

# **TBI Services Coordinating Council**

Comparison of 1998 Report to Governor and; NYS Traumatic Brain Injury 2012 Five-Year Action Plan

# NYS TBI Report to Governor George E. Pataki <sup>1</sup>

The TBI Program has made significant progress in creating services to enable the return of many brain injured people to New York State from expensive, out of state care facilities. The program has also secured federal approval for a special Medicaid waiver that allows people with TBI to like in a community-based setting rather than in nursing homes.

#### The purpose of the 1998 Report to the Governor is to:

- Provide a status of efforts which have been underway in New York State since 1985
  to create an integrated system of health care and supportive services for people who
  have experienced brain injuries.
- Focus on the activities that took place in response to 1994 legislation establishing the TBI Program within the New York State Department of Health (DOH).



# NYS Traumatic Brain Injury 2012 Five-Year Action Plan<sup>2</sup>

The last plan, prepared in 1998, focused on the pressing need to repatriate over six hundred people with TBI from out of state nursing homes, and implementation of the Medicaid TBI home and community-based waiver program.

#### The purpose of the 2012 Plan is to:

- Guide continued progress in assisting New Yorkers who live with TBI and their families;
- Address the need for TBI prevention; and
- Improve access to needed care and services so that individuals may return to community life after an injury.

<sup>2</sup> The plan was developed in fulfillment of a grant provided by the Health and Human Services, Health Resources and Services Administration Grant. (HRSA)



# Recommendations 1998 Report



## **Recommendations 1998 Report**

The foundation for a comprehensive system of health care, rehabilitation, and education for individuals with TBI is in place. Recommendations include:

- Ensuring that adequate funding is available to support the growing number of people receiving services under the Medical waiver, especially in the areas of housing and regional resource development capacity in New York City.
- Asses the impact of managed care on access to routine and specialized health care services for individuals with TBI, and the impact on the integration of rehabilitation efforts.
- Assess how welfare reform issues will affect people with TBI.



## **Recommendations 1998 Report**

- Continue the coordinated efforts with providers, advocacy organizations, other governmental agencies, and individuals with TBI and their families.
  - To help people who survive bran injuries resume productive lives in their communities to the best of their abilities.
- Continue to educate people with TBI, their families, providers and advocates about the services New York has created.
- Create an accurate, appropriate information system that will assist consumers, service coordinators and providers to develop optimal service plans for individuals with TBI;
  - Such a system will also give policymakers a better understanding of the true costs and benefits of TBI services and thereby help them to make informed decisions about the future.



# **Recommendations 1998 Report**

- Examine fully the long-term benefits of rehabilitation as well as ways to improve rehabilitation within the state.
- Secure funding for housing and other Medicaid waiver Services due to the growing number of people receiving services under the waiver, increased funding is necessary.
- Improve rehabilitation because it improves quality of life by enabling people with TBI to return to their homes, schools and workplaces.



# Work Group Recommendations for 2012 Five-Year Action Plan



### Recommendation: 2012 Five Year Plan Public Awareness

- Ensure public awareness about TBI, current research and knowledge about injuries and prevention strategies.
- For instance, the importance of
  - Seeking treatment from a health care professional when a possible concussion or brain injury has occurred and;
  - Cognitive and physical rest after a brain injury.



## 2012 Five Year Plan: Insurance Coverage Observation

- A cornerstone of the NYS TBI program has been the **Medicaid Home and Community Based Services waiver** that serves over 2,700 persons annually.
- However, only a small percentage of New Yorkers with TBI access waiver services due to eligibility restrictions:
  - Medicaid eligible
  - Nursing home level of care
  - Between the ages of 18 and 64
- The rest receive services through
  - Private or Medicare health insurance
  - Medicaid state-plan health benefits
  - Pay out of pocket.
- Even individuals living with TBI who have health insurance benefits may need services not covered by their plan.
- The number of those who go without any care is unknown.



### Recommendations 2012 Five Year Plan

- Reduce programmatic barriers to treating needs beyond the TBI
  - Substance abuse
  - Mental health care
  - Help reentering community life
- Continue to aid schools to help children with a TBI return successfully to their academic life.
  - After sustaining a TBI, school aged children may have symptoms that cause difficulties in the classroom.
  - Because TBI is an invisible injury, changes to a student's thinking, learning, and behavior may be blamed on other causes.
- Provide TBI-tailored assistance for adults ready to reenter the workforce.
  - NYS Adult Career and Continuing Education Services-Vocational Rehabilitation (ACCES-VR)
    offers a full range of employment and independent living services, including transitional
    services, vocational rehabilitation, independent living, and business services.



## Recommendation 2012 Five Year Plan

- Continue efforts to close the information gap to assist veterans in securing benefits and services.
  - Despite the greatly expanded Federal and State response to TBI among the military, many New York veterans and their families continue to be unaware of the totality of benefits available to them.
  - These needs will become greater with the withdrawal of troops from Iraq and Afghanistan.



# Stakeholder Recommendations (Five-Year Action Plan)



# Enhance Public Knowledge of TBI Treatment and Prevention/ Spreading the word about TBI

- Timely update of state agency websites with easily accessible current information for individuals with TBI, families, discharge planners, and service providers.
   Status: This action has been initiated.
- Support activities to develop and disseminate public information about TBI treatment, resources, and prevention from a variety of sources, including the CDC and BIANYS. Status: This action has been initiated.



# Improve Access to Community Based TBI Services

- Examine ways to enhance access to service coordination and other TBI services regardless of eligibility for Medicaid and/or the TBI waiver program.
- Support inclusion of service coordination and cognitive rehabilitation in the definitions of essential health benefits by New York State under the Federal Affordable Health Care Act.
- Encourage amendment of NYS Insurance Law to mandate inclusion of TBI related services such as cognitive rehabilitation, like the enacted 2011 Autism Insurance Reform Act.
- Disseminate research results for emerging treatment modalities.
- Incorporate services that meet the unique needs of people with TBI within Medicaid.



### **Access to Community Based TBI Services Continued**

- Encourage further collaboration between the State and Federal veterans' systems and public/ private sector health and community-based programs to improve veterans' access to needed care within their home community.
- Encourage Traumatic Brain Injury Services Coordinating Council (TBISCC) to increase cross state agency collaboration, by amendment of Chapter 196 of the Laws of 1994 to expand membership to:
  - Include the State Office of Aging, NYS Homes and Community Renewal, Division of Veterans Affairs, Departments of Labor, and the criminal justice and crime victim agencies to support TBI collaborative activities at the local level.
- Support TBISCC legislative proposal to establish a TBI Trust Fund, similar to other states, to support the cost of certain TBI services for those not eligible for Medicaid funded, or otherwise insurance covered, programs and services.
  - A fund could also be used to support the cost of public information networks and designated staff to coordinate TBI related activities.



# Enhance TBI Provider Training to Improve TBI Diagnosis and Treatment/ Statewide Training

- Encourage links with major university graduate schools of professional training to place student interns in model TBI provider agencies.
- Collaborate with key professional associations statewide to develop TBI peer training opportunities, and mentor programs in service provider agencies to assist in the orientation and training of new professionals.
- Examine Federal and other clinical TBI guidelines and protocols for appropriate use by NYS local emergency response community, to ensure rapid identification of possible TBI and mitigate post-injury outcomes.
- Encourage standardized on-line curricula for TBI provider training, including emerging protocols, community resources, discharge planning, and case management.
- Explore instituting a TBI certification requirement for TBI service providers, such as the Certified Brain Injury Specialist (CBIS) or other national certification program.



# **Educational/Vocational Opportunities for Children and Adults**

#### 1998

- Promote educational equity and excellence for students with disabilities while ensuring that they receive the rights and protection to which they are entitled,
- Assure appropriate continuity between the child and adult services systems,
- And provide the highest quality vocational rehabilitation and independent living services to enable people to work and live independent, economically productive lives.

#### 2012 Action Plan

- Support the State Education Department (SED) to enhance transition programs/protocols for a child's appropriate gradual return to school academic work and physical activity, after sustaining a brain injury.
- Identify resources to provide technical support to school districts to assist teachers, students with TBI and their families.



# Implementation/ Initiated Actions



### **MRT Recommendations:**

- Establish managed long term care plans to provide services in the most integrated setting appropriate to the needs of qualified members with disabilities; plans must include a person-centered care management function that enables the member and his/her informal supports to drive the development and execution of the care plan. Status: **This action** has been initiated by the MRT proposal #90.
- Ensure Behavioral Health managed care services promote wellness and meet the secondary and/or tertiary mental health /substance use/addiction needs. Status: This action has been initiated by the MRT proposal #93.
- Promote underutilized programs such as the Consumer Directed Personal Assistance Program that are cost-effective and build on consumers' strengths. Status: **This action has been initiated by the MRT proposal #1427.**
- Create financing mechanisms that strengthen the financial viability of New York's essential community provider network. Status: **This action has been initiated by the MRT proposal #67.**



## **MRT Recommendations:**

- Identify out of State nursing home placements and seek to repatriate those individuals within three years. Status: **This action has been initiated by MRT Proposal**
- Ensure that existing standards of care are enforced in teaching hospitals and training clinics, so that provided care is of the highest quality and equivalent to all patients regardless of payer source, and address disparities through targeted training for NYS' health care workforce. Status: This action was approved in early 2012 by the MRT for implementation as part of the Phase Two process.
- Mandate cultural competency training to promote care and reduce disparities for all individuals including but not limited to people with disabilities. Status: This action was approved in early 2012 by the MRT for implementation as part of the Phase Two process.



## **MRT Recommendations:**

- Explore alternative models, such as transitional living, supported apartments, congregate
  housing options or family care, as well as continuation of established rental subsidies
  after the transition to a managed care environment. Status: This action was initiated by
  the Medicaid Redesign Team proposal #196 and will continue as a focus of MRT
  Phase Two activities, including funding for development.
- Incorporate a housing focus in development of Managed Long-Term Care and Care Coordination Models. Status: This action was initiated by the Medicaid Redesign Team proposal #196 and will continue as a focus of MRT Phase Two activities, including funding for development.



#### Contact us:

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