Traumatic Brain Injury Services Coordinating Council

Legislative Report

December 2025

TABLE OF CONTENTS

INTRODUCTION 1

INITIAL FINDINGS SUPPORTING DOCUMENTATION 2

RECOMMENDATIONS 2

I – Establish the Empire State Brain Health and Family Support Data Collaborative 2

II – Establish a Comprehensive Traumatic Brain Injury Registry 3

III – Develop Targeted Implementation Strategies and Resources 4

IV – Promote Provider Education 4

CONCLUSION 5

Traumatic Brain Injury Services Coordinating Council Legislative Report

Introduction

The New York State Public Health Law authorized the establishment of the Traumatic Brain Injury Services Coordinating Council for the purpose of advising the New York State Department of Health on long range goals, objectives and priorities for serving individuals with traumatic brain injury. Pursuant to New York Public Health Law § 2744(2), this report presents recommendations based on existing data and input from individuals with traumatic brain injuries and their families, as well as managed care organizations, the Brain Injury Association of New York, and staff from the Office for People With Developmental Disabilities, Office of Mental Health, State Education Department, Justice Center for the Protection of People with Special Needs, Office of Addiction Services and Supports, Office for the Prevention of Domestic Violence, Office for the Aging, Department of Veterans Services.

The Council has reviewed service availability and accessibility, emerging trends in the incidence or traumatic brain injury and services, as well as a wide array of pertinent topics including:

- Medicaid waiver disparities and administrative efficiencies that can be achieved within the waivers.
- The integration of traumatic brain injury services into managed care.
- Expansion of service choices for those with traumatic brain injury and their families.
- Supporting guardianship and alternatives to guardianship.
- Strengthening peer support networks.
- Establishing a voluntary traumatic brain injury data repository and registry.
- Addressing social determinants of health that affect those with traumatic brain injury such as access to transportation and housing.
- Need for higher home care service levels in service plans (20-50+ hours per week of care, 24/7 or live-in).
- Advancing alternatives for community living.
- Collaborating with the Centers for Medicare and Medicaid Services to improve rural health outcomes.
- Streamlining Medicaid eligibility and renewals with user-friendly tools.

Developed within eight months of the act establishing the Traumatic Brain Injury Services Coordinating Council's effective date of April 9, 2025, this report establishes a foundation for annual updates.

Initial Findings Supporting Recommendations

Department of Health data[1] shows traumatic brain injury services are concentrated in urban centers such as New York City, Rochester, and Buffalo, with significant gaps in rural counties such as Ulster, Franklin, and Wyoming where access to Level I/II trauma centers is limited. Costs for private traumatic brain injury care reportedly range from $500-$1,000 per month; however, this data is anecdotal. Gaps in access to care are exacerbated by a lack of transportation, social isolation, and provider shortages in rural areas.

Feedback from individuals with traumatic brain injuries and their families also indicates that transportation barriers, limited provider options, weak support networks, and challenges in maintaining Medicaid eligibility for higher levels of home care services are limitations that hamper service accessibility for those with traumatic brain injury regardless of their geographic location be it urban, suburban or rural.

Hospital discharge data indicates a rise in traumatic brain injury diagnoses among adults over 65 driven by falls, other accidents, and substance use, which have increased demand for long-term care and advanced home care, substance use treatment and comprehensive tracking of incidence patterns and service needs.[2]

Health care providers could benefit from up-to-date information on brain injury, with a focus on emerging trends, social determinants of health interventions, and systematic data collection for population health management.

New York currently lacks a centralized system to track traumatic brain injury incidence, prevalence, service utilization, and long-term outcomes. Existing data demonstrates differences in access to services by Medicaid enrollees and those individuals with traumatic brain injury who are currently ineligible for Medicaid supports.

Recommendations

I. Establish the Empire State Brain Health & Family Support Data Collaborative

The Council recommends that the Department of Health establish the Empire State Brain Health Care and Family Support Data Collaborative ("the Collaborative") with the purpose of supporting individuals with traumatic brain injury and their families. The Collaborative, in coordination with the Office of Information Technology Services, would utilize existing statewide contracts to fulfill the following objectives:

a) Deliver advanced business-intelligence capabilities, real-time dashboards, and predictive analytics.

b) Enable seamless, HIPAA-compliant data exchange with universities, colleges, hospital systems, hospital and nursing home discharge planners, Regional Resource Development Centers, and other interested research partners.

[1] Data for 2024/2025 obtained from Statewide Planning and Research Cooperative System at: www.health.ny.gov/statistics/prevention/injury_prevention/traumatic_brain_injury/index.htm

[2] *Ibid.*

c) Identify evidence-based, health care technologies (e.g., Personal Emergency Response System monitors, remote monitoring capabilities, smart-home sensors, wearables, telehealth) in order to integrate effective technologies into the service package.

d) Partner with the Empire AI Consortium and New York academic institutions to develop and pilot responsible Artificial Intelligence (AI) solutions (e.g., risk-prediction models, multilingual virtual assistants, remote-monitoring algorithms), focused on brain care and family support.

e) Ensure at-risk populations are included in assessment of and responses to brain injury, such as victims of domestic abuse, individuals incarcerated or experiencing higher rates of arrest, older adults, substance users, school athletes, immigrant trauma victims, and the homeless.

f) Advance research opportunities and solutions to develop and increase neurobehavioral care.

g) Assess opportunities to repatriate New York residents back into their homes through tracking of out-of-state placements and development of the services needed to allow repatriation.

h) Identify and provide survivor- and family-centered resources and tools to help New York residents and caregivers locate services, understand Medicaid options, connect with peers, and manage long-term recovery.

II. Establish a Comprehensive Traumatic Brain Injury Registry

The Council recommends that there be collaboration with existing and emerging information resources to systematically track incidence of traumatic brain injury statewide by demographics (i.e., age, geographic location, race/ethnicity), service utilization patterns, social determinants of health factors, treatment outcomes, and long-term needs.

The registry should include the following:

a) Voluntary enrollment with robust privacy protections (HIPAA-compliant).

b) Integration with existing systems (eMedNY claims, hospital discharge data, Medicaid waiver records, workers compensation).

c) Real-time dashboards for policymakers to identify service gaps and emerging trends.

d) A research support component to support federal grant applications and evidence-based interventions.

e) Stakeholder governance including traumatic brain injury survivors, families, and advocacy groups to ensure community trust and utility.

III. Develop Targeted Implementation Strategies and Resources

a) Evaluate and Expand Technology: Assess the technologies available to individuals with traumatic brain injury, including telehealth, home monitoring, and assistive technology systems. Partner with existing systems including federal and state agencies and academic institutions to align options available to people with traumatic brain injury statewide and pilot telehealth modalities, with a particular focus on underserved and rural areas and adults injured after age 21.

b) Explore Access to Advanced Home Care for Individuals with Traumatic Brain Injury: Partner with managed care plans and state agencies that support people with traumatic brain injury rehabilitation to develop an advanced home care service model that employs skilled nursing and intensive therapies, along with telehealth in order to offer patient choice between virtual, in-person, and in-home care to address transportation barriers that limit access to services.

c) Fund Rural/Underserved Peer Support and Service Sites: Enable individuals with brain injury, as well as their families and guardians to obtain access to services designed for individuals with traumatic brain injuries and their families. Allocate budget resources to establish new traumatic brain injury service sites in rural counties and areas with identified service gaps. Sites should include access to rehabilitative services, assistive technology, and peer-led support groups.

d) Participate in Rural Health Initiatives: Engage the Centers for Medicare and Medicaid Services to leverage federal rural health programs (e.g., Medicare Rural Hospital Flexibility Program, Frontier Community Health Integration Project), to enhance traumatic brain injury service infrastructure, workforce development, and telehealth reimbursement in underserved counties, in order to address systemic rural health disparities.

e) Pilot a Cost-Efficient Housing Model: Collaborate with existing state agencies and programs, including local housing providers, to pilot a shared-living model intentionally designed for individuals with traumatic brain injury. Draw on peer input, the experience of day activity centers, successful housing models, and advanced home care service models for those with traumatic brain injury to propose a pilot of cost-efficient housing supported by wrap-around services (e.g., case management).

f) Support Legal Protections and Alternatives to Guardianship: Work with state agencies that support individuals with traumatic brain injuries and their families and the Guardianship Association of New York State to identify legal advisers who can provide guardianship resources and help address alternatives to guardianship.

IV. Promote Provider Education

The Traumatic Brain Injury Services Coordinating Council strongly recommends the promotion of provider education through the following methods:

a) Use resources available from state and national brain injury associations to advance brain injury awareness and education and ensure that all providers are prepared to support the special needs of individuals living with effects of traumatic brain injury.

b) Develop training to include modules on facilitating peer support groups, delivery of advanced home care, and navigating Medicaid eligibility to enhance individual supports. Encourage state agencies, clinicians, community providers, and individuals with or impacted by a brain injury to participate. Provide incentives (e.g., stipends, certification) for completion of the training.

c) Recommend health providers include and be given credit for traumatic brain injury training as a part of their annual continued education topics.

Conclusion

The Traumatic Brain Injury Services Coordinating Council believes these recommendations will help to further build a comprehensive source of information to support evidence-based planning, collaboration with care partners to address rural health disparities, and implement systemic improvements in service delivery that are administratively efficient and support health equity. These recommendations will enhance the state's ability to track trends, identify gaps, and measure outcomes, while health partnerships will unlock resources for necessary infrastructure improvements. By empowering individuals with traumatic brain injury and their families through the Medicaid Traumatic Brain Injury Waiver and other programmatic choices, alternatives to guardianship support, peer networks, advancements in home care, and streamlined Medicaid eligibility tools, we will significantly improve the quality-of-life for traumatic brain injury survivors across New York State. Additionally, we believe that alternatives to guardianship, peer networks and models of home care that are specific to those with traumatic brain injury can help to promote New York as a leader in the care of individuals with traumatic brain injury and their families.

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