

Brain Injury Matters

# STRATEGIC DIRECTION

2020/21 – 2021/22



## FOREWORD

Brain Injury Matters recognises the ongoing challenge to put the lived experience of people with an acquired brain injury at the centre of any policy discussion, service development or mainstream or specialist system reform.

Our new Strategic Direction takes up that challenge. But as a self-advocacy organisation with a long history, we know from experience that getting our voice heard is never easy or straightforward. COVID-19 has made that even tougher. We have had to work hard in these strange times to maximise the involvement of our members in the development of this two-year plan.

We have taken the opportunity to refresh our vision and mission, as well as list our values for the first time. The five goals of this Strategic Direction are Empowerment, Awareness, Being a Voice, Address Isolation and Sustainability. This is a multi-pronged approach, seeking to build the capacity of people with an Acquired Brain Injury to speak for ourselves and improve our inclusion in the community.

I am excited about the future of Brain Injury Matters. To all our members, continue to be the self-advocates I know you all are! Remember, we are experts in our own lives. To our supporters and funders, we look forward to your involvement and support.



Brent Alford  
Chairperson

August 2020

## **1. Introduction**

This Strategic Direction provides a framework to guide the specific activities and projects undertaken by Brain Injury Matters in pursuit of its vision of people with an Acquired Brain Injury (ABI) flourishing in our community. It was produced during the grip of the COVID-19 pandemic, a time of great uncertainty and significant adjustment for people with an Acquired Brain Injury.

## **2. Who are we?**

Brain Injury Matters (BIM) is a Disabled Peoples Organisation (DPO) and a voice of people with an ABI in Victoria. Formed over 20 years ago, BIM is the only incorporated ABI self-advocacy organisation entirely governed and led by people with an ABI in Australia. All our office bearers and committee of management members have an ABI. BIM is well respected and has been the recipient of sector awards. We believe in the social model of disability, addressing attitudinal, communication, institutional and physical barriers preventing our inclusion in the Australian community by continuing to share our lived experience of disability.

## **3. How was this Strategic Direction developed?**

This 2-year strategic direction is the result of a consultative process, primarily driven by the express views and priorities of people with an ABI. Key to ensuring that the Strategic Direction truly reflects the needs of people with an ABI is the BIM Needs Survey 2020 (the Survey). The Survey was conducted in February and March 2020 using Survey Monkey. The survey questions were informed by a desktop review of strategic plans, academic research, and information from like organisations in the self-advocacy and/or ABI arenas within Australia and internationally. This desktop review performed a dual purpose – firstly informing the survey, and then validating the strategic direction itself. Several interviews with key stakeholders also took place, though this was curtailed due to the impact of the COVID-19 pandemic.

In summary, this Strategic Direction is informed by:

- The Needs Survey of Brain Injury Matters members (n= 53)
- Stakeholder interviews (n=2)
- Desktop review of strategic plans of ABI self-advocacy and other organisations, and relevant academic research

A draft of the strategic direction was distributed to the BIM Committee of Management for comment and a virtual meeting was conducted in June 2020 to provide an opportunity for feedback. A survey on the key aspects of the next draft of the strategic direction was then distributed to all BIM members, and changes made accordingly.

## **4. Vision**

People with an Acquired Brain Injury lead dignified and meaningful lives in an inclusive community

## **5. Mission**

To support and empower people to advocate for themselves and enhance the lives of other people with an Acquired Brain Injury

## 6. Our Core Values

Our values remain constant. The values listed below are reflective of what BIM stands for and how we have always strived to operate and will continue to do so.

- **Inclusion** – All people with an ABI are recognised and respected as valued and contributing members of society
- **Agency** – Supporting people with an ABI to make their own decisions and choices through access to information, self-advocacy training and connections with groups and the community
- **Collaboration** – Fostering a spirit of collaboration within our organisation, the ABI community, mainstream organisations, and all people with a disability
- **Co-design** – People with a disability are meaningfully involved in all aspects of services, policies, and programs – defining, conceptualising, designing, developing, implementing, and reviewing
- **Equity** – Pursue opportunities for people with a disability so they can access, participate fully and flourish in all areas including the law, employment, education, and housing
- **Transparency and Accountability** – We will operate in an open and honest manner, be accountable to our members and meet all our legal and fiduciary requirements and those of our funders
- **Respect** – All people are treated with dignity and courtesy including people with a disability, members of BIM, staff, and stakeholders
- **Diversity** – We strive to reflect, and accept without question, people from diverse backgrounds, including cultural, demographic and gender

## 7. What are the key issues for people with an Acquired Brain Injury?

ABI has an enormous impact on a person's life. In addition to the functional, physical, cognitive, and behavioural impacts, there are significant social challenges including isolation, reduced, or changed social networks, unemployment, altered relationships/family dynamics and depression, which can be overlooked. Often it is at the point of hospital discharge back to the community after the injury, that these social impacts become apparent. There can be a sense of loss which typically occurs after this intense rehabilitation in hospital and rehabilitation centres. People are often "grappling to accept their disability, comparing their Old Me to their New Me"<sup>1</sup>, accompanied by a loss of both motivation and sense of self-worth.

BIM members identified 'addressing social isolation' (73% of survey respondents) as the most important issue facing people with an ABI. Other key issues identified were advocacy, income and financial support, housing, health, employment, and disability support (including NDIS, and other support agencies).

A lack of confidence (63%) and a lack of knowledge about where to find help (59%) are the main barriers were identified by the Survey that prevent people with an ABI from participating or contributing to their community.

The survey findings confirmed that supporting people with an ABI with their self-advocacy combined with raising awareness of ABI in the community should continue to be key functions of BIM.

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<sup>1</sup> Dr Christine Durham, 2012, *Empowering People with ABI to Acquire Better Insight into Brain Injury: An Application of Educational Principles*, PhD Thesis

## 8. What is our focus and how will we achieve it?

As a self-advocacy organisation, our aim is to support and increase the capacity of people with an ABI to find their voice at an individual, community and systems level. This then requires us to work at these three interconnected levels to ensure lasting change.

BIM has developed five goals with objectives and strategies for our work over the next two years.

### **Goal 1: Empowerment**

Empowering people living with an Acquired Brain Injury through facilitating self-advocacy and providing peer support

#### Objectives

- Build the individual confidence and skills of people with an ABI to self-advocate in their own lives and then potentially on behalf of others
- Provide a holistic range of information to people with an ABI, particularly the lived experience of others with ABI

#### Strategies

- Provide and/or link people with an ABI to individual capacity building training, supporting people with their personal journey, post-injury
- People with an ABI getting information about the lived experience of others with an ABI from a variety of sources – peers and BIM as well as by digital means like the ABI Wise App, websites, and social media
- Seek opportunities to initiate new and/or support existing peer support groups

### **Goal 2: Awareness**

Raising awareness about the effects of Acquired Brain Injury through community education

#### Objectives

- Extend the community's understanding of ABI to support inclusion of people with an ABI in the community
- Broaden the ABI sector's understanding and acceptance of the social impacts of ABI

#### Strategies

- Promote a broader understanding of the functional, physical, cognitive, behavioural, with a focus on the social impacts of ABI through a range of digital platforms and other mechanisms
- Build awareness and understanding of the lived experience of ABI and the social impact of ABI, by engaging with the ABI rehabilitation and disability service sectors
- Be involved in clinical and other research to ensure the voice and experience of people with an ABI contributes to the body of knowledge and understanding of Acquired Brain Injury
- Develop a community education strategy including information sessions to a range of audiences including schools, community organisations, ABI professionals and service providers

- Actively seek to be involved in advocacy conference presentations, panels, and information booths such Having Your Say and ABI specific conferences
- Explore the concept of a Brain Injury Identity Card

### **Goal 3: Address Isolation**

Providing support to alleviate the isolation and marginalisation experienced by people living with an Acquired Brain Injury

#### Objectives

- Promote a more holistic approach to rehabilitation and support of people with an ABI, in partnership with rehabilitation services and service providers
- Increase the BIM membership base and the level of engagement by members to address social isolation
- Engage with people with an ABI living in rural and remote communities

#### Strategies

- Ensure all information on BIM's digital platforms is accessible
- Promote our ABI Wise App as an information source and point of connection for people with an ABI, targeting people with a newly acquire brain injury exiting ABI rehabilitation centres and hospitals
- Track the digital reach of the various BIM platforms – ABI Wise App, Facebook, Instagram, and website
- Support regular social catchups for BIM members including digital platforms to engage with people living in rural and remote areas
- Ensure information is up to date to support referrals of individual people with an ABI to supports like peer support groups, and service providers
- Identify and engage with touchpoints in the community and mainstream services, including mental health, drug and alcohol and homelessness services, and provide them with information on BIM and the ABI Wise App
- Connect with people with an ABI who have received their disability by non-traumatic causes

### **Goal 4: Being a Voice**

Being a voice of people with an Acquired Brain Injury to inform local, state, and national bodies around relevant issues

#### Objectives

- Represent the best interests of people with an ABI, so that funders and policymakers take account of the lived experience of ABI in public policy and service system development and implementation
- Contact, engage, support, and represent people with an ABI from a range of backgrounds and circumstances

## Strategies

- Establish consultative mechanisms with key stakeholders and decisionmakers including the NDIA, Transport Accident Commission, Office of Disability, and the Office of the Public Advocate to address the issues impacting on people with an ABI
- Conduct the BIM Needs Survey on an annual basis and utilise the findings to engage with a range of stakeholders
- Establish contact and maintain liaison with all Victorian ABI rehabilitation centres and hospitals
- Promote improved approaches by service providers, informed by the lived experience of people with ABI in the acute care, assessment, rehabilitation, and community reintegration phases of their injury
- Work to promote fairness, access, and equality for people with an ABI in their interactions with the criminal justice system
- Explore opportunities within BIM or other organisations, for individuals with ABI to advocate on behalf of others with an ABI and/or people with a disability more generally
- Seek to employ people with an Acquired Brain Injury in BIM whenever possible including the provision of the range of supports and adjustments to achieve this

## **Goal 5: Sustainability**

Being a sustainable, accountable, and transparent organisation

### Objectives

- Enhance the internal capacity of BIM including governance, policies/procedures/systems, staff training and support, IT
- Strengthen our communication with BIM members
- Broaden our partnerships with organisations to increase our policy impact and boost our long-term sustainability

### Strategies

- Improve existing, and develop new internal and external communication methods with members and stakeholders, through the development and implementation of a communication strategy, inclusive of digital platforms
- Seek a diversified funding base
- Regularly review organisational policies and procedures, and update as required
- Develop and support a volunteer program to support the organisation's internal functioning, and activities to support people with an ABI
- Enhance relationship building with other community groups and mainstream organisations to explore synergies and share resources
- Monitor, and enhance, as appropriate, IT operations and security
- Pursue a best practice, accessible web site (work towards compliance with Web Content Accessibility Guidelines (WCAG) version 2.1) and ABI Wise App
- Network more proactively with the broader advocacy sector, particularly systemic advocacy organisations to ensure that the

experiences and views of people with an ABI are included in policy discussion and development whenever possible

- Provide appropriate training and professional development opportunities for all Committee of Management members and staff
- Annually review the Strategic Direction to ensure that it is meeting the current and future needs of the organisation
- Develop and review induction processes, and provide and maintain an operational policy manual for committee of management members and staff