

Report to the  
North Dakota Department of Human Services  
Behavioral Health Division

**North Dakota Brain Injury  
Needs Assessment Report: Appendices  
June 2016**



*Prepared by  
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# **APPENDIX 1**

## **Narrative Responses on the Questionnaires**

## Survivor Questionnaire Narrative Data

### **Q15. What are the most important and immediate needs for you**

nothing
I am fortunate in that most if not all of my needs are being met. I have a support system at home and also outside the TBI Survivor support group
I did not know about services that were available, and I did not try to get help. I was just stumbling along and doing the best I could. I was at least 15 years before I admitted to myself that I was a different person
Housing, Money Management
Get my own place. Get a FT job in my field
I need help with food control. I don't know when to stop eating. Medication help
School accommodations relearning time management skills
I need case management - I struggle with filling med box and taking meds on time, forget some meds. Have looked for new apartment, but I don't qualify for low income assistance and can't afford to pay more for rent. I feel very isolated and would like to have neighbors I can visit with. My Safety had an attempted break-in at my apt. Not feeling safe in apt. Management has towed my car 2x because I forgot to put handicap placard in my car. cost \$175 to get out of tow place
Doctors who understand brain injury & are up to date in knowledge
seeing my kids. Live on my own
Job loss & understanding
nothing
all my needs are being taken care of
more information & understanding from family & friends of medical side of TBI
I needed help to read & count & basically do everything again and all I had was my family & me being stubborn and wanting to prove the doctors wrong that I would never be ok again. Now I am better then ok and happy to help other survivors move forward
no help to get him to a job because we live 20 miles away
Eyes & Balance . Lack of information after the surgery, it would be cool if there would have been a TBI spookperson to enlightn one on help, support groups
I want to get berrer, but its coming. Im working hard at it.
Keep learning to live with the skills I have learned
job, paying bills, community events
keeping on track
employment, community involvement
Getting my life in order. Getting a job that I can enjoy and make enough money to apy my bills. Im so tired that Im sure I can't work very long in a day, so, im afraid I won't make enough money for a while.
Transportation if dad was not here. Also housing
Dual Diagnosis/TBI treatment currently only offered in MN. Transportation services. Funding for tools, services, support of our disability. The advocates now have no funds to supply any needs or supports
Proper Diagnosis/Testing

Memory Aids, sleep Aids, closer/better healthcare services (less than 50 miles) right now I drive 250 mi round trip for healthcare
Someone to guide me to what services are available, finding a job, being able to complete my rehab & contribute to society & make the world a better place.
I'd like to prove that I can handle/manage my social security income without having to have a representative payee that I'll never meet because they are so far away. I'm currently in Grand Forks, ND, they are in Northwood, ND.
A. Being able to go to Dic. Rec Center can not afford \$6.00 a day fee. B. Stay in AA group meetings. C. Focus on my goals positive outlooks.
I have people coming once a week to help me with my medication. House work & taking me to the doctors - But they lack experience. They don't seem to see my mistakes and how to help me!!
Doing things for activity. Keeping me from being alone a lot and I get 4 hours a week community option thru S Services, 4 hour a week comes down to about 3-4 hours she writes They don't care I need more help in doing things
Cooking, scheduling, money management, waking up at night when there's an emergency, socializing with my busy schedule.
Continued care & support by spouse, support by employer & fellow employees, community & church support
want to go home & return function to be able to teach again -
cognition skills, memory skills, word usage, responses, speaking, correct word responses, thinking, body balance
NA
employment
Getting Risperdal
unable to multi task, confusion when rushed, memory lapses
1. financial, employment, 2. emotional security, 3. social, 4. financial security, 5. purpose, 6. meaning, 7. interpersonal, 8. healthy living, 9. need meaningful achievement, socialization, 10. wellness. 11. career, 12. success and enjoyment of life, 13. disconnectedness from: people, success, realizing what I need to do to be happy, joyous, 14. confusion, 15. always staying sober. (Priority)
Life, in general, is difficult and challenging due to the effects of the stroke, diabetes, blood clotting disorder and right arm amputation.
Organizing writing for books as well as book art work and other business to be dynamics. The majority is hand written due to my inability to sit at a computer post car accident. Today I can for limited time. Glasses, a times, and wrist braces for computer work are also in need as well as a stool to aid in sitting correctly. A dragon program to transfer hand written onto the computer (one with a recorder) is also necessary for my business which I have invested years into.
Staff at DBGGR do a great job, but often don't know how to deal w/my mental health/TBI diagnoses, as I don't always respond consistently w/behavior modification programs. I am very impulsive and have severe anger/aggression issues which often makes me too volatile for staff to work with me.

The important & immediate <u>needs should have</u> come from advice or care directive after ER, but one is Not told <u>anything</u> - shipped out after tests, and then left to figure things out on their own. Many times making your condition worse, because you think it's not that bad - but pretty soon you figure out - wow - this is NOT Good - buy you totally ahve to search out alternative methods & help for your condition if you want to get Better.
Consistency in day to day living. Counseling to deal with life since TBI.
Ongoing support
Understanding TBI Injury, dealing with pain issues, as well as sleep issues, medication, fatigue. There is No Coordinated Plan for Recovery.
HBOT VA Awareness, HBOT Make Success Stories more accessible - uninformed regulations to govern HBOT in medical facilities.
1. House repair and maintenance, cleaning. Kitchen and bathroom need to be updated. 2. Legal aid, or some form of legal assistance.
I have a lot of difficulties w/directions & becoming turned around. My husband is an awesome help and explains things well & draws maps all the time for me.
Health, rest, money, something to do, get bored easily.
Being able to pay for the necessities to live.
Medical assisatnce from Mid Dakota Clinic on diet and health. They have a new FREE service of educated staff (I just learned of). Independent Living helpful with money, activities. I need for [people to realize I need to rest when my brain is tired. To many activities & running - outside pressure from those that don't understand my limits.
Need to go back to school in order to move forward in life. I do not have the financial means to do this.
1. Continued cognitive rehabilitation & psychological counseling. 2. Manage symptoms & develop new ways of dealing with my brain injury. 3. Learn how to live again & get basics of sleeping, eating, exercising, and socialing down. 4. Build cognitive endurance. 5. Manage my finances - I'm blowing through my life savings quickly. 6. Try to find a job that I can do, is healthy for me and not harmful to my health & wellbeing, is rewarding and that will support me & keep me off welfare.
Insurance so I can receive the therapy I need. Financial Assistance for someone who has worked to get to retirement resources it has limited to therapy & needs Thank God for those who will work with you by payment.
NA
NA
Would like ot get out of Dakota Alpha and live on the farm.
To get back on my feet and get back home.
Finding a job
Getting short-term memory back
Want to go back to work, need job coach
Job, mental health
Coping skills & medication to keep my disorder stable
1. Independence - driving independence. 2. Social connections. 3. Adequate housing. 4. Phase in work environment with mentoring.
Money - nearly completely without funds, 3 surgeries in 4 years - <u>NO</u> support in ND - Sad. Graduated financial assistance - professional level job re-entry - we don't all lick envelopes - and God less sincerely those who do.

## Survivor Questionnaire Narrative Data

### Q16. How do you see those needs being addressed?

The needs are being addressed simply by having the support at home that I have
My wife give me most help. WE have a support group tht is an immense part of help that I need
I already have assistance
They are being addressed, staff help me every day with both
communicating with professors and NDSU disability services Continuing to attend cognitive-communication therapy
tryng to do all of this on my own but I have trouble with follow through and often forget things. I have a car but my driving is not good, Theres no bus service where I liv. Don't know what to do. Non of my needs are being met.
I don't know. I don't know their system.
The staff take me to see my kids!! I am working to be able to live on my own
Raise awareness & provide medical info to public
Im happy our state is finally understanding there is a huge need to help brain injury survivors and looking at ways to give that help
Keep seeing an eye dock
My husband is working with me and giving me challenges for me to work at. Since there isnt much stuff around.
I have a great team of people helping me in all areas I have services for.
more staff
they help me keep motivated to stay on track
more job coaching
Hopefully through WSI Vocational supports. I will take my tests this week to see where my needs are.
don't know
No Dept of Human Services at all other than support services. Put funding in the hands of local advocates and develop individual plans & support for our needs, each of us with TBI have completely different needs that are both small and big. The state of ND is blind of the needs of all disabled citizens, quit funding Human Services and fund advocates.
Individual Care and Not the "Revolving Door" testing that tries to get you out as fast as they can
Need closer assistance, and better services.

I get rent assistance from Burleigh Co. Housing. My caregiver helps me with transportation & making my appts/schedule. I am working with Community Options to get me ready to go back to work.
A. See what is left on budget    B. I like going to groups people are there.    C. Looking at my thoughts
They don't seem to be addressed. I can't afford anymore assistance who are knowledgeable on brain injury.
Doctors and people helping me needs to understand that a brain injury has <u>so</u> much less energy than we once had. We need breaks and days off.
These needs are being met.
not well - roadblocks with therapy - mostly due to BCBS denials
more. I have had to do it myself & the answers I give or questions I ask are not understood what I am trying to say. People don't think I have a prolem. It's even in my writing.
NA
community options
Need a Pro Bono professional appointment and in turn a prescription & a way to pay for it.
?
Im not sure nothing yet have worked. My parents can't help me anymore financially and do not understand.
As his parents - we work hard to be in tune with our son's needs and see ethat they are met. We have few major issues and are grateful to his primary care physician and counselor for their help and support. We have a very caring and supportive family who care deeply for our sone, also. By God's grace, life goes fairly smoothly.
Brain injury project is now helping me get organized. Voc Rehab was basically a hinder in holding me back. Vickey Gross aided as a go-between...yet so far has not gone forward. Brain Injury helped with a used laptop. Other needs I as yet, do not see help for.
It isn't really being addressed to my knowledge. I would have very limited services in ND if my parents did not have adoption Medicaid for me as the Tricare coverage is very limited.
They are <u>NOT</u> addressed within Hospitals or ER Professionals. When you have a major head injury, you should have a <u>TEAM</u> to go to for help in assessing your needs - which can be many <u>and</u> varied.
Staff is very involved to be sure I complete chores every day. I see a counselor
From one specialist to the next I was very fortunate to be cared for by a knowledgeable "team". The person having the biggest impact in "re-directing" my mind was the speech therapist. 1. Primary physician, 2. MeritCare ER/infection <u>Control</u> , Dr. The Dr. who diagnosed and facilitated need to initiate anti viral IV meds resulted in positive outcome. I walked out of the Hospital!!! 3. Psychiatrist. 4. Speech Therapist.
Group meetings have been best for understanding along with educating myself about TBI. Pain has not yet been resolved along with sleep problems.



W/opposing view and the pro's not given enough tools to tell our stories and to address the HBOT history of improvement.
Fine
Can't get the proper help.
Receiving disability & settlement from work accident.
When I am overwhelmed I have to just stop. Needs start with home, health, food. Good source of transportation. My phone has become my best friend once I learn the ins and outs numbers - calendars to remind of events, the camera is good short term reminder of where I was. Text - good source of conversations - it can fill in where I lack.
I don't. This is N. Dak. Not really know for being up to date on many fronts.
1. Continue working with Progressive Therapy Associates & counselor for items 1-4. 2. I need help with items 5 & 6 but am not finding assistance available until I've been declared disabled by SSDI, which will take years to get to, or until I've lost everything and quality for government financial aid. I'm falling between the cracks because I'm not terminally ill, or have a very clear cut brain injury. There is no assistance until I'm completely in poverty and have bene out of work for years. Entering the workforce after being unemployed is going to be extremely difficult and I'm not finding assistance to do that because I'm not injured severely enough.
My one resources & savings are gone now. & I still am u/able to get insurance I hope they get addresses as the TBI for athletic get more recognition.
NA
NA
No one is pushing me out, but when it's time for me to go, they won't keep me here.
People helping me each day with my therapies.
They are not being addressed
Good. The therapies are helping me with my memory.
Still waiting for services thru rehab since end of March
Don't
They are as of now
Development of more TBI resources.
They are not being addressed. A am concerned of becoming homeless - shocking - I have no family here and I am needing to move away after 30 years. Sad situation. I have paid my dues and worked since age 12 but no help here???

## Survivor Questionnaire Narrative Data

### Q17. Comments

None at this time
I wish doctors would have referred me for cognitive services sooner or at least let me know they exist if the need persisted for a certain amount of time
My terrible horse accident was in 2010. My entire brain was damaged so my chances of getting back to normal was less than 5%. The only thing my family was told to do for me was pick a nursing home to take care of me, there is nothing else. It was a miracle that I work up and was able to rebuild my life. There was very little help for me so I did most of it on my own and learned more in 6 months that should have taken 5 years. I only found out about NDBIN in the fall of 2014 as I was setting up a Brain Injury Support Group to help other survivors that were as lost as I was in the sea of no help.
It just nice to meet with people in the know that work with people like us. I don't want to be a drain on the system but it good to know there help out there
there isn't much around. Could use some services to deal with certain things.
I wish Minnesota someday would have the services that I get through ND through Heart Springs, progressive therapy - TBI, Traumatic Brain Injury Art Studio. Their awesome.
want to be employed to become a better person
need more speech and social skill help
Need to trust to communicate a plan jointly and with respect clients choices. No income guidelines as it leaves most TBI victims without any services for everyday activities, being independent in both social & recreational choices. I received SSDI and am disabled and should not have to advocate for services, tools, and support for normal life.
I was an active person and this was a new life for me to live. I have worked hard to better my life, so are looking for extra tips that maybe I didn't learn in Physical Therapy to make my life better!
There does not seem to be any PT/OT therapy to improve my function. I realize it ws a major stroke but my brain is fairly intact - unable to get approval from BCBS for PT/OT therapy. I am 62 years old & have aa lot left to offer - but am not being given the chance for improvement - am being forced into medicaid in order to survive. Wife and I have worked our entire life- paid taxes, saved for retirement & now have t o spend down in order to get care. It will not take long paying \$12,000 a month for nursing home with some minimal rehab.....
The elementary school, middle schools need to know about these & the teachers need to be educated about these behaviors & to respond appropriately to the child. Parents, also, need to understand these problems & what to do. There is such a lack of knowledge of TBI. It is always focused on football players. Legislation should be noted to have the education taught to teachers, schools, etc.

I am grateful to have a wonderful support system in my family; my husband, parents, & close family. They are very helpful & uplifting. It is challenging to live w/a brain injury and M.I. (mental illness). I have resource tools that help me w/daily living. In the past, I have been a M.I. advocate thru public speaking & help others feel that they are not alone. I spoke to a Brain Injury Support Group twice, in Fargo. Thru that experience I was able to touch others lives and meet other professionals in the medical field, as well as other survivors. I plan to study & earn a certification as a mental health/women's health advocate, going to bless others, impaired, teach, mental & grieve along their journey. Daily living skills, tools & experiences shared to help other survivors thrive in life. Thank you for allowing me to be part of this questionnaire.

Tested by VA. Incomplete services because I am Not Afgan or Iraq Vet. Tests showed problems but not addressed!

I'm stuck, everything seems against me, want something to believe in. Almost total failure achieving wellness, security, career, relationships, purpose, meaning. I am alone, fearful, angry, frustrated, confused. Existence marked by struggle, constantly. I'm miserable, vindictive, aggressive. I'm violent. I'm high functioning with no support from friends (I don't have any), Family, etc. I have worth for sure, I'm on a new med, going to start seeing Progressive Therapy Associates in Fargo, see a doctor and psychiatrist, people (Stacy Steele) from Community Options. I have a 4 year degree I haven't used and would enjoy helping TBI survivors some how. IOK maybe I'm just stuck. I want to end the system of failure! keep building for myself. Not sure how but will keep on trying. Maybe I can work in recovery somehow. Firstly I have got to get myself out of crisis mode. Keeping positive is invaluable, tough through with wide mood swings and depression.

As one who does a great deal of research, I appreciate knowing more info when it come available - and will share.

ER doctors treat this Traumatic event like it's NO BIG deal - do all the tests, scans, etc, but then really drop the ball from there. Head injuries should be taken seriously - just like concussions, cancer, or any other disease or medical issue. Everyone in the medical community seems way behind the 8 ball on this - OR don't they want to get education or involved. Controlled by Insurance, that may actually be the Real problem. All my good deal (aside from a good neuro doc, that I found on my own) came from alternative therapies and gifted people in their field of expertise - chiropractor, massage therapy, cranial/sacral massage, core synchronism, without those folks, I would be in much worse shape.

My accident occurred Dec 2, 2014 and it has taken me far longer to get services that meet my needs. Such as pain, sleeplessness, understanding TBI. I find Health Care providers are lax or not knowledgeable about TBI and the needed diverse treatments that may be needed. After my accident there was a rush to release me without further diagnostic tests etc .And give further care as needed. I am still not "There" yet.

Being a North Dakotan w/congressional review I still face adversity in our Veterans Admin. The VA just not wanting change - they are supportive of medications.

On question #10 - I need help and assistance both with my health, and my residence, but cannot get any help!

Having a brain injury is a long road to recovery. The state has to set up a better system of care. Doctors, specialist, personal trainers, psychologist, social workers, advocates, even police and lock up facilities. With the right alignment - you could have a smoother alignment of services & support for someone with a brain injury (which also help the family that takes the brunt of the work). You have to have people that can see the betterment of the client as a family would. No one person should have the control & stopping are inhibiting the advancement of care of such persons. Dead ending a persons life is the easy solution to any problem which doesn't make the system work - ends up costing more in the end & a very frustrated - injured individual.

There needs to be efforts for educational experiences to be able to get back into school and financial backing to pay for that education. \$900 per/mo is a joke, a slap in the face expecting that one is expected to live on that.

1. SSDI is nearly impossible to get unless you have a severe brain injury. Mild to moderate are left with no help. 2. Medical Assistance does not cover a lot of the newer therapies for brain injury rehabilitation. If they do it's so difficult to jump through their hoops to get coverage. Brain injury rehabilitation continue to change so quickly the government systems can't keep up - they are very out dated with their policies & practices. They have too many limits on how long therapy can go on for and don't recognize cognitive rehabilitation as a necessary part of recovery. 3. We need more help to get back into the workforce. It's so difficult because we need accommodations and we need someone to help advocate & represent us w/employers. 4. Government programs make it hard to get back into the workforce. You are trapped in poverty because of their structure. 5. We need programs to help retrain us for new jobs. If there was assistance to get retrained it would help tremendously. 6. Continue funding for programs & conferences to help families understand & care with brain injury.

Finally someone believes me and doesn't shove it under a rug as Mental Illness.

ND takes work away from poor kids. I see no future here despite years of hard work - no real support for job re-entry or interim financial assistance - to help get back on my own and be successful independent person - so scared all the time. Shouldn't need a lawyer for disability apps either - if I could fill it out I would.

## Family Caregiver Data

### Q15. What are the most important and immediate needs for the person with brain injury to whom you provide support?

None at this time
Exercise PT/OT
HE doesn't live with us. I know that I can't be with him 24/7 so he makes decisions on his own. He is seeing a therapist for his TBI, but it's a combination of ...slow recovery, making bad choices, self medicating as a mom, just worrying about him and his safety. WSI is somewhat helpful but will cut his \$ off shortly. He doesn't have a job yet... not ready to work (he feels)... doctor says as of this week that he is. He is lost... worry is not knowing what comes next for him
Don't get to see him very often. He would like to see me more also
I would like to see follow up testing as to any long term effects of the injury - not sure how to go about doing that with his doctor
HE needs something to do, not wanting to listen to mom telling him what to do. Socializing cuz his friends abandoned him no one to tell us how to deal with the at home day to day living
To have someone or a facility to support his or her needs because their memory is none of what their life used to be. To help them learn the basic life functions that we take for granted
She was in the hospital got to learn also how to deal with the brain injury. Most of the stuff I worked with her and what I learned in the past years to help her better
Retraining his brain to pick up some of what he lost- memory and emotion the most. Getting his GED. Sleep at night, get up for the day and find a purpose to look forward to it.
support from family and friends understand from family and friends. Understanding from community and doctors. A TEAM of healthcare providers who communicate about what's expected with medication
He has a memory problem & I work mostly now as an advocate. His injury was 30 plus years ago, so we go from full time care to him cares for himself most of the time but still prompting
someone to help stay with him so I can get away by myself at least one day every week or two
Been unable to speak and walk. Her right side is paralyzed
Transportation
transportation, mobility, long term care
a knowledgeable care coordinator
someone to visit with them
memory loss - short term concentration - short
Our son functions fairly well subsequent to his stroke in June 2013. He struggles with various aspects of expressive aphasia. His condition is complicated due to type 1 diabetes (diagnosed @ 10 yrs old) and a rare blood clotting disorder (diagnosed @ 14 yrs old). In 2010, he had half of his right arm amputated, losing his dominant hand. He is challenged/unable to read, write, do basic math, etc., as a result of the stroke.
To regain use of R leg so he can transfer with one & come home - he has a hemiplegia. Care giver & he fell at home & they tore his R ACL & has a small tibial fx.

I believe there should be a system in place for couples or Family members for information if behaviors with the older person who has sustained a TBI in his/her youth. I see a need for neuro-psych who will handle older married couples with a spouse who sustained a TBI in youth. For my son, I would like to see more _____ on Early onset of dementia in person who sustain TBI.
Continued support by employer & fellow employees
Lack of understanding of someone w/ TBI and mental health issues. Limited services/knowledge on treatment options. We were fortunate to have adoption Medicaid for our child or services would be extremely limited through our insurance (Tricare), in ND.
housing - Hannah want to live on her own & there is not supported living for TBI survivors in the Devils Lake area. Medical professionals who have worked w/& understand BI. We traveled the state trying to find BI specialists. Now we go to Mayo Clinic BI Clinic yearly where the specialists are - even though MDMA will not pay as they claim we have the services here! Transportation - lack of in rural areas.
Vulnerability to harm by making bad choices such as incorrect socialization on internet. Prompts to provide personal care - bathing , dental and room care.
Family, there is no support to bring the family & TBI person info to understand what <u>Dad</u> is dealing with! Kids don't understand & Dad thinks he gets all the breaks - kids don't understand.
affordable dental care, job training/coaching, education/training funds, to be able to walk safely on his own & go out in the community without assistance
money - time - job or something
cooking cleaning companionship
short term memory living at Dakota Alpha
One of our care givers has helped us for over 30 years, and still can't seem to see the problems we have. Always going to take them to a doctor or for help that he has used and not helped. I'd say education to people that want to help in the medical field or home care
Pain management, sleep issues, chronic fatigue
More supervision
1. Connections to friends/social with like individuals. 2. Phase - in work program with mentoring. 3. Housing for Independent living (possibly @ some care). 4. Driving assistance or dependable, inexpensive driving resource (currently Kyle has waited 1 hour to be picked up for dial-a-ride). This is unacceptable. 5. Acceptance (not just by Kyle but within community).
Supported housing
Memory issues. Health related injury & complications resulting from head injury not covered by insurance.
Going back to work-(limited basis)

## Family Caregiver Data

### Q16. How do you see that need being addressed?

NA
To whom ever can help Medicare only pays if this is progress. What about the people who take longer with progressing
WSI following through with Vocational support...which has just started questionnaire have just been filled out, haveent started talking their computer tests yet. IF the Doctor would just take back the "release to work full tome OK" My son may have a fair chance at his WSI vocational training. He want to be back at work, but his employer gave away his job.
There are different things being started to help people with Brain Injuries because they are realizing that TBI's are very common
I think a brain injury person needs extra things along the line maybe more what I can do and Understand.
I simply don't know. At one time seeing a psychologist would have worked, but now he won't even do that because it'[s over a computer, and there is no one - we could just as well be living in the wild for the absence of medical help up here - almost want to lie and say he is a vet so maybe then he could find help.
Last year 2015, I had an article written about my son in our local newspaper for Briain Injury awareness month. Through that article I found out "Freedom Resousces" and what we call our "Angel" Rececca Quinn. Through her we discovered there is indeed a Brain Injury Newtork. She has steared us and guided us to get "real" help and understanding
He received training to learn to manage thing for the fist time last year very helpful I would like to see a little follow up once a year at least
Some one to come into our home or a rest home day care facility in the area
more affordable costs for taxi's
facility provides great care , being far away it is harder to care full tme and work full time
I am the care coordinator, with no training, limited knowledge - do the best I can
it is being addressed by neighbors and family as best we can
Guidance on how to help spouse without him losing his self respect. Trying to help him but not over step in helping him to retain as much memory and concentration as possible.
He has regular appts with his primary care physician, a counselor and wound care specialist (when he has open wounds/leg ulcers due to the blood clotting disorder & complicated by the diabetes). Speech therapy discharged him about a year ago because he had plateaued in his learning, was inconsistent in his retention, and sometimes seemed to be regressinbg.
BCBS is & has been refusing rehab services to him. He got 3 weeks covered - took him home as they would not cover anyumore - they then refused Home health therapy - now with the knee injury they have refused rehab for the R knww.
Taking time to have workshops with professional& family members & at such meetings the professional persons really listen to what is needed.
Yes. this support is being met

It hasn't been to our knowledge. We recently started corresponding w/Nikki, who has been helpful, though the services are limited in the area/state. We have to drive to Fargo for any neuro/psych services, which can be very inconvenient and costly.
There are 2 places in ND, but reimbursement issues need to change so there are ways to address supported living providers are willing to provide, but re-imbusement rates have to change. Drs need to work together & in teams like Mayo. We had to move Dveils Lake support group for ththose don't drive so they could get to support group by walking. Ttransport is DL stops at 5:30 & there is nothing on weekends. They need to stop using DL transport for piublic school children & only use it for needs of elderly & disabled.
Group home does very well at providing that.
Mom & kids (3) went to a referred counselor who after 3 visits admitted he do not know enough about TBI patients.
working with Community Options in their skill smart program. Volunteering and re-learning computer skills. Working with personal trainers & doing, physical therapy until insurance maximum is reached.
\$ social security ?? More groups to attend daily
It is very slow. And if the company we use that have staff and if they don't train the staff and still say they assist people with brain injury
Coordination of health care professionals working in cooperation for health of patients.
Me spending more time or getting volunteers
1. Possibly a grou home for TBI individuals, ideally located in Grand Forks. (apartment & single rooms) 2. A living skills/recreational bldg. designed to help TBI individual meet and learn new skills (not a sheltered workshop). A place where they can congregate, recreate and build on skills in an authentic environment staff by learned TBI professionals.
unsure
Hasn't happened in 25 years, don't have faith it will happen....
Aplyed to no VOC rehab, takes forever to get answers



## Family Caregiver Data

### Q17. Other Comments

What does a person have to do to get the help for the person that is WC bound and needs exercise?
My son is 24 years old...he was injured in a fall at work that is medically recorded as his 9th concussion. WE are thinking he has more, but just didn't go to the doctor. Throughout his years of 13-22 years old he has had many set backs I believe because of his reoccurring concussions. When he was 22 years old, I saw for the first time in my life my son as he should be. He for the 1st time held a job for 2 years, full benefits, went to work everyday, understood responsibility, worked many hours of overtime and had a job he loved. He was actually asking me about putting \$ away for retirement!! PINCH ME !! Then his fall happened and he's has loss of memory etc all signs of a TBI. I feel helpless he also does. For once he was like many young adults that had a grip on life... I don't know how much better he will get... I guess I am hopeful he will get back to his "best he was" before this fall, I'll take anything that even looks close, so will he. I can't help thinking though, it might get worse. He does drink a lot. ONE good fall on one of those nights, will set him back again. He's young and I'll end with... I'm so worried & afraid for him. Thanks
S
I can be contacted if you wish: Sherri Peterson 701-389-0408 Injured person is my son.
We don't know a day that isn't running on negativity, anger, not feeling well and up all night. We don't know what it's like to have no enthusiasm, no desire to improve his attitude, nothing we do or say is good enough.
My son's accident occurred 7 years ago. After 8 days in a coma-28 days in the hospital, they sent him home. He was still seeing snakes coming out of the light fixtures, paper towels were turning into rats. Ooze coming off the shower walls. "See your general practitioner" they said. No one said this is a Brain Injury Network! It took 3 yrs. to get him disability where a neurologist would see him. We need a Brain Injury registry so these injured people know where to get help
If you haven't seen the movie Concussion with Will Smith, please do we are dealing with problem such as CTE now.
Our city is small ( less than 800 population) & don't have anyone to help. My husband with TBI does not remember his accident, so he is not filling out the yellow questionnaire. His problem now is dementia.
After our child was discharged, her primary care provider was/is considered the "primary" person directing care, who referred us to a neuropsych dr. - still feel like I am the care coordinator - not sure who is the best practitioner to see for this type of SEVERE TRAUMATIC BRAIN INJURY -
Most of our training has been "on the job". We have learned a lot by trial & error. All things considered, life goes pretty smoothly.

Very frustrated!! Little to kn knowledge on stroke rehab in Minot My husband is a high school science teacher & I feel with the appropriate rehab he may be able to teach again. We are in the wrong age group - not medicare eligible not medicaid eligible. I am a Registered nurs - work full time, he a full time science teacher. We have to pay out of pocket for all PT/OT services.

One of the most urgent needs is another two or three homes like the HI Soaring Eagle Ranch. I so believe in the Open Door style management. My son was to be "put in a nursing home and we go on with out lives". He has gone beyond andy expecations and I owe that to a program that has people with disbailities work @ what they can, get out & be part of a community, & all staff & management work @ having the individual feel good about himself/herself.

TBI survivors need services like DD world. Not rolled into DD world, but a specific array of services w/BI specialists to carry out services & work with survisors. We need nationally trained BI specialists.

Need support for the kids so they can undersand what their Dad is going thru.

Having the people help in community projets. Having group that have the same problems work together or go on activity together. These people who have an injury need experience help and guidance. I've seen some of the help misinform the brain injury person about them

ER doctors/nurses need more info on TBI and protocol should include follow up.

Issue can't be ignored needs to be addressed & acknowledged by services & resources

There needs to be more info available to families while loved one is stuck in hospital

## ND Brain Injury (Agency Questionnaire)

**Q12. What are the most important and immediate needs for people with Brain Injury to whom you provide support?**

A continuum of housing options and supports, case management/increased resource facilitation, specialized mental health and addiction treatment services provided by clinicians who really understand brain injury, day or resource centers where a variety of things are provided for persons with brain injuries like socialization/recreation, employment opportunities, mentoring, support groups, independent living skills building, etc.; and services/supports for caregivers.
Housing, available finances, supports in the community
They need assistive technology (AT) devices and services sooner rather than later. They also need the dollars to pay for it. Currently, AT is not suggested in many cases until they get to vocational rehabilitation. AT is needed for all areas of life, so it should be suggested as soon as the client and their support system are ready to hear about it.
In addition, the needs of some people with Brain Injury may be better addressed by going back to a separate Brain Injury Waiver.
Assistance with day to day living strategies supports. Organizing the individuals' day and keeping them on task for having effective tasks and skills completed on a day to day basis
sober social support
How to best support the individual we serve in his day to day life.
Providing information to the client and family about brain injury, which includes what they can expect and strategies to use. Resources. Many families report they are not being educated in these ways. We need brain injury services available to ALL individuals with TBI, regardless of the cause.
Funding if they do not qualify for DD funding.
There is a need for housing support like ISLA, need for day supports, need for family respite, need for extended service slots, and need for additional supported employment slots
Lack of housing for the Brain Injured person, lack of family support for family services like respite care, lack of day habilitation (day supports), lack of pre-vocational and supported employment services, lack of long term supports (Extended Services and Case Management)
The amount of supports needed are not adequately met due to limitations within the waiver or due to financial limitations if they are private pay
Proper placement. Our brain injury residents are young (in their 50's) and our little "grandpa's and grandma's" don't understand the behavior of these residents and are scared and they have to be mixed in with our elderly population
Establishing and maintaining family support
Funding so we can provide Supported Employment Services
Extended Services to enable long term job coaching and supports on the job.
As stated the current county waiver system is not adequate.

people get kicked out of the hospital too soon. the family is so happy they are walking and talking and its a miracle and all that and then the behaviors and different personalities start about 1 year after injury, in my experience. This is what they are not prepared for.
Staff education
Social Security, health insurance coverage, employment, housing.
assistance with ADL
Individualized supports to assist with daily issues, including dealing with anxiety/anger, accessing services, and assistance in organizing daily responsibilities.
A need for flexible staffing in a transitional living situation
Assessment with appropriate interventions.

## ND Brain Injury (Agency Questionnaire)

### Q13. How do you see that need being addressed?

Funding streams for housing options and case management/resource facilitation need to be developed and/or increased, increased training for clinical staff, someone really needs to champion and lead the charge for these things. That has been lost.
Develop housing for specific survivors that would be staffed 24 hours per day, which would include supports, transportation, prompts and reminders
We can address the issue of public awareness to a certain extent and will increase our efforts to spread the word about assistive technology (AT) throughout the state. There needs to be a change (in policy, legislatively, etc.), so dollars for AT are allocated when needed. For example, in the current continuum of care for North Dakotan's with brain injury with Community Options and Voc Rehab, AT is not offered until the Vocational Rehabilitation step, which is generally very late in the recovery process for most. AT should be provided in the beginning, as it can not only increase independence right away, but it can help with recovery and rehabilitation. With AT, many people find that there is hope again, then they may accelerate to the next stage of the game and think about employment. For example, how does one even think about getting a job when self-management has not been successfully addressed? Many times there are great AT solutions for that.
Regardless if there is any money at all in any of the phases, there should at least be a mention of or referral to an assistive technology provider. That way the individuals and their family members can, at the very least, get the information they need to make informed decisions. IPAT offers free AT demonstrations, low cost AT device rentals that could be taking place at the very beginning. In addition, IPAT has several equipment acquisition programs and may know of other funding sources that are available to aid in the purchase of AT devices and services.
There needs to be a way to pay individuals to help out individuals with brain injury to organize their days and keep them on the right track. This may only involve cueing or guidance, but there needs to be a payment for that as family is not always available to provide this.
Training and consultation with medical providers and Behavioral Analysts.
Education provided by medical, rehabilitation or medical case management staff. This needs to occur fairly early in the process so families have this information. The legislature needs to allow all persons with brain injuries to be served with these programs.
Not really being addressed.
A Brain Injury waiver (1915 (i) waiver) could specifically address only the needs of brain injury and could be matched with a federal match ultimately costing the state less to build a system of care.
All the above listed needs could and should be funded by a 1915 (i). The state need to have a 1915 (i) or other waiver just for Brain Injury.
Some of the limitations within the waiver could be reconsidered.
There needs to be a bigger state facility that cares for these type of residents.
Supporting individuals to contact family.

Very little movement.
State needs to allocate Extended Service Slots in the Rocky Mountain Monitoring System. And there needs to be a form of case management in DHS.
We are grateful to have Rebecca Quinn and her staff as a resource.
Families are not ready to hear this until they are face to face with it and wondering what happened. You can offer support groups and stuff but that approach doesn't work with many. I almost would like to see a brain injury specialist in each region of the state to do education, support, information etc. with people in the area.
Research and development of training classes for staff.
individualized care plans and nursing care
Inadequate funding limits the level of supports able to be provided.
Change in the method of financing 24-hour transitional living
Education with staff.

## ND Brain Injury (Agency Questionnaire)

### Q14. Other comments:

The development of the ND Brain Injury Network was a strategic move to have a one-stop shop in place for individuals with brain injury and caregivers. Its lost its place in the system and that needs to be reversed. The potential is there for good, solid coordination of efforts for individuals with brain injury and their caregivers, training for professionals, direction and vision regarding the needs of individuals and caregivers, and a vehicle to make system changes.

This type of service cannot go away when an individual has a job either because they some individuals may still need assistance in getting their home life in order even while holding down a job.

Something needs to be done for the citizens of ND! I don't understand how you can be born with a disability in the state of ND and get a ton of services but if you are a hard working, tax paying individual and you get a Brain Injury you get very,very limited service or even have to move out of state to get services.

We would never serve this type of individual. They would not fit in our level of care.

**ND Brain Injury (Agency-based Direct Service Provider Questionnaire)**

**Q.12 Here is a list of some possible training topics on Brain Injury. Indicate to what degree YOU need training on each topic:**

I don't have a lot of experience working with brain injuries
There is always room for improvement on all areas - I believe staff that do not have an interest in this area need more ongoing training on a regular basis.

**Q. 13 What are the most important and immediate needs for the person with brain injury to whom you provide support?**

Support and understanding of brain injury symptoms by medical doctor (just because someone can walk and talk, does not mean they are "fine")
Client's lack of understanding of the severity of their situation ex child custody issues, legal issues- and no known way to help them recognize this or to know if they are even capable of understanding this.
support in navigating community resources
basic living skills
The person needs financial, cognitive, and emotional support. All too often a person with a brain injury cannot do their previous job or needs to work with reduced hours due to mental fatigue and cognitive impairments. This means that the income is drastically less and puts an additional stress on the family in addition to the fact that the family is already struggling with the consequences of the brain injury. A reduced income means that the person often cannot pay for the services that are needed such as speech, PT, OT, Neuro-optometry, Neuropsychology, mental health etc. In addition to this, brain injuries are often missed by some medical providers therefore referrals for services do not happen when they are most needed. This often results in additional depression, anxiety, and other mental health concerns that further complicates the picture and prolongs recovery.
some kind of social support
remaining safe in their home while still being independent
Varies greatly with the individuals. Most need daily supports with managing medications, health, finances, ADLs.
Support him with managing his behaviors.
Community supports, housing, financial support
Learning how to start over, relearn how to do things without becoming upset/discouraged that they may not be able to function as well as before the injury-
cognitive support, financial support, support with transit, and scheduling appointments
Adequate services to families who have a person with a TBI in their home.
Semi- independent living environments that offer on staff supports as needed with various services provided depending on clients needs.menu of services
Transition into the community with more supports.
Not enough trained Qualified Service Providers to help individuals with brain injuries.
Better understanding by staff members on repetitive questioning, etc.



Employment support, transportation, personal care assistance
Under HCBS services, there are no services providing medical transportation or medical monitoring/coordination. Also there are no services to provide socialization with or without peers (take to a movie, etc)
supportive living environments
How to manage and what services would benefit someone with a TBI.
available caregivers and access to services and transportation in the rural area
housing in an appropriate and least restrictive setting
Housing and transportation. Caregivers.
assist family and care providers to manage behaviors
assessment
flexibility in service delivery
increase service options
best practice screening tool to access services
Financial-Not enough hours to help someone obtain and maintain a job due to funding resources as well as in residential support for those who live independently with support. Family has had to help.
Helping individual's cope with their current limitations and gaining insight into their disability.
That is very one on one for the person, sometimes I am just meeting them for the first time and they have a new BI, sometimes they have had a BI for many years and did not know it until we are talking about history and then it is discovered that "it is a possibility " and I approach the subject very carefully so an assessment is needed, I have never been wrong when I have sent someone for assessment they have always been DX's with BI. One lady had a BI from 10+ years ago, she had no idea why she could no longer do the things she used to do... It is all individual to the person.
The person I am serving is rapidly declining in there older age more staff support was needed and granted. They need another surgery but we are needing to support her by going through the doctor recommendations before they consider surgery. This individual is in need of more assistance doing everything day tasks and walking has become severely difficult, we have supported her with PT and using a gate belt and wheelchair to safely transport her.
The most important need of the person I support with a brain injury is guidance. This person may not understand all of the consequences of their actions, and many times will make decisions that could cause mental or physical harm.
Find employment
Understanding and support
The current county waiver system is inadequate.
Managing dual diagnoses and behaviors
Finding an appropriate discharge destination when they are fully rehabbed and need to move to a lower level of care but aren't quite ready to live completely independently.
assistance with all ADL

Affordable, accessible apartments to create an independent living environment, adequate support services and providers, social and recreational opportunities with appropriate transportation options
To understand what the brain injury is Education
On going supports to assist with anger management, employment issues and arranging/coordinating services and benefits.
Financial and emotional support

**Q. 14 How do you see those needs being addressed?**

More training of the nuances of brain injury symptoms, potential delay in onset of symptoms, impairments in awareness compromising a patient's ability to recognize and report symptoms themselves, and other functional, pertinent information being shared with medical professionals in the area (general practitioners, neurologists, nurse practitioners, etc).
unknown
somewhat by case management and some agency resources
often are not addressed
There needs to be a standardized protocol for ER and primary care medical staff for brain injury. People may or may not be told that they had a concussion and often are just sent home to "sleep it off" without any follow up or recommendations on what to do if the symptoms persist. There needs to be one database or designated spot the person with a brain injury can go to to even know what they will needs to consider such as medical professionals, support groups, who to contact for emotional and financial support, etc.
funding increase, change in determination of DD services, increase of knowledge of TBI's that hinder iADL's and ADL's. A person may not be qualified for DD, but still can not get help through the county or state either for services to assist them (shopping, cleaning, personal cares, etc)
The people I serve receive services thru the Dept. of Developmental Disabilities. Funding for these services is generally very good, and supports are available.
He has 24 hour staff support and a Positive Behavior Support Plan in place for him.
They are not being addressed
Counseling strategies
staff and agency support.
More dollars for programs and apartments build to better serve the clients needs.
Need for monitored living facilities.
Somewhat
I believe he receives services from Voc Rehab for employment training. We are able to provide some transportation for non medical trips. We also provide respite care to assist his fulltime caregivers.
The Medicaid Waiver would have to be changed to screen separately for TBI without the stringent screening criteria now. (Client has to meet at least 8 hour of supervision per day or meet specific rehab potential). Once the screening criteria was changed, and then the services could be changed for case managers to be able to authorize more medical and apt coordination, and also socialization tasks.

I am not aware of anything being done to address this issue
Additional services and awareness of TBIs.
dont really see them being addressed much
The client moves to Bismarck where there are more resources
increased training for HCBS Case Managers
more funding for case management
I don't believe they are being addressed
Uncertain as all goes back to funding. Family and staff have worked closely together as well as accessing funds from NDAD.
Brain Injury Support Network and Community Options
Again all individual to the person, sometime s we can take care of it "in house" with our programs and classes, sometimes they need referral, most often it is a combination of the two.
See above it was explained
Staff are given training with a behavioral analyst to better understand how the person thinks and how to best guide them to make healthy decisions.
Meeting with the client. Complete interest assessments.
Unknown
We are grateful for Rebecca Quinn and her staff.
We contact outside sources
There are currently not enough brain injury centered facilities in ND that are options for this population.
by individualized care plans and trained staff
Community/systems change
We have a monthly Brain Injury support group
Encourage people with Brain Injury to attend seminars.
Supports are available to address these issues, but funding has limited the extent of these.
This is not addressed to the extent needed at all. Insurance provides minimal if any financial support and social security rarely recognizes TBI as a disability qualifying individuals for support. Additionally, lack of understanding often leads to lack of family or spousal support emotionally.

## ND Brain Injury (Agency-based Direct Service Provider Questionnaire)

Q. 15 Other comments:

<p>The unethical internal operations of WSI need to be completely overhauled. WSI does not make decisions based on medical necessity and instead makes the road to recovery even more challenging for the person with a brain injury. Several of my patients have been denied services when all of the medical documentation indicates that the services are warranted and completely necessary. In fact, every therapist at our clinic has not only received denials regarding coverage, but also receives a verbal attack letter from the claims adjuster questioning their ethics and knowledge regarding brain injury. This letter occurs even if the survivor has three or more medical providers saying that the services warranted. This appears to be a scare tactic that is used in hopes that no other requests will be made for therapy services.</p>
<p>It would be beneficial for staff to be able to attend Brain Injury Workshops.</p>
<p>More input needs to be gathered from case managers that are trying to put together community based services for survivors of BI in order to adequately determine the effectiveness of current programs and the development of expanded community based services. Not all \$\$ should be spent on job training.</p>
<p>The person I have been referring to has his own home and is not eligible for medicaid nor EBT. benefits. Funds are through SS and medicare.</p>
<p>BI is very personal and individualized and personally I dislike seeing it all get placed into one large basket. It is on a spectrum, individual and unique, what works for one person will not work for another. People with kittle or no knowledge of BI hear it and immediately think it is the end of the world, it is not. Some very good things can come from BI as well, though none of us would want to have what happened again, there are silver linings, not for all... there are also some very great things coming up for people with Brain Injuries- We need to restore hope.</p>

## **Appendix 2**

# **Needs Assessment Questionnaires**

## Brain Injury Agency Questionnaire

The Behavioral Health Division of the ND Department of Human Services is gathering information on services and supports for ND citizens with brain injury. The ND Center for Persons with Disabilities (NDCPD) at Minot State University has been contracted to conduct the statewide needs assessment.

You have been selected to participate in the needs assessment because we understand you provide services for individuals with brain injury. **If you do not provide services to ND citizens with brain injury, DO NOT complete this questionnaire.**

This questionnaire is designed to gather information about brain injury (see definition below), along with resources, supports, services and needs in the state. All information will be kept confidential and no individual names will be used.

This questionnaire has been reviewed and approved by both the ND Department of Human Services Brain Injury Coalition and the Minot State University Institutional Review Board for the Protection of Human Subjects. The contact person for this study is Dr. Brent A. Askvig at Minot State University (701-858-3580). If you have questions for the Department of Human Services please contact Ms. Stacie Dailey at 701-328-8941. If you have questions about the human subjects research approval, please contact Dr. Jynette Larshus (701-858-4324).

This questionnaire will take between 15 and 30 minutes to complete. Please answer all questions if possible.

**ND Brain Injury Project  
ND Center for Persons with Disabilities  
Minot State University  
500 University Avenue West  
Minot, ND 58707**

*For the purposes of this needs assessment, a brain injury is:*

**as an injury to the brain which occurs after birth and which is acquired through traumatic or non-traumatic insults. For this needs assessment, non-traumatic aneurysm and stroke shall be included.**

The definition **does not include** hereditary, congenital, non-traumatic encephalopathy, or degenerative brain disorders or injuries induced by birth trauma.

# Brain Injury Agency Questionnaire

Please answer the following questions for the time period  
January 1, 2015 to December 31, 2015.

<p>1. How would you classify your agency?</p> <p><input type="checkbox"/> Public</p> <p><input type="checkbox"/> Private (for profit)</p> <p><input type="checkbox"/> Private (not for profit)</p>		
<p>2. What is the total number of individuals, regardless of disability, served by your agency?</p> <p style="text-align: right;">_____</p>		
<p>3. What is the total number of individuals with Brain Injury served by your agency?</p> <p style="text-align: right;">_____</p>		
<p>4. What is the zip code of your primary agency address? _____</p>		
<p>5. For each of the following service categories, indicate if you provide that service for individuals with Brain Injury.</p>		
<b>Service Category</b>	<b>YES, we provide this service</b>	<b>NO, we do not provide this service</b>
<b>Employment Supports</b> (such as job training, work accommodations, finding a job)		
<b>Recreation/Social Programming</b> (such as adaptive recreation, social skills groups, spiritual programs)		
<b>Independent Living Skills Supports</b> (such as money management, daily cares supports, dressing, eating)		
<b>Mental Health Supports</b> (such as anger management training, counseling services, psychological supports)		

<b>Education Supports</b> (such as GED, public school, college, vocational training)		
<b>Substance Abuse Supports</b> (such in-patient or out-patient substance abuse counseling, addiction treatment, AA meetings)		
<b>General Health Management Supports</b> (such as smoking cessation, dietary counseling, exercise classes)		
<b>Legal Supports</b> (such as legal assistance, legal representation)		
<b>Cognitive/Memory Supports</b> (such as memory training, problem solving skills training)		
<b>Housing Supports</b> (such as finding an apartment or home; rental assistance; heating assistance, etc.)		
<b>Other</b> (please describe)		
<b>Other</b> (please describe)		
<p><b>6. Many provider agencies work with other agencies in coordinating/organizing services for individuals with Brain Injury. From your perspective, are any of the following items an issue in your work?</b></p>		
	<b>YES</b>	<b>NO</b>
Lack of understanding of Brain Injury		
Inadequate screening/protocol to identify Brain Injury		
Lack of involvement in treatment plan for an individual following discharge from the hospital		
Lack of coordination with other services		
Inadequate Brain Injury eligibility criteria for services		
Inadequate financial resources for your agency		
Other (please describe)		
Other (please describe)		



7. Sometimes there are problems in getting or using services or supports for a person with a brain injury. Which of the following are barriers for your agency? (check all that apply)

- |   |  |
|---|--|
| <ul style="list-style-type: none"> <li><input type="checkbox"/> Inadequate support from family</li> <li><input type="checkbox"/> Inadequate peer support</li> <li><input type="checkbox"/> Inadequate community support</li> <li><input type="checkbox"/> Lack of acceptance of having a brain injury</li> <li><input type="checkbox"/> Lack of advocates for people with brain injury</li> <li><input type="checkbox"/> Lack of understanding of brain injury by providers</li> <li><input type="checkbox"/> Inadequate support for family caregivers</li> </ul> | <ul style="list-style-type: none"> <li><input type="checkbox"/> Inadequate financial resources</li> <li><input type="checkbox"/> Long travel distance for services</li> <li><input type="checkbox"/> Lack of appropriate transportation</li> <li><input type="checkbox"/> Inadequate health resources</li> <li><input type="checkbox"/> Lack of individualized services</li> <li><input type="checkbox"/> No centralized source for information on brain injury</li> </ul> |
|---|--|

8. How many staff members within your agency provide direct services to individual with Brain Injury?

\_\_\_\_\_

9. To what extent do you feel your agency staff are educated/trained to serve persons with Brain Injury?

Highly trained/educated		Moderately trained/educated		Not at all Trained/educated
5	4	3	2	1

**10. Check any/all of the following approaches that your agency uses to provide training/education to your staff about Brain Injury:**

- Formal mentoring
- Informal mentoring
- Agency-designed training sessions
- Support for staff to attend workshop or conferences outside the agency
- Support for staff to take college courses
- Support for staff to take online/external training modules (not college)
- Bring in outside speakers/consultants on Brain Injury topics
- Other (please describe) \_\_\_\_\_
- We DO NOT provide training/education to our staff on Brain Injury

**11. Here is a list of some possible training topics on Brain Injury. Indicate to what degree your current staff need training on each topic.**

	This is a high training need		This is a moderately high training need		We do not need training on this topic
TRAINING TOPICS	5	4	3	2	1
Initial assessment/screening for a Brain Injury					
Diagnostic evaluation for a Brain Injury					
Brain Injury prevention					
Rehabilitation strategies					
Transitioning from Hospital/ Rehabilitation to home and community					
Family and survivor support network development					

Managing behavioral health needs of individuals with Brain Injury					
Case management/service coordination strategies					
Other (please describe)					
Other (please describe)					
Other (please describe)					

**12. What are the most important and immediate needs for people with brain injury to whom you provide support?**

**13. How do you see that need being addressed?**

**14. Other comments:**

**For more information on services, supports and resources on brain injury, go to <http://www.ndbin.org>**

# Brain Injury Agency-Based Direct Service Provider Questionnaire

The Behavioral Health Division of the ND Department of Human Services is gathering information on services and supports for ND citizens with brain injury. The ND Center for Persons with Disabilities (NDCPD) at Minot State University has been contracted to conduct the statewide needs assessment.

You have been selected to participate in the needs assessment because we understand you provide services for individuals with brain injury. **If you are not an agency-based direct service provider of a person with a brain injury, DO NOT complete this questionnaire.**

This questionnaire is designed to gather information about brain injury (see definition below), along with resources, supports, services and needs in the state. All information will be kept confidential and no individual names will be used.

This questionnaire has been reviewed and approved by both the ND Department of Human Services Brain Injury Coalition and the Minot State University Institutional Review Board for the Protection of Human Subjects. The contact person for this study is Dr. Brent A. Askvig at Minot State University (701-858-3580). If you have questions for the Department of Human Services please contact Ms. Stacie Dailey at 701-328-8941. If you have questions about the human subjects research approval, please contact Dr. Jynette Larshus (701-858-4324).

This questionnaire will take between 15 and 30 minutes to complete. Please answer all questions if possible.

**ND Brain Injury Project  
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*For the purposes of this needs assessment, a brain injury is:*

**as an injury to the brain which occurs after birth and which is acquired through traumatic or non-traumatic insults. For this needs assessment, non-traumatic aneurysm and stroke shall be included.**

The definition **does not include** hereditary, congenital, non-traumatic encephalopathy, or degenerative brain disorders or injuries induced by birth trauma.

# Brain Injury Agency-Based Direct Service Provider Questionnaire

Please answer the following questions for the time period  
January 1, 2015 to December 31, 2015.

<p>1. What is the total number of individuals, regardless of disability, served by <u>YOU</u> personally?</p> <p style="text-align: center;">_____</p>												
<p>2. What is the total number of individuals <u>with Brain Injury</u> served by <u>YOU</u> personally?</p> <p style="text-align: center;">_____</p>												
<p>3. What is the zip code of the location where you primarily serve persons with Brain Injury?</p> <p style="text-align: center;">_____</p>												
<p>4. How would you classify the type of agency for which you work? (select only 1 choice)</p> <p style="margin-left: 20px;"> <input type="checkbox"/> Public  <input type="checkbox"/> Private/for profit  <input type="checkbox"/> Private/non-profit         </p>												
<p>5. For each of the following categories, indicate if <u>YOU</u> personally provide these service for individuals with Brain Injury.</p> <table border="1" style="width: 100%; border-collapse: collapse; margin-top: 10px;"> <thead> <tr> <th style="text-align: center; padding: 5px;"><b>Service Category</b></th> <th style="text-align: center; padding: 5px;"><b>YES, I provide this service</b></th> <th style="text-align: center; padding: 5px;"><b>NO, I do not provide this service</b></th> </tr> </thead> <tbody> <tr> <td style="padding: 5px;"><b>Employment Supports</b> (such as job training, work accommodations, finding a job)</td> <td style="width: 150px; height: 40px;"></td> <td style="width: 150px; height: 40px;"></td> </tr> <tr> <td style="padding: 5px;"><b>Recreation/Social Programming</b> (such adaptive recreation, social skills groups, spiritual programs)</td> <td style="width: 150px; height: 40px;"></td> <td style="width: 150px; height: 40px;"></td> </tr> <tr> <td style="padding: 5px;"><b>Independent Living Skills Supports</b> (such as money management, daily cares supports, dressing, eating)</td> <td style="width: 150px; height: 40px;"></td> <td style="width: 150px; height: 40px;"></td> </tr> </tbody> </table>	<b>Service Category</b>	<b>YES, I provide this service</b>	<b>NO, I do not provide this service</b>	<b>Employment Supports</b> (such as job training, work accommodations, finding a job)			<b>Recreation/Social Programming</b> (such adaptive recreation, social skills groups, spiritual programs)			<b>Independent Living Skills Supports</b> (such as money management, daily cares supports, dressing, eating)		
<b>Service Category</b>	<b>YES, I provide this service</b>	<b>NO, I do not provide this service</b>										
<b>Employment Supports</b> (such as job training, work accommodations, finding a job)												
<b>Recreation/Social Programming</b> (such adaptive recreation, social skills groups, spiritual programs)												
<b>Independent Living Skills Supports</b> (such as money management, daily cares supports, dressing, eating)												

<b>Mental Health Supports</b> (such as anger management training, counseling services, psychological supports)		
<b>Education Supports</b> (such as GED, public school, college, vocational training)		
<b>Substance Abuse Supports</b> (such in-patient or out-patient substance abuse counseling, addiction treatment, AA meetings)		
<b>General Health Management Supports</b> (such as smoking cessation, dietary counseling, exercise classes)		
<b>Legal Supports</b> (such as legal assistance, legal representation)		
<b>Cognitive/Memory Supports</b> (such as memory training, memory aids or assistive devices)		
<b>Housing Supports</b> (such as finding an apartment or home; rental assistance; heating assistance, etc.)		
<b>Other</b> (please describe)		
<b>Other</b> (please describe)		

6. What is the average number of hours each week you provide services for people with Brain Injury?

\_\_\_\_\_

7. About how long have you been providing services for people with Brain Injury?

- This is my first year
- 1 – 5 years
- 6 – 10 years
- 11 – 15 years
- 16 – 20 years
- More than 20 years

**8. Many direct support providers work with other agencies in coordinating/organizing services for individuals with Brain Injury. From your perspective, are any of the following items an issue in your work?**

**YES**

**NO**

	YES	NO
Lack of understanding of Brain Injury		
Inadequate screening/protocol to identify Brain Injury		
Lack of involvement in treatment plan for an individual following discharge from the hospital		
Lack of coordination with other services		
Inadequate Brain Injury eligibility criteria for services		
Inadequate financial resources for your agency		
Other (please describe)		

**9. Sometimes there are problems in getting or using services or supports for a person with a brain injury. Which of the following are barriers for YOU? (check all that apply)**

- Inadequate support from family
- Inadequate peer support
- Inadequate community support
- Lack of acceptance of having a brain injury
- Lack of advocates for people with brain injury
- Lack of understanding of brain injury by providers
- Inadequate support for family caregivers

- Inadequate financial resources
- Long travel distance for services
- Lack of appropriate transportation
- Inadequate health resources
- Lack of individualized services
- No centralized source for information on brain injury

10. To what extent do YOU feel you are educated/trained to serve persons with Brain Injury?

<b>Highly trained/educated</b>		<b>Moderately trained/educated</b>		<b>Not at all Trained/educated</b>
<b>5</b>	<b>4</b>	<b>3</b>	<b>2</b>	<b>1</b>

11. Check any/all of the following approaches that your agency has provided training/education to you about Brain Injury:

- Formal mentoring
- Informal mentoring
- Agency-designed training sessions
- Support for staff to attend workshop or conferences outside the agency
- Support for staff to take college courses
- Support for staff to take online/external training modules (not college)
- Bring in outside speakers/consultants on Brain Injury topics
- Other (please describe) \_\_\_\_\_
- My agency DOES NOT provide training/education to our staff on Brain Injury



12. Here is a list of some possible training topics on Brain Injury. Indicate to what degree YOU need training on each topic:

	This is a high training need		This is a moderately high training need		I do not need training on this topic
TRAINING TOPICS	5	4	3	2	1
Initial assessment/screening for a Brain Injury					
Diagnostic evaluation for a Brain Injury					
Brain Injury prevention					
Rehabilitation strategies					
Transitioning from Hospital/ Rehabilitation to home and community					
Family and survivor support network development					
Managing behavioral health needs of individuals with Brain Injury					
Case management/service coordination strategies					
Other (please describe)					
Other (please describe)					
Other (please describe)					

13. What are the most important and immediate needs for the person with brain injury to whom you provide support?

14. How do you see those needs being addressed?

15. Other comments:

**For more information on services, supports and resources on brain injury, go to <http://www.ndbin.org>**

## Brain Injury Survivor Questionnaire

The Behavioral Health Division of the ND Department of Human Services is gathering information on services and supports for ND citizens with brain injury. The ND Center for Persons with Disabilities (NDCPD) at Minot State University has been contracted to conduct the statewide needs assessment.

You have been selected to participate in the needs assessment because of your experiences and perspectives on brain injury.

This questionnaire is designed to gather information about brain injury (see definition below), along with resources, supports, services and needs in the state. All information will be kept confidential and no individual names will be used.

This questionnaire has been reviewed and approved by both the ND Department of Human Services Brain Injury Coalition and the Minot State University Institutional Review Board for the Protection of Human Subjects. The contact person for this study is Dr. Brent A. Askvig at Minot State University (701-858-3580). If you have questions for the Department of Human Services please contact Ms. Stacie Dailey at 701-328-8941. If you have questions about the human subjects research approval, please contact Dr. Jynette Larshus (701-858-4324).

This questionnaire will take between 15 and 30 minutes to complete. Please answer all questions if possible. **The completed questionnaire should be mailed to:**

**ND Brain Injury Project  
ND Center for Persons with Disabilities  
Minot State University  
500 University Avenue West  
Minot, ND 58707**

*For the purposes of this needs assessment, a brain injury is:*

**as an injury to the brain which occurs after birth and which is acquired through traumatic or non-traumatic insults. For this needs assessment, non-traumatic aneurysm and stroke shall be included.**

The definition **does not include** hereditary, congenital, non-traumatic encephalopathy, or degenerative brain disorders or injuries induced by birth trauma.

# Brain Injury Survivor Questionnaire

**1. I am a:**

- Person with a brain injury
- Guardian/official representative of a person with a brain injury
- Caregiver/support staff for a person with a brain injury

**2. The individual with a brain injury is:**

**Gender**

- Female
- Male

**Age:** \_\_\_\_\_

**Military Status**

- Active duty military
- Retired military
- Did not serve in the military

**3. I identify my race/ethnicity as:**

- White
- American Indian or Alaska native
- Black or African American
- Asian
- Hispanic or Latino
- Native Hawaiian or other Pacific Islander
- Two or more races

**4. My residence Zip Code is** \_\_\_\_\_

**5. I live:**

- Alone
- With a spouse/significant other
- Family member (who is not my spouse)
- Non-relative room mate
- Other (please describe) \_\_\_\_\_

**6. My residence is:**

- My own home or apartment
- Dakota Alpha
- Hospital
- TBI residential facility (Dakota Pointe, HI Soaring Eagle, etc.)
- Assisted living facility
- Skilled Nursing Facility
- Basic Care Facility
- Other (please describe) \_\_\_\_\_

**7. My brain injury(s) is a result of: (Check all that apply)**

**Age when injury occurred**

- |   |       |
|---|-------|
| <input type="checkbox"/> Motor vehicle accident               | _____ |
| <input type="checkbox"/> Bicycle crash                        | _____ |
| <input type="checkbox"/> Pedestrian accident                  | _____ |
| <input type="checkbox"/> Anoxia (lack of oxygen to the brain) | _____ |
| <input type="checkbox"/> Substance abuse                      | _____ |
| <input type="checkbox"/> Assault                              | _____ |
| <input type="checkbox"/> Fall                                 | _____ |
| <input type="checkbox"/> Domestic violence                    | _____ |
| <input type="checkbox"/> Stroke                               | _____ |
| <input type="checkbox"/> Non-traumatic aneurysm               | _____ |
| <input type="checkbox"/> Firearm (gunshot)                    | _____ |
| <input type="checkbox"/> Sports/recreation injury             | _____ |
| <input type="checkbox"/> Blast/explosion                      | _____ |
| <input type="checkbox"/> Other (please describe) _____        | _____ |
| <input type="checkbox"/> Unknown                              |       |

**8. I have health insurance through: (check all that apply)**

- Private/commercial health insurance (e.g., Blue Cross/Blue Shield, Sanford Health, etc.)
- Medicaid
- Medicare
- Medicaid Expansion
- Other (please describe) \_\_\_\_\_
- I DO NOT have health insurance

**9. I also experience the following conditions(s): (check all that apply)**

- Mental Illness
- Substance abuse
- Developmental disability (e.g., autism, intellectual disability, cerebral palsy)
- Dementia
- Sensory disability (e.g., vision loss, hearing loss)
- Physical Disability
- Other (please describe) \_\_\_\_\_

**10. Due to my brain injury and associated conditions, I usually need personal supervision and assistance:**

- 16 – 24 hours each day
- 8 – 15 hours each day
- 1 – 7 hours each day
- I do not need personal supervision and assistance each day

**11. For each of the general categories of services, place a checkmark in column 1) if you need this service, in column 2) if you get this service, and in column 3) when you get the service, circle the word that tells how good the service is.**

Service/Support Category	<u>1</u>	<u>2</u>	<u>3</u>			
	I need this service	I get this service	When I get this service it is			
			Excellent	Good	Fair	Poor
<b>Employment Supports</b> (such as job training, work accommodations, finding a job)			Excellent	Good	Fair	Poor
<b>Recreation/Social Programming</b> (such adaptive recreation, social skills groups, spiritual programs)			Excellent	Good	Fair	Poor
<b>Independent Living Skills Supports</b> (such as money management, daily cares supports, dressing, eating)			Excellent	Good	Fair	Poor
<b>Mental Health Supports</b> (such as anger management training, counseling services, psychological supports)			Excellent	Good	Fair	Poor
<b>Education Supports</b> (such as GED, public school, college, vocational training)			Excellent	Good	Fair	Poor
<b>Substance Abuse Supports</b> (such in-patient or out-patient substance abuse counseling, addiction treatment, AA meetings)			Excellent	Good	Fair	Poor

<b>General Health Management Supports</b> (such as smoking cessation, dietary counseling, exercise classes) <b>Legal Supports</b> (such as legal assistance, legal representation) <b>Cognitive/Memory Supports</b> (such as memory training, memory aids or assistive devices) <b>Housing Supports</b> (such as finding an apartment or home; rental assistance; heating assistance, etc.) <b>Other</b> (please describe)			<b>Excellent</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>
			<b>Excellent</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>
			<b>Excellent</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>
			<b>Excellent</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>
			<b>Excellent</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>

**12. Sometimes people with a brain injury have difficulties with various behaviors. In column 1) place a check beside those behaviors that you have. In column 2) place a check if the behavior has prevented you from getting a service or support, and in column 3) write in the service or support you didn't get.**

	<b>Column 1</b>	<b>Column 2</b>	<b>Column 3</b>
<b>Behavior</b>	<b>This can be a problem for me.</b>	<b>This behavior prevented me from getting a service or support.</b>	<b>Because of this behavior, I did not get this service or support.</b>
Difficulty controlling my temper			
Impatient			
Frequent complaining			
Violent or aggressive behavior			
Impulsive			
Inappropriate social behavior			
Overly dependent on others			
Making poor decisions			
Refuse to admit difficulties			
Childish or immature			
Lack of initiative			
Irritable			
Anxiety, tension, uptight			
Sudden rapid mood changes			
Lack of interest in things			
Depression/low mood			
Irresponsible and can't be trusted			
Trouble sleeping			

13. Sometimes there are problems in getting or using services or supports for a person with a brain injury. Which of the following are barriers for you? (check all that apply)

- |   |  |
|---|--|
| <ul style="list-style-type: none"> <li><input type="checkbox"/> Inadequate support from family</li> <li><input type="checkbox"/> Inadequate peer support</li> <li><input type="checkbox"/> Inadequate community support</li> <li><input type="checkbox"/> Lack of acceptance of having a brain injury</li> <li><input type="checkbox"/> Lack of advocates for people with brain injury</li> <li><input type="checkbox"/> Lack of understanding of brain injury by providers</li> <li><input type="checkbox"/> Inadequate support for family caregivers</li> </ul> | <ul style="list-style-type: none"> <li><input type="checkbox"/> Inadequate financial resources</li> <li><input type="checkbox"/> Long travel distance for services</li> <li><input type="checkbox"/> Lack of appropriate transportation</li> <li><input type="checkbox"/> Inadequate health resources</li> <li><input type="checkbox"/> Lack of individualized services</li> <li><input type="checkbox"/> No centralized source for information on brain injury</li> </ul> |
|---|--|

14. Tell us how knowledgeable and skilled your primary service provider is to provide supports to you. (circle one) *If you do not have a service provider, leave this blank.*

<b>Very knowledgeable and skilled</b>	<b>Somewhat knowledgeable and skilled</b>	<b>Has very little knowledge and skill</b>	<b>No skill or knowledge to help me</b>
---------------------------------------	---	--	---

15. What are the most important and immediate needs for you?

16. How do you see those needs being addressed?

17. Other comments:

**For more information on services, supports and resources on brain injury, go to <http://www.ndbin.org>**



## Brain Injury Family Caregiver Questionnaire

The Behavioral Health Division of the ND Department of Human Services is gathering information on services and supports for ND citizens with brain injury. The ND Center for Persons with Disabilities (NDCPD) at Minot State University has been contracted to conduct the statewide needs assessment.

You have been selected to participate in the needs assessment because of your experiences and perspectives on brain injury. **If you are not a caregiver of a family member with a brain injury, DO NOT complete this questionnaire.**

This questionnaire is designed to gather information about brain injury (see definition below), along with resources, supports, services and needs in the state. All information will be kept confidential and no individual names will be used.

This questionnaire has been reviewed and approved by both the ND Department of Human Services Brain Injury Coalition and the Minot State University Institutional Review Board for the Protection of Human Subjects. The contact person for this study is Dr. Brent A. Askvig at Minot State University (701-858-3580). If you have questions for the Department of Human Services please contact Ms. Stacie Dailey at 701-328-8941. If you have questions about the human subjects research approval, please contact Dr. Jynette Larshus (701-858-4324).

This questionnaire will take between 15 and 30 minutes to complete. Please answer all questions if possible. **The completed questionnaire should be mailed to:**

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*For the purposes of this needs assessment, a brain injury is:*

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The definition **does not include** hereditary, congenital, non-traumatic encephalopathy, or degenerative brain disorders or injuries induced by birth trauma.

# Brain Injury Family Caregiver Questionnaire

1. As a caregiver of a family member with a brain injury, I am a:

- Spouse
- Sibling
- Parent
- Child of person with brain injury
- Significant other
- Other (please describe) \_\_\_\_\_

2. I am paid to provide care to my family member:

- Yes
- No

3. I identify my race/ethnicity as:

- White
- American Indian or Alaska native
- Black or African American
- Asian
- Hispanic or Latino
- Native Hawaiian or other Pacific Islander
- Two or more races

4. My age is \_\_\_\_\_

5. My residence Zip Code is \_\_\_\_\_

6. I have received training/education in brain injury and caregiving by: (select all that apply)

- College/University degree
- Workshops
- Conferences
- Individualized Consultant training
- Informal self-study
- Formal training modules (face to face or online)
- I have received no training
- Other (please describe) \_\_\_\_\_

**7. The individual with a brain injury is:**

**Gender**

- Female
- Male

**Age:** \_\_\_\_\_

**Military Status**

- Active duty military
- Retired military
- Did not serve in the military

**8. The person for whom I provide care has a brain injury as a result of:**

- Motor vehicle accident
- Bicycle crash
- Pedestrian accident
- Anoxia (lack of oxygen to the brain)
- Substance abuse
- Assault
- Fall
- Domestic violence
- Stroke
- Non-traumatic aneurysm
- Firearm (gunshot)
- Sports/recreation injury
- Blast/explosion
- Other (please describe) \_\_\_\_\_
- Unknown

**9. Where do you provide care for your family member with a brain injury? (select one)**

- In my home/apartment
- In his/her own home/apartment
- In a medical facility
- In an assisted living facility/nursing home
- In a group home or residential facility
- In a correctional facility
- Other (please describe) \_\_\_\_\_

**10. How far do YOU travel to provide care to the person with a brain injury? (check one)**

- I live with the person
- Less than 20 minutes away
- Between 20 minutes & one hour away
- Between one and two hours away
- More than two hours away

**11. How long have YOU been providing care to the person with a brain injury? (check one)**

- 0 – 6 months
- Between 6 months and 1 year
- Between 1 and 2 years
- Between 2 and 5 years
- More than 5 years

**12. How many hours per week do YOU provide care to the person with brain injury?**

- 1 – 5 hours per week
- 6 – 10 hours per week
- 11 – 15 hours per week
- 16 – 20 hours per week
- More than 20 hours per week

**13. Sometimes there are problems in getting or using services or supports for a person with a brain injury. Which of the following are barriers for the person whom you provide care? (check all that apply)**

- |   |   |
|---|---|
| <ul style="list-style-type: none"><li><input type="checkbox"/> Inadequate support from family</li><li><input type="checkbox"/> Inadequate peer support</li><li><input type="checkbox"/> Inadequate community support</li><li><input type="checkbox"/> Lack of acceptance of having a brain injury</li><li><input type="checkbox"/> Lack of advocates for people with brain injury</li><li><input type="checkbox"/> Lack of understanding of brain injury by providers</li><li><input type="checkbox"/> Inadequate support for family caregivers</li></ul> | <ul style="list-style-type: none"><li><input type="checkbox"/> Inadequate financial resources</li><li><input type="checkbox"/> Long travel distance for services</li><li><input type="checkbox"/> Lack of appropriate transportation</li><li><input type="checkbox"/> Inadequate health resources</li><li><input type="checkbox"/> Lack of individualized services</li><li><input type="checkbox"/> No centralized source for information on brain injury</li></ul> |
|---|---|

**14. Do you belong to a caregiver support group?**

Yes

No

**If no, are you interested in participating in a support group?**

Yes

No

**15. What are the most important and immediate needs for the person with brain injury to whom you provide support?**

**16. How do you see that need being addressed?**

**17. Other comments:**

**For more information on services, supports and resources on brain injury, go to <http://www.ndbin.org>**

## **Appendix 3**

### **Focus group protocol and questions**

## Focus Group Session

We appreciate that you are able to join us in today's focus group. We look forward to hearing your thoughts and ideas on ways to improve the system of care for Brain injury individuals, families and service providers.

Below you will find the list of questions that will be asked in today's session. Please take a few minutes to review these questions and write down your thoughts you may want to share during the session.

We will gather the sheets upon completion of the session as a backup for notes during the session.

1. What are the services and supports that were helpful to individuals with Brain Injury and the families?
2. What services and supports are missing to provide services to Brain Injury individuals and the families?
3. Removing all barriers, money, travel, etc. what would be the ideal roadmap from injury onset to the highest level of independence?

## **Appendix 4**

### **Agency and contact information for questionnaire distribution**

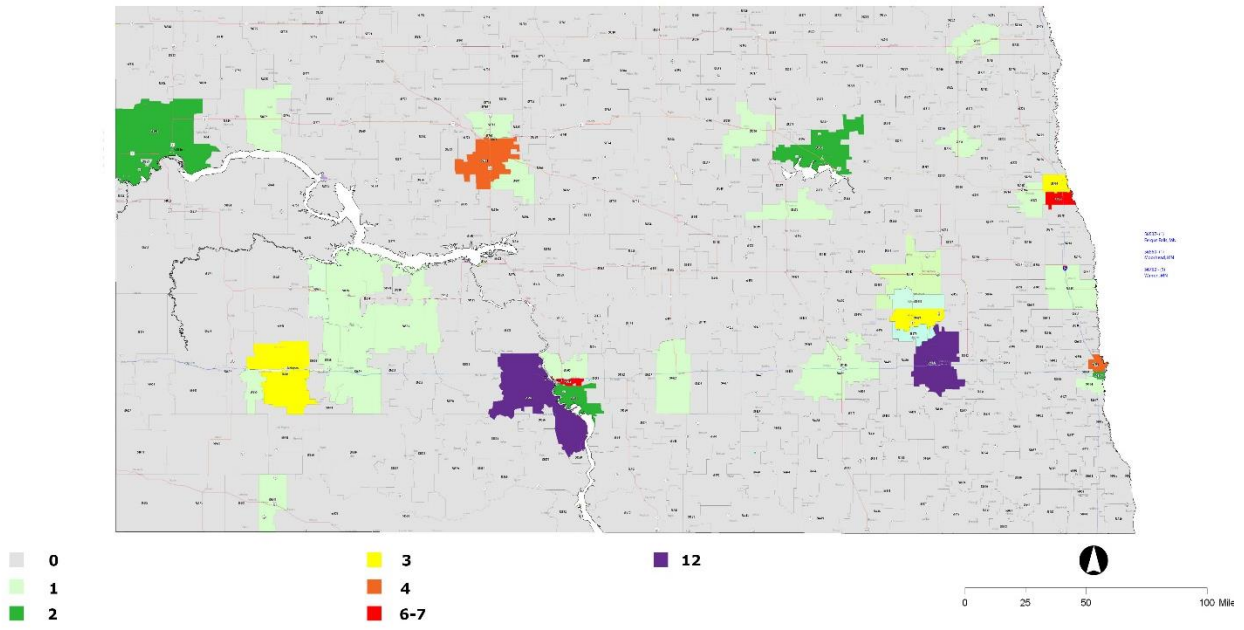


**Agencies and contact staff who assisted in distributing the brain injury needs assessment questionnaires**

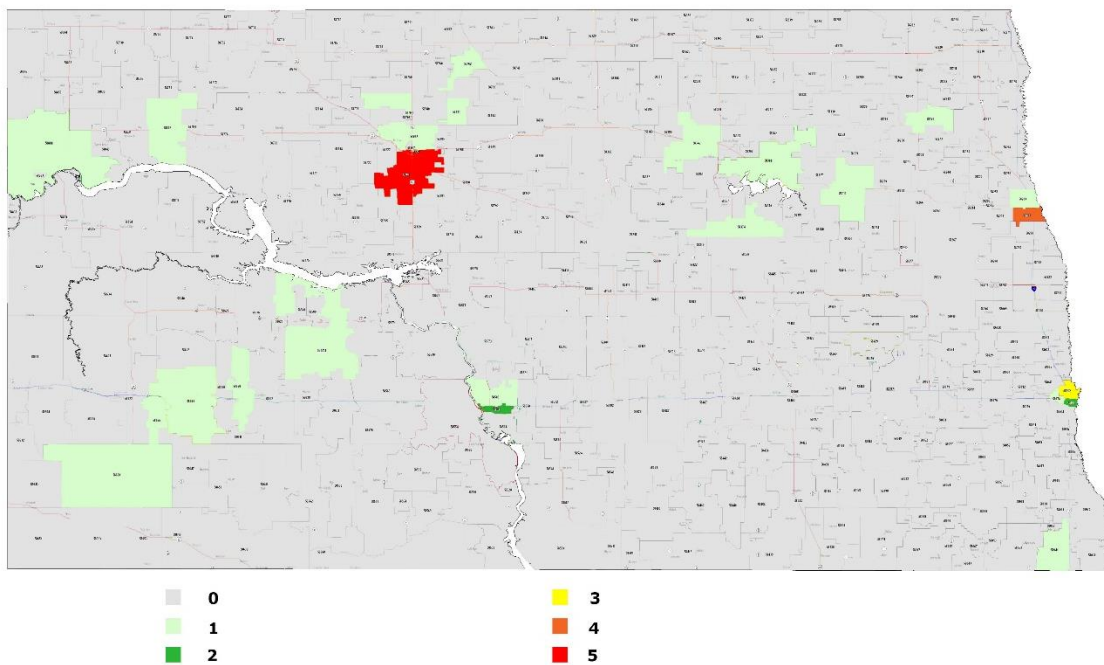
Alpha Opportunities Inc	Sue Kurtz
Brain Injury Support Group Grand Forks	John Hricak/Rebecca Quinn
Sanford Brian Injury Support Group	Miranda Harvey
Community Options	Trini Gress, Stacey Steele
Community Living Fargo	Jim Berglie
HIT Inc. (Dakota Alpha, Dakota Pointe)	Blaine Kinkaid
Enable Inc.	Jon Larson
Lake Region Corp Devils Lake	Jeff Jacobson
ND Development Center	Sue Foerster
Open Door Valley City (HI Soaring Eagle)	Mary Simonson
Pride Inc.	Tony Baker
Progressive Therapy	Jan Nelson
Sanford Health Coordinated Treatment Center Fargo	Carla Houle
Success Unlimited Grand Forks	Tanja Kapinos
Onward Together Support Group; Fargo	Nan Kennelly
Triumph Jamestown	Jennifer Barnard
Hawks Point Support Group; Dickinson	Shannon Binstock
Home Community Based Services (HCBS)	Katherine Barchenger
NDAD (Grand Forks, Fargo, Minot, Williston)	Leslie Stastny
VA Office; (Bismarck, Fargo Minot)	Dinell Polsfut, Skye Carpenter, S. Belohlavek
North Dakota Brain Injury Network	Rebecca Quinn, Nike Livedalen, Carmen Hickel
North Dakota Vocational Rehabilitation Offices	
North Dakota Department of Human Services	Jeff Stenseth
North Dakota Long Term Care Association	Shelley Peterson
North Dakota Housing Authority	Tom Alexander
North Dakota P&A	Theresa, Denise
Centers for Independent Living (Bismarck, Fargo, Grand Forks, Minot)	Royce Schultz, Nathan Aalgaard, Scott Burlingame, LaRae Gustafson

## **Appendix 5**

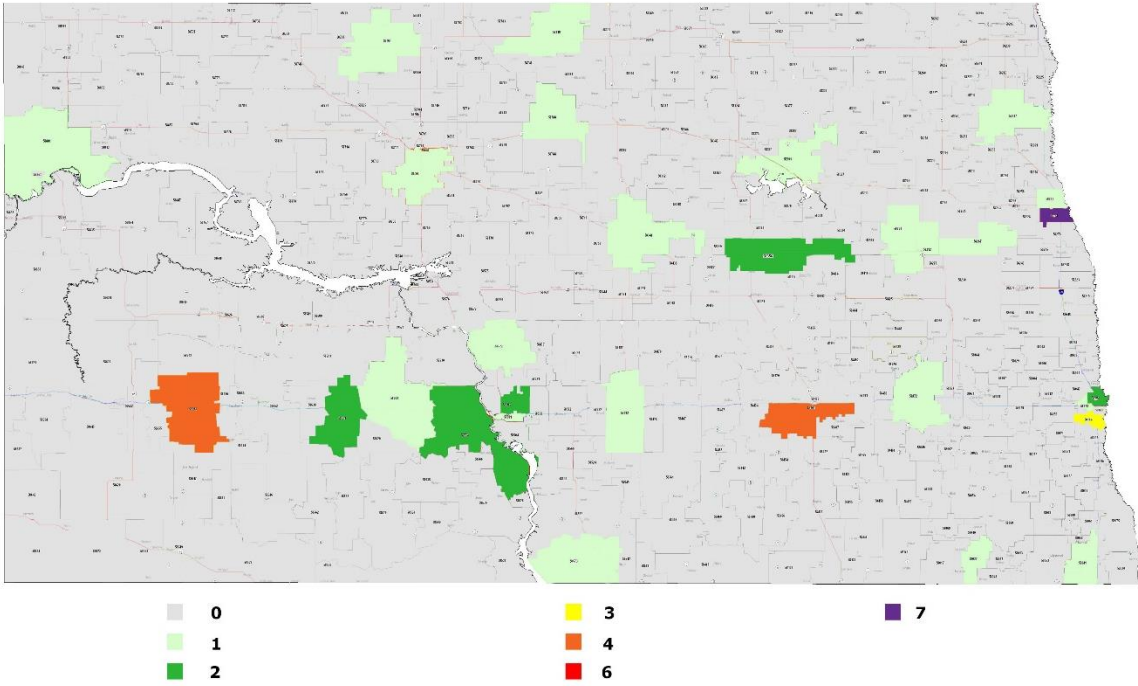
### **Zip codes maps of questionnaire respondents**



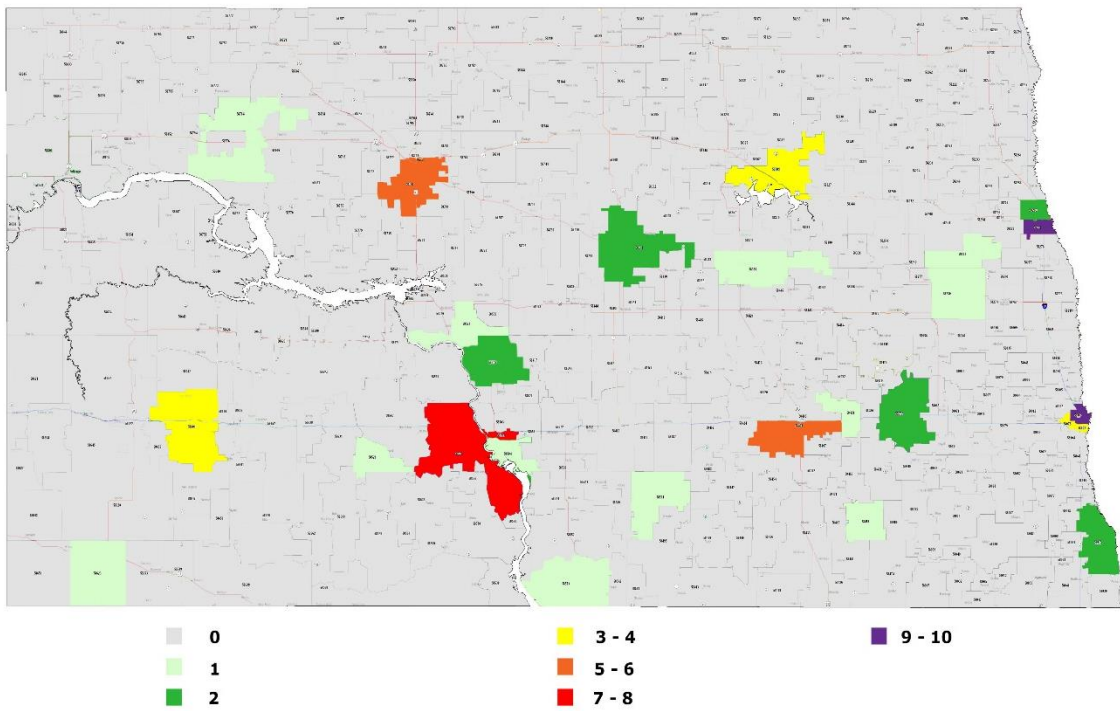
*Survivor respondents by zip code.*



*Family caregiver respondents by zip code.*



*Agency representative respondents by zip code.*



*Agency-based caregiver respondents by zip code.*