# Traumatic Brain Injury Advisory Board Toolkit

Developed in partnership by the ACL State Grantees serving on the *Advisory Boards & Engaging Persons with Traumatic Brain Injury* Workgroup

April 2021

**ACL**
Administration for Community Living

**TBI SPP**
Traumatic Brain Injury
State Partnership Program

# Toolkit Sections

*We invite your feedback on this Toolkit. Please [complete a brief survey](http://uaa.co1.qualtrics.com/jfe/form/SV_0PdnIQFiq8CZ77L) (http://uaa.co1.qualtrics.com/jfe/form/SV_0PdnIQFiq8CZ77L) to share your thoughts on the individual sections.*

# Introduction

States across the U.S. have established or are working toward implementing a TBI advisory council or board. These boards serve to identify and report on gaps in resources and services and make recommendations on ways to improve and develop needed resources and services that benefit people living with a brain injury; their caregivers, family members, and health care providers; and community stakeholders. Such boards are also a requirement of states awarded grants through the U.S. Department of Health and Human Services Administration for Community Living (ACL) Traumatic Brain Injury State Partnership Program. And as part of its commitment to person-centered planning, the Administration for Community Living encourages that people with brain injury comprise a 50% representation on these boards.

Brain injury advisory boards can be legislatively mandated or organized on a volunteer basis. In addition to formalizing identified state gaps and needs, they also provide a state of the state summary of brain injury services, gaps and needs on an annual basis to their state's legislature, governor and other public and private stakeholders. Each BI advisory board determines its own scope and focus, but their common goal is to improve quality of life for citizens living with brain injury, their families, and supporters. It is the work of state BI Advisory Boards to develop goals and a state plan that reflect the needs of the state's TBI population.

This TBI Advisory Board Toolkit aims to provide guidance and best practices to help state programs establish or sustain these advisory boards and, most importantly, to help them *fully engage* all advisory board members, especially people with brain injury, in planning and leading state work. (BI leadership groups may also be referred to by states as councils, committees, and workgroups. For the purposes of this toolkit, the term BI Advisory Board is used throughout.)

This Toolkit includes 14 individual components/sections developed by grantees of the ACL Traumatic Brain Injury State Partnership Program. We invite you to provide your feedback on any/all sections. ***Please [complete a brief survey](http://uaa.co1.qualtrics.com/jfe/form/SV_0PdnlQFiq8CZ77L) (http://uaa.co1.qualtrics.com/jfe/form/SV_0PdnlQFiq8CZ77L) to share your thoughts.*** Your feedback will be used for edits and revisions as the toolkit evolves.

# Background

This Toolkit was created by the *Advisory Boards and Engaging Persons with Traumatic Brain Injury* Workgroup of the ACL Traumatic Brain Injury State Partnership Program (TBI SPP). The TBI SPP awarded grants to states in 2018 in two categories: Mentors and Partners. Grantees were assigned to workgroups established in accordance with topics relating to states' goals. The Mentor grantees who have expertise in each topic work with Partner states to help develop, implement and/or expand activities relating to these topics. Tennessee and West Virginia were awarded Mentor Grants and lead the efforts of the *Advisory Boards and Engaging Persons with Traumatic Brain Injury* Workgroup.  In addition to Tennessee and West Virginia, the Workgroup is comprised of 10 Partner Grantees: Alaska, Arkansas, California, Georgia, Kentucky, Maryland, Massachusetts, Minnesota, Rhode Island, and Virginia.

Product development is one of the requirements by ACL for the workgroups. As a result, the *Advisory Board and Engaging Persons with Traumatic Brain Injury* Workgroup determined state brain injury programs would benefit from a toolkit to assist states on how to structure an advisory body, both legislatively sanctioned/governor appointed or community organized, to guide activities, oversee grant efforts and provide infrastructure for creating service systems that benefit individuals with brain injury and families. The toolkit demonstrates structure and process for states who are just starting with advisory board implementation and provides resources for states who need assistance with full engagement of seasoned members and agencies.

The grantees involved in developing the individual sections of this Toolkit are listed on the section heading pages.

*Note*: The term advisory board is used to describe a necessary component per the TBI Act, which stipulates that state programs establish an advisory board to "…advise and make recommendations to the State on ways to improve services coordination regarding TBI. Such advisory boards shall encourage citizen participation through the establishment of public hearings and other types of community outreach programs. In developing recommendations under this paragraph, such boards shall consult with Federal, State, and local governmental agencies and with citizens groups and other private entities."

## 01

# Describing Board Member Roles & Responsibilities

*In this section we identify positions within the board, along with essential requirements and responsibilities of board members.*

*States Involved:  WV, MA, MN*

# Best/Promising Practices

Advisory boards focused specifically on traumatic brain injury commonly use promising practices to describe the role of an advisory board member and to solicit applications. Descriptions often incorporate the following elements:

- A brief review of the board and its function within the larger network
- Roles and responsibilities of members including conflict of interest disclosures
- Opportunities available to members including potential specialized committee service
- A list and description of committees within the board
- A sample agenda and minutes
- Contact information for individuals who are interested in applying.

Adhering to best practices, other boards also include the following in board member descriptions:

- Board member compensation (if applicable)
- Specific skill sets or experiences sought from members
- Board structure and/or an organization chart illustrating the board's role in larger efforts and its relationship with other entities
- Benefits of board service (e.g., greater opportunity to support and expand capacity of larger network; deep involvement in activities; and opportunity to network with others who have significant expertise in the area).

# Descriptions Based on Roles and Opportunities

Board member descriptions are often delineated by the type of membership and additional roles each member may currently provide. Specifically, different responsibilities may exist for voting vs non-voting members, board officers, and members who are engaged in committee activities. Below are board member descriptions from national samples.

## Members (Voting or Non-Voting)

- Convey the priorities and recommendations of the TBI Advisory Board to other relevant state or private boards, commissions, committees or workgroups on which members participate.

- Update the TBI Advisory Board on the work of other relevant boards, commissions, workgroups and committees.

- Contribute to products (of various media formats including annual report, presentations) to particular audiences with recommendations for variety of areas including federal funding dedicated to services for individuals with a traumatic brain injury.

- Help build capacity and training to address the needs of individuals with traumatic brain injury.

- Contribute to discussions and implemented plans to coordinate services for individuals with traumatic brain injury.

## Leadership

- Provide oversight and direction in areas of focus for the board.

- Provide or contribute to the logistics for meetings; setting agenda and overseeing work plan for the board.

- Develop and disseminate minutes to various audiences.

- Develop and sustain new member orientation methods.

- Ensure website and other information about the board and its roles is available through various formats for members to disseminate to partners

## Additional Committee Work

- Contribute to the group efforts in the specific focus area of the committee (e.g., finance, education initiatives).

# General Responsibilities to Consider

Board members job descriptions also incorporate expectations of the members' involvement with the board. These commonly include:

- Attending board meetings and other events/functions (noting frequency and total number in a given year).

- Review agenda and supporting materials prior to board meetings.

- Provide support and advice to program(s), assist in the development of new programs, and identify best practice standards.

- Realistically assess the demand for practices, tools, and resources within the field that are either evidence-based or practice-based in nature.

- Identify and present opportunities for program in the noted areas of interest for the program (e.g., service, education, research).

- Assist in the identification and recruitment of new board members.

- Provide recommendations for topic presenters for advisory board meetings.

# Personal Characteristics to Consider

Board descriptions may also incorporate particular characteristics thought to be needed by the board or those that strongly contribute to the board mission. Best practices within this area have included such characteristics as:

- Ability to listen, work well with people individually and in a group, and provide constructive feedback.

- Willing to ask questions, share ideas, opinions, and experiences.

- Possess an understanding and appreciation of, or a willingness to learn, the history and purpose of the board and its mission.

- Demonstrate high ethical standards and integrity, both personally and professionally.

- Adhere to board policies, including maintaining the confidentiality of information and conflict of interest disclosure procedures. See the section "Orientation of Board Members" in this toolkit for more information about how to incorporate conflict of interest policies.

**02**

# Creating Bylaws

*In this section we provide descriptions and examples of the rules and procedures used by brain injury advisory councils, committees, and boards in various states.*

**States Involved:** *TN, RI, GA*

# Best/Promising Practices

Bylaws are an organization's written rules and serve as an internal affairs guidebook. They establish procedures for holding elections, organizing meetings, quorum requirements, membership structure, and other essential operations. They should serve as an organizational manual and guide.

Bylaws are structured with section headings called Articles and subheadings called Sections. Below are brief explanations of the terms that are often used in bylaws, either as Articles or Subheadings. Not all these terms are used in all bylaws; select the ones pertinent to your needs. When writing bylaws, start with an outline format. This will make your bylaws readable and standardized to other bylaws. Use language that is simple yet clear.

| Term | Explanation |
|---|---|
| Name/ Organization | The name of the entity. Option: include the name of your state. |
| Purpose(s) | Why the entity has been organized and specific activities of the entity. |
| Vision | The declaration of the entity's objectives, intended to guide its internal decision-making. |
| Authority Clause | How the entity was established and empowered, i.e., by legislation. The authority clause may dictate such things as the composition of the entity, the number of members, etc. |
| Mission | A formal summary of the aims and values of the entity. |
| Members | May include the required qualifications, the number of members, the appointment process, term limits, removal and resignation. NOTE: Membership composition with 50% representation by persons with brain injury is strongly encouraged. |
| Qualifications | Attributes or accomplishments required for membership. |
| Dismissal of Members | Describes the terms for which a member is dismissed; may be dependent on meeting attendance. |
| Officers | May include titles of officers, election guide, term limits, and duties. |
| Duties | The specific tasks assigned to each officer and/or member. |

| Term | Explanation |
| --- | --- |
| **Meetings** | The frequency, the type of meeting, what constitutes a quorum. |
| **Attendance** | Minimum attendance requirements and subsequent consequences |
| **Committees** | Types of committees could include standing committees of various titles, ad hoc, task forces along with meeting requirements and duties |
| **Responsibilities** | Specific duties of officers and/or committees |
| **Council Staff** | Describes source and responsibilities of administrative staff |
| **Nominations and Elections** | Development of a nominating committee; how members are nominated and elections conducted |
| **Terms** | The length of time a member serves; may include the maximum number of terms or years to be served |
| **Quorum** | The minimum number of members that must be present at any meetings to make the proceedings of that meeting valid |
| **Rules** | May refer to Robert's Rules of Order for instances not covered in the bylaws |
| **Parliamentary Authority/ Procedure** | Describes how business will be conducted. Often refers to Robert's Rules of Order |

| Term | Explanation |
|------|-------------|
| **Order of Business** | The topics to be included in a typical agenda |
| **Conflict of Interest** | A situation in which an individual has competing interests or loyalties. Members may sign a conflict of interest policy |
| **Voting** | May include quorum, voting privileges, voting methods, proxy voting |
| **Amendment to Bylaws** | The procedure and required approvals for changes to the bylaws |

## Referenced Materials

Bylaws from the following states were used to develop this guide: CA, FL, MN, NY, NC, ND, OH, SC, VA.

# 03

# Developing a
# Mission Statement

*In this section we include the definition and information regarding the difference between a mission and vision statement. Examples of a mission statement are also included.*

*States Involved: WV, AK, AR*
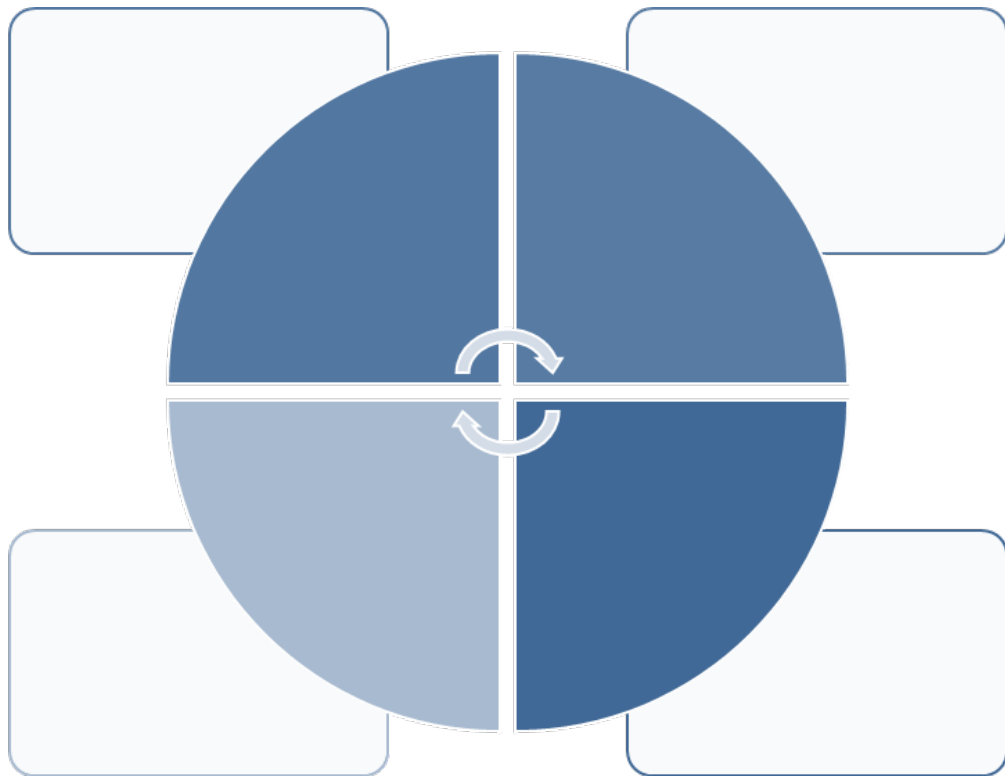
# Mission Statement, Defined

Merriam-Webster defines a mission statement as:

> *A formal summary of the aims and values of a company, organization, or individual.*
>
> *A statement of the purpose or goal of a business or organization.*

A mission statement helps organizations with strategic direction.

Characteristics of a mission statement include:

- Concise (usually one sentence)
- Outcome-Oriented (explains what your organization is trying to achieve)
- Inclusive (broad statement about your key goals)
- Value (show value through the good that you do)
- Credible (realistic, not impossible)
- Motivation (promotes engagement with your organization)

A mission statement answers these four questions:

1. What do we do?
2. How do we do it?
3. Whom do we do it for?
4. What value are we bringing?

## Mission statement vs. vision statement—What is the difference?

A vision statement describes the future, and not just the future of the organization, but rather a future intent/outcome for a community as a result of the organization's work. A mission statement, on the other hand, describes how the organization might achieve its vision by "declaring the purpose an organization serves to its audience" (Kolowich, 2019).

## Elements of Mission Statements

Mission statements may include different elements based on the fit and representation desired by each advisory council. The following elements may be considered when developing a mission statement:

The advisory council…

- Demonstrates powerful, effective collaborations of the TBI community to funders, legislators, citizens, and others

- Directs the brain injury community in the prioritized provision of well-coordinated and improved supports and services

- Represents commitments of collaborative efforts

- Guides planning and provides direction needed to achieve long-term goals and objectives

## Example Mission Statements

### State TBI Advisory Board Examples

*To advise and work in collaboration with the Department of Social and Health Services (DSHS) and other stakeholders to advise the Governor, the Legislature and the Secretary of the Department of Social and Health Services on the best ways to create and provide an array of coordinated, accessible services and supports which promote optimal quality of life for all individuals with traumatic brain injury and their families.*

> —Washington Traumatic Brain Injury Strategic Partnership Advisory Council

*The purpose of the Traumatic Brain Injury Advisory Committee is to provide recommendations to the Commissioner of the Department of Human Services on program development and concerns regarding the health and human service needs of persons with traumatic brain injury.*

> —Minnesota Traumatic Brain Injury Advisory Council

*To understand, educate, and advocate for the needs of all Alaskans regarding traumatic and acquired brain injury.*

> —Alaska Traumatic Brain Injury Advisory Council

*To engage in advocacy and prevention activities in order to serve those traumatic brain injury survivors and their families.*

> —Tennessee Traumatic Brain Injury Program

*To identify needs, gaps in services, and potential funding resources by building relationships and collaborating with elected officials and heads of state agencies that will influence policy, promote prevention, education, and effective interventions that impact outcomes in order to support recovery and quality of life for every Marylander affected by brain injury.*

—Maryland Brain Injury Advisory Board

### Brain Injury Organization Examples

*To advance awareness, research, treatment, and education and to improve the quality of life for all people affected by brain injury.*

—Brain Injury Association of America:

*To raise awareness and enhance the quality of life for all people affected by brain injury.*

—Minnesota Brain Injury Alliance

*To minimize brain injury through prevention and to support, educate and advocate for individuals with brain injuries and their families.*

—Brain Injury Association of New York State

*To help children and adults with a brain injury build the skills and confidence they need to lead a fulfilling and productive life.*

—Brain Injury Services

*To encourage federal and state legislation and policy that supports the expressed needs of individuals with brain injury and their families.*

—United States Brain Injury Alliance

### Additional Corporate and Nonprofit Examples

*To refresh the world in mind, body and spirit. To inspire moments of optimism and happiness through our brands and actions.*

> —Coca-Cola Company

*Build the best product, cause no unnecessary harm, use business to inspire and implement solutions to environmental crisis.*

> —Patagonia

*To create and promote great-tasting, healthy, organic beverages.*

> —Honest Tea

*Provides children from birth through age 12, living in homeless or low-income situations, with the essential items they need to thrive – at home, at school, and at play.*

> —Cradles to Crayons

## References

Answer 4 Questions to Get a Great Mission Statement – Forbes
(forbes.com/sites/patrickhull/2013/01/10/answer-4-questions-to-get-a-great-mission-statement/#5802fafd67f5)

50 Example Mission Statements (topnonprofits.com/examples/nonprofit-mission-statements/)

Basics of Developing Mission, Vision and Value Statements
(managementhelp.org/strategicplanning/mission-vision-values.htm)

Kolowich, Lindsay (2019, January 27). 17 Truly Inspiring Company Vision and Mission Statement Examples [blogpost]. Retrieved from blog.hubspot.com/marketing/inspiring-company-mission-statements

## 04

# Agenda Templates & Suggestions

*In this section we identify common topics to be discussed and share sample agendas and time frame recommendations.*

*States Involved: TN, GA, KY*

# Agenda Templates

The following templates are meant to be a general guide for the usual components of a TBI Advisory Council meeting. Not all elements will be applicable to every meeting.

| Agenda Template 1 | Agenda Template 2 |
|---|---|
| Welcome & Introductions | 9:30–9:40 Welcome & Introductions |
| Public Comment period, partner sharing, and board/council member announcements | 9:40–10:00 Public Comment period, partner sharing, and board/council member announcements |
| Minutes review and approval | |
| Old Business | 10:05–10:30 Old Business |
| Subcommittee Reports | 10:30–10:45 Subcommittee Reports |
| Break | 10:45–11:00 Break |
| New Business | 11:00 – 11:45 New Business |
| Question & Answer period, next meeting date | 11:45 – 12:00 Question & Answer period, next meeting date |
| Adjourn | 12:00 Adjourn |

# Agenda Suggestions and Considerations

Council meetings ideally would provide in-person and virtual options for meaningful engagement by all.

An agenda for a TBI Advisory Council/Board should be sent in advance of the meeting date and should include the following:

- Meeting Date
- Time (start and end)
- Location
- Agency logo
- Agency mission statement
- A notation to mark decisions that require a quorum

# 05

# Statutes and Mandates

*This section takes a look at how brain injury programs are established/authorized within state governments.*

*States Involved:  WV, KY, MD*
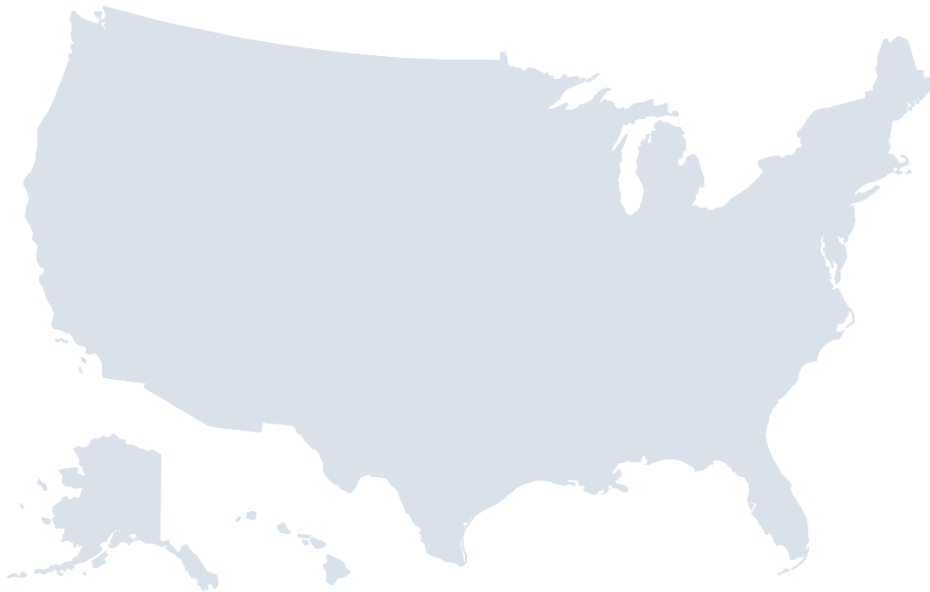
# Federal ACL Requirement

Per 42 U.S. Code § 300d–52 – State grants for projects regarding traumatic brain injury, all recipients of this funding opportunity must agree "to establish an advisory board within the appropriate health department of the State or American Indian consortium or within another department as designated by the chief executive officer of the State or American Indian consortium."

# Best/Promising Practices

States across the U.S. have established or are working towards implementing a TBI advisory council or board. The tables below are adapted from research by the TBI Coordinating Center, the Federal TBI Partner Grant Advisory Board Workgroup and publicly available information. The first table lists states that have legislatively established Advisory Councils along with the enabling legislation; the second table lists states that are established by some other mechanism. **This list is subject to change as states continue to create/modify existing legislation as warranted.**

**Legislatively established**

| State | Establishing legislation | Entity designation |
|---|---|---|
| Alabama | Code of Alabama Section 22-11D-5 | Advisory Council |
| Arizona | A.R.S § 41-3201 | Advisory Council |
| Colorado | Section 26-1-302, C.R.S. | Board |
| Connecticut | Substitute House Bill No. 5249 | Advisory Board |
| Florida | Florida Statute 381.78 | Advisory Council |
| Hawaii | Statutes Act 333 | Advisory Board |
| Illinois | Head and Spinal Cord Injury Act | Advisory Council |
| Indiana | IC 16-41–42.2 | Research board |
| Iowa | Code of Iowa 135.22A, Code of Iowa 135.22B | Advisory Council |
| Kentucky | Kentucky Revised Statute 211.50_X | |
| Louisiana | Louisiana Revised Statutes 46:2634 | Advisory Board |
| Maine | §19001. Acquired Brain Injury Advisory Council | Advisory Council |
| Maryland | Maryland Health-General Article § 13–2105(1) | |
| Massachusetts | The 190th General Court of the Commonwealth of Massachusetts Title II Chapter 10 Section 59 Chapter 602 of the Acts of 1956 Chapter 6 Section 74 | (Trust fund) |
| Minnesota | Minnesota Statutes section 256B.093 | Advisory Committee |

| State | Establishing legislation | Entity designation |
| --- | --- | --- |
| Missouri | RSMo 192.745 | Advisory Council |
| Montana | House Bill 698 | Advisory Council |
| New Hampshire | NH Revised Statute 137-K:2 | Advisory Council |
| New Jersey | New Jersey Revised Statute 30:6F-3 Executive Order 84 | Advisory Council |
| New Mexico | New Mexico Statute § 27-1-16 (2014) | Advisory Council |
| New York | Article 27-CC | Coordinating Council |
| North Carolina | General Statute 143B-216.65-66 | Advisory Council |
| Ohio | ORC Section 3304.231 | Advisory Committee |
| Oklahoma | Joint Resolution No. 1040 | Advisory Council |
| Rhode Island | H 7456 | Advisory Commission |
| South Carolina | Article 6 on the South Carolina TBI Leadership Council | Leadership Council |
| Tennessee | T.C.A § 68-55-101 | Advisory Council |
| Texas | Texas Brain Injury Advisory Council Report | Advisory Council |
| Utah | Utah Code Ann. § 26-54 | Advisory Committee |
| Virginia | Code of Virginia § 51.5-9.1 | Repealed |
| Vermont | § 7801 | |
| Washington | House Bill 2055 | Advisory Council |
| West Virginia | Formerly in code – now in transition | Advisory Board |

**Established via other mechanism**

| State | Establishing document | Entity designation |
| --- | --- | --- |
| Alaska | MOA between ABIN and State of Alaska SDS | |
| Arkansas | In process | |
| California | In process | |
| Georgia | Georgia Annual Report FY 2017 | Commission |
| Idaho | Advisory Board nonprofit bylaws | |
| Kansas | In process | |
| Mississippi | 2015 Annual Report | Advisory Council |
| Nebraska | Nebraska Traumatic Brain Injury Council Handbook | Advisory Council |
| North Dakota | North Dakota Brain Injury Advisory Council Bylaws | Advisory Council |
| Oregon | In process | |
| Pennsylvania | Per HRSA grant requirement | Advisory Board |

# Referenced Materials

Tim Williams, et al, Advisory Board TBICC Research, 11/14/18

# 06

# Recruitment Techniques

*In this section we describes techniques to identify and recruit members.*

*States Involved:  TN, MN, MA*

# Best/Promising Practices

Finding the right people to serve on your Advisory Board requires having a process in place. While the actual selection may be someone else's responsibility, soliciting nominations is a critical step. Suggestions for identifying and recruiting potential members include:

- Identify skills and experience needed on the Board to accomplish goals

- Start by assessing the current board to determine current gaps in skills

- Identify key stakeholders from brain injury related organizations and programs

- Identify key stakeholders from other state or federal agencies and organizations

- Develop a vetting mechanism

- To assure a diverse cultural representation of key stakeholders on the board, reach out to your communities' cultural leaders. Consider recruiting from populations represented in your state, i.e., Black or African American, American Indian, Asian, veterans, Hispanic or Latino, and Lesbian, Gay, Bisexual, and Transgender (LGBTQI) community organizations. Consider developing a diversity recruitment plan for your board

- Consider the bylaw legal requirements of the make-up of the board, if applicable
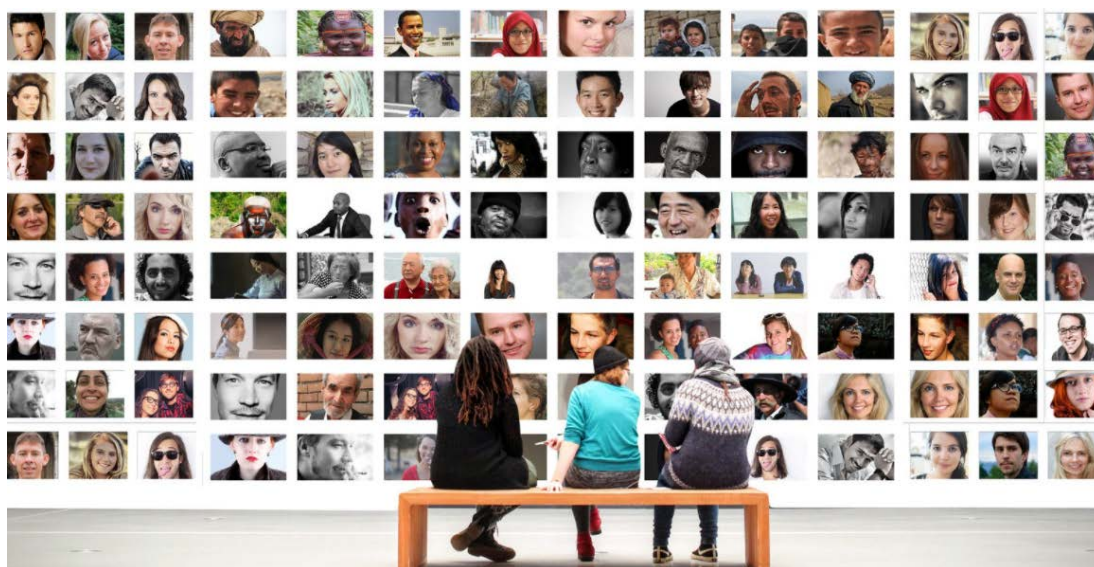
- Develop a nomination form and request a letter of interest

- Check with your state regarding appointment requirements

- Create a Council description and expectations of members; include any regulated criteria

- "Swap" members by developing relationships with other disability-related boards

- Invite potential members to attend meetings

- Encourage community members to serve on committees

- Use social media platforms to encourage nominations

- Make announcements of Board member openings at related events

- Post board openings on your website

- Post board openings with the Secretary of State, if possible

- Involve former members – ask for suggestions for new members

- Serve refreshments at meetings

- Announce board vacancies at support group meetings

- Make sure you have state agencies represented on your board that are involved in making recommendations for changes to and expansion of services

- Consider reaching out to other ACL-related organizations such as Centers for Independent Living, Protection and Advocacy, and the Council on Developmental Disabilities

## Referenced Materials

Council of Nonprofits: Finding the Right Board Members for Your Nonprofit
(councilofnonprofits.org/tools-resources/finding-the-right-board-members-your-nonprofit)

Ascend Nonprofit Consulting: Creative Ways to Recruit Great Board Members
(ascendnonprofits.wordpress.com/2013/04/13/25-fun-creative-ways-to-recruit-great-board-members/)

# Tips & Tricks for Getting People Involved and Engaged

*In this section we identify successful strategies to involve and engage members, ensure attendance, meet accessibility requirements and other helpful techniques.*

**States Involved:** *WV, RI, TN, KY*
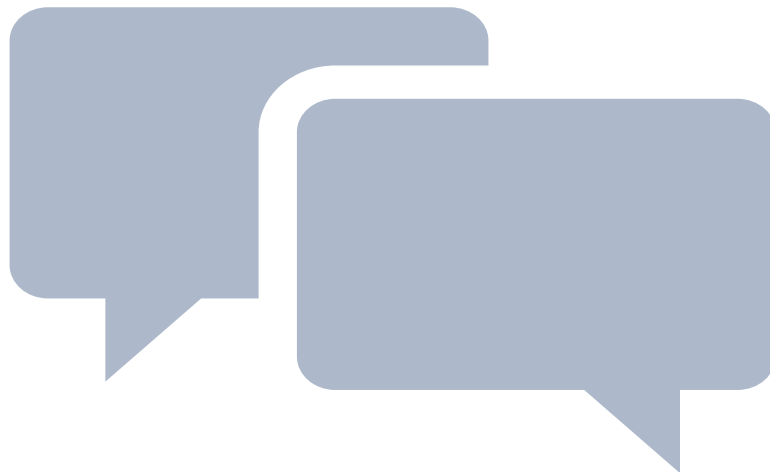
# Involvement and Engagement Considerations

- Build a connection through personal interaction

- Exercise sensitivity and understanding of the wants and needs of persons with brain injury

- Develop communication methods with the group

- Create opportunities for positive member engagement

- Send agenda in advance of the meeting

- Ask a current member to serve as mentor/buddy to a new member

- Use purposeful seating—mix up populations at the table

- Use name tents

- Note the accomplishments of the group and recognize individuals

- Acknowledge individuals and ideas

- Assign tasks or workgroups

- Clearly identify goals and timelines

- Extend invitations to events as an option to be more involved

- Make phone calls after the meeting to provide any needed clarification

1. **Ensure Attendance**
   - Make phone calls before meeting
   - Send a reminder email

2. **Address Accessibility**
   - Address transportation issues
   - Use a meeting location that is accessible and easy to navigate
   - Ensure parking accessibility
   - Reimburse mileage/stipend for attending meetings
   - Invest in bus tickets where public transportation is available and reliable

3. **Optimal Communication Options**
   - Teleconference and phone options
   - Provide webcam/microphone
   - Keep presentations accessible, check reading level
   - Interpreters/ translator options available
   - Cultural awareness
   - Culturally linguistic appropriate services

4. **Amenities to consider**
   - Water, coffee, snack
   - Accessible restrooms

5. **Trainings to consider**
   - Meeting expectations
   - What to expect from the board
   - How does a survivor's participation make a difference?
   - What does one hope to gain from the experience?

**08**

# Advisory Board Composition

*In this section we identify examples of individuals within the community who would be valuable to the board makeup.*

*States Involved:  TN, AR, MD*

If the membership of a Brain Injury Advisory Board is legislatively mandated and/or governor-appointed, the governor may only appoint a specified number of positions while other positions are filled by state agencies or organization representatives such as advocacy groups (the state Brain Injury Association or Alliance, for example). If membership is voluntary, the organizing group may use existing board compositions across the U.S. and guidelines set by the Administration for Community Living to extend invitations to key stakeholders in the development of a leadership group.

Membership terms may be predetermined, but are usually 2-4 years. Some states allow members to reapply once a term is complete. The majority of these positions are not compensated; however, travel to/from meetings is often reimbursed.
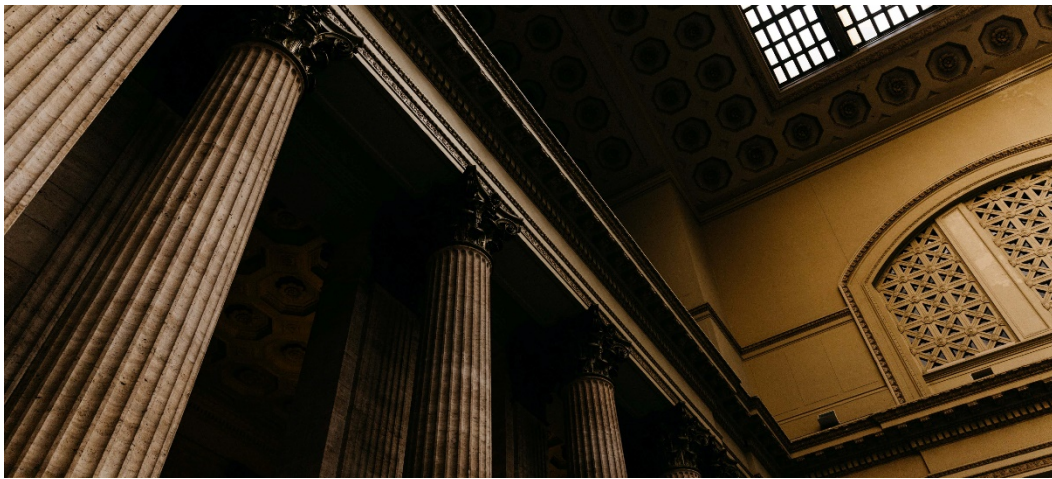


An application process to become a member may also be available in some states. Each state determines how many positions will be available.

The ability to vote on motions by members may also be mandated or pre-established. For example, most states allow each member to vote. However, for some leadership groups, if more than one individual is representing an agency or organization, the vote may be consolidated to one. Some boards have non-voting members, but any active member should have voting rights unless there is a conflict of interest.

## Brain Injury Board Members

Brain injury advisory boards generally bring together representation from both the public and private sectors of the population. This composition ensures a wide variety of perspectives and expertise, including that of the person living with a brain injury.

Membership may consist of the following individuals, agencies, and organizations:

- Individuals living with brain injury
- Family members and caregivers
- Advocates
- Veterans service groups as well as state departments of Veteran Affairs (VA) and VA Hospitals
- Criminal justice/law enforcement
- Community programs and service providers
  - Coalition Against Domestic Violence
  - High school athletic association
  - Rehabilitation facilities
  - Therapy organizations (e.g., LoveYourBrain Yoga)
- Elected Officials
  - State representative
  - State senator
- Health Care Professionals
  - Behavioral health (mental health and addiction professionals)
  - Nurse
  - Occupational, physical, and/or speech therapists
  - Neuropsychiatrist
  - Neuropsychologist
  - Physical Medicine and Rehabilitation (PM&R) Physician
  - Paramedic
  - Sports medicine
- Brain injury organizations and foundations
  - State Brain Injury Association/Alliance
- State/federal agencies/organizations
  - Bureau of Behavioral Health
  - Bureau for Medical Services
  - Department of Corrections
  - Department of Education
  - Department of Homeland Security
  - Department of Military Affairs and Public Safety
  - Department of Public Health
  - Department of Veterans Affairs
  - Disability Rights

- State Vocational Rehabilitation Administration
- Family and Social Services Administration
- Independent Living Council
- Long-Term Care Ombudsman
- Protection and Advocacy Agency
- State Assistive Technology Program
- Developmental Disability Council
- TBI Model System
- Child Death Review
- Trauma System staff/Registry staff

# Board Member Attendance Expectations

- It is expected that Board Members make every effort to attend Board and Committee meetings

- Participation by use of technology (i.e., audio/video communications) is acceptable

- If Board Member is unable to attend, it is good practice to notify the Board Chair in advance and consider identifying a proxy to represent them during scheduled meetings

- In the event that Board Members find they are unable to participate to the extent necessary, they should consider resigning from the Board

- For additional information regarding engagement, please refer to Section 7: the "Tips and Tricks" component of this toolkit.

## 09

# Important Partners

*In this section we explain the importance of having people with brain injury as board members, along with identifying what partners can represent the critical issues in your state.*

*States Involved: WV, AK*

The Administration for Community Living (ACL) is committed to independent living and person-centered planning for persons with brain injury. ACL believes that persons with brain injury and other disabilities should be engaged in and lead the decision-making processes about their services and supports. ACL encourages having persons with brain injury comprise a 50% representation on Advisory Boards. In U.S. code § 300d-52, the composition of an Advisory Board is specifically described. (Please refer to Section 8: Board Composition for more details.)

It is recommended that states consider aligning with important partners to address specific, critical issues that have an impact on services, supports and needs of persons with brain injury. Flexibility and understanding of shared mission and goals should guide the role of identified Partners.

## Suggested Roles and Opportunities for Partners

- Attend Board/Council meetings as member or guest
- Join subcommittees and ad hoc committees that focus on specific issues
- Serve as a subject matter expert to the state Brain Injury Board/Council
- Participate on Speakers bureau
- Support and or testify on behalf of legislative initiatives related to brain injury supports and services



**The following are examples of relevant issues and possible partners:**

**Aging**

Older adults are vulnerable to TBI secondary to falls.  Individuals aging with a history of brain injury may seek services from their states' senior services agencies.

**Potential Partners:** State Department of Aging, local Area Agencies on Aging (AAAs), Aging and Disability Resource Centers (ADRCs), Silver Sneakers programs, Senior Centers, Alzheimer's Association



## Criminal and Juvenile Justice Systems

Studies suggest that a history of TBI is common among inmates, including women and adolescents, occurring among an estimated 25% to 87% of the jail and prison population. Many people in prisons and jails are living with brain injury-related problems that complicate their management and treatment while they are incarcerated. If and when prisoners are released, these problems will also pose challenges when they return to the community.

**Potential Partners:** State department of corrections, community re-entry programs, parole and probation

## Domestic Violence

TBI often goes undiagnosed amongst people who experience intimate partner violence (IPV). It is not uncommon for victims of IPV to be exposed to multiple injuries to the brain. The existence of brain injury among this population and resulting functional implications of brain injury often go unrecognized both by the individuals affected and by domestic violence professionals and law enforcement.

**Potential Partners:** Domestic violence shelters; law enforcement

## Employment

People with brain injury, especially moderate to severe are more likely to be unemployed or underemployed compared to their same age peers without brain injury.

**Potential Partners:** State Department of Vocational Rehabilitation, State Department of Employment Development, Workforce Development Boards, Independent Living Centers, State Vocational Rehabilitation, Department of Labor, Work Centers/One Stops, Offices of Employment First

## Housing/Homelessness

People living with brain injury are well represented among homeless populations, at least 50%, the same as incarcerated individuals.

**Potential Partners:** Healthcare for the Homeless, Homeless shelters, Community Action Agencies



## Injury Prevention

There are many ways to reduce the chances of sustaining a traumatic brain injury.

**Potential Partners:** Health Department injury prevention program, Safe Kids, Governor's Highway Safety Office, Falls Prevention program, Child Abuse Prevention agencies, Department of Education, local chapter of American Academy of Pediatrics, Injury Control Research Centers, Center for Injury Science

## Law Enforcement

Individuals living with a history of BI are overrepresented in the criminal justice system. Police who interact with persons with a brain injury need to be aware of common signs and symptoms of brain injury and techniques for communicating and de-escalation.

**Potential Partners:** Crisis intervention in law enforcement, Crisis Intervention Training (CIT) coordinators, domestic violence shelters, judges, guardians ad litem

## Mental Health

Individuals with a history of TBI are often served in mental health settings.

**Potential Partners:** State Behavioral Health Administration/Services Behavioral Health Court, National Alliance for the Mentally Ill (NAMI), On Our Own chapters; Suicide Coalitions, Peer Mentor programs

## Opioids

Individuals with brain injury are at risk of initiation into opioid use/misuse for treatment of pain associated with the sequela of the brain injury. Individuals who survive opioid overdose(s) may incur acquired brain injury secondary to anoxia/hypoxia. A history of TBI is common among individuals being treated for opioid use disorder and standard treatment approaches can be challenging. Adaptations for people with TBI increase the likelihood of successful recovery from opioid use disorder.

**Potential Partners:** Substance abuse disorder professionals, local health departments, overdose fatality review teams, Governor's Opioid Council representative; regional SAMHSA representative

## Children/Youth with Special Health Care Needs

Concussion/mTBI/Moderate/Severe/Sports Injuries – Children who have incurred a brain injury or multiple brain injuries have the potential for short and/or long-term cognitive, physical, emotional and psychosocial challenges which impacts brain development including adverse childhood experiences (ACES). Mild traumatic brain injury (mTBI), or concussion, in children is a rapidly growing public health concern because epidemiologic data indicate a marked increase in the number of emergency department visits for mTBI over the past decade.

**Potential Partners:** Department of Education, coaches, athletic trainers, school nurses, children's hospitals, Family Voices, Center for Parents Information and Resources, Early Intervention systems, pediatric neuropsychologists; Title 5 Representative

## Service Members/Veterans

Rates of brain injury are high among those who have been deployed as well as those who have incurred brain injury in training accidents and incidents on and off base.

**Potential Partners:** State Department of Veteran Affairs, Veteran Service Organizations, State Army National Guard Units, Federal Veterans Affairs, Mental Illness Research Education and Clinical Centers

## Substance Abuse

Many people who incur a traumatic brain injury have a substance use problem prior to their injury. In addition, some studies have indicated that between 10% and 20% of persons who have experienced a traumatic brain injury develop a substance use problem for the first time after their injury.

**Potential Partners:** State department of substance abuse services

## Suicide

Some studies have estimated that those who have incurred brain injury are seven times more likely to attempt or complete suicide than those who do not have a history of brain injury.

**Potential Partners:** National Alliance for the Mentally Ill (NAMI), state behavioral health administrations, other advocacy groups for mental health such as On Our Own chapters

## Tribal/Cultural Organizations

High rates of brain injury among tribal communities.

**Potential Partners:** Tribes, Historically Black Colleges and Universities (HBCUs), Associated Jewish Charities

# Robert's Rules of Order, Simplified

*In this section we identify and explain Robert's Rules of Order and offer simplified variation.*

*States Involved:  TN, MD, AR*

The many rules of parliamentary law are really applications to different situations of a few fundamentals. All law is founded on justice, and parliamentary law is no exception. Its foundation is justice to all: the member, the minority, the majority, the absentee, the organization. The great underlying rule is the Golden Rule.  As this basic fact is grasped, the entire structure of parliamentary procedure becomes the practice of obedience, self-control, courtesy and patience.

1. **The organization is paramount.**  To it belongs the power. Its interest and convenience supersede those of an individual member.

2. **All members are equal.**  Each member has an equal right to propose business, discuss it, and vote – rights which cannot be suspended or restricted save in the interest of the whole, and then only by a two-thirds vote.

3. **One thing at a time.** There can be but one main proposition before the assembly at one time. Only one member can have the floor at one time.

4. **Full discussion before action.** This applies to all main propositions and may be suspended only by a two-thirds vote.

5. **Proposition rather than persons.** The objective is the opinion and decision of the group upon the proposition, hence debate is impersonal.

6. **Propositions may yield to privileges.** Matters affecting the convenience or privileges of the assembly or an individual may interrupt consideration of a question.

7. **No discussion for interruptions.**  Matters of sufficient urgency to interrupt discussion may not themselves be discussed.

8. **No discussion for suspension**. Motions which have the effect of suspending a rule are not debatable.

9. **No second time in the same form.**  To protect the assembly against waste of time, a question once decided may, as a general rule, not be presented again at the same meeting in the same form under similar circumstances unless a reconsideration is ordered.

10. **The majority decides – usually.**  The majority decides all ordinary questions, but it requires more than a majority to limit a member's parliamentary rights to introduce and discuss questions and vote, or to suspend or modify (without notice) a rule of order previously adopted.

11. **Two-thirds vote for extraordinary questions** – such as motions to amend bylaws, to change or repeal (without notice) a motion previously adopted, to suspend the rules, or restrict the rights of members to introduce questions, discuss them and vote.

12. **Silence gives consent.** The right to vote must be exercised. Silence has the same effect as assent to the will of the prevailing side.

# Duties of the Chair

The duties of the presiding officers are to:

- Call the meeting to order

- State the business before the assembly

- Recognize members and assign them the floor

- State the question and put it to a vote

- Announce the result

- Decide points of order

- Use Robert's Rules as needed

*\* Duties of other officers, committee/subcommittee chairs may also be defined as needed*

## Suggestions for orderly meetings of a Brain Injury Advisory Council

**Seated at the table:** Only TBI Advisory Council members and TBI Program staff.

**Participation in discussion:** Anyone who wishes to speak must raise their hand and wait to be recognized by the Chair.

**Speakers** are requested to speak clearly, succinctly, and loudly enough for all to hear; other attendees should give attention to the speaker.

**Motions** may be made and seconded only by Council members.

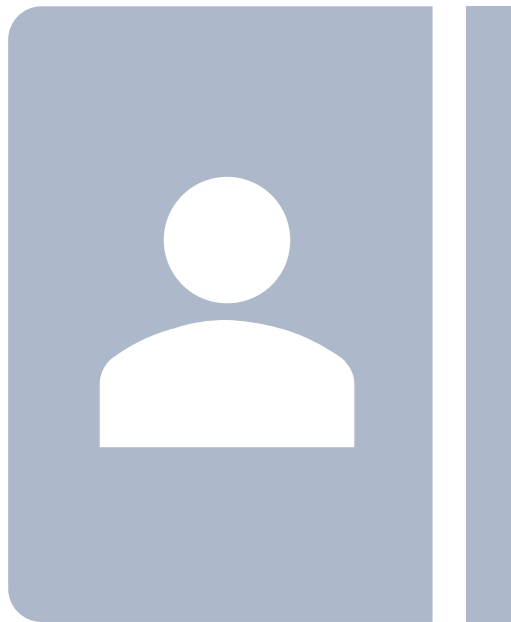**Handouts** available on Simplified Robert's Rules of Order for attendees.

## Referenced Materials

Lewis, A. and Robert, H. (2006) *Robert's Rules Simplified*, Dover Publications, Inc.

# 11

# Orientation Plan for New Board Members

*In this section we identify specific trainings and content that would be useful in preparing new board members for service.*

*States Involved: MN, GA, WV*

# Best/Promising Practices

When onboarding a new member to a brain injury advisory board or council, there can be a steep learning curve. This learning curve can encompass knowledge of state infrastructure around brain injury, the intricate partnerships within the brain injury community and the culture of disability etiquette within each state.

An orientation plan for new board members should try and focus on:

- New member's learning and accommodation needs for inclusion
- Current members introductions
- New member interest and strengths discovery
- Informing the new member on infrastructure and partnerships
- The state's brain injury service network
- Operations of the committee/board
- Forming expectations with the new member
- Closing with free-flowing conversation
- Follow-up with the new member

However informative your plan may be, the key is to have a strong follow-up on orientation for the new board member and to identify a person or welcoming committee that is responsible for organizing and implementing the orientation plan for new members. A sample of board orientations for new members is below *(see Example 1).*

One main starting point that has been effective is to first assess the **new members learning and *accommodation needs***. One method for this is to use a Member Needs Survey *(see Example 2)*. All members can be asked to fill out the member needs survey prior to the first orientation meeting. The purpose of this survey is for committee leadership to be aware of individual needs which will allow members to participate more fully and make adjustments as able. Ask the new member only to provide information that they are comfortable sharing.

Another way of orienting someone in a meaningful way is to put an emphasis on the value of the professional relationship between members. At this stage, introductions can really form an impression with the new member. This says that the current committee they are joining values people first and foremost. Have the *current members introduce themselves,* their affiliation, their roles on the board, why they were drawn to the board and one personal thing. This can be done in a zoom call, recorded video, or by reading written biographies created by each member.

This is a good way to transition into the *new member's interests and strengths discovery*. To keep members engaged it is best practice to involve the member in finding ways to utilize their strengths and interests. This line of discovery may guide the chair of the committee to facilitate engagement in meaningful board activities for this new member. For example, the new member may work in a setting with children with brain injuries and when asked about their strengths and interests their answer may relate to return to school activities. The board chair can guide talks to the committee or boards activities around this topic and invite them to join in those activities.

This is a good time in orientation to dive into *informing on infrastructure and partnerships*. Topics like history and overview of the brain injury prevalence in your state, the Advisory Committee's background, mission and authority, the relationship and roles between the Advisory Committee and the Lead Agency, member's position description, information about the lead agencies organizational structure, all of the committee's partnerships, funding, and hand out a list of acronyms that may be used, even though we try and refrain from using jargon they may come across it with partners and in legislation.

It is also important to provide training regarding the *brain injury service network.* Some of the service training resources that could be included during orientation is information on the state's registry information, data training, injury and prevention, brain injury basics, disability services, aging services, deaf and hard of hearing services, children and family services, behavioral health services, chemical dependency services, juvenile justice services, brain injury associations, aging and disability resource center (ADRC), and how to be legislatively savvy.

During orientation, the board needs to discuss the *operations of the board.* Operations of the board may include information on current committee strategic goals, work plan updates, reimbursement, lodging, mileage, and technical setup for remote meetings. Providing members with a list of board

members' contact information and assigning a mentor may be helpful. This would be the time to go through the operations manual with the new member.

***Forming expectations*** *with the new member* is important to ensure the committee member knows what is expected of all board members. This can include things like legal and ethical considerations as well as valuing diversity. The board orientation should also include information on the meeting schedule, attendance expectations, and participation in subcommittees. One suggestion to promote advisory board participation is the utilization of a Memorandum of Understanding (MOU) agreement expressing a commitment for a specific period of time. An advisory board member can designate an individual, a proxy, to represent them by completing an alternate contact/proxy form. *Refer to your state's rules, requirements, regulations and/or legislation as to use of a proxy*. The **closing of the meeting** should include free conversation and information regarding the next meeting date.

Once orientation is completed, the board should **follow up** with the new board member by setting up a pre-call to each meeting for the first 6 months with the new members being onboarded. The agenda can be discussed ahead of time and this will form a community of practice. The board can start to invite any member who may want to prepare for the meeting with someone else.

**Example 1: Orientation Structure Samples**

*Sample 1*

Majority of the afternoon that day was spent on a group activity focused on establishing priorities, brainstorming goals and relationship building to move the council forward as a cohesive group.

*Sample 2*

Day 1 Discussing logistics, informing

Day 2 Forming expectations

Day 3 Member interest and strengths discovery, survey, and training schedule for the new board member

**Example 2: TBI Advisory Committee**
**Member Needs Survey**

**Member Name:** _____   **Date:** _____

**Please check any of the following that would help you better participate in meetings. Add any additional comments below.**

**It would help me to sit (circle one):**
- o Near screen/presenter
- o Front of Room
- o Back of Room
- o Near phone speaker
- o Other:

_____

**I have difficulty with the following (circle all that apply):**
- o Fluorescent lights/indoor lights
- o Sound
- o Colors
- o Smells
- o Other:

_____

**The following would be helpful (circle all that apply):**
- o Schedule breaks if meetings are longer than 1 hour
- o Provide materials in larger font
- o Provide the agenda ahead of time

**Requests of meeting moderator (circle all that apply):**
- o Pause the group to check for understanding
- o Break down instructions into smaller parts
- o Provide instructions in writing
- o Help limit side conversations
- o Speak slowly
- o I use Metro Mobility

**Online Accessibility Issues (circle one):**
- o I don't have internet access
- o I don't have a smart phone or a computer to attend virtual meetings

# Known Gaps

Each state advisory board is different. Some are legislatively mandated and some are not. That being said, each orientation to your state's board will be different. This hinders the quality and standardization of the board's orientations across the county.

**12**

# Meeting Federal Recommendations and Requirements

*In this section we identify and describe how to ensure that you are meeting the federal recommendation for Council composition, specifically for legislatively mandated or governor appointed boards.*

*States Involved:  WV, RI, MN*

# Best/Promising Practices

Traumatic Brain Injury (TBI) advisory boards that meet federal recommendations and requirements are appointed by the governor through executive order or are legislatively mandated. Other terms used interchangeably with boards may include commissions, task forces, or councils. If a board has the ability to make rules and have the force of law, it is created by legislation while boards created to serve in an advisory capacity may be created by legislation or by an executive order by the governor. Each state has specific rules for development of boards.

Boards that are created by the governor through executive action may define the membership and overall structure, but expenses must be covered by the governor or the agency that wants the advisory board. Boards that are created by legislation will also define membership and overall structure, but will also further define the following areas:

- Purpose of the Board
- Reporting Requirements
- Board Expenses (e.g., finances, budget, spending authority, funding)
- Membership
  - Appointment of Membership (e.g., number appointed by governor, number serving on board per statute)
  - Composition/Representation (e.g., defining the qualifications of each of the members)
    - People with traumatic brain injury and caregivers
    - Healthcare professionals (e.g., neurologist, physiatrist, occupational therapist, physical therapist, speech language pathologist, case manager)
    - Agency representation (e.g., Department of Education, DHHR)
  - Compensation (e.g., will members be reimbursed or no reimbursement)
- Terms of Office Membership
  - Terms of office (e.g., length of term, term limit)
  - Vacancies (e.g., Governor appoints new member, previous member serves until a new member is appointed)
  - Nominations (e.g., recommendations, recommendations)

- Removal (e.g., unexcused absences)

■ Officers and Duties

- Types of officers (e.g., chairperson, vice chairperson, secretary)
- Election of officers (e.g., majority vote, quorum)
- Terms of office (e.g., length of term, term limit)
- Duties of officers (e.g., responsibilities, roles, assignments)
- Vacancies (e.g., new elections, change of officer role)
- Removal of officers (e.g., just cause, vote)

■ Meetings

- Frequency of meetings (e.g., times per year)
- Attendance (e.g., excused, unexcused)
- Meeting notices (e.g., notification timeframes, location of announcements)
- Minutes (e.g., minutes available to committee, timeframe to send)
- Voting (e.g., who is allowed to vote, number of votes)
- Quorum (e.g., number of voting members required, in person or technology allowed)
- Parliamentary authority (e.g., Robert's Rules of Order)
- Special committees (e.g., ad hoc committees, task forces, appointed by chair)

## References

Washington State Office of the Governor (2004). Boards & Commissions. Retrieved on February 15, 2021 from https://www.digitalarchives.wa.gov/GovernorLocke/boards/role.htm

Secretary of State, Mac Warner. Appointments of State Officials. Retrieved on February 15, 2021 from https://sos.wv.gov/admin-law/Pages/AppStOff.aspx

Rhode Island's Governor's Permanent Advisory Commission on Traumatic Brain Injuries: Bylaws.

**13**

# Funding Resources

*In this section we provide description on identifying and securing allocated funding or other sources within the state for specific items within an Advisory Board.*

*States Involved:  TN, GA*

# Best/Promising Practices

Traumatic brain injury (TBI) advisory boards are subject to each individual state's originating statute or authorizing document from a state entity. As such, each TBI advisory board must follow law or guidelines that prescribe the advisory board's mission, vision, goals and objectives. To ensure the financial well-being of the TBI advisory board and its long-term sustainability, states will need to access resources from potential funders across the spectrum of federal, state, and local governments. Additionally, nonprofit organizations and foundations may be suitable for collaboration and funding resources. Finally, if applicable and appropriate, approaching private business may be another potential source of funding.

For funding from federal, state and local governments, collaboration on shared goals can be a source of in-kind and revenue funding. Providing services for citizens with TBI cuts across nearly all government departments such as health and human services, behavioral and mental health, addictive diseases, corrections, aging, children and youth, recreation, etc. Knowing who potential partners are and knowing what partners are receiving grant funding is key to sustainability.



The following list provides names of programs that receive state and federal funding that serve among their populations, individuals with traumatic and acquired brain injury. The federal government maintains a database of funding opportunities (grants.gov/applicants/apply-for-grants.html) where State TBI Advisory Board members can learn of grants they can apply for in partnership with state agencies and partners, many of whom are represented on state TBI Advisory Boards.

In no particular order, potential funders or access to funding:

1. Home and Community-Based waivers (Aging, Blind & Disabled) through the state's Medicare and Medicaid agency

2. Aging Services which also include Area Agencies on Aging (AAA), Aging and Disability Resource Centers (ADRCs) and allied disability programs such as statewide independent living councils (SILCs)

3. State and local Department of Health (e.g., collaborating on prevention initiatives, sources of health and injury related data)

4. Departments of Education for: Head Start programs, local boards of education, state university systems and private schools and colleges office on disabilities

5. Local recreation departments, sports leagues and associations

6. Hospitals and hospital associations, community clinics, private practice groups and teaching hospitals

7. Courts, accountability courts, prosecutors and private practice law firms

8. Nonprofit organizations such as the state's United Way chapter, community foundations, philanthropists and faith-based groups and charities

9. Professional associations: the state's Brain Injury Association or Brain Injury Alliance affiliate as well as national brain injury advocacy organizations such as the National Association of State Head Injury Administrators (NASHIA), fundraising organizations like the Association of Fundraising Professionals, regional or state public relations councils, all of which can get you in front of potential funders

## 14

# Full Participation Guidelines

*The tips and tools provided contribute to the full and meaningful participation of everyone in meetings, work groups and conferences.*

*States Involved:  TN and TBI Technical Assistance and Resource Center*

Full Participation involves **supporting individuals with brain injury by providing tools, resources, and supports so that t**hey are equal, contributing members with a sense of belonging.  The original Full Participation Guide was created in 2008 to help states meet this level of support.  The updated document is intended as a guide for best practices and can be used readily and frequently by states and partners across all states and settings. The tips and tools provided contribute to the full and meaningful participation of everyone in meetings, work groups and conferences.

## Full Participation Work Group Members

**Original Members (2008)**
- William Crum – Ohio
- Robert Demichelis – BIAA
- Paula Denslow – Tennessee
- Marilyn Hern – Idaho
- Ralph William Shields – New York
- Marilyn Spivack – Massachusetts
- Cari Watrous – Maryland

**Current Members (2020)**
- Paula Denslow – Director, TN Brain Links, and Family Member
- Cheryl Kempf – Traumatic Brain Injury Advisory and Leadership Group (TAL-Group)
- Martin Kerrigan – TAL-Group
- Maria Crowley – Traumatic Brain Injury Technical Assistance and Resource Center

## Overview

The Administration for Community Living (ACL) operates by the standard that all people can live with dignity, make their own choices, and participate fully in society. Programs supporting individuals with brain injury should provide tools, resources, and supports for integrating people with disabilities fully into community, work, and recreation to promote equal opportunities, self-determination, and respect.[1] When full participation of individuals with traumatic brain injury (TBI) and family members is a key principle, their presence does not constitute full participation unless they are equal, contributing members with a sense of belonging. To follow this principle, people may need support or accommodations.

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[1] https://acl.gov/about-acl/administration-disabilities

ACL's TBI State Partnership Program (TBI SPP) funds lead state agencies to increase and facilitate access so that all individuals with TBI, families and caregivers can obtain accessible and person-centered services and supports. Grant recipients collaborate across state systems to increase the program's reach and ensure that all systems have the competencies to best serve the TBI community. By inviting and supporting individuals with TBI, families and caregivers to feel that they are part of a community, full participation is achieved.



The Traumatic Brain Injury Technical Assistance and Resource Center (TBI TARC), under the administration of the Human Services Research Institute in partnership with the National Association of State Head Injury Administrators (NASHIA) worked with TBI SPP grantees and members of the Center's TBI Advisory and Leadership Group (TAL-Group) in the review and revision of the original document. The original document, developed by the Full Participation Work Group to focus on full participation as one of the key principles of the Federal TBI Program, has been updated to ensure current principles and platforms are included and applied.

*Full Participation Work Group Goals:*

- To identify concrete examples of full participation of individuals with TBI and family members and create full participation across all settings, services and individuals, regardless of disability, gender, race, ethnicity, age or religion.

- To identify and develop resources that will assist the Federal TBI Program, the TARC, and all other key stakeholders to better

understand, practice, and encourage the full participation of individuals with TBI and family members within the Federal TBI Program.

- ■ To provide recommendations and proposed outcome measures for incorporating mechanisms of assuring the full participation of individuals with TBI and family members within the Federal TBI Program.

## Introduction

The topic of full participation has been a focus area of the Federal TBI Program and remains a commitment as States work within their TBI statewide Advisory Boards/Councils, contractual activities, training initiatives and communities.

In 2008, the Full Participation Work Group established a Survey Subcommittee in order to study this area, and was charged with interviewing State/Protection & Advocacy (P&A) grant projects to assess the perceptions and realities of the full participation of individuals with TBI and family members on their TBI Advisory Boards/Councils. The subcommittee developed a Full Participation Questionnaire (Appendix A). Interviews were conducted with select participants from P&As and TBI advisory bodies. The original document highlights primary findings: laying the foundation of full participation concepts; conducting outreach; and providing accommodations.

This updated document is intended as a guide for best practices. As additional information is developed, it can be updated and used readily and frequently by grantees and partners across all states and settings. The tips and tools provided contribute to the full and meaningful participation of everyone.

**par·tic·i·pa·tion**, noun

1: the act of **participating**

2: the state of being related to a larger whole

**be·long,** verb

1: to feel and be a part of ...

2: to enjoy a sense of contribution, value, self-worth

3: to truly believe one is a natural and equal part of the whole

4: comfortable…welcome

**com·mu·ni·ty**, noun

1: a unified body of individuals:

2: a group linked by a common policy

3: an interacting population of various kinds of individuals in a common location

# Building a Solid Foundation

### QUESTION: How do we move from the ideals of full participation to truly implementing and activating full participation?

**ANSWER:** Create an environment and establish the building blocks and practices conducive to full and meaningful participation.

**TIPS:**

- Ensure that individuals with TBI and family members are equal partners in TBI program activities to develop a collaborative, team-based partnership of shared responsibilities and decision-making

- Talk with individuals with TBI and family members about their understanding and expectations of TBI Program participation

- Use people-first language for everyone as it emphasizes respect, individuality, and equality

- Allocate funding for and provide necessary expenses to ensure the full participation of all in TBI Program activities: time, travel, support, accommodations, etc.

- Recognize the inherent knowledge, experience, and expertise of individuals with TBI and family members by promoting their participation in leadership roles.

## QUESTION: How are attitude, commitment and value demonstrated?

**ANSWER:** Setting the tone and embracing equal input with flexible thinking creates a winning and welcoming environment for everyone to establish the building blocks. It is important to recognize that we all bring value and different assets to the table and have a variety of contributions to make.

**TIPS:**
- Recognize and utilize the strengths and abilities of all participants.

- Individuals with TBI and family members are valuable resources who can and should share the responsibility and accountability of TBI Program activities.

- Getting to know all fellow TBI Program members builds cohesion which enhances everyone's full participation.

- Formally acknowledge individual contributions, expertise, and value.

## QUESTION: How is understanding and knowledge created?

**ANSWER:** Providing comprehensive orientation, ongoing education, and training for all TBI Program participants is necessary as everyone involved has the same need for knowledge to fully participate.

**TIPS:**
- Individuals with TBI and family members may need more time for orientation and education with regard to the TBI Program, advisory body or group.

- TBI Program staff may need more time for orientation and education with regard to individuals with TBI and family members and how best to work and communicate with all types of abilities and differences.

- Make use of glossaries, training manuals, and other informational resources.

- Avoid the unnecessary use of acronyms and jargon.

- Adhere to universal processes for documents, training, etc. whenever possible.

## QUESTION: Why are organizational structures and processes necessary?

**ANSWER:** Organizational structures and processes provide the vehicle and framework for engaging everyone's full participation. Structure and process are an absolute necessity for individuals with brain injury to fully engage and participate.

**TIPS:**

- Assure there is a statement of purpose so that all participants have a clear and cohesive awareness and understanding of the purpose and function of the TBI Program, advisory body, and their activities.

- Create and routinely review member-developed vision, mission, and principles.

- Establish and adhere to advisory body bylaws/guidelines for governance.

- Define advisory body membership, leadership roles, and responsibilities with job descriptions and ensure equal access to participation by all members.

- Develop and follow policies and procedures.

- Assure frequent, active and equitable engagement by all participants.

- Establish workgroups and encourage input from every member.

- Hold regularly scheduled meetings, with ample notice.

- Provide agendas, meeting materials, and other relevant information as appropriate and in a timely manner, and when possible in advance.

- Formulate and utilize a work plan with goals, objectives, activities, responsibilities, timelines, an evaluation plan, and outcomes measures.

- Formalize the process by which materials (agendas, notes, etc.) will be sent out prior to meetings and then again after meetings (minutes, action items, etc.)

- Schedule breaks at regular intervals throughout the meeting and encourage and remind participants to self-break as needed.

## QUESTION: Why are accommodations essential?

**ANSWER:** Soliciting the need for and providing accommodations creates a level playing field and allows for the full participation of all parties. Individuals with brain injury may not recognize that an accommodation could be of assistance to them or may not be able to identify exactly what accommodation might be helpful. A person may also be uncomfortable requesting an accommodation as that individual might not want to be seen as being different, or not able to manage independently.

The need for accommodation may not always be what it seems. One example is sensitivity to fluorescent lighting. Sometimes with this type of lighting, an individual with a brain injury can become fatigued and cognitive skills can deteriorate, causing a loss of concentration, slowed processing, headaches, etc. The individual may not be aware that the lights are the source of these issues. All they know is that every time they attend a meeting, they get headaches. By outward appearance, having shorter meetings may be considered the accommodation, when in actuality a different type of lighting may be needed instead.

**TIPS:**
- Provide education and training on accommodations (physical and virtual environments and information formats).

- Conduct group and individual discussions using plain language (for example, by asking "What would help to make it easier for you to …?, "is there a way that works best for you?").

- Inquire about the need for accommodations during the interview process, orientation, and at other times as needed.

- When possible, provide participants' preferred choice of environment and modality by which meetings and activities are conducted (i.e., teleconference, videoconference, face-to-face meetings).

- Regularly check in with the individual to make sure that the accommodations are working and to see if there is a need for any changes or additional accommodations.

- Know what questions to ask and when to ask. Someone may not know what it is that is bothering them or causing difficulties unless they are told about it.

# Outreach and Recruitment

Outreach is a recognized responsibility of everyone involved with TBI programs for improving training, planning and program diversity. It is important to conduct outreach to inform, to educate, and to link to other communities and populations to assure the full participation of individuals with TBI and family members. Effective outreach can broaden the understanding of the needs of individuals with TBI and family members and serve as a tool for recruiting potential participants in a TBI advisory body or work group. It is essential that group participants reflect the diverse backgrounds of individuals with TBI and family members. Advisory bodies and committees must strive to build relationships with a variety of individuals and organizations in the community. Advisory bodies and communities create opportunities to make the most of their available resources in all activities, including outreach, through building a solid foundation.



## QUESTION: Why is outreach important?

**ANSWER:** Outreach provides opportunities to establish relationships with a variety of individuals and communities, including those that are unserved and underserved.

**TIPS:**
- Outreach fosters support for the TBI Program.
- TBI Programs learn about the needs of individuals with TBI and family members from a variety of communities within their States.
- Outreach identifies, develops, and builds resources.

- Partners, collaborators, and advisory bodies can educate communities about the needs of and resources available to individuals with TBI and their families.

- Outreach promotes awareness of advisory body and TBI Program activities.

- Outreach creates awareness of opportunities to participate in TBI Program activities.

- Outreach encourages paying attention to current trends and needs.

- Outreach enhances advisory body recruitment.

## QUESTION: How does a program prepare itself to conduct outreach?

**ANSWER:** Preparation begins with the foundation of the TBI Program.

**TIPS:**
- Create an expectation that outreach is part of the TBI Program's mission.

- Make outreach one of the values of the TBI Program.

- Include outreach in the written mission and values of the TBI Program and how they relate to the TBI State Plan.

- Discuss the importance of outreach with all potential partners.

- Provide an orientation handbook to all new advisory body members that has a section devoted to outreach and its importance to the work of the advisory body and TBI Program.

- Identify needed characteristics and skill sets of diverse populations and communities, with a connection to the mission of the TBI Program.

- Create a plan to conduct outreach.

## QUESTION: How does the TBI Program ensure effective communication with respect to the mission, purpose, and activities?

**ANSWER:** Speak plainly and create materials that are accessible and user-friendly.

### Verbal Communication

- Don't use jargon and limit the use of acronyms.

- Seek feedback from participants during communication.

- Listen with openness to new and different ideas.

- Have a written plan so people can refer to it.

### Written Communication

- Written material should include people first language* and plain language without too much information on one page.

    *People first language puts the person before the disability, and describes what a person has, not who the person is.  For more information, visit the [Disability Is Natural website](disabilityisnatural.com/people-first-language.html) (disabilityisnatural.com/people-first-language.html).

- Make materials available in alternative formats as needed. Add enriched text or accessible versions as possible.

- If information needs to be translated into another language, make sure the translation is in keeping with the literacy and dialect of the individual. Check to see if translations are accurate and appropriate.

### TIPS:

- Be flexible; know that individuals will process and engage differently.

- Understand the population and community involved.

- Recognize how communities interact and make accommodations as needed.

- Keep the message clear, concrete and simple. Focus can be a challenge for individuals with TBI.

## QUESTION: How do members of the advisory body or group engage in outreach?

**ANSWER:** Members can develop and carry out an outreach plan by actively utilizing the various strengths of the advisory body.

### TIPS:

- Ask what communities need to be contacted.

- Reaching out to unfamiliar communities where cultures and languages may be different can create feelings of apprehension and uncertainty.

- Check to see if there are TBI Program participants with contacts in the community.

- Determine if there are other government offices, community or not-for-profit organizations, and individuals to partner with to carry out plans and activities.



## QUESTION: How does an advisory body or group learn about new communities?

**ANSWER:** Reach out to other individuals and organizations to learn about the community.

**TIPS:**
- Consider contacting institutions such as local schools, colleges and universities, homeless shelters, disability advocacy organizations, prisons and penal institutions, senior community centers, domestic violence programs, assisted living facilities, organizations and state agencies that work with people with TBI and Veterans organizations. These resources can introduce a group to the community and their trusted leaders and provide information on the best way or ways to approach outreach.

- Use local medical/community contacts; often individuals are hesitant to share personal information and they may already have a dialogue established with a medical or childcare provider.

- When entering a new community, start where the community is; allow the community to identify their own needs, customs, concerns, and preferences. Ask for a tour, be introduced by the director. Trust happens more easily when a new community member makes it evident that you are welcome.

- Be prepared to listen and learn, ask questions and do not assume you know best.

- Invite representatives of organizations and communities to meet with participants of your TBI Program or advisory body.

- Hold meetings in the identified community so that community leaders and representatives can attend.

## QUESTION: How do you build relationships with community members?

**ANSWER:** Outreach is a tool for building relationships which takes time. Be prepared to step out of your comfort zone and move away from familiar surroundings.

**TIPS:**
- Maintain ongoing contact with community leaders, service organizations, and others who are well connected in the community.

- Participate in events that are important to the target community, have materials available to distribute, and be available for discussion.

- Use a variety of information formats, including websites, newsletters, and local media outlets that focus on your work in the community.

- Look at ways to be responsive to community needs and link them to other resources or provide other assistance.

- Look to a variety of individuals that represent the spectrum of individuals with brain injuries and their families.

## QUESTION: How will the TBI Program and/or advisory body carry out the actual outreach?

**ANSWER:** Outreach begins with identifying and learning about the community. As you develop relationships with members of the community you can use them to help develop your outreach plan.

**TIPS:**

■ Identify the best strategies to reach out to the community, such as face-to-face contacts, local radio, newspaper articles, brochures.

■ Materials need to be relevant to the community. Consult with community members on language, colors, and use of symbols. If people are pictured or identified in a document, make sure they represent the community.

■ Identify goals and objectives, develop strategies and create a plan.

■ Identify responsibilities and timelines.

■ Create a system for holding people accountable.

■ Create an evaluation plan with outcome measures.

■ Evaluate the resources needed to conduct effective outreach – people, time, money and connections.

■ Keep all participants and communities informed of progress and challenges.

■ Update/amend plans as needed.

■ Involve state brain injury advocacy organizations in the process of identifying individuals that may want to participate.

## QUESTION: How can you welcome new members or representatives from other communities?

**ANSWER:** Anytime someone new comes into an existing group, they are a guest. Treat new members or other representatives the way a guest would be treated and make them feel comfortable.

**TIPS:**

■ Greet people with a smile and be friendly courteous and patient.

■ Remember it is difficult to be the "new person" feel "different."

■ If there is anything new members or other representatives need to know ahead of time, make sure the information is received in a timely manner.

■ Include new members and other representatives in the socializing of the group before, during, and after meetings.

- Ask new members and other representatives to evaluate and share experiences with the group.

- Individuals from some communities may not want to join for a variety of reasons; however, they may be good resources to help your group maintain contact with the community.

- Meet with new members before a meeting in order to make them feel comfortable and prepared.

- Consider pairing new members with existing members of the Advisory Board to serve as a "mentor."

# Understanding Accessibility & Providing Accommodations

***Full participation is one of the guiding principles of the Federal TBI Program.*** To enter into conversation about full participation of individuals with TBI and family members, there must be a shared understanding of the implications of full participation, the attitudes of and expectations about what that participation will accomplish and look like. To achieve full participation, reasonable accommodations for individuals with TBI may need to be provided. Accommodations can range from meeting length, structure, and pace, providing a note taker, elimination of side bar conversations, etc. Full participation can be particularly challenging as accommodations are, like people with disabilities, diverse – and the accommodation for one individual may not be the accommodation for another individual with similar residual effects.

To assist in assessing the need for accommodations, an Accommodations Checklist of potential accommodations has been developed (Appendix B). This is not an exhaustive list, but a means of stimulating discussion with individuals with TBI. Common barriers to full participation on the part of individuals with TBI are generally related to barriers in information capture, information storage, information retrieval, and information use. This document can also be used in a variety of settings and with other populations of people with disabilities. Within this framework, guidance regarding several of the key elements of providing accommodations is presented below.

## QUESTION: What are reasonable accommodations?

**ANSWER:** The Americans with Disabilities Act mandates equal access for people with disabilities in several areas, including employment, transportation, public accommodations, communications and access to state and local government programs and services.  Adjustments, modifications or provision of services and equipment may be necessary to enable an individual with a disability to enjoy equal opportunities in community, work and recreation. The phrase reasonable accommodation is routinely used to include physical, program or cognitive access needed under other circumstances, such as public programs or providing private services. There are numerous low- and high-tech solutions for providing assistance to individuals with TBI.  For more information about reasonable accommodations visit the Job Accommodation Network website (askjan.org/soar.cfm).
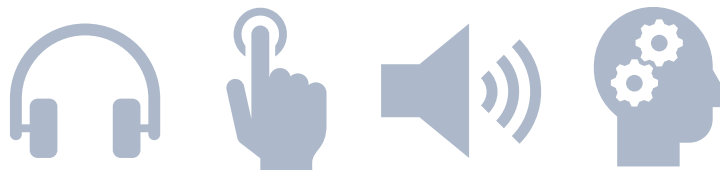
## QUESTION: What is meant by accessibility?

**ANSWER:** The dictionary defines accessible as "capable of being seen, reached, used, understood or appreciated". Accessibility extends beyond physical space to involve full affordability to facilities, materials, experiences, and people.

**TIPS:**
- A sense of "belonging" is necessary for accessibility to be fully realized. Belonging in this context means having a sense that a person is in the right place and feels comfortable participating, rather than being just a spectator. This kind of belonging requires respect and equality.

- Accommodations must be appropriate for all the participants, and the materials, the pace and structure of a meeting, and time allotted for different activities must respect differences among individuals.

- Materials provided need to follow Section 508 of the Rehabilitation Act, as amended by the Workforce Investment Act of 1998 (P.L. 105-220) which requires federal agencies to "develop, procure, maintain and use information and communications technology that is accessible to people

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with disabilities". For more details on what is involved, visit [Section508.gov](https://Section508.gov).  Websites and associated resources also need to be accessible as well, following Web Content Accessibility Guidelines (WCAG). For more information about this topic, visit [w3.org/WAI/standards-guidelines](https://w3.org/WAI/standards-guidelines).

- Universal access benefits everyone.

## QUESTION: Are reasonable accommodations requests considered for family members?

**ANSWER:** Yes, provided the interests of the person with the TBI are respected.

## QUESTION: What are cognitive accommodations? How do I obtain information about them?

**ANSWER:** By definition, cognitive means; "of or relating to being, or involving conscious intellectual activity (such as thinking, reasoning, or remembering) as contrasted with emotional processes." Ongoing discussions with all participants in the TBI Program and the community promote understanding of current strategies and accommodations.

**TIPS:**
- Provide materials in advance when possible.

- Make available materials in universally accessible and/or alternative formats.

- Provide audio or video access to the session or allow recording.

- Provide meeting transcripts when possible.

- Repeat a question to the group, then respond with the answer.

- Invite participants to bring a companion or offer a mentor to accompany and assist.

- In advance of an event, prepare individuals for what will take place (e.g., share how many people will be in attendance, explain roles, discuss what will be going on during each part of the meeting). This is especially useful when done at the conference center/hotel before the meeting begins.

- Provide individuals the opportunity to ask questions about materials/topics that are scheduled to be discussed prior to the meeting.

- Allow for virtual attendance if needed and be cognizant of the needs that may arise from working within this platform.

- Create a separate quiet room during meetings if possible, to provide individuals with brain injury some cognitive respite from visual and auditory surroundings.

### QUESTION: Who is responsible for ensuring accommodations are provided?

**ANSWER:** A designated person in a leadership role.

### QUESTION: What is the process of having accommodations met?

**ANSWER:** Verbal or written requests can be made by the individual with TBI. As a reminder, a person may also not know what to ask for – acknowledge this might be the case in certain situations and proceed accordingly.

**TIPS:**
- Review identified requests with the individual to ensure understanding of the need and suggestions for how to approach it.

- Include language on all requests documents stating, "all are encouraged to participate; if accommodations are needed, contact the designated person."

- Provide for opportunities to regularly check to make sure accommodations are being met, with verbal and written reminders.

### QUESTION: What types of accommodations can be provided?

**ANSWER:** Functional, physical and cognitive – create an environment which is welcoming to everyone. Accommodations must be appropriate for all participants. Materials, the pace of a meeting and the time allotments for different activities must respect differences among individuals.

### QUESTION: Are there some accommodations that are unable to be provided?

**ANSWER:** Providing accommodations is an ongoing process of learning and understanding the need to improve communication and accessibility for everyone.

## QUESTION: How do you know what accommodations might be optimal?

**ANSWER:** Ask individuals directly what their needs are; they are the expert on their disability. The key to this asking is in the listening that follows. Use "common sense" rules; treat others as you want to be treated, respectfully and honestly. Consider utilizing an accommodations checklist (Appendix B). Also check legal requirements and timelines for providing accommodations. There are considerations which are essential in providing reasonable accommodations:

- There must be a process in place.

- There must be person in a leadership role that has the responsibility of promoting the process and serves as keeper of the process. This person must be known as the responsible party for accommodations on an ongoing basis to ensure that all members are aware of his/her role.

- For the person in need of accommodation(s), it is imperative that you ask for what you need. Too often individuals with TBI and family members do not want to bother or burden people with their needs. Additionally, individuals with TBI often try to fit in, think that they are okay, and do not have needs – when, in fact, they do.

- Always look for what is underneath or below the surface, which may be causing the need for an accommodation. Often an underlying emotional/behavioral limitation is being manifested as a cognitive or physical limitation. Sometimes, an individual with TBI is not able to communicate his/her need while in the midst of confusion or "being stuck."

- Consider a committee that supports the need for accommodation as a potential option.

Most importantly, recognizing, appreciating and fostering the value the full participation provides is critical to improving the lives of individuals with TBI, their families, and their communities. When the time and effort is made to implement the full participation and accommodations process up front, it generally leads to better outcomes.

# Additional Resources

The content provided in this Resource Tool is the responsibility of the authors and does not necessarily reflect the views of the Federal TBI Program or related partners. Additional resources that might be useful:

Accessible Meetings, Events and Conferences Guide
adahospitality.org/accessible-meetings-events-conferences-guide/book

Accessible Guidelines for Speakers
ndrn.org/images/Documents/Resources/Webcasts/PR/AccessibilityGuidelines_Speakers7-09-10.pdf

Involving Consumers on Advisory Boards
mtdh.ruralinstitute.umt.edu/?page_id=1031

Iowa Brain Injury Council Handbook
idph.iowa.gov/Portals/1/userfiles/32/ACBI/2019-2020%20ACBI%20member%20handbook%20Final%20pckedits%20%281%29.pdf

Making Accessibility Real: A Guide for Planning Meetings, Conferences and Gatherings
aucd.org/docs/HCBSAccessibleMeetings.pdf

Accessible Meetings and Events: University of Georgia
eoo.uga.edu/sites/default/files/accessiblemeetingsandeventsuga.pdf

SAMHSA's Guidelines for Consumer and Family Participation
samhsa.gov/grants/applying/guidelines-consumer-participation

Cultural Competence and Disability
store.samhsa.gov/sites/default/files/d7/priv/sma14-4849.pdf

Hosting Virtual Meetings
Brain Injury Association of Virginia Virtual Tip Sheet Series
biav.net/support-groups/

Texas OABI PSA Video Series:
hhs.texas.gov/services/disability/acquired-brain-injury/educational-videos

Tennessee Disability Pathfinder: Accessible Virtual Connections
vkc.vumc.org/vkc/pathfinder

*Source: The Compass, Issue Title: Navigating a Virtual World, June 2020*

# Full Participation Self Survey

Created December 2006
Updated July 2020

**State Lead Agency:**

**Advisory Board/Council OR Meeting/Event:**

**Participant Name and Title/Role:**

**Date:**

**Questions:**

1. What is your process of recruiting members?

2. Is there outreach to a variety of communities?

3. How do you orient members?

4. Is on-going education & training provided? If so, what?

5. What percentage of individuals with TBI and family members is represented in your group?

6. Are the individuals with TBI and family members active participants?

7. How is this representation defined in membership? Legislatively or otherwise?

8. Are the individuals with TBI and family members active leaders?

9. Does the group tend to retain individuals with TBI and family members or is there a lot of turnover?

10. Has systems change been enhanced by this level of individual and family member participation?

11. In what other ways are individuals with TBI and family members involved with your activities?

12. Do you solicit requests for and provide accommodations, as needed?

13. Do you follow up on effectiveness of accommodations provided?

14. Are there accommodations you have been unable to provide?

15. Where do you see room for improvement with regard to full participation?

16. What do you need help with regarding full participation?

# Accommodations Checklist

A person with brain injury can utilize a checklist of accommodations to express their particular needs. Some of the common barriers to full participation are generally related to challenges in information capture, storage, retrieval and use. This is a starting point for providing a more complete accommodations checklist. Common uses might include access related to in-person meetings, online meetings, transportation, scheduling, directions, and facilities. Lastly, please keep in mind that patience, courtesy and flexibility are always good practice.

| ✓ | Individual Experience | Barrier | Possible Accommodations |
|---|---|---|---|
| | Too much information- feel confused, overwhelmed, lost much of the time | Memory impairment; attention issues; fatigue | Break into steps (chunking), provide handouts, use summaries, test with persons with brain injury (of various levels) before finalizing accommodation. Pair with a mentor or other member to assist during meeting. |
| | Information is too complicated | Difficulty attending to more than one topic at a time; difficulty with concepts, grey areas, or complex topics | Simplify, break into steps, provide written summary, as well as detailed handout; consider audio format. Arrange for a notetaker. Pair with a mentor or other member to assist during meeting. Review information before meeting when possible. Get closure on one topic before starting another topic. |
| | Information presented too quickly | Difficulty tracking; memory; processing speed | Slow down/pause in between points to give attendees time to process and make notes; encourage note writing; ask when to move on; encourage attendees to ask clarifying questions; encourage "clarify and verify" communication strategy. Ask for visual checks during virtual meetings. |
| | Cannot remember points | Memory impairment | Provide written handouts, details and summaries. Provide materials in advance. Summarize, go over points, assignments, at end of session. Provide meeting notes, summary in follow up and in a timely manner. |
| | Personal mode is auditory | Processing issue | Provide audio of presented material; allow recording with permission of others; give participants information about recording options (e.g., phone, iPad, allowing such devices during presentations). |

| ✓ | Individual Experience | Barrier | Possible Accommodations |
|---|---|---|---|
| | Personal mode is visual | Processing issue | Provide copies of PowerPoints, forms, summaries, lists of contact names and numbers (identified by function). Provide in advance when possible. |
| | Do not know why I'm here | Orientation | Provide orientation session prior to meeting. Encourage notes for cueing. Provide orienting visual cues during duration of meeting. |
| | Lighting is too harsh | Fluorescent light is stressful and can trigger seizures in some individuals | Use natural light, bring in incandescent lighting and turn off fluorescents. |
| | Too much background noise | Difficulty filtering out background noises | Provide or suggest bringing ear protectors to give people "noise breaks" to relieve stress. Provide quiet rooms; avoid side conversations; do not host in places close to busy roads, kitchens, service areas. Do not use typical room dividers for breakout sessions (not noise-proof enough). |
| | Laser pointers are distracting in PowerPoint presentations; too much information in slides | Too much visual stimulation | Ask participants if this is an issue; if so, have person use physical pointer. Break down information on slides into chunks or bullets; discourage use of animation in slides, provide at universal reading levels. |
| | Cannot use the information | Difficulty with prospective planning | Provide an aide/notetaker/interpreter or encourage family member/friend to also join. Encourage sequential task completion with organized bullet points or ordered steps: listed and numbered. |
| | Cannot see the big picture | Difficulty with concepts | Provide summary statements in the form of "This is why XYZ information matters to me," or similar. Start with "here is where we want to end up; here is where we need to start to get there." |
| | There are side conversations | Cannot concentrate on main discussion. Inability to filter outside conversations | Remind participants of conference meeting etiquette. Be respectful of other attendees. |
| | Distracted by crowds | Overstimulation | Plan/schedule coming and going times during sessions. Hold smaller gatherings when possible. |
| | No room or place to write notes | Cannot capture thoughts, items for later recall | Provide notepaper or sticky notes, day planner inserts |

| ✓ | Individual Experience | Barrier | Possible Accommodations |
|---|---|---|---|
| | | | with wide enough lines, grey paper. Provide pencils. Capture information on laptop or iPad. Consider notetaker. |
| | Fatigue | Exhaustion. Inability to focus, concentrate | Provide sufficient breaks. Host shorter meetings, presentations. Consider all factors that may contribute to fatigue & remedy. Ask for visual checks during virtual meetings. |
| | Overstimulating environment | Carpet pattern, "busy" wallpaper, lighting, etc. | Consider different meeting space and/or facility. Consider alternative meeting format – i.e., virtual or teleconference. Ask for visual checks during virtual meetings. |
| | General distractions | Anything that interrupts train of thought, processing | Turn cell phones, personal devices off or place on silent mode and respond away from meeting area. Avoid side conversations, chaotic situations. Ask for visual checks during virtual meetings. |
| | Too much material. Cannot find material when needed. Get overwhelmed with so much material | Confusion | Do not overload meeting packets. Color-code materials to agenda items, meeting days, subject matter. Place in meeting packet in order needed. Pair with mentor/other member to assist during meeting. Meet afterward to review, process, answer any questions that were not asked during meeting. |
| | Virtual meetings are exhausting, hard to follow and too long | Fatigue, processing, attention, distractions, busy screen | Encourage hardware and software preparation, practice and early logon before meetings. Minimize other distractions. Change computer settings regarding light and color. Use a chat or question feature to ask questions. Ask for recording of meeting or transcripts. |

# Resources for Accessible Virtual Meetings

Full Participation Workgroup: TBI Technical Assistance and Resource Center
Updated July 2020 (Created March 2008)
Compiled by Donna DeStefano, Tennessee Disability Coalition

**Virtual Meetings for People with Disabilities** by Mike Shea
Brief information on accessibility guidelines and Zoom meetings
rockymountainada.org/news/blog/virtual-meetings-people-disabilities

**How to Make Your Virtual Meetings and Events Accessible to the Disability Community** by Alaina Leary
General overview, includes guidance for planning, holding, and post-event activities rootedinrights.org/how-to-make-your-virtual-meetings-and-events-accessible-to-the-disability-community/

**Best video conferencing apps and software for accessibility**
Includes: advantages and disadvantages of video conferencing apps and services and tips for better video calls
bighack.org/best-videoconferencing-apps-and-software-for-accessibility/

**The Inaccessible Internet May 26, 2020 Source: Slate**
adasoutheast.org/news/articles.php?id=9611
Excerpt: "Employees now working from home are also facing videoconferencing challenges. Alaina Lavoie, a writer, editor, and social media manager in Boston, finds these calls overstimulating for her as an autistic person. "I have to focus and spend a lot more energy on video calls than I would on meeting in person or an audio call with no video component," she said over email. She finds herself needing to take multiple breaks during calls because the pressure of deciding whom to look at or when it's appropriate to speak exhausts her energy. 'I think it increases accessibility if events are available to watch later, especially since with a virtual event it's so easy to record it and upload it.'"

**Toward More Accessible Work Environments**
alltogether.swe.org/2020/05/toward-more-accessible-work-environments/
Excerpt: "Though telework is a best practice, Cokley said there's a "real fear" that employers can say, 'Well, it's cheaper to be in an older building with stairs and no elevator, so maybe Sally can just telework like she did during the pandemic.'"

**COVID-19 Response: Digital Accessibility and Other Best Practices for Remote Work**
https://disabilityin.org/resource/covid-19-response-accessible-tools-and-content/

**What is a Webinar? And Zoom webinars**
accessibilityonline.org/ao/program-format/
General resource with info on Zoom, including Zoom accessibility, help for first-time users, and hot keys and shortcuts.

**Holding Accessible Meetings – election focus**
*NOTE: Only PDF available*
ifes.org/sites/default/files/inclusion_insights_holding_accessible_and_inclusive_virtual_meetings.pdf
Includes a table describing some common reasonable accommodations for persons with different types of disabilities and accessibility features of virtual meeting platforms

**How to Host Effective and Accessible Online Meetings with Deaf Participants**
National Deaf Center on Postsecondary Outcomes
Tips from the National Deaf Center on Postsecondary Outcomes

**Hear and Connect: Zoom and Captioning for Hearing Loss**
chchearing.org/blog/zoom-captioning-hearing-loss/

**Accessibility Tips for a Better Zoom/Virtual Meeting Experience**
deafhhtech.org/rerc/accessible-virtual-meeting-tips/
Focused on the needs of Deaf and hard-of-hearing participants in virtual workplace meetings; many have also been tested in cross-disability meetings

**20 Tips for Teaching an Accessible Online Course**
washington.edu/doit/20-tips-teaching-accessible-online-course

**American Foundation for the Blind - Additional Resources for Remote Instruction**
afb.org/about-afb/events-and-awards/afblc-2020-overview/virtual-afblc/remote-instruction/resources

**Free audiobook, "Meet Me Accessibly – A Guide to Zoom Cloud Meetings from a Blindness Perspective"** mosen.org/zoom/
A three-hour audiobook, written and narrated by Jonathan Mosen

Includes basics of attending your first Zoom meeting to content sharing of a video and audio from a computer or iDevice

**Zoom tutorial overview with screen reader part 1: Joining a Zoom meeting and downloading Zoom**
youtube.com/watch?v=24PTpKlLwMU&list=PLng32LADAwnqs1F7RNiANbueTs1uVz5S9&index=2&t=0s

**Cisco Webex Meetings and Cisco Webex Events Accessibility Features**
help.webex.com/en-us/84har3/Cisco-Webex-Meetings-and-Cisco-Webex-Events-Accessibility-Features

Screen Reader Support—The Webex Meetings and Webex Events applications are tested to work with the latest version of the Freedom Scientific JAWS screen reader. All the keyboard shortcuts listed in the Keyboard Navigation section work with screen readers. Screen readers are unable to read content from shared presentations, shared applications, and shared desktops.

**University of Connecticut IT Accessibility - WebEx by Cisco**
accessibility.its.uconn.edu/webex-by-cisco/#

Follow the steps below to specify the closed caption option:
Depending on the operating system you are using, do one of the following:
Windows: In the Meeting window, on the Meeting menu, choose Options. The Meeting Options dialog box appears, with the General tab selected by default.
Mac: On the Meeting Center menu, select Preferences. Select Tools.
Do one of the following:
To enable: check the Enable Closed Captioning box.
To disable: Uncheck the Enable Closed Captioning box.
Click Apply, then click OK.
To select another participant to transcribe, select the participant's name on the Participants panel; then right-click (Windows) or select ctrl and then click (Mac), then select Change Role To > Closed Captionist.

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## Captioning
**Web Captioner**, a free tool for real-time captioning: webcaptioner.com/

**10 Free Tools to Make Your Video Captioning Process Easier**
Source: Amara (updated 2/2020)  blog.amara.org/2018/05/02/10-free-tools-to-make-your-captioning-process-easier-in-2018/

Note: Amara is a project of the Participatory Culture Foundation (PCF), a nonprofit 501c3. We are driven by our mission to foster a media ecosystem that enables everyone to benefit from online video content. Content that can enrich lives, but is not currently available to those who cannot hear or understand the language of the video. We believe a participatory and inclusive world leads to a more understanding and caring society.

**Federal Social Media Accessibility Toolkit Hackpad**
digital.gov/resources/federal-social-media-accessibility-toolkit-hackpad/

**How to Add Closed Captions & Subtitles to WebEx Recordings**
3playmedia.com/solutions/how-it-works/how-to-guides/captions-subtitles-transcription-for-webex-recordings/

*We invite your feedback on this Toolkit. Please [complete a brief survey (http://uaa.co1.qualtrics.com/jfe/form/SV_0PdnlQFiq8CZ77L)](http://uaa.co1.qualtrics.com/jfe/form/SV_0PdnlQFiq8CZ77L) to share your thoughts on the individual sections.*