



Survivor Engagement Lessons from The TAL-Group's Advocacy Journeys

On April 29, 2020 the Traumatic Brain Injury Technical Assistance and Resource Center held the kickoff meeting of the TBI Advisory and Leadership Group (TAL-Group). The TAL-Group, which guides the Center's priorities and assists with activities, is composed of nine survivors of brain injury: Kaitlyn Behnke, Anne Forrest, Clifford Hymowitz, Cheryl Kempf, Martin Kerrigan, Kelly Lang, Carole Starr, Ann Zuccardy, and Eric Washington. Co-led by Kelly Lang and Carole Starr, the TAL-Group will meet semi-annually. The goal of each meeting is to discuss areas that can be used to provide guidance to the TBI State Partnership Program grantees. Below is a summary of the discussion regarding lessons learned from the members' journeys as survivor leaders.



The importance of other people. Brain injury survivors usually don't become advocates all on their own; survivors need to be supported and encouraged by others—individuals and organizations. Engaged survivors are developed through successful participation in things like peer mentoring programs, brain injury support groups, speaker bureaus, and volunteering.



The value of a personal invitation. Unlike a blanket email looking for survivors to be part of committees, a personal invitation—especially from someone the survivor knows, looks up to, and trusts—makes one feel wanted and more likely to participate.



The importance of acceptance. It is important to understand that survivors need time—they are experiencing a great deal of grief and it may take some time for them to be ready to be advocates. It's a journey that happens slowly, in stages. Offer specific, small

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opportunities for people to get involved that meet them where they are, so they can grow gradually into larger advocacy roles. Success at small tasks can grow into success at larger tasks.



The role of support. Because survivors often feel “less than,” they may need some “hand-holding” to be part of teams and encouragement to recognize ways they can contribute and use their story. Survivors feel alone in their injury. They don’t want to feel alone on committees too. They want to feel that their lived experience is valued, listened to and acted upon, that they are not there as a “token”.



The recognition that advocacy can help with finding meaning after brain injury. For some survivors who choose to participate on committees, it can be about more than the work of the committee. It can be a place to go, a role, an opportunity to use one’s story to help others and find a new identity as a brain injury advocate.

ABOUT TBI TARC

The Traumatic Brain Injury Technical Assistance and Resources Center (TBI TARC) is an initiative from the Administration for Community Living that helps TBI State Partnership Program grantees promote access to integrated, coordinated services and supports for people who have sustained a TBI, their families, and their caregivers. The Center also provides a variety of resources to non-grantee states, people affected by brain injury, policymakers, and providers.

