

June 15, 2010

Ms. Monica Stevenson  
Attention: MCC Strategic Framework  
U.S. Department of Health and Human Services  
200 Independence Avenue, S.W., Room 736-E  
Washington D.C. 20201

**Re: Comments regarding HHS's proposed Strategic Framework on Multiple Chronic Conditions, 2010-2015**

Dear Ms. Stevenson:

On behalf of the Brain Injury Association of America and the 1.7 million Americans who sustain a traumatic brain injury (TBI) each year, I am writing to express both support for and concerns with the proposed strategic framework on multiple chronic conditions detailed in the draft "Strategic Framework 2010-2015 Optimum Health & Quality of Life for Individuals with Multiple Chronic Conditions" (May 2010).

BIAA strongly endorses the development and implementation of a strategic framework for the U.S. Department of Health and Human Services to improve the health status of individuals with concurrent multiple chronic conditions. We agree with you that the enactment of health care reform legislation provides our nation with a window of opportunity to address the unique health care needs of individuals with concurrent multiple chronic conditions by focusing on prevention and management of these conditions. Our prevention efforts must address not only primary prevention initiatives but also include secondary and tertiary prevention. We must transform our system of care to ensure access to a full continuum of medically necessary treatment, including rehabilitation, furnished by accredited programs in the most integrated treatment settings appropriate as determined by interdisciplinary teams of qualified and specialized clinicians in concert with the patient and his/her family.

**BIAA's overarching concern is that the draft document does not include traumatic brain injury in the list of conditions that constitute concurrent multiple chronic conditions.** Below is our rationale for including traumatic brain injury in the list of concurrent multiple chronic conditions and additional comments regarding the four goals included in the strategic framework.

## **TBI and Concurrent Multiple Chronic Conditions**

According to the CDC, each year 1.7 million American children and adults seek treatment for identifiable traumatic brain injuries (TBIs) from falls, car crashes and other external blows to the head. An estimated 1.6 to 3.8 million individuals annually incur sports-related concussions but do not seek immediate treatment. Additionally, each year nearly 1 million Americans sustain acquired brain injuries (ABIs) from strokes, infections, tumors, toxins and metabolic causes.

No two brains are alike so no two injuries are alike; however, any brain injury—regardless of cause, type or severity—can temporarily or permanently impact brain and body functions. Common changes after TBI include the presence of physical, cognitive, and behavioral functional limitations. Physical limitations include balance, mobility, motor coordination, persistent headaches, fatigue or weakness, hearing, vision or sensory loss, as well as seizures and sexual dysfunction. Cognitive limitations include memory loss, problem solving, sequencing, decision making, judgment, processing speed, planning, organization, attention, concentration, initiation, speech, and language. Behavioral impairments include depression, anxiety, stress, disinhibition, aggression, failed response to social cueing, lack of emotional control, frustration, mood swings, difficulty relating to others and reduced self-esteem. Separately and together, these limitations impair physical, communicative, cognitive, social, emotional and psychological performance that undermines health, function, community integration and productive living.

As noted in [Conceptualizing Brain Injury as a Chronic Disease](#), TBI is not an event or an outcome. Indeed, it is the start of a lifelong disease causative and disease accelerative process that predisposes individuals to re-injury and the onset of multiple conditions. For example, brain injury has been linked to epilepsy, Parkinson’s and Alzheimer’s disease. Individuals with brain injury manifest neurologic, neuroendocrine and psychiatric disorders as well as cardiovascular, musculoskeletal, gastrointestinal, urologic and sexual dysfunction. Individuals who survive a TBI past the first have a seven-year reduction in life expectancy and are:

- 37 times more likely to die from seizures
- 12 times more likely to die from septicemia,
- 4 times more likely to die from pneumonia
- 3 times more likely to die from other respiratory conditions
- 3 times more likely to die from circulatory conditions

For many individuals who sustain brain injury, the effects may be moderate and when properly treated, full or near full recovery is possible. However, CDC estimates that each year at least 125,000 brain injury survivors will develop a permanent disability and the onset of concurrent multiple chronic conditions. For these reasons, BIAA offers commentary on the four overarching goals described in your draft framework.

### **I. Provide better tools and information to health care and social service workers who deliver care to individuals with MCC**

According to the CDC, there are at least 3.1 million Americans living with a lifelong disability as a result of TBI. These individuals interact with a variety of allied health professionals on a daily basis. Regrettably, there are many neurologists, psychologists, home health workers and other specialists who lack knowledge and experience in treating persons with TBI. Therefore, BIAA strongly supports HHS in its training and best practice dissemination goals for both licensed professionals and paraprofessional workers.

BIAA also supports evidence-based guidelines, as stated in Goal 1; however, because of the complexity of the brain and the recognition that each brain reacts differently to both the injury and treatment, it is important that evidence-based guidelines are not the only measure used to identify standard treatments. In treating and managing brain injury, lack of evidence does not mean lack of efficacy. Consensus-based guidelines within the field must also be considered when developing best practices in brain injury disease management.

## **II. Maximize the use of proven self-care management and other services by individuals with MCC**

BIAA supports facilitating in-home and community-based services *after* the patient has had access to a full continuum of medically necessary treatment (including rehabilitation) furnished by accredited programs in the most appropriate treatment setting as determined by an interdisciplinary team of qualified and specialized clinicians in concert with the patient and his/her family.

The treatment continuum for patients with brain injury begins with acute medical treatment, which is necessary to save lives and arrest disease progression in the early minutes and hours after injury. Acute treatment may be provided in the emergency room, trauma unit, intensive care unit, medical/surgical floor or similar hospital-based location.

Acute and post-acute treatment includes 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, duration and intensity. 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.

Some individuals with brain injury are able to return home directly from the hospital, but many patients need the clinically-effective and cost-efficient medical treatment that is primarily available from specialty rehabilitation hospitals or residential/transitional rehabilitation facilities. Early discharge from a rehabilitation facility may be detrimental to the patient's recovery, thereby increasing the likelihood of re-hospitalization and reducing the effectiveness of treatment in in-home and community-based settings.

## **III. Foster health care and public health system changes to improve the health of individuals with MCC**

Since TBI may be the underlying cause of patients who present with neurologic conditions or organ dysfunction, BIAA enthusiastically supports finding new and better ways to improve chronic care coordination. Brain injury mirrors other chronic conditions (i.e., cancer, asthma, and diabetes) in that the disease may be stable for a period of time and then may become unstable. In fact, it is well documented that individuals with brain injury may attain a plateau in functional restoration prior to entering a secondary recovery phase. For this reason, individuals with brain injury may need renewed access at any point along the treatment continuum throughout their lives. Ongoing disease management is critical to maintaining long-term functionality and quality of life.

#### **IV. Facilitate research to fill knowledge gaps about individuals with MCC**

BIAA applauds HHS for including epidemiology research in the strategic framework. In the case of TBI, it is important that the occurrences of the many conditions that develop post injury are documented and studied so that in the future these multiple conditions can be better managed.

On behalf of the Brain Injury Association of America (BIAA), our national network of state affiliates, and hundreds of local chapters and support groups from across the country, thank you for the opportunity to comment on HHS's proposed Strategic Framework on Multiple Chronic Conditions, 2010-2015. We are enthusiastic about your work and hope that you will remember brain injury as you move forward.

Sincerely,



Susan H. Connors  
President/CEO