

Making the Most of Lived Experience

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People who live with the everyday challenges of brain injury have unique and valuable knowledge to inform human service system improvement efforts¹. However, the symptoms of brain injury can make participating on teams challenging. Those with and without brain injuries share the responsibility to make lived experience understandable and actionable. The following are tips for supporting professional and people with brain injury to make the most of the lived experience of brain injury when collaborating as a team.

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

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 bullet point list, instead of long narrative or prose directions.

¹ 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.



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
- Make time to allow pacing as appropriate, and on the schedule of the individuals participating

Allow for processing time

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

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

- Limit any crosstalk or switching back and forth between different 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 that 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 specific accommodations that work 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.

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
- 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

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.

