# Federal Public Policy Platform

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***NASHIA assists State government in promoting partnerships and building systems to meet the needs of individuals with brain injuries and their families***

# National Association of State Head Injury Administrators

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***"Giving States a Voice"***

## ABOUT NASHIA

The National Association of State Head Injury Administrators (NASHIA) is a nonprofit, voluntary membership organization established by State government employees to help States plan, implement and administer public programs and services for individuals with brain injury (TBI) and their families. NASHIA members represent a broad spectrum of State agencies, including health, Vocational Rehabilitation, mental health, Medicaid, social services, developmental disabilities and education. Since 1990, NASHIA has been the source of information and education for State employees and the collective voice of State government on federal brain injury issues.

NASHIA reaches out to State agency employees and welcomes other advocates, professionals and organizations with an interest in State policy and service delivery to become a member. For further information, visit www.nashia.org.

## MISSION

The mission is to assist State government in promoting partnerships and building systems to meet the needs of individuals with brain injury and their families.

## PRINCIPLES

**NASHIA:**

- Respects the past and embraces the future.
- Values diversity, creativity, innovation and individuality in people and systems.
- Is goal-directed, and strives to learn from others.
- Believes brain injury is a significant public health and disability concern that requires resources for prevention, research and service delivery commensurate with its scope and impact at the local, State and federal level.
- Believes individuals with brain injuries have the right to a life in the mainstream of society with the full range of service and support options necessary to meet individualized needs across the lifespan.
- Believes State service delivery systems should outreach to and support all individuals with brain injuries, including those from culturally and linguistically diverse communities, in setting their own goals, determining their own needs, and choosing their own services and supports in culturally appropriate environments.
- Believes service delivery systems should be accessible, available, acceptable, appropriate, and affordable, and respect the values, knowledge, and history of individuals with brain injury and their families.
- Believes individuals with brain injury, their circle of supports, and their families should be active participants in the planning and implementation of service delivery systems that balance financial responsibility with the dignity of risk.
- Values collaborative approaches across organizations and systems and the contributions of all partners and stakeholders who share NASHIA's goals.

## FEDERAL PUBLIC POLICY PLATFORM

### About TBI

Traumatic brain injury (TBI) contributes to a substantial number of deaths and permanent disability among Americans each year. The Centers for Disease Control and Prevention (CDC) estimates that at least 1.7 million Americans seek treatment from emergency department visits, hospitalizations or result in death annually. This is an increase from 1.4 million reported in the previous report conducted by the CDC in 2004, mostly as the result of the examination of emergency department visits. The 2010 report noted that there were large increases in emergency department visits among children and older adults.

A TBI is caused by a sudden jolt, blow or penetrating injury to the head that disrupts the normal function of the brain. Falls and motor vehicle crashes are the primary cause of injuries with sports, recreational injuries, work-related and war-related injuries as also causes of TBI. TBI can happen to anyone at any age at any time. The injury often results in problems with thinking, memory, emotions, behavior, language, physical mobility and sensory that affects how a person is able to live and work independently.

TBI is a complex disability that challenges States' response to individual and family needs ranging from rehabilitation to community and family support to long-term care. Individuals may only need time-limited services, while others may need long-term services and supports or services on an intermittent basis. Individuals may have other contributing problems such as substance abuse, depression and anxiety. This requires services and funding to be flexible in order to meet the individual needs. It also requires professionals, support staff and providers to be knowledgeable in TBI treatment, rehabilitation, services, care and supports across service systems.

The Institute of Medicine (IOM) 2005 evaluation of the HRSA Federal TBI Program noted that the quality and coordination of post-acute TBI service systems remain inadequate, although progress has been made in some States. State and federal funding for TBI rehabilitation, long-term care and community supports have been difficult to obtain to support the array of needs. As a result, families tend to be the primary caretakers. As families age, there are few options for housing, assistance with activities of daily living and other long-term care needs. Without effective and coordinated systems individuals with TBI become unemployed, homeless, or institutionalized or placed in nursing homes or correctional facilities. This is costly financially to taxpayers and emotionally to families.

### State and Federal Role

Individuals with TBI and their families are most likely to seek public services and assistance from health, Vocational Rehabilitation, Medicaid, social services, mental health or developmental disabilities agencies or a combination of these agencies that together provide the necessary services and supports. States strive to provide coordinated systems of care with the goal of providing the right services at the right time.

States use a variety of federal, general revenue, dedicated funding and local resources for planning, developing and administering an array of services and supports -- but it is never enough. State TBI programs are often limited to revenue generated by dedicated funds derived from traffic fines, with a very few States using general revenue (State) primarily to support programs. Other States provide services through Medicaid State Plan services and through Home and Community-Based Services (HCBS) Waiver programs. Some States use all of these resources as well as other federal programs designed for individuals with disabilities or who have health care needs.

Because of the wide range of needs and the potential impact of the myriad of federal programs on individuals with TBI, NASHIA reviews and monitors all federal programs that offer assistance and supports to individuals with disabilities. These programs, with adequate funding and training in TBI,

can fill in the gaps in service delivery. However, coordination of these resources is critical to avoid duplication of services, and to maximize all resources. Therefore, NASHIA supports policies that promote systems change to improve access, quality of services, outcomes and cost-effectiveness.

### Federal TBI Act

The Traumatic Brain Injury (TBI) Act of 1996, as amended in 2008, authorizes the US Department of Health and Human Services (HHS), Health Resources and Service Administration (HRSA) to award grants to (1) States, American Indian Consortia and territories to improve access to service delivery and to (2) State Protection and Advocacy (P&A) Systems to expand advocacy services to include individuals with traumatic brain injury. The HRSA, Maternal Child Health (MCH), Children's Program administers the Federal TBI Grant Program.
The TBI Act also authorizes funding to the Centers for Disease and Prevention (CDC) for conducting public education, prevention and surveillance. This is the *only* program Federal program offering assistance to States to expand service delivery. The 2000 Amendments added authority for appropriating funding to HRSA for State P&A systems.

For the past fourteen years the HRSA Federal TBI State Grant Program has supported State efforts to develop four core components: establishing an advisory board, designating a lead State agency, conducting a needs and resources assessment and developing a State action plan. States have also used grant funds to expand and to improve services to underserved and unserved populations, including children and youth; veterans and returning troops; and individuals with co-occurring conditions.

### NASHIA Public Policy

NASHIA priorities are influenced by emerging issues and impact on State systems and availability of services to individuals with TBI and their families. NASHIA offers *primary support* to legislative, funding or regulatory initiatives that directly and exclusively impact service delivery for individuals with TBI and their families. This includes initiating, researching or drafting legislative language or funding proposals; educating legislators and other public policy makers and actively building coalitions to partner with and to support TBI initiatives. NASHIA also *supports* (or *opposes*) and *monitors* other federal legislative and funding that impacts all individuals with disabilities, including TBI.

NASHIA regularly informs members of key issues through its publication, *Capitol News*, Action Alerts and a legislative grid of pertinent legislation. These materials, fact sheets and NASHIA correspondence are posted on the public policy section on the NASHIA website: www.nashia.org.

### TBI Stakeholders

NASHIA regularly communicates and partners with the TBI stakeholders (Brain Injury Association of America and National Disability Rights Network) and belongs to the American Brain Coalition, Consortium for Citizens with Disabilities (CCD), and the Disability and Rehabilitation Research Coalition (DRRC).

NASHIA also works closely with the Congressional Brain Injury Task Force, which was created to promote TBI awareness and education. Each March, the Task Force sponsors a Brain Injury Awareness Day featuring a Fair that provides an opportunity for national and federal organizations and agencies to showcase information on brain injury, programs and initiatives; a briefing on current issues; and a reception in honor of the Task Force and Awareness Day.

The NASHIA Public Policy Committee and staff developed this platform, which was adopted by the membership during the annual meeting held in September 2010 in Minneapolis, Minnesota.

## PRIMARY SUPPORT

### 1. Traumatic Brain Injury (TBI) Act Programs

The President has proposed level funding ($10 million) for FY 2012, same as the past two years for the State and Protection & Advocacy (P&A) Grant Programs combined. Of that amount, approximately $6 million has been available for the State Grant Program, which includes funding for the TBI Technical Assistance Center. Approximately $3 million is for the P&A Grant Program, and the remaining is for HRSA administration costs.

In FY 2009, HRSA increased the State grant awards from $118,000 to $250,000 for four years to support the work that is expected. While NASHIA supports the increased amount for State grant awards, this policy drastically reduced the number of States receiving grants due to the appropriation level.

NASHIA continues to support necessary funding for all States, territories, District of Columbia and the American Native Indian Consortium to have TBI grants. In addition, NASHIA supports the IOM recommendations that HRSA appoint a national TBI Program Advisory Board to articulate a vision for the program; develop an action plan for HRSA; and advocate for relevant federal agencies to furnish needed data to address TBI in eligibility rules for other federal programs.

**NASHIA recommends:**

- Elevating the **status** of the TBI program within the US Department of Health and Human Services to acknowledge the magnitude of TBI; the need for an array of rehabilitation and community services and long-term supports, including services for returning servicemembers/veterans, young adults and the elderly with TBI
- Increased funds to expand the number of State grants
- Increased funds to increase the amount of the P&A Awards
- Increased funds for data surveillance, to expand prevention and public education efforts, and to promote clinical guidelines

### 2. TBI Act Reauthorization

The TBI Act of 1996, as amended, expires at the end of FY 2012. The law authorizes funding to the US Department of Health and Human Services, HRSA TBI Federal program and to the CDC for injury prevention, surveillance and public education.

Since the beginning of the program, grants have been awarded to 48 States, one Territory and the District of Columbia to support needs and resources assessment; advisory boards and establishing a lead agency within States. States have also used the grants to expand service delivery to under or unserved populations, and to improve systems through training, public education, interagency collaboration and other activities. These competitive grants have changed over the years from one-two year planning grants and three year implementation grants to, now, four year State partnership grants.

NASHIA has supported moving the grant process from a competitive grant process to a formula-based process where there is a method for allocating funding to all States. To do that will require adequate funding, and new legislative provisions adopt the formula funding approach. Such provisions may need to include an appropriation level that would have to be met before switching to the formula process, much like the provisions for the P&A TBI program.

**NASHIA recommends:**

- Reducing/eliminating match requirements
- Formula funding in lieu of competitive grants
- Relocating the administration of the program from Children's Program within HRSA to another location to broaden its focus
- Requiring public input in determining priorities for grant program (i.e., Federal Register, a national advisory board)
- Establishing a federal interagency work group to promote collaboration and maximization of resources across federal programs
- Incorporating outcomes that reflect the goals of the grants, in addition to the HRSA's Children's Program focusing on health outcomes for children

**3. Returning Troops/Veterans**

TBI is a significant injury for servicemen and women in Iraq and Afghanistan wars who are exposed to improvised explosive devices (IEDs). As a result, Congress has increased funding to the Department of Defense (DoD) and the Department of Veterans Affairs (VA) for improved identification, treatment, care and assistance to those who are injured. DoD has implemented screening for mild TBI in its post-deployment health assessment (PDHA) and prior to deployment. DoD has also provided guidance and training for health care providers.

In October 2008, the Army National Guard implemented a blast tracking system to report those exposed to IEDs who may not be readily identified as TBI. The information is placed into the soldier's personnel records which will document Line of Duty with regard to future TBI related symptoms. Language was included in the FY 2009 Defense Appropriation acknowledging that initiative and calling for all branches of the military to do the same.

The Caregivers and Veterans Omnibus Health Services Act signed into law last May 2010 directed VA to begin providing caregiver support by January 30, 2011 (P. L.111-163). Among the services required by the caregivers law are training in the provision of care, respite care, technical assistance, counseling, and financial support for those who give up the opportunity to work in order to provide needed care to their injured loved ones. The National Defense Authorization Act, Public Law 111-383, tied the Department of Defense's stipend for caregiver services to the amounts of the caregiver stipend to be developed under Public Law 111-163.
States have also implemented initiatives to screen, provide outreach and information to returning servicemembers with TBI. Some of these initiatives are the result of the HRSA Federal TBI Grant Program, while other efforts have been initiated by the Governor and the State legislature.

**NASHIA recommends:**

- Initiatives and funding that would require DoD and VA to fund and coordinate with State government outreach, information, follow-up and coordination of resources for returning soldiers for traumatic brain injury, including those who may not be diagnosed or misdiagnosed
- Increased funding for the Defense and Veterans Brain Injury Center to improve outreach, identification, treatment, family assistance, rehabilitation, vocational rehabilitation and community-reentry programs

- VA funding to support brain injury home and community-based services waiver options to veterans with brain injury

- Funding and implementation of the caregiver support and training as directed by the Caregivers and Veterans Omnibus Health Services Act

**4. Employment, including Transition Services**

Employment is an important and achievable goal for individuals with TBI who either return to work after injury or who obtain employment for the first time. Returning to work for individuals with brain injury is challenging, success rates range from 22% to 55%, and wage levels for those who returned to work post-injury have also been low. Studies report favorable employment outcomes for individuals with brain injury participating in supported employment. However, a one-size fits all approach will not work with brain injury. There needs to be a full array of options to help people become employed and lessen the dependence on SSDI and other governmental programs.

The Workforce Investment Act (WIA) of 1998 (Public Law 105-220) integrates several federal employment and training programs, and is the primary workforce development vehicle of the U.S. Department of Labor. The WIA created one-stop career centers to provide access to training and employment services for a range of workers, including low-income adults and youth, dislocated workers, and people with disabilities.

Title IV of the WIA reauthorized the Rehabilitation Act of 1973, as amended, through FY 2003. The legislation authorizes funding to State Vocational Rehabilitation agencies to help individuals with disabilities to obtain employment. The US Department of Education, Rehabilitation Services Administration administers the funding for the State VR program. Services provided by VR include, but not limited to; assessment to determine eligibility; counseling and guidance; referral to other services; job-related services, including job search and placement assistance, job retention services, follow-up services, and follow-along services; training and other services; on the job or other related personal assistance; supported employment and transition services. Transition services are to assist students to move from school to post school activities, including postsecondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation.

The President's FY 2012 budget includes proposals that would consolidate Title I VR programs, including supported employment, Projects with Industry, and migrant, personnel training, and seasonal farm workers programs. The $56.3 million additional funds requested under the Title I program are for the coordination of these consolidated programs. The purpose of the proposed consolidation is to streamline and provide accountability for these programs.

**NASHIA recommends:**

- Reauthorization the Rehabilitation Act and the Workforce Investment Act (WIA)

- Funding Supported Employment and the Partner in Industry Councils (PIC) programs

- Training WIA One Stop Programs to be knowledgeable about brain injury

- Strong linkages between Vocational Rehabilitation, WIA, Ticket to Work and Individuals with Disabilities Education Act (IDEA)

- Increased VR funding and resources to support transitional services for students with brain injury from school to work

- Funding for research in best practices in vocational training and job retention for individuals with brain injury

- Increasing funding for State Vocational Rehabilitation programs significantly above the required Consumer Price Index (CPI) level

- Incentives for employers to expand work opportunities for individuals with brain injury in integrated employment at competitive wages

- Incentives to encourage full implementation by States to establish Medicaid buy-in programs for people with brain injury who work

**5. Dual Diagnosis/Co-Occurring Conditions**

Individuals with TBI often have problems associated with substance abuse or mental health or both conditions. Emotional problems after TBI may be associated with depression, anxiety and substance abuse/dependency. People who experience brain injuries often have a prior history of substance use/ or abuse. Individuals with primary diagnosis of mental health or substance abuse treatment services may also have an undocumented TBI.

The US Substance Abuse and Mental Health Services Administration (SAMHSA), established in 1992, provides funding for substance abuse and mental health services to the people most in need and to translate research in these areas more effectively and more rapidly into the general health care system. The Center for Substance Abuse Treatment works with States and community-based groups to improve and expand existing substance abuse treatment services under the Substance Abuse Prevention and Treatment Block Grant Program. The Center for Mental Health Services (CMHS) helps States to improve and increase the quality and range of their treatment, rehabilitation, and support services for people with mental illness, their families, and communities. CMHS supports outreach and case management programs for Americans with severe mental illness who are homeless and supports the development and adoption of "models" for improving services.

Since 2003, the SAMHSA has funded the Co-Occurring Center for Excellence (COCE) to assist States and providers with co-occurring conditions associated with mental health and substance abuse issues. This model could be expanded to include TBI or a separate center established for TBI and co-occurring conditions to help TBI, mental health/behavioral health and substance abuse professionals and providers to better understand how to assess and manage these co-occurring conditions.

**NASHIA recommends:**

- Reauthorization of SAMHSA, including new provisions for funding State grants and technical assistance for State mental health/behavioral health and substance abuse agencies to assist with screening co-occurring conditions for brain injury, and providing appropriate treatment for individuals with mental health, behavioral health, and/or substance abuse problems who may also have a brain injury

- Education and training among TBI professionals and providers that may primarily serve individuals with TBI, but who may also have co-occurring conditions

- Funding and policies to support coordination of resources among the HRSA Federal TBI Program, CDC and SAMHSA

## SECONDARY SUPPORT

Individuals with TBI and their families may be eligible for programs offering services, supports and assistance to individuals with other disabilities or other health care needs. Individuals with brain injury may also seek assistance, based on their financial need, for such programs as food stamps and heating assistance, as well as Social Security Administration Disability programs. NASHIA supports funding and legislation for these critical resources that improve rehabilitation, health care, education, employment, community living and overall quality of life for individuals with traumatic brain injury, their families and circles of support.

## APPROPRIATIONS AND BUDGET PROCESS

**6. Appropriations for Health and Disability Programs; and Public Assistance**

At the time of this publication Congress was still working on funding for FY 2011 federal programs. On February 11, 2011, Congress passed a Continuing Resolution contains drastic cuts, including numerous eliminations, to domestic discretionary programs. These cuts include full elimination of the Corporation for National and Community Services (-$1 billion); supported employment State grants (-$28 million); and a cut to the Maternal and Child Block Grant of -$50 million. An amendment offered also prohibits any funds to be used to implement the Affordable Care Act. And, the Low Income Home Energy Assistance Program (LIHEAP) would see funding drop by about $2.5 billion from an authorized 2009 total of $5.1 billion. As a compromise, Congress passed another short-term CR and reduced federal spending by $4 billion. These actions signal the desire to eliminate federal programs and drastically cut spending. The President's FY 2012 budget also contains measures to eliminate or trim more than 200 programs and reduce the deficit by $1.1 trillion over the next decade.

**Budget Resolution**

Each year, the US House of Representatives and Senate are to develop a joint budget resolution which guides the process for developing the spending bills for the coming fiscal year. The discretionary parts of the budget are addressed through annual appropriations bills. The mandatory parts of federal spending are handled through reconciliation bills (I.e. Medicaid, Supplemental Security Income (SSI), and Medicare). The process is also to take into account revenue, including any revised tax policies. Using revenue projections, Congress outlines anticipated increases or decreases in spending across the discretionary and mandatory parts of the federal budget. These amounts are provided to the House and Senate Appropriations Committee and Subcommittees to guide them as to funds available to allocate to specific programs.

**NASHIA recommends:**

- That critical entitlement programs, such as Social Security, Medicaid, Medicare, food stamps, are strengthen, not weakened

- That the Social Security trust funds be protected for use by current and future beneficiaries

- That discretionary programs affecting individuals with disabilities are protected from cuts or elimination (i.e. public transportation, job training, meals-on-wheels, training for health care professionals)

- Legislation to phase out Medicare's 2-year waiting period under which people with disabilities qualify for Medicare coverage 24 months after receipt of Social Security Disability Insurance (SSDI) benefits

**7. Children and Youth with TBI, including Education**
Children and youth with TBI and their families may need assistance and supports to help with transition from hospital to home and assistance with daily activities of living, including service coordination, respite, therapies, in-home support, home-modifications and assistive technology. In some States this assistance may be provided through the special health care needs program, State TBI program, Medicaid, and/ or developmental disabilities programs and services.

Children and youth with TBI are likely to have very different educational needs than prior to their injuries. They may receive special education and related services afforded to them under the Individuals with Disabilities Education Act (IDEA), which entitles individuals with disabilities to a free, appropriate public education to help with their educational needs. Children and youth who do not qualify for special education services may qualify for educational accommodations and modifications under a 504 plan (Rehabilitation Act of 1973) and under the Americans with Disabilities Act (ADA).

The IDEA Amendments of 1990 added TBI and Autism as disability categories for reporting children receiving special education services with these diagnoses. Prior to that change, children may have been reporting as receiving special education services under the categories of other health impairments, serious emotional disturbances, learning disability or mental retardation.

IDEA authorizes funding for Parent Information and Training Centers to provide training and information to parents of children with disabilities on how they can improve educational results for their children and on their legal rights and protections. The program also provides technical assistance to centers.

The No Child Left Behind (NCLB) Act of 2001, which expired in September 2007, requires schools to have a plan to help all students meet challenging academic standards and requires systemic accountability for the outcomes of all students, including students with disabilities.

**NASHIA recommends:**

- Prioritized funding for Special Health Care Needs (MCH Block Grant) to provide service coordination and other assistance to children and youth with TBI and their families

- Policies that support transition from the children's health care needs programs to adult programs

- Maintaining the State Children's Health Insurance Program (SCHIP)

- Continued support of Medicaid-eligible children with disabilities to obtain health-related services, including transportation, during the school day under the student's Individualized Education Program IEP)

- Maintaining the entitlement to the Medicaid Early Periodic Screening, Diagnosis, and Treatment (EPSDT) program

- Incentives for States to implement the option in state Medicaid plans for families of children with disabilities to buy into Medicaid, if private health insurance is not available or does not meet their needs

- Reauthorization of both IDEA and NCLB and funding for:

    - Highly qualified general and special education teachers with sufficient skills and knowledge to teach grade-level content and to teach diverse learners, including individuals with cognitive and behavioral problems relating to brain injury
    - Improved graduation rates of students with disabilities, including brain injury
    - Resources for public schools to meet the needs of all students, including those with brain injury
    - Closer coordination of NCLB and IDEA policies to support educational needs of children and youth with brain injury
    - Funding to conduct research on promising practices with regard to screening, identification, and developing educational and behavioral strategies relating to brain injury

- Full funding for IDEA

- Legislation affording protections, including sanctions, against abuse, aversive interventions, and the inappropriate use of physical, mechanical, and chemical restraints and seclusion for all students in schools

- Opportunities for adult education, vocational training, post-secondary education, and lifelong learning opportunities for students with disabilities, particularly students with brain injury

- Emphasis on parent act programs to provide assistance to parents of children with brain injury receiving special education services

**8. EMS/Trauma Care**

Treatment for brain injury begins at the time when the emergency medical services (EMS) team arrives to the injury scene and begins assessment and management of the injuries; and transporting the individual to the appropriate trauma center or hospital, depending on the severity of the injuries. EMS systems include emergency calls to 9-1-1; dispatch of emergency personnel to the scene of trauma; and triage, treatment, and transport of patients by ambulance and air medical service. The speed and quality of EMS services are critical factors in a patient's outcome.

Federal funding for EMS has declined since the early 1980s, when there was a push to develop more organized systems of EMS services across the country. Now, EMS systems differ across and within States and local areas. Nearly half of these systems are organized and delivered through the local fire department. 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. In addition, there are more than 6,000 9-1-1 call centers, each run differently by police, fire, county or city government or other entities.

To help rural areas HRSA provides grants for improving EMS/Trauma Care. The Federal Emergency Medical Services for Children (EMSC) Program is also administered by HRSA in the Maternal and Child Health Bureau, and is designed to ensure that all children and youth receive appropriate care in a health emergency. Since its establishment, the EMSC Program has provided grant funding to all 50 States, the District of Columbia, and five Territories. EMSC was recently reauthorized through 2014 as part of health care reform legislation (ACA). This legislation authorized $26.250 million for EMSC in FY 2011. In FY 2010, EMSC received its first funding increase in almost a decade, to $21.5 million.

**NASHIA recommends:**

- Legislation and funding to support improved coordination of EMS systems across the country, including rural settings
- Standardized protocols for EMS practices, based on evidence-based research
- Funding to support organized State trauma systems
- Increased funding for EMSC programs to the authorized level

### 9. Health Care, Medicare and Medicaid

H.R. 3590, the Patient Protection and Affordable Health Care Act (P.L. 111-148), which passed in 2010, was designed to reform the nation's health care system. The reform legislation prohibits insurance companies from discriminating because of pre-existing conditions; from dropping coverage due to a person's illness; extends to the age of 26 that children may remain on their parent's insurance; prohibits lifetime and annual caps; reduces disability health disparities; and prohibits discrimination based on health status, as well as those that focus on wellness and prevention. The law also defined essential benefits package to include rehabilitative and habilitative services and devices; mental health and substance use disorder services, including behavioral health treatment; preventive and wellness services and chronic disease management; pediatric services, including oral and vision care.

Due to the economic downturn, Congress increased the Medicaid federal share ($87 billion) to States in the American Recovery and Reinvestment Act (ARRA) which was signed into law in 2009; and extended the enhancement by way of the Education Jobs and Medicaid Assistance Act, to provide an additional $16.1 billion through June 30, 2011.

There is push back by some members of Congress to reduce or eliminate provisions of the health care reform law, including federal funding to implement the law.

**NASHIA recommends:**

- Maintaining health care reform (ACA) provisions affecting TBI (i.e. pre-existing conditions, rehabilitation coverage, long-term care)
- Adequate funding to carry out the intent of the health reform law (ACA)
- Maintaining the individual entitlement to a full range of Medicaid health and long-term supports and services for all eligible children and adults with disabilities, including brain injury
- Extending the temporary increase in the federal share of Medicaid spending beyond June 30, 2011 to address the economic crises facing States across the country and ensure that States maintain their level of effort
- Medicaid reimbursement for a 30-day emergency supply of medication in anticipation of potential disasters, epidemics, or other emergencies
- Funding for demonstration programs to implement individual care coordination for individuals with brain injury, particularly those who have complex and chronic health care needs
- Expanding preventive and restorative dental coverage under the ACA

- Funding for the Prevention and Public Health Fund and increase funding for primary and secondary prevention and wellness programs for individuals with disabilities

- Funding for training of all health care providers about the needs of children and adults with brain injury, including practices to prevent secondary conditions and to help transition youth with disabilities to adult care providers

- Legislation to eliminate Medicare's "in the home" restriction for coverage of mobility devices (i.e. wheelchairs and scooters) for those with expected long-term care needs

- Improve Medicaid portability so that beneficiaries and families are not disadvantaged by moving from one State to another

**10. Disability and TBI Research**

The National Institutes of Health (NIH) and the National Institute for Disability and Rehabilitation Research (NIDRR) are primary funders of disability and rehabilitation research. NIDRR currently funds 16 TBI Model Systems and one Research and Training Center (R&TC) on TBI. NIDRR conducts comprehensive and coordinated programs of research and related activities to assist in the achievement of the full inclusion, social integration, employment and independent living of people with disabilities.

NIH brain injury research is conducted by the National Institute of Neurological Disorders and Stroke (NINDS). NINDS conducts and supports research on TBI to better understand the biological mechanisms of injury, to develop tools for improved diagnosis, and to develop effective treatments to improve functional outcomes and quality of life. The mission of the NINDS Office of Translational Research (OTR) is to facilitate the preclinical discovery and development of new therapeutic interventions for neurological disorders.

**NASHIA recommends:**

- Increased funding for NIDRR TBI Model Systems and Research and Training Centers funded by NIDRR, to add one new Collaborative Research Project

- "Line-item" status for TBI Model Systems of Care within the NIDRR budget

- Continued coordination of Department of Veterans Affairs and the Department of Defense (VA/DoD) and civilian disability and rehabilitation research capacity

- A comprehensive government-wide strategic plan for disability and rehabilitation research

- Enhancing and coordinating research science at NIH

- Translating and disseminating findings on brain injury research and rehabilitation to State and community brain injury programs

**11. Developmental Disabilities (DD) Act Reauthorization**

The Developmental Disabilities Assistance and Bill of Rights (DD) Act (Public Law 106-402) expired in 2007 and is due for reauthorization. The Act establishes and authorizes funding for the State and Territorial councils on DD, P&A Systems, University Centers for Excellence on DD, Family Support Programs and Projects of National Significance. The DD Act ensures that individuals with

developmental disabilities and their families participate in the design of and have access to culturally competent services, supports and other assistance and opportunities that promote independence, productivity, integration and inclusion in the community.

**NASHIA recommends:**

- Reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act
- Protection and expansion of the authority of Protection and Advocacy Systems to investigate abuse, neglect, and deaths and to pursue class action litigation
- Reauthorization of the Title III Program for Direct Support Workers to address the direct support workforce shortage and improve the recruitment, training, support, and retention of a qualified direct service professional workforce in each State
- Reauthorization and funding for the Title II Family Support program and formula grant funding to every State and Territory with a separate authorization and appropriation line item
- Retaining federal funding for self-advocacy leadership activities directed by self-advocates with appropriate organizational and infrastructure supports

**12. Aging and TBI**

As individuals with TBI age, they may need long-term community services and supports, especially if their caregivers are no longer able to care for them. In addition, falls are the leading cause of unintentional death among people 65 and older. These individuals are often undiagnosed as their symptoms may be attributed to other causes (i.e. dementia, poor nutrition). The US Administration on Aging (AoA), established by the Older Americans Act (OAA) in 1973, as amended in 2006, funds transportation, referrals to home care, health, legal aid and other social services for older Americans. The reauthorized law promotes consumer-directed and community-based long term care.

AoA funds States to develop Aging and Disability Resources Centers (ADRCs) as a single point of entry. The previous Congress increased funding for these Centers. The 2006 reauthorization of the Older Americans Act amended the National Family Caregiver Support Program (NFCP) to include individuals with disabilities of any age within the definition of "child." The law also includes caregivers of individuals with Alzheimer's or related disorders "family caregiver" and decreases the specified age for relative caregivers.

**NASHIA recommends:**

- Funding for National Family Caregiver Support Program to accommodate needs of aging caregivers of adults with lifelong TBI-related disabilities
- AoA funded caregiver training on TBI screening, identification and symptoms among the elderly
- Policies that promote coordination between HRSA Federal TBI Federal Program and AoA to improve training and information among community and long-term care providers about TBI

**13. Prevention**

TBI is a serious public health problem, contributing to a substantial number of deaths and permanent disability. Falls and motor vehicle related injuries are the primary causes with assaults/weapons, occupational, war-related and sporting injuries also contributing causes. There are several federal

agencies involved in some aspect of prevention including the National Highway and Traffic Administration (NHTSA), CDC, AoA (falls prevention in collaboration with CDC), and the HRSA MCHB child health prevention program. These federal agencies provide information, data and funding to programs to assist the public in changing behavior, sometimes through legislative remedies, or through improvement of environmental designs (i.e. road conditions) or products designed to prevent injuries (i.e. helmets).

**NASHIA recommends:**

- Funding for NHTSA programs and incentives to States to encourage (a) mandatory laws requiring motorcycle helmet usage for all riders, (b) primary safety belt laws, (c) open container laws and (d) strong DUI or DWI laws; and incentives for State legislation to ban cell phone texting while driving

- Legislation to improve management of sports-related concussions; improved helmets used in sports; and to educate the public regarding sports-related injuries

- Reauthorization of SAFETEA-LU and funding for National Highway and Traffic Safety Administration (NHTSA) programs and incentives to States to expand traffic safety programs

- Increased funding to CDC/AoA for fall related injuries among the elderly

**14. Community Living Assistance Services and Supports**

Individuals with brain injury may need an array of services and supports to successfully reintegrate and to live in their homes and communities. These services may range from personal assistance; transportation; counseling; housing assistance; service coordination/case management; assistive technology to assist with activities of daily living; and respite care services to provide temporary relief for family or other primary caregiver. States use a variety of funding streams to pay for these services, including Medicaid State Plan services and Home and Community-Based Waiver Services.

The Patient Protection and Affordable Care Act (Public Law 111-148), signed into law in 2010, included several provisions to help individuals with disabilities needing long-term care supports and services by expanding a number of programs and policies to assist States in financing these options. These include the new optional Medicaid State Plan service called the Community Choice First Act to offer community-based attendant services and supports to those beneficiaries meeting the State's criteria for nursing facility eligibility; revised and improved policies for providing HCBS services as State option plan service; extending the Money Follows the Person (MCP) demonstration grants through September 2016; and new incentives for shifting beneficiaries out of nursing homes and into home and community-based services.

ACA allows for grants to encourage a career path for the existing direct care workforce and calls for the establishment of improved training for the next generation of direct care workers. Funding was also included to help people navigate their long-term care through Aging and Disability Resource Centers. The new law established Community Living Assistance Services and Supports (CLASS), a voluntary public insurance program financed by enrollees.

As the result of the new law, HHS created a CLASS Office within the Administration on Aging to assist with the CLASS provisions. HHS also established the Federal Coordinated Health Care Office, charged with improving care for persons dually eligible for Medicare and Medicaid services.

**NASHIA Recommends:**

- Continued funding to assist States in rebalancing systems to provide community services and supports; including funding for Money Follows the Person Demonstration Grants
- AoA training on brain injury and collaboration with Aging and Disability Resource Centers and State brain injury programs
- Implementation of the Community Living Assistance Services and Supports (CLASS) long-term insurance plan
- An increased federal match (FMAP) for home and community-based services (HCBS)
- Incentives for States to provide community attendant services and supports
- A policy to support decoupling the eligibility for the home and community-based waiver from eligibility for institutional services
- Training for workers who provide direct supports to people with disabilities to be well trained in brain injury
- Funding for and proper implementation of the Frank Melville Supportive Housing Investment Act of 2010
- Continued coordination of policies and funding between Department of Housing and Urban Development (HUD) and HHS to support housing for individuals with disabilities, including brain injury
- Support for families or other caregivers
- Funding the Assistive Technology (AT) Act, and training on AT for brain injury

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