to also work on communication between programs. Areas also reported as needing improvement/enhancement are increased vocational services and residential services for higher need individuals.

#### **Education and Prevention**

While it is difficult to attribute reductions in injuries to the activities and initiatives provided by the ABI Partnership's education and prevention programs, efforts to provide services in response to injury rates and community needs continued this contract period.

The ABI Partnership Project continues to provide and support high caliber educational events and conferences. These events also provide opportunities for cross training in other human service sectors and assists in building working relationships with these sectors. The Provincial Education and Prevention Coordinator has also continued to build partnerships with many other sectors as well. Examples of these partnerships include Safe Saskatchewan and the Saskatoon Falls Consortium.

The Community Grant Program continues to enhance the injury prevention activities across the province. These grants have provided support to initiatives in all regions of the province. The top five funded projects were in the areas of general injury prevention, alcohol/drug/impaired driving, bike/skateboarding/inline skating safety, child passenger restraint, and other traffic safety.

The four Regional Coordinators continued with community development efforts in the area of injury prevention and education. In response to high traffic and risk related injuries the Regional Coordinators have been assisting communities in organizing the PARTY program. This program continues to be popular and the Coordinators will be looking for other community partners to facilitate this program.

Other areas of focus were on Child Passenger Safety and Bicycle Safety and Helmet Use. The expected outcomes were an increase in awareness and knowledge in both areas. From the surveys conducted it appears that these outcomes were achieved and work will continue in these areas.

The two provincial education and prevention programs continued to provide quality service in the area of child injury prevention (SPI) and education and support to survivors and families (SBIA). These two programs continue to be responsive to the needs of the community and their members.

From the service provider surveys it appears that most programs that collaborate with the Education and Prevention services are generally satisfied with the working relationship, as when asked if they would collaborate again, 98.6% indicated that they would. In addition, it appears community partners feel the Education and Prevention services understand and attend to requests well (98.5%) and the quality of service that they provide was excellent (98.2%).

# Recommendations

# **Clients**

# 1. Form a Complex Needs Client Working Group.

Programs report that they are serving more clients with complex needs. Therefore, it could be beneficial for a working group to develop processes for working with these individuals.

# 2. Review the working relationship of the Partnership with Addictions and Mental Health.

Client access to Mental Health and Addiction services is an ongoing reported concern. Therefore, a review of the working relationship between the ABI Partnership Project programs and Mental Health and Addiction services may be necessary. This may involve a review of roles and mechanisms for working together, where partnerships could be developed to enhance individual areas of expertise.

# 3. Review the outcomes survey administration protocol.

As client outcome data was limited, the administrative protocol for the five outcome measures should be reviewed. Altering the distribution process may increase the return rate. In addition, as the length of time between initial survey completion and re-surveying is only one year, increasing this timeframe may lead to finding statistically significant changes in outcomes.

# 4. Review the Goal Attainment methodology.

A review of the Goal Attainment methodology would be beneficial to ensure consistency within and between programs.

# 5. Site level programs to analyze outcome data for program improvement.

Programs should be responsible for evaluating their individual program effects and should utilize outcome data (e.g., goal attainment, satisfaction, etc.) and critically analyze this information for areas of potential program improvement.

# 6. Individual programs responsible for utilization of appropriate evaluation tools.

Where evaluation tools do not meet the needs of individual programs, these programs should be encouraged to develop or locate tools more suited to their program/client needs.

# 7. Individual programs should develop client orientation materials.

Orientation materials should outline program roles and functions, as well as what the client can expect from services. In addition, it would be beneficial to develop public relations materials that outline roles and service function for community partners and families.

# 8. Implement a recreation and leisure services outcome tool.

Recreation and leisure services account for 16% of total service events. Therefore, it would be beneficial to develop or locate an outcome measure specifically designed for this area.

# 9. Develop a consultation tracking tool in the ABI Information System.

In order to better capture the degree to which programs augment other services, develop a tool to track consultation services within the ABI Information System.

# 10. Review admission criteria.

Admission "criteria" of all programs needs to be reviewed to ensure that no clients are being excluded who should not be.

# Family

# 1. Family needs should be assessed separately.

Family members' needs should be assessed and incorporated into the service plan. Family needs may be different and separate from the needs of the individual with the ABI.

# 2. Family should be seen independently, as necessary.

Family members should be provided the opportunity to meet individually with program staff, apart from the individual with an ABI, to allow family members/caregivers to express their needs freely.

# 3. Involve family members in more educational/psycho-educational and formal support opportunities.

# 4. Programs to examine public relations to families.

Many family members were unable to identify the programs they were involved with by name or at all.

# 5. Develop new family service tracking in the ABI Information System.

In order to better capture the degree to which programs are working with families, it would be beneficial to develop a tool to track family services within the ABI Information System where registration (demographic) information is not required.

# Service Provider

# 1. Make reporting requirements proportionate to funding level.

As some programs have limited staff and administrative support, reporting requirements become more costly and labour intensive for some and impact service provision. Therefore, it would be beneficial to make reporting requirements proportionate with the total funding received and to further streamline reporting and evaluation requirements across the Partnership.

# 2. Increase public relations activities.

An increase in public relations activities, especially to other health and human services sectors, should occur. It should include written information describing detailed program functions, along with what can be expected from the particular ABI service would be beneficial.

# 3. Develop communication plan for shared clients.

Programs should develop a communication/information plan to ensure consistency when working with shared clients.

# 4. Review service gaps.

Review identified service gaps to determine which should be prioritized and develop a plan to address them, if applicable. Also, consideration of alternative service provision methods in the north would be beneficial.

# 5. Develop tool to communicate evaluation and reporting purposes.

The Provincial Office and the Outcomes Working Group need to develop a mechanism to communicate evaluation and reporting purposes and outcomes to front-line staff.

#### **Education and Prevention**

# 1. Develop a future service delivery plan for the PARTY program.

Review and develop a plan for future delivery of the PARTY program to ensure that the program runs smoothly and delivery can be increased. As well, partnering with the new Project Hope staff within the regions would be beneficial.

# 2. Review and update prevention and education materials.

As necessary, review and update materials related to Education and Prevention activities, particularly Brain Walk.

#### 3. Enhance Prevention and Education links to Saskatchewan Health website.

Consider enhancing the Saskatchewan Health web page to include a listing of resources available and links to other injury prevention sites and/or advertise existing sites better.

# 4. Develop a communication plan for upcoming events.

Programs should develop communication/information plan to ensure community partners are aware when activities are taking place in their communities.

# 5. Continue to provide education sessions and conferences.

Continue to provide high quality education sessions in response to the needs to the ABI Partnership Project service providers and community.

# 6. Update provincial child injury report and expand to include lifespan data.

Consider updating the provincial child injury report and expand it to include a life-span perspective, in partnership with other agencies.

7.	Continue to monitor injury rates in order to target injury prevention services.			

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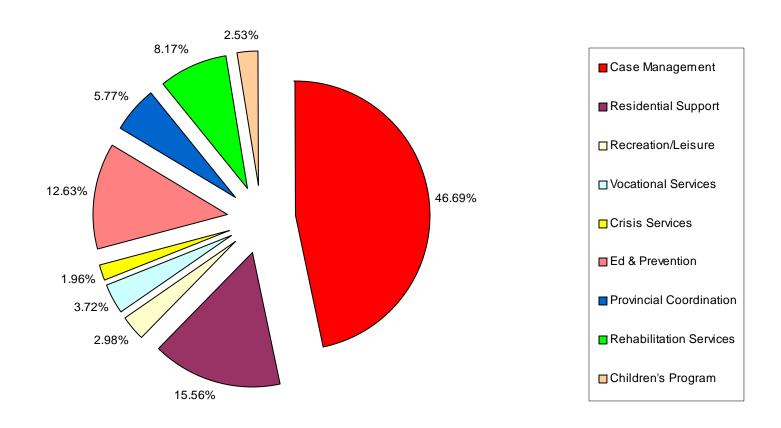
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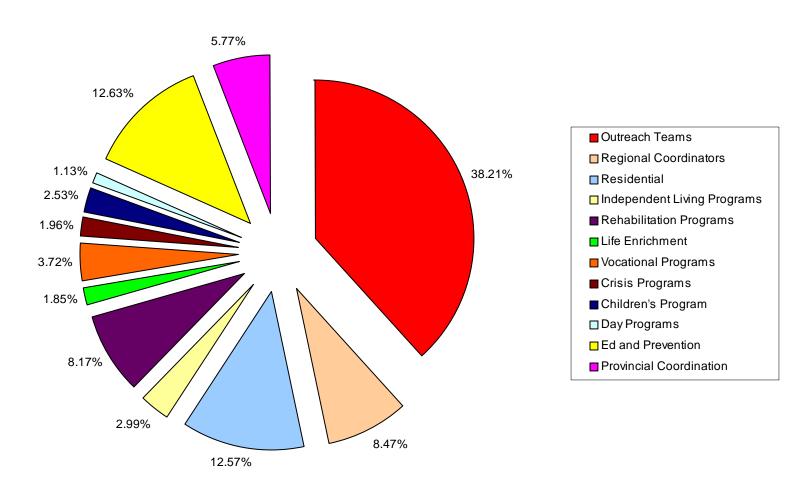
# **APPENDICES**

# APPENDIX 1 – Funding Charts

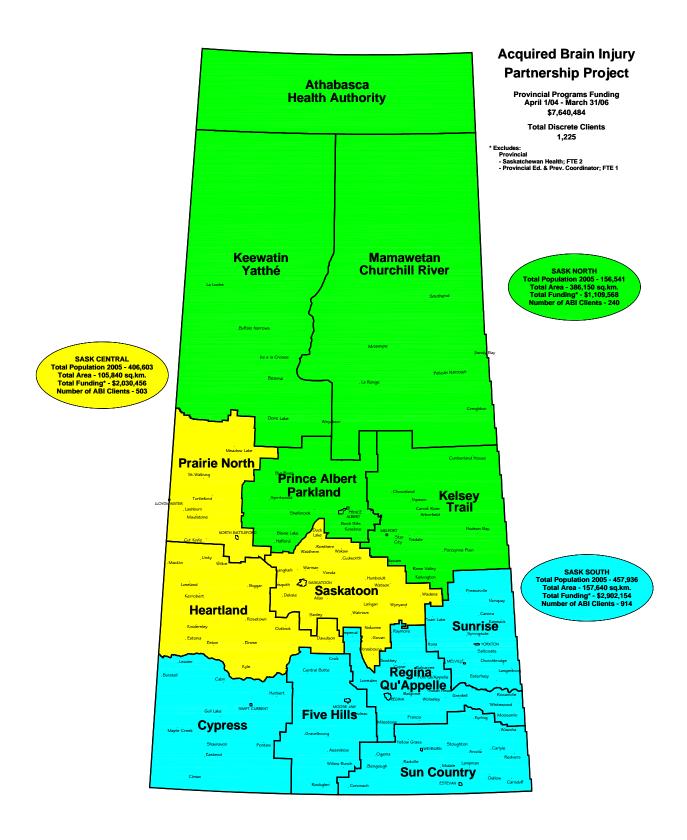
## Percentage of Funding by Service Type 2004-2006 Total Funding by Service type \$7.64 million



## Percentage of Funding by Program Type 2004-2006 Total Funding by Program Type \$7.64 million



## APPENDIX 2 - Service Map



## APPENDIX 3 – Evaluation Tools

## Mayo Portland Adaptability Inventory

Circle the number of one <u>and only one</u> of the statements below each problem area to describe any problems you may have in each area. If you cannot decide which statement best describes your problem, circle the one that comes closest.

#### 1. WALKING AND MOBILITY

- 0 No problem
- 1 A little problem that does not interfere with my activities
- 2 A bigger problem that <u>does</u> interfere with my activities or requires me to use an aid like a cane or wheelchair
- 3 Need someone else to help me move about

#### 2. USE OF ONE OR BOTH HANDS

- 0 No problem
- 1 A little problem that does <u>not</u> interfere with my activities
- 2 A bigger problem that does interfere with my activities
- 3 Cannot use either hand

#### **3. HEARING** (with a hearing aid if I use one)

- 0 No problem
- 1 A little problem that does <u>not</u> interfere with my activities
- 2 A bigger problem that <u>does</u> interfere with my activities
- 3 Am deaf of nearly deaf

#### **4. VISION** (with glasses if I use them)

- 0 No problem
- 1 A little problem that does <u>not</u> interfere with my activities
- 2 A bigger problem that does interfere with my activities
- 3 Am blind or nearly blind

#### 5. SPEECH

- 0 No problem
- 1 A little problem that does not interfere with my activities
- 2 A bigger problem that <u>does</u> interfere with my activities
- 3 Cannot speak or can barely speak

#### **6. PAIN** (headaches, backache, other pain)

- 0 No problem
- 1 A little problem that does <u>not</u> interfere with my activities
- 2 A bigger problem that does interfere with my activities
- 3 Hardly do anything because of my pain

#### 7. COMMUNICATING WITH OTHER PEOPLE

- 0 No problem
- 1 A little problem but <u>usually</u> communicate effectively
- 2 A bigger problem that often interferes with communication or requires use of a communication aid
- 3 Have extreme difficulty communicating with anyone

#### 8. REMEMBERING NEW THINGS

- 0 No problem
- 1 A little problem that does <u>not</u> interfere with my activities
- 2 A bigger problem that <u>does</u> interfere with my activities
- 3 Hardly remember anything new

#### 9. CONCENTRATING

- 0 No problem
- 1 A little problem that does not interfere with my activities
- 2 A bigger problem that does interfere with my activities
- 3 Cannot keep my attention on anything for more than a few seconds

#### 10. SOLVING NEW PROBLEMS

- 0 No problem
- 1 A little problem that does <u>not</u> interfere with my activities
- 2 A bigger problem that does interfere with my activities
- 3 Unable to solve any new problems without help

#### 11. SPATIAL RELATIONSHIPS (like direction finding or putting things together)

- 0 No problem
- 1 A little pr0blem that does <u>not</u> interfere with my activities
- 2 A bigger problem that does interfere with my activities
- 3 Need help with all activities that require spatial relationship skills

#### 12. FUND OF INFORMATION

- O Remember about as much of what I learned in school as most people
- 1 Probably remember a little less of what I learned in school than most
- 2 Remember a lot less of what I learned in school than most
- 3 Hardly remember anything that I learned in school

#### 13. ANGER AND IRRITABILITY

- 0 No problem
- 1 Other people feel I have a problem with this, but I do not agree
- 2 Sometimes I yell or scream at people
- **3** Sometimes I strike or hit people

#### 14. ANXIETY AND TENSION

- 0 No problem
- 1 A little problem that does not interfere with my activities or for which I am receiving treatment
- 2 A bigger problem that <u>does</u> interfere with my activities
- 3 I feel like I should be in the hospital for this

#### 15. DEPRESSION

- 0 No problem
- 1 A little problem that does not interfere with my activities or for which I am receiving treatment
- 2 A bigger problem that does interfere with my activities
- 3 I feel like I should be in the hospital for this

\_\_\_\_\_

#### 16. INDEPENDENT LIVING

- O Live independently and handle my own finances
- 1 Live independently but does <u>not</u> handle my own finances
- 2 Live with help (such as, in a half-way house, supervised apartment, or with an attendant)
- 3 Need full-time supervision or have no regular place to live

#### 17. DRESSING, PERSONAL HYGIENE, FEEDING MYSELF

- 0 No problem
- 1 Sometimes need reminders or a little help to get going on these activities
- 2 Often need help with these activities
- 3 Always need help with these activities

#### 18. WORK OR SCHOOL

- 0 Working, homemaking, or going to school without any special help
- 1 Working, homemaking, or going to school with some restrictions because of my injury but <u>without</u> special help
- 2 Working, homemaking, or going to school <u>with</u> special help such as sheltered or supported work or tutoring
- 3 Not working, homemaking, or going to school

#### 19. LEISURE ACTIVITIES

- 0 Normal participation in leisure activities
- 1 Normal participation in leisure activities, but <u>sometimes</u> need reminders or help to get going in such activities
- 2 Normal participation in leisure activities, but <u>always</u> need reminders or help to get going in such activities
- 3 Little participation in leisure activities

#### 20. DRIVING

- O No problem or choose not to drive
- 1 Sometimes I or other people worry that I am not a safe driver
- 2 Has been in accidents or gotten fines for driving since my accident
- 3 Cannot drive because of my injury or license suspended

#### 21. GETTING ALONG WITH FAMILY AND VERY CLOSE FRIENDS

- 0 No problem
- 1 Little problems
- 2 Big problems
- 3 Has no family or very close friends

#### 22. GETTING ALONG WITH OTHER FRIENDS AND ACQUAINTANCES

- 0 No problem
- 1 Often count on my friends to keep me involved
- 2 Almost always count on my friends to keep me involved
- 3 Have very few friends or acquaintances

#### 23. SOCIAL BEHAVIOR

- 0 No problem
- 1 Sometimes people seem a little offended by my behavior
- 2 Often people are offended by my behavior
- 3 Very serious problems, such as with the law, have occurred because of my behavior

------

#### 24. UNDERSTANDING MY BRAIN INJURY

- O Understand what my disabilities are and how they affect my life
- 1 Understand what my disabilities are, but do not see how they interfere with my life
- 2 Other people see much bigger problems related to my brain injury than I do
- 3 I feel that my brain injury has not changed anything for me

# **25. DELUSIONS AND HALLUCINATIONS** (seeing, hearing, or believing things that other people do not think are real)

- 0 None
- 1 A little problem that does not interfere with my activities or for which I am receiving treatment
- 2 A bigger problem that does interfere with my activities
- 3 I feel like I should be in the hospital for this

#### **26. PARANOIA** (feeling other people are out to get me)

- 0 None
- 1 A little problem that does not interfere with my activities or for which I am receiving treatment
- 2 A bigger problem that does interfere with my activities
- 3 I feel like I should be in the hospital for this

#### 27. INITIATION (getting myself going on activities)

- 0 No problem
- 1 A little problem that does <u>not</u> interfere with my activities
- 2 A bigger problem that does interfere with my activities
- 3 Always need someone else to remind me to get going

#### 28. LAW VIOLATIONS

- 0 None
- 1 Convicted of misdemeanor(s) (*definition* any minor offence carrying lesser punishment then for a felony)
- 2 A felony conviction (*definition* a major crime punishable by death or imprisonment in the penitentiary)
- 3 More than one felony conviction

#### 29. ALCOHOL USE

- O None or occasional use
- 1 Sometimes I or other people feel I should cut down on my drinking
- 2 Interferes with some of my other activities
- 3 Interferes greatly with my other activities or I think I need treatment

#### **30. ILLEGAL DRUG USE**

- 0 None
- 1 Sometimes other people think I have a problem with drugs
- 2 Interferes with some of my activities
- 3 Interferes greatly with my activities or I think I need treatment

## **Community Integration Measure**

For the following statements, please indicate whether you agree or disagree. For the purposes of this questionnaire, "this community" means the place where you're living right now where you can get most of the things you need.

### 1. I feel like part of this community, like I belong here.

1	2	3	4	5
always	sometimes	neutral	sometimes	always
agree	agree		disagree	disagree

### 2. I know my way around this community.

1	2	3	4	5
always	sometimes	neutral	sometimes	always
agree	agree		disagree	disagree

## 3. I feel like I know the rules in this community and I can fit in with them.

1	2	3	4	5
always	sometimes	neutral	sometimes	always
agree	agree		disagree	disagree

## 4. I feel that I am accepted in this community.

1	2	3	4	5
always	sometimes	neutral	sometimes	always
agree	agree		disagree	disagree

## 5. I feel that I can be independent in this community.

1	2	3	4	5
always	sometimes	neutral	sometimes	always
agree	agree		disagree	disagree

#### 6. I like where I'm living now.

1	2	3	4	5
always	sometimes	neutral	sometimes	always
agree	agree		disagree	disagree

7. There are people I feel close to in this community.

12345alwayssometimesneutralsometimesalwaysagreeagreedisagreedisagree

8. I know a number of people in this community well enough to say hello and have them say hello back.

12345alwayssometimesneutralsometimesalwaysagreeagreedisagreedisagree

9. There are things that I can do in this community for fun, in my free time.

1 2 3 4 5 always sometimes neutral sometimes always agree disagree disagree disagree

10. I have something to do in this community during the main part of my day that is useful or productive.

12345alwayssometimesneutralsometimesalwaysagreeagreedisagreedisagree

## **Sense of Coherence**

Here is a series of questions relating to various aspects of our lives. Each question has seven possible answers. Please circle the number that expresses your answer, with numbers 1 and 7 being the extreme answers. If the words under 1 are right for you, circle 1, if the words under 7 are right for you, circle 7. If you feel differently, circle the number which best expresses your feeling. Please give only one answer to each question.

1. When you talk to people, do you have the feeling that they don't understand you?					ou?		
	1 never have this feeling	2	3	4	5	6	7 always have this feeling
2.In	the past, when yo have the feeling t		omething which	ch depended ı	ipon coopera	tion wit	h others, did you
	1 surely wouldn't get done	2	3	4	5	6	7 surely would get done
3.	Think of the peop feel closest. How		-		ily, aside fron	n the on	es to whom you
	1 you feel that they're strangers	2	3	4	5	6	7 you know them very well
4.	Do you have the	feeling that yo	ou don't really	care about w	what goes on a	around y	ou?
	1 very seldom or never	2	3	4	5	6	7 very often
5.	Has it happened i thought you knew	-	t you were sur	prised by the	behavior of	people v	whom you
	1 never happened	2	3	4	5	6	7 always happened
6.	Has it happened t	hat people wh	nom you coun	ted on disapp	ointed you?		
	1 never happened	2	3	4	5	6	7 always happened

7.	Life is:						
	1 full of interest	2	3	4	5	6	7 completely routine
8.	Until now your li	fe has had:					
	1 no clear goals or purpose at all	2	3	4	5	6	7 very clear goals and purpose
9.	Do you have the	feeling that y	ou're being tr	eated unfairly	y?		
	1 very often	2	3	4	5	6	7 very seldom or never
10.	In the past 10 year	rs, your life l	nas been:				
	full of changes without your knowing what will happen next	2	3	4	5	6	7 completely consistent and clear
11.	Most of the thing	s you do in th	ne future will	probably be:			
	1 completely fascinating	2	3	4	5	6	7 deadly boring
12.	Do you have the	feeling that y	ou are in an u	nfamiliar situ	ation and do	n't know	w what to do?
	1 very often	2	3	4	5	6	7 very seldom or never
13.	What best describ	es how you	see life:				
	1 one can always find a solution to painful things in life	2	3	4	5	6	7 there is no solution to painful things in life

14.	When you think a	about you	life, you ver	ry often:			
	1 feel how good it is to be alive	2	3	4	5	6	7 ask yourself why you exist at all
15.	When you face a	difficult p	oroblem, the	choice of a so	lution is:		
	1 always confusing and hard to find	2	3	4	5	6	7 always completely clear
16.	Doing the things	you do ev	ery day is:				
	a source of deep pleasure and satisfaction	2	3	4	5	6	7 a source of pain and boredom
17.	Your life in the fu	uture will	probably be:				
	1 full of changes without your knowing what will happen next	2	3	4	5	6	7 completely consistent and clear
18.	When something	unpleasar	nt happened i	n the past you	ır tendency w	as:	
	1 "to eat yourself up" about it	2	3	4	5	6	7 to say "OK, that's that, I have to live with it" and go on
19.	Do you have very	/ mixed uj	o feelings and	d ideas?			
	1 very often	2	3	4	5	6	7 very seldom or never
20.	When you do son	nething th	at gives you	a good feelin	g:		
	1 it's certain that you'll go on feeling good	2	3	4	5	6	7 it's certain that something will happen to spoil the feeling

21.	Does it happen th	at you have	feelings inside	e you would 1	rather not feel	1?	
	1 very often	2	3	4	5	6	7 very seldom or never
22.	You anticipate that	at your perso	onal life in the	future will b	e:		
	1 totally without meaning or purpose	2	3	4	5	6	7 full of meaning and purpose
23.	Do you think that	there will a	lways be peop	ole whom you	'll be able to	count o	n in the future?
	1 you're certain there will be	2	3	4	5	6	7 you doubt there will be
24.	Does it happen th	at you have	the feeling tha	at you don't k	now exactly	what's	about to happen?
	1 very often	2	3	4	5	6	7 very seldom or never
25.	Many people – ev certain situations.		_			ke sad s	acks (losers) in
	1 never	2	3	4	5	6	7 very often
26.	When something	happened, h	ave you gener	ally found th	at:		
	you over-estimate or under-estimate its importance	2	3	4	5	6	7 you saw things in the right proportion
27.	When you think of have the feeling the		s you are likel	y to face in ir	mportant aspe	ects of y	our life, do you
	1 you will always succeed in overcoming the difficulties	2	3	4	5	6	7 you won't succeed in overcoming the difficulties

28.	How often do yo life?	ou have the	e feeling that t	here's little 1	neaning in th	e things yo	u do in your daily
	1 very often	2	3	4	5	6	7 very seldom or never
29.	How often do ye	ou have fee	elings that you	re not sure	you can keep	under cont	rol?
	1 very often	2	3	4	5	6	7 very seldom or never

## **Quality of Life**

Here is a series of questions relating to your quality of life. Each question has five possible answers. For the following statements, please circle the number that expresses your answer, with numbers 1 and 5 being the extreme answers. Please circle only one answer to each question.

## 1. I know that I will gradually improve.

1	2	3	4	5
always	sometimes	neutral	sometimes	always
agree	agree		disagree	disagree

### 2. I have experts in brain injury who can help me.

1	2	3	4	5
always	sometimes	neutral	sometimes	always
agree	agree		disagree	disagree

## 3. I can get help with my problems.

1	2	3	4	5
always	sometimes	neutral	sometimes	always
agree	agree		disagree	disagree

## 4. I have ways of taking my mind off my problems.

1	2	3	4	5
always	sometimes	neutral	sometimes	always
agree	agree		disagree	disagree

## 5. I can accept what cannot be changed.

1	2	3	4	5
always	sometimes	neutral	sometimes	always
agree	agree		disagree	disagree

## 6. My life is different since my brain injury, but is satisfying in new ways.

1	2	3	4	5
always	sometimes	neutral	sometimes	always
agree	agree		disagree	disagree

7.	I can	keep	my	feelings	under	control.
		CP	,	5		001111 011

	1 always agree	2 sometimes agree	3 neutral	4 sometimes disagree	5 always disagree
8. I	can usually w	ait and not act on	my first impulse	<b>e.</b>	
	1 always agree	2 sometimes agree	3 neutral	4 sometimes disagree	5 always disagree
9. I	can come up	with several soluti	ons to problems	<b>S.</b>	
	1 always agree	2 sometimes agree	3 neutral	4 sometimes disagree	5 always disagree
10.	I know who	en I am tired and n	eed to take a br	eak.	
	1 always agree	2 sometimes agree	3 neutral	4 sometimes disagree	5 always disagree
11. I	have enough	to do most days.			
	1 always agree	2 sometimes agree	3 neutral	4 sometimes disagree	5 always disagree
12.I	have things to	o look forward to e	each day or weel	<b>.</b>	
	1 always agree	2 sometimes agree	3 neutral	4 sometimes disagree	5 always disagree
13. I	am finding e	njoyment in life.			
	1 always agree	2 sometimes agree	3 neutral	4 sometimes disagree	5 always disagree

## **Problem Checklist**

On the left you will find a list of symptoms often encountered by a person after a brain injury. Next to each item, you are asked to indicate whether this is something you experience. If you answer YES, then you will be asked to indicate how much of a problem this presents in your daily functioning. Circle one of the numbers from 1(No Problem) to 7(Severe Problem). The higher the number you circle, the more of a problem it is for you. Please complete all items.

Do you experience			If yes, ho			roblem does this present in your			
	NO	YES	No Problem			Moderat Problem	_		Severe Problem
1. Visual problems; difficulty seeing	N	Y	1	2	3	4	5	6	7
2. Hearing difficulties	N	Y	1	2	3	4	5	6	7
3. Poor balance	N	Y	1	2	3	4	5	6	7
4. Doing things slowly	N	Y	1	2	3	4	5	6	7
5. Difficulty pronouncing words clearly (dysarthria)	N	Y	1	2	3	4	5	6	7
6. Problems with coordination	N	Y	1	2	3	4	5	6	7
7. Fatiguing quickly; getting tired easily	N	Y	1	2	3	4	5	6	7
8. Headaches	N	Y	1	2	3	4	5	6	7
9. Dizziness/vertigo	N	Y	1	2	3	4	5	6	7
10. Sensitivity to noise	N	Y	1	2	3	4	5	6	7
11. Sensitivity to light	N	Y	1	2	3	4	5	6	7
12. Problems with taste or smell	N	Y	1	2	3	4	5	6	7

Do you experience			If yes, ho			oblem do	es this p	present	in your
	NO	YES	No Problem			Moderat Problem	_		Severe Problem
13. Difficulty remembering the right word (workfinding)	N	Y	1	2	3	4	5	6	7
14. Expressing self in a wordy, roundabout way	N	Y	1	2	3	4	5	6	7
15. Being easily distracted (e.g., in a noisy room)	N	Y	1	2	3	4	5	6	7
16. Poor concentration for extended periods of time (e.g., reading in a quiet room)	N	Y	1	2	3	4	5	6	7
17. Being forgetful; difficulty remembering things	N	Y	1	2	3	4	5	6	7
18. Difficulty thinking clearly and efficiently	N	Y	1	2	3	4	5	6	7
19. Difficulty planning and organizing things	N	Y	1	2	3	4	5	6	7
20. Difficulty setting realistic goals	N	Y	1	2	3	4	5	6	7
21. Difficulty following through or finishing things	N	Y	1	2	3	4	5	6	7
22. Apathy, lack of interest in things	N	Y	1	2	3	4	5	6	7
23. Lack of initiative, don't start things up	N	Y	1	2	3	4	5	6	7

Do you experience		If yes, how much of a problem does this present in daily functioning?							in your
	NO	YES	No Problem			Severe Problem			
24. Irritability	N	Y	1	2	3	4	5	6	7
25. Restlessness	N	Y	1	2	3	4	5	6	7
26. Temper outbursts	N	Y	1	2	3	4	5	6	7
27. Mood swings, quick emotional shifts	N	Y	1	2	3	4	5	6	7
28. Difficulty bringing emotions under control once expressed	N	Y	1	2	3	4	5	6	7
29. Getting into arguments with others	N	Y	1	2	3	4	5	6	7
30. Being physically violent	N	Y	1	2	3	4	5	6	7
31. Getting bored easily	N	Y	1	2	3	4	5	6	7
32. Complaining about things	N	Y	1	2	3	4	5	6	7
33. Dependency on others	N	Y	1	2	3	4	5	6	7
34. Needing supervision	N	Y	1	2	3	4	5	6	7

Do you experience			If yes, how much of a problem does this present in your daily functioning?						
	NO	YES	No Problen	1		Moderat Problem	_		Severe Problem
35. Anxiety/tension	N	Y	1	2	3	4	5	6	7
36. Depression	N	Y	1	2	3	4	5	6	7
37. Loneliness	N	Y	1	2	3	4	5	6	7
38. Loss of confidence	N	Y	1	2	3	4	5	6	7
39. Changes in appetite	N	Y	1	2	3	4	5	6	7
40.Sleep disturbance	N	Y	1	2	3	4	5	6	7
41. Low sexual drive	N	Y	1	2	3	4	5	6	7
42. High sexual drive	N	Y	1	2	3	4	5	6	7
43. Changed personality	N	Y	1	2	3	4	5	6	7

## Summary Report of Goal Attainment for:

	<b>2</b> 1		
Program Name:		Date:	

Goal Area	# Achieved	# Partially	# Not	# Withdrawn
		Achieved	Achieved	
Cognitive				
Memory				
Attention/concentration				
Functional Independence				
Transportation				
Handling money				
Nutrition/Meal Prep				
Dressing/Grooming/Hygiene				
Time/Fatigue Management				
Home Management				
Eating Skills				
Physical				
Housing				
Other:				
Psycho-social/Emotional				
Anger Management				
Stress Management				
Behaviour Management				
Pain Management				
Mood Management				
Relationships with others				
Sexuality				
Communication				
Recovery Activities				
Other:				
Community Activities				
Employment				
Education				
Leisure Activities				
Volunteering				
Community				
Involvement/Groups				
Spirituality				
Other:				
Other (Please specify)				
Maintenance				
Understanding ABI				
Total Goals:	l	Total	Clients:	
Total Goals Achieved:				
Total Goals Partially Achieved:				

Total Goals:		Total C	lients:
Total Goals Achieved:			
Total Goals Partially Achieved:			
Total Goals Not Achieved:	_		
Total Goals Withdrawn:			
% Achieved:			
(Total goals achieved/(Total goals-C	Goals withdrawn)	x 100	

# Interview Schedule for Clients of the Acquired Brain Injury (ABI) Partnership Project

- 1. Please tell me about your experience with the ABI program.
  - a. (prompt) Please tell me all the different services you've been involved with through the ABI program.
- 2. When you first started in the program, what goals did you want to work on?
- 3. Have you gained everything you wanted to from the services you've received from the ABI program?
  - a. (prompt) If yes, what kinds of things did you achieve?
    - i. (prompt) How did the services you received from the ABI program help you to achieve these things?
  - b. (prompt) If no, what haven't you achieved?
    - i. (prompt) Did you ask someone from the program to help you achieve these other things?
      - 1. (prompt) If yes, what was their response and how did that response make you feel?
      - 2. (prompt) If no, what stopped you from asking someone for help?
- 4. How do you think the ABI program improved your life?
  - a. (prompt) Please tell me **all the things** the program has helped you with.
  - b. (prompt) What was the **most useful part or parts** of the program?
  - c. (prompt) What made this part or parts more useful than other parts?
  - d. (prompt) What was the **least useful part or parts** of the program?
  - e. (prompt) What made this part or parts less useful than the other parts?
  - f. (prompt) What person or people do you think helped you the **most**? How?
  - g. (prompt) What person or people do you think helped you the **least**? What did they do?
- 5. Are you able to do the things that you want to do?
  - a. (prompt) How do you think the services you received from the ABI program helped you with this?
  - b. (prompt) What more would you like the ABI program to do for you?
- 6. Was it easy for you to access the services through the ABI program?
  - a. (prompt) What made it easy to access the services?
  - b. (prompt) What made it difficult to access the services?

# Interview Schedule for Family members of Clients of the Acquired Brain Injury (ABI) Partnership Project

- 1. Please tell me your perceptions of the ABI.
- 2. What services has your family member received through the ABI program?
- 3. Do you think all the services provided to your family member were helpful?
  - a. (prompt) If yes, how were they helpful?
  - b. (prompt) If no, what wasn't useful about them?
- 4. Do you think the service providers were responsive to your family member's needs??
  - a. (prompt) If yes, please explain how they were responsive?
  - b. (prompt) If no, how would you have changed the way in which they delivered services to suit your family member better?
- 5. What expectations or goals did you have before your family member started receiving services from the ABI program?
- 6. Have these expectations or goals been realized?
  - a. (prompt) If yes, how do you think the services provided by the ABI program have contributed to reaching these expectations or goals?
  - b. (prompt) If no, how do you think the services provided could have been more effective?
    - i. (prompt) Have you spoken to someone in the ABI program about getting more effective services for your family member?
      - 1. (prompt) If yes, what was there response? How did that response make you feel?
      - 2. (prompt) If no, what stopped you from asking for help?
- 7. How do you think the services offered by the ABI program have improved your family member's life?
  - a. (prompt) What is the improvement to your family member's quality of life?
  - b. (prompt) How have the services assisted your family member with reintegration into a home setting? How have services assisted with involvement in the community?
  - c. (prompt) In your opinion, what was the **most useful part or parts** of the program **for your family member**?
  - d. (prompt) What made this part or parts more useful than other parts?
  - e. (prompt) What was the **least useful part or parts** of the program **for your family member**?
  - f. (prompt) What made this part or parts less useful than the other parts?
  - g. (prompt) What person or people do you think **helped your family** member the most?

- h. (prompt) What person or people do you think **helped your family member the least**?
- i. (prompt) What person or people do you think **helped you the most**?
- j. (prompt) What person or people do you think helped you the least?
- 8. In your opinion, do you think the services provided by the ABI program have helped your family member to do the things that he/she wants to do?
  - a. (prompt) If yes, how have the services helped?
  - b. (prompt) If no, what sorts of services do you think your family member needs to do the things they want?
    - i. (prompt) Do you think that the ABI program can help your family member with these goals?
- 9. While your family member has been involved with the ABI program, have there been long periods of time when he/she wasn't accessing services?
  - a. (prompt) If yes, how long was the timebetween services?
    - i. (prompt) Did you attempt to get services (either from the ABI program, from another program, or privately) during these breaks in service? If yes, what other service? If no, what brought you back to (accessing) the original service?

Theme: Partnership/collaboration

How did you think ABI programs worked together? Do you feel programs were communicating the necessary information to reach your family member's goals?

- b. (prompt) W
  - i. (prompt) W

# Interview Schedule for Service Providers of Clients of the Acquired Brain Injury (ABI) Partnership Project

- 1. Please explain, generally, how you assist the clients of the ABI Partnership Project?
- 2. What was the initial prognosis for the client selected for this review? *Probe could get one word answer.* 
  - a. What were the client's presenting problems?
- 3. What were your or other service providers' **initial expectations** of recovery for this client?
- 4. What services had this client received before you met him/her for the first time?
- 5. In your opinion, were the services this client had received up to the time that you first saw him/her appropriate based on **initial expectations**?
  - a. (prompt) If yes, how do you think these previous services prepared this client for your interventions?
  - b. (prompt) If no, in what way or ways was your client not ready for your interventions?
    - i. (prompt) How did you address this readiness?
- 6. In your opinion, how do you think you have assisted in the recovery of this client?
  - a. What were the particulars of the interventions that you implemented?
  - b. How successful were your interventions?
  - c. Upon reflection, do you think everyone's initial expectations of recovery were realistic?
    - i. If no, what do you believe are more realistic expectations?
  - d. Upon reflection, how do you think the interventions (implemented by you or previous service providers) could have been changed to maximize the client's recovery?
- 7. What were the **client's and/or family member's** expectations of recovery?
  - a. How did you incorporate family/client expectations into your service plan?
- 8. If the **clients and/or family member's expectations** were different from the professionals/service providers, did you adjust your interventions to address these differing expectations?
  - a. (prompt) If yes, how did you alter your interventions?
    - i. (prompt) Were your adjustments successful?
      - 1. (prompt) If yes, please explain how?
      - 2. (prompt) If no, why do you think your adjustments were not successful?

- ii. (prompt) In your opinion, do you think the adjustments you made to this client's interventions met this client's and/or family member's expectations?
  - 1. (prompt) If yes, how were the expectations met?
  - 2. (prompt) If no, how did you explain this to the client and/or family member?
    - a. (prompt) What was the response?
- b. (prompt) If you did not adjust your interventions to address client/family expectations, why didn't you? and, How did you explain this to the client and/or family member?
- 9. How have you partnered with other service providers to meet client need/goals?

Who are these partners? probe – both within and outside the Partnership?

- 9. 10. When you completed your interventions with this client was the client referred to another service affiliated with the ABI partnership program?
  - a. (prompt) If yes, which service and why were they referred there?
  - b. (prompt) If no, why were they not referred to another ABI partnership service?

# Acquired Brain Injury Partnership Project Family Focus Group Questionnaire

- 1. How are the ABI Partnership Project services meeting the needs of your family member with a brain injury?
- 2. Please describe any needs that are not being met.
- 3. How do the ABI Partnership Project services affect you as a family member? What services helped you the most?
- 4. What kinds of education and information about brain injury have you been provided through the Project? How helpful has the educational material been? What other educational needs do you have regarding brain injury?
- 5. What kind of support do you receive regarding your family member with brain injury?
- 6. What are the strengths of the ABI Partnership Project? What are the weaknesses of the Project?
- 7. What improvements need to be made with respect to services for people with brain injury? (time permitting)
- 8. Is there anything else you would like to say?

## APPENDIX 4 – Client Results Data Tables

## Analysis of the Mayo Portland Adaptability Inventory

Scale	Mean	SD	t	df	р
MP Physical/Medical 1	3.73	2.86	662	69	.509
MP Physical/Medical 2	3.54	3.06	.663		
MP Cognition 1	5.39	4.07	<i>52</i> 0		.592
MP Cognition 2	5.56	4.19	538	69	
MP Emotion 1	1.96	1.67	240	69	.728
MP Emotion 2	2.01	1.77	349		
MP Daily Activities 1	4.43	4.21	1.815	69	.074
MP Daily Activities 2	3.66	3.89	1.813		
MP Social Behaviour 1	1.17	1.51	956	69	.342
MP Social Behaviour 2	1.37	1.96	930		
MP Behaviour Scale 1	1.44	1.79	-2.511	69	.014*
MP Behaviour Scale 2	1.94	2.24	-2.311		
MP Total Score 1	18.07	10.08	160	69	.873
MP Total Score 2	18.24	13.52	100		

<sup>\*</sup>Significant at p≤.05

## Analysis of the Problem Checklist

Scale	Mean	SD	t	df	р
PCL Aff/Beh exp 1	.41	.28	20	70	767
PCL Aff/Beh exp 2	.42	.30	30	70	.767
PCL Aff/Beh sev 1	1.52	1.27	.99	70	.326
PCL Aff/Beh sev 2	1.40	1.34	.99	70	.520
PCL Cognitive exp 1	.52	.32	-1.93	69	.058
PCL Cognitive exp 2	.58	.34	-1.93	09	.036
PCL Cognitive sev 1	2.09	1.76	95	69	.348
PCL Cognitive sev 2	2.24	1.74	93		.540
PCL Physical exp 1	.45	.29	.002	69	.998
PCL Physical exp 2	.45	.30	.002		.998
PCL Physical sev 1	1.77	1.50	20	60	775
PCL Physical sev 2	1.73	1.43	.29	69	.775

Analysis of the Quality of Life, Community Integration, and Sense of Coherence Measures

Scale	Mean	SD	t	df	p
QOL 1	27.20	8.09	1.06	70	202
QOL 2	28.07	10.49	-1.06	70	.292
CIM 1	17.46	7.06	387	68	.700
CIM 2	17.72	7.18	367	08	.700
OL-Comp 1	47.04	10.79	.353	70	725
OL-Comp 2	46.62	11.58	.333	70	.725
OL – Manage 1	51.14	10.62	2 027	70	021*
OL – Manage 2	48.82	11.47	2.037	70	.021*
OL – Meaning 1	39.75	9.12	2.256	70	0.45*
OL – Meaning 2	37.46	10.44	2.356	70	.045*
OL – Total 1	138.06	27.66	1 927	70	072
OL – Total 2	133.18	30.87	1.827	70	.072

<sup>\*</sup>Significant at p≤.05

# APPENDIX 5 - Family Results Data Tables

Demographics of caregivers/family members (FNQ)

Demographic Variable	Total (N=74)
Mean Caregiver age Years	40.05
Mean	49.05
SD	11.13
Range	21-91
Gender of Caregiver	
Male	19 (25.7%)
Female	55 (74.3%)
Caregiver Income Range	
No answer	8 (10.8%)
Less than \$19,000	17 (23%)
\$20,000 to 29,999	8 (10.8%)
\$30,000 to 49,999	24 (32.4%)
\$50,000 to 69,999	7 (9.5%)
More than \$70,000	10 (13.5%)
Caregiver Highest Level of Education	
No answer	4 (5.4%)
Elementary	1 (1.4%)
High School	31 (41.9%)
Some University	15 (20.3%)
University	11 (14.9%)
Graduate Degree	12 (16.2%)
Lives with Person with ABI	
No answer	2 (2.7%)
Yes	55 (74.3%)
No	17 (23%)
Relationship to Survivor	
Parent	33 (44.6%)
Spouse	27 (36.5%)
Child	8 (10.8%)
Other relative	6 (8.1%)
Place of Residence	
Rural (pop. less than 5,000)	35 (47.3%)
Urban (pop. greater than 5,000)	39 (52.7%)
Orban (pop. greater than 3,000)	37 (32.170)
Home Health Region	22 (20 70)
Regina Qu'Appelle	22 (29.7%)
Saskatoon	19 (25.7%)
Prairie North	7 (9.5%)
Kelsey Trail	6 (8.1%)
Other	20 (27%)

Demographics of ABI survivor (FNQ)

Demographic Variable	Total (N=74)	
Age at time of Injury (years)		
Mean	31.26	
SD	18.74	
Range	1 – 75	
Time since injury (months)		
Mean	55.41 (4.6 years)	
SD	55.38	
Range	5 – 364 (30.33 years)	
Cause of Injury		
MVC/MCC	29 (39.2%)	
Fall	12 (16.2%)	
Stroke	9 (12.2%)	
Aneurysm	6 (8.1%)	
Tumor	6 (8.1%)	
Other	12 (16.2%)	

## Services/Service Providers accessed (FNQ)

	Caregiver	Survivor	
No Service	42	4	
ABI Outreach South	8	27	
ABI Outreach Central	10	19	
ABI Outreach North	6	11	
ABI Coordinator	3	6	
SBIA	7	18	
Sask. Abilities Council	1	21	
Partners in Employment	0	11	
Other Funded Program	5	33	
Private Psychology/Therapy	3	10	
Other (non-funded program)	6	20	

## Family needs most frequently rated as 'unmet' or 'partly met' (FNQ)

I need	Endorsement (%	Scale
To have patient's friends understand. his/her problems.	70.3	Community Support
To have enough resources for the patient (rehabilitation programs, physical therapy, counseling, job counseling).	64.9	Professional Support
Help getting over my doubts and fears about the future.	63.5	Emotional Support
To get a break from my problems and responsibilities.	63.5	Instrumental Support
To have enough resources for myself or the family (e.g., financial or legal counseling, respite care, counseling, nursing or day care).	62.2	Professional Support
To discuss my feelings about the patient with someone who has gone through the same experience.	58.1	Emotional Support
To pay attention to my own needs, job, or interests.	56.8	Not part of scales
To told how long each of the patient's problems is expected to last.	55.4	Professional Support
Help remaining hopeful about the patient's future.	54.1	Emotional Support
Help preparing for the worst.	54.1	Emotional Support
To be told if I am making the best possible decisions about the patient.	54.1	Not part of scales