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/BIserviceproviderKSsurvey

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

<table>
<thead>
<tr>
<th></th>
<th>Currently using</th>
<th>Used in the past</th>
<th>Need but have not accessed</th>
<th>Did not need</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brochures</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Conferences</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Formal trainings</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information/self-study trainings</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Individualized consultations</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Workshops</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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
   - [ ] Slightly aware
   - [ ] Moderately 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
   - [ ] A few difficulties
   - [ ] Quite 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.

- Did not receive a referral
- Long waiting list
- Service providers do not understand brain injury
- Service providers are not available in my community
- Too expensive
- 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?

<table>
<thead>
<tr>
<th></th>
<th>Not a barrier</th>
<th>Minor barrier</th>
<th>Major barrier</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being afraid to ask for help because of what others might think</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Health insurance does not cover it</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Lack of appropriate transportation</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Lack of access to technology</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Inadequate community support</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Inadequate family support</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Inadequate financial resources</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Inadequate peer support</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Lack of advocates</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Lack of individualized services</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>No centralized source for brain injury information</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Other (please describe):</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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?

<table>
<thead>
<tr>
<th>Service</th>
<th>No gap</th>
<th>Slight gap</th>
<th>Moderate</th>
<th>Significant</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>Academic accommodations (services and supports for academic challenges)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Advocacy services (support navigating legal, medical, and/or brain injury support services)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Care coordination/case management (a professional to help arrange the services you need)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cognitive therapy (for attention, memory, initiation, problem solving, etc.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community and social skills training (how to act with others and/or in public)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Counseling/behavioral health services</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Daily living skills training (to improve ability to shop, cook, do laundry, manage money, etc.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employment/vocational services (help getting or keeping a job)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Financial planning/budgeting</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home care support (assistance with bathing, dressing, meal preparation, etc.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Housing assistance (help finding a place to live)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Independent living services</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical therapy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary care provider</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social or recreation support (help with loneliness, opportunities to be around others)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Speech therapy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support groups</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transportation assistance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Caregiving Experiences

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

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caused you to stop working?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caused you to reduce the number of hours you work?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prevented you from gaining employment?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caused you personal financial hardships?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caused you to feel emotional stress as a caregiver?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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.

<table>
<thead>
<tr>
<th>Challenge</th>
<th>No challenge</th>
<th>Minor challenge</th>
<th>Major challenge</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attending to my own care needs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coordinating appointments and care for the individual with a brain injury</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Finances (paying bills, budgeting, etc.)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Finding paid caregivers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maintaining intimate and/or family relationships</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Making friends</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transportation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

- □ All of them
- □ Most of them
- □ A few 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?
### Services & Support for Caregivers

14. Where do YOU go for social/emotional support? Select all that apply.

- [ ] Family
- [ ] Support group
- [ ] Friends
- [ ] Church/synagogue
- [ ] Other caregivers
- [ ] Online support group(s)
- [ ] I’m currently not receiving support
- [ ] Other (please specify): ____________________________________________________________

15. What type of services, coping mechanisms, and/or resources have you used for yourself as a caregiver to someone with a brain injury?

<table>
<thead>
<tr>
<th>Service Description</th>
<th>Currently Using</th>
<th>Used in the Past</th>
<th>Needed but couldn’t get</th>
<th>Did not need/ not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advocacy services (support navigating legal, medical, and/or brain injury support services)</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Alcohol and/or other substances</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Counseling/behavioral health services</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Educational events</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Financial support</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Physical exercise</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Respite care</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Social opportunities</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Support group</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Other (please describe):</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

16. Did any of the following stop you from getting the support you need as a caregiver or family member to someone with a brain injury? Select all that apply.

- [ ] No barriers
- [ ] Afraid to ask for help because of what others might think
- [ ] Health insurance does not cover
- [ ] Lack of transportation
- [ ] Lack of access to technology
- [ ] Do not feel comfortable using it
- [ ] Other (please describe): ____________________________________________________________
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?

☐ 1 individual
☐ 2 individuals
☐ 3 individuals
☐ 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:

☐ Spouse/Partner
☐ Parent
☐ Child (under the age of 16)
☐ Child (16 or older)
☐ Other (please specify): ____________________________________________________________
21. What role(s) do you serve for that individual? Select all that apply.
- [ ] Paid caregiver
- [ ] Unpaid caregiver
- [ ] Legal guardian
- [ ] Payee or conservator
- [ ] Active Durable Power of Attorney
- [ ] Other (please specify): ________________________________

22. About how often do you provide care to that individual?
- [ ] I do not provide hands on care
- [ ] A few days per week
- [ ] I provide care 24 hours per day
- [ ] A few days per month
- [ ] Every day for a few hours
- [ ] Only occasionally or as needed

23. How long have you been providing care to that individual?
- [ ] Less than 1 year
- [ ] 1 to 3 years
- [ ] More than 5 years
- [ ] 3 to 5 years

Demographics
24. County where you live: ________________________________

25. Your present age: _______________

26. Are you:
- [ ] Female
- [ ] Prefer not to say
- [ ] Male
- [ ] _________________

27. What is your race/ethnicity? Select all that apply.
- [ ] American Indian or Alaska Native
- [ ] Native Hawaiian or other Pacific Islander
- [ ] Asian
- [ ] White
- [ ] Black/African American
- [ ] Prefer not to say
- [ ] Hispanic/Latino
- [ ] Other (please specify): ________________________________

28. What is the highest degree or level of education you have completed?
- [ ] Less than a high school diploma
- [ ] Associate degree
- [ ] High school diploma or equivalent
- [ ] Bachelor’s degree
- [ ] Trade/technical/vocational training
- [ ] Graduate or professional degree
- [ ] Some college, no 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?

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.

<table>
<thead>
<tr>
<th>Name:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Email:</td>
</tr>
<tr>
<td>Street Address:</td>
</tr>
<tr>
<td>City, State, Zip:</td>
</tr>
<tr>
<td>Phone Number:</td>
</tr>
</tbody>
</table>