

# Engagement Strategies for Survivors

A companion piece to the *Traumatic Brain Injury Advisory Board Toolkit*, produced April 2021

Written by members of the TBI Advisory and Leadership (TAL) Group | August 2021



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***This guide is a resource for individuals with brain injury to be fully participating board members. It was developed by the TBI Advisory and Leadership (TAL) group to serve as a companion document to the Traumatic Brain Injury Advisory Board Toolkit.***

***The TAL group is part of the Traumatic Brain Injury Technical Assistance and Resource Center (TBI TARC), funded by the Administration for Community Living.***

## Introduction

Joining a board is a great way to use your experience to make a difference. Attending your first meeting can feel overwhelming; it's important to make this a positive experience. To be effective, there are several things to consider. Knowing yourself, what you need and how to get it, will make you successful. These are the principles of self-advocacy.

## Are you ready to serve on a board?

Serving on a board is an opportunity to impact the larger brain injury community. Is it the right time in your personal journey to actively participate on a broader scale? Each board has its own “personality”: mission, size, composition, and processes. It might be more formal or casual in terms of meeting flow. It is important to be aware of how your board works. Only you can answer the question of whether you are ready.

### Questions to consider:



- What are my strengths/skills?
- Why do I want to be involved with this board?
- Do I have enough information about this board to effectively participate?

- What kind of time commitment is required? How often does the board meet and for how long? Are there outside committee meetings to attend?
- Do I have strategies for coping with my brain injury?



## Strategies

If you're unsure of your strengths/skills, ask people who know you well. Consider attending a meeting as a guest to determine if this board is an activity you want to join. Talk with the board chair and/or existing members to hear about their perspectives and experiences. Give yourself permission to ask questions before deciding.

## Components for being a successful board member

***Telling Your Story***—You may be asked to share some of your brain injury story either during a board meeting or for other audiences, such as legislators or committees. Think about and select the most relevant parts of your experience to share. Consider the board's mission and how your story fits. Brief is better; this helps to maximize your story's power.

## Questions to consider:



- Why am I telling my brain injury story during a meeting?
- At what point during a meeting is it appropriate to share?
- How much of my experience should I share?
- Do I need to write a script to structure my story and tell it briefly?



### Strategies

Practice telling your story and sharing with a friend, family member or service provider. You can also create a practice session online using a platform such as Zoom. Using the recording feature, you can see and hear how your story sounds. During a meeting, pay attention to how and when experienced board members tell their brain injury stories.

**Coping With Emotions**—Events that activate feelings of personal loss can be difficult to manage and may happen unexpectedly. It is ok if it happens while participating on a board, but it is a good idea to be prepared for how to cope with it.

### Questions to consider:



- Be aware if I start to feel overwhelming emotions during a meeting, and think: What brought on those feelings for me?
- What coping skills have I developed to deal with brain injury emotions?
- Who can I talk to about this?



### Strategies

Pause, breathe, and analyze the situation. It's ok if you need to step away to process your emotions.

Try connecting to a peer or someone else who understands. If you continue having a hard time managing the situation, consider talking to a professional who understands brain injury.

**Organizing Yourself**—When you first join a board, there can be a lot of information to process, which might feel overwhelming at first. Strategies can help you manage the information.

### Questions to consider:



- How do I manage details about the meetings? Digital vs paper system?  
If this is challenging, who can I reach out to for help?
- Will this meeting be in-person or virtual? If virtual, can I locate and manage the meeting links and other pertinent information online? If in-person, do I know where to go?
- Have I familiarized myself with the meeting agenda, minutes, participant responsibilities and the process?
- Do I have contact info for the other board members?
- Have I put the meeting schedule into my calendar?



### Strategies

A board member or chair can provide or direct you to information (website, calendar notifications, emails, agendas, minutes, reports, etc.). Ask other board members how they organize themselves.

**Asking for Accommodations**—As a survivor, you may need accommodations to participate fully. It's important to know what you need and how to request it.

### Questions to consider:



- What accommodations do I need?
- How far ahead do I need to request them?
- Who is the contact person to ask for accommodations?
- How will I communicate my request—phone call, email, in-person meeting?



### Strategies

If you are unsure what accommodations you need, connect with other individuals on the board. For example, you might find captioning or transcriptions, a meeting mentor, or having written information about the meeting useful. Before the meeting, request your accommodations and confirm that they will be in place.



**Getting Involved & Staying Engaged**—Once you have attended a few board meetings, it is good to determine if you feel this activity is something you enjoy doing and if you want to continue participating.

### Questions to consider:



- Have I given myself enough time to get used to being on a board?
- How does participating on the board impact my brain injury challenges?
- Can I identify the projects for which I am best suited? What is my capacity?
- After participating for a while, do I feel like my contributions are valued?
- If I am feeling overwhelmed or undervalued, who on the board can I talk to?



### Strategies

It is important to know your abilities and recognize which meetings, tasks or environments might be a good fit for you. If you are concerned and want to leave, talk with someone on the board first. Boards can benefit from your feedback. Give yourself permission to say no; there might be other meetings that are a better fit for you.

We hope this guide has provided helpful information and strategies for you as a board member. For additional resources and checklists, contact the Traumatic Brain Injury Technical Assistance Resource Center at [tbitarc@hsri.org](mailto:tbitarc@hsri.org).

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## ABOUT TBI TARC

The Traumatic Brain Injury Technical Assistance and Resource Center (TBI TARC) is an initiative from the Administration for Community Living that helps TBI State Partnership Program grantees promote access to integrated, coordinated services and supports for people who have sustained a TBI, their families, and their caregivers. The Center also provides a variety of resources to non-grantee states, people affected by brain injury, policymakers, and providers.

