2019 Living with Brain Injury Survey Results

Nebraska needs assessment surveys of individuals with a brain injury, their family members, and service providers.

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2019 Living with Brain Injury Survey Results:
A Nebraska Needs Assessment

March 2019

Nebraska VR
Program for Acquired Brain Injury

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The Living with Brain Injury Survey is comprised of three separate surveys for individuals with a brain injury, their family members/caregivers, and service providers serving individuals with brain injury. The survey was conducted primarily online with a paper option available by request during the months of January and February of 2019.

A total of 114 individuals with a brain injury, 68 family members/caregivers, and 46 service providers participated in the 2019 Living with Brain Injury Survey.

Selected Results for Individuals with a Brain Injury

The survey for individuals with a brain injury asked questions about 30 unique services. These 30 services are ranked from highest to lowest in terms of the percentage of respondents who indicated that they are currently in need of the service in Table 1 below. “Currently in need” is defined as those who indicate that they are in need of the service; have requested, but not received the service; or are on a wait list for the service. In addition, Table 1 also indicates the percentage who report experiencing at least one barrier to obtaining the service among those who have ever used the service or are in need of the service.

Four of the top five services indicated as being currently in need fall under the category of “care coordination”. These top 5 services also tend to have relatively high rates of barriers as evidenced by the fact that at least 70% or more who are in need of or have ever accessed the service report at least one barrier. The service indicated as being most in need among individuals with a brain injury was “general information/referral for any type of service”, indicated as a need by 29.0% of respondents. More than four-in-five (81.7%) of respondents who are in need of or have ever accessed general information/referral services reported experiencing at least one barrier to obtaining the service (Table 1, next page).

> "Don't ever quit trying to get better."
>
> - Individual with a brain injury

> "We are brain damaged but want to be treated as human beings just like everyone."
>
> - Individual with a brain injury

Table 1	Services indicated as being “currently in need” and their barrier rates	
	% currently needing this service*	**% reporting at least one barrier to this service°**
1. General information/referral for any type of service (n=107 and 60)	29.0%	81.7%
2. Cognitive and/or behavioral supports (improving everyday skills and/or reducing unwanted behaviors or moods) (n=85 and 39)	25.9%	71.8%
3. Information, referral, education and/or resources about brain injury (n=107 and 66)	23.4%	74.2%
4. Service and funding application assistance (insurance, Social Security, etc.) (n=106 and 48)	22.6%	72.9%
5. Case management/service coordination (n=104 and 48)	22.1%	70.8%
6. Brain Injury support group (n=72 and 57)	18.1%	59.6%
7. Chore services (n=86 and 21)	16.3%	66.7%
8. Legal services (n=105 and 34)	16.2%	64.7%
9. Transportation (n=82 and 20)	15.9%	65.0%
10. Assistive technology, specialized equipment and/or home modifications for accessibility (n=86 and 25)	15.1%	84.0%
11. Pain management (n=77 and 40)	14.3%	57.5%
12. Financial/money management (such as budgeting and maintaining a check book) (n=86 and 13)	14.0%	92.3%
13. Primary medical care (physician, hospitalization, rehabilitation) (n=75 and 57)	13.3%	71.9%
14. Mental health counseling (individual or family) (n=73 and 48)	12.3%	62.5%
15. Affordable housing (n=84 and 20)	11.9%	80.0%
16. Job finding/placement services (n=68 and 18)	10.3%	77.8%
17. Post-secondary education supports (community/vocational college, college, university) (n=68 and 22)	10.3%	63.6%
18. Independence skills training (n=83 and 22)	9.6%	81.8%

Table 1 continued

	% currently needing this service*	% reporting at least one barrier to this service°
19. Ancillary medical care (includes nursing, OT, PT, speech/language therapies, nutrition/dietary services, etc.) (n=75 and 40)	6.7%	74.0%
20. Personal care/attendant services (n=84 and 12)	6.0%	66.7%
21. Temporary staffing and employment agency services (n= 67 and 8)	6.0%	-
22. Internet-based employment services (n=67 and 11)	4.5%	72.7%
23. Unemployment services (n=68 and 14)	4.4%	71.4%
24. Respite care (n=83 and 7)	3.6%	-
25. Day or residential treatment for serious mental illness (n=72 and 10)	2.8%	90.0%
26. Substance use evaluation/treatment (n=71 and 5)	2.8%	-
27. Early intervention (children, 0-2) (n= 66 and 1)	1.5%	-
28. Parenting or child care supports (n=71 and 5)	1.4%	-
29. Educational adjustments under a Section 504 Plan (children and youth, 5-21) (n=65 and 3)	0.0%	-
30. Special Education services under an Individualized Education Program (IEP) (children and youth, 3-21) (n=64 and 3)	0.0%	-

Note: Data are masked when the number of respondents is less than 10.

*Percentage indicating that they are in need of the service; have requested, but not received the service, or on a wait list for the service

°The percentage reporting at least one barrier to the service among those who have ever used the service or are in need of the service

"[Have] patience and do not give up. If one [service] doesn't work, try another until you find one you are comfortable with."

- Individual with a brain injury

In my particular case, my mild traumatic brain injury impaired me enough to prevent me from successfully completing my usual tasks and proving to be fully functional, but it was not "severe" enough to receive much support, so I was stuck in the middle of seeming fine to others but being far from fine in reality."

- Individual with a brain injury

The survey for individuals with a brain injury bundles services into six groups with an additional set of questions specific to Nebraska VR services. For each of these six “service bundles” as well as Nebraska VR services, the number one barrier was identified as “providers do not understand brain injury" by those who are currently in need of or have ever accessed services within the service bundle (Table 2).

> The brain injured are grossly misunderstood."
>
> - Individual with a brain injury

Table 2 **Top 5 barriers* by “service bundle”**

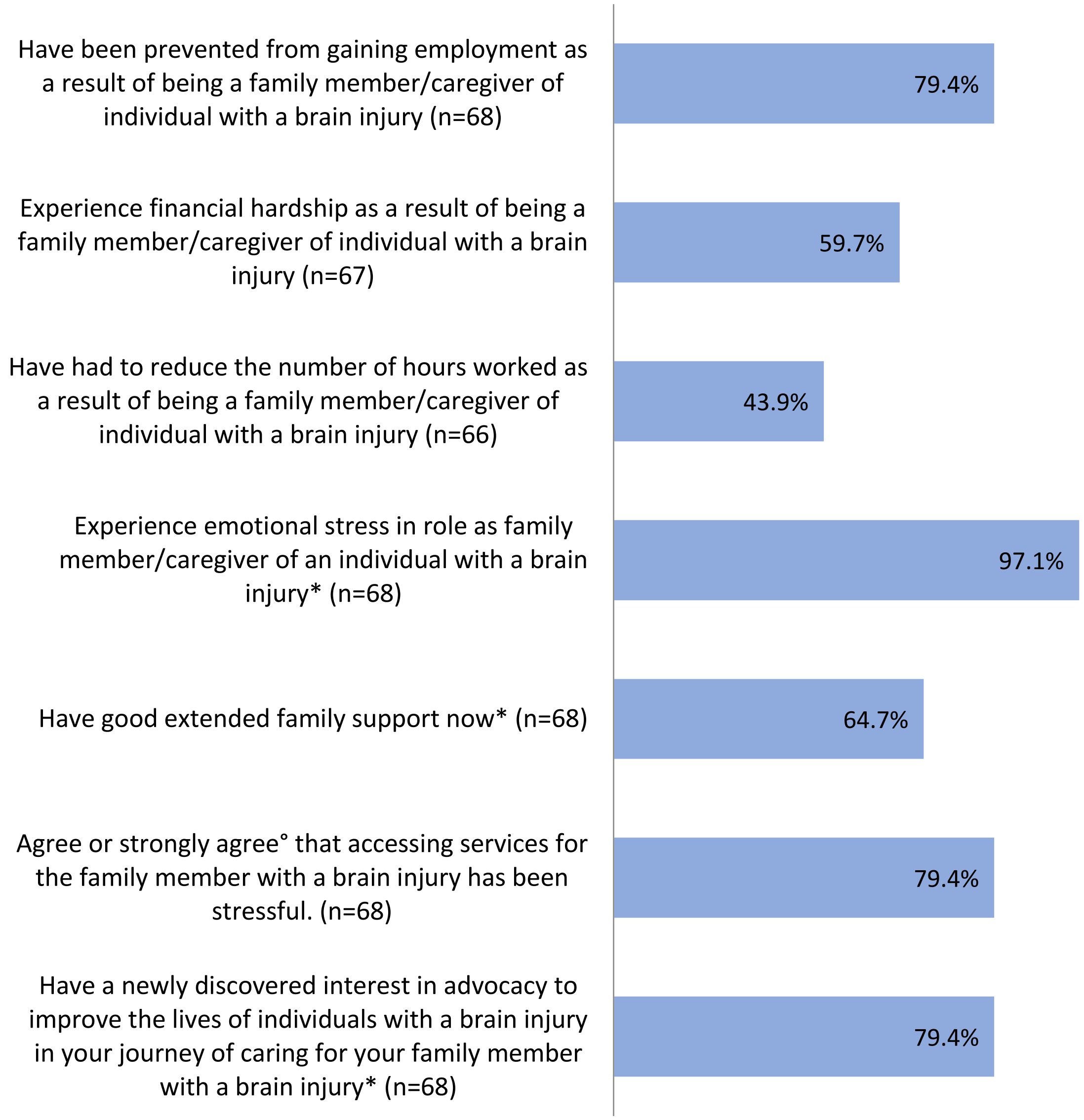
Care Coordination Services (5 unique services)	**Independent Living Services** (9 unique services)	**Physical Health and Well-Being Services** (3 unique services)	**Mental and Emotional Health and Well-Being Living Services** (5 unique services)	**Education Services** (4 unique services)	**Employment Services** (4 unique services)	**Nebraska VR Services**
(n=66)	**(n=39)**	**(n=57)**	**(n=57)**	**(n=22)**	**(n=18)**	**(n=23)**
1. Providers do not understand brain injury (38.4%)	1. Providers do not understand brain injury (22.7%)	1. Providers do not understand brain injury (34.8%)	1. Providers do not understand brain injury (29.7%)	1. Providers do not understand brain injury (36.4%)	1. Providers do not understand brain injury (52.0%)	1. Providers do not understand brain injury (52.0%)
2. Too expensive (20.1%)	2. Too expensive (20.1%)	2. Health insurance does not cover (26.4%)	2. Too hard to get it (14.1%)	2. Providers do not understand my culture, beliefs, or preferences (13.6%)	2. Don’t feel comfortable using it (9.8%)	2. Providers do not understand my culture, beliefs, or preferences (17.4%)
3. Health insurance does not cover (16.0%)	3. Too hard to get it (17.5%)	3. Too expensive (22.2%)	3. Health insurance does not cover (13.7%)	3. Too hard to get it (9.1%)	3. Too hard to get it (9.1%)	3. Too hard to get it (13.0%)
4. Not available near me (15.6%)	4. Not available near me (11.2%)	4. Lack of transportation (12.0%)	4. Lack of transportation (12.1%)	4. Lack of transportation (9.1%)	4. Long waiting list (8.4%)	4. Long waiting list (8.7%)
5. Lack of transportation (14.9%)	5. Lack of transportation (11.4%)	5. Not available near me (9.3%)	5. Too expensive (10.6%)	5. Too expensive (9.1%)	5. Providers do not understand my culture, beliefs, or preferences (7.9%)	5. Don’t feel comfortable using it (8.7%)

*An average of the barriers identified for each of the unique services within each service bundle among those who have ever used or are in need of each unique service. Each unique service had 10 barrier categories plus an option to indicate other barriers. Nebraska VR services were not broken down into unique services.

Selected Results for Family Members of Individuals with a Brain Injury

Family members of individuals with a brain injury were asked a series of questions about the impact of being a family member/caregiver of someone living with a brain injury. A selection of results is presented below in Figure 1.

Figure 1. Selected survey items for family members/caregivers



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*Percentage responding "Yes" or "Somewhat". Other response options include "Very little" and "Not at all".
°Response options: strongly disagree, disagree, neutral, agree, strongly agree

> "It gets tough and sometimes frustrating. It is worth the hard walk with my Father though."
>
> - Family member of an individual with a brain injury

Selected Results for Brain Injury Service Providers

Brain injury service providers were asked a series of questions about the same 30 services that individuals with a brain injury were asked about. These 30 services are again rank ordered by the percentage of individuals with a brain injury who indicated that they are currently in need of the service in Table 3 below. Additionally, the percentage of service providers who report a "moderate" or "significant" gap is also displayed for each service. A relatively high percentage of service providers tended to perceive moderate or significant gaps in most services.

Table 3 **Services indicated as being "currently in need" by individuals with a brain injury and gaps perceived by service providers**

	Individuals with a brain injury indicating that they currently need this service*	Service providers reporting a "moderate" or "significant" gap°
1. General information/referral for any type of service (n=107 and 32)	29.0%	71.9%
2. Cognitive and/or behavioral supports (improving everyday skills and/or reducing unwanted behaviors or moods) (n=85 and 31)	25.9%	87.1%
3. Information, referral, education and/or resources about brain injury (n=107 and 34)	23.4%	76.5%
4. Service and funding application assistance (insurance, Social Security, etc.) (n=106 and 31)	22.6%	90.3%
5. Case management/service coordination (n=104 and 31)	22.1%	80.7%
6. Brain Injury support group (n=72 and 30)	18.1%	76.7%
7. Chore services (n=86 and 26)	16.3%	80.8%
8. Legal services (n=105 and 25)	16.2%	88.0%
9. Transportation (n=82 and 28)	15.9%	85.7%
10. Assistive technology, specialized equipment and/or home modifications for accessibility (n=86 and 30)	15.1%	86.7%
11. Pain management (n=77 and 25)	14.3%	80.0%
12. Financial/money management (such as budgeting and maintaining a check book) (n=86 and 30)	14.0%	83.3%
13. Primary medical care (physician, hospitalization, rehabilitation) (n=75 and 26)	13.3%	73.1%

Table 3 continued

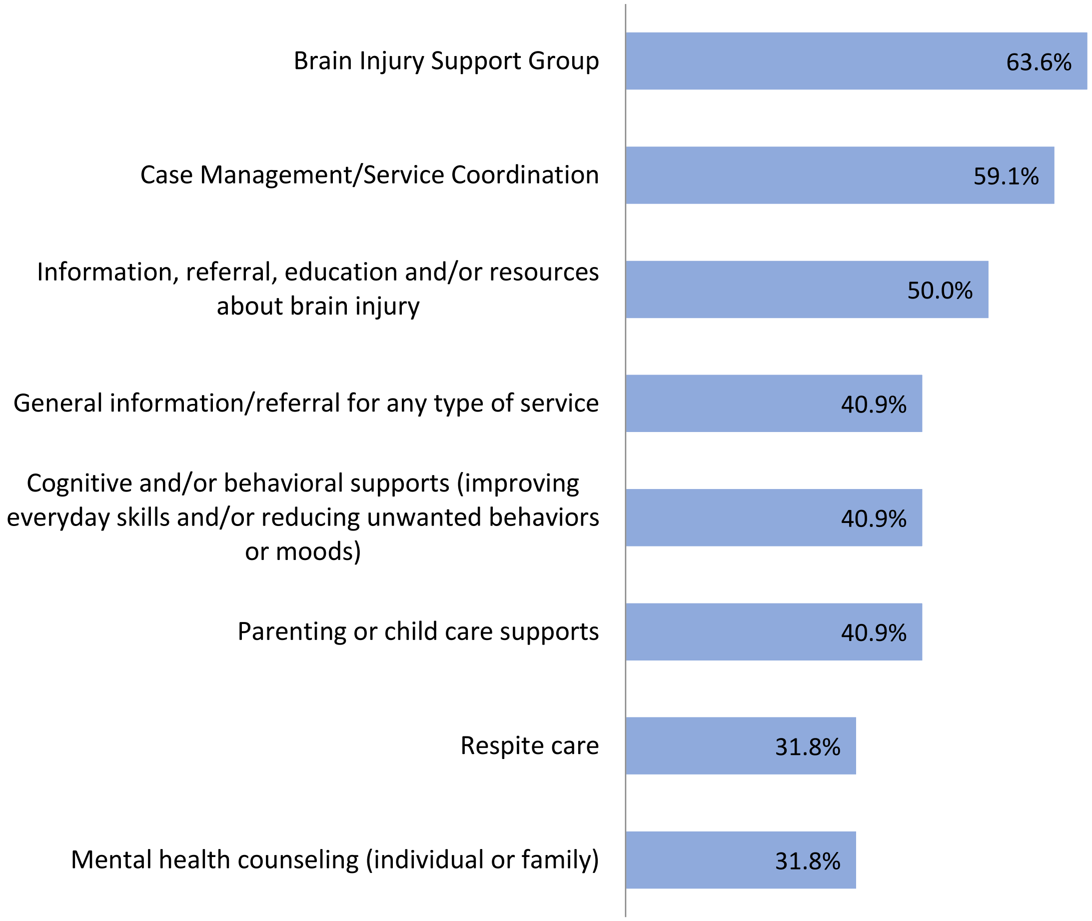
	Individuals with a brain injury indicating that they currently need this service*	Service providers reporting a "moderate" or "significant" gap°
14. Mental health counseling (individual or family) (n=73 and 30)	12.3%	83.3%
15. Affordable housing (n=84 and 29)	11.9%	93.1%
16. Job finding/placement services (n=68 and 31)	10.3%	74.2%
17. Post-secondary education supports (community/vocational college, college, university) (n=68 and 29)	10.3%	62.1%
18. Independence skills training (n=83 and 30)	9.6%	83.3%
19. Ancillary medical care (includes nursing, OT, PT, speech/language therapies, nutrition/dietary services, etc.) (n=75 and 27)	6.7%	66.7%
20. Personal care/attendant services (n=84 and 26)	6.0%	88.5%
21. Temporary staffing and employment agency services (n= 67 and 23)	6.0%	82.6%
22. Internet-based employment services (n=67 and 23)	4.5%	69.6%
23. Unemployment services (n=68 and 23)	4.4%	87.0%
24. Respite care (n=83 and 20)	3.6%	83.3%
25. Day or residential treatment for serious mental illness (n=72 and 28)	2.8%	78.6%
26. Substance use evaluation/treatment (n=71 and 27)	2.8%	77.8%
27. Early intervention (children, 0-2) (n= 66 and 22)	1.5%	45.5%
28. Parenting or child care supports (n=71 and 26)	1.4%	96.2%
29. Educational adjustments under a Section 504 Plan (children and youth, 5-21) (n=65 and 27)	0.0%	48.2%
30. Special Education services under an Individualized Education Program (IEP) (children and youth, 3-21) (n=64 and 28)	0.0%	46.4%

*Percentage indicating that they are in need of the service; have requested, but not received the service, or on a wait list for the service

°Percentage of service providers reporting a moderate or significant gap in services. Response options: NO GAP - all who need this service are able to get it, SLIGHT GAP - most who need this service are able to get it, MODERATE GAP - some who need this service are unable to get it, SIGNIFICANT OR LARGE GAP - many who need this service are unable to get it, UNKNOWN. Those responding "unknown" are not included in the analysis (i.e. counted as missing)

Brain injury service providers were asked if there were any services that their organization would provide if more funding were made available for individuals with a brain injury in Nebraska (such as through a state trust fund or other mechanism). The top services indicated by respondents that their organization would provide in such a circumstance are presented below in Figure 2. Among the top 5 services in Figure 2 there is fairly close alignment with the top services indicated as being most in need by individuals with a brain injury (compare to Table 3 above).

Figure 2. Top services organizations would provide if more funding were made available for individuals with a brain injury in Nebraska (such as through a state trust fund or other mechanism) (n=22) (from a list of 30 services)



> "I have served this population for 26 years and I see some hope, but then that hope is persistently fading due to the economic state of Nebraska, legislation not seeing/understanding the needs of BI on Nebraskans and no one seems to really care about the plight of those trying to recover from BI in the state of Nebraska. We need legislation to recognize and implement incoming money for BI."
>
> - Brain injury service provider

Brain injury service providers were asked to indicate the barriers for each service that their organization provides. An average across the top 10 most provided services reveals that "lack of funding/compensation to provide the service" is the top barrier, with an average of 52.5% of respondents indicating this as a barrier for the service their organization provides (Table 4).

Table 4 **Organizational barriers to providing services (an average across the top 10 most provided services by the respondents' organizations) (n=26)**

No barriers	Not enough staff	Lack of training for staff	Lack of funding/ compensation to provide service	Lack of awareness that your organization offers the service	Knowing appropriate referral sources	Other
23.0%	33.5%	25.5%	52.5%	27.1%	21.2%	0.0%

> "[Brain injury] is mostly unknown to the majority of Nebraskans until it hits home."
>
> \- Brain injury service provider

2019 Living with Brain Injury Survey Results: A Nebraska Needs Assessment

Introduction

The Living with Brain Injury Survey is comprised of three separate surveys for individuals with a brain injury, their family members/caregivers, and service providers serving individuals with brain injury. The three separate surveys that comprise the Living with Brain Injury Survey are needs assessment surveys, designed for the purpose of being able to assess needs and gaps in services for individuals with a brain injury and their family members/caregivers, as well as the overall service system's ability to deliver those services.

The last time a needs assessment was conducted on brain injury in Nebraska was in 2010. This current needs assessment seeks to dive deeper into the specific services that are of highest need for individuals with a brain injury in Nebraska. In order to create survey instruments that accurately capture this type of information, numerous brain injury needs assessments were reviewed, including projects from Missouri, Iowa, and Minnesota, among others.

Methodology

The Living with Brain Injury Survey was conducted primarily online via SurveyMonkey with a paper option available upon request during the months of January and February of 2019. A single survey link housed all three surveys. Depending upon how a respondent identified their self, they were directed to the appropriate survey for them as either an individual with a brain injury, family member/caregiver, or service provider. Respondents who fit more than one of these descriptions were instructed to take multiple surveys from their different perspectives.

The primary administrators of the survey were Nebraska VR and the Nebraska Brain Injury Advisory Council along with local support groups. Numerous other agencies/organizations sent the survey out their respective lists of contacts. As many individuals with a brain injury, family members/caregivers, and service providers were invited to participate in the survey as possible. The following organizations were contacted to help administer the survey to their respective contact lists:

- Brain Injury Alliance of Nebraska
- Disability Rights Nebraska
- Statewide Independent Living Council
- Nebraska Association of Service Providers
- Independence Rising
- League of Human Dignity
- The ARC
- Planning Council on Developmental Disabilities
- Aging and Disability Resource Center
- Quality Living, Inc.
- Goodwill Industries of Greater Nebraska
- Ollie Webb Center – Omaha
- Region III Behavioral Health

A total of 114 individuals with a brain injury, 68 family members/caregivers, and 46 service providers participated in the 2019 Living with Brain Injury Survey.

Survey Results for Individuals with a Brain Injury

A total of 114 individuals with a brain injury participated in the survey. However, responses for certain survey items were much lower than the total number of participants due to questions not being applicable or perhaps simply being skipped. Use caution when interpreting these results.

Respondent Demographics

Demographics of the individuals with a brain injury who responded to the survey are presented below in Tables 5 and 6.

Table 5	**Respondent Demographics**	
	Total number of surveys collected	***114***
Urbanicity* (n=78)	*Large Urban*	59.0%
	Small Urban	28.2%
	Rural	35.9%
Gender (n=78)	*Male*	37.2%
	Female	59.0%
	Other°	3.8%
Race/ethnicity (n=78)	*White/Caucasian*	92.3%
	Non-White/Caucasian	7.7%
Primary language (n=78)	*English*	97.4%
	All other languages (includes bi-lingual and multi-lingual)	2.6%
Age group (n=78)	*24 and under*	2.6%
	25-44	23.1%
	45-64	59.0%
	65 and over	15.4%
Veteran status (n=76)	*Veteran of U.S. Armed Forces*	5.3%
	Non-veteran	94.7%

*See Appendix D for urbanicity definitions.

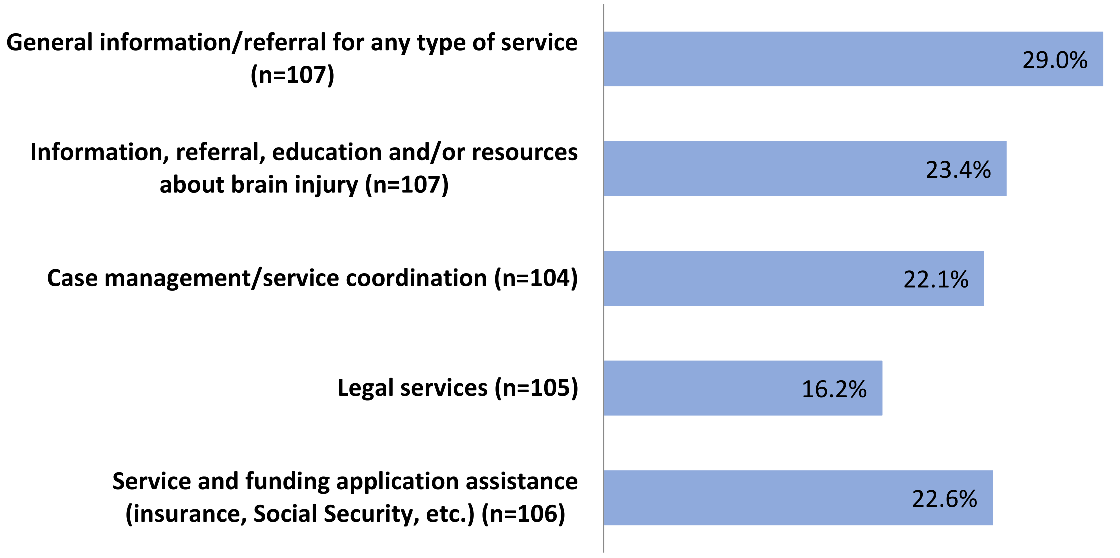
°"Other" gender includes non-binary/third gender, transgender, prefer to self-describe, and prefer not to say

Table 6	**Housing and Employment**	
Housing situation (n=77)	*In a house or apartment independently*	59.7%
	In a house or apartment with family and/or a caregiver	27.3%
	In Licensed Assisted Living	1.3%
	In a group home	2.6%
	In a nursing home	3.9%
	In a rehabilitation facility	1.3%
	Other	3.9%
Employment status (n=78)	*Employed full-time (30 or more hours per week)*	24.4%
	Employed part-time (less than 30 hours per week)	9.0%
	Unemployed, but currently in job training	0.0%
	Unemployed, but desire to work	11.5%
	Unemployed and unable to work due to disability	33.3%
	Student	1.3%
	Homemaker	0.0%
	Retired	10.3%
	Volunteer	3.9%
	Other	6.4%

Care Coordination Services

Care coordination services were some of the most commonly indicated services as being “currently in need”. Figures 3 through 5 present responses from individuals with a brain injury in terms of their current need for care coordination services, barriers to these services, and how well these services have met the needs of those who have utilized them.

Figure 3. Percentage <u>currently in need</u>* of Care Coordination Services



*Percentage indicating that they are in need of the service; have requested, but not received the service, or on a wait list for the service

> “Agencies and people find it hard to believe that I am disabled and have a TBI because I look in their eyes "Normal".
>
> - Individual with a brain injury

Note: see Appendix A for specific barriers for each of the services listed in the figure below.

Figure 4. Percentage reporting at least one barrier to Care Coordination Service(s) [among those who have ever used the service or are in need of the service]

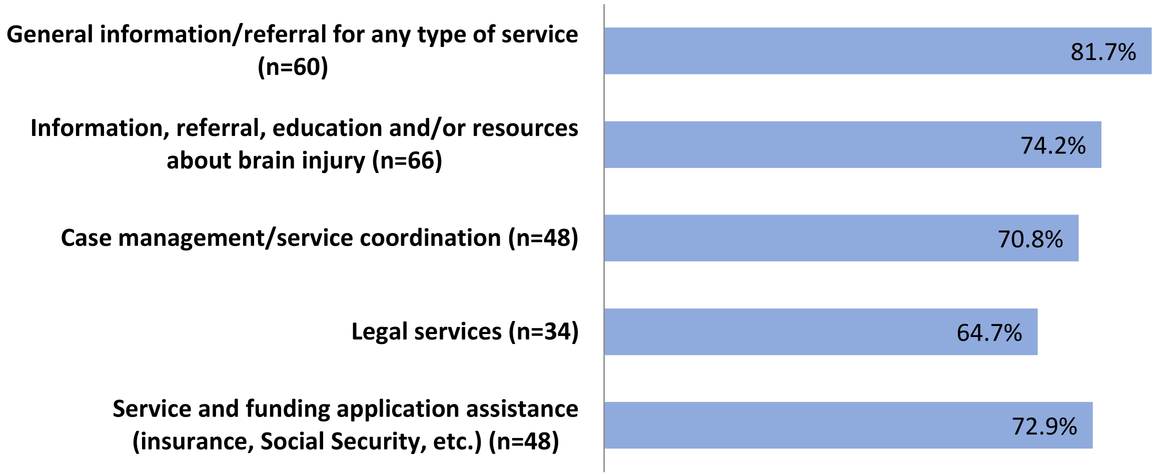
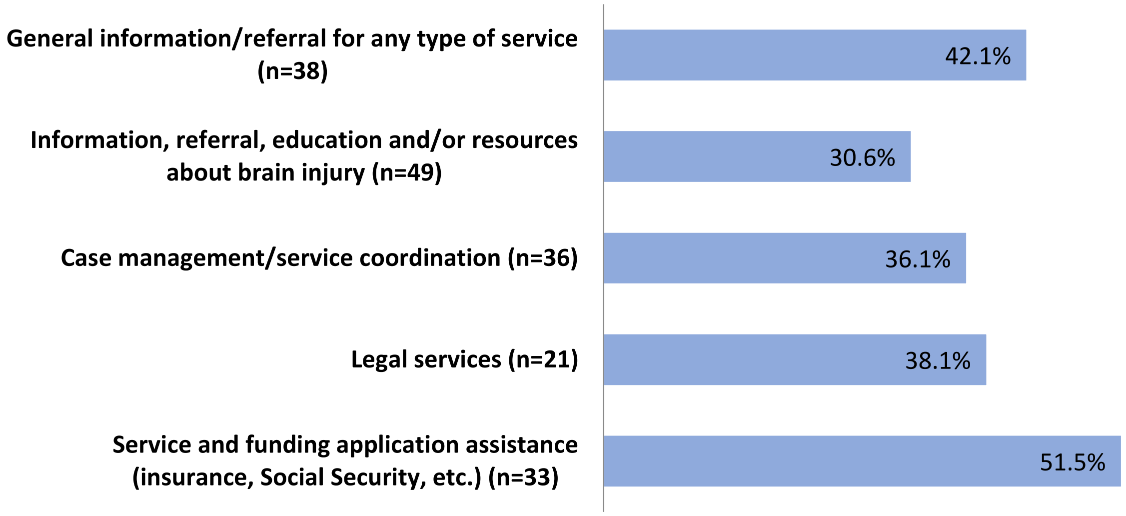


Figure 5. Percentage reporting that the Care Coordination Service(s) met all or most of their needs* [among those who have ever used the service]



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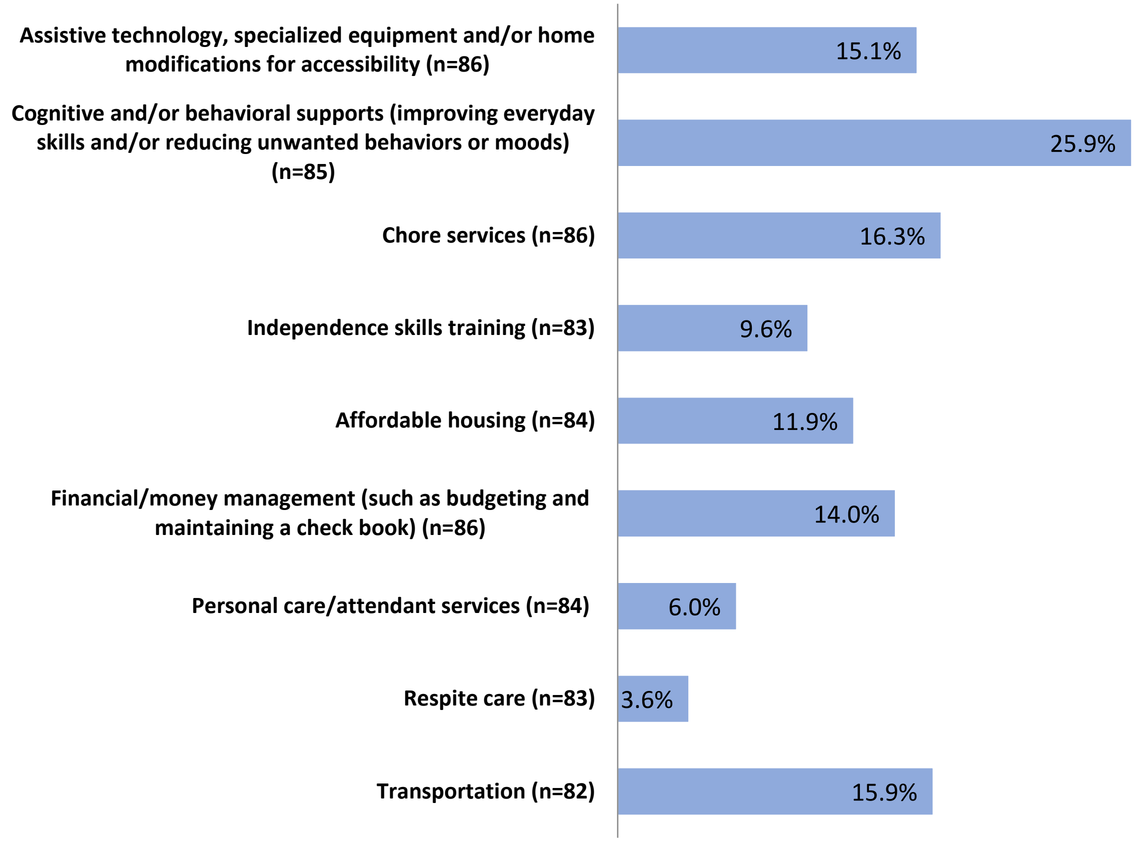
*Response options: This service met all of my needs, This service met most of my needs, This service met some of my needs, This service met none of my needs, I am currently using this service and it's too early to tell if it is meeting my needs. Those selecting this final option are not included in the analysis (i.e., counted as missing).

Independent Living Services

Figures 6 through 8 present responses from individuals with a brain injury in terms of their current need for independent living services, barriers to these services, and how well these services have met the needs of those who have utilized them.

Figure 6. Percentage currently in need* of Independent Living Services



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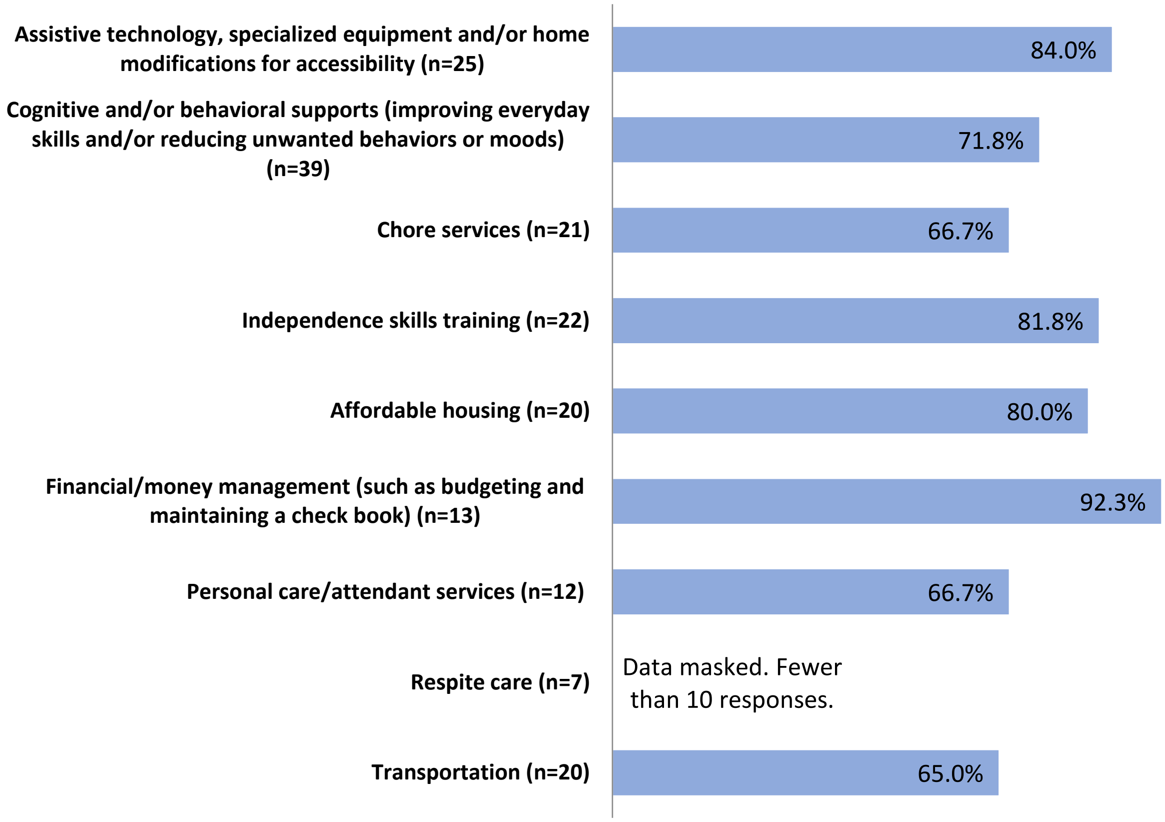
*Percentage indicating that they are in need of the service; have requested, but not received the service, or on a wait list for the service

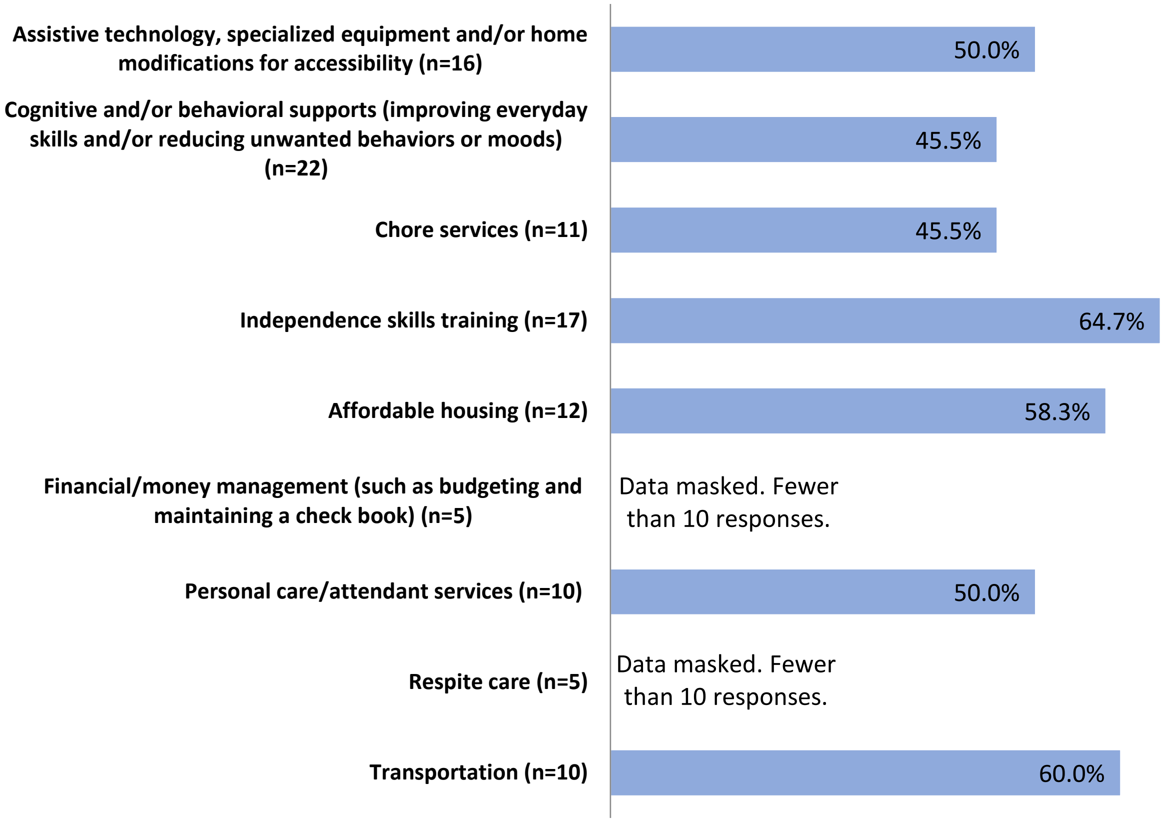
Note: see Appendix A for specific barriers for each of the services listed in the figure below.

Figure 7. Percentage reporting <u>at least one barrier</u> to Independent Living Service(s) [among those who have ever used the service or are in need of the service]



> "Felt I had to do most everything on my own with the exception of a few of my providers at rehabilitation who were there for me post rehab."
>
> - Individual with a brain injury

Figure 8. Percentage reporting that the Independent Living Service(s) met all or most of their needs* [among those who have ever used the service]



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*Response options: This service met all of my needs, This service met most of my needs, This service met some of my needs, This service met none of my needs, I am currently using this service and it's too early to tell if it is meeting my needs. Those selecting this final option are not included in the analysis (i.e., counted as missing).

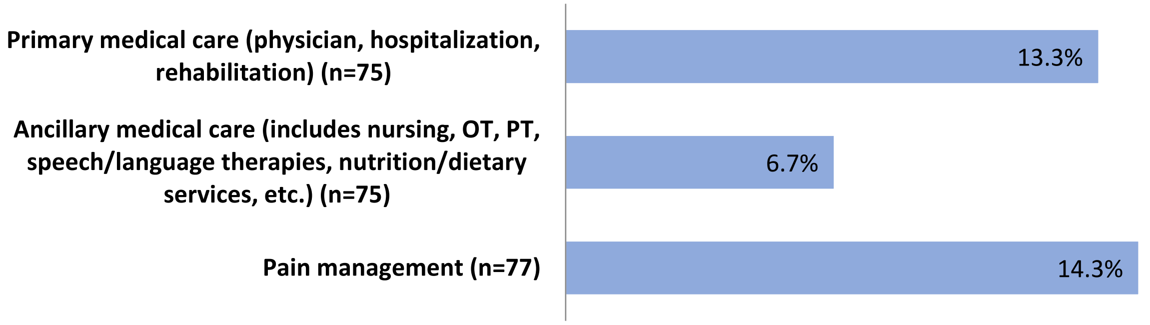
> "[We] need more services in out-state Nebraska."
>
> - Individual with a brain injury

> "[We] need community housing for semi-independent living for younger adults that isn't mostly senior citizens. Something that makes the brain injured person feel independent and not in a care facility."
>
> - Individual with a brain injury

Physical Health and Well-Being Services

Figures 9 through 11 present responses from individuals with a brain injury in terms of their current need for physical health and well-being services, barriers to these services, and how well these services have met the needs of those who have utilized them.

Figure 9. Percentage currently in need* of Physical Health and Well-Being Services



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*Percentage indicating that they are in need of the service; have requested, but not received the service, or on a wait list for the service

Note: see Appendix A for specific barriers for each of the services listed in the figure below.

Figure 10. Percentage reporting at least one barrier to Physical Health and Well-Being Service(s) [among those who have ever used the service or are in need of the service]

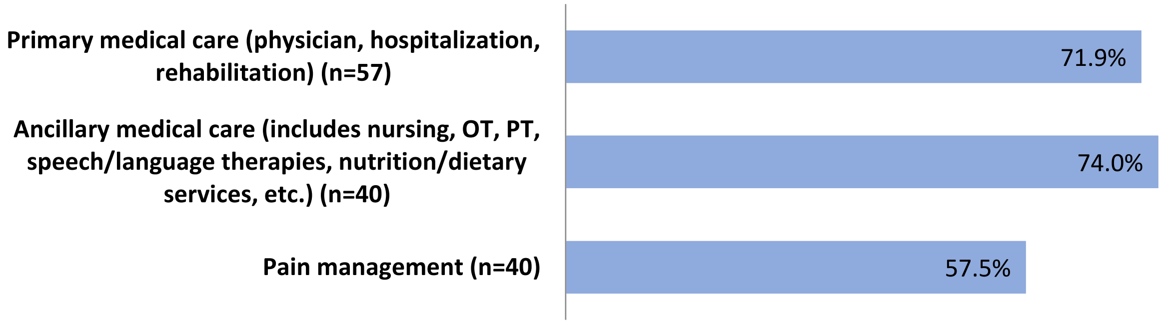
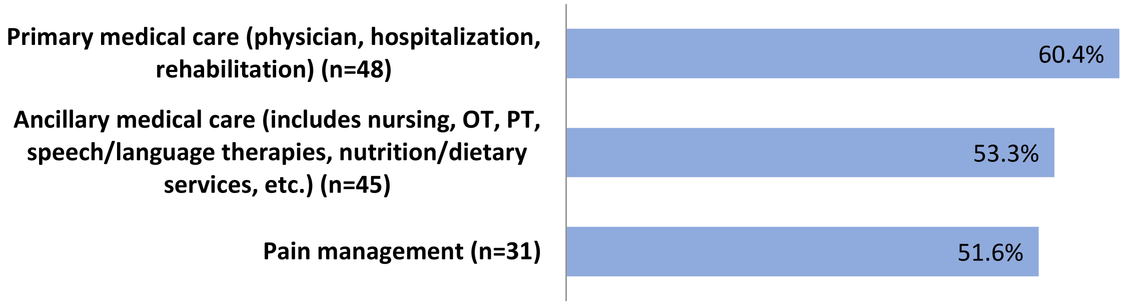


Figure 11. Percentage reporting that the Physical Health and Well-Being Service(s) met all or most of their needs* [among those who have ever used the service]



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*Response options: This service met all of my needs, This service met most of my needs, This service met some of my needs, This service met none of my needs, I am currently using this service and it's too early to tell if it is meeting my needs. Those selecting this final option are not included in the analysis (i.e., counted as missing).

> "It is my impression that a person with a mild brain injury has to figure things out on their own. Trying to get a provider to understand that there is something wrong even though you appear normal… There is a lot of room for improvement in the areas of immediate assistance and education for medical professionals and the public… I hope you are gaining good information from this survey to change our lawmaker's minds about helping brain injury sufferers."
>
> \- Individual with a brain injury

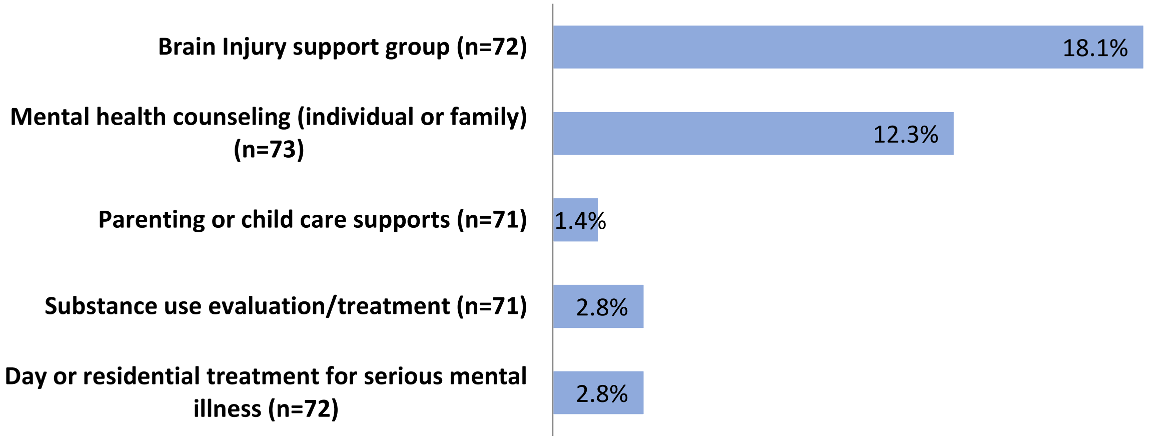
> "It would be wonderful if Primary Physicians received more knowledge regarding the seriousness of a TBI."
>
> \- Individual with a brain injury

> "I feel like medical providers and the education system still do not understand brain injury and/or understand the resources needed to be successful."
>
> \- Individual with a brain injury

Mental and Emotional Health and Well-Being Services

Figures 12 through 14 present responses from individuals with a brain injury in terms of their current need for mental and emotional health and well-being services, barriers to these services, and how well these services have met the needs of those who have utilized them.

Figure 12. Percentage currently in need* of Mental and Emotional Health and Well-Being Services



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*Percentage indicating that they are in need of the service; have requested, but not received the service, or on a wait list for the service

> "The only way I was able to get mental health services is my provider provided me the services pro bono. I was going through many stressful issues after BI which included legal problems, financial, abuse, losing job, losing friends and family, etc. This is what every individual needs but insurance runs out to quickly."
>
> - Individual with a brain injury

> "I feel that people in general need more education about TBI's. My family/friends still today don't know why I have emotional breakdowns, my temper is up and down and they think I should be able to control it. I would like to see group supports for TBIs [that are] easy to find for individuals like me who want to talk to others dealing with TBIs."
>
> - Individual with a brain injury

> "[I'm] having a hard time finding support groups for individuals who have TBIs."
>
> - Individual with a brain injury

Note: see Appendix A for specific barriers for each of the services listed in the figure below.

Figure 13. Percentage reporting <u>at least one barrier</u> to Mental and Emotional Health and Well-Being Service(s) [among those who have ever used the service or are in need of the service]

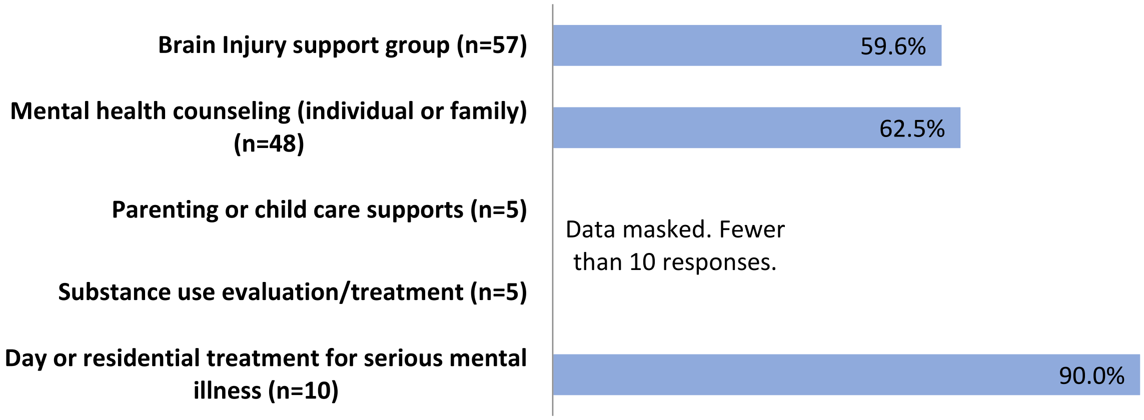
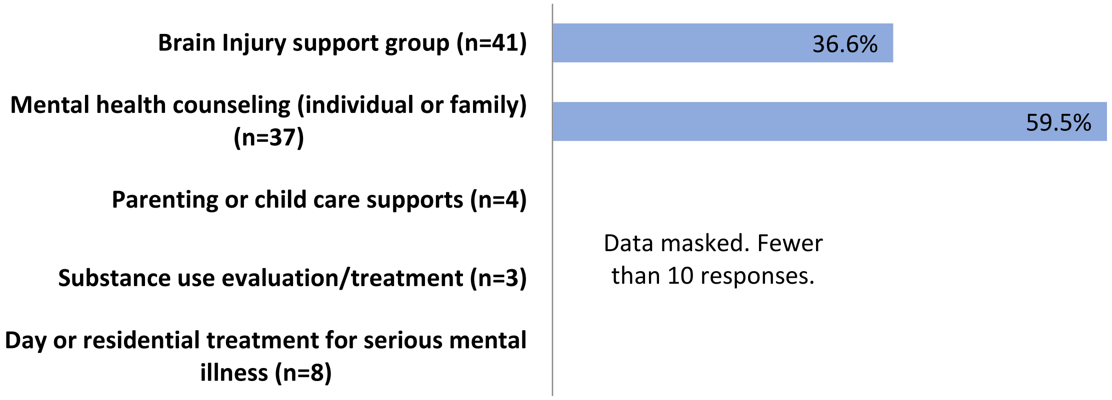


Figure 14. Percentage reporting that the Mental and Emotional Health and Well-Being Service(s) <u>met all or most of their needs*</u> [among those who have ever used the service]



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*Response options: This service met all of my needs, This service met most of my needs, This service met some of my needs, This service met none of my needs, I am currently using this service and it's too early to tell if it is meeting my needs. Those selecting this final option are not included in the analysis (i.e., counted as missing).

> "[We] need more specially trained therapists in methods effective for people with TBI.
>
> - Individual with a brain injury

Nearly half of individuals with a brain injury report that they have ever experienced serious mental health issues (Figure 15).

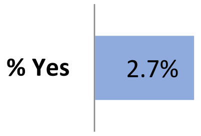
Figure 15. Have ever experienced serious mental health issues* (n=74)

---

*Serious mental health issues were defined to include "severe major depression, severe bipolar disorder, and other such issues."

A small percentage (2.7%) of respondents indicated that they have ever needed substance abuse evaluation or treatment because of misuse of opioid prescriptions.

Figure 16. Have ever needed substance abuse evaluation or treatment because of misuse of opioid prescriptions (n=74)

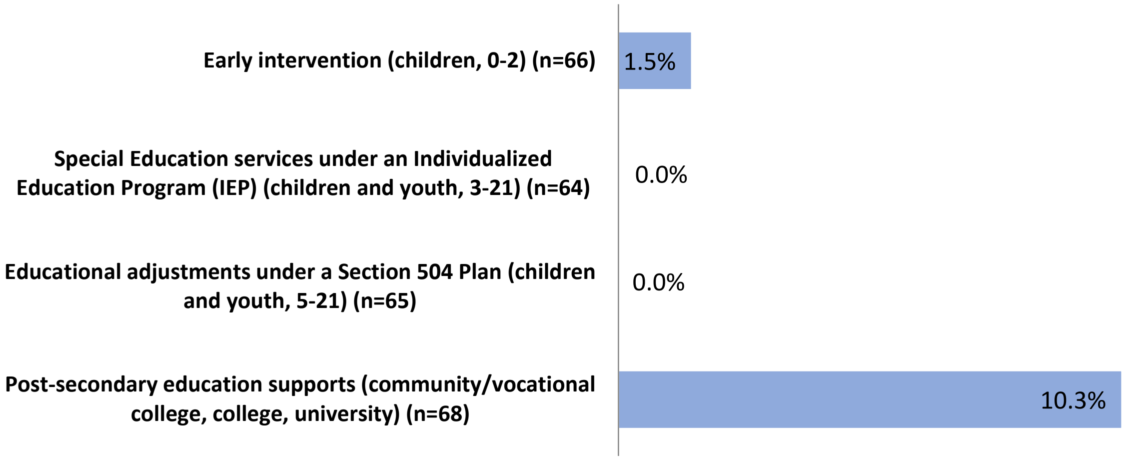


> "The brain injured are grossly misunderstood. I did not understand until it happened to me. Our family still feels I should be well "next week". I have finally come to terms with the new me. I tell people it's a better version. My husband gets very emotional. He is very worried about our finances. We have had to foot the entire amount of expenses because their auto insurance was terrible. I want to perhaps write and speak about this to somehow make a positive out of such a negative."
>
> - Individual with a brain injury

Education Services

Figures 17 through 19 present responses from individuals with a brain injury in terms of their current need for education services, barriers to these services, and how well these services have met the needs of those who have utilized them.

Figure 17. Percentage currently in need* of Education Services



*Percentage indicating that they are in need of the service; have requested, but not received the service, or on a wait list for the service

Note: see Appendix A for specific barriers for each of the services listed in the figure below.

Figure 18. Percentage reporting at least one barrier for Education Service(s) [among those who have ever used the service or are in need of the service]

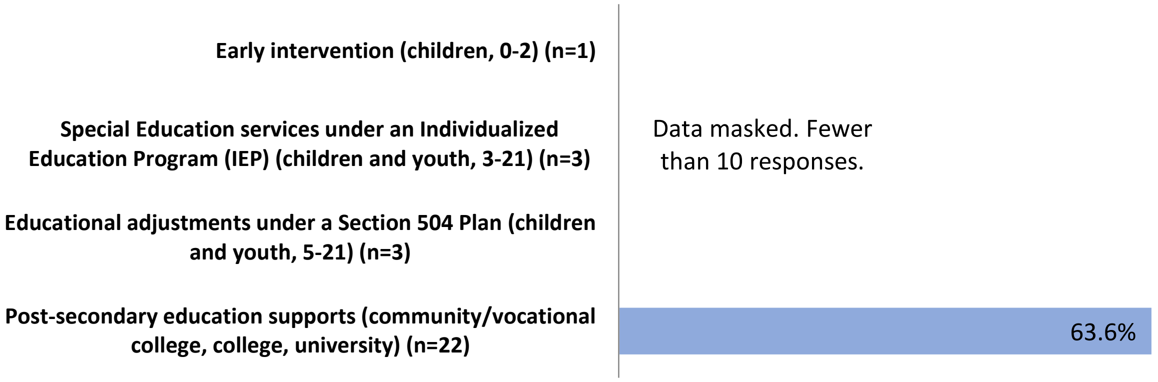
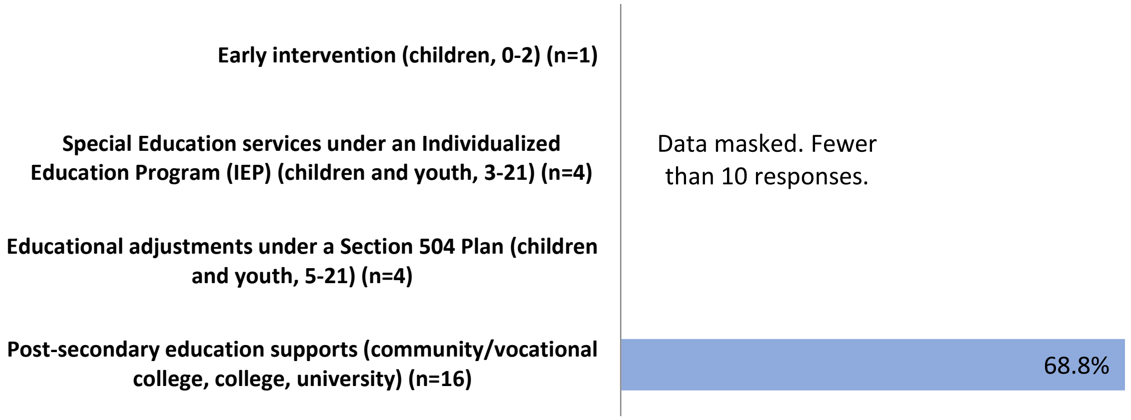


Figure 19. Percentage reporting that the Education Service(s) met all or most of their needs* [among those who have ever used the service]



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*Response options: This service met all of my needs, This service met most of my needs, This service met some of my needs, This service met none of my needs, I am currently using this service and it's too early to tell if it is meeting my needs. Those selecting this final option are not included in the analysis (i.e., counted as missing).

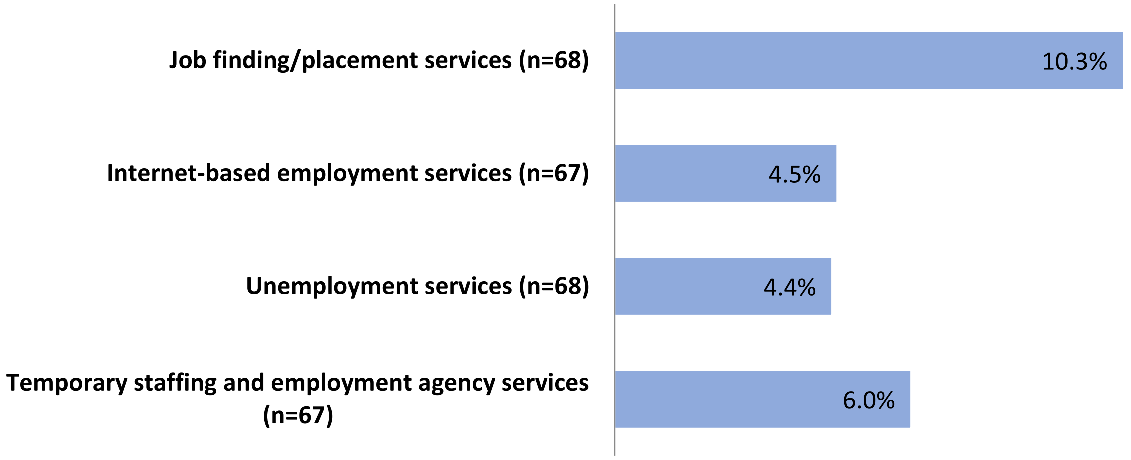
> "Accommodations and assistance from [educational] institutions are really difficult to receive."
>
> - Individual with a brain injury

> "I would love to go back to college. I was going when I had my brain injury, but have a tough time retaining information due to short-term memory loss."
>
> - Individual with a brain injury

Employment Services

Figures 20 through 22 present responses from individuals with a brain injury in terms of their current need for employment services, barriers to these services, and how well these services have met the needs of those who have utilized them.

Figure 20. Percentage currently in need* of Employment Services



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*Percentage indicating that they are in need of the service; have requested, but not received the service, or on a wait list for the service

Note: see Appendix A for specific barriers for each of the services listed in the figure below.

Figure 21. Percentage reporting that the Employment Service(s) met all or most of their needs* [among those who have ever used the service]

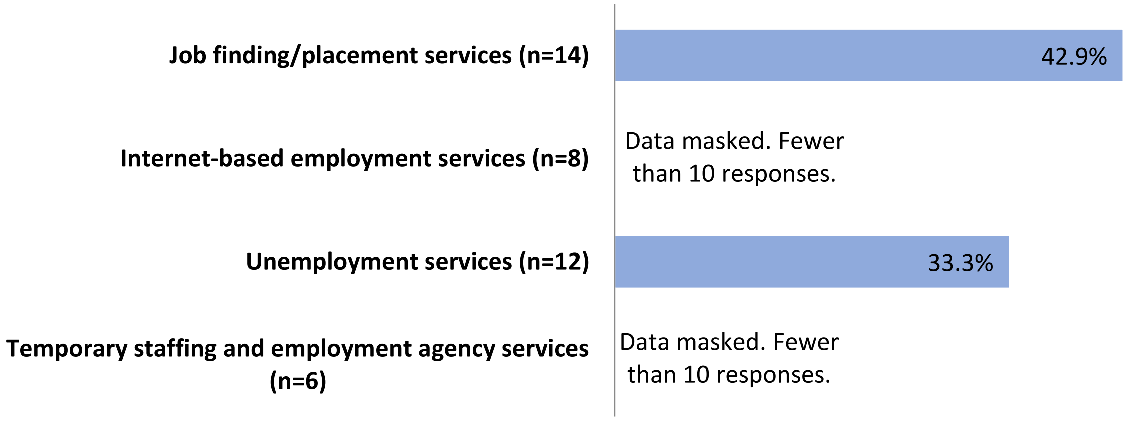
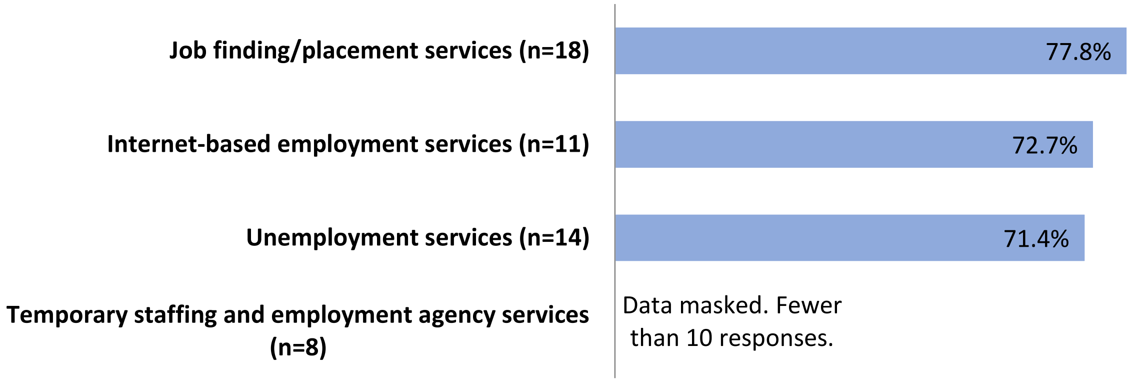


Figure 22. Percentage reporting at least one barrier for Employment Service(s) [among those who have ever used the service or are in need of the service]



*Response options: This service met all of my needs, This service met most of my needs, This service met some of my needs, This service met none of my needs, I am currently using this service and it's too early to tell if it is meeting my needs. Those selecting this final option are not included in the analysis (i.e., counted as missing).

> "Providers [of employment services] have preconceived [ideas] and expectations of people with brain injury."
>
> - Individual with a brain injury

> "I feel so different from day to day I am not ready to hold down any type of hourly job."
>
> - Individual with a brain injury

> "My supervisor was understanding at first, but became impatient with me a few months even though she said she understands. She can't understand because she's never had a brain injury."
>
> - Individual with a brain injury

Nebraska VR Services

Just over one-third of respondents indicated that they have ever received services from Nebraska VR (Figure 23). Just over half of those respondents who have received services from Nebraska VR indicated that they received those services at Lincoln (Figure 24).

Figure 23. Have you ever received any of the services below from Nebraska VR? (select all that apply) (n=69)

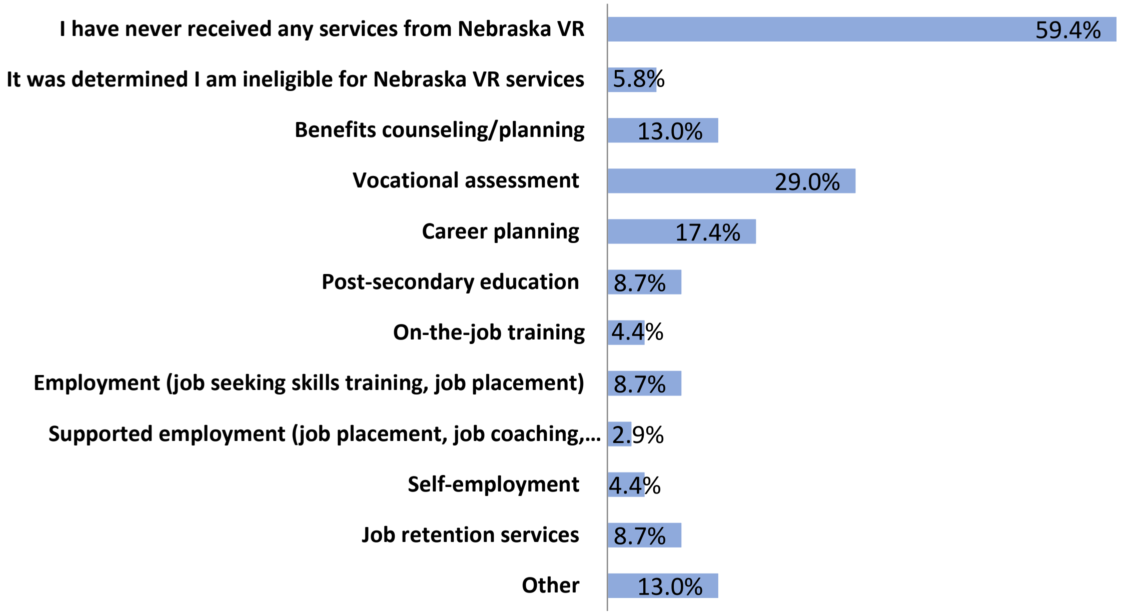
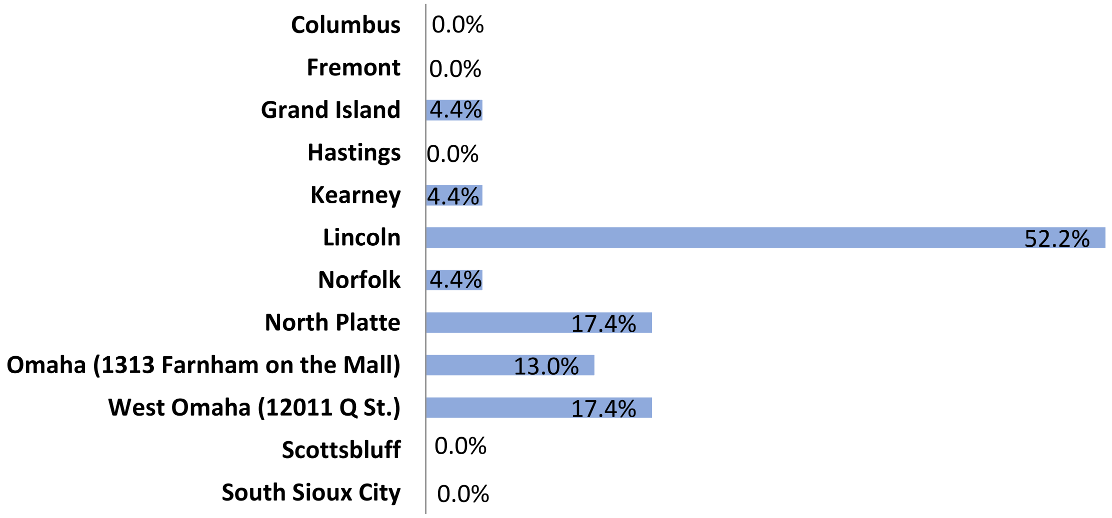
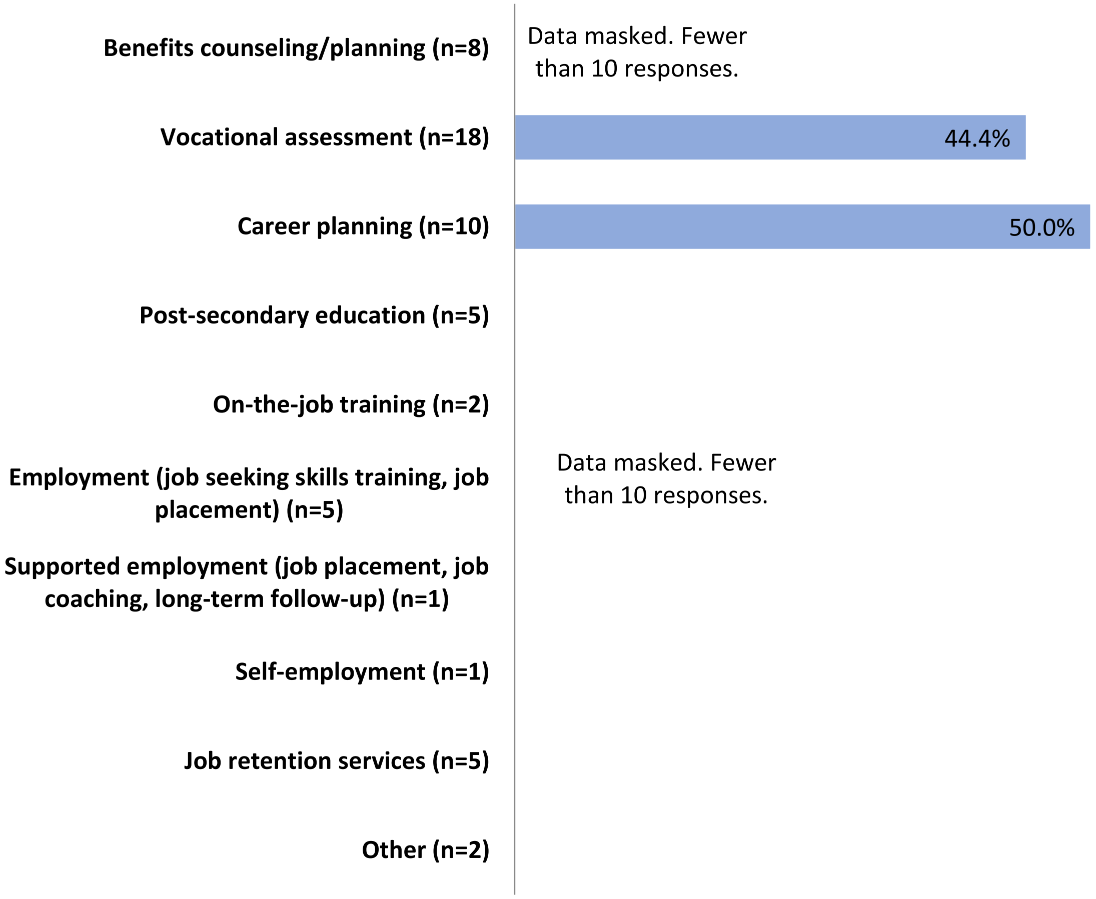


Figure 24. At which Nebraska VR Service Office(s) did you receive services? [among those who have received services from Nebraska VR] (n=23)



For most Nebraska VR services, there were not enough individuals who have used the services to report on how well those services met their needs. Less than half (44.4%) of respondents who received a vocational assessment indicated that the service met all or most of their needs and exactly half of those who received career planning reported that the service met all or most of their needs. However, note the low number of responses on these two survey items (Figure 25).

Figure 25. Percentage reporting that the Nebraska VR Service(s) met all or most of their needs* [among those who have ever used the service]



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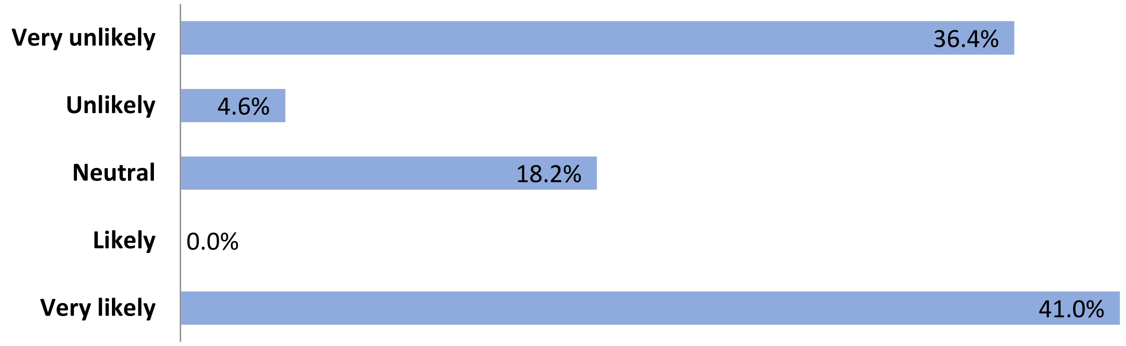
*Response options: This service met all of my needs, This service met most of my needs, This service met some of my needs, This service met none of my needs, I am currently using this service and it's too early to tell if it is meeting my needs. Those selecting this final option are not included in the analysis (i.e., counted as missing).

> "Each individual is unique. I think it would be beneficial to have a TBI survivor working at the department(s) dealing with TBI survivors."
>
> \- Individual with a brain injury

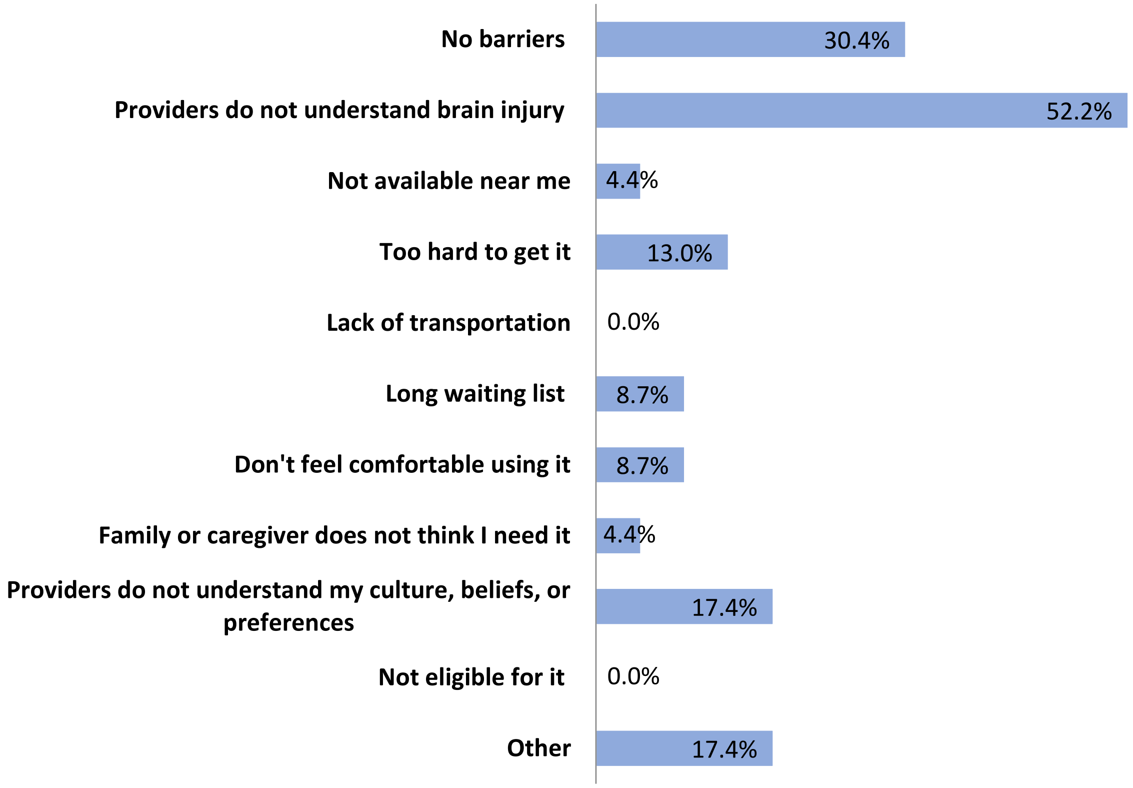
Respondents were overall neutral on average in terms of their likelihood to recommend Nebraska VR to a friend or family member (Figure 26).

Figure 26. How likely are you to recommend Nebraska VR to a friend or family member who experiences a disability [among those who have received services from Nebraska VR] (n=22)



The top barrier experienced by those who have received services from Nebraska VR was "providers do not understand brain injury" (Figure 27).

Figure 27. Have you experienced any of the following barriers related to the Nebraska VR service(s) you have received? [among those who have received services from Nebraska VR] (n=23)



Survey Results for Family Members of Individuals with a Brain Injury

A total of 68 family members of individuals with a brain injury participated in the survey. Use caution when interpreting these results due to the low number of respondents.

Respondent Demographics

Demographics of the family members of individuals with a brain injury who responded to the survey are presented below in Table 7. Approximately two-thirds (66.2%) of family members also indicated that they are a caregiver.

Table 7 **Respondent Demographics**

	Total number of surveys collected	***68***
Type (n=68)	*Family member and caregiver*	66.2%
	Family member (non-caregiver)	33.8%
Urbanicity* (n=66)	*Large Urban*	62.1%
	Small Urban	19.7%
	Rural	18.2%
Gender (n=68)	*Male*	14.7%
	Female	85.3%
	Other°	0.0%
Race/ethnicity (n=67)	*White/Caucasian*	100%
	Non-White/Caucasian	0.0%
Primary language (n=68)	*English*	100%
	All other languages (includes bi-lingual and multi-lingual)	0.0%
Age group (n=68)	*24 and under*	0.0%
	25-44	29.4%
	45-64	50.0%
	65 and over	20.6%
Veteran status (n=68)	*Veteran of U.S. Armed Forces*	4.4%
	Non-veteran	95.6%

*See Appendix D for urbanicity definitions.

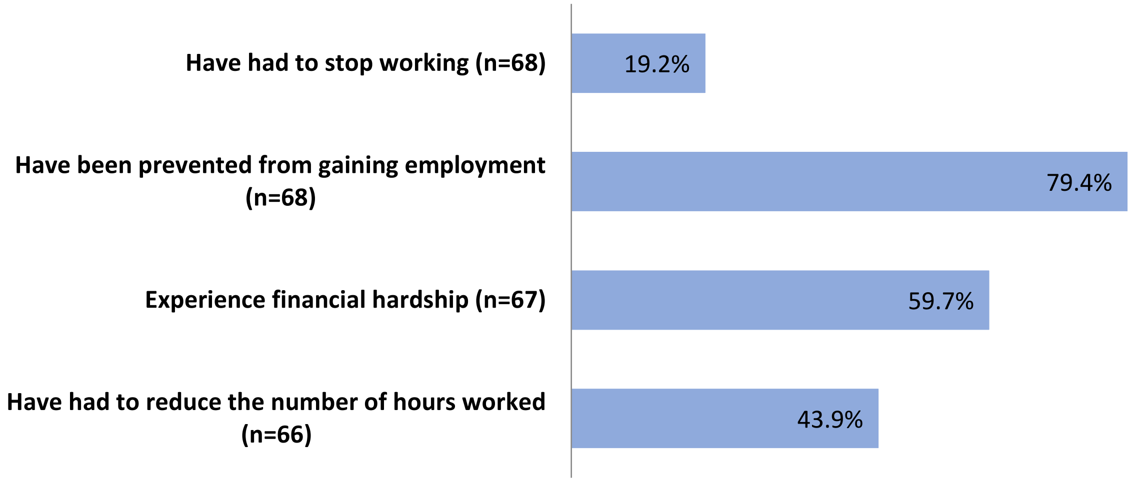
°"Other" gender includes non-binary/third gender, transgender, prefer to self-describe, and prefer not to say

Financial Impact of Being a Family Member of an Individual with a Brain Injury

Being a family member/caregiver of an individual with a brain injury appears to have a considerable financial impact on the family. Four-in-five family members (79.4%) reported that they have been prevented from gaining employment and three-in-five (59.7%) reported that they have experienced financial hardship, as a result of being a family member/caregiver of an individual with a brain injury (Figure 28).

Figure 28. Financial impacts of being a family member/caregiver of an individual with a brain injury

As a result of being a family member and/or caregiver of an individual with a brain injury...



> "I pray that they change laws in the state of Nebraska so we can get the help my son needs."
>
> - Family member of an individual with a brain injury

> "I had no idea what "you're embarking on a marathon of events" meant at the of my son's accident 21 years ago."
>
> - Family member of an individual with a brain injury

> "You give me hope that our state is interested in helping our family and advocating for resources and assistance. Being a caregiver is a lonely pursuit."
>
> - Family member of an individual with a brain injury

Social-Emotional Aspects of Being a Family Member of an Individual with a Brain Injury

There are also considerable social-emotional aspects of being a family member/caregiver of an individual with a brain injury. Nearly all family members (97.1%) responded that they experience at least some emotional stress as a result of being a family member/caregiver of an individual with a brain injury. Four-in-five (79.4%) family members agreed or strongly agreed that accessing services for their family member has been stressful (Table 8).

Table 8 **Social-Emotional aspects of being a family member/caregiver of an individual with a brain injury**

	Yes	Somewhat	Very little	Not at all
Experience emotional stress in role as family member/caregiver of an individual with a brain injury (n=68)	66.2%	30.9%	2.9%	0.0%
Have good extended family support now (n=68)	35.3%	29.4%	20.6%	14.7%
Had good extended family support when family member was first diagnosed with a brain injury (n=66)	50.0%	25.8%	10.6%	13.6%

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
Accessing services for my family member with a brain injury has been stressful. (n=68)	5.9%	1.5%	13.2%	36.8%	42.7%

> "It can be very emotionally stressful for all family members (parents, siblings) along with close friends when watching a loved one suffer symptoms of a TBI."
>
> - Family member of an individual with a brain injury

> "What to do with her, if something should happen to myself…?"
>
> - Family member of an individual with a brain injury

Understanding the Family Member’s Disability

The vast majority of family members indicated that they have at least a somewhat clear understanding and awareness about their family member’s disability. However, 41.2% reported that they need additional information/education to better understand their family member’s disability (Table 9).

Table 9 **Understanding the family member’s disability**

	Yes	Somewhat	Very little	Not at all
Have a clear understanding and awareness about family member’s disability (n=68)	70.6%	22.1%	5.9%	1.5%
Need additional information/education to better understand the family member’s disability [% Yes*] (n=68)	41.2%			

*Yes/no response options

> “We wish we had more help with understanding long-term effects and how to deal with them.”
>
> - Family member of an individual with a brain injury

> “[There is a] lack of awareness and support for the majority of folks that appear to be "fine" who in fact do have challenges resulting from TBI.”
>
> - Family member of an individual with a brain injury

> “I am not sure where to find resources to help build new pathways in his brain.”
>
> - Family member of an individual with a brain injury

Interest in Advocacy

Four-in-five (79.4%) of family members indicated that they have a newly discovered interest in advocacy to improve the lives of individuals with a brain injury in your journey of caring for their family member with a brain injury. Over half (53.7%) of family members reported that they need additional information/education to better engage in advocacy (Table 10).

Table 10 Interest in advocacy

	Yes	Somewhat	Very little	Not at all
Do you have a newly discovered interest in advocacy to improve the lives of individuals with a brain injury in your journey of caring for your family member with a brain injury? (n=68)	45.6%	33.8%	16.2%	4.4.%
Need additional information/education to better engage in advocacy to improve the lives of individuals with a brain injury [% Yes*] (n=67)	53.7%			

*Yes/no response options

> "My son is falling through the cracks of support system."
>
> - Family member of an individual with a brain injury

> "Resources for mild TBI people are hard to find."
>
> - Family member of an individual with a brain injury

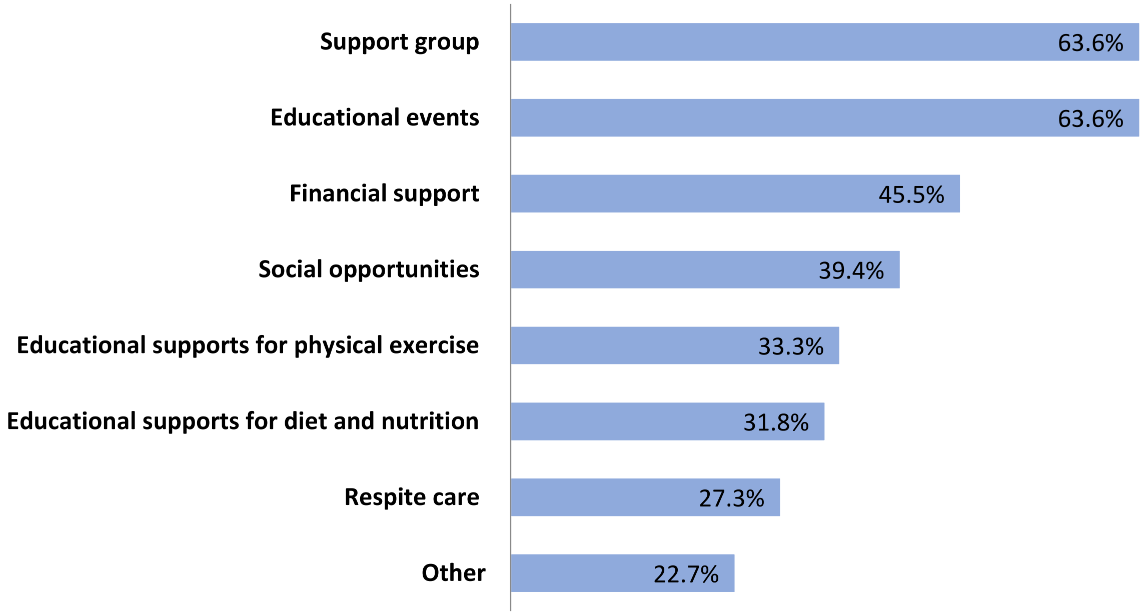
> "My family member with a TBI has a dual diagnosis in mental health. There are few or no providers with adequate training for her in our area on our insurance."
>
> - Family member of an individual with a brain injury

> "Navigating the school system is difficult at best."
>
> - Family member of an individual with a brain injury

Services for the Family Member Caregiver

The top two services that were most commonly identified by family members as being helpful to them as a caregiver are support group and educational events. Each of these two services was selected by nearly two-thirds (63.6%) of family member respondents (Figure 29).

Figure 29. What services would be helpful to you as a caregiver? (select all that apply) (n=66)



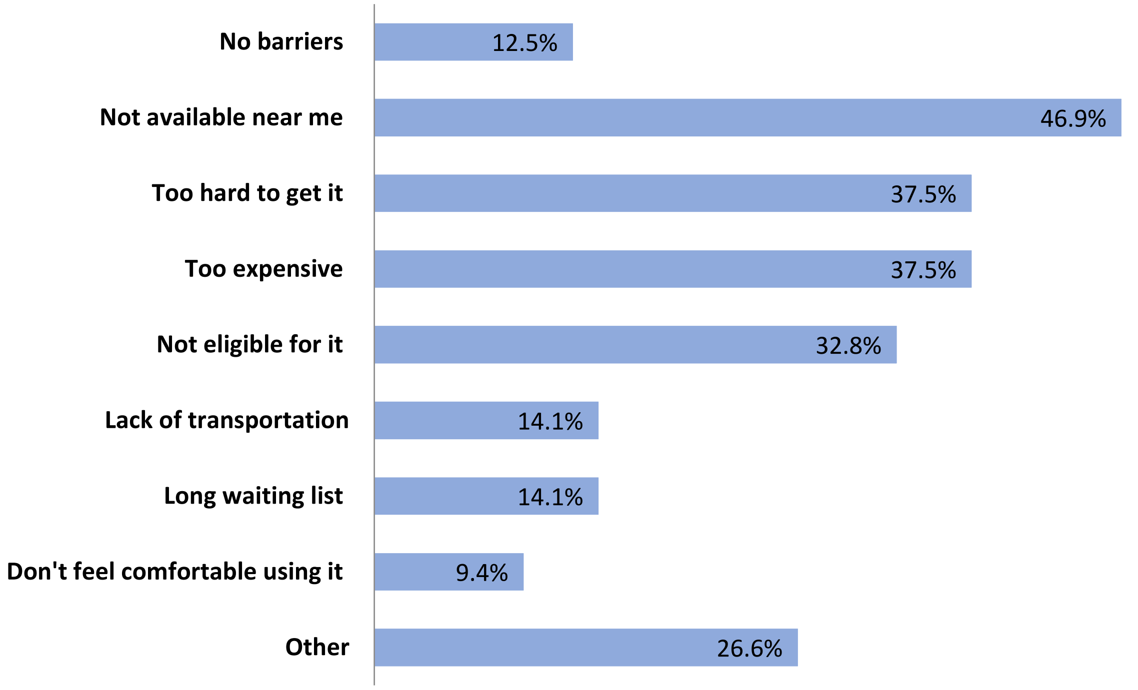
Other responses: resource facilitation/case management, home assistance respite care, insurance, transportation, help in applying for assistance, legal assistance, assistive technology, and other responses.

> "The support group that Gina chairs has been a lifesaver!"
>
> - Family member of an individual with a brain injury

> "It's very stressful at times. When you are together 24/7 with no help. Have been looking for day services to give us a break from each other."
>
> - Family member of an individual with a brain injury

The top three barriers to receiving those services listed in Figure 29 above were "not available near me", "too hard to get it", and "too expensive" (Figure 30).

Figure 30. Barriers to receiving services that would provide assistance to family members/caregivers (n=64)



Other responses: don't know what is available and/or how to find it, individual with brain injury does not want help, don't qualify for services, and other responses.

> "I see the need for more resources for families and the individual with the TBI. I see the need for financial and educational support."
>
> - Family member of an individual with a brain injury

> "Some days are very trying."
>
> - Family member of an individual with a brain injury

Survey Results for Brain Injury Service Providers

A total of 46 brain injury service providers participated in the survey. However, responses for certain survey items were much lower than the total number of participants due to questions not being applicable or perhaps simply being skipped. Use caution when interpreting these results.

Respondent and Organizational Demographics

Respondent and organizational demographics are presented in Tables 11 through 14. Respondents reported a wide range in terms of the number of individuals with a brain injury that their organization serves directly each year, ranging from 1 individual to 500 (Table 13).

Table 11 **Role within organization (n=46)**

Administrator	Program manager	Direct service professional	Administrative professional	Other
19.6%	21.7%	32.6%	0.0%	26.1%

Other responses: BIRSST, resource facilitation, council member, research, board member/governance, office director, options counselor, school nurse, social worker, faculty

Table 12 **Reach of organization (n=46)**

Serves individuals statewide	Does not serve individuals statewide
46.0%	54.0%

Table 13 **Approximate number of individuals with a brain injury directly served by organization per year (n=36)**

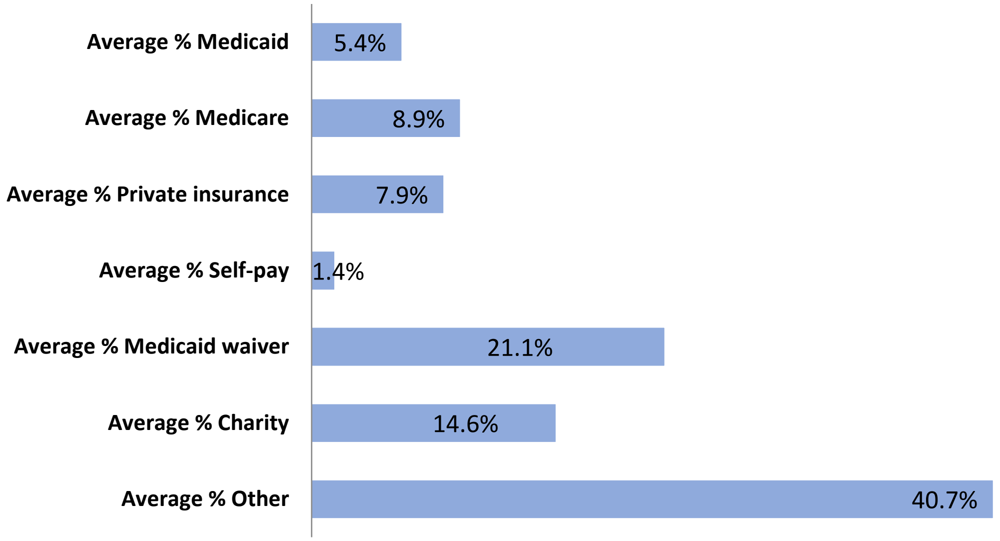
5 or fewer	6-20	21-50	51-100	More than 100	*Range*
25.0%	16.7%	22.2%	8.3%	27.8%	***1 to 500***

See also Appendix B for a report on a different set of services provided by the organizations.

Table 14	**Services provided by organization (multiple responses) (n=46)**
Acute care	0.0%
Post-acute care (residential)	4.4%
Post-acute care (non-residential)	6.5%
Residential rehabilitation	8.7%
Outpatient treatment/therapies	13.0%
Assisted living	10.9%
Independent Living	8.7%
Behavioral/Mental Health	13.0%
Substance use treatment	4.4%
Vocational rehabilitation/employment	34.8%
Community-based supports (not in home)	23.9%
Community-based supports (not in home)	17.4%
Aging	4.4%
Educational programs	32.6%
Caregiving, Respite	13.0%
Protection and advocacy	15.2%
Homeless services	6.5%
Veterans and military	4.4%
Information/Referral	37.0%
Care Coordination/Case Management	23.9%
Other: BIRSST and School nursing	4.4%

The most common funding source for serving individuals with a brain injury was identified as "other", which likely indicates grant funding (Figure 31). Note that only 15 individuals responded to this survey item.

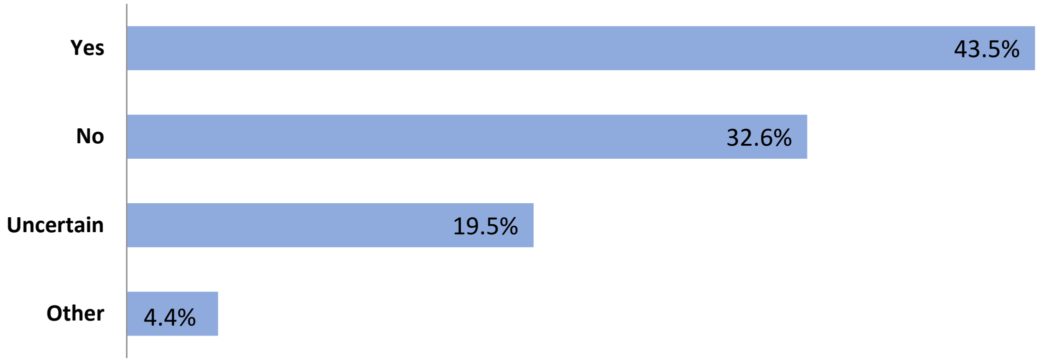
Figure 31. Average estimated percentage of funding per funding source for serving individuals with brain injury (n=15)



Brain Injury Screening

Less than half (43.5%) of brain injury service provider respondents indicated in the affirmative that their organization conducts screening from brain injury (Figure 32).

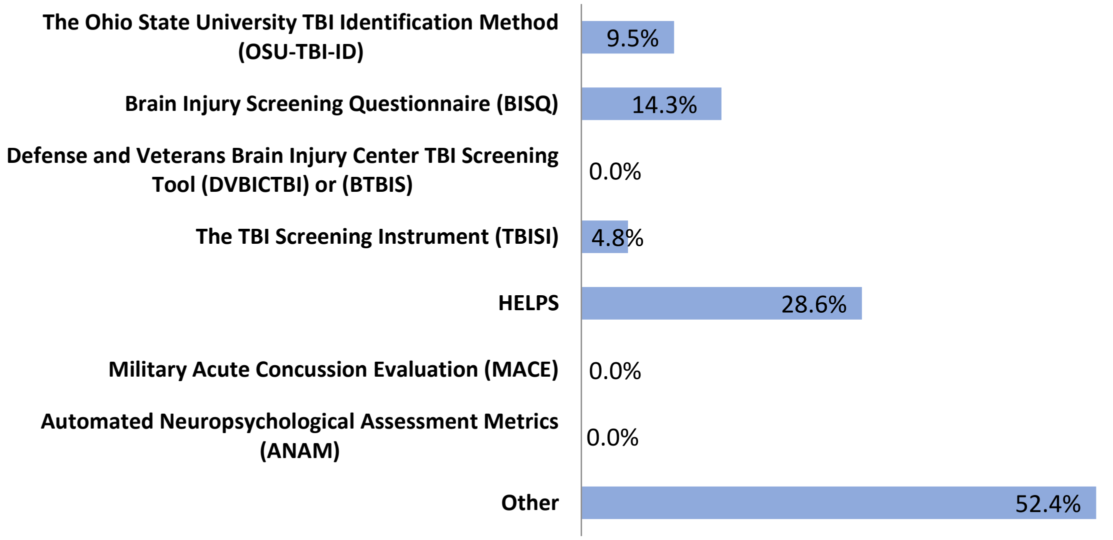
Figure 32. Organization conducts screening for a lifetime history of potential brain injury incidents using a brain injury screening instrument (n=46)



Other responses: provide education and training about the screening tools.

Among those who conduct brain injury screening, a wide array of instruments were reported as being used (Figure 33).

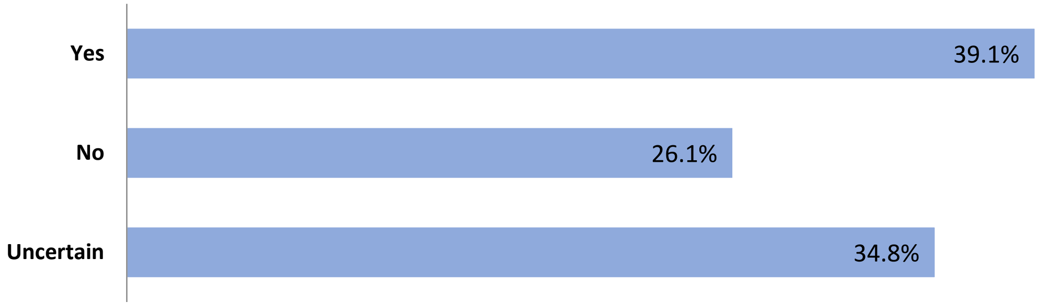
Figure 33. Screening instrument used [among those who report conducting screening from brain injury] (n=21)



Other responses: SAFE Child Screening Tool, Nebraska VR ABI screen, self-report, general questionnaire, Amended OSU tool, unknown

Around two-in-five (39.1%) of brain injury service providers who did not currently conduct screening indicated that they were interested in learning more about how to conduct screening (Figure 34).

Figure 34. Individual and/or organization is interested in learning more about how to screen individuals for a lifetime history of potential brain injury incidents [among those who do not currently conduct screning] (n=23)



> “It's difficult because it's never the same, every injury, every person, every event. Though there are similarities, the differences define it.”
>
> - Brain injury service provider

Organizational Barriers

Brain injury service providers were asked a series of questions about 30 services (the same list was also use for a series of questions for individuals with a brain injury). Providers were asked about barriers to the services they provide. Due to a small number of respondents (less than 10) data on barriers are not able to be presented on 19 of the 30 services. For the 11 services with enough responses, barriers are presented in Table 15 below.

Table 15 **Organizational barriers to providing Select Services [among those who provide the service]**

	No barriers	Not enough staff	Lack of training for staff	Lack of funding/ compensation to provide service	Lack of awareness that your organization offers the service	Knowing appropriate referral sources	Other
General information/referral for any type of service (n=25)	32.0%	16.0%	20.0%	28.0%	28.0%	44.0%	0.0%
Information, referral, education and/or resources about brain injury (n=26)	15.4%	26.9%	26.9%	38.5%	34.6%	42.3%	0.0%
Case Management/Service Coordination (n=20)	25.0%	20.0%	15.0%	55.0%	40.0%	30.0%	0.0%
Service and funding application assistance (Insurance, Social Security, etc.) (n=11)	18.2%	45.5%	45.5%	54.6%	27.3%	18.2%	0.0%
Assistive technology, specialized equipment and/or home modifications for accessibility (n=11)	27.3%	0.0%	9.1%	63.6%	9.1%	0.0%	0.0%
Cognitive and/or behavioral supports (improving everyday skills and/or reducing unwanted behaviors or moods) (n=14)	21.4%	42.9%	42.9%	57.1%	21.4%	21.4%	0.0%
Independence skills training (n=10)	30.0%	60.0%	30.0%	50.0%	40.0%	10.0%	0.0%

Table 15 continued.

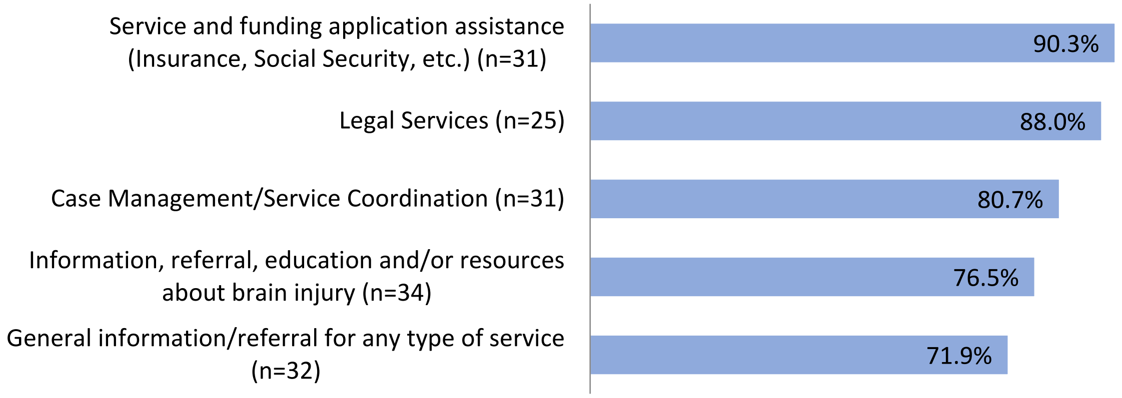
	No barriers	Not enough staff	Lack of training for staff	Lack of funding/ compensation to provide service	Lack of awareness that your organization offers the service	Knowing appropriate referral sources	Other
Financial/money management (such as budgeting and maintaining a check book) (n=11)	36.4%	36.4%	36.4%	36.4%	18.2%	0.0%	0.0%
Transportation (n=13)	7.7%	76.9%	23.1%	53.9%	23.1%	23.1%	0.0%
Post-secondary education supports (community/vocational college, college, university) (n=14)	21.4%	14.3%	14.3%	64.3%	21.4%	14.3%	0.0%
Job finding/placement services (n=17)	17.7%	29.4%	17.7%	76.5%	35.3%	29.4%	0.0%
Data are masked for 19 other services due to having less than 10 responses.							

> "I think Nebraska's medical model does a good job serving people with brain injury as long as there is coverage for that service. Once those benefits or services run out, there is not adequate community-based support."
>
> -Brain Injury Service Provider

Perceived Gaps in Services

Figures 35 through 40 present the perceived gaps in services among the brain injury service providers across six bundles of services. Respondents perceived relatively high gaps for many of the services.

Figure 35. Percentage of service providers reporting a "moderate" or "significant"* gap within Care Coordination Services

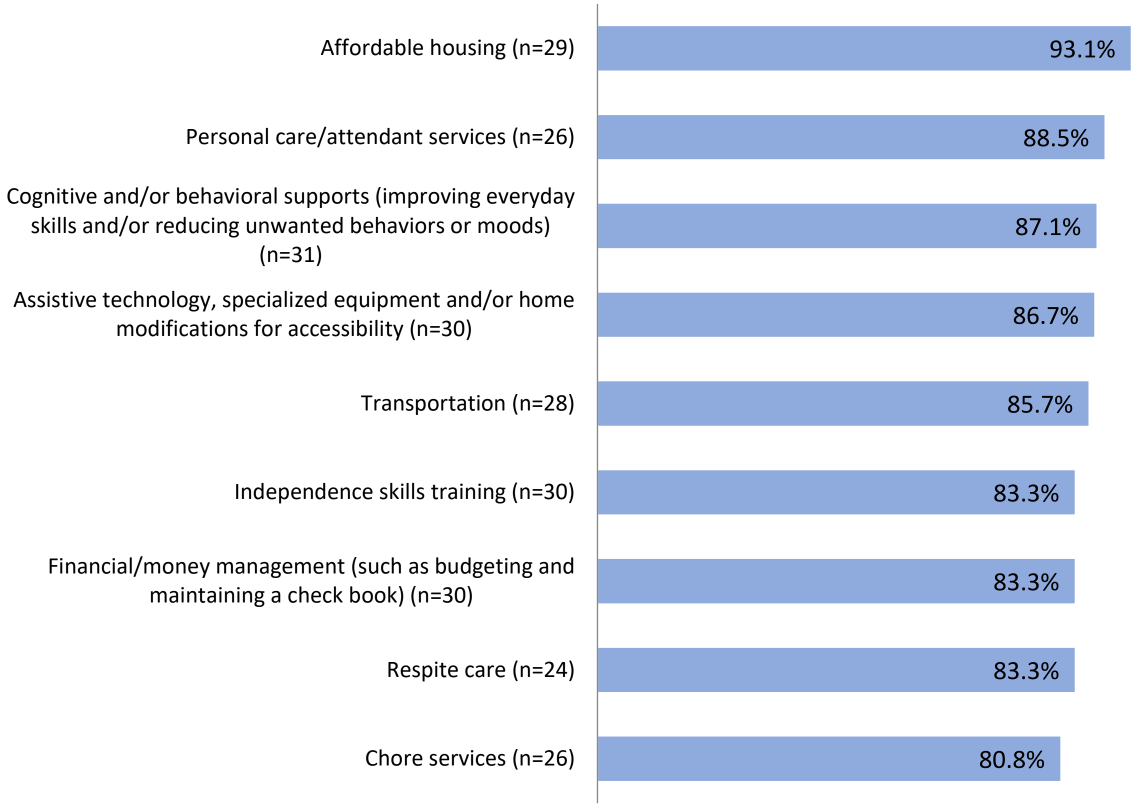


*Response options: NO GAP - all who need this service are able to get it, SLIGHT GAP - most who need this service are able to get it, MODERATE GAP - some who need this service are unable to get it, SIGNIFICANT OR LARGE GAP - many who need this service are unable to get it, UNKNOWN. Those responding "unknown" are not included in the analysis (i.e. counted as missing)

> "There are organizations doing this work that lack funding."
>
> -Brain Injury Service Provider

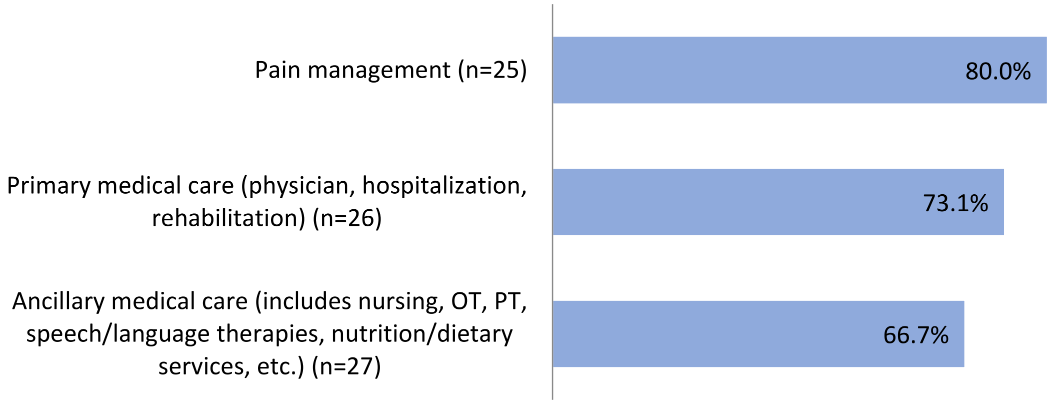
> "People with BI can provide service, education and supports as well as need these services."
>
> -Brain Injury Service Provider

Figure 36. Percentage of service providers reporting a "moderate" or "significant"* gap within Independent Living Services



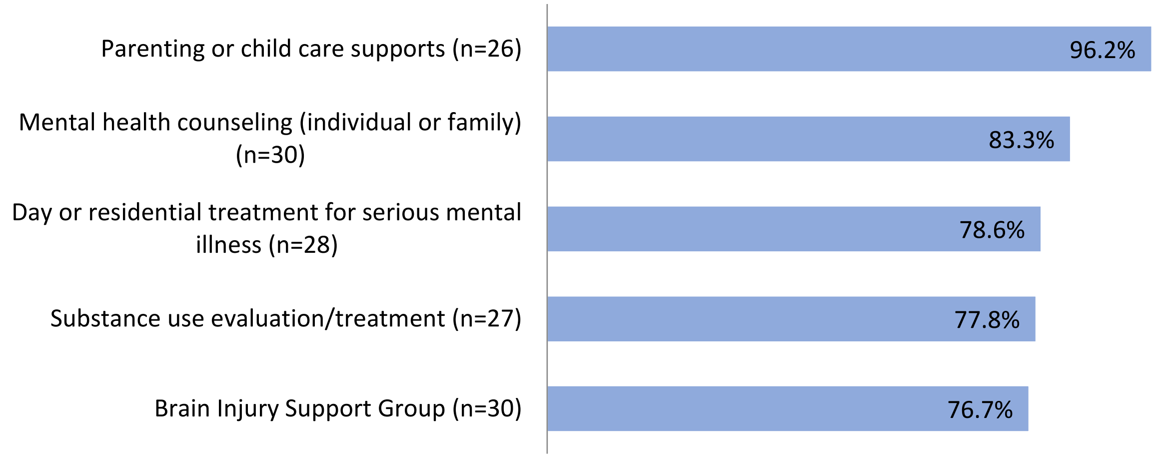
*See note below Figure 35.

Figure 37. Percentage of service providers reporting a "moderate" or "significant"* gap within Physical Health and Well-Being Services



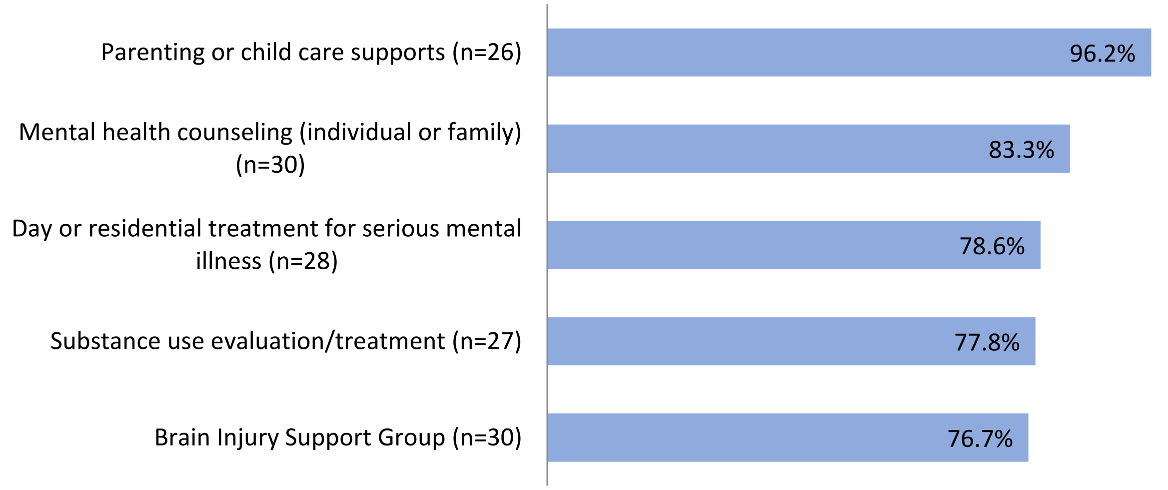
*See note below Figure 35.

Figure 38. Percentage of service providers reporting a "moderate" or "significant"* gap within Mental and Emotional Health and Well-Being Services



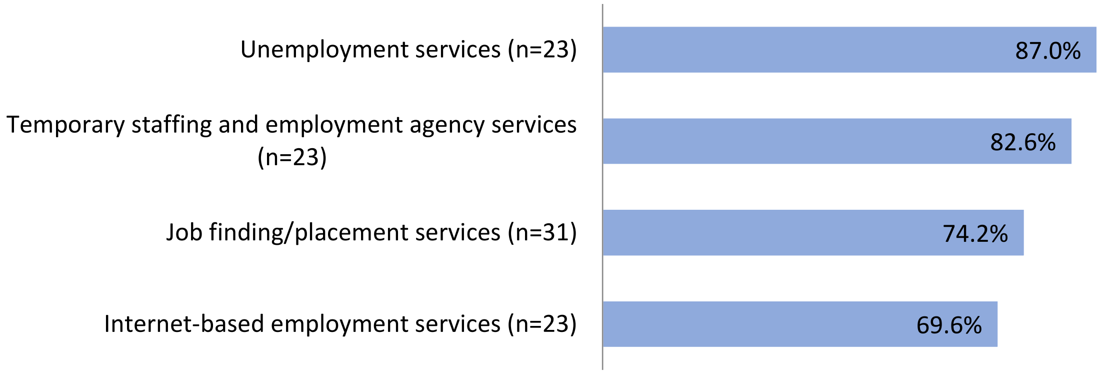
*See note below Figure 35.

Figure 39. Percentage of service providers reporting a "moderate" or "significant"* gap within Education Services



*See note below Figure 35.

Figure 40. Percentage of service providers reporting a "moderate" or "significant"* gap within Employment Services



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*See note below Figure 35.

> "Madonna, UNMC and QLI have been working well for our individuals with BI, although, they can only take in so many and so many more need their services but do not have access to them, nor get the time of services they need due to lack of beds or insurance."
>
> -Brain Injury Service Provider

> "When an individual isn't eligible for Medicaid/Medicare and has no SPMI diagnosis, there is no funding or services for an individual needing case management services or Day Services."
>
> -Brain Injury Service Provider

Potential Opportunities for Expanding Services

Brain injury service providers were asked indicate areas where their organization would be able to offer more services if funding were made available for individuals with a brain injury in Nebraska (such as through a state trust fund or some other mechanism). Results for all 30 services are presented below in Table 16.

Table 16	**If more funding were made available for individuals with a brain injury in Nebraska (such as through a state trust fund or some other mechanism), are there any additional services that your organization might be able to provide that it is not currently providing? (n=22)**	
Care Coordination	*General information/referral for any type of service*	40.9%
	Information, referral, education and/or resources about brain injury	50.0%
	Case Management/Service Coordination	59.1%
	Legal Services	27.2%
	Service and funding application assistance (Insurance, Social Security, etc.)	22.7%
Independent Living	*Assistive technology, specialized equipment and/or home modifications for accessibility*	27.3%
	Cognitive and/or behavioral supports (improving everyday skills and/or reducing unwanted behaviors or moods)	40.9%
	Chore services	18.2%
	Independence skills training	22.7%
	Affordable housing	22.7%
	Financial/money management (such as budgeting and maintaining a check book)	27.3%
	Personal care/attendant services	22.7%
	Respite care	31.8%
	Transportation	27.3%
Physical Health and Well-Being	*Primary medical care (physician, hospitalization, rehabilitation)*	9.1%
	Ancillary medical care (includes nursing, OT, PT, speech/language therapies, nutrition/dietary services, etc.)	9.1%
	Pain management	9.1%
Mental and Emotional Health and Well-Being	*Brain Injury Support Group*	63.6%
	Mental health counseling (individual or family)	31.8%
	Parenting or child care supports	40.9%
	Substance use evaluation/treatment	22.7%
	Day or residential treatment for serious mental illness	27.3%

Table 16 continued

Education	*Early intervention (children, 0-2)*	18.2%
	Special Education services under an Individualized Education Program (IEP) (children and youth, 3-21)	13.6%
	Educational adjustments under a Section 504 Plan (children and youth, 5-21)	22.7%
	Post-secondary education supports (community/vocational college, college, university)	18.2%
Employment	*Job finding/placement services*	18.2%
	Internet-based employment services	22.7%
	Unemployment services	13.6%
	Temporary staffing and employment agency services	13.6%
Other	*Other*	18.2%

Other responses: further evaluation for those with a positive TBI screening result, enhance awareness/access of services, expand current services.

> "We need a bigger voice from those we serve and to get them and the BI professionals involved. Otherwise, we will always flounder and the few of us that work so tirelessly with this population will die out."
>
> -Brain Injury Service Provider

> "Waivers work great, but we need funds for individuals with TBI to expand."
>
> -Brain Injury Service Provider

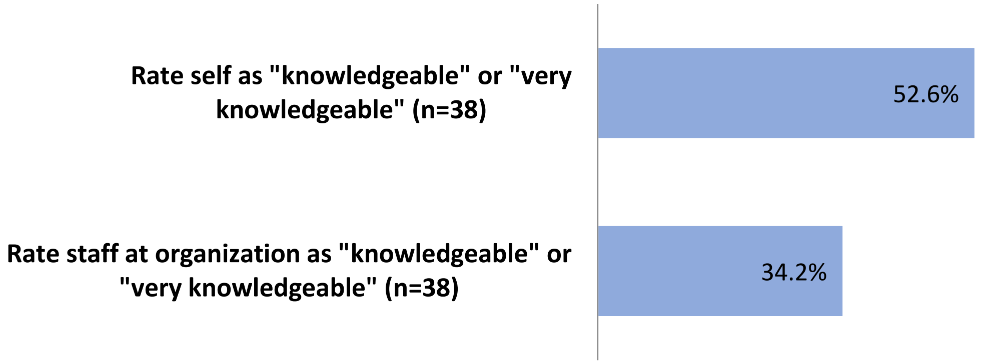
Brain Injury Training Needs

A strong majority (86.8%) reported that staff at their organization have participated in training or educational opportunities specifically on brain injury (Figure 41).

Figure 41. Staff at organization have participated in training or educational opportunities specifically on brain injury (n=38)

Over half (52.6%) of respondents rated themselves as “knowledgeable” or “very knowledgeable” about brain injury. Respondents generally perceived other staff at their organization as less knowledgeable than themselves, with just 34.2% perceiving staff at their organization as knowledgeable or very knowledgeable.

Figure 42. Ratings on the knowledge of brain injury and needs for individuals living with a brain injury*



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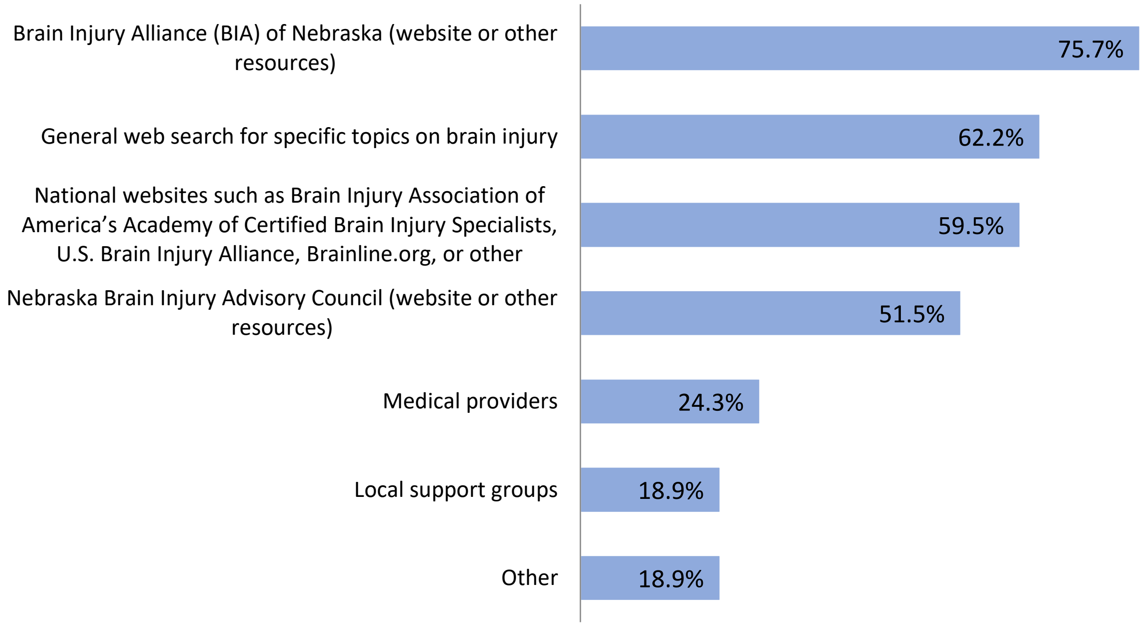
*Response options: not at all knowledgeable, slightly knowledgeable, somewhat knowledgeable, knowledgeable, very knowledgeable

> “If we are educated, we can help educate individuals and families.”
>
> -Brain Injury Service Provider

Sources for Information about Brain Injury

The top source for information about brain injury was the Brain Injury Alliance (BIA) of Nebraska, with three-fourths indicting the BIA as one of their sources for information about brain injury (Figure 43).

Figure 43. Sources for information about brain injury (n=37)



Other responses: Nebraska VR, doctors, connecting with other professionals, research, other brain injury service providers

> "Increase the number of professionals in Nebraska who understand brain injury so individuals can be better supported in their community."
>
> -Brain Injury Service Provider

> "Brain Injury Alliance of Nebraska has the best platform from which to connect families to services, to each other and to further education."
>
> -Brain Injury Service Provider

Conclusion

- ***Regardless of the service, individuals with a brain injury feel that service providers do not understand brain injury.***

Across seven different bundles of services, the number one barrier reported by individuals with a brain injury who have either received the service or are in need of the service is that "providers do not understand brain injury." Brain injury service providers themselves seem to echo this sentiment by the fact that just half (52.6%) of service providers rated themselves as "knowledge or very knowledgeable" in terms of their knowledge of brain injury and the needs of individuals with a brain injury. Just one-in-three (34.2%) service providers rated staff at their organization as "knowledge or very knowledgeable" about brain injury.

- ***Care coordination services are the most needed types of services as reported by individuals with a brain injury.***

Among those services indicated as being "currently in need" (i.e., those services that respondents are in need of; have requested, but not received, or are on a wait list) four of the top five fall within the category of care coordination. These services include information and referral, service and funding application assistance, and case management/service coordination. The only service in the top five of most needed services that was not a care coordination service was cognitive and/or behavioral supports (an independent living service).

Care coordination services also tend to have relatively high "barrier rates" (i.e., the percentage of those who have accessed the service or are in need of the service who report at least one barrier to the service). Most notably, general information/referral for any type of service has a barrier rate of 81.7%.

- ***Family members of individuals with a brain injury experience significant financial and emotional hardships and are in need of support services.***

Four-in-five (79.4%) family members reported that they have been prevented from gaining employment as a result of being a family member/caregiver of an individual with a brain injury. Nearly all (97.1%) of family members report that they experience emotional stress in their role as a family member/caregiver of an individual with a brain injury.

The top two services, each reported by approximately two-thirds (63.6%) of family members, that would be helpful for them as a caregiver were support group and educational events. The top barrier to receiving these types of support services for the family member is that they are not available nearby (reported by 46.9% of family members).

- ***Brain injury service providers perceive considerable gaps in most services for individuals with a brain injury.***

Across a list of 30 services, the average percentage of brain injury service providers who perceive a moderate or significant gap (indicating that some or most individuals who need the service are unable to get it) is 77.6%. The top three services have “gap ratings” of over 90%. These three services are parenting or child care supports, affordable housing, and service and funding application assistance.

- ***Brain injury service providers are prepared to provide those services that are most needed for individuals with a brain injury if more funding is made available.***

Brain injury service providers were asked what services their organization would provide if more funding were made available for individuals with a brain injury in Nebraska (such as through a state trust fund or other mechanism). The top services that organizations would be able to provide with more funding include those services that were most needed by individuals with a brain injury, such as care coordination services, brain injury support group, and cognitive and/or behavioral supports. In fact, the top five services that brain injury service providers are prepared to provide if more funding were available fell somewhere within the top 6 list of services that were reported as being currently in need by individuals with a brain injury.

Appendix A – Specific Barriers to Services Reported by Individuals with a Brain Injury

Specific barriers to each unique service are presented below in Tables A1 to A7. Note that responses are masked when the number of respondents for a specific service is less than 10.

Table A1	**Specific barriers to Care Coordination Services [among those who have ever used the service or are in need of the service]**				
	General information/ referral for any type of service (n=60)	**Information, referral, education and/or resources about brain injury (n=66)**	**Case Management/ Service Coordination (n=48)**	**Legal Services (n=34)**	**Service and funding application assistance (insurance, Social Security, etc.) (n=48)**
No barriers	18.3%	25.8%	29.2%	35.3%	27.1%
Providers do not understand brain injury	53.3%	45.5%	35.4%	26.5%	31.3%
Not available near me	16.7%	18.2%	18.8%	11.8%	12.5%
Health insurance does not cover	23.3%	16.7%	18.8%	14.7%	6.3%
Lack of transportation	20.0%	16.7%	12.5%	14.7%	10.4%
Too expensive	31.7%	13.4%	10.4%	32.4%	12.5%
Long waiting list	8.3%	6.1%	2.1%	2.9%	10.4%
Don’t feel comfortable using it	5.0%	1.5%	8.3%	5.9%	10.4%
Family or caregiver does not think I need it	8.3%	1.5%	2.1%	8.8%	2.1%
Providers do not understand my culture, beliefs, or preferences	5.0%	1.5%	0.0%	0.0%	2.1%
Not eligible for it	8.3%	4.6%	4.2%	8.8%	12.5%
Other	10.0%	10.6%	12.5%	8.8%	12.5%

Table A2 **Specific barriers to Independent Living Services (part 1) [among those who have ever used the service or are in need of the service]**

	Assistive technology, specialized equipment and/or home modifications for accessibility (n=25)	Cognitive and/or behavioral supports (improving everyday skills and/or reducing unwanted behaviors or moods) (n=39)	Chore services (n=21)	Independence skills training (n=22)
No barriers	16.0%	28.2%	33.3%	18.2%
Providers do not understand brain injury	36.0%	35.9%	19.1%	50.0%
Not available near me	12.0%	12.8%	9.5%	13.6%
Too hard to get it	20.0%	18.0%	19.1%	9.1%
Lack of transportation	8.0%	2.6%	14.3%	18.2%
Too expensive	32.0%	25.6%	14.3%	13.6%
Long waiting list	12.0%	5.1%	4.8%	4.6%
Don’t feel comfortable using it	4.0%	2.6%	9.5%	0.0%
Family or caregiver does not think I need it	0.0%	0.0%	0.0%	0.0%
Providers do not understand my culture, beliefs, or preferences	8.0%	7.7%	4.8%	0.0%
Not eligible for it	8.0%	0.0%	9.5%	0.0%
Other	20.0%	7.7%	9.5%	4.6%

Table A3 **Specific barriers to Independent Living Services (part 2) [among those who have ever used the service or are in need of the service]**

	Affordable housing (n=20)	Financial/money management (such as budgeting and maintaining a check book) (n=13)	Personal care/attendant services (n=12)	Respite care (n=7)	Transportation (n=20)
No barriers	20.0%	7.7%	33.3%	Data masked. Fewer than 10 responses.	35.0%
Providers do not understand brain injury	5.0%	30.8%	0.0%		5.0%
Not available near me	0.0%	23.1%	8.3%		10.0%
Too hard to get it	25.0%	15.4%	8.3%		25.0%
Lack of transportation	5.0%	7.7%	8.3%		25.0%
Too expensive	15.0%	15.4%	25.0%		20.0%
Long waiting list	10.0%	7.7%	0.0%		5.0%
Don’t feel comfortable using it	5.0%	15.4%	25.0%		5.0%
Family or caregiver does not think I need it	0.0%	7.7%	0.0%		0.0%
Providers do not understand my culture, beliefs, or preferences	0.0%	15.4%	0.0%		0.0%
Not eligible for it	10.0%	0.0%	0.0%		0.0%
Other	15.0%	15.4%	8.3%		5.0%

Table A4 Specific barriers to Physical Health and Well-Being Services [among those who have ever used the service or are in need of the service]

	Primary medical care (physician, hospitalization, rehabilitation) (n=57)	Ancillary medical care (includes nursing, OT, PT, speech/language therapies, nutrition/dietary services, etc.) (n=40)	Pain management (n=40)
No barriers	28.1%	26.0%	42.5%
Providers do not understand brain injury	47.4%	32.0%	25.0%
Not available near me	8.8%	4.0%	15.0%
Health insurance does not cover	21.1%	38.0%	20.0%
Lack of transportation	14.0%	12.0%	10.0%
Too expensive	21.1%	28.0%	17.5%
Long waiting list	3.5%	6.0%	2.5%
Don’t feel comfortable using it	5.3%	4.0%	7.5%
Family or caregiver does not think I need it	0.0%	2.0%	0.0%
Providers do not understand my culture, beliefs, or preferences	7.0%	10.0%	2.5%
Not eligible for it	0.0%	4.0%	0.0%
Other	12.3%	2.0%	5.0%

Table A5 **Specific barriers to Mental and Emotional Health and Well-Being Living Services [among those who have ever used the service or are in need of the service]**

	Brain Injury support group (n=57)	Mental health counseling (individual or family) (n=48)	Parenting or child care supports (n=5)	Substance use evaluation/ treatment (n=5)	Day or residential treatment for serious mental illness (n=10)
No barriers	40.4%	37.5%	Data masked. Fewer than 10 responses.		10.0%
Providers do not understand brain injury	14.0%	25.0%			50.0%
Not available near me	5.3%	4.2%			10.0%
Health insurance does not cover	12.3%	18.8%			10.0%
Too hard to get it	15.8%	6.4%			20.0%
Lack of transportation	15.8%	10.4%			10.0%
Too expensive	8.8%	22.9%			0.0%
Long waiting list	0.0%	2.1%			0.0%
Don’t feel comfortable using it	8.8%	2.1%			10.0%
Family or caregiver does not think I need it	3.5%	0.0%			0.0%
Providers do not understand my culture, beliefs, or preferences	1.8%	2.1%			20.0%
Not eligible for it	0.0%	0.0%			10.0%
Other	14.0%	10.4%			40.0%

Table A6 **Specific barriers to Education Services [among those who have ever used the service or are in need of the service]**

	Early intervention (children, 0-2) (n=1)	Special Education services under an Individualized Education Program (IEP) (children and youth, 3-21) (n=3)	Educational adjustments under a Section 504 Plan (children and youth, 5-21) (n=3)	Post-secondary education supports (community/vocational college, college, university) (n=22)
No barriers	Data masked. Fewer than 10 responses.			36.4%
Providers do not understand brain injury				36.4%
Not available near me				4.6%
Too hard to get it				9.1%
Lack of transportation				9.1%
Too expensive				9.1%
Long waiting list				4.6%
Don't feel comfortable using it				4.6%
Family or caregiver does not think I need it				0.0%
Providers do not understand my culture, beliefs, or preferences				13.6%
Not eligible for it				0.0%
Other				27.3%

Table A7 **Specific barriers to Employment Services [among those who have ever used the service or are in need of the service]**

	Job finding/ placement services (n=18)	Internet-based employment services (n=11)	Unemployment services (n=14)	Temporary staffing and employment agency services (n=8)
No barriers	22.2%	27.3%	28.6%	Data masked. Fewer than 10 responses.
Providers do not understand brain injury	44.4%	54.6%	57.1%	
Not available near me	0.0%	0.0%	0.0%	
Too hard to get it	11.1%	9.1%	7.1%	
Lack of transportation	11.1%	9.1%	0.0%	
Too expensive	0.0%	9.1%	0.0%	
Long waiting list	0.0%	18.2%	7.1%	
Don’t feel comfortable using it	11.1%	18.2%	0.0%	
Family or caregiver does not think I need it	0.0%	9.1%	0.0%	
Providers do not understand my culture, beliefs, or preferences	16.7%	0.0%	7.1%	
Not eligible for it	5.6%	0.0%	7.1%	
Other	11.1%	18.2%	7.1%	

Appendix B – Specific Services Provided by Brain Injury Service Providers

Table B1 presents a list of 30 services and the percentage of service provider respondents who reported that their organization offers each service.

Table B1	**Specific services provided by organization**	
Care Coordination (n=45)	*General information/referral for any type of service*	57.8%
	Information, referral, education and/or resources about brain injury	64.4%
	Case Management/Service Coordination	51.1%
	Legal Services	4.4%
	Service and funding application assistance (Insurance, Social Security, etc.)	26.7%
	None of the above	8.9%
Independent Living (n=41)	*Assistive technology, specialized equipment and/or home modifications for accessibility*	26.8%
	Cognitive and/or behavioral supports (improving everyday skills and/or reducing unwanted behaviors or moods)	34.2%
	Chore services	12.2%
	Independence skills training	26.8%
	Affordable housing	4.9%
	Financial/money management (such as budgeting and maintaining a check book)	26.8%
	Personal care/attendant services	19.5%
	Respite care	9.8%
	Transportation	31.7%
	None of the above	39.0%
Physical Health and Well-Being (n=39)	*Primary medical care (physician, hospitalization, rehabilitation)*	10.3%
	Ancillary medical care (includes nursing, OT, PT, speech/language therapies, nutrition/dietary services, etc.)	20.5%
	Pain management	10.3%
	None of the above	76.9%
Mental and Emotional Health and Well-Being (n=38)	*Brain Injury Support Group*	21.1%
	Mental health counseling (individual or family)	21.1%
	Parenting or child care supports	13.2%
	Substance use evaluation/treatment	7.9%
	Day or residential treatment for serious mental illness	7.9%
	None of the above	60.5%

Table B1 continued

Education (n=39)	*Early intervention (children, 0-2)*	15.4%
	Special Education services under an Individualized Education Program (IEP) (children and youth, 3-21)	20.5%
	Educational adjustments under a Section 504 Plan (children and youth, 5-21)	23.1%
	Post-secondary education supports (community/vocational college, college, university)	35.9%
	None of the above	56.4%
Employment (n=39)	*Job finding/placement services*	43.6%
	Internet-based employment services	18.0%
	Unemployment services	2.6%
	Temporary staffing and employment agency services	7.7%
	None of the above	53.9%

Appendix C – Open-Ended Comments

All comments are presented unedited as they were provided by respondents.

Comments from Individuals with a Brain Injury

Table C1 **Comments regarding barriers for Care Coordination Services**

- I was looking for information about how to prepare for future expected degeneration of cognitive functions. No one deals with that.
- Due to long illness and years of retraining and being unable to work (and family members who were willing to support me to keep me off of disability), I am not eligible for any disability payments.
- The attorneys always refer you to agencies, that this isnt anything that they have worked with before
- Agencies and people find it hard to believe that I am disable and have a TBI because I look in their eyes "Normal".
- Requested it several times from Madonna Outpatient and have been refused. If VR has it, has never been offered.
- Very few, if any, services/providers available for my type of brain injury
- I have been in Lincoln 3 years have not seen or heard anyone in such a long why did they encourage when I first got , I accept that this group are hypercritical and judgmental
- Visual services were not detected until 17 years post BI. This led to many additional physical and sensory issues for the rest of my life.
- attitudanal barriers particulary with in brain injury alliance and support groups

Table C2 **Comments regarding barriers for Independent Living Services**

- Don't know who to ask
- I am unable to do it myself. A family member keeps track for me and we are a team....using her brain ☺
- people I get assistance from dont understand my Cognitive or behavioral moods and depression, aniexity, sadness, scared, or ptsd
- I was a passenger in a car accident and now have post issues.
- "Red tape" issues with referrals to receive these services continually
- Felt I had to do most everything on my own with the exception of a few of my providers at rehabilitation who were there for me post rehab.

Table C3 **Comments regarding barriers for Physical Health and Well-Being Services**

- The provider thought I was fine
- Being overseas.
- I cannot find any providers that can help my pain

- Providers try to group me into a certain category regarding my pain before even listening to my issues
- He's retiring
- Lack of care coordination, lack of cooperation and collaboration between professionals, unwillingness to consider psychological impacts of BI, stigma and discrimination about mental illness, lack of knowledge about mental illness, lack of understanding about increased risk of suicide with BIs, especially multiple ones, lack of appreciation of impacts of all social roles with meaning when brain injured
- Completing this for elderly parent (80 yrs) and not sure they understand all the information presented
- I am back to public speaking 3 times a mo w/the help of my husband. It's a fine line what I can attempt in between that won't tip me over the edge to so much pain or out of the ability to form words proper to speak. We desperately need the income. We are barely holding on.
- Lack of providers/services in my area
- After I arrived here had to have wrist surgery and I am in constant pain, just accepted as my punishment, that's 43 years no one cares what I had to endured, ever night I beg m lord to take me away
- Mental health was the best for me since my professional assisted in helping me understand BI since family, friends, employers did not understand this. Worst part was VR not understanding BI as well as employers and this led to my losing my job and career. If both of these entities worked together, it would have been more successful for me and my future earnings. Instead, I had to start all over which was very difficult as well as going back to school which I could not afford.

Table C4 Comments regarding barriers for Mental and Emotional Health and Well-Being Services

- Having a hard time finding support groups for individuals who have TBI's.
- Other BI service providers will not accept care coordination with mental health provider and will not use her expertise and understanding of my complicated mental illnesses to improve my BI rehab progress.
- I wonder who is really in the online groups. I am in two of them. Anyone can sign up under any name and read your remarks. I have had a really negative experience with a Lincoln doctor and I wonder about the driver of the car I was in when our settlement isn't finished.
- Always having to repeat myself to new providers
- I use a service dog, there are many misunderstandings about them, like confrontational building managers.
- Have not seen Nebraska Medical Professional, only when I sprained my ankle or need surgery was unbearable now I have much worse problems I have lost so many of my teeth since I moved here, how about my pace maker which was installed in 2010 in Utah came to Nebraska they changed the batterierd for over 3 years has not been working, I am 70 years now I have asked my lord just let me die. I have given up on my 3 times , my lord had my life in his hands 4 times and brings me back to the same mess I was in.In 43 years recovery not too many could or would accept even my lord doesn't want me.
- The only way I was able to get mental health services is my provider provided me the services pro bono. I was going through many stressful issues after BI which included legal problems,

financial, abuse, losing job, losing friends and family, etc. This is what every individual needs but insurance runs out to quickly.

Table C5 Comments regarding barriers for Education Services

- I would love to go back to college. I was going when i had my brain injury, but have a tough time retaining information due to short-term memory loss.
- Vocational Rehab is a huge barrier to getting education and training needed for successful use of asstive BI technology and return to the workforce,

Table C6 Comments regarding barriers for Employment Services

- Voc Rehab doesnt under BI, refuse to earn about BI, don’t care about people with BI and resist vigorously providing services to them, especially services timely enough to do any good. All they do is delay, delay, delay.
- I feel so different from day to day I am not ready to hold down any type of hourly job. Speaking is 45 minutes so I can do that and my husband and I know how to work together. I used to take calls from our home for West in Omaha. We now have 2 dogs so I don't have perfect silence. That type of work will not work anymore. I need to be home for my writing when I am up to it.
- providers have preconceived and expectations of people with brain injury

Table C7 If a Nebraska VR service did not meet your needs, please explain why.

- VR shifted me off to Ollie Webb and that job coach had brain problems like not listening and talking all the time. Then they assigned me a different person who appreciated me but it did not really help with the stressors st work. The person I wanted said she would not be available.
- Job opportunities
- They give up too early and don't understand how to work with a person with a brain injury
- Industry methods were startlingly behind the times, test materials old, and out-of-date, and instructor uninformed.
- VR professionals do not understand BI. I know they receive training, but this needs to be more ongoing so that they will learn on the job as they go with more supports via BIA-NE as well as having someone do more job coaching with each VR employee. VR workers need assistance with all of the nuances of BI and this is not an easy task to learn. Again, this needs to be more of a team approach and together we can all assist VR counselors to deal more effectively with the physical, sensory, cognitive, and personality domains of BI. The goal is to get individuals with BI to be successful, however, I believe that VR has become a stopping point for most individuals with BI. Let's turn this around. I know that this can be accomplished with some good professionals working together.
- I attended college but no help in finding job
- Lost my job because VR takes FOREVER to do anything. They delay until you give up and go away. Do not listen. Revolves around them, not the person. Again, they delay until it’s too late

to get what you need, they are unconscionable about this. They don’t really don’t want to help. They have no understanding of BI AND CLEARLY DO NOT THINK THEY NEED IT. They believe that you might know best what you need, you just need assistance getting it. They have extremely low expectations of the person being served and actively discourage you having hopeful goals for meaning employment. ATP also takes FOREVER. They DONT LISTEN to you knowing what you need, you can give them very specific details about what you need assist with BI, THEY IGNORE IT, THINKTHEY KNOW BEST ANDWHAT YOU GET, WHEN YOU FINALLY GET SOMETHING, and I seriously mean finally, it’s nnot what will work for you because they get the wrong thing because it’s too late and not what will help with your need because they havent listened or believed you are the expert about you. All the energy I haveexpendedtrying and failingto get help with BI informed has been worse than wasted. It depleted what little momentum, initiative and energy my BI left me and I gained nothing. They are not person-centered in the least, not at all BI knowledgeable and aren’t interested in serving people with BIs, to say nothing about competent at it. All VR is is a full employment agency for VR employees. Institutional-centered, in no way person centered. Total culture and system change needed
- did nothing to actually help me move forward with recovery and rehab to normal life
- gained nothing from it

Table C8	General comments regarding services for individuals with brain injury

- Need community housing for semi independent living for younger adults that isn't mostly senior citizens. Something that makes the brain injured person feel independent and not in a care facility
- My supervisor was understanding at first, but became impatient with me a few months even though she said she understands. She can't understand because she's never had a brain injury.
- I feel that I and others were poorly diagnosed upon reporting to hospital. I think smaller town hospitals in Nebraska need to be using better protocol such that brain injury is found right away.
- I am very satisfied with my life after my accident. I feel like I am getting the most out of life when I consider what I can now offer.
- More awareness of the issues at hand. I was so uninformed or aware of this simple subject with deep avenues.
- My brain injury was 35+ years ago so I'm hopeful that services have changed for us but my hope would be that there would be more immediate follow up after the injury to discuss what to expect and the resources available.
- We are brain damaged but want to be treated as human beings just like everyone also the people who have cancer get more help and understanding what they are going through, Everyone treat TBI like freaks, I would rather be dead than continue as I have been through all those things I wasn't warned I was going to have to go,
- You need one of your responses to be n/a and or one not sure.
- I feel that people in general need more education about TBI's. My family/friends still today don't know why I have emotional breakdowns, my temper is up and down and they think I should be able to control it. I would like to see group supports for TBI's easy to find for individuals like me who want to talk to others dealing with TBI's.

- I need time to put my thoughts together.
- More services in Western Nebraska.
- Don't ever quit trying to get better.
- Need more services in out-state Nebraska.
- I had my injury out of state and before I moved to Nebraska. Some of my survey answers apply to another state, different insurance, and different time period needs. After moving to NE, I had to research independently for services, if available, for my needs. I still do, yet Support Group helps immeasurably.
- I do not have health insurance, and have requested help with services, but have never received any
- Staff at nursing home need training to deal with behaviors associated with TBI. Need more specially trained therapists in methods effective for people with TBI.
- Brain cancer resulting in brain injury. I believe being elderly is another barrier in the system to understanding what is needed to help and being open to that help.
- Having a meeting time during the day would be great. Most TBI survivors are ready for bed prior to the 7pm meeting at Village Inn on 72 & Giles in Omaha/Papillion, NE.
- The brain injured are grossly misunderstood. I did not understand until it happened to me. Our family still feels I should be well "next week". I have finally come to terms with the new me. I tell people it's a better version. My husband gets very emotional. He is very worried about our finances. We have had to foot the entire amount of expenses because their auto insurance was terrible. I want to perhaps write and speak about this to somehow make a positive out of such a negative. Perhaps being a part of your team on the 27th would be a start. I will be there the 28th and 29th in Kearney too.
- My son has a very severe traumatic brain injury. Unable to verbalize or take care of himself at all.
- Need more research on brain hypoperfusion - its causes and possible reliefs. Believe this condition is causing most of my issues both physically and mentally/emotionally and I can't find anyone that knows about it, what can be done, and IF something CAN be done, there is nothing around here (Sarpy Cunty, NE) that is available
- It is my impression that a person with a mild brain injury has to figure things out on their own. Trying to get a provider to understand that there is something wrong even though you appear normal. Finding available resources such as support groups and outpatient rehab is an extreme challenge when you are not functioning well and in pain. When you do get to the right place the system is bogged down and trying to stay afloat financially while awaiting assistance is nearly impossible. Additionally, insurance does not cover necessary services compounding the stressors. There is a lot of room for improvement in the areas of immediate assistance and education for medical professionals and the public. Brain injuries are more common than any one person is initially led to believe. I hope you are gaining good information from this survey to change our lawmaker's minds about helping brain injury sufferers.
- My life is very good all thing taken into account(no drivers liscense&subpar short term memory).
- I feel like medical providers and the education system still do not understand brain injury and/or understand the resources needed to be successful. Post-secondary education is a joke when it comes to receiving accommodations and assisting students with disabilities. Especially when you don't have a physical disability that is visible to the eye, accommodations and assistance from institutions is really difficult to receive.

- People were not unkind; they were simply not informed as to what editors now do, and how they do it (on computer screens vs. on paper, with proofreaders marks) Bringing this up with them was not viewed as confrontational; there was simply a response of their own powerlessness.
- In my particular case, my mild traumatic brain injury impaired me enough to prevent me from successfully completing my usual tasks and proving to be fully functional, but it was not "severe" enough to receive much support, so I was stuck in the middle of seeming fine to others but being far from fine in reality.
- Each individual is unique. I think it would be beneficial to have a TBI survivor working at the department(s) dealing with TBI survivors.
- It's difficult because it's never the same, every injury, every person, every event. Though there are similarities, the differences define it.
- It would be wonderful if Primary Physicians received more knowledge regarding the seriousness of a TBI. Thank you!
- Since I am so unhappy in Nebraska when I was encouraged to come to Lincoln by the TBI group and then having to adjust being alone for 3 years, since I no longer have a car when the representative Gina well tell I came to one meeting when I arrived. Never heard from anyone concern about me, after what I receive from San Degio BIF was there for me like no one bothered to help me that includes the government.I would like to share what I have endured on my own, I do not want pity just understanding I am a human being that I never had a life
- Nebraska does not have enough housing or staff for individuals with brain injuries.
- Patience and do not give up. If one doesn't work, try another until you find one you are comfortable with.
- facilitators in support groups & staff in BIA are very patronizing and have zero expectations for people with brain injuries. The annual conference should be renamed as a provider conference because that is what it truly is

Comments from Family Members of Individuals with a Brain Injury

Table C9	General comments regarding being a family member/caregiver of an individual with a brain injury

- Our 38-year old daughter suffered brain injury due to encephalitis approximately two years ago. She is presently in a nursing home, and I am her guardian since she is mentally incapacitated. Everyone associated with the nursing home agrees that setting is not the best place for my daughter, but there are really no other options for residential care at this time.
- There doesn't seem to be many services available for respite and for semi independent living for the younger adult that isn't a nursing home or senior citizens home.
- I had no idea what “you’re embarking on a marathon of events” meant at the of my sons accident 21 years ago.
- It’s very stressful at times. When you are together 24/7 with no help. Have been looking for day services to give us a break from each other.
- It is difficult
- I found the need for nursing homes willing to take a brain injury patient non existent. That was after Madonna LTAC. There need to be placement facilities that will accept brain injuries!
- The journey of helping a family member who is living with TBI has been confusing, mysterious, and stressful. Places like QLI and Madonna do not include and support family caregivers and do not provide information that would help and educate family members on how to help and get support for their person living with BI. QLI and Madonna do not really support patients if they do not like them or if they think that the patient is not submissive and obedient enough. State and federal government supports do exist, but to find and access them is so difficult. Just writing this, I have started crying because answering the question brings back so many upsetting memories and a lot of current stress. Without resource facilitation, I would be in even more distress than I am right now. Once I found a support group and once my patient was willing to connect with our resource facilitator, things got better.
- I am mother and guardian for my son who has a traumatic brain injury. I like the support groups for TBI.
- Support for siblings would be nice
- I see the need for more resourced for families and the individual with the TBI. I see the need for financial and educational support.
- It is a difficult position! Takes a lot of patience, education, time & devoted love. It’s not for everyone or every family member
- It’s hard to understand. Because she has the injury you can’t get her to go for help. She has a hard time functioning and keeping a job. I haven’t known who to turn to so I found the brain injury alliance for direction.
- The daily frustration I feel for the lack of services for my brother is overwhelming. Living West of Lincoln makes it difficult if not impossible to get any assistance. The total lack of appropriate residential facilities is disgusting and the constant excuses/run around giving by places that might be appropriate has made what is already a difficult situation even worse.
- My daughter was diagnosed due to an accident in 2005 and yes I was a medical assistant at the time but it was hard cause back then very little was known about brain injury and I knew the nursing side of it in a general circumstance but most was me doing research on the internet and its very hard when not even her physician knew but was treating her with having a brain tumor which are kinda of the same but not really and that was the frustrating part but

she is also my daughter and I had to look at all aspects. Looking back now I wish I had known more like I do now but I wouldn't change anything. Thanks to the brain injury foundation cause it does help when someone has knowledge and information about things instead of being left in the dark...

- It gets tough and sometimes frustrating. It is worth the hard walk with my Father though
- I pray that they change laws in the state of Nebraska so we can get the help my son needs.
- When my father was first diagnosed, he was in the hospital and then Madonna for three weeks. The only option for care after Madonna was QLI, but he didn't get accepted. There was absolutely zero support and I had the responsibly of taking care of him and putting my career on hold at age of 29. After a several months he turned 55, so we were able to put him in assisted living -- but even then, it wasn't the right place for him. He was too young and mobile for assisted living. (He needed cognitive help and not physical help.) He passed away shortly after we transferred him to Assisted Living. I've always been upset by the lack of education and support when he was first diagnosed. No one ever truly set expectations for me while at Madonna, or made me feel like there would help to at least set a plan for the future, and what that would look like. When he was first diagnosed, I honestly thought he'd be in rehab for months and then could go back home. Insurance was awful and he was sent to my home way too quickly. On top of all of this, my Dad did not want to go home with me or understand at all why he was going home with me... and I struggled daily with not being able to work and also trying to figure out what to do to help him.
- For rural caregivers (outside of the Lincoln/Omaha metro) transportation, travel time, lodging, appointment scheduling, and resources for fuel and vehicle repair while care giving are the most difficult road blocks.
- My daughter Cassidy, TBI 2011, now 24 years old is in an EFH. It has been a long, hard 7 years. My daughter is doing better.
- In my experience, if you're responsible have insurance and a decent paying salary insurance only gives you so many days of service for therapy etc. and we make too much money so Medicaid will take my spouses money leaving me to pay bills etc. with my salary which is not feasible especially with 2 young children in daycare.
- the support group that Gina chairs has been a lifesaver!
- Some days are very trying.
- It is a tough job
- Joe's injury changed our world completely.
- Things have gotten better over the years, but there is a real change in our home from before the accident.
- It can be very emotionally stressful for all family members (parents, siblings) along with close friends when watching a loved one suffer symptoms of a TBI. We wish we had more help with understanding long term effects and how to deal with them.
- It has been very difficult to find the right placement for our 38 yr old daughter. Who has brain injury from illness (post 2 years). We need help finding a care facility or rehab center that would help her learn/relearn skills. It has been difficult finding out information of services offered for people like her.
- I’m glad to have found this resource but resources for mild Tbi people are hard to find. Locating resources at physicians offices would have been a life saver at the beginning of our journey. Thanks for the work you do!
- our TBI group has made such a huge difference in understanding a brain injury and what the results will be afterwards.

- Since I live in Sarpy and he in Lancaster, it's a good half hour or more one way and if the weather is bad, I don't like to be on the roads. Doesn't mean his needs don't have to be met. There is no constant help.
- My family member with a TBI has a dual diagnosis in mental health. There are few or no providers with adequate training for her in our area on our insurance.
- It can be stressful when in the community and not sure of the behavior the person may exhibit based on environment and mood that day.
- It is so frustrating knowing the right thing to do for my older child. Doctors are often not trained in TBI or post concussion syndrome, and for the first year dismissed him as being overly sensitive. Being the soul person helping is so hard because the symptoms of post concussion syndrome include difficulty communicating, an inability to make decisions even when knowing the right decision leaving me to make the decisions, and often not the right ones. The one suffering PCS has good moments, or will have times with energy and then does the normal things people do, a long walk, taking an Uber to enjoy time in a park, and then the consequence of being worn out and not feeling well for days at a time afterwards and having to stay in and rest when even reading is hard. The sorrow watching your child unable to live like he used to, like others do, not being able to live normally. I pay everything for him as he cannot work, sound and noise being long lasting effects of the initial concussion. Everywhere there is sound, music in a store or restaurant. He has only limited time now and then, half an hour perhaps, on a computer. He cannot watch movies, the telephone bothers him. I wonder what will he do when I am gone as I am getting old now. Where do I turn to help him? Right now he stays with someone because I can pay for that. What of his future? I don't know. He wants to heal, to get better, to work, to marry someday. After two years none of this is possible. I pray to God that someday he can take care of himself.
- I am not sure where to find resources to help build new pathways in his brain. He has no insurance so where to get help with his drinking, finding jobs he can do and social life.
- We’ve learned a lot as a family about TBI since our daughter was diagnosed. We had no idea what was going on with her.
- I feel Ne has a good support system but more support and services are needed to help find jobs. Thank you for arranging this survey.
- My son is falling through the cracks of support system. He’s not disabled enough for group home but can’t hold a job to supplement his disability enough to live on his own. He has trouble with social interaction so has been taken advantage of numerous times and lost most of the money he has. Navigating the SS system and HHS is a nightmare and he is not able to do that himself. Housing is impossible to get at a price he can afford being on disability. Any jobs he gets are intolerant of his disability and they fire him often.
- Would be nice to help ones with brain injury that has no insurance to get assistance to deal with all their expenses
- We were VERY fortunate to have been able to receive an adequate diagnosis for our son, but even that alone cost over $4000.00 dollars. He did not have insurance at the time, but even if he had, it would not have been covered since it was part of a forensic evaluation. I have worked with many clients who are veterans. The VA does not do an adequate job of diagnosing brain injury, in my opinion, so clients are left to obtain this diagnosis on their own, something that is not doable if one is unemployed, substance involved, homeless, etc. There needs to be better and more widely available adequate diagnostic and treatment availability in the state. I spent many years after my son's brain injury providing education as a conference presenter on the issue. Those with brain injuries are 20% more likely to become

substance involved and are 50% more likely to fail treatment, yet screening for brain injury in treatment facilities is not adequate or not done at all, and it certainly does not occur in legal circles. I would like to see that rectified. My son was facing a 40 year prison sentence. After adequate diagnosis and rehabilitation, he is now gainfully employed, just bought a home, is substance free and is able to maintain relationships - none of which was true in the first years after his brain injury. We are grateful that he is doing as well as he is, but we were completely on our own getting there, both financially and in other ways - except for Gina Simanek at Brain Injury Alliance. We found her to be supportive and helpful on the emotional side. Nebraska is always near the bottom of the states for meeting mental health needs. I would have to say the same is true for meeting the needs of those with brain injury. We traveled out of state to have our son evaluated. I am saddened that there are so many in Nebraska who cannot get needs met here. I will also say that Voc Rehab has not been helpful with clients who screen positive for brain injury. There needs to be a broader understanding of ways that things like chemotherapy, West Nile virus, etc. can compromise brain health. It is not always about an assault, you know? Even when the TBI is "mild", the effects are not mild. That word needs to be stricken from the literature. If you have cancer there is a 5 year mark after which you are considered cured. There is no such mark with TBI. My son is at risk for dementia at any time because of the brain injury. So much needs to change!

- I feel that as a sister to a younger brother who has a brain injury is very challenging. The social ques that he struggles with are challenging for everyone involved and you can be putting fires out with others because of his actions. He doesn't always understand the right from wrong or if he has over stepped so I want EVERYONE to know how serious a brain injury is and that he is not picking up their ques so sometimes you have to be forward and then that upsets him when we have these conversations with him. I would love to have a counselor that specializes in this that would be covered by medicare for him. I also hate the fact that we have to always worry about finances for him. He gets disability but because he was so young when it happened he doesn't have enough to survive on. So we have to pick and choose what types of services he can have based on his medicare. He has a brace that he wears that is installed in his boots and he has to go through hoops just to be able to get it when his shoes need to be replaced and if it breaks more hoops. Someone that lives with a brain injury has constant hoops and it would be amazing to lessen them for those people as well as the family members and support members. I could go on forever about making resources more accessible to people! I really hope that with Medicaid expanding some of this may be a little easier
- You give me hope that our state is interested in helping our family and advocating for resources and assistance. Being a caregiver is a lonely pursuit.
- my daughter suffers from anoxic brain injury from ARDS ie lack of oxygen. It seems if it's not traumatic brain injury there aren't services to help:(
- Navigating the school system is difficult at best. I work in the school system and still found it extremely difficult and frustrating to try and convince the school something was still going on with my son after his severe concussion. I had to fight to get a 504 with accommodations the school doesn't think he needs and my son refuses to take. Exact words from the counselors mouth "you need to decide if you want your son in advanced classes and struggling or in regular classes with all A's."
- What to do with her, if something should happen to myself. Not any group homes for only tbi individuals, or apartments with some help.
- The lack of awareness and support for the majority of folks that appear to be "fine" who in fact do have challenges resulting from TBI.

Comments from Brain Injury Service Providers

Table C10	What changes in services would you recommend to better meet the needs of individuals with TBI and their families in Nebraska?

- There are organizations doing this work that lack funding. There is BI funding coming into the state that doesn't get to these organizations,
- More resources in rural areas.
- increase education, support, and case management services
- More funding to assist individuals live independently so they don't end up in appropriate settings, such as assisted living, nursing homes, etc.
- When an individual isn't eligible for Medicaid/Medicare and has no SPMI diagnosis, there is no funding or services for an individual needing case management services or Day Services
- More services and funding in general. There are a lot of gaps.
- Understanding TBI as often people forget easily that someone has this disability
- Awareness of services
- Centralized services
- Supported Employment providers throughout the state
- Yearly free training for VR and ATP staff to assist clients with TBI, in employment and educational accommodations. Where to seek out other resources to assist them. If we are educated we can help educate individuals and families.
- More awareness to general public
- The top of my list are better services through vocational rehabilitation where VR will work with BIA-NE in a team approach to learn from one another in assisting/serving individuals with BI; substance abuse programs/mental health programs/corrections and prison systems need more education and services about BI since they have revolving doors where these populations never improve and they are always coming back since the systems not assist nor are they appropriate for individuals with BI.
- Job location and job training services are abysmal for people with brain injuries living in Nebraska.
- Medical and Housing institutions like Quality Living Inc (QLI) to have additional locations so that it can more easily be accessed, considered, and utilized for those experiencing a TBI that live in the central and western parts of the State.
- State funding
- Increase the number of professionals in Nebraska which understand brain injury so individuals can be better supported in their community. Increase brain injury prevention. Increase Brain Injury case management type services so individuals can be supported in the community.
- Assistance for parents/family with accessing support groups and financial assistance. Assistance for schools in finding appropriate vocational placements/job coaching/transportation for rural students having TBI.
- a more integrated system of care is needed with providers, family, patients and others interact. The council is a step in this direction but limited in capacity and mission. 2) Additional outpatient and support group activities. NE is blessed with "deep end" providers, but much less after the crisis.
- Limiting the gap between medical-family-schools.
- Understand spectrum that is BI. People with BI can provide service, education and supports as well as need these services. Build the specific system.

<table>
<tr><th>Table C11</th><th>What do you think is working best in the current system of care for individuals with TBI and their families in Nebraska?</th></tr>
<tr><td colspan="2">• Brain Injury Alliance of Nebraska has the best platform from which to connect families to services, to each other and to further education. Needs to be expanded.
• The BI conference
• acute care, post acute rehab...service coordination, follow up care, and support after discharge is the problem
• Waivers work great, but we need funds for individuals with TBI to expand.
• Information is available. Schools are much better educated on brain injury.
• Madonna program
• BAINE
• funding for educational learning
• Madonna, UNMC and QLI have been working well for our individuals with BI, although, they can only take in so many and so many more need their services but do not have access to them, nor get the time of services they need due to lack of beds or insurance.
• I think Nebraska's medical model does a good job serving people with brain injury as long as there is coverage for that service. Once those benefits or services run out, there is not adequate community-based support.
• Health/Rehab programs for folks with TBI.
• Growing awareness of the issue. 2) Deep end acute and intermediary care.
• Unsure
• Nebraska state brain injury conference
• BIA-NE focus specifically on the individual/family with BI.</td></tr>
</table>

<table>
<tr><th>Table C12</th><th>What other additional comments or ideas would you like the people who plan statewide services and supports to know?</th></tr>
<tr><td colspan="2">• Work with what is working, stop trying to create something new. That is not smart management and will lead to fractured services.
• There needs to be better support and case management after discharge into the community.
• Offer education on BI every few years.
• Great staff makes a world of difference
• I have served this population for 26 years and I see some hope, but then that hope is persistently fading due to the economic state of Nebraska, legislation not seeing/understanding the needs of BI on Nebraskans and no one seems to really care about the plight of those trying to recover from BI in the state of Nebraska. We need legislation to recognize and implement incoming money for BI. Without this legislation, we are doomed to thrive as other states have in serving their BI population such as Iowa, Kansas, Minnesota, Colorado, etc. What is it going to take? All of us working together, not just the BIA-NE or the BI Advisory Council. We also need a bigger voice from those we serve and to get them and the BI professionals involved. Otherwise, we will always flounder and the few of us that work so tirelessly with this population will die out.
• Thank you for your work in this arena. It is mostly unknown to the majority of Nebraskans until it hits home.
• Unsure</td></tr>
</table>

- Combine Developmental Disability with Brain Injury waver - Wyoming did this back in the late 1990's.
- BIA-NE to build a statewide network of lifespan all BI. Instead of dispersing focus put efforts towards building a statewide network for people in need to know where to contact without all the current confusion.

Appendix D – Urbanicity Definitions

The urbanicity definitions (large urban, small urban, and rural) were created by Nebraska DHHS. The three broad urbanicity categories defined below by grouping different metropolitan, micropolitan, and non-metropolitan classifications.

Large Urban

- *Core metropolitan* (Douglas, Sarpy, Lancaster)
- *Core metropolitan outlying* (Washington, Saunders, Seward, Cass)

Small Urban

- *Non-core metropolitan* (Dakota, Hall)
- *Non-core metropolitan outlying* (Howard, Hamilton, Merrick, Dixon)
- *Micropolitan* (Scotts Bluff, Lincoln, Dawson, Buffalo, Adams, Madison, Dodge, Platte, Gage)

Rural

- *Micropolitan outlying* (Banner, McPherson, Logan, Gosper, Kearney, Clay, Pierce, Stanton)
- *Non-metro/micro with large town* (Dawes, Box Butte, Cheyenne, Cherry, Keith, Custer, Red Willow, Phelps, Holt, York, Jefferson, Richardson, Nemaha, Otoe, Saline, Butler, Colfax, Cuming, Wayne)
- *Non-metro/micro with no large towns* (Sioux, Kimball, Morrill, Sheridan, Garden, Deuel, Grant, Arthur, Perkins, Chase, Dundy, Hooker, Thomas, Hayes, Hitchcock, Frontier, Furnas, Harlan, Keya Paha, Brown, Blaine, Rock, Loup, Boyd, Garfield, Wheeler, Valley, Sherman, Franklin, Greeley, Webster, Nuckolls, Nance, Boone, Antelope, Polk, Fillmore, Thayer, Pawnee, Johnson, Knox, Cedar, Thurston, Burt)