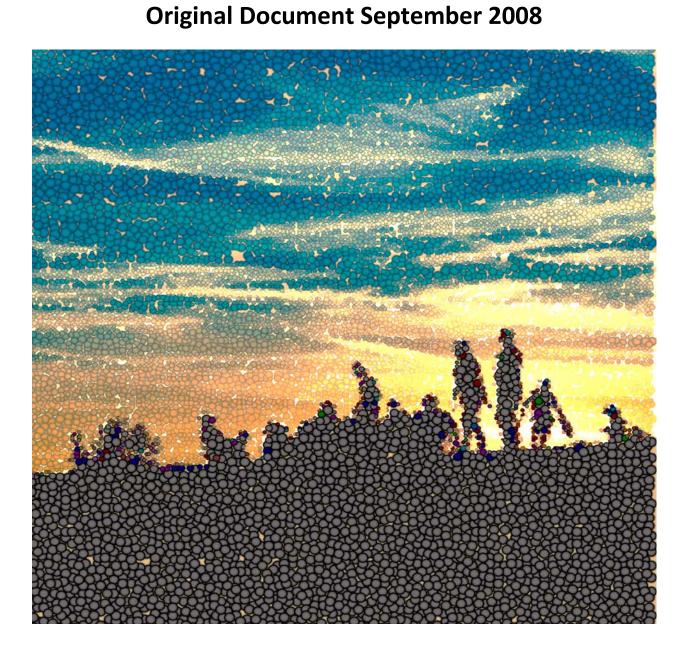






# Full Participation Guidelines Updated July 2020



Recommendations for ensuring meaningful engagement for individuals and family members in program activities

### Table of Contents

3
3
4
5
6
9
5
0
1
2
5

### Full Participation Guidelines: Purpose & Workgroup Members

#### Purpose

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 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 (<u>https://acl.gov/about-acl/administration-disabilities</u>). 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. ACL's TBI State Partnership Program (TBI SPP) funds lead state agencies to increase

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 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.

- 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, on-going 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.

- 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.

- 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.

- 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 <u>disabilityisnatural.com/people-first-language.html</u>

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.

- 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.

- 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.

- 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.

- 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, questions regarding several of the key elements of providing accommodations are 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 Accommodations Network: <u>askjan.org/soar.cfm</u>

#### 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 with disabilities". For more details on what is involved visit: <u>https://www.section508.gov/</u>. Websites and associated resources also need to be accessible as well, following Web Content Accessibility Guidelines (WCAG). For more information about this topics visit: <u>https://www.w3.org/WAI/standards-guidelines/wcag/.</u>
- 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 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.

#### TIP:

- 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\_Speaker s7-09-10.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: <u>biav.net/support-groups</u>

#### 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, Date: June 2020

### Appendix A: 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?

### 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 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).
	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.

✓	Individual Experience	Barrier	Possible Accommodations
	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 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.

✓	Individual Experience	Barrier	Possible Accommodations
	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.

### Appendix C: Resources for Accessible Virtual Meetings

Full Participation Work Group: 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 <u>rootedinrights.org/how-to-make-your-virtual-meetings-and-events-accessible-to-the-disability-community/</u>

#### 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

disabilityin.org/resource/covid-19-response-accessible-tools-and-content/ From Disability: IN's COVID-19 Response Series

#### 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 user, and hot keys and shortcuts.

# Holding Accessible Meetings – election focus *NOTE: Only PDF available*

<u>ifes.org/sites/default/files/inclusion insights holding accessible and inclusive virtual meetings.pdf</u> 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
- free download is available at https://mosen.org/zoom/

# Zoom tutorial overview with screen reader part 1: Joining a Zoom meeting and downloading Zoom

<u>youtube.com/watch?v=24PTpKILwMU&list=PLng32LADAwnqs1F7RNiANbueTs1uVz5S9&index=2&t</u> =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.

#### 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) Web: <u>blog.amara.org</u>

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

<u>3playmedia.com/solutions/how-it-works/how-to-guides/captions-subtitles-transcription-for-webex-</u> recordings/