

Advocacy Recommendations to BIC from PODD

Priority

1. Survivor Service:

- **Problem:** At this time, there is no mechanism in Delaware set up to receive referrals and provide support to a survivor of a brain injury, or their caregivers, to help them access services. This care is critical because DE brain injury survivors, are in need of a more accurate plan/schedule of monitoring and care from initial injury forward, to ensure an optimal level of, and opportunity for, complete rehabilitation and recovery.
- **Statement of Need:** We know from the DHIN data that only 14% of Delawareans receive follow up care within the critical first 30 days following a moderate or severe TBI.
- **Proposal:** Advocate for funding to establish a tracking system. The tracking system should ensure survivors of a TBI are followed in their treatment and are receiving appropriate services to ensure appropriate follow up care in a timely manner. Develop a Brain Injury Services Navigation Program to address this gap and facilitate greater independence in the community for these survivors. **Recommend BIC adopt as a priority.**
- **Examples:** A brain injury survivor often has difficulty retaining information and or processing multistep instructions. This creates a cognitive gap. The survivor needs coordinated follow-up to ensure all appropriate treatments and therapies are administered. This may incur weeks of follow-up or years.

2. Provider training

- **Problem:** Lack of appropriate brain injury specific training for medical providers and affiliated staff to recognize that symptoms are related to a previous brain injury.
- **Statement of Need:** There is a great need in Delaware to develop legislation mandating basic brain injury training for medical providers and affiliated staff.
- **Proposal:** Create legislative mandate to increase required brain injury education for state nursing programs, medical provider credentialing, and affiliated staff certification to increase training for recognition and treatment of brain injury patients. E.g., Certified Brain Injury Specialist (CBIS). **Recommend Policy & Law Committee adopt as a priority and draft legislation in collaboration with the BIC.**

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- **Example:** BI survivors often get misdiagnosed or dismissed due to a lack of understanding of the way the brain changes when a person incurs a brain injury. Symptoms often present in multiple minor ways that may be missed by a provider unless they receive appropriate training. Partner with BIADE to bring the BIAA CBIS training to Delaware as an opportunity for Medical and Insurance Provider staff, First Responders, Educators and others dealing directly with BI survivors to learn more about diagnosis, treatment, sequelae, and the benefits of brain injury specific training and ongoing care.

3. Intake/Discharge Process:

- **Problem (1):** People with brain injuries are not being screened appropriately for mental health issues.
- **Statement of Need:** Develop brain injury specific mental health screening.
- **Proposal:** Request legislation requiring minimum screenings and funding dedicated to adapting hospital and provider intake forms to include screening for behavioral issues directly related to sustaining a traumatic brain injury. **Recommend Policy & Law Committee adopt as a priority and draft legislation in collaboration with the BIC.**
- **Examples:** When an individual incurs a brain injury it changes the way the brain operates. Brain injury survivors typically have at least some cognitive impairments, but it is different from typical mental health diseases and needs to be addressed differently.

4. Intake/Discharge Process:

- **Problem (2):** Delaware brain injury data shows that brain injuries are not being appropriately tracked especially when listed as the 2nd or 3rd diagnosis.
- **Statement of Need:** Medical professionals must redesign intake forms to ask patients if they have **ever** had one or more concussions/brain injury to track incidents of brain injuries more adequately.
- **Proposal:** Advocate for in-take forms to ensure use of appropriate brain injury codes when entering data on patients to diagnose current or historical symptoms related to brain injuries. (Critical particularly in Emergency Departments and with new providers.) **Recommend that BIC adopt as a priority.**

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- **Examples:** If an individual is in some type of accident, they may incur multiple injuries. Medical Personnel will triage the patient for the most urgent/serious injury and treat that first. Often a concussion or related brain injury may not be the most critical at the time. However, due to the nature of a brain injury the patient will need specific follow-up care. If the patient isn't screened for a brain injury in order to enter a diagnosis noting the brain injury, then the follow up care doesn't occur.

5. Intake/Discharge Process:

- **Problem (3):** Lack of a lifelong tracking and monitoring system for brain injury survivors, starting at initial injury.
- **Statement of Need:** Recognize the chronic, long term, life altering effects of all types of Brain Injuries, and emphasize the need to track and anticipate the potential symptoms and side effects.
- **Proposal:** To establish a system to track brain injury survivors following their initial brain injury care throughout their lifetimes. **Recommend that BIC work with partners to establish this system.**
- **Example(s):** Utilize tracking systems available for other recognized Lifelong Disease and injury monitoring, and redesign for use with BI survivors.

6. Intake/Discharge Process:

- **Problem (4):** People with brain injuries are not receiving appropriate and timely follow-up care for their long-term chronic disabilities caused by their brain injury.
- **Statement of Need:** Delaware needs a Brain Injury Navigator/Case Management Program to follow persons with brain injuries over the course of their lifetime, to track treatments using appropriate brain injury codes.
- **Proposal:** Develop a statewide continuing program to ensure that navigators/case managers are receiving appropriate brain injury training to recognize diagnoses that are a direct result of the survivor's original brain injury and to establish a system to track brain injury survivors following their initial brain injury care throughout their lifetimes. **Recommend that BIC work with partners to establish this system.**

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- **Examples:** In addition to ensuring brain injury survivors are receiving all necessary follow up care a case manager can ensure they are also managing the other social determinants of health such as housing, transportation, adequate food, safe living quarters, etc.

7. Insurance

- **Problem (1):** Insufficient coverage for brain injury survivors to get needed community-based coverage to include advancing treatment options throughout their lifespan.
- **Statement of Need (1):** Need to expand current insurance coverage to ensure all necessary treatments and follow-up care are provided to brain injury survivors to include long-term care and support services (LTSS) in the community for brain injuries which are life-long injuries.
- **Proposal (1):** Advocate and work with Legislators, stakeholders, and insurance providers offering data to inform and make necessary changes in coverage for brain injury survivors. **Recommend Policy & Law Committee adopt as a priority and draft legislation in collaboration with the BIC.**
- **Example (1):** Brain Injury Survivors are not always coded correctly and are therefore not receiving appropriate treatment. Severe Concussions or mTBIs and TBIs are not followed through the life of the survivor. E.g., Causation for many known symptoms of brain injuries is not linked back to the original brain injury. E.g., Seizures typically occur years later and are not linked to the original brain injury as causation.

8. Insurance

- **Problem: (2):** Medical providers who are not certified in brain injury treatment frequently treat new symptoms as new illnesses instead of as a direct cause and effect of a previous brain injury. Noting the connection is important. Providers working with brain injury survivors need to have staff qualified and educated in brain injury diagnosis and care to understand and advocate for the specialized needs of their survivor patients and the required services for rehabilitation and recovery.
- **Statement of Need (2):** Brain Injury Survivors need someone at their medical provider's facility who understands the significance of seemingly unrelated symptoms and how they arise from the brain injury not a mental health condition. Expand availability of the Certified Brain

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Injury Specialist Certification (CBIS) training program so that it is easily and affordably available to Provider staff.

- **Proposal (2):** Advocate for a change in the regulations regarding certification of a provider to require someone from their facility to complete Certified Brain Injury Specialist (CBIS) certification.
Recommend Policy & Law Committee adopt as a priority and draft regulations in collaboration with the BIC.
- **Example (2):** A provider treating a survivor of a brain injury for a shoulder injury, may not realize that the person is unable to follow a standard written home exercise program but may need instructions to include pictures to facilitate compliance. A majority of brain injury survivors are misdiagnosed with a mental illness following their injury. New symptoms related to the brain injury are significantly increased with the increased risk lasting as long as 15 years from the injury date. Long-term effects include Memory loss, Mood swings, Impaired language skills, Coma/loss of consciousness, Loss of sensation in the extremities (fingers, toes, etc..) Increased risk of stroke/seizure, Impaired cognitive function, and sleeping issues.

9. Insurance

- **Problem (3):** Insurance providers are not currently working with Alternative therapy providers whose services benefit brain injury survivors but are not covered by insurance.
- **Statement of Need (3):** Brain Injury survivors need insurance providers to restructure coverage for brain injury care and services to include alternative therapies and increased length of coverage to provide for long-term rehabilitation and recovery.
- **Proposal (3):** Advocate with insurance providers to address and eliminate barriers to payment of medically necessary services and treatments for diagnosed individuals with brain injuries. **Recommend that BIC adopt as a priority.**
- **Proposal (3a):** Advocate for insurance providers to restructure coverage to include at least minimal initial alternative therapy options to adequately track whether the alternative therapy is viable for continued coverage. **Recommend that BIC adopt as a priority.**
- **Proposal (3b):** Advocate for insurance providers to restructure coverage for brain injury care and services to provide an increased

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length of coverage to allow for long-term rehabilitation and recovery.
Recommend that BIC adopt as a priority.

- **Example (3):** Currently SPECT Scans and Neurofeedback therapy is not covered by insurance but assists medical providers in improving their plan of care by showing specifically where brains are impacted. Additionally, brain injury patients are able to maintain their rehabilitative status and improve with minimal sessions of on-going PT, OT, and SLP.

10. Disability Discrimination – HB No. 199

- **Problem:** Delawareans with brain injuries are being discriminated against solely because of their diagnosis.
- **Statement of Need:** Add Delawareans with brain injuries to the Delaware Disability Law.
- **Proposal:** Advocate for Delawareans with brain injuries to be included in the Delaware Disability Law in the Delaware Code to prevent discrimination by professionals in the executive, legislative, and judicial branches, as well as by public and private service providers.

Recommend Policy & Law Committee adopt as a priority and draft legislation in collaboration with the BIC.

- **Example:** Frequently life situations for brain injury survivors result in impediments and violations of their rights to life, health, education, freedom of expression, benefits from scientific progress, enjoyment of life in the community, family life, and equality. Impediments and violations of the rights of people with brain injuries are often hidden since they may not be in a position to advocate for themselves. Family members are often burdened with grief over the loss of the pre-brain injury person and the demands of care for the post brain injury person. Even within the disability community issues affecting brain injury survivors are largely invisible and marginalized. See this article: <https://www.hhrjournal.org/2020/06/the-neglect-of-persons-with-severe-brain-injury-in-the-united-states-an-international-human-rights-analysis/>.

11. Funding:

- **Problem:** Insufficient funding for continued prevention, outreach, and data development.
- **Statement of Need:** Advocate to obtain permanent legislative funding for Brain Injury Initiatives.

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- **Proposal (1):** Establish permanent funding for specialized provider services and brain injury specific programs for survivors; E.g., Make the TBI Fund permanent in the Delaware Code. **Recommend Policy & Law Committee adopt as a priority and draft legislation in collaboration with the BIC.**
- **Proposal (2):** Establish permanent funding for Acquired Brain Injuries (ABI). **Recommend Policy & Law Committee adopt as a priority and draft legislation in collaboration with the BIC.**
- **Examples:** Brain injuries are a chronic condition that require life-long care. Dedicated funding is critical to the continuity of care for brain injury survivors (both ABI and TBI) to ensure appropriate services are available, procedures are followed, and accommodations are made to ensure the best possible outcomes for the full reintegration of brain injury survivors into the community. Need funding in order to produce, print, and disseminate flyers, fact sheets, videos, and public awareness campaign on brain injuries in Delaware.

12. **In state facilities:** Construction of new facilities is a multi-partner/multi-agency/expensive endeavor.

- **Problem:** Statistics show a significant number of DE BI survivors are forced to seek out-of-state, post-acute rehabilitation facilities, due to the lack of in-state trauma level centers which is difficult on the survivor and the families.
- **Statement of Need:** There is insufficient in-state programs, long-term care rehabilitation centers and facilities focused and certified to treat brain injuries.
- **Proposal:** Advocate for the development of in-state treatment programs using available data in order to attract facilities who will provide/build in-state rehabilitation and long-term care facilities for brain injury survivors. **Recommend that BIC work with partners to establish this system.**
- **Examples:** Create business and tax incentives to encourage large facilities in the region to open satellite or full facilities in Delaware.

13. **Congressional Brain Injury Task Force** Completed 5/13/22 -- Lisa Blunt-Rochester

- **Problem:** Without appropriate representation on the Congressional Brain Injury Task Force, Delaware brain injury survivors are not a part of the national conversation to improve the lives of brain injury survivors.

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- **Statement of Need:** Delaware does not have representation on the Congressional Brain Injury Task Force.
- **Proposal:** Request at least one representative from Delaware's Congressional Delegation or a representative from Delaware to the Congressional Brain Injury Task Force. **Recommend that BIC & SCPD work with partners to write letters requesting designation of a representative from Delaware to the Congressional Brain Injury Task Force.**
- **Examples:** The **Congressional Brain Injury Task Force** was co-founded by Rep. Pascrell in 2001. First and foremost, the task force strives to increase awareness of brain injury in the United States. It also supports research initiatives for rehabilitation and potential cures. Lastly, it hopes to address the effects these injuries have on all Americans, including children, members of the Armed Forces, and athletes. Pascrell also personally advocates for funding programs at the Department of Defense that go towards TBI research and treatment, such as the Psychological Health and Traumatic Brain Injury Research Program, the Defense and Veterans Brain Injury Center, and the National Intrepid Center of Excellence. [What Is the Congressional Brain Injury Task Force? \(advancedrm.com\).](#)
- **Why don't we already have representation?**

No one from Delaware's Congressional Delegation has joined the **Congressional Brain Injury Task Force** and neither has anyone from Delaware.

The mission of the Congressional Brain Injury Task Force is to further education and awareness of brain injury and support funding for basic and applied research, brain injury rehabilitation, and development of a cure. Please join the Task Force to help make life better for individuals with brain injury and their families. [Join the Congressional Brain Injury Task Force | BIAA \(biausa.org\)](#)
- **Is this a National-level task force?**

Yes, see attached list of the Congressional Brain Injury Task Force's current membership.