

Nebraska Brain Injury Needs Assessment Report 2024



Report of the Nebraska Brain Injury Needs Assessment 2024 findings. Nebraska Vocational Rehabilitation and Brain Injury Advisory Council. Report prepared by Partners for Insightful Evaluation.

Nebraska Traumatic Brain Injury Needs Assessment Report
December 2024

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Contents

Executive Summary	5
Methodology	5
Key Results	5
Prevalence & Cause of Brain Injury	5
Gaps in Services	5
Successes	5
Barriers	5
Recommendations	5
Introduction	6
Methodology.....	6
Results	7
TBI Registry & Mailings.....	7
TBI Registry Data	7
TBI Registry Mailings.....	11
TBI Registry Caller Survey Data	12
Needs Assessment Surveys	14
Individuals with Brain Injury	15
Family Members/Caregivers	27
Service Providers	36
Resource Facilitation	44
Acquired Brain Injury Interview	45
Brain Injury Screening Results	46
Functional Impacts	46
Conclusions.....	47
Successes	47
Gaps in Services & Supports	47
Key Barriers.....	48
Recommendations	48
Appendix A: Data Sources.....	49
Primary Data	49
Individuals with Brain Injury Survey	49
Family Member / Caregiver Survey.....	49
Service Provider Survey	49
Secondary Data.....	49
Acquired Brain Injury (ABI) Interview Data	49
Administrative Data	49

Resource Facilitation Data	50
TBI Registry	50
TBI Registry Mailings.....	50
TBI Registry Caller Survey Data	50
Appendix B: Additional Data	52
TBI Registry Data	52
TBI Rates by Local Health Department District	52
Appendix C: Survey Respondent Demographics.....	55
Individuals with Brain Injury Survey	55
Family Member/Caregiver Survey	55
Appendix D: Resource Facilitation Areas of Need	56

Executive Summary

With strong support and coordination from Nebraska VR (Vocational Rehabilitation) and the Brain Injury Advisory Council (BIAC), Partners for Insightful Evaluation (PIE) conducted a statewide brain injury needs assessment in 2024. This needs assessment provides an opportunity to 1) inform the Brain Injury State Plan and 2) understand what services, supports and assistance are available to those who have experienced a brain injury, particularly as a way to identify any unmet needs. The last needs assessment was conducted in 2020.

Methodology

A variety of data was utilized for the needs assessment. Three surveys were conducted to collect data from across the state. One survey was for individuals with brain injury, another was for family members/caregivers of those with brain injury, and the third was for service providers who may serve individuals with brain injury. This was complemented by secondary data, which included TBI Registry data, Resource Facilitation data from the Brain Injury Alliance of Nebraska, and the Acquired Brain Injury (ABI) Interview Form data from Nebraska VR. All data was compiled, analyzed, and reported by PIE. When possible and applicable, comparisons are made to findings from previous brain injury needs assessments conducted in Nebraska.

Key Results

Prevalence & Cause of Brain Injury

The TBI Registry served as a key mechanism for Nebraska to monitor how many people have experienced a traumatic brain injury. Given the limitations of that data, other sources – such as the ABI Interview Form and Resource Facilitation data – can be used to further understand the prevalence and cause of brain injury.

Top Causes of TBI from TBI Registry	Top Causes of BI from Resource Facilitation Data	Top Causes of TBI from ABI Interview Data
• Falls • Struck by/against • Motor vehicle	• Motor vehicle crash – car crash • Fall • Assault (other)	• Moving vehicle accident – car/truck • Other • Fall

Gaps in Services

Successes

Barriers

Recommendations

Various recommendations are outlined in the needs assessment report, some of which are already underway.

Introduction

Brain injuries – also called Acquired Brain Injury (ABI) – is damage to the brain after birth that is not hereditary (inherited from a parent), congenital (condition or trait that exists at birth), or degenerative (graduate deterioration). This includes traumatic brain injury (TBI) and non-traumatic brain injury, which is the result of an illness, oxygen deprivation, aneurysm, or other causes. TBIs are caused by an external physical force, such as a bump, jolt, or blow to the head.¹ In some cases, it can result in total or partial functional disability and/or psychosocial impairment.

TBIs are a serious public health problem. The Centers for Disease Control and Prevention (CDC) reported approximately 214,110 TBI-related hospitalizations in 2020 and 6,9473 TBI-related deaths across the nation in 2021.² Based on data from Nebraska's TBI Registry, the number of reported TBIs in the state rose from 11,317 in 2017 to 14,591 in 2022, marking a nearly 30% increase.

With support and coordination from Nebraska VR (Vocational Rehabilitation), the Brain Injury Advisory Council (BIAC), and the Brain Injury Data Workgroup, Partners for Insightful Evaluation (PIE) conducted a statewide brain injury needs assessment in 2024. Needs assessments were previously done in 2019³ and 2020⁴, though the latter had a focus specifically on mental health and brain injury.

There were two priorities of the needs assessment: inform the Brain Injury State Plan and understand the services, supports, and other assistance available to people with TBI, including the extent of unmet needs. Findings from the needs assessment are shared with the BIAC and other key partners to identify what is working with the service delivery system and identify potential solutions to address gaps and barriers. Although the focus is on traumatic brain injury, non-traumatic injuries are explored as well to gain a better understanding of services gaps, successes, and challenges in Nebraska.

Methodology

A variety of data sources were used for the statewide needs assessment (Figure 1). Primary data – meaning data collected by the BIAC for the purpose of the needs assessment – was collected through three online surveys. The remaining data came from secondary sources. A summary of all the data sources, including the collection process and date range of information included for each source, is included in Appendix A. Copies of the three surveys can be obtained from Nebraska VR or PIE.

¹ Traumatic brain injury. (2024). National Institute of Neurological Disorders and Stroke.

<https://www.ninds.nih.gov/health-information/disorders/traumatic-brain-injury-tbi>

² This was the most recent data available at the time of this report. It was obtained from the Centers for Disease Control and Prevention at <https://www.cdc.gov/traumatic-brain-injury/data-research/index.html>.

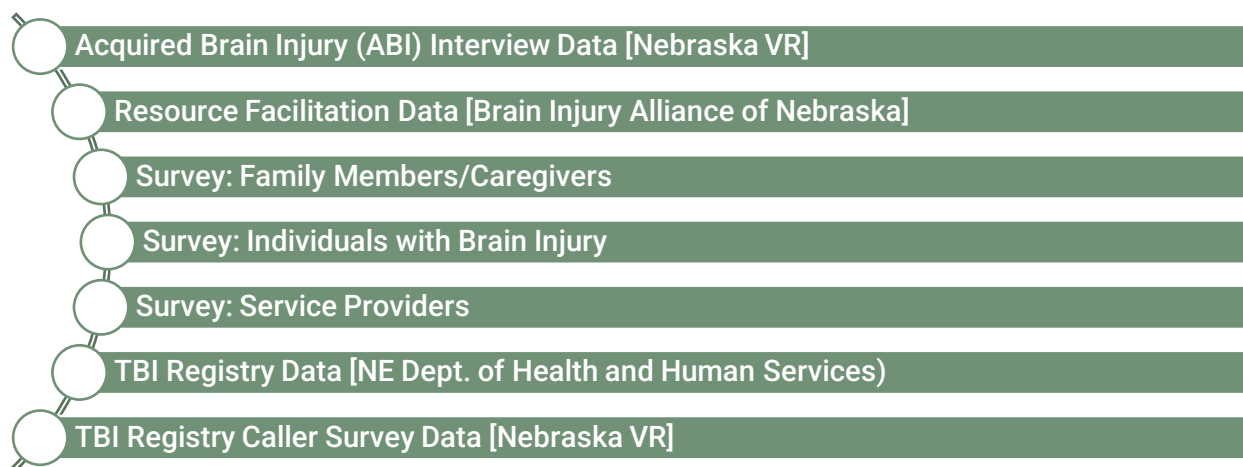
³ 2019 Living with brain injury survey results. (2019).

https://braininjury.nebraska.gov/sites/default/files/doc/Living_with_Brain%20Injury_Survey_Results%20May_2019.pdf

⁴ 2020 Living with brain injury survey results: Brain injury and behavioral health (2020).

<https://braininjury.nebraska.gov/sites/default/files/doc/2020%20Living%20with%20Brain%20Injury%20Surveys%20RESULTS%20FINAL%202-3-2021%5B3%5D.pdf>

Figure 1: Primary and secondary data were used to conduct the statewide brain injury needs assessment.



Results

TBI Registry & Mailings

One of the primary ways to monitor traumatic brain injury in Nebraska is through the state's TBI Registry. The Registry began in 1991 after a legislative bill known as the Brain Injury Registry Act.⁵ The intent was to ensure that there was a database to collect information about individuals who had a brain injury – not only to plan for treatment and rehabilitation efforts, but also to prevent head injuries as well.

TBI Registry Data

TBI cases are identified using patients' diagnostic code, which are based on the International Classification of Diseases, 10th Revision, Clinical Modification (ICD 10 CM). Table 3 outlines the codes that are factored into the TBI definition. This is a system for health care providers to classify diseases and medical conditions for diagnosis and medical claims.⁶

Table 1: A series of ICD-10 codes are used to identify individuals in Nebraska who were diagnosed with a traumatic brain injury

Codes ⁷	Description
S02.0, S02.1-	Fracture of skull
S02.8, S02.91	Fracture of other specified skull and facial bones; Unspecified fracture of skull
S04.02, S04.03-, S04.04-	Injury of optic chiasm; injury of optic tract and pathways; injury of visual cortex
S06-	Intracranial injury
S07.1	Crushing injury of skull
T74.4	Shaken infant syndrome

As noticed in Appendix A, one limitation of the TBI Registry data is that it primarily accounts for patients seen at a hospital. Although state statute (§81-653 to 81-662) requires that any hospital, rehabilitation center, psychologist or physician report information about individuals

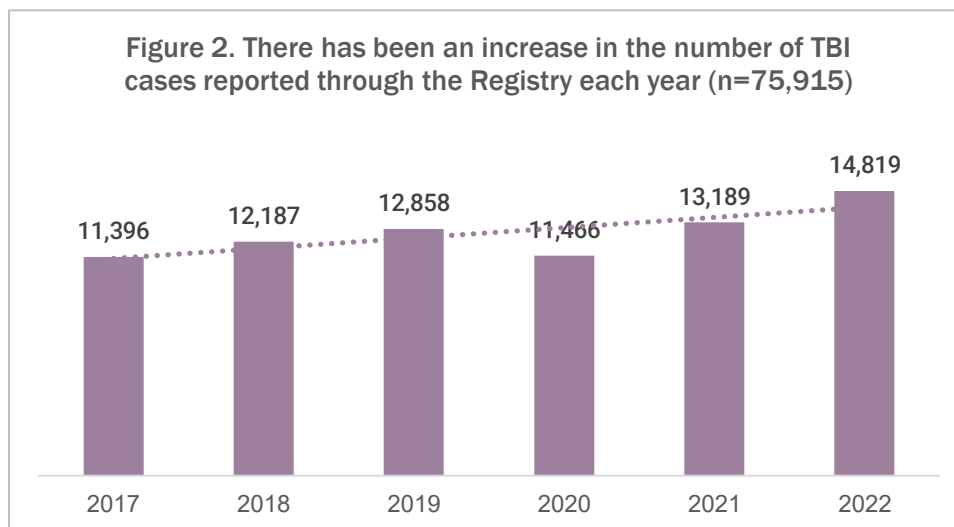
⁵ Legislative Bill 81-653: <https://nebraskalegislature.gov/laws/statutes.php?statute=81-653>

⁶ Traumatic Brain Injury Center for Excellence. ICD-10-CM coding guidance for traumatic brain injury. <https://health.mil/Reference-Center/Publications/2020/07/31/ICD10-Coding-Guidance-for-TBI>

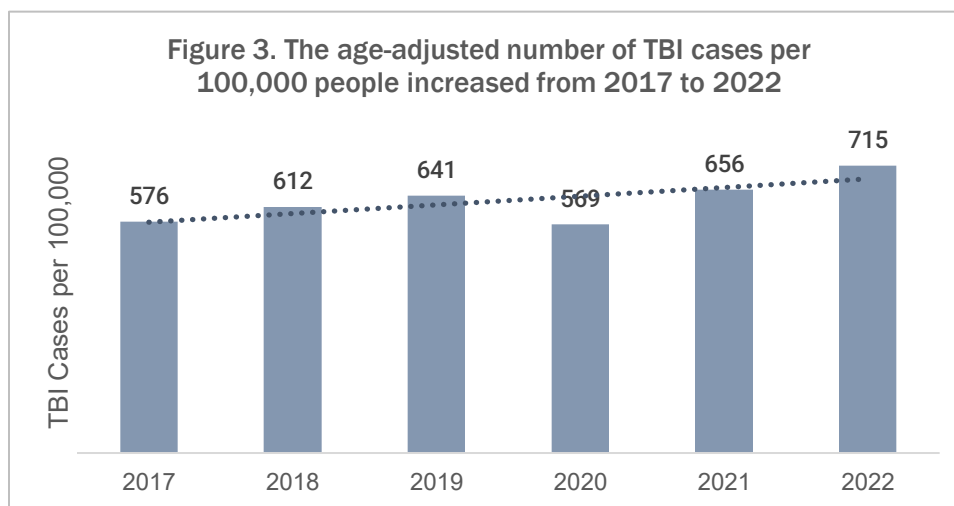
⁷ “-” indicates any 4th, 5th, or 6th character

sustaining a TBI to the Department of Health and Human Services (DHHS), data predominately reflects those seen in a hospital setting. It also does not include other acquired brain injuries.

Based on the TBI Registry data, there has been about a 29% increase in the annual number of TBI cases in Nebraska from 2017 to 2022 (Figure 2). The total number of TBI cases reported during this six-year period was 75,915, with an average number of TBI cases per year of 12,652.



Another way to explore the data is through an age-adjusted rate for TBIs. This means that the rates of TBI were statistically adjusted to account for differences in age distribution. It provides a more accurate comparison of TBI incidence each year. In this case, it would mean that the higher TBI rates in 2022 are likely not due to differences in ages for Nebraska's population. Except for 2020, the age-adjusted TBI rates have been on the rise since 2017 (Figure 3).

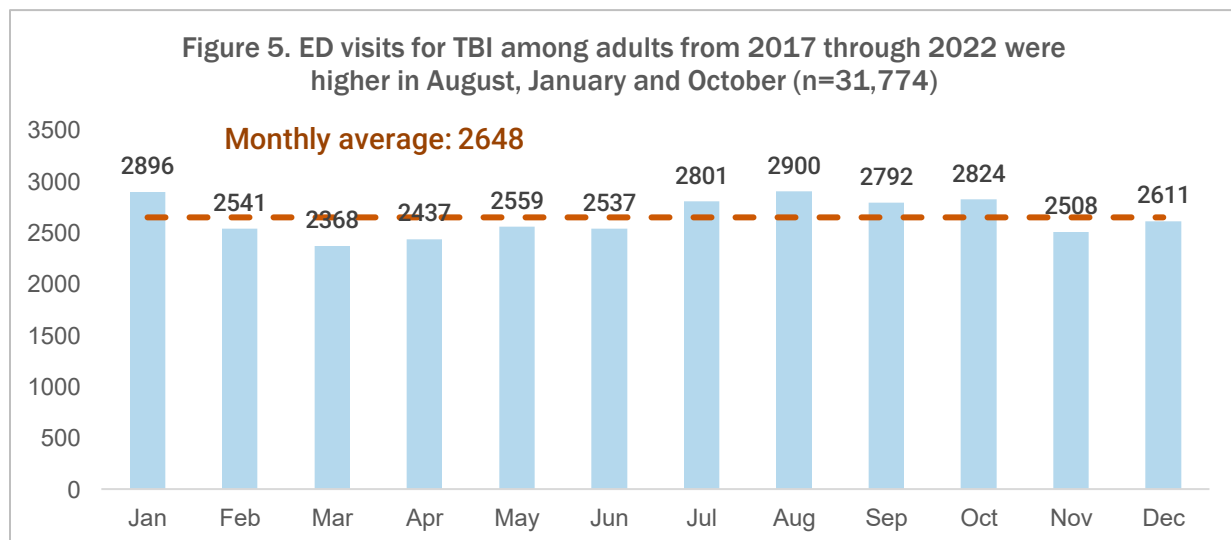
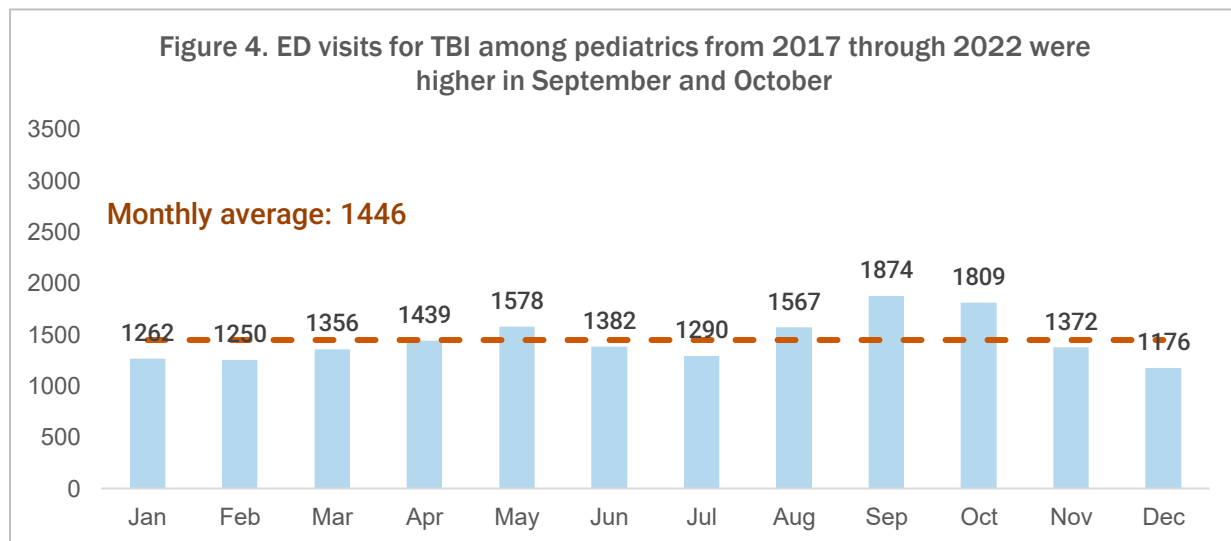


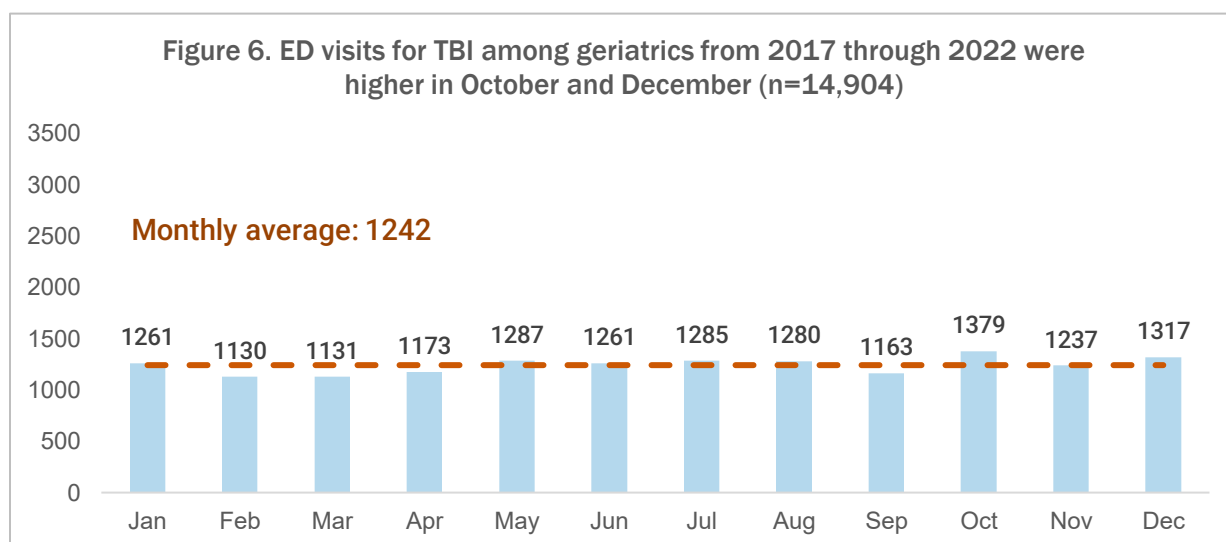
Elderly individuals (those 75 and older) had the highest rates of hospitalization and emergency department (ED) while children younger than five and teens (ages 15 to 19) had the next highest rates of ED visits. That does vary slightly by gender, however. In fact, the top five highest TBI cases based on age and gender in Nebraska between 2017 and 2022 were as follows:

1. Females over the age of 85 (n=4,073)
2. Males between the ages of 15 and 19 (n=4,040)

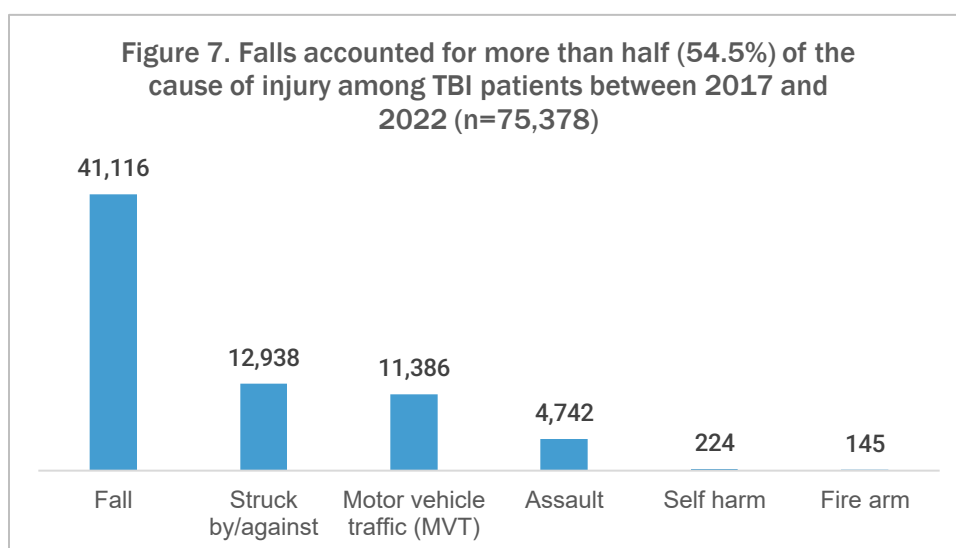
3. Females between the ages of 75 and 84 (n=4,028)
4. Females between the ages of 65 and 74 (n=3,879)
5. Females between the ages of 15 and 19 (n=3,721)

The TBI Registry data indicates that during the six-year period, about 85% of the TBI cases were admitted as ED patients. The remaining cases were admitted via a trauma center (10%) or urgent care (4%). A more in-depth look at the ED data shows that pediatrics accounted for 27% of the visits that had a recorded TBI code. Adults accounted for 50% while geriatrics reflected for 23%. The three categories of patients varied when they saw the highest rates of TBI visits. Patients under the age of 16, for example, had higher ED visits in September and October (Figure 4). For adults, ED visits were highest in August and January (Figure 5). ED visits among geriatric patients were highest in October and December (Figure 6).



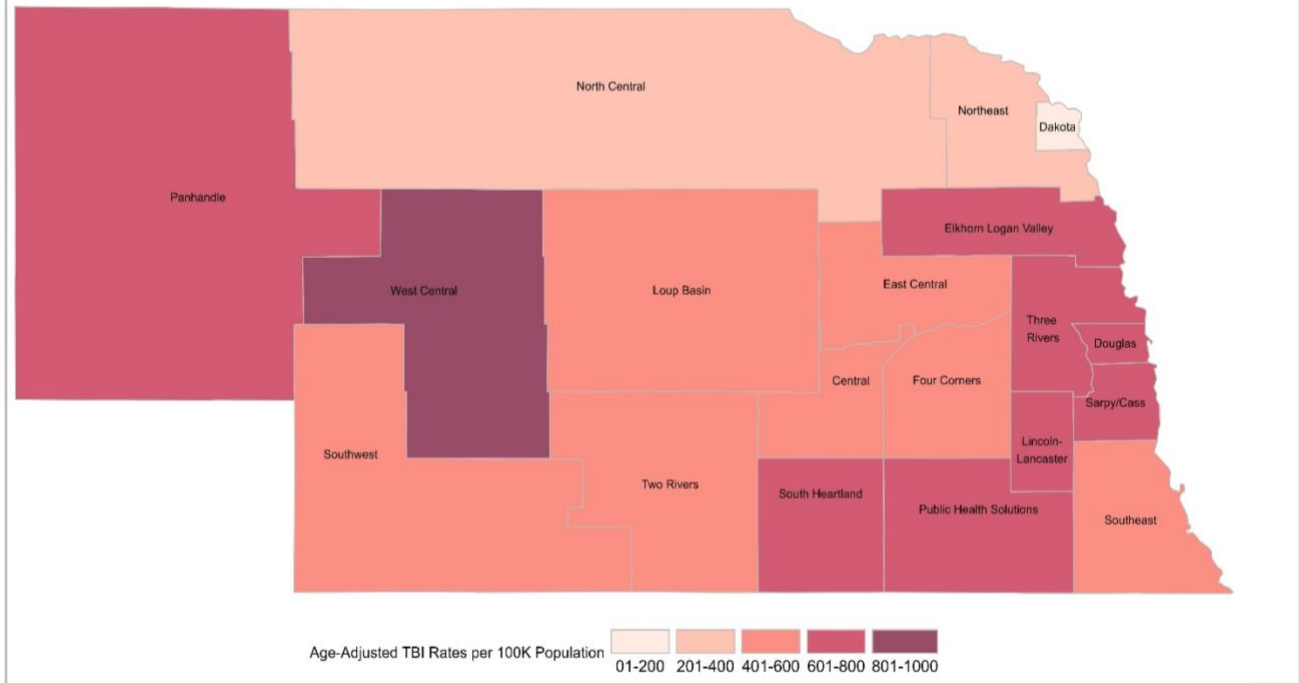


Falls were the leading cause of TBIs from 2017-2022, accounting for more than half of reported cases (Figure 7). The next most common type of injury was struck by/against, which reflected 17% of the TBI patients.



TBI rates did vary by geographic area. Analysis was done by local health department regions to better align with prevention and management efforts. Based on TBI Registry data from 2017-2022, West Central District Health Department had the highest rates of TBI (Figure 8). They cover six counties, including Arthur, Hooker, Lincoln, Logan, McPherson, and Thomas. Lincoln-Lancaster County Health Department has the next highest, followed by Three Rivers Public Health Department (Dodge, Saunders, and Washington counties) and Sarpy Cass Public Health Department.

Figure 8: TBI rates from 20017 through 2022 varied by local health department districts (n=75,915)



Rates for all 19 local health departments – including annual rates and the list of counties affiliated with each LHD district – are included in Appendix B.

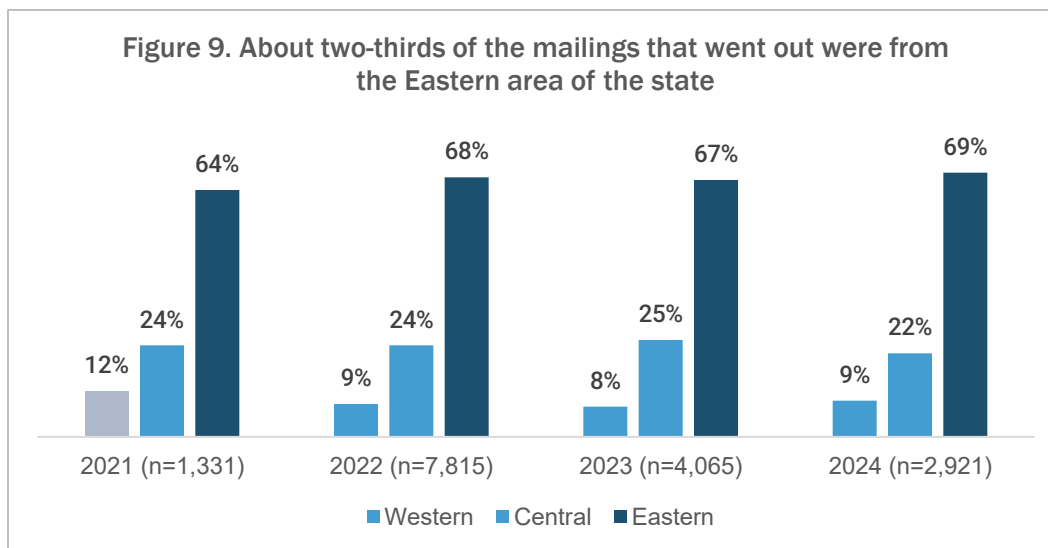
TBI Registry Mailings

As part of the Brain Injury Registry Act (LB 928), information is required to be sent to individuals with reported brain injuries to help them access necessary and appropriate services related to the injury. Through 2024, that was done in the form of a letter and a brochure that was customized based on the region of the state (western, central or eastern) and age (0 to 21, 22 through 59 and 60+) of the individual.⁸

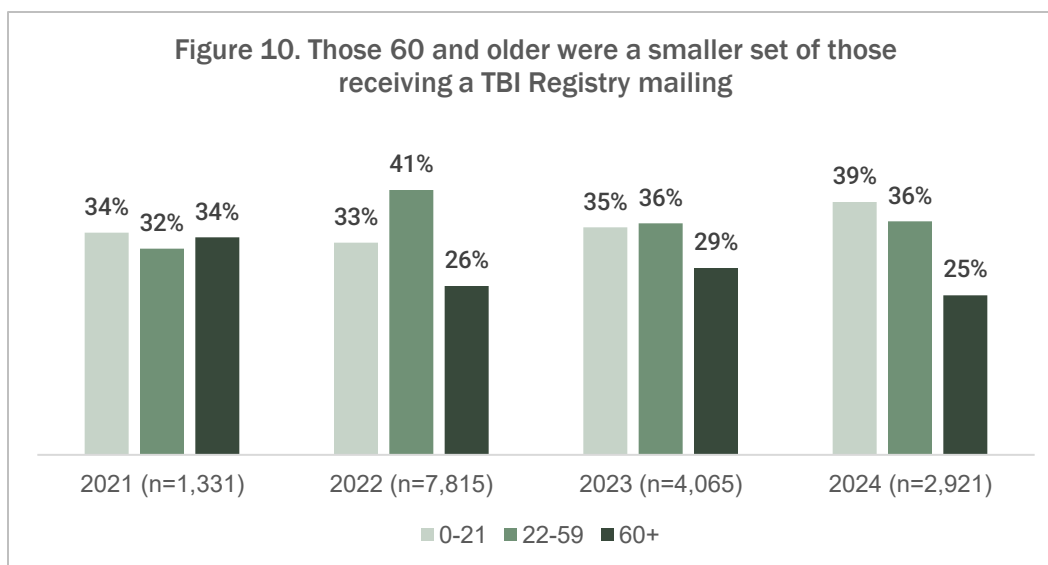
Mailing lists are supplied by DHHS to Nebraska VR based on the TBI Registry. This helps ensure that mailings are provided to those who have not previously been contacted and to mitigate contacting those who may have passed away. The address list is also reviewed by the print shop to remove any incomplete or missing addresses. Primarily because the data is supplied by hospitals through electronic health records, information is supplied to individuals by mail. Email addresses are not included in the mailing list provided to Nebraska VR.

⁸ In early fall 2024, a subgroup from Nebraska's Brain Injury Advisory Council revised the materials included in the mailings. The letter was updated based on examples from other states, and rather than having customized brochures, a rack card highlighting brain injury symptoms and four key organizations to contact was developed.

Between June 2021 and December 2024, there were 19,708 mailings sent. Although the geographic information was not summarized for the last two mailings in 2024, a majority during this time period were for those located in the Eastern part of the state (Figure 9).



The other customization was related to age. Among the mailings sent, people were less likely to fall into the age range of those 60 and older (Figure 10).

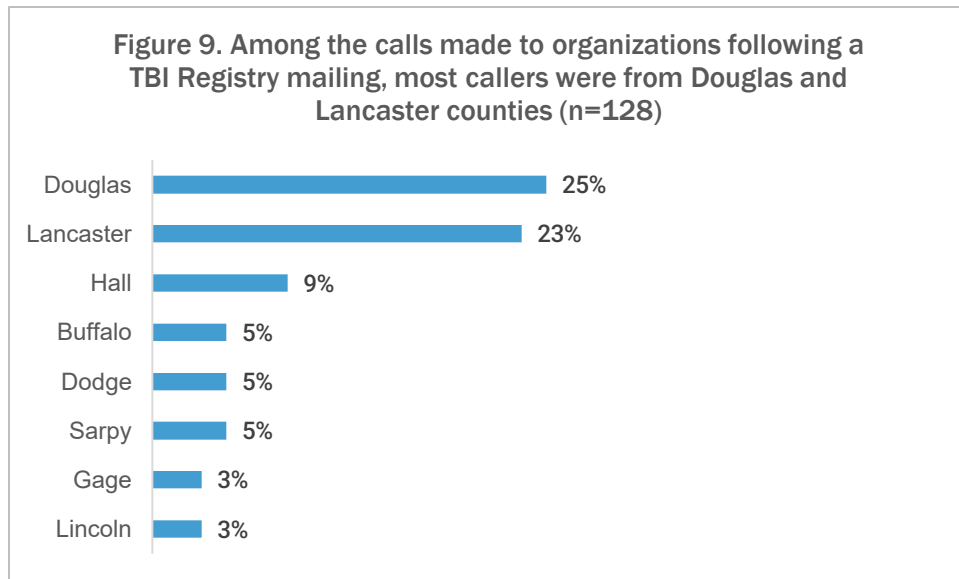


TBI Registry Caller Survey Data

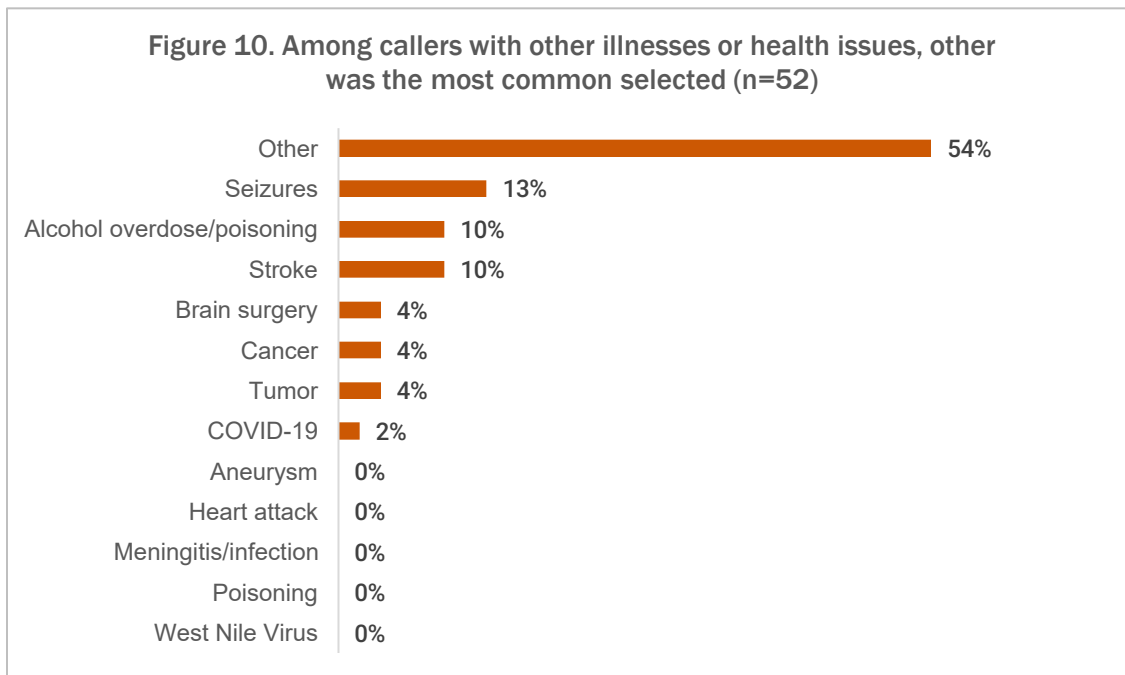
Organizations listed as a resource in the brochures that are sent as part of the TBI Registry mailings are notified prior to the information being sent. This is to keep agencies informed about the volume of mailings and remind organizations to track whether calls are received because of the letter and/or brochure. Should organizations receive calls because of the mailings, they are encouraged to complete an online survey about the call. The survey was modified in the spring of 2022 to better track data needed for federal grant reporting purposes.

From May 2022 through December 2024, a total of 190 calls were logged through the survey from the Brain Injury Alliance of Nebraska and Nebraska VR. However, about 28% (n=54) of the callers noted that they received the brain injury registry letter in error. Callers who did not

receive the letter in error (n=136) primarily came from Douglas County and Lancaster (Figure 9). Callers reported being from 28 different counties in Nebraska.⁹

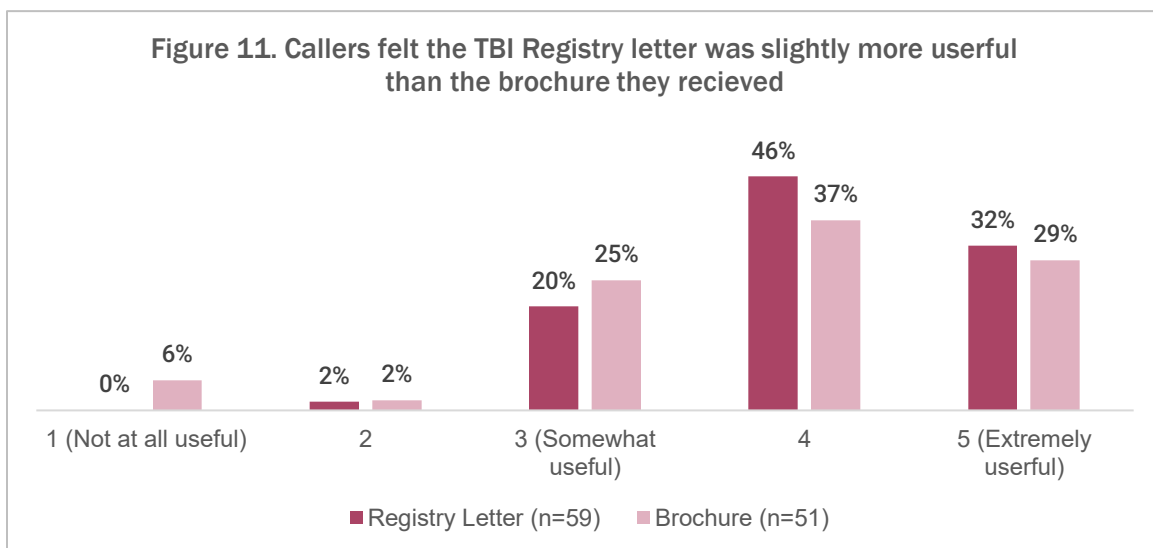


Beyond TBI, additional health conditions were documented from those who called upon receiving the TBI Registry letter. As shown in Figure 10, “other” was the most commonly reported. Among those responses, broken bones (n=5), arthritis (n=3), and other physical injuries (n=3) were reported. Two callers also referenced the following health conditions or issues: autism, behavioral health challenges, headaches/migraines, learning disability, and post-traumatic stress disorder (PTSD).

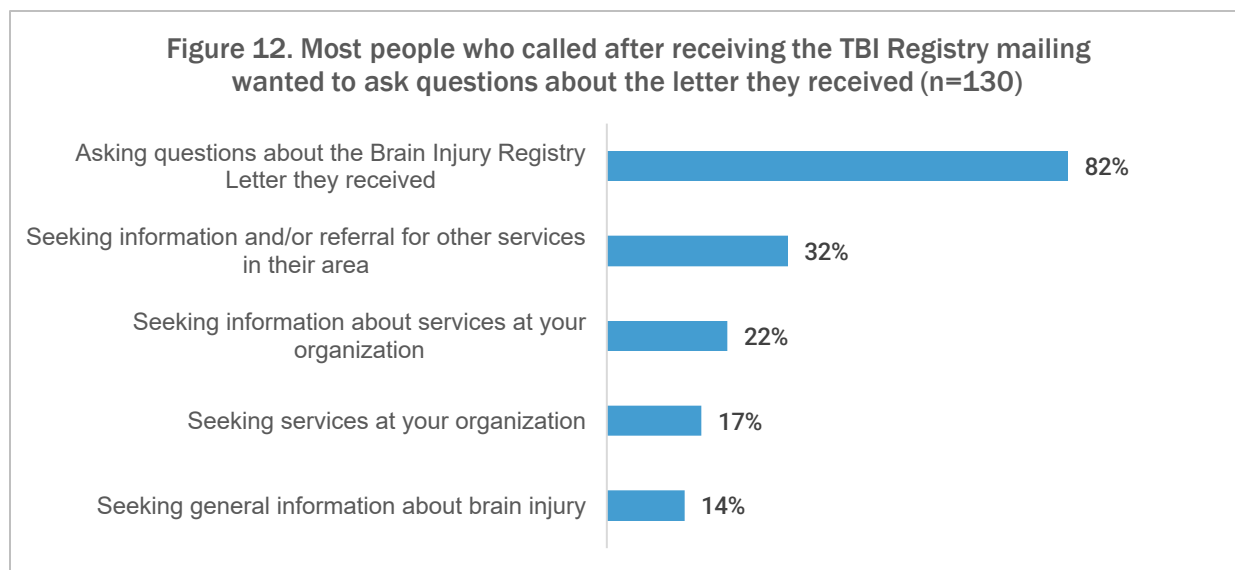


⁹ Burt and Cuming both had three callers each. There were two callers from Fillmore, Madison, Otoe, Perkins, and Platte County. There was one caller reported from each of the following counties: Box Butte, Dawson, Harlan, Kearney, Keith, Merrick, Morrill, Nemaha, Polk, Red Willow, Saline, Thurston and Webster.

When possible, organizations asked callers about how useful the TBI Registry letter and brochure were. Results indicate that – among those who did not receive the letter in error – nearly all were satisfied with both materials. There was a slightly higher level of satisfaction reported with the letter than with the brochure (Figure 11).



Most of the people who called after receiving a TBI Registry mailing did so because they had questions about the letter they received (Figure 12). However, about one-third of the callers were looking for information and/or referrals for services within their area.



Needs Assessment Surveys

The demographics of respondents for each survey are summarized in Appendix C. To better understand geographic differences, the county of each respondent was coded into three categories based on the rural/urban classifications provided by DHHS's Division of Public Health Disparities Demographic Data Recommendations.¹⁰ Although results are summarized in

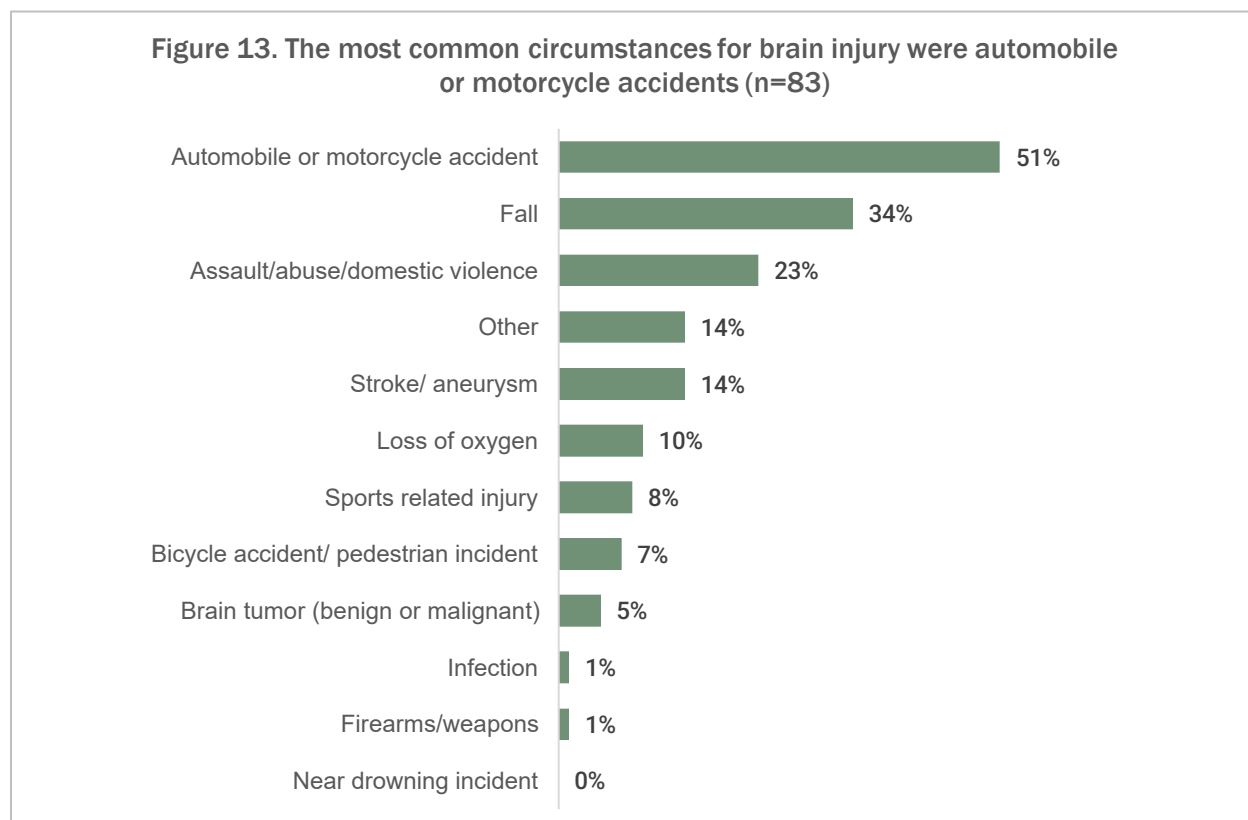
¹⁰ Division of Public Health, Nebraska Department of Health and Human Services. *Disparities demographic data recommendations*. (Nov. 2016). <https://dhhs.ne.gov/Reports/DHHS%20Demographic%20Data%20Recommendations%20Report.pdf>

this report, aggregate results from each survey are also available on the BIAC website as infographics.

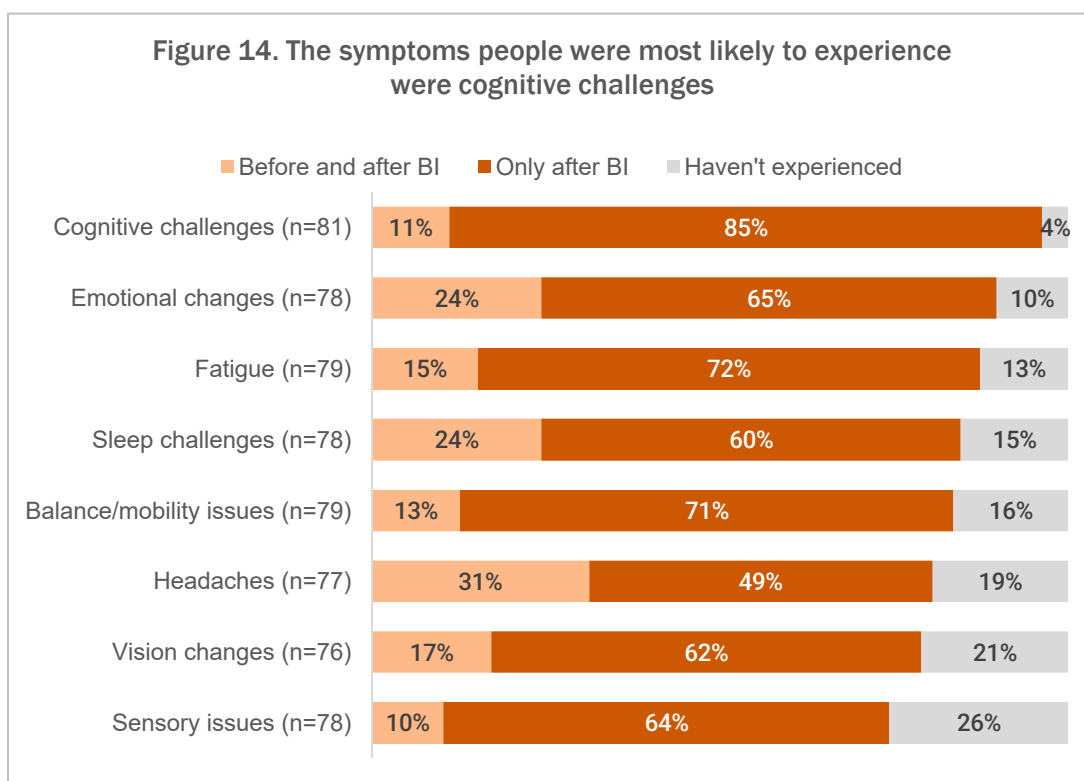
Individuals with Brain Injury

Brain Injury Causes & Symptoms

Based on the survey data, about half of the respondents (52%) reported experiencing one brain injury in their lifetime while 35% reported having two to five brain injuries. The remaining 14% experienced more than 5 brain injuries. The most common circumstances experienced by respondents that may have resulted in a brain injury include automobile or motorcycle accidents (51%), falls (34%), and assault/abuse/domestic violence (23%) (Figure 13). This is somewhat consistent with the common causes reported through the TBI Registry, though falls are more common from that data source.

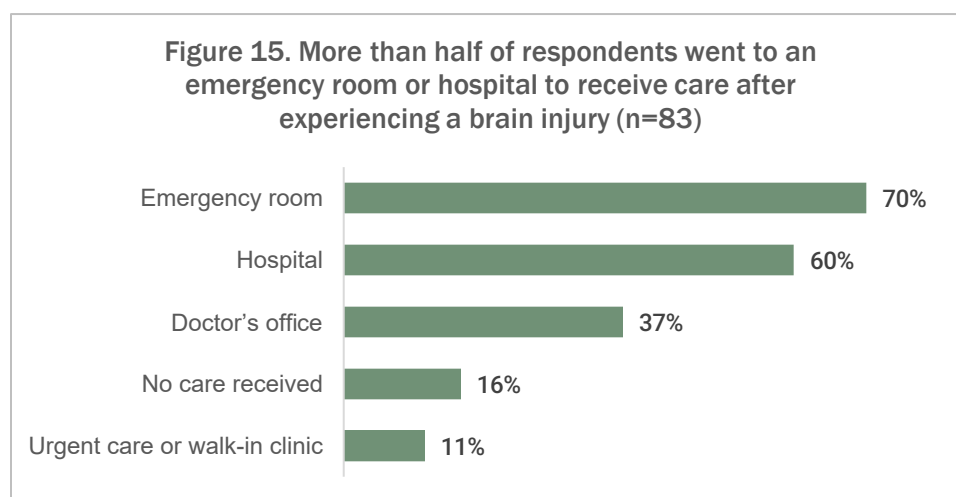


To better understand symptoms, survey respondents were asked to report whether certain symptoms were something they experienced before their brain injury or only after. **The most common symptom— particularly after a brain injury – related to cognitive challenges.** That was defined in the survey as having problems with memory or problem solving (Figure 14). The next most common symptom was emotional changes, though 24% of those who have that symptom experienced it before their brain injury as well. Although sensory issues were the least reported symptom, it was still reported by 74% of the respondents, which is not an unsubstantial amount. Among the 81 survey respondents, the average number of symptoms experienced was 6.5 out of the 8 listed. **This indicates that symptom management may be a key aspect of brain injury recovery and support.**

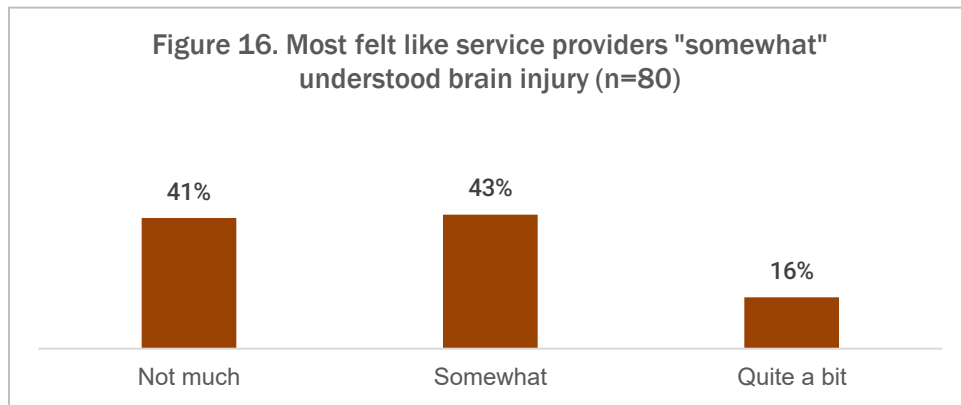


Accessing Services and Resources

When asked to indicate the places where they went to receive care after experiencing a brain injury, more than half of respondents said they went to an emergency room (70%) or hospital (60%), and about 16% said they did not receive any care for their brain injury (Figure 15). Given so many respondents did visit an emergency department or hospital, it is likely their information would be reflected in the TBI Registry data.



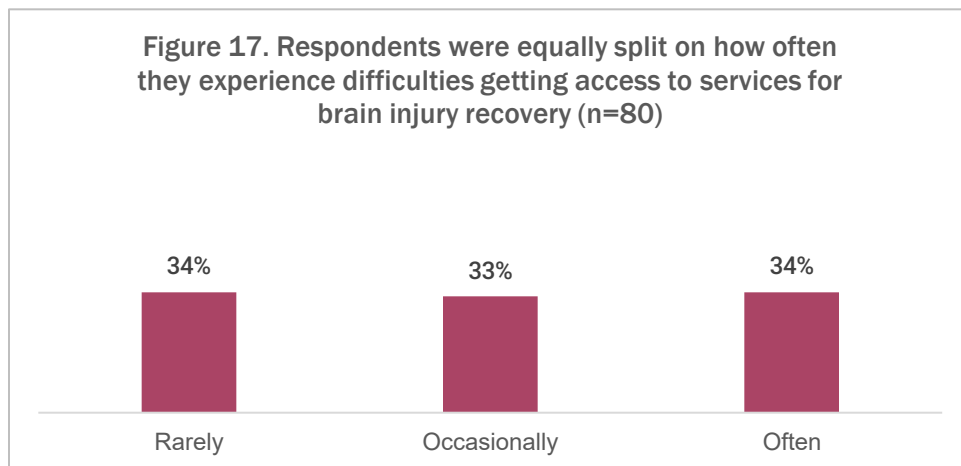
Respondents had mixed perceptions regarding how much they felt like service providers understood brain injury. Although most felt service providers have “somewhat” understood brain injury, it was followed closely but having “not much” understanding of brain injury (Figure 16). **This indicates there is a need to further educate service providers on brain injury.**



Given the small number of respondents, there isn't a statistically significant difference with how people responded to the question. However, it may be important to note that:

- Among those who reported that service providers understood "quite a bit" about brain injury (n=13), a majority of them (75%) travel 30 minutes or less for brain injury services.
- Among those who reported that service providers had "not much" understanding of brain injury (n=33), more than half (64%) were from urban-small counties or rural counties and 61% reported having experienced more than one brain injury.

Responses also varied about how difficult people felt it was to get services for brain injury recovery. In fact, there was almost an even split among the three response options (Figure 17).



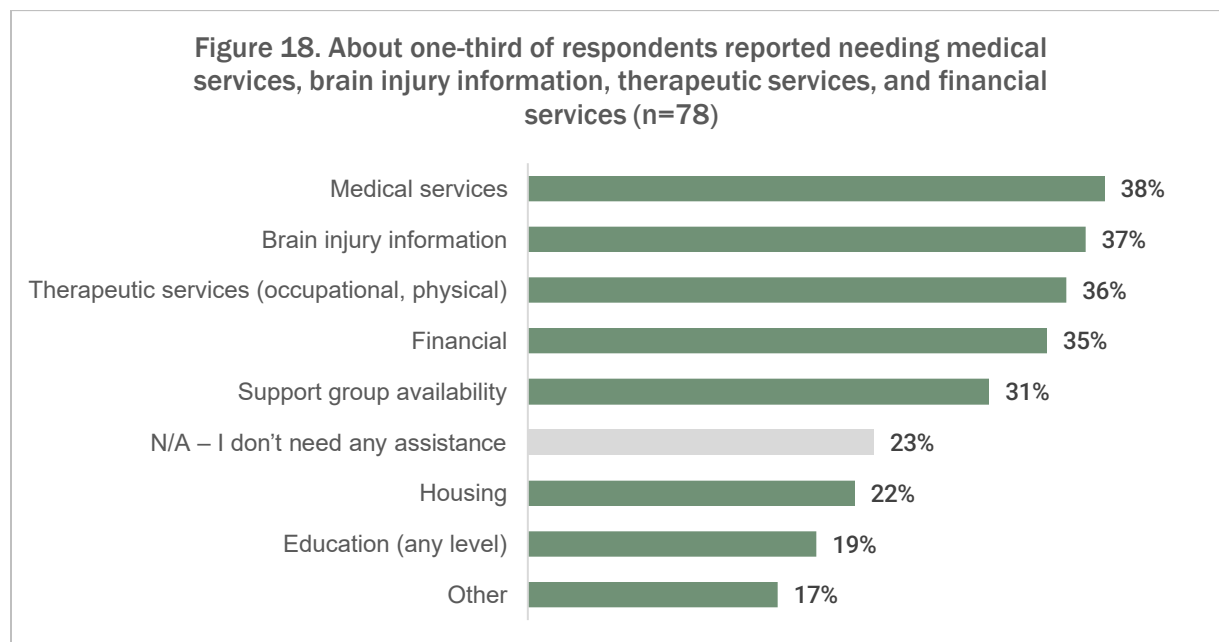
Similar to service provider understanding of brain injury, many of those who reported that they "rarely" experience difficulties getting access to services for brain injury recovery, a majority (74%) travel 30 minutes or less to obtain brain injury services. Those who reported they "often" had trouble getting access to services for brain injury recovery (n=27) were not more likely to have to travel a certain amount of time to obtain services, though. In fact, there was a relatively even split reporting they travel 30 minutes or less (28%), 30 minutes to 2 hours (36%) and more than two hours (36%).

Results also show that among those who reported "rarely," more than half (59%) also indicated on another survey question that they did not need any assistance living with their brain injury. This could be because those who "rarely" experienced difficulties accessing services for brain injury were also more likely to experience one brain injury in their lifetime rather than 2 to 5 or more than 5.

People who “often” have trouble accessing services reported they needed the following assistance for living with their brain injury:

- Brain injury information – 56%
- Financial – 56%
- Medical services – 56%
- Therapeutic services – 44%

This is comparable to the aggregate results regarding what type of assistance people reported needing for living with brain injury (Figure 18). Based on the results, about one-fourth of respondents did not need services. Some of the additional services mentioned for the “other” response included counseling, support with getting employment accommodations, assistance with organization, legal advice, speech therapy, family and caregiver help, vision check-ins, and strength and balance therapy.



There was not a geographic difference among the different service needs. Those who mentioned needing support groups, for example, came from a range of counties. Among those respondents, 28% were from rural counties while 44% were from urban-large counties (primarily Lancaster and Douglas).

Respondents were also asked an open-ended question about what services they need to help them live their best life after brain injury. A total of 57 responded to the question, with the results being categorized into key themes. However, some respondents mentioned they did not know or did not feel there were services they would need (Figure 19).

Among those who indicated there was a need for services (n=48), about one-third noted services that were related to medical and therapeutic support. The next most common need related to housing and living assistance. Services that were selected by more than 10% of the respondents are outlined in Table 2.

Figure 19: Open-ended responses fell into about a dozen types of services (n=57)

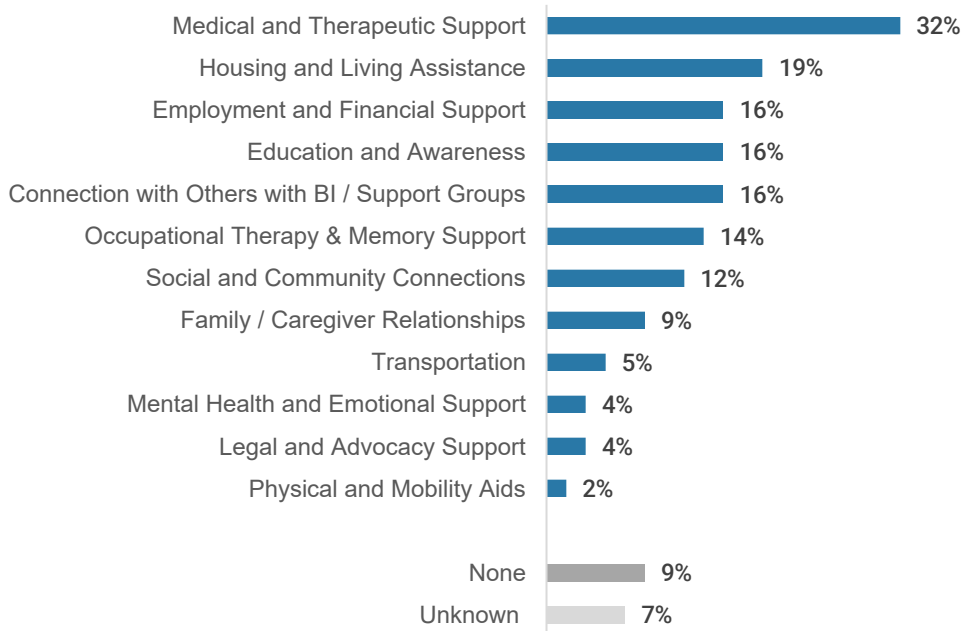


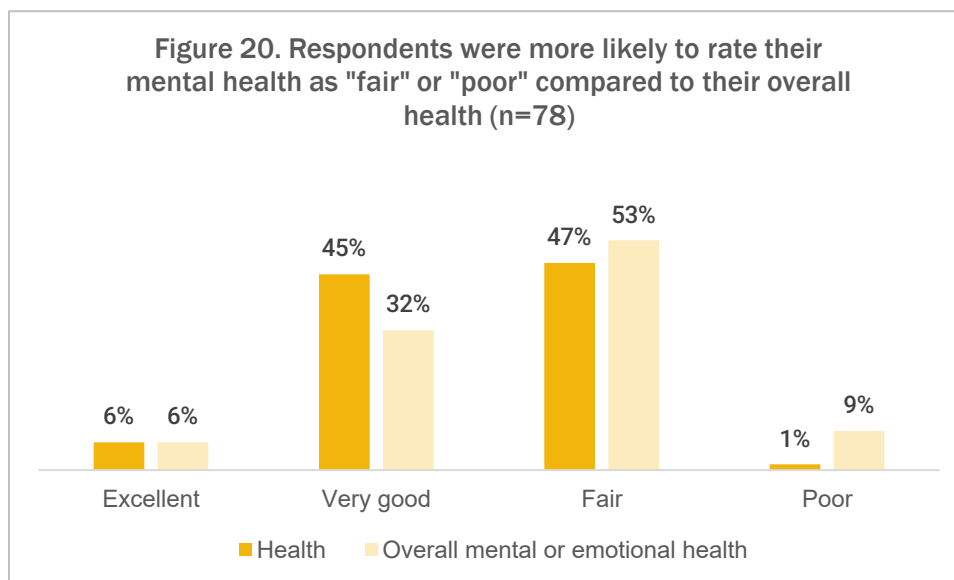
Table 2. Open ended responses were coded into key categories, with seven representing more than 10% of the responses

Service Category	Description
Medical and Therapeutic Support	Vision therapy, neuro-ophthalmology, ENT [ear, nose and throat], vestibular therapy, cognitive therapy, speech therapy, aphasia support, neurofeedback, physical therapy, general practitioner, assistance navigating the medical system and insurance
Housing and Living Assistance	Affordable housing, assistance with home (house cleaning, lawn care), wanting to live independently with in-home care, living facility that caters to TBI
Employment and Financial Support	Employment services, job assistance, help with getting employer to understand challenges of brain injury, financial support for care
Education and Awareness	Education about brain injury (for individual and the community), post-treatment education and understanding how to live with a brain injury, help understanding available services and how to access them
Connection with Others with BI / Support Groups	Support groups, being able to hear from others who have experienced brain injury, validation from others with similar experiences
Occupational Therapy and Memory Support	Learning independence, understanding how to better function, occupational therapy/help, brain games
Social and Community Connections	Activities, help with meeting new people, support to not feel alone, access to a rec center

Health Status and COVID-19 Impact

When asked to rate their general health and their mental/emotional health on a 4-point scale, about half (51%) rated their general health as “excellent” or “very good.” However, only 38%

rated their mental/emotional health as excellent or very good (Figure 20). Additional analysis indicates that those who indicated their overall health was “fair” or “poor” were also more likely to report their overall mental or emotional health was fair. In fact, only 19% of those who reported their overall health was “fair” or “poor” noted that their overall mental health was “good.”



The question regarding general health was included in the survey to offer a comparison to data obtained through the Nebraska Behavioral Risk Factor Surveillance System (BRFSS). Based on BRFSS data from 2022, 15.1% of Nebraskans reported that their general health was fair or poor.¹¹ This is substantially lower than the ratings from the individuals with brain injury survey. Even more interesting is that the 15% reported in 2022 was the highest it had been since 2011. Although the sample size is small, **this may indicate that those who have experienced a brain injury have a lower quality of health overall.**

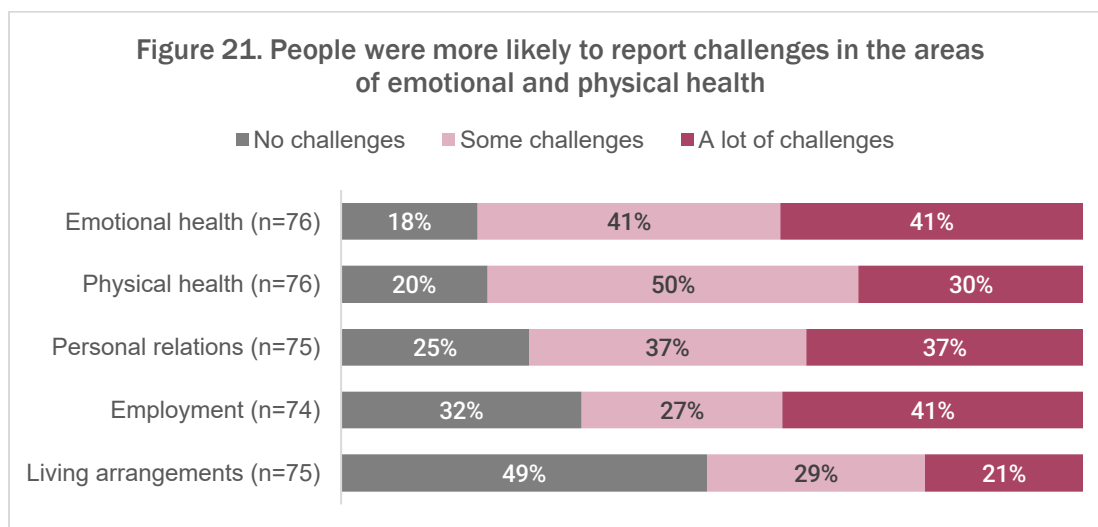
Preliminary research indicated that those who have experienced a brain injury may have additional challenges with COVID-19. Survey results indicated that about 59% of the respondents had ever tested positive for COVID-19. Of the 46 who reported testing positive for COVID-19, 11 (24%) said they experienced symptoms related to long-COVID, and 15 (33%) said that COVID-19 made their brain injury symptoms worse. Only eight (about 11%) of respondents said that they were denied or unable to access rehabilitation or other types of services for their brain injury during the COVID-19 pandemic.

When asked to describe how, if at all, the COVID-19 Pandemic impacted their life, respondents mentioned feelings of loneliness and isolation, mental and physical health impacts (e.g., depression, long-COVID, fatigue), impacts on daily life and work, and limited access to in-person services. Some respondents noted that COVID-19 did not have much or any impact on their life, and a few noted the positive impact of having expanded access to online services due to the pandemic.

¹¹ https://datanexus-dhhs.ne.gov/views/BRFSS_PROD_2022/OverallNew?%3Aembed=y&%3Aiid=1&%3AisGuestRedirectFromVizportal=y

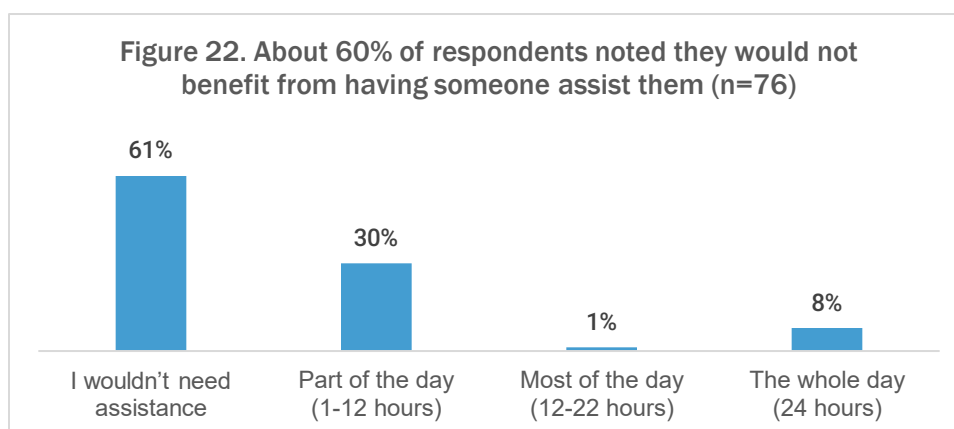
Impact of Brain Injury on Daily Living

When asked if they've experienced problems or difficulties with areas of daily living since their brain injury or injuries, more than three quarters report "some challenges" or "a lot of challenges" with their emotional or physical health (Figure 21). This may not be surprising given the results of the questions related to overall health and mental/emotional health. Among the five categories, survey respondents report having at least some challenges in more than 3 categories. For those who reported having "no challenges" in three or more of the areas (n=17), about half (47%) reside in urban-large counties.



Interestingly, while employment had 32% of people indicating there were "no challenges," it has the highest percentage of people reporting "a lot of challenges," along with emotional health. Analysis showed that there was not a geographic difference among those who reported having "a lot of challenges" with employment.

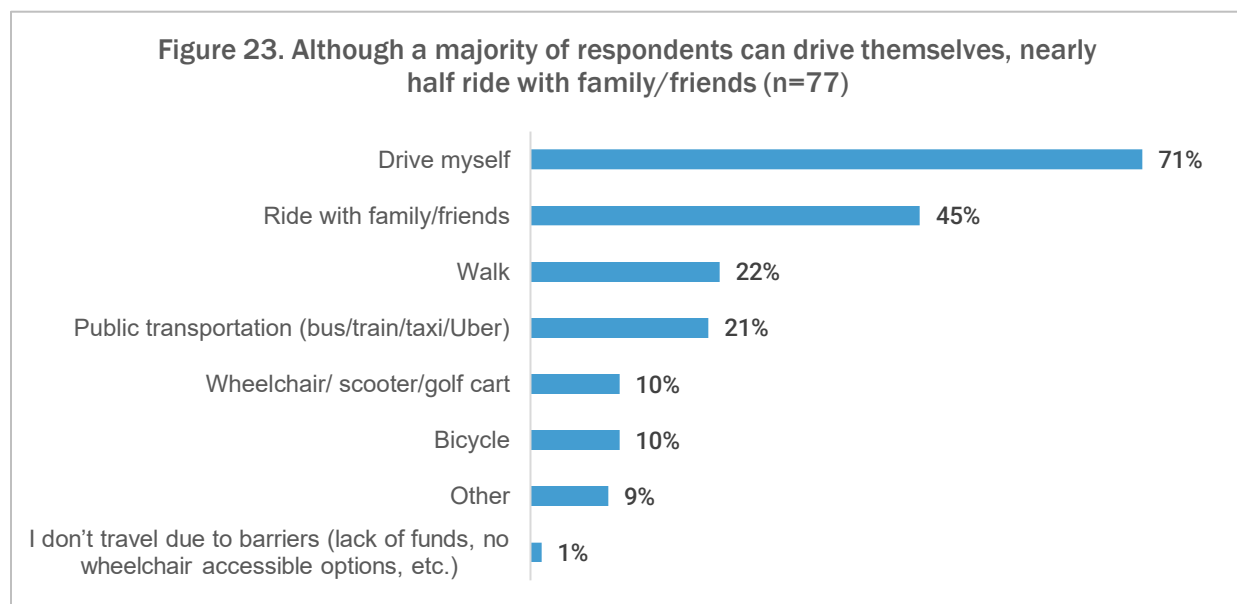
Despite some of the challenges the survey respondents experience, about 60% reported they would not need assistance from someone during the day. However, nearly 10% would benefit from having someone assist them for 12 or more hours a day (Figure 22).



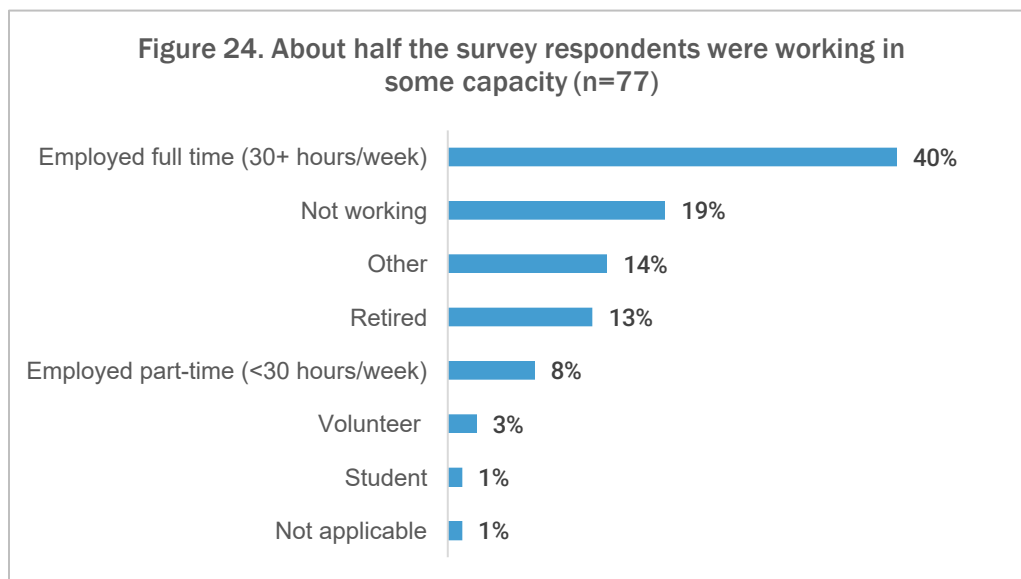
Among those who indicated they would benefit from having someone the whole day (n=6), all but one indicated that they currently have support for that amount of time during the day. People who felt they would benefit from having someone for part of the day – anywhere from 1 to 12 hours – varied in their current level of assistance. More than one-third of those respondents (n=8, 36%) had assistance for part of the day. However, the remaining respondents did not have

any assistance at all. Although they varied in the type of county they reside in (29% rural, 43% urban-small), they were more likely to have experienced more than one brain injury.

Some of the support that individuals need may relate to travel and transportation. Among the survey respondents, about 70% are able to drive themselves to get from place to place (Figure 23). Roughly 77% of respondents reported their transportation for getting to appointments, therapies, and other activities was “very reliable.” **This indicates that, while there are some exceptions, transportation is not a substantial challenge for those who have experienced a brain injury.**

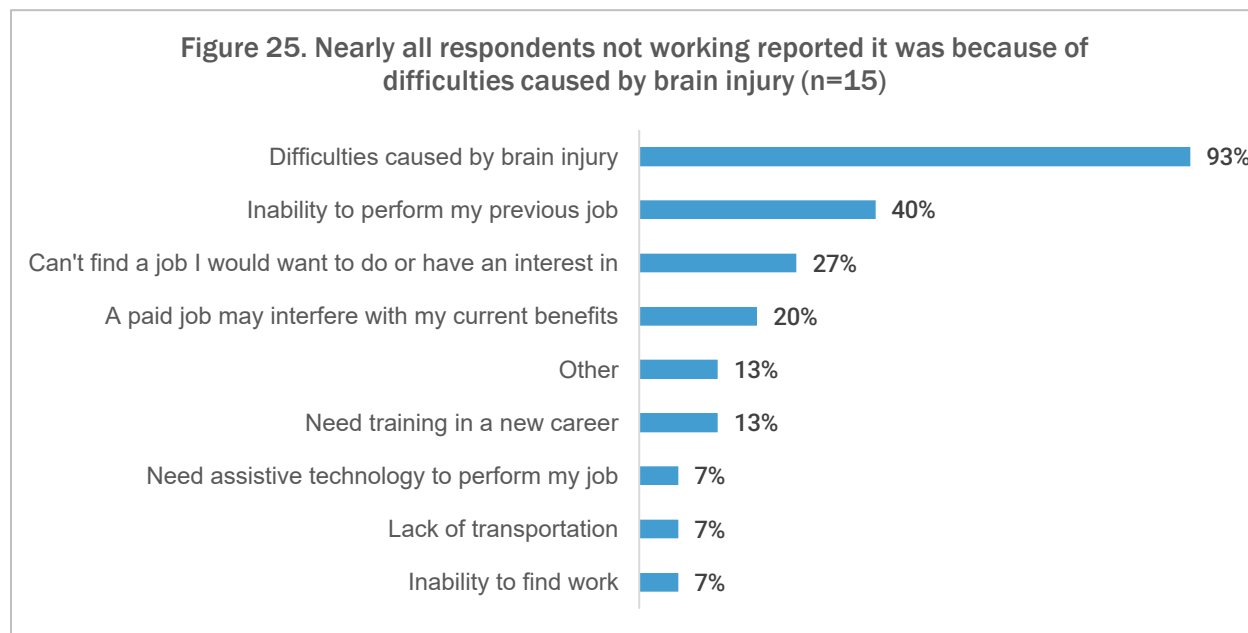


When it comes to employment, slightly less than half of the respondents (40%) were working full-time while 8% were employed part-time (Figure 24). Among those who were employed full-time, about 58% reported through a previous survey question that they had “some” or “a lot” of challenges with employment.



There was variation in those who reported “other” for their employment status. Three of those respondents (27%) indicated they were self-employed while another three indicated that they were disabled. Two recently left the work force – one for retirement and another for termination – while another was working to find employment with Nebraska VR.

Among the 19% that indicated they were not working, nearly all indicated that part of the reason was due to difficulties caused by their brain injury (Figure 25). Results also indicate that among those not working, 79% have “a lot of challenges” with employment.



Service Use

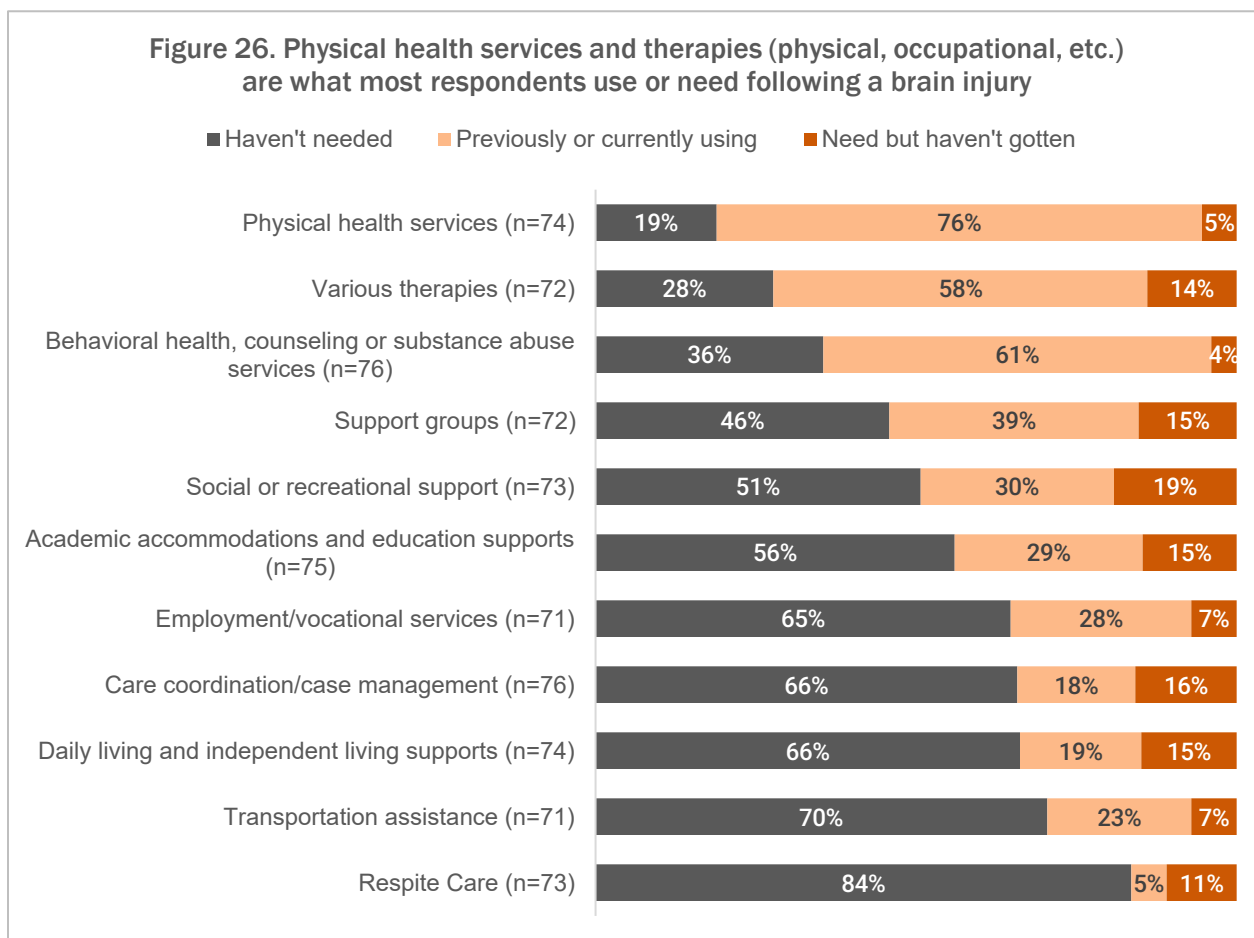
The survey assessed the use of services within 11 categories. Each category had a description of what types of services it included (Table 3).

Table 3. Respondents were asked about 11 service categories to assess use and availability

Category	Description
Academic accommodations and education supports	Services and supports for academic challenges
Behavioral health, counseling, and substance abuse services	Therapist, psychologist, psychiatrist, substance use evaluation, etc.
Care coordination/case management	A professional to help arrange services you need
Daily and independent living supports and services	Assistive technology, meal preparation, support through personal care attendant, money management, etc.
Employment/vocational services	Help getting or keeping a job, such as vocational rehabilitation, supportive employment, job placement, unemployment services, etc.
Physical health services	Primary care provider, nurses, dental, vision, nutrition services, pain management, etc.)
Respite care	Someone who provides a short-term break for caregivers
Social or recreational support	Opportunities to be around others, ways to reduce loneliness,

Support groups	In-person or online support groups for individuals with brain injury
Transportation assistance	Transportation company, HandyVan, vouchers for public transportation, etc.
Various therapies	Includes physical therapy, occupational therapy, speech/cognitive therapy, etc.

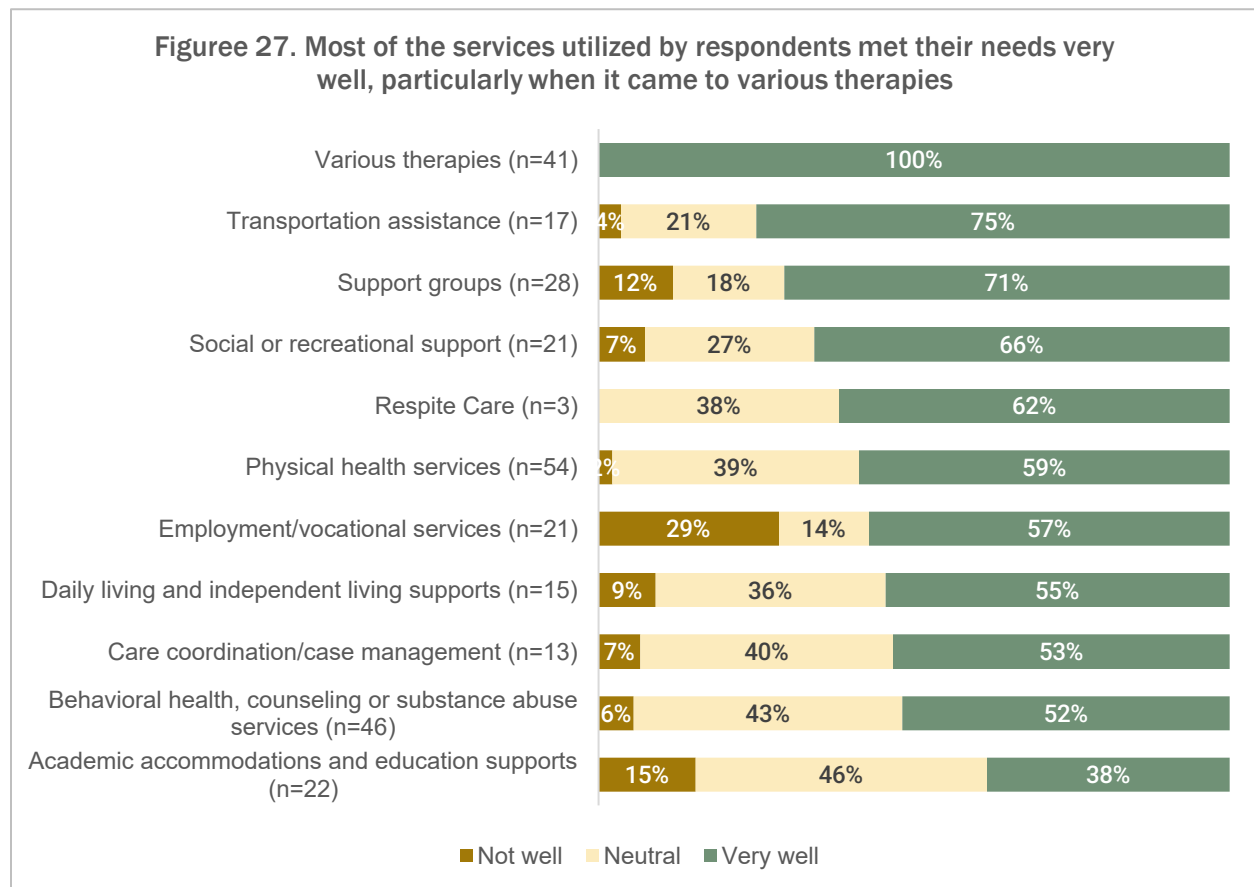
Whether a survey respondent previously used or is currently using a service was combined to explore to what degree people may be able to access services. Based on the results, individuals with brain injury were most likely to use or need physical health services, various therapies, and behavioral, counseling, or substance abuse services (Figure 26). The most common type of service that people need but haven't been able to access is social or recreational support.



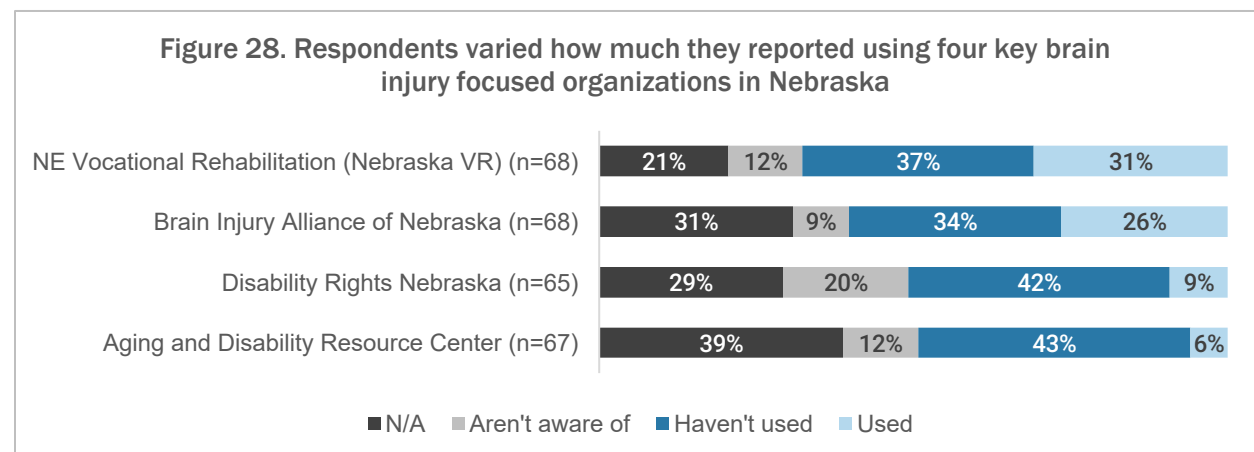
People were least likely to report needing respite care, though this could be because the response is from the individual with the brain injury rather than a family member or caregiver. There were also 70% who reported they haven't needed transportation assistance. This is consistent with the results regarding transportation from earlier in the survey.

On average, among the 11 categories, there are two that respondents have needed but not been able to access. There does seem to be a slight geographical difference. Among the respondents who did not mark "need but haven't gotten" among any of the categories, only 2 (6%) were from rural areas.

People who were able to access services felt that, in general, their needs were met “very well” (Figure 27). The areas where people felt their needs were “not well” met were in the areas of employment/vocational services, academic accommodation and education supports, and support groups. Results should be interpreted with caution with the small number of respondents for some of the services.



Although individuals with brain injury can access services from a range of organizations, there are four that tend to address brain injury-related services. About one-third of respondents felt that the four organizations were not applicable to them, there were quite a few respondents that were aware of but hadn't used the services following their brain injury (Figure 28).



Respondents were also asked to indicate if they were aware of Medicaid Waiver options (Aged and Disabled Waiver, Developmental Disabilities Waiver, and the TBI Waiver). Most (62%) said they were not aware of these options, and 30% said they were aware of them but did not qualify.

Potential Improvements

As aspect of the survey was determining what changes may help better assist and support those who have experienced a brain injury. Open-ended responses from 33 individuals were categories into three key areas: education and awareness, increased support and resources, and policy changes.

Education and awareness were noted among a variety of audiences. This included:

1. Medical providers. This includes doctors, nurses, and other healthcare providers on identifying and treating brain injury. Some indicates that many doctor's don't inquire about past accidents or use any screening tools, which may hinder proper diagnosis.
2. General public. Some respondents emphasized the importance of educating people about "invisible" disabilities like brain injury. Many individuals noted that they feel misunderstood and wanted people to have more empathy for their experiences.
3. Employers. A handful of respondents noted it would be especially helpful to push for trainings among schools and workplaces. There seemed to be insufficient support or education about brain injuries, particularly in these spaces where assistance or understanding may be needed.
4. Schools. In particular, respondents felt it was necessary to education school systems on the impacts of head injury, even as early as middle school. This seemed to be an avenue to help with prevention as well. *"It should be understood before making the decision to play contact sports i.e., football in High School."*

Many also noted the need for increased brain injury support and resources. In particular, respondents noted that it would be helpful to have:

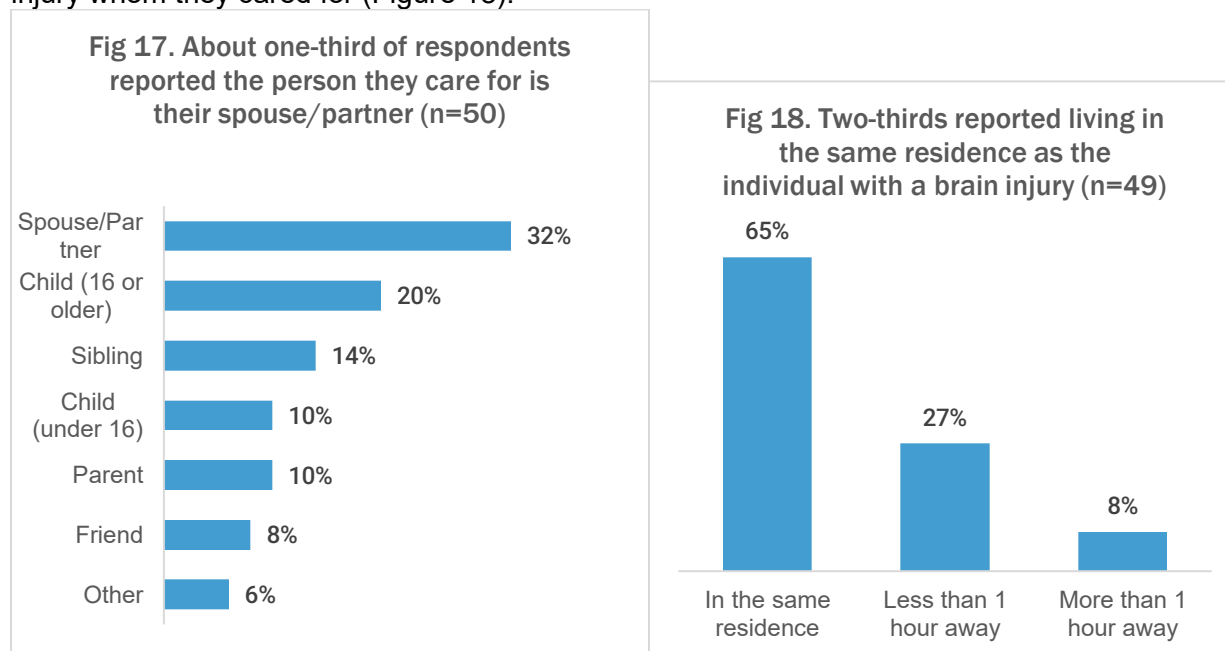
1. More accessible services and resources in rural locations or more remote areas, like western Nebraska. *"After you get a BI there's no support available unless you live in Lincoln/Omaha."*
2. A brain injury hotline, funding, and/or information about services that are available for those who have experienced a brain injury. People who noted this mentioned that it was important to have clearer information about what was available.
3. Medical and vocational support. As seen through other areas of the survey, respondents noted that people want more access to medical providers who understand brain injury.
4. More culturally and linguistically appropriate materials, even just regarding what a brain injury looks like or what someone may experience. *"We need this information in different languages and targeting diverse communities so they also get the information in a culturally-relevant way."*
5. Services and efforts focused on prevention. One respondent noted that *"Prevention isn't addressed by anyone in the state."* However, a brain injury can affect your whole life.

The final key area was related to legislative or policy changes. One individual noted that it would be helpful to "have state legislators pass bill to allow Medicare gap coverage for disabled people under 65." Another noted that while they do not qualify for Medicaid, it's challenging because there are still major hurdles and barriers. *"As a single person with an IDD and a TBI now, I still need an advocate."*

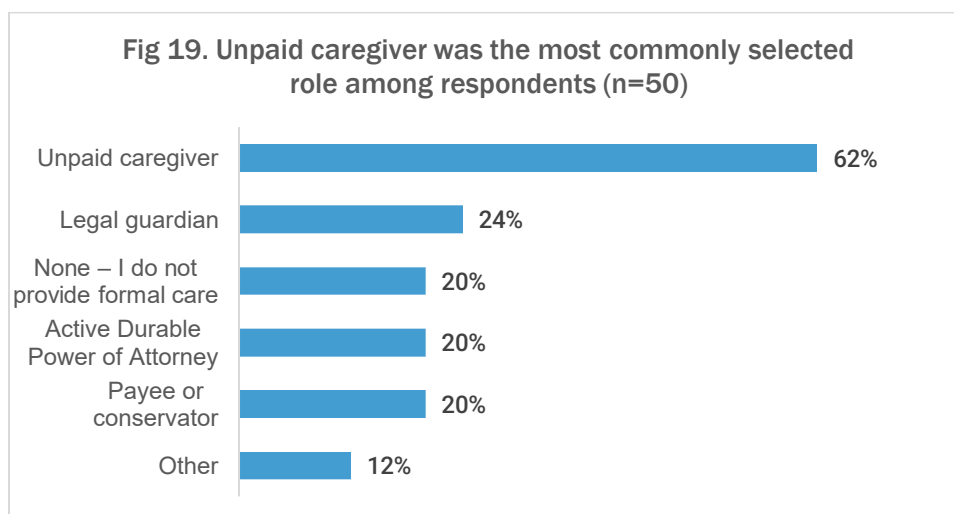
Family Members/ Caregivers

Caregiver Information

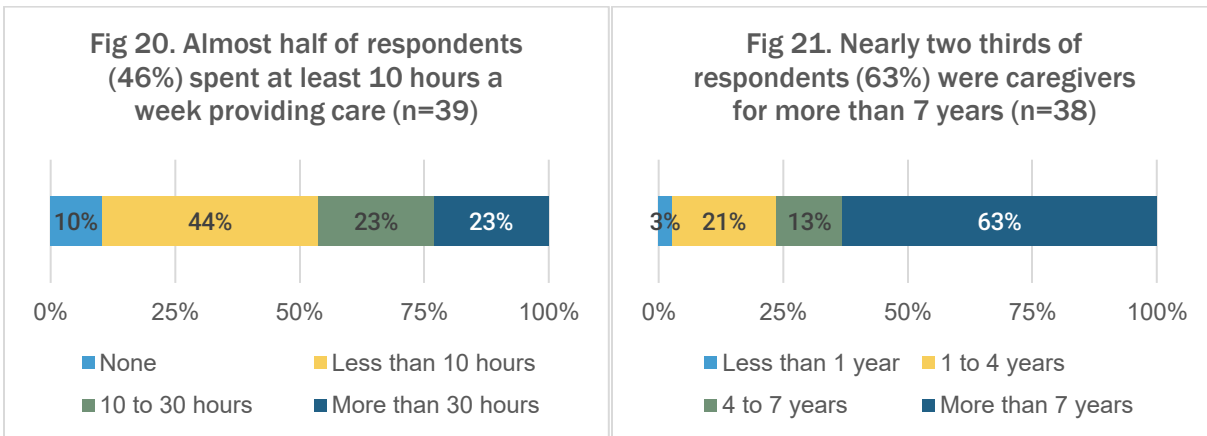
Among the 50 people who provided answers on the survey, about one third (32%) said that the individual with a brain injury whom they cared for was a spouse or partner (Figure 17), and about two thirds (65%) reported living in the same residence as the individual with the brain injury whom they cared for (Figure 18).



When asked to select the caregiving role(s) they served in relation to the person with the brain injury, most respondents (62%) said they served in an unpaid caregiver role (Figure 19).

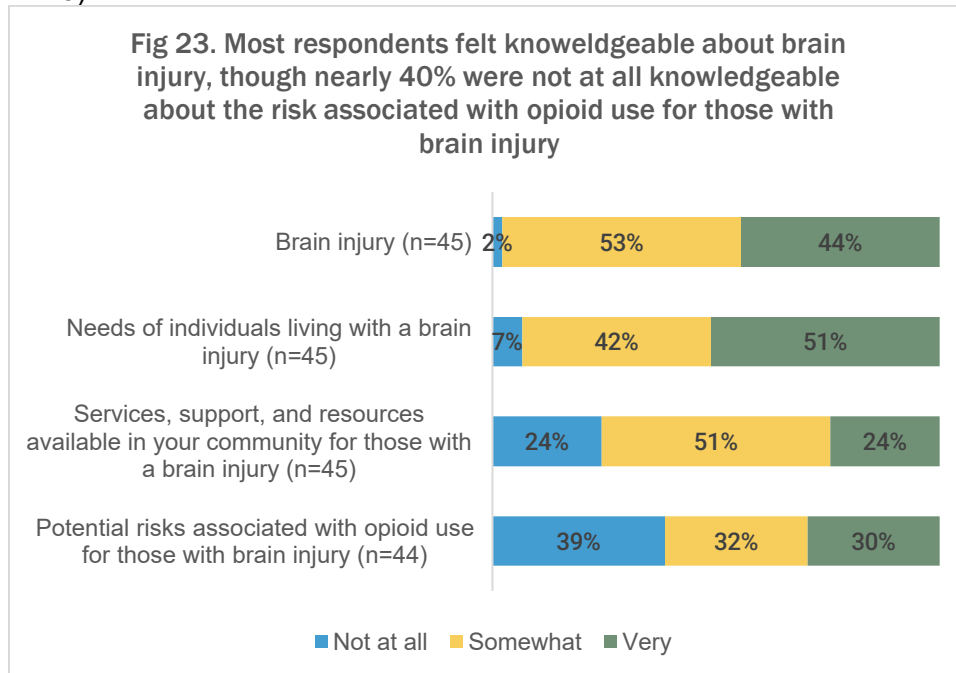


The amount of time spent each week providing care to an individual with a brain injury varied among respondents, with 46% saying they spent at least 10 hours a week providing care and 44% spending less than 10 hours a week providing care (Figure 20). Nearly two thirds of respondents (63%) said they had been caregivers for more than seven years (Figure 21), and less than half (42%) said they were the only caregiver for the individual with a brain injury (Figure 22).



Brain Injury Education & Awareness

Respondents were asked to indicate their level of knowledge regarding brain injury topics on a three-point scale. Most respondents felt knowledgeable about brain injury, though nearly 40% were not at all knowledgeable about the risk associated with opioid use for those with brain injury (Figure 23).



Respondents were asked an open-ended question regarding the types of training, resources, or materials (if any) that would be helpful to better understanding brain injury and how to care for someone who has experienced it. A total of 25 individuals provided a response, which were summarized across eight different categories.

- 1. Personal Experience & Lack of Resources:** Several caregivers described their personal experiences, highlighting a lack of resources when their loved ones first incurred a brain injury. They felt there was limited support and had to rely on their own judgment, particularly in rural areas like Nebraska.
- 2. Understanding Brain Injury:** Caregivers expressed a need for educational resources explaining which parts of the brain are affected by injury, symptoms (both short- and long-term), and the potential changes in behavior or personality. This includes identifying

brain injuries and understanding emotional and behavioral aspects, such as anger or forgetfulness.

3. **Information on Specific Types of Injuries:** There was a desire for information on brain injuries that occur at birth, as most materials focus on injuries occurring later in life. Caregivers also wanted resources related to adults who can function independently but still struggle emotionally or behaviorally.
4. **Training for Medical and Mental Health Providers:** A common theme was the need for better training for medical and mental health professionals about the impacts of brain injury, as some caregivers felt their loved ones were misdiagnosed or misunderstood by professionals.
5. **Support for Caregivers:** Caregivers suggested having PowerPoints, handbooks, peer or mentor support, and online training options to help them navigate the complexities of caring for someone with a brain injury. They also mentioned wanting to join support groups to connect with others in similar situations.
6. **Legal and Educational Support:** Legal advice regarding medical prescriptions and doctor awareness was a concern. In the educational setting, caregivers wanted more awareness of how brain injuries impact learning, emotional well-being, and executive functioning.
7. **Practical Needs:** Caregivers noted that transportation for individuals with brain injuries would be helpful, and they desired cognitive training classes for their loved ones to potentially re-enter the workforce.
8. **General Requests:** Some caregivers simply wanted to know what services and resources were available to them, as navigating the system can be overwhelming. They also requested training on medical needs specific to brain injury care.

Caregiver Supports

Respondents were asked where they go for social and emotional support related to caregiving from a list, given a list of options. As shown in Figure 24, more than half of the respondents who provided an answer to the questions said they relied on friends and/or family for support. When asked to select which supports or services would be helpful to them as a caregiver from a list, at least half said educational events or financial support would be helpful (Figure 25). Other responses to this question that were specified include mentions of support and/or networking groups for caregivers, information to better understand what the person with the injury is going through, as well as programs and places for treatment. Respondents were also asked to select options from a list of barriers that prevent them from getting supports and services that would be helpful to them as caregivers. About a third of respondents either said those services were not available, they were not eligible for those services, or they selected the “other” options (Figure 26). Among those who selected “other,” many noted specific circumstances or reasons why those services were not available or why they were not eligible for those services.

Fig 24. More than half of the respondents relied on family and/or friends for support in caregiving (n=44)

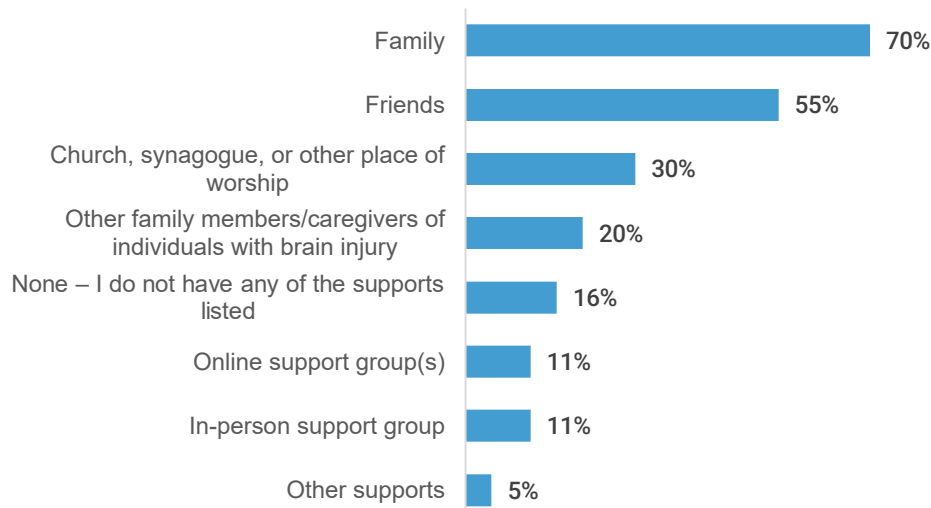


Fig 25. At least half of the respondents said that educational events or financial support would be helpful to them as a caregiver (n=38)

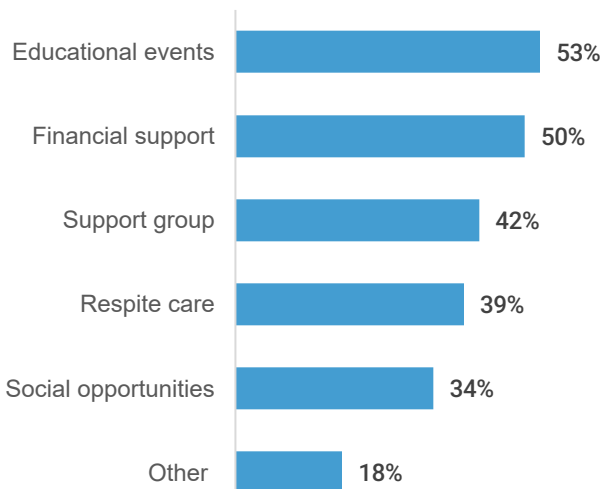
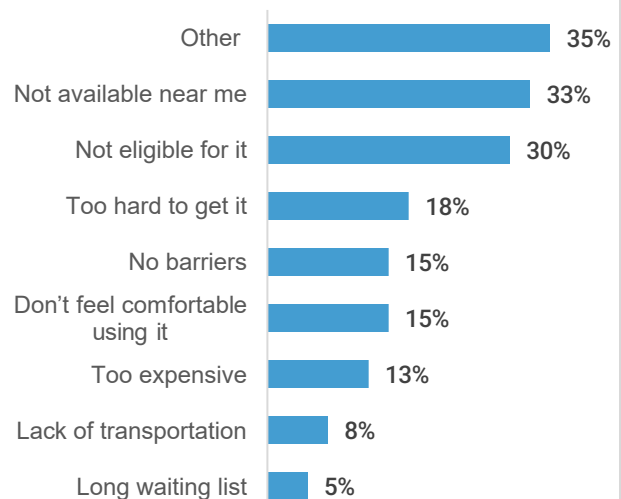


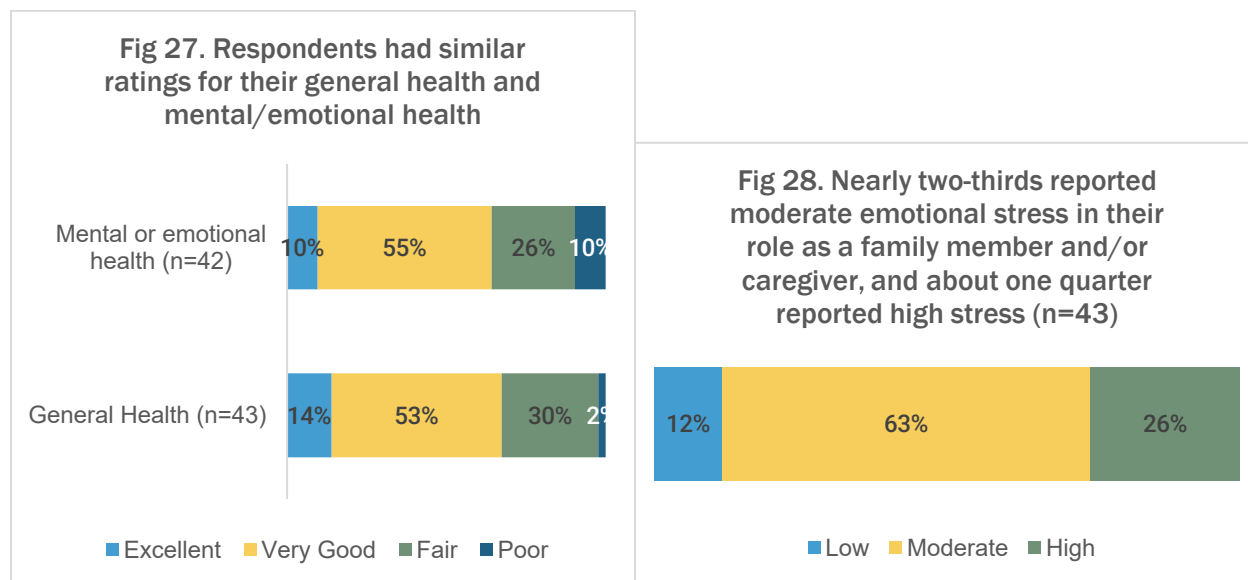
Fig 26. About a third of the respondents said services were not available, they were not eligible, or selected other (n=40)



Mental and Physical Health

When asked questions regarding their mental and physical health, respondents gave similar ratings for each, with about two-thirds of respondents reporting excellent or very good general or mental/emotional health (Figure 27). Nearly two-thirds reported moderate emotional stress in their role as a family member and/or caregiver, and about one quarter reported high stress (Figure 28). Respondents were also asked if they have used any mental health or counseling services due to their role and responsibilities as a family member and/or caregiver of an individual with a brain injury. While 44% said no, they haven't needed those services, 42% said they have used those services, and 14% said they needed those services but haven't received

them. All 18 individuals who reported receiving these services said those services either helped or somewhat helped them get the support they needed as a family member or caregiver.



Life Changes and Caregiving Challenges

When asked to indicate if caregiving responsibilities resulted in specific life changes related to work or finances, 56% reported that their caregiving responsibilities results in personal financial hardships (Figure 29). When given a list of challenges people may experience as an unpaid caregiver to someone with a brain injury and asked to indicate how much of a challenge (major, minor, or no challenge), respondents were less likely to report experiencing challenges with transportation or working, and about two-thirds of respondents said coordinating appointments, attending to their own care needs, and finances were a major or minor challenge (Figure 30). Additionally, while about three quarters of respondents agreed that they understand their family member's disability, a similar percentage of respondents also agreed that it has been stressful accessing services for the individual with a brain injury (Figure 31).

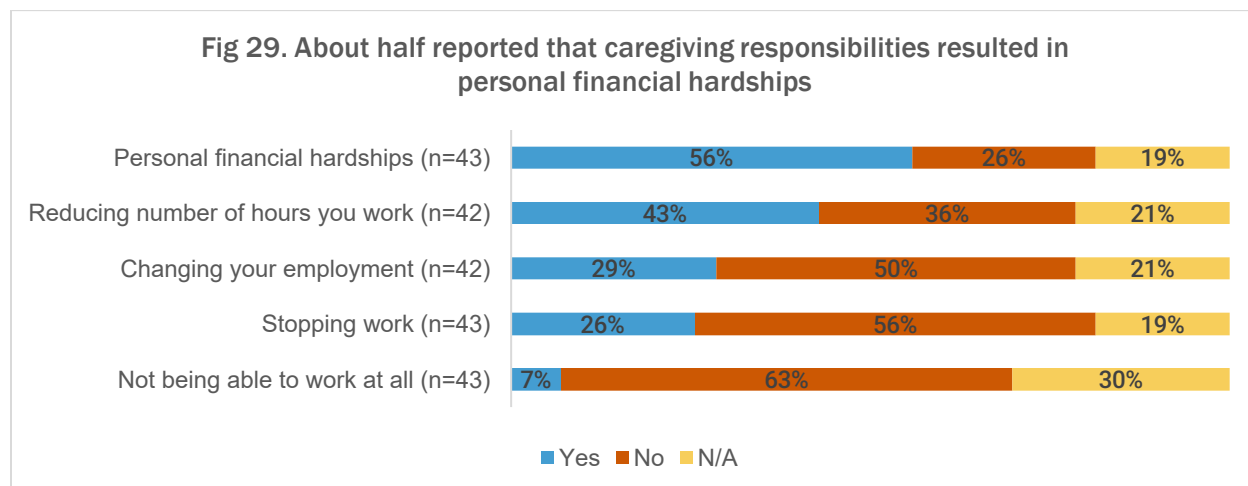


Fig 30. Respondents were less likely to experience challenges with transportation and working

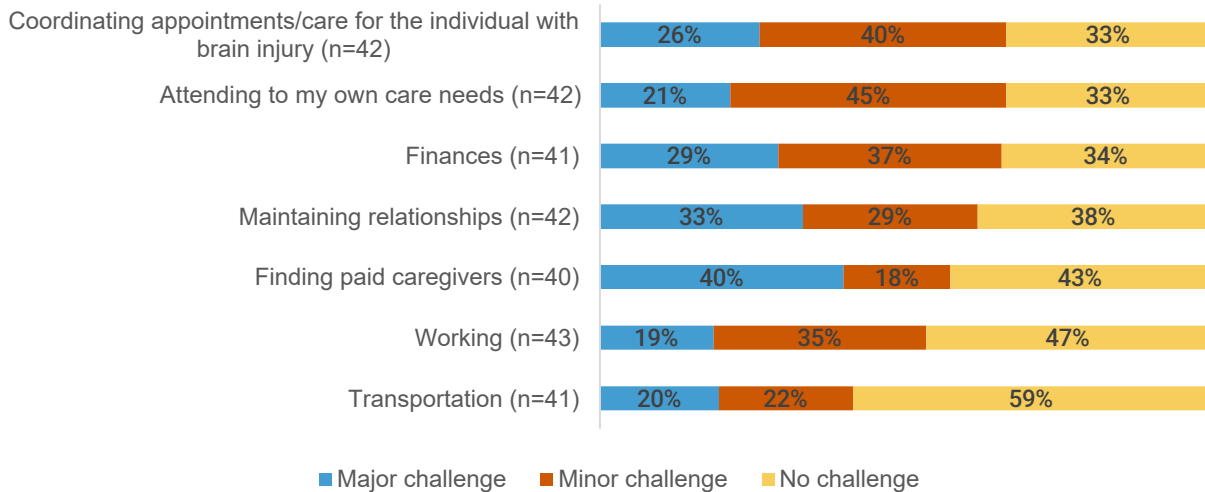
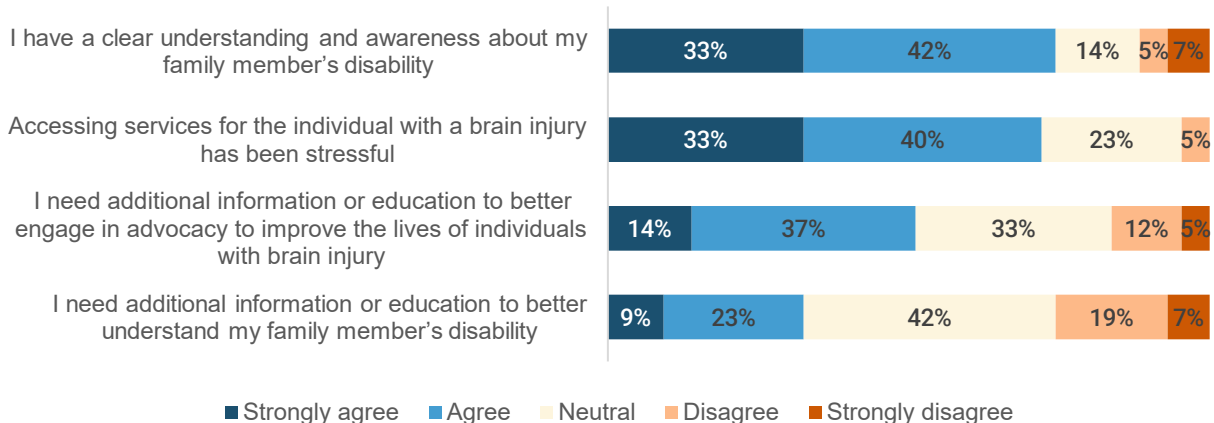


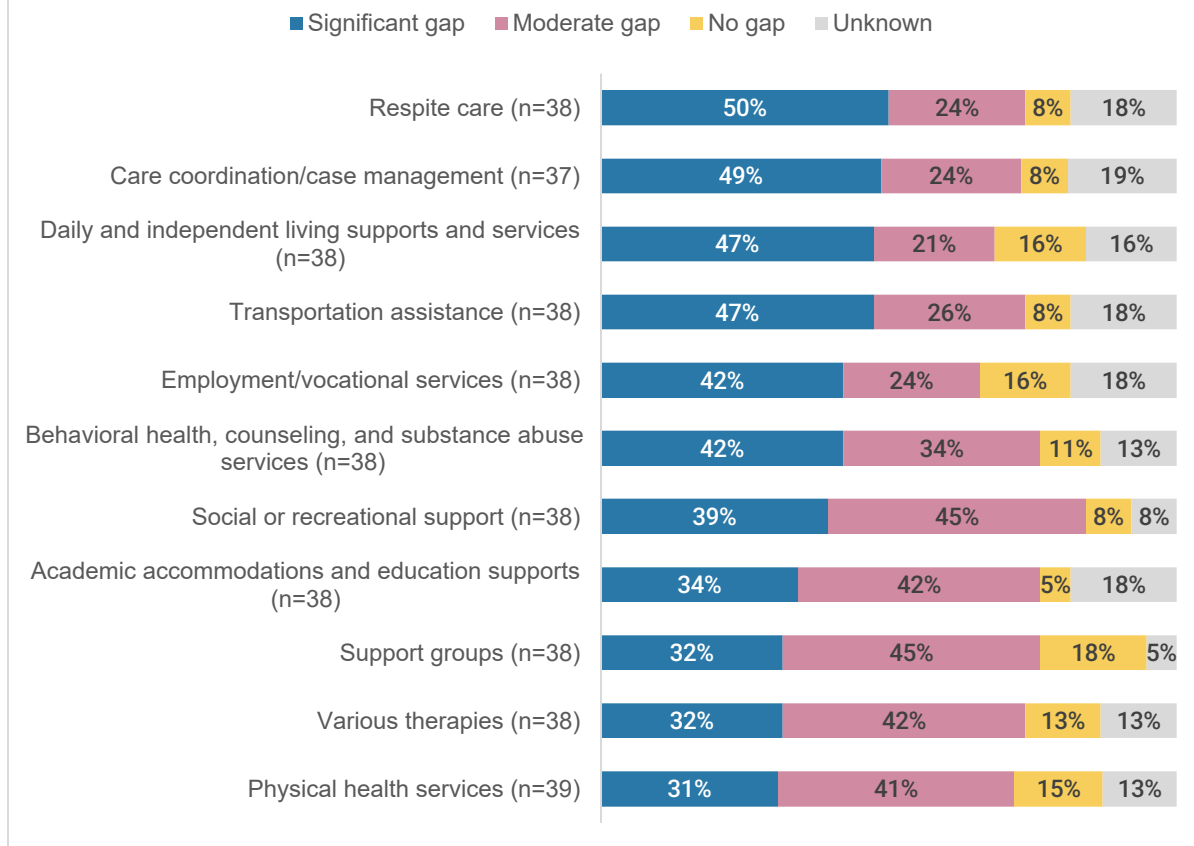
Fig 31. A majority agree they understand their family member's disability but that it has been stressful accessing services for the individual with a brain injury (n=43)



Services

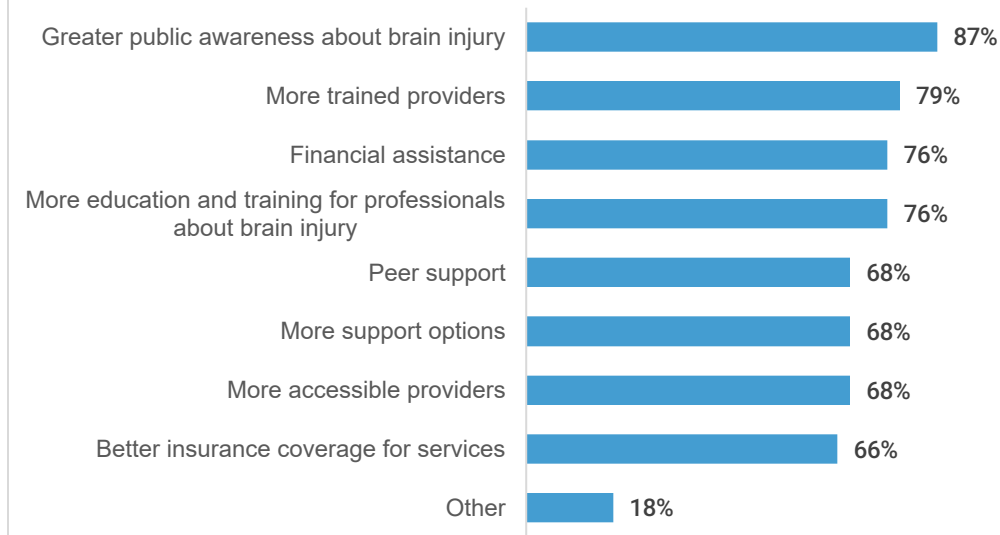
When asked how much difficulty respondents have had trying to coordinate services for the individual with a brain injury (such as knowing what services to seek or who to schedule appointments with), **80% reported experiencing either some or a lot of difficulties**, and 20% reported experiencing no difficulties. 38 respondents provided an answer to the question, “In one or two words, what comes to mind when you think of brain injury services in Nebraska?” Among those who provided an answer, respondents described brain injury services in Nebraska as poor, minimal, and inaccessible, with many questioning whether services even exist. Rural areas were particularly noted for a lack of resources and support, while some mentioned the Brain Injury Alliance of NE and Madonna Rehab as key but limited resources. **Overall, services were described as growing but inadequate, hard to access, and not publicly known.** As shown in Figure 32, when asked to describe how much of a gap there was for specific services for individuals with a brain injury, about half of respondents felt there were significant gaps in respite care and in care coordination/case management.

Fig 32. About half of the respondents felt there were significant gaps in respite care and care coordinate/case management



When asked to select from a list of things that could improve services for those with a brain injury, increased public awareness about brain injury, more trained providers, financial assistance, and more education/training for professionals about brain injury were all selected by at least three quarters of respondents (Figure 34).

Fig 34. Increase awareness and more trained providers were the top suggestions for improving services for those with brain injury (n=38)



Potential Improvements

At the end of the survey, respondents were asked two open-ended questions: 1) “What could be done to better help individuals with brain injury in your community or state?” and 2) “What could be done to better help family members and/or unpaid caregivers of individuals with brain injury in your community or state?” 26 respondents provided an answer to one or both of those questions, and the results were summarized by theme for each question.

To help individuals with brain injury

1. Employment and Job Support:

- Many respondents emphasize the importance of providing job opportunities for individuals with brain injuries, along with job coaching to help them succeed.
- There's a recognition that employment can give individuals a sense of accomplishment and identity, but continuous support may be needed, especially for those with long-term effects like memory issues.

2. Training for Professionals:

- Respondents call for better training for healthcare professionals, caseworkers, and primary care providers in understanding and addressing brain injuries.
- There is a need for specialized education in medical schools and continuing education programs to better equip professionals in recognizing and treating brain injury-related challenges.

3. Access to Services and Resources:

- There is a desire for improved access to brain injury services, especially in rural areas where some people have to travel long distances to access care.
- Better transportation options and more local service availability are highlighted as key needs.

4. Specialized Facilities and Housing:

- Several respondents note the lack of appropriate care facilities, such as nursing homes or assisted living centers, that are trained to care for individuals with traumatic brain injury (TBI).
- Suggestions include more TBI-focused facilities and training for existing facilities, particularly for individuals who cannot live independently or require respite care.

5. Awareness and Education:

- Public education campaigns and awareness efforts are seen as crucial, not only for the general population but also within schools and the legal system, which may not fully accommodate individuals with brain injuries.
- Respondents suggest more support groups, peer mentoring, and programs like "big brother" initiatives to create community connections for those affected by TBI.

6. Rehabilitation and Long-Term Support:

- There is a strong call for better access to rehabilitation services, regardless of insurance coverage or financial situation, including post-acute care and ongoing re-evaluations for placement in care facilities.
- Social support, such as more mental health resources and social events for individuals with TBI, is also seen as vital for long-term well-being.

7. Family Education and Support:

- Educating families about brain injury and the resources available is seen as an important step in improving care.
- Respondents note that families often struggle to find appropriate support for their loved ones, particularly when it comes to navigating care options and transportation services.

To help family members and/or unpaid caregivers

1. Employment and Financial Support

- Many caregivers expressed a need for employment assistance or supported employment opportunities for their family members with brain injuries.
- Financial support was a major theme, including suggestions for funding transportation costs, financial assistance for caregiving spouses, and programs to address legal problems resulting from brain injury.

2. Access to Services and Resources

- Several responses indicated a need for improved access to mental health supports and services, including better pathways for Medicaid and disability qualification.
- There was a strong desire for clearer information to be provided at hospitals and by healthcare professionals, along with more awareness and education about available community services.

3. Respite Care and Support Groups

- The lack of respite care was a recurring issue, with many caregivers requesting more opportunities for short-term relief, including evening and weekend availability.
- Support groups for both individuals with brain injuries and their caregivers were frequently mentioned as essential but lacking in accessibility or availability.

4. Healthcare and Diagnostics

- Caregivers expressed frustration with the lack of diagnostic tools, such as affordable and accessible SPECT scans, and the overall lack of qualified providers.

- Some responses highlighted the need for medical professionals to better listen to family members and take their input seriously.

5. Awareness and Stigma

- Reducing the stigma associated with brain injury was a key concern, alongside raising awareness in schools and the wider community.
- Peer support, especially in rural areas where services are limited, was seen as a crucial missing element.

6. Geographic and Rural Challenges

- Rural caregivers emphasized the lack of resources in less-populated areas and the need for action rather than just discussions from fund managers and policymakers.
- Transportation challenges, particularly in western parts of the state, were also noted as significant barriers to accessing care.

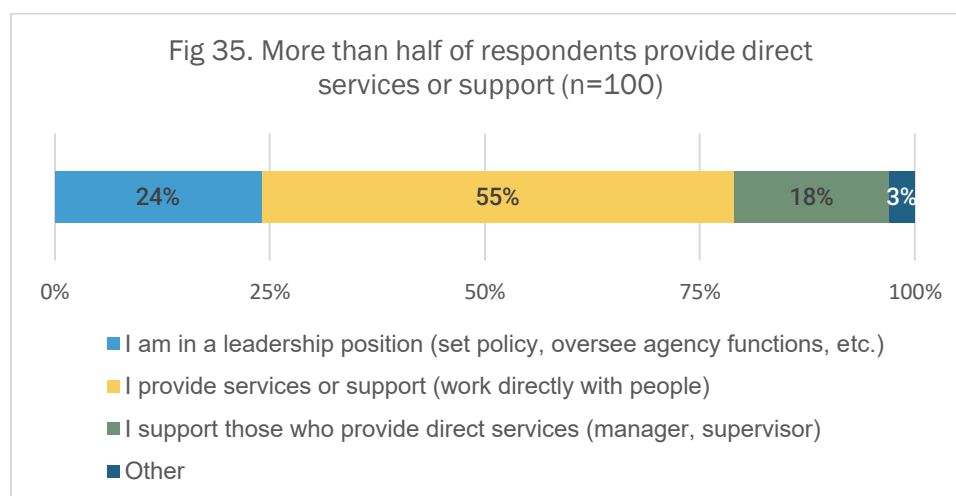
Service Providers

There were 112 people who provided a response on service provider survey. Those who completed the survey represented 58 different organizations across the state, with the most represented organizations being Nebraska VR (n=16), QLI (n=6), Madonna Rehabilitation Hospital (n=5), Brain Injury Alliance of NE (n=5), and Assistive Technology Partnership (n=5).

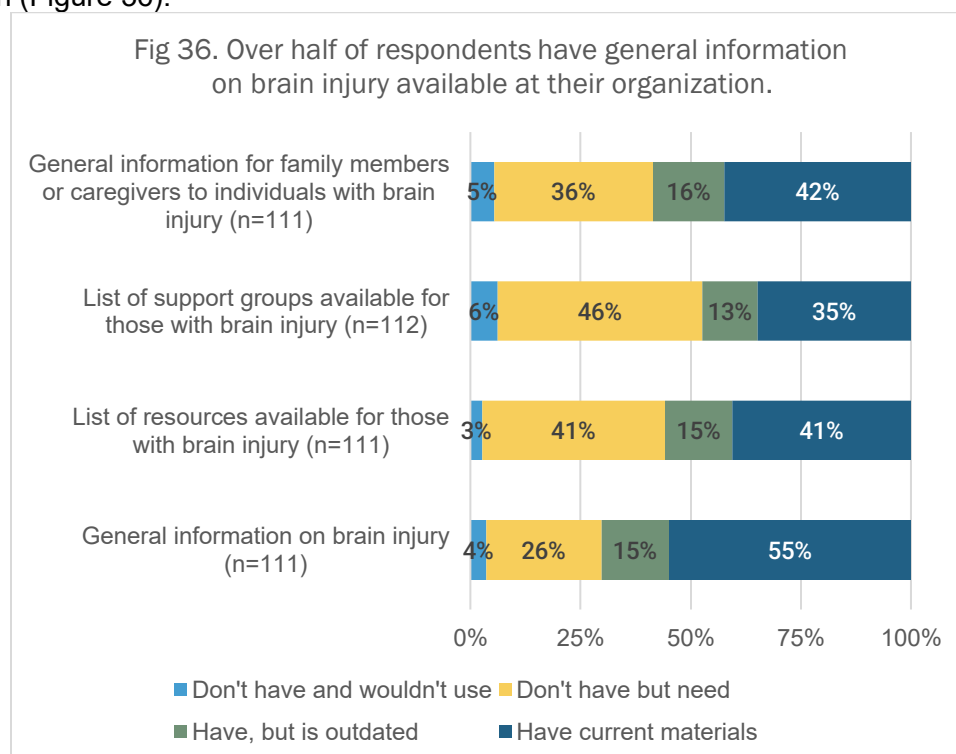
When asked where their office was physically located, respondents cited 26 different counties or regions across the state; however, Douglas (n=16) and Lancaster (n=14) were the most often cited counties for office locations. Respondents were also asked to indicate where their agency serves individuals with brain injury. Overall, respondents said they served individuals in 67 of Nebraska's 93 counties, and 29 said they serve all counties in the state. In terms of the populations served, Table 1 shows the number and percent of respondents who reported that their organization served a specific demographic group.

Children (ages 1 through 12)	39	35%
Youth (ages 13 through 17)	55	49%
Adults (ages 19 through 64)	71	63%
Older adults (age 65 and older)	64	57%
Rural	58	52%
Incarcerated	23	21%
Veterans	45	40%
Individuals experiencing homelessness	39	35%
Native Americans	46	41%

When asked to about their role within their organization, more than half of respondents (55%) said they provide direct services or support to people (Figure 35).



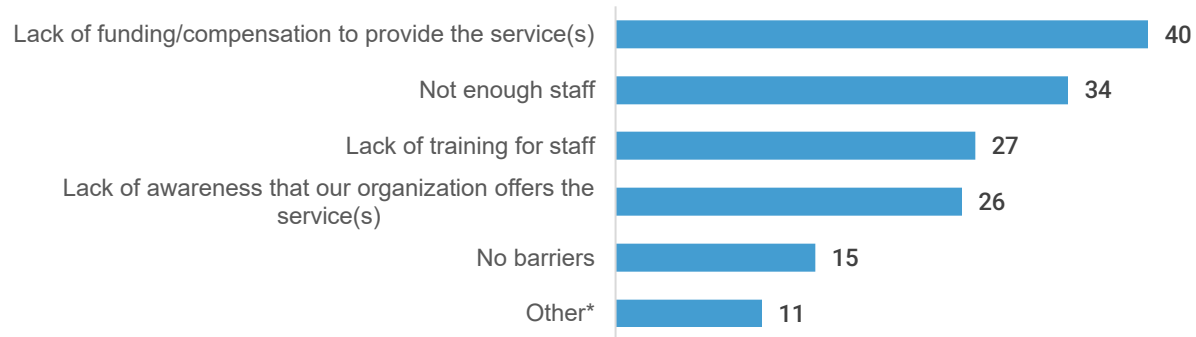
In terms of informational materials that are offered at the organizations, more than half of respondents (55%) said their organization offers general information on brain injury, and 46% said don't have a list of support groups for those with brain injury but would need that information (Figure 36).



Services Offered & Gaps

When asked to report on the top barriers for the services their organization provides, funding and staffing issues emerged as the top concerns (Fig 38).

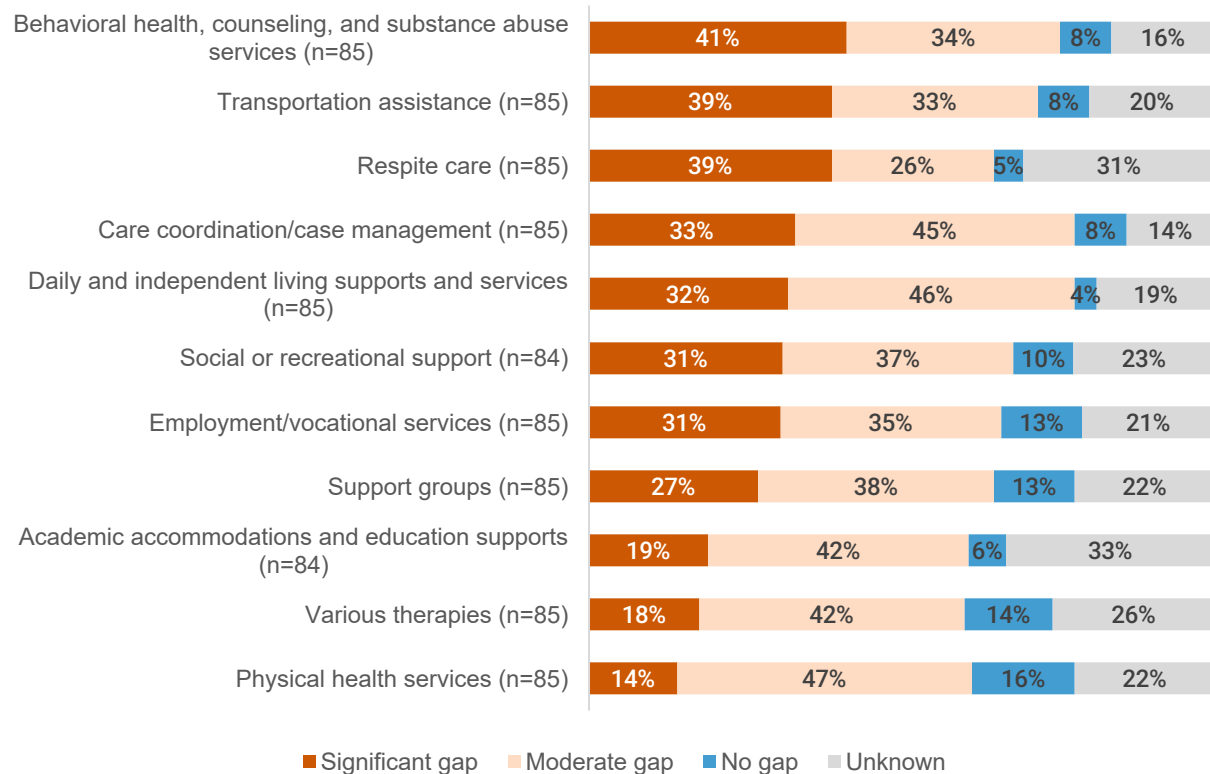
Fig 38. Funding and staffing issues were the top barriers selected by respondents.



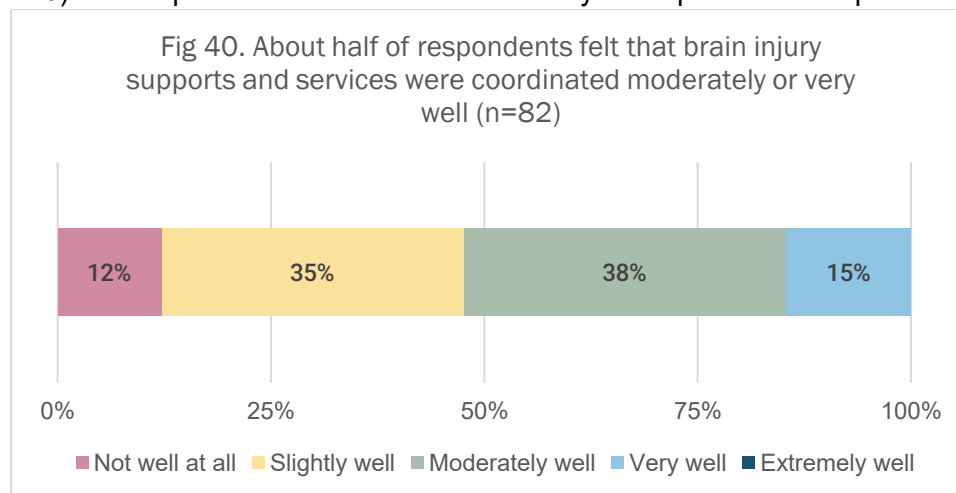
*Other response options include lack of resources, lack of employment supports, lack of up-to-date or relevant trainings, operating costs, and lack of service providers.

For each of the services listed in Figure 39, respondents were asked how large the gaps are in their region for certain services that people with brain injury may need. As shown in Figure 39, around 40% of respondents reported significant gaps for their area in behavioral health, counseling, and substance abuse services, transportation assistance, and respite care.

Fig 39. Around 40% reported significant gaps in behavioral health, counseling, and substance abuse services, transportation assistance, and respite care.



When asked about service and support coordination in their area, about half (52%) of respondents felt that brain injury supports and services were coordinated moderately or very well (Figure 40). No respondents selected the extremely well option for this question.



Respondents were asked an open-ended question to list any services that are not offered in their region that they believe would be beneficial to individuals who have experienced a brain injury. A total of 39 respondents provided a valid response, and their responses highlight gaps in services for individuals with brain injuries across various regions. Key areas identified include the need for employment resources, transportation for those in rural areas, and more professionals trained in brain injury care. Respondents also emphasized the lack of affordable mental health services, caregiver support, and recreational activities. Respondents expressed a need for support groups, including those tailored to young patients and their families, as well as the need for case management and community peer support.

Additionally, respondents mentioned the absence of cognitive rehabilitation services, inpatient acute rehab for severe cases, and more outreach to raise awareness of available services. A notable concern is the geographic disparity in available services, with rural and western regions having fewer resources than urban and eastern areas. Specialized treatment, like SPECT scanning, and services for those with complex neurobehavioral changes are also lacking.

When asked to indicate which items from a list could help improve services for those with a brain injury, more education and training for professionals, greater public awareness, and more trained providers emerged as top areas that could help improve services for those with a brain injury (Figure 41). Table 2 shows the percentage of respondents from each region who selected each item.

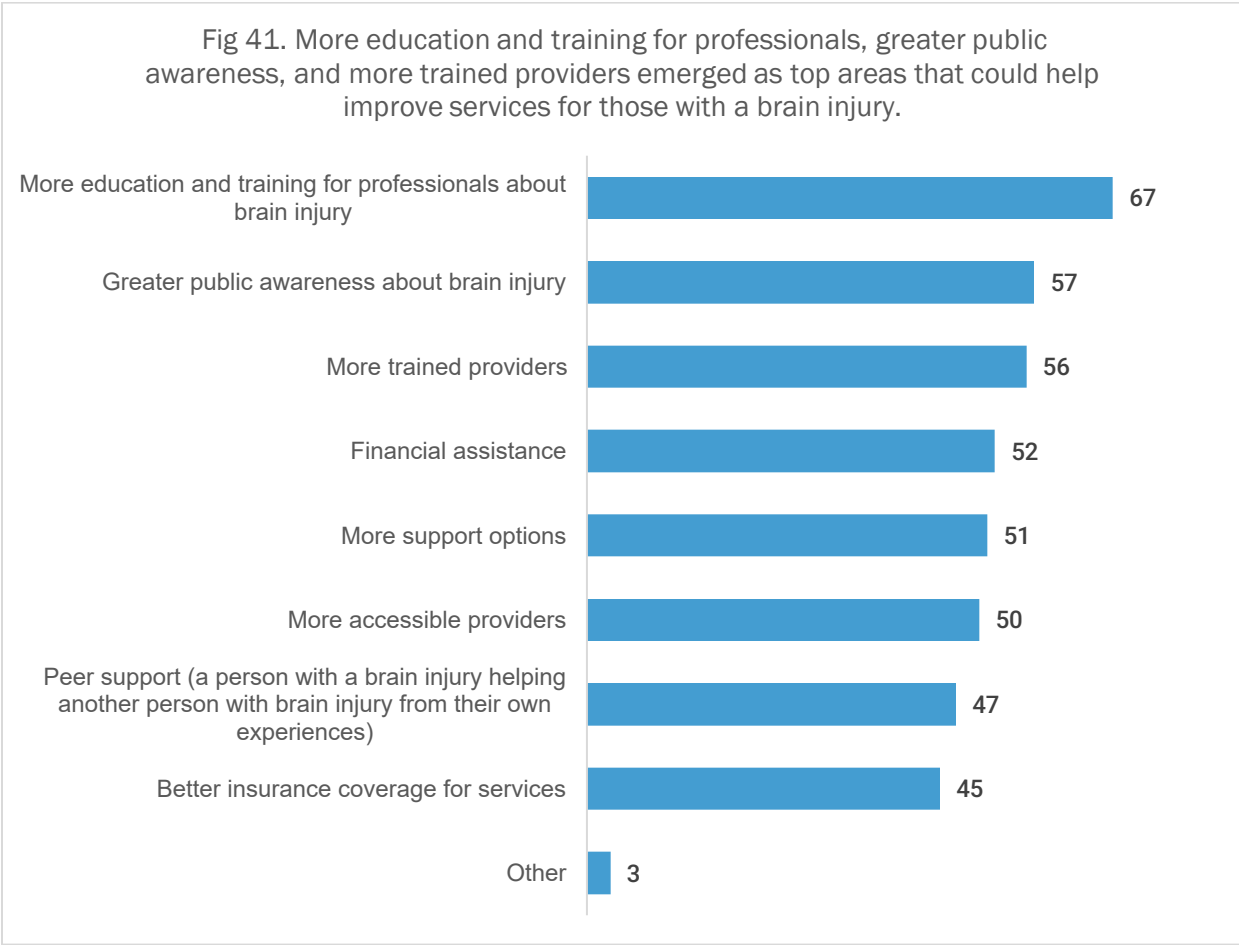
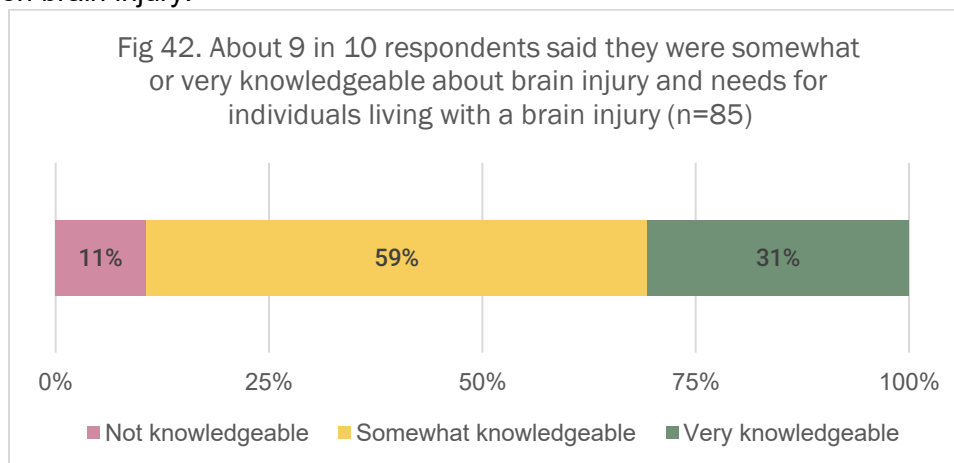


Table 2: The percentage of respondents from each region who selected an item that could help improve services for those with a brain injury.

	More education and training for professionals about brain injury	Greater public awareness about brain injury	More trained providers	More accessible providers	More support options	Financial assistance	Better insurance coverage for services	Peer support (a person with a brain injury helping another person with brain injury from their own experiences)
Omaha Metro (n=20)	75%	50%	60%	45%	55%	65%	50%	50%
Lancaster (n=14)	79%	86%	64%	71%	57%	71%	79%	57%
Panhandle (n=11)	91%	64%	82%	55%	73%	55%	27%	55%
South Central (n=8)	88%	88%	100%	100%	100%	88%	63%	88%
Southwest (n=6)	83%	50%	50%	50%	33%	17%	33%	50%
East Central (n=5)	80%	80%	60%	40%	40%	40%	100%	60%
Northeast (n=5)	80%	80%	80%	40%	60%	60%	40%	20%
North Central (n=2)	50%	50%	100%	100%	100%	50%	50%	50%
Southeast (n=1)	0%	0%	100%	100%	0%	100%	100%	0%

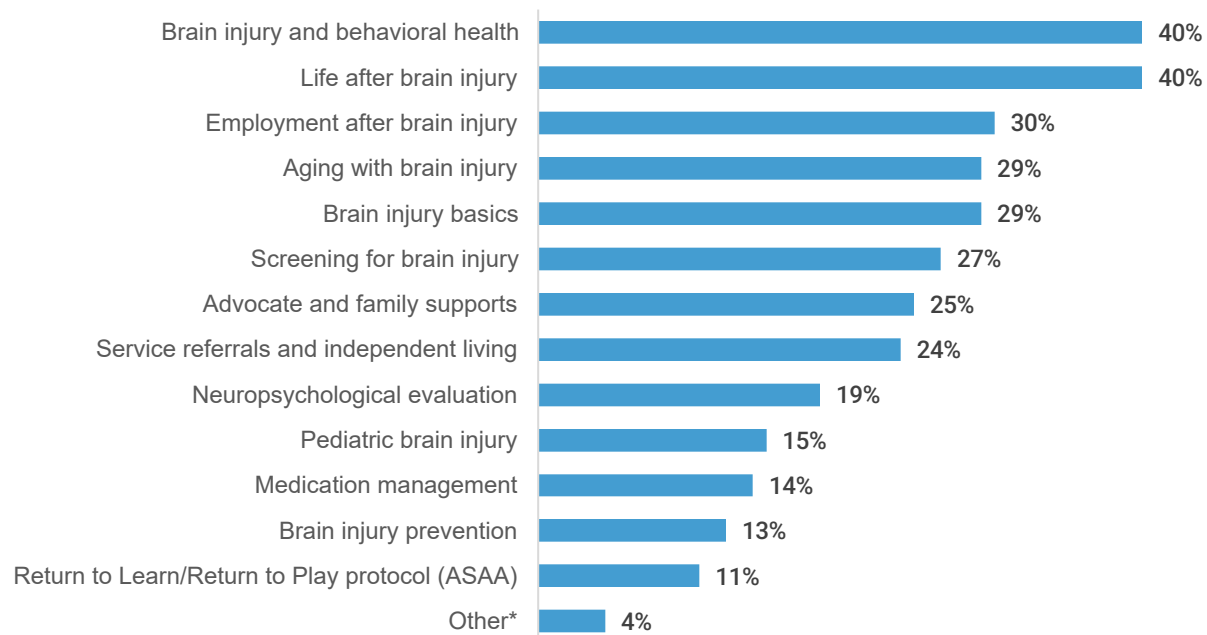
Brain Injury Training and Education

When asked to rate their own knowledge of brain injury and needs for individuals living with a brain injury, nearly 9 in 10 respondents said they were somewhat or very knowledgeable (Figure 42). When asked about their participation in training or educational opportunities regarding brain injury, only 13% said they had not participated in any trainings or educational opportunities, and roughly 84% of respondents said they were at least somewhat interested in additional training or education on brain injury.



When asked what type of brain injury training they or their organization would consider attending, brain injury and behavioral health and life after brain injury were the most selected options (Figure 43). Other responses that were specified included: universal supports to accommodate the needs of a person with a brain injury, more affordable CEUs, acute brain injury rehabilitation, and concussions.

Fig 43. Brain injury and behavioral health and life after brain injury were the most selected trainings that respondents would be interested in attending. (n=112)



General Questions

When asked an open-ended question about what they think is working well in the current system of care for individuals with brain injury and their families in Nebraska, 31 respondents provided an answer, and those answers were categorized according to the following themes:

1. **Availability of Resources:** There is a good amount of resources available, particularly in Eastern Nebraska, including acute care, occupational therapy (OT), physical therapy (PT), and speech therapy (ST). The presence of specialized facilities like Level 1 trauma centers, acute rehab, and specialized care systems (such as LTACH and QLI) also seems to be a positive aspect.
2. **Specialized Support and Services:** Support groups, Medicaid waiver services, and training programs are mentioned as beneficial. The BIA-NE is noted for providing resource facilitation and support. The school system has improved its response to brain injuries over the past 20 years.
3. **Improved Medical Understanding and Services:** The medical field is seen as making progress in understanding brain injuries and improving treatment. Acute care services, particularly for traumatic brain injury (TBI), are mentioned positively, especially once patients are engaged in the inpatient rehabilitation system.
4. **Connections and Collaborations:** There are positive collaborations with various community organizations, including juvenile justice programs and domestic violence services. Additionally, individuals are becoming more willing to work with each other to improve care for brain injury patients.
5. **Accessibility for Certain Populations:** For families who are knowledgeable or well-versed in TBI, resources are easier to find. In larger communities, the system seems to work better, with more available resources and less waiting time for specific services such as AD/TBI waivers.

Respondents were also asked about what they recommend for improving services and support for individuals with brain injury and their families in Nebraska. 42 respondents provided an answer, and those answers were categorized according to the following themes:

1. Public Awareness and Education:

- More outreach and public awareness campaigns about brain injury.
- Increased education for emergency room staff, employers, and the general public, particularly regarding the impact of brain injuries and how to support those affected.
- More education for medical professionals and behavioral health staff to understand brain injury better.

2. Access to Services:

- Improved access to resources, especially in rural Nebraska, where people are often underserved.
- Easier access to services with minimal barriers, such as more information on where to go for help and what resources are available.
- Support for accessing housing and transportation for individuals with brain injuries, including those just out of rehabilitation.

3. Training and Support for Providers:

- More providers trained in brain injury care.
- Additional training for staff in all fields who work with brain injury patients.
- More training opportunities for behavioral health staff and care professionals.

4. Employment and Rehabilitation Services:

- More supported employment programs to help individuals with brain injury retain jobs.
- Expansion of cognitive rehabilitation services and post-acute care options.
- Better access to neurobehavioral services, including inpatient and residential options.

5. Caregiver and Family Support:

- More financial assistance and respite care options for caregivers, with better support to prevent burnout.
- Advocacy services to help individuals with brain injury navigate medical appointments and access necessary care.
- Increased peer and community support through support groups and community services tailored to brain injury.

6. Rural Focus:

- A greater focus on expanding services to rural areas, where there is a shortage of specialized brain injury care.
- More outreach and education for rural employers and facilities to better understand brain injury and support employees who have sustained one.

7. Additional Services:

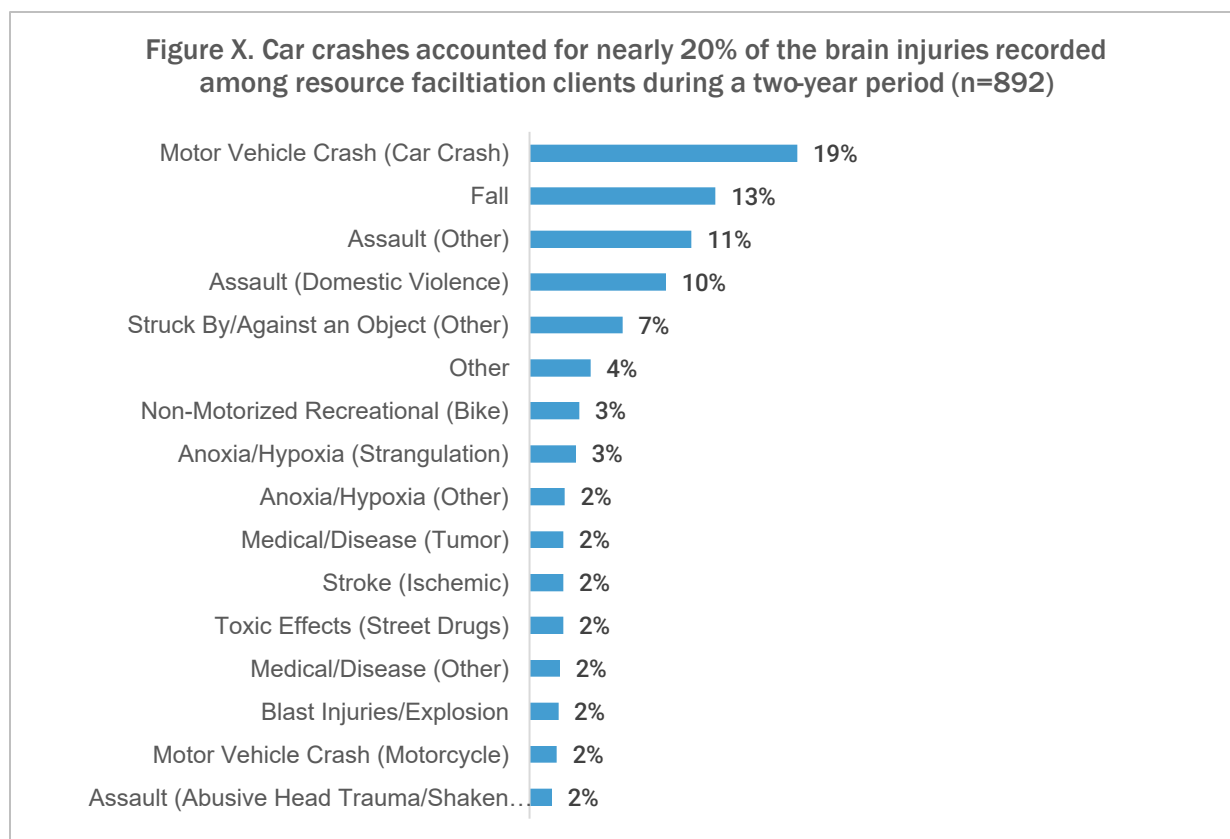
- More day services, community support programs, and brain injury-specific services.
- Enhanced financial assistance for basic needs, such as housing, utilities, and food, while individuals are in therapy or care management.

Resource Facilitation

Resource Facilitation is provided by the Brain Injury Association of Nebraska (BIA-NE). It is a free service for individuals who have experienced brain injury, their family members/caregivers and service providers.¹²

Between January 2023 and December 2024, roughly 545 individuals had brain injuries documented, accounting for 898 brain injuries. On average, people reported 1.6 injuries. While 395 (72%) reported one brain injury, there were 51 clients (9%) that had more than three brain injuries recorded. It is important to note, however, that the process for collecting information about brain injuries varies by staff member. While some do a full brain injury screening to capture all brain injuries, some document the most severe or more important one(s) noted by the client.

Among those, motor vehicle crashes – and in particular, car crashes – were the most common (Figure X). There were also 23 causes of brain injury that accounted for 1% or less of the injuries recorded among those clients.

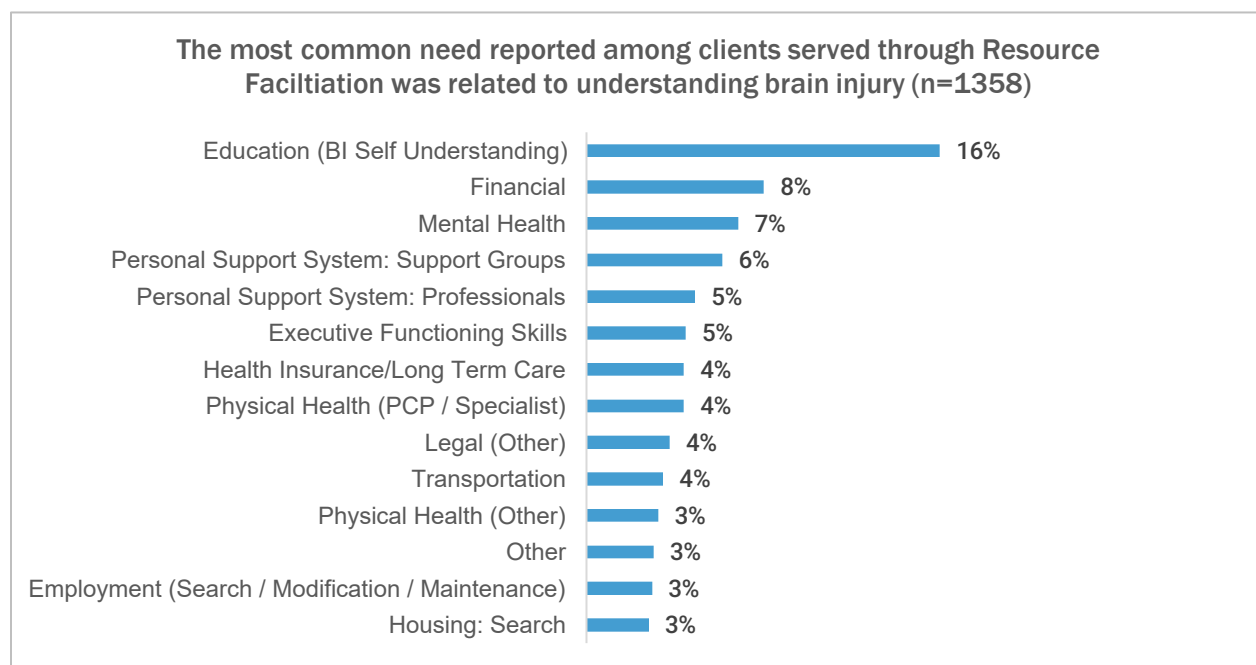


Within the BIA-NE's database, all brain injuries are automatically classified as a non-TBI or TBI based on the type of injury. This is to align with other states who utilize a similar data entry and reporting system. There were 750 injuries classified, with a majority (n=573, 76%) being TBI. For each injury, staff can also indicate whether the client experienced any feelings of being dazed or confused. That was the case for 55% of the recorded injuries.

As part of the intake process, Resource Facilitators capture the core needs of each client. This helps prioritize what types of services and support the client should be connected to through

¹² <https://biane.org/resource-facilitation/>

resource facilitation. Although staff can write in an open-ended response to describe the need, each need is then categorized into one of 51 types (Appendix D). From January 2023 through December 2024, there were 1,358 needs documented among ### unique clients. The most common need related to clients needing a better understanding of brain injury (Figure XX).¹³



[insert data on addressing needs – how many were completed, still in progress, or didn’t have resources available to meet the needs; also summarize the geographic location of needs to see if there are differences]

Additional reports related to Resource Facilitation are available on the BIA-NE website.

Acquired Brain Injury Interview

Nebraska VR’s Acquired Brain Injury (ABI) Interview Form and process is based on the Ohio State University TBI Identification Method (OSU TBI-ID), developed by Dr. John Corrigan and Dr. Jennifer Bogner; a standardized and validated procedure for eliciting lifetime history of TBI via a structured interview.¹⁴ Nebraska VR’s version elicits responses for both traumatic injuries and non-traumatic illnesses and events that have resulted in long-term challenges and may present barriers to employment.

The Nebraska VR ABI interview is conducted with individuals working with Nebraska VR. The process begins with a pre-screening question on the application for services. This is the first step in identifying applicants with potentially undiagnosed ABI. If the applicant answers “Yes” or “Not Sure” to this question on the application, staff interview the applicant for their lifetime

¹³ The following accounted for 2% of the needs documented: housing (stability), housing (financial assistance), and personal support system (family/friends). There were 19 categories that each accounted for 1% of the needs documented. Seven categories were reported six times or less, making it less than 1%.

¹⁴ Corrigan, J. D., & Bogner, J. (2007). Initial reliability and validity of the Ohio State University TBI Identification Method. *The Journal of head trauma rehabilitation*, 22(6), 318–329.
<https://doi.org/10.1097/01.HTR.0000300227.67748.77>

history of possible ABI incidents using the Nebraska VR ABI Interview Form, entering the applicant's answers in the agency's database.

ABI interview data collected from February 2022 to January 2024 were analyzed for the purposes of this report. During this period, 757 individuals were screened. Of those:

- 29 (about 4%) were veterans,
- 592 (about 75%) lived on their own/independent,
- 269 (about 34%) were in competitive, integrated employment, and
- 76 (about 10%) were in school or training.

Brain Injury Screening Results

There were 583 individuals (77% of those screened) that resulted in a probable TBI. Of those who reported a brain injury, 75% reported one injury, and the average number of injuries experienced was 1.34, with a range of 1-5. This is similar to the data seen among clients served through resource facilitation, where the average number of injuries for 545 individuals was 1.6.

Among the individuals served by Nebraska VR, slightly less than two-thirds (n=373, 64%) were treated in a hospital or ER. Similar to the survey data, it may indicate that some of their information is known through the TBI Registry. Just over half of the individuals (n=332, 57%) had a loss of consciousness with their injuries while 67% resulted in the individual feeling dazed or having a memory gap. The average age at the time of injury was 21 years, with a range of 0 to 68 years of age.

Among the injuries, the most common cause was moving vehicle accident, specifically in a car or truck. That accounted for 25% of the injuries, which is similar to the resource facilitation data. The second most common cause was other, which accounted for 21% of the injuries, and 16% were due to falls.

Within the screening results, there were also 218 individuals (29% of those screened) that reported an illness or event that affected their brain – a non-TBI. Of those who reported an illness or event, 77% reported one illness/event. The average number of illnesses/events experienced was 1.14, with a range of 1-3.

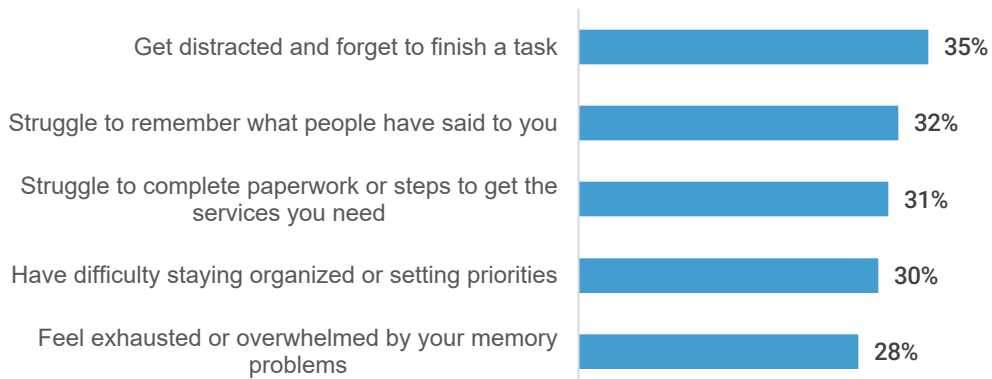
A total of 248 illnesses/events were reported by the 218 individuals. The average age at time of injury was 25 years, with a range of 0-78. This is a slightly higher average age and a slightly larger range of ages than the TBI events. The top three illness or event types identified through the screening was other (28%) followed by seizures (27%) and stroke (19%).

Functional Impacts

For those who have experienced a brain injury, additional questions were asked to assess how often they experienced specific challenges in the time since their injury, illness, or event occurred. There are 21 different topic areas that are assessed, where people can select never, seldom, often, or depends.

Among the 21 topics, there were five functional impacts that were experienced most commonly (Figure X).

Figure X. Since an individual's injury, illness, or event, there are five impacts that rose to the top as being the most common



Conclusions

Successes

- About one third of individuals with brain injury survey respondents reported they "rarely" experienced difficulty in getting access to services for brain injury recovery.
- The vast majority (96%) of respondents to the individuals with a brain injury survey said their transportation was somewhat or very reliable.
- Respondent to the provider survey reported that their organizations offer a wide array of services for individuals with brain injury, with care coordination/case management, independent living supports/services, and behavioral health/counseling/substance abuse services being among the top services offered. Services and resources were more available in the eastern part of the state and in larger communities.
- Providers reported that there has been improved medical understanding and services related to brain injury and more connections and collaboration between community organizations to help meet the needs of individuals with brain injuries.
- When asked about service and support coordination in their area, about half (52%) of respondents to the provider survey felt that brain injury supports and services were coordinated moderately or very well.
- About 9 in 10 respondents to the provider survey said they were somewhat or very knowledgeable about brain injury and needs for individuals living with a brain injury.

Gaps in Services & Supports

- About a third of individuals with brain injury survey respondents reported they "often" experienced difficulty in getting access to services for brain injury recovery.
- Physical health services and therapies emerged as the top service types used or needed by respondents following their brain injury.
- Nearly two-thirds (62%) of respondents to the individuals with brain injury survey were not aware of Medicaid Waiver options (Aged and Disabled Waiver, Developmental Disabilities Waivers, and TBI Waiver).
- About half of respondents to the family member/caregiver survey felt there were significant gaps in respite care and in care coordination/case management.

- About 40% of respondents to the provider survey reported significant gaps for their area in behavioral health, counseling, and substance abuse services, transportation assistance, and respite care.

Key Barriers

- Cognitive challenges were most common symptoms and challenges that were reported to have occurred after having a brain injury.
- Nearly half of individuals with a brain injury survey respondents reported having to travel 30 minutes or more to get services for their brain injury recovery.
- More than three quarters of respondents to the individuals with brain injury survey reported some or a lot of challenges with their emotional or physical health.
- Family members/caregivers reported a significant amount of time providing care for an individual with a brain injury, with about 46% saying they spent at least 10 hours a week providing care, and 63% saying they have been providing care for more than seven years.
- Nearly two-thirds reported moderate emotional stress in their role as a family member and/or caregiver, and about one quarter reported high stress.
- More than half of respondents to the family member/caregiver survey reported that caregiving responsibilities resulted in personal financial hardships
- Issues related to funding/compensation and staff shortages were among the top barriers reported by respondents to the provider survey.
- From 2017-2022, the annual number of TBI cases reported to the registry increased by 29%, and most of the reported TBIs were from falls.

Recommendations

1. Address issues related to access and availability of services, support, and resources, particularly for those living in rural areas.
2. Explore opportunities to expand or enhance cognitive rehabilitation services and post-acute care options.
3. Explore opportunities to offer support for family members/caregivers, including educational events, financial support, assistance with care coordination, more respite care options, and stress management.
4. Promote greater public awareness and education about brain injury through media campaigns.
5. Explore opportunities to increase awareness of existing services and support, particularly for Medicaid Waiver options and employment services.
6. Offer more training opportunities to healthcare professionals, caseworkers, primary care providers, and other providers in understanding and addressing brain injuries. Training topics that providers expressed the most interest in attending include *brain injury and behavioral health* and *life after brain injury*.
7. Explore ways to address fall prevention, as this is the leading cause of reported TBIs.

Appendix A: Data Sources

Primary Data

Individuals with Brain Injury Survey

A survey was developed and implemented by Partners for Insightful Evaluation (PIE) in conjunction with Nebraska VR, the Brain Injury Advisory Council, and the Brain Injury Data Workgroup. Although the survey was geared toward individuals with a brain injury, it could be completed by family members and/or caregivers on behalf of the individuals. It was made publicly available on March 12, 2024 prior to the Nebraska Brain Injury Conference. The survey, which was available online and on paper, could also be completed over the phone or zoom. PIE, Nebraska VR and members of the BIAC reached out to 232 organizations to help promote the survey. The survey closed on May 3, 2024 with 83 people answering at least one question.

Family Member / Caregiver Survey

A survey was developed and implemented by Partners for Insightful Evaluation (PIE) in conjunction with Nebraska VR, the Brain Injury Advisory Council, and the Brain Injury Data Workgroup. This survey was for family members and unpaid caregivers and support persons of individuals living with a brain injury in Nebraska. The survey was not meant to not include personal attendants or other paid caregivers. It was made publicly available on March 12, 2024 prior to the Nebraska Brain Injury Conference. The survey, which was available online and on paper, could also be completed over the phone or zoom. PIE, Nebraska VR and members of the BIAC reached out to 232 organizations to help promote the survey. The survey closed on May 3, 2024 with 50 people answering at least one question.

Service Provider Survey

A survey was developed and implemented by Partners for Insightful Evaluation (PIE) in conjunction with Nebraska VR, the Brain Injury Advisory Council, and the Brain Injury Data Workgroup. This survey was for professionals who work for organizations or individuals (such as personal care attendants or paid caregivers) that provide services and support to individuals living with brain injury in Nebraska. It was made publicly available on March 12, 2024 prior to the Nebraska Brain Injury Conference. The survey, which was available online and on paper, could also be completed over the phone or zoom. PIE, Nebraska VR and members of the BIAC reached out to 232 organizations to help promote the survey. The survey closed on May 3, 2024 with 112 people answering at least one question.

Secondary Data

Acquired Brain Injury (ABI) Interview Data

There is a question on the application for Nebraska VR services about whether an individual may have an acquired brain injury. If someone selects “yes” or “not sure,” they will be interviewed by VR staff using a specific form to capture details about their potential brain injury. It is a two-page questionnaire that helps identify potential brain injuries as well as the challenges a person may experience and how often. Although the screening has been going on for awhile, Nebraska VR transitioned to doing an interview and entering that information into a database in February 2022. When people conduct the interview, they can either complete the form on paper or enter it directly into the database. That data included in the needs assessment report spans from February 15, 2022 through January 31, 2024.

Administrative Data

The primary administrative data used as part of the needs assessment analysis and reporting were meeting minutes. This primarily included minutes from Brain Injury Advisory Council

meetings (three meetings from 2023 and three meetings from 2024), meetings of the Brain Injury Oversight Committee (four in 2023 and four in 2024), and meetings from the Brain Injury Data Workgroup (six in 2023 and three in 2024). Results from the previous needs assessments were also consulted during the development of this report to provide additional context and trend information.

Resource Facilitation Data

This is data from the Brain Injury Association= of Nebraska. Their Resource Facilitation program transitioned to a new database in December 2022, so data included in the needs assessment report spans from January 1, 2023 through December 31, 2024. There are key data elements that are required (such as demographics and injury information) and other elements that are encouraged but not required (education, employment, etc.). For the needs assessment, it was primarily injury information and areas of need data that were utilized.

TBI Registry

The Nebraska Department of Health and Human Services (DHHS), Division of Public Health maintains a central registry for traumatic brain injuries. State law (§81-653 to 81-662) requires that any hospital, rehabilitation center, psychologist or physician report the following information about the person sustaining the injury to the Nebraska Department of Health and Human Services: name, social security number (if known), date of birth, gender, residence, date of injury, final diagnosis or classification of injury, cause of injury, place where injury occurred, identification of the reporting source, dispensation upon discharge, and any additional information. Diagnosis and treatment information are collected from the patient's medical record. The TBI Registry data is primarily acquired by medical entities submitting data to the Nebraska Hospital Association. Data pertaining to TBI is sent to DPH for analysis and reporting, then subsequently provided to Nebraska VR and the Brain Injury Advisory Council. For this report, data was obtained through the 2024 TBI Registry Annual Report developed by DHHS and includes data from 2017 through 2022.

TBI Registry Mailings

In 2008, the Nebraska Legislature passed LB 928 (Brain Injury Registry Act), which requires that information be sent to individuals with reported brain injuries to help them access necessary and appropriate services related to the injury. Nebraska VR maintains an agreement with DHHS, Division of Public Health to provide the required follow-up contact in the form of a letter and brochure listing TBI resources and contact information to everyone placed on the Registry. For each mailing, the aggregate numbers are monitored in an Excel file by Nebraska VR to determine changes over time. Data included in this report spans from June 2021 through December 2024. However, the geographic and age breakdowns were not available for the two mailings in the fall of 2024.

TBI Registry Caller Survey Data

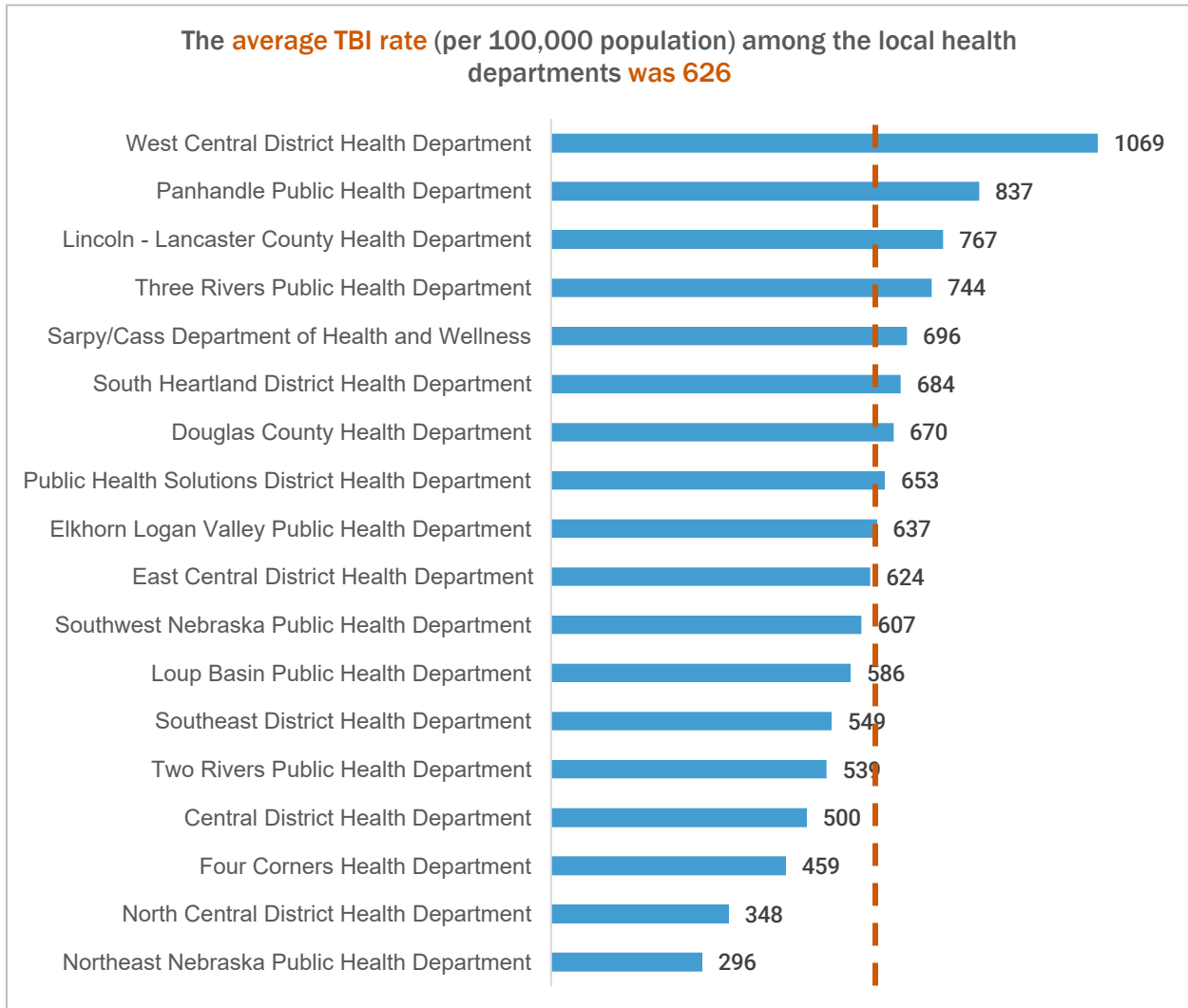
In 2008, the Nebraska Legislature passed LB 928 (Brain Injury Registry Act), which requires that information be sent to individuals with reported brain injuries to help them access necessary and appropriate services related to the injury. Nebraska VR maintains an agreement with DHHS, Division of Public Health to provide the required follow-up contact in the form of a letter and brochure listing TBI resources and contact information to everyone placed on the Registry. Agencies who are mentioned in the letter and/or brochure are notified prior to mailings being sent to help monitor the impact of the letters. Any agency who receives a call because of the TBI Registry mailing is encouraged to complete an online survey to document the call. This survey captures information about the individuals who called and what information or services were provided to the caller. Additional data is collected via the survey on the perceived usefulness of the TBI Registry letter and brochure. The survey data is monitored and reported

by Partners for Insightful Evaluation. Data from the survey includes calls that occurred between May 2022 (when the survey was revised) through 2024.

Appendix B: Additional Data

TBI Registry Data

TBI Rates by Local Health Department District



Local Health Department	Counties Included
Central District Health Dept.	Hall, Hamilton, Merrick
Douglas County Health Dept.	Douglas
East Central District Health Dept.	Boone, Colfax, Nance, Platte
Elkhorn Logan Valley Public Health Dept.	Burt, Cuming, Madison, Stanton
Four Corners Health Dept.	Bulter, Polk, Seward, York
Lincoln - Lancaster County Health Dept.	Lancaster
Loup Basin Public Health Dept.	Blaine, Custer, Garfield, Greeley, Howard,

	Loup, Sherman, Valley, Wheeler
North Central District Health Dept.	Antelope, Boyd, Brown, Cherry, Holt, Keya Paha, Knox, Pierce, Rock
Northeast Nebraska Public Health Dept.	Cedar, Dixon, Thurston, Wayne
Panhandle Public Health Dept.	Banner, Box Butte, Cheyenne, Dawes, Deuel, Garden, Grant, Kimball, Morrill Scotts Bluff, Sioux, Sheridan
Public Health Solutions District Health Dept.	Fillmore, Gage, Jefferson, Saline, Thayer
Sarpy/Cass Department of Health and Wellness	Cass, Sarpy
South Heartland District Health Dept.	Adams, Clay, Nuckolls, Webster
Southeast District Health Dept.	Johnson, Nemaha, Otoe, Pawnee, Richardson
Southwest Nebraska Public Health Dept.	Chase, Dundy, Frontier, Furnas, Hayes, Hitchcock, Keith, Perkins, Red Willow
Three Rivers Public Health Dept.	Dodge, Saunders, Washington
Two Rivers Public Health Dept.	Buffalo, Dawson, Franklin, Gosper, Harlan, Kearney, Phelps
West Central District Health Dept.	Arthur, Hooker, Lincoln, Logan, McPherson, Thomas

Below is a table that denotes the TBI rate by year for each of the local health departments (LHD). Color-coding is used to denote which has the lowest rates (green) and the highest rates (red) for each year.

Local Health Department	2017	2018	2019	2020	2021	2022	LHD Average
Central District Health Department	346	446	490	479	534	706	500
Douglas County Health Department	640	691	690	545	678	778	670
East Central District Health Department	615	703	597	526	620	688	625
Elkhorn Logan Valley Public Health Department	598	693	635	606	659	328	587
Four Corners Health Department	397	480	431	384	437	620	458
Lincoln - Lancaster County Health Department	665	844	847	695	784	773	768
Loup Basin Public Health Department	475	477	576	618	638	736	587
North Central District Health Department	420	290	383	339	436	275	357
Northeast Nebraska Public Health Department	289	220	237	280	391	360	296
Panhandle Public Health Department	934	943	1187	650	757	773	874
Public Health Solutions District Health Department	511	519	735	566	772	713	636

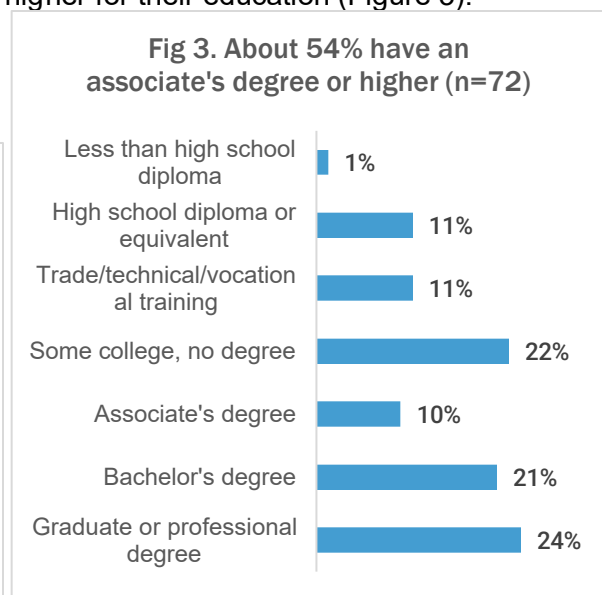
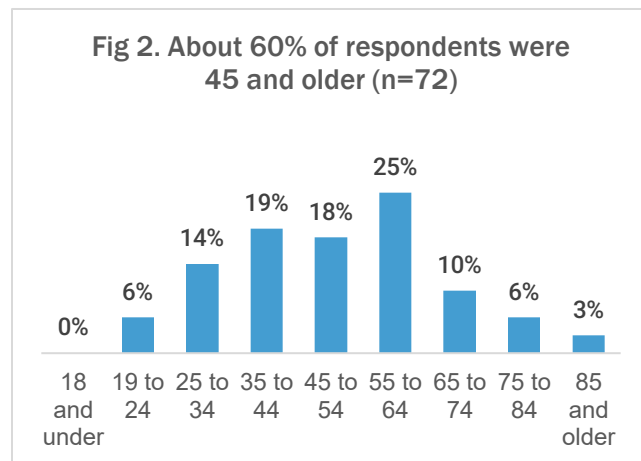
Sarpy/Cass Department of Health and Wellness	680	743	770	588	666	742	698
South Heartland District Health Department	663	777	751	498	648	765	684
Southeast District Health Department	475	512	621	533	587	565	549
Southwest Nebraska Public Health Department	489	565	866	563	505	696	614
Three Rivers Public Health Department	571	614	611	769	872	1012	742
Two Rivers Public Health Department	391	417	519	569	600	734	538
West Central District Health Department	1156	948	1274	1084	881	1072	1069
Annual Average	573	605	679	572	637	685	

Appendix C: Survey Respondent Demographics

Individuals with Brain Injury Survey

There were 83 people who answered the first few questions of the individuals with brain injury survey. Among those, about 85% were the individuals who have experienced a brain injury, and the remaining 15% were respondents who completed the survey on behalf of an individual with brain injury.

Respondents reported being from 24 different counties in Nebraska, and the most frequently represented counties were Lancaster (n=17), Lincoln (n=12), Douglas (n=9), and Buffalo (n=5). Most respondents (69%) were female, and 88% of respondents reported their race/ethnicity as white. Roughly 60% of respondents were 45 years and older, and all were over the age of 18 (Figure 2). Few respondents (4%) were multilingual or ever served in the military (6%). More than half reported having an Associate degree or higher for their education (Figure 3).



Family Member/Caregiver Survey

Demographic questions were at the end of the survey, and 39 respondents provided demographic information. Respondents reported being from 24 different counties in Nebraska, and the most frequently represented counties were Buffalo (n=6), Lancaster (n=5), and Lincoln (n=5). Most respondents (85%) were female, and 92% of respondents reported their race/ethnicity as white. About three-quarters of respondents were 45 years and older, and all but one respondent was over the age of 24. About 70% reported having an Associate degree or higher for their education.

Appendix D: Resource Facilitation Areas of Need

Areas of need reflect what anyone (regardless of whether they've had a brain injury) may need. The goal is to identify the core need of what someone truly needs and not necessarily the service they were connected with to address it. For example, if someone needs therapy but cannot afford it so the client was referred to a religious organization, the area of need is talk therapy.

Category	What belongs / description of the category
Education (BI Self Understanding)	Goals related to client wanting to better understand their brain injury and its impact on their life
Education (Continuing Education)	All other forms of adult education and learning (not necessarily formalized)
Education (Higher Education)	An optional final stage of formal learning that occurs after high school. Often delivered at universities, academies, colleges, seminaries, conservatories, and institutes of technology, higher education is also available through certain college-level institutions, including vocational schools, trade schools, and other career colleges that award academic degrees or professional certifications
Education (Other)	Education-related goals that don't fit well into any of the other Education categories, such as conferences or professional development
Education (Pre-K -12)	GED support, individualized education plans (IEPs), 504 plans, help finding school supplies, referral to special education, concussion management/return to learn
Employment (Accommodations)	Accommodations and discrimination in the workplace
Employment (Job Search / Modification / Maintenance / Development)	Anything related to seeking, modifying, or maintaining employment
Employment (Other)	Employment-related goals that don't fit well into any of the other Employment categories
Executive Functioning/ Organizational Skills	Filing/organizing paperwork in general, creating systems for organization within the home; Activities of Daily Living (ADL) goals - tools, equipment or help related to bathing/showering, personal hygiene and grooming, dressing, toilet hygiene, functional mobility/walking, or self-feeding
Financial	Only benefits that appear here are non-restricted cash assistance directly to client, anything else that is a pass through should be categorized elsewhere
Food / Nutrition	SNAP benefits, food banks/pantries, info about healthy eating
Health Insurance/Long Term Care	Medicaid, Medicare, Private Insurance, Medicaid Home and Community Based Services (HCBS)
Home (Clothing)	Clothes for school or employment; getting weather appropriate clothing (coats and mittens for winter)
Home (Furniture & Housewares)	Help with needs related to non-permanent items within the home
Home (Other)	home-related goals not accurately captured in one of the other Home categories

Home (Repair / Modification / Maintenance)	Responsibilities related to the upkeep or modification of the home itself and its external surroundings (i.e. lawn, landscaping, patios/decks, sidewalks, driveways, garage)
Housing (Financial Assistance)	Rent assistance, section 8 application, subsidized housing application, Low income mortgage programs
Housing (Other)	General housing, Moving Logistics
Housing (Search)	Needing to find a location to live - rental options, purchase options, accessible housing, supported living options, nursing home options, Assisted Living options
Housing (Stability)	Actions or approaches to stay in current housing - through roommate searches, recertifications, dispute resolution with landlords, voucher modifications
Legal (Attorney Referrals)	All external referrals related to law firms and agencies for legal-related needs
Legal (Family / Guardianship / POA)	legal matters specific to family concerns including guardianship and power of attorney
Legal (Other Support)	Direct support provided by BIANE related to legal needs; goals that don't fit well into any of the other Legal categories
Medication	Any needs related to medication (prescription or over-the-counter)
Mental/Emotional Health (Talk Therapy)	Needing access to a professional (licensed mental health practitioners, counselors, psychologist) to provide counseling services
Mental/Emotional Health (Psychiatry/Medication Management)	Referral to psychiatry or partnering with medical professional (nurse practitioner, physician's assistants, primary care providers) to prescribe psychiatric medications to help patients with mental health issues, which could include antidepressants, antipsychotics, mood stabilizers, stimulants
Mental/Emotional Health (Neuropsychologist)	Professionals that explore how brain conditions affect behaviors and cognitive skills (mood, behavior and thinking skills); provide neuropsychological testing
Mental/Emotional Health (Cognitive Behavioral Therapy)	Form of therapy that aims to reduce symptoms of various mental health conditions, primarily depression, post-traumatic stress disorder (PTSD), brain injury and anxiety disorders; very structured approach with limited number of sessions and potentially homework between
Other	any goal that does not fit well into any of the other categories
Personal Support System (Family / Friends)	Helping client find ways to socialize, finding opportunities to meet people, helping client to re-connect with family
Personal Support System (Service Animal / Pet)	Any pet or service animal related need
Personal Support System (Support Groups)	Referrals to Support Groups
Physical Health (Chiropractor)	Licensed health care profession that uses manual therapy, such as spinal manipulation, to treat conditions such as back pain, neck pain, headaches, and hand or foot problems
Physical Health (Dental)	Help with Dental needs
Physical Health (Massage)	Massage therapists manipulate clients' soft tissues and joints to treat injuries and promote general wellness
Physical Health (Neurologist)	Medical doctor who diagnoses, treats and manages disorders of the brain and nervous system (brain, spinal cord and nerves)

Physical Health (Physiatrist)	Medical doctor who specializes in physical medicine and rehabilitation (PM&R). They treat patients with a variety of conditions, including chronic pain, injuries, and illnesses, to help them regain physical functionality and improve their quality of life
Physical Health (Primary Care)	A physician who provides both the first contact for a person with an undiagnosed health concern as well as continuing care of varied medical conditions, not limited by cause, organ system, or diagnosis
Physical Health (Vision)	Help with Vision Needs - such as glasses, eye exams, large print materials
Physical Health (Other)	finding some types of durable medical equipment (not furniture - hospital bed, for example)
Rec/Leisure	Referrals to recreation or activity based programming, assistance with finding rec or leisure related resources or equipment
Rehab Therapy (SLP)	Help with speech, language, social communication, cognitive-communication, and swallowing disorders
Rehab Therapy (PT)	Physical therapy may include exercises, massages and various treatments based on physical stimuli (e.g. heat, cold, electrical currents or ultrasound). The aim is to relieve pain, help you move better or strengthen weakened muscles.
Rehab Therapy (OT)	Occupational therapy intervention uses everyday life activities (occupations) to promote health, well-being, and your ability to participate in the important activities in your life.
Substance Use	Assistance finding substance use treatment providers and related resources
Supervision	Services that support individuals that need some level of supervision
Technology (Acquisition)	Assistance finding assistive or other technologies
Technology (Other)	Any other type of technology need
Technology (Setup / Training)	Assistance setting up or troubleshooting existing technology; Learning how to use technology - such as email, smartphone, or other specific apps
Transportation	Assistance finding or navigating transportation needs
Volunteering	Connecting to volunteer opportunities