



## 2020 Brain Injury Services Survey

### Results

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## Introduction and Methodology

The Brain Injury Alliance of Nebraska (BIA-NE) developed the Brain Injury Services Survey for the purpose of learning more about what life is like for individuals with a brain injury several years after their injury. Questions that guided the development of the survey include:

- What is life like now compared to before sustaining a brain injury?
- What issues and barriers still persist?
- What services have been helpful in recovery?
- What are the most prominent needs for those several years post-injury?

The Brain Injury Services Survey was conducted online and was administered to individuals who are three or more years post-injury. The respondents included primarily individuals who have received services from BIA's Resource Facilitation (RF) program as well as some other individuals with a brain injury who have not been involved with the RF program.

A total of 27 individuals of brain injury participated in the survey (Table 1).

<b>Table 1</b>	<b>Brain Injury Services Survey Response Rate</b>	
<b>Number of surveys completed</b>	<b>Number of survivors invited to participate in the survey</b>	<b>Response rate</b>
27	180	15.0%

Note: 7 out of 27 respondents received help filling out the survey.

## Brain Injury History and Demographics

Table 2 presents the brain injury history of the respondents. Most respondents have been living with their brain injury for many years: the median time since first brain injury was 11.5 years and the median time since worst brain injury (if more than one brain injury has been sustained) was 8 years ago (Table 2).

Table 2	Brain Injury History	
<b>Number of brain injuries sustained (n=27)</b>	1-3	74.1%
	4-6	7.4%
	More than 6	18.5%
<b>Time since first brain injury (n=27)</b>	<i>Less than two years ago</i>	7.4%
	<i>2-4 years ago</i>	22.2%
	<i>5 or more years ago</i>	70.4%
	<b>Median</b>	<b>11.5 years</b>
<b>Time since worst brain injury (if have had more than one) (n=27)</b>	<i>Less than two years ago</i>	7.4%
	<i>2-4 years ago</i>	22.2%
	<i>5 or more years ago</i>	70.4%
	<b>Median</b>	<b>8 years</b>
<b>Type of brain injury sustained (n=27) (multiple responses possible)</b>	<i>Traumatic (such as motor vehicle crash, fall, assault, or other traumatic event)</i>	88.9%
	<i>Stroke</i>	3.7%
	<i>Anoxic/hypoxic</i>	7.4%
	<i>Infection, tumor, or other medical cause</i>	3.7%

Table 3 presents demographics of the respondents.

<b>Table 3</b>	<b>Respondent Demographics</b>	
<b>Age (n=27)</b>	<i>Under 20</i>	0.0%
	<i>20-39</i>	25.9%
	<i>40-59</i>	59.3%
	<i>60 and over</i>	14.8%
	<b>Median age</b>	<b>49 years</b>
<b>Home location (n=26)</b>	<i>Omaha Area*</i>	42.3%
	<i>Lincoln Area°</i>	30.8%
	<i>Greater Nebraska</i>	26.9%
<b>Gender (n=27)</b>	<i>Male</i>	51.9%
	<i>Female</i>	48.2%
<b>Level of education completed (n=27)</b>	<i>High school diploma / GED</i>	29.6%
	<i>Higher education certification</i>	7.4%
	<i>College degree</i>	48.2%
	<i>Advanced degree</i>	7.4%
	<i>None of the above</i>	7.4%
<b>Race/ethnicity (n=26)</b>	<i>White/Caucasian</i>	92.3%
	<i>Non-White/Caucasian</i>	7.7%

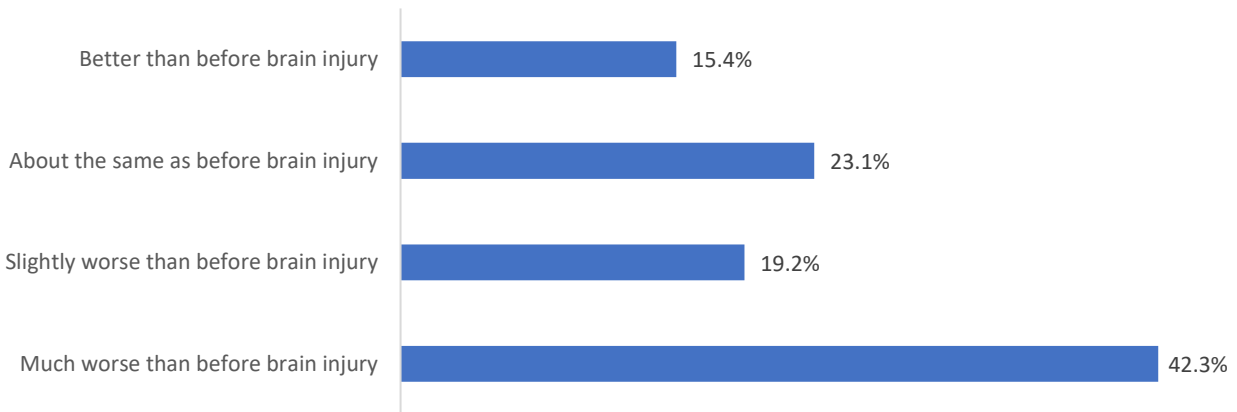
\*Omaha Area includes Douglas and Sarpy Counties and Council Bluffs.

°Lincoln Area includes Lancaster and Seward Counties.

## Life After Brain Injury

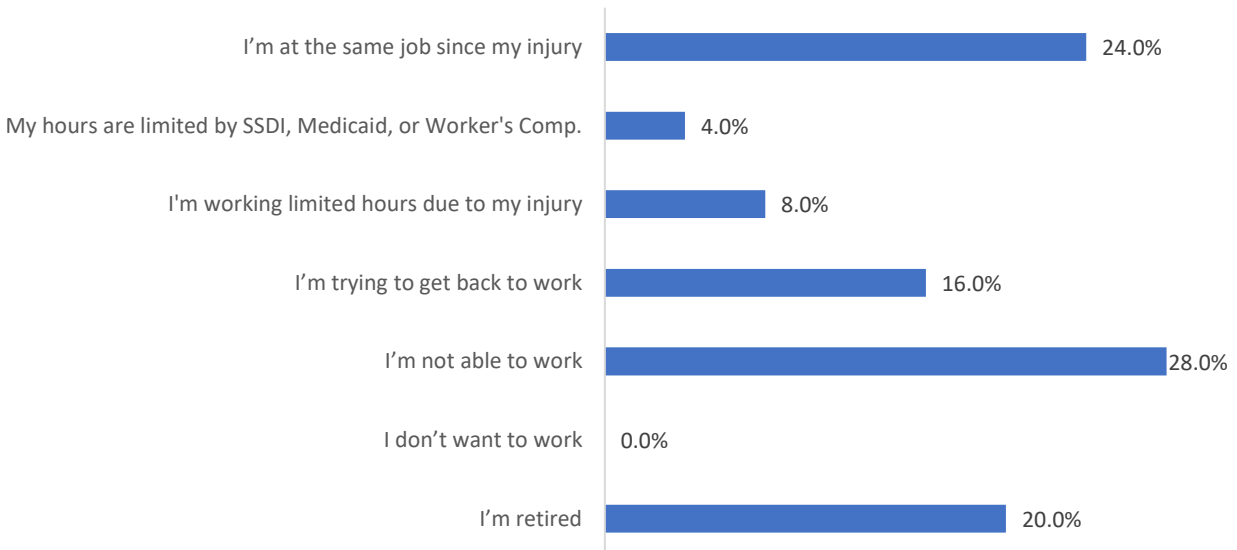
A majority (61.5%) of respondents report that their quality of life is either slightly worse or much worse than before their brain injury (Figure 1).

**Figure 1. How do you feel about your quality of life? (n=26)**



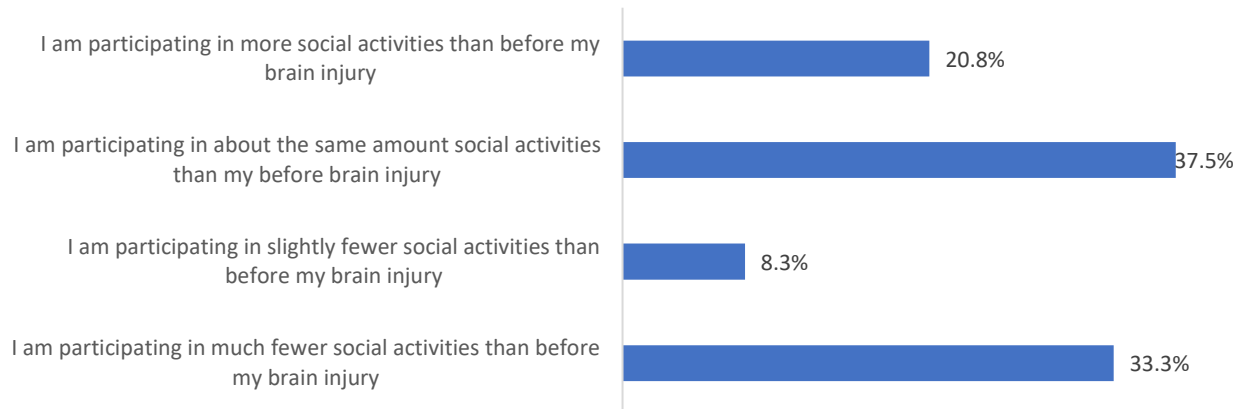
Most respondents have been impacted in some way in their ability to work since sustaining a brain injury. Just 24.0% reported that they are at the same job and 20% reported that they are retired. The remainder have varying impacts on their current ability to work (Figure 2).

**Figure 2. Have you been able to return to work? (n=25)**



Respondents were mixed in terms of their participation in social activities. Most (58.3%) reported that they are participating in more or about the same amount of social activities than before their brain injury. The remainder (41.6%) reported that they are participating in slightly or much fewer social activities (Figure 3).

**Figure 3. Do you participate in social activities? (n=24)**

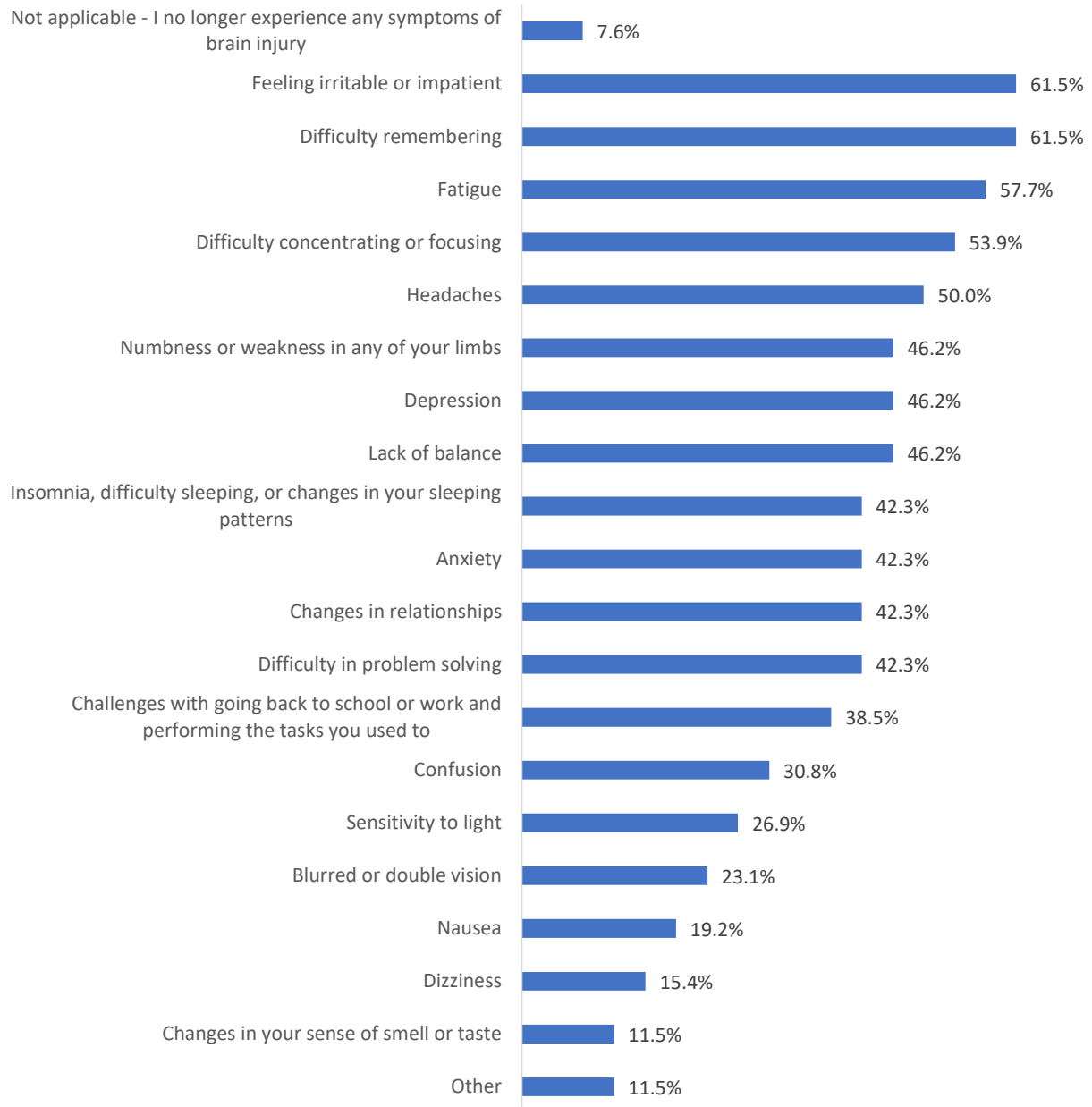


“Life saving techniques have continuously evolved to the point where survival after a BI is very common now, This is a very good thing, but that is only half of the battle. A life being saved is always going to be a good thing, but what kind of life is it going to be? Helping this population find their way back into society is an enormous challenge that we are only at the very beginning of addressing, as this issue will just continue to grow.”

-Survivor of brain injury

Respondents report experiencing numerous symptoms of brain injury, despite the fact that most are several years post-injury. From a long list of symptoms, respondents reported experiencing 7.7 symptoms on average. The most common symptoms include feeling irritable or impatient, difficulty remembering, fatigue, difficulty concentrating or focusing, and headaches. Each of these symptoms were reported by half or more of respondents (Figure 4).

**Figure 4. Are you still experiencing any of the following symptoms of brain injury? (select all that apply) (n=26)**  
***AVERAGE: 7.7 symptoms***

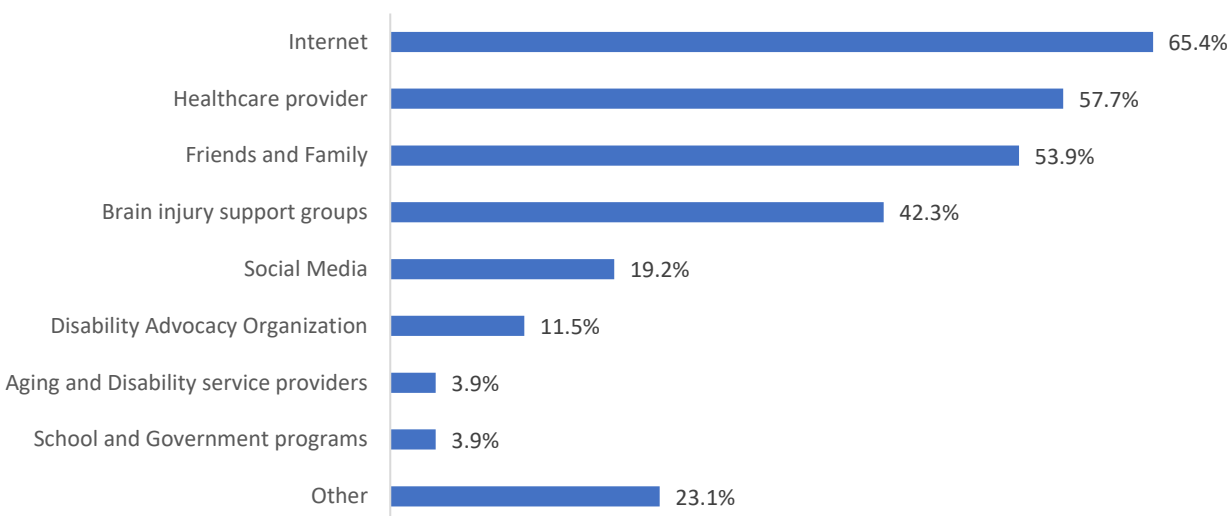


**Other responses:** Physical tolerance for activity; Balance issues , partial paralysis; smells/ differences

## Services and Support

Internet was most commonly selected as the source for information about brain injury resources and services (Figure 5).

**Figure 5. Where do you turn to for information about brain injury resources and services? (select all that apply) (n=26)**



**Other responses:** Brain Injury Alliance (4), BI community I've met through BIANE, Self-advocacy and various challenges equal therapy in finding solutions, I am an advocate for Nebraska Injured Brain Network (John Ferrone)

### Data Clarification (Figure 5)

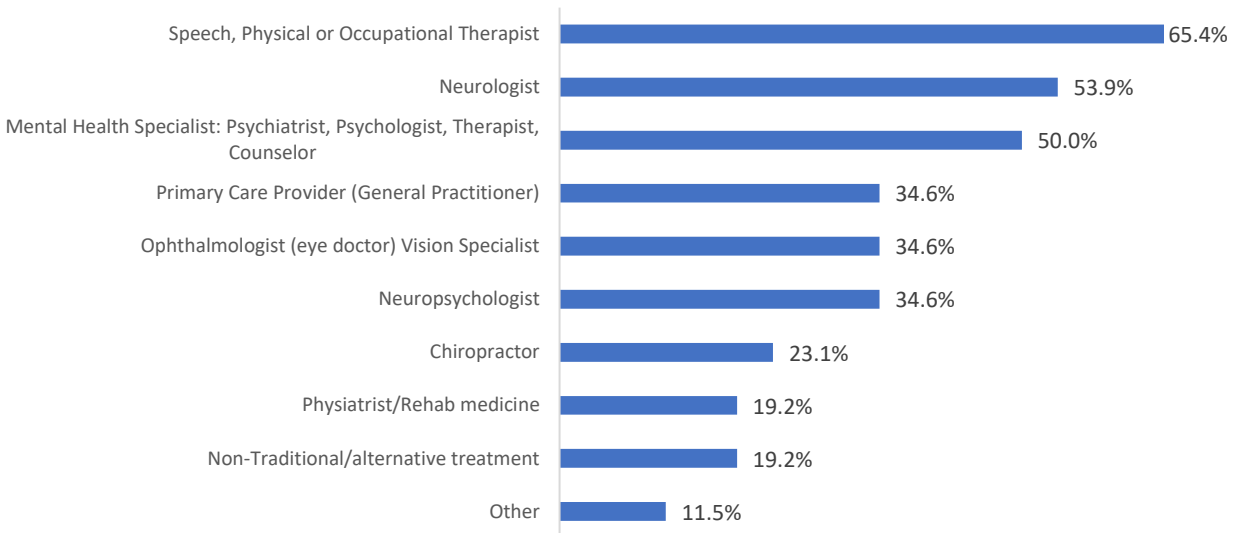
Although "Internet" was the most commonly selected source for information about brain injury, just one respondent (out of a possible 26) selected internet or social media as their only source for information about brain injury.

The vast majority of respondents (24 out of 26) selected one or more of the following for their source(s) for information about brain injury: healthcare provider, friends and family, brain injury support group, disability advocacy organization, aging and disability service providers, and school and government programs.



Speech, physical, or occupational therapist was most commonly selected as the medical-based service that has helped since brain injury (Figure 6).

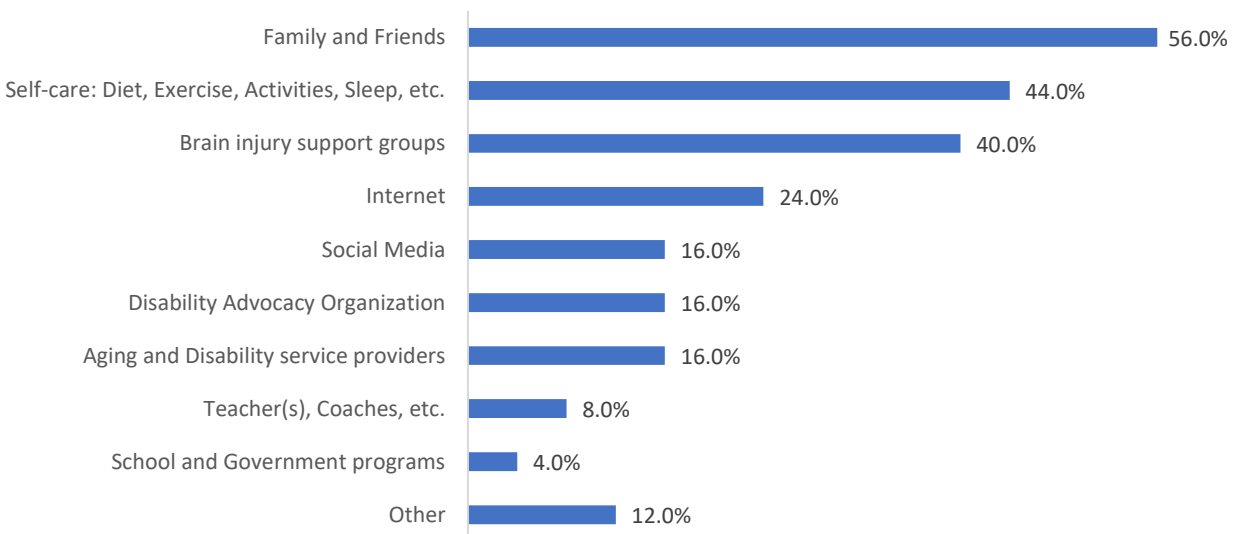
**Figure 6. From the list below, what medical-based services have helped you since your brain injury? (select all that apply) (n=26)**



**Other responses:** Great nutrition and exercise, Support group professionals, SURGEONS

Family and friends were the most commonly selected community-based support that has been helpful since brain injury (Figure 7).

**Figure 7. What community-based support and/or services have you found to be the most helpful since your injury? (select all that apply) (n=25)**

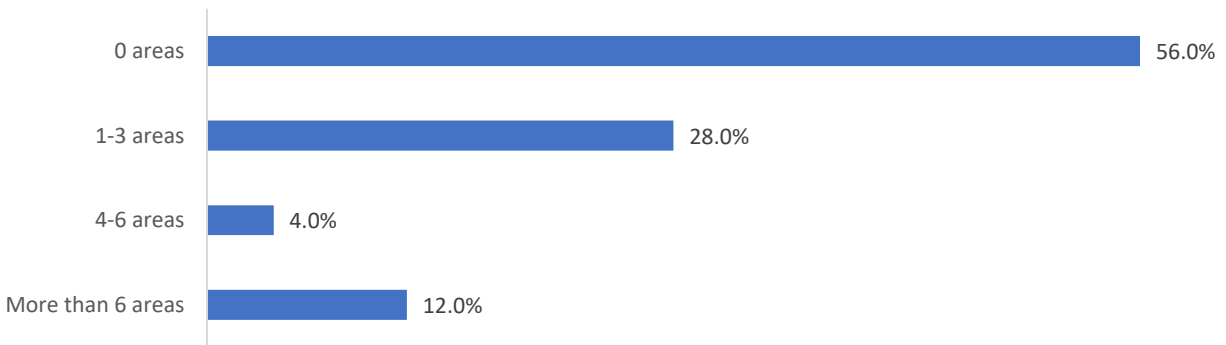


**Other responses:** Brain Injury Alliance (3), League of Human Dignity, Don't really have any sources besides neurologist with headaches, ENOA

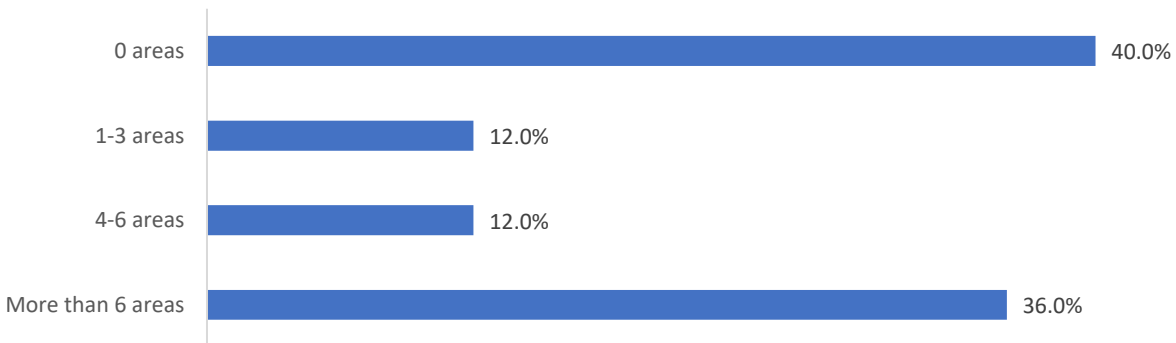
## Current Needs

The Survey of Unmet Needs and Services Utilized (SUNSU) is a validated instrument that was included within the Brain Injury Services Survey. Quite simply, the SUNSU includes a long list of services and respondents are asked to indicate if they are receiving help now for a service or are needing/wanting help (see next page for a full tabulation of the SUNSU). On average, respondents reported that they are receiving help now in 1.9 areas (Figure 8) and are needing/wanting help in 5.2 areas (Figure 9).

**Figure 8. SUNSU: Number of areas "receiving help now" (n=25)**  
**AVERAGE: 1.9 areas**



**Figure 9. SUNSU: Number of areas "needing/wanting help" (n=25)**  
**AVERAGE: 5.2 areas**



"I am a daily advocate of how life must be confronted, accepted, and be proud of one's new self. So many cannot understand for many years why they have changed, caregivers are mystified, everyone wants life as it was. After a reclusive life, which many experience from profound depression, I was able to pull out from a dark world and reconfigure my life for going forward. I try to pass optimism and understanding with everyone who is affected, survivors and caregivers."

-Survivor of brain injury

Table 4 presents a full tabulation of the SUNSU. By far, the area with the highest area of need was improving my memory, solving problems better. Other areas of higher need include increasing educational qualifications; managing stress, emotional upsets; and improving my health (Table 4).

<b>Table 4</b>	<b>Survey of Unmet Needs and Services Utilized (SUNSU) (n=24)</b>		
	<b>Receive help now (within the past 12 months)</b>	<b>Need/want help</b>	<b>Neither receiving help nor needing help</b>
Traveling in my community	24.0%	12.0%	64.0%
Finding housing that is affordable and accessible	12.0%	24.0%	64.0%
Increasing my income	4.0%	28.0%	68.0%
Improving my job skills	4.0%	28.0%	68.0%
Finding paid employment	8.0%	24.0%	68.0%
Increasing my educational qualifications	4.0%	32.0%	64.0%
Coordinating the services I receive	4.0%	28.0%	68.0%
Managing my money, pay bills	20.0%	16.0%	64.0%
Increasing my independence in housekeeping, cooking, shopping	16.0%	20.0%	64.0%
Caring for my children	0.0%	0.0%	100.0%
Handling legal problems	0.0%	12.0%	88.0%
Feeling part of my community	12.0%	20.0%	68.0%
Finding places and opportunities to socialize with others	16.0%	28.0%	56.0%
Obtaining personal care attendance/personal assistant services	8.0%	16.0%	76.0%
Controlling alcohol and/or drug use	4.0%	4.0%	92.0%
Improving my memory, solving problems better	0.0%	44.0%	56.0%
Controlling my temper	12.0%	12.0%	76.0%
Improving my mood	16.0%	28.0%	56.0%
Managing stress, emotional upsets	16.0%	32.0%	52.0%
Expressing my needs, understanding others	8.0%	24.0%	68.0%
Fulfilling my needs for intimacy	0.0%	16.0%	84.0%
Obtaining equipment such as wheelchairs, computer, etc.	4.0%	20.0%	76.0%
Improving my health	4.0%	32.0%	64.0%
Increasing my independence in eating, dressing, bathing, toileting, etc.	8.0%	4.0%	88.0%
Increasing my independence in walking, lifting, balancing	4.0%	16.0%	80.0%
Participating in sports and recreation	0.0%	28.0%	72.0%
Participating in religious services or spiritual programs	8.0%	8.0%	84.0%

## Open-Ended Comments

Tables 5 through 8 present open-ended comments.

Table 5	<b>What services and supports are missing in Nebraska for people living with effects of a brain injury?</b>
<p><b><i>Support Groups</i></b></p> <ul style="list-style-type: none"> <li>• A place to socialize with others with brain injuries on a regular basis.</li> <li>• Interaction with others with similar disabilities and working a part time job that allows me to help others even tho I have struggles.</li> <li>• Support groups Resources of all kinds</li> <li>• TOO MANY - Big issues with finding safe people to talk with; reading assistance with short outings and/or walks</li> </ul> <p><b><i>Services in Rural Areas</i></b></p> <ul style="list-style-type: none"> <li>• There are not enough appropriate facilities or organizations for individuals with a brain injury and physical limitations to live in rural areas. I am not able to live close to my family an receive the help I need.</li> <li>• Cost available services. Medicaid does not make much available due to cost. My son is 46 and there is nothing in central Nebraska for facilities. He is in franklin and I live in Kearney so would be nice if he could be here in town for both of us</li> </ul> <p><b><i>Non-traditional Treatments</i></b></p> <ul style="list-style-type: none"> <li>• The most helpful services for my recovery and my daughter’s recovery (she has also suffered head injuries) have come from non-traditional practitioners. These practitioners are often times not well known to those needing their services. There are also a limited number of them, even in larger cities, which limits easy access. Some of these practitioners are not covered by insurance which means higher out-of-pocket costs despite the effectiveness of the treatment. I would also like to see more education regarding dysautonomia. It has been the biggest issue since my concussion and yet the majority of traditional practitioners do not identify it as a related outcome. Therefore, people do not receive the treatment and support needed.</li> <li>• Need more alternative treatments or easier access to them.</li> </ul> <p><b><i>Education for Providers and Other Professionals</i></b></p> <ul style="list-style-type: none"> <li>• Skilled and informed healthcare providers. Educators who are trained in supporting students when they return to the school environment with a brain injury. Laws that protect the brain injured from being fired, especially when the brain injury is invisible.</li> <li>• Very few mental health support providers are educated about TBI. Awareness of the effects and symptoms offered to them in continued education seminars would be a good possible opportunity.</li> </ul> <p><b><i>Other Comments</i></b></p> <ul style="list-style-type: none"> <li>• BIANE is doing a terrific job in being involved, deeply involved, by asking questions within support groups, from social media collective thought, conference, referrals and community support.</li> </ul>	

- Support in the home to establish order and simplicity in moving forward in life. Advocacy for education or work.
- Supervised living facility with persons my age that are safe and would encourage my growth
- My injury was more than 30 years ago, and when my injury occurred, there was very little available specifically for BI. I was very fortunate to have a family (mother) who was incredibly supportive. My injury occurred at the end of my junior year of high school. When I started college at the University of Nebraska at Lincoln 19 months after the accident I was fortunate to find the office of Services for Students with Disabilities. That office and the woman who started it was a god send for me. They were able to address the vast majority of my needs as I was fortunate to not have any real needs beyond academic “stuff” after my injury.
- Helping people with TBI's
- very little help available.

Table 6	What would you like others to know about living after brain injury?
<p><b><i>Life is difficult</i></b></p> <ul style="list-style-type: none"> <li>• At this time it is too overwhelming for me as I am still trying to learn how to live with my TBI.</li> <li>• Life after a brain injury is very difficult. I've been doing this for 20 years and the struggles are still very real. It depends, I think on the type and severity of the injury. Every TBI is different.</li> <li>• Even a mild TBI, such as a concussion, can cause significant issues in one's life. These issues can vary in severity from day to day and may take much longer than society tells us in order to heal. People may not be able to see these changes/problems, but the survivor is aware of them all too well.</li> <li>• It is an incredibly isolating experience. I say that in hind sight, because as I was going through it, I really did not think too much about it. I realize that this was due to a combination of things ... I was the first person to go start to finish with a BI at UNL (according to Dr. Christy Horn, the woman who started the SSD office). Because of that, I really did not have any “role models” or people I could speak to who understood what I was dealing with (I know Gina can relate to this ...). I would like to think this has changed in the time since I was in college, but I can not be sure of that.</li> <li>• Your life is never the same again.</li> <li>• shit is not the same</li> <li>• The problems that remain from brain injury are usually the same regardless of how long a person has had one. It doesn't go away. It's a broken brain not a broken limb.</li> </ul> <p><b><i>Life is difficult, but there is hope</i></b></p> <ul style="list-style-type: none"> <li>• I am a daily advocate of how life must be confronted, accepted, and be proud of one's new self. So many cannot understand for many years why they have changed, caregivers are mystified, everyone wants life as it was. After a reclusive life, which many experience from profound depression, I was able to pull out from a dark world and reconfigure my life for going forward. I try to pass optimism and understanding with everyone who is affected, survivors and caregivers.</li> <li>• It can be difficult but you can pull through it</li> <li>• It's hard and lonely but I am blessed to be alive and trying with my family to fulfill my life as best I and we can.</li> <li>• It is very difficult but it can be done</li> <li>• have lots of bad days , but have some good days too.</li> </ul>	

- never ever give up; focus one day at a time even if that means breaking it down into the 'morning time'/ 'afternoon time'/ evening time. try a routine start by 1 chore minimum per day. okay to make mistakes, just learn from them.

***Survivors are misunderstood***

- People sometimes think I don't know anything
- That we might 'look good,' but everyday tasks still require far more cognitive effort than those who do not have a brain injury. We can be 'fine' one minute, and then be exhausted the next. We tell people what they want to hear, that we are fine. But really we're faking it and doing the best we can with what we have.
- It can be the unseen injury.
- Hidden and unseen TBI doesn't give others judgmental rights to categorize.

***Other Comments***

- Awareness of programs to help (support groups, assistance with options for treatment/recovery, unusual/unexpected side effects...appetite, variation in emotions/moods, seizures)
- The brain heals. Relationships with someone who can't handle the stress of not knowing outcomes OR just using the situation to blame and abandon might not. Brain injury shows character of folks.

Table 7	<b>How best can disability advocacy organizations like the Brain Injury Alliance of Nebraska (BIA-NE) help you and others that have experienced a brain injury?</b>
	<p><b><i>One-on-one support</i></b></p> <ul style="list-style-type: none"> <li>• I would like for them to come visit me and get to know me at QLI as well as others like me so they can get to know more of us in skilled care.</li> <li>• Since resources have always been short, it is wonderful to see that BIANE is getting a bit of funding from the State of NE to operate rather than continuing only on challenging grants necessary annually. BIANE is the hope and resource facilitator for so many who have been a survivor, or newly challenged. Although I have been fortunate to survive, and now actually thrive in creating my own future. Many cannot because of the lack of understanding what resources might be available, yet BIANE builds upon those who have experienced brain injury and their suggestions to build the platform for the future. I am very proud of BIANE and the work being done.</li> <li>• Be available when we need you. And the BIA-NE provides lots of resource information. And many of its leaders and administrators are always willing and able to help.</li> <li>• Support, resources and connections are most helpful.</li> <li>• Connecting to other resources.</li> <li>• It would be nice to have someone come help sort out stuff from nine kids and a 27 year marriage!</li> <li>• be more involved</li> <li>• more staff and more availability.</li> <li>• Point them in the right direction. After having a TBI for 18+ yrs with little to no support, that's exactly what I received when I contacted the BIA-NE. Thanks Chris!</li> </ul>

- Help get disability
- making it easier to see and afford a professional that knows about brain injuries.
- Education and letting them know what options are available.

***Awareness, Public Education, and Advocacy***

- I am incredibly fortunate in that I no longer need any type of assistance. But when my injury occurred, and the fact that I survived, I was very much an anomaly. Again, my injury was over 30 years ago, and in the last 30+ years life saving techniques have continuously evolved to the point where survival after a BI is very common now, This is a very good thing, but that is only half of the battle. A life being saved is always going to be a good thing, but what kind of life is it going to be? Helping this population find their way back into society is an enormous challenge that we are only at the very beginning of addressing, as this issue will just continue to grow. The BIA-NE can help by doing all they can to raise awareness about this injury in the hope that it eventually be recognized by others.
- I have attended workshops here in Kearney both for my son and I. I enjoyed the interaction with others and knowing that you are not alone.
- Educate the public and healthcare professionals what TBI really is and how diverse the symptoms and recovery may be.
- The BIA-NE has already done so much to help my daughter and I help others. They've given us numerous advocacy opportunities as well as opportunities to build community with other brain injury survivors and caregivers. They supported us when we began a concussion/TBI support group focused on those in their teens and 20s. We're so blessed to have connected with BIA-NE.
- Continue to shine a light on the need and continue to facilitate support groups. Also, advocating for appropriate legislation is very important.

***Support Groups***

- (see previous comment)
- Provide group meetings in southeast Nebraska locations other than Lincoln. I live in Tecumseh

Table 8	What other thoughts would you like to share?
	<ul style="list-style-type: none"> <li>• I would like people to know that my family wants to care for me at home but they are not able to due to many different factors.</li> <li>• I have nothing else to share at this time.</li> <li>• Continued community awareness is important to support those of us living with brain injuries. Also, emergency room providers are the WORST when it comes to understanding concussion and how to communicate care for a concussion to the injured person and their families. Perhaps legislation is needed to require emergency room staff to have specialized training in the diagnosis and treatment of concussion - especially for females.</li> <li>• Don't Quit</li> <li>• Thank you for your interest and support in my situation. It's so helpful to have connections that help in different ways. It's very hard to find anyone who understands.</li> <li>• It takes a good support system to recover.</li> <li>• Brain Injury might just be a gift in discovery of self and beginning again!</li> <li>• Prayer helps</li> </ul>

- Why is it that we have drug advertisements and lawyers willing to chase any suit available on TV and never a educational ad about TBI survival.
- hope this survey will actually help get some of these met. I have found that in most cases people in the 'administrative' style jobs/careers do not actually "get" brain injury- just think they do. The people that actually work day-to-day with brain injury are the closest to actually "getting" it. Have yet to meet the exception.
- Health care providers need more information and education regarding Brain Injury, whether recent or yrs/decades old.
- need more services for brain injuries.



## Conclusion

The results from this survey illustrate the long-lasting, life-changing impacts of a brain injury. The respondents to this survey have a median time since their first brain injury of 11 ½ years. Nevertheless, they report experiencing an average of eight symptoms of brain injury, with feeling irritable or impatient, difficulty remembering, fatigue, difficulty concentrating or focusing, and headaches as being among the most commonly reported symptoms they continue to live with. As one survivor succinctly noted: *“The problems that remain from brain injury are usually the same regardless of how long a person has had one. It doesn’t go away. It’s a broken brain not a broken limb.”*

Most (61.5%) respondents to this survey feel that their quality of life is slightly worse or much worse than before their brain injury. Nevertheless, many survivors remain hopeful. Most (58.3%) respondents reported that they are participating in more the same amount of social activities compared to before their brain injury. Survivors recognize the persistent challenge and isolation of a brain injury, but they point to their ability to endure:

*“It can be difficult, but you can pull through it.”*

*“It’s hard and lonely but I am blessed to be alive and trying with my family to fulfill my life as best I and we can.”*

*Never ever give up; focus one day at a time... [It is] okay to make mistakes, just learn from them.*

*“I was able to pull out from a dark world and reconfigure my life for going forward. I try to pass optimism and understanding with everyone who is affected, survivors and caregivers.”*

We asked respondents an important question (in open-ended format): How best can disability advocacy organizations like the Brain Injury Alliance of Nebraska (BIA-NE) help you and others that have experienced a brain injury? The most recognizable theme from these open-ended responses was to continue (or expand) the one-on-one support of **Resource Facilitation**. There were 12 such open-ended comments on this theme. As one respondent noted: *“[Brain injury survivors have a] lack of understanding what resources might be available, yet BIANE builds upon those who have experienced brain injury and their suggestions to build the platform for the future. I am very proud of BIANE and the work being done.”*

A second theme found within these comments focused on **awareness, public education, and advocacy**:

*“The BIA-NE can help by doing all they can to raise awareness about this injury in the hope that it eventually be recognized by others.”*

*“Educate the public and healthcare professionals what TBI really is...”*

*“Continue to shine a light on the need.”*

Finally, the third theme found within these comments keyed on the value of **support groups**, of which this comment is emblematic: *“The BIA-NE has already done so much to help my daughter and I help others. They’ve given us numerous advocacy opportunities as well as opportunities to build community with other brain injury survivors and caregivers. They supported us when we began a concussion/TBI support group focused on those in their teens and 20s. We’re so blessed to have connected with BIA-NE.”*