

2017 Missouri Traumatic Brain Injury Needs Assessment Executive Summary

*Report on the TBI Survivor / Family Needs Assessment Survey and
the Professional Service Provider Needs Assessment Survey*

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Executive Summary

The Missouri Traumatic Brain Injury (TBI) Needs Assessment is supported through the Missouri TBI Implementation Partnership project. The overall goal of this project is *“to provide individuals with traumatic brain injuries and their families with improved access to comprehensive, multidisciplinary, coordinated, and easily accessible systems of care.”*

Historically the State of Missouri has conducted needs assessments every five years to inform the development of a Missouri Five Year Plan, which guides the provision of services and supports for individuals with TBI and their families. As a part of this project, an intensive needs assessment was completed ten years ago that involved interviews and focus groups with survivors, their families, and the professionals that serve them. A needs assessment conducted approximately five years ago was designed to build upon the earlier effort through surveys focused on survivors, their families, and the professionals who serve them. The current needs assessment, conducted with survivors of TBI, their family members, and professionals, builds upon these previous efforts and provides updated information on current needs of, and service availability to, the Missouri TBI community. Results will again be used to inform the development of a Missouri Five Year Plan.

Background

In Missouri, the number of TBIs treated in emergency rooms and hospitals is tracked by the Missouri Information for Community Assessment (MICA). This data shows that around 15,000 people are treated for traumatic brain injury each year in Missouri. In 2014, a total of 16,839 people who had a skull fracture or intracranial injuries visited an emergency room. Of these, 4,824 (29%) received inpatient hospitalization. Many more people who sustain a TBI go untreated, seek care in another medical setting, or are misdiagnosed. While there is no

estimate for unreported TBIs in Missouri, some estimate the national figure to be as high as 3 million annually.

Methodology

The research team at the University of Missouri—Kansas City Institute for Human Development (UMKC-IHD) collected survey data from multiple sources to determine the mental and behavioral health needs of Missouri’s TBI survivors, their families, and service professionals. The Missouri TBI Survivor and Family Needs Assessment included 49 questions regarding TBI survivors’ demographics, perceived needs, satisfaction regarding the services they received/are receiving, as well as the barriers they are facing. Links to the online version and paper copies were disseminated throughout the state by support coordinators and service provider organizations.

The Missouri TBI Professional Needs Assessment included 45 questions about professional affiliation, services provided, knowledge, training needs and perception of barriers and gaps in service related to TBI. The web link to the electronic questionnaire was distributed to a wide group of professionals including medical personnel, school nurses, educators, veteran service personnel, vocational rehabilitation staff and a number of general community groups such as first responders and law enforcement personnel.

Key Findings

TBI Survivor and Family Member Needs Assessment Survey

- The majority of individuals with TBI (63.0%) were diagnosed within the first week of injury—51.8% were diagnosed in the same day as the injury.
- There were marked increases in which of the following health conditions TBI survivors experienced from before to after the TBI occurred: cognitive (9.1% vs. 82.6%), physical

(9.8% vs. 63.0%), behavior change (11.2% vs. 60.1%), language (7.2% vs. 54.7%), depression (24.3% vs. 65.9%), and chronic pain (12.3% vs. 54.0%)

- Most respondents reported that the following areas of their lives got worse after their TBI: psychological status (87.2%), income (85.9%), general health (85.3%), employment (83.7%), interpersonal / social (80.8%), marriage (76.2%), education (66.7%), and living situation (59.3%)
- Over half of respondents (54.7%) reported that they want to live in a different place from where they are currently living. Of those, 51.0% wanted to live “independently without assistance” or “in own apartment/home with outside assistance” and about 48% wanted to live with family.
- Over a quarter of respondents (27.5%) identified insufficient financial resources as a barrier to their desired living situation, followed by lack of employment (15.6%) and need help coordinating and planning for services (11.2%).
- When asked, “Did anyone provide you with information or advise you about services available for people with traumatic brain injury?” less than half of the survivors (44.6%) reported that information had been provided.
- Almost 85% of TBI survivors received emergency room care at the time of injury and reported that they were generally satisfied with these services.
- Among the 186 people who received hospital admission at the time of injury, about half (58.1%) reported that they received discharge planning services before they left. The average level of satisfaction with the discharge planning service is 3.2, which is between satisfied and very satisfied
- The average satisfactory rating for Medical and Hospital Services was “*Satisfied*”.

- The average satisfactory rating for Acute Rehab services was almost “*Very Satisfied*”.
- The average satisfactory rating for Community Services and Supports was almost “*Very Satisfied*”.
- There is a statistically significant increase in satisfaction level with home health from year 2011 to year 2017.
- There is a statistically significant increase in satisfaction levels with financial management, legal services, and housing assistance from year 2011 to year 2017.
- Over half of the respondents (n=181, 65.6%) reported that they have met professionals providing services related to TBI who need to learn more about TBI.
 - ✓ The most frequently identified professionals who need to learn more about TBI include teachers (76.8%), law enforcement personnel (72.4%), and principals (70.2%).
 - ✓ Most of these respondents (82.3%) indicated that professionals need more general knowledge about TBI. Respondents also indicated that professionals need additional training or information on managing cognitive changes (76.2%), specific knowledge about needs (76.2%), and additional information on available services for TBI (76.2%).

Professional Needs Assessment Survey

- Most professionals reported having either minimal (44.3%) to moderate (41.3%) knowledge of available supports and services for individuals with TBI and their families, whereas fewer than 10% reported having a great deal of knowledge on the subject.
- Over half of respondents (58.3%) served 20 or fewer individuals with TBI in the last five years.

- There was a significant increase in the mean rating of service adequacy from five years ago to today for the following services:
 - ✓ Urgent care
 - ✓ Doctor's office service
 - ✓ Hospital discharge planning
 - ✓ Acute rehab services (inpatient/outpatient rehab, and home health)
 - ✓ Service coordination
 - ✓ Mental health counseling
 - ✓ Information and referral
- Mean service adequacy ratings of respite service are significantly lower in 2017 than 2012.
- Adequacy in discharge planning and continuing education have had a statistically significant increase since 2007.
- Adequacy in inpatient rehab is significantly lower in 2017 than it was 10 years ago.

The findings of this needs assessment are not definitive; they suggest areas to explore in greater depth regarding TBI and survivors' needs for resources and support. The findings could be considered when improving policies and strengthening programs throughout Missouri.