June 22, 2012

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

Dear Governor Christie:

As Commissioner of the Department of Human Services, I am pleased to submit to you A Report to the Governor and the Legislature of the State of New Jersey on the State Division of Disability Services.

New Jersey has provided its residents with disabilities an important and valuable resource in the Division of Disability Services. The Division has been instrumental in building a strong relationship with other disability-related organizations statewide, providing information and referral services to citizens with disabilities in the state of New Jersey, and acting as a single point of entry to access all available services for individuals and families who need disability services. The Division continues to be proud and honored to serve citizens with disabilities and will continue to meet its legislative mandate to provide an equal playing field for New Jersey’s citizens with disabilities.

Sincerely,

Jennifer Velez
Commissioner
# NJ Traumatic Brain Injury Fund Report – 2012

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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 – 2012

This report is written in accordance to P.L. 2001, c 332 (N.J.S.A. 30.6F-B), which states, in part, “C.30:6F-7 Annual report on status of fund.

"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 supports to survivors of Traumatic Brain Injury, the Fund also contracts with the Brain Injury Alliance (BIA) of New Jersey to provide outreach and education on brain injuries. The Alliance provides many services that intersect with the Fund’s objectives for New Jersey residents who have survived a Traumatic Brain Injury.

THE FUND AT A GLANCE 2012

- The Fund received approximately 200 requests for applications, which raised the number of eligible recipients to approximately 1,400.
- The annual cap for 2012 per individual was $3,000, with a lifetime cap of $100,000. To date, no applicants have reached their lifetime cap.
- The average award for 2012 was approximately $2,450.
- The Fund also recouped $200,114.21 as a result of litigation settlements.

SANDY RELIEF AND RESPONSE

In the aftermath of Superstorm Sandy, routine Fund operations were suspended to allow staff to focus on relief efforts. Wellness calls were placed to applicants and beneficiaries who resided in the affected areas. Staff responded to individual needs and assisted people in need by making connections with emergency management relief and resource agencies. Staff also directly assisted 82 beneficiaries in completing the requisite paperwork for support from their private insurance, FEMA, and the American Red Cross.
PURPOSE OF THE TRAUMATIC BRAIN INJURY FUND

The purpose of the Traumatic Brain Injury (TBI) Fund is to support 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. Also, in accordance with its legislation, the Fund provides support for education and outreach for prevention of brain injuries through a contract with the Brain Injury Alliance of New Jersey.

ELIGIBILITY REQUIREMENTS OF THE TBI FUND

Fund applicants must meet the following three criteria:

1. Provide medical documentation of a Traumatic Brain Injury, as defined by the Centers for Disease Control (CDC)
2. Must be a NJ resident for at least 90 consecutive days prior to application date
3. Have less than $100,000 in liquid assets

The Fund serves as the payer of last resort for all supports and services

APPLICATION PROCESS FOR THE TBI FUND

When an application request is made, Fund staff send out an application (to be completed by the applicant, a family member or guardian) and medical document forms, which are completed and signed by a physician, who can verify the clinical information about the client. A Fund case manager is assigned to contact the applicant, family member or guardian to schedule an assessment.

When the case manager meets with the applicant, family member and/or guardian, s/he gathers socioeconomic information as well as any benefits they may be receiving (Medicare, Medicaid, etc.), dates of when the injury occurred and how the injury was sustained. In cases for which the applicant may not be using benefits and services effectively, the case manager offers suggestions regarding what is available and how they can be used as a compliment to the Fund.
ROLE OF THE TBI FUND CASE MANAGER

Case managers are assigned based upon the county in which the applicant lives.

If the applicant requires assistance completing the application, Fund staff may assist over the phone, or a case manager may go to the applicant’s home. Staff is committed to preventing an individual’s disabilities from impacting Fund participation.

Based upon the assessment interview, the case manager writes a support plan requesting essential services for the client.

Plans submitted by case managers are screened by Fund staff to ensure adherence to Fund regulations, and then abstracted for review by the TBI Fund Review Committee.

Upon determination of the committee, letters are mailed to clients informing them of the committee’s decision. The Committee may decide to approve, modify or deny a plan.

Approval letters, signed by the Fund Manager, are mailed to clients, along with letters of guarantee of payment to the approved provider(s), with copies of both to the assigned case manager.

Upon receipt of the approval letter, the case manager informs the client and the provider(s) that services may begin. A schedule and/or an appointment are arranged with the client and provider.

The guarantee of payment (GOP) letter includes the service approved, the total amount of funding approved, and the beginning and ending dates within which services must be performed.

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 above award or date. Any additional treatments other than those listed above require Fund approval prior to rendering service. The TBI Fund is the payer of last resort.”

In the event the Committee denies a plan, the client has the right to reconsideration by the TBI Fund Review Committee. A written request for reconsideration must be received within 30 calendar days of the date of the denial letter, and must state the reason(s) why the client disagrees with the decision reached by the TBI Fund Review Committee. They may provide additional information and/or supporting documentation with their request for an appeal.
DEFINITION OF TRAUMATIC BRAIN INJURY

The Fund uses the Federal CDC definition for Traumatic Brain Injury, which states, in part, “A TBI is caused by a bump, blow or jolt to the head or a penetrating head injury that disrupts the normal function of the brain.”

COMMON CAUSES FOR TRAUMATIC BRAIN INJURY

According to the Centers for Disease and Control Injury Prevention Center, the leading causes of Traumatic Brain Injury nationally are:

*Chart and statistics courtesy of Brain Injury Association of America

Falls: 35.2%
Other: 21%
Motor Vehicle: 17.3%
Struck by/Against: 16.5%
Assault: 10%

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 75.
NATIONAL STATISTICS ON TBI

- 5.3 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
- 235,00 will survive after hospitalization
- Approximately 80,000-90,000 will have permanent injuries
- 50,00 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

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 (TBI) are most often 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.
- The leading cause of TBI in New Jersey historically 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 by far 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 as likely as women to sustain a TBI due to an assault. The rate per 100,000 is 15.8 for males and 3.0 for females.
Statistics Courtesy: New Jersey Department of Health and Senior Services

Rates are age-adjusted to the US 2000 Standard population.
Source: 2003 CNS Injury Surveillance data, OISP, CHS, NJDHSS

**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
- aphasia
- vision loss (optic nerve damage, hemianopia, diplopia)
- hearing/auditory deficits

Open head injuries may cause bleeding, swelling and bruises.

**DEFINITION OF ACQUIRED BRAIN INJURY**

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

**COMMON CAUSES FOR ACQUIRED BRAIN INJURY**

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/brain bleed
HISTORY OF THE TBI FUND

In 2002, through a surcharge on New Jersey motor vehicle registrations, the State of New Jersey established the TBI Fund (PL 2001, Chapter 332, Section 5). 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.

CHANGES TO THE REGULATIONS IN 2009

In the summer of 2009, owing to the economic downturn, the Fund experienced unprecedented and unanticipated growth, more than doubling in the number of clients. The number of applications received each month went from 15-20 to approximately 300. In addition, requests for assistance from the Fund increased such that the average award to an individual swelled from $3,000 to $6,000. 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 flat.

Immediate action needed to be taken. The New Jersey Advisory Council on Traumatic Brain Injury (appointed by the Governor), which is identified in the statute as the body to oversee the Fund, endorsed the Division’s plan for restructuring and placed a hold on all newly submitted Fund applications.

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 criteria and covered services under the Fund.

The regulations changed the definition of brain injury, made changes in service coverage, and instituted limitations on the duration of some services. 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 used was found in the federal TBI Act (different from the CDC definition) and that 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.

- Having the ability to lower the annual cap on services from $15,000 per year in order to stay within budget.

- Defining the nature and scope of various services for clarity and consistency.
Changing the “order of selection” that is to be invoked if the Fund has insufficient resources to approve all applications.

Changing the “order of selection” that is to be invoked if the Fund has insufficient resources to approve all applications.

Eliminating services that have been determined to not meet the criteria of being necessary for an individual with brain injury.

The Fund also ceased paying for the following services:

- 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.

This change allowed the Fund to focus on services that are directly related to Traumatic Brain Injury treatment and rehabilitation, and to avoid services and supports that were normative or custodial in nature.

Active clients with acquired brain injuries were disqualified from the TBI Fund as their respective funding years ended, and referred to other state and federal programs, wherever possible.

**THE TRAUMATIC BRAIN INJURY FUND TODAY**

Currently, the Fund accepts applications from survivors of Traumatic Brain Injury (TBI). The Fund is serving approximately 1,200 clients. Service requests submitted by case management agencies are being processed and services rendered on a timely basis, usually within two to four months from date of application.

Approximately 25 new application requests per month are being received by the Fund, with approximately 15 per month becoming new referrals to case management agencies.

The most frequently requested services include:

- Cognitive therapy
- Assistive technology
- Vision care
- Companion services
The Fund no longer supplements other State or federal programs; thus, all approved services are covered solely 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.

Providers are paid within 60 days of receipt of invoice.

NEW JERSEY ADVISORY COUNCIL ON TRAUMATIC BRAIN INJURY

Legal Authority: Executive Order # 84 of 05/28/98

The TBI Fund Advisory Council is charged with the following: (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; (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 1 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 and Senior Services, Community Affairs, Labor, Banking and Insurance, Law and Public Safety, and Treasury and/or their designees, also serve on the Council.

The statute governing the Advisory Council states the following:


3.a. There is established within the Department of Human Services the New Jersey Advisory Council on Traumatic Brain Injury.

b. The council shall be composed of 26 members as follows: the Commissioners of Human Services, Education, Health and Senior Services, Community Affairs, Labor and Banking and Insurance, the Attorney General and the State Treasurer, or their designees, who shall serve ex of ficio and 18 public
members, who shall be appointed by the Governor, with the advice and consent of the Senate. Of the public members, eight shall be survivors of Traumatic Brain Injury or the family members of these persons and at least five shall be representatives of the following groups: public or private health-related organizations, disability advisory or planning groups within the State, the Brain Injury Association of New Jersey, injury control programs at the State or local level, and the Center for Health Statistics in the Department of Health and Senior Services for data research purposes.

c. Public members shall serve for a term of three years from the date of their appointment and until their successors are appointed and qualified; except that of the members first appointed, six shall serve for a term of one year, six shall serve for a term of two years and six shall serve for a term of three years. Vacancies shall be filled for the balance of the unexpired term in the same manner as the original appointments were made. A member of the council shall be eligible for reappointment.

d. The public members who are serving on the New Jersey Advisory Council on Traumatic Brain Injury established by Executive Order No. 84 of 1998, on the effective date of this act may complete the duration of their term as members of the council established pursuant to this act and are eligible for appointment to the council established pursuant to this act.

e. The members of the council shall meet quarterly and the Commissioner of Human Services, or his designee, shall serve as chair of the council.

f. The members of the council shall serve without compensation, but shall be reimbursed for necessary and reasonable expenses actually incurred in the performance of their duties, within the limits of funds appropriated or otherwise made available to the council for this purpose.

C.30:6F-4 Duties of the council.

4. The council shall:
   a. Advise and make recommendations to the Department of Human Services and other related State agencies on ways to improve and develop services regarding Traumatic Brain Injury, including the coordination of these services between public and private entities; date of this act may complete the duration of their term as members of the council established pursuant to this act and are eligible for appointment to the council established pursuant to this act.

   b. Encourage citizen participation through the establishment of public hearings and other types of community outreach and prevention activities;

   c. Encourage and stimulate research, public awareness, education and prevention activities;

   d. Oversee any programs created under the federal law, Pub. L.104-166, known as the Traumatic Brain Injury Act, and any successive amendments to that act, and report to the federal government regarding these programs; and
e. Advise the Commissioner of Human Services on the administration of the Traumatic Brain Injury Fund established pursuant to section 5 of this act.

**TBI FUND REVIEW COMMITTEE**

The TBI Fund Review Committee hears abstracts of support requests (care plans) written by case managers to determine the outcome of those requests based upon the guidelines and regulations of the Fund. The committee consists of the Director of the Division of Disability Services, a member of the NJ Brain Injury Alliance, a family member of a brain injury survivor, a brain injury survivor, a professional in brain injury, and two members of the advisory council. The committee meets approximately six times a year.

Among the areas the Committee looks for are:

- Ensures the request has a clear link to Traumatic Brain Injury
- There is an attainable outcome and need or necessity
- Clear longevity of service when sponsorship is over
- The plan contains a good use of Fund resources
- The request made is for more than just financial relief, and has a rehabilitative goal

**SERVICES AND SUPPORTS**

Currently, The Fund covers the following services, defined as:

- **Service coordination**: the provision of Intensive assistance with resource coordination and advocacy
- **Nursing services**: an assessment and intervention related to professional nursing practice.
- **Neuropsychiatric/neuropsychological evaluation**: an assessment of the beneficiary's deficits and strengths with recommendations for a treatment plan if necessary
- **Medication management**: monitoring of prescription medication, drug interactions, and modifications
- **Prescription medication**: medications to treat/manage the traumatic brain injury
- **Counseling services**: providing coping skills and strategies to deal with adjustment problems
- **Cognitive rehabilitation therapy**: to improve memory, orientation, reasoning, appropriate verbal and behavioral responses.
● **Physical therapy**: to improve or maintain physical function, including muscle tone, gait and mobility.

● **Occupational therapy**: to improve or maintain fine motor coordination and dexterity related upper body functions.

● **Speech-language therapy**: to improve vocal and verbal skills, comprehension and expression, compensatory strategies or other treatments related to swallowing.

● **Alternative therapy**: aqua therapy, biofeedback/neurofeedback, chiropractic care, hippo therapy, and acupuncture/acupressure

● **Structured day program**: meaningful group or individual activities to develop or maintain function and independence

● **Life skills training**: teaching specific instrumental activities of daily living to increase independence and function

● **Vocational services**: Prevocational and extended vocational support to obtain and maintain employment

● **Educational service**: supports related to an educational program or tutoring

● **Respite care**: intermittent, temporary or short-term care to provide relief to or replace an absent or incapacitated unpaid caregiver.

● **Medical care**: medical evaluations treatment

● **Vision care**: eye exams, treatment, and eyeglasses/contact lenses

● **Dental care**: rehabilitative or restorative dentistry

● **Protective legal services**: guardianship services, preparation of a special needs trust and similar services

● **Personal care**: assistance with personal hygiene, and activities of daily living

● **Behavior management**: the assessment and treatment of maladaptive or aggressive behavior

● **Substance abuse evaluation/treatment**: to resolve alcohol and/or drug problems

● **Companion care**: non-medical care, supervision and socialization provided to the beneficiary to insure safety and enhance quality of life.
● **Parental support**: coaching and training the parent to perform parental care responsibilities independently

● **Household management**: organizing the daily activities of managing a household, including shopping, meal preparation, housekeeping, bill paying and assistance with mail

● **Financial management**: assistance with bill paying, banking and long-term financial planning

● **Transportation/vehicle modification**: medical transportation or modification of the vehicle so the individual can use or be transported to medical appointments, treatment facilities or vocational programs.

● **Environmental modifications**: ramps, room alterations, and devices to assist with activities of daily living

● **Durable medical equipment**: walkers or wheelchairs, etc., which are necessary for health, safety and function.

● **Assistive technology**: computer for cognitive rehabilitation, GPS, adaptive software

### TBI Fund Applicants by County

The percentages of TBI Fund applicants by county are as follows:

1. Middlesex County 8.6%
2. Camden County 8.5%
3. Ocean County 8.2%
4. Bergen County 8.0%
5. Burlington County 7.5%
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%

100%

TBI Fund Revenue vs. Expenditures 2003-2012
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</table>

**Note**- $2,179,000.00 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.

**EDUCATION, OUTREACH AND PREVENTION**

The Fund provided $758,660 for education and outreach to raise public awareness and prevention of brain injury. Through legislation, the Brain Injury Alliance (BIA) of New Jersey is contracted with this responsibility.

Using the Fund’s purposes as objectives, the Brain Injury Alliance of New Jersey focuses on four primary program goals.

**Goal 1**
The promotion of the TBI Fund, as well as other brain injury resources.

**Goal 2**
To provide information about Traumatic Brain Injury to those directly affected by injury. This includes consumers and professionals.

Training sessions are scheduled by the NJ BIA throughout the year titled, “Brain Injury Basics” and “Brain Injury 101”, to educate brain injury survivors and their families about brain injury.
The BIA also offers Information and Referral services, as well as a library of resources available to survivors, families and professionals.

Family Support Specialists meet with families to assist them with information and resources that may be available to them, as well as assistance with adjustment to TBI.

**Goal 3**
To raise awareness of Traumatic Brain Injury, its incidence and prevention. The general public is the target for these activities.

**Goal 4**
Targeted public campaigns for brain injury prevention. Other aspects of brain injury, such as falls by elders, sports concussion, and automobile crashes, have been subjects of these campaigns.

In addition to the above services, the Brain Injury Alliance also provides: summer respite programs, county based support groups; mentor programs; family support and care coordination; injury prevention services, and systems advocacy.

**CASE HISTORIES FROM THE TBI FUND**

**Joseph**

Joseph is a 7 year old boy from Hunterdon County. He survived a TBI from a car crash in 2007. He has permanent physical and speech deficits

With the assistance of the Fund, Joseph was able to receive an iPad to assist with communication and coordination and some home modifications that increase his independence and mobility around his home.

**Gary**

Gary is 48 year-old male from Somerset County who was injured in a motor vehicle crash while riding as a passenger in October of 1981. He was transported to a local trauma unit and was in a coma for five weeks. His injuries included chest and pulmonary contusions and a traumatic brain injury. He received two and half years of rehabilitation services. Gary’s injury left him with profound cognitive deficits which left him incapable of doing paperwork.

The TBI Fund has provided the applicant with service coordination to assist him with applying and reapplying to Social Security and navigating the appeals process. Gary was also assisted with applying for General Assistance and utility assistance.
**Stephanie**

Stephanie is a 61-year-old woman from Ocean County who was struck by a car in January 2005 as a pedestrian. The car hit her from behind and proceeded to run her over. She requires the assistance of a cane to walk, but she can perform the rest of her ADLS independently. She experiences very poor concentration, poor short term memory, and very limited coping abilities.

Stephanie has received a variety of services from the Fund including cognitive therapy, medical transportation, neuro-feedback, and service coordination. Recently, she benefited from life skills training in which she has demonstrated improvement with initiating, prioritizing and following through with tasks such as applying for low income housing.

**Alan**

Alan is a 49-year-old man from Warren County who was working under a vehicle in 1982 when it fell on his head. Due to his injury, the applicant has cognitive impairment and struggles to initiate and sustain conversation without cueing. He is also in chronic pain, and his balance and mobility were severely impacted.

The TBI Fund has been providing the Alan with household management so that he can maintain the upkeep of his apartment. The applicant, with assistance, is able to maintain the cleanliness of his kitchen and bathroom and with step-by-step instructions, can actively participate in doing his laundry and other tasks which are essential to his quality of life and independence in the community.