

2020 Living with Brain Injury Surveys Results

Brain Injury and Behavioral Health

Nebraska needs assessment surveys of individuals living with a brain injury, their family members, and behavioral health providers on the intersection of brain injury and behavioral health



**2020 Living with Brain Injury Surveys Results:
*Brain Injury and Behavioral Health***

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Nebraska VR
Program for Acquired Brain Injury

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Contents

| | |
|--|----|
| Executive Summary | 1 |
| Introduction and Methodology | 1 |
| Selected Results for Individuals Living with a Brain Injury | 1 |
| Selected Results for Family Members of Individuals with a Brain Injury | 5 |
| Selected Results for Behavioral Health Providers | 6 |
| Introduction | 11 |
| Methodology | 11 |
| Survey Results for Individuals Living with a Brain Injury | 12 |
| Respondent Demographics | 12 |
| Services and Supports | 13 |
| Behavioral Health | 15 |
| Substance Misuse | 21 |
| Chronic Pain..... | 22 |
| COVID-19 | 23 |
| Perceptions of Behavioral Health and Brain Injury | 24 |
| Tele-Health | 26 |
| Survey Results for Family Members of Individuals with a Brain Injury..... | 27 |
| Respondent Demographics | 27 |
| Mental Health..... | 28 |
| Substance Misuse | 30 |
| Behavioral Health Services for the Family Member with a Brain Injury..... | 30 |
| Support..... | 33 |
| Survey Results for Behavioral Health Providers | 34 |
| Respondent Demographics | 34 |
| Awareness of Brain Injury | 36 |
| Screening for Brain Injury..... | 37 |
| Clinical Treatment of Individuals with a Brain Injury..... | 38 |
| Referrals and Resources for Brain Injury..... | 39 |
| Training and Education on Brain Injury | 41 |
| Barriers Related to Brain Injury and Behavioral Health..... | 43 |
| COVID-19 | 45 |
| Conclusion – 10 Key Takeaways | 46 |
| Appendix A: Open-Ended Comments | 48 |
| Appendix B: Urbanicity Definitions..... | 58 |

Executive Summary

Introduction and Methodology

The 2020 Living with Brain Injury Surveys are comprised of three separate surveys for individuals with a brain injury, their family members/caregivers, and behavioral health providers. The surveys focused on the intersection of brain injury and behavioral health. The survey was conducted primarily online with a paper option available by request during the months of October and November of 2020.

A total of 57 individuals with a brain injury (BI), 30 family members/caregivers, and 38 behavioral health (BH) providers participated in the 2020 Living with Brain Injury Survey.

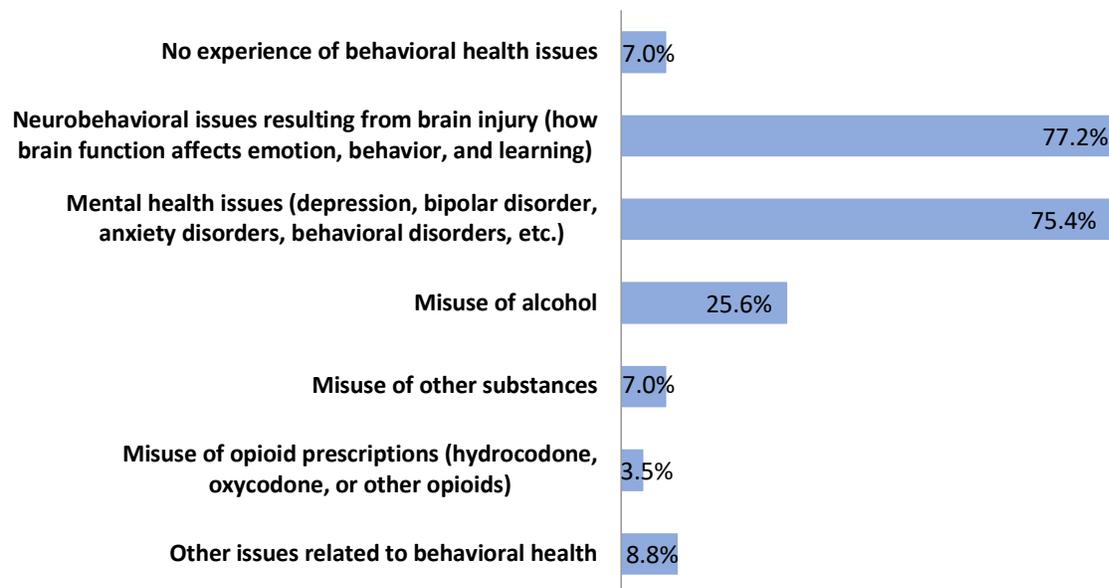
Selected Results for Individuals Living with a Brain Injury

The vast majority (93%) of individuals living with a brain injury had at least some experience of behavioral health issues. Approximately three-in-four had experience of Neurobehavioral and/or mental health issues. A small, but notable minority, also reported misuse of alcohol, substances, and/or opioids (Figure 1).

"I cannot help being depressed. It is not under my control and I cannot think myself out of it."

- Individual living with a brain injury

Figure 1. Current or past experiences of behavioral health issues (n=57)



Other experiences: internet addiction disorder, seizures, food, self-pleasure

Among individuals living with a brain injury with an experience of behavioral health issues, the number one reported barrier to obtaining behavioral health services is “providers do not understand brain injury” (reported by 61%). Behavioral health providers themselves are in agreement, with 77% reporting this same issue as a barrier. Family members tended to report a fewer number of barriers than individuals with a brain injury and behavioral health providers, yet this issue was the second most commonly reported barrier by family members. Lastly, it is important to note that 86% of all individuals with a brain injury with an experience of behavioral health issues reported at least one barrier to obtaining behavioral health services (Table 1).

| Table 1 | | |
|---|--|--|
| Top 5 reported/perceived barriers to obtaining behavioral health services for someone with a brain injury | | |
| Individuals with BI (n=51) (with experience of BH issues) | Family Members (n=22) (whose family member with BI experiences BH issues) | Behavioral Health Providers (n=31) |
| <ol style="list-style-type: none"> 1. Providers do not understand brain injury (60.8%) 2. Reluctancy to seek help due to stigma (37.3%) 3. Health insurance does not cover (27.5%) 3. No providers available in the local community (27.5%) 3. Too expensive (27.5%) 3. Difficulty following up on tasks related to services (27.5%) | <ol style="list-style-type: none"> 1. Did not receive a referral to BH services from primary medical provider (31.8%) 1. No providers available in the local community (31.8%) 2. Providers do not understand brain injury (27.3%) 2. Reluctancy to seek help due to stigma (27.3%) 2. Health insurance does not cover (27.3%) 2. Too expensive (27.3%) | <ol style="list-style-type: none"> 1. Providers do not understand brain injury (77.4%) 2. Reluctancy to seek help due to stigma (74.2%) 3. Health insurance does not cover (58.1%) 4. Did not receive a referral to BH services from primary medical provider (54.8%) 5. Application and paperwork process are too difficult (51.6%) |
| <i>No barriers (13.7%)</i> | <i>No barriers (13.6%)</i> | <i>No barriers (0.0%)</i> |

"I struggled how to cope with the side-effect of anger as a result from the TBI. Whether the therapist was aware of common side-effects or not, I felt completely misunderstood as I was chastised for my actions during a time that was very confusing for me."

- Individual living with a brain injury

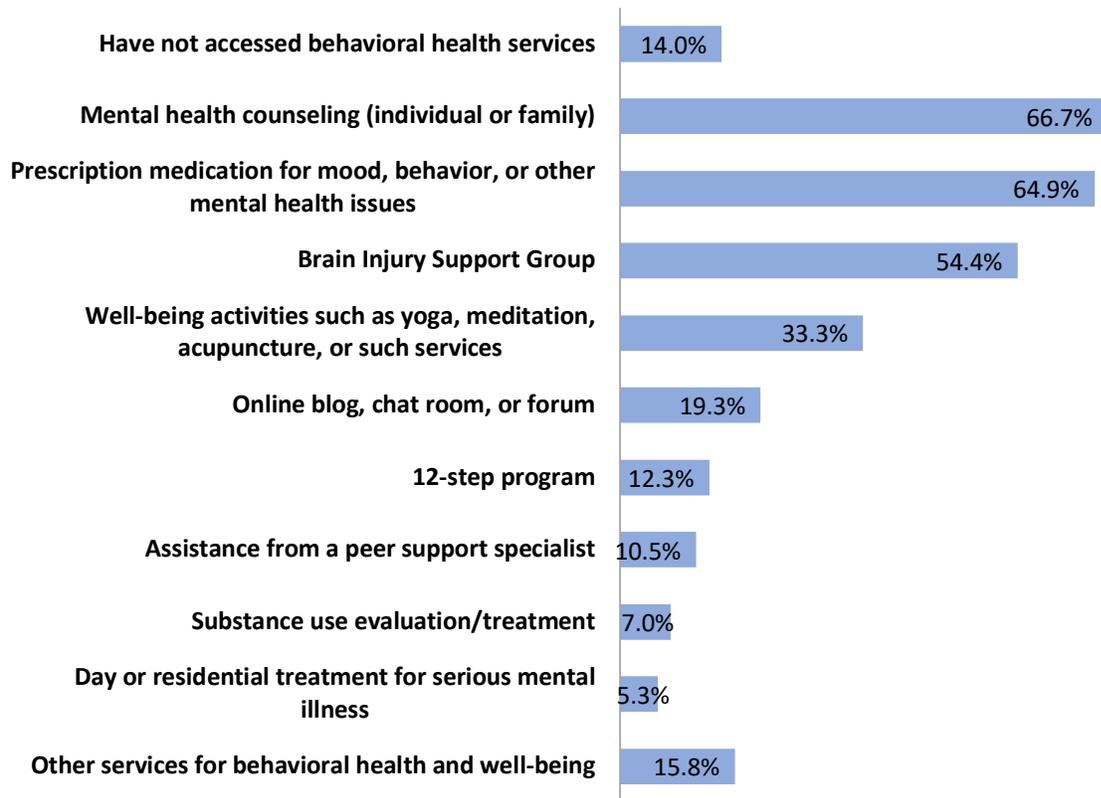
"I would venture to say that most in my own profession do not know that anxiety and depression are the two most common emotional components of TBI, yet most do not even screen for brain injury, let one actually knowing what to do with it."

- Behavioral health provider

The vast majority (86%) of individuals living with a brain injury have accessed (and may be currently accessing) one or more behavioral health and well-being service as a result of having a brain injury. The most commonly accessed services include mental health counseling (67%); prescription medication for mood, behavior, or other mental health issues (65%); and brain injury support group (54%) (Figure 2).

"I had behavioral health problems before my wreck, but it got a lot worse after it. I could no longer function the way I use to, I wasn't me anymore. I hated it. I didn't understand, or accept, that I would have to work around my injury."
 - Individual living with a brain injury

Figure 2. Current and/or past use of behavioral health and well-being services as a result of having a brain injury (n=57)



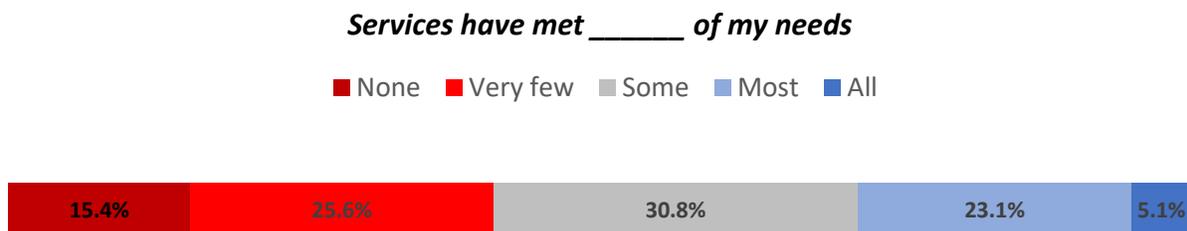
Other services: VA, anger management, hotlines, previous training in brain injury, College Disability Rights organizations, supplements/herbs, BIA-NE, neuropsychologist, physical therapy, Prisms, holistic healing, Madonna

Among those living with a brain injury who have ever received behavioral health services, feelings are mixed as to how well the behavioral health services they have received have met their needs. A plurality (41%) say that behavioral health services have met “none” or “very few” of their needs, 31% say the services have met “some” of their needs, and just 28% say the services have met “most” or “all” of their needs (Figure 3).

"I had no idea there was the possibility of "retraining your brain" so-so-speak. Insightful therapy could have helped me realize I still had potential and to not simply give up things I could no longer do as well."

- Individual living with a brain injury

Figure 3. Overall, how well have the behavioral health services you have received met your needs as an individual with a brain injury? (among those who have ever received behavioral health services) (n=39)



"It's depressive not finding help or know where help is."

"While evidenced based, most treatment plans completely disregard person-centered planning and involvement as each individual is unique."

"There needs to be a link between the behavioral health and the primary care physicians or other care givers to include mental health services into their plan of recovery."

"A big impact would be to have the medical providers get additional training and understanding brain injury. Then, them having a commitment to make appropriate referrals for their patients."

- Individuals living with a brain injury

Selected Results for Family Members of Individuals with a Brain Injury

Nearly all (97%) of family members experience at least some emotional stress in their role as a family member and/or caregiver of an individual with a brain injury (Figure 4).

Figure 4. Experience emotional stress in role as family member and/or caregiver of an individual with a brain injury (n=30)



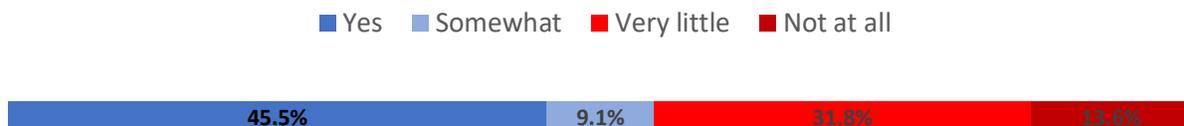
In spite of the emotional stress that family members report, a relatively small minority (23%) report that they have accessed any type of mental health counseling services due to their role and responsibilities of being a family member and/or caregiver of an individual with a brain injury (Figure 5).

Figure 5. Have accessed any type of mental health counseling services due to role and responsibilities of being a family member and/or caregiver of an individual with a brain injury (n=30)



Just under half (46%) of family members reported that they have support from other members of their family to assist with the care plan for their family member with a brain injury. A small minority (9%) responded “somewhat”, and the remainder (45%) responded “very little” or “not at all” (Figure 6)

Figure 6. Do you have support from other members of your family to assist with the care plan for your family member with a brain injury? (n=24)



"It is the hardest task I have ever had and I am 59 years old. I not only make sure she is safe from others, but also safe from herself. I can't trust her or anyone to keep her safe, so I don't get to take breaks. But we are blessed and I love her and am her mother, and that is what mothers do.... we love and care for our children."

- Family member of an individual with a brain injury

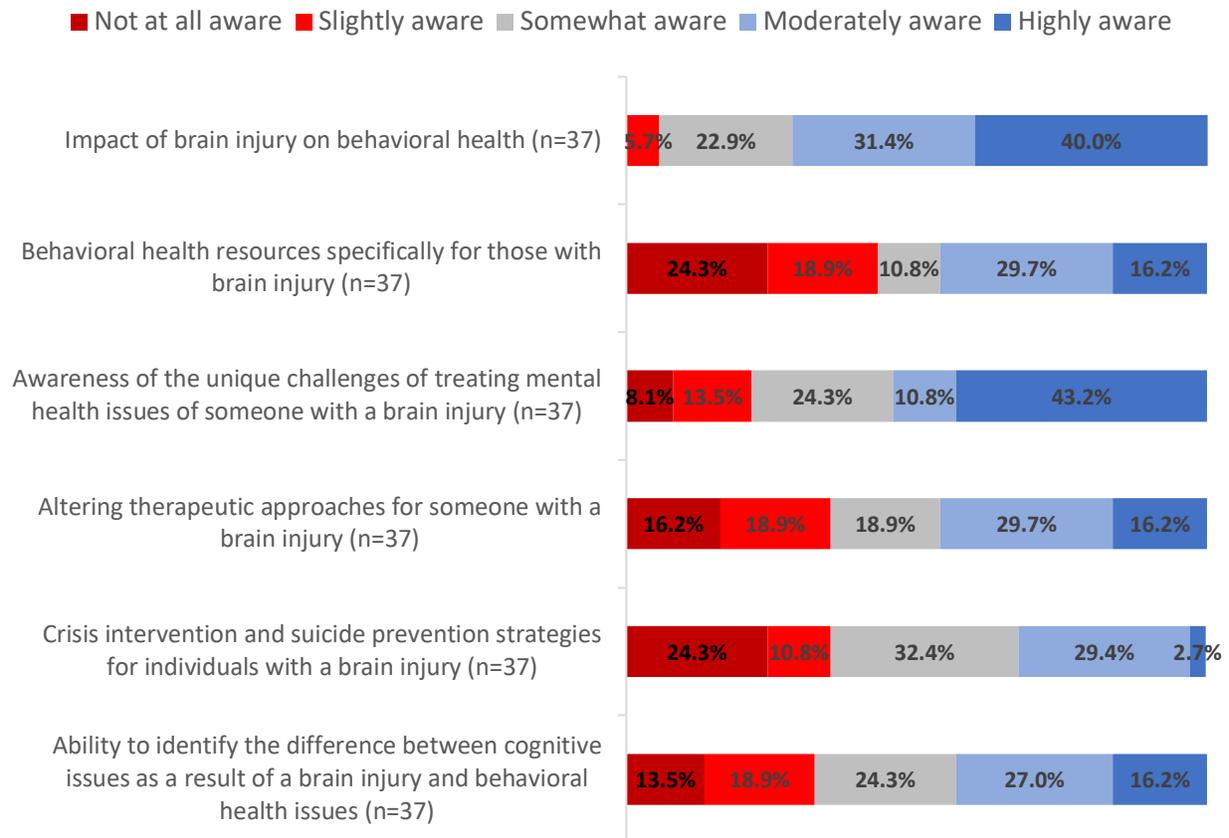
Selected Results for Behavioral Health Providers

Behavioral health providers report mixed levels of awareness of the intersection between brain injury and behavioral health. A few areas of apparent need for education and training include behavioral health resources specifically for those with brain injury (44% reported being “moderately” or “highly aware”), crisis intervention and suicide prevention strategies for individuals with a brain injury (31% reported being “moderately” or “highly aware”), and the ability to tell the difference between cognitive issues as a result of brain injury and behavioral health issues (43% reported being “moderately” or “highly aware”) (Figure 7).

"This area is misunderstood and mis-diagnosed. The general community and providers do not recognize the levels of TBI. Mild and moderate TBI needs intervention as much as severe. There is also a lack of acknowledgement for SUD [substance use disorder] regarding TBI."

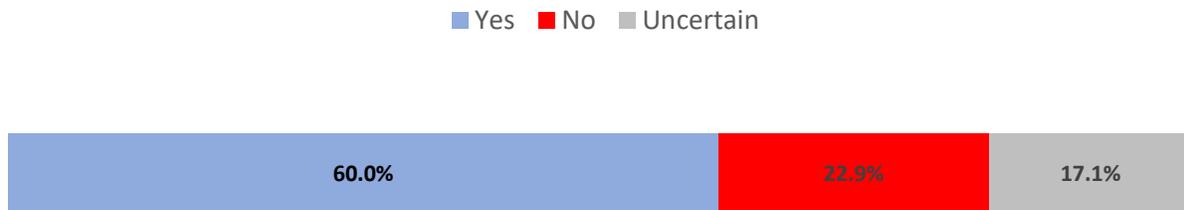
- Behavioral health provider

Figure 7. Awareness of Brain Injury and Behavioral Health



Most providers (60%) report that they treat individuals living with a brain injury. A notable minority (17%) do not know if they do or not (Figure 8).

Figure 8. Do you treat individuals living with brain injury (n=38)



Just over half (55%) of behavioral health providers reported that they screen for a lifetime history of brain injury (Figure 9). *However, among those who do screening, 86% report using only an informal set of questions at intake.*

Figure 9. Screen individuals for a lifetime history of potential brain injury incidents (n=38)

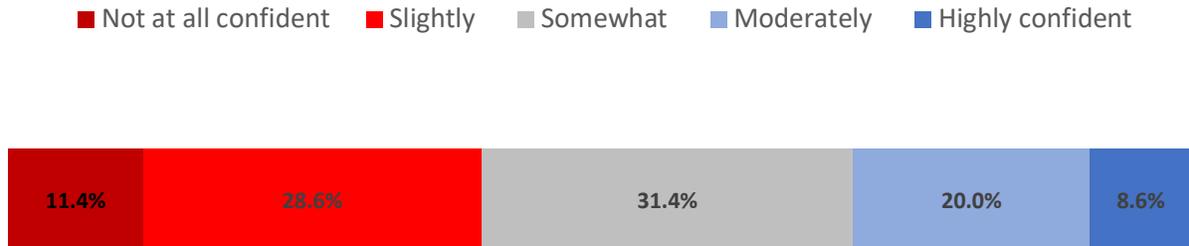


"The impacts of brain injury are not adequately understood/recognized either in the medical or mental health community. Dr. Wayne Gordon states that "Unidentified TBI is a major unrecognized cause of social, vocational and educational failure." I believe this to be true and yet there is no adequate, systemic screening mechanism in any of these arenas. I believe that counseling and social work education programs should all be educated in depth about TBI and that screening should be taught in mental health programs and mandated. People with TBI are 20% more likely to become substance involved and 50% more likely to fail treatment so I think the same needs apply in the substance use fields as in the mental health system, yet we are failing these clients in an alarming way, including with inappropriate personality disorder diagnosis when the actual issue is brain injury. Travesty."

- Behavioral health provider

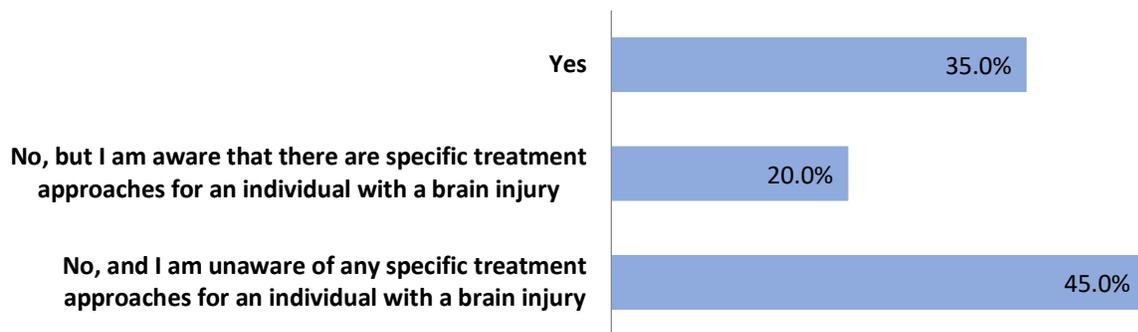
Behavioral health providers reported mixed levels of confidence in providing behavioral health treatment for an individual with a brain injury. A plurality (40%) reported that they are “not at all” or “slightly confident”, 31% reported being “somewhat confident”, and 29% reported being “moderately” or “highly confident (Figure 10).

Figure 10. How confident do you (or would you) feel in providing behavioral health treatment for an individual with a brain injury? (n=35)



Among those who treat individuals living with a brain injury, just one-third (35%) report that they use specific therapeutic approaches for an individual with a brain injury. Nearly half (45%) are unaware of any specific treatment approaches for an individual with a brain injury (Figure 11).

Figure 11. Do you use specific therapeutic approaches for an individual with a brain injury?(among those who treat individuals living with a brain injury) (n=20)



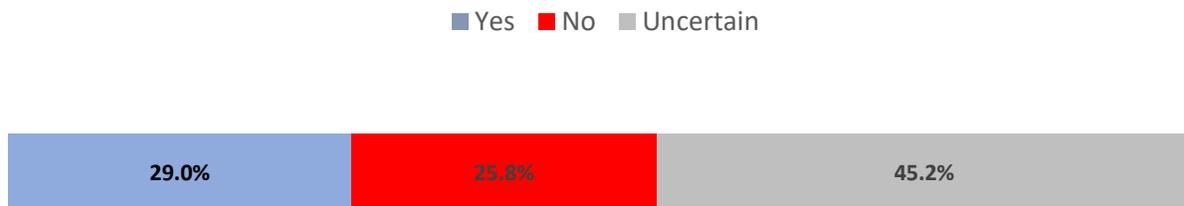
Just over half (54%) of behavioral health providers have participated in training or educational opportunities specifically on brain injury (Figure 12).

Figure 12. Have participated in training or educational opportunities specifically on brain injury (n=31)



A minority (29%) of behavioral health providers indicated that the mental health education system provides them with any opportunities to learn about specific health treatment options for individuals with a brain injury. About one-in-four (26%) indicated that this is not the case and a plurality (45%) were uncertain (Figure 13).

Figure 13. Does the mental health education system provide you with any opportunities to learn about specific health treatment options for individuals with a brain injury (n=31)



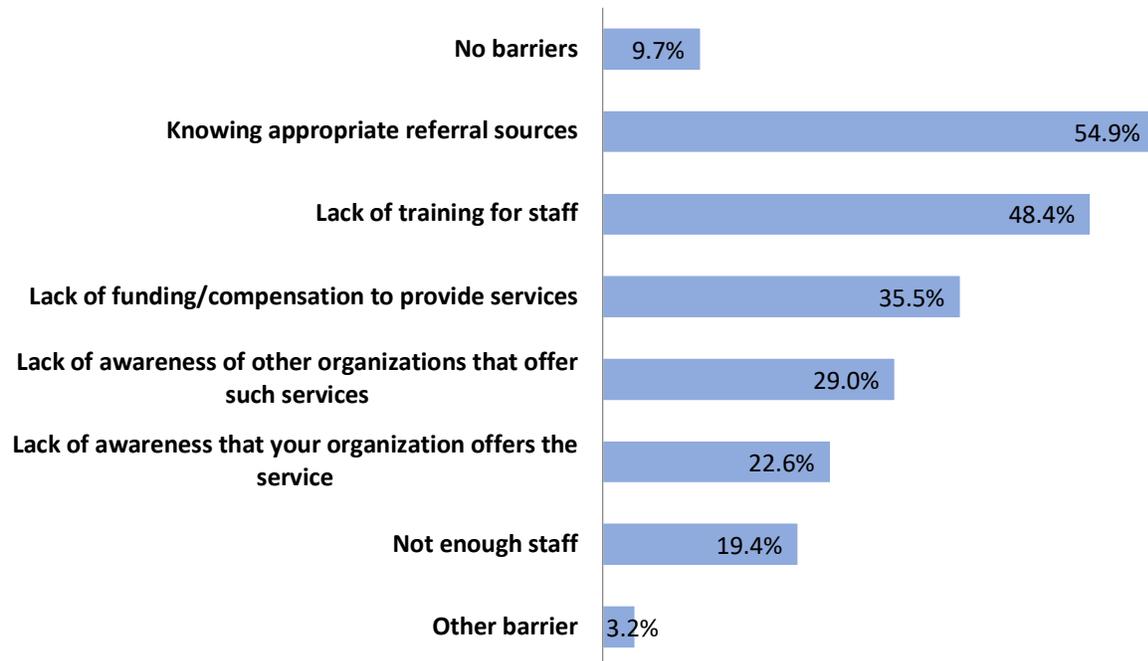
Three-in-four (74%) behavioral health providers are interested in receiving training on brain injury and its impact on behavioral health (Figure 14).

Figure 14. Are you interested in receiving training on brain injury and its impact on behavioral health? (n=31)



The top three barriers to providing behavioral health services for individuals with a brain injury are “knowing appropriate referral sources” (reported by 55% of behavioral health providers), lack of training (48%), and lack of funding/compensation to provide services (35%) (Figure 15).

Figure 15. Does your organization experience any of the following barriers to providing behavioral health services for individuals with a brain injury? (n=31)



Other barriers: barriers posed by insurance companies with regard to alternative treatments/approaches such as SPECT scanning.

"I am primarily a substance use education provider (IOP program) and often wonder how many of my clients have undiagnosed brain injuries. I have fair awareness of the issues with brain injuries and often wonder how to get my clients assistance when they majority have no income and may not grasp the need for assessment for such as their life experience is not open to see the possibility."

- Behavioral health provider

2020 Living with Brain Injury Surveys Results: Brain Injury and Behavioral Health

Introduction

Previous research in Nebraska estimates that approximately half of all individuals living with a brain injury experience behavioral health issues, and these issues often go undiagnosed and untreated (2010 Nebraska Traumatic Brain Injury Needs and Resources Assessment). In order to learn more about this intersection between brain injury and behavioral health, Nebraska VR and the Nebraska Brain Injury Advisory Council administered the 2020 Living with Brain Injury Surveys: Brain Injury and Behavioral Health.

The 2020 Living with Brain Injury Surveys are comprised of three separate surveys for individuals with a brain injury, their family members/caregivers, and behavioral health providers. The three separate surveys that comprise the 2020 Living with Brain Injury Survey are needs assessment surveys, designed for the purpose of being able to assess needs and gaps with regard to behavioral health issues for individuals with a brain injury and their family members/caregivers, as well as gauging the current understanding and practice of behavioral health providers as it relates to brain injury.

Methodology

The 2020 Living with Brain Injury Surveys: Brain Injury and Behavioral Health were conducted primarily online via SurveyMonkey with a paper option available upon request during the months of October and November of 2020. 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 behavioral health 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, the Nebraska Brain Injury Advisory Council, the Brain Injury Alliance of Nebraska, and local brain injury support groups. As many individuals with a brain injury, family members/caregivers, and behavioral health providers were invited to participate in the survey as possible.

A total of 57 individuals with a brain injury (BI), 30 family members/caregivers, and 38 behavioral health (BH) providers participated in the 2020 Living with Brain Injury Survey.

Survey Results for Individuals Living with a Brain Injury

Respondent Demographics

A total of 57 individuals living with a brain injury responded to the survey. For most (71%), their most recent brain injury occurred five or more years ago. Other demographics are detailed in Table 2 below.

| Table 2 | Respondent Demographics | |
|---|---|-----------|
| <i>Total number of surveys collected</i> | | 57 |
| <i>Time since most recent brain injury (n=49)</i> | <i>Less than one year</i> | 4.1% |
| | <i>1-2 years</i> | 20.4% |
| | <i>3-4 years</i> | 4.1% |
| | <i>5 or more years ago</i> | 71.4% |
| <i>Severity of most severe brain injury (n=49)</i> | <i>Mild (loss of consciousness for 0-30 minutes)</i> | 38.8% |
| | <i>Moderate (loss of consciousness for 30 minutes – 24 hours)</i> | 12.2% |
| | <i>Severe (loss of consciousness for over 24 hours)</i> | 24.5% |
| | <i>Unsure</i> | 24.5% |
| <i>Urbanicity* (n=50)</i> | <i>Large Urban</i> | 48.0% |
| | <i>Small Urban</i> | 36.0% |
| | <i>Rural</i> | 16.0% |
| <i>Gender (n=49)</i> | <i>Male</i> | 32.7% |
| | <i>Female</i> | 61.2% |
| | <i>Other/prefer not to say</i> | 6.1% |
| <i>Race/ethnicity (n=49)</i> | <i>White/Caucasian</i> | 95.9% |
| | <i>Non-White/Caucasian</i> | 4.1% |
| <i>Age group (n=50)</i> | <i>24 and under</i> | 2.0% |
| | <i>25-44</i> | 32.0% |
| | <i>45-64</i> | 52.0% |
| | <i>65 and over</i> | 14.0% |

*See Appendix B for urbanicity definitions.

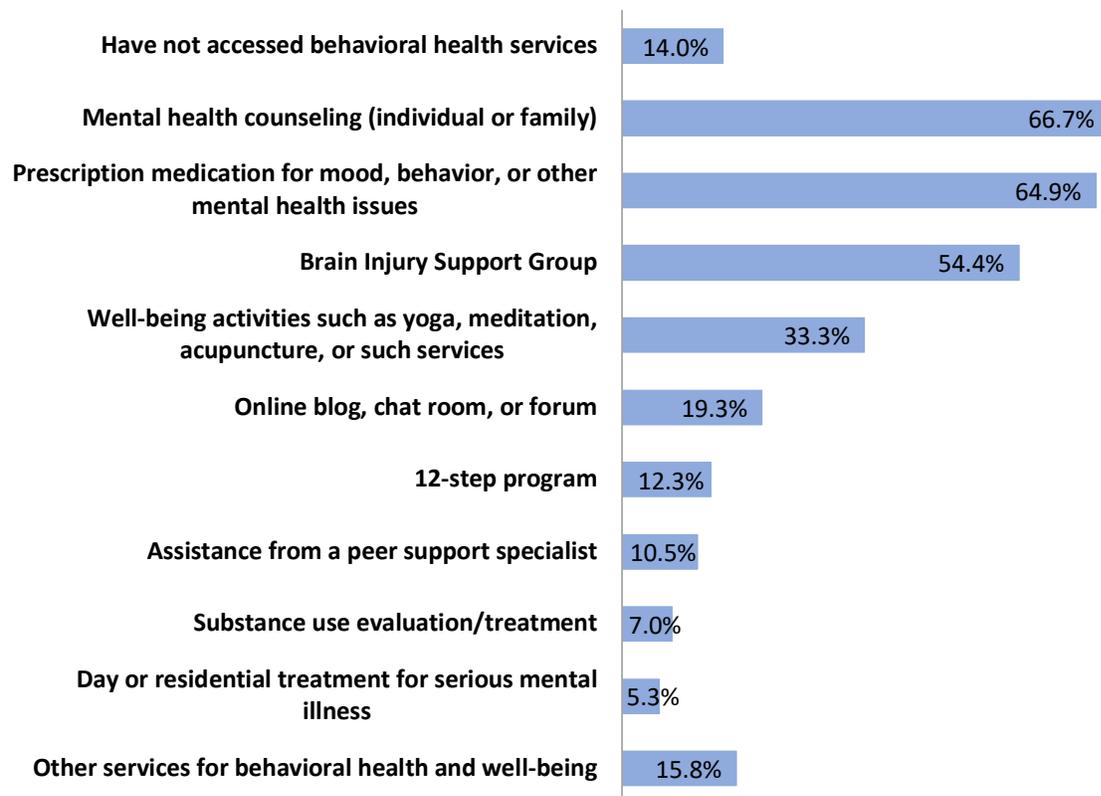
Services and Supports

The vast majority (86%) of individuals living with a brain injury have accessed (and may be currently accessing) one or more behavioral health and well-being service as a result of having a brain injury. The most commonly accessed services include mental health counseling (67%); prescription medication for mood, behavior, or other mental health issues (65%); and brain injury support group (54%) (Figure 16).

"I had behavioral health problems before my wreck, but it got a lot worse after it. I could no longer function the way I use to, I wasn't me anymore. I hated it. I didn't understand, or accept, that I would have to work around my injury."

- Individual living with a brain injury

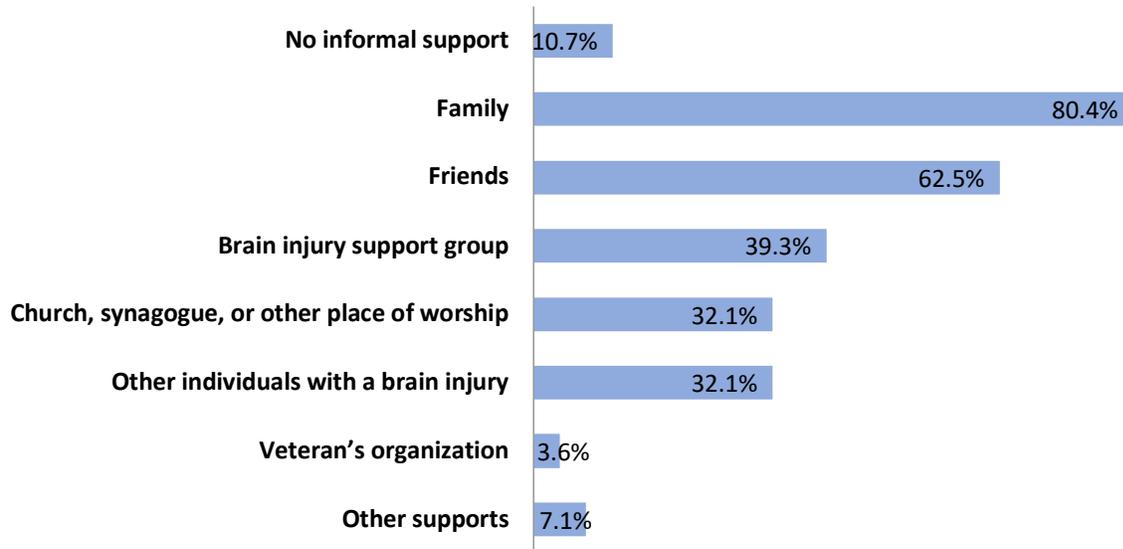
Figure 16. Current and/or past use of behavioral health and well-being services as a result of having a brain injury (n=57)



Other services: VA, anger management, hotlines, previous training in brain injury, College Disability Rights organizations, supplements/herbs, BIA-NE, neuropsychologist, physical therapy, Prisms, holistic healing, Madonna

Most (91%) individuals living with a brain injury have at least one informal support. Four-in-five (80%) have family as a support (Figure 17).

Figure 17. Current informal supports (n=56)



Other supports: BIA-NE, Madonna, doctors, hotline, creative outlets, yoga, animals, outdoors

"Had I known what I know now.... I would like people to know that their loves ones they've known their whole life can easily and suddenly act uncharacteristically. Support, patience, and understanding are important."

"Overall, society & those suffering with a BI need to understand this may be an outcome of brain injury so it can be better understood and de-stigmatized. There is still such a lack of knowledge and supports."

- Individuals living with a brain injury

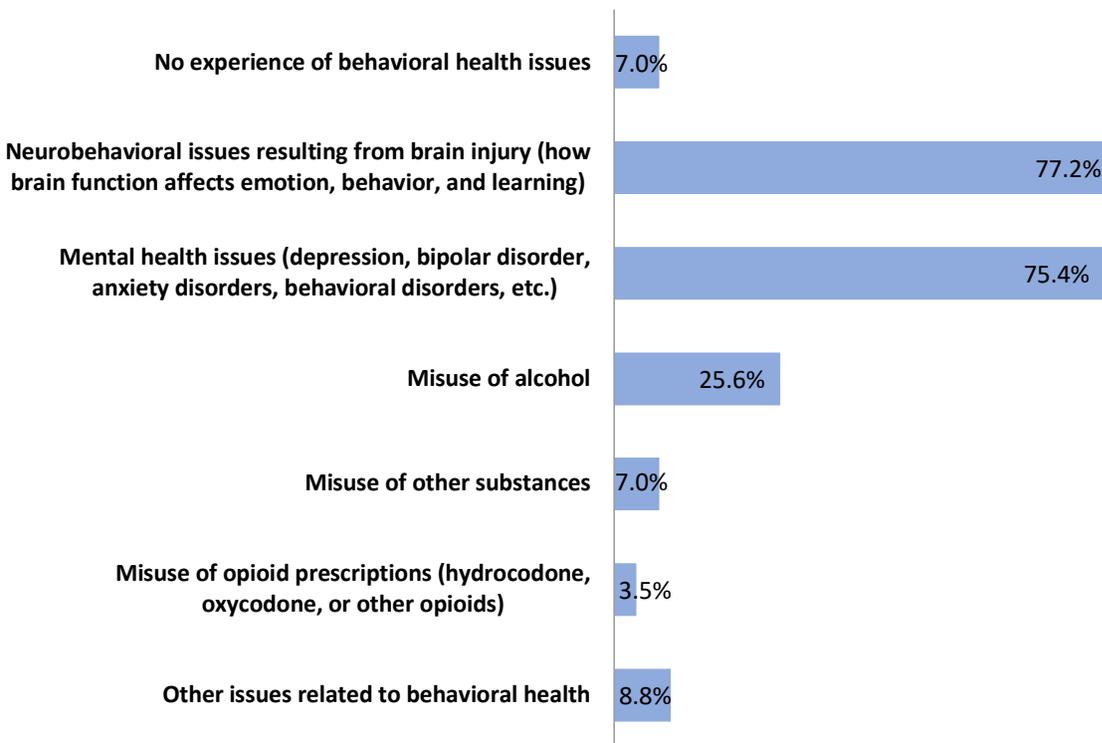
Behavioral Health

The vast majority (93%) of individuals living with a brain injury had at least some experience of behavioral health issues. Approximately three-in-four report experience of neurobehavioral and/or mental health issues. A small, but notable minority, also reported misuse of alcohol, substances, and/or opioids (Figure 18).

"I cannot help being depressed. It is not under my control and I cannot think myself out of it."

- Individual living with a brain injury

Figure 18. Current or past experiences of behavioral health issues (n=57)

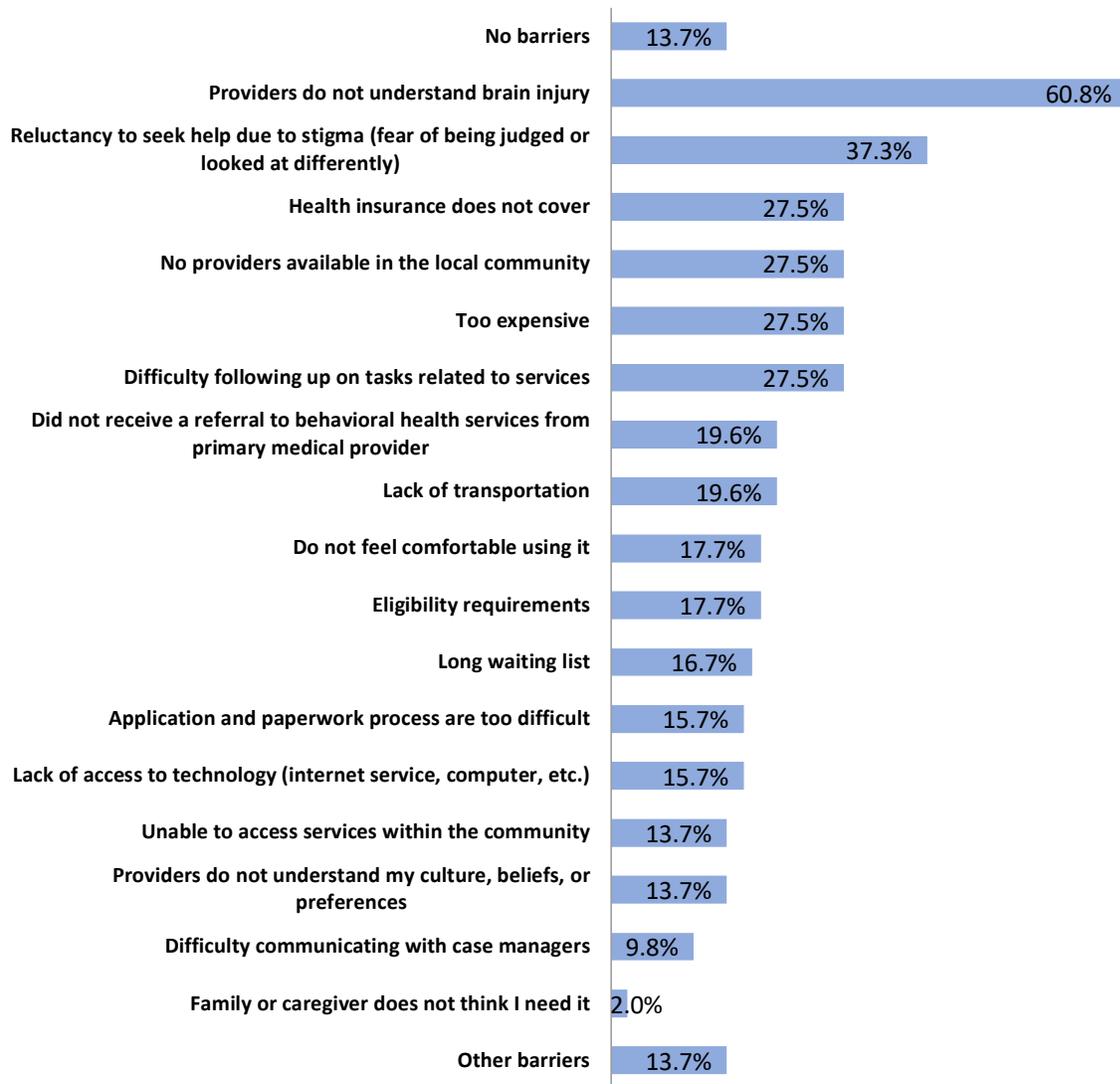


Other experiences: internet addiction disorder, seizures, food, self-pleasure

Among individuals living with a brain injury with an experience of behavioral health issues, the number one reported barrier to obtaining behavioral health services is “providers do not understand brain injury (reported by 61%) The vast majority (86%) of individuals with a brain injury who experience of behavioral health issues report at least one barrier to obtaining behavioral health services (Figure 19).

"I struggled how to cope with the side-effect of anger as a result from the TBI. Whether the therapist was aware of common side-effects or not, I felt completely misunderstood as I was chastised for my actions during a time that was very confusing for me."
 - Individual living with a brain injury

Figure 19. Barriers to obtaining behavioral health services (among those with experience of behavioral health issues) (n=51)



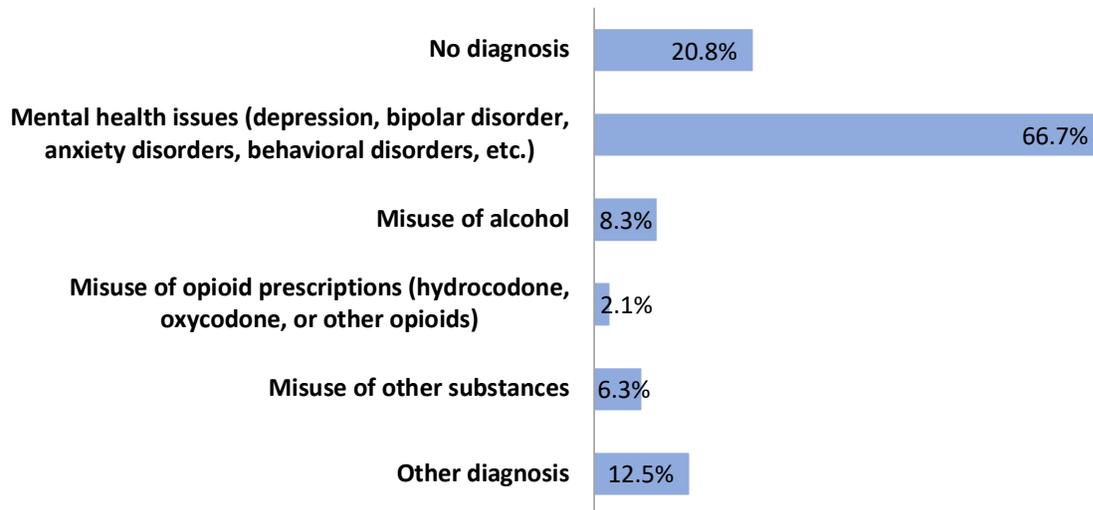
Other barriers: wheelchair access, mask requirements, doctors not returning calls, technology, inadequate services with knowledgeable providers, providers not trained in certain techniques such as EMDR, work comp refuses approval

Two-in-three (67%) of individuals living with a brain injury who also report experiencing behavioral health issues reported that they have a mental health diagnosis (Figure 20).

"Sadly, I'm either very happy or very sad or mad. I don't have very much of a balance or tolerance."

- Individual living with a brain injury

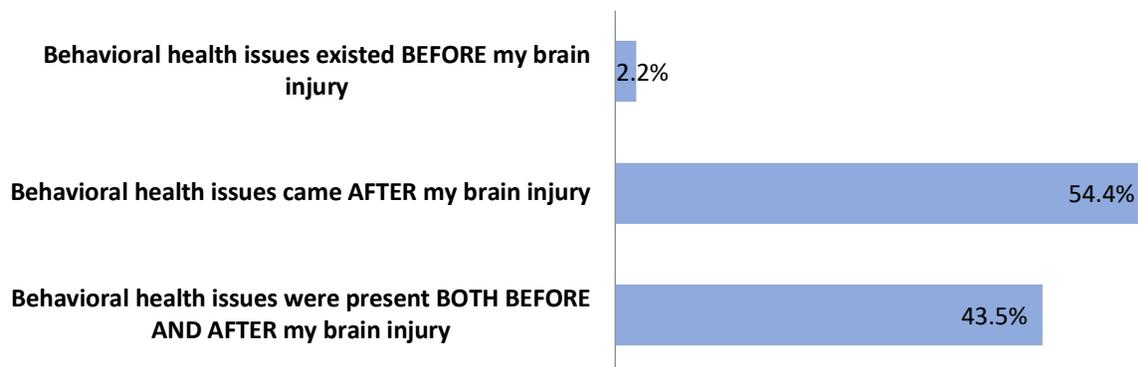
**Figure 20. Behavioral health diagnoses
(among those with experience of behavioral health issues) (n=48)**



Other diagnoses: PTSD, ADHD, PVTS, DID

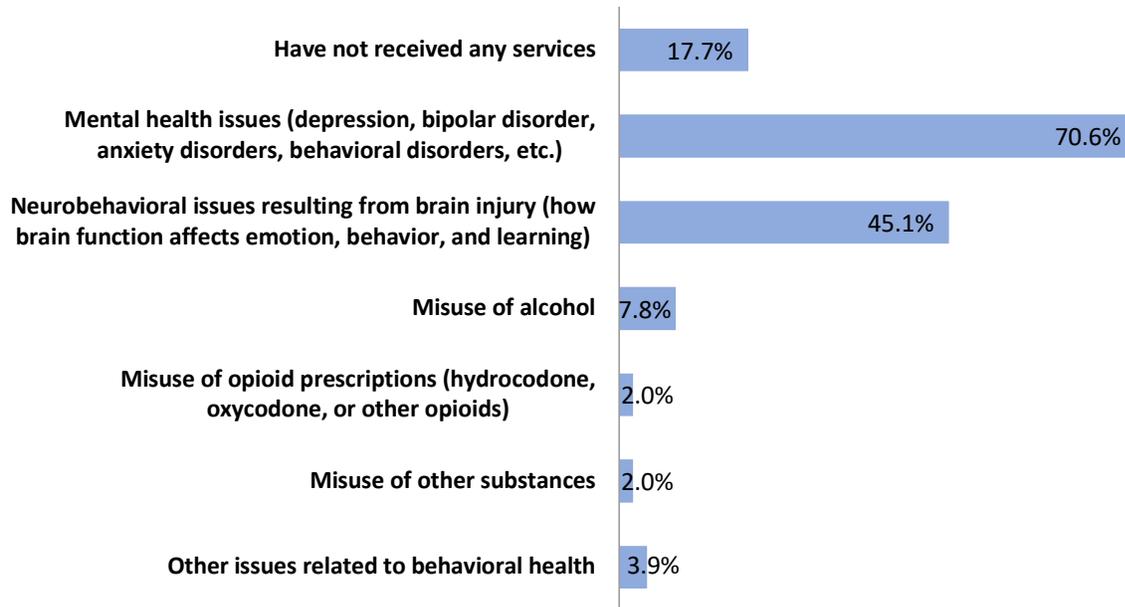
Most (54%) of those living with a brain injury who experience behavioral health issues reported that their issues came after their brain injury (Figure 21).

**Figure 21. Behavioral health issues existed...
(among those with experience of behavioral health issues) (n=46)**



Among those living with a brain injury and also having an experience of behavioral health issues, 82% have received at least some behavioral health service, with the most common being services for mental health issues (71%) and neurobehavioral issues (45%) (Figure 22). *It is worth noting gaps in services here. Among those who report having mental health issues, 79% have received mental health services. Among those who report neurobehavioral issues, 55% have receive neurobehavioral services.*

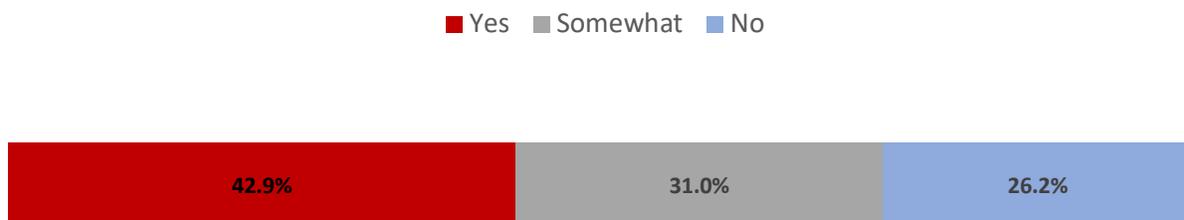
**Figure 22. Have received behavioral health services for...
(among those with experience of behavioral health issues) (n=46)**



Other issues: internet addiction, DID, PTSD, ADHD

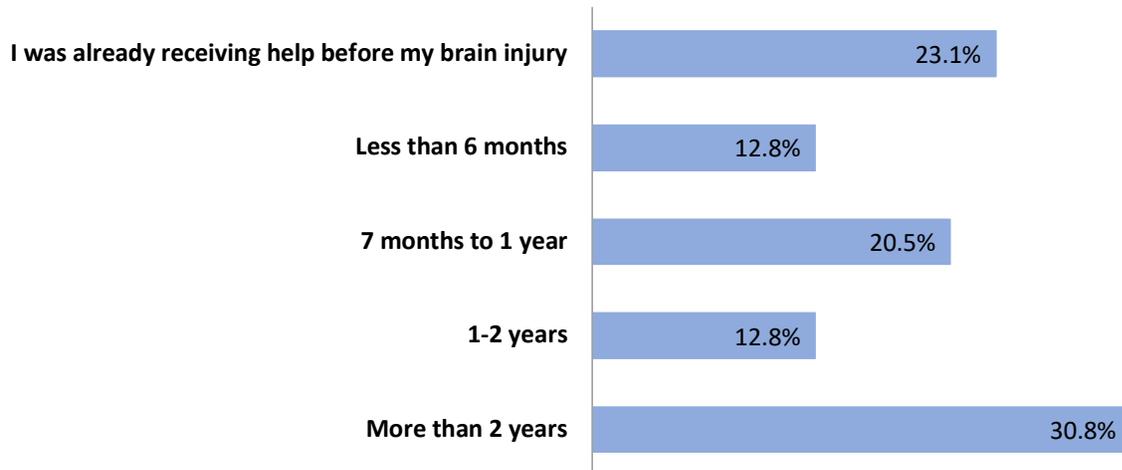
A plurality (43%) of those with a brain injury who have accessed behavioral health services reported feeling stigma when seeking for services (Figure 23).

**Figure 23. Were you uncomfortable seeking help for your behavioral health issues because of a fear of stigma or being judged?
(among those who have ever received behavioral health services) (n=42)**



Those living with a brain injury who have received behavioral health services reported a varying length of time between their brain injury and accessing behavioral health services. Over half (56%) reported seeking help within one year (Figure 24).

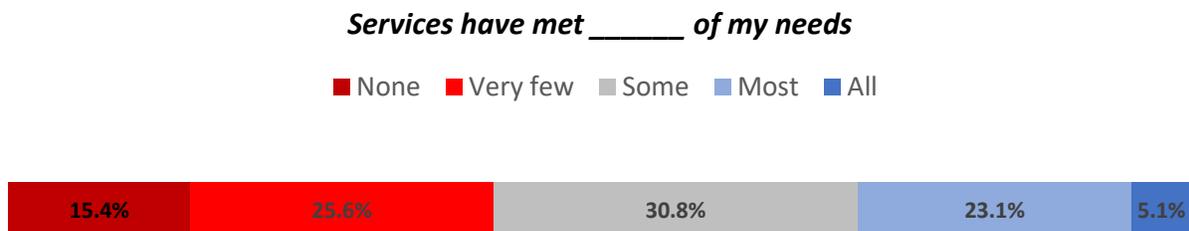
Figure 24. How long after your brain injury did you seek any type of help with behavioral health?
(among those who have ever received behavioral health services) (n=39)



Among those living with a brain injury who have ever received behavioral health services, feelings are mixed as to how well the behavioral health services they have received have met their needs. A plurality (41%) say that behavioral health services have met “none” or “very few” of their needs, 31% say the services have met “some” of their needs, and just 28% say the services have met “most” or “all” of their needs (Figure 25).

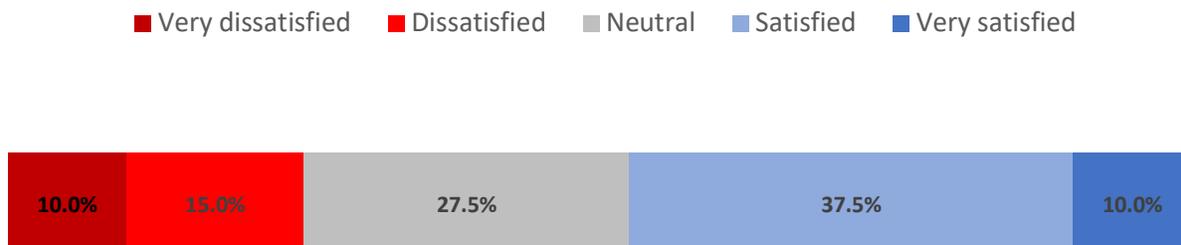
"I had no idea there was the possibility of "retraining your brain" so-so-speak. Insightful therapy could have helped me realize I still had potential and to not simply give up things I could no longer do as well."
- Individual living with a brain injury

Figure 25. Overall, how well have the behavioral health services you have received met your needs as an individual with a brain injury?
(among those who have ever received behavioral health services) (n=39)



Satisfaction with behavioral health services is also mixed, but slightly positive, among those with a brain injury who have received behavioral health services. One-in-four (25%) reported being “very dissatisfied” or “dissatisfied” with the behavioral health services they received, 28% were “neutral”, and nearly half (48%) were satisfied or very satisfied (Figure 26).

**Figure 26. Satisfaction with behavioral health services
(among those who have ever received behavioral health services) (n=40)**



In an open-ended survey item, individuals living with a brain injury were asked, “Is there anything that would have helped you find behavioral health providers more easily?” Many comments keyed on the themes of “providers who understand brain injury” and “a resource linking to providers who understand brain injury”. Below are some representative quotes from these two themes. See Appendix A for all of the responses to this survey item.

Is there anything that would have helped you find behavioral health providers more easily?

Providers who understand brain injury

“For the correlation of the brain injury to the behavioral health concerns to have been identified sooner. For quite a while just thought it was just a phase.”

“I was 15 when my TBI occurred. The therapist I saw treated me as if I was just a young, disrespectful teen in need of an attitude adjustment.”

“No, only because I had existing providers before my brain injury who I liked and really understood my injury and how it changed me. I have a wonderful counselor and behavioral health provider for my psychiatric meds.”

A resource linking to providers who understand brain injury

“List of providers who co-treat brain injury/behavioral health on local brain association websites.”

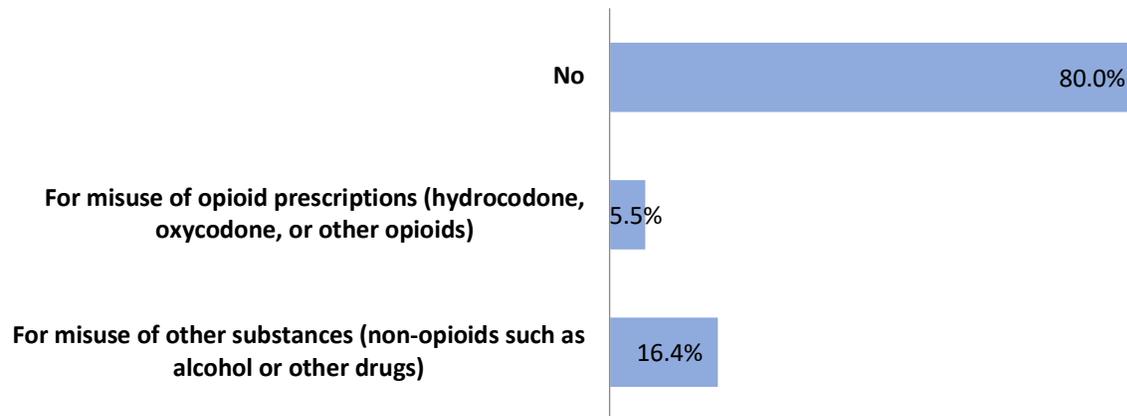
“Better referrals that were targeted to my needs. A person I trust that I like who could tell me about my needs and how to get help.”

“Being referred to someone who is trained in behavior health with brain injury would have been better.”

Substance Misuse

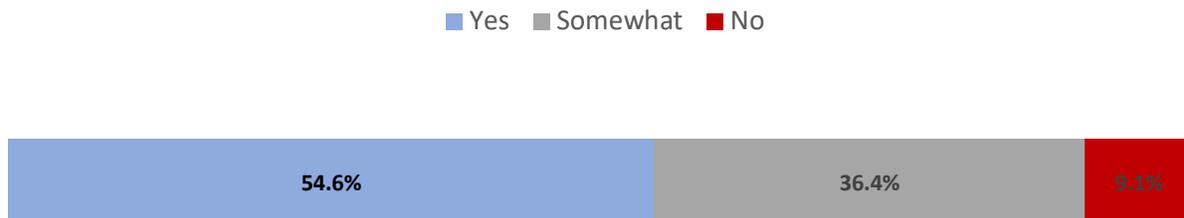
One-in-five (20%) individuals with a brain injury reported that they have ever needed substance misuse evaluation or treatment as a result of opioid prescriptions or misuse of other substances (Figure 27).

Figure 27. Have ever needed substance misuse evaluation or treatment (n=55)



Among the minority of individuals with a brain injury who have needed treatment for substance misuse issues, 55% reported unequivocally that treatment has been able to help them and 36% reported that treatment has been able to help them “somewhat” (Figure 28).

Figure 28. Has treatment been able to help with your substance misuse issues? (among those who have ever needed substance misuse evaluation or treatment services) (n=11)



Chronic Pain

Approximately two-thirds (67%) of individuals with a brain injury reported that they have chronic pain as a result of an injury (Figure 29).

"We deal with pain every day."

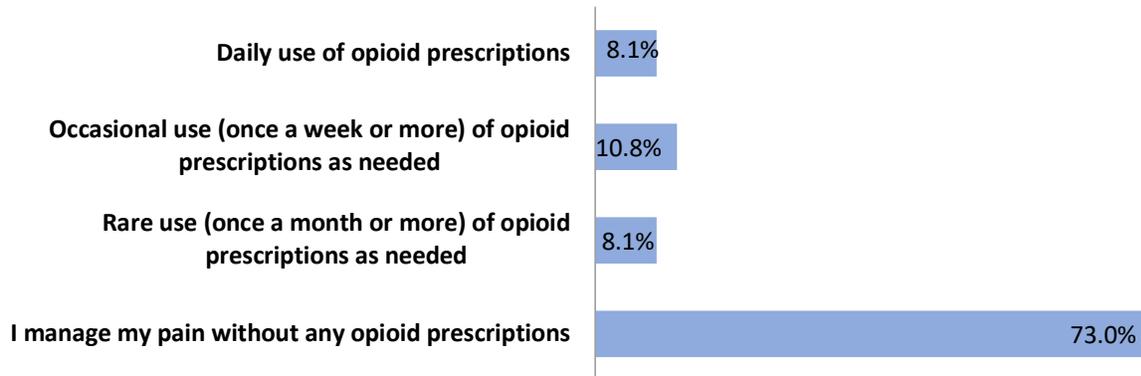
- Individual living with a brain injury

Figure 29. Do you have chronic pain as a result of an injury (n=55)



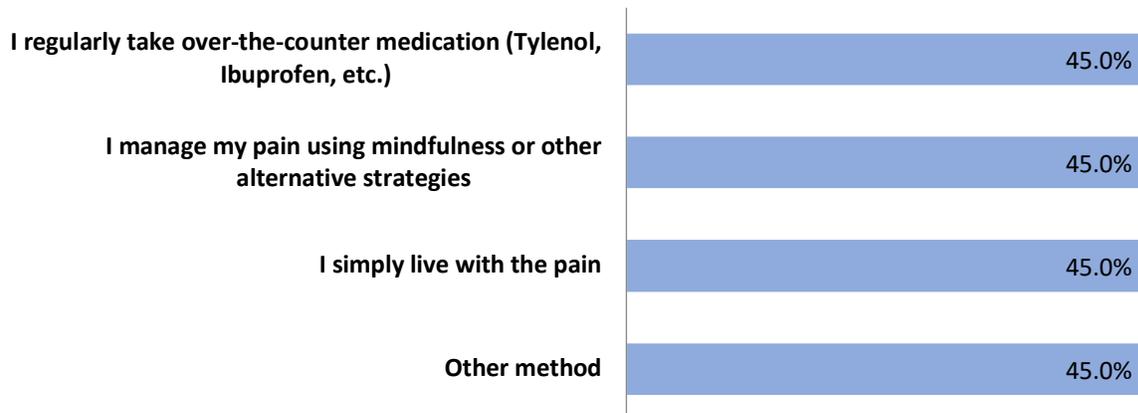
The considerable majority (73%) of those with chronic pain, manage their pain without any opioid prescriptions (Figure 30).

Figure 30. What best describes your use of opioid prescriptions (hydrocodone, oxycodone, or other opioids) to treat your chronic pain? (among those with chronic pain) (n=37)



Among those who manage their chronic pain without any use of opioids, a variety of methods were employed, with an exactly even distribution across over-the-counter medication, mindfulness and other strategies, simply living with the pain, and other methods (45% reported for each of these methods) (Figure 31).

Figure 31. Pain management strategy (among those with chronic pain who manage the pain without any use of opioids) (n=20)

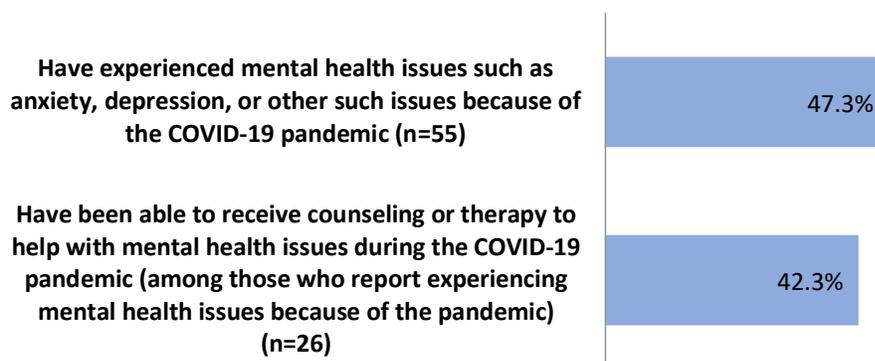


Other strategies: relaxation, migraine medication, headache hats, spinal cord stimulator, chiropractor, functional neurologist, OMT provider, anti-seizure medication, CBD oil, flexeril twice a month, exercise, animals, occasional OTC, prescribed non-opioids

COVID-19

Nearly half (47%) of individuals living with a brain injury reported that they have experienced mental health issues because of the COVID-19 pandemic. Among these, less than half (42%) have been able to receive counseling or therapy to help with mental health issues during the pandemic (Figure 32).

Figure 32. COVID-19 and Mental Health



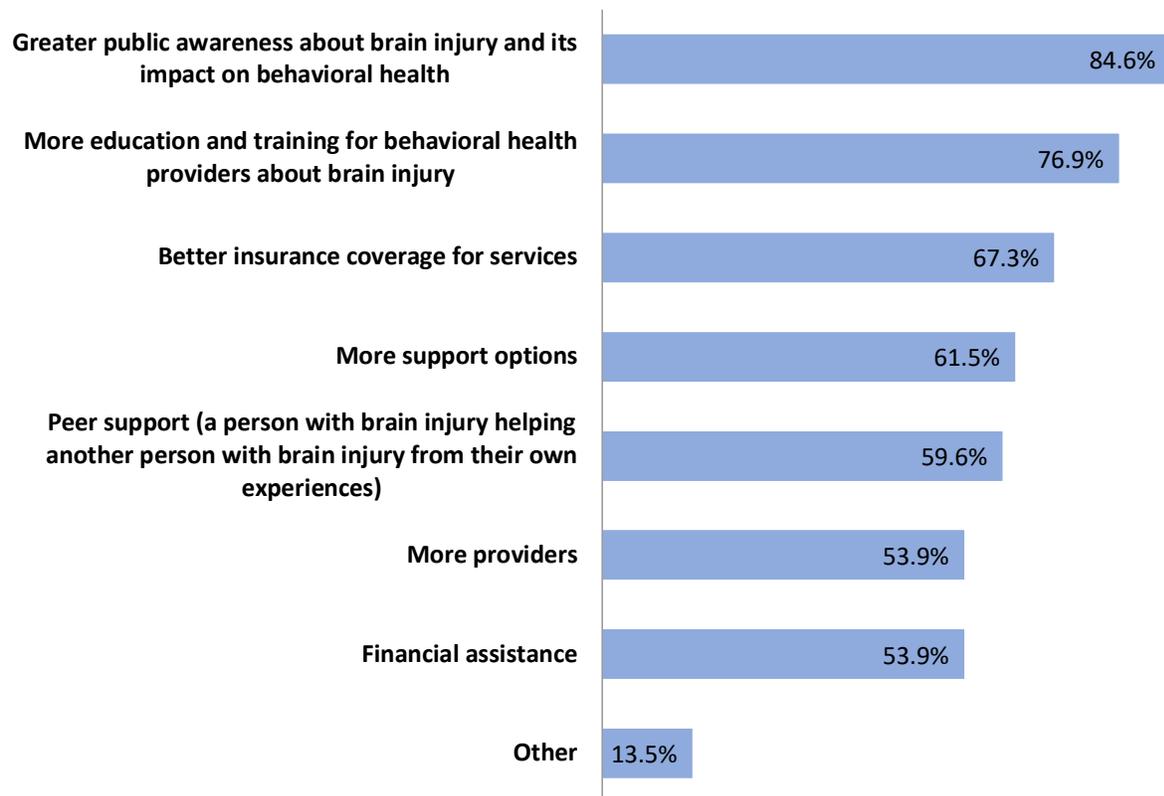
Perceptions of Behavioral Health and Brain Injury

When asked what needs to be done to improve behavioral health services for individuals with a brain injury, individuals with a brain injury most commonly selected “greater public awareness about brain injury and its impact on behavioral health (selected by 85%), followed by more education and training for behavioral health providers about brain injury (77%), and better insurance coverage for services (67%) (Figure 33).

" There is a direct cause and effect of ANY type of brain injury on behavioral health. The question is, why do we have a lack of resources to educate ALL people as an injury can occur any place, any time to anyone. Let's get Nebraska smart about it all."

- Individual living with a brain injury

Figure 33. What do you think needs to be done to improve behavioral health services (mental health counseling, substance abuse treatment, and other such services) for individuals with a brain injury? (select all that apply) (n=52)



Other: adjustment of treatment around two years after TBI, connecting to a resource facilitator (Gina Simanek) who understands what it's like to have a brain injury, help with disability claims, better listing of where to go, fewer but more precise terms to define brain injury, better insurance coverage for brain injury, medicating with alcohol

In an open-ended survey item, individuals living with a brain injury were asked, “What can be done to help individuals with a brain injury who also have issues with behavioral health?” Many comments keyed on the themes of “providers who understand brain injury”, “peer support”, and “public education on brain injury to reduce stigma”. Below are some representative quotes from these three themes. See Appendix A for all of the responses to this survey item.

What can be done to help individuals with a brain injury who also have issues with behavioral health?

Providers who understand brain injury

“Find providers who handle both. Get them information.”

“Stop assuming mental illness is an ‘also have’ with brain injuries. It’s part of, not also.”

“Neurologists should be better informed of services available to help.”

“More providers and more providers who understand BI.”

Peer support

“I think the power of having someone else who understands-- another person with a brain injury or who has had one be able to talk to them.”

“Peer support would be extremely helpful for both the receiver and the giver.”

“Peer support and case managers in agencies with capacity to support my unique needs.”

Public education on brain injury to reduce stigma

“Education for the general public to reduce stigma, focusing on the fact that mental health and brain injuries do very often occur together.”

“Overall, society & those suffering with a BI need to understand this may be an outcome of brain injury so it can be better understood and de-stigmatized. There is still such a lack of knowledge and supports.”

“If a person with BI could believe that getting help with behavioral health is appropriate and not a condemnation, that would be good.”

“Education that behavioral issues are common after injury and not to be ashamed or feel weak.”

Tele-Health

Just over half (52%) of individuals living with a brain injury reported that they have ever used tele-health for behavioral health services (Figure 34).

Figure 34. Have ever used tele-health for behavioral health services (n=52)



Regardless whether if they have used tele-health before, individuals with a brain injury were asked to rate their comfort level around using tele-health. Exactly half said they are or would be comfortable using tele-health (Figure 35).

Figure 35. Comfort level using tele-health (n=52)

■ Not very comfortable ■ Somewhat comfortable ■ Comfortable



Survey Results for Family Members of Individuals with a Brain Injury

Respondent Demographics

A total of 30 family members of individuals living with a brain injury responded to the survey. Respondent demographics are detailed in Table 2 below.

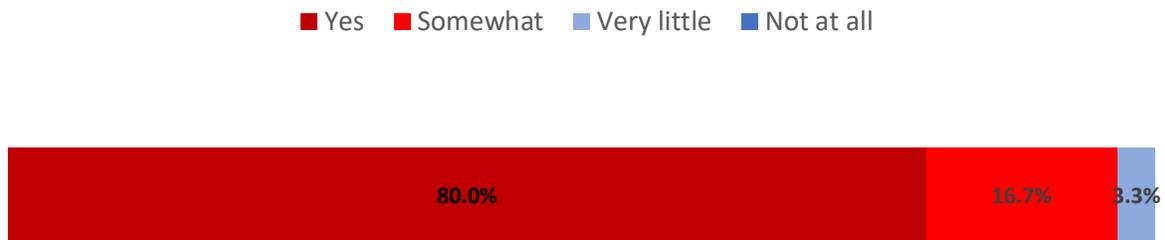
| Table 3 | Respondent Demographics | |
|--|--------------------------------|-----------|
| <i>Total number of surveys collected</i> | | 30 |
| <i>Time since family member's most recent brain injury (n=22)</i> | <i>Less than one year</i> | 13.6% |
| | <i>1-2 years</i> | 22.7% |
| | <i>3-4 years</i> | 13.6% |
| | <i>5 or more years ago</i> | 50.0% |
| <i>Urbanicity* (n=22)</i> | <i>Large Urban</i> | 50.0% |
| | <i>Small Urban</i> | 31.8% |
| | <i>Rural</i> | 18.2% |
| <i>Gender (n=21)</i> | <i>Male</i> | 23.8% |
| | <i>Female</i> | 71.4% |
| | <i>Other/prefer not to say</i> | 4.8% |
| <i>Race/ethnicity (n=22)</i> | <i>White/Caucasian</i> | 86.4% |
| | <i>Non-White/Caucasian</i> | 13.6% |
| <i>Age group (n=)</i> | <i>24 and under</i> | 4.6% |
| | <i>25-44</i> | 40.9% |
| | <i>45-64</i> | 31.8% |
| | <i>65 and over</i> | 22.7% |

*See Appendix B for urbanicity definitions.

Mental Health

Nearly all (97%) of family members experience at least some emotional stress in their role as a family member and/or caregiver of an individual with a brain injury (Figure 36).

Figure 36. Experience emotional stress in role as family member and/or caregiver of an individual with a brain injury (n=30)



In spite of the emotional stress that family members report, a relatively small minority (23%) report that they have accessed any type of mental health counseling services due to their role and responsibilities of being a family member and/or caregiver of an individual with a brain injury (Figure 37).

Figure 37. Have accessed any type of mental health counseling services due to role and responsibilities of being a family member and/or caregiver of an individual with a brain injury (n=30)



"It is the hardest task I have ever had and I am 59 years old. I not only make sure she is safe from others, but also safe from herself. I can't trust her or anyone to keep her safe, so I don't get to take breaks. But we are blessed and I love her and am her mother, and that is what mothers do.... we love and care for our children."

- Family member of an individual with a brain injury

"It affects our mental health as well. It is so depressing when you realize that not only do they have a disability but there are not services and supports for them, post injury."

"It can be very stressful living with one with a brain injury. Feel alone at times."

"It's made my life and the life of my second child hell we live in fear all the time as he is so aggressive at simplest unexpected moments."

"Being a family member/caregiver of a person with a brain injury, greatly impacts the caregiver's life. It is vitally important for the caregiver to find ways to care for themselves first of all, using mental health counselors, seeking help to support the person with a brain injury, exercise and taking part in activities for your own enjoyment. I as a caregiver, have to care for myself first and become healthy functioning so I can care for the person with the traumatic brain injury."

- Family members of individuals with a brain injury

Among those family members who have sought mental health services due to the stress of their role as a family member of someone with brain injury (note the small number of respondents), the percentage reporting the helpfulness of the services and the percentage perceiving a stigma are presented in Figures 38 and 39. Most family members report that the services have been at least somewhat helpful (Figure 38) and over half perceive at least "somewhat" of a stigma (Figure 38).

Figure 38. Mental health services have helped manage the stress of being a family member and/or caregiver of an individual with a brain injury (among those who have accessed mental health services) (n=7)

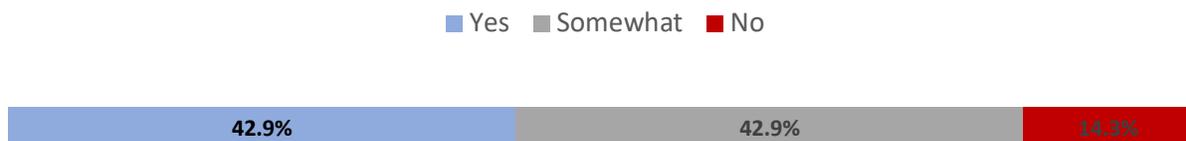
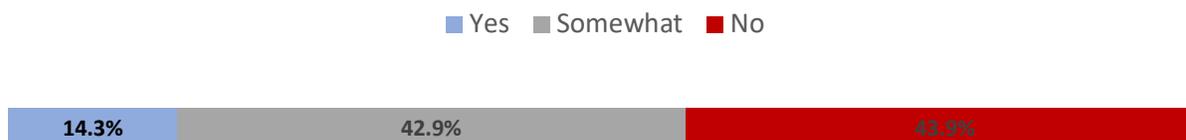


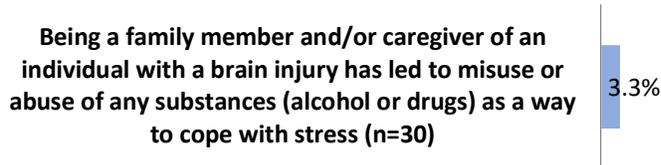
Figure 39. Felt uncomfortable seeking mental health counseling services because of a fear of stigma, being judged, or being seen differently (among those who have accessed mental health services) (n=7)



Substance Misuse

Just one family member reported that they have misused substances as a result of being a family member and/or caregiver of an individual with a brain injury (Figure 40).

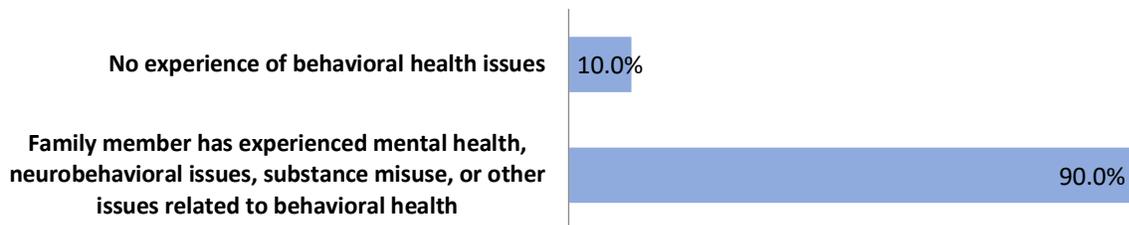
Figure 40. Substance misuse as a result of being a family member and/or caregiver of an individual with a brain injury (n=30)



Behavioral Health Services for the Family Member with a Brain Injury

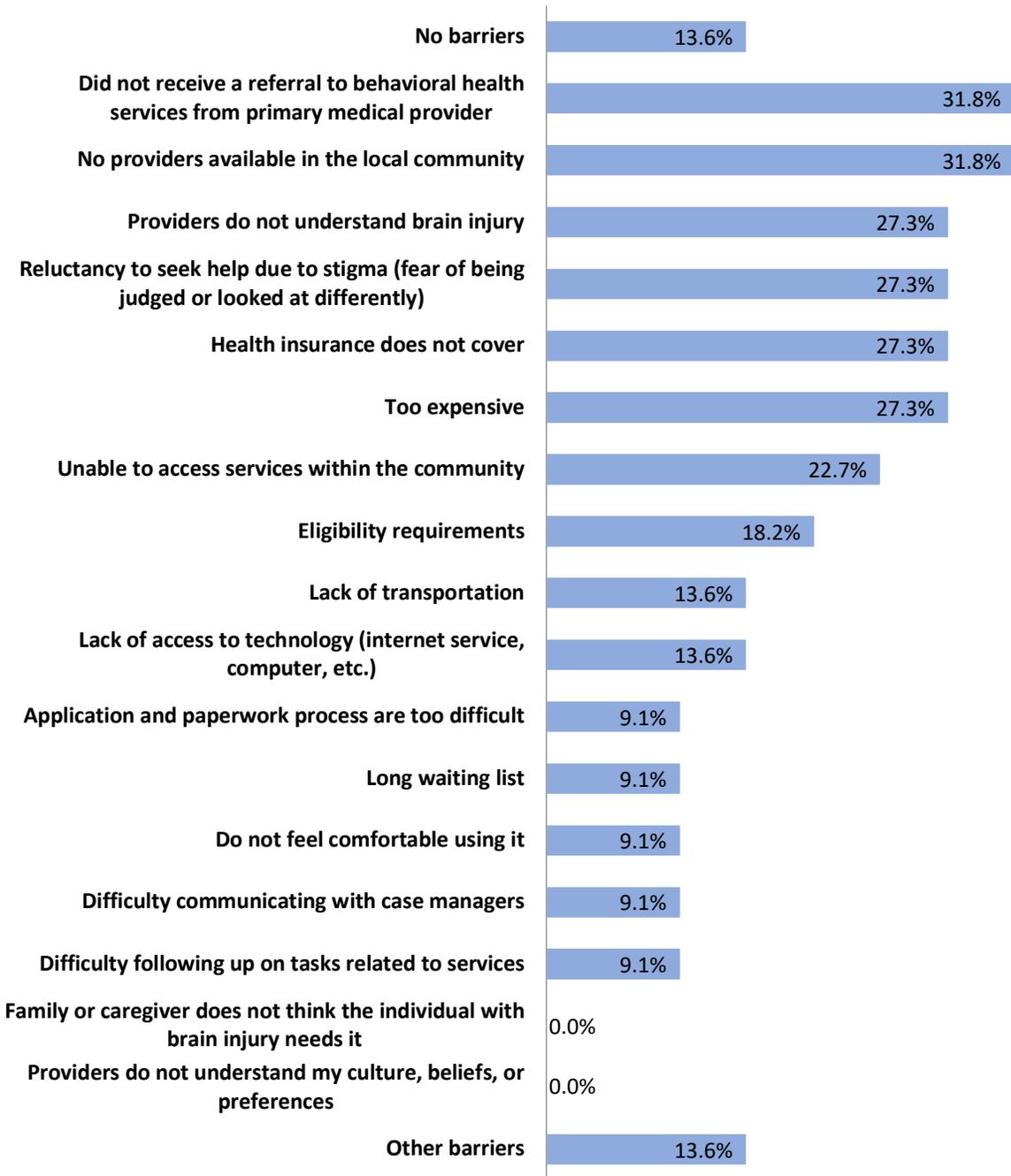
The vast majority (90%) of family members reported that their family member with a brain injury has experienced some form of behavioral health issue (Figure 41, compare to Figure 18 above).

Figure 41. Family member's with a brain injury current or past experiences of behavioral health issues (n=30)



Among family members who report that the individual in their family with a brain injury has experienced behavioral health issues, the top barriers were “did not receive a referral to behavioral health services” and “no providers available in the local community” (Figure 42, compared to Figure 19 above).

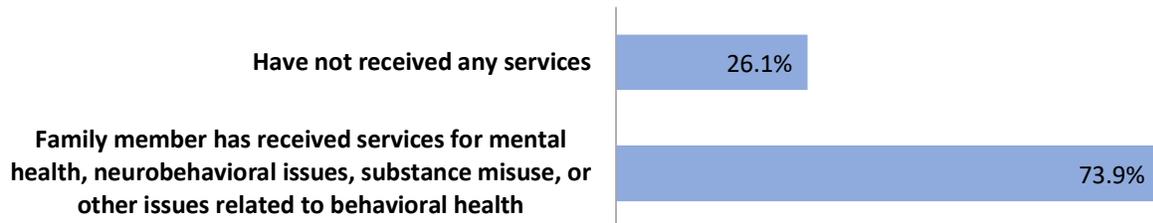
Figure 42. Barriers to obtaining behavioral health services for the family member with a brain injury (among those with experience of behavioral health issues) (n=22)



Other barriers: individual with injury refuses it, has aphasia (difficulty talking)

Among family members who report that the individual in their family with a brain injury has experienced behavioral health issues, three-in-four (74%) report that their family member with a brain injury has received some type of behavioral health service (Figure 43, compare to Figure 22 above).

Figure 43. Family member with a brain use of behavioral health services (among those with experience of behavioral health issues) (n=23)



Among family members who report that the individual in their family with a brain injury has received behavioral health services, feelings are generally neutral to slightly positive in terms of how well the services have met the needs of the individual with brain injury (Figure 44) and overall satisfaction with the services (Figure 45) (compare Figures 25 and 26 above).

Figure 44. Overall, how well have the behavioral health services you have received met your needs as an individual with a brain injury? (among those who have ever received behavioral health services) (n=39)

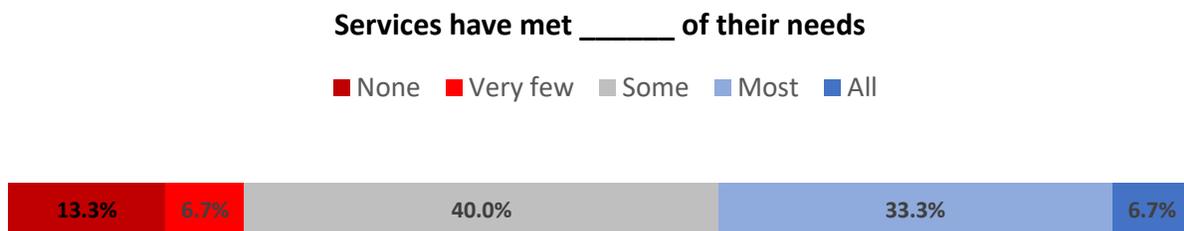
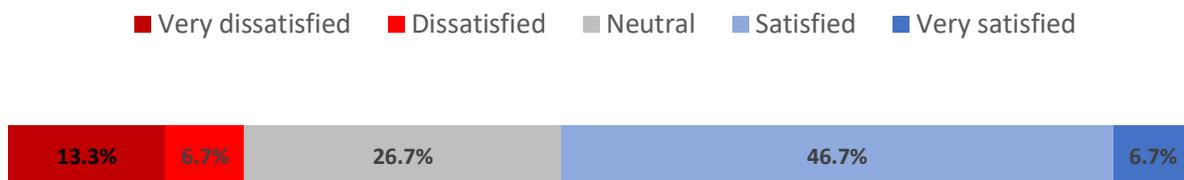


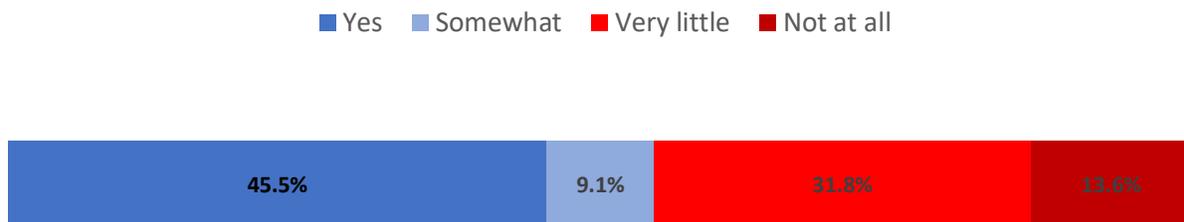
Figure 45. Satisfaction with behavioral health services for the family member with a brain injury (among those who have ever received behavioral health services) (n=15)



Support

Just under half (46%) of family members reported that they have support from other members of their family to assist with the care plan for their family member with a brain injury. A small minority (9%) responded “somewhat”, and the remainder (45%) responded “very little” or “not at all” (Figure 46).

Figure 46. Do you have support from other members of your family to assist with the care plan for your family member with a brain injury? (n=24)



“The stress on family members who are the primary caregiver from the initial injury and through recovery is enormous. Your focus is on your child's recovery. Other members of the family may not fully understand the mental burden, stress on the caregiver and the emotional impact, chemical changes in the body as a reaction to the stress.”

“It's a day to day, moment to moment existence. You should always have someone to lean on and cherish the time good and bad. Family is important.”

- Family members of individuals with a brain injury

Survey Results for Behavioral Health Providers

Respondent Demographics

A total of 38 behavioral health professionals responded to the survey. Respondents represented a variety of behavioral health professionals including mental health practitioners (35%), psychologists (14%), social workers (14%), drug and alcohol counselors (10%), and others (28%) in the behavioral health field. Other demographics are detailed in Table 4 below.

| Table 4 | Respondent Demographics | |
|---|---|-----------|
| | <i>Total number of surveys collected</i> | 38 |
| Profession (n=29) | <i>Psychologist</i> | 13.8% |
| | <i>Licensed Mental Health Practitioner</i> | 34.5% |
| | <i>Licensed Master Social Worker</i> | 13.8% |
| | <i>Licensed Drug and Alcohol Counselor</i> | 10.3% |
| | <i>Other*</i> | 27.6% |
| Years as a behavioral health provider (n=25) | <i>Less than one year</i> | 4.0% |
| | <i>1-2 years</i> | 4.0% |
| | <i>3-4 years</i> | 0.0% |
| | <i>5-10 years</i> | 20.0% |
| | <i>More than 10 years</i> | 72.0% |
| Work setting (n=30) | <i>A community organization offering various services including behavioral health</i> | 16.7% |
| | <i>Independent/private practice</i> | 33.3% |
| | <i>Educational setting</i> | 16.7% |
| | <i>Faith-based organization</i> | 16.7% |
| | <i>Hospital inpatient setting</i> | 3.3% |
| | <i>Hospital outpatient setting</i> | 6.7% |
| Counties served (n=30) | <i>All Nebraska counties</i> | 23.3% |
| | <i>Various individual counties in Nebraska</i> | 76.7% |

*Other professions include: peer support, speech language pathologist, service development manager

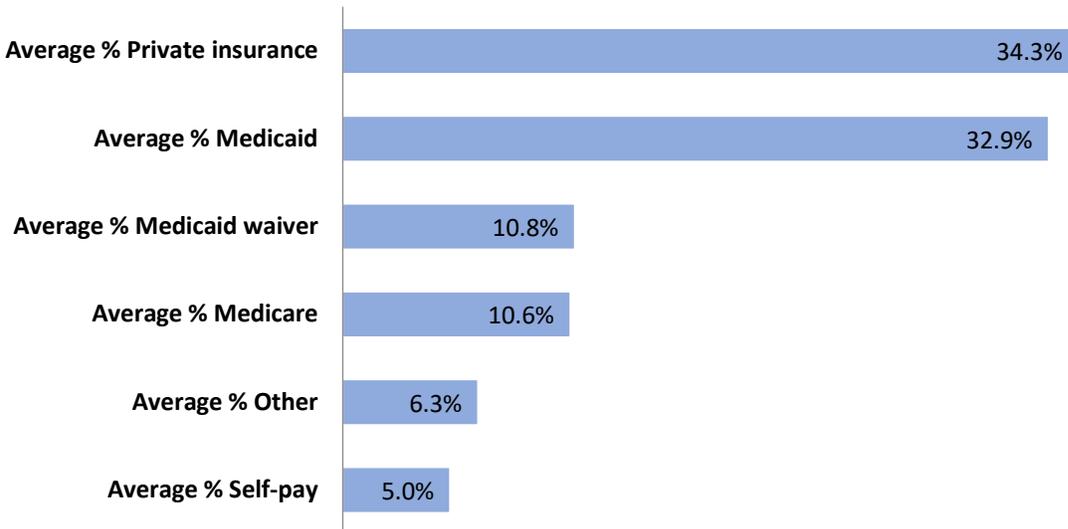
°Other work settings include: behavioral health authority, development disability provider

The approximate number of individuals with a brain injury served is described in Table 5 below. Respondents' organizations ranged from serving 2 to 100 individuals with a brain injury per year, with many not knowing how many individuals with a brain injury they have served (Table 5).

| Table 5 | Approximate number of individuals with a brain injury directly served by respondent or respondent's organization per year (n=30) | | | | |
|-------------------|---|--------------|---------------------|----------------|--------------|
| 5 or fewer | 6-20 | 21-50 | More than 50 | Unknown | Range |
| 16.7% | 10.0% | 13.3% | 6.7% | 53.3% | 2-100 |

A relatively small number of respondents reported their payer mix, which is aggregated in Figure 47 below.

Figure 47. Average estimated percentage of funding per funding source for serving individuals with brain injury (n=12)



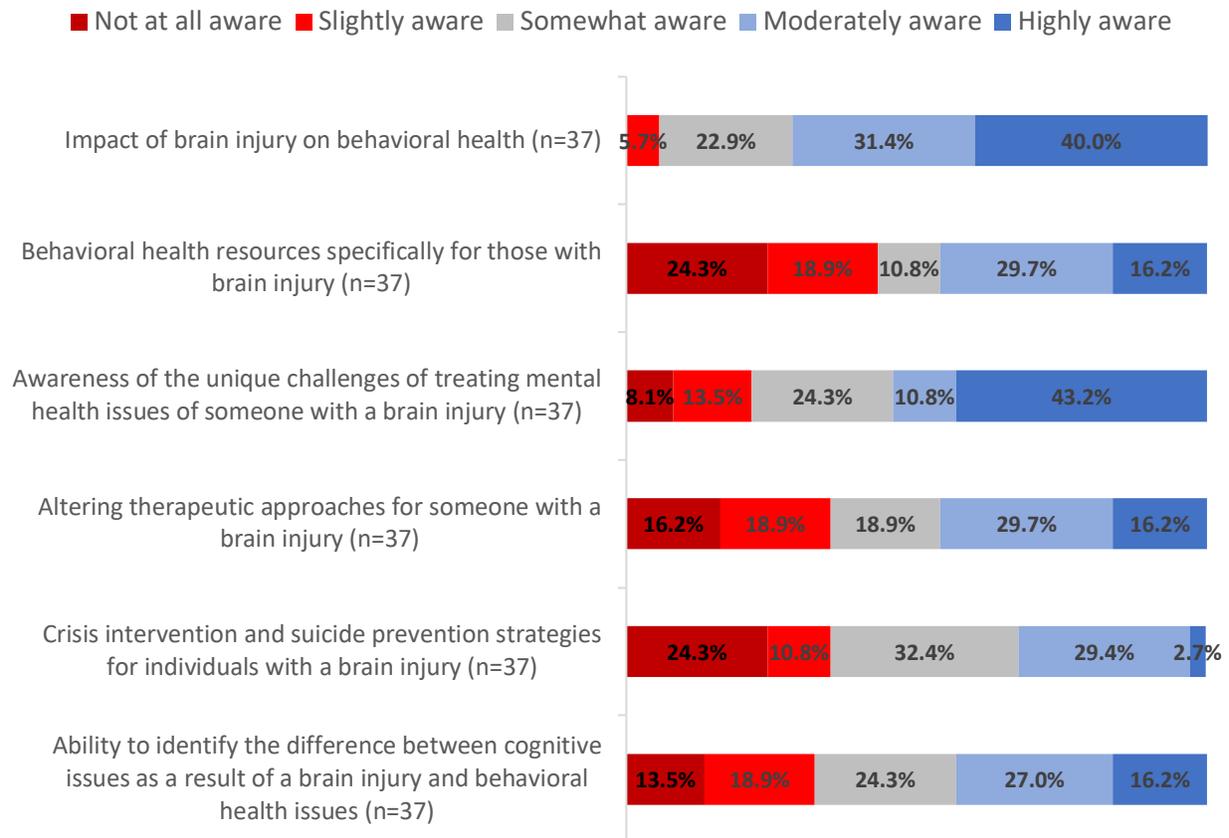
Awareness of Brain Injury

Behavioral health providers report mixed levels of awareness of the intersection between brain injury and behavioral health. A few areas of apparent need for education and training include behavioral health resources specifically for those with brain injury (44% reported being “moderately” or “highly aware”), crisis intervention and suicide prevention strategies for individuals with a brain injury (31% reported being “moderately” or “highly aware”), and the ability to tell the difference between cognitive issues as a result of brain injury and behavioral health issues (43% reported being “moderately” or “highly aware”) (Figure 48).

"This area is misunderstood and mis-diagnosed. The general community and providers do not recognize the levels of TBI. Mild and moderate TBI needs intervention as much as severe. There is also a lack of acknowledgement for SUD [substance use disorder] regarding TBI."

- Behavioral health provider

Figure 48. Awareness of Brain Injury and Behavioral Health



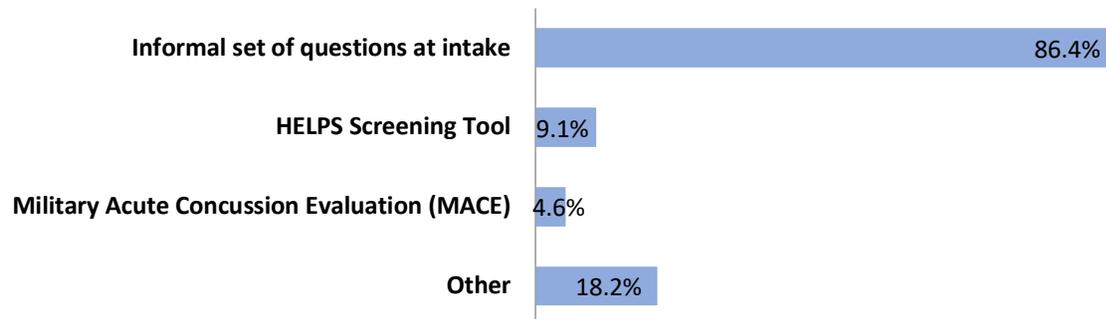
Screening for Brain Injury

Just over half (55%) of behavioral health providers reported that they screen for a lifetime history of brain injury (Figure 49). However, among those who do screening, 86% report using only an informal set of questions at intake (Figure 50).

Figure 49. Screen individuals for a lifetime history of potential brain injury incidents (n=38)



Figure 50. Screening tool/methodology used (among those who screen individuals for a lifetime history of potential brain injury) (n=22)



Other responses: TOP, DLA 20, biopsychosocial, neurofeedback, clinical interviews, CereScan for SPECT scanning

"The impacts of brain injury are not adequately understood/recognized either in the medical or mental health community. Dr. Wayne Gordon states that "Unidentified TBI is a major unrecognized cause of social, vocational and educational failure." I believe this to be true and yet there is no adequate, systemic screening mechanism in any of these arenas. I believe that counseling and social work education programs should all be educated in depth about TBI and that screening should be taught in mental health programs and mandated. People with TBI are 20% more likely to become substance involved and 50% more likely to fail treatment so I think the same needs apply in the substance use fields as in the mental health system, yet we are failing these clients in an alarming way, including with inappropriate personality disorder diagnosis when the actual issue is brain injury. Travesty."

- Behavioral health provider

Just over half (58%) of behavioral health providers are interested in learning more about how to screen individuals for a lifetime history of potential brain injury incidents (Figure 51).

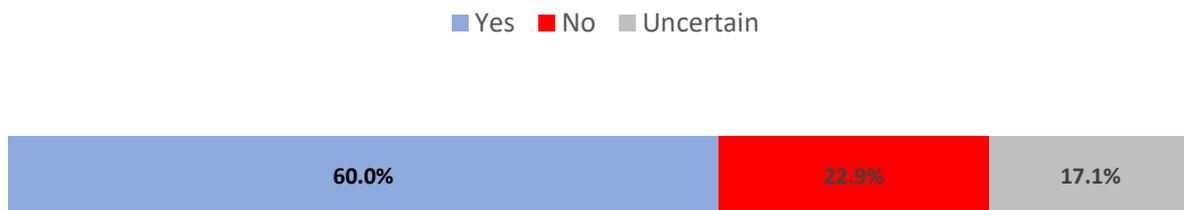
Figure 51. Interested in learning more about how to screen individuals for a lifetime history of potential brain injury incidents (n=38)



Clinical Treatment of Individuals with a Brain Injury

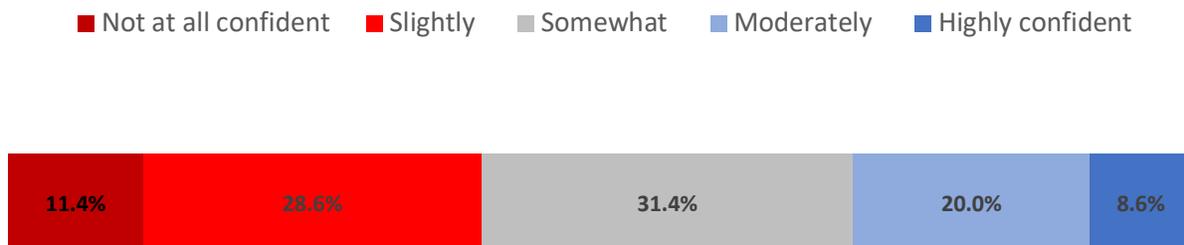
Most providers (60%) report that they treat individuals living with a brain injury. A notable minority (17%) do not know if they do or not (Figure 52).

Figure 52. Do you treat individuals living with brain injury (n=38)



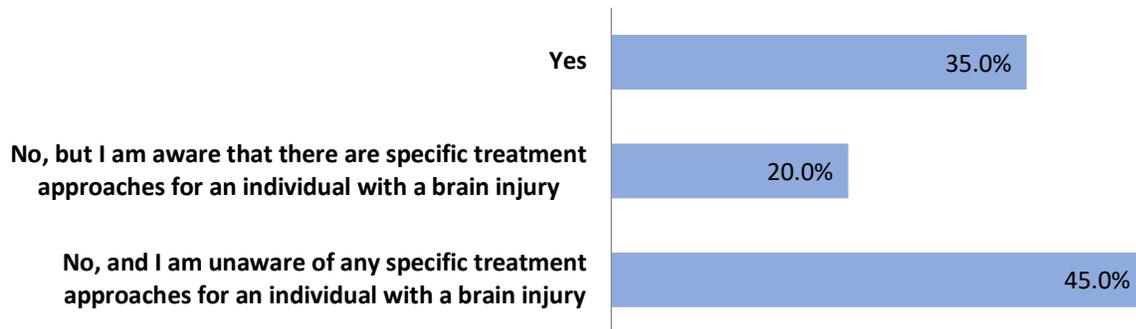
Behavioral health providers reported mixed levels of confidence in providing behavioral health treatment for an individual with a brain injury. A plurality (40%) reported that they are “not at all” or “slightly confident”, 31% reported being “somewhat confident”, and 29% reported being “moderately” or “highly confident (Figure 53)

Figure 53. How confident do you (or would you) feel in providing behavioral health treatment for an individual with a brain injury? (n=35)



Among those who treat individuals living with a brain injury, just one-third (35%) report that they use specific therapeutic approaches for an individual with a brain injury. Nearly half (45%) are unaware of any specific treatment approaches for an individual with a brain injury (Figure 54).

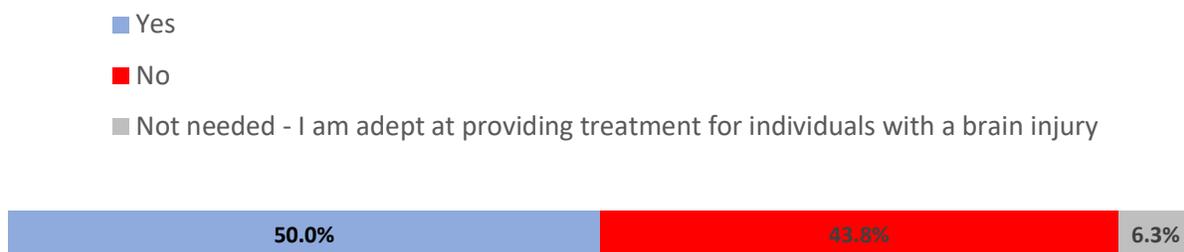
Figure 54. Do you use specific therapeutic approaches for an individual with a brain injury?(among those who treat individuals living with a brain injury) (n=20)



Referrals and Resources for Brain Injury

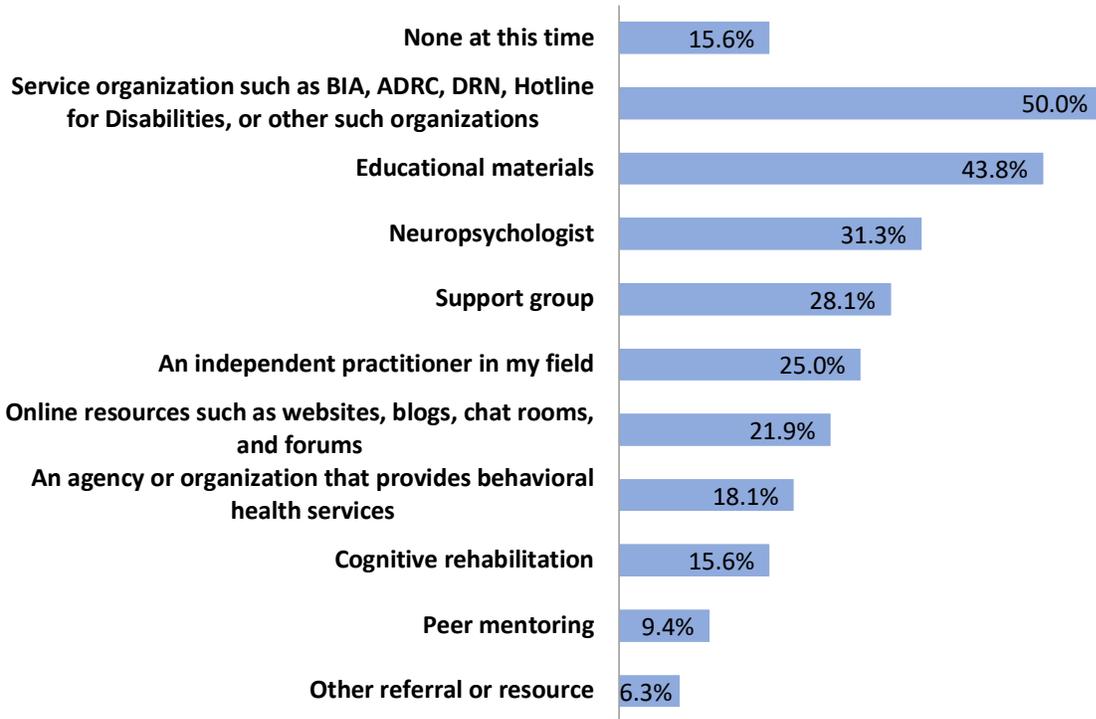
Half of all behavioral health providers reported that they have an organization or professional with whom to consult when providing treatment for a client with a brain injury (Figure 55).

Figure 55. When providing treatment for a client with a brain injury, do you feel like you have an organization or professional with whom to consult or to whom you might provide a referral? (n=32)



The top referral/resource used for treating individuals with a brain injury was a service organization (Figure 56).

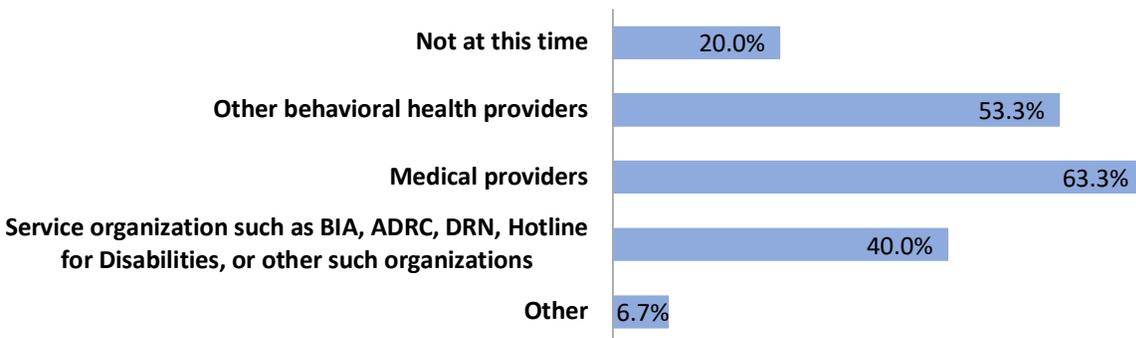
Figure 56. Referrals and resources used for treating individuals with a brain injury (n=32)



Other referrals: school trainer, medical professionals, alternative treatments (NIR, HBOT, etc.), SPECT scanning

Just over half (53%) of behavioral health providers reported collaboration with other behavioral health providers and nearly two-thirds (63%) reported collaborating with medical providers (Figure 57).

Figure 57. Do you collaborate with any of the professionals listed below in order to better serve your clients? (n=30)



Other professionals: Madonna, CereScan for SPECT scanning (especially in more complex cases)

Training and Education on Brain Injury

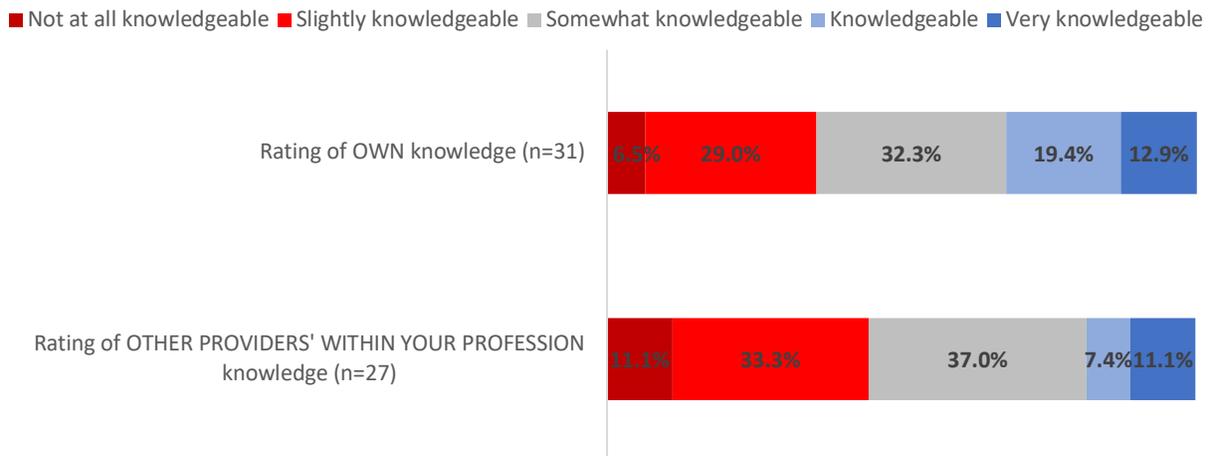
Just over half (54%) of behavioral health providers have participated in training or educational opportunities specifically on brain injury (Figure 58).

Figure 58. Have participated in training or educational opportunities specifically on brain injury (n=31)



Behavioral health providers were asked to rate their own knowledge and the knowledge of other providers in terms of brain injury and needs for individuals living with a brain injury. Just one-in-three (32%) rated themselves as “knowledgeable” or “very knowledgeable”. An even lower percentage (18%) rated other providers within their profession as knowledgeable” or “very knowledgeable” (Figure 59).

Figure 59. Ratings of own and other providers' knowledge of brain injury and needs for individuals living with a brain injury

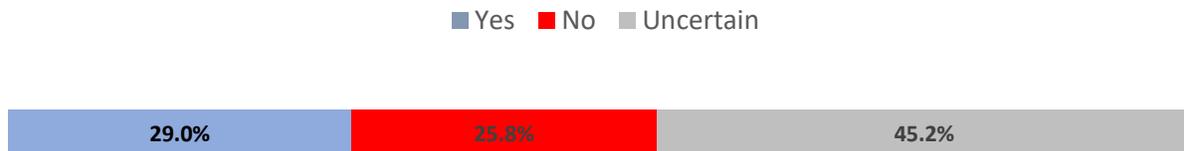


“I would venture to say that most in my own profession do not know that anxiety and depression are the two most common emotional components of TBI, yet most do not even screen for brain injury, let alone actually knowing what to do with it.”

- Behavioral health provider

A minority (29%) of behavioral health providers indicated that the mental health education system provides them with any opportunities to learn about specific health treatment options for individuals with a brain injury. About one-in-four (26%) indicated that this is not the case and a plurality (45%) were uncertain (Figure 60).

Figure 60. Does the mental health education system provide you with any opportunities to learn about specific health treatment options for individuals with a brain injury (n=31)



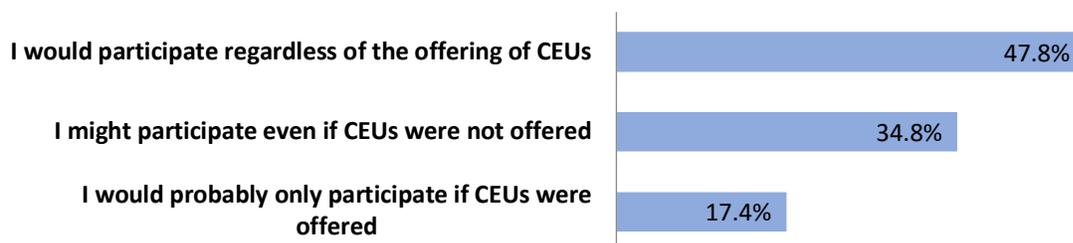
Three-in-four (74%) behavioral health providers are interested in receiving training on brain injury and its impact on behavioral health (Figure 61).

Figure 61. Are you interested in receiving training on brain injury and its impact on behavioral health? (n=31)



Approximately half (48%) of providers interested in training would participate in a training on brain injury and behavioral health regardless of whether CEUs were offered and one-third (35%) “might participate” if CEUs were not offered (Figure 62).

Figure 62. How important are continuing education units (CEUs) to you and a potential training on brain injury and its impact on behavioral health? (among those who are interested in receiving training on brain injury and its impact on behavioral health)



Barriers Related to Brain Injury and Behavioral Health

The top three barriers to providing behavioral health services for individuals with a brain injury are “knowing appropriate referral sources” (reported by 55% of behavioral health providers), lack of training (48%), and lack of funding/compensation to provide services (35%) (Figure 63).

Figure 63. Does your organization experience any of the following barriers to providing behavioral health services for individuals with a brain injury? (n=31)



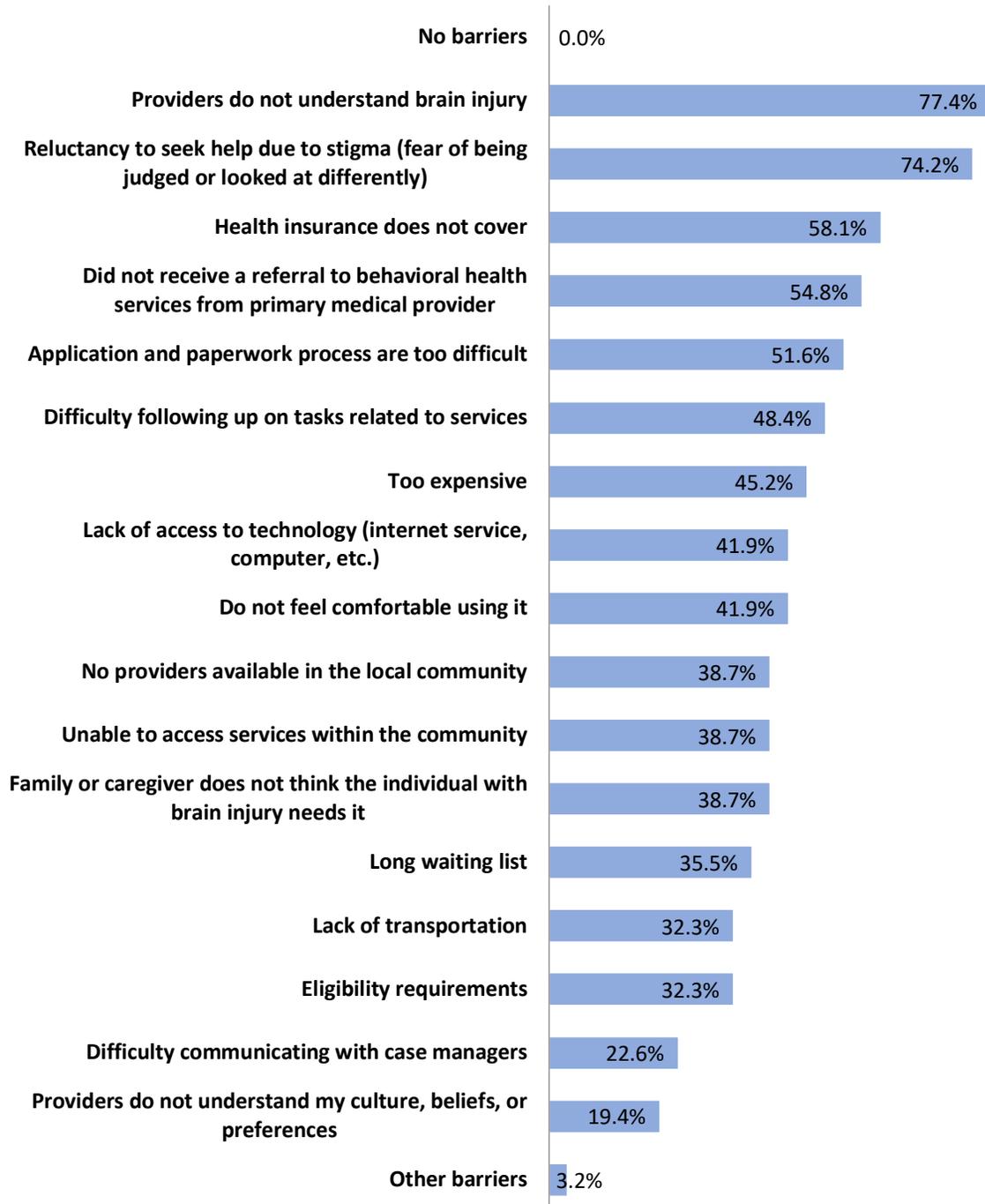
Other barriers: barriers posed by insurance companies with regard to alternative treatments/approaches such as SPECT scanning.

"I am primarily a substance use education provider (IOP program) and often wonder how many of my clients have undiagnosed brain injuries. I have fair awareness of the issues with brain injuries and often wonder how to get my clients assistance when they majority have no income and may not grasp the need for assessment for such as their life experience is not open to see the possibility."

- Behavioral health provider

Behavioral health providers perceived numerous barriers to obtaining behavioral health services for individuals with a brain injury, with the top reason being “providers do not understand brain injury (reported by 77%) (Figure 64, compare to 19 above).

Figure 64. Barriers to obtaining behavioral health services for a survivor of brain injury (n=31)

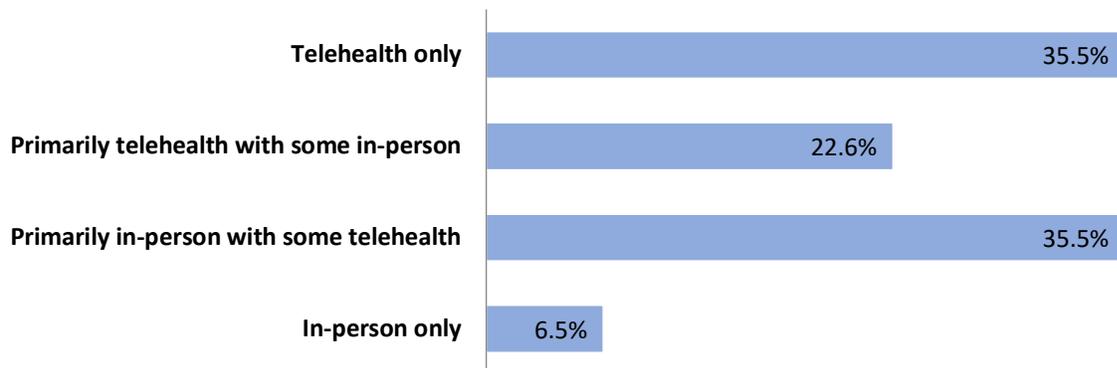


Other barriers: no not recognize the need for or benefit from mental health supports

COVID-19

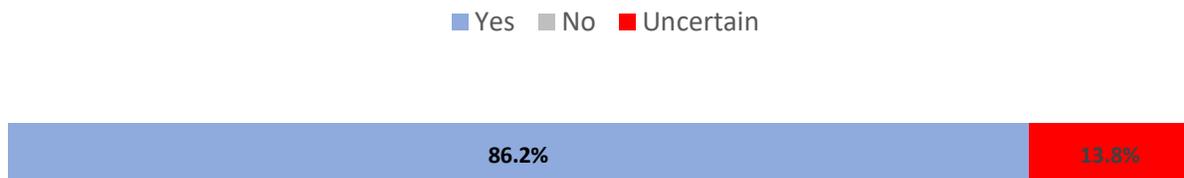
Nearly all (93%) of providers reported using tele-health in some capacity during the pandemic (Figure 65).

Figure 65. What best describes your use of tele-health during the COVID-19 pandemic? (n=31)



The vast majority (86%) of those currently using tele-health, plan to use it as long as it is covered by insurers (Figure 66).

Figure 66. Do you plan to continue using tele-health as long as it is covered by insurers? (among those currently using tele-health) (n=29)



Conclusion – 10 Key Takeaways

- 1. The vast majority of individuals living with a brain injury experience behavioral health issues and have accessed behavioral health and well-being services as a result of their brain injury.***
 - ➔ The vast majority (93%) of individuals living with a brain injury have some experience of behavioral health issues. The most common issues are neurobehavioral issues (reported by 77%) and mental health issues (reported by 75%). About one-in-four (26%) reported misuse of alcohol, opioid prescriptions, and/or other substances.
 - ➔ The vast majority (86%) of individuals living with a brain injury have accessed (and may be currently accessing) one or more behavioral health and/or well-being service as a result of having a brain injury. The most commonly accessed services include mental health counseling (67%); prescription medication for mood, behavior, or other mental health issues (65%); and brain injury support group (54%).
- 2. The number one barrier to obtaining behavioral health services for individuals living with a brain injury is “providers do not understand brain injury”.***
 - ➔ Among individuals living with a brain injury with an experience of behavioral health issues, the number one reported barrier to obtaining behavioral health services was “providers do not understand brain injury” (reported by 61%). Behavioral health providers themselves are in agreement, with 77% reporting this same issue as a barrier for individuals with a brain injury.
- 3. Individuals living with a brain injury who have accessed behavioral health services generally feel neutral about the how well the behavioral health services have met their needs.***
 - ➔ Among those living with a brain injury who have ever received behavioral health services, feelings are mixed as to how well the behavioral health services they have received have met their needs. A plurality (41%) say that behavioral health services have met “none” or “very few” of their needs, 31% say the services have met “some” of their needs, and just 28% say the services have met “most” or “all” of their needs.
- 4. Nearly all family members of individuals with a brain injury experience emotional stress, but relatively few have accessed mental health counseling due their role and responsibilities of being a family member and/or caregiver of an individual with a brain injury. Many family members also lack support from other members of their family.***
 - ➔ Nearly all (97%) of family members experience at least some emotional stress in their role as a family member and/or caregiver of an individual with a brain injury. Yet, a relatively small minority (23%) report that they have accessed any type of mental health counseling services due to their role and responsibilities of being a family member and/or caregiver of an individual with a brain injury.
 - ➔ Nearly half (45%) of family members reported having very little or no help or support from other members of their family to assist with the care plan for their family member with a brain injury.

- 5. Behavioral health providers report relatively low levels of awareness about the intersection of brain injury and behavioral health.**
 - ➔ 31% of providers reported being “moderately” or “highly aware” of crisis intervention and suicide prevention strategies for individuals with a brain injury.
 - ➔ 43% of providers reported being “moderately” or “highly aware” of the difference between cognitive issues as a result of brain injury and behavioral health issues.
 - ➔ 44% of providers reported being “moderately” or “highly aware” of behavioral health resources for those with brain injury.

- 6. About half of behavioral health providers screen individuals for a lifetime of potential brain injury, and most who do so, do an informal screening.**
 - ➔ Just over half (55%) of behavioral health providers reported that they screen for a lifetime history of brain injury. However, among those who do screening, 86% report using only an informal set of questions at intake.

- 7. Most behavioral health providers treat individuals living with a brain injury, but they are mixed in terms of their confidence of providing adequate treatment for an individual with a brain injury.**
 - ➔ Most providers (60%) report that they treat individuals living with a brain injury. A notable minority (17%) do not know if they do or not.
 - ➔ A plurality of providers (40%) reported that they are “not at all” or “slightly confident” in terms of providing adequate treatment for an individual with a brain injury, 31% reported being “somewhat confident”, and 29% reported being “moderately” or “highly confident.”
 - ➔ Among those who treat individuals with a brain injury, just 35% reported that they use specific therapeutic approaches for an individual with a brain injury.

- 8. Approximately half of behavioral health providers have participated in training or educational opportunities specifically on brain injury. The education system does not appear to provide these opportunities with any regularity.**
 - ➔ Just over half (54%) of behavioral health providers have participated in training or educational opportunities specifically on brain injury.
 - ➔ A minority (29%) of behavioral health providers indicated that the mental health education system provides them with any opportunities to learn about specific health treatment options for individuals with a brain injury. About one-in-four (26%) indicated that this is not the case and a plurality (45%) were uncertain.

- 9. Most behavioral health providers are interested in receiving training on brain injury.**
 - ➔ Three-in-four (74%) behavioral health providers are interested in receiving training on brain injury and its impact on behavioral health.

- 10. Top barriers to providing behavioral health services to individuals with a brain injury as reported by behavioral health providers include not knowing appropriate referral services and lack of training.**
 - ➔ The top three barriers to providing behavioral health services for individuals with a brain injury are “knowing appropriate referral sources” (reported by 55% of behavioral health providers), lack of training (48%), and lack of funding/compensation to provide services (35%).

Appendix A – Open-Ended Comments

All comments are presented verbatim.

Comments from Individuals with a Brain Injury

| Table A1 | Is there anything that would have helped you find behavioral health providers more easily? |
|---|--|
| <p><i>Providers who understand brain injury</i></p> <ul style="list-style-type: none"> • No, only because I had existing providers before my brain injury who I liked and allay understood my injury and how it changed me. I have a wonderful counselor and behavioral health provider for my psychiatric meds • I was 15 when my TBI occurred. The therapist I saw treated me as if I was just a young, disrespectful teen in need of an attitude adjustment. I struggled how to cope with the side-effect of anger as a result from the TBI. Whether the therapist was aware of common side-effects or not, I felt completely misunderstood as I was chastised for my actions during a time that was very confusing for me. Now, I have a Master's in Community Counseling. I had no idea there was the possibility of "retraining your brain" so-so-speak. Insightful therapy could have helped me realize I still had potential and to not simply give up things I could no longer do as well. • more providers with tbi knowledge/experience • for the correlation of the brain injury to the behavioral health concerns to have been identified sooner. For quite awhile just thought it was just a phase <p><i>A resource linking to providers who understand brain injury</i></p> <ul style="list-style-type: none"> • list of providers who co-treat brain injury/behavioral health on local brain association websites • If I had more information on providers in my area • Better referrals that were targeted to my needs. A person I trust that I like who could tell me about my needs and how to get help. • being referred to someone who is trained in behavior health with brain injury would have been better. • A resource list of those who understand BI <p><i>Other responses</i></p> <ul style="list-style-type: none"> • I would like some kind of follow up check up. • Yes, more information. Plus being able to afford it. Cost is a big factor • Getting my life back, since my parents locked me up in a nursing home/assisted living and they think I'm stupid. • Live in a larger community I live in small town • More dv related groups I incorporating CTBI • INSURANCE PROVIDER - TREATMENT APPROVAL MEDICAL PROVIDER WITHOUT BELIEF THAT ALL BRAIN INJURIES HEAL WITHIN 6 MONTHS • More expertise in CTBI due to DV | |

- Communication with more people that have same issues. I didn't want to continue saying anything about symptoms, seemed like a dead end.
- Transportation was and is a problem because I can not drive as a result of my hemorrhagic massive stroke.
- I relocated to Nebraska from a different state. It was by hard work on my part and dumb luck that I came across a Brain Injury Support Group located in Omaha. Now it seems some professional therapists are aware and making referrals.

| | |
|-----------------|---|
| Table A2 | Reasons treatment has been <u>unable</u> to help with substance misuse issues (among those who report that treatment has not been able to help them) |
| | <ul style="list-style-type: none"> • While evidenced based, most treatment plans completely disregard person-centered planning and involvement as each individual is unique. Yes, we know it's dangerous. We know it's not healthy and we know the potential consequences. No one ever helped me explore what led me to make those decisions despite the consequences. |

| | |
|-----------------|---|
| Table A3 | What can be done to help individuals with a brain injury who also have issues with behavioral health? |
| | <p><i>Providers who understand brain injury</i></p> <ul style="list-style-type: none"> • Transportation, education to providers • Find providers who handle both. Get them information. • Behavioral therapy who understands tbi and insurance that cover payment • Continue use of and promote through professional referrals the state BIA-NE expertise, trainings, supports and information, as well as local support groups (including locations, times, phone numbers). A big impact would be to have the medical providers get additional training and understanding brain injury. Then, them having a commitment to make appropriate referrals for their patients. • training is the biggest thing, I think, as well as trying to bring general awareness and acceptance. • Better diagnostic and education for health care providers. Increased awareness in the community. • Understanding, none of us are the same. • Stop assuming mental illness is an 'also have' with brain injuries. It's part of, not also. • Neurologists should be better informed of services available to help. I was a behavioral health foster parent and it never occurred to me until now that I could receive services there. • More providers and more providers who understand BI • Education • There needs to be a link between the behavioral health and the primary care physicians or other care givers to include mental health services into their plan of recovery <p><i>Peer Support</i></p> <ul style="list-style-type: none"> • I think the power of having someone else who understands-- another person with a brain injury or who has had one be able to talk to them. I think Dr's need to be educated on support systems and the significance of them. You can medicate people and that's super important and necessary BUT if they don't have a support system day in and out life is hard and at times |

too much to handle. My own primary care provider just gave me pain pills and comfort. She was a great lady but NOT educated about brain injuries and that mild brain injuries can be severe. Even though I look fine I'm not. Huge thing for providers and everyone in America to learn about brain injuries (and other health issues) - just because I look normal I'm not anymore, I'm in constant pain and have deficits that people don't know about and most that I can cover up or skirt the issue. I think it's very important that once you are diagnosed with a brain injury at the ER the ER should send you home with information on brain injuries and that concussions are brain injuries and can be long term or permanent depending on how many concussions you've previously had. I think they need to be given a brochure to the brain injury alliance of NE. That way they have a person of contact who can give more information about the injuries, symptoms, possible options for care, Dr's, support groups in NE. etc etc

- peer support would be extremely helpful for both the receiver and the giver
- peer support and case managers in agencies with capacity to support my unique needs
- Definitely get peer support involved with police activities 24 hours with crisis management and Emergency Management within the community. If my brain doesn't even know where I am or what's going on with the situation how can I comply? I would like to get a demarcation on our permanent records saying we are brain injury Alliance NE and always be taken to a hospital over punitive incarceration
- Brain injury support is necessary over years of healing, too little exists for most due to lack of resources (financial mostly).
- Peer to Peer Support that understands self medicating for effects of a TBI that are related to behaviors. To sleep, to relax, need to drink.

Public education on brain injury to reduce stigma

- Education for the general public to reduce stigma, focusing on the fact that mental health and brain injuries do very often occur together
- find treatment(s) for each kind of issue(s) - public awareness of where to go to find options to medical; transportation; outlets for exercise; where to seek financial assistance.
- Overall, society & those suffering with a BI need to understand this may be an outcome of brain injury so it can be better understood and de-stigmatized. There is still such a lack of knowledge and supports.
- reducing the stigma around behavioral health
- If a person with BI could believe that getting help with behavioral health is appropriate and not a condemnation, that would be good. If medical providers, case managers, and resource facilitators could sit down with the person with BI and say, I think this person could help you, and here is an appointment, that would help. Also, appointments closer together would help, as a person with BI loses focus after a longer period of time.
- Education that behavioral issues are common after injury and not to be ashamed or feel weak

Other responses

- CBT exercise teaching deep breathing and mindfulness
- Care and support showed or given to use people who are very injured.
- A demarcation on our permanent list or record. Sometimes I cannot comply due to my PTSD CTBI. If police had better training, listened to 911 calls and peer support on 911 calls was available 24 hr a day
- Go over what they lost as a result or cannot do as well. Go over future goals - not matter how unrealistic they may seem because this can be a hopeless time. Make a plan on

achieving goals. Make it individualized. More people need to understand Dialectical Behavior Therapy or Eye Movement Desensitization and Reprocessing . DBT delves deep into the causes and reasons we CHOOSE behaviors and teaches mindfulness. Many therapies have more of a Psycho-Educational Model approach under Cognitive Behavioral Therapy: "this is what you did wrong; this is what you need to do; here's your consequence". EMDR also is very effective in dealing with trauma. If trauma is never addressed, trying to address behavior is moot.

- more accessibility services that can identify and assist in maintaining independence - while being aware of the behavioral health challenges that come with some head/brain injury

| Table A4 | What would you like people to know about how a brain injury impacts behavioral health? |
|----------|---|
| | <ul style="list-style-type: none"> • That it confuses you and us! • I would like people to know first off that a concussion is very serious and depending on how many the person has had prior to the current one adds on to the severity of the recent injury and the possible permanency of symptoms. I'd like people to know that, duh, once the brain has been injured depending on what area the brain was damaged the most those symptoms will be related. But even if the frontal lobe isn't effected as much the pain, executive functioning, fatigue, support system level and etc all impact how a person with a brain injury is with their mental health. The isolation alone of not having another person understand how you're feeling can leave you feeling hopeless, misunderstood and alone. • That it does last for a long time. • Everything, its depressive not finding help or know where help is. • its often hard to distinguish whether the mental health is a disorder or just a result of the tbi • You have been born again if you survive but are not the same mentally and emotionally. So don't or stop treating me like I'm stupid. • That I cannot help being depressed. It is not under my control and I cannot think myself out of it. • We are upset easily some have ptsd we deal with pain every day and tire easily. We don't have the ability to make the best decision due to anxiety. • I'm not crazy! Just constantly concussed. • Individuals with brain injury are not always obvious (visually, like broken leg). People with brain injury can be very personable, fun, knowledgeable, etc., just like people without brain injury. Understand that people with brain injury don't necessarily make a decision about how their interactions/behaviors should go. Be kind, understanding, patient, and respectful. • Had I known what I know now.... I would like people to know that their loves ones they've known their whole life can easily and suddenly act uncharacteristically. Support, patience, and understanding are important. I had difficulty with thought and speech organization (among other vicissitudes). When struggling, often times I would just give up and move on to something else. I was not aware that I could take it slowly, write things down, and make a new habit or way of completing a task. I thought my potential was just gone for good and that was that- just deal with it. It's easy to give up when you're 15, your therapist won't listen, and that's all you know at your young age. • Occasional impulsive or unexplained behaviors can occur. • my injury challenges my ability to follow through on basic steps in my recovery, providers need patience and training. I am recovering and making improvements, slow and steady. |

- each person responds differently and has a different reaction. each person can still function in today's society.
- I had behavioral health problems before my wreck, but it got a lot worse after it. I could no longer function the way I use to, I wasn't me anymore. I hated it. I didn't understand, or accept, that I would have to work around my injury. I don't think very many people understand that. I get just as frustrated with it as anyone else does.
- that patience is needed, and understanding is needed, it also is important to have access to wrap around services that include behavioral, neurological and physical health
- Brain Injuries can affect mood and behavior greatly after an injury.
- Even what is seen as a mild brain injury (concussion), can impact one's mood. I felt at times I was on a roller coaster of emotion that I couldn't get off no matter how badly I wanted to.
- I have 2 catchphrases. One is 'I'm not crazy I'm constantly concussed'. The second is 'brain injury the invisible disability. #dontbeascarecrow use your brain. It's the only thing we all got that's just ours. Also the death and grieving of the old self when the new self finally comes out of denial about the brain injury and the limitations and perhaps new gifts that Ctbi has brought
- We may look fine but we are not the same
- Brain injury is not widely known or understood
- I lose my temper, get irritable, am impatient, and all of this is discouraging as I try to move forward.
- Misdiagnosis leads to wrong treatment, failure to help anyone.
- It is all no fault I can't just 'get over it' or stop experiencing it. There isn't just one 'right' way to be a BI survivor. Stop trying to fix how I am experiencing my reality. We are not all brave or noble or picturesque. All of us deserve care and acceptance, not just the easy ones that make providers feel good about themselves.
- I'm still the same person, and the same person I used to be. I still like to read, I like to make jokes. I love my family, my parents, my brothers, my sister in heaven, my kids. I miss seeing my kids and I wish I could would have the opportunity to spend more time with them.
- Show them the graphs of what lies below the surface that they cannot see. Just because they can't see it doesn't mean it doesn't exist.
- Well, how does breast cancer impact behavioral health? Most people don't understand what Brain Injury is, to start. The public awareness is abysmal on brain injury, breast cancer, everyone knows.
- Brain injury effects every system not just physical and obvious health issues but chemicals in your brain as well
- It's part of the brain injury, not necessarily part of the person.
- Many problems are not visible.
- Brian injury is not something that can be seen and can affect every one differently. The problem is that you can't see the injured brain. Someway if we can decrease the gap from the injured person and anyone who has to work with them or make decisions for or about them. Communication is probably the key.
- How difficult it is to control emotions and just needing to isolate to shut down.

| Table A5 | Additional comments |
|-------------|---|
| | <ul style="list-style-type: none"> • One of the best things that happened to me after my brain injury was connecting to the brain injury alliance with Gina Simanek. She works for them AND has a brain injury. She was able to be there for me emotionally and she was such a lifesaver, literally to me to have someone that understands what it's like to have a brain injury. We had very very different symptoms but yet she understood everything. No one else understood. Esp since I was categorized as having had "mild" brain injuries but yet had tremendous disabling pain, cognitive deficits, vision issues etc. I had been at Madonna as an outpatient for 6 months but none of the staff or counselor have had a brain injury so it was maddening at times to not have anyone understand. It was Gina who connected me to a vision Dr, other areas of help, education for me and helping me learn more about my injuries. • Learning a "new normal" is necessary - understanding the impact on the brain and where in the brain - all BI is not the same and needs to be addressed • It would be great if doctors that diagnose brain injury like concussions and near internal decapitation would provide any info on what side effects etc you could have. • I used to have more patience, acceptance of others with different opinions other than mine. Sadly I'm either very happy or very sad or mad. I don't have very much of a balance or tolerance. Which makes me so sad bc I used to be able to be in the middle and see the gray areas in life. Now I'm very black and white, very happy or very low or mad. • I think the most important thing is that health care providers learn more about brain injury and are more aware of what it can do to the brain and how it can cause anger so easy. • The injury does last. • Its separate depression caused by brain injury. • my brain injury has resulted in many mental health diagnoses that I don't believe I would have if I didn't have a brain injury. • No comments on that. But I have met Chris at the Leid Center (Bellevue) and I talked to her about my brain injury. And I have tried to find the kind of doctor she recommended but have had no luck. And then I saw Chris again not to long ago at UNO for the Caregiver retreat. • Most of the issues deal with memory and learning capability. • Routine MRIs we're making condition worse. We suspect a reaction to the dye used for contrast. • I had craneotomy and have been convicted do to my lack of ability to control my behavior. I can no longer work due to the above • Hoping to join peer support on 911 calls • affects not just the brain-injured individuals but their family, friends&strangers that aren't very educated on the arrects of a brain injury. • I feel fortunate to have had professional training and experience regarding brain injury prior to my personal experience. This enabled me to have an understanding about what was happening and what could be lingering symptoms of brain injury, which I feel took some of the fear out of the situation (some, not all of the fear). When something big like brain injury happens - you have to learn the new you. • This individual has MS and other issues which make identification of behaviors difficult. • Behavioral health supports for caregivers of those with injured brains is also needed. • quite the adventure I never wanted to have anger and frustration - every single day • Brain injury affects every aspect of my life. Chronic pain only worsens my symptoms. It's invisible, not irrelevant, faked, or untrue... thank you for asking for my opinions. |

- I am messed up. No one can understand how my BI makes me feel. I cannot multitask. I am impatient. I have to try hard to control my anger. I cannot deal with uncertainty.
- Neurologists need to stop turfing mental health BI issues to mental health professionals and MH professionals need to stop turfing BI issues back to neurologists. They are separate only in your heads, my line. It ends up leaving me in the lurch and holding the bag. If facing it makes you uncomfortable, imagine how it is to me.
- Thanks!
- There is a direct cause and effect of ANY type of brain injury on behavioral health. The question is, why do we have a lack of resources to educate ALL people as an injury can occur any place, any time to anyone. Let's get Nebraska smart about it all.
- Role of brain injury in anger

Comments from Family Members of Individuals with a Brain Injury

| Table A6 | Do you have anything you would like to relate about how being the family member and/or caregiver of an individual with a brain injury impacts one's mental health? |
|----------|---|
| | <ul style="list-style-type: none"> • It is hard to figure out how to do everything. • Being one of the two caregivers for an adult child that has had deficits in the frontal lobe executive part, from a massive hemorrhagic stroke has been very stressful. Luckily I have family support and friend support to get back to my own life such as going to my book clubs, playing golf and reading. I find that our adult daughter "slips through the cracks" for benefits for an Enable bank account because her disability isn't developmental disability. Last I think a massive hemorrhagic stroke technically is not considered a TBI, but I sure think it should be classified as that, thank you. Karen Liebenritt • It can be very stressful living with one with a brain injury. Feel alone at times. People are few because they don't want others to know family has injured brain • It is the hardest task I have ever had and I am 59 years old. I not only make sure she is safe from others, but also safe from herself as she has 'Severe Short term memory loss'. I am also raising her child who has severe mental trauma from her mom's lifestyle before and after her TBI! My task is 365 days a year 24/7. I tried taking a vacation once only to come home to my TBI daughter 5 times over the legal amount of alcohol. I can't trust her or anyone to keep her safe, so I don't get to take breaks. :(But we are blessed and I love her and am her mother, and that is what mothers do.....we love and care for our children. • It affects our mental health as well. It is so depressing when you realize that not only do they have a disability but there are not services and supports for them, post injury. • It rearranges my entire life • It's a day to day, moment to moment existence. You should always have someone to lean on and cherish the time good and bad. Family is important. • The lack of transportation in our situation is the biggest barrier. We are about halfway between Ogallala and North Platte. Respite care is needed as well. • The stress on family members who are the primary caregiver from the initial injury and through recovery is enormous. Your focus is on your child's recovery. Other members of the family may not fully understand the mental burden, stress on the caregiver and the emotional impact, chemical changes in the body as a reaction to the stress. . • Being a family member and caregiver of an individual with BI is a long, hard slog, and not giving up is key to progress. Keeping trying to find help is also important. COVID restrictions have lost us some necessary helps. I have needed and receive psychotherapy to help me. Codependency is an issue, but working with a person living with BI means that regular codependency helps do not consistently apply. • It's made my life and the life of my second child hell we live in fear all the time as he is so aggressive at simplest unexpected moments • Being a family member/caregiver of a person with a brain injury, greatly impacts the caregiver's life. It is vitally important for the caregiver to find ways to care for themselves first of all, using mental health counselors, seeking help to support the person with a brain injury, exercise and taking part in activities for your own enjoyment. I as a caregiver, have to care for myself first and become healthy functioning so I can care for the person with the traumatic brain injury. |

Comments from Behavioral Health Providers

| Table A7 | Informal questions used to screen for brain injury (among those who report using “informal set of questions” so screen for a lifetime history of potential brain injury) |
|----------|---|
| | <ul style="list-style-type: none"> • Have you suffered a head injury? Have you been in a car accident? Has a medical profession ever started you had a concussion or other brain injuries? • Do you have a history of seizures, head injuries, or concussions? • Have you ever had an injury hurting your head, brain, skull? For example, hit your head hard, have a concussion, etc. • Whether they have ever been injured in an accident; whether they have ever been hospitalized for physical/mental health reasons. • Have you ever experienced head trauma? How has that affected you? Do you have any limitations, that you are aware of, as a result? • Any significant medical history of illnesses or injuries? • Have you had an accident that caused a head injury. • Have you ever had a brain injury? • Have you ever suffered a brain injury, concussion, accident involving head injury? • When injury occurred, how it occurred, how serious was injury (loss of consciousness, hospitalization) • Have you ever lost consciousness due to a blow to the head or been diagnosed with a TBI? • Just small talk to begin, get connected & build trust. Then ask them to talk about their life story & listen for anything that will lead me to drill down questions; head trauma, drug use ect. • Date of head trauma, LOC or alteration of consciousness, length of AGA/PTA, GCS (if relevant), onset/course of cognitive issues, coinciding symptoms like headache, dizziness, imbalance, etc., pain meds used s/p injury, functional impact at school, work, etc. |

| Table A8 | Treatment modalities that work best for an individual with a brain injury |
|----------|---|
| | <ul style="list-style-type: none"> • Integration with Health care provider, motivational interviewing, cognitive rewards, person centered care • CBT mostly in conjunction with medical providers and only for mild cases up to this point. • CBT • I use portions of the STEP Executive Manual from Mt. Sinai School of Medicine. It has specific cognitive rehabilitation approaches. They also have a manual that focuses on before/after brain injury in several areas, i.e. relationships, work, etc. To help people understand the changes that have occurred in their lives and adaptations they have made. I also give information about nutritional and lifestyle approaches that can help restore as well as more novel approaches such as NIR and HBOT, etc. |

| Table A9 | Do you strongly recommend any organizations and/or professionals you use as referrals or resources for individuals with a brain injury who have behavioral health needs? |
|---|---|
| <ul style="list-style-type: none"> • Lanning Center, Hastings • Nebraska Brain Alliance • BIA-NE • NE Brain Injury Alliance, Community Alliance (Dr Jai), and the VA. • Eileen Curry, Madonna • Medical professionals who can support rehabilitation in natural ways, i.e. supplementation, hormone balancing, etc. rather than or in conjunction with psychotropic medications. Referral to alternative treatments such as NIR, HBOT, etc. as needed. Referral for SPECT scanning which has been a game changer for most. • BIA | |

| Table A10 | Do you have any observations you would like to share regarding the impact of brain injury on behavioral health and the subsequent need for services? |
|---|---|
| <ul style="list-style-type: none"> • This area is misunderstood and miss diagnosed. The general community and providers do not recognize the levels of TBI. Mild and moderate TBI needs intervention as much as severe. There is also a lack of acknowledgement for SUD regarding TBI. • Substance abuse can play a role in brain injuries and is there any information about that. • I am primarily a substance use education provider (IOP program) and often wonder how many of my clients have undiagnosed brain injuries. I have fair awareness of the issues with brain injuries and often wonder how to get my clients assistance when they majority have no income and may not grasp the need for assessment for such as their life experience is not open to see the possibility. • We work mostly with Veterans. TBI & PTSD are both very common with Vets. Symptom to both are very similar and often a co-occurring disorder. • Just that the impacts of brain injury are not adequately understood/recognized either in the medical or mental health community. Dr. Wayne Gordon states that "Unidentified TBI is a major unrecognized cause of social, vocational and educational failure." I believe this to be true and yet there is no adequate, systemic screening mechanism in any of these arenas. I believe that counseling and social work education programs should all be educated in depth about TBI and that screening should be taught in mental health programs and mandated. People with TBI are 20% more likely to become substance involved and 50% more likely to fail treatment so I think the same needs apply in the substance use fields as in the mental health system yet we are failing these clients in an alarming way, including with inappropriate personality disorder diagnosis when the actual issue is brain injury. Travesty. • I would venture to say that most in my own profession do not know that anxiety and depression are the two most common emotional components of TBI, yet most do not even screen for brain injury, let one actually knowing what to do with it. | |

Appendix B – 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)