

**New York State
Traumatic Brain Injury
Five-Year Action Plan**



2012

ACKNOWLEDGEMENTS

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I. Executive Summary

Beginning in 1985 the Department of Health (DOH), in collaboration with other New York State agencies, took a broad leadership role to address needed services and affordable housing for people living with brain injuries. Despite much progress over more than twenty-five years, there remains a high incidence of traumatic brain injury (TBI) among children and adults—including veterans returning from the wars in Iraq and Afghanistan. The following is an updated TBI Action Plan to guide future action.

Chapter 196 of the Laws of 1994 established the DOH as the State agency with central responsibility for administering and coordinating TBI policy, including implementation and management of a new TBI program. A TBI Action Plan, prepared in 1998, focused on the repatriation of over six hundred people with TBI living in out of state nursing homes, and on the implementation of the Medicaid (MA) TBI Home and Community Based Services Section 1915(c) waiver program authorized in 1995. Today, over 2,700 individuals receive services and supports through the TBI waiver. While a majority of those cared for out of state returned to New York through the initiatives in the early 1990's, as part of Governor Andrew M. Cuomo's Medicaid Redesign Team (MRT) activities, new action is being taken to repatriate all Medicaid recipients living in out-of-state nursing homes to New York communities and implement procedures to reduce future out of state placements.

Public awareness of the risk and prevention of TBI has improved significantly, largely through the efforts of State and Federal public health campaigns, legislation, advocacy groups, academic and professional sports organizations, the mainstream media, and entertainment industry. Resources needed to effectively address barriers to prevention, recovery and community care are now at the forefront of TBI policy development, particularly in regard to high risk groups, such as veterans and sports participants.

A 2009-2013 Federal Health Resources and Services Administration (HRSA) TBI Implementation Grant (#H21MC06742) provided financial support for the update of the TBI Action Plan. In 2010 the funds underwrote the costs associated with a comprehensive, community based, needs and resource assessment.

Responses to the needs and resources assessment indicated that the TBI waiver program has successfully improved access to community based care for eligible persons. However, it indicated that significant challenges remain related to: 1) inadequate access to services for those not eligible for the waiver; 2) assistance for children and adults preparing to return to school and work; and 3) affordable and accessible housing.

In 2011, Governor Cuomo embarked on a transformative restructuring of the Medicaid system to shape policy, reduce costs, and increase quality and efficiency in the

provision of health care.¹ This updated TBI Action Plan (Section VI of this report) recognizes the need to address the enormity of the personal and financial impact of injury and reflects the changing health care environment.

The 2012 TBI Action Plan recommendations reflect the needs assessment findings and the input of the many stakeholders who contributed their knowledge and expertise to the project. Specifically, the recommendations address TBI system change requirements to: 1) enhance public knowledge of TBI treatment and prevention; 2) improve availability/access to community based TBI services; 3) enhance TBI provider training, diagnosis and treatment; 4) maximize educational/vocational opportunities; and 5) address the need for accessible affordable housing.

¹ www.health.ny.gov, Medicaid Redesign Team, Redesigning the Medicaid Program.

II. Purpose

The following New York State TBI Action Plan was developed to address the increasing demand for a cost effective system of care for children and adults who have traumatic brain injuries.

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.

III. Emerging Trends

Definition and Prevalence

Traumatic Brain Injury (TBI) occurs when a sudden trauma causes damage to the brain. TBI may result when the head suddenly and violently hits an object, undergoes a sudden acceleration-deceleration movement (e.g. shaking or whiplash), or when an object pierces the skull and enters brain tissue. A mere bump on the head may cause the brain to strike against the skull, or cause a shifting of the brain, stretching or tearing the brain cells enough to cause a serious injury.²

Persons who have sustained a concussion, recognized as a type of TBI, are now known to be at increased risk for subsequent injury, particularly if the prior concussion has not healed. Repeated concussions and/or TBI may result in cumulative neurological and cognitive deficits, and if reoccurring within a short period (i.e. hours, days or weeks) may result in permanent damage and/or death.

Each TBI is unique and complex, no matter how similar the causal events, and may result in a variety of short and long-term effects. Many persons who sustain a TBI recover completely, but it may take weeks, months or longer. Even a mild TBI may have long lasting cognitive and behavioral effects.³

The Centers for Disease Control and Prevention (CDC) has conservatively estimated that 5.3 million U.S. citizens, or two percent of the population, lives with disability because of a TBI.⁴ Widening methodologies used to identify and treat TBI injuries emphasize the need for collaboration on every level to assure maximum positive outcomes from a network of cost efficient treatment and post injury supportive services.

Increasing Incidence

TBI is a public health issue of enormous consequence.⁵ The Centers for Disease Control and Prevention (CDC) estimates 1.7 million TBI related emergency department visits, hospitalizations, and deaths occur annually in the United States. TBI is a

² www.Brainline.org

³ Defense Centers of Excellence, Case Management of Concussion/Mild/TBI; November 2010, p.7.

⁴ CDC Estimates of Traumatic Brain Injury – Related Disability, CDC Report to Congress, 1999, p.15. (The report notes the estimate is conservative as the “The model does not account for disability among people who visited emergency departments or outpatient clinics with a TBI but were not admitted to the hospital. Because of this, our estimate of 5.3 million U.S. citizens living with TBI – related disability may be low. “) A 2005 study, by Zaloshnja, Eduard, Miller, T, Langlois, J, et. al, “Prevalence of Long Term Disability From TBI in the Civilian Population of the United State, 2005” published in the Journal of Head Trauma Rehabilitation Nov/Dec 2008 Vol. 23, Issue 6 p394-400 estimated the number of persons in the U.S. living with a long term disability from TBI to be 3.17 million. While the 1999 estimate of 5.3 million people is dated, it remains the statistic used by CDC.

⁵ www.Brainline.org, preventing treating, and living with traumatic brain injury.

contributing factor in one third of all injury-related deaths in the United States.⁶ Known TBI incidents are greater in number than incidents of spinal cord injury, HIV/AIDS, breast cancer and multiple sclerosis *combined*.⁷ The CDC estimates that the number of sports and recreation related concussions (mild TBI) occurring each year in the United States ranges from 1.6 - 3.8 million, many of which are not seen in a hospital or emergency room.⁸ Direct medical costs and indirect costs, such as lost productivity, resulting from TBI are estimated to exceed \$76 billion in the United States annually.⁹

While available data underscores the extent of this public health issue, the incidence of TBI among the general population is likely to be significantly undercounted, because the injured person does not always seek medical treatment, or may be treated in a physician's office or urgent care clinic from which incidence data is not collected.¹⁰ In fact, certain CDC estimates suggest that persons who did not seek care may account for one fourth of all persons with a TBI.¹¹

The most recent DOH hospital based data for New York State reveals over 140,000 incidents led to an emergency department visit or in-patient hospitalization with a diagnosis of TBI in 2009, a 63% increase from 2005. Of the 2009 incidents, over 122,000 reflect emergency department visits, an additional 20,000 cases required in-patient hospitalization. In the same year, more than 2,000 deaths were attributed to TBI.¹² Based on CDC information with regard to unreported injuries, the total annual number of new TBI cases may be higher.¹³

Falls, the leading cause of TBI for New Yorkers, make up half the TBI cases among children aged 0 to 14 and nearly two thirds (60.7%) of cases among adults 65 years or older. Motor vehicles crashes are the second leading cause of TBI for all age groups, and the leading one among persons aged 15-25, followed by assaults. TBI incurred from being struck by or against something is the third major category among New York's children ages 19 and younger.¹⁴

⁶ Traumatic Brain Injury in the United States, Emergency Department Visits, Hospitalizations and Deaths, 2002-2006, Centers for Disease Control and Prevention, p. 5.

⁷ Brain Injury Association of America.

⁸ Langlois JA, Rutland, Brown W, Wald M. The epidemiology and impact of traumatic brain injury: A brief overview. *J Head Trauma Rehab* 2006; 21(5) 375-8.

⁹ Finkelstein E. Corso P., Miller T. and associates. *The Incidence and Economic Burden of Injuries in the United States*. New York (NY): Oxford University Press; 2006.

¹⁰ Faul, M., Xu, L, Wald, M.M., & Coronado, V.G. (2010). *Traumatic brain injury in the United States: Emergency department visits, hospitalizations, and deaths, 2002-2006*. Atlanta, GA: Centers for Disease Control and Prevention, National Center for Injury Prevention and Control.

¹¹ Centers for Disease Control and Prevention, *MMWR*, Vol. 60, No. 5, 2, May 2011.

¹² NYS-DOH Injury Prevention Program, *Incidence of TBI Emergency Department Visits and Hospitalizations*, SPARCS data, March 2011.

¹³ In prior years, grant funding allowed DOH to perform more in depth analysis of TBI incidence and validation of data, however when the Federal grants expired in 2005, the more detailed TBI analysis ended as well.

¹⁴ NYS-DOH Injury Prevention Program, *Incidence of TBI Emergency Department Visits and Hospitalizations*, SPARCS data, March 2011.

Education and Prevention

Due to the incidence and cost burden of TBI, the CDC and NYS have made TBI education and prevention a priority, resulting in public/private collaborative efforts to increase knowledge about TBI. The efforts include distribution of tool kits, targeted to students, school nurses and faculty, coaches, and physicians. These materials have been distributed by DOH, the Brain Injury Association of New York State (BIANYS) and other organizations throughout New York. Similar materials specific to New York State have been developed by the DOH Injury Prevention Program and are being distributed throughout the State.¹⁵

In October 2011, the CDC activated an on-line TBI training program for clinicians, following the curriculum previously developed specifically for athletic coaches. The training programs are also available free of charge on the CDC website. In addition, CDC is establishing an advisory group to develop guidelines for pediatric treatment of mild TBI for issuance by 2013.¹⁶

Children, Youth and Sports

The cause of TBI in children varies according to age group. Cases of TBI in infants and toddlers are primarily caused by falls, abuse, and neglect.¹⁷ Early elementary aged children sustain TBI primarily from falls and pedestrian motor vehicle accidents. Older elementary children, through middle school age, sustain TBI mainly as the result of pedestrian related bicycle or motor vehicle accidents and sports. High school youth sustain TBI largely from motor vehicle accidents, assaults and sports.¹⁸ Although common in organized athletic activities, a concussion may occur anywhere, including the playground or backyard.

The importance of proper recognition and management of concussion has emerged as essential to recovery and the prevention of further brain injuries. Research now indicates that both cognitive and physical rest are crucial for recovery from a TBI. Appropriate rest is especially important to avoid a phenomenon known as “second impact syndrome” (SIS) whereby a successive brain injury occurs before recovery from an earlier one is complete.¹⁹ The consensus of TBI experts convened at the 2008 Zurich International Conference on Concussion in Sport, is that the “cornerstone of concussion management is physical and cognitive rest until symptoms resolve, and

¹⁵The CDC kits are available free of charge on-line at www.CDC.gov/concussion and DOH materials are available at www.health.ny.gov.

¹⁶ www.cdc.gov/concussion.

¹⁷ Brain Trauma Foundation Webinar: Neurorehabilitation of Pediatric TBI, presentation by Joelle Mast PhD. MD, Blythedale Children’s Hospital, Valhalla, NY, August 17, 2011, and NYSDOH Injury Prevention Program, SPARCS, January 2010.

¹⁸ Ibid.

¹⁹ www.cdc.gov/Concussion, Facts about Concussion and Brain Injury, Consensus statement on concussion in sport – The 3rd International Conference on concussion in sport, held in Zurich, November 2008.

then a gradual program of increased exertion prior to medical clearance and return to play.”²⁰

Nationwide, an estimated 44 million youth are involved in organized sports.²¹ The health and safety concerns for young people involved in community-based youth sports led to the creation of the State University of New York (SUNY) Youth Sports Institute. In February 2008, the Institute Academic Advisory Board developed an educational curriculum to train and certify youth coaches on a common set of minimum standards.²² Since March 2008, the Institute reports to have trained 10,000 non-school youth coaches, using the network of New York’s community colleges as the venue for the in-person training.

On September 19, 2011, Governor Andrew M. Cuomo signed the Concussion Management and Awareness Act. Effective July 1, 2012, the bill requires implementation of concussion management protocols in public schools, directly addressing the area of sports injury.²³

Adults

Falls are the major cause of TBI among adults aged 44 and older. For persons 65 years and older who require hospitalization, half of these injuries occur at home.²⁴ Adults 75 years and older have the highest rates of TBI-related hospitalizations and death.²⁵ Prevention efforts to reduce the incidence of avoidable TBI are a continuing need for older New Yorkers.

The DOH Injury Prevention Program conducts TBI surveillance across all age categories to guide their prevention work, with the goal of reducing the incidence of injury. The DOH Injury Prevention Program, among others, is promoting greater awareness, particularly among seniors, of the benefits of regular exercise to maintain strength and balance, safer home surroundings, regular vision exams, and having medications routinely checked by a health care provider.²⁶

Substance Abuse

Alcohol use at the time of injury is common with TBI hospital admissions. Nationally, approximately three-quarters of all patients admitted to hospitals for TBI have measurable amounts of alcohol in their blood upon admission, one-third to one-half are

²⁰ McCrory, P. Johnston, K., Mewsuwisse, W. et. al. Consensus Statement on Concussion in Sport 3rd International Conference on Concussion in Sport Held in Zurich, November 2008, *Clinical Journal of Sports Medicine*, Vol. 19 No. 3, May 2009.

²¹ CDC presentation October 3, 2011, Meeting of the National Association of State Head Injury Administrators.

²² The SUNY Youth Sports Institute, *Parents’ Guide to Youth Sports*, 2010. The training includes a module on Health and Safety that specifically covers sports concussions.

²³ Chapter 496 of the Laws of 2011, Senate bill 3953-B.

²⁴ Bureau of Injury Prevention, NYS DOH, SPARCS GEN06MTH 2005–2009.

²⁵ Preventing Traumatic Brain Injury in Older Adults, CDC, pg.1.

²⁶ *Ibid*, p. 5-6.

intoxicated at the time of injury.²⁷ In what may be a complicating factor for brain injuries, some medications used to treat cognitive disruption or pain from a TBI have the potential of increased risk for substance abuse.²⁸ The NYS Office of Alcohol and Substance Abuse Services (OASAS) found that half of enrolled clients have probable TBI.²⁹

Individuals with TBI have experienced little success using traditional substance abuse treatment programs. The TBI home and community based waiver offers substance abuse services that provide individually designed interventions by staff certified/licensed by OASAS and experienced in providing services to individuals with TBI.

Veterans

National estimates indicate that 200,000 military service members have sustained a TBI since 2000 while serving in either Operation Enduring Freedom (OEF) in Afghanistan or Operation Iraqi Freedom (OIF). This has led to TBI being termed the “signature injury” of these wars.³⁰ The State is home to nearly one million veterans, including more than 85,000 residents who participated in OEF, OIF, and/or Operation New Dawn since September 11, 2001.³¹

The New York State Division of Veterans Affairs (DVA) responded to this dramatic change in needed stateside assistance with dedicated advocacy and counseling for New York State veterans and their families to ensure they receive available benefits and services. DVA maintains an informational website at veterans.ny.gov and a network of counselors stationed in over 70 offices across the State.

Veterans who return from active duty undergo a process of reintegration back to their communities and civilian life. The process involves “Yellow Ribbon”, and other events held over a 90-day period, specifically for returning veterans, to educate them about the types of assistance, resource support, and available referral programs. A unique aspect of the Yellow Ribbon Reintegration program in New York is required attendance at confidential Vet Center counseling. Nearly sixty percent of screened veterans have asked for some type of follow up assistance.

In 2010, New York State veterans were the focus of a study, issued by the Rand Corporation that reaffirmed the need to improve the service delivery system for veterans with TBI and other injuries. The report, “A Needs Assessment of New York State Veterans”, studied a statistical sample of veterans and identified the following barriers to care: the complexity of the VA health system; the reluctance of some veterans to

²⁷ Substance Abuse and Mental Health Services Administration, Substance Abuse Treatment Advisory, Treating Clients with Traumatic Brain Injury, October 2010, Volume 9, Issue 2, pg. 2.

²⁸ Ibid, pg. 4.

²⁹ Office of Alcohol and Substance Abuse Services (OASAS) The Traumatic Brain Injury and Chemical Dependency Connection, Addiction Medicine Educational Series Workbook, p.32.

³⁰ <http://www.dvbic.org/TBI-Numbers.aspx>.

³¹ NYS Division of Veterans Affairs, Annual Report, 2009, pg. 9.

access that system; and the need for better outreach to connect veterans with care coordinators providing personalized assistance across a range of service sectors.³²

In some cases, New York veterans and their families continue to be unaware of the totality of benefits available to them, including those living with TBI. The DVA has made progress in closing that information gap with its active outreach and collaboration with the Federal Veterans' Administration (VA), other military based organizations, and state and community based agencies.

On Nov. 10, 2011, Governor Cuomo issued Executive Order #34, continuing the NYS Council on Returning Veterans and Their Families, and broadening its membership and mission.³³ The Council membership was expanded to include the Commissioners of Homes and Community Renewal, the Department of Economic Development, the State Education Department, and the Director of the State Office for the Aging. The Council mission was expanded to focus on housing assistance, academic, and employment opportunities.

On a national level, recognition of the incidence of war-related TBI among military personnel has led to numerous efforts. Beginning in August 2003, mandatory TBI screening for medically evacuated personnel, regardless of injury or illness, was implemented in certain VA Medical Centers. Three years later, the Military Acute Concussion Evaluation (MACE) tool was implemented, followed in 2009 by the Mild Traumatic Brain Injury Pocket Guide. The Pocket Guide was developed by the Defense Centers of Excellence for Psychological Health and Traumatic Brain Injury (DCoE), to provide primary care providers with a comprehensive, quick clinical guidance to assess and treat service members and veterans who sustain a mild TBI.³⁴

The DCoE was established in 2007 to lead a national network of military, federal, family and community leaders to serve the needs of "warriors and their families with psychological health and/or traumatic brain injury concerns." The initiative includes collaboration with the Defense and Veterans Brain Injury Center (DVBIC) charged to develop and provide TBI specific evaluation, treatment and follow-up care for all military personnel, their dependents, and veterans with a brain injury. The federal Substance Abuse Mental Health Services Administration (SAMHSA) is also actively assisting veterans and their families to address their many needs.

In 2008, New York was one of 10 states selected through a competitive process to participate in a National Behavioral Health Conference and Policy Academy on Returning Veterans and their Families sponsored by the SAMHSA, the VA and the Department of Defense (DOD).

³² Schell, T. and Tanielian, T. (eds), A Needs Assessment of New York State Veterans, Final Report to the New York State Health Foundation, RAND Corp., January, 2011, pg. 55.

³³ See Appendix I for Executive Order #34, 2011.

³⁴ Defense Centers of Excellence for Psychological Health and Traumatic Brain Injury, the Defense and Veterans Brain Injury Centers, Mild Traumatic Brain Injury Pocket Guide, 2009, pg. 1.

The NYS DVA represented the State at the Academy, and subsequently developed a four point comprehensive action plan for “Returning Veterans and Their Families.”³⁵ This comprehensive strategy focuses on four broad priorities:³⁶

1. Establish a sustained infrastructure to address the multiple needs of veterans and their families,
2. Facilitate engagement and involvement of returning veterans and their families,
3. Increase political and public will to serve veterans and their families, and
4. Improve quality services for veterans their families.

When fully implemented, the Action Plan for Returning Veterans and their Families is expected to produce even greater success in responding to the needs of New York’s veterans and their families. New York was also chosen in 2011 by SAMHSA to receive technical assistance in developing and conducting local Regional Policy Academies, which will create a locally driven response plan to coordinate benefits and services.

Criminal Justice System

The national prevalence of TBI among incarcerated adults, recently estimated at eighty (80) percent,³⁷ has been the subject of research, but few have examined TBI among juvenile offenders. However, a recent project in Texas found that statistics among those juveniles who self-reported a TBI related to the increased likelihood in convictions, violent acts, mental illness, and substance abuse.³⁸ TBI has a profound effect on youth and adults prior to, during, and after incarceration, as well as, implications for the communities to which they return after release. Since an estimated 110,000 individuals are involved in the New York State correctional and parole systems,³⁹ the implication of TBI within the New York judicial and criminal justice system warrants greater attention.

New York State Medicaid Reform

New York Medicaid expends over \$53 billion annually to provide health care to nearly five million people. These costs are borne by state, county and federal governments.⁴⁰ It is within that context that Governor Cuomo stated in January of 2011: “it is of compelling public importance that the State conduct a fundamental restructuring of its Medicaid program to achieve measurable improvement in health outcomes, sustainable cost control and a more efficient administrative structure”.⁴¹

³⁵ New York State Division of Veterans Affairs, Council on Returning Veterans and their Families, Report, September 2009, p. 2.

³⁶ Ibid.

³⁷ http://www.hhsc.state.tx.us/hhsc_projects/abi/index.shtml, Spotlight: Texas TBI Juvenile Justice Partnership Pilot Program, Nov. 10, 2011.

³⁸ Ibid.

³⁹ NYS Department of Correctional Services and Division of Parole, <http://www.doccs.ny.gov/>.

⁴⁰ Medicaid Redesign Team, Redesigning the Medicaid Program, <http://www.health.ny.gov>.

⁴¹ Ibid.

The Governor established a Medicaid Redesign Team (MRT) to find ways to reduce costs and increase quality and efficiency in the Medicaid program. An initial list of 274 proposals were presented and ten work groups were formed to focus on specific reform policy: Managed Long Term Care Implementation and Waiver Redesign; Affordable Housing; Basic Benefit Review; Behavioral Health Reform; Health Disparities; Health Systems Redesign; Medical Malpractice Reform; Payment Reform and Quality Measurement; Program Streamlining and State/Local Responsibilities; and Workforce Flexibility and Change of Scope of Practice.

The Action Plan recommendations for this report are made within the context of the developing Medicaid redesign and are based upon the findings of needs assessments and collaboration with TBI stakeholders.

IV. Needs Assessment Summary

Individuals Living with TBI

Under the auspices of the HRSA TBI Grant (#H21MC06742), in 2010 a survey was administered to a sample of the State's population to assess the adequacy of services provided in New York State for persons living with a TBI. Of the approximately 2,700 participants in the New York State Medicaid (MA) TBI Home and Community Based Services (HCBS) waiver, 1,600 were randomly selected for the survey. Four hundred individuals were selected from the Brain Injury Association of New York State (BIANYS) non-professional membership list, and 300 surveys were sent to the BIANYS Family Advocacy Counseling and Training Services (FACTS) coordinators for distribution at TBI support group meetings.⁴²

Individuals had the choice of completing the survey on-line, by phone, or by mail. A total of 784 surveys were completed and returned. Adjusting for the number of surveys deemed "non-deliverable", the response rate was 40 percent.

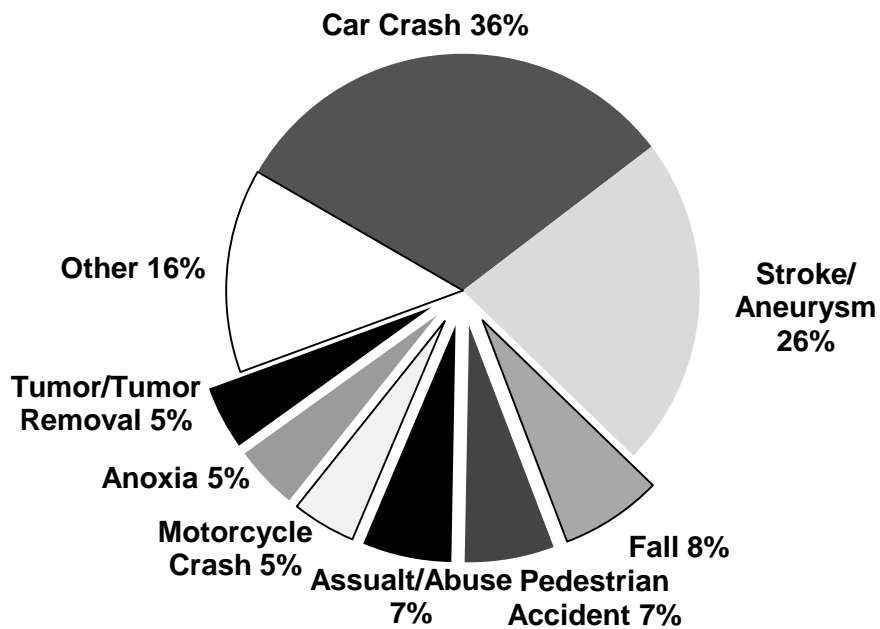
Demographics of the survey respondents include:

- Median age of 48 years
- 59% male, 41% female
- Average age at time of injury was 32 years (range was under one year to 86)
- Average length of time since injury was 15 years (range was less than one year to 62 years)
- 15% self-reported their TBI as "mild"; 42% as "moderate"; and 43% as "severe"

As shown in the following chart, the majority (36%) of the respondents reported brain injuries resulting from vehicle crashes, followed by stroke (26%), falls (8%), assault/abuse (7%) and pedestrian accidents (7%). The remaining 16% of injuries were spread across a variety of causes, such as bicycle accidents, sports injury, and gunshot.

⁴² Comprehensive results of the survey of individuals with TBI and their families and providers are found in Appendix E and F respectively.

Cause(s) of Brain Injury



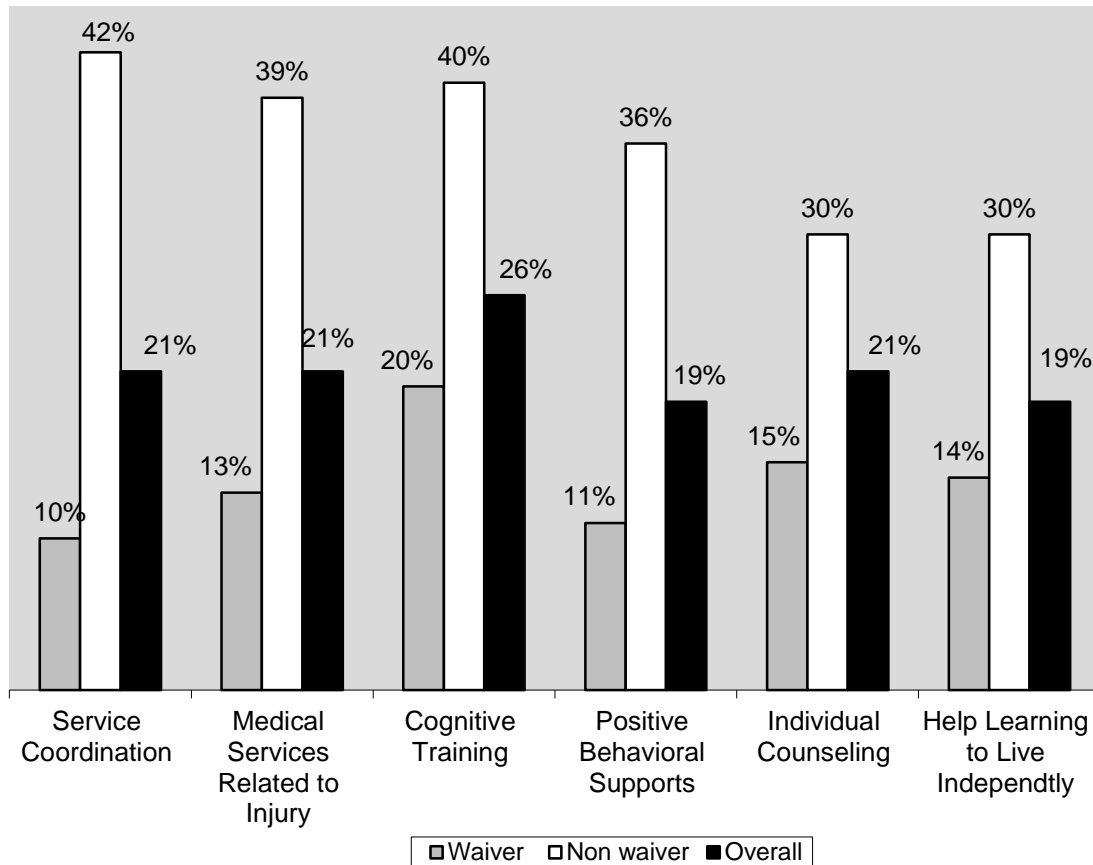
Four hundred eighty nine (68%) respondents reported they were TBI Medicaid Home and Community Based Services (HCBS) waiver participants. A comparison of demographics between the waiver survey respondents and the universe of those on the TBI waiver revealed no important differences in terms of median age, gender, ethnicity and region of the state where they reside. However, as a group, TBI waiver participants reported more positively about their access to needed community services and quality of life following their TBI.

Summary Findings

Respondents were asked to identify the services they needed but were not receiving; significantly, reports of inaccessible services were reported at twice the rate from non-TBI waiver participants than for participants.

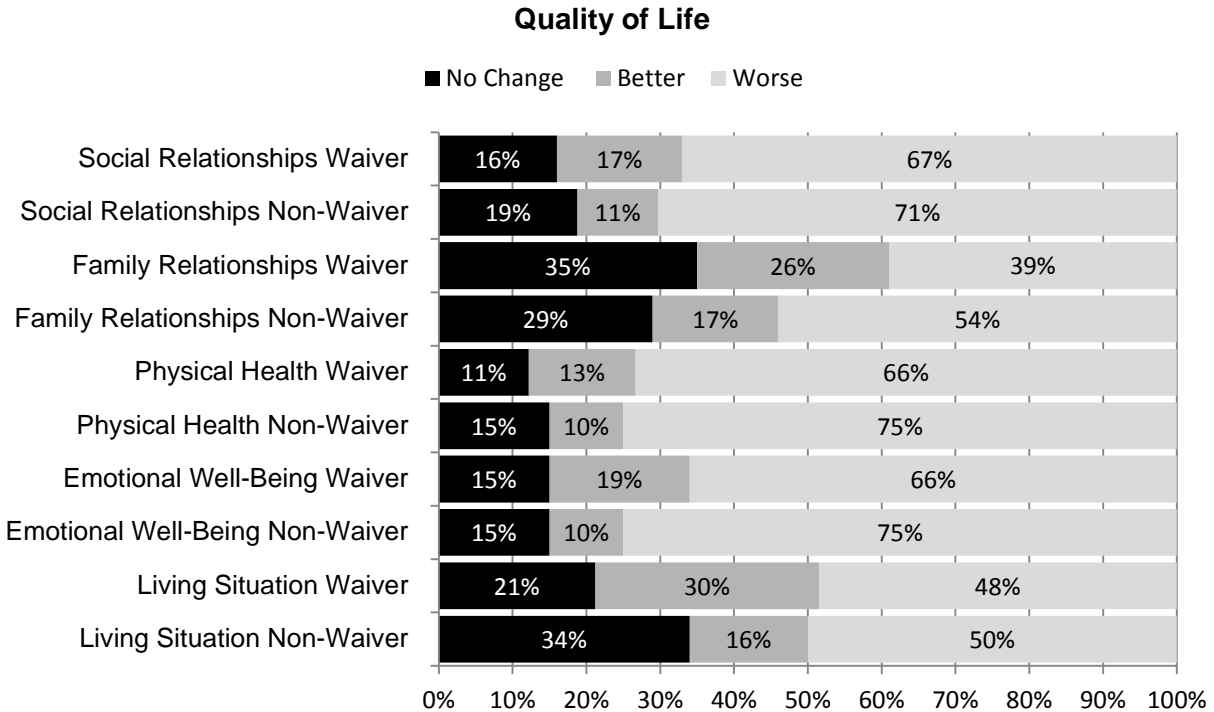
The next chart indicates the percentage of the six highest categories of continuing unmet service need.

Unmet Service Need Reported by Twice the Number of Non Waiver Survey Respondents as Waiver Enrollees



Living situations varied significantly between TBI waiver and non-waiver respondents. Fifty-six percent (56%) of respondents on the TBI waiver live alone, compared to thirty-two percent (32%) of non-waiver participants. Approximately twenty percent (20%) of both waiver and non-waiver participant respondents reported that they live with their parents.

Responses to quality of life questions reveal significantly similar rates of decline in reported quality of life among TBI waiver and non-waiver participants. More than fifty percent (50%) reported the injury changed their life for the worse in many areas, particularly with regard to social and family relationships, physical health and emotional well-being, and living situation. In two areas, family relationships and living situation, waiver participants indicated greater levels of improved and less worsening of quality of life than non-waiver participants. This result may be attributed to the available supportive services and housing subsidies to the waiver group. The following chart illustrates the reported quality of life responses.



Sixty percent (60%) of respondents reported they were not aware of New York’s Protection and Advocacy Services, thirty percent (30%) were not aware of the Brain Injury Association of New York State, a statewide advocacy organization on behalf of persons with brain injuries and their families, and twenty (20%) did not know about the TBI waiver. The reported lack of awareness of available TBI services and advocacy assistance reveal the continued need for education/outreach efforts.

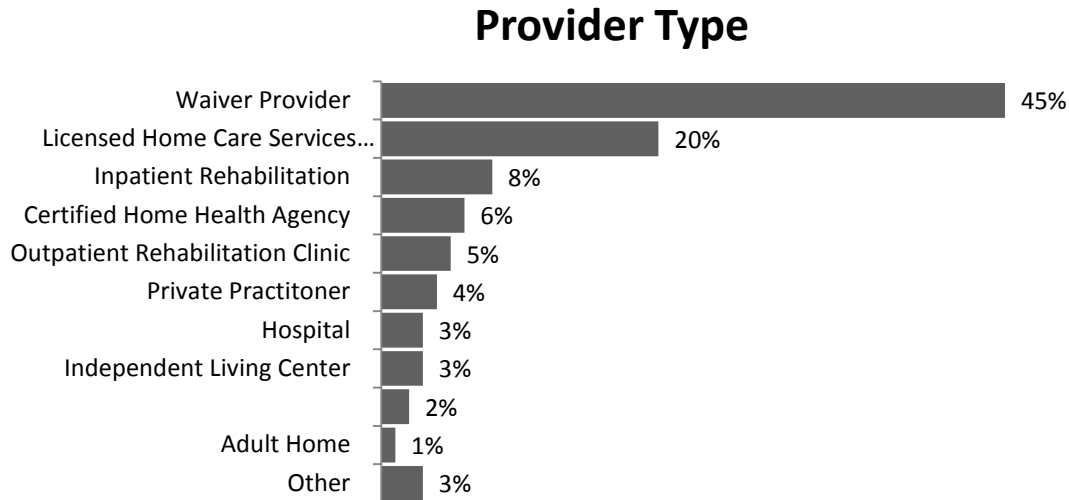
Provider Survey

To assess availability of services in New York State for persons living with a Traumatic Brain Injury (TBI), providers were asked to complete an on-line survey that included an opportunity to note their perspective on how the coordination and delivery of TBI services could be improved.

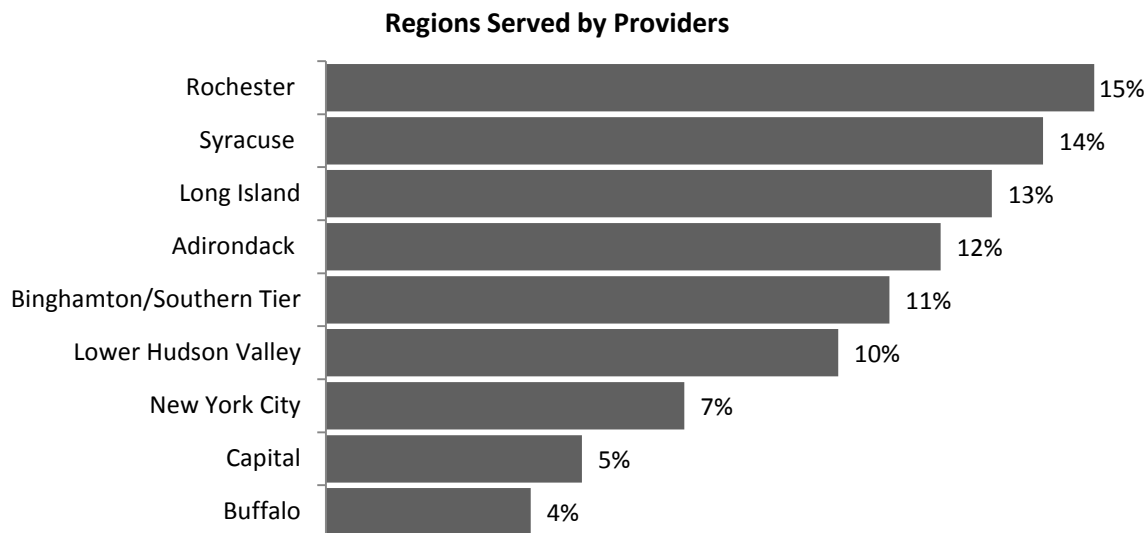
In the fall of 2010, major provider associations were notified about the web-based survey and asked to encourage their members to respond. Providers were also notified of the survey through the Department of Health on-line health care provider network; provider based statewide associations and the Brain Injury Association of New York State (BIANYS) websites.

One hundred eighty-two providers, representing 120 organizations, completed the survey. Forty-five percent (45%) self-reported as Medicaid waiver providers; seventy-three percent (73%) of whom were specifically TBI waiver providers. Thirty-three (33%) were Nursing Home Transition and Diversion Medicaid waiver providers; sixteen percent (16%) reported they provided services through the Office of People with Developmental Disabilities waiver.

The chart below indicates the array of responding service provider types.



While the number of responses varied by geographic region, there was statewide and regional representation indicated by the chart below.



Thirty-five (35) service categories were listed in the survey, including community based medical services, rehabilitation, counseling and psychotherapy, and educational and employment training/placement services. Respondents were asked to indicate which services they provided. Twelve (12) of the listed services were reported as provided by at least thirty-three (33%) of respondents. The main categories of service provision were medical, counseling/psychotherapy, and community based services. (See Figure 4 of Appendix F)

The survey asked providers to identify sources from which they received patient referrals for TBI services. The majority, sixty-seven percent (67%), reported clients were referred from Medicaid waiver programs; half from individual self-referrals (51%), and more than one-third (37%) from hospitals.

Recommendations/Comments Submitted with the Surveys

The survey also asked respondents to comment and/or make recommendations about the TBI service system. Nearly 580 respondents living with TBI submitted comments on how to improve the TBI service system. Suggestions from individual and service providers were considered in development of the TBI Five Year Action Plan.

Individual respondents most frequently mentioned the need for the following:

- More resources, including a “central statewide information and referral center”
- Greater access to services and supports regardless of Medicaid waiver eligibility
- Greater access to service coordination, optimally prior to hospital discharge

- More support for families including counseling, respite, and referral services
- Cross-discipline TBI provider training
- Establish services to assist children and adults returning to school and work
- Expand housing options to include transitional and congregate living models

The provider survey response to the request for suggestions for system change mirror, in part, those generated from the survey of individuals living with TBI, indicating an appreciation for the unique challenges faced by the populations they serve. Provider suggestions included the following:

- Maximize public TBI education outreach efforts including web-based information
- Promote conventional and web-based provider training opportunities to enhance TBI diagnosis and treatment, strategies for working with persons with TBI and their with families, available service/support systems, and treating co-existing mental health and substance abuse
- Enhance identification/coordination of needed quality TBI services for children
- Establish services to prepare and assist children and adults returning to school and work

V: Remaining Gaps in NYS TBI Services

Much progress has been made about the knowledge and treatment of TBI in the last two decades. Increased access to medical care, community based supports, accessible affordable housing and transportation has been substantial since the New York TBI Waiver was established in 1994. However, based upon the results of the surveys conducted in 2010 and discussions with TBI stakeholders, service accessibility remains largely dependent upon a person's awareness of available assistance, health care insurance status, eligibility for Medicaid waiver services, geographic availability of needed care, and availability of family and social supports in their lives.

Public awareness

Public awareness about TBI still lags behind 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 for cognitive and physical rest after a brain injury is not yet well known among the public, parents, and many professionals.

Insurance Coverage

A cornerstone of the New York State TBI program has been the Medicaid Home and Community Based Services waiver that serves over 2,700 persons annually. However, because the waiver serves only Medicaid eligible individuals with a nursing home level of care need injured between the ages of 18 and 64, a small percentage of individuals in the State living with TBI access the specialized community services available through the waiver.

The majority of New Yorkers living with TBI who receive services do so through private or Medicare health insurance, Medicaid state-plan health benefits, or 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.

Program Limitations

Programmatic barriers also remain in the treatment of individuals with TBI who have needs beyond the injuries themselves, such as substance abuse, mental health care or help reentering community 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. Providing assistance to schools to help children with a TBI return successfully to their academic life is an ongoing need.

Oftentimes, a graduated return to academic work is needed for the student while they recover.⁴³

There is a similar need for TBI tailored assistance for adults ready to reenter the workforce. Toward this end, the 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.⁴⁴ However, workforce reentry remains a particularly difficult process for many people following a TBI.

Geographic Limitations

Place of residence may also affect access to needed care. For instance, service coordination, day programs, medical services related to TBI, and/or neurobehavioral services provided by clinicians with specialized training to address maladaptive behaviors may not be available in every community.⁴⁵

Veteran 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. Continued efforts are needed to close that information gap to assist veterans in securing benefits and services. These needs will become greater with the withdrawal of troops from Iraq and Afghanistan.

⁴³ Concussion in the Classroom, A guide for students, parents, teachers, nurses, guidance counselors, school psychologists and other school staff, Concussion Management Program, Central New York Sports Concussion Center; REAP The Benefits of Good Concussion Management, Rocky Mountain Youth Sports Medicine, by Karen McAvoy, PsyD.

⁴⁴ A full description of the services is posted at: <http://www.p12.nysed.gov/specialed>.

⁴⁵ Results of NYS DOH TBI 2010 Needs Assessment, "percent in need of service but not receiving it by region".

VI. Overview and Action Recommendations

OVERVIEW

The following recommendations address identified system enhancements needed to improve outcomes for persons living with TBI regardless of age or Medicaid eligibility status. The recommendations were developed over two years with the analysis of the grant surveys and collaborative discussion with TBI stakeholders and are informed by the work to redesign Medicaid with the overarching requirement that all State funded activities must be effective, efficient and implemented within the State's available resources.

The following recommendations should be considered as a guide, to challenge and encourage collaboration among stakeholders to realize the possibility of community integrated care in the least restrictive setting appropriate for persons who live with brain injury. Several recommendations have been initiated while others will require a longer term effort.

RECOMMENDATIONS

1. Enhance Public Knowledge of TBI Treatment and Prevention

The nationwide incidence of TBI exceeds that of multiple sclerosis, spinal cord injuries, HIV/AIDS and breast cancer combined, resulting in an extraordinary human and financial cost.⁴⁶ Despite the recent surge in public TBI awareness and education, lack of common knowledge continues to be a prime barrier to effective TBI prevention, rapid diagnosis, and access to treatment and other interventions that improve post injury outcomes.

Stakeholder Recommended Actions:

- 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.

2. Improve Access to Community Based TBI Services

Despite the wide range of services and supports now available to people with TBI in New York, there remains an unmet need for post injury resources. Two critical needs are service coordination and cognitive rehabilitation among individuals ineligible for Medicaid and the 1915 (c) TBI waiver services.⁴⁷

⁴⁶ "Comparison of Annual Incidence", Brain Injury Association of America, www.bia.org.

⁴⁷ 2010 DOH needs assessment and statewide discussions with other stakeholders. See appendix C.

Stakeholder Recommended Actions:

- 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. ⁴⁸ Status: This action requires a longer term effort.
- Encourage amendment of NYS Insurance Law to mandate inclusion of TBI related services such as cognitive rehabilitation, similar to the enacted 2011 Autism Insurance Reform Act. ⁴⁹ Status: This action requires a longer term effort.
- Disseminate research results for emerging treatment modalities. Status: This action requires a longer term effort.
- Incorporate services that meet the unique needs of people with TBI within Medicaid. Status: This action has been initiated by the MRT Proposals #68 (Repatriation) and #90 (Managed Long Term Care). ⁵⁰
- 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. ⁵¹ Status: This action is underway.
- 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. Status: This requires action by the TBISCC, Legislature and Governor.
- 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. Status: This requires action by the TBISCC, DOH, Legislature and Governor.

⁴⁸ Institute of Medicine, "Cognitive Rehabilitation Therapy for Traumatic Brain Injury, Evaluating the Evidence, Report Brief", October 2011; Center for Consumer Information and Insurance Oversight, "Essential Health Benefits Bulletin", December 16, 2011, http://cciio.cms.gov/resources/files/Files/2/12162011/essential_health_benefits_bulletin.pdf.

⁴⁹ Autism Insurance Law, Signed November 1, Chapter 595 of the Laws of 2011 (S.4005-A/A.6305-A).

⁵⁰ MRT #68 and #90, www.health.ny.gov/health_care/medicaid/redesign.

⁵¹ The RAND study reported half of the veterans surveyed prefer using civilian providers. (RAND Study, January 2011).

In addition, the Five Year TBI Action Plan supports the following 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.⁵² Status: This action has been initiated by the MRT proposal #90.⁵³
- Ensure Behavioral Health managed care services promote wellness and meet the secondary and/or tertiary mental health /substance use/addiction needs.⁵⁴ Status: This action has been initiated by the MRT proposal #93.⁵⁵
- Promote underutilized programs such as the Consumer Directed Personal Assistance Program that are cost-effective and build on consumers' strengths.⁵⁶ Status: This action has been initiated by the MRT proposal #1427.⁵⁷
- Create financing mechanisms that strengthen the financial viability of New York's essential community provider network.⁵⁸ Status: This action has been initiated by the MRT proposal #67.⁵⁹
- 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 #68.⁶⁰

3. Enhance TBI Provider Training to Improve TBI Diagnosis and Treatment

There was consensus among providers and persons with TBI for the need of enhanced training and education across related provider/professional disciplines.

Stakeholder Recommended Actions:

- Encourage links with major university graduate schools of professional training to place student interns in model TBI provider agencies. Status: This action requires a longer term effort.

⁵² MRT Managed Long Term Care Implementation and Waiver Redesign Work Group Final Recommendations, principles 2, 4, 7, www.health.ny.gov/health_care/medicaid/redesign.

⁵³ MRT #90 www.health.ny.gov/health_care/medicaid/redesign.

⁵⁴ MRT Behavioral Health Reform Work Group, Final Recommendations, number 9, www.health.ny.gov/health_care/medicaid/redesign.

⁵⁵ MRT #93 at www.health.ny.gov/health_care/medicaid/redesign.

⁵⁶ MRT Workforce Flexibility and Scope of Practice, Final Recommendations, number 11, www.health.ny.gov/health_care/medicaid/redesign.

⁵⁷ MRT #1427 www.health.ny.gov/health_care/medicaid/redesign.

⁵⁸ MRT Payment Reform and Quality Measurement Work Group Final Recommendations, number 4, www.health.ny.gov/health_care/medicaid/redesign.

⁵⁹ MRT #67, www.health.ny.gov/health_care/medicaid/redesign.

⁶⁰ MRT #68, www.health.ny.gov/health_care/medicaid/redesign.

- 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. Status: This action requires a longer term effort.
- 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. Status: This action requires a longer term effort.
- Encourage standardized on-line curricula for TBI provider training, including emerging protocols, community resources, discharge planning, and case management. Status: This action requires a longer term effort.
- Explore instituting a TBI certification requirement for TBI service providers, such as the Certified Brain Injury Specialist (CBIS)⁶¹ or other national certification program. Status: This action requires a longer term effort.

In addition, the Five Year TBI Action Plan supports the following MRT recommendations:

- 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.⁶² Status: This action was approved in early 2012 by the MRT for implementation as part of the Phase Two process.⁶³
- Mandate cultural competency training to promote care and reduce disparities for all individuals including but not limited to people with disabilities.⁶⁴ Status: This action was approved in early 2012 by the MRT for implementation as part of the Phase Two process.⁶⁵

4. Maximize Educational/Vocational Opportunities for Children and Adults

If managed well within the first weeks post injury, most mild traumatic brain injuries resolve successfully over time.⁶⁶ To maximize a student's recovery and successful return to school, collaboration is needed between school officials, faculty, students and their

⁶¹ Brain Injury Association of America CBIS at www.aacbis.net.

⁶² MRT Health Disparities Work Group Report, Final Recommendation 6, www.health.ny.gov/health_care/medicaid/redesign.

⁶³ MRT #90, www.health.ny.gov/health_care/medicaid/redesign.

⁶⁴ MRT Health Disparities Work Group Report, Final Recommendation 7, www.health.ny.gov/health_care/medicaid/redesign.

⁶⁵ Ibid.

⁶⁶ Collins, MW, Lovell, MR, Iverson, GL, Ide, T. Maroon, J. Examining concussion rates and return to play in high school football players wearing newer helmet technology, A three-year prospective cohort study. *Neurosurgery*, 2006; 58:275-286.

families, in consultation with their health care provider. Accommodations in the child's academic program may be needed during recovery to facilitate his/her full return to school work.⁶⁷ Adults who sustain a TBI may be prohibited from returning to their prior work due to the injury and need specialized vocational assistance to learn new skills, or individual accommodations in the workplace.

Stakeholder Recommended Actions:

- 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. Status: This action requires a longer term effort.
- Identify resources to provide technical support to school districts to assist teachers, students with TBI and their families. Status: This action requires a longer term effort.
- Encourage development of transitional outreach activities for school systems to improve access to adult education and workforce development opportunities, for students with disabilities as they prepare to transition from school to adult life. Status: This action requires a longer term effort.
- Encourage facilitated access for adults reentering community life following a brain injury to employment, adult education, and vocational services provided by State and other community-based organizations, including SED, Higher Education Services Corporation, State University of New York, City University of New York, Department of Labor, the Division of Veterans Affairs, and Independent Living Centers. Status: This action requires a longer term effort.

5. Address Need for Accessible Affordable Housing

Access to affordable, accessible housing is the foundation of a strong community based service system. Despite State and federal housing subsidy programs, housing remains a major barrier to community based care.

Stakeholder Recommended Actions:

- Explore partnership with NYS Homes and Community Renewal (HCR) to apply for federally funded housing grant programs aimed at expanding investment opportunities for accessible housing statewide. Status: This action requires a longer term effort.
- Explore HCR and local housing authorities' ability to designate persons with TBI as a high priority population for HUD Housing Choice Voucher (Section 8) program. Status: This action requires a longer term effort.

⁶⁷ Concussion in the Classroom, Concussion Management Program, Syracuse, NY, www.upstate.edu/concussion.

In addition, the Five Year TBI Action Plan supports the following 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.⁶⁸ 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.⁶⁹
- Incorporate a housing focus in development of Managed Long Term Care and Care Coordination Models.⁷⁰ 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.⁷¹

⁶⁸ MRT Affordable Housing Work Group, Final Recommendations, www.health.ny.gov/health_care/medicaid/redesign.

⁶⁹ MRT #196, www.health.ny.gov/health_care/medicaid/redesign.

⁷⁰ MRT Affordable Housing Work Group, Final Recommendations, www.health.ny.gov/health_care/medicaid/redesign.

⁷¹ MRT #196, www.health.ny.gov/health_care/medicaid/redesign.

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APPENDIX A

NEW YORK TBI ACCOMPLISHMENTS - HISTORY OF OVER 25 YEARS OF PROGRESS

1980 Brain Injury Advocacy - Raising Awareness

In 1980, family members and professionals joined together out of common concern for the quality of life of their family members and patients with brain injuries. Their efforts led to the founding of the National Head Injury Foundation, now known as the Brain Injury Association of America (BIAA) and later to creation of a New York State chapter in 1982—the New York State (NYS) Head Injury Foundation, now known as the Brain Injury Association of New York State (BIANYS). Their mission has been to be a voice for persons with brain injuries, their families, and the professionals who serve them.

1985 – NYS Initial Response to Brain Injury Reform

Chapter 156 of the Laws of 1985, instructed the Department of Health (DOH) to “*study the issue of “head injury” and the problems faced by individuals with such injuries seeking services*”. This action was in response to the situation, identified by families and advocates of over six hundred persons with brain injuries who primarily were living in out-of-state nursing facilities.⁷² This was primarily due to a lack of appropriate services in New York.

1986 – Department of Health (DOH) Designated as Lead Agency for TBI Response

DOH published reports describing the limitations of the existing service delivery system to meet the needs of persons with traumatic brain injury (TBI).⁷³ A 1986 report concluded that: “*The quality of the life for head injured New Yorkers is not good. They are exiled out of state or home doing little or severely frustrated by inappropriate schooling or employment. Depression is frequent, and suicide is not rare. It is not enough to save the lives of the head injured: their permanently disabling brain injury necessitates development of services tailored to the needs of this growing population.*”⁷⁴

Specifically the reports indicated:

- Lack of an organized system of care for individuals with head injury
- Regulatory policy based upon outdated and/or uninformed assumptions regarding models of care and market forces
- Gaps in services in some regions, particularly Upstate areas
- Statewide service gaps for individuals in coma and/or in need of long term care

⁷² Chapter 156 of the Laws of 1985.

⁷³ New York State Services for Traumatic Brain Injury, A Report to Governor George Pataki and the NYS Legislature, NYS Department of Health, TBI Program, March 1998, p.11.

⁷⁴ Ibid.

- Over 600 individuals with TBI living in out-of-state nursing homes at an estimated Medicaid cost of \$58 million per year, in addition to personal costs in terms of diminished quality of life for the individuals and their families

In response to the reports, DOH was designated as the lead State agency for head injury services. The initial charge had two primary goals: 1) develop a community-based system of care designed specifically for individuals with head injuries, and 2) repatriate (or divert) individuals with head injury from out-of-state nursing home placement to their home community.

1989 – Head Injury Advisory Council Formed

The 1986 report led to the creation of the Head Injury Advisory Council to advise the Commissioner of Health on brain injury policy.⁷⁵ The Council was intended to bring the needs of individuals with TBI, with regard to their ability to live and receive care within their community, to the attention of other State agencies. The Council confirmed out-of-state institutional placements of persons with brain injuries as a priority issue.

Over the next 10 years, State initiatives aimed at the development of an integrated system of care designed to repatriate and divert individuals with TBI from out-of-state placement were put into effect. These initiatives included establishment and/or improvement in TBI prevention, emergency room and trauma care, certified inpatient TBI rehabilitation units, medical model outpatient services, enhanced extended care service incentives, and community based services and supports.

The Injury Prevention Program instituted epidemiological studies and increased surveillance related to head injury. New initiatives included targeting bicycle safety and the use of helmets, with efforts by strong advocate partnerships, led to enactment of the NYS Helmet Law in 1994.⁷⁶

The Council, now named the Traumatic Brain Injury Services Coordinating Council (TBISCC), continues to meet regularly, providing expert discussion on emerging trends in TBI care, and serving as an avenue through which stakeholders may participate. Council members are appointed by the Governor, the Majority Leader of the Senate and the Speaker of the Assembly.

1989/1997 – Emergency Room and Trauma Care

In 1989, DOH developed the “New York State Appropriateness Review Standards for Trauma Centers”; the goal was to guide the regionalization of trauma care in the state.⁷⁷ In 1990, DOH established a State Trauma System and Registry with designated regional and area

⁷⁵ New York State Department of Health, ‘Head Injury in New York State, A Report to the Governor and Legislature, NYS Department of Health 1986.

⁷⁶ NYS Helmet Law, 1994, Section 1238(5) NYS Vehicle & Traffic Law.

⁷⁷ NYS-DOH, “Where New York State Stands In Treatment and Services For People with Traumatic Brain Injury, a Report to the Governor and The New York State Legislature, April, 1995, p. 15.

trauma centers throughout the State.⁷⁸ These efforts culminated in 1997 when New York adopted “Guidelines for the Management of Severe Head Injury”.⁷⁹

1992 – Integrated System of Care Development

While efforts aimed at prevention and improved quality of trauma and acute care were critical, there was an acknowledged need to address the large number of individuals who survived injury but could only access appropriate long-term care from out-of-state nursing homes.

As first steps in the development of an integrated in-state system of care, DOH established standards for TBI acute rehabilitation, short and long-term care (extended care), and completed assessments to determine the number and location of TBI beds needed throughout the State. A Certificate of Need (CON) process was set to develop over 500 specialized TBI beds for inpatient rehabilitation and coma recovery. A \$25 a day add-on was provided to facilities for each individual served that met the definition of a TBI extended care resident.⁸⁰ During this time, DOH also developed standards for comprehensive outpatient rehabilitation.

A panel convened by the National Institutes of Health recommended that TBI rehabilitation draw on the skills of many specialists in the areas of physical therapy, occupational therapy, speech/language, physical medicine, psychology/psychiatry, and social supports to improve the person’s ability to function at home and in society.⁸¹

During this time, public awareness increased about the needs of persons with brain injury. Reports of poor care and unacceptable financial procedures at out-of-state placement facilities began to surface. The situation led to surveys conducted by DOH, an investigation by the FBI, and a Congressional hearing by the Subcommittee on Human Resources and Intergovernmental Relations, which reported that individuals in out-of-state facilities were either not benefitting from the placements, or worse, not receiving appropriate care.

In recognition of the shared and overlapping responsibilities for the State response to TBI, a formal collaboration between DOH and the Office of Mental Retardation and Developmental Disabilities, (now the Office for People with Developmental Disabilities (OPWDD) was initiated. The OPWDD commitment was outlined in a 1992 report “*Traumatic Brain Injury: The OMRDD Response*”.

The federal Health Care Financing Agency (HCFA) now named the Centers for Medicare and Medicaid Services (CMS) streamlined the Medicaid waiver application and worked proactively with states to implement new home and community based services waivers.

⁷⁸ NYS Appropriateness Review Standards for Trauma Centers” NYS Trauma Program; www.health.ny.gov/nysdoh/ems/nystrauma.htm.

⁷⁹ The Brain Trauma Foundation and the American Association of Neurological Surgeons, Guidelines for the Management of Severe Head Injury, 1995.

⁸⁰ An extended care TBI resident is at least 3 months post injury, having a traumatically acquired, non-degenerative, structural brain damage or anoxia, and has participated in intensive in-patient rehabilitation for persons in a hospital or nursing home; and assessed to no longer benefit from intensive rehabilitation.

⁸¹ National Institutes of Health Consensus Development Conference on Rehabilitation of Persons with Traumatic Brain Injury Statement, Bethesda MD, September 1999.

OPWDD secured waiver approval in 1991. Approval for the DOH TBI waiver was granted in May 1995.

As an initial step, individuals injured during their developmental years, before age twenty-two, were given access to the OPWDD Medicaid Home and Community Based Services (HCBS) 1915(c) waiver. OPWDD made startup funds available to service providers to establish brain injury treatment programs. Funds were also used to establish a statewide Family Advocacy Counseling Training Services (FACTS) under the auspices of BIANYS through which coordinators continue to assist eligible individuals and their families to access needed community based care.

1994 – Traumatic Brain Injury Program

Chapter 196 of the Laws of 1994 codified, within DOH, the New York State Traumatic Brain Injury Program.⁸²

Primarily, the legislation required:

- Development of a comprehensive statewide program that includes “medical, housing, vocational, community re-entry” services and programs;
- Development of educational programs on the causes and prevention of TBI, as well as, outreach and information services regarding assistance available to persons with TBI;
- Contracting with independent consultants to assess the needs of persons with TBI and manage, within funds available, the program; and
- Establish the TBI Services Coordinating Council charged with recommending to DOH long-range objectives, goals and priorities, and providing advice on the planning, coordination and development of needed services.⁸³

1995 – DOH Medicaid TBI Waiver for Community Based Care:

Pursuant to the 1994 statute, the Medicaid waiver to meet the needs of adults living with TBI was approved by the Federal government in May 1995. Regional Resource Center (RRDC) contracts with not-for-profit organizations were competitively established to implement the waiver, oversee development of needed services, and repatriate identified individuals from out of state nursing homes. The following year a statewide Neurobehavioral Project was established to help providers develop the expertise needed to address TBI related behavioral issues that challenge an individual’s ability to remain in the community.

The TBI waiver continues to serve eligible adults with brain injury. In 2011, approximately 2,700 individuals received community based services and other supports through the waiver as an alternative to institutional care.

⁸² Article 27 - CC of the Public Health Law, Sections 2740-2744 Laws of New York, 1994; Chapter 196.

⁸³ Article 27 - CC of the Public Health Law, Section 2744 (3).

1995 – Accessible Housing

Accessible housing was identified as a primary barrier to the return of people with TBI to their communities. Over the course of eighteen months in the mid-1990s, review of a variety of housing models and options resulted in the current State funded housing subsidy program for TBI waiver participants. Similar to the Federal Housing Choice Vouchers program, Section 8, the TBI housing subsidy provides rental assistance for living arrangements chosen by waiver participants within reasonable parameters. This assistance has allowed eligible waiver participants to live in their communities.

1998 – TBI Implementation Report

In March 1998, DOH issued a TBI Implementation Report, which provided a background on the unique needs of people with TBI, and information regarding ongoing related activities and services that had taken place in response to the 1994 TBI legislation.⁸⁴

The report noted significant progress in creating services to enable the return to New York of over half the persons with TBI previously living in out-of-state facilities. This progress was primarily due to access to services through the newly implemented MA waiver services and housing programs established by DOH, SED and OPWDD. The report concluded, “The challenge is to continue to improve services for New Yorkers who experience TBI.”⁸⁵

⁸⁴ New York State Services for Traumatic Brain Injury, A Report to Governor George E. Pataki and The New York State Legislature, March 1998.

⁸⁵ Ibid, p. 29.

APPENDIX B

DEFINITION OF TRAUMATIC BRAIN INJURY

Section 2741 of the New York State Traumatic Brain Injury Program (Article 27-CC of the Public Health Law) states:

“The term ‘traumatic brain Injury’ means an acquired injury to the brain caused by an external physical force resulting in total or partial disability or impairment and shall include but not be limited to damage to the central nervous system from anoxic/hypoxic episodes” (lack of oxygen), “or damage to the central nervous system from allergic conditions, toxic substances and other acute medical/clinical incidents. Such term shall include, but not be limited to, open and closed brain injuries that may result in mild, moderate, or severe impairments in one or more areas, including cognition, language, memory, attention, reasoning abstract thinking, judgment, problem-solving, sensory perceptual and motor abilities, psycho-social behavior, physical functions, information processing and speech.

Such term shall not include progressive dementias other mentally impairing conditions, depression and psychiatric disorders in which there is no known or obvious central nervous system damage, neurological, metabolic and other medical conditions of chronic, congenital or degenerative nature or brain injuries induced by birth trauma.”⁸⁶

There are three categories of TBI: mild, moderate and severe. The severity of the injury is determined at the time of injury as outlined in the table below. If a person meets criteria in more than one category, the higher severity level is assigned.⁸⁷

TBI Severity

Closed Brain Injury	Alteration of Consciousness	Loss of Consciousness	Post Traumatic Amnesia	Structural Imaging
Mild TBI	<24 hours	0 – 30 minutes	< 24 hours	Normal
Moderate TBI	>24 hours	> 30 minutes but < 24 hours	>24 hours but <7 days	Normal/Abnormal
Severe TBI	>24 hours	> 24 hours	>7days	Normal/Abnormal

⁸⁶ New York State Public Health Law Article 27-CC, Section 2741.

⁸⁷ Assistant Secretary of Defense Memorandum, “Traumatic Brain Injury: Definition and Reporting,” October 1, 2007. Defense Centers of Excellence for Psychological Health and Traumatic Brain Injury, Case Management of Concussion /Mild TBI, Guidance Document, November 8, 2010, Brain Injury Association of America, www.biausa.org.

APPENDIX C

HRSA TBI GRANT MEETING PRESENTATIONS & STAKEHOLDERS LISTING

- NYS Traumatic Brain Injury Services Coordinating Council
September 2009
Winter 2010, Spring 2010, Fall 2010
Winter 2011, Spring 2011, Summer 2011
State Agency TBI Assessment Discussions January - February 2011
April 20, 2012
- NYS Division of Veterans Affairs
Winter 2010, Summer 2010, Fall 2010, Spring 2011, Fall 2011, Winter 2012
- Council on Returning Veterans and their Families
Fall 2009, Spring 2010, Fall 2010, Winter 2011, Fall 2011, Winter 2012
- Brain Injury Association of New York State (BIANYS)
Annual Conference June 2010, 2011, 2012
Meetings of the Board, Winter 2009, Spring 2011
Meetings with FACTS coordinators, Spring 2010, 2011
- Providers of Services to Persons with TBI
Waiver Providers Fall 2009
Roundtable on Children with TBI Summer 2011
Concussion Management Roundtable Fall 2011
OASAS TBI and Addiction Conference, Spring 2012
- Regional Resource Development Center Specialists (RRDS)
Fall 2009, Fall/Winter 2010, Winter/Summer/Fall 2011, Spring 2012
- New York Public Welfare Association
Annual Conference 2009, 2011
- Health Resources and Services Administration
National Leadership Meeting, Plenary Session, March 2012

State Agencies: Department of Health
Department of Financial Services (Insurance)
Office of Mental Health
State Education Department
Office of Crime Victim Services
New York State Division of Veterans Affairs
Office of People with Developmental Disabilities
Office of Alcohol and Substance Abuse Services
New York State Developmental Disabilities Planning Council
Commission on Quality of Care and Advocacy for People with Disabilities

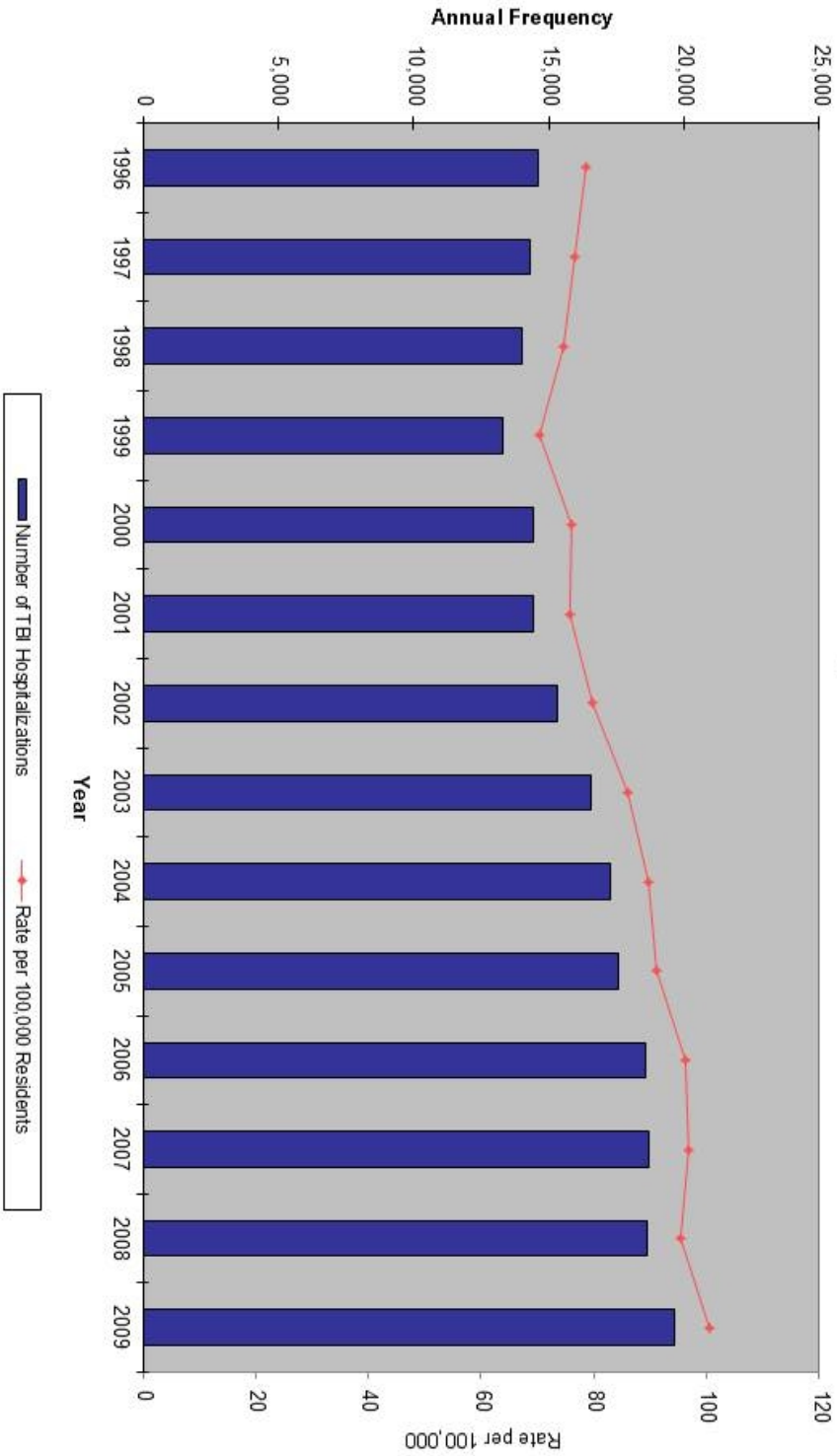
HRSA GRANT STAKEHOLDER LISTING Continued

- Traumatic Brain Injury Services Coordinating Council
- New York State, HRSA Grant TBI Ombudsman
- The Brain Injury Association of New York State, BIANYS
- Regional Resource Development Centers, RRDC
- Home Care Association of New York State
- Hospice and Palliative Care Association of NYS
- Healthcare Association of NYS
- Greater NY Healthcare Facilities Association
- Greater NY Hospital Association
- Community Health Care Association of New York State
- Southern New York Hospital Association
- Medical Society of the State of New York
- NYSARC, Inc.
- New York State Health Facilities Association
- New York State Association of Health Care Providers
- United Cerebral Palsy Associations of New York State
- County Nursing Facilities of New York
- Empire State Association
- New York State Association of County Health Officials
- Leading Age New York, formerly NYAHS
- Inter-county Health Facilities Association
- New York State School Boards Association
- American Academy of Pediatrics, Chapters 2 & 3
- University at Buffalo Concussion Clinic
- New York State Athletic Trainers Association
- New York State Public High School Athletic Association
- New York State Council of School Superintendents
- Mount Sinai School of Medicine
- University of Rochester School of Medicine and Dentistry
- North Shore Health System
- Rusk Institute of Rehabilitation Medicine, NYU Langone Medical Center
- New York State Athletic Trainers' Association
- Upstate University Hospital Concussion Management Program
- New York Youth Sports Institute

APPENDIX D

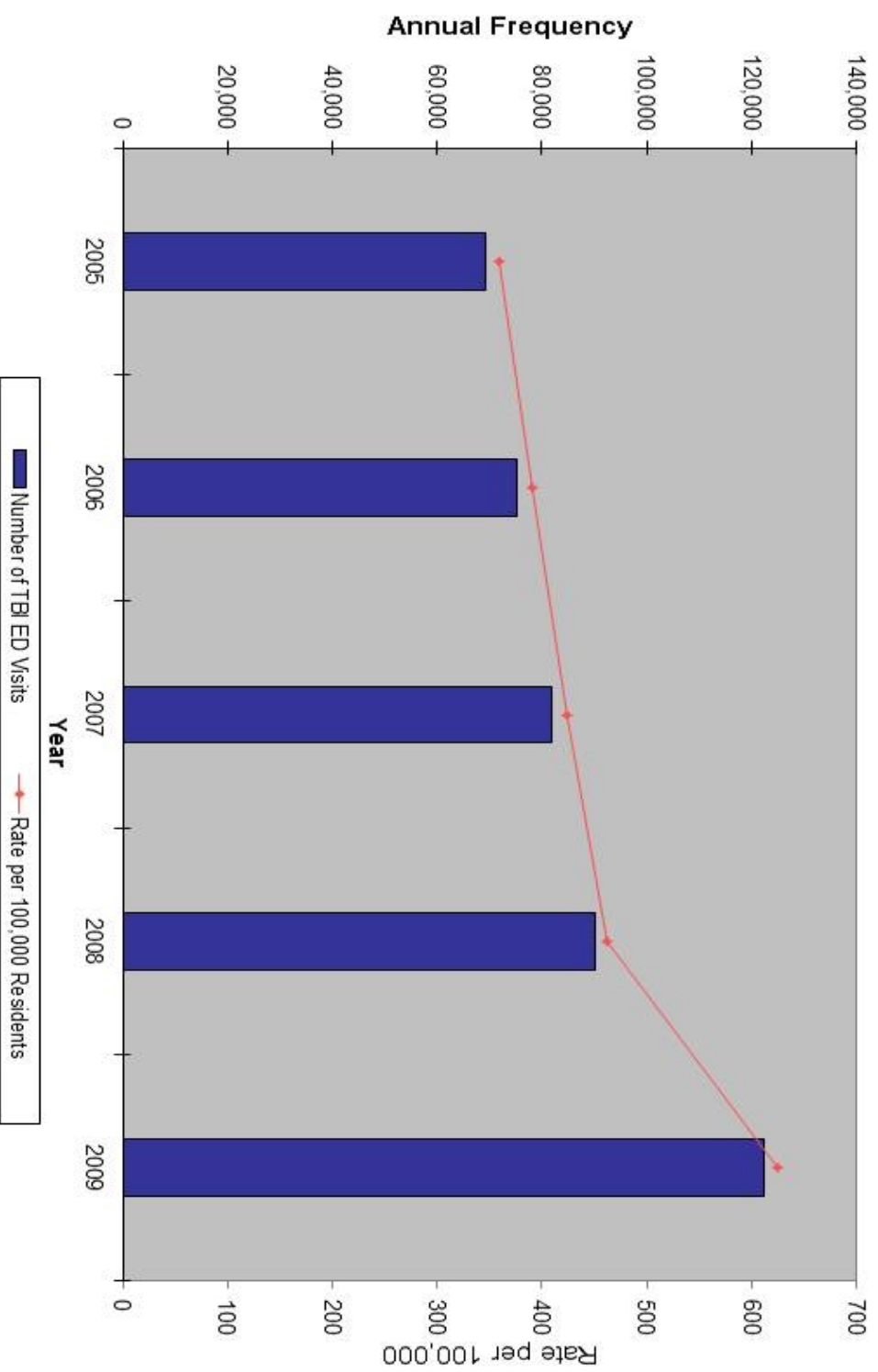
NEW YORK STATE TBI STATISTICS

**Incidence of Traumatic Brain Injuries
Hospitalizations
New York State Residents, 1996-2009**



Source: NY SPDH, Bureau of Injury Prevention
www.health.ny.gov/prevention/injury_prevention/
 SPARCS March 2011

Incidence of Traumatic Brain Injuries Emergency Department (ED)[†] Visits New York State Residents, 2005-2009



[†]The incidence of ED visits does not include patients that were subsequently admitted into the hospital.

Source: NYSDOH, Bureau of Injury Prevention
www.health.ny.gov/prevention/injury_prevention/
 SPARCS March 2011

Incidence of Traumatic Brain Injury
Hospitalizations and Emergency Department† (ED) Visits
 New York State Residents, 1996-2009

Characteristics	Hospitalizations		ED [†] Visits	
	Annual Frequency	Rate per 100,000 Residents	Annual Frequency	Rate per 100,000 Residents
Year of Discharge	14,609	78.6	n/a	n/a
1996	14,289	76.6	n/a	n/a
1997	13,993	74.6	n/a	n/a
1998	13,307	70.5	n/a	n/a
1999	14,446	76.0	n/a	n/a
2000	14,452	75.7	n/a	n/a
2001	15,315	79.9	n/a	n/a
2002	16,543	86.0	n/a	n/a
2003	17,289	89.7	n/a	n/a
2004	17,560	91.2	69,225	359.5
2005	18,583	96.3	75,319	390.1
2006	18,676	96.8	81,821	424.0
2007	18,631	95.6	90,013	461.8
2008	19,634	100.5	122,209	625.4
2009				

Rate = Frequency/Population *100,000 Source: NYSDOH, Bureau of Injury Prevention
www.health.ny.gov/prevention/injury_prevention/

SPARCS March 2011

APPENDIX E

2010 SURVEY OF INDIVIDUALS LIVING WITH TBI AND THEIR FAMILIES

Report of

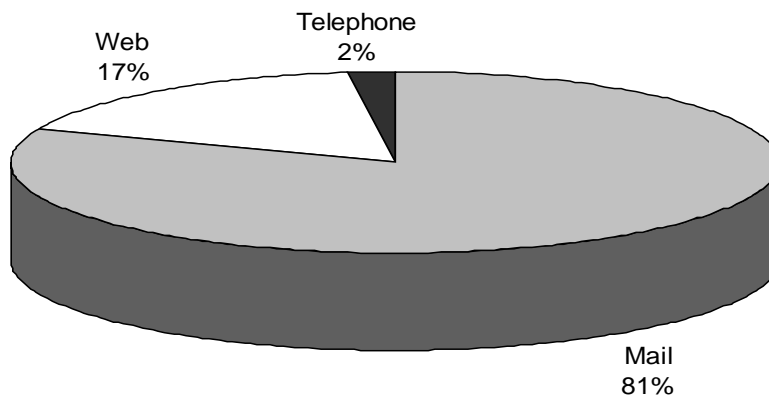
2010 TBI Needs and Resource Assessment Survey

To assess services provided in New York State to persons living with a TBI, a survey was administered to samples of TBI populations. The first sample was comprised of persons whose names were selected from the participant list of the TBI Home and Community Based (HCBS) Medicaid waiver. Of the 2,827 persons on the TBI waiver in New York State as of May 2010, 1,600 were randomly selected to receive the survey. The second sample was those from the membership list of the Brain Injury Association of New York State (BIANYS). Four hundred individuals were selected from the non-professional membership list of the BIANYS to receive the survey. Another 300 surveys were sent to Family Advocacy Counseling and Training Services (FACTS) coordinators for distribution at TBI support group meetings.

All surveys included a postage paid, return envelope addressed to the TBI Grant Project. Individuals had the choice of completing the survey on-line, by phone, or mailing the copy they received back to the grant project staff. A total of 784 surveys were completed and returned. Adjusting for the number of surveys deemed “non-deliverable” by the U.S. Postal Service, a response rate of 40% was achieved.

The majority of surveys, 641, were returned by mail followed by 127 on-line submissions and 16 by phone interview, as shown in Figure 1.

Figure 1
Survey Response Method



Four hundred eighty nine (68%) respondents reported they were TBI Waiver participants. A comparison of demographics between the waiver survey respondents and the universe of those on the TBI waiver revealed no important differences. Nearly identical characteristics were found between the survey sample of TBI waiver respondents and the TBI waiver population overall in terms of median age, gender, ethnicity and region of the state where they reside.

Two hundred thirty three (32%) respondents indicated they were not enrolled in the TBI waiver. Identifying persons living with brain injury among the general population remains a challenge particularly in attempting to assess their need for services and planning service delivery. Given this fact, it is unclear if the responses of this latter group are a good representation of the non-TBI waiver population.

Other limitations in the distribution of the survey need to be acknowledged. Responses from individuals identifying themselves as veterans and families of children with TBI were negligible. A number of states have a TBI registry, which New York does not. The lack of a registry restricted the survey distribution to persons with TBI not enrolled in the TBI waiver and limited the response rate of the non-waiver population. Given the incidence of pediatric TBI cases, among the general population and of veterans, particularly those returning from Iraq and Afghanistan, with additional funding, future research and survey efforts could be better targeted to these specific groups.

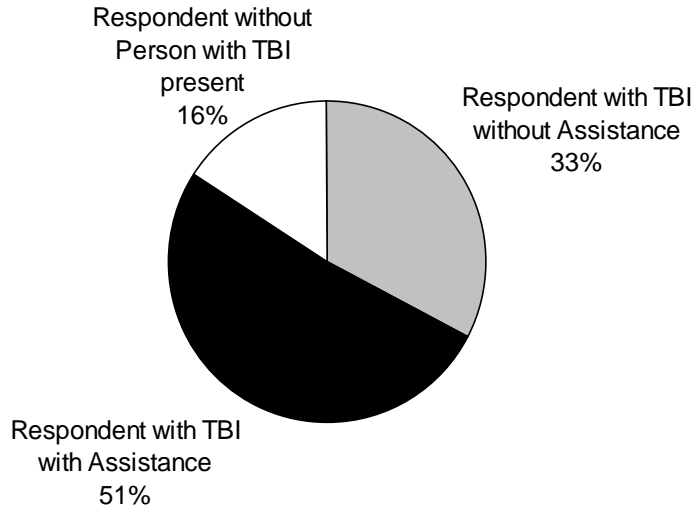
Findings of Needs and Resources Assessments

In the eighteen years since the enactment of the New York State Traumatic Brain Injury (TBI) Program, significant progress has been made in the delivery of services for persons living with TBI, particularly those enrolled in the State's Home and Community Based (HCBS)1915(c) TBI Waiver. Survey responses affirm this system improvement, and point to gaps that remain within the TBI service delivery system. Analysis of the survey responses provides a view of the current system of care from the vantage point of New Yorkers with brain injuries and their families.

Respondents Demographics

One third of respondents completed the survey without assistance; over half reported that they had help. Sixteen percent of respondents completed the survey without the person with TBI present or participating. These findings are shown in Figure 2.

Figure 2
Survey Respondents



The median age of respondents was 48 years; more than half were male (59%). The average age at time of injury was 32 years, with the age range of less than one year to 86. The length of time since injury ranged from less than a year to 62 years, with the average being 15 years. Fifteen percent of respondents self-reported their injury was “mild” with 42% and 43% reported to have a “moderate” and “severe” injury respectively. Figures 3 and 4 show the age categories and gender of survey respondents.

Figure 3
Age of Survey Respondents with TBI

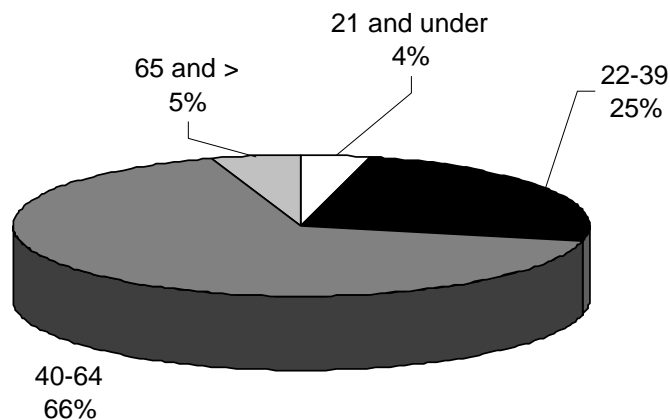
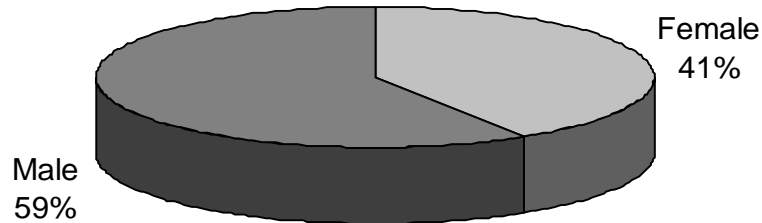
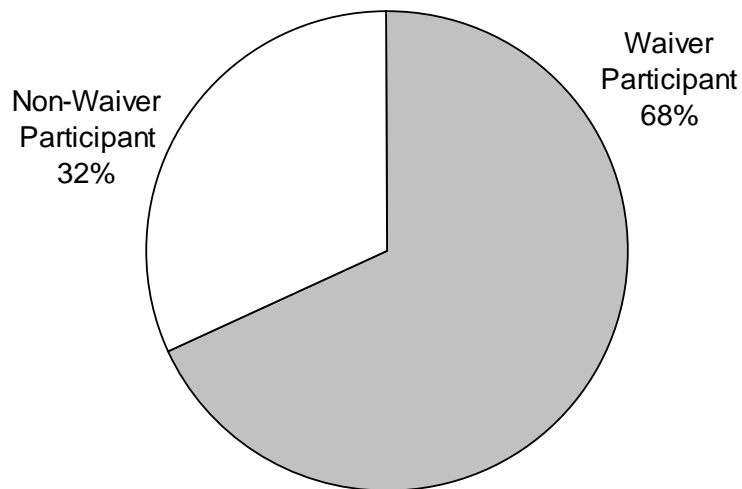


Figure 4
Gender of Survey Respondents



Sixty eight percent, (68%) of respondents indicated they received services from a Home and Community Based Waiver; 32% reported they did not. Of the 32% who reported they did not receive services from a HCBS waiver, 62% indicated they were not aware of these programs.

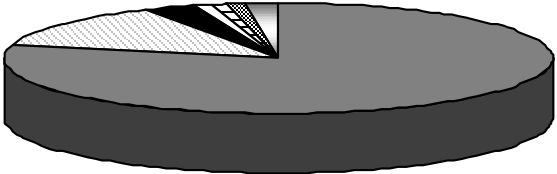
Figure 5
Home & Community Based Waiver Enrollment Status



As shown in Figure 6, nearly eighty percent of survey respondents were White, non-Hispanic, followed by 13 percent Black, and three percent Hispanic. Whether the findings reflect the demographics of the overall State population living with TBI is unknown, as such data is not available. States, which have a TBI registry, are better equipped to define specifics about their TBI population.

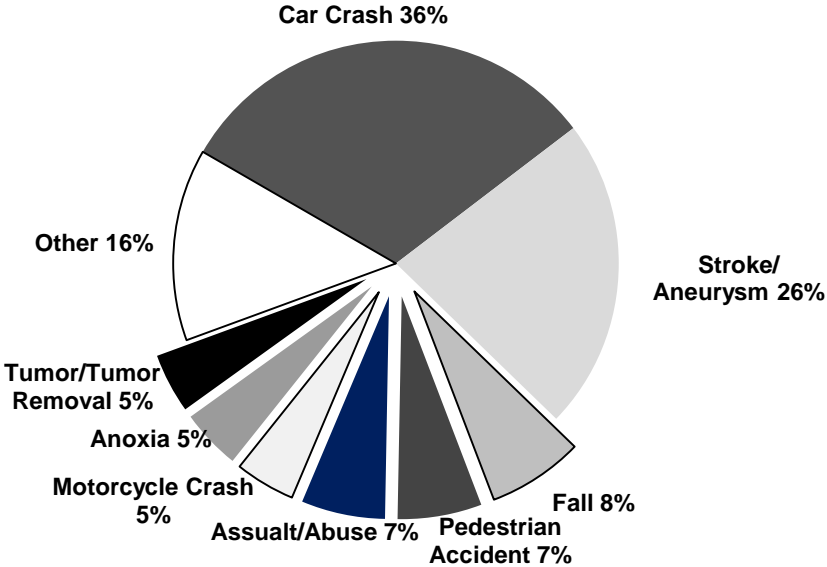
Figure 6
Race/Ethnicity of Persons with TBI
who Responded to the Survey

- White 79%
- Black 13%
- Hispanic 3%
- Mixed 1%
- Asian/Pacific Islander 1%
- Native American 1%
- Other 2%



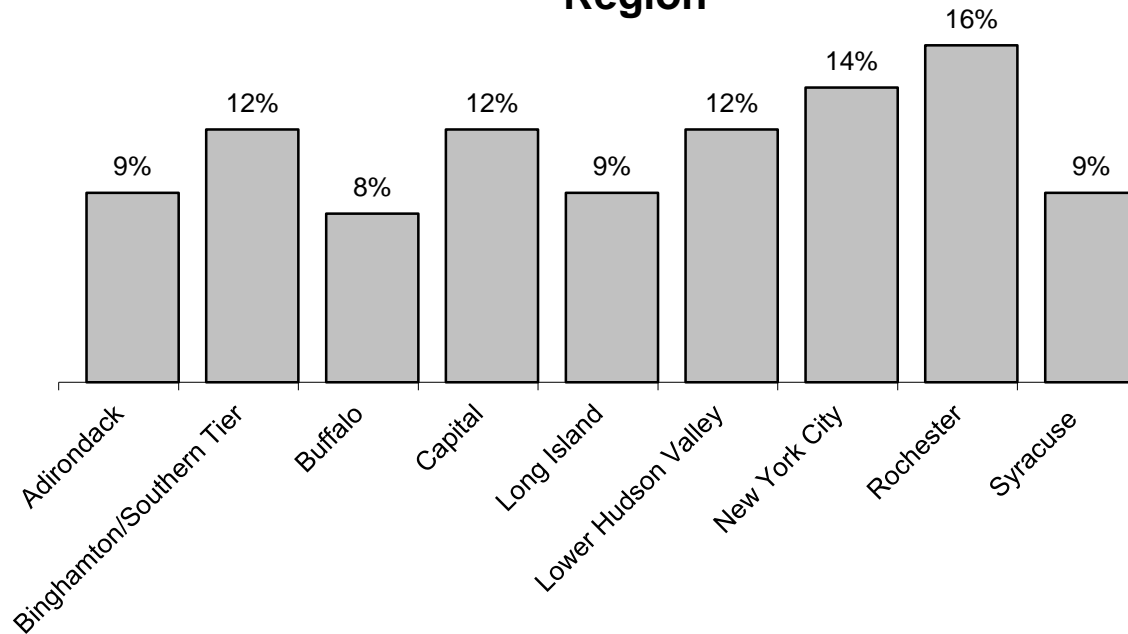
Respondents were asked to identify causes of their brain injury. Thirty-six percent of the brain injuries reported by respondents resulted from vehicle/ crashes, followed by stroke (26%), fall (8%), assault/abuse (7%), and pedestrian accidents (7%). The remaining 31 percent of injuries were spread across a variety of other causes as shown in the following graphic.

Figure 7
Cause(s) of Brain Injury



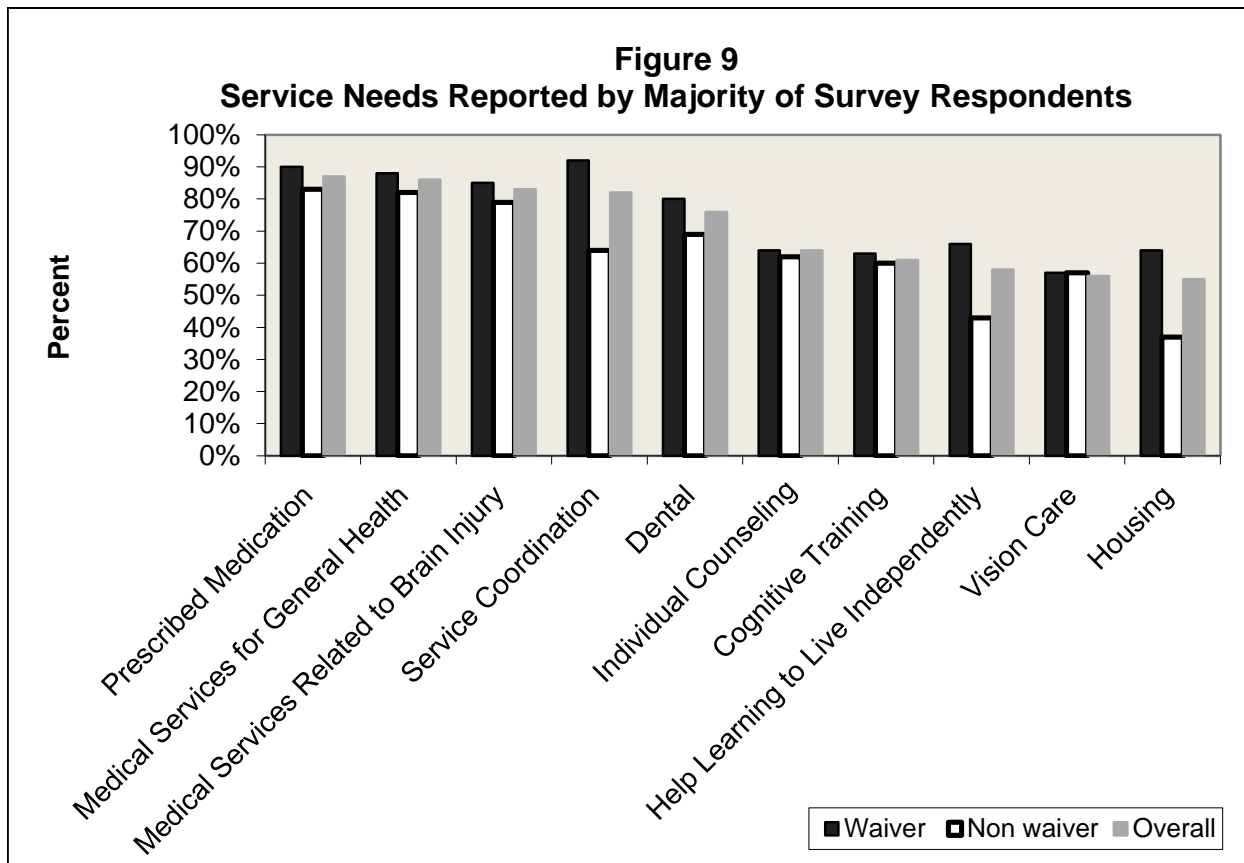
The regions of the state where survey respondents live were analyzed in accordance with the nine TBI regions of the Waiver and are shown in Figure 8. Response percentages mirror the residential demographics of the Waiver program but not necessarily that of the overall TBI population in the State, as previously noted.

Figure 8
Residence of Survey Respondents by NYS
Region



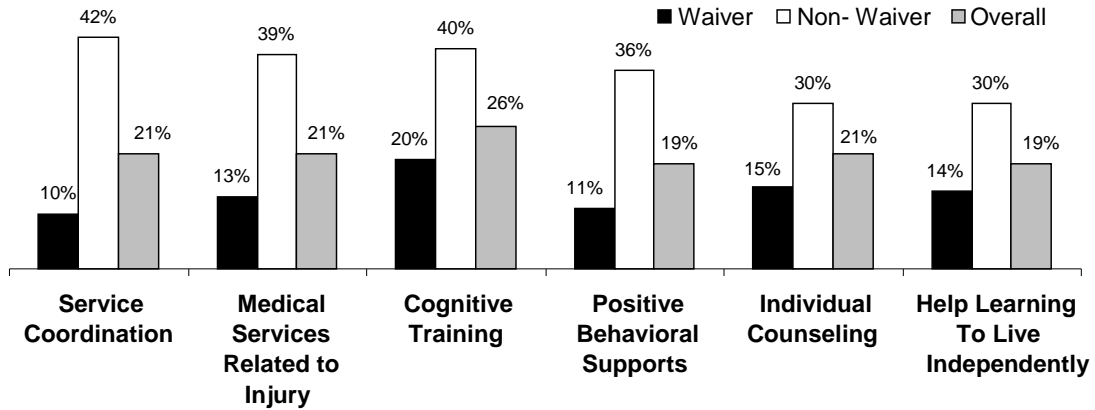
Variation across regions was found in reported unmet service needs as well as between TBI waiver participants versus those not enrolled. For example, in six categories of service, data indicates that persons outside the waiver have ongoing needs at twice the rate of those in the waiver. In contrast, larger percentages of TBI waiver participants identified more categories of needed services than did non-waiver participants. This may be related to the fact that waiver participants also reported more severe levels of brain injury, and significantly more lived alone than did non-participants.

Out of the twenty-five services listed in the survey, ten were identified as a need by more than 50 percent of respondents. These services are shown in Figure 9. Half are medically related and may be related to larger system issues and this should be reviewed in relation to all populations. These can be difficult to access for the Medicaid population in general. The remaining services, service coordination, cognitive training, help learning to live independently, individual counseling and housing assistance are services included in the TBI waiver and may be more easily accessible for enrollees in the waiver.



When respondents were asked to identify the services they needed but were not receiving to meet those needs, reports of inaccessible services were twice more likely from non-TBI waiver participants than participants. The percentages of ongoing need reported among TBI waiver and non-waiver participants in the six highest categories of continuing unmet need are shown in Figure 10.

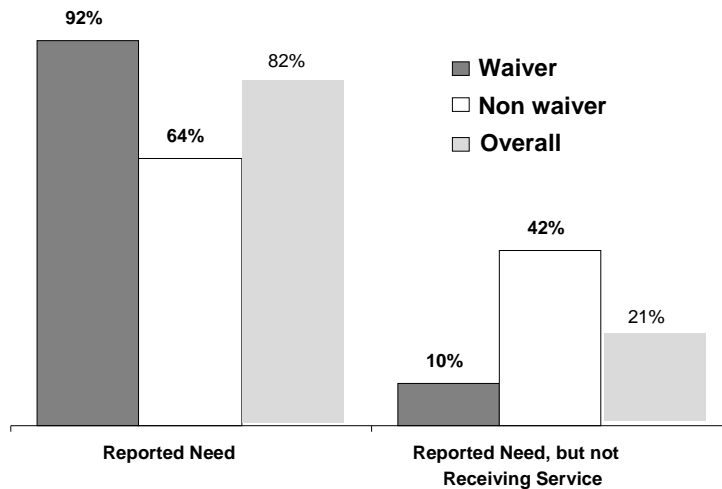
Figure 10
Unmet Service Needs Reported by Twice the Number of Non-Waiver
Survey Respondents as Waiver Enrollees



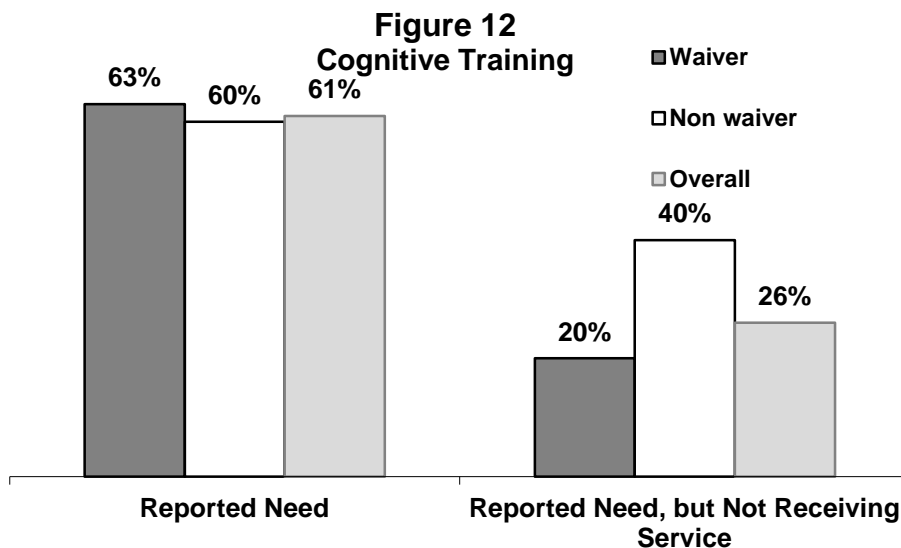
The following discussion covers the services that were identified as high need.

Service Coordination: Over eighty percent (80%) of survey respondents identified service coordination as a need. Nearly all (90%) of the TBI waiver respondents reported they received this service and it met their needs, however, it was the greatest unmet need listed by non-waiver respondents (42%). (Figure 11) It was also the most frequently mentioned need in the open-ended questions regarding how to improve services and supports in NYS. The importance of service coordination to assist individuals with TBI to navigate the service system was also frequently mentioned in respondents' written comments about how the service system can be improved.

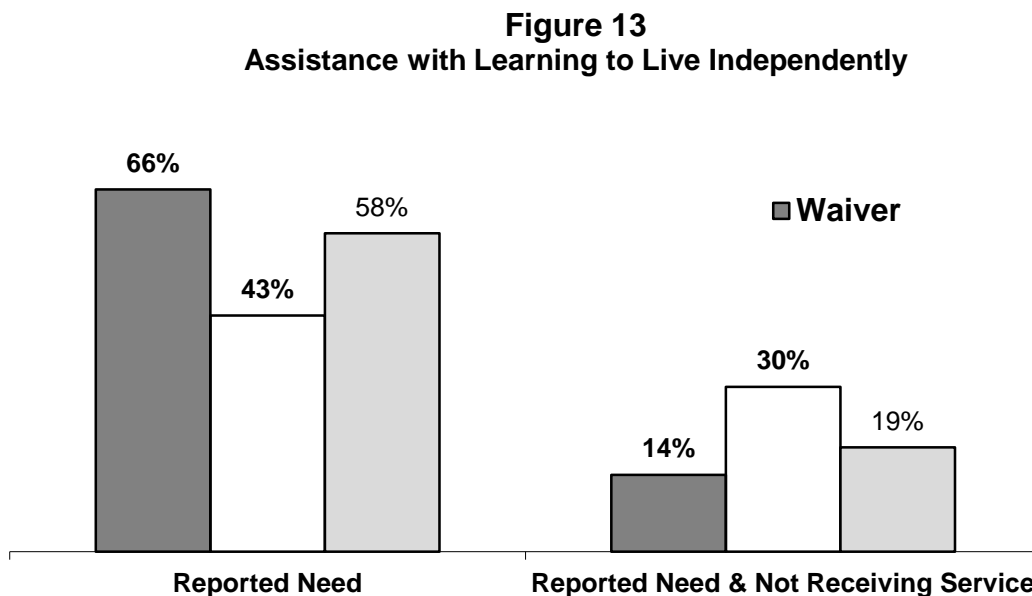
Figure 11
Service Coordination



Cognitive training or rehabilitation was reported as the greatest area of unmet need overall. Sixty one percent (61%) of respondents indicated it was a need, with one-quarter (26%) citing it as an unmet need. Forty percent (40%) of non-TBI waiver respondents reported it as an unmet need, twice the rate of waiver respondents as shown in Figure 12.

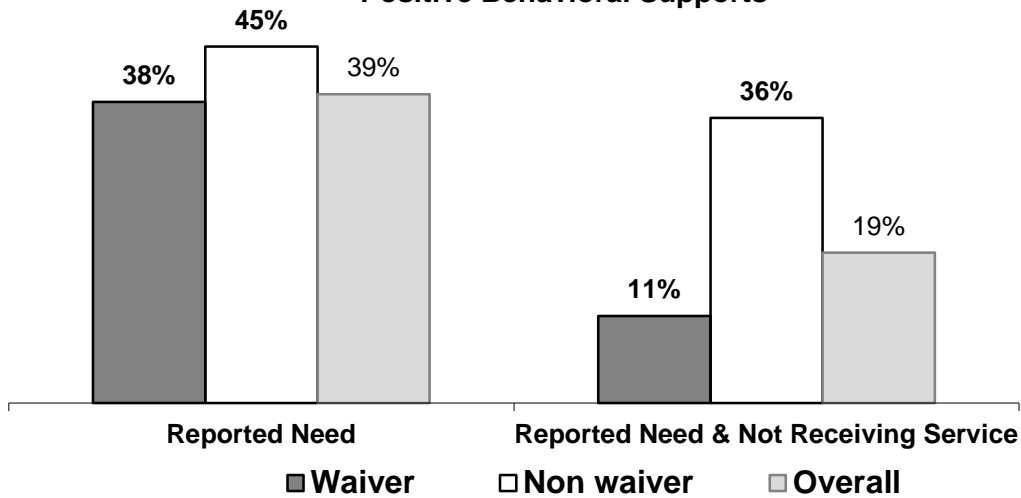


Assistance in learning to live independently was a reported need among 58% of respondents. Termed, “Independent Living Skills Training or (ILST)”, these services provide assistance with: self-care, medication management, interpersonal skills, socialization, problem solving skills, money management etc. Non-waiver respondents (30%) reported it as an unmet need at twice the rate of waiver enrollees (15%). (Figure 13) The TBI waiver includes ILST as a service.



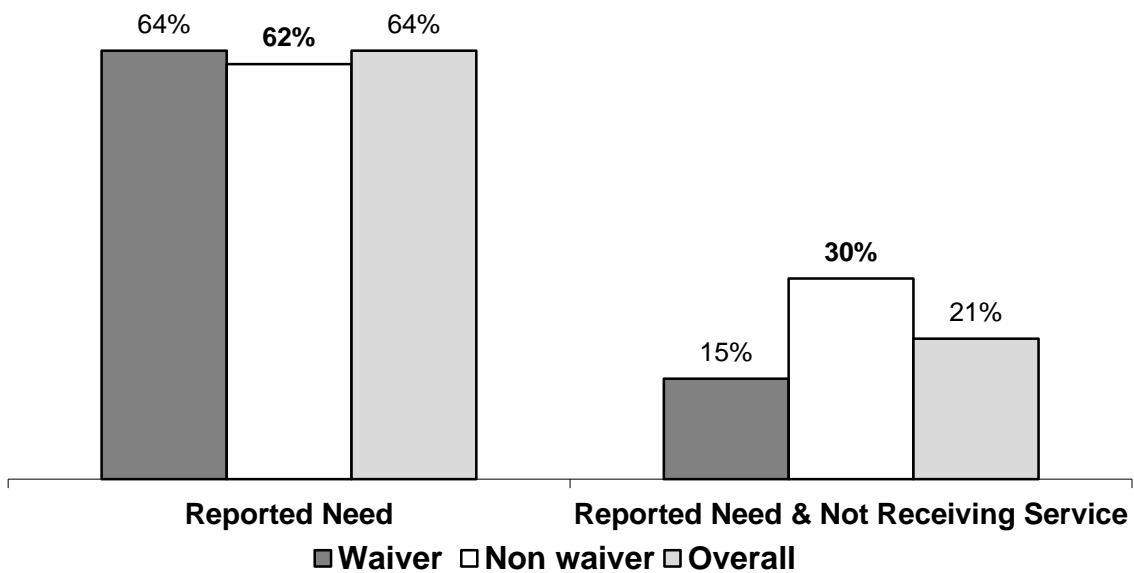
Positive Behavioral Supports are a TBI Waiver service and provided to persons who have significant behavioral difficulties that jeopardize their ability to remain in the community, due to inappropriate responses to events in their environment. The goal of these services is to decrease the intensity or frequency of targeted behaviors and to teach more socially appropriate/effective behaviors. This was reported as an ongoing need of 36% of respondents not on the TBI waiver. (Figure 14)

Figure 14
Positive Behavioral Supports

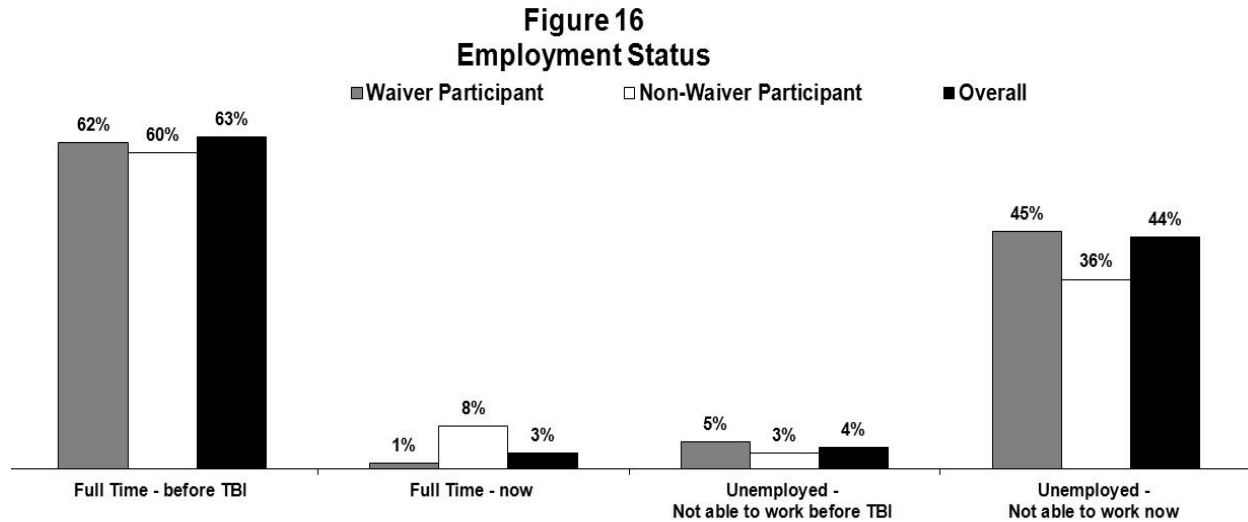


Individual Counseling was a reported need by over 60% of respondents. Respondents not on the waiver reported this service as a need at twice the rate (30%) than of waiver participants (15%). (Figure 15)

Figure 15
Individual Counseling

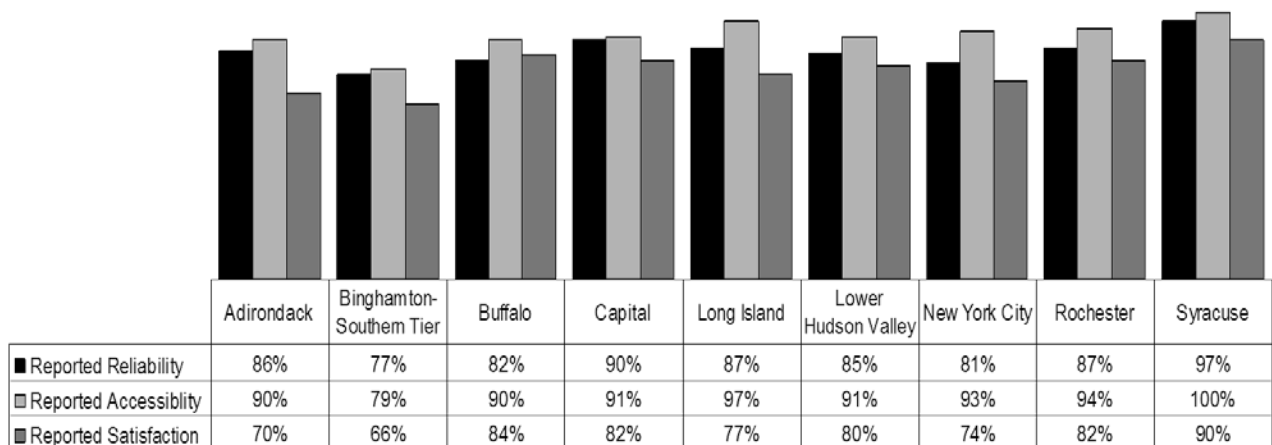


Employment status revealed similarities among all respondents. All reported a significant shift from full time employment prior to the injury (63%) to post injury unemployment (44%). Fourteen percent of respondents indicated they were unemployed but looking for work. (Figure 16)



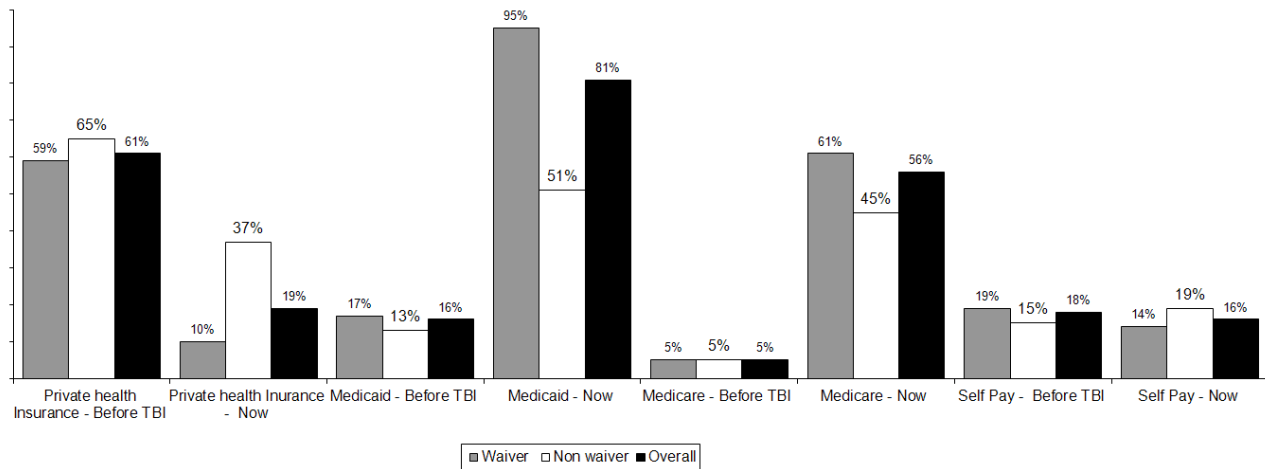
Transportation was generally reported to be reliable and accessible across the nine regions by a majority of respondents (90%). The exception was the Binghamton-Southern Tier area, in which accessibility in transportation received a 79% response rate. Rates of satisfaction with transportation increased with age ranging from 63% among those 21 years or younger to 85% for those 65 years or older. (Figure 17)

Figure 17
Transportation



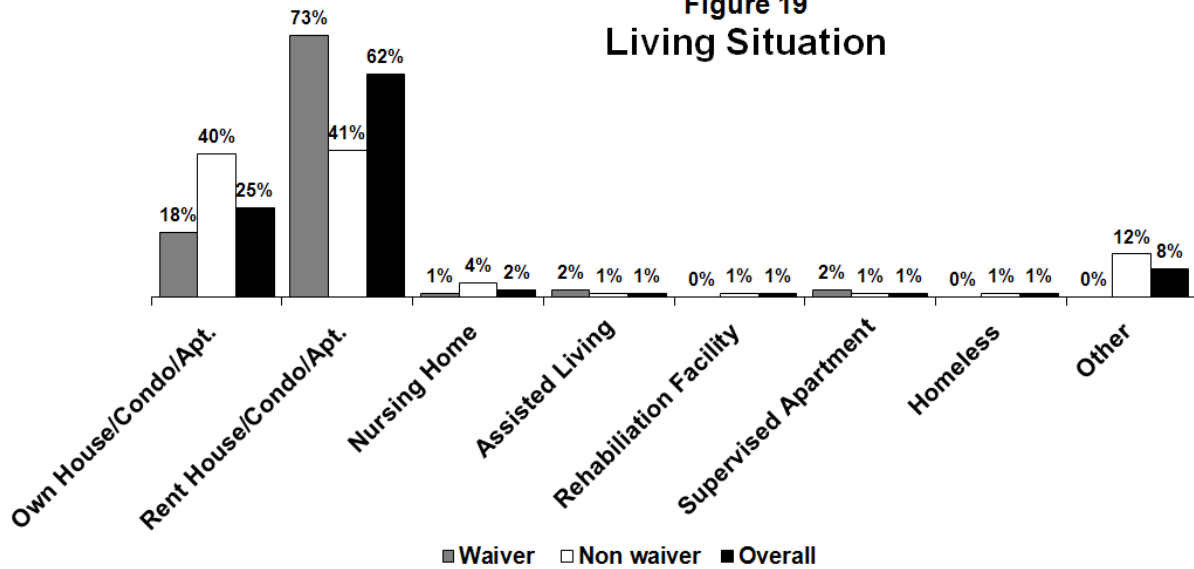
Health insurance coverage was reported by two-thirds of respondents as consisting of private health insurance prior to their TBI, shifting to less than 20% after their injury. A concomitant increase in Medicaid coverage was reported. Sixteen percent of respondents reported Medicaid coverage prior to their TBI rising to 81% after the injury. Similar increases in Medicare coverage occurred, with 5% having such coverage prior to the injury, and 56% reporting Medicare coverage now. (Figure 18)

Figure 18
Payor Source Of Health Care



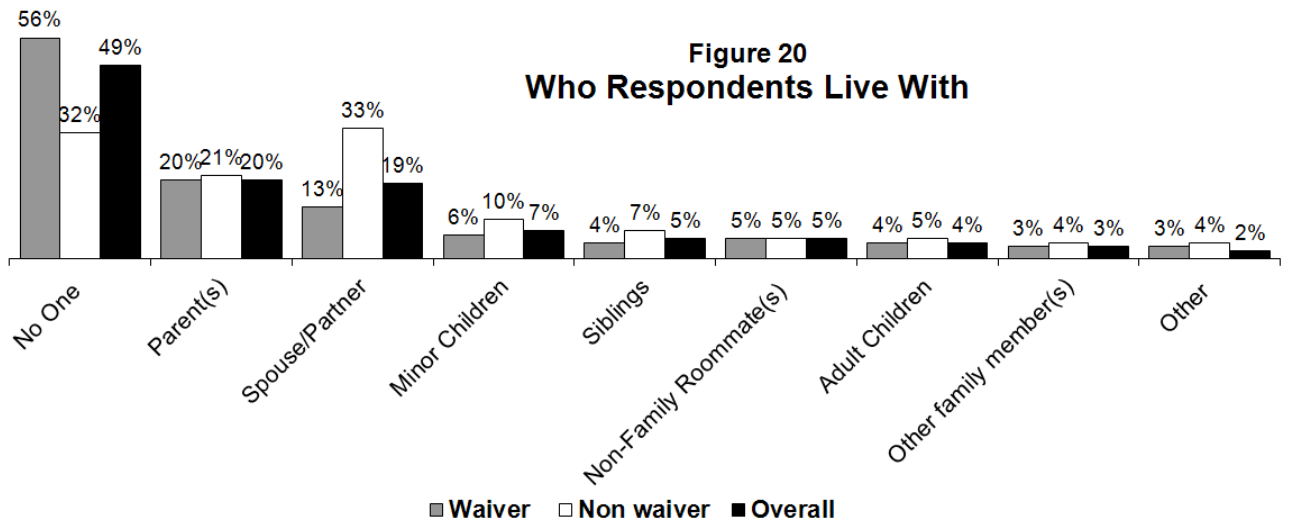
Housing assistance was identified as a need by 55% of respondents overall, with 64% of persons enrolled in the TBI waiver and 37% percent non-waiver participants. (Figure 19) Alternative housing options were advocated for in written comments including transitional living, group homes including those capable of caring for medically involved persons, similar to the models used by the Office of People with Developmental Disabilities, small adult homes, and family care type homes. Continuation of housing subsidies for waiver participants was identified as a need and important support.

**Figure 19
Living Situation**



Living situations varied significantly between TBI waiver and non-waiver respondents perhaps reflecting the availability of housing subsidies for waiver participants. Fifty-six percent (56%) of respondents on the TBI waiver live alone versus 32% of persons not on the TBI waiver. Significant differences were found between these groups in the category of “living with spouse/partner”, with 33% of non-waiver participants reporting they lived with a spouse/partner compared to 13% of waiver participants. Similar percentages of both populations reported they lived with their parents. (Figure 20)

**Figure 20
Who Respondents Live With**



Responses to the quality of life survey questions reveal significantly similar rates of decline in reported quality of life between TBI waiver and non-waiver participants. More than 50% reported the injury changed their life for the worse in many areas. The following charts illustrate the decline reported. (Figures 21 – 27)

Figure 21
Quality of Life

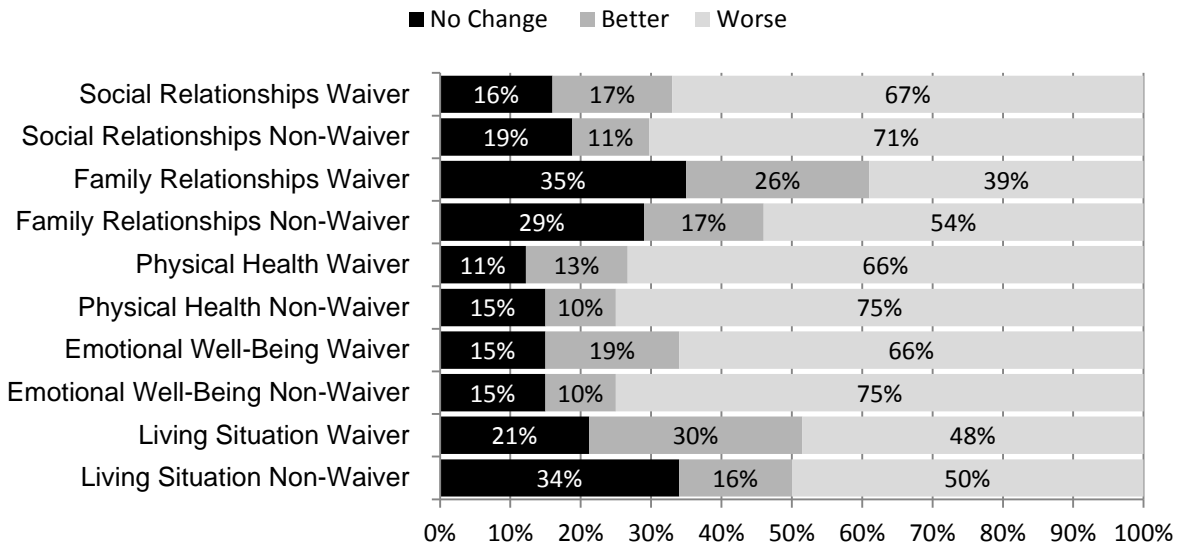


Figure 22
Reported Quality of Life Physical Health

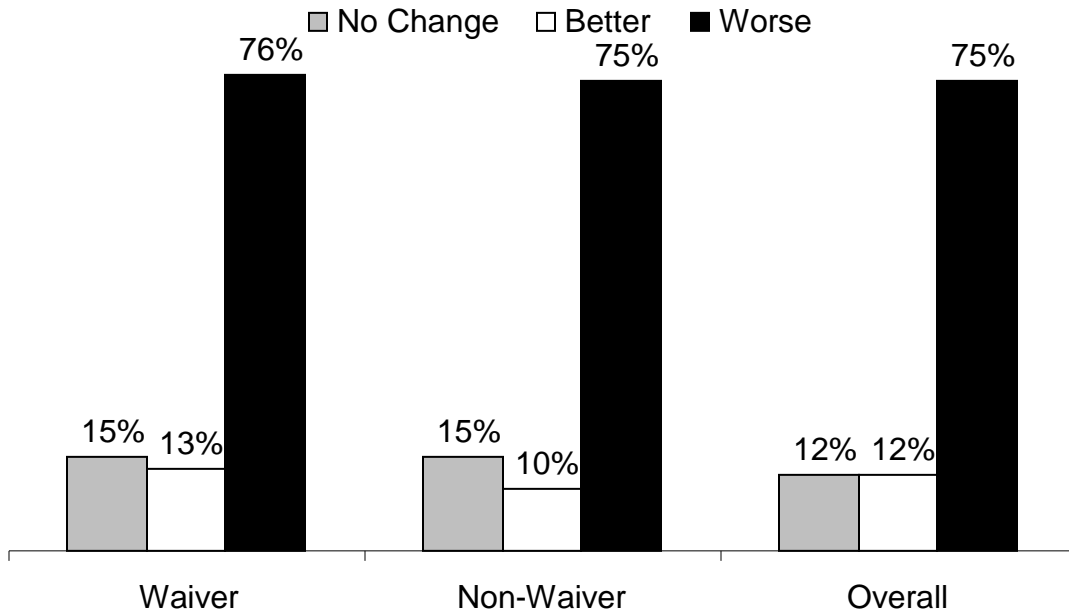


Figure 23
Emotional Well Being

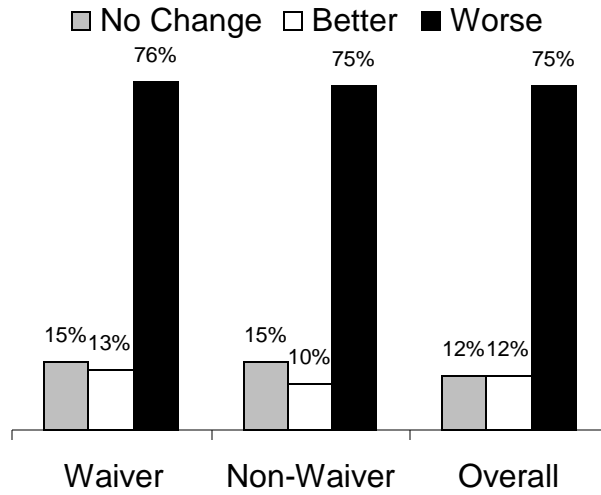


Figure 24
Reported Quality of Life - Family Relationships

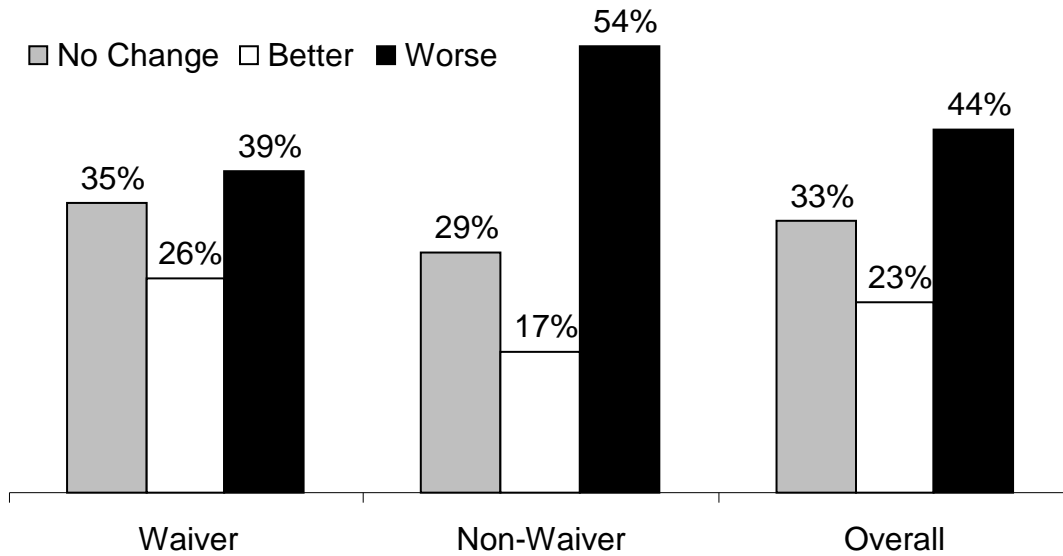


Figure 25
Reported Quality of Life -

Leisure/Recreational Activities

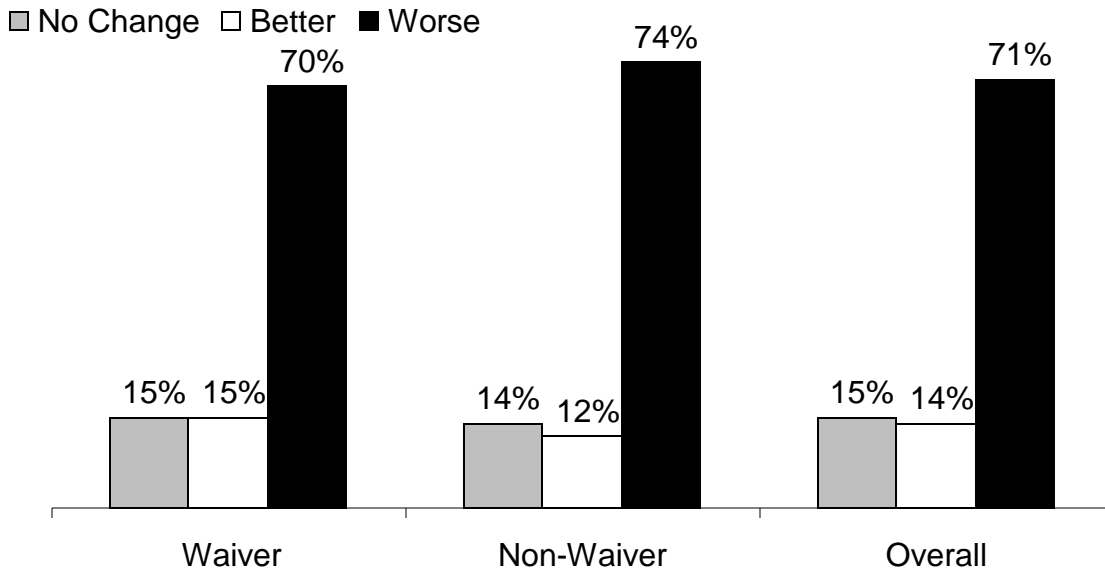
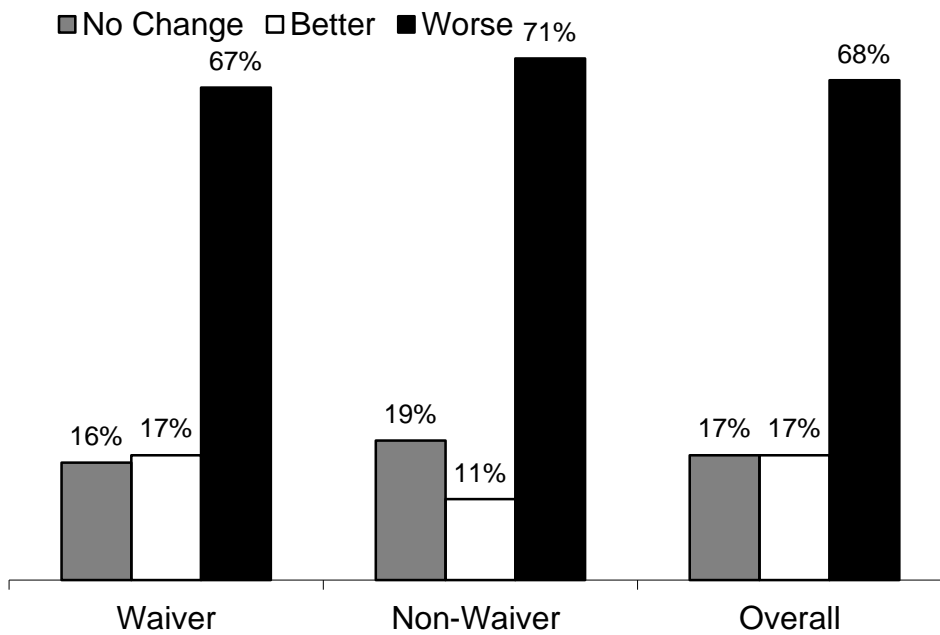
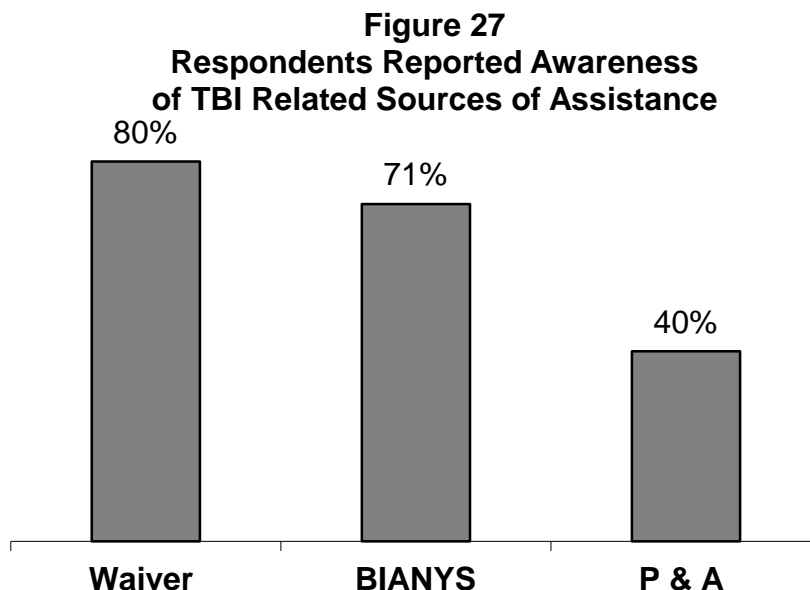


Figure 26
Reported Quality of Life -
Social Relationships



Awareness of TBI services and advocacy assistance reveal the continued need for education/outreach efforts. Sixty percent of respondents reported they were not aware of New York’s Protection and Advocacy Services, 30% were not aware of the BIANYS and twenty percent did not know about the TBI Waiver. The majority of written comments called for more “accessible, user friendly” information about TBI and the services available to those with such injuries and their families. (Figure 27)



Nearly 580 respondents wrote comments on how to improve the TBI service system. The most frequently mentioned areas are noted as follows:

- Service coordination for individuals with TBI and their families, regardless of waiver eligibility, to help navigate the service system beginning as soon after the injury as possible (optimally prior to hospital discharge);
- Easily understood and accessible information about the TBI service system, including a “central statewide information and referral center”;
- More training for physicians and community based providers/staff on TBI;
- Maintain existing housing assistance services and expand housing options including congregate living models; and
- More support for families is needed including counseling, respite, and referral services.

APPENDIX F

PROVIDER SURVEY

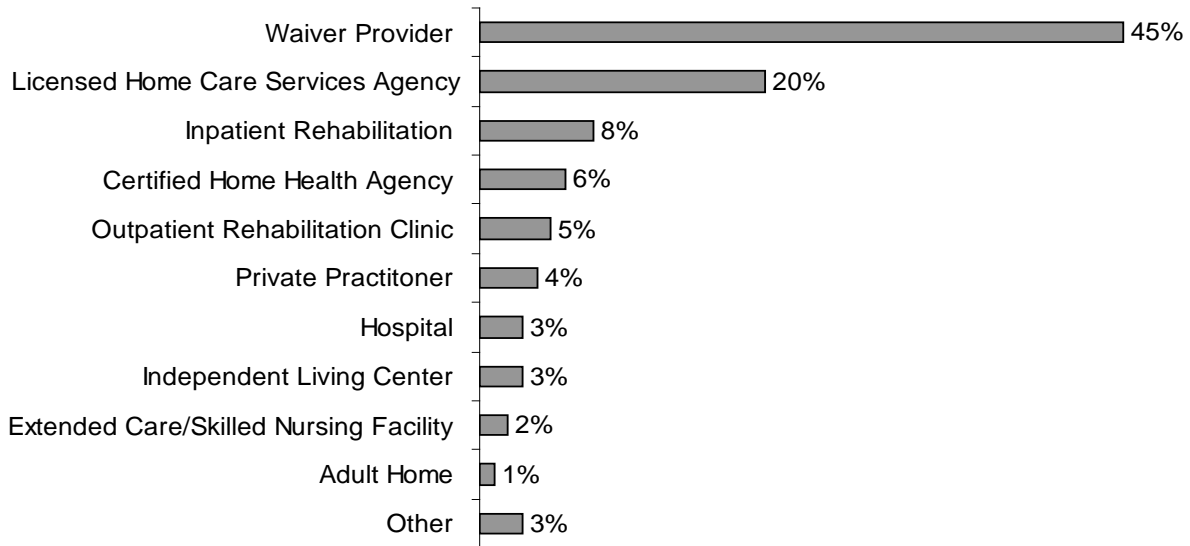
Report of 2010 TBI Implementation Grant Provider Survey Analysis

To assess services provided in New York State to persons living with a Traumatic Brain Injury (TBI) providers, including hospitals, home care agencies, and extended care facilities were requested to complete an on-line survey. Providers were also asked to include their perspective on how coordination and delivery of services could be improved.

The survey was posted on Survey Monkey, a web-based survey tool, during October 2010. Major provider associations representing hospitals, extended care facilities, home care agencies were notified in writing about the survey with a request to encourage their members to respond. Providers were also notified of the survey through the State's on-line health care provider network, and web sites of provider-based statewide associations, and the Brain Injury Association of New York State (BIANYS) web site.

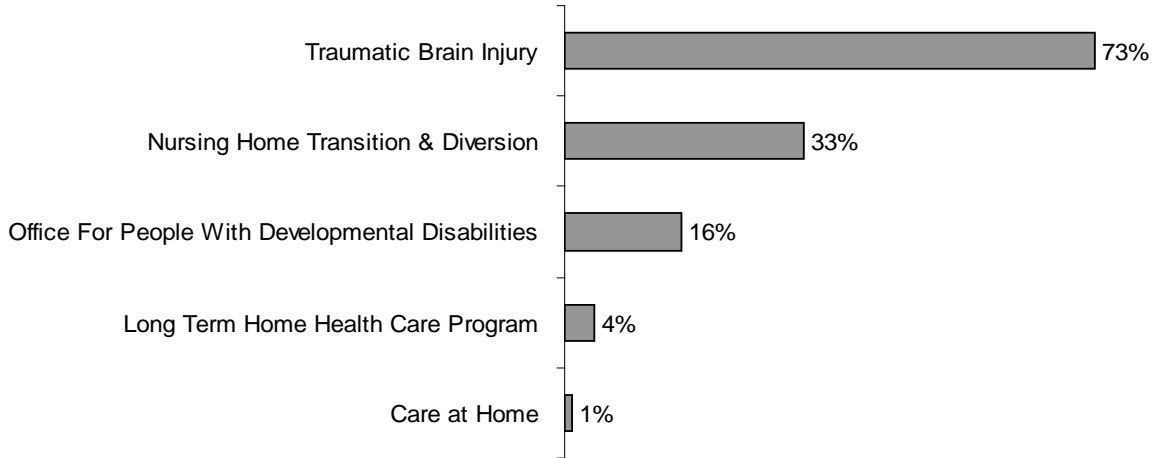
One hundred eighty-two individual providers representing 120 organizations completed the survey, including, hospitals, private practitioners, home care agencies, in-patient and outpatient rehabilitation organizations, and individual Medicaid Home and Community Based waiver providers as shown in Figure 1. Providers of more than one type of service, i.e. a hospital that also provides outpatient rehabilitation, were asked to complete a separate survey for each category.

Figure 1
Survey Responses by Provider Type
n=182



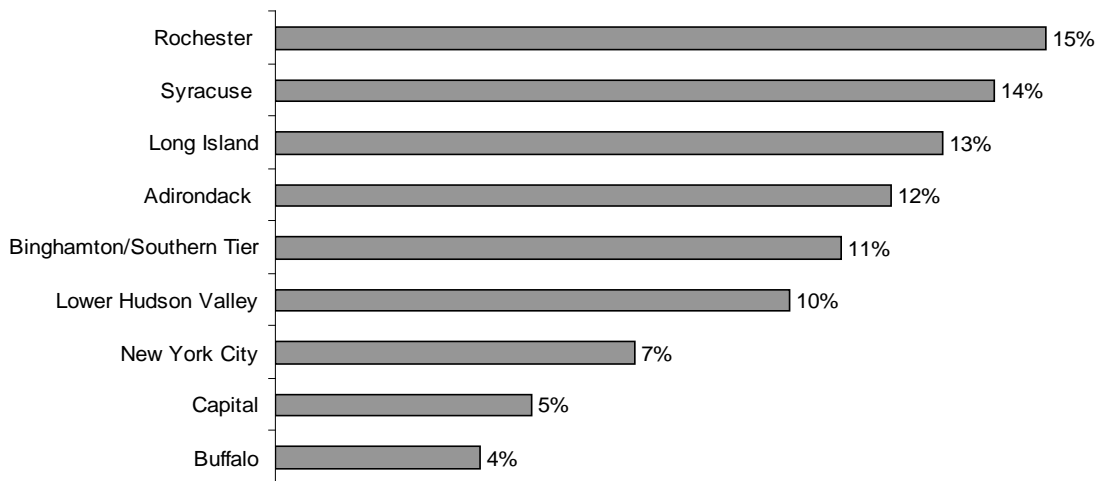
A breakout of respondents by Medicaid waiver provider-type indicates that the majority were Department of Health (DOH) TBI and Nursing Home Transition and Diversion (NHTD) waiver providers, followed by those providing services for the Office for People With Developmental Disabilities (OPWDD). Respondents also included a small group of Long Term Home Health Care Program (LTHHCP) and Care at Home (CAH) waiver providers. Figure 2 shows the percentages for each waiver provider type. This response rate represents twenty-six percent (26%) of enrolled TBI waiver providers, 14% of NHTD waiver providers and less than 1% of CAH and LTHHCP providers.

Figure 2
Survey Responses by Waiver Type
n= 81



The number of provider responses varied by geographic region, but represent all of the nine regions of the TBI waiver program, as shown in Figure 3.

Figure 3
Regions Served by Provider Survey Respondents
n=182



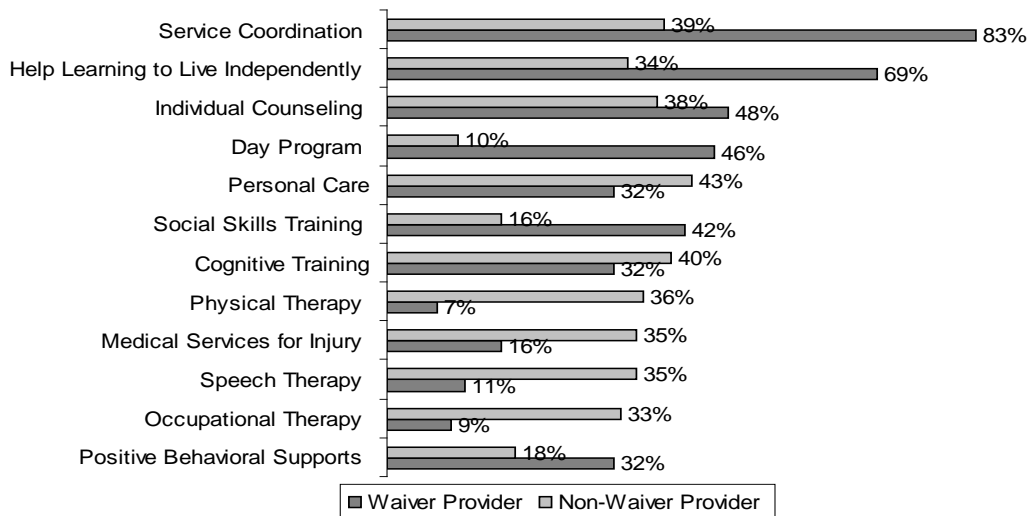
Thirty-five services were listed in the survey from which respondents were asked to indicate which they provided, including:

- **Medical Services:** medical services for general health/prevention and those to address the effects of the brain injury, nursing services, dental services, and vision services

- Rehabilitation Services: speech, occupational and physical therapies, assistive technology services, durable medical equipment, and cognitive training
- Counseling and Psychotherapy Services: individual counseling, family counseling, psychiatric services, and substance abuse treatment services
- Community Based Services: service coordination, personal care support, respite, independent living skills, money management, positive behavioral supports, social skills training, day program, housing assistance, home modifications, leisure/recreational social activities, support groups, legal services, parenting support services, and information and referral
- Educational and employment: support services needed to learn in school through high school, supports provided for post-secondary educational programs, pre-vocational services, supported employment and job placement services

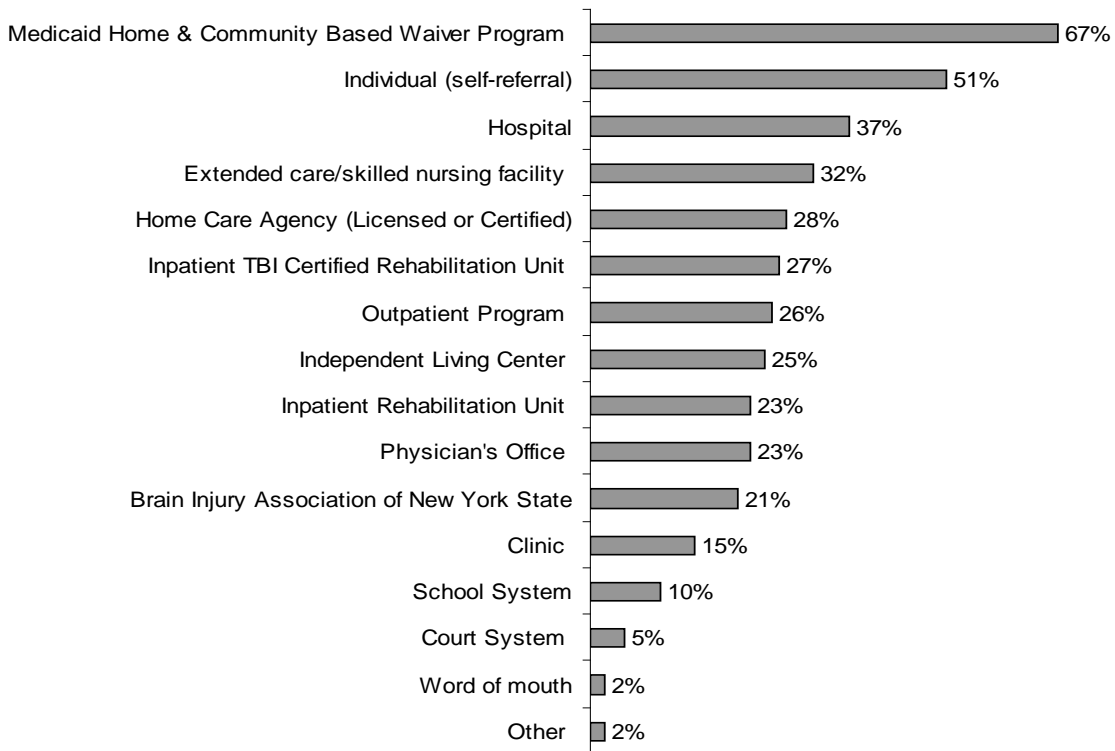
The twelve services identified in Figure 4 were reported as provided by at least one third of survey respondents.

Figure 4
Reported Services Provided by One-Third or More of Survey Respondents
n=165

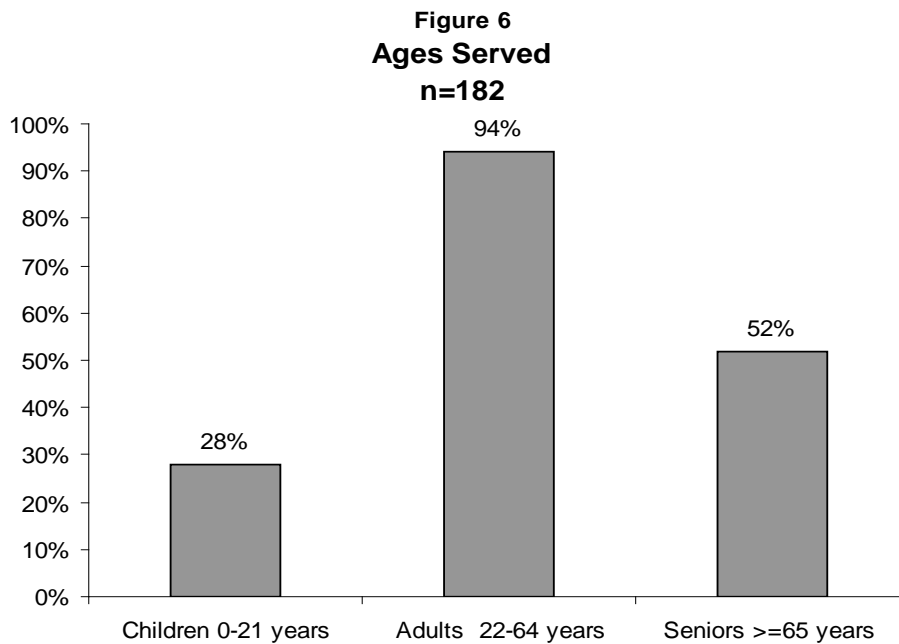


The survey asked providers to identify sources of referrals for services. The majority were reported to come from the Medicaid Home and Community Based Waiver programs (67%); half from individual, self-referrals (51%); and more than one-third from hospitals (37%). Almost one-third of the reported referrals are from extended care/skilled nursing facilities (32%). Figure 5 shows the 16-referral categories and their reported percentages. Respondents were asked to identify all sources of referrals hence the responses shown in Figure 5 exceed 100 percent.

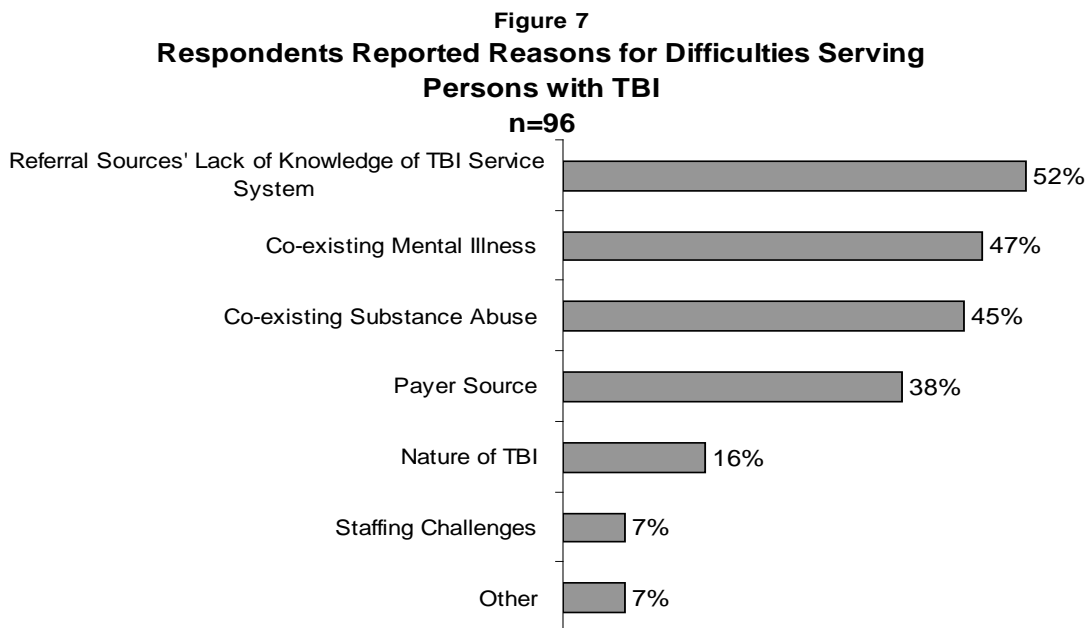
Figure 5
Reported Referral Sources
n=177



The majority of respondents reported serving persons between 22 – 64 years of age, followed by seniors over age 65. Approximately one quarter serve children 21 years of age and younger as shown in Figure 6.



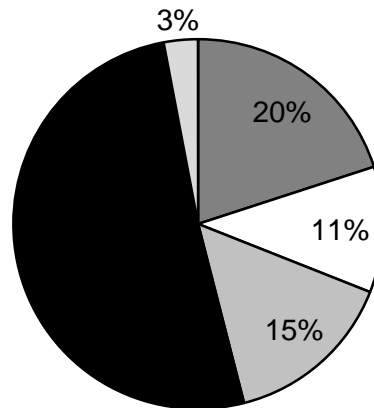
Respondents were evenly split on the issue of difficulties serving persons with TBI. Forty-seven (47%) responded that they do not have difficulties and 53% reported in the affirmative. Reasons for the difficulties varied. As shown in Figure 7, of those who answered in the affirmative, 52% reported referral sources' lack of knowledge of the TBI service system as a problem, followed by co-existing mental illness (47%), substance abuse (45%), payer source (38%), and the nature of TBI itself (16%).



Respondents were asked to report whether they currently have an electronic health record (EHR) system, and if not, if they had plans to establish one in the future. Twenty percent reported they have an operational EHR. Eleven percent (11%) reported having a plan for an operational EHR within a year; another 15% reported having a plan for an operational EHR within three years. Over fifty percent reported they do not have nor plan to have an EHR. These results are shown in Figure 8.

Figure 8
Electronic Health Record Status of Survey
Respondents
n=159

- Currently have an operational EHR
- Plan to have an EHR Within 1 Year
- Plan to have an EHR within 3 Years
- No Plans for an EHR
- Other



Finally, the survey also sought providers' perspectives on system change that could improve the effectiveness of services for persons with TBI. A list of categories was provided, along with the opportunity to specify additional suggestions. Leading the list of TBI system enhancements was development of "web-based" TBI provider education opportunities (64%), followed by enhancements to information about TBI in general (58%) and TBI services/supports specifically (40%), expanded availability of culturally and linguistically diverse materials (29%), and the need to streamline and/or reduce paperwork (4%).

In both this survey and a prior one of individuals living with TBI and their families, there was a low rate of response with regard to system change to address the unmet needs of children with TBI, particularly in comparison to their high incidence of TBI. This finding reveals the challenge and the need to identify and implement more effective outreach efforts for the pediatric population.

The provider survey response to the request for suggestions for system change mirror in part those generated from the survey of individuals living with TBI, indicating an appreciation among providers about the unique challenges faced by population they serve.

Recommended Actions for the 5-Year Plan

Public Education Outreach Efforts:

Engage in a TBI public awareness campaign about brain injury and available resources, with state-of-the-art interactive web site as an ongoing forum for individuals, families, discharge planners and service providers focused on information about available services and links to other appropriate sites.

TBI Provider Training Opportunities to Enhance TBI Diagnosis and Treatment:

Develop web-based training in targeting certain areas identified by providers. Including strategies for working with persons with TBI and their with families, TBI service/support systems available in New York State, treating co-existing mental health and substance abuse issues, positive behavioral supports, and Medicaid waiver programs.

Enhance coordinated, quality services for children:

Identify methods to survey children with TBI and families to identify their service needs, gaps, and develop recommendations to achieve coordinated delivery of needed services.

APPENDIX G

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APPENDIX H

SELECTED RESOURCES FOR PEOPLE WITH TBI IN NEW YORK STATE

Federal and State

DisabilityInfo.gov is a federal website providing information to link persons with disabilities to resources and information they need.

Social Security Administration

Social Security Disability (SSD) and Supplemental Security Income (SSI) are often available to people with TBI. It is suggested people apply immediately as the process is time consuming.

(800) 772 – 1213

www.ssa.gov

New York State Department of Health:

Injury Prevention Program

(518) 473 – 1143

www.health.ny.gov/prevention/injury

New York State TBI Waiver Program

(518) 474-5271

[http:// www.health.ny.gov](http://www.health.ny.gov)

Trauma Centers: There are 40 hospitals designated by the state as Trauma Centers best equipped to provide care for severely injured trauma patients. All hospitals have a written transfer agreement with a trauma center for the transfer of severely injured trauma patients. The list of trauma centers may be viewed at [http:// www.health.ny.gov](http://www.health.ny.gov), by typing in: Trauma Centers in the search box.

Stroke Centers: The Department of Health designates 119 hospitals as Stroke Centers to improve the standard of quality and access to care for patients with a presumptive diagnosis of stroke. The list of Stroke Centers may be viewed at [http:// www.health.ny.gov](http://www.health.ny.gov) by typing in : Stroke Centers in the search box.

Office of People with Developmental Disabilities

(For persons who receive a TBI prior to age 22.)

(866) 946 – 9733

www.opwdd.ny.gov

Office of Alcoholism and Substance Abuse (OASAS)

Its mission is to improve the lives of New Yorkers by leading a premier system of addiction services through prevention, treatment, recovery.

518473 - 3460

www.oasas.ny.gov

State Education Department

Information about education of children in pre-kindergarten through grade 12.

www.nysed.gov

ACCESS - VR

Adult Career and Continuing Education Services – Vocational Rehabilitation

(800) 222 – 5627

www.access.nysed.gov/vr

New York State Commission on Quality of Care and Advocacy for People with Disabilities

Persons with disabilities may obtain advocacy services, including legal services through the Commission.

(800) 624 - 4143

www.cqc.ny.gov

New York State Division of Veterans Affairs

Provides service, advocacy and counseling for New York State veterans and their families.

(888) 838 – 7697

www.veterans.ny.gov

Support, Advocacy & Resource Information

Brain Injury Association of New York State (BIANYS)

BIANYS is a statewide association that advocates on behalf of individuals with brain injury and their families, and promotes prevention. BIANYS provides education, advocacy and community support services and includes LEARNet, a website that provides access to acquired /Traumatic brain injury education consulting services to schools, and families.

(800) 228 – 8201, (800) 444 - 6443 or (518) 459 - 7911

www.bianys.org

Family Advocacy, Counseling and Training Support (FACTS) Coordinators

The FACTS program is a family support services program for persons who have sustained their brain injury before the age of 22. The program is operated by the Brain Injury Association of New York State (BIANYS) and funded by the NYS OPWDD. Users of the FACTS program must be residents of the counties served by a FACTS coordinator. A list of FACTS coordinators and counties they serve can be obtained at www.bianys.org or by calling (800) 228 – 8201, (800) 444 – 6443, or (518) 459 – 7911.

New York Association on Independent Living Centers

The association is a network of community centered advocacy organizations in New York State which offers benefits, advisement, peer support, independent living skills, training and legal assistance to persons with disabilities.

(518) 465-4650

www.ilny.org

APPENDIX I

2011 EXECUTIVE ORDER CONTINUING THE STATE COUNCIL ON RETURNING VETERANS AND THEIR FAMILIES

WHEREAS, thousands of New York State residents are veterans who have served in armed conflicts over the last several decades, including Operation Enduring Freedom in Afghanistan and Operation Iraqi Freedom in Iraq; and

WHEREAS, many currently deployed military personnel, including National Guard and Reserve members, have returned and will return from ongoing conflicts in Afghanistan and Iraq; and

WHEREAS, a significant number of veterans who served on active duty in armed hostilities are at risk to return home with – or later develop – physical disabilities, medical conditions, mental illnesses and/or substance abuse disorders, including but not limited to traumatic brain injury and post-traumatic stress disorder, impacting not only those veterans but their families as well; and

WHEREAS, the prolonged nature of the economic recession on the national and state level has had a detrimental impact on the employment opportunities available to returning veterans; and

WHEREAS, it is important to assure that all available resources are marshaled to help returning veterans and their families in addressing these challenges; and

WHEREAS, it is necessary to ensure that federal, state and other funding and service resources which are or become available to help veterans and their families, especially those experiencing multiple challenges, are coordinated as well as possible and used in the most effective and efficient manner; and

WHEREAS, it is critical that veterans and their families are aware of and have access to such resources and services; and

WHEREAS, increased public awareness of the sacrifices and needs of returning veterans and their families is essential to help returning veterans transition back into their home communities and workplaces; and

WHEREAS, it is crucial to recognize that veterans returning from active duty bring with them skills, training and experience which could be used in a variety of job settings, and that any barriers to the application of such skills, training and experience where appropriate should be identified and eliminated; and

WHEREAS, the New York State Council on Returning Veterans and Their Families was established by Executive Order 12 issued by Governor David Paterson on November 11, 2008 to address a number of the issues set forth above; and

WHEREAS, the extended duration of the ongoing military conflicts and the consequential increase in the number of veterans returning therefrom makes it important to continue such Council but with a reinvigorated membership and updated mission, and to take prompt action to identify ways in which veterans can obtain credit for the skills, training and experience they acquired while in military service for purposes of securing employment with state or local governments; and

NOW, THEREFORE, I, ANDREW M. CUOMO, Governor of the State of New York, by virtue of the authority vested in me by the Constitution and Laws of the State of New York do hereby order as follows:

1. The New York State Council on Returning Veterans and Their Families (the Council) is hereby continued, and its membership and mission are broadened as set forth below.
2. The members of the Council shall consist of the Director of the Division of Veterans' Affairs, the Commissioner of the Office of Alcoholism and Substance Abuse Services, the Commissioner of the Department of Health, the Commissioner of the Office of Mental Health, the Adjutant General of the Division of Military and Naval Affairs, the Commissioner of the Department of Labor, the Commissioner of Homes and Community Renewal, the Commissioner of the New York State Department of Economic Development, the Commissioner of the State Education Department, the President of the Higher Education Services Corporation, and the Director of the Office for the Aging, or their designees, and additional members appointed by the Governor, including one representative of local government, one or more veterans or family members of veterans, one representative of an organization that provides behavioral health services to veterans, one representative of an organization that provides substance abuse services to veterans, and an individual with academic expertise in veterans' affairs. The Director of the Division of Veterans' Affairs or a designee thereof shall serve as the Chair of the Council.
3. A majority of the members of the Council shall constitute a quorum and all recommendations of the Council shall require approval of a majority of the total members of the Council.
4. No member of the Council shall be disqualified from holding any public office or employment, nor shall he or she forfeit any such office or employment by virtue of his or her appointment hereunder. Members of the Council shall receive no compensation for their services but shall be allowed their actual and necessary expenses incurred in the performance of their functions hereunder. All members of the Council shall serve at the pleasure of the Governor and vacancies shall be filled by the Governor. The Governor may appoint additional voting and non-voting members to the Council as necessary.
5. The Council is charged with making recommendations to assist in the coordination of State strategy to accomplish the following:
 - a. Increase public awareness of the needs of returning veterans and their families and the value that veterans offer to communities as a result of their service;
 - b. Conduct education and outreach to ensure that veterans and their families are aware of available resources and services to help them address physical health and mental health and substance abuse problems resulting from active duty;
 - c. Properly identify veterans and their families and ensure that they are aware of and have access to available benefits and services;
 - d. Identify and eliminate barriers to the prompt and accurate diagnosis of physical disabilities, medical conditions, mental illnesses and/or substance abuse disorders affecting returning veterans and their families;
 - e. Identify and eliminate barriers to service so that veterans, particularly those with more than one disability or condition, have sufficient access to needed resources and services;
 - f. Encourage the development of a viable referral network, including peer-to-peer systems;

g. Maximize the resources available to help returning veterans and their families address physical disabilities, medical conditions, mental illnesses and/or substance abuse disorders arising from active service, including funding and services available through federal, state and non-governmental sources;

h. Coordinate resources and services available for returning veterans and their families that address physical disabilities, medical conditions, mental illnesses and/or substance abuse disorders resulting from active duty to maximize efficiency and effectiveness;

i. Provide returning veterans with assistance in locating appropriate housing as needed and resolving housing-related difficulties;

j. Assist with the credentialing of military specialties into civilian occupations, so that the skills, education, training, experience, and credentials acquired by veterans during their military service can be used to expand their employment opportunities;

k. Provide returning veterans with information and assistance in meeting their academic goals, including information and assistance regarding scholarship opportunities and higher education loans; and

l. Any additional matters as directed by the Chair of the Council or the Governor or his designee.

6. The Chair shall continue the advisory body comprised of various stakeholders representing a broad range of interests related to the well-being of veterans and their families, who can call upon their experience and expertise to assist the Council in its work. Membership on such advisory body should reflect the diversity of veterans and their families in New York State so as to be culturally competent.

7. The Council shall issue reports to the Governor of its activities, findings and recommendations in furtherance of the purposes of this Order from time to time as directed by the Governor or the Governor's designee.

8. Every agency and authority of this State shall cooperate with the Council and furnish such information and assistance as the Council determines is reasonably necessary to fulfill the purposes of this Executive Order.

9. Every agency and authority of this State is hereby directed to review paths into the civilian workforce and identify ways the State can better recognize the skills, education, training, experience, and credentials acquired by veterans while in military service, including by reviewing licensure and educational credit programs to identify ways qualifying military training and experience can be counted.

10. This Executive Order revokes and supersedes Executive Order 12, issued by Governor Paterson on November 11, 2008.

G I V E N under my hand and the Privy Seal of the State in the City of Albany this tenth day of November in the year two thousand eleven.

BY THE GOVERNOR