NJ Traumatic Brain Injury (TBI) Fund Department of Human Services Division of Disability Services 2011



# Annual Report to the Governor and the Legislature of the State of New Jersey

Chris Christie, Governor Kim Guadagno, Lt. Governor Jennifer Velez, Commissioner, Department of Human Services Joseph M. Amoroso, Director, Division of Disability Services Harry J. Pizutelli, TBI Fund Manager, DDS



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CHRIS CHRISTIE GOVERNOR KIM GUADAGNO LT. GOVERNOR Jennifer Velez Commissioner

Honorable Chris Christie, Governor State of New Jersey State House Trenton, NJ 08625 July 1, 2012

Dear Governor Christie:

In compliance to P.L. 2001, c 332 (N.J.S.A. 30.6F-B, I am pleased to present to you the Traumatic Brain Injury (TBI) Fund Annual Report for FY 2011.

The TBI Fund provides financial supports and services to New Jersey residents, who have survived a life changing Traumatic Brain Injury (TBI), to obtain post-acute and rehabilitative services needed to live within the community, and maximize their quality of life. In addition, the Fund promotes education, prevention and awareness in collaboration with the Brain Injury Alliance of New Jersey.

It is estimated that 12,000 to 15,000 New Jersey residents sustain brain injuries from traumatic events each year, of which 1000 are fatal. Approximately 175,000 New Jersey residents currently live with traumatic brain injuries.

Traumatic brain injuries are not age restrictive. As a result, the TBI Fund, administered by the Department of Human Services' Division of Disability Services, currently serves over 1,200 New Jersey residents, ranging from infants to seniors who have survived a mild to severe brain injury.

The New Jersey Department of Human services is dedicated to continuing to provide quality service to State residents with TBI.

Sincerely,

Jennifer Velez Commissioner

## NJ Traumatic Brain Injury Fund Report – 2011

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#### **TBI Fund Quick Facts**

- Fund revenues equal \$3.4 million annually
- 1,200 active recipients currently
- Average award amount \$1,200.00
- The majority of Traumatic Brain Injuries impact those under 35 years of age
- The effects of brain injury are similar for all racial and ethnic groups

## NJ Traumatic Brain Injury Fund Report - 2011

This report is written in accordance to P.L. 2001, c 332 (N.J.S.A. 30.6F-B), which states:

"The Department of Human Services shall report annually on the status of the fund to the Governor and to the Senate and General Assembly committees with responsibility for issues affecting health or human services..."

In addition to providing direct supports to survivors of Traumatic Brain Injury, the Fund also contracts with the Brain Injury Alliance (BIA) of New Jersey to provide outreach, support and education on brain injuries. The Alliance provides many services in conjunction with the Fund's objectives for New Jersey residents who have survived a Traumatic Brain Injury (See section XVIII).

The Fund currently has approximately 1,200 eligible recipients. The annual cap is \$3,000, with a lifetime cap of \$100,000. To date, no applicant has reached their lifetime cap. Average awards for the year are approximately \$1,200. Fund revenue comes from a \$0.50 surcharge from each MVC vehicle registration.

### I. Authority

Statutory Citation: P.L. 2001, c 332 (N.J.S.A. 30:6F-6B) Regulatory Citation: N.J.A.C. 10:141

### **II.** Purpose of the Traumatic Brain Injury Fund

The purpose of the Traumatic Brain Injury (TBI) Fund is to provide financial support to New Jersey residents who have survived a traumatic brain injury to obtain post-acute and rehabilitative services and supports they need to live within the community. The Fund sponsors services and supports that foster independence and maximize quality of life. The Fund does this in two ways:

- 1. Awards to applicants by purchasing supports and services on their behalf; and
- 2. Sponsorship of activities that promote education, awareness and prevention of Traumatic Brain Injury in association with the Brain Injury Alliance of New Jersey.

## **III.** Eligibility for the TBI Fund

• The Fund is the payer of last resort and must be utilized after other benefits and funding sources have been exhausted, or when they do not exist.

To be eligible for services and supports sponsored under the TBI Fund, an individual applicant must:

- Present medical documentation that confirms the presence of a Traumatic Brain Injury as defined by the <u>Centers for Disease Control and Prevention</u>. The Fund serves individuals with all levels of TBI: mild, moderate or severe;
- Be a resident of the State of New Jersey for at least 90 days prior to the date of application; and
- Have liquid assets that do not exceed \$100,000. For the purposes of eligibility, liquid assets are defined as assets that can be accessed as cash within 30-days and excludes the applicant's primary home, vehicle, and retirement resources recognized by the IRS.

## **IV.** Supports and Services

The Fund currently as 1,200 eligible recipients who are actively receiving services based on the approval of an individualized Support Plan, designed with the assistance of a contracted case manager and approved by the Fund Review Committee. For 2011, the maximum annual award was \$3,000 with a lifetime cap of \$100, 000. The average award is \$1,200.

## **V.** Application Process for the TBI Fund

Individuals seeking service from the Fund are required to complete an application and have their doctor complete a medical documentation form that confirms the presence of a TBI. Individuals who cannot successfully complete this process independently can receive assistance from Fund staff.

Completed applications are reviewed by the Fund Manager who confirms eligibility. The individual then is assigned to a case management agency. The case manager meets with the applicant and/or his/her family to discuss needed supports and services. The case manager contacts vendors, gets pricing, and creates a Support Plan with appropriate justifications and supporting documentations.

The Support Plan is returned to the Fund staff to remove any identifying information about the applicant and the vendors to avoid any potential for bias.

Abstracts are then considered by the Fund Review Committee. The Committee may decide to approve, deny, modify, or ask for additional information about the Support Plan. Plans that are denied can be reconsidered with additional justification for the Committee to review at the next scheduled meeting. Should the denial be upheld, applicants may request a Fair Hearing through the Office of Administrative Law.

Award letters are issued to approved beneficiaries with a Guarantee of Payment Letter (GOP) issued to the vendor of service. The case manager assists in coordinating services as necessary. In 2011, the Review Committee approved 90% of presented cases.

The GOP letter includes the service approved, the total amount of funding approved, and the beginning and ending dates of services.

Included in each GOP letter is the following statement, "It is the responsibility of the provider to ensure that the amount billed does not exceed the award amount or valid date. The TBI Fund is not responsible for the cost of any supports, items or services beyond the Definition of Traumatic Brain Injury

The Fund recently has adopted amendments to its regulations at N.J.A.C. 10:141. These amendments include a change in the definition of Traumatic Brain Injury that is used to determine eligibility for benefits from the Fund. The Fund now uses the Federal CDC definition for traumatic brain injury.

## VI. TBI Fund Review Committee

The Review Committee hears abstracts of support requests (Support Plan) written by case managers to determine the outcome of those requests based upon the guidelines and regulations of the Fund. The Committee includes the Director of the Division of Disability Services, the Director of the Brain Injury Alliance of New Jersey, a family member of a brain injury survivor, a brain injury survivor, a professional working in the in brain injury field, and two members of the New Jersey Advisory Council on Traumatic Brain Injury. Each application is reviewed on an individual basis, but each Committee member reviews cases against the standards and measures below:

- There is a clear link to the care and/or rehabilitation of Traumatic Brain Injury;
- Services are clinically needed and have an attainable goal or outcome;
- The services will yield benefits that will continue after Fund sponsorship has ended;
- The request is a good use of Fund resources with reasonable and customary pricing;
- The request made is for more than just financial relief and has a rehabilitative goal.

#### **Top 10 Requested Services from the TBI Fund**

1. Cognitive Therapy	6. Vision Services
2. Assistive Technology	7. Transportation Services
3. Home and Vehicle Modification	8. Household Management
4. Service Coordination	9. Neuropsychology/Counseling Services
5. Pharmaceuticals	10. Companion Services

## VII. History of the TBI Fund

The Fund began operations in 2004, after legislation was passed in 2002 (PL 2001, Chapter 332, Section 5.)

In 2002, through a surcharge on New Jersey Motor Vehicle Registrations, the State of New Jersey established the TBI Fund. The Department of Human Services, through the Division of Disability Services, administers the program. It took two years to start the Fund operations because regulations had to be created and published in the NJ Register, forms for application were developed, procedures were created and staff was hired. The first application request was received on May 3, 2004.

## VIII. New Jersey Advisory Council on Traumatic Brain Injury

#### **Legal Authority:**

#### Executive Order # 84 of 05/28/98

The TBI Fund Advisory Council is charged to: (a) advise and make recommendations to the Department of Human Services and the other related State agencies on ways to improve services regarding traumatic brain injury, including the coordination of such services between public and private entities; (b) encourage citizen participation through the establishment of public hearings and other types of community outreach and prevention activities; and (c) encourage and stimulate research and prevention activities; and oversee any programs created under federal Public Law 104-166 known as the Traumatic Brain Injury Act and any successive amendments to said Act, and report to the federal government regarding such programs. The Advisory Council oversees the program and makes recommendations at quarterly meetings.

Members include eight individuals who are survivors of traumatic brain injury or the family members of such individuals, and at least one individual representing each of the following groups: public or private health-related organizations, disability advisory or planning groups within the State, the Brain Injury Alliance of New Jersey, injury control programs at the State or local level, and the Center for Health Statistics for data research purposes. The Commissioners of the Departments of Human Services, Education, Health, Community Affairs, Labor, Banking and Insurance, Law and Public Safety, and Treasury and/or their designees also serve on the Council.

## IX. Education, Awareness, and Prevention Activities

The TBI Fund's enabling statute requires that the Brain Injury Alliance of New Jersey receive a portion of the Fund's revenue to provide education, awareness and prevention activities. The 2011 contract award for these projects totaled \$837,472. The Brain Injury Alliance of New Jersey has created four goals for 2011, and has developed activities in support of each goal. Highlights are:

#### Goal 1: Promote the TBI Fund

Staff actively refers clients to the Fund.

#### Goal 2: Provide Support to individuals who have survived brain injury and their families

BIANJ maintains a schedule of trainings entitled "Brain Injury Basics" and "Brain Injury 101."

BIANJ maintains a reference/lending library on topics related to brain injury.

BIANJ Family Support staff visit individuals and families to provide support and guidance.

#### Goal 3: Promote Public Awareness of the Incidence and Prevalence of Brain Injury

BIANJ has developed fact sheets and materials that identify the symptoms and causes of brain injury.

#### **Goal 4: Promote Awareness and Prevention in Special Populations**

BIANJ has initiated several targeted campaigns for special populations including: falls in the elderly population and sports related concussions.

## **X.** Changes to the Fund's Regulations

From 2007 through 2009, the Fund experienced tremendous growth, more than doubling the number of clients served. In the summer of 2009, the Fund experienced unprecedented and unanticipated growth. The number of applications received each month went from 15-20 to approximately 300. In addition, requests for assistance from the Fund increased so much so that the average award to an individual went from \$3,000 to \$6,000 for a year. This growth led to an increase in expenditures for client services, administrative costs for case management and operations, while the revenues generated from the collection of Motor Vehicle Registrations remained stable. The New Jersey Advisory Council on Traumatic Brain Injury (appointed by the Governor) oversees the Fund. As a result, the Council was advised of the impending financial crisis

with the Fund in April 2009. Division staff presented the Council with a variety of options for restructuring the Fund and sought their advice. There were two presentations to the Council on this issue. At the June 9, 2009 Council meeting, the members, by vote, endorsed the Division's plan for restructuring the Fund. Formal amendments to the current regulations were drafted by staff.

Also, effective November 1, 2009, a hold was placed on all newly submitted Fund applications and the applicants were advised that their submissions would not be processed until a later date.

With an impending shortfall, the Traumatic Brain Injury (TBI) Fund published new regulations in the New Jersey Register on December 21, 2009 (41 N.J.R. 4657), making certain changes in eligibility and covered services under the Fund.

The proposed regulations changed eligibility, service coverage, and instituted limitations on the duration of some therapeutic services. These revisions were made for the purpose of keeping the Fund financially viable. The changes included:

- Amending the definition of Traumatic Brain Injury (TBI) to reflect the federal Centers for Disease Control & Prevention (CDC) definition of TBI. Previously, the definition from the federal TBI Act (different from the CDC definition), included individuals with acquired, as well as traumatic, brain injuries. Acquired Brain Injuries include: Stroke, Brain Tumors, Anoxia and Aneurysms.
- Limiting the duration of cognitive, physical, occupational and speech language therapy.
- Lowering the annual cap on services from \$15,000 per year.
- Changing the "order of selection" that is to be used if the Fund has insufficient resources to approve all applications.

Eligible services covered by the Fund also changed, including, but not limited to; the elimination of certain services such as:

- Massage therapy
- Gym/Fitness memberships
- Services rendered by out-of-state providers
- Personal care services that are deemed to be custodial in nature
- Payment of medical co-pays and insurance premiums.

These changes enabled the Fund to focus on services directly related to Traumatic Brain Injury treatment and rehabilitation.

Active clients with Acquired Brain Injuries were disqualified as their respective funding years ended, and referred to other state and federal programs.

\*Note -Bill #A1005, S786 has been introduced to the NJ Legislature to create an Acquired Brain Injury Fund. At the time of this printing, the legislation is still in review.

## XI. 2011 Issues and Trends

The TBI Fund's 2011 activities were centered around continuing to transition operations based on the recent amendment to the regulations. The Fund no longer accepts applications from individuals with ABI, but continues to support existing ABI clients until the end of their approved funding.

The Fund saw an increase in applicants who sustained their TBI as a result of military service, and, accordingly, has forged closer collaborations with veterans' service agencies in New Jersey.

Approximately 20 new application requests per month are being received by the Fund, with approximately 10 per month becoming new referrals to case management agencies.

The most frequently requested services include:

- Cognitive therapy;
- Assistive technology;
- Vision care; and
- Companion services.

All approved services are covered by the Fund when there is no other coverage or insurances.

Several procedural changes have been put into place to ensure efficiencies in payment of invoices, timely processing of applications, and referrals to case management.

## XII. Looking Ahead to 2012

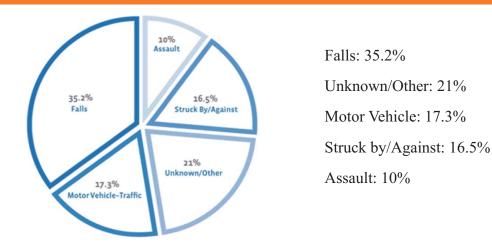
The Fund will complete the disqualification of individuals with Acquired Brain Injuries (ABI), and will reevaluate the annual cap limit based upon demand for services and availability of revenue.

#### **APPENDIX 1 - Brain Injury Basics**

#### **Common Causes for Traumatic Brain Injury Nationally**

According to the Centers for Disease and Control Injury Prevention Center, the leading causes of traumatic brain injury nationally are:

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\*Chart and statistics courtesy of Brain Injury Association of America (2011)

More than half of all traumatic brain injuries to people under the age of 75 years are a result of motor vehicle crashes. Falls are the leading cause of head injuries in people over the age of 75.

#### **Symptoms of Traumatic Brain Injury**

People who sustain a head injury may experience many different symptoms, including, but not limited to:

- loss of consciousness;
- concussion;
- memory loss (long and/ or short term);
- headache;
- confusion; or
- difficulty speaking/hearing/vision loss.

Open head injuries may cause bleeding, swelling and bruising on the head.

#### **Common Causes for Acquired Brain Injury**

An acquired brain injury is an injury to the brain, which is not hereditary, congenital, degenerative, or induced by birth trauma. An acquired brain injury is an injury to the brain that has occurred after birth.

Types of acquired brain injury include (but are not limited to):

- stroke (CVA);
- anoxia loss of oxygen to the brain;
- hypoxia Deficiency in the amount of oxygen reaching body tissues;
- tumor;
- aneurysm; or
- brain bleed.

#### **National Statistics on TBI**

- A million people have a brain injury in the U.S., equivalent to 2% of the population.
- A brain injury occurs every 23 seconds and 1.4 million people are hospitalized each year.
- 235,000 will survive after hospitalization.
- Approximately 80,000-90,000 will have permanent injuries.
- 50,000 will not survive.
- Males sustain almost 3 times the number of brain injuries than females.
- Motor vehicle collisions are the leading cause of brain injuries.
- Leading cause of brain injury in children are falls, motor vehicle crashes and assaults.

\*Statistics courtesy of Center for Disease Control and Prevention (2010)

#### **Traumatic Brain Injury in New Jersey**

According to the Center for Health Statistics -

- Brain injuries affect thousands of New Jersey residents every year. Traumatic Brain Injuries (TBIs) most often are caused by a blow or jolt to the head, and can severely disrupt normal brain functions.
- Each year, in New Jersey, there are nearly 9,000 TBIs resulting in hospitalization or death. Approximately 10% of TBIs are fatal. Many TBIs go unreported.
- TBIs range from mild to severe and can cause impairment of cognitive and physical abilities, as well as changes in behavior or emotional functioning. Seemingly mild TBIs can have significant effects that do not immediately appear.
- Historically the leading cause of TBI in New Jersey has been vehicle crashes (including automobiles, bicycles, and recreational vehicles), followed by falls and assaults. However, in 2003, falls became the leading cause of TBI in New Jersey, responsible for more than 20% more TBIs than vehicle crashes.
- Self-inflicted TBI, mostly gunshot wounds, are the most lethal, with nearly 97% resulting in death. Males are 13 times more likely to sustain a TBI due to self-injury than women.
- Men are over five times more likely than women to sustain a TBI due to an assault. The rate per 100,000 population is 15.8 for males and 3.0 for females.

Statistics Courtesy: New Jersey Department of Health Rates are age-adjusted to the US 2000 Standard population. Source: 2003 CNS Injury Surveillance data, OISP, CHS, NJDHSS

## **TBI Fund Applicants by County**

The percentages of TBI Fund applicants by county are as follows (2004-2011):

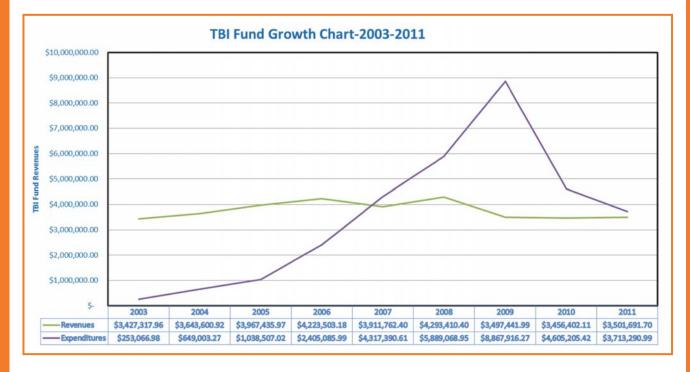
1)	Middlesex Count	8.8%
2)	Camden County	8.6%
3)	Ocean County	8.3%
4)	Bergen County	8.1%
5)	Burlington County	7.6%
6)	Essex County	7.4%
7)	Monmouth County	7.2%
8)	Mercer County	6.7%
9)	Morris County	5.8%
10)	Gloucester County	4.9%
11)	Union County	3.9%
12)	Passaic County	3.7%
13)	Somerset County	3.0%
14)	Atlantic County	2.9%
15)	Hudson County	2.7%
16)	Sussex County	2.5%
17)	Cumberland County	2.2%
18)	Hunterdon County	1.9%
19)	Warren County	1.7%
20)	Cape May County	1.1%
21)	Salem County	1.0%

## Major Causes for TBI (Based on Fund Clients Statistics)

The major causes of TBI for Fund clients have been due to:

- 1) Falls;
- 2) Motor Vehicle/Motorcycle Crashes;
- 3) Assaults;
- 4) Gunshot Wounds; and
- 5) Pedestrian Accidents.

#### Growth of the Fund -2003-2011



Note- \$2,179,000 was taken from the Fund's surplus in 2009. The money was returned, and then paid back in 2010.

The Fund was operating with a surplus until 2007, when expenditures increased due to the number of applicants increasing

#### **APPENDIX 2 - Histories of 3 Individuals Served by the TBI Fund**

**#1** - Sara is a 46 year-old from Ocean County who was injured in a motor vehicle crash when her car was rear-ended by another vehicle in October of 2001. She was employed full-time as an administrative assistant.

After her injury, she was transported to a local trauma unit and was in a coma for two weeks. Her injuries included a broken leg, two cracked ribs, and a traumatic brain injury.

After several weeks in the hospital and a rehabilitation facility, Sara returned home to her husband and two young children (8 years and 5 years). Her bodily injuries healed with time; however, as a result of her TBI, she had short-term memory loss, vision and hearing impairments and difficulty with organization.

The TBI Fund provided funding for cognitive therapy to assist her with her memory and organization, as well as household management to assist with organizing her mail and performing household tasks.

She now receives funding for neuro-opthomology services to improve her vision, which has improved with the purchase of prism glasses, paid for by the Fund.

Sara is now able to care for her family and perform several of the household tasks she was not able to perform immediately after her TBI.

**#2** - George is a 52 year-old male from Burlington County who sustained a traumatic brain injury as a result of a work-related accident, when a piece of heavy equipment fell on his head. As a result of his TBI, George was unable to work due to the physical nature of his previous occupation in construction. He became depressed and had recurring headaches and blurred vision. His workers' compensation and health insurance provided the medical coverage he needed. However, the Fund was asked to pay for an assistive technology evaluation which, when completed, recommended a GPS to assist George with directions to get him to his destinations safely, and a computer/cognitive software to aid him with his memory. The Fund also provided Service Coordination to assist him and his family with applying for other State and/or Federal programs. As a result of this assistance, he was able to receive benefits from the Division of Vocational Rehabilitation Services (DVRS) for job training and Social Security Disability Insurance (SSDI).

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#3 - Peter is a 20 year-old male from Passaic County who sustained a traumatic brain injury as a result of an assault in 2009. While walking through a park with a friend, he was confronted by three young men who demanded Peter and his friend turn over their money and jewelry to them. When Peter refused, one of the youths assaulted him with a baseball bat, causing head and bodily injuries. The injuries left Peter unconscious and bleeding from the head. Peter's friend assisted in bringing him home. His mother took him to the hospital emergency room. Peter was examined and x-rays were taken, along with a CAT scan of his head. The examination revealed Peter had sustained a traumatic brain injury, and a broken wrist.

After several weeks at a rehabilitation center, Peter was released and sent home. His mother contacted the TBI Fund and completed an application.

The Fund case manager met with Peter and his family, and suggested the family contact the Victim of Crime Compensation Office.

The family requested that the Fund assist with an assistive technology evaluation, which recommended software that would allow Peter to utilize cognitive exercises to improve his short-term memory loss.