

# Organization SPOTLIGHT: Brain Injury Association of Delaware

## Introduction

The Delaware Statewide Independent Living Council (DE SILC) is pleased to present its first organizational SPOTLIGHT feature. SPOTLIGHT focuses on disability organizations in Delaware and highlights the services and supports they offer to assist people with disabilities and their family members. By gaining knowledge through these Spotlight articles, readers can learn more about the organizations. Disclaimer: The Delaware Statewide Independent Living Council is only responsible for the information it creates on its website. For this month's organizational SPOTLIGHT, the

### [Brain Injury Association of Delaware](#)

was interviewed. Cheryl Doucette, Executive Director, and Amy Kratz, peer support group leader, were our featured guests. Additional information was received from members of the Board of Directors President Dr. Terry Harrison-Goldman and Vice President Stefanie Lancaster. Keep reading to learn more about the Brain Injury Association of Delaware!

## Background – Fast Facts About Traumatic Brain Injury (TBI) Statistics

This SPOTLIGHT begins with some TBI facts. According to a Delaware Division of Public Health [traumatic brain injury stats document \(PDF\)](#),

approximately 1.4 million traumatic brain injuries occur annually. A traumatic brain injury can result from a penetrating injury or blow to the head. Brain Injury Association of Delaware's Board of Directors President Dr. Harrison-Goldman shared with us the following information about the leading cause of brain injury: "This tends to depend on age. But the leading causes are falls, motor vehicle accidents, public or domestic violence, combat injuries, and sports injuries."

Board of Directors Vice President and brain injury survivor Stefanie Lancaster added: "53.11% of all brain injuries incurred in Delaware are due to Falls. 18.35% is due to Motor Vehicle accidents." Another fact is that it is important to effectively communicate with people who experience traumatic brain injury.

## Tips and Strategies for Promoting Successful Interactions

People living with a *traumatic brain injury* (TBI) face a range of challenges. These can include physical, cognitive, or sensory issues. For many survivors, a term which many with brain injury prefer to use, one aspect that can be frustrating in their recovery is a lack of or misunderstanding from family and friends. Additionally, misconceptions held by the general community can be problematic. Representatives from the Brain Injury Association of Delaware suggest the following tips and strategies for promoting successful positive interactions.

- First, treat individuals with a TBI just as you would any other person. They are still a person with feelings, opinions, and goals. Respect is of utmost importance.
- Treat them as an adult if they are an adult.
- As tempting as it is to do everything for a loved one, or to jump in to ‘help,’ to relearn tasks and skills, repetition and practice are needed. This makes it important for survivors of TBI to actively participate in daily activities. Encourage them to perform some tasks on their own. Instead of assuming they need assistance and automatically delivering support, ask first.
- Apathy and lack of motivation can be a common occurrence in recovery secondary to changes in cognitive functions. It is important to think about how to positively encourage the individual to practice (without stating “you need to be more active”).
- We naturally want to comfort those who have been hurt, but we need to think about the language we use and the impact our words may have. For example, language such as “Don’t worry, I forget things all the time too.” For someone who is experiencing memory problems after a TBI, this may not be helpful and can even seem patronizing. Keep in mind that the differences between normal forgetfulness and memory problems after brain injury are very different.
- Be patient. Many individuals with TBI may take a while to collect their thoughts and share what they are trying to say. Listen and try to provide resources and tips to help them share their thoughts.
- Be understanding as they may ask you to repeat things often. They too might say the same thing over and over.

Assumptions, myths, stereotypes, and misinformation often impede our interactions with individuals with disabilities. You play a key role in the interaction. Be respectful, patient, and kind. One of the Brain Injury Association of Delaware’s crucial services is its support groups.

## Brain Injury Association of Delaware – Support Groups

The Brain Injury Association of Delaware (BIADE) offers five support groups; two virtual and three in-person. Meetings are open to people with brain injury, their family and friends, partners of people with brain injury, and caregivers. The team is looking to expand the groups to include a unique hybrid model that would offer support specifically geared to the caregiver.

To facilitate trust, which is an essential element for successful peer support services, BIADE embraces a dynamic where the group leader is a brain injury survivor and a peer. Cheryl Doucette, BIADE's Executive Director, shared: "Amy Kratz, who facilitates our peer support groups, is not talking at the members, she's talking with them. She's sharing her struggles. In turn, they share their struggles. Amy stated: "By listening to other survivors and hearing their stories members build a special connection. They have the unique opportunity to compare their journey to recovery and benefit from hearing each person's experience, the resources they have untapped, and the creative solutions they have discovered. It's all about sharing; it's empowering!" Executive Director Cheryl Doucette added: "Amy single-handedly really kept the light and the fire going with our support groups through the pandemic when most organizations literally shut down and discontinued their services. Amy was like, no, we're doing this!" Amy transitioned their support group to an online format. Their Zoom presence has been so successful that even when they went back to in-person meetings, they kept that Zoom group operational because the participants were so connected. Many with TBI find travel and in-person exhausting, so members responded well to sitting in their own living room while interacting with their peers." Another of the Brain Injury Association of Delaware's connection services is an annual conference.

## Brain Injury Association of Delaware – Annual Conference

Every year, the Brain Injury Association of Delaware hosts an Educational Conference. The goal is to educate, recognize, and celebrate! The program offers a wealth of information to the diverse audience impacted by TBI: survivors, caregivers, and the many professionals who serve this community. CEUs are offered, and recognition is given to the many businesses and individuals who have really helped the organization throughout the year. The highlight of the event is the survivor's celebration which recognizes individuals and businesses that have helped BIADE throughout the year. BIADE also provides monthly educational webinars, The Educate Delaware series, which is funded by Highmark. The next program will highlight Wade Scott from Delaware Elder Law who will share critical legal information and walk participants through the maze of forms that are often necessary. One important aspect that BIADE recognizes is that those with TBI often require more flexibility when events are scheduled. In addition to programs being offered live, an on-demand component is available. This SPOTLIGHT concludes with BIADE's vision for the future and their contact information.

## Brain Injury Association of Delaware – Vision for the Future

The organization's goal for the future is to become a nationwide hub of information for people who have brain injuries. Cheryl Doucette shared that it is "the agency's vision to become a hub site providing a one-stop shop for any brain injury survivor and their family. We are currently

seeking funding from Highmark and other donors to implement a Customer Relationship Management System (CRM). Our plan is to establish a formal navigation system where all patients being discharged from the hospital or an acute facility are referred directly to us so that we can immediately share that message of community and hope. To communicate that we care and that we are here for them. This level of engagement goes beyond simple information and referral. During that initial connection, we would listen to understand their needs and then point them in the right direction to the services they require. In addition, we would initiate follow-up in 30, 60, 90, 120 days to ensure they got that help because that is often the missing link. “So, really our goal is to become that navigation hub having trained professionals in all three counties - Kent and Sussex County and New Castle. The service delivery system for individuals with TBI and their families is put together with bubble gum and duct tape; the concept of the navigation hub would provide a solid foundation of resources and services aimed at meeting the individuals' specific needs.”

#### Contact Information

If you would like to learn more about the Brain Injury Association of Delaware, you can check out the following:

[Brain Injury Association of Delaware website,](#)

[Brain Injury Association of Delaware Facebook page,](#)

[Brain Injury Association of Delaware on Twitter,](#)

[Brain Injury Association of Delaware on LinkedIn](#)

and

[Brain Injury Association of Delaware's YouTube channel.](#)

**Stay tuned for the Delaware Statewide Independent Living Council's next SPOTLIGHT!**