

2019 Highlights of Pennsylvania's Traumatic Brain Injury Advisory Board



Programs, Activities and Supports

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. The Board is comprised of a variety of stakeholders representing: State agencies and offices; TBI programs and providers; as well as people who have sustained a TBI and family members. The Department has continued to support the Board while utilizing HRSA and Administration for Community Living (ACL) funding for other TBI programming.

Pennsylvania Statistics:

- **209,880** people are living with brain injury related disabilities;
- **138,600** adults and children sustain a brain injury every year;
- **1,980** die from brain injuries each year;
- **11,088** are hospitalized each year after a brain injury;
- **15,840** are seen in the Emergency Room following a brain injury each year; and
- **17,107** Pennsylvania children (19 or under) have sports-related brain injuries.

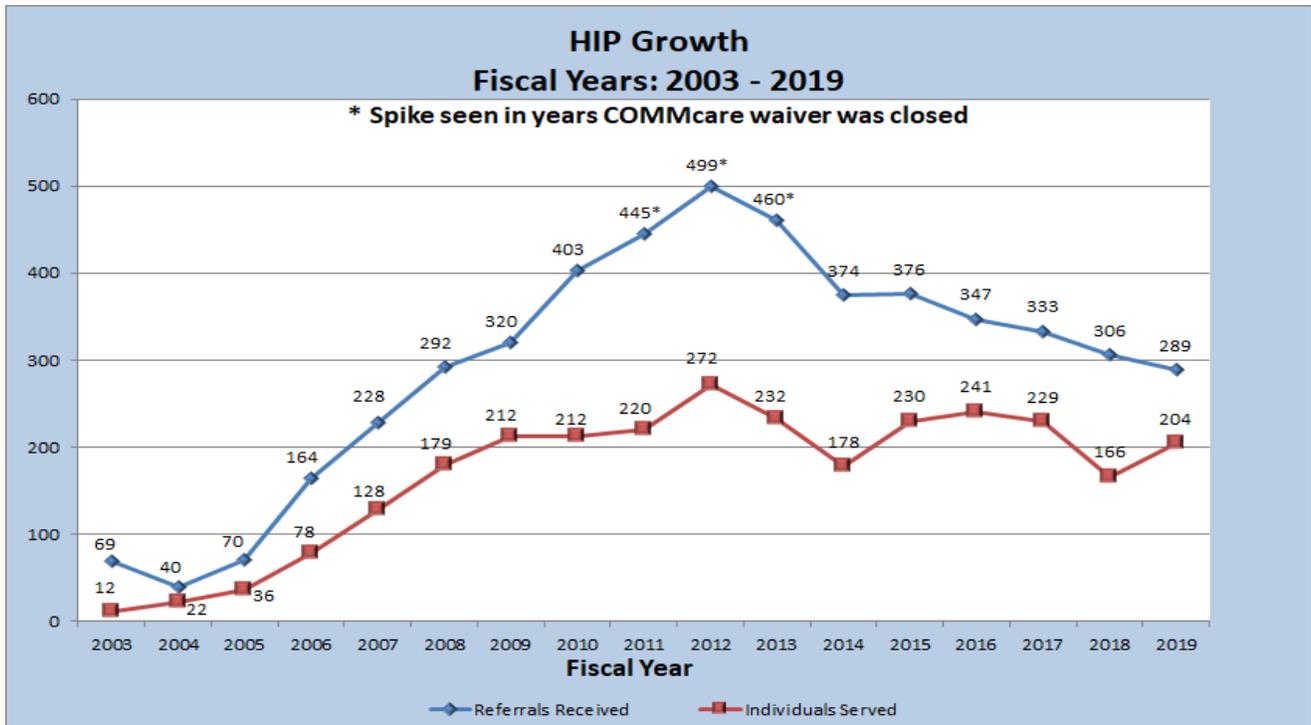
Is TBI Preventable? More than 85% of all TBIs can be prevented by one of the following:

- Seat belts are 57% effective in preventing traumatic and fatal brain injuries;
- Properly fitted helmets reduce the risk of brain injuries by 88%; and
- Over half of all brain injuries are related to alcohol and drug abuse
- Nearly 20% of all older adult falls result in a brain injury.

Head Injury Program

The Head Injury Program (HIP) was created in 1988 by the Emergency Medical Services Act of 1985 and pays for head injury rehabilitation services for people with a TBI who qualify. 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.

Referencing the chart below, **in 2019 there were 206 individuals served.** HIP funding continues to decrease, and was reduced to 4.3 million in FY 2018/2019 (was 4.65 in FY 2016/2017; 4.7 in FY 2015/2016). In 2019, more individuals received outpatient services, which helped stretch the funding dollars as those services often do not require the full funding allocation.



Administration for Community Living Grant

In 2019, the Department continued work on a three-year grant from the ACL. The Department has selected three focus areas for this grant: NeuroResource Facilitation, Juvenile Justice, and Older Adults. The ACL TBI State Implementation Partnership Grant will conclude on May 31, 2021. ACL has approved applications for carry over funding again this year, for which the Department will apply. If approved, the un-utilized funding will be split between Counseling and Rehabilitation, Inc. (C&R, Inc.) and the Brain Injury Association of Pennsylvania (BIAPA).

NeuroResource Facilitation Program:

As part of the ACL grant, the Department partnered with Counseling and Rehabilitation, Inc. (C&R, Inc.) to implement and facilitate the NeuroResource Facilitation Program (NRFP). The NRFP helps Pennsylvania residents, age 18 and older with TBIs, and their family members 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 TBIs in Pennsylvania.

At the beginning of 2019, the Department and C&R, Inc. finalized the grant agreement and developed promotional materials about the NRFP. On March 18, 2019, the NRFP rolled out in the South Central and Southeastern regions of Pennsylvania, and by December 2019 it was

available statewide. From March to December 2019, C&R, Inc. personnel promoted the program by disseminating information to and/or conducting presentations about the NRFP to approximately 40 organizations of various disciplines that serve individuals with TBIs and brain injury support groups. Additionally, C&R, Inc. personnel attended various community meetings to gather information about resources for NRFP participants and to share information about the NRFP. By December 31, 2019, there were 51 participants referred to the NRFP. Individuals in the NRFP have been provided with information about, been referred to, and/or have received assistance to apply for services through public transportation or paratransit providers, Section 8 Housing, their local Area Agency on Aging, the Tri-State Advocacy Project, Pennsylvania Health Law Project, the Office of Vocational Rehabilitation (OVR), the Office of Long-Term Living, Community Health Choices, brain injury support groups affiliated with the Brain Injury Association of Pennsylvania (BIAPA), and/or medical/clinical programs and providers.

Juvenile Justice Technical Assistance and Training:

In 2019, BIAPA and the Department were able to provide both training and technical assistance within the juvenile justice system through a grant from ACL. The focus of this grant is on providing education, training and technical assistance to existing juvenile service providers in PA. Outreach has targeted potential residential and outpatient facilities as well as probation departments in order to identify potential sites for training and consultation. Almost 900 individuals received education, training or technical assistance throughout the year.

TBI Education, Training, and Outreach for Older Adult Populations:

The Department was awarded a grant through the ACL to provide outreach and training to those working in eldercare in PA in collaboration with BIAPA. The focus of the grant is to increase awareness of the issue of brain injury in older adults. Outreach was targeted to eldercare facilities including PA's LIFE centers throughout the state. During 2019, twelve trainings were provided statewide.

Community HealthChoices (Department of Human Services/Office of Long-Term Living):

On January 1, 2018, Phase 1 for Community Health Choices (CHC) was implemented in a 14-county area of Southwest, PA. Phase 2 was implemented on January 1, 2019 in a five-county area of Southeast. CHC is a Medicaid managed care program that includes physical health benefits and long-term services and supports (LTSS). The program is nationally referred to as a managed long-term service and supports program (MLTSS). The following individuals could 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; and individuals currently enrolled in the LIFE Program only if they expressly select to transition from LIFE to a CHC managed care organization (MCO). The following individuals are not eligible for CHC: people receiving long-term services and supports through the OBRA waiver and are not nursing facility eligible; and individuals with an intellectual or developmental disability receiving services beyond supports coordination through the Department of Human Services' (DHS) Office of

Developmental Programs and are residents in a state-operated nursing facility, including the state veteran's home.

The goal of CHC is to serve more people in the community in order to give them the opportunity to work, spend more time with their families, and experience an overall better quality of life. CHC was developed to enhance access to and improve coordination of medical care and to create a person-driven, long term support system in which people have choice, control, and access to a full array of quality services that provide independence, health, and quality of life. LTSS help eligible individuals to perform activities in their home such as bathing, dressing, preparing meals, and administering medications.

The following graphic represents the CHC Phases:



The MCOs participating in CHC include:

MANAGED CARE ORGANIZATIONS

- The selected offerors were announced on August 30, 2016.



➤ www.AmerihealthCaritasCHC.com



➤ www.PAHealthWellness.com

UPMC Community HealthChoices

➤ www.upmchealthplan.com/chc

DHS - OLTL will continue to provide information about relevant CHC topics through various means on specific topics, narrated training segments and statewide provider assistance events. DHS - OLTL will also provide awareness flyers to participants, Aging Well events will be held and communication sessions will be held for Service Coordinators and nursing facilities throughout the Commonwealth. Information on CHC is located on DHS's website at www.HealthChoices.pa.gov.

DHS - OLTL continues to provide ongoing CHC updates at stakeholder's meetings and through Third Thursday webinars. OLTL has both a Provider and Participant Helpline as resource information contacts. The following resources are available:

RESOURCE INFORMATION

CHC LISTSERV // STAY INFORMED: <http://listserv.dpw.state.pa.us/oltl-community-healthchoices.html>

COMMUNITY HEALTHCHOICES WEBSITE: www.healthchoices.pa.gov

MLTSS SUBMAAC WEBSITE:
www.dhs.pa.gov/communitypartners/informationforadvocatesandstakeholders/mltss

EMAIL COMMENTS TO: RA-PWCHC@pa.gov

OLTL PROVIDER LINE: 1-800-932-0939

OLTL PARTICIPANT LINE: 1-800-757-5042

INDEPENDENT ENROLLMENT BROKER: 1-844-824-3655 or (TTY 1-833-254-0690)
or visit www.enrollchc.com



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BrainSTEPS – Child & Adolescent Brain Injury School Re-Entry Program: <http://www.brainsteps.net/> #1-724-944-6542:

BrainSTEPS (Strategies Teaching Educators, Parents, and Students) is an educational initiative delivered through statewide Intermediate Units (IUs). It was created by the Department in 2007 and is jointly funded by the Department and the PA Department of Education, Bureau of Special Education via the Pennsylvania Training and Technical Assistance Network (PaTTAN). BrainSTEPS supports children and adolescents who have sustained acquired brain injuries by offering training and consultation to school staff. As of 2019:

- 30 BrainSTEPS teams with approximately 250 educational consultants from IUs, school districts, and medical rehabilitation facilities;
- BrainSTEPS teams are in place in 28 IUs across the State and 2 large school districts;
 - 564 new students were served in 2019;
- 5,381 students have been served since inception of program;
- Referrals came from the following sectors in 2019:
 - School staff – 67%;

- Families- 13%;
- Rehabilitation professionals-12%;
- Medical professionals– 5%;
- Other/Advocates – 3%;
- Severity of student brain injury referrals were:
 - Concussions/mild TBIs –71%;
 - Moderate or Severe TBIs – 16%;
 - Non-TBIs –13%;
- Most prevalent grades at injury were 9th (72), 10th (87), and 11th (77) graders;
- Three most prevalent ages at injury are 15 (93), 16 (77), & 17 (60);
- Students were referred from 55 counties and 208 school systems, which include private, parochial, charter, and cyber schools; and
- 2,600 Return to Learn Concussion Management Teams across the Commonwealth, which are specialized to help academically monitor concussions initially. If symptoms persist beyond 4-6 weeks, student are referred to a BrainSTEPS team for continued brain injury consultation.

Public Awareness:

- **Brain Injury Trainings** - The Department has partnered with BIAPA to provide training and technical assistance to individuals likely to work with justice-involved youth and older adults with brain injury. BIAPA delivered seventeen trainings, provided technical assistance to five organizations, and presented at two conferences and one webinar. Groups who received trainings and technical assistance included a variety of juvenile justice professionals and facilities and eldercare providers and facilities.
- **Brain Injury Resource Line (BIRL) #1-800-444-6443** is maintained by BIAPA. It is designed to give resource information to all who call. The BIRL is staffed by eight trained volunteers who work as a team and participate in ongoing training to increase their capacity to assist callers. The team of volunteers participates in an in-person training annually at the BIAPA Conference. In November 2018, a team of presenters from Moss Rehab provided a full day in-person training for the team as well. This was made possible through the Moss TBI Model System grant and will occur again in the fall of 2020. As an outreach initiative, business cards were produced for the BIRL and made available to stakeholders across the Commonwealth to ensure all are aware of the BIRL number and use it.
- **Support Groups** - Brain injury support groups are the front-line tool of affiliation for individuals with brain injury and their families. BIAPA maintains contact with these support groups to provide information and support as needed and works with individuals to start new groups in the communities where they live.
 - There are 52 support groups listed on the BIAPA website. Some counties have multiple support groups, while many counties in rural PA have no

support groups. Support group facilitators were invited to a networking luncheon to share ideas at the BIAPA Annual Conference.

- **RESTART** – Kevin McDonald is a Traumatic Brain Injury Survivor from 2009. While trying to acquire municipal assistance he found that there is minimal help at neither the State nor Federal level for “Advanced Level of Rehab” survivors. Because of this, he officially established and staffed a Non-Profit Fund to assist other TBI Survivors. 'RESTART Your Life / RENEW Your Mind' began in 2014, is based in West Chester, PA and has reached Brain Injury Survivors across PA as well as parts of New Jersey, Delaware, and Maryland. Funds are raised through private & corporate donations, as well as various fund-raising events & are distributed (to those deemed eligible) for assistance moving forward with resources, education, advocacy, and opportunities to attend a "Once in a Lifetime" event after sustaining BI. Most recently RESTART has become engrained in Awareness, Advocacy, & Education.

Awareness efforts include an annual awareness event in West Chester as well as presenting to support groups and other organizations across Southeastern PA. Advocacy efforts include participation in the PA TBI Advisory Board, PA Brain Injury Coalition, TBI Awareness Day on Capitol Hill, Co-Founder of the Brain Injury Awareness Day at the Harrisburg State Capitol. Education efforts include first responder awareness training, and community events as well as personal consultation.

In 2019 RESTART accumulated the following stats:

- 32 brain injury survivors assisted financially or were provided transportation to events;
 - Over 100 survivors or caregivers supported in some manner (consulting, recommendations, peer support, etc);
 - 63 in attendance at the third annual RESTART Awareness Event;
 - Estimated to have communicated with hundreds regarding various brain injury topics, BI awareness;
 - Partnered with Melissa Carmen for 2ND Annual BI Awareness Day in Harrisburg;
 - Met with congressional members in Washington, DC for the fifth consecutive year to discuss Brain Injury goals of the Brain Injury Association of America;
 - Purposely increased BI awareness and networking efforts electronically through social media increasing attention and awareness of those living with brain injury and the caregivers’ perspective; and
 - Received ACBIS Brain Injury Fundamentals Certification.
- **Council on Brain Injury (CoBI)** – CoBI is a nonprofit corporation that was formed in memory of Dr. David Strauss (co-founder of ReMed) after he died in 2004 at the age of 48 from a brain tumor. David was a larger than life force in the brain injury field and

CoBI's mission is to support prevention, education, and research to help improve the lives of individuals and their families who have been impacted by this life altering event. Funds raised through CoBI sponsored conferences, golf tournaments and tribute programs are used to provide grants to various programs and organizations who assist those with brain injuries and their families.

Updates for 2019:

- CoBI continued to support ReDiscoverU, which provides classes and activities to adults with brain injury in the Paoli, Pittsburgh and Erie areas. Some of the classes/activities offered included: Rock Climbing, Access Sports Day, Share Night, and several socials;
- CoBI continued to sponsor a one-day Annual Spring Conference in Pittsburgh; over 100 professionals attended;
- CoBI also sponsored several free Clinical Forums for professionals, including: Brain Injury in Childhood, Legal and Financial Issues for People with Disabilities, Medical Marijuana & TBI, and Compassion Fatigue in Brain Injury Rehab;
- Grants totaling just over \$35,000 were provided to 23 different organizations who provided a broad range of programs and services across the Commonwealth. Grants fell into 3 general categories: Education/Prevention; Quality of Life and Advocacy; and Research. Programs included fitness training for individuals with disabilities, adaptive sports, equestrian therapy, art therapy, music caregiver support, research projects, and a one-day retreat for caregivers;
- Additionally, a total of \$3,300 was provided in grants to 13 support groups in PA. These grants are available to help fund support groups and alleviate out of pocket expenses for those who run them;
- CoBI participated in the planning committee for the Model Systems Brain Injury Conference and sponsored two sessions: Tai Chi and Jazz Unwind; and
- Each year, CoBI selects one individual and one organization that have made a significant impact on improving the lives of people with brain injury. For 2019, the individual award winner was Dr. Drew Nagele and The Jazz Sanctuary was selected as the organization award winner.

Ongoing Activities:

PATS Concussion Education Program:

Through a grant with the PA Department of Health, the Pennsylvania Athletic Trainers' Society (PATS) developed a plan to identify, address and eliminate health disparities in the populations served by Title V, specifically concussion education for youth in 6th grade and under who participate in sports and those individuals affiliated with these youth sports. Due to

unanticipated delays the grant was only able to run from March through December during 2019.

The PATS work plan provides educational trainings throughout all of Pennsylvania (PA), both rural and urban areas, both of which experience significant health disparities. Further, by taking a statewide approach PATS is educating all affiliated with our target population, the best practices in concussion identification and management will result in more health equity for all young athletes in PA. The PATS plan will help all young athletes with concussions achieve better health outcomes and eliminate health disparities.

PATS partnered with Sports Safety International (SSI) to provide online training for PATS ConcussionWise Instructors (CWIs):

- **36** CWI's were trained or renewed based on a first come first served basis;
- **117** total presentations have been made by 23 different CWIs;
- **3,152** youth in 6th grade and under who participate in sports were educated about concussions;
- **751** coaches and parents participating in youth sports in 6th grade and below were educated about concussions;
- PATS partnered with iHeart Radio to provide Public Service Announcements (PSAs) regarding the AT's role in concussion education to youth sports participants throughout the Commonwealth in conjunction with the PA DOH and SSI; and
- The PSAs were broadcast on numerous iHeart radio outlets throughout the Commonwealth from **March through May** resulting in **1,733,333** media impressions and again **October through November** for **666,667** media impressions and totaling in **2,400,000** media impressions.

The Pennsylvania Shaken Baby Syndrome (SBS) Prevention Program

(<https://www.health.pa.gov/topics/programs/Pages/Shaken-Baby-Syndrome.aspx> #1-717-772-2763) - The SBS Prevention Program is an injury prevention program supported by the Department. PA Hospitals and birthing centers are required per Act 2001-176, 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 2001-176.

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

PA Dept of Health Head Injury Program (HIP) #1-717-772-2763 (8:30 AM – 4PM)

<https://www.health.pa.gov/topics/programs/Pages/Head-Injury.aspx>

PA Dept of Health NeuroResource Facilitation Program (NRFP) #1-717-772-2761 (8:30 am – 4:00 pm)

<http://neuroresource.health.pa.gov>

Brain Injury Help Line #1-866-412-4755

Brain Injury Resource Line (BIRL) #1-800-444-6443

BIAPA #1-866-635-7097

www.biapa.org

Disability Rights Pennsylvania #1-800-692-7443

www.disabilityrightspa.org

PA Health Law Project #800-274-3258

www.phlp.org

The Traumatic Brain Injury Advisory Board meetings are open to the public. If you would be interested in attending a meeting, please contact Julie Myers, Dept. of Health: julimyrs@pa.gov; # 717-772-2763.