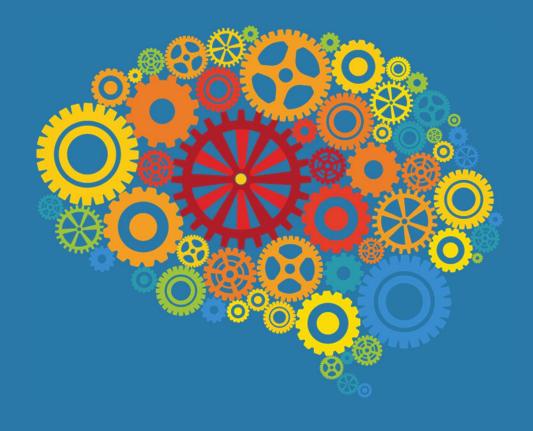
# Nebraska Brain Injury Needs Assessment Report 2024





Report on the Nebraska Brain Injury Needs Assessment 2024 findings. Done in conjunction with Nebraska VR and the Brain Injury Advisory Council, with the report prepared by Partners for Insightful Evaluation.

#### Nebraska Brain Injury Needs Assessment Report June 2025

If you have any questions or concerns regarding the information reported within, please contact us at:

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# **Acronyms**

Below are common acronyms used throughout the report.

ABI: Acquired Brain Injury

BIA-NE: Brain Injury Association of Nebraska.

Note: Their agency name changed in 2025. In some areas of the report, they are listed as the Brain Injury Alliance of Nebraska, as that is the terminology used on the needs assessment surveys.

**BIAC**: Brain Injury Advisory Council

**CDC**: Centers for Disease Control and Prevention

**DHHS**: Department of Health and Human Services

DPH: Division of Public Health

**LHD**: Local Health Department

Nebraska VR: Nebraska Vocational Rehabilitation

TBI: Traumatic Brain Injury

### Introduction

A brain injury – also called Acquired Brain Injury (ABI) – is damage to the brain after birth that is not hereditary (meaning it is not inherited from a parent), congenital (indicating it was a condition or trait that existed at birth), or degenerative (which occurs from gradual deterioration). This includes traumatic brain injury (TBI) and non-traumatic brain injury.

- Non-traumatic brain injuries are the result of illness, oxygen deprivation, aneurysm, or other internal causes. This may include stroke, brain tumors, and infections such as
- TBIs are caused by an external physical force, such as a bump, jolt, or blow to the head. 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 TBIrelated deaths across the nation in 2021.2 Additionally, in a summary study of CDC and other data, it is estimated that about one in four adults (between 19% and 29%) have experienced a concussion or TBI while about 10% of children and adolescents experience a concussion or TBI during a 12-month period.<sup>3</sup>

With support and coordination from Nebraska VR (Vocational Rehabilitation) and the Brain Injury Advisory Council (BIAC), a statewide brain injury needs assessments was conducted by Partners for Insightful Evaluation (PIE) throughout 2024. Previous needs assessments were done in 2010<sup>4</sup>, 2019<sup>5</sup> and 2020<sup>6</sup>, though the latter focused on the connection between brain injury and mental health.

There were two goals for the 2024 needs assessment: 1) inform the Brain Injury State Plan and 2) understand the services, supports, and other assistance available to people with TBI. including the extent of unmet needs and service gaps. Although the focus is on TBI, nontraumatic 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 needs assessment. Each source is summarized in this section to provide context for the results, as this report is meant to triangulate current data available. This means that multiple data sources are used to strengthen results or conclusions,

<sup>&</sup>lt;sup>1</sup> Traumatic brain injury. (2024). National Institute of Neurological Disorders and Stroke. https://www.ninds.nih.gov/health-information/disorders/traumatic-brain-injury-tbi

<sup>&</sup>lt;sup>2</sup> 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.

<sup>&</sup>lt;sup>3</sup> Daugherty J, Peterson A, Black L, Waltzman D. Summary of the Centers for Disease Control and Prevention's Self-reported Traumatic Brain Injury Survey Efforts. J Head Trauma Rehabil. 2025 Jan-Feb 01;40(1):E1-E12. doi: 10.1097/HTR.0000000000000975. Epub 2024 Jul 22. PMID: 39038104; PMCID: PMC11693486.

<sup>&</sup>lt;sup>4</sup> 2010 Nebraska traumatic brain injury needs and resources assessment. (2010). https://braininjury.nebraska.gov/sites/default/files/doc/resources/TBI-Needs-Resources-Assessment-Results-2010-FINAL-1-2.pdf

<sup>&</sup>lt;sup>5</sup> 2019 Living with brain injury survey results. (2019).

https://braininjury.nebraska.gov/sites/default/files/doc/Living with Brain%20Injury Survey Results%20 May 2019.pdf

<sup>6 2020</sup> 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%20Sur veys%20RESULTS%20FINAL%202-3-2021%5B3%5D.pdf

which should offer a more comprehensive understanding of brain injury prevalence, impacts, service gaps, and challenges in the state.

# **Primary Data**

Primary data – meaning data collected for the purpose of the needs assessment – was collected through three surveys. Each survey was developed by PIE in conjunction with Nebraska VR, the BIAC, and the Brain Injury Data Workgroup. The surveys used in 2019 and 2020 served as a starting point for each survey, and assessments from other states were reviewed by PIE to integrate pertinent questions. Final copies of the surveys can be obtained from Nebraska VR or PIE.

All three surveys were disseminated and available March 12, 2024 through May 3, 2024 to streamline data collection. The public release of the surveys aligned with the Nebraska Brain Injury Conference in 2024, coordinated by the Brain Injury Association of Nebraska. Promotion was done at the conference to encourage people to participate in and promote the surveys.

Additional promotion was done through a dissemination list. This was created by PIE and Nebraska VR (with feedback from the BIAC and BI Data Workgroup) to reach three key groups:

- 1) Organizations that previously received or participated in the surveys
- 2) Key agencies that serve individuals with brain injury
- 3) Brain injury and stroke support groups.

A total of 232 organizations were contacted about the surveys using a variety of promotional materials (see Appendix A). The agencies contacted represented 20 different types of organizations (local health departments, medical nonprofit, state associations, etc.) from at least 44 different cities in Nebraska. About 16% of the organizations contacted were ones that have statewide reach or coverage, such as a state agency or association. Nearly all the organizations included on the dissemination list were contacted twice about the surveys.

The respondent demographics for the individuals with brain injury and family member/caregiver survey are summarized in Appendix B. Additional analysis was done based on respondent demographics to determine similarities or differences in responses. 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 (DPH) Disparities Demographic Data Recommendations. Aggregate results from each survey are also available on the BIAC website.

#### **Individuals with Brain Injury Survey**

Although the survey was geared toward individuals with brain injury, it could be completed by family members and/or caregivers on behalf of the individual. The survey, which was available online and on paper, could also be completed over the phone or Zoom as an interview. **There were 83 people who answered at least one question.** Of those, four people completed the survey via paper and sent it to PIE for data entry. No one requested to do the survey through phone or interview.

<sup>&</sup>lt;sup>7</sup> 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

<sup>&</sup>lt;sup>8</sup> The three infographics summarizing aggregate data from each survey are available here under the "TBI Needs and Resources Assessments" section: <a href="https://braininjury.nebraska.gov/resources/brain-injury-data-and-statistics">https://braininjury.nebraska.gov/resources/brain-injury-data-and-statistics</a>

The survey was 73 questions; however, with the skip patterns used in the survey, it is unlikely a person would have been asked all 73 questions. There was also an optional section of the survey. Participants were asked at the end of the base survey if they wanted to answer additional guestions (13 in total). There were 39 out of 70 individuals (56%) who responded that they would answer the extra questions. It is important to note that there was not a skip pattern to determine or validate the brain injury status; all information about brain injuries was selfreported by the respondent.

#### Family Member / Caregiver Survey

The family member/caregiver survey was intended for family members, unpaid caregivers, and individuals who support those living with a brain injury in Nebraska. The survey was not meant to include personal care attendants or other paid caregivers (people serving in those roles were instead encouraged to complete the service provider survey). Although nearly all respondents completed the survey online, there was a paper version available. The survey could also be done over the phone or as an interview with PIE via Zoom. The survey was 37 questions total. though 3 questions were based on skip patterns and may not have been asked of all survey respondents. There were 50 people who answered at least one question in the survey.

#### **Service Provider Survey**

This survey was for professionals who work for organizations or individuals (such as those who serve as personal care attendants or paid caregivers) that provide services and support to individuals living with brain injury in Nebraska. This survey was only available online due to the skip patterns. One of the skip patterns was based on agency type (behavioral health, medical organization, community-based organization or nonprofit, state agency, and other) and the other was related to type of role within the agency (those who work directly with people, those in supervisory or manager roles, and those who are in leadership positions).

There were roughly 28 questions on the survey for each person, though the total number of questions varied slightly based on the agency type and role within the organization. There were 112 people who answered at least one question. Those who completed the survey represented 58 different organizations across the state, with the most represented organizations being Nebraska VR (n=16), Quality Living Inc., or QLI (n=6), Madonna Rehabilitation Hospital (n=5), Brain Injury Alliance of NE (n=5), and Assistive Technology Partnership (n=5).

### **Secondary Data**

The secondary data – meaning the information was previously collected and/or compiled by another agency - used in the needs assessment was determined with input from the BI Data Workgroup. Although there are a variety of data sources that contain information regarding brain injury in Nebraska, there were six that were most pertinent to the needs assessment.

#### Acquired Brain Injury (ABI) Interview

The Acquired Brain Injury (ABI) Interview Form data is from Nebraska VR. The form and process are based on the Ohio State University TBI Identification Method (OSU TBI-ID), developed by Dr. John Corrigan and Dr. Jennifer Bogner. It is a standardized and validated procedure for eliciting lifetime history of TBI via a structured interview. 9 Nebraska VR's version helps capture both traumatic injuries and non-traumatic illnesses and events that have resulted in long-term challenges and may present barriers to employment.

<sup>&</sup>lt;sup>9</sup> 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

The Nebraska VR application contains a question 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 the ABI Interview 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 several years, Nebraska VR transitioned to conducting an interview and entering that information into a database in February 2022. When VR staff conduct the interview, they can either complete the form on paper or enter it directly into the database. The data utilized for the needs assessment is from interviews conducted between January 1, 2023 and December 31, 2024. During that time, there were 912 individuals screened. Data was analyzed by PIE.

#### Brain Injury Association of Nebraska Resource Facilitation Data

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 or caregivers and service providers. 10 Clients are classified as either an Information & Referral (I&R) case or a Case Management (CM) case. In addition to a standard intake form, there are additional forms and screening tools that may be used by the Resource Facilitator to better understand needs, successes, and challenges of those who have experienced brain injury. Those are primarily completed for those who receive Case Management.

Information collected by the BIA-NE is entered into a SalesForce database. That is also where service provision is tracked, including referrals, resources, and support provided to clients. Data is exported into Microsoft Excel by PIE for analysis. The data utilized for the needs assessment is for clients who were served by a Resource Facilitator between January 1, 2023 and December 31, 2024, which accounted for roughly 739 unique individuals. Reports for the BIA are available on their website. 11

#### **TBI Registry**

One of the primary ways to monitor TBI in Nebraska is through the TBI Registry. The DHHS Division of Public Health maintains a central registry for traumatic brain injuries. The Registry began in 1991 after a legislative bill passed, known as the Brain Injury Registry Act. 12 The intent is to utilize information not only to plan for treatment and rehabilitation efforts, but also to prevent head injuries as well.

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 DHHS:

- Name
- Social security number (if known)
- Date of birth
- Gender
- Residence
- Date of injury
- Final diagnosis or classification of injury
- Cause of injury

<sup>10</sup> https://biane.org/resource-facilitation/

<sup>&</sup>lt;sup>11</sup> Resource Facilitation efforts are summarized on a bi-annual basis. Reports are available at https://biane.org/brain-injury/behavioral-health/ under the "More on our work with high risk populations" section.

<sup>&</sup>lt;sup>12</sup> Legislative Bill 81-653: https://nebraskalegislature.gov/laws/statutes.php?statute=81-653

- Place where injury occurred
- Identification of the reporting source
- Dispensation upon discharge

TBI cases are identified using diagnostic codes, which are based on the International Classification of Diseases, 10<sup>th</sup> Revision, Clinical Modification (ICD 10 CM). This is a system for health care providers to classify diseases and medical conditions for diagnosis and medical claims. 13 Table 1 outlines the codes that are factored into the TBI definition.

Table 1: A series of ICD-10 codes are used to identify individuals who were diagnosed with a TBI

Codes <sup>14</sup>	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-,	Injury of optic chiasm; injury of optic tract and pathways; injury of
S04.04-	visual cortex
S06-	Intracranial injury
S07.1	Crushing injury of skull
T74.4	Shaken infant syndrome

For this report, data was obtained through the 2024 TBI Registry Annual Report developed by DHHS and includes data from 2017 through 2022. 15 One limitation of the data is that it primarily reflects patients who were discharged from a hospital with a TBI diagnosis. Data in the TBI Registry is obtained through the Nebraska Hospital Association and provided to DHHS. In 2022, there were 123 entities that submitted data for inclusion in the TBI Registry. Among those entities, 71% were hospitals and 27% were affiliated with clinics. It is also important to note that the TBI Registry does not include other acquired brain injuries, so data is only related to TBIs. This means it does not contain information related to strokes, for example.

#### **TBI Registry Mailings**

The Brain Injury Registry Act includes a requirement to send information to individuals with reported brain injury. The primary purpose is to ensure those individuals can get access to necessary and appropriate services related to the injury. Nebraska VR maintains an agreement with the Division of Public Health at DHHS to provide the required follow-up contact to individuals. 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. 16

After receiving the TBI Registry data, DHHS generates a mailing list to provide to Nebraska VR. 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 verified by the print shop to remove incomplete or inaccurate addresses that are undeliverable. Primarily because the data is supplied by hospitals through electronic health records, information is

<sup>&</sup>lt;sup>13</sup> 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

<sup>14 &</sup>quot;-" indicates any 4th, 5th, or 6th character.

<sup>&</sup>lt;sup>15</sup> At the time of this report, the 2024 TBI Registry Annual Report was in the process of being revised by DHHS. Some of the data included in this report may be updated.

<sup>&</sup>lt;sup>16</sup> 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.

supplied to individuals by mail. Email addresses are not included in the mailing list provided to Nebraska VR.

For each mailing sent out by Nebraska VR, aggregate numbers on the number of letters sent to each region and age group are monitored in an Excel file by Nebraska VR. Data included in the needs assessment report spans from June 2021 through December 2024.

#### TBI Registry Mailing Caller Survey Data

Agencies that are mentioned in the TBI Registry letter and/or brochure included in the mailing materials are notified prior to each mailing being sent. This is to keep agencies informed about the volume of mailings and remind organizations to track calls that they may receive as a result of the mailing. Any agency who receives a call due to the mailing is encouraged to complete an online survey to document the engagement.

The TBI Registry mailing caller 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 PIE. The TBI Registry mailing caller survey data outlined in the needs assessment includes calls that occurred between May 2022 (when the survey was revised) through December 2024. A total of 109 calls were documented during that time period, though about 28% (n=54) noted they received the letter in error. Data entered into the online survey is exported by PIE and analyzed in Excel.

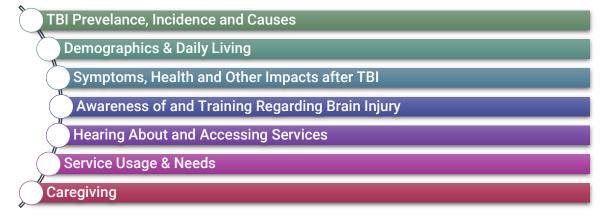
#### **Administrative Data**

The key administrative data used as part of the needs assessment analysis and reporting were meeting minutes. This primarily included minutes from BIAC 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 referenced during the development of this report to provide additional context and trend information.

# Results

Results are organized into 7 categories (Figure 1), with information then summarized by data source. At the end of each section there is a summary (outlined in a light blue box) that provides a high-level overview of all the data presented in that section to help provide an overall synopsis of the findings.

Figure 1. Results from the needs assessments are organized by 7 categories



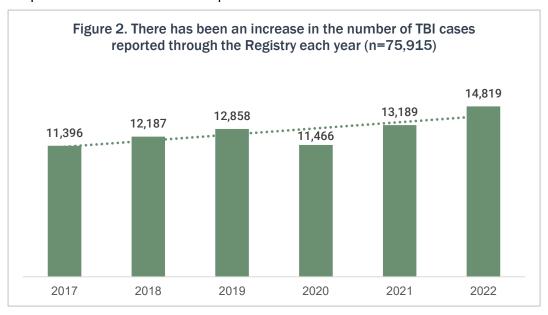
# **TBI Prevalence, Incidence & Causes**

Prevalence shows the proportion of people who have a particular condition within a population at a given time. 17 Understanding the statewide prevalence of TBI in Nebraska, for example, would provide a sense for how many residents at a given time would have experienced at least one TBI in their lifetime. Incidence, on the other hand, describes the number of new cases that may occur during a specific time period.

The precise number of people who have experienced a TBI is generally not known, so determining the prevalence and incidence can be challenging. Various data sources are available to offer insights to how many Nebraskans have experienced a brain injury – either for the first time (incidence) or at any point (prevalence).

#### **TBI Registry**

The TBI Registry Annual Report made available in June 2024 highlights data through 2022. In 2022, there were 14,819 TBI cases reported. This reflects 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. It is important to note, though, that these are the number of cases of TBI and may not reflect unique individuals if someone experienced more than one TBI.

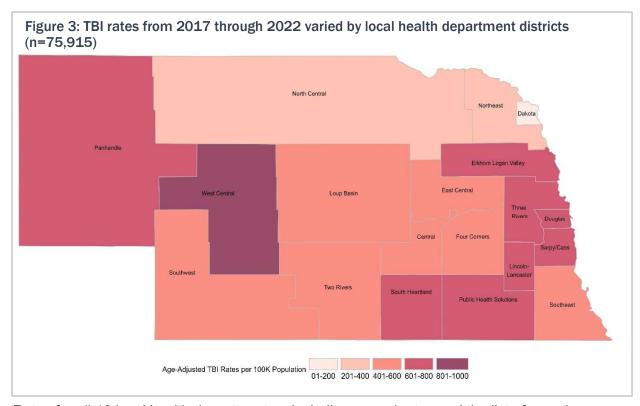


TBI rates did vary by geographic area. Analysis was done by local health department (LHD) regions to better align with prevention and management efforts. The rates are determined by looking at how many TBI cases occurred for residents within that region compared to the total population in that area. The TBI rate for Lincoln-Lancaster County, for example, would highlight how many people living in Lancaster County has experienced a TBI compared to the total number of people living in Lancaster.

Based on TBI Registry data from 2017 through 2022, West Central District Health Department had the highest rates of TBI (Figure 3). That health department region covers six counties, including Arthur, Hooker, Lincoln, Logan, McPherson, and Thomas. Lincoln-Lancaster County

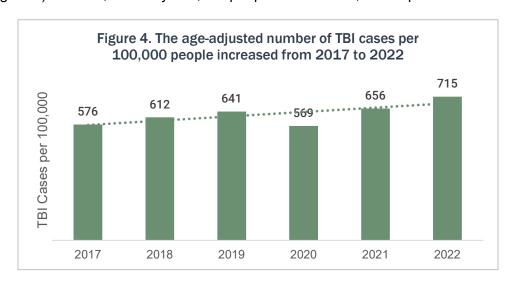
<sup>&</sup>lt;sup>17</sup> Eagye P, Whiteneck G.G., Harrison-Felix C.L. (2019). Report on methods to estimate traumatic brain injury prevalence and Home and Community Based Services use by state.

Health Department has the next highest, followed by Three Rivers Public Health Department (Dodge, Saunders, and Washington counties) and Sarpy Cass Public Health Department.

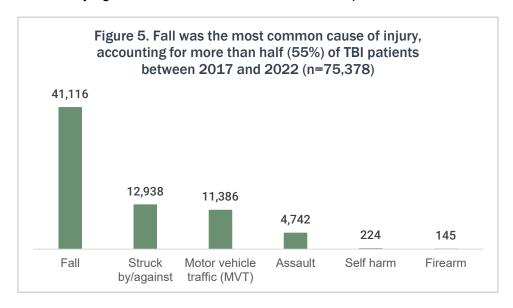


Rates for all 19 local health departments – including annual rates and the list of counties affiliated with each LHD district – are included in Appendix C.

Another way that the TBI Registry data is explored is through 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 rates 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 4). In 2022, for every 100,000 people in Nebraska, 715 experienced a TBI.

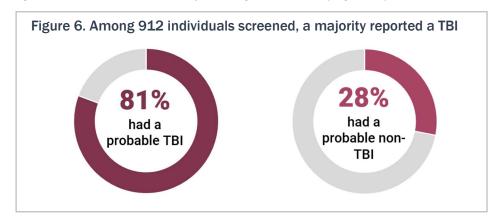


Data from the TBI Registry indicates that falls were the leading cause of TBIs from 2017 to 2022. accounting for more than half of reported cases (Figure 5). The next most common type of injury was struck by/against, which reflected 17% of the TBI patients.



#### **ABI Interview**

In 2023 and 2024, there were 912 individuals screened by Nebraska VR using the ABI Interview. There were approximately 4,482 Nebraska VR applications from January 1, 2023 through December 31, 2024, so about 20% of applicants may have experienced a brain injury. As noted, the form captures both traumatic injuries and non-traumatic illnesses and events, with data indicating that TBIs were more likely among applicants (Figure 6).



#### Traumatic Brain Injury

About 81% (n=736) of those screened resulted in a probable TBI. Of those who reported a brain injury, 73% noted one injury. In total, there were 1,040 brain injuries reported among the 736 individuals. The average number of injuries experienced was 1.41.

About 62% of the 1,040 brain injuries reported were ones that were treated in a hospital or ER. This may indicate that some of that information regarding those brain injuries is captured through the TBI Registry given how that data is compiled. Just over half of the individuals (n=551, 53%) had a loss of consciousness with their injuries while 65% resulted in the individual feeling dazed or having a memory gap.

Among the injuries, the most common cause was moving vehicle accident, specifically in a car or truck. That accounted for 25% of the injuries. The second most common cause for TBI was other, which described 21% of the injuries, and 16% were due to falls. About 15% (n=138) of those screened reported having a repeated impact to their head. The average age at the time of the initial impact was 17 years, though the age ranged from 0 to 64. Although other was the most common injury type for the repeated impact injuries (46%), about 23% reported the reported impact was from domestic/intimate partner violence while 14% were from football.

#### Non-Traumatic Brain Injury

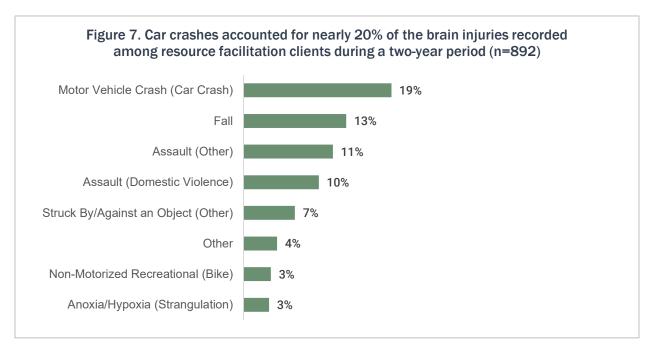
Within the screening results, there were also 256 individuals (28% of those screened) that reported an illness or event that affected their brain – a non-TBI. Of those who reported an illness or event, 85% reported one illness/event. The average number of illnesses/events experienced was 1.19, with a range of 1 to 4. A total of 305 illnesses or events were reported by 256 individuals. The top three illness or event types identified through the screening was other (28%) followed by seizures (27%) and stroke (19%).

#### **Resource Facilitation**

Between January 2023 and December 2024, about 545 individuals had brain injuries documented through the BIA-NE's database, accounting for a total of 898 brain injuries. It is unknown to what degree these individuals may have information captured through the ABI Interview data or the TBI Registry data.

On average, people reported 1.6 brain 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 (also using a modified version of the OSU screening tool), some staff aim to capture the most severe or more important one(s) noted by the client rather than retrieving a full history.

Among the injuries recorded, motor vehicle crashes – and car crashes in particular – were the most common (Figure 7). Not included in Figure 7 are the eight causes that accounted for 2% of the brain injuries each. There were also 23 causes of brain injury that accounted for 1% or less of the injuries recorded among those clients.

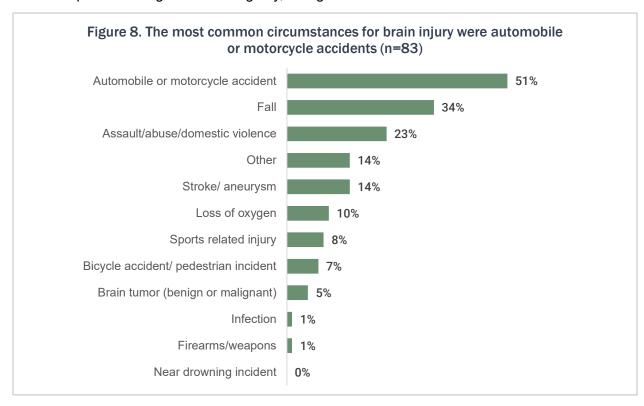


Within the BIA-NE's database, all brain injuries are classified as a non-TBI or TBI based on the type of injury. This is to align with other states who utilize a similar data collection and reporting system. There were 750 injuries classified, with a majority (n=573, 76%) being TBI. For each injury reported by clients, staff can also indicate whether the client experienced any feelings of being dazed or confused. That was the case for 55% of all the recorded injuries. This is somewhat comparable to the ABI Interview data, where 81% of the individuals screened had a probable TBI (compared to 28% that had a non-TBI) and 65% of the injuries resulted in the individual feeling dazed or confused.

#### **Individuals with Brain Injury Survey**

Based on the survey data, about half of the respondents (52%, n=42) reported experiencing one brain injury in their lifetime while 35% reported having two to five brain injuries. The remaining 14% (n=11) experienced more than 5 brain injuries.

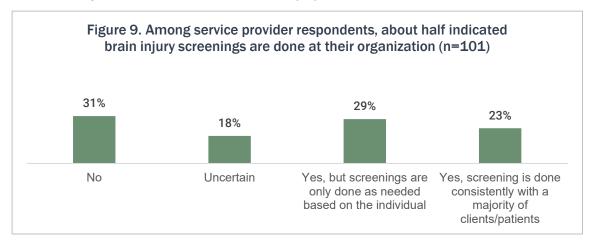
The most common circumstances experienced by respondents that may have resulted in a brain injury include automobile or motorcycle accidents (51%), falls (34%), and assault/abuse/domestic violence (23%) (Figure 8). This is relatively consistent with the common causes reported through the TBI Registry, though falls are more common from that data source.



Although the survey did not include a question about whether people felt dazed or confused following their brain injury or injuries, there was a question about whether they were ever knocked out or lost consciousness. Among the respondents, a majority (70%, n=58) had. About half of those who had lost consciousness (45%, n=26) were knocked out or unconscious between 30 minutes and 24 hours.

#### **Service Provider Survey**

An aspect that can assist with tracking brain injury is conducting screenings. Based on results from the 2024 service provider survey, brain injury screenings are being conducted at a variety of organizations through different tools (Figure 9). The most common approach to screening for brain injury is having an informal set of questions at intake (42%, n=22). Other instruments include the ABI interview through Nebraska VR (21%, n=11), the Ohio State University TBI Identification Method (21%, n=11), the HELPS screening tool (13%, n=7), and the BISQ, or the Brain Injury Screening Questionnaire (13%, n=7). Information was not captured regarding how many individuals are typically screened each month or year and, of those, what portion typically screen as having a possible or probable brain injury.



#### **Administrative Data**

The survey for individuals with brain injury used in 2020 did not include questions about the cause of the injury, though it did inquire about what year(s) their brain injury occurred and how their brain injury was classified. Those results show that among the survey respondents (n=57), a majority experienced their most recent brain injury five or more years ago. Although 39% reported having a mild brain injury (meaning loss of consciousness occurred for 0 to 30 minutes), nearly 25% reported a severe brain injury (having a loss of consciousness for over 24 hours). Information regarding brain injuries was not captured through the 2019 survey.

Screening for brain injury remains a consistent topic within needs assessments and statewide meetings. Information was first sought in 2020 as part of the needs assessment, where 55% of providers reported that they screen for lifetime history of brain injury. Again, that needs assessment was focus primarily on behavioral health, so service providers primarily reflect those in the behavioral health field. Similar to the 2024 results, the most common mechanism of screening was through informal questions.

Increase screening initiatives was seen as a success of the system through the Brain Injury Advisory Council meeting minutes. In fact, results from projects with regional centers and youth treatment centers were shared, highlighting that typically 75-86% screen as having potential brain injuries. It was also noted that Nebraska VR is the only state that currently includes a question about brain injury on their intake form, allowing at least one state agency to help identify individuals who may need services.

#### **SECTION SUMMARY**

Determining exact prevalence (total cases) and incidence (new cases) of brain injury in Nebraska is difficult due to data limitations and variations in reporting. However, the TBI Registry offers meaningful insight. From 2017 to 2022, the registry recorded 75,915 TBI cases. There were 14,819 cases reported in 2022 alone - marking a 29% increase since 2017. Other sources provided by Nebraska VR and BIA-NE supplement this data, revealing high rates of lifetime experience of TBI, with individuals often experiencing more than one injury. For example, the ABI Interview showed 81% of 912 individuals screened in 2023–2024 had probable TBIs. averaging 1.41 injuries per person.

Falls are the leading cause of TBIs in Nebraska, accounting for more than half of the cases reported in the TBI Registry from 2017 to 2022. Other major causes include being struck by or against an object (17%) and motor vehicle accidents. In other data sources like the ABI Interview and Resource Facilitation data, car crashes were the most common injury cause, followed by "other" (a broad category), falls, and incidents such as domestic violence and sports injuries. The survey for individuals with brain injury also shows a similar pattern, with 51% of respondents citing vehicle accidents, 34% falls, and 23% abuse or assault as likely causes. Across sources, a substantial proportion of individuals reported experiencing symptoms such as confusion, memory gaps, or loss of consciousness, indicating the severity and impact of these injuries.

Screening practices for brain injury vary across service providers. The most common approach – at least among those who participated in the 2024 service provider survey - was asking informal questions of clients or patients at intake. Increased screening is likely a strength of the brain injury service delivery system in Nebraska, with some agencies identifying potential brain injuries in 75% or more of the individuals screened.

# **Demographics & Daily Living**

Understanding the demographics of those who have experienced a brain injury may provide further insight into the population and could potentially point to prevention efforts. Information about daily living includes aspects such as housing, employment, education, and more. In addition to better understanding the population of those who have experienced a brain injury. this may also start to showcase the potential impact and needs as it relates to brain injury.

#### **TBI Registry**

Based on the TBI Registry data, elderly individuals (those 75 and older) had the highest rates of hospitalization and emergency department (ED) visits while children younger than five and teens (ages 15 to 19) had the next highest rates of ED visits. The median age of a TBI patient visiting the ED was 30 years.

There is some variation with gender. Based on data from 2017 through 2022, the top five highest TBI cases 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)

Given the data source for the TBI Registry, information regarding the primary payer is known for those who receive a TBI diagnosis. Between 2017 and 2022, about one-fourth (26%) of the ED visits were covered by commercial insurance. Medicare and Medicaid accounted for 42% of the TBI-related ED visits. Less common were worker's compensation (2.3%) and the Veterans Administration plan (1.3%).

During that same five-year period, data from the TBI Registry also shows that the majority (89%) of patients with a TBI-related ED visit were discharged home. Slightly less than 5% of patients were discharged or transferred to another short term general hospital for inpatient care. About 2%, however, were missing discharge status information, so it is not known where they were discharged to following their ED visit.

#### **ABI Interview**

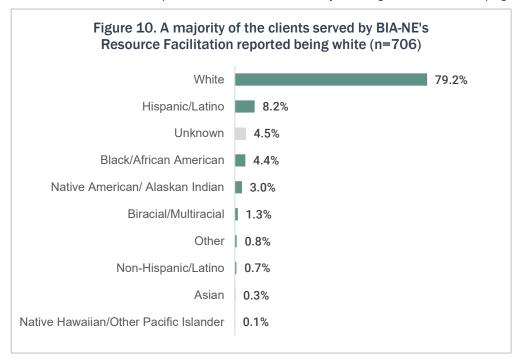
The average age among the 912 individuals screened by Nebraska VR was 39, though the ages ranged between 16 and 78. The average age at the time of TBI was 21.5 years, with a range of 0 to 84 years of age. The average age at the time of injury for non-traumatic brain injury was 26 years, with a range of 0 to 70. This may indicate that quite a few people had experienced their brain injury years before applying for services through Nebraska VR.

The ABI Interview data also shows that about 3% (n=27) were veterans. Additionally, 78% (n=709) lived on their own or independently, and 34% (n=310) were in competitive, integrated employment.

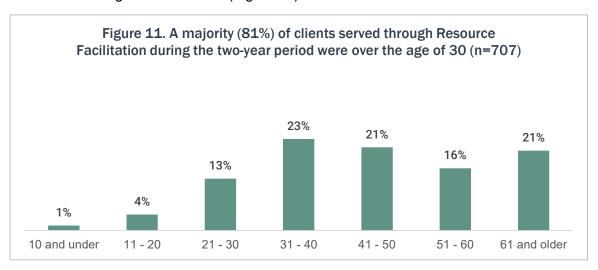
#### **Resource Facilitation**

Throughout 2023 and 2024, roughly 739 unique individuals were served through Resource Facilitation. There was a relatively even split between females (49.8%, n=355) and males (50.2%, n=358).

Although most of the clients were white (4.5% were "unknown," indicating the staff member did not ask the client about their race), there was some diversity among clients served (Figure 10).



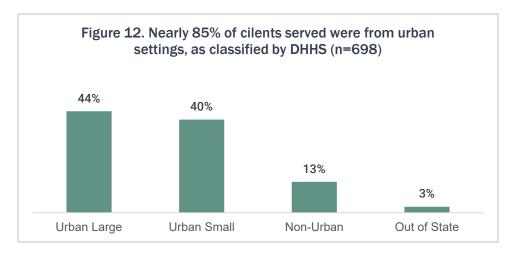
The average age among those served was 45. Although there is quite a large range of ages being served by the BIA-NE – the youngest was 2 while the oldest was 96 – about half (45%) were between the ages of 31 and 50 (Figure 11).



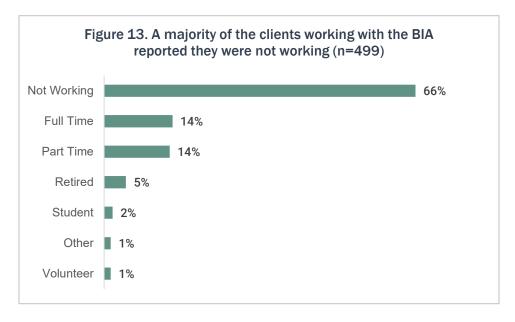
Clients served during the two-year period were from 65 counties in Nebraska (n=698). Slightly more than one-third (38%) were from Douglas and Lancaster County. However, the county most reflected through the data is Lincoln County, where 29% of the clients were located. This is primarily due to the BIA's engagement with the Lincoln County Jail. In fact, among the 679 clients that had a description of their primary address, 10% (n=71) were listed as incarcerated. There were also a small percentage of clients (5%, n=33) that were reported as being homeless.

As noted earlier, the geographic analysis done for this needs assessment is based on the geographic distinctions outlined by DHHS. Among the clients served through Resource

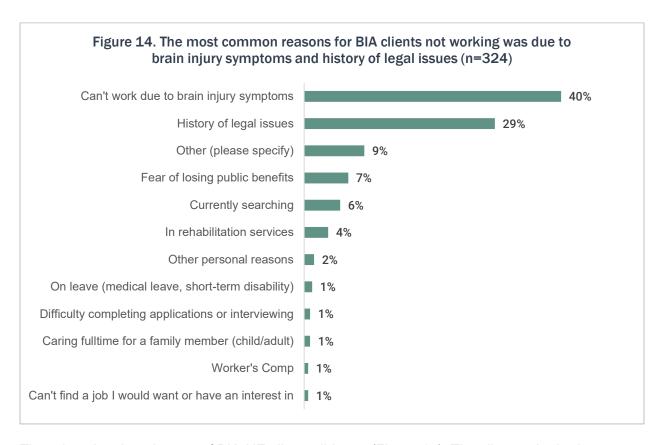
Facilitation, there was a relatively even split among those from urban large and urban small counties (Figure 12). There were also a handful of individuals (3%, n=18) that were out of state. Those clients were primarily from Iowa, though also represented individuals from South Dakota. Kansas, Missouri, Utah, and Colorado.



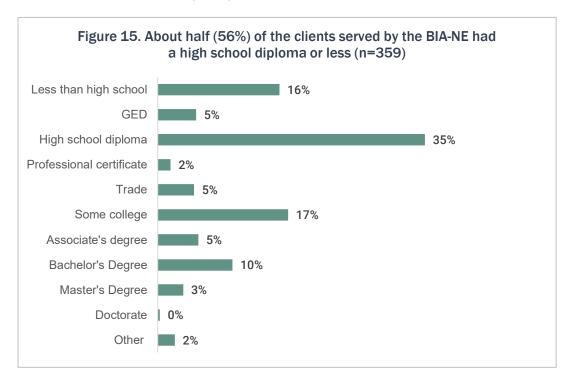
The employment status was available for 499 clients. There were 15 clients, however, that had two employment statuses recorded in the database, indicating the individual experienced a change in their employment while receiving or in between receiving services from the BIA. About two-thirds of the clients served had an employment status of "not working" at some point during their engagement with the BIA (Figure 13). There were slightly equal numbers of clients who reported working full-time (14%, n=72) and working part-time (14%, n=69).



The reasons for not working varied by individual. Just under half (40%) indicated they could not work due to their brain injury symptoms (Figure 14). There were also nearly 30% that had a history of legal issues, such as incarceration.



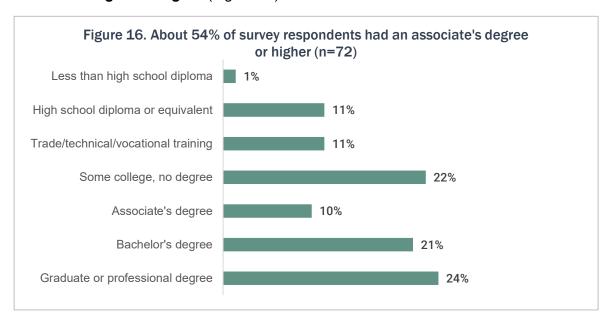
The educational attainment of BIA-NE clients did vary (Figure 15). The clients who had an "unknown" listed in the database (n=99) were not factored into the breakdown.



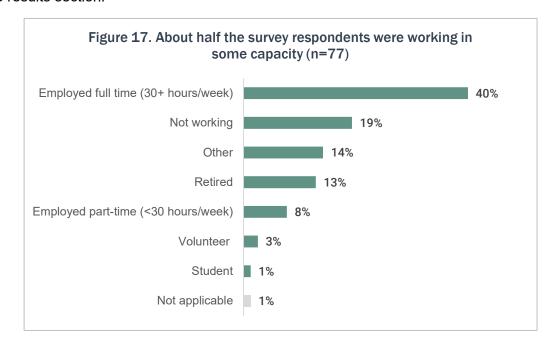
#### **Individuals with Brain Injury Survey**

As noted, the demographics of the respondents to the survey are outlined in Appendix B. More than half (60%) of the respondents were 45 years of age and older. They were also more likely to be female than male (69% compared to 29%), and predominantly white (88%).

Educational attainment was slightly different from those served through Resource Facilitation. While half of those individuals had a high school diploma or less, that was only the case for 12% of the survey respondents. In fact, slightly more than half of the survey respondents had an associate's degree or higher (Figure 16).

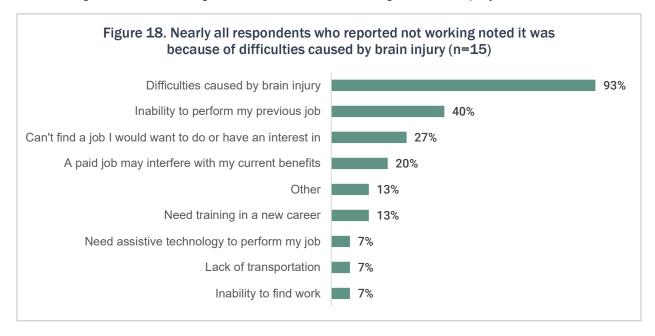


When it comes to employment, slightly less than half of the respondents (40%) were working full-time while 8% were employed part-time (Figure 17). Among those who were employed fulltime, about 58% reported through a previous survey question that they had "some" or "a lot" of challenges with employment. That information is further explored through the next category in the results section.

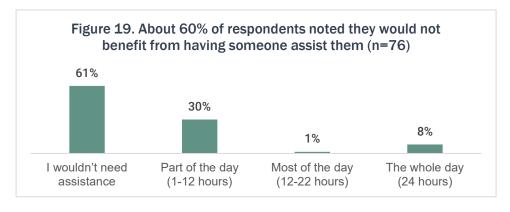


There was variation in those who reported "other" for their employment status. Three of those respondents (27%) indicated they were self-employed while another three indicated that they were disabled. Two recently left the work force – one for retirement and another for termination - while another was 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 18). Results also indicate that among those not working, 79% have "a lot of challenges" with employment.

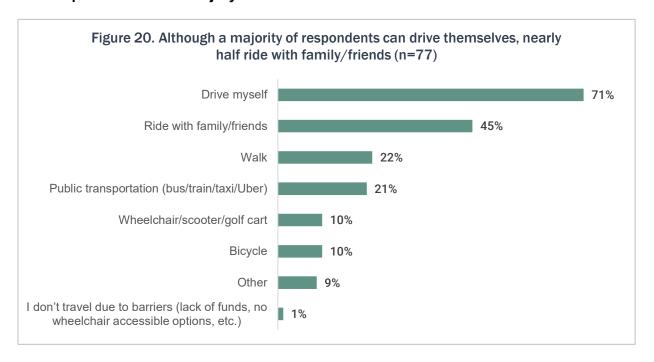


Among the survey respondents, about 60% indicated they would not need assistance from someone during the day. However, nearly 10% would benefit from having someone assist them for 12 or more hours a day (Figure 19).



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 versus 43% urban-small), they were more likely to have experienced more than one brain injury.

Some of the support that individuals currently have may relate to travel and transportation. Among the survey respondents, about 70% are able to drive themselves to get from place to place (Figure 20). 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.



#### SECTION SUMMARY

Data shows that individuals affected by brain injuries in Nebraska span all age groups, though certain populations are at higher risk. According to the TBI Registry, elderly adults – especially females over age 85 – had the highest rates of TBI-related hospitalizations and ED visits. Teen males (ages 15–19) also ranked high in ED visit rates, indicating that both aging and adolescent populations are particularly vulnerable. Insurance coverage data show that Medicare and Medicaid covered 42% of TBI-related ED visits, suggesting a portion of the population affected may have lower incomes or be older adults.

The ABI Interview and Resource Facilitation data showed additional insights. The average age of those screened through Nebraska VR was around 39-45, with many having experienced their injury years earlier. Roughly half of BIA-NE clients were between ages 31 and 50. Gender distribution was even for BIA-NE, while survey respondents were predominantly female (69%). Most individuals across datasets identified as white, though some racial and ethnic diversity was present.

While most individuals (78%) reported living independently, fewer were fully integrated into the workforce. Only 34% of ABI Interview participants, 40% of survey participants and 15% of Resource Facilitation clients were employed full-time. Employment challenges were often attributed to the effects of brain injury. Additionally, while educational levels varied, survey respondents tended to report higher levels of education compared to Resource Facilitation clients.

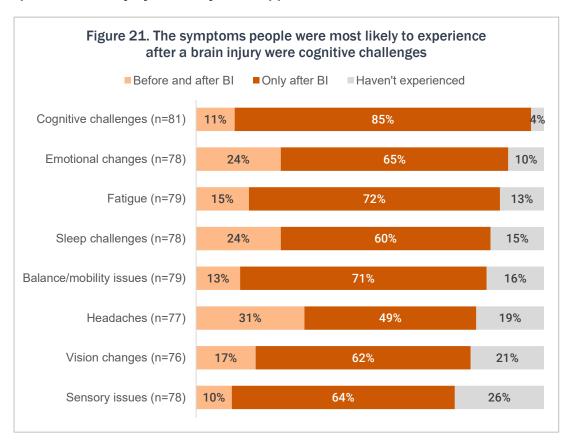
About 60% of survey respondents said they did not require daily assistance, but 10% indicated they would benefit from 12 or more hours of help each day. Many who needed part-time assistance were not currently receiving it, and a history of multiple brain injuries was more common in this group. Despite these challenges, most respondents (70%) were able to drive themselves, and 77% described their transportation as "very reliable," suggesting that mobility and access to services are manageable for many, though not all.

# **Symptoms, Health & Other Impacts after TBI**

There are a variety of symptoms that someone may experience because of a brain injury. In some cases, there may be co-occurring health conditions as well, some of which can make those symptoms worse. Having this information can point to challenges that individuals with brain injury may experience and need assistance with mitigating.

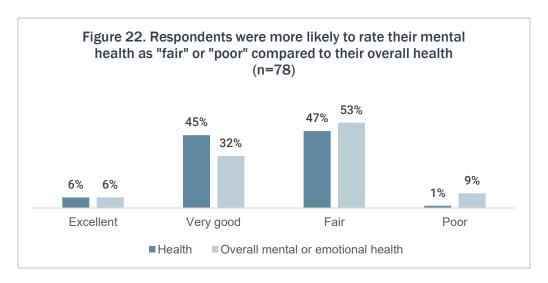
#### **Individuals with Brain Injury Survey**

To better understand symptoms, survey respondents were asked to report whether certain symptoms were something they experienced before or after their brain injury. The most common symptom – particularly after a brain injury – related to cognitive challenges (Figure 21). That was defined in the survey as having problems with memory or problem solving. 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.



#### General Health Status

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 22). 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. 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 in Nebraska 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.

Although the BRFSS does not ask about mental health status in a similar fashion, there is an indicator regarding the average number of days mental health was "not good" in the past 30 days. For Nebraskans in 2022, the average was 4.1 days. A similar question was asked for physical health as well. The 2022 data indicates the average number of days physical health was not good in the past 30 days was 3.5. This may indicate a similar trend to what is seen in the individuals with brain injury survey where mental health is rated slightly lower compared to physical health.

#### COVID-19 Impact

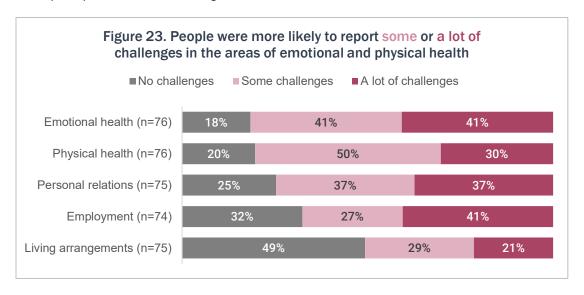
Preliminary research indicated that those who have experienced a brain injury may have additional challenges with COVID-19. Survey results indicated that about 59% of the respondents had ever tested positive for COVID-19. Of the 46 who reported testing positive for COVID-19, 11 (24%) said they experienced 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 inperson 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.

Nebraska Department of Health and Human Services. BRFSS dashboard.
<a href="https://dhhs.ne.gov/Pages/Public-Data-Dashboards.aspx">https://dhhs.ne.gov/Pages/Public-Data-Dashboards.aspx</a>
Selected health indicator: General health fair or poor, Adults 18 and older.

#### 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 23). 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 counites.



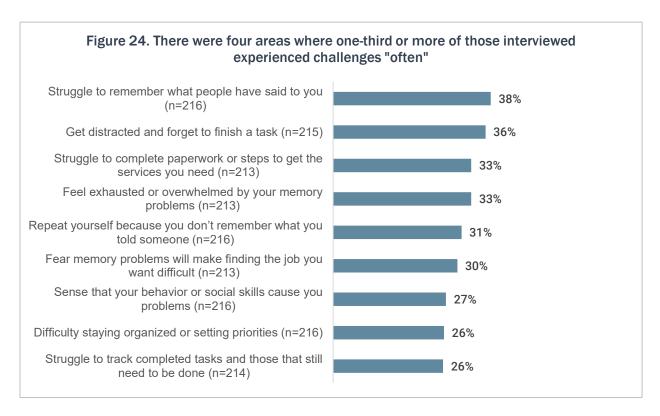
Interestingly, while 32% of people indicated they had "no challenges" with employment, it also had the highest percentage of people reporting "a lot of challenges," along with emotional health. Analysis showed that there was not a geographic difference among those who reported having "a lot of challenges"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

#### **ABI Interview**

As noted, part of the ABI Interview through Nebraska VR assesses how often people may experience specific challenges following their potential injury, illness, or event. There are 21 different areas that are assessed, where people can select one of four options; never, seldom, often, or depends (see Appendix D for list of questions).

Among the 21 topics, there were nine functional impacts that were experienced by 25% or more of those who responded (Figure 24). Many of these relate to cognitive challenges, further illustrating that cognitive symptoms are prevalent for those with brain injury.

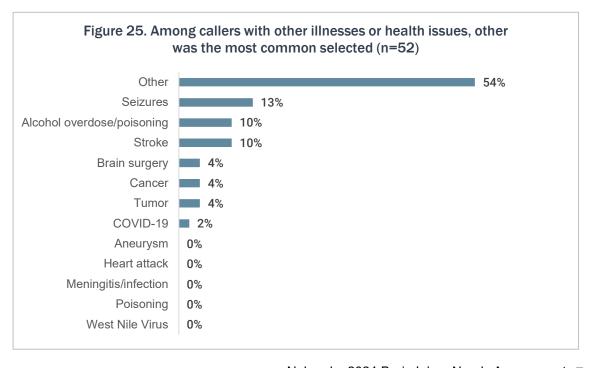
There were also three functional impacts that were "never" experienced by half or more of those interviewed. Those related to 1) difficulty getting ready for appointments/activities on time (52% responded never among 211); 2) difficulty reading maps or understanding diagrams (50% responded never among 206); and 3) difficulty finding your notes or to do lists (50% responded never among 207). Additional data is available in Appendix C.



Preliminary analysis shows that the 217 unique individuals who completed the functional impacts portion of the interview experienced an average of five challenges "often" and eight types of challenges "never."

#### TBI Registry Mailing Caller Survey

Beyond TBI, additional health conditions are documented from those who called upon receiving the TBI Registry letter. As shown in Figure 25, "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).

#### **Administrative Data**

Results from previous brain injury needs assessments in Nebraska indicate that there is a prevalence of behavioral health issues. Based on the results from the 2020 assessment, 93% of individuals with brain injury experienced some type of behavioral health issue. The most common issues tended to be related to neurobehavioral issues (77%) and mental health issues (75%). As noted, though, the 2020 needs assessment was specifically focused on the intersection of brain injury and mental health. In the 2019 needs assessment, about 43% of individuals with brain injury reported experiencing serious mental health issues.

#### **SECTION SUMMARY**

Individuals with brain injuries often face a wide range of symptoms and challenges, many of which are interconnected with their overall health and daily functioning. Survey data and ABI Interview data provide insights into these impacts and highlight the importance of coordinated care and support.

Data indicates that cognitive challenges (e.g., memory and problemsolving) were the most reported symptoms after brain injury. Emotional changes were also frequent, though 24% experienced them prior to injury. Through the survey, individuals reported 6.5 out of 8 possible symptoms and through the ABI interview, on average people reported experiencing at least five of the functional impacts often. This indicates a high level of multi-symptom burden.

Compared to 2022 state data (BRFSS), individuals with brain injuries were more likely to rate their health poorly, suggesting a lower quality of life. About half the survey respondents (51%) rated their general health as "excellent" or "very good," while only 38% felt similarly about their mental/emotional health

Other impacts are also experienced following a brain injury. Most reported difficulties in three or more areas of daily living, particularly employment and emotional health.

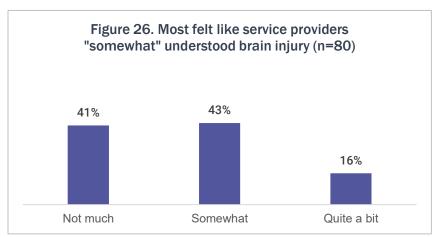
The findings illustrate that individuals with brain injury commonly experience complex, overlapping challenges related to symptoms, health, and daily living. Mental health concerns, cognitive impairments, and functional limitations are especially prevalent. Recovery and quality of life for this population require comprehensive, coordinated support services, especially in light of added burdens like COVID-19 and co-occurring conditions.

# **Awareness of & Training Regarding Brain Injury**

A common theme identified in the previous needs assessments pertained to people – from the general public to service providers – having an understanding or awareness of brain injury. That was explored through the surveys in 2024 as well to determine what training gaps may still exist and to what degree education around brain injury may still be needed.

#### **Individuals with Brain Injury Survey**

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 by providers having "not much" understanding of brain injury (Figure 26). 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.

A core aspect of the survey was determining what changes may help to better assist and support those who have experienced a brain injury. Open-ended responses from 33 individuals were categorized into three areas, with one being education and awareness. There were four audiences that respondents felt needed to have enhanced education and awareness about brain injury. This included:

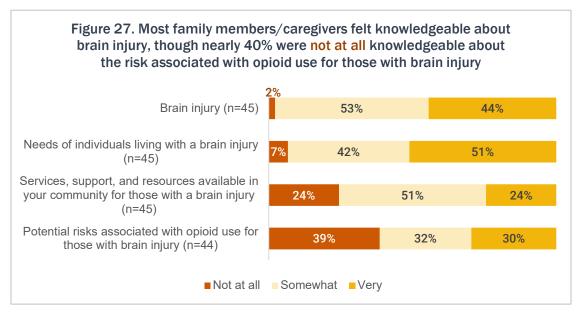
- 1. **Medical providers**. This comprises doctors, nurses, and other healthcare providers, and many noted that it was important for this audience to have an understanding of how to identify and treat brain injury. Some indicated that many doctors don't inquire about past accidents or use any screening 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 empathy may be beneficial.

4. **Schools**. Respondents felt it was necessary to educate 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."

One respondent expressed frustration that "understanding brain injuries usually only happens when someone either gets one, or a person close to them sustains one." As a result, they felt it was essential to "educate all teachers, medical providers, and those who work with the community. Make it mandatory for hospitals and medical clinics." Not only is understanding brain injury important, but also "Medical providers and therapists should listen to people. I'm the expert on myself and what I need."

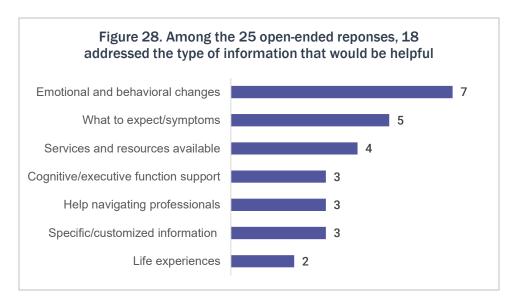
#### Family Member/Caregiver

Those participating in the family member/caregiver survey were asked to indicate their level of knowledge regarding brain injury topics. 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 27). That statement was assessed because of a goal included in Nebraska's Brain Injury State Plan. This is in part because more recent research suggests that individuals with brain injury may be more susceptible to opioid misuse and the risk for opioid use disorder (OUD).<sup>19</sup>



There were 25 people who offered feedback on what types of training, resources, or materials (if any) would be helpful to better understanding brain injury and how to care for someone who has experienced it. The most common topic related to emotional and behavioral changes, followed closely by what to expect and symptoms that the individual with a brain injury might experience (Figure 28). As one respondent noted, "It's more of the emotional and behavioral aspect of the injury that I need help with. He's explosive to anger, irrational, forgetful of the events of the situation, and dismissive to the other the second the conversation gets hard and not in his favor." Another respondent noted that knowing "what to expect from the brain injury and how the person will change" would be particularly helpful.

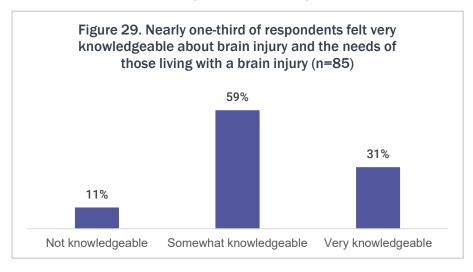
<sup>&</sup>lt;sup>19</sup> Adams RS, Corrigan JD, Dams-O'Connor K. Opioid Use among Individuals with Traumatic Brain Injury: A Perfect Storm? J Neurotrauma. 2020 Jan 1;37(1):211-216. doi: 10.1089/neu.2019.6451. Epub 2019 Aug 16. PMID: 31333067; PMCID: PMC7364315.



The open-ended feedback also provided initial insight into how people would prefer to receive information. Among the 25 respondents, eight included information regarding which mechanism they would like for getting such information. The most common (n=5) included classes and presentations followed closely by support groups or network (n=4).

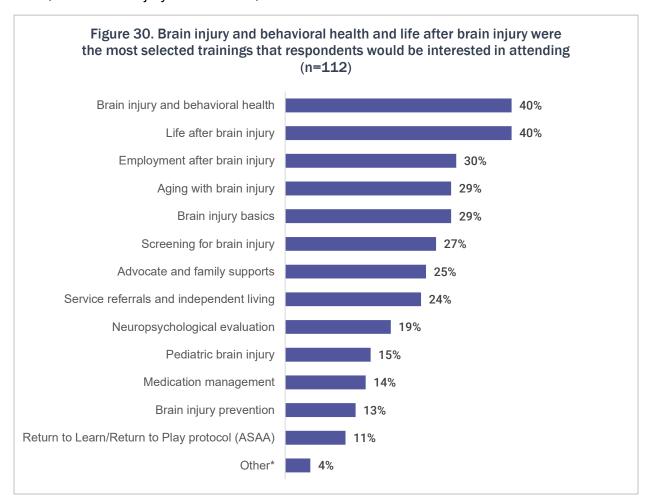
#### **Service Provider Survey**

Results from the service provider survey indicate that most (89%) feel at least somewhat knowledgeable about brain injury and the needs for individuals living with a brain injury (Figure 29). However, it may be important to keep in mind the types of respondents who received information about and participated in the survey. Some information is provided in Appendix B and outlined in the service provider survey results summary report on the BIAC website.



The high level of knowledge reported among respondents may be due to previous training they have experienced. Approximately 38% noted they had "quite a bit" of training and educational opportunities on brain injury. Only 13% reported they had no previous training or educational opportunities. Despite feeling relatively knowledgeable about brain injury, more than half (54%) indicated they would like to receive additional training or education on brain injury.

More specifically, respondents seemed interested in learning about brain injury and behavioral health as well as life after brain injury (Figure 30). 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.



#### **Administrative Data**

Similar to the coding of open-ended responses to the individuals with brain injury survey, there are key audiences that emerged through the administrative data regarding awareness and understanding of brain injury: service providers and the general public.

#### Service Providers

Results from the 2019 and 2020 needs assessments identify that "providers do not understand brain injury" as the key barrier to services. In fact, in 2020 when the needs assessment focused on behavioral health, 61% of individuals with brain injury and 77% of behavioral health providers recognized lack of knowledge as a barrier. Furthermore, in 2020 it was reported that only 43% of behavioral health providers feel "moderately" or "highly aware" of the difference between cognitive issues from brain injury versus behavioral health issues.

Findings from 2020 also demonstrate that 45% of providers were unaware of specific treatment approaches for individuals with brain injury. In fact, only 35% of providers who treat individuals with brain injury use specific therapeutic approaches for them.

Perhaps as a result, provider education became a core area of need from the 2020 needs assessment. This is also because 77% of individuals with brain injury recommended more education and training for providers. Similar to the 2024 results, though, about 74% of providers indicated they would be interested in receiving training on brain injury and its impact on behavioral health.

Results from the 2019 needs assessment, which had a broader focus with service providers, indicate that about 53% of providers felt knowledgeable or very knowledgeable about brain injury. This is lower than what was found through the 2024 survey, as noted above. However, there may be slightly different respondents so it is unclear whether the increase in perceived knowledge about brain injury is due to efforts to train providers in Nebraska or not.

Minutes from the Brain Injury Advisory Council meetings indicated that mental health providers are lacking in brain injury training. By not having that background knowledge or context, emotional health support can be affected among those who have experienced a brain injury. Among the Brain Injury Oversight Committee meetings, minutes reveal a need for increased awareness and accurate identification of brain injuries, especially in high-risk populations. Although trainings have been offered consistently by the BIA-NE – with evaluations showing an increased understanding of brain injury and improved ability to support individuals – there may be limited reach for one organization within the full state.

#### General Public

General public awareness was also a key need highlighted in 2019 and 2020. In fact, 85% of individuals with brain injury identified public awareness as a major need.

### **SECTION SUMMARY**

Data reveals persistent gaps in awareness, training, and ultimately service delivery related to brain injury in Nebraska. Individuals with brain injury emphasized a strong need for increased education and awareness across four key sectors:

- Medical providers often miss or inadequately screen for past brain injuries.
- The general public lacks understanding of brain injury as an "invisible" disability, contributing to stigma and lack of empathy.
- Employers and schools were identified as underprepared to support individuals with brain injuries, especially regarding accommodations and injury prevention education.

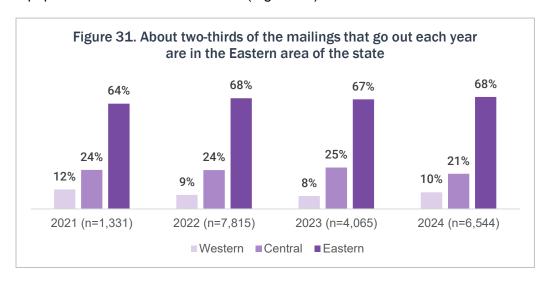
While most caregivers felt somewhat informed, there were some gaps related to trainings and resources. In particular, nearly 40% lacked awareness about opioid risks for those with brain injury and the most common training need related to the emotional and behavioral changes following injury as well as understanding symptoms and what to expect over time from the individual with a brain injury.

# **Hearing About and Accessing Services**

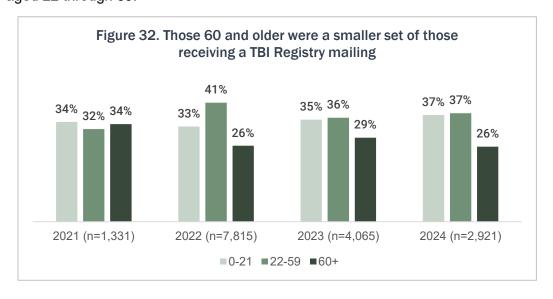
This section explores how people hear about and get connected to services after experiencing a brain injury. This is a key aspect of the TBI Registry Mailing, as part of the legislative effort is to ensure those who experience a brain injury can access appropriate services for their recovery.

#### **TBI Registry Mailings**

Between June 2021 and December 2024, there were 19,755 TBI Registry mailings sent. A majority of those letters were sent to the Eastern portion of the state, which is to be expected given the population of Omaha and Lincoln (Figure 31).



The other customization for the TBI Registry mailings was related to age. Among the letters sent, people were less likely to fall into the age range of those 60 and older (Figure 32). Other than the mailings sent in 2022, the range of letters sent for those 0 to 21 was comparable to those aged 22 through 59.



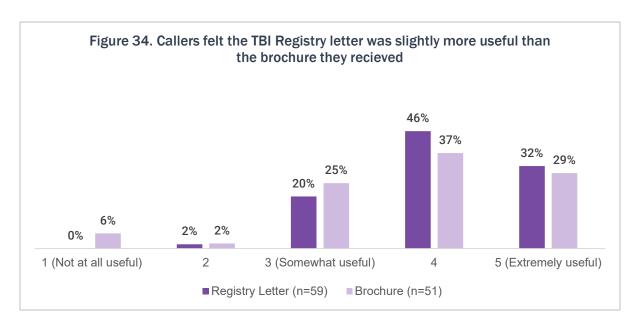
## **TBI Registry Caller Survey Data**

From May 2022 through December 2024, a total of 190 calls were logged through the survey from the BIA-NE 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 and Lancaster (Figure 33). Callers reported being from 28 different counties in Nebraska. <sup>20</sup>

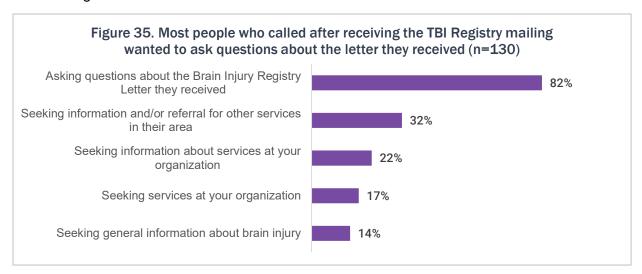


When possible, organizations asked callers about how useful the TBI Registry letter and brochure were. Results indicate that – among those who did not receive the letter in error – nearly all were satisfied with both materials. **There was a slightly higher level of satisfaction reported with the letter than with the brochure** (Figure 34).



<sup>&</sup>lt;sup>20</sup> 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.

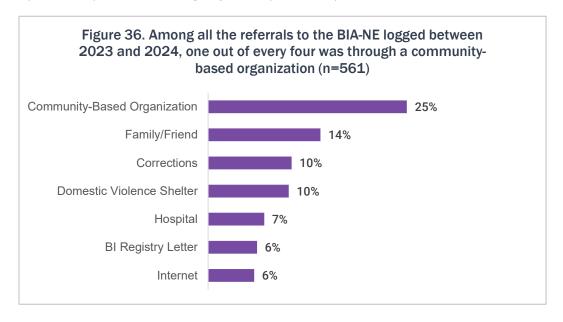
Most of the people who called after receiving a TBI Registry mailing did so because they had questions about the letter they received (Figure 35). However, about one-third of the callers were looking for information and/or referrals for services within their area.



Data also indicates for 52% of the calls, information or referrals were provided to the individual during that specific call. In fact, about 20% of callers received general information about brain injury.

#### **Resource Facilitation Data**

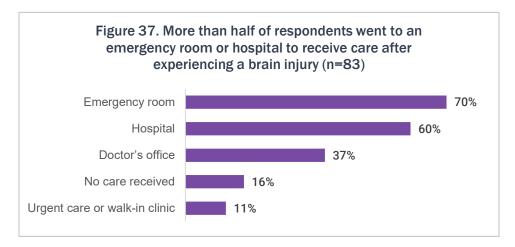
Part of the intake form with clients is asking how the individual heard about the BIA. These are tracked in the database as inbound referrals. A total of 561 inbound referrals were logged between January 1, 2023 and December 31, 2024. One-fourth of those were from communitybased organizations (Figure 36). At least 51 unique agencies were specified for how people heard about the BIA. There were also a portion of clients who heard about the BIA through a hospital (7%, n=39) and the BI Registry letter (6%, n=34).



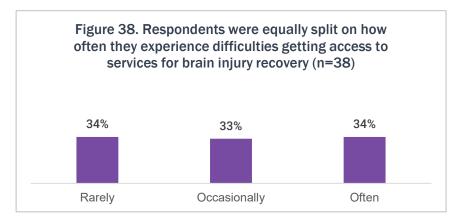
# **Individuals with Brain Injury Survey**

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 37). Given so many respondents did visit an emergency department or hospital, it is likely their information would be reflected in the TBI Registry data.



Responses 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 38).



Among 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%) 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%) and therapeutic services (44%).

#### **Administrative Data**

Based on findings from the 2020 needs assessment, referrals to connect people to services may be a barrier to access. Based on the survey conducted, 55% of providers reported not knowing appropriate referrals sources when serving individuals with brain injury. About 32% of family members/caregivers reported that a barrier was not having a referral from their primary medical provider. Findings in 2019 illustrated that there was a geographic access issue. Rural access to services was limited, with "not available near me" being a common barrier for many services, especially for family member support services.

Many discussions also took place among statewide groups regarding outreach to those who have experienced a brain injury. It was not uncommon, for example, for people to receive registry letters without knowing they had a brain injury due to lack of communication and/or coding errors at the medical facility that made the diagnosis.

It has also been noted among partners that access to services for teenagers and children is a challenge. Many do not know how to seek resources specifically for that population, which can create delays with the recovery process and getting necessary supports. Additionally, individuals with brain injury and their families face complex funding guidelines, eligible criteria, and waiting lists when trying to access services. Minutes from a Brain Injury Oversight Committee meeting described this as "navigating an ocean with no compass." More specific barriers to service are outlined in the next section of the report.

#### **SECTION SUMMARY**

Accessing services after a brain injury remains a complex process with multiple entry points and varying levels of effectiveness. The TBI Registry mailing has been a significant tool for outreach, with nearly 20,000 letters sent between mid-2021 and 2024. Caller survey data shows that while many recipients found the letters helpful, nearly one-third received them in error, often due to miscommunication or medical coding issues. Among valid recipients, most called with questions rather than immediate service needs, but about one-third sought referrals, and more than half received some form of support during the call. In addition, 561 inbound referrals to the BIA-NE were logged between 2023 and 2024, with a notable portion coming from community-based organizations, highlighting the importance of local partnerships in facilitating access.

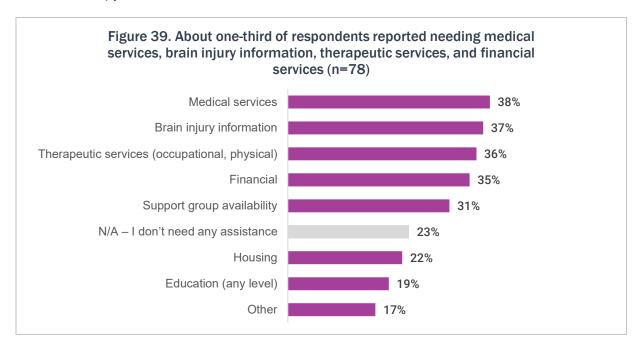
Survey and administrative data reinforce that hospitals and emergency rooms are common first points of contact, but follow-up access to brain injury services varies widely. Some individuals report little to no difficulty obtaining services, often correlating with having experienced only one brain injury and requiring minimal ongoing support. Others, especially those with more complex needs, report significant barriers—such as lack of referrals, financial strain, or limited availability of services. These challenges are particularly acute for rural residents, children, and teenagers, and are often compounded by unclear eligibility criteria and waitlists. Collectively, these findings suggest that while initial outreach efforts like the TBI Registry are valuable, systemic barriers, inconsistent referral pathways, and service navigation difficulties continue to limit timely and equitable access to recovery support.

# **Services Usage & Needs**

As noted throughout the report, individuals with brain injury experience a variety of symptoms and thus often have a range of service needs. This section aims to summarize results from different data sources regarding service needs and to what degree services have been used in Nebraska. It also explores gaps in services, primarily to identify potential areas of improvement for the brain injury service delivery system.

# **Individuals with Brain Injury Survey**

Although the survey for individuals with brain injury included a range of guestions regarding what types of services people utilize and/or need, the first two were primarily about what general assistance they would need for best living with a brain injury. Results show that about one-fourth of respondents did not need services (Figure 39). However, one-third or more of the respondents indicated a need for medical services, brain injury information, and therapeutic 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 people responded to the question, with the responses being categorized into key themes (a description of what is included under each theme is summarized in Table 2). However, some respondents mentioned they did not know or did not feel there were services they would need (Figure 40). Among those who indicated there was a need for services (n=48), about one-third reported 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.

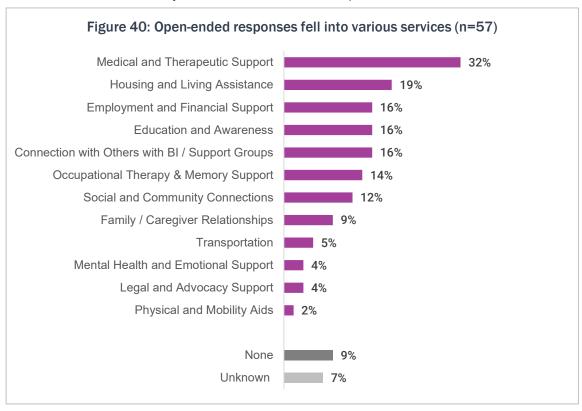


Table 2. Open ended responses were coded into key categories, with seven representing more than 10% of the responses

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 individuals 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

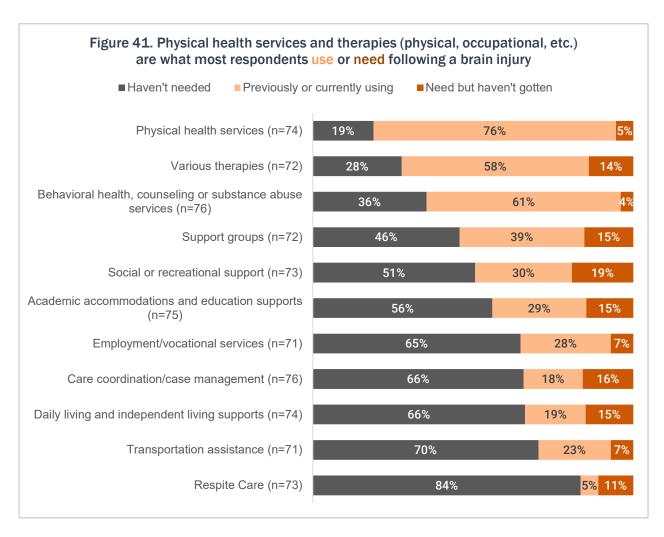
A key focus across all surveys was assessing the availability and use of 11 categories of services. Table 3 describes each category, which were included on each of the surveys for consistency and respondent understanding.

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

Category	Description
Academic accommodations	Services and supports for academic challenges
and education supports	
Behavioral health,	Therapist, psychologist, psychiatrist, substance use
counseling, and substance	evaluation, etc.
abuse services	
Care coordination/case	A professional to help arrange services you need
management	
Daily and independent living	Assistive technology, meal preparation, support through
supports and services	personal care attendant, money management, etc.
Employment/vocational	Help getting or keeping a job, such as vocational
services	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	Opportunities to be around others, ways to reduce loneliness
support	
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.

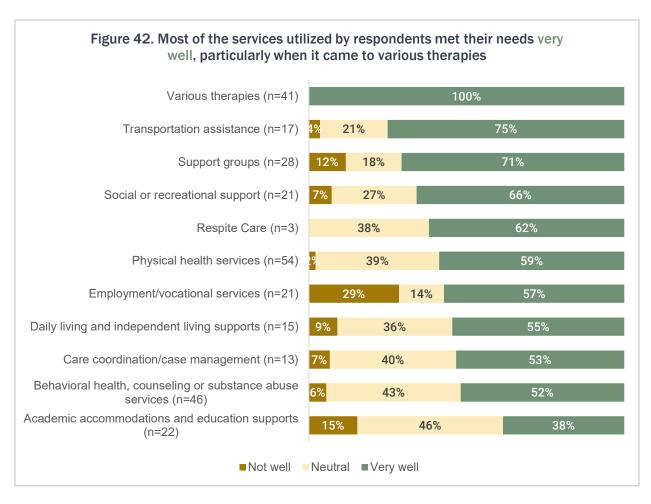
For each type of service, individuals with brain injury were asked to indicate whether it was a type of service they were currently using, used in the past, needed but couldn't get, or haven't needed. For analysis purposes, responses for currently using and used in the past were combined.

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 41). The most common type of service that people need but haven't been able to access is social or recreational support. 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.

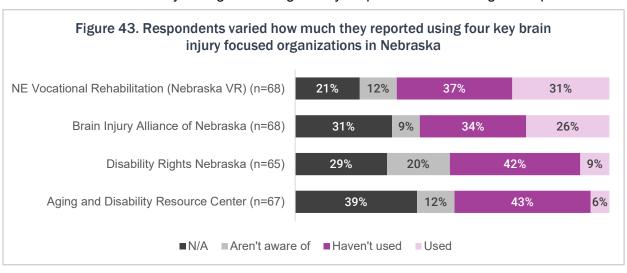


People were least likely to report needing respite care, though this could be because this is from the perspective of the individual with a brain injury rather than a family member or caregiver. There were also 70% who reported they haven't needed transportation assistance. This is consistent with the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

People who were able to access services felt that, in general, their needs were met "very well" (Figure 42). 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. However, 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. Although one-third of respondents felt that the four organizations were not applicable to them, there were guite a few respondents that were aware of but hadn't used the services following their brain injury (Figure 43). It is important to keep in mind, however, that these are also agencies that may have promoted the survey, so the level of awareness may be higher among survey respondents than the general public.



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.** Perhaps in part because of this, another key need identified through open-ended responses to the survey was related to legislative or policy change. 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 [intellectual and developmental disability] and a TBI now, I still need an advocate."

An 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 categorized into three key areas, one of which was increased 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," despite a brain injury potentially affecting your whole life.

#### **Resource Facilitation Data**

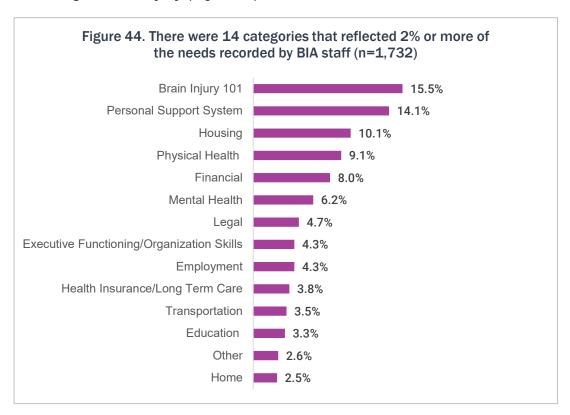
As part of the intake process, Resource Facilitators capture the core needs of each client. This helps prioritize what types of services and support the BIA-NE staff should help connect the client with as part of their brain injury recovery journey. Although the need is an open-ended field for staff to complete, each need is categorized into one of 56 types (Appendix D).<sup>21</sup>

From January 2023 through December 2024, there were 1,732 needs documented among 647 unique clients. Although the average number of needs per client was 2.6, the range varied anywhere from one need to 18 needs. It is important to note, however, that in 2024 the database was modified for staff to track needs that the BIA identified but was able to work on at the present time.

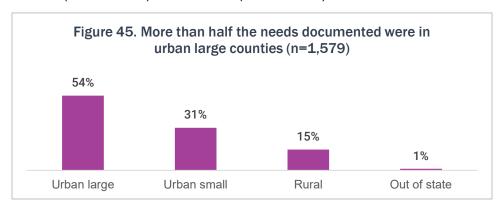
The 1,732 needs during the two-year time period fell into 53 of the 56 needs categories. Many of the needs reflect subsets of larger topics. For example, the "Personal Support System" need has categories to reflect needs for personal support systems through 1) faith/religion, 2) family/friends, 3) service animal/pet, and 4) support groups. **Among all the need categories**,

<sup>&</sup>lt;sup>21</sup> Prior to 2025, there were only 51 categories. The BIA-NE team conducted a review of common needs to revise the categories to more accurately reflect the needs. Data was retroactively updated when possible.

# the most common related to the client or family member/caregiver needing a better understanding of brain injury (Figure 44).<sup>22</sup>



Each need is also tied to the county in which the client was located at the start of services with the BIA. That data indicates that half of the needs occurred or were at least documented for clients located in large urban areas, with the most common counties being Douglas (25%, n=396), Lancaster (21%, n=332), and Lincoln (19%, n=294).



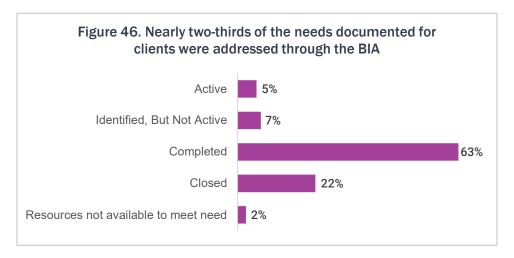
Each need documented typically has a status affiliated with it to denote if it was or could not be addressed through Resource Facilitation. There are five types of status options:

- Active: BIA is currently working with the client to address that need
- Identified, but not active: Although staff identified this as a need for the client, it is not an immediate need being addressed, as other needs should be met first

<sup>&</sup>lt;sup>22</sup> The following categories reflected less than 2% of the needs during that time frame: Addiction support, food / nutrition, behavioral health, medication, technology, rehab therapy, rec/leisure, volunteering, safety, mental/emotional health, communication, intimate partner violence/human trafficking, and supervision.

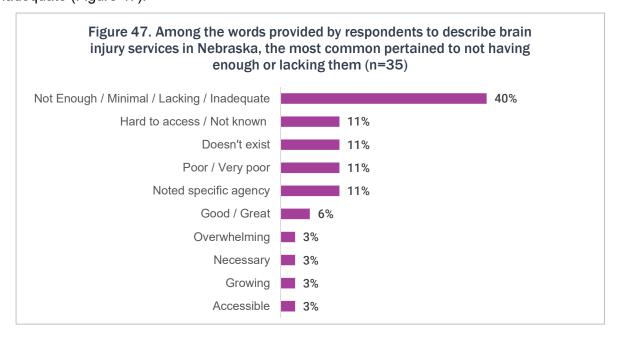
- Completed: the need was addressed by the BIA
- Closed: Status of the need is not known because engagement with the client stopped
- Resources not available to meet need

There were 1,737 needs documented that have a status.<sup>23</sup> A majority (63%) were needs that were addressed by the BIA in some capacity – whether it be through a referral, offering resources, providing education, or a combination of those (Figure 46). **The common categories where resources were not available to meet the need included housing, physical health, and transportation.** There was not a geographic difference for needs that could not be met due to responses not being available; resources were as likely to be unavailable in urban counties as in rural ones.



#### Family Member/Caregiver Survey

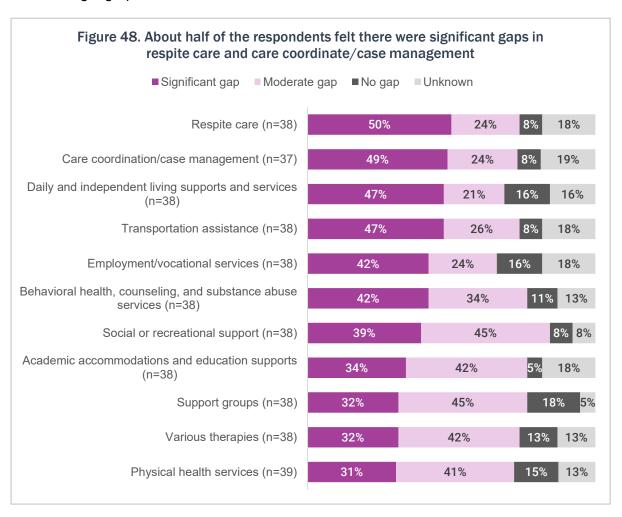
When asked to provide one or two words to describe brain injury services in Nebraska, nearly half (14 of the 35 responses) included words that noted that services were minimal or inadequate (Figure 47).



<sup>&</sup>lt;sup>23</sup> This is higher than the number of needs presented in Figure 44 as there were three needs documented that were not assigned a category.

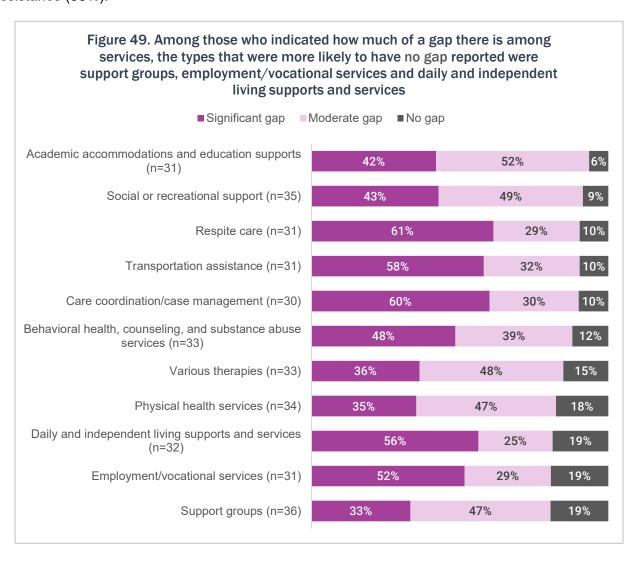
Using the same list of services outlined on the survey for individuals with brain injury (see Table 3), family members/caregivers reflected on to what degree gaps might exist in services for those with a brain injury in their community. The survey included guidance that a significant gap means that many who need this service are unable to get it while a moderate gap would indicate that some who need this service are unable to get it.

About half the respondents felt there was a significant gap in respite care and care coordination/case management (Figure 48). The areas where there was a higher percentage of respondents reporting no gaps included support groups (18%), daily and independent living supports and services (16%) and employment/vocational services (16%). Given the small number of respondents, there was not a correlation between the level of gap reported and the individual's geographic location.

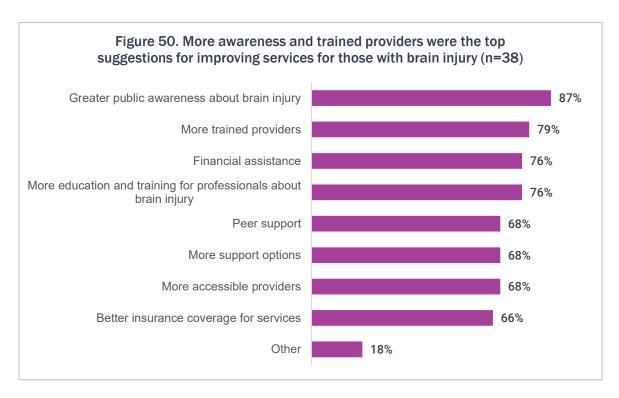


When those who reported "unknown" among the gaps are removed, the results are slightly different. About one in five respondents did not know whether there were gaps in care coordination/case management, respite care, transportation assistance, employment/vocational services, or academic accommodations and education supports. Figure 49 displays the results from the survey question without the unknown responses and is organized by those that have significant and moderate gaps.

Based on that, one of the largest gaps may be in academic accommodations and education support, with 94% indicating there's either a significant or moderate gap in that service. The services that have the highest percentage of respondents indicating there is a significant gap still include respite care (61%), care coordination/case management (60%), and transportation assistance (58%).



To improve services for those with a brain injury, a majority of respondents (86%) noted that greater public awareness about brain injury would be helpful. Slightly more than three quarters of respondents also reported that having more trained providers, financial assistance, and more education/training for professionals about brain injury would help with improving services for those with brain injury (Figure 50).



Among those who selected the "other" response in Figure 48, suggestions included transportation support (n=2), public education on brain injury (n=1), and social organizations (n=1). The biggest thing people noted, however, was continual support to help professionals get back to employment (n=3). As one participant noted, "Services that focused on return to his own industry are limited. He can work, but without additional support he may not ever be able to use his professional license or achieve his dream of going to grad school."

Employment and job support also came up as a need among the responses for the final two open-ended questions in the survey, along with public awareness about brain injury and training for professionals about brain injury (Table 4).

Table 4. There were seven topics that family members/caregivers explained would better help individuals with brain injury or support family members/caregivers (n=26)

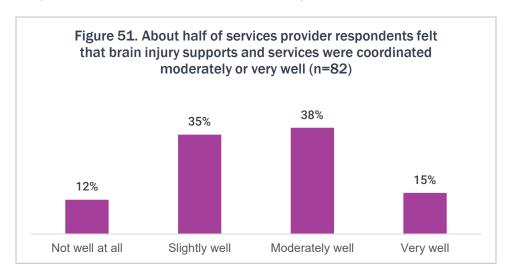
Key Topic	Description
Employment and Job Support	<ul> <li>Many respondents emphasize the importance of providing job opportunities for individuals with brain injuries, along with job coaching to help them succeed.</li> <li>There's a recognition that employment can give individuals a sense of accomplishment and identity, but continuous support may be needed, especially for those with long-term effects like memory issues.</li> </ul>
Training for Professionals on Brain Injury	<ul> <li>Respondents call for better training for healthcare professionals, caseworkers, and primary care providers in understanding and addressing brain injuries.</li> <li>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.</li> </ul>
Improved Access to Services and Resources	<ul> <li>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.</li> </ul>

	<ul> <li>Better transportation options and more local service availability are highlighted as key needs.</li> </ul>
Specialized Facilities and Housing	<ul> <li>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).</li> <li>Suggestions include more TBI-focused facilities and training for existing facilities, particularly for individuals who cannot live independently or require respite care.</li> </ul>
Awareness and Education	<ul> <li>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.</li> <li>Respondents suggest more support groups, peer mentoring, and programs like "big brother" initiatives to create community connections for those affected by TBI.</li> </ul>
Rehabilitation and Long- Term Support	<ul> <li>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.</li> <li>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.</li> </ul>
Family Education and Support	<ul> <li>Educating families about brain injury and the resources available is seen as an important step in improving care.</li> <li>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.</li> </ul>

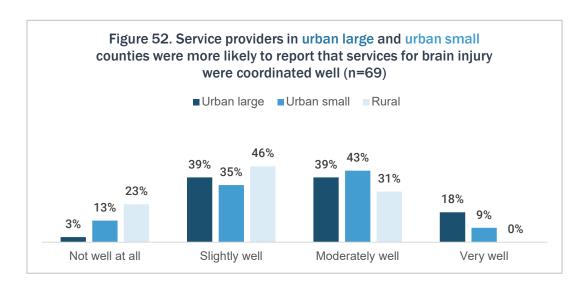
# **Service Provider Survey**

# General Brain Injury Services

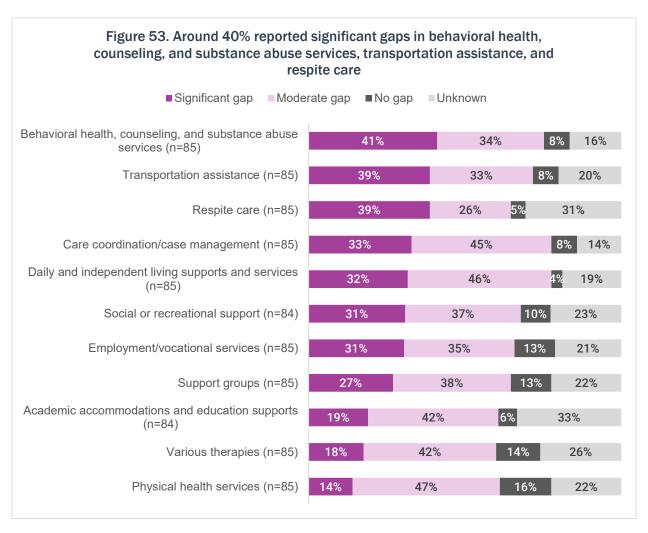
When asked about service and support coordination in their area, about half (52%) of respondents felt that brain injury supports and services were coordinated moderately or very well (Figure 51). No respondents selected the extremely well option for this question.



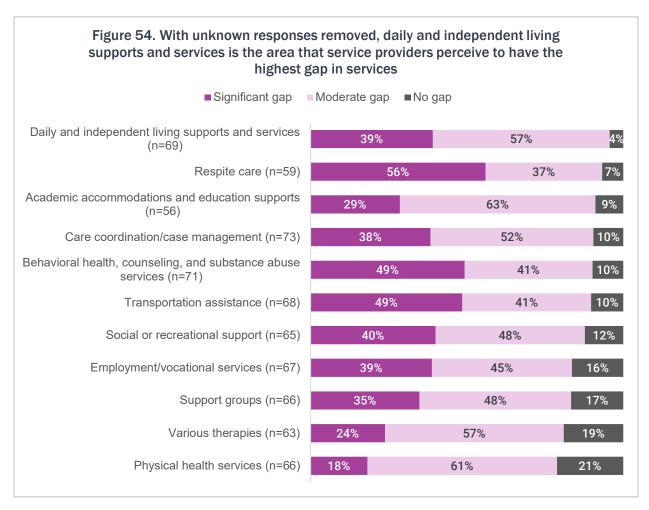
Although not statistically significant, there was a difference in how well service providers felt brain injury supports and services were coordinated based on their geographic location. Those from urban large counties were more likely to report that things were coordinated moderately or very well. In fact, no one from a rural county selected "very well" as a response (Figure 52).



The same question regarding perceived gaps in services asked of family members/caregivers was also asked of service providers. The key difference between both audiences was around behavioral health, counseling, and substance abuse services, with 41% of service providers noting it was a significant gap (Figure 53). Although 42% of family members/caregivers noted it was a significant gap, it was sixth in the list of 11 topics.



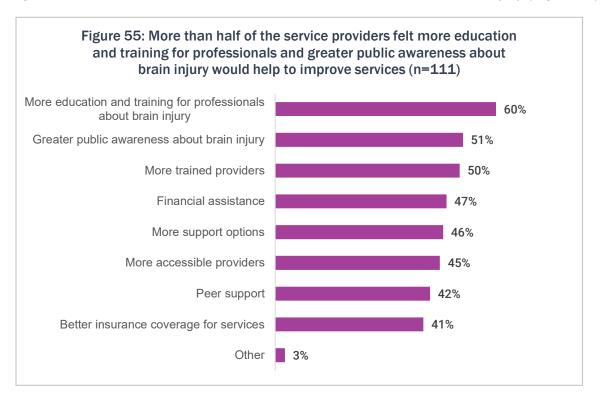
Services providers were more likely to select "unknown" regarding what type of gap in service they felt existed in their geographic area. Removing those responses modifies the list slightly regarding the types of services that have the most gaps (Figure 54). Similar to the family member/caregiver survey, academic accommodations and education supports are higher when the unknown responses are removed.



Respondents were asked to note any services that are not offered in their region that they believe would be beneficial to individuals who have experienced a brain injury. Among the 39 responses, key areas identified include the need for employment resources, transportation for those in rural areas, and more professionals trained in brain injury care. The lack of affordable mental health services, caregiver support, and recreational activities were also noted as gaps within their area. 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.

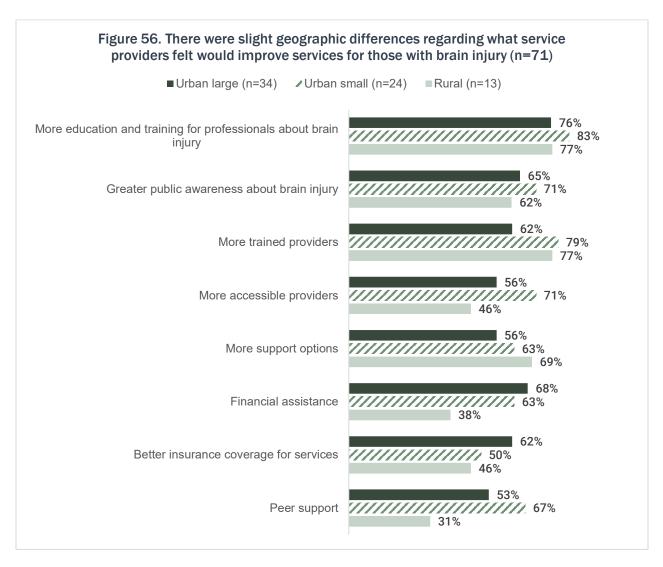
Additionally, respondents mentioned the absence of cognitive rehabilitation services, inpatient acute rehab for severe cases, and more outreach to raise awareness of available services. A notable concern is the geographic disparity in available services, with rural and western regions having fewer resources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

Similar to the survey for family members/caregivers, feedback was sought from services providers regarding what would 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 55).



Geographic differences were also explored to understand what would help improve services for those with brain injury. Given the small number of responses, particularly when broken out by county type, results should be interpreted with caution. However, Figure 56 does highlight some interesting findings, such as:

- More accessible services and peer support were both things that were more likely to be seen as improving services in urban small counties compared to urban large and rural.
- Having more support options was more likely to be selected by those in rural counties compared to urban large counties.
- Those in urban large counties were almost twice as likely to select financial assistance as being something that would help improve services compared to those in rural counties.
- More trained providers was more likely to be selected among those in urban small and rural counties than urban large counties.



Service providers brought up similar topics in their open-ended responses as the family members/caregivers for improving services and support for individuals with brain injury as well as their families. Public awareness, training for providers, and employment and rehabilitation services remain a common thread (Table 5).

Table 5. There were seven topics that family service providers noted to better help individuals with brain injury in their community or state or support family members/caregivers (n=42)

Key Topic	Description
Public Awareness and Education	<ul> <li>More outreach and public awareness campaigns about brain injury.</li> <li>Increased education for emergency room staff, employers, and the general public, particularly regarding the impact of brain injuries and how to support those affected.</li> </ul>
Access to Services	<ul> <li>Improved access to resources, especially in rural Nebraska, where people are often underserved.</li> <li>Easier access to services with minimal barriers, such as more information on where to go for help and what resources are available.</li> <li>Support for accessing housing and transportation for individuals with brain injuries, including those just out of rehabilitation.</li> </ul>

Training and Support for Providers	<ul> <li>More providers trained in brain injury care.</li> <li>Additional training for staff in all fields who work with brain injury patients.</li> <li>More training opportunities for behavioral health staff and care professionals.</li> </ul>
Employment and Rehabilitation Services	<ul> <li>More supported employment programs to help individuals with brain injury retain jobs.</li> <li>Expansion of cognitive rehabilitation services and post-acute care options.</li> <li>Better access to neurobehavioral services, including inpatient and residential options.</li> </ul>
Caregiver and Family Support	<ul> <li>More financial assistance and respite care options for caregivers, with better support to prevent burnout.</li> <li>Advocacy services to help individuals with brain injury navigate medical appointments and access necessary care.</li> <li>Increased peer and community support through support groups and community services tailored to brain injury.</li> </ul>
Rural Focus	<ul> <li>A greater focus on expanding services to rural areas, where there is a shortage of specialized brain injury care.</li> <li>More outreach and education for rural employers and facilities to better understand brain injury and support employees who have sustained one.</li> </ul>
Additional Services	<ul> <li>More day services, community support programs, and brain injury-specific services.</li> <li>Enhanced financial assistance for basic needs, such as housing, utilities, and food, while individuals are in therapy or care management.</li> </ul>

Despite some of the challenges and gaps, however, service providers did note things that seem to be working well with the brain injury service delivery system. Among the 31 open-ended responses, five key themes emerged (Table 6).

Table 6. There were five common topics that service providers felt were working well in the current

system of care for individuals with brain injury and their families (n=31)

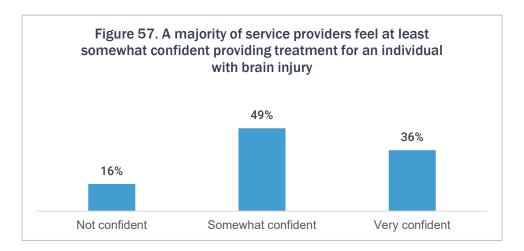
Key Topic	Description
Availability of	There is a good amount of resources available, particularly in Eastern
Resources	Nebraska, including acute care, occupational therapy (OT), physical
	therapy (PT), and speech therapy (ST). The presence of specialized
	facilities like Level 1 trauma centers, acute rehab, and specialized care
	systems (such as LTACH and QLI) also seems to be a positive aspect.
Specialized	Support groups, Medicaid waiver services, and training programs are
Support and	mentioned as beneficial. The BIA-NE is noted for providing resource
Services	facilitation and support. The school system has improved its response to
	brain injuries over the past 20 years.
Improved	The medical field is seen as making progress in understanding brain
Medical	injuries and improving treatment. Acute care services, particularly for TBI,
Understanding	are mentioned positively, especially once patients are engaged in the
and Services	inpatient rehabilitation system.
Connections	There are positive collaborations with various community organizations,
and	including juvenile justice programs and domestic violence services.
Collaborations	Additionally, individuals are becoming more willing to work with each other
	to improve care for brain injury patients.

Accessibility for Certain Populations

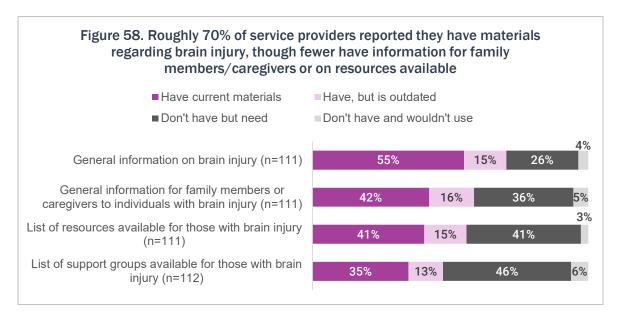
For families who are knowledgeable or well-versed in TBI, resources are easier to find. In larger communities, the system seems to work better, with more available resources and less waiting time for specific services such as AD/TBI waivers.

# Organizational Efforts

Feedback was also sought from service providers regarding their role in offering brain injury services and support. Among the respondents, the majority felt relatively confident in providing services to or treatment for an individual with a brain injury (Figure 57). It is important to note. however, that outreach was done to organizations that commonly serve those with brain injury. As noted in the methods, the most common respondents were from organizations such as Nebraska VR, BIA-NE and QLI.



More than half of the 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 58).



#### **Administrative Data**

Results from previous needs assessments highlighted similar results when it comes to service needs and utilization. In the 2020 report, for example, the key barriers for accessing services

included 1) knowledge and training gaps regarding brain injury; 2) referral and resource limitations; 3) access and insurance barriers; and 4) stigma. Similar themes were identified in the 2019 report, with the key barriers being provider knowledge, financial barriers, limited services in rural areas, and insurance coverage.

The priority service needs did vary between the two reports primarily due to the area of focus. With the 2020 needs assessment focused on mental health, specialized services that address both brain injury and behavioral health was the key service need. In 2019, care coordination was identified as the most needed service category.

Qualitative information through meeting minutes helped identify challenges regarding services but also things that are working well with the brain injury service delivery system (Table 7).

Table 7. BIAC and the Brain Injury Oversight Committee have discussed key successes and challenges in recent years regarding the brain injury service delivery system in the state

challenges in recent years regarding the brain injury s	service delivery system in the state	
Key Successes	Key Challenges	
<ul> <li>Resource facilitation has continued to expand throughout the state</li> <li>The creation and continued monitoring of the Brain Injury State Plan seems to help enhance communication among partners</li> <li>Expanded services for TBI Waiver including personal care, companion services, respite, and more</li> <li>There has been a heightened focus on training opportunities, with evaluations showing an increased understanding of brain injury</li> </ul>	<ul> <li>Transportation challenges, particularly in rural areas</li> <li>Limited availability of respite care</li> <li>Lack of providers trained in brain injury, particularly in rural areas</li> <li>Limited service options for teenagers and children, which can lead to delays with getting younger individuals support</li> </ul>	

#### SECTION SUMMARY

The report reveals that individuals with brain injury in Nebraska have diverse and complex service needs, with the majority requiring access to medical, therapeutic, and behavioral health services. While some respondents to the individuals with brain injury survey indicated they did not need services, many cited the need for specialized support such as cognitive therapy, housing assistance, employment accommodations, and counseling. Across all respondent groups – individuals with brain injury, family members/caregivers, and service providers - there was strong agreement that critical service gaps persist, especially in areas like care coordination, respite care, behavioral health, and access to transportation in rural areas.

Geographic disparities were a consistent theme. While urban areas, particularly Douglas and Lancaster counties, have more accessible services, rural regions face significant shortages in providers and resources. Respondents in rural areas were less likely to feel that their needs were well met and more likely to report gaps in service availability. Access to brain injury-specific facilities and providers, particularly for cognitive rehabilitation and long-term support, was especially limited outside of major population centers.

Across surveys, there was a strong need for increased awareness, education, and professional training on brain injury, both for providers and the public. Many individuals were unaware of Medicaid waiver options or found them difficult to qualify for, highlighting a need for clearer, more accessible information. Employment support, including job coaching and advocacy with employers, was another key need identified. Service providers and caregivers alike emphasized the importance of expanding vocational services and making them more adaptable to individuals' evolving needs post-injury.

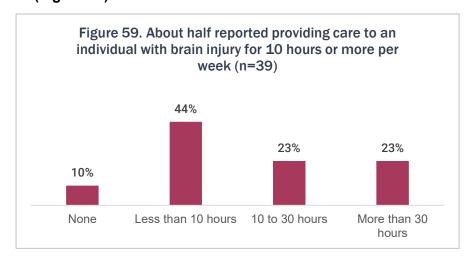
In addition to service access, the need for systemic improvements emerged. Respondents recommended expanding public education campaigns, increasing rural outreach, developing culturally and linguistically appropriate materials, and enhancing peer and community support. Although some existing programs, like resource facilitation and trauma center partnerships, were viewed positively, overall service coordination was seen as only moderately effective, especially in rural areas. The findings reinforce the need for a more integrated, inclusive, and geographically equitable brain injury service system across Nebraska.

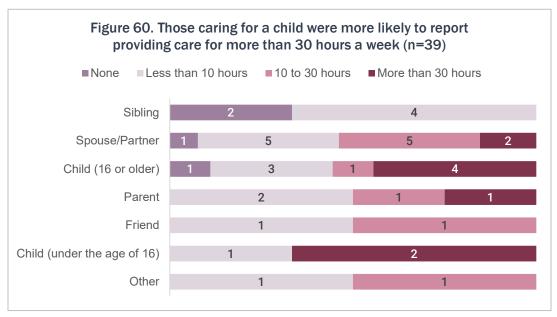
# **Caregiving**

Providing care for individuals with brain injury may be formal (such as having personal care attendants), but often is done through more informal approaches, such as support offered through a family member or friend. Particularly following the COVID-19 pandemic, research highlights the need to better understand and address needs of caregivers.

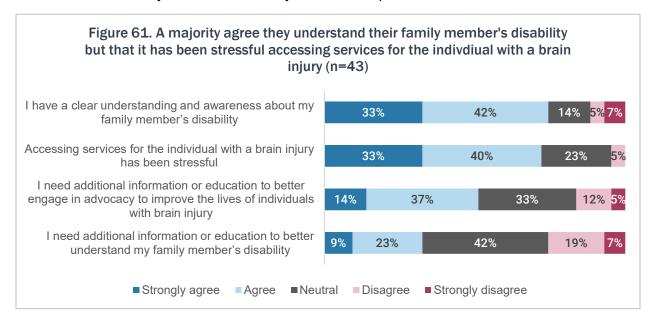
### Family Member/Caregiver Survey

A variety of individuals responded to the family member/caregiver survey (see demographics in Appendix B), offering insights into the caregiving experience. Among the respondents, nearly half (46%) reported spending at least 10 hours a week providing care for the individuals with a brain injury (Figure 59). That did vary slightly based on the relationships the respondent had to the individual with a brain injury. Although the sample size was relatively small, those who are providing care to a child - regardless of age - were likely to spend more time providing care (Figure 60).

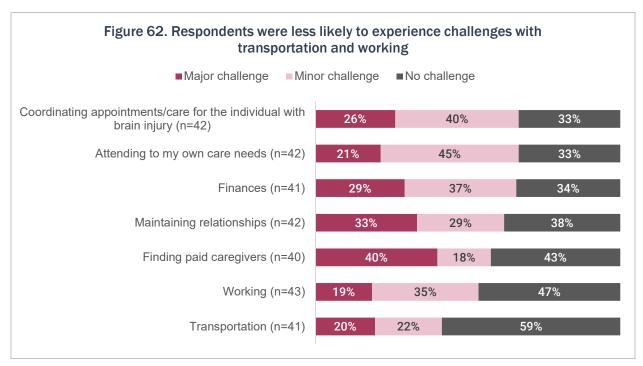




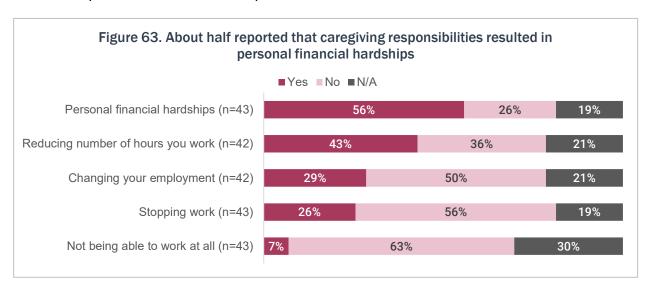
On the whole, caregivers reported having a good understanding and awareness about the disability of the individual with a brain injury (Figure 61). About 75% had a clear understanding and awareness, though there were 32% who agreed that having additional information to better understand their family members' disability would be helpful.



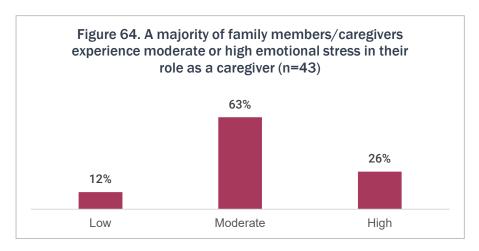
As Figure 61 noted, accessing services for an individual with brain injury is reported as being stressful. This aligns with another survey question regarding challenges of caregiving, where two-thirds of family members/caregivers reported they experienced challenges with coordinating appointments and care for the individual with a brain injury. A similar proportion reported challenges with attending to their own care needs and finances (Figure 62). However, the area that has the highest level of "major challenge" being reported was for finding paid caregivers.



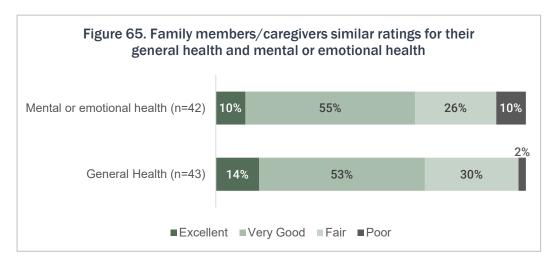
While working and transportation were less likely to be reported as challenges, quite a few did report having changes in their employment as a result of caregiver, whether it was having to reduce the number of hours they work or changing their employment (Figure 63). Although very few reported not being able to work at all, more than half the respondents noted that caregiving resulted in personal financial hardship.



Perhaps given some of those challenges, 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 64). 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.

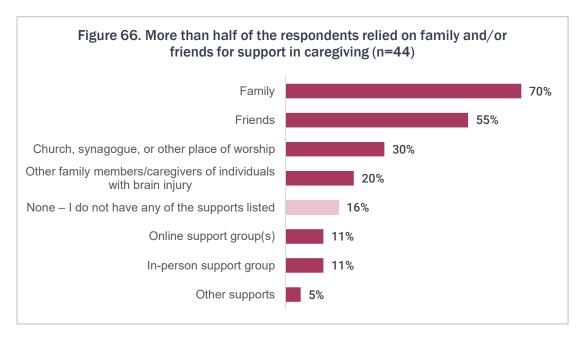


In addition to asking individuals with a brain injury about their mental and physical health, family members/caregivers also rated both on a four-point scale. Respondents gave similar ratings for each, with about two-thirds of respondents reporting excellent or very good general or mental/emotional health (Figure 65).

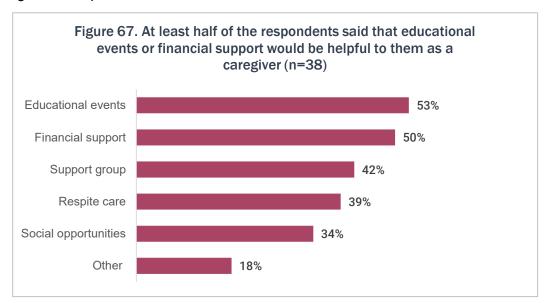


Results were comparable to what was seen among individuals with brain injury, with about half (51%) rating their general health as "excellent" or "very good." However, as noted in that section of the report, it's still substantially different from the results seen through the Nebraska BRFSS data. In 2022, roughly 15% of Nebraskans reported that their general health was fair or poor. This indicates that family members/caregivers to individuals with a brain injury have a lower quality of health overall.

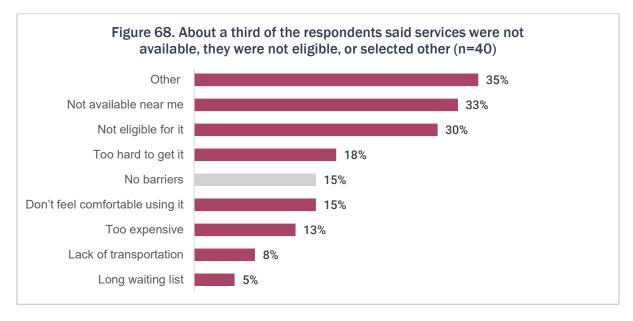
Respondents were asked where they go for social and emotional support related to caregiving, given a list of options. As shown in Figure 66, more than half of the respondents said they relied on friends and/or family for support. There were also 16% who reported that they did not have any of the supports listed among the response options.



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 67). Those who selected "other" included support and/or networking groups specifically for caregivers and information to better understand not only what the person with the injury is going through, but also 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 68). 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.



Many of the challenges and barriers that were noted throughout the survey also came up in the open-ended responses that people provided to a question regarding what could be done to better help family members and/or unpaid caregivers. Coding of the responses identified six core topics (Table 8).

Table 8. There were six topics that family members/caregivers explained would better help individuals with brain injury or support family members/caregivers (n=26)

Key Topic	Description	
Employment		
and Financial	<ul> <li>Many caregivers expressed a need for employment assistance or supported employment opportunities for their family members with brain</li> </ul>	
Support	injuries.	
Сарроп	<ul> <li>Financial support was a major theme, including suggestions for funding</li> </ul>	
	transportation costs, financial assistance for caregiving spouses, and	
	programs to address legal problems resulting from brain injury.	
Access to	Several responses indicated a need for improved access to mental	
Services and	health supports and services, including better pathways for Medicaid	
Resources	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.	
Respite Care	The lack of respite care was a recurring issue, with many caregivers	
and Support	requesting more opportunities for short-term relief, including evening	
Groups	and weekend availability.	
	Support groups for both individuals with brain injuries and their	
	caregivers were frequently mentioned as essential but lacking in	
Healthcare and	<ul> <li>accessibility or availability.</li> <li>Caregivers expressed frustration with the lack of diagnostic tools, such</li> </ul>	
Diagnostics	Caregivers expressed frustration with the lack of diagnostic tools, such as affordable and accessible SPECT scans, and the overall lack of	
Diagnostios	qualified providers.	
	<ul> <li>Some responses highlighted the need for medical professionals to</li> </ul>	
	better listen to family members and take their input seriously.	
Awareness and	Reducing the stigma associated with brain injury was a key concern,	
Stigma	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.	
Geographic and	Rural caregivers emphasized the lack of resources in less-populated	
Rural	areas and the need for action rather than just discussions from fund	
Challenges	managers and policymakers.	
	Transportation challenges, particularly in western parts of the state,	
	were also noted as significant barriers to accessing care.	

### **Administrative Data**

Previous needs assessment also highlights the caregiver/family impact. In fact, both reports highlight significant emotional stress on caregivers – in 2019 and 2020, about 97% of family members/caregivers reported experiencing emotional stress due to their role as a caregiver. Support for caregivers was also identified as a key need in the 2019 report, particularly with respite care and education.

### **SECTION SUMMARY**

The results highlight the considerable demands placed on caregivers of individuals with brain injury, many of whom are family members providing unpaid support. Nearly half of survey respondents spent at least 10 hours a week caregiving, with parents of children with brain injury often providing even more time. Emotional stress was common, with nearly two-thirds of respondents reporting moderate stress and a quarter experiencing high levels of stress. Mental health and counseling services were used by 42% of caregivers, and those who accessed such services generally found them beneficial. Coordinating care, attending to personal health needs, and financial strain were among the most frequently cited challenges faced by caregivers.

Financial and work-related hardships were notable but varied, with around half of caregivers reporting financial difficulties. A smaller percentage experienced disruptions to their employment. Despite these pressures, caregivers generally rated their own health—both physical and emotional—as "excellent" or "very good," although still lower compared to the general Nebraska population. Most respondents felt they understood the disability of their family member, but many also found it stressful to navigate and access necessary services. Social and emotional support most often came from friends and family, although a notable portion lacked any form of support from the listed options.

Survey respondents identified key areas for improving caregiver support, including financial and employment assistance, better access to services (especially in rural areas), and increased availability of respite care and support groups. Respondents also expressed a need for more qualified healthcare providers, clearer diagnostic tools, and greater recognition of caregiver input in healthcare settings. Reducing stigma and improving public awareness—especially in schools and underserved regions—were emphasized as important steps. Overall, the report underscores a continuing and urgent need for systemic improvements to ease the burden on caregivers of individuals with brain injury.

# **Conclusions**

Brain injuries – including TBIs – remain a significant public health concern in Nebraska. From 2017-2022, the annual number of TBI cases reported to the TBI Registry increased by 29%, and most of the reported TBIs were from falls. Other data sources indicate that motor vehicle accidents are the most common type of injury (25% of the TBI injuries reported through the ABI Interview, 19% of the injuries reported through Resource Facilitation data, and 51% of the injuries reported through the survey for individuals with brain injury).

Severity of brain injuries is also of concern. The ABI Interview data indicates that about half the individuals had a loss of consciousness with their TBI and 65% resulted in the individual feeling dazed or having a memory gap. About half the injuries reported through Resource Facilitation also resulted in an individual feeling dazed or confused, and 70% of the survey respondents reported being knocked out or losing consciousness.

Given the extent and severity of TBI, a key focus of the needs assessment was reviewing the various data sources to identify strengths of the brain injury service delivery system, but also gaps and potential areas of improvement. While key findings were noted throughout the report, they are summarized here for a comprehensive overview.

# **Notable Wins & Successes**

# **Among Individuals**

Results – particularly from the survey for individuals with brain injury – did point to areas where those who have experienced a brain injury are having successes or are at least less likely to run into challenges. For example:

- About one third of the survey respondents reported they "rarely" experienced difficulty in getting access to services for brain injury recovery.
- The vast majority (96%) of respondents said their transportation was somewhat or very reliable. Responses to other survey questions also indicate that transportation is likely not a major barrier for most, though it does seem to impact those in rural areas more than in urban areas.
- Roughly half (49%) reported they have "no challenges" with their living arrangements.
- Two-thirds felt they could advocate for policy, program, and service improvements. There were 33% who noted they would not be able to do so.

Another success is that a majority of family members/caregivers are knowledgeable about brain injury and the needs of those living with brain injury. A fair amount of service providers also noted they feel knowledgeable about brain injury, though as noted throughout the report, it is important to be cognizant of which organizations participated in the survey.

# Within the System

The service delivery system is slightly more challenging to assess given the system varies based on the geographic region. However, results do point to aspects that seem to be working well. Based on survey results:

- About half (52%) of respondents to the service provider survey felt that brain injury supports and services were coordinated moderately or very well. That does vary by geographic area, though, with providers in rural areas being less likely to feel like services are coordinated well.
- More organizations are screening for brain injury. Additionally, many of the agencies that
  are screening end up identifying a relatively high proportion of people with a possible or
  probable brain injury. These likely include individuals who may not have otherwise been
  aware of a potential brain injury, providing an opportunity to get support.

- It's also a success that Nebraska VR has integrated brain injury screening into their application process.
- People seem to feel that support groups are adequately available throughout the state.
   Nearly 20% of family members/caregivers reported there was "no gap" in that service.
   Among individuals with brain injury, roughly 40% were currently using or previously used them, though 46% reported they didn't need a support group.

# **Key Challenges, Barriers & Gaps**

# **Among Individuals with Brain Injury**

As noted, people may experience a range of challenges following a brain injury – with many noting co-occurring symptoms. There were five areas that seemed to rise to the top as key barriers or hurdles people with brain injury experience:

- Cognitive challenges were most common symptoms and challenges that were reported to have occurred after having a brain injury. In fact, among the survey respondents, 85% only reported experiencing cognitive challenges after their brain injury.
- When asked to rate their **general health** on a four-point scale, about half (49%) rated their general health as "fair" or "poor." Based on BRFSS data from 2022, about 15% of Nebraska reported that their general health was "fair" or "poor," indicating that those who have experienced a brain injury may have a lower quality of health overall.
- 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**. Perhaps in part due to that, physical health services and therapies emerged as the top service types used or needed by respondents following their brain injury.
- **Employment** proves to be a key barrier for many after a brain injury. About 34% of ABI Interview participants, 40% of survey participants and 15% of Resource Facilitation clients were employed full-time. Among the survey respondents who reported working full time, more than half (58%) indicated that they had "some" or "a lot" of challenges with employment. There was also anywhere from 20% to 60% who reported not working, with the most common reason being due to their brain injury symptoms.

# **Among Family Members/Caregivers**

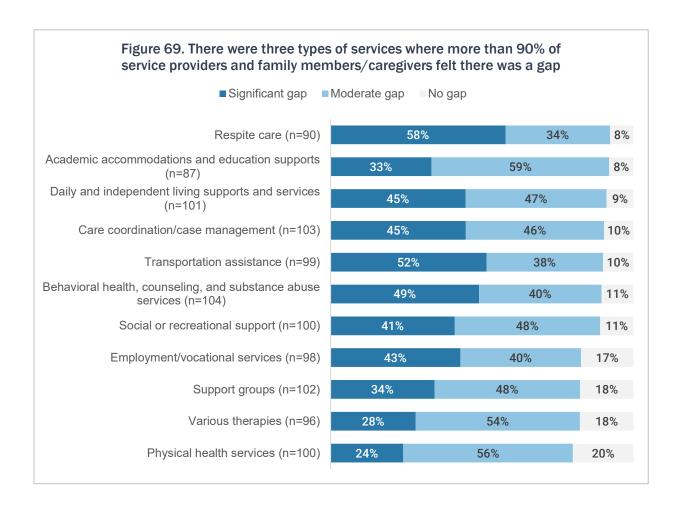
Especially during and following the pandemic, a larger focus has been placed on understanding the experiences of family members/caregivers. In fact, the 2019 and 2020 brain injury needs assessments in Nebraska found that about 97% of family members/caregivers reported experiencing emotional stress due to their role as a caregiver.

- Nearly two-thirds reported moderate **emotional stress** in their role as a family member and/or caregiver, and about one quarter (26%) reported high stress. This could be due to a variety of factors.
  - More than half of respondents (56%) reported that caregiving responsibilities resulted in **personal financial hardships**. There were also 43% that noted they had to reduce the number of hours they work due to caregiving responsibilities.
  - About 16% of respondents noted they have no supports such as family, friends, online support groups, etc. – to lean on for social or emotional support related to caregiving.
- When it comes to challenges of caregiving, the top two were coordinating appointments
  or care for the individual with a brain injury and attending to their own care needs.
  However, the area that had the largest proportion of respondents noting there was a
  major challenge was related to finding a paid caregiver. There were 40% who
  reported it as a major challenge. This is perhaps not surprising, given that half the family
  members/caregivers noted that respite care was a significant gap.
- When asked to rate their **general health** on a four-point scale, about one-third (32%) rated their general health as "fair" or "poor." As noted earlier, 50% of the respondents to

the individuals with brain injury survey rated it that way, and in 2022, about 15% of Nebraska reported that their general health was "fair" or "poor."

### Within the System

- A continual trend seen through the results of the brain injury needs assessment is the desire for increased education and awareness around brain injury. Although employers and schools were noted as key audiences to prioritize outreach to, the larger need pertains to service providers and the general public.
  - About 41% of survey respondents felt like **service providers** had "not much" understanding of brain injury. Only 16% reported that in general, their service providers understood brain injury "quite a bit." Although not statistically significant, among those who reported that service providers had "not much" understanding of brain injury, more than half were from urban-small or rural counties.
  - Public awareness remains a gap, particularly for reducing stigma and informing people about the signs, symptoms, and long-term impacts of brain injury.
- Service coordination, referrals, and system navigation remain a challenge. Current and previous needs assessment data demonstrate that all individuals (those with brain injury, family members/caregivers, and service providers) find it confusing to navigate available services. This is made even more challenging when trying to understand eligibility criteria and Medicaid waivers. Although it's slowly improving, systems for referring individuals post-injury isn't as streamlined as it could be to ensure people are getting connected to appropriate resources and support.
  - Nearly two-thirds (62%) of the 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 a third of individuals with brain injury survey respondents reported they "often" experienced difficulty in getting access to services for brain injury recovery.
- Some of the challenges related to service navigation could also be related to limited services and/or gaps in services. When aggregating the results from the family member/caregiver survey and the service provider survey, more than 90% reported there was a moderate to significant gap in respite care, academic accommodations and educational supports, and daily and independent living supports and services (Figure 69). This aligns with many of the challenges and barriers noted among the individuals with brain injury. Results from that survey also indicate that nearly half the respondents have to travel 30 minutes or more to get services for their brain injury recovery.



### **Recommendations**

The recommendations outlined are meant to help minimize the barriers and challenges that were reported through the results. Opportunities can be explored through the Brain Injury Advisory Council and key partners, as the ability to implement recommendations may be dependent on capacity and resources. Most of the recommendations pertain to brain injury services or awareness. Some are based on feedback obtained through the surveys conducted as part of the needs assessment.

### **Services**

#### **Individuals with Brain Injury**

- 1. Given the challenges with accessing and coordinating services, some respondents suggested having a more centralized way to obtain information about services for **brain injury**. Creating some type of hub or "no wrong door" model can help individuals and families more effectively navigate services. This could be an online resource portal, a brain injury hotline, or others. The BIAC could explore how other states address this type of model, not only in the realm of brain injury, but potentially other populations or considerations as well.
- 2. Improve public outreach. In addition to being a mechanism to inform people about services and support available, having a multi-lingual and culturally competent awareness campaign that targets more underserved populations or high-risk groups (youth and elderly adults may be one, based on the TBI Registry data) may be beneficial.

- 1. Increase awareness about existing supports and services, particularly for the Medicaid Waiver options and employment services.
- 3. Address issues related to access and availability of services and support, particularly for those living in rural areas. This is an area where there may be capacity and resource limitations. If possible, finding ways to increase investments into rural health services could enhance access to support. There may also be opportunities to invest or promote telehealth infrastructure to deliver services in the more rural and frontier counties.

#### Family Members/Caregivers

- 1. Explore mechanisms to offer direct support for family members/caregivers, including educational events, financial support, assistance with care coordination, more respite care options, and stress management. Respite care in particular came across as a substantial need among family members/caregivers and was also noted as a gap among service providers.
- Increase availability of support resources for families and caregivers. About 16% reported they do not currently have supports available related to the social and emotional needs of caregiving. About 70% rely on family, which may increase burden on family members. This could be through support groups specifically for caregivers, social opportunities, online networks, etc.

#### Other

- 1. **Explore ways to address fall and motor vehicle accident prevention.** These tend to be the top two causes of TBI in Nebraska. Some survey respondents indicated it would be important to focus on prevention, as it does not seem to be something that's addressed in a coordinated way. This may be particularly important following the repeal of the motorcycle helmet law in 2024.<sup>24</sup>
- 2. **Strengthen data systems and outreach following TBI diagnosis.** Although the TBI Registry mailing provides a much-needed opportunity to ensure people are aware of and can get connected to services, many reach out to organizations because they feel they have received the letter in error.
  - a. Collaborate with key hospitals or clinics to ensure education is happening within hospitals/clinics regarding the brain injury diagnosis. That may also create an opportunity to more immediately connect people to services related to brain injury understanding or recovery.
  - b. Continue monitoring impact and feedback on the TBI Registry mailing content to ensure it is user-friendly. As noted, initial modifications were made in 2025 to streamline getting resources and information to those who were added to the TBI Registry. Evaluating those efforts can ensure an effective approach is being used.

### **Awareness**

#### **General Public**

 Promote greater awareness and education about brain injury through a media and/or public awareness campaign. The focus should be on reducing stigma and improving understanding.

2. Incorporate brain injury education into school curricula and workplace training. Some individuals with a brain injury indicated they are unable to work due to their symptoms. However, even those working full time have some or quite a bit of challenges with employment. Part of this may pertain to the lack of awareness, accommodations,

<sup>&</sup>lt;sup>24</sup> Motocycle helmet requirements updated. (March 2024). <a href="https://update.legislature.ne.gov/?p=36185">https://update.legislature.ne.gov/?p=36185</a>

and empathy from employers.

#### **Services Providers**

- 1. Create a more coordinated training approach to ensure providers are being adequately educated on brain injury. This includes healthcare professionals, caseworkers, primary care providers, and other service providers. Training continues to be a key priority identified through needs assessment, and while there are increased training opportunities, there may be value in having a more coordinated push to ensure those across the state can participate, attend, or receive education in some manner related to brain injury.
  - 1. Training could focus on brain injury screening, treatment, and behavioral health impacts. This would also align with the training topic that service providers expressed the most interest in attending – brain injury and behavioral health, and life after brain injury. The latter was also noted as a training need among family members/caregivers.

## **Appendix A: Survey Promotional Efforts**

**Promotional Flyer** 

# Nebraska's 2024 **Brain Injury Needs Assessment**



Take the survey(s) that apply to you and help Nebraska VR and the Brain Injury Advisory Council improve brain injury services and supports in our state. Survey results will be collected into early May 2024.

#### Individuals with Brain **Injury Survey**

This is for people in Nebraska who have experienced a brain injury. Although people can assist or fill out the survey on behalf of someone with a brain injury, the questions should be answered from the point of view of the person with the brain injury.

### Family Members & **Unpaid Caregivers** Survey

This is for family members and unpaid caregivers and support persons of individuals living with a brain injury in Nebraska. This does not include personal attendants or other paid caregivers.

### Service Provider Survey

This is 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.



For more information and to complete a survey, use the QR code or visit rb.gy/88pp0j







### **Outreach**

#### **Provider + Survey Promotion**

Audience: This email template is for organizations that are encouraged to complete the service provider survey AND help promote the other two surveys. When sending the email, please be sure to attach the PDF of the flyer and the dissemination email template.

Email Subject Line: Surveys to help improve services for brain injury in Nebraska

#### Greetings!

Nebraska VR (Vocational Rehabilitation) and the Nebraska Brain Injury Advisory Council (BIAC) are conducting a statewide brain injury needs assessment. As part of the project, three surveys are available here: rb.qv/88pp0i

We are reaching out to encourage you to:

- 1. Complete the service provider survey. It can also be shared with other staff members or organizations who may want to provide feedback.
- 2. Help promote the surveys for the individuals with brain injury and family members/caregivers, using some of the suggestions below.

The feedback collected from the surveys will help identify service gaps and barriers as well as resource and training needs. It will also help the Nebraska VR and BIAC better understand the successes and challenges of those navigating life after a brain injury.

A flyer is attached to help you share information about the surveys. It contains a link and QR code to the survey website.

#### Ways to Share

- Send the flyer and/or information about the surveys through listservs as applicable or appropriate.
  - A sample email template is attached.
- Post the flyer in waiting rooms or other public places.
- Promote or have the survey available at events or places where people may be gathering, such as support groups, workshops, events, etc.
  - Paper copies of the survey can be requested as needed.
- Share the surveys on social media.
  - o Nebraska VR will have a post on Facebook through their page if your organizations would like to share it with your followers.

We appreciate your support and assistance with sharing the surveys! If you have any questions or would like more information, please contact Liz Gebhart-Morgan with Partners for Insightful Evaluation at liz@pievaluation.com.

With appreciation,

[Insert sender name/information]

# **Appendix B: 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. The table below summarizes the demographics of the respondents.

Are you	As an individual who has experienced a brain injury	85%
completing this survey: (n=82)	On behalf of the individual with brain injury	15%
	Male	29%
Gender (n=72)	Female	69%
, ,	Other/prefer not to say	1%
	American Indian or Alaska Native	0%
	Asian or Pacific Islander	3%
	Black or African American	3%
Race/ethnicity	Hispanic or Latino	1%
(n=72)	Native Hawaiian or other Pacific Islander	0%
	White	88%
	Prefer not to say	4%
	Other	4%
	18 and under	0%
	19 to 24	6%
Age group (n=72)	25 to 34	14%
	35 to 44	19%
	45 to 54	18%
	55 to 64	25%
	65 to 74	10%
	75 to 84	6%
	85 and older	3%
	English	96%
Primary	Spanish	0%
Language (n=71)	Bi-lingual/multi-lingual	4%
	Other	0%
Military Service	Yes	6%
(n=72)	No	94%
	Less than a high school diploma	1%
	High school diploma or equivalent	11%
Educational	Trade/technical/vocational training	11%
Attainment	Some college, no degree	22%
(n=72)	Associate's degree	10%
-	Bachelor's degree	21%
	Graduate or professional degree	24%
·	·	

# **Family Member/Caregiver Survey**

There were 50 people who answered the first few questions of the family member and unpaid caregiver survey. The table below summarizes the demographics of the respondents.

	Male	15%
Gender (n=39)	Female	85%
	Other/prefer not to say	0%
	American Indian or Alaska Native	0%
	Asian or Pacific Islander	0%
	Black or African American	3%
Race/ethnicity	Hispanic or Latino	5%
(n=39)	Native Hawaiian or other Pacific Islander	0%
	White	92%
	Prefer not to say	0%
	Other	0%
	18 and under	3%
	19 to 24	0%
	25 to 34	10%
	35 to 44	13%
Age group (n=39)	45 to 54	18%
	55 to 64	38%
	65 to 74	18%
	75 to 84	0%
	85 and older	0%
	English	95%
Primary	Spanish	2.5%
Language (n=39)	Bi-lingual/multi-lingual	2.5%
	Other	0%
	Less than a high school diploma	3%
	High school diploma or equivalent	8%
Educational	Trade/technical/vocational training	8%
Attainment	Some college, no degree	13%
(n=39)	Associate's degree	10%
	Bachelor's degree	23%
	Graduate or professional degree	36%
	Spouse/Partner	32%
	Child (16 or older)	20%
Person with	Sibling	14%
Brain Injury is	Child (under 16)	10%
(n=50)	Parent	10%
	Friend	8%
	Other	6%
		-

Living	In the same residence	65%
Arrangement	Less than 1 hour away	27%
(n=49)	More than 1 hour away	8%
	Unpaid caregiver	62%
	Legal guardian	24%
Caregiving Roles	None – I do not provide formal care	20%
Served (n=47)	Active Durable Power of Attorney	20%
	Payee or conservator	20%
	Other	6%
	Less than 1 year	3%
How Long	1 to 4 years	21%
Serving as Caregiver (n=38)	4 to 7 years	13%
Caregiver (II-30)	More than 7 years	63%

### **Service Provider Survey**

Below is the list of agencies where those individuals were employed.

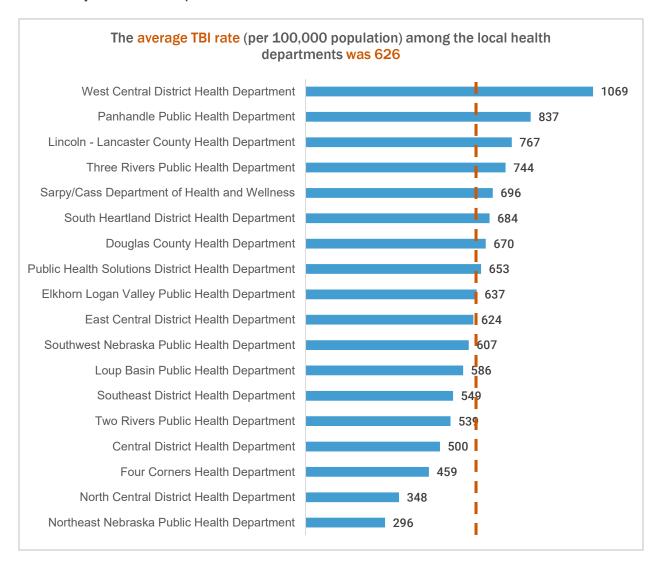
- 1. Aging office
- 2. Aging Office of Western Nebraska
- 3. Angel Guardians, Inc.
- 4. Assistive Technology Partnership
- 5. Avera St. Anthony's Hospital
- 6. Brain Injury Alliance of Nebraska (now the Brain Injury Association of Nebraska)
- 7. Bryan Medical Center
- 8. CAPWN
- 9. CEDARS
- 10. CHI Health
- 11. CHI Health Plainview
- 12. Children's Nebraska
- 13. Columbus Community Hospital
- 14. Community Action
- 15. Community Action Head Start
- 16. Community Action Partnership of Mid-Nebraska
- 17. Cottonwood Villa
- 18. CrossRoads Resources, LLC
- 19. Disability Rights Nebraska
- 20. Easterseals Nebraska
- 21. enCourage Advocacy Center
- 22. Envisions
- 23. Families and Connections Collaborative Services
- 24. Goodwill Industries
- 25. Goodwill Industries of Greater Nebraska
- 26. Heartland Family Service
- 27. HOJ DD Services LLC
- 28. Infinity Dreams LLC
- 29. Jonesbrook Estates, LLC. Assisted Living
- 30. League of Human Dignity
- 31. Liebe's Home of Hope
- 32. Live Well Home Care Nebraska

- 33. Lutheran Family Services
- 34. Madonna Rehabilitation Hospitals
- 35. Madonna TherapyPlus
- 36. Moore Counseling, LLC
- 37. Mosaic
- 38. Mother of Mercy LLC
- 39. Nebraska Commission for the Blind and Visually Impaired
- 40. Nebraska Medicaid PSE
- 41. Nebraska VR
- 42. Nebraska Youth Leadership Council
- 43. North Platte Opportunity Center
- 44. North Platte Public Library
- 45. NorthStar Services (Bloomfield Nebraska)
- 46. Ogallala Counseling Inc, P.C.
- 47. Pender Community Hospital
- 48. Pride Ridge Home Care
- 49. Quality Living Inc
- 50. Region 6 Behavioral Healthcare-Professional Partner Program
- 51. Region I Office of Human Development
- 52. Region V Systems Family & Youth Investment
- 53. Regional West Medical Center
- 54. Rejoice Developmental Disability LLC
- 55. Sarpy/Cass Health Department
- 56. Unnamed
- 57. West Holt Memorial Hospital
- 58. Willow Rising

# **Appendix C: 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	Burt, Cuming, Madison, Stanton
Dept.	
Four Corners Health Dept.	Bulter, Polk, Seward, York
Lincoln - Lancaster County Health	Lancaster
Dept.	
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

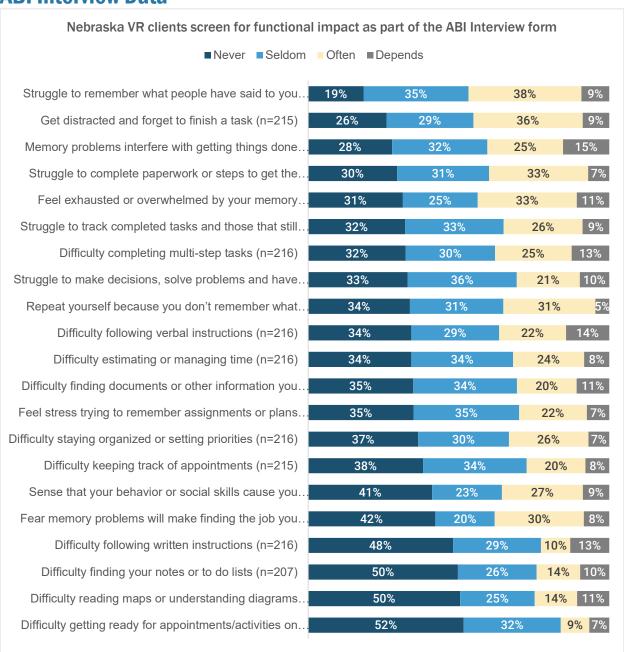
Northeast Nebraska Public Health Dept.	Cedar, Dixon, Thurston, Wayne
Panhandle Public Health Dept.	Banner, Box Butte, Cheyenne, Dawes,
	Deuel, Garden, Grant, Kimball, Morrill,
	Scotts Bluff, Sioux, Sheridan
Public Health Solutions District	Fillmore, Gage, Jefferson, Saline, Thayer
Health Dept.	
Sarpy/Cass Department of Health	Cass, Sarpy
and Wellness	
South Heartland District Health Dept.	Adams, Clay, Nuckolls, Webster
Southeast District Health Dept.	Johnson, Nemaha, Otoe, Pawnee,
	Richardson
Southwest Nebraska Public Health	Chase, Dundy, Frontier, Furnas, Hayes,
Dept.	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 LHDs. 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	

### **ABI Interview Data**



# **Appendix D: Secondary Data Response List**

# Nebraska VR – ABI Interview Challenges

In the time since the injury, how often	Never	Seldom	Often	Depends
Do your memory problems interfere with getting				
things done on time?				
Do you get distracted and forget to finish a task?				
Do you struggle to remember what people have				
said to you?				
Do you repeat yourself because you don't				
remember what you told someone?				
Do you have difficulty staying organized or setting				
priorities?				
Do you have difficulty finding your notes or To Do				
Lists?				
Do you have difficulty estimating or managing				
time?				
Do you have difficulty keeping track of				
appointments?				
Do you feel exhausted or overwhelmed by your				
memory problems?				
Do you have difficulty finding documents or other				
information you need?				
Do you have difficulty getting ready for				
appointments or activities on time?				
Do you struggle to track completed tasks and				
those that still need to be done?				
Do you have difficulty completing multi-step tasks?				
Do you have difficulty following verbal (spoken)				
instructions?				
Do you have difficulty following written				
instructions?				
Do you have difficulty reading maps or				
understanding diagrams or charts?				
Do you feel stress trying to remember your				
assignments or plans for the day?				
Do you sense that your behavior or social skills				
cause you problems?				
Do you struggle to complete paperwork or steps to				
get the services you need?				
Do you struggle to make decisions, solve				
problems and have good judgment?				
Do you fear memory problems will make finding				
the job you want difficult?				

### **BIA 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.

Need Category	What belongs / description of the category
Addiction Support	Assistance finding substance use or chemical dependency treatment providers and related resources [Certified Alcohol and Drug Counselor (CADC), Certified Advanced Alcohol and Drug Counselor (CAADC); Alcoholics Anonymous (AA)]
Behavioral Health	Referrals to/support from behavioral health providers; needing access to a professional (licensed mental health practitioners, counselors, psychologists) to provide counseling services
Brain Injury 101	Goals related to client wanting to better understand their brain injury and its impact on their life; may also be training for caregivers to understand handling specific symptoms or emergencies; information on how to understand or begin to manage a range of brain injury symptoms
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; cognitive exercises; memory aids

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; could also include financial planning, such as managing long-term costs for care and rehabilitation; gas vouchers
Financial (Budgeting)	Financial literacy, budgeting
Food / Nutrition	SNAP benefits, food banks/pantries, info about healthy eating
Health Insurance/	Medicaid, Medicare, Private Insurance, Medicaid Home and
Long Term Care	Community Based Services (HCBS); assistance with claims for medical expenses and rehabilitation services
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 /	Responsibilities related to the upkeep or modification of the home
Modification /	itself and its external surroundings (i.e. lawn, landscaping,
Maintenance)	patios/decks, sidewalks, driveways, garage); modifications may be adjustments for safety and accessibility
Housing (Financial	Rent assistance, section 8 application, subsidized housing
Assistance)	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; could include supporting or advocating with client on disability claims or injury related lawsuits
Medication	Any needs related to medication (prescription or over-the-counter)
Mental Wellness / Self-Help	Art, coping skills, anxiety, depression, exercise, music therapy; more personal things that people can do to address their emotional health independently
Mental/Emotional	Professionals that explore how brain conditions affect behaviors and
Health (Neuropsychologist)	cognitive skills (mood, behavior and thinking skills); provide
(Neuropsychologist) Mental/Emotional	neuropsychological testing  Referral to psychiatry or partnering with medical professionals (nurse
Health (Psychiatry/	practitioners, physician's assistants, primary care providers) to
Medication	prescribe psychiatric medications to help patients with mental health
Management)	issues, which could include antidepressants, antipsychotics, mood stabilizers, stimulants

Other	Any goal that does not fit well into any of the other categories
Personal Support	Connecting client to churches/religious organizations to explore faith
System	and the faith community
(Faith/Religion)	
Personal Support	Helping client find ways to socialize, finding opportunities to meet
System (Family /	people, helping client to re-connect with family; access to social
Friends)	networks, such as caregiver supports or family counseling; re-
	integration support to help with re-establishing roles in family, work,
	or community life
Personal Support	Any pet or service animal related need
System (Service	
Animal / Pet)	
Personal Support	Referrals to Support Groups; facilitating access to peer groups
System (Support	
Groups)	Licensed health care preferation that uses manual therapy such as
Physical Health (Chiropractor)	Licensed health care profession that uses manual therapy, such as spinal manipulation, to treat conditions such as back pain, neck pain,
(Chiropractor)	headaches, and hand or foot problems
Physical Health	Help with Dental needs
(Dental)	Troip with Dontal ficous
Physical Health	Massage therapists manipulate clients' soft tissues and joints to treat
(Massage)	injuries and promote general wellness
Physical Health	Medical doctor who diagnoses, treats and manages disorders of the
(Neurologist)	brain and nervous system (brain, spinal cord and nerves)
Physical Health	Finding some types of durable medical equipment (not furniture -
(Other)	hospital bed, for example); mobility assistance, such as wheelchairs,
	walkers, or other aids; information on clinical trials
Physical Health	Medical doctor who specializes in physical medicine and
(Physiatrist)	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
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Physical Health	A physician who provides both the first contact for a person with an
(Primary Care)	undiagnosed health concern as well as continuing care of varied
	medical conditions, not limited by cause, organ system, or diagnosis
Physical Health	Help with Vision Needs - such as glasses, eye exams, large print
(Vision)	materials
Rec/Leisure	Referrals to recreation or activity based programming, assistance
	with finding rec or leisure related resources or equipment, identifying
	day program for socialization purposes
Rehab Therapy	Referrals to neuropsychologist, Madonna's mild TBI clinic, long-
(Multi)	COVID
Rehab Therapy (OT)	Occupational therapy (OT) intervention uses everyday life activities
	(occupations) to promote health, well-being, and the ability to
	participate in the important activities in life
Rehab Therapy (PT)	Physical therapy (PT) 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 individuals
	move better or strengthen weakened muscles.

Rehab Therapy (SLP)	Speech-Language Pathologists (SLPs) help with speech, language, social communication, cognitive-communication, and swallowing disorders
Safety	Self-defense, mitigating vulnerabilities from scams
Sleep	Strategies or resources to help clients better manage sleep
Supervision	Services that support individuals that need some level of supervision
Technology (Acquisition)	Assistance finding assistive devices (for mobility or communication) or other technologies; may include monitoring systems that include wearable health monitors or in home safety systems
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