

## **Better Together: Brain Injury Survivors Building Community & Making a Difference Q&A**

**Q: I am curious to know, have any of you been discriminated against/treated differently after the TBI?**

Kelly: I have not been treated differently or discriminated but I have watched this happen to my daughter multiple times. She was 3 years old at the time of her injury and at every level of school (preschool, elementary, middle, high school, and community college) she experienced ridicule, teasing, bullying, and being treated as "less than". She was called stupid, slow, retard, and other derogatory names. Unfortunately, this has all influenced her self-esteem and self-worth.

**Q: My one question I wish this panel could answer is how does a person with a brain injury process rejection or a lack of acceptance from their own family when what the individual is dealing with on a daily basis is real and in need of support and not suppression?**

Kelly: This is a hard question. It is difficult when our own families do not recognize or acknowledge our injuries. My experience has been to keep talking about it and advocating for yourself. It sometimes takes a long time for family members to accept it whether it is because they feel guilty, don't recognize the signs, or are in denial. I would also suggest talking with a case manager or therapist who may have tools to help you manage the feelings.

**Q: Did you organize yourselves as a survivor group and coordinate/facilitate your own meetings or did you ask a mentor to help organize and/or facilitate or coordinate your regular meetings? And did you practice this presentation ahead of time?**

Kelly: At the beginning of the Collaborative Carole Starr, Eric Washington, and I spoke and decided to develop this group to support one another. NCAPPS gave us the zoom meeting time and we did everything else. The three of us met each month to discuss what topic area was relevant and planned the discussion whether it would be a "fishbowl" discussion or a round-robin. A fishbowl has a few people highlighted who talk about their experiences and afterward the remainder of the group joins in. There was a core group that came each month, and we built a strong network among us which I hope we will be able to continue in some form.

**Q: Do y'all have any recommendations for working with and advocating for TBI survivors virtually and over the phone during COVID when certain organizations have a policy of not meeting people in person, especially for TBI survivors who are not tech savvy? How did y'all work around this for your project?**

Kelly: I attended the meeting virtually before and knew the Collaborative would be virtual since there were teams all over the country. I did not have a problem with the technology. Some need to adjust their screens to compensate, others turn off their cameras to give their eyes a rest, and others take breaks when possible.

**Q: Are there federally/state funded organizations for TBI survivors?**

Kelly: Most states have associations, alliances, or other brain injury organizations and the funding can be federal, state, and/or local. Each state has unique systems in place. Some of these provide advocacy, case management, support, and programming. The Brain Injury Association of America has a resource coordinator who can direct you as well.