

Kansas Brain Injury Assessment: Feedback from Family Members & Unpaid Caregivers

This survey is for family members and unpaid caregivers/support persons of individuals living with a brain injury in Kansas. We value your input and would appreciate hearing about your experience and opinions.

A few notes about the survey:

- Your responses will be anonymous.
- It will take 15 to 20 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 wish to complete the survey over the phone instead, please contact Liz Gebhart-Morgan with Partners for Insightful Evaluation at liz@pievaluation.com or 402-417-0034.

Thank you in advance for your participation in this survey!

***NOTE:** This survey is meant to capture the experiences of those who are serving as an unpaid caregiver or natural supports for those living with a brain injury. That includes family members, legal guardian, durable power of attorney, etc. This would NOT include personal care attendants or other paid roles. Those individuals are encouraged to complete the service provider survey: <https://www.surveymonkey.com/r/BlserviceproviderKSsurvey>*

1. Which types of resources have you utilized to better understand caregiving for an individual with a brain injury?

	<i>Currently using</i>	<i>Used in the past</i>	<i>Need but have not accessed</i>	<i>Did not need</i>
Brochures	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Conferences	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Formal trainings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information/self-study trainings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Individualized consultations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Workshops	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. How do you feel about the amount of information and resources you have received related to caregiving?

- It's been less than I would like It's been more than I would like
 It's been about right

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

- Not at all aware Moderately aware
 Slightly aware Very aware

4. How much difficulty have you had trying to access and coordinate services for the individual with a brain injury (for example, knowing who to schedule appointments with, what services are needed, etc.)?

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

5. Which of the following challenges or barriers have you experienced when trying to get the individual with the brain injury help from services? Select all that apply.

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

6. From your perspective as a caregiver, to what degree are each of these barriers to getting services and supports for the individual with a brain injury?

	<i>Not a barrier</i>	<i>Minor barrier</i>	<i>Major barrier</i>
Being afraid to ask for help because of what others might think	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Health insurance does not cover it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of appropriate transportation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of access to technology	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate community support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate family support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate financial resources	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate peer support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of advocates	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of individualized services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
No centralized source for brain injury information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other (please describe):

7. What information, services, or resources have been helpful for you and/or the individual with the brain injury, and why? Please use the space on the top of the next page if needed.

8. From your perspective, how would you describe the gaps for the following services for people with a brain injury?

	No gap	Slight gap	Moderate	Significant	Unknown
	<i>All who need this service can get it</i>	<i>Most who need this service can get it</i>	<i>Some who need this service are unable to get it</i>	<i>Many who need this service are unable to get it</i>	
Academic accommodations (services and supports for academic challenges)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Advocacy services (support navigating legal, medical, and/or brain injury support services)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Care coordination/case management (a professional to help arrange the services you need)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cognitive therapy (for attention, memory, initiation, problem solving, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Community and social skills training (how to act with others and/or in public)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Counseling/behavioral health services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Daily living skills training (to improve ability to shop, cook, do laundry, manage money, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Employment/vocational services (help getting or keeping a job)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Financial planning/budgeting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Home care support (assistance with bathing, dressing, meal preparation, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Housing assistance (help finding a place to live)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Independent living services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physical therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Primary care provider	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social or recreation support (help with loneliness, opportunities to be around others)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Speech therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Transportation assistance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Caregiving Experiences

9. Has being a family member and/or caregiver to someone with a brain injury...

	Yes	No	Not Applicable
Caused you to stop working?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Caused you to reduce the number of hours you work?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Prevented you from gaining employment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Caused you personal financial hardships?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Caused you to feel emotional stress as a caregiver?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10. Below are some of the challenges people may experience as an unpaid caregiver/family member to someone with a brain injury. Indicate how much of a challenge each one currently is for you.

	No challenge	Minor challenge	Major challenge
Attending to my own care needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Coordinating appointments and care for the individual with a brain injury	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Finances (paying bills, budgeting, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Finding paid caregivers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Maintaining intimate and/or family relationships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Making friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Transportation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Working	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

11. Did any of those problems become worse because of the COVID-19 pandemic?

- All of them A few of them
 Most of them None of them

12. How often did you experience barriers with accessing or receiving services (either for yourself or the individual with the brain injury) during the COVID-19 pandemic?

- Never Often
 Rarely Always

13. What are some of the biggest changes and/or challenges you've experienced due to being a caregiver?

Potential Improvements

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

18. What do you wish you would have known when you first became a caregiver?

Caregiving Demographics

19. For how many individuals with a brain injury do you serve as an unpaid caregiver or natural support?

- | | |
|--|--|
| <input type="checkbox"/> 1 individual | <input type="checkbox"/> 3 individuals |
| <input type="checkbox"/> 2 individuals | <input type="checkbox"/> More than 3 individuals |

For the next 4 questions, answer them about the individual that you provide the most time and support to.

20. Is the person that you are serving as a caregiver for the most your:

- | | |
|--|--|
| <input type="checkbox"/> Spouse/Partner | <input type="checkbox"/> Child (under the age of 16) |
| <input type="checkbox"/> Parent | <input type="checkbox"/> Child (16 or older) |
| <input type="checkbox"/> Other (please specify): _____ | |

21. What role(s) do you serve for that individual? Select all that apply.

- Paid caregiver
- Unpaid caregiver
- Legal guardian
- Other (please specify): _____
- Payee or conservator
- Active Durable Power of Attorney

22. About how often do you provide care to that individual?

- I do not provide hands on care
- I provide care 24 hours per day
- Every day for a few hours
- A few days per week
- A few days per month
- Only occasionally or as needed

23. How long have you been providing care to that individual?

- Less than 1 year
- 1 to 3 years
- 3 to 5 years
- More than 5 years

Demographics

24. County where you live: _____

25. Your present age: _____

26. Are you:

- Female
- Male
- Prefer not to say
- _____

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

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

28. 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

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

- Yes
- No

General Feedback

30. Is there anything else you wish to tell us that we did not include on the survey?

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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:	