**Brain Injury Matters 2020 Needs Survey**

**Who are we?**

Brain Injury matters (BIM) is a Victorian self-advocacy organisation of people with an acquired brain injury (ABI). It was formed over 20 years ago and BIM is the only ABI self-advocacy organisation that is 100% governed and led by people with disability in Australia. All office bearers and the Committee of Management are people with an ABI.

**What is the impact of Acquired Brain Injury?**

ABI has an enormous impact on a person’s life. In addition to 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. Traditionally this is a hard to reach group, given the acquired nature of ABI and individuals having no previous connection to the disability community. Many people struggle with the adjustments resulting from their ABI, emphasising theimportance of social rehabilitation, alongside physical and cognitive rehabilitation.

**What is our focus?**

BIM has as its goals:

* Empowering people living with an acquired brain injury through facilitating self-advocacy and providing peer support.
* Raising awareness about effects of acquired brain injury through community education.
* Providing support to alleviate the isolation and marginalisation experienced by people living with acquired brain injury.
* Giving a voice to people with acquired brain injury to inform local, state and national bodies around relevant issues.

**What are our key activities?**

BIM’s key activities are:

* Updating and promoting our ABI Wise App as an information source and point of connection for people with an ABI
* Developing Peer Support Groups
* Regular liaison with key stakeholders and decision makers to address the issues impacting on people with an ABI
* A referral point for individual people with an ABI to supports like peer support groups and service providers
* Self-development training and social catchups for BIM members
* Promoting the lived experience of disability in community awareness campaigns

**What are the key issues?**

As a member driven and led organisation, BIM conducted a survey of its members in March 2020 to guide its priorities in the short and medium term. The survey had a 33% response rate (n=52) which reflects the real engagement of people with brain injury in guiding their organisation.

The key findings from the BIM 2020 Needs Survey are:

* Addressing social isolation (identified by 73% of respondents) is the key support area that most respondents think is most important to people with an ABI. Importantly 40% of respondents said they would be interested in becoming involved in BIM by 'sharing my journey to help others'. Rounding out the top 5 areas were advocacy, income and financial support, communication and housing. Other important areas were health, employment and disability supports (including NDIS, and other support agencies).
* A lack of confidence (63%) and lack of knowledge about where to find help (60%) are the main barriers respondents believe prevent people with an ABI from participating or contributing to their community. The ‘poor attitudes of people in the community (50%)’, was another significant barrier.
* Raising awareness of ABI in the community (57%) and supporting people with an ABI with their self-advocacy (55%) are what respondents think should be the core focus of BIM. These findings confirm that its members believe that self-advocacy and awareness should continue to be high priorities for BIM, aligning with our goals.

* People with an ABI value getting information about brain injury and ABI services from a variety of sources – peers and BIM members as well as by digital means like the ABI Wise App, websites, and social media. But gaps remain, as 16% of people with an ABI reported they did not know where to get good information.