

# ONE VOICE FOR BRAIN INJURY CONSORTIUM



## One Voice for Brain Injury Consortium Recommendations to Strengthen Existing Legislation and Programs for Individuals with Brain Injury and Their Families

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### **Brain Injury Background**

The U.S. Centers for Disease Control and Prevention estimates that there were 2.4 million emergency department visits, hospitalizations, or deaths associated with TBI alone or in combination with other injuries in the United States in 2009. Brain Injury is a leading cause of death and disability in the United States that affects persons of all ages, races/ethnicities and incomes. Any injury to the brain – regardless of type, cause or severity – can change the way a person moves, talks, thinks, feels and acts. TBI can cause epilepsy and increase the risk for Alzheimer’s disease, Parkinson’s disease and other brain disorders that become more prevalent with age.

To restore or maintain function individuals who sustain brain injuries may need treatment and/or services on a short, long-term or episodic basis. Treatment encompasses emergency medical services; comprehensive rehabilitation to help individuals regain lost skills and/or learn compensation strategies to overcome impairments; transition services from medical/rehabilitation to home, school/work and community; ongoing management for chronic conditions resulting from the injury; and an array of home and community services that support family caregivers and assist individuals with brain injury in living as independently as possible.

Treatment and services may be furnished by a combination of private/public providers and funded by private insurance, Workers' Compensation, Medicare, Medicaid, and other state and federal health care and disability programs.

Research is critical to help professionals, providers and payers develop and provide appropriate treatment, rehabilitation and interventions for successful outcomes in all settings – medical, rehabilitation, education, community and employment. State and national data is necessary to determine the incidence and prevalence; strategies for addressing primary and secondary prevention and service delivery systems; and evaluation.

### **Barriers and Gaps in Services**

While there have been many accomplishments over the years, there is still no cohesive national public policy or plan to support a coordinated system of care, and furthermore, funding remains woefully inadequate to address the array of treatment, and short and long-term needs of all Americans with brain injury. Advances in treatment over the past twenty years have led to more people surviving brain injury, often requiring extended rehabilitation and life-long services in order to return to live successfully in their homes and communities. Yet, people find that they are often unable to access these services due to being underinsured or uninsured, or find that the needed services are unavailable. Thus, individuals and their families often look to public funded programs and resources that may have been established for other populations generally before society became aware of the specific needs of the increasing number of individuals surviving brain injury.

Regrettably, many individuals with brain injury and their families find that these federal programs are often difficult to access for a number of reasons:

- 1) Eligibility criteria for state/federal programs may be based on diagnosis (i.e. physical disabilities, intellectual and developmental disabilities (I/DD), mental health, and substance abuse services); age at the time of injury (i.e. I/DD, special health care needs and aging programs); and/or financial eligibility requirements often associated with these systems, particularly with regard to a spouse who is married to a non-injured working spouse (i.e. Medicaid);
- 2) Services provided to similar populations do not address the cognitive and behavioral challenges experienced by many individuals with brain injury;
- 3) Lack of professionals, paraprofessionals and providers with experience and expertise in brain injury treatment and service delivery; and
- 4) Lack of sufficient funding for programs at the state level to provide the array of necessary services and supports.

### **Public Policy Recommendations**

The One Voice for Brain Injury Consortium recognizes that some of the challenges experienced by individuals who sustain brain injuries and their family caregivers can partly be addressed by modification of existing programs and coordination of efforts and resources at the federal level,

including those which impact research, prevention, data, health care, services and supports. We also recognize that there are other Senate Committees which may have policy jurisdiction for programs that impact brain injury, such as Medicare and Medicaid, and, of course, the Senate Appropriations Committee which appropriates funding. The following recommendations address existing programs which are critical for individuals with brain injury.

### **Improve Federal and State TBI Service Delivery Systems**

#### **1) The Traumatic Brain Injury Act of 1996, as amended**

The TBI Act of 1996, as amended, is the only federal law authorizing funding specifically for TBI activities involving research studies, data collection, prevention, public awareness, consumer advocacy and service system coordination. The Consortium recommends reauthorization of the TBI Act of 1996 with the following improvements:

- ***Elevate the HRSA Federal TBI State Grant Program within the U.S. Department of Health and Human Services***

We recommend that Congress elevate the Federal TBI State Grant Program (42 USC 300d-52) and the Protection & Advocacy (P&A) TBI Program (42 USC300d) within the U.S. Department of Health and Human Services (HHS) by deleting the reference to Health Resources and Services Administration from current law in order to:

- integrate TBI into the HHS long-term services initiatives, which also rely on Aging and Disability Resource Centers as the entry point into these systems;
- promote collaboration with Aging on fall-related TBIs among older adults;
- include TBI in the veterans initiatives between HHS and Department of Veterans Affairs (VA) to support home and community-based services for veterans with TBI;
- assure that families who are primary caregivers for their members with a brain injury are included in the Lifespan Respite Care Program; and
- coordinate/enhance services for individuals with TBI of all ages who may also be eligible for services provided through I/DD and other disability systems.

***A fuller explanation of the rationale for moving the Federal TBI State Grant Program within the U.S. Department of Health and Human Services (HHS) may be found in Appendix D.***

However, elevating the HRSA Federal TBI Program should not change the mission of the program to help states to address gaps in service delivery that may impact children, youth and adults and other underserved and unserved populations, such as victims of domestic violence, returning service members, and students with mild TBI (concussions). This action would be budget neutral.

- ***Promote federal interagency collaboration and the development of a National Brain Injury Plan to improve TBI service delivery***

Under 42 USC 300d-52, the Secretary of HHS is to ensure that activities under this section (HRSA State Grant Section) are coordinated as appropriate with other Federal agencies that

carry out activities regarding TBI. As the result of TBI stakeholder encouragement and congressional budget language, HRSA recently convened the Federal Interagency Work Group to coordinate federal resources. HRSA is now embarking on developing a “roadmap” for TBI with consumer and stakeholder input. We believe that while HRSA should be commended for this action, amending this section to formally create an interagency body under the Secretary would result in a long desired goal of developing a national plan to improve service delivery for individuals with brain injury of all ages and their families.

Therefore, we believe Congress should direct HHS to create a ***TBI Blue Ribbon Committee*** consisting of experts in the field (both researchers and clinicians), individuals with brain injuries, family members, state and federal programs to develop a National Brain Injury Plan. This Plan needs to be universally accessible, seamless, standardized, and provide an evidence-based system of care for every American who has an acquired brain injury.

The National Brain Injury Plan needs to address the coordination and integration of care between (1) Acute Care (EMS, Acute Hospital); (2) Acute Rehabilitation (In-Hospital Rehabilitation); (3) Post-Acute Care (Skilled Nursing, Residential Rehabilitation, Assistive Living, Home Health Programs, Out-Patient Rehabilitation and Habilitation Services); and (4) Long-term Care (Community Integration, Community Supports/Services, Chronic Care). The coordination and integration of care needs to include all age groups, i.e. children/adolescents, adults, and older adults, as well as brain injury severity (mild, moderate, severe, chronic). The National Brain Injury Plan will also include a comprehensive system of longitudinal data collection on all individuals insured. The National Brain Injury Plan also needs to address the prevention of brain injuries, the use of rural tele-health systems to reach each person in their home community, and developing a comprehensive interagency research agenda.

- ***Amend/clarify that appropriations for the TBI State Grant program may be used for providing service coordination and other services on an ongoing basis.***

The HRSA Federal TBI State Grant Program has interpreted current statutes as prohibiting states from providing services with grant funds, although states are allowed to use grant funds to create services, such as service coordination. We recommend that language be added to clarify that grant funds may be used to pay for services, such as information & referral services, service coordination, screening and any other service identified as a need by the state advisory board and identified in the state plan, in order to address gaps in service delivery and continue services once established.

- ***Establishing a funding formula that allows distribution of funding to all eligible States, Territories, American Indian Consortium and District of Columbia***

Funding under the Federal TBI State Grant Program is currently distributed on a competitive grant basis. Twenty states are receiving funding, and rather than re-bid grants that were set to expire this year, HRSA extended funding for a fifth year. This means that the majority of states have been unable to access funds for the past four years, and it will be five years before grant funds will be available through this process. We recommend that all eligible entities who meet other specified requirements, such as required state match, receive funding annually in order to sustain activities on an on-going basis. This approach is similar to the section relating to the Protection & Advocacy (P&A) Systems Grant Program whereby all state P&As receive an

allotment. Depending on the level of appropriations state P&As in larger populated states may also receive funding above that base level. We recommend that the state grant program move to a similar method for distributing funds.

## **Improve Educational Outcomes for Students with TBI**

### **1) Individuals with Disabilities Education Act**

The 1990 Individuals with Disabilities Education Act (IDEA) added TBI to the list of disability categories with regard to children and youth who may be served under the act. Prior to the 1990 law, students with TBI may have been eligible for special education and related services under another disability category, such as specific learning disability, other health impairment, or emotional disturbance, and would have been counted under those categories with regard to Child Find requirements. Similarly, students with non-traumatic brain injuries currently may be served under these categories.

While schools are to report all students with disabilities under Child Find, whether receiving special education services or not, the numbers reported for TBI are significantly less than other data collected through hospitals, Emergency Medical Services (EMS) and emergency department (ED) data. To improve reporting under Child Find requirements and educational outcomes, the Consortium recommends amending the IDEA to:

- *Strengthen Child Find requirements to improve strategies for identifying children and youth with brain injury and coordinating with other state programs, such as Title V programs for children with special health care needs and state Medicaid and SCHIP initiatives, in order to improve referral by health care professionals and transition from medical/hospital settings to school.*
- *Authorize a National Dissemination Center on Brain Injury to disseminate best practices and policies on TBI screening, assessment, and educational strategies.*
- *Emphasize that Parent Training and Information Centers (PTI), which are funded in every state, should include expertise and resources on TBI to help families navigate the educational system.*
- *Authorize funding for tele-education to help school districts and families obtain assistance on assessment, evaluation, behavioral and educational strategies, particularly in rural areas.*
- *Add Acquired Brain Injury as a distinct category of disabilities eligible for special education services to more appropriately serve students with non-traumatic brain injuries, such as strokes, brain tumors, brain cancer, anoxia, and infections.*

### **2) Elementary and Secondary Education Act**

The One Voice for Brain Injury Consortium recommends reauthorization of the Elementary and Secondary Education Act, as amended by No Child Left Behind, with the following improvements:

- *Support training and research initiatives and programs to enhance effective transition services from secondary education to postsecondary education and employment for students with TBI.*
- *Enhance adult education, vocational training, post-secondary education, and lifelong learning opportunities for students with disabilities, particularly students with TBI.*
- *Expand and improve in-service and pre-service personnel preparation under Part D of IDEA, NCLB, and the Higher Education Act so that all special education teachers are highly qualified and develop programs to expand the pool of undergraduates majoring in special education with training in TBI screening, identification and education and behavioral strategies.*

### **Improve Health Care and Rehabilitation Access and Outcomes**

While private and public payers pay for emergency, trauma and acute intensive care necessary to save an individual's life, the rehabilitation coverage necessary for an individual to recover after brain injury is generally limited due to inadequate coverage in insurance policies written to address acute rather than rehabilitative needs. In many instances policies governing coverage are designed to save costs through arbitrary caps and bundling often based on diagnosis or measures used for determining progress or type of facility where rehabilitation is provided. In addition, a substantial number of individuals are underinsured or uninsured. According to data from NIDRR at least two-thirds of patients discharged from rehabilitation hospitals after a typical stay of 16 days get no further treatment. The lack of necessary rehabilitation coverage results in patients of all ages being discharged each year from hospitals to nursing homes – shifting costs from Medicare to Medicaid – or to home with no rehabilitative services.

Spending for rehabilitation accounts for less than 1.2 percent of total Medicare expenditures, however, the President is proposing additional cuts for post-acute care that would account for more than 25 percent of the President's proposed Medicare total cuts. Of \$393 billion in Medicare and Medicaid cuts proposed by the President, nearly \$100 billion would come from post-acute care providers. Lack of access to rehabilitation services early on minimizes the likelihood of good recovery, including living independently and returning to work. This leads to underproductive citizens and greater stress on an overburdened social services system. By not spending money on rehabilitation early on, we increase costs and decrease tax payer revenue.

As Medicare, Medicaid and private insurers are the primary payers of care, treatment and rehabilitation, the Consortium recommends the following:

#### **1) Ensuring Rehabilitation Coverage**

Medically-necessary treatment for people with brain injury is highly individualized and specialized. Payment approaches that focus on cost-containment rather than person-centered care undermine recovery by incentivizing “sicker and quicker” discharge, often to nursing homes where the opportunity to restore maximum levels of health and function is poor and likely more costly over the course of one's lifetime. Alternatively, children and adults who have sustained brain injuries are discharged directly home, where family members are unprepared and ill equipped to handle the burden of care. The Consortium recommends:

- *Assurance that Accountable Care Organizations and other proposed “care bundling” mechanisms authorized by the Affordable Care Act are subjected to rigorous study prior to wide-scale implementation.*
- *Congress direct HHS to analyze health outcomes of individuals with brain injury to discern differences by state, benchmark plan, and individual carrier and undertake comparisons in health outcomes for patients who are covered by individual and small group plans versus large group plans (i.e., those plans subject to Employment Retirement Income Security Act regulations) and issue regulations establishing minimum standards of care, if necessary.*
- *Authorization of demonstration projects to encourage State Insurance Exchanges to sell supplemental health plans to cover catastrophic care with a small portion of each annual premium (e.g., \$2) allocated to a national trust fund that supplements treatment for individuals who are uninsured or underinsured.*

## **2) Expand and Coordinate Research**

To further research addressing treatment and rehabilitation the Consortium recommends that Congress:

- *Support studies and research to discern appropriate length of stay and “best practices” for individuals receiving inpatient or out-patient rehabilitation services to restore cognitive, physical and emotional functioning, which may be paid for by private insurance, Medicaid or Medicare.*
- *Support the work of the NIH, DoD and VA, which established the Federal Interagency TBI Research (FITBIR) database, and encourage the FITBIR to also involve and coordinate with other federal agencies associated with TBI research (i.e. NIDRR, CDC and OSERS).*
- *Add NIDRR funded TBI model systems to address children and youth. Current NIDRR TBI Model Systems support innovative projects and research in the delivery, demonstration, and evaluation of medical, rehabilitation, vocational, and other services designed to meet the needs of individuals with TBI age 16 and older.*

## **3) Social Security Act – Medicare (Title XXVIII)**

Medical rehabilitation is a critical component for individuals with brain injury and is necessary to maximize patient health, preventing subsequent medical complications, improving functional skills, restoring independence, and promoting participation in society. The One Voice Consortium is extremely concerned that efforts to reduce Medicare spending not be shouldered by cuts in medical rehabilitation, whether provided in inpatient settings or post-acute care settings. Therefore, the Consortium recommends:

- *That Congress make no further reduction in Medicare payments to Inpatient Rehabilitation Facilities (IRFs) and no increase to the minimum percentage of patients admitted with one of 13 qualifying medical conditions, which is currently set at 60 percent in accordance with the Medicare, Medicaid and State Children’s Health Insurance Program (SCHIP) Extension Act of 2007.*

- *That Congress make permanent the Medicare Part B Outpatient Therapy Cap Exceptions Process to allow for reasonable and necessary therapy services for individuals with brain injury.*
- *That Congress not shifting costs to beneficiaries in an attempt to balance budget shortfalls by reforming Medicare.*

#### **4) Social Security – Medicaid (Title XIX)**

Medicaid is the nation's largest health care program providing assistance with health and long-term care services for low-income Americans, including people with chronic illness and severe disabilities. To better serve individuals with brain injury who are eligible for Medicaid, the Consortium recommends that Congress:

- *Amend/clarify individuals with brain injury are eligible as a chronic condition for health homes established by the Affordable Care Act-Section 2703. (Health homes are a Medicaid State Plan option available for states to design programs to better serve persons with chronic conditions, including serious and persistent mental health conditions.)*
- *Not transform Medicaid into a block grant program, which would result in further inconsistencies in access to care for Medicaid beneficiaries across states.*
- *Encourage HHS to assist primary care providers participating in the Early Periodic Screening, Diagnosis, and Treatment (EPSDT) program in identifying and diagnosing TBI.*

#### **5) Field EMS Quality, Innovation and Cost Effectiveness Improvements Act**

As treatment of brain injury generally begins at the scene of the injury, Emergency Medical Services (EMS) is critical in managing injuries; providing immediate treatment; and providing rapid transport to designated hospitals. EMS in the United States has grown substantially over the past 30 years. These systems differ across and within States and local areas. Nearly half of these systems are organized and delivered through the local fire departments. Other systems are operated by municipal or county governments, or may be delivered by private companies, including for-profit ambulance providers and hospital-based systems. There are more than 6,000 9-1-1 call centers, each run differently by police, fire, county or city government or other entities. The Consortium, therefore, recommends that Congress:

- *Enact the Field EMS Quality, Innovation and Cost Effectiveness Improvements Act (H.R. 809) and appropriate necessary funds to support better coordination of EMS systems across the country; and to establish an Office of EMS and Trauma within HHS to plan, implement and evaluate a national strategy for trauma care improvement.*

### **Improve and Expand Community Long-Term Services and Supports to Include TBI**

#### **1) Older Americans Act**

The Older Americans Act, as amended, authorizes appropriations for the Administration on Aging (now the Administration for Community Living) to administer grants for Caregiver Programs; injury and falls prevention; and to improve state and local infrastructure for



community long-term supports for older Americans and individuals with disabilities. The Aging and Disability Resource Center (ADRC) Program serves as the single point of entry for many long-term services and support (LTSS), including information and resource (I&R) services, and planning for older Americans and those with disabilities. The program is a collaborative effort of the Administration for Community Living (ACL), the Centers for Medicare and Medicaid Services (CMS), and the Veterans Health Administration (VHA), to support state efforts to streamline access to LTSS options for older adults, including older veterans, and individuals with disabilities. The ADRCs have traditionally worked closely with aging and physical disabilities populations. The Consortium recommends:

- ***Amend/appropriate funding with regard to the Older Americans Act for technical assistance to Aging and Disability Resource Centers (ADRCs) established under Section 202(8) to better address I&R services, hospital transition and discharge planning programs, and options for counseling of individuals with TBI.***
- ***Amend the Older Americans Act's Title IV – Activities for Health Independence, and Longevity, Section 401 by adding TBI to:*** “(12) building public awareness of cognitive impairments such as Alzheimer’s disease and related disorders with neurological and organic brain dysfunction, depression, and mental disorders.”
- ***Amend the Older Americans Act, under section 306 relating to Area Agency on Aging (AAA) plans, approved by each state agency, pertaining to in-home support for families of older adults to include TBI.*** (Section. 306 of the Older Americans Act of 1965, as amended, (B) in-home services, including supportive services for families of older individuals who are victims of Alzheimer’s disease and related disorders with neurological and organic brain dysfunction).
- ***Amend Section 372, pertaining to the National Family Caregiver Support Act that gives priorities*** (1) to family caregivers who provide care for individuals with Alzheimer’s disease and related disorders, ***to include TBI***; and under (2) and for grandparents or older individuals, who provide for care children with severe disabilities, ***to include TBI***.

## **2) Social Security Act – Medicaid (Title XIX) -- Nursing Facilities**

Presently, the age when a TBI occurred will result in different outcomes with regard to long-term services and supports. The Federal Nursing Home Reform Act of 1987 requires states to ensure all individuals entering a Medicaid certified nursing facility are screened for mental illness and intellectual or developmental disability and placed in a nursing facility only if needed. This provision does not apply to individuals with brain injury, unless the person falls under the definition for developmental disability within the state. Individuals with brain injury, regardless of age, are more likely to remain in a nursing facility with no alternatives for home and community-based services.

Eligibility for nursing facility care is further defined by the states using level of care assessments, which vary across the states. To be eligible for HCBS services waiver participants must also meet these criteria. Some states have assessed that individuals with brain injury have been ineligible for HCBS services due to the state’s requirement that to qualify for long-term services and supports a person needs “hands on” assistance with bathing, dressing, etc. Individuals with

TBI may be able to do these things, but only if reminded or prompted to do so. To remedy these issues the Consortium recommends Congress:

- *Amend the requirements of United States Code 483.100 through 483.138 (42 U.S.C. 1396r - relating to nursing facility) governing the state's responsibility for preadmission screening and annual resident review (PASARR) of individuals with mental illness and mental retardation to include individuals with TBI, in order to assure that nursing facility placement is appropriate in lieu of home and community-based services and supports. (42 U.S.C. 1396r).*
- *Encourage CMS to work with states on level of care assessments which recognize the individual's cognitive disabilities and need for verbal assistance, physical cueing, prompting, accommodations, and supervision in order to carry out activities of daily living (ADLs).*
- *Extend spousal impoverishment rules (Section 1924 to Title XIX of the Social Security Act) that apply to spousal protections when one spouse enters a nursing home to include home- and community-based services so that families may remain together – especially young couples with children, whereby the non-injured spouse is the income provider, caretaker and the primary caretaker of the children.*

### **Improve Vocational and Employment Outcomes**

#### **1) Workforce Investment and Rehabilitation Act**

Return to work and maintaining successful employment is a significant challenge for many individuals with brain injury. The Consortium recommends that Congress reauthorize the Workforce Investment Act (WIA) and Vocational Rehabilitation (VR) Act and:

- *Request a report from the Office of Special Education and Rehabilitative Services (OSERS) or from the Government Accountability Office (GAO) on the number of individuals with brain injury, including returning service members with TBI, who are served by state VR agencies, their employment outcomes, including wage and job type, and recidivism in the analyses.*
- *Continue Supported Employment as a separate program from Title 1 of the Rehab Act.*
- *Authorize funding for the NIDRR TBI Model Systems to identify and report best practices for overcoming barriers and obtaining/maintaining employment for individuals with TBI.*

### **Improve and Expand Services for Veterans and Military with TBI**

Improvements in military medicine have allowed servicemen and women to survive injuries in Iraq and Afghanistan that would have been deadly in previous conflicts. Many of these warriors will need care to sustain their health and quality of life throughout their lifetimes. The Consortium recommends that Congress:

- *Monitoring the Department of Veterans Affairs' implementation of the Honoring America's Veterans and Caring for Camp Lejeune Families Act of 2012 to ensure wounded warriors achieve and sustain functional gains made through rehabilitation.*
- *Reauthorize the Assisted Living – TBI pilot project, included in the National Defense Authorization Act (NDAA) of 2008, which allows veterans with moderate to severe brain injuries to access a wide range of post-acute treatment services that help improve and maintain their skills; allow them to reside in non-institutional settings; and allows the Veterans Health Administration to make complementary and comprehensive services available in an organized, cost-effective manner at non-VA facilities.*

### **FY 2014 Appropriations**

The One Voice Consortium believes that sequestration has been harmful to domestic discretionary programs across the board and has significantly affected programs, including research, impacting the lives of individuals with brain injury. For FY 2014 these cuts should not only be restored, but increased since TBI programs are woefully inadequately funded currently.

The Consortium also requests, wherever possible, that budget language be included to direct federal programs to coordinate resources, and to take in to account individuals with brain injury who may be or could be impacted by their programs. For example, federal agencies, such as SAMSHA, who may gather data through reporting systems and state-based surveys, could be encouraged to add TBI-related questions in order to identify individuals with co-occurring conditions that would include brain injury (i.e. mental illness and brain injury; substance abuse and brain injury). These opportunities will help to identify systems that may be serving individuals with TBI and encourage collaboration so that brain injury related conditions will be treated appropriately by the array of professionals involved with the health care system.

With regard to FY 2014, the Consortium supports:

#### **Department of Education**

##### **National Institute on Disability and Rehabilitation Research (NIDRR)**

- Increase the number of multicenter TBI Model Systems Collaborative Research projects from 1 to 4, each with an annual budget of \$1 million (current is \$600,000).
- Increased funding for the National Data and Statistical Center immediately by \$100,000 annually to allow all participants to be followed; when re-competed, increase from \$625,000 to \$1 million annually.
- Increased funding for the NIDRR TBI Model Systems (\$13M), of which 16 centers would receive an additional \$150,000 annually from the current average of \$437,500; and the number of TBI Model Systems would be increased from 16 to 18.
- NIDRR's request for a \$1.2 million increase for employment research activities under a "new regulatory framework" that NIDRR plans to have in place by 2014, for a total request of \$110 million. (Include budget language requesting employment research on best practices for obtaining and retaining employment for individuals with TBI.)

##### **Office of Special Education Programs (OSEP)**

- The President's request of a \$10 million increase over the 2012 level to provide support for programs of research on families of children with disabilities within the Institutes of

Education Sciences. The Consortium recommends that research should specifically include students with TBI in the priorities for research. (The Administration is proposing research to include technology for special education; developmental outcomes and school readiness of infants, toddlers, and young children with disabilities; educational outcomes in core subject areas for children with disabilities; and social and behavioral outcomes. The IES Special Education Studies and Evaluation program is funded at the FY12 level of \$11.4 million.)

### **Department of Health and Human Services (HHS)**

- Budget language supporting HHS to provide leadership in coordinating and maximizing policies and resources across agencies to improve identification, assessment, public awareness, information & resources, professional training and service delivery.
- Support funding to assist states in developing state regionalized trauma systems of care.

### **Administration for Community Living (ACL)**

- Require/urge states to include participation by individuals with TBI and TBI state programs in their long-term care initiatives supported by federal grants to assist states in expanding community long-term services and support options.
- Encourage the Administration to expand HHS/VA Memorandum of Understanding to provide Veteran Directed HCBS through ADRCs to include veterans with TBI and to coordinate with state Brain Injury HCBS Waiver programs, state TBI programs and other community resources in order to maximize community resources.
- Request HHS to report on how states receiving grants to develop lifespan respite care programs in accordance with the Lifespan Respite Care Act of 2006 have addressed the needs of caregivers caring for individuals with TBI.

(“In carrying out the Act, the Committee urges the Secretary to ensure that State agencies and ADRCs use the funds provided by this Act to serve all age groups and disability categories without preference. In addition, assurances should be made that ADRCs will reach and serve family caregivers who remain at greatest risk of having no respite services, especially caregivers caring for individuals with Multiple Sclerosis, ALS, autism, spinal cord injury, traumatic brain injury, adults with developmental and cognitive disabilities, individuals – including children – with emotional or mental health conditions, and children with all other types of developmental disabilities and chronic conditions.”)

### **Centers for Disease Control and Prevention -- National Center for Injury Prevention and Control (NCIPC)**

- \$3M annually to advance research on TBI identification and promote retrospective cohort studies and identification in administrative datasets.
- An increase of \$10 million to strengthen state injury and violence prevention programs to:
  - Fund core state injury and violence prevention programs nationwide
  - Support injury surveillance initiatives in all 50 states through funding, standardizing data elements and improving data collection for a clearer picture of risks, trends and progress.
  - Improve long-term health impact by facilitating and improving the evaluation of injury and violence prevention program and policy interventions and strategies.
- Funding and priorities for developing and disseminating screening tools and incentives to screen/identify TBI among diverse groups, such as victims of domestic violence, older adults, substance abuse, mental health, youth services, youth and adults in correctional systems.

- An increase of \$20.7 million to strengthen older adults falls prevention efforts by disseminating the Stopping Elderly Accidents, Deaths and Injuries (STEADI) Toolkit; creating tools to support the implementation of effective programs; and increasing the number of states that use a comprehensive approach to preventing older adult falls.
- Increased funding by \$5.7 million for the CDC Injury Center to strengthen injury and violence prevention research by increasing the number of research centers housed at universities and medical centers.

#### **Centers for Medicare and Medicaid Services**

- Request CMS assist State Medicaid Directors in identifying (screen, diagnose) children and youth with TBI under the EPSDT program (Early and Periodic Screening, Diagnosis and Treatment).

#### **National Institutes of Health (NIH)**

- Funding for the Project B.R.A.I.N. initiative (\$100 M), which is the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative aimed at revolutionizing our understanding of the human brain in order to help people suffering from such devastating conditions as TBI.

#### **National Institute of Neurological Disorders and Strokes (NINDS)**

- The Administration's request for \$10 million to support a TBI Research Initiative that includes a prospective study of 5,000 adults and children with TBI. Complementing this investigation, a study of 1,000 children will specifically evaluate the effectiveness of six major critical care guidelines for severe, pediatric TBI that are based on expert opinion rather than compelling experimental evidence to provide an evidence base for better diagnosis and treatment of TBI.

#### **Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), National Center for Medical Rehabilitation Research (NCMRR)**

- Increasing the NICHD program \$1.214 million, or 1.6 percent above the FY 2012 level, to help support a new, comprehensive effort to accelerate research on the epidemiology, diagnosis, and treatment of concussion, or mild TBI, across the life span.
- Coordinate rehabilitation research across the agency and with the DOD, VA, and other federal partners.

#### **Health Resources and Services Administration (HRSA)**

- Sufficient funding to support grants for all eligible state/territories/American Indian Consortium to expand service delivery
- Increased funding for state P&As
- Budget language supporting interagency collaboration (TBI Working Group)

#### **Health Resources and Services Administration (HRSA)**

##### **Emergency Medical Services and Emergency Medical Services for Children**

- Appropriate initial and ongoing funding to support the development of regional and state pediatric trauma systems as authorized by the Patient Protection and Affordable Care Act.

**Health Resources and Services Administration (HRSA)  
Maternal and Child Health Block Grant**

- Require federal coordination to improve children’s services under the Title V Children with Special Health Care Needs program, including care coordination, for children with TBI and the federal TBI Act State Grant Program.
- Funding to analyze data from a collegiate sports surveillance system and from state sports-related concussion legislation pertaining to school age athletes to assess the incidence of MTBI among participants – including numbers identified, referral to physician/medical provider, effects of concussion after return to school.

**Substance Abuse and Mental Health Services Administration (SAMHSA)**

- Direct SAMHSA to prioritize treatment of co-occurring conditions as part of the Substance Abuse Prevention and Treatment Block Grants awarded to States.
- Direct SAMHSA to develop and test models for serving individuals with brain injury who experience significant neurobehavioral sequela within its Center for Mental Health Services, which helps States improve the quality and increase the range of treatment and support services made available to people with mental illness, their families and communities.
- Request that SAMHSA acknowledge TBI as a co-occurring condition and integrate TBI into its national online registry of interventions supporting mental health promotion and treatment and substance abuse prevention and treatment to include interventions that address cognitive and behavioral issues as the result of a TBI; collaborate with other federal programs involved in TBI service delivery (HRSA, VA, DoD); and acknowledge TBI as a co-occurring condition in its priorities for Community Mental Health Services Block Grant and Substance Abuse Prevention & Treatment Block Grant funding to states, especially with regard to “trauma,” which SAMHSA has identified as a priority.

In closing, we appreciate the opportunity to convey our recommendations and look forward to further collaboration.

Sincerely,

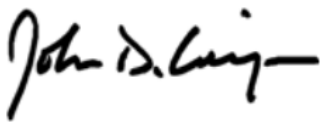
(please see next pages for signatures)



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John Corrigan, PhD  
Friends of TBI Model Systems



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The Sarah Jane Brain Foundation



Barbara Geiger-Parker, MCRP  
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## Appendix A: Overview of Federal Policy Achievements

Over the past 25 years, Congress has addressed many issues related to brain policies and funding, primarily with the Departments of Education (ED) and Health and Human Services (HHS) and more recently within the Departments of Defense and Veterans Affairs for research, treatment, rehabilitation and care for veterans and returning service members with TBI and their families. These achievements include:

- Since 1987, appropriations to the National Institute on Disability Rehabilitation and Research (NIDRR) for TBI Model Systems (16 centers) and the TBI Model Systems National Data Center;
- NIDRR currently funding two Rehabilitation Research & Training Centers on TBI and associated research projects. The two currently funded RR&T Centers are: Developing Strategies to Foster Community Integration and Participation (TIRR Memorial Hermann and Baylor College of Medicine in Houston, TX) and Center on Interventions for Children and Youth (Children’s Medical Center, Cincinnati, OH);
- The 1990 Individuals with Disabilities Education Act reauthorization added TBI as a disability category;
- The TBI Act of 1996, as amended, authorizing funding to:
  - The Centers for Disease Control and Prevention (CDC) to determine incidence and prevalence of TBI, conduct public awareness and prevention programs;
  - The National Institutes of Health (NIH) to conduct TBI research; and
  - The Health Resources and Services Administration (HRSA) for state grants to improve service delivery. The 2000 amendments authorized funding to HRSA to expand advocacy services provided by state Protection & Advocacy Systems to include individuals with TBI; and
- Enactment of the Dignified Treatment of Wounded Warriors Act as part of the National Defense Authorization Act of 2008, the landmark legislation establishing the Defense Centers of Excellence for TBI and Psychological Health, mandating pre- and post-deployment screening of service members, extending coverage periods for military insurance beneficiaries and authorizing the U.S. Department of Veterans Affairs to contract with civilian providers for hospital care and medical services.
- The Patient Protection and Affordable Care Act, which defined essential health care benefits to include rehabilitation and provides incentives to states to improve long-term services and supports to individuals with disabilities and older adults.

Over the years, several federal agencies have collaborated, formally and informally, to advance research and data collection and improve access to care and service system coordination. For example, NIH’s National Institute of Neurological Disorders and Strokes (NINDS), DOD and the VA established the Federal Interagency TBI Research (FITBIR) database and developed Common Data Elements (CDEs) for clinical research to foster comparison across clinical studies and sharing of data. Through report language, Congress has also encouraged the Federal TBI Program, housed in HRSA, to convene an interagency working group to facilitate collaboration and coordination of resources. A national TBI “Roadmap” is now in development with TBI stakeholder and consumer input.

## **Appendix B: Acronyms**

**ABI** – Acquired Brain Injury

**ACL** – Administration for Community Living (HHS)

**ACRM** – American Congress of Rehabilitation Medicine

**BIAA** – Brain Injury Association of America

**CDC** – Centers for Disease Control and Prevention

**HRSA** – Health Resources and Services Administration

**NASHIA** – National Association of State Head Injury Administrators

**NABIS** – North American Brain Injury Society

**NCIPC** – National Center for Injury Prevention and Control (CDC)

**NIH** – National Institutes of Health

**NIDRR** – National Institute of Disability Rehabilitation and Research

**NINDS** – National Institute of Neurological Disorders and Strokes

**SJBF** – Sarah Jane Brain Foundation

**TBI** – Traumatic Brain Injury

**USBIA** – United States Brain Injury Alliance

## **Appendix C: About One Voice for Brain Injury Consortium**

The One Voice for Brain Injury Consortium is comprised of seven national organizations representing the interests of individuals with brain injury and their families, and professionals involved in some aspect of research, treatment, rehabilitation and service delivery. These organizations include: the American Congress of Rehabilitation Medicine, Brain Injury Association of America, Friends of the TBI Model Systems, National Association of State Head Injury Administrators, North American Brain Injury Society, Sarah Jane Brain Foundation, and the United States Brain Injury Alliance.

### **The Consortium's Guiding Principles:**

Public policy must support:

1. Individuals with brain injury to live a productive life in the most integrated setting appropriate, which is of their choosing;
2. Evidence-based practices across health care, disability, education, and payer systems;
3. Funding and payment policies throughout the spectrum of care for medical and rehabilitative treatment and services/supports addressing needs over the lifespan;
4. Training/education for physicians, allied health, and disability and human services professionals; legislators; and relevant disability and human services professionals to recognize acquired brain injury and to address its deleterious effects;
5. Research across all domains of service delivery (i.e., primary, secondary, tertiary prevention), medical and rehabilitation treatment, education and community living/participation.

### ***About Consortium Members:***

#### **American Congress of Rehabilitation Medicine (ACMR)**

ACRM is comprised of specialized health care and research colleagues to develop and share knowledge that advances rehabilitation research and evidence-based clinical practice and focuses on emerging issues, trends and research on brain injury, outcomes measurement, spinal cord injury and stroke. The organization has a long history, founded in 1923 as the American College of Radiology and Physiotherapy, a professional association of physicians who used physical agents to diagnose and treat illness and disability. For more information: <http://www.acrm.org/>

#### **Brain Injury of Association America (BIAA)**

The Brain Injury Association of America (BIAA) is the country's oldest and largest nationwide brain injury advocacy organization, founded in 1980 by individuals and family who wanted to improve the quality of life for their family members and patients who had sustained brain injuries. The mission is to advance brain injury prevention, research, treatment and education and to improve the quality of life for all people affected by brain injury. The Association is dedicated to increasing access to quality health care and raising awareness and understanding of brain injury. With a network of state affiliates, local chapters and support groups, BIAA is the voice of brain injury. For more information: <http://www.biausa.org/>

### **Friends of TBI Model Systems**

The Friends of TBI Model Systems is comprised of the 16 Traumatic Brain Injury Model Systems (TBIMS), sponsored by the National Institute on Disability and Rehabilitation Research (NIDRR). NIDRR supports innovative projects and research in the delivery, demonstration, and evaluation of medical, rehabilitation, vocational, and other services designed to meet the needs of individuals with TBI. NIDRR awards TBI Model Systems grants to institutions that are national leaders in medical research and patient care; these institutions provide the highest level of comprehensive specialty services from the point of injury through eventual re-entry into full community life.

### **National Association of State Head Injury Administrators (NASHIA)**

The National Association of State Head Injury Administrators (NASHIA) is a non-profit organization established by State government employees to help one another plan, implement, and administer public programs and services for individuals with brain injury and their families. The Association is an outgrowth of the first State of the States in Head Injury Meeting held in 1990. For further information: [www.nashia.org](http://www.nashia.org)

### **North American Brain Injury Society (NABIS)**

The North American Brain Injury Society (NABIS) is comprised of professional members involved in the care or issues surrounding brain injury. The principal mission of the organization is moving brain injury science into practice. The Association was created specifically to address the needs of multidisciplinary professionals dedicated to brain injury - providing education programs, scientific updates and a platform for communication and professional exchange. For further information: <http://www.nabis.org/>

### **Sarah Jane Brain Foundation (SJBF)**

The Sarah Jane Brain Foundation (SJBF) is an advocacy organization founded in New York City in 2007 by Patrick Donohue, whose daughter was violently shaken by her nurse caregiver. The mission is to advance knowledge of the brain and to fully fund and implement the National Pediatric Acquired Brain Injury Plan (PABI Plan) to create a seamless, standardized, evidence-based system of care that is universally accessible for all children and young adults with a pediatric acquired brain injury regardless of where they live in the United States. For further information: <http://www.thebrainproject.org/>

### **United States Brain Injury Alliance (USBIA)**

The United States Brain Injury Alliance (USBIA) is a nationwide network of active and inter-dependent, state based, non-profit organizations working with and for their citizens with brain injury. USBIA Members respond to hundreds of thousands of information and resource requests each year. USBIA and its Members support individual advocacy, systems advocacy, awareness, prevention, support, research and community engagement at the state level. For more information: <http://usbia.org/>

**Appendix D: August 5<sup>th</sup>, 2013 letter to Sen. Harkin and Sen. Alexander**

August 5, 2013

The Honorable Tom Harkin  
Chairman, Committee on Health,  
Education, Labor and Pensions  
United States Senate  
731 Hart Senate Office Building  
Washington, DC 20510

The Honorable Lamar Alexander  
Ranking Member, Committee on Health,  
Education, Labor and Pensions  
United States Senate  
455 Dirksen Senate Office Building  
Washington, DC 20510

Dear Chairman Harkin and Ranking Member Alexander:

Six leading brain injury organizations – American Congress of Rehabilitation Medicine, Brain Injury Association of America, Friends of the TBI Model Systems, National Association of State Head Injury Administrators, North American Brain Injury Society, and United States Brain Injury Alliance – which serve and represent the interests of the 3.5 million Americans who sustain traumatic brain injuries each year as well as their family caregivers, clinicians, researchers, public program administrators and other professionals, are pleased to provide the following consensus recommendations on the reauthorization of the Traumatic Brain Injury (TBI) Act of 1996, as amended:

***1) Transfer the HRSA Federal TBI Grant Program to the Administration for Community Living within the U.S. Department of Health and Human Services***

We recommend Congress transfer the Federal TBI State Grant Program (42 USC 300d-52) and the Protection & Advocacy (P&A) TBI Program (42 USC300d) to the Administration for Community Living (ACL) within the U.S. Department of Health and Human Services (HHS) by deleting the reference to Health Resources and Services Administration from current law. This action would be budget neutral.

The ACL was created to address the community needs of individuals with disabilities across the lifespan and services for older adults by combining the Administration on Aging, Administration on Intellectual and Developmental Disabilities (AIDD) and the Office of Disabilities to coordinate services and resources. Transferring the TBI State Grant and P&A Grant programs ACL would help to integrate TBI into the HHS long-term services initiatives, which also rely on Aging and Disability Resource Centers as the entry point into these systems; promote collaboration with Aging on falls related TBIs among older adults; include TBI in the veterans initiatives between HHS and Department of Veterans Affairs (VA) to support home and community-based services for veterans; assure that families who are primary caregivers for their members with a brain injury are included in the Lifespan Respite Care Program; and

coordinate/enhance services for individuals with TBI who may also be eligible for services provided through I/DD and other disability systems.

State protection and advocacy systems already receive funding from the AIDD to protect and advocate for the rights of people with developmental disabilities (PADD). AIDD also funds 68 University Centers for Excellence in Developmental Disabilities (UCEDDs) to provide education, research and services. A few HRSA TBI State grantees have partnered with the UCEDD in their states for assistance with person centered training, project evaluation, and other activities associated with their grant work.

In addition, S. 1356, the Workforce Investment Act of 2013, marked up by the S. HELP Committee last week, calls for moving both the Independent Living program and the **National Institute on Disability and Rehabilitation Research (NIDRR)** from the U.S. Department of Education to the ACL. NIDRR currently funds 16 TBI Model Systems, two Rehabilitation Research and Training Centers on TBI and related TBI research projects. Should these programs be transferred, then transferring the Federal TBI Program would further enhance collaboration and maximization of resources within the ACL.

We would be remiss if we did not call attention to the need to add model systems to address children and youth. NIDRR TBI Model Systems support innovative projects and research in the delivery, demonstration, and evaluation of medical, rehabilitation, vocational, and other services designed to meet the needs of individuals with TBI age 16 and older. We believe similar research capabilities should be extended to children and youth.

***2) Promote Federal Interagency Collaboration and the Development of a National Federal Plan to Improve TBI Service Delivery***

Under 42 USC 300d-52, the Secretary of HHS is to ensure that activities under this section (HRSA State Grant Section) are coordinated as appropriate with other Federal agencies that carry out activities regarding TBI. As the result of TBI stakeholder encouragement and congressional budget language, HRSA recently convened the Federal Interagency Work Group to coordinate federal resources. HRSA is now embarking on developing a “roadmap” for TBI with consumer and stakeholder input.

We believe that while HRSA should be commended for this action, amending this section (42 USC 300d-52) to formally create an interagency body under the Secretary involving stakeholders and consumers would ensure collaboration among federal and state entities involved in research, prevention, data, health and medical care, education, vocational rehabilitation and the range of community services and supports offered to individuals with brain injury of all ages. Furthermore, we believe Congress should direct HHS to conduct an audit of all TBI research conducted by federal agencies, and to develop a national plan for addressing the array of needs of individuals with brain injury and their families, taking into account resources and services across federal agencies.

***3) Amend/clarify that appropriations for the TBI State Grant program may be used for providing service coordination and other services on an ongoing basis.***

The HRSA Federal TBI State Grant Program has been awarding time-limited grants to state agencies since 1997, and each funding cycle has required states to initiate new projects to complete within a 3-4 year time period. While this approach has allowed states to develop new initiatives, including capacity for service coordination, it has been difficult to sustain these services once the grant has expired. As HRSA has interpreted current statutes to prohibit states from providing services with grant funds, we recommend that language be added to clarify that grant funds may be used for services, such as information & referral services, service coordination, screening and any other service identified as a need by the state advisory board and identified in the state plan.

Current statute (42 USC 300d-52): (f) allows “Use of State and American Indian consortium grants”;

- “To develop, change, or enhance community-based service delivery systems that include timely access to comprehensive appropriate services and supports”; and
- (D) “To develop individual and family service coordination or case management systems.”

***4) Establishing a funding formula that allows distribution of funding to all eligible States, Territories, American Indian Consortium and District of Columbia***

Funding under the Federal TBI State Grant Program is distributed on a competitive grant basis. Twenty states are receiving funding, and rather than re-bid grants that were set to expire this year, HRSA extended funding for a fifth year. This means that the majority of states have been unable to access funds for the past four years, and it will be five years before grant funds will be available through this process. We recommend that all eligible entities, meaning those who meet other specified requirements such as required state match, receive funding annually in order to sustain activities on an on-going basis. This approach would be similar to the section relating to the Protection & Advocacy Systems Grant Program whereby all state P&As receive an allotment. Depending on the level of appropriations state P&As in larger populated states may also receive funding above that base level. We recommend the state grant program move to a similar method for distributing funds.

In closing, we appreciate the opportunity to convey our recommendations and look forward to further collaboration.

Sincerely,

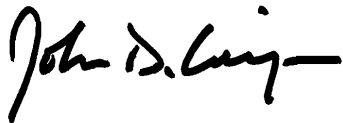
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