



Saskatchewan
Health



ACQUIRED BRAIN INJURY A STRATEGY FOR SERVICES

PROGRAM EVALUATION REPORT

December, 1998

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This report is the product of the contributions of a large number of people. We wish to thank clients, family members, service providers and key informants for their willingness to participate in the evaluation of the ABI Pilot Project. We also wish to acknowledge the contribution of Cathy Ellis who was contracted to undertake the qualitative portion of the evaluation. Her report appears in Section 3 of this evaluation. A special thank you is extended to the short-term evaluation working group for their suggestions and input.

The evaluation of the ABI Pilot Project was a complex undertaking due to the comprehensive nature and broad scope of the strategy for services. We believe the report provides useful information for determining the future directions and priorities for service delivery.

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A INTRODUCTION AND BACKGROUND TO THE ACQUIRED BRAIN INJURY PILOT PROJECT

Saskatchewan Health and Saskatchewan Government Insurance (SGI) have established a partnership to create a coordinated and integrated continuum of community-based services for individuals who have an acquired brain injury and their families.

A variety of forums, surveys and reports compiled since 1992 identified a critical need for post-acute, community-based services for persons with an acquired brain injury. While some services did exist at the time, little coordination or integration of these services was evident. Rehabilitation ceased, in many cases, when the individual left the hospital setting. Survivors of acquired brain injury, their families and professionals alike were in need of education and support.

In 1995, SGI introduced the Personal Injury Protection Plan (PIPP), which substantially increased the benefits available for rehabilitation services. Saskatchewan Health is a member of the SGI Rehabilitation Advisory Board that was created to assist with PIPP implementation. This Board recommended that SGI invest in the enhancement of ABI services to support the new Personal Injury Protection Plan.

In response to this recommendation, Saskatchewan Health and SGI co-chaired a multidisciplinary provincial working group from January to August in 1995 to develop a strategy for a three year Pilot Project. The working group was comprised of a variety of health professionals, representatives from both rural and urban health, survivors of ABI, family members, a representative from Saskatchewan Education, Training and Employment and representatives of community based organizations. These deliberations resulted in the development of a blueprint for a Pilot Project called "*Acquired Brain Injury - A Strategy for Services.*"

The Pilot Project has been funded by SGI with a commitment of \$9.3 million over three years, while Saskatchewan Health has provided management and coordination of the project. An Advisory Group has been in place to provide ongoing consultation.

The Pilot Project officially began in January of 1996. Since that time, three inter-disciplinary outreach teams and twenty-seven community-based programs have been funded to enhance services to better meet the needs of clients with an acquired brain injury and their families. Four of the programs focus primarily on injury prevention. The Pilot also strives to enable clients to receive rehabilitation, housing and vocational services as close to their home communities as possible. New and innovative partnerships between service providers have been developed and prevention and education activities have also been supported. To date, over 600 individuals have received assistance from the Pilot Project.

The outreach teams are located in Prince Albert, Saskatoon, and Regina. The overall goal of these teams is to work in partnership with each client, in conjunction with the family and community, to promote and achieve successful community (re)integration. They do this by:

- Providing coordination and program support to communities planning for the return of an individual with ABI;

- Providing training to local community care givers;
- Providing rehabilitation planning and treatment support;
- Promoting integration of individuals with ABI into their home communities;
- Providing individual case coordination services;
- Linking with discharge planners in the acute care setting; and
- Serving as a resource for community service providers (including formal and informal) by maintaining contact and being accessible to respond to issues as they arise.

The staffing composition of each team varies according to the need in each particular region. Combinations of health care professionals, such as speech language pathologists, recreation therapists, social workers, occupational therapists, physical therapists, neuropsychologists, rehabilitation assistants, behaviour therapists, vocational counsellors, and psychometricians are often part of the team organization.

The twenty-seven community-based funded programs provide services in the areas of residential services, vocational services, day programming, care coordination, crisis management, physical therapy, educational services, children's programming and injury prevention. A more comprehensive listing of each program and the services provided is available by contacting the Provincial ABI Coordinator.

Prevention and education are important components of the strategy because acquired brain injuries are largely preventable. Within the Pilot Project, education is aimed at changing risk behaviours, raising awareness of ABI and imparting specific knowledge and skills to those with ABI, their families, and care givers. Education and prevention activities are offered through the outreach teams, funded projects and Northern Prevention & Education Coordinator. A full-time Provincial Education and Prevention Coordinator provides program support and consultation to these initiatives.

A Community Grants Program was introduced in 1997 by SGI and the ABI Pilot Project to enable community groups to establish, enhance or deliver programs that address issues in their community related to traffic safety and/or injury prevention. Grants as large as \$10,000 and as small as \$53 have been awarded as part of this program. In total, 103 projects received \$110,116.50 during the initial year of the program.

B DESCRIPTION OF THE EVALUATION

The program evaluation process began in December 1996 with a Program Evaluation Focus Day that brought together stakeholders from around the province to discuss what the evaluation should encompass.

Using the outcomes of the Evaluation Focus Day as a guide, and in consultation with evaluation experts within Saskatchewan Health, the Program Coordinator and the Evaluation Assistant identified the goals of the evaluation as being:

- To monitor the progress of program implementation;
- To assist in enhancing the ABI program as it develops; and,
- To meet the requirements of the funding agents.

In order to accomplish this, the evaluation focussed on service delivery with respect to integration and coordination of services, types and levels of services available, client access to these services and client/family satisfaction with the services. A work plan was then developed utilizing the program logic evaluation model. Four evaluation questions were identified:

1. Is there improved integration/coordination between services?
2. Has there been an increase in the types and levels of service provided?
3. Has the awareness of the community increased for persons with ABI and the supports available to them?
4. Has the awareness of the community increased toward prevention of ABI?

The workplan is included in Appendix A. This plan was reviewed and accepted by the Provincial Advisory Committee.

The evaluation process was then broken into two parts – a qualitative information piece and a quantitative data portion. The evaluation focuses on the ABI Pilot Project as a whole and is not an evaluation of each individual program. Given the time constraints, it was not feasible to measure client outcomes however, a working group has been established to develop a clinical outcomes measurement tool.

B.1 QUALITATIVE COMPONENT

A Working Group was created to assist in designing a process for the qualitative evaluation. Efforts were made to gain input from as many stakeholders as possible within the province through the use of focus groups, interviews with clients and families, a family satisfaction survey and a provincial consultation day.

An external evaluator was hired to carry out the focus groups and interviews and to assist with the analysis of a Family Satisfaction Survey. The Family Survey was adopted from the Family Support Services program at Bloorview MacMillan Centre in Toronto, Ontario and results were reviewed and analyzed using the statistical analysis program SAS.

The Working Group also assisted the Pilot Project administrative staff and the contract Evaluator to draft questions for the focus groups and interviews, and reviewed the emerging themes as presented by the Evaluator.

A Provincial Consultation Day was held in May, 1998 to identify areas for improvement within the Pilot and make suggestions for the future. Participants included representatives from the Outreach Teams, the 27 Funded Projects, Health Districts, Pilot Project Administrative staff, SGI Personal Injury Specialists, Saskatchewan Health Management, SGI Management, Saskatchewan Workers' Compensation Board, Saskatchewan Housing/Municipal Government, Community Living/Saskatchewan Social Services and members of the Provincial Advisory Committee.

B.2 QUANTITATIVE DATA

The quantitative component of the evaluation required extensive data collection from the Outreach Teams and funded projects. The Evaluation Assistant worked closely with a consultant from Saskatchewan Health, the outreach teams, and the funded projects to draft data collection forms. Given the nature and scope of the funded projects, many of the forms had to be tailored to meet individual project needs and reporting restrictions. The community-based programs vary in their capacity to collect information and, therefore, several projects were not able to provide information in a format consistent with the rest of the Pilot Project. These included Saskatoon Crisis Intervention Service, Mobile Crisis Services Inc. (Regina), and the Saskatchewan Brain Injury Association. As well, Career Headways and the Saskatchewan Abilities Council programs, due to the nature of services provided, were not able to provide similar information for some sections of their reports.

Through a series of consultative meetings with each project and outreach team, the forms were modified and were in use by October of 1997. The forms collect demographic information, as well as information to assist in answering the evaluation questions. The forms will be in use until December 31, 1998 to provide a full year of data for analysis. The information is collected on a quarterly basis, and includes demographic data (age, gender, type of injury, type of residence) as well as information on care planning meetings, follow-up activities, referrals, and amount of service provided. Data is also collected on education activities and travel time for each outreach team and some of the funded projects. At the direction of the Provincial Advisory Group, all of the data submitted is in aggregate form and there are no client identifiers.

It is important to note that the numbers presented in this report are considered minimum amounts, due to the likelihood of recording error, and the different reporting summaries for some of the projects. As well, the data base currently contains information on the client only and does not include demographic information on family members who may also be receiving programs and services. The Pilot Project was designed to provide enhanced services and support to family members as well as clients; however, we have not yet identified a method for collecting this information.

C QUALITATIVE INFORMATION: What People Told Us

C.1 THE EVALUATION

A researcher, in collaboration with the ABI Short Term Evaluation Working Group, carried out a qualitative evaluation of the ABI Pilot Project between January and July of 1998. The purpose of the evaluation was to determine how well the services are received by clients and their families, and to obtain opinions about the Pilot Project from service providers in the province.

The research instruments (refer to Appendix B) were designed to collect ideas, opinions, and statements from clients, families, and staff about their personal involvement with the ABI Pilot. The researcher interviewed twelve clients (aged 16 and up) from various locations in Saskatchewan. One respondent decided to not continue her involvement with the research, leaving eleven client interviews that could be used. The researcher facilitated four focus groups with families. One of these focus groups was organized specifically for families with children who have brain injuries as some of the funding from the Pilot Project was allocated specifically in support of programs and services for children. Also, no clients under the age of 16 were interviewed. Seven staff focus groups were conducted as part of the evaluation, including staff from the three outreach teams as well as staff from funded programs and one with SGI Personal Injury Specialists. (Refer to Appendix B for a detailed description of the methodology). The researcher interviewed five people (called key informants in the research) who are considered specialists in their area and are familiar with the Acquired Brain Injury Pilot Project. Most have knowledge about services for people with brain injury both before and after the initiation of the Pilot Project.

Once the interviews were transcribed, the researcher identified themes that appear in the text of this evaluation. The main themes that emerged were:

- ABI Service Provision;
- Acquired Brain Injury as a Family Concern;
- Education and Prevention Programs; and
- Coordination of ABI Services.

Most of these themes emerged as a result of specific questions asked to the respondents. Other important themes, in order of those most frequently cited, were:

- Importance of Follow-up;
- Advocacy on Behalf of Clients and Families;
- Services for Clients with Addictions;
- The Need for Friends and Social Opportunities;
- Empowerment and Overcoming of Obstacles; and
- Lack of Residential Options.

Quotes are used in the analysis of the interviews to allow the voices of the respondents to appear as part of the text. In the quotes used in the text, the respondents speak about “the ABI Team.” This may mean the outreach team or the group of people working on a funded project or a combination of the two. When asked by the researcher if they meant the outreach team, the respondents did not always know if the persons they were referring to were part of one of the three outreach teams. Initials have been used in the quotes to replace names. The initial bears no relationship to the name of the individual being spoken about.

C.2 ANALYSIS: THEMES FROM INTERVIEWS

C.2.1 ABI Service Provision

C.2.1.1 Clients

Clients considered themselves fortunate to have received services that assisted them in learning how to cope with their disability. Some of the services that clients received were physiotherapy, personal counselling, personal support, sleep clinics, recreational activities and leisure assessments, help in dealing with other systems such as justice and education, vocational training, re-integration into the school system, and job placement. The assessments and explanations of the results were important to the clients and this helped them adjust to the changes they experienced as a result of the injury. Sometimes people said that they did not think that they would suffer any consequences as a result of their injury but a year or two post-injury, they began to have trouble coping with stress and difficulty remembering things. The ABI Pilot Project provided a constant person or group of people who were there to support the client as he/she encountered difficulties and successes in re-integrating into the community.

“Before my injury I was very outgoing, fun to be with... always into stuff... Since my accident I have become a totally different person... Without the support of truly wonderful staff that run the ABI Outreach Team... I really have no idea of where I’d be. I would be very much withdrawn and very fearful and I probably wouldn’t be driving, probably wouldn’t be willing to stay alone... The ABI Outreach Team has brought out a lot of good in me... it’s just something that I’m thankful for.”

Some clients accessed the ABI Pilot Project counselling services for help in understanding what they were feeling. Having someone who understood the impact of acquired brain injury on one’s emotional life was very valuable to clients.

“It was good because I needed to talk about how I was feeling...and it was a relief that they came because at least they knew what it [brain injury] is... they know I’m not just forgetful.”

Most clients liked the relaxed, flexible atmosphere of the Pilot Project. They were pleased with being able to meet with the outreach team in their own home, a donut shop, or in other places. The meetings took place from one to two hours depending on the needs of the client. Some clients appreciated the fact that the same outreach workers followed them through the rehabilitation and community integration process staying as a contact even when the client might be involved with other programs.

“What I appreciated about it and still do is that it’s not like I went from the outreach team ...and suddenly left there and went to a whole new organization. D. is still involved with me and with them [Career Headways] so it’s not like I’ve been left hanging so to speak.”

One client stated that although it might not have been in the mandate of the ABI Pilot Project to help get witnesses for his court case, that service was one of the most useful interventions that he received during his involvement with the ABI Pilot Project. The support from the ABI staff at that time, and the counselling he received, helped him get through a very difficult period.

Several clients stressed the importance of getting appropriate services through the ABI Pilot soon after the injury. One client, whose injury occurred several years ago, indicated that he could have improved a lot more and avoided acquiring bad habits if a program had been available immediately after his injury. Very few local programs were available specifically for people with brain injury before the Pilot Project. Now, with the ABI Pilot, clients can choose between different kinds of services and have choices about activities within their individual programs.

“[Before the ABI program] I just stayed home... No physio, no nothing.”

“All the way along they gave me the opportunity to make decisions for myself... I went back to [work] for two weeks in June and I wasn’t ready and think that they knew that I wasn’t ready but I had to be the one to find out that I wasn’t ready... So they let me choose even in spite of it not being the best choice, let me experience what it was like, and showed me how to fix things... I consider myself very lucky to have gotten into the program, to not have to have waited.”

Many times, Aboriginal clients from the North did not stay in the city for rehabilitation because they felt isolated being away from their home environments. They were therefore not able to get services such as physiotherapy which were only available in larger centres. One client said that his mother wanted him to stay in the city to get therapy but he went home because he felt uncomfortable there. He lived with his mother for two years before he began to get services from the ABI Project.

“...The wife I was living with wanted to come home and I didn’t want to be alone...in Saskatoon by myself. [It] seemed strange.”

In terms of improvements to ABI services, some of the clients indicated that they needed to be in a support group where they can share their stories and difficulties and be reassured that they are not alone.

C.2.1.2 Families

Families as well as clients valued the continuity of care that the ABI staff provided.

“The program started right about the time that my husband was being released from [acute care rehabilitation] so they have provided a lot of support throughout each of the stages...A lot of adapting...the outreach team have been very helpful to me in that.”

Many family members reiterated clients' comments about the flexibility of the project. They liked the fact that staff from the ABI Pilot Project came out to the house and helped their family member begin activities such as swimming. Others were grateful for assistance they received in getting their children re-integrated into the school system.

“But when she came back to school, where I live there are no services...absolutely no speech pathologist...no physiotherapist...no occupational therapist. So they were really good about coming out to my community and helping the teachers do a pupil plan so that we could apply to Saskatchewan Education for high-needs funding.”

Families who could compare services before and after the inception of the ABI Pilot Project appreciated the support from the ABI staff and the improvement in their family member's quality of life. One mother talked about her situation when her son was injured more than a decade ago. She wasn't able to access services or obtain an understanding of his injury. Since the ABI Project, she has been able to learn about the injury and to understand the effect on her son and on herself.

“I did it on my own and it's very stressful that way... He had to learn how to walk, how to talk, how to go to school and [how to] go through the system and deal with life. I never gave up...I kept at it and at it because this is my son...[Now] he's come to Career Headways...and they always kept very up to date with him. They were able to help him...live in the real world, how to deal with issues...like anger... The kid turned around in a complete circle and he has a job now and he's happier and more secure about himself and life...I know today that we will always have the support of Career Headways and SGI...”

More than one family member commented that, due to a lack of insight, their injured relative left the rehabilitation hospital too early and therefore did not get appropriate treatment. Families indicated that their injured family member does not use available services because, due to the brain injury, the client is unable to recognize the need to do so.

“We took my brother once or twice [to the support group] and he didn’t think that he was injured and he looked around the room and he looked down upon the other people there in the room, thinking that he wasn’t anything like those people.”

Another problem identified by several family members is that some injured individuals received a financial settlement from SGI without restrictions or guidance on how to use the money. Often clients do not know how to budget and spend all of their money immediately without thinking of the future.

“He bought a car and can’t drive. Bought a stereo for his car. He just wastes it and he could use this when he’s older and needs it, but no, it’s all going out the window. No judgement, yet you’re given that lump of money every month. If they’re in a situation like that, SGI should have a fund set up for them later on in life.”

Families suggested ideas for improvement to service delivery including hiring more staff and increasing services in the rural areas. Even those whose family members are getting services in the city felt that their family member could use more specific therapies. Families in the north say there are not enough accessible services for people with disabilities. Of the few services that are available in northern towns, most are not wheelchair accessible. Families, as well as staff, suggested that the health districts and other funding agencies should contribute financially to the ABI Pilot Project in order to provide additional needed services.

C.2.1.3 Staff

Staff described how they were able to help clients access therapies, tutors for school, and recreational activities, as well as achieve a general re-integration into the community. One staff person indicated that the ABI Project has the greatest impact on those individuals whose brain injury occurred between three and six years ago because they are at the stage where they want to move on. He suggested that services have the least impact on some of the clients who have recently sustained severe brain injuries and who don’t yet accept that they have problems. All groups interviewed, including SGI and the key informants, commented that service provision is much better now than it was in the past.

“In past roles that I’ve played in health care, I have seen and worked with a number of individuals who have suffered brain injury and were really lost within the services of the health care system, social services, education system, employment...The ABI Pilot Project has been an effective resource to these people, returning one back to the community...and it’s really helping them or directing them in a way that they can become more normalized in society.”

Staff, as well as key informants, explained that before the ABI Pilot Project, people who had sustained an acquired brain injury were often referred to mental health services, as no other services were available. As well, sometimes people were not diagnosed properly, as there was a lack of understanding and knowledge about acquired brain injury. Staff indicated that increased services for clients, together with increased awareness of acquired brain injury, has resulted in more individuals being accurately diagnosed with an acquired brain injury. As a result, once the client has been diagnosed, the staff from the ABI Pilot Project have been able to help them receive appropriate services to meet their needs and the needs of their family.

Staff identified a number of barriers to effective service delivery. Some staff indicated concerns about the lack of professionals knowledgeable enough about ABI to deal with mental health issues, sexuality, life skills, personal counselling, depression and other complex needs of survivors of brain injury. Also, some clients who required additional support services such as a one-to-one worker or specialized equipment had to pay for it. In rural health districts, it has been difficult to access services because service providers are already overburdened. Specifically, professional services such as speech and language pathology, occupational therapy, and physiotherapy are needed in the rural areas and in the north. Staff also mentioned a shortage of leisure programs designed to reduce isolation for this population. Some staff indicated that because there are limited numbers of service providers, a group approach using day programming for life skills and pre-employment skills would be effective for meeting the needs of more than one client at any given time.

Staff cited a number of problems in trying to provide services in the north and in rural areas. Many individuals who live in the far north are not able to stay in the larger cities for therapy because they feel uncomfortable and alone. Staff suggested that a center to provide therapy and training to northern clients who have sustained an acquired brain injury is needed in Prince Albert. Some staff from the northern outreach team expressed concern that sometimes they can’t provide services as quickly as they would like or get back to clients as often as they would like because of the great distances to travel and the small size of their outreach team. As well, other areas in Saskatchewan, such as the southwest, require ABI staff to travel long distances in order to meet the needs of their clients.

“...The numbers and the areas are very, very hard to manage for one individual. I think funding or...a de-centralization of some of the funded projects or utilizing their services, bringing them to the more rural areas would be a huge benefit...”

Staff members often commented that there are many clients in the province who were injured a number of years ago and who want services. Due to this, the staff emphasized that more people have to be hired on the outreach teams in order to meet the continuously increasing demand. SGI staff agreed with this suggestion especially if clients whose injury occurred before 1995 are to also receive services from the outreach teams. One staff member suggested that there are already a lot of people doing coordination but not enough people offering therapeutic ABI services such as physiotherapy or occupational therapy in rural areas.

Some staff emphasized that the scope of the ABI Pilot Project has been too broad. ABI staff try to initiate prevention and education activities, try to be case managers for their clients, and try to carry out therapeutic services when no other resources have been available. Because of this, staff have felt pressure for time. Some staff from funded projects have been hesitant to expand their provision of services. They don't want to create expectations that they may not be able to fulfill because of the three-year time frame of the ABI Pilot Project and because of the uncertainty of future funding. Having more secure core funding would assist in planning future programs.

C.2.1.4 SGI Staff

Most SGI staff indicated that the major strength of the Pilot Project has been the personalized services of the outreach teams - the fact that team members have worked with clients in their home communities to set up programs and activities. The SGI staff emphasized that communication has been very good with the ABI Pilot Project staff. These individuals have helped SGI staff with their claimants and treat them like colleagues.

Some SGI staff indicated that all the outreach teams need to get private therapists involved whenever necessary instead of placing SGI clients on a waiting list to get therapeutic services. The cost for such services is covered for individuals who are recipients of benefits provided by the Personal Injury Protection Plan.

They also suggested that cases be turned over to a different outreach team if, by doing so, services can be provided more efficiently with respect to travel. They indicated that the coordination of services by the Outreach Teams is improving but they would prefer to have more consistency amongst the three teams with respect to service delivery.

C.2.1.5 Key Informants

All key informants agreed with the other groups interviewed that the ABI Pilot Project has had positive results to date. Key informants stated that strengths of the ABI Pilot Project include the presence of knowledgeable staff around the province, services for students who have sustained a brain injury and follow-up on clients after discharge from acute care or rehabilitation.

Critiques focus on expanding the ABI Pilot Project to include more staff, improving referrals and linkages with acute care, earmarking funding for treatment programs in

the north, and improving the communication and dialogue between the Pilot Project and other sectors. Although one key informant acknowledged that the ABI Pilot Project provided services to First Nations on and off reserve, he suggested tailoring some services particularly to First Nations' people.

Some key informants wonder whether acquired brain injury is the “new diagnosis of the year” around which services will be organized. There was a query around why other neurological insults (such as Fetal Alcohol Syndrome) could not be under the mandate of the ABI strategy.

One of the key informants made comments about funding and education, and wondered whether local school boards should be responsible for developing a vocational program for students with acquired brain injury, or whether these costs should be shared provincially. A key informant proposed the need for more research on how to provide services to persons who have sustained a brain injury and who want to re-enter the education system.

One key informant's perspective differed from that of the other key informants. The respondent commented that in his/her experience the staff may recommend programs for clients, but do not have the capacity to provide funding for the development of the needed program. The key informant recommends streamlining the system to get services to the client more quickly, rather than having so many meetings and people involved in each case. The key informant felt that people whose injuries were not caused by motor vehicle accidents should be entitled to the same services as the SGI clients, because in certain areas of the province, many brain injuries result from other causes.

C.2.2 Acquired Brain Injury is a Family Concern

C.2.2.1 Clients

Most clients who talked about their families said that the family gets information and knowledge about acquired brain injury from the ABI outreach team and that the team is open and available for support. Several clients talked about the support they get from their families. Some felt the injury brought their family closer together. Another client expressed appreciation for support from his family, friends, and community and realized that the community he lives in is a supportive environment for him and his family. Some clients stated that it is frustrating for their family members to adjust and adapt to living with the way they are now and with their deficits such as memory loss.

C.2.2.2 Families

Families described different experiences, ranging from support to isolation, which occurred as a result of their loved ones' injuries. Most families who have had involvement with an outreach team appreciated the support provided to them as well as to the client.

Many family members said that when they left the hospital, they felt vulnerable and in need of support. Knowing that they could count on the support, help, and

understanding of an outreach team member has been invaluable. Some family members said that when the outreach team is helping the client, the family members are able to get on with their lives, cope better, and be supported as they continue to support their loved one.

“I feel these people are my link to making my life as normal as it can be now...it helps me cope and adjust to the changes. I think everyone needs that.”

Another impact of acquired brain injury on families is the lack of communication with their injured family member. Sometimes this was due to the survivor’s lack of insight or a communication problem resulting from the injury. This is one of the reasons that the families said they needed support from the outreach teams as well as the opportunity to talk to others about their feelings and challenges that they face.

“...it will do you no good to say to your head injured [relative], ‘Do you know what I’m going through?’ ...They have no idea of what they’re going through, so the least of their worries is what you’re going through. They’re in a world that has been completely turned upside down, rearranged, and they are trying to come to some grips with it.”

Family members from more than one focus group strongly emphasized the need for more support groups for families. Whereas some people said they received support from being in a family or spousal support group, others had not heard of these groups and expressed a need to have people to talk to who understood their situation. They particularly stressed that a support group should be made up of family members and not include clients. Some rural families said that they would like to go to a weekend retreat, such as the one offered for spouses in Watrous, where workshops and discussion groups about acquired brain injury would be offered. Several family members stressed the need for more social workers and counselling for both clients and their families.

“I needed some outlet other than my family, because they were always coming to me because I was supposed to know it all and I was exhausted.”

“We haven’t really received any emotional support from anyone. It’s more information that we’ve received and talking in general about the difficulties. I wish there would have been something available. You don’t know what to do and how to cope with it and there is so much anger involved.”

More than one family member emphasized that there should be people who are personally affected by acquired brain injury, be they survivors or caregivers, as part of the outreach teams, or that acquired brain injury survivors should be consulted about program development.

C.2.2.3 Staff

Some staff spoke of the importance of providing a link to the family and the client so that they do not feel isolated. Contact with the staff from the ABI Pilot Project has assisted the families in realizing that they are not the only ones who are coping with brain injury and to connect to others for support. Staff have tried to provide families with knowledge and awareness of acquired brain injury, what the effects of a brain injury are on the client, and how they can learn to support their injured family member. Often this support has prevented family break-up.

Staff mentioned the positive impact their work has had on families and the changes in the ways clients and families cope as a result of support from the ABI Pilot Project.

“When I got involved, his behaviour was really quite poor and his mother has been able...to put supports within the home in terms of lists and schedules which makes a dramatic difference in terms of how he manages... When changes happen it really impacts her and she’s picking up the pieces and really needs the support and has really appreciated it.”

Some staff mentioned difficulties in assisting families who have serious psycho-social problems which were accentuated as a result of their family member sustaining a brain injury. Getting help for such families in small rural areas has been difficult. Rural families are often reluctant to come to a larger centre for services because they do not have respite services available in their home community to care for their injured family member during their absence.

C.2.2.4 Key Informants

This group of respondents was not asked to specifically comment on the impact of acquired brain injury on families.

C.2.3 Education and Prevention

C.2.3.1 Clients

Most clients emphasized that they received a great deal of information about acquired brain injury, how it affected them, and the expected course of their recovery. They stated that the staff from the ABI Pilot Project provided the information to them in both verbal and written forms. Most clients said that information about brain injury and how their injury impacted them was also provided to their family members, although some survivors said that their family members did not request or want more information.

“... They were very, very good, upfront, telling you any information about yourself that you needed to know even things that you didn’t want to necessarily know... They were able to say, ‘Yes, this is going to happen,

and don't worry about this and give yourself five years for this, and you're doing great, and don't worry about that.'"

C.2.3.2 Families

Most families indicated that they received considerable information from the ABI staff and that they could get more information when they needed to. Ways of obtaining information ranged from individual conversations with ABI staff to books, pamphlets and looking up topics on the Internet. Some families mentioned being familiar with education and prevention programs, such as those promoting the use of helmets for sports.

Families, as well as several clients, spoke of the need for public information and increased awareness about acquired brain injury for taxi drivers, police and teachers. Families expressed an interest in having a resource centre to provide information and resources about acquired brain injury. Some families wanted to know more specific things about their family member's injury including the impact of the injury on emotional development and how to parent a child with an acquired brain injury. One family member said that he/she would like to have a list of all the facilities and programs that could be accessed in Canada. Families as well as staff, including those from SGI, suggested that there should be pamphlets or booklets describing all the services available in the province for people with acquired brain injury. Some staff suggested that a brief newsletter be written on a regular basis with a small paragraph on each of the funded projects. The newsletter could also include some other useful information or research findings.

One spouse pointed out that there is a deficit of information about the needs of clients' spouses. Both the client and the family need to know how the other feels and what they are going through.

"Also I would like to see information packages for people with injuries and the caregivers. A lot of the stuff is about my spouse and what he's going through, and what he's feeling like and yet my husband has read nothing about how I'm feeling and what it's like for me."

C.2.3.3 Staff

All staff members were pleased with the amount and type of continuing education they have been receiving and all want to continue taking part in educational events. Some of the most useful educational workshops that were mentioned were: "*Brain Trust*"; "*Level One Certificate in Home and Community-based Rehabilitation for Persons with Acquired Brain Injury*"; education on substance abuse; and education with the focus on children, the schools, and behavioral issues. Staff often have education days and can choose the subjects they need to know more about, such as legal issues, sleep disorders, grief, etc.

“My staff described the education and training that they received through this project as an opportunity of a lifetime.”

Staff expressed a need for more information on: substance abuse and acquired brain injury; issues surrounding sexuality; cross-cultural awareness, specifically about First Nations’ people; and supportive employment and strategies for dealing with problems that might occur in a work site. Staff also identified the need to learn more about headaches, re-integrating families into the community, better ways to connect with the resources in the communities, working with people coming out of correctional institutions, and behavioral management strategies. Some people wanted more information about strategies that could be used in connecting with teachers and other professionals in the schools. One person said they would like to have the opportunity to go and work with somebody who had done this kind of work for a long time. He said that one week of mentorship would be very useful for him.

Some staff suggested that all educational sessions be recorded on audio or video tape to ensure that the information can be used later on by people who are not able to attend. Some family members also wanted to have video taped sessions available to use as a resource and to help their injured family member review information. This was considered to be particularly important for survivors whose injury has resulted in a memory deficit.

Staff expressed the need to share and coordinate educational activities so there could be consistency throughout the province and suggested developing information packages that could be shared amongst everyone who provides education and prevention activities. Some of the funded project staff commented on the lack of coordination of prevention and education initiatives in the province.

“We’re appreciative of the opportunity to participate and get our message out into the general community and have the opportunity to do that. The message has been somewhat fractured or fragmented by the number of organizations and the lack of any type of comprehensive approach around prevention and education.”

C.2.3.4 Key Informants

Acquired brain injury now has more visibility because there are more public information and prevention programs available as a result of the ABI Pilot Project. The key informants approve of the work that the ABI staff have been doing in the schools, both in the area of prevention and in assisting student academic re-integration after an injury. Another identified strength of the Pilot Project is the capacity and commitment to bring in renowned and knowledgeable speakers for conferences and workshops.

Although there is a better awareness of the challenges of ABI as a result of more people working in the area, there remains a need for more time to be dedicated to increasing awareness of ABI Services with various agencies and organizations

C.2.4 Coordination of Services

C.2.4.1 Clients

Clients said that staff from the ABI Pilot Project worked well together to get appropriate services for them.

“When I have a problem, they’re on it. I tell one of them and they let me know that they all get together and talk about what they can do for me to help.”

Families, staff including SGI staff, and some clients suggested that the northern and central regions should have district coordinators thus making coordination of services similar to that in the southern region. The presence of such staff would increase availability of services for people within their own communities.

C.2.4.2 Families

Families viewed members of the ABI Pilot Project as being valuable in helping them sort through problems in various institutions, to find resources, and to be the common link between them and other services in the community. The ABI Pilot Project’s role in coordinating services was perceived to be positive by almost all of the families.

“L. has been very good about helping us access other programs or pointing out other programs in the community that might be available for us... There’s just this big, huge gap out there [and] there doesn’t seem to be any real cohesive kind of planning or team approach... The outreach team is the first time that we’ve experienced anything close to that so it was welcomed with great relief... The school has one idea about how things should be dealt with and one doctor really doesn’t know what the other doctor is doing... So, when...we got involved with [the outreach team] at least we had someone that we could turn to that had a bigger picture...”

The outreach teams’ communication with acute care and rehabilitation services in the larger centres, and with other caregivers in smaller centres has been important. Families commented on the need to have a coordinated effort in place to ensure a continuity of services and care. This need was met with most families interviewed.

Families as well as staff commented that physicians need to have more information about the ABI Pilot Project. As well, some parents mentioned a lack of understanding on the part of community institutions with respect to the ABI Project. For example, before the ABI Project was introduced to one school, teachers from the school thought that the ABI Pilot Project would fund any special needs that a child who had sustained a brain injury might have, such as additional staffing. Several parents indicated that as

the ABI Project grows and matures, closer relationships will need to be developed with other community institutions, programs and services.

“[An improvement would be] a closer relationship with schools, school boards, special education teachers, language arts pathologists in the school systems...there’s an opportunity to be involved in some of the numerous in-service days...”

C.2.4.3 Staff

Staff mentioned that one of the positive aspects of their work in coordinating services has been the fact that they have been able to refer and link families to programs in the community and coordinate services with local service providers in the area. The district coordinators in the South and the rehabilitation assistants who work in the North have provided follow-up services and contact with the client and family. Referrals to and from other programs have occurred regularly, and the staff from the ABI Pilot Project have educated themselves about other linkages and supports in the community. The Justice System and the Education System were noted as some of the areas where linkages have proven beneficial for clients.

“When we bring together different agencies or service providers or schools and parents, and they’re all sitting at one table to discuss the well-being of that individual to do the case management and everybody walks out with a little piece of something...because they know that they’re not going to enter into this just by themselves. They’ve, all of a sudden, developed a whole network of individuals to support them too.”

A number of staff as well as some families and key informants commented that the ABI Pilot Project needs to develop closer links and stronger relationships with acute care to ensure greater continuity for both the survivor and families upon discharge from hospital. Staff thought that mild cases going directly from acute care to the home are cases that have tended to get missed. Staff mentioned that some people are sent home from the emergency rooms without any indication that something is wrong, and no referral or follow-up to see how they are doing later on. Education and coordination are needed so that mild cases will not fall between the cracks. Some staff discussed the difficulties in coordinating services for people who have “hidden disabilities” (a brain injury) as opposed to those who have a physical disability.

“...somebody may have just walked into emergency, have had no physical problems, and nobody has really recognized that...he’s sustained a head injury and has been sent home with a checklist of what to watch for, but nothing else. And then their problems become more evident as time goes on and it’s that family that starts to struggle with trying to find resources or find out what’s wrong with their individual.”

The coordination of services in the cities is considered to be stronger than in the rural areas. Sometimes it has been hard to coordinate services because the services required have not been available in the rural health districts. Given this lack of resources, the rehabilitation assistants, in particular, stressed that the outreach team needs to be present to supervise and to carry out a thorough assessment of each client that they, as rehabilitation assistants, will be responsible for following up on.

“We have a long way to go to be providing the most effective services... with the local health district and the community health nurses on the reserve so they take ownership rather than having the ownership on the outreach team... I think there could be a better link between the outreach team and the people working in the community.”

Several staff identified the challenges they faced in working with other service providers. Staff commented that they have often been unable to access mental health services for clients as ABI has not been perceived as part of the mandate of mental health by providers in some areas of the province. As well, one staff member discussed the obstacle of not being able to refer some clients to Community Living, even though clients could benefit from the program. Clients who have severe behavioral problems are hard to support and staff indicated that there are not enough services to deal with these types of problems. The ABI Pilot Project has a designated behavior management therapist, as part of the pediatric team who works primarily with childrens' behavioral problems. Several staff mentioned the need to have this type of expertise more widely available and accessible for adults. ABI staff said that they should work with mental health services to better serve clients with behavioral problems.

“The other thing is support from mental health... whether a lack of coordination or a lack of expertise with the mental health people, to help us deal with ABI clientele ... but maybe they don't have the staff either to help us deal with really difficult clients.”

There was discussion about the need for case managers however the definition of case management does not seem to be the same for everyone. All staff who spoke about case management agree that a case manager could prevent duplication of services and facilitate referrals. There is no consensus as to whether the case manager should be a member of the client's community or a member of the outreach team.

One staff member commented that some of the people working in the funded projects have not understood the roles of the outreach teams. The staff member went on to say that this may be due to a perception that each outreach team seems to have a different mandate which has been very confusing.

C.2.5 Follow-up of Clients

There were no specific questions asked to any of the respondents about follow-up. The responses given came as part of responses to other questions about service provision.

The topic of follow-up was raised in a number of the interviews with clients and the focus groups of family and staff, as well as with key informants. Clients, families, staff, and key informants commented that, before 1996, follow-up services were less available and little time was dedicated to each client. Clients were often not seen by rehabilitation services until three months or a year after they were released from the rehabilitation centre.

C.2.5.1 Clients

Clients indicated they have felt supported through receiving services and follow-up and appreciated being able to talk about their progress and day to day difficulties or successes with the team.

“That’s the thing, on the outreach team... They kinda make you feel good when they do come, and even when they [don’t], they phone... I feel they’ve done their job, the best that they can.”

C.2.5.2 Families

Outreach team members have provided families with support as the injured family member moved from hospital to the community and re-integrated into the community. The follow-up has reduced stress and has reassured the family that someone is there when they need help.

“We were in the hospital and then we were referred to the Kinsmen Children Centre. That’s where we met L and O, they belong to the ABI program, and they were very helpful there because our daughter was still under the auspices of doctors. Both L and O have phoned I think probably once every other week to make sure everything is going ok and following up. I know that both L and O phoned the school every other week or every week to... see if there is anything they can do be it education for the other kids or whatever.”

Some family members indicated a need for more follow-up in the rural areas. Others emphasized a need for improved follow-up when clients move from a rural to urban center. One mother commented on the lack of follow-up until a crisis occurred with her son.

“There really wasn’t very good follow-up or evaluation of what was put in place up to where we crisised and needed more help and we felt there was a real gap in the program right then. Since we’ve crisised as a family it’s been a lot better... [But] it had to come from us before we got any services back.”

She went on to suggest changes to follow-up in the vocational program in which her son was involved.

“When they got him into the work program, they expected the employers that he was working for to do the evaluation of how he was doing on the job. I don’t think that was fair to the employer. They should have been doing more of an evaluation and/or giving some clues to the employer as to what to be looking for and more background knowledge of what’s happened. I don’t think that took place.”

C.2.5.3 Staff

Staff in the outreach teams and funded projects emphasized the importance of following through with the client and their family. Before the Pilot Project, there was little opportunity for clients to receive follow-up services after their initial treatment at the rehabilitation hospital.

“...people with acquired brain injury were released from [the rehabilitation] and follow-up was done... follow-up meaning in a year’s time, and in the meantime any progress they made at [the rehabilitation] was lost within a month or so.”

Sometimes staff had a chance to follow clients through different programs and see positive changes and successes. However, at times staff indicated that they have not followed through as thoroughly or as often as they would have liked because of time constraints caused by heavy caseloads and the large geographic area to be served.

C.2.5.4 Key Informants

One key informant echoed the statements of staff in saying that an important component of the work of the outreach team has been that it maintains contact with clients after discharge from acute care or rehabilitation hospitals. This was never done before the ABI Pilot Project.

C.2.6 Advocacy on Behalf of Clients and Their Families

C.2.6.1 Clients

ABI staff members have acted as advocates and supporters to students with ABI and their families. The staff have accessed special assistance when needed at school and have made the necessary adjustments for injured students to return to the classroom. Many clients have received help in getting back to school or work. Staff have empowered clients to make decisions and have assisted those who are students to choose classes in which they can succeed, based on information about the client’s

preferences and their injury. A young student talked about the type of advocacy he has received at school through the local ABI Community Coordinator.

“They explained to the teachers, to the counsellors, to everybody as best they can, about what I’m going through, the family’s going through...about brain injuries and what can be helped to prevent this...and to watch out for different things ...and what classes to choose and stuff like that.”

Sometimes a retraining program or a work experience program has been organized for the client and guided by a member of the ABI staff. One client pointed out that he had to come to one of the larger cities to get the help he needed for a supervised work placement. Clients appreciated the opportunity to be retrained or assisted to get back into the workforce.

“[In my town] they might counsel me and help me find something that I’d like to try but they won’t be able to situate me in a job and stuff. I’d have to do that all by myself.”

C.2.6.2 Families

Families agreed with clients that ABI staff advocated for the client and assisted the client to get back to work or to find work placements. Some parents indicated that they have had to fight to get extra help for their children in the schools, and to receive services in the health districts, such as physiotherapy. They have relied on staff from the ABI Pilot Project to help them access the appropriate services for their child. Sometimes ABI staff have helped to obtain a teaching assistant, in order to support the child’s progress in school, or have made other suggestions that were acted on by the school.

Families who were able to compare services before and after the ABI Project were enthusiastic about the way that ABI staff worked for them. Previously, there was no help in the form of advocacy and families remember those times when they had great difficulties in accessing education and services for their children who had sustained a brain injury.

“ We had nothing. It was me and [the hospital] and the government in a war. My son was on the borderline... the school didn’t want him... it really hurts.”

C.2.6.3 Staff

Staff reiterated the themes of the importance of advocacy in the areas of school, re-integration into work, links with the medical system and the justice system.

A staff member gave the following example of advocacy with a client and his work placement:

“...he identified where he wanted to work because he still had that ability...to make decisions of where he thought employment would be pleasurable... and he chose to work at a [hardware store]. We approached the [hardware store] and asked if... they would be prepared to do... a job coaching opportunity for him to regain the skills. We met with the employers and ... the funding agency and ...when he had to learn something new, we found out what he had to learn and what strategy he had to put into place to learn it... We had him working first of all for two hours a day, then ...three, and then four, to eventually... a full day. At the end of the six months he was offered a full-time position.”

C.2.6.4 Key Informants

Key informants felt that one of the strengths of the ABI Project has been the provincial focus of the strategy enabling involvement of clients, family members, agencies, and organizations from around the province. Project staff have helped to make acquired brain injury more visible both through programs designed especially for people who have sustained a brain injury and by education and prevention initiatives. One critique is that the ABI Pilot should be able to do more than just identify training opportunities for people who have sustained an acquired brain injury but should also fund the training.

C.2.7 A Need for Friends, Relationships and Social Activities

C.2.7.1 Clients

The ABI staff have tried to get survivors involved and be a part of activities in the community according to their abilities and preferences. Making friends, keeping friends and having adequate leisure activities are problems for many clients. One man commented that he has friends but acknowledged that if his injury had been more severe he might have lost friends. The friends with whom he played sports changed after his injury when he could no longer play those sports. Other clients keep to themselves because of difficulties hearing or speaking or other physical disabilities. They may also have problems understanding conversation when they are in groups, difficulties in knowing what to say to people, and a general sense of unease with their new self. Fatigue also plays a role in limiting their social activities.

People who have a brain injury change and it takes time for them to re-adjust to their new self and to develop new goals and interests. Clients said that their old friends sometimes avoid them. This has led to more isolation because it is difficult for them to make new friends.

“I feel separate from people because of my brain injury.”

“...[I] have friends but now they hardly come here. When [I’m] out I hardly ever talk because nobody seems to be talking with me.”

C.2.7.2 Families

Families agreed that having social relationships has been a problem for their injured relative. Unfortunately their family member has sometimes been isolated as a consequence of his/her injury.

“You have a head injury happen, to one of the members of the socializing group, and then no one talks to you anymore, no one wants to have anything to do with you anymore.”

C.2.8 **Overcoming Obstacles and Becoming Empowered Through the ABI Project**

C.2.8.1 Clients

Many clients have overcome obstacles as a result of services received from the ABI Pilot Project. Surmounting obstacles has made a big difference in the clients’ quality of life.

“I think my confidence went up...I can do things...that I wouldn’t think of doing before. Anything...mostly anything...go up to talk to strangers I guess. [Before] I’d have had to bring somebody [to the interview] to do the talking for me.”

This person went on to explain that the staff from the ABI Pilot Project offered to assist him in moving to a city in central Saskatchewan to get vocational training. Shortly after his injury he left the city and did not get the appropriate rehabilitation services because he felt uncomfortable staying in the big city by himself. He now feels that he would be all right for a while in the city.

Other clients have had to overcome both physical and mental barriers to their independence.

“Physical, mental, those sort of things...way better than before... I am learning, and I am doing well in physio, the body.”

“I’m a lot less fearful of new things...I feel a little bit more secure about myself and my acquired brain injury that I’m not so isolated...I’m just a lot more confident in myself, you know, because of it or a part of it [ABI Project].”

C.2.8.2 Families

Families agreed that the ABI Pilot Project improved the quality of life for survivors of acquired brain injury. One family member was pleased that the staff from the ABI Pilot Project helped the client learn to get up when he fell, to be able to be away at school, to use a computer and to become independent. Others were happy that the client could find and participate in leisure activities to occupy their time and to overcome isolation. Staff, as well as family members, commented that the clients' quality of life improved as the client accessed vocational training, job placements, or returned to school.

C.2.8.3 Key Informants

One key informant mentioned that she knew a client who is “coming alive,” using her voice and improving her physical abilities, as a result of the services offered. No other respondents made comments about individual clients who had overcome obstacles.

C.2.9 Services for ABI Clients with Addictions

One client stated that the most helpful program he had been referred to through the ABI Project was the Calder Centre in Saskatoon. (This is a residential drug and alcohol addiction treatment program.) He went to the Calder Centre program several times and found the structured environment very helpful.

There were a number of people from both family and staff focus groups who mentioned the lack of programs for clients who were experiencing problems with addictions. In the province there are no programs that are designed specifically for people who have addictions and who have also sustained a brain injury.

One family talked about their difficulties in accessing appropriate treatment for their child who has both a brain injury and an addiction problem. When the client could no longer stay at home because of the disruptions the addiction caused to other siblings, there were few places that were available to meet the client's needs.

“We were sort of left, we felt, dangling for about a month, because they wouldn't acknowledge...his addictions problem...I think the ABI needs to work more with that especially if there are other teenagers like our son who have an addictions problem as well as a brain injury problem. They need to be able to combine someplace in Saskatchewan that works with both and they're just barely getting started in this area.”

C.2.10 Residential Options

C.2.10.1 Families

A few families spoke about not having access to any kind of residential program. In the north, families mentioned a scarcity of accessible living arrangements for disabled people.

Only one family whose child was in Pearl Manor (a residence providing supervised apartment living) was interviewed. This family described their child as having a problem with substance abuse. One key informant also mentioned that people who have sustained a brain injury have been able to access Pearl Manor, one of the services funded by the Pilot Project. ABI staff also indicated that the lack of residential options has been a problem. The parent of a youth using the services in Pearl Manor commented:

“The good thing about the program in Regina right now is that they do have somebody in residence that’s a counsellor...particularly that if they have a bad night or need somebody...somebody is there on site... I think that more units similar to that [are needed] for teenage kids...that have similar problems because they don’t want to be put with people who have handicaps that are older or younger...They want to be treated like teenagers.”

C.2.10.2 Staff

Almost all staff agreed that the number of residential options, particularly with younger people who have sustained a brain injury, has been one of the biggest gaps in the ABI Project. If families have the option of using respite services for their son or daughter, they can take a break from the stress of caring for their family member. Clients of any age who are alone and require supervision need a place to live. Both families and staff affirm that housing should be made available for young people who have sustained brain injuries since current long-term care facilities are not appropriate for them.

“...sometimes it is a fact that a family can’t keep them at home. They just, they can’t meet the needs, and home care can’t supply those needs... and there’s no place to go except for senior citizen complexes which puts them in a whole different category than what they are...”

In the north, staff discussed the need for a wheelchair accessible residential center, preferably located in Prince Albert, where services could be provided to northern residents.

C.3 THE SURVEY OF FAMILY MEMBERS

C.3.1 Introduction to the survey

The purpose of the survey of family members was to determine how well the services of the ABI Pilot Project were meeting the needs of survivors and their families. The survey instrument was adapted from the Family Support Service at the Bloorview-McMillan Centre in Toronto. The survey contained questions in the areas of program and staff responsiveness, growth in knowledge and skills, utilization of community resources, building a support system, and general satisfaction with the program. Respondents used a Likert scale (strongly disagree, disagree, agree, strongly agree and N/A) to mark their opinions and some added written comments at the end of each section. For more details on survey methodology or to see the survey instrument, refer to Appendix B.

Only one survey was given per client (to one family member). For the purpose of this survey, family referred to spouse or common-law partner, or if the individual was a child, the parent or guardian. Adult children or siblings who were primary caregivers were eligible to receive the survey, but paid caregivers were not. The survey was delivered to family members by the outreach team members and staff from the funded projects. Family members returned the survey by mail to Saskatchewan Health for analysis using the statistical program SAS. There were 218 surveys given out and 80 surveys returned, giving a 36.7% response rate. Of the 80 surveys returned, 13 were returned from families in the northern area, 22 from the central area, and 32 from the southern area. Thirteen family members did not include their postal code so their area of residence is unknown.

C.3.2 Survey results

C.3.2.1 Program and Staff Responsiveness

Almost all respondents (93%) strongly agree or agree that staff have listened and responded to the families' concerns, questions and ideas, and the same number indicate that they have been active participants in meetings with staff for activities such as assessments and treatment planning. Nearly everyone (95%) indicated that they have received information that is clear and useful, and help is based on the families' perceived needs (91%). Eighty-two percent of respondents strongly agree or agree that they were informed of a variety of choices in how they can be served. Most families (89%) felt confident that their opinions were used in treatment planning for their family member, while the same number of respondents felt that their concerns were acknowledged and addressed.

The vast majority of people who commented about program and staff responsiveness stated that they received excellent support from ABI staff and were pleased with services they were able to access through the ABI Pilot Project. Criticisms about program and staff responsiveness were few but several people made comments about lack of follow-up, staff being slow to respond in a crisis, or not being able to get appropriate therapeutic services. One respondent stated that her relative has been on a waiting list for over six months, and wondered if service would have been provided more quickly if he/she had a SGI claim.

C.3.2.2 Growth in Knowledge and Skills

The second area of the survey focused on growth in knowledge and skills. Almost all respondents stated that they were more competent now in dealing with their family member than before the Pilot Project. Ninety-one percent of respondents strongly agreed or agreed that they are more confident in helping their relative, while eighty-five percent (85%) felt that they were more aware of how to support the community re-entry of their injured relative. Most family members (94%) felt that they understood their relatives' special needs better than before and were satisfied that the clients' strengths have been built on (88%). Almost all family members (90%) strongly agreed or agreed that they can handle the special challenges associated with their relative's acquired brain injury.

Families said that they had a better understanding about brain injury and how it affects their family member. They felt more confident in providing care and felt supported by the ABI staff. Criticisms dealt with having to wait for services, staff not having adequate time to spend with clients, and lack of support groups for families.

C.3.2.3 Utilization of Community Resources

The responses to this part of the survey indicated that families felt that they could utilize community resources better than before their involvement with the Pilot Project. Most respondents (88%) strongly agreed or agreed that they know more about community resources and programs pertaining to acquired brain injury. Eighty-six percent strongly agreed or agreed that they know how to obtain help from professionals when they want other programs or people to work with their relative. Ten percent of respondents did not know how to get this type of help from professionals. Most family members (85%) felt more confident in contacting programs and services in the community to help their relative, while nearly 8% did not feel confident in contacting these programs.

Many family members commented that coordination and referral to other community programs was good and they could access services through the help of ABI staff. Suggested improvements included increasing the number of staff to adequately meet client's needs, increasing services outside of the large urban area, and creating more services and awareness of existing services for people with an acquired brain injury.

C.3.2.4 Building a Support System

Most respondents indicated that they were well supported as a result of their involvement with the acquired brain injury pilot. Eighty-eight percent of families believed that they were as involved as they wished to be in the rehabilitation of their relative, while 9% wanted to be more involved. Most respondents (84%) revealed that they have more people that they can call on to help them or their family member, while 15 % of family members felt that they do not have more people to help them or their relative. A large number of family members felt less alone as a family member as a result of being involved with the ABI Pilot Project. Another 10% of families either still feel alone or never did feel alone as a family member.

Fifty-four percent agreed that they have sufficient resources for themselves as a family member, and 26% strongly agree. Seventeen percent of families still do not feel that they have sufficient resources for themselves. Most respondents (89%) felt that service providers work together more effectively (since the Pilot Project) and 8% of families did not think that services are better coordinated.

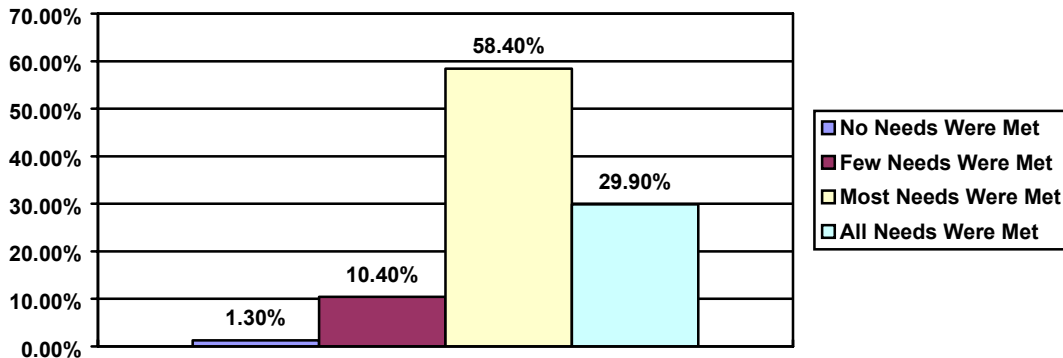
Most written comments in the area of building a support system expressed praise for the support the ABI Pilot Project extends to families. The biggest criticism was a lack of support groups for families. Some families expressed dissatisfaction with the lack of counselling, follow-up of clients, residential options, and appropriate services in rural areas. One person said that cultural involvement as a healing process is needed. Several people suggested that more staff and resources are needed.

C.3.2.5 General Satisfaction with the ABI Pilot Project

Most families expressed satisfaction with the Pilot Project and services that they received. Fifty-eight percent of families felt that most of their needs were met through the ABI Pilot Project. Thirty percent of family members felt that their involvement with the Pilot met all of their needs,

while 10% of respondents indicated that it met only a few of their needs. Only 1% said that the ABI Pilot Project met none of their needs. (See Figure 1)

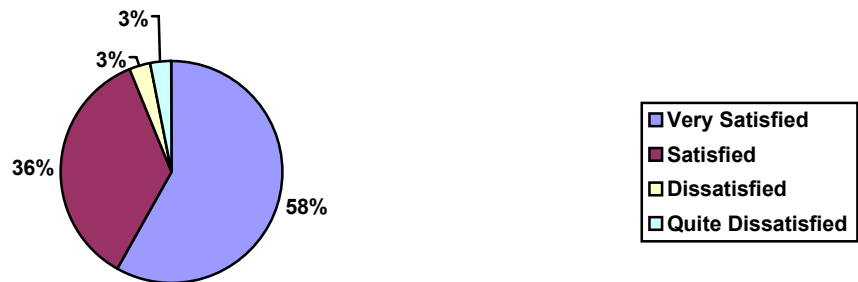
Figure 1 Family Needs Met Through ABI Pilot Project



Fifty-eight percent of families were very satisfied with the services that they received from the ABI Pilot Project and 36 % were satisfied with the services. A small number (2.6%) of respondents were dissatisfied with services while the same number were very dissatisfied with the services provided by the ABI Pilot Project. (See Figure 2)

Figure 2

Family Level of Satisfaction With Services Received Through the ABI Pilot Project



Families made numerous comments in response to the question of what they liked best about the ABI Pilot Project. Most comments centered on the dedication of staff and excellent services provided. The supported employment services, assessment skills, and support received from staff were praised. The next comment area requested their ideas for improvement to the Pilot Project. Suggested improvements included increases in funding as well as increases in the numbers of staff and therapists; services for people more than three years post –injury; and residential options. They identified a need for more support groups for families; more education and awareness for physicians and other health professionals; and more therapists and services in areas other than the larger cities.

One family member wrote:

“When things seemed hopeless and we were out of options, this project gave us hope. It has given L. some pride, some self-confidence, new friends and a role in life that he can handle. Most of all it has brought resources together within a community...it is a powerful link and has made all the difference.”

C.4 DISCUSSION

The clients interviewed were selected randomly, through a stratified sampling method (see methodology in the Appendix B). The researcher does not claim that those randomly picked are representative of all clients in the ABI Pilot Project. A variety of clients from different geographic areas were desirable since they might have different experiences due to their location in the province. The clients interviewed for the evaluation needed to be capable of two-way communication. This did not allow for input from those clients with more cognitive deficits who are also receiving services. Only 11 client interviews were used in the research. The people interviewed came from cities, small towns and rural areas in the province. The small number of interviews, and the fact that the researcher was only able to interview them once, makes it difficult to get a completely accurate picture of their experiences with ABI services. The fact that they did not know the interviewer could be viewed as an advantage or disadvantage depending on what individuals wanted to say. There were only two cases where the researcher interviewed the families after interviewing the clients (in the north) and was able to get a slightly broader picture of the clients and their lives. Clients and families who had individual interviews were able to read a summary of their interview and respond to it. One person responded with a request for a small change in the interview summary, and one person decided to withdraw participation in the research after reading the summary.

An evaluation using outcome measures was not done and will be carried out at a later date to assess changes in clients’ capacities as a result of using ABI services.

Time was a factor in the scope of this evaluation as a short time frame was required to meet the year-end of the funding agency. This limited the amount of time the researcher was able to spend interviewing clients.

Families in each of the three areas served by the outreach teams (north, central and south) attended group interviews (focus groups). The ABI outreach teams chose participating families. The coordinators were asked to include a variety of families - those served by SGI and others, and those whose family members were injured both pre- and post-1995. A specific focus group was comprised of parents whose children had sustained a brain injury, as the ABI Pilot Project has funded projects and specialized services serving pediatric clients. Two family members were not able to attend but sent letters indicating their experience with the ABI Pilot Project. It is possible that families who were less pleased with services did not agree to attend or were not selected by the ABI staff.

The provision of services means different things to different people who have sustained a brain injury. The people living in poverty in the north have unmet needs regarding basic housing, transportation, and accessibility for people with limited mobility. One client did not have a bed appropriate to his disability. Another did not have a room of his own. Although this may not be included in the mandate of the ABI Pilot Project, some thought needs to go into meeting basic client needs. As well, in the north, the extended families caring for clients are sometimes large, and some caregivers do not have information about the ABI Project or education about acquired brain injury. It may be difficult to get the whole family together to share the information. Another barrier to providing information about acquired brain injury is language. For many northern aboriginal people, English is a second language and there are no materials available in Cree or Dené.

In the area of coordination of care, there were differences between staff in the south and other staff. The members of the northern team emphasized that they were very short-staffed. Both staff in the north and the central areas stated that because there are no local coordinators at a district level, it has been harder to perform their duties. Without a resource person familiar with acquired brain injury at a local level, the outreach team members have needed to spend more time in each community arranging services and support, and often provide basic education about acquired brain injury. Travel to outlying rural areas is time consuming.

There were discussions about the use of case managers for managing client care. Some staff regard themselves as case managers while others believe that there is role confusion about who coordinates services for the client. Others said that designated case managers are needed in addition to the ABI staff who provide therapies to the client. There were comments about the location of the managers, specifically whether case management should occur in the area where the client lives or be centrally managed.

The survey for family members was given out to families during a time frame of several months. The survey showed a variety of responses ranging from very satisfied with many aspects of the services to a small number who were very dissatisfied with some services. It is not known whether those family members not returning the survey would have answered differently. The northern area of the province had the smallest return rate (only 13 surveys were returned) making it more difficult to get a good picture of opinions about services from those families living in the north.

The results of the survey did not differ significantly from the content of the family focus groups. Most families were very satisfied with the services provided by the Pilot Project. There seemed to be fewer comments in the survey from families of children in school, or those families may have responded to the surveys but did not comment on the work that the ABI team is doing with their children in the schools. The main difference in data gleaned from the survey is that there are people who have not received services and who are on waiting lists, or who were not allotted the time that they felt was needed. This supports staff comments about high caseloads and the need for additional personnel in the outreach teams. As well, criticisms of the Pilot Project from family members who responded to the survey show the same problems as were discussed in the focus groups. As well, one family member mentioned a need for cultural involvement in the healing process.

Not surprisingly, data from the focus groups and the survey shows that the north and the rural areas of the province are considered to have fewer available services, including therapies and residential services.

C.5 CONCLUSIONS

The ABI Pilot Project was well received by clients and families who were interviewed. Services that were appreciated include the personalized services available in the clients' home or community and the support given to both client and family. Specific therapies were often cited as crucial factors in clients' recoveries. Receiving help with re-integration back into the schools and work placements was a high priority for those interviewed. Many clients have few friends and efforts of the staff from the ABI Pilot Project to get them started with leisure activities and to get them involved in the community are important. Although clients who were within three years post injury were a priority of the ABI Pilot Project, many success stories were related concerning clients whose injuries occurred more than three years ago.

It is clear that the staff from the ABI Pilot Project play a tremendous role in helping families to access services and to cope. There were a substantial number of family members who felt that more emphasis needed to be placed on supporting the family, especially with support groups for family members only, or weekend educational and supportive sessions.

A list of all available services and facilities in the province for ABI clients is needed. A periodic newsletter could advise staff, clients and families of the activities of the funded projects, and could contain other practical and informative articles.

While outreach teams spend considerable time and effort in coordinating services for clients, difficulties are cited in accessing specialized therapies and programs in northern and rural areas. Services are mostly centered in the three largest cities and there are many recommendations to try to provide services in areas other than these large centers. More therapists such as physiotherapists, occupational therapists, and speech and language pathologists are needed to provide service in rural Saskatchewan. Small outreach teams, large caseloads, and a wide geographical area result in some difficulty providing adequate follow-up for clients and families. There are differences between the roles of the outreach teams in the north, central and south regions. Most respondents recommended a service provision model using local coordinators as exists in the southern region.

More residential options need to be available both for respite services to give families a break and for residences for young people who can't live on their own. As well, many respondents identified a lack of programming for life skills and pre-vocational training. Services for clients who had problems with drugs and alcohol are also seen as inadequate.

Even though the ABI Pilot Project has only been fully implemented for a short period of time, it is a successful model and has provided a valuable service both to people who have sustained an acquired brain injury and to their families. One family member commented:

“Our son is about to start on sort of a work experience program so we are really pleased at this point. At the beginning, it was scary because we went home and thought everyone else would understand and nobody understands unless they've been there... With the combination of SGI and the outreach [team] support... [it] was superb. We are very thankful for where we are today.”

D QUANTITATIVE INFORMATION: What the Numbers Tell Us

The ABI Pilot Project outreach teams and funded programs began collecting quantitative statistics in October, 1997. The statistics are submitted on a quarterly basis. This report contains information on the quarters October to December, 1997 and January to March, 1998, which are preliminary statistics. The information provided in the first quarter of the current report may not be completely accurate, as this quarter was used to introduce and trial the data collection forms. In addition, certain projects were not able to provide complete information for the first quarter. As a result, there is not enough information to conduct a full analysis of the data at this time. Therefore, a supplementary report will be developed which will include an analysis of more extensive data. The data in the supplementary report will also become the baseline for future data collection.

The statistics collected will be used to assist in answering the program evaluation questions that were generated at the beginning of the evaluation process.

D.1 IS THERE IMPROVED INTEGRATION / COORDINATION BETWEEN SERVICES?

The feedback provided by clients, families and service providers in the qualitative evaluation indicates that there have been perceived improvements in the integration and coordination of services for persons with acquired brain injuries. In order to capture data relevant to this question, the projects collected statistics on the type and number of referrals, episodes of care planning meetings and contacts occurring for follow-up services.

During the first two quarters of collection (October to December 1997 and January to March 1998), the outreach teams made 102 referrals to funded programs within the Pilot Project. The funded programs made a total of 62 referrals to the outreach teams. Statistics were also collected on interactions occurring with programs outside of the ABI Pilot Project. From October 1, 1997 to March 31, 1998 the funded projects received 30 referrals from the Education System in Saskatchewan. For the purpose of this evaluation, the Education System refers to schools and school divisions, teachers, regional colleges, SIAST and university programs. In this same time period, Rehabilitation Services made 69 referrals to the outreach teams. Rehabilitation Services includes health district therapies, rehabilitation centres, and community therapies. It does not include private practice therapists or centres. The funded projects also made 25 referrals to the Department of Social Services, including the Community Living Division, social workers, and Child and Family Services.

The outreach teams documented a total of 1,634 care planning episodes over the two quarters. Of these episodes, 259 were with the funded programs, 131 with Rehabilitation Services, 138 with SGI Adjusters and 76 with the Education System. The funded projects recorded a total of 905 care planning episodes, 84 of which occurred with Rehabilitation Services, 63 with the Education System and 39 with Residential Services. Residential services includes services such as approved

homes, long term care, housing authorities, special care homes, respite services, group homes, personal care homes, private care homes and landlords.

The Pilot Project programs collected information on follow-up activities in two categories: *Communication* and *In Person*. *Communication* refers to follow-up contacts occurring through phone calls, fax, e-mail, and voice mail. *In Person* implies that the worker met with the agency.

During the first two quarters, the outreach teams and funded projects reported 466 *Follow-Up Communication* contacts with each other. The funded projects tabulated 105 *Communication* contacts with the Education System, 76 with Other Health Care Professionals, and 102 contacts with Residential Services. The category, Other Health Care Professionals, includes physicians, nurses, pharmacists, psychologists, social workers, dentists, psychiatrists and nutritionists. The outreach teams registered 619 *Communication* contacts to clients, 438 to SGI Adjusters, 415 to Rehabilitation Services and 270 contacts to the Education System.

The *Follow-Up In Person* statistics reveal a total of 160 in-person contacts between the outreach teams and the funded projects. As well, the outreach teams met with clients to provide follow-up services 299 times over the two quarters of data collection. The funded projects met with members of the Education System 51 times. The qualitative evaluation indicates that parents particularly appreciated the support provided by the outreach teams in assisting children to return to school.

The outreach teams, and some funded projects, have also been collecting information on the time they spend travelling to provide service to clients. In two quarters, the outreach teams have spent 1,746 hours travelling, while the funded projects have spent 1,470 hours travelling.

D.2 HAS THERE BEEN AN INCREASE IN THE TYPES AND LEVELS OF SERVICE PROVIDED?

To respond to this question, the ABI Pilot Project programs were asked to collect information on the type of service they provide to clients and the amount of time they spend providing this service. This data was collected in order to determine if increased service is being provided during the period of the Pilot Project. We do not have any data on the amount of service provided prior to the Project therefore it is not possible to undertake a pre and post analysis.

During the first quarter, the funded projects provided a total of 6,041 hours of service to clients with acquired brain injuries. The outreach teams supplied 3,181 hours of service to clients. Sixty percent of the service hours provided by the outreach teams was spent on case management (1,910 hours), while only 9% of the service delivery provided by funded projects to clients consisted of case management (556 hours). Of the 6041 hours of service from the funded projects, 2,255 hours (37%) were spent providing therapeutic services, such as recreation and leisure activities, behavioural interventions, speech language interventions, nursing care, physical interventions, and occupational therapy interventions. In contrast, the outreach teams spent only 321 hours (10%) providing therapeutic services.

The funded projects are the primary service providers in the area of vocational and avocational support to clients. Career Headways and 3 branches of the Saskatchewan Abilities Council were funded to provide mainly vocational and avocational programming. In the first two quarters,

Career Headways provided 159 hours of service that was directly employment related and 1,519 hours of other related services. Programs delivered by the three branches of the Saskatchewan Abilities Council offered 656 hours of vocational and life enrichment programming. The remainder of the funded projects supplied approximately 184 hours of vocational training to clients and the outreach teams spent approximately 58 hours providing this service. This data reflects the role of the outreach teams as case managers, with the funded projects tending to provide more direct, rehabilitative assistance.

The ABI Pilot Project was also intended to increase services to families of persons with acquired brain injuries. During the first two quarters, the funded projects reported 1,062 hours of service provided to families. The Outreach Teams submitted 496 hours of services to family members. This number only reflects activity of two of the outreach teams, as one team was unable to provide this data during the first quarter.

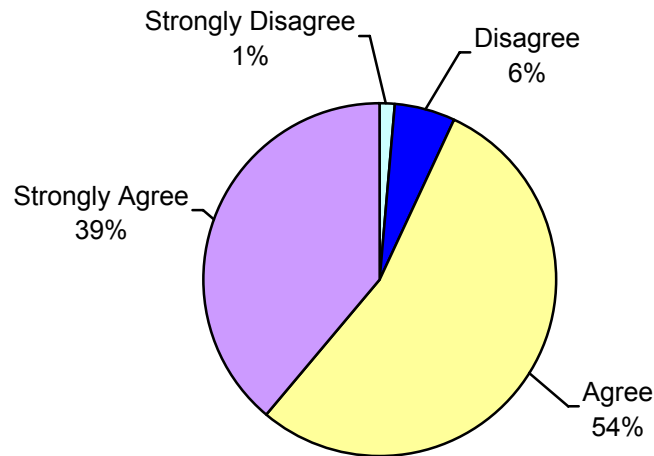
D.3 HAS THE AWARENESS OF THE COMMUNITY INCREASED FOR PERSONS WITH ABI AND THE SUPPORTS AVAILABLE TO THEM?

Several areas of the data collection process were created to address this question. The Funded Projects and Outreach Teams together contributed over 75 hours of training to family members and supporters to enable them to provide services to their family member with a brain injury. The Pilot Project programs also offered 213 hours of general education to family members and supporters, and 243 hours of client-specific education to communities. Client-specific education includes providing the community with information and resources to help them understand and meet the needs of a particular client. The qualitative evaluation indicates that family members are more aware and knowledgeable about ABI and the community resources available to them as a result of services provided.

Three questions on the Family Survey addressed the issue of awareness. A majority (88.1%) of the respondents agreed or strongly agreed with the statement “*I now know more about community agencies, services, and programs that can help our family and our relative with a brain injury*”. Most (85.9%) respondents also indicated that they know how to get help from professionals when they want others to become involved in providing service to their family member with a brain injury. In addition, 84.6% of participants in the survey indicated a higher level of confidence in contacting services and programs in the community. (See Figure 3)

Figure 3

Know More About Community Agencies, Services and Programs



In addition to the education hours offered through the Pilot Project, it is interesting to note the number of client and family self-referrals to Pilot Project services. Of the client and family referrals received by the outreach teams and funded projects, 120 incidents have been self-referrals from either the client or a family member. This does not imply 120 separate people being referred to the Pilot, as some clients or families may self-refer themselves to more than one project.

Education and training continues to be a priority for the ABI Pilot Project. In August, 1998 the Certificate Training Program in Home and Community-based Rehabilitation of Persons with Acquired Brain Injury – Level 1 was held at the University of Saskatchewan. One hundred seventy-five people attended the training, including health care and education professionals, as well as survivors and family members. A significant majority of these individuals were not employees of programs in the Pilot. In 1997, 53 people from Saskatchewan attended the same training in Edmonton, most of whom were employed through Pilot Project services.

D.4 HAS THE AWARENESS OF THE COMMUNITY INCREASED TOWARD PREVENTION OF ABI?

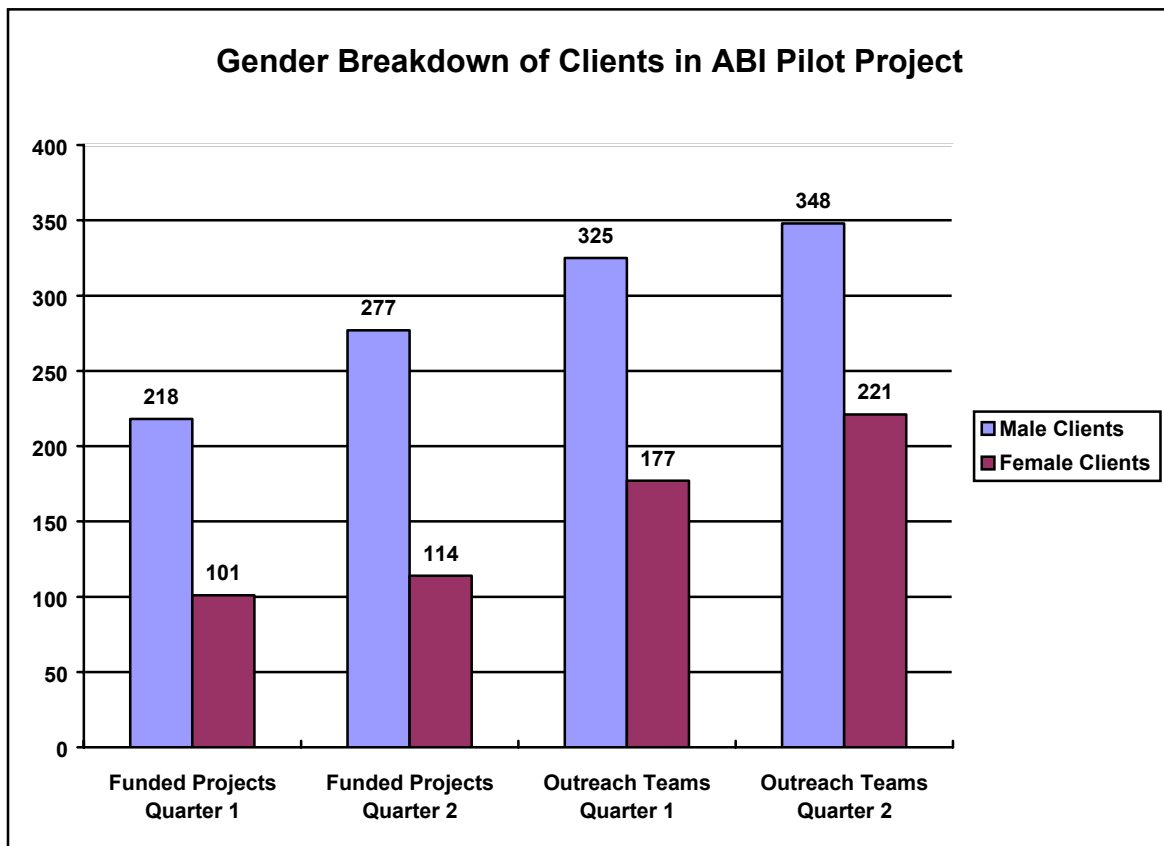
Although the pilot currently does not have an accurate measure of awareness with respect to prevention of ABI, education in this area continues to be offered through the funded projects, outreach teams and the ABI Education & Prevention Coordinator. From October 1, 1997 to March 31, 1998, over 312 hours of General Education have been provided to adults, children and professionals, with 5,891 people attending the various events.

D.5 DEMOGRAPHICS

As part of the data collection process, the Pilot Project programs collected basic demographic information in the areas of age, gender, place of residence and cause of injury. These statistics use the same definition as those provided by the Saskatchewan Client Information Profile – Intake (SCIP-I) forms. At the direction of Saskatchewan Health and the ABI Advisory Group, client identifiers were not used when collecting demographics. Therefore, the following statistics provided by the outreach teams and by the funded projects are inflated due to an overlap in clients. In many instances, one client can be receiving services from more than one program at a time.

For the purpose of these statistics, an active client is one who has received services in the applicable quarter. An inactive client is a client who has not received services in the past quarter. The majority of clients served by the ABI Pilot Project are male. In the first quarter, the funded projects had a total caseload (active and inactive) of 218 (188 active) males, and 101 (83 active) females. In the second quarter, the funded projects reported 277 (240 active) males and 114 (106 active) females. The outreach teams experienced a similar gender mix in caseloads. In the first quarter, they reported 325 (203 active) males and 177 (117 active) females. In the second quarter, these numbers had risen to 348 (199 active) males and 221 (144 active) females.

Figure 4



It also appears that a majority of the clients served by the ABI Pilot Project are between the ages of 23 and 65. This is a large age-span and needs to be broken down into more detail in the future. The funded projects reported a caseload of 220 (195 active) persons within this age category in the first quarter, and 279 (241 active) in the second quarter. The outreach teams' caseload in this age level was 303 (178 active) people in the first quarter and 328 (176 active) in the second quarter.

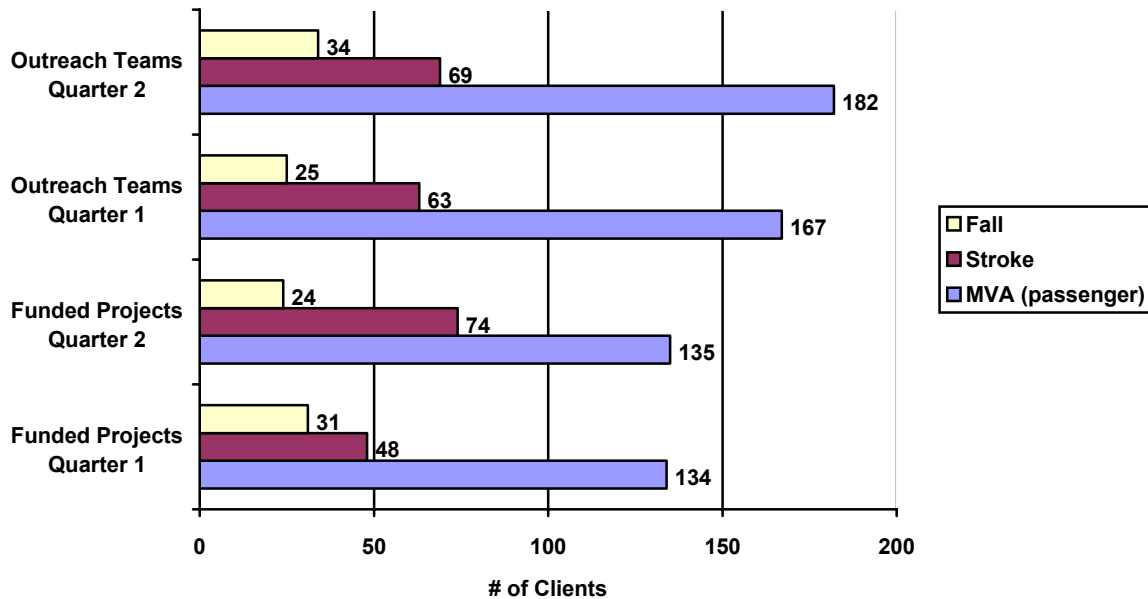
The ABI Pilot Project also targeted specific services towards children and youth. In the first quarter, the outreach teams documented 64 (53 active) clients under the age of 16, and 77 (57 active) in the second quarter. The funded projects reflected a caseload of 20 (20 active) clients under the age of 16 in the first quarter, and 32 (27 active) in the second quarter.

In addition, at the end of the second quarter the funded projects were serving 167 family members. The outreach teams had a caseload of 53 family members.

The leading cause of injury for clients served by the ABI Pilot Project, in both quarters, was motor vehicle accidents, where the survivor was either driving or a passenger in the vehicle. Strokes and then falls were the next highest causes of brain injury. (See Figure 5)

Figure 5

Major Causes of Injury for Clients In the ABI Pilot Project



A majority of clients served by the Pilot Project live in the community (independently or supported in a home or apartment). The funded projects reported 259 clients in this type of living situation in the first quarter and 322 in the second quarter. The outreach teams also reported a majority of clients in these residential arrangements, with 373 in the first quarter and 403 in the second. The funded project statistics showed 10 clients living in group homes in the first and second quarter, while the outreach teams showed only 2 for each quarter. The funded projects also recorded 24 clients living in special care homes, personal care homes or approved homes in the first quarter and 39 in the second. The outreach teams reported 31 clients living in institutional care settings in the first quarter and 26 in the second.

E PROVINCIAL CONSULTATION MAY, 1998

E.1 PARTICIPANTS

- Three Outreach Teams: Saskatchewan North, Central & South.
- Representatives from 25 funded programs (includes representatives from health districts directly involved in the ABI Pilot Project).
- Representatives from health districts not directly involved in the ABI Pilot Project.
- Members of the Provincial Advisory Committee.
- ABI Pilot Project Administrative Staff.
- SGI Personal Injury Specialists.
- Saskatchewan Health Management.
- SGI Management.
- Representatives from Workers' Compensation, Saskatchewan Housing/Municipal Government, Community Living/Saskatchewan Social Services.

A detailed participant list is available by contacting the Provincial ABI Coordinator.

E.2 GOALS OF THE CONSULTATION

A Provincial Consultation was undertaken with those stakeholders involved with the ABI Pilot Project who:

- Provide services and programs to individuals with an ABI and their families.
- Develop and deliver education and prevention programs in order to:
 - Share progress of the pilot project in meeting the objectives as outlined in the ABI Strategy for Services;
 - Identify what is still needed/what adjustments need to be made in programs and services for individuals with ABI and their families;
 - Develop concrete recommendations for future development of ABI services and programs; and
 - Provide a forum for networking and relationship building on a provincial level for those involved in service and program delivery within the scope of the ABI Pilot Project.

E.3 MORNING SESSION

Participants were provided with a brief history of the pilot project and an overview of activities undertaken since the launch of the Pilot Project in January, 1996.

Participants were asked to meet in regional groupings, North, Central and South to discuss three questions and to prioritize the top 5 issues identified from the discussion. An additional group consisting of those individuals interested in education and prevention were asked to meet together and to also discuss three questions and to prioritize the top 5 issues.

Results of these discussions are summarized in the following table (Table 1):

Table 1

Summary of Provincial Consultation

E.3.1 Regional Group Discussions			
Question	North	Central	South
<p><i>What is working well in our region with respect to the ABI Pilot Project?</i></p>	<ul style="list-style-type: none"> ➤ Awareness/Education and Understanding: <ul style="list-style-type: none"> ➤ community; ➤ family; ➤ clients; and ➤ team members. ➤ Network development/coordination. ➤ Commitment. ➤ Increased programming in communities. ➤ Prevention services: <ul style="list-style-type: none"> ➤ improved residential services & programming. 	<ul style="list-style-type: none"> ➤ Service provided has encompassed all areas of the individual including the spiritual, physical, psycho-social, intellectual and emotional needs. ➤ Client improvements are apparent in speech, physical ability, emotional well being and behaviour. ➤ A good job being done in developing services and expertise in the home community. ➤ Awareness of ABI is increasing in the business community and this community is making efforts to include and employ survivors or provide volunteer experience in the work place. ➤ Service providers enjoy what they do and have fun! ➤ A cohesive group of service providers in the area of ABI is being developed and becoming known as a good resource for ABI issues and a group for brainstorming or access to resources. ➤ Individual service providers are more efficient as a result of sharing caseloads. ➤ Linkages with education and leisure services are being well established. 	<ul style="list-style-type: none"> ➤ Function and role of district coordinators is unique to the south: <ul style="list-style-type: none"> ➤ ABI coordinators have knowledge of service areas and makes work of outreach teams easier. ➤ Outreach team is working with existing programs including home care, mental health, community living, acute care and rehab units to create a network of service and support. ➤ A good relationship has been developed with the SGI personal injury specialists. ➤ A continuity of service has been developed for individuals leaving active rehab. ➤ Communication between funded groups and outreach teams. ➤ Education support. ➤ Willingness to share resources. ➤ Increased awareness of ABI developing amongst health care workers in the community.

Table 1

Summary of Provincial Consultation

E.3.1 Regional Group Discussions			
Question	North	Central	South
<p><i>Based on our learning to date from the implementation phase of the Pilot Project, what needs are still not being met in our region for individuals with an ABI and their families?</i></p>	<ul style="list-style-type: none"> ➤ Lack of resources; the north has the largest geographic area to cover but the smallest staff. ➤ Residential services needed including: <ul style="list-style-type: none"> ➤ respite; ➤ young adults/children; and ➤ options closer to home. ➤ Vocational opportunities & career counselling. ➤ More awareness of ABI amongst: <ul style="list-style-type: none"> ➤ front line staff in health and community services; and ➤ community leaders. ➤ Difficult for rehabilitation assistants to take ownership of service delivery. 	<ul style="list-style-type: none"> ➤ Other health care providers are still not aware of the availability of ABI services. ➤ Mild ABI often not diagnosed or misdiagnosed as chronic pain. ➤ Emphasis on functional recovery results in a decrease in awareness of the impact of a possible brain injury and possible missed diagnosis. ➤ Family physicians lack awareness of the symptoms of ABI. ➤ Family support groups are not always appropriate for all families. ➤ Need for more vocational opportunities/meaningful activity. ➤ Additional funding for those individuals requiring individualized one on one support in the workplace. ➤ A need for increased communication between the Pilot Project and acute care. ➤ Need for increased advocacy. ➤ Lack of transportation services inhibits spontaneity. ➤ Increased funding for the extras for clients. ➤ A need to address sexuality issues for clients. ➤ Increased special education and life skills options for adults. ➤ Need to increase collaboration with bands regarding funding. ➤ More day programming needed. ➤ More pre-employment/life-skills programs. ➤ More housing options needed. ➤ More consistency between Social Services, Health and Workers Compensation Board. 	<ul style="list-style-type: none"> ➤ Absence of flexible residential services; need to cover the basics and get people stabilized and then work on social skills, work, etc. Need a wider range of residential options so people can stay in their community. In some instances there is nothing available. ➤ Service availability particularly in educational system not consistent in all areas. Educational system in urban areas tends to be less flexible especially for services for older students, 18 – 19 yrs. Rural systems tend to have more flexibility. ➤ Lack of ABI specific ABI/substance abuse resources. Training is needed but also specialized programs for those with ABI. ➤ Family burden issues: lack of respite and coping mechanisms, a need for education on family burden. ➤ Lack of programming for hard to serve populations-still not being well served: <ul style="list-style-type: none"> ➤ unemployable males 25-30 years of age; ➤ severe behaviour problems including sexually inappropriate behaviour; and ➤ extreme impairment- youth inappropriately placed in long term care facilities-not a good fit. ➤ Gaps in education for front line workers and caregivers. ➤ Difficulties in working with 3rd party funding systems. It is difficult to establish long term funding; Social Services/Community Living only provide short-term funding. ➤ Physicians not always aware of ABI services or ABI symptoms. Not an issue for Regina as much as other areas in the South.

Table 1

Summary of Provincial Consultation

E.3.1 Regional Group Discussions			
Question	North	Central	South
<p><i>What adjustments or modifications need to be made to service delivery and program development in order to more adequately respond to existing needs in our region?</i></p>	<ul style="list-style-type: none"> ➤ More staff and funding in order to more adequately program for such a vast area. ➤ Case Manager and Rehab. Assistant in each health district. ➤ Residential options to include transitional supportive living situations closer to home and in small communities. ➤ Vocational programming and opportunities. ➤ Continuing education for front line staff. ➤ Social Services to provide client specific funding for an advocate for the disabled. 	<ul style="list-style-type: none"> ➤ Review work load and resource allocation. ➤ Community ABI coordinators in each health district. ➤ Address inequities for people not covered by insurance. ➤ Realistic boundaries and policies need to be developed. ➤ Long-term care case management. ➤ Increase community awareness of ABI. ➤ Services should be based on need and not on diagnosis. ➤ Increase focus on needs of families. ➤ Review of administration – currently a dual structure. ➤ Strengthen linkages with aboriginal service providers. ➤ Work with Justice. 	<ul style="list-style-type: none"> ➤ Improvement needed in case management system. ➤ Develop solutions for ABI clients regarding substance abuse/addictions. ➤ Explore and expand residential options. ➤ Develop support/resources for families to prevent burnout. ➤ More coordination and involvement of other systems such as Education, Social Services, Justice, Housing, WCB. Need an inter-disciplinary approach. ➤ Increase education awareness of ABI with physicians and acute care staff. ➤ Better balance between coordinators and outreach service providers. ➤ Improve service to aboriginal people particularly those on reserves. ➤ Allocate resources based on local program development and needs. ➤ Designate case managers. ➤ More equity between public and third party clients. ➤ Enhance social/recreational opportunities. ➤ Develop/refine criteria regarding service provider roles. ➤ More education for service providers in the aboriginal community. ➤ Develop client-centred data base. ➤ Promote inter-disciplinary approach.

Table 1

Summary of Provincial Consultation

E.3.2 Prevention/Education Group	
<p><i>What is working well with respect to ABI education and prevention program development and delivery in the province?</i></p>	<ul style="list-style-type: none"> ➤ Prevention programs receiving strong support and assistance from ABI coordinators. Coordinators have helped to get foot in the door, assist with set up and movement of survivors for presentations, logistics, introduce to communities, publicity and supportive follow-up. ➤ Provincial ABI Education and Prevention Coordinator has been very open and willing to listen to new ideas, is doing a good job. ➤ Supporting accessibility to the level I certification in community and home based rehabilitation a positive action. ➤ Support and education provided to families through the provincial conference and retreat for women facilitated by SBIA. More opportunities now for non-professionals for education. ➤ Investment in staff in north a positive move. This will lead to identifying needs of communities and development of partnerships with community agencies to increase awareness and skill level of community agencies. ➤ Positive relationships and working in partnership with outreach teams. ➤ Awareness is being raised in health districts regarding prevention and education about ABI. This allows smaller communities to find ways of removing barriers and develop seamless services through education. ➤ Agencies appreciate access to educational resources. ➤ Education received from outreach teams has been excellent. ➤ Co-operative approach has encouraged SGI's involvement in education and prevention. ➤ Funding and recognition of projects at local level is appreciated. ➤ Community grants are appreciated. ➤ Overall impression that there is greater public awareness of ABI. ➤ Greater awareness of concussion in sport.

Table 1

Summary of Provincial Consultation

E.3.2 Prevention/Education Group	
<p><i>What gaps or needs still exist in the area of education and prevention program development and delivery in the province?</i></p>	<ul style="list-style-type: none"> ➤ Integration of information about brain functioning/injury with school curriculum. ➤ Post rehabilitation for family members and survivors – information/integrated approach to provide lifestyle information and support to survivor and family members – case management approach. ➤ Better information/resources available in language and format that is survivor and family friendly: <ul style="list-style-type: none"> ➤ culturally appropriate; ➤ starts where people are at; and ➤ language appropriate regarding North. ➤ Consumer and community information to remove stigma and reduce barriers. Some false perceptions and information out there. ➤ Survivors consumed with surviving. Need to promote understanding of that for community and families and employers. ➤ Support survivor and family support groups. ➤ Use Saskatchewan situations in prevention/education program. ➤ Better coordination of prevention initiatives. Departments of government and SGI need to coordinate. Encourage groups to focus on what they do well and cooperate with each other. ➤ Develop some standards for prevention and education. ➤ Some regular funding needed for prevention activity. ➤ Ease work of volunteers, use Outreach teams on regular basis. ➤ Referrals – educate community on how and who to refer individuals to. ➤ Formal caregivers in home care and special care systems need additional training in order to provide better care to people with ABI and behaviour management issues. ➤ More hands on, practical training needed. ➤ Professionals need to be aware of support family may need. Find ways of using experts to assist families ➤ More government collaboration is needed with non-government/volunteer community re: prevention and awareness projects. ➤ Cost of national conference in June is offensive and limits access. ➤ All training events and educational events should be accessible. High costs are a barrier.

Table 1

Summary of Provincial Consultation

E.3.2 Prevention/Education Group	
<i>What adjustments or modifications need to be made to existing education and prevention programs?</i>	<ul style="list-style-type: none"> ➤ Screen information for clear language, cultural relevance and accuracy. ➤ Provide more training to professional service providers. ➤ Use ABI experts to train professionals within community generic services. ➤ Educational materials need to be more interactive and more fun, not just lectures. ➤ Standardization and consistency of prevention and education. ➤ Promote co-operation/collaboration to improve cost effectiveness and efficiency. ➤ Look at costs of translating, using video and audio resources in Cree and Dené. ➤ Don't forget to listen to survivors and their families. ➤ More work/information/collaboration with recreation, sports organizations regarding concussion and sports injuries. ➤ Need to acknowledge/confirm that we are focussed on injury prevention relevant to motor vehicle collisions and sports - not all ABI prevention such as stroke

E.4 AFTERNOON SESSION

The facilitators and recorders from each regional group presented the priority issues resulting in the identification of several common themes. Participants were asked to meet in groups according to theme and develop specific recommendations to be taken into consideration for future planning of services and programs in the area of Acquired Brain Injury. The themes and recommendations developed during this process are described below together with recommendations from the Education and Prevention Group discussion:

E.4.1 Recommendations

E.4.1.1 Education and Prevention:

1. Language/format of materials and resources needs to be survivor/family friendly as well as culturally appropriate and at an accessible literacy level. Availability of materials in Cree and Dené would be beneficial.
2. Post rehabilitation information for family members and survivors needs to be available at a community level and available for professionals and education and school curriculum.
3. Community information on brain injury needs to be widely available in order to increase awareness and reduce barriers for those with an ABI as well as to increase support to families.
4. Education and training to be provided to formal service providers in home care and long term care sectors where ABI and behaviour management is an issue and concern.
5. Work with government departments to develop prevention curriculum directed at young people.
6. Collaboration between government departments, SGI and volunteer organizations on prevention, education. Development of different funding models.
7. ABI information needs to be included in formal training programs.

E.4.1.2 Vocational Training and Opportunities:

1. Vocational counsellor position to be added to each outreach team to support rural and northern areas.
2. Develop a glossary of terms for ABI, example: “Job Coach”.
3. ABI rep to get involved in PIND & SLFDP
4. More education to teachers regarding ABI.
5. Need readily available trained job coaches.
6. Recognize value formal & informal assessment level. Recognize various methods of assessment.

7. Consider pre-injury functioning when setting expectations for vocational pursuits post injury.

E.4.1.3 Coordination & Involvement of Other Systems:

1. Develop a strategy to provide awareness education about ABI targeted at special groups.
2. Give out or provide packages of information for professionals and ask to speak at a meeting.
3. Due to busy schedules, physicians and acute care nurses are a difficult group to educate. A general information package on ABI should be sent to College of Physicians and Surgeons, SMA etc.
4. Invite individuals from Education, Social Services, Justice, WCB, Private Insurance Companies, Canada Pension Plan, HRDC, Saskatchewan Medical Association, Saskatchewan Housing, Home Care, Saskatchewan Registered Nurses Association, Special Education, Recreation and Neuro Nurses, SARC at district and provincial levels. A provincial committee to be developed to include these individuals.
5. Pilot Project should contact the new Office of Disability Issues to find out what the role and mandate of this new department is all about and find out how to work together.
6. Develop a provincial directory listing - who to contact in each health district regarding ABI services.

E.4.1.4 Addictions and Substance Abuse:

1. Need ABI- specific addictions assessment tools dealing with such areas as seizure issues and medical approaches.
2. Long term residential treatment program needed including life skills training and recreational opportunities.
3. Provide education to addictions counsellors and NNADAP.
4. Research needed regarding best practices in the area of ABI and addictions.
5. Enhanced community-based specialized follow-up resources.
6. Specific addictions training for ABI workers.
7. Explore ethics/feasibility of mandatory treatment.

E.4.1.5 Leisure/Recreational, AVocational and Meaningful Activity:

1. Provincial meetings to discuss current services and share ideas, problem solve, lobbying.
2. Transitional community recreation therapists to be employed by health districts.
3. Work with the Saskatchewan Brain Injury Association to develop initiatives to address leisure and recreational needs provincially.

4. Volunteer agency to coordinate support persons, volunteers to support individuals in their leisure with the ideal goal of becoming volunteers themselves.
5. Lobby governments for improved transportation and accessibility funding.
6. Need to work with community recreation directors to address lack of leisure opportunities in rural areas.

E.4.1.6 Programs and Services for Hard to Serve Clients:

Includes:

- 23-50 years, unemployable.
 - Individuals with severe behaviour problems.
 - Young adults with severe cognitive and physical impairments requiring assistance with daily living.
 - Individuals with sexually inappropriate behaviour.
 - Individuals who have exhausted many systems and programs.
 - Individuals who do not have family or community support or co-operation.
 - Individuals with motivational issues.
1. Individualized service is vital for this group of people.
 2. Multi-system/service delivery is required.
 3. Walls and barriers must become invisible.
 4. Funding issues need to be addressed.
 5. Education and supported personnel to be in place.

E.4.1.7 Family Burden:

1. ABI education for community counsellors.
2. Education for ABI teams regarding when to refer.
3. Increased family awareness regarding respite (what is available).
4. Education for families including siblings:
 - education day for families with separate groups for parents, young children adolescents;
 - if smaller groups are arranged be sure to address population cohesiveness; and
 - connect with those who have already established programs.

E.4.1.8 Residential/Housing Options:

1. Develop regional group homes/transitional living programs with appropriate staffing. Services needed would span the vast range of residential needs.
2. Develop an outreach system that would be attached to the above which would provide monitoring to those living independent on an as needed basis (daily, monthly weekly).

3. Develop (or expand as in Regina and P.A.), the monitoring system for those in their own dwelling/apartment etc.
4. Organize with the support agencies or service clubs to provide furniture etc.
5. Work with Saskatchewan Housing to try and develop some options for the ABI population to access low income housing. Start with regional offices. Many ABI clients are single young men who currently don't qualify for affordable housing.

E.4.1.9 Case Management:

1. Change name to case coordination/advocacy.
2. Provide education to the most constant person (i.e.: family, friend, caregiver etc.) to be "case manager".
3. Avoid situation such as using person with conflict of interest. (i.e.: people controlling finances).
4. No one agency can be sole "case manager" but as much as possible maintaining consistency, shared responsibility and continuity of service.
5. All service providers should be provided with education in case coordination and be expected to practice these skills.
6. Expectation that ABI outreach team can "case manage". This is not realistic, ownership for this must be passed on.
7. Meeting between all services gives great case management – great concept but takes a lot of time and coordination in the long term.

E.4.1.10 Challenges to Delivery of Services in Remote Areas:

1. The issue of travel with respect to time required as well as travel conditions and budgetary considerations should be taken into account when developing programs.
 - travel has not been factored into staffing requirements
 - staff working in the north spend about 25% of their time travelling therefore 1 full-time equivalent (FTE) in the south is essentially 1.25 FTE in the north.
 - weather and forest fires are hazards which limit travel and access to clients in certain areas during certain times of the year.
 - travel budgets for staff and clients need to reflect that transportation is not always readily available. In some communities, there is only one taxi and burden of locating transportation is placed on the family.
 - staff may need to make several trips to a remote community or stay several days in order to assist client/family to set up supports. This will also include community education.

2. In order to prevent staff burnout, ensure staff have clearly defined expectations and know of the time commitment required for a position in a remote area. This information needs to be consistent regarding health districts and outreach teams.
 - confusion exists regarding definition of *Overtime* and *Time Off* between health district and outreach teams in the north. The rehabilitation assistants who are employees of the health districts are given mixed messages.
3. An ABI community coordinator is required in remote areas to facilitate linking client with appropriate resources. Ideally every health district should have an ABI coordinator.
 - Sometimes the resources are available however the client does not know how to access them.
4. An advocacy program is required in remote areas to assist individuals in moving or accessing services outside their home community.
 - Often individuals from remote areas, particularly the north, do not know how to use a pay phone, access taxi services or even speak English.
5. Ensure that information for front line staff in health districts is not just sent to Community Service Coordinators.
 - Information about training opportunities, consultations etc. is often not passed on from senior levels due to time constraints. Senior staff often don't have time to communicate with front line staff.
6. Remote communities need easier access to therapists. There does not seem to be a coordinated plan for support to individuals with disabilities at a community level. Too many people still need to move to larger centres for housing and services.

F Results of the Evaluation, Recommendations and Proposed Action Plan

RESULTS OF THE EVALUATION:

Clients and families who participated in the evaluation process indicate a high level of satisfaction with the services received through the ABI Pilot Project. Services that are appreciated include the personalized services available in the client's home or community and the support given to both client and family. Clients who were within three years post injury have been, and are, a priority of the ABI Pilot Project. However, many success stories were related concerning clients whose injuries occurred more than three years ago and who greatly valued the increased availability of services and programs now in existence.

Input from clients, family members, staff and other professionals knowledgeable about Acquired Brain Injury has provided valuable direction to future service delivery and program development in the area of ABI in the Province of Saskatchewan. Specific results of the Evaluation as well as recommendations and proposed future actions, are described below.

These findings are based only on the input received from those stakeholders who participated in the evaluation and may not reflect the views of all clients, family members, service providers and staff involved in the ABI Pilot Project. Additional details on who participated in the evaluation and how these individuals were chosen can be found in Appendix B which describes the methodology used in the Qualitative Evaluation.

The evaluation of the ABI Pilot Project has demonstrated that:

- There is a high level of satisfaction amongst survivors and families with respect to the services and programs provided through the ABI Pilot Project. In general, services and programs are reported as being both valuable and beneficial.
- Survivors and families find that there is now more support available to them than existed prior to the Pilot Project.
- Survivors particularly valued the assistance they received through the Pilot Project with respect to returning to work or school and finding new leisure activities.
- Survivors appreciated having outreach staff meet with them in their home community decreasing the need to travel to urban areas for service.
- Family members found programs and staff to be responsive to their needs.

- Families expressed that they are more knowledgeable about ABI and more confident in dealing with their family's situation as a result of services received through the Pilot.
- Families reported that they are more aware of community resources and can utilize these resources better than before their involvement with the Pilot Project.
- Parents of children with ABI particularly valued the assistance provided through the Pilot in assisting their children in returning to school.
- Survivors and families appreciated the emotional support provided through the Pilot as well as the availability of resources to assist them in understanding the impact of the brain injury. Families expressed a strong desire to have more support groups and support networks developed in the future.
- Family members find that coordination of services has improved through the implementation of the pilot project. This coordination, however, was regarded by clients, families and staff as more successful in urban areas than in rural areas due to what is considered to be scarce resources with respect to therapies, residential options, home care and vocational opportunities in rural and small communities.
- The service delivery model that has evolved in the southern region comprised of an outreach team and community based ABI Coordinators, as well as other community based services, is the model preferred by the majority of staff from the Outreach Teams, funded programs and SGI.
- Both ABI and SGI staff regard their working relationships to be effective in coordinating services for clients.
- All staff involved in the pilot greatly valued the educational and training opportunities offered.
- Staff involved in the program indicated a need for increased coordination of prevention and education activities throughout the province.
- There is significant agreement amongst clients, families, and staff that gaps in programming and service still remain with respect to:
 - Residential options;
 - Appropriate resources for the treatment of substance abuse/addictions for survivors of ABI; and
 - Meaningful activity for those clients unable to return to work.

RECOMMENDATIONS AND ACTION PLAN:

The following recommendations and action plan have been developed by the Provincial Coordinator, Evaluation Assistant and Provincial Education and Prevention Coordinator, with input from the Provincial Advisory Committee and are based on the findings of the evaluation.

Recommendation #1:

Increase the number of ABI Coordinators, particularly in the central region, and increase human resources in the Northern Outreach Team in order to provide more comprehensive support to survivors and family members in rural and remote areas. The ABI Coordinator positions should include responsibility for case management, community development and community education.

Action:

- Discussions with the Sask Central Outreach Team indicate that a minimum of two, and if possible, three ABI Coordinator positions could be added to the Sask Central Region. Further discussions to take place with the Sask Central Team to determine where, based on identified need and current caseloads, these positions would be most beneficially located. The appropriate health districts will then be contacted for support and further development of this proposal.
- Based on our learning and experience to date with the ABI District Coordinator positions, an orientation program will be developed to assist the Sask Central Team as well as the relevant health districts and staff in development of these positions and services.
- Discussions will be initiated with the Prince Albert Health District and the Northern ABI Working Group to determine the additional human resources for the Northern Outreach Team.

Recommendation #2:

Review the scope and mandate of the services provided through the ABI Pilot with respect to the definition of ABI currently being used in the pilot project and priority for service to individuals who are within 3 years post-injury

Action:

- The Provincial Coordinator will seek direction from the Provincial Advisory Committee on this issue.

Recommendation #3:

Enhancement of community residential options particularly for individuals who display challenging behaviours and for young survivors who require intensive lifelong support.

Action:

- A working group will be developed to create a provincial strategy to improve residential options for individuals with ABI including identification of staffing needs and funding sources to meet the residential needs of those with challenging behaviors. Possible options to be considered will include:
 - Further exploration of the health/housing partnerships currently being initiated in North Battleford and Prince Albert
 - Partnerships with Saskatchewan Housing and health districts to develop community-based options outside of the major urban areas.
 - An evaluation of Pearl Manor to determine the appropriateness of duplicating this model in other areas of the province.
 - Collaboration with long-term care to identify the needs of young people with ABI currently residing in long-term care facilities.
- An allocation of funding to be made within the next phase of the program for the implementation of recommendations of the working group.
- A provincial conference or forum will be developed focussing on residential options and exploration of models available in other parts of Canada and appropriate to Saskatchewan.

Recommendation #4:

Increased access to professional therapies for individuals in rural and remote areas.

Action:

This recommendation will be submitted for inclusion in the Provincial Rehabilitation Strategy currently being developed by Saskatchewan Health. The Rehabilitation Strategy is focussing on physiotherapy, occupational therapy, audiology, speech language pathology and respiratory therapy. It will make recommendations to Saskatchewan Health and health districts on ways to improve client-centered service delivery, accessibility, and coordination and integration of rehabilitation services.

Recommendation #5:

Given the significant numbers of individuals with ABI who require support for substance abuse and addictions, including problem gambling, continued efforts need to focus on education about these issues as well as the development of partnerships between those with expertise in substance abuse and addictions and those with expertise in the area of ABI.

Action:

- A Substance Abuse and ABI Workshop was held in May 1998 for all staff involved in the ABI Pilot Project followed by a one day training session for those staff most involved in clinical interventions with clients. Approximately 20 alcohol and drug counselors also attended a two hour presentation on this issue. This training will continue to be offered in the province.
- Collaboration will continue with the Saskatchewan Health Provincial Alcohol and Drug Program Consultant and with the Provincial Alcohol and Drug Working Group on development of appropriate educational resources for addictions workers.
- Collaboration to take place with the Saskatchewan Health Provincial Program Consultant on Problem Gambling on the provision of ABI training and resource materials to individuals working in the area of problem gambling.
- A comprehensive educational package is currently being developed in collaboration with the Sask Central Outreach Team and Saskatoon District Health. The package will contain information on a variety of issues, including substance

abuse, and will be a useful tool for survivors, family members, survivors, addictions workers and other professionals.

- Educational activities and resources will continue to be provided to all staff involved in the delivery of ABI services and programs.

Recommendation #6:

Vocational and avocational options need to include increased availability of life enrichment, day program and leisure activities for those individuals unable to undertake full-time, paid, competitive employment.

Action:

- Consultation will take place with appropriate stakeholders to develop a strategy to address needs in the area of life enrichment and day programming. Consultation will include reviewing the results of the Leisure Needs Assessment currently being facilitated by the Saskatchewan Brain Injury Association as part of the Neurotrauma Initiative.
- Current programs such as those offered by the Saskatchewan Association for the Rehabilitation of the Brain Injured (SARBI) and the Lloydminster and Area Brain Injury Society (LABIS) will be reviewed to explore the possibility of expanding these programs as well as developing similar programs in other areas of the province.
- Continuation of funding support is recommended for the existing vocational programs and services being funded through the Strategy. A focus for additional funding will be for the development and implementation of a life enrichment strategy.

Recommendation #7:

Enhance and develop different kinds of support networks for families of survivors.

Action:

- Exploration of other models and kinds of supports needed by families.
- Expand role of Rehabilitation Assistants in Northern Saskatchewan to include responsibility for development of local support networks.

- The new ABI Coordinator positions recommended for the Central Region will be developed to include this responsibility similar to the current role of the ABI Coordinators in the Southern Region.
- Ongoing consultation with the Saskatchewan Brain Injury Association to facilitate collaborative relationships between the Association and ABI Coordinators and the Outreach Teams in the development of support groups and support networks throughout the province.
- The Outreach Teams and funded projects will be encouraged to continue in their mandate of providing support to family members.

Recommendation #8:

Continue to provide ongoing education for those working with individuals with ABI including family members and those in the health, education, leisure and justice sectors.

Action:

- A public education campaign on the issue of concussion will be developed and implemented in partnership with other provincial agencies including the Saskatchewan Sport Medicine Association, University of Regina.
- ABI clinical treatment guidelines and protocols regarding concussion will be explored. The Provincial Education and Prevention Coordinator will investigate national developments in this area as well as international resources. Endorsement by the Saskatchewan College of Physicians and Surgeons will be requested. Information will be distributed to the health districts for use in Emergency Rooms, Walk-In Clinics etc.
- The Provincial Education and Prevention Coordinator will focus on intersectoral collaboration to target specific sectors including acute care for identification of educational needs and appropriate training strategies.
- A comprehensive educational package is currently being developed in collaboration with the Sask Central Outreach Team and Saskatoon District Health. The package will contain information on a variety of issues and will be a useful tool for survivors, family members, teachers and other professionals.

Recommendation #9:

Prevention activities with respect to the causes of Traumatic Brain Injury must continue to be a priority. High risk behaviour is a primary cause of brain injury.

Action:

- Review and evaluate the current prevention strategy to determine future directions and priorities and consistency with priorities identified in the “Child Injury in Saskatchewan” Report prepared by the Saskatchewan Institute on Prevention of Handicaps.
- Pursue intersectoral partnerships and linkage with the Assistant Deputy Minister’s (ADM) Forum with respect to injury prevention for children.
- Research and implement prevention activities targeting adults.

Recommendation #10:

Increased coordination of prevention and educational activities to ensure consistency and accuracy of content.

Action:

- Regional intersectoral injury prevention roundtables will be developed to review prevention/educational activities and formulate a coordinating mechanism.
- Development of all new materials by programs involved in the Pilot to be coordinated, when possible, by the Provincial Education and Prevention Coordinator.

Recommendation #11:

Explore the development of a Provincial Directory of services and programs available in the Province.

Action:

- This need had previously been identified and will be a priority for the Provincial Education and Prevention Coordinator. Emphasis will be placed on developing a

mechanism that is easily maintained and updated given the changing nature of programs and services.

Recommendation #12:

Increase accessibility of education and prevention materials to those who require materials in languages other than English and/or in a non-written format.

Action:

- The Provincial Education and Prevention Coordinator will explore ways of making materials available in Cree & Dené as well as in Braille and by Audio Tape.

Recommendation #13:

Liase with other government departments as well as the aboriginal community and related organizations, including the Assistant Deputy's Forum to address ongoing program and policy development as appropriate.

Action:

- This activity will be a priority for the Provincial Coordinator who will also work in consultation with the newly developed Office of Disability Issues located within the Department of Social Services.

APPENDIX A – Evaluation Workplan

EVALUATION QUESTION	INFORMATION REQUIRED	SOURCE OF INFORMATION	METHOD FOR COLLECTING INFORMATION
Service Delivery			
a) Has there been improved integration/coordination of services?	Number of referrals from "who to who" (providers within and outside of district)	<ul style="list-style-type: none"> ➤ Utilization Reports ➤ Client Records ➤ Service Providers ➤ Clients ➤ Families ➤ Supporters 	<ul style="list-style-type: none"> ➤ Record review ➤ Surveys - follow-up <ul style="list-style-type: none"> - Duplication - "runaround" - timeliness - communication before and after program.
	Number of case care planning meetings/client - agencies involved	<ul style="list-style-type: none"> ➤ Utilization Reports ➤ Client Records ➤ Service Providers 	<ul style="list-style-type: none"> ➤ Record review ➤ Surveys - follow-up <ul style="list-style-type: none"> - Duplication - "runaround" - timeliness communication before and after program.
	Number of follow-ups/client - when, who, why	<ul style="list-style-type: none"> ➤ Utilization Reports ➤ Client Records ➤ Service Providers ➤ Clients/Families 	<ul style="list-style-type: none"> ➤ Record review ➤ Surveys - follow-up <ul style="list-style-type: none"> - Duplication - "runaround" - timeliness communication before and after program.
	Number of telephone calls/information sharing on a one-on-one basis regarding client	<ul style="list-style-type: none"> ➤ Client Records ➤ Service Providers 	<ul style="list-style-type: none"> ➤ Record review ➤ Surveys - follow-up <ul style="list-style-type: none"> - Duplication - "runaround" - timeliness communication before and after program.

EVALUATION QUESTION	INFORMATION REQUIRED	SOURCE OF INFORMATION	METHOD FOR COLLECTING INFORMATION
	Provider & client perceptions/viewpoints on service delivery	<ul style="list-style-type: none"> ➤ Service Providers ➤ Clients/Families ➤ Supporters 	<ul style="list-style-type: none"> ➤ Record review ➤ Surveys - follow-up <ul style="list-style-type: none"> - Duplication - "runaround" - timeliness communication before and after program.
b) Has there been an increased capacity (availability/ accessibility) of services for clients/supporter	Pre ABI services (type) Available	<ul style="list-style-type: none"> ➤ Health districts ➤ Outreach Teams ➤ Workload Data sheets 	Questionnaire
	Post ABI services (type) available	<ul style="list-style-type: none"> ➤ Health districts ➤ Outreach Teams 	Questionnaire
	Quantities of Services (pre & post) to ABI clients -# of clients with ABI - total units/service for ABI clients	<ul style="list-style-type: none"> ➤ Service Providers ➤ Health districts ➤ ABI Coordinator ➤ Outreach Team ➤ Assessment Form ➤ Progress reports ➤ Workload Data sheets 	Record Review - may need to develop a blank form for them to fill in
	Waiting times for clients to access services (pre/post) - by service	<ul style="list-style-type: none"> ➤ Client ➤ Family ➤ Supporter 	Survey
	Distance to services (by service type - pre & post)	<ul style="list-style-type: none"> ➤ Client ➤ Family ➤ Supporter 	Survey
	Need all of the above information for family/supporter	<ul style="list-style-type: none"> ➤ Client ➤ Family ➤ Supporter 	Survey

EVALUATION QUESTION	INFORMATION REQUIRED	SOURCE OF INFORMATION	METHOD FOR COLLECTING INFORMATION
Program Education			
a) Has the awareness of the community increased for persons with ABI and the supports available to them?	Community - specifics Knowledge of <ul style="list-style-type: none"> ➤ types of services available ➤ location of services ➤ access (who, where) ➤ symptoms, non-medical supports (school, work) for clients/family ➤ Number of self-referrals 	Community	Survey
b) Has the awareness of the community increased toward prevention of ABI?	Community -specifics Knowledge of <ul style="list-style-type: none"> ➤ risk activities ➤ methods of prevention ➤ focus on - children/parents ➤ adults, care givers, service providers, farmers/miners, blue collar, white collar 	Community	Survey
	**Accuracy of the information - look at coding surveys and compare to actual services in the area.		

APPENDIX B – Evaluation/Qualitative

Evaluation Methodology

Evaluation Goals:

The goals of the evaluation are:

1. To monitor the progress of the strategy implementation;
2. To assist in enhancing the development of the ABI Project;
3. To meet the requirements of the funder as described below.

SGI and Saskatchewan Health Expectations: (taken from the minutes of a meeting to discuss evaluation of the Pilot Project, held on December 10, 1996.)

“At this point, Saskatchewan Health and SGI were asked what they hoped to see in two years time. SGI hoped to have information that would support continued funding for the ABI Pilot Project. This would include demonstrated community awareness for the services developed and that the community considered these services of value. Saskatchewan Health hoped to see evidence of health districts having enhanced capacity to manage people who have sustained an acquired brain injury in an integrated and coordinated manner. Both hoped to see a framework in place for long-term evaluation, including improved rehabilitation outcomes and a client information system in place.”

In order to accomplish these goals, we focussed on integration and coordination of services, access to services, and whether felt needs were being met. We wanted to know about people’s experiences with the ABI Pilot Project and gave them a chance to state their views on the ABI Pilot Project, the successes, shortcomings or areas where they felt that gaps exist. We asked questions about education received regarding acquired brain injury, supportive services to clients, emotional support, and residency issues.

The framework for long-term evaluation and a client information system was not covered in the qualitative evaluation.

The qualitative evaluation utilized a variety of methods to find out perceptions and lived experiences with the program. We gathered information from clients of the Pilot Project

(people who have sustained an acquired brain injury), their families, staff who work in the Pilot Project, Project coordinators, people who are “experts” in the field and are familiar with this Pilot Project, and SGI Personal Injury Specialists.

Methodology:

The methods that were used to gather information are:

- key informant interviews (5);
- personal interviews with participants age 16 and over (12);
- survey to families of current clients of the ABI Pilot Project;
- focus groups with family members (4);
- focus groups with ABI Pilot Project staff and coordinators (6);
- Focus group with SGI Personal Injury Specialists (1);
- Interviews with families of clients of the ABI Pilot Project (2).

Key Informant Interviews:

The key informant interviews were set up and conducted by telephone. People who were asked to be key informants were sent a letter explaining the purpose of the research. When called to make the appointment for the interview, their consent to be interviewed by a fifteen to twenty-minute telephone interview indicated their consent to participate in the evaluation research. Persons who were selected for the key informant interviews were “experts” in their field, had a view of the Pilot Project overall, and in most cases had experience working with persons who had sustained an acquired brain injury before the program. These informants included physicians, people who worked in acquired brain injury treatment or rehabilitation, or re-integration of people with acquired brain injury to educational or vocational programs. The researcher took notes while she conducted the interviews over the phone. Care was taken not to disclose the identities of the key informants.

Personal Interviews with Clients of the ABI Pilot Project:

The interviews with clients took place in the clients’ homes, or an available office or meeting room when that was the clients’ preference. All the interviews were taped with the agreement of the client. The researcher conducted the interviews at times convenient to the clients. The interviews lasted up to one hour.

Client Characteristics:

Clients must have been previously or currently active in the ABI Pilot Project, 16 years of age and over; able to have two way communication with the researcher; understood and

signed a consent form; and their parent or guardian signed the consent as well if they were under 18 years.

Selection Process:

The area of Wollaston Lake was chosen by the ABI Evaluation Assistant and Provincial ABI Coordinator as one of the sites to conduct both family interviews and client interviews to get a picture of available ABI services in a northern community. For the rest of the province, the selection process consisted of choosing through stratified sampling. The random selection does not imply that the clients interviewed represent the views of other clients of the ABI Pilot Project in the province. The selection of clients was carried out throughout the province because there are differences in service provision in various areas in the province.

Random Selection through Stratification:

The three outreach team coordinators (from north, central and south areas) obtained a client list from their area, and the clerical person from each area randomly selected 25 names from the area list of clients who were 16 years of age and older. The area outreach team coordinators confirmed that the 25 people randomly selected were capable of two-way communication. If any of the clients could not communicate, or chose not to participate, the clerical person selected the next person on the list (after the person who was discontinued). The list of 25 people with their Saskatchewan Client Information Profile Intake (SCIP-I) forms was sent to the Provincial ABI Coordinator's office at Saskatchewan Health. The name, date of injury, whether in the Personal Injury Protection Plan (PIPP) or not, age, address and phone number was obtained. The name and identifiers of the clients were not revealed in the research.

The final selection process consisted of choosing through stratified sampling. Twelve clients were interviewed altogether. For each person selected randomly, an alternate was also chosen in case the first person did not agree or was unable to be interviewed.

The researcher planned to conduct four interviews in each of the three areas (south, central, and north). However, while four were conducted in the north area, in the central area only three were conducted, and in the south area five were conducted. The largest city in each area was used as a base from which to select clients: Regina (south); Saskatoon (central); and Prince Albert (north). Two clients were randomly picked from each area list to be interviewed in each of the larger cities. A client from a smaller centre (small city or town) from each area list was randomly chosen, with sufficient alternates if the person was unable or unwilling to participate. Finally, a person living in a rural area was randomly chosen from both central and south areas, with sufficient alternates. Given the interviews conducted in Wollaston Lake, no additional rural interviews took place in the north.

Approximately 50% of clients were those whose injury occurred before 1995, and the other half after 1995, allowing some comparison between the previous system of care and the ABI Pilot Project. We assured that at least 50% of those chosen for interviewing were clients under the PIPP program.

The ABI outreach team coordinators or their designates contacted the clients, who were randomly selected, to tell them about the research project. They asked clients if they were interested in receiving further information. If the clients expressed interest in the research, the Evaluation Assistant for the ABI Pilot Project, called them and sent them a letter. If a client initially agreed to participate, the Evaluation Assistant phoned them to tell them about the research and asked them if they wished to participate further. If the client was still interested in participating, the Evaluation Assistant arranged a time and location for the interview. She then sent them a letter with general information about the research, the interview questions, and a confirmation of the date and location of the interview. The ABI Evaluation Assistant made a reminder phone call to the client the day before the interview. Cathy Ellis conducted all the interviews. After the interview, the tape was transcribed, and a summary of their interview was sent to the client, so that they could make any changes they felt necessary to their interview, as well as to check for accuracy of the interviewer's comprehension of the interview. Twelve clients were interviewed altogether, and one client decided to opt out of the research after receiving the interview summary.

Survey of Family Members:

Due to time and financial constraints, the survey was not mailed to family members of clients who had sustained an acquired brain injury. Since the clients' names and addresses form the Pilot Project's database, it would have taken a great deal of time to find the appropriate contacts and addresses of family members. Instead, the outreach teams and funded projects gave a questionnaire survey to all families who had a family member currently receiving services from the ABI Pilot Project. Only one survey was given per client (to one family member.) For the purpose of this survey, family referred to spouse, or common-law partner; or, if the individual was a child, the parent or guardian received the survey. Adult children or siblings who were primary caregivers could have received the survey, but paid caregivers did not. The survey emphasized the areas of education, supportive services, emotional support, and coordination of services. The survey package contained a self-stamped, self-addressed envelope to return the survey by mail. The Evaluation Assistant coordinated the distribution, collection, and data entry of these surveys.

The survey instrument used was from the Family Support Service at the Bloorview-McMillan Centre in Toronto. The results were analyzed using the statistical program, Statistical Analysis for the Social Sciences (SASS). Cathy Ellis assisted in the analysis of the results. The survey of family members was especially useful because the evaluation committee decided not to interview ABI clients who were under 16 years of age, and an idea of the program's strengths and weaknesses could be obtained from

families of participants of all ages. The survey was sent to all families regardless of age of the client. Families that did not have written English skills were encouraged to use a family member to translate. If a family member was not available or appropriate as a translator, attempts were made to assist the individual to locate an alternate resource.

Focus Groups:

All focus group participants signed consent forms. The focus groups were taped. Focus groups typically lasted between one and a half to two hours. A note-taker was present in some of the focus groups as well as the facilitator.

Larger groups were divided into two smaller groups, as necessary in the same location. One focus group was conducted after the other.

Family focus groups consisted of a variety of family members whose sons, daughters, mothers, grandmothers, husbands and wives had sustained acquired brain injuries. Various family members from rural areas were present as well as those who lived in the cities. The focus groups took place in Saskatoon, Regina and Prince Albert.

The eleven focus groups consisted of:

- The Sask South Outreach Team (Regina);
- The Sask Central Outreach Team (Saskatoon);
- The Sask North Outreach Team (Prince Albert);
- The five ABI coordinators in southern Saskatchewan (Regina);
- The staff of funded projects in southern, central, and northern Saskatchewan (Saskatoon, two groups);
- SGI Personal Injury Specialists (Saskatoon);
- Families of Children with acquired brain injuries (Saskatoon);
- Families of Clients (Regina);
- Families of Clients (Saskatoon); and
- Families of Clients (Prince Albert).

The locations in brackets indicate where the focus group took place. The outreach teams identified the families for the focus groups with an emphasis on obtaining a balance of rural and urban families.

Interviews of Families in Wollaston Lake:

Two families were interviewed in Wollaston Lake. The interviews were done individually, and were done with the help of a local health worker as the translator. A summary of the individual interviews was returned to the participating families.

All family members who took part in the individual interviews signed a consent form.

Analysis of Data:

The researcher studied the transcriptions of the interviews for themes emerging from the data. All data was coded by themes. To strengthen the themes, the researcher used direct quotes as much as possible to give people who were interviewed a chance to have their own words describe their experience.

Sharing the Research Methods and Emerging Themes with the Evaluation Committee:

The Short-term Evaluation Working Group looked at the survey and interview instruments and gave feedback that the researcher incorporated into the survey and lists of questions where possible. When the emerging themes from the focus groups and interviews were identified, a summary of these was sent to the evaluation committee. Since members of the Short Term Evaluation Working Group were closely involved with many aspects of the ABI Project, they could discern whether the emerging themes “ring true” for them. If not, the researcher would have to revisit the data. Because of a short time frame, there was not an opportunity for a more participatory methodology.

Validation of Data Gathered with Those Participating in Interviews:

The clients of the ABI Pilot Project and the two family members who were interviewed received a summary of their transcript. If they felt that the summary did not represent a true picture of their experience, they let the researcher know in writing or spoke to her about it by phone.

The two families interviewed had the opportunity to look at the summaries of their interviews and to call the researcher if anything was incorrectly represented. During the key informant interviews, the researcher read what she had written as their responses back to them, and they had a chance to correct her if she made errors in her note taking.

Informed Consent:

Participation in all focus groups and interviews was voluntary. Everyone who participated was told that they could withdraw at any time. Each person was asked to sign a consent form. Everyone who signed a consent form as well as the key informants was sent the executive summary of the research.

Questions for ABI Program Participants

Minimum biographical data: Male or female, area, year of injury.

1. What kinds of services are you receiving since your injury? How did you find out about them?
2. What do you do on a daily basis? Do you get any help to do those things? Who helps you?
3. Do you have friends? What do you do with your friends or your family?

If you were injured before 1995 answer # 4 and #5.

4. What kind of help did you get before 1995? Where did you get it? How useful was it? What kind of help did you get after 1995? Where did you get it? How useful is it?
5. Can you talk about services you received before 1995, compared to the services you are getting now? In what way has your life changed since the ABI Project began in 1995?

Then everyone to go on to #6.

6. Are the staff knowledgeable about acquired brain injury?
7. Do staff share information with you in a way that you are satisfied with?
8. Are you informed about your progress in a way that you can understand?
9. Are you involved in the decisions that affect you? Do you have control over choices for services in your life?
10. Does your family have enough education about your brain injury and your needs?
11. Do you have some needs that are not being met now?
12. Can you think of ways to improve services for people with brain injury?
13. Is there anything else that you would like to say?

<p style="text-align: center;">Questions for Staff (working in one of the 22 programs or area coordinators) Focus Groups</p>

Confirm area (south, central or north); and main type of program:

- residential
- supportive community integration or employment
- other

1. What kinds of continuing education or training about acquired brain injury have you received through the provincial ABI Pilot Project? Do you have enough continuing education about acquired brain injury?
2. Have there been noticeable prevention education activities in your area. Please describe.
3. Do you have any comments about the effectiveness of the ABI Pilot Project as compared to available services previous to the Pilot?
4. Please comment on coordination of ABI services within areas and throughout the province.
5. What gaps do you see in services?
6. What is the overall impact of the services on people with acquired brain injury?
7. What improvements need to be made?
8. Is there anything else you would like to say?

Questions for Key Informants

1. Please describe in general your involvement in the ABI Pilot Project. (Area: north, central or south, and whether involved in treatment, administration, etc.)
2. What is the overall impact of the Pilot Project on people with acquired brain injury?
3. What kinds of acquired brain injury prevention or education activities are you aware of in the community through the provincial ABI Pilot Project?
4. If you were involved with people with acquired brain injury before the Pilot Project in 1995, please compare services for people with acquired brain injury before 1995, and services with the ABI Pilot Project?
5. From your perspective, what are the strengths of the Pilot Project? What are the weaknesses?
6. What changes or improvements are needed in the Pilot Project?
7. Is there anything else you would like to say about the ABI Pilot Project?

<p style="text-align: center;">Focus Group and Interview Questions for Families of Participants of the ABI Program</p>

Minimum biographical data: (north, south, central, age of family member with an acquired brain injury, year of injury)

1. What is your relationship to your family member with brain injury?
2. How are the services meeting the needs of your family member?
3. Please describe any needs that are not being met.
4. How do the services affect you as a family member? What services helped you the most?
5. What kinds of further education and information about brain injury have you been provided with through the project? How helpful has the educational material been to you? What other educational needs do you have regarding brain injury?
6. What kinds of brain injury prevention or education activities are you aware of in the community through the provincial Pilot Project?
7. What kind of emotional support do you receive regarding your family member with brain injury?
8. What are the strengths of the project? What are the weaknesses of the project?
9. What improvements need to be made in respect to services for people with brain injury?
10. Is there anything else you would like to say?

Focus Group for Saskatoon and Regina SGI Personal Injury Specialists

1. Do ABI staff have enough continuing education about acquired brain injury?
2. Do SGI Personal Injury Specialists have access to new research or information about acquired brain injury through the Pilot Project?
3. Have there been noticeable prevention education activities about acquired brain injury in your area? Please describe.
4. Do you have any comments about the effectiveness of the ABI Pilot Project as compared to existing programs previous to the Pilot?
5. Please comment on coordination of ABI services within areas and throughout the province.
6. How is coordination of services with SGI Personal Injury Specialists and the ABI staff? Describe ABI and SGI service coordination, from your perspective.
7. What is the overall impact of the program on people with acquired brain injury? Give some examples of stories of clients who are in the ABI Project. (In the transcript, the person's identity will be protected).
8. What gaps do you see in services?
9. Is there anything else you would like to say?

Information for Research Participants

DATE – 1998

For involvement in the evaluation of the Acquired Brain Injury Pilot Project.

Introduction:

This research is to evaluate the Acquired Brain Injury Pilot Project in Saskatchewan. The purpose is to see how the ABI Pilot Project has affected the lives of those with acquired brain injury and their families. Researchers will look at the effectiveness of the Pilot Project from the point of view of clients in the program, families of those with acquired brain injury, staff and other people working with clients of the ABI Pilot Project.

Saskatchewan Health is carrying out the evaluation.

Your Participation in the Evaluation:

A researcher will interview between 10 and 15 people in Saskatchewan who are clients in the ABI Pilot Project.

- If you consent to be interviewed, the interview will take about one hour.
- You could be interviewed in your home or another place.
- The interviewer will ask you about your life since you had the injury and how you are involved with the ABI Pilot Program.
- Cathy Ellis is the interviewer. She is a nurse with training in research.
- Your interview will be taped unless you do not want it taped. In that case, the interviewer will take notes.
- Your name will not be used in the interview. Identifying information about your injury will not be used in the report.
- After the interview, we will send you a summary of what you have said. If you want to add or change something, you can do this by phone to the ABI evaluation office at Saskatchewan Health.

Risks of Participation in the Evaluation:

- There are no anticipated side effects.
- When you talk about your experiences with acquired brain injury, it may bring up difficult memories and subjects.

- One of your workers at the ABI Project can talk to you about difficult subjects and memories if you wish.
- If there are questions that you do not want to answer, you can leave them out.

Potential Benefits of the Evaluation:

- The evaluation should be able to point out positive aspects and service gaps in the ABI Pilot Project.
- If there are things that need to be changed in parts of the Pilot Project, the evaluation can make these recommendations.
- Some services may be improved as a result of the evaluation.

Voluntary Participation:

- Taking part in the evaluation and the interview is voluntary.
- Taking part or not taking part will not affect your treatment in the ABI Project, now or in the future.
- If you choose to take part, you can still withdraw at any time.
- You will be asked to sign a consent form before the interview.

We will call you by telephone to confirm the date and time of the interview.

If you have any questions, please call one of the people listed below.

- Janine (Johns) Bonokoski, Evaluation Assistant at Saskatchewan Health.
 - Phone: 787-1512
- Darlene Bessey, ABI Provincial Coordinator, Saskatchewan Health.
 - Phone: 787-6949

Sincerely,

Cathy Ellis
Interviewer for the Acquired Brain Injury Pilot Project Evaluation

Consent to Participate in Research

I, _____ volunteer to take part in an evaluation of the experience of people involved in the Acquired Brain Injury Pilot Project.

I understand that:

- My taking part in the evaluation is voluntary.
- I may withdraw from the evaluation at any time.
- Taking part, or not taking part or withdrawal will not affect my participation in the ABI Pilot Project.
- The interview will be tape-recorded.

I understand that people will not be able to identify me:

- My name will not be used.
- Description of my injury, which might identify me, will not be used.
- Only the researchers at Saskatchewan Health will hear the tapes or see the written copy of what I have said.
- The tapes will be erased as soon as the evaluation is completed, and the typed copies will be destroyed three years after the evaluation is completed.

Date	Signed by Participant
Date	Signed by Researcher

I can contact the people listed below about the evaluation.

- Janine (Johns) Bonokoski, ABI Evaluation Assistant, Saskatchewan Health:
 - Phone: 787-1512
- Darlene Bessey, ABI Provincial Coordinator, Saskatchewan Health:
 - Phone: 787-6949

<p style="text-align: center;">Information for Research Participants (for Family Members of ABI Clients)</p>

DATE -- 1998

For involvement in the evaluation of the Acquired Brain Injury Pilot Project.

Introduction:

This research is to evaluate the Acquired Brain Injury Pilot Project in Saskatchewan. The purpose is to see how the ABI Pilot Project has affected the lives of those with acquired brain injury and their families. Researchers will look at the effectiveness of the Pilot Project from the point of view of clients receiving services, families of those with acquired brain injury, staff and other people working with ABI clients.

Saskatchewan Health is carrying out the evaluation.

Your Participation in the Evaluation:

A researcher will carry out several group interviews of families of clients in the ABI Pilot Project. These group interviews are called focus groups.

- If you consent to be interviewed, the focus group will take about two hours.
- You could be interviewed in your home or another place.
- The interviewer will ask opinions about services your family member is receiving.
- Cathy Ellis is the interviewer. She is a nurse with training in research.
- The focus group will be taped.
- Your name will not be used in the interview. We do not want to identify you. Details about your family member will not be mentioned in the evaluation report, or will be changed so that others do not identify you or your family member.
- If you have to travel or get a respite caregiver for your family member in order to be able to come to the focus group meeting, an honorarium will be given to you.

Risks of Participation in the Evaluation:

- There are no anticipated side effects.
- When you talk about your experiences as a family member of someone with acquired brain injury, it may bring up difficult memories and subjects.
- One of the workers at the ABI Project can talk to you about difficult memories if you wish.

- If there are questions that you do not want to answer, you can leave them out.

Potential Benefits of the Evaluation:

- The evaluation should be able to point out positive aspects and service gaps in the ABI Pilot Project.
- If there are things that need to be changed in parts of the Pilot Project, the evaluation can make these recommendations.
- Some services may be improved as a result of the evaluation.

Voluntary Participation:

- Taking part in the evaluation and the focus group is voluntary.
- Taking part or not taking part will not affect your family member's treatment in the ABI Project, now or in the future.
- If you choose to take part, you can still withdraw at any time.
- You will be asked to sign a consent form before the focus group.

We will call you by telephone to confirm the date and time of the focus group and to see if you require assistance for travel or respite care.

If you have any questions, please call one of the people listed below.

- Janine Johns, Evaluation Assistant at Saskatchewan Health.
 - Phone: 787-1512
- Darlene Bessey, ABI Provincial Coordinator, Saskatchewan Health.
 - Phone:787-6949

Sincerely,

Cathy Ellis
Interviewer for the Acquired Brain Injury Pilot Project Evaluation

Consent to Participate in Research (for family members)
--

DATE -- 1998

I, _____ volunteer to take part in an evaluation of the experience of people involved in the Acquired Brain Injury Pilot Project.

I understand that:

- My taking part in the evaluation is voluntary.
- I may withdraw from the evaluation at any time.
- Taking part, or not taking part or withdrawal will not affect my family member's receiving services from the ABI Pilot Project.
- The interview will be tape-recorded.

I understand that people will not be able to identify my family member or me:

- My name will not be used.
- Description of my family member's injury, which might identify us, will not be used.
- Only the researchers at Saskatchewan Health will hear the tapes or see the written copy of what I have said.
- The tapes will be erased when the evaluation is completed, and the typed copies will be destroyed three years after the evaluation is completed.

Date	Signed by Participant
Date	Signed by Researcher

I can contact the people listed below about the evaluation.

- Janine (Johns) Bonokoski, ABI Evaluation Assistant, Saskatchewan Health:
 - Phone: 787-1512
- Darlene Bessey, ABI Provincial Coordinator, Saskatchewan Health:
 - Phone: 787-6949

<p style="text-align: center;">Information for Research Participants (for interviewing family members of Acquired Brain Injury clients)</p>

DATE --1998

For involvement in the evaluation of the Acquired Brain Injury (ABI) Pilot Project.

Introduction:

This research is to evaluate the Acquired Brain Injury Pilot Project in Saskatchewan. The purpose is to see how the ABI Pilot Project has affected the lives of those with an acquired brain injury and their families. Researchers will look at the effectiveness of the project from the point of view of clients who are receiving services, families of those with an acquired brain injury, staff and other people working with ABI clients.

Saskatchewan Health is carrying out the evaluation.

Your Participation in the Evaluation:

A researcher will carry out several interviews of families of clients in receiving services. These interviews will be carried out on an individual basis in your own community.

- If you consent to be interviewed, the interview will take about one to one-and-a-half hours.
- You could be interviewed in your home or another place.
- The interviewer will ask your opinions about the ABI Pilot Project.
- Cathy Ellis is the interviewer. She is a nurse with training in research.
- The focus group will be taped.
- Your name will not be used in the interview. We do not want to identify you. Details about your family member will not be mentioned in the evaluation report, or will be changed so that others do not identify you or your family member.
- If you have to travel or get a respite caregiver for your family member in order to come to the focus group meeting, some money will be given to you to cover these expenses.

Risks of Participation in the Evaluation:

- There are no anticipated side effects.
- When you talk about your experiences with acquired brain injury, it may bring up difficult memories and subjects.

- One of the workers at the ABI program can talk to you about difficult memories if you wish.
- If there are questions that you do not want to answer, you can leave them out.

Potential Benefits of the Evaluation:

- The evaluation should be able to point out positive aspects and service gaps in the ABI Pilot Project.
- If there are things that need to be changed in parts of the Pilot Project, the evaluation can make these recommendations.
- Some services may be improved as a result of the evaluation.

Voluntary Participation:

- Taking part in the evaluation is voluntary.
- Taking part or not taking part will not affect your family member's treatment in the ABI Project, now or in the future.
- If you choose to take part, you can still withdraw at any time.
- You will be asked to sign a consent form before the focus group.

We will call you by telephone to confirm the date and time of the interview and to see if you require assistance for travel or respite care.

If you have any questions, please call one of the people listed below.

- Janine Johns, Evaluation Assistant at Saskatchewan Health.
 - Phone: 787-1512
- Darlene Bessey, ABI Provincial Coordinator, Saskatchewan Health.
 - Phone: 787-6949

Sincerely,

Cathy Ellis
Interviewer for the Acquired Brain Injury Pilot Project Evaluation

ACQUIRED BRAIN INJURY PILOT PROJECT

Postal Code: _____

Date: _____

Satisfaction Survey (Family)

Please indicate how satisfied you were with services you received from the Acquired Brain Injury Pilot Project. For each item, put a check to show how strongly you agree or disagree with that statement. Your response to each statement is important to us.

GOAL I - Program and Staff Responsiveness

	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
The staff listened and responded to my concerns, questions, and ideas.	_____	_____	_____	_____	_____
In my meetings with staff (for assessments, treatment planning, etc.) I felt I was an active participant and not just a listener.	_____	_____	_____	_____	_____
Staff gave me information that was clear and useful to me.	_____	_____	_____	_____	_____
The help we received was based on our family's needs and priorities.	_____	_____	_____	_____	_____
I was informed of a variety of choices for how our family could be served.	_____	_____	_____	_____	_____
My opinions were used in treatment planning for my brain injured relative and our family.	_____	_____	_____	_____	_____
When I brought up a new concern, the team acknowledged and responded to it.	_____	_____	_____	_____	_____

Comments:

ACQUIRED BRAIN INJURY PILOT PROJECT

GOAL II - Growth in Knowledge & Skills

	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
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Because of my participation with the Acquired Brain Injury Pilot Project...

I feel more confident about how my family and I are helping our relative with the brain injury.

_____	_____	_____	_____	_____	_____
-------	-------	-------	-------	-------	-------

I am more aware of how to support the community re-entry of my injured relative.

_____	_____	_____	_____	_____	_____
-------	-------	-------	-------	-------	-------

I have a clearer picture of the abilities and special needs of my injured relative.

_____	_____	_____	_____	_____	_____
-------	-------	-------	-------	-------	-------

I feel satisfied that my injured relative's strengths have been recognized and built on.

_____	_____	_____	_____	_____	_____
-------	-------	-------	-------	-------	-------

I feel our family is better able to handle the special challenges associated with having a relative with a brain injury.

_____	_____	_____	_____	_____	_____
-------	-------	-------	-------	-------	-------

Comments:

GOAL III - Utilization of Community Resources

	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
--	-------------------	----------	-------	----------------	-----

Because of my participation with the Acquired Brain Injury Pilot Project...

I now know more about community agencies, services, and programs that can help our family and our relative with a brain injury.

_____	_____	_____	_____	_____	_____
-------	-------	-------	-------	-------	-------

I know how to get help from professionals when I want other programs or people to work with my injured relative and/or family.

_____	_____	_____	_____	_____	_____
-------	-------	-------	-------	-------	-------

ACQUIRED BRAIN INJURY PILOT PROJECT

	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
--	-------------------	----------	-------	----------------	-----

Because of my participation with the Acquired Brain Injury Pilot Project...

I now feel more confident in contacting services and programs in the community who might help our injured relative and/or our family.

_____	_____	_____	_____	_____
-------	-------	-------	-------	-------

Comments:

GOAL IV - Building a Support System

	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
--	-------------------	----------	-------	----------------	-----

Because of my receiving services from the Acquired Brain Injury Pilot Project...

My family is as involved as we wish to be in the rehabilitation of our injured relative.

_____	_____	_____	_____	_____
-------	-------	-------	-------	-------

I have more people who I can call on to help me and/or my injured relative.

_____	_____	_____	_____	_____
-------	-------	-------	-------	-------

I feel less alone as a family member.

_____	_____	_____	_____	_____
-------	-------	-------	-------	-------

I feel I have sufficient resources for myself as a family member.

_____	_____	_____	_____	_____
-------	-------	-------	-------	-------

My family member's support systems (professionals, agencies and service providers) are working together more effectively.

_____	_____	_____	_____	_____
-------	-------	-------	-------	-------

Comments:

ACQUIRED BRAIN INJURY PILOT PROJECT

GOAL V - General Satisfaction

For the following questions, please circle the number that best corresponds to your answer.

To what extent have the services you received through the Acquired Brain Injury Pilot Project met your needs?

4	3	2	1
All of my needs were met.	Most of my needs were met.	Only a few of my needs were met.	None of my needs were met.

Overall, how satisfied are you with the services you received from the Acquired Brain Injury Pilot Project?

4	3	2	1
Very Satisfied	Satisfied	Dissatisfied	Quite Dissatisfied

What did you like best about the Acquired Brain Injury Pilot Project?

What needs improvement with respect to services and programs for individuals with an acquired brain injury and their families?

Thank you for giving us this feedback!