Acquired Brain Injury Sector Project – Final Report

Prepared for Province of Alberta,
Community and Social Services

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1.0 Introduction and Context

Acquired brain injury (ABI) is a major cause of disability in Alberta. It is often described as a silent epidemic due to the relative invisibility of ABI individuals' impairments and disabilities, and the absence of accurate data regarding its incidence and prevalence. In Alberta, as is the case around the world, the incidence and prevalence of individuals living with an ABI is increasing. This is severely challenging public health care and community resources available to address it.

The Government of Alberta (GoA) estimates 5,000 Albertans suffer a head injury each year; published research suggests this is likely a very conservative figure. The existing prevalent population of Albertans who have survived a brain injury and are living with its consequences can be defensibly estimated to be as high as 365,500 (based on a rate of 8.5% per 100,000 persons in published research in Ontario). This number will continue to grow with advancements in lifesaving stroke and trauma response, and our aging population. Traumatic brain injury will be Canada's most prevalent neurological condition — exceeding dementia — by 2031.

ABI occurs after birth and is the consequence of stroke, trauma, traumatic injury (TBI), infectious disease, tumour, hypoxia, or alcohol and drug use. It excludes brain injuries related to congenital disorder or a degenerative disease.

The impacts of ABI are often profound and life-long. They include deficits in any or all of cognition, memory, speech, motor skills and behaviour. The lives of those with an acquired brain injury, and their families, are very often turned on end as they face employment loss, social isolation, a shortage of suitable housing, financial strain, emotional distress and a lifetime of dealing with an evolving variety of cognitive, physical and social impairments.

> "My perception sucks...if I see something, I can't distinguish if it's good or bad, friend or foe." Asked where he'd be without the support of the agency that helps him, he said: "If I was living without support, I would be evicted. I can't organize. I can't put things away appropriately. My apartment looks like a bomb went off. Where would I be? I'd be homeless or back in jail."
>
> *– ABI individual (Male, traumatic brain injury from a beating)*

Yet after leaving hospital, ABI individuals and their caregivers struggle to find the help and resources they need. Rather than a coordinated easy-to-navigate system, they encounter a bewildering world in which finding the right resources — be it housing, rehabilitation, community integration, or support for families and caregivers — is often a matter of luck. The lucky make it on to waiting lists for services for which demand already far exceeds capacity. The most fortunate receive services at the moment they are most needed.

> “We had a hospital bed. I did diaper changes, bathing. I did it all. He was 18. He was still in a wheelchair then. It was tough getting him from the house to the car. He’s a big man.”
>
> *– Mother of ABI individual (40-year old male injured in a car crash at age 16)*

Upon completing a rehabilitation or community integration program, ABI individuals very often find themselves adrift and searching for support, at risk of losing the gains they had made. ABI programs and services are often extremely limited in supply and always short-term in nature. Services dwindle as the time since injury increases. With nowhere else to turn, many ABI individuals have little choice but to return to hospital emergency departments.

> “What I don’t like is all the sudden stops...your life stops when you have a stroke. Everything has changed. Now you’re in Fanning, then that stops (and you have to move.) Now you’re in a nursing home and starting over again. You’re in a program, you get to know everybody, then all of a sudden, that ends. It’s not fair to these people. They’ve become a part of something because they aren’t part of anything anymore, and then it’s over. It’s a lot of endings.”
>
> *– ABI Family Member (stroke)*

This situation generates unnecessary expense for the public health care system which could be addressed by providing less-expensive, community-based ongoing rehabilitation and support. Likewise, a lack of ongoing support for family caregivers means they must seek help for medical issues arising from their health care burden, or issues around failure of the family unit.

Absent a major medical or prevention breakthrough, brain injury incidence and prevalence in Alberta will continue to climb, with concussion a growing issue repeatedly identified in our interviews. Because ABI often has lifetime impairments and disabilities, increased prevalence means increased long-term demands on all segments of Calgary’s ABI Continuum of Care (Continuum). As Calgary’s post-acute Continuum already struggles with capacity, its ability to deal with increased new cases and growing prevalent ABI population will be further stretched and this segment of profoundly impacted Albertans will be under-served.

Other jurisdictions, such as Ontario, have identified that while attention is usually focused on the acute (public health care) end of the continuum, ABI individuals spend a lifetime in the post-acute (community-based) end of the continuum, yet the growing issues there remain unaddressed.

Within this context, Alberta Community and Social Services in 2018 launched a year-long project to engage with Calgary’s ABI service providers to develop recommendations for creating a stable and sustainable Continuum of Care providing quality services that support client outcomes. The Project included an examination of the sector’s current state and an imagining of a desired future state, engagement with subject matter experts and stakeholders, and a literature review. It was also greatly informed by the steering committee members' collective 100+ years of experience in the brain injury sector.

For methodology details, please see Appendix I. Appendix II contains an assessment of the Continuum's strengths and opportunities. The literature review is shown in Appendix III. Stakeholder questions are contained in Appendix IV and a compelling synopsis of our interviews with ABI individuals and caregivers is in Appendix V.

As in many jurisdictions researched, Calgary's Acquired Brain Injury (ABI) Continuum of Care is provided in several distinct phases, typically:

- In hospital:
    - Acute Care (emergency treatment, intensive care unit, specialty medical services, physician services);
    - Inpatient Rehabilitation (inpatient rehabilitation and transitional residential treatment);
- Outside of hospital:
    - Post-Acute, Community-Based Rehabilitation and Long-Term Care (home, long-term residential treatment facilities, outpatient rehabilitation and day treatment, school and vocational services).

This Project focuses on adult ABI in Calgary's Continuum of Care outside of hospital, with intentional emphasis on community-based rehabilitation. Pediatric brain injury is excluded. While stroke is an ABI and a significant part of all provider's service delivery, like other ABI types, stroke has its own unique characteristics. Therefore, some ABI statistics in this report include stroke while others do not.

This report represents the steering committee's best thinking about ABI in the Calgary Continuum. While the analyses and engagements suggest many possibilities for improving service accessibility, availability and outcomes, the steering committee was highly mindful of scarce resources and sensitive to Alberta's economic reality, limiting its recommendations to three key areas:

1. clarifying the mandate of our sector;
2. central navigation, data and information;
3. multi-directional transition housing.

2.0 Situation Assessment and Analysis

2.1 The Current Situation

ABI Incidence in Calgary and System Capacity

ABI is clearly a pressing and growing health issue in Calgary, albeit as scarcely-visible statistically as ABI individuals are in daily society. As the only systematic and robust data gathering about ABI is by AHS, it provides the best-available (though likely very conservative) assessment of ABI scope, for several reasons:

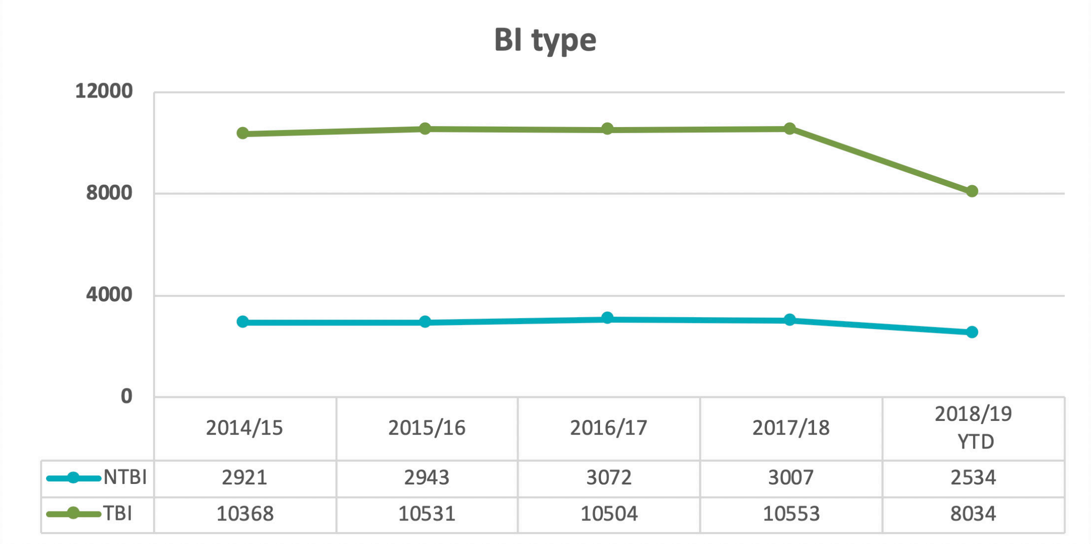
- There is no centralized case management, navigation or data collection across all community services for ABI individuals, which would enable a factual and defensible estimate of ABI incidence and prevalence. Calgary's ABI community agencies are so fiscally-stressed that their resources have long been focused on client care rather than data collection and analysis. Their data collection is limited to tracking client service gross volumes, a variety of client care statistics, and outcomes related to professional protocols or under their contractual funding obligations.
- Every brain injury is unique and every ABI individual has a different route through the Continuum. There are many entry points into Calgary's ABI Continuum, and many opportunities to by-pass it, and the number of persons who bypass either AHS and/or the entire Continuum is unknown:
    - ABI individuals may enter the system through a physician, through Emergency, or through hospital;
    - ABI individuals may not be properly diagnosed with a brain injury and their appearance may be completely normal, or they may request medical attention years after their injury, or they may not seek medical attention at all;
    - ABI individuals may have numerous brain injuries over their lifetimes and re-enter or bypass the Continuum.

Therefore, the only reasonable basis for estimating Alberta's ABI incidence and prevalence is to supplement AHS data with rates found in credible science literature, and these vary widely; please see Appendix III – Literature Review. Based on Calgary's current population, estimated incidences of brain injury of up to 22,800 can be defensibly made. Likewise, the number of people in Calgary who have had a brain injury — the majority of whom will be managing some degree of life-long physical, cognitive or social impairment — can be defensibly estimated as being up to 107,000 persons. More statistically sound ABI prevalence estimates require significant data gathering and analyses which are beyond the scope of this work; the Literature Review describes one such example.

Even conservatively estimated ABI incidence and prevalence substantially exceed the capacity of Calgary's community Continuum of Care, whose maximum treatment capacity under current funding levels is 500 per year at best, particularly considering the fact that much of the prevalent brain injured population requires periodic, life-long access to treatment and services.

Except as noted, the tables which follow throughout this document were provided by AHS (Foothills Medical Centre) using a variety of AHS databases

Table 1 – ED/UCC Brain Injury Visits – Calgary Urban



	2014/15	2015/16	2016/17	2017/18	2018/19 YTD
NTBI	2921	2943	3072	3007	2534
TBI	10368	10531	10504	10553	8034

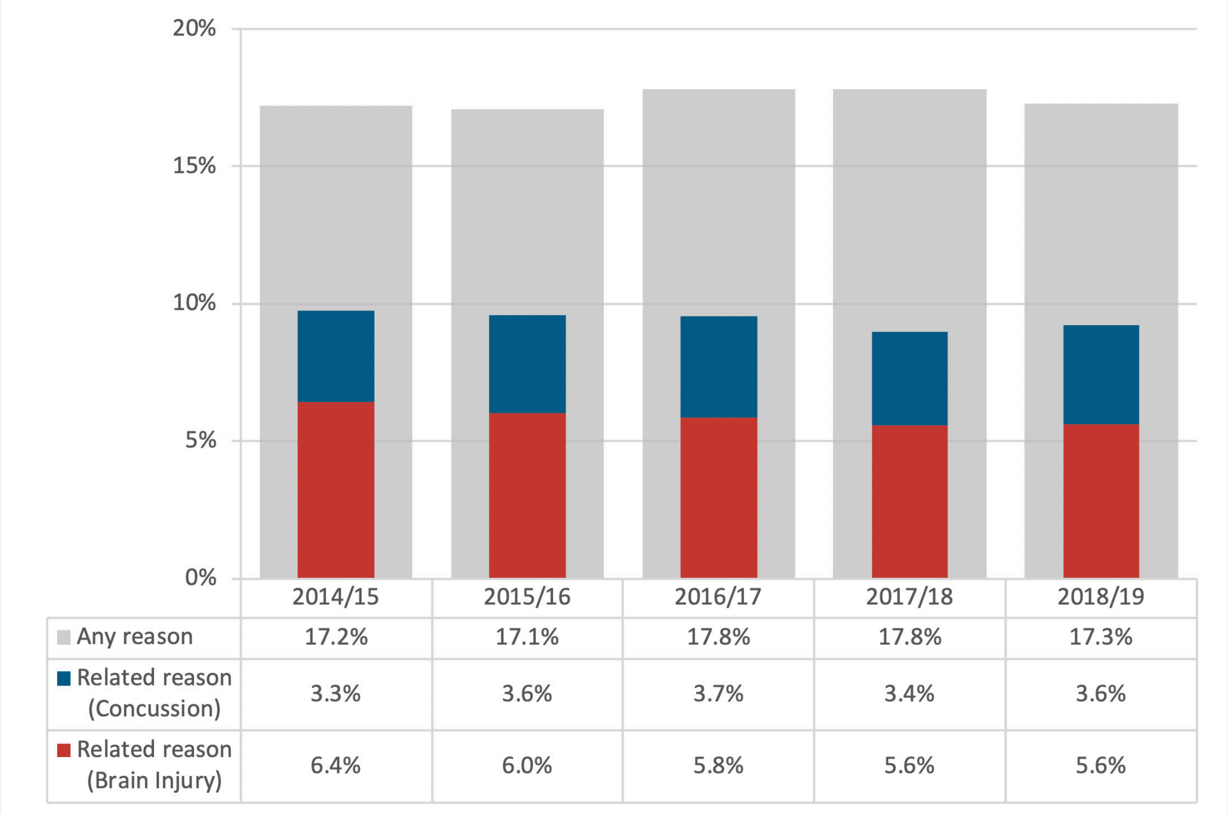
Source: AHS Tableau Dashboard, May 2019
Inpatient (IP) & Emergency Department (ED)/Urgent Care Centre (UCC) Measures

Table 1 indicates the modestly upward trend in incidences of Brain Injury (Traumatic Brain Injury, excluding concussion, and Non-Traumatic Brain Injury, exclusive of stroke) for the past five years as presented at AHS Inpatient, Emergency Department and Urgent Care Centres within Calgary's city limits. There are important qualifications to note for this table:

- 2018-2019 is a partial year of April-December 2018 which, extrapolated, would show approximately 3,000 Non-Traumatic Brain Injuries and 10,000 Traumatic Brain Injuries, continuing this upward trend.
- The table excludes stroke. The addition of stroke incidences to these data would increase total incidences by approximately 18,000 per year.
- The table excludes concussions. The addition of concussion incidences to these data would increase total incidences by approximately 10,000 per year.

As discussed earlier, these data do not account for the number of ABI presenting elsewhere, those going undiagnosed, or ABI which by-pass the Continuum.

Table 2 – ED/UCC Brain Injury and Concussion Visits
who Revisited an ED/UCC within 30 days – Calgary Urban



	2014/15	2015/16	2016/17	2017/18	2018/19
⬜ Any reason	17.2%	17.1%	17.8%	17.8%	17.3%
🟦 Related reason (Concussion)	3.3%	3.6%	3.7%	3.4%	3.6%
🟥 Related reason (Brain Injury)	6.4%	6.0%	5.8%	5.6%	5.6%

Source: AHS Tableau Dashboard, May 2019

Inpatient (IP) & Emergency Department (ED)/Urgent Care Centre (UCC) Measures

Table 2 shows the revisitation frequency to Calgary's Emergency Department and Urgent Care Centres within 30 days. In the current year, 17.3% of ABI/concussion patients revisit ED/UCC within 30 days, roughly half of which revisited due to issues related to their ABI or concussion (i.e. 5.6% for reasons related to brain injury and 3.6% related to concussion; the remaining 8.1% revisited for other reasons). A very modest downward trend is evident, although AHS' analyst judged it as not likely significant.

Current State Map

■ Nodes ◆ Triage ★ Gaps

INJURY

ENTRY POINTS

- ■ Undiagnosed, unreported, untreated
- ■ FMC Acute Unit 58
- ■ Other Hospitals
- ■ Personal Physician

CLIENT PROFILE

- ★ Client characteristics[1] that influence access to services

TRIAGE

- ★ No single, comprehensive case mgt
- ◆ Referrals from family, health care providers, helping agencies
- ◆ FMC Triage & Case Mgt (lifelong)
- ★ Not all referral points are fully informed or can meet service requirements
- ◆ Self-triage

HOUSING

- ■ Home unsupported
- ★ No transition housing
- ■ Homecare transition services
- ■ Home supported
- ★ Housing for mild BI
- ★ Housing for moderate B
- ■ Supported Living SL2
- ■ Supported Living SL3
- ■ Supported Living SL4
- ■ URSA apartments
- ★ Homeless
- ■ Longterm care
- ★ Housing for severe BI
- ■ Accessible Housing (non-profit)
- ■ Calgary Housing Authority
- ■ Calgary Homeless Foundation
- ★ Dual-diagnoses housing
- ★ Affordability of renovations for BI accessibility
- ★ Housing for best outcomes

REHABILITATION

- ■ FMC
- ■ Calgary Brain Injury Program
- ■ AHS Physiatrist
- ★ Accessing AHS Physiatrist
- ■ Early Supported Discharge
- ■ CAR
- ■ ARBI
- ■ Private providers (for-profit and non-profit)
- ★ Hand-off after rehab for person with lifelong condition
- ■ Halvar Jonson [3]
- ■ Fanning Centre
- ★ Geographically-accessible rehabilitation
- ★ Vocational rehabilitation
- ★ Maintenance rehabilitation
- ■ Calgary Community Aids for Independent Living
- ★ Neuropsychologist

COMMUNITY INTEGRATION AND SUPPORT

- ■ URSA
- ■ SABIS Survivor Support Groups
- ◆ SABIS Service Coordination [2]
- ■ Brain Injury Assist Supports for Community Living
- ■ URSA Supports for Community Living
- ■ ARBI Community Integration
- ■ BIA Vocational Rehab
- ★ General disability programs
- ★ Support for co-morbidity
- ■ March of Dimes
- ★ Support workers in the home
- ★ Support workers in community programs
- ★ Concussion peer support
- ■ Stroke Recovery Association
- ■ Adult Day Support Program for Seniors (C3)
- ■ C3 (Comprehensive Community Care)

SUPPORT FOR FAMILIES AND CAREGIVERS

- ■ Psychosocial support
- ★ Counselling and supports for families
- ■ SABIS caregiver support group
- ■ ARBI social worker for family support
- ■ Alta Brain Injury Caregiver Society
- ★ Affordable and appropriate respite care [5]

SYSTEM / META

- ★ Funding
- ★ Low profile of ABI
- ★ System lacks cohesiveness / hard to navigate
- ★ Tracking size and scope of BI (no registry)
- ★ No funding for inter-disciplinary clinics
- ★ Inconsistent and discontinuous data collection
- ★ No systemic tracking of longitudinal functional outcomes
- ★ Mental health / BI / Addiction — no one mechanism to serve
- ★ Repeat visits (survivor and families) resulting from lack of maintenance
- ★ Conferences/PD/Best practice sharing
- ★ Individual long term updated plan
- ★ Transportation [4]
- ★ Responsiveness to client profile
- ★ Hand off among / between service providers
- ★ No single network /community of practice in Alberta
- ★ Longterm care can serve as exclusion criteria for other services
- ■ Alberta Brain Injury Network

- ★ Support for BI survivors who are physically independent but have invisible impairments
- ★ Concussion population increasing without funding

Unplanned and Undesirable Nodes: Adults with ABI who fall through the cracks may enter by default into the criminal justice system, homelessness, at-risk housing arrangements, chronic unemployment, addictions, and find their community among gangs and other high-risk environments.

[1] Client characteristics such as speed of recovery, geographic location, family support, pre-morbidity, dual-diagnoses, ethnicity and language, strongly influence their ability to access services.

[2] SABIS needs a neuropsych report or discharge doc in order to be eligible for services.

[3] Halvar Johnson — range is 6 months – 2 years, ave 8 months. Geography is a barrier to access.

[4] Transportation issues for First Nations and rural communities a tremendous challenge — no Handibus outside the city limits.

[5] Without access to respite care, families and caregivers are unable to access the supports which are in place to help them.

Revision 2 Nov. 5 2018

The steering committee developed this Current State Map through a facilitated process. Four categories of care resources are shown in black, gaps are shown in red, and triage guidance through the existing Continuum is shown in blue.

Because every ABI individual's circumstances and injury are unique, no journeys through the Calgary ABI Continuum are the same, nor orderly. (This is consistent with other jurisdictions in the Literature Review).

The ABI individual's journey begins with a traumatic or non-traumatic brain injury. The Map's second horizontal layer shows several entry points into the Continuum – through physicians, the Emergency Department and Foothills Medical Centre (FMC) Unit 58, or other hospitals. Brain injuries may also go undiagnosed, unreported and untreated, with ABI individuals entering the Continuum at any time throughout life, perhaps once symptoms and difficulties become apparent or chronic.

The Map's third horizontal layer shows two key influencers on the ABI individual's journey:

- their own informal profile, i.e. individual characteristics, which influence their access to services. These could include family caregivers who help them navigate the Continuum, awareness of the available options available, personal financial resources, etc.;
- the formal or informal triage process, which could include formal referrals within the health care system or through FMC, or the ABI individual's own self-triaging.

From this point, the ABI individual (and family caregiver, if applicable) enter the post-acute community stages, where they may encounter resources in the four categories shown: housing, rehabilitation, community integration and support, and support for families and caregivers.

The Continuum is actually discontinuous, with many gaps impacting accessibility to — and the availability and appropriateness of — care throughout the ABI individuals' lifetimes. While each category of care has its own gaps, the Map's fifth column lists systemic gaps impacting accessibility or quality of care, such as funding for ABI services or inconsistent and discontinuous data collection. Most ABI individuals face a life-long journey through the Continuum, however, their access to services may be limited due to any given service provider's policy and capacity restrictions. Therefore, ABI individuals may move through a variety of nodes in the Continuum in either a random or planned way or re-enter it through any entry point. In general, community-based service availability decreases as the time since injury grows. ABI individuals often bounce back into the public health care system.

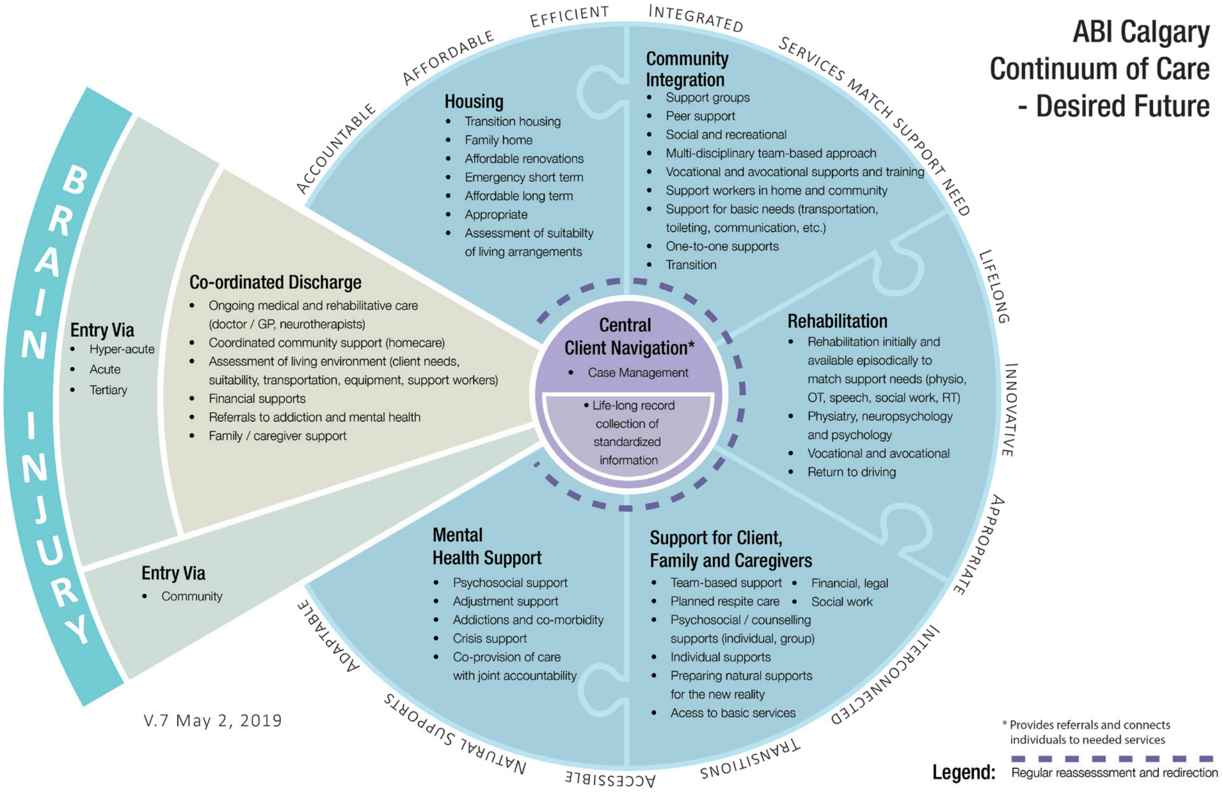
Navigating the Continuum is tenuous, as there is currently no consistent navigation support system available to all ABI individuals and their families to help access suitable resources through their life-long journey. There is no centralized, life-long file on each client, contributed and accessible to the Continuum's various service providers. Current navigation assistance depends instead on the ABI individual's entry point into the Continuum, the triaging which took place, engaging AHS'

Coordinated Discharge process or the Southern Alberta Brain Injury Society (SABIS), or receiving informal advice from any member of the Continuum.

The bottom layer of the Current State Map captures additional unplanned and undesirable destinations for ABI individuals – the criminal justice system, homelessness or at-risk housing arrangements, substance abuse, chronic unemployment, or other high-risk environments.

2.2 A Vision for What Should Be: The Future State Map

Like the Current State Map, the Future State Map was developed by the steering committee through a facilitated process. It reflects the steering committee's desired — but very practical — future vision for Calgary's ABI Continuum of care.



While every individual's journey through the Continuum remains unique, it will be guided by central client navigation using a centralized, life-long record of standardized information contributed and accessible to the client and the community agencies serving them. Each ABI individual's journey is enhanced or course-corrected through a re-assessment at three to six months post-discharge to determine how they are doing, with redirection to different services if necessary, followed by coordinated, regular re-assessments and redirection at intervals throughout life. This is a major and much-needed improvement over the often unguided and random journey through the present Continuum which all too often ends in undesirable and unplanned circumstances.

In this future state, the ABI individual need only reach the Map's centre where the support exists to effectively navigate the Continuum. Central navigation plots a route through the Continuum for the ABI individual and their family, their needs are understood, and they are consistently assisted in obtaining help. ABI individuals can cycle through the system as often as needed as they deal with the challenges which their injury, impairments, and life throw at them.

The map's general architecture also reflects major changes from the old Continuum. The silo-ing of community services and agencies is replaced with much closer coordination and collaboration. While some ABI individuals will enter the Continuum through the community, the majority of ABI individuals will enter the continuum through Alberta Health Services' Co-ordinated Discharge process. However they enter the Continuum, ABI individuals receive the same centralized navigation, record-keeping and re-assessment. Gaps in the old Continuum are replaced with characteristics of the new Continuum, shown wrapped around the perimeter of the circle, i.e. lifelong, accessible, adaptable, matched to need, accountable, etc.

Each of the new Continuum's elements contain important changes which address the current system's known gaps. For example:

- Housing Selection is based on an assessment of the suitability of the ABI individual's living arrangements, which will naturally evolve over time. There are more housing options available, including transitional housing which provides a bridge among all long-term living arrangements, and improves the ABI individual's chances of success.
- Community Integration includes vocational and avocational supports and training which greatly improve ABI individuals' chances of regaining employment within their individual potential. The multi-disciplinary, team-based approach will be more efficient in assessing and meeting ABI individuals' needs and reducing the chances of at-risk or homeless situations, or remaining in publicly-funded hospital beds when more cost-effective and suitable care should be available.
- Rehabilitation is available episodically to meet ABI individuals' changing needs over a lifetime, rather than being limited to one early, short-term and intense phase. The Map also reflects the required growing emphasis on mental health support to ABI individuals, which is currently a key gap.

The Future State Map's most anticipated difference is in ABI individuals' and their families' improved outcomes from their journey through this Continuum.

3.0 Recommendations

The following recommendations arise from the examination of the sector's current state and imagining of a desired future state — not a Rolls Royce future state, but a functional Oldsmobile. To belabour the automobile metaphor, the Continuum of Care's current state is best described as a collection of unassembled car parts, with no engine or steering wheel, and no road map.

Without question, every agency and individual in Calgary's Continuum of Care works very hard, making excellent use of existing but limited resources to produce the best possible outcomes for ABI individuals. That said, the steering committee identified numerous opportunities to strengthen the system's sustainability and improve outcomes for ABI individuals. In making its recommendations, the steering committee was highly mindful of scarce resources and sensitive to Alberta's economic reality and limited its recommendations to these three key areas:

1. clarifying the mandate of our sector;
2. central navigation, data and information;
3. multi-directional transition housing.

Implemented individually, each recommendation involves small investments which will drive significant value: making the best possible use of resources to improving outcomes for ABI Albertans and their families and increasing the Government of Alberta's return on investment (ROI) by enhancing the Continuum's efficiency and effectiveness in supporting Alberta's burgeoning ABI population. Implemented collectively, the three recommendations lay the foundation for transformational change in Alberta's ABI sector. For example, a multi-direction transition housing program, utilizing existing infrastructure, will keep ABI individuals out of significantly more costly hospital and long-term care beds.

The steering committee is committed to starting work to move these recommendations forward: mapping data collection practices and moving to a common standard across community agencies; mapping each agency's current mandates and identifying commonalities and outliers; and continuing this collaboration among government and community agencies.

RECOMMENDATION #1: CLARIFY THE MANDATE

The growing size and scope of the population served by Calgary's ABI Continuum of Care means that already-stretched resources are now trying to serve larger populations with a broader scope of medical issues and life-long impacts requiring ongoing treatment and services. All providers in the Calgary Continuum, including AHS, are dwarfed by the growing number of cases including concussion, and struggle to provide services meeting this growing demand. While the ABI sector has always responded to pressure for services from this expanding population when care appeared unlikely otherwise, this is no longer sustainable. As examples:

- Concussion - increasing popular awareness of concussion is helping fuel concussion case growth and expectations for its care, with concussion patients flooding the entire system. Many service providers cannot keep up, and demand for concussion care has outstripped system capacity and its ability to care for traditional ABI cases — which also continue to grow — while concussion cases are not receiving the most suitable treatment.
- Mental Health – even though the ABI sector lacks resources and expertise to effectively deal with mental health issues and deliver good outcomes, the mental health sector screens out ABI individuals whose primary diagnosis is mental health.

It is hoped that clarifying the mandate of the sector will increase understanding of the current scope of treatment, how it has changed, the impacts of these changes, and the resource implications. It should enable re-alignment of services to follow the clarified mandate and therefore provide some relief for overtaxed resources, enable development of a fact-based case for additional resources to support those deemed in-scope or, alternately, redirect those deemed out-of-scope to more appropriate, and cost-effective, resources.

The steering committee recommends:

- clarifying the sector's mandate, as a pathway to sustainability in an environment of scarce resources;
- accessing federal dollars to invest in improved vocational rehabilitation to increase the ability of eligible individuals to return to work.

Best Practice Evidence

- The Ontario Neurological Federation has identified the imbalance of attention and resources between the continuum's acute care end (in which individuals have a relatively short stay) and the post-acute (community) end, in which individuals stay a lifetime. They characterize issues in the community continuum as being "heaped".

- Edmonton Brain Care Centre treats concussion services as a separate stream, which is funded differently than regular ABI, requires concussion individuals to complete three months post-injury before entering its program, and limits them to up to 10 sessions with an Occupational Therapist.

Impacts on ABI individuals and Families

- ABI individuals are perplexed by the varying service criteria among the Calgary Continuum's service providers. Clarification of service criteria will help them avoid misaligned service and treatment options and help them navigate to service providers who can help them, making the best use of available resources.

- ABI individuals who have the highest need for treatment and services by Calgary's ABI Continuum should see greater accessibility to these services if services outside of a clarified mandate are no longer provided.

Benefits to GoA

- Given creep in the breadth of services provided to the ABI population, clarity of the Calgary Continuum's service mandate will mean more targeted and efficient use of public dollars and help ensure the size and needs of other populations are understood and services are designed to meet their needs.

- Among brain injury types, concussion individuals are more likely to return to employment and community participation, therefore appropriately serving them has an excellent ROI. Focused concussion services would provide opportunities for investment in innovation around symptom awareness, knowledge of symptom management and treatment, and the ability to self-manage, using centralized websites, discussion boards and e-learning. Combined, these would reduce demand on the regular ABI Continuum and ensure costly public health care resources (including the Emergency Room) are devoted to those concussion patients whose injury severity means they need to see AHS.

- Vocational rehabilitation has a major beneficial impact on ABI individuals' ability to return to appropriate gainful employment. Compared to other provinces, Alberta is under-served in vocational rehabilitation. Use of federal vocational rehabilitation funds would be very cost-effective in ensuring more concussion and other ABI individuals can return to work.

RECOMMENDATION #2: CENTRAL NAVIGATION, DATA AND INFORMATION

Central navigation — helping ABI individuals and their families navigate the Continuum of Care — would tremendously benefit ABI individuals’ outcomes and quality of life and offers significant benefits to the GoA. While implementing a full case management approach is not included in these recommendations due to scarce resources, the following recommendations would significantly impact system efficiency and outcomes while providing a strong foundation for case management in the longer term.

This recommendation encompasses three key elements:

- **Central Navigation –** a central office acts as a clearing house for new and existing ABI cases, helping navigate ABI individuals and their families to the most appropriate treatment and services as they are available. This ensures equitable, efficient access to services matched to needs, when services are available; this currently may mean persons are navigated to a waiting list.
- **Central Data –** Calgary’s ABI community agencies standardize collection of as much demographic, treatment and service, and outcome data as possible for ABI individuals; ultimately all ABI individuals and their data are tracked in a centralized database. Central data is a large undertaking which we recommend be addressed in a series of incremental steps:
    - Determine what data Calgary’s ABI community agencies currently collect and should collect;
    - From this day forward, log and track every new person who enters the Continuum of Care – both Alberta Health Services (AHS) Calgary Brain Injury Program (CBIP) and community ABI agencies;
    - For those already in service, determine how to get them into the new system;
    - Leverage and supplement existing AHS navigation and data collection resources.
- **Central Information –** a single, website-based, central depository of current information and resources is provided for all ABI individuals and their families in Alberta. This gives ABI individuals and families efficient access to accurate information.

Best Practice Evidence

- Case management is a worldwide-recognized ABI best practice. Central navigation, data and information are key ingredients in a case management approach to treatment and services, enabling coordination and support an individual's lifetime access to treatment and services.

- Poor or inconsistent data collection creates systemic inefficiencies across the continuum of care. Following injury, ABI individuals and family members struggle to find timely, accurate and credible information on brain injury symptoms, treatment, and available resources. This search becomes an ongoing, frequently unguided lifetime quest, often with mixed success.

Impacts on ABI individuals and Families

- Efficient connection to information and access to the most appropriate available treatment and services through a single point of contact would help ABI individuals and their families more efficiently access available treatment and services in the Calgary Continuum, improve outcomes, save countless hours of stressful research, and avoid misinformation.

- ABI often has long-term memory and cognition impacts, such that ABI individuals can rarely recall treatments and services received, from whom, and when. A single point of contact with an enduring record of ABI individuals' treatments and service histories means a higher likelihood of connecting ABI individuals with the most suitable treatment and services on an ongoing basis.

Benefits to GoA

- Connecting ABI individuals and their families with the right services helps ensure the ABI system is not clogged up with persons going to the wrong services. This can capitalize on the success of Alberta Supports and AHS' current use of a coordinator to help place Calgary Brain Injury Program patients with community agencies.

- The proposed incremental approach to building centralized data maximizes chances of long-term success and immediate positive impacts, with the least resource use and risk. It also permits the ABI sector to learn from existing GoA data-sharing initiatives.

- Compiled, factual ABI data will help GoA accurately understand ABI's scope in Alberta, anticipate future resource requirements and make the best possible decisions for this sector regarding mandate, service mix and resolution of gaps. This will help ensure the right services are available at the right time, improving outcomes for Albertans.

- Collection of common data regarding ABI individuals' outcomes paves the way for more effective performance measurement of the Continuum of Care, thereby supporting Recommendation #1 (clarify sector mandate).

- Calgary's ABI Community agencies will be enabled to make the most efficient use of funding, by relying on an established treatment history record rather than spending time piecing together often-fragmentary patient data, and being able to rely on consistent referrals and referral data from a single, knowledgeable point-of-contact.

- Efficiently connecting and re-connecting ABI individuals over their lifetimes with community treatment and services means their seeking fewer, inefficient uses of public health care services and Emergency Room re-admissions to deal with issues which have arisen. Appropriately connecting ABI individuals to treatment and services creates family resiliency. This creates vast efficiencies in use of publicly-funded AHS and CSS services and supports Recommendation #3 (multi-directional transition housing).

- GoA can be assured Albertans have a reliable, single source of information on ABI and its treatment, service options and learning resources rather than on random sources such as the rumour mill, internet searches, or medical practitioners unaware of best practices (particularly concussion). Availability of accurate information on the nature and treatment of concussion would help steer Albertans with concussion directly to the right service providers rather than having them show up at Emergency. Creating a well-informed population of ABI individuals and their families will enable them to seek care from the most appropriate providers which is aligned with providers' mandates. This supports Recommendation #1 (clarify mandate).

RECOMMENDATION #3: TRANSITIONAL HOUSING

ABI housing encompasses both the physical residence and the supported living programs and services which ABI individuals need. Insufficient and inappropriate housing for ABI individuals means their needs are not being met and government resources are not being deployed for the greatest possible good. All types of ABI housing are required in Calgary; the steering committee agrees that transitional housing is the highest priority housing option needed.

This recommendation envisions transitional housing with appropriate infrastructure, providing a supportive environment and programs aligned with need, with professional supports available. Such housing is community based, usually small form-follows-function apartment-style units accessible to those with physical and cognitive impairments, and has several units for cost-effectiveness. It matches the lowest burden of care with the most cost-effective services and is part of a dynamic continuum and can adapt to an ABI individual's changing housing needs over their lifetime.

Best Practice Evidence

- Earlier intervention in an ABI individual's recovery is more effective than intervention later. Appropriate living environments have a high and lasting impact on ABI individuals' long-term physical, cognitive and social functioning and maintenance of the gains made during rehabilitation; inappropriate housing has negative life-long consequences.

- Transitional housing is a well-known best practice enabling timely and accurate assessment of ABI individual needs and potential, helps ensure they are placed in appropriate housing, provides the opportunity for efficient continued treatment and services, and is far more cost-effective and suitable than extended hospital stays.

Impacts on ABI individuals and Families

- Transitional housing helps ABI individuals maintain the gains realized in their publicly-funded acute and post-acute AHS treatment and provides a smoother transition into longer-term living situations which will, in turn, help them enjoy higher quality of life and reach their full potential, including participation in society and employment.

- For those returning home, transitional housing provides much-needed time for home modifications for physical accessibility, and the opportunity for family caregivers to be trained in and adapt to their new duties.

- Providing ABI individuals with a place to go whenever their current living arrangements are no longer suitable reduces the likelihood of ending up in limbo, homeless, in long-term (geriatric) care, or in the criminal justice system.

- Transitional housing enables continued community-based treatment which might otherwise be able unavailable due to transportation and accessibility issues.

Benefits to GoA

- Whereas ABI individuals should progressively move through the system to less-expensive services, the current situation keeps them drawing on already over-taxed and expensive publicly-funded health care and long-term care services. Without transitional housing, hospitals become ABI individuals' default homes, they cycle chronically through Emergency, or they may default to placement in long-term care facilities, all of which inefficiently use resources. Reduced hospital bed stays while awaiting appropriate housing or home renovations create dramatic cost savings, as would decreased re-entries into the health care system to address relapses. Transitional housing increases the ROI on the public's investment in acute and post-acute treatment and rehabilitation.

- Transitional housing provides an opportunity to collaborate across GOA ministries in a pan-disability approach and re-purpose existing GoA infrastructure. It capitalizes on collaborative work already underway for disabled and complex needs individuals across several stakeholder ministries: Community and Social Services (CSS), AHS, Housing, and Justice, along with local municipalities, utilizing a CSS-developed service protocol. This model recognizes ministries' complementary interests in addressing the needs of ABI individuals.

- As other injury categories (e.g. stroke or spinal injury) also require transitional housing, there are potential economies of scale in combining these with ABI transitional housing.

4.0 CONCLUSION

While ABI may be a silent epidemic — nearly statistically invisible, with many ABI individuals out of sight and out of mind — it profoundly affects a significant group of Albertans who first struggle with understanding and accessing treatments and services, and later with a complex, long-term web of impairments impacting quality of life and full participation in society and employment.

Comprehensive hard data on the Continuum's community portion is scarce, but a cursory review of data from the acute care sector — the start of the Continuum of Care journey for most ABI individuals — reveals a story of increasing incidence, and therefore, prevalence, which even presently outstrips available treatment and services from the post-acute community sector and pressures it to provide treatment and services which most ABI individuals require for a lifetime.

The existing Continuum of Care depicted in the Current State Map provides good short-term outcomes for those who are able to access services, but is hampered by many gaps which impact accessibility, efficiency, delivery of long-term ABI individual outcomes, and therefore sustainability. The Future State Map's Continuum provides a practical, collaborative vision which aligns with best practice and provides vast improvements in all areas.

Interviews with stakeholders — system participants, ABI individuals and families — provided concrete ideas and recommendations for what areas need the most improvement. Best practitioners provided inspiring models which are reflected in the final recommendations. The literature review provided insights from credible research literature focused on specific aspects of ABI incidence, prevalence, treatment and services. While it did not provide for any revolutionary or silver bullet solutions, it does affirm that many gaps and challenges faced by Calgary's Continuum of Care are not unique, and informs how they should be addressed.

Faced with a broad spectrum of issues, challenges and gaps and a realistic vision for something better and more sustainable, the steering committee faced the daunting task of choosing the fewest, highest-leverage interventions which would make the best use of limited resources in a complex and dynamic system. It identified three key areas which will make significant differences for the largest number of ABI individuals, provide a high ROI for the GoA, and will go a long way in helping ensure the sector's sustainability.

Overcoming the after-effects and reaching one's fullest potential after a brain injury requires resilience, determination, persistence and resources. Inspired by this spirit in ABI individuals, the steering committee is committed to continuing the culture of collaboration and the collaborative community-government model realized during this Project, in working to build a more resilient, accessible and sustainable Continuum of Care for Calgarians.

The steering committee thanks the Government of Alberta for funding this study and empowering focused collaboration in exploring the issues and opportunities of Calgary's ABI Continuum of Care, and setting a foundation for further collaboration and progress among community and government service providers to better serve ABI individuals and their families.

GLOSSARY

- ABI – Acquired Brain Injury
- Acquired Brain Injury – a brain injury which occurs after birth and is the consequence of stroke, trauma, infectious disease, tumour, hypoxia, or alcohol and drug use and excluding brain injuries related to congenital disorder or a degenerative disease
- Acute care – active but short-term treatment for a severe injury or episode of illness, an urgent medical condition, or during recovery from surgery
- AHS – Alberta Health Services
- ARBI – Association for the Rehabilitation of the Brain Injured, a community service provider in the Calgary ABI Continuum of Care
- A$ - Australian Dollars
- BI – Brain Injury
- BIA – Brain Injury Assist Ltd.
- CAR – Community Accessible Rehabilitation, a Government of Alberta-funded neurological rehabilitation program for adults
- CBIP – Calgary Brain Injury Program
- Co-morbidity – the presence of one or more additional conditions co-occurring with a primary condition
- CSS – Government of Alberta, Community and Social Services
- Dual diagnosis – the condition of suffering from a mental illness and a comorbid substance abuse problem
- EBCC – Edmonton Brain Care Centre
- FMC – Foothills Medical Centre
- GoA – Government of Alberta
- Incidence – The number of occurrences of an injury event over a year
- k – Thousand
- M - Million
- Neuropsychologist – a specialized medical practitioner who provides diagnosis and treatment of behavioral and cognitive effects of a neurological trauma or condition
- ONF – Ontario Neurotrauma Foundation
- OT – Occupational therapist
- PDL – Positive Developments Ltd.
- Physiatrist – a specialized medical practitioner who combines physical medicine and rehabilitation to enhance and restore functional ability and quality of life to those with physical impairments or disabilities
- Pre-morbidity – preceding the occurrence of symptoms of disease or disorder
- Prevalence – The number of people in a defined geographic region who have ever had an ABI are living with symptoms or problems related to it

- PT – Physiotherapist
- RLA – Rancho Los Amigos, Los Angeles
- RT– Recreational therapist
- SABIS – Southern Alberta Brain Injury Society, a community service provider in the Calgary ABI Continuum of Care
- SCLS – Supports for Community Living Services, a short term, goal based program for individuals who require minimal supports to develop or relearn their skills in order to maximize their independence
- Sequelae – after-effects of an injury
- TABIN – Toronto ABI Network
- TBI – Traumatic Brain Injury – a brain injury which results from trauma
- URSA – Universal Rehabilitation Service Agency, a community service provider in the Calgary ABI Continuum of Care

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Please see Appendix III for references used in the Literature Review.

Appendices

APPENDIX PAGE

Appendix I – Scope of Work, Organization and Methodology

SCOPE OF WORK

The Project was initiated and funded by the Alberta Ministry of Community and Social Services, intended to "engage the sector through a series of facilitated conversations/ consultations" and "explore innovative options that will allow us to continue to provide quality services while balancing our current fiscal environment with increased demand for services and support."

The Project's scope was defined to include the following:

- "Current state understanding and profile of services and supports", encompassing a narrative depicting the sector's current state, a visual illustrating the currently-available continuum of supports and service flow, and the inter-relationship of participants in the sector;
- "A vision for sector sustainability", encompassing "a continuum and alignment of supports and services to best position the sector for continued stability and sustainability in the future", examination of inter-relationships among service providers to "ensure good outcomes and continuous improvement based on a review of best practice approaches" and a review and analysis of demographics and service utilization levels and their trends;
- A final report, including recommendations which would:
    - "inform decisions that support quality service delivery, enhance effectiveness and efficiency;
    - create a climate for collaboration, creativity and innovation within the sector;
    - support positive outcomes and service experience for adults with ABI;
    - consider and evaluate options that may include, but are not limited to, network models, partnerships/alliances, and/or collaborative mergers".

Formal evaluation of existing supports and services, and implementation of any recommendations were excluded from the Project scope.

The Project was to be developed through facilitated "measured conversations with sector partners and Community & Social Services", governed by a Steering Committee using a project plan. A literature review and/or a national/international environmental scan for best practices and delivery models was also required.

ORGANIZATION

Table 3 – ABI Sector Project Steering Team
Allan Govender, Regional Director, Regional Supports Services, Calgary Region, Community and Social Services (Project Co-Chair)
Mary Ellen Neilson, Executive Director, Association for the Rehabilitation of the Brain Injured (ARBI) (Project Co-Chair)
Michele Brooks, Executive Director, Positive Developments Ltd. and Brain Injury Assist Ltd.
Natasha Brzoza, Executive Director, Southern Alberta Brain Injury Society (SABIS)
Lynn Cilia, Administrator, ARBI (Project Administrator)
Jen Coulthard, Executive Director - Outpatient Medicine, Allied Health, Transition Units & Neuro Rehab, Alberta Health Services
Ana Gollega, Program Director, ARBI
Heather Hansen, Senior Manager and Acting Regional Director, Disability Services
Jason Knox, Manager - Tertiary Neuro Rehabilitation Unit 58, Alberta Health Services
Pam McGladdery, Executive Director, Universal Rehabilitation Service Agency (URSA)

METHODOLOGY

This Project integrated a variety of approaches:

- Facilitated conversations among sector participants, primarily the Steering Committee, through a series of focused sessions;
- Development of maps by the Steering Committee of the current state of ABI in Calgary and the desired future state;
- Engagement of Calgary ABI stakeholders, including ABI and medical practitioners, ABI individuals and family caregivers;
- Engagement of subject matter experts and best (or promising) practitioners in Alberta, Ontario and the United States; and
- Development of a literature review encompassing 70 resources.

Steering Committee members were provided with the literature review and a summary of recommendations from Calgary's ABI stakeholders, ABI subject matter experts and best practitioners, and asked to identify implications and prioritize a focused set of high-leverage recommendations for Calgary's Continuum. Throughout the process, they were encouraged to engage their own organizations and practitioner communities throughout the Project.

STAKEHOLDER ENGAGEMENT - ABI INDIVIDUALS AND CAREGIVERS

We conducted one-on-one interviews with nine individuals who have first-hand experience with Calgary's Continuum of Care. These were selected from a larger list recommended by the steering committee to represent the diversity of ABI individuals and their families. We spoke with four adults who live with an acquired brain injury and five individuals actively involved in supporting an ABI family member. Consistent themes emerged from the interviews.

A synopsis of our interviews with ABI individuals and their families is contained in Appendix V. While we committed to protecting their anonymity in this report, quotes from ABI individuals and their family members are included, where appropriate, across this report.

STAKEHOLDER ENGAGEMENT - CALGARY CONTINUUM STAKEHOLDERS

We interviewed ten Albertan ABI stakeholders, with a focus on persons who work in the Calgary Continuum. These were shortlisted by the Steering Committee from a longer list they recommended. Stakeholders came from the following organizations:

- A Clinical Neuropsychologist in private practice – Calgary, Alberta
- Alberta Health Services (Allied Health, Calgary Zone) – Calgary, Alberta
- Alberta Health Services (Community Assisted Rehabilitation) – Calgary, Alberta
- Alberta Health Services (Early Supported Discharge) – Calgary, Alberta
- Alberta Brain Injury Caregivers' Society – Red Deer, Alberta
- Alberta Brain Injury Initiative & Network – Edmonton, Alberta
- Foothills Medical Centre Brain Injury Rehabilitation Program – Calgary, Alberta
- Halvar Jonson Centre for Brain Injury – Ponoka, Alberta

All stakeholders were engaged using a standardized set of questions (see Appendix IV) in telephone and/or face-to-face interviews of an hour to ninety minutes each. Their insights and recommendations were often very similar and are captured in Appendix II.

STAKEHOLDER ENGAGEMENT - SUBJECT MATTER EXPERTS / BEST PRACTITIONERS

We contacted five best practitioners who were recommended by the Steering Committee who operated outside of the Calgary ABI Continuum. Interviews of up to 80 minutes were conducted with representatives of the following organizations:

- Edmonton Brain Care Centre – Edmonton, Alberta (EBCC)
- Toronto ABI Network – Toronto, Ontario (TABIN)
- Ontario Neurotrauma Foundation – Toronto, Ontario (ONF)
- NeuroRestorative – Ann Arbor, Michigan
- Rancho Los Amigos – Los Angeles, California (RLA)

While all best practitioners' circumstances were somewhat unique due to their geographic location, organization, governance and purpose, many described similar best practices which they had implemented, were striving towards, or otherwise admired. All were willing to continue their engagement with this Project. Selected observations are included in Appendix II. Their comments fell into the following categories:

- Service Coordination and Navigation, Case Management
- Collaborative, Multi-Disciplinary Team
- Concussion Services
- Lifetime Relationship
- Data Tracking and Documentation
- Effective Relationships and Networks
- Continuum of Care
- Leadership, Management and Professional Development
- Housing
- Mental Health
- Wellness, Recreation and Community Integration
- Vocational rehabilitation
- Mentoring
- Family Involvement
- Transportation
- Advocacy and Profile, Fundraising

LITERATURE REVIEW

We conducted a literature review, as required by the Project's scope of work. This is attached as Appendix III.

The Literature Review informed the Project by providing credible information about aspects of the continuum, helping better understand issues surrounding Calgary's Continuum and informing potential solutions. The Literature Review is intended to have a point of view and support the Project's work; it is not an academic work, nor intended to be a stand-alone, publishable work. It used 70 published peer-reviewed academic journals and published government and non-government agency reports sourced from academic library databases. Selected observations are included in Appendix II.

No revolutionary solutions to Calgary's ABI Continuum of Care were found. The Literature Review affirms soundly that the issues faced in Calgary's Continuum closely parallel those faced elsewhere. This is especially true for the post-acute Continuum, which struggles with aligning resources to best deal with new incidences and address the needs of the burgeoning prevalent population which requires long-term support. In other words, the gaps identified by the Steering Committee are all legitimate and truly need attention.

Appendix II – Strengths and Opportunities

STRENGTHS – The following strengths of Calgary's Continuum were identified by the Steering Committee:

- **Collaboration and Connection –** AHS, CSS and community Continuum participants are familiar with each other and have identified their coordination points, such as inter-agency meetings and referrals. There has been improvement in transition from the acute portion of the continuum to the post-acute, community portion.
- **Knowledge –** many participants in the ABI Continuum have a long history in the sector and were involved in developing and improving the current array of ABI services. The Steering Committee participants are knowledgeable leaders in the sector.
- **Resilience and Persistence –** All community agencies are resilient, having weathered changes in mandate, funding, and growing ABI incidence and prevalence. All view the Continuum as a work in progress, with little satisfaction for the status quo. The Steering Committee is proud of the number of persons their organizations serve, given limited resources.
- **Patient-Centred Care –** There is a strong ethos of patient-centred and family-centred care which drives the participants' work. Existing programs such as the CBIP were developed based on engagement with clients and families to improve outcomes.
- **Acknowledgement of Complexity –** The fact that two GoA ministries are represented on the Steering Committee shows acknowledgement of the complexity of the challenges facing the ABI Continuum and willingness to collaborate to address it.
- **Effort and Client Outcomes –** Every Continuum participant works hard to produce the best outcomes they possibly can. Families and ABI individuals provide very positive feedback about the services and care they receive.

OPPORTUNITIES – The following opportunities were synthesized from several sources:

- gaps identified by the steering committee in the existing Calgary Continuum;
- the steering committee's aspirational Future State Map;
- insights gathered from interviews with stakeholders and subject matter experts, best practitioners, ABI individuals and their family members;
- insights from the Literature Review.

Each of these opportunity categories is consequential; collectively, they impede the efficiency and effectiveness of Calgary's Continuum and ABI individuals' outcomes.

Table 4 - Opportunities
Opportunity A: Build capacity to address current and future service level needs and address gaps.
Opportunity B: Improve navigating the system of services and supports.
Opportunity C: Create the ability to track ABI incidence, treatment and outcome data through a central registry.
Opportunity D: Change capacity for concussion patients who are swamping the system.
Opportunity E: Increase ABI-suitable housing.
Opportunity F: Provide the right rehabilitation at the right time, including long-term maintenance support to prevent loss of gains.
Opportunity G: increase supports for families and unpaid caregivers.
Opportunity H: Increase support for transition to the community.
Opportunity I: Create capacity and competency for co-morbidities.
Opportunity J: Increase access to professional support.
Opportunity K: Enhance the ABI network, sharing of best practices and professional development.
Opportunity L: Build awareness of sector services within the medical community and enhance the ABI sector's profile externally to enable better awareness of ABI and resourcing.

OPPORTUNITY A: BUILD CAPACITY TO ADDRESS CURRENT AND FUTURE SERVICE LEVEL NEEDS AND ADDRESS GAPS.

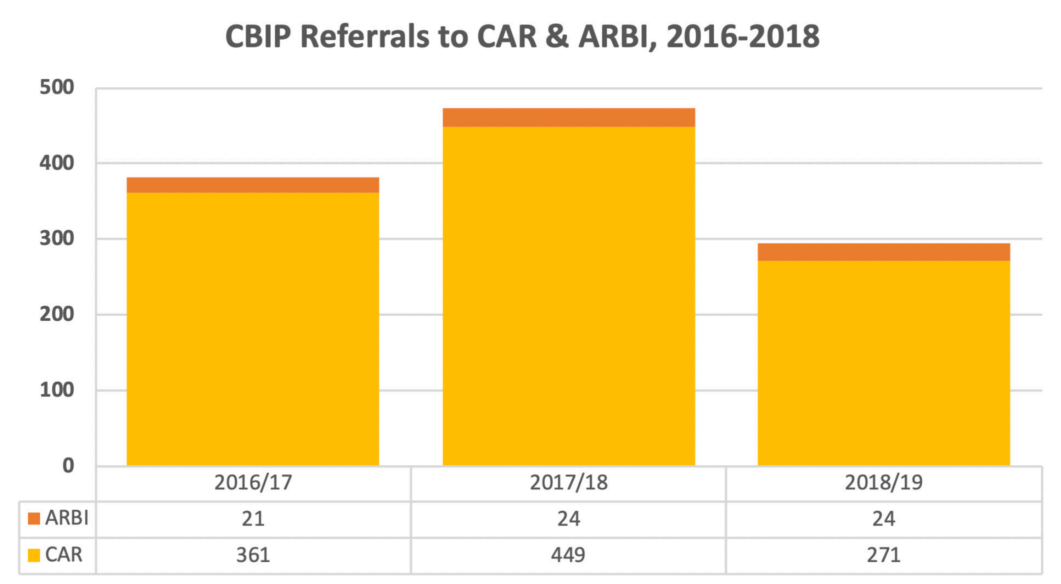
> "Common sense suggests that it makes little sense for society to spend millions on snatching people back from the jaws of death, but spend much less time on helping them to regain lives that have value and quality to them"
>
> *(Gentleman, 2001, "Rehabilitation after traumatic brain injury" Trauma, p. 202)*
>
> "We're working on his social skills. He's 40. It's a lonely life for (him). He wants a girlfriend. There is no real place to meet a girlfriend."
>
> *– Family member of ABI individual (car crash at age 16)*

The Situation - Demand exceeds supply for all ABI services, particularly in the community, including housing, rehabilitation, community support and integration, family support, mental health and addictions co-morbidity. Calgary's Continuum of Care has numerous identified gaps.

- The number of new ABI incidents greatly exceeds the community Continuum's capacity and Calgary's community agencies typically have wait lists.
- Some clients are accessing non-ABI services such as volunteer-led recreational classes for general disabilities which are not necessarily beneficial.

Clients with medical legal files or active disability insurance, with access to other resources, are drawing on already over-taxed publicly-funded resources.

Table 5 – Calgary Brain Injury Program Referrals to Community Accessible Rehabilitation and the Association for the Rehabilitation for Brain Injury



	2016/17	2017/18	2018/19
🟧 ARBI	21	24	24
🟨 CAR	361	449	271

Source: AHS, CBIP Database, May 2019

ARBI's capacity is fully utilized to the maximum of its AHS-contracted limits, constraining its ability to serve referrals from AHS, even though referrals to AHS-funded CAR fluctuates. **Please note that the 2018/19 year is April-December 2018.**

Table 6 – Number of ABI individuals Served and Average Waiting List for Services – Calgary Continuum of Care (Community Agencies – Most Recent Available Year)

Community Agency	Total Number of Referrals	Number ABI individuals Served	Average Waiting List
ARBI	58	On-site: 55 clients Outreach: 31 clients Community Integration Program: 30 clients	2.5 months
URSA	58	58	SCLS: 4 Clients waitlisted for 6 months
SABIS	276	276	2 months
Brain Injury Assist	53	SCLS: 45 clients	1.5-2 months
Total	**445**	**495**	

Table 6 shows the number of ABI individuals served in each organization's most recent year, and the average waiting list for service. Compared to the ABI incidence represented in Table 1 and the estimated prevalent population requiring lifetime access to care, the capacity of Calgary's ABI community agencies is vastly exceeded by the demand for their services by new ABI incidents and the life-long needs of the current and future prevalent population.

Literature Review Insights

- Our ability to treat ABI-caused deficits has not kept up with the ability to save human life, and ABI cases are increasing in both number and complexity. Improved ABI survival means more ABI individuals must deal with injury consequences and need long-term support.
- There is an illogical imbalance between the acute (public health) and post-acute (community) continuum portions. While the continuum's acute care end is relatively well-resourced and organized, the continuum's community-based end is consistently criticised for being relatively poorly-resourced, inflexible, uncoordinated, fragmented and inaccessible.
- A large Australian study of non-traumatic BI individuals showed long term brain injury care costs may exceed the combined costs of hospital, medical and paramedical care. The lifetime cost of brain injury per patient was estimated between A$2.6 M and A$5 M.
- ABI individuals discharged from hospital may wait long periods for admission into community rehabilitation programs and seek piecemeal care on their own from physiotherapists, psychologists, psychiatrists, neurologists, family physicians, chiropractors, walk-in clinics and emergency rooms. Because many rehabilitation services are not funded publicly, ABI individuals and families must undertake this cost burden (in the absence of insurance).
- By 2031, 450,000 TBI Canadians will require informal family-provided care, a level second only to Alzheimer's, at an average of 18 hours of informal care per week per individual.

Insights from SMEs and Best Practitioners

- ONF identified the need to re-balance emphasis in its continuum of care from focusing on front end acute care to the longer period of time an ABI individual spends in their continuum's community end. Funders and stakeholders pay more attention to the acute care end of the continuum, while issues in the community end are simply heaped.

Recommendations for the Calgary Continuum:

- Redirect concussion patients out of ABI stream toward more appropriate resources.
- Look at a gathering place suc has a clubhouse offering ABI-specific services and social interaction opportunities.
- Redirect those with active legal medical files/active disability insurance to services covered by insurance.

OPPORTUNITY B: IMPROVE NAVIGATING THE SYSTEM OF SERVICES AND SUPPORTS.

> "It would help if you could understand things more clearly about brain injury. Maybe because at the beginning you're in shock you're not able to absorb it. There's no central place to find out what's available. It would be nice to sit with a professional at different points in this journey."
>
> *– ABI family member*

The Situation – Navigating the Continuum is challenging and clients are not set up for success.

- Calgary's community ABI services and their varying intake criteria, program limits and waiting lists are very difficult to understand and navigate: clients often don't know what services are available, which they should access, or how to access them without a single source of advice, funding and assistance in accessing them. ABI individuals without a family advocate are especially challenged in successfully articulating their cases for service.
- AHS' Coordinated Discharge process provides some navigation advice for ABI individuals and families, but generally serves those receiving acute and post-acute services from AHS. Stroke patients have no equivalent case manager/navigator.
- Calgary's community agencies must hand-off clients among themselves. Lack of central navigation and a centralized registry hampers coordination and treatment planning.
- ABI individuals' varying characteristics (e.g. recovery speed, location, family support, pre-morbidity, dual-diagnoses, language and financial resources) can all impact service access

Literature Review Insights

- Case management is a relatively low-cost, high-impact way of improving effective access to the Continuum by ABI individuals and their families. The vast majority of ABI individuals who use case management find it valuable.
- Saskatchewan's ABI Working Group recommended a provincial ABI coordinator in 1995; this has also been identified as a priority for Alberta's continuum since at least 2003.
- For case management to be successful, community-based services must be available in sufficient quantity to meet demand for services in a timely way.

Insights from SMEs and Best Practitioners

- EBCC's case management helps ensure all ABI individuals are streamed into needed services, or placed on waiting lists.
- TABIN manages more than 1,000 referrals annually for community-based programs and fields calls from physicians, clients and families. Operating since 1995, its role is to find access to services and it provides early notification to the network about those leaving acute care and their needs. TABIN does not do actual case management; other community agencies do, but with long waiting lists.
- Ontario's health care system is organized into nearly a dozen Local Health Information Networks or LHIN. Every LHIN has an ABI navigator who connects to housing, rehabilitation, community integration, family support, etc. While not care coordinators, they make linkages among the system's nodes to ensure efficient flow.
- EBCC and TABIN also provide a centralized source of information accessible by ABI individuals and families to help understand what services are available.

Recommendations for the Calgary Continuum:

- Implement lifetime case management, which is essential to good and sustained outcomes. Case managers need to know key people, how to make the case for services, know all the options/inclusion criteria/philosophy of staff, and put it all together for the client.

OPPORTUNITY C: CREATE THE ABILITY TO TRACK ABI INCIDENCE, TREATMENT AND OUTCOME DATA THROUGH A CENTRAL REGISTRY.

The Situation - Without a central ABI registry, the growing number of ABI individuals living in Calgary, and their after-effects, are unknown. This makes comprehensive life-long case management and planning of service capacity impossible.

- No single, commonly-accessible, continuum-wide system for collecting and tracking individual ABI individual treatment and outcome data exists in Calgary.
- Comprehensive individual long-term treatment plans are not available and treatment is based on community agencies' best – but piecemeal – efforts, and no single agency can treat ABI individuals in a comprehensive, long-term way.
- Calgary's ABI community agencies have limited data gathering and tracking capacity; each tracks only their discipline-specific data and individual outcomes. Data sharing between AHS and community agencies is extremely limited and constrained by privacy regulations and medical protocol.
- Information quality and completeness about ABI individuals' medical situation, past care received, and current issues varies widely; community agencies must piece this together because ABI individuals may lose track of previous treatments.
- Because each brain injury is unique, outcomes will vary for each patient. One patient may recover their speech, another may regain the ability to drive, another may be able to make a short field trip to a mall, while another may return to their prior occupation. This makes it extremely difficult to identify outcomes in common.

Literature Review Insights

- Brain injury is often described as a silent epidemic in part due to the absence of accurate data regarding its incidence and prevalence.
- Effective data tracking is essential to successful case management; it is complicated by the lack of standardized outcome measurement tools for ABI across its various disciplines.

Insights from SMEs and Best Practitioners

- Best practitioners agree on the importance of an efficient data tracking tool; some are more successful than others in accomplishing this.
- EBCC uses a centralized database tool which includes in-house and third-party treatments and programs, including patient outcomes. AHS data is not included.
- TABIN tracks all referrals but not patient outcomes. It has developed standardized forms to ensure data is collected consistently across agencies, such as those for referrals.
- ONF is working on a protocol for common patient outcome measurement, given the lack of data tracking and sharing by community agencies.

Recommendations for the Calgary Continuum:

- Implement lifelong, accurate records of treatment/outcomes/goals/assessments, updated and accessible to all service providers. This enables case management and takes the onus off brain injury clients/families to remember aspects of treatment and drives efficiency into the system

OPPORTUNITY D: CHANGE CAPACITY FOR CONCUSSION PATIENTS WHO ARE SWAMPING THE SYSTEM.

The Situation - Concussion is a hot topic with fast-growing caseloads, but much misinformation and misdirection exists, contributing to poor outcomes.

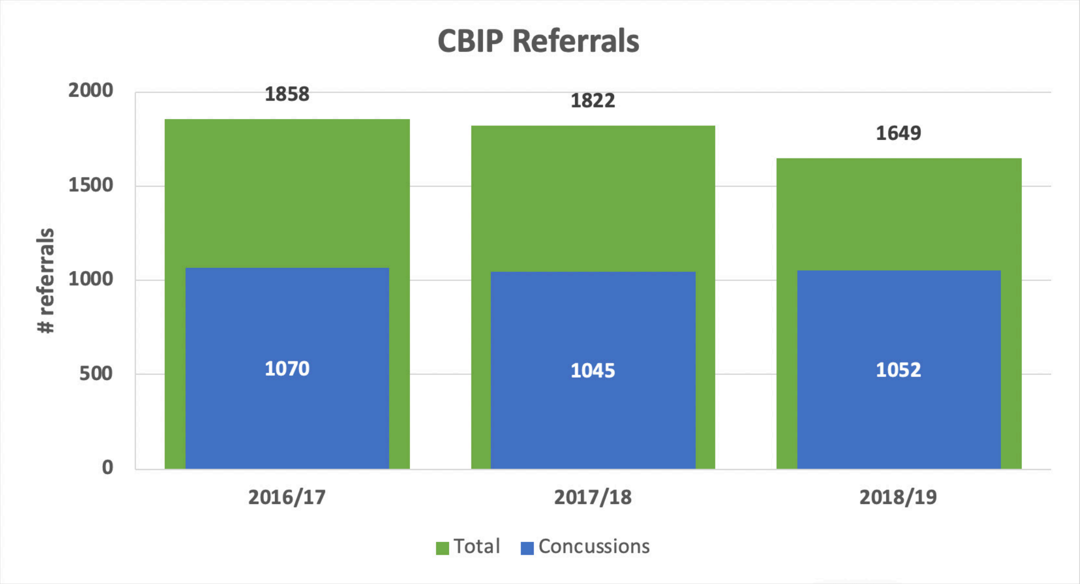
- Concussions have multiple entry points into the Continuum and point of entry affects the wait time for treatment.
- No treatment, too little treatment or the wrong treatment all lead to poor outcomes.
- Resources to support concussion individuals are not keeping up with growing demand. By not being differentiated from other ABI types, concussions use the existing system for treating moderate to severe brain injury, which is already over-taxed. This means concussion individuals cannot access care needed for them to return to normal life and employment.
- Concussion recovery should usually take weeks or months; research does not support intensive treatment. Over-medicalization can lead to mental health issues, e.g. depression.
- Family physicians don't have good information on concussion treatment and emergency room visits are not a good use of resources

Table 7 – Brain Injury and Concussion Clinic Visits							
Year	Total	New Visit	Clinic Follow-Up	Botox / Inj	Off Site	Phone F/U	Telehealth New & F/U
2014/15	2089	843	1059	77	27	75	8
2015/16	2540	1023	1234	70	43	149	21
2016/17	3054	1226	1285	117	19	389	18
2017/18	3485	1280	1400	211	7	582	5
2018/19 YTD	2563	951	1003	205	11	391	2

Source: AHS Millennium, May 2019

Table 7 shows the steady upward trend in total visits 2014-2017 to Foothills Medical Centre's Brain Injury and Concussion Clinic for all ABI types including concussion. The increase between 2018 and 2019 is less dramatic because the criteria for appearance at the clinic were tightened. AHS representatives stated that triage of concussion patients in the Calgary Brain Injury Program has increased by 1,000 per year, reinforcing the need for awareness and education programs to help re-direct these appearances to resources which would also better meet their needs, as most do not need Calgary Brain Injury Program services. **Please note that the 2018/19 year is April-December 2018.**

Table 8 – Concussion Referrals to Calgary Brain Injury Program as a Proportion of Total Referrals



Source: AHS, CBIP Database, May 2019

Concussion is "swamping the system", continuing to grow as a proportion of total BI referred to the Calgary Brain Injury Program. **Please note that the 2018/19 year is April-December 2018.**

Literature Review Insights

- Concussions are increasingly being recognized as brain injuries with significant potential long-term disabilities leading to depression or dementia. Like all brain injuries, recurrent concussions soon after prior injuries are worse, because recovery is incomplete.

Insights from SMEs and Best Practitioners

- EBCC treats concussion services as a separate stream funded differently than regular ABI. Except in severe cases, concussion patients need to have reached three months post- injury before acceptance into the EBCC program, and program wait lists are common. EBCC limits concussion individuals to up to 10 occupational therapy sessions.

Recommendations for the Calgary Continuum:

- Educate doctors, service providers, concussion patients, others about symptoms, recovery steps, best practices, recovery base rates and personality and psychological factors that can lead to poor outcomes.
- Offer education sessions focused on concussion patients rather than grouping them with severe brain injuries. A well-designed on-line tool supplemented with group education sessions would be very effective.
- Tighten referral criteria to direct concussion patients toward more appropriate resources, creating room for ABI patients requiring more intensive therapy, in the critical early window.

OPPORTUNITY E: INCREASE ABI-SUITABLE HOUSING.

> "In my house there are 16 stairs to get up and down. When I was in my wheelchair I had to bum my way up the stairs. I had a commode in my room."
>
> *- ABI individual (West Nile Neurological Encephalitis), describing returning to her home, after months in hospital, in a wheelchair*

> "It wasn't a place for a young man. There needs to be somewhere so their friends feel comfortable visiting them. I have a dream young kids will have a place they can go with programs suited for young people. And programs in place where they can have a peer. Someone more like them."
>
> *– Parent of an ABI individual (injured in car crash, age 16) regarding placement in the Dr. Vernon Fanning long-term care centre in the early months after his injury*

The Situation - There is a lack of suitable housing of all types to meet the needs of adults with ABI.

- ▹ Many ABI individuals require specialized housing; their needs vary over time as their impairments evolve and they may transition multi-directionally among various housing situations. The ABI diagnosis prevents individuals accessing some types of available housing. Calgary's acute ABI housing shortage includes:
  - Transitional Housing – Specialized ABI housing for those transitioning from hospital into the community, or from one housing type to another;
  - Mild and Moderate ABI Housing – Housing for those requiring only moderate support from a social or support worker;
  - Dual-Diagnosis Housing – Housing for those with mental health or substance abuse diagnosis requires specialized supports.
  - Without suitable housing, long-term institutionalization at publicly-funded facilities for seniors or dementia sufferers (e.g. Fanning Centre) becomes a default destination.
- ▹ To live at home, ABI individuals may require home renovations to accommodate physical impairments, but such renovations may be unaffordable or time-consuming.

Literature Review Insights

- Living environments encompass the physical space plus support and treatment, and services for safety, recovery, life habits and well-being. They profoundly impact ABI individuals' cognitive, behavioural and physical outcomes.
- ABI dual-diagnosis individuals face limited prospects for progress and higher likelihood of relapse. Some ABI individuals end up homeless as an outcome of their after-effects; this eliminates their chances of accessing diagnosis, treatment or improving.
- Frequent default housing solutions — hospital beds or geriatric facilities — are both a poor use of resources and deprive individuals of ABI-specific or age-appropriate social, cognitive and rehabilitative services when these are all significant to their successful recovery. They are particularly devastating to young ABI individuals.
- Returning home may not be the best choice for ABI individuals; semi-structured environments such as group homes or foster families show better results in accomplishing life habits and social integration than home environments or highly-structured institutional settings such as nursing homes or long-term care facilities.

Insights from SMEs and Best Practitioners

- NeuroRestorative has apartment-style housing units available for ABI individuals while in outpatient treatment, part of a continuous support system offered by that firm. Their 12-unit apartment provides full accessibility, 24-hour support, and a variety of programs, recreational, and leisure activities.

Recommendations for the Calgary Continuum:

- Secure sufficient housing for ABI individuals with different levels of disabilities and impairments. Such housing should include supports and supervision. While all types of ABI housing are needed, transitional housing is a priority.

OPPORTUNITY F: PROVIDE THE RIGHT REHABILITATION AT THE RIGHT TIME, INCLUDING LONG-TERM MAINTENANCE SUPPORT TO PREVENT LOSS OF GAINS.

> “What I don’t like is all the sudden stops...your life stops when you have a stroke. Everything has changed. Now you’re in Fanning, then that stops (and you have to move.) Now you’re in a nursing home and starting over again. You’re in a program, you get to know everybody, then all of a sudden, that ends. It’s not fair to these people. They’ve become a part of something because they aren’t part of anything anymore, and then it’s over. It’s a lot of endings.”
>
> *– ABI Family Member (stroke)*
>
> “If not for WCB, where would we be and where would our daughter be? She would be in the Fanning Centre or long-term care. I’d be ill, too, with stress. We would have been bankrupt.”
>
> *– Family Member of ABI individual (car crash, covered by Workers Compensation and resident in a group home)*

The Situation - Many ABI clients receive too little rehabilitation, rehabilitation at the wrong time, or too little, too late. Without long-term maintenance resources, ABI clients may lose the rehabilitation gains they have made.

- Intensive rehabilitation at the right time in a person’s recovery would result in massive cost savings for the system – a larger upfront investment providing large long-term returns.
- Many ABI individuals are cut off from publicly-supported rehabilitation programs after they, or the agency, reach a specified number of hours, versus having achieved their goals. Those with financial resources may access private providers, but most ABI individuals and their families find themselves in long-term financial crisis.
- Periodic rehabilitation is needed to help ABI individuals maintain gains from their intense, post-acute rehabilitation and to deal with their evolving impairments and after-effects. Some individuals forget their rehabilitation strategies, others turn up years later and are placed on wait lists; still others may wish to access previously-declined services.
- Maintenance rehabilitation is essentially non-existent, as Calgary’s existing resources are already overwhelmed with new cases, or individuals don’t meet entry criteria. ABI individuals then have little choice but to re-appear at AHS, generating unnecessary expense better-addressed by providing less-expensive community rehabilitation and support.

- While vocational rehabilitation increases ABI individuals' re-employability prospects, publicly-funded vocational rehabilitation for ABI individuals is not available, except for WCB-eligible injuries. Unemployed ABI individuals must rely on their families for assistance and family members may in turn need to leave employment to care for them.
- Publicly-funded, professional and intensive rehabilitation is not available in the home; travel is required, but even within the Calgary region it can be very difficult for ABI individuals, hard to arrange, and costly.
- ABI has cognitive, physical and behavioural impacts but not enough inter-disciplinary clinics exist in Calgary to holistically address ABI individuals' needs. This would save resources continuum-wide and lessen the challenges in finding and accessing care.

Literature Review Insights

- Patients in intensive outpatient/community-based rehabilitation have the best outcomes, especially when immediately post-injury.
- ABI has significant and enduring physical, cognitive, psychological and behavioural after-effects creating life-long impairments and disabilities notwithstanding the injury's classified severity (i.e. mild, moderate or severe). Life-long impairments mean ABI individuals require ongoing accessibility to rehabilitation and support services.
- People with neurological conditions have 12 times higher unemployment than those without neurological conditions. Less than 40% of Canadian TBI individuals and only 25% of stroke individuals are working; over one-quarter are permanently unable to work.

Insights from SMEs and Best Practitioners

- All acknowledge the long-term nature of ABI after-effects and establish lifetime relationships with ABI individuals. EBCC permits moderate to severe ABI individuals to reactivate their involvement with the centre whenever they want; RLA encourages ABI individuals and families to make RLA "home base", notwithstanding financial resources.
- NeuroRestorative said the importance of vocational rehabilitation cannot be overstated, and must start as early as possible. It provides vocational specialists who arrange for community placements and workshop settings from basic through to skilled levels.
- NeuroRestorative finds providing reliable transport helps ABI individuals consistently attend rehabilitation appointments, minimizing late arrivals or no-shows.

Recommendations for the Calgary Continuum:

- Invest in upfront intensive treatment, i.e. physical rehabilitation, psychological, etc., augmenting with aides as a cost-effective enhancement, particularly in outpatient or tertiary systems.
- Allow providers to adjust the duration and intensity of rehabilitation to fit the needs of clients rather than having hard and fast rules about extent and duration of treatment.
- Expand home and community-based services.
- Clients should be able to access AHS-funded occupational therapy after 18 months.
- Add peer support programs to bridge the gap between professional and natural support.

OPPORTUNITY G: INCREASE SUPPORTS FOR FAMILIES AND UNPAID CAREGIVERS.

“We had a hospital bed. I did diaper changes, bathing. I did it all. He was 18. He was still in a wheelchair then. It was tough getting him from the house to the car. He’s a big man.”

– Mother of ABI individual (40-year old male injured in a car crash at age 16)

“It’s a 24-hour job. We bring her home for a weekend once a month. She’s able to get around the house on her own. We have to be hyper vigilant. It’s exhausting.”

– Family Member of ABI individual (car crash, covered by Workers Compensation and resident in a group home)

“You put yourself last. You need some break from the burden. Where do the friends go? They all go back to their lives. If you had someone to give you a break…. that would be great.”

– Family member of ABI individual (stroke)

The Situation - More and better support is needed for family members and unpaid caregivers.

- A family member with a brain injury affects every aspect of family life. Families are often unprepared for their new reality and the significant and complex burden of care.
- Family psycho-social support in Calgary is limited to a few peer support groups; one-on-one counselling is extremely rare. As default caregivers, family members are often too exhausted — or the caregiving burden is too large — for them to access to these supports.
- Family caregivers need to access competent respite care from time to time, so that they may maintain their own health, quality of life and effectiveness, and to access the supports which can help them. Calgary’s respite care is expensive and extremely limited.

Literature Review Insights

- ABI's impact on ABI individuals and their families is described as, "physical, psychological, financial, legal and social devastation". Impacts can include psychological disorders, increased prescription/non-prescription drug consumption, financial difficulties, poor social adjustment and increasing isolation, marital breakdown, low satisfaction with life, loss of lifestyle and independence, deterioration of overall health and higher mortality. Without ongoing support, family caregivers enter the medical system.
- ABI caregiving is hard work and the burden is uniquely difficult compared to other diseases due its longer-term nature, ABI individuals' challenging behaviours, and inaccessibility of ABI-specific services. Families may lack required caregiving skills and have difficulty understanding and accessing available resources and supports.
- Caregiver well-being impacts ABI individual well-being; caregivers who are functioning well emotionally can contribute to better outcomes for the ABI individual. Family caregivers report numerous unmet needs and services which have stopped or became inaccessible for which they must fill the void. Family caregivers need long-term access to a variety of psychological, informational, leisure, transport, respite care and peer support services.

Insights from SMEs and Best Practitioners

- NeuroRestorative emphasized the importance of family involvement throughout the ABI individual's participation with the organization. Trust between family, patient and NeuroRestorative are critical, particularly given NeuroRestorative's mandate to return the ABI individual to the highest-possible level of function within the critical first 18 months.
- RLA is also trying to build family caregiver support groups.

Recommendations for the Calgary Continuum:

- Provide suitable and sufficient respite care for ABI individuals

OPPORTUNITY H: INCREASE SUPPORT FOR TRANSITION TO THE COMMUNITY.

> "You stay only so long AHS would allow. There's no follow up, no community for a person with a brain injury. It's here you go, make it in the world"
>
> *– ABI individual*

The Situation - Clients and families would benefit from additional and better-coordinated support for transition from acute/inpatient care to community care.

- Early weeks/months following treatment are challenging for both clients and families, and reality is often harsher than anticipated. Awareness of their new reality can lead to depression and anxiety.
- Initial living arrangements may prove to be inappropriate, and there is no suitable housing for ABI individuals when transitioning from hospital into the community.

Literature Review Insights

- Transition quality greatly impacts ABI individuals' longer-term success in accomplishing daily living activities, community integration, maintaining rehabilitation gains and quality of life.
- ABI's life-long impacts and numerous transitions are more complex than other illnesses. Transition to life outside of hospital is a major step for which many feel unprepared.
- Many effective transition strategies are available, including ABI-specific transitional housing, "trial run" home visits, skills development services, family support, and using case management to help locate and access appropriate services.

Insights from SMEs and Best Practitioners

- EBCC's coordinator administers a leisure companion support program, providing companions (often university students) who accompany ABI individuals to the gym, church, for coffee, etc.
- RLA's foundation builds community partnerships which have included participation in events and light work in a local store. RLA's peer mentorship program provides mentors throughout all stages of the continuum and mentors may become trained coaches, program leaders, or even paid RLA staff.

Recommendations for the Calgary Continuum:

- Secure ABI-appropriate transitional housing for Calgary ABI clients.
- Coordinate client discharge so clients leave hospital with a clear plan based on pre-discharge assessment of living arrangements and family supports so they are well-connected to care and clients and family know who to call.
- Provide a portion of in-hospital pre-discharge rehabilitation in a home-like environment.
- Re-assess client living arrangements shortly after discharge, and adjust as required.

OPPORTUNITY I: CREATE CAPACITY AND COMPETENCY FOR CO-MORBIDITIES.

The Situation - The system lacks capacity and competency in supporting clients who have the co-morbidities of brain injury and/or addiction and mental health struggles.

- ABI individuals dealing with mental health and/or substance abuse issues require specialized professional supports.
- Despite the frequent cross-over between brain injury and mental health issues, Calgary's Continuum is barely set up to treat either one or the other, let alone both. Co-morbidities such as mental health or drug and alcohol abuse create a complex situation in which the Calgary Brain Injury Program must treat brain injury while managing patients' other medical issues.
- Few services are able to treat ABI clients who also have addictions or mental health challenges. There is no single agency or mechanism to serve their complex needs.
- There is uncertainty about whether to treat brain injury or mental health/addiction first.
- This impacts the effectiveness of ABI Individuals' mental health, brain injury or addictions treatment and increases the probability of relapses and multiple returns into the health care system.
- Those with co-morbidities are under-served on all fronts. Patients often bounce between mental health, brain injury and addictions systems. There are few housing options available for clients with these co-morbidities.

Table 9 – Calgary Brain Injury Program Referrals

Year	Total referrals	Mental health	Chronic alcohol or drug addiction	Alcohol or drug use at time of injury	Previous brain injury
2016/17	1858	176	68	96	144
2017/18	1822	187	29	84	107
2018/19 YTD	1649	225	46	97	146

Source: AHS, CBIP Database, May 2019

Table 9 shows the significant proportion of patients referred to the Calgary Brain Injury Program who have mental health, alcohol or drug use, or a previous brain injury. **Please note that the 2018/2019 year is April-December 2018, or three-quarters of a year.** For the last full year, 2017-2018, the table shows that of the 1,822 patients referred to the program, 187 had mental health issues, 29 had chronic alcohol or drug addiction, 84 reported alcohol or drug use at the time of injury, and 107 had previous brain injuries. These categories are not exclusive. Some patients may have had concurrent issues and others may not.

Literature Review Insights

- There are clear connections and high co-existence among ABI, various forms of mental illness, and substance abuse. ABI and substance abuse each increase the risks of the other. Diagnoses of all three should be expected.
- Specialized identification, treatment, support and accommodation are required for successful outcomes. Failed treatments in one area lead to relapses in the others.

Insights from SMEs and Best Practitioners

- ONF spoke of initiating several projects to better integrate mental health and ABI services, a move supported by its stakeholders.
- NeuroRestorative's treatment team includes clinical psychologists who are substance abuse specialists.

Recommendations for the Calgary Continuum:

- Train service providers and professionals in brain injury and to be proficient in recognizing mental health and addiction issues so these issues may be referred to specialized professionals.
- Foster better collaboration between practitioners in all three streams: brain injury, mental health and addiction.

OPPORTUNITY J: INCREASE ACCESS TO PROFESSIONAL SUPPORT.

The Situation - Too few brain injury clients get the psychosocial support they require and end up with adjustment issues, depression and other mental health problems.

- Some ABI individuals would benefit from lifetime access to a physiatrist. Some community rehabilitation programs require physiatrist certification as an admission pre-requisite, requiring re-admission to AHS, which faces ongoing capacity issues treating new incidences and cannot provide timely access to prevalent ABI individuals.

- Many ABI individuals need access to specialized psychological care, notably neuropsychology, to successfully deal with ongoing impairments, behavioural and cognitive after-effects. Calgary has very few publicly-funded neuropsychologists, impacting ABI individuals' ability to integrate with their communities or hold employment.

- Some patients at 12 to 18 months post-injury have never received psychosocial intervention (one Calgary stakeholder estimates only 10 to 20 per cent of brain injury patients he sees have received appropriate psychosocial support). They are depressed and can't get off the couch, stop following programs or develop unhealthy addictions and this places their outcomes at risk. Those with mental health issues pre-injury have much poorer outcomes without post-injury support.

Literature Review Insights

- 90% of ABI individuals are confronted with life-long cognitive, psychological, behavioural or psychiatric challenges which undermine successful community integration, independent living, relationships, and employment.
- We tend to underestimate the enduring nature of ABI's barriers to community participation; between 26% and 45% of ABI individuals are inadequately reintegrated post-injury. Psychosocial and behavioural difficulties limit role resumption and community integration more than do physical deficits.
- About 30% of Canadian TBI individuals living with a neurological condition reported they had fair or poor health. Canadian brain injury, brain tumour and stroke individuals all reported severe levels of disability and many report mood disorders.

Insights from SMEs and Best Practitioners

- A highly collaborative, flexible, multi-disciplinary team is essential. This includes regular information-sharing among team members regarding clients, processes and issues.

Recommendations for the Calgary Continuum:

- ABI Patients should receive three to five counselling sessions within a month or two of discharge from hospital and should receive mental health monitoring after discharge.
- Social workers/occupational therapists could provide helpful education to aid in post-injury adjustment.
- Establish and capture mental health ratings, along with ratings about quality of life, physical functioning, goals achieved and use them to evaluate program effectiveness.

OPPORTUNITY K: ENHANCE THE ABI NETWORK, SHARING OF BEST PRACTICES AND PROFESSIONAL DEVELOPMENT.

The Situation - Alberta's ABI community is challenged by the lack of a comprehensive central Alberta network *embracing all community agencies.* This hampers sector efficiency and effectiveness.

- While Calgary's community agencies meet regularly to discuss client matters, a comprehensive central Alberta network *embracing all community agencies* would enable better capacity analysis and planning, inter-agency coordination, understanding and proliferation of best practices, and access to funded professional development for ABI practitioners. The end result would be better access to quality treatment for ABI individuals.
- There are few professional development opportunities available for ABI practitioners and little available funding (or time) to access those available. Therefore, best practices cannot be shared and the entire Continuum's ongoing improvement is impaired.

Literature Review Insights

- While significant, this topic was not researched in the Literature Review.

Insights from SMEs and Best Practitioners

- All best practitioners emphasized the importance of good relationships within their continuum of care, starting with hospitals.
- TABIN is member-based and works for its members, and its members are highly invested in TABIN's work. Strong and "warm" handoffs are an essential part of referrals among TABIN's members. Seen as an impartial, centralized voice, TABIN provides a centralized forum for members to collaboratively work on issues with a very patient- and client-focused approach which engages all stakeholders. Key to this success is the role played by TABIN's project manager, who makes fast and effective interventions in process issues.
- Ontario's provincial ABI network meets quarterly with its ABI LHIN Navigators to discuss issues and strategies.
- Best practitioners spoke of the importance of professional development for ABI workers. This is challenging because funding is scarce. RLA provides monthly ABI education sessions across the entire continuum to build awareness of its programs.

Recommendations for the Calgary Continuum:

- Eliminate barriers to entry and participation in Alberta's existing brain injury network.
- Build on the success of the current project to address continuum-wide issues, clarify mandates and optimize use of community resources.

OPPORTUNITY L: BUILD AWARENESS OF SECTOR SERVICES WITHIN THE MEDICAL COMMUNITY AND ENHANCE THE ABI SECTOR'S PROFILE EXTERNALLY TO ENABLE BETTER AWARENESS OF ABI AND RESOURCING.

The Situation - Too few doctors and service providers in the community understand the breadth and depth of brain injury services and the service offerings of individual organizations. The ABI sector has a low profile within the general public and is not well-understood.

- ABI is often misrepresented in popular media: in movies, coma patients wake up and resume their normal lives. However, the reality is quite different.
- Unlike other illness categories, ABI has a relatively low profile, lacks a national champion, and ABI individuals are often invisible in the community. Combined, this impairs the sector's ability to obtain funding.
- Funding for services throughout the community Continuum does not align with the current and future need for services. Community agencies cannot serve incoming "new" ABI cases to the degree needed, let alone provide ongoing maintenance and support to the prevalent population living with ABI and evolving lifetime impairments and after-effects.
- Because every ABI individual's injuries and circumstances are unique, the ABI Continuum requires flexibility in responding to their needs such as length of treatment programs. Limited resources mean the Continuum has reduced flexibility to respond to individual needs, impacting outcomes.

Literature Review Insights

- While significant, this topic was not researched in the Literature Review.

Insights from SMEs and Best Practitioners

- EBCC spoke of the need to build awareness and enhance the profile of Adult ABI, finding that adults with ABI who are not cared for by family have no real advocates. This is compounded by popular culture's portrayal of brain injury.
- RLA has a foundation which works very hard to locate community and corporate partners and raise funds for its ABI activity.

Recommendations for the Calgary Continuum:

- Better educate the community, including family doctors and service providers, about the services offered by individual organizations and share widely information about changes in admission criteria, etc.
- Continue to build awareness, familiarity and collaboration within the ABI community along the entire Continuum.
- Work on areas collaboratively, across Ministries and agencies. This, for example could see sharing access to AHS health care records with the ABI community as part of government's information-sharing strategy.

Appendix III – Literature Review

1.0 INTRODUCTION

1.1 Purpose and Limitations

For the purposes of this literature review, acquired brain injury (ABI) occurs after birth and is the consequence of stroke, trauma, known as traumatic brain injury (TBI), infectious disease, tumour, hypoxia, or alcohol and drug use. It excludes brain injuries related to congenital disorder or a degenerative disease (Lorenz and Katz, 2015; Brain Injury Australia, 2007 cited in Mahar and Fraser, 2012(2); Fortune and Wen cited in Turner, Fleming, Cornwell et al, 2007).

The purpose of this literature review is to obtain credible information about various aspects of the Acquired Brain Injury (ABI, BI) continuum of care (continuum) to inform the Acquired Brain Injury Sector Project (ABI Project, Project) and better understand issues surrounding Calgary's Continuum and potential solutions. It focuses on the post-discharge portion of the Continuum, i.e. following acute care and inpatient rehabilitation. Given the scope of this project, this literature review does not provide an exhaustive analysis of any specific aspect of ABI or the Continuum and it is not intended to be a stand-alone, publishable work.

1.2 Methodology

This literature review relies solely on published, peer-reviewed academic journals and published reports from government and non-government agencies such as the Public Health Agency of Canada and the Canadian Institute for Health Information. Material was accessed from academic library databases using a range of search keywords based on topics raised by the ABI Project's Steering Committee (Steering Committee) and subject matter experts interviewed as part of the Project. Subject matter expert recommendations on useful articles were also followed.

Articles were prioritized for review based on publication date and factors such as study sample size, quantitative methodology and location, especially Canada, the United States, Australia and the United Kingdom. A quantitative analysis of article results was not done. This review did not attempt to achieve balanced representation among articles about ABI, TBI, stroke, nor among mild, moderate or severe brain injury severity although, where possible, the injury nature and severity are cited in text.

2.0 ABI INCIDENCE AND PREVALENCE

2.1 ABI Incidence

Brain injury is a major problem in Canada (Tator, 2010) and traumatic brain injuries form "...a significant portion of the burden of neurological conditions in Canada" (Canadian Institute of Health Information, 2007 cited in Tator, 2010, p. 714). While "ABI is the principal cause of disability in our society" (Rees, 2005 cited in Mahar and Fraser, 2012(2), p. 70), brain injury is often described as a silent epidemic due to the relative invisibility of ABI survivors' impairments and disabilities and the absence of accurate data regarding its incidence and prevalence (e.g. Lefebvre and Levert, 2012, p. 197).

"Incidence" refers to annual occurrences of brain injuries; the estimated incidence of brain injury varies among studies:

- 11.4 per 100,000 population (severe TBI, Canada) (Zygun et al, 2005 cited in Canadian Institute for Health Information, 2007)
- 92.1 per 100,000 (TBI, Quebec indigenous persons) (Lasry, Dudley, Fuhrer et al, 2016)
- Over 100 per 100,000 (mild TBI, England) (Thornhill, Teasdale, Murray et al, 2000)
- 118 per 100,000 (TBI, Finland) (Winqvist, 2007 cited in Corrigan, Selassie and Orman, 2010)
- 120 per 100,000 (TBI, North America) (several authors cited in Baptiste, Dawson, Streiner et al, 2015) 222 per 100,000 (TBI, Saskatchewan) (Acquired Brain Injury Working Group, 1995)
- 250-300 per 100,000, 90% of which is mild TBI (TBI, unspecified) (MacMillan, 1981 and Wasserburg, 2002 cited in Zumstein, Moser, Mottini et al, 2011)
- 506.4 per 100,000 (TBI, United States) (Langlois, 2006 cited in Corrigan, Selassie and Orman, 2010)
- 600 per 100,000 (mild TBI, Canada) (Cassidy et al, 2004 cited in Canadian Institute for Health Information, 2007)
- 1,750 per 100,000 (TBI, New Zealand) (McKinlay, 2008 cited in Corrigan, Selassie and Orman, 2010)
- 1,800 per 100,000 (mild TBI, Ontario, adults 18 and over) (Levy, Langer and Bayley (not dated) cited in Hunt, Zanetti, Kirkham et al, 2016).

In the United States, between 1.4 and 17 million (M) Americans annually sustain a TBI (Finkelstein, 2000 and Langlois, 2004 cited in Zaloshnja, Miller, Langlois et al, 2008; Centers for Disease Control and Prevention, National Centre for Injury and Prevention and Control, 2010 cited by Chen, Bushmeneva and Zigorski, 2012); 1.1 M Americans with TBI are treated and released from emergency departments, 235,000 are hospitalized for non-fatal TBI and 50,000 die annually (Langlois, 2006 cited in Corrigan, Selassie and Orman, 2010). 124,000 (43%) of TBI discharges from acute care will develop long term disability annually (Selassie, 2008 cited in Corrigan, Selassie and Orman, 2010). No literature we found suggested that annual incidence of ABI is declining (for example, Colantonio, Howse, Kirsh et al, 2010), and concussions are increasingly being recognized as brain injuries with significant potential long-term disabilities leading to depression or dementia (Tator, 2010).

Recurrence of TBI is significant because recurrent TBI patients – even those with mild TBI – have poorer outcomes in terms of longer disabilities and more severe symptoms and co-morbidities (several authors cited in Lasry, Liu, Powell et al, 2017). Recurring brain injuries soon after prior injuries are worse because recovery from the preceding injury is incomplete (Lasry, Liu, Powell et al, 2017).

Brain injury incidence is very difficult to estimate, for many reasons, and it is likely that all brain injury incidence and prevalence figures are underestimated (Corrigan, Selassie and Orman, 2010). Population-based studies, which review incidence of a particular group over long periods, are large, costly and complicated; by tallying certain statistics such as emergency room or hospitalization cases or excluding certain populations, such as the military, studies can arrive at different estimated incidence.

For example, calculating incidence using only hospitalized brain injuries will overlook brain injuries which present at emergency departments and are released; using both emergency department presentation and hospitalization data means overlooking brain injuries presenting at family physicians and those never reported which go untreated (Corrigan, Selassie and Orman, 2010). How head injury is defined (e.g. ABI versus TBI) and how severity is categorized, e.g. mild, moderate or severe, can also vary (Corrigan, Selassie and Orman, 2010; Menon et al, 2010 cited in Lasry, Liu, Powell et al, 2017; Acquired Brain Injury Working Group, 1995; Colantonio, 2010). Furthermore, brain injuries may be mis-diagnosed in hospital or diagnostic data may be incorrectly recorded and the injury not reported or treated.

2.2 ABI Prevalence

Whereas incidence describes the number of injuries, prevalence is defined as "the number of people in a defined geographic region... who have ever had a TBI and are living with symptoms or problems related to the TBI" (Corrigan, Selassie and Orman, 2010, p. 76). Given the fact that brain injury often results in long-term or lifetime impairments and disabilities, prevalence "... is an important indicator of the ongoing impact of TBI on society and the need for ongoing resources" (Corrigan, Selassie and Orman, 2010, p. 79) and should be of interest to policy-makers (Zaloshnja, Miller, Langlois et al, 2008).

In the United States, an estimated 1.1% of the population (or between 3.17 to 3.32 M persons) have disability from a traumatic brain injury (Zaloshnja, Miller, Langlois et al, 2008). "Disability was defined broadly and included inability or substantial difficulty performing activities of daily living, having post-injury symptoms that prevented the person from doing the things they wanted to do, and poor cognitive and mental health scores on standard measures based on findings from a previous population-based study" (Selassie, 2008 quoted in Corrigan, Selassie and Orman, 2010).

Prevalence estimates found in the literature include:

- .14% (Brain tumour, Canada) (Public Health Agency of Canada, 2014)
- .98% (Stroke, Canada) (Public Health Agency of Canada, 2014)

- 1.1% (TBI with disability, United States) (Zaloshnja, Miller, Langlois et al. 2008)
- 1.6% (TBI, Canada (projection for 2011) (Public Health Agency of Canada, 2014)
- 2% (TBI with disability, United States) (National Center for Injury Prevention and Control, 1999 cited by Chen, Bushmenova, Zagorski et al, 2012))
- 5.7% (TBI, Australia) (Anstey, Butterworth, Jorm et al, 2004)
- 8.5% (TBI, New England) (Silver, Kramer and Greenwald et al, 2001)
- 37% (adult males, with at least one mild TBI in their lifetime, United States) (American College of Surgeons, 2009, cited in Zumstein, Moser, Mottini, 2011).

ABI prevalence is also very difficult to estimate. In-depth prevalence estimates must account for factors such as population estimates and growth, brain injury incidence rates, nuanced injury coding in hospital, reduced life expectancy for BI survivors and BI-related deaths (Zaloshnja, Miller, Langlois et al, 2008). Interview-based studies which ask subjects to recall if they ever had a brain injury are criticized because recall may be faulty (Corrigan, Selassie and Orman, 2010). We also don’t follow TBI survivors over time to see who recovers and who has life-long problems, nor those treated outside of hospital or those never treated at all: one study estimated that less than half of TBI of patients presented again in hospital after discharge and only 28% sought treatment from rehabilitation services (Thornhill, Teasdale, Murray et al, 2000).

2.3 Forecasted Incidence and Prevalence

Both the incidence and prevalence of brain injury in Canada are predicted to grow. The Public Health Agency of Canada (2014, p. 68) predicts TBI incidence will grow from 60 per 100,000 in the year 2021 to 70 per 100,000 by the year 2031. The prevalence of Canadians with TBI will increase at about 2% per year, reaching 640,100 by 2021 and 780,300 by 2031 (Public Health Agency of Canada, 2014, p. 66) TBI will be Canada’s most prevalent neurological condition (Public Health Agency of Canada, 2014).

By 2031, the number of new hospitalizations with TBI will increase by 28% and the number of Canadians age 65 and over with TBI will have more than doubled. By then, the number of Canadians living with severe disability from Alzheimer’s will reach the same level of those hospitalized with TBI (Public Health Agency of Canada, 2014) although hospitalized TBI survivors will still have the highest level of disability (Public Health Agency of Canada, 2014). This trend is significant because BI is a risk factor for Alzheimer’s, other dementias and epilepsy (Public Health Agency of Canada, 2014).

2.4 Challenges in Describing ABI Severity

Current indices of ABI severity “have very low discriminatory power in predicting longer-term outcomes of TBI... The intuitive assumption that the greater the severity score, the more likely the injury will result in disability is supported only in cursory indices of association” (Corrigan, Selassie and Orman, 2010, p. 78). Likewise, Thornhill, Teasdale, Murray et al (2000) challenge the validity of mild as a brain injury classification, finding that the proportion of individuals who survive their brain injury with a disability are roughly equal across the range of severities – 47% (mild), 45% (moderate) and 48% (severe).

2.5 ABI Risk Factors

Risk factors for TBI include: age and gender (Thurman, 1999 cited in Corrigan, Selassie and Orman, 2010), low socio-economic status (Thurman, 1999 cited in Corrigan, Selassie and Orman, 2010; Acquired Brain Injury Working Group, 1995); disrupted families, premorbid history of learning or attention deficits; substance abuse history or drinking before injury; (Acquired Brain Injury Working Group, 1995). Risk of recurrent TBI increases with being male, having had prior TBIs, or alcohol use (Lasry, Liu, Powell et al, 2017). Up to 5.5% of TBI survivors will have another TBI after 1 year (Lasry, Liu, Powell et al, 2017).

2.6 ABI and Indigeneity

Aboriginals are disproportionately represented among the TBI population (Adekoya, 2002 cited in Corrigan, Selassie and Orman, 2010; Acquired Brain Injury Working Group, 1995; Lasry, Dudley, Fuhrer et al, 2016). In the Calgary Health Region, across every age category, "Aboriginal Canadians were at much higher risk than the reference population... of sustaining severe trauma (257.2 v. 68.8 per 100,000)..." (Karmali, Laupland, Harropp et al, 2005, 10%), and significantly higher for men than women (Karmali, Laupland, Harropp et al, 2005, 40%). TBI incidence in selected indigenous populations in Quebec (2002 to 2012) was 92.1 per 100,000 person years, far higher than the provincial average. Different mechanisms of injury were found in different aboriginal geographic groups, for example, rural environments had more transport-related accidents (Lasry, Dudley, Fuhrer et al, 2016).

2.7 Implications for Calgary's Continuum

Applying the above prevalence range of 1.1% to 8.5% to Alberta's estimated population of 4.3M people (Province of Alberta, 2018) suggests 47,300 to 365,500 persons are living in Alberta with some degree of disability from a brain injury, or between 13,941 and 107,724 persons within Calgary's city limits (using Calgary's 2018 population of 1,267,344 (City of Calgary, 2018)). This is usefully contrasted against the capacity of Calgary's few community-based brain injury service organizations. A similar comparison was done with the estimated prevalence of 31,000 South Australians living with ABI repercussions with the limited capacity of the small community organizations in that region which provide rehabilitation, home support, workshops, etc. with long waiting lists (Mahar and Fraser, 2012(2)). While all persons in the prevalent population won't all need services all the time, those with brain injury disabilities and impairments often need to access services throughout their lifetimes, as shown elsewhere in this literature review (e.g. Mahar and Fraser, 2012(2)).

Absent a major medical or prevention breakthrough, brain injury incidence and prevalence in Calgary will continue to climb, with concussion being a particular issue identified in our interviews. Because BI often has lifetime impairments and disabilities, increased prevalence means increased long-term demands on all segments of Calgary's Continuum. As Calgary's post-acute Continuum already struggles with capacity, its ability to deal with increased new cases and growing prevalent BI population will be further stretched and this segment of profoundly impacted Albertans will be under-served.

3.0 SURVIVORS, REHABILITATION AND THE CONTINUUM OF CARE

3.1 The Nature of the ABI Continuum of Care

The notion of a Brain Injury continuum of care started in the 1970s (Goka and Arakaki, 1994). Brain injury is heterogeneous; therefore, the continuum of care must adapt to a wide variety of injury severities, patient circumstances, needs and after-effects (sequelae). “It should be understood that this “continuum” of care is not linear. One does not progress through all phases of the recovery process and neatly transition from one to the next. This is the challenge – determining who fits where and at what time” (Goka and Arakaki, 1994, p. 420).

There are many different continuum of care models (e.g. Goka and Arakaki, 1994; Lorenz and Katz, 2015; Cioe and Seale, 2018). However, they generally appear to contain the following stages:

- In hospital:
    - Acute Care – emergency treatment, intensive care unit, specialty medical services, physician services;
    - Inpatient Rehabilitation – inpatient rehabilitation and transitional residential treatment;
- Outside of hospital:
    - Post-Acute, Community-Based Rehabilitation and Long-Term Care – home, long-term residential treatment facilities, outpatient rehabilitation and day treatment, school and vocational services.

Degeneffe, Green and Jones (2016) tell us, “The provision of outpatient and other community-based supports is critically important to help injured persons maintain and build on rehabilitation gains made during inpatient ABI rehabilitation” (pp. 128-129). Access to post-acute care is critical in “...address(ing) ABI impairment and increase(ing) the potential for vocational participation, independent living, and overall positive quality of life” (Degeneffe, Green and Jones, 2016, p. 133).

A study of 119 Australian survivors of severe TBI demonstrates a surprising breadth of services in the post-acute continuum; in that country it includes “accommodation, home support, respite, day activity, legal, crisis, ethnic services, miscellaneous, medical and allied health, financial, vocational and educational, transport” (Hodgkinson, Veerabangsa, Drane et al, 2000, pp. 1214-1215). A study of 21 family caregivers in a large Western U.S. city identified the most helpful services in the early stages of post-acute discharge as falling into three categories:

- “Professional Consultation and Assessment”, including telephone or in-person consultations with physicians, psychologists or social workers, as well as referrals to other providers and neuropsychological assessment;
- “Therapy and Intervention”, including day treatment, physical therapy, a vestibular programme, community transitions programme, vision care, occupational therapy, and home health care;
- “Peer Support”, including recreational programmes, information/referral and support to ABI organizations, and support groups (Degeneffe, Green and Jones, 2017, p. 94).

3.2 Rehabilitation in the Continuum of Care

Rehabilitation is “typically composed of a highly individualized set of evidence-based services provided by an interdisciplinary or transdisciplinary team that develops a therapeutic relationship with the person served” (Malec and Kean, 2016, p. 1371). For ABI survivors, effective rehabilitation includes “... (1) assisting participants to develop and use compensatory strategies to address residual cognitive deficits; (2) arranging environmental supports, which includes family relationships, accommodations at work placement sites, and transportation, to maximize participants’ functioning; (3) providing counselling and education to address personal and family adjustment and improve accurate self-awareness; (4) providing transition from simulated activities in the clinic to productive activities in the community” (Sander, Maestas and Sherer, 2012, p. 844).

A combination of intensive rehabilitation and supportive living works best: a recent study of 3,087 ABI individuals across 13 U.S. states demonstrated a combination of rehabilitation and supported living resulted in “...substantially improved ability, adjustment, and community participation over the course of rehabilitative treatment” (Malec and Kean, 2016, p.1376) compared to supportive living only. Patients in intensive outpatient/community-based rehabilitation have the best outcomes (Malec and Kean, 2016), and immediate post-injury admission into rehabilitation creates substantially better outcomes than later admission (Malec and Kean, 2016).

A surprisingly broad spectrum of ABI survivors’ long-term needs (or “life habits”) must be supported with human assistance, encompassing both “Activities of Daily Living” (such as nutrition, personal care, mobility) and “Social Roles” (community life, work or leisure activities) (Lamontagne, Ouellet and Simard, 2009). ABI survivors may only be able to complete less than two-thirds (59%) of their life habits without assistance, and human assistance is three times more important than technical assistance, or adaptation (Lamontagne, Ouellet and Simard, 2009, p.696). Interestingly, human assistance is required more often to carry out life habits related to social roles than the activities of daily living (Lamontagne, Ouellet and Simard, 2009).

3.3 The Long-Term Nature of ABI Impairments and Disabilities

ABI has significant and enduring life-long implications; survivors generally do not just “get better” and a large proportion will have ongoing physical, cognitive, psychological and behavioural sequelae creating life-long impairments and disabilities notwithstanding the injury’s classified severity, whether mild, moderate or severe (Zumstein, Moer, Mottini et al, 2011; Thornhill, Teasdale, Murray et al, 2000; Ponsford, Downing, Olver et al, 2014).

Mild brain injury does not mean sequelae will be limited and short term in nature. As cited earlier, a Glasgow study which followed 549 TBI survivors admitted to hospital found nearly equal percentages of mild, moderate and severe injury survivors still had moderate or severe disability a year after injury; the degree of disability rose with the severity of the injury (Thornhill, Teasdale, Murray et al, 2000).

Life-long impairments mean ABI survivors require ongoing accessibility to rehabilitation and support services. In one Swiss study, just over one-third (37%) of a group of 86 mild TBI survivors demonstrated significantly poorer general health and lower quality of life 10 years after injury (Zumstein, Moer, Mottini et al, 2011). They showed significant worsening of mental functions, notably: fatigue, insomnia, exhaustion, adynamia, rapid exhaustibility, headache, restlessness, hypersomnia, irritability, tenseness, anxiety and balance problems and difficulty maintaining employment (Zumstein, Moer, Mottini et al, 2011). Over half (52.3%) showed impaired memory and concentration. Their findings challenged the misperception that mild brain injury meant limited and short-term sequelae.

Likewise, an Australian study of 141 patients with complicated mild-to-severe TBI over ten years post-injury measured a comprehensive array of outcomes including: neurological functioning, mobility, cognition, behaviour, communication, emotional state, independence in personal, domestic and community activities of daily living, leisure activities, employment and relationship status. Even though subjects had received inpatient rehabilitation with continuing therapy as needed, support for return to work or study, and funding for home help or attendant care support, there were many persisting sequelae and impairments after 10 years; most problems identified two years post-injury were still extant ten years post-injury (Ponsford, Downing, Olver et al, 2014). While survivors demonstrated good mobility and independence in daily living, one-third reported relationship difficulties, 40% still required more support than before their injury; less than half were employed, over 50% reported concentration difficulties, and more than 60% reported balance and "persistent memory problems" (Ponsford, Downing, Olver et al, 2014). The authors concluded that there was an ongoing need for "...rehabilitation for cognitive, behavioural, psychological, and social issues that limit community participation in individuals with TBI..." (Ponsford, Downing, Olver et al, 2014, p. 75).

3.4 Gaps in the Continuum and Unmet Needs

Our ability to treat ABI-caused deficits has not kept up with the ability to save human life (Goka and Arakaki, 1994). Improved survival of ABI persons means more survivors are "confronted with not only the overwhelming consequences of the injury, but also the possible need for ongoing support for many years" (several authors, cited in Mahar and Fraser, 2012(2), p. 69). There is both an increase in cases and an increased complexity of cases which the continuum must manage, including co-morbid medical and mental health conditions (Munce, Vander Laan, Levy et al, 2014).

While the acute care end of the continuum is relatively well-resourced and organized, the community-based end of the continuum is consistently criticised for being relatively poorly-resourced, inflexible, uncoordinated, fragmented and inaccessible (e.g. Mahar and Fraser, 2012(2); Munce, Vander Laan, Levy et al, 2014; Degeneffe, Green and Jones, 2017; Acquired Brain Injury Working Group, 1995; Lefebvre and Levert, 2012). A comprehensive literature review on ABI survivors' unmet needs in Ontario found the predominant theme "...the lack of appropriate health, community and social services" (Munce, Hemraj, Jaglal et al, 2013 cited in Munce, Vander Laan, Levy et al , 2014, p. 1042); this is a world-wide issue (Degeneffe, Green and Jones, 2017).

The imbalance between the acute and post-acute, community-based continuum portions is illogical: "Common sense suggests that it makes little sense for society to spend millions on snatching people back from the jaws of death, but spend much less time on helping them to regain lives that have value and quality to them" (Gentleman, 2001, p. 202; see also Munce, Vander Laan, Levy et al, 2014 and Lefebvre, Pelchat, Swaine et al, 2005). Brain Injury Australia asserts, "Policy makers do not understand nor acknowledge the impact of ABI and this has contributed to a fragmented approach to policy and service development, program funding, and inevitably, extensive unmet need for all concerned" (Brain Injury Australia, 2007 quoted in Mahar and Fraser, 2012(2)).

Several barriers impact accessibility to post-acute services: lack of community resources (Lefebvre and Levert, 2012); lack of awareness of services or lack of insurance (Degeneffe, Green and Jones, 2016), or survivors' poor awareness of their own needs (Heinemann, Sokol, Garvin et al, 2002).

A 2014 study of 42 organizations in the Ontario continuum identified the following issues and needs in their continuum of care:

- ▹ "Mental health – High incidence/co-existence of ABI and mental health requires effective intervention and breaking down of silos between agencies, systems, ministries, funding sources...";
- ▹ "Behavioural/cognitive challenges – Programmes throughout the system that are meaningful and age appropriate to minimize behavioural challenges and account for cognitive challenges are needed...";
- ▹ "Addictions – High incidence/co-existence of ABI and addictions speaks to the urgent need for collaboration, education, and cross-training...";
- ▹ "Housing – Housing and support for individuals with an ABI are a continuum to address the needs of the people with ABI...";
- ▹ "Outreach services and community-based programmes, life skills training and vocational support – Community-based services need to be more goal oriented and outcome based";
- ▹ "Caregiver and respite services – Various models: in home respite, day programmes, residential service, camps, Kids Country Club, host family model."

Many identified a wait time for services and most maintained a waitlist due to insufficient funding (Munce, Vander Laan, Levy et al, 2014, pp. 1044-1047).

Analysis of the Massachusetts continuum of care in 2015 revealed the following gaps:

- ▹ "Governance: Public services for people with severe brain injury are uncoordinated and scattered between different organizations";
- ▹ "Post-Acute Rehabilitation: While good emergency care saves lives after a brain injury, access to rehabilitation to support recovery is suboptimal...and patients in a coma who are candidates for rehabilitation "encounter eligibility requirements that severely limit their access to care";
- ▹ "Transitions: Case Management: Independent case management that is not tied to providers or payers is lacking";
- ▹ "Transportation: Transportation is also

needed to support appropriate care and transitions between types of care”;

- “Data for Decision-Making: Payers and providers at all stages of care need data and information to understand outcomes from services and support and to support transitions”;
- “Community: Housing and Day Programming: People on disability in MA are priced out of market-rate apartments”;
- “Prevention: preventing further harm from brain injury for MA youth in the juvenile justice system could provide significant individual and societal benefits” (Lorenz and Katz, 2015, pp.5-6).

Likewise, Saskatchewan’s Acquired Brain Injury Working Group (1995) found staff members were insufficiently skilled and knowledgeable about ABI, and their services were not provided appropriately; many could not take on ABI clients due to their challenging behaviours. Specific gaps identified included:

- “prevention, education and training”;
- “supportive services for families”;
- “coordination of services”;
- “lifeskills, avocational and vocational activities”;
- “social, recreational and leisure options”;
- “residential service options” (Acquired Brain Injury Working Group, 1995, pp. 16-18).

Lefebvre, Pelchat, Swaine et al (2005) studied eight moderate-to-severe TBI survivors (within 2-6 years post-injury) to understand the nature of their experiences during the course of their treatment in the continuum; they also interviewed a total of 45 family members, health professionals and physicians. While satisfied with the availability of services in the acute care and inpatient rehabilitation stages, most survivors and their families criticized the lack of available resources when they returned home (Lefebvre, Pelchat, Swaine et al, 2005). A later study underscored the need for “very long-term services”... “Even many years after getting the TBI, respondents said that they were still looking for services to help them meet their various needs” (Lefebvre and Levert, 2012, p. 205).

Unmet needs long after injury often are “emotional, cognitive, and social needs” and they persist even in the absence of physical impairments (Heinemann, Sokol, Garvin et al, 2002, p. 1058). Likewise, “...more than 10 years following rehabilitation, many... feel isolated, are idle, and are at risk for mental health problems, violence, drug addiction and homelessness” (Lefebvre and Levert, 2012, p. 197). A study of survivors 7 years post-injury found unmet needs fell into a wide spectrum of 27 different social, emotional, psychological and vocational types, the most prevalent being:

- improving memory or problem-solving skills (51.9%);
- increasing income (50.5%);
- improving job skills (46.3%);
- finding places and opportunities to socialize with others (41.6%);
- increasing educational qualifications (40.2%) and
- managing stress and emotional upsets (40.2%).

More than 1 in 5 participants in this study identified 20 unmet needs; while perceived needs may decline over time, the authors asserted this is more a function of the survivor tolerating their situation rather than having their needs satisfactorily met (Heinemann, Sokol, Garvin et al, 2002).

The experience of Calgary's Steering Committee parallels the literature's findings: the needs of ABI survivors throughout the Continuum are long-term, broad and diverse, and commonly go unmet due to resource limitations. The ability of the existing post-acute Continuum to adequately serve Calgary's growing ABI incidence and prevalence therefore seems dubious.

3.5 Utilization of the Continuum

Notwithstanding the quality of care or gaps in the Continuum, utilization can vary widely, reflecting the heterogeneity in ABI survivors, their needs, and availability of the services (Degeneffe, Green and Jones, 2017). A study of 119 Australian severe TBI survivors found utilization varied based on the time post-injury (Hodgkinson, Veerabangsa, Drane et al, 2000). Cohorts within four years post-injury used services as part of their rehabilitation to restore function, adjust to their disability and integrate with the community, while cohorts from six to seventeen years post-injury used services primarily to respond to life changes (e.g. relationship, living situation, employment or crisis), and a small number used services to continue to assist with their adjustment to disability and community integration. More psychosocially-disabled survivors used more services (Hodgkinson, Veerabangsa, Drane et al, 2000).

There is a surprising overall lack of utilization of services for brain injury, even in the presence of significance impairments (Turner, Fleming, Ownsworth et al, 2008). A study of 1,381 mild TBI survivors found nearly half (42%) did not seek medical care, in particular, older persons, persons injured playing sports or injured in the home, those with a high annual income or those feeling only "dazed". Of those not seeking medical care, 75% simply felt they didn't need it (Setnik and Bazarian, 2007). This low utilization significantly exceeded earlier findings that 25% of TBI recipients didn't seek medical attention (CDC, 1991, cited in Setnik and Bazarian, 2007). This is concerning because "...even patients with mild TBI can benefit from obtaining medical care" (Setnik and Bazarian, 2007, p. 5), in part because 50% will develop post-concussive syndrome, "a complex of symptoms including headaches, dizziness, sleep disorders and cognitive dysfunction" (several studies cited in Setnik and Bazarian, 2007, p. 5).

3.6 Outcomes Measurement for the Continuum

Outcomes of the post-acute Continuum are very hard to measure, due to both the wide range of potential outcomes and the many variables influencing them (e.g. the injury itself and the intensity, expertise, timing, duration and follow-up of treatment) (Brain Injury Association of America, cited in Cioe and Seale, 2018). This is made more difficult by:

- the lack of "...universally accepted outcome measurement tools";
- "outcome measurement research has not translated to better predictability of outcome";

- "most persons with brain injury do not have adequate funding to support access to the full continuum of care necessary for value-based service delivery models" (Cioe and Seale, 2018, p. 375).

The absence of widely-accepted measures means the field lacks "...a common language and the ability to benchmark against like programs or define best practices for community-based treatment" (American Congress of Rehabilitation Medicine, cited in Cioe and Seale, 2018, p. 376). Therefore, more standardized and systematic measurement of outcomes at each stage of the continuum are needed (Cioe and Seale, 2018).

3.7 Case Management

Interviews with subject matter experts and the Steering Committee frequently identified the lack of case management as a serious gap. Some elements of case management are currently being provided for a limited population of BI persons for a portion of their post-injury lives. Case management was generally conceptualized to be lifelong, professional assistance provided to the ABI survivor and their family in navigating the continuum of care, where they could re-connect with the continuum as required, rely on the case manager's guidance on which services were most suitable, be assisted in accessing those services, and have a continually-updated, lifetime record of their treatment and outcomes.

Case management would indeed seem to be a relatively low-cost, high-impact way of improving effective access to the continuum by ABI survivors and their families. Heinemann, Sokol, Garvin et al (2002) remind us "The evidence of broad unmet service needs highlights the importance of resource and service coordination for persons with TBI" (Heinemann, Sokol, Garvin et al , 2002, p. 1059). A survey of 596 ABI survivors found 88% of those who used case management found it valuable (Ontario Brain Injury Association cited in Baptiste, Dawson, Streiner et al, 2015). Beyond individual case management, Saskatchewan's Acquired Brain Injury Working Group recommended a Provincial ABI Coordinator to coordinate programs and services across the province over two decades ago (Acquired Brain Injury Working Group, 1995). Case management was also identified as a significant need in Alberta's Continuum (Gowdy, 2003; Calgary Health Region and Province of Alberta, 2005).

It is important to note that case management is no substitute for availability of needed services; for case management to be effective, community-based services obviously still need to be available in sufficient quantity and quality to meet demand in a timely way, and awareness of the availability and benefits of case management services must be built (Baptiste, Dawson, Streiner et al, 2015).

4.0 NEUROLOGICAL AND BEHAVIOURAL OUTCOMES AND COMMUNITY PARTICIPATION

4.1 ABI Impact on Community Participation

90% of ABI survivors are “confronted with psychological, behavioural or psychiatric challenges” (Mahar and Fraser, 2012(2), p. 68) and these “undermine successful community integration” (Lock, Jordan, Bryan & Maxim, 2005 cited in Mahar and Fraser, 2012(1), p. 49) covering “all key domains of the individual’s life including independent living, relationships, and employment” (Tsaousides & Gordon, 2009, cited in Mahar and Fraser, 2012(1), p. 49). ABI-based cognitive, behavioural and psychological deficits do not diminish over time (Mahar and Fraser, 2012(2); Kelly, Brown, Todd et al, 2008) and difficulties in community participation are seen in research from 1-10 years post-injury (e.g. Sander, Maestas, Sherer et al, 2012).

There is a tendency to underestimate the enduring nature of ABI’s barriers to community participation; between 26% and 45% of ABI survivors “are inadequately reintegrated postinjury” (Mahar and Fraser 2012(1), p. 55). Research shows “...psychosocial and behavioural difficulties limit role resumption and community integration more than do physical deficits” (Hodgkinson, Veerabangsa, Drane et al, 2000, p. 1208). Community integration is of interest because it creates positive outcomes for ABI survivors and their caregivers (e.g. Mahar and Fraser, 2012(2)); collapse of the survivor’s social and family networks makes it harder for the survivor to adapt (Lefebvre, Pelchat, Swaine et al, 2005).

High incidences of cognitive, behavioural, emotional and communication issues are reported (e.g. Ponsford, Downing, Olver et al, 2014; Kelly, Brown, Todd et al, 2008). A major literature review on community participation barriers common to ABI survivors identified the following:

- “Cognitive Barriers” include impacts to: executive dysfunction – the ability to make plans, set goals, remember them and understand consequences; memory, such as the inability to keep appointments or pay bills inhibits successful functioning in society; self-regulation, including behaving according to social norms, particularly in unstructured situations; self-awareness adjustments to their injury and coping, and attention and concentration including the ability to focus, concentrate and remain on task;
- “Behavioural Barriers” include: aggression, which is a particular issue when combined with a tendency for disinhibition; irritability, which shows up as impatience and unexplained rage; and disinhibited behaviour such as inappropriate questions, lewd remarks, or sexually inappropriate behaviour;
- “Psychosocial Barriers” include: severe depression; anxiety, which impedes reintegration into home, community and workplace; various personality changes such as “...aggression, irritability, apathy, impulsivity, disinhibited behaviour, affective mood”; lack of motivation or lethargy; alcohol and drug abuse; and fatigue, which may affect over two-thirds of survivors (Mahar and Fraser, 2012(1), pp. 51-54).

Neurological conditions lead to poorer general health, poorer mental health, feelings of stigmatization, impose limitations on daily life and impair function that affect quality of life (Public Health Agency of Canada, 2014). About 30% of Canadian TBI survivors living with a neurological condition, and nearly 60% of those with brain tumours and over 50% of those who have had a stroke, reported they had fair/poor health (Public Health Agency of Canada, 2014). Brain injury, brain tumour and stroke survivors all reported severe levels of disability; over 35% of TBI and brain tumour survivors reported mood disorders, the highest of all conditions surveyed, as did 23% of stroke survivors (Public Health Agency of Canada, 2014).

Even though ABI survivors' changes and impairments are very evident to family and caregivers, survivors may be unaware of them, and they may not be immediately evident to the general community. Survivors therefore find it hard to identify themselves and seek accommodations (Mahar and Fraser, 2012(2)). Social reintegration is made harder with the loss of pre-injury friends and social networks who are unable to cope with the survivor's impaired "social competence" (several authors cited in Mahar and Fraser, 2012(2)). Lost social support and meaningful relationships mean the survivor has nothing to do, reduces their involvement in leisure activities, increases engagement in transient relationships, all in turn further undermining their social competence, and participation in normal and valued life roles (Mahar and Fraser, 2012(2)). Behavioural disturbances can also lead to institutionalization or imprisonment (Kelly, Brown, Todd et al, 2008, p. 458).

Kelly, Brown, Todd et al (2008) studied the behaviour, disability, and care and needs of 190 Australian ABI clients averaging nine years post-injury who were undergoing behavioural management treatment. More than 80% exhibited verbally and physically aggressive behaviour, were "moderately" disabled and unemployed, most (70%) displayed serious behavioural issues and 60% required daily support. (Kelly, Brown, Todd et al, 2008). Such severely-impacted survivors require support "...not just in inpatient or transitional settings, but within the community and as required throughout a person's life" (Kelly, Brown, Todd et al, 2008, p. 467). As treatment for ABI survivors increasingly shifts to community-based rehabilitation and reintegration, community agencies' ability to provide effective rehabilitation and behaviour management for such individuals is a growing issue (Kelly, Brown, Todd et al, 2008).

4.2 Community Re-integration Strategies

Successful community integration requires access to "...a variety of services, including case management, accommodation, and vocational and recreational services. Some services may need to continue for many years or be restarted during a crisis" (Hodgkinson, Veerabangsa, Drane et al, 2000, p. 1208). "There is a clear need for the development of an effective intervention strategy that encompasses a comprehensive, holistic approach to the restoration of cognitive, psychological, and functional deficits associated with brain injury" (several authors cited in Mahar and Fraser, 2012(2), p. 71). Such programs need to be both "meaningful and age appropriate" (Munce, Vander Laan, Levy et al (2014)). Lamontagne, Ouellet and Simard

(2009) assert that “Rehabilitative efforts perhaps need to be re-thought to acquire a better balance between the offer of services directed towards ADL [Activities of daily living] and toward social roles” (Lamontagne, Ouellet and Simard, 2009, p. 699).

Our subject matter expert interviews identified the high need for ongoing lifetime accessibility to support for survivors during challenging situations, in order to top up their rehabilitation, support them if their progress was slow, provide meaningful community interaction, or provide their caregivers with respite. Some subject matter experts identified clubhouses as a promising practice (with one ABI-specific Canadian clubhouse mentioned in London, Ontario).

Clubhouses have been long-used in the psychosocial rehabilitation field and are “... intentionally formed, non-clinical, integrated therapeutic working communities composed of adults and young adults diagnosed with serious mental illness (members), and staff who are active in all clubhouse activities” (several authors cited in McKay, Nugent, Johnsen et al, 2018, p. 29). They generally “...strive to help members participate in mainstream employment, educational opportunities, community-based housing, wellness, or health promotion activities, reduce hospitalizations or involvement with the criminal justice system, and improve social relationships, satisfaction, and quality of life.” (McKay, Nugent, Johnsen et al, 2018, p. 29). McKay, Nugent, Johnsen et al’s (2018) comprehensive literature on clubhouses concluded that while supporters of the clubhouse model declared many positive outcomes for clubhouse members (as above), and qualitative results appeared promising, these claims had not yet been subjected to rigorous research.

5.0 FAMILY IMPACTS AND CAREGIVING

5.1 ABI Impacts on Family Relationships

ABI is truly a family affair and is a well-known cause of difficulties for family members of ABI survivors. The impact on mild TBI survivors and their families is described as, "...physical, psychological, financial, legal and social devastation..." (Landau and Hissett, 2008, p. 83). The "ambiguous loss" associated with a loved one's ongoing brain injury impairments is harder to deal with than the finality of their death (Landau and Hissett, 2008, p. 70). Without warning or readiness, the family's system plunges into disorder with the loss of the person they once knew. For the family, the ABI survivor becomes "...a stranger in their midst who has become the predominant presence in every conversation and major decision" (Landau and Hissett, 2008, p. 71).

The relationships, boundaries and roles of both the ABI survivor and family members become convoluted. The survivor's "new physical and emotional deficits that profoundly alter their family and social interactions" (Landau and Hissett, 2008, p. 71) mean ABI survivors lose their sense of self and feel guilty about their "diminished" family role and their inability to meet their own and others' expectations. Families generally show compassion for the survivor, willingness to work around their behaviour and shoulder additional duties, possibly based on preconceived and unrealistic expectations that these changes will be short term.

Their unrealistic expectations can leave the survivor feeling even more frustrated and helpless (Landau and Hissett, 2008). While expectations change over time as a survivor's impairments become more evident (Chleboun and Hux, 2011), emotions run high with repeated realizations of the survivor's slow speed of recovery and the permanence of some impairments (Chleboun and Hux, 2011). The "... unspoken obligation to protect the survivor" (Chleboun and Hux, 2011, p. 773) means the family may hesitate to discuss important issues to shield the survivor from feeling the guilt and burden of family difficulties (Landau and Hissett, 2008).

Unsurprisingly, ABI is associated with distressed relationships (Kreutzer, Sima, Marwitz et al, 2016; Wood and Yurdakul, 1997) and threatens marital quality and generates a higher risk of marital breakdown (Kreutzer, Sima, Marwitz et al, 2016). Observed divorce or separation rates range from 17% (Kreutzer et al, 2007 cited in Kreutzer, Sima, Marwitz et al, 2016) to 22.4% (5 years post-injury, cited in Ponsford, Downing, Olver et al, 2014) or even as high as 48.86% (8 years post-injury, cited by Wood and Yurdakul, 1997). This is significant because marital breakdown creates additional negative mental health outcomes for ABI survivors of (Kreutzer, Sima, Marwitz et al, 2016).

5.2 ABI Impacts on Family Caregivers

Discharge of ABI survivors into family care is extremely common. One study cites 80% of TBI individuals are discharged home to live with family or relatives (Brzuzy and Speziale, 1997 and Smith, Vaughan, Cox et al, 2006, both cited in Lamontagne, Ouellet and Simard, 2009). Family members "...are expected to provide ongoing support and care after rehabilitation" and their presence "...is an essential ingredient to the smooth flow of day-to-day life" (Lamontagne, Ouellet and Simard, 2009, p. 694). In fact, close relatives are primary providers of care to ABI survivors no matter what the ABI survivor's living environment is, including long-term care facilities (Lamontagne, Ouellet and Simard, 2009).

Family members caring for ABI survivors are subject to a range of profound and long-term impacts, including: grief, stress, depression, anxiety, psychosomatic disorders, increased consumption of prescription and non-prescription drugs, financial difficulties, role changes, poor social adjustment, increasing social isolation, impaired immune function, low levels of satisfaction with life, loss of lifestyle and independence, deterioration of overall health and higher mortality rates. (Murray, Maslany and Jeffery, 2006; Smeets, Van Heugten, Geboers et al, 2012; Harding, Gao, Jackson et al, 2015; Turner, Fleming, Ownsworth et al, 2008; Las Hayas, de Arroyable and Calvete, 2015). At the very time when family members need the support of friends and networks, their networks and connections to work, community, jobs and activities are impacted. Their former roles are displaced by the burden of care and isolation created by their obligations to the survivor, and friends do not understand what they are enduring (Chleboun and Hux, 2011; Wood and Yurdakul, 1997).

Caregiving for ABI survivors is hard work. In the post-acute phase, family caregivers provide "physical, emotional, financial, domestic, transportation, and respite support." (Turner, Fleming, Cornwell et al, 2007, p. 1124). Because TBI survivors suffer from an "intricate mix of cognitive, psychological and physical impairments resulting from brain damage", family caregiving for them is a more complex endeavour than for other disability types (Lamontagne, Ouellet and Simard, 2009, p. 700). A large-scale study of over 400 UK caregivers found the ABI caregiving burden to be uniquely difficult compared to caregivers of advanced cancer or dementia due to the longer-term nature of daily caring activities, as ABI patients are relatively younger than advanced cancer or dementia patients, survivors' challenging behaviours, and the relative lack of accessible ABI-specific services (Harding, Gao, Jackson et al, 2015).

5.3 Family Caregiver Support and Well-Being

Caregiver well-being impacts ABI survivor well-being; caregivers who are functioning well emotionally can contribute to better outcomes for the ABI survivor, particularly in the first six months after injury. However, family dysfunction impacts survivor and family adaptation to injury-related changes (Sander, Maestas, Sherer et al, 2012).

Caregiver and family needs appear to be as heterogeneous as ABI injuries and they change over time. In the early stages of BI treatment, families engage in a "frenzied search for information" during a period of deep "anxiety, confusion, and uncertainty" (Lefebvre and Levert, 2012, p. 199). Later, their information-gathering focuses on the long-term consequences of the injury, professional and social re-integration, and understanding the survivors' behaviours they are witnessing (Lefebvre and Levert, 2012). While support of family and friends is indispensable during the acute care stage, families later need support in adapting to the new realities of life and their roles, and learning how to care for their survivor (Lefebvre and Levert, 2012). During acute care and rehabilitation, close relationships are needed with medical professionals, but in post-rehabilitation the family re-focuses on networking among various institutions and community organizations to obtain support for themselves and the survivor (Lefebvre and Levert, 2012). The transition from acute care is also the beginning of financial stress for the survivor and their family, as either may have to give up their work (Turner, Fleming, Cornwell et al, 2007, p. 1126).

Lacking "...experience with identifying, obtaining or maintaining vital services and support systems" (Department of Human Services, 2004, cited in Mahar and Fraser, 2012(2), p. 70), the needs of family caregivers grow beyond medically-based supports to community-based supports; they spend more time dealing with their survivor's unmet needs yet become less able to access supports, with diminishing connections to rehabilitation professionals and programs (Murray, Maslany and Jeffery, 2006).

Caregivers' search for services continues many years post-injury (Lefebvre and Levert, 2012). A study of 66 Saskatchewan caregivers whose survivors ranged from 5 months to 174 months post-injury reported less than half of their needs (43%) actually being met (Murray, Maslany and Jeffery, 2006). Families find themselves filling the void left by services which have stopped or became inaccessible (Lefebvre and Levert, 2012). To persist in their role while mitigating the impact on their lives, caregivers must be resilient and have good coping skills (Smeets, Van Heugten, Geboers et al, 2012; Las Hayas, de Arroyable and Calvete, 2015).

Supporting family caregivers is "...a social responsibility", given the extraordinary long-term burden placed on them (Lamontagne, Ouellet and Simard, 2009). Increasing use of family caregivers means "...the provision of support and health care to caregivers to both enable them to care and reduce their morbidity and mortality is becoming a pressing public health issue" (Harding, Gao, Jackson et al, 2015, p. 446). Family members need long-term services, including:

- psychological support and counselling;
- respite services such as day centres, in-home care, weekend lodging and host families;
- access to "leisure, transport, and escort services";
- receipt of information on ABI;
- access to and support from peers who have been in similar experiences;
- interventions which "...target mastery and coping skills of both caregivers and patients" (Smeets, Van Heugten, Geboers et al, 2012; Degeneffe, Green and Jones, 2016; Lefebvre and Levert, 2012; Murray, Maslany and Jeffery, 2006; Munce, Vander Laan, Levy et al, 2014).

The Project's Steering Committee has identified lack of caregiver support as a gap in Calgary's Continuum; the above list and research (e.g. Smeets, Van Heugten, Geboers et al, 2012) both suggest that, while helpful, respite care alone is not the sole answer to relieving caregiver burden and maintaining their well-being.

5.4 Impacts of ABI on Relationships Beyond the Family

Relationships beyond the family are also affected by brain injury. Post-injury, survivors' new cognitive, motor and sensory functioning limitations affect the many roles they formerly played in many networks and their networks must shift from being social to supportive (Chleboun and Hux, 2011). Depending on the survivor's personality change, changes in social competence, or impairments restricting their pastimes and interests, they may lose formerly close friendships (Wood and Yurdakul, 1997; Chleboun and Hux, 2011; Mahar and Fraser, (2012(2)); Lefebvre, Pelchat, Swaine et al, 2005).

5.5 Interventions Supporting Survivors' Relationships and Networks

The literature supports the need for comprehensive long-term support for ABI survivors, and those who are close to them, which go beyond restoring survivors' function of daily living. Rehabilitation professionals must address survivors' psychosocial functioning in addition to their practical daily living functional limitations (Chleboun and Hux, 2011).

ABI treatment should include assessment of and support for marital relationships (Kreutzer, Sima, Marwitz et al, 2016) and identify the specific needs of families (Headway Victoria, 2005, cited in Mahar and Fraser, 2012(2)). Families need support in "...finding their new joint reality with its own strengths and resilience so that they may move forward together with more certainty, clarity and realistic expectations, less ambiguity and false hope" (Landau and Hissett, 2008, p. 78). Family member treatments should encompass "...all of the long-term cognitive, physical, emotional and relational losses (both apparent and ambiguous)", provided by a coordinated treatment team including "...primary care; neurology; family therapy; cognitive therapy; vision therapy; physical therapy; dental, periodontal and orthodontic services; occupational therapy; organizational skills; and workplace retraining...pain management and trauma relief..." (Landau and Hisset, 2008, p. 82).

Beyond the family, rehabilitation professionals must "shift their focus from rehabilitation of the survivor to rehabilitation of the social support structure in which the survivor functions" (Chleboun and Hux, 2011, p. 776), acknowledging the struggles of the survivor's entire support network in adjusting to the survivor's changes, as the survivor "...is working to re-acquire lost skills and reintegrate into social and community settings" (Chleboun and Hux, 2011, p. 776).

6.0 LIVING ENVIRONMENTS AND TRANSITIONAL ISSUES

Calgary's Steering Committee identified availability of sufficient and suitable living environments for ABI survivors as a significant gap in its Continuum, including during transition into the post-acute phase. Arguably, as incidence of ABI and its prevalence in the population grows, this is a gap that will become more severe over time.

6.1 The Importance of Suitable ABI Living Environments

Suitable living environments are critical in ensuring the best possible recovery and quality of life outcomes for ABI survivors – for them, "living environments" go well beyond physical living space, and encompass "...all of an individual's ABI-specific housing, support and treatment needs..." (Colantonio, Howse, Kirsh et al, 2010, 33%), including services suited to their safety, recovery and well-being (e.g. Colantonio, Howse, Kirsh et al, 2010). A Quebec study of 136 assistance-dependent survivors with moderate-to-severe TBI who lived in a variety of settings (from home through to structured, long-term care) found significant impacts on their quality of life, ability to rehabilitate, social participation and performance of their routine "life habits" such as bathing, dressing and grooming (Lamontagne, Poncet, Careau et al, 2013).

In a study of ABI survivor discharges in Ontario from 2003-2006, Chen, Zagorski, Parsons et al (2012) found the majority (74.7%) of TBI discharges were to the home, with fewer discharged to institutionalized care (15.5%), or inpatient rehabilitation (9.8%). Survivors' use of services after acute care were influenced by three factors: "predisposing factors" including demographic characteristics, social structure, and beliefs; "need factors", which are indicators of perceived and diagnosed severity of health condition and "enabling factors" such as family financial situation and community resources" (Chen, Zagorski, Parsons et al, 2012, p. 2). As older individuals were more likely to be discharged to inpatient rehabilitation or institutionalized and their relative proportion of the population increases, planning and preparation are required to meet this need (Chen, Zagorski, Parsons et al, 2012).

6.2 Gaps in ABI Living Environments

The ABI housing gap is not unique to Calgary; the literature repeatedly describes shortages of suitable living environments (e.g., Colantonio, Howse, Kirsh et al, 2010 (Ontario); Dwyer, Heary, Ward et al, 2017 (Ireland); Lamontagne, Poncet, Careau et al, 2013 (Quebec). In a study of 56 highly-credible key stakeholders drawn from across Ontario's ABI continuum, Colantonio, Howse, Kirsh et al (2010) identified a lack of resources, such as physical structures, trained staff and accessibility as a key issue: "Many patients, once ready to be released from acute care and rehabilitation facilities, have nowhere to go." (Colantonio, Howse, Kirsh et al, 2010, 33%).

While frequently used as default housing solutions, hospital beds or geriatric facilities are both a poor use of resources and deprive survivors of ABI-specific or age-appropriate services (Colantonio, Howse, Kirsh et al, 2010; see also Dwyer, Heary, Ward et al, 2017); the latter are particularly unsuitable for behavioural problems. Colantonio, Howse, Kirsh et al (2010, 66%) recommended increasing "...

living environments and discharge locations including apartments serviced by other agencies, outpatient programs and conversion of space in long-term care settings into specialized units and/or for short-stay housing" and "more secured units incorporated into facilities" to deal with ABI survivors with behavioural issues (see also Munce, Vander Laan, Levy et al, 2014).

Returning to home may not be the best choice for ABI survivors (Lamontagne, Poncet, Careau et al, 2013). A study of 136 assistance-dependent moderate-to-severe TBI survivors in Quebec found they performed significantly more of their life habits with less difficulty and had better social participation scores when in a semi-structured environment such as a group home or with foster families providing assistance for daily activities than either at home with family, a relatively unstructured setting, or in nursing homes, long-term care facilities or other highly-structured institutional settings. Semi-structured environments appear to provide enough professional assistance to meet individual needs while providing more flexibility, opportunities for adaptation and ability to perform life habits, better than the untrained assistance from living with already-busy family members or the inflexible support in structured settings such as nursing homes (Lamontagne, Poncet, Careau et al, 2013).

An ABI survivor's living environment, or residential setting, should be selected thoughtfully, based on "...the interaction between the level of autonomy of the TBI survivor, the available help and the choice of residential setting" rather than mere availability (Lamontagne, Ouellet and Simard, 2009, p. 700). Human assistance is an important enabler for ABI survivors to improve their social participation, not just their day-to-day life habits, its provision often falls to family members. They asserted, "It remains surprising and somewhat alarming that the need for human assistance was not more strongly associated with different residential settings" (Lamontagne, Ouellet and Simard, 2009, p. 700).

Calgary's Steering Committee identified the placement of ABI individuals in nursing homes, which primarily serve senior citizens or persons with degenerative conditions like dementia versus other alternatives as a specific gap in the Calgary Continuum. Such placements deprive ABI survivors' social, cognitive and rehabilitative needs at a time when these are all significant to their successful recovery of functioning (Dwyer, Heary, Ward et al, 2017).

Used as waiting environments for ABI survivors awaiting more suitable placement, nursing homes mean delaying ABI survivors' rehabilitation and loss of the rehabilitation gains made before discharge from hospital, representing a waste of taxpayer resources (Colantonio, Howse, Kirsh et al, 2010). Furthermore, recovering ABI survivors have no common ground with persons at the end of life (Dwyer, Heary, Ward et al, 2017).

A study of Irish adults with severe ABI (aged 38-53) who were placed in nursing homes revealed how they had to cope with the "...impact of resident deaths, feelings of misplacement, disempowerment, depression, isolation, boredom and identity issues" (Dwyer, Heary, Ward et al, 2017, p. 9). This situation was described as, "fundamentally wrong, unethical, and contrary to stated government policy" (ABI Ireland, cited in Dwyer, Heary, Ward et al, 2017, p. 2).

6.3 Transition from Acute Care and Inpatient Rehabilitation

As an illness with life-long impacts, ABI creates many transitions (O'Neil-Pirozzi, Lorenz, Demore-Taber et al, 2015). Transition from hospital-based acute care and inpatient rehabilitation to recovery and life outside of hospital is a major step for ABI survivors and their families and a distinct part of the continuum (Turner, Fleming, Cornwell et al, 2007). An important time for survivors coping with and adjusting to their disabilities (Fleming et al, 2002, cited in Turner, Fleming, Ownsworth et al, 2008), generally, "...patients reported feeling ill-prepared for community living and the emotional challenges of living with a long-term condition. Once discharged from rehabilitation, they felt isolated and had difficulty identifying and accessing community services" (Cott, 2004, cited in Turner, Fleming, Ownsworth et al, 2008, p. 1154).

While transition is complex for any illness, ABI survivors' transition issues are "... compounded... due to the long-term and multi-faceted nature of injury-related deficits...and the impact of poor self-awareness on their ability to identify realistic life goals" (several authors, cited in Turner, Fleming, Ownsworth et al, 2008, p. 1171). Promise and excitement mix with stress, emotion and challenge (Turner, Fleming, Ownsworth et al, 2008) from the survivor's growing self-awareness of their new limitations, changes to their sense of identity, autonomy, self-esteem, and realization of how life has changed and their role in it (Turner, Fleming, Ownsworth et al, 2008).

Many factors impact the transition experience: severity of the original injury, the survivor's level of disability, the survivor's self-awareness of deficits, availability and quality of social support, pre-morbid personality, occupational status, educational attainment, and survivors' and family members' coping strategies (Turner, Fleming, Cornwell et al, 2007). ABI survivors and their families need support during transition in: psychological support, discharge preparation, family support services, post-discharge therapy and case management, and opportunities to identify and engage in meaningful activities. (Turner, Fleming, Cornwell et al, 2007).

Better outcomes are created by practices including:

- short "trial run" visits home before discharge to help survivors and caregivers manage their expectations and reduce the shock of self-awareness;
- transitional living services generally focusing on "...development and acquisition of everyday skills such as completing personal and domestic tasks, building and maintaining social relationships, managing and organizing one's time, and accessing the community";
- comprehensive and well-planned communication, as survivors and their families' ability to absorb what has been told to them is limited;
- providing family access to post-discharge follow-up supports, such as psychological support to help them cope with their new situation;
- providing access to sufficient ABI-specific post-discharge services, including rehabilitation of long-term duration, given the long-term nature of their support requirements;

- using case management to help ABI survivors and families locate and access appropriate services. Coordinated community-based delivery of services should include weekly phone contact, monthly home visits and home-based treatment. Just regular phone follow-up helps to identify transition problems and line up further support needs, improving survivors' function and quality of life;
- having reliable social networks of family and friends, being able to access social and community activities and having meaningful activities in which to engage in. (Turner, Fleming, Cornwell et al, 2007, pp.1123-1128; several authors cited in Turner, Fleming, Ownsworth et al, 2008, p.1168; Paterson et al, quoted in Turner, Fleming, Ownsworth et al, 2008, p.1159; O'Neil-Pirozzi, Lorenz, Demore-Taber et al, 2015, p.1548; Bell et al quoted in Turner, Fleming, Ownsworth et al, 2008, pp.1167-1168).

7.0 MENTAL HEALTH AND SUBSTANCE ABUSE

The Steering Committee has identified a gap in Calgary's Continuum in effectively diagnosing, treating and meeting the unique needs of ABI survivors who may also be dealing with mental illness, substance abuse, or have the "trifecta" of all three situations. That combination of diagnoses makes acute and post-acute brain injury treatment even more complex and requires organizational capability and professional specialization, all of which are lacking in Calgary. It is logical to assume that the treatment gap for these individuals will parallel Calgary's growing population.

7.1 Mental Illness and ABI

There are clear connections between mental illness of various forms and ABI. A study of over 2,400 male and female Australians across a variety of age groups found TBI, including mild TBI is associated with higher levels of anxiety, depression, mental health symptoms (Anstey, Butterworth, Jorm et al, 2004). A study of over 5,000 people in New England found TBI survivors had "significantly poorer physical health, emotional health and memory problems", particularly major depression, dysthymia, panic disorder, OCD, phobic disorder, alcohol and drug abuse – than those who had not had TBI (Silver, Kramer and Greenwald et al, 2001, p. 940). Survivors' TBI history and psychiatric morbidity remain associated throughout life, with psychiatric symptoms remaining decades after injury (Anstey, Butterworth, Jorm et al, 2004).

Australian individuals dually-diagnosed with both TBI and mental illness reported "...profound experiences of loss, particularly loss of important relationships and valued social roles..." and "...lack of: ability to make life choices; social acceptance and an appropriate occupation..." (Cocks, Bulsara, O'Callaghan et al, 2014, pp. 416-419). They have a high need for family support and are challenged in finding and using ongoing and appropriate community support, "...including community transitioning, specialist services which could respond to dual diagnoses, and inappropriate accommodation..." (Cocks, Bulsara, O'Callaghan et al, 2014, pp. 417-419).

Effective treatment of mental illness and ABI is an issue commonly cited in the literature. Gaps cited include: meeting dual-diagnosis individuals' long-term needs; enhanced and specialized training for practitioners who work with them; enhanced family support; enhanced education and employment opportunities; specialized accommodation (Cocks, Bulsara, O'Callaghan et al, 2014); integration among "agencies, systems, ministries, funding sources"; more flexible inclusion criteria; increased numbers of specialists (Munce, Vander Laan, Levy et al, 2014, p. 1047); and better coordination between mental health and brain injury specialists (Hodgkinson, Veerabangsa, Drane et al, 2000).

7.2 Substance Abuse and ABI

The co-incidence of substance abuse and ABI is well-researched. Each increases risk of the other (e.g. Sacks, Fenske, Gordon et al, 2009; Corrigan and Deutschle, 2008) and all three diagnoses of substance abuse, brain injury and mental illness can be expected (Corrigan and Deutschle, 2008). Nearly three quarters of 50 participants in treatment programs for substance abuse and mental illness in Ohio reported having had a head injury causing loss of consciousness or requiring medical care. Those with TBI had significantly more psychiatric diagnoses – and more complex diagnoses – than those without; head injuries earlier in life were also linked with earlier substance abuse and more psychiatric, and more complex diagnoses (Corrigan and Deutschle, 2008).

Identification of, and accommodation for, brain injury sequelae are essential to the successful treatment of substance abuse (Sacks, Fenske, Gordon and Hibbard, et al, 2009). A major study of 845 individuals in substance abuse treatment programs in New York State found TBI individuals more likely to have previously had failed mental health and substance abuse treatments; earlier diagnosis of TBI during substance abuse treatment could avoid a history of relapses and set up a stronger foundation for successful substance abuse treatment (Sacks, Fenske Gordon and Hibbard et al, 2009). In Ontario, the "...High incidence/co-existence of ABI and addictions speaks to the urgent need for collaboration, education, and cross-training..." (Munce, Vander Laan, Levy et al, 2014, p. 1047).

8.0 MARGINALIZATION: HOMELESSNESS AND CRIMINALITY

The literature gives credibility to the Calgary Steering Committee's assertion that Calgary's ABI survivors can end up in homelessness or criminality. While direct causality cannot be found, a logical conclusion would be that effective long-term treatment for ABI survivors might well reduce undesirable social outcomes such as homelessness or criminality.

8.1 Criminality and ABI

While definitive proof of ABI causing criminality is not available, criminality and brain injury are credibly associated. Pickelsimer (2009) (quoted in Corrigan, Selassie and Orman, 2010) found a 60.3% TBI prevalence in the offender population. In a study of over 130,000 West Australians born in 1980-1985, there was a "modest risk of offending, including violent offending, following a hospital-documented TBI" with common TBI sequelae such as "behavioural dysregulation, aggression or impulsivity" potentially causing criminal behaviour (Schofield, Malacova, Preen et al, 2015, p. 6/12). Criminals with TBI also show a higher likelihood of recidivism (Ray and Richardson, 2017). However, the research is inconclusive: one study found TBIs involving loss of consciousness over 24 hours to be linked to increased risk of criminal arrest, but more compelling TBI-criminality links were not found (Elbogen, Wolfe and Cueva et al, 2015).

8.2 Homelessness and ABI

Several researchers have explored the connection between brain injury and homelessness and suggest a causal linkage (e.g. Anderson, Kot, Ennis et al, 2014; Hwang, Colantonio, Chiu et al, 2008). While BI among homeless populations often go undetected (Anderson, Kot, Ennis et al, 2014), there is a high prevalence of lifetime brain injury among the homeless (Hwang, Colantonio, Chiu et al, 2008). A large study of 904 men and women at an Ontario homeless shelter found just over half (53%) had a traumatic brain injury, and 12% had experienced moderate to severe brain injury.

The majority (70%) of those studied became homeless after their first traumatic brain injury (Hwang, Colantonio, Chiu et al, 2008, p. 9), a marked contrast with the widely-quoted estimate of 8.5% prevalence of brain injury in the general population (Silver, Kramer, Greenwald et al, 2001). Brain-injured homeless people showed "significantly higher lifetime prevalence of seizures; higher prevalence of mental health problems, alcohol problems, and drug problems; and poorer mental and physical health status..." (Hwang, Colantonio, Chiu et al, 2008, p. 8; see also Anderson, Kot, Ennis et al, 2014, p. 2213).

9.0 THE ECONOMICS OF ABI

The cost terrain for Acquired Brain Injury is complex and broad. Availability and accuracy of costs in various stages of the BI continuum varies but it is clear that Acquired Brain Injury costs are substantial. "Considering the significant cost of care and the loss of productivity and increased resources necessary to care for these individuals (based on quality of life measures), TBI is a striking public health problem" (Silver, Kramer and Greenwald et al, 2001, p. 942).

Because many brain injury survivors require long term – or even lifetime – care, costs may be incurred well past the acute care and inpatient rehabilitation phase (Ponsford, Spitz, Cromarty et al, 2013; Chen, Bushmeneva, Zagorski et al, 2012). The costs of long-term care for ABI survivors in Calgary's Continuum deserve study, particularly in light of waiting lists, eligibility restrictions, and the relatively short duration of service each provider can provide under contract. If community-based providers had the capacity to meet the needs of Calgary's prevalent ABI population, literature suggests the costs of the post-acute continuum might well exceed the costs of acute care.

9.1 Direct costs of ABI

In Canada in 2000-2001, direct costs for hospitalization, physician care, drugs, research and long-term care facilities, totalled $151.73 M for head injury and $664.86 M for stroke (Canadian Institute for Health Information, 2007). Direct health care costs for TBI in British Columbia in 2010-2011 were $86.839 M or $26,900 per capita, second only to spinal cord injury and five times more than Alzheimer's (Public Health Agency of Canada, 2014). A large-scale study of over 43,000 TBI and non-traumatic BI ("nTBI") patients in Ontario from 2004 to 2007 found an average cost of $32 thousand (k) per TBI patient and $38 k per non-traumatic BI patient (Chen, Bushmeneva, Zagorski et al, 2012).

Patients with brain dysfunction stay in rehabilitation centres an average of 36 days, longer than other types of rehabilitation patients (Canadian Institute of Health Information cited in Chen, Bushmeneva, Zagorski et al, 2012). Patients discharged into Ontario's rehabilitation facilities cost an average of $93.3 k for TBI and $82.2 k for nTBI patients (Chen, Bushmeneva, Zagorski et al, 2012). Similarly, an Australian study of 1,237 mild-to-severe TBI patients over a ten year period showed long term brain injury care may exceed the combined costs of hospital, medical and paramedical care (Ponsford, Spitz, Cromarty et al, 2013); they estimated the lifetime cost of brain injury per patient was $2.6 M (moderate) and $5 M (severe) (Ponsford, Spitz, Cromarty et al, 2013).

9.2 Indirect and Hidden Costs of ABI

Survivors discharged from hospital may wait long periods for admission into community-based rehabilitation programs, during which time those who can afford it seek care on their own from physiotherapists, psychologists, psychiatrists, neurologists, family physicians, chiropractors, walk-in clinics and emergency rooms (Hunt, Zanetti, Kirkham et al, 2016).

A study of adult mild TBI Ontario survivors in 2013-2014 awaiting admission into referred tertiary care found 201 patients undertook an astonishing 6,794 health care provider visits, at an estimated cost of over $500,000, extrapolated to $11 M annually across all of Ontario (Hunt, Zanetti, Kirkham et al, 2016). Because many community rehabilitation services are not funded publicly, in the absence of insurance, survivors and families must undertake this cost. The number of survivors who could not afford such treatment can only be speculated on.

Many hidden costs of ABI for the survivor, their family and society remain unresearched; these include lost employment for survivor or family caregiver, costs of family break-up, shortened lifespan and premature death, transportation to and from – and time spent in – medical appointments (Chen, Bushmeneva, Zagorski et al, 2012; Hunt, Zanetti, Kirkham et al, 2016).

People with neurological conditions, excluding migraines, have 12 times higher unemployment than those without neurological conditions (Public Health Agency of Canada, 2014). Less than 40% of TBI survivors and only 25% of stroke survivors report themselves as working; over one-quarter of TBI and stroke survivors reported themselves as permanently unable to work (Public Health Agency of Canada, 2014).

The estimated total lifetime costs of all medically-treated TBI cases in the United States for the year 2000 was $60.4 billion (B) including $51.2 B in productivity losses – excluding costs of extended rehabilitation, life-long supports and services, lost quality of life, lost productivity or quality of life for caregivers (Zaloshnja, 2006 cited in Corrigan, Selassie and Orman, 2010). On average, Canadian men and women with TBI are estimated to lose 19.8 years and 21.2 years “in full health”, respectively (Public Health Agency of Canada, 2014). Indirect economic costs of TBI-caused premature death were $63 M in 2011 and for TBI-caused working age disability, $7.3 B in 2011 (Public Health Agency of Canada, 2014).

9.3 Forecasted ABI Growth

The forecasted growth of Canadian brain injury incidence and prevalence means its costs will increase; the total economic costs of TBI in Canada will exceed $8 B by 2031; the indirect economic costs of TBI-caused premature death will be $49 M, and for TBI-caused working age disability, $8.2 B by 2031. By 2031, 450,000 Canadians will require “informal health care” due to TBI, a level second only to Alzheimer’s, equating to an average of 18 hours of informal care per week per survivor (Public Health Agency of Canada, 2014).

10.0 ABI IN ALBERTA

The needs of Alberta's brain injury survivors and their families have been the subject of several formal and substantial studies since 2000 (see, for example, Gowdy (2003), p.1). This literature review includes three of those studies.

10.1 Building Better Bridges

The Province of Alberta's report Building Better Bridges: Final Report on Programs and Services In Support of Persons with Developmental Disabilities (Zwozdesky, 2000) identified the need for services for the brain injured to parallel those already provided for the Persons with Developmental Disabilities (PDD) community. It also identified the long-standing conversations about Alberta's ABI community, saying, "The issues surrounding those with acquired brain injury have been discussed for many years but little has been 'actioned' to date" (Zwozdesky, 2000, p. 35). Building Better Bridges supported the need for development of a policy framework and inter-ministry work to identify respective ministries' roles and responsibilities. It identified the need to compile "...hard data...before specific policy directions, programs and services, and specific funding requirements can be determined" and suggested that Alberta's brain injury organizations required practical and financial help in doing so.

Building Better Bridges recommended, "That the Ministry of Health and Wellness, in partnership with regional service providers and representatives of the brain injury community, proceed immediately to develop a response and a concrete action plan regarding the needs of those with acquired brain injury..." (Zwozdesky, 2000, p. 36) including an assessment of scope and need, analysis of gaps in service, analysis of costs, a policy framework and an implementation strategy, all to be completed by July, 2000 (Zwozdesky, 2000, p. 36).

10.2 Adversity and Action

Adversity and Action: Alberta Provincial Needs Assessment for Adults who are Severely Injured as a result of Acquired Brain Injury (Gowdy, 2003) was authored partly in response to the issues identified and commitments made in *Building Better Bridges.* Governed by an advisory committee, *Adversity and Action* compiled provincial and national statistical data, conducted face-to-face surveys with sixty persons, collected 120 written surveys of persons connected with the BI community, and held in-depth interviews with nine brain injury survivors and/or their family members and caregivers. It cited a significant consistency across all of the surveys and interviews about the nature of ABI survivors', and their families', needs, their unmet needs, and their low level of satisfaction with current service levels.

It summarized the community's needs as including:

- "...a clear need for the use of a case management approach for all Albertans with severe disabilities as a result of acquired brain injury";
- "...safe living arrangements...(in)...age appropriate personal care homes..." complete with in-house rehabilitation by staff trained in ABI;

- "Community, social and recreational programs..." to support community integration and skills development, with increased support to ensure safe access;
- ongoing community-based rehabilitation using a combination of professionals and volunteers;
- provision and maintenance of rehabilitation equipment;
- attention to the needs of rural Albertans with ABI;
- expanded outreach rehabilitation programs;
- "Immediate and ongoing support...for families of adults who have suffered severe brain injury..." including information, peer support and, "recognition of the need to be treated with dignity and respect";
- re-examination of financial support beyond that provided by current AISH and CPP programs to ensure coverage of board, lodging and living expenses so that poverty did not worsen "...an already greatly diminished quality of life";
- more easily-accessed transportation options such as transit passes in urban areas; and
- development of prevention and education programs (Gowdy, 2003, pp. 44-45).

10.3 Calgary Brain Injury Strategy

Calgary Brain Injury Strategy: Foundations for Direction (2005) was produced by a collaborative partnership between the Calgary Health Region and the Province of Alberta (Alberta Seniors and Community Supports). Driven by the goal to "develop a service delivery model for acquired brain injury survivors in the Calgary Region" (Calgary Health Region and Province of Alberta, 2005, p. 3), it envisioned a service delivery system which was, variously, "...inclusive, accessible and flexible...", robust enough to deliver specialized services in all client locations, and "...able to provide service over the lifespan and when the survivor is ready to receive it".

Calgary Brain Injury Strategy cited the need for both "ongoing consistent services, or bursts of intensive services" to meet clients' needs for lifelong supports and services and called for "accountable service delivery" managed across multiple private and public agency partnerships (Calgary Health Region and Province of Alberta, 2005, pp. 3-4).

Calgary Brain Injury Strategy: Foundations for Direction cited the needs expressed in *Adversity and Action* and several other studies, included a literature review and three working groups drawn from the public and community sectors, but was challenged in obtaining representation by ABI survivors and their families. Using a systems analysis approach, its conceptual service delivery model identified the individual perspective, encompassing physical, cognitive, behavioural and support needs, and a system perspective spanning the acute care, post-acute care and community lifelong support phases (Calgary Health Region and Province of Alberta, 2005, pp. 24-32).

Survivors' core needs were matched to the phases of the continuum of care; these needs were identified as:

- "advocacy";
- "transition management";
- "case management";
- "personal/social network";
- "rehabilitation";
- "cognition";
- "access";
- "complex needs" (Calgary Health Region and Province of Alberta, 2005, p. 32).

The report's comprehensive recommendations were focused in three key areas:

- "Service Delivery" – including:
  - an acute care/emergency department task force to develop follow-up strategies;
  - creating a Traumatic Brain Injury Manager within an Acquired Brain injury Program;
  - building capacity to serve BI survivors with complex needs;
  - developing a transition management strategy for youth and building community capacity for adults;
  - a cross-sector steering committee to resolve issues with standards of care, service variation and barriers;
  - innovative strategies to mitigate family burdens and stresses).
- "Data Management and Evaluation" – including:
  - developing an ABI survivor database;
  - standardizing assessment tools and measured outcomes).
- "Education and Awareness" – including:
  - incorporating prevention material in Alberta Education curriculum;
  - standardizing information and education available to survivors upon discharge;
  - creating a provincial health television channel;
  - facilitating partnerships to provide telehealth capability;
  - coordination of caregiver training by the Alberta Brain Injury Initiative;
  - using HealthLink as a source of information for ABI and concussion clients (Calgary Health Region and Province of Alberta, 2005, pp. 39-47).

There is a striking symmetry and overlap among the needs and recommendations identified in the above reports, and the gaps, issues and opportunities identified by the current Steering Committee regarding Calgary's Continuum. The critical mass among these reports, the current Steering Committee's work, and this literature review surely gives a compelling platform for focused and effective work to move forward now, conclusively, to build an effective Continuum for Calgary's ABI survivors and their families.

11.0 CONCLUSION

This literature review is intended to obtain credible information about various aspects of the Acquired Brain Injury's Continuum to inform the Acquired Brain Injury Sector Project and better understand issues surrounding Calgary's Continuum and potential solutions, with a focus on the post-discharge portion of the Continuum, i.e. following acute care and inpatient rehabilitation. Alignment among the reviewed literature and the Steering Committee's observations about Calgary's Continuum – and particularly gaps in the Continuum – suggests that the Steering Committee's, and Calgarians', experiences with Calgary's Continuum are not particularly unique, nor of less urgency than other jurisdictions. It also suggests that, via observations of how other practitioners have grappled with and attempted to resolve similar issues in post-acute ABI care, there are many practical solutions available, albeit no easy ones.

The literature demonstrates that ABI incidence and prevalence, though hard to definitively measure, are significant, and even crude estimates of ABI incidence and prevalence in Calgary suggest that the Continuum will be severely taxed in the coming years with the trend towards increased incidence and prevalence. The notion of a continuum of care is well-established. Effective continua of care provide a comprehensive and flexible array of information, rehabilitation, community integration, living and caregiver resources, which are accessible over the ABI survivor's lifetime depending on the severity of their original injury and the resulting disabilities they must live with. Gaps in the continuum of care are well-established and are an area of concern for the BI community in every sector we researched. Case management is an essential element of effective continua, but must be backed with availability of quality services.

The majority of ABI survivors have a variety of neurological and behavioural issues, the severity of which ranges from mild issues to profound disabilities and which do not generally decrease over time. These issues have substantial impacts on survivors' ability to integrate with their communities, and they create real difficulties for families and caregivers. The burden on family caregivers is extremely heavy and they require access to quality information and support, the needs for which vary over the survivor's treatment and recovery. The impact of ABI reaches beyond the survivor and their immediate family to relationships with their extended networks, in turn often limiting the ability of these networks to support them. Suitable transitional and long-term living environments, which encompass survivors' housing, support and treatment needs, are essential to survivors' safety, rehabilitation, community integration and quality of life. There are significant issues with living environments which do not provide specialized ABI support. Family members are still heavily implicated in care for the survivor, no matter their living environment.

There are strong and proven relationships among ABI, mental health and addiction issues, which require specialized treatment; treating one issue without effective attention to the other(s) is likely to produce poor outcomes and relapses. There are also relationships between ABI and marginalization from society in the forms of criminality and homelessness, even though direct causality has yet to be proven.

ABI has significant direct and indirect costs, and ABI is a major cost in Canadian health care. When effective ABI treatment is not accessible in the post-acute continuum – available from community ABI agencies for example, the health care system, ABI survivors and their families all undertake significant, hidden, costs. Furthermore, there are costs to society due to things such as disrupted participation in the workforce by the survivor and/or their family, family unit breakdown and divorce, homelessness and criminality.

Forecasted growth in ABI incidence and the growing population of ABI survivors who remain affected or disabled means this cost burden will continue to increase, and the community portion of the Continuum will continue to struggle to provide accessible and effective services. ABI in Alberta and the challenges and opportunities in serving this largely hidden population of disabled people has been comprehensively and repeatedly studied, and identified needs and recommendations are consistent.

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Appendix IV – Stakeholder Questions

Interview Question Set for Interviewees who work in the Calgary System

Reflecting on the system of supports — including housing, rehabilitation, community integration, support for families and the system overall — for adults with ABI in the Calgary region:

- What is working well?
- What is not working well?

What best or promising practices from elsewhere would you like to see adopted in the Calgary system? Why do you see them as best practices?

The goal of this project is to ensure a stable and sustainable sector providing quality services that support client outcomes. What are the opportunities to improve the system? What should be the priorities for making changes? What principles should be used to evaluate potential changes? (Probe: What specific small, medium or large adjustments or changes would you recommend? What do you think the impact of that would be? Why?)

Of all of the changes that could be made, if you could make just one change within the current resources, what would it be? Why?

We are conducting a literature review as part of this project. What academic papers would you recommend I put on my must-read list? (Ask for details — name, authors).

What else is important for me to know that I have not already asked you about?

Interview Question Set for Interviewees who work in systems other than Calgary (Edmonton, Ontario, Michigan, Rancho Los Amigos)

Please give me an overview of how your system provides for the needs — such as housing, rehabilitation, community integration, family support and others — for adults with Acquired Brain Injury. (Probe for details around degree of severity served, how the system might be different depending on severity, if/how the system maintains a long-term relationship with the survivor, how their particular organization fits within the system. Ask for numbers — how many people served, out of a potential population served?)

From your experience, what are the system elements that make the biggest difference for survivors accessing the system of supports? What are the absolute essentials? (Probe for details. When did the system begin the practice? What difference did it make? What evidence exists? How costly was it?)

What are the gaps in your region or system? (Probe: Who, if anyone, falls through the cracks? What allows for that? What do you plan to do to address the gaps?)

What data is tracked in your system? What data do you consider essential to delivering good client outcomes? What data is essential to monitoring the effectiveness of your system? The stability and sustainability of your system? How is this data shared with other participants in your system?

What do you consider to be the best practices for supporting good outcomes for adults with ABI and their families? Why do you characterize them as best practices? What are the outcomes of these best practices?

If you could share lessons learned or offer advice to the Calgary region, what would you tell those working to enhance the system?

We are conducting a literature review as part of this project. What academic papers would you recommend I put on my must-read list? (Ask for details — name, authors).

What have I not asked you that I should have done?

Interview Question Set for Families

Tell me about your experience of being a family member of an adult with Acquired Brain Injury in the Calgary region. (Probe for details about severity of the injury, year of injury, post-injury housing, rehab, community support and family support accessed).

Reflecting on the supports — including housing, rehabilitation, community integration, support for families and the system overall — for adults with ABI in the Calgary region:

- What would you say is working well?
- What is not working well?

The goal of this project is to ensure a stable and sustainable sector providing quality services that support client outcomes. Given that ABI is a sector under pressure, resources are restricted and value for money must be a driving principle, what suggestions do you have for improving the system? What specific small, medium or large adjustments or changes would you recommend?

If you could see only one of these suggestions implemented, what would it be? Why?

What else is important for me to know that I have not already asked you about?

Interview Question Set for ABI individuals

Please tell me about your experience. (Probe for details about severity of the injury, year of injury, post-injury housing, rehab, community support and family support accessed).

- From your experience, what would you say is working well?
- What is not working well?
- What would have made your experience (even) better?

The goal of this project is to ensure clients like you get the support you need. What suggestions do you have for improving the system?

What else is important for me to know that I have not already asked you about?

Appendix V –
Synopsis of Interviews with ABI Individuals and Caregivers

Family members described lives turned upside down by the injury to their loved ones. They cited loneliness as friends and family drifted away, worry about what would happen to their loved ones when they are no longer able to care for them, and a financial burden that is often crushing.

> "I'm getting tired," she said. "I'm 68. This is my whole life."
>
> *— Family member who has been caring for ABI son since he was injured in a car crash 24 years ago*

Bewilderment and confusion soon layered over the fear that set in the moment they learned a family member had been injured. Family members spoke of not knowing, as the days turned into weeks and months and years, what to expect, what recovery would or would not look like, not knowing where to turn for help and not knowing what services were available or how to access them. One parent spoke of the role of luck in learning about programs and resources — overhearing another family mention something, being in the right place at the right time. "It would help if you could understand things more clearly about brain injury. Maybe because at the beginning you're in shock you're not able to absorb it. There's no central place to find out what's available. It would be nice to sit with a professional at different points in this journey."

Housing

Discharge from the acute care system brings a whole new set of overwhelming issues, with housing at the top of the list. Returning to the family home often presented tremendous challenges. A woman whose brain injury was the result of contracting West Nile Neurological Encephalitis describes returning to her home, after months in hospital, in a wheelchair. "In my house there are 16 stairs to get up and down. When I was in my wheelchair I had to bum my way up the stairs. I had a commode in my room." The mother of a man, now 40, recalled caring for her son when he first returned home after his car crash at age 16. "We had a hospital bed. I did diaper changes, bathing. I did it all. He was 18. He was still in a wheelchair then. It was tough getting him from the house to the car. He's a big man."

A woman in her 50s described how once a month she collects her mom, who is partially paralyzed from a stroke, from the nursing home where she now lives so that her mom has an outing to look forward. Once they arrive at the woman's home, the physical demands of getting her mom into her house are staggering and require special equipment and hauling heavy wheelchairs and lifting devices up and down sets of stairs multiple times.

The stress of trying to care for someone with physical and cognitive challenges and, in some instances, a very different personality than they once knew is often physically, mentally and emotionally exhausting and for some, beyond their capabilities. The parents of a young woman who suffered a brain injury in a car crash in 2015 said they are fortunate in that Workers Compensation covers expenses associated with their daughter's work-related injury. She lives in a group home and stays with her parents for a weekend each month. "It's a 24-hour job. We bring her home for a weekend once a month. She's able to get around the house on her own. We have to be hyper vigilant. It's exhausting."

A man who acquired his brain injury in a prison beating described the supports he requires to live as independently as possible. Without support, he's at risk of eating rotten food from his fridge because he no longer has a sense of smell, he misses appointments because his ability to navigate time is impaired and he gets lost because he can't follow a map or directions. "My perception sucks," he says. "If I see something, I can't distinguish if it's good or bad, friend or foe." Asked where he'd be without the support of the agency that helps him, he said: "If I was living without support, I would be evicted. I can't organize. I can't put things away appropriately. My apartment looks like a bomb went off. Where would I be? I'd be homeless or back in jail."

A number of those interviewed spoke of the inappropriateness of some of the housing they accessed. The mother of the 16-year-old car crash survivor said her son spent a few weeks at the Carewest Dr. Vernon Fanning long-term care centre in the early months after his injury.

"It wasn't a place for a young man. There needs to be somewhere so their friends feel comfortable visiting them. I have a dream young kids will have a place they can go with programs suited for young people. And programs in place where they can have a peer. Someone more like them." The young woman injured in the car crash in 2015 lives in a supported facility. She is in her 20s and the other residents are in their 60s and 80s. The loss of same-age peers is deeply felt.

Said a stroke survivor: "When I got here the house wasn't ready and I spent three weeks in seniors homes. It felt like an institution. You're there with people who had become senile. There were not too many people like me. I felt isolated over there. No social life. You're living in a surgical place, no one is pushing them to be social. It is lonely to be there. Even though you're amongst so many people, you are lonely."

> "You put yourself last. You need some break from the burden. Where do the friends go? They all go back to their lives. If you had someone to give you a break... that would be great. "
>
> — *Family member of ABI Individual (stroke)*

Forever

Exhaustion and depression are common among brain injury survivors and their families. Lifelong deficits mean lifelong challenges, but programs and services are finite. Once an individual has completed a program or reached the maximum number of hours allotted to them, they are discharged. “You stay only so long AHS would allow. There’s no follow up, no community for a person with a brain injury. It’s here you go, make it in the world,” said one.

“What I don’t like is all the sudden stops,” said another. “Your life stops when you have a stroke. Everything has changed. Now you’re in Fanning, then that stops (and you have to move.) Now you’re in a nursing home and starting over again. You’re in a program, you get to know everybody, then all of a sudden, that ends. It’s not fair to these people. They’ve become a part of something because they aren’t part of anything anymore, and then it’s over. It’s a lot of endings.”

Family members are often forced to quit jobs to care for their loved ones, causing financial stress. “Family members can’t be paid. That’s a law that has to be changed. So many people quit jobs to help their parents. Why can the government pay someone else to care for your parents (in a long-term care facility), but not you?”

“If not for WCB, where would we be and where would our daughter be? She would be in the Fanning Centre or long-term care. I’d be ill, too, with stress. We would have been bankrupt.”

The daughter of the woman who suffered the stroke 2.5 years earlier said about 80 per cent of her mental energy is focused on caring for her mom. Her business is suffering. Friends and family who showed support in the early weeks after the stroke have stopped coming around. She suffers from depression, isn’t eating or sleeping well. “You put yourself last. You need some break from the burden. Where do the friends go? They all go back to their lives. If you had someone to give you a break…. that would be great.”

Loneliness and social isolation are common. One survivor described how going out of her house is often overwhelming as she struggles with sensory overload. One parent said her son still acts like he did when he was 16 at the time of his injury. “We’re working on his social skills. He’s 40.

It’s a lonely life for (him). He wants a girlfriend. There is no real place to meet a girlfriend.”

That mother has been caring for her son for 24 years. It is her full-time job. She spends her days driving him to appointments and recreation opportunities, so he can have a life. We conducted her interview while she waited at the coffee shop at a sports complex while her son participated in a program.

“I’m getting tired,” she said. “I’m 68. This is my whole life.”