



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

Summary of a webinar from October 5th, 2021

### Introduction

In this webinar, brain injury survivors talked about the NCAPPS [Brain Injury Learning Collaborative](#). Learning Collaborative teams include people with brain injury. Fifteen states joined the Learning Collaborative. They worked to make brain injury services more person-centered.

### What was the Learning Collaborative like?

Carole said in the beginning, “We felt like we were drowning...this was too much.” Brain injury survivors felt overwhelmed with the number of meetings and e-mails. They weren’t sure how they fit it. Austin wondered, “Where do I fit in? What’s my purpose? What am I doing here?” Some people even wanted to quit.

Even so, they were excited. Amy said, “There was some excitement in being involved in such an important project. And such a much-needed project to better serve people.” Rodney said, “I decided to get really involved, as much as I could, with the group. Started speaking more and voicing my opinion more.” Kelly said, “We developed this support network for ourselves. We could talk about things with each other because we could understand what each of us was going through.”

### How can brain injury survivors be involved in collaboratives?

The speakers had ideas about how survivors could be involved. Amy says to take baby steps at the beginning of a project. Maria says, “Reach out for help to advocate for yourself early and often.” Kelly found the support of the group helpful. She said, “You can do more together, rather than trying to do it all alone.” They also came up with their own tools. They used Google calendars or sticky notes.

Speakers had ideas about how groups could include brain injury survivors. The instructors had a monthly meeting for survivors to share their feedback. Carole says it’s important to know where people are on their journey. Austin says to ask brain injury survivors what would help them participate. He says, “Don’t just ask, listen to what they say. It might not meet your expectations. Remember, they have more personal experience with this.” Rodney says you can give people different options like small tasks that they can work on. Maria said she would like to see more people from different communities be involved.

The speakers on this webinar were:



**Kelly Lang** has been a brain injury survivor, caregiver, and advocate for 20 years. She served on the board of the Brain Injury Association of Virginia for 6 years and was recently on the faculty of the NCAPPS Brain Injury Collaborative. Kelly is currently a member of the Brain Injury Association of America's Advisory Council and the Virginia Brain Injury Advisory Council. Kelly has also presented to local, state, and national groups.



**Carole Starr** sustained a brain injury in a car accident, which left her unable to return to her life as an educator and classical musician. Over time, Carole reinvented herself. She's now a national keynote speaker, the author of the award-winning book *To Root & To Rise: Accepting Brain Injury* and the founder/facilitator of Brain Injury Voices, a nationally recognized survivor volunteer group. Carole is a member of the NCAPPS faculty.



**Eric Washington** sustained concussion and spinal cord injury while playing football for the University of Kansas. After recovering from his injury, he graduated with a bachelor's degree in Applied Behavioral Sciences. Today, he is a passionate advocate for TBI survivors of color, and TBI survivors who are homeless. Eric served as a faculty member on the NCAPPS Brain Injury Learning Collaborative and was particularly instrumental in supporting brain injury survivor support groups in Colorado.



**Austin Duncan** is a severe TBI survivor and medical anthropologist working with the Sonoran Center for Excellence in Disability and Department of Pediatrics at the University of Arizona. His NSF-sponsored research focuses on the sociological intersections and public policies of neurological disabilities, including Traumatic Brain Injury (TBI). He teaches courses in disability studies to students with the UA College of Medicine and College of Social and Behavioral Sciences.



**Maria Martinez** holds degrees in Art Education and English as a Second Language from University of Northern Colorado. She has worked in the fields of domestic violence and corrections. Maria is a survivor of a stroke and a brain injury. Maria is a support group leader, peer mentor, brain injury advocate and non-profit Director. She is a board member of the Colorado Advisory Board, Professional & Lived Experience Contributor to the NCAPPS Learning Collaborative and National TBI TARC.



**Amy Robinson** is a proud parent/caregiver and advocate for her 11-year-old son who has multiple special health needs. She is also an assistant professor in the Department of Communication Sciences and Disorders at University of North Dakota (UND) where she supervises support groups for patients with an aphasia diagnosis. Prior to UND, Amy spent 20+ years working for Robbinsdale, MN public schools as a speech-language pathologist. She regularly consults with North Dakota Brain Injury Network and received her Certified Brain Injury Specialist (CBIS) certification in Spring of 2020.



**Rodney Smith** is a U.S. Army veteran, father, grandfather, and TBI survivor and advocate. He sustained brain injury when a pickup truck failed to see him and crossed the road in front of his motorcycle. Rodney got involved with the Brain Injury program in West Virginia with the hope that he could help people with TBI, and their families have better lives and avoid the frustrations he went through trying to find right help after his accident.