

***Evaluation of the Saskatchewan  
Acquired Brain Injury Partnership's  
general services***

Prepared for the ABI Partnership Advisory Committee  
by Laurence Thompson Strategic Consulting  
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***Final report***

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## **Acronyms**

ABI	acquired brain injury
ABIIS	Acquired Brain Injury Information System (the Saskatchewan ABI Partnership database of acquired brain injury client information)
GCS	Glasgow Coma Scale (a widely used clinical scale to assess the severity of a brain injury)
MPAI	Mayo-Portland Adaptability Inventory (a detailed tool for assessing the impact of a brain injury on the functioning of an ABI survivor)
TBI	traumatic brain injury (from a blow to the head)



## Table of contents

<b>Summary.....</b>	<b>v</b>
<b>Background and process.....</b>	<b>1</b>
Evaluation history .....	1
Purpose of current evaluation .....	1
Requirements of the call for proposals .....	1
What this evaluation adds .....	2
The evaluation process .....	2
Evaluation frameworks .....	2
Summary of the evaluation process .....	4
<b>Methods.....</b>	<b>5</b>
Overview .....	5
Phase 1: Development of the evaluation plan .....	5
Phase 2. Data collection .....	5
Phase 3. Data analysis .....	5
Data collection .....	6
Interviews .....	6
Program data .....	7
Data analysis .....	7
Interviews .....	7
Registry data .....	7
Service data .....	8
Health region groupings .....	8
Financial data .....	9
Outcomes data .....	9
<b>Findings .....</b>	<b>11</b>
Data availability and quality .....	11
Interview data .....	11
Registration and service data .....	12
Outcomes data .....	12
Program design .....	12
1. Does the ABI program design match the original program design?	
2. Does the ABI program design incorporate new knowledge on effective programs since the original program was designed?	
Program implementation .....	15
3. Has the ABI program been implemented as originally designed?	
4. Does current implementation of the ABI program incorporate new knowledge of effectiveness? If so, how? If not, why not?	
Program description .....	15
5. What are the actual inputs, activities, outputs and outcomes of the current ABI program?	
6. How do they match or differ from those planned?	
Program improvement .....	16
7. Is the ABI program being implemented as efficiently as the current program design allows? If not, what are the opportunities for improving efficiency?	
8. Is the ABI program design as effective as current knowledge of ABI rehabilitation allows? If not, what are the opportunities for improving effectiveness?	

The client experience .....	17
9. How comprehensive is the service coverage of all potential clients?	
10. How accessible are services to clients? (hours, location)	
11. How acceptable are services to all clients? Do clients start to use services that are related to their needs?	
12. How continuous are services? Do clients continue to be engaged in services that are related to their needs?	
13. How effective are services in meeting realistic client goals and improving their ability to live as independently as possible and integrate into the community?	
Service characteristics .....	26
14. What are the characteristics of services provided, by program and by each client?	
The service provider / ABI survivor relationship .....	27
15. How important is the therapeutic relationship between ABI survivor and service provider?	
16. What are the characteristics of successful therapeutic relationships?	
Service access and equity .....	29
17. What is the availability of service?	
18. Are there geographic differences in the characteristics of services?	
Client characteristics .....	30
19. What are the characteristics of ABI survivors?	
Outcomes .....	31
20. What are the predictors of successful outcomes for ABI clients?	
<b>Conclusions .....</b>	<b>37</b>
Limitations .....	37
Discussion .....	37
Data quality and comprehensiveness .....	37
Principal evaluation questions .....	38
What has been added by this evaluation to previous evaluations .....	38
Recommendations .....	41
Status of recommendations from previous evaluations .....	41
Recommendations arising from this evaluation .....	42
<b>References .....</b>	<b>45</b>
<b>Appendix 1. Program logic models for planning and evaluation .....</b>	<b>47</b>
<b>Appendix 2. Planned program logic model for the ABI Partnership .....</b>	<b>49</b>
<b>Appendix 3. Client journey map for the ABI Partnership .....</b>	<b>54</b>
<b>Appendix 4. Ethics and operational approvals .....</b>	<b>55</b>
<b>Appendix 5. Consent forms for staff and clients and family .....</b>	<b>56</b>
<b>Appendix 6. Detailed program logic model indicators for the ABI Partnership: actual in relation to planned .....</b>	<b>64</b>

## Summary

### Background

In December 2009 the Saskatchewan Acquired Brain Injury (ABI) Partnership requested proposals for an evaluation of general services for ABI clients. The ABI Partnership selected Laurence Thompson Strategic Consulting (LTSC) to conduct this evaluation.

The ABI Partnership defined the principal evaluation question as: “What aspects of service delivery are most effective for eliciting positive outcomes for ABI survivors?” It required three components of the ABI program to be assessed:

- the therapeutic relationship;
- service availability; and
- client engagement with service.

This evaluation built on the four previous evaluations of ABI program general services to:

- present overall frameworks for continuing to develop the program;
- provide evidence on what works best to improve or maintain client outcomes;
- seek more family input on services; and
- re-assess program functioning and identify any gaps in programming.

### Methods

The evaluation was conducted from May 2010 to June 2011. It was based on a rapid review of published research studies world-wide, in-person interviews with 25 staff, 15 ABI survivors, and 11 family members across Saskatchewan, and a review of registration, service and outcomes data collected by the ABI Partnership from 2004 to 2010. LTSC carried out the research review and interviews and analyzed the interview notes and program data to prepare this report.

### Findings

The findings are organized by the 20 research questions used in the evaluation.

#### *Program design*

##### *1. Does the ABI program design match the original program design?*

The ABI program design remains close to the original program design laid out in 1995.

##### *2. Does the ABI program design incorporate new knowledge on effective programs since the original program was designed?*

Knowledge of effective programs has changed little since the program structure was designed in 1995. Generally, ABI Partnership programs are based on current knowledge.

#### *Program implementation*

##### *3. Has the ABI program been implemented as originally designed?*

The program is still being delivered largely as originally designed in 1995.

##### *4. Does current implementation of the ABI program incorporate new knowledge of effectiveness? If so, how? If not, why not?*

Staff attend annual professional development sessions for clinical knowledge. There has been little new knowledge of program effectiveness in community-based support of ABI survivors in the past 15 years. Suggested changes were listed in section 2 above.

##### *5. What are the actual inputs, activities, outputs and outcomes of the current ABI program?*

We used a program logic model framework to map the program.

##### *6. How do they match or differ from those planned?*

Inputs (funding and staffing) have been delivered as planned. Planned activities are generally implemented by funded programs. However outputs for most programs were only partly met, or, for two program components, clearly not met. While we estimate that most eligible ABI clients

are being engaged in programs by the outreach teams and regional co-ordinators, program outcomes of most other programs either were only partly not met, or there was insufficient data to assess whether they were met.

#### *Program improvement*

7. *Is the ABI program being implemented as efficiently as the current program design allows? If not, what are the opportunities for improving efficiency?*

There is wide variation among programs in the mix of programs delivered in each health region sector and in the program outputs per unit of input (funding dollars or staffing FTEs). This large variation suggests there are opportunities for improving efficiency or effectiveness or both by determining which mix of services results in the best client outcomes, and why.

8. *Is the ABI program design as effective as current knowledge of ABI rehabilitation allows? If not, what are the opportunities for improving effectiveness?*

The research review suggests more emphasis be put on specific cognitive and behavioural interventions; on ensuring referral for treatment of aggression, agitation, and attention and concentration with medication; and on family support. Another opportunity for improving effectiveness is the integration of the Mayo-Portland Adaptability Inventory (MPAI) outcome measure into clinical data collection for all clients. This data will improve the capacity of the ABI Partnership for internal evaluation and improvement through feedback on what services and programs are resulting in better client outcomes.

#### *The client service experience*

9. *How comprehensive is the service coverage of all potential clients?*

Intake of new clients in 2009-10 was just over 300 clients. We estimate the program reaches somewhere between all and one-third of those who might meet the criteria for services. Two regional sectors had markedly lower rates of new clients in 2009-10 compared to the provincial average: the North and Saskatoon Health Region.

One thousand fifty clients received service in 2009-10, about 100 clients served per 100,000 population. The North and Saskatoon Health Region had rates of service one-fifth lower than the provincial average, while Prince Albert Parkland and Regina Qu'Appelle Health Regions had rates more than one-fifth higher than the provincial average.

The differences in service coverage are partly related to per-capita funding allocations. Prince Albert Parkland and Regina Qu'Appelle Health Regions are funded and staffed well above the provincial average, while ABI services for health regions in the North, the Rural - South and the Rural - Central sectors are funded and staffed well below provincial averages.

10. *How accessible are services to clients? (hours, location)*

No clients or family members identified hours of access to service as an issue. Northern clients identified long distances to services and infrequent face-to-face contact with case managers as a concern. There are not direct service programs within the three northern health authorities.

11. *How acceptable are services to all clients? (Do clients start to use services that are related to their needs?)*

Almost all clients and family members would recommend to someone else to use ABI Partnership services. Most stated that their relationship with their primary program staff contact was going well. Clients and family members described their program staff member as helpful, caring, supportive, and understanding.

12. *How continuous are services? (Do clients continue to be engaged in services that are related to their needs?)*

There are few barriers to programs; clients can access programs through either internal, external or self-referral. Many programs will re-activate a client without the need for repeating a full intake process.



While three-quarters of clients use services for less than two years, some long-term clients do receive services for many years.

*13. How effective are services in meeting realistic client goals and improving their ability to live as independently as possible and integrate into the community?*

Clients experience very little change in their workforce or living status over time. The ABIIS data revealed that only four per cent of clients change their overall workforce status during their time in the ABI program; two per cent move from the unpaid workforce into the paid workforce, while two per cent move the other way.

Almost all clients who first receive services while in a dependent, supported, or independent living situation remained in the same situation in the year they stopped receiving services. Again, according to ABIIS registration data, only two per cent of clients changed categories of living situation while receiving ABI program services over the five years reviewed.

Clients achieve 62 per cent of the goals they set and partially achieved a further 29 per cent over the period 2007-09.

Staff reported a strong goal focus. In response to the question “How do you discharge a client?”, staff most often responded that their program discharged clients when goals are met. Staff use goal attainment to measure progress of clients.

*Service characteristics*

*14. What are the characteristics of services provided, by program and by each client?*

The most frequently provided services are case management, recreation and leisure, psycho-social and behavioural, and cognitive services.

*The service provider - ABI survivor relationship*

*15. How important is the therapeutic relationship between ABI survivor and service provider?*

Staff emphasized the importance of establishing a good relationship with a client as the basis for other interventions and support.

*16. What are the characteristics of successful therapeutic relationships?*

Clients and family members said that the factors that had helped them most were information and support, a good relationship with program staff, and advocacy and referrals.

Staff said that staff characteristics that help a staff-client relationship work well are empathy, compassion, and understanding from staff; respectful, non-judgemental staff; staff flexibility and creativity; and available and accessible staff.

Staff said that the staff-client relationships that work well are based on collaboration, equality and good communication. They reported that in their experience client - staff relationships break down when there is disagreement on goals, poor communication or rapport, problems with client accessibility to staff, lack of client motivation or lack of family or community supports.

*Service access and equity*

*17. What is the availability of service? and*

*18. Are there geographic differences in the characteristics of services?*

Rates of service are particularly low in relation to provincial averages in the North and the Rural - South. They are low for many, but not all, programs in the Prince Albert Parkland, Rural - Central and Saskatoon sectors. They are high compared to provincial averages for most programs in Regina Qu'Appelle.

*Client characteristics*

*19. What are the characteristics of ABI survivors?*

Almost all brain injuries have occurred within the past five years.

Over the six years from 2004-05 to 2009-10, half of clients' brain injuries were due to trauma (blows to the head) and half due to other causes (mainly tumours and stroke). We were not able

to assess severity because the Glasgow Coma Scale is collected for fewer than ten per cent of clients (six per cent in the most recent year).

In interviews, clients focussed on memory and cognitive difficulties as consequences of their injuries. Family members most often spoke of client emotional and psychological difficulties.

Staff emphasized family and community support and client motivation, insight and absence of mental health or addiction issues as important in client readiness for services.

### *Outcomes*

#### *20. What are the predictors of successful outcomes for ABI clients?*

We were unable to assess predictors of goal attainment, as these data are not reported on a client-specific basis, but only in aggregate.

Analysis of first and last living situation, employability, and workforce status of clients during up to a six-year period shows little change in these statuses between first and last registry reports.

MPAI assessment scores are a more sensitive measure than changes in workforce or living status. Analysis of the change in MPAI scores from first assessment to follow-up at 18 months showed that these scores do improve significantly between first and follow-up assessment for the small number of clients for whom these data are collected.

Clients with a low-functioning baseline score show greater improvement than clients with a higher-functioning initial score. Clients in the Saskatoon Health Region show substantially greater improvement (nine points on an approximately 100-point scale) compared to clients in any other health region. No specific services were associated with improved client outcomes in our analysis, but the analysis suggests that with more data the service “Therapeutic - Psycho-social & behavioural” as delivered to clients resident in the Saskatoon Health Region may be associated with improved outcomes for clients.

## **Discussion, conclusions, and recommendations**

### *Status of recommendations from previous evaluations*

From previous evaluations, there is still implementation work to do on:

- housing;
- integration or linkage of ABI programs with addictions services;
- support for meaningful activity;
- family support; and
- integration of outcome / progress indicators into the ABIIS.

### *Recommendations arising from this evaluation*

#### **Improvement of data collection, quality and management**

Collect outcomes data

1. Integrate goal setting and attainment data into the ABIIS.
2. Integrate the Mayo-Portland Adaptability Inventory into the ABIIS.

Improve data quality and usefulness by improving access and ensuring regular updating

3. Ensure on-line access to the ABIIS is easily available to all staff.
4. Reinforce with programs and staff the importance of regularly updating registration information.

#### **Service delivery improvement**

Improve Northern and rural service access

5. Improve service delivery in rural areas and especially the North.

Add research

6. Add a research component to the ABI Partnership.

Shift programming to interventions with evidence of effectiveness

7. Shift resources towards interventions with evidence of effectiveness.

Focus future evaluation on how services improve outcomes

8. Focus future evaluation on the relationship of services to improvements in MPAA scores.

Increase the focus on support systems

9. Ensure assessment of and service planning for the family support system.

10. Address housing issues in an integrated way with other community partners.

Explore service and funding variation and lags as opportunities for improvement

11. Explore why there is variation across programs in rates of service delivery.

12. Explore why the time from injury to service appears to be so long.

13. Shift resources to ensure that they match current population distributions.



## Background and process

### *Evaluation history*

The Acquired Brain Injury ABI Partnership program was originally designed by a multidisciplinary ABI Working Group established in 1994 by Saskatchewan Government Insurance (SGI) and Saskatchewan Health. The Working Group was asked to develop a provincial strategy for an integrated, community-based rehabilitation program for people with ABI, linking existing resources with new program developments. The Working Group reported in 1995 (Acquired Brain Injury Working Group, 1995).

Saskatchewan Health (now the Saskatchewan Ministry of Health) agreed to co-ordinate and administer the program. SGI provided most of the funding. The original program was designed to promote self-determination of individuals with ABI and their participation and integration into community life. It also was designed to provide education and support to professionals and others who cared for people with ABI.

Since the program was originally designed and implemented in the mid-1990s, four general service evaluations have been completed, in 1998, 2004, 2006 and 2010 ([Author not stated], 1998; Acquired Brain Injury Partnership Project, 2004, no date, and 2010).

The 1998 evaluation of the pilot program implemented in 1995 found:

- a high level of client and family satisfaction with services
- that service access and responsiveness improved with the start-up of the ABI program
- a need for more co-ordination of prevention activities
- gaps in:
  - residential support;
  - addictions support; and
  - development of meaningful activity.

The 2004 evaluation found:

- a focus on client and program outcomes;
- that the program model was effective and evidence-based;
- a break-even cost benefit ratio;
- that clients were satisfied;
- that clients maintained their functioning during service; and
- that programs were assisting clients with goals.

The 2006 evaluation reported that:

- services addressed identified client needs;
- improvements in services for families were needed;
- general satisfaction with services among clients; and
- satisfaction with education and prevention services.

The most recent, 2010 evaluation found:

- improvement in client outcomes from intake to follow up;
- almost all goals set were attained;
- almost all clients maintained functioning during services;
- a wide range of education and prevention activities were being implemented; and
- a need to improve information systems.

### *Purpose of current evaluation*

#### **Requirements of the call for proposals**

In December 2009 the ABI Partnership issued requests for proposals for three evaluation proposals covering:

- a child passenger safety program;

- services to difficult-to-serve clients; and
- general services.

This evaluation addresses the third evaluation topic, general service for ABI clients.

The ABI Partnership defined the principal evaluation question as follows: “What aspects of service delivery are most effective for eliciting positive outcomes for ABI survivors?” The ABI Partnership RFP also listed three required components of the ABI program to be assessed:

- the therapeutic relationship;
- service availability; and
- client engagement with service.

During the evaluation planning process, the ABI Partnership directed that the evaluation scope did not include evaluation of the education and prevention programs, but only of direct service programs.

### **What this evaluation adds**

This evaluation builds on the four previous evaluations of ABI program general services to:

- present overall frameworks for continuing to develop the program, after 15 years of successful implementation;
- provide evidence on what works best to improve or maintain client outcomes;
- seek more family input on services; and
- re-assess program functioning and identify any gaps in programming.

### **The evaluation process**

The evaluation process for this evaluation was conducted in four phases:

1. Development of the evaluation plan;
2. Data collection;
3. Data analysis; and
4. Report writing.

These are described in detail in the methods section.

### **Evaluation frameworks**

We used two frameworks for evaluating the ABI Partnership: a program logic model and a client journey map. We describe these in detail in the following sections.

#### **Program logic model**

Appendix 1 outlines the framework, rationale and use of program logic models. Appendix 2 presents a *planned* logic model for the ABI Partnership overall program, including contractual program goals, activities, outputs and outcomes. The cells of this *planned* program logic model have been filled in based on the ABI Partnership Project Contract Service Schedules provided by the ABI Partnership, supplemented by input from provincial staff and Outreach Team managers.

Evaluation questions addressed using the program logic model framework included:

#### *Program design*

1. Does the ABI program design match the original program design?
2. Does the ABI program design incorporate new knowledge on effective programs since the original program was designed?

#### *Program implementation*

3. Has the ABI program been implemented as originally designed?
4. Does current implementation of the ABI program incorporate new knowledge of effectiveness? If so, how? If not, why not?

*Program description*

5. What are the actual inputs, activities, outputs and outcomes of the current ABI program?
6. How do they match or differ from those planned? (The planned components of the program logic model are outlined in Appendix 2.)

*Program improvement*

7. Is the ABI program being implemented as efficiently as the current program design allows? If not, what are the opportunities for improving efficiency?
8. Is the ABI program design as effective as current knowledge of ABI rehabilitation allows? If not, what are the opportunities for improving effectiveness?

**Client journey map**

The client journey map (Appendix 3) reflects the policy shift towards patient-centred health care and the concepts of customer experience, journey or relationship mapping and management that come out of commercial marketing (Cabinet Office, Government of the United Kingdom, no date; Quality Improvement Agency for Lifelong Learning, 2007; van Oosterom, 2010).

LTSC used these concepts to develop an approach to evaluate outcomes from the client experience point of view. On the proposed client journey map in Appendix 3, the client journey flows from left to right. The rows represent alternate paths the client can take in his or her journey.

*Evaluation questions on the client journey*

The client journey framework was used to frame questions such as:

9. How comprehensive is the service coverage of all potential clients?
10. How accessible are services to clients? (hours, location)
11. How acceptable are services to all clients? (Do clients start to use services that are related to their needs?)
12. How continuous are services? (Do clients continue to be engaged in services that are related to their needs?)
13. How effective are services in meeting realistic client goals and improving their ability to live as independently as possible and integrate into the community?

**Further analysis**

Based on the evaluation requirements of the ABI Partnership we also assessed the following evaluation questions:

*Service characteristics*

14. What are the characteristics of services provided, by program and by each client?

The service provider - ABI survivor relationship

15. How important is the therapeutic relationship between ABI survivor and service provider?
16. What are the characteristics of successful therapeutic relationships?

*Service access and equity*

17. What is the availability of service?
18. Are there geographic differences in the characteristics of services?

*Client characteristics*

19. What are the characteristics of ABI survivors?

*Outcomes*

20. What are the predictors of successful outcomes for ABI clients?

## Summary of the evaluation process

Table 1 provides a summary of the research questions, methods used, and data sources.

**Table 1. Research questions, data collection and analysis, and data sources**

Research question	Data collection and analysis	Source
What are the characteristics of services provided, by program and by each client? <ul style="list-style-type: none"> <li>Type of service provided</li> <li>Intensity of service (frequency and duration of service events)</li> <li>Length of service episodes (from admission to discharge)</li> <li>Any other significant characteristics identified and for which data are available</li> </ul>	Descriptive statistics by program and by client Qualitative insights and interpretation informed by client and staff interviews.	ABIIS Client / staff interviews
How important is the therapeutic relationship between ABI survivor and service provider? What are the characteristics of successful therapeutic relationships?	Interviews with 25 staff, 15 ABI survivors and 10 family members distributed across programs and geographic service regions. Interviews were used to determine the nature of the therapeutic relationship between ABI survivor and service provider and each person's assessment of the effect of that relationship upon outcomes.	Client / staff interviews
What is the availability of service?	Compare service hours available per client per week and per episode of care by program and region.	ABIIS Client /staff interviews
Are there geographic differences in the characteristics of services?	Using the results of the descriptive data analyses of service characteristics, we determined if there are any regional differences in service characteristics.	ABIIS
What are the characteristics of ABI survivors? <ul style="list-style-type: none"> <li>time since injury</li> <li>injury type and severity</li> <li>insight into injury</li> <li>readiness for service</li> </ul>	Descriptive statistics by program and by client Qualitative insights obtained from interviews on the item of insight into injury	ABIIS Client / staff interviews
What are the predictors of successful outcomes for ABI clients?	Outcome data was obtained from all available complete pre-post MPAL measures received by the ABI Partnership. Outcomes tested using this longitudinal data set include: <ul style="list-style-type: none"> <li>client functioning;</li> <li>independent living; and</li> <li>integration into the community.</li> </ul> We used multiple regression analysis for continuous outcomes.	ABIIS and complete MPAL pre-post data, linked anonymously



## Methods

### Overview

The evaluation was conducted in four phases, from May 2010 through June 2011. The phases are summarized below.

#### Phase 1: Development of the evaluation plan

In this first phase LTSC prepared and had approved a detailed evaluation plan in August 2010.

#### Phase 2. Data collection

The data collection phase included obtaining research ethics approvals, conducting 50 in-person interviews across Saskatchewan, and obtaining program data from the ABI Partnership. This phase was completed in January 2011.

Research ethics approval applications began once the evaluation plan was approved. The ethics review and operational approval process required four months to complete and required separate submissions to eight approval bodies.

All organizations and individuals contacted for interviews were co-operative and helpful. All interviews arranged were completed; there were no no-shows. We reached saturation in the family and client interviews (the same themes were being repeated and no significant new themes were emerging in the last interviews) indicating that we had a large enough sample for this kind of qualitative research.

LTSC received all program administrative data requested from the ABI provincial office in anonymized, usable format by October 2010.

Measurement of actual inputs was based on financial information supplied by the ABI Partnership. Measurement of actual activities and outputs was based on program service data submitted to the Acquired Brain Injury Information System (ABIIS) and provided by the ABI Partnership. Measurement of outcomes was based on individual change in Mayo-Portland Adaptability Inventory scores between assessment and discharge or follow-up at 12 or 18 months, on aggregated reports of progress in goal attainment, and on analysis of registration data on workforce and living status of clients.

#### Phase 3. Data analysis

LTSC conducted both qualitative data analysis of the interview notes and quantitative data analysis of the program administrative and outcome data provided from the ABIIS database and the Mayo-Portland Adaptability Inventory (MPAI) outcomes data. Before analyzing the ABIIS data LTSC first conducted data cleaning and data quality analysis.

LTSC used two frameworks to evaluate general ABI service delivery and answer the main evaluation question. To examine the program from a program management and funder point of view, we used a program logic model framework. We used a client journey framework to examine the program from a client experience point of view.

##### *Completing the program logic model*

LTSC used the following data sources supplied by the ABI Partnership provincial office to populate the program logic model:

- Financial data on Partnership funding and in-kind contributions;
- Annual reports of service statistics from programs funded by the ABI Partnership;
- Anonymized demographic and service event information from the Acquired Brain Injury Information System (ABIIS); and
- Outcome data (aggregated reports of goal attainment by year and program, and pre-post test scores from the Mayo-Portland Adaptability Inventory).

### *Completing the client journey map*

We used the ABIIS database to identify all new clients for the four years from 2005-06 to 2008-09 and to attempt to follow their progress through the client journey map with at least one year of follow up. Data on incidence of ABI and the client journey through acute treatment until assessment by ABI Partnership rehabilitation programs was estimated from other data sources.

We used these indicators to assess, as much as possible, availability of service, success in establishing therapeutic relationships, ABI clients' engagement with services, and the outcomes of services in improving ABI client functioning, independent living, and integration into the community.

## **Phase 4. Report writing**

LTSC presented a preliminary presentation on findings to the ABI Partnership Advisory Committee in February 2011. We next prepared and submitted a draft written report for review by the ABI Provincial Office and Advisory Group in May 2011. Based on comments and input from that review, LTSC will submit a final report reflecting those comments, as well as presenting a final PowerPoint presentation on the project June 9, 2011.

## **Data collection**

### **Interviews**

#### **Interview instruments**

LTSC developed the interview instruments based on the evaluation questions and submitted them for review by the ABI Partnership and then by various ethics review boards.

#### **Ethics and confidentiality for client and family interviews**

Ethics review was sought and obtained in each Regional Health Authority from which interviewees received services. A list of the eight ethics and operational approvals received and dates of approval is attached as Appendix 4. The interview consent forms for staff and clients / family members are attached as Appendix 5.

LTSC requested potential staff, client and family interview participants according to an interview matrix of types of interviewees (staff, family, or client), geographic region of service, and type of program. This matrix was reviewed and approved by the ABI Partnership.

Program staff approached clients and their families and asked for their agreement to be interviewed. Program staff either arranged a time and provided a private location for the interview in a site to which the client and / or family were accustomed, or, after obtaining the interviewee's permission, provided contact information to LTSC to directly arrange an interview. Names of program staff in positions selected to be interviewed were provided directly to LTSC by the program and LTSC then approached them to request an interview. Interviewees were offered the option of an off-work-site interview for privacy or their convenience. LTSC obtained written consent at the commencement of each interview. Interviewees were conducted in private and were recorded by interviewer notes.

Interviews were planned with 25 staff and 15 ABI survivors and 10 family members, distributed across programs and geographic service regions. Interviews were used to determine the nature of the therapeutic relationship between ABI survivor and service provider and each person's assessment of the effect of that relationship upon outcomes.

Two interviewers each carried out about half of the 60 to 90-minute in-person interviews. A single interview was conducted by telephone at the interviewee's request.

## Program data

### Time period for evaluation

LTSC conducted two analyses; the analysis, data sources and time periods covered by each were:

1. A descriptive analysis of program use, using the program logic model as a framework, based on program, financial and ABIIS registration and service data from the 2009-10 fiscal year;
2. A longitudinal cohort analysis of outcomes using six years of Acquired Brain Injury Information System (ABIIS) and available MPAI baseline and outcome assessment data for the fiscal years 2004-05 through 2009-10.

### Registration, service, financial and outcomes data

The ABI Partnership provided LTSC the following data sets and instruments:

- A complete set of all **registration data** with an anonymous linkable client identifier attached to each record for the time period of six government fiscal years from April 1, 2004 through March 31, 2010;
- **Service data** with an anonymous linkable client identifier attached to each record linkable to the registration data, for the same time period;
- **Financial reports** showing budgeted and actual funding to each ABI Partnership Program, including provincial co-ordination. Reports to show data for total, ABI Partnership, in-kind, and other source funding, for the fiscal year 2009-10.
- **Mayo-Portland Adaptability Inventory (MPAI) assessment data** linkable to individual registration and service data with an anonymous identifier. The MPAI data set included available baseline (collected early in program contact) and follow-up (collected at 18 months post-baseline or at termination of program contact) assessments, back to the first date the MPAI was used (2004). The data set included all individual items (approximately 34) as well as the sub-scale and overall summary scores. Two different versions of the MPAI were provided, versions 3 and 4, which had been used sequentially by the ABI program.
- **Aggregate goal attainment reports** by year and service agency for fiscal year 2008-09.

## Data analysis

### Interviews

Notes from the structured interviews were transcribed and organized according to the topic addressed, regardless of where it came up in the interview. Notes were combined and coded by a research associate who had not been involved in the interviews. Semi-structured coding was used; domains were identified by the questions asked, but the responses within each domain were coded qualitatively by themes that emerged from the data. This coding was then reviewed independently by the lead evaluator.

Counts of themes were tabulated. These counts are intended as indications of how frequently particular themes were mentioned and should not be interpreted as results of a quantitative survey.

### Registry data

Registry data was restructured into a single data file with six years of registry data for each individual who had received service, uniquely identified with a scrambled identifier, and calculated indicators of their living situation and workforce status at the start and end of their period of service.

## Workforce status

The ABI Partnership supplied definitions used in the data registry in a code sheet used by all Partnership programs. We combined the original data coding to create the following workforce status variables, based on the coding in the data registration form:

Not in paid workforce:

- Out of workforce (retired / not applicable / unemployable);
- Unpaid work (volunteer / homemaker);
- Student.

In paid workforce:

- Supported employment;
- Competitive employment;
- Unemployed.

The detailed definitions of these created variables are described in Table 2.

**Table 2. Variable definitions based on registration categories of “Current Employment”**

Variable	Yes (1)*
Not in paid workforce	Out of workforce = 1 OR Unpaid worker = 1 OR Student = 1
Out of workforce	Current Employment = 'Currently Medically Restricted' OR 'Retired' OR 'Not Applicable' OR 'Unemployable'
Unpaid worker	Current Employment = 'Volunteer Work' OR 'Homemaker'
Student	Current Employment = 'Student'
In paid workforce	Supported employment = 1 OR Competitive employment = 1 OR Unemployed = 1
Supported employment	Current Employment = 'Sheltered' OR 'Supported Employment' OR 'Transitional Employment' OR 'Integrated Work Setting (expired category)'
Competitive employment	Current Employment = 'Full Time Competitive' OR 'Part Time Competitive' OR 'Competitive Employment (expired category)' OR 'Seasonal Employment' OR 'Self Employed'
Unemployed	Current Employment = 'Unemployed'

\* All other values = 0 (No)

Values in single quotes (") are values of the ABIIS registration system category “CurrentEmployment”.

## Service data

The ABI Partnership supplied six years of service data; each record included coding for the type of service, the date, and an anonymized linkable unique identifier for the client receiving the service. For analysis we combined the annual service records into one service record for the six years aggregated to show the total service events, by type of service, received by each client in each year. Each record also contained a variable to indicate the year of service.

Data were provided to us by the ABI Partnership with only the fiscal year of registration and the calendar year of first injury. (The purpose for this was to increase the anonymity of the data.) To estimate the length of service since registration and the time from injury to first service, we used the mid-point of the relevant calendar or fiscal year as the estimated date of injury or registration. For individuals or small groups this may result in inaccurate estimates of time since injury or time since registration, but for large groups it will give accurate estimates of the average of these intervals.

## Health region groupings

The focus of the analysis was on the client experience. For this analysis, therefore, we grouped clients by where the client lived, rather than from where they received their service. We did this

in order to analyze access to service from the client point of view, distinguishing between agricultural rural, Northern and urban residence.

There were enough clients in the major urban health regions for statistical analysis that distinguished clients living in each health region. For the smaller numbers of clients residing in rural and Northern health regions, we grouped them by residence into Rural - South, Rural - Central and North, based on what we expected their experience of access to service would be (such as distance to service and whether local services were available).

These groupings of clients do not always correspond to service areas. For example, clients residing in the Rural - Central grouping of health regions received services from two outreach teams (Table 3). However, the numbers were too small to further separate these clients by which service centre they received service from.

**Table 3. Classification of clients by home health regions for purposes of evaluation**

Evaluation health region grouping	Health Region	ABI Partnership outreach team service area
North	Athabasca	North
	Keewatin Yatthé	North
	Mamawetan Churchill River	North
PAPHR	Prince Albert Parkland	North
RQHR	Regina Qu'Appelle	South
Rural - Central	Heartland	Central
	Kelsey Trail	North
	Prairie North	Central
Rural - South	Cypress	South
	Five Hills	South
	Sun Country	South
	Sunrise	South
Saskatoon HR	Saskatoon	Central

## Financial data

The ABI Partnership supplied data on Partnership funding and in-kind fund raising by funded programs for fiscal year 2009-10, and for staffing in full-time equivalents (FTEs) for each funded program for fiscal year 2008-09. We used these data to calculate population rates of funding and staffing by health region sectors of service agencies.

## Outcomes data

We evaluated outcomes of clients overall and in relation to the services they received using three approaches: changes in registration status, direct clinical functional assessment using the Mayo-Portland Adaptability Inventory (MPAI), and aggregate goal attainment data.

### Tracking outcomes of clients through registration and service records

Program records (registration and service records in the ABIIS system) provide information on client demographics, brain injury characteristics, service characteristics (outputs) and changes in workforce and living status (outcomes). We used these data for two purposes: to paint a picture of clients and the ABI program's initial contact with delivery of services to clients, and to determine changes in clients' workforce and living status over time. We used a five-year cohort of clients first registered from the 2005-06 through the 2009-10 fiscal years to conduct this analysis. To ensure that all clients were new, we used registration data from the year 2004-05 as a washout year: any client registered in that year was excluded from the analysis, to ensure we were examining only new clients.

Firstly we analyzed the 1,541 new clients over the five years from the 2005-06 through the 2009-10 fiscal years. Secondly we compared the 312 clients first registered in the most recent year, 2009-10, to the 1,229 clients first registered in the previous four years to determine if recent clients are any different than previous clients. Finally, we looked at changes from first registration to the most recent years of registration, for all clients first registered in the four years 2005-06 through 2008-09. We excluded clients newly registered in 2009-10 to ensure we had at least one year of follow up for all new clients. We did, however, keep in the analysis the service records from the year 2009-10 for any clients previously registered, as part of their record of follow-up.

### **Mayo-Portland Adaptability Inventory (MPAI) assessments**

MPAI assessment data was combined into a single analysis file, using an anonymized unique identifier to link the data to registration and service data. To conduct the analysis we had to address several issues as described below.

1. Data collected using the MPAI version 3 was not usable, as it was collected for years prior to the six-year registration cohort we had available for linking. We were only able to use data from the MPAI version 4 (MPAI4), which had been used from 2004-05 onwards.
2. In many cases, assessments conducted were incomplete, follow-up assessments were not done, or, occasionally, a follow-up assessment was done with no baseline assessment. We only included assessments with complete baseline and follow-up MPAI assessments.
3. There are three ways to administer the MPAI assessment: self-report by the client, family report, or staff assessment. Inspection showed that in cases where there were multiple reports on the same client, the self-report of the client often varied greatly from the staff assessment. Staff assessments were the most complete. We therefore used as our first choice the staff pre-post assessment pair. If that were missing we then used the client self-assessment pair. There were no complete pairs of family assessments available where both of the other two sources were missing, so we did not use any family assessments. In all cases we matched the pre-post assessment from the same source. (That is, we did not combine a baseline assessment from one source with a follow-up assessment from a different source.).

We then calculated the difference in scores (change score) for each matched pair for the total score and each sub-scale score as outcome variables. We predetermined before doing the analysis that the change in the MPAI4 total score would be the primary end point in the analysis.

### **Goal attainment**

We reviewed aggregate goal attainment data previously reported in *ABI Partnership (2010)*. Goal attainment data is submitted to the ABI Partnership by funded programs in aggregated form for the program; it is not submitted for individual clients. Therefore we were unable to conduct predictive modelling of goal attainment.

## Findings

### Data availability and quality

#### Interview data

Most interviews were carried out as planned. There were seven minor changes due to programs being unable to arrange interviews as requested. We substituted these with comparable interview subjects in other programs. As well, two family members attended one interview in the place of one.

Fifty-one interviews were therefore completed with 25 staff members, 15 clients and 11 family members, selected to be representative of the programs and health regions in the ABI Partnership (Table 4.)

**Table 4. Interviewee characteristics**

Interviewee characteristic	Count
<b>Staff</b>	<b>25</b>
Programs:	
case management	12
children	1
crisis management	1
education and prevention	1
independent living	3
life enrichment	2
provincial	1
rehabilitation	3
supportive employment	1
<b>Clients</b>	<b>15</b>
Time in ABI program:	
6 months or less	5
6 to 18 months	5
18 months or more	5
<b>Family members</b>	<b>11</b>
Time client was in program:	
less than a year	5
a year or more	6
<b>All</b>	
Health region or health region grouping:	
North (Athabasca, Keewatin Yatthé, and Mamawetan Churchill River Health Regions)	3
Prince Albert Parkland Health Region	8
Regina Qu'Appelle Health Region	10
Rural - Central (Heartland, Kelsey Trail, and Prairie North Health Regions)	6
Rural - South (Cypress, Five Hills, Sun Country, and Sunrise Health Regions)	9
Saskatoon Health Region	14
province-wide program	1
<b>Total</b>	<b>51</b>



## Registration and service data

Administrative data (registration and service data) was generally complete and of good quality. The completeness of these data appears to be the result of the registration and service databases being used to support clinical service delivery and to justify ABI Partnership funding and program staffing levels.

## Outcomes data

### MPAI data

The MPAI is a validated functional assessment tool designed for assessing and measuring progress of clients with brain injury. It is the most sensitive outcome measure available for assessing objective progress and outcomes of clients. Ideally it would be collected for all clients as a pre-post measure. However, MPAI data is treated as a separate data collection process and is not included in the ABIIS system. For various reasons, there is resistance to using the measure. As a result the completion rate of this valuable assessment and outcome measurement tool is, especially for follow up, extremely low.

### Goal attainment

Because goal attainment data is not collected on the ABIIS system, but is collected separately and submitted by programs in aggregate only, we could not conduct an analysis of goal attainment for individual clients.

## Program design

### 1. Does the ABI program design match the original program design?

The ABI program design continues to remain close to the original program design laid out in the original 1995 strategy (Acquired Brain Injury Working Group, 1995).

The original strategy included the following major components:

- a provincial ABI Co-ordinator;
- provincial co-ordination and delivery of prevention, education, training and research;
- community-based programs and services, built around three outreach teams, delivered through multi-disciplinary teams, and providing regionally initiated social, recreational, leisure, vocational, avocational or other rehabilitative programs;
- residential programs; and
- program evaluation.

The current program continues to implement the original design.

### 2. Does the ABI program design incorporate new knowledge on effective programs since the original program was designed?

A rapid review of recent research evidence of basic knowledge of brain injury community support after active rehabilitation confirms that knowledge of effective programs has changed little since the Partnership program structure was designed in 1995. A brief summary of evidence gleaned from our rapid review of research reviews for community-based brain injury rehabilitation published from 2006-2010 follows.

### Interventions for children

#### *Frameworks vary but with little research evidence on outcomes*

Long-term rehabilitation interventions for children are not well developed and there has been little research or evaluation in this area. Clinicians advocate both holistic approaches of rehabilitation in the child's everyday context, and intensive skill-based treatments in areas such as functional adaptation or restoring cognitive functions. There is little research or evaluation



evidence to support either approach (Anderson & Catroppa, 2006; Marcantuono & Prigatano, 2008; Cole, Paulos, Cole & Tankard, 2009).

Marcantuono and Prigatano (2008) present the theoretical case for a holistic rehabilitation approach. Cole, Paulos, Cole and Tankard (2009) suggest the following “theoretical clinical guidelines”:

- select developmentally appropriate interventions;
- match interventions to the family;
- provide advocacy;
- provide injury education;
- focus on family realignment;
- appropriately adjust the child's environment; and
- provide skills training to the family and child.

#### *The key goal is return to school*

Return to school is usually a key adaptive goal for children (Anderson & Catroppa, 2006).

#### *Family support is important*

Family support is important, as most long-term rehabilitation will occur within the family unit (Anderson & Catroppa, 2006).

Acquired brain injury in a child has a great impact on the family as a whole, creating family psychological distress. Yet family functioning affects a child's recovery from brain injury (Cole, Paulos, Cole & Tankard, 2009).

There is limited research evidence to support involvement of family members in rehabilitation treatment. Parents or guardians of children seen in an emergency department benefit from receiving an information booklet on traumatic brain injury (Laatsch, Harrington, Hotz et al., 2007).

#### *Specific cognitive interventions may be effective*

A systematic review of evidence for cognitive and behavioural treatment in children with acquired brain injury recommended, with limited evidence, attention remediation (Laatsch, Harrington, Hotz et al., 2007)

Slomine and Locascio (2009) reviewed evidence for cognitive rehabilitation for children in a variety of treatment domains including attention, memory, unilateral neglect of stimuli, speech and language, executive functioning, and family involvement and education. While they identified evidence for a number of specific interventions to address each of these areas of cognition, they noted the need for more research.

## **Adults**

#### *Frameworks exist but are not supported by research evidence*

As it is for children's rehabilitation, there is ongoing debate among clinicians between holistic approaches and skill-specific approaches for adult brain injury rehabilitation. As for children's rehabilitation, there is little evidence to decide the question. Martelli Nicholson and Zasler (2008) present a case for a holistic approach, while Uomoto (2008) presents a skill-specific model.

#### *There is little evidence for effectiveness of ABI interventions*

Most rehabilitation interventions for acquired brain injury are supported by limited or no evidence (Cullen, Chundamala, Bayley et al., 2007; Geurtsen, van Heugten, Martina & Geurts, 2010; McCabe, Lippert, Weiser et al., 2007).

#### *Comprehensive rehabilitation has some positive effects*

Comprehensive rehabilitation programs reduce psychosocial problems and increase community integration and employment (Geurtsen, van Heugten, Martina & Geurts, 2010).

*There is limited evidence on effectiveness of some specific programs*

For community rehabilitation Cullen and colleagues found limited evidence for positive effects of community-based social and behavioural rehabilitation, vocational rehabilitation, supported employment, and support groups. The authors found moderate evidence for benefits of patient involvement in goal setting.

Day-treatment programs are an effective program delivery mode for improving outcomes (Cullen, Chundamala, Bayley et al., 2007; Geurtsen, van Heugten, Martina & Geurts, 2010).

Community-based treatment of clients with a dual-diagnosis of traumatic brain injury and substance abuse is not effective (Cullen, Chundamala, Bayley et al., 2007).

There is moderate evidence that behavioural management, combined with caregiver education, fails to reduce caregiver burden (McCabe, Lippert, Weiser et al., 2007).

*Medication is effective for management of agitation and aggression and of attention and concentration*

Beta-blockers have the best evidence for efficacy among psychotropic medications for management of agitation and/or aggression following acquired brain injury. There is insufficient evidence to evaluate other medications often used for this purpose (Fleminger, Greenwood, Olive, 2006).

There is strong evidence for effectiveness of treatment with medication to improve attention (primarily speed of processing), particularly with methylphenidate (Fleminger, Greenwood & Oliver, 2006; Rees, Marshall, Hartridge et al., 2007). Computerized training programs to enhance attention are not effective. There is moderate evidence that dual-task training improves processing speed (Rees, Marshall, Hartridge et al., 2007).

*Cognitive rehabilitation can be effective*

Cognitive rehabilitation has a small positive treatment effect. Specifically, there is evidence for the effectiveness of attention training after traumatic brain injury and language and visuospatial training for aphasia and neglect syndromes after stroke (Rohling, Faust, Beverly & Demakis, 2009).

There is evidence for three recommendations in cognitive rehabilitation (Rees, Marshall, Hartridge et al., 2007):

- specific interventions for functional communication deficits, including pragmatic conversational skills;
- memory strategy training for persons with mild memory impairments; and
- strategy training for attention deficits.

*Executive functioning: some interventions are effective*

There is moderate-to-limited evidence for group intervention and goal-management training and some evidence for drug treatment to address executive functioning deficits (Rees, Marshall, Hartridge et al., 2007).

*Exercise improves cognitive function*

There is some evidence of positive effects of physical exercise on improvements in cognitive function after ABI (Devine & Zafonte, 2009).

*Active rehabilitation not needed for mild brain injury*

For mild brain injury, there is strong evidence most patients recover with appropriate information and no other specific intervention (Turner-Stokes, Nair, Sedki et al. 2009).

*Multidisciplinary community-based rehabilitation can be effective, especially for stroke*

For moderate to severe injury, there is strong evidence of benefit from intensive early rehabilitation programs and community outpatient therapy after discharge from inpatient

rehabilitation. There is limited evidence of improvements from specialist multi-disciplinary community rehabilitation (Turner-Stokes, Nair, Sedki et al. 2009).

Evidence for efficacy of post-acute rehabilitation services is strongest for stroke. There is insufficient evidence to assess rehabilitation in outpatient settings for other conditions (Prvu Bettger & Stineman, 2007).

### **Evaluator's assessment**

Generally, from our assessment of overall program design, this current knowledge is reflected in the ABI Partnership programs.

The rapid review of evidence suggests that more emphasis should be put on specific cognitive and behavioural interventions, on ensuring referral for drug treatment for aggression, agitation, and attention and concentration, and on family support.

## **Program implementation**

### **3. Has the ABI program been implemented as originally designed?**

The program is still being delivered largely as originally designed in 1995. The original and current program designs were described previously in response to research question 1. Later in this evaluation we report that the activities outlined in the planned programming appear to be being delivered as planned.

### **4. Does current implementation of the ABI program incorporate new knowledge of effectiveness? If so, how? If not, why not?**

Staff report ongoing annual professional development sessions for clinical knowledge. However, there has been little new knowledge of effectiveness in community-based support of ABI survivors in the past 15 years. Suggested changes are listed in section 2 above.

## **Program description**

### **5. What are the actual inputs, activities, outputs and outcomes of the current ABI program?**

The program remains very similar to the description in the most recent previous program evaluation (Acquired Brain Injury Partnership Project (2010)). A completed summary logic model of actual compared to planned ABI Partnership inputs, activities, outputs and outcomes is presented in Table 5. A detailed logic model with program indicators in each cell is attached as Appendix 6. This detailed logic model provides the supporting evidence for the summary Table 5.

### **6. How do they match or differ from those planned?**

Inputs (funding and staffing) have been delivered as planned. Planned activities are generally implemented by funded programs. However outputs for most programs were only partly met, or, for two program components, clearly not met. While we estimate that most eligible ABI clients are being engaged in programs by the outreach teams and regional co-ordinators, program outcomes of most other programs either were only partly not met, or there was insufficient data to assess whether they were met.

**Table 5. Summary of ABI Partnership planned program logic model and of actual results in achieving planned targets\***

Program description (goals, objectives, target groups)	Inputs (2009-10)			Activities	Outputs	Outcomes
	(\$000s)		FTEs			
	Partner-ship	In-kind				
Provincial co-ordination of ABI Partnership	259	67	3.0	✓	✓	✓
Case management - outreach teams	1,716	795	27.1	✓	X	✓
Case management - regional co-ordination	383	87	5.6	✓	✓	✓
Education & prevention (not assessed)	441	217	5.5			
Crisis management	94	47	1.0	✓	partly	?
Independent living	143	39	2.9	✓	partly	partly
Life enrichment	119	86	3.5	✓	partly	partly
Supported employment & vocational training	179	90	3.3	✓	partly	partly
Residential	599	67	11.9	✓	partly	partly
Child & youth program	109	7	1.8	✓	X	?
Day programming	68	98	2.6	✓	partly	?
Rehabilitation	383	92	6.8	✓	partly	?
Total	4,234	1,694	72.0			

\* Colour shading of **red** indicates that targets for planned activities, outputs or outcomes were clearly not met, **yellow** that they were partly met, **green** that they were fully met, **light blue** that no targets were set, and **orange** that there was insufficient data to assess.

This table is based on Appendix 6, where full detail is provided.

## Program improvement

### 7. Is the ABI program being implemented as efficiently as the current program design allows? If not, what are the opportunities for improving efficiency?

The data presented in the next section, on comprehensiveness of the service coverage of all potential clients, demonstrates that there is large unexplained variation in service delivery across health region sectors in the ABI Partnership. The information required to determine the most effective or efficient way of delivering services is data on comparative outcomes. We will return to this discussion later in the report after the analysis of outcomes.

### 8. Is the ABI program design as effective as current knowledge of ABI rehabilitation allows? If not, what are the opportunities for improving effectiveness?

As reported in the assessment of research question 2, the results of the rapid review of evidence suggests that more emphasis should be put on specific cognitive and behavioural interventions, on ensuring referral for drug treatment for aggression, agitation, and attention and concentration, and on family support.

Another key opportunity for improving effectiveness is the integration of the MPAI outcome measure into clinical data collection for all clients to improve the internal capacity of the ABI Partnership for evaluation and improvement. We will discuss this in the Conclusions section of this report.

## The client experience

### 9. How comprehensive is the service coverage of all potential clients?

Program data indicates that the three top sources of ABI clients are trauma, stroke and brain tumour. The data summarized in Table 6 indicate population rates of major selected causes of brain injury. These data suggest that about 40 to 75 people per 100,000 per year are hospitalized for traumatic brain injury or head injury and 20 people per 100,000 per year have moderate to severe traumatic brain injury. (Colantonio (2009, pp. 180-81) reported that 38 per cent of admissions to hospital for TBI in Ontario fit their criteria for TBI with Abbreviated Injury Scale (AIS)  $\geq 3$  (moderate to severe)).

Arbitrarily applying the same rate of severe brain injury to strokes and brain tumours as to traumatic brain injury, we would have a rate of moderate to severe brain injury for tumours of about 8 / 100,000 and for stroke of about 60 / 100,000. This, plus other minor causes, would give a ballpark estimate of moderate to severe brain injuries per year of about 90 / 100,000 people. However, Engberg (2007, p. 223-24) reported that the national rate of post brain injury patients (trauma and hemorrhagic stroke only) in Denmark was 12 / 100,000 in 2002 and that traumatic brain injury and hemorrhagic stroke provided about equal number of brain injury patients. However this rate did not include ischemic stroke, which occurs about three times as frequently as hemorrhagic stroke. Nor did it include brain tumours and other minor causes of acquired brain injury. A rate of 30 / 100,000 would be a reasonable estimate with these factors taken into account.

Therefore, these data suggest that in the Saskatchewan population of about one million, somewhere between 300 and 900 acquired brain injuries per year fit the criteria of moderate to severe injury for admission to ABI Partnership services.

Actual intake of new clients in 2009-10 was just over 300 clients across the whole Partnership (Table 7). The rate of intake in relation to population averaged 30 clients per 100,000 people across the province in 2009-10. This suggests that province-wide, the program reaches somewhere between all and one-third of those who might meet the criteria for services.

Two regional sectors had markedly lower rates of new clients per 100,000 population in 2009-10 compared to the provincial average: the North (14) and Saskatoon (23) (Table 7).

One thousand fifty-one clients were provided service across the whole Partnership in 2009-10; this was a province-wide rate of about 100 clients served per 100,000 population. The North and Saskatoon had rates of client coverage one-fifth lower than the provincial average, while Prince Albert Parkland and Regina Qu'Appelle had rates more than one-fifth higher than the provincial average (Table 7).

For service coverage, an average of 3,800 direct client services were provided per 100,000 population across the province in 2009-10. However, the rate of service coverage to population was dramatically lower for residents of the North, where it was only 600 per 100,000 people, one-sixth the provincial rate. The rate of service coverage was also one-third lower for residents of the Rural - South. On the other hand the rate of service coverage was substantially higher for residents of the Regina Qu'Appelle Health Region, at 6,400 per 100,000 people, two-thirds higher than the provincial average.

The reasons for differences in client and service coverage may relate to the allocation of inputs. To test this, we calculated rates of inputs (ABI Partnership funding allocations) in relation to population for the health regions (Table 8).

This analysis shows an almost six-fold difference in per capita funding between the sector with the lowest funding (the four rural southern RHAs) and that with the highest (Prince Albert Parkland). Similarly there was a four-fold difference in staffing between the same two sectors. Prince Albert Parkland and Regina Qu'Appelle health regions are funded and staffed well above the provincial average, while rural health regions in the North, the Rural - South and the Rural - Central sectors are funded and staffed well below provincial averages.

**Table 6. Population rates of hospitalization for selected causes of acquired brain injury**

Condition	Location	Incidence / 100,000	Year	Definition	Reference	Comments
<b>Traumatic brain injury (TBI)</b>	Denmark	17	2002	diffuse brain lesions & contusions	Engberg (2007)	registered in a national database
	Calgary Health Region	11	1999 - 2000	Injury Severity Score (ISS) $\geq$ 12 in ER	Zygun (2005)	measured among residents of the region arriving live at hospital emergency
	Ontario	19	2001 - 2002	admitted to hospital with Abbreviated Injury Scale (AIS) $\geq$ 3	Colantonio (2009)	indirectly measured from provincial administrative databases
		37	2002 - 2007	hospitalized for any TBI	Colantonio (2010)	indirectly measured from administrative databases
	Canada	74	2004-05	any hospitalization for head injury	CIHI (2007)	Canadian hospitalization databases
		20		any hospitalization for specified condition		
<b>Brain tumour</b>		146				
<b>Stroke</b>	Denmark	15	2002	traumatic intracranial hemorrhages	Engberg (2007)	registered in a national database

TBI : traumatic brain injury

**Table 7. Service coverage by health regions, new and total clients and total direct services\* per client, 2009-10**

Health regions	Population 2009	New clients		Total clients		Total direct services	
		Count	Rate / 100,000 population	Count	Rate / 100,000 population	Count	Rate / 100,000 population
North <sup>1</sup>	36,400	5	14	29	80	219	602
Prince Albert Parkland	77,668	28	36	106	136	2,438	3,139
Regina Qu'Appelle	253,809	87	34	314	124	16,228	6,394
Rural - Central <sup>2</sup>	159,382	49	31	138	87	5,609	3,519
Rural - South <sup>3</sup>	208,388	74	36	212	102	4,697	2,254
Saskatoon	300,638	68	23	247	82	10,274	3,417
<b>Total<sup>4</sup></b>	<b>1,036,285</b>	<b>312</b>	<b>30</b>	<b>1,051</b>	<b>101</b>	<b>39,465</b>	<b>3,808</b>

\* Direct services are services provided directly to clients, including case management; a small number of no shows of clients for service are included.

1 North: Athabasca, Keewatin Yatthé, Mamawetan Churchill River

2 Rural - Central: Heartland, Kelsey Trail, Prairie North

3 Rural - South: Cypress, Five Hills, Sun Country, Sunrise

4 One new client and five total clients had no home health region recorded.



**Table 8. Allocation of inputs\* to health regions, by population**

Health regions	Population 2009	Funding (2009-10) (\$000s)	Staffing (2008-09) (FTEs)	Funding / 100,000 people (\$000s)	FTEs / 100,000 people
North <sup>1</sup>	36,400	106	1.3	291	3.6
Prince Albert Parkland	77,668	656	10.6	845	13.6
Regina Qu'Appelle	253,809	1,413	26.9	557	10.6
Rural - Central <sup>2</sup>	159,382	233	6.8	146	4.3
Rural - South <sup>3</sup>	208,388	484	7.0	232	3.4
Saskatoon	300,638	1,341	19.4	446	6.5
<b>Total</b>	<b>1,036,285</b>	<b>4,234</b>	<b>72.0</b>	409	6.9

\* ABI Partnership funding

1 North: Athabasca, Keewatin Yatthé, Mamawetan Churchill River

2 Rural - Central: Heartland, Kelsey Trail, Prairie North

3 Rural - South: Cypress, Five Hills, Sun Country, Sunrise

## 10. How accessible are services to clients? (hours, location)

In open-ended interviews, no clients or family members identified hours of access to service as an issue. Northern clients did identify long distances to services and infrequent face-to-face contact with case managers as a concern. Northern clients receive case management and outreach services contracted from Prince Albert Parkland RHA. There are no direct service programs within the three northern health authorities. Here are some of the comments clients and family members made:

*I would like to see someone come up here more often and discuss what would be good for [my relative] -- try to get him out of town or find him a place somewhere. He is really struggling right now. There is no support. Talking on the phone doesn't really resolve anything. I would like to see some help for me. . . . [What would you like to see for yourself?] . . . I am looking for a counsellor. I don't want to be on depression pills. My doctor is trying to refer me . . . I am stressed out. I feel like packing up and moving away from everything -- but you can't run away from your problems. I caught him a few times trying to hang himself. It would be nice if they could do something before he gets hurt or he hurts someone else. Right now he is on medication to make him sleep. If not he walks around the house all night and keeps me up. [family member #18]*

*[What has worked well?] They helped me with information about what I was going through. I haven't had a chance to meet with other ABI survivors. . . . I don't know of any other ABI survivors in this community. . . . [What would you like to see changed?] . . . It seems okay to me. I haven't had any problems or concerns. They tell me to phone me if I have any concerns. I have done that a few times. [client #16]*

*The ABI program came to see me in [a major city hospital]. Then the ABI program called and then they came to see me a [short time] ago for the first time. They gave me information on my injury and tried to help me out. They kept calling me but I couldn't figure out who they were. They tried to help me set up my appointments. There were . . . appointments set up in [a city] but no arrangements made for travel and I didn't know anything about it. . . . [What would you like to see changed?] Get the appointments set up properly and arrange transportation and arrange home care. . . . It would be nice to have a pamphlet to explain all the resources . . . , how to arrange trips, everything. . . . I don't get much help at all. I have applied to*

welfare, and started getting money but it is not enough for the special diet required. I am not on a disability allowance. The ABI people didn't help with this or mention it. I am not getting home care and no other services. . . . [Would you recommend to someone else to come to this program?] That's hard to say. I don't get much help at all. [client #20]

#### **11. How acceptable are services to all clients? Do clients start to use services that are related to their needs?**

Twenty-three of 25 clients and family members would recommend to someone else to use ABI Partnership services.

Eighteen of 25 stated that their relationship with their primary program staff contact was going well; only two would like more help or support.

Clients and family members identified the following positive characteristics of their program staff member's behaviour towards them:

- Helpful (13)
- Caring, supportive, understanding (6)
- Friendly, pleasant (4)
- Professional, knowledgeable (3)

Of the two clients or family members who identified that they would like more support, one identified that their support worker was not available enough, the other that the support worker "hovers".

#### **12. How continuous are services? Do clients continue to be engaged in services that are related to their needs?**

##### **Accessing services**

Staff described multiple ways of accessing their programs based on client and family needs:

- Internal referral (21)
- External referral (20)
- Self-referral (of client or family member) (18)

##### **Reactivation of services**

Another issue in the continuity and relevance of services is whether, how and how easily service can be reactivated after a period of inactivity. Staff reported the following methods for reactivating inactive clients:

- Client can request reactivation (16)
- The intake process is redone (8)

##### **Flow of clients through the ABI program**

While most clients are short-term clients who receive services for one or two years, some long-term clients have been receiving services for many years.

Tables 9 and 10 summarize the path of clients through the overall ABI program. Table 9 presents the annual registration and departure of clients from the program by year. Table 10 reorganizes the presentation of the same data to show the attrition from the program by years of service since first registration. Overall, about two-thirds of new clients remain after one year, two-fifths after two years, and one-quarter after three years.



**Table 9. Annual inflow and outflow of new clients, 2005-06 to 2009-10**

First registration year	Last registration year					Total
	2005-06	2006-07	2007-08	2008-09	2009-10	
2005-06	85	79	44	18	64	<b>290</b>
2006-07		116	71	44	66	<b>297</b>
2007-08			113	87	101	<b>301</b>
2008-09				117	224	<b>341</b>
2009-10					312	<b>312</b>
<b>Total</b>	<b>85</b>	<b>195</b>	<b>228</b>	<b>266</b>	<b>767</b>	<b>1,541</b>

**Table 10. Attrition of new clients by years since first registration in ABI program, 2005-06 through 2008-09, with at least one year follow up**

	Registered	Attrition by average years of service			
		<1	<2	<3	<4
<b>Data</b>					
<b>Counts by registration year</b>					
2005-06	290	85	79	44	18
2006-07	297	116	71	44	
2007-08	301	113	87		
2008-09	341	117			
<b>Total</b>	<b>1,229</b>	<b>431</b>	<b>237</b>	<b>88</b>	<b>18</b>
<b>Analysis</b>					
Annual attrition of registrants remaining in previous year (%)*		35	75	59	41
Annual attrition of original registrants (%)*		35	27	15	6
Proportion of original registrants remaining (%)*	100	65	38	23	17

### **13. How effective are services in meeting realistic client goals and improving their ability to live as independently as possible and integrate into the community?**

The characteristics of new clients at first registration are presented in Table 11. Notable findings include the following:

#### **Overall characteristics of clients at time of first registration**

At first registration during the years 2005-06 through 2009-10:

- About 300 new clients are registered province-wide per year.
- The Glasgow Coma Scale is reported for very few clients (nine per cent overall)
- Most clients (73 per cent) receive services for one year or less before leaving the program.
- Fifty-four per cent of clients are out of the workforce altogether and 17 per cent are unemployed.
- The causes of brain injury are roughly equally divided between trauma from all causes and other causes (mainly stroke).

### Comparison of most recent clients to previous years

Comparing clients first registered in the most recent year (2009-10) to clients registered in the previous four years (2005-06 to 2008-09) shows the following:

- Overall, the number and characteristics of new clients over the past five years remained stable: there is little difference between the number and most characteristics of clients in the most recent year (2009-10) compared to the previous four years.
- There has been a slight decline in the proportion of clients who have Registered Indian status, from 15 per cent from 2005-06 through 2008-09, to 12 per cent in the most recent year. This has occurred despite growth in the status Indian population.
- The proportion of clients for whom the Glasgow Coma Scale has been reported is lower in the most recent year (6 per cent).
- The proportion of clients requiring living support at first registration increased from 36 per cent from 2005-06 through 2008-09 to 43 per cent in the most recent year, 2009-10, suggesting new clients have heavier needs in the most recent year.
- Time from injury to first registration dropped from an average of 4.0 years from 2005-06 through 2008-09 to 2.9 years in 2009-10.

**Table 11. Characteristics of new clients at first registration, selected fiscal years**

Variable	Four years 2005-06 to 2008-09*		Most recent year: 2009-10*		All five years 2005-06 to 2009-10*	
	%	mean	%	mean	%	mean
<b>Client demographics</b>						
Age						
not recorded	2		1		2	
18-49 years	47		50		47	
50 years or more	51		49		51	
Gender						
Female	34		37		35	
Male	66		63		65	
Postsecondary education	20		19		20	
Status Indian	15		12		14	
<b>Injury characteristics</b>						
Cause of injury						
Trauma	46		46		46	
Stroke	33		37		34	
Tumour	8		7		8	
Other	13		11		13	
Glasgow Coma Scale						
reported	10		6		9	
of those reported		8.9		9.6		9.0
Insured	32		31		32	
Living situation						
Independent	63		55		61	
Requires support	36		43		37	
<b>Service characteristics</b>						
Home Health Region						
Regina Qu'Appelle	26		28		26	

Variable	Four years 2005-06 to 2008-09*		Most recent year: 2009-10*		All five years 2005-06 to 2009-10*	
	%	mean	%	mean	%	mean
Saskatoon	23		22		23	
Other	51		50		51	
Length of service from ABI program (years)*		1.3		na		na
One year or less	73			na		na
More than one year	27			na		na
Year first registered (fiscal year)						
2005-06					19	
2006-07					19	
2007-08					20	
2008-09					22	
2009-10					20	
Time since injury (years)		4.1		2.9		3.8
within past 15 months	70		77		70	
<b>Workforce status</b>						
Not in paid workforce	65		70		66	
Out of workforce	53		57		54	
Unpaid employment	3		2		3	
Student	10		10		10	
In paid workforce	35		30		34	
Supported employment	3		1		3	
Competitive employment	15		12		14	
Unemployed	17		17		17	

Total cohort of new clients, 2005-06 to 2009-10, N=1,541; new clients during four years 2005-06 to 2008-09, N=1,229; new clients during most recent year, 2009-10: N=312

na: not applicable (insufficient follow up)

### Client workforce status outcomes

Analysis of changes in client workforce status and living situation over five years indicated very little change in the status of clients over time (Table 12). This is similar to the findings of the 2010 evaluation (Saskatchewan Ministry of Health, 2010, p. 35.)

According to ABIIS registration data, only four per cent of clients changed their overall workforce status during their time in the ABI program; two per cent moved from the unpaid workforce into the paid workforce, while two per cent moved in the opposite direction.

**Table 12. Overall workforce status at first and last year registered in ABI program, 2005-06 through 2008-09, with at least one year follow up**

At first registration	At last assessment (latter of last service year or 2009-10)		
	Not in paid workforce	In paid workforce	Total
<b>Number</b>			
Not in paid workforce	773	29	802
In paid workforce	28	399	427
<b>Total</b>	<b>801</b>	<b>428</b>	<b>1,229</b>
<b>Percentage</b>			
Not in paid workforce	63%	2%	65%
In paid workforce	2%	32%	35%
<b>Total</b>	<b>65%</b>	<b>35%</b>	<b>100%</b>

Note: Light-blue shaded cells indicate clients who stayed in the same workforce status from first registration to last assessment

Ninety-four per cent of clients stayed in the same detailed workforce status from first registration to last assessment (indicated by the shaded diagonal line of cells, Table 13). Only six per cent changed their detailed workforce status. Only eleven clients (less than one per cent) moved into the status of supported or competitive employment from unemployment or not being in the paid workforce.

**Table 13. Detailed workforce status at first and last year registered in ABI program, 2005-06 through 2008-09, with at least one year follow up**

At first registration	At last assessment (latter of last service year or 2009-10)						
	Not in paid workforce			In paid workforce			Total
	Out of Workforce	Unpaid employment	Student	Supported employment	Competitive employment	Unemployed	
Number							
Not in paid workforce							
Out of Workforce	619	0	3	2	2	19	645
Unpaid employment	3	35	1	1	0	2	42
Student	2	0	110	0	0	2	114
In paid workforce							
Supported employment	0	0	1	31	1	0	33
Competitive employment	6	1	2	0	173	7	189
Unemployed	15	2	2	1	4	182	206
Total	645	38	119	35	180	212	1229
Percentage							
Not in paid workforce							
Out of Workforce	50%	0%	0%	0%	0%	2%	52%
Unpaid employment	0%	3%	0%	0%	0%	0%	3%
Student	0%	0%	9%	0%	0%	0%	9%
In paid workforce							
Supported employment	0%	0%	0%	3%	0%	0%	3%
Competitive employment	0%	0%	0%	0%	14%	1%	15%
Unemployed	1%	0%	0%	0%	0%	15%	17%
Total	52%	3%	10%	3%	15%	17%	100%

Note: Light-blue shaded cells indicate clients remaining in the same workforce status from first registration to last assessment

### Client living status outcomes

Living situation also remained very consistent between the first and last registration in the five years of service observed (Table 14). According to ABIIS registration data, almost all clients who started off at their first registration in a dependent, supported, or independent living situation remained in the same situation in the first of either the year they stopped receiving services, or 2009-10 (indicated by the shaded cells in the diagonal line). Only 26 clients (two per cent) changed categories of living situation while receiving ABI program services over this five-year period.

**Table 14. Living situation at first and last year registered in ABI program, 2005-06 through 2009-10**

At first registration	At last assessment (latter of last service year or 2009-10)				
	Dependent	Supported	Independent	Other	Total
<b>Number</b>					
Dependent	218	4	2	0	<b>224</b>
Supported	0	202	12	0	<b>214</b>
Independent	6	7	754	1	<b>768</b>
Other	0	0	1	22	<b>23</b>
<b>Total</b>	<b>224</b>	<b>213</b>	<b>769</b>	<b>23</b>	<b>1,229</b>
<b>Percentage</b>					
Dependent	18%	0%	0%	0%	<b>18%</b>
Supported	0%	16%	1%	0%	<b>17%</b>
Independent	0%	1%	61%	0%	<b>62%</b>
Other	0%	0%	0%	2%	<b>2%</b>
<b>Total</b>	<b>18%</b>	<b>17%</b>	<b>63%</b>	<b>2%</b>	<b>100%</b>

### Goal attainment

The 2010 evaluation report (Acquired Brain Injury Partnership Project, 2010) reviewed client goal attainment data for 2007-09. That report showed 62 per cent of goals achieved and 29 per cent partially achieved, overall (pp. 32-34). Achievement rates were highest for goals in the domains of Community Activities and Other, lower for Functional Independence and Psycho-social / Emotional, and lowest in the domain of Cognitive goals (where just below fifty per cent were achieved). We did not update this analysis to 2009-10 data for this report.

In interviews, staff indicated a strong goal focus. For example, in response to the question “How do you discharge a client?”, staff responded that their program discharged clients when:

- Goals met (17)
- Death / too old / needs more care / moved away (10)
- Inappropriate for program (behaviourally) (3)

### Family involvement

Staff interviewed identified the following ways they use to connect with family or other caregivers:

- Family is consulted / updated (23)
- Family actively involved in care (14)
- Offer direct family support / education (11)

## Service characteristics

### 14. What are the characteristics of services provided, by program and by each client?

#### Type of service provided

Tables 15 and 16 in section 18 following provide an overview of data on overall and geographic distribution of services in the ABI Partnership. The most frequently provided services are case management, recreation and leisure, psycho-social and behavioural, and cognitive services.

In interviews, clients and family members interviewed reported using the following services:

- Referrals (10)
- Family support programs (9)
- Social activities (8)
- Vocational and educational activities (8)
- Outings and recreational activities (7)
- Life skills (5)

Staff members reported the following services provided:

- Referrals (20)
- Case management (18)
- Life skills (15)
- Education (15)
- Recreation and leisure (12)
- Counselling (11)
- Vocational (6)
- Therapy (3)

Services reported by staff generally matched the service descriptions of the agencies in which they worked.

#### **Intensity of service (frequency and duration of service events)**

Clients and family members interviewed reported an average of six program contacts per month. The range was wide, from daily (weekdays) to quarterly. In their interviews, program staff emphasized that frequency of service depends highly on the situation of the individual client.

Table 16 following provides data on the frequency of service events in relation to population.

#### **Length of service episodes (from admission to discharge)**

Analysis previously presented in Table 10 indicates that 73 per cent of clients receive service for one year or less from ABI Partnership programs.

#### **Any other significant characteristics identified and for which data are available**

Descriptive statistics by program and health region sector are provided in Table 15 following.

### ***The service provider / ABI survivor relationship***

#### **15. How important is the therapeutic relationship between ABI survivor and service provider?**

In their interviews, staff emphasized the importance of establishing a good relationship with a client as the basis for other interventions and support. Staff frequently used words such as “non-judgemental”, “respectful”, “co-operation”, “understanding”, “trust” and “acceptance” to describe the foundations of an effective relationship with a client. Here are a few examples of how staff described the importance of a good relationship:

*“Understanding of the struggles of where the client is and their current struggles of [is important]. For example, clients from the reserve -- until I went to the reserve and saw the situation, I used to think clients were being non-compliant when they didn't show up on time, or didn't call and cancel appointments, or didn't call in every three months.” [staff #12]*

*“Trust is key to the relationship; . . . the support worker must establish a relationship.” [staff #22]*

*“There has to be a respectful relationship, where they feel I value them and am acting in their best interest.” [staff #24]*

*“You need to maintain rapport with the client.” [staff #38]*

*“[There must be] good relationships, trust, [you must] create a comfortable space.” [staff #17]*

*“Respect; seeing client as a person with . . . talents, skills and abilities, with a lot to offer.” [staff #52]*

## **16. What are the characteristics of successful therapeutic relationships?**

### **Factors that most help clients and family members**

In open-ended interviews, clients and family members identified the following factors that had helped them most:

- Information and support for the client (12)
- The relationship with the service provider staff (8)
- Advocacy and referrals (7)
- Information and support for the family (4)

### **Staff characterization of their relationship with clients**

Staff, when asked to describe the actual typical relationship between ABI survivor and service provider in their program, identified the following:

- Professional (staff in particular emphasized professional boundaries) (10)
- Flexible, depending on needs of client (9)
- Supportive / helping / mentoring (9)
- Collaborative (7)
- Compassionate / caring (4)
- Respectful / non-judgmental (4)

### **Factors that make a relationship work well**

Staff identified a number of factors that in their experience make a provider / client relationship work well.

#### *Provider factors*

- Empathy / compassion / understanding (14)
- Respectful / non-judgemental provider (13)
- Flexibility / creativity (8)
- Availability / accessibility (8)
- Knowledge (6)

#### *Relationship / mutual factors*

- Collaboration / equality (9)
- Good communication (5)
- Trust (4)

#### *Client factors*

- Client willingness / dedication / commitment (5)

### **Factors that cause a client /provider relationship to break down**

Staff identified the following factors that in their experience can cause a client / provider relationship to fail to work or to break down:

#### *Relationship factors*

- Disagreement on goals (10)
- Poor communication or rapport (9)
- Personality / personal characteristic conflicts (7)

#### *Program / staff factors*

- Accessibility problems (10)



- Lack of knowledge (4)
- Lack of empathy (3)

#### Client factors

- Addictions and substance abuse (9)
- Lack of client motivation (6)
- Mental health issues (5)
- Homelessness, nomadic lifestyle (3)
- Aggression or safety issues (2)

#### Family factors

- Lack of family / community supports (5)

### Service access and equity

#### 17. What is the availability of service?

This is addressed in the next section, Section 18.

#### 18. Are there geographic differences in the characteristics of services?

Service data (Tables 15 and 16) indicate that rates of service are particularly low in relation to provincial averages in the North and the Rural - South. They are low for many, but not all, programs in the Prince Albert Parkland, Rural - Central and Saskatoon sectors. They are high compared to provincial averages for most programs in Regina Qu'Appelle. These findings were confirmed with interview data in which clients indicated that access to service and contact with service providers is more difficult in the North and easiest in the cities.

**Table 15. Service counts by health regions, by service, 2009-10**

Direct client services (count)	Home Health Region						Total
	North	PAPHR	RQHR	Rural - Central	Rural - South	SHR	
Case Management	154	940	4,737	729	2,111	3,103	11,807
Consultation	10	124	756	330	328	962	2,515
Life Skills Training	0	54	1,242	759	142	533	2,730
No Show	2	1	12	14	28	56	113
Residential	0	52	459	6	71	100	688
Therapeutic							0
Cognitive	2	90	2,487	60	341	388	3,368
Exercise & physical	0	161	190	876	146	89	1,462
Nursing, including medical management	0	0	704	0	69	210	983
Therapy (PT, OT, SLT)	0	140	277	242	148	272	1,079
Psycho-social & behavioural	1	341	2,063	360	398	1,866	5,032
Recreation & leisure	47	503	2,190	2,192	683	2,160	7,779
Educational	0	0	126	0	66	25	217
Vocational	5	33	490	32	78	392	1,040
Other	0	0	507	23	116	174	820
<b>Total direct services</b>	<b>219</b>	<b>2,438</b>	<b>16,228</b>	<b>5,609</b>	<b>4,697</b>	<b>10,274</b>	<b>39,520</b>

- 1 North: Athabasca, Keewatin Yatthé, Mamawetan Churchill River
- 2 Rural - Central: Heartland, Kelsey Trail, Prairie North
- 3 Rural - South: Cypress, Five Hills, Sun Country, Sunrise

**Table 16. Rates\* of service by health regions in relation to provincial averages, by service, 2009-10**

Direct services	Home Health Region						Total
	North	PAPHR	RQHR	Rural - Central	Rural - South	SHR	
Case Management	423	1,210	1,866	457	1,013	1,032	1,139
Consultation	27	160	298	207	157	320	243
Life Skills Training	0	70	489	476	68	177	263
No Show	5	1	5	9	13	19	11
Residential	0	67	181	4	34	33	66
Therapeutic							
Cognitive	5	116	980	38	164	129	325
Exercise & physical	0	207	75	550	70	30	141
Nursing, inc. medical management	0	0	277	0	33	70	95
Therapy (PT, OT, SLT)	0	180	109	152	71	90	104
Psycho-social & behavioural	3	439	813	226	191	621	486
Recreation & leisure	129	648	863	1,375	328	718	751
Educational	0	0	50	0	32	8	21
Vocational	14	42	193	20	37	130	100
Other	0	0	200	14	56	58	79
<b>Total direct services</b>	<b>602</b>	<b>3,139</b>	<b>6,394</b>	<b>3,519</b>	<b>2,254</b>	<b>3,417</b>	<b>3,814</b>
<b>Population</b>	<b>36,400</b>	<b>77,668</b>	<b>253,809</b>	<b>159,382</b>	<b>208,388</b>	<b>300,638</b>	<b>1,036,285</b>

\* Red shading indicates a population service rate 20 per cent or more below the provincial average. Blue shading indicates a rate 20 per cent or more higher than the provincial average. No shading indicates a rate within 20 per cent of the provincial average population rate of service provision for that service

1 North: Athabasca, Keewatin Yatthé, Mamawetan Churchill River

2 Rural - Central: Heartland, Kelsey Trail, Prairie North

3 Rural - South: Cypress, Five Hills, Sun Country, Sunrise

## Client characteristics

### 19. What are the characteristics of ABI survivors?

#### Time since injury

While a few injuries date back five decades, the average time from injury to registration for service was 3.8 years for new clients over the five years from 2004-05 through 2009-10.

#### Injury type and severity

Of the cohort of clients over the past six years, half have had ABI due to traumatic injuries, half due to other causes (mainly tumours and stroke). We were not able to assess severity, because the Glasgow Coma Scale is collected for fewer than ten per cent of clients (six per cent in the most recent year).

#### Insight into injury

In interviews, clients focussed on the following difficulties as consequences of their injuries:

- Memory and cognitive difficulties (10) (identified more by clients)
- Emotional and psychological difficulties (7) (identified more by family members)
- Motor difficulties (5)

- Speech and communication (4)
- Vision (4)

### **Readiness for service**

Staff emphasized family and community support and client motivation, insight and absence of mental health and addictions issues as important in client readiness for services (see next section).

## **Outcomes**

### **20. What are the predictors of successful outcomes for ABI clients?**

Staff identified a strong goal focus in their assessment of client outcomes. Asked, “How do you track or assess client outcomes?”, they responded with:

- Goal review (20)
- MPAI (8)
- Case conference (6)

In interviews, program staff identified the following predictors of successful outcomes in response to the question, “From your experience, what predicts successful outcomes for ABI clients?”:

#### **Family factors**

- Family / community support (16)

#### **Client supports**

- Financial resources (7)
- Housing (5)

#### **Client factors**

- High client motivation (9)
- High client insight (4)
- Absence of dual diagnoses (4)
- Type of injury / medical fitness (4)

#### **Program / staff factors**

- Individualized goals (7)
- Timely service (3)

#### **Relationship factors**

- Good provider / client relationship (6)

### **Outcome data**

#### *Goal attainment*

We were unable to assess predictors of goal attainment, as these data are not reported on a client-specific basis, but only in aggregate.

#### *Outcomes from registry data*

Analysis of first and last status of clients during up to a six-year period from ABIIS registry data, on living situation, employability, and workforce status, shows little change in status between first and last registry reports. Assuming registry reports are updated at least annually, this suggests these outcomes change little as a result of ABI Partnership services. This is consistent with the findings of the 2010 evaluation.

#### *MPAI scores*

Analysis of the change in MPAI assessment scores from baseline to follow-up showed the following results:

- A total of 162 baseline and follow-up complete pairs were available for analysis, 79 using the MPAI version 3 and 83 using the MPAI version 4.
- The MPAI version 3 total score improved 1.3 points on a 90-point assessment instrument (~1.4%).
- The MPAI version 4 total score improved 8.2 points on a ~100 total point assessment instrument (~8%).

## Predictive analysis

### MPAI predictive analysis

We analyzed outcomes of the MPAI version 4 using 64 available cases (Table 17). We conducted an analysis to predict change scores in the MPAI4 from baseline to follow-up. Sixty-four cases were available with complete outcome data. We included in the analysis the following potential predictor variables: Age (18-49 / 50 years or more), workforce status (in / not in paid workforce), gender (male / female), home health region (Regina Qu'Appelle / Saskatoon / other), Insured (yes / no), living situation (independent / requires support), education (less than postsecondary / postsecondary), and cause of injury (trauma / non-trauma). Other variables available, but not included because of low response (fewer than ten cases) or low variability (fewer than ten values for one value of a dichotomous variable), were Registered Indian status and Glasgow Coma Scale.

**Table 17. Characteristics\* of MPAI4 pre-post assessments analyzed**

Variable	Mean	SD
Time lapse between pre and post scores (days)	437	235
Total score (out of ~100)	34.7	19.9
Sub-scale scores		
ability	12.1	8.1
adjustment	15.4	9.1
participation	11.9	8.0
Pre-post change in total score (primary endpoint)	-9.1	14.6
Pre-post change in sub-scale scores (secondary endpoints)		
ability	-2.8	6.3
adjustment	-3.8	6.8
participation	-3.4	5.0

\* N = 64. Outcome variables are measured by the professionally completed MPAI4 for 61 of 64 cases; three cases were self-reports. Higher scores indicate more severe problems in adaptation to ABI. Negative change scores indicate improvement.

In bivariate analysis with the primary endpoint of change in total MPAI4 score from baseline to follow up, two variables were statistically significant at the  $p \leq 0.05$  level (Table 18). In multivariate analysis, only the MPAI4 baseline score and Home Health Region: Saskatoon predicted changes in the MPAI score from baseline to follow-up assessments (Table 19).

### Interpretation

These results show that the change in score (a negative change or co-efficient represents improvement, as a lower score represents higher functioning (like golf)) is inversely related to the baseline score. That is, a client with a high (low functioning) baseline score is more likely to show improvement than a client with an already low initial score.

Secondly, these results show that clients resident in the Saskatoon Health Region had substantially greater improvement (nine points on an approximately 100-point scale) compared to clients living in any other health region. This difference in outcomes for Saskatoon residents also applies to the Abilities and Adjustment sub-scales, but not to the Participation sub-scale.

**Table 18. ABI client and program characteristic variables significantly\* correlated with change in MPAI4 overall and sub-scale scores from baseline to follow-up assessments**

Variable	Change in . . .			
	Overall MPAI4 score (primary endpoint)	MPAI sub-scales		
		Abilities	Adjustment	Participation
	<i>p</i>	<i>p</i>	<i>p</i>	<i>p</i>
MPAI4 overall baseline score	< 0.001	< 0.001	0.003	0.002
Home Health Region: Saskatoon / all other health regions	0.028	0.007	0.016	
Home Health Region: Regina RHA / all other health regions				0.025

\* Pearson correlation,  $p \leq 0.05$

N=64

Blank cells indicate a non-significant correlation.

The model R squared statistic of 0.29 indicates that the model explains 29 per cent of the variation in overall outcomes in clients and 34 per cent of the variation in the Abilities sub-scale. These are therefore moderately strong prediction models.

The next step in our analysis was to determine whether providing ABI services had any further effect on client endpoints of MPAI4 scores, after adjustment using the predictor model described above. Sixty-three cases had complete service data. The services listed in Table 20 had sufficient variation to include in the analysis. The criterion for including a service in the analysis was that service variable values could be categorized into at least two categories with 10 or more cases in each category.

When the significant service variables from the bivariate analysis reported in Table 20 were added to the multivariate prediction models described in Table 19, no service variables entered the multivariate model at the significance level of  $p \leq 0.01$ . (Model building method and criteria were the same as described in the note to Table 19.)

**Table 19. Multivariate model for predicting changes in overall MPAI4 score (primary endpoint) and sub-scale scores from baseline to follow-up assessments**

Client characteristic: indicator / comparison	Change in . . .							
	Overall MPAI4 score (primary endpoint)		MPAI sub-scales					
			Abilities		Adjustment		Participation	
	B	<i>p</i>	B	<i>p</i>	B	<i>p</i>	B	<i>p</i>
Constant			4.40	0.003				
MPAI4 overall baseline score	-0.36	< 0.001	-0.16	< 0.001	-0.13	0.001	-0.10	0.002
Home Health Region: Saskatoon RHA / all other health regions	-9.09	0.006	-4.66	0.001	-4.51	0.005		
Model Adjusted R squared	0.29		0.34		0.21		0.13	

N=64.

Model building specifications: method: forward stepwise regression, dropping of included non-significant variables at each step; criterion for variable entry  $p \leq 0.01$  in; criterion for dropping an included variable:  $p > 0.011$ .

Blank cells indicate a variable not included in the model for that endpoint.

**Table 20. Service\* variables included in the analysis and frequency of selected values**

Variable / categories	Percentage
Case management	
16 or fewer services	51
17 or more services	49
Consultation - any	52
Therapeutic - therapy (physical, occupational, or speech-language) - any	39
Therapeutic - psycho-social & behavioural - any	19
Therapeutic - recreational & leisure - any	30
Total direct services (tertiles) (excludes Administration & No show)	
1 to 15	33
16 to 40	33
41 or more	33

\* Count of services of the type indicated, provided to a client, from the month of the baseline MPAI4 assessment to the month of the MPAI4 follow up assessment, inclusive.

To assess what services associated with Home Health Region = Saskatoon were associated with the predictive significance of that variable, we next ran a regression model excluding the Home Health Region variables, but including the significant service variables from the bivariate analysis in Table 21. No service variables were significant at the  $p \leq 0.01$  criterion for entry into the multivariate model. However, one variable was very close to the selected significance threshold in several models. In all multivariate models predicting change in MPAI4 total and sub-scale scores except for the MPAI4 “Participation” sub-scale, the significance of the service variable “Therapeutic - Psycho-social & behavioural - any” ranged just outside the predetermined significance criterion, from  $p = 0.011$  to  $p = 0.015$  (data not presented in a table). To further explore this, we attempted to explore the interaction between Home Health Region = Saskatoon and “Therapeutic - Psycho-social & behavioural - any”. However, there were no cases in the small data available where this service was coded as provided in Saskatoon, so we were unable to test this interaction.

**Table 21. ABI service\* variables significantly\*\* correlated with change in MPAI4 overall and sub-scale scores in bivariate analysis**

Service type: indicator / comparison	Change in . . .			
	Overall MPAI4 score (primary endpoint)	MPAI sub-scales		
		Abilities	Adjustment	Participation
	<i>p</i>	<i>p</i>	<i>p</i>	<i>p</i>
Case management: 17 or more services / 16 or fewer services				0.042
Consultation: any / none			0.042	
Therapeutic - psycho-social & behavioural: any / none	0.005	0.001	0.007	
Therapeutic - recreational & leisure: any / none	0.036		0.032	0.002

\* Any service of the type indicated, provided to a client, from the month of the baseline MPAI4 assessment to the month of the MPAI4 follow up assessment, inclusive.

\*\* Pearson correlation,  $p \leq 0.05$ ; N=63; blank cells indicate a non-significant correlation.

*Interpretation*

This finding suggests that something about the service the services as delivered to clients resident in the Saskatoon Health Region results in substantially improved outcomes for clients. The analysis further suggests that the service “Therapeutic - Psycho-social & behavioural - any” may be associated with improved outcomes.

When we explored with the Saskatoon ABI Outreach Team what service is coded as “Therapeutic - psycho-social & behavioural”, the Team manager reported that this coding is used for consults with a neuro-psychologist for assessments of some clients and for direct therapy and counselling with some clients. The neuro-psychologist also sits in on weekly case conferences and provides advice and input on new clients. Case managers use the information from the assessments and case conference participation of the neuro-psychologists for planning their support services and approach to their clients. Saskatoon ABI Outreach Team reported that while the neuro-psychologist’s services are available to the two other Outreach Teams for assessments, they are the only Team where a neuro-psychologist participates in case conferencing and individual therapy / counselling. Saskatoon ABI Outreach Team also employs a psycho-metrician to conduct the testing of clients used by the neuro-psychologist in his assessments.





## Conclusions

### Limitations

While the registration and service delivery data was overall of good quality, we did face some data limitations in this evaluation that restricted our ability to conduct analysis or to reach clear conclusions. These data limitations included:

- We were not able to estimate severity of brain injury because the Glasgow Coma Scale (GCS) was reported for only nine per cent of clients registered over the past five years, and for only six per cent of registrants in the most recent year reviewed.
- The absence of change in the living and workforce status of clients from first to last registration in the six-year time frame of this evaluation raises a question as to whether programs regularly update registry information, and therefore, whether this information can be relied upon as a source of data for evaluating outcomes.
- The extremely low completion of the baseline and follow-up MPAI assessments meant that we were unable to comprehensively use this sensitive evaluation instrument to assess outcomes. Only 63 of 1,500 clients - four per cent - over the past five years had complete MPAI data.
- Data collected by the ABIIS system is typical of health services administrative data in that it collects data cross sectionally (in a fiscal year) by program. Fortunately a unique identifier is used. This allowed us to track clients, anonymously, across multiple programs and years, and to construct a profile of the flow of clients in their progress through services from first registration to discharge or loss of contact.

### Discussion

#### Data quality and comprehensiveness

##### Clinical data on severity of injury

Since a program criterion is that ABI Partnership services are provided to clients with a moderate or severe brain injury, but not for mild brain injury, this data limitation raises the question of how program partners assess whether a client is eligible for the program without information such as the GCS. Either clients are being admitted or denied service based on other clinical information, in which case this information should be collected in the registration database, or clients are being admitted or denied service on unclear or arbitrary grounds, in which case there is an issue about equity of access.

##### Outcomes data

###### *Living situation and workforce status*

Living situation and workforce status information shows negligible changes in these outcomes while clients engage in ABI Partnership programming. It is not clear whether programs routinely update all registration information annually; if they do not, important information that can be used to assess program outcomes is missing. The Partnership should review and emphasize with its component programs the importance of updating registration information at least annually.

###### *MPAI*

The low completion rate of the MPAI was a serious handicap to evaluating the outcomes of specific components of the ABI Partnership's programs. Integration of the MPAI instrument into the routine assessment of clients, and its use for client care planning and monitoring of clinical progress, would also ensure these data are collected for overall evaluation purposes.

### **Data to show the flow of clients**

With some time and effort, we were able to construct data that showed the flow of the same clients over time (a cohort analysis), rather than a picture of clients at one point of time (a cross-sectional analysis). Both views of clients have their uses; a cross-sectional approach tends to focus on service and program delivery, while a cohort approach tends to focus on the client journey. Unfortunately, there were too many gaps in the data for us to complete an actual client journey map. The proposed client journey map in Appendix 3 could, however, be used to guide future data development and analysis to shift the perspective from the service providers' point of view to the point of view of clients' experience.

### **Principal evaluation questions**

The ABI Partnership defined the principal evaluation question as: "What aspects of service delivery are most effective for eliciting positive outcomes for ABI survivors?" It required three components of the ABI program to be assessed:

- the therapeutic relationship;
- service availability; and
- client engagement with service.

We respond to each of these questions with the evaluator's overall assessment in the following sections.

#### **Therapeutic relationship**

Both program staff and clients and families emphasized the importance of the relationship between them. Clients and families were overwhelmingly positive about their experience with these relationships.

#### **Service availability**

Service availability is very good in the three major cities, but diminishes with distance from the cities. It is least available in the North, where there is little face-to-face contact with clients and families and no local programming. There are, however, examples of strong local service delivery in rural areas, such as East Central SARBI at Kelvington.

#### **Client engagement with service**

Clients are successful in engaging with services when there is a good relationship with service providers. Family support also helps. Engagement is driven mainly by the needs and goals of clients. Engagement breaks down when there is no family support, poor rapport with staff, disagreement on goals (perceived by staff as unrealistic goals), and when other aspects of the client's life (often mental health and addictions issues) overwhelm the client and family's ability to cope.

### **What has been added by this evaluation to previous evaluations**

This evaluation built on the four previous evaluations of ABI program general services to:

- present overall frameworks for continuing to develop the program;
- provide evidence on what works best to improve or maintain client outcomes;
- seek more family input on services; and
- re-assess program functioning and identify any gaps in programming.

We summarize following what this evaluation has added in each of these four areas:

#### **Overall frameworks for continuing to develop the program**

There is no consensus in the field on a framework for long-term rehabilitation and support for ABI clients and no findings in the research evidence to settle the debate. The two frameworks proposed focus around a holistic approach to rehabilitation in the context of the client's life, and

intensive skill-based treatments in areas such as functional adaptation or restoring cognitive functions. There is little research or evaluation evidence to support either approach. Both have apparent strengths and weaknesses at first look. Aspects of both approaches are apparent in the programming we reviewed in Saskatchewan.

In the absence of hard research on which approach (or more likely, which aspects of each approach) provide most benefit to clients and families, evaluative data is needed. Saskatchewan has a huge advantage in that it delivers one co-ordinated program to an entire population in a geographic area, and it has an integrated system-wide information system.

This suggests two steps to better determine what approaches have the most benefit. The first is to add a component that was intended in the original program design but has not been implemented: research. This would best be done by partnering with external researchers in the field, perhaps even contacting leading researchers and offering access to data and support to involve clients and families.

The second step is to strengthen the already impressive integrated provincial information system, ABIIS, by integrating into everyday data collection and use outcomes data, specifically goal setting and attainment and the MPAL functional assessment instrument.

### **What works best to improve or maintain client outcomes**

Available research provides some, but not a great deal, of guidance on what works best to improve client outcomes. Research does suggest that the most fruitful interventions are various cognitive and behavioural interventions and treatment with medication to manage specific conditions: agitation and aggression, and attention and concentration.

There is little or no evidence for or against other major interventions supported by the ABI Partnership, such as vocational, recreation and leisure, and educational approaches. However, the program registration data we analyzed do indicate that there is negligible change in the broad outcomes of living situation and workforce participation as a result of engagement in ABI Partnership services.

However, the limited data using a more sensitive clinical functioning assessment, the MPAL, do show overall improvement. Further, the data suggest that programming in Saskatoon and psycho-social and behavioural therapy may be associated with more improvement in clients. Future confirmation is required with larger data sets, as well as exploration of the differences in services across sites to better understand and explain this finding. This suggestion is, however, consistent with the research evidence previously described.

### **Family support and housing**

Staff identified that they connect with family or other caregivers primarily through consulting or updating them. The focus is very much on the client, rather than the family. When describing what they did, program staff focussed on describing client programs.

In interviews, family members often described the stresses involved in understanding and adapting to behavioural and role changes of their brain-injured family member. Family members noted with appreciation the basic information they had received about brain injury and what to expect as a result in the behaviour and capabilities of their family member. When asked what services they had used, family members frequently mentioned family support programs.

These two perspectives indicate some disconnect between the needs of family members and the priorities of staff. While staff did recognize the importance of a family support system for successful adaptation to a brain injury by a client, they tended to see the maintenance of this support system as a responsibility of the family while the staff focussed on the client, rather than as something to which a staff member could proactively contribute.

A second support issue is that of housing. This is a major concern for some clients, especially those with more severe loss of functioning and who may struggle with addictions as well as brain injury. Safe, adequate housing is a key support for those struggling with disabilities and dysfunctions as well, such as mental health and addictions.

The ABI Partnership supports three approaches to address the housing needs of clients. These are firstly a fully funded, intensive supported housing program in Regina, secondly a program to support community housing options in Prince Albert, and thirdly the inclusion of housing assistance in general case management elsewhere.

The first option, dedicated, intensive supported housing, is very expensive. That is likely why only one program is supported, and why it only serves a small number of clients. This option is not a province-wide solution.

The other two options also have limitations. Programs using the second and third options struggle to address housing needs in the face of the lack of housing options available in the community.

ABI programs are not large enough on their own to influence social policy on housing; however, other social and health programs also face housing issues for their clients. ABI clients would be best served if the ABI Partnership and its component programs were to form partnerships with other social and health service programs to advocate for and develop housing alternatives to meet their needs collectively, rather than individually.

### **Program functioning and gaps**

#### *Service variation offers opportunity for improvement*

For a provincial program, there is remarkably wide variation among programs in the mix of programs delivered in each health region sector and in the outputs achieved per unit of funding dollars or staff positions.

Health services that vary according to differing characteristics of clients can indicate appropriate client centredness. However, variation in services that is unrelated to clients' characteristics, or that simply reflects provider preferences, does represent an opportunity for improving efficiency, effectiveness, or both. Why? If there are two ways of providing a service for the same kind of clients, one way either has better outcomes, or costs less, or both. This is a matter for evidence, rather than provider preference, to decide.

Here again, a richer database on outcomes would provide a valuable mine for program managers, future evaluators and researchers to draw from to learn more about what works.

#### *The time from injury to service appears to be too long*

Estimated time from injury to first registration, while it has dropped over the previous four years, was still 2.9 years in 2009-10. If this number is accurate (again, better information systems would help determine this) this indicates an unacceptably long lag in obtaining services for most clients. It suggests that many clients, rather than moving seamlessly into community support services for brain injury upon their discharge from acute care, in fact follow a different and more roundabout path. It may be that a client is discharged and perhaps struggles in the community for a year or two before s/he or his/her family recognizes that their life has not returned to what it was pre-injury and that they need help. This suggests a need for the ABI Partnership to engage in outreach and education to potential first contact points in the community for ABI survivors seeking help, such as family physicians and mental health and addictions services.

#### *Program outputs do not match contracted targets*

For the majority of ABI Partnership programs, program activities do appear to be implemented as planned; however, a high proportion of programs do not meet the targeted requirements for program outputs set out in the funding agreements. It is not clear why this is so. It may be that the targets are too ambitious, or it may be that the programs struggle to focus on achieving the targets. However, the fact that for some targets there is variation among programs, with some achieving similar targets while some do not, suggests that there is room for improvement and for learning from each other about more efficient ways of doing programming.

*Northern and rural service access is limited*

Analysis of service data indicates lower provision of ABI program services in rural areas and, especially, the North. The Status Indian population is also under-represented among clients in comparison to their proportion in the population, even though it is likely that this population experiences a higher rate of serious ABI. Our interviews confirmed limited access to and use of services by the Northern, rural and Aboriginal populations.

Other health and social service programs have also struggled with reaching harder to reach and service populations. Successful approaches in other sectors have included locally based, rather than itinerant service, and, for Aboriginal people, having staff familiar with Aboriginal languages and culture deliver programs.

*Programming using interventions with evidence of effectiveness*

There is not a great deal of evidence about what works or does not in community support for ABI survivors. But there is some, and some of it is new since the ABI program was originally designed in 1995. After 16 years, the program design remains fundamentally sound, but it could be improved with some minor revisions that reflect and put into practice some of the new evidence on what works that has been accumulated in the past decade.

## Recommendations

### Status of recommendations from previous evaluations

We reviewed the major areas of recommendations from previous evaluations (Table 22).

**Table 22. Status of major recommendations from previous evaluations**

Recommendation	First recommended:	Current status
More co-ordination of prevention activities	1998	provincial education and prevention co-ordinator position created
Address gaps in:		
residential support		support workers in Central and North; funded residential program in Regina; housing remains a significant issue for some clients
addictions support		referral to addictions services; no integrated services
development of meaningful activity		vocational involvement of clients (paid or unpaid) does not change through involvement in ABI Partnership programs
Improve services for families	2006	families are consulted and involved as part of the service plan for the client; services still focus on the client
Improve information systems	2010	important outcome / progress indicators (MPAI and goal attainment) are not yet integrated into the client-specific data collection system

From previous evaluations, there is still implementation work to do on:

- housing;
- integration or linkage of ABI programs with addictions services;
- support for meaningful activity;
- family support; and
- integration of outcome / progress indicators into the ABIIS.

## Recommendations arising from this evaluation

Based on the findings and discussion previously presented, we make the following recommendations in the areas of data collection, quality and management, and service delivery:

### Improvement of data collection, quality and management

#### *Collect outcomes data*

1. Integrate goal setting and attainment data into the ABIIS.
2. Integrate the Mayo-Portland Adaptability Inventory into the ABIIS and use it as an instrument for assessment of all clients at intake and at regular followup intervals. Use the information in case management as the foundation for service planning and for assessment of client progress.

#### *Improve data quality and usefulness by improving access and ensuring regular updating*

3. Ensure on-line access to the ABIIS is easily available to all staff who require it so that it can be used in clinical settings to update and access required client information.
4. Reinforce with all programs and their staff the importance of regularly (at least annually) updating registration information for all clients.

### Service delivery improvement

#### *Improve Northern and rural service access*

5. Improve service delivery in rural areas and especially the North. In the North, at a minimum ensure face-to-face contact with all clients and families quarterly. Consider different models of service delivery in the North and in rural areas with high Aboriginal populations. Such models might include staff based in the North and staff familiar with Aboriginal languages and culture.

#### *Add research*

6. Add a research component to the ABI Partnership, preferably by offering research opportunities and support to external researchers in the field.

#### *Shift programming to interventions with evidence of effectiveness*

7. Research evidence and program data indicate the most promising areas for improving effectiveness are cognitive and behavioural interventions and treatment with medication for specific conditions. In the absence of either research evidence or program data indicating improvement in client outcomes with other programming, funding and staffing resources should be shifted towards these interventions with evidence of effectiveness.

#### *Focus future evaluation on how services improve outcomes*

8. Focus future evaluation on the relationship of services to improvements in MPAI scores, as the MPAI is an adaptation outcome assessment instrument with demonstrated sensitivity to client changes in adaptation to brain injury.

#### *Increase the focus on support systems*

9. Ensure assessment of the family support system as part of client assessment and include a service plan for proactively addressing family needs and engaging and supporting the family to support the client.
10. Address housing issues in an integrated way with other community partners facing similar issues for their clients.

#### *Explore service and funding variation and lags as opportunities for improvement*

11. Explore why there is variation across programs in rates of service delivery and in meeting contracted output targets. Large variation should be treated as learning and improvement

opportunity by ABI provincial staff in cooperation with task groups of program managers and staff.

12. Explore why the time from injury to service appears to be so long and develop strategies to ensure a more seamless transition from inpatient rehabilitation to community support.
13. Shift resources to ensure that they match current population distributions across health regions and communities.





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## Appendix 1. Program logic models for planning and evaluation

### What are program logic models?

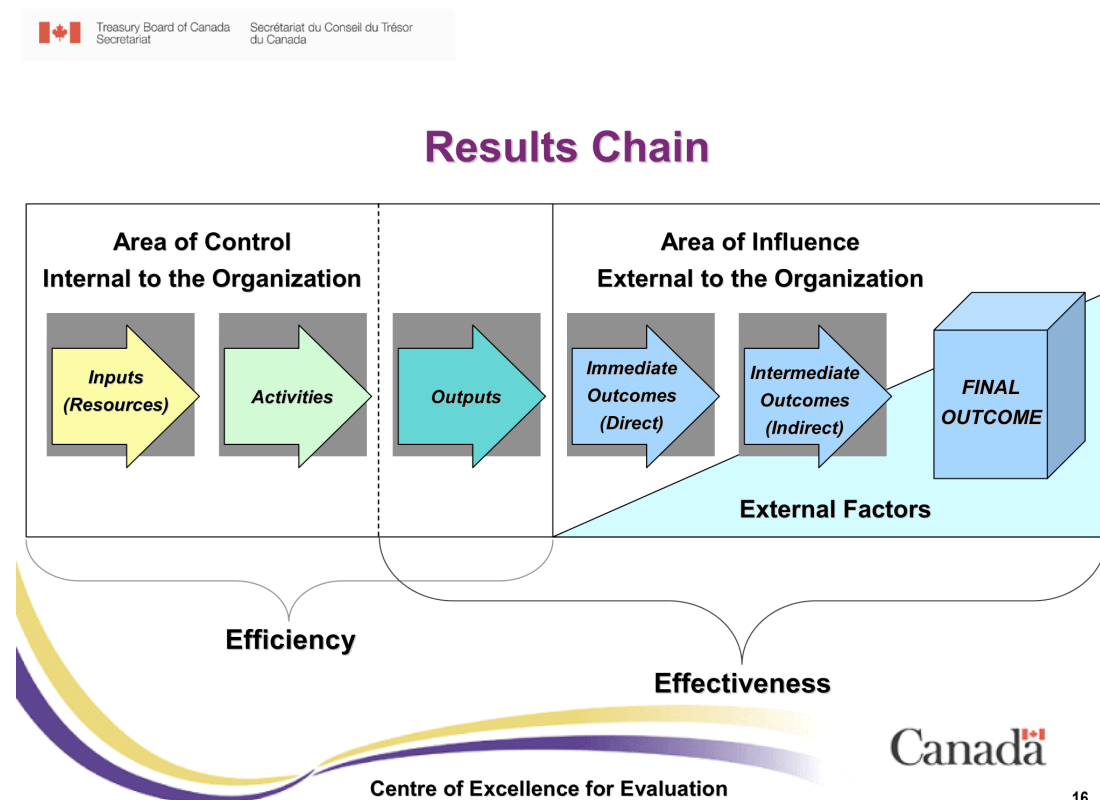
A program logic model is a road map for a program. It sets out a logical, causal progression, for a program like steps in a journey. These steps are:

- Set **goals**, objectives and target populations (program description);
- Allocate or receive **inputs** or resources;
- Carry out **activities** required in order to create program outputs;
- Create **outputs** (often services) that affect clients or populations external to the program; and
- Create desired changes in the clients or population served (**outcomes**).

Figure 1 illustrates a general logic model (here called a “results chain”). This one was developed by the Treasury Board Secretariat (Government of Canada).

The distinctions between activities, outputs and outcomes are important, but often confused. Activities are *internally* oriented. Outputs *directly* affect the people served by the program. Outcomes are *changes in the clients or population served* (not changes within the organization or its activities or outputs).

Figure A1.1



Source: Treasury Board Secretariat (2003). Results-based management and accountability frameworks (RMAFs). Ottawa: Treasury Board of Canada (p. 16).

### What are program logic models for?

Program logic models are used to:

- map, and so clarify for managers and staff, program linkages between activities, outputs and the expected outcomes;

- communicate succinctly and clearly to others the rationale, activities and expected results of the program;
- shift the program focus from activities and services to client outcomes;
- test whether the program makes logical sense; and
- provide a framework for performance measurement and evaluation.

### How do you use program logic models?

Program logic models are used both for program planning and evaluation (Table A1.1). In planning mode, program logic models prompt planners to ask, “What is planned or expected to happen at each link in the chain?”

In evaluation mode, logic models prompt evaluators to ask, “What actually happened at each link in the chain? Were planned results actually achieved at each step in the program logic model?”

**Table A1.1. A general program logic model framework for program planning and evaluation**

Program logic model component	Planning question	Evaluation question
<b>Program description</b> (Goals, objectives, target groups)	What are the goals, objectives, and target groups?	What are the goals, objectives, and target groups?
<b>Inputs</b> (resources to be used)	What are the planned resources?	What are the actual resources received?
<b>Activities</b> (activities to be carried out in order to produce outputs)	What are the planned activities?	What activities have actually happened?
<b>Outputs</b> (planned products of program received by clients in the target groups)	What are the planned program outputs in the target group?	What are the actual program outputs in the target group?
<b>External factors</b> (other relevant factors in environment that also affect outcomes)	What external factors are also expected to affect outcomes, in addition to program outputs? What are the planned adjustments for this?	What external factors have affected outcomes, in addition to program outputs? What adjustments were made for this?
<b>Outcomes</b> (expected changes in clients in target groups)	What are the planned outcomes in the target groups?	What are the actual outcomes in the target groups?

### Accountabilities

- Program designers and funders are responsible for setting program goals, deciding on the amount and allocation of inputs, the selection of organizations or managers to manage activity and outputs. Ultimately, therefore, program designers (policy makers) and funders are accountable for outcomes.
- Project managers are accountable for their area of control: efficient management of inputs to achieve activities and outputs.

### Performance indicators

- Performance indicators can be attached to all key aspects of the program logic model, to monitor implementation of activities, outputs, and outcomes.

## Appendix 2. Planned program logic model for the ABI Partnership

(from the evaluation plan)

### Program logic model overall program description

#### Goal (Vision)

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

#### Overall activities (Mission)

"enhanced training opportunities for service providers, outreach assessment and case management, and community-based rehabilitation program enhancement. The strategy is to link existing resources with program development" (Acquired Brain Injury Working Group (1995). Acquired brain injury: strategy for services. p. 7 ).

#### Target groups

Saskatchewan residents with traumatic, pathological and chronic brain injuries (not including progressive disabilities such as Alzheimer's Disease or Multiple Sclerosis, or developmental disabilities such as Cerebral Palsy). The focus is on clients and their families injured within the past three years ago, with moderate to severe injuries, in need of specific supports and assistance to maximize their independence in their communities. However, clients will not be excluded based on time since injury, age, or co-morbid / concurrent condition.

Table A1. Saskatchewan acquired brain injury planned program logic model

Program description (goals, objectives, target groups)	Inputs	Activities	Outputs	Outcomes
<b>Provincial co-ordination of ABI Partnership</b> <ul style="list-style-type: none"> <li>Achieve program goals</li> <li>Manage finances appropriately</li> <li>Evaluate results</li> </ul>	<ul style="list-style-type: none"> <li>Annual budget</li> </ul>	<ul style="list-style-type: none"> <li>Financial administration</li> <li>Evaluation</li> <li>Prevention and education</li> </ul>		<ul style="list-style-type: none"> <li>Program successfully managed</li> <li>Program evaluations completed</li> </ul>
<b>Case management - outreach teams (3)</b> <ul style="list-style-type: none"> <li>Co-ordinate services for all ABI clients and their families within a geographic area</li> <li>Consulting support to other programs and to Regional Co-ordinators</li> <li>Community education</li> <li>Prevention services</li> </ul>	<ul style="list-style-type: none"> <li>Annual Partnership funding</li> <li>In-kind support</li> </ul>	<ul style="list-style-type: none"> <li>Client assessment, case management and limited direct service</li> <li>Family case management and education</li> <li>Development of and consultation to other services</li> <li>Community education</li> <li>Prevention</li> </ul>	<ul style="list-style-type: none"> <li>Service to 8-12 new clients per year, and 25-30 active clients at any time, per FTE</li> </ul>	<ul style="list-style-type: none"> <li>New clients with ABIs engage and link to services</li> </ul>

Program description (goals, objectives, target groups)	Inputs	Activities	Outputs	Outcomes
<b>Case management - regional co-ordination</b> <ul style="list-style-type: none"> <li>co-ordinate services for clients and families within a designated Regional Health Authority outside the centres where Outreach teams are located</li> </ul>	<ul style="list-style-type: none"> <li>Annual Partnership funding</li> <li>In-kind support</li> </ul>	<ul style="list-style-type: none"> <li>Client case management and limited direct service</li> <li>Family case management and education</li> <li>Development of and consultation to other services</li> <li>Community education</li> <li>Prevention</li> </ul>	<ul style="list-style-type: none"> <li>Service to 8-12 new clients per year, and 25-30 active clients at any time, per FTE</li> </ul>	<ul style="list-style-type: none"> <li>New clients with ABIs engage and link to services</li> </ul>
<b>Education and prevention</b> <ul style="list-style-type: none"> <li>Create awareness, provide education and resources and collaborate through a community development process with government agencies, schools, regional health authorities, community-based agencies, survivors, and family members</li> <li>Information sharing</li> <li>Decrease ABI incidence</li> </ul>	<ul style="list-style-type: none"> <li>Annual Partnership funding</li> <li>In-kind support</li> </ul>	<ul style="list-style-type: none"> <li>School programs (Brain Walk, PARTY, etc.)</li> <li>Bike rodeos, scooter safety</li> </ul>	<ul style="list-style-type: none"> <li>Increased awareness of brain injury risk and consequences:</li> <li>Number of participants in programs</li> <li>Resources developed and distributed</li> </ul>	<ul style="list-style-type: none"> <li>Decreased incidence of brain injury and risky behaviours</li> </ul>
<b>Crisis management</b> <ul style="list-style-type: none"> <li>Case management and crisis intervention for "difficult to manage" ABI clients in Regina and Saskatoon</li> </ul>	<ul style="list-style-type: none"> <li>Annual Partnership funding</li> <li>In-kind support</li> </ul>	<ul style="list-style-type: none"> <li>Co-ordinate and manage services for "difficult to manage" ABI clients</li> <li>Provide immediate intervention in crisis situations</li> <li>Facilitate successful engagement or re-engagement of ABI individuals by mainstream services</li> <li>Ensure the necessities of life are provided for ABI clients</li> </ul>	<ul style="list-style-type: none"> <li>Service to 8-12 new clients per year, and 15-20 active clients at any time, per FTE</li> </ul>	<ul style="list-style-type: none"> <li>Client crisis situations are resolved</li> <li>Potential harm to clients is reduced</li> <li>Clients in crisis successfully engage with mainstream services</li> </ul>
<b>Independent living</b> <ul style="list-style-type: none"> <li>To support clients to live as independently as possible in their community, in Moose Jaw, Estevan and Yorkton</li> </ul>	<ul style="list-style-type: none"> <li>Annual Partnership funding</li> <li>In-kind support</li> </ul>	<ul style="list-style-type: none"> <li>Assess client's residential needs with the ABI Regional Co-ordinator</li> <li>Teach and reinforce basic living skills.</li> <li>Assist clients to attend appointments for services</li> <li>Provide recreational and social opportunities.</li> <li>Assist clients in exercise programs</li> </ul>	<ul style="list-style-type: none"> <li>Service to 5-10 new clients per year, and 10-15 active clients at any time, per FTE</li> </ul>	<ul style="list-style-type: none"> <li>Clients live in the community, as independently as possible</li> </ul>

Program description (goals, objectives, target groups)	Inputs	Activities	Outputs	Outcomes
<b>Life enrichment</b> <ul style="list-style-type: none"> <li>To provide opportunities for leisure, recreation and socialization in Regina and Saskatoon</li> </ul>	<ul style="list-style-type: none"> <li>Annual Partnership funding</li> <li>In-kind support</li> </ul>	<ul style="list-style-type: none"> <li>Assist clients to discover the possibilities of his or her life</li> <li>Facilitate community-based socialization activities</li> <li>Organize and facilitate individual and group activities with the long term objective of clients being able to independently, with support, arrange their own quality of life activities</li> <li>Assist clients with developing and practicing socially appropriate behaviours</li> <li>Assist clients with scheduling transportation</li> <li>Assist clients to make social, leisure and recreational connections in the community</li> </ul>	<ul style="list-style-type: none"> <li>Regina: service to 5 new clients per year, and 45 active clients at any time</li> <li>Saskatoon: service to 8-12 new clients per year, and 20 active clients at any time</li> </ul>	Clients achieve goals in relevant goal areas
<b>Supported employment and vocational training</b> <ul style="list-style-type: none"> <li>Increased participation in employment by clients leading to improved quality of life, in Regina, Saskatoon and Meadow Lake</li> </ul>	<ul style="list-style-type: none"> <li>Annual Partnership funding</li> <li>In-kind support</li> </ul>	<ul style="list-style-type: none"> <li>Facilitate paid employment with placement, training and other supports</li> </ul>	<ul style="list-style-type: none"> <li>service to 10-15 new clients per year, and 40-60 active clients at any time in Regina</li> <li>service to 10-20 new clients per year, and 40-60 active clients at any time in Saskatoon</li> <li>service to 1-2 new clients per year, and 5-10 active clients at any time , per FTE, in Meadow Lake</li> </ul>	Clients are successfully employed

Program description (goals, objectives, target groups)	Inputs	Activities	Outputs	Outcomes
<b>Residential</b> Regina and Prince Albert: <ul style="list-style-type: none"> <li>to enable clients to live more independently</li> </ul> Regina: <ul style="list-style-type: none"> <li>short-term refuge for clients in crisis; and</li> <li>respite for caregivers and clients</li> </ul>	<ul style="list-style-type: none"> <li>Annual Partnership funding</li> <li>In-kind support</li> </ul>	Regina and Prince Albert: <ul style="list-style-type: none"> <li>Provide living support to clients in the community</li> <li>Assess and teach independent living skills,</li> <li>Organize social, recreation and leisure activities</li> <li>Assist with money management</li> <li>Assist clients to access health services</li> <li>Case management of services to residents</li> <li>Train clients in cognitive strategies</li> <li>Train in communication skills, anger management, coping and problem solving.</li> <li>Provide training in healthy life skills</li> <li>Assist clients to move to a more independent living situation</li> <li>Provide training and support in medication management</li> </ul> Regina: <ul style="list-style-type: none"> <li>Provide 24-hour supervised joint housing</li> </ul>	Regina: <ul style="list-style-type: none"> <li>Service to 8-12 new clients per year</li> <li>Service to 5-8 active clients at any time per FTE</li> </ul> Prince Albert: <ul style="list-style-type: none"> <li>Service to 8-12 new clients per year</li> <li>Service to 15-25 active clients at any time per FTE</li> </ul>	Clients live in the community as independently as possible
<b>Child and youth program</b> <ul style="list-style-type: none"> <li>to improve community integration of child and youth clients aged 6-22 years in Saskatoon and area</li> </ul>	<ul style="list-style-type: none"> <li>Annual Partnership funding</li> <li>In-kind support</li> </ul>	<ul style="list-style-type: none"> <li>Develop and implement an individual Community Integration Plan</li> <li>Support the family to integrate the client with the community</li> <li>Link participants to community resources</li> <li>Reduce barriers that hinder community integration through advocacy</li> </ul>	<ul style="list-style-type: none"> <li>Service to 5-10 new clients per year, and 15-20 active clients at any time</li> </ul>	Clients are more integrated into the community
<b>Day programming</b> <ul style="list-style-type: none"> <li>to assist individuals in developing psycho-social and independent living skills in Saskatoon</li> <li>to foster growth in clients through leisure, recreational and social activities in the Lloydminster area</li> </ul>	<ul style="list-style-type: none"> <li>Annual Partnership funding</li> <li>In-kind support</li> </ul>	<ul style="list-style-type: none"> <li>Provide clients opportunities to work on skills in a safe, supportive setting, including social skills and communication, life skills, recreation and leisure opportunities (Saskatoon)</li> <li>To educate clients on ABI, healthy choices, and lifestyles (Saskatoon)</li> <li>The programs and services offered include: a life enrichment program, support groups, one on one support, a resource library and community awareness building (Lloydminster)</li> </ul>	Saskatoon <ul style="list-style-type: none"> <li>Service to 4-8 new clients per year, and at least 8 active clients at any time</li> </ul> Lloydminster <ul style="list-style-type: none"> <li>Service to 5-10 new clients per year, and 15-20 active clients at any time</li> </ul>	Clients have increased psycho-social and independent living skills



Program description (goals, objectives, target groups)	Inputs	Activities	Outputs	Outcomes
<b>Rehabilitation</b> <ul style="list-style-type: none"> <li>Facilitate reintegration of clients aged 16 years or older in Saskatoon, Regina and Kelvington and areas, with severe effects of ABI, into the community or other appropriate programs</li> <li>Improve speech / language functioning within Kelsey Trail Health Region</li> <li>Keewatin Yatthé, Mamawetan Churchill:</li> <li>Co-ordinate services, train paraprofessional staff, build community supports</li> </ul>	<ul style="list-style-type: none"> <li>Annual Partnership funding</li> <li>In-kind support</li> </ul>	<p>Regina and Kelvington:</p> <ul style="list-style-type: none"> <li>Assess and develop a plan for new clients</li> <li>Train and rehabilitate clients in daily living skills, therapeutic recreation, life enrichment and leisure and social activities.</li> <li>Develop friendships between clients and volunteers</li> <li>Provide outreach and supportive training to other organizations</li> </ul> <p>Kelsey Trail RHA:</p> <ul style="list-style-type: none"> <li>Speech language therapy</li> </ul> <p>Keewatin Yatthé, Mamawetan Churchill:</p> <ul style="list-style-type: none"> <li>Case management, training, building community supports</li> </ul>	<p>Saskatoon:</p> <ul style="list-style-type: none"> <li>Output not specified (Saskatoon)</li> <li>Service to a maximum of 20 active clients at any time (each)</li> </ul> <p>Kelsey Trail:</p> <ul style="list-style-type: none"> <li>Service to 8-12 new clients per year, and 25-30 active clients at any time</li> </ul> <p>Keewatin Yatthé:</p> <ul style="list-style-type: none"> <li>Service to 5-10 new clients per year, and 8-15 active clients at any time, per FTE</li> </ul>	<p>Clients are more integrated into the community</p>

## Saskatchewan acquired brain injury proposed client journey map

Client outcomes									
Client brain injury occurs	Client survives Initial Injury	Client returns to community	Client receives referral to ABI Outreach Team (ORT)	Client initially engaged with ABI ORT	Client baseline assessment	Referrals made in domains requiring support or remediation	Client is initially engaged in referral service	Client is engaged in service	Client outcome (at 18 months - change from baseline)
Indicators	% receiving acute treatment	% discharged to community	% referred to ABI ORT	% registered by ABI ORT	Client baseline measures in each domain (at ABI Outreach Team assessment) requiring support or remediation	Domains in which referrals made or services provided	Client attends referral service	Client remains involved in service or successfully completes service	Client follow-up measure in each domain at 18 months or discharge
Steps in the client journey									
Brain injury occurs	Client hospitalized	Client returns to community	Client receives referral to ABI ORT	Client attends intake interview with ABI ORT	Client assessed by ABI ORT, goals are mutually set, and needs for support or remediation identified from among following domains: <ul style="list-style-type: none"><li>• Self-care - daily activities</li><li>• Socialization</li><li>• Cognitive</li><li>• Behavioural</li><li>• Independent living</li><li>• Independent use of public transportation</li><li>• Medication management</li><li>• Money management</li><li>• Employment / purposeful activity</li><li>• Addictions</li></ul>	Client receives direct service from ABI ORT and/or receives referrals to address assessed needs	Client initially engages in referral service	Client continues to engage in referral services	Client: improves maintains state deteriorates no data
						No referral made/service provided	Client drops out		
							Client does not attend service		
						Referral is unsuccessful (referral service refuses referral as outside mandate)	Client experiences crisis, addressed by crisis services		
				No client assessment completed					
				Client does not participate in / attend intake					
		Client referred to ABI Outreach Team							
		Client dies in hospital or transfers to Special Care							
		Client dies before hospitalization							

## Appendix 4. Ethics and operational approvals

RHA	Submitted	Approved
Regina Qu'Appelle Health Region	September 22, 2010	October 26, 2010
Prince Albert Parkland Health Region	August 25, 2010	September 9, 2010
University of Saskatchewan (ethics approval for Saskatoon Health Region)	September 29, 2010	November 10, 2010
Saskatoon Health Region (operational approval)	November 26, 2010	December 2, 2010
Prairie North Health Region	October 7, 2010	December 13, 2010
Sun Country Health Region	October 28, 2010	November 15, 2010
Five Hills Health Region	October 28, 2010	November 25, 2010
Kelsey Trail Health Region	November 26, 2010	December 15, 2010

## Appendix 5. Consent forms for staff and clients and family

(Consent forms varied slightly by ethics board; these are the consent forms for Regina Qu'Appelle Health Authority)

### Client and family



### SUBJECT INTERVIEW INFORMATION AND CONSENT FORM

for the

#### Evaluation of the Acquired Brain Injury Partnership Project's Service Delivery Model

<b>Local Site Investigator:</b>	Blaine Katzberg, BSc, BScOT Therapy Manager Orthopedic Services, ABI Outreach Team, Regina Qu'Appelle Health Region (306) 766-5580
<b>Provincial Lead Investigator:</b>	Laurence Thompson, BA, MA President Laurence Thompson Strategic Consulting (306) 668-0080
<b>Sponsor:</b>	Saskatchewan Acquired Brain Injury Partnership Project, funded by Saskatchewan Government Insurance

#### 1. Introduction

You are being invited to participate in this research because you have received Acquired Brain Injury (ABI) services funded by the Saskatchewan Acquired Brain Injury Partnership Project or you are a family member or caregiver of such a person.

#### 2. Your Participation is Voluntary

Your participation is entirely voluntary. It is up to you to decide whether or not to take part in this study. Before you decide, it is important to understand what this research involves. This consent form tells you about the study, why the research is being done, what you will be asked to do, and the possible benefits and risks of participation.

If you wish to participate, you will be asked to sign this form. If you decide to take part in this study, you are still free to withdraw at any time without giving any reason for your decision. You are free to not answer any question or to not talk about any topic. You may leave at any time.

If you do not wish to participate, you do not have to provide a reason for your decision not to participate. You will not lose the benefit of any services to which you are entitled or which you are presently receiving based on your decision not to participate.

**Please take time to read the following information carefully and discuss it with family, friends, or health care providers.**

**3. Who is Conducting the Study?**

The study has been sponsored by the Saskatchewan ABI Partnership Project. Laurence Thompson Strategic Consulting has been contracted to conduct this research.

**4. Background**

The ABI Partnership Project is sponsored by Saskatchewan Government Insurance (SGI) and the Saskatchewan Ministry of Health. Since 1994, the ABI Partnership supports a provincial community-based rehabilitation program for people with Acquired Brain Injury. Every few years, the ABI Partnership evaluates its program to make sure it is working well and to find ways to improve it. This is the fifth evaluation. Your input will help improve the program in the future.

**5. What is the Purpose of the Study?**

The study seeks to answer the question: “What aspects of service delivery are most effective for eliciting positive outcomes for ABI survivors?”

**6. Who Is Being Asked to Participate in the Study?**

Service providers who are involved in delivering services to ABI survivors or their families, adult brain injury survivors, and adult family members of brain injury survivors will be asked to participate in these interviews.

**7. Who should not participate in the study?**

Brain injury survivors and family members should not participate in the interview if:

- They are under the age of 18 years; or
- They cannot be interviewed in English; or
- They are not competent to give informed consent to the interview.

**8. What Does this Study Involve?**

This evaluation is being carried out across Saskatchewan in the fall of 2010. We will interview 25 service providers, 15 ABI survivors, and ten family members. This study will involve meeting a researcher at a time and location that you are comfortable with, and talking to one of the researchers regarding your experience with the service you received for your acquired brain injury. The researcher will take notes about what you say. The interview will take an hour to an hour and a half.

**9. What are my Responsibilities?**

There are no requirements being asked of you in order to participate in this study.

**10. What are the Possible Harms or Side Effects of Participating?**

There are no known harms or side effects anticipated as a result of participating in this study.

**11. What are the Benefits of Participating in This Study?**

The benefits of participating in this study include an opportunity to discuss the service that you’ve received, and to offer comments that will be presented to service providers that work with survivors of brain injury. Your comments will help us improve the services in future.

**12. What if New Information Becomes Available That May Affect My Decision to Participate**

If, during the course of this study, new information becomes available that may be related to your willingness to continue to participate, this information will be provided to you by the investigator.

**13. What Happens if I Decide to Withdraw My Consent to Participate?**

You may decide to stop participating at any time. If you withdraw, you will not lose the benefit of any services to which you are entitled or which you are presently receiving based on your decision not to participate. You do not have to provide a reason or explanation to withdraw from this study. If

you choose to withdraw, the data you provided up to the point of your withdrawal point will be destroyed if you request it.

**14. What Happens if Something Goes Wrong?**

You do not waive any of your legal rights by signing this consent form.

**15. After the Study is Finished**

The results for this study will be reported in a written report to the ABI Partnership Project in 2011. If you wish to learn about the results of this study, you can give us your name and address or email on a card and we will make sure you receive a copy in the mail or by email.

**16. What Will the Study Cost Me?**

There are no costs to you in order to participate in this project. We will reimburse you \$20.00 for your travel costs and other costs. If your costs are greater than \$20.00, we will reimburse your reasonable costs with receipts. You will not receive any payment for participating other than these expense reimbursements.

**17. Will My Taking Part in This Study Be Kept Confidential?**

Your privacy will be respected. No information that discloses your identity will be released or published without your specific consent to the disclosure. The researchers' report will not identify you or any information that could be used to identify you.

The researchers will store their notes of their interview with you without your name on it. It will be identified only with a study code. A list with your name and study code will be kept separate from your interview notes, locked in the researcher's office. Only the researcher and his staff will see that list. The data will be stored in paper and password protected electronic format at the researcher's office. It will be destroyed after five years of storage.

The data you provide in your interview will be grouped together with other interviews to produce a report on how well ABI Partnership-funded services meet client needs. Results of this research will be disseminated through reports and presentations.

The researcher may use quotes from the interview with you in his report, but he will not identify you or use a quote that might identify you.

However, research records identifying you may be inspected in the presence of the investigator or his/her qualified designate, by representatives of the ABI Partnership Project, or by the Regina Qu'Appelle Health Region Research Ethics Board for the purpose of monitoring the research. Rarely, your study documents may be obtained by courts of law. This type of access to your personal information may include copying and taking away copies of the personal information you provided.

**18. Who Do I Contact if I Have Questions About the Study During My Participation?**

If you have any questions or desire further information about this study before or during participation, you can contact Blaine Katzberg at 766-5580 or Laurence Thompson at 1-306-668-0080 or email Laurence Thompson at [thompson@LTSC.ca](mailto:thompson@LTSC.ca).

**19. Who Do I Contact if I Have Any Questions or Concerns About My Rights as a Participant During the Study?**

If you have any concerns about your rights as a research subject and/or your experiences while participating in this study, you may contact Dr. Elan Paluck, Chair of the Regina Qu'Appelle Health Region Research Ethics Board, at 306-766-5451.

**20. Ethics Review**

This study was reviewed and approved by the following Research Ethics Boards on the following dates: Regina Qu'Appelle Health Region: October 26, 2010

**21. Subject Consent To Participate:**

This consent form is not a contract. You do not give up any of your legal rights by signing it.

Please read through the following checklist and put a check mark in each box to indicate your agreement with the statements.

- ☐ I have read and understood the subject information and consent form.
- ☐ I have had sufficient time to consider the information provided and to ask for advice if necessary.
- ☐ I have had an opportunity to ask questions and have had satisfactory responses to my questions.
- ☐ I understand that all of the information collected will be kept confidential and that the result will only be used for evaluation objectives.
- ☐ I understand that my participation in this study is voluntary and that I am completely free to refuse to participate or withdraw from this study at any time without repercussions to me.
- ☐ I understand that I am not waiving any of my legal rights as a result of signing this consent form.
- ☐ I understand that there is no guarantee that this study will provide any benefits to me.
- ☐ I have read this form and I freely consent to participate in this study.
- ☐ I have been told that I will receive a dated and signed copy of this form.

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Printed Name of Subject

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Signature

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Date

---

Printed Name of Principal

---

Signature

---

Date

Investigator/Designated Representative

## Staff



### SUBJECT INTERVIEW INFORMATION AND CONSENT FORM

#### for the

#### Evaluation of the Acquired Brain Injury Partnership Project's Service Delivery Model

<b>Local Site Investigator:</b>	Blaine Katzberg, BSc, BScOT Therapy Manager Orthopedic Services, ABI Outreach Team, Regina Qu'Appelle Health Region (306) 766-5580
<b>Provincial Lead Investigator:</b>	Laurence Thompson, BA, MA President Laurence Thompson Strategic Consulting (306) 668-0080
<b>Sponsor:</b>	Saskatchewan Acquired Brain Injury Partnership Project, funded by Saskatchewan Government Insurance

#### 1. Introduction

You are being invited to participate in this research because you help provide Acquired Brain Injury (ABI) services funded by the Saskatchewan Acquired Brain Injury Partnership Project.

#### 2. Your Participation is Voluntary

Your participation is entirely voluntary. It is up to you to decide whether or not to take part in this study. Before you decide, it is important to understand what this research involves. This consent form tells you about the study, why the research is being done, what you will be asked to do, and the possible benefits and risks of participation.

If you wish to participate, you will be asked to sign this form. If you decide to take part in this study, you are still free to withdraw at any time without giving any reason for your decision. You are free to not answer any question or to not talk about any topic. You may leave at any time.

If you do not wish to participate, you do not have to provide a reason for your decision not to participate. Your decision not to participate will have no effect upon your employment.

**Please take time to read the following information carefully and discuss it with family, friends, or colleagues.**

#### 3. Who is Conducting the Study?

The study has been sponsored by the Saskatchewan ABI Partnership Project. Laurence Thompson Strategic Consulting has been contracted to conduct this research.

#### 4. Background

The ABI Partnership Project is sponsored by Saskatchewan Government Insurance (SGI) and the Saskatchewan Ministry of Health. Since 1994, the ABI Partnership supports a provincial community-based rehabilitation program for people with Acquired Brain Injury. Every few years,



the ABI Partnership evaluates its program to make sure it is working well and to find ways to improve it. This is the fifth evaluation. Your input will help improve the program in the future.

**5. What is the Purpose of the Study?**

The study seeks to answer the question: “What aspects of service delivery are most effective for eliciting positive outcomes for ABI survivors?”

**6. Who Is Being Asked to Participate in the Study?**

Service providers who are involved in delivering services to ABI survivors or their families, adult brain injury survivors, and adult family members of brain injury survivors will be asked to participate in these interviews.

**7. Who should not participate in the study?**

Health service providers should not participate in the study if they are under the age of 18 years.

**8. What Does this Study Involve?**

This evaluation is being carried out across Saskatchewan in the fall of 2010. We will interview 25 service providers, 15 ABI survivors, and ten family members. This study will involve meeting a researcher at a time and location that you are comfortable with, and talking to one of the researchers regarding your experience with providing services to clients and families with acquired brain injury. The researcher will take notes about what you say. The interview will take an hour to an hour and a half.

**9. What are my Responsibilities?**

There are no requirements being asked of you in order to participate in this study.

**10. What are the Possible Harms or Side Effects of Participating?**

There are no known harms or side effects anticipated as a result of participating in this study.

**11. What are the Benefits of Participating in This Study?**

The benefits of participating in this study include an opportunity to discuss the service that you provide and to offer comments that will help improve services to survivors of acquired brain injury and their families in future.

**12. What if New Information Becomes Available That May Affect My Decision to Participate**

If, during the course of this study, new information becomes available that may be related to your willingness to continue to participate, this information will be provided to you by the investigator.

**13. What Happens if I Decide to Withdraw My Consent to Participate?**

You may decide to stop participating at any time. If you withdraw, your employment will not be affected in any way based on your decision not to participate. You do not have to provide a reason or explanation to withdraw from this study. If you choose to withdraw, the data you provided up to the point of your withdrawal point will be destroyed if you request it.

**14. What Happens if Something Goes Wrong?**

You do not waive any of your legal rights by signing this consent form.

**15. After the Study is Finished**

The results for this study will be reported in a written report to the ABI Partnership Project in 2011. If you wish to learn about the results of this study, you can give us your name and address or email on a card and we will make sure you receive a copy in the mail or by email.

**16. What Will the Study Cost Me?**

There are no costs to you in order to participate in this project. You will not receive any payment for participating in the study.

**17. Will My Taking Part in This Study Be Kept Confidential?**

Your privacy will be respected. No information that discloses your identity will be released or published without your specific consent to the disclosure. The researchers' report will not identify you or any information that could be used to identify you.

The researchers will store their notes of their interview with you without your name on it. It will be identified only with a study code. A list with your name and study code will be kept separate from your interview notes, locked in the researcher's office. Only the researcher and his staff will see that list. The data will be stored in paper and password protected electronic format at the researcher's office. It will be destroyed after five years of storage.

The data you provide in your interview will be grouped together with other interviews to produce a report on how well ABI Partnership-funded services meet client needs. Results of this research will be disseminated through reports and presentations.

The researcher may use quotes from the interview with you in his report, but he will not identify you or use a quote that might identify you.

However, research records identifying you may be inspected in the presence of the investigator or his/her qualified designate, by representatives of the ABI Partnership Project, or by the Regina Qu'Appelle Health Region Research Ethics Board for the purpose of monitoring the research. Rarely, your study documents may be obtained by courts of law. This type of access to your personal information may include copying and taking away copies of the personal information you provided.

**18. Who Do I Contact if I Have Questions About the Study During My Participation?**

If you have any questions or desire further information about this study before or during participation, you can contact Blaine Katzberg at 766-5580 or Laurence Thompson at 1-306-668-0080 or email Laurence Thompson at [thompson@LTSC.ca](mailto:thompson@LTSC.ca).

**19. Who Do I Contact if I Have Any Questions or Concerns About My Rights as a Participant During the Study?**

If you have any concerns about your rights as a research subject and/or your experiences while participating in this study, you may contact Dr. Elan Paluck, Chair of the Regina Qu'Appelle Health Region Research Ethics Board, at 306-766-5451.

**20. Ethics Review**

This study was reviewed and approved by the following Research Ethics Boards on the following dates: Regina Qu'Appelle Health Region: October 26, 2010

**21. Subject Consent To Participate:**

This consent form is not a contract. You do not give up any of your legal rights by signing it.

Please read through the following checklist and put a check mark in each box to indicate your agreement with the statements.

- ☐ I have read and understood the subject information and consent form.
- ☐ I have had sufficient time to consider the information provided and to ask for advice if necessary.
- ☐ I have had an opportunity to ask questions and have had satisfactory responses to my questions.
- ☐ I understand that all of the information collected will be kept confidential and that the result will only be used for evaluation objectives.
- ☐ I understand that my participation in this study is voluntary and that I am completely free to refuse to participate or withdraw from this study at any time without repercussions to me.
- ☐ I understand that I am not waiving any of my legal rights as a result of signing this consent form.
- ☐ I understand that there is no guarantee that this study will provide any benefits to me.
- ☐ I have read this form and I freely consent to participate in this study.
- ☐ I have been told that I will receive a dated and signed copy of this form.

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Printed Name of Subject

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Signature

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Date

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Printed Name of Principal

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Signature

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Date

Investigator/Designated Representative

## Appendix 6. Detailed program logic model indicators for the ABI Partnership: actual in relation to planned

**Table A6.1. Saskatchewan acquired brain injury planned program logic model and actual results**

Colour shading of **red** indicates planned activities, outputs or outcomes were clearly not met, **yellow** that they were partly met, and **green** that they were fully met. **Light blue** indicates that program data did not state an indicator or target for planned activities, outputs or outcomes; **orange** indicates that there was not sufficient data available to assess the achievement of planned activities, outputs or outcomes

Program logic model component	Planned	Actual
<b>Provincial co-ordination of ABI Partnership</b>		
<b>Description</b>	Achieve program goals through provincial co-ordination	
<b>Inputs</b>	Partnership funding (\$000s): 259	As planned
	In-kind contributions (\$000s)	67
	Staffing (FTEs): 3.0	As planned
<b>Activities</b>	Financial administration	Financial administration carried out as per plan
	Prevention & education	Not within scope of this evaluation
	Evaluation	Evaluations in 2011, 2010, 2006, 2004 & 1998
<b>Outputs</b>	Finances managed appropriately	Program funds distributed each year
	Prevention & education co-ordinated	Not evaluated
	Results evaluated	Evaluations completed
<b>Outcomes</b>	Manage finances appropriately	Provincial Auditor has expressed no specific concerns about this program
	Evaluate results	Program directions continued
	Prevention & education co-ordinated	Not evaluated
<b>Case management - outreach teams</b>		
<b>Description</b>	Co-ordinate services for all ABI clients & their families within a geographic area	
	Consulting support to other programs & to Regional Co-ordinators	
	Community education	
	Prevention services	
<b>Inputs</b>	Partnership funding (\$000s): 1,716	As planned
	In-kind contributions (\$000s)	795
	Staffing (FTEs): 27.1	As planned
<b>Activities</b>	Client assessment, case management & limited direct service	All activities are being carried out (staff interviews).
	Family case management & education	
	Development of & consultation to other services	
	Community education	
	Prevention	
<b>Outputs</b>	Service to 8-12 new clients per year per FTE	6.6 new clients / year / FTE (179 new clients / year)
	Service to 25-30 active clients at any time per FTE	21.9 active clients / year / FTE (593 active clients / year)
<b>Outcomes</b>	New clients with ABIs engage & link to services	Estimated that between one-third and all eligible ABI clients engage with services each year.

Program logic model component	Planned	Actual
Case management - regional co-ordination		
Description	co-ordinate services for clients & families within a designated Regional Health Authority outside the centres where Outreach teams are located	
Inputs	Partnership funding (\$000s): 383	As planned
	In-kind contributions (\$000s):	8
	Staffing (FTEs): 5.6	As planned
Activities	Client assessment, case management & limited direct service	All activities are being carried out as planned (staff interviews).
	Family case management & education	
	Development of & consultation to other services	
	Community education	
	Prevention	
Outputs	Service to 8-12 new clients per year / FTE	13.0 new clients / year / FTE (73 new clients / year)
	Service to 25-30 active clients at any time / FTE	34 active clients / year / FTE (189 active clients / year)
Outcomes	New clients with ABIs engage & link to services	Estimates suggest most eligible clients initially engage and link to services
Education & prevention		
Description	Create awareness, provide education & resources & collaborate through a community development process with government agencies, schools, regional health authorities, community-based agencies, survivors, & family members	Not within scope of this evaluation to assess
	Information sharing	
	Decrease ABI incidence	
Inputs	Partnership funding (\$000s): 441	
	In-kind contributions (\$000s): 217	
	Staffing (FTEs): 5.5	
Activities	School programs (Brain Walk, PARTY, etc.)	
	Bike rodeos, scooter safety	
Outputs	Increased awareness of brain injury risk & consequences: <ul style="list-style-type: none"><li>• # of participants in programs</li><li>• Resources developed, distributed</li></ul>	
Outcomes	Decreased incidence of brain injury & risky behaviours	
Crisis management		
Description	Case management & crisis intervention for “difficult to manage” ABI clients in Regina & Saskatoon	
Inputs	Partnership funding (\$000s): 94	As planned
	In-kind contributions (\$000s):	47
	Staffing (FTEs): 1.0	As planned

Program logic model component	Planned	Actual
Activities	Co-ordinate & manage services for “difficult to manage” ABI clients	Crisis management services are not well integrated with other ABI services. The separate evaluation on difficult-to-manage clients may provide more information on these activities.
	Provide immediate intervention in crisis situations	
	Facilitate successful engagement or re-engagement of ABI individuals by mainstream services	
	Ensure the necessities of life are provided for ABI clients	
Outputs	Service to 8-12 new clients / year / FTE	Service to 4 new clients / year / FTE (4 new clients / year)
	Service to 15-20 active clients at any time, / FTE	Service to 30 active clients / year / FTE (30 active clients / year)
Outcomes	Client crisis situations are resolved	Insufficient data to assess; a separate evaluation of difficult-to-manage clients may provide an assessment of these outcomes
	Potential harm to clients is reduced	
	Clients in crisis successfully engage with mainstream services	
Independent living		
Description	To support clients to live as independently as possible in their community, in Moose Jaw, Estevan & Yorkton	
Inputs	Partnership funding (\$000s): 143	As planned
	In-kind contributions (\$000s):	39
	Staffing (FTEs): 2.9	As planned
Activities	Assess client’s residential needs with the ABI Regional Co-ordinator	All activities are being carried out as planned (staff interviews).
	Teach & reinforce basic living skills	
	Assist clients to attend appointments for services	
	Provide recreational & social opportunities.	
	Assist clients in exercise programs	
Outputs	Service to 5-10 new clients / year / FTE	Service to 2.1 new clients / year / FTE (6 new clients / year)
	Service to 10-15 active clients at any time, / FTE	Service to 12.4 active clients / year / FTE (36 active clients / year)
Outcomes	Clients live in the community, as independently as possible	While some clients do achieve independent living, registration data shows almost no change in independent living status of clients as a result of engagement with ABI Partnership services
Life enrichment		
Description	To provide opportunities for leisure, recreation & socialization in Regina & Saskatoon	
Inputs	Partnership funding (\$000s): 119	As planned
	In-kind contributions (\$000s):	86
	Staffing (FTEs): 3.5	As planned
Activities	Assist clients to discover the possibilities of his or her life	All activities are being carried out as planned (staff interviews).
	Facilitate community-based socialization activities	

Program logic model component	Planned	Actual
	Organize & facilitate individual & group activities with long term objective of clients being able to independently, with support, arrange their own quality of life activities	
	Assist clients with developing & practicing socially appropriate behaviours	
	Assist clients with scheduling transportation	
	Assist clients to make social, leisure & recreational connections in the community	
<b>Outputs</b>	Regina: service to 5 new clients / year, & 45 active clients at any time	Regina: service to 5 new clients & 41 active clients / year for 1.0 FTE
	Saskatoon: service to 8-12 new clients / year, & 20 active clients at any time	Saskatoon: service to 4 new & 24 active clients / year for 2.0 FTE
	Yorkton: resources shown as allocated, but no outputs specified in Service Schedules	Yorkton: service to 5 new and 17 active clients / year for 0.5 FTE
<b>Outcomes</b>	Clients achieve goals in relevant goal areas	During 2007-09, clients achieved 62 per cent of goals and partially achieved 29 per cent province-wide.
<b>Supported employment &amp; vocational training</b>		
<b>Description</b>	Increased participation in employment by clients leading to improved quality of life, in Regina, Saskatoon & Meadow Lake	
<b>Inputs</b>	Partnership funding (\$000s):179	As planned
	In-kind contributions (\$000s):	90
	Staffing (FTEs): 3.3	As planned
<b>Activities</b>	Facilitate paid employment with placement, training & other supports	All activities are being carried out as planned (staff interviews).
<b>Outputs</b>	Regina: service to 10-15 new clients / year, & 40-60 active clients / FTE	Regina: service to 15 new & 57 active clients / year / FTE
	Saskatoon: service to 10-20 new clients / year, & 40-60 active clients / FTE	Saskatoon: service to 9.5 new & 19.5 active clients / year (19 new & 39 active clients, 2.0 FTE)
	Meadow Lake: service to 1-2 new clients / year, & 5-10 active clients / FTE	Meadow Lake: service to 0 new clients & 13 active clients / year / FTE (0 new & 4 active clients, 0.3 FTE)
<b>Outcomes</b>	Clients are successfully employed	While some clients do achieve employment, registration data shows almost no change in workforce status of clients as a result of engagement with ABI Partnership services
<b>Residential</b>		
<b>Description</b>	Regina & Prince Albert: to enable clients to live more independently	
	Regina: short-term refuge for clients in crisis; & respite for caregivers & clients	
<b>Inputs</b>	Partnership funding (\$000s): 599	As planned
	In-kind contributions (\$000s):	67
	Staffing (FTEs): 11.9	As planned

Program logic model component	Planned	Actual
<b>Activities</b>	Regina & Prince Albert: <ul style="list-style-type: none"> <li>• Provide living support to clients in the community</li> <li>• Assess &amp; teach independent living skills,</li> <li>• Organize social, recreation &amp; leisure activities</li> <li>• Assist with money management</li> <li>• Assist clients to access health services</li> <li>• Case management of services to residents</li> <li>• Train clients in cognitive strategies</li> <li>• Train in communication skills, anger management, coping &amp; problem solving.</li> <li>• Provide training in healthy life skills</li> <li>• Assist clients to move to a more independent living situation</li> <li>• Provide training &amp; support in medication management</li> </ul> Regina: provide 24-hour supervised joint housing	All activities are being carried out as planned (staff interviews).
<b>Outputs</b>	Prince Albert: service to 8-12 new clients / year Prince Albert: service to 15-25 active clients at any time / FTE Regina: service to 8-12 new clients / year Regina: service to 5-8 active clients at any time / FTE	9 new clients / year service to 13.3 active clients / year / FTE (40 active clients / year) 5 new clients / year service to 3.3 active clients / year / FTE (29 active clients / year)
<b>Outcomes</b>	Clients live in the community as independently as possible	While some clients do achieve independent living, registration data shows almost no change in independent living status of clients as a result of engagement with ABI Partnership services
<b>Child &amp; youth program</b>		
<b>Description</b>	To improve community integration of child & youth clients aged 6-22 years in Saskatoon & area	
<b>Inputs</b>	Partnership funding (\$000s): 109 In-kind contributions (\$000s): Staffing (FTEs): 1.8	As planned 7 As planned
<b>Activities</b>	Develop & implement an individual Community Integration Plan Support the family to integrate the client with the community Link participants to community resources Reduce barriers that hinder community integration through advocacy	All activities are being carried out as planned (staff interviews).
<b>Outputs</b>	Service to 5-10 new clients / year Service to 15-20 active clients at any time	1 new client / year 14 active clients / year
<b>Outcomes</b>	Clients are more integrated into the community	Insufficient data to assess



Program logic model component	Planned	Actual
<b>Day programming</b>		
<b>Description</b>	Assist individuals in developing psycho-social & independent living skills in Saskatoon	
	Foster growth in clients through leisure, recreational & social activities in the Lloydminster area	
<b>Inputs</b>	Partnership funding (\$000s): 68	As planned
	In-kind contributions (\$000s):	98
	Staffing (FTEs): 2.6	As planned
<b>Activities</b>	Provide clients opportunities to work on skills in a safe, supportive setting, including social skills & communication, life skills, recreation & leisure opportunities (Saskatoon)	All activities are being carried out as planned (staff interviews).
	To educate clients on ABI, healthy choices, & lifestyles (Saskatoon)	
	The programs & services offered include: a life enrichment program, support groups, one on one support, a resource library & community awareness building (Lloydminster)	
<b>Outputs</b>	Saskatoon: Service to 4-8 new clients / year	Service to 8 new clients / year
	Saskatoon: Service to at least 8 active clients at any time	Service to 12 active clients / year
	Lloydminster: Service to 5-10 new clients / year	Service to 2 new clients / year
	Lloydminster: Service to 15-20 active clients at any time	Service to 17 active clients / year
<b>Outcomes</b>	Clients have increased psycho-social & independent living skills	Insufficient data to assess
<b>Rehabilitation</b>		
<b>Description</b>	Facilitate reintegration of clients aged 16 years or older in Saskatoon, Regina & Kelvington & areas, with severe effects of ABI, into the community or other appropriate programs	All activities are being carried out as planned (staff interviews).
	Improve speech / language functioning within Kelsey Trail Health Region	
	Keewatin Yatthé, Mamawetan Churchill: Co-ordinate services, train paraprofessional staff, build community supports	
<b>Inputs</b>	Partnership funding (\$000s): 383	As planned
	In-kind contributions (\$000s):	92
	Staffing (FTEs): 6.8	As planned
<b>Activities</b>	Regina & Kelvington: <ul style="list-style-type: none"> <li>Assess &amp; develop a plan for new clients</li> <li>Train &amp; rehabilitate clients in daily living skills, therapeutic recreation, life enrichment &amp; leisure &amp; social activities.</li> <li>Develop friendships between clients &amp; volunteers</li> <li>Provide outreach &amp; supportive training to other organizations</li> </ul>	All activities are being carried out as planned (staff interviews).

Program logic model component	Planned	Actual
	Kelsey Trail RHA: speech language therapy: no FTEs specified	
	Keewatin Yatthé, Mamawetan Churchill: Case management, training, building community supports: 0.8 FTEs, contracted to PAPRHA	While case management activities are being undertaken from Prince Albert, we did not find evidence of training of paraprofessional staff or of building community supports within the North
<b>Outputs</b>	Saskatoon: output not specified	No planned target specified; 5 new clients / year ; 30 active clients / year
	Regina: service to a maximum of 20 active clients at any time	20 active clients / year
	Kelvington: service to a maximum of 20 active clients at any time	23 active clients / year
	Kelsey Trail: service to 8-12 new clients / year	Service to 38 new clients / year
	Kelsey Trail: service to 25-30 active clients at any time	Service to 48 clients / year
	Keewatin Yatthé: service to 5-10 new clients / year	Service to 3 new clients / year
	Keewatin Yatthé: service to 8-15 active clients at any time / FTE	Service to 9 clients / year
	Mamawetan Churchill: output not specified	Service to 13 new clients & 26 active clients / year
<b>Outcomes</b>	Clients are more integrated into the community	Insufficient data to assess