# Full Participation Guidelines Summary

Full Participation involves supporting individuals with brain injury by providing tools, resources, and supports so that they 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 grantees 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. This summary is intended to provide a brief overview on following this principle.

States and partners can establish the building blocks and practices conducive to full and meaningful participation to so that individuals with TBI and family members are equal partners in TBI Program activities, and there is a collaborative, team-based partnership of shared responsibilities and decision-making. By recognizing the inherent knowledge, experience, and expertise of individuals with TBI and family members and promoting their participation in leadership roles, organizations can foster an environment of full participation in all activities.

Effective recruitment and outreach involving individuals with TBI and family members can also help to create opportunities making the most of diverse backgrounds and available resources in all activities, through building a solid foundation.

Individuals with disabilities such as TBI may need supports or accommodations to optimally participate in training, meetings, or events. Modifications or provision of services and equipment may be necessary or helpful. Functional, physical, and cognitive accommodations can create a space which welcomes everyone. To assist in assessing the need for accommodations for individuals with TBI, a checklist of potential accommodations might be useful. This document can also be used in a variety of settings and with other populations of people with disabilities.

To build a solid foundation for full participation, it is vital to create an environment and work towards applying practices conducive to achieving this goal. Individuals with TBI and family members are equal partners in TBI program activities and can collaborate, share responsibilities and guide decisions. Focus on emphasizing respect, individuality, and equality across all activities. Recognize the inherent knowledge, experience, and expertise of individuals with TBI and family members by promoting their participation in leadership roles.

**Points to consider for full participation across workgroups, events and advisory councils:**
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?

# Appendix B: Accommodations Checklist

Full Participation Work Group: TBI Technical Assistance and Resource Center
Updated July 2020 (Created March 2008)

A person with brain injury can use 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). |
| | 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). |

| ✓ | Individual Experience | Barrier | Possible Accommodations |
|---|---|---|---|
| | 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 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. |