# TBI SURVIVOR AND FAMILY NEEDS ASSESSMENT SURVEY RESULTS

## PROJECT BACKGROUND

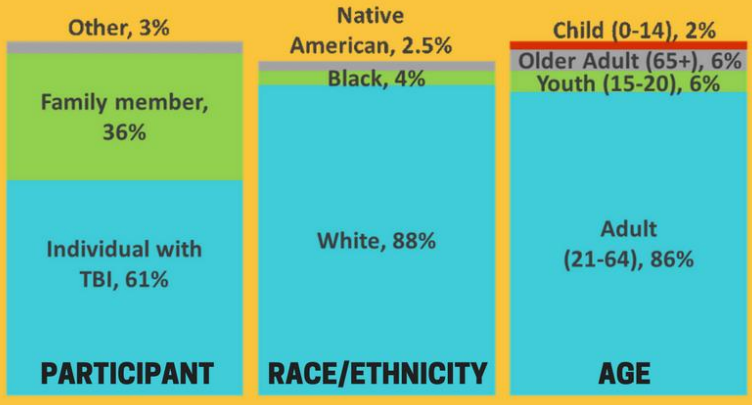
The Missouri Traumatic Brain Injury (TBI) Needs Assessment gathered information from survivors, family members, and professionals on the needs of and service availability to the Missouri TBI community. The goal of the needs assessment was to systematically identify needs and measure the gaps between current conditions and wanted conditions through participation of these groups.

An intensive needs assessment was done five years ago that involved interviews and focus groups with survivors, their families, and the professionals who serve them. The assessment conducted over the past year was designed to build upon this effort.

## WHO PARTICIPATED?

**276** Survivors and family members completed the needs assessment survey

### PARTICIPANT DEMOGRAPHICS




57.6% of participants were male; 41.3% were female

Participants represented 146 zip codes in 55 Missouri counties. Other participants included residents of Kansas (6), Illinois (4), and Iowa (2).

## TBI AND OTHER HEALTH CONDITIONS

**65%** of participants experienced TBI **less than 10 years ago**

**63.4%** reported their age **at the time of injury** as between **21-64 years old**

**52.6%** reported being diagnosed with TBI on the **same day** as the injury

### PARTICIPANT REPORTED HEALTH CONDITIONS

| HEALTH CONDITION | BEFORE TBI | AFTER TBI |
|---|---|---|
| Behavior change | 11.2% | 60.1% |
| Chronic pain | 12.3% | 54.0% |
| Cognitive | 9.1% | 82.6% |
| Depression | 24.3% | 65.9% |
| Language | 7.2% | 54.7% |
| Physical | 9.8% | 63.0% |
| Sensory | 9.4% | 50.0% |
| Sleep disorder | 13.0% | 50.4% |

## IMPACT OF TBI

Life areas rated by **at least 75% of participants** as having **worsened** included:

- Marriage (76.2%)
- Interpersonal/social (80.8%)
- Employment (83.7%)
- Income (85.9%)
- General health (85.3%)
- Psychological status (87.2%)

### LIVING ARRANGEMENTS: CURRENT AND DESIRED

| LIVING OPTIONS | CURRENTLY LIVING | DESIRED LIVING |
|---|---|---|
| Assisted living facility | 1.1% | 1.1% |
| Group home | 1.1% | 0.7% |
| Independently without assistance | 26.4% | 38.0% |
| Nursing facility | 2.2% | 0.0% |
| Own home with outside assistance | 17.0% | 16.7% |
| With family member | 47.1% | 29.0% |
| Other | 5.8% | 6.9% |

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## SERVICES AND SUPPORTS

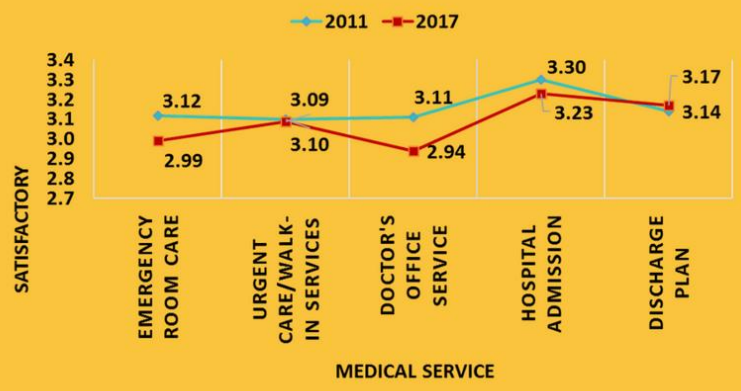
**50.7%** **of survivors reported receiving no information about services available for people with TBI.**

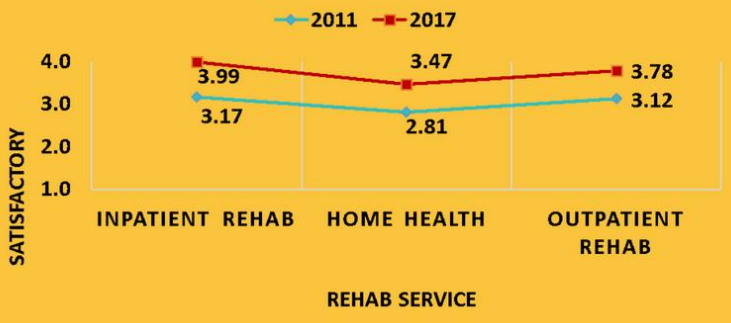
**Participants were asked to report services needed but not received. These included:**

- Information and referral (37.3%)
- Recreation services (30.8%)
- Continuing education related to TBI (29.3%)
- Financial management (29.0%)
- TBI support groups (28.6%)
- Service coordination (24.6%)

## SERVICE SATISFACTION: 2011 VS. 2017

0 = Don't Know; 1 = Very Inadequate; 2 = Somewhat Inadequate; 3 = Somewhat Adequate; 4 = Very Adequate




## PROBLEMS ACCESSING SERVICES

- Difficulty understanding process (43.1%)
- Unaware of services and resources (40.2%)
- Inability to pay for needed services (31.2%)
- Insurance does not cover needed services (30.1%)
- Services and resources not located locally (26.8%)
- Lack of support (25.7%)

## SERVICES LISTED BY PARTICIPANTS AS WORKING WELL

- TBI support groups
- Service coordination/ case management
- Medical care, respite, other support
- Vocational rehab, other rehab
- BIA and facility resources

## IMPROVEMENT FOR PROFESSIONALS

**65.6%** of participants responded that they have met professionals who need to learn more about TBI

**Professionals rated as needing improved TBI knowledge:**

**MEDICAL/HOSPITAL**
family medical provider (54.7%)
Emergency room medical provider (47.0%)
Nurse (44.8%)

**COMMUNITY SERVICE PROVIDERS & PERSONNEL**
Law enforcement (72.4%)
Social worker (64.6%)
Mental health professional (61.3%)

**EDUCATOR/SCHOOL**
Teacher (76.8%)
Principal (70.2%)
School nurse (66.9%)

**REHABILITATION**
Administrator (62.4%)
Physical therapist (59.1%)
Occupational therapist (57.5%)

**SUGGESTED AREAS OF IMPROVEMENT**

- General TBI knowledge (82.3%)
- Managing cognitive changes (76.2%)
- Specific knowledge about needs (76.2%)
- Available TBI services (76.2%)
- Managing emotional/ behavioral changes (74.0%)
- Managing medical/ physical changes (68.5%)
- Interpersonal (52.5%)
- Promoting skills for independence (50.8%)
- Employment (40.3%)
- Housing (33.1%)

## IMPROVEMENT TO STATEWIDE SERVICES

Participant suggestions to improve statewide services and supports for people with TBI and their families:

- TBI education and awareness to general public, medical professionals, and service providers
- TBI support (such as in-home respite, support groups, people first support)
- Easy access to resources and TBI programs

Brain Injury Association of Missouri | Missouri DHSS Department of Health and Senior Services | UMKC Institute for Human Development