Kansas Brain Injury Assessment: Individuals with a Brain Injury Survey

This survey is for individuals living with a brain injury in Kansas. We would appreciate hearing about your experiences and opinions. Your feedback will help find ways that organizations in Kansas can better serve those with a brain injury.

A few notes about the survey:

- Your responses will be anonymous.
- It will take 30 to 45 minutes to complete.
- If you are able, we ask that you complete the survey in its entirety. As a thank you for your time, at the end of the survey, you can enter your name into a drawing for a chance to win an Amazon gift card.

Phone option. *If you prefer to complete this survey over the phone instead, please contact Liz Gebhart-Morgan with Partners for Insightful Evaluation at liz@pievaluation.com or call 402-417-0034*.

Thank you in advance for your participation in this survey! Your input is incredibly valuable!

NOTE: This survey is meant to capture the experiences of the individual living with a brain injury. *If you are assisting or filling out this survey on behalf of someone with a brain injury, please answer the questions from the point of view of the person with the brain injury.*

Injury & Impacts

1. Age of your first brain injury: _____

2. How many total brain injuries have you experienced? _____

3. Indicate how many times you have experienced each type of brain injury listed below.

	Haven't experienced	1 Time	2 – 4 Times	5 or More Times
Automobile or motorcycle accident	☐	☐	☐	☐
Assault/abuse/domestic violence	☐	☐	☐	☐
Bicycle accident/pedestrian incident	☐	☐	☐	☐
Brain tumor (benign or malignant)	☐	☐	☐	☐
Fall	☐	☐	☐	☐
Firearms/weapons (gunshot to head)	☐	☐	☐	☐
Infection	☐	☐	☐	☐
Loss of oxygen supply (anoxia)	☐	☐	☐	☐
Near drowning incident	☐	☐	☐	☐
Sports related injury	☐	☐	☐	☐
Stroke/aneurysm	☐	☐	☐	☐
Other (please describe):				

4. About how long **AFTER** your first injury were you diagnosed with a brain injury?
   - ☐ Less than 3 months after injury
   - ☐ 3 to 6 months after injury
   - ☐ 6 months to 1 year after injury
   - ☐ 1 to 5 years after injury
   - ☐ More than 5 years after injury
   - ☐ I don't know or I am unsure

5. Select all that apply regarding your most severe brain injury:
   - ☐ No loss of consciousness
   - ☐ Loss of consciousness for 30 minutes or less
   - ☐ Loss of consciousness between 1 and 24 hours
   - ☐ Loss of consciousness for more than 24 hours
   - ☐ Treated by a doctor or therapist for a head injury
   - ☐ Had bleeding in the brain
   - ☐ Admitted to the hospital
   - ☐ Kept in the hospital for at least one night

6. Below are some commonly reported symptoms people may experience after having a brain injury and may not be a complete list. Select any you have experienced since your injury.
   - ☐ Anger
   - ☐ Balance/mobility issues
   - ☐ Changes in personality
   - ☐ Changes in sight
   - ☐ Depression
   - ☐ Difficulty controlling emotions
   - ☐ Difficulty following through on tasks
   - ☐ Difficulties with sleep
   - ☐ Fatigue
   - ☐ Headaches
   - ☐ Impulsivity
   - ☐ Memory issues
   - ☐ Sensitivity to light
   - ☐ Sensitivity to noise
   - ☐ Other (please describe):

7. Where do you go for social or emotional support? Select all that apply.
   - ☐ Family
   - ☐ Friends
   - ☐ Others with brain injury
   - ☐ I'm currently not receiving support
   - ☐ Other (please specify): _____
   - ☐ Support group
   - ☐ Church/synagogue
   - ☐ Online support group(s)

8. How often do you feel alone or isolated?
   - ☐ Never
   - ☐ Rarely
   - ☐ Often
   - ☐ Always

9. Indicate how much of a challenge you feel that each item on this list is for you.

	No challenge	*Minor challenge*	*Major challenge*
Coordinating doctor visits/appointments	☐	☐	☐
Finances (paying bills, budgeting)	☐	☐	☐
Finding resources and services	☐	☐	☐
Getting out in the community	☐	☐	☐
Household chores (laundry, washing dishes, sweeping, etc.)	☐	☐	☐
Maintaining intimate and/or family relationships	☐	☐	☐
Making friends	☐	☐	☐
Transportation	☐	☐	☐
Working	☐	☐	☐
Other challenges (please describe):			

10. Did any of the challenges in the previous question become worse during the COVID-19 pandemic?

☐ All of them ☐ A few of them

☐ Most of them ☐ None of them

11. Describe how the COVID-19 pandemic impacted your life as an individual with a brain injury.

12. If you would like, share how your brain injury or symptoms have changed your life.

Daily Living

13. What is your living situation? Select one.

- ☐ Alone
- ☐ With spouse/partner or other family members who I rely on to assist me with daily activities
- ☐ With spouse/partner or other family members who I do not rely on for assistance with daily activities
- ☐ In a group home
- ☐ In an adult care home or assisted living facility
- ☐ In a rehabilitation facility
- ☐ Moving between family and friends' homes
- ☐ Other (please specify): _____

14. How do you usually travel from place to place? Select all that apply.

- ☐ Drive myself
- ☐ Bicycle
- ☐ Walk
- ☐ Ride with family/friends
- ☐ Public transportation (bus/train/taxi/Uber)
- ☐ Wheelchair/scooter/golf cart
- ☐ I don't travel due to barriers (lack of funds, no wheelchair accessible options, etc.)
- ☐ Other (please specify): _____

15. How much of your day do you need someone available for assistance?

- ☐ None
- ☐ 1 to 7 hours each day
- ☐ 8 to 15 hours each day
- ☐ 16 to 24 hours each day

16. Since your injury, have you had help on a regular basis from anyone listed below with things such as meals, finances, care services, etc.?

	No, I haven't had this	*Yes, but not consistently since my injury*	*Yes, this person has helped since my injury*
Paid support staff/caregiver	☐	☐	☐
Spouse/partner or other family member (paid)	☐	☐	☐
Spouse/partner or other family member (unpaid)	☐	☐	☐
Friend	☐	☐	☐

Employment

17. What is your employment status?

- ☐ Student
- ☐ Employed part-time
- ☐ Employed full-time
- ☐ Retired
- ☐ Volunteer
- ☐ Not working – *skip to #19*

18. Is your current employment: – *after answering, skip to #20*

- ☐ The same as before my injury, without supports or accommodations
- ☐ The same as before my injury but with supports or accommodations
- ☐ A new job without supports or accommodations
- ☐ A new job with supports or accommodations

19. If you are not working, please check all of the following reasons that apply:

- ☐ My choice
- ☐ Previous job no longer an option
- ☐ Difficulties caused by brain injury(s)
- ☐ Can't find a job I would want to do or have an interest in
- ☐ Loss of benefits if employed or working
- ☐ Lack of transportation
- ☐ Lack of childcare
- ☐ Lack of training and education
- ☐ Need assistive technology to perform my job, such as screen readers, text-to-speech systems, phones with large buttons, etc.
- ☐ Other (please specify): _____

20. Which supports, if any, do you have to help with finding or keeping a job? Select all that apply:

- ☐ Family/friend advocate
- ☐ Vocational Rehabilitation counselor
- ☐ Job coach
- ☐ Other (please specify): _____
- ☐ Employment specialist
- ☐ None

Resources & Services

21. How aware are you of services, support, and resources available in your community for those with a brain injury?

- ☐ Not at all aware
- ☐ Slightly aware
- ☐ Moderately aware
- ☐ Very aware

22. How much difficulty have you had getting access to services to help with your brain injury?

- ☐ No difficulties
- ☐ A few difficulties
- ☐ Quite a few difficulties
- ☐ A lot of difficulties

23. What care coordination support do you have to help you access services?

- ☐ I have a professional care coordinator or case manager
- ☐ I rely on family or friends to help me access services
- ☐ I need, but do not have, someone to help me access services
- ☐ I do not need help accessing services
- ☐ I do not know what care coordination is

24. Mark your level of agreement with the following statements.

	Strongly disagree	*Disagree*	*Neither*	*Agree*	*Strongly Agree*
There are enough brain injury services available in my community.	☐	☐	☐	☐	☐
It would be helpful for me to know about mental health services for brain injury.	☐	☐	☐	☐	☐
I helped identify my treatment and rehabilitation goals.	☐	☐	☐	☐	☐
I am aware of my rights and what services or care should be available to me as a person with a brain injury.	☐	☐	☐	☐	☐

25. Which organizations have you accessed since your brain injury?

	Currently using	*Used in the past*	*Needed but couldn't get*	*Did not need*	*I don't know this organization*
Area Agency on Aging or Aging & Disability Resource Center	☐	☐	☐	☐	☐
Brain Injury Association of Kansas and Greater Kansas City	☐	☐	☐	☐	☐
Developmental Disability Agency	☐	☐	☐	☐	☐
Disability Rights Center	☐	☐	☐	☐	☐
Independent Living Center	☐	☐	☐	☐	☐
Kansas Rehabilitation Services (vocational rehab)	☐	☐	☐	☐	☐
Managed Care Coordination (through Sunflower, United or Aetna)	☐	☐	☐	☐	☐
United States Brain Injury Alliance	☐	☐	☐	☐	☐
Veteran's Affairs	☐	☐	☐	☐	☐
Youth Services	☐	☐	☐	☐	☐

26. What type of services have you utilized since your brain injury?

	Currently using	*Used in the past*	*Needed but couldn't get*	*Did not need/ not applicable*
Academic accommodations (services and supports for academic challenges)	☐	☐	☐	☐
Advocacy services (support navigating legal, medical, and/or brain injury support services)	☐	☐	☐	☐
Care coordination/case management (a professional to help arrange services you need)	☐	☐	☐	☐
Cognitive therapy (for attention, memory, initiation, problem solving, etc.)	☐	☐	☐	☐
Community and social skills training (how to act with others and/or in public)	☐	☐	☐	☐
Counseling/behavioral health services	☐	☐	☐	☐
Daily living skills training (to improve ability to shop, cook, do laundry, manage money, etc.)	☐	☐	☐	☐
Employment/vocational services (help getting or keeping a job)	☐	☐	☐	☐
Financial planning/budgeting	☐	☐	☐	☐
Home care support (assistance with bathing, dressing, meal preparation, etc.)	☐	☐	☐	☐
Housing assistance (help finding a place to live)	☐	☐	☐	☐
Independent living services	☐	☐	☐	☐
Physical therapy	☐	☐	☐	☐
Primary care provider	☐	☐	☐	☐
Social or recreation support (help with loneliness, opportunities to be around others)	☐	☐	☐	☐
Speech therapy	☐	☐	☐	☐
Support groups	☐	☐	☐	☐
Transportation assistance	☐	☐	☐	☐

27. Which services have been the most helpful or useful to you, and why?

28. Which of the following challenges or barriers have you experienced when trying to get help from any services? Select all that apply.

- ☐ Did not receive a referral
- ☐ Service providers do not understand brain injury
- ☐ Application and paperwork process are too difficult
- ☐ Service providers are not available in my community
- ☐ Too expensive
- ☐ Long waiting list
- ☐ Eligibility requirements
- ☐ Insurance limitations
- ☐ Lack of brain injury diagnosis documentation from qualified medical providers
- ☐ None
- ☐ Other (please describe): _____

29. Did any of the following stop you from getting the help you needed? Select all that apply.

- ☐ Afraid to ask for help because of what others might think
- ☐ Health insurance does not cover
- ☐ Lack of appropriate transportation
- ☐ Lack of access to technology
- ☐ Do not feel comfortable using it
- ☐ Family or caregiver does not think I need it
- ☐ Difficultly communicating with service providers
- ☐ Difficulty following up on tasks related to services
- ☐ None on this list
- ☐ Other (please describe): _____

General Feedback

30. What would help to improve services for those with a brain injury? Select all that apply.

- ☐ More education and training for professionals about brain injury
- ☐ Greater public awareness about brain injury
- ☐ More service providers
- ☐ More awareness about organizations that can provide support
- ☐ Better service coordination
- ☐ Improved case management
- ☐ Financial assistance
- ☐ Better insurance coverage for services
- ☐ Training for caregivers
- ☐ Peer support (a person with a brain injury helping another person with brain injury from their own experiences)
- ☐ Other (please specify): _____

31. What could be done to better help individuals with brain injury in your community or state?

Home and Community Based Services (HCBS) Brain Injury (BI) Waiver Program through Medicaid

The next set of questions are for individuals who are currently or were previously part of the Home and Community Based Services (HCBS) Brain Injury (BI) Waiver program. This is a Medicaid service offered through the Kansas Department for Aging and Disability Services (KDADS).

32. Have you or are you currently receiving services from the Home and Community Based Services Brain Injury Waiver Program?

- ☐ Yes, I previously have
- ☐ Yes, I currently am – *skip to #35*
- ☐ No – *skip to #35*
- ☐ Unsure – *skip to #35*

33. In your experience, are there enough resources and support available to you once you are no longer on the waiver program?

- ☐ Yes
- ☐ No
- ☐ Unknown

34. If you answered no to the previous question, what services or resources do you feel are missing?

Telehealth Services

35. Have you used your computer or a screen to meet with your doctor or receive therapy (telehealth)?

☐ Yes ☐ No, but I would ☐ No, and I wouldn't

36. Would you consider utilizing a computer or screen to meet with a doctor in any of the following situations?

	Yes, definitely	*Yes, probably*	*No, probably not*	*No, definitely not*
For a new patient/first time visit	☐	☐	☐	☐
For a visit with a health care professional you have already seen in the past/return visit	☐	☐	☐	☐
For a mental health concern	☐	☐	☐	☐
For a support group or mentor meeting	☐	☐	☐	☐
For physical therapy	☐	☐	☐	☐
For occupational therapy	☐	☐	☐	☐
For speech therapy	☐	☐	☐	☐

37. Which of the following would concern you about telehealth visits? Select all that apply.

☐ Privacy
☐ Difficulty seeing or hearing the health care professional
☐ Technical difficulties using the technology
☐ Lack of adequate internet service
☐ Screen time barriers
☐ Not feeling connected to the health care professional
☐ Health care professional not being able to do a physical exam
☐ Quality of care not being as good as a face-to-face visit
☐ Other (please specify): _____

Demographics

38. County where you live: _____

39. Your current age: _____

40. Are you:

- ☐ Female
- ☐ Male
- ☐ Prefer not to say
- ☐ _____

41. What is your race/ethnicity? Select all that apply.

- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Black/African American
- ☐ Hispanic/Latino
- ☐ Native Hawaiian or other Pacific Islander
- ☐ White
- ☐ Prefer not to say
- ☐ Other (please specify): _____

42. What is the highest degree or level of education you have completed?

- ☐ Less than a high school diploma
- ☐ High school diploma or equivalent
- ☐ Trade/technical/vocational training
- ☐ Some college, no degree
- ☐ Associate degree
- ☐ Bachelor's degree
- ☐ Graduate or professional degree

43. Have you served or are you currently serving in the military?

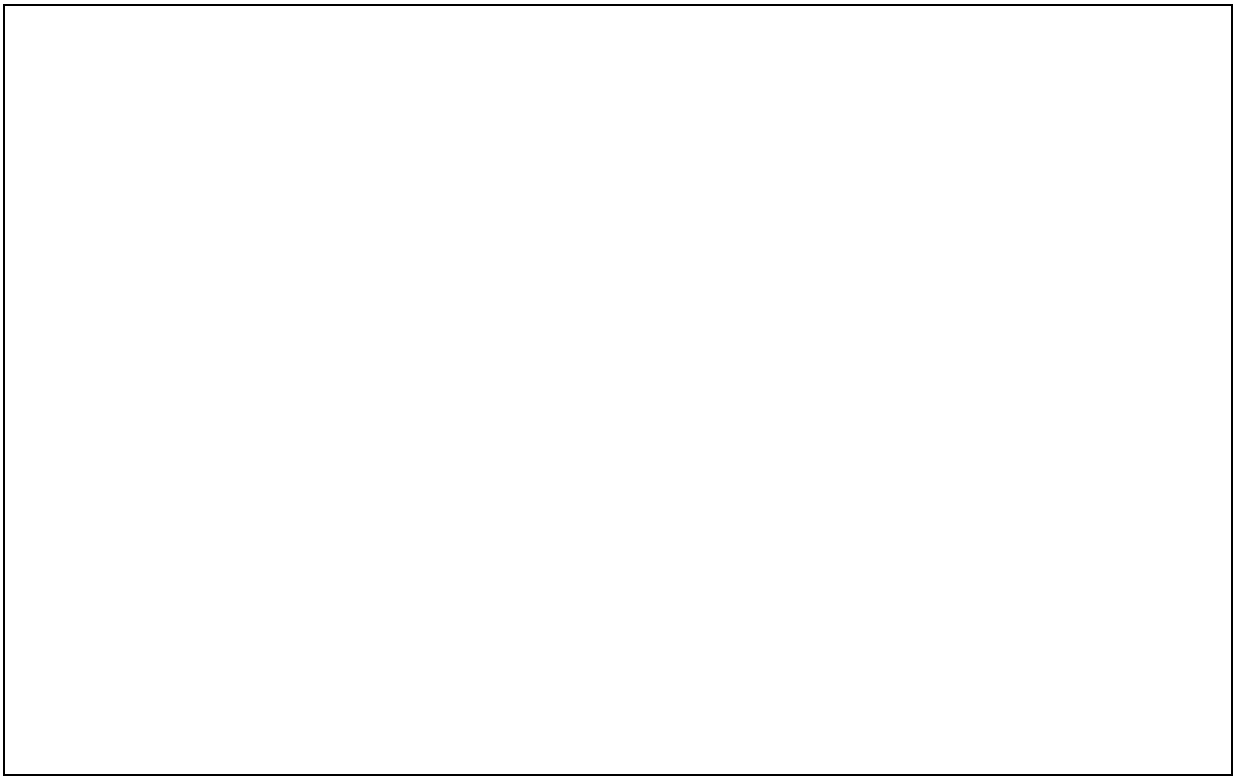
- ☐ Yes
- ☐ No

44. What type of insurance coverage do you <u>currently</u> have? Select all that apply.

- ☐ Insurance through current or former employer
- ☐ Insurance through spouse or another family member
- ☐ Insurance purchased directly from an insurance company
- ☐ Medicare (for people 65 and older or people with certain disabilities)
- ☐ Medicaid
- ☐ TRICARE or other military health care
- ☐ Military/Veteran's Affairs (VA)
- ☐ Indian Health Service
- ☐ No health insurance
- ☐ Unknown or unsure
- ☐ Other (please specify): _____

Final

45. Is there anything else you wish to tell us that we did not include on the survey? Please use the space on the top of the next page if needed.



Thank you for participating in this survey! We really appreciate your time and feedback.

If you are interested in being entered into a drawing to win an Amazon gift card, complete the information below. Your information will not be connected to your survey answers. A gift card will be emailed (or mailed, if needed) to you in August or early September 2022 as a thank you for participating in this survey.

Name:	
Email:	
Street Address:	
City, State, Zip:	
Phone Number:	