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A REVIEW OF EFFORTS TO PREVENT AND TREAT TRAUMATIC BRAIN INJURY

HEARING

BEFORE THE

SUBCOMMITTEE ON HEALTH

OF THE

COMMITTEE ON ENERGY AND COMMERCE
HOUSE OF REPRESENTATIVES

ONE HUNDRED TWELFTH CONGRESS

SECOND SESSION

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A REVIEW OF EFFORTS TO PREVENT AND TREAT TRAUMATIC BRAIN INJURY

MONDAY, MARCH 19, 2012

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON HEALTH,
COMMITTEE ON ENERGY AND COMMERCE,
Washington, DC.

The subcommittee met, pursuant to call, at 3 p.m., in room 2123, Rayburn House Office Building, Hon. Joe Pitts (chairman of the subcommittee) presiding.

Members present: Representatives Pitts, Burgess, Shimkus, Blackburn, Guthrie, Upton (ex officio), and Pallone.

Staff present: Brenda Destro, Professional Staff Member, Health; Debbee Keller, Press Secretary; Peter Kielty, Associate Counsel; Ryan Long, Chief Counsel, Health; Carly McWilliams, Legislative Clerk; Katie Novaria, Legislative Clerk; John O'Shea, Senior Health Policy Advisor; Monica Popp, Professional Staff Member, Health; Alli Corr, Democratic Policy Analyst; Elizabeth Letter, Democratic Assistant Press Secretary; Karen Nelson, Democratic Deputy Committee Staff Director for Health; and Anne Morris Reid, Democratic Professional Staff Member.

Mr. PITTS. The subcommittee will come to order. The chair recognizes himself for 5 minutes for an opening statement.

OPENING STATEMENT OF HON. JOSEPH R. PITTS, A REPRESENTATIVE IN CONGRESS FROM THE COMMONWEALTH OF PENNSYLVANIA

As many of you know, March is Brain Injury Awareness Month. According to the CDC, an estimated 1.7 million people sustain a traumatic brain injury each year. And of that figure, 1.365 million, or 80 percent, are treated and released from the emergency room; 275,000 are hospitalized; and 52,000 will die. TBI affects everyone. It is not restricted to one race, gender, or socioeconomic group.

While children age 4 and under and adults over the age of 75 are particularly at risk, brain injury affects soldiers, athletes, and even Members of Congress, like our former colleague Gabby Giffords.

The annual cost of TBI is estimated at $48 billion, but dollars alone do not paint a complete picture of the scope of these injuries. It does not take into account the suffering of a person with a brain injury who may be disabled for life, or the strain of loved ones that TBI places on family members who are so often the caregivers.

Federal efforts to address TBI began with the Traumatic Brain Injury Act of 1996. The act aimed to identify and increase awareness of TBI through new research and programs. The TBI Amend-

ments of 2001 amended the 1996 law by extending the authorization to include the implementation of a national trauma brain injury education and awareness campaign.

The Traumatic Brain Injury Act of 2008 reauthorized the program. It also authorized CDC and NIH to conduct a study to examine the information gathered by HHS, assess appropriate interventions, and develop practiced guidelines. I look forward to the results of the study which will come out in November of this year.

The 2008 act also focused on the incidence and prevalence of TBI, uniform reporting, and linking individuals with TBI to support services and academic institution to conduct research.

I would like to hear an assessment from each of our witnesses of these Federal programs. What have we learned about the causes, the diagnosis, the treatment of TBI through HHS' efforts? How is that knowledge being applied in real-world situations? And I would also like to hear their ideas about where we should go from here.

I would like to say a special hello to Dr. Flaura Winston from the Children's Hospital of Philadelphia. CHOP is a wonderful institution that has served many of my constituents. And I would also like to welcome those with us today who have TBI, as well as their families and caregivers who make enormous sacrifices every day, and we are glad that you are all here.

I yield the balance of my time to the vice chairman, Dr. Burgess.

[The prepared statement of Mr. Pitts follows:]

Opening Statement of the Honorable Joseph R. Pitts
Subcommittee on Health
Hearing on "A Review of Efforts to Prevent and Treat Traumatic Brain Injury"
March 19, 2012
(As prepared for delivery)

As many of you know, March is "Brain Injury Awareness Month."

According to the CDC, an estimated 1.7 million people sustain a traumatic brain injury each year, and of that figure, 1.365 million, or 80 percent, are treated and released from the emergency room, 275,000 are hospitalized, and 52,000 will die.

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It is not restricted to one race, gender, or socio-economic group. While children aged four and under and adults over the age of 75 are particularly at risk, brain injury affects soldiers, athletes, and even members of Congress, like our former colleague Gabby Giffords.

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OPENING STATEMENT OF HON. MICHAEL C. BURGESS, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF TEXAS

Mr. BURGESS. I thank the chairman for the recognition. Today's hearing is of vital importance, as the Center for Disease Control estimates that over 1 ½ million people sustain a traumatic brain injury annually and over 52,000 of them do not survive. Of those that do survive, 11,000 are children. This makes pediatric-acquired brain injury the number one cause of death and disability for children. There exists no viable reparative therapeutic option for patients, and all of the interventions are designed to prevent progression of the injury or secondary injury.

In order to successfully treat traumatic brain injuries, we must equip healthcare professionals and researchers with the resources needed to achieve the goal of improving outcomes and quality of life for those affected. Although there are numerous research projects underway across the country, including the University of Texas and North Texas Brain Injury Model System, a TBI center, a centralized and coordinated research approach that avoids duplication is lacking. And a Government Accountability Office report released this January entitled "Coordinating Authority Needed for Psychological Health and Traumatic Brain Injury Activities," it emphasized the need for coordination of care and coordination of services in traumatic brain injury in patients in the Department of Defense. They noted that conducting their research, there was no central location to obtain accurate and timely information on traumatic brain injury and they had to use a variety of resources in order to obtain their data.

I believe we will not achieve our goals to better coordinate research and support services if we don't get a grasp, and this hearing is designed to do that on funding in projects that are meant to address traumatic brain injury.

H.R. 2600 would lead State centers, like the Center for Brain Health at the University of Texas at Dallas, the country's lead virtual center category for pediatric-acquired brain injury, to continue benefiting individuals with evidence-based systems of care. Additionally, the money will be allocated from the available discretionary funds and will be on hand to advance our knowledge of the brain over the next several years.

Thank you, Mr. Chairman, for the recognition. I will yield back my time.

Mr. PITTS. The chair thanks the gentleman and now recognizes the ranking member of the subcommittee, Mr. Pallone, for 5 minutes for an opening statement.

OPENING STATEMENT OF HON. FRANK PALLONE, JR., A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW JERSEY

Mr. PALLONE. Thank you, Mr. Chairman. Today this committee will have the opportunity to hear from some of the leading experts in the traumatic brain injury community about an update on the current landscape of traumatic brain injury prevention, research, and treatment.

As we all know, traumatic brain injuries are a very serious spectrum of disease that can have devastating outcomes. When I was

chairman of the subcommittee, we held a field hearing regarding pediatric sports-related concussions in New Jersey, and today I look forward to an informative hearing that takes a broader perspective on this critical issue.

According to the CDC over 1.7 million people are subjected to a traumatic brain injury each year. Furthermore, traumatic brain injuries account for one-third of all injury-related deaths. These statistics only tell part of the story, as currently it is unclear how many people are misdiagnosed or don't receive treatment after a traumatic brain injury.

Traumatic brain injury also affects many sectors of our population. These injuries continue to plague primarily our young people and the elderly, some of the most vulnerable members of our society. Traumatic brain injuries also have a profound impact on our military and the sports community. In addition, I would be remiss, as my chairman said, if I didn't mention how a member of our own body, Gabby Giffords, was also a victim of traumatic brain injury while performing her congressional duties.

Consequently, we must prioritize this issue in our prevention and research efforts. It is my understanding that the overwhelming majority of people that suffer a traumatic brain injury do not die from their injury. However, that also means that these patients are at risk of developing the long-term implications that can develop from an even mild traumatic brain injury. Patients can suffer from cognitive impairments like memory loss, impaired communication skills, mental illness, epilepsy and are even at risk of developing Parkinson's Disease or Alzheimer's Disease. These complications can create devastating disability and hinder an individual's productivity. They also create a tremendous emotional and financial burden to families and society as a whole. Ensuring that these patients have access to innovative and vital treatments and social services is a great challenge that we must all work together to achieve.

Since the passage of the Traumatic Brain Injury Act of 1996 and subsequent reauthorization, several Federal agencies have led efforts to understand, prevent, and treat traumatic brain injury. Most recently, these efforts have undergone formal coordination through the Federal Interagency Committee on Traumatic Brain Injury. This committee, which includes HHS agencies and nonHHS agencies, will hopefully accelerate and coordinate developments in traumatic brain injury initiatives, and I look forward to hearing more about their proposed plans and activities.

I would also like to highlight the importance of Federal partnerships with the States in addressing this important cause. I greatly appreciate the presence of Mr. William Ditto, who hails from the great State of New Jersey. Mr. Ditto is the recently retired director of the New Jersey Traumatic Brain Injury Program and also represents the National Association of State Head Injury Administrators. Mr. Ditto along with his colleagues have made great strides in leveraging their limited Federal and State funds to coordinate and provide services for individuals with traumatic brain injury. Strengthening partnerships like these will improve the outcomes of the families and patients affected by traumatic brain injury.

So I look forward to today's testimony. And Mr. Chairman, I would like to ask—as I think you know, Congressman Bill Pascrell, my colleague from New Jersey, has really been a leader on this whole issue. And I know he is not a member of the committee, but he asked if I could by unanimous consent—I will ask unanimous consent to include his statement into the record.

Mr. PITTS. Without objection, so ordered.

[The prepared statement of Mr. Pascrell follows:]

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COMMITTEE ON WAYS AND MEANS
SUBCOMMITTEE ON HEALTH

COMMITTEE ON THE BUDGET

Congress of the United States
House of Representatives

Statement for the Record
Congressman Bill Pascrell
U.S. House of Representatives Energy and Commerce Subcommittee on Health Hearing: "A Review of Efforts to Prevent and Treat Traumatic Brain Injury"
March 19, 2012

Chairman Pitts and Ranking Member Pallone, thank you for holding this hearing on the vitally important issue of traumatic brain injury.

As the Co-Chair and founder of the Congressional Brain Injury Task Force, I have long advocated on behalf of both the civilian and military populations who struggle with the problem of brain injury. Since its founding in 2001, the Task Force's mission has been to expand the understanding and public awareness of brain injury. According to the Centers for Disease Control and Prevention (CDC), each year an estimated 1.7 million people sustain a traumatic brain injury (TBI). Unfortunately, TBI is a contributing factor to a third (30.5%) of all injury-related deaths in the United States. Beyond these numbers, TBI has become the "signature wound" of the wars in Iraq and Afghanistan, with 20% soldiers deployed are estimated to have experienced a brain injury. The brain injuries of our soldiers have spurred Congress to make unprecedented investments in brain injury research—research that will benefit soldiers and civilians alike for years to come.

As witnesses today this afternoon will attest, TBI does not discriminate; it truly impacts all sectors of the population. Recent media reports have highlighted its impact on athletes, our service members and even a Member of this chamber, with former Congresswoman Gabrielle Giffords suffering a TBI last year in the wake of a tragic shooting. Both the prevalence and complexity of these injuries call for more research.

The federal government must help address lagging public awareness of brain injury and its consequences and the relative lack of scientific knowledge we have about this ubiquitous injury. In Congress, we have been working tirelessly to correct both of these deficits. The Traumatic Brain Injury (TBI) Act, last reauthorized in 2008 and once again up for renewal this year, is the only federal law that specifically addresses the issues faced by the TBI community. The continuation of this program takes important steps forward in ensuring proper collaboration between civilian brain injury efforts and the work being done by the Department of Defense and the Veterans Administration. For example, the Traumatic Brain Injury Act established a CDC/NIH study, in collaboration with the DOD and VA, to identify the best methods of coordinating prevalence data, in order to ensure that national research takes into account the incidence of brain injuries among our nation's veterans and that current information about diagnosis and treatment are shared between the civilian and military scientific communities.

The TBI Act is an important tool providing for collaboration in the TBI research community, and care for those individuals who have suffered a TBI. The TBI Act currently authorizes:

- the Health Resources and Services Administration (HRSA) to assist States in developing and expanding service delivery capacity for individuals with traumatic brain injury and their families,
- HRSA to make grants for the Protection and Advocacy for Traumatic Brain Injury (PATBI) program, which provides critical advocacy services to ensure that people with TBIs live full and independent lives free from abuse and neglect,
- the Centers for Disease Control and Prevention (CDC) to conduct surveillance, prevention and public education programs, and,
- the National Institutes of Health (NIH) to conduct of basic and applied research in TBI.

I hope that as we continue to discuss the impact of TBI in the community, that the Congress will prioritize the reauthorization of this critically important legislation. In the last few years, we have learned more about the brain than we have over the last century. This knowledge should be applied to protect our fellow Americans. It is important to remember that these wounds may be invisible many times, but the consequences are very real.

Thank you.

Bill Pascrell, Jr.
Member of Congress

Mr. PALLONE. Thank you, Mr. Chairman. As I said, I look forward to the testimony, and I appreciate the fact that you held this hearing today. Thank you.

Mr. PITTS. The chair thanks the gentleman. And I now recognize the chairman of the full committee, Mr. Upton, for 5 minutes for an opening statement.

OPENING STATEMENT OF HON. FRED UPTON, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF MICHIGAN

Mr. UPTON. Well, thank you, Mr. Chairman. According to a recent report from the CDC, at least 1.7 million folks sustain a traumatic brain injury every year. We don't have to look very far to see the profound effects of a major TBI. Children injured by caretakers or car accidents, athletes impaired by multiple concussions, or soldiers disabled from war—and even one of our colleagues wounded at a constituent event in Arizona last year.

With efforts being undertaken at the Department of Veterans Affairs, the Department of Defense, and several agencies at the Department of HHS, it is incumbent upon us to examine these activities so that they can work in a coordinated and efficient manner. And I proudly serve on the Congressional Brain Injury Task Force and encourage bipartisan support for TBI research and rehabilitation. And with that support, I am confident that the committee will make even greater strides to help patients living with the aftermath of TBI.

So I want to extend a warm welcome to the families attending today's hearing as part of Brain Injury Awareness Month, and I look forward to your testimony. And I yield back to the chairman.

Mr. PITTS. The chair thanks the gentleman.

Today we have four witnesses on our panel: Dr. Bonnie Strickland, Director, Division of Services for Children With Special Health Care Needs, U.S. Department of Health and Human Services; Mr. William Ditto, retired Director of the Division of Disability Services, New Jersey Department of Human Services; Dr. Flaura Winston, Children's Hospital of Philadelphia; and Dr. Mark Ashley, President, Centre for Neuro Skills.

Your written testimony will be made part of the record. We ask that you summarize your opening statements in 5 minutes.

STATEMENTS OF BONNIE STRICKLAND, DIRECTOR, DIVISION OF SERVICES FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS, HEALTH RESOURCES AND SERVICES ADMINISTRATION, DEPARTMENT OF HEALTH AND HUMAN SERVICES; WILLIAM A.B. DITTO, DIRECTOR (RETIRED), DIVISION OF DISABILITY SERVICES, NEW JERSEY DEPARTMENT OF HUMAN SERVICES, ON BEHALF OF THE NATIONAL ASSOCIATION OF STATE HEAD INJURY ADMINISTRATORS; FLAURA KOPLIN WINSTON, PROFESSOR OF PEDIATRICS, UNIVERSITY OF PENNSYLVANIA SCHOOL OF MEDICINE, SCIENTIFIC DIRECTOR, CENTER FOR INJURY RESEARCH AND PREVENTION, CHILDREN'S HOSPITAL OF PHILADELPHIA; AND MARK J. ASHLEY, PRESIDENT, CENTRE FOR NEURO SKILLS, ON BEHALF OF THE BRAIN INJURY ASSOCIATION OF AMERICA

Mr. PITTS. And Dr. Strickland, you are recognized at this time for 5 minutes to summarize and make your opening statement.

STATEMENT OF BONNIE STRICKLAND

Ms. STRICKLAND. 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 Programs. I am Dr. Bonnie Strickland, Director of the Division of Services for Children With Special Healthcare Needs in the Maternal and Child Health Bureau at the Health Resources and Services Administration, Department of Health and Human Services.

HRSA and our HHS colleagues appreciate your interest in our work, and HRSA welcomes this opportunity to discuss our TBI program with you and to provide some highlights of other HHS activities.

Congress has charged HRSA with implementing a grant program to Sates and American Indian consortia to improve access to rehabilitation and other services. The NIH has responsibility in the areas of research, and the CDC has responsibility for prevention and surveillance. SAMHSA also conducts activities through the authorities provided under the Public Health Service Act.

HRSA's TBI program consists of two distinct grant programs: State implementation partnership grants and protection and advocacy grants. State partnership grantees are required to have or develop a statewide needs and resource assessment and a comprehensive statewide action plan. With these tools, Sates have made remarkable progress in increasing access to TBI services and supports through a TBI screening program, training health professionals and service coordination. HRSA's protection and advocacy programs provide specialized legally based services to help recipients understand laws to facilitate self-advocacy. Training in self-advocacy ensures that individuals with TBI and their families can pursue needed services, even if outside representation is unavailable.

NIH has primary responsibility for TBI research. The breadth of NIH research reflects the complexity of the problems that TBI represents, both immediately and in the aftermath of the injury. For example, NIH supports studies of the mechanisms of damage, development of diagnostics and therapies, clinical trials and research

on brain plasticity and recovery. NIH also leads a broad range of research related to TBI rehabilitation, falls in the elderly, and disorders that often co-occur with TBI, such as posttraumatic stress disorder.

CDC is responsible for TBI prevention and surveillance. The agency disseminates and implements evidence-based TBI educational materials and clinical guidelines, informed evidence-based policies through activities such as the Heads Up Initiative, and educates health departments and community-based organizations on shaken baby syndrome.

CDC also worked with national experts to produce the field triage guidelines for the injured patient, which provides uniform standards for emergency medical service providers and first responders to ensure that patients with TBI are taken to hospitals best suited to address their particular injuries.

SAMHSA focuses primarily on behavioral health aspects of TBI. SAMHSA maintains strong partnerships with the VA and DOD to prepare community behavioral healthcare systems to provide services that reflect an understanding of military culture, servicemember's experiences, and the range of potential post-trauma effects. This is primarily accomplished through SAMHSA Servicemembers, Veterans, and their Families Policy Academics. Additionally, SAMHSA has developed training materials for behavioral health providers who encounter veterans or servicemembers with TBI.

In 2011 HRSA convened the first meeting of the Federal Interagency Committee on Traumatic Brain Injury in order to share information, facilitate collaboration, and minimize duplication across agencies.

To facilitate this purpose, the committee plans to create a centralized online clearinghouse of Federal resources. The current representatives on the committee are the Departments of Defense, Education, and Veterans Affairs, the Social Security Administration, and with NHHS, the Agency for Health Care, Research and Quality, the Indian Health Service, CDC, NIH, SAMHSA and HRSA.

Our agencies complement each other's work. For example, CDC surveillance may identify an abnormally high incidence of TBI in child athletes in a particular State and they may develop educational materials to address the issue. HRSA's State grantee might then use the CDC material to conduct a statewide education campaign for students, parents, and schools about the risks and consequences of TBI. Likewise, HRSA's grantee might utilize a screening protocol that was informed by NIH research in order to implement a student athlete TBI screening program. In addition to education and screening, HRSA would connect students and families with needed resources.

Strategies like these allow HRSA State grantees to leverage resources of other agencies to identify and serve children with or at risk of sustaining a TBI. Opportunities for such a collaboration is a key focus of the interagency committee. HRSA committed to ensuring that individuals with TBI and their families have accessible and appropriate services and supports.

NIH, CDC, and SAMHSA are making strides in the respective areas of research prevention and surveillance and behavioral health. We are working together to ensure that our efforts are complementary and to achieve cross-departmental coordination and strategic leveraging of resources to address the full spectrum of needs of individuals and families impacted by TBI.

Mr. Chairman, this completes my prepared remarks. Once again, thank you for the opportunity to testify today and provide an overview of our TBI program.

[The prepared statement of Ms. Strickland follows:]

Statement of

Bonnie Strickland, Ph.D.

Division Director,
Division of Services for Children With
Special Healthcare Needs
Maternal and Child Health Bureau

Health Resources and Services Administration
U.S. Department of Health and Human Services

Before the
Committee on Energy and Commerce,
Subcommittee on Health
U.S. House of Representatives
Washington, D.C.
March 19, 2012

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),

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[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.

Mr. PITTS. The chair thanks the gentlelady and recognizes Mr. Ditto for 5 minutes for your opening statement.

STATEMENT OF WILLIAM A.B. DITTO

Mr. DITTO. Thank you very much, Chairman Pitts and Ranking Member Pallone from New Jersey. Just to clear things up, I am the retired director of the Division of Disability Services in the New Jersey Department of Human Services, since I have been given a variety of interesting previous titles when I was introduced. But I am really here today not so much in that role, but more in my role as the Chair of the Public Policy Committee for the National Association of State Head Injury Administrators, better known as NASHIA.

We are the only nonprofit organization that represents State government agencies and services who are involved in the provision of short- and long-term rehabilitation and community services for individuals with TBI and their families. And I am pleased to give you an opportunity to understand where State government stands with regard to serving these individuals.

The big item here that I want to emphasize is that no two individuals with TBI are the same, and neither are any two States the same with regard to the extent that they are able to address these needs. The one thing that is the common thread throughout this country is that brain injury is, in fact, the leading cause of disability not only in the State of New Jersey, but all across the country.

And I think this has not been recognized and not been recognized well. And if you go out on the street and ask folks what is the most significant disability, you will get mental retardation, cerebral palsy, autism, all sorts of different things; but in truth, it is, in fact, head injury. And head injury is such a disability because it is cradle-to-grave. It affects people in all age categories. And as a result, individuals with this type of disability have to interface with a lot of different governmental programs over their time as a survivor of brain injury. And as someone on the panel has already—someone on the committee has already mentioned, individuals with brain injuries are, in fact, surviving and they are thriving to the extent that they can get services that they need.

In the early 1980s, families began advocating for States to provide rehabilitation in other services, and there are so many different needs for people with brain injuries. There really are no two individuals with brain injuries who are just the same. We also have the mild, moderate, and severe classification of brain injury, which makes it in my experience a little less clearcut. In many other forms of disability, we can quite clearly state what the extent of the disability is through clinical observation and medical evaluation. This is not true with brain injury. Not only that, but there was for a long time a feeling that people with brain injury could only achieve a certain plateau, a certain level, and nothing would happen after that.

Research has proven that individuals, even 10 years post brain injury, can make significant improvements when given the right services. About 20 States administer Medicaid home- and community-based services programs for individuals with disabilities that

are intended to provide for service in lieu of a more extensive institutional or long-term care. What our big concern at this point is that the systems need to be coordinated, and they need to be available to people of all ages. We have found from the CDC, who has moved brain injury up to the top of its list of concerns—and it was not always at the top of this list—we have found from them that the leading cause right now is falls, falls in individuals over the age of 75. And I think we are all familiar with the baby boomers and where we are headed with that. I myself am one of them. And then in addition to that, it is in children under 4.

So look at that age spectrum we have; there are people suffering from brain injuries throughout the progression of life. It is not just the typical younger adult male crash victim or the returning servicemember, it is really a large number of people. And individuals with brain injuries and their families are specifically looking to States for help and support.

We would propose in terms of the Federal HRSA–TBI grants program that the grants be shifted away from short-term projects to allow States to maintain and expand initiatives. We would ask that States are given additional flexibility to use funds for case management and other services, that States can target their grant requests on populations which they identify as underserved, and that the program move from a competitive grant program to a formula-funded approach, contingent upon the availability of Federal funds, to allow each State to receive a predictable amount of funding.

Right now the program is competitive in nature. I believe 21 States are receiving grants. The rest of the States are not receiving grants, and they are relying totally on their own resources to be able to do that. So just as States are required to coordinate and maximize State and Federal programs and resources, NASHIA supports the Federal Interagency Task Force that HRSA has created to promote Federal coordination of all resources.

We look forward to that time when the task force will invite stakeholders such as NASHIA, the Brain Injury Association of America, the National Disability Rights Network, as well as individual TBIs and their families to provide input as we develop a national plan and priority for TBI. Thank you.

Mr. PITTS. The chair thanks the gentleman.

[The prepared statement of Mr. Ditto follows:]

TESTIMONY SUBMITTED BY THE

National Association of State Head Injury Administrators

TO THE

HOUSE COMMITTEE ON ENERGY AND COMMERCE SUBCOMMITTEE ON HEALTH

March 19, 2012

Dear Chairman Joe Pitts and Ranking Member Frank Pallone:

Thank you for this opportunity to testify before the Committee regarding federal programs that serve individuals impacted by traumatic brain injury (TBI). My name is William A.B. Ditto, and I recently retired as the Director of the New Jersey Division of Disability Services. I currently serve as the Chairman of the Public Policy Committee for the National Association of State Head Injury Administrators (NASHIA), which is a non-profit organization representing State governmental officials, who administer an array of short-term and long-term rehabilitation and community services for individuals with TBI and their families.

I am pleased to be here today to talk about issues affecting State government in terms of serving individuals with TBI and their families, and how the Federal HRSA TBI Program assists States to be able to do so. As no two individuals with TBI are the same, no two States are the same with regard to the extent to which they are able to assist individuals and their families.

In the 1980's, families began advocating for States to provide rehabilitation and other assistance not otherwise covered by insurance or by existing State systems for individuals with disabilities. In order to expand services to individuals with TBI, States needed to determine which State agency or agencies should be responsible for providing or overseeing services; what type of services or assistance should be provided; how should the services be paid for; and to determine the eligibility criteria for those needing services.

Since individuals may be injured at any age, have differing needs due to severity of injury, have different resources available to them, and their needs change over time, States have generally taken multiple approaches to address these variables. Some

States expanded systems designed for individuals with developmental disabilities, mental health, special health care needs and vocational rehabilitation to also serve TBI; other States have created dedicated funding streams for TBI services; others have expanded Medicaid to cover those who are Medicaid eligible; and many States use a combination of these funds.

Most State programs identify a point of contact, which may be a case manager or service coordinator, who then will work with the individual to assess their needs and develop a plan for services and outcomes. The TBI program may be administered by the State public health, Vocational Rehabilitation, mental health, Medicaid, developmental disabilities, education or social services agencies. Most states have also created advisory councils or boards to promote interagency coordination and to obtain input from consumers and others with regard to developing a State plan.

Currently, almost half of all States have enacted laws to create State accounts dedicated to serving the needs of individuals with TBI. Usually these accounts, or trust funds, are financed through traffic violation fines, and are appropriated for such purposes as TBI prevention, public education, research, TBI registries, provider training and other related services.

About 20 States administer Medicaid Brain Injury Home and Community-Based (HCBS) Waiver programs offering an array of services for those who are Medicaid eligible. A Waiver program is designed to maintain a person in the home and community, in lieu of more expensive institutional or nursing home programs. Individuals with TBI may be also served in other State waiver programs designed for individuals with physical disabilities, developmental disabilities, seniors and other populations. These waiver programs vary greatly across the States both in terms of numbers served and the level of care the State defines for eligibility purposes.

Why have States developed services and supports for this population, especially with State budgets so austere? Without appropriate services and supports, individuals with TBI may become homeless, or inappropriately placed in more costly institutional settings. Some individuals are placed in expensive residential programs and some end up in correctional facilities due to their cognitive and behavioral impairments. A report issued by the Centers for Disease Control and Prevention (CDC) indicated that 25-87% of inmates report having experienced a TBI; this is a stark contrast compared to the 8.5% of the general population that has experienced a TBI. States are also obligated to provide care for this population as mandated by the Americans with Disabilities (ADA) Act which requires States to provide services in integrated community settings.

In more recent years, returning servicemembers and veterans with TBI have turned to the States for help in locating family supports and community services. Some States have used their Federal HRSA TBI State Grant and/or other State resources to address these issues, often in collaboration with the State Veterans agency, National Guard, and state and local veterans' organizations. Members of the National Guard and Reserve generally return to their own home after deployment, and are apt to look for resources within the community. These members may not be eligible for TRICARE insurance, once they are deactivated or leave duty. Some members also elect to maintain insurance provided by their employer.

While the number of Americans who sustain a TBI is increasing, especially among senior and veterans populations, States are experiencing significant budget cuts impacting rehabilitation and community services available for individuals with TBI. Some States do not have a funding stream specific to the needs of individuals with TBI. The HRSA Federal TBI Grant Program assists such States to develop and leverage State/federal resources to build identification and service delivery systems.

NASHIA strongly supports the reauthorization of the federal Traumatic Brain Injury (TBI) Act, and recommends that changes be made to give stability to State TBI efforts, and to ensure that all States may participate in the program. NASHIA recommends:

1) That grant awards be shifted away from a short-term project focus to allow States to maintain and expand activities initiated through the grant funds.

2) That States are given additional flexibility to use funds for case management and other services, allowing those States that have a solid infrastructure to provide critical services.

3) That States target their grant requests on populations that they identify as underserved or unserved, such as children, victims of domestic violence, veterans and returning servicemembers.

4) That the program move from a competitive grant program to a formula funded approach, contingent upon availability of federal funds, to allow each State to receive a predictable amount of funding for use to build upon existing programs. In a 2010 NASHIA survey of States that administered federal TBI grants, 9 States reported that once they no longer received federal grant funding, activities previously conducted diminished in scope, particularly with regard to planning, capacity to expand services, and training to providers, professionals and caretakers. The grant funding provided necessary resources to keep the State focused on systems change.

Finally, just as States are required to coordinate and maximize State and federal programs and resources, NASHIA supports the Federal Interagency Task Force that HRSA has created to promote federal coordination of resources. We look forward to when the Task Force will invite stakeholders, such as NASHIA, Brain Injury Association of America (BIAA), National Disability Rights Network (NDRN), as well as individuals with TBI and their families to provide input as they develop a national plan and priorities for TBI.

In closing, thank you for your support for addressing the issues affecting Americans with TBI. Please do not hesitate to contact us if we can be of further assistance.

Mr. PITTS. And recognizes Dr. Winston for 5 minutes for an opening statement.

STATEMENT FLAURA KOPLIN WINSTON

Ms. WINSTON. Good afternoon. Thank you Chairman Upton, Chairman Pitts, Vice Chair Burgess, Ranking Member Pallone, and distinguished members of the subcommittee for calling this hearing and inviting me to testify. I am encouraged to see the increased focus on child traumatic brain injury, or TBI, along with the emerging emphasis on prevention. My name is Dr. Flaura Koplin Winston. I serve as Scientific Director for the Center for Injury Research and Prevention at the Children's Hospital of Philadelphia, or CHOP, as well as Professor of Pediatrics at the University of Pennsylvania. In addition to being a doctorly trained bioengineer, I am a board-certified practicing pediatrician and a public health researcher.

The Children's Hospital of Philadelphia is the Nation's largest pediatric healthcare network and is home to one of the largest pediatric research programs in the U.S. I am humbled by the commitment and skill that the hospital brings to pediatric injury, much of which is enabled by investments from the Federal Government.

I came to care about TBI early in my training. When I would hear the trauma transport helicopter, I felt a sense of dread for the family whose life would be changed by their child's TBI. Every day more than 125 of our Nation's children are hospitalized or die from TBI. Car crashes, sports, falls, and child abuse are the likely causes, largely preventible events, at great cost to families and to society. Annually estimated, TBI costs are more than $29 billion for children who die and $53 billion for those who are hospitalized. Therefore as a Nation, I propose that our primary success metric should be annual reductions in pediatric traumatic brain injuries.

To reduce the TBI burden, I propose three priority areas: one, prevention; two, timely state-of-the-art acute care; and three, optimal recovery. I hope to demonstrate the importance of research and its translation, professional training and coordinated efforts. Together we can address child TBI so that our children and grandchildren can reach their full potential. The good news is that we know how to avoid TBI. Protect the brain from blows and jolts. Prevention is the best medicine. If you get your grandson into a car seat, or your daughter's sports league to adopt safe play, you can reduce the chance of TBI. Unfortunately, many safety strategies were designed for adults, not for children.

Let me demonstrate how we can do better. At CHOP we found that early air bags in cars designed to save adults could fatally injure a child. A research-supported effort by government and industry to improve air bag design, policies and education, and now child air bag deaths are rare. Dramatic success like these require strong science and collaboration. The National Science Foundation has provided us with opportunities to work with partners to protect our children's brains in a world designed for adults.

Research funded by NIH, CDC, HRSA and DOT taught us another important lesson. When it comes to TBI, child age affects the brain's response to impact and recovery. For example, we now know that infants with severe TBI have the worst prognosis. We

also know that when compared to adults, older children with milder TBI recover more slowly with more physical, emotional, and cognitive challenges. Federal-funded biomechanics and other foundational research is teaching us why. Sadly, given the limits of current prevention efforts, TBI will continue.

Our next level of defense is timely and proficient acute care. Over the past decade the CDC, HRSA, and many others have raised awareness about early recognition and response to TBI. Children with severe TBI require highly specialized aggressive care in the hours after impact. Children with more mild TBI require cognitive and physical rest within the first 48 hours. Federal investments in basic and translational research are leading to improved strategies for those on the front line. And I suggest taking this to the next step by including industry in our partnerships.

Unfortunately, the reality is that there are limits to current prevention and treatment. This is why recovery is our third line of defense. One of the 15 children who suffers a TBI today could have been your child or mine, and they now face the long road ahead to recovery. We need to be empowered with the best tools to restore vital cognitive function and help our loved ones recover fully. HRSA funding enabled innovative partnerships between schools and clinicians. These need to continue.

I want to close by looking forward. Recently I was selected as a hero by a local elementary school's children because I work to save lives. They too want to save lives, but I worry that their dreams may be stunted. We need to shore up the necessary training and funding opportunities that young people will need to become tomorrow's investigators, inventors, innovators, and clinicians in pediatric injury.

Mr. Chairman, Ranking Member Pallone, and members of the subcommittee, as policy members please know I am grateful for your role in helping to save children's lives. I thank you for inviting me to testify and look forward to answering your questions. As you consider this issue I want to leave you with one thought: The average medical cost for children hospitalized for TBI is $40,000. That is a lot of helmets.

[The prepared statement of Ms. Winston follows:]

Testimony of

Flaura Koplin Winston, MD, PhD
Founder and Scientific Director of the Center for Injury Research and Prevention
The Children's Hospital of Philadelphia Research Institute
Professor of Pediatrics
University of Pennsylvania

Before the

Subcommittee on Health
Energy and Commerce Committee
United States House of Representatives

"A Review of Efforts to Prevent and Treat Traumatic Brain Injury"

March 19, 2012

Good afternoon. Thank you Chairman Pitts, Ranking Member Pallone and distinguished members of the Subcommittee for calling this hearing and drawing attention to traumatic brain injury, the leading cause of injury death in children. I am honored to have been invited to testify. I am encouraged to see the increased focus on this very serious issue along with the emergent emphasis on prevention.

My name is Dr. Flaura Koplin Winston. I serve as Scientific Director and Founder of The Children's Hospital of Philadelphia Research Institute's Center for Injury Research and Prevention and Professor of Pediatrics at the University of Pennsylvania. In addition to being a doctorally-trained bioengineer, I am a board-certified, practicing pediatrician. The Children's Hospital of Philadelphia, or CHOP as it is more widely known, is the nation's largest pediatric healthcare network with over 50 locations throughout Pennsylvania and New Jersey, and over 1 million patient encounters every year. CHOP has consistently been a world leader in the advancement of healthcare for children by integrating its mission of excellent patient care, innovative research and high-quality professional education, along with advocacy, into all of its programs.

I came to care about pediatric brain injury from my earliest days in training at CHOP and Penn. As a pediatric medical resident, when I would hear the PennStar helicopter landing on the roof, I felt a sense of dread for the family whose life would be changed by their child's traumatic brain injury. The leading causes of pediatric traumatic brain injury (TBI) occur with motor

vehicle crashes, sports, falls and child abuse – largely preventable events with very costly outcomes. Head injuries were and remain very common. Each year, over 6,000 children and youth 0-19 years of age die from TBI, but deaths are just the "tip of the iceberg." An additional 60,000 children and adolescents are hospitalized, many suffering lifelong disabilities, and over 600,000 are treated in emergency departments each year for TBI. The cost to our nation's families associated with caring for pediatric brain injuries is too high. The primary goal must be to reduce the number of injuries. I suggest the metric on which to measure our nation's response: the number and severity of these injuries that occur each year.

In my testimony, I will focus on three main points in regard to pediatric traumatic brain injury: (1) prevention; (2) the need for timely and proficient acute care within the hours or days post-injury; and (3) recovery and reintegration into society.

The good news is that unlike with many other neurological conditions, we know the underlying cause of traumatic brain injury. When a brain is exposed to mechanical energy that exceeds its tolerance, injury occurs. However, as the majority of research efforts have focused on adult brain injury, the scientific foundation for pediatric brain injury is limited. Children are not small adults: traumatic brain injury in children is quite different from that of adults and varies across the pediatric age range. The brain is undergoing active development at least through age 25, changing structurally and functionally, which affects prognosis and influences the way care needs to be delivered. Although it was once believed that the immature brain is more resilient than that of an adult, recent data show that this is untrue, especially for the youngest children

who have the worst outcomes. In fact, prognosis for severely brain-injured children under the age of two is poor and comparable to that of the elderly. Also, when compared to adults, children and adolescents are more vulnerable to the long-term effects of concussion and recover more slowly. It is important to take caution when referring to concussions in children as mild as they are still brain injuries. Many lead to poor neurological outcomes that adversely affect the child's quality of life - with long lasting neurocognitive deficits such as impaired thinking, memory problems, and emotional or behavioral changes.

I want to emphasize the most important point - the brain is the organ that is least able to heal. Therefore, prevention is the best medicine and should be a primary strategy for maximum impact and return on investment. Research thus far has shown that something as simple as wearing a bike helmet or putting children in age and weight appropriate car-seats or boosters prevents life-altering injury and saves lives. However, many proven effective strategies to prevent brain injury are not fully implemented while others were designed for adults but not optimized for the developing, pediatric brain. New and improved child-focused strategies will only emerge from investments in basic and translational biomechanical, behavioral, and medical research to inform new safety products and their testing, new programs and new policies.

It was this type of funding and research that helped me identify airbag-related deaths in children, determining that these early airbags, designed to save adult lives in motor vehicle crashes, could actually cause a fatality in a child. This research informed efforts by the National

Highway Traffic Safety Administration, industry and other stakeholders-- all focused on reducing child injury. Advanced airbags, new policy and education emerged. And now child airbag deaths are rare. Dramatic prevention successes like these have taught me that we can prevent injury with strong science and its application to protect children in a world designed for adults.

Should a brain injury occur, timely and proficient acute care is vital. Delayed or inappropriate care can worsen the insult, resulting in secondary damage, and upset the delicate balance needed for healing. For the more severe brain injuries, we often refer to the hours after an injury as the "golden window" during which time the initiation of aggressive care, as needed, can reduce the secondary injuries. Emergency medical services for children and pediatric trauma centers such as CHOP are vital to this level of care. For less severe traumatic brain injuries, cognitive and physical rest must be initiated immediately – with the first 48 hours proving crucial to recovery. As many of these children with mild TBI may not come to hospitals, primary care physicians, schools and sports leagues need to be aware of the latest recommendations and implement them.

Federal funding has been crucial to advancing our understanding of the injured pediatric brain and its recovery and this work is informing new therapeutics. I encourage the National Institutes of Health (NIH) and other federal agencies to continue to invest in understanding why and how a blow to the head turns into a devastating brain injury and what we can do to mitigate that. Accordingly, I respectfully suggest that Congress build upon this important

commitment to the NIH and all federal agencies that have a vested interest in pediatric brain injury. Further, it is vital that the infrastructure is in place to rapidly translate science into tested treatments and then into clinical care.

Recovery from a brain injury can be a long and challenging road for children and their families. For many victims of traumatic brain injury, full recovery is not possible. Here, too, an enhanced scientific foundation and its translation will lead to major advances. For now, to ensure that children with traumatic brain injuries reach their full potential, sustained and coordinated multidisciplinary rehabilitation and support for the families is needed to address the physical, psychosocial and cognitive needs.

As a general pediatrician, I see children and their families whose lives are forever changed both by the acute injury and by its long-lasting effects on the child and the family members who must care for him. It is here that I see a commonality with other forms of neurologic or neurodevelopmental conditions, such as stroke, meningitis, tumors and autism. Injured children and their parents can suffer post-traumatic stress reactions following the injury which get in the way of recovery. Families often describe themselves as "lost at sea" without the services and coordination needed for rehabilitation and reintegration – such as training healthy brain cells to take on the tasks of the dead brain cells to help a child talk, walk, or cognitively process new information. Clinicians, communities and schools need to work together to reintegrate the child and his new special needs and optimize a functional recovery. Evidence-based care models and tested and proven effective online resources are needed to support these efforts.

Children and adolescents with TBI depend on the coordinated efforts of our health, education and labor sectors for the support they need.

As evidenced by this hearing today, pediatric brain injury prevention has many stakeholders. There are clear roles for everyone in this room. Improved implementation of proven effective programs, products and policies will result from coordination, cooperation and communication across governmental departments and non-governmental organizations. For example, the National Science Foundation has presented us with multiple opportunities to not only partner with government but also with industry to field real results in child injury prevention and these efforts have been wildly successful.

Further, the CDC will be releasing a National Action Plan for Child Injury Prevention which will provide action steps that can be taken in areas such as research, data, education, and health systems to prevent child injuries from occurring. It also seeks to incorporate child injury prevention into existing systems and strategies at the national, state, and local level. I was honored to participate in the work-group that created this important document, which will provide a meaningful roadmap for ensuring better health outcomes for America's children.

I close today by thanking you for giving this issue the attention it deserves and for bringing together this panel to discuss it. Although no single effort will provide the solution to this complex problem, I've shed light on a number of ways we can tackle this issue. It will take coordinated efforts by multiple governmental departments and agencies, industry and

nongovernmental organizations, communities, schools and families to optimize our response. Fortunately, there is a well-established public health framework for success that identifies the key opportunities for reducing the impact of traumatic brain injuries on children. This includes preventing the injury-producing event, reducing the likelihood and severity of any resulting injury, and optimizing treatment and recovery.

A month ago I was interviewed by elementary school students as one of their heroes because I save lives. They, too, want to save lives. But I worry that their dreams are limited because we have not shored up the necessary training and funding opportunities they need to become tomorrow's investigators, inventors and clinicians in pediatric injury.

I want to close by leaving you with a frightening statistic: today alone, 15 children will die of traumatic brain injury, an additional 150 will be hospitalized and 1500 will be treated in an emergency department. It is because of these staggering statistics that I have devoted my professional life to the prevention and treatment of pediatric injury. We can stem the pediatric brain injury epidemic and reduce the incidence of devastating injuries and poor outcomes with increased awareness, resources, research and coordination.

Mr. Chairman, Ranking Member Pallone and members of the Subcommittee, I thank you again for inviting me to testify and look forward to answering your questions.

Good afternoon. Thank you Chairman Pitts, Ranking Member Pallone and distinguished members of the Subcommittee for calling this hearing and drawing attention to traumatic brain injury, the leading cause of injury death in children. I am honored to have been invited to testify. I am encouraged to see the increased focus on this very serious issue along with the emergent emphasis on prevention.

My name is Dr. Flaura Koplin Winston. I serve as Scientific Director and Founder of The Children's Hospital of Philadelphia Research Institute's Center for Injury Research and Prevention and Professor of Pediatrics at the University of Pennsylvania. In addition to being a doctorally-trained bioengineer, I am a board-certified, practicing pediatrician. The Children's Hospital of Philadelphia, or CHOP as it is more widely known, is the nation's largest pediatric healthcare network and houses one of the largest pediatric research programs in the country.

I came to care about pediatric brain injury from my earliest days in training at CHOP and Penn. As a pediatric medical resident, when I would hear the PennStar helicopter landing on the roof, I felt a sense of dread for the family whose life would be changed by their child's traumatic brain injury. Traumatic brain injury is the leading cause of child injury death and is caused by motor vehicle crashes, sports, falls and child abuse – largely preventable events with very costly outcomes. As a nation we should measure our success by annual reductions in pediatric brain injuries. In my testimony, I will focus on three main points in regard to pediatric traumatic brain injury: (1) prevention; (2) the need for timely and proficient acute care within the hours or days post- injury; and (3) recovery and reintegration into society.

The good news is that unlike with many other neurological conditions, we know the underlying cause of traumatic brain injury. When a brain is exposed to mechanical energy that exceeds its tolerance, injury occurs. However, as the majority of research efforts have focused on adult brain injury, the scientific foundation for pediatric brain injury is limited. Children are not small adults: traumatic brain injury in children is quite different from that of adults and varies across the pediatric age range. I want to emphasize the most important point - the brain is the organ that is least able to heal. Prevention is the best medicine.

Should a brain injury occur, timely and proficient acute care is vital. Delayed or inappropriate care can worsen the insult, resulting in secondary damage, and upset the delicate balance needed for healing. For the more severe brain injuries, we often refer to the hours after an injury as the "golden window" during which time the initiation of aggressive care, as needed, can reduce the secondary injuries. For less severe traumatic brain injuries, cognitive and physical rest must be initiated immediately – with the first 48 hours proving crucial to recovery.

Federal funding has been crucial to advancing our understanding of the injured pediatric brain and its recovery and this work is informing new therapeutics. I encourage the NIH and other federal agencies to continue to invest in understanding why and how a blow to the head turns into a devastating brain injury and what we can do to mitigate that. Recovery from a brain injury can be a long and challenging road for children and their families. Here, too, an enhanced scientific foundation and its translation will lead to major advances. Clinicians, communities and schools need to work together to reintegrate the child and his new special needs and optimize a functional recovery. Evidence-based care models and tested and proven effective online resources are needed to support these efforts.

As evidenced by this hearing today, pediatric brain injury prevention has many stakeholders. There are clear roles for everyone in this room. Improved implementation of proven effective programs, products and policies will result from coordination, cooperation and communication across governmental departments and non-governmental organizations.

I want to close by leaving you with a frightening statistic: today alone, 15 children will die of traumatic brain injury, an additional 150 will be hospitalized and 1500 will be treated in an emergency department. It is because of these staggering statistics that I have devoted my professional life to the prevention and treatment of pediatric injury. We can stem the pediatric brain injury epidemic and reduce the incidence of devastating injuries and poor outcomes with increased awareness, resources, research and coordination.

Flaura Koplin Winston, MD, PhD.
Center for Injury Research and Prevention at The Children's Hospital of Philadelphia
March 19, 2012

Mr. PITTS. The chair thanks the gentlelady and recognizes Dr. Ashley for 5 minutes for an opening statement.

STATEMENT OF MARK J. ASHLEY

Mr. ASHLEY. Good afternoon, Chairman Pitts, Ranking Member Pallone, and members of the subcommittee. Thank you for the opportunity to testify today. My name is Dr. Mark Ashley. I am the President and CEO of the Centre for Neuro Skills which operates brain injury rehabilitation programs in California and Texas. I also serve as the Chairman Emeritus of the Brain Injury Association of America, which represents the 5.3 million children and adults in the U.S. who have long-term disability as a result of traumatic brain injury.

In 1972 my brother Steve sustained a catastrophic brain injury while in the Navy. For 8 years he lay incontinent, unable to move, unable to speak, communicating through eye blinks only. When I completed my professional training in 1980 I co-founded the Centre for Neuro Skills and admitted my brother. After 18 months of intensive rehabilitation, Steve regained continence, speech, movement in all extremities, and was able to actually feed himself.

I hope to provide you today with several key points. The first is that traumatic brain injury affects people of all ages and is more prevalent than new diagnoses of all cancers in the U.S. There are over 4,000 people who will sustain a brain injury every day in the United States. The injury is heterogeneous and unpredictable. Treatment is very complex and highly specialized. Treatment, particularly rehabilitation in post-acute settings, is clinically effective and cost efficacious. There is significant variability in access to medically necessary health care for patients with traumatic brain injury. And research funding is not adequate to match the significance of this public health threat.

TBI is not an event or an outcome, it is a catastrophic condition, and it is the start of lifelong disease, causative and disease accelerative processes. In the early weeks after an injury, the brain's metabolism stabilizes and improves. This allows the brain to find and use undamaged alternate pathways to perform tasks; a workaround, if you will. To maximize recovery, however, the brain must grow new neurons, new glial cells, new synapses, and new vascular structures. In short, grows new brain. The process is demand-induced and is rate-limited. It occurs slowly. For children and adolescents, early recovery gives way to later deficits in behavior, new learning, and in skill acquisition. There is not a single pathway or course of treatment for catastrophic traumatic brain injury. Instead, care is provided across a spectrum of settings, including nonhospital-based rehabilitation facilities that evolved in response to demands for less costly treatment.

When my brother was injured 40 years ago, his initial hospital stay was over 12 months and his rehabilitation, initiated 8 years later, lasted 18 months. More recently, ABC News journalist Bob Woodruff and Congresswoman Gabriel Giffords made miraculous recoveries after a year or more of intensive rehabilitation. Today, however, most patients with moderate to severe brain injuries average just 19 days in the hospital and just 26 days or less in post-acute rehabilitative treatment.

What surprises most people is that today many patients do not receive complete rehabilitation. They include older patients, minorities, those who have no insurance or who are covered by Medicare and Medicaid, even many who have insurance. The consequences of this shortsighted approach include more medical complications, greater permanent disability, family dysfunction, job loss, homelessness, impoverishment, medical indigents, suicide, and involvement with the criminal or juvenile justice system.

Inadequate treatment leads to lost productivity and greater use of medication, durable medical equipment, income maintenance programs, and long-term care and institutionalization. In contrast, the consequences of adequate medical treatment—that is, rehabilitation of sufficient scope, timing, and duration—are well documented but are not well known in the general medical community or among payors, patients, or families. Proper acute and post-acute treatment and disease management help to restore maximum levels of function, reduced long-term disability and suffering, rather than merely accommodating for it.

My company provides post-acute treatments by physicians, licensed therapists, and other allied health professionals in assisted living facilities, like many other companies. Therefore, we are not eligible to be a Medicare provider. And because we do not have a Medicare provider number, we cannot accept TRICARE patients through a normal admissions process.

Currently my company is participating in the VA's assisted living traumatic brain injury pilot project. However, we are voluntarily supplementing the care paid for by the VA with more frequent and intensive therapies, because after 32 years of clinical practice I know that is what our service members need and firmly believe it is what they deserve. TBI can change how you move, talk, think and feel, it can change the length of your life and its quality. Individuals with brain injury, and their loved ones, are rarely able to advocate for themselves. They rely on policymakers to invest wisely in prevention, treatment, including medically necessary rehabilitation, and in research.

In 2011 the NIH spent $81 million on traumatic brain injury research, as compared to $5.4 billion in cancer. The disparity is enormous, given the similarity in annual incidents and higher societal costs associated with brain injury.

The Brain Injury Association supports basic science research as envisioned by the One Mind Campaign. Investment in epidemiologic research by the CDC strongly advocates for more rehabilitation research for children and adults by the National Institute on Disability and Rehabilitation Research. We cannot sacrifice care while the field works toward a cure; therefore, BIA strong supports reauthorization of the TBI Act. We urge policymakers to move away from time-limited project-oriented grants, to formula funding so that all States and territories can build a sustainable infrastructure to address this growing public health problem.

Finally, as you have learned today, administering treatment at the proper time and with the right scope, intensity, and duration by a well-skilled workforce yield significant cost savings in both the public and private sectors and vastly improves outcomes, functional independence, and life satisfaction.

We hope you will take action leading to better health, enhanced employment and education, and more fairness in equality for this vulnerable population. Thank you.

Mr. PITTS. The chair thanks the gentleman and thanks each of you for your opening statements.

[The prepared statement of Mr. Ashley follows:]

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THE VOICE OF BRAIN INJURY

Testimony of Mark J. Ashley, Sc.D., CCC-SLP, CCM
Chairman Emeritus, Brain Injury Association of America

On

A Review of Efforts to Prevent and Treat Traumatic Brain Injury

Prepared for the Subcommittee on Health
Committee on Energy and Commerce

March 19, 2012

Good afternoon, Chairman Pitts, Ranking Member Pallone, and members of the health subcommittee. My name is Dr. Mark Ashley. I am honored to testify today about a topic that has been my life's work: Traumatic Brain Injury (TBI).

I am the President/CEO of the Centre for Neuro Skills, which operates brain injury rehabilitation programs in California and Texas. I am an adjunct professor in the Department of Communication Disorders and Sciences in the College of Education at Southern Illinois University and serve on the clinical practice committee of the American Congress of Rehabilitation Medicine. My textbook, *Traumatic Brain Injury Rehabilitation,*[1] which has been in continuous print for more than 17 years, is now in its third edition.

I'm here today in my volunteer capacity as Chairman Emeritus of the Brain Injury Association of America (BIAA). Founded in 1980, BIAA is the nation's oldest and largest brain injury advocacy organization, serving and representing the 5.3 million children and adults in the U.S. who have sustained TBIs, their families and the professionals who advance research and provide treatment. BIAA advocates for timely access to expert trauma care, specialized rehabilitation and long-term services and supports so that people like my brother, your neighbor, parent, or spouse, and our children can live healthy, independent and satisfying lives.

My work in brain injury stems from personal experiences. In 1972, my brother, Stephen Ashley, sustained a catastrophic brain injury while serving in the United States Navy. Neither he, nor the rest of my family, ever fully recovered. My medical career began as a graduate student treating patients with brain injury. Following graduation, I co-founded the Centre for Neuro Skills (CNS) in 1980 and admitted my brother, eight years after his injury. For those eight years, he laid incontinent, unable to move, unable to speak, communicating through eye blinks only. After 18 months of intensive rehabilitation, he regained continence, movement in all extremities, regained speech, was able to feed himself. He married and fathered a child. Stephen is deceased now but his legacy lives on.

I hope to provide you with several key points today about Traumatic Brain Injury (TBI):

1. TBI is more prevalent than new diagnoses of all cancers and affects people of all ages.
2. TBI is a disease, is disease causative and is disease accelerative. It is immensely complex and requires highly specialized treatment.
3. There is significant variability in access to medically necessary health care interventions for individuals sustaining brain injuries due to factors such as state or residency, type of coverage, particular provider and advocacy skills of family members.
4. TBI treatment is clinically effective and cost efficacious.
5. Research funding is not adequate to match the significance of this public health threat.

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[1] Ashley, M.J., ed. *Traumatic Brain Injury: Rehabilitation, Treatment and Case Management*. Third Edition ed., ed. M.J. Ashley. 2010, CRC Press: Boca Raton.

Prevalence

The CDC reports 1.7 million Americans are diagnosed with a TBI in the U.S. each year.[2] Additionally, the CDC estimates that between 1.6 and 3.2 million concussions are sustained through sporting events.[3] By comparison, NIH reports 1.6 million new diagnoses of all types of cancer each year in the U.S.

The annual incidence of TBI is up from 1.4 million just two years ago and does not reflect TBIs sustained in Iraq and Afghanistan. Of the civilians currently injured, 52,000 die and 275,000 are hospitalized.[2] Seniors and children are at greatest risk for injury. Almost half a million (475,000) children age 0 to 14 visit emergency departments for TBI each year.[2]

Let me put these numbers in perspective. Today, more than 4,000 people in the U.S. will sustain a TBI. Recall the horror of 9/11, when the death toll was 2,752 lives or Pearl Harbor where the toll was 1,178 lives. In the latter examples, lives were lost. In brain injury, many whose lives are saved say they are not worth living. And unthinkably, parents pray they will outlive their children.

Disease

No two brain injuries are alike. The same force applied to the brains of different individuals can result in different levels of injury severity and vastly different outcomes. An injury to the brain causes changes that can temporarily or permanently diminish a person's physical or communicative abilities, impair cognitive skills and interfere with emotional and behavioral well-being. In other words, a TBI can affect how we move, talk, think and feel.

Physical challenges may include balance or coordination difficulty, fatigue, weakness, hearing or vision impairment, sensory loss and seizures. Speech language can be severely impaired or lost altogether. Cognitive challenges may involve memory loss, difficulty with planning, organization, problem solving, decision making or judgment, slowed processing speed and reduced attention or concentration. Psychosocial challenges may include depression, stress, anxiety, aggression, frustration or mood swings, difficulty relating to others and reduced self-esteem. Simply put, every skill we possess can be at risk following a brain injury.

Brain injuries are heterogeneous and unpredictable, treatment is complex and outcomes are variable. The Brain Injury Association of America recognizes TBI is the start of disease-causative

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[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: Centers for Disease Control and Prevention, National Center for Injury Prevention and Control; 2010.

[3] Langlois JA, Rutland-Brown W, Wald MM. The epidemiology and impact of traumatic brain injury: a brief overview. J Head Trauma Rehabil 2006;21(5): 375–8.

and disease-accelerative processes involving the central nervous, autonomic nervous, endocrine and immune systems that result in chronic respiratory conditions, widespread infections, neurologic disorders and psychiatric diseases as well as musculoskeletal, bowel, bladder and sexual dysfunction. We are just beginning to understand the impact of brain injury on diseases such as Parkinson's disease, Alzheimer's disease, Multiple Sclerosis, Amyotrophic Lateral Sclerosis, and, as we are learning from retired athletes, Chronic Traumatic Encephalopathy.

The consequences of inadequate medical treatment for individuals with brain injuries and society are well known. Inadequate treatment often results in higher levels of medical complications, permanent disability, family dysfunction, job loss, homelessness, impoverishment, medical indigence, suicide and involvement with the criminal or juvenile justice system. Inadequate treatment also leads to lost productivity and greater utilization of publically-funded income maintenance programs (such as SSI and SSDI), medication, durable medical equipment, long-term care and institutionalization. Thus, the burden of care for brain injury is systematically transferred from private insurance companies to families and then to taxpayers at the federal, state and local levels.

The consequences of adequate medical treatment are also well known. Acute and postacute treatment include disease management, mitigation and prevention as well as treatment to promote neurophysiological remodeling and reorganization through physical, occupational and speech therapies and other rehabilitative interventions of sufficient scope, timing, intensity and duration. These treatments restore maximum levels of function and reduce long-term disability and pain, rather than merely accommodating for disability through durable medical equipment or medication. More specifically, medically necessary rehabilitative services:

- Prevent, mitigate, reverse or arrest neurophysiological disease processes;
- Speed recovery (better outcomes and enhanced likelihood of discharge to one's home, living longer and retaining a higher level of function post injury or illness);
- Improve long-term cognitive and physical function, improve overall health status and improve the likelihood of independent living and quality of life;
- Decrease the likelihood of homelessness, joblessness, impoverishment, family system disintegration, incarceration, and medical indigence;
- Decrease reliance on various public health and assistance programs;
- Halt or slow the progression of primary and secondary disabilities (maintain functioning and prevent further deterioration); and
- Facilitate return to work in appropriate circumstances.

Yet, this disease and the benefits of treatment are not well understood in the general medical and allied health communities. Further, treatment requires specialized settings designed to maximize patient outcomes. Just as you would not expect surgery to be conducted outside an operating theatre, each phase of treatment following brain injury requires specially designed settings.

In the early weeks after injury, recovery is dependent upon the brain's metabolism which stabilizes and improves. Recovery of function occurs as the brain finds and uses available undamaged, alternate pathways to perform tasks. This process is a little like using side streets instead of the beltway. In order to maximize recovery, the brain must grow new neurons, glial cells, synapses and vascular structures—in short, new brain. This process is demand-induced, meaning that it occurs only when there is sufficient environmental demand for new structures. Demand must be controlled, properly timed, of sufficient intensity and duration and expertly applied. This is what proper rehabilitation induces.

The process of growing new structures is rate-limited: it only can occur so quickly. This has bearing on how long the process can be expected to take, contrasted with how long most patients are given for treatment. Interestingly, TBI-related hospitalizations increased by 19.5% from 2002 to 2006[1] while lengths of stay decreased sharply. When my brother was injured 40 years ago, his initial hospital stay was over 12 months; today, patients with moderate to severe TBI spend just 19 days in the hospital.[4]

In part, reduced lengths of stay are due to advances in diagnosis through CT (computed tomography) scans and MRI (magnetic resonance imaging), life-sustaining technologies such as ventilators and NG (nasogastric) tubes, and improved monitoring of oxygen, heart rate, blood flow and intracranial pressure. Neurosurgeons are perfecting procedures to accommodate for the brain's natural bruising and swelling after injury and can administer nutrition, pharmacological agents and electrical stimulation to save the patient's life, reduce secondary injury and speed recovery. Nevertheless, there is enormous pressure by both public and private payers for acute care hospitals to discharge patients "sicker and quicker."

A recent analysis of three archival datasets (CDC's Central Nervous System Injury Surveillance database; National Trauma Data Bank; and National Study on the Costs and Outcomes of Trauma) encompassing 68,000 patient records indicates that among people age 16 and older with moderate to severe injuries, only one in four is referred to rehabilitation. The investigation showed that the decision to discharge a patient directly home from the hospital is due to severity-related factors, while the decision to discharge to rehabilitation is driven by sociobiologic and socioeconomic factors.[5]

We all witnessed the incredible recoveries of ABC News journalist Bob Woodruff and Congresswoman Gabrielle Giffords following TBI. What you don't see is the thousands of people who are desperate because they can't access similar treatment. Peter King, father of four adult children, married, and in business with one of his sons in a small plastering company

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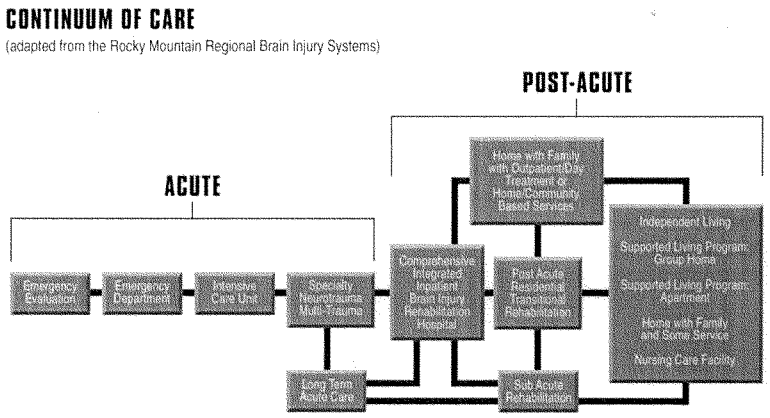
[4] TBI Model Systems, 2011. Retrieved on March 14, 2012 from https://www.tbindsc.org/Documents/2011%20TBIMS%20National%20Database%20Update.pdf.

[5] Cuthbert JP, Corrigan JD, Harrison-Felix C, Coronado V, Dijkers MP, Heinemann AW, Whiteneck GG. Factors that predict acute hospitalization discharge disposition for adults with moderate to severe traumatic brain injury. Arch Phys Med Rehabil 2011;92:721-30.

was struck by a drunk driver while riding his motorcycle. His adult daughter, a passenger, was killed. Mr. King struggled with his brain injury for 14 months until his insurer finally authorized 47 days of postacute rehabilitation. While awaiting treatment, he buried his daughter, was jailed, lost his wife to separation and lost his business. Two weeks after discharge, despondent and frustrated, he took his own life.

Spectrum of Care

Unlike most medical conditions, there is not a single pathway or course of treatment for catastrophic TBI. The continuum of care spans emergency evaluation, medical/surgical services, rehabilitation and long-term disease management. Care is provided in a variety of treatment settings that decrease in medical acuity from hospital-based trauma centers and intensive care units, to acute, subacute and postacute rehabilitation facilities, and home and community-based placements where the primary focus moves from medical stabilization to recovery-inducing treatments.



Progression along the continuum is not linear—many patients make gains quickly while some may regress backwards. Access to the entire continuum is not uniform. Reasons for inconsistent access include scarcity of beds, inconsistent payer coverage, poor awareness of the need for highly specialized treatment in the general medical, allied health and lay communities and a lack of understanding of the long-term health and cost benefits to maximizing disability reduction immediately proximal to onset of this disease.

Ironically, the latter half of the care spectrum—that which is commonly referred to as postacute—evolved in the 1980s in response to demands to develop less costly, non-hospital-based treatment settings that could address specific TBI-related disability and disease presentations. Today, older patients, minorities and those without insurance or who are covered by Medicare and Medicaid are far less likely to receive postacute rehabilitation.[5] These patients are at greater risk for re-injury and re-hospitalization due to unresolved physical and cognitive deficits. Family caregivers are rarely equipped or trained to manage the extraordinary burdens placed on them so soon after a loved one's injury.

My company, CNS, provides patients with TBI a broad range of postacute treatments, including physical, occupational, speech language therapies, behavior modification programs, psychological counseling plus family education, home evaluations and case management in residential facilities and day treatment clinics. Care is provided by physicians, licensed therapists and other allied health professionals in real-world settings. We work to restore, not accommodate for lost function, thereby mitigating or slowing disease progression and maximizing health outcomes and personal independence.

Like many other postacute treatment providers, CNS is accredited by CARF (the Commission on Accreditation of Rehabilitation Facilities), my staff is certified by the Academy of Certified Brain Injury Specialists, and we are licensed as an assisted living facility. Because CNS is not a hospital, nursing home, home health agency or doctor's office, we are not eligible to be a Medicare provider. And because we do not have a Medicare provider number, we cannot accept TRICARE patients through our normal admissions process.

Currently, CNS is participating in the Veterans Health Administration's Assisted Living-Traumatic Brain Injury (AL-TBI) pilot project; however, we are voluntarily supplementing the care paid by the VA with more frequent and intensive therapies because after 35 years of clinical practice, I know that's what our service members need and firmly believe they deserve it. Arbitrary limits on the frequency, intensity and duration of rehabilitation treatment are not justified in the scientific literature, disallow patients' attainment of maximal functional outcome and unnecessarily increase societal costs.

Variability in Access to Treatment

A survey conducted by BIAA showed there is significant variability in access to medically necessary health care for individuals sustaining brain injuries. The major factors influencing this variability include: state of residency; type of coverage (accident and health, no-fault auto, workers compensation, Medicare/Medicaid); particular provider (willingness and knowledge and experience of medical director, case management staff); and/or advocacy skills of the family and the experience and sophistication of the provider's staff in their dealings with insurers (e.g., exchange of benefits, extra-contractual services, Letters of Agreement). Importantly, public and private carriers need to be as informed of the latest and best treatment

approaches for people with brain injury as the medical community. When both act are better informed, they can act in concert to achieve better outcomes and better cost savings.

Treatment is Clinically Effective and Cost Efficacious

Over the years, CNS and many other postacute treatment providers have welcomed VA clinicians who wished to observe our treatment protocols and management policies and procedures. In 2010, I was honored to participate in the Blue Ribbon Symposium on Traumatic Brain Injury and Post Traumatic Stress organized for Gen. Peter Chiarelli, then Vice Chief of Staff of the U.S. Army. Appended to this testimony is a compilation of research findings I reported to the General with respect to the efficacy and cost effectiveness of rehabilitation.

In summary, the research demonstrates treatment of appropriate scope, duration, timing and intensity delivered by an interdisciplinary team of experienced and specialized clinicians results in shorter lengths of stay, increased rate of recovery, improved extent of recovery, less overall cost for treatment, less caregiver burden, fewer hours of attendant care per day, and greater lifetime cost savings.[6]

Further, the evidence shows that even late rehabilitation, as in the case of the VA's AL-TBI, is cost-effective and improves function and independence so much so that the lifetime cost savings outweigh the rehabilitation costs. Similarly, ongoing disease management results in fewer difficulties with activities of daily living, significantly reduced morbidity, and significantly reduced severity of symptoms as well as a decreased reliance on pharmacological interventions and durable medical equipment, lower long-term care costs and greater likelihood of return to school and work.[6]

For children and adolescents, the ability to return to school is critical. Following a moderate or severe brain injury, new learning and the development of milestone skills is a challenge. Many postacute facilities include a classroom setting with a curriculum that enhances success. An educational team works with the parents, child and local school district to create an Individualized Education Program (IEP) so the patient, or student, can continue to earn school credit. Most parents prefer to care for their injured child at home. That's true for spouses too, but a postacute residential facility provides a safe, structured, supervised environment that successfully bridges the transition from hospital to home.

Six years ago, the United Kingdom developed a typology for extracting reliable evidence from studies that are not randomized controlled trials (RTCs) and showed that that the findings

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[6]Ashley MJ. Maximizing rehabilitation outcomes and cost efficiency following acquired brain injury. Brain Injury Source 2010:10-21.

compared favorably to those derived from RCTs.[7] Despite these finding and the U.S. Preventive Health Task Force's admonition to use all levels of evidence, we do not do so in brain injury. This was illustrated in a recent comparative effectiveness investigation sponsored by the Agency for Healthcare Research and Quality in which a comprehensive search strategy spanning 30 years of published research on multidisciplinary rehabilitation of moderate to severe TBI of adults yielded 1,616 studies, of which only 16 were deemed usable by the contractor. Consequently, investigators could not draw any conclusions about the effectiveness or comparative effectiveness of TBI rehabilitation.[8]

Conversely, in a report released in October 2011, panelists from the National Academies' Institute of Medicine (IOM), who analyzed the effectiveness of cognitive rehabilitation for patients with TBI determined:[9]

- Despite the scarcity of conclusive high quality evidence, we support the ongoing use of promising practices/approaches while improvements are made in the standardization, design, and conduct of research studies.
- Limitations of the evidence do not rule out meaningful benefit.
- Policy should facilitate the application of techniques based on best available evidence with the proviso that objectively measurable functional goals are articulated and tracked and treatment continues so long as it is medically necessary.

Research Funding

Unlike many other health conditions, such as breast cancer, wherein affected individuals and their loved ones can advocate for and raise funds for research, that is not the case for people with brain injury. They rely on surrogates to advocate for them and for policymakers to invest wisely in prevention, treatment and research.

In 2011, the National Institutes of Health invested only $81 million in TBI.[10] That includes all investigations funded by the National Institutes on Neurological Disorders and Stroke (NINDS),

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[7] Turner-Stokes L, et al. Generating the evidence base for the national service framework for the long term conditions: a new typology. Clinical Medicine 2006;6(1): 91-97.

[8] Agency for Healthcare Research and Quality. Comparative effectiveness: Multidisciplinary postacute rehabilitation for moderate to severe traumatic brain injury in adults (DRAFT). 2012; Report No. XX. Retrieved on March 10, 2012 from http://www.effectivehealthcare.ahrq.gov/ehc/products/283/930/Rehab-and-TBI_DraftReport_20120112.pdf.

[9] IOM (Institute of Medicine). 2011. *Cognitive Rehabilitation Therapy for Traumatic Brain Injury: Evaluating the Evidence.* Washington, DC: The National Academies Press.

[10] NIH. 2012. Retrieved on March 13, 2012 from http://www.report.nih.gov/rcdc/categories/.

the National Center for Medical Rehabilitation Research (NCMRR) and the National Institute of Child Health and Human Development (NICHD). By contrast, NIH invested $5.4 billion in cancer research. Even with Congresses' recent infusions into DoD and VA TBI research, the gulf is enormous. As policymakers and advocates, how do we explain this to individuals and families who are suffering so much?

The Brain Injury Association of America supports basic science research as envisioned by the One Mind Campaign, investment in epidemiological research by the Centers for Disease Control and Prevention and recognizes the need for more rehabilitation research, for children and adults, at the National Institute on Disability and Rehabilitation Research, which is housed in the U.S. Department of Education.

BIAA also supports the adoption and widespread use of a more precise system for classifying injury severity and the development of a taxonomy of TBI impairments and interventions that would strengthen research methodology and transparently communicate treatment plans to payers and patients. We believe the taxonomy should be established alongside the development of medical treatment guidelines for postacute rehabilitation of moderate and severe TBI that would be applicable for both civilian and military populations.

We cannot sacrifice care while the field works toward a cure. Therefore, BIAA strongly supports reauthorization of the TBI Act, the only federal law that specifically addresses the development and coordination of systems of care and long-term services and supports at the state level for the civilian population through a grant program administered by the Health Resources and Services Administration. We urge policymakers to move away from time-limited, project-oriented grants to formula funding so that all states and territories can build a sustainable infrastructure to address this growing public health problem.

Conclusion

As your witnesses today have testified, individuals with brain injury are a growing segment of the U.S. population. The injury happens in an instant and exacts a devastating toll on the patient and his or her loved ones. But we know that by administering treatment at the proper time and with the right scope, intensity and duration by a well-skilled workforce yields significant cost savings in both the public and private sectors and vastly improves health outcomes, functional independence and life satisfaction.

Our job as advocates is to identify barriers and opportunities. Your job as a member of Congress is to support prevention, research, and treatment that will lead to better health, enhanced employment and education and more fairness and equality for this vulnerable population. We have made great strides in the last 30 years, but much remains to be accomplished on behalf of individuals with brain injury and their families.

Thank you for giving me the opportunity to testify today. I look forward to answering your questions.

Mr. PITTS. I will now begin the questioning, and I will recognize myself 5 minutes for that purpose.

Dr. Strickland, the committee applauds your efforts to convene an interagency working group, to maximize resources and coordinate Federal efforts related to traumatic brain injury. Would you please review the goals of the working group, and what is the role of the stakeholders within the group and how do they receive public input?

Ms. STRICKLAND. Thank you. The purpose of the Federal Interagency Coordinating Council is, as I said in the testimony and in my statement, to facilitate greater collaboration and coordination across the agencies that are working on TBI activities. We want to maximize the activities and we want to minimize duplication of effort. We also want to create a common vision across the multiple programs that are going on not only in HHS, but across government, around traumatic brain injury. And above all, we want to be able to collaborate and leverage each other's resources.

One of the ways that we are doing that is through a clearinghouse of Federal tools. We are hoping, and we are just throwing this out now, we are hoping that we will be able to include tools produced by all of the Federal programs in one place that would be accessible to the public and to each other so that we wouldn't duplicate effort and that we could use our scarce resources to launch out into new areas.

Mr. PITTS. Thank you. Dr. Winston, we have always heard of the plasticity of young brains and their remarkable ability to adapt to the surgical removal of part of the brain. Yet in your testimony, you mention that young brains are actually harmed more than the brains of older individuals. Would you elaborate on this difference?

Ms. WINSTON. Yes. Children differ from adults biomechanically, cognitively, emotionally, socially, and these differences affect injury and its recovery. Just think about normal children and the amazing changes that occur as your children grow up. Think about when you held your baby, think about when you taught your older child how to ride a bike or your teenage how to drive. Just as they are different on the outside, their brains are different on the inside. And new research is showing that this fundamental knowledge of the brain and its response to injury is yielding some surprises.

We used to think that children were more resilient, their brains were more resilient to impact. But in fact, let me give you three examples. Adult skulls fracture on impact, infant skulls bend, and when they bend it presses on the brain and can cause damage. Another is that infants have stiffer brains. People used to think that that was protective. But in fact, they injure at much lower levels of impact and energy. And then finally, some new research that was done by—the first research was done by Dr. Susan Margulies at the University of Pennsylvania.

New research that was done by Dr. Fred Rivera at Harborview shows that for mild traumatic brain injury, we start to see that there are disabilities that emerge that might not have been thought to be the case. And here there is a slight difference. It is the teenagers who have more disability from the same level of mild traumatic brain injury. And I think that this really shows that we are just beginning to truly understand the biomechanics of brains,

the biology of what happens in the event of an injury, and this knowledge and this furthering of our understanding of our scientific foundation is going to help us to come up with better helmets, better prevention strategies and better therapies and, I hope, better recovery.

Mr. PITTS. You mentioned the short-term and the long-term effects of brain injury in children. Can you have long-term effects without noticing any short-term injury?

Ms. WINSTON. I think that you usually will see something early on. But there are some subtle differences. Children are continuing to develop as we go forward. I often talk about children as an unfinished painting, right. We don't know where they are going to go, we don't know what their potential is going to be. And so as they get older there might be need for certain—certain cognitive abilities that weren't needed early on, and they will come through.

Again, there was a study that was recently done that showed that at 36 months after a traumatic brain injury, children with moderate to severe brain injury had much poorer function than they did at baseline and that they had no improvement between 24 and 36 months. And so this really gives us pause that we don't know enough about how to optimize therapy and optimize recovery, but we really need this in order to better inform our future interventions.

Mr. PITTS. The chair thanks the gentlelady, and recognizes the ranking member, Mr. Pallone, 5 minutes for questions.

Mr. PALLONE. Thank you, Mr. Chairman. I wanted to start with Mr. Ditto. It is my understanding that the treatment of traumatic brain injury is very complex and, unlike other diseases, the treatment of course has to be tailored for each individual and the outcomes can be variable as well. And I realize there is a great importance in an interdisciplinary approach towards treatment and management of patients. Particularly those with severe diseases may require a broad range of services, including health care, education, vocational rehab, and housing. And State health departments like yours or like the New Jersey Department of Health, play a critical role in serving as access points.

Can you tell us more about the importance of an interdisciplinary approach in case management in the treatment? In addition, can you highlight ways that you have been successful in providing these services in New Jersey?

Mr. DITTO. Of course. Again, I am from the Department—I was previously with the Department of Human Services. We have got to get that health out of there. Not that I don't like health. But I do want to say that it is very true that one of the most critical services for individuals with brain injury, regardless of the age at which the brain injury occurred, is the ability to get service coordination and multidisciplinary intervention into the picture, because it requires a lot of different folks with a lot of different specialties to be able to help people, because no two people, as I said before, are alike.

And so when we look at this, the important element is to have one central coordinating individual—and that is usually a case manager—that the family and the individual can work with to structure the kind of individualized service package and then fol-

low along. Case management isn't successful if you just say to somebody, oh, well, there is a treatment place over here that you could go to, they are open on Monday and Wednesday. You need to not only tell them about it, maybe you need to go there with them the first time to get them introduced. Maybe you need to follow up. Maybe you need to check with the program to see if their attendance has dropped off. You need to have someone who is measuring progress.

Case managers look at where they start with their clients and they move forward. And case management can come from a variety of sources. The Title 5 Maternal and Child and Health Program provides States with funds to provide case management to children with diseases and disabilities. And I can tell you in the State of New Jersey, it is a highly effective program that works very well in terms of providing that level of intervention helping families negotiate.

It is harder in the adult system for us to offer those kinds of services because there are not entitlement programs that we can turn to. So for the individual with an adult onset brain injury, States have developed things like State trust funds. And we did that in New Jersey, a surcharge on motor vehicle registrations. Those of you in New Jersey know that we register and reregister our cars every year and pay a fee for it. And we got them to take a dollar of that fee and put it aside into a trust fund, and we use that trust fund money to help support education, outreach, awareness, and direct services.

The most requested service in the State of New Jersey by people of all ages, from children through 99-year-old people, was case management, was someone to help them negotiate and navigate the system, and somebody with sufficient training to be able to understand the subtle differences between people with brain injury.

If you see someone who has had a severe brain injury and they are in a wheelchair, you obviously see, oh, they have physical impacts from it. But so often for people with brain injury, they don't look any different than you and I do, but they have the problems of cognitive dysfunction, they have the problems of impulsivity, aggressiveness, they have impaired processes that lead to social problems. And one of the things States are very concerned about is a lot of individuals who have brain injuries end up in our justice system, end up in our prisons. And I hate to tell you, but it is true, they end up in State psychiatric hospitals. And frankly, a State psychiatric hospital is not a place for an individual with brain injuries to be.

I spent a good deal of the last 10 years of my professional career trying to get people out of inappropriate placements and back into the community. But the funding for this is very, very difficult. There is more funding available on the child side than there is on the adult side. We are trying to tap into the aging piece of this and get more help from the Administration on Aging. But it comes back to the issue of really seeing that this is a lifelong disability that impacts people of all ages, and we have to look carefully at what systems have already been put in place out there that we can knit together to provide a comprehensive service. And even if we can't afford to buy all the treatment we need for people, at least if we

can give them case management services and get them somebody who can help to coordinate their medical care with their rehabilitation care, with their education program, with community supports and services, can make a tremendous difference.

And again, as I say, when I look back on our TBI fund in New Jersey, which was very successful, the most frequently requested service was case management beyond all others. And we offered a very broad range of home modifications and treatment services and all sorts of things, and people opted—the thing that was most opted for was case management.

But it is not equal across the country. When you go from State to State, and that is the luxury of working in a national organization like I do, when you go from State to State, there is such a big variation in what is available to people. And really this is a lifelong disability from which people, in my view—and I know not everyone likes this term—but they survive. I am not sure they recover. They survive. They learn compensatory strategies, they learn how to cope with the world, they learn how to make their way and improve their social interaction and minimize, hopefully, their involvement with the legal system. But it is a lifelong disability. You don't just wake up one day and say, oh, I don't have a brain injury any longer, everything is back to normal and I am perfectly fine. It is there forever. Thank you.

Mr. PITTS. The chair thanks the gentleman, and recognizes the vice chairman of the committee, Dr. Burgess, 5 minutes for questions.

Mr. BURGESS. Thank you, Mr. Chairman. Dr. Winston, along that line, do you have a sense as to—I mean, clearly States are doing things differently among the several States. Do you have a sense as to whether or not there is any coordination at the State level as to adopting the best practices, what is working in one location might be transferrable to another location, is there communication along these lines, are States looking at what programs are working in other areas?

And then I want to go to Dr. Strickland as to what the Federal oversight of that is. But do you get a sense there are States that are doing it right and States that show room for improvement?

Ms. WINSTON. Well, I have to say that it is not my expertise to look at what States are doing, so I can't really give you a full answer. I can speak to one program that HRSA funded that is in Pennsylvania that might be of help to you. In Pennsylvania, there is this group—there is a program that is called Brain STEPS to try to reintegrate children into the school system; because, understand, that is the job of children is to go to school and to get back in there. And now every school district in Pennsylvania has been trained in traumatic brain injury and there is coordination between these school districts and the local health care teams.

So I think that there are some models. I was hearing them from the panel members here. We need to build the collaboration. And, again, I want to reiterate, it is not just within the public sector, it is also with the private sector. It is really important to keep them together. So I would like to actually give my time over to Dr. Strickland.

Mr. BURGESS. Let me just ask you one follow-up on that before we leave it. Then, what type of coordination do you see between the schools and the Department of Education in this regard, because obviously the schools may become the de facto rehabilitation center for children with brain injury. How do they integrate with the State Departments of Education or the Federal Department of Education?

Ms. WINSTON. I can tell you that one of the main things I do for children, as a practicing pediatrician for children with special healthcare needs, is to try to get them into an individualized educational plan to get them the medical care that they need at the schools. And this does require a tremendous amount of coordination.

Mr. BURGESS. And how receptive is the Department of Education, the State Department of Education to those?

Ms. WINSTON. Well, they are limited by their budgets as well. Clearly we have challenges to fund our public education system. But I can tell you that that is a part where the State and the school districts are really trying to make this better for children. But it is a very challenging thing to provide the kind of care that these children need day in and day out at school. They also need wraparound services with someone who is there with them in school to deal with their emotional outbursts, to deal with other things. So it is a really challenging situation.

Mr. BURGESS. I am sure it is. Dr. Strickland, let me just ask you a question. The total budget for HRSA in the President's fiscal year budget for this year?

Ms. STRICKLAND. 9.76.

Mr. BURGESS. 9.76?

Ms. STRICKLAND. Million.

Mr. BURGESS. For the total of HRSA?

Ms. STRICKLAND. I would have to get back with you on that. You mean of all related activities?

Mr. BURGESS. Yes.

Ms. STRICKLAND. Everything related? I would have to check with our colleagues and see. But through the Traumatic Brain Injury Act, our program receives——

Mr. BURGESS. Within your division of the agency, the budget is?

Ms. STRICKLAND. $9.76 million.

Mr. BURGESS. No, no. The total HRSA budget. It is going to be in excess of $8 million, is it not?

Ms. STRICKLAND. Oh, for everything?

Mr. BURGESS. Yes.

Ms. STRICKLAND. In HRSA? Oh, yes, $700 million.

Mr. BURGESS. Did the President's request increase last year to this year?

Ms. STRICKLAND. Yes.

Mr. BURGESS. About how much, again, for the total of HRSA?

Ms. STRICKLAND. I don't remember.

Mr. BURGESS. The figure I have been given is $228 million. Does that sound about right?

Ms. STRICKLAND. I would have to get back with you.

Mr. BURGESS. And then we are spending on traumatic brain injury how much?

Ms. STRICKLAND. $9.76 million.

Mr. BURGESS. I mean, that just seems thin given the total HRSA budget, does it not?

Ms. STRICKLAND. We do a lot with the resources that we have. We can always do more with more.

Mr. BURGESS. It seems thin, given the requested increase. Now, I grant you Congress is supposed to do the budget, and Congress does the appropriation, so there is always a disconnect between what the President's request is and what the actual dollars are. But it just almost seems out of line, it seems out of kilter there. Is it because you are not asking for enough? I mean, Frank, he loves to give you money, so ask him. He will do it, he will write the check himself; I have seen him do it on this committee when he was chairman, subcommittee chairman.

Well, I guess my point is it seems like there is a disconnect between the level of funding for traumatic brain injury and HRSA and all of the other many things that HRSA does, however great and wonderful they are. And I am just asking as we go through this, that is something we might spend a little time and a little attention to see if there are places where perhaps other funds could be freed up in other areas and delivered to this very pressing need.

Thank you, Mr. Chairman, for the indulgence. I yield back.

Mr. PITTS. The chair thanks the gentleman. The other members seem to have stepped out, so we will begin round two of questioning.

Dr. Strickland, the GAO just found that NIH, DOD, and VA each lack comprehensive information on health research funded by the other agencies. GAO raised concerns about the potential for unnecessary duplication and urged the agencies to find ways to coordinate their efforts.

Question: How is TBI research that is conducted by NIH, DOD, and VA coordinated among the three agencies?

Ms. STRICKLAND. Well, I would reiterate that both DOD and VA are members of the newly established Interagency Coordinating Council. We will have our second meeting actually at the end of this week. But specifically, NIH has partnered with the DOD in building a central Federal interagency brain injury research database that will allow access to researchers across the multitude of research done by both agencies. This is important, because that helps us establish better TBI classification systems, better diagnostic criteria for mild TBI, predictive markers for dementia, and a host of other activities that can only really be achieved through that type of collaboration. So I think that the acronym is FITBIR. The Federal Interagency Traumatic Brain Injury Research database I think is going to be a real facilitator.

Mr. PITTS. So you are working to improve access to databases——

Ms. STRICKLAND. Right.

Mr. PITTS (continuing). And electronic information on the funded research?

Mr. Ditto, how are the States working with returning servicemembers or veterans, and how do States coordinate these services with the veterans organizations.

Mr. DITTO. Well, actually the States have had an interesting opportunity over the last several years. The Veterans Administration actually established a program in conjunction with the Department of Health and Human Services that is called Consumer Directed Home and Community-Based Veterans Services.

Mr. DITTO. And it was modeled after a program that was done in a number of States in which individuals were given an individual budget and then allowed to decide how to use that money to meet their specific needs. And so the States have gotten involved—it is a slow process, but it is taking off—in getting involved in understanding that the returning service people, once they have had the acute care and they go through the acute rehabilitation phase through Veterans Affairs, they then need sort of a stepdown after that. They are not ready to just go back into their communities and live. They need an environment, a therapeutic environment, not as intense as intense physical rehab is, but something that is more a day-to-day living, kind of getting adjusted program.

And so I think we are making headway with that, because before, to be perfectly blunt, in most States the Department of Defense was placing individuals in long-term care facilities and nursing homes. And so we are getting away from that.

I think also the States are reaching out to their Veterans Administration agencies to network with them and to become involved with them and to open up the doors to what the State may have to offer in terms of helping out with this. Many times Veterans employees are just not aware of the scope of brain injury programs and, frankly, because this has become the signature injury of this war, this is the first time that people started looking at these other programs that were out there dealing with people who had acquired their brain injuries in a different way other than combat.

Mr. PITTS. Thank you. Dr. Ashley, you described the variability of post-acute care for TBI patients. What are the factors that cause this variability? And also would you—I only have so much time—describe the difference in rehab and rehabilitation of children's versus adults?

Mr. ASHLEY. Yes, sir. The first part of your question is what accounts for the variability. It begins with the lack of understanding of the condition itself. As I mentioned earlier, in the general medical community and in the payer community, there is not a good understanding of the neurophysiologic and neuroanatomic principles of neuroplasticity as a recovery mechanism for brain injury. It used to be thought that what you see at 6 months is what you get. Today we understand that what we do in the environment by creating appropriately structured demand, reprograms existing cells to take over function or induces growth in the brain for development of new structures to take on function.

So without the proper knowledge in the medical community or in the payer community that underlies this, it is treated as though it is a broken bone. A broken bone takes 6 weeks to heal, and we get 2 weeks or so in rehabilitation for the brain. Wholly inappropriate.

We also have rehabilitation policy insurance plans that were designed for musculoskeletal and orthopedic rehabilitation 4 decades ago when it first came into being. It has not morphed into covering the rehabilitation needs that we now see with surviving neurologic

injuries. So we spend a great deal of money to keep a person alive and we basically spend no money to give them any quality of life afterward. The injustice here is that we actually have the ability to do it. So we are simply withholding this care and calling it something other than medical treatment and constraining it in policy by either licensure restriction or by benefit restriction. One or both.

I apologize, the second part of your question? Oh, the difference between children and adults.

Mr. PITTS. Yes.

Mr. ASHLEY. Euphemistically it is said that children are not little adults. I think Dr. Winston touched on it very nicely when she indicated the pathophysiology of a child's brain is substantially altered with an injury and differs substantially from adults. One of the areas that we have to really investigate has to do with the onset of lifelong disease processes that arise from the changes in the brain metabolically and neurophysiologically. Once altered, it is difficult to know if these changes actually revert to normal or not.

There is great suspicion, for example in pediatric injury, that neuroendocrine abnormalities contribute to a failure of the system to further mature appropriately. As a consequence we have to really call into question the role of even occult brain injury, much less more obvious brain injury, in conditions that might lead to dyslexia, agraphia, dyscalculia, difficulties with reading, writing, math, and so on that we have bundled under learning disabilities as an example.

Further, as we see the difference in children, we have medication differences, pharmacologic interventions that are not effective with children, or put children at risk that can be used in adults. And then of course, we have the real social dilemma in terms of how we treat these children. It is difficult to amass them in a single environment and take them out of their cultural surroundings—family, school, et cetera. So unfortunately, because of vagaries of rehabilitation coverage, the schools do end up being the de facto rehabilitation setting. It is not what they are trained for, it is not what they are prepared for. They certainly have stepped up and tried to address the problem, but the medical rehabilitation of children really ought to be left to medical professionals.

Mr. PITTS. The chair thanks the gentleman and recognizes the ranking member for 5 minutes for questions.

Mr. PALLONE. Thank you, Mr. Chairman. I want to ask Dr. Winston, you described how the majority of research is focused on traumatic brain injury in adults and that the scientific foundation for pediatric brain injury is limited. And you mentioned the need for focused research investments to inform new safety products, programs, and policies that will better prevent and reduce the severity among children.

It seems that you believe there is an important role for NIH and other Federal agencies and Congress to build upon existing research on pediatric brain injury. But could you just share your perspective on specific pediatric research questions that could be further—or should be further explored?

Ms. WINSTON. Thank you very much for asking that question. We need to build up our scientific foundation so that we can improve and be more efficient in how we deliver our care. I like to think

about it in five categories: first, to improve the prevention strategies, we need to understand the who, what, where, when, how, and why of pediatric injury, using biomechanics, behavioral science, epidemiology and the like. We need to improve our methods and measures for studying, diagnosing, and following the course of TBI. Biomarkers are also important. We need to conduct—work to know what works and what doesn't, how to improve on therapies that are currently done, how to deliver it in the best ways possible. We need to know how to get state-of-the-art to the field, to the frontline. And we need to support innovation research for the development of new safety products, biomarkers and therapeutics. And we must not forget to train our next generation to be scientists of pediatric injury.

There are two resources I call the committee's attention to that would be able to give you more complete answers. I am trying to be brief here. The first is a very exciting initiative that I was part of—actually both I was part of—that would be released by the CDC, I think next month, and it is a national action plan for child injury prevention that provides action steps in research, data, education, health systems, communication to prevent child injuries from occurring. It also seeks to incorporate child injury prevention into existing systems and strategies at the national, State and local level.

A second very exciting initiative is the National Institute of Childhood Health and Development is interested in childhood injury, and I applaud leadership for their interest in this. The Society for Advancement of Violence and Injury Research under the direction of the President. Dr. Fred Rivera tapped into experts in the field and enumerated important next steps in child injury research. And I recommend that you get ahold of that as well.

From the personal perspective, there is a range, a wide range, whatever we need to do. I think we can prioritize and we should.

Mr. PALLONE. Thank you very much. Dr. Ashley, in your testimony I am struck by the continuous care that is needed for people with traumatic brain injury. And you stated that those Americans who have experienced moderate to severe traumatic brain injury, their recovery often extends beyond their hospitalization and requires ongoing extensive rehab.

You also testified that it is the start of a disease-causative and disease-accelerative process. Can you elaborate on the extent to which more serious brain injuries are lifelong conditions? I know you mentioned that, but if you want to talk about it a little more.

Mr. ASHLEY. Yes, sir. The difficulty that we see, of course, is that anything and everything that a human being does is mediated by the brain. So when the brain is injured, the potential for impacting any and every organ system in the body and its function exists. At the most basic level, when a brain cell is injured—and you have 100 billion of them—that begins a neurodegenerative process, the end of which we are not sure exists. In fact, a few hours after an injury to the brain, we see inflammatory processes around the body initiated. In about a third of all individuals late in life, we will see those same processes reinitiate. So we change how the brain's biochemistry works. The brain functions in various degrees of bioenergetic crisis following a brain injury, almost indefinitely.

As a result, what happens is the metabolic demand creates tremendous stress within the system that triggers a number of degenerative processes. So we are beginning to reconsider lifelong diseases or diseases we have known lifelong as Parkinson's, amyotrophic lateral sclerosis, multiple sclerosis, Neimann Picks, Huntington's chorea, and so on, as lipid metabolic disorders that may have an origin in alteration in the brain's neurophysiology after a brain injury. You see this made manifest in the recent press over retired athletes with repetitive concussions from the Sports Legacy Institute and the work being done at Boston University on the posthumously donated brains of retired professional athletes. We see the changes in the brain in a condition called chronic traumatic encephalopathy that has been identified as a single example of these lifelong conditions and progressive conditions.

Mr. PALLONE. Thank you. Thank you, Mr. Chairman.

Mr. PITTS. The chair thanks the gentleman and recognizes the gentleman from Illinois, Mr. Shimkus, 5 minutes for questions.

Mr. SHIMKUS. Thank you, Mr. Chairman. I appreciate the panel being here. I apologize for not being here for opening statements. I was giving a tour of Wounded Warriors in the Capitol, and they just left and it gave me time to get back here. And so in that venue, obviously, some of my questions will be asked.

Just at the outset, Dr. Strickland, we think it is applaudable for us to try to organize these agencies and try to maximize the focus. We know that you have got the Federal Interagency Committee, the Federal Clearinghouse for TBI, the Federal Interagency for TBI Research database, the Center for Neurosciences and Regenerative Medicine. How are you going to try to coordinate these groups? I think everyone knows and the President has also said we have got to get efficient and we have got to pare down redundancies. How are you going to go about doing that?

Ms. STRICKLAND. Well, I should clarify that the interagency committee that HRSA is convening is really not to achieve that intraagency——

Mr. SHIMKUS. Do you think that is an important thing to do?

Ms. STRICKLAND. I think it is very important thing to do within each agency. Ours is more of an informal group so that we can be aware of what our agencies are doing and better align what we are doing with our scarce resources with the resources of others. There is certainly still a need for agencies to coordinate their activities within their own agencies and on dedicated activities of similar interest and similar focus.

Mr. SHIMKUS. And I think we are going to try policy-wise and budgetary-wise to really streamline this process, not just in this area, but healthcare research dollars because we do seem to have sometimes multiple agencies doing similar things, but they are not coordinated and they are not feeding back the same information and there is not one clearinghouse. So we are not sure we—we are getting a return on that investment. The question is: Are we getting as big a return on investment as we should? That is not even in the Agency, that is some of the healthcare research in the Department of Defense, as you know, and the like.

Let me go to Mr. Ditto. How many States are working with returning servicemembers or veterans?

Mr. DITTO. Give me a quick number? Probably about 15 or 20, from what we are aware of. Now, some States are very advanced in this. The State of Massachusetts, for instance, has a very involved, elaborate program that they have been working on for years, but they had a lot of commitment of resources at the State level that helped to bring this collaboration together and to work on it.

What I am worried about from the standpoint of our organization and representing State government is that we just don't have every State working on this, but every State has returning service people. So right away we are in sort of a difficult position, because we are really not necessarily reaching people.

The other thing is, and I am sure it is no surprise to you, most of the public entitlement programs across the country, especially like Medicaid, become the payer for long-term services for people with various disabilities, including brain injury. And most States are seeking to reduce and decrease their expenditures under the Medicaid program for various reasons, for obvious reasons.

And it worries me because what is happening is in some respects people with brain injuries are just being mixed in or lumped in in States with other groups of people with disabilities, and yet as you have heard from the experts, the treatment and management of these individuals is quite different. We are looking at quite a different approach to doing something. And because it is a lifelong disability and because the impairments persist over time, over a long period of time, it really requires a lot of resources. And States are not—I don't think States don't want to do the right thing, I just think they are having a very difficult time with the funding. And with constrictions in programs and with the small amount of money that HRSA gets to support, through the TBI Act, what needs to be done, this system is not—the amount of money that is being given to HRSA is not reflective of the magnitude of the problem of brain injury. That is the simplest way I can say it.

Mr. SHIMKUS. And we appreciate that. What about in your coordination with States? And how are the veterans organizations linked in at all?

Mr. DITTO. Veterans organizations are linked in. In fact, we have have some very interesting developments in a number of States where the National Guard came to the State and said, We would like to do something with the people we are sending out to combat. And so they were pretested before they left on assignment with a base measure of their brain function, et cetera. And then when something happened to them, they were sent home and retested. Because of baseline, there was an ability to determine whether or not any brain damage had been sustained. And if so, then plan an appropriate treatment. So both the local service organizations as well as the State veterans service organizations, as well as the Federal veterans department, Veterans Affairs, I think are all very interested in this. NASHIA has tried to work with these organizations and encouraged our States to work with them. But when we ended up with 21 States getting grants from HRSA, it made it difficult for the rest of the States to get replacement funding from the legislature and the Governor to fill the void of trying to continue the momentum of this.

Mr. SHIMKUS. My time has expired. I appreciate the answers. I will just finish on this, especially your last point, because as Members of Congress, one of things that we do numerous times is we do constituent service and we do a lot of Veterans Affairs issues, and have a baseline on disability and percentages, and be able to get through that system sooner rather than later, instead of reinventing the wheel—and some of the lag time, it is just really abysmal—that would be helpful too. So appreciate the testimony. Thank you, Mr. Chairman.

Mr. PITTS. The chair thanks the gentleman. Dr. Winston, I didn't get to you, so I have just one follow-up, if you would. In your testimony you discuss the importance of the golden window. In acute treatment, are you aware of any studies of treatment of children with TBI during the golden window?

Ms. WINSTON. Yes. So the question is about the golden window, it used to be called the golden hour. We are now learning that it is important to have aggressive care for a longer period of time, as we heard terrific testimony on. You know, the fact is it is very difficult to do acute care research. And I think there is work out there to try to start bridging together emergency departments in hospitals to try to build networks where this kind of research can be done.

Just beginning—I personally could get back to you on specific information—but I know of a very exciting study with adults that just came out from the University Pennsylvania found that early, aggressive, expensive care had important long-term consequences. I think that we give, and I think you would agree, too little too late. And sometimes too late, too little, even late. We really need to get in there, particularly for very serious injuries, we need to get in there and work with the brain's ability to heal and reduce the secondary injuries that might occur from hypoxia or from low oxygen or a low blood flow.

I think for mild traumatic brain injury, the window is a little bit longer, it is 48 hours. And I applaud the CDC and others to try to get that awareness out there that early recognition response is needed.

But I want to challenge, if I may give you a challenge that we are experiencing, the growing awareness for early recognition has really turned into some real challenges by parents who want some sound answers. They want to know things like after how many concussions should my child be removed from contact sports? How long are injured brains vulnerable to a second impact? Does the risk differ by age? And why did my child get a concussion when they were wearing a helmet? Our science today does not answer these questions.

Clinicians on the front lines are also asking questions. I think you might find this interesting. Visits for concussions, because of awareness, have skyrocketed at the Children's Hospital of Philadelphia's Care Network, increasing 458 percent since 2009. We are struggling to meet the demand. We need research and leadership to provide evidence-based recommendations. It can't be this broadbrush because we just can't afford it and we don't have enough trained providers.

I know that, Chairman Pitts, you have been very, very helpful in trying to make sure that we shore up the training that is necessary for this specialized care that children need. Thank you very much for that. We need better standards for safety equipment, biomarkers for traumatic brain injury so we can follow the course of care; better tools to use in the field and in the clinics, evidence-based and tested protocols. These don't exist right now.

And just to reiterate, for the young athlete in particular, their job is not playing on the field, it is actually learning. And we can't forget that. We need to make sure that we protect their brains so that they can become the leaders in society that many of them hope to become.

Mr. PITTS. Thank you. And that effort for the Children's Hospital GME training was bipartisan. My colleague, Mr. Pallone, was a great advocate of that as well. Do you have any follow-up?

Mr. PALLONE. No. Mr. Chairman, first of all, thank you for what you just said and your comment about concussions in sports. I agree. I wanted to ask unanimous consent to submit the statement of our full committee ranking member, Mr. Waxman.

Mr. PITTS. Without objection, so ordered.

[The prepared statement of Mr. Waxman follows:]

Statement of Rep. Henry A. Waxman
Ranking Member
Committee on Energy and Commerce
Subcommittee on Health Hearing on "A Review of Efforts to Prevent and Treat Traumatic Brain Injury"
March 19, 2012

The subject of today's hearing is a growing and significant public health problem: traumatic brain injury.

TBI is an unexpected blow or jolt to the head, affecting people of all ages. A soldier with a blast injury, an elderly person who's fallen, or a young driver involved in a car crash can all experience TBI. The gunshot wound suffered by Congresswoman Gabby Giffords is also a form of TBI.

CDC estimates that nearly two million Americans experience a TBI each year. The vast majority of these individuals have an injury that can be treated in a hospital emergency room. But one in five Americans is not as fortunate. Their injuries can have more devastating consequences and result in death or lasting disability. In fact, TBI contributes to one-third of all injury-related deaths in the U.S. There are also an estimated five million Americans living with a TBI-related disability.

These statistics help illustrate the pervasiveness of TBI. But the numbers do not fully account for the traumatic brain injuries experienced by our men and women in uniform. Nor do they document the impact of TBI among Americans who receive no treatment at all for this kind of wound. And, of course, they can never completely explain the emotional and financial burden of TBI on affected people and their families, or its heavy societal and economic toll.

As we hear from our witnesses, I think we should keep three things in mind:

- First, TBI differs from other conditions in the range and magnitude of resulting health effects. TBI can lead to deficits in cognitive and motor function, sensory impairments, and the onset of mood disorders or other forms of mental illness.
- Second, there is no one-size-fits-all approach for treating TBI because of its varied course. This is true even if there are similarities in how health professionals may care for TBI patients who also suffer from co-occurring conditions such as epilepsy.

- Finally, we have several proven interventions that can help limit the number of traumatic brain injuries and their impact. We've taken important steps in recent years to both better prevent TBI in the first place and ensure access to needed medical and rehabilitation services when these injuries do occur. But clearly, much more can and should be done.

I thank our four witnesses for being here this afternoon and for their testimony on this issue.

Mr. PITTS. That concludes our hearing. The members may give you questions. We ask that you respond to those questions once you get them promptly. And I remind members that they have 10 businesses days to submit questions for the record and that means they should submit their questions by the close of business on Monday, April the 2nd.

Excellent hearing. Wonderful testimony. We thank our expert panel for your very important testimony and answers to our questions.

Without objection, the subcommittee is adjourned.

[Whereupon, at 4:22 p.m., the subcommittee was adjourned.]