

Making the Most of Lived Experience

By: Carole Starr, Kelly Lang, and Eric Washington for the National Center on Advancing Person-Centered Practices and Systems

People who live with the everyday challenges of brain injury have unique and valuable knowledge to help guide human service system improvements. But some symptoms can make it difficult for people with brain injury to participate on the teams and work groups that meet to discuss and plan improvements. Those with and without brain injuries share the responsibility to make lived experience understandable and actionable.

The following are tips that professionals* and people with brain injury can use to make the most of the lived experience of brain injury when collaborating on teams.

For Human Service Professionals

Be clear on the role of people with lived experience

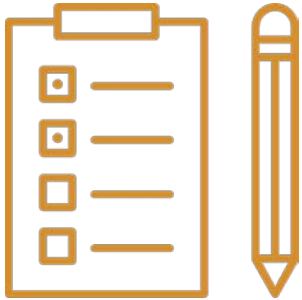
- Determine the specific questions you need answered or tasks completed by someone with lived experience.
- Be sure that these questions or tasks are appropriate to each person's knowledge, skills, and experience.

*People with brain injuries can certainly be professionals. We use the term "professional" here to describe the role of people who usually convene a group and contribute expertise or experience that is different from a lived experience of disability.

Offer reassurance to people with lived experience about the importance of their role on the team

- Recognize and confront “imposter syndrome.”
- Make people feel part of the team so that they are comfortable enough to offer and explain their story in the moments when it is helpful.

Give clear, concrete directions



- Break it down into “chunks” to make it easier to understand.
- Consider including the implicit “in between” steps that you might not always mention.
- Use concise visuals, such as a bulleted list, instead of long narrative or prose directions.
- Give people with lived experience time to prepare and complete tasks
- Don’t send or ask for information last minute.
- Make deadlines as far out as possible, with an opportunity to check in.
- Allow time for people with a brain injury to pace themselves as their needs and schedules require.

Allow for processing time

- Take a moment in a meeting or conversation to allow information to settle, especially when switching topics.

Recognize and respect different ways of communicating

- When talking to a person with brain injury, address the person rather than the person's caregiver/assistant who might be facilitating the communication.
- Recognize that some people may experience difficulty in word and memory retrieval.
- Be intentional in respecting those who communicates without words.



Keep conversations to one person talking, about one topic at a time

- Limit any crosstalk or switching back and forth between topics.
- Recognize that while this guidance applies to all groups, it's especially relevant for groups that include people with brain injuries. Members may have issues with sound sensitivity and be unable to filter background noise from the more important information.

Limit/minimize jargon

- Say or write out acronyms. It's not enough to do this only once.
- Be ready and willing to repeat explanations for concepts or words more than you might otherwise expect.

For People with Brain Injury

Focus on what you *can* do

- Honor the unique role you play on the team. Do not concentrate your energies on what you can't do or what others are already doing.
- Don't get caught up in trying to complete tasks, participate in conversations, or understand concepts that are unrelated to how you can help.

Understand your brain injury and accommodations needed to participate

- Know yourself and your brain injury. It's a process to recognize your personal challenges and the accommodations that work best for you.
- When you need an accommodation, speak up as early as possible, and be clear about what you need.
- Be prepared if your accommodations are not met. Know your limits and non-negotiables; don't push yourself to participate when you know it won't work.



Take the physical and mental breaks that you need

- Allow yourself extra time to recover and process information.
- Be aware of brain overwhelm/overload and stop when you need to.



- Remember that team projects are marathons not sprints. Pace yourself while keeping deadlines in mind. Taking breaks will help you participate fully and avoid poor decisions or doing low-quality work.
- Let your colleagues know signs that you might show when overwhelmed ahead of the time.

Be ready for feelings of grief

- Understand that your brain injury grief and loss might be triggered.
- Use strategies to process that grief in a healthy way, such as self-reflection.
- If necessary, ask for the time or other accommodation you need.

Know when to tell your story

- Your brain injury story is powerful, when used in the right context.
- But your story is not always appropriate to the task or question at hand.
- Listen and wait for the moment when your experience can meaningfully inform a conversation or decision.

Benefits and Challenges of Collaborating with People with Brain Injury on Teams

Benefits



- People with brain injury bring authenticity, credibility, tenacity, empathy, resilience, patience, strength, creativity, and unique insights.
- As people experienced with accessing and using supports, people with brain injury can provide a reality check and point out what are realistic and unrealistic expectations.
- The results of team activities are more likely to benefit people with brain injury.
- People with brain injury can leverage their networks and bring perspectives from their peers.
- Making teams more accessible benefits all team members, not just people with brain injury.

Challenges



- No matter how diverse the team is, it is impossible to fully capture the perspectives of all people with brain injury.
- People with brain injury may experience fatigue, memory issues, and other cognitive and emotional challenges that make participation difficult. These challenges can be different from day to day.

- It's a process to make sure that people with brain injuries feel welcomed and valued as contributing members of the team. Roles and expectations for team members with brain injuries need to be thought out and communicated. Insufficient engagement could result in people feeling isolated, frustrated, self-critical, or bullied.
- People with brain injuries often need extra time for sharing and processing information.
- When the content is technical, it's more difficult to reduce jargon and complexity.
- Strategies are needed for full inclusion of people with significant disability—for example, those who communicate without words.

National Center on Advancing Person-Centered Practices and Systems

Visit us at <https://ncapps.acl.gov/> | Email us at ncapps@hsri.org

The National Center on Advancing Person-Centered Practices and Systems (NCAPPS) is an initiative from the Administration for Community Living and the Centers for Medicare & Medicaid Services that helps States, Tribes, and Territories implement person-centered thinking, planning, and practice in line with U.S. Department of Health and Human Services policy. The goal of NCAPPS is to promote systems change that makes person-centered principles not just an aspiration but a reality in the lives of people who require services and supports across the lifespan.

