

Beyond Checking the Box

Full Engagement Strategies
for Improving Participation of
Persons with Lived Experience

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Contents

Background.....	1
Strategies for Full Participation on Advisory Boards/Councils	2
Macro-level strategies:.....	2
Tangible meeting structure and operations strategies	4
Pre-meeting strategies.....	4
Meeting day strategies.....	6
Post-meeting strategies	7
Final Recommendations	8
Supplemental Information.....	9
Examples of Post-Meeting Surveys	9
Participatory Action Research (PAR) Model	15

Background

The Administration for Community Living (ACL) requires ACL Traumatic Brain Injury State Partnership Program grantees maintain a minimum of 50% of individuals with brain injury on the state advisory board/council. It is important to recognize the unique value-adding perspective individuals with lived experience bring to disability advisory boards/councils. Most of the 31 grantees have met that requirement. However, several states indicated that they could benefit from a facilitated discussion related to full participation of individuals with lived experience on their advisory boards/councils.

In response, the Traumatic Brain Injury Technical Assistance and Resource Center (TBI TARC) hosted a meeting with the following states: California, Colorado, Idaho, Kentucky, Louisiana, North Dakota, New Jersey, and Pennsylvania. During this discussion, the group shared challenges and successes they had with engagement strategies. Meeting participants agreed that these states would benefit from technical assistance from the TBI Advisory Leadership Group (TAL-Group).

The TBI TARC enlisted the support of two TAL-Group members, Kelly Lang and Martin Kerrigan. Lang and Kerrigan participated in two listening sessions. The first was with state program managers and staff members to learn about their challenges in obtaining full participation and engagement from those with lived experience. The second meeting focused on individuals with lived experience who are or have participated on advisory boards/councils and learned why they may not feel fully engaged. Based on those listening sessions, Lang and Kerrigan developed set of strategies for full participation, which are detailed in this document.

States may need to address a variety of obstacles to ensure full participation of individuals with lived experience. The greatest challenge arises when advisory boards/councils are written into statute. Changing laws can be complex and may not always benefit the program. However, the strategies presented in the following section can help states with either governor-appointed or volunteer-based boards/councils to increase engagement from individuals with lived experience.

Strategies for Full Participation on Advisory Boards/Councils

Macro-level strategies:

- If the board/council is in statute, weigh the pros and cons of changing the statute to allow for a minimum of 50% individuals with brain injury to be appointed.
 - Suggest that ACL write a memo indicating the requirement. States could use this to leverage legislative changes.
 - For states that are required to host in-person meetings, suggest that ACL “strongly” recommend hybrid option for advisory board/council meetings.
 - Some individuals with lived experience prefer in-person meetings and others prefer virtual meetings. Offering a virtual option makes meetings accessible to more people. It is recommended that one person manages the in-person meeting and another manages the virtual meeting option.
- Full participation starts with effective recruitment strategies. While not the intent of this resource, states should review their approach to recruiting individuals with brain injury to ensure they recruit members who —given access to supports and accommodations—have the capacity and desire to fully participate on the board/council. States can also call upon their partners to assist (e.g., protection and advocacy programs, state brain injury affiliates, alliances, and associations).
- Candidates should be aware of what the board/council does and doesn’t do. For example, it needs to be clear whether a board/council makes fiduciary, policy, or programming decisions or whether they only make recommendations.
- Engage your state’s Protection & Advocacy agency in working with individuals with lived experience on boards/councils. These agencies are an asset for ensuring individuals with lived experience are equal representatives with equal

voices on boards/councils. Protection & Advocacy agencies devote considerable resources to ensure full access across a variety of programs including boards/councils.

- Provide training for state advisory board/council leaders on how to recruit members, conduct the interview process, and onboard new members.
- Develop a relationship and build trust with the member. This is key to helping the member feel welcome and empowered to share at meetings. Identify each member's strengths, resources, and their "why" for wanting to be on the board/council.
- Develop and implement an onboarding process for new board/council members, including providing an overview of the purpose of the board/council, the structure of the meetings, and the goals of the group. Consider recording orientation videos so new members can reference both audio/visual documentation and written documentation.
- Pair every new board/council member with a veteran member representing the opposite group. For example, any new member with lived experience would be paired with a veteran member without lived experience and vice versa.
 - This reduces the "us" and "them" mentality.
 - Onboarding programs for members (both those with lived experience and others). Both perspectives are valuable; sometimes the person in most need of information is the person without lived experience.
- Include individuals with lived experience on every committee, sub-committee, and executive committee when allowable. Advocate for change if this is not allowed.
- Consider hosting an annual retreat to refresh board processes, enhance participation, and ensure the direction of the board/council reflects its members

as a whole. A retreat could also provide opportunities for relationship building among members.

- Ensure state brain injury program leaders/advisory board/council leaders are aware of ACL toolkits and guides such as:
 - [Traumatic Brain Injury Advisory Board Toolkit](#)
 - [Engagement Strategies for Survivors](#)
 - [Full Participation Guidelines](#)

Tangible meeting structure and operations strategies

- Establish a standing subcommittee of individuals with lived experience—possibly family members as well—where members can discuss meeting agendas, topics, etc. Consider naming a spokesperson who reports back to the whole board with any questions or concerns the group may have. Hold the subcommittee meeting just prior to the whole board/council meeting.
- Develop a consistent structure for the meetings. Develop group norms, rules, and values, and ensure all members adhere to them.
- Schedule meetings for the same day, time, and location, when feasible.

Pre-meeting strategies

- Send meeting agendas three days to one week ahead of meetings. Offer the option of a pre-meeting to review the agenda and provide an explanation of items, if needed. It is also a good time to review procedures. This will help ensure the needs of those with lived experience are considered.
- Do not overpack your agendas. Allow ample time for processing and participation during the meetings. Also, build in time for breaks where possible.
- If an agenda item requires a vote, provide information ahead of the meeting enable informed decision-making. During the meeting and prior to voting, ask if

people need additional information on the topic. Clearly identify on the agenda those items which require a vote.

- Ensure all documents provided are Section 508 compliant and are written in plain language.
- Provide technology orientation and support for those who will access meetings virtually.
- Ensure acronyms/initialisms are spelled out on all documents. Avoid using acronyms/initialisms in speech during the meeting.
- Provide meeting materials in multiple modalities. If meeting in person, always provide hard copies of materials.
- Assist members in obtaining accommodations to attend and fully participate in meetings. Some may need assistance with travel arrangements and/or reimbursements, physical assistance, assistance with materials, etc.
- Consider compensation for board/council members who are volunteers. Pay for their time at the meeting as well as time to prepare for the meeting.
- Pay for travel, parking, lodging, and other related expenses.
- Consider hosting meetings in places with close access to a variety of transportation modes.
- Consider establishing a co-leadership model for the board/council as a whole and for subcommittees that includes representation from individuals with lived experience and those without. Provide mentoring of new chairs or co-chairs by outgoing chairs/co-chairs.
- Provide a resource depository for all documents pertinent to the board/council (e.g., bylaws).

Meeting day strategies

- Provide a slide deck with information including the agenda on it for a point of reference.
- Provide documents both electronically and on paper as needed.
- Include an ice breaker at the start of meetings to get people comfortable with talking in the group.
- If returning to a previously discussed topic/item, “refresh” the board/council by briefly summarizing what is being discussed. This is best practice and will likely benefit most people since there is often a substantial amount of time between meetings.
- Don’t assume an individual is perseverating or ignoring meeting norms and rules. They may be taking advantage of limited opportunities to share thoughts and ideas. Ensure that everyone has adequate time to share and create a document to store ideas that are not pertinent to the current meeting (e.g., create a “parking lot” for ideas), etc.
- Include training on brain injury basics for all board members to ensure level setting and consider including individuals with lived experience in conducting training.
- Use the “step up and step back” approach to ensure equal opportunity for participation. For example, if you are someone who often talks, pause a moment to ensure quieter individuals or those who need more time to process have an opportunity to talk. Similarly, if you are someone who does not talk often, find opportunities to “step up.”
- Validate people’s input at meetings. Here are some examples:
 - **Mindful listening.** [Pay attention](#) to what the other person is saying, avoid distractions (including your own emotions), and don’t judge.

- **Be aware of your facial expressions.** Are you making [eye contact](#)? Avoid rolling your eyes or looking away. Are you frowning or laughing? What's appropriate for the situation?
- **Think about your physical gestures.** Does your body language suggest you're listening, or are your arms crossed?
- Allow for multiple modes of participation. For example, if in a virtual setting, allow people to use the chat feature, raise their hands, provide input verbally, use whiteboards, etc. Also, give as much opportunity for discussion as possible.
- Use small groups for discussion in person and breakout rooms virtually to allow opportunities for those who are uncomfortable speaking in larger groups.
- To accommodate those who may need more time to process, use polls (if hybrid or virtual) to elicit feedback anonymously. This will help to destigmatize input .
- Allow time for 5- to 10-minute “bio breaks” during the meeting. Bio breaks refresh the brain and body, and allow for continued focus.

Post-meeting strategies

- If a mentor program is in place, remind board/council members to reach out to mentors with any questions following a meeting.
- Allow members to respond to agenda items after a meeting. Some individuals may need additional time to process information before commenting. Allow for post-meeting comments through a variety of communication channels (e.g., phone, ZOOM, survey).
- Send out a post-meeting survey to gather general feedback from the meeting and/or topics discussed. Examples of post-meeting surveys from Colorado, Alaska, and Virginia are included in “Supplemental Information.”

Final Recommendations

The group discussion led to additional suggestions for distribution and document maintenance:

- Make every effort to ensure that this document is a living document, reviewed routinely and updated as needed.
- Recommend that ACL cites this document within future funding opportunities to promote the use of these engagement strategies.
- Consider distribution to other programs, boards/councils, and systems for use on best practice.

Supplemental Information

Examples of Post-Meeting Surveys

Virginia

The Virginia Brain Injury Council (VBIC) distributes a survey to all members immediately following each meeting. The survey includes the following questions:

1. Did this meeting meet your expectations? Yes/No
2. Do you feel that your input was heard and valued at this meeting? Yes/ No
3. Do you feel that the thoughts and questions of others were encouraged at this meeting? Yes/No
4. Do you feel the needs and preferences of people living with brain injury and their caregivers were represented at this meeting? Yes/No
5. Were the materials provided for this meeting helpful? Yes/No
6. Please let us know anything you thought went well at this meeting or any improvements we can make. Thank you.

Colorado

For 2022-2023, the Colorado Advisory Council for Brain Injury (CACBI) sent its members an Annual Feedback Survey, which included the following questions:

1. If you recall missing any meetings this past year, what were the main reasons?
 - Don't think I missed any meetings last year
 - Had other work commitments
 - Had other personal commitments
 - Wasn't able to join virtually
 - Forgot
 - It wasn't a priority
 - Other
2. We've spent a lot of time on the Council's bylaws and group agreements in hopes of developing shared expectations and responsibilities for creating and maintaining a safe,

inclusive, and productive council. Please provide any feedback on this process and/or ideas for how we can continue to hold each other accountable to these agreements.

3. Please rate how safe, inclusive, and productive CACBI feels for you. Ratings: “Not at all,” “Somewhat,” or “Very much”
 - Safe
 - Inclusive
 - Productive

4. Please rate how comfortable you are sharing your thoughts and ideas with CACBI through the following mechanisms. Ratings: “Not at all,” “Somewhat,” or “Very much”
 - Raising my hand and speaking during the full group meetings
 - Chatting a message to the group during the full group meeting
 - Speaking during breakout groups or subcommittee meetings
 - Using brainstorming tools, like jam board or google docs
 - Emailing MINDSOURCE staff after the meeting
 - Surveys or feedback forms

Please provide any comments as to why these spaces or tools aren't comfortable for you and what we can do to change that.

5. Please rate how valued you feel your thoughts and ideas are by the group. Ratings: “Not at all,” “Somewhat,” or “Very much”

6. How are you feeling about the new State Plan?
 - Super excited about it!
 - Mostly excited about it
 - Can get on board but not excited about it
 - Have big concerns about it
 - Not really sure what's in the plan and what it means

7. If you're not excited about the State Plan, please explain what would need to happen to get you there.

8. What trainings do you think the Council would benefit from as we move to implementing the new State Plan?

9. As we finalize the State Plan draft, we want to be sure to get broad community engagement, particularly from people impacted by brain injury and especially those who live in rural areas or identify as a person of color or with the LGBTQIA+ community. What groups would you suggest MINDSOURCE reaches out to get feedback on the plan?
10. If you would be willing to partner with MINDSOURCE to engage a community group, please share your name below and the group you have in mind. If you want your survey responses to remain anonymous, please reach out to [contact] with your ideas via email.
11. How long have you been part of CACBI?
 - Less than 1 year
 - 1 year
 - 2 years
 - 3 years
 - 4 years
 - 5 years (the beginning)
12. Do you have a brain injury? Yes/No
13. Please share any additional suggestions or ideas for CACBI as we move into a new fiscal year with new chairs and a new state plan.

Alaska

For 2022, the Traumatic and Acquired Brain Injury (TABI) Advisory Council distributed to its members the survey below:

Introduction: Thank you for your work on the Alaska Traumatic and Acquired Brain Injury (TABI) Advisory Council. We would like to ask you to tell us about your satisfaction with the council. We are also interested in hearing about engagement and how we can make sure all members have equal chance to participate.

Please complete each question by checking the box that best shows your level of agreement. We also welcome additional comments and suggestions you have for improving this council. If you have questions about this survey, contact [CONTACT].

Participation in this survey is voluntary and your responses are anonymous. Thank you in advance for your valuable feedback.

1. Do you identify as an individual with a brain injury? Yes/No

2. Council activities: Please rate your level of agreement with the following statements from “Strongly Disagree” (0) to “Strongly Agree” (5)

The TABI Advisory Council:

	0	1	2	3	4	5
Has a clear vision	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Encourages people to work together	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Is making progress toward meaningful objectives	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Has members who advocate effectively	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

For statements rated 2 or less, please explain why you disagreed or what improvements could be made.

3. Opinions: Please rate your satisfaction with the following aspects of the TABI Advisory Council. Ratings from “Very Dissatisfied” (0) to “Very Satisfied” (5)

	0	1	2	3	4	5
Participation of people with lived experiences of TABI	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Diversity of council members	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often meetings happen and how long they last	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

For statements rated 2 or less, please explain why you were dissatisfied or what improvements could be made.

4. Next, we would like to ask about your experience serving on the TABI Advisory Council. Please rate your agreement with the following statements. Ratings from “Strongly Disagree” (0) to “Strongly Agree” (5)

	0	1	2	3	4	5
I am satisfied with what has been accomplished	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My contributions are valued	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Meetings run smoothly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Members seem well informed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

For statements rated 2 or less, please explain why you disagreed or what improvements could be made. For statements rated 3 or more, please explain why you agreed or what works well and should be maintained.

5. Please rate your level of agreement with the following aspects of subcommittee work (e.g., in the Prevention/Awareness/Resources subcommittee). Ratings from “Strongly Disagree” (0) to “Strongly Agree” (5)

	0	1	2	3	4	5
Attending the subcommittees is a good use of my time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The goals we have worked on are clearly defined	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
We have accomplished goals over the past 12 months	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

For statements rated 2 or less, please explain why you disagreed or what improvements could be made. For statements rated 3 or more, please explain why you agreed or what works well and should be maintained.

6. Please rate your level of agreement with the following statements from “Very Uncertain” (0) to “Very Certain” (5)

How certain are you that:

	0	1	2	3	4	5
The TABI Advisory Council will make positive changes for people with brain injury in Alaska	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Alaska is better off today because of the TABI Advisory Council	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

For statements rated 2 or less, please explain why you are uncertain or what can be done to increase your certainty.

7. TABI Advisory Council success in 1 year would be:

8. TABI Advisory Council success in 5 years would be:

9. Are there any accessibility accommodations we could provide to increase your engagement in the council? Yes/No

10. Please describe the accessibility accommodations we could provide.

11. Would you like to add any further comments or suggestions about the TABI Advisory Council?

Participatory Action Research (PAR) Model

The following is a description of the PAR model which may help to frame effective engagement for individuals with lived experience.

Science has long accepted the unique perspective of the individual with lived experience of brain injury. In 1985, famed neurologist, naturalist, and author Oliver Sacks noted in his seminal *Man Who Mistook His Wife for a Hat*, that such individuals' "inner state" or "situation" was important to their treatment. By noting that such an inner state was "unimaginably remote" from anything "even the most sensitive observer has ever known," Sacks implied the importance of patient participation in treatment.

In its, "Nothing About Us Without Us: Involvement in Research from the Perspective of Persons with brain injury and Family Members," the Brain Injury Association of America explains that, "a growing recognition that, in order to maximize the value of research, consumers must be engaged as collaborators" began with NIDILRR's (National Institute on Disability, Independent Living, and Rehabilitation Research) 1989 recognition of the need for use of the participatory action research model (PAR). These same principles can apply to participant engagement on advisory boards.

NIDILRR's ultimate adoption of the PAR was an attempt to close a 1980s "credibility and relevance" gap between the research and the individuals the research was aimed at helping.¹ Pursuant to PAR, research was only valuable if it "served the [empowerment and self-reliance] interests of its consumers," and "to do so consumers must be involved in the research from initial design of the project through ... actions arising from the research." William H. Graves, then NIDILRR director, noted that PAR did that work, "by involving individuals who have the most to gain from each research effort, more relevant questions will be asked and more relevant and appropriate intervention strategies will be developed ... better dissemination strategies will occur and more interest and commitment in using the product of the research endeavor will occur."

The ACL's 2021 Traumatic Brain Injury State Partnership Program (SPP) HHS-2021-ACL-AOD-TBSG-0070² states: "Individuals with TBI and other disabilities ... have the right to be engaged in and lead the decision-making processes related to their services and supports."

The draft tips above focus on the special steps that must be taken for members with lived experience to participate. Like other above noted ACL guidance, the tips must be balanced with the addition of an explanation or at least mention of PAR value-added intent behind the grant requirement that individuals with lived experience are part of advisory boards.

¹ University of Kansas, Beach Center on Families and Disability paper, "Participatory Action Research and Public Policy, <https://files.eric.ed.gov/fulltext/ED344358.pdf>

² <https://apply07.grants.gov/apply/opportunities/instructions/PKG00266188-instructions.pdf> p 6.