



# NORTH DAKOTA BRAIN INJURY NETWORK

## NDBIN Needs Assessment Survey Results

July 2021

# Background

In May of 2021, the North Dakota Brain Injury Network (NDBIN) launched a needs assessment survey to help identify gaps in services and improve services for people with a brain injury living in North Dakota.

This anonymous survey was designed for survivors to tell us what they think people with brain injury need, and how satisfied they are with the resources that they have found available. The purpose of this survey was to achieve a better understanding of whether individuals with brain injury have been able to access services related to their brain injury and what service gaps exist.

NDBIN's staff, along with Karen Vanderzanden, research analyst with Healthcare Workforce Safety, submitted to the University of North Dakota's Internal Review Board (IRB) and were granted permission to utilize this virtual survey across North Dakota.

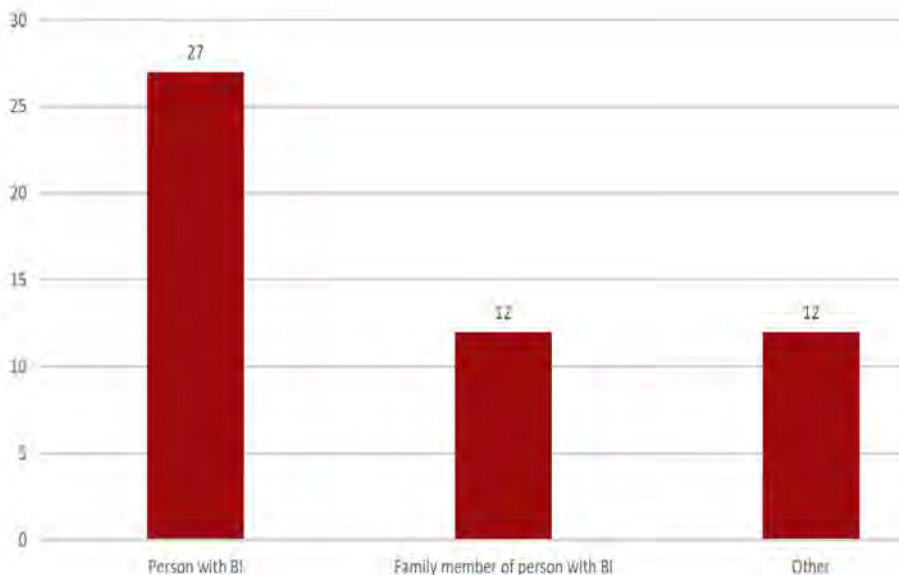
The survey window was open for two months. Recruitment emails, Facebook posts, website posts, and personal referrals were made to survivors across North Dakota during that time. The following are the results from that survey:

## Total Responses = 51

- Fully Completed Surveys = 31
- Partial Completions = 20

## Q1. Which best describes you (person completing the survey)?

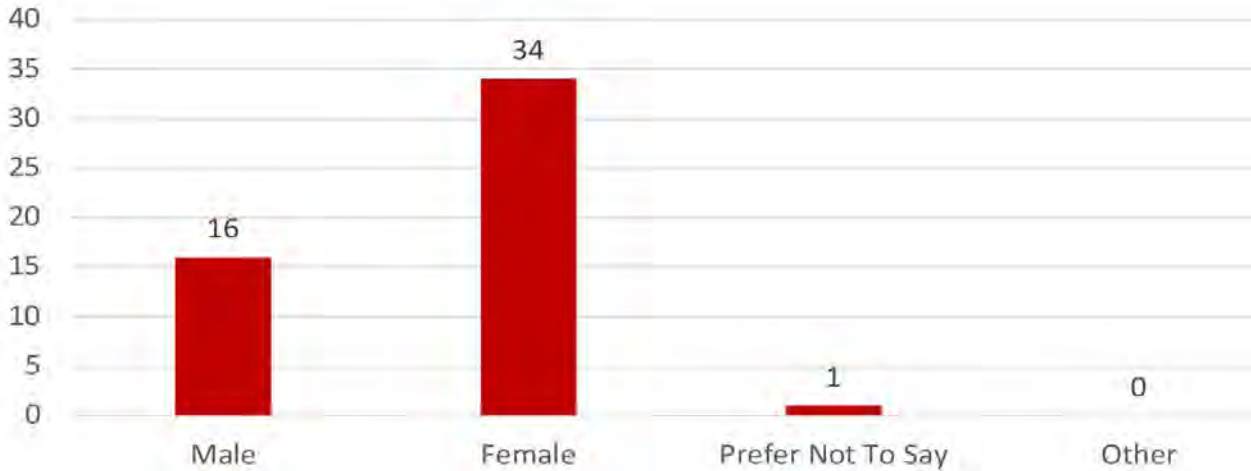
- Person with brain injury = 27 (52.9%)
- Family member of person with brain injury = 12 (23.5%)
- Other (specify) = 12 (23.5%)
  - » "Work with individuals with brain injury"
  - » "Case manager"
  - » "Occupational Therapist"
  - » "Educator of student with TBI"
  - » "Profession"
  - » "Social worker who works with people with brain injuries"
  - » "I work in brain injury services"
  - » "Health Care provider"
  - » "CVSO"
  - » "Acute care physical therapist"
  - » "Facilitate a BI support group"
  - » "Special Education teacher"



It is important for the reader to note that the intent of this survey was for either the survivor themselves to fill it out independently, or have a caregiver to the survivor assist them in filling it out. It appears NDBIN could have been better about conveying that message in that many providers to individuals with brain injury started the survey, but then did not complete it once they got into questions that were more client specific. It is NDBIN's intent to modify our next survey so that a provider could fill it out.

## Q2. What is your gender?

- Male = 16 (31.4%)
- Female = 34 (66.7%)
- Prefer not to say = 1 (2.0%)
- Other = 0 (0%)

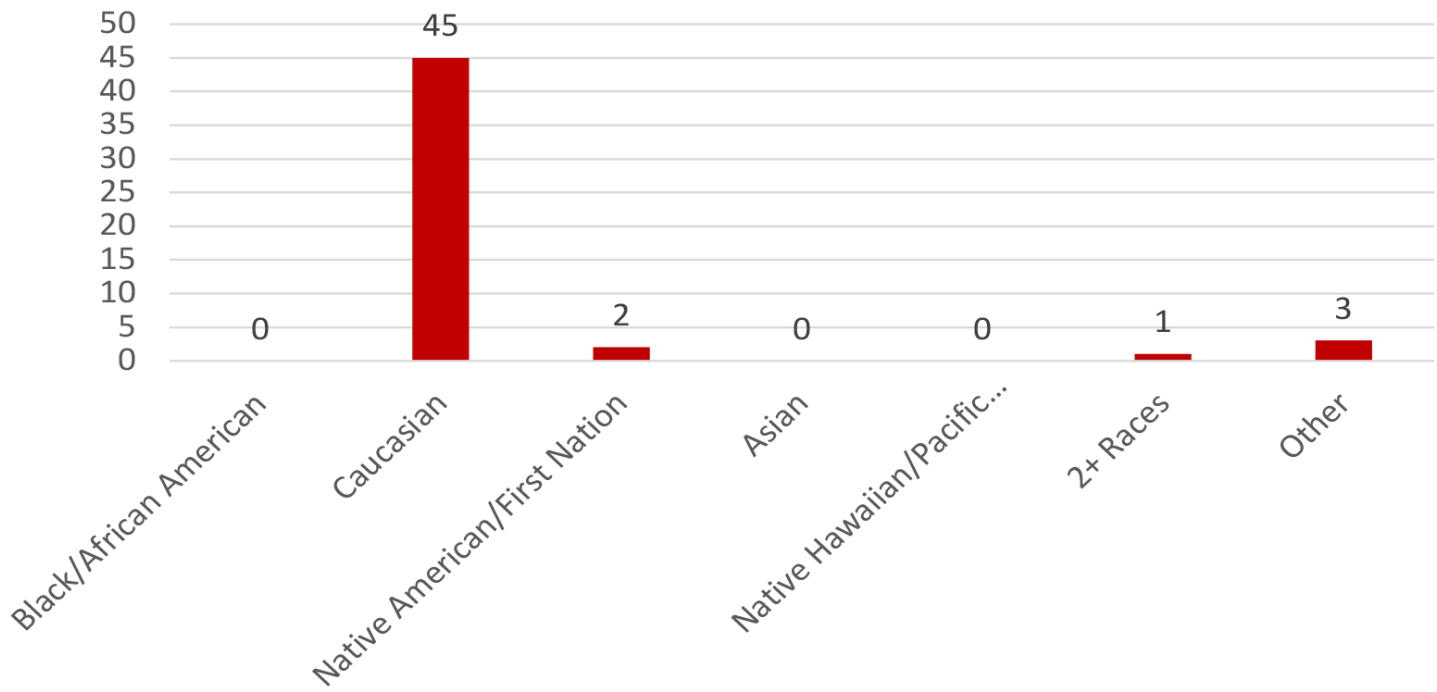


## Q3. What is your current age in years?

- Total responses = 51
- Min = 23 years old
- Max = 76 years old
- Mean = 47.4 years old
- Std Dev. = 15.2 years old

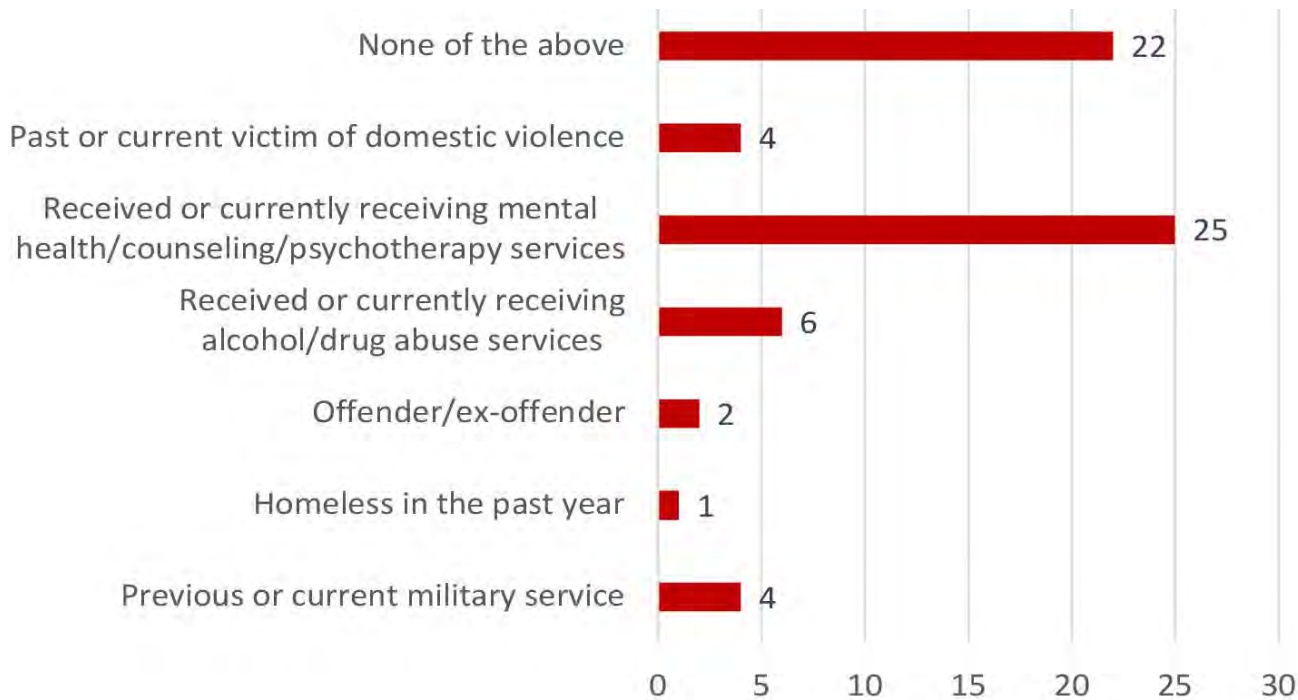
## Q4. What is your Ethnicity/Race?

- Black/ African American = 0
- Caucasian = 45
- Native American and/or First Nation = 2
- Asian = 0
- Native Hawaiian or other Pacific Islander = 0
- Two or more races = 1
- Other (please specify) = 3
  - » White
  - » White
  - » None



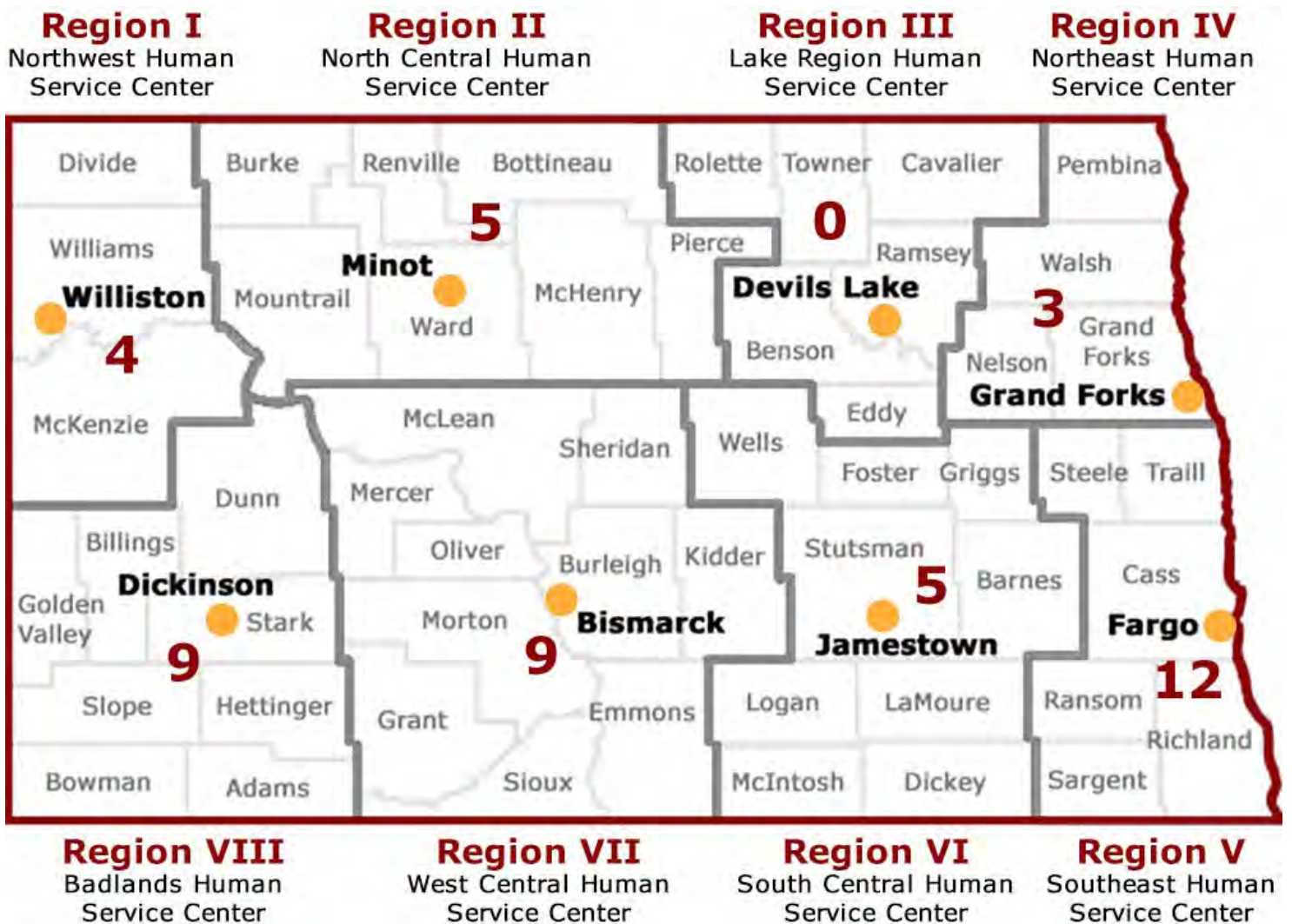
**Q5. Please check all categories that apply to you:**

- Previous or current military service = 4
- Homeless in the past year = 1
- Offender/ex-offender = 2
- Received or currently receiving alcohol/drug abuse services = 6
- Received or currently receiving mental health/counseling/psychotherapy services = 25
- Past or current victim of domestic violence = 4
- None of the above = 22
- \*Missing = 2



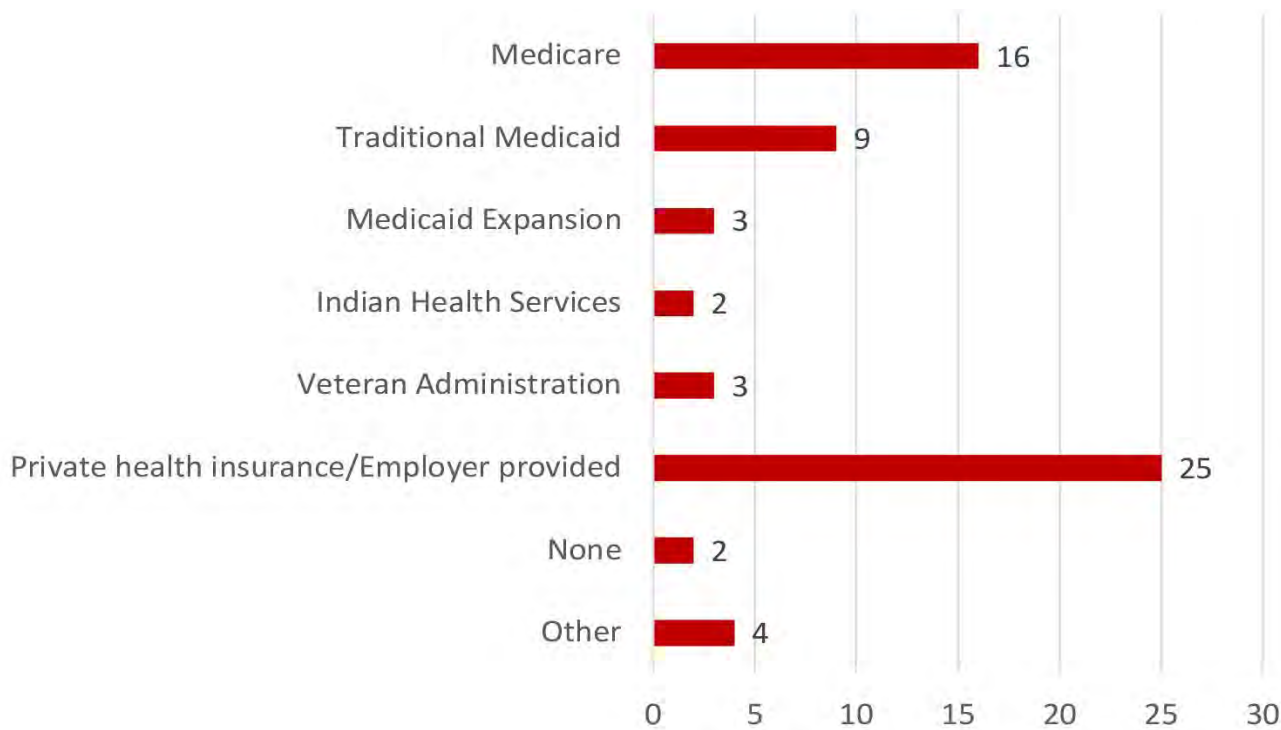
## Q6. What is the zip code of your current residence?

- 58103 = 6 (Fargo)
- 58102 = 1 (Fargo)
- 58501 = 5 (Bismarck)
- 58601 = 5 (Dickinson)
- 58078 = 3 (West Fargo)
- 58201 = 3 (Grand Forks)
- 58401 = 3 (Jamestown)
- 58503 = 3 (Bismarck)
- 58636 = 2 (Halliday, Twin Buttes, Werner)
- 58655 = 2 (Zenith, Daglum)
- 58002 = 1 (Arbaska [West of Mapleton])
- 58075 = 1 (Wahpeton)
- 58421 = 1 (Carrington)
- 58433 = 1 (Edgeley)
- 58554 = 1 (Mandan)
- 58701 = 1 (Minot)
- 58703 = 1 (Minot)
- 58730 = 1 (Crosby)
- 58736 = 1 (Drake)
- 58746 = 1 (Kenmare)
- 58763 = 1 (New Town)
- 58801 = 2 (Williston)
- 58852 = 1 (Tioga)
- 94553 = 1 (Martinez, California [near San Francisco])
- \*Missing = 3



### Q7. What health insurance do you currently use?

- Medicare (for those over age 65 or disabled) = 16
- Traditional Medicaid (for those with low income) = 9
- Medicaid Expansion (Sanford Medicaid) = 3
- Indian Health Services = 2
- Veteran Administration = 3
- Private health insurance/Employer provided = 25



### Q8. How many brain injuries have you sustained?

- 22 of our respondents have sustained 1 brain injury. 6 people have sustained 2 injuries, 3 people sustained 3 injuries, and 3 people sustained 4 injuries.

### Q9. How old were you at the time of your first brain injury?

- The minimum age for this response was at birth, or 0 years old. The maximum age was 71. The average age was 21 years old (6 participants) of participants at the time of their first brain injury.

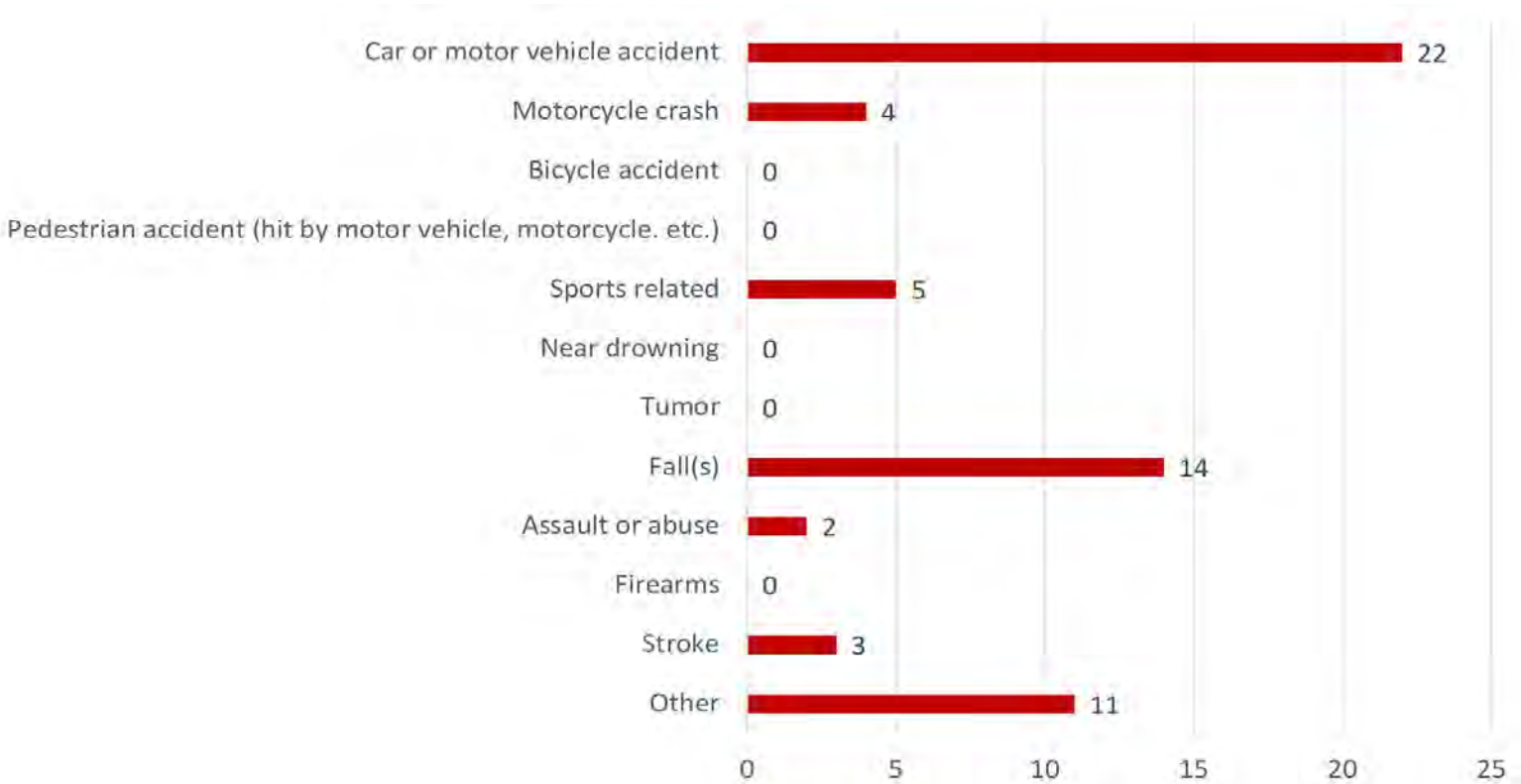
### Q10. How old were you when your most recent injury occurred?

- Often times individuals sustain more than one injury. The minimum age for this response was at birth, or 0-year-old. The maximum age was 76 years old. The average age for a most recent injury is 37 years old.

### Q11. How did you sustain your brain injuries? If you have had more than one brain injury, select all that apply.

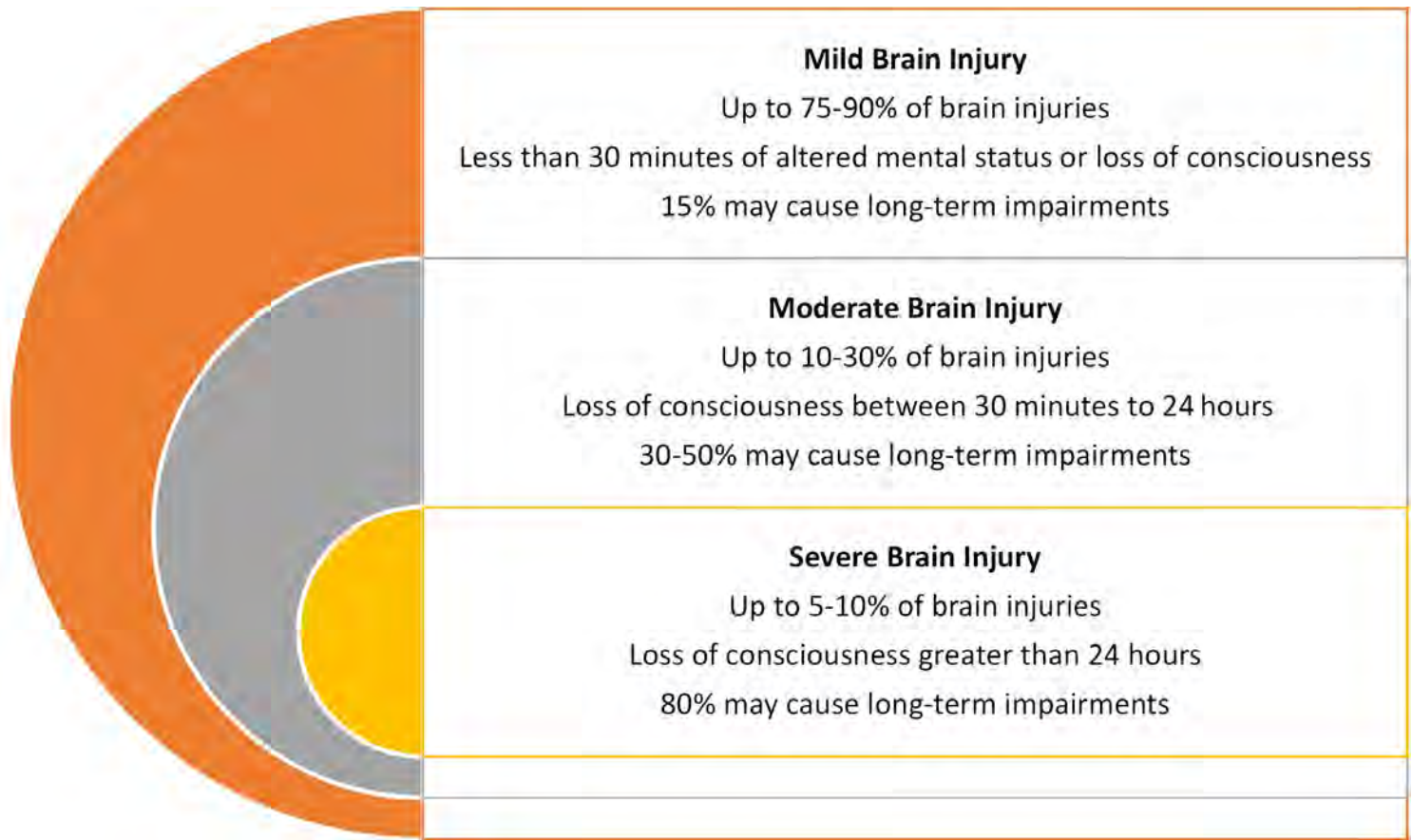
- Car or motor vehicle accident = 22
- Motorcycle crash = 4
- Bicycle accident = 0
- Pedestrian accident (hit by a motor vehicle, motorcycle, bike, etc.) = 0
- Sports related = 5
- Near drowning = 0
- Tumor = 0

- Fall(s) = 14
- Assault or abuse = 2
- Firearms = 0
- Stroke = 3
- Other (describe) = 11
  - » Lifted up unexpectedly and dropped
  - » Undetermined stroke-like event
  - » Waterskiing
  - » N/A = 2
  - » Encephalitis = 2
  - » Snowmobile accident
  - » Dementia
  - » Brain survey, concussion from knocking head on concrete
- \*Missing = 9



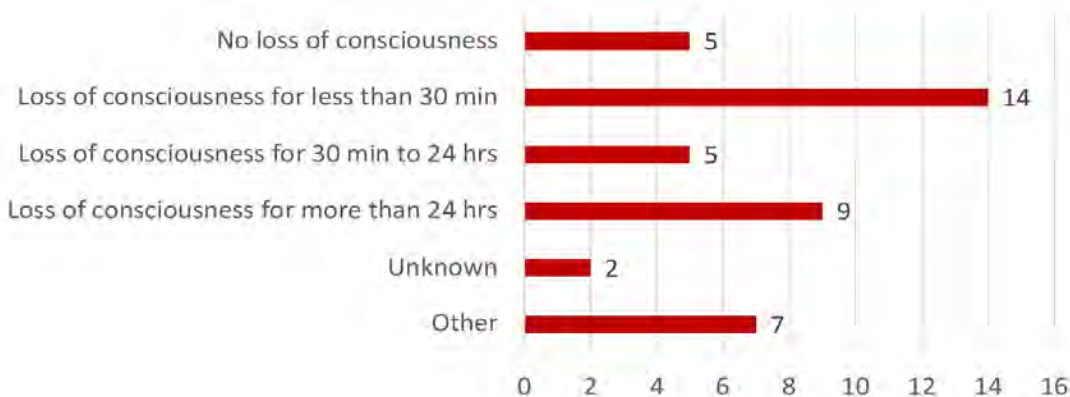
### Q12. How severe was your most significant brain injury?

- Severity of brain injury is typically determined by loss of consciousness. Some injuries are severe and others are mild. Concussions are a mild form of brain injury and are common. There may or may not be a period of unconsciousness immediately following the event. No two brains are the same. The results of a brain injury, which can affect various areas of the brain depending on the type and severity of accident, vary widely from person to person.



**The following is how individuals who took this survey ranked the severity of their injury.**

- No loss of consciousness = 5 (Mild)
- Loss of consciousness for less than 30 minutes = 14 (Mild)
- Loss of consciousness for 30 minutes to 24 hours = 5 (Moderate)
- Loss of consciousness for more than 24 hours = 9 (Severe)
- Unknown = 2
- Other (describe) = 7 (Variety of Severity levels)
  - » “Coma for 3 months. Many mental and physical changes”
  - » “17-year-old was in a coma for several weeks”
  - » “Coma for over 90 days”
  - » “Brain bleed”
  - » “Brain bleed, vision affected, balance affected”
  - » N/A = 2
- \*Missing = 9





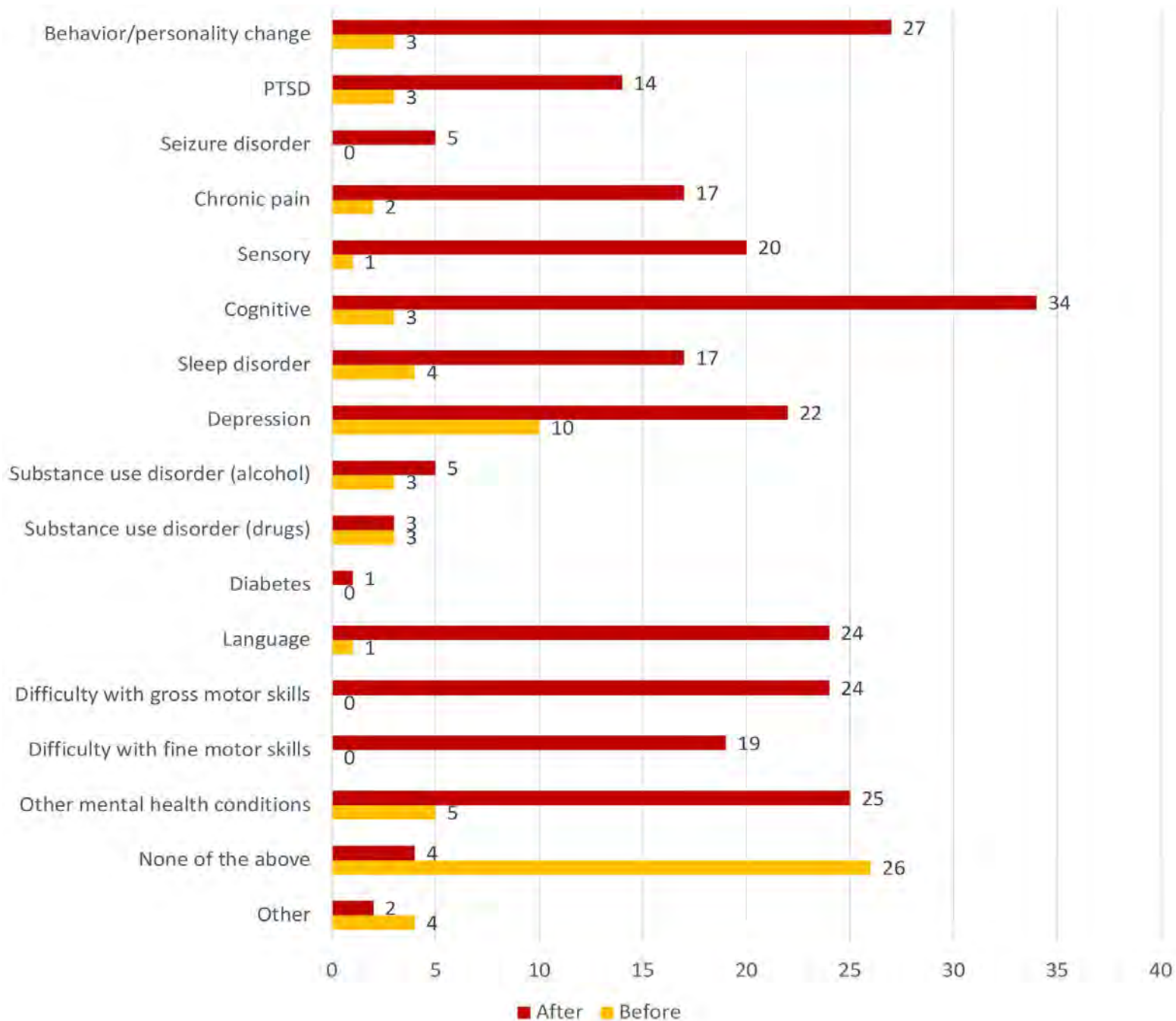
**Q13. Please indicate any disabilities or significant health conditions that you already had BEFORE the brain injury (Mark all that apply):**

- Behavior/personality change (e.g., acting out, aggression, social inappropriateness) = 3
- Post-Traumatic Stress Disorder (PTSD) = 3
- Seizure disorder = 0
- Chronic pain (e.g., headaches) = 2
- Sensory (vision, hearing, taste, smell) = 1
- Cognitive (memory, processing, problem solving) = 3
- Sleep disorder = 4
- Depression = 10
- Substance use disorder (alcohol) = 3
- Substance use disorder (drugs) = 3
- Diabetes = 0
- Language (e.g., communication, expression, and understanding) = 1
- Difficulty with gross motor skills (e.g., sitting, standing, walking, running) = 0
- Difficulty with fine motor skills (e.g., grasping, object manipulation, drawing) = 0
- Other mental health conditions (e.g., anxiety) = 5
- None of the above = 26
- Other (describe) = 4
  - » "Learning difficulties"
  - » "ADD"
  - » "Anxiety"
  - » N/A
- \*Missing = 8

**Q14. Please indicate any disabilities or significant health conditions that you developed AFTER the brain injury (mark all that apply):**

- Behavior/personality change (e.g., acting out, aggression, social inappropriateness) = 27
- Post-Traumatic Stress Disorder (PTSD) = 14
- Seizure disorder = 5
- Chronic pain (e.g., headaches) = 17
- Sensory (vision, hearing, taste, smell) = 20
- Cognitive (memory, processing, problem solving) = 34
- Sleep disorder = 17
- Depression = 22
- Substance use disorder (alcohol) = 5
- Substance use disorder (drugs) = 3
- Diabetes = 1
- Language (e.g., communication, expression, and understanding) = 24
- Difficulty with gross motor skills (e.g., sitting, standing, walking, running) = 24
- Difficulty with fine motor skills (e.g., grasping, object manipulation, drawing) = 19
- Other mental health conditions (e.g., anxiety) = 25
- None of the above = 4
- Other (describe) = 2
  - » "Dementia"
  - » N/A
- \*Missing = 10

## Q13 and Q14 Figure: Before and After Consequences



# Consequences

Many survivors physically appear to be as they were before the injury. Cognitive deficits (memory, organization, motivation, processing speed, etc.) and personality changes are what typically manifest, but these changes often are not acknowledged as results from the injury. It is difficult for people close to the survivor to recognize deficits because on the outside, the person appears to have recovered. This gives the impression that the survivor should also be acting and speaking as they would have before experiencing the injury. Although a person may recover medically, pre-injury cognition may not completely return.

After sustaining a brain injury, medical and psychological issues are often identified. Seizures are a common neurological effect, but other systems in the body such as the digestive, respiratory, and cardiovascular, can be impacted as well. Mental illness and substance abuse are also common following brain injury. Negative feelings, attitudes, and poor coping skills can result not only from the realization of the severity of injury, but with the difficulties of being accepting of post injury life, thus, mental illness and substance abuse are also common following a brain injury.

A common myth is that when the brain is injured, it can mend completely – like a broken arm. Unfortunately, brain cells do not regenerate like skin or bone cells. Rehabilitating from a brain injury takes time because damaged cells need to relearn how to do things while the brain uses healthy cells to compensate.

While it is important to understand changes that may have a negative impact, the best resources for recovery are an individual's current strengths, abilities, and interests. As many individuals with brain injury have said: "It's not about what you lost. It's about how you use what you have left!"

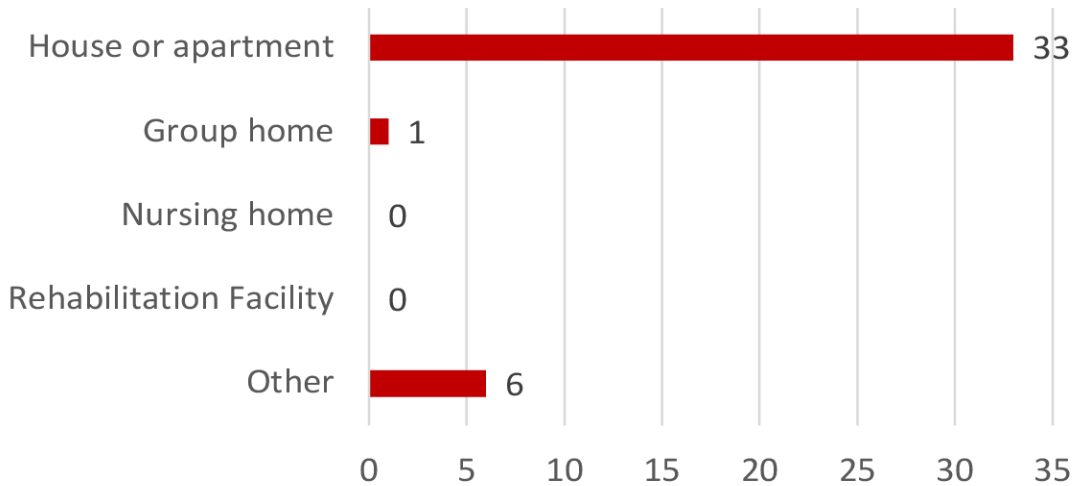
## Q15. Has the injury affected any of the following areas of your life? (Mark all that apply)

- Marriage/romantic relationship
  - » No change = 6
  - » Is better = 1
  - » Is worse = 18
  - » Not Applicable = 14
  - » \*Missing = 12
- Interpersonal/social
  - » No change = 4
  - » Is better = 1
  - » Is worse = 30
  - » Not Applicable = 3
  - » \*Missing = 13
- Education
  - » No change = 9
  - » Is better = 2
  - » Is worse = 17
  - » Not Applicable = 11
  - » \*Missing = 12
- Employment
  - » No change = 4
  - » Is better = 2
  - » Is worse = 29
  - » Not Applicable = 5
  - » \*Missing = 11
- Income
  - » No change = 4
  - » Is better = 3
  - » Is worse = 25
  - » Not Applicable = 7
  - » \*Missing = 12
- Living situation
  - » No change = 17
  - » Is better = 3
  - » Is worse = 12
  - » Not Applicable = 8
  - » \*Missing = 11
- General Health
  - » No change = 8
  - » Is better = 0
  - » Is worse = 28
  - » Not Applicable = 4
  - » \*Missing = 1
- Parenting
  - » No change = 7
  - » Is better = 0
  - » Is worse = 5
  - » Not Applicable = 27
  - » \*Missing = 12
- Psychological status
  - » No change = 5
  - » Is better = 1
  - » Is worse = 29
  - » Not Applicable = 5
  - » \*Missing = 11

	No Change	Is Better	Is Worse	Not Applicable
Marriage/romantic relationship	6	1	18	14
Interpersonal/social	4	1	30	3
Education	9	2	17	11
Employment	4	2	29	5
Income	4	3	25	7
Living situation	17	3	12	8
General health	8	0	28	4
Parenting	7	0	5	27
Psychological status	5	1	29	5

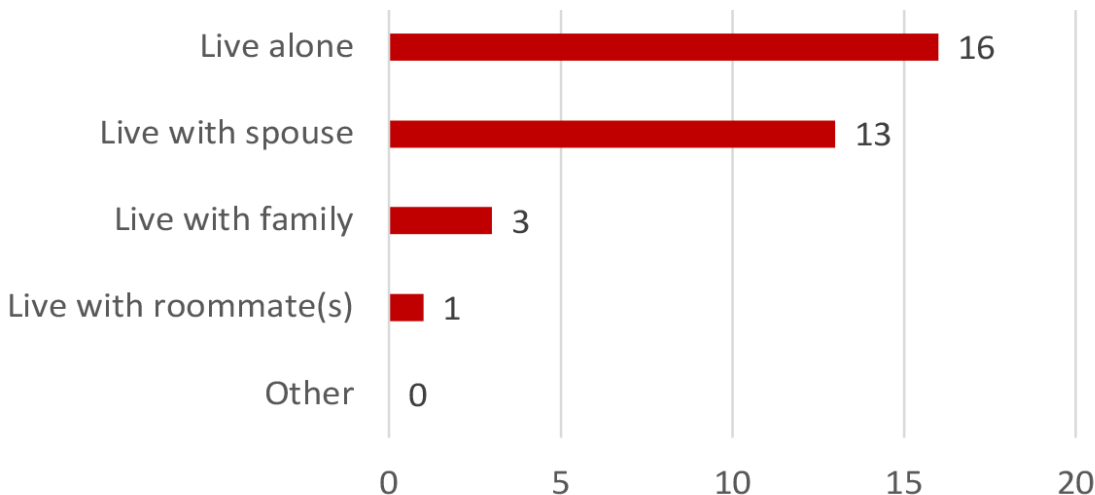
## Q16. Where are you currently living?

- House or apartment = 33
- Group home = 1
- Nursing home = 0
- Rehabilitation facility = 0
- Other (describe) = 6
  - » “Psychiatric hospital” = 2
  - » “With parents” = 2
  - » “With grandparents”
  - » “Memory care facility”
- \*Missing = 11



### Q16.1. (If 'House or apartment' for Q16) Select the option that best describes the current living situation in your house or apartment:

- Live alone = 16
- Live with spouse = 13
- Live with family = 3
- Live with roommate(s) = 1
- Other = 0
- \*Missing = 18



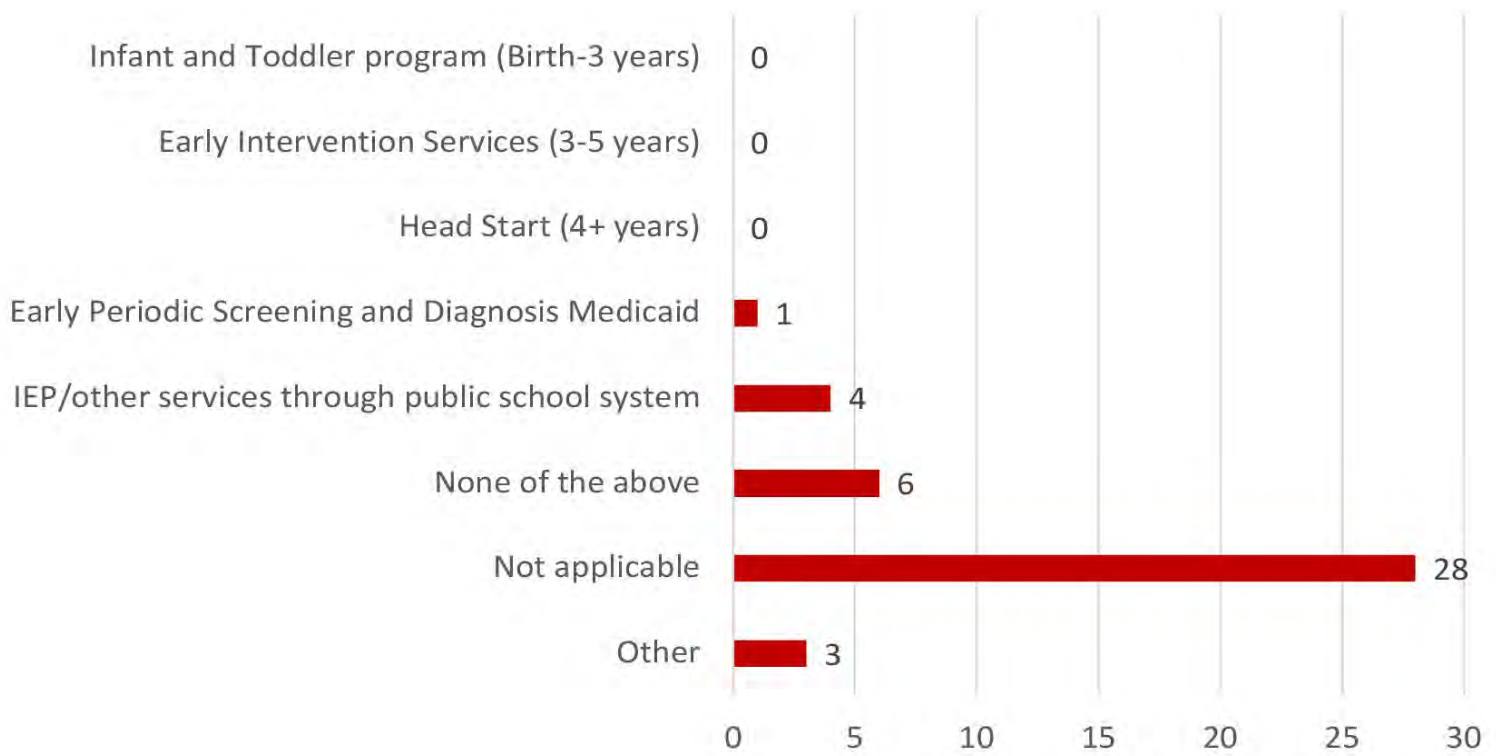
## Q17. If you are unsatisfied with your current living situation, why? (Mark all that apply)

- Not applicable = 18
- Can't get the in-home services I need (e.g., personal care, homemaking services) = 5
- Can't get the medical care I need = 5
- Can't get the rehabilitation therapy I need (e.g., physical, speech, occupational) = 5
- Don't have access to transportation = 1
- Insufficient financial resources = 6
- Lack of access to accessible and affordable housing = 0
- Lack of employment = 4
- Need help coordinating and planning for services = 8
- Need specialized training and services (e.g., cognitive training, behavioral supports, community living skills training) = 8
- Other (describe) = 7
  - » "Wanting to try new therapies and can't do it because the facility doesn't allow anything that isn't FDA approved. Trying to find a good neurologist is terribly hard in ND."
  - » "Need cognitive, planning help"
  - » "Ok now, after injury needed in home services that were unavailable"
  - » "Lack of peer support in the community"
  - » "Hard to get motivated – to declutter – very overwhelming"
  - » N/A = 2
- \*Missing = 13



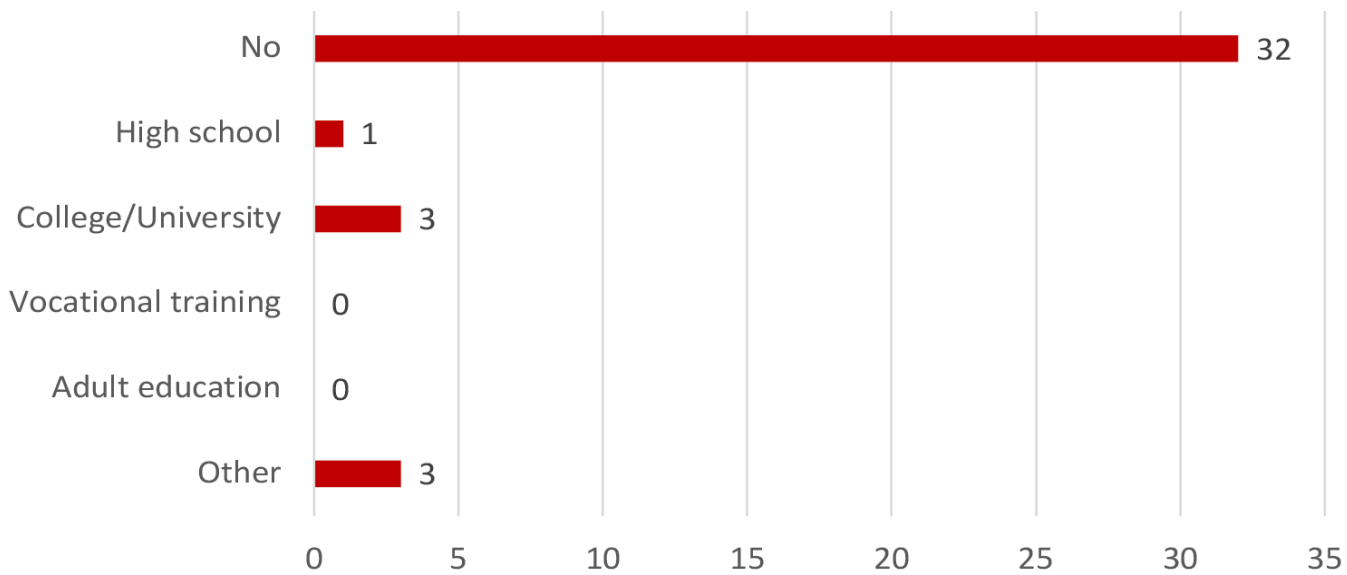
**Q18. If you were under the age of 18 at the time of your brain injury, did you use any of the following state programs as a result of your brain injury? (Select all that apply)**

- Infant and Toddler program (Birth-3 years) = 0
- Early Intervention Services (3-5 years) = 0
- Head Start (4+ years) = 0
- Early Periodic Screening and Diagnosis (EPSDT) Medicaid = 1
- IEP or other services offered through public school system = 4
- None of the above = 6
- Not applicable = 28
- Other (specify) = 3
  - » “All I know was pre-school. Don’t know if I used any of those other state programs”
  - » Pre-school, Special Ed class
  - » I was not finished with high school but was 18 and went to disability room when I came back to school to finish
- \*Missing = 11



**Q19. Are you enrolled in school?**

- No = 32
- High school = 1
- College/University = 3
- Vocational training = 0
- Adult education = 0
- Other (explain) = 3
  - » “Trying for GED”
  - » “I wish I was”
  - » N/A
- \*Missing = 12



**Q20. Have you received any special education services, supports, or accommodations in a school or college program?**

- No = 22
- Yes (explain) = 17
  - » “Had help my senior year through the disability room at school”
  - » “DSS @ UND, various accommodations to meet the need (x2)”
  - » “Pre-school, Special Ed class”
  - » “Human Services trying to get one on one testing due to memory loss”
  - » “When I was in college I did get tutoring, studying accommodations”
  - » “I’ve tried but it’s hard to get TBI accommodations as the needs are poorly understood”
  - » “During my last year of high school I was in the disability program”
  - » “Note taker, extended time to test, quiet area to test”
  - » “special ed & InVest”
  - » “Special ED class”
  - » “I received accommodations via UND’s Disability Services as a student 2012-2016”
  - » “not in school or college”
  - » N/A
- \*Missing = 12





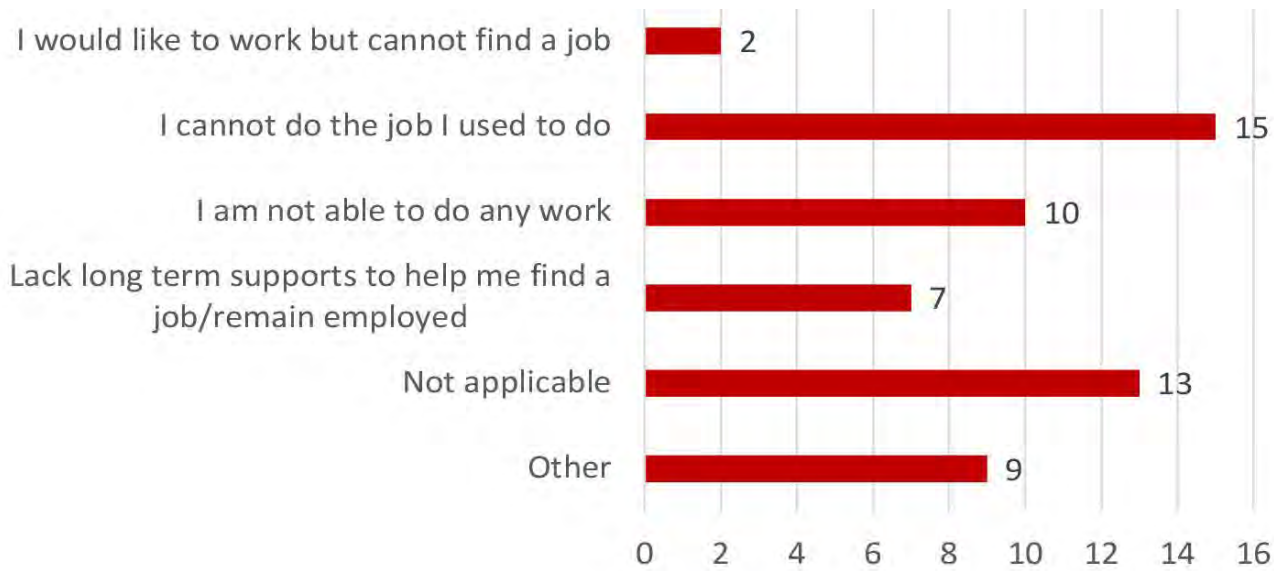
## Q21. What is your current work situation?

- I have not worked since the brain injury = 8
- I am not working now, but I have worked since the brain injury = 7
- I am looking for work = 0
- I have a part-time job = 6
- I have a full-time job = 11
- I am doing volunteer work = 0
- Does not apply (child, retired, etc.) = 0
- Other (explain) = 7
  - » “Self-employed”
  - » “Did some volunteer work but haven’t done any since covid”
  - » “Was retired on disability 2 years after my accident”
  - » “He does work in a group cleaning needs alot of prompts and sometimes refuses to do certain tasks. Tried to get him a job, but he cannot function alone.”
  - » “I did work part time after the injury, but I couldn’t handle it.”
  - » “Retired (due to stress at the job which was not good for my brain injury)”
  - » “Am working very little (not really enough to call it part-time); doing volunteer work”
- \*Missing = 12



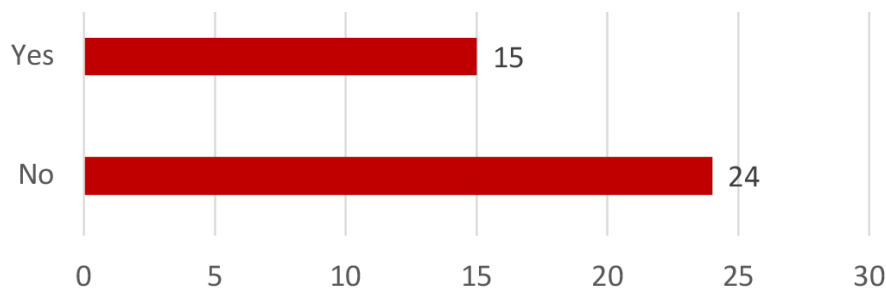
## Q22. If you are unsatisfied with your current work situation, why? (Select all that apply)

- I would like to work but cannot find a job = 2
- I cannot do the job I used to do = 15
- I am not able to do any work = 10
- I lack long term supports or accommodations to help me find a job and/or remain employed = 7
- Not applicable = 13
- Other = 9
- \*Missing = 12



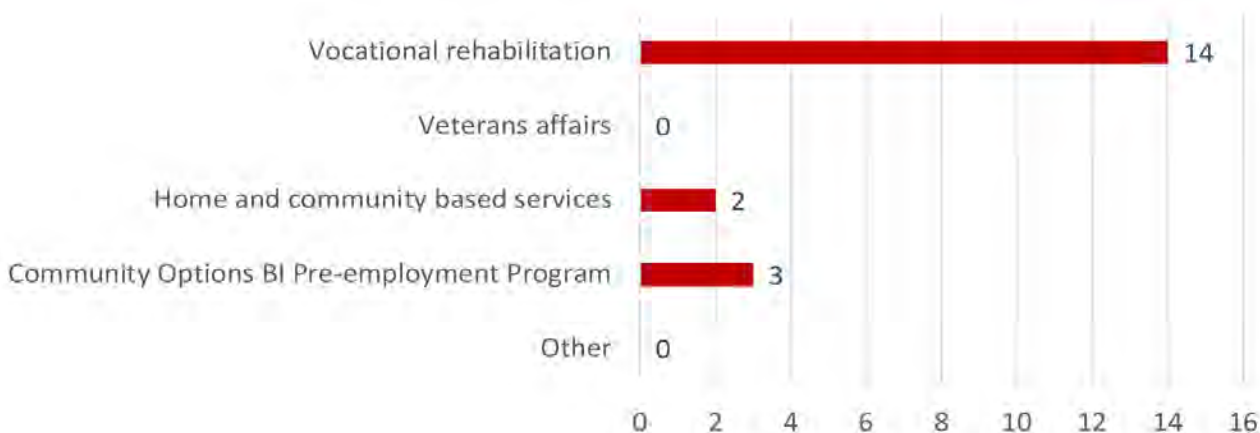
**Q23. Have you accessed any services to help with employment? (e.g., vocational rehabilitation, job coaching, etc.)**

- Yes = 15
- No = 24
- \*Missing = 12



**Q23.1. (If 'Yes' for Q23) What employment assistance have you accessed? (Select all that apply)**

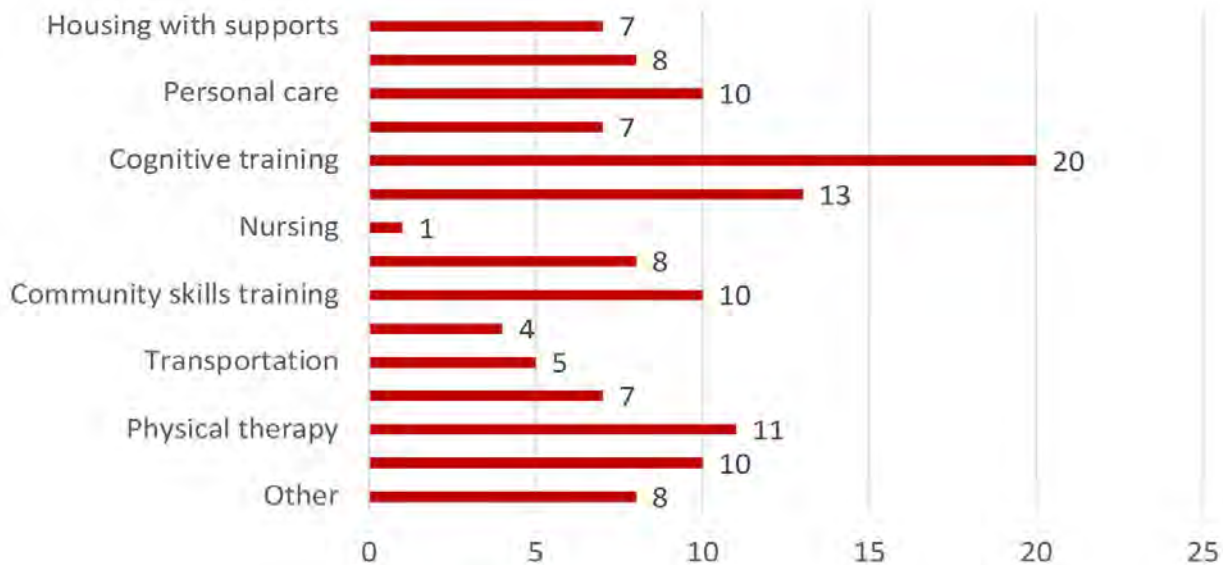
- Vocational Rehabilitation = 14
- Veterans Affairs = 0
- Home and Community Based Services = 2
- Community Options Brain Injury Pre-Employment Program = 3
- Other (specify) = 0



	I currently use this service	I have used this service in the past	I have heard of this service but never used it	I have never heard of this service
North Dakota Brain Injury Network	20	8	9	1
State or Medicaid Home and Community Based services	5	4	14	13
Occupational Therapy	3	15	14	4
Speech and language therapy	3	16	16	1
Physical Therapy	5	18	10	3
Mental health psychotherapists/counselors	10	13	9	3
BI support groups	12	6	14	5
State vocational rehabilitation	1	11	20	4
Community Options Pre-employment Program	0	2	23	10
Centers for Independent Living	4	2	23	6
Protection and Advocacy	0	6	25	4
North Dakota BI Advisory Council	3	3	20	9
Veterans Services	0	2	25	9
Residential Placement	3	0	22	10

### Q25. What areas do you still need or want more assistance with? (Check all that apply)

- Housing with supports = 7
- Employment = 8
- Personal care = 10
- Chores = 7
- Cognitive training = 20
- Speech therapy = 13
- Nursing = 1
- Recreation = 8
- Community skills training = 10
- Money management = 4
- Transportation = 5
- Occupational therapy = 7
- Physical therapy = 11
- Counseling = 10
- Other (explain) = 8
  - » "I had to take a cut in pay because I can't get my GED, and covid was no help with it. I work 12 hour shifts and time is not on my side."
  - » "insurance coverage"
  - » "His place at Dakota Point is awesome, but they don't have enough staff to take him places all the time especially now with COVID. Would be nice to hook him up with other events, etc. but he would have to have someone with him. Myself and his sister in town could help with that if we just had some events."
  - » None (x4)
  - » N/A
- \*Missing = 13



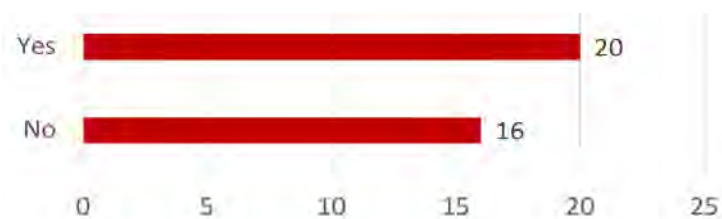
**Q26. What problems do you have in getting the services you need related to brain injury? (Mark all that apply)**

- Difficulty understanding process or paperwork = 14
- Insurance does not cover needed services = 14
- Difficulty with English language = 2
- Lack of support/patient advocacy = 10
- Difficulty with enrollment/admissions = 2
- Lack of transportation = 3
- Do not have insurance = 2
- Need help with financial management = 3
- Do not have support to get a job = 2
- Services and resources not located locally = 15
- Do not have support to live where I want to live = 1
- Unaware of services and resources = 9
- Inability to pay for needed services = 7
- Other (explain) = 9
  - » "Difficulty getting motivated to seek assistance. I do ok and am certainly functional, but struggle with some cognitive issues, attn, organization..."
  - » "Because I live at home with parents and QSP services for me are very limited because programs don't help if I get help from parents or QSP (my mom is my QSP)"
  - » "Not interested"
  - » "I have been able to access the help I needed from community-based support group and the ND Brain Injury Network"
  - » "I don't qualify for Medicaid"
  - » "Anxiety about head getting hurt again"
  - » None (x3)
- \*Missing = 17



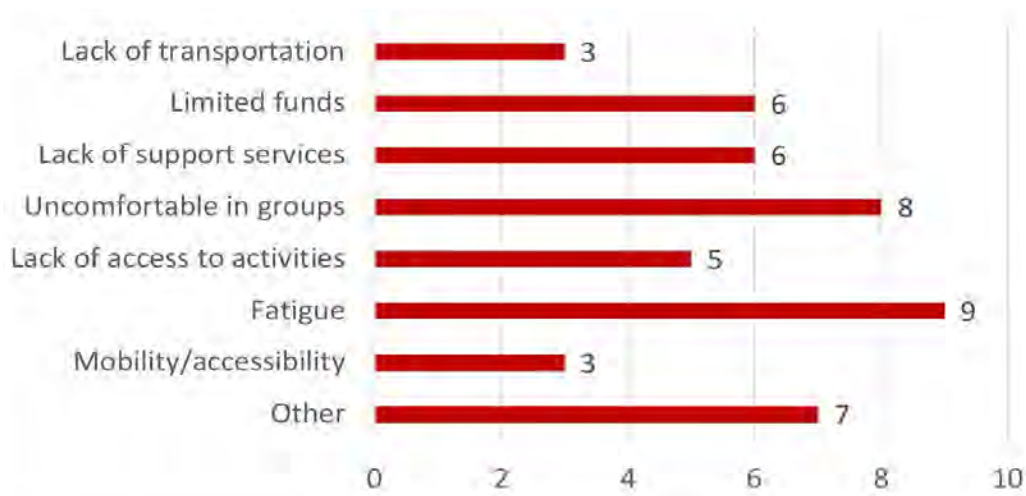
### Q27. Are you able to participate in community activities as often as you want?

- Yes = 20
- No = 16
- \*Missing = 15



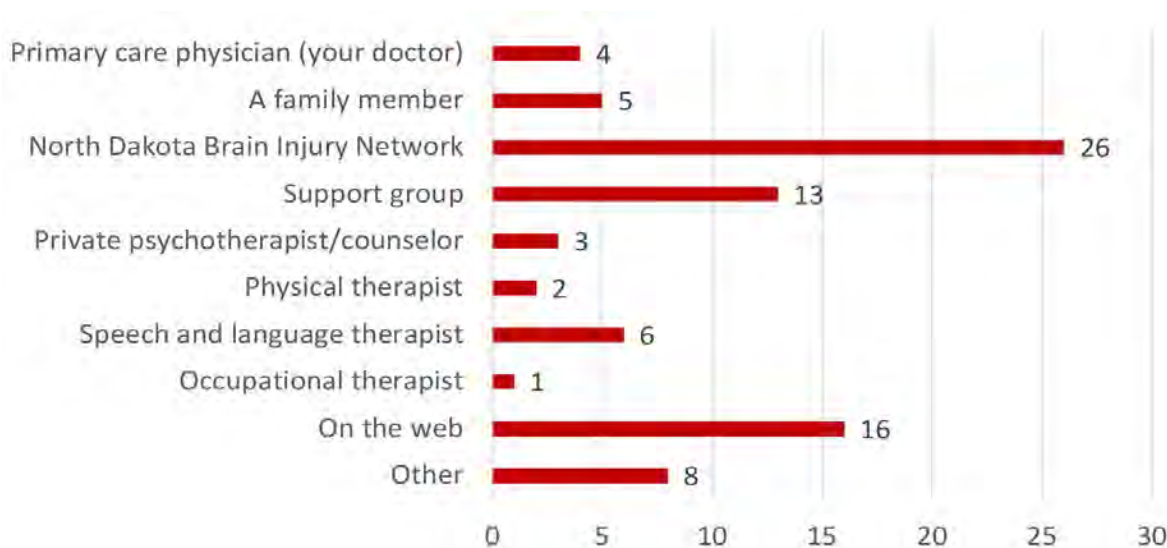
### Q27.1. (If 'No' for Q27) Why aren't you able to participate in community activities as often as you want? (Select all that apply)

- Lack of transportation = 3
- Limited funds = 6
- Lack of support services = 6
- Uncomfortable in groups = 8
- Lack of access to activities = 5
- Fatigue = 9
- Mobility/ accessibility = 3
- Other (explain) = 7
  - » "Time of activities"
  - » "Dementia"
  - » "Chronic pain limits my activities & social life. Also any travel for too long of a time or distance"
  - » "Limitation in eyesight & hearing"
  - » "My job does not allow me time to work and recover from being tired out, I worked 3 months of night shifts, 12 hour shifts, every other weekend off. I spend that catching up on sleep then training myself to go back to day shifts/ night shifts."
  - » "COVID protocols, cannot go independently would need to have someone there to watch him"
  - » "Self-esteem and self-confidence have hit rock bottom."



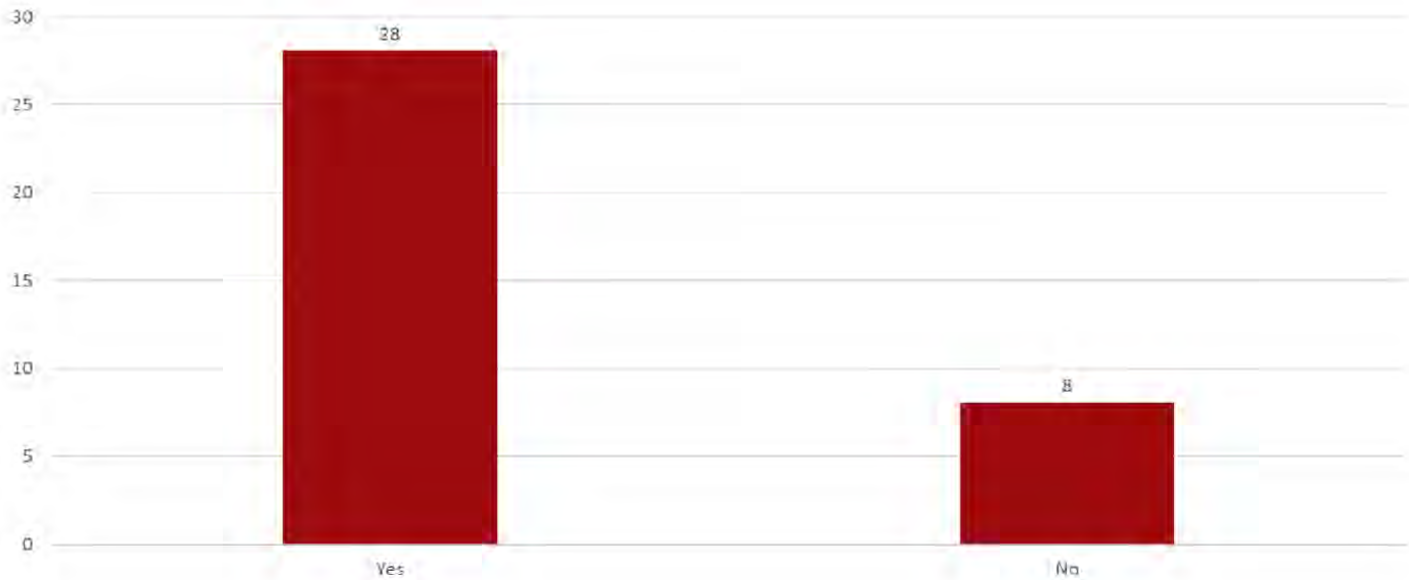
**Q28. Where do you get most of your information about brain injury and brain injury related services? (Check all that apply)**

- Primary care physician (Your doctor) = 4
- A family member = 5
- North Dakota Brain Injury Network = 26
- Support group = 13
- Private psychotherapist/counselor = 3
- Physical therapist = 2
- Speech and language therapist = 6
- Occupational therapist = 1
- On the web = 16
- Other (explain) = 8
  - » “School”
  - » “Experience and past work with providers”
  - » “Facebook”
  - » “As a rehabilitation specialist. I have many resources available”
  - » “My case worker mostly.”
  - » “His home where he is living is good at sharing resources”
  - » “Friend”
  - » “Neurologist”
- \*Missing = 15



## Q29. Have you met professionals who need to learn more about brain injury?

- Yes = 28
- No = 8
- \*Missing = 15



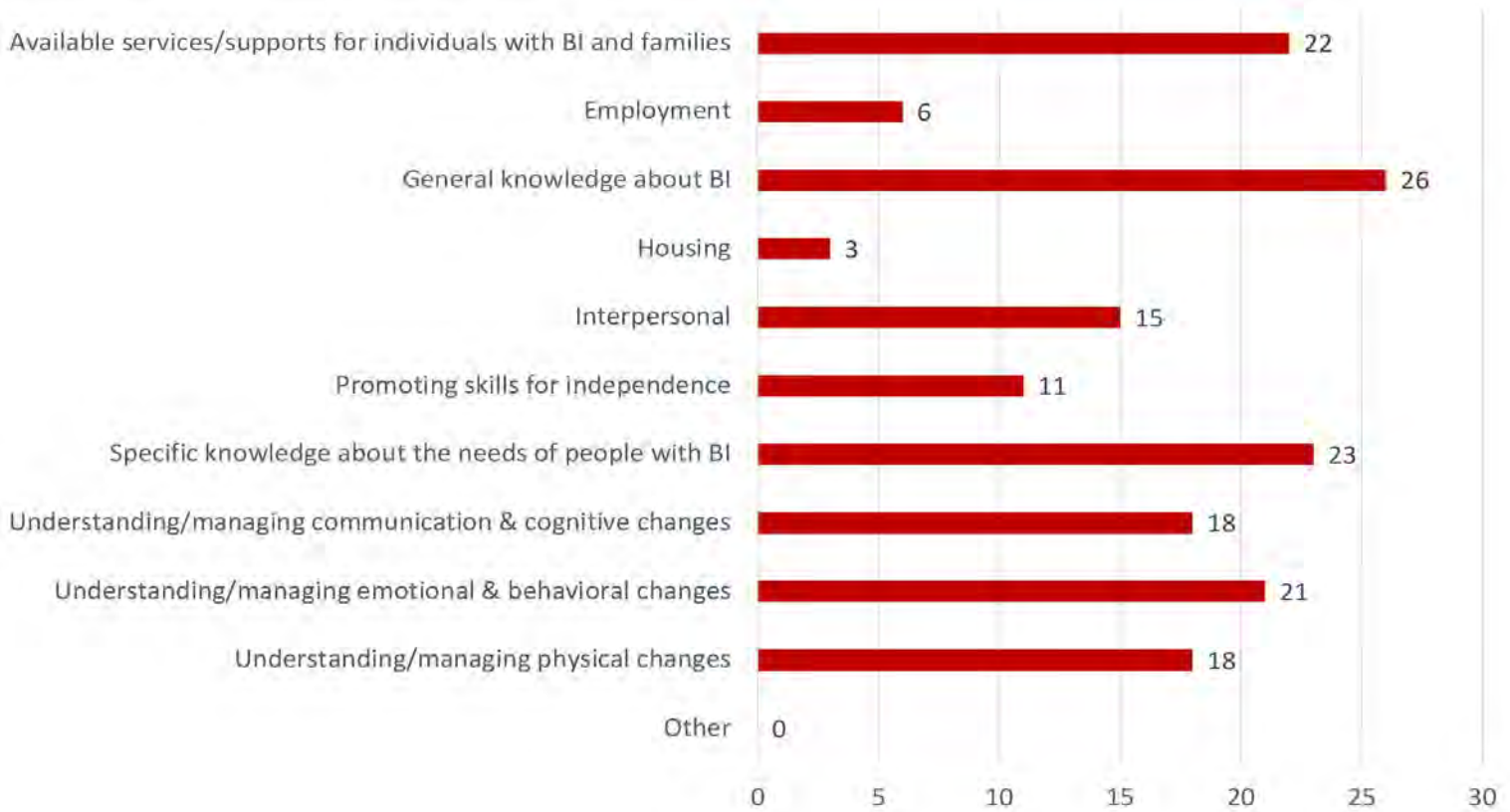
## Q30. (If 'Yes' for Q29) Who are these professionals? (Mark all that apply)

- Other (specify) = 3
  - » This is based on anecdotal stories regarding sports functions
  - » BSC nursing staff also dismissive of TBIs

Medical/Hospital Personnel	Rehabilitation Personnel	Community Service Providers and Professionals	Educator/School Personnel
First responders = 11	Occupational Therapist = 7	Mental health professional = 14	Coach = 7
Discharge planner = 14	Physical therapist = 11	Attorney = 12	Principal = 8
ER medical provider = 17	Speech therapist = 4	In home care provider = 10	School nurse = 6
Family medical provider = 25	Other = 5	Law enforcement personnel = 4	Teacher = 13
Nurse = 17		Military service personnel = 4	Other = 3
Psychologists/Neuropsychologists = 19		Social worker = 10	
Other = 7		Vocational rehabilitation personnel = 12	

**Q31. (If 'Yes' for Q29) What additional training or information do these professionals need to improve their capacity to serve people with brain injury and their families? (Mark all that apply)**

- Available services and supports for individuals with brain injury and their families = 22
- Employment = 6
- General knowledge about brain injury (e.g., causes, types) = 26
- Housing = 3
- Interpersonal = 15
- Promoting skills for independence = 11
- Specific knowledge about the needs of people with brain injury = 23
- Understanding and managing communication and cognitive changes = 18
- Understanding and managing emotional and behavioral changes = 21
- Understanding and managing physical changes = 18
- Other = 0
- \*Missing = 23





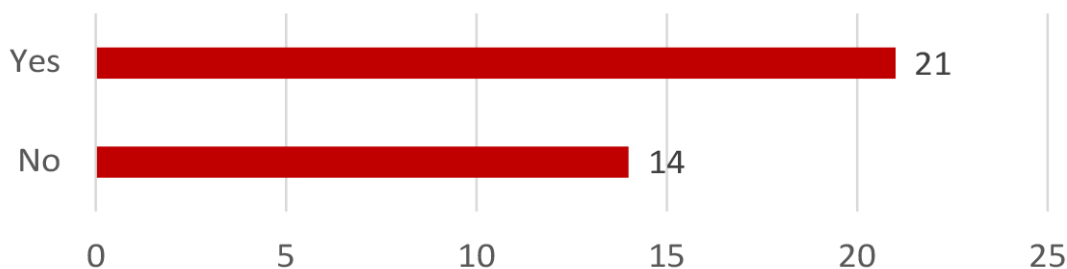
**Q32. Using the list below, which are most important to you when it comes to what you want others in your community to know and understand about brain injury? (Select up to 3 options)**

	Frequency
Brain injury frequently results in challenges and disabilities that others cannot necessarily see	27
After the brain injury, the individual may never be the same person they were before	17
Daily functioning can vary depending on symptoms that are easily affected by stress or medical symptoms	14
Brain injury results have different outcomes, and everyone has unique symptoms	13
Individuals with memory or language changes are not less intelligent than before their brain injury	10
People with brain injury do not need pity but do need compassion and respect	8
Brain injury impacts how I express myself	6
To be more aware of the consequences of brain injury	3
My "main goal" is to live in the community like anyone else as a "member" of my community	1
To be more aware about how brain injury can be prevented	1

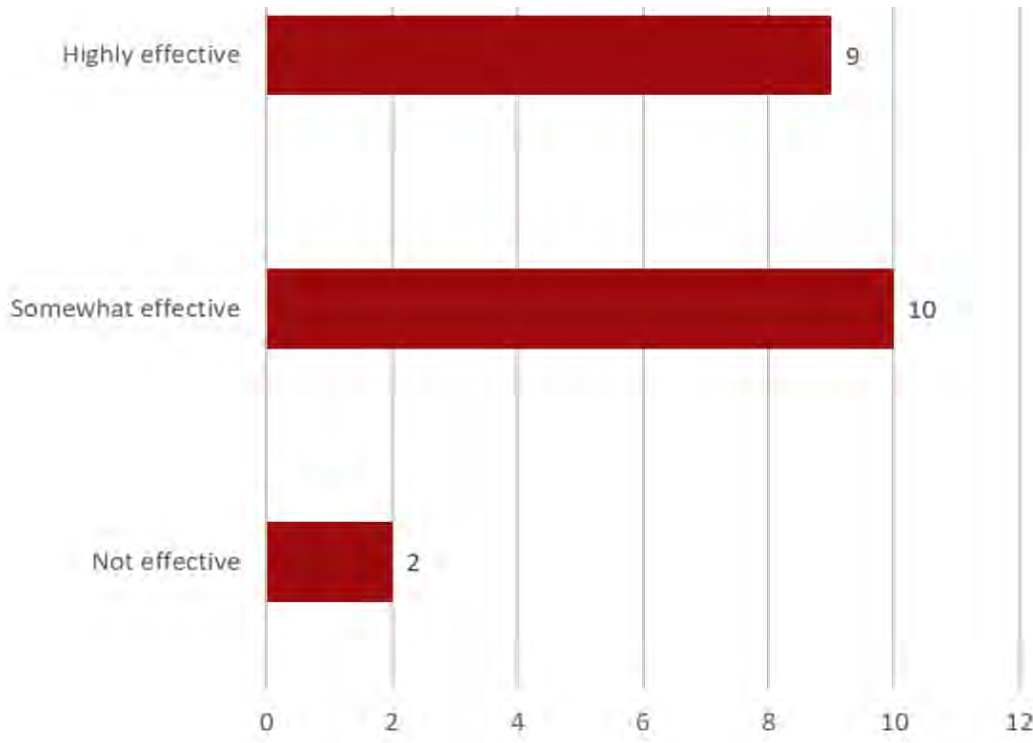
**Q33. What type of impact has the COVID-19 pandemic had on your day to day life**

	No Impact	Moderate Impact	High Impact
Transportation	20	9	5
Finances	19	11	4
Access to medical appointments	17	13	4
Emotional well-being (depression, loneliness, etc.)	12	9	13
Social activities	5	11	18
Fear/anxiety levels	9	14	11

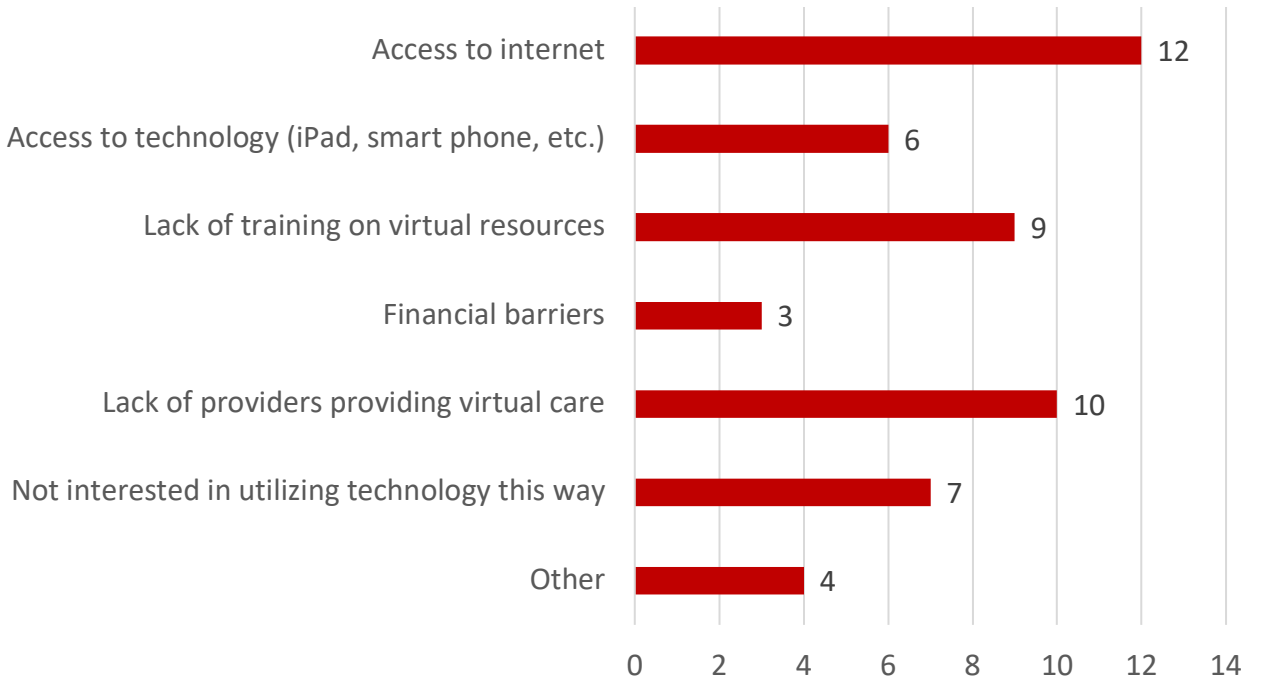
**Q34. Have you ever accessed medical care, therapy, or support groups virtually?**



**Q35. (If 'Yes' for Q34) How effective did you feel this type of access was in addressing your needs?**



**Q36. What factors have influenced the effectiveness and access to medical care, therapy, or support groups virtually? (Check all that apply)**



*The following are all direct quotes from the individuals filling out this survey:*

**Q37. What services do you think are helping you the most now with your injury?**

- Receiving none (x3)
- “My Botox injections to battle my chronic migraine headaches after accident”
- “Finding adequate placement”
- “Support group/ socialization/NDBIN Info!”
- “Seeing a psychologist weekly. Knowing about BIN.”
- “Support Groups”
- “North Dakota Brain Injury Network.”
- “Support group”
- “We have a good Neurologist now, i am very thankful for Brain Injury Network for resources and the opportunity for a voice and new ideas/information to help care for my son.”
- “Dakota Center for Independent Living, Bis-Man transit & the Capital Area Transit buses, West Central Human Service Center, Brain Injury Support Group.”
- “Independent living day supports. Makes it so I don’t have to live with my parents. Love being more independent. Job coach - so I can have a job.”
- “Help with my daily hygiene, social interaction with my HIT program. Probono clinics at college with students and activities with DCIL.”
- “My neurologist and instagrammers”
- “Knowledge of state programs”
- “The online virtual support group.”
- “I just want to get my GED so I can get equal pay, benefits, time off, and be treated like a man, not a loser! I need to be able to study, and right away do my testing, and help with questions being explained. I took it 3 times and failed them by 1 point, went back and tried again, but then before we got started we were shut down. I do NOT understand why Algebra is of high importance, that without passing it, I won’t get a GED. I have short term memory loss very bad, and some long term memory loss. I took my tests without anyone knowing I had this disability, and I did it on my own. Now I have a case worker trying to get a private testing done so I can keep my job !!!!”
- “Support groups, because they provide: An Inclusiveness of a group who have gone through similar things. Ideas to improve in daily activities situations.”
- “I greatly appreciate the NDBIN and take part in the webinars and educational offerings as a professional. I am impressed with all the services and resources that are available. I appreciate all the options for support groups. I have attended them (in person) prior to the pandemic, but not virtually. I attend as a rehab professional, as well as a brain injury survivor. Loved the Unmasking event that I attended. I am grateful for the entire staff! They are truly amazing. Thank you for all you do. This is such a great survey - good job!”
- “BI Support Group.”
- “Physical Therapy”
- “ND Brain Injury Network, Virtual support group(s), UND DSS”
- “Monthly support group”
- “Residential setting with structure, routine, and 24-hour care”
- “PT and vision therapy”
- “Hyperbaric chamber, neurofeedback, right eye program, counseling and social activities”

### Q38. What additional services would you like to help you with your brain injury?

- “Post traumatic brain injury syndrome”
- “Brain injury specialists who understand.”
- “More in state BI residential facilities”
- “More info on effects over time, as we age, things we can do to help offset effects”
- “Getting back to meetings!!”
- “Contact with someone from NDBIN to talk about my new normal, if there’s hope, and what’s available in GF regarding services. A list of compassionate, knowledgeable providers who don’t make me feel worse during an appointment--and less likely to try again.”
- “I am now retired from work, and so that makes life after brain injury easier. Most of my issues have been addressed as well as can be, and I know what limits I have, but am always hoping to help & educate as much as can to those who are new to brain injury and may need help or resources”
- “Local support group.”
- “Just resources, like books, blogs to help deal with emotional support for myself and how to deal with an aging son with a brain injury. Medical knowledge of proper treatment for seizures associated with TBI and other treatments available. He recently got Toxic on too much medication from an ER doctor who didn’t know what he was doing.”
- “School and employment opportunities.”
- “More help with cognitive and emotional issues as well as physical. Motivational help to keep me motivated.”
- “I would really like to be able to get into a functional neurologist, if insurance would cover it.”
- “Get services even though I am not on Medicaid”
- “Not sure. communication, socializing.”
- “Tell Norm at Williston to allow me to have Danielle with, study, and test with her help on explaining the meaning of questions. I don’t expect to get answers, but I do need help with the words and meaning. We have been trying for months now, and all I get are more excuses. I went to Williston yesterday thinking I was being tested only to find out we did not follow Norm’s “protocol”. I don’t need more of this, I need my GED..... and I have tried but it wears me out studying and I forget by the time I get to the college to test. I am done with it.”
- “Ways to deal with TBI Survivors, their support personnel, and the general public, without feeling self-consciousness or uncomfortable!”
- “Not sure. I know there are services available that I could access if I desired. I think art events are very helpful.”
- “Local support group options, Local speech therapy options, Case management”
- “Help with my service dog in training”
- “Services that help friends and family understand how to interact with someone with a brain injury”
- “A bit of help with cleaning. I have a studio and extremely tidy already. But it would be nice to have a little help every now and then. The fatigue in this, is off the charts.”
- “Insurance coverage for hyperbaric chamber and neurofeedback”
- None (x3)

### Q39. What other additional comments or ideas would you like to share with the individuals who plan statewide services and supports?

- “Need to get info out their better so more people are aware of services available.”
- “BI services and care are very limited in ND”
- “Thank you for asking!”
- “So far keep doing what you are doing and also keep doing things that will challenge us at least mentally!”
- “Is there a list of statewide resources that exists for us? It would be helpful to have all info in one place, because we waste so much time and energy dealing with our injuries. Is there someone to advocate for us? Is there someone who can take an hour to go over the resource list in this survey to tell us about those services, or to see if we qualify, or provide contact? Can a creative outlet (art group) be created for everyone in the state? Not just for those who live in Fargo?? I’m thankful that NDBIN exists, but I feel like we must go to you. I understand that we must make initial contact, but I felt very alone/forgotten after my initial meeting. I was hoping/expecting that someone would check in to see how things were going, if I had questions, or needed resources or maybe someone to tell me that what I’m experiencing is normal in the TBI world. It takes me a long time to ask for help because I am embarrassed. And to go to your office each time takes SO much physical and emotional energy to get ready and fight anxiety to get there. How can YOU become more accessible to US? What can you do to help those of us who fall in the gap of our spouses earning too much to qualify for Medicaid, etc., but too little to pay all of the bills-particularly medical bills. We’re also stuck because I do not qualify for disability. What is available to us besides bankruptcy and never doing anything fun because we’re broke?? Thank you for your dedication and your willingness to better learn our needs via this survey.”
- “These type of surveys are great to gather information and continue in providing the best help/ education/ resources”
- “Thank you!”
- “Virtual events are a great idea. I work from home now but can travel as well. So any blogs, or newsletters, etc. would be great to know where to find.”
- “From her guardian - Wish I could find a “case manager” for living with TBI. Looking for someone who understands severe TBI and is familiar with area Medical providers experienced with TBI. Someone who would take the time to understand my daughter’s injury and direct me to appropriate providers, medications, therapy, etc.”
- “Government programs need to understand that due to cognitive issues a lot of brain injury patients can’t be left alone. Every brain injury is different with different functionality. Some of us will never be able to be alone again.”
- “We need more services for severely injured individuals”
- “To be able to have an easier connection with urban American Indians including those on the reservations. For them to know about these resources.”
- “Danielle has helped me a lot, she knows what I am going through, she understands, but she can’t do this alone and follow all of the rules and regulations put in that do not help, they hinder getting help. I want to take my GED, and I want to do it NOW. I NEED IT to keep my job and get my \$5.00 an hour cut back on my pay ! I put in 96 hours the last two weeks, it is not easy to get up and run 45 miles one way for NOTHING, like I did yesterday. This is not help, it only makes me angry and less trusting of any hope or promises made.”
- “Find ways to get information to as many TBI Survivors and their support persons as possible. There must some venues to get support and information out that have not yet been explored. Does the ND Brain Injury Network have a list of all TBI Survivors in the state and contact information for both TBI Survivors and their support?”
- “See above. You are all awesome!”

- “Help with resources and financial support for development of local programming and support group.”
- “Vote Trump!!”
- “More coordination of services, more visibility of services, education for health professionals and families needed, remove barriers to access services”
- “I just wish State Medicaid and Social Security would be more educated on brain injury. My Hope is that they must complete a course / class on brain injury, as soon as they secure the job.”
- “More organization in social activities and community and medical people to be better educated about TBI”
- None x3