Statement of

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Chairman Pitts, Ranking Member Pallone, and Members of the Subcommittee, thank you for the opportunity to testify today on the Department of Health and Human Services Traumatic Brain Injury (TBI) programs. I am Dr. Bonnie Strickland, Director of the Division of Services for Children with Special Health Care Needs in the Maternal and Child Health Bureau at the Health Resources and Services Administration (HRSA), Department of Health and Human Services. HRSA and our colleagues carrying out TBI activities throughout HHS appreciate your interest in this work. HRSA welcomes this opportunity to discuss our Traumatic Brain Injury (TBI) Program with you and to highlight other related HHS activities.

HRSA Overview

HRSA helps the most vulnerable Americans receive quality health care. HRSA works to expand access to health care for millions of Americans—the uninsured, the underserved and the medically and economically vulnerable.

HRSA recognizes that people need to have access to health care and, through its programs and activities, the Agency seeks to meet these needs. The Agency collaborates with government at the Federal, State, and local levels, and also with community-based organizations, to seek solutions to health care problems. In all of these efforts, we collaborate with colleagues across the Federal government and with State and local governments, community-based organizations, health care providers and institutions, and a range of other partners.

HRSA's Vision, Mission and Goals

HRSA's vision for the nation is healthy communities and healthy people. Our mission is to improve health and achieve health equity through access to quality services and a skilled health workforce. We carry out our mission by working toward four major goals: improving access to quality care and services; strengthening the health workforce; building healthy communities; and improving health equity. We are pleased to have the opportunity to share with you today some of our activities to improve access to services and support for individuals with traumatic brain injury and their families.

TBI Background

Traumatic brain injury is an *alteration in brain function, or other evidence of brain pathology, caused by an external force*.[1] The external force could be an object striking the head, the head striking an object, or a force penetrating the skull. On average, at least 1.7 million American civilians sustain a TBI each year.[2] That means someone suffers a brain injury every 19 seconds in the U.S. At least 5.3 million individuals in the U.S. have sustained at least one TBI.[3] These numbers are likely an underestimate of the true prevalence of TBI as they are based on TBI that

[1]Menon, DK, Schwab, K, Wright, DW, & Maas, AI. (2010). Position statement: definition of Traumatic Brain Injury. *Archives of Physical Medicine and Rehabilitation, 91*(11). 1637-1640.
[2] Faul M, Xu L, Wald MM, Coronado VG. *Traumatic Brain Injury in the United States: Emergency Department Visits, Hospitalizations and Deaths 2002–2006.* Atlanta (GA): Centers for Disease Control and Prevention, National Center for Injury Prevention and Control; 2010.
[3] Thurman, DJ et al. *Traumatic Brain Injury in the United States: A Report to Congress.* Atlanta (GA): Centers for Disease Control and Prevention, National Center for Injury Prevention and Control (1999).

provokes hospital or emergency care. Individuals that experience subtle symptoms may not seek medical attention, may not receive a diagnosis of TBI, and would not be tracked by national surveillance measures that contribute to the aforementioned statistics. These national estimates also do not include individuals with TBI who may be treated in military hospitals.

Nearly half a million emergency room visits for TBI each year are for children age 14 and under.[4] Across affected population groups, adults 75 and older are most likely to be hospitalized and die as a result of TBI. TBI affects every age group across the lifespan, although certain age groups are at increased risk for TBI, including children (ages 0-4), youth (ages 15-19), and older adults (ages 65 or older).[5]

A TBI can occur in seconds, and in nearly any environment. Although certain activities and lifestyles – such as sports and other recreational activities, and professions that involve the potential for injury or violence – are often associated with TBI, anyone in any place can be at risk. According to the Centers for Disease Control and Prevention (CDC), some of most common causes of TBI include falls (35.2%), motor vehicle crashes (17.3%), striking an object/being struck by an object (16.5%), and assaults (10%).[6]

The symptoms that result after a TBI vary by individual, but may include memory loss, difficulty concentrating, confusion, irritability, personality changes, fatigue and headaches. TBI is often referred to as a "silent epidemic" because it does not always result in a change in physical appearance, and may not be recognized.

It is estimated that up to 90,000 of individuals that sustain a TBI each year will experience long-term, possibly life-long, impairments due to their injury. In the United States, at least 3.2 million Americans have a long-term or life-long need for help to perform activities of daily living as a result of TBI.[7] TBI contributes to nearly one-third of all injury deaths each year in the United States.

The direct costs (*e.g.*, medical expenses) and indirect costs (*e.g.*, lost wages) of TBI in the United States have been estimated at $76.5 billion or more, according to the Center for Disease Control and Prevention.[8] In addition to lost wages of the injured person and their caregiver(s), individuals with TBI may need a variety of services and supports, including: cognitive, physical, and/or occupation rehabilitation; speech and language therapy; educational supports and accommodations; employment supports and accommodations, including vocational counseling, skills assessment, job re-training and on-site coaching; independent living skills training; and training to utilize different modes of transportation.

Individuals with TBI and their families often encounter barriers to accessing services. There are multiple reasons for this, such as failure to obtain a correct diagnosis (or any diagnosis at all),

[4] *Ibid., n.2.*
[5] *Ibid.*
[6] *Ibid.*
[7] Selassie AW, Zaloshnja E, Langlois JA, Miller T, Jones P, Steiner C, "Incidence of Long-Term Disability Following Traumatic Brain Injury Hospitalization in the United States, 2003," *Journal of Head Trauma Rehabilitation* 23:2 (2008): 123-131.
[8] Coronado, McGuire, Faul, Sugerman, Pearson. The Epidemiology and Prevention of TBI (in press) 2012.

lack of insurance or inadequate insurance to access critical services, a shortage of trained providers proximal to the family, chronic unemployment, and challenges with navigating the complex service and support infrastructure.

Legislative Authority

In July 1996, Congress enacted Public Law (P.L.) 104-166 "to provide for the conduct of expanded studies and the establishment of innovative programs with respect to [TBI]." The law was amended by the Traumatic Brain Injury Act of 2008, P.L. 110-206. Under this law, as amended, HRSA was charged with implementing a grants program to States and American Indian Consortia (formerly called the TBI State Demonstration Grant Program) to improve access to rehabilitation and other services. The National Institutes of Health (NIH) was delegated responsibility in the area of research and the CDC in the area of prevention and surveillance. While not specifically identified by Public Law 104-166, The Substance Abuse and Mental Health Services Administration (SAMHSA) also carries out TBI activities through the authorities provided under the Public Health Service Act.

HRSA's TBI Program

HRSA's Traumatic Brain Injury Program was established to ensure that individuals with TBI and their families have access to appropriate, adequate care to support recovery, maximize independence, and promote reintegration. The HRSA TBI Program was most recently reauthorized as part of the Traumatic Brain Injury Act of 2008 to increase access to rehabilitation and other services. The Traumatic Brain Injury Grant Program funds the development and implementation of statewide systems that ensure access to comprehensive and coordinated TBI services including transitional services, rehabilitation, education and employment, and long-term community support. HRSA's TBI Program consists of two distinct grant programs: State Implementation Partnership Grants, and Protection and Advocacy Grants for Individuals with Traumatic Brain Injury. Forty-eight States, two Territories and the District of Columbia have been funded since FY 1997 under the TBI State Grant Program. In FY 2012, $9.76 million was appropriated for the Traumatic Brain Injury Grant program. This figure has been relatively consistent since the original authorization.

State Implementation Partnership Grants

Since the program's inception in 1996, it has been a requirement that each State Implementation Partnership Grant TBI grantee either has or develops four core components: a statewide advisory board, a lead state agency for TBI, a statewide needs and resources assessment, and a comprehensive statewide action plan. In addition to these four core components, grantees are encouraged to develop partnerships for sustainability, focus on selected high risk populations, and implement activities that foster access to services.

The program has evolved from being a demonstration program to a full implementation program with the grants developing from planning grants to full implementation partnership grants. The current authorization for the program is more specific in terms of both sustainable systems change in states and in how grant funds ought to be used to accomplish this over-arching goal.

For 2009, the guidance for new awards was changed to reflect an increased emphasis on those special populations with high rates of TBI that have not necessarily received adequate attention in the past, including veterans who have not accessed the VA for care, children and youth, incarcerated juveniles, those with substance abuse problems, as well as Native Americans and African Americans. The amount of each award is $250,000 per State for each of the four fiscal years (FYs) 2009-2012. Seventeen new awards were made in FY 2009. There were three new awards made in 2010 and one additional award in 2011.

States have made remarkable progress in developing and linking accessible TBI services and supports, as well as educating consumers, families and professionals about the needs of individuals with TBI. Activities include screening for TBI in criminal/juvenile justice facilities, homeless shelters, and schools, training health professionals in various disciplines to identify and effectively serve individuals with TBI, providing case management services to coordinate care across treatment areas, and assisting families who are transitioning from one system to another (*e.g.*, military discharge to community re-entry, hospital acute care to school re-entry). Grantees share best practices for increasing access to services through the TBI listserve, which currently has 1,489 subscribers, as well as the online TBI Collaboration Space, which has 1693 registered users and houses nearly 1,600 products, including training curricula, screening tools, and best practice models, many of which have been developed by the grantees and their partners.

State Protection and Advocacy Systems Grants

The TBI Protection and Advocacy (P&A) grantees provide legal advice, self-advocacy training, and legal representation on a variety of issues that affect individuals with TBI, including housing, employment, education, health care, and benefits. The advice and representation provided by these grantees may be the only reason an individual is able to remain employed, receive adequate educational accommodations, protect their assets from would-be financial predators, remain in their home, and access needed health and rehabilitative services.

Individuals with TBI often need a spokesperson or advocate to articulate their service needs and to navigate complicated state systems of care. Symptoms that result from TBI are often complex and frequently develop or change over time; therefore, a coordinated State system of services and supports needs to be flexible, creative, and cost effective in the approaches to service delivery. The work of the TBI P&A grants has been instrumental in assisting individuals and families develop self-advocacy skills that will be utilized throughout the individual's life.

P&A programs provide specialized, legally-based services to help recipients understand laws to facilitate self-advocacy. Training in self advocacy has led to survivors and families advocating and gaining access to community support services, educational supports, affordable housing, customized integrated employment, and appropriate assistive technology. Training in self-advocacy ensures that individuals with TBI and their families can pursue the services they need even if outside representation is unavailable. In FY2011 the TBI P&A grants provided information and referrals to 1,685 individuals, conducted 1,025 training sessions with 59,000 individuals, and provided 847 case representations. The HRSA P&A grantees also provide litigation services.

In addition to the previous examples of work accomplished by the HRSA TBI program grantees, in April 2008, HRSA's TBI program conducted the first ever Service Members with TBI Summit. The focus of the summit was on service members returning from the wars and how HRSA's grantees can serve them. Several service members talked about the troubles they and their families faced since returning home and how several community programs, some of which were funded by HRSA, have helped. Twelve of HRSA's 21 current TBI grantees are working with veterans and active duty service members.

Traumatic Brain Injury Work by Other HHS Agencies

There are several agencies across the Department of Health and Human Services and elsewhere in the Federal government that work on traumatic brain injury issues. The agencies' activities complement each other. Each agency brings its own specialized expertise to the table.

NIH

NIH supports extensive research on TBI, from laboratory studies through phase III clinical trials of emergency treatments, and the development of rehabilitation interventions. The breadth of NIH TBI research reflects the complexity of the problems that TBI presents, both immediately and in the aftermath of the initial injury. The National Institute of Neurological Disorders and Stroke (NINDS) leads NIH TBI research and supports studies of the mechanisms of damage, development of diagnostics and therapies, and clinical trials, as well as research on brain plasticity and recovery. The National Center for Medical Rehabilitation Research (NCMRR), within the Eunice Kennedy Shriver National Institute of Child Health & Human Development (NICHD), leads research, development, and testing of TBI rehabilitation. Other components of the NIH also support relevant research as appropriate to their missions. For example, the National Institute of Aging (NIA) supports research on falls in the elderly and the National Institute of Mental Health (NIMH) supports research on disorders that often co-occur with TBI such as Post Traumatic Stress Disorder. Regarding rehabilitation research, NIH's TBI Clinical Trials Network established protocols for clinical management of TBI that have been widely adopted. Over the last decade, a NCMRR-funded center for cognitive rehabilitation established benchmarks for neuropsychological assessment of progress and outcomes in TBI, especially measuring attention and executive function.

CDC

CDC's National Center for Injury Prevention and Control serves as part of a unified Federal response to TBI by conducting population level TBI surveillance and engaging in educational efforts to prevent, recognize, and respond to TBI. In addition, CDC works with a variety of Federal and non-Federal agencies to reduce the burden of TBI among the U.S. population. For example, CDC improves and enhances nationwide TBI surveillance; develops and disseminates evidenced-based TBI educational materials; disseminates and implements evidence-based TBI clinical guidelines; informs evidence-based policies through activities such as the *Heads Up* initiative, which is cited in some States' legislation as a resource for training that is required among sports coaches; educates health departments and community-based organizations on shaken baby syndrome; and has collaborated with experts from around the country to develop

and publish the *Field Triage Guidelines for the Injured Patient*, which advises on uniform standards for emergency medical service (EMS) providers and first responders to ensure that patients with TBI are taken to hospitals that are best suited to address their particular injuries.

SAMHSA

SAMHSA maintains strong partnerships with the Department of Veterans Affairs and the Department of Defense to prepare community behavioral health care systems to provide trauma-informed services that reflect an understanding of military culture, service members' experiences, the range of post-trauma effects, and the effects of traumatic brain and other physical injuries. This is primarily accomplished through SAMHSA's Service Members, Veterans, and their Families Policy Academies, through which SAMHSA has provided—and continues to provide—intensive technical assistance to 23 States, two Territories, and the District of Columbia to help them enhance their behavioral health systems. SAMHSA will host an additional three Policy Academies so that all States and Territories can benefit from the opportunity.

Additionally, SAMHSA's National Child Traumatic Stress Network (NCTSN) has developed training materials for behavioral health providers who encounter veterans or service members with traumatic brain injury. These materials were developed in collaboration with the Department of Veterans Affairs, VA Palo Alto Health Care Polytrauma Program. This two-hour comprehensive training is available through the NCTSN's Learning Center Military Families Program. SAMHSA also provides grants to support local and statewide expansion of jail diversion programs for people with post-traumatic stress and other trauma-related disorders, with a priority to provide needed services to veterans returning from Iraq and Afghanistan. Beyond the mental health related programs referenced above, SAMHSA implements activities related to TBI through its Center for Substance Abuse Treatment.

Federal Collaboration and Coordination

HRSA established and convened the first meeting of the Federal Interagency Committee in 2011. This collaborative of Federal agencies that have programs with relevance to TBI have assembled to create and contribute to a centralized online clearinghouse of Federal resources pertaining to traumatic brain injury; share information regarding upcoming agency activities or events related to traumatic brain injury; review program strategic plans, materials and funding opportunities to facilitate collaboration, maximize activities, minimize duplication of efforts and fill service gaps; and develop and disseminate media to build awareness and promote greater visibility of associated Federal programs.

The current representatives on the committee are the Department of Defense (DoD), National Institute on Disability and Rehabilitation Research (NIDRR) of the Department of Education, and the Department of Veterans Affairs (VA), the Social Security Administration and, within HHS, the Agency for Healthcare Research and Quality, CDC, HRSA, the Indian Health Service, NIH, and SAMHSA.

Membership of the Committee continues to increase as several agencies without dedicated TBI programs have expressed interest in partnering and staying abreast of the Committee's activities. Each agency is also partnering with stakeholders to ensure they are receiving input from the populations they are serving. The agencies are complementary in their approach to meeting the needs of individuals with TBI and their families. HRSA, CDC, and NIH are working together to address potential cases. For example, CDC surveillance may identify an abnormally high incidence of TBI in child athletes aged seven to ten in a particular State. HRSA's State grantee could implement an educational campaign for students, parents, and school staff about the risks and consequences of TBI using educational materials developed by CDC. HRSA's State grantee could also implement a screening protocol in regional schools with return-to-play guidance that has been informed by the research NIH has conducted. Using this strategy, the HRSA State grantees leverage resources of the other agencies to identify children at risk or already affected by TBI and subsequently provide information and referrals, service coordination, advocacy training to support reintegration to the classroom, and other needed services. Additional opportunities for collaboration and leveraging of resources among agencies will be identified during future Committee meetings.

The Committee will have its second in-person meeting in March 2012 to preview its first collaborative product: the newly developed Federal Clearinghouse for Traumatic Brain Injury. This public website will house resources with relevance to TBI that have been developed by Federal agencies. All materials will be free to download and distribute, ensuring that they are available for public and professional education and outreach.

Visitors to the site will not only have access to current and diverse materials relevant to TBI, but will also be connected to the complementary TBI activities within the agencies represented, thereby promoting greater visibility and awareness of the unique role each Federal agency has in relation to TBI.

To support a seamless and effective system of care for individuals with TBI, the HRSA TBI Program has forged partnerships with other Federal agencies whose programs have relevance to TBI. For example, HRSA shares CDC resources with HRSA grantees for their use in educating families, health care providers, teachers, and athletic coaches about TBI. In addition, HRSA participates in monthly meetings with other Federal agencies, including the Administration on Developmental Disabilities at the Administration for Children and Families and SAMHSA, to coordinate data collection.

NIH collaborates extensively with DoD, VA, CDC, NIDRR of the Department of Education, and other agencies on TBI research and related issues. In 2011, NIH announced a partnership with the DoD in building a central Federal Interagency Traumatic Brain Injury Research (FITBIR) database on TBI studies. This database will allow comparison across a broad range of TBI studies and aid in the development of better TBI classification systems (which is essential for clinical trials), better diagnostic criteria for mild TBI, predictive markers for dementia and other delayed problems, and improved evidence based guidelines for care, from injury through rehabilitation. The NINDS Common Data Elements (CDE) project developed data standards for TBI that will be incorporated in the database, working with NIH, DoD, VA, NIDRR of the

Department of Education, and other agencies, as well as the TBI research and medical community.

The Center for Neurosciences and Regenerative Medicine (CNRM) is another major collaborative program across the Federal Government involving NIH, the Uniformed Services University, and the new Walter Reed National Military Medical Center. CNRM is a joint effort to bring together the expertise of clinicians and scientists across disciplines to catalyze innovative approaches to TBI research. CNRM researchers carry out a wide range of studies, including diagnostics and biomarkers, neuroprotection and models, regeneration and neuroplasticity, and rehabilitation, including many active clinical investigations at the NIH Clinical Center and Walter Reed.

FITBIR reflects coordination and collaboration among NIH, VA, CDC, DoD, NIDRR of the Department of Education, and other Federal agencies on several levels. NIH scientific staff, for example, participate on grant and programmatic review panels and advisory boards for the DoD and VA on research for TBI and spinal cord injury, and DoD and VA representatives serve as *ex officio* members on the NINDS Advisory Council. NIH and other agencies have also collaborated on specific research projects. Joint scientific workshops also frequently bring Federal agencies and the scientific community together to attack issues that are critical for TBI research.

HRSA is committed to ensuring that individuals with TBI and their families have accessible, available, acceptable, and appropriate services and supports. NIH, CDC and SAMHSA are making strides in the respective areas of TBI research, prevention and surveillance, and behavioral health. We are working together to ensure that our efforts are complementary and provide an opportunity for cross departmental collaboration and leveraging of resources strategically to address the full spectrum of needs of individuals and families impacted by traumatic brain injury.

Mr. Chairman, thank you for the opportunity to testify today and provide an overview of our TBI programs.