

Evidence Brief: Does participation in community-based advocacy and education activities in the community support improved outcomes after TBI?

Key evidence to guide decision making

- Advocacy and education programs, specifically public presentations, can build communication skills. There is **evidence** that participation in these programs improves **speech clarity and expression conciseness** for people with TBI (Hoepner et al., 2022).
- Social participation, control over life events, and gaining political power such as through advocacy have been shown to **positively influence health and quality of life**, especially for people who have experienced TBI (Malec et al., 2009).
- Participation in advocacy and education programs aligns with INCOG 2.0 guidelines, which recommend that interventions should focus on improving and restoring cognitive and communication functions with **gradual reintegration to daily functions and productive activities**. (Togher et al., 2023).

Community-based advocacy activities: What are the benefits?

1. Building communication skills

Advocacy programs, particularly public presentations, have been shown to improve speech clarity and expression (Hoepner et al., 2022). By participating in advocacy activities, people with acquired brain injury (PwABI), can enhance their communication and cognitive skills, which are key rehabilitation goals. Practising in real-world settings will help PwABI to develop skills that are directly transferable to everyday interactions.

The communication opportunities this activity provides includes:

- Development of expressive language skills (both written and verbal)
- Goals related to articulation and verbal expression
- Goals related to discourse - topic maintenance, verbosity, cohesion, use of formal language, social cognition (judging the tone of language appropriate to a more formal/professional setting).
- Ability to respond accurately and appropriately to audience questions Vs reading aloud a prepared speech
- Adjustment to injury and acceptance of where they are at in order to move forward. Clients are supported to update the talks to reflect changes in their perception, and focuses and can look back on how far they have come through the process of updating their story
- Providing educational talks helps some clients develop insight and better problem solving as they are being asked to reflect on their own actions and give advice to others (e.g. Traffic offenders, young drivers, future professionals).
- Supporting fellow speakers in group presentations- role of teacher/colleague vs passive communication partner which is more typical in traditional therapy setting.

2. Confidence and self-efficacy

Engaging in advocacy can build PwABI's confidence and self-efficacy, leading to improved mental health and support them to take a more proactive approach to their rehabilitation (Gagnon et al., 2015). Through advocacy involvement, PwABI can build social connections and support networks, which are necessary for emotional support and successful reintegration into their communities, (Malec, 2009). Research also shows that using key aspects of narrative storytelling results in positive therapeutic benefits on clients who share their stories to help others. It helps to contribute to psychological and emotional care by validating clients' experiences (D'cruz et al., 2020).

3. Communicating in real-world contexts

Community-based advocacy activities offer practical, real-world opportunities for PwABI to use and refine their communication and cognitive skills, enhancing the overall effectiveness of their rehabilitation. MacDonald (2017) notes that rehabilitation programs should provide opportunities for PwABI to practise their communication skills in contexts where they live, work and socialise. The real-world nature of these tasks builds greater motivation compared to traditional therapy activities.

What are the risks of not supporting advocacy opportunities?

1. Impacts on rehabilitation goals, risk of social isolation and reduced self-esteem

Without funding PwABI may miss out on critical opportunities to improve their communication skills and achieve their rehabilitation goals, thus impacting on their recovery process. Denying the PwABI opportunities to participate in advocacy activities can lead to increased social isolation and a sense of disconnection from their communities, which can have an adverse effect on their mental wellbeing and quality of life. The PwABI may also experience lower self-esteem and find it challenging to be motivated and engaged in their rehabilitation. This idea is supported by Hawley and colleagues (2017), whose findings suggest that individuals with ABI who did not receive self-advocacy interventions have shown a decline in a range of outcome measures including the Satisfaction with Life Scale (SWLS).

2. Limited public awareness and understanding of ABI

Public education about ABI can significantly improve public knowledge and awareness, which Schellinger et al., (2018) notes are often inadequate. Particularly in Australia, awareness is mainly confined to competitive sports contexts (Ansari et al., 2024). A lack of advocacy may perpetuate public misunderstanding and stigma regarding ABI, this can then have a negative impact on PwABI's reintegration into the community.

Ultimately, should community-based advocacy activities not be funded, the PwABI's potential to improve through real world practice and the overall success of their rehabilitation will be limited. The risks of not supporting community-based advocacy activities impacts directly on their rehabilitation goals, with consequences of social isolation, dealing with community stigma and reduced opportunities to enhance communication skills in everyday situations.

Feedback from people with ABI who have participated in advocacy and education activities

The following quotes have been collected from people with ABI who have experienced the benefits of sharing their stories:

"I'm passionate about getting my message through to young drivers about the dangers on the road."

"These talks also help me in lots of ways:

- They help me deal with my own grief*
- These talks help me make better life decisions*
- Helping others gives me a sense of value and confidence"*

"I enjoy talking to students and drivers. I also speak to traffic offenders so they can be more sensible on the road. Some of them are pretty shocked at how I'm still here telling my story and how I got through it all. I just tell my story and hope it gets through to them and they don't do the silly stuff like I was doing."

"Sharing my story has been therapeutic in so many different ways. It helps me put my thoughts into words and I find my words flow. It's hard to tell progress with a brain injury especially because I hide it so much. But when I have to put together my story, this has made me understand how far I've come and that my hard work is paying off. Being invited to speak gives me a tiny semblance of my former life as I would do a lot of talking in my old job. Standing here today builds my confidence and gives me hope for my future."

"I am keen to do more of these talks. It's pretty simple. I'm trying to spread the awareness of brain injury which is a hidden problem. But I primarily do these talks for me because it's improving my public speaking skills and confidence."

References

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