# Table of Contents

Collaborative Effort 3

Understanding Traumatic Brain Injury 4

Understanding Traumatic Brain Injury in Arkansas 6

Traumatic Brain Injuries in Arkansas by County 7

Development of an Arkansas TBI Advisory Board Workgroup 8

Arkansas TBI Advisory Board Workgroup 9
  * State Plan Development Sub-Workgroup 10
  * Trust Fund/Waiver/Financial Strategies Sub-Workgroup 11
  * Underserved Populations Sub-Workgroup 12

2018 – 2021 Arkansas State Plan for Traumatic Brain Injuries 13
  * Focus Area 1: Arkansas State Plan for Traumatic Brain Injuries 14
  * Focus Area 2: Trust Fund/Waiver/Financial Strategies 16
  * Focus Area 3: Underserved Populations 17

Communicating the Process and the State Plan 18
  * TBI Advisory Board Workgroup Meetings 18
  * Assessment Surveys 18

Arkansas TBI Advisory Board Workgroup Participants 19
Collaborative Effort

The Arkansas State Plan for Traumatic Brain Injury (2018 – 2021) is being developed by the Arkansas TBI Advisory Board Workgroup in conjunction with the Administration for Community Living (ACL) TBI State Partnership (TBI SPP) grant and partnerships between the Arkansas Trauma Rehabilitation Program (ATRP), Institute for Digital Health & Innovation (IDHI), at the University of Arkansas for Medical Sciences (UAMS), and the Arkansas Department of Health (ADH).

In July, 2018, IDHI UAMS received a $450,000 grant from the U.S. Department of Health and Human Services, ACL. The Traumatic Brain Injury State Partnership Program State Funding Opportunity was awarded in the amount of $150,000 a year for three years. The Arkansas Department of Health (ADH) contributes $75,000 annually through a partnership with the Arkansas Trauma Rehabilitation Program (ATRP). Efforts and outcomes of the grant support work being done by ATRP.

ATRP maintains the Arkansas TBI Registry, which was established by Arkansas Statute 20-14-793. The statute requires that all hospitals, attending physicians, public, and private social agencies refer every Arkansas resident who is newly-identified as having sustained a moderate to severe traumatic brain injury to the registry within five days of diagnosis.

ATRP also serves as a resource center offering information about services such as the TRIUMPH Call Center and teleclinic opportunities with brain injury specialists located at UAMS.

Per grant expectations, deliverables for Arkansas over the next three years include:

- Forming an advisory board with survivor engagement
- Identifying and developing a plan for the underserved populations within the TBI community
- Building a waiver program and/or trust fund

This document outlines the history of the Arkansas Advisory Board Workgroup affiliated with the TBI SPP grant and current efforts to develop an Arkansas State Plan for Traumatic Brain Injuries.
**Understanding Traumatic Brain Injury**

*Brain injury is often referred to as the “Silent Epidemic”. Sometimes physical challenges are visible, but the cognitive, emotional, behavioral and social challenges caused by brain injury are often the most disabling and difficult for the public to understand.*

According to the Brain Injury Association of America, brain injury is a major public health problem impacting thousands of people across the United States, including those who live in Arkansas.

Traumatic Brain Injury (TBI) is defined as a blow, jolt or penetration to the head that disrupts the function of the brain. Most TBIs are caused by falls, jumps, motor vehicle traffic crashes, being struck by a person or a blunt object, and assault. Blast injuries sustained in combat are a growing cause of TBI.

While TBI can affect men and women of all ages, males are about one and a half times more likely than females to sustain a TBI. The three age groups at highest risk for a TBI are 0 – 4 years, 15 – 24 years, and 85 years and older.

TBI can range from mild to severe, and the effects can be temporary or permanent. Many people who experience a TBI have long-term or lifelong disabilities as a result of impairments in a number of areas including:

- Thinking and Reasoning
- Memory
- Speech
- Behavior
- Vision
- Understanding Words
- Attention
- Problem Solving
- Physical Activities
- Hearing

These impairments can affect a person’s physical, cognitive, behavioral, and emotional well-being, which subsequently impacts self-concept, family and social relations, education, and learning performance. These secondary disabilities can cause significant long-term problems with independent living, community integration, employment, and financial stability.

The short- and long-term consequences of a TBI create a significant public health burden across the country. Because TBIs affect different areas of the brain in different ways, no two brain injuries are like. As a result, a range of services that can meet individual needs and change over time is necessary.

Improvements in health care and technology are helping people with TBI live longer, healthier lives, so the need for services to assist those with TBI and their family members is growing. Educating the public about TBI is vital to improving the lives of people living with brain injuries.
Because prevention is the only real cure for TBI, efforts to promote the use of seatbelts, child safety seats, and helmets and to reduce the occurrence of child abuse, domestic violence, and other non-accidental injury are vital to reducing the number of lives impacted by a TBI.

Many states, including Arkansas, have taken steps to prevent long-term harm to student athletes who sustain concussions. Prevention measures are essential to reducing the social and economic burden caused by TBI.
Understanding Traumatic Brain Injury in Arkansas

In Arkansas, resources to help people living with brain injury, their family members, caregivers, and providers are not as robust as needed to properly care for this underserved population. In addition to the injury-related challenges, those impacted by brain injury may have difficulty navigating, accessing, receiving, and paying for services, especially in rural areas.

Several studies have indicated that up to 67% of people living with brain injuries receive no additional services following discharge from acute care hospitals. There is also clear evidence that the lack of rehabilitation for TBI survivors results in less participation in the workforce and the community, while those admitted to long-term care facilities have the poorest outcomes.

To help address this issue, almost half of the states have enacted legislation designating funding, usually associated with traffic fines and/or surcharges to vehicle registration and motor vehicle licenses, for an array of programs and services for individuals with TBI and their families. Arkansas is one of the few states that does not have a fund generator. Arkansas also lacks a waiver program specifically for people living with brain injuries.

Arkansas’s aging population also faces risk of resources and services related to TBI. Data collected by the National Council on Aging indicates that falls are the leading cause of TBI among adults over the age of 65. The Arkansas State Plan on Aging (2016) cites U.S. Census Bureau estimates for 2013 that ranked Arkansas 10th in the nation for percentage of persons aged 60 and above. ACL data from 2012 highlights the U.S. Census Bureau estimate that 26% of the Arkansas population will be over the age of 60 by the year 2030.

Without access to appropriate resources and services, people living with brain injury and their family members often experience unemployment, social isolation, re-occurring hospitalizations, institutionalization, and homelessness.

References:
This map reflects moderate to severe TBIs reported to the Arkansas TBI Registry as of June 12, 2019. Mild TBIs are not currently entered into the TBI Registry.
Development of an Arkansas TBI Advisory Board Workgroup

In August, 2018, an interest meeting was held with those living with brain injuries, family members, caregivers, organizations, and agencies that work with the TBI population to explain the ACL SPP grant, the ATRP program, the TBI Registry, and to ask for support and input for the development of an advisory board workgroup and a state plan. From this meeting, an Arkansas TBI Advisory Board Workgroup was formed on a volunteer basis.

In February, 2019, three sub-workgroups were formed from the Advisory Board Workgroup based on interest and expertise. Sub-workgroup participants began to tackle specific issues related to Arkansas. The Arkansas sub-workgroups align with ACL national workgroups.

Both the advisory board workgroup and the sub-workgroups meet on a quarterly basis or more often if needed. The efforts of these workgroups are forming the framework for the Arkansas State Plan for Traumatic Brain Injuries (2018 – 2021).

Collaboration on the Arkansas State Plan is an ongoing effort among grant partnerships, participants of the Arkansas TBI Advisory Board Workgroup, TBI community, and other stakeholders from across the state.
Arkansas TBI Advisory Board Workgroup

The mission of the Arkansas TBI Advisory Board Workgroup is to improve upon Arkansas’s TBI infrastructure in an effort to maximize independence, wellbeing, and health of persons with TBI, their family members, caregivers, and providers.

To identify ways to achieve goals set within the focus areas outlined in the plan, each participant of the TBI Advisory Board Workgroup also contributes their expertise and knowledge to a sub-workgroup. The efforts of these sub-workgroups are outlined in this working plan.

Program leaders and the Arkansas TBI Advisory Board Workgroup will continue to identify partnerships that can leverage outcomes consistent with those identified in the working plan.

The Arkansas TBI Advisory Board Workgroup does not have the resources to accomplish this plan alone, but rather identifies itself through its mission as the organization that must lead in the establishment of these collaborative partnerships.

TBI Advisory Board Workgroup participants are currently engaging on a volunteer basis.

As previously mentioned, participants in the TBI Advisory Board Workgroup also volunteer to serve in a specific sub-workgroup based on their interests and expertise. The sub-workgroups meet at least once per quarter and are tasked with providing updates at the quarterly TBI Advisory Board Workgroup meeting.

The sub-workgroups are listed below.

- TBI State Plan Development
- Trust Fund/Waiver/Financial Strategies
- Underserved Populations
State Plan Development Sub-Workgroup

The mission of the State Plan Development sub-workgroup is to guide public communication for the TBI Advisory Board workgroup and sub-workgroup efforts and the Arkansas State Plan and to determine the structure of the Arkansas State Plan.

Tasks:

- Benchmark states with existing plans
- Determine what information should be included and how it should be structured in the Arkansas State Plan
- Incorporate the outcomes of sub-workgroups and Advisory Board Workgroup feedback into the plan
- Determine how the plan, quarterly Advisory Board Workgroup, and sub-workgroup meeting efforts should be publicly communicated
- Provide updates at quarterly Advisory Board Workgroup meetings
- Other tasks identified by the sub-workgroup
Trust Fund/Waiver/Financial Strategies Sub-Workgroup

The mission of this sub-workgroup is to research and identify ways to develop and implement a trust fund and/or waiver program(s), and to identify financial strategies for the state’s underserved populations, including those over the age of 21 who receive Medicaid benefits.

Tasks:

- Benchmark states with existing trust fund and waiver programs
- Work toward development of a trust fund and/or waiver program by identifying funding sources and opportunities
- Promote understanding of service coverage (i.e., Medicaid, Medicare, Money Follows the Person, Social Security, and private insurance)
- Identify specific areas of need within the TBI community (i.e., respite assistance, transportation, education, etc.)
- Provide updates at quarterly Advisory Board Workgroup meetings
- Other tasks identified by the sub-workgroup
Underserved Populations Sub-Workgroup

The mission of the Underserved Populations Sub-Workgroup is to identify ways to promote and disseminate resources, services, education, and information within the TBI community, especially in the underserved populations identified by the ACL TBI SPP for 2018 – 2021.

Tasks:

- Benchmark states with existing plans
- Identify gaps in resources and services that are needed to integrate TBI survivors back into their communities
- Brainstorm ideas and develop solutions to fill the gaps
- Identify community and survivor engagement opportunities and events to provide support and information
- Provide updates at quarterly Advisory Board Workgroup meetings
- Other tasks identified by the sub-group
The development of an Arkansas State Plan for Traumatic Brain Injuries brings the hope of preventing TBI, increasing public awareness of TBI, increasing knowledge/education of best practices, and increasing services and supports for people living with brain injuries and their families. Arkansas must continue to build upon the foundation established within this plan to provide appropriate and accessible services to all persons who have been affected by TBI.

The TBI Advisory Board Workgroup and sub-workgroups are newly-formed in Arkansas; however, work has begun to develop and establish goals within the focus areas listed below.
Focus Area 1: Arkansas State Plan for Traumatic Brain Injuries

**Goal 1: Develop framework for an Arkansas State Plan for Traumatic Brain Injuries**

- Sub-Workgroup was formed to develop a state plan
- Sub-Workgroup led the development and implementation of the needs assessment surveys
- Sub-Workgroup meets on a quarterly basis to review the state plan framework and to review and incorporate information collected from the needs assessments into the plan
- Current version of the Arkansas State Plan for Traumatic Brain Injuries is available on the TBI SPP website

**Goal 2: Incorporate input from TBI survivors, caregivers, family members, and providers to identify gaps in resources and services**

- Needs assessment surveys have been developed and are currently being implemented at various events across the state
- The State Plan Development Sub-Workgroup meets quarterly to review and incorporate information from the needs assessments into the state plan
- Needs assessment tools are available on the TBI SPP website
Goal 3: Hold regional events to engage the TBI population, share resources, and collect data for use in the Arkansas State Plan for Traumatic Brain Injuries

- Regional events are ongoing and will continue to be developed in collaboration with ATRP, Advisory Board Workgroup participants, people living with brain injury, and state agencies/organizations that serve the TBI population.
- Year 1 included a goal of four regional events, which was exceeded (see map below).
- Year 2 includes a goal of at least four additional regional events to be held in different locations than Year 1 events.
Focus Area 2: Trust Fund/Waiver/Financial Strategies

**Goal 1: Identify ways to develop and implement a trust fund and/or waiver program(s)**

- Sub-workgroup was formed to research the most feasible implementation
- Sub-workgroup determined that a trust fund is the first step for Arkansas
- Sub-workgroup is in the process of identifying a champion to move the development of a trust fund forward
- Sub-Workgroup meets on a quarterly basis

**Goal 2: Identify financial strategies for the state’s underserved populations, including those over the age of 21 who receive Medicaid benefits**

- Sub-workgroup was formed to research current pathways
- Sub-workgroup determined that an algorithm that depicts different situations is a possible outcome
- Sub-Workgroup meets on a quarterly basis
Focus Area 3: Underserved Populations

Goal 1: Identify underserved populations in Arkansas (i.e., rural, incarcerated, homeless, etc.)

- Sub-workgroup was formed to identify underserved populations in the state
- Sub-workgroup is currently reviewing the change to the Arkansas Medicaid Passe Program and the impact on the state’s underserved population

Goal 2: Identify ways to promote and disseminate resources, services, education and information within the TBI community

- Efforts are currently underway through workshops, conferences, exhibits, etc.
- Year 2 includes:
  - 4-episode teleconference series to educate the TBI population and professionals on topics of interest
  - Update to the Family Resource Guide, which is given as a reference in rehabilitation centers
  - Research into the possibility of hosting a one-day respite camp

Goal 3: Implement a survey for the homeless population to align with ACL national workgroup initiatives

- Year 2 will include the implementation of a survey in the UAMS 12th Street Clinic, which serves much of the local homeless population
- Efforts will align with the national undeserved sub-workgroup along with an emphasis on local issues
Communicating the Process and the State Plan

TBI Advisory Board Workgroup Meetings

Efforts of the TBI Advisory Board Workgroup and access to all meetings are open to the public. Meetings are held on a quarterly basis in Little Rock and announced on the website listed above.

Once a meeting is held, either quarterly advisory board workgroup or sub-workgroup, the following information is posted to the website:

- Agenda
- Minutes
- Support Materials (i.e., slide decks, handouts, etc.)

Assessment Surveys

The TBI Advisory Board Workgroup requests public input to the Arkansas State Plan for Traumatic Brain Injuries.

The first implementation of the needs assessment survey was on April 24 at the 7th Annual Day at the Capitol for Disabilities. Since that time, it has been distributed at conferences and presentations. In addition, a short 5-question paper survey was designed for use at the Regional Brain Injury Workshops, which are being held across the state. The short survey focuses on the three most important needs of workshop participants in relation to TBI.

Two assessment surveys are available online and on paper:

- People Living with Brain Injury, Caregivers, and Family Members
- Healthcare Professionals Working with the Arkansas TBI Population

Information obtained through the needs assessment surveys will help identify gaps in resources and services for those impacted by brain injury in our state.
Arkansas TBI Advisory Board Workgroup Participants

We would like to extend a special thanks to the participants of the Arkansas TBI Advisory Board Workgroup who are contributing their knowledge, time, and efforts to the development of a working plan that helps to meet the needs of Arkansas TBI population, including family members, caregivers, and providers.

A directory of participants is available on the TBI SPP website:
https://idhi.uams.edu/programs/trauma-telemedicine-programs/tbi-state-partnership-program/

<table>
<thead>
<tr>
<th>Statewide Participants</th>
<th>Sub-Workgroup</th>
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<tbody>
<tr>
<td>Sha Anderson</td>
<td>Executive Director</td>
</tr>
<tr>
<td>10 Corporate Hill Drive, Suite 240 Little Rock, 72205</td>
<td></td>
</tr>
<tr>
<td>Sheila Beck</td>
<td>Therapy Coordinator</td>
</tr>
<tr>
<td>390 Woodland Heights Rd. Little Rock, 72212</td>
<td></td>
</tr>
<tr>
<td>Charlotte Bishop</td>
<td>State Ombudsman</td>
</tr>
<tr>
<td>P.O. Box 1437, Slot S530 Little Rock, 72203</td>
<td></td>
</tr>
<tr>
<td>Stacy Gravett</td>
<td>Counselor, Pulaski County</td>
</tr>
<tr>
<td>900 W. 7th Little Rock, 72201</td>
<td></td>
</tr>
<tr>
<td>Sara Hodge</td>
<td>Speech Pathologist</td>
</tr>
<tr>
<td>1309 Hunters Code Little Rock, 72211</td>
<td></td>
</tr>
<tr>
<td>Kelsey Ingle</td>
<td>Speech Pathologist</td>
</tr>
<tr>
<td>800 Cache Rd North Little Rock, 72116</td>
<td></td>
</tr>
<tr>
<td>Name</td>
<td>Position</td>
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<tr>
<td>Rani Lindberg, MD</td>
<td>Medical Director, Brain Injury Medical Team</td>
</tr>
<tr>
<td>4301 W. Markham, Slot 602 Little Rock, 72205</td>
<td></td>
</tr>
<tr>
<td>Tom Masseau</td>
<td>Executive Director</td>
</tr>
<tr>
<td>400 W. Capitol Suite 1200 Little Rock, 72201</td>
<td></td>
</tr>
<tr>
<td>Jim Mather</td>
<td>Executive Director</td>
</tr>
<tr>
<td>1918 Birch Ave. Fayetteville, 72703</td>
<td></td>
</tr>
<tr>
<td>Miranda Morris</td>
<td>Executive Director</td>
</tr>
<tr>
<td>1410 W. Capitol Suite 300 Little Rock, 72201</td>
<td></td>
</tr>
<tr>
<td>Joe Page III</td>
<td>Warden and Person Living with Brain Injury</td>
</tr>
<tr>
<td>P.O. Box 240 Tucker, 72168</td>
<td></td>
</tr>
<tr>
<td>Dan Parker</td>
<td>RN and Caregiver</td>
</tr>
<tr>
<td>6600 Studer Rd. Little Rock, 72223</td>
<td></td>
</tr>
<tr>
<td>GiGi Parker</td>
<td>Speech Pathologist and Caregiver</td>
</tr>
<tr>
<td>6600 Studer Rd. Little Rock, 72223</td>
<td></td>
</tr>
<tr>
<td>Susan Pierce</td>
<td>Director of Policy and Planning</td>
</tr>
<tr>
<td>400 W. Capitol Suite 1200 Little Rock, 72201</td>
<td></td>
</tr>
<tr>
<td>Kevin Sexton, MD</td>
<td>Physician and Person Living with Brain Injury</td>
</tr>
<tr>
<td>4301 W. Markham Slot 420-1 Little Rock, 72205</td>
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<tr>
<td>Aleecia Starkey</td>
<td>Speech Pathologist</td>
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<tr>
<td>Jon Wilkerson</td>
<td>Person Living with Brain Injury</td>
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<tr>
<td>Tina Benton</td>
<td>Program Director – ANGELS, Oversight Director, Center for Distance Health</td>
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<tr>
<td>Terri Imus</td>
<td>Director of Operations, Trauma Telemedicine Coordinator, TBI SPP Principal Investigator</td>
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<tr>
<td>Kim Lamb</td>
<td>Assistant Director, TBI SPP Communications</td>
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<tr>
<td>Daniel Bercher</td>
<td>Assistant Director, ATRP</td>
</tr>
<tr>
<td>Stanley Ellis</td>
<td>Education Director</td>
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<tr>
<td>Eddie Williams</td>
<td>Nurse Educator, ATRP</td>
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<tr>
<td>Kristen Alexander</td>
<td>Health Educator, ATRP</td>
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<td>Amber Watson</td>
<td>Administrative Coordinator, ATRP</td>
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The Arkansas State Plan for Traumatic Brain Injury (2018 – 2021) is being developed through collaborative partnerships at the state and national level.

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