

# Traumatic Brain Injury: Missouri Five-Year Plan 2024-2029



MISSOURI DEPARTMENT OF  
**HEALTH &  
SENIOR SERVICES**

**UMKC** Institute for  
Human Development  
A University Center for Excellence in Developmental Disabilities

 **BRAIN INJURY  
ASSOCIATION  
OF MISSOURI**

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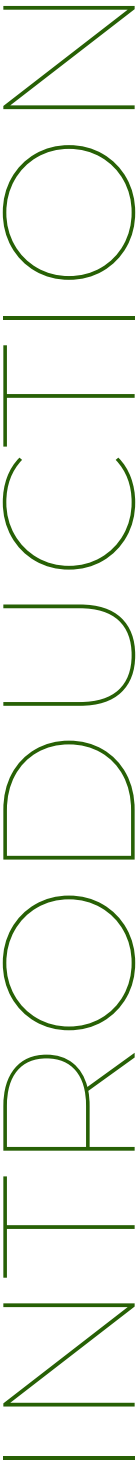
Acknowledgments

# ACRONYMS

There are several acronyms referenced throughout this plan that are defined below:

ABI	Adult Brain Injury
ACL	Administration for Community Living
AT	Assistive Technology
BI	Brain Injury
BIA-MO	Brain Injury Association of Missouri
CBIS	Certified Brain Injury Specialist
CDC	Centers for Disease Control and Prevention
CILs	Centers for Independent Living
DHSS-ABI	Missouri Department of Health and Senior Services, Adult Brain Injury Program
DMH-DD	Department of Mental Health – Developmental Disabilities
MBIAC	Missouri Brain Injury Advisory Council
MICA	Missouri Information for Community Assessment
MIVPAC	Missouri Injury and Violence Prevention Advisory Committee
MO F2F	MO Family-to-Family
MoAT	MO Assistive Technology
MOBIRF	MO Brain Injury Resource Facilitation
MOCADSV	MO Coalition Against Domestic and Sexual Violence
PSAT	Program Assessment Sustainability Tool
TBI	Traumatic Brain Injury
UMKC-IHD	University of Missouri-Kansas City, Institute for Human Development
VR	Vocational Rehabilitation

## Background



Missouri is a recipient of a Traumatic Brain Injury (TBI) State Partnership Program grant awarded by the U.S. Department of Health and Human Services, Administration for Community Living. This funding supports a variety of TBI-related activities across the state, including the formation of a five-year state plan to create and strengthen person-centered and culturally competent systems of services and supports to maximize the independence and well-being of people with TBI across the state. This plan will serve as a guiding document to orient and organize the work of state agencies and other grant partners.

The development of the state plan was facilitated by grant partner, University of Missouri-Kansas City, Institute for Human Development (UMKC-IHD). The grant lead, Missouri Department of Health and Senior Services, Adult Brain Injury Program (DHSS-ABI) and other partners, including Brain Injury Association of Missouri (BIA-MO), also played a consistent and active role in creating the plan.

## Methodology

The development of Missouri's Five-Year Brain Injury State Plan took place over the course of a year and was divided into three primary phases. Each stage supported a data-driven, representative final product.

In **Phase One**, the grant team reviewed past Missouri Five-Year State Plans to solidify an understanding of preceding objectives and to identify opportunities for continuity. The team also compiled TBI state plans from other grantee states and reviewed their plans. This process promoted an understanding of common national TBI priorities and provided concrete examples of activities to be translated into a Missouri context. It also provided a foundation for making structural and organizational updates to the state plan.

In this phase, we also conducted a review of existing TBI-related data in Missouri. Incidence and prevalence rates of TBI are difficult to reliably capture, but this summary looked at a variety of sources to understand the impact that TBIs have on Missourians and existing needs of those affected by a TBI. This report sets the stage for the creation of the state plan by creating a foundation of knowledge about TBI in the state and issuing a list of recommendations to improve the lives of TBI survivors and the people who support them in Missouri.

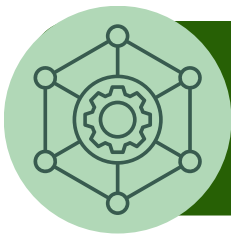
Updates on state plan progress and findings from the data summary were presented to the Missouri Brain Injury Advisory Council (MBIAC) at their quarterly meeting. Council members provided feedback and asked questions about the process. At this meeting, a Five-Year State Plan Subcommittee was formed.

A first draft of the Five-Year State Plan began to take shape during **Phase Two** of this process. Based on findings from past Missouri state plans, other states' TBI plans, and the MO TBI Data Summary, the grant team began to identify key focus areas for the 2024-2029 plan. Over a series of meetings, representatives from DHSS-ABI, BIA-MO, and UMKC-IHD developed a basic outline for the plan's priority areas and began to identify realistic and actionable activities for each. This framework was disseminated to the Five-Year State Plan Subcommittee and several working meetings were held with this group to workshop and build out the plan. After several meetings and rounds of feedback, a draft of the plan was completed and presented at the next MBIAC meeting. Meeting participants had the opportunity to make comments and suggestions, which were considered for the final plan. In this phase, the grant team also met with a representative from another state in a similar stage of their five-year state plan development process. This peer learning opportunity provided space for brainstorming and best practice sharing.

In the final stage of plan development, **Phase Three**, a full draft of the Five-Year State Plan was completed. A more condensed, accessible version was also developed and disseminated for public comment. Two open-ended questions were asked about the plan: What excited people about it, and what was missing from it. A Likert-scale question about overall satisfaction with the plan was also asked. Finally, people were able to write any additional thoughts in a comment box. The plan was disseminated virtually, and partner organizations helped spread the word through support groups, social media, the MBIAC, and more.

## Plan Implementation

Many of the activities listed in this state plan are related to activities proposed in the ACL TBI State Partnership Program Grant. As such, many will be led by members of the grant team (DHSS-ABI, BIA-MO, and UMKC-IHD). Other partners who may contribute to the implementation of specific state plan activities are listed alongside those activities.



## Infrastructure

## Education & Awareness



## Resources

## Prevention



# Priority Area 1: Infrastructure



## Key Findings

- MO TBI Data
  - o Current and comprehensive data on incidence, prevalence, experiences, and outcomes among TBI survivors in Missouri is limited.
  - o Accessing data from a representative sample of TBI survivors statewide is a challenge.
  - o TBI data from racially, ethnically, and geographically diverse populations is limited.
    - Limited data suggest TBI survivors of different backgrounds report differences in their experiences.
- Statewide feedback suggests a need to streamline system of supports to reduce confusion and fragmentation. MBIAC plays a crucial role in shaping policy and systems change.

## Goal 1: Establish an annual MO 'state of the state on brain injury' data brief.

### *Year 1 Activities:*

1. Analyze and summarize Needs Assessment as well as data from DHSS-ABI Program and Brain Injury Waiver (BIW).
  - a. Utilize ABI Program Service Coordinator Assessment results to guide trainings and programming.\*
  - b. Conduct evaluation of BIW. Use data to guide programmatic improvement.\*
  - c. Summarize and disseminate Needs Assessment and other research findings through reports, conferences, and digital media.\*
2. Prioritize recruitment of diverse input for grant activities (e.g. needs assessments).\*

\*Funded grant activities

### *Years 2-5 Activities:*

1. Establish a data-focused MBIAC sub-committee.
2. Identify additional data sources and explore data sharing agreements (e.g. registry data, Missouri Information for Community Assessment (MICA) disparities in outcomes, quality, per capita spending related to other states).



3. Monitor change over time on key indicators to demonstrate trends and progress.
4. Foster awareness of data brief.

### *Stakeholders and Potential Partners:*

Individuals with lived experiences and families as well as BIA-MO, DHSS-ABI, UMKC-IHD and MBIAC

## Goal 2: Enhance diversity and reach of the MO Brain Injury Advisory Council (MBIAC).

### *Year 1 Activities:*

1. Increase survivor membership and engagement in MBIAC; foster recruitment through partnerships and support groups.\*
2. Recruit representation from Centers for Independent Living (CILs) and Protection & Advocacy to serve on MBIAC.\*
3. Participate in monthly National workgroups to learn about programmatic and systems best practices.\*

### *Years 2-5 Activities:*

1. Continue MBIAC member survey to monitor progress and ensure diverse representation.\*
2. Recruit representation from leadership in Aging field to serve on MBIAC.
3. Recruit representation from Veteran community to serve on MBIAC.
4. Establish partnerships with outdoor/recreational groups and initiatives to provide unique opportunities for TBI survivors to participate in outdoor programming and activities.\*
5. Develop accessible board training and resource kit. \*
6. Create sustainability plan for funding activities beyond grant period using Program Assessment Sustainability Tool (PSAT).\*

\*Funded grant activities

### *Stakeholders and Potential Partners:*

Individuals with lived experiences and families as well as BIA-MO, DHSS-ABI, UMKC-IHD and MBIAC





## Goal 3: Enhance and expand statewide collaborative model for robust continuum of care and support to Missourians living with brain injury.

### *Year 1 Activities:*

1. Initiate MO Brain Injury Resource Facilitation (MOBIRF) Pilot in St. Louis area, including the identification of and outreach to potential referral sites within the St. Louis rehabilitation community.\*
2. Collaboratively create a logic model to support the development and strategic implementation of MOBIRF, in addition to establishing clear expectations for all stakeholders.\*
3. Establish a formalized referral process between state departments and community resources including BIA-MO, DHSS-ABI, Department of Mental Health – Developmental Disabilities (DMH-DD), MO Assistive Technology (MoAT), and Vocational Rehabilitation (VR) Departments.
4. Complete MOBIRF Pilot in St. Louis area and strategically begin to roll out an early version of the MOBIRF Model to other targeted areas.\*
5. Increase client access to meaningful assistive technology (AT) through regional AT Academy Trainings for staff.\*

### *Years 2-5 Activities:*

1. Develop a formalized MOBIRF Model that can be replicated across Missouri, regardless of community, and shared on a national level.\*
2. As MOBIRF continues to evolve based on experience and feedback from various communities, further expand MOBIRF's reach to areas not already targeted.\*
3. Establish a plan for targeted outreach to social service networks serving populations such as youth, re-entry, justice-involved, domestic violence, and behavioral health.
4. Implement strategic outreach efforts to other states to identify best practices.
5. Determine feasibility of a long-term maintenance program for individuals with lived experience who are no longer receiving funded services.

\*Funded grant activities

### *Stakeholders and Potential Partners:*

Individuals with lived experiences and families as well as BIA-MO, DHSS-ABI, UMKC-IHD, MBIAC, NASHIA, MO VR, and MoAT

# Priority Area 2: Education & Awareness



## Key Findings

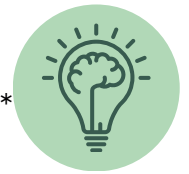
- Service providers report that they feel they lack the knowledge or skills to best serve people living with a brain injury (BI).
  - In 2019, 76% of community service providers indicated that they had moderate, minimal, or no knowledge of TBI supports and services.
  - Those who did indicate higher levels of awareness of supports and services often indicated that they did not have knowledge about the adequacy of available services.
- Among surveyed professionals, medical and school personnel were most likely to report that they had no knowledge or minimal knowledge about services for those with lived experience.
- TBI training opportunities are not reaching community-based supports and services providers. Only about half of surveyed professionals indicated that TBI training was part of their professional education.
- In the survey, many of those with lived experience indicated that they have had negative experiences in healthcare settings, often related to a lack of empathy from their provider and a lack of confidence in their provider's knowledge of brain injury-related issues. Nearly 60% say their doctor does not understand their TBI. Overall, respondents reported feeling misunderstood, anxious, and frustrated with past interactions with providers.
- Family members and those with lived experience are also interested in additional information and education opportunities, according to the 2019 survey which indicated that nearly 75% had at least one unmet information and referral need. This survey also revealed that the biggest barrier to accessing needed services was being unaware of available services and resources. Additionally, there was considerable interest in TBI-related continuing education opportunities on topics such as aging with a brain injury, ongoing care, and support after a brain injury.

**Goal 1:** Develop and expand learning opportunities for professionals, including school personnel, community-based supports and services providers, and healthcare professionals.

### *Year 1 Activities:*

1. Enhance Brain Injury Education online training.\*
2. Expand BIA-MO's Sports Concussion Seminars to include diverse presenters and on-demand viewing options.\*

3. Increase capacity of partner organizations to effectively serve brain injury survivors through Certified Brain Injury Specialist (CBIS) training.\*
4. Continue BIA-MO Annual Conference for professionals.\*



### *Years 2-5 Activities:*

1. Expand reach of BIA-MO Speaker's Bureau educational presentations and recorded trainings.\*
2. Explore partnerships and strategies to expand brain injury-related awareness and learning opportunities for healthcare providers and those working within the legal field.

\*Funded grant activities

### *Stakeholders and Potential Partners:*

Survivors and families, BIA-MO, DHSS-ABI, UMKC-IHD, MBIAC, Missouri Athletic Trainers' Association \*

## Goal 2: Develop and expand learning opportunities for survivors, families, and caregivers.

### *Years 1-5 Activities:*

1. Continue Brain Injury Fact of the Day (BIA-MO).\*
2. Launch a brain injury podcast to expand upon content covered in Survivor and Family Seminars (BIA-MO).\*
3. Expand BIA-MO Survivor and Family to make them available on-demand on BIA-MO website.\*
4. Explore partners beyond TBI.

\*Funded grant activities

### *Stakeholders and Potential Partners:*

Individuals with lived experiences and families as well as BIA-MO, DHSS-ABI, UMKC-IHD, MBIAC, MO Family-to-Family (MO F2F) and American Stroke Foundation

# Priority Area 3: Resources



## Key Findings

- One of the biggest barriers those with lived experience encounter when accessing supports and services is difficulty understanding processes and completing paperwork.
  - In a 2017 survey, 43% of survivors identified this as an issue they encounter.
- Many have unmet needs related to continuing education resources and information and dissemination resources, indicating a need for accessible, culturally competent materials.
- Although concussion estimates vary, there are estimates that approximately 30% of the U.S. adult population has sustained a concussion in their lifetime. Another study found that 42% of those who fit the CDC definition of having a sustained TBI never sought medical treatment. Because of this, identifying TBI is an important part of connecting those with lived experience to services and supports, and TBI screenings are effective in identifying potential brain injuries.
- Previous data show that “Return to Learn” academic adjustments are not often consistently used in schools throughout Missouri.

## Goal 1:

Develop and expand access to culturally competent resources that promote self-determination, independence, and quality of life.

### *Year 1 Activities:*

1. Make publicly available TBI documents 508 compliant, including Concussion Management “The Team Plan” and others.\*
1. Review and update BIA-MO BI Recovery Step-by-Step Guide and distribute to new medical and community-based care providers.\*
2. Extend access to and awareness of Get Schooled on Concussions (GSOC) materials for school personnel throughout the state.

### *Years 2-5 Activities:*

1. Use The TBI 2022 Data Summary: Report on Missouri TBI Data for 5-Year State Plan to guide ongoing information and resource development and dissemination efforts.\*
2. Partner with MoAT to enhance and expand TBI tech kits (incorporating outcomes evaluation) and to develop person-centered and culturally competent assessments to match survivors with AT.\*



3. Enhance BIA-MO Community Resource Services by exploring text options and additional networking opportunities to learn best practices. Explore partnerships that can inform culturally competent content and strategies to reach a more diverse population (e.g. Health Literacy Media).\*
4. Increase diversity of support group offerings through specialized support group pilots (e.g. groups for teens with a BI, for those who are long-term survivors, or for residents of rural communities—including farmers and ranchers).\*
5. Explore potential opportunities to partner with MoAT regarding their efforts to address the “Digital Divide”.

\*Funded grant activities

### *Stakeholders and Potential Partners:*

Individuals with lived experiences and families as well as, BIA-MO, DHSS-ABI, UMKC-IHD, MBIAC, school personnel, medical providers, and associations such as Missouri Rural Health Association

## Goal 2: Expand community-based brain injury screening capacity and opportunities.

### *Years 1-5 Activities:*

1. Expand TBI screenings at health-related community events and health fairs throughout the state, conducted by DHSS-ABI Service Coordinators.\*
2. Explore using evidence-based screening tool, such as Ohio State University (OSU) Screener at screening events and potentially explore embedding OSU Screener in DHSS-ABI intake process.
3. Increase capacity of school personnel to support students in Return-to-Learn and through TBI screenings.

\*Funded grant activities

### *Stakeholders and Potential Partners:*

Individuals with lived experiences and families as well as BIA-MO, DHSS-ABI, UMKC-IHD, MBIAC, school personnel, local public health departments and Area Agencies on Aging (AAAs)

# Priority Area 4: Prevention



## Key Findings

- While rates of concussions, or mild TBIs, vary, one study estimates that approximately 30% of the adult population in the U.S. has sustained a concussion at some point in their lives.
- School sports are governed by Return to Play protocol established by Missouri's Interscholastic Youth Sports Brain Injury Prevention Act, but club sports are not held to these same protocols.
- Previous data show that in Missouri:
  - Athletic trainers are often available only sporadically at sporting events.
  - Rates of annual concussion education among school professionals is low.

## Goal 1: Develop and distribute youth-focused brain injury prevention information and resources.

### *Years 1-5 Activities:*

1. Develop prevention-focused curriculum or resource, guided by the BIA-MO Save Your Brain program content, that teachers may incorporate into their lessons.
2. Non-School Team Initiative: Provide education and resources to encourage concussion prevention, care management and protocol development for recreational, community, club and other non-school associated teams.
3. Partner with the MO Department of Natural Resources (MO DNR) to expand use of bike helmets through an awareness campaign and helmet distribution events.\*
4. Collaborate with ThinkFirst Missouri to assist in targeting youth-related prevention efforts.

\*Funded grant activities

### *Stakeholders and Potential Partners:*

Survivors and families, BIA-MO, DHSS-ABI, UMKC-IHD, MO DNR, school personnel, non-school sports teams, coaches, leaders, and personnel, and UM Extension



## Goal 2: Enhance Missouri's injury prevention network through strategic relationship building.

### *Years 1-5 Activities:*

1. Establish or enhance MBIAC representation on existing relevant councils and coalitions, such as Show Me Falls Free Missouri Coalition.
2. Identify collaborators for violence prevention efforts statewide, such as Missouri Injury and Violence Prevention Advisory Committee (MIVPAC) and MO Coalition Against Domestic and Sexual Violence (MOCADSV).
3. Foster community partnerships with youth-focused organizations.\*
4. Identify potential partnerships within the areas of reentry/justice-involved and behavioral health.

\*Funded grant activities

### *Stakeholders and Potential Partners:*

Individuals with lived experiences and families as well as BIA-MO, DHSS-ABI, UMKC-IHD, MBIAC, MOCADSV, MIVPAC

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