

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 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.

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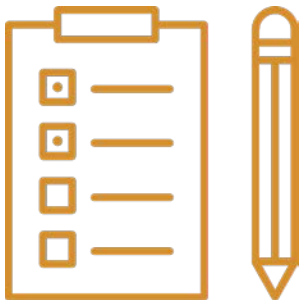
https://ncapps.acl.gov/docs/BI_LivedExperienceTipSheet%20200402v2.pdf



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



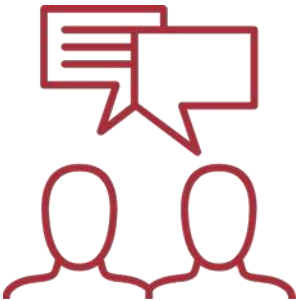
- Break it down into “chunks” to make it easier to understand.
- Consider including the implicit “in between” steps that you might not always mention.
- Use concise visuals, such as a bulleted list, instead of long narrative or prose directions.
- Give people with lived experience time to prepare and 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.

National Center on Advancing Person-Centered Practices and Systems

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