



# Traumatic Brain Injury (TBI) Task Force

Final Report

## **Executive Summary**

Arkansas has a disproportionate burden of Traumatic Brain Injury (TBI), with mortality rates exceeding the national average. Defining the problem of Arkansans living after suffering a TBI is more difficult, as the state is one of only three states without a state-funded TBI agency. The Center for Applied Research and Evaluation at the University of Arkansas for Medical Sciences and Arkansas Children's Hospital, in collaboration with a TBI Partnership facilitated by the Arkansas Department of Health, conducted focus groups throughout the state to assess the needs of TBI survivors, their families, and medical service providers. These focus groups were funded by a Health Resources and Services Administration (HRSA) TBI grant to the health department. Additionally, an on-line survey was conducted by the Brain Injury Association of Arkansas. The three top issues identified were the need for coordinated advocacy efforts, access to education and resources, and increased funding for services. The formation of a state wide Traumatic Brain Injury Commission is recommended to improve the understanding and outcomes of TBI. The TBI Commission will establish a centralized Arkansas TBI registry, build an information clearinghouse on TBI, and link Arkansans with TBI resources within the state and throughout the nation.



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### Introduction

Each year in the United States an estimated 1.5 million Americans sustain a traumatic brain injury (TBI). About 80,000 people annually experience the onset of long-term disability following TBI. It is estimated that over 5.3 million Americans are living with disabilities resulting from TBI. The severity of disability following a moderate to severe TBI results in significant cost in medical and nursing care as well as loss of productivity from those unable to return to work. TBI affects all age groups, but rates are highest in young adults (ages 15-24 years) and older adults. In addition, the war in Iraq and Afghanistan has resulted in approximately 30% of wounded soldiers returning home who have suffered TBI's. The reintegration of these soldiers to civilian life will eventually place additional burdens on our society. TBI is the signature injury of this war.

### The Problem

For many individuals and families, a traumatic brain injury is the beginning of a lifelong disability. Like spinal cord injury, blindness, and developmental disabilities, TBI entails a lifetime of needs and required services. Since many TBI survivors may never again be contributing members of society, this disability constitutes a significant financial and social impact on society and families. The impact on families should not be discounted since, like most neurological trauma, TBI takes a toll on everyone connected with the individual.

For those who sustain TBI in the state of Arkansas, access to care through emergency care and acute hospitalization is generally available. If acute care costs are not covered by commercial insurance, it may be shouldered by Medicaid, Medicare or the admitting hospital. After initial treatment, however, bigger gaps exist, particularly in acute rehabilitation, post acute rehabilitation, outpatient rehabilitation, and skilled nursing facilities if the individual does not have insurance or once limits on insurance are reached. If these areas cannot be addressed, the state often becomes the caregiver through Medicaid, the correctional system, or other social services. For adults in Arkansas, available services are minimal.

Because there is no active surveillance or registry for this problem, it is not known exactly how many Arkansans sustain a TBI annually, nor is there complete information on the number of Arkansans living with TBI-related disability. However, some data sources can approximate these numbers.

## The Voices of Arkansas

*I remember at the time of the injury I got where I couldn't walk. I had to crawl out to the car and have someone take me to the hospital but I guess I was lucky. The doctor called me a hypochondriac and sent me home...*

—Survivor, Central AR

*I go without food a lot. I make sure my son eats 3 meals a day, but I don't mind, I have no problem eating once a day to cut back on food to help, and I don't go anywhere I don't have to so I don't have to spend the gas because I, I don't have any money and I don't have any coverage...*

—Survivor, Southeast AR

*I think my brother, one of his things is his loss of autonomy: he can't live where he wants to, he can't do what he wants to, he can't say what he wants to, he can't drive, he can't work. His life has just been ripped away from him. He is lucky to be alive, and I think most days he is glad to be alive...*

—Sister of Survivor, Northwest AR

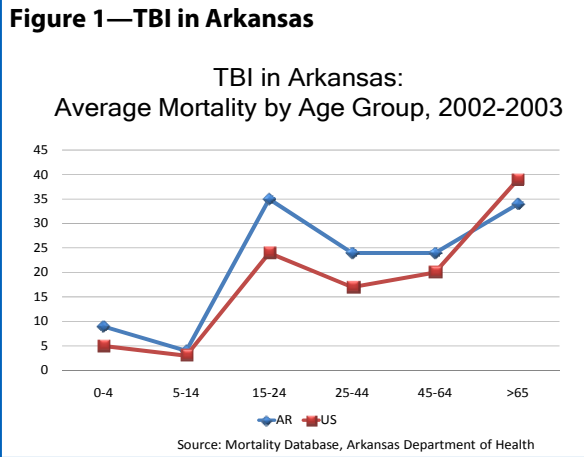
*There's not much. I mean, you can come to the support groups and try to discuss and try to see if anybody else has any ideas and stuff, but there's no, there's no real central location to go to or ask....*

—Family Member/Caregiver, Central AR

*Believe me... it was the most traumatic experience I have ever been through, because no one could tell me anything. Everybody says, we don't know, that meant as far as care and anything else.*

—Mother/Caregiver, Central AR

State vital records and the AR Hospital Discharge database, both maintained by the Arkansas Department of Health, allow some estimates to be made about deaths and hospitalizations associated with TBI. (See Figure 1)



On average, 614 deaths occurred in Arkansas each year between 1999 and 2004. Arkansas rates for TBI mortality are higher than those of the United States for most age groups. In addition, about 2,200 hospital discharges for TBI were recorded in the state annually from

2000-2006, consistent with a recent report from the Centers for Disease Control and Prevention. Both of these data sources, while valuable, are collected for purposes other than surveillance, limit identifiable data for cases, and are not available for years after the TBI occurs.

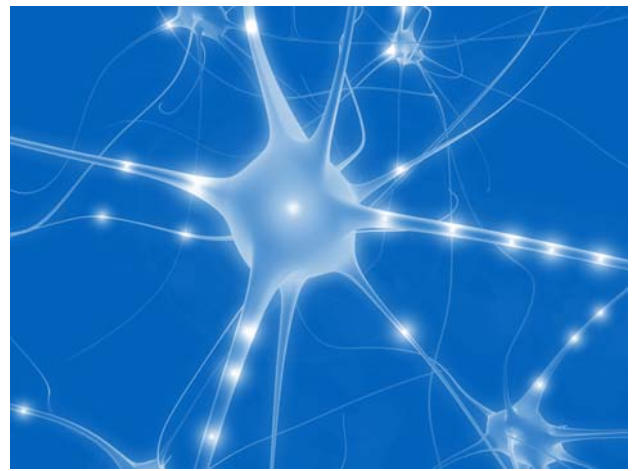
The lack of accurate information limits effective delivery of services for those with a TBI in Arkansas, and also restricts the state from pursuing appropriate federal funds to adequately meet the needs of TBI survivors and their families. It is estimated that about four out of every 10 persons hospitalized for TBI have at least one unmet service need a year after injury—this reflects thousands of individuals across Arkansas. Focus groups to assess these needs were conducted across the state and included TBI survivors, their families, and medical service providers. Focus group comments included throughout this report indicate profound challenges to these groups. In addition, an on-line survey conducted by the Brain Injury Association of Arkansas indicates that many Arkansans with TBI and their families face serious needs in a number of areas, including lack of local services for TBI (43% of those responding to survey), lack of awareness of services and resources (42%), and inability to pay for needed services (30%). Others noted needs for education about dealing with behavioral, personality, and physical changes experienced after TBI, daycare facilities, and respite care.

## Functions of the TBI Commission

### Traumatic Brain Injury Registry

The Traumatic Brain Injury Commission will establish a centralized TBI registry to track and monitor TBI incidence in Arkansas, build an information clearinghouse on TBI, and link Arkansans with TBI resources within Arkansas and throughout the United States.

The TBI Commission will be used to establish a mechanism for emergency rooms, hospitals, attending physicians, public and private health agencies, human services, and social agencies to report TBI's soon after the identification or diagnosis of these injuries. Since Arkansas is a rural state, a centralized registry would pinpoint the unique needs of every quadrant of the state. Resources in each county could be identified, and those counties without resources targeted for improvement.



## The Voices of Arkansas

*I wish there was some place I could get help. 'Cause, there's so much I'd like to do... mostly my therapy is getting used to the fact that I am who I am. You know I went through psychiatrists, psychologists, just to, for me to accept the fact that this is who I am. That's basically the medical answer to my problem is to be happy like I am...*

—Survivor, Central AR

*I don't know, um, my speech is very hard, and um, went almost 2 or 3 years not verbalizing nothing like that, but I'm walking again, I'm doing right, I'm not drinking and drugging, it's a good day today, cause tomorrow I don't know I could be dead but I'm alive today...*

—Survivor, Northwest AR

*My life was changed maybe 100%, uh, I lost 99% of my friends because I averaged at least 20 seizures a day... lost all of my friends, I lost my job, I lost my ability to do the things that I normally did...*

—Survivor, Southeast AR

*I would like to see a list of care providers. I don't mean a medical care... providers, you know, doctors, therapists, I would like to see all of that, a brain injury commission. That's the reason I am here actually...*

—Family Member/Caregiver, Central AR

*I just know for brain injury a lot of them are young men and young women... but there is a huge segment of the population with TBI that are not helped...*

—Sister of Survivor, Northwest AR



## The Voices of Arkansas

*...if I knew someone who had sustained a brain injury, I would tell them that it is going to be a long and hard road but you cannot give up...*

—Survivor, Central AR

*Then there's no, I mean, there's just nothing available hardly at all for places for people with brain injuries to go during the day. There's no, I mean, adult day care facilities they're oriented towards Alzheimer's and stuff and um, there's, there's just not very many activities...*

—Family Member/Caregiver, Central AR

*That's the bottom line. What do you expect? What's the long term prognosis? What am I to expect and how do I deal with it and who do I go to professionally? Those answers...No answers...it's like a shot in the dark...*

—Family Member/Caregiver, Central AR

*...if people can post things too about doctors and maybe some sort of discussion things that you can say well, you know I'm looking for such and such. Even just finding a dentist and stuff sometimes can be challenging and just to the small things you don't think of....*

—Family Member/Caregiver, Central AR

*All hospitals in the state need to have information on what to do with persons with brain injury. What do we do with them? What do we tell their family? Where do we tell them to go, because see I got none of that information...*

—Family Member/Caregiver, Central AR

Information gathered by the registry will: (1) provide accurate data on the incidence of TBI's to assist agencies in determining needs for programs and services, (2) identify trends in psychiatric and nursing home placements and emergency room visits to avoid ineffective and inefficient use of the system, and (3) provide data to leverage other sources of funding from federal and private grants.

### *Education and Resource Identification*

Through an information referral website developed by the TBI Commission, families and referring agencies will be linked to needed services and resource throughout the state. In addition, the website can also aid other state agencies with treatment and placement options when they are confronted with decisions. The website will network all stakeholders with the latest in healthcare updates and best practices information. Primary care physicians statewide can be linked to agencies and healthcare providers engaging in cutting edge work in brain injury treatment, rehabilitation and pharmacology. given the rural nature of Arkansas, the website can provide an important source of support and communication for families and survivors unable to attend regular TBI survivor meetings.

Education and support for people with TBI and their families will be conducted in all quadrants of the state. In addition, ongoing education for medical and education professionals will be provided. The goal will be to connect all stakeholders with the optimal resources and eliminate unnecessary and inappropriate placements. Educational programs will be geared to helping all stakeholders navigate within their communities to find services that currently exist. The website can link stakeholders with educational opportunities and vice versa with the seminars providing information on maximizing website information and communication/support opportunities.

### *Advocacy*

The Commission will act as a systems advocate for TBI survivors. By looking at Medicaid waiver programs, current service models, and current distribution of services statewide the commission will aid in cost savings and greater service utilization. By becoming the eyes and ears of TBI in Arkansas, the Commission can become a resource for best practices and grant opportunities that will result in savings and eliminate the constant need to reinvent the wheel. By communicating with other commissions, healthcare providers and agencies state and nationwide, and disseminating the information via the website and onsite conferencing, the Commission can use what has worked successfully to expand and improve services in Arkansas.

If these goals and objectives are met, costs to the state toward the care of a person with TBI would likely be decreased. Organizations and individuals who come in contact with survivors and family members would be educated and trained in identifying needs and accessing services, thereby reducing inpatient placements, emergency room care and psychiatric placements. In addition, federal and grant funds can be targeted to lessen the burden on state funds.

## Goals and Objectives

The primary goal of the TBI Commission will be to improve the understanding and outcomes of TBI. The Commission will actively promote effective treatment and needed services for TBI among Arkansas citizens. The Commission will have the following initial objectives:

- ⇒ Establish a registry of persons who have sustained TBIs.
- ⇒ Review current resources available to aid TBI survivors.
- ⇒ Produce and maintain a website to provide information and referrals for all TBI stakeholders statewide.
- ⇒ Conduct statewide workshops and conferences to provide education and training for all TBI stakeholders.
- ⇒ Advocate for TBI survivors for needed services.
- ⇒ Establish programs and service agreements that connect survivors, families, and agencies with needed services.
- ⇒ Train healthcare professionals and agency personnel about how to help the TBI population.
- ⇒ Assist agencies and private healthcare organizations in developing programs and services to slow the revolving door of inpatient psychiatric, nursing home, and emergency room visits.
- ⇒ Access existing federal dollars that are currently available only to state-funded TBI programs.

Given the current lack of information, programs can be initially evaluated by tracking the numbers of contacts to the commission's website and offices. The old adage of "shining a light on an issue" applies in this instance. It is anticipated that the state will see less reliance on inpatient and emergency care for TBI once the Commission is established, the registry begins providing vitally needed information, and services are better coordinated.

## Methods and Timeline

The first action to be taken by the Commission will be the establishment of the registry using models from effective systems in other states. An epidemiologist and research analyst will establish systems and guidelines for collecting and analyzing data. It is proposed that the TBI Commission will be administered jointly with the Spinal Cord Commission. This relationship will make this activity less costly and more efficient, in part because it will enable the commission to use a part-time epidemiologist for the first two year budget cycle.

Once data collection guidelines are established, a website will be developed to collect data and information about TBI, and later to disseminate information. The website will be expanded over the two-year period and be monitored by the Commission regularly. The objective will be to have a useful and easily accessible system for all stakeholders that will be dynamic and grow over time.



## The Voices of Arkansas

*I had a wonderful job in management at a major corporation, 2 college degrees. I had a 4.0 GPA in both of them. I haven't been able to work since. And they told me I was the worst case scenario in the state of Arkansas for Epilepsy...*

—Survivor, Southeast AR

*I actually had to quit my job and stay home full time to devote myself solely to him [son] and that cut our income in half. Even half the income we still exceeded the income and didn't qualify for any type of services absolutely none...*

—Mother/Caregiver, Northwest AR

*Yeah, I think it's really hard, you know, to keep on. Brain injury survivors need rehabilitation for so long and insurance will only pay for a little while and, and they really need it for years often times...*

—Family Member/Caregiver, Central AR

*...and have case workers throughout this state know to refer people, families, and patients to, an organization and... case workers that can help the family too ...*

—Family Member/Caregiver, Central AR

*.....you don't think about it [Traumatic Brain Injury] until it hits home, and you don't realize what isn't available to help people until your looking for it yourself and it's not there...*

—Sister of Survivor, Northwest AR



Educational programs will be developed for healthcare professionals, agency personnel, educators, family members and survivors and disseminated through a series of conferences and seminars. All of these stakeholders will benefit from best practice information, federal initiatives, and case study information delivered regionally and on the web by brain injury specialists.

It will be a primary goal of the Commission to utilize every means possible to leverage federal dollars and grants to support the commission. With the spotlight currently on brain injury, it is time to act and the establishment of the TBI Commission could not come at a better time. **As one of only three states (Arkansas, Louisiana, and South Dakota) that do not have a state-funded TBI agency, Arkansas is losing access to federal funds designed to benefit TBI survivors in Arkansas.**

## The Voices of Arkansas

### Obstacles for families/caregivers

*Lack of TBI education for teachers and school staff*

*Finding community based resources*

*Getting proper therapy*

*Availability of information on where to go for assistance*

*Lack of support groups*

### Suggestions from families/caregivers

*Widespread recognition of the problem and need for services*

*Appropriate people and organizations should maintain communication with and support for patients after discharge*

*More information*

*Counseling resources*

*(Above taken from results of online survey)*

*I don't think our situation will ever improve*

*—Participant in Online Survey*

## Budget

In order to optimize funding and decrease overhead costs, the Task Force recommends that the TBI Commission be combined with the present Arkansas Spinal Cord Commission. There has been ongoing dialogue with Spinal Cord commission staff and members to facilitate this cost-saving measure. This merger will decrease operational costs, provide experienced administration, and allow the TBI Commission to utilize experience, resources, and a functional model already established and working with the spinal cord disability population.

New funding for the TBI Commission will be required to carry out the proposed mission. Priorities will include 1. development and implementation of the TBI registry, 2. development of educational and information and referral resources for survivors and families, including a website and educational workshops and materials and 3. systems advocacy to include TBI needs in health care, educational, vocational and other existing service systems.

This will be carried out in the 2009 – 2011 biennium with a request for three (3) staff, professional services contracts for development, operational funds to provide needed equipment/supplies and funding for materials, services and resources to conduct educational programs. Every effort will be made to use these funds to match federal and private grant funding to expand services and meet the significant needs of these Arkansas citizens with traumatic brain injuries.

