

An abstract graphic consisting of several overlapping circles and lines. Two large circles are at the top right, one smaller one is in the middle right, and a large shaded circle is at the bottom right. Lines connect these circles and extend across the page.

Traumatic Brain Injury Needs Assessment Survey

The information gathered will be used to help develop a Missouri Plan to improve services and supports for people living with Traumatic Brain Injury (TBI) and their families.



Institute for Human Development
A University Center for Excellence in Developmental Disabilities (UCEDD)

A collaborative project of the Missouri Department of Health and Senior Services and the University of Missouri Kansas City-Institute for Human Development.

**Missouri Traumatic Brain Injury Implementation Partnership Project
Survivor & Family Needs Questionnaire**

The information gathered will be used to help develop a Missouri Plan to improve services and supports for people living with Traumatic Brain Injury (TBI, all ranges of severity including concussion) and their families. Your opinions and responses are very important to this effort. After you complete the survey please return in the postage paid return envelope provided. You may also complete this survey online at: <http://j.mp/2iapLL8>. We anticipate it will take approximately 15 to 25 minutes to complete. Thank you for participating. We very much appreciate your time in completing this important survey.

The survey is anonymous, and you will not be individually identified. Participation in the survey is voluntary. You are not required to participate. You may also choose not to answer any specific questions. By completing the survey and returning it to the investigators, you are volunteering to participate in this research.

If you have any questions about this needs assessment project you may contact **Dr. George S. Gotto** from the UMKC Institute for Human Development at (816) 235-5334 or gottog@umkc.edu. If you have any questions about your rights as a research participant, please contact the Office of UMKC's Institutional Review Board at (816) 235-5927. Thank you for your support and cooperation.

Demographics
<p>1. Which best describes you (person completing survey)?</p> <p><input type="checkbox"/> I am a person with TBI (if under age 18 please complete with parent/guardian)</p> <p><input type="checkbox"/> I am a family member of a person with TBI (responding on behalf of a survivor of TBI)</p> <p><input type="checkbox"/> Other: Please Specify _____</p>
<p>2. Which best describes you (survivor of TBI):</p> <p><input type="checkbox"/> Child with TBI (0-14 years old) <input type="checkbox"/> Adult with TBI (21-64 years old)</p> <p><input type="checkbox"/> Youth with TBI (15-20 years old) <input type="checkbox"/> Older Adult with TBI (65 years or older)</p>
<p>3. Are you (survivor of TBI) a military service member?</p> <p><input type="checkbox"/> Current military service member</p> <p><input type="checkbox"/> Former military service member</p> <p><input type="checkbox"/> Never a military service member</p>
<p>4. Gender of person with TBI:</p> <p><input type="checkbox"/> Male</p> <p><input type="checkbox"/> Female</p> <p><input type="checkbox"/> Other (e.g. transgender)</p>
<p>5. Race/ Ethnicity of person with TBI:</p> <p><input type="checkbox"/> White Non-Hispanic <input type="checkbox"/> Asian</p> <p><input type="checkbox"/> Black Non-Hispanic <input type="checkbox"/> Pacific Islander</p> <p><input type="checkbox"/> Hispanic <input type="checkbox"/> Native American</p> <p><input type="checkbox"/> Other: _____</p>
<p>6. The zip code in which the person with TBI currently lives:</p> <p>Zip code: _____</p>

TBI and Other Health Conditions

7. In what year did the injury occur? _____

8. Age at the time of injury? _____

9. How long after the injury were you (survivor of TBI) diagnosed with the TBI?

- | | | |
|-------------------------------------|---|---------------------------------------|
| <input type="checkbox"/> Same day | <input type="checkbox"/> Within 6 months | <input type="checkbox"/> 1-5 years |
| <input type="checkbox"/> First week | <input type="checkbox"/> 6 months to 1 year | <input type="checkbox"/> Over 5 years |

10. Please indicate any disabilities or significant health conditions that you (survivor of TBI) already had **BEFORE** the TBI (*Mark all that apply*):

- | | |
|--|--|
| <input type="checkbox"/> Behavior / personality change (e.g. acting out, aggression, social inappropriateness) | <input type="checkbox"/> Post Traumatic Stress Disorder (PTSD) |
| <input type="checkbox"/> Chronic pain (e.g. headaches) | <input type="checkbox"/> Seizure disorder |
| <input type="checkbox"/> Cognitive (memory, processing, problem solving) | <input type="checkbox"/> Sensory (vision, hearing, taste, smell) |
| <input type="checkbox"/> Depression | <input type="checkbox"/> Sleep disorder |
| <input type="checkbox"/> Diabetes | <input type="checkbox"/> Substance use disorder (alcohol) |
| <input type="checkbox"/> Language (e.g. communication, expression, and understanding) | <input type="checkbox"/> Substance use disorder (drugs) |
| <input type="checkbox"/> Physical (balance, other mobility) | <input type="checkbox"/> Other mental health conditions (e.g. anxiety) |
| | <input type="checkbox"/> Other: _____ |

11. Please indicate any disabilities or significant health conditions that you (survivor of TBI) developed **AFTER** the TBI (*Mark all that apply*):

- | | |
|--|--|
| <input type="checkbox"/> Behavior / personality change (e.g. acting out, aggression, social inappropriateness) | <input type="checkbox"/> Post Traumatic Stress Disorder (PTSD) |
| <input type="checkbox"/> Chronic pain (e.g. headaches) | <input type="checkbox"/> Seizure disorder |
| <input type="checkbox"/> Cognitive (memory, processing, problem solving) | <input type="checkbox"/> Sensory (vision, hearing, taste, smell) |
| <input type="checkbox"/> Depression | <input type="checkbox"/> Sleep disorder |
| <input type="checkbox"/> Diabetes | <input type="checkbox"/> Substance use disorder (alcohol) |
| <input type="checkbox"/> Language (e.g. communication, expression, and understanding) | <input type="checkbox"/> Substance use disorder (drugs) |
| <input type="checkbox"/> Physical (balance, other mobility) | <input type="checkbox"/> Other mental health conditions (e.g. anxiety) |
| | <input type="checkbox"/> Other: _____ |

Impact of TBI on You (Person Completing Survey)

12. Has the injury affected any of the following areas of **YOUR (person completing survey) life?** (*Mark all that apply*)

a. Marriage / romantic relationship

No change Is better Is worse

b. Interpersonal / social

No change Is better Is worse

c. Education

No change Is better Is worse

d. Employment

No change Is better Is worse

e. Income

No change Is better Is worse

f. Living situation

No change Is better Is worse

g. General health

No change Is better Is worse

h. Parenting

No change Is better Is worse

i. Psychological status

No change Is better Is worse

Living Situation

13. Where do you (survivor of TBI) currently live?

Assisted living facility

Group home (residential care facility)

Independently with no assistance

Other: _____

Nursing facility

Own apartment / home with outside assistance

With family member

14. Where do you (survivor of TBI) want to live?

Assisted living facility

Group home (residential care facility)

Independently with no assistance

Other: _____

Nursing facility

Own apartment / home with outside assistance

With family member

15. If you (survivor of TBI) are not living where you want to live, why not? (*Mark all that apply*)

Not applicable

Can't get the in-home services I need (e.g. personal care, homemaking services)

Can't get the medical care I need

Can't get the rehabilitation therapy I need (e.g. physical, speech, occupational)

Don't have access to transportation

Insufficient financial resources

Lack of access to accessible and affordable housing

Lack of employment

Need help coordinating and planning for services

Need specialized training and services (e.g. cognitive training, behavioral supports, community living skills training)

Other: _____

→ If you (survivor of TBI) are currently living in a nursing facility, please answer Questions 16-19.

→ If not living in a nursing facility, please skip to Question 20.

16. How long have you (survivor of TBI) lived in a nursing facility?

- | | | |
|---|---|--|
| <input type="checkbox"/> Less than 3 months | <input type="checkbox"/> 6 months to 1 year | <input type="checkbox"/> 3 to 5 years |
| <input type="checkbox"/> 3 to 6 months | <input type="checkbox"/> 1 year to 3 years | <input type="checkbox"/> 5 years or more |

17. You (survivor of TBI) moved to a nursing facility from:

- | | | |
|---|------------------------------------|---------------------------------------|
| <input type="checkbox"/> Acute rehabilitation program | <input type="checkbox"/> Hospital | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Group home | <input type="checkbox"/> Your home | _____ |

18. Reason for admission to the nursing facility (Mark all that apply):

- Couldn't get the in-home services I need (e.g. personal care, homemaking services)
- Couldn't get the medical care I need
- Couldn't get the rehabilitation therapy I need (e.g. physical, speech, occupational)
- Insufficient financial resources
- Lack of access to accessible and affordable housing
- Lack of access to transportation
- Lack of employment
- Lack of help coordinating and planning for services
- Lack of needed specialized training and services (e.g. cognitive training, behavioral supports, community living skills training)
- Other: _____

19. Do you (survivor of TBI) wish to return to the community from the Nursing Facility?

- Yes (answer question 19a) No (answer question 19b)

a. If yes, what is preventing you (survivor of TBI) from moving (Mark all that apply)?

- Couldn't get the in-home services I need (e.g. personal care, homemaking services)
- Couldn't get the medical care I need
- Couldn't get the rehabilitation therapy I need (e.g. physical, speech, occupational)
- Insufficient financial resources
- Lack of access to accessible and affordable housing
- Lack of access to transportation
- Lack of employment
- Lack of help coordinating and planning for services
- Lack of needed specialized training and services (e.g. cognitive training, behavioral supports, community living skills training)
- Other: _____

b. If no, why not? _____

Services and Supports

20. Following your injury, did anyone provide you (survivor of TBI) with information or advise you about services available for people with traumatic brain injury?

Yes No (go on to question 21)

a. Was this information provided before you left the hospital or doctor's office?

Yes No

b. Who provided you with information or advised you? (Mark all that apply):

Attorney

Rehabilitation staff / vocational rehabilitation

Brain Injury Association (BIA)

Social worker / service coordinator / counselor

Family / friends

Other: _____

Medical professional (doctor, PA, nurse) _____

Medical and Hospital Services

For questions 21-24, please tell us where you (survivor of TBI) received care at the time of injury. For each service received, please also rate your satisfaction with the service.

21. Received emergency room care at time of injury:

Yes No (go on to question 22)

a. Please rate your level of satisfaction with the emergency room care:

Very Dissatisfied

Very Satisfied

1

2

3

4

22. Received urgent care or walk-in clinic services at time of injury:

Yes No (go on to question 23)

a. Please rate your level of satisfaction with the urgent care or walk-in clinic services:

Very Dissatisfied

Very Satisfied

1

2

3

4

23. Received doctor's office services at time of injury:

Yes No (go on to question 24)

a. Please rate your level of satisfaction with the doctor's office services:

Very Dissatisfied

Very Satisfied

1

2

3

4

24. Admitted to a hospital at the time of injury:

Yes No (go on to question 25)

a. Please rate your level of satisfaction with the hospital services:

Very Dissatisfied				Very Satisfied
1	2	3	4	
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

b. Did you receive discharge planning services before you left? (someone giving you information about the care you would need at home and helping to arrange services)

Yes No (go on to question 25)

c. What kind of discharge plans were provided to you by the hospital?

- Discharge to home with home-based rehabilitation services
- Discharge to home with travel outpatient therapy and services
- Discharge to nursing home or facility
- Discharge to residential brain injury rehabilitation program

d. Please rate your level of satisfaction with the discharge planning services:

Very Dissatisfied				Very Satisfied
1	2	3	4	
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Acute Rehabilitation Services

Please tell us about any acute rehabilitation services *related to brain injury* that you (survivor of TBI) are currently receiving or have received in the past. Acute rehabilitation offers therapy for speech, physical movement, thinking problems (e.g. memory, problem solving), emotional issues, sensory issues, occupational therapy, and taking care of yourself.

25. Inpatient Rehabilitation

- Currently receiving services Needed services but did not receive (go on to question 26)
- Received services in the past Did not need (go on to question 26)

a. Level of satisfaction with inpatient rehab services:

Very Dissatisfied				Very Satisfied
1	2	3	4	
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

26. Home Health (nursing or therapies)

- Currently receiving services Needed services but did not receive (go on to question 27)
- Received services in the past Did not need (go on to question 27)

a. Level of satisfaction with home health services:

Very Dissatisfied				Very Satisfied
1	2	3	4	
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

27. Outpatient Rehabilitation

- Currently receiving services Needed services but did not receive (go on to question 28)
 Received services in the past Did not need (go on to question 28)

a. Level of satisfaction with outpatient rehabilitation services:

Very Dissatisfied			Very Satisfied
1	2	3	4
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Community Services and Supports

Please describe the services you (survivor of TBI) received in the past or are currently receiving. Please also rate your level of satisfaction with these services.

28. Employment Services

- Currently receiving services Needed services but did not receive (go on to question 29)
 Received services in the past Did not need (go on to question 29)

a. Level of satisfaction with employment services:

Very Dissatisfied			Very Satisfied
1	2	3	4
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

29. In-Home Services (e.g. attendant care, homemaker services)

- Currently receiving services Needed services but did not receive (go on to question 30)
 Received services in the past Did not need (go on to question 30)

a. Level of satisfaction with in-home services:

Very Dissatisfied			Very Satisfied
1	2	3	4
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

30. Transportation Services

- Currently receiving services Needed services but did not receive (go on to question 31)
 Received services in the past Did not need (go on to question 31)

a. Level of satisfaction with outpatient transportation services:

Very Dissatisfied			Very Satisfied
1	2	3	4
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

31. Service Coordination or Case Management Services

- Currently receiving services Needed services but did not receive (go on to question 32)
 Received services in the past Did not need (go on to question 32)

a. Level of satisfaction with service coordination or case management services:

Very Dissatisfied			Very Satisfied
1	2	3	4
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

32. Treatment for Substance Use Disorder

- Currently receiving services
- Needed services but did not receive (go on to question 33)
- Received services in the past
- Did not need (go on to question 33)

a. Level of satisfaction with substance use services:

Very Dissatisfied			Very Satisfied
1	2	3	4
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

33. Mental Health Counseling

- Currently receiving services
- Needed services but did not receive (go on to question 34)
- Received services in the past
- Did not need (go on to question 34)

a. Level of satisfaction with mental health counseling services:

Very Dissatisfied			Very Satisfied
1	2	3	4
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

34. Use of Assistive Technologies (such as a communication board or wheelchair)

- Currently receiving services
- Needed services but did not receive (go on to question 35)
- Received services in the past
- Did not need (go on to question 35)

a. Level of satisfaction with assistive technologies:

Very Dissatisfied			Very Satisfied
1	2	3	4
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

35. Respite Care

- Currently receiving services
- Needed services but did not receive (go on to question 36)
- Received services in the past
- Did not need (go on to question 36)

a. Level of satisfaction with respite care services:

Very Dissatisfied			Very Satisfied
1	2	3	4
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

36. TBI Support Groups

- Currently receiving services
- Needed services but did not receive (go on to question 37)
- Received services in the past
- Did not need (go on to question 37)

a. Level of satisfaction with TBI support groups:

Very Dissatisfied			Very Satisfied
1	2	3	4
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

37. Assistance with Financial Management

- Currently receiving services Needed services but did not receive (go on to question 38)
 Received services in the past Did not need (go on to question 38)

a. Level of satisfaction with financial management assistance services:

Very Dissatisfied			Very Satisfied
1	2	3	4
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

38. Recreation Services

- Currently receiving services Needed services but did not receive (go on to question 39)
 Received services in the past Did not need (go on to question 39)

a. Level of satisfaction with recreation services:

Very Dissatisfied			Very Satisfied
1	2	3	4
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

39. Legal Services

- Currently receiving services Needed services but did not receive (go on to question 40)
 Received services in the past Did not need (go on to question 40)

a. Level of satisfaction with legal services:

Very Dissatisfied			Very Satisfied
1	2	3	4
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

40. Section 8 or Other Housing Assistance

- Currently receiving services Needed services but did not receive (go on to question 41)
 Received services in the past Did not need (go on to question 41)

a. Level of satisfaction with housing assistance services:

Very Dissatisfied			Very Satisfied
1	2	3	4
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

41. Assistance Applying for Social Security Disability Benefits

- Currently receiving services Needed services but did not receive (go on to question 42)
 Received services in the past Did not need (go on to question 42)

a. Level of satisfaction with assistance:

Very Dissatisfied			Very Satisfied
1	2	3	4
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

42. Continuing Education Related to TBI (seminars, workshops, conferences, classes, or newsletters)

- Currently receiving services Needed services but did not receive (go on to question 43)
 Received services in the past Did not need (go on to question 43)

a. Level of satisfaction with continuing education related to TBI:

- | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|
| Very Dissatisfied | | | Very Satisfied |
| 1 | 2 | 3 | 4 |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

43. Community Living Skills Training (such as cooking or money management)

- Currently receiving services Needed services but did not receive (go on to question 44)
 Received services in the past Did not need (go on to question 44)

a. Level of satisfaction with community living skills training:

- | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|
| Very Dissatisfied | | | Very Satisfied |
| 1 | 2 | 3 | 4 |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

44. Information and Referral Services (information about how to find the services you need)

- Currently receiving services Needed services but did not receive (go on to question 45)
 Received services in the past Did not need (go on to question 45)

a. Level of satisfaction with information and referral services:

- | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|
| Very Dissatisfied | | | Very Satisfied |
| 1 | 2 | 3 | 4 |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Additional Needs

45. Do you have any other comments about services that you need or that you have had trouble getting?

**46. What problems do you (survivor of TBI) have in getting the services you need related to TBI?
(Mark all that apply):**

- | | |
|---|---|
| <input type="checkbox"/> Difficulty understanding process or paperwork | <input type="checkbox"/> Insurance does not cover needed services |
| <input type="checkbox"/> Difficulty with English language | <input type="checkbox"/> Lack of support/patient advocacy |
| <input type="checkbox"/> Difficulty with enrollment/admissions | <input type="checkbox"/> Lack of transportation |
| <input type="checkbox"/> Do not have insurance | <input type="checkbox"/> Need help with financial management |
| <input type="checkbox"/> Do not have support to get a job | <input type="checkbox"/> Services and resources not located locally |
| <input type="checkbox"/> Do not have support to live where I want to live | <input type="checkbox"/> Unaware of services and resources |
| <input type="checkbox"/> Inability to pay for needed services | <input type="checkbox"/> Other: _____ |

47. What services and supports do YOU think work well for people with TBI and their families in MO?

48. Have you met professionals who need to learn more about TBI?

Yes No (go on to question 49)

a. If yes, who are these professionals? (Mark all that apply)

Medical/Hospital Personnel

- Discharge planner
- Emergency room medical provider
- Family medical provider
- Nurse
- Psychologists / neuropsychologists
- Other: _____

Educator/School Personnel

- Coach
- Principal
- School nurse
- Teacher
- Other: _____

Community Service Providers & Professionals

- Adult brain injury program provider
- Attorney
- First responders
- In home care provider
- Law enforcement personnel
- Mental health professional
- Social worker
- Vocational rehabilitation personnel
- Other: _____

Rehabilitation Personnel

- Administrator
- Occupational therapist
- Physical therapist
- Speech therapist
- Other: _____

Military Service Personnel

b. What additional training or information do these professionals need to improve their capacity to serve people with TBI and their families? (Mark all that apply):

- Available services and supports for individuals with TBI and their families
- Employment
- General knowledge about TBI (e.g. causes, types)
- Housing
- Interpersonal
- Promoting skills for independence
- Specific knowledge about the needs of people with TBI
- Understanding and managing communication and cognitive changes
- Understanding and managing emotional and behavioral changes
- Understanding and managing medical and physical changes
- Other _____

49. What do YOU feel needs to be done to improve statewide services and supports for people with TBI and their families?

Please enter your responses online at <http://j.mp/2iapLL8>, scan and email your completed survey to gottog@umkc.edu, or print and mail to:

George S. Gotto
UMKC Institute for Human Development
215 West Pershing Rd., Floor 5
Kansas City MO, 64108

Thank you for taking the time to complete this survey. If you would like more information about services and supports for TBI in Missouri, please visit the Department of Health and Senior Services website:

<http://health.mo.gov/living/families/shcn/>