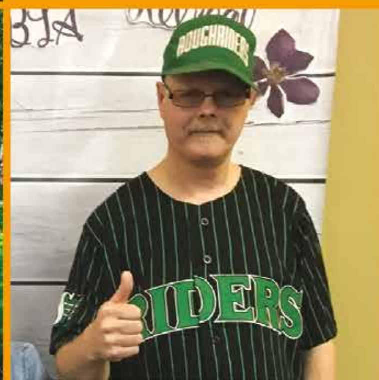
Meeting the Housing Needs of Brain Injury Survivors

Needs Assessment and Solutions



A Publication of the

Saskatchewan Brain Injury Association

MISSION STATEMENT

The Saskatchewan Brain Injury Association strives to prevent brain injuries and to improve the lives of brain injury survivors and their families.

VISION STATEMENT

Brain injuries are reduced and there exists a provincial continuum of support informed by those with lived experience that encompasses all those affected by brain injury.

VALUES

We value and believe in:

- the dignity and self worth of the individual with an acquired brain injury; their contribution and that of family members is valued
- sharing the lived experience; survivors and their families educating others about living with an acquired brain injury
- promoting connections for support, education and understanding
- the value of group and individual support for individuals and families coping with effects of a brain injury; support and respite for families
- partnerships with other community organizations/governments to create and enhance services and programs for people with acquired brain injury
- asset based approaches

GLOSSARY OF TERMS:

ABI - Acquired Brain Injury
CPP - Canada Pension Plan
PCH - Personal Care Homes
SACL - Inclusion Saskatchewan
SAID - Saskatchewan Assured Income for Disability
SBIA - Saskatchewan Brain Injury Association
SGI - Saskatchewan Government Insurance
WCB - Workers' Compensation Board

PHOTOS

Our photos show SBIA members who are not only brain injury survivors but also those who support them. Photos were taken at SBIA events.

Date of publication: June 2020

FOREWORD

Every 3 minutes, someone in Canada acquires a brain injury.[1]

The physical, social, emotional and economic consequences of brain injury – which last a lifetime – can be devastating not only to the survivors themselves, but also to their family and friends.

Having worked with brain injury survivors and their families in Saskatchewan for more than a decade, I have learned that their greatest unmet need is appropriate housing. This housing gap costs. It unfairly burdens families, often leading to breakdown. It leaves young people warehoused in geriatric nursing homes. It contributes to homelessness. Too often, acute care hospitals and prisons fill the gap, becoming the most expensive, yet regressive, housing options for brain injury survivors. Without supportive housing, the recovery of brain injury survivors is impaired.

WHO ARE WE?

The Saskatchewan Brain Injury Association (SBIA) was established in 1985 by the families of brain injury survivors. Since then, SBIA has been dedicated to preventing brain injuries and improving the quality of life for survivors of Acquired Brain Injury (ABI), their families and caregivers. To ensure that they have access to resources regardless of their location, SBIA offers information through a provincial toll-free phone line, website and social media. It also encourages the formation of local support chapters. Throughout the province, SBIA organizes a variety of programs and retreats, all of which create a highly valued community for ABI survivors and their loved ones. One frequent comment at SBIA programs is, "People here get it. I don't have to explain myself." In addition to programs, SBIA strives to increase awareness about brain injury and its prevention in the wider community. SBIA programs and services are provided free of charge.

THE GOAL OF THIS REPORT

This report was created to show the urgent need for ABI-specific, long-term residential options in Saskatchewan and to make recommendations for meeting that need. This report reflects the experience of SBIA members and is not meant to be a formal, academic study.

Within these pages, we:

- outline the impact of ABI on survivors and their caregivers
- identify the barriers to finding appropriate housing with support services
- explain how the creation of long-term provincial housing options would improve the quality of life for many affected Saskatchewan residents.

With your support, we can truly make a difference in the lives of brain injury survivors and those who care for them.

Sincerely,

Glenda James
Executive Director,
Saskatchewan Brain
Injury Association

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SECTION 1.0

EXECUTIVE SUMMARY

THE PROBLEM

WHY IT MATTERS

It is Government's "vision to improve disability programs and services to meet Government's goal of making Saskatchewan the best place in Canada to live for persons with disabilities".[2] The needs of brain injury survivors are often overlooked even though more than 1.5 million people in Canada are experiencing disability as a result of their injury[1].

Without appropriate support, individuals with Acquired Brain Injuries (ABI) are not able to continue to recover or live independently. When housed in inappropriate facilities, survivors can also lose the skills they have fought to regain after injury. Overall, their quality of life is diminished.

THE SOLUTION

MULTI-LEVEL SUPPORT STRUCTURE

SECTION 2.0

ACQUIRED BRAIN INJURY:

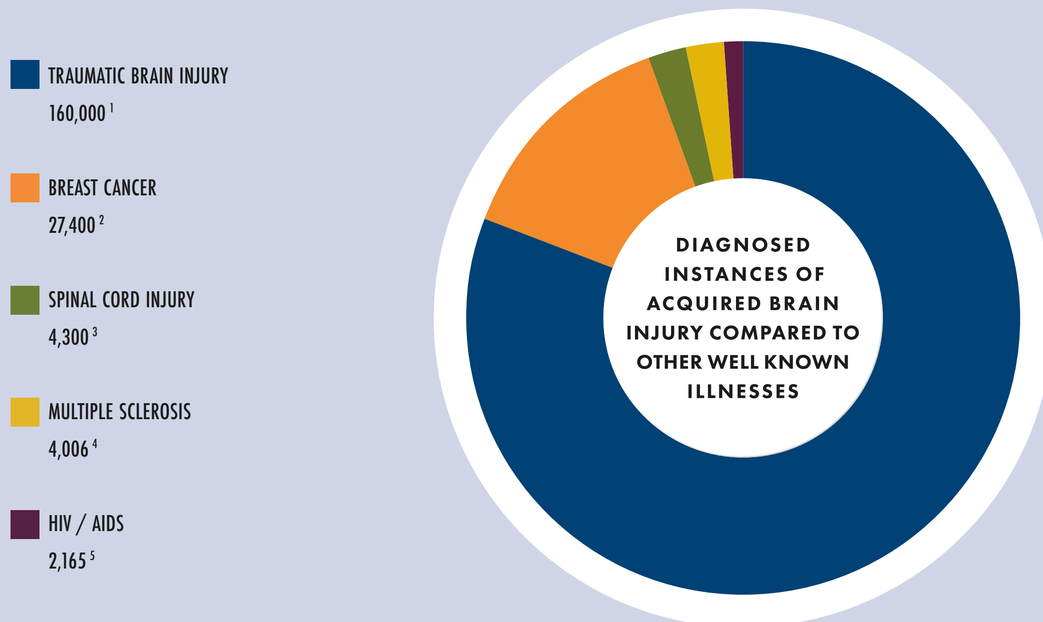
WHAT YOU NEED TO KNOW

SASKATCHEWAN
Rush
LACROSSE CLUB
BRAIN BOOGIE
Columbia
Canada

WHAT IS ABI?

Acquired Brain Injury (ABI) refers to a sudden impact on brain function that occurs sometime after birth, which interferes with the brain's ability to perform the way it normally does. The causes of brain injury vary. Falls, motor vehicle accidents, violent trauma, substance abuse, illness and oxygen deprivation are common causes. ABI affects every level of society in greater numbers than is commonly realized and, because of the brain's crucial role in controlling body functions and behaviour, the results of a brain injury are diverse and unpredictable. Common negative effects that brain injury has on cognition, mobility, emotional stability, and social interactions are usually permanent, and life-altering.

ESTIMATED NUMBER OF NEW DIAGNOSES EACH YEAR IN CANADA



[1] *Brain Injury Canada. (n.d.). Acquired Brain Injury (ABI) - The Basics.*

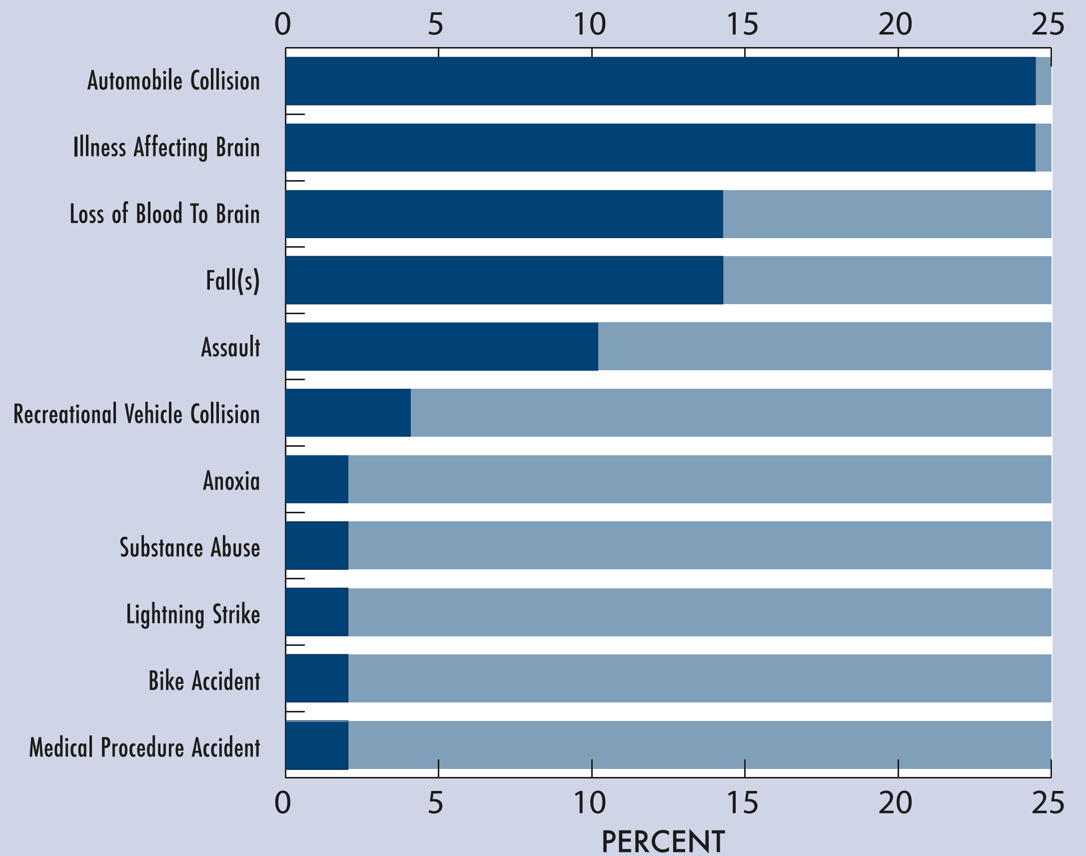
[2] *Canadian Cancer Society. (2020). Breast Cancer Statistics.*

[3] *Praxis Spinal Cord Institute. (2019). Understanding SCI.*

[4] *MS Society. (2018). PHAC releases incidence and prevalence rates of Multiple Sclerosis in Canada.*

[5] *CATIE - Canadian AIDS Treatment Information Exchange. (2016). The Epidemiology of HIV in Canada.*

CAUSES OF INJURY AMONG SBIA SURVEY PARTICIPANTS



Please Note:
The total on this graph exceeds the sample size because some individuals sustained more than one brain injury. This graph accounts for all brain injuries sustained throughout the lifetime.

Right now, there are more than 1.5 million Canadians living with brain injuries and 160,000 more are sustained each year.[1]

ABI: THE SILENT EPIDEMIC

Many people are surprised to learn that ABI occurs more frequently than many higher profile medical conditions; in fact, it is diagnosed more often than spinal cord injury, HIV/AIDS, multiple sclerosis and breast cancer combined.[3]

Right now, there are more than 1.5 million Canadians living with brain injuries and 160,000 more are sustained each year. **In Saskatchewan alone, there are over 2,200 new cases each year.** [4]

Given these statistics, ABI clearly constitutes a major public health issue and, while acute care has advanced substantially in recent years, long-term care – including housing – remains a challenge. Improvements in trauma treatment mean that more people who sustain ABIs are surviving their initial injury and, while this is of course desirable, it also means the number of people living with the effects of ABI continues to grow. Far too many of these survivors lack access to appropriate housing and other essential long-term supports.

Despite its ubiquity and uniquely devastating effects, ABI struggles to gain proportional awareness amongst government agencies and the general public. Through various means, including publications like this report, SBIA seeks to increase awareness of the ABI epidemic and the urgent need for far more resources to deal with it.

BRAIN INJURY CAN HAPPEN TO ANYONE, ANYWHERE, ANYTIME.
Saskatchewan Brain Injury Association

THE EFFECTS OF A BRAIN INJURY CAN BE AS VARIED AND AS UNIQUE AS THE INDIVIDUALS THEMSELVES.
Saskatchewan Brain Injury Association

Every day, in Canada alone, over 400 people join the growing list of people who have sustained brain injuries.[1]

THE COMPLEXITY OF ABI

Anyone can sustain a brain injury or suddenly find themselves caring for a survivor. It can happen **anywhere** and at **anytime**. **ABI is one of the leading causes of death and disability globally.**[5]

The sheer numbers are staggering, but other aspects of ABI also contribute to making it one of the most complex public health crises worldwide. Foremost among these challenges is the fact that every brain injury manifests itself in different, and unpredictable, ways. Since our brains control every aspect of our being – physical, mental, and emotional – the effects of a brain injury can drastically alter any area of a person's life. Reduced mobility and cognitive function are common results, but so are profound changes to an individual's character and personality. Family members often find they are not only dealing with an injured loved one, but also with someone who suddenly seems like a different person in so many ways.

Each brain injury is unique. The wide range of symptoms and levels of severity makes treatment of ABI far more complex and challenging than that of other acquired medical conditions. Rehabilitation and care need to be specifically tailored to each ABI survivor and often involves alterations to nearly every aspect of the survivor's life – even the most mundane and personal aspects, such as eating or using the bathroom.

PHYSICAL CHANGES AFTER ABI	COGNITIVE EFFECTS OF ABI	BEHAVIOUR CHANGES AFTER ABI
Loss of mobility (walkers or wheelchairs)	Lack of concentration	Emotional distress
Headaches	Slowed processing	Low self-esteem
Fatigue	Slowed reaction times	Anxiety
Sleep disturbance	Memory impairments	Flat effects
Weakness	Slower retrieval of words	Depression
Numbness	Slower retrieval of information	Social isolation
Dizziness	Interference with learning	Irritability
Balance issues	Interference with social skills	Frustration
Sexual desire heightened or diminished	Confusion	Impulsivity
Involuntary movement	Disorientation	Lack of empathy
Loss of co-ordination	Compromised executive function	Emotional volatility
Muscles may atrophy	Loss of reading skills	Difficulty multi-tasking
Vision impairment	Comprehension impairments	Heightened distractibility
Hearing impairment	Disassociation between cause and effect	Initiative diminished
Speech and language impairment		Lack self-control

SECTION 3.0

WHAT SBIA MEMBERS SAY THEY NEED

Relationships
Sizes
All Kinds
Marissa
Friendships
Leanne

WHAT SBIA MEMBERS SAY THEY NEED

Over the course of several summers, beginning in 2012, SBIA hired senior university students to conduct surveys and interview SBIA members about their service and housing needs. We surveyed 40 brain injury survivors and 25 family caregivers in total. The findings are shown in charts throughout this report.

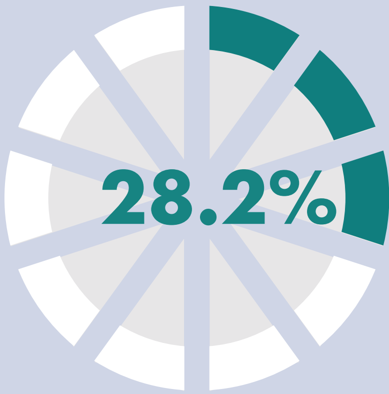
IN BOTH INTERVIEWS AND SURVEYS, THREE FACTORS WERE INDICATED:

1. Caregivers are unable to carry the full responsibility of providing care.
2. Survivors living independently still need caregivers to intervene frequently.
3. Social, emotional cognitive and physical rehabilitation are unavailable in personal care homes.

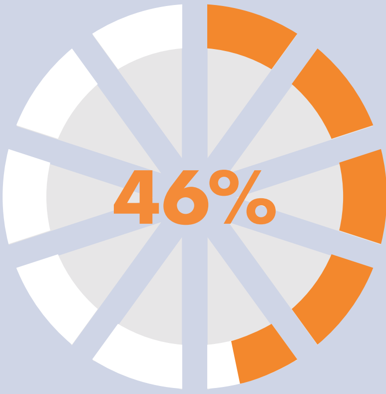
SURVIVORS' CURRENT LIVING SITUATION

Survivors and caregivers are generally content with the care received in primary care settings and for the first three years post-injury when they were involved with the medical system. However, once they were no longer eligible for these care options, they highlighted gaps in securing appropriate housing options – both transitional and long-term – as well as respite and on-going community support.

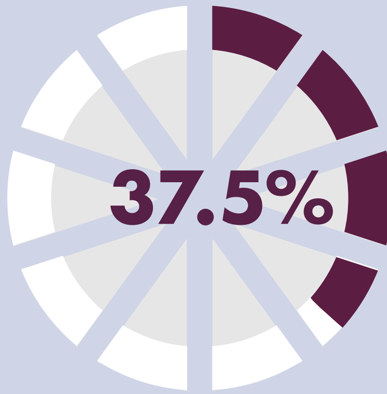
Only 28.2% of the survivors in our surveys live alone and, even though they live independently, their caregivers are still largely responsible for their well-being and frequently have to intervene. Although 46% of survivors were able to continue living with their families who provide care, 37.5% of caregivers feel that their loved ones are still not living in an environment that facilitates recovery. In addition, caregivers feel that they are unable to carry the full responsibility of providing care.



live alone



continue living with their families who provide care



of caregivers feel loved ones' living environment does not facilitate recovery

Some caregivers at the time of their interview, or in the recent past, had their loved ones living directly in the hospital for periods of weeks to months because of the lack of housing options. Their loved ones either did not fit the criteria of personal care homes or could not be given residence due to waitlists. Given the high costs of each Saskatchewan hospital bed, this is an economically unfeasible option in the face of an already climbing annual healthcare expense.

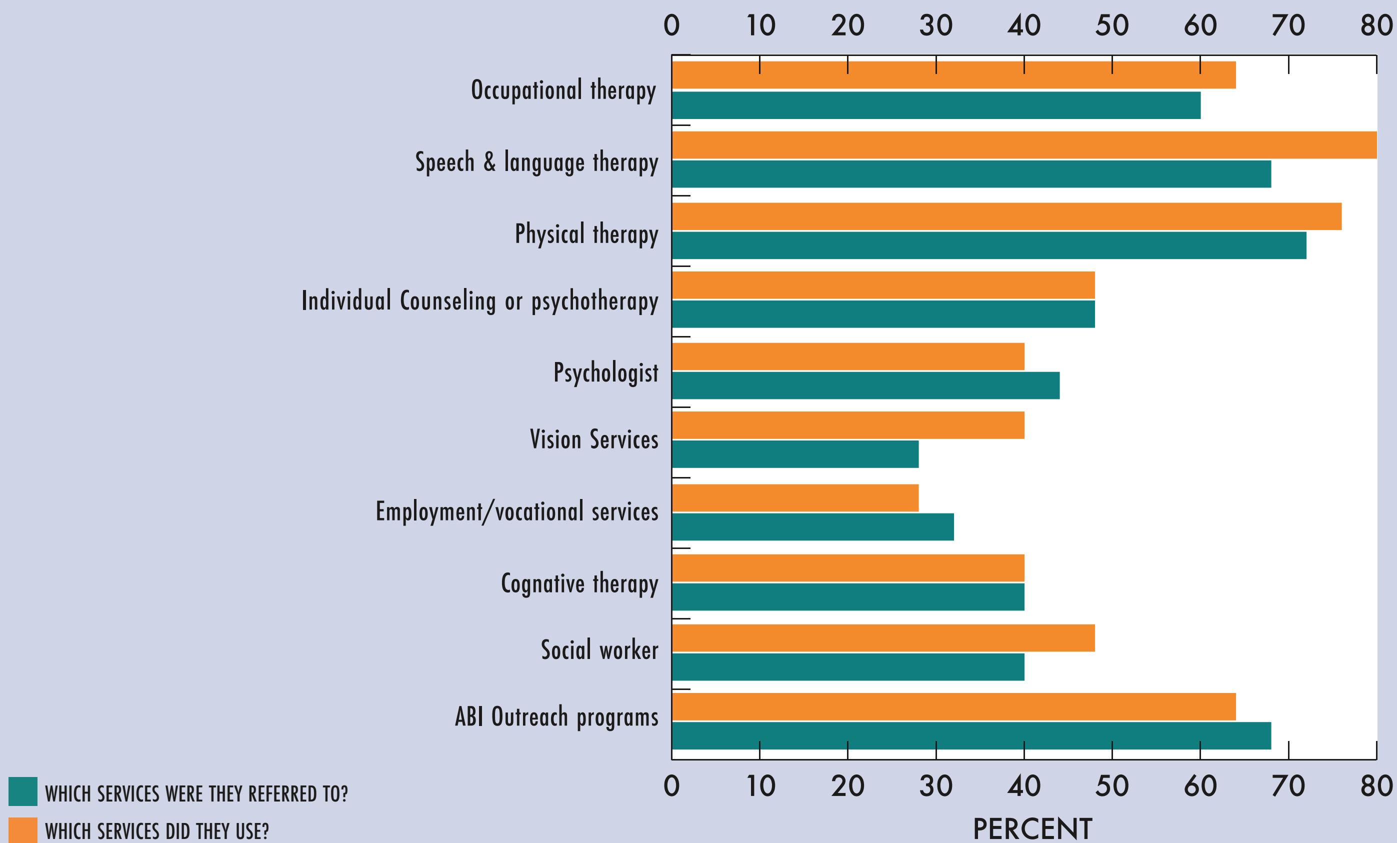
The main concern in regards to survivors living in personal care homes was that they do not receive the social, emotional and physical rehabilitation necessary to promote their recovery.

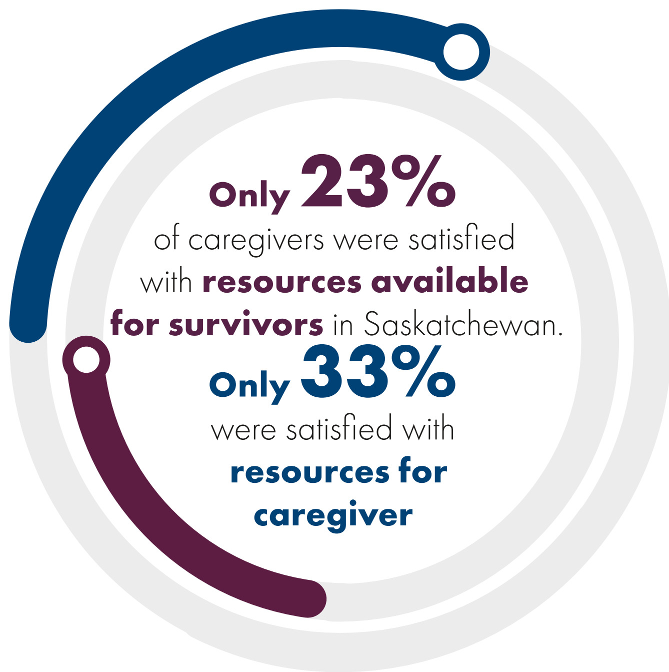
BETTER ACCESS TO ESSENTIAL SERVICES

Because brain injuries often occur during youth – 25 was the average age of injury according to SBIA's survey – the bulk of one's lifetime may be spent working to recover the functions that were lost.

When questioned about the current resources available to survivors, only half of the survivors and 23% of caregivers surveyed were satisfied. A mere 33% of caregivers were satisfied with resources on offer for caregivers.

THE AVERAGE AGE AT THE TIME OF INJURY AMONG THOSE SURVEYED WAS





While, upon leaving the medical system's care, most survivors receive referrals for further rehabilitation and services, SBIA's survey found that about 44% did not access those services. The reasons given were: the absence of appropriate service providers in their area, a lack of transportation to the service, insufficient finances to purchase services or misdiagnoses at the time of their initial medical examination. It is also important to note that 25% of survivors did not get a post-injury referral, which could indicate that knowledge of ABI services may not be widely available in all of the province.

SUPPORT FOR INDIVIDUAL CHALLENGES

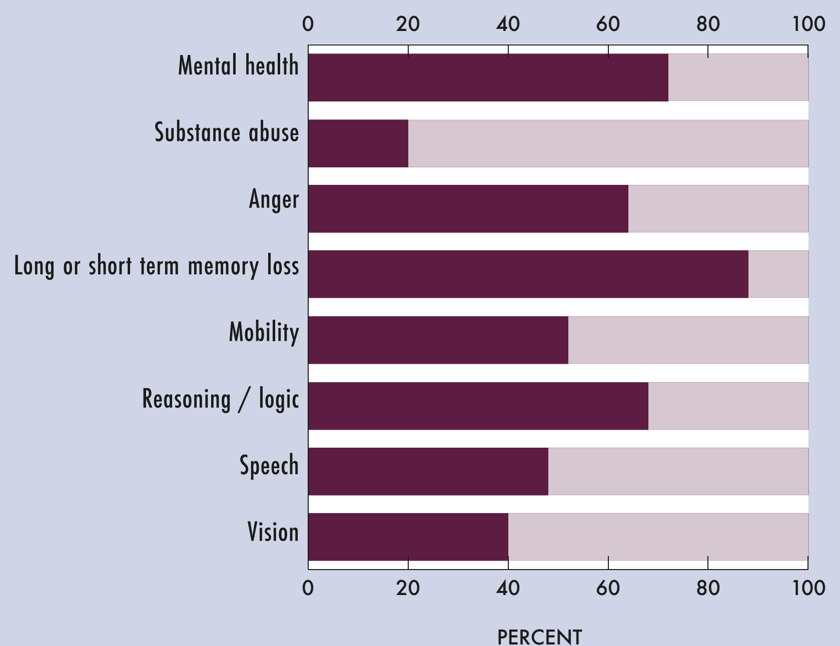
In their interviews, caregivers expressed a deep concern about finding programs and accommodation services that would aid their loved ones once they were unable to.

Every brain injury is different, but the most commonly experienced challenges among those surveyed were mobility-related (50%) leading to the need to use canes, walkers, wheelchairs and scooters. Many also indicated that memory, changes in sleep patterns, feeling frustration and fatigue were their main challenges.

The other effects survivors experienced varied greatly from person-to-person, but touched on all areas of their lives: physically, where some reported difficulties related to vision and bladder control; cognitively, as problem-solving, focus and learning new information proved challenging for some; emotionally, where controlling temper and mental illnesses like depression, for instance, were disclosed; and socially, where having conversations one-on-one or in a group were particularly difficult. This speaks to the wide variety of needs that must be addressed when considering housing options for ABI survivors.

WHAT CHALLENGES DOES YOUR LOVED ONE FACE?

Details from caregivers about loved ones' challenges

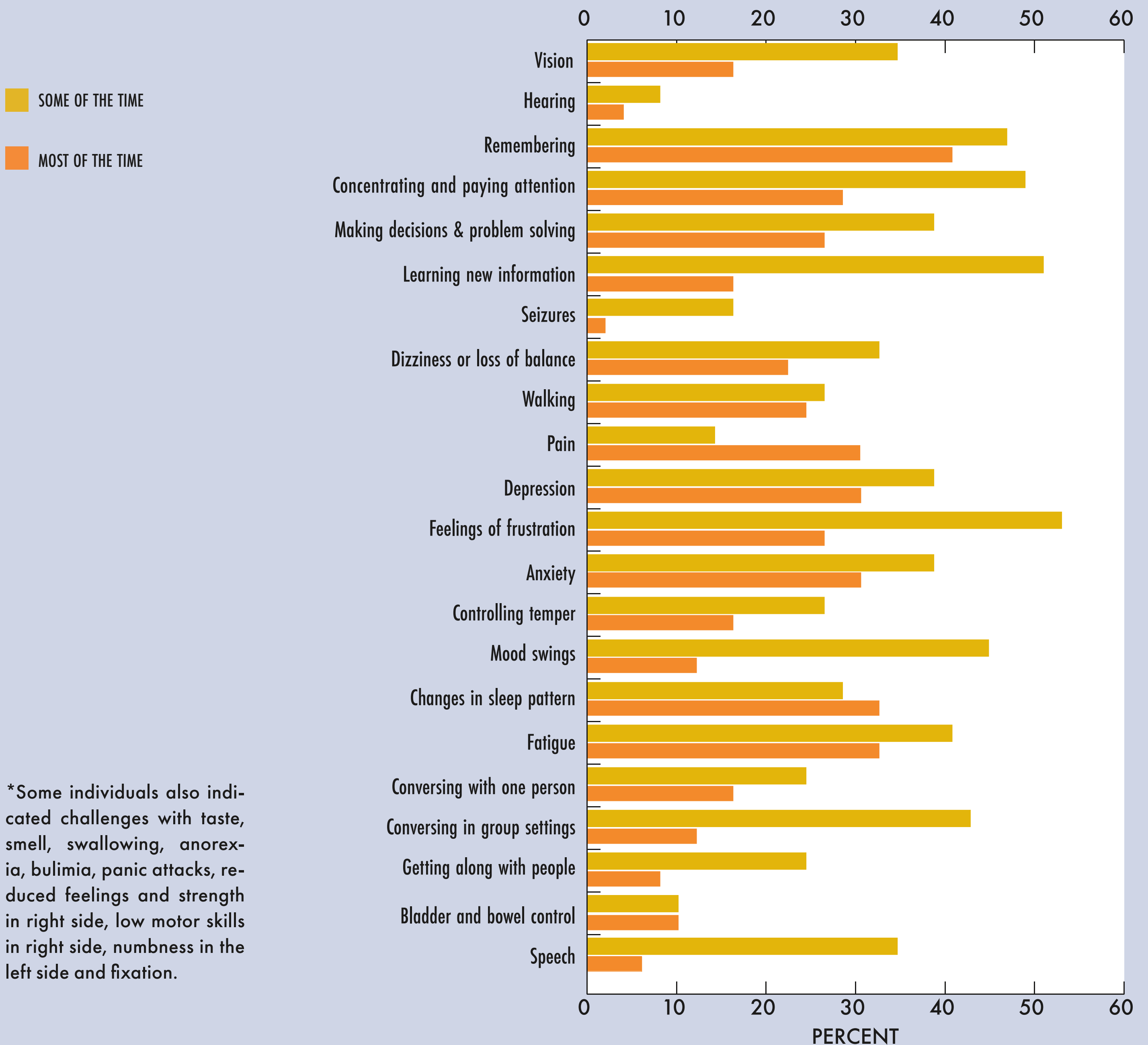


Additional challenges as indicated in the "Other" column:

- Fear (1)
- Sleeping (1)
- Obsessing (1)
- Living independently (1)
- Hearing (1)
- Inability to read/write (1)
- Behaves like a child (1)

According to those surveyed, assistance is also needed with daily activities, such as: getting dressed/grooming, housework, meal preparation, shopping, transportation and managing finances.

DETAILS FROM SURVIVORS ABOUT THE CHALLENGES THEY FACE



*Some individuals also indicated challenges with taste, smell, swallowing, anorexia, bulimia, panic attacks, reduced feelings and strength in right side, low motor skills in right side, numbness in the left side and fixation.

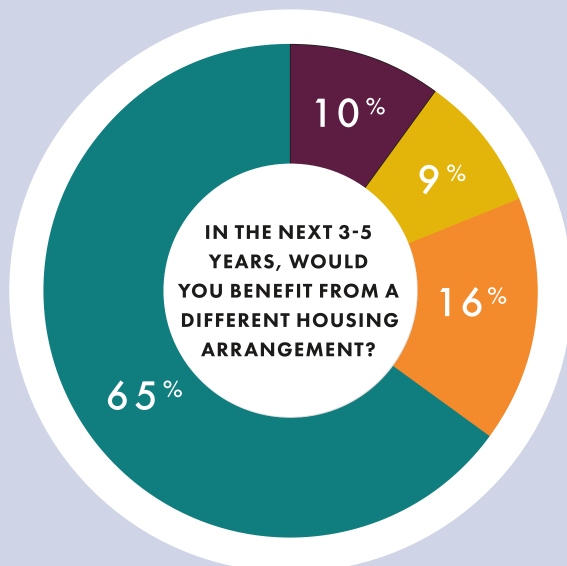
PERSONAL AND SOCIAL DEVELOPMENT OPPORTUNITIES

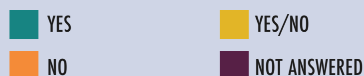
Making new friends and developing a social life were areas of greatest dissatisfaction among those surveyed. This was followed by speaking and expressing themselves, enjoying leisure activities and participating in activities in the community. Many also indicated that they wanted opportunities for work and further education.

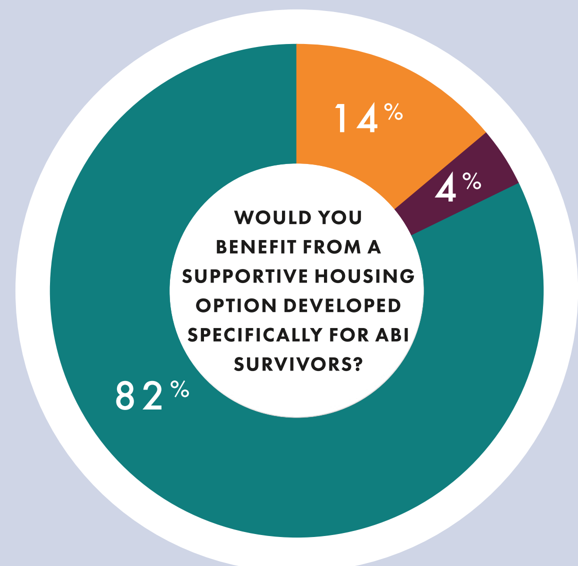
ABI-SPECIFIC ACCOMMODATIONS

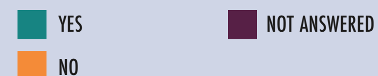
Two thirds of respondents expressed that they would benefit from a different housing arrangement than their current one within the next 3-5 years. When asked about whether they felt they would benefit from a specialized housing option tailored specifically to ABI, over 75% said 'Yes'. Those that answered 'No' tended to be survivors who had recovered enough to function at or close to the level they did pre-injury.

NEED FOR SUPPORTIVE HOUSING



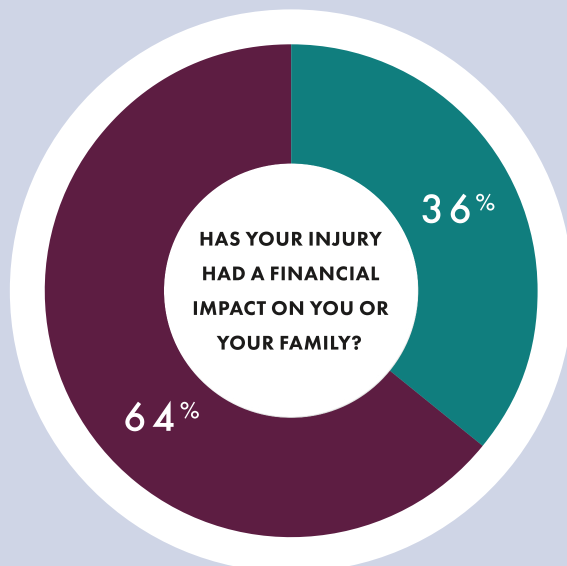


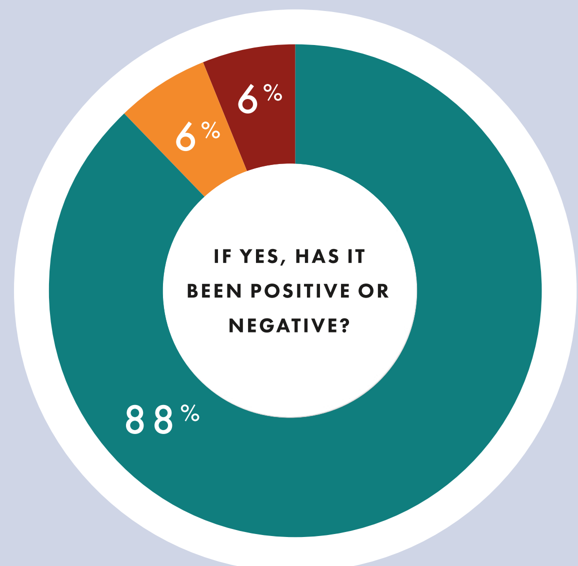




The need for specialized supportive housing was one of the largest concerns echoed in both caregiver and survivor data. It was mentioned in the majority of surveys from both populations, and in 100% of the interviews conducted with survivors and caregivers. In addition to concerns about finding qualified caregivers, social opportunities and transportation, the financial costs of housing were of great concern.

FINANCIAL IMPACT OF INJURY

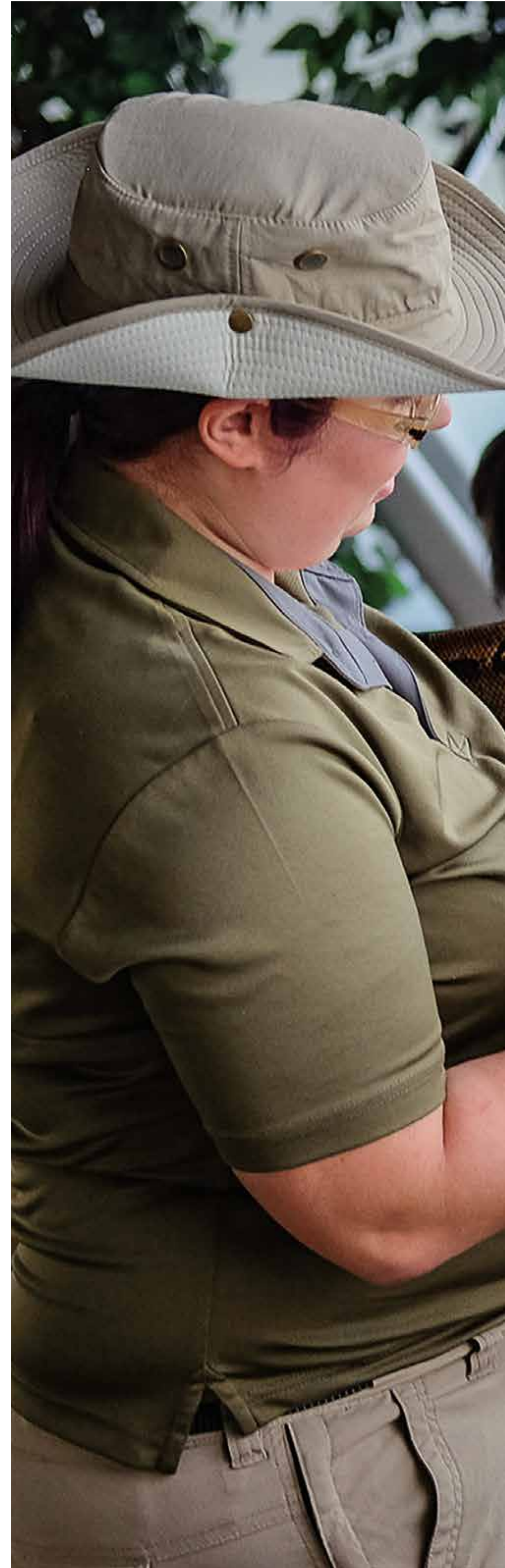




SECTION 4.0

SUPPORTIVE HOUSING:

AN INTRODUCTION



OUR PROJECT

The purpose of this project is to outline the needs of brain injury survivors in Saskatchewan and examine the housing options available for them.

Our method involved:

1. Preliminary research, focused on developing a comprehensive understanding of the prevalence of ABI and housing options currently available to ABI survivors in Saskatchewan and across Canada;
2. A thorough review of available literature on the subject; and
3. Analysis of two different surveys conducted in Saskatchewan: one focussing on ABI survivors, one on family caregivers.

Our research has proven, beyond a doubt, that long-term, ABI-specific housing is sorely lacking in Saskatchewan. What follows are our key findings in regards to the current state of housing for ABI survivors in our province.

SUPPORTIVE HOUSING: A DEFINITION

When we refer to "Supportive Housing" for ABI survivors, we mean housing that:

- Integrates long-term housing units for ABI survivors;
- Has on-site support services that are available to residents of the housing facility

In the definition of "Supportive Housing"

- "Long-term" means residents are not restricted by policy to occupancies of less than 90 days;
- "On-site support services" are physically offered in the building's offices or common areas, and include but are not limited to:
  - Personal care services;
  - Health and community support referrals;
  - Life skills and job readiness training;
  - Assistance with meal preparation and housekeeping;
  - Counselling and outreach services

"Housing unit" means residential sleeping accommodations where the resident:

- Controls access to the room or rooms the resident or resident's family sleeps in;
- Has access to private or shared bathroom facilities;
- Has access to private or shared cooking facilities. [6]

EXISTING SUPPORTIVE HOUSING FOR ABI SURVIVORS IN SASKATCHEWAN

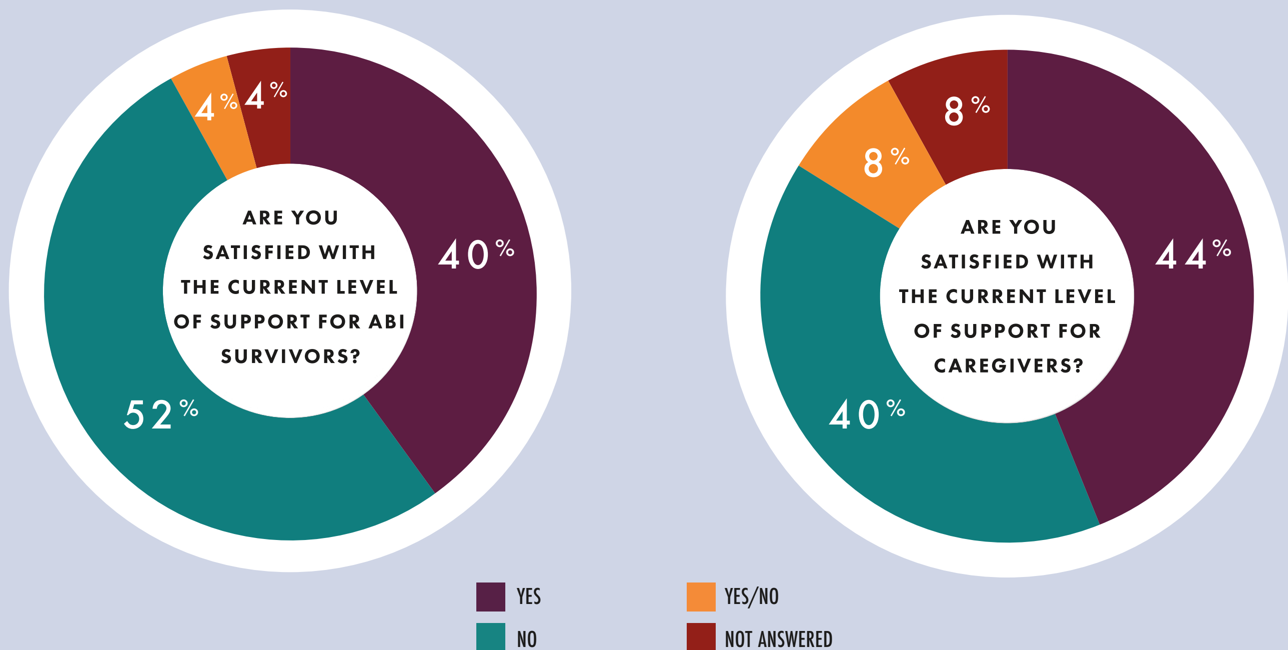
ABI housing is an issue across Canada, but especially in Saskatchewan. While some types of supportive housing exist in Saskatchewan, they lack the capacity to address the multifaceted complexity of long-term ABI care.

Proper ongoing ABI support involves:

- assistance with mobility and other physical problems;
- support for cognitive issues, such as memory deficits;
- management of emotional challenges; and
- guidance and support regarding social interaction.

In Saskatchewan, there are no long-term housing options that incorporate these services.

It should be noted that, although Phoenix Residential's PEARL Program in Regina does provide housing specifically for brain injury survivors, it is a limited option for only 10 people who can live independently. Further, it offers short-term, transitional housing, as residents can only stay for a maximum of one year [7]. More is needed.



Appropriate housing is the most important factor in a survivor's quality of life.

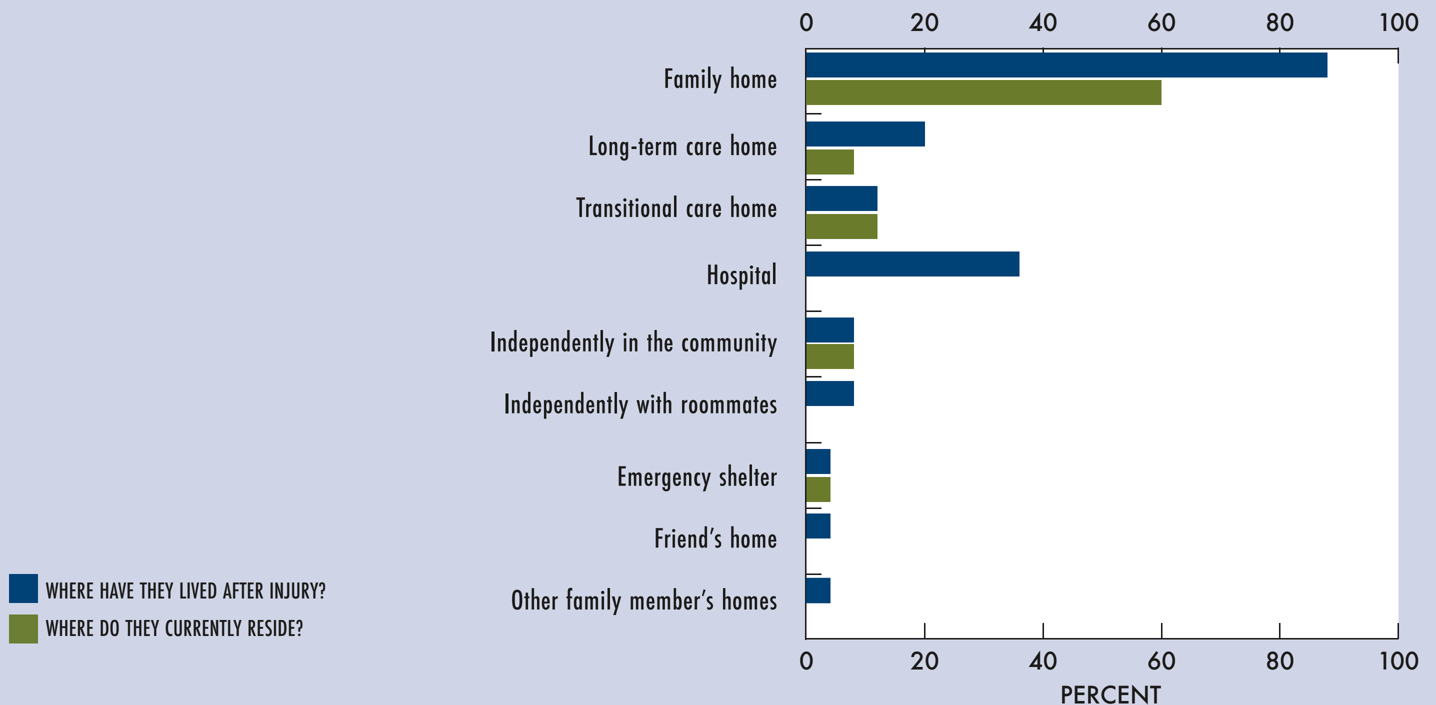
HOUSING REALITIES FOR SURVIVORS OF ABI

Several factors, including the age of the individual and the severity of the injury, determine the housing options available to ABI survivors in our province.

At present, the options are limited to survivors living:

- independently,
- independently with informal family support,
- independently with formal support (home care or private agency),
- in a transitional setting, or
- in an institutional setting.

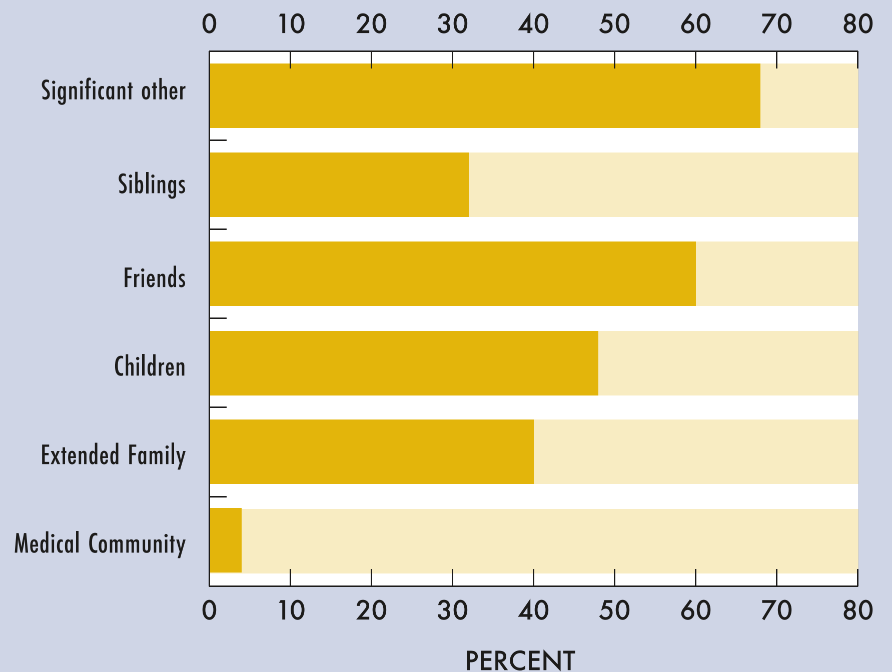
Current literature on the subject identifies the three most common housing realities for ABI survivors as living at home with informal family support; institutionalization in unsuitable facilities, primarily seniors' care homes; and homelessness. Following are details of the inadequacies of each of these situations:



1. LIVING AT HOME WITH INFORMAL FAMILY SUPPORT

At first, the option of ABI survivors living at home and relying on a parent, sibling, spouse, or other family member for support may seem like the best option, but it's often far from an ideal solution. Although family members are a crucial part of an ABI survivor's recovery and rehabilitation, they rarely have the specialized training required to provide proper day-to-day care and therapy. Burnout is common because the physical and emotional stress of being a caregiver, on top of the trauma of having a loved one who has been profoundly injured, can be a crushing mental weight. For those serving as both breadwinner and caregiver, it is overwhelming.

WHICH OF YOUR RELATIONSHIPS HAVE BEEN IMPACTED EMOTIONALLY AS A RESULT OF ABI?



Family members generally assume the responsibilities of primary caregiver out of love and a sense of duty. They may not be emotionally, physically, mentally, or financially prepared for the task. In most cases, the family is forced into the situation simply due to a lack of appropriate alternatives, which leads to additional stress, anxiety, depression, and worse. Although well-intentioned, the family caregiver scenario far too often results in reduced quality of life for everyone involved. As one SBIA member expressed, "This is the fast track to poverty."

2. INSTITUTIONALIZATION IN UNSUITABLE FACILITIES, PRIMARILY SENIORS' CARE HOMES

Seniors' care homes offer high-level personal care and support for daily needs, but these are deliberately designed for the elderly. As such, they are not a good fit for ABI survivors, especially those under 65. Superficially, the needs of many geriatric patients and ABI survivors may seem similar, but, in reality, they are substantially different, particularly in the support and therapy they require.

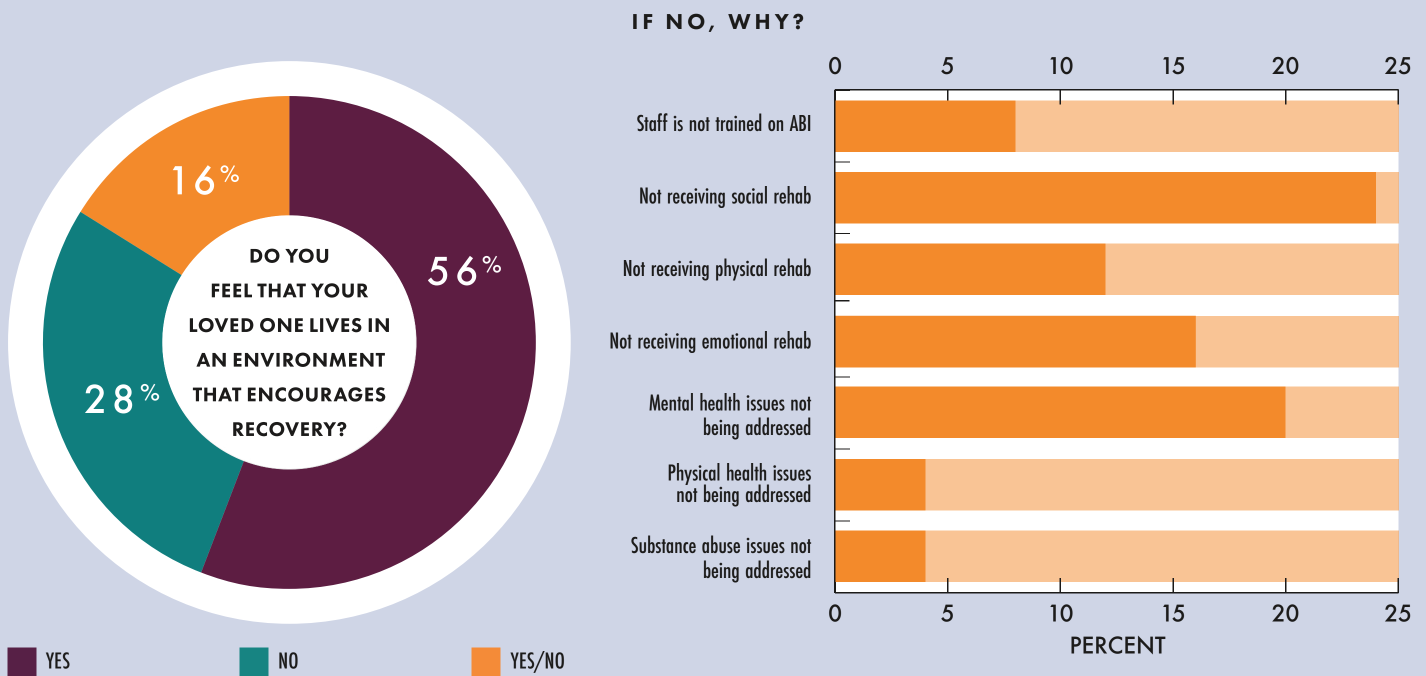
Younger people with brain injuries are not senior citizens, and are very aware of that fact. Such placements are very distressing for both the survivor and the family. Treating youth in facilities meant for the elderly is problematic. Negative effects of such a placement include a lack of ABI-specific therapy, an absence of age-appropriate activities and stimulation, social isolation from age peers, a dearth of privacy, and general difficulty living with frail and terminally ill seniors.

In stark terms, seniors' homes are meant to make inevitable deterioration and death manageable for the elderly. ABI survivors and their families should be able to expect therapies aimed at improvement or stabilization for what may be decades of life that they may have remaining. For this, and other reasons, ABI-survivors inappropriately housed in seniors' care facilities lose their independence, instead of regaining it.

> "Placement into aged care facilities is a direct result of the lack of appropriate living environments for ABI survivors."[8]

Personal Care Homes (PCH) are another common option that does not meet the needs of ABI survivors. SBIA found, through its research on PCH in Saskatchewan, that they are licensed and monitored by Saskatchewan Health, but they are privately owned and operated. Their funding requirements are frequently a barrier to access for many clients. As a result, many cannot accommodate brain injury survivors whose incomes are usually less than $1500 per month.

The nature of ABI also poses a barrier to PCH options. Problems with memory may cause issues in such a setting where there may be strict rules. Often there is a zero tolerance policy towards both drugs and alcohol but it is not uncommon for ABI survivors to forget them. In such scenarios, survivors lose their housing and attempts at finding alternatives are too often futile.



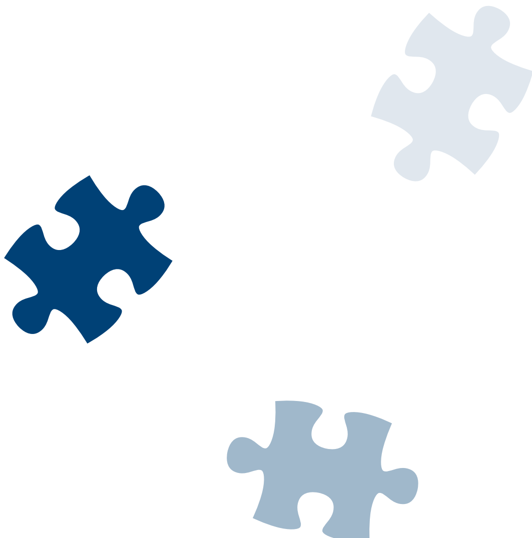
Additional responses included:

- Survivor needs to learn how to live on his own
- Other residents determine what survivor can and can't do based on her limitations
- Survivor lives on her own so there is no one to encourage/motivate her to do her physio
- Caregiver feels like they are burning out, worried that they will not longer be able to provide good care

3. HOMELESSNESS

Clearly the worst living situation for most people, including ABI survivors, is homelessness. Nevertheless, without dedicated, long-term, ABI-specific housing, it is far too often the direct result of a brain injury. The rising cost of housing in Saskatchewan has meant that many people are having trouble finding acceptable accommodations, and those with brain injury face even more obstacles to securing suitable, standard housing.

There have been recent cases where ABI survivors are forced to find short-term accommodation in emergency shelters because they have no living options available to them. Such environments are unacceptable options for survivors and introduce high risks to a population often living with mental health challenges.

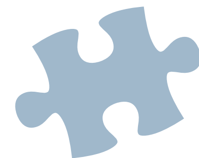


In 2020, a study published by the Lancet found that more than 50% of the homeless population studied had an acquired brain injury. [9]

> "Behaviour problems are often an indication of my inability to cope with a specific situation and not a mental health issue. I may be frustrated, in pain, overtired or there may be too much confusion or noise for my brain to filter."
>
> -SBIA member

THE SOLUTION: SUPPORTIVE HOUSING SPECIFIC TO ABI

ABI-specific housing facilities must include professional staff, specifically trained to understand and work with ABI. It would be beneficial to also have on-site staff who are trained in the four main areas of ABI rehabilitation: Physical Therapy, Emotional Therapy, Speech and Communication Therapy, and Cognitive Therapy.



CHALLENGES OF ABI THAT SPECIFICALLY IMPACT HOUSING

PHYSICAL CHANGES	EMOTIONAL CHALLENGES	COGNITIVE CHANGES	SPEECH & COMMUNICATION
Reduced mobility, paralysis and decreased balance require special modifications to housing structure and design. Rooms and hallways must be spacious to allow for wheelchair and walker access. Staff must be trained on proper lifting techniques and other physical assistance strategies. Appliances must be built at accessible heights to allow residents to independently utilize all house features.	Staff must be trained on managing emotional changes in ABI residents, for example, staff should be able to: • Recognize that irritability is a common effect of brain injury. Proper management would be centered around patience and understanding. • Manage anxiety and depression. • Help residents develop healthy coping strategies. • Support residents in managing their anger in an acceptable way.	Memory challenges can have a significant impact on the ABI living experience. For example, they may forget: • to turn the stove off • to pay the rent • when they last ate, leading to overconsumption Longer processing times can also influence the living experience • An ABI survivor may have to be told things multiple times before the point actually sinks in. A proper housing facility would anticipate such procedures for any unforseen issue that arise.	Speech and communication difficulties are different for every ABI survivor. Supportive housing should have the capacity to address a wide range of communication changes. For example: • If a resident has dysarthria, the facility should have a speech and language therapist on-hand to help rehabilitate the damaged area of the brain. • If a resident has lost their ability to speak staff should be trained on ASL (American Sign Language). They should be able to use ASL as well as teach it.

SECTION 5.0

A SOLUTION FOR SASKATCHEWAN

RATIONALE

We know that Saskatchewan is committed to serving people experiencing disability. Indeed, it is the government's aspiration "to improve disability programs and services to meet Government's goal of making Saskatchewan the best place in Canada to live for persons with disabilities" [2].

Survivors of ABI are often overlooked as a population that experiences disability because other groups, like those with congenital disability; mental illness; or age-related declines in cognitive and physical function, are more well-known. Nevertheless, ABI survivors, along with their caregivers and loved ones, experience disability as a result of the physical, cognitive and mental health effects of the injury.

As the 2015 Saskatchewan Disability Strategy points out, experience with disability is impacted significantly by "the interaction between their health condition and their physical and social environment" [2]. Therefore, by creating housing that meets the specific physical, therapeutic, and social needs of brain injury survivors, we can potentially minimize (or, in some cases, even eliminate) the disabilities that are experienced.

Rehabilitation continues for the rest of the ABI survivor's life, and our front-line experience and research confirms that appropriate supportive housing is the single most important factor in a survivor's life-long recovery process. Unfortunately, the need for supportive ABI housing far exceeds the available resources.

Our recommendations are underpinned by the results of our research, the principles outlined in the Saskatchewan Disability Strategy, and the Canadian Human Rights Act, which states that:

> "all individuals should have an opportunity equal with other individuals to make for themselves the lives that they are able and wish to have and to have their needs accommodated, consistent with their duties and obligations as members of society, without being hindered in or prevented from doing so by discriminatory practices based on race, national or ethnic origin, colour, religion, age, sex, sexual orientation, gender identity or expression, marital status, family status, genetic characteristics, disability..." [10]

VISION

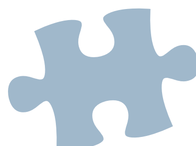
We envision supportive housing options where, above all, brain injury survivors are valued and contributing members of a community. The ideal supportive housing complex would incorporate elements seen in some supported housing or co-housing models in Canada and abroad, like:

- Brain Injury Clubhouse Alliance (International)
- Krempels Center (Portsmouth, NH, U.S.A.)
- Prairie Spruce Commons (Regina, SK)
- Cheshire Homes Society of British Columbia
- Traverse Independence (Kitchener, ON)
- Phoenix Residential Society (Regina, SK)
- Jasper House (Vancouver, BC)
- The Camphill Movement (International, Angus, ON)

Following are the key principles that future supportive housing should prioritize in order to best serve brain injury survivors, caregivers and their loved ones in Saskatchewan.

1. ENGAGED RESIDENTS

Brain injury survivors would be fully engaged in the design and operation of a complex, following the models offered by the Clubhouse Alliance, Krempels Center and Prairie Spruce Commons. Because residents contribute to the design of the community with their individual needs in mind, those living at Prairie Spruce Commons develop a deeper sense of belonging within their home [11]. Krempels Center encourages and incorporates input from survivors in all phases of program development [12]. In the Clubhouse, members work side by side with staff as peers, receiving the necessary support while maintaining ownership of service planning and the course of their rehabilitation [13]. They have meaningful work and responsibilities according to their preferences. By implementing these aspects, we could create a quality living complex that encourages integration, community, and a strong sense of belonging.



2. ABI-TRAINED STAFF

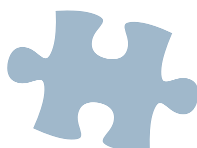
Proposed facilities would offer support services that are developed by individuals who understand the unique and diverse challenges of brain injury. Programs would be developed by professionals who are not only trained specifically on ABI, but are also experienced in the field. Like Krempels Centre, the organization would operate on the basis of meeting clients' individual needs and appropriately responding to any changes in needs that may arise over the lifetime [12].

3. PROMOTING GROWTH AND INDEPENDENCE

We recommend a continuum of services that support survivors' desire to maximize their own independence. One model is the system in place at Cheshire Homes Society of British Columbia (CHSBC). Each of its houses provide a particular level of support and as clients progress through each stage, they upgrade to a more independent living situation. The end goal is for ABI survivors to gain the skill sets necessary to participate in the broader community. Some people have moved through each of the stages and have gone on to continue education, attain part-time employment, and/or become mentors to other ABI survivors [14].

By operating on the belief that residents can continue their recovery by working through stages of independent living, CHSBC encourages residents to continue working towards bettering their quality of life [14].

Like Krempels Centre, the Clubhouse model provides a place where members participate in decisions about the programs and also contribute in their own unique ways to the clubhouse functions. It is a place for survivors to gather and learn together. Contributions to the operation of the complex may include helping with food preparation, cleaning, building and yard maintenance as they are able to and in partnership with others who have different skills[13].



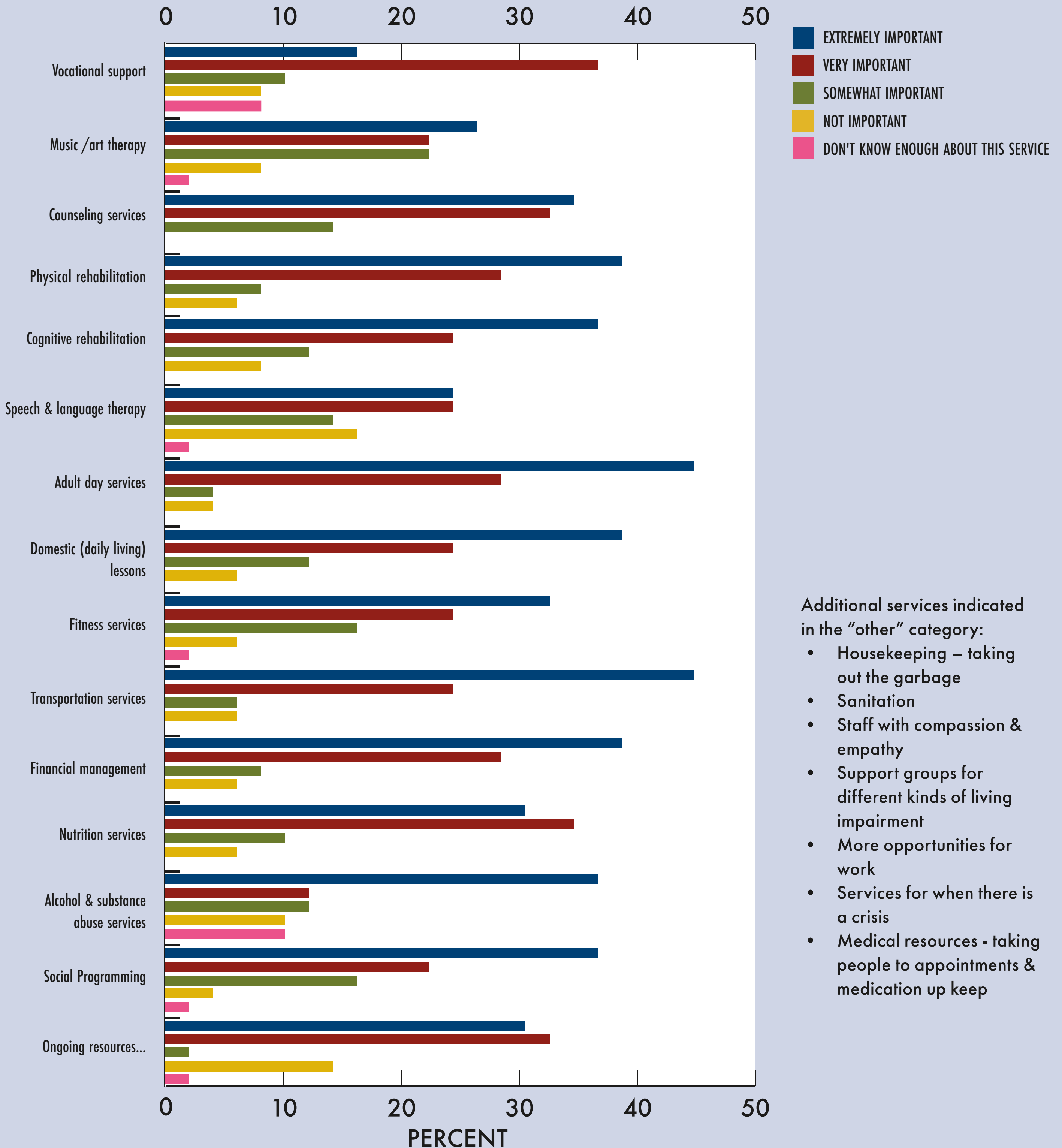
> "I would like to see housing options for those in rehab and for those who are stabilized - they can help and support each other."
>
> -SBIA member

4. FLEXIBLE SUPPORT STRUCTURE

Any future housing projects should incorporate flexibility in the support that is offered to ABI survivors. Traverse Independence's structure provides an excellent example of this as it runs multiple living programs for survivors of ABI that can be adapted to assist individuals with differing levels of function. They offer a "Bridging Hospital to Home" program, which offers strategic support, helping to ease the transition from hospital to community living; a 'Short-Term Placement' program, providing temporary placements in furnished apartments with 24-hour care; 'Transitional Living', which is similar to CHSBC's progression model discussed previously; and a group home, providing cognitive, emotional, and behavioral support [15]. This is a flexible and functional structure that better suits the complexity of the ABI experience[15].

Phoenix Residential Society's McEwen Manor in Regina offers well-designed bachelor apartments that allow for private, independent living. The main floor offers community spaces for lounging, socializing, cooking/eating together, as well as classroom spaces for programs. Caseworkers for the residents have on-site offices, which enable access to individual support and/or problem solving when situations arise[16].

IF YOU FEEL YOU WOULD BENEFIT FROM A SUPPORTIVE HOUSING OPTION, WHAT SERVICES WOULD YOU WANT TO INCLUDE?



Additional services indicated in the “other” category:

- Housekeeping – taking out the garbage
- Sanitation
- Staff with compassion & empathy
- Support groups for different kinds of living impairment
- More opportunities for work
- Services for when there is a crisis
- Medical resources - taking people to appointments & medication up keep

5. INTEGRATED REHABILITATION

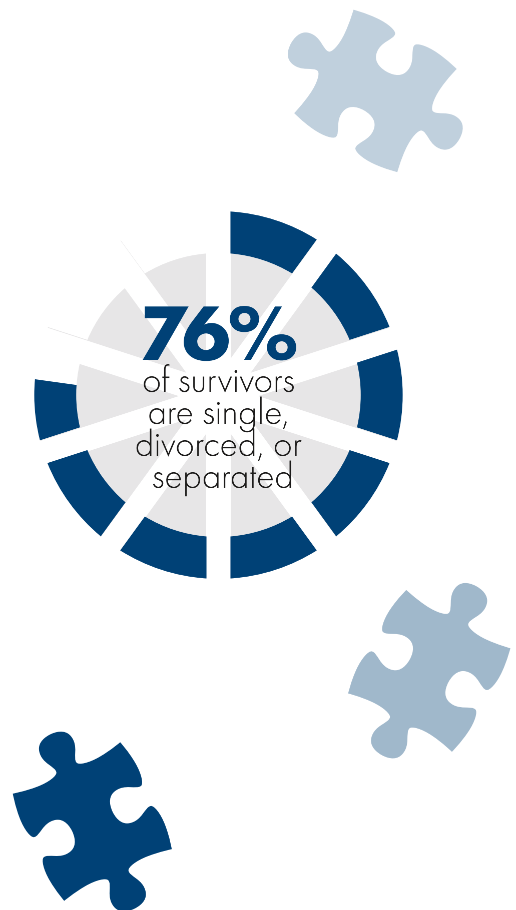
An ABI-specific supportive housing complex in Saskatchewan would incorporate rehabilitation options right into its structure, similar to The Jasper House. This would be comprised of an on-hand rehabilitation team offering occupational therapy, physiotherapy, nursing and personal care, which would enable residents to further their rehabilitation progress at home [17].

Daily living activity training, group therapy and recreation programming are necessary features that future housing projects should incorporate as well [17].

6. BALANCING PRIVACY WITH SOCIAL OPPORTUNITIES

76% of the survivors who participated in our survey reported that they are either single, divorced, or separated, which means that **having social programming services available to them is crucial.** In fact, social programming was one of the most requested services for an ABI housing complex, according to our surveys.

We envision a physical structure that encourages both social contact and individual privacy, much like the model at Prairie Spruce Commons. While not expressly created for ABI survivors, its private living spaces, designed for independence, and its shared communal areas, which build a sense of community, would benefit ABI survivors. It would encourage both independent living and community re-integration as well as address the feelings of isolation and the mental health challenges that are common consequences of ABI [11].



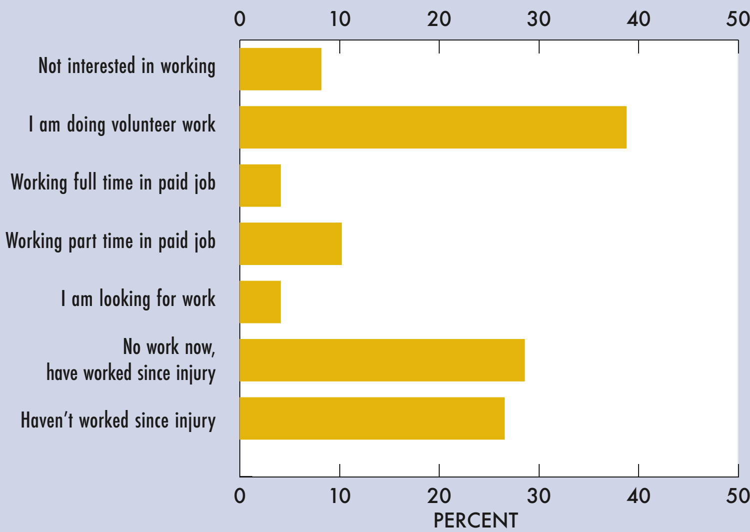
THERE IS NO
CURE FOR
A BRAIN INJURY.
ONLY PREVENTION.
Saskatchewan
Brain Injury
Association

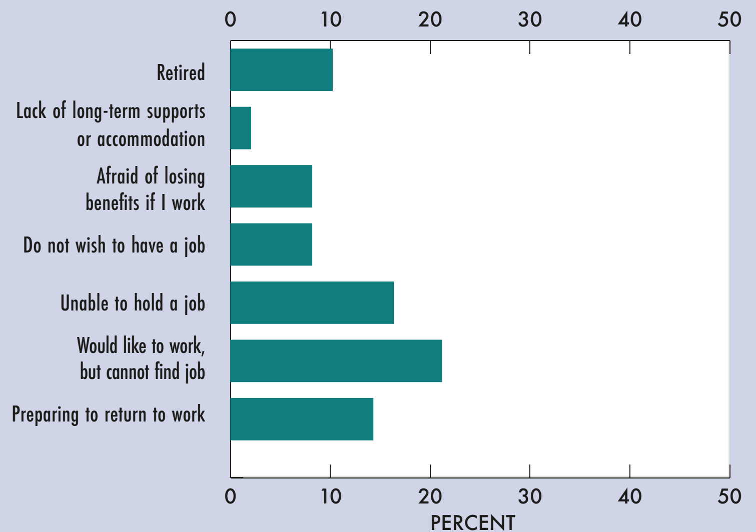
TOGETHER
WE CAN MAKE
A DIFFERENCE!
Saskatchewan
Brain Injury
Association

7. LEARNING AND WORKING OPPORTUNITIES

The vast majority of ABI survivors surveyed as part of our project were interested in undertaking paid work, but only 14% of them were engaged in full- or part-time paid work. Many of those who were not working attributed it to the complexities of their brain injuries. Others worried that employment could have a negative financial impact on them as they could lose much-needed benefits.

HOW DOES INJURY IMPACT PARTICIPANTS' CURRENT WORK SITUATION?

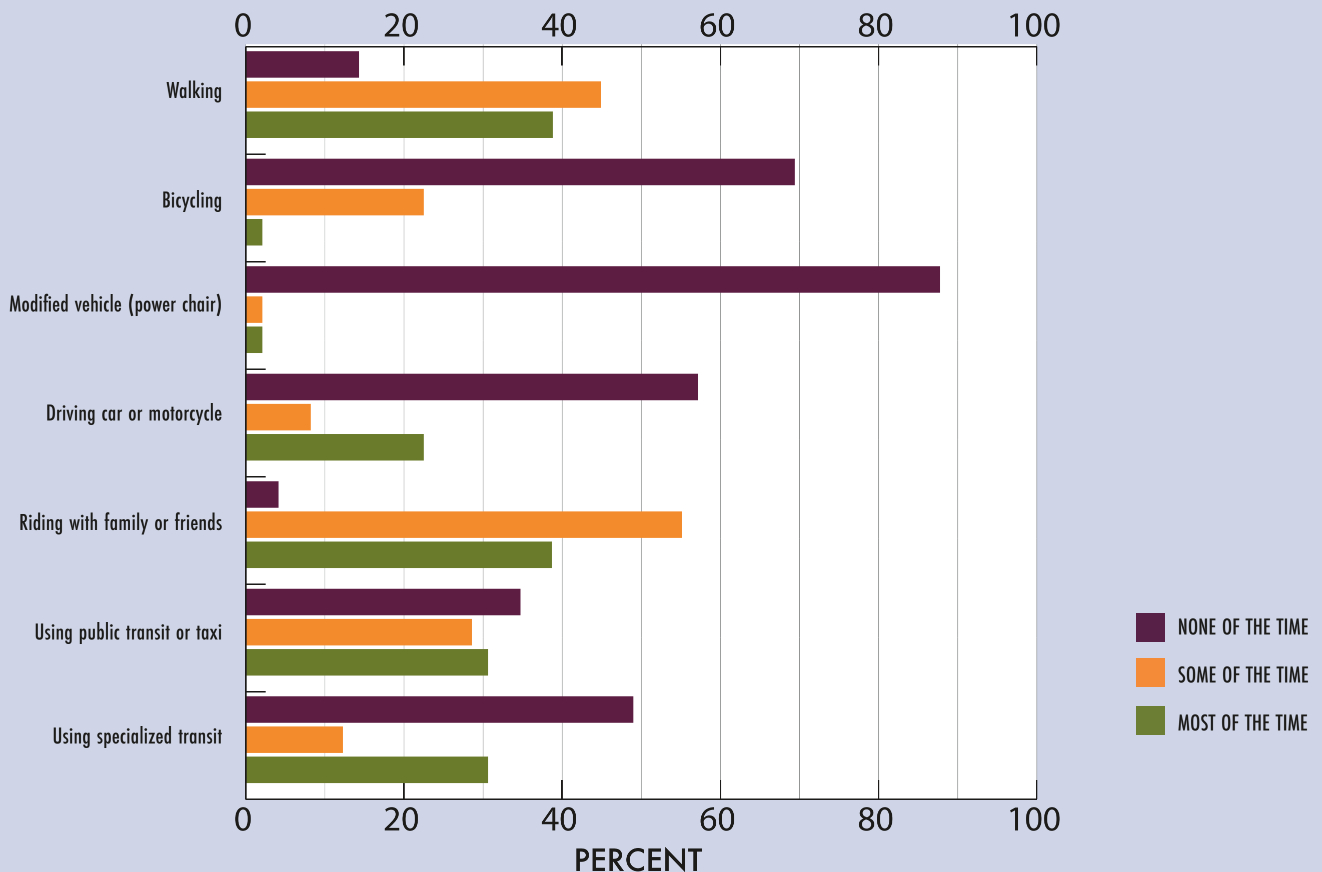




Opportunities for survivors to learn and work are essential as they re-establish a sense of purpose in the community. However, the broader business community may not be willing or able to accommodate workers with brain injury so work opportunities could be integrated into the complex. By providing these services on-site, the transportation barriers that many survivors highlighted in our surveys are eliminated, allowing for optimal accessibility and maximal service usage. The Camphill Movement has an outstanding model to draw from as it provides a wide variety of job skills training and development opportunities for its residents. It offers recreational activities, academic education, volunteer placements, and jobs in and outside of the community – all of which are tailored to individuals' skill sets, functional capabilities, and interests. This continued development encourages lifelong recovery for ABI survivors [18].

Krempels Center also provides a strong model for educational and developmental programs that address all of the challenge areas, such as functional and cognitive skill building, social and communication skill building, mental health, physical wellness, community connection, and creative expression [12].

WHAT DO YOU USE FOR TRANSPORTATION



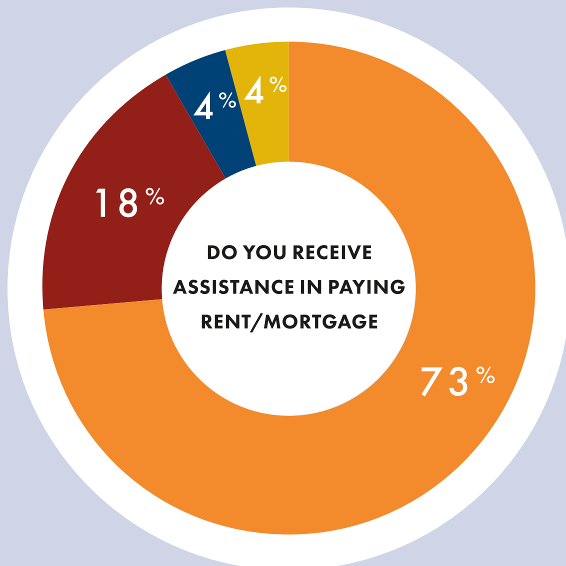
8. AFFORDABLE ACCOMMODATION AND SERVICES

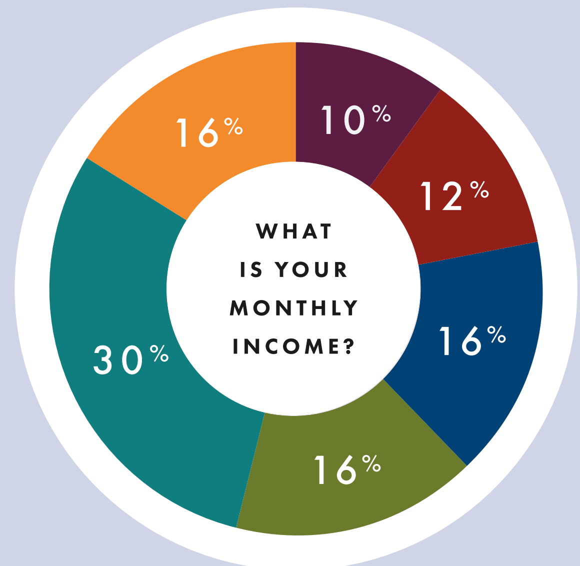
Many brain injury survivors require full-time care and support for the remainder of their lifetime. However, facilities that provide this level of care in Saskatchewan cost more than what the majority of survivors and their families can afford.

More than half of the ABI survivors who participated in our surveys had a monthly income of less than $1500 and 1/3 of all these participants receive no financial assistance. Therefore, affordability is an important consideration when designing a supportive housing complex for survivors of ABI.

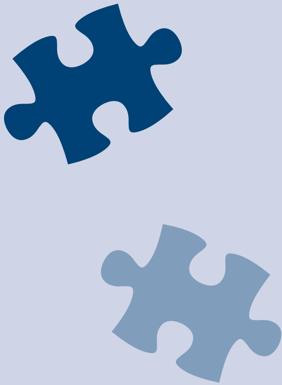
Krempels Center's approach alleviates some of the financial burden on ABI survivors and their families by offering scholarships to those who would otherwise be unable to afford their services. We also envision a system that ensures that supportive housing is accessible to survivors regardless of their financial situations [12].

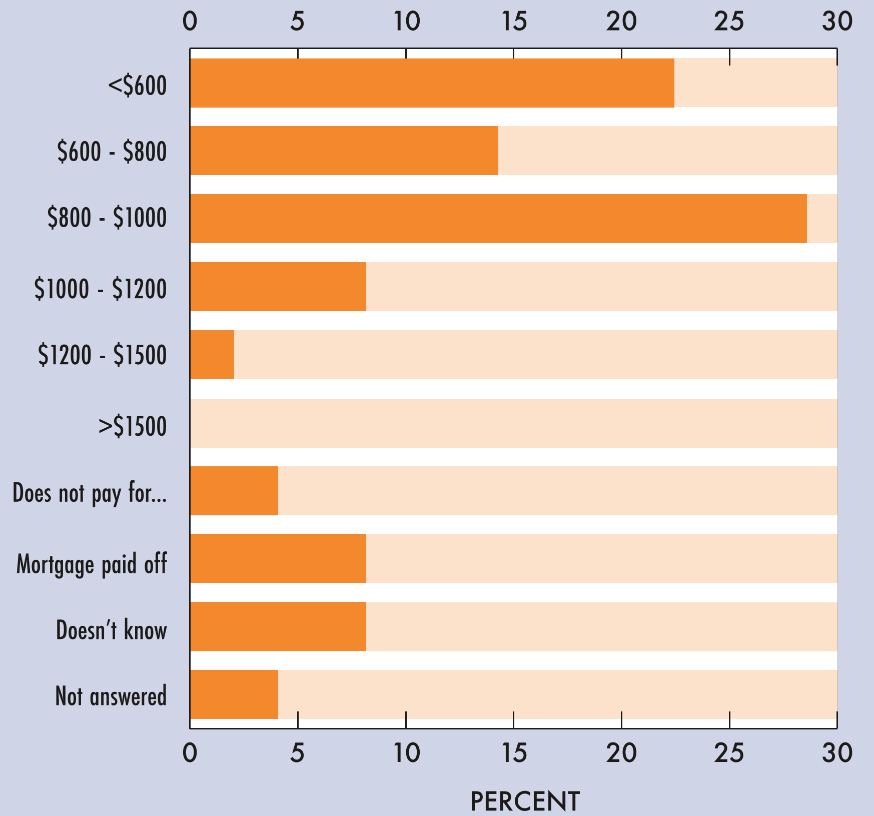
HOW HAS INJURY IMPACTED PARTICIPANTS' HOUSING SITUATION?



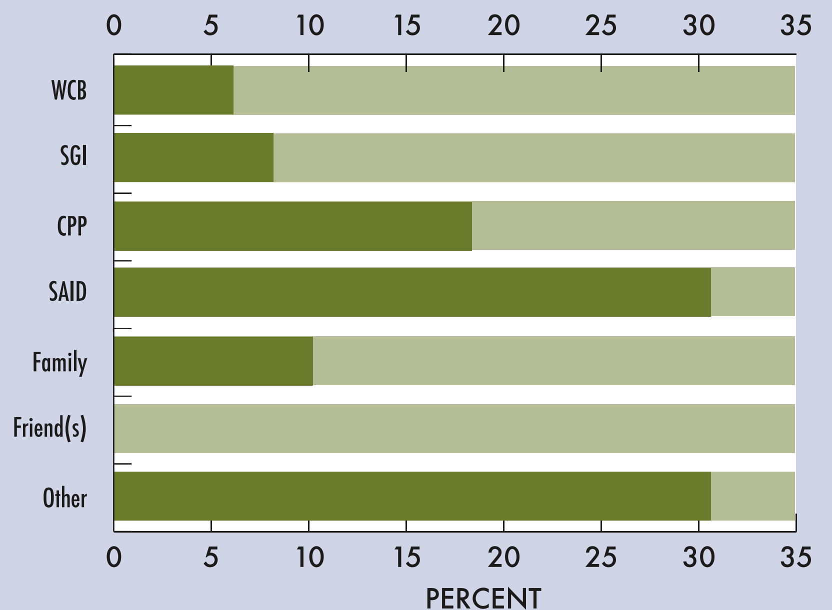


HOW MUCH IS YOUR MONTHLY RENT?





IF YOU HAVE SOURCES OF ASSISTANCE, WHO PROVIDES THEM?



i. Other sources of financial assistance were indicated as:
Sun Life (1), alimony (3), child support (1), pension (1), Rental supplement (1), Long-term disability from work (3), Great West Disability plan (1), federal government disability benefits (2), and daughter's death benefits (1)

PROPOSED MODEL FOR SASKATCHEWAN

We propose the development of housing facilities that incorporate the following key elements from each of the housing facilities previously presented as models.

A. AFFORDABILITY

The supported housing complex would offer affordable accommodation and services to all survivors of brain injury, regardless of their financial situation.

B. MULTI-LEVEL SUPPORT

The proposed model would include three separate levels of accommodation that would be structured as follows:

LEVEL 1 – HIGH-LEVEL SUPPORT

Residents who have just departed a clinical rehabilitation setting, for example, would receive higher levels of support that would work to "bridge the gap between hospital and home" [15]. This level of care would include intimate personal care.

This portion of the complex would provide care 24 hours a day with medically-qualified employees, all of whom have completed an ABI-training course, who would work in shifts. This could also accommodate those who are currently housed in seniors' care facilities so that they would receive care with an appropriate focus on the needs of young people with ABI.

LEVEL 2 – ABI-SPECIFIC SUPPORTED LIVING

The complex would have individual suites that allow for privacy and independence, and shared communal areas that encourage social contact and community. Residents would be actively involved in the design and operation of their own living space, which would ensure that it specifically addresses the needs of ABI survivors.

In terms of design, this complex would be entirely accessible for all types of mobility impairment (e.g. accessible bathrooms, wide hallways to allow for wheelchair access, communal kitchen spaces with low countertops and pantries, etc.). There would also be space for ABI services built into the structure of the complex. For example, the bottom floor could contain office space for social workers and caseworkers, and the basement could have rehabilitation spaces built into communal gym and exercise areas.

The complex would adopt the idea that everyone contributes as part of its operation. Residents would assume responsibility for specific jobs within the home determined by their skillsets, interests, and abilities. For example, an individual may assume the responsibility of doing dishes after communal breakfasts. This would allow that survivor to contribute in the community while simultaneously practising hand-eye coordination as part of their physical rehabilitation. With the expectation that everyone must contribute, there is great opportunity for meaningful involvement in the cohousing community, as well as concurrent opportunity for everyday recovery.

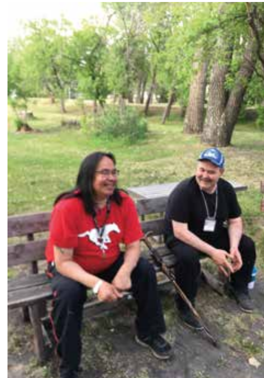
LEVEL 3 – INDEPENDENT LIVING SUITES

Suites such as those at PEARL Program in Regina would allow Level 3 residents greater independence. However, unlike those at PEARL Program, these suites would be available for long-term residency.

24-hour care would not be provided at this level. However, support staff would be available for certain periods throughout each day. Support time designations would be determined by staff and residents beforehand, and be based on the particular needs of the residents. For example, in a home where residents experience challenges with food preparation, staff could provide support during meal times. If certain residents require assistance with maintaining medication rituals, support could be provided during those times as well. There would also be a crisis support team on-call 24/7 and the number to call would be clearly displayed throughout the complex.

C. ABI TRAINED SUPPORT TEAMS ON SITE

It is imperative that staff in the complex have training in ABI so that they can provide appropriate support. We recommend having in place a medical care team, rehabilitation team, and recreational programming team on site. It is important that these types of services are readily available to residents so we can maximize barrier-free service usage and encourage optimal recovery. Brock University in St. Catharines, Ontario offers ABI training as a certificate program in partnership with Ontario Brain Injury Association.



D. ENGAGED RESIDENTS

Because this is a personal home for each of the individuals who reside there, their participation in the operations of the complex is a requirement. Although support must be on-hand and accessible at all times, 24-hour care must not be misinterpreted as imposing strict rules and limitations. Although some “rules” may be necessary, like a loose curfew to encourage regular sleep hours for brain recovery or a sign-in/sign-out procedure to inform staff when residents exit the home, it is important to avoid rules that insinuate a reward/punishment system as that compromises a comforting home environment. This undermines residents and is, ultimately, counterproductive for ABI recovery. A system that encourages as much independence, freedom and exploration as possible is paramount.

E. LEARNING OPPORTUNITIES

A housing project would also provide learning opportunities that encourage skills development, personal growth, independence in daily living, exercise and recreation activities, as well as employment.

The program development phase would incorporate input from the residents, but the educational and developmental programs would address:

- challenge areas that are specifically related to ABI (functional and cognitive challenges, social and communication challenges, mental health challenges, etc.)
- programs that address concerns related to general health, wellness, and community connection

All programs would be designed and delivered by professionals, who are trained and experienced with ABI and accommodating a variety of individual needs. They should be able to respond appropriately to changes in needs that may arise over the lifetime. Bringing in guest instructors is one way to offer diverse options (e.g. visual art teachers).

In addition to skills training and development, work and volunteer placements could be arranged to fit with individuals’ skillsets, functional capabilities, and personal interests.

F. COMMUNITY INTEGRATION OPPORTUNITIES

One of the concerns about an ABI-specific housing complex is that it could cause segregation from the broader community. This is an important concern that a housing project would need to address.

While the goal is to provide appropriate housing for brain injury survivors, it does not need to be limited to that population. A designated number of suites could be made available for people who do not experience brain injury but could contribute to the community of people who live in the complex. Applications from the broader community can be invited and residents for those suites would be selected according to the contribution they could make to the community. Some might be artists who could share their skills with other residents, perhaps even in an apprenticeship type of program. Some might be students in health studies or related fields who, by living with people who have diverse needs, may be able to develop a depth of understanding about the brain injury experience that formal studies cannot impart.

The programs offered in a housing complex need not limit the programs that residents can access. Rather, the support staff could assist in informing residents about community programs and facilitating their access and transportation to them. Without that type of support, many survivors would not be able to join broader community programs, regardless of where they live or what they wish to join.

A housing complex that caters to the unique needs of a particular group can remove many of the factors that cause them to experience disability. When the appropriate supports are provided in house, as they are in many of the more high-end seniors' housing complexes, the quality of life can increase.

It would be desirable to provide some studio and workshop spaces in the complex. It may also be desirable to offer some commercial space on the street front. Eaton's Centre in Moose Jaw, which converted a former Eaton's department store into a seniors' centre with housing on the upper floors, generates operating revenue by renting out commercial space on the street front.

All of these options provide additional opportunities for residents of the housing complex to integrate into the broader community while still receiving the supports that mitigate their experiences of disability with a thoughtfully designed building.

G. RESPITE AND GUEST ACCOMMODATIONS

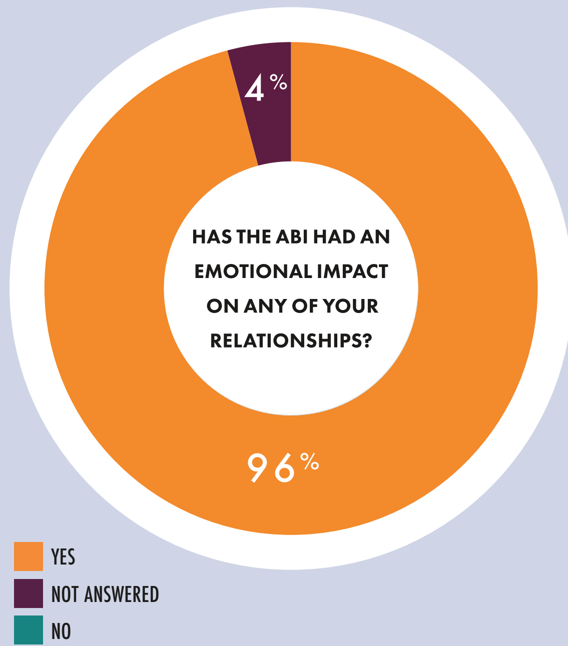
Rooms or suites for respite accommodation at each level will be needed. These may also be booked for guests so that family members who live far away can more easily visit their loved ones.

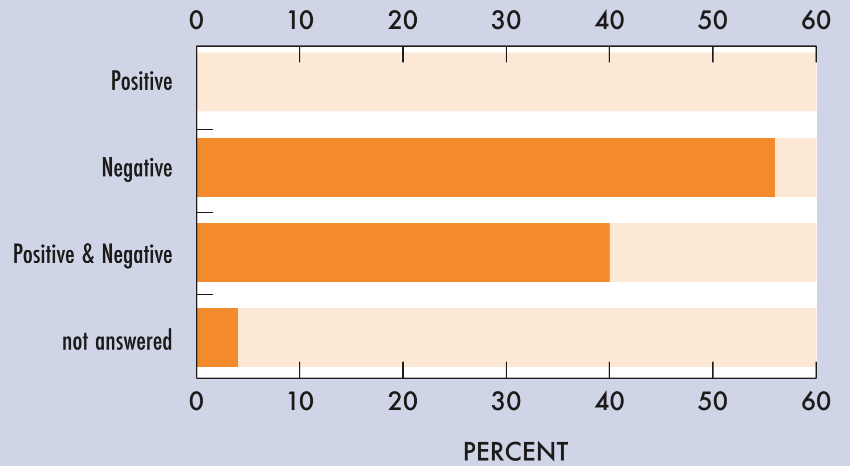
Respite is a need that is often expressed by families who care for a brain injury survivor. Current respite options are extremely limited and must be booked months in advance. If plans change, the respite booking may be forfeited.

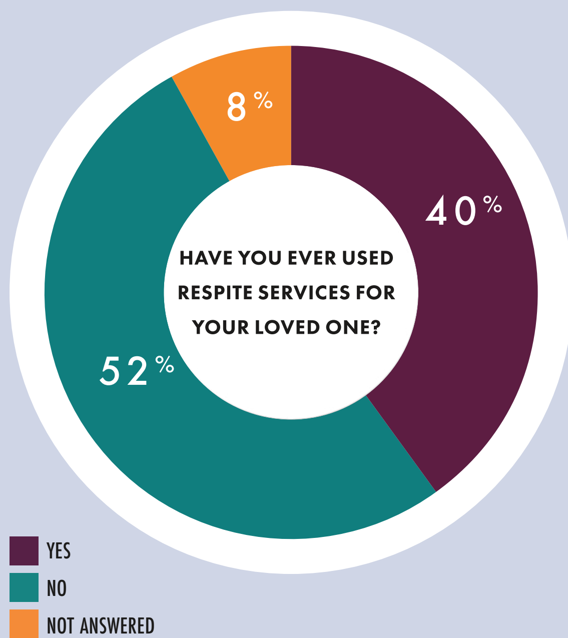
Family illness or crisis cannot be planned and too often families find themselves without respite when it is most needed.

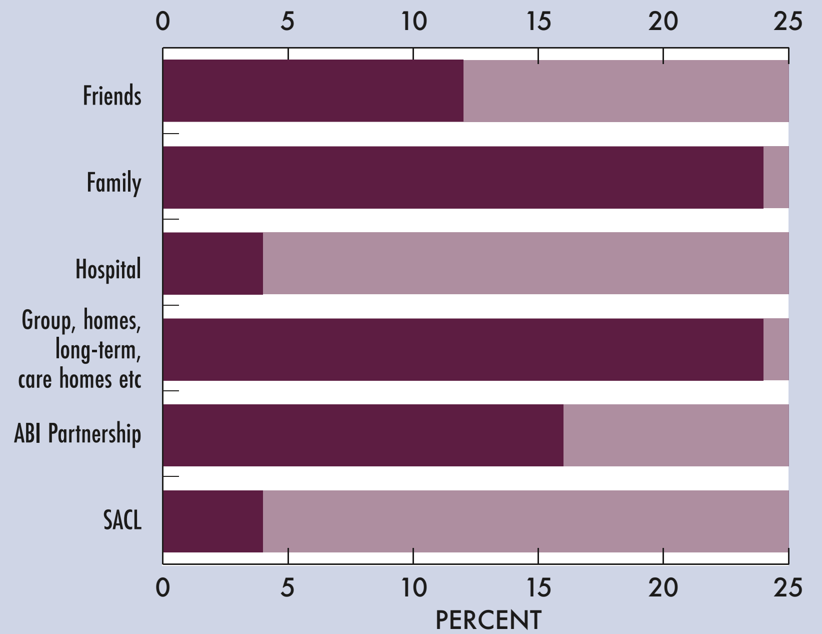
Respite facilities for people who experience disability do exist but most are designated for specific diagnoses and either are not available to brain injury survivors or are not appropriate. Having respite in a building where some of their friends live is less disruptive than being sent to a care complex where one is not known and does not know anyone.

IMPACT OF INJURY ON CAREGIVER



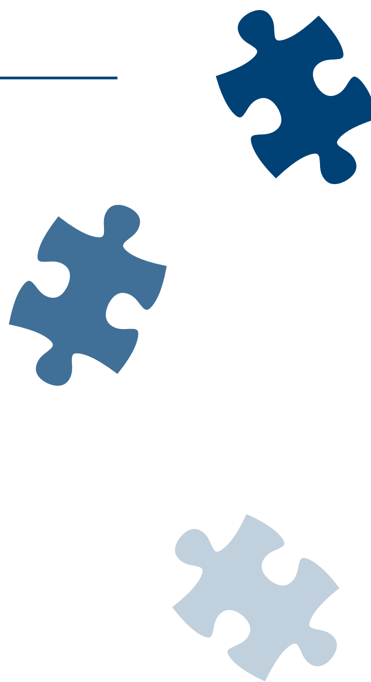






SECTION 6.0

CONCLUSION



Appropriate ABI-specific supportive housing would engage survivors in its design and operations so they can thrive and grow throughout their lives.

Access to adequate and appropriate housing services is an urgent need for the Saskatchewan population living with the effects of brain injury. Without it, many ABI survivors are left without the support they require to continue their recovery, gain their independence, and contribute meaningfully to the community. The absence of these much-needed housing services also places the responsibility to provide this care on family members who are already overstretched and lack the resources, funding and expertise to meet the complex needs of their loved ones with ABI.

Building an ABI-specific supported living complex is the single, most effective way to address all of these issues.

The proposed model outlined in this report ensures that all ABI survivors, regardless of the severity of their injury, receive the best possible care by:

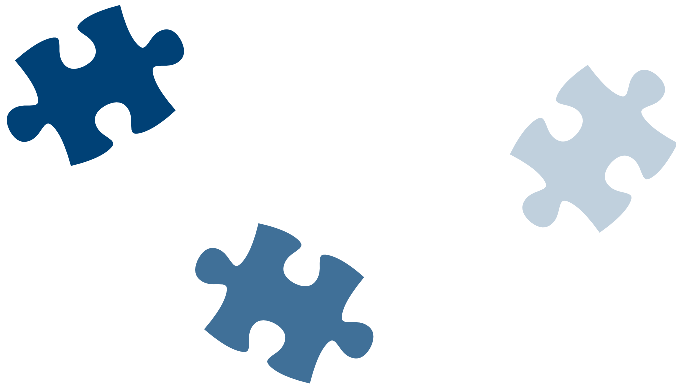
- Engaging survivors (and their families) in both the complex's design and operations
- Providing on-site support services by people who are trained in ABI
- Promoting personal growth and independence
- Offering flexibility in the programs and services that are provided
- Incorporating on-site specialized rehabilitation teams
- Providing in-house programs that encourage community integration for residents at each level of housing
- Including private living quarters as well as communal spaces
- Offering both learning and working opportunities
- Being affordable for those with limited incomes

We recognize that our recommendations for ABI-specific housing are ambitious and that a project of this nature would take time and resources to complete. Nevertheless, the establishment of housing facilities of this nature will not only be **more cost-effective than current options,** such as housing survivors indefinitely in acute care hospitals, but will also contribute significantly to making Saskatchewan a national leader in providing optimal support for *all people* experiencing disability.

SECTION 7.0

REFERENCES

AND FURTHER READING



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FURTHER READING

GENERAL INFORMATION ABOUT ABI AND ABI SERVICES

Saskatchewan Brain Injury Association: http://www.sbia.ca

Acquired Brain Injury Partnership Project: https://www.abipartnership.sk.ca/education

Brain Injury Canada: http://www.braininjurycanada.ca

IMPACT ON FAMILY AND CAREGIVERS

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TRAINING FOR ABI WORKERS

http://obia.ca/brock-university-certificate-courses/

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