

**EVALUATION OF THE ABI PARTNERSHIP PROJECT'S SERVICE
DELIVERY MODEL FOR DIFFICULT TO SERVE POPULATIONS**

Final Report

Prepared for
**Acquired Brain Injury Partnership Project
Saskatchewan Health
Saskatchewan Government Insurance**

Prepared by
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May 2012

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EXECUTIVE SUMMARY

The Acquired Brain Injury (ABI) Partnership Project is a joint initiative between Saskatchewan Health and Saskatchewan Government Insurance. The aim of the ABI Partnership Project is to develop and implement services and supports for acquired brain injury survivors and their families. Each year in Saskatchewan, approximately 2,200 people sustain an acquired brain injury. ABI survivors experience different levels of severity, but about 150 of the people who are injured each year further require multiple services and lifetime supports. For several ABI survivors, the injury is accompanied by significant behavioural change or additional challenges (acquired either before or after the ABI) that can compound client needs.

Even though the majority of service providers report that they enjoy the variability and challenge of responding to these unique service needs, many providers struggle to find effective service solutions for certain groups of ABI survivors. The reasons why it is more challenging to provide services for some clients as opposed to others is currently not known, and there is not a clear understanding of what constitutes a complex case as yet. Understanding this population of complex clientele is integral to altering service delivery to better benefit this client group.

In order to increase the retention of, and improve service delivery to, complex ABI clients, the ABI Partnership Project it contracted R. A. Malatest & Associates Ltd. to evaluate the service delivery model for this group. The ultimate purpose of the study is to equip service providers with a set of service delivery tools and best practices, which will enable them to improve client outcomes among complex clients.

Key findings from the evaluation are detailed below:

Which groups create challenges to provide services for, and in what ways are they complex cases?

Notably, complex clients often had compounding issues above and beyond an ABI. Analysis of the data from the service provider survey, focus groups, key informant interviews, and literature review show the following to be the most common factors contributing to difficulty serving:

1. *Substance abuse issues, (3.3.1)*
The affects of drugs and alcohol on the brain of an ABI survivor are much more potent. Drugs and alcohol can also cause greater brain damage to an ABI survivor. ABI survivors with substance abuse issues are also harder to find service providers for and ultimately require greater time and effort from case managers. Substance abuse issues of ABI survivors are also not always known until the client and the case manager build rapport.
2. *Mental health needs, (3.3.2)*
Underlying mental health issues tend to manifest in substance abuse issues. ABI recovery can often foster feelings of isolation, depression, frustration when an ABI survivor is unable to return to life as 'normal'. Mental health not only impacts the ABI survivor but also their family, friends, colleagues, and the community around them.
3. *Living in remote or inaccessible locations, (3.2.3)*
As an environmental factor that can lead to clients being deemed as complex cases, literature on the subject suggests that those who live in rural communities cannot easily access service providers and/or other supports. Living in a remote location can limit the amount of follow-up and client outcome tracking that can be provided. This does not

afford ABI survivors the same protections against relapsing, or falling back on past habits for example. Home visits are often impossible for service providers, and for those service providers who do make visits to rural communities, they tend to occur infrequently.

4. *Economic Factors, (3.3.4)*

ABI survivors who are impoverished have a greater likelihood of becoming homeless and transient. Homeless clients are much harder to locate, often miss meetings and appointments, and consequently, do not obtain services that they need. For ABI survivors who had supported a family financially pre-injury, being able to obtain employment is often a challenge. In many instances, the inability of the ABI client to obtain employment creates tension in family relationships and contributes to further stress and tension.

5. *Severe Brain Injury, and (3.3.5)*

Behavioural changes, cognitive limitations, and loss of functionality are often the result of severe brain injuries. Certain types of brain injuries, such as frontal lobe damage can also lead to aggressive behaviours in ABI survivors, which can be dangerous for family members and service providers. Often this produces strain within the family and may lead to clients being denied services. Severe brain injury can also produce memory issues for ABI survivors. Clients who miss appointments with service providers and miss treatments are often required to re-book appointments and have a more difficult time obtaining treatment and services.

6. *Low or Insufficient family Support. (3.3.6)*

Low levels of family support were felt to be a factor in determining if a client was difficult to serve, because without support within the home clients often do not properly follow treatment plans. When family members do have contact with the ABI survivor, but influence negative behaviours, or foster dysfunction within the family, this can lead to a client becoming a complex case. Family members sometimes influence substance abuse habits, steal a client's medication for their own use, and can influence clients to miss treatment and appointments. Family members can also set unrealistic goals for an ABI survivor, which can complicate a client's case and make it difficult to succeed and make meaningful improvements to their quality of life. Furthermore, when an ABI survivor used to be the major financial contributor in a family, this can produce a great deal of financial, and relationship strain within the family which can add to familial dysfunction. Depending on the client, aggressive behaviour can also produce a dangerous living arrangement where one did not previously exist for members of the family.

Factors that lead to clients presenting with complex cases often overlap, meaning that multiple factors may be presented concurrently by one client. A client need not present with all of these factors to be deemed a complex case, nor does the absence of each factor mean that they are necessarily a non-complex case. Rather, it is that each client should be assessed on a continuum of complexity. As many service providers reported, complex clients are the few cases that take up the majority of their time.

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SECTION 1: PROJECT OBJECTIVES AND METHODOLOGY

1.1 Project Background

1.1.1 The Acquired Brain Injury (ABI) Partnership Project

The Acquired Brain Injury (ABI) Partnership Project is a joint initiative between Saskatchewan Health and Saskatchewan Government Insurance. The aim of the ABI Partnership Project is to develop and implement services and supports for acquired brain injury survivors and their families. Specifically, it aims “to establish a ‘comprehensive, integrated system of supports, resources and services that will enhance the rehabilitation outcomes and improve the quality of life for individuals with acquired brain injuries and their families’” (Acquired Brain Injury 1995). The original goal of the partnership was not to duplicate services that are already offered in the Province, but to augment services for ABI survivors and fill in service needs and identify delivery gaps. Acquired brain injuries can have a variety of effects on survivors who experienced brain damage from injury or illness. Physical effects include bruising, bleeding, swelling, fever, lack of blood/oxygen, shearing/tearing of cells, and increased pressure in the brain. The consequences of ABI can lead to unemployment, financial problems, social isolation and the diminishment of a support network. Often, rehabilitation and recovery from ABI is a lifelong endeavor.

Each year in Saskatchewan, approximately 2,200 people sustain an acquired brain injury. ABI survivors experience different levels of severity, but about 150 of the people who are injured each year further require multiple services and lifetime supports. For several ABI survivors, the injury can be accompanied by significant behavioural change or additional challenges (acquired either before or after the ABI) that can compound the client’s needs. Since the Partnership’s inception in 1996, the ABI Partnership Project has provided services for over 3,700 individuals with Acquired Brain Injury.¹ Through both their Outreach Teams and other funded programs, the ABI Partnership has coordinated (short, intermediate, and long-term) service delivery in a host of areas for its clients.

The ABI Partnership Project seeks to provide multidisciplinary outreach services and programs to ABI survivors and their families, to help clients receive rehabilitation, life enrichment, residential and vocational services and support as close to their home communities as possible. In this way, the Partnership focuses on assisting survivors of ABI to re-engage with life as fully as possible. In an effort to enable survivors to remain in their home community without sacrificing the benefits of specialized supports and services, the ABI Partnership Project presently runs 36 community-based programs that serve residents located across Saskatchewan. Programs available to clients include:

- Client assessment,
- Case management,
- Crisis management services;

¹ http://www.abipartnership.sk.ca/html/about_us/index.cfm



- In-house residential programs;
- Supportive living services for those who do not require 24-hour care;
- Supported Employment program to guide and support ABI survivors in searching for, finding, and maintaining employment;
- Vocational training programs focused on ABI survivors;
- Access to a speech language pathologist;
- Independent living programs that provide support to survivors, family members, and caregivers; and
- Day programs with ABI survivors to teach life skills.

The Partnership has had great success working towards its goals, as new partnerships are forged and the project expands. However, as new clients with unique needs are referred from rehabilitation services (33%), acute care (26%), and other health care services and professionals (15%) to the Regional Outreach Groups the challenge remains to meet the needs of each client.

The Partnership functions as a network that connects different service providers across the province of Saskatchewan. The Partnership Project Outreach Teams and five Regional Coordinators provide a point of first contact for ABI survivors. At this point of first contact, a case manager will be assigned to provide an assessment, evaluate the client's needs, and establish goals for their rehabilitation. The case manager will also help the client navigate other funded agencies to obtain services, such as: substance abuse treatment, vocational training, housing services, and programs that address the identified needs of the client.

Service needs of clients vary due to the unique nature of each brain injury. No two brain injuries are alike, nor are the challenges faced by each client. The pattern of each survivor's impairments depends on the type and severity of the injury, the part of the brain that was affected, and the persistence of each deficit. Thus, each survivor presents a unique set of service needs. The project has the ability to arrange and facilitate a number of different services, such as: assessment, case management, consultation, support, education for individuals, families, or service providers, rehabilitation, life enrichment programming, vocational programming, crisis management, housing, and independent living and working programs. In all, the ABI Partnership Project coordinates a network of different service providers working together to provide services for individuals with ABI. The ABI Partnership Project is in a unique position in the Province of Saskatchewan, as it arranges multiple service providers for each client in order to assist in the successful integration of ABI survivors into their communities. While it may be easier to find some clients suitable programs and treatment, others present a complex array of challenges that need to be addressed above and beyond ABI. These clients are often more complex cases to manage because of the unique set of challenges they present.

It is critical that existing social services, health care providers, community programs, and other agencies work together in partnership with all of the service providers, in order to ensure that the work of the ABI Partnership Project is carried through successfully. In addition, coordination of efforts between all parties involved will help ABI survivors achieve more successful outcomes. Primarily, it is the job of the Outreach Teams and Regional Coordinators to make sure that the needs of clients are identified and met through the available service providers within the Partnership.



Three multi-disciplinary Outreach Groups exist within the province and geographically support clients in the Northern, Central, and Southern Saskatchewan. Each group is based out of Prince Albert (North), Saskatoon (Central), and Regina (South) respectively. These Outreach Groups coordinate services province wide and assist ABI clients, and their families, in navigating services and supports.

The Outreach Teams and Regional Coordinators

In Saskatchewan there are three regional outreach teams that provide services such as: case assessment, case management/coordination, consultation, and at times provide direct service delivery, such as crisis management. For example, in the northern district of the province, the Outreach Team has access to a speech pathologist who also works as a regional case coordinator. Case coordinators and other members of the Outreach Teams are primarily the key contacts for clients and their families in navigating the services that are available through the Partnership. The Outreach Teams provide a multidisciplinary approach to improving client outcomes and quality of life. Individuals who work with clients over a long-term basis often build a rapport with clients and their families while working towards the goal of improving their quality of life.

In order to work towards quality of life improvements, each client that is referred to the Outreach Teams is provided a thorough assessment in order to identify their individual needs. This assessment requires information on the client's medical background, current functioning, and goals. The assessor then provides recommendations and educational information to help the client achieve their goals. The assessor concludes the assessment process by establishing a follow-up date to meet with the client.

The crisis management role of the Outreach Teams encompasses a reactive approach to issues faced by complex clients. Key informants noted that this generally included answering distressed phone calls from clients or individuals who had direct contact with complex clients. The crisis management role taken on by members of the Outreach Teams tends to focus on smoothing out situations involving clients and "putting out small fires". Seemingly mundane issues can be quite stressful for ABI survivors and many clients need assistance to handle them. In providing crisis management a service provider could face a breadth of issues relating to sexual abuse, substance abuse, mental health issues, and, at times, day-to-day health related issues.

The majority of clients are referred to the Partnership from rehabilitation and acute care facilities. In keeping with the original goal of the Partnership, to assist clients with the transition between acute care and rehabilitation, and bridge the gap between the client and the community, while not duplicating services that are already available, the Outreach Teams have been successful in their approach. The Outreach Teams' primary goals are to identify, coordinate, and support community programs that meet a range of needs of each individual ABI survivor. They also help support the needs of an ABI survivor's family, find appropriate residential options, and facilitate education and training of those who will be involved in an ABI survivors support network.



As part of the ABI Partnership, there are five regional Coordinators to assist their regional health groups in the North, Central, and Southern regions. These coordinators are located in Swift Current, North Battleford, Weyburn, Yorkton, and Moose Jaw. Their primary responsibilities include community development and case management to accomplish the reintegration of ABI survivors into the community. The following are examples of programs and services within the Partnership that clients are often referred.

Housing

PEARL Manor is a seven suite apartment block with 24-hour staff that incorporates respite and crisis management offered through Phoenix Residential Society in the City of Regina. The goal of this program is to enable ABI survivors to live more independently in the community by assisting in the restoration of as much functional ability and quality of life as possible. This is one example of a residential care facility that is available for Outreach Team members and Regional Coordinators to refer their clients. Finding suitable and affordable homes for clients was one of the most difficult tasks that members of the Outreach Teams and Regional Coordinators shared with the Consultant.

Independent Living and Working Programs

SMILE Services Inc. (Estevan), SIGN (Yorkton), and Thunder Creek Rehabilitation Association (Moose Jaw) all provide life skills training, rehabilitation, recreational activities, vocational support, as well as many other services. These programs provide assistance in the areas of independent and supportive living for clients with ABI who are referred to this service.

Rehabilitation Programs

The Saskatchewan Association for the Rehabilitation of the Brain Injured (SARBI) offers psychosocial rehabilitation, a recreational program, and family support for individuals with ABI. Currently services are available in Saskatoon, Kelvington, and Regina for clients over the age of 18, but preferably under the age of 35, who are not a danger to themselves or others. In fact, rehabilitation services are a common service for case managers to refer clients and in addition, they are also the most likely type of service provider to refer clients to the ABI Partnership Project for assessment.

Vocational Services

Multiworks Vocational Training Corp. provides ABI survivors rehabilitation and greater quality of life outcomes through vocational training and services in Meadow Lake, Saskatchewan. Services that are available through this provider include life skills training, vocational/avocational services, the development of social skills, and education, which are highly valuable and rewarding for ABI survivors. The Saskatchewan Abilities Council also offers recreational, rehabilitation, and vocational programs to individuals with ABI Regina and Saskatoon.



1.1.2 Complex Clients

Even though the majority of service providers report that they enjoy the variability and challenge of responding to these unique service needs, many service providers and case managers struggle to find effective service solutions for certain groups of ABI survivors. The reasons why some clients are more complex than others is currently not fully understood by service providers, and as yet there is not a clear definition of what constitutes being a complex case. Understanding the population of complex cases is integral to developing a strategy of best practices in order to better serve those clients with complex issues.

1.1.3 Purpose of Study

Four evaluations of the ABI Partnership Project have been conducted in the past. Beginning in 1998, an evaluation was conducted to examine the pilot project. The evaluation of 1999 through to 2003 included a cost-benefit analysis, site-level process evaluations, and focused on client outcomes. For the period 2004 to 2006 the evaluation was limited to measuring outcome measures and service statistics for entry into the ABIIS, focusing on clients, service providers, and families. The evaluation of 2007 to 2010 focused on program monitoring of partnership service provisions, client outcomes, and education and prevention.

The current evaluation focused on ways to identify complex populations, and identify best practices in order to augment the regular service delivery to better work with this population. This includes identifying what services and tactics work best with complex ABI survivors, and where there is need for improvement to better accommodate ABI survivors who present complex cases.

This study was structured to answer the following three research questions:

1. Which groups present complex cases, and in what ways are they complex?
2. Which aspects of service delivery are most effective for eliciting positive outcomes for complex ABI survivor populations?
3. Are there best practices that can be identified for working with complex cases?

1.2 Research Methods

In order to report on the characteristics of complex clients in the province of Saskatchewan, this study has utilized the following primary and secondary research tools. Recommendations are based on the findings from these methods. The methods utilized in this evaluation are as follows:

- A literature review,
- Key informant interviews,
- A service provider survey,
- Service provider focus groups, and
- A case file review.



1.2.1 Literature Review

In order to gain a better understanding of the nature of complex clientele in the provision of services for individuals with acquired brain injuries, the Consultant conducted a literature review. Literature reviewed included sources from academic literature, literature provided by the client, and literature from other jurisdictions.

As part of the literature provided by the client, the Consultant received the previous ABI Partnership Project evaluations and reviews, background documents on the ABI partnership project (e.g., pamphlets, information sheets), and results from service provider staff surveys/consultation.

Journals reviewed by the Consultant included:

- Journal of Neurotrauma;
- Journal of Head Trauma Rehabilitation;
- Clinical Psychology Review;
- Occupational Therapy in Health Care;
- Brain Injury;
- Journal of Neuroscience Nursing;
- Current Opinion in Neurology;
- Journal of Clinical Nursing;
- Social Care and Neurodisability;
- Journal of Primary Care and Community Health;
- Disability Rehabilitation;
- Journal of Dual Diagnosis;
- NeuroRehabilitation; and
- Rehabilitation Psychology.

The literature review process helped the Consultant better understand what constitutes complex ABI survivors. Several studies identified a number of characteristics as indicators of being a complex case (see: Ylvisaker & Feeney, 2000; Pcikelsimer, Selassie, Sample, Heinemann, & Veldheer 2007; Colantonio, Howse, Kirsh, & Chiu, 2010; Truelle, Fayol, Montreuil, & Chevignard 2010; and Kerr, Oram, Tinson, & Shum, 2011;). Research from these and other sources helped the Consultant in designing the instruments used in this study.



1.2.2 Key Informant Interviews

Interviews were held with members of the ABI Partnership Project, academics in the field of ABI, and representatives from similar ABI service delivery projects across Canada.

In total, the Consultant completed 10 interviews in June and July 2010. As a qualitative measure, the findings from the key informant interviews informed the development of the staff survey, focus group moderator's guide, literature review, and the case file review.

1.2.3 Service Provider Survey

The service provider survey was a quantitative tool designed to gather data from service providers involved in the ABI Partnership Project, and included both full time and part time staff. The survey was programmed into the Consultant's CallWeb platform, and administered to the service providers using a mixed-mode approach, which allowed respondents to complete the survey either over the phone or online. The survey was field-tested prior to full administration. In total, the Consultant completed 57 surveys with ABI service provider staff from a sample of 83 staff, representing a valid response rate of 69%.

Data from this survey helped the Consultant to better understand the profile of complex clients, and why they are seen this way. This tool also helped the Consultant understand the effects of being complex on the client's family, the service provider, and the client themselves.

1.2.4 Service Provider Focus Group

To provide qualitative context to the findings of the service provider survey, the Consultant held focus groups with service providers. Three focus groups were held in March 2011 in Regina, Saskatoon, and Prince Albert with a total of 18 participants from service-providing organizations. The goal of these focus groups was to obtain knowledge from informed professionals about their experiences with the ABI Partnership Project, its clients, and operations. In order to develop a model of best practices for complex clients, this insider knowledge of the Partnership helped the Consultant understand what practices work and do not work, as well as where improvements need to be made.

1.2.5 Case File Review

ABI Partnership Project client data was used for the case file review. The case files were reviewed using a standardized, universal tool developed by the Consultant. While the Consultant had initially proposed to conduct the file review on-site, ethical considerations entailed that ABI Partnership Project staff completed all file review activities using a secure online data entry tool (CallWeb).

The goal of conducting case file reviews was to ascertain the actual experience of individuals living with an ABI for the purposes of evaluating service delivery and developing best practices for working with this population.



As a measure of short, intermediate, and long term success with complex clients, a goal assessment was conducted. A number of other indicators were also reviewed at this time including: demographic data, client service history, information about the client's ABI, and information about concurrent conditions. In order to obtain a percentage of the goal attainment any client obtained, the Consultant measured the number of goals: cognitive, functional independence, psycho-social/emotional, community activities, or other, that the client wished to achieve divided by the total number of goals less the number of goals withdrawn from completing.

Case File Reviews helped the Consultant answer several important research questions that this study posed. Aside from gaining information on the clients, their ABI, and the unique challenges they each face, this data also shed light on the profile of complex clients, the programs and services ABI Partnership Project clients have access to, the level of productivity clients have achieved, and most importantly, how easy is it for complex ABI survivors to navigate the services available within the Partnership.

A randomized sample was drawn from ABI Partnership Project client data from all three Outreach Teams (North, Central, and South). Each case within the sample was flagged by case workers as being either complex (population of interest) or not complex (comparison group). The definition which case workers used to flag cases was derived from the findings of the service provider survey, and from the literature. The sample was drawn from the 2008-2009 fiscal year client data, which totals 544 client files². In total, 244 client case files were reviewed, producing a margin of error of plus or minus 4.7% (19 times out of 20). The methodology of this part of the study involved statistical comparisons between the population of interest and the comparison group to identify differences that may explain or predict whether a given individual may be a complex case. It was the intent of this research to aid case workers and service providers to be able to take a more informed approach to their clients.

1.3 Research Considerations

The Consultant recommends the following be considered while reviewing this report:

- This report reflects the findings of the consultations at the time that the research was undertaken.
- The opinions included in this report are of those individuals consulted during the research process, and may not necessarily reflect the opinions of all individuals within each group.

In general, when reporting key themes from key informant interviews, the following descriptions have been used:

² The 2008-09 fiscal year was chosen as it was the most recent year where the outreach teams had goal attainment records for every client. These records extend back to a client's program registration.



- No/None: refers to instances where no individual identifies the particular issue.
- Few/Very Few: refers to instances where only one or two individuals may have expressed a particular opinion.
- Some: refers to instances where between one-quarter and one-half of the individuals interviewed expressed a particular opinion.
- Several/Many/Most: Refers to instances where the majority of, but not all, interviewees were of the same opinion and/or held similar perceptions regarding a selected issue or topic.
- All: Reflects consensus across all stakeholder groups. All interviewees questioned on the topic expressed the same view or held the same/similar opinions.



SECTION 2: FINDINGS

2.1 The ABI Partnership

Conceptualizing “complex” clients

The purpose of this report is to identify and report on a segment of clients who, according to most service providers are deemed to be “complex” cases. There is a certain level of ambiguity that accompanies this terminology; however, this report intends to clarify this issue and establish a framework of best practices in order to better serve this proportion of clients.

2.2 Defining Complex Clients

2.2.1 Literature Review

Literature on ABI indicates that complex ABI survivors include individuals who have needs that go beyond their ABIs. These may include mental health and/or addictions issues, a lack of family support, a lack of appropriate and/or stable housing, as well as individuals with behavioural challenges such as lack of inhibition and aggression, or any combination of these (Colantonio, 2010). Other needs of complex ABI survivors may include mental disability and/or cognitive impairments in addition to their ABI (e.g., FASD), as well as physical disabilities (NODHC, 2004) and substance abuse issues (Graham and Cardon, 2008). Findings from the literature review consistently state that the complex and multiple needs of complex ABI survivors are often not being met through present structures of programs and services (Ylvisaker and Feeney, 2000; Pickelsimer et al, 2007; Truelle et al, 2010).

With an understanding that complex clients often have compounding issues that need to be addressed, above and beyond their ABI, data obtained from key informant interviews, focus groups, and service provider survey all support findings from the literature review. All sources point to similar characteristics when defining clients with acquired brain injury who present complex cases.

2.2.2 Service Provider Survey

As seen below, (Figure 2-1a), complex clients are characterized as often lacking family support (85%). A majority of service providers surveyed suggested that complex clients are commonly engaged in high-risk lifestyles prior to (67%) or since (54%) their ABI, which may have included substance abuse. Thus, 65% of service providers noted that clients with substance abuse problems, either before or after their ABI, present more complex cases.³ Several economic factors, such as low socio-economic status (64%), insufficient/poor housing (56%), and unemployment/lack of employment (37%) were also suggested as being highly correlated with clients` status as a complex case (Figure 2-1a).

³ Service providers were not asked which substances (e.g., alcohol, marijuana, etc.) were abused by difficult to serve individuals.

Figure 2-1a
Common Factors/Characteristics of Complex Clients

| Reasons | Percent |
|--|---------|
| Low level of family support | 85% |
| High-risk lifestyle prior to injury | 67% |
| Substance abuse (before and/or after ABI) | 65% |
| Low socio-economic status | 64% |
| Severity of injury | 58% |
| Housing status (insufficient/poor housing) | 56% |
| Concurrent medical conditions (occurring with or after the injury) | 56% |
| High-risk lifestyle after injury | 54% |
| Low education level | 42% |
| Pre-existing medical conditions (pre-injury) | 42% |
| Area of the brain injured | 40% |
| Age at injury (i.e., younger) | 39% |
| Employment status (i.e., unemployed) | 37% |
| Type of injury (traumatic/pathological) | 33% |
| Cause of injury (i.e., assault versus accidental/natural causes) | 23% |
| Aboriginal status | 21% |
| Gender (i.e., male) | 19% |
| Current age (i.e., younger clients) | 12% |
| Other | 6% |

n=57

Reference= Service Provider Survey B4a ("Please indicate what common factors or characteristics you have noticed among difficult to serve ABI clients. Please select all that apply.")

Note: Percentages add to more than 100% because of multiple responses.

Although living a high risk lifestyle before, and after, ABI was seen as a common factor in being identified as a complex client in Figure 2-1a, none of the open ended responses from service providers and minimal discussion of this was provided from the key informant interviews. Additionally, given that high risk lifestyles also included substance use, and the potential dual reporting of this, there is negligible evidence to support an in depth analysis of this high risk lifestyles pre or post-injury.

Notably, several factors were not as likely to be felt by service providers as being a common characteristic of those who present complex cases. Only one-in-five (21%) of service providers felt that Aboriginal status was a common factor among clients who present complex cases. However, as is demonstrated in the case file review (Figure 2-17) Aboriginal clients make up 55% of those complex case files. The disparity between these two statistics could be the



product of environmental factors such as, the location that a client resides or socio-economic status. In fact, there is nothing to indicate that being Aboriginal is in and of itself a determining factor in being identified as a complex client. There is obviously some incongruity between the perceived complex cases and clients who do present a complex case, which needs to be examined further. As well, relatively few service providers (19%) felt that a common characteristic of clients who present complex cases was being male and only 12% of service providers felt that younger clients more commonly exhibited complex cases. In addition, assault or violence as the cause of injury (23%) as well as the type of injury (i.e., if the injury was violent or traumatic in nature – 33%), were not seen as common characteristics of clients who present complex cases by most respondents.

Together, this data suggests that, while factors like Aboriginal status, gender, and age were felt by some service providers to be associated with being complex, they were not viewed as contributing factors to clients being seen as complex cases. Furthermore, being male, Aboriginal, and young were not seen as being directly indicative of a client being a complex case but rather, it is more likely that individuals with these characteristics were more likely to exhibit the risk factors associated with complex cases, such as: living in remote locations, high-risk lifestyle prior and after injury, low socio-economic status and substance abuse. On the other hand, factors such as low levels of family support, substance abuse, and previous high-risk lifestyles are generally viewed as factors associated with ABI clients identified as complex cases (Figure 2-1a).

When asked to identify which factor most contributes to a client being complex, over one-quarter (26%) of service providers stated that substance abuse contributes most to a client being deemed a complex case, while 14% identified a high-risk lifestyle prior to their injury - which may have included substance abuse – as contributing most to a client being deemed a complex case. Service providers were asked to rank the top five factors that they felt were important to determining whether a client was a complex case. Although only 7% of survey respondents identified a low level of family support as a contributing factor to clients being deemed a complex case, at the same time a relatively high proportion of respondents (44%) ranked this factor as one of the three main contributing factors to clients being deemed a complex case (Figure 2-1b). Therefore, although low level of family support was only the fourth most important factor in determining if a client is a complex case, it was a consistent important factor in this process.

Figure 2-1b
Factors/Characteristics contributing most to being complex

| Reasons | Percent |
|--|---------|
| Substance abuse (before and/or after ABI) | 26% |
| High-risk lifestyle prior to injury | 14% |
| Severity of injury | 9% |
| Low level of family support | 7% |
| Low socio-economic status | 5% |
| Housing status (insufficient/poor housing) | 5% |
| Area of the brain injured | 4% |
| Concurrent medical conditions (occurring with or after the injury) | 4% |
| Low education level | 2% |
| Age at injury | 2% |
| Cause of injury | 2% |
| Other | 9% |

n=57 (including 'no response')

Reference= Service Provider Survey B4b ("Now we would like you to consider the factors or characteristics you just mentioned. We would like you to rank those factors in terms of those which seem to contribute the most to whether or not a client is difficult to serve. Please rank only the top five factors. Rank them from one to five, with one being the biggest contributor and five being the lowest of the five. If you have indicated fewer than five factors, please rank them from biggest contributor to least contributor, starting with one as the biggest contributor.")

2.2.3 Focus Groups

Findings from focus groups confirm and lend additional insight into observations from the literature review and service provider survey. A number of participants from the focus groups discussed a notion that being complex cases usually implies that there is a mixture of compounding factors involved with a client's rehabilitation. The greater the number of compounding factors involved (for example: substance abuse, low family support, high risk lifestyle), the greater the challenge of providing rehabilitation services to such complex ABI clients.

Several reasons were provided by focus group participants as to what constitutes a complex client. Participants reported substance abuse, transience, mental health, and economic factors as contributing to what constitutes a complex case. In fact, many of the participants agreed that complex clients faced a number of barriers in their rehabilitation on top of ABI. Participants also noted that a strong relationship between the service provider and the client could make a great deal of a difference for the client.

"[Complex cases are] where the brain injury is not the only barrier to progression."

- Focus Group Participant

Participants also noted that client's families played a substantial role in whether a client was complex. Notably, service providers reported that expectations of family members exceed what



is readily achievable by ABI clients, and that some families can be overprotective of their loved ones who need access to services. As a compounding issue, service providers reported that in families where substance abuse is present that this can have a very negative influence on a client's progress.

Economic factors were also reported as a key factor determining if a client presented a complex case, and that living in poverty can affect other issues that can lead to a client being deemed a complex case. Housing, health, and transportation are all factors that can be affected by a client's socio-economic status and compound the issue of providing services for ABI rehabilitation. Furthermore, substance abuse and addiction also adds a level of complexity to a client's case that compounds the issue of ABI rehabilitation along with socio-economic factors. An ABI client may spend what money they have on drugs and alcohol, leaving nothing for essentials. Service providers also reported that continuity of care was important for ABI clients post-addiction because too often clients relapse because of negative social, familial, or other environmental factors. Factors such as these add to the complexity of an individual's case and provide a challenge for service delivery and rehabilitation.

Responses from the focus groups as well as the key informant interviews were meant to inform the other evaluation techniques that were used in this analysis. The qualitative responses from each are meant to guide the interpretation of quantitative data and provide an informed and insightful perspective to the analysis. Service providers from the focus groups gave the Consultant a perspective of the Partnership and service delivery.

2.2.4 Key Informant Interviews

Interviews were conducted with individuals who are experienced in the area of ABI rehabilitation and exhibit expertise in the area of complex clients. Several of the key informants identified economic factors, substance abuse, mental health issues, severity of injury, and low family support as factors that contribute to a complex client's case, while some also identified living in a remote location as a factor. In fact, several of the key informants also reported that these factors had a compounding effect, meaning that more than one factor may be present in a complex case. In addition to ABI treatment, case managers also have to take into consideration the effects that several factors have in relation to one another.

Some key informants also noted that there are quite a few services available for ABI clients, but because of the issues presented by complex clients they are often not eligible for or turned away from various service providers.



2.2.5 Case File Review

Findings from the case file review suggest that there are a considerable number of complex cases of ABI survivors in Saskatchewan. Slightly more than one-third (37%) of individuals included in the case file review were recorded as being complex cases by service providers in the case file review. Incidentally, when survey respondents were asked to estimate the percentage of complex clients, the average noted by all respondents (n=53) was 38%, which suggests that there is relatively consistent findings as to the proportion of ABI survivors who would be classified as complex cases.

Findings from the service provider survey suggested that gender and age of clients – particularly whether a client was male and/or younger– could be associated with being deemed a complex case. Analysis also revealed that clients between the ages of 26 and 39 were noted as being more complex than those 56 years of age or older (50% compared to 19%).⁴ Although clients between the ages of 26 and 39 were more likely to a complex case this is likely not a consequence of age directly, but due to other risk factors that clients in this age range tend to exhibit.

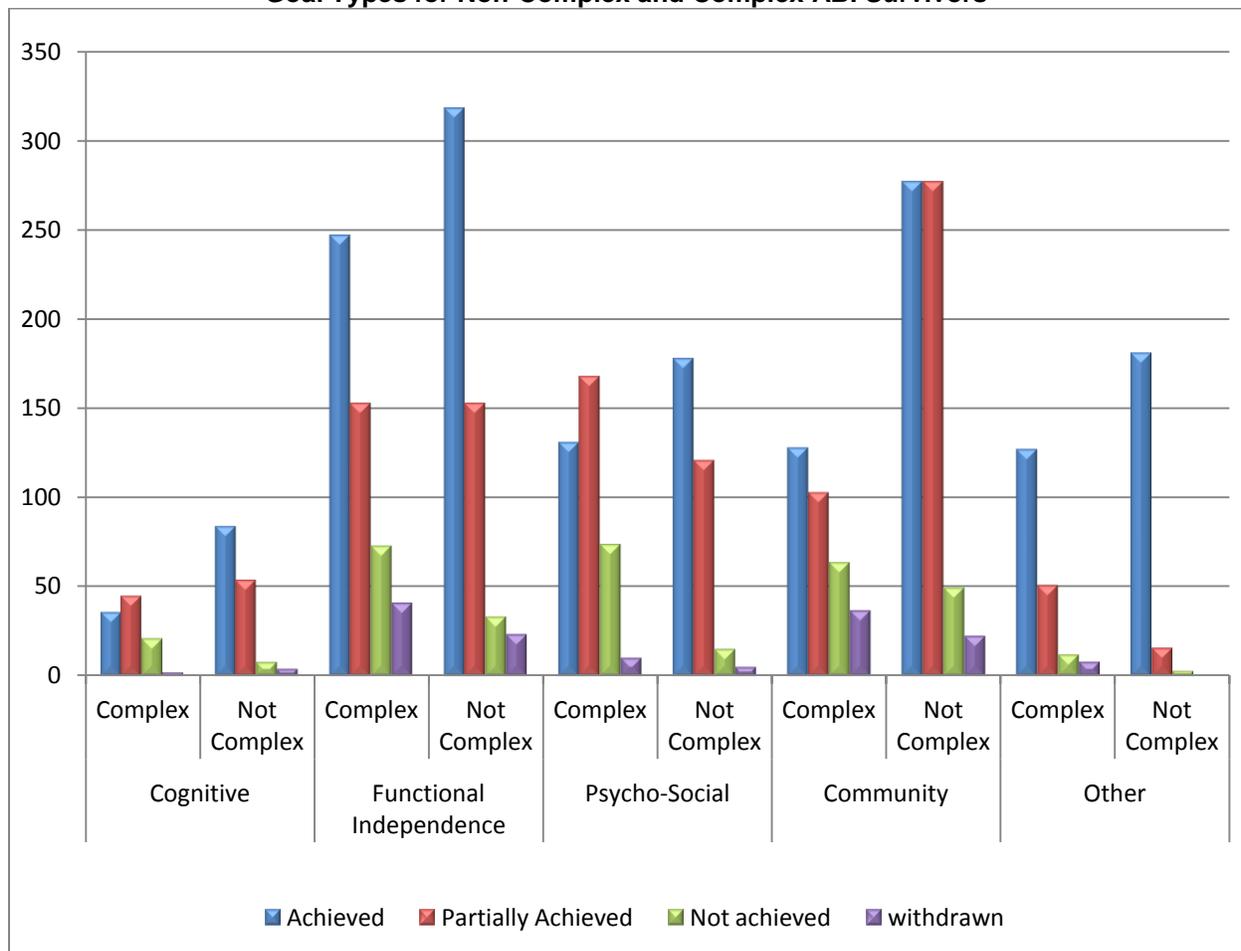
2.2.6 Goal Attainment

As a standard tracking tool implemented by the Partnership Project in 2004, clients' goal attainment is regarded as a very useful tool in identifying and working towards positive client outcomes. Notably for this study, the Consultant was able to use this tool to measure the effects of being deemed a complex case with client outcomes. As a client outcome measure, analysis of the client's goal attainment data provided some insight as to the efficacy of service provider techniques in relation to substance abusers and non-substance abusers and any potential service delivery gaps.

Figure 2-2 shows a comparison between complex cases and non-complex cases subgroups of the sample by the type of goals. Figure 2-3 pertains only to clients who were not identified as complex cases, whereas Figures 2-4 pertains to clients who were identified as being complex cases in the case file review. Figure 2-5 also shows a clear distinction between complex and non-complex ABI survivors and the proportion of goals each group achieved.

⁴ Analysis of case file review data showed that the gender and family of clients was not associated with whether a client was deemed a complex case; most clients tended to be male (61% compared to 39% female).

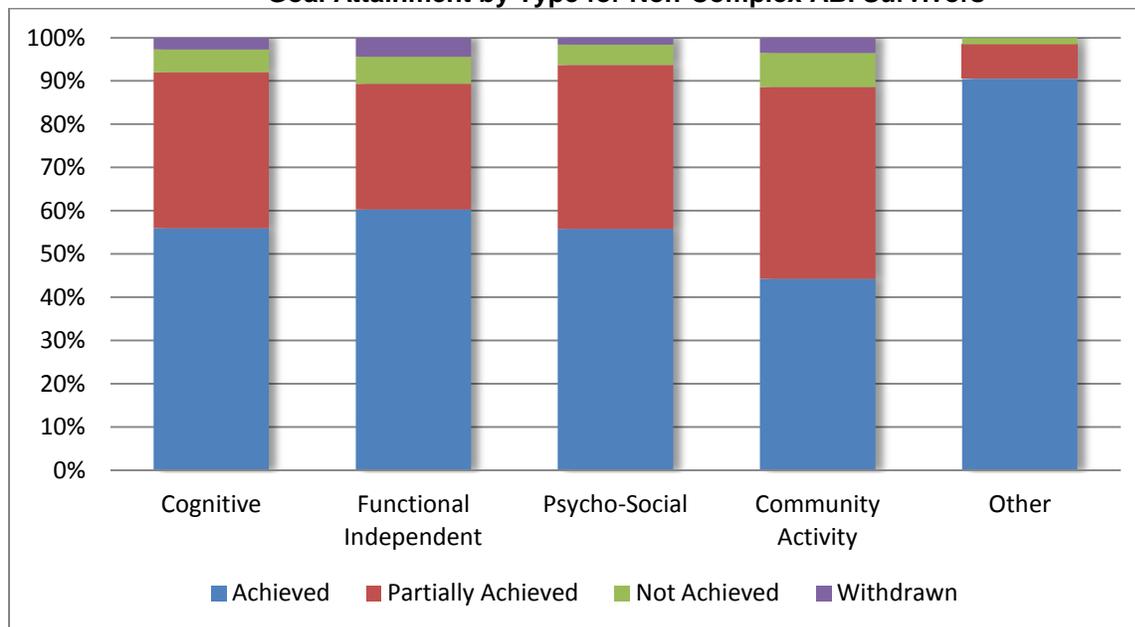
Figure 2-2
Goal Types for Non-Complex and Complex ABI Survivors



Source: Case File Review, N: 87 for Complex Clients, N: 148 for Not Complex Clients

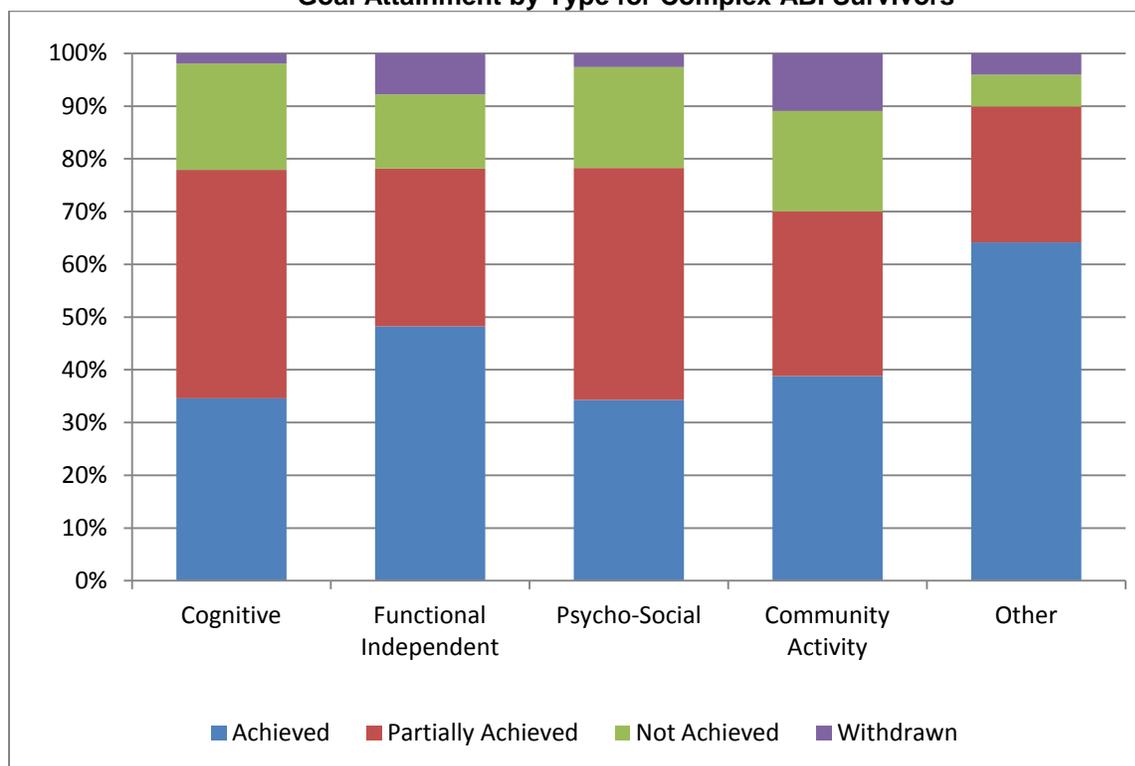


Figure 2-3
Goal Attainment by Type for Non-Complex ABI Survivors



Source: Case File review, N = 148

Figure 2-4
Goal Attainment by Type for Complex ABI Survivors



Source: Case File Review, N = 87

The following figure shows the percentages of each goal type achieved by complex clients and non-complex clients. It is clear that of each type of goal complex clients achieve a smaller proportion of their goals.

Figure 2-5
Comparison of complex and Non-complex clients
by Percentage of Goal Attainment and Goal Type

| | Complex clients | Non-Complex clients |
|-------------------------|-----------------|---------------------|
| Cognitive | 35% | 56% |
| Functional Independence | 48% | 60% |
| Psycho-Social | 34% | 56% |
| Community Activity | 39% | 64% |
| Other | 64% | 90% |

Note: percentages displayed above indicate the proportion of goals achieved by each subgroup, and excludes those goals that are partially achieved, not achieved, and withdrawn.

2.3 Factors That Compound Complex Cases:

Complex clients provide a unique challenge to service providers for a number of reasons. Typically, complex clients possess a number of additional ailments, challenges, or conditions beyond an ABI. Factors that became apparent in the focus groups, interviews, surveys, and in the literature include:

1. Substance abuse issues, (2.3.1)
 - Included in the measurement of substance abuse is alcohol, marijuana, crack/cocaine, heroin/opiates, ecstasy/MDMA, other illegal drugs, non-prescription over the counter drugs, prescription drugs, and others substances.
2. Mental health needs, (2.3.2)
 - In order to conceptualize mental health needs the Consultant adopted the definition used by the Mental Health Commission of Canada (MHCC) being: “a state of well-being in which the individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his own community.” (MHCC 2007). Clients who lacked the fundamentals associated with having a balanced mental health state were deemed as being as complex cases.
3. Living in remote or inaccessible locations, (2.2.3)
 - Remote locations were defined as locations that were greater than two hours outside of an urban centre. Service providers were asked which scenario best describes the client’s living arrangement. Whether they lived in an urban centre, in a rural environment within two hours of an urban centre, or in a rural environment more than two hours from an urban centre.



4. Economic factors, (2.3.4)
 - Low socio-economic status, homelessness, and transience were economic factors identified as common characteristics of complex clients. Service providers were asked to determine if each of these descriptions pertained to the client.
5. Severe brain injury, (2.3.5)
 - Key informant interviews and service providers both stated that the severity of an ABI could also lead to a client being deemed as a complex case. Severe brain injuries tend to alter an ABI survivor's personality and/or behaviour. Specific types of injuries such as frontal lobe damage might alter a client's judgement, or impair mental cognition and functionality.
6. Low or insufficient family support.(2.3.6)
 - Clients who had no contact with their families, negatively impactful family contact, or unsupportive families were included in this measure. Negatively impactful family contact included those families labeled as dysfunctional or otherwise did not foster positive rehabilitation outcomes for the client. Often this was comprised of family members supporting a client's drug habit, or family members who use the client's medication for their own use.

As a principle of a client-centred approach, rehabilitation and treatment should focus on the individual not the symptom. It is also not practical to address the needs of a client and ignore the environment in which they exist. Although these six factors are analyzed independently of one another, one must understand that complex clients tend to present multiple risk factors concurrently.

These six factors that were analyzed in-depth emerged from all four lines of evidence. In addition to the significant amount of literature that was devoted to each topic, as contributing to the client being classified as a "complex case". Substance abuse was seen as one of the major factors that compounded the ability to serve ABI survivors. Additionally, a significant amount of the literature was devoted to this subject of treatment for ABI survivors. The degree of family support that ABI survivors receive was also recognized as a major factor contributing to being deemed as a complex client, which arose from the data as well as a number of scholarly sources. Mental health issues were frequently referenced in the literature, by survey participants, focus groups, and key informant interviews; enough to warrant further research. Additionally, several other factors that were identified through the service providers survey, focus groups, and the key informant interviews are believed to increase the likelihood of an ABI survivor being deemed as a complex case. The area in which an ABI survivor lives was seen as contributing to being deemed as a complex case; those who live in rural locations do not have the same access to services as do those who live in urban locations. A number of economic factors, such as low socio-economic status were also noted as contributing to one being deemed as a complex case by many respondents. The severity of injury was also noted as an important factor in determining if a client is complex, as severe brain injuries can lead to aggressive behaviour and other behavioural changes.

Each risk factor need not be present to be considered a complex client, nor is the absence of all of these factors predictive of being a non-complex client. Each complex client is a unique case

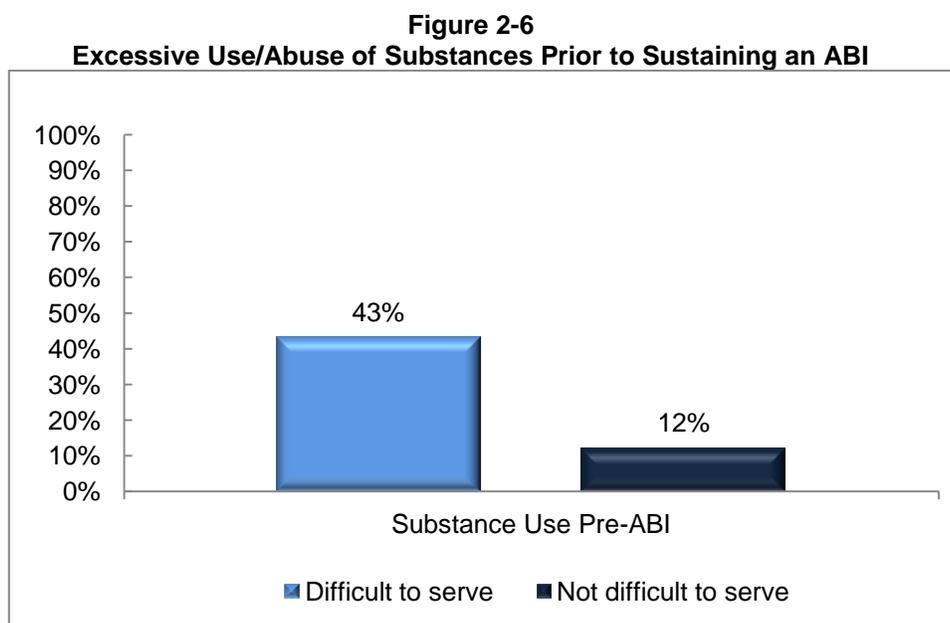


that presents multiple conditions that overlap and inhibit ABI rehabilitation. When receiving treatment for one condition it is not possible to ignore other conditions that a client presents. Each of the following sections 2.3.1 to 2.3.6 will address one of these emergent factors.

2.3.1 Substance Abuse Issues

Addictions and substance use had considerable influence on whether individuals were classified as complex cases in the case file review. As noted below in Figure 2-6, individuals who engaged in substance use prior to sustaining an ABI were more likely than those who had not (43% compared to 12%) to be noted as complex cases. The most common substances abused prior to sustaining an ABI were alcohol (90%), marijuana (38%), and cocaine/crack (10%).⁵

Case file review data was utilized to determine if a correlation existed between prescription drug use and substance abuse, as per the suggestions of some key informant interview participants. This analysis showed that there was no significant relationship between prescription drug use and substance abuse, either before or after an ABI.



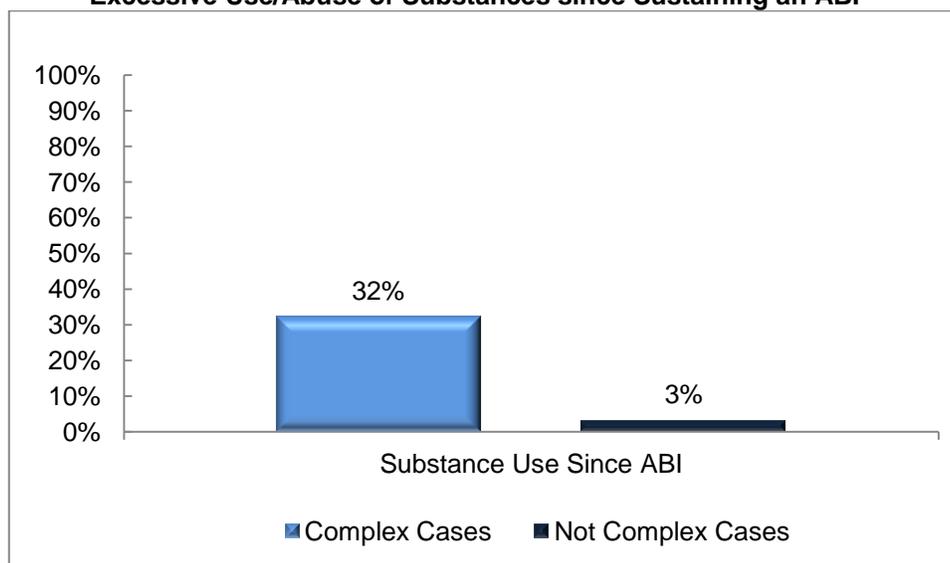
n=246

Reference= Case File Review C5 ("Was the client known to excessively use or abuse substance (legal or illegal) prior to sustaining an ABI?")

⁵ Respondents provided multiple responses.

Substance abuse *since* sustaining ABI also has a considerable impact on being classified as a complex case in the case file review. As seen below in Figure 2-7, individuals who engaged in substance use since sustaining an ABI were more likely than those who had not (32% compared to 3%) to be noted as being deemed a complex case. The most common substances abused after sustaining an ABI were alcohol (85%), marijuana (36%) and cocaine/crack (12%)⁶. Of note, the most common substances abused since sustaining an ABI did not vary from those abused prior to sustaining an ABI.

Figure 2-7
Excessive Use/Abuse of Substances since Sustaining an ABI



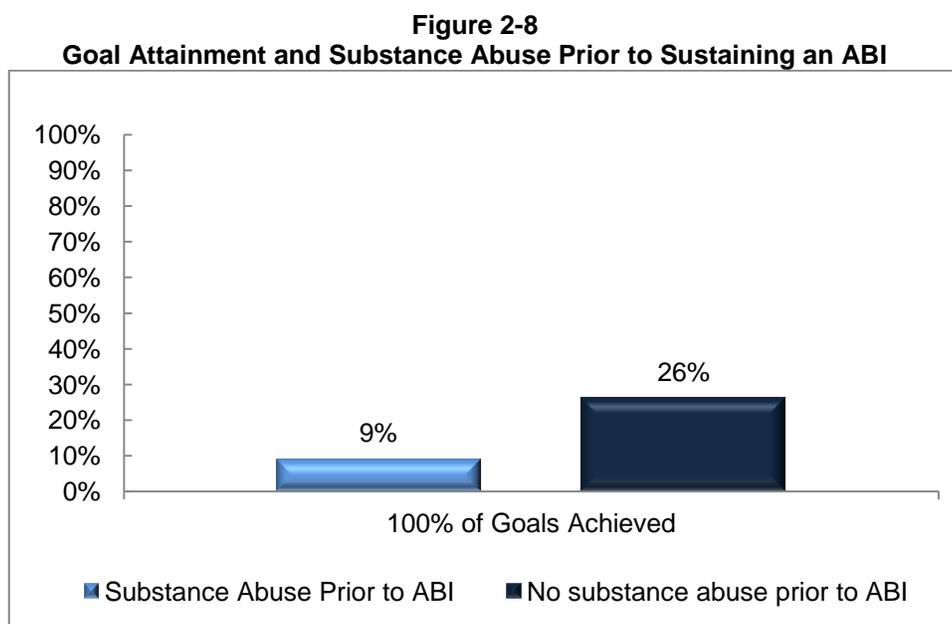
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Reference= Case File Review C6 ("Has the client been known to excessively use or abuse substance (legal or illegal) since sustaining an ABI?")

⁶ Respondents provided multiple responses.

Goal Attainment and Substance Abuse

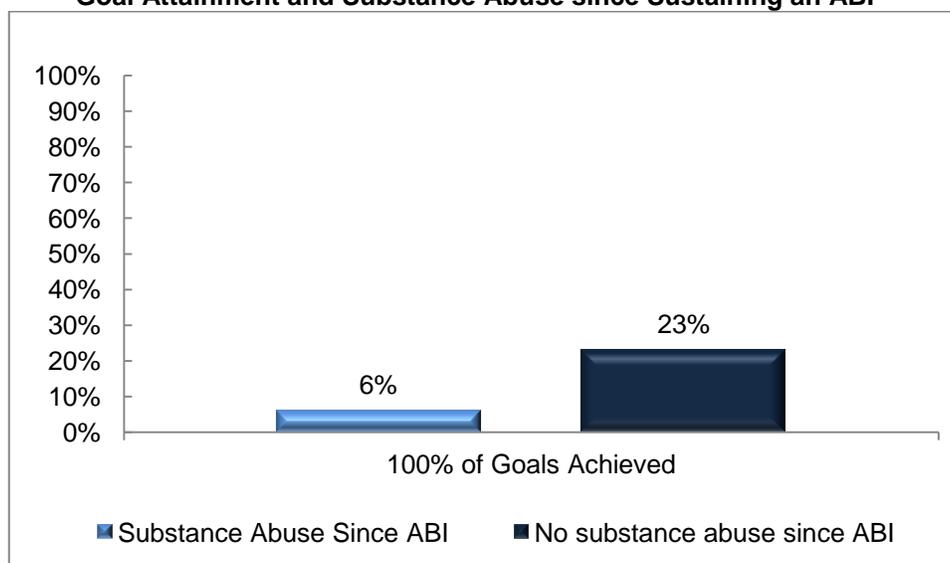
Substance abuse prior to sustaining ABI also impacts individual goal attainment (Figure 2-8); those individuals who engaged in substance abuse prior to sustaining an ABI were less likely than those who did not (9% compared to 26%) to have achieved 100% of their goals.



n=246
Reference= Case File Review (Goal Attainment)

Those individuals who have engaged in substance abuse since sustaining an ABI were 17% less likely than those who did not (6% compared to 23%) to have achieved 100% of their goals (Figure 2-9).

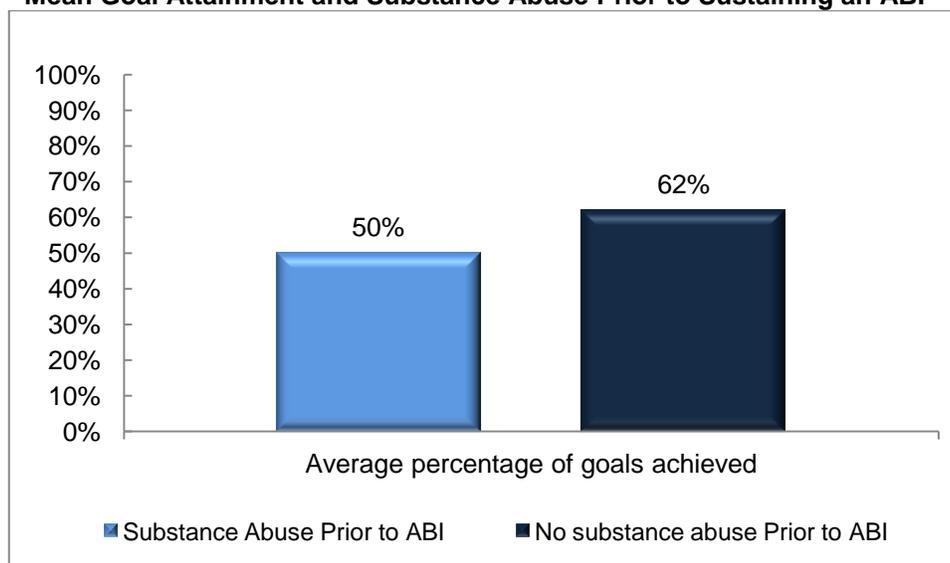
Figure 2-9
Goal Attainment and Substance Abuse since Sustaining an ABI



n=246
Reference= Case File Review (Goal Attainment)

Regarding the average percentage of goals achieved by clients, those who abused substances prior to their ABI tended to achieve fewer of their goals (50%) as compared to those who had no substance abuse history prior to their ABI (62%) (Figure 2-10).

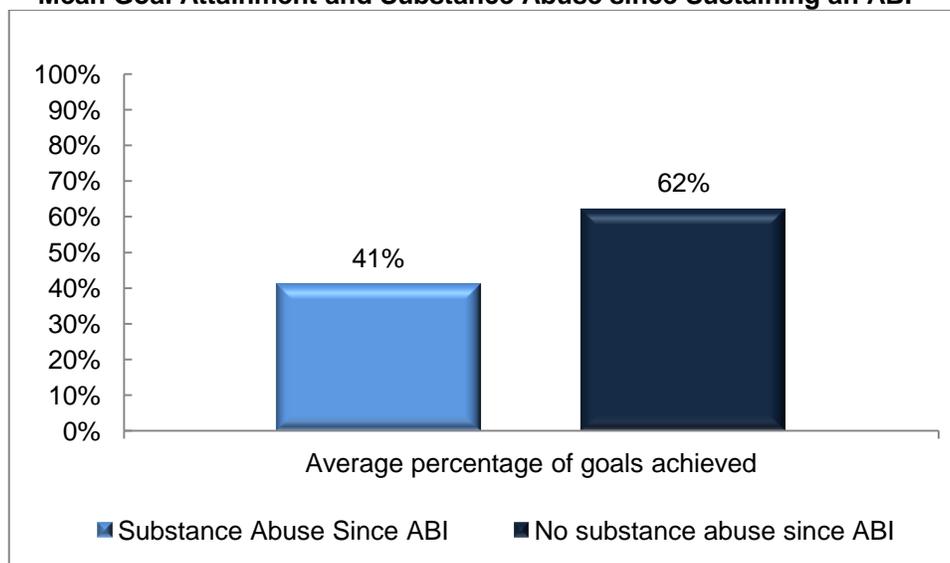
Figure 2-10
Mean Goal Attainment and Substance Abuse Prior to Sustaining an ABI



n=246
Reference= Case File Review (Goal Attainment)

Those who have abused substances since their ABI also tended to achieve fewer of their goals (71%) as compared to those clients who were not involved with substance abuse since acquiring ABI (62%) (Figure 2-11).

Figure 2-11
Mean Goal Attainment and Substance Abuse since Sustaining an ABI



n=246
Reference= Case File Review (Goal Attainment)

As well, analysis of the data revealed that clients between the ages of 26 and 39 were more likely than clients older than age 65 (20% compared to 9%) to currently be involved in substance abuse. No statistically significant differences were noted between substance abuse and region of residence or gender.

Substance abuse and addictions are key factors in classifying an ABI survivor as a complex client. Participants in key informant interviews and focus groups described, in detail, the prevalence of addictions and associated issues of mental health needs among complex ABI survivors. In particular, addictions and substance abuse were noted as a “common problem” among complex clients. Additionally, focus group participants and service providers both stressed that the existence of addictions issues were often a common predictor of whether a client would be a complex case.

For many ABI survivors, substance abuse was a part of life before the injury and continues to be post-injury. For some, it is a catharsis to manage boredom and frustration. Substance abuse has profound negative impact on the recovery process for individuals with ABI. Substance use in conjunction with an ABI is a dangerous mixture. Risks that are associated with substance use and addiction include: decreases in level of concentration and memory, increased depression, and trouble balancing, walking and talking. These risks are already associated with ABI; however, substance use and addiction exacerbates the issue. In addition, the brain is more sensitive to substances post-injury and so substance use and addiction increases the risk of further brain injury (Corrigan and Lamb-Hart, 2004).

Key informants further stressed that these individuals face unique challenges related to addressing their addictions issues in light of their ABIs. Some key informants noted that



individuals with ABIs and addictions issues may be sent to drug rehabilitation centres. Even if a client receives successful treatment for their addictions, risk factors for relapse may still exist within their community. According to findings in the literature, relapses often occur because of a lack of continuity of care between residential drug rehabilitation and community-based care, as well as the presence of family and friends with addictions and substance abuse issues (McCull et al, 1999). Moreover, findings in the literature also suggest that some ABI survivors can experience challenges with substance abuse after transitioning to independent living (especially if it also was a pre-morbid condition) and that the influence of old friends, as well as the mental health issues associated with boredom, and loneliness, are all risk factors that can lead to relapse (McCull et al, 1999; and Ponsford, Whelan-Goodinson, & Bahar-Fuchs 2007).

Further, finding and placing ABI client`s with addictions issues into appropriate care was frequently noted as being difficult. Several service providers and key informants reported that ABI survivors with addictions issues may not always be accepted into conventional treatment programs because of their ABI. These findings are consistent with the literature on ABI as substance abuse programs often “screen out” people with ABI. Many ABI service providers are unprepared to serve individuals with substance abuse issues (McGlynn, 2005). This speaks to their need to separate out clients that need to be treated solely for their addictions, rather than needing to be treated for their addictions as well as their ABI issue. Thus, as noted by some key informants, some addictions services will not accept ABI survivors unless other symptoms of the ABI are already being managed.

Focus group participants noted that addiction issues are not always known by their individual case managers when they begin working with a client and may only come to light once they have been working with a client for some time. This is counter-productive and underscores the necessity to address substance abuse issues early in a treatment strategy.

The conundrum then exists, how do you treat substance abuse of ABI survivors when some service providers will not accept clients who have unmanaged challenges associated with their ABI? The problem exists that many ABI clients with substance abuse and drug related problems face challenges in achieving positive rehabilitation outcomes, which create additional challenges to service providers.

2.3.2 Mental Health Needs

Mental Health, although not directly stated as a common factor in Figure 2-1a in determining if a client is a complex case, interacts with nearly every factor listed below. The World Health Organization (also adopted by Canada) defines mental health not only as the “absence of mental illness” but also as “a state of well-being in which the individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his own community” (2007). Given the nature of some ABI survivors to struggle with basic functions of day-to-day life, following this definition, it is likely that there is a greater prevalence of mental health issues among ABI survivors. In several instances, key informants also noted that weak family support and/or family dysfunction, feelings of isolation, or the disparity between desired goals and the reality of what goals are achievable can lead to depression among complex clients. According to Mental Health Commission of Canada (MHCC), depression is listed as one of many ailments that contribute to



mental health of Canadians. ABI survivors face a number of challenges in overcoming their own disabilities, and the fact that many are deemed as complex cases puts a high volume of ABI survivors at a greater risk of developing mental health conditions, such as depression or anxiety.

Additionally, as stated by the MHCC, mental health issues can have a tremendous impact on family, friends, colleagues, and the communities around those who suffer from mental health issues. Substance abuse is also often indicative of underlying mental health issues, and substance abuse can contribute to the development of mental health issues later in life (MHCC 2007: 12). Given the compounding factor of mental health issues and the challenges faced by ABI survivors, ongoing mental health programming could be a beneficial focus of any service delivery strategy. Unfortunately however, some key informants noted that mental health services are unavailable for ABI survivors unless they have been diagnosed with the most severe level of mental health issues. Largely, it can be accepted that mental health needs go hand-in-hand with the delivery of services to ABI survivors for the purposes of enhancing their quality of life, which is the goal of the Partnership.

After examining the case file review data, the Consultant determined that there was too few cases (N=10) to make a comparison between goal attainment and mental health of ABI clients.

2.3.3 Living in Remote or Inaccessible Locations

It is often the case that clients who live in rural or remote locations are seen as complex clients. Living in a remote location places its own stresses on service delivery. Arranging transportation to and from a service provider for a client who lives multiple hours away can be expensive and difficult to coordinate. Home visits are infrequent or impossible, appointments may be missed practitioners rarely visit remote locations; thus, some remote clients do not often receive an adequate level of treatment. Regardless of the client's characteristics and conditions, it is more difficult to arrange services for clients who live in remote locations than is the care for urban based clients (Keightley et al. 2009).

Keightly et al. (2009) noted that a major factor that inhibits service provision is the location in which the client resides. As this study found, ABI survivors living in remote communities "don't have true access" to service providers (Keightly et al. 2009: 255). Limited support systems exist outside of more densely populated regions. Following-up with and tracking client outcomes is also difficult for service providers to provide for clients who reside in a remote location. Respondents from the focus groups felt that living in rural communities was a factor in whether a client would be seen as a complex case. Similar sentiments were also expressed by the key informants.

The data from the case file review could not be used to determine whether there was an association between the location of a client's residence and whether they were deemed as a complex case because there were substantively few respondents who lived in rural locations more than two hours from an urban centre (n=11).



2.3.4 Economic Factors

Economic factors also play a role in determining whether a client is deemed as a complex case for several reasons. As noted previously in Figure 2-1a, 64% of service providers indicated in the service provider survey that low socio-economic status was a common factor in determining if a client was complex. This factor was only ranked as the fifth most important factor in determining if an ABI survivor is deemed as a complex case; however, this is still a very common factor. Figure 2-1a indicates service providers also identify insufficient/poor housing (56%), and unemployment/lack of employment (37%) as being common factors among complex clients.

Information gained from key informant interviews and focus groups provide additional insight as to why the economic factors of a client contribute to the client's description as a complex case. As it is difficult to provide services for ABI survivors who live in remote locations, it is also difficult to provide services for clients who are transient and difficult to locate, even if they do reside in an urban environment. For this reason, homeless, or those ABI survivors who do not have a fixed permanent address, are often deemed as complex clients. Homeless and transient individuals also often miss meetings or appointments with various service providers. Consequently a service provider reported that individuals are being placed at "the back of the line," and "[suffering] lost opportunities" to make progress.

Additionally, and of important note, several key informants and much of the literature on ABI survivors recognize that it can be easy for many ABI survivors to become impoverished or become homeless post-injury (see: Hwang, Colantonio, Chiu, Tolomiczenko, Kiss, Cowan, Redelmeier, and Levinson 2008). Service providers expressed concern that obtaining employment for many ABI survivors is challenging, and due to the lack of funding from service and government programs, funds may only cover the bare essentials. Additionally, within a family, if the ABI survivor was previously the sole income provider and was unable to return to work, this could produce a great deal of economic strain within the family.

2.3.5 Severity and Type of Brain Injury

Some experts noted that complex clients could have severe brain injury and/or frontal lobe damage, which can impair an individual's impulse controls, which can lead the individual to be more aggressive, act out without warning, and permanently change their level of functioning, both cognitively and behaviorally. In this circumstance, an ABI survivor might be deemed as a complex case for several reasons. Depending on the severity of injury and the specific effects that this has on the client, tasks such as setting goals is an example provided by key informants that has been difficult for ABI survivors with cognitive limitations.

Those who suffer from a severe brain injury could also be susceptible to greater levels of frustration. This is due, in part, to their inability to make the realization that they may not be able to perform tasks at the same level of functioning as they could previous to ABI. Wanting their old life back as soon as possible is one factor that can lead to frustration and impatience, which influences whether their case is deemed complex. A key informant reported that for those ABI survivors who, as a result of their injury, have undergone behavioural changes are more susceptible to encountering barriers from service providers. Memory issues can also be



attributed to severe brain injury and ultimately lead to a client being deemed as a complex case. By forgetting appointments and meetings with service providers, clients may lose their scheduled access to programs or services.

Key informants stated that damage to the frontal lobe of the brain can impair a client's judgement and impulse control. In addition, findings from the literature confirm that, clients who exhibit aggressive behaviour are also considered as complex cases. Often, service providers will not admit a violent client into a program or ban them from the program after observing violent behaviour. Generally though, clients who experience cognitive and other limitations due to the severity of their injury take longer to rehabilitate and more effort to assist, which leads to the more likely prognosis of being deemed as a complex case.

2.3.6 Low or Insufficient Family Support

The support of family members – or lack thereof – plays a key role in determining whether or not an individual who has survived an ABI is considered a complex case. In the context of this evaluation, 'family members' and 'family' has been defined not only as a client's immediate family (i.e., nuclear family), but also extended family members and other relatives who may be involved in a client's care.

Participants in key informant interviews stressed that a lack of family support or negative family influence was generally a good predictor of whether an individual would be deemed as a complex case. Family supports are critical in ensuring a client follows treatment plans and successfully moves forward on their path and towards their goals. Families provide important ongoing supports that cannot be replaced by service providers. However, several respondents did note that a lack of family support was not, in and of itself, a guarantee that an individual will be considered a complex case, and noted that service providers have had success with clients who had a complete lack of family support.

Key informants and focus group participants further noted that families, when present, can often have a negative impact on ABI survivors, which also makes the individual likely to be a complex case. Often, the expectations of families regarding what they feel their loved one should be capable of after suffering an ABI do not always match up with the reality of the ABI. It was expressed that sometimes family members expect that the ABI survivor will return to normal in a short period of time, when in fact, it is much more likely that living with the effects of an ABI is a life-long endeavour, and successfully managing these effects may take years. Managing these family expectations becomes difficult for service providers, to the point where some service providers suggested that the needs of some of these families were more difficult to address than those of the clients. Findings from the literature support this view; for example, stress and negative expectations of family members have been associated with behaviour problems in children with ABI (Bowen et al, 2009), and some parents may have trouble "letting go" and giving their ABI survivor children the chance to live independently.

Focus group participants noted that family members can hinder rehabilitation progress and treatment of ABI survivors with negative or harmful behaviours (i.e., supplying survivors with drugs or alcohol, stealing medication, etc.). Negative relationships such as this may also be the caveat for ABI clients to relapse, miss service appointments, or otherwise be deemed as a

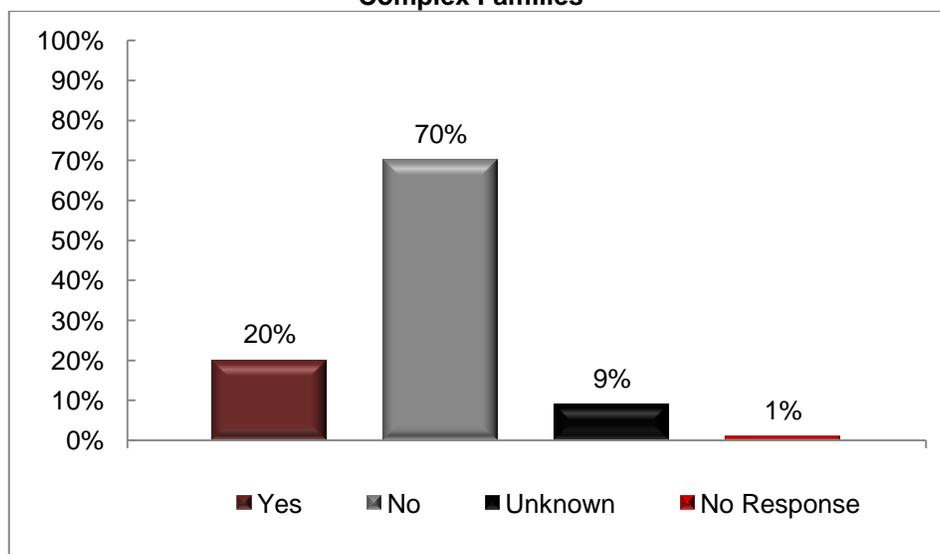
complex case. Related to this, some families may have pre-existing dysfunctions (e.g., substance abuse) that exacerbate challenges for ABI survivors (Ergh et al, 2002).

On the other hand, there are a number of issues that living with an ABI survivor can exert on the client's family members. ABI is most often associated with cognitive and behavioural changes, personality alterations, and can also disrupt familial roles and relationships. Depending on the severity of the injury and the type of behaviour changes, if a client possesses violent behaviours as a result of an ABI, this may place family members at risk. Truelle et al. also found that spousal divorce rate five years after ABI tends to be about 58% (2010). This is not unforeseen given that caring for a family member with ABI can produce stress, depression, anxiety, psychosomatic disorders, increased consumption of prescription and non-prescription drugs, financial difficulties, role changes, poor social adjustment, and increasing social isolation (Murray, Maslany, & Jeffery 2006). Over time, families also tend to report an increasing number of unmet needs (Murray et al. 2006).

Although none of the service providers or key informant interview participants noted issues with family well being after ABI, this issue is worth noting. ABI survivors and their families face significant challenges to the family dynamic and within their relationships after injury. If the ABI survivor financially supported the family, financial support will need to be sought by another member. Additionally, due to cognitive and personality changes in the ABI survivor other family members may need to adapt. Altogether, ABI survivors are not the only ones experiencing stress and obstacles, their families may also be in need of services for counselling and therapy (Murray et al. 2006).

Of respondents who had contact with their family members, one-in-five (20%) individuals included in the case file review were noted as having families that were deemed as complex (Figure 2-12).

Figure 2-12
Complex Families

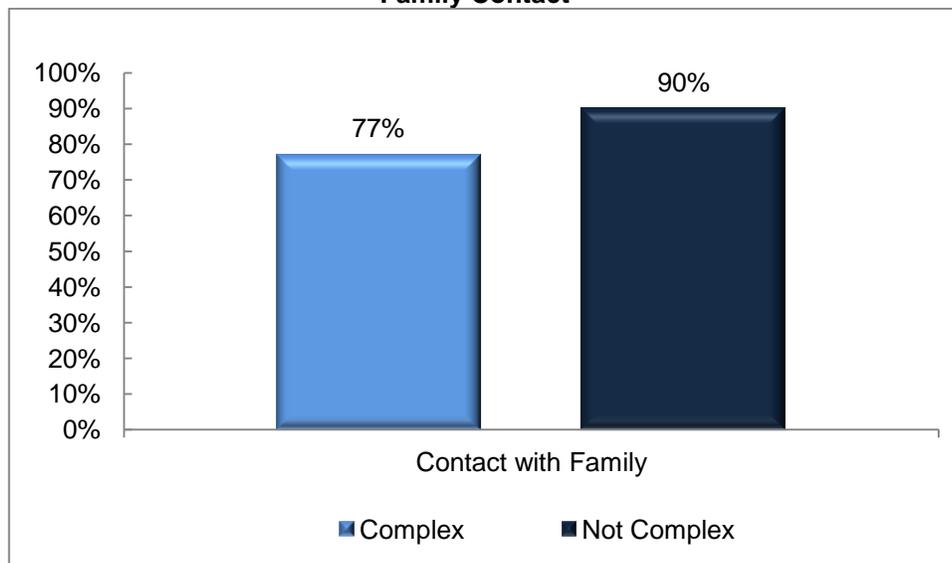


n=208 (Those who answered 'yes' to C8)

Reference= Case File Review D3 ("Is the client's family difficult to serve, or does the client's family hinder service efforts in any way?")

Family contact and support were related to whether individuals were deemed as complex cases, which is consistent with the reports from key informant interviews and focus group participants. Individuals who were noted as complex cases tended to have less contact with their families (77% compared to 90%) than those who were not noted as complex cases, as seen in Figure 2-13.

Figure 2-13
Family Contact

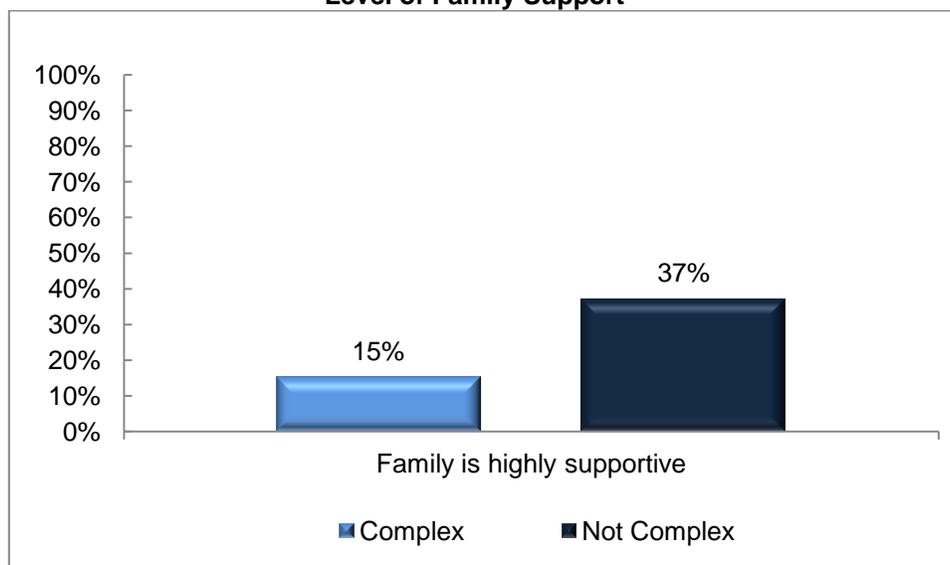


n=246

Reference= Case File Review C8 ("Is the client currently in contact with other family members (regardless of relationship or care status?")

Further, the level of family support was related to whether an individual was deemed as a complex case. Individuals who were noted as complex cases were *less* likely to have a family that was highly supportive than those individuals who were not noted as complex cases (15% compared to 37%; Figure 2-14).

Figure 2-14
Level of Family Support



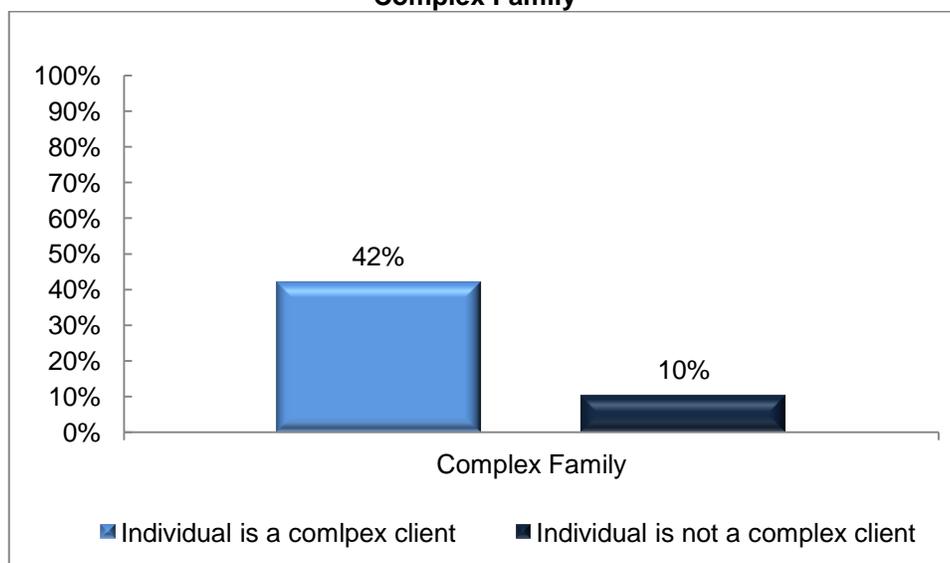
n=208

Reference= Case File Review C10 ("In your opinion, which of the following best characterizes the level of support this client's family has for the treatment or services the client receives through the ABI Partnership program?")

A relationship exists between whether individuals are deemed as complex cases and whether families are deemed as complex cases as well. As seen below (Figure 2-15), individuals who were noted as complex cases were more likely than those who were not deemed as complex cases (42% compared to 10%) to have a complex family.

Although the evidence supporting a client's positive familial contact (those who participate in goal attainment and decision making) is less indicative of the client not being deemed as a complex case, the evidence offers more convincing support for the notion that negative familial contact (those who hinder quality of life gains) with the client is highly indicative of the client being deemed as a case. As a mechanism that could further increase a client's likelihood of not being deemed as a complex case, fostering positive familial relations could have a greater impact. In order to determine the causal relationship between positive and negative family support and being deemed as a complex client further studies are needed. Additionally, in the interests of increasing the frequency by which clients and their families are *not* deemed as complex, determining what measures can be utilized after an ABI has been diagnosed and a complex family support network exists; determining what measures can rectify the familial support network requires further research.

Figure 2-15
Complex Family



n=208

Reference= Case File Review D3 ("Is the client's family difficult to serve, or does the client's family hinder service efforts in any way?")

Families are most commonly described as being complex (Figure 2-16) when family members have their own personal issues (e.g., addictions issues), and/or family members do not follow goals and plans set out for the individual with ABI. The following, are reasons why an ABI survivors` family is deemed as a complex case. Notably, it was found that of the families that are complex, 9% do not hinder service delivery at all. When asked to identify the factors that contribute to a client`s family being complex multiple responses were solicited from the respondents, thus the cumulative percentage expressed in Figure 2-16 exceeds 100%.

Figure 2-16
Reasons for Families Being Complex

| Reasons | Percent |
|---|---------|
| The family member(s) had their own problems (e.g., substance abuse, mental health issues) | 37% |
| Family does not follow goals/plans set out for client | 32% |
| Due to cultural differences, family was not interested in services | 10% |
| The family member(s) are unable to cope with an ABI survivor | 10% |
| Family does not contact us (e.g., does not return phone calls or emails) | 7% |
| There is a language barrier with the family | 5% |
| There is no family involvement with client | 2% |
| Other | 2% |
| Family did not hinder service delivery | 9% |

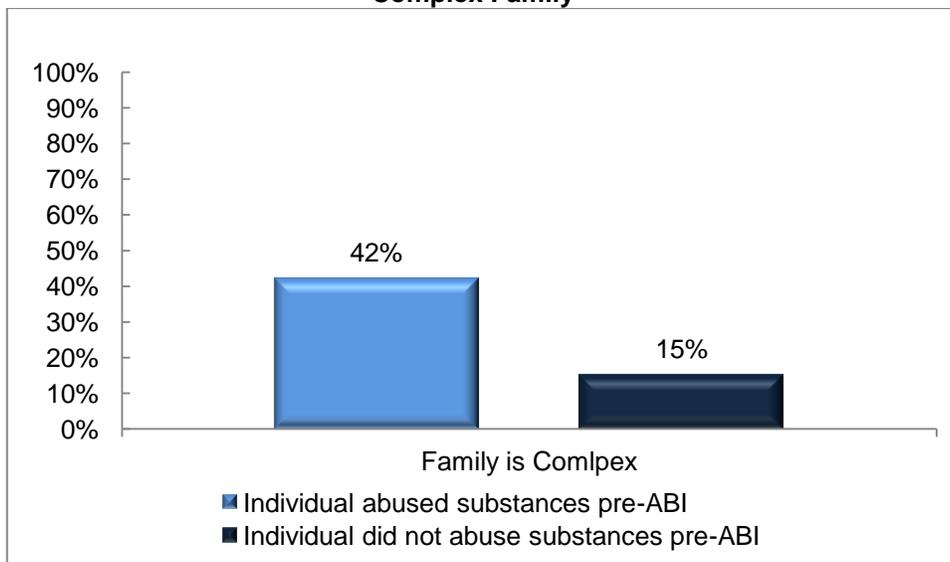
n=41 (Those responding 'yes' to D3)

Reference= Case File Review D4 ("How is the client's family difficult to serve, or how does the client's family hinder service?")

Note: Percentages add to more than 100% because of multiple responses.

Analysis of data from the case file review also suggests that there is interplay between family support and substance abuse which is consistent with the literature (McColl et al. 1999). Clients noted as having abused substances before their ABI were much more likely to have a complex family (Figure 2-17).

Figure 2-17
Complex Family

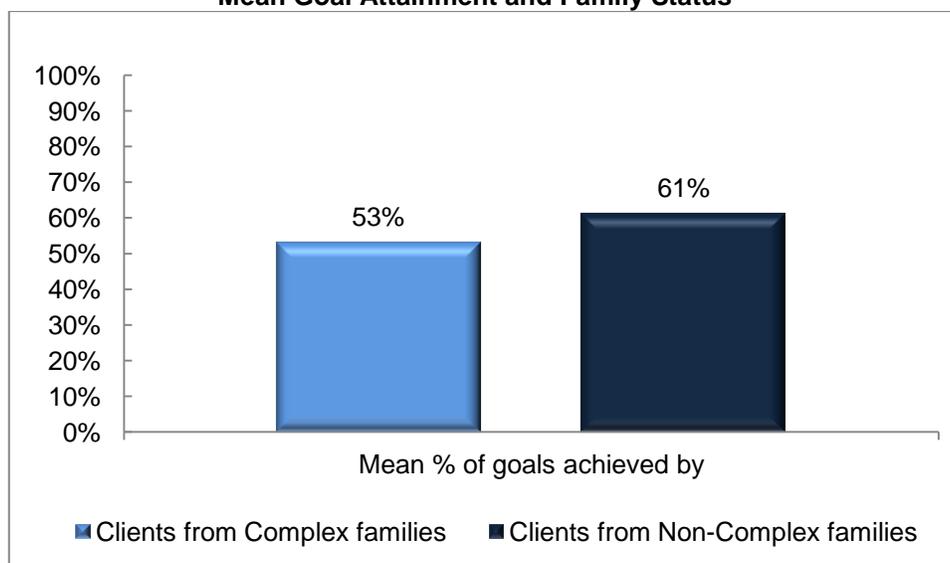


n=208

Reference= Case File Review D3 ("Is the client's family difficult to serve, or does the client's family hinder service efforts in any way?")

Clients with complex families also tended to achieve fewer of their goals (Figure 2-18) (53%) for clients with complex families as compared to (61%) goal attainment for clients from non-complex families.

Figure 2-18
Mean Goal Attainment and Family Status



n=246

Reference= Case File Review (Goal Attainment)

Clients with a parent or guardian as primary caregiver were more likely to be noted as having a complex family (46% compared to 20%). When the parent is the caregiver of the ABI survivor, the family is often more deemed as complex. This may be due to the stress experienced by the family who do not have the necessary supports or resources in place.

2.4 Issues Faced by Aboriginals

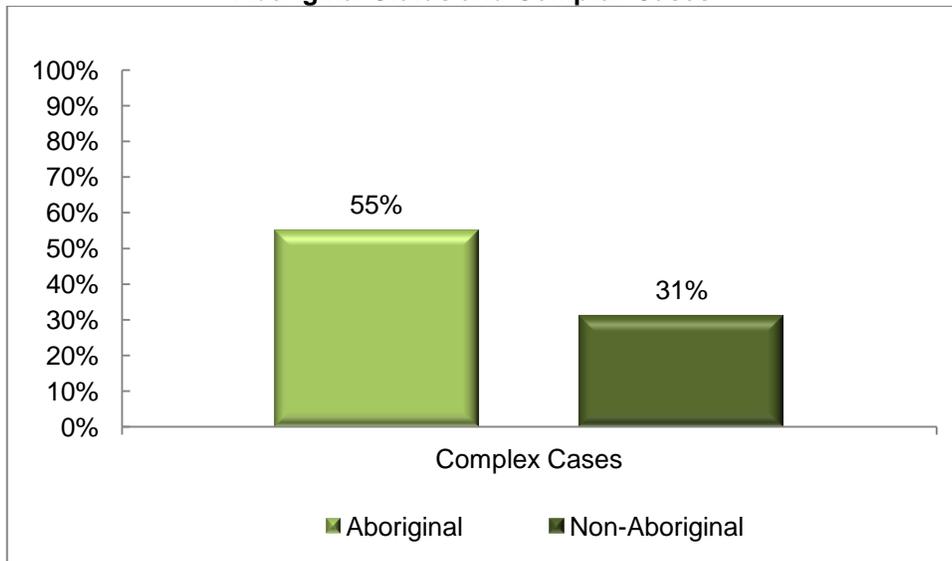
Findings from the literature review suggest that Aboriginal ABI survivors face unique sets of circumstances and challenges compared to non-Aboriginal individuals, including greater challenges obtaining services and experiences of or expectations of stigmatization (Keightley et al, 2009); however, it was also noted in the key informant interviews and service provider survey that most ABI survivors face stigmatization. Further, high rates of co-morbidity (e.g., substance abuse, mental disorders, FASD, behavioural disorders) make it particularly difficult to treat an Aboriginal individual and admit him or her to rehabilitation programs. As well, adjustment to urban centers, loss of family/community support, and loss of access to culture and language have been identified as factors that make some young Aboriginals who migrate to cities for services complex cases (Keightley et al, 2009).

The health of the Aboriginal population has lagged behind that of non-Aboriginals on many indicators, such as life expectancy, all causes of mortality, addictions rate, and suicide rates. However, Aboriginal communities have shown and continue to show tremendous resilience in the face of adversity and challenges, most of which have been imposed upon them through a history of colonization and marginalization. Their resilience testifies to the great strength of their communities and cultures. However, because many of the social determinants of health remain unaddressed in Aboriginal communities, Aboriginal individuals are at greater risk of experiencing poorer physical and mental health, addictions issues, or family dysfunction – all factors that negatively impact an ABI survivor's ability to cope with and recover from the injury, particularly if such conditions pre-date the injury.

Findings from the case file review suggested that Aboriginal ABI survivors in Saskatchewan experience a unique set of inequalities and challenges related to ABI. In particular, data suggests that Aboriginal status is associated with several factors related to being noted as a complex case. It is important to note that Aboriginal status was not specifically mentioned by key informants or focus group participants as related to being deemed as a complex case. Notably, one-in-five (21%) of service providers felt that Aboriginal status was common among those who are deemed to be complex cases. However, based on the case file review, the majority of complex cases were Aboriginal. Although, it is possible that service providers under reported the number of Aboriginals who present complex cases, the case file reviews suggest that Aboriginals make up a greater proportion of this population than is perceived by service providers.

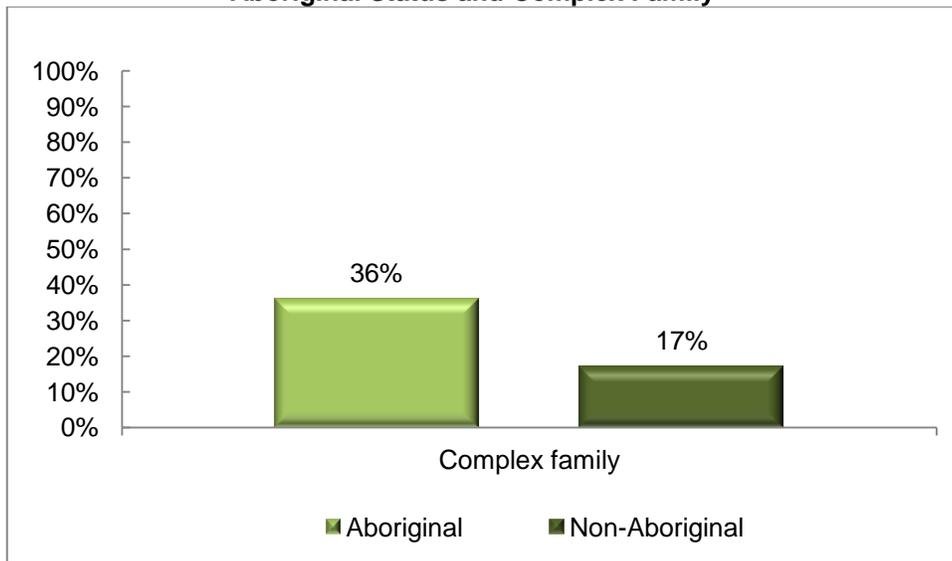
Data from the case file review suggests that Aboriginal individuals are more likely to be noted as a complex case (Figure 2-19). It is however, important to note that Aboriginal individuals are also more likely to have substance abuse issues and family support issues that, in turn, make them more likely to be deemed as a complex case. Aboriginal ABI survivors were more likely to have complex families than those who are non-Aboriginal (Figure 2-20), Aboriginals were more likely to abuse substances prior to ABI than those who were non-Aboriginal (Figure 2-22), and Aboriginals were more than twice as likely to abuse substances after ABI as those who were non-Aboriginal (Figure 2-21). Taken at face value, Figure 2-21 does not describe the entirety of issues faced by Aboriginals. Aboriginal status is, in and of itself, not indicative of being a complex client, other risk factors such as low family support, and substance abuse issues are directly linked to being deemed as a complex case regardless of clients Aboriginal status.

Figure 2-19
Aboriginal Status and Complex Cases



n=236 (excluding 'No response')
Reference= Case File Review D1 ("Would you consider this client difficult to serve?")

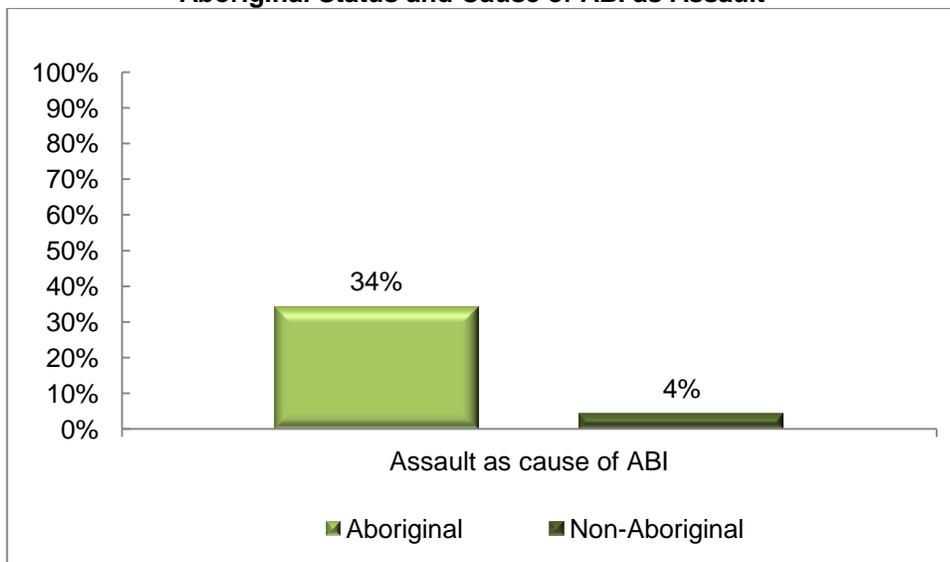
Figure 2-20
Aboriginal Status and Complex Family



n=208
Reference= Case File Review D3 ("Is the client's family difficult to serve, or does the client's family hinder service efforts in any way?")

Consistent with findings from the literature that suggest that Aboriginal individuals are more likely to be victims of assault and violent crime, Aboriginal individuals were more likely to have a blow to the head (assault) as a cause of their ABI (34% compared 4%) than non-Aboriginals (Keightley et al, 2009).

Figure 2-21
Aboriginal Status and Cause of ABI as Assault

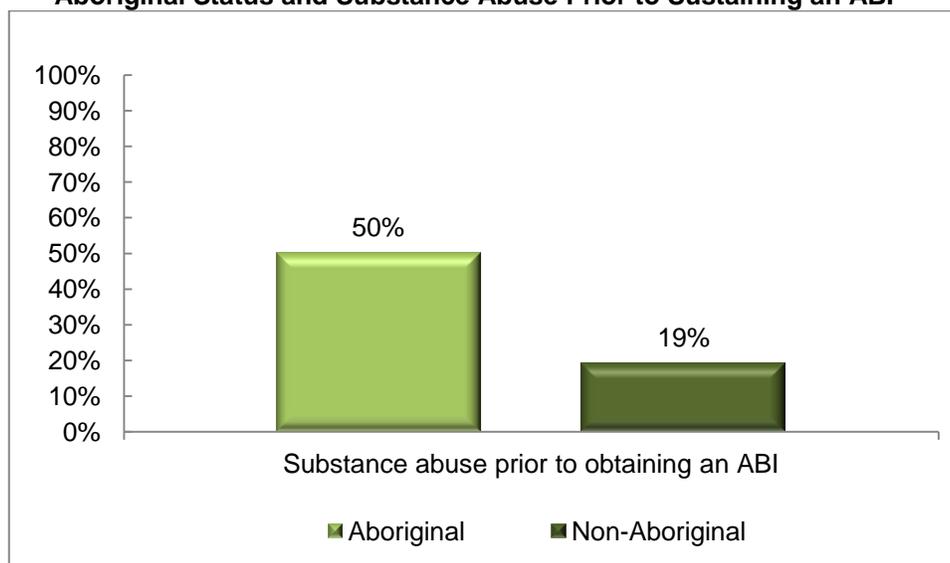


n=208

Reference= Case File Review B4 ("What was the cause of the client's injury?")

Aboriginal individuals identified in the case file review were more likely to have abused substances before their ABI (50% compared to 19%) than non-Aboriginal individuals (Figure 2-22), which is consistent with literature that suggests higher rates of substance abuse among Aboriginal populations (cf., Khan 2008; Health Canada, 2006). Similarly, Aboriginal individuals were more likely to have abused drugs since their ABI (24% compared to 11%) than non-Aboriginal individuals (Figure 2-23).

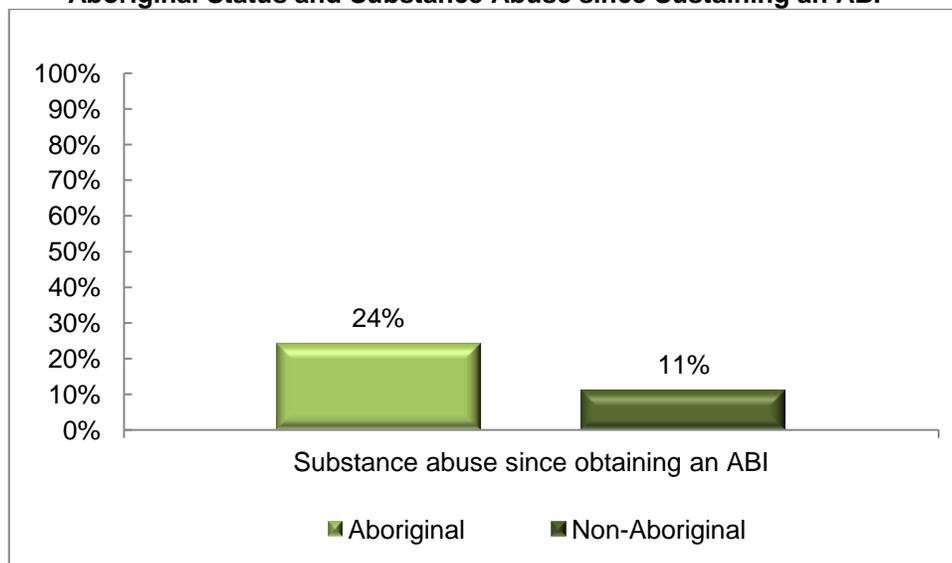
Figure 2-22
Aboriginal Status and Substance Abuse Prior to Sustaining an ABI



n=246

Reference= Case File Review C5 ("Was the client known to excessively use or abuse substance (legal or illegal) prior to sustaining an ABI?")

Figure 2-23
Aboriginal Status and Substance Abuse since Sustaining an ABI



n=246

Reference= Case File Review C6 ("Has the client been known to excessively use or abuse substance (legal or illegal) since sustaining an ABI?")

Other significant ways in which Aboriginal individuals differed from non-Aboriginal individuals in the case file review include:

- Aboriginal individuals are more likely to live in a remote rural area (18% compared to 3%) than non-Aboriginal individuals;
- Aboriginal individuals, on average, achieve fewer of their goals than non-Aboriginal individuals (47% on average compared to 61% on average); and
- Aboriginal individuals, on average, were noted as having a lower level of family support than non-Aboriginal individuals (6.8 out of 10 on average compared to 7.8 out of 10 on average).



2.5 The Effects of a Complex Clientele

Given the range of difficulties, struggles, and challenges associated with service delivery with complex ABI survivors, this can have a profound effect on service providers themselves. Several factors were noted by service providers within the focus groups, the service provider survey, and also by key informant interviews. Notably, and nearly universally, burnout, frustration, and fatigue were effects associated with managing complex clients as part of one's caseload. Others also noted that because of the complex cases, where there tends to be multiple compounding issues presented by complex clients there was a struggle to both properly diagnose clients, and to find the appropriate services and programs that match the client's needs.

2.5.1 Service Provider Burnout

As complex clients tend to have multiple challenges, their treatment is usually more complex and the strains on service providers increase as extra time and effort are needed in order to arrange services for a host of conditions and ailments on top of the issues related to ABI recovery and rehabilitation. Service providers often expressed that burnout or frustration was higher when dealing with complex clients. Generally, service providers felt that rehabilitation took longer and they experienced more set-backs along the path to recovery. At the same time however, of those who noted that complex clients required more attention and effort on their part, some suggested that as a service provider, they focused on even the smallest of successes in order to stay motivated. Additionally, injury appropriate timeframes were necessary in order to manage one's expectations. One key informant noted that given the nature of ABI, and specifically with complex clients, understanding the nature of the injury and developing a timeframe that is appropriate for recovery is essential to mitigate burnout. Rehabilitation does not take days, weeks, or months but rather, years and decades.

2.5.2 Appropriate Service Provision for Clients with Multiple Conditions

Complex clients tend to present with multiple conditions that compound the issue of an ABI. With the issue of multiple conditions, service providers have difficulty finding or determining:

- Proper diagnoses of multiple concurrent conditions;
- Which of the client's conditions need to be treated first;
- If any programs will accept the client with multiple conditions; and
- Which program will be best suited for the client given their multiple needs.

According to one key informant, many symptoms of ABI mimic psychiatric illness. Consequently, many clients are placed in psychiatric care so that they are receiving some form of care and not being forced to adjust without any appropriate supports. Factors that characterize complex clients do compound one another, and overlap, which can make it hard to diagnose the conditions being presented by a client and identify their needs.

A common response from the key informants suggested that complex clients had a greater difficulty being placed in community programs, or obtaining services from service providers, than did other ABI survivors. Often they suggested that because of a client's multiple conditions



some programs would reject complex clients because they were not equipped to handle other conditions that the client presents. In many cases service providers reported, that clients would have to have their substance abuse, or mental health issues managed before admission into programs for rehabilitation. On the other hand, service providers expressed that some substance abuse or mental health programs could not accommodate clients with an ABI.

Others suggested that aggressive clients would be banned from facilities after a violent encounter. One of the service providers suggested that some services were framed as being “barrier creating” rather than “door opening”. Thus, clients who are kept from being admitted to programs because they do not fit the requirement of the program due to compounding issues, are clients who need treatment the most.

Complex clients with multiple conditions, present more challenges for service providers to find the right services, which can best serve these client. The major issue related to these clients who present multiple conditions centres around the uncertainty of which conditions should be treated first. Alternatively, some service providers took a moment to consider what the real issue at hand could be. In many situations, facilities or programs that will admit clients with multiple conditions may not be able to offer the most appropriate services to address these clients` needs.

2.6 Recommendations for Best Practices

In addition to the tools used and efforts already being made by the ABI Partnership Project and service providers, the Consultant developed a list of actionable best practices. These best practices are based on information obtained through the literature on complex ABI survivors, the focus groups with service providers, key informant interviews, and the service provider survey. This list is intended to augment or adapt the services that are already being provided through the Partnership and bolster the efforts already undertaken.

The best practices recommended below are intended to help service providers obtain the greatest quality of life changes for ABI survivors with complex challenges. The ultimate purpose of this evaluation is to equip service providers with a set of service delivery tools and best practices enabling them to improve client outcomes among complex clients. Several of these best practices, tailored specifically to those ABI survivors who present as complex cases, are discussed below. A number of key informants, and service providers, as well as the literature on ABI identified the following as best practices. This section of the report is not meant to identify areas of which the partnership, or service providers are lacking or providing poor services, but to note the responses made by key informants, and service providers with regards to best practices; some of which may already be practiced by service providers or implemented within the Partnership.

Recommendations of the Consultant include:

1. Better collaboration among all those involved in rehabilitation

To ensure a continuity of care across service providers who treat any given client, there should be a high level of collaboration and cooperation between the various service providers. Ideally, different service providers would work towards the same goals and



not overlap or duplicate services. This would be fostered through an open dialogue between the multiple service providers.

Information sharing was reported as one hurdle to this process of collaboration. A few service providers and key informants stated that restrictions imposed by the Freedom of Information and Protection of Privacy Act and The Health Information Protection Act limit the ability of some service providers to share information in case files and client information. Legal clarification should determine what exactly is prohibited and to what extent information can be shared between service providers. In addition, formal memorandum of understanding (MOU) should be developed to specify the practices and process through which such information can be shared. Future training for service providers could also include this legal clarification.

Due to the nature of complex clients, many tend to require the services of multiple service providers. As a result, service providers must realize that they are not working independently of one another. Although, they may focus on one aspect of the client's needs, the client cannot compartmentalize their life so succinctly. Several service providers have suggested solutions, such as: co-case management, and joint cooperation between service providers; however, regardless of the type of cooperation established between service providers, there must be comprehensive information sharing regarding their shared client's holistic needs.

2. Develop an internship or mentorship program for new service providers

Several service providers suggested that in order to help young and inexperienced service providers acclimatize to, not only complex clients, but all ABI survivors generally, a comprehensive internship or mentorship program should be established. Difficulties faced by new service providers could be mitigated and their concerns addressed by more experienced staff members who might be able to share their insight, tips, and past experiences. Having a well established mentorship program may also reduce the likelihood of new staff being overwhelmed and possibly burning out too quickly.

A program such as this could be adopted by all service providers that fall under the umbrella of the Partnership, and not just by the Outreach Teams, or funded agencies. A mentorship/internship program could initially be piloted by a few service providers and later be modeled for adoption by other service providers within the Partnership.

3. Allow information sharing on a large scale throughout the Partnership

Key informants and service providers reported that shared experiences and knowledge exchange among the staff would be beneficial to everyone involved with ABI clients. Although each client presents a unique case, lessons from one individual's successes with a complex client could help others with their clients. Equally so, identifying practices that have not worked with clients could also be beneficial. Adopting such a practice, could also help mitigate stress and foster a sense of camaraderie among service providers.



Although, it is known that groups of service providers such as the Outreach Teams do hold regular meetings in order to share information among their members, broader information sharing of such a nature needs to take place throughout the partnership. Conventional meetings would be impractical for service providers from across the province to attend, but if a virtual information sharing platform were to be utilized for this purpose, information could be accessible to every service provider under the umbrella of the Partnership. Producing an online forum where ideas can be shared and discussed would be effective in reaching a wide audience. It should be noted that the success of online information sharing is greatly dependent on how well it is organized, as well as how motivated the end users are to utilize it. The manner in which information should be shared was not specified by any service providers or key informants; however, the Consultant understands that a web tool utilized by the Partnership, SharePoint exists. With some adaptations to this tool it is possible to see this recommendation come to fruition.

As an online forum that is accessible to all service providers, the potential exists to make further improvements to the ABI Partnership website's staff forum to include case studies, foster discussion and learning, and share success stories, among other potential learning opportunities. In order to ensure successful enhancement to the ABI Partnership's website staff forum, efforts must be taken to make certain all service providers are aware of its existence and its purpose. As well, the forum will need to be managed by the Partnership to ensure that new materials are available on a consistent basis, questions are addressed in a timely manner, and that there are stimulating discussions. By regularly updating the website with new topics and discussions, there will be a greater chance of having service providers return to the forum on a regular and consistent basis to learn from others within the Partnership.

Sharing information via the online forum will also allow more continuous flow of information on a year round basis to augment the training and development offered at Brain Trust, the annual ABI Partnership conference. In fact, topics of interest from the conference could also be used to provide content on the forum.

Generating a platform that all service providers under the Partnership can take part in will likely improve their ability to deliver context specific care to each of their clients. Sharing ideas, successes, failures, and innovations will only further improve the ability of service providers that is already being done within the Partnership.

4. Following through with client referrals

Service providers who regularly interact with complex clients should continue to strive for consistency with these clients, especially when making referrals. Clients who thrive in routinized environments will benefit most from an approach to referrals that is consistent and thorough. As the referrals process is a potential challenge for some clients, ensuring that the client makes the connection with a new service provider is crucial.

Additionally, although it is not a practice of service providers within the Partnership to make blind referrals, it was reported by a number of service providers that in some rare



instances when blind referrals did take place, clients often did not show up, or follow through with the service providers they were referred to. Although there is no quantitative evidence to demonstrate the frequency of blind referrals, responses from the service provider survey indicates that blind referrals do occur.

Ultimately, a consistent approach among service providers may aid to reduce the number of clients who end up missing out on the care they need. The ABI Partnership could look into making a formal policy within the Partnership that blind referrals should not be made. Alternatively, this could be the subject of a Partnership-wide training session. Ideally, referrals should be made in-person from one service provider to another. This way the client can be introduced to the new service provider and a strong connection can be made. Follow up should also be part of the referral process to ensure that a client is returning to the program on a consistent basis and progression is continuously monitored. Again, this may require development of more comprehensive information sharing protocols.

5. Proactive case management

A number of service providers suggested, that being proactive rather than reactive in case management would benefit complex clients. As an active role in case management, service providers are often called upon to anticipate potential problems that their clients may face. Indeed, initial client assessments can be invaluable in identifying potential problems. For example, by identifying that a client's family members have a history of substance abuse, when the time arrives for an ABI client to exit substance abuse treatment, a case manager could make alternative arrangements for their client in order to ensure that their client does not re-enter a home environment where there is a greater risk that relapse can occur.

Case managers and service providers take on the role of advocate for their clients on many occasions, and proactive case management is but one example of the way in which they work for their clients. Being proactive is integral to case management because it has the potential to minimize the amount of time needed in a crisis management role. This is often unavoidable with complex cases, but in order to minimize the amount of time devoted to this time consuming role, being proactive could be highly beneficial.

6. Adopt Motivational Interviewing techniques

As a tactic to help motivate a client to engage in the process of rehabilitation and potentially change behaviour, motivational interviewing should be adopted by ABI Partnership staff. By adopting this client-centred technique that focuses on identifying client's strengths and their own goals this could help evoke their own motivations for change and promote autonomy in decision making (Rollnick et al. 2010). Although this is not a widely used practice in service provision of ABI survivors there is "a small but emerging evidence base" that motivational interviewing can work with ABI survivors (Medley and Powell, 2010). Indeed, some key informants suggested that motivational interviewing could be highly beneficial to engage, not only with complex clients, but all ABI survivors.



Importantly, motivational interviewing could be highly beneficial when establishing realistic goals that the client recognizes as important in achieving. Additionally, Lane-Brown and Tate (2010) identified that motivational interviewing can address apathy and lack of motivation towards achieving goals. This best practice may require additional training as well as monitoring to better assess this identified service delivery approach.

7. Adopt culturally safe practices to better serve Aboriginal clients

Recognizing that Aboriginals comprise a significant proportion of ABI survivors in the Province of Saskatchewan efforts should be made to enhance services in order to more effectively help in the rehabilitation of Aboriginal clients who present as complex cases.

An important consideration is that cultural safety is less about cultural *awareness* on the part of the service provider and more about the understanding of the power inherent in their position, particularly if the service provider is non-Aboriginal (i.e., from the dominant culture) and coming into the community from outside the community's culture (Smye et al, 2010). To that end, authors writing about cultural safety stress that service providers "without in-depth knowledge of Aboriginal culture can still perform their work in a culturally safe manner," reinforcing the idea that cultural safety is, at its core, about power, and empowering Aboriginal individuals and communities.

Future training for service providers could include culturally safe techniques or situational role-playing as part of professional development sessions. It is also a possibility that the Partnership could engage in capacity building initiatives which would enhance the pool of qualified Aboriginal candidates available to work within the Partnership or to support service providers who work with Aboriginal clients.

2.7 Service Delivery Gaps

Complex ABI survivors present a challenging and unique opportunity for the ABI Partnership Project Outreach Teams and partnered service providers to work towards improving their client's quality of life and rehabilitation outcomes. Complex ABI clients tend to present multiple service challenges that extend beyond ABI itself. As such, some programs and services may not be able to accommodate or adapt in the ways required by the multiple sets of challenges that complex clients present. The Consultant, through the use of primary and secondary research tools, has been able to identify several areas in which the needs of complex clients can be further improved.

2.7.1 Service Barriers

Service providers stated that it is often the case that complex ABI survivors are not accepted into programs because of the multiple challenges they present. Alternatively, complex clients are sometimes ejected or removed from programs because of undesirable behaviour or because they don't meet the requirements of the program. A number of service providers suggested that many services would screen out clients that they could not manage through their program and often complex clients were not accepted for treatment. This speaks to the



unavailability of specific programs and the necessity for services that are tailored to complex clients.

Many service providers stated that currently most addiction service providers require that psychiatric symptoms be well managed before a client can be admitted. Others stated that some programs lacked an in-depth understanding of the various needs of complex ABI clients. Not recognizing that complex clients may be more prone to aggression because of severe brain damage, or other extensive challenges, may also lead to a client being removed from a program or not being admitted.

Addiction programs were reported as being particularly challenging for complex ABI clients to gain access to. Some substance abuse programs will require that other compounding issues presented by an ABI client be managed before they can be accepted into the program. By offering specific drug treatment programs designed for ABI survivors, many barriers could be removed and complex clients may be in a better position to obtain the services they need. Offering addiction treatment that is created to work with ABI survivors, could reduce the stigmatization, mitigate relapse, and help ensure that addiction counselors recognize, and are educated in regards to the needs of complex ABI clients.

2.7.2 Addiction and Mental Health

Service providers felt that mental health issues were common among the issues faced by complex clients. Additionally, service providers did not feel that these needs were being adequately met by the services and programs available to complex ABI survivors. Mental health issues often manifest in substance abuse and addiction according to the MHCC (2007), which service providers also felt was an unmet need of many complex clients.

Service providers felt that addiction and substance abuse treatment programs were often ineffective for one of two reasons. Primarily, a lack of understanding and education in regards to ABI was often cited as a cause, which rendered treatment of complex clients ineffective. Secondly, the lack of follow-up after treatment resulted in many ABI clients reverting back to old habits. Given that complex clients tend to have families with complex problems, which includes dealing with substance abuse issues and/or other family dysfunction the potential exists for a complex client to relapse following addiction treatment in the absence of any follow-up supports and monitoring.

2.7.3 Program Goals

Service providers felt that unrealistic goals were sometimes created for complex clients by some programs. Unrealistic goals present a challenge to complex ABI survivors because they may not address the client's needs and set the stage for client failure. There is a lack of education in this circumstance which should be addressed to better provide appropriate services for complex clients. Although this is not reflective of the majority of cases that are handled by case managers or coordinators within the Partnership, for some clients, who do not "buy-in" to treatment strategies this gap exists. Service providers suggested that it is often difficult for clients with complex needs to stay motivated and working towards goals that they do not feel a vested interest in. When goals have been set by a service provider or case manager with no



input from the client it is less likely that the client will have success. Ensuring that a client has ample input in the establishment of their goals may ensure that the client stays motivated and focused on making a commitment to their rehabilitation.

2.7.4 Housing Limitations

Numerous service providers suggested that there are insufficient and inadequate housing options available to meet the needs of complex ABI clients. The options that are available are either too expensive for the budget of the average client or unsuitable given the needs of most complex clients.

Service providers, focus group participants, and key informants all urge that there is a need for increased availability of housing options for clients. Respondents differed in their opinions with regards to the length and intensity of care that was needed, but some suggested that more short-term options need to be available for clients, whereas others stressed the need for supportive long-term housing with the availability of 24/7 care on the other hand. The need for both exists, and each has its benefits. While some clients require short-term housing in order to transition from one stage of life to another, finding suitable and stable long-term residences for clients should be the goal of any case manager. Finding appropriate housing for ABI clients is an important part of meeting any clients' basic needs, which is not currently being properly addressed. In this context, service providers would be in an advocacy role for the partnership to help ensure suitable social housing is developed that can specifically meet the needs of complex ABI clients.

2.7.5 Education Provisions for Acute Care Practitioners and Families

Ideally, family education would begin as early as possible. According to Coco et al (2010) it is important to provide practical education to family members about ABI during the acute care phases to help better understand their ABI survivor family member and their needs. This education will also help families better manage their own expectations. It was reported by service providers that many family members were not adequately ready to care for or accommodate an ABI survivor outside of the acute care facility. Rotondi et al. (2010) and Coco et al. (2011) found that many family members of ABI survivors feel that they have not been provided with adequate education and preparation regarding future care for an ABI survivor will require.

The potential exists for the ABI Partnership to provide educational materials for acute care practitioners and facilities in order to assist acute care providers prepare the families of ABI survivors for the upcoming transition. As an ABI survivor transitions from an institutional setting into the community, family members need to be adequately prepared for this transition.

At the present time, when an ABI client is referred to a service provider within the Partnership from an acute care facility there is often insufficient education provided for the family of the ABI survivor regarding the Partnership or the recovery and rehabilitation process. Some service providers reported that it was extremely difficult to work with families of ABI survivors, who were uninformed of the condition of their ABI family member and had unrealistic goals set for them. This further hindered the progress.



By ensuring that a standard educational training guide is provided for acute care practitioners regarding the ABI Partnership Project, practitioners will be able to relay this information more easily to family members of an ABI survivor. Service providers reported that a large number of family members of ABI survivors were not prepared for the transition from acute care facilities to community based programs, which is consistent with the literature. A few key informants also reported that in order to better educate family members of ABI survivors, education should begin while the client is still in recovery at an acute care facility. Acute care practitioners are brain injury specialists, but they are not necessarily knowledgeable of the ABI Partnership Project.

2.7.6 Substance Abuse Treatment and ABI Programming in Tandem

It is recognized by several key informants and service providers that when substance abuse treatment and ABI rehabilitation are offered separately they do not seem to be very effective, nor is it easy for complex clients to be accepted into substance abuse treatment without well managed concurrent issues. As these two programs are currently offered separately this produces a gap in effective service delivery, especially for complex clients who often also possess substance abuse issues.

Alternatively, by offering specific drug treatment programs designed for complex ABI survivors, many rigid barriers can be removed and an effective program can be developed to manage substance abuse and ABI in tandem. Key informants also recognized that such a program being delivered in tandem could reduce stigmatization that ABI clients in substance abuse treatment will not be successful, and such a program could be a more effective treatment option for both substance abuse and ABI rehabilitation among complex clients.



CONCLUSIONS

This report has been able to thoroughly identify what contributes to an ABI client being a complex case. In order to better serve this group of clients the Consultant has also identified a number of best practices that will make better usage of Partnership resources and ultimately help attain better quality of life outcomes for complex ABI clients. The Consultant has also noted several service gaps that complex ABI clients encounter.

Serving clients with ABI is a challenge unto itself, but when concurrent issues also impact service delivery, there is a need to provide a more comprehensive set of services. There are a number of reasons why clients could be deemed as a complex case, however no matter what the reason; it is evident that complex clients in most cases require more time and attention than usual. Some service providers and experts expressed a similar sentiment that complex clients were the few clients, who took up the most of their time. Generally, complex client's exhibit one or more of the six factors that this study identified in conjunction with an ABI.

Key Findings:

Complex Cases

Generally, the Consultant has found that complex clients are clients who have other issues besides an ABI. These issues tend to make it more difficult to arrange for services for these clients and it generally takes more effort and time for service providers to achieve comparable outcomes as other non-complex clients. According to a number of service providers, complex clients are viewed as the 20% of clients who take up 80% of a case manager's time. Complex clients tended to be those clients who present one or a combination of the following factors:

1. Substance abuse issues;
2. Mental health needs;
3. Lived in remote rural locations;
4. Exhibited economic risk factors;
5. Experienced severe brain injury; and/or
6. Have low or insufficient family support.

The existence of one of these factors in combination with an ABI was sufficient to deem a client as a "complex case"; however, clients often present multiple conditions concurrently which only compound the issue of service delivery. Indeed, due to the nature of compounding issues with complex clients most of the service gaps that have been identified in this report stem from this issue.

Service gaps

Rigid service provisions present a challenge for complex clients because they often exclude clients from a program who present with issues that cannot be addressed or accommodated within the program. Mental health issues were often identified as manifesting in substance abuse. Furthermore, substance abuse treatment programs were identified as often being unable to accommodate clients who exhibit mental health issues, and conversely mental health issues



were often unable to be treated unless substance abuse was under control. The issue illustrated with this service gap is exemplary of problem with compounding factors of complex clients. Although, an ABI client with a substance abuse issues would generally take longer, and more effort to rehabilitate than a client with an ABI alone, the presence of mental health needs on top of a substance abuse issue creates additional complexity and requires more effort and attention from service providers and case managers. Substance abuse and mental health needs provides a good example of compounding difficulties because they often coexist; however, any factor that contributes to a client being a complex case can have a similar compounding effect. Several service gaps were identified by this study and they include:

1. Service barriers;
2. Addiction and Mental Health;
3. Program goals;
4. Housing limitations;
5. Education provisions for acute care practitioners and families; and
6. Substance Abuse Treatment and ABI Programming in Tandem.

Engaging clients on a level that allows them to buy-in to their rehabilitation strategy can be highly successful in achieving positive quality of life outcomes. However, for some complex clients who are a challenge to engage in the process of formulating goals this gap exists. There potentially is a solution that could address, not only this gap in complex clients establishment of goals, but could be useful for all ABI clients. There is also a limitation on the availability of housing for ABI clients, especially for complex clients. This continues to be an issue within the ABI Partnership, and also continues to be a gap that is not easily addressed.

Also stemming from the challenge of compounding issues that complex clients tend to present is the challenge of finding appropriate services for any given client, given their needs. Given a client's compounding issues, finding the appropriate order in which to treat these issues is a challenge to establish and facilitate. As one of the most common factors that contribute to client's being deemed as complex cases, substance abuse issues among ABI survivors are often difficult to treat due to the predominantly bifurcated treatment options. The separation of ABI rehabilitation and substance abuse treatment seems to have limited efficacy for complex clients.

As a significant proportion of ABI clients are referred to the partnership from acute care facilities, there exists the potential for a much earlier education program for families of clients with the Partnership and with acute care practitioners. This early education for family members could help establish a realistic sense of what to expect from their loved one, and ease the transition from acute care facility to community based programming. Additionally, family members can perform a central role in ABI rehabilitation by assisting their loved one and maintaining their focus, and participation in their programming, but this can prove to be challenging and burdensome. Often family members of ABI survivors are in need of assistance themselves, such as: therapy and counselling.



Best Practices

Seven recommendations have been formulated based on the best practices identified through this study in order to aid service providers to provide their clients with a better quality of service and provide this service more efficiently and effectively. Understanding that the ultimate goal of the Partnership is to enhance rehabilitation outcomes and improve quality of life for ABI clients, identifying the best practices possible for service providers will make a significant impact. The recommendations of this study are addressed towards the service providers within the Partnership in order to enhance service delivery and achieve better quality of life outcomes for clients.

Best practices that this study has identified include:

1. Better collaboration among all those involved in rehabilitation;
2. Develop an internship/mentorship program for new service providers;
3. Allow information sharing on a large scale throughout the Partnership;
4. Following through with client referrals;
5. Proactive case management;
6. Adopt motivational interviewing techniques; and
7. Adopt culturally safe practices to better serve Aboriginal clients.

As complex clients tend to have multiple challenges above and beyond ABI, multiple service providers will likely be involved in a complex client's rehabilitation and care. In order to offer the most effective and efficient services for the client these service providers should effectively communicate and coordinate the different services that they provide for the client in order not to duplicate services or negate the work being done by other service providers. Efforts should also be made to identify the extent to which information can be shared between service providers given the restrictions of FOIP legislation. In fact, to borrow from a practice already being utilized by the Outreach Teams, who hold meetings to debrief and share ideas among the group there should be some form of information sharing platform available throughout the Partnership for all service providers to share their successes, failures, and innovations.

It should be standard practice among service providers to avoid making blind referrals. Establishing a consistent practice of introducing complex clients to new service providers avoids the potential danger that a client will miss out on treatment and rehabilitation that they need. By noticing the potential danger in making blind referrals, service providers could take a proactive role with their clients. In an effort to minimize the amount of time spent in a crisis management role, if service providers could anticipate potential problems they may be able to mitigate issues before they escalate.

Complex clients can be a challenge to experienced service providers, let alone new and inexperienced service providers. In order to assist new staff acclimatize the demands of complex clients an internship or mentorship program should be established to pair new staff with experienced staff. This could be an invaluable learning experience for new staff. Another learning experience that could be valuable to help complex clients buy-in to their treatment is motivational interviewing. This technique helps service providers identify the needs and values that are important to their clients and will help develop context specific care. Ideally, the client



will develop a vested interest in their own rehabilitation as well as become interested, and motivated to participate in their rehabilitation and treatment. Another technique that could be very valuable for service providers to learn is culturally safe practices in order to appropriately work with Aboriginal ABI clients. Alternatively, the Partnership could incorporate the use of Aboriginal counselors to work with service providers or to assist Aboriginal ABI clients.



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APPENDICIES

2.8 Appendix 1 – Sample of Focus Group Guide

Introduction:

Hello and thank you for agreeing to participate in this focus group today.

We have invited you here today to discuss the Acquired Brain Injury Partnership Project's service delivery model for difficult to serve populations. This focus group is intended to help understand more about difficult to serve clients, and how to improve service delivery for those clients.

Before we begin, I would like to talk a little about what will happen to the data that is collected here today. The data we collect today will be combined with that of the other focus groups and analyzed in aggregate. We don't typically use quotes from focus groups, and when we do, we do not attribute them to an individual, but rather cite them as being a focus group participant in general. In this case, it would be a participant of the _____<region> group. The video and audio recordings of this session will be used to ensure that the notes we take are as accurate as possible. They are used by Malatest only and are not given to the ABI Partnership Project or to anyone else. These tapes will be destroyed five years after

I would like to start out with a round of introductions. Please tell us your first name, and describe a little bit about what it is you do. I'll start with myself.

My name is _____ and I am a researcher with R. A. Malatest & Associates, Ltd. Our company has been commissioned by the ABI Partnership Project to conduct this research.

Introductions around the table (5 minutes)

Section A – What is a Difficult to Serve Client? (20 – 40 minutes)

In this part of the focus group, we are trying to create a definition of what 'difficult to serve' might mean. I'd like you to think about what kinds of things might make a client difficult to serve.

A1. From your perspective, what does 'difficult to serve' mean? (Probe: What do you see as being difficult to serve? How might a client be difficult to serve? Are there factors within a client's control that contribute to being difficult to serve? Outside of a client's control? What are these factors?)



A2. What role does the service provider play in whether a client is difficult to serve?
(Probe: Can a client be more difficult for one service provider and less difficult for another? Why?)

A3. What role does a client's family play in whether the client is difficult to serve?
(Probe: how can family make clients less difficult to serve? How can family make clients more difficult to serve? Does family play a large role in whether someone is difficult to serve?)

A4. [To be asked if focus group occurs after survey] The survey identified a number of factors as being contributors to whether a client is difficult to serve. I'd like to discuss these factors with you. For each factor, I would like to ask about how that factor contributes to a client being difficult to serve.

[Discuss factors identified in survey phase]

Section B – What Are the Consequences of Being Difficult to Serve? (30 – 45 minutes)

Now I'd like to discuss the consequences or implications of being difficult to serve.

B1. In terms of the receiving services, what are the consequences of being difficult to serve for the client? *(Probe: how is the provision of service impacted for that client?)*

B2. How does being difficult to serve affect a client's outcomes?

B3. How does being difficult to serve impact a client's family? *(Probe: What consequences does being difficult to serve have on client families?)*

B4. How does having a difficult to serve client affect the service provider? *(Probe: what are the consequences of difficult to serve clients for service providers?)*



Section C – Improving Services for Difficult to Serve Clients (30 – 45 minutes)

Now that we've discussed a little bit about what it means to be difficult to serve, and what the consequences might be of being difficult to serve, I'd like to discuss how service providers might meet those challenges.

C1. Are there things that service providers can do to help make it easier to serve these clients? *(Probe: What works? What works for you? Have you come across any best practices?)*

C2. Are there things that service providers do that sometimes make it harder to serve clients? *(Probe: Is there anything that doesn't work? Is there anything that makes things worse?)*

C3. Are there common service practices that don't seem to have an effect or benefit for difficult to serve clients? *(Probe: Can these practices be eliminated for this group? Why do they work for other clients but not these clients?)*

C4. Are there things that families can do to help make clients less difficult to serve? *(Probe: How can we work with or help families to do these things? How can we better work with resistant families?)*

C5. What else can help improve services for difficult to serve clients?

Section D – Other Comments and Close (5 – 30 minutes)

Those are all the questions that I have for today. Before we go, do you have any other comments or any other suggestions?

I'd like to thank you for taking the time to participate today. Our discussion will be used to help aid service provider's understanding of what works and what doesn't work in helping difficult to serve clients. We are hoping to develop a list of best practices and lessons learned from this research.

The results of this research are scheduled for release sometime around March 31, 2012.



2.9 Appendix 2 – Sample of Key Informant Interview Guide

| |
|----------------------|
| Name: |
| Position or Role: |
| Date and Time: |
| In-person/Telephone: |

Introduction

The Acquired Brain Injury (ABI) Partnership Project is a joint initiative between Saskatchewan Health and Saskatchewan Government Insurance. The aim of the ABI Partnership Project is to develop and implement services and supports for acquired brain injury survivors and their families. The ABI Partnership Project has contracted with R. A. Malatest & Associates Ltd. to conduct an evaluation of the Project's service delivery model for difficult-to-serve clients. The ultimate goal of this study is to enhance the service delivery approach of the ABI Partnership Project for difficult-to-serve clients.

As an individual with experience or expertise in the rehabilitation of and the provision of services to ABI survivors, you are invited to participate in a Key Informant Interview. The aim of this interview is to gather your opinions and knowledge on which ABI clients are difficult to serve, what it means to be difficult to serve, and what best practices can be garnered in order to improve the services received by the difficult to serve client populations.

This interview is expected to take between 30 and 45 minutes of your time. Thank you very much for your participation in this important research.

Confidentiality and Privacy

Your participation in this research is voluntary. Every effort will be made to ensure that the information collected is accurately recorded and used. Any information you provide will be kept confidential, and used only for research purposes.

Do you have any questions or require additional information before we begin?



Section A. What is the Difficult to Serve Population?

To begin with we have several questions about the difficult to serve ABI survivor population. Part of discovering best practices in providing services for difficult to serve populations is identifying what difficult to serve populations are, and defining what it means to be difficult to serve.

When answering these questions, please consider the various ways in which it can be difficult to provide services to ABI survivors. We would like you to think in terms of groups or populations, rather than individuals you may have worked with as a service provider.

A1. In your opinion and experience, what makes an ABI survivor client difficult to serve?

A2. Are there factors that can be used to predict whether a given individual will be difficult to serve? If so, what are the factors? (Examples: severity/type of injury, demographic factors, comorbidities, family situation, etc.)

A3. a. What consequences does being difficult to serve have for the client?

b. For service providers?

c. For family members?

A4. How prevalent are clients who are difficult to serve? That is, what proportion of the ABI survivor client base is difficult to serve?



Section B. Providing Service to the Difficult to Serve Population?

This section explores the provision of services to difficult to serve populations in greater detail.

B1. What are the systemic barriers faced by difficult to serve populations in accessing services? How can these be overcome?

B2. What are the non-systemic challenges in providing services to difficult to serve populations?

B3. How can these challenges in providing services to difficult to serve populations be overcome?

B4. Are you aware of any best practices in providing services to difficult to serve populations? If yes, what are they?

B5. Are there other ways in which service providers could improve the ways in which services are provided to difficult to serve populations? If yes, what are they? How about for family members?

B6. What do service providers who work with difficult to serve clients need to know or be aware of in order to provide effective service?



Section C. Other Comments

C1. Is there anything we haven't discussed today that you feel should be included in this interview? Do you have any additional comments?

Thank you for your participation!

If you have any questions or concerns, please do not hesitate to contact Eleanor Hamaluk at:

e.hamaluk@malatest.com

R. A. Malatest & Associates, Ltd.

#300, 10621-100 Ave

Edmonton, AB T5J 0B3

1-877-665-6252

Or you may contact Kealee Playford at :



2.10 Appendix 3 – Sample of Service Provider Survey

Introduction:

The Acquired Brain Injury (ABI) Partnership Project has contracted with R. A. Malatest & Associates Ltd. to conduct research into difficult to serve populations. As part of this research, you are being invited to participate in a survey about your experiences providing services to ABI survivors.

The responses you provide in this survey are reported in aggregate. Neither the ABI Partnership Program nor your supervisors or managers will be told that you have participated or will be given your answers.

Results for this research are currently scheduled to be released in March 2012. The results will be disseminated to service providers such as yourself. The feedback you give us today will help provide best practices in service delivery for difficult to serve clients, which is expected to help service providers to continue to deliver high quality service to all clients.

Please complete this survey by November 19th, 2010.

This survey is also available online at <<website>>, or over the phone at 1-866-247-6465. Please retain the Reference ID at the bottom of this page in order to access your survey.

Please fax or mail your completed survey to R. A. Malatest & Associates at:

Fax: 1-866-448-9047
Mail: #300, 10621-100 Ave
 Edmonton, AB, T5J 0B3
 1-877-665-6252

If you have questions about this research, you may contact:

Eleanor Hamaluk,
 Research Associate
 R. A. Malatest & Associates, Ltd.
 #300, 10621-100 Ave
 Edmonton, AB, T5J 0B3
 1-877-665-6252
e.hamaluk@malatest.com

or

Kealee Playford
 ABI Partnership Project
 Ministry of Health
 3475 Albert Street
 Regina, Saskatchewan, S4S 6X6
 306-787-0525
Kealee.Playford@health.gov.sk.ca



Section A – About You:

First, we have a few questions about you. These questions pertain to your role within the ABI Partnership Project and the work you do with clients.

A1. How long have you worked for the ABI Partnership Project?

Is this number in:

- Years?
- Months?

A2. How long have you worked in the ABI survivor service provision field (including your time spent at the ABI Partnership Project)?

Is this number in:

- Years?
- Months?

A3. Please indicate which of the following *best* describes your involvement with the ABI Partnership Project? Are you

- Employed full-time?
- Employed part-time?
- A volunteer?
- A practicum student?
- Other (please specify): _____?

A4. What is your highest level of education or training? Please select one.

- Less than high school/GED
- Completed high school/GED
- Some post-secondary (any)
- Completed diploma/certificate program or college degree
- Completed undergraduate university degree
- Completed Master's degree or professional designation
- Complete Ph.D

A5. What is your *primary* role within the ABI Partnership Project? Please select one. If you have multiple roles, please select the one that you spend the most time on per week.

- Office administration or reception
- Management or supervision
- Development of programs or services for clients
- Administration of programs/services/treatment to clients
- Other client-based (specify): _____
- Other non-client based (specify): _____



A6. Please indicate any other roles you may have within the ABI Partnership Project. Please select all that apply.

- Office administration or reception
- Management or supervision
- Development of programs or services for clients
- Administration of programs/services/treatment to clients
- Other client-based (specify): _____
- Other non-client based (specify): _____
- No other roles

A7. Do your roles with the ABI Partnership Project bring you into direct contact with clients at any time, *or* are you involved in providing or developing services/treatments/programs for clients?

- Yes
- No
-

A8. What is your current client caseload?

- Not Applicable

Section B – Difficult to Serve Clients

This research focuses on service delivery for difficult to serve client populations. Part of this research includes defining what makes clients difficult to serve, and what a difficult to serve client population is.

B1. Considering the work you do with clients, in your experience and opinion, what makes a client difficult to serve?

B2. Thinking about the clients that you have had difficulty serving, have you noticed any common factors or characteristics shared by some or all of those clients?

- Not Applicable

B3. Considering the proportion of your clients who you have identified as difficult to serve, have you noticed any common factors or characteristics shared by some or all of those clients?



- Yes
- No

GO TO B4
GO TO SECTION C

B4a. Please indicate what common factors or characteristics you have noticed among difficult to serve ABI clients. Please select all that apply. There is also space to indicate any that might have been missed in this list.

- Current age
- Age at injury
- Ethnicity
- Gender
- Nature of injury
- Education level
- Employment status
- Housing status
- Level of family support
- Substance use
- Lifestyle prior to injury
- Lifestyle after injury
- Pre-existing medical conditions
- Other (specify): _____

Please provide more details or explanations of the above, if necessary:

B4b. Now we would like you to consider the factors or characteristics you just mentioned. We would like you to rank those factors in terms of those which seem to contribute the most to whether or not a client is difficult to serve. Please rank only the *top five factors*. Rank them from one to five, with one being the *biggest contributor* and five being the lowest of the five.

If you have indicated fewer than five factors, please rank them from biggest contributor to least contributor, starting with one as the biggest contributor.

- ___ Current age
- ___ Age at injury
- ___ Ethnicity
- ___ Gender
- ___ Nature of injury
- ___ Education level
- ___ Employment status
- ___ Housing status
- ___ Level of family support
- ___ Substance use



- Lifestyle prior to injury
- Lifestyle after injury
- Pre-existing medical conditions
- Other (specify):

Section C – Service Delivery for Difficult To Serve Clients:

This section asks about service provision for difficult to serve clients. We will ask about what works and what doesn't work in providing services to these client groups.

C1. Considering your experiences working with difficult to serve clients or client groups, have you noticed any ways in which service providers can help improve outcomes for those clients?

- Yes **GO TO C2**
- No **GO TO C3**

C2. In your experience, what can service providers do to help improve outcomes for difficult to serve clients? That is, what do you identify as best practices for helping these clients receive better services?

C3. In your experience, have you noticed common service practices that are particularly *ineffective* at reaching or helping difficult to serve clients? If yes, what service practices are typically ineffective or hindering?

- I have not noticed practices that hinder service provision with these clients **GO TO C5**

C4. Considering the practices that you've identified as being ineffective or hindering, why do you think these practices are so ineffective at helping difficult to serve client groups?



C5. In your experience and opinion, is there anything else that can be done to help improve services for difficult to serve clients?

- Nothing more

Section D – Other Comments:

D1. Do you have any other comments for us today?

- No further comments

D2. We may be conducting focus groups at a later date regarding this subject. Participation in focus groups is optional. We would like to ask your permission to contact you at a later date to ask if you wish to take part of a focus group. You do not have to decide now. If you already know you do not wish to be part of a focus group, please indicate so. Otherwise, please confirm your contact information so that we may contact you to invite you to participate.

What is your name: _____

What is the best phone number to reach you at: _____

- No, I do not wish to participate in a focus group. Please do not contact me to invite me to participate.

Those are all the questions we have for you for today. Thank you for participating in this research!



2.11 Appendix 4 – Sample of Case Review Log

[PAGE INTRO]

Introduction:

This data collection tool is intended to ensure that data from the case files is as complete as possible for analysis. Much of the information for this form will be drawn from the ABIIS in a de-identified form. Where ABIIS information is available, it will be pre-supplied.

Instructions:

For each question in this case file review tool, please enter in the information for the current case. If the information is not available for this file, please indicate that it is not available.

You may be asked to fill in information gaps that were left out of the ABIIS, and you will be asked about the client's known medical conditions, medications, substance use, and family situation. Finally, you will be asked about how difficult it is to provide services to this client and/or his or her family.

Please do not enter names, Saskatchewan Health numbers, contact information, or other personally identifiable information in this form.

[PAGE TELKEY]

Reference ID:

Each case has been assigned a Reference ID for use with this study. The Reference ID is different from the client's Saskatchewan Health number, ABIIS identifier, or other number used to identify clients. Each Reference ID is unique. If you are unsure about the Reference ID for the client case you are entering, please contact your Outreach Team Manager for the correct Reference ID to use.

Please enter the Reference ID for this case.

Reference ID:

[PAGE SECTION A]

Section A: Demographics

These questions represent the client's demographic characteristics.

[PROGRAMMER NOTE: Please use the ABIIS field codes as variable identifiers for these variables. The ABIIS field codes are provided below each question. Do not call up questions in



this section unless there is no ABIIS entry for this client

If all variable identifiers are already provided, display this text: All demographic data for this case was included in the sample file.]

What is the client's:

[PAGE QA1 - GENDER]

Gender? 1. Male
 {Gender} 2. Female
 9. Not Known

[PAGE QA2 - AGE]

Date of Birth (mm/dd/yyyy)?
 {Birthdate (mm/dd/yyyy)} 9. Not Known

[PAGE QA3 - ORIGIN]

Province/Country of Origin?
 {Prov/Org} 9. Not Known

[PAGE QA4 – ETHNICITY]

Ethnicity? 1. Status Indian
 {Ethnicity} 2. Non-Status Indian
 3. Metis
 4. Non-Aboriginal
 9. Not Known

[PAGE QA5 – EMPLOYMENT]

Current Employment? 1. Full Time Competitive
 {Current Employment} 2. Part Time Competitive
 3. Self-Employed
 4. Seasonal Employment
 5. Supported Employment
 6. Transitional Employment
 7. Volunteer Work
 8. Homemaker
 9. Student
 10. Retired



11. Sheltered
12. Unemployed
13. Currently Medically Restricted
14. Unemployable
15. Not Applicable
16. Not Known

[PAGE QA6 – EDUCATION]

- | | |
|--|---|
| Highest level of education completed? {Education Level} | <ol style="list-style-type: none"> 1. None 2. Preschool/Kindergarten 3. Elementary School (Grades 1-8) 4. Secondary School (Grades 9-12) 5. Post-Secondary School (University, technical school, etc.) 6. Not Known |
|--|---|

[PAGE QA7 – LIVING]

- | | |
|---|--|
| Current living situation? {Living Situation} | <ol style="list-style-type: none"> 1. Approved Home 2. Correctional Centre 3. Group Home 4. Hospital Resident 5. Long Term Care Facility 6. No Fixed Address 7. Personal Care Home 8. Child (under 18) no extra support 9. Child (under 18) requiring extra support 10. Independent in home or family home 11. Independent with difficulty 12. Supported with limited assistance (less than 8 hours/day) 13. Supported requiring assistance (greater than 8 hours/day) 14. Supervised 15. Not Known |
|---|--|

[PAGE QA8 – REGION]

- | | |
|--|--|
| Home health region? {Home Health Region } | <ol style="list-style-type: none"> 1. Athabasca Health Authority 2. Cypress Health Region 3. Five Hills Health Region 4. Heartland Health Region 5. Keewatin Yatthé Health Region 6. Kelsey Trail Health Region 7. Mamawetan Churchill River Health Region 8. Prairie North Health Region 9. Prince Albert Parkland Health Region |
|--|--|



10. Regina Qu'Appelle Health Region
11. Saskatoon Health Region
12. Sun Country Health Region
13. Sunrise Health Region
14. None
15. Not Known

[PAGE QA9 – REFERRAL]

Referral source?

{From Referral Source }

1. Aboriginal Community
2. ABI Outreach Team
3. ABI Education and Prevention Coordinator
4. ABI Partnership Project Program
5. ABI Regional Coordinator
6. Acute Care Services
7. Addictions Services
8. Children's Rehabilitation
9. Client Self-Referrals
10. Cognitive Disability Strategy
11. Community Services
12. Day Program
13. Justice/Legal/Police Services
14. Employability Assistance for People with Disabilities (EAPD)
15. Education System
16. Family
17. Funding Resource
18. Home Care
19. Long Term Care/Special Care Homes
20. Mental Health Services
21. Miscellaneous
22. Other Health Care Professionals
23. Other Health Services
24. Private Therapies
25. Recreation and Leisure Services
26. Rehabilitation Services
27. Residential Services
28. Saskatchewan Brain Injury Association (SBIA)
29. Saskatchewan Government Insurance
30. Social Services
31. Spiritual Services
32. Vocational/Avocational Services
33. Worker's Compensation Board
34. Not Known



[PAGE SECTION B]

Section B: Injury Data

This section asks about the client's injury. For this section, please provide answers for the client's most recent injury, if the client has sustained more than one ABI.

[PROGRAMMER NOTE: Please use the ABIIS field codes as variable identifiers for these variables. The ABIIS field codes are provided below each question. Do not call up questions in this section unless there is no ABIIS entry for this client]

[PAGE QB1 – GCS]

What was the client's Glasgow Coma Scale rating at the time of injury?

{GCS}

9. Not Known/Not Applicable

[PAGE QB2 – INJURY DATE]

What was the date of the client's injury? (Please provide in dd/mm/yyyy format)

{Date of Injury}

9. Not Known

[PAGE QB3 – INJURY AGE]

What was the client's age at the time of his or her injury?

{Age at Time of Injury}

Is that in:

{Age Type}

1. Years
2. Months
3. Age at Injury Not Known



[PAGE QB4 – CAUSE]

What was the cause of the client's injury?

- {Cause of Injury}
1. Aneurysm
 2. Anoxia
 3. Bicycle (not including Motor Vehicle Collision – MVC)
 4. Blow to head (assault)
 5. Blow to head (driving accident)
 6. Blow to head (not assault)
 7. Blow to head (sports related)
 8. Encephalitis/Meningitis
 9. Fall
 10. Motorcycle (passenger)
 11. MVC (bicycle)
 12. MVC (driver or passenger)
 13. MVC (pedestrian)
 14. Other (not Traumatic Brain Injury, i.e. substance abuse, dehydration, lupus, seizures, etc.)
 15. Penetrating (missile wounds)
 16. Shaken Baby Syndrome
 17. Snowmobile Crash
 18. Stroke
 19. Traumatic Brain Injury (including electric shock or unidentified)
 20. Tumour
 21. Not Known

[PAGE SECTION C]

[PROGRAMMER NOTE: Please call up all questions in this section.]

Section C: Non-ABIIS Data

This section asks several questions about the client which are not recorded in the ABIIS database. You may need the client's file in order to answer these questions.

[PAGE QC1 – OLDCONDITIONS1]

Did the client suffer from any pre-existing medical conditions or mental illnesses *prior* to sustaining an ABI?

1. Yes [CONTINUE TO NEXT QUESTION]
2. No [SKIP TO PAGE QC2]
3. Not Known [SKIP TO PAGE QC2]



[PAGE QC1B – OLDCONDITIONS2]

Please list all known pre-existing medical conditions or mental illnesses suffered by the client *prior* to sustaining an ABI.

[PAGE QC2 – NEWCONDITIONS1]

Has the client suffer from any *new* medical conditions or mental illnesses *since* sustaining an ABI?

1. Yes [CONTINUE TO NEXT QUESTION]
2. No [SKIP TO PAGE QC3]
3. Not Known [SKIP TO PAGE QC3]

[PAGE QC2B – OLDCONDITIONS2]

Please list all known *new* medical conditions or mental illnesses suffered by the client *since* sustaining an ABI.

[PAGE QC3 – OLDMEDS1]

Was the client on any prescription medications *prior* to sustaining an ABI?

1. Yes [CONTINUE TO NEXT QUESTION]
2. No [SKIP TO PAGE QC4]
3. Not Known [SKIP TO PAGE QC4]

[PAGE QC3B – OLDMEDS2]

Please list all prescription medications known to be used by the client *at the time of injury*.



[PAGE QC4 – NEWMEDS1]

Is the client *currently* on any prescription medications?

1. Yes [CONTINUE TO NEXT QUESTION]
2. No [SKIP TO PAGE QC5]
3. Not Known [SKIP TO PAGE QC5]

[PAGE QC4B – NEWMEDS2]

Please list all prescription medications known to be used by the client *currently*.

[PAGE QC5 – OLDDRUGS1]

Was the client known to excessively use or abuse substances (legal or illegal) *prior* to sustaining an ABI?

1. Yes [CONTINUE TO NEXT QUESTION]
2. No [SKIP TO PAGE QC6]
3. Not Known [SKIP TO PAGE QC6]

[PAGE QC5B – OLDDRUGS2]

Which substances was the client known to use excessively or abuse *prior* to sustaining an ABI?

1. Alcohol
2. Marijuana
3. Cocaine/Crack
4. Heroin/Opiates
5. Ecstasy/MDMA
6. Other illegal drugs (specify): _____
7. Non-prescription (OTC) medications (specify): _____
8. Prescription medications (specify): _____
9. Other substance (specify): _____

[PAGE QC5C – OLDDRUGS3]

Was this substance use considered to be the cause of the client's ABI?



1. Yes
2. No
3. Not Known

[PAGE QC6 – NEWDRUGS1]

Has the client been known to excessively use or abuse substances (legal or illegal) *since* sustaining an ABI?

1. Yes [CONTINUE TO NEXT QUESTION]
2. No [SKIP TO PAGE QC7]
3. Not Known [SKIP TO PAGE QC7]

[PAGE QC6B – NEWDRUGS2]

Which substances is the client known to use excessively or abuse *since* to sustaining an ABI?

1. Alcohol
2. Marijuana
3. Cocaine/Crack
4. Heroin
5. Ecstasy/MDMA
6. Other illegal drugs (specify): _____
7. Non-prescription (OTC) medications (specify): _____
8. Prescription medications (specify): _____
9. Other substance (specify): _____

[PAGE QC7 – LOCATION]

Which best describes the client's location?

1. In a remote rural area more than two hours from an urban centre
2. In a rural area within two hours of an urban centre
3. In an urban centre
4. No Response

[PAGE QC8 – FAMILYYN]

Is the client currently in contact with other family members (regardless of relationship or care status)?

1. Yes [CONTINUE TO NEXT QUESTION]
2. No [CONTINUE TO NEXT SECTION]
3. Not Known [CONTINUE TO NEXT SECTION]



[PAGE QC9 – FAMCARE]

What is the role of family members in this client's ongoing care?

1. A parent or guardian is the client's primary caretaker
2. Another immediate relative (brother, sister, child) is the client's primary caretaker
3. A member of the client's extended family (grandparents, aunts, uncles, etc.) are the client's primary caretaker
4. Family members are not primary caretakers but provide care or assistance to this client in other ways
5. Family members are not involved in providing primary care for this client
6. This client does not require a primary caretaker
7. No Response

[PAGE QC10 – FAMRELS]

In your opinion, which of the following best characterizes the level of support this client's family has for the treatment or services the client receives through the ABI Partnership Program?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---------------------------------|---|---|---|-------------------------------|---|---|---|---|-----------------------------|
| Family is not at all supportive | | | | Family is somewhat supportive | | | | | Family is highly supportive |

98. Not Known [CONTINUE TO NEXT SECTION]

99. No Response [CONTINUE TO NEXT SECTION]

[PAGE SECTION D]

[PROGRAMMER NOTE: Please call up all questions in this section.]

Section D: Difficult to Serve Clients

This section asks about whether the client is difficult to serve. Difficult to serve can mean a number of things. It can mean that the client:

- Is non-compliant or resistant to services, or treatments;
- Has behaviours that make him or her difficult, dangerous, or excessively unpleasant to serve, and/or;
- Uses large amounts of service or treatment time with little perceived improvement or benefit.

Please think of all the ways a client may be difficult to serve. We will also be asking about whether the client's family is difficult to serve.

[PAGE QD1 – DTSYN]

Would you consider this client difficult to serve?



1. Yes [CONTINUE TO PAGE QD2]
2. No [CONTINUE TO PAGE QD3]

[PAGE QD2 – DTSSCALE]

On a scale of one to 10, where one represents a client who is only minimally difficult to serve, five represents a client that is moderately difficult to serve, and 10 represents a client who is extremely difficult to serve, how difficult to serve would you consider this client?

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|----|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---|---|---|---|---|---|---|---|---|----|

99. No Response

[PAGE QD3 - DTSFAMYN]

[PROGRAMMER NOTE: Ask only if YES to QC8]

Is the client's family difficult to serve, or does the client's family hinder service efforts in any way?

1. Yes [CONTINUE TO PAGE QD4]
2. No [CONTINUE TO END]
3. Unknown [CONTINUE TO END]

[PAGE QD4 - DTSFAMHOW]

How is the client's family difficult to serve, or how does the client's family hinder service?

[PAGE QD5 - ACHGOALS]

What factors really helped you to achieve goals with this client?



[PAGE QD6 - HINGOALS]

What factors really hindered your ability to achieve goals with this client?

[PAGE QD7 - RETRO]

In retrospect, would you have done anything differently?

[END]

[CONTINUE TO GOAL ATTAINMENT TOOL]



[PAGE INTRO]

Introduction:

This next data collection tool is intended to capture the client's goal attainment outcomes. The client's profile is collected in an additional form. These forms will be linked with the database information containing the client's service history.

Instructions:

For each question in this case file review tool, please enter in the information from the paper copy of the goal attainment form for the current case. For each goal category, please indicate the *number of goals* that were:

- Achieved;
- Partially Achieved;
- Not Achieved; and
- Withdrawn.

If there are no goals for that particular field, enter a 0.

[PROGRAMMER NOTE: Please allow up to 3 digits for each goal]

[PAGE QA1 – COG]

Section A – Cognitive Goals:

Please indicate the number of *cognitive goals*:

[PROGRAMMER NOTE: Please use the following data entry format for each page, unless otherwise specified]

| | |
|--|----------------------|
| Achieved | <input type="text"/> |
| Partially Achieved | <input type="text"/> |
| Not Achieved | <input type="text"/> |
| Withdrawn | <input type="text"/> |
| ○ Not applicable/no goals in this category | |

[PAGE QA2 – MEM]

Please indicate the number of *memory goals*:



[PAGE QA3 – ATN]

Please indicate the number of *attention/concentration goals*:

[PAGE QB1 – FUNC]

Section B – Functional Independence Goals:

Please indicate the number of *functional independence goals*:

[PAGE QB2 – TRANS]

Please indicate the number of *transportation goals*:

[PAGE QB3 – MONEY]

Please indicate the number of *handling money goals*:

[PAGE QB4 – NUTR]

Please indicate the number of *nutrition/meal preparation goals*:

[PAGE QB5 – DRESS]

Please indicate the number of *dressing/grooming/hygiene goals*:

[PAGE QB6– TIME]

Please indicate the number of *time/fatigue management goals*:

[PAGE QB7 – HOME]

Please indicate the number of *home management goals*:

[PAGE QB8 – EAT]

Please indicate the number of *eating skills goals*:

[PAGE QB9 – PHYS]



Please indicate the number of *physical goals*:

[PAGE QB10 – HOUSING]

Please indicate the number of *housing goals*:

[PAGE QB11 – FIOOTHER]

Please indicate the number of *other functional independence goals*:

(Specify total): _____

Achieved

Partially Achieved

Not Achieved

Withdrawn

- Not applicable/no goals in this category

[PAGE QC1 – PSYCH]

Section C – Psycho-Social/Emotional Goals:

Please indicate the number of *psycho-social/emotional goals*:

[PAGE QC2 – ANGER]

Please indicate the number of *anger management goals*:

[PAGE QC3 – STRESS]

Please indicate the number of *stress management goals*:

[PAGE QC4 – BEHAV]

Please indicate the number of *behaviour management goals*:

[PAGE QC5 – PAIN]



Please indicate the number of *pain management goals*:

[PAGE QC6 – MOOD]

Please indicate the number of *mood management goals*:

[PAGE QC7 – RELS]

Please indicate the number of *relationships with others goals*:

[PAGE QC8 – SEXUALITY]

Please indicate the number of *sexuality goals*:

[PAGE QC9 – COMMU]

Please indicate the number of *communication goals*:

[PAGE QC10 – RECOVERY]

Please indicate the number of *recovery activity goals*:

[PAGE QC11 – PEOTHER]

Please indicate the number of *other psycho-social/emotional goals*:

(Specify total): _____

Achieved

Partially Achieved

Not Achieved

Withdrawn

- Not applicable/no goals in this category

[PAGE QD1 – COMMA]



Section D – Community Activity Goals:

Please indicate the number of *community activity goals*:

[PAGE QD2 – EMPL]

Please indicate the number of *employment goals*:

[PAGE QD3 – EDU]

Please indicate the number of *education goals*:

[PAGE QD4 – LEIS]

Please indicate the number of *leisure activity goals*:

[PAGE QD5 – VOLUN]

Please indicate the number of *volunteering goals*:

[PAGE QD6 – COMMINV]

Please indicate the number of *community involvement/groups goals*:

[PAGE QD7 – SPIRIT]

Please indicate the number of *spirituality goals*:

[PAGE QD9 – CAOTHER]

Please indicate the number of *other community activity goals*:

(Specify total): _____

Achieved

Partially Achieved

Not Achieved

Withdrawn

- Not applicable/no goals in this category



[PAGE QE1 – OGOALS]

Section E – Other Goals:

Please indicate the number of *other goals*:

(Specify total): _____

Achieved

Partially Achieved

Not Achieved

Withdrawn

- Not applicable/no goals in this category

[PAGE QE2 – OADVO]

Please indicate the number of *advocacy goals*:

[PAGE QE3 – OUNDER]

Please indicate the number of *understanding ABI goals*:

[PAGE QE4 – OCRISIS]

Please indicate the number of *crisis intervention/secondary prevention goals*:

[PAGE QE5 – ONAVMED]

Please indicate the number of *medical system navigation goals*:

[PAGE QE6 – ONAVFIN]

Please indicate the number of *financial system navigation goals*:

[PAGE QG1 – TOTALS]

Section G – Goal Totals:



Please indicate the totals from the goal attainment sheet:

| | |
|---------------------------------|----------------------|
| Total Goals: | <input type="text"/> |
| Total Goals Achieved: | <input type="text"/> |
| Total Goals Partially Achieved: | <input type="text"/> |
| Total Goals Not Achieved: | <input type="text"/> |
| Total Goal Withdrawn: | <input type="text"/> |
| % Achieved: | <input type="text"/> |

[PAGE END]

**Those are all the questions for this client.
To proceed to the next client, hit "continue".
Thank you.**