

# 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 people with brain injury can use to make the most of the lived experience of brain injury when collaborating on teams.

## 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.

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\*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.

## 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**

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