

**PENNSYLVANIA**

**DEPARTMENT OF HEALTH**

**TRAUMATIC BRAIN INJURY**

**STATE ACTION PLAN**



*Edward G. Rendell, Governor*

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## I. Executive Summary

The Pennsylvania Department of Health, as part of the Traumatic Brain Injury Planning Grant awarded by the Health Resources and Services Administration (HRSA), formed the Traumatic Brain Injury Advisory Board. This Advisory Board currently consists of representatives of the Departments of Health, Aging, Labor and Industry, Public Welfare, Education, and Insurance. In addition, organizations such as the Brain Injury Association of Pennsylvania, Inc. (BIAPA), the United Cerebral Palsy of Pennsylvania, the Centers for Independent Living and the Pennsylvania Association of Rehabilitation Facilities (PARF) and individuals with traumatic brain injury and family members were included as members of the Advisory Board. Members of the public who attended the meetings of the Advisory Board included representatives of Pennsylvania Protection and Advocacy and the Hospital and Health System Association of Pennsylvania as well as head-injured persons and members of their families.

The Department of Health entered into a contract with the University of Pittsburgh to conduct a survey of head-injured persons and family members. Advisory Board representatives also participated in focus groups held at two locations in Pennsylvania.

From the results of the survey, discussion groups, and discussions at the many meetings, the Advisory Board developed a recommended State Action Plan. The Department of Health reviewed the Advisory Board's recommendations and is submitting this final version of the State Action Plan. This State Action Plan will guide the state of Pennsylvania toward the following vision.

The overall vision of the Department of Health is that there will be culturally sensitive, effective systems of care for a person with a traumatic brain injury and his or her family that will:

- Improve self-esteem by empowering the utilization of all services available/needed
- Assist with coping with adjustment issues
- Help decrease frustration by removing barriers to services
- Provide an opportunity to maintain a positive outlook by having options to choose from to reach the highest level of function possible
- Enhance community inclusion and reduce isolation

This document contains the updated Action Plan, of the Pennsylvania Department of Health. This is the first update of the Departments' original Action Plan, which was issued in April, 2003. It is the result of deliberations in committee and in full board meetings of the Brain Injury Advisory Board with subsequent approval through the Department of Health.

### Update to the State Action Plan

The original goals of the State Action Plan were as follows:

- 1) ***Create a clearinghouse for TBI information, referral, and support, accessed by a toll-free number and through the Internet. Personnel trained in TBI will staff this clearinghouse and will have an up-to-date resource directory and information library available to them.***

- 2) *Enhance local service systems for persons with TBI by developing linkages between existing programs, and by sharing information with advocacy organizations.*
- 3) *Provide TBI training and technical assistance to the wide variety of people affected by and involved in TBI, including injured persons, families, public and private service providers, educators and legislators.*
- 4) *Reduce the number of brain injuries in Pennsylvania by increasing public awareness about risk factors, and providing education and strategies to reduce the incidence and prevalence of TBI. This should be accomplished through a coordinated system of education and information dissemination.*

In order to fulfill the vision developed by the TBI Advisory Board and address the issues identified in the Needs Assessment, the four original goals needed to be modified. The TBI Advisory Board recognized the need to update the TBI State Action Plan including action steps, time frames, and necessary resources within the Plan to reflect accomplishments and areas of improvement.

At the January 20, 2005 Board meeting, five new subcommittees were formed to assist with updating the Plan and work on specific goals and activities. They included the following: State Action Plan Update; Statewide Summit/Conference Planning; Public Awareness/Linkages; Prevention; and Development of By-laws. After discussions by the State Action Plan subcommittee followed by input from the Prevention Chairperson, it was decided to combine the Prevention and Public Awareness/Linkages subcommittees. This new subcommittee will focus on educating the public about the causes, effects, and treatment of brain injury, and the identification of risk factors that can lead to brain injury.

The four subcommittees will present their recommendations to the TBI Advisory Board for approval. The Department of Health will review the recommendations for consideration, solicit approval, and develop implementation plans.

The TBI Advisory Board recognizes that the State Action Plan is a working document. Updates and revisions will continue as a result of TBI Advisory Board accomplishments and plans for the future.

## **II. BACKGROUND**

Over 15,000 Pennsylvanians sustain traumatic head injuries each year, and the devastating effects are often felt for years after the initial injury occurs. Each year, more than 1,000 injured persons experience injuries so disabling that they require intense hospitalization and acute rehabilitation services.

The Centers for Disease Control and Prevention estimate that 5.3 million people are living with the results of Traumatic Brain Injury. Using Pennsylvania's overall population data, it is estimated that 245,000 of these people are residents of the Commonwealth.

The majority of traumatic brain injuries affect young people, especially teenagers and young adults. However, a study commissioned by the Department of Health, *Traumatic Brain Injuries in Pennsylvania, 1995-1999*, revealed that over twenty-eight percent of all individuals discharged from a hospital in Pennsylvania who had a traumatic brain injury were 65 years of age or older.

The enormous impact of these injuries is felt throughout the community health system and human services system. For example, according to the Pennsylvania Department of Health *Head and Spinal Cord Injuries in Pennsylvania 1995*, over \$360 million were spent on acute services for traumatic brain and spinal cord injuries. The cost for medical intervention and support over a lifetime after traumatic brain injury is even greater.

Personal costs are also high. Traumatic brain injuries (TBI) often result in life-altering and sometimes life-long disabilities. People with such injuries may face a lifetime of paralysis, seizures, memory loss, decreased social capacity, depression, or personality disorders such as temper flare-ups, aggression, cursing, and inappropriate sexual behavior. In addition, traumatic brain injury alters the life of the immediate family of the injured person. Careers are impacted; relationships change, and extensive pressures are felt as the family struggles with all of the issues relating to this devastating injury. From health care to rehabilitation concerns, and from legal to financial issues, families are suddenly thrust into areas in which they have limited or no experience.

In August 2001, the Secretary of Health appointed a Traumatic Brain Injury Advisory Board (Advisory Board). Funding for the Advisory Board was received from the TBI Planning Grant awarded by the Health Resources and Services Administration (HRSA). The Advisory Board was comprised of 18 members. The following state agencies were assigned as members of the Advisory Board to act on behalf of their Departments in working towards the development and implementation of this State Action Plan.

- Department of Health (Lead Agency)
- Department of Aging
- Department of Labor and Industry
- Department of Public Welfare
- Department of Education
- Department of Insurance
- Department of Corrections

In addition, representatives of the Brain Injury Association of Pennsylvania, Inc. (BIAPA), the United Cerebral Palsy of Pennsylvania, the Centers for Independent Living, and the Pennsylvania Association of Rehabilitation Facilities (PARF) joined with individuals with traumatic brain injury and family members to form the Advisory Board. Representatives of Pennsylvania Protection and Advocacy, and

the Hospital and Health System Association of Pennsylvania routinely attended meetings of the Advisory Board as members of the public.

These agencies and individuals have brought to the table extensive knowledge of existing programs and gaps in service. By sharing information and identifying common concerns, the Advisory Board has greatly enhanced collaboration regarding TBI among State agencies. The Advisory Board created the catalyst for a lifespan approach to planning for TBI services that assures the inclusion of minorities, children, adults, and older adults. The Advisory Board serves as a central point to bring together current information and to identify the potential for collaboration on an on-going basis. In addition, it places Pennsylvania in a position to apply for grant funding through strong collaborative efforts.

### **III. Assessments**

The Pennsylvania Department of Health contracted the University of Pittsburgh to conduct the TBI individual and family surveys. The surveys were conducted in 2002 to identify the medical and social needs of individuals with traumatic brain injury and members of their families. In this survey, participants were asked to identify their major areas of needs and concerns. The Traumatic Brain Injury Advisory Board was instrumental in designing the needs assessment and publicizing two toll-free telephone lines designed to encourage individuals with a TBI and family members to volunteer for the needs assessment surveys. No existing questionnaire was found to be adequate for such a needs assessment. Therefore, two questionnaires were developed: one for injured persons and one for family members. In the questionnaires people were asked to identify services that were both important and unmet in various stages of their experience. These stages included “acute care”, “rehabilitation”, “return home” and “current situation”.

The assessment was completed through telephone interview surveys. There were 305 individuals or potential candidates interviewed for the needs assessment but only 206 qualified as having and being able to complete the survey. The needs assessment summary report identified the five highest needs and unmet needs for persons who have experienced a TBI, and family members. The top five unmet needs were: 1) Need for greater public awareness, community understanding and acceptance of those with brain injury; 2) Need to have experts available locally who specialize in brain injury; 3) Need for those affected by TBI to be educated about their injuries and prognosis for recovery; 4) Need to have opportunities for the injured to socialize; and 5) Need for a central location where information on available services can be easily obtained. The complete Needs Assessment report is included as Appendix A.

In addition to the survey, focus group discussions were held at two locations: Wilkes-Barre and Danville. The focus groups were organized through Brain Injury Support groups that meet in these areas. These discussions involved five support groups and approximately 55 people.

Participants in the focus groups noted that funding is available for medical services, but the duration of those services is too limited. They stated that continuing rehabilitation programs for life-long living needs are required after in-patient rehabilitation. The participants noted that these programs may be as

simple as routine physical fitness programs, but should be conducted with some guidance and supervision.

Participants also expressed concern with the limitation of insurance coverage, including limits on physical and cognitive rehabilitation. They cited the need to continue services and supports after insurance coverage stops. This is especially important since the family provides most of the supports that are used by individuals with traumatic brain injury.

The respondents to the survey and participants in the focus groups cited the need for ongoing home and community-based services. They stressed that funding of quality, reliable services and caregiver support is necessary. Waiver services that allow the caregiver to work as well as funding to allow the family to be the caregiver were identified needs, in addition to the need for adequate respite care and day care, home health services, appropriate case management, advocacy services, housing assistance, support for housing modification, and improved public transportation.

Education of injured persons, families, providers, and the public was identified as important in both the survey and focus groups. Important to this effort would be to create a single point of entry and/or information, where all services and information could be accessed. This education effort should address early identification and insurance issues as well as those involved with day-to-day living.

In the focus groups, a recommendation was made to establish mini-grants that could be utilized by support groups, local service groups, and faith-based organizations to provide social activities for individuals with TBI.

The TBI Resource Subcommittee of the Advisory Board developed and conducted a survey for post-acute brain injury rehabilitation facilities and rehabilitation hospitals. The survey was conducted to identify what services are available for individuals with TBI. The list of providers was obtained from the Pennsylvania Association of Rehabilitation Facilities (PARF) and the Hospital and Healthcare Association of Pennsylvania. Surveys were mailed to 152 providers, with a 35% response rate.

## **IV. Vision and Goals**

### ***Vision:***

The overall vision of the Department of Health is that there will be culturally sensitive, effective systems of care for a person with a traumatic brain injury and his or her family that will:

- Improve self-esteem by empowering the utilization of all services available/needed
- Assist with coping with adjustment issues
- Help decrease frustration by removing barriers to services
- Provide an opportunity to maintain a positive outlook by having options to choose from to reach the highest level of function possible
- Enhance community inclusion and reduce isolation

To fulfill this vision, the Department of Health recommended the following four goals:

**Goal 1:**

***Create a clearinghouse for TBI information, referral, and support accessed by a toll-free number and through the Internet. Personnel trained in TBI will staff this clearinghouse and will have an up-to-date resource directory and information library available to them.***

The TBI Information and Referral Clearinghouse provides the vehicle for coordinating the program information from state agencies, providers, and the healthcare community. It can ultimately become a key point of entry with data collection and follow-up to determine the effectiveness of referrals.

The Department of Health will maintain the contract for the TBI clearinghouse. It is intended that the Clearinghouse will be one of the first contacts for individuals with traumatic brain injury and their families. There will be a public education campaign to increase awareness of information and resources available. The clearinghouse will continue to have a toll-free telephone line and website that can be used to provide information about traumatic brain injury. The contractor will maintain the tracking system to track the number of individuals interested in traumatic brain injury services, the services that they require, and their satisfaction with these services. The resource directory, information library and public service announcements will be updated periodically.

**Goal 1 Updated:**

***Increase use and awareness of the TBI Information and Referral clearinghouse by persons with TBI, families, providers and others interested in brain injury as a key resource of information for TBI services and supports in Pennsylvania. Link the clearinghouse to other major informational resources in state government providing assistance and information on public resources for persons with TBI and their families.***

**Toll-Free Line** - A new contractual agreement was developed with Policy Studies, Incorporated (PSI), to operate the Pennsylvania Health and Human Services Call Center (HHSCC). PSI oversees several of the Commonwealth's existing toll-free lines. The HHSCC accommodates the needs of TBI survivors, family members, and the public through inclusion of a line dedicated to TBI issues and needs. Per the contractual arrangement, this toll-free line is staffed with trained responders who will address the needs of the TBI population and their families. HHSCC staffs the line from 8:00 a.m. until 8:00 p.m., Monday to Friday and 8:00 a.m. to 6:00 p.m. on Saturdays, with voice mail during non-operating hours. There is a database to enter caller information that will be used for evaluation and monitoring purposes. To determine if the consumers are receiving appropriate services, surveys are randomly administered to callers of the toll-free line. The HHSCC can also link the callers to other services such as website addresses and support group information. At the conclusion of each call, information about the Brain Injury Association of Pennsylvania (BIAPA) is provided and a referral is offered. For this line to effectively and informatively operate, the educational and skills-based training course for the toll-free line staff was conducted by the BIAPA. This course is focused on Introduction to Brain Injury, and includes skills-based training, such as how to obtain information on TBI resources, recreation and leisure, long-term care programs, and AdultBasic Insurance. The training addresses cultural competence, caring customer service, and methods for effective communication.

**TBI Resource Directory** - The Department of Health conducted a TBI Planning Grant Resource Survey, which includes data integral to the creation of a TBI Resource Directory that will be made available in print and on-line through the DOH's website for TBI information. The DOH contractor for the toll-free line, PSI, will maintain the database for the Resource Directory. The Resource Directory and website will be a resource for the staff answering calls to access information about resources available by specific locality.

**TBI Information Library** – Informational materials and current research is being compiled for the TBI Information Library with the assistance of the Traumatic Brain Injury Advisory Board and contacts made by the Department of Health with other states. The primary responsibility for the maintenance of this Library is charged to PSI. These printed materials will be housed at the HHSCC and will be mailed to those who call requesting information about TBI.

**DOH Website** – HHSCC developed a TBI Website, [www.helpinpa.state.pa.us](http://www.helpinpa.state.pa.us), which includes informational material about the condition and treatment of TBI, protection and advocacy services, as well as links to other websites. There will be a link to the Department of Health's website. This site will include a database of community and State resources, as well as information pertaining to the TBI Advisory Board. The Department of Health has recently updated its Head Injury Program website which will be expanded to include the above referenced information.

**Goal 2:**

***Enhance local service systems for persons with TBI by developing linkages between existing programs, and by sharing information with advocacy organizations.***

There are several publicly funded resource systems that offer services and support to people who have sustained a traumatic brain injury. These are associated with (and in some cases are funded by) various departments of the Commonwealth, including the Department of Health, the Department of Public Welfare, the Department of Education, the Department of Aging, and the Department of Labor and Industry. The Vocational Rehabilitation Program administered by the Department of Labor and Industry and the Head Injury Program administered by the Department of Health are examples of these programs. In addition, there are three Medicaid waiver programs, (OBRA, Independence, and COMMCARE Waivers), administered by the Department of Public Welfare which can benefit individuals with TBI.

The regulations for Public Law 101-476, the Individuals with Disabilities Education Act (IDEA), now include Traumatic Brain Injury as a separate disability category. There is an understandable need for information and assistance in developing appropriate programs for students with TBI in public school after medical discharge. There are needs to identify children with brain injury within the education system; to increase service capacity in the education system; to train educators about brain injury and train professionals for evaluation and treatment. Additional needs would be to develop cohesive, statewide rules for administering a menu of appropriate services based on best practices and to create and support an infrastructure to facilitate coordination of services across all of the systems involved for each individual with brain injury.

The Department of Health also has a “Special Kids Network” which includes resources for children with disabilities, including TBI. The Department of Aging has The PrimeTime Health Program, The Fall Reduction Initiative: Establishing New Directions for Safety (FRIENDS) and the APPRISE program (APPRISE is a free health insurance counseling program designed to help Pennsylvanians with Medicare which involves volunteers). These programs can serve as models for other State agencies to include people of all ages with TBI. A system of care could be further developed to go across the lifespan by coordinating and expanding these existing services.

There are public and private partnerships such as the Department’s TBI Advisory Board, the State Health Improvement Plan (SHIP), the Long Term Care Council, the Council on Aging, the Community Living Advisory Committee, the Home and Community-Based Services Stakeholder Planning Team, and the Family Health Advisory Council. All of these should be utilized in developing a statewide system of supports for citizens who are dealing with the issues of TBI.

There are voluntary statewide committees developed out of needs identified by the community. Examples include the Joint Committee on Mental Health of Older People, local public and private partnerships such as the Office of Vocational Rehabilitation and private industry, and The Children’s Hospital of Philadelphia’s Community Collaborative on Developmental Disabilities Focusing on Transition under the auspices of the LEND. The DOH proposes to have TBI issues on the agenda of all appropriate inter-agency forums and partnerships. By doing so, many people throughout the State will add to the collective thinking and planning for increasing and enhancing services for individuals with TBI. TBI has been represented at the Autism Task Force meetings and at the Home and Community-based Stakeholder Planning Team meetings. Sustaining an active, engaged TBI Advisory Board and the mechanisms described above would keep the focus on coordination of funding and services.

Linkages among all stakeholders in the state of Pennsylvania are necessary. Communication and coordination among all state programs will ultimately result in informed choices and optimizing services and supports for people with traumatic brain injury. These linkages should accommodate:

- Community Living (and the supports to allow it – personal care, respite care, accessibility issues, therapies, reassessment of need, etc.)
- Transportation (for therapies, appointments and social events) - address training issues, regaining drivers license, transportation system issues
- Social Supports
- Case Management (to provide support, information and referrals such as re-evaluations as needed)
- Cognitive Retraining
- Employment (training, assistance, volunteering)
- Life Planning
- Quality, Effective Services for individuals with traumatic brain injury in or close to their community

**Goal 2 Updated:**

***Enhance local service systems for persons with TBI by developing linkages between existing programs and establishing a collaborative partnership among state agencies, service providers, consumers of the services and advocacy organizations.***

DOH created and expanded linkages among existing State programs through Pre-enrollment Assistance provided by the Brain Injury Association of Pennsylvania (BIAPA) and through referrals from the Information and Referral Clearinghouse, DOH District Health Offices, and among state and local inter-agency task forces that already exist. DOH selected the BIAPA as the provider of Pre-enrollment Assistance to help people with brain injury to become enrolled in the Commonwealth's Head Injury Program and/or all other appropriate services offered within the State. The development of common goals that will benefit individuals with TBI and their families through cross-system coordination, and coordination of funding streams and services is necessary to provide efficient, effective services to persons with TBI and their families. Mechanisms to coordinate services and promote cooperation among the various agencies involved would address gaps and overlaps that exist. It would prevent agencies from working at cross-purposes and ensure that opportunities for consistency of services across the state are not missed, thus allowing for scarce funds being used in the most efficient manner.

The public remains largely unaware of brain injury, its consequences and means of accessing available resources and information. The brain injury support group system is a primary front line tool in supporting individuals with TBI and families after sustaining a TBI. The current network of groups is comprised of groups started by people with a brain injury, along with groups started by providers who recognize a local need for a group. Some groups are relatively small and nearing extinction, while others are robust and healthy. There are many areas in the Commonwealth where no support groups are available within a reasonable driving distance. The goal of the support group funding opportunity was to provide support to individuals and families dealing with brain injury through a strengthening and expansion of new and existing support groups. To expand their existing TBI support/activity groups, four TBI support groups received funding in Year 2 of the Implementation Grant.

The TBI Statewide Summit/Conference subcommittee is planning a Statewide Summit for the fall of 2005 with a follow-up meeting to be held in the spring of 2006. Recently in Pennsylvania, both State and grass-roots initiatives have begun mobilizing to improve services for individuals with brain injury. The Summit will bring together advocates and consumers, researchers, service providers, and State policy makers to address issues around collaborating across Departments to streamline services and reduce costs; improving access to services for persons with brain injury using the resources currently available; identifying gaps in services and strategies to fill those gaps with creative thinking; and developing action plans based on the ideas generated at the Summit.

**Goal 3:**

***Provide TBI training and technical assistance to the wide variety of people affected by and involved in TBI, including injured persons, families, public and private service providers, educators and legislators.***

A cadre of speakers, trained in traumatic brain injury issues needs to be developed for education programs at all levels. The training program can be built in a sequential manner. Once a target population is identified, materials and presentations should be prepared for presentation to that population. Then strategies for disseminating this material should be developed and utilized. Initially, when targeting individuals with traumatic brain injury and their families, the support groups existing throughout the state can be used as a forum. For providers, professional conferences can be utilized.

For state agency workers, in-service training days can be provided. There are a number of existing meetings and gatherings through which this can be accomplished. There are efforts in other states that could be replicated. A review of their activities could accelerate progress in this goal.

The DOH proposed a statewide, regional cross-system training be developed as an option for all case managers from state level agencies such as the Office of Social Programs, the Office of Mental Health and Substance Abuse Services, the Office of Mental Retardation, the Department of Aging, hospitals, and home care agencies in the bio-psycho-social aspects of TBI. Professionals and family members would be chosen from each identified region to be trained in a TBI curriculum approved by the Department of Health. The national Medical Home Initiative sponsored by the American Academy of Pediatrics, Shriners Hospitals, Family Voices and others has successfully utilized a similar training model.

**Goal 3 Updated:**

***Provide TBI Training to a wide variety of targeted groups affected by and involved in TBI, including individuals with brain injury and their family members, public and private service providers, educators, and legislators.***

Develop or identify training opportunities, trainers, and materials/presentation. Conduct TBI training opportunities for targeted populations. The training can be built in a sequential manner. Once a target population is identified, the mechanism to provide the training will be developed, training conducted, and evaluated. The next population would be identified.

**Goal 4:**

***Reduce the number of brain injuries in Pennsylvania by increasing public awareness about risk factors, and providing education and strategies to reduce the incidence and prevalence of TBI. This should be accomplished through a coordinated system of education and information dissemination.***

In all of the surveys and discussions that have been conducted, it was found that there is a need to increase public awareness of traumatic brain injury and its devastating effects on our state and its citizens. It was also found that there is a need to educate the public on the potential offered by injured persons at all levels of community living. Persons who have sustained a traumatic brain injury offer a tremendous pool of resources that are underutilized in Pennsylvania as well as other states.

Efforts in accomplishing this goal should:

- Increase education and public awareness of TBI
- Increase statewide education and awareness on TBI by developing and implementing a statewide education campaign utilizing materials available through the HRSA, the TBI Technical Assistance Center, Brain Injury Association of Pennsylvania, and other states.
- Increase public awareness of the positive abilities of brain injured persons through the development and dissemination of a series of public service advertisements on traumatic brain injury.
- Increase education and awareness and understanding of TBI through participation in all possible public forums, (attending other Stakeholder meetings, presenting at various conferences, debates,

discussion groups, news panel discussions, etc.), to educate the public on all aspects of traumatic brain injury.

- Increase brain injury education and awareness in schools.
- Increasing the awareness of TBI by identifying the risk factors.
- Providing safety prevention strategies and education programs to reduce the incidence of TBI.
- Promoting appropriate interventions to prevent TBI and the secondary conditions associated with TBI.
- Increasing surveillance efforts to better identify the magnitude of TBI and provide data to enhance prevention efforts and improve the lives of people with TBI.
- Collaborating with other public and private partners in TBI prevention activities.

Education is an issue that has been identified in both the state survey and in focus groups. The issue is not a simple one, however, it involves all levels of those associated with traumatic brain injury. Individuals with traumatic brain injury, family members, service providers (public and private), educators, and legislative leaders--all are in need of education. These needs should be met by a coordinated system of education and awareness, and information that should be developed and expanded on an annual basis.

There is a need to access existing educational materials, courses, brochures and other effective media for communication and education. In addition, educational materials in a number of formats (such as recorded medium, Braille, alternate languages, etc.) need to be developed or obtained for presentation to individuals with traumatic brain injury as well as seasoned professional providers.

**Goal 4 Updated:**

**Increase public awareness about TBI injuries, including risk factors, through a coordinated system of education and information dissemination.**

The Department of Health accepted applications related to education and awareness of the causes of traumatic brain injury as a result of sports or other activities. Funding was made available to support educational activities related to causes and consequences of concussions/mild-severe TBI. These educational activities will teach schools, community sports programs, and organizations about how to prevent and identify the next steps in the event that children and youth sustain concussions, which could result in mild to severe head injury. The ultimate goal of the project was to assist communities to learn about traumatic brain injury, incorporate a prevention plan, and offer resources to appropriately intervene on behalf of youth who are suspected of having a concussion/mild-severe head injury in Pennsylvania. The TBI Education Project was designed to empower communities by providing support for activities that educate individuals that work with children and youth about TBI; educate about how to recognize concussions and the potential for mild to severe TBI; and the tools to prevent unnecessary complications resulting from a secondary concussion or head injury that has the potential to lead to permanent disability.

The DOH, with assistance from the TBI Advisory Board, has begun to purchase current educational materials such as videos, books, and tapes from the Brain Injury Association of America, the Traumatic Brain Injury Technical Assistance Center (TBITAC), as well as material developed by other states to share with selected contractors and for use in trainings.

The TBI Statewide Summit will provide education and information through advanced-level introductory TBI material and through the facilitation of workgroups. Participants will work to identify barriers and brainstorm solutions in key areas of need. The areas may include improving the coordination of educational services for children with brain injury; developing opportunities for work and other productive activity in the community, across the lifespan of an individual with a brain injury; and improving continuity of services and collaborations among service agencies and providers.

## **V. State Action Plan with Action Steps**

The Department of Health has adopted the following revised State Action Plan with action steps. Each of the action steps in this plan requires varying degrees of inter-agency cooperation and/or funding. A continued focus on returning the person who has sustained a traumatic brain injury to the highest level of performance and participation possible is critical. The specific action steps are as follows:





<b>Strategy/Goal: Increase use and awareness of the TBI Information and Referral Clearinghouse by individuals with TBI, families, providers and others interested in brain injury as a key resource of information for TBI services and supports in Pennsylvania. Link the Clearinghouse to other major informational resources in state government providing assistance and information on public resources for persons with TBI and their families.</b>				<b>Goal 1</b>
Action Steps	Timeframe	Resource Needed	Responsibility	Outcome Measures
1. Design the model TBI clearinghouse of information	2003 Completed	Information re: models from other DOH programs and other states	Department of Health (DOH)	
2. Develop resources database and tracking system for incoming callers' requests	2003 Completed March 2005	Brain Injury Association of Pennsylvania (BIAPA) provided the Resource Directory	DOH contractors (BIAPA and Policy Studies, Inc.)	
3. Develop the toll free line menu, library, and website.	2003 Completed March 2005	DOH contractor for toll-free line, website and library.	DOH, DOH contractor	
4. Clearinghouse is set up, policies and procedures put into place, staff are trained	2003 – Conducted on March 2005	TBI training, Brain Injury 101 for Call Center staff	DOH, DOH contractors	
5. Appropriate Call Center line staff received specific training on TBI. BIAPA provides training to the HHSCC staff on TBI and how to	2003-2004 March 25, 2005	Call Center staff are hired. BIAPA provides a one-day training on Brain	DOH, DOH contractor	

use the database. TBI clearinghouse begins taking calls, provides information and referral to callers.		Injury 101 and how to use the database.		
6. TBI Clearinghouse begins to take calls, provides information and referrals and mails materials to callers.		March 28, 2005	Policy Studies, Inc hires 6 staff to answer the Brain Injury Help Line. The Help Line went live on March 28, 2005 and received 10 calls the first week.	DOH, DOH contractor
TBI Clearinghouse refers to appropriate state providers for publicly funded programming.		2003 Ongoing as of March 28, 2005	DOH Head Injury Program, CommCare, Independence, and OBRA Waivers, as well as DOE, OVR, PENNDOT.	DOH, DOH contractor
6. Expand/update resource directory, website information, library, and public awareness of clearinghouse.		2004 Ongoing from March 2005	Update survey of providers	DOH in conjunction with TBI Advisory Board Call Center
7. Provide information on the Clearinghouse services to persons/organizations for the year.		2004 Ongoing from March 2005	Expanded public awareness of service availability. The Health and Human Services Call Center provides Outreach efforts to the public to increase awareness of the Brain Injury Help Line	DOH contractor

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<p>8. Evaluate the Call Center, at least annually.</p>		<p>2004 Ongoing, from March 2005</p>	<p>DOH TBI Line Manager provides monthly reviews of services provided through calibration. Call Center conducts random surveys to callers, requesting input on the satisfaction of services received.</p>	<p>DOH, and Call Center, with input from the Advisory Board</p>
<p>9. Expand/update resource directory, website information, library, and public awareness campaign.</p>		<p>2008</p>	<p>Two TBI trainings and Resource Directory updates will be provided by BIAPA, Call Center sends surveys to providers for updates, TBI Line Manager analyzes monthly reports to areas of need and to target resources to those areas. Update survey of providers</p>	<p>DOH, TBI Advisory Board</p>

<b>Strategy/Goal: Enhance local service systems for persons with TBI by developing linkages between existing programs, and by sharing information on services and programs with advocacy organizations.</b>				<b>Goal 2</b>
Action Steps	Outcome Measures	Timeframe	Resources Needed	Responsibility
1. Evaluate extent to which state programs refer to each other (baseline assessment)		2003 2005 to 2007	Surveys, examination of agency protocols	DOH, Advisory Board
2. Developed funding opportunities to create and/or expand support groups for persons with TBI and families to promote education and networking at the grass roots level focused on TBI		March 2005 and April 2005 to March 2006		DOH, input from Advisory Board
3. Hire a Support Group Coordinator to identify and establish a regional speakers' bureau to be accessed by local support groups and to develop new support groups in underserved areas		October 2005 to 2006		DOH provider
4. Increase the Head Injury Provider network, to serve more individuals in more areas of the state.		2006	Change HIP requirements to certify more Rehabilitation Providers as HIP providers	DOH
5. Create linkages among existing state programs		2003-2005 to 2007	Resource Directory, identify key personnel at each agency who are responsible for facilitating services for people with brain injury	DOH, Advisory Board
6. Explore where state and local inter-agency task forces already exist and develop brain injury awareness in the task forces and		2004 2005 to 2007	Local participation by OVR, CIL, DPW, DOH, DOE, PENNDOT, PIAT, PDA, Long Term Care Council, and any other group dealing with brain	DOH, Advisory Board

committees. Autism task force and other Home and Community based services stakeholder groups			injury in that locale	
7. Provide Pre-enrollment Assistance services to persons with brain injuries to enter the state system and receive the necessary assessment, rehabilitation and case management services in as timely a manner as possible.		October 2004 to June 2008		
8. Evaluate programming		2006	Data Analysis	DOH, Advisory Board

<b>Strategy/Goal: Provide TBI Training to a variety of targeted groups affected by and involved in TBI, public and private service providers, educators, legislators, and community at large..</b>			<b>Goal 3</b>
Action Steps	Timeframe	Resources Needed	Responsibility
1. Identify a targeted population, develop the training and material; identify the trainer, hold the training, evaluate the training and identify the next targeted population to train on TBI specific issues.	April 2005 to March 2006	Cooperation for in-service training times from OVR, CIL, MH/MR, DPW, DOH, DOE, PENNDOT, PIAT, PDA, PPA, PMS. Data on areas of need. Trainer develops materials and curriculum to meet the identified training needs of this population.	DOH, TBI Advisory Board, subcommittee, Training Consultant
2. Identify the next targeted population, develop the training and material; identify the trainer, hold the training, evaluate the training and identify the next targeted population to train on TBI specific issues.	April 2005 to March 2006	Cooperation for in-service training times from OVR, CIL, MH/MR, DPW, DOH, DOE, PENNDOT, PIAT, PDA, PPA, PMS. Data on areas of need. Trainer develops materials and curriculum to meet the identified training needs of this population.	DOH, TBI Advisory Board, subcommittee, Training Consultant
3. Identify the next targeted population, develop the training and material; identify the trainer, hold the training, evaluate the training and identify the next targeted population to train on TBI specific issues.	2006-2007	Cooperation for in-service training times from OVR, CIL, MH/MR, DPW, DOH, DOE, PENNDOT, PIAT, PDA, PPA, PMS. Data on areas of need. Trainer develops materials and curriculum to meet the identified training needs of this population.	DOH, TBI Advisory Board, subcommittee, Training Consultant
4. Identify the next targeted population, develop the training and material; identify the trainer, hold the training, evaluate the training and identify the next targeted population to train on TBI specific issues.	2007-2008	Cooperation for in-service training times from OVR, CIL, MH/MR, DPW, DOH, DOE, PENNDOT, PIAT, PDA, PPA, PMS. Trainer develops materials and curriculum to meet the identified training needs of this population.	DOH, TBI Advisory Board, subcommittee, Training Consultant

<b>Strategy/Goal: Increase public awareness concerning TBI Injuries including risk factors, through collaborative partnerships and a coordinated system of education and information dissemination.</b>			<b>Goal 4</b>
<b>Action Steps</b>	<b>Timeframe</b>	<b>Resources Needed</b>	<b>Responsibility</b>
1. Develop and implement a public education campaign for the state of PA (Public Awareness)	2006	Get, review and recommend materials. Sources: PA Division of Health Risk Prevention, BIAA, TBITAC, BIAPA, PLCB	DOH, Advisory Board, PA Division of Health Risk Prevention
2. Identify and engage in all possible forums for education (outreach and public awareness).	2006	Debate, discussion groups, education TV and radio news shows, NPR. Strategize how to get to more people (prevention message in relevant newsletters, present at national meetings)	Advisory Board members
3. Conduct Brain injury prevention awareness programs for students and parents in the schools.	2006-2007	Materials from BIAA, TBITAC, BIAPA, PLCB, Coordinator Relationship with DOE, School Nurse Association	DOH
4. Conduct brain injury awareness programs for sports athletic programs (had a Board presentation by ImPACT)	2006-2007	Partnership with Pittsburgh “Return to Play” materials from BIAPA, TBITAC, BIAA, PLCB. (prevention message in relevant newsletters, present at national meetings)	DOH
5. Conduct brain injury awareness programs for police, corrections, prisons	2006	Staff presenter, materials from BIAA, TBITAC, BIAPA, PLCB (prevention message in relevant newsletters, present at national meetings).	DOH
6. Conduct brain injury awareness programs for EMS, hospital ER	2005	Staff presenter, materials from BIAA, TBITAC, BIAPA, PLCB	DOH

and trauma teams		(prevention message in relevant newsletters, present at national meetings)	
7. Partner with health professional organizations to develop injury prevention CE programs for primary care physicians and allied health professionals.	2005	Catalog and assess existing CE, develop educational materials and obtain appropriate credentialing.	DOH, PMS, POMS
8. Develop and disseminate a series of public service announcements on brain injury (public awareness)	Completed in 2003- Held in Scranton by Tom Carroll and Mike Miller	BIAA PSAs with addition of DOH toll free number, BIAPA toll free number, TV and radio time	DOH, DOE, BIAPA
9. Develop a method of evaluation to determine effectiveness of all activities.		Data analysis	DOH, Advisory Board
10. Conduct brain injury awareness programs for targeted populations such as police, corrections, prisons (Summit/conference)	March 2006	Staff presenter, Materials from BIAA, TBITAC, BIAPA, PLCB	DOH, DOH contractor

**ADDITIONAL RECOMMENDATIONS FROM THE TBI ADVISORY BOARD:**

The Department of Health recognizes the many contributions made by the TBI Advisory Board and their recommendations for the State Action Plan.