



ACQUIRED BRAIN INJURY Supports & Services

Background

As of June 2024, the Government of Canada has completed two readings of Bill C-277, an act to create a national brain injury strategy. Once fully passed, we will need to create strategies to address the needs of people living with acquired brain injury (ABI) in each province.

We need direction for a Manitoba-specific strategy to meet the unique needs of Manitobans living with stroke, traumatic and non-traumatic brain injuries. Unmet needs are detrimental & costly for all of Manitoba.

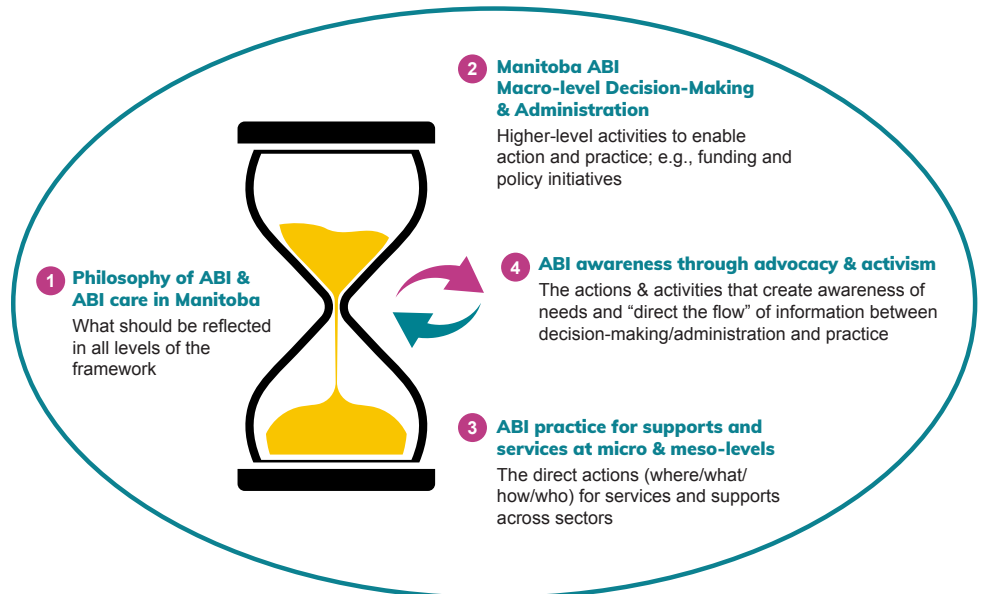
The Brain Injury in Manitoba (BIMb) project

We brought together people in the Winnipeg Region to understand their current experiences and develop ideas to address existing and long-term needs, possible improvements, and the foundations of a Manitoba brain injury supports & services strategy.

- We held a Winnipeg **World Café on Brain Injury** in November 2023 with 10 people who live with brain injury or stroke, 2 caregivers, and 23 people with work-related experience.
- We developed the Hourglass Manitoba Brain Injury Strategy Framework based on key insights from the World Café.
- We held 4 online feedback sessions with people with lived and work-related brain injury experience.

The Hour-glass Manitoba Brain Injury Strategy Framework

Our proposed framework identifies 4 components and how they interact to improve brain injury supports & services in Manitoba and respond to changing needs over time. Within each component, we identify multiple ideas to address needs, challenges, and make improvements.



The next step in the BIMb project is to explore the framework in other areas of the province.

Recommended Actions

Shared Philosophy

- Focus on thriving in one's community
- Treat ABI as a chronic or long-term health & life condition
- Work toward equity-based care

Practice (Micro-Meso)

- Increase support & service options
- Improve ABI care case management & navigation
- Create more varied supportive housing options

Administration/Decision-Making (Macro)

- Increase funding and decrease funding access barriers
- Improve current system integration

Advocacy & Activism

- More ABI education to address awareness & stigma
- Include the voices of people with lived experience

Phase 1 of the BIMb project was funded through March of Dimes Canada (MB region) funds and Dr. Engel's research start-up funds of University of Manitoba. Project contact: Dr. Lisa Engel lisa.engel@umanitoba.ca

Together we can

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BUILD A BETTER FUTURE FOR MANITOBANS

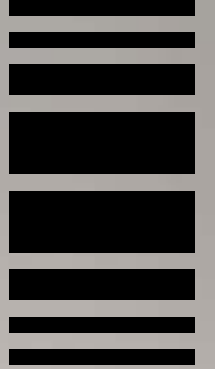
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whose lives are
impacted by
brain injury



Project Phase 1

Stakeholder Report
& Recommendations
for a Manitoba Brain
Injury Strategy



Disclaimer of Endorsement

The logos and organization names used in this report are representative of the listed authors (project team) and their collaboration and work on this project. Any organization named or whose logo is used does not indicate direct or indirect organizational endorsement, favouring, or support of this report or the recommendations for action outlined in this report. The opinions and interpretations in this report and related infographic are those of the authors and do not necessarily reflect those of authors' affiliated organizations.

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Last, we are very grateful to the people in the Winnipeg region with lived and work-related brain injury experience who provided their time, knowledge, expertise, and collaboration/networking.

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Table of Contents

Project & Report Preamble	4
Key Terms	5
Executive Summary	6
Summary: 10 Key Recommendations for Action	7
Why Are We Doing The Brain Injury in Manitoba (BIMb) Project?	9
What is our Goal for the BIMb Project?	11
What did we do for Phase 1 of this Project?	12
Our Findings: The Hour-glass Manitoba Brain Injury Strategy Framework	13
Conclusions from BIMB project (Phase 1)	19
Next Steps & Future Project Work	20
Appendix A: Key Recommendations in Depth	21
Appendix B: History of ABI Supports and Services in Manitoba	24
Appendix C: Tables of Key World Café Ideas Discussed	26

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Project & Report Preamble

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* Other staff were involved in the development, data collection, analysis, or writing sections of this report but did not review its final versions and are not named as report co-authors—however, their input along the way to the BIMb project is valued.

Key Terms

Acquired Brain Injury (ABI)

Damage to the brain that occurs after birth, caused by:

- (1) traumatic injury reasons such as an vehicular crash, weapon wounds, or fall where there is a force to the head/brain;
- (2) non-traumatic reasons including drug/substance poisoning, anoxic/hypoxic events, or brain surgery or radiotherapy; or
- (3) biological disease related reasons of brain change such as stroke, tumour, or meningitis. ^{A, 1-4}

Brain Injury in Manitoba (BIMb) project

A community-driven project that has been developed from partnership between community members and researchers with ABI experience and expertise.

Lived ABI experience (Lived-ABI)

person(s) whose own lives have been influenced by brain injury, including people living with brain injury, caregivers, family, or involved close-others. We specifically do not use the word “patient,” as it is not an identity many persons living with chronic ABI identifies.

Work-related ABI experience (Work-ABI)

Person(s) involved in volunteer or paid work that has been influenced by people living with ABI. The work can be related to diverse jobs directly or indirectly associated with ABI across many sectors (e.g., health/rehabilitation, community, addictions, housing, family services, or justice).

Macro level

The larger aspects or fators of a population or society that can indirectly influence individuals or families (e.g., political laws or policies, governmental decisions, cultural practices).

Meso level

Aspects, factors, or experiences of groups that can influence an individual or family (e.g., community groups, local health-care professionals or clinical teams).

Micro level

Aspects, factors, or experiences directly linked to an individual or family that can influence outcomes.

^ASuperscript numbers used throughout this report are related to the supporting references. The full references list can be accessed from lisa.engel@umanitoba.ca

EXECUTIVE SUMMARY



Acquired brain injury (ABI) is one of the largest diagnostic groups and leading causes of disability around the world, including in Manitoba.

Brain injury can affect any area of a person's functioning, including cognitive/thinking, emotional/mental health, physical, sensory, immunological, and behavioural functioning. Due to the widespread effects, ABI can also then change any area of life including family life, housing, employment, leisure transportation, and community participation, with changes often lasting a long time and for many, a lifetime. These long-term challenges are strongly associated with many detrimental consequences, especially when needs are not met. This includes high rates of homelessness and secondary health concerns. Thus, changes after ABI can create challenging situations for not only the person but also for their families, close others, and communities. Of concern to all citizens, these unmet needs after ABI are costly and have negative effects not just on those directly impacted by ABI, but to all of society.

In Manitoba people living with ABI, their families, and their close others have many unmet needs directly related to ABI. Brain injury supports and services are chronically underfunded to meet the immediate and long-term needs of those living with ABI, and since the COVID-19 pandemic ABI supports and services have declined. **Of great concern, there lacks a strategy in Manitoba of how to meet the needs of people affected by ABI.** While in Canada a bill is progressing

through the federal government (i.e., Bill C-277: A national strategy on brain injury), we do not have information on what an effective strategy for brain injury in Manitoba should be.

Therefore, we developed the **Brain Injury in Manitoba (BIMb) project**, and to do this project we formed a diverse and multi-disciplinary project team of people with lived, work, and research-related ABI experience. **The goal of the BIMb project is to develop a unified understanding, focus, and recommendations for innovative action, research, advocacy, and policy change that will improve the supports, services, and the quality of life of Manitobans living with ABI.** We have addressed our project goal in the Winnipeg region, which was Phase 1 of the BIMb project and is the focus of this report.

In Phase 1 of the BIMb project we completed the Winnipeg World Café on Brain Injury in November 2023 with 35 people with lived or work-related ABI experience; in-depth analysis of collected data from the World Café using the diverse perspectives of our project team; and four online anonymous Townhalls in March 2024 with the wider Winnipeg ABI community to get feedback about our findings.

Through these activities and analysis of information we collected, we have developed the "**Hour-glass Manitoba Brain Injury Strategy Framework.**"

Our proposed framework encompasses four main inter-related components that are needed to adequately address the needs of Manitobans living with brain injury:

1. Philosophy of ABI and ABI care;
2. Macro-level decision-making and administration;
3. Practice for supports and services at micro and meso-levels; and
4. Awareness through ABI related advocacy and activism.

Within this dynamic framework, the four components work together to ensure the Manitoba strategy has continual flow and connection between parts of the framework. This connection ensures the ABI system is responsive to the support and services needs of individuals and the Manitoba brain injury community over time and as needs may change over time and contexts. Within each of the 4 categories we highlight specific needs, actions, or ideas that are inherent to addressing each category. These have been documented in priority areas based on how often they came up in the discussions of the Winnipeg World Café and the ideas were endorsed by online Townhall participants. These formed the basis of our key recommendations for action.

However, Winnipeg is only one part of Manitoba. As the BIMb project continues, we are continuing this work to meet the goal and objectives of the BIMb project across different regions of Manitoba and with different sub-groups of people affected by ABI to identify how the Manitoba Brain Injury Strategy Framework is responsive to the unique needs of people across the province.

Summary: 10 Key Recommendations for Action



Finding 1

Participants expressed positive and negative feelings about the current ABI supports and services available in the Winnipeg region. Positive feelings were attributed to having private insurance funds and other funding sources that made it possible to access privatized services. Negative experiences of current ABI supports and services were impacted by lack of access to services including confusion where and how to access supports and services.

- **One:** Government commitment to improving outcomes and quality of life for those living with ABI
- **Two:** Provincial funding from across sectors (e.g., health, families, justice, housing) to improve supports and services access sensitive to the unique needs of those living with ABI
- **Three:** Decision-makers and service providers work together to improve timely access to supports & services
- **Four:** Government of Manitoba and decision-makers improve system navigation and case-management for those living with ABI, especially those experiencing challenges chronically or a long-time after sustaining an ABI

Finding 2

Survivors of ABI have unique, distinct, and varying needs that are often unmet.

- **Five:** All stakeholders improve equity-focused ABI supports and services access & care
- **Six:** The Government of Manitoba and decision-makers further develop much needed and varied supportive housing options and address the high rates of homelessness for people living with ABI
- **Seven:** All key stakeholders from lived, work, and research-related experiences, and including governmental and other decision-makers, form a cross-sector steering committee that aims to improve coordination and integration of services for people living with ABI within a provincial strategy for ABI

Finding 3

There exists a relationship between community-focused care and recognizing ABI as a chronic health and living condition requiring long-term supports. Improving awareness of ABI and advocating for structural improvements is needed.

- **Eight:** All levels of practice, decision-making, and administration across sectors view and treat ABI as a chronic health & living condition, and align with proposed action of federal Bill C-277
- **Nine:** Government of Manitoba, in partnership with community organizations and guided by persons with lived ABI experience, develop an ABI prevention, awareness, and education strategy for the general public, health professionals and all decision-makers
- **Ten:** All work undertaken in response to this report and/or all work done to improve outcomes for people living with ABI include the voice of persons living with ABI

The Next Needed Steps from Phase 1

We propose ten key recommendations to address needed supports and services for people in Manitoba affected by acquired brain injury (ABI). These ten recommendations relate to three overarching key findings (outlined above and are given in more detail in **Appendix A** at the end of this report).



A collaborative effort is needed

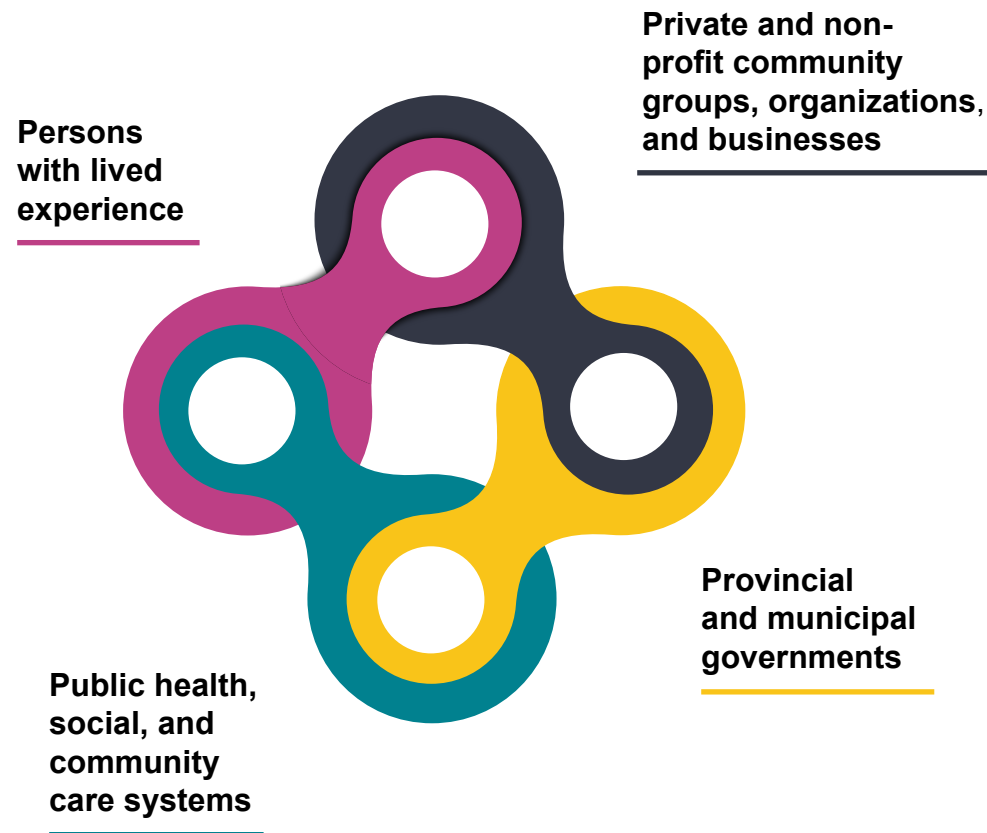
Addressing the long-term needs of ABI utilizes the resources. Not addressing the long-term needs of people living with ABI is costly for many different people and areas of our community and society in Manitoba. Therefore, addressing these recommendations will need to be a concerted and collaborative effort involving a wide array of people and groups including:

Decision-makers and service providers across sectors:

- Decision-makers from multiple portfolios in the **provincial and municipal governments** (e.g., education; families; health, seniors, and long-term care; housing, addictions, and homelessness; justice; labour and immigration; Manitoba Indigenous reconciliation; sport, culture, heritage, and tourism; transportation and infrastructure);
- Decision-makers from the **public health care system** across primary-care, acute, rehabilitation/sub-acute, and community levels of care; and
- **Private and non-profit community groups, organizations, and businesses** whose service recipients include people living with ABI.

Persons with lived experience:

- Including people living with ABI, their families, and their close others.





Why Are We Doing The Brain Injury in Manitoba (BIMb) Project?

Imagine your whole life, from how you think, feel, and move to every area of your self-care, community participation and how you maintain your health, is changed because of one life experience. For the tens-of-thousands people living with acquired brain injury (ABI) in Manitoba, this is reality.

From something that can develop slowly over time, such as a brain tumour, or something that can happen instantaneously, such as a stroke or a hit to the head in a vehicle crash, an ABI can change every aspect of someone's functioning and life. Living with the cognitive/thinking, emotional/mental health, physical, sensory, immunological, behavioural, social, and community living changes after ABI can pose long-term and even life-long challenges for the person, their families or close-others, and the communities that support them.

Yet, despite people living with ABI being one of the largest diagnostic groups of people experiencing chronic or long-term changes related to a health-related condition, they are also one of the most underfunded and underserved health diagnostic populations. At least 1.5 million Canadians live with ABI.⁵⁻⁸ While statistics for Manitobans living with all types of ABI are not currently collected, we know that in 2020-2021 there were over 35,000 Manitobans who live with the effects of stroke (i.e., one type of ABI),⁹ and that there are approximately as many people living with ABI caused by other reasons.⁵⁻⁶

That means that currently there could be upwards of 70,000 Manitobans living with ABI. However, currently there are not enough supports and services for the needs of all Manitobans living with ABI.

Of great concern, around the world, people living with ABI report many serious unmet needs,¹⁰⁻¹² this includes in Manitoba although there is less available data specific to Manitoba.¹³⁻¹⁴ Although ABI is a chronic health condition,¹⁵⁻¹⁶ it is not just related to health! ABI can impact someone's entire life and functioning and changes can last a lifetime, with challenges often worsening if needs go unmet.¹⁶⁻¹⁷ This is due to ABI being related to high rates of cognitive, communication, mental health, physical, sensory, immune, and other impairments or disabilities, and these changes can lead to disabling declines in a person's health, activities of daily living, and community participation.¹⁶⁻¹⁹

Unfortunately, many ABI survivors, including those in Manitoba, are not able to access adequate care, services, and supports needed to address their ABI challenges or life needs.^{1,10-11,13} Brain injury supports and services to meet needs in Manitoba have a long and fluctuating history, where supports and services in Manitoba have often been inadequate to meet the needs of people living with ABI in Manitoba (please see **Appendix B** for a brief timeline of ABI supports and services in Manitoba). Recent years have seen declines in available supports and services, particularly for post-acute/post-rehabilitation and chronic phases after ABI.

There are high rates of harmful and costly outcomes for people living with ABI including:^{1-2, 14, 20-23}

- challenges or decreased ability to meet personal needs or accomplish daily activities;
- social relationship difficulties;
- increased loneliness and isolation;
- challenges with participation and performance in education pursuits;
- decreased paid employment rates, especially in jobs with higher incomes;
- increased rates of poverty and financial vulnerability;
- increased experiences of housing issues or homelessness; and
- increased involvement with the health, social-care, justice or family/child welfare systems after ABI.



Continued • Why Are We Doing The Brain Injury in Manitoba (BIMb) Project?

The **Brain Injury in Manitoba (BIMb) project** arose in 2022 out of conversations between people with lived and work-related ABI experience who were concerned about current unmet needs and equity in supports and services for Manitobans living with brain injury.

The discussions identified shared concerns including:

- In Manitoba, we are not adequately addressing the currently unmet needs of Manitobans living with brain injury, their families, and their communities.
- Unmet needs results in potential harmful consequences and ends up being very costly for individuals, families, communities, organizations that support them, and our municipal and provincial governments.
- We need a Manitoba strategy on brain injury that includes, but is not limited to, the healthcare sector to help support the widespread and long-term needs of people affected by brain injury in our province!

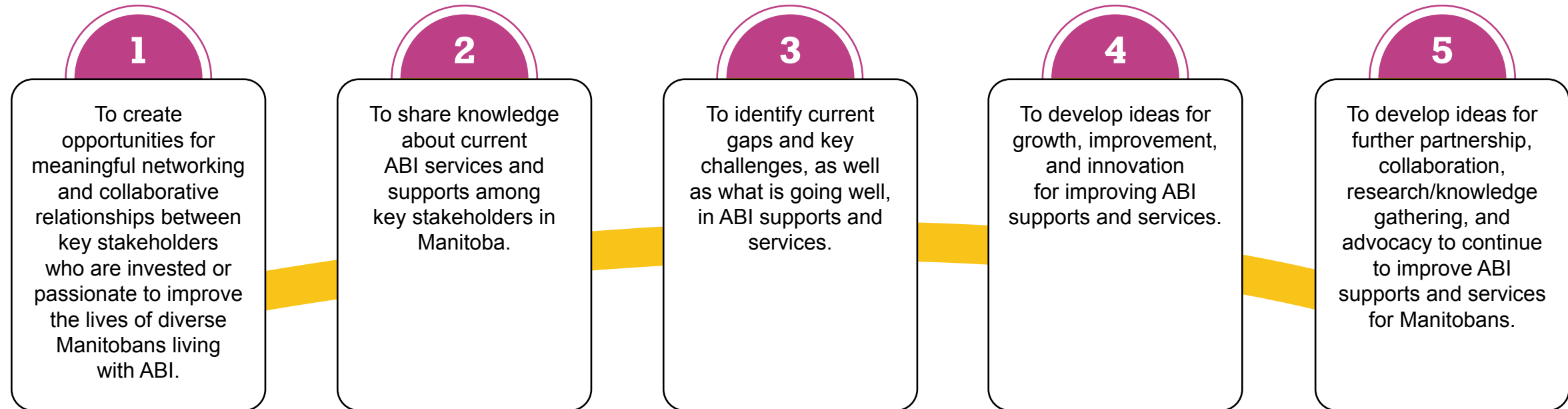
“An Act to Establish a National Strategy on Brain Injuries” (i.e., Bill C-277), which is before the Canadian federal government, offers great hope to the larger Canadian ABI community.²⁵⁻²⁷ Once Bill C-277 is fully passed federally, provinces will be tasked with creating and implementing strategies on ABI to meet the needs in each provincial context. To date, no Manitoba strategy on ABI exists that is inclusive of the various sectors related to the needs of people living with the chronic and long-term changes after ABI. However, **as Manitobans we need to do the work now** to identify needs, challenges, and ideas for improvements that can be foundational to an **innovative and meaningful Manitoba ABI strategy**.

What is our Goal for the BIMb Project?

The overall goal of the BIMb project is to develop a unified understanding, focus, and recommendations for innovative action, research, advocacy, and policy change that will improve the supports, services, and the quality of life of Manitobans living with acquired brain injury (ABI).

We have five objectives to meet this goal. This report addresses the activities and findings to address this goal and objectives for Phase 1 (Winnipeg region). As a project team we worked to start addressing this goal and objectives in Winnipeg as a starting point of the BIMb project (i.e., Phase 1). Winnipeg represented a close geographic area to connect people with lived and work-related ABI experience to gather initial ideas as we worked on developing relationships and plans in other areas of the province for later BIMb project phases.

Our five objectives to meet the BIMb project goal include





What did we do for Phase 1 of this Project?

To accomplish the goal and objectives of the BIMb project in the Winnipeg Region (Phase 1) we used a three-step community-engaged approach that connected with the larger group of people with lived ABI experience and work-related experience within a 40 km radius from the perimeter of Winnipeg (Manitoba, Canada). Our steps included:

- 1 **Completion of the Winnipeg World Café on Brain Injury Supports & Services.**
- 2 **Collaborative analysis and discussion as a BIMb project team about the World Café information gathered and findings to include a varied perspective on the meaning of what we heard and gathered at the World Café.**
- 3 **Four townhall sessions to further exchange ideas about our findings from the World Café with the larger Winnipeg ABI community whose lives, work, or both have been influenced by ABI.**

1 Our **Winnipeg World Café on Brain Injury** took place the afternoon November 15, 2023 at Siloam Mission, a location specifically selected to highlight the realities of not meeting the long-term needs and the known higher rates of homelessness for people living with ABI.²¹⁻²² The afternoon was structured around 4 main questions with the same questions discussed at the same time in small groups and each question was allotted 20-30 minutes. For each discussion people joined different tables to hear from a variety of different people at the World Café where a table host facilitated discussions and a table notetaker documented ideas of what the discussions were about. We engaged with **35 participants^B** in the Winnipeg World Café, encompassing a wide range of perspectives on ABI. All participants were adults with either lived or work-related ABI experience within the Winnipeg region (i.e., within 40 km of city limits). This consisted of 12 participants with lived ABI experience and 23 work ABI from various sectors related to ABI care and support, rehabilitation, community programs, administration and policy, and related University education training programs.

2 Second, we used a **collaborative and multi-perspective approach to make sense or interpret the information we gathered from the Winnipeg World Café** (i.e., analysis process). From a scientific approach we used a descriptive content analysis

and framework approach. This analysis included six different team members who had different lived and work-related ABI experiences, ages, cultural backgrounds, education levels, and professions. The findings from these six people then were further discussed with the larger project team.

We counted how many times certain ideas came up in the collected World Café data to get a sense of what collectively held more space and time in the discussions and within the developed strategy framework. As part of this we also collected and analyzed written responses to a question during the World Café, some of the writing that we present in this report.

3 Third, after analyzing the information from the Winnipeg World Café, we held **four online Townhall Sessions on Brain Injury Supports & Services in Winnipeg** in March 2024. At each Townhall we provided a 30-minute presentation about the findings from the information gathered from the World Café and then listened to and documented any feedback provided by the people involved in the townhalls.

^B The Winnipeg World Café received research ethics approval from the University of Manitoba Health Research Ethics Board and the Brandon University Research Ethics Board. All World Café participants completed written informed consent prior to participation. The anonymous townhalls did not collect identifiable data and received an ethics waiver through the University of Manitoba Health Research Ethics Board.

Our Findings: The Hour-glass Manitoba Brain Injury Strategy Framework

From our findings, we propose the “Hour-glass Manitoba Brain Injury Strategy Framework.” This framework not only builds on the strengths of the current system but also highlights the current challenges to living with brain injury in Manitoba. The framework developed from our analysis of the discussions and information gathered about current challenges and ideas and dreams for future improvements, where discussions of challenges and future improvements were most often intertwined.

Our proposed “Hour-glass Manitoba Brain Injury Strategy Framework”, encompassing four main components and represented by a second metaphor—the hourglass:

1. Philosophy of ABI and ABI care;
2. Macro-level decision-making and administration;
3. Practice for supports and services at micro and meso-levels; and
4. Awareness through ABI related advocacy and activism.

Appendix C provides tables of all the sub-categories of ideas discussed in each of the four major categories of the hour-glass framework.

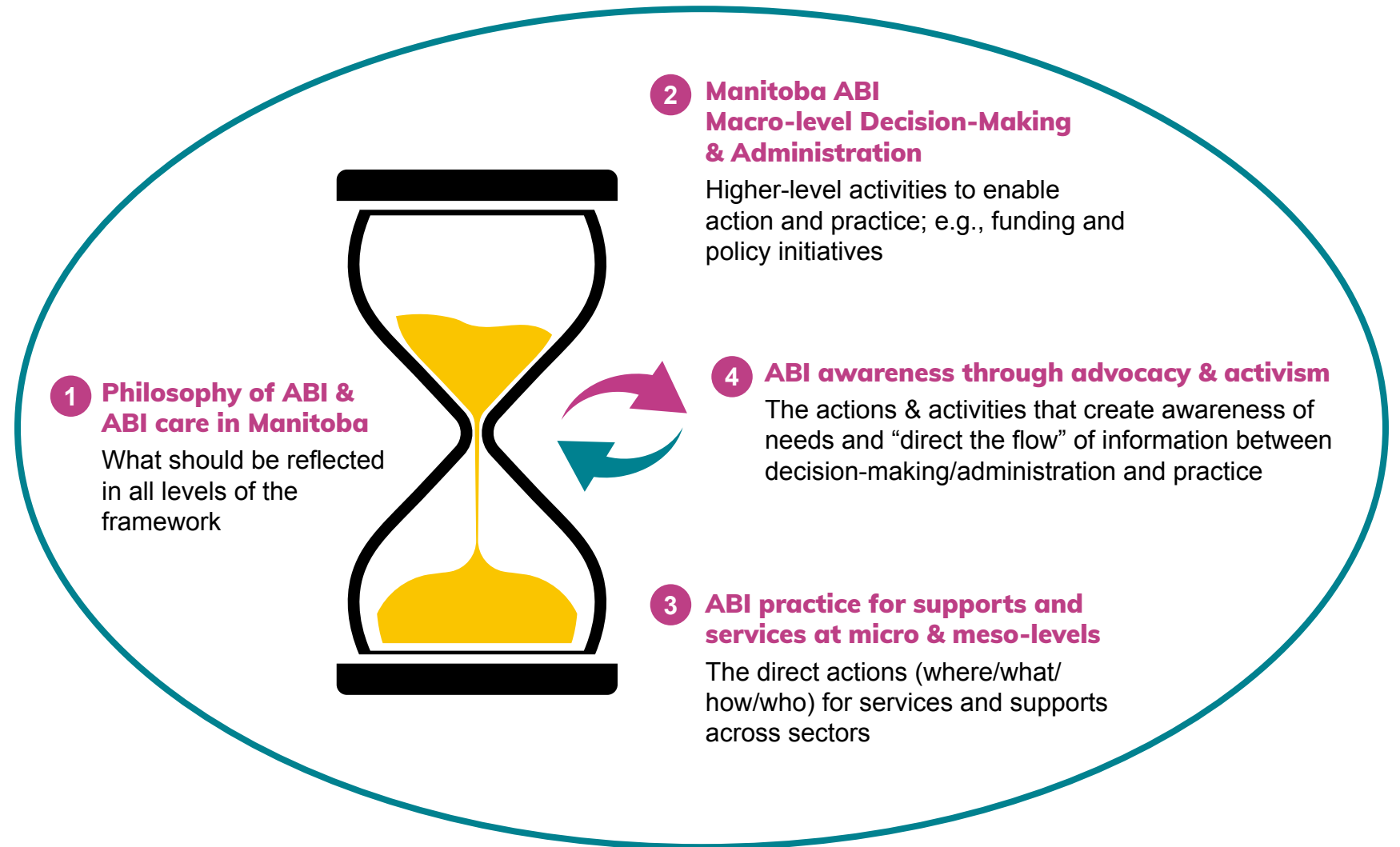


Figure: Proposed framework for a Manitoba Brain Injury Strategy (“the hour-glass”)

1

Philosophy of ABI & ABI care in Manitoba

i.e. what should be reflected in all levels of framework

The philosophy flows between the decision-making processes and the practice and services ABI survivors and families experience (i.e., the hourglass neck). Thus, the philosophy informs all levels of supports and services. ABI awareness is gained through advocacy and activism that also abides by the same philosophy, impacting all aspects of decision-making, administration, practice, and services.

The brain injury strategy framework we developed from Phase 1 data gathered includes seven important components (i.e., sub-categories) in the philosophy category (**Appendix C**). These sub-categories would be foundational to all other aspects of ABI framework and provide the ideology for all levels involved in brain injury care, from direct service providers, inpatient and community-based programs, non-profit organizations, private practice, and governments at all levels.

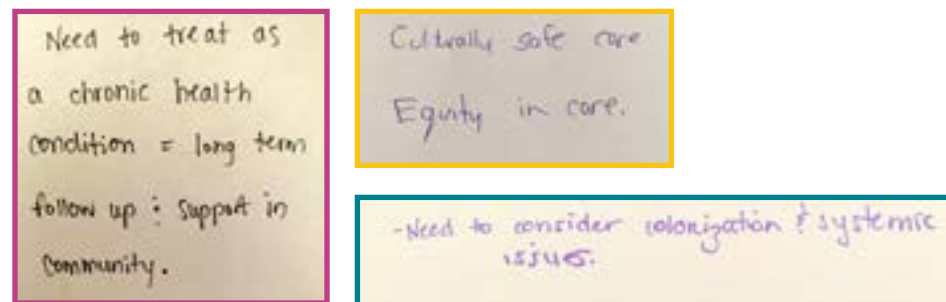
Important to highlight is the inter-related sub-categories of “community-focused care” and “ABI as a chronic health and living condition needing long-term supports”, that together acknowledge that ABI changes are often lifelong. Participants shared that the current funding system and services overall do not address the long-term needs of individuals living with brain injury in Winnipeg. However, participants also stressed that feeling loved and worthy through community-connection was and is foundational to living with ABI.

“Equity focused care that acknowledges the unique needs of equity deserving ABI sub-groups” was also highlighted by participants. This sub-category acknowledges that certain sub-groups of ABI survivors have distinct needs or increased unmet needs that require focused efforts to be able to meet their needs and to foster thriving in the community and well-being.

Specific sub-groups highlighted in our BIMb Phase 1 data:

- Indigenous peoples and communities;
- Displaced persons (refugees) and new Canadians;
- People living with ABI related to a drug poisoning or drug-related anoxic (lack of oxygen) incident(s), who have few specific supports and services available currently but are a growing sub-group of people living with ABI;
- People with intersectionality experiences such as those experiencing co-morbidity (e.g., dual diagnosis of ABI & mental health/addictions);
- People with decreased personal funds or finances (i.e. lower socio-economic status (SES), people with non-insured injuries);
- People experiencing economic challenges, housing issues or homelessness after ABI;
- People living with severe impairments after ABI, especially those currently being discharged to Personal Care Homes as more appropriate supportive living situations are not available for them; and
- People living in rural Manitoba who have less access to supports or services.

Figure: Written response examples of philosophy sub-categories



2

Macro-level decision-making & administration

The macro-level category focuses on the factors that can be addressed at the decision-making and administration levels. This includes funding, programming, supports available, and how services are planned and provided for individuals living with ABI. There are six sub-categories within this category.

One of the most discussed subcategories during the Winnipeg World Café on Brain Injury, and further confirmed in online townhall feedback, was “funding for ABI supports and services”, at individual, community, and system levels. Challenges in accessing individual level funds, such as insurance funding after an ABI occurred, were identified as current barriers to accessing supports and services and to optimizing well-being. However, the Phase 1 participants also emphasized the need for increased funding specific for ABI supports and services, which participants felt required a commitment from the government and organizations providing ABI care to commit to funding and prioritization of ABI programs and services. Participants highlighted that the lack of

funding affects access to much-needed supports. If more publicly funded, free, or low-cost supports and services were available, then it would require less individual funds to meet needs and would decrease the financial demands individuals living with ABI face in meeting their own needs, recovering from ABI, and maintaining health and wellbeing. As the effects of brain injury are often lifelong, people living with the long-term changes after brain injury need funding for support to continue beyond the initial acute-timeline funding window, which usually is seen as only lasting 6-months to 1-year after ABI. Participants identified the existing challenges with integration and leadership having no common vision and a lack of evidence-based planning and focus on an administration level was contributing to the funding challenges in Manitoba.

Further, several World Café tables spoke about “building the ABI service provider expertise in Manitoba”, which requires support and commitment from administrators and decision-makers to provide training opportunities and hire more trained care providers. Further, an attendee at an online townhall further added depth to this subcategory by noting that access to ABI-specific service provider opportunities for professional development within the province are very limited, and either requires participants to only rely on online options or find funds to attend out of province educational options, funds which often are not available. To optimize ABI supports and services in the province, access to needed professional development specific to ABI is necessary.

Figure: Written response examples of decision-making/administration sub-categories

Lack of community supports
Lack of affordable / funded supports
System hard to navigate

Lack of Brain Injury Education for Medical Professionals And Educators for families To make informed decisions about Care.

Brain Injury
"Coordination of Services Needs to Improve."
(not of wait lists)

3

Micro & meso-level practice for ABI supports & services

This category of the framework focused on practice-related aspects that support ABI survivors and their families, or what is happening at a “boots on the ground” reality. Challenges and areas for improvement related to the supports and services in practice were the most discussed category during the World Café. However, this could be related to the lived and work-related experiences of the World Café participants.

A consistent message across the World Café discussions and online townhall feedback was the need for enough supports and services for people living with ABI that are accessible in a timely manner to be able to thrive. However, the need to create and optimize supports and service practices was often intertwined with funding discussions (i.e., macro level decision-making category). There was a noted need for enhanced supports required to address living conditions upon acquiring an ABI. However, gaps in support services, challenges finding and accessing service, and long waitlists reportedly left people with

a newly acquired brain injury experiencing significant challenges—challenges that often worsened as they waited for supports and services.

Participants also highlighted the need for better ways to help people navigate and access the supports and services available. Participants discussed the need for case managers/navigators and navigation maps as important for ABI survivors and families accessing supports and service programs in the current complex system of supports and services. Participants also noted how this was inter-related to the macro-level ideas of better service integration. In this reciprocal relationship, if the service system was less siloed and better integrated, then the need for case managers/navigators and navigation maps to help people with lived ABI experience navigate the system could become less critical.

Of specific importance was the need to improve access to timely and accurate ABI diagnostic services, as diagnosis was noted as the gateway to accessing needed funding, supports, and/or services.

Some other specific services noted and looking to be prioritized:

- Community and needs-based supports;
- Interdisciplinary rehabilitation services; and
- Supportive housing options.

Figure: Written response examples of supports and services practice sub-categories

Appropriate referrals in the health care system
More resources needed

Underdiagnosing ABI,
people feeling alone and discharged without supports

4

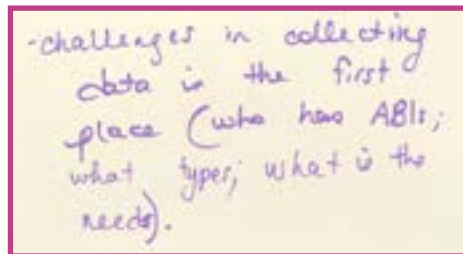
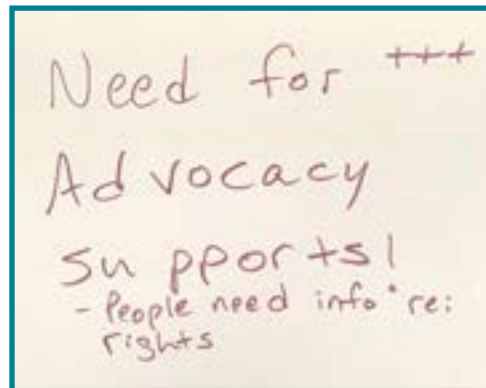
Awareness through ABI related advocacy & activism

The last part of our proposed ABI strategy framework was the need for advocacy and activism for improving awareness of ABI and for ensuring that the flow of information between the strategy framework continually happens. We define these as:

- Advocacy as the act or process of supporting a cause or proposal; and
- Activism as a doctrine or practice that emphasizes direct vigorous action especially in support of or opposition to one side of a controversial issue.^c

Advocacy and activism to create awareness and educate about ABI was noted as needed at many different levels: new survivors, families and close others, general service providers (e.g., family/primary care physicians), governmental officials, and the general public. Education and awareness were noted as improving supports and services and to addressing general stigma about living with ABI. Further, important to advocacy and activism was ensuring this was getting the voice of people living with ABI heard, which included having initiatives from a “grass-roots”, lived experience, or a “nothing about us without us” approach.³⁴

Figure: Written response examples of advocacy and activism sub-categories



^c Definitions from Merriam-Webster online dictionary. Retrieved April 2024 from <https://www.merriam-webster.com>.

An inter-connected strategy framework

Overall, the parts of our proposed framework are connected and dynamic (i.e., changing), as can be seen in the visual hour-glass figure. Further, there are inter-related ideas in different categories of the model that can directly related to changes or action between main categories and their identified ideas or subcategories (see table on this page for inter-related examples). Therefore, the strategy categories, as interconnected and dynamic, all need to be included and addressed for the ABI strategy to be effective of meeting the needs of Manitobans living with ABI.

Table: Examples of inter-related subcategories (category where idea from)	
Family-centered philosophy (philosophy)	Family-based supports/services (practice)
Focus on anti-oppression to combat stigma related to ABI (philosophy)	Awareness & education about ABI (advocacy and activism)
Equity focused with acknowledging the unique needs of equity deserving ABI sub-groups (philosophy)	Culturally-sensitive/safer, trauma-informed & relationship-based care/ practice (practice)
Funding to ABI supports/services and for those with lived experience to access needed supports/services (decision-making/administration)	Enough and timely supports/services for people living with ABI to thrive (practice)
Integration of services & leadership and vision for MB ABI Strategy (decision-making/administration)	Case management & navigation help to access needed ABI services/supports (practice)

Conclusions from BIMB project (Phase 1)

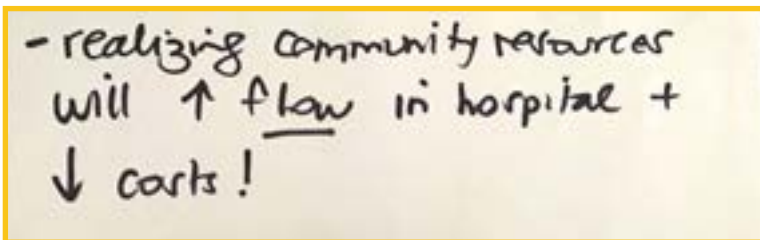
After extensive engagement with the lived and work-related ABI experience, we have developed and propose a comprehensive framework for a Manitoba Brain Injury Strategy and provided our recommendations for action as related to the strategy.

Who should care about this strategy? Simply, everyone—as we all pay through social costs of ABI for unmet needs and any of us could be someone with lived ABI experience at some point in our lives. Therefore, who should care includes:

- People whose lives are impacted by ABI;
- People whose paid or volunteer work is influenced by ABI;
- People in the general community; and
- Health authority and governmental administrators and decision-makers.

Everyone needs to care, considering the very high rates of people living with ABI in Manitoba and the significant impact of unmet needs leading to very deleterious and costly consequences to individuals, families, communities, governments, and society. Increased money is spent addressing the consequences of unmet needs after ABI, that can often spiral to further detriments and costs over time. The time is now to invest in not only preventing ABI and preventing the deleterious consequences when it does occur, but also having a strategy and practice in place to better meet the needs of Manitobans living with ABI.

However, it is important to note that this framework does not just sit within a health context or only within the formal healthcare system, but acknowledges the broader ABI community, that is intersectoral and crosses the boundaries of the public systems/ institutions as well as private and non-profit organizations.



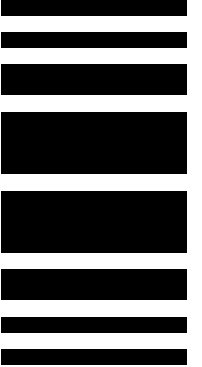
- realizing community resources will ↑ flow in hospital + ↓ carts!

Figure: Response from World Café participant about impact addressing ABI needs in Manitoba

Next Steps & Future Project Work

From the start of the BIMb project, as a team we knew that the experiences and needs of people affected by ABI who live outside Winnipeg are different or unique to those people affected by ABI who live in Winnipeg. Over 2022 and 2023, our project team, in a model of shared project decision-making, development, and implementation, developed the goal and objectives for the project, but we always envisioned the BIMb project within a framework for multiple BIMb project phases to account for experiences across Manitoba.

Our next steps will be in consultation and partnership with people across the province in how best to reach the BIMb project goal and objectives. We anticipate that as this project progresses our team will change and grow to become engaged and sensitive to local area key stakeholders and lived, work, and research-related experts. We look forward to this continued work and engaging with new people as we meet the BIMb project goal and objectives. We also will work to engage with decision-makers and key stakeholders across the province, including those in various government offices and ministries effected by and related to ABI, Shared Health Manitoba, the Manitoba health regions, community-care organizations, and Indigenous groups and communities to begin work on further developing an ABI strategy in Manitoba and working to addressing our recommended areas for action.



Appendix A: Key Recommendations in Depth

Finding 1

Participants expressed both positive and negative feelings about the current ABI supports and services available in the Winnipeg region. Positive feelings of current ABI supports and services were attributed to having private insurance funds and other funding sources that made it possible to access privatized services. Positive experiences were strengthened through the involvement of natural support systems such as family, and professional supports such as service providers and organizations. Negative experiences of current ABI supports and services were impacted by lack of access to services including confusion where and how to access supports, resulting in people feeling angry, frustrated, confused, lost, alone, and sad.

□ **Recommendation One: Acquired Brain Injury Philosophy – Live and Thrive**

This report recommends that the Government of Manitoba along with community partners and people with lived ABI experience, commit to enhancing and improving outcomes for people living with ABI by focusing on how people can live and thrive in their community.

Details: The intent of this recommendation is to enhance the overall wellbeing of those living with ABI through community involvement that promotes inclusion. This may include recreational opportunities, access to health care and services in community, varied housing options and employment opportunities that increase intrinsic feelings of value and belonging.

□ **Recommendation Two: Macro Decision Making and Administration – Improved Access**

This report recommends that provincial funding is allocated to improve access to ABI support programs and services.

Details: The intent of this recommendation is to ensure that there are locally accessible supports for those living with ABI, that cover a range of services including:

- Timely screening, assessment, and diagnostics;
- Short-term recovery services with referral to long-term and specialized outpatient services; and
- Specialized community-care services for long-term needs and changes over time.

□ **Recommendation Three: Micro/Meso Practice for Supports and Services – Improved Response**

This report recommends that service providers improve processes so that there is an increase in timely response, to meet the needs of people living with ABI.

Details: The intent of this recommendation is to develop and implement a tracking tool or mechanism, whereby follow-up services are tracked from point of assessment, for the purpose of improving efficiency in response to requests for service.

□ **Recommendation Four: Micro/Meso Practice for Supports and Services – Improved Attachment**

This report recommends that the Government of Manitoba improve attachment to supports and services, through enhanced ABI case-management, and system navigation.

Details: The intent of this recommendation is to ensure that people with brain injuries have a system navigator and case manager to ensure that they are properly screened, assessed, and matched with funded resources that are appropriate to them and their support needs.

- The aim is to ensure that people who have cognitive impairment(s) can access resources, no matter who their support system is, the source of their injury or income level. Case managers can act as knowledge experts of services and the system to help guide those experiencing through the complex health and social services system.
- Currently, case managers and system navigators don't exist for everyone with a brain injury after the age of 18. Many people with brain injury fall outside of eligibility criteria for other cognitive based support services.

Appendix A: Key Recommendations in Depth (continued)

Finding 2

Survivors of ABI have unique, distinct, and varying needs that are often unmet

□ **Recommendation Five: ABI Philosophy – Equity**

Informed by persons with lived ABI experience,, Shared Health, other health authorities, community partners and orgnaizations, and other groups or organizations across different sectors work to improve equity focused access to needed supports and services that are sensitive to the unique needs of living with ABI.

Details: The intent of this recommendation is to develop person-centered, trauma-informed and culturally appropriate strategies and response processes, aimed to meet the needs of the following sub-groups:

- Indigenous peoples and communities.
- Displaced persons (refugees) and new Canadians.
- People with intersectionality experiences such as those experiencing co-morbidity (e.g., dual diagnosis of ABI & mental health/addictions).
- People with limited income, those experiencing economic challenges and those who have injuries for which insurance will not cover.
- People experiencing homelessness, who are at risk of homelessness, or who have unstable living conditions.
- People living with drug poisoning.
- People living with severe impairments after ABI, specifically those currently being discharged to Personal Care Homes due to lack of supportive housing; and
- People living in rural Manitoba, who have limited access to supports and services.

□ **Recommendation Six: Micro/Meso Practice for Supports and Services -Supportive Housing**

This report recommends that the Indigenous, Federal, Provincial, and Municipal governments and governance bodies collectively work with the housing and homelessness sector, along with community partners, such as the Canadian Mental Health Association and Manitoba Brain Injury Association, to develop varied supportive housing options for those people living with ABI who have diverse housing and support needs.

Details: The intent of this recommendation is to meet the housing needs of those living with ABI, and to mitigate the risk of ever experiencing homelessness. People living with ABI have a spectrum of acuity needs and therefore require various housing options that may range from temporary transitional housing, to permanent supportive housing with wrap-around services.

□ **Recommendation Seven: Macro Decision Making and Administration – Systems Integration**

This report recommends that the Government of Manitoba, Shared Health, rehabilitation service providers, community service providers and other representatives working to provide supports and services to those living with ABI, develop a steering committee whose purpose it is to improve coordination and system integration.

Details: The intent of this steering committee should be to improve communication within and between service providers both in healthcare and other community sectors, provide opportunities for cross-sectoral conversations, and improve the continuity of services provided to those living with ABI.

Appendix A: Key Recommendations in Depth (continued)

Finding 3

There exists a relationship between community-focused care and recognizing ABI as a chronic health and living condition, requiring long-term supports. Improving awareness of ABI through the voices of people with lived ABI experience and advocating for structural improvements is needed

□ **Recommendation Eight: ABI Philosophy – Bill C-277**

This report recommends that treating ABI as a chronic health and living condition is embedded into legislation, and that subsequent action is taken by all levels of government and health serving systems, to create processes that align with Bill C-277.

Details: The first intent of this recommendation is to enact Bill C-277, A National Strategy on Brain Injury. A National Strategy on Brain Injury would require the Federal Minister of Health to consult with provincial governments responsible for health, Indigenous groups and relevant stakeholders, to develop a national strategy to support and improve brain injury awareness, prevention and treatment as well as the rehabilitation and recovery of persons living with a brain injury.

The other intents of this recommendation are: to provincially recognize ABI as a chronic health condition; to create effective and long-term supports that meet the needs of people living with ABI; and align with the values described in Bill C-277.

□ **Recommendation Nine: Advocacy and Activism – Public Education and Awareness**

This report recommends that Government of Manitoba, in partnership with community organizations, and guided by people with lived ABI experience, develop an awareness and education strategy that aims to improve the prevention of ABI, as well as increased awareness about living with ABI, among the general public, health professionals, and decision-makers.

Details: The first intent of this recommendation is, through consultation with people with lived ABI experience, identify priority areas that require broader public understanding and research related to ABI in Manitoba. This may include preventing the occurrence of ABI (possibly through partnership insurance or community organizations), examining incidence and prevalence of ABI in Manitoba over time, understanding brain health, and reducing stigma surrounding those who live with ABI.

The second intent of this recommendation is to develop a public awareness strategy/campaign, reflecting the areas of priority.

□ **Recommendation Ten: Advocacy and Activism – Lived-Expert Voice**

This report recommends that all work undertaken in response to this report and/or all work done to improve outcomes for people living with ABI include the voice of people with lived ABI experience.

Details: The intent of this recommendation is to ensure that the voices of those living with ABI are amplified, prioritized, and reflected in policy decision-making processes. All people with lived ABI experience must be compensated for their time and expertise.

Appendix B: History of ABI Supports and Services in Manitoba

~1990

- Manitoba Head Injury Association formed (later becomes Manitoba Brain Injury Association (MBIA));
- Health Sciences Centre (HSC) opened the RR5 Head Injury Rehabilitation Unit;

1992

- Easy Street officially opened and offers a variety of health & rehabilitations services on the main level of Misericordia Health Centre (MHC);

1994

- Manitoba Public Insurance (MPI) implemented Personal Injury Protection Plan, which increased more immediate access to rehabilitation funds for motor vehicle incident related ABI and created growth in private rehabilitation services in Manitoba, but associated with developing a 2-tiered health/ABI services system in Manitoba;

1995

- NeuroRecovery Services starts (ABI Case Management and Residential program offered by Society for Manitobans with Disabilities (SMD));

1996

- SMD sold 50% of NeuroRecovery Services to Occupational Rehabilitation Group of Canada (ORGOC);

1997

- OBIA NeuroBehavioural Course offered in Winnipeg through NeuroRecovery Services;

1999

- Transitional Living Centres opened in Winnipeg by ORGOC, and at the time is the largest ABI-only rehab program outside of public system (rehabilitation/residential program; fee-for-service program);

1999-2001

- Brain Injury Feasibility Task Group Review by Dr. Jay Brolund (Selkirk Mental Health Centre (SMHC)) released; report provided to Minister of Health in 2001;

2000

- Brandon Support Services offered residential care to brain injury survivors. Was later purchased by CBI Home Health;

2001

- Special Contracts - Funding program starts allowing regional health authorities (RHA) to purchase spots in private rehab & residential programs to reduce pressure on long term beds in hospitals;

Early 2000's

- HSC opened NeuroSurgery unit with Dr. West and Dr. Kaufman;
- Post Acute NeuroSurgery Unit (PANSU) opened at Seven Oaks Hospital^A;
- All of NeuroRecovery Services sold to Life Works;

2003

- “Acquired Brain Injury in Manitoba: A Profile and Discussion Report by Working Group on Acquired Brain Injury”, released by Manitoba Health^B;
- Health Coordination Programs in Winnipeg Regional Health Authority (WRHA) developed intensive Case Management Program for Home Care clients (many who live with ABI) to address needs of individuals post-hospital living in the community (i.e., 4 housing programs, specially trained staff 24 hr/day);

^APANSU has moved multiple times (e.g., to Grace Hospital) and is now at Concordia Hospital in Winnipeg as of 2024

^BManitoba Health later became Shared Health in 2018

Appendix B: History of ABI Supports and Services in Manitoba (continued)

2006

- “Manitoba Model: Acquired Brain Injury Services” report released by Manitoba Health’s Community-Based ABI Services Planning Committee;

2007

- The Health Sciences Centre (HSC) RR5 Head Injury Rehabilitation Unit and the Stroke Rehabilitation Unit moved to Riverview Health Centre in Winnipeg; Head Injury Unit becomes the Riverview Traumatic Brain Injury (TBI) Unit;

2008

- Thompson’s 5-bed ABI Transitional Residence opened by Manitoba Health
- Manitoba Health opened Selkirk Mental Health Centre 20-bed rehabilitation program for ABI
- SMHC offers OBIA NeuroBehavioural Course;

2009

- Manitoba Health opened SMHC 5-bed Transitional Residence, which provided longer term support and rehabilitation for recovery to many people who had experienced ABI;

2013

- St. Amant opened 2 group homes for 6 individuals with ABI due to hospital pressures as a lack of appropriate discharge options with sufficient supports;

~2014

- Action Marguerite opened a 9-bed locked residential unit for ABI^C;

2015

- Manitoba Public Insurance (MPI) opened 4-bed home in Brandon to care for 4 individuals with sever ABI^D;

2019

- March of Dimes Canada (MODC) started in Manitoba. From 2019-2024 primarily providing support services for people from Nunavut with a few exceptions for MPA clients^E;

Early 2020s

- SMHC 5-bed Transitional Residence closed during the Covid-19 pandemic;

2022

- Special contracts funding program from Shared Health (started in 2001 by Manitoba health) frozen;
- March of Dimes Canada released “Environment scan on Manitoba Brain Injury Supports & Services” which highlights continued gaps in ABI services across Manitoba^F;

2023-24

- Spring 2023: March of Dimes Canada’s Regional Director (Meredith Daun) participated in MB Housing Day at the legislature, advocating to MLAs about homelessness and brain injury;
- November 2023: Winnipeg World Café On Brain Injury happens (part of BIMb, phase 1; focus on current state and ideas for improvements to brain injury supports & services);
- December 2023: Health Sciences Centre in Winnipeg (Shared Health) opened 28 bed acute-care stroke unit;
- To current: BIMb Team continues advocacy to governmental, health authority, and other decision-makers.

^C Action Marguerite continues to house a “young-person’s” program and supports many ABI survivors as of 2024

^D Originally operated by Brandon Support Services; as of 2024 operated by CBI Home Health Services

^E MODC started in Manitoba in December 2019 but experienced slowed development in province during the Covid-19 pandemic

^F Led by Meredith Daun (March of Dimes Canada, Regional Director – Manitoba) completed Spring-Fall 2022; October 2022 sent to current Manitoba Members of Legislature

Appendix C: Tables of Key World Café Ideas Discussed

Table C.1: ABI strategy philosophy

Subcategories (7)	Count
Focus for thriving & living in the community (connection in and to one's community)	31*
Treating ABI as a chronic health & living condition needing long-term supports	14*
Equity focused, with acknowledging the unique needs of equity deserving ABI sub-groups	13*
Focus on anti-oppression to combat stigma related to ABI	10
Holistic, comprehensive, varied “needs-based” care model – focus on all needs after ABI (not just health)	10
Family-centred philosophy	6
Promoting post-ABI positive sense of self, self-love, and acceptance	3

Table C.2: Decision-making & Administration (macro level)

Subcategories (6)	Count
Funding/money to ABI supports/services & for those with lived experience to access needed supports/services	39*
Improve system integration (i.e., unified leadership and vision; connected services)	29*
Building ABI expertise of service providers in MB	7
Government commitment to optimizing ABI care	7
Acknowledgement & attention that addressing ABI across MB is beneficial & needed for MB	6
Evidence-based planning & focus	3

*Highlighted ideas with an asterisk in each table are the most frequently discussed ideas and the focus of this reports key recommendations for action.

Numbers in each table = count of how many times each philosophy sub-idea noted in the collected World Café information

Appendix C: Tables of Key World Café Ideas Discussed (continued)

Table C.3: Practice for Supports & Services (micro/meso level)

Subcategories (9)	Count
Enough and timely supports/services for people living with ABI to thrive	40*
Case management & navigation help to access needed ABI services/ supports	35*
Varied supportive housing options to meet diverse needs	20*
Timely, accessible, accurate, and up-to date screening and diagnostics	13
Vocational support for ABI survivors – education & employment needs	9
Family-based supports/services	6
Culturally sensitive/safer, trauma-informed & relationship-based care/practice	5
Access to enriched & engaging environments	1
Access to assistive technology	1

Table C.4: Decision-making & Administration (macro level)

Subcategories (3)	Count
Awareness & education about ABI to people with lived experience, work-related experience (e.g., health professionals), community & general public	33*
Getting the voice of people with ABI heard (nothing about us, without us)	20*
Creating & using evidence & knowledge about ABI in Manitoba	7