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

North Dakota Brain Injury Needs Assessment: Final Report

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Prepared by
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Executive Summary

For people with brain injury in North Dakota, services and supports for the condition are few, are disparate, and are disjointed.

The North Dakota Center for Persons with Disabilities (NDCPD) at Minot State University was contracted by the ND Department of Human Services, Behavioral Health Division, to conduct a statewide needs assessment on the numbers of people with brain injury in the state, and the needs, services, and potential gaps for this population. NDCPD designed and conducted a four pronged needs assessment over a period of seven months. This process included conducting a program and services review, gathering data via questionnaires of various target populations, conducting focus groups around the state, and gathering personal stories of ND citizens who have survived brain injuries. The data gathered were both quantitative (numerical) and qualitative (written and oral commentary) in nature. A listing and description of significant findings was produced, and a brief comparison of these results with a previous 2005 statewide needs assessment was completed. An overview of the results is provided here.

Definition of Brain Injury for this Needs Assessment

Per the guidance from the ND Department of Human Services, the following definition and description of brain injury was used.

Brain Injury (BI) is defined as an injury to the brain which occurs after birth and which is acquired through traumatic or non-traumatic insults. The state definition does not include hereditary, congenital, non-traumatic encephalopathy, non-traumatic aneurysm, stroke, or degenerative brain disorders or injuries *induced by birth trauma. However, for purposes of this needs assessment non-traumatic aneurysm and stroke shall be included.*

This definition was a combination of the recently revised North Dakota definition of brain injury (which contains both traumatic and non-traumatic brain injury) with the inclusion of stroke.

Incidence and Prevalence of Brain Injury in North Dakota

This needs assessment found that there is no definitive method to determine precise numbers of individuals with brain injury in ND. This actually coincides with findings from the national Centers for Disease Control and Prevention (2015). If we use the CDC estimates (extrapolated to ND) we might reasonably expect to have 8,872 and 14,695 people with TBI in our state. We can then add the extrapolated numbers of possible ND citizens living with stroke (14,024) to get a total of between 22,896 and 28,719 people in ND who could fall with our definition of brain injury for this report. This would be between 3.02% to 3.79% of our current state population. There are many reasons for not having precise figures, including no national or state brain injury registry, variations in the state and national definitions used for the condition.

Significant Findings

The major summary finding is that **for people with brain injury in North Dakota, services and supports for the condition are few, are disparate, and are disjointed**. There are also significant findings that can be grouped by (1) the lack of and need for services for the population, (2) the need for education about brain injury, and (3) the need for better data collection and coordination. These findings are, in no particular order of importance:

1. **Overall, there are insufficient services for people with brain injuries.**
    a) There is a lack of a continuum of resources, supports and services for brain injury in North Dakota and there are disparities across the state.
    b) Brain injury and the associated conditions impact daily functioning people with brain injury and impact their access to services.
    c) There are problems with care coordination across existing programs within the state.
    d) Families reported a high need for family and survivor support systems.
    e) People with brain injury need transitional services, case management, employment supports, and transitional housing.
    f) Participants reported frustrations and problems with eligibility for access to treatment for brain injury, especially after hospitalization.
2. **Overall, there is insufficient education and training about brain injury and its impact on individuals, families and the community.**
    a) North Dakota needs more public education about brain injury.
    b) Various service providers, medical personnel, and community agency staff need education and training about working with people with brain injury.
3. **Overall, there are insufficient data systems and reporting processes for determining accurate census information on brain injury.**
    a) Definitional variations between the state definition and national reporting systems makes state to national comparisons difficult.
    b) Current in-state data collection systems are not coordinated to show a comprehensive picture of the numbers of citizens needing brain injury services.

Comparison to the 2005 Statewide Needs Assessment

While there were some methodological differences between this 2016 needs assessment and the study conducted in 2005, many of the findings were similar. One major conclusion of the 2005 report was that the state did not have a comprehensive system of services and supports for people with TBI. The authors suggested that the current system was “fragmented” and did not address the needs of people with TBI. This coincides with the general theme and individual findings of the 2016 study. The 2005 report lists several major findings including a need for increased access to TBI information, a need for education, training and awareness on TBI, enhanced services for people with TBI, and increased supports for people with TBI and their caregivers, particularly family caregivers. Again, the 2016 report confirms many of these items. Finally, the authors of the 2005 report listed several barriers or gaps in services such as a shortage of TBI advocates, no central source of information or resources, lack of knowledge by individuals about TBI services, inadequate financial resources, lack of individualized services and an overall lack of understanding of TBI by service providers. This 2016 report confirms many of these findings except for the item about central source of information or resources. ND currently supports the ND Brain Injury Network (NDBIN) which operates out of the UND Center for Rural Health and provides a central source of information to individuals, families, and providers.

Introduction

In 2015, the Centers for Disease Control and Prevention (CDC) published a report to Congress on traumatic brain injury in the United States (CDC, 2015). The report was designed to inform Congress about (1) the burden of TBI including information about the incidence and prevalence of TBI; (2) the outcomes of TBI measures and factors that influence those outcomes; and (3) the assessment of the current status and effectiveness of TBI rehabilitation services across the US. The authors concluded that there are significant challenges facing the nation regarding TBI services and supports. While there has been progress, the ability to quantify the numbers of individuals with TBI across the US is difficult. The various natures of TBI makes it difficult to determine a consistent set of evidence-based interventions for the population. The effects of community-based interventions after acute rehabilitation are not clear. And the program models implemented by states varies so much that cross-state comparisons are difficult. The CDC report lists recommended next-steps that include a better understanding of effective rehabilitation protocols, service models that support parents and caregivers in the rehabilitation process, an analysis of cost-benefit effects of various rehabilitation services, the use of technologies and distance delivery protocols in service delivery, and an integrated system of supports and services as follow-up for individuals with TBI after acute rehabilitation therapies.

While there has been much recent national attention to the issues surrounding brain injury, there have also been recent efforts in North Dakota to address the information, services and support needs of citizens with brain injury. The North Dakota Brain Injury Network (NDBIN) has outlined the state's legislative, state agency, and committee work from 1987 through 2015 (see https://www.ndbin.org/brain-info). The activities have included the establishment of the ND Department of Human Services as the lead state agency in work on brain injury, the establishment and then subsequent removal of a brain injury registry, planning grants, and state allocations for resource facilitation, informal supports, prevocational training, and social and recreation events. Most recently, the state legislature budgeted for a Return to Work program, additional funds for resource facilitation, and a change in the state definition of brain injury.

This Needs Assessment Report in Context

Clearly this needs assessment does not, and should not, stand alone as the definitive perspective on current views and information about services, supports and systems for people with brain injury in our state. There are numerous committed professionals, legislators, survivors, family members, advocates and service providers who have great expertise, knowledge and information to guide future decisions about how to address issues in our state. Thus it is important to know about a few resources that should be simultaneously referenced when doing strategic planning, legislation and discussions about the future for people with brain injury in ND.

2005 State Report. In 2005, the Center for Rural Health at the University of North Dakota produced a report entitled *Findings from the North Dakota Assessment of Traumatic Brain Injury Needs and Resources* (Muus, et al., 2005). This report details a statewide needs assessment conducted in 2004 and 2005 to assess the current needs and resources for brain injury in ND. The authors employed four questionnaires for data gathering. These questionnaires were designed for (1) individuals with TBI, (2) these individuals’ caregivers, (3) TBI agency representatives, and (4) TBI service providers. In addition, they conducted numerous focus groups throughout the state. The report details the findings and provides a draft plan of action. The primary action areas included Sustainability; Education and Awareness; Enhancement of Services; Supports; and Tribal Issues. A comparative of the 2005 study results and this needs assessment’s findings are presented later in this report. NDCPD staff would suggest using the 2005 report as one of the baseline components of the full assessment of ND's status of services and supports for people with brain injury.

ND Legislative History on Brain Injury. An important review of ND's legislative and agency work on brain injury is found at the ND Brain Injury Network site (https://www.ndbin.org/brain-info). There is an outline of activity from 1987 through 2015 which shows the initiation of various programs, features and systems including lead agency designations, previous state plans, and the initiation and dissolution of a state brain injury registry.

National Association of State Head Injury Administration (NASHIA). The NASHIA is an important resource for groups trying to gain an understanding of national and state-by-state work in brain injury (http://www.nashia.org/). The website contains contact information for every state head injury administrator, an organizational strategic plan which includes a national policy plan, national and state conference notices, training materials, and many reports on state and national priorities. (Of particular interest here may be NASHIA's report on funding state TBI programs through trust funds, see http://www.nashia.org/StateIssues.asp).

Centers for Disease Control and Prevention (CDC). The national CDC has a specific site on traumatic brain injury in its Injury Prevention and Control Center and includes training materials, statistics and data, and other information useful to individuals seeking to understand brain injury (see http://www.cdc.gov/TraumaticBrainInjury/index.html). Of particular importance is a recent CDC report to Congress on traumatic brain injury. The report outlines national gaps and future goals in research and in understanding the nature and extent of brain injury in the United States. An additional important CDC report examines TBI in the prison population.

Defining Brain Injury

There are several definitions used in the medical and rehabilitation field regarding brain injury. These include traumatic brain injury, brain injury, head trauma, closed head injury and many others. The most common term in the literature is traumatic brain injury (TBI) and is defined by the CDC as: *"…a disruption in the normal function of the brain that can be caused by a bump, blow, or jolt to the head or a penetrating head injury" (Marr & Coronado, 2004, as cited on p. 15 of CDC, 2015.).* However for the purposes of this needs assessment, a different definition was used to guide the data collection activities. This definition takes into account both traumatic and non-traumatic injuries (based on the recently changed ND definition of brain injury) and includes stroke.

Brain Injury (BI) is defined as an injury to the brain which occurs after birth and which is acquired through traumatic or non-traumatic insults. The state definition does not include hereditary, congenital, non-traumatic encephalopathy, non-traumatic aneurysm, stroke, or degenerative brain disorders or injuries induced by birth trauma. However, for purposes of this needs assessment non-traumatic aneurysm and stroke shall be included.

Purpose of this Needs Assessment

The North Dakota Department of Human Services, Behavioral Health Division, contracted with the ND Center for Persons with Disabilities to "research and conduct a state-wide brain injury needs assessment to describe the current brain injury population, incident rates, and prevalence rates; identify the impact of brain injury and service needs of individuals with brain injury and their families; and to describe existing services, service continuum, and supports."

The purpose was to obtain a written report of the current landscape of brain injury occurrence and status in North Dakota. The report will be made available to the ND Brain Injury Advisory Council as part of its strategic planning efforts, and to others as determined by the ND Department of Human Services.

Design of the Brain Injury Needs Assessment

NDCPD designed, with input and assistance from Stacie Dailey and the ND Brain Injury Advisory Council, a four pronged approach, and accompanying instruments, for the needs assessment. This included conducting a program and services review, gathering data via questionnaires of various target populations, conducting focus groups around the state, and gathering personal stories of ND citizens who have survived brain injuries (see Figure 1). Each of the approaches is described more fully in the following pages.

Figure 1. Four Pronged Approach for Data Collection for this Needs Assessment

Program and Services Review

The program and services review included two main components, a review of national and other state initiatives for services and supports for brain injury, and then a review and description of ND's programs, services and supports. This second process included reviews of websites and printed materials, along with interviews and discussions with various people either through referral or direct contact.

Questionnaires

For this needs assessment, NDCPD staff developed four questionnaires, each designed for specific populations (see Table 1). One questionnaire was designed for brain injury survivors while another was designed for family caregivers. Two other questionnaires were developed for agency-related staff. One was designed for agency-employed caregivers and another for representatives from agencies connected to services and supports for people with brain injury. The survivor and family caregiver questionnaires were distributed in paper/hard copy format, while the agency-related questionnaires were distributed via a Survey Monkey link. Copies of the questionnaires are shown in the Appendix.

Table 1. Purposes of the Questionnaires

Family Caregiver Questionnaire: Find out the relationship of the family member to whom they provide services; find out characteristics about the person they serve; find out about training the caregiver has received; find out about the time commitment they have in providing services; Find their perceptions on barriers/problems for people with BI; Find their thoughts on caregiver support networks; Find their perceptions on biggest/largest problems; Find their perceptions about how to address those barriers **Survivor Questionnaire:** Find out the characteristics of the survivor; Find out about health insurance and health status/related conditions; Find out needs for support/supervision; find out their service needs; Find out their living arrangements; Find out the constellation of services they need, they get, and the quality of the services; Find out about behavioral health conditions they experience and the impact of those conditions; Find their perceptions on barriers/problems for people with BI; Find their thoughts on workforce training; Find their perceptions on biggest/largest problems; Find their perceptions about how to address those barriers

Agency questionnaire: Find out the number of people with BI they serve; Find out the constellation of services they provide; Find their perceptions on barriers/problems for people with BI; Find their thoughts on workforce training; Find their perceptions on biggest/largest problems; Find their perceptions about how to address those barriers

Agency-Based Direct Service Provider Questionnaire: Find out the number of people with BI these providers serve; find out the constellation of direct services they provide; Find their perceptions on barriers/problems for people with BI; Find their thoughts on workforce training; Find their perceptions on biggest/largest problems; Find their perceptions about how to address those barriers

Focus Groups

NDCPD staff conducted multiple focus groups across the state with stakeholders. These included survivors of brain injury, family members, agency representatives, direct service providers, and others who were interested in the process. The purpose was to get a narrative (qualitative) data set that allowed constituents to talk about what was working, and what was not working in the state's system of services and supports for people with brain injury.

Personal Stories

One way to better understand the impact of brain injury on individuals is to listen to their stories (Mason, 2009). NDCPD staff conducted personal interviews with 8 individual survivors from across the state. These individuals graciously gave of their time and their personal experiences to explain what it is like to live in ND with a brain injury.

The data from across these four facets of the needs assessment encompassed the results for this report. Data were analyzed using descriptive statistical methods along with appropriate qualitative data analyses as appropriate to result in summary data findings.

Counting North Dakota Citizens who Experience Brain Injury

One component for this project was to determine incidence rates and prevalence rates of brain injury in North Dakota. This contracted component was designed so that various state constituents might have a better understanding about the nature of and number of individuals in our state who experience brain injury. NDCPD undertook many efforts to gather information to determine both incidence and prevalence rates of brain injury in North Dakota. We must tell the readers up front that we were unable to determine definitive data in either incidence or prevalence. However, we do provide multiple data pieces that do two things. They tell us about the complexity of counting people with brain injury, and they tell us about the numerous ways that people are approaching data collection within our state.

First, the multiple data pieces point out the complexity of counting an extremely varied and complex condition. Definitions differ. National data sources generally use the term Traumatic Brain Injury which is an acquired brain injury from sudden trauma (National Institute of Neurological Disorders and Stroke, 2016). The definition used for this needs assessment uses the term brain injury from both traumatic and non-traumatic causes (see page 11) and includes stroke. Degrees of the condition differ. There are varying degrees of brain injury and its causes and while some are counted quite regularly (e.g., cause of brain injury at hospitalization), other individuals with possible brain injury are not counted at all (e.g., those who experience concussive events that might lead to brain injury yet never access medical care or specialized services).

Second, the multiple data pieces tell us about the ways that state and private agencies approach data collection. Some programs approach data collection as the gathering of newly screened or diagnosed or treated or reported conditions within a year (e.g., incidence figures on county eligibility screenings). Other programs report all current numbers of individuals receiving services with that diagnosed condition regardless of when it was first recorded (e.g., DPI data on children with TBI served in schools).

To better understand some of the numbers and data presented in this report, one needs to understand the terms incidence and prevalence. An *incidence rate* is a probability of occurrence of a condition in a population within a specified period of time. It is sometimes loosely expressed simply as the number of new cases during some time period; for example, the American Cancer Society estimates that about 246,660 new cases of invasive breast cancer will be diagnosed in women in 2016. *Prevalence,* on the other hand, is the proportion of cases in the population. For example, the CDC reports the prevalence of autism is 1 in 68 people in the US.

National data and extrapolation to North Dakota. One method to determine the number of people within a given geographical area at a particular time is to conduct a census. Neither ND nor the US has census data on brain injury (as defined for this needs assessment) or even for traumatic brain injury (see CDC, 2015). Even if we had those data, there may be varying factors that make the numbers somewhat suspect. For example, the presence or absence of qualified diagnosing staff may inflate or deflate the data. So what do the national data tell us about North Dakota?

Traumatic Brain Injury. The national CDC data focus on TBI, not brain injury as defined for this needs assessment. So for TBI, the CDC estimates that 1.7 million TBIs occur annually in the U.S. (2002-6) and about a half million were children (0-14 years). This is an incidence number.

The CDC’s traditional method of reporting relies on hospital data to determine incidence (see Figure 2). These data show the total combined rates for traumatic brain injury (TBI)-related emergency department (ED) visits, hospitalizations and deaths. These data have increased over the past decade. Total combined rates of TBI-related hospitalizations, ED visits, and deaths climbed slowly from a rate of 521.0 per 100,000 in 2001 to 615.7 per 100,000 in 2005. The rates then dipped to 595.1 per 100,000 in 2006 and 566.7 per 100,000 in 2007. The rates then spiked sharply in 2008 and continued to climb through 2010 to a rate of 823.7 per 100,000.

In comparison to ED visits, the overall rates of TBI-related hospitalizations remained relatively stable changing from 82.7 per 100,000 in 2001 to 91.7 per 100,000 in 2010. TBI-related deaths also decreased slightly over time from 18.5 per 100,000 in 2001 to 17.1 per 100,000 in 2010. Note that the axis scale for TBI-related deaths appears to the right of the chart and differs from TBI-related hospitalizations and ED visits.

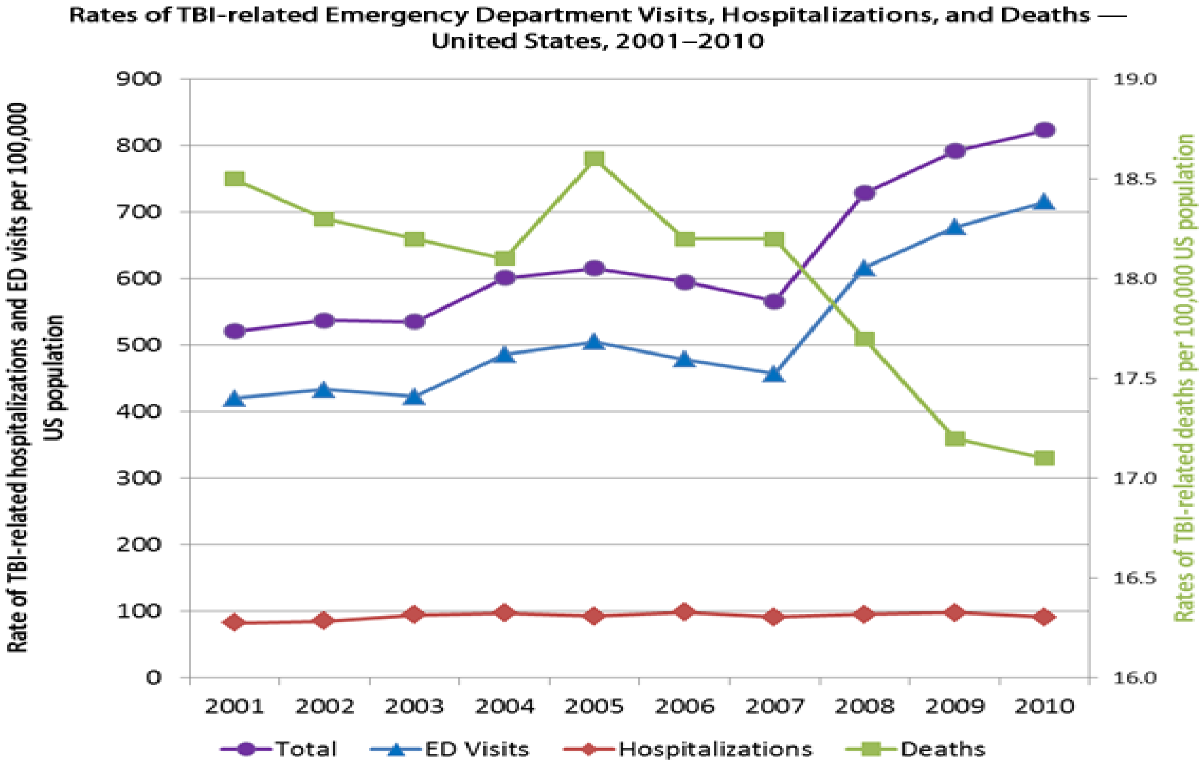


Figure 2. Data obtained from the CDC national website on traumatic brain injury.

The CDC also uses national prevalence estimates of TBI based on studies done in South Carolina and Colorado in 2008 and 1999 (CDC, 2015). Those data (some 17 years old and others at least 8 years old) suggest that, at those times, there were between 3.2 million and 5.3 million citizens with TBI in the US. (CDC, 2015, p. 19). If one were to use these figures and extrapolate to ND's current population, the estimated prevalence would be between 8,872 and 14,695 people with TBI in our state in 2015.

TBI in Prisons and Jails. The CDC released a report on what is known about TBI in prisons and jails in the US. (see http://www.cdc.gov/traumaticbraininjury/pdf/Prisoner_TBI_Prof-a.pdf). This report suggests that there are great numbers of prisoners who have had head injuries or TBI. The CDC suggests that 25% to 87% of the jailed population (depending on the cited studies) report having a head injury or TBI. That is compared to a generally accepted number of 8.5% in the general population. The report goes on to state that prisoners with TBI experience many associated conditions (e.g., severe depression, anxiety, anger control problems) and may not full access to TBI treatment protocols. The CDC recommends: further research to determine how TBI should be treated/managed in prisons; increased screening to identify TBI and associated conditions; train community re-entry staff to address potential TBI issues at transition and discharge; and better data collection to determine the actual number of prisoners who have TBI.

Stroke. The US National Center for Health Statistics shows that approximately 6.3 million US adults have had a stroke. The Center suggests that this is about 2.4% of all adults in the country (http://ftp.cdc.gov/pub/Health_Statistics/NCHS/NHIS/SHS/2014_SHS_Table_A-1.pdf). Using that percentage and other data from the US Census Bureau, we would extrapolate that, with 756,927 citizens in ND and 584,348 of them being adults, that one could estimate that there are about 14,024 adults in ND who have had a stroke. This would be a prevalence number. (Later we will see what the incidence numbers are from the ND Stroke Registry).

North Dakota Data. There are two broad categories within the definition of brain injury used for this needs assessment; brain injury and stroke. We used any available sources of information to determine either incidence or prevalence numbers for our state.

Brain Injury. ND has a state trauma registry to allow one to access traumatic brain injury numbers. The trauma registry in ND is part of the North Dakota Department of Health, Division of EMS and Trauma. The department has established minimum data elements and all hospitals must report data. Lindsey Narloch, Trauma Data Manager, provided the following information from the Trauma registry, from 2014 and 2015 (see Figure 3). These data show that falls and motor vehicle accidents were the most common causes of traumatic brain injury over these two years.

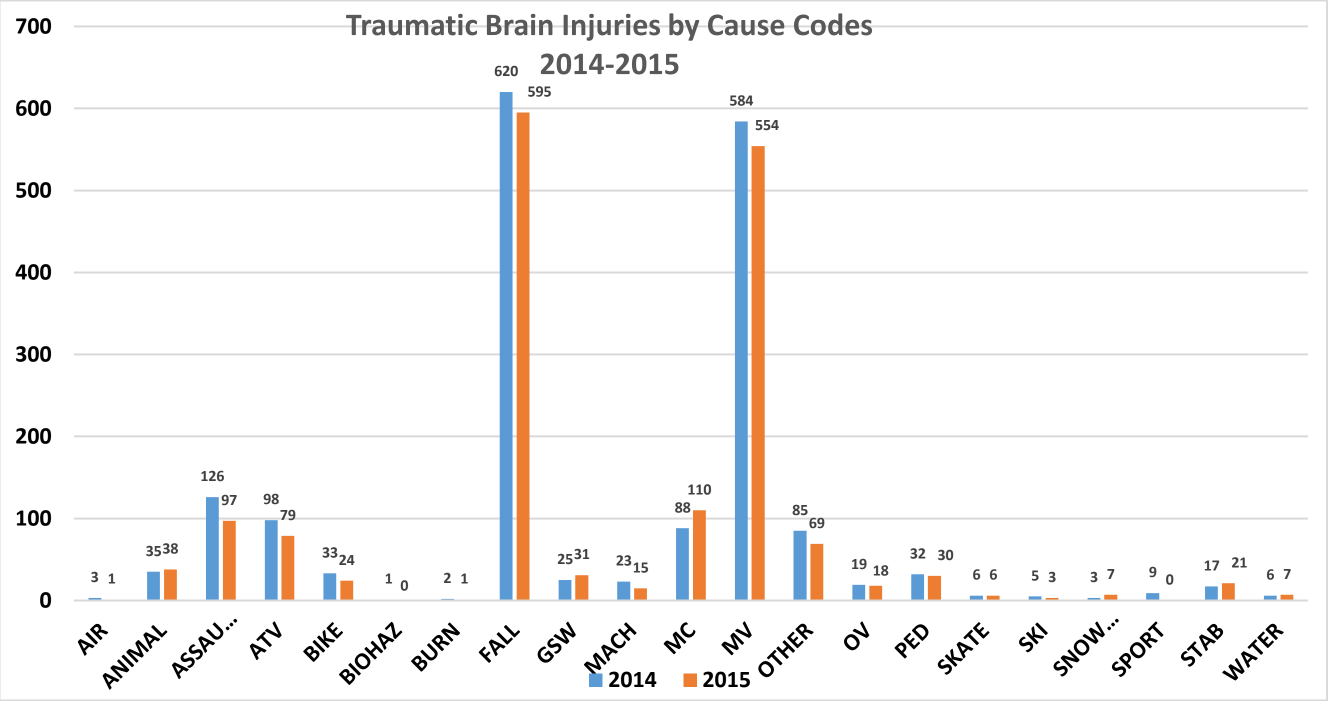
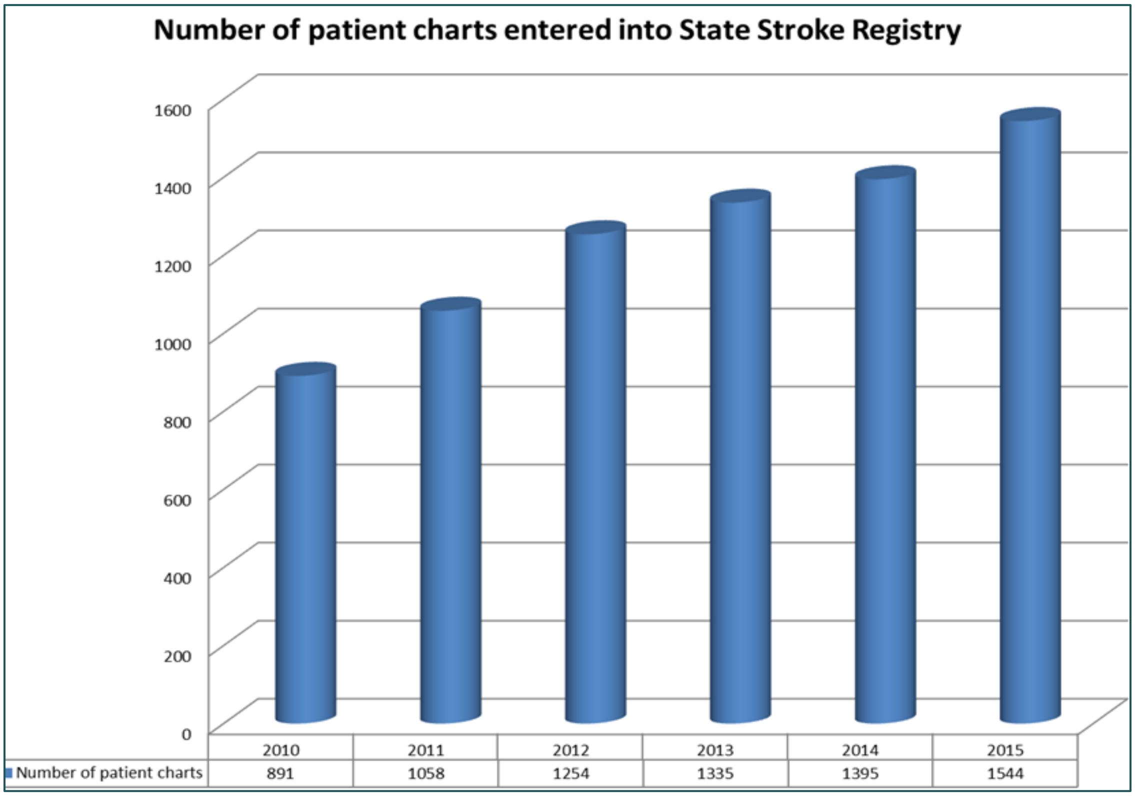


Figure 3. Traumatic brain injuries by cause for 2014 for ND.

***Key:** Air-Skydiving, Airplane; Animal: any attack from an animal resulting in Head Injury; Assault: Head Injury from fight, altercation, ATV: 3,4,5,6,7,or 8 wheels; Bike: (2 wheel); Biohazard: Chemical ingestion; Burn: burn; Fall: trips, hitting head; GSW: Gunshot wound; Mach: Machinery; MC: motor cycle; MV: motor vehicle; Other: anything that does not fall into one of these categories; OV: other vehicle (go carts), rodeo events, horse riding; Ped: pedestrian; Skate: ice, roller, skateboard, wakeboard; Ski: snow, cross country waterski; Snowmobile: snow machine, snowmobile; Sport: any school sport related injury to head; Stab: stabbing with any object to the head; Water: transportation of water craft or activity.*

Stroke. The state Stroke Registry is managed by the Heart Disease and Stroke Prevention Program, under the Division of EMS & Trauma, ND Department of Health. Shila Thorson is the Stroke/Cardiac System Coordinator. ND's stroke registry is not a mandated process and is dependent on hospitals entering data into the system. In general the larger hospitals are more consistent in this data entry. It is not clear whether the hospital systems account for duplications. Critical access hospitals are required to report per joint commission accreditation purposes (Thorson, personal communication, 2016). Figure 4 shows the data entered into the stroke registry from 2010 through 2015. These incidence figures show a linear increase over time.



	2010	2011	2012	2013	2014	2015
■ Number of patient charts	891	1058	1254	1335	1395	1544

Figure 4. Stroke registry entries from 2010 through 2015.

Sports head injuries. There has been significant national and state attention on sport-related head injuries. Thus NDCPD staff contact representatives from colleges/universities and the ND State High School Activities Association to gather information on sport injuries. NDCPD staff met with Rick Hedberg, MSU Athletic Director and their trainer, Robyn Gust. The focus at the NCAA schools is on the head injury protocol (doing the right things for their students to safely return them to school). They reported that they have no requirements to report data to any central source. Robyn indicated that Division I may have more stringent reporting requirements and they may report something to a national data base, but was unsure if this was the case.

Brenda Schell from the ND High School Athletic Association provided the most recent school Concussion Surveys. Reporting these data is not mandated, but rather is the result of a survey done annually by the NDHSAA. The NDHSAA does get good cooperation, however, and the data are broken down for each sport. See Table 2 for the two year data on concussions by sport. These have been arranged by the highest to lowest number of concussions in the 2014/15 year. The largest number of concussions were reported for football, with boys and girls basketball, volleyball, hockey and wrestling having significant numbers of reports. Of the top 10 reasons, the sports are split nearly evenly by gender. Overall, the total number of concussions in ND school sports increased by 81 within a year.

*ND Screening for brain injury***.** While, North Dakota does not currently have a registry system for individuals with brain injury, the state does a screening process at the regional human service centers to determine how many individuals are coming through the system. The screenings are conducted by the assigned Case Manager at the Human Service Center and the results are reported to the State. They continue to track this information with the intent that

Table 2. 2014/14 and 2014/15 NDHSAA Concussion Survey Data

Sport	Schools reporting 2013-2014	Concussions reported 2013-2014	Schools reporting 2014-2015	Concussions reported 2014-2015
Boys Football	105	273	130	273
Boys Basketball	113	49	133	87
Girls Basketball	113	64	131	71
Boys Hockey	20	33	30	49
Girls Volleyball	106	49	130	48
Boys Wrestling	64	44	75	37
Girls Hockey	13	13	19	23
Cheerleading (all)	46	21	49	20
Boys Soccer	14	12	15	18
Girls Soccer	12	11	19	17
Girls Gymnastics	9	5	19	10
Girls Softball	42	11	60	9
Girls Track & Field	108	5	129	8
Boys Swimming & Diving	12	5	19	6
Girls Swimming & Diving	11	7	20	5
Boys Baseball	79	4	98	4
Boys Track & Field	107	1	129	3
Girls Tennis	14	2	21	1
Boys Tennis	13	1	19	1
Boys Golf	90	1	109	1
Girls Cross Country	60	0	78	1
Girls Golf (A)	29	0	28	1
Boys Cross Country	59	1	80	0
Girls Golf (B)	77	0	87	0
Total Concussions		**612**		**693**

services may be needed in the future. Lauren Sauer from the Department of Human Services reports a total of 6,890 individuals were screened through Human Service Centers across ND from July, 2013- June, 2014. Of this total 2,468 TBI screens indicated Possible TBI to Severe TBI. This is 35.8% of the total screens completed at ND Department of Human Service Centers. Table 3 shows the number of individuals screened and the possibility of TBI.

Table 3. ND TBI screening data for 2013-2014 fiscal year.

Number and Percent of Individuals by TBI Worst Injury Score.

Worst Injury Score	# of Individuals	% of Individuals
1 - Improbable TBI	4,422	64.2%
2 - Possible TBI	662	9.6%
3 - Mild TBI	1,346	19.5%
4 - Moderate TBI	314	4.6%
5 - Severe TBI	146	2.1%
Total	6,890	100%

Students with TBI in the schools. The North Dakota Department of Public Instruction (DPI), Office of Special Education conducts an annual child count by disability category each December. This federally mandated child count collects information from ND’s schools regarding the number of children enrolled in schools and receiving services in special education. The count is done using the primary disability diagnosis of the child and covers the age range from 3 through 21 years. Figure 5 shows the numbers of students with the primary disability label of Traumatic Brain Injury (the federal special education category title) in the state from December 1999 through December 2015. While there was a dip in the data from 2006 through 2010, the numbers suggest a relatively stable rise from January 1999 to January 2015. It should be noted that, in some instances, students may have a secondary disability label, and this could include traumatic brain injury. These data were not collected for this report. (Data from https://www.nd.gov/dpi/uploads/84/19992015ChildCountComparisonbydisability.pdf)

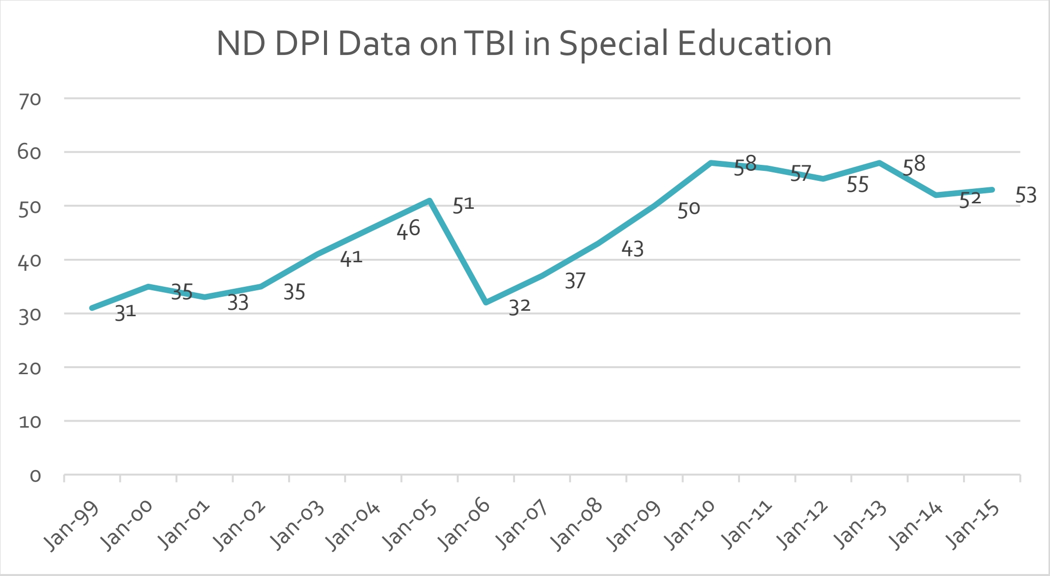


Figure 5. TBI Enrollment in Public Schools in North Dakota 1999 – 2015.

Summary on Incidence and Prevalence of Brain Injury in ND

We don’t know exactly how many people are living with BI or stroke in North Dakota. Making sense of the available numbers is difficult. ND has no census-oriented brain registry so it is impossible to determine any precise numbers of citizens who experience the condition. However, this is not an unusual or unique problem in the US. In fact, the CDC uses hospital emergency room, hospitalization and death report data to estimate incidence of brain injury in the county. ND has a variety of data sets that capture, to some extent, some pieces of the puzzle in determining the incidence and/or prevalence of brain injury in our state. However, comparisons to other states is not likely due to varying data collection methods, and especially due to definitional differences.

Perhaps our best estimates are to use extrapolations from the national data. If we use the CDC estimates (extrapolated to ND) we might reasonably expect to have between 8,872 and 14,695 people with TBI in our state. We can then add the extrapolated numbers of possible ND citizens living with stroke (14,024) to get a total of between 22,896 and 28,719 people in ND who could fall with our definition of brain injury for this report. This would be between 3.02% to 3.79% of our current state population.

We should mention that there also appear to be increasing incidence numbers in our state reports and registries. In most cases these are actual raw numbers and are not recorded as percentages of the population. Thus, as population rises it might be reasonable to expect that the raw counts would also rise. However, we have no information to indicate that this is or is not the only reason for the recorded increases.

Needs Assessment Data

Overview of Systems, Services and Supports in Other States

One component of the needs assessment contract was to gather general information on how other states were approaching data collection, services provision and general outcomes evaluation for persons with brain injury. NDCPD staff conducted literature reviews, made phone calls to various other states' officials, and examined online reports and websites. NDCPD staff gathered information and ideas on how these states approach brain injury supports and services, and how their service systems are designed. These states were selected from referrals and ideas from Advisory Council members, reviews of literature (especially CDC information) and from the three contiguous states. The information is not meant to be comprehensive or fully cover all aspects of state systems, which are often complex. Rather this information is meant to give some type of overview should others chose to follow up on various topics of interest.

California. NDCPD staff spoke with Karen Jacoby of the California Department of Public Health. She stated that the state of California receives funds from State Grant and Trust Funds that are received from traffic violations to support work on TBI. They have five legislative mandates to provide services for Community Living, Supported Living, Vocational, Professional, and Information and Referral. The state works with seven non-profit organizations that provide services in the area of medical model, psycho social, independent living centers, TBI specific behavior program, and day programming. California also has independent living centers for individuals with all disabilities.

Jacoby stated that the California Department of Public Health Epicenter (Injury Data Online) has data on hospital and emergency room patients with non-fatal TBIs, has incidence of TBI-related emergency visits, hospitalizations, and deaths (by sex, by age group). These data correlate precisely with the CDC national report data. Further, Jacoby said statistics for brain injury is an ongoing discussion in California. They, like most other states, have no central brain injury registry, but instead have bits and pieces of data all over the place, depending on which program collected it.

Colorado. NDCPD staff spoke with two individuals in Colorado, Gavin Atwood, CEO of the Brain Injury Alliance of Colorado and Judy Dettmer, Program Director of the Colorado Brain Injury Program. The Brain Injury Program in Colorado is part of the Colorado Department of Human Services, Division of Vocational Rehabilitation. Funds for services, education and research are generated via the Colorado Traumatic Brain Injury Trust Fund. The fund was established in 2002 by the Colorado legislature to provide state wide care coordination and services to children and adults with traumatic brain injury, sponsor educational programs about TBI and fund TBI research. Funds for the Colorado TBI Trust Fund come from surcharges on traffic ticket convictions for speeding, DUI, DWAI and the children’s helmet law.

In Colorado, surveillance is mandated and public hospitals are required to report all brain injuries to the state. However, the Brain Injury Alliance of Colorado (BIAC) is not privy to this hospital association data even though, BIAC is the “go-to” organization in the state. Hospitals refer their TBI patients to them. BIAC focuses on educating hospitals to make sure they are aware of their services. They call this “systemizing” – a system that ensures that BI patients get referred to BIAC.

Judy Dettmer said they have an important public/private relationship where the state Department of Human Services and BIAC work well together. They also have a Health Resources and Services Administration (HRSA) grant that has created a screening and identification process with their criminal justice system. Presently Colorado has a brain injury waiver with 320 slots available. This number is increasing due to activity to remove barriers to referral and services

Colorado's funding for brain injury is diverse and includes grants, fund-raising activity, and contracts with the total amount about one million dollars annually. They also have a trust fund that funds case management services. The Human Service Center does provide the Case Management services for individuals with brain injury. Housing is provided by five agencies that have group homes for individuals with brain injury.

Minnesota. NDCPD staff spoke with Mark Kinde, Injury and Violence Prevention Program Director at the Minnesota Department of Health. Minnesota has a Brain Injury Waiver that provides funding for home and community-based services for children and adults who have an acquired or traumatic brain injury. People may receive waiver services in their home, in a biological or adoptive family's home, a relative's home, a family foster care home, a corporate foster care home, a board and lodging facility, or in an assisted living facility. If married, a person may receive waiver services while living at home with his or her spouse.

Minnesota Department of Health has MIDAS (Minnesota Injury Data Access System) as its primary data collection system. MIDAS is primarily used to track injury and violence data, but includes TBI (not stroke and aneurism). Data are available on "hospital-treated injuries" for TBI much like the information found on the national CDC site. Kinde stated that the state "traumatic brain injury/spinal cord registry" is forthcoming. MN also uses the state vital statistics department to get TBI numbers such as incidence by county, age group, cause, impact on patient, mortality rates, and recommendations for prevention.

South Dakota. NDCPD staff interviewed Doris Schumacher, President of the Brain Injury Alliance of SD. The SD BI Alliance "*is a nonprofit statewide organization of individuals,* *families and organizations who educate the public, advocate to improve the quality of life for people with brain injury and their families and support programs to help prevent brain injury"(from* http://braininjurysd.org/index.html *).* The Alliance meets quarterly and they have no funding nor paid employees.

Schumacher told of her son, who had an accident in Indiana. He was sent back to a Sioux Falls hospital initially. Then, with help from a hospital social worker, he was sent to Omaha, NB for rehabilitation for about a year. They have been a primary source of support since then. Apparently, most brain injury resource pamphlets provided by SD hospitals are from other states.

Other work in South Dakota includes: a work group through State Center for Disabilities (Sanford Hospital); Independent Living Choices which is funded by both grants from the Federal Department of Education and by local contributions. They will provide services right in the home; four support groups in the 4 major SD cities. These are not run by the state; Lifescape – which was formed in SD (2014) by combining SD Children's Care Hospital and SD Achieve. They are an independent non-profit (Rapid City and Sioux Falls). Their mission is to empower children and adults with disabilities. Brain injury resources are available if the BI was acquired before age of 22. Schumacher also noted that housing for those in transition was "an elusive ordeal".

Montana. NDCPD staff spoke with Kristen Morgan, Director for the Brain injury Alliance of MT. The BI Alliance provides resources, referrals, and advocacy services. The Alliance manages a BI Helpline (a 24-month follow-up program). This program has funding in the state budget. It helps people prepare various strategies to deal with their needs. It uses a database (obtained from MN) that tracks participant's calls and includes self-assessment tools. The database includes things like; 1) what did we work on during last call, 2) what were the goals, etc. It can generate reports that can be used to support requests for funding and to justify program activity. Colorado also uses this database.

Montana has no trauma registry. They must network with hospitals to get data and to provide education for both survivors and hospital professionals. The focus is on making sure people don't fall through the gaps. The state is working on establishing a brain injury registry.

The major challenge in Montana is its rural nature. Providers, even if payment is available, are often not willing to travel the distances required to serve rural residents. There are not many residential options, especially in rural area; so, most BI survivors end up in nursing homes, where the services not always appropriate.

Summary of findings from state systems reviews. It appears that these states are using various means to organize and provide services, conduct information dissemination and gather statewide data on the extent of needs for persons with brain injury. It is interesting to note the varied methods that some states are using to fund these efforts. Some examples included traffic violation fees, children's helmet law fees, state trust funds, a statewide Medicaid waiver program, and grants. However, South Dakota's Brain Injury Alliance receives no funding.

The states' data collection processes are also in various stages. For example, California collects data that matches the CDC reported categories of hospitalizations, ER visits, etc., but has no mandated registry. Colorado has mandated surveillance reporting by hospitals, but those data may not be widely available. Minnesota uses an injury database to track TBI but it is not necessarily sufficient for all their needs and is thus considering a combined TBI and spinal cord injury registry. Another relevant feature for consideration is that all of these states are using the definition for traumatic brain injury, similar to ND's previous definition and in congruence with the CDC's definition and data.

Overview of Systems, Supports, and Services in North Dakota

NDCPD staff examined literature from our state, held interviews and conversations with various representatives of state agencies, private agencies, and other individuals, and reviewed documents and websites to develop a picture of ND's systems, services, programs and offerings for individuals with brain injury. This was done without consideration of the funding source. Thus this overview includes state-funded, non-funded, fee-for-service and other funded services and systems. While every attempt was made to include any and all programs and services, the staff realize that it is possible they may have missed some relevant programs.

ND Brain Injury Advisory Council. The NDBIN website describes the Council as follows: *The North Dakota Brain Injury Advisory Council advises the North Dakota Department of Human Services and was established in 2007. The council began as a forum for stakeholders to discuss brain injury resources in North Dakota. It has grown into a group that works on developing outreach, education, services, and ongoing system improvement in the state to meet the needs of all brain injury survivors. The council is currently working on establishing bylaws and formalizing membership. All Advisory Council meetings are open to the public.* (see https://www.ndbin.org/about-us/advisory-council). Previous meeting minutes and the proposed Bylaws are displayed at the NDBIN website.

ND Brain Injury Network (NDBIN). NDBIN is operated out of the University of North Dakota, Center for Rural Health, through a contract with the ND Department of Human Services. The program website at http://ndbin.org states that "*the purpose of the North Dakota Brain Injury Network is to provide information and support to individuals with brain injury and family members, and to assist them with navigating the service system. We are committed to increasing the public's awareness about brain injury. Our knowledgeable staff can provide outreach,* *education, and resource navigation.*" Services include problem solving and emotional support, information and resource dissemination, assistance in identification and access of programs and benefits, outreach training and education, and referral information and assistance.

Programs and Services Administered through Aging Services Division – The North Dakota Department of Human Services, Aging Services Division, administers programs and services that enhance the ability of older individuals and individuals with physical disabilities to maintain as much independence as possible and remain in their own homes and communities.

Federal funding through the Older Americans Act provides the foundation for programs and services that enable individuals to remain safe, active, and healthy in their own homes and communities. The federal funds are allocated annually by Congress. Additional funding for services includes state funds that are appropriated biennially by the state legislature. Programs and services include: Information and Assistance, Options Counseling, Assistive Safety Devices, Family Caregiver Support Program, Health Maintenance, Legal Assistance, Congregate and Home-Delivered Meals, Senior Companion, Vulnerable Adult Protective Services, and Senior Community Service Employment. State-funded services include the Dementia Care Services Program, Guardianship Establishment Program, and Telecommunications Equipment Distribution Program.

The 1915 (c) Medicaid Home and Community-Based Services (HCBS) waiver was created to offer a variety of services and support that allow individuals to stay in their homes instead of getting care in a nursing home. Services include: Adult Day Care, Adult Foster Care, Adult Residential Services, Case Management, Chore Service, Emergency Response System, Environmental Modification, Extended Personal Care/Nurse Education, Family Personal Care, Home-Delivered Meals, Homemaker Services, Non-Medical Transportation, Respite Care, Specialized Equipment, Supervision, Supported Employment, and Transitional Living Services. The 1915 (c) Medicaid Technology Dependent waiver provides attendant care, case management, non-medical transportation, and specialized equipment to allow individuals who are ventilator-dependent remain in their own homes and communities.

The Medicaid State Plan – Personal Care Services (MSP-PC) helps individuals with daily living activities such as bathing, dressing, transferring, toileting, preparing meals, housework, and laundry so they can continue to live in their homes and communities.

The Service Payments for the Elderly and Disabled (SPED) and Expanded Service Payments for the Elderly and Disabled (Ex-SPED) are state-funded programs that complement other programs and services that allow individuals to stay in their homes instead of getting care in a nursing home. Services include: Adult Day Care, Adult Foster Care, Case Management, Chore Service, Emergency Response System, Environmental Modification, Extended Personal Care/Nurse Education (SPED only), Family Home Care, Home-Delivered Meals, Homemaker Services, Non-Medical Transportation, Respite Care, and Specialized Equipment

Hospital Services. A frequently needed set of services for individuals with brain injury are provided by hospitals. Often this occurs in emergency room care and trauma treatment. North Dakota provides different levels of healthcare for brain injury based on standards verified by the American College of Surgeons. There are 45 hospitals throughout ND with varying designations of Trauma Level Hospitals. There are five levels of trauma care designation, each requiring minimal sets of programs, services, facilities and staff for the particular designation. The most sophisticated designation is Level I with the lowest designation (regarding trauma) is Level V.

Currently there are no Level I Trauma centers in ND, which provide the highest level of surgical care to trauma patients. A Level I trauma center has research requirements related to trauma and is a leader in trauma education, injury prevention and is a referral resource for communities in nearby regions.

ND has six Level II trauma centers, which function at nearly the same level as Level I facility but without the required research component. They include Altru, Grand Forks; Sanford, Fargo; Essentia, Fargo; Sanford, Bismarck; CHI St. A’s, Bismarck; Trinity, Minot. These hospitals attempt to assure 24 hours a day coverage of various surgical specialists. Level II Trauma Medical Directors and Coordinators within ND help in the designation process for the Level IV and V facilities in the state, and providing follow-up on patient care outcomes. There are currently no Level III Trauma Centers in ND, which do not have the full availability of physician specialists available, but do have resources for emergency resuscitation, surgery and intensive care of most trauma patients.

ND has eight facilities that have Level IV trauma designation. These hospitals are Dickinson, Bowman, Hettinger, Fort Yates, Mobridge, SD, Jamestown, Williston, and Cavalier and provide evaluation, stabilization and diagnostics for trauma along with the presence of a physician for 24 hour care for the injured patient.

The majority of ND’s hospitals (30 of them) are at trauma Level V. These facilities are designated by the Department of Health with assistance of staff from the Level II facilities. A Level V facility provides evaluation, stabilization and appropriate diagnostics for each trauma patient presenting to their emergency room. When appropriate, these patients must be transferred to a higher level of care center. An ATLS certified physician, physician’s assistant or nurse practitioner must be available 24 hours a day to care for injured patients.

Residential Services/Transitional Services. North Dakota has 34 provider agencies that serve individuals with Developmental Disabilities. In some cases, these programs provide individualized services for persons who may experience brain injury. However, the individual generally must have a primary diagnosis of intellectual disability and thus the brain injury is secondary. The tracking of persons with brain injury within these provider programs is not systematic nor easily accessible without contacting individual programs and reviewing individual client files. However, some of these providers have developed service programs specifically for persons with brain injury. These include HIT (Dakota Alpha and Dakota Pointe), in Mandan and Open Door Center (HI Soaring Eagle Ranch) in Valley City.

Dakota Alpha. This is a 20-bed residential facility serving individuals with brain injuries or physical disabilities. They have 9 beds licensed for individuals needing long-term placement, and 11 beds licensed for individuals needing transitional rehabilitation services. Transitional services mean the length of stay is limited and usually lasts between two months and two years. Dakota Alpha offers physical, occupational, and speech therapies, independent living skills training, cooking instruction, social services, recreational activities, and dietary services. Dakota Alpha is staffed 24 hours a day by licensed nursing personnel. Services are provided under the supervision of a consultant medical director, psychologist, psychiatrist and other community consultants. Dakota Alpha is operated by HIT Incorporated.

Dakota Pointe. This 10-bed residence provides adult residential services funded through the HCBS Medicaid Waiver. Adult residential services are home-like residential and support services provided to individuals who have a brain injury. Dakota Pointe is licensed as a basic care facility. With trained staff on duty 24 hours a day, the program is designed to provide structure and to creatively meet the needs of each individual by providing opportunities to achieve their highest level of independence. He/she will work on a variety of daily living skills which include cooking, cleaning, laundry, budgeting, personal hygiene, setting up transportation, and acquiring work or volunteer work. The individual will also work on self- esteem and attend support groups focusing on brain injuries. Dakota Pointe is operated by HIT Incorporated.

HI Soaring Eagle Ranch. HI Soaring Eagle is an 11 bed facility that is operated by the Open Door Center in Valley City that provides adult residential services funded through the HCBS Medicaid waiver. It is licensed as a basic care facility for individuals with a brain injury. This is a program that provides individuals with brain injury with services that foster emotional and physical growth, and enhance self-worth and personal development. The program also provides BI transitional and work experiences services. HI Soaring Eagle also assists individuals who live in their own home. Training for both programs is individually designed based on the person needs.

Community Options Inc. Another program (not necessarily designated as only a DD provider program) is Community Options. This agency is dedicated to supporting people, through individual choice, to live a lifestyle which gives dignity and respect. Community Options works with a variety of people, some with disabilities and some without. Community Options serves approximately 1,000 individuals throughout the state in locations such as Bismarck, Minot, Fargo, Grand Forks, Devils Lake, Jamestown, Fort Yates, Fort Totten and New Town. Community Options currently provides services to 65 individuals with brain injury.

Community Options began a pre-vocational initiative for persons with brain injury with two programs called Skill Smart and Work Start. The Skill Smart program focuses on building confidence, effective communication, following instructions, social skills, personal appearance and stamina. The Work Start Program is an evidence-based employment program working on resume writing, application submissions, interview assistance, on/off site job coaching, competitive employment and employer support and training.

Related Services Programs. There are a variety of related services and support programs throughout the state that include programming for persons with brain injury. Several of those are described here.

Progressive Therapy Associates. Progressive Therapy Associates in Fargo, ND, is a group of specialized experts in cognition and communications. Their speech language pathologists provide a customized approach to therapy that balances both education and support with compassion. Progressive Therapy Associates was established in November of 2010 by Janet Grove and Jodi Hedstrom to address a growing need in the Fargo area for specialized services that were not available. Progressive Therapy Associates provides services to individuals following Stroke, Traumatic Brain Injury, Concussion, and Berard Auditory Integration Training.

Onword Therapy. Onword Therapy is located in Fargo, ND and is operated by Speech-Language Pathologists who specialize in treatment of cognitive and communication disorders. As a private practice they offer personalized care and convenience that is impossible to duplicate in a large institutional setting. They are offer a variety of speech services including attention, memory, problem solving, organization, planning, reasoning, speed of processing, reading fluency, verbal fluency and executive functioning.

Rehab Vision. This program has been serving southwest North Dakota for more than 25 years. They offer Physical, Occupational and Speech Therapy. The therapists treat a variety of ailments and conditions in three Dickinson locations seeing patients at all stages of life-pediatric through geriatric. Rehab Vision offers services to Individuals following strokes, head injuries, muscular dystrophy, Parkinson's disease, multiple sclerosis, cerebral palsy, ALS (Lou Gehrig's disease) and developmental delays/disorders, focusing on helping achieve maximum recovery and quality of life.

Centers for Independent Living. There are four regional centers for independent living that provide services and supports to citizens in North Dakota. Each center has its own mission, but generally they provide supports for independent living for individuals with any disability, including a brain injury. Dakota Center for Independent Living in Bismarck and Dickinson, promotes full inclusion for people with disabilities by advocating for the reduction of architectural social and attitudinal barriers. It believes in self-determination for people with disabilities and creates the environment in which it is achieved. Freedom Resource Center in Fargo and Jamestown provides services that increase independence for people with disabilities, including, budgeting, meal planning, social skills, training, organizational skills, driver's test training and personal care. Independence Inc. located in Minot and Williston, works to empower people with disabilities to fully participate in the communities in which they live. They provide services to assist people in removing the barriers that keep them from being fully integrated. Services they provide include information and referral, individual advocacy, independent living skills training, systems advocacy, and peer mentoring. Options Resource Center, located in East Grand Forks, provides services to maximize the independence of individuals with disabilities. They offer a number of services some include accessibility assistance, advocacy services, benefits assistance, housing, information and referral, personal assistance and recreational groups.

Each independent living centers provides information and referral, direct service, and community education and outreach. Information and Referral includes the provision of information to persons with disabilities, service providers, and community members on disability and independent living topics and issues; and referral assistance to link individuals with appropriate organizations, services and resources. Direct Service is based on the structured process of service delivery which is provided on the one-to-one basis to persons with significant disabilities The Direct Service Program offers persons with disabilities more intense help in identifying and resolving barriers that hinder them from living at the highest level of independence possible. This program utilizes a host of services incorporating legislative mandates of service delivery. Community Education and Outreach is a program area that encompasses various services such as community education outreach activities and systems advocacy. Community education predominantly involves educating the general community of the issues and barriers affecting person with disabilities.

Support Groups. There are a variety of support groups for people with brain injury throughout ND. Some are operated specifically through a services program while others are more organically developed and operated by advocates and family members. The ND Brain Injury Network website lists the following support groups across ND.

- Brain Injury and Stroke Support Group, Sanford Health, Bismarck
- Sharon Lutheran Church, Brain Injury Support Group, Grand Forks
- Sanford Health Coordinated Treatment Center Support Group, Fargo
- Progressive Therapy Associates, Fargo
- Onward Together, Fargo
- Hawks Point, Dickinson
- Heart Springs – Community Healing Center, Bismarck

- Mental Health America of North Dakota (Depression, Stress and Anxiety Management), Fargo
- Mental Health America of NBD: Veterans' PTSD Family Support Group, Bismarck
- North Dakota Brain Injury Network Support Groups in Bismarck, Minot, Devils Lake

Social and recreational programming. North Dakota supports five programs for supported social and recreational activities for individuals with brain injury. These are operated on contracts from the ND Department of Human Services to HIT in Mandan, the Dakota Center for Independent Living in Bismarck, Onward Therapy in Fargo, Heartsprings in Fargo, and Sanford in Fargo. These contracts provide supplements to various support groups for integration into the community through attendance at community events and recreation activities.

Other provided information. During the needs assessment process, individuals were either referred to NDCPD staff, or directly contacted us to discuss needs, gaps, concerns and other information related to brain injury services and supports in North Dakota.

Pre-Employment and Return to Work Programming. The North Dakota Department of Human Services provided funding for two employment related programs for people with brain injury, a pre-vocational program and a return to work program. Both were funded via a state procurement process to Community Options. Skill Smart is a pre-vocational program designed to teach pre-employment skills such as social skills, work stamina and community integration. Work Start is the initial return to work program that provides workplace supports and job coaching that leads to longer-term employment. These programs were initially funded for 100 individuals, 50 in pre-vocational and 50 in return to work programming. In addition, legislative funds were provided to the Department of Human Services, Behavioral Health Division for up to 38 extended services placements for individuals with brain injury. The ND budget allocation process in the spring of 2016 has reduced funding for these programs and has resulted in decreased numbers of individuals served from the target of 138 individuals to 81 people with brain injury. In addition, there is a 12 person waiting list for entry into pre-vocational programming. According to this information, there is an identified need for vocational training and employment supports for persons with brain injury.

Difficulties in accessing home and community based services. Penny Woodward, a county social services social worker who assists individuals in applying for home and community based services, spoke about the difficulties in assisting persons with brain injury. In many cases, the individual is not eligible for state services because of the diagnosis, or lack thereof, for brain injury. The individuals need significant supports in completing the application materials, and there are often not sufficient resources for that support. Then, the applications are reviewed and often services denied due to restrictions in the funding stream, lack of appropriate documentation or diagnosis, or availability of service slots. Ms. Woodward also spoke about the screening process for TBI at the social services offices. In many cases, the screening instruments are not completely explained and the training for use is sometimes not completed. There are also some times when the screening is not completed due to caseload, timing, and other factors. Further, the reporting to the state is sometimes inconsistent and thus doesn’t always capture the true need in the counties.

Questionnaire Data

Target audiences, distribution and return rates. The questionnaires were designed for specific purposes and for specific audiences. Two questionnaires, the survivor questionnaire and the family caregiver questionnaire, were designed for delivery and completion in hard copy (paper) format. The other two questionnaires, the agency-based direct care provider questionnaire and the agency representative questionnaire, were designed for delivery and completion via electronic means using email and Survey Monkey.

In most cases, the questionnaires went to possible participants through an agency or personal contact. We used over 25 agencies and nearly 30 individuals to assist in the distribution. This was the most viable method for getting the questionnaires in front of respondents. Agencies that provided direct supports to people with brain injury sent the questionnaires directly to survivors and their family caregivers and assured anonymity for the respondents. NDCPD sent out 487 BI Survivor and 465 Family Caregiver surveys in this manner. For online questionnaires, the agency representatives usually sent the URL (website address) via email to their list of possible respondents. There was no way to track the number of contacts used by the agency representatives as those remained confidential and were not shared with us. NDCPD did track the zip codes of all four sets of returned questionnaires. Maps of the zip codes of the respondents for the questionnaires are shown in the Appendix document. In nearly all cases, the respondents were from the major ND cities, primarily along US Highway 2 and along Interstate 94, with few respondents from more rural areas. This may speak to the difficulty in finding individuals with brain injury who live in rural communities and do not access services in larger ND towns.

Brain Injury Survivor Questionnaire

General demographics. NDCPD staff distributed 487 questionnaires to survivors. A total of 89 usable questionnaires were received. Of these 89 questionnaires, 81 (93.1%) were completed by the individual themselves, 2 (2.3%) were completed by a guardian, and 3 (3.4%) were completed by a caregiver/support staff person. There were 33 females and 53 males with three not identifying gender. The average age of the survivor was 47.7 years. Nine individuals identified as retired military personnel and 2 were noted to be active military. Respondents indicated the age that the brain injury occurred (first brain injury). The average age was 33 years, 7 months, with a range from infancy (shaken baby) to age 74. Seven survivors listed multiple ages for additional brain injuries.

The racial/ethnicity of the respondents is shown in Table 4. The respondent racial/ethnicity composition was roughly the same as the ND 2014 Census estimates.

Table 4: Race and Ethnicity of Participating Survivors and ND Census Comparison

	White	**American Indian or Alaska native**	**Black or African American**	**Asian**	**Hispanic or Latino**	**Native Hawaiian / Pacific Islander**	**Two or more races**
Respondents	80 (92.0%)	3 (3.4%)	0 (0%)	1 (1.1%)	2 (2.3%)	0 (0%)	2 (2.3%)
ND Census distribution (2014) *	89.1%	5.4%	2.1%	1.3%	3.2%	0.1%	2.0%

* ND 2014 Census estimates from http://www.census.gov/quickfacts/table/PST045215/38

Living arrangements of respondents. The survivors reported their living arrangements on two factors; 1) with whom they live, and 2) the type of residence. These are shown in Table 5. The data show that fully one third live with a variety of other residents with just under one third living alone. Most are in their own home or apartment and 21 live in one of the state's TBI residential program housing units. It is important to note that while nearly all participants indicated with who they live, only about two thirds indicated their type of residence.

Table 5: Living Arrangements of Survivor Participants

With whom they live	Alone	With a spouse or significant other	Family member who is not a spouse	Non-relative roommate	Others		
	26 (29.9%)	19 (21.8%)	12 (13.8%)	1 (1.1%)	31 (35.6%)		
Type of residence *	**Own home or apartment**	**TBI residential program**	**Hospital**	**Assisted Living**	**Skilled Nursing**	**Basic Care**	**Other**
	33	21	0	0	2	0	7

* Note: 26 participants did not respond to this item

Causes of brain injury. Participants were asked to indicate the cause(s) of their brain injury (see Table 6). They were allowed to indicate more than 1 cause, either for the same injury or for subsequent/repeated injuries.

Table 6. Cause of Brain Injury

Cause	Number of Participants
Motor vehicle accident	34
Fall	14
Stroke	6
Blast explosion	5
Bicycle crash	5
Firearm	4
Sport/recreation injury	3
Non-traumatic aneurysm	3
Domestic violence	3
Substance abuse	2
Assault	2
Pedestrian accident	1
Anoxia	1
Unknown	1
Other *	25

* Other causes included huffing, tumor, horse riding, shot with arrow, shaken baby, diving accident, encephalitis, and brain cancer.

Health insurance coverage. Only 2 respondents indicated that they did not have health insurance. The most frequently reported sources of insurance were Medicaid, Medicare and private insurance. Thirty five of the respondents had more than one source of health insurance.

Associated conditions. Respondents were asked with they experienced any associated conditions along with their brain injury (see Table 7). Respondents could select as many conditions as they experienced.

Table 7. Associated Conditions Experienced with Brain Injury of the Respondents

Mental Illness	Substance abuse	Developmental disability	Dementia	Sensory disability	Physical disability	Other *
23	9	4	11	31	38	23

* Includes learning disability, bone flap removal, balance issues, depression, ataxia, speech impairment, PTSD.

Level of supervision/assistance. Participants were asked about the amount of time they needed personal supervision and assistance (see Table 8). Of the 83 participants who answered this question, the majority (39) indicated they did not need assistance or supervision.

Table 8. Level of Supervision and Assistance Needed by Participants

Level of assistance	Number (percent)
1 – 7 hours each day	19 (22.4%)
8 – 15 hours each day	2 (2.4%)
16 – 24 hours each day	24 (28.2%)
No supervision or assistance needed	39 (47.1%)

Types of services needed and received. Participants were asked to select the general categories or types of services they needed and that they received (see Table 9). They were allowed to select as many categories as necessary. The most frequently selected categories were employment supports, cognitive and memory training, independent living skills, recreation and social programming, housing and mental health services. The largest discrepancies between services needed and services received was in housing, legal supports, employment supports and cognitive and memory training.

Table 9. Types of Services Needed and Received as Selected by Participants

Type of Service	Needed	Received
Employment Supports	38	32
Cognitive and Memory Training	37	31
Recreation and Social Programming	31	26
Housing	31	21
Independent Living Skills	30	30
Mental Health Services	29	38
General Health Management	25	24
Legal Supports	25	13
Education Supports	17	13
Substance Abuse Services	5	9
Other *	6	2

* Includes family supports, gas money, social skills training at work, home care, medical personnel providing better after care advice and transportation.

Quality of service received. Participants were asked to rate the quality of the services they received from 1 – Poor to 4 – Excellent (see Table 10). The data in the table are displayed as averages of the rankings across all participants.

Table 10. Ratings of Quality of Services Received by Participants

Type of Service	Average Rating
Cognitive and Memory Training	3.32
Housing	3.31
Independent Living Skills	3.13
General Health Management	3.10
Substance Abuse Services	3.10
Mental Health Services	3.08
Recreation and Social Programming	3.08
Employment Supports	3.05
Legal Supports	2.88
Education Supports	2.73
Other	3.00

Problematic behaviors. There are several behaviors and conditions frequently associated with brain injuries and strokes. Sometimes these behaviors are evident and exhibited by individual survivors. Participants were asked to indicate if any of these conditions or behaviors were problematic for them (see Table 11).

Table 11. Associated behaviors and conditions of respondents.

Behavior/Condition	Number of Respondents	Percent of Respondents
Impatient	53	59.6%
Depression or low mood	52	58.4%
Irritable	49	55.1%
Anxiety/tension/uptight	48	53.9%
Impulsivity	48	53.9%
Trouble sleeping	46	51.7%
Lack of interest in things	44	49.4%
Difficulty controlling temper	43	48.3%
Poor decision making	40	44.9%
Refuse to admit difficulties	35	39.3%
Sudden rapid mood changes	35	39.3%
Lack of initiative	32	36.0%
Inappropriate social behavior	29	32.6%
Overly dependent on others	21	23.6%
Frequent complaining	20	22.5%
Childish or immature behavior	19	21.3%
Irresponsible and can't be trusted	17	19.1%
Violent/aggressive behavior	16	18.0%

Difficulties encountered in getting services. It is possible that one or more of these behaviors or conditions could have a detrimental effect on survivors' abilities to get services. They were asked in indicated any/all behaviors or conditions that prevented them from getting a service or support. These data are presented in Table 12.

Table 12. Behavior or condition prevented survivor from getting service or support.

Behavior/Condition	Number of Respondents	Percent of Respondents
Anxiety/tension/uptight	10	11.2%
Depression or low mood	9	10.1%
Poor decision making	8	9.0%
Trouble sleeping	8	9.0%
Irresponsible and can't be trusted	7	7.9%
Lack of initiative	7	7.9%
Impatient	7	7.9%
Refuse to admit difficulties	6	6.7%

Difficulty controlling temper	6	6.7%
Irritable	6	6.7%
Sudden rapid mood changes	6	6.7%
Impulsivity	5	5.6%
Inappropriate social behavior	5	5.6%
Overly dependent on others	5	5.6%
Frequent complaining	5	5.6%
Lack of interest in things	4	4.5%
Childish or immature behavior	4	4.5%
Violent/aggressive behavior	3	3.4%

Other barriers to getting services. Survivors were asked to select any/all conditions or situations that may be barriers to them obtaining services. These were not behavioral or medical or health conditions but rather situational/support conditions that may help/hinder access to services (see Table 13).

Table 13. Barriers to getting services.

Barrier to Getting Services	**Number of Respondents**	**Percent of Respondents**
Lack of understanding of BI by providers	40	44.9%
Lack of advocates	36	40.4%
Inadequate financial resources	34	38.2%
Lack of acceptance	30	33.7%
Long travel distance for services	30	33.7%
Inadequate community support	29	32.6%
No centralized source for BI information	29	32.6%
Lack of individualized services	27	30.3%
Inadequate health resources	26	29.2%
Inadequate family support	24	27.0%
Inadequate support for family and caregivers	20	22.5%
Inadequate peer support	19	21.3%
Lack of appropriate transportation	17	19.1%

Survivor ratings of primary care provider. The survivors were asked to rate their primary care providers on a four point scale from very knowledgeable and skilled to no knowledge or skill. Only 61 of the 89 respondents completed this item. The results are shown in Figure 6.

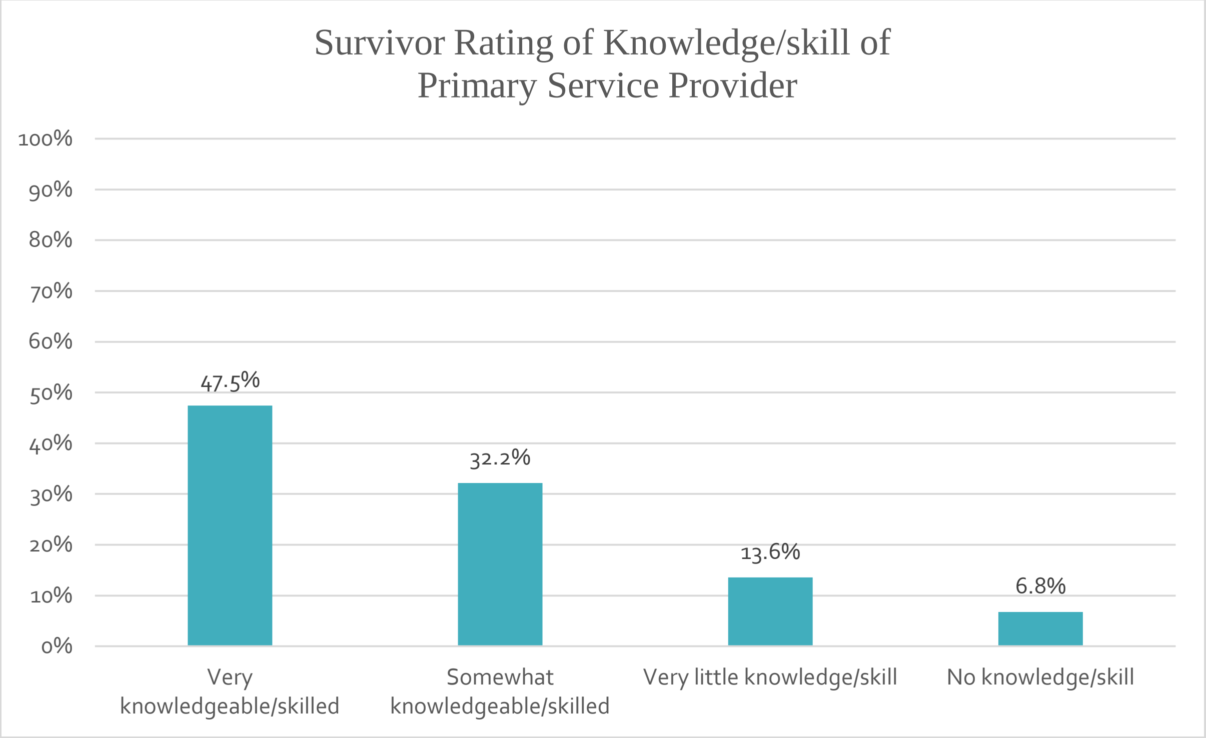


Figure 6. Survivor ratings of primary service provider.

Qualitative data from Survivor questionnaire.

Participants were asked several questions to which they could give narrative responses. NDCPD staff analyzed the narrative responses and determined the themes/findings for the questions. The analyses consisted of four staff independently reading through all the narrative responses, and then developing 3 or 4 categorical summary statements about the themes of the responses. Next, the staff met and discussed their summary statements, giving examples from the narrative that backed those themes. Staff discussed similarities and differences amongst their statements, and then agreed on the following themes. These are reported here.

Survivors were asked about their most immediate needs. The themes for their responses are shown in bold and actual verbatim comments are shown in italics.

1. **Need people who know about BI, its impact on people, and then can relay information and resources to survivors and families and other professionals.**
    - *Doctors who understand brain injury and are up to date in knowledge.*
    - *More information and understanding from family and friends of medical side of TBI.*
    - *Lack of information after surgery, it would be cool if there would have been a TBI spookperson to enlighten one on help, support groups.*

2. Survivors need assistance in getting and keeping jobs. They want to be employed, but understand there may be limitations as to what they can do.

- *Want to go back to work, need job coach.*
- *Job loss and understanding.*
- *Getting my life in order. Getting a job that that I can enjoy and make enough money to pay 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.*

3. Survivors need sufficient finances to get the services and supports they need.

- *Being able to go to Dic Rec center can not afford $6.00 a day fee.*
- *Financial, employment,..... financial security*
- *Being able to pay for necessities to live.*
- *Financial assistance for someone who has worked to get to retirement resources it has limited to therapy and needs. Thank God for those who will work with you by payment.*
- *Money – nearly completely without funds, 3 surgeries in 4 years – NO support in ND – Sad.*

4. Access to and transitions to community living and housing is a need.

- *Get my own place.*
- *Housing. Money management.*
- *I did not know about services that were available…*
- *Want to go home and return function to be able to teach again.*
- *Adequate housing.*

Next, they were asked about <u>how their needs might be addressed</u>. The themes for their responses are shown in bold and actual verbatim comments are shown in italics. (*Note: we kept the particular spellings and sentence structures as written by the respondents. This was not meant as disrespect, but rather to show the survivors actual words and meanings.)*

1. **Financial assistance for services and supports would be one way to address the immediate needs.**
    - *Put funding in the hands of local advocates and develop individual plans and support for our needs.*
    - *Development of more TBI resources.*
    - *My parents can't help me anymore financially and do not understand.*
    - *My one resources and savings are gone now and I still am unable to get insurance.*

2. **If many people (docs, nurses, case managers, public, etc.) got training on BI, this would help a lot.**
    - *Raise awareness and provide medical info to public.*
    - *I have had to do it myself and the answers I give or questions I ask are not understood what I am trying to say. People don't think I have a problem. It's even in my writing.*
    - *Doctors and people helping me needs to understand that a brain injury has so much less energy than we once had.*

3. **Things are OK as they are now.**
    - *Already have assistance.*
    - *I have a great team of people helping me in all areas I have services for.*
    - *They are being addressed, staff help me every day with both.*

4. **Things are so bad, they will never get better.**
    - *The state of ND is blind of the needs of all disabled citizens, quit funding Human Services and fund advocates.*
    - *I'm not sure nothing yet have worked.*
    - *I don't. This is N. Dak. Not really know for being up to date on many fronts.*

5. **The families provide great supports.**
    - *My husband is working with me and giving me challenges for me to work at.*
    - *My wife give me most help. We have a support group that is an immense part of the help that I need.*
    - *As his parents – we work hard to be in tune with our son's needs and see that they are met.*

Family Caregiver Questionnaire

Only 39 family caregivers completed the questionnaire. These individuals indicated their relationship to the person with a brain injury (see Figure 7). Most were either a parent or a spouse of the individual. Five of these caregiver indicated they were paid for their caregiving while 32 were not paid and there were two non-respondents to this question. The average age of the respondents was 59.7 years with a range from 31 years old to 88 years old. All indicated their race as white/Caucasian.

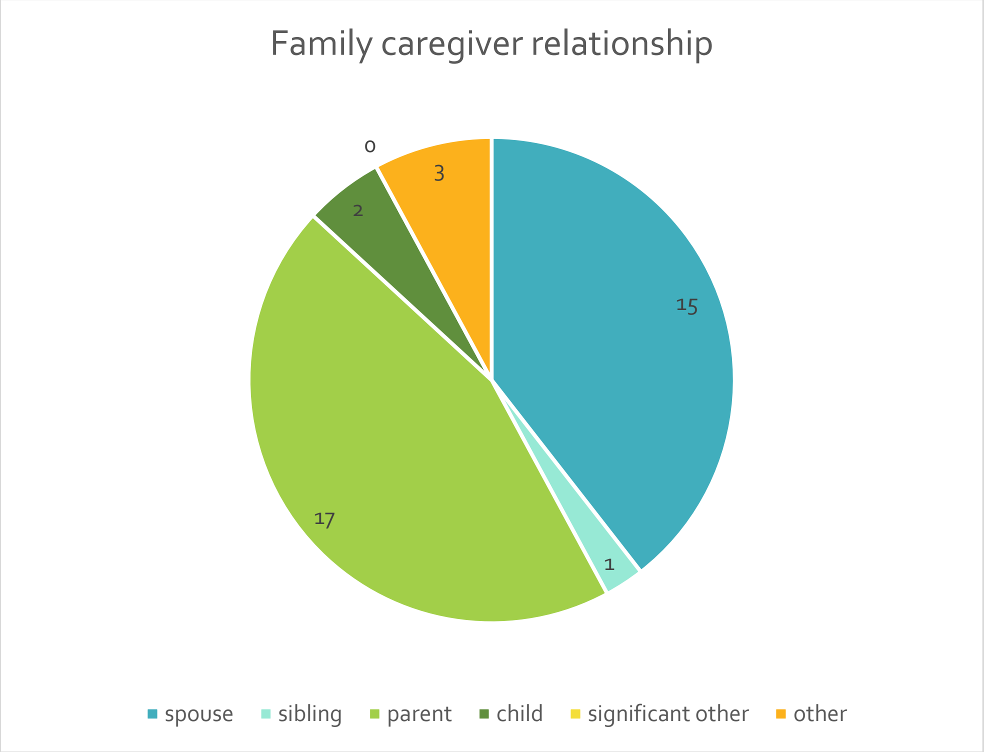


Figure 7. Relationship of family caregiver to person with brain injury.

Caregiver training in brain injury. The family caregiver were asked where/how they had received training in brain injury, and 18 of the 38 (47.4%) had received no training (see Table 14). The next most frequent method was done through informal self-study. Some of the methods under “Other” included mentoring by professionals, talking to others, and observations from being in the field of brain injury.

Table 14. Caregiver training in brain injury.

Training Method	Number of Respondents	Percentage of Respondents *
No training	18	47.4%
Informal- self study	12	31.6%
Workshops	5	13.2%
Conferences	5	13.2%
Individualized consultation	3	7.9%
Formal training modules	3	7.9%
College/university	2	5.3%
Other	7	18.4%

** Respondents could chose more than one training method.*

Demographics of the survivors. The survivors supported by these were 10 females and 27 males. The average age of the survivors was 45.8 years old and 6 were retired military, one was active military and the remainder were non-military. The cause of the brain injury is shown in Table 15. Motor vehicle accidents were the leading cause, followed by falls, stroke and other. The responses to other included infection, shaken baby and work accidents.

Table 15. Cause of survivor's brain injury.

Cause of brain injury	Number*
motor vehicle	15
fall	8
stroke	7
firearm	2
blast/explosion	2
sports/recreation injury	1
anoxia	1
substance abuse	1
domestic violence	1
non-traumatic aneurysm	1
assault	0
bicycle crash	0
pedestrian accident	0
other	8

* The caregivers could list multiple causes if appropriate.

Where care is provided. The family caregivers indicated that their own home and the survivor's home were the most frequent places where they provided care (see Table 16).

Table 16. Where family caregivers provide care.

Where care is provided	**Number**
In **my** home/apartment	18
In **her/his** own apartment/house	13
Group Home/ Residential facility	5
Assisted Living/ Nursing Home	4
Medical facility	1
Correctional facility	0
Other	4

The category "Other" included varying sites such as coming home on weekends or varying sites depending on medical condition at the time. The majority of the caregivers stated that they lived with the survivor (see Table 17) and thus had no travel time. However, six family caregivers indicated that they traveled more than one hour to provide care.

Table 17. Time for Travel to Provide Care.

Travel Time to Provide Care	**Number**
I live with the person	23
Less then 20 minutes	7
Between 20-60 minutes	3
Between 1-2 hours away	1
More than 2 hours away	5

Caregiver years providing care and hours per week. The caregivers provided data on the length of time they had been providing care to the survivor (see Table 18) and the number of hours per week they provided care (see Table 19). The data show that the majority of these family caregivers have provided care to the survivor for more than five years. Also, the majority provide care for the survivor for over 20 hours per week.

Table 18. Length of Time Family Caregivers have Provided Care to Survivor

Length of Time Providing Care	Number
0-6 months	2
Between 6 months-1 yr	2
Between 1-2 yrs	4
Between 2-5 yrs	10
More than 5 yrs	19

Table 19. Hours per Week Providing Care to Survivor.

Hours providing care per week	Number
1-5 hours per week	6
6-10 hours per week	5
11-15 hours per week	4
16-20 hours per week	6
More than 20 hours per week	18

Barriers for the survivors (family caregiver perspective). The family caregivers were asked to select any issues or conditions that they thought were barriers for the survivors (see Table 20). The most frequently cited barriers were inadequate financial resources, lack of acceptance, inadequate support for family and caregivers, lack of individualized services, and no central source for BI information.

Table 20. Barriers to getting services for survivors (family caregiver perspective).

Barrier to Getting Services	Number of Respondents	Percent of Respondents
Inadequate financial resources	17	44.7%
Inadequate support for family and caregivers	16	42.1%
Lack of acceptance	16	42.1%
No centralized source for BI information	16	42.1%
Lack of advocates	15	39.5%
Lack of understanding of BI by providers	15	39.5%
Lack of individualized services	15	39.5%
Inadequate community support	10	26.3%
Inadequate family support	10	26.3%
Long travel distance for services	10	26.3%
Inadequate health resources	9	23.7%
Inadequate peer support	9	23.7%
Lack of appropriate transportation	6	15.8%

Participation in support groups. Only 9 of the family caregivers stated they attended support group meetings. Of the 28 who did not participate in support groups, 17 of them (approximately 60%) stated they were interested in going to a support group meeting. Of those who didn't attend, some stated that the meeting times didn't work with their schedules, or they would only attend if it was for TBI survivor caregivers.

Qualitative data from Family caregiver questionnaire.

Participants were asked several questions to which they could give narrative responses. NDCPD staff analyzed the narrative responses and determined the themes/findings for the questions. These are reported here.

Family caregivers were asked about the most immediate needs. The most salient responses were grouped as follows.

1. **There is a need for more knowledgeable providers and general public about BI and services**
    - *A knowledgeable care coordinator.*
    - *Lack of understanding of someone with TBI and mental health issues.*
    - *Understanding from community and doctors.*

2. **There is a need for transportation services for people with BI**
    - *Transportation.*
    - *Transportation, mobility…*
    - *Transportation – lack of in rural areas.*

3. **There is a need for housing**
    - *Housing for Independent living (possibly @ some care)*
    - *H. want to live on her own & there is not supported living for TBI survivors in the Devils Lake area*
    - *Someone to help stay with him…*

4. **Need for socialization and links to community interaction.**
    - *He needs something to do*
    - *Someone to visit with them.*
    - *Connections with friends/social with like individuals.*

5. **A need for job coaching and training for employment.**
    - *Phase in work program with mentoring*
    - *Going back to work – (limited basis)*
    - *Continued support by employer & fellow employees*

Next, the family caregivers were asked about how the needs might be addressed. The most salient responses were grouped as follows.

1. **One approach to meeting the needs is to assure better access to quality services and information.**
    - *Coordination o health care professionals working in cooperation for health of patients.*
    - *There are different things being started to help people with Brain Injuries because they are realizing that TBI's are very common.*
    - *Last year 2015 I had an article written about my son in our local newspaper for Brain Injury awareness month. Through that article I found out "freedom Resources" and what we call our "angel" Rebecca Quinn. Through her we discovered there is indeed a Brain Injury Network. She has steered us and guided us to get "real" help and understanding.*

2. **We need to remove barriers for eligibility and payment through third party, insurance and other program requirements to get services.**
    - *To whomever can help Medicare only pays if this is progress. What about the people who take longer with progressing?*
    - *BCBS is & has been refusing rehab services to him. He got 3 weeks covered – took him home as they would not cover anymore – they then refused Home health therapy…*
    - *…reimbursement issues need to change so there are ways to address supported living providers willing to provide, but reimbursement rates have to change.*

3. **Providing training and education for providers and the community about BI.**
    - *Mom & kids (3) went to a referred counselor who after 3 visits admitted he do not know enough about TBI patients.*
    - *Taking time to have workshops with professionals and family members & at such meetings the professional persons really listen to what is needed.*

4. **Several folks said they had no solutions.**
    - *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.*
    - *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.*
    - *Haven't happened in 25 years, don't have faith it will happen.*

Agency-Based Direct Service Provider Questionnaire

General information on clientele served. The agency-based direct service providers were asked two questions about the numbers of people they served. First, they were asked about the total number served, and then they were asked by the number of individuals with brain injury that they served. These data are provided in Table 22.

Table 22. Numbers of Clientele Served by Responding Direct Service Providers

Total number people served		***Number of people with brain injury served***	
Average	*Range*	*Average*	*Range*
44.27	0 - 335	4.18	0 – 50

Type of agency. Respondents were asked by the type of agency they had. Figure 8 shows that 49% of the respondents worked in public agencies, and 41.7% worked in private, non-profit programs. Less than 10% of the respondents worked in private, for-profit agencies.

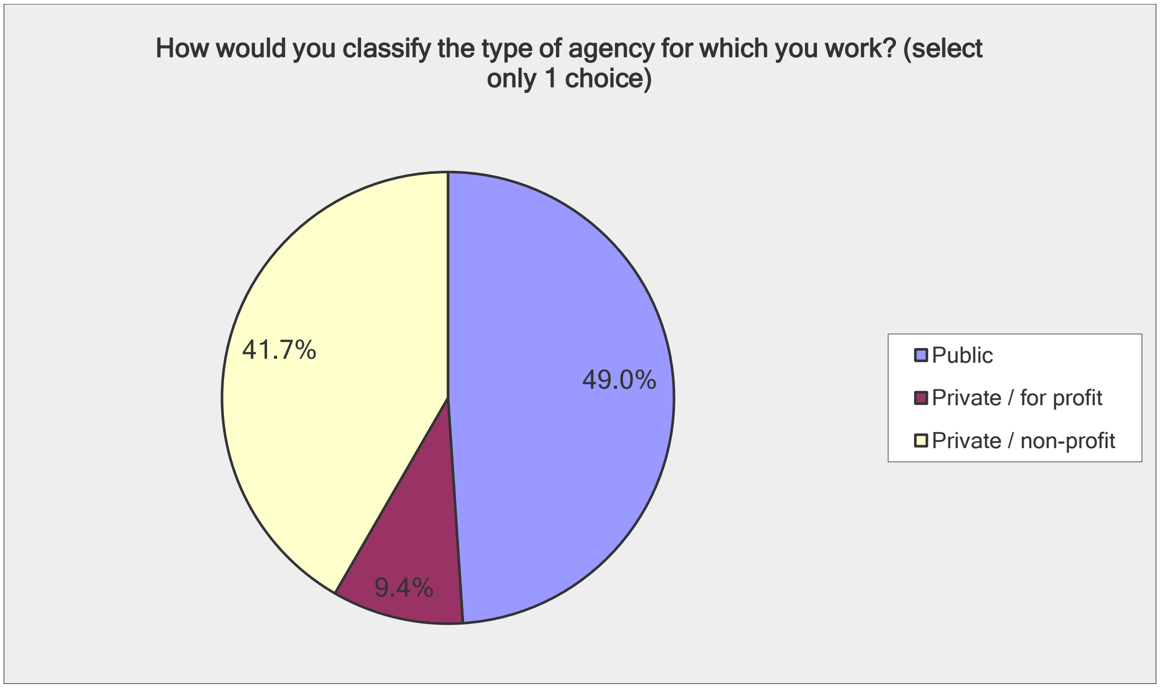


Figure 8. Type of agency of respondents.

Agency-based direct service providers were asked to what extent they felt they were trained to work with individuals with brain injury. They responded on a five point scale with 1 being not at all trained or educated to 5 being highly trained and educated. Seventy one providers responded with an average rating of 2.96. This is just slightly below the level of moderately trained or educated. The direct service workers indicated they worked from an hour or less each week to 168 hours (24 hours per day x 7 days) each week with an average of 22.5 hours per week.

The workers indicated the types of supports they provide to citizens with brain injury (see Figure 9). The most frequently listed support was independent living skills followed by recreation/social programming, housing and cognitive/memory supports.

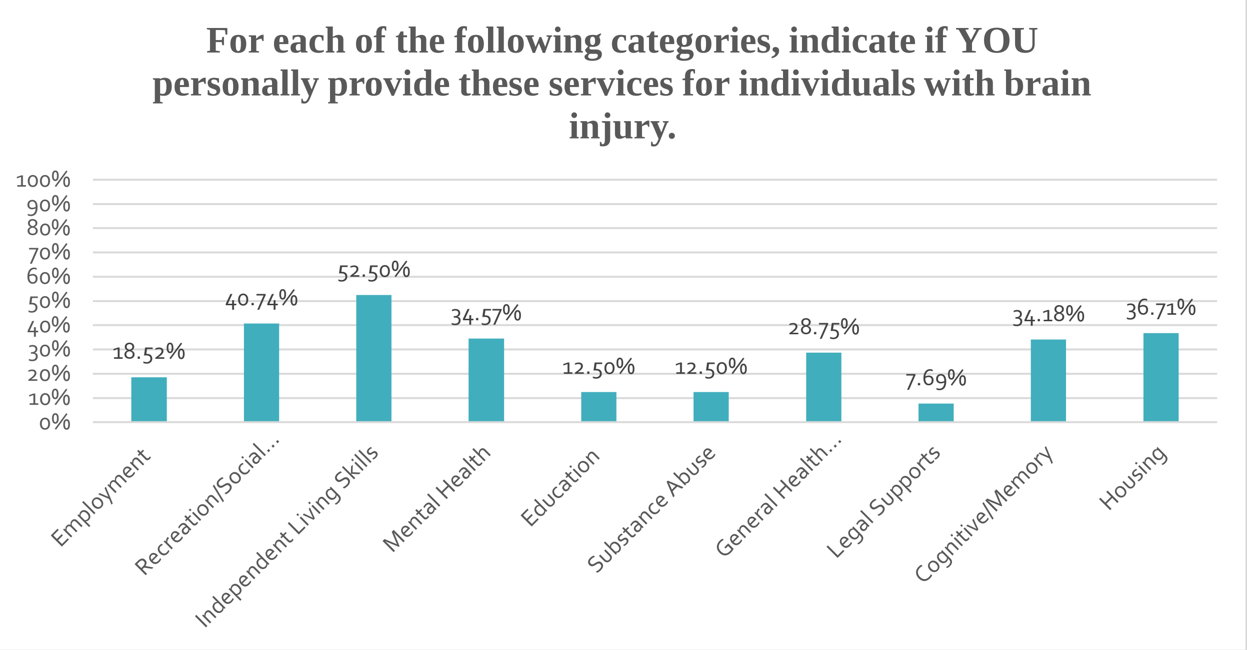


Figure 9. Support services provided by workers to individuals with brain injury.

Figure 10 shows the responses to the number of years the agency workers have been providing services for people with brain injury. The distribution is bi-modal showing two high points. The highest level is 1 to 5 years, and the next is more than 20 years.

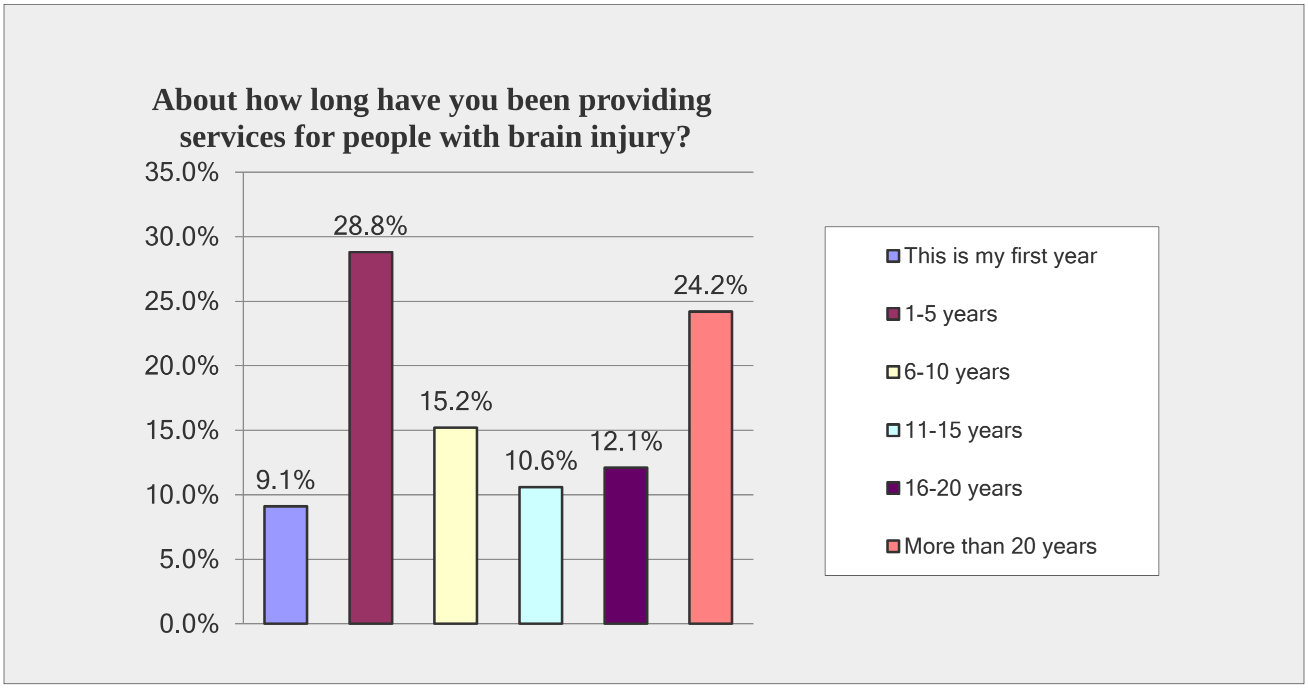


Figure 10. Length of time providing services for people with brain injury.

The direct support providers indicated that there were multiple issues in working with other agencies (see Figure 11). The top issues were lack of understanding of brain injury, inadequate financial resources for the agency, and lack of coordination of services with other agencies.

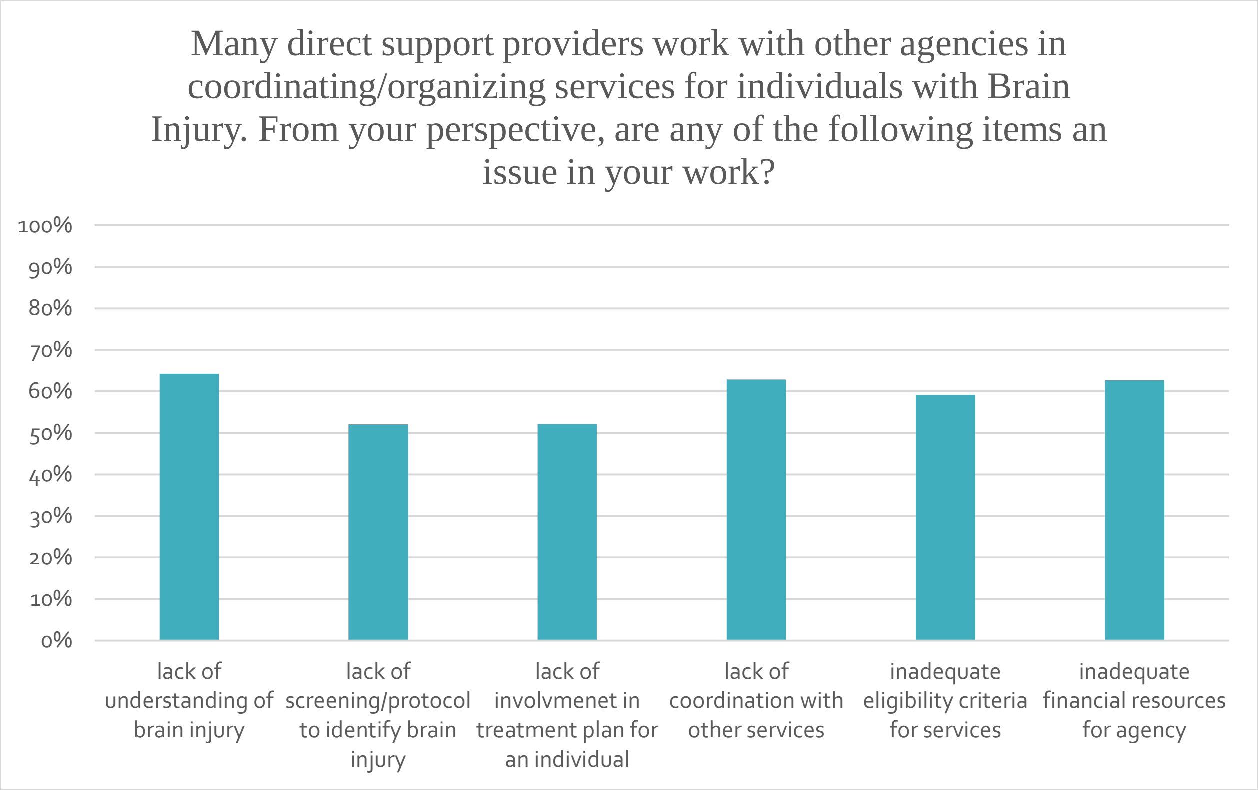

Many direct support providers work with other agencies in coordinating/organizing services for individuals with Brain Injury. From your perspective, are any of the following items an issue in your work?

Figure 11. Percent of respondents indicating a problem with these issues.

Figure 12 shows the respondents' answers to how their agencies had provided training to them about brain injury (the respondents could chose more than one approach). Nearly 60% indicated that their agency provided support to attend workshops or conferences outside the agency. About 35% however, indicated that they received no training or education by their agency.

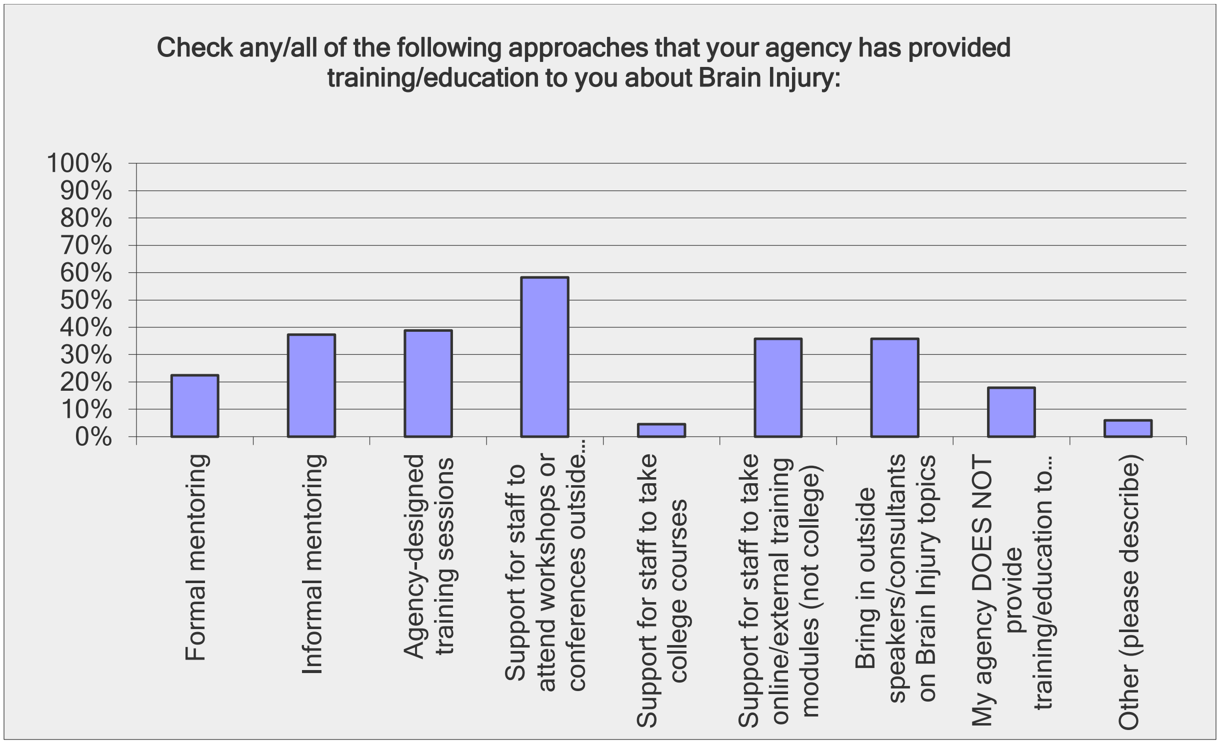


Figure 12. Agency approaches to training direct support providers on brain injury.

Direct service workers rated the following topic areas the highest; managing behavior health needs, rehabilitation strategies, and case management/service coordination (see Figure 13).

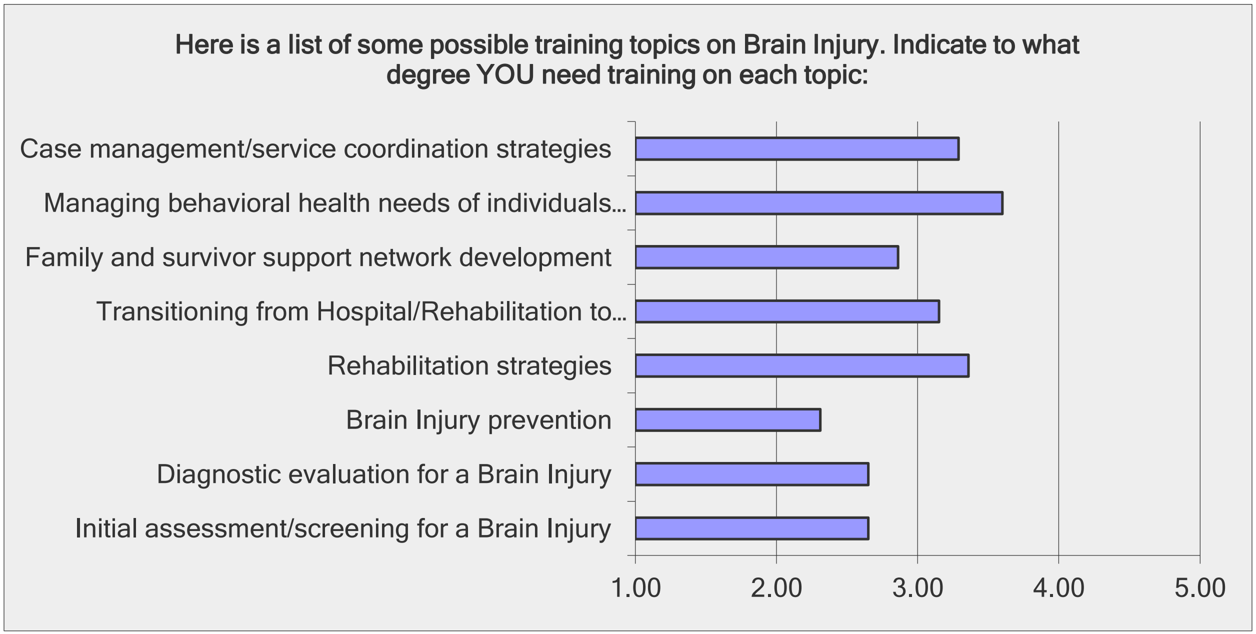


Figure 13. Respondent ratings of need for training on various topics.

Agency service providers were asked barriers to services or supports for the people they worked with (see Figure 14). Fully two thirds of the respondents indicated that inadequate financial resources was a barrier. Other items receiving high percentages were inadequate community support, long travel distance for services, and lack of individualized services.

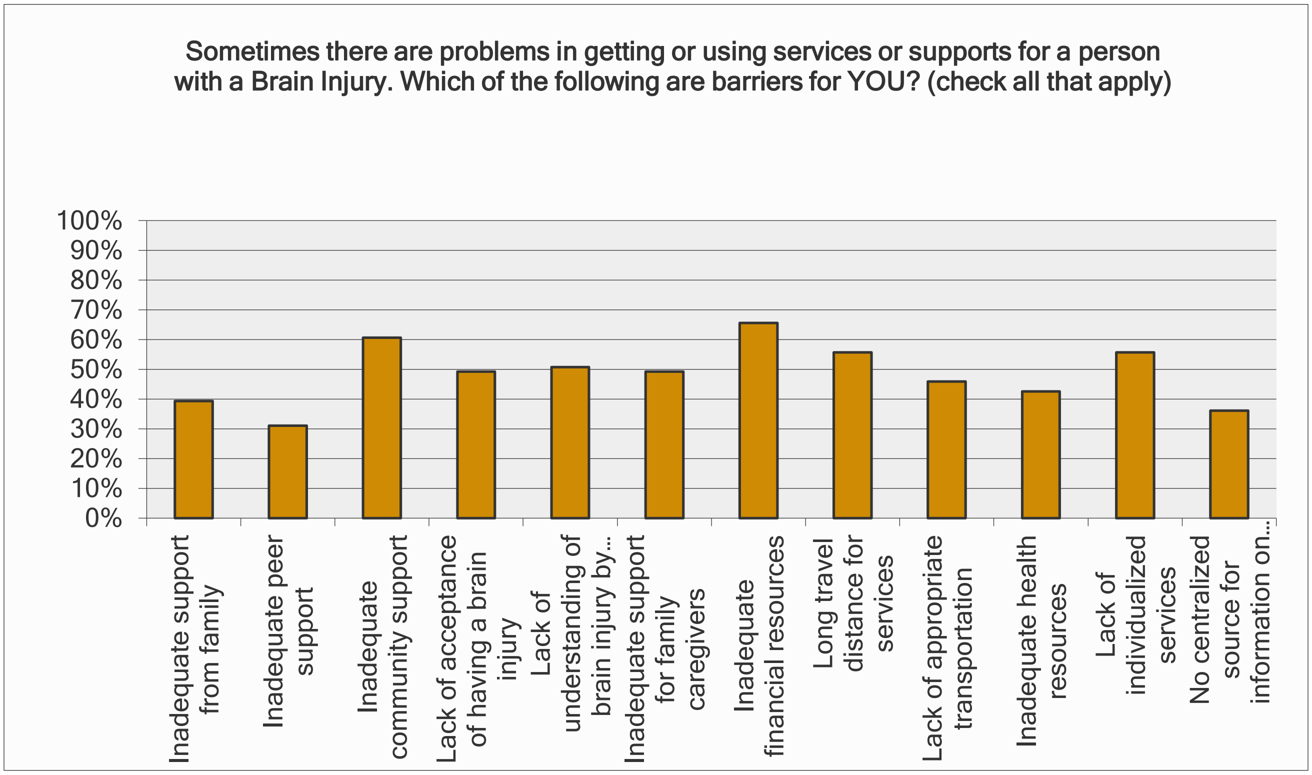


Figure 14. Barriers for service providers in obtaining services or supports for people with brain injury.

Qualitative data from agency-based direct care provider questionnaire.

Participants were asked several questions to which they could give narrative responses. NDCPD staff analyzed the narrative responses and determined the themes/findings for the questions. These are reported here.

Agency-based caregivers were asked about the most immediate needs. The most salient responses were grouped as follows.

1. **Need community education and understanding, especially amongst service providers.**
    - *Support and understanding of brain injury symptoms by medical doctor (just because someone can walk and talk, does not mean they are fine.*
    - *Better understanding by staff members on repetitive questioning*
    - *To understand what the brain injury is – education.*

2. **Financial supports**
    - *The person needs financial…support. A reduced income* (due to injury and inability to work) *means that the person often cannot pay for the services that are needed…*
    - *Financial – not enough hours to help someone obtain and maintain a job due to funding.*
    - *Financial support.*

3. **Support for care coordination and navigation of services**
    - *Transition into the community with more supports.*
    - *How to manage and what services would benefit someone with a TBI.*
    - *Arranging/coordinating services and benefits.*

Next, they were asked about how the needs might be addressed. The most salient responses were grouped as follows.

1. **Viewed making systems changes in several areas as a way to address problems.**
    - *The Medicaid Waiver would have to be changed to screen separately for TBI without the stringent criteria now.*
    - *Community/systems change.*
    - *Supports are available to address these issues, but funding has limited the extent of these.*

2. **Providing more funding for services and supports**
    - *More funding for case management.*
    - *More dollars for programs and apartments build to better serve the clients needs.*
    -

3. **Providing training and education to multiple providers would help.**
    - *Awareness of TBIs*
    - *Increased training for HCBS Case Managers.*
    - *Lack of understanding often leads to lack of family or spousal support emotionally.*

Service Agency Questionnaire

Representatives from service agencies were asked to complete a questionnaire online via Survey Monkey. The respondents indicated the nature of their agency (see Figure 15).

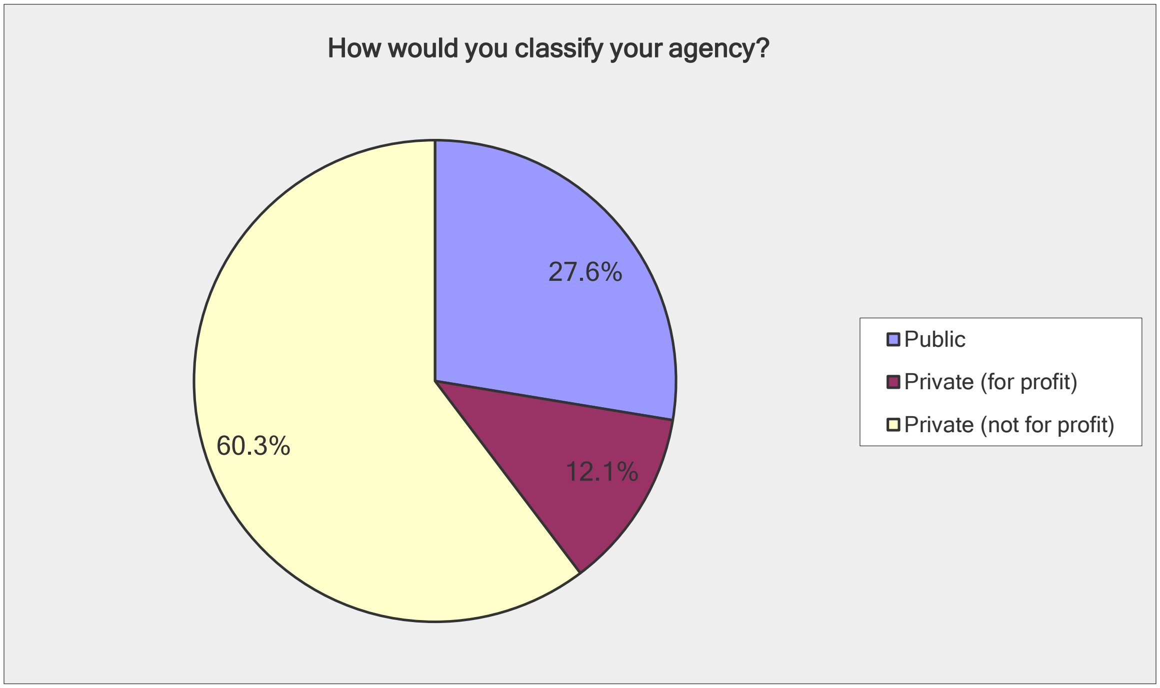


Figure 15. Agency type of respondents.

Over 60% of the respondents were in private, non-profit agencies and just over a quarter were in public agencies. Representatives responded to the question about the number of individuals overall that they served. The total was 12,928 and the average number per agency was 243.92 people. These agencies served 839 individuals with brain injury with an average of 17.12 people with brain injury per agency.

The agency representatives indicated whether they did or did not provide supports across a variety of categories (see Figure 16).

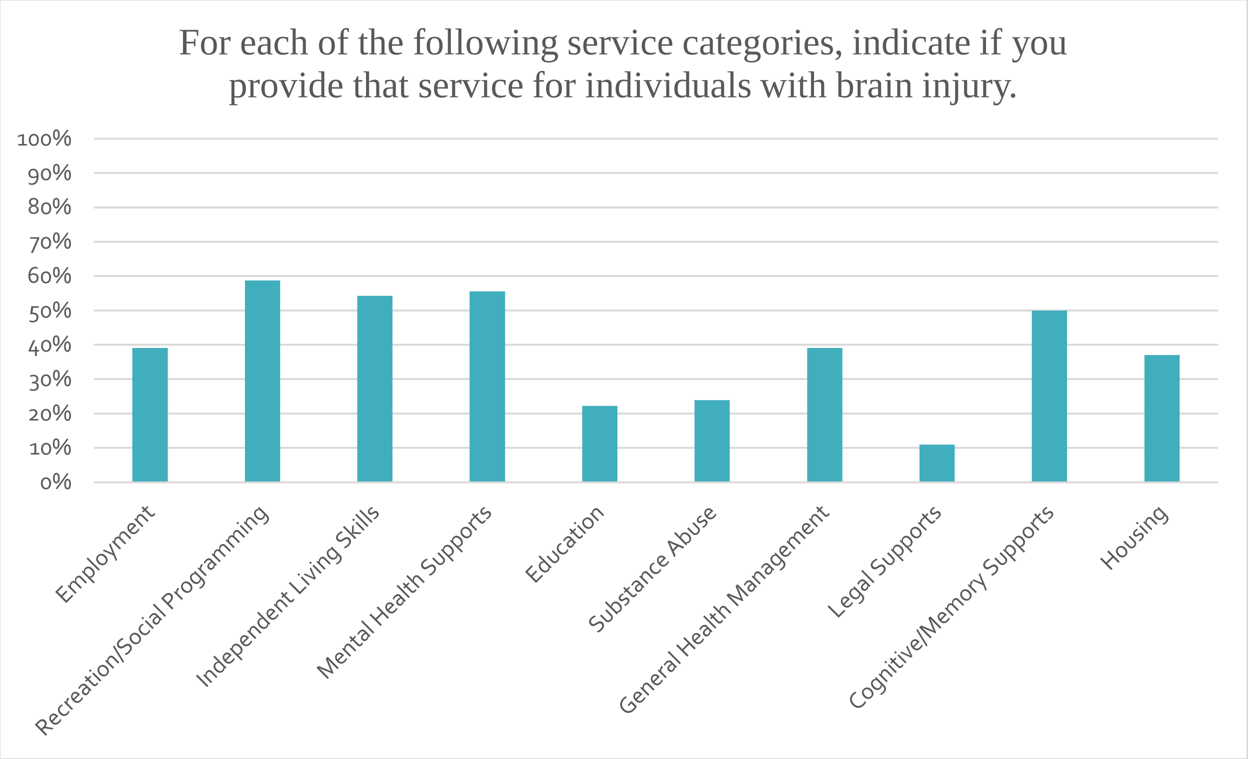


Figure 16. Percent of agencies providing services.

The agency representatives indicated whether issues were problematic when working with other agencies (see Figure 17). The most frequently cited issues were in lack of coordination with other services, inadequate eligibility criteria, and inadequate financial resources. Thirty five agencies listed one or more barriers for getting services for people with brain injury (see Figure 18). The two most commonly cited barriers were inadequate financial resources and long travel distances. Also over half of the representatives indicated lack of understanding of the brain injury providers and inadequate community support.

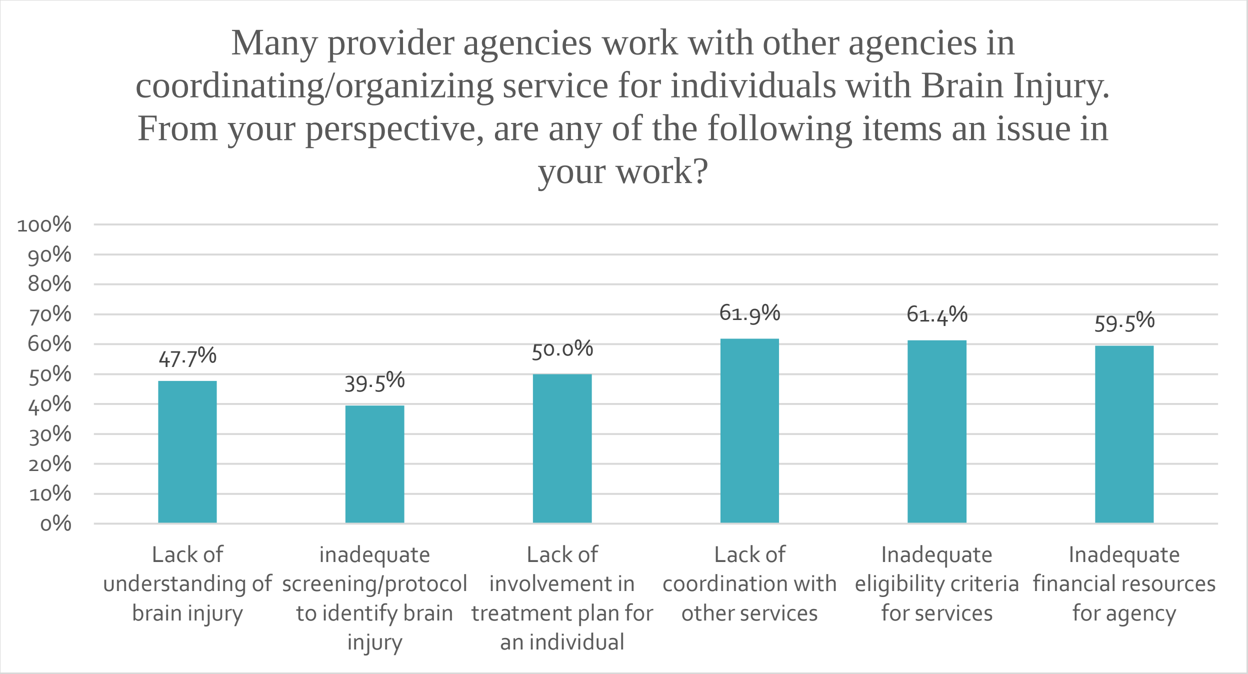


Figure 17. Issues in working with other agencies.

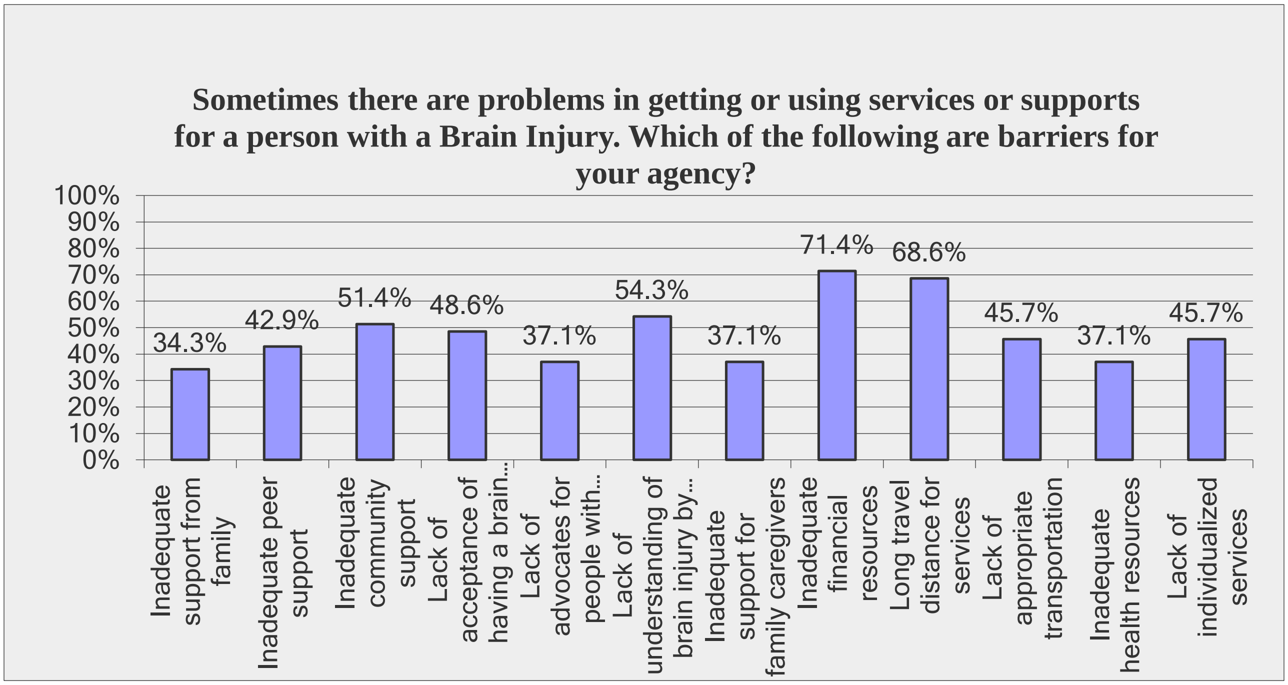


Figure 18. Barriers for getting services for people with brain injury.

Thirty seven agencies indicated the number of staff they had available to provide direct services to individuals with brain injury. They had 792 staff, with an average of 21.4 staff per agency. The range was 0 to 180.

The representatives indicated how well trained the staff were, rating the preparation from 1 not at all trained or educated to 5 being highly trained and educated. The average rating was 3.30, or just above the level of moderately trained and educated.

The approaches used for training staff included supporting staff to attend conferences or workshops outside the agency, providing agency-designed training, and using informal training methods (see Figure 19). Only 11% did not support any training for staff on brain injury.

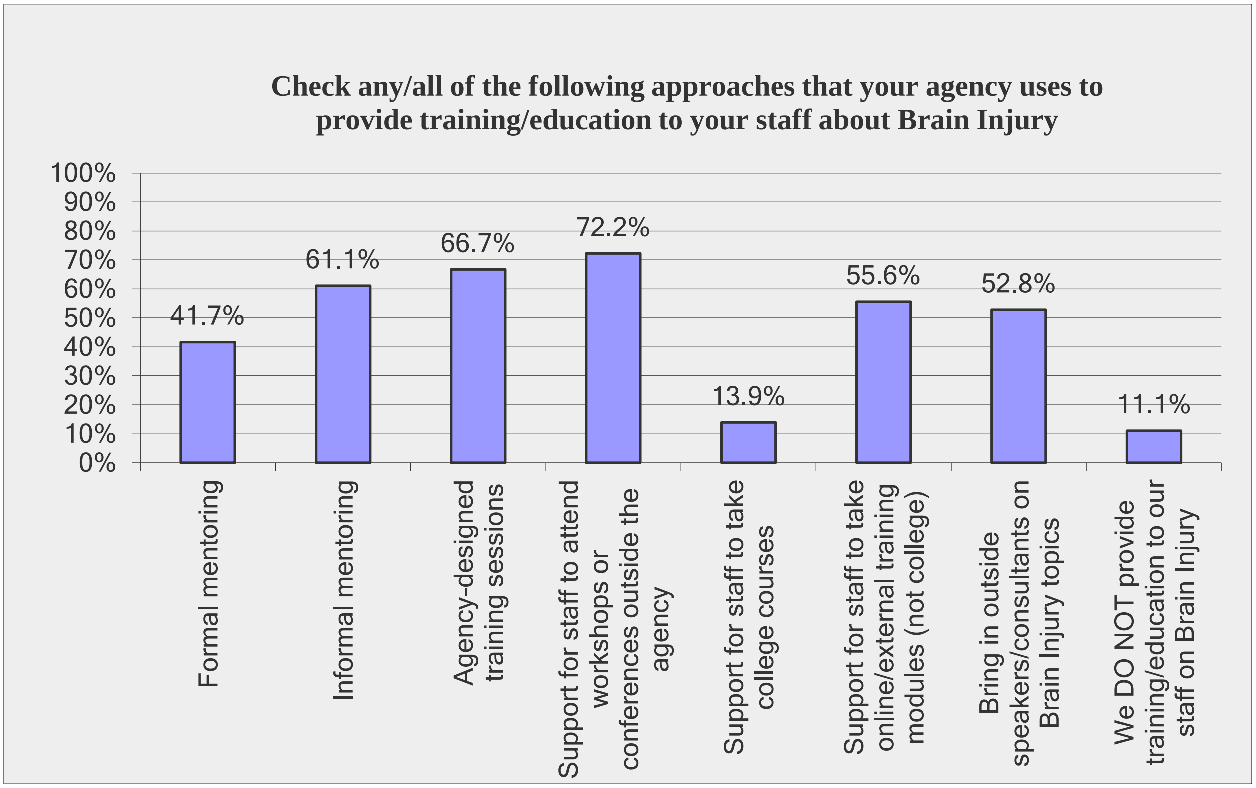


Figure 19. Training approaches for staff.

Agency representatives rated the degree to which staff needed training in a variety of topics (see Figure 20). The rating scale was from 1 being no training was needed to 5 being a high training need topic for their staff. The highest need area was managing behavioral health needs, followed by rehabilitation strategies, and case management/service coordination strategies. However, overall the need for training across the areas was low to moderate.

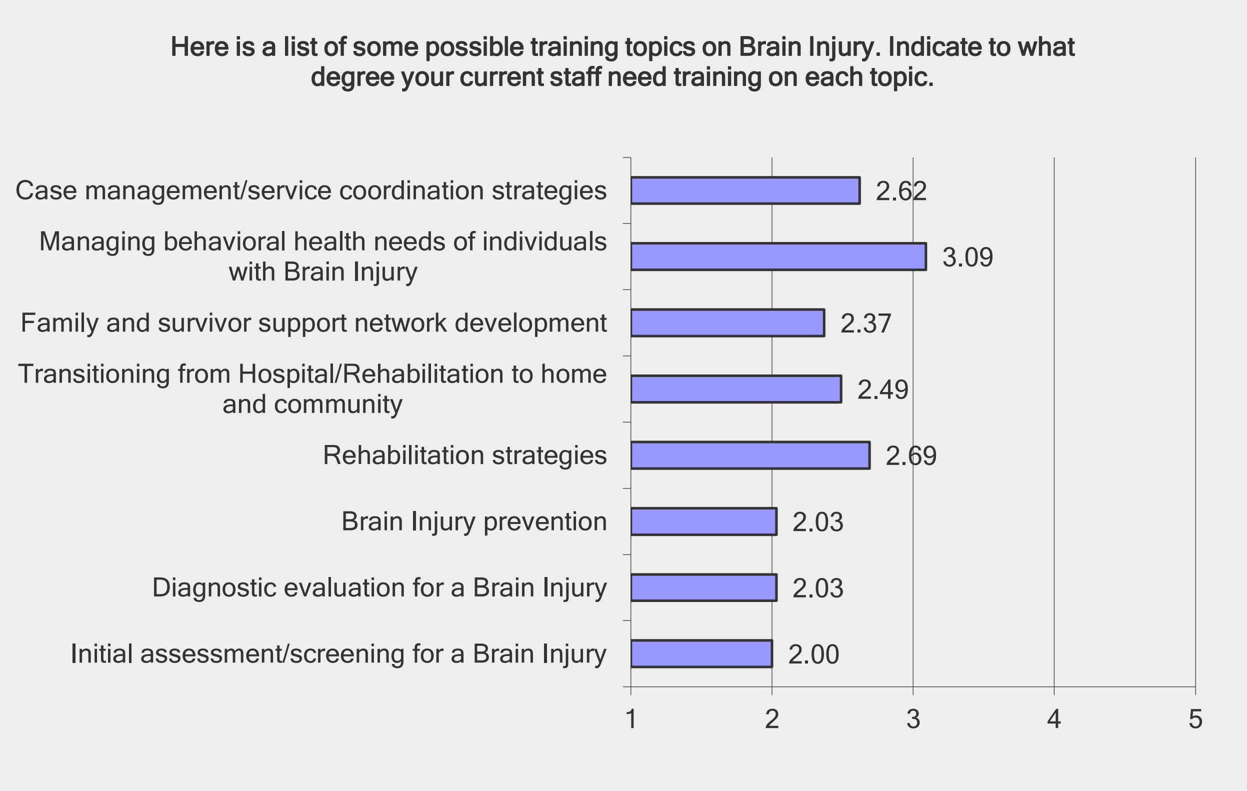


Figure 20. Degree of training needed per topic by agency staff

Qualitative data from agency representative questionnaire.

Participants were asked several questions to which they could give narrative responses. NDCPD staff analyzed the narrative responses and determined the themes/findings for the questions. These are reported here.

Agency representatives were asked about the most immediate needs. The most salient responses were grouped as follows.

1. **Need for individualized and appropriate housing options**
   - *A continuum of housing options and supports…*
   - *There is a need for housing support like ISLA, need for day supports…*

- *Proper placement. Our brain injury residents are young (in their 50s) and our little 'grandpa and grandmas' don't understand the behavior of these residents and are scared and they have to be mixed in with our elderly population.*

2. **Support for more and varying employment options**
    - *Extended services to enable long term job coaching and supports on the job.*
    - *Lack of pre-vocational and supported employment services.*
    - *Lack of long term supports (extended services and case management)*

3. **Need for funding and finances for services**
    - *As stated the current county waiver system is not adequate.*
    - *Funding if they do not qualify for DD funding.*
    - *Funding so we can provide support employment services.*

4. **Need for supports for daily living skills**
    - *Individualized supports to assist with daily issues.*
    - *Assistance with day to day living strategies supports.*
    - *Independent living skills.*

5. **Generally need more individualized options for all supports**
    - *Individualized supports to assist with daily issues.*
    - *A need for flexible staffing in a transitional living situation.*
    - *Specialized mental health and addiction treatment services…*

Next, they were asked about how the needs might be addressed. The most salient responses were grouped as follows.

1. **Make changes or bring back BI waiver, look at 1915 (i)**
    - *A brain injury waiver (1915(i) 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 needs to have at 1915(i) or other waiver just for Brain injury.*
    - *Some of the limitations within the waiver could be reconsidered.*

2. **Support individualized care plans for persons with BI**
    - *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.*
    - *Individualized care plans and nursing care.*

3. **Staff training and education**
    - *Increased training for clinical staff.*
    - *Research and development of training classes for staff.*
    - *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.*

4. **Support various housing options**
    - *Funding streams for housing options.*
    - *Change in the method of financing 24-hour transitional living.*
    - *Develop housing for specific survivors that would be staffed 24 hours per day, which would include supports, transportation, prompts and reminders.*

Focus Group Results

NDCPD hosted 11 focus groups with a total of 76 participants across ND from March 2016 to May 2016. These focus groups were organized variously, but most included a mix of constituents. The meetings were generally conducted by one NDCPD staff member who recorded the entire meeting with participant permission. Table 23 shows the sites and participants of the focus groups.

Table 23. Focus group sites and numbers of participants

Focus Group Sites (number of meetings)	BI survivors	Agency Providers	Family Members caregivers	Other	Total Participants
Bismarck (2)	9	9	4	0	22
Devils Lake (2)	4	3	4	0	11
Dickinson (1)	9	3	2	1 BI survivor caregiver	15
Grand Forks (2)	6	5	0	0	11
Fargo (3)	4	7	2	0	13
Minot (1)	0	4	0	0	4

After the focus groups were held, NDCPD staff listened to the digital recordings of the meetings and compiled notes on relevant comments, important topics and frequently mentioned responses. This was done independent of other staff and no discussion was held on the topics and findings until all staff had completed the listening and individual data analyses.

Next, the NDCPD staff met together to discuss their findings for each general question/area posed during the focus group. The staff discussed their findings, provided background information to verify their findings, and then discussed differences and similarities. This information was then charted and consensus was reached on explanatory statements of the data. These are presented as follows.

Primary Topics Found in Focus groups

Q1 – What services and supports were helpful?

- Family and Friends,
- Mentor or dialogue with those who have same experience,
- NDBIN, P & A, Community Options, Progressive therapy, CILs, MFP, HIT, (happy with services and supports they provide)
- GOD - church and religious organization supports
- Rehab centers – mostly out of state…referred by docs to these places
- support groups
- when hospitalized and in acute care settings, the professionals there were good.

Quotes for services that were helpful:

> *"Most helpful was family and caretakers."*
>
> *"I have 4 or 5 advocates helping me with stuff, just kinda, they make me feel like a human. It doesn't seem anything gets done, they are helping me along the way."*
>
> *"I came to Devils Lake outpatient therapy at Heartland and they are great."*
>
> *"Dakota Center for Independent Living helped me find a different Doctor to get my medication figured out."*
>
> *"Our family has done everything pretty much everything on our own. We have figured it all out."*
>
> *"Neuro Ophthalmology can make all the difference in the world to someone's recovery."*
>
> *"Outside of ND we got a referral or transfer or we insisted on a transfer to the Hennepin County Medical Center in Minneapolis and they saved her life." "So we had outside hospitals, but we had insurance, and not Medicaid, so we insisted we moved her out. We had someone in MN help us find a place and we got to a Traumatic Pediatric Brain Injury Unit."*
>
> *"If it would not have been for God and my Church and family I would not be where I am today."*

"I have two services that come into my home, one comes in one week and the other comes in the next week. Because of the left sided paralysis from the injury, they check my blood sugar and set up my medication, take me to the doctor and nine out of ten time they help me reorder my medication. "I self-pay for these services. (Enable and CHI St A's Homecare and Hospice.

"The Advocates, he was the one that helped me get on disability, he set up the court dates for disability, because they were backlogged two years."

"My son's sister who lives in Bismarck ND, knew someone at Dakota Center for Independent Living and this is how we got help, assistance and different questions we had."

"Our church group did a lot of things for me."

"This support group gives me hope." (Dickinson)

Q2 – What services and supports are missing?

- Common need to deal with people in health care and daily living who do not understand brain injury
- More information to survivors when they leave the hospital
- Couldn't get services from agencies (eg., VR) because made too much money part of ongoing inability to qualify due to finances
- Lack of consistency in services – many professionals are contradictory
- Lack of follow up from medical professionals.
- Education on brain injury for ER staff, doctors, nurses, and health professionals
- Lack of respect and poor treatment - treated like a child
- Transition from acute care to home….when available, really needed and appreciated….when not there, really needed!!! Brain injury case management is needed to help in transition from hospital to more permanent of living arrangements
- Needed more referrals to specialists; they wouldn't look at head or head injury even when I asked.

- Need for transitional living arrangements - between hospital and home…
- Lack of transportation for services or couldn't get reimbursement for travel
- Slots for extended employment and ongoing supports
- Need for services in RURAL areas – services are too concentrated
- No advocates for living, general supports, financial, emotional support (LONG TERM!!)
- Continuum of care
- Bring back brain injury waiver!!
- Support for family members because person has changed,
- Take away financial eligibility to access services…
- Individualized programming, not whole group all/nothing services….
- Not enough neurologists, neuro-psychologists, behavioral counselors, case workers with BI experience or other specialists - have to go out of state to get that help

Quotes for services that are missing:

"Getting someone to help them is very difficult."

"They be living in their own homes, they would have all the supports that they needed, all the money that they needed, they would have friendship, the social life, peer support, independence…" "An ideal thing would be for a company that does it all…"

"I think having someone or an agent or something to be able to help them through that process so that there is some familiarity there for that individual and for that family that when I'm sustained a BI, this is who I'm going to work with from the early identification all the way through the way up to the continuum of care."

"More beds needed for care for BI survivors between hospital and home. Family cannot effectively care for someone who needs special care. ND has very limited beds for BI patients."

"I don't have nobody, I had to learn by trial and error. I wish my home town would had been aware of what a BI was and how to deal with it and help BI instead of saying, 'I told you an hour ago how did you forget?'"

"ID/DD waiver open to all disability groups, as a menu of here's all the services that are available according to our ND state plan and you, based on your needs can plug into the services you need within that universal state plan."

"People who say they want to help and don't, the system is not helping in general."

"A lot of agencies I think don't understand and the cognitive issue that go along with brain injury."

"One of the big things I'm totally against is this income base crap, because all of us have different needs. Everyone has different needs and how can you base that on income. If you need it that should be a service provided."

"Transportation stops at 5:30 and there is nothing on weekends. They need to stop using transport for public school children and only use it for needs of elderly and disabled."

"Everything has to be pre-approved." If something comes up within the month, they can't go because it has to be pre-approved."

"One thing with the Brain Injury social recreation, it's so limited there because it has to be somebody with a traumatic brain injury, so your talking strokes or dementia, they're left out."

"People with Brain Injury should not be sent to facilities that does not have a Rehab person who does not understand Brain Injury at all."

"Level of care for every disability is the same, well not every disability fits into the level of care they have. What's the level of care for Head Injury?"

"Many people leave the Emergency Room and have no idea they have a Brain Injury."

"All of the other programs we have, this is a team of people through department of human services, medical providers, and they get together once a month or every so ofter, and they all everybody is kind of on the same page, but it's more than just meeting me, or their case manager or there's no really a connection with all of it…"

"When people have dual-diagnosis, traumatic brain injury, or mental health, or traumatic brain injury and addiction health, or traumatic brain injury and a severe physical disability there's nothing out there."

"Somebody should stand up and then whether it's their job or not, somebody should stand up for what their brochure or organization says they should stand up and tak the bull by the horns. And nobody wants to take responsibility." "I don't like to ask for help, but I've had to stand up and ask for help because that's what they want you to do and they don't do anything. They claim that you don't qualify or whatever their brochure says."

"In order to get to the VR and get extended services, they have to have slots available to fit them into, and those slots were decreased, so there are no longer as many extended services slots as there were before."

"Transportation-lack of in rural areas."

<u>If there was a perfect Roadmap for services and supports, what would it look like ?</u>

- Transportation and education would be great!
- Programming continuum similar to ND's DD system
- Waiver program that is cohesive amongst the various providers, agencies, and systems.
- Levels of care for the brain injury
- Services with no financial barriers
- Treatment is a process…no cure…needs to be realization by ALL that it is ongoing and won't necessarily be the same as before….
- Advocates for the person throughout the entire process; systems navigator is needed
- Accommodations from employers
- Hotline for families…
- A RESPECTFUL system that is individualized, ongoing and they are assisted throughout

Personal Stories

NDCPD staff interviewed brain injury survivors who told us their personal stories. They told us about the injury incident, the extent of the injuries, the immediate recovery period, the post recovery processes, and successes and challenges of living daily with brain injury in North Dakota. These stories are told by North Dakota citizens who live with a brain injury or stroke. Some stories suggest relatively successful processes and outcomes while others are more tragic and dire. The stories are not meant to be complete biographies, but rather some glimpses into the real lives of real survivors in our state.

Gary Crowdus

On May 5, 2012, after playing basketball on a Monday night, I ate supper and went to put my dishes in the sink. When I turned to start talking to a friend I hit the floor (from what I'm told). I did not realize what had happened until a day or two later. I'm told I was conscious during some of that time, but I recall only bits and pieces of those two days and none of it made any sense to me. I remember hearing people talking, but I could not see them; and could not later recall the content of any conversations I had during this time. My understanding now is that my heart went into atrial flutter (irregular heartbeat and blood pooled at the bottom of my heart). When it was shocked back into a regular beat, the pooled blood flushed out and a tiny clot went through my system. When it hit my brain, it was "lights out".

I spent 35 days as an inpatient (acute care and rehab) at Trinity Hospital. I remember that everyone was extremely nice and helpful except for the overnight nurses. They were traveling nurses and were from some other country based on their heavy accents. When supervisors were gone they were very inattentive, didn't answer the bell when I needed something, were not on time with meds and very short with their answers. I remember each morning a nurses- aid would come in and talk to me and it felt so good knowing she was there and because she was so helpful. For the first week in the hospital I was in and out of consciousness, but understanding everything that was happening to me. I was on a heavy dose of narcotics.

I went to the inpatient rehabilitation facility two weeks after my stroke. It was in the old St. Joseph's Hospital building. I was given very good care there, especially by the physical and occupational therapy staff. They pushed me to work harder than I wanted to, but as hard as I needed to recover. The entire staff was very good at taking care of me. I felt safe and content with my surroundings and well supported.

My life is now a lot different. I live in Minot in a condo. My activity level is the biggest change after my stroke. Initially, I had no movement in my right side and had no voice; to move my fingers took tremendous effort. I was shown a piece of paper I had asked for in the emergency room that first night (asked for paper and pencil). I had written 9mm (which is a gun). The thought of being helpless was something I did not want to endure or put on anyone else. My brother flew up from Florida for a couple of weeks and he was the biggest motivator for me with the things he said. He truly saved me from a terrible life by encouraging me to work harder than was expected, instead of as little as I had to. Support is terribly important after a stroke. It's hard for anyone to think they can recover when nothing works and it's easy to give up. Support and encouragement, and sometimes tough love like my brother gave, is needed to motivate someone to put out the tremendous effort needed to recover. The only way to survive and recover from a stroke is to concentrate on what you can do, not on what you can't do anymore. Your life that was is no longer the life you have. Accepting that is key to recovery.

My typical day: get up about 6 or 7 o'clock, shower, get breakfast, play with the dog and then watch "First Take" on Sports Center. I have retired and taken up woodworking, some drawing and various projects around the garage.

At this point, my support is mainly from friends and family. I do go to a stroke group once a month and I’m on the Board for stroke services at Trinity Hospital. Trinity Hospital provided the support services after my stroke. The support services were great. I was never a big fan or supporter of therapy until I needed it and saw what they can do and will do to help people regain some normalcy in the lives of their patients.

My future plans? Enjoy life, make the most of each day. I saw first-hand how quickly life can be taken from you. In two seconds my healthy physical life went from great to zero; and only by the grace of God there was someone with me when my stroke happened. The doctor said if no one would have been there, I would not have survived. I am still in recovery four years later. My speech is not what it was and I have lost a lot of strength and endurance. It’s a continuing struggle to communicate and let people help me with things I had always done myself.

For the most part, Trinity Hospital and its staff (except the traveling nurses) were wonderful. I don’t know what else they could have done to make a bad situation for me bearable.

Some additional thoughts in casual conversation after the interview:

- Considering the incoherent condition I was in during the first couple days, this is rationale for not expecting survivors to make any legally binding decisions (including signatures) during that time.
- It would be very helpful to survivors to have someone to talk to (a mentor, etc.) that had experienced a stroke and had gone through rehab. Patients, especially younger ones, are often afraid and confused (need reassurance and support). I remember a very meaningful and helpful conversation I had with a nurse that had fairly recently had a stroke. I was surprised, encouraged and very grateful that she shared her experience with me.
- There were ongoing issues with third-party payers. This is not uncommon for someone requiring several months of healthcare services, but even more difficult to deal with after having a stroke.

Hannah – I'm the Same But I'm Different

What is the difference between a young, active 15 year old before a horrific car accident, and a young, working 24 year old with a brain injury? There are no differences and there are a 1,000 differences. Hannah is the same young woman as she was when she was 15. But at the same time Hannah is a different young woman from her 15-year-old self.

Hannah Anderson grew up in Leeds ND, the youngest child of Duane and Lisa Anderson. As a young girl she grew up across the street from the local school. Hannah was involved in her church, in school activities, with her family, and with her friends. She was in band, sang at church and in school, and dreamed of being a 2nd grade teacher one day.

On November 12, 2007, much of that changed. Hannah and three of her friends were in her car on the way to her Grandmother's to watch a movie. But they never got to see the movie. A terrible car accident left two friends unharmed, one friend slightly injured, and Hannah with severe injuries, including a brain injury. Hannah was transported to a hospital 90 minutes away, and then quickly airlifted to the Hennepin hospital in Minneapolis.

While she doesn't remember the day or the events, or even much of the next several weeks after the injury, Hannah states that she went to the level 1 trauma center in the intensive care unit for three weeks. She was in a medically induced coma for 11 days, and first opened her eyes on Thanksgiving Day that year. After leaving Hennepin Hospital, she transferred to the Gillette's children's hospital for 6 weeks. She says that the rehabilitation at Gillette's was "hard work". She worked with therapists in physical and occupational therapy, speech, education/school, music, and recreation. Hannah had to learn to walk, talk, eat, and even learn to breathe again. This therapy continued at home until she went to college.

The first thing that Hannah remembered after the accident was a hospital visit by Miss Minnesota America. This actually set in motion her later involvement with pageants. Also, as her communication returned, Hannah's sign language ability came back first. Learned when she was in pre-school, Hannah has become fairly proficient in this mode of communication.
The road back to school and her recovery was difficult. Even though Hannah lived across the street from the school, she needed a bus, and then later a car ride, to get to school. Walking was still difficult and learning could be very hard. She attended classes at the high school, some with her classmates, and some in a special education resource room. Nearly every day, she had a para-educator with her throughout the school day. This followed the hospital directive to have 24 hour care.

Prior to the accident, Hannah was very involved with school, church and community activities. One of her favorite activities was to hang out with friends. But the aftermath of the accident changed that. Hannah's parents went to school and spoke with her classmates about the changes in her. They wanted to let the other students know that she was different, but still Hannah. While she never used the word "bullying", Hannah did state that other students made fun of her and very few of them hung around with her anymore. She thinks this may have been because of the changes evident in her (trouble with motor skills, difficulty with communication) or because she now had an adult with her all the time (the para-educator or parents).

While the educational road was tough, Hannah graduated on time with her classmates. To the surprise of her family and her classmates, she even sang a musical solo at commencement. She worked hard to memorize the song, and the music teacher was a great help. One gets the impression that Hannah wanted to show everyone that she was still capable, that she was still talented, and that she wanted to show others that she could and would work hard to accomplish her goals.

To continue moving toward her goals, Hannah enrolled in a small bible college. She took four years to get the general studies 2-year degree, but was so thankful for the help and assistance of her parents and the college staff. The teachers gave her extra time and accommodations and always asked Hannah how she could best access the information in the classes.

At 24 years of age, Hannah works part time, lives with her parents, and is still involved with her church. She works mornings at an elementary school as a classroom aide, using her skills in sign language to assist a youngster with schoolwork. She got the job through family connections, and talks about how her employer and co-workers work around her needs. Hannah needs “brain breaks” at least twice during her work period. These 10-minute breaks in a quiet dark room allow her to have a calming period and “settles” her for the next series of work tasks. Hannah states that mornings are her best time, so this work arrangement is optimal. In addition, some of her work uses her sign language skills and she is very proud of that.

The effects of the brain injury are typically not visible to others. One sees a beautiful, bright and engaging young person. But the brain injury has a significant impact on Hannah. She still has some vision difficulties, which makes climbing open staircases hard. Short-term memory is affected. Hannah needs to write things down to remember them. She sometimes has trouble sleeping. She needs daily breaks, even when she isn’t working. She is afraid of getting lost when she drives. Hannah’s processing speed is impacted. She gets tired and fatigue drags her down. She sometimes forgets things, and can become frustrated. She had trouble thinking of the right word in conversations. Hannah has trouble remembering lists and names. Hannah has changed.

But in some ways Hannah hasn’t changed. She still has many of the same goals and aspirations just like many 24-year-old young women. Hannah wants to marry a farmer with strong Christian faith. She wants to live in the country on a farm, and work part time. And she wants 1 or 2 children. She loves her job and feels pride in the work she does. And she still shows an independent streak with her parents.

But achieving her goals won’t be easy. She lives with her parents, in the country outside a very small town. Hannah often depends on her family for support, and doesn’t get too many chances to be around many people her age. Her classmates have married and many have left the area.

Hannah uses joking and humor to get through difficult situations. She progressed through the hard work of therapy by joking with her therapists. When asked about the marriage and dating situation, she stated that while it hasn’t worked out yet, she does have the song for “Farmers Only.Com” memorized! Also, she wants others to know that she does have a brain injury. She once wrote “TBI” (traumatic brain injury) on a band aid and put it on her forehead so that others would remember her condition.

And Hannah has stretched her wings. Because of that first memory and visit by Miss Minnesota America, she entered two Miss ND International pageants. She didn’t originally tell others about her brain injury, but during the second day of competition, she revealed that she had a head injury. That night, during the final events, Hannah earned the Director’s Choice award for her hard work, her success and her perseverance. She also received a standing ovation from the crowd after her short acceptance speech. And while she admits to being crazy about cats, she gets into some pretty intense discussions with her mother about getting her own assistance dog. Oh, and there is the question about maybe doing one more pageant. So some things don’t change between mothers and daughters!

Skip-People Need to Understand

Skip Miller wants people to see that she is an individual, she has survived, and she wants people to be educated. This is her story:

I have survived fifteen different Brain Injuries that started when I was fifteen years old. In 1958 services were very limited and Medical Professionals were not aware of Brain Injuries. I don’t remember some of the injuries, as I would wake up in the hospital. I did not receive therapy or referrals for services, but do know that I have difficulties with scattered thoughts and short term memory loss, speaking my thoughts, balance and numbers.

I feel like have I have lost my identity and my actual age. I could not remember how to dance or bowl, two things I truly enjoyed. I would go to get help and professionals looked at me not identifying problems because I looked okay. They neglected to see what was going on inside.

I did my own research, got involved with groups, and worked through the issues myself. I have attended college, been able to graduate with three degrees, all very difficult, but I accomplished this with help from my instructors.

I have seen Counselors, Psychologists, and Neurologists. I have been through Alcohol treatment and attended anger management counseling. I currently see a Mental Health Counselor and go to Physical Therapy.

I have received assistance from IPAT for equipment, Vocational Rehabilitation for job placement, and Protection and Advocacy. My son helps me with money management.

I have lived alone, for some time, but do depend on my son for help. I still drive even though my son has concerns about my ability.

I have to ask people to repeat questions, explain questions, and I need time to think about my response. This is the result of my many Brain Injuries.

In the future I would like to see more education regarding Brain Injury. Teachers need to be more aware of signs and how to interact with children who have Brain Injuries. Professionals need to be educated on how to treat individuals that have Brain Injury. More awareness with Medical Professional on recognizing sign and symptoms of Brain Injury would also be helpful.

Kyle Johnson - Determined and Positive

I met Kyle Johnson at his parent's split level home. As I entered the home, Kyle was coming up the stairs at a slow pace, using both hand rails to walk, fatigued by the time he was at the top stair. Kyle has to speak slowly and think about his words. This is Kyle's story:

In August, 2013 I had been at my job for the city of Grand Forks Health Department for eight seasons, working in the Mosquito Control Branch. I enjoyed what I did working from May–September. This day was no different from the rest. We were out of town working in the country.

I remember it being a nice sunny day. I was driving an ATV and we had crossed over Rail Road tracks on a country road. We were coming back over the tracks, completing our work. That day my life changed. I do not remember any further events from that day.

I was transferred to Altru Hospital in Grand Forks, ND. I was in the hospital for three weeks, and was in a coma for one and a half of those three weeks. I had a trach, received physical therapy, occupational therapy and speech therapy. My parents were left to make very difficult decisions regarding my care, uncertain of my recovery.

After the three week stay, I no longer needed acute medical care. Recovering slowly from my injuries of internal bleeding, a left broken ocular eye socket and traumatic brain injury, I was not ready for Acute Inpatient Rehab in Grand Forks, and decisions needed to be made. The Social Worker gave my parents options, (not in ND), therefore I would be leaving my support systems, still needing twenty-four hour care. I was transferred to Bethesda, in Minnesota, from September to November just three weeks after a life changing event. Following my Rehabilitation at Bethesda, I was transferred to Courage Center in Minnesota for continued therapy and independent living skills. I was likely to have family support through all of the life changing events.

I was discharged to go home from November 2013 to February 2014 to be with my family, as I was unable to live alone. I was given referrals for therapy, independent living skills, caregivers came into my parents' home and I also attended out-patient therapy. It was then recommended by Workforce Safety. I attended QLI Tri Dimensional Rehab, in Omaha Nebraska, for continued Independent Living training. I was at QLI from September 2015 to November 2015 and was discharged. I wanted to continue the program, however, was unable to complete the program, due to funding issues through Workforce Safety and Insurance (WSI).

I am currently living at home with my parents. I continue with speech therapy, literacy group and conversation group (as speaking clearly is still difficult), physical therapy, (walking long distances is still difficult) and music therapy. I am paying for these services on my own. At the one year mark, financial support for my therapy was done. My parents are my support system. They do my cooking, laundry, transportation, and paying my bills.

I am receiving limited income from WSI, SSDI, and I'm still working four hours per week for the City of Grand Forks. I am unable to receive the Medicaid drug plan due to financial restrictions. The earning limitations are frustrating to me as I did not choose this injury. I have an open case with WSI, and am working with a Lawyer to assist myself with needed services.

My future plans include; working more than four hours per week, however, due to limited mobility, needing increased rest, and financial restrictions I am currently doing what my mind and body can tolerate. I would like to live in my own apartment with someone else. I would like to drive and increase my social involvement, as most of my thirty-one year old friends are married and have families. I do not feel comfortable going out, feeling like a burden and at times I feel like a baby. “I don’t want people to have to wait for me or slow down because of me.”

I would like to see more rehab, for as long as you need it. If you are making slow progress, you should be able to continue rehab, you should not be denied, because of progress. You should not be limited on your earnings, and denied benefits due to an injury.

My recommendation would be more living options with support to teach you how to become more independent at your own pace and not pushed to make a certain amount of progress or be discharged.

My future is to be determined to get stronger and eventually live in my own apartment, drive my own car and go back to work.

Kyle’s determination and positive attitude earned him the “Tenacious Inspiration Award” from the Courage Center in 2014, something he is very proud to share. After visiting with Kyle, I would say an award well deserved.

Shannon-Keep Moving Forward

Shannon Binstock currently lives with her family in South Heart, ND. In 2010 she was a thirty-three year old mother and married to her husband, Tom. They had three children, ages ten, nine, and two. That spring they brought one more into their family. Shannon's six month old nephew, who was adopted, and is now a permanent member of their family.

The family is active in their church and the children are involved in school activities. Shannon and her husband had the opportunity to work together at Stockmen's Livestock Exchange in Dickinson, ND twice a week on sale days. "We came from farm and ranching families so, working with horses and cattle was not new to us," they had mentioned.

This is Shannon's story as told to her by family and with the help of the Caring Bridge journal which her mother updated during her recovery:

"It was a beautiful morning on July 15, 2010. I went to work at Stockmen's and was responsible for moving the cattle to a pen after they had been sold that day. I was riding a tall horse I had rode many times before. He was so tall that I had to crawl up on the fence to get in the saddle. I learned later that the horse was wearing the wrong saddle and it needed to be changed. I was to take a mean bull down the alley and into a pen, but the pain from the saddle caused the horse to act up. He began jumping and bucking, as we started taking the bull down the alley. I was yelling at him to stop as everyone was watching. The bull hit the gate to the pen he was going into and the workers ran to help close that gate. They thought for sure they would turn around and see me off the horse, still yelling at him. Instead I was laid out on the concrete alley, with one less shoe and missing my glasses." Shannon explained of her incident is that she lost balance when trying to get off the horse and the horse's hoof connected with the left side of her skull as she fell. Shannon, chuckling, adds "The one time you need some cow shit to land on, I only had concrete." The workers immediately ran to check on her and saw blood pooling from her head. The sale was stopped and the ambulance was called. With tears in her eyes Shannon explains a co-worker went to get her husband. He walked up then turned away and said,

"I can't stand here and watch my wife die."

"I was loaded into the Dickinson Ambulance, where I was taken to the Dickinson hospital. The Sheriff came to assess the situation, and he spoke to the Tom. The Sheriff also called our pastor." The Sheriff, not knowing if Shannon would make it, asked the pastor to take Tom to the hospital and help him deal with this terrible accident. "At this point, it was unclear if I was going to live. At the hospital, I had an MRI and it was determined I was not going to make it. I was immediately transferred to St. Alexius in Bismarck, ND. During the trip, the ambulance had to stop once or twice, due to me waking up and trying to sit up not aware of my injury. I was told later how it was so strange that I had almost no bruises anywhere on my body, however my head was a Hot Mess."

"Upon arriving at St. Alexius, I had a CAT scan taken of my head, showing serious damage to the left hemisphere. They placed a valve immediately to drain the blood collecting on my brain," Shannon explained how lucky she was that Dr. Monasky was on call, a Neurosurgeon from the East coast and had experience with head trauma and could complete a surgery, if needed.

"At the same time that I was being taken to St. Alexius, our pastor had made a few phone calls so our church community was making a prayer chain. They prayed for me to survive this terrible accident, prayed for my recovery, and for God to reach down and save me. I feel those prayers and my faith saved my life."

"My first couple days did not look good. I was kept in an induced coma. My Mom and Tom stayed close to keep a close eye on me, requesting the staff to check on me repeatedly. My mother felt that I was getting worse and her continued persistence kept everyone on their toes. So, one more CST scan was taken and the scan determined the blood was crushing my brain, mostly the right hemisphere, and would require an emergent craniotomy. Tom knew how upset I would be if I would wake up with a shaved head, but this was necessary. They knew the chances for me to live were 50/50, and there was no guarantee I wouldn't end up severely, mentally handicap, or simply brain dead," Shannon mentioned.

"They took a large piece of the right side of my skull off, since that was the only portion that didn't have any damage from the accident. After the surgery, I was kept in an induced coma for almost two weeks and then woken for nourishment. I was in the hospital for a total of two months. During this time, I received physical therapy, occupational therapy, and speech therapy, and had a short stay at a complex acute hospital for one week." Shannon later returned to St. Alexius for more intense therapy in the Acute Inpatient Rehabilitation program.

"Nearly two months after the accident, I woke up. I only knew who I was and who my parents were, not where I was, why I was there, or what year it was. My current state of mind was back in 1992 or 1993. I was about 16 and there was no way I was married. I wasn't excited about going home with Tom. My children had a difficult time coming to see me in the hospital and now I was going home with them and didn't believe I was their mother. My now three-year-old son was happy his mom came home and she was learning the same things he was. We watched cartoons together and we learned to tie our shoes at the same time."

Nearing the discharge day, the family had to make some decisions. They were told to Google 'Brain Injury' for ideas on how to help Shannon or find a skilled nursing facility for her. "It was still early in my recovery and I would need twenty-four hour care. A cousin volunteered to help Tom and I with my recovery. She would be my day-care giver so Tom could go back to work."

"It was October and my speech was improving and memories were coming back. My memories were not always good ones, most were difficult memories from my past. This was also the month that I was healthy enough that my Doctor was able to return that piece of my skull they had removed from the craniotomy," Shannon laughs, referring to this as her Birthday present. "I was happy to have my head back in one piece, but sad to wake up with no hair on the right side."

"Because my ambulation and fine motor skills were fine, I had to focus on my memory. I was contacted by a speech pathologist from Rehab Vision in Dickinson, to work on my memory. Workforce Safety had contacted her, and we started meeting once a week to improve my cognition. I started with very basic simple words and short-term memory. We would work for one hour and then I would go home and sleep for four hours. In less than one year I was able to accomplish what they told me would take up to five years to accomplish. My attitude was 'I am not going to be special, I'm going to be awesome!' I pushed myself every day to learn more and complete those Brain Train lesson on the computer."

"In those first few months, my memory was still very impaired and the simplest tasks were difficult. I was still sleeping fifteen hours per day. I was making progress even from watching simple shows, such as Sesame Street and relearning basic words and actions. Each day, I would wake up and remember a few more things that had been missing from my memory of the last seventeen years. I did a lot of praying and asking God to help me out! I knew my husband was trying to help, but he would act more like my father, which made it very difficult."

“At my one year checkup after the accident, just nine months after leaving the hospital, the Doctor didn’t recognize me. He was surprised about the progress I had made and told me I was one-hundred percent healthy, both physically and mentally healthy. Most patients with head injuries as severe as mine they can barely talk, much less take care of themselves and their families. My chances of getting this healthy was less than five percent. I was able to return to work, but in an office not working directly with the cattle. I was good at my job, my organization skills and math were amazing, but with any brain injury you lose the filter in your brain, and I would say whatever I wanted. I would not always say appropriate things, and that made my co-workers uncomfortable. I was asked not to return to work. I didn’t understand that what I was saying was offensive. I have since been employed to clean offices, work with marketing and retail, and have learned to rebuild those filters of what is and what isn’t okay to do and say. I have excellent organization abilities and I help different businesses get everything organized. I also have my own business where organization is key, and am doing very well and enjoy the work. Better yet, I can work as hard as I am able to and take brain breaks anytime they are needed. I have always been artistically talented, so I also paint, draw or sew in my spare time.”

“In the future I would like people to be educated about brain injuries. I organized the Traumatic Brain Injury Survivor Support group for the Dickinson area, and I help families and people who encounter brain injury any way I can by providing support and information. I use humor to help them cope, and share as much as I can to help them make their life better with all these new complications. I remind them God didn’t give up on them, so why give up on themselves?”

“I would like to see services for individuals and their families that need assistance in locating resources, which are available in more ways than just the internet. It would be beneficial to have a place to help you find options that might give you a better understanding of people who are suffering in this scary, new brain injury world they have been thrown into. I look totally fine and healthy, but that doesn’t mean I don’t have problems and daily struggles. I have a hidden injury and that makes it that much harder for people to believe it is real. I have discovered that music helps me concentrate. Also, having a journal to write my thoughts and experiences down helps to rebuild the memory and bring back some happiness on those ‘I can’t do it’ days.”

Craig - My Invisible Injury

Craig Anderson is a 24 year old, sharing his story with me in a dimly lit room, with little noise. He is effected by bright lights, noises and needs to rest several times a day to get brain energy to do simple tasks. Craig went from being an outgoing fun loving person to showing little emotion and then becoming angry.

Craig was having a difficult time concentrating, asking me to repeat questions and think about his responses from what he calls “an invisible injury”.

This is Craig’s story:

On September 12, 2014, Craig was working for a construction company in Fargo, ND. He was up in the boom lift by a house with a flat roof, working, and a bee hive was right by the house. Not a big fan of bees Craig remembers being in a hurry to get up and complete the work and get out of there. As the lift reached its height above the house the boom head jumped out of the cradle, unable to lower the lift, Craig had to use the weight of his body to release the spool for the strap and the bar slipped out. When the bar slipped, it jolted Craig, making him fall into the side of the lift hitting his head. The other workers came up and asked Craig if he was ok. Craig remembers he did not lose consciousness, but was seeing stars, taking him a few minutes to figure out what had happened. He was able to lower the lift, called his company, was asked to finish the job and went back up in the boom lift. Upon going up he became disorientated and was unable to complete the job or lower the lift. Another worker arrived, went up in another lift and assisted him to lower the lift he was in. Due to Craig’s injury he was taken to Worker Force Safety and Insurance (WSI) to explain his injury. By the time he arrived at WSI he could not remember how the injury occurred, so they encouraged him to go home. Craig went home and laid down. He did not remember the rest of the day.

He started working with WSI, seeing Doctors and had gone through several tests, and told several times that he should return to work. Having been released to work, he returned to his job a few hours a day. Still struggling with his inability to manage his thoughts, headaches and an irregular sleep pattern he was terminated. His supervisor texted him telling him he needed to grow up, stop acting childish and be a responsible adult.

Craig was sleeping 20 plus hours per day, unable to prepare food, or complete simple activities of daily living. He was missing scheduled appointments and unable to manage a schedule without help from his mother.

Following the return to work release, Craig and his mother were visiting and Craig became angry, pushing his mother. This was a sign that Craig was no longer Craig. He had never been that angry or disrespectful to his mother.

Today, Craig has an open case with WSI, focusing on work reentry, and attending scheduled Doctor’s appointment as required by WSI. He is scheduled to attend classes and take the IME test, which will help identify employment interests. A big concern for Craig is losing his WSI benefits as this is his only source of income.

Craig feels the best treatment has been the Cognitive Therapy offered at Progressive Therapy Associates. This has helped him learn to use a planner to follow a daily schedule, and learn how to use brain energy to do as much as possible each day. He still needs frequent rest breaks to complete Activities of Daily Living. He also attends a support group sponsored by Progressive Therapy Associates were he has met other young people. He has joined a Rec Volleyball league and feels this helps with his social skills. These are services Craig is paying for on his own.

In the future Craig would like to educate young people and the public about the effects of concussions and brain injuries. He recommends services be available for assistance with daily routine, someone to assist with cooking, laundry, transportation, and medication assistance. For financial support, he suggests not having to fight to receive services, by seeing physicians and going to classes that are not scheduled according to person's ability to attend. He would also like to see medical staff that understand Brain Injury and how it affects your life. Craig wishes people would have known him before his brain injury.

John - Run John Run

John lives a busy lifestyle, likes to be around people, and works at making a difference in people's lives. In October of 2013, John encountered an event that nearly ended his abilities to make this difference.

John finished work on October 27, 2013 following his shift at the University of Mary College, as a Food Service Manager. While John was driving home on his scooter, he saw a headlight, turning to his left, he saw a big white bumper, and was slammed into the back of the scooter being thrown one-hundred and eighty-five feet. John blacked out on impact, but does remember getting up and wandering around calling 911, giving information about the accident and hanging up after telling them to get an ambulance out there. John credits an ICU nurse on the way to work, as his "Angel" who stopped to help with the accident. John feels she saved his life.

John was transferred to St. Alexius Hospital in Bismarck, needing, immediate surgery for internal bleeding. He also encountered broken bones in his face, broken ribs, a broken vertebrae and a large cut on his head, which required twenty-eight staples and two units of blood. Following the surgery, John's anticipated stay was two weeks for recovery and Inpatient Rehabilitation. John states "I am a quick healer and don't like to sit around". He requested to leave after five and a half days. His plan was to heal at home and do therapy on his own. He was discharged home and received a prescription for pain medication.

During John's recovery he was healing and getting better each day but the pain medication became a "natural habit" and when he was no longer able to refill the prescription he began to substitute alcohol. John, determining a need for help, eventually checked himself into alcohol treatment and is successfully maintain sobriety and keeps busy with his employment.

Following his recovery, John was able to return to work in December, however, the drive past the accident site was disturbing, therefore, John finished out the school year and choose not to return the following year. He was able to establish new employment working more than 40 hours per week successfully. He also has his own business.

The after effects from the accident leave John with short term memory loss and post-traumatic stress disorder (PTSD), a mood disorder that results in anger issues, which have affected his ability to deal with daily situations. These include incidence of being denied public services due to anger outbursts.

It was also difficult for John to schedule an appointment with a Doctor for his PTSD, as they were booked several months out and financial difficulties left John without his medication for his PTSD. John is now happy to report he has an upcoming appointment to help with this disorder.

John still has some difficulties, but always wants to keep busy and is willing to help others. John will continue to work with the Brain Injury Advisory Board to help others who encounter life changing events.

John's future includes working with Legislation to help people get needed counseling, and follow up services following a Brain Injury. He targets himself as one of the lucky ones and was able to return to work.

John has started fund raising events to assist ours with the same difficulties.

Joe - Trying To Get Better

I had a great childhood. I was a smart curious kid. I enjoyed my youth, goofing around, being daring, getting suspended from school for silly things, but I was very smart. I never needed to study, I always had good grades. I was in the ND State Spelling Bees, in 5th, 6th, 7th, and 8th grade, receiving the Presidential Award in 6th grade. I went on to college and received an Associate Degree in Sales and Marketing. I was proud of my accomplishments.

I am not proud of my life today. I am 35 years old, codependent on my parents for a place to live, financial support and my mother helps me make doctor's appointments for my ADHD.

I should not be alive, I should be a vegetable. I nearly died from a Heroin overdose in 2014. This along with being in and out of jail for 37 months of my life for alcohol, and drugs, not including the many inpatient and outpatient treatments. I have lived in many places with many people and done many things.

My Brain Injuries are a big part of my life. I never had legal issues, until I hit my head. People don't understand what is going on in your head. I can't concentrate, my mind wanders, I have headaches, and my anger and impulsivity are linked to being stupid and arrogant. If I ask too many questions or don't understand they think I'm are smarting off. My life "sucks". I don't like where I am in life, but holding out for a better future.

My first injury was at age 16 in 1997. I was rear-ended by a car on my way to confirmation. Following this accident I did receive therapy for my visible injuries. I had severe headaches following this accident and required injections to cope with the headaches. I did attend physical therapy for back pain, but no further treatment for the changes in cognition.

In between my first accident and 2006, I had sports related injuries, I was in fights and when I asked too many questions in the correctional system I was put down or beat up. It took me a long time to learn to "shut up."

On New Year's Eve in 2006, I encountered a blow to the head as I was driving my girlfriend's car going down University Ave., in Fargo, ND. I had mixed a drink put it in the car and took off. A lady failed to yield at a light and I was T-boned by her van.

I don't remember much of the accident, my brain was foggy, and the police were asking me so many questions. My first memory was at the hospital. I know I was bleeding from my face and my knee was aching. The police followed the ambulance to the hospital wanting me to take a breathalyzer, because of the drink I had in my car. I can understand them requesting this as I did have a drink in the car, but had not had a drink. I started arguing with the police and the nurses, the nurses sided with the police and I now realize that is a no win situation. I did finally agree to blow in the breathalyzer and was unable to blow air due to blood coming out of a punctured hole in my check. I had a hole in my check and my thoughts were "the police don't care." I couldn't remember who was in the car so I kept asking for my girlfriend. I was concerned about my girlfriend, demanding that they tell me she was okay, not realizing she was not in the car with me.

During my time in the Emergency room an assessment or treatment for a possible head injury was never questioned. I did pass the breathalyzer, they wanted me to get up and hop, again arguing that I could not hop due to the pain in my knee. I was given crutches, had stiches in my cheek and was discharged. Again, I was never evaluated for a brain injury, even though I lost consciousness. I had struck my head, had a knee injury and a laceration on my cheek. I did receive information for follow up appointments for my knee and cheek. I followed through with the appointments to re-check my knee and had the stiches removed, but did not mention or request follow up for the change of processing, impulsivity or change in my behavior or cognition.

I spent much of my next years in and out of the correctional system for things I am not proud of, and learned the hard way not ask to many questions or make the guards mad. I did assist a lot of the other prisoners with education and tutored many of the prisoners. I learned to cope with the thoughts in my head and move through each day.

My most recent brain injury occurred in 2015 while driving a dirt bike, resulting in a crash where I struck my head. I did not have a helmet, and broke my clavicle. I was taken to the emergency room to be evaluated and told it would heal. I feel that my lack of insurance determined the treatment. No evaluations were done for the knock on my head and I did not question a possible brain injury. Today, I struggle with the brain injury and have a clavicle bone that did not heal properly.

Though I am certain I have had many brain injuries, I now focus on getting my life together. I currently receive support and help from Progressive Therapy Associates through cognition training and scheduling. They have me using a planner and following time lines. My parents and family have been my support system. I am hoping the new medication for ADHD will also help in straightening out my life. I have lived in the state of Minnesota and they were helpful with housing and a food allowance, which is better then what they offer in North Dakota. They offer many more services to individuals with disabilities and want you to be successful. During my multiple treatments, I have never had anyone address or help me with my brain injuries.

I would like to see more halfway houses to help individuals who also suffer from drug and alcohol addiction that could also deal the brain injury. I feel we need assistance with job placement, job retraining. Doctors and law enforcement who can communicate with individuals with disabilities as well.

I plan is to stay clean, work on getting a job and to live by my 7 year old daughter.

Summary of Findings

The ways in which brain injuries occur and then manifest themselves in individuals is highly varied (CDC, 2015). Motor vehicle accidents, falls, sports injuries, strokes, aneurysms, and a myriad of other conditions and events can result in brain injury. Thus, by nature and definition, brain injuries are often idiosyncratic; that is, they are specific and individualized to the person with the condition. Of course, this means that services and supports must often be individualized to the conditions, needs, and circumstances of the affected survivor. There is no "one way" to best serve all individuals with brain injury.

Major Theme for These Findings. What is clear from this needs assessment is that there are significant findings that make individualized services and supports difficult for citizens of North Dakota. An overarching theme of the significant findings suggests:

> For people with brain injury in North Dakota, services and supports for the condition are few, are disparate, and are disjointed.

The findings of this needs assessment suggest that North Dakota does not have the full complement or in some cases sufficient options, for many of the services that brain injury survivors need. For example, ND has several Level 2 trauma centers at hospitals that can provide immediate care and stabilization for persons with a brain injury. However, the highest level of care, Level 1 trauma centers, does not exist within the state. Individuals who need that level of service and support must be transported out of state. Further, there are few neurologists who specialize in brain injury and few psychologists with expertise in counseling and supports for people with brain injury.

Second, there are disparities in access to existing services. Not surprisingly, some of these disparities are geographically defined. If one lives in or near a larger community such as Fargo, Grand Forks, Bismarck or Minot, access to service providers is greater than someone from a more rural community. Given that 36 of ND's 53 counties (68%) are designated as frontier (the most rural designation in the US Census system classification), this is problematic. Access to professionals and service agencies, when they exist, is compounded by where one lives.

A second feature of disparity has to do with classification or categorization of the disability. There are many programs and services available for people with varying disabilities (e.g., developmental disability, intellectual disability, mental health disability, addiction, etc.) across the state. However, the classification or categorization name can either facilitate access to services, or inhibit access to services. For example, if an individual with an addiction and a brain injury is labeled primarily (first) as someone with a brain injury, access to services for the addiction can be compromised. Similarly, if one has a primary diagnosis of physical disability (and not brain injury), that individual may have better access to therapeutic supports than someone with the reverse diagnosis (brain injury first, and then physical disability).

Finally, the existing services and supports are often disjointed. A term frequently used in the literature on brain injury is "continuum of care" (see Goki & Akakari, 1994). This terminology suggests that there is a range (continuum) of services that are interconnected. Service providers in one specialty area are knowledgeable about the range of options and are linked to other providers and specialists along the continuum. This is done so that patients (survivors) do not fall through the proverbial "cracks" in services. Ideally, there would be no cracks.

But our findings suggest that there are cracks, and sometimes chasms, in the service system. Survivors often spoke about how they were either given little, or no, or incorrect information for the next steps in their recovery journeys. They spoke about how providers often didn't know about next steps. And some were told to simply Google options for services once they left the hospital. There appears to be only isolated and sporadic instances of service coordination for brain injury in North Dakota.

Major Findings in This Needs Assessment

Given the vast amount of data from this needs assessment, one can find individualized findings that point to specific cases or circumstances. Rather than list any and all findings, we reviewed all the data to develop the previously mentioned theme statement, and then the following list of major findings. One should consider these major findings in the context of the context of a continuum of care, which examines systems and services from the initial injury and treatment, through the processes of acute therapy, initial in-patient rehabilitation, transitional services, out-patient community-based services, and ongoing services and supports. It is difficult to state that a particular finding applies to only one phase or stage of the continuum. In many cases, such as family participation in the recovery process, or care coordination for the survivor, the findings flow across the continuum. The major findings, not listed in any order of importance, are:

1. **Overall, there are insufficient services for people with brain injuries.**
   a) There is a lack of a continuum of resources, supports and services for brain injury in North Dakota and there are disparities across the state.
   b) Brain injury and the associated conditions impact daily functioning people with brain injury and impact their access to services.

   c) There are problems with care coordination across existing programs within the state.
   d) Families reported a high need for family and survivor support systems.
   e) People with brain injury need transitional services, case management, employment supports, and transitional housing.
   f) Participants reported frustrations and problems with eligibility for access to treatment for brain injury, especially after hospitalization.

2. **Overall, there is insufficient education and training about brain injury and its impact on individuals, families and the community.**
   c) North Dakota needs more public education about brain injury.
   d) Various service providers, medical personnel, and community agency staff need education and training about working with people with brain injury.
3. **Overall, there are insufficient data systems and reporting processes for determining accurate census information on brain injury.**
   c) Definitional variations between the state definition and national reporting systems makes state to national comparisons difficult.
   d) Current in-state data collection systems are not coordinated to show a comprehensive picture of the numbers of citizens needing brain injury services.

1. Overall, there are insufficient services for people with brain injuries.

We did not find evidence of a state-wide system or continuum of services and supports specifically for individuals with brain injury. There were both in and out of state options for initial treatment and care for the injury in Level 1 trauma centers (only out of state) and Level 2 trauma centers (in state). There did not appear to be state-wide system for care coordination (see more on this in item 9 below), but we did find that some programs provided this service (e.g., ND Brain Injury Network staff) in certain circumstances. Further, there were inconsistent reports of knowledge about resources that were available on brain injury. For example, some individuals stated that NDBIN had great resources and supports (such as the ND Mind Matters conference). But others had no knowledge of ND BIN or any other state or national clearing house or resource center of materials (such as the CDC website). The data suggest that there are some geographical disparities in services and supports. For example, private providers such as Progressive Therapy and Onward Therapy provide services to clientele predominantly in eastern ND. There does not appear to be a similar provider or system in central and western ND.

The questionnaire responses, and in particular the personal stories, tell about how a brain injury, and the associated conditions, impact people with brain injury. Survivors experience related medical, social, communication, perception, cognitive functioning, mobility, and many more difficulties in their lifelong recovery. Attention problems impact work performance. Anger impacts social relationships, housing access, and employment. Medical needs impact financial status, attendance at work, and physical endurance and emotional states. These impacts complicate life, and recovery, for citizens with brain injury.

Care coordination is a term used to denote the linkages and communications amongst providers and service recipients within a system. The basic idea is that the individual receiving services, and those providing services, are in consistent, constant communication so that all necessary and available and appropriate services are provided. This extends from pre-eligibility through to ongoing follow-along in services. Participants said they need assistance navigating and accessing the various eligibility determinations, services, and financial limitations. There were variations in access to and success of care coordination across the state.

Survivors who attend support groups or other sponsored meetings such as the statewide brain injury conference state the great importance it has in their lives. They get a chance to talk with others about their struggles and possible solutions. They feel at ease around others who are more likely to understand them than the general public does. Unfortunately there are relatively few support groups across the state, and some are not well attended. In addition, while families provide many meaningful and important supports for survivors, they stated that they could easily burn out. They worry about the future of their family member with brain injury. At times, these family members are the only support that the survivor receives. When they are no longer able to provide that support, they worry about what will happen. Some family members attend support groups, but again, there are few in number across the state, and often families attend because they are providing transportation for a survivor. It is not clear if there are any specific support groups or support programs for family caregivers.

One common message from nearly every constituent was the necessity of transitional services. Clearly, the initial brain injury and treatment is so important for long term survival and positive outcomes. But most of that comes through medical systems. When medical treatment ends, and when in-patient rehabilitation is no longer provided, the constituents expressed a great need for case management (see comments on care coordination later), and in particular access to supportive and transitional housing. Many individuals are not able to live on their own following medical rehabilitation. And many individuals do not have access to supportive families to either provide daily living and housing supports, or even financial supports. And so individuals are often faced with homelessness, nursing home services (which are not necessarily designed for those with brain injury), or unsupported living arrangements. NDCPD staff heard about the dire consequences when individuals do not have appropriate supports for housing and daily living skills. One comment often made to the authors was that people wished that individuals with brain injury had the same continuum of housing options as those people with developmental disabilities in our state.

Further, there was commentary about employment supports and services for people with brain injury. Some smaller pilot programs have started to demonstrate possibilities beyond typical employment training and support programs like Job Service or Vocational Rehabilitation. These pilot programs are examining the impact of ongoing, individualized employment supports for people with brain injury. However, the pilot programs are impacted by funding allocations and are limited in both the number of people served, and time constraints for the funding.

Access to services in North Dakota, and in nearly every situation where state and/or federal funding is used, requires some process for eligibility determination. It is rare that people do not have to “prove” that they have a condition, or level of need, or financial constraints or some other criteria to get a social service. This is easier when there are specific programs for specific groups of people. Unfortunately, there are few if any specific programs for people with brain injury in North Dakota. Thus, individuals must attempt to qualify for important services through other means. The participants in the needs assessment talked frequently about the difficulties in getting access to services once they left the hospital. Either the conditions for eligibility were too narrow, or were income-based, or were left to various other judgments such that individuals often didn't get services they needed. In some cases, the individuals actually have the finances to pay for services, but cannot access the services because they are reserved only for those without financial capability. In others, there are so few spots or options, that individuals are put on waiting lists with the hope that a space opens for them. And often the individuals must find these options on their own, and sometimes too late. Confusion and frustration was a common theme.

2. **Overall, there is insufficient education and training about brain injury and its impact on individuals, families and the community.**

Throughout the questionnaires, during the focus group meetings, in discussions with service providers, and in the personal stories, we found evidence that participants believe there is a need for increased community education followed by targeted group education and training about brain injury. Survivors stated that they though providers didn't always know about brain injury and associated conditions. Agencies reported a need for managing behavioral health needs of individuals and strategies for case management. And survivors reported that over half of their providers were somewhat knowledgeable or had no/very little knowledge or skill in providing services for brain injury. One consistent finding was the report of lack of specific knowledge about brain injury or post-injury services by medical and allied health professionals.

3. **Overall, there are insufficient data systems and reporting processes for determining accurate census information on brain injury.**

The national Centers for Disease Control and Prevention (CDC) reports that accurate incidence and prevalence data are lacking nationwide. In fact, the figures used for population estimates of traumatic brain injury are derived from two individual state studies, one of which is over 15 years old. The data on TBI in the national prison population is also variable, with suggestions of between 25% to up to 87% of prisoners having a brain injury. Further, there are differences in the ways that states collect data on brain injury. Some attempt to use registries, which have some inherent difficulties in definition and reporting compliance. Other states use other existing data sources such as hospitalization information, death reports, or trauma registries. However, these systems do not account for those who experience a brain injury and do not receive hospital or emergency room services. Further, there are ongoing issues with reporting compliance.

North Dakota has multiple measures and data sources that might lead one to believe we can get a good idea of the numbers of people with brain injury and stroke in our state. However, all of the issues mentioned above are factors in getting an accurate account. North Dakota does not currently have a brain injury registry. North Dakota has varying methods of reporting possible incidence figures on brain injury and stroke including the ND Stroke Registry, the ND Trauma Registry, data on TBI screenings at regional human service centers, concussion and head injury reports from high school sports, and numbers of students with a primary disability of TBI special education services within the state. However, all of the data reporting and compliance problems experienced nationally are experienced in North Dakota. This is further compounded by the differing definitions used. Some reporting systems use the older state definition of traumatic brain injury and not the newer definition of brain injury which includes non-traumatic cases. Thus, until there are clear data collection systems that coincide with good national data systems, and consistent definitions of brain injury, there is not likely to be a definitive answer to the question about how many people with brain injury are in North Dakota.

Limitations

Every research study or needs assessment has limitations, and this report is no exception. The authors urge readers to consider these issues when using and interpreting the data. The first issue has to do with the limited access and thus responses to our questionnaires and focus groups. While we had nearly 300 responses across the four questionnaires, and over 70 participants in the focus groups, these are rather small numbers when one sees that there may be over 22,000 individuals with brain injury in our state. Thus, the findings only have significance for these respondents, and may not necessarily apply to all ND residents with brain injury.

Second, we were not able to get information on brain injury services, gaps and needs for all agencies. We do not have information overall on brain injury and the Native American population, the military population or the prison population in our state. All of these groups are cited in studies to have increased incidence of brain injury due to their unique population characteristics. Thus, we may be missing some important information from these groups.

This study was not designed to determine the actual utilization or effectiveness of specific services or systems in North Dakota. Thus, one should not suggest that something is or is not working as it was initially designed. Effectiveness of services for people with brain injury is difficult to measure (CDC, 2015), and cannot be done within a short time frame such as this needs assessment process.

Finally, this needs assessment is really just a short time-frame snapshot of information, needs and gaps within the state. There is ongoing work at the federal and state levels regarding services and supports for people with brain injury. One should not suggest that this is a comprehensive definitive picture for North Dakota, but should rather view this as one more piece in analyzing our programs and making decisions about future actions.

Brief Comparison of this Needs Assessment with the 2005 North Dakota Needs Assessment

NDCPD staff were asked to do a brief comparison of the findings of this needs assessment with the major findings of the 2005 needs assessment. In 2005, staff from the Center for Rural Health at the University of North Dakota published a report entitled *Findings from the North Dakota Assessment of Traumatic Brain Injury Needs and Resources*. This report was supported by federal funding from the Health Resources and Services Administration at the US Department of Health and Human Services. The intent of the report was to examine services and resource needs for persons with traumatic brain injury in the state.

One major conclusion of the report was that the state did not have a comprehensive system of services and supports for people with TBI. The authors suggested that the current system was “fragmented” and did not address the needs of people with TBI. The 2005 report lists several major findings including a need for increased access to TBI information, a need for education, training and awareness on TBI, enhanced services for people with TBI, and increased supports for people with TBI and their caregivers, particularly family caregivers. The authors also listed several barriers such as a shortage of TBI advocates, no central source of information or resources, lack of knowledge by individuals about TBI services, inadequate financial resources, lack of individualized services and an overall lack of understanding of TBI by service providers. An Action Plan was suggested by the authors of the 2005 report. This plan included the major themes of Sustainability, Education and Awareness, Enhancement of Services, Supports, and Tribal Issues. Objectives and action items were proposed in the plan.

Near the end of the current Needs Assessment process, NDCPD staff were asked to comment on the comparisons of results between the 2005 study and the present needs assessment. Our brief analysis indicates that the overall conclusions between the studies, along with many of the barriers to services are exceedingly similar. The 2005 report stated that “North Dakota does not have a comprehensive system of services for individuals with TBI.” And the existing services are fragmented and do not adequately address the needs of citizens with TBI. Our major finding is that “For people with brain injury in North Dakota, services are few, are disparate, and are disjointed.” In other words, one might say the results are the same after 11 years.

Both studies found similarities in the need for ongoing community and provider education about brain injury. Participants in both studies asked for individualized services, better financial resources and eligibility systems to access services, and some mechanism for case management or care coordination. Participants also indicated a need for support systems (emotional, counseling, etc.) for people with brain injury and for their caregivers.

The present study provided a review of data collection systems on brain injury in an attempt to determine the incidence and/or prevalence of survivors in ND, and the 2005 study did not address this issue. Also, the 2016 report used a different definition of participants in the study. The 2005 report used the terminology of traumatic brain injury while the 2016 study used a much broader definition of brain injury along with the inclusion of stroke. The 2016 study report included personal stories of individuals with brain injury, while the 2005 study conducted a larger number of focus groups. Also, the 2016 report did not include recommendations for action or action plan steps. Finally, NDCPD did not conduct an analysis or review of the success, or lack thereof, of the action plan and steps. This was a conscious decision as there were a multitude of complex economic, political and societal changes that would clearly impact the implementation and success of the plan.

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