BRAIN INJURY ADVISORY BOARD ANNUAL REPORT

2024

Table of Contents

Preface **2**

Brain Injury Advisory Board Overview **2**

Brain Injury Data **3**

Brain Injury Program Report **4**

PA DOH State Funded Programs

Head Injury Program **5**
Pre-enrollment Assistance **6**

Title V Maternal and Child Health Services Block Grant Funded Programs

Acquired Brain Injury Program **6**
BrainSTEPS Program **7**
Opioids and Brain Injury Training Program **8**
Safety in Youth Sports Training Program **9**
Shaken Baby Syndrome **9**

Administration for Community Living Funded Programs

NeuroResource Facilitation Program **9**
Intersectionality of Domestic Violence and Brain Injury **11**
Brain Injury Outreach, Training and Technical Assistance **13**
Brain Injury Advisory Board Workgroups **13**

PA DHS State Funded Programs

OBRA Waiver **17**
Community HealthChoices **17**

Brain Injury Partners

Brain Injury Association of Pennsylvania **19**
Model Systems **21**
Brain Injury Coalition **22**

Resources **23**

Preface

In Pennsylvania, the prevalence of traumatic and non-traumatic brain injuries highlights the urgent need for comprehensive services, support and advocacy. Needs and challenges exist in all parts of the state, including both urban and rural settings. It is necessary for us to address these challenges head-on and ensure that every Pennsylvanian affected by brain injury receives the support and resources they need to live an everyday life.

This annual report summarizes the efforts being made by a variety of stakeholders to meet the needs of the citizens of Pennsylvania impacted by the effects of brain injury. It chronicles the efforts to raise awareness, advocate for policy change, and provide essential services to those in need, throughout the state.

Board Overview

The Department of Health (Department) formed the Traumatic Brain Injury (TBI) Advisory Board (Board) in 2000 to support the responsibilities essential to the Health Resources & Services Administration (HRSA) Planning and Implementation Grant process, which became the Administration for Community Living (ACL) TBI State Partnership Grant. The Department has continued to support the Board while utilizing HRSA and Administration for Community Living (ACL) funding for other TBI programming.

In December of 2023, the Board received approval from the Secretary of the Department of Health to officially change the Board's name to the Brain Injury Advisory Board. This change aligns with the Board's commitment to inclusivity and facilitates a more understanding and responsive approach to the diverse challenges encountered by individuals affected by all forms of acquired brain injuries.

The Board consists of 22 voting members and is comprised of a variety of stakeholders representing:

- Individuals with a brain injury
- Family members and caregivers of individuals with a brain injury
- Community-based organizations in brain injury service provision and advocacy
- Researchers
- State agencies and offices
- Disability Rights Pennsylvania
- Rehabilitation and Community Providers Association (RCPA)

The Board provides advice and expertise to the Pennsylvania Department of Health in the determination of service and support needs of individuals with brain injuries and the implementation of services to those individuals and their families and caregivers. The

Board plays an integral role in making recommendations regarding future activities to be placed in the Brain Injury State Action Plan, thereby improving access to brain injury services in Pennsylvania through information and education.

The board worked together to update the state action plan. It will be finalized and approved in 2025.

Brain Injury Data

Pennsylvania Statistics:

- 543,288 people in PA living with brain injury related disabilities
- 17,107 citizens age 19 or younger have sports-related brain injuries, with over 15,000 seen in the ER in Pennsylvania
- 138,600 new brain injuries sustained by adults and children each year
- Approximately 50% of individuals participating in substance use treatment have a brain injury
- 4,744 citizens died from fatal substance use overdoses in 2023
- More than 85% of all TBIs involve lack of seatbelts, improper fit of a helmet, use of alcohol and drugs or falls (especially in older adults)

BIAPA (2021) DDAP(2023)

Many people who experience a mild brain injury, such as a concussion, receive medical care from a physician's office, urgent care center or perhaps no medical attention at all. The data above is underrepresented because reporting is not required for TBI treated in settings other than hospitals. It is also unknown how prevalent brain injury related disabilities are in Pennsylvania because prevalence data is not currently collected.

Center for Disease Control (CDC) National Statistics:

- An estimated 2.8 million people sustain a TBI annually. Of them:
  - 50,000 die,
  - 282,000 are hospitalized, and
  - 2.5 million, nearly 90%, are treated and released from an emergency department.
- TBI is a contributing factor to a third (30%) of all injury-related deaths in the United States.
- Most TBIs that occur each year are mild, commonly called concussions.
- Direct medical costs and indirect costs of TBI, such as lost productivity, totaled an estimated $60 billion in the United States in 2000.
- Every year, more than 795,000 people in the United States have a stroke.
- 87% of strokes are ischemic strokes, in which blood flow to the brain is blocked.
- Ruptured brain aneurysms are fatal in about 50% of cases. Of those who survive, about 66% suffer some permanent neurological deficit.

Most common causes of TBI

- Falls
    - Falls lead to nearly half of the TBI-related hospitalizations

- Fire-arm-related injury
    - Firearm-related suicide is the most common cause of TBI-related deaths in the United States

- Motor vehicle crashes
- Assaults

Most common causes of non-traumatic brain injuries (nTBI)

- Stroke
- Substance overdose
- Aneurysm
- Tumor
- Infectious disease that affects the brain
- Lack of oxygen to the brain

BRAIN INJURY PROGRAM REPORT

Pennsylvania Department of Health's Programs that Support Brain Injury

The Department of Health (DOH) receives funding for brain injury programs through state funding and two federal grants - the Title V Maternal and Child Health Services Block Grant, and the Administration for Community Living (ACL) Traumatic Brain Injury State Partnership Program Grant. The following programs provide services and support to individuals with traumatic and/or non-traumatic brain injuries throughout the lifespan, caregivers, providers, and professionals.

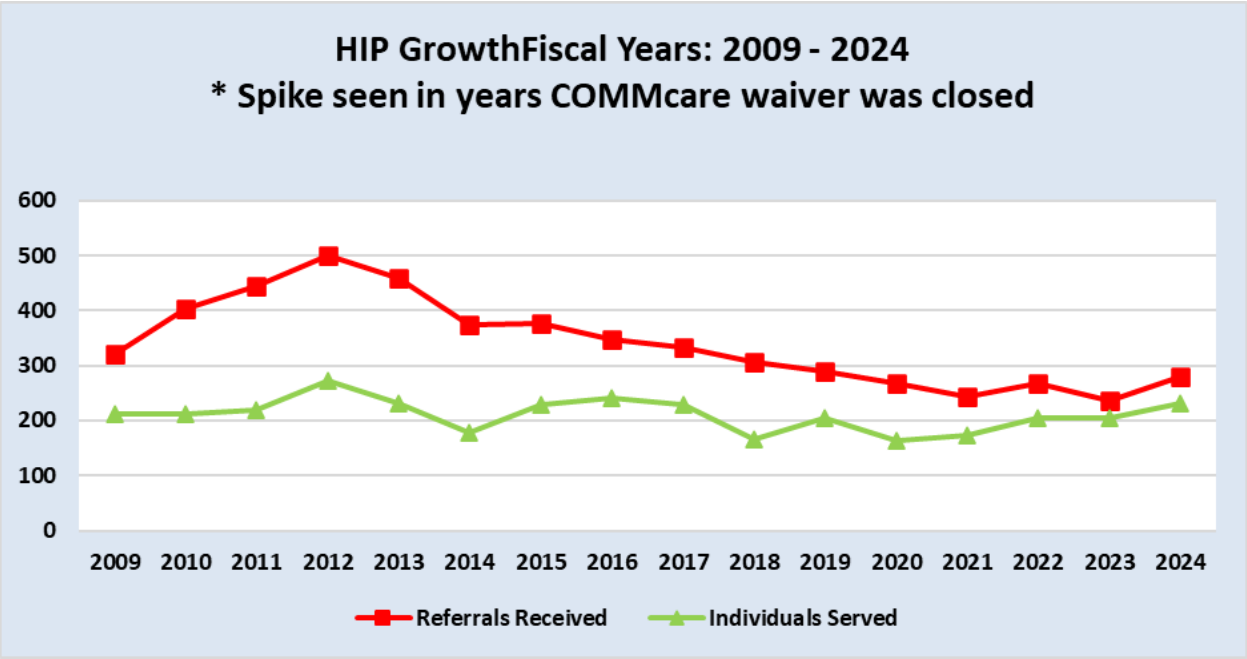
State-Funded Program

The only DOH state funding dedicated to the provision of brain injury services and supports is through the Emergency Medical Services Act of 1985. This act established the Catastrophic Medical and Rehabilitation Fund, which states funding is to be made available for trauma victims to purchase medical, rehabilitation and attendant care services when all alternative financial resources have been exhausted. These funds are acquired through traffic violations. The following program was established to distribute those funds:

Head Injury Program

The Head Injury Program (HIP) was created in 1988 with the goal of helping individuals with a TBI live as independently as possible in their homes and communities by providing funding for qualified individuals to receive head injury rehabilitation services. Enrolled individuals may receive up to 12 months or $100,000 for rehabilitation services, followed by a maximum of six consecutive months or $1,000 for case management to assist with transition out of the HIP. The goal of the program is to help individuals with a TBI live as independently as possible in their homes and communities. In December 2018, the age limit to apply for the HIP was decreased from 21 to 18 years of age. HIP funding decreased from $4.2 million in State Fiscal Year (SFY) 2022/2023 to $4.1 million in SFY 2023/2024. In SFY 2024/2025, the approved budget was **increased** to $4.2 million. Per House Bill 1459, $250,000 of the HIP budget is to be allocated to Emergency Responder Mental Wellness and Stress Management. Therefore, $3.95 million will be used for the HIP in SFY 2024/2025.

Referencing the chart below, **there were a total of 232 individuals served in SFY 2024**, which is an increase from SFY 2023. Referrals to the program increased from 237 in SFY 22-23 to 279 in SFY 23-24 due to increased outreach efforts by the Department. Referral numbers do not include re-enrollments, which began to be considered for individuals in need of additional rehabilitation in August of 2021. In SFY 23-24, 15 re-enrollments were accepted for additional rehabilitation.



- **Pre-enrollment Assistance**

Pre-enrollment Assistance is a service that helps individuals with Traumatic Brain Injury (TBI) and their family members apply for brain injury services through the Department of Health's (DOH) Head Injury Program (HIP) and provide information regarding other brain injury services offered in the Commonwealth of Pennsylvania. A Pre-enrollment Assistance Coordinator is assigned to each applicant of the HIP. The coordinator is available to assist individuals in their home, community, or hospital. They will help individuals complete the application process needed to become enrolled in HIP.

Coordinators:

- Provide information about the HIP.
- Meet with applicants and family members to assess all available financial help.
- Assist applicants and family members in identifying the best resources and programs to meet rehabilitation needs.
- Provide information, referral, and contact information on other resources available in Pennsylvania.
- Assist with obtaining medical records.
- Assist in choosing a HIP rehabilitation provider for an assessment

To learn more about HIP or to request an application, please contact HIP at:
Phone: (717) 772-2763
Email: RA-DHBFHHIP@pa.gov

Title V Maternal and Child Health Services Block Grant Funded Programs

Title V funding is a key source of support for promoting and improving the health and well-being of the nation's mothers, children-including children with special health care needs, and their families. Pennsylvania is one of the few states to use this funding for the provision of brain injury services and supports for children with and without special health care needs. The following programs are funded through the Title V Maternal and Child Health Services Block Grant:

Acquired Brain Injury Program

The Acquired Brain Injury Program (ABIP) was created in 2020 with funding made available through the Title V Maternal and Child Health Block Grant. At the time of its creation, the ABIP was developed to provide specialized brain injury rehabilitation for individuals aged 18-21 with a nTBI. The intent was to bridge a gap for individuals who are beyond school age, but not yet of the age to apply for waiver services. In June of 2021, due to a low number of referrals, the program was updated to expand the age

range for eligibility to 18-25. A total of six individuals received rehabilitation services through the ABIP prior the program termination on May 31, 2024, due to low enrollment.

BrainSTEPS (Strategies Teaching Educators, Parents, and Students)

The Department, in partnership with Department of Education and the Brain Injury Association of Pennsylvania (BIAPA), has implemented BrainSTEPS since 2007. BrainSTEPS is a child and adolescent brain injury school re-entry program that provides brain injury-related consultation and training to school staff, students, parents, and caregivers in all Pennsylvania Public Schools following a student's acquired brain injury. An acquired brain injury includes TBIs of all severities and nTBIs that have occurred after birth. BrainSTEPS is comprised of four Regional Team Liaisons and over 230 brain injury consultants serving on regional teams based out of all 29 educational Intermediate Units and two school districts.

To ensure children and adolescents with a brain injury from either a traumatic (TBI) or non-traumatic (nTBI) cause receive care in a well-functioning system through high school graduation, BrainSTEPS provides the following supports to students, their families or caregivers, and schools:

- Identification of students with brain injury
- School re-entry planning
- Educational plan development, including IEP/504 Plan support, academic adjustments/ accommodations, and strategy selection
- Teacher, peer, and family training
- Annual monitoring of student until graduation
- Family support and resource sharing
- Return to Learn concussion management
- Facilitation of communication between healthcare provider, school staff, and family

In 2024, BrainSTEPS received a total of 404 new referrals. Of those referrals 82 students sustained a moderate to severe TBI, 241 students sustained a concussion, and 81 students sustained a non-traumatic brain injury (n-TBI). This is a slight increase from 2023. Referrals dropped significantly during the COVID-19 pandemic and have slowly increased.

To promote consistency of the BrainSTEPS teams, a Brain Injury Supports Framework (BISF) Online Application tool is used to guide BrainSTEPS team members, students, their caregivers, and their school team through determining appropriate academic supports, based on presenting signs and symptoms of the student's brain injury. Once the tool is completed, it is embedded into the student's person-centered care plan and is disseminated to the student, their caregivers, and the school staff involved in the student's case. In 2024, BrainSTEPS teams provided 4,851 consultation hours to support 1,447 students with a TBI or nTBI.

Anyone can refer a student to the program through the following ways:

- **Website:** http://www.brainsteps.net
- **Phone:** (724) 944-6542

Brain Injury and Opioids Training Program

The DOH contracts with the Brain Injury Association of PA (BIAPA) to develop and provide the Brain Injury and Opioids awareness and training program. The purpose of the program is to educate brain injury and substance use professionals on the correlation between brain injury and opioid use. Training content includes basic information about brain injury, screening for brain injury, factors that impact the response to traditional treatment for those with cognitive impairment, suggested ways to adapt interventions to meet the needs of individuals with brain injury, and brain injury resources. In 2024, BIAPA provided 17 trainings and have trained 727 professionals in the substance use disorder community. Thirteen additional trainings are scheduled for upcoming months and a total of 23 trainings will be completed by the end of the contract year. Once trained, individuals are invited to an "Ask the Expert" Lunch and Learn session held quarterly. It is an informal meeting held virtually to provide an opportunity to discuss ways to apply the training to their work with individuals with brain injury. Topics are driven by the attendees and have included tools to identify cognitive symptoms, using case examples for problem solving, and ideas about adapting treatment to meet the needs of clients with cognitive impairments. Two asynchronous learning tools developed through this project are routinely shared with Lunch and Learn attendees: 1 on screening for a history of brain injury and 1 on identifying brain injury symptoms in those who screen positive for a history of brain injury. These tools are narrated presentations and can be found on the BIAPA website.

A new training on the intersection of brain injury and opioids misuse was developed for Brain Injury Providers. This training was approved by the DOH and sessions are in the process of being scheduled.

An opioids summit, entitled "Bridging Systems for Impactful Solutions will bring together stakeholders from the Brain Injury Community, Substance Use Disorder Community and other relevant stakeholders. The Summit will be held on April 22, 2025 in Harrisburg, PA. It will be an exclusive gathering of experts, practitioners, and stakeholders working at the intersection of brain injury, substance use, and co-occurring disorders. This summit offers a unique opportunity to discuss critical issues, share insights, and collaborate on the development of more effective treatment and intervention strategies.

Safety In Youth Sports Program

DOH contracts with the Pennsylvania Athletic Trainers Society (PATS) for the Safety in Youth Sports Program (SYSP). SYSP was created as a response to the Safety in Youth Sports Act which includes DOH providing education to students, parents, and coaches on the risks of concussion. PATS contracts with Sport Safety International (SSI) to create the ConcussionWise educational videos used during the training. During 2024, PATS provided 135 trainings serving 2,051 youth, 178 coaches, and 57 parents for a total of 2,286 participants. There were 15 Athletic Trainers who provided this training.

The Pennsylvania Shaken Baby Syndrome (SBS) Prevention Program

The SBS Prevention Program is an injury prevention program supported by the Department. PA Hospitals and birthing centers are required per Act 2002-176, to provide parents with specific educational materials related to the risks and consequences of shaken baby or infant head trauma. The Department oversees the distribution and use of these materials. The Department continues to provide technical assistance to hospitals and birthing centers concerning the requirements of Act 2002-176. In 2024, state funds were made available to update the educational brochure. Once finalized, this will be available to new parents who give birth starting in 2025.

For additional information:

- **Website:** http://www.health.pa.gov/shakenbabyprogram
- **Phone**: (717) 772-2763

Administration for Community Living (ACL) Traumatic Brain Injury State Partnership Program Grant

In 2024, the Department continued its work on ACL's TBI State Implementation Partnership Grant. This is a five-year grant that began on August 1st, 2021 and is set to end on July 31st, 2026. The goal of this grant is to create and strengthen systems of services and supports that maximizes the independence, health and well-being of people with traumatic brain injuries across the lifespan, their family members, and their support networks. The Department has five focus areas for this grant: the NeuroResource Facilitation, Intersectionality of Intimate Partner Violence and TBI, Juvenile Justice, Older Adults, and the Brain Injury Advisory Board. In March of 2022, ACL awarded the Department supplemental funding to expand the public health work force. The Department focused these funds on expanding the NeuroResource Facilitation Program to identify and address the service and support gaps caused by the COVID-19 pandemic. This funding ends March 31st, 2025. The following programs are funded through the ACL TBI State Partnership Program Grant:

NeuroResource Facilitation Program (NRFP)

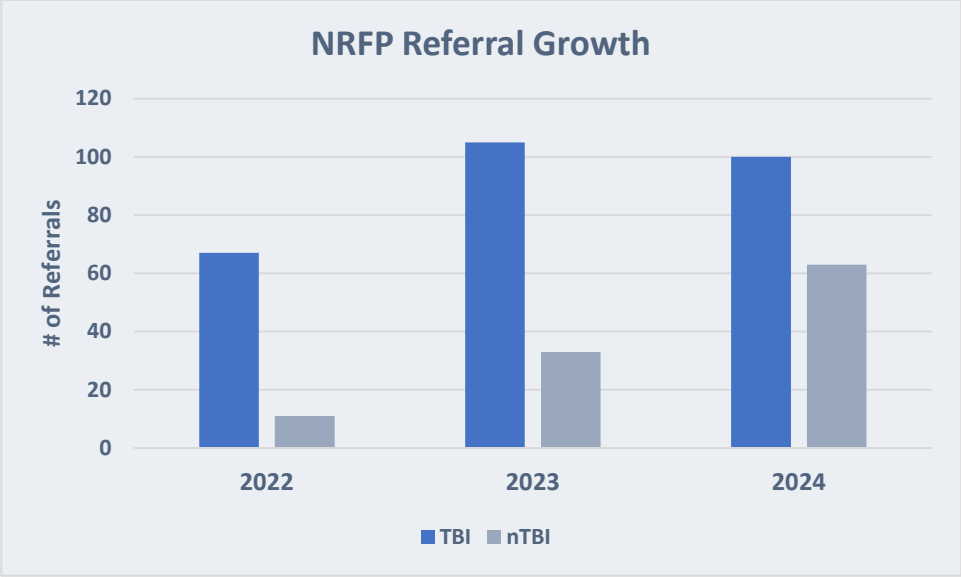
The Department partners with BIAPA to implement the NRFP. This program focuses on helping PA residents with a TBI and nTBI, ages 18 and older, their family members, and

caregivers to identify, navigate, and access brain injury resources, services and supports in their local area. The goal of the program is to maximize the health, independence, and overall well-being of individuals with a TBI statewide. Enrolled individuals receive care coordination services for up to 20 hours or six months, whichever comes first. To ensure individuals can access the needed services and supports in their geographical location, they are assigned a NeuroResource Facilitator (NRF) located in their region. The NRFP provides services and supports throughout the Commonwealth. At the request of the enrolled individuals, services were provided virtually, over the phone, or in-person.

NRFs will:

- Collaborate with the individual and their support team to develop a person-centered care plan that assists the individual to identify what current services and supports are in place, identify and prioritize any unmet needs, and create goals to address those unmet needs.
- Identify resources, services, and supports that will address the individual's and/or their caregivers unmet needs.
- Assist with locating and coordinating appropriate services and supports.
- Ensure the individual and their caregivers can continue to access resources, services, and supports, after completing the program.

Referring to the chart below, in 2024, the NRFP received 163 referrals. Of those referrals, there were 100 individuals with TBI and 63 individuals with a nTBI. Although there was a slight decrease in referrals for individuals with a TBI, there was a 50% increase in referrals for individuals with nTBI from 2023.



Anyone can refer an individual to the program through the following ways:

- **Phone:** (717) 772-2763
- **Email:** RA-DHBFHNRFP@pa.gov

- **Expanding the Public Health Workforce through NRFP**

  In 2023, the Department partnered with BIAPA to expand the NRFP to identify the service and support gaps caused by the COVID-19 pandemic and address them. The Department and BIAPA conducted two focus groups with individuals with a brain injury and caregivers to better understand how the pandemic impacted their service and support needs. The following gaps were identified:

  1. Social Isolation
  2. Access to quality and timely healthcare
  3. Employment
  4. Compounding symptoms
  5. COVID-19 Information

  To address the identified gaps, the following actions were taken in 2024:

  - A bi-monthly support group for individuals with a brain injury that contracted the COVID-19 virus was established and is co-facilitated by two NRFs. This support group was expanded in 2024 to include additional chronic diseases that impact individuals with a brain injury.
  - A series of informational articles relating to the COVID-19 pandemic, accessing healthcare, advocacy in regard to healthcare needs, and safety precautions to prevent exposure was developed and disseminated in the BIAPA monthly newsletter.
  - A Brain Injury Emergency Preparedness Guide was developed to provide individuals with a brain injury and their caregivers information on what kinds of emergencies are likely to occur in Pennsylvania, an emergency self-assessment to determine how ready an individual is when an emergency occurs, an emergency plan, and resources to ensure service and support gaps do not occur. The Guide will be made available to the public in 2025.

Intersectionality of Domestic Violence and Brain Injury Training

Pennsylvania Coalition Against Domestic Violence (PCADV) is a member-led domestic violence coalition that provides support to 59 local domestic violence programs that provide free and confidential services to people who have experienced domestic violence in all 67 counties of the Commonwealth. The Coalition works in collaboration with these member programs to deliver a continuum of services, supports, and systems to help survivors find safety, obtain justice and build lives free of abuse.

- **Training and Education:** Throughout 2024, PCADV facilitated multiple training sessions about the intersection of domestic violence and brain injury to educate a

variety of professionals who are likely to encounter survivors of domestic violence There were 284 participants at a total of 11 educational offerings. These include:

  - **Domestic Violence Program Trainings**: Provided training to eight PCADV domestic violence member programs. A total of 163 domestic violence advocates received training to help them engage in discussions with survivors about the possibility of a brain injury and to provide meaningful referrals when the possibility of a brain injury may exist.
  - **EMS Training**: In March, PCADV conducted a training session at the EMS West Conference, focusing on strategies to identify and ask about brain injury due to domestic violence. A total of 55 EMTs participated. Additionally, EMS providers in Allegheny County received training on addressing the intersection of domestic violence and brain injury. A total of 20 EMS providers were in attendance.
  - **Attorney Network Training**: In January, a training was provided for the Domestic Violence Attorney Network on strategies for discussing brain injury with clients. A total of 46 attorneys attended this session, recognizing their unique role in connecting survivors with resources.

- **Revisions to Training Materials**: PCADV updated their brain injury training materials to include additional resources, such as the BI Resource Line, for member domestic violence programs.

- **Resource Development:**
  - **Toolkit for Professionals on the Intersection of Domestic Violence and Brain Injury:** PCADV developed a comprehensive toolkit for domestic violence advocates, EMS providers, substance use providers, and brain injury providers. This toolkit, is currently in the final stages of approval by the Department of Health (DOH), will include sections tailored to each professional role with tangible guidance on supporting survivors and connecting them to resources. The toolkit is slated to be distributed in 2025.
  - **Technical Assistance**: Ongoing technical assistance was provided to domestic violence programs, including strategies for discussing brain injury with survivors and engaging EMS providers to increase awareness.
  - **Promotional Efforts**: Resources were continuously shared with healthcare providers and EMTs to encourage discussions about brain injury with domestic violence survivors and to connect them with appropriate services.
  - **Brain Injury Association of PA Conference**: In June, a PCADV Health Education Specialist attended the annual conference to further inform PCADVs work and to network with experts in the field.

- **Continued Engagement and Feedback**:

This past year has been marked by significant progress in educating professionals, developing resources, and strengthening collaboration among partners. Moving forward, efforts will continue toward enhancing training programs, finalizing and

distributing the toolkit, and seeking opportunities to increase awareness and support for domestic violence survivors with brain injuries. PCADV remains committed to advocating for survivor-centered, trauma-informed approaches to address this critical issue.

Brain Injury Training, Technical Assistance and Outreach

The Department continues its partnership with BIAPA to provide training, technical assistance, and outreach services to professionals working with the juvenile justice population, older adult populations, and other health and human services professionals likely to encounter individuals with a brain injury.

- **Juvenile Justice**
  Brain injury training and technical assistance were primarily provided to juvenile justice service providers and outreach was conducted to additional providers and professionals serving youth involved in the juvenile justice system. The purpose of this initiative is to offer technical assistance including training and consultation related to identifying youth with a history of brain injury through screening, providing/referring for neurocognitive testing, and facilitating potential resources for youth with brain injury. In 2024, a total of 42 trainings were provided to audiences within the Juvenile Justice System, with a total of 476 attendees. Technical assistance continues to be provided virtually to the Bureau of Juvenile Justice Services.

- **Older Adult Training and Outreach**
  Brain training and outreach were provided to professionals working with the older adult population. The purpose of this initiative is to increase brain injury awareness of the etiology, causes of sustained injuries, and the impact and management of symptoms. The demand for trainings for professionals working with this population has diminished over time. While many trainings for this group were held in past years of the grant, only two trainings were held in 2024, reaching 30 attendees.

- **Health and Human Services Professionals Training**
  Brain injury trainings were provided to a variety of health and human services professionals likely to encounter individuals with a brain injury, including behavioral health professionals; the Legal Clinic for the Disabled; two residential facilities that are not brain injury specific but have residents with brain injury; and the Synapse Club at the University of Pittsburgh. In 2024, twelve trainings were provided to 236 attendees.

Advisory Board Workgroups

The Brain Injury Advisory Board has established three workgroups to effectively address the objectives outlined in its state action plan. These workgroups bring together individuals with diverse expertise, including individuals with lived experience, family members, caregivers, healthcare professionals, researchers, advocates, and community stakeholders, to address specific goals related to brain injury prevention, treatment, and rehabilitation. Through structured collaboration and regular meetings, each workgroup focuses on key areas such as education, resources, system collaboration, and health equity for individuals with brain injuries. By harnessing collective knowledge and resources, these workgroups aim to drive innovation, accountability, and progress towards the overarching goals of the Brain Injury State Action Plan, ensuring impactful outcomes for those impacted by brain injury.

- **Education and Resource Facilitation Workgroup**
  The Education and Resource Workgroup focuses on increasing knowledge and awareness of available brain injury education, training, technical assistance and resources for individuals with a brain injury, their families and caregivers, and professionals. In 2024, the workgroup focused on the following key activities:

    - **Resource Development**: The workgroup developed a general information slide deck on brain injury. This resource aims to educate individuals working with survivors, even if they are not brain injury specialists. This resource is encouraged to be used by any person sharing general brain knowledge with people who may interact with a person with a brain injury.

    - **Quiz-Style Resource Exploration**: The group discussed creating a ‘quiz’ tool to help survivors identify appropriate resources based on their needs. While funding was unavailable for development, this remains a priority for future exploration.

    - **Awareness Initiatives**: The workgroup brainstormed ideas to raise awareness among first responders about brain injury, including discussions on Yellow Dot and Blue Envelope programs.

    - **State Action Plan**: The workgroup has been reviewing the State Action Plan to identify ways in which we can contribute to the success of the Plan by creating and sharing materials to uplift the needs of people with brain injuries across the Commonwealth.

- **Systems Workgroup**
  The Systems Workgroup is focused on identifying and establishing partnerships with key state agencies, healthcare providers, and community organizations to

enhance services and supports systems for individuals with brain injury and their families. In 2024, the workgroup focused on the following key activities:

- **PA Opioid Trust Fund:** The workgroup explored options for utilizing funds from the PA Opioid Trust Fund to fund a pilot program. In 2024, $150 million was to be distributed to counties. Berks County Council on Chemical Abuse oversees the distribution of Opioid Settlement Funds in Berks County. The workgroup was able to connect to the Reading Hospital Emergency Department (ED) to discuss options and the feasibility of expanding the warm hand-off program for individuals entering the emergency room with an overdose to be screened for brain injury. The workgroup assisted with the development of a concept paper to submit to the Berks County Council on Chemical Abuse, which outlines a pilot project that will be implemented by the Brain Injury Association of Pennsylvania. The project will focus on screening for brain injury in people treated and released from the emergency room at Reading Hospital Tower Health and a variety of other settings for opioid overdose. The goal is to connect those who screen positive for history and symptoms of brain injury to additional brain injury treatment and resources to be braided with and used in their substance misuse treatment to enable treatment to become more effective. The pilot project will use NeuroResource Facilitators (NRFs) to provide initial brain injury training to staff working in targeted settings. NRFs will then conduct screenings to determine if there has been a lifetime history of brain injury. When there is a positive screening for brain injury, the NRFs will provide training to staff on integrating cognitive strategies into their current treatment for substance use disorder and behavioral health. It will also link those who screened positive to other brain injury resources.

- **Brain Injury Screening:** Connecting with Reading Hospital Tower Health ED doctors, social workers and administrators as well as community-based professionals to learn about their current process to identify and treat individuals entering the ED with a drug overdose. After several meetings, the workgroup was able to determine where we could integrate brain injury screening to the follow up care.

- **Exploration of Systems:** The workgroup continued to explore other systems of care where brain injury could show up in greater proportion than the regular population. Identified corrections, juvenile justice, mental health, veterans, and child welfare. The workgroup will continue to make connections with those systems that could benefit from brain injury training and screening.

- **Health Equity Workgroup**

  The Health Equity Workgroup focuses on increasing knowledge and awareness of the Pennsylvania Brain Injury Advisory Board to increase stakeholder diversity and representation and foster greater collaboration. In 2024, key activities include:

  - **Gaps in Representation:** The workgroup continues to focus on supporting the Board with developing a comprehensive list of gaps in representation on the Board, recruiting new board members to fill gaps in representation, serving as a representative of brain injury on other boards, councils, and taskforces, and identifying guest speakers to educate the Board in the areas that may be lacking representation.

  - **Recruitment and Retention of Board Members:** The workgroup focused much of their efforts around developing tools to help the Board with recruitment of new and retention of current Board members. With review by the workgroup and Board, it was found that the Board is still in need of four survivors to complete the Board membership. The Health Equity Workgroup developed the following document and possible initiatives which were brought forward to the Board in effort to assist in recruitment of brain injury survivors for the Board.
    - The first document was a Brain Injury Board Recruitment Flyer and together they worked on developing a recommended plan for distribution to present to the Board, which was approved by the Board.

    - There were two other continued initiatives from earlier in the year:

      1. The Board 'Welcome Wagon', where prospective Board members are welcomed to their first meeting and assigned a Board member liaison.
      2. "Town hall' meetings offered virtually, twice a year for those who cannot make the Board meetings in person. This allows for everyone to be updated on the Board's actions. The Health Equity Workgroup felt that this is one way to allow all people, no matter their location, to learn about and have a voice about topics which are discussed at the BI Advisory Meetings, even if they are not able to attend the quarterly Board meetings in person.

Department of Human Services, Office of Long-Term Living: OBRA & Community HealthChoices (CHC) Waivers

OBRA Waiver

The Omnibus Budget Reconciliation Act (OBRA) Waiver is a Home and Community-Based Waiver program for individuals with a developmental physical disability (including brain injury). The waiver provides access to a wide array of services that are designed to allow individuals to live in the community and remain as independent as possible.

The following individuals may be eligible to qualify for OBRA:

- A resident of Pennsylvania.
- Age 18-59. Individuals who turn age 60 while in the waiver are able to continue to receive services through the OBRA Waiver until services are no longer needed. New applicants age 60 and older will be referred to other programs.
- Have a severe developmental physical disability requiring an Intermediate Care Facility/Other Related Conditions (ICF/ORC) level of care.
- The disability must result in substantial functional limitations in three or more of the following major life activities:
    - Self-care, communication, learning, mobility, self-direction and capacity for independent living.
- Meet the financial requirements as determined by your local County Assistance Office.

Other related conditions (ORCs) include physical, sensory, or neurological disabilities which manifested before age 22 and are likely to continue indefinitely.

Community HealthChoices Waiver

Community HealthChoices (CHC) is a Medicaid Long-Term Services and Supports managed care program that was developed to enhance access to and improve coordination of physical health benefits and long-term services and supports (LTSS) and to create a person driven, long term support system in which people with physical disabilities have choice, control, and access to a full array of quality services that provide independence, health, and quality of life. The goal of CHC is to serve more people in the community in order to give them the opportunity to live independently, work, and spend more time with their families. LTSS help eligible individuals to perform activities in their home such as bathing, dressing, preparing meals, administering medications and to remain involved in their community. The following individuals may be eligible to qualify for CHC:

- Individuals who are 21 years of age or older and dually eligible for Medicare and Medicaid.
- Individuals who are 21 years of age or older and eligible for Medicaid (LTSS) because they need the level of care provided by a nursing facility.
- Individuals currently enrolled in the LIFE Program only if they expressly select to transition from LIFE to a CHC MCO.

The following individuals are **not** eligible for CHC:

- Individuals receiving long-term services and supports through the OBRA waiver and are not nursing facility eligible.
- Individuals who do not meet the Medicaid financial eligibility criteria.
- Individuals who reside in a state veteran's home.

Pennsylvania also offers another managed care program that could serve individuals with a brain injury. It is the Living Independence for the Elderly (LIFE) which is nationally known as the Program of All-Inclusive Care for the Elderly (PACE). To be eligible for the program, a participant must be NFCE, 55 years old and have a LIFE program in their area. LIFE is an all-inclusive program providing all necessary services to the participant. A major component is the day center that provides a variety of services including a medical clinic.

In 2024, the end to the Public Health Emergency (PHE) continued to cause significant barriers to CHC and LIFE participants with a TBI receiving services, their families, and service providers. As COVID-19 preventions and restrictions ended, many congregate settings began the process of reopening. However, many providers faced continuing staffing shortages to provide all the necessary services for participants. The staffing issues continued to impact the whole continuum of health care services for participants at the state level and nationally. OLTL, the CHC MCOs, LIFE program and service providers continued trying to meet participants' needs. During the pandemic, OLTL allowed some services to be provided virtually but as the PHE ended some of these service flexibilities also ended. OLTL is continuing to allow certain services to be provided virtually/telephonically. OLTL also worked to disburse and monitor the American Rescue Care Plan Act (ARPA) funds to some providers in the CHC program.

Since the end of the PHE, participants have gone through the MA redetermination process to ensure that they are still eligible for services through the MA program. For CHC, OLTL is working with the participants, advocates and providers in an effort to ensure that all participants who are eligible for program services are able to maintain their eligibility.

The MCOs participating in CHC include:

- **AmeriHealth Caritas**
  Website: www.amerihealthcaritaschc.com
  Phone: 1-855-235-5115 (TTY 1-800-235-5112)

- **Keystone First**
  Website: www.keystonefirstchc.com
  Phone: 1-855-332-0729 (TTY 1-855-235-4976

- **PA Health and Wellness**
  Website: www.PAHealthWellness.com
  Phone: 1-844-626-6813 (TTY 1-844-349-8916)

- **UPMC Community HealthChoices**
  Website: www.upmchealthplan.com/chc
  Phone: 1-844-833-0523 (TTY 711)

OLTL will continue to provide information about relevant CHC topics through various means on specific topics, narrated training segments and statewide provider assistance events. Information on CHC is located on DHS's website at: www.HealthChoices.pa.gov. OLTL continues to provide ongoing CHC updates at stakeholder's meetings and other webinars as requested. OLTL has both a Provider and Participant Helpline as resource information contacts.

The following resources are available:

BRAIN INJURY PARTNERS

BRAIN INJURY ASSOCIATION OF PENNSYLVANIA (BIAPA)

The Brain Injury Association of Pennsylvania was formed in 2001, with a dedicated volunteer Board of Directors. The Association works to prevent brain injury and improve the quality of life for people who have experienced brain injury, their family members and caregivers through support, education, advocacy, and research. The work of the

Association is accomplished through paid professional staff and hundreds of volunteers. BIAPA is the official Pennsylvania state-chartered affiliate of the Brain Injury Association of America. BIAPA offers the following programs:

- **Brain Injury Resource Line (BIRL)**
  The Brain Injury Resource Line (BIRL), maintained by BIAPA, serves as a vital resource for callers seeking information and support. In 2024, BIRL received 320 new calls. Managed by the BIAPA Director of Programs and staffed by trained volunteers, BIRL continues to leverage the online resource manual developed and implemented last year. This dynamic, database-formatted manual allows real-time updates, eliminating the need for multiple versions. New sections and resources are added regularly. Volunteers participate in ongoing training and mentoring to enhance their ability to assist callers, including quarterly virtual meetings and an annual in-person training at the BIAPA conference.

- **Support Groups**
  Brain injury support groups serve as critical points of connection for individuals with brain injuries and their families. BIAPA maintains relationships with these groups, providing ongoing information and assistance while supporting the establishment of new groups in communities where they are needed.
  A comprehensive listing of local support groups, including their meeting formats, is available on the BIAPA website at https://biapa.org/programs/support/ and is shared monthly in the BIAPA e-newsletter. Currently, 31 local support groups are listed.
  Additionally, BIAPA offers two statewide virtual support groups: One is geared toward survivors with care partners welcomed as well, and one specifically for caregivers. Both groups meet monthly and will continue indefinitely. The *Coping with COVID* support group, launched in December 2022, expanded its focus to include broader health concerns and was renamed *Health Matters*. This group will continue through March 2025.

- **Brain Injury Ambassador Program**
  Launched in Spring 2020, the Pennsylvania Brain Injury Ambassador Program continues to provide crucial support to families and caregivers of individuals with brain injuries receiving inpatient rehabilitation across the state. The program connects families early in the recovery process, offering guidance on available resources and support services.

  Six trained Brain Injury Ambassadors collaborate with rehabilitation facility liaisons to provide referred families with essential information. Ambassadors establish ongoing communication channels, ensuring families receive the BIAPA newsletter and are aware of BIRL as a future resource.

  Although originally designed for in-person meetings, all interactions have remained virtual since the program's inception, proving to be an effective and efficient communication method. Currently, eleven inpatient rehabilitation

hospitals actively refer families to the program. In 2024, the program received 84 new referrals bringing the total number of referrals to 300.

- **ReDiscover U Program**
  In January 2023, BIAPA assumed responsibility for the *ReDiscover U* program at the request of the Council on Brain Injury, which initially developed and administered it before their dissolution. This virtual, adult evening school-style program met weekly throughout 2024, with a break in July and August. This program covers a wide range of topics from *Emotional Wellness* to *The America's Cup* as well as a share night once a month. The program provided an engaging learning experience in a vibrant environment. Each session, exclusively attended by individuals with brain injuries, averaged 11 participants.

- **Clinical Forum**
  In January 2023, BIAPA also assumed the *Clinical Forum Series*, an educational initiative originally created and managed by the Council on Brain Injury. This virtual program provides free training opportunities for professionals in the field, including those seeking contact hours for certification through the Academy of Certified Brain Injury Specialists (ACBIS).

  The 2024 Clinical Forums covered the following topics:
  - *The Cranio-Cervical Connection: Link between Body and Brain*
  - *Suicidality and Self-Harm in Individuals with TBI: Characterization, Assessment, and Management*
  - *Anger Self-Management Training for People with Moderate-Severe Traumatic Brain Injury*
  - *Formalizing a Disorders of Consciousness Program for Pediatric Patients at the Children's Hospital of Philadelphia*

  These sessions continue to serve as valuable educational resources for a national audience professionals dedicated to improving brain injury care and support.

PA MODEL SYSTEMS: MOSS TRAUMATIC BRAIN INJURY MODEL SYSTEM

The Traumatic Brain Injury Model System (TBIMS) Program began in 1987 to improve care and outcomes for individuals with TBI. There are currently 16 TBIMS centers funded, one of which is the Moss Traumatic Brain Injury Model System at the Moss Rehabilitation Research Institute/Moss Rehab in Elkins Park, Pennsylvania.
The TBI Model System (TBIMS) centers provide a multidisciplinary system of rehabilitation care, including emergency medical, acute medical, and post-acute services to improve care and outcomes for people with TBI. In addition to providing direct services, these centers play a pivotal role in building the national capacity for high-quality treatment and research serving persons with TBI, their families, and the communities in which they reside.

The Traumatic Brain Injury Model Systems (TBIMS) National Database is a prospective, longitudinal multi-center study which examines the course of recovery and outcomes following the delivery of a coordinated system of acute neurotrauma and inpatient rehabilitation. The database includes large scale follow-up to 30 years post-injury. The Moss TBIMS has enrolled1513 individuals into the study and is currently following 920 or these individuals over time.

The current local project being conducted by the Moss TBIMS is a randomized controlled trial of an intervention to help individuals with TBI to increase physical activity. This project is entitled *Get Up and Go*. To date, 33 participants have been enrolled, and the project is on track to enroll of 70 participants by the end of the study.

The Moss TBIMS also participates in 3 collaborative research projects:

- *State Programs and Outcomes from TBI* (led by Ohio State University)
- *Multidimensional Health Perceptions after Traumatic Brain Injury* (led by UTHealth Houston / TIRR Memorial Hermann)
- *Associations of Early Life Adversity and Neighborhood Environment with TBI Outcomes in the TBIMS National Database* (led by Mount Sinai in New York)

The Moss TBMIS is collaborating with BIAPA on an outreach project to review the demographic datasets from various BIAPA programs and compare these datasets to state-level data. Findings identified the need for outreach to specific groups. The next step is to recruit individuals from underrepresented groups in the datasets to join a focus group discussion related to how to improve outreach.

PA BRAIN INJURY COALITION

The Pennsylvania Brain Injury Coalition is made up of a group of brain injury stakeholders from organizations and individuals who work together with the Pennsylvania Brain Injury Legislative Caucuses to address the needs of the individuals in Pennsylvania living with brain injury related issues, at the legislative level.
The priorities for 2024 included:

- Addressing the impact of the low reimbursement rates for residential habilitation which has resulted in some providers going out of business, and waitlists for being considered for this level of care, delaying consumer access to care.
- Access to post-acute NeuroRehabilitation services immediately following acute hospital discharge supported by the Brandeis study https://www.frontiersin.org/journals/public-health/articles/10.3389/fpubh.2021.753447/full
- Continuing efforts to educate and train healthcare professionals for people who have unintentional opioid overdose resulting in brain injury.
- Ensuring appropriate educational supports for children with brain injury including concussion
- Identifying and supporting other populations where brain injury is over-represented and underserved (for example: unhoused, mental health, domestic violence, substance abuse)

- Encouraging additional legislators to join the Brain Injury Legislative Caucuses.
- Working on modifications to expand the scope of the Safety and Youth Sports Act.

RESOURCES

For additional information or inquiries regarding brain injury services in Pennsylvania, please contact or go online at:

- **PA Department of Health Brain Injury Advisory Board**
  The Brain Injury Advisory Board meetings are open to the public. If you would be interested in attending a meeting, please call: **1-866-412-4755**

- **PA Department of Health Head Injury Program (HIP)**
  Website: https://www.health.pa.gov/topics/programs/Pages/Head-Injury.aspx
  Phone: 717-772-2763 (8:30 AM-4 PM)

- **PA Department of Health BrainSTEPS**
  Website: http://www.brainsteps.net
  Phone: (724) 944-6542

- **PA Department of Health NeuroResource Facilitation Program**
  Website: https://www.health.pa.gov/topics/programs/Pages/NeuroResource-Facilitation-Program.aspx
  Phone: 1-866-412-4755

- **Brain Injury Help Line**
  Phone: 1-866-412-4755

- **Brain Injury Resource Line (BIRL)**
  Phone: 1-800-444-6443

- **BIAPA**
  Website: www.biapa.org
  Phone: 1-866-635-7097

- **Disability Rights Pennsylvania**
  Website: www.disabilityrightspa.org
  Phone: 1-800-692-7443

- **PA Health Law Project**
  Website: www.phlp.org
  Phone: 800-274-3258