



Center *for*
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University of North Dakota
School of Medicine & Health Sciences

Findings from the North Dakota
Assessment of Traumatic Brain Injury
Needs and Resources

Kyle Muus, Ph.D.
Sue Offutt, Ph.D.
Mike Cogan, Ph.D.
Robin Medalen, M.S.W.
Erin Haugen, M.A.

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*Connecting resources and knowledge to strengthen
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Executive Summary

Traumatic brain injury (TBI) is an important public health problem that afflicts the citizens of the United States, as well as North Dakota. Through the North Dakota Department of Health's federally-funded TBI Planning grant, UND Center for Rural Health researchers and project staff conducted an assessment of needs and resources for persons with TBI and their families in the state. Two assessment efforts, focus groups and surveys, were implemented in 2004-2005 to gain insight into the most pressing needs for persons with TBI and their families. Four distinct groups were targeted for study participation: individuals with TBI; TBI caregivers; TBI agency representatives; and TBI service providers.

Focus group discussion yielded four prominent themes: increased access to TBI information and resources; increased TBI education, training, and awareness; enhancement of TBI services; and increased support for persons with TBI and their families/caregivers. Via surveys, individuals with TBI indicated prominent obstacles for accessing TBI services. Their most frequently mentioned barriers included a shortage of strong TBI advocates, absence of a centralized source of TBI information, inadequate knowledge of TBI services in the state, inadequate personal financial resources, lack of individualization of TBI services, and lack of understanding of TBI by service providers.

Using the assessment findings as a framework, TBI staff and members of the TBI Advisory Committee developed a plan of action to address the needs of North Dakotans with TBI and their families. This plan (Appendix B) serves as a blueprint for improving the life circumstances of these persons through sustainability, education and awareness, enhancement of services, and increased support.

Introduction

Traumatic brain injury (TBI) is damage to the brain caused by an external physical force that may produce a diminished or altered state of consciousness (BIA, 2004). This injury causes impairment of cognitive, physical, behavioral, and/or emotional functioning. TBI-related disabilities tend to be permanent but can improve over time with rehabilitation, accepting and coping with the disability, and learning compensatory strategies to offset deficits (Smith & Greenwald, 2003). TBI is an important U.S. public health problem; however, since the problems due to TBI are often not visible (e.g., impaired memory) and public awareness is limited, it is frequently referred to as the “silent epidemic” (BIA, 2004).

TBI is a leading cause of morbidity and mortality among children and young adults in the U.S. (Thurman et al., 1999). Each year, approximately 1.5 million Americans incur a TBI (Sosin et al., 1996), of which about 230,000 are hospitalized (Langlois et al., 2004). Annually, about 80,000-90,000 persons are permanently disabled from TBI in the U.S. (Langlois et al., 2004). Each year, approximately 50,000 Americans die from TBI, accounting for one-third of all trauma-related deaths (Sosin et al., 1995). Adolescents, young adults, and elders are most likely to incur a TBI (CDC, 1997).

Falls are the leading cause of TBI, accounting for about 28% of all cases (Langlois et al., 2004). Among young children and elderly persons, falls are the leading cause of TBI. The second leading cause of TBIs is motor vehicle crashes (MVCs; 20% of TBIs). Violence (e.g., assaults) is the third most common cause of TBI (11% of all cases) and a leading cause of TBI for persons aged 25-34 years (Dawodu, 2005).

The estimated financial impact of TBI in the U.S. is approximately \$37.8 billion per year (Max et al., 1991). Entailed in this estimate were the following: \$4.5 billion in direct expenditures

for health care services; \$20.6 billion in injury-related work loss and disability; and \$12.7 billion in lost income from premature death. In addition, TBI levies immeasurable physical, mental, and emotional costs against family members, loved ones, and friends (Thurman et al., 1999).

North Dakota does not have a reliable method for monitoring the number of TBI incidents. Thus, National TBI percentage estimates must be applied to state population to derive approximate rates of traumatic brain injuries, deaths, and disabilities. According to CDC estimates, North Dakotans experience the following TBI-related incidents per year: 112 fatalities; 431 hospitalizations; 2,281 emergency department visits; and 153 disabilities. Approximately 12,844 North Dakotans are currently living with one or more TBI-related disabilities, based on national TBI incidence estimate of 2 percent.

History of TBI Programs in North Dakota

Efforts to address the problem of TBI in North Dakota began in the 1980s with the formation of the Head Injury Association of North Dakota (HIAND). This Association's board of directors consisted of representatives from a mix of public and private entities whose concerns and interests spanned the spectrum of TBI from prevention to treatment to rehabilitation. The organization obtained federal IRS 501c3 status and began receiving charitable donations. A grant from the Rocky Mountain Brain Injury Center further strengthened the organization and increased its visibility.

In 1987, the HIAND introduced legislation that established TBI as a mandated reportable medical condition and required the North Dakota Department of Health (NDDoH) to establish a TBI Registry. The legislation was passed, mandating TBI as a reportable condition by a physician or medical facility and required the NDDoH to establish and maintain the registry. However, the

legislature did not provide funding to establish and maintain the registry. Soon thereafter, the NDDoH was the recipient of a CDC injury surveillance and prevention capacity building grant. Funding under this initiative was utilized to establish the TBI registry.

A significant drawback to the TBI surveillance system was that the system relied on participating medical facilities to voluntarily complete an injury report card on TBI cases and forward the case report card to the NDDoH. The injury report cards were generally completed in emergency departments and in most instances, reflected preliminary diagnoses. The injury report cards did not contain any treatment or discharge disposition information.

In 1989, the HIAND introduced legislation that established the North Dakota Department of Human Services (DHS) as the lead agency in North Dakota for delivery of TBI services. This legislation also required the NDDoH to provide to the DHS, the names and addresses of individuals who were listed in the TBI registry. Under the new legislation, DHS was to forward to these listed individuals information on medical, rehabilitation, and social services that were available in North Dakota. A joint effort was undertaken by the HIAND, the NDDoH and DHS to develop a brochure with the service-related information for individuals with TBI. The brochure contained the following information:

- a. a list of health facilities that offered TBI-related acute care and rehabilitation services;
- b. contact information for the DHS regional offices across the state;
- c. contact information for the NDDoH's Injury Prevention Program; and
- d. contact information for the HIAND.

The NDDoH maintained the TBI Registry until 1994 when the CDC surveillance and prevention funding ceased. As the surveillance system was reliant on voluntary submission of injury forms and had no dedicated funds to maintain it, reporting compliance among participating facilities

dropped off significantly. In 1999, the TBI reporting and TBI registry statute was repealed by the legislature at the request of the NDDoH. During this same time period, the grant funding for the HIAND expired, their executive director resigned, and the association became inactive.

The Indigenous Peoples' Brain Injury Association (IPBIA) was established in 1994. This Association, established for the benefit of all tribes in North Dakota, is composed of consumers, families, and service providers. The IPBIA has become a recognized leader in the area American Indian TBI issues and has hosted a national conference on TBI.

In 1994, North Dakota received approval for a home and community-based services (HCBS) Medicaid Waiver for TBI to enable eligible individuals to choose between receiving care in an institutional care setting or in their own home with the assistance of various community-based services. The TBI Waiver currently serves 28 individuals with TBI unduplicated per year, for the 2005 federal fiscal year. There are fifty-three slots available. The TBI waiver is a five year program that ends in 2007 and is subject to federal review for renewal in 2006. Currently, such services are being provided through the Waiver in four North Dakota counties: Stark; Morton; Burleigh; and Barnes. The average number of individuals on the Waiver is approximately 30 persons. The overall average cost per person on the Waiver is \$2,447.99.

During the 2005 ND legislative session, Protection and Advocacy advocated for Medicaid to immediately allow money to follow one person as they transitioned from institution care to home- and community-based services. As a result, the DHS Division of Medical Services has committed to full funding for a specific young person with intense health care needs, to move from a nursing facility to a private apartment. Following this pilot effort, there could be broader implementation for persons who can establish a reasonably safe plan for home- and community-based services that is approximately cost-neutral.

In April 2003, the DHS was awarded a TBI Planning Grant from Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau. The DHS was unable to administer the grant and subsequently transferred the funds and responsibilities to the NDDoH. The University of North Dakota School of Medicine's Center for Rural Health (CRH) was selected as the contractor to form the TBI advisory committee, conduct the statewide TBI needs assessment, and write a plan of action to address the needs of North Dakotans with TBI and their families. Prior to submission of the grant, the HIAND became reactivated. The Association has recruited new board members, conducts meetings on a regular basis, and has co-sponsored a statewide TBI conference in each of the last few years.

Overview of Current TBI Services in North Dakota

North Dakota does not have a comprehensive system of services for individuals with TBI. Those individuals who are eligible for the 1915(c) Medicaid Waivers for Home and Community Based Services for Individuals with TBI (i.e., TBI Waiver) in general have better services and supports. Availability of services under the waiver depends on a multitude of eligibility factors. North Dakota has a fragmented system of services and supports that does not address the comprehensive needs of children, adolescents, adults, and elders with TBI. The following section provides an overview of TBI-related agencies, programs, and services.

TBI Waiver. A 'Medicaid Waiver' is an agreement between the Centers for Medicare and Medicaid (CMS) and a state's Medicaid Agency to provide specialized services not generally available under Medicaid to those qualifying for home and community based services. The goal of the waiver is to support individuals with TBI to obtain their optimum level of independence in their communities. Services and supports covered in the TBI Waiver include: behavioral

management/programming; case management; chore services; environmental modifications (limited); non-medical transportation; prevocational services; residential care; respite; specialized equipment and supplies; substance abuse counseling; supported employment services; training for family caregivers; and transitional living. Services are provided through eight local organizations that have been approved as TBI Waiver providers. To be eligible for the TBI Waiver, an individual with TBI must: be a Medicaid recipient; have had a neuropsychological evaluation; have been diagnosed with TBI or acquired brain injury; have been screened and determined eligible for nursing facility level-of-care; be age eighteen or older (cannot be under an Individual Education Plan); be disabled as determined by Social Security Administration criteria; and be capable of directing his/her own care or have a responsible party acting in the recipient's behalf, as determined by the Individual Care Plan (ICP) team.

Residential and Transitional Care Services. North Dakota has five specialized TBI service agencies: Dacotah Alpha, Mandan; Dakota Pointe, Bismarck; H.I. Soaring Eagle Ranch, Valley City; Enable, Bismarck; and Support Systems, Bismarck. These agencies provide a variety of services and programs designed specifically to meet the needs of individuals with TBI. Examples of such services include: daily living skills; pre-vocational and vocational training; social and recreational activities; behavior management; support groups; supported residential services; residential treatment; medication administration; cognitive rehabilitation; and transportation.

Hospitals. North Dakota has 45 hospitals with 33 designated as trauma centers. North Dakota does not have any Level I trauma centers, but it does have six Level II trauma centers: St. Alexius Medical Center, Bismarck; MedCenter One, Bismarck; MeritCare Hospital, Fargo; Innovis Health, Fargo; Trinity Hospital, Minot; and Altru Hospital, Grand Forks. The overwhelming majority of the state's trauma centers are at Level III or higher. St. Joseph's Hospital in Dickinson is the only Level

III trauma center. In addition, there are twenty-one Level IV trauma centers, and six Level V trauma centers. Given the vast geography of the state and the limited presence of Level II trauma care, patients with moderate to severe head trauma often require lengthy ambulance transport times.

Altru Health System, Grand Forks, is the only North Dakota facility that is licensed to provide specialized acute rehabilitation services. There are six other hospitals (Ashley Medical Center in Ashley; MedCenter One in Bismarck; St. Alexius Medical Center in Bismarck; MeritCare Hospital in Fargo; Union Hospital in Mayville; and Trinity Hospital in Minot) that provide sub-acute rehabilitation services. The quality of case management, family education, and discharge planning varies among facilities; the time duration for services is dependent on the individual's insurance coverage.

Head Injury Association of North Dakota (HIAND). The mission of HIAND, according to its by-laws, is to: advocate for the head injury population of North Dakota, establish support groups for survivors of head injury and their families; network information; bring awareness to the public; provide prevention programs; become allied with facilities, organizations, government agencies and local and national leaders for the purpose of bringing quality of life and coping mechanisms to those involved with head injury.

Indigenous People's Brain Injury Association (IPBIA). Goals of the organization are to: have the best possible recovery for the loved one who has sustained a brain injury; allow for understanding that there is a need for both Native American Healing Philosophy and Western Medical Conceptions when addressing TBI issues; track, educate, support and advocate for brain injured people and their families; and understand that prevention is the only cure for TBI.

Division of Vocational Rehabilitation (DVR). Vocational Rehabilitation provides training and employment services to individuals with disabilities so they can become and remain employed. The

North Dakota DVR has a responsibility to serve anyone who is eligible and living in the state. The state VR program coordinates with the Tribal 121 Vocations Rehabilitation Projects in North Dakota to serve American Indians with disabilities. American Indians can choose to receive services from state and/or tribal Vocational Rehabilitation programs. Limitations on the length of time that DVR can serve an individual means that these services do not fully address the long-term employment supports required by many individuals with TBI.

Division of Aging. In addition to being home to the TBI waiver, Division of Aging administers programs and services that assist older adults and people with physical disabilities to live safely and productively in the most appropriate and least restrictive setting. The Division administers programs, including the Home and Community Based waiver for the Aged and Disabled, Service Payments for the Elderly and Disabled Program (SPED), Expanded Service Payments for the Elderly and Disabled Program (Ex-SPED), and Older American Act Services. Some of their provided services include personal attendant care, case management, homemaker services, transportation, respite care, and adult day services.

Human Service Centers. The North Dakota Department of Human Services operates eight regional human service centers. Each serves a designated multi-county area, providing counseling and mental health services, substance abuse treatment, disability services, and other human services. These centers provide services that help vulnerable North Dakotans of all ages to maintain or enhance their quality of life, which may be threatened by lack of financial resources, emotional crises, disabling conditions, or an inability to protect themselves. These agencies support the provision of services and care as close to home as possible to maximize each person's independence while preserving the dignity of all individuals and respecting their constitutional and civil rights.

Developmental Center. The North Dakota Developmental Center is a state-operated, comprehensive support agency for people with mental retardation/developmental disabilities. The agency provides specialized services and acts as a safety net for people whose needs exceed community resources. The Developmental Center does serve individuals with TBI.

North Dakota State Hospital. The State Hospital provides psychiatric and chemical dependency treatment to North Dakotans who require in-patient or specialized residential care. Inpatient services include short-term stabilization, trauma program, geropsychiatric services, and psychosocial rehabilitation services. A transitional living program on campus provides a residential level of care for individuals preparing to return to their home communities.

Nursing Homes. In North Dakota, there are 83 skilled nursing facilities that are licensed by the state and certified by the Centers for Medicare & Medicaid Services to participate in the Medicare/Medicaid programs. The number of persons with TBI that are residents of these facilities is unknown.

North Dakota Center for Independent Living (CILs). The purpose of Independent Living Services is to eliminate barriers and provide assistance to individuals with disabilities (including TBI) so they can live and work independently in their homes and communities. Some of the services used by individuals with TBI include independent living skills training, personal assistance services, housing assistance, transportation assistance, social and recreational activities, self and systems advocacy, peer counseling, and information and referral. Outreach services are provided to surrounding North Dakota counties and reservations.

North Dakota Protection and Advocacy (P&A). The P&A is an independent state agency whose mission is to champion the equality and inclusion of people with disabilities where they live, learn, work, and play. This program serves persons whose brain injuries occurred after birth, are relatively

stable, and cause significant impairments to one's emotions, behavior, or thinking. P&A advocates for people with TBI to receive individualized services in institutions and community settings, and investigates allegations of abuse and neglect of persons with TBI in cooperation with Aging Services Division. The program advocates for people with TBI to have meaningful choices in their vocational and pre-vocational services. Also, P&A highlights the needs of people with TBI when advocating for people with disabilities who encounter the criminal justice system and guardianship services.

County Social Service Boards. North Dakota has four counties (Stark, Morton, Burleigh, and Barnes) that provide case management services for individuals with TBI under the TBI Waiver funds. Additional services provided by the county social services include heating assistance, Medicaid, basic care assistance, home and community-based services and supports for elderly and disabled individuals, personal care assistance, and referrals to other local resources and programs.

North Dakota Association for the Disabled, Inc. (NDAD). NDAD is a nonprofit, charitable organization assisting the mentally and physically disadvantaged within our state, many of whom are not eligible for services from other agencies. NDAD works with a variety of agencies (i.e., local school districts, vocational rehabilitation, human service centers) to coordinate services for clients and to limit duplicative efforts. Services that are provided by NDAD include financial assistance, information and referral, and advocacy.

Focus Group Methodology

Focus Groups involving persons with TBI, caregivers, agency representatives, and service providers were used to measure perceptions of the accessibility and availability of services, barriers to service access and utilization, and unmet individual and program needs. The list of focus group

questions were developed by UND Center for Rural Health (CRH) researchers with input from members of the ND TBI State Planning Grant Advisory Committee. All proposed questions and prompts were reviewed by Advisory Committee members for appropriateness and social/cultural sensitivity. The final list of questions/prompts contained eight subject headings: introductions; medical services; transition services; employment services; general services; advice to a friend that has just sustained a TBI; best system of services; and additional comments.

In spring 2004, two focus group sessions (one for persons with TBI; one for TBI caregivers, agency representatives, and service providers) were conducted in each of ten North Dakota cities (total number of groups=20): Fargo; Valley City; Bismarck; Williston; Grand Forks; Standing Rock Reservation; Trenton; Fort Berthold Reservation; Spirit Lake Reservation; and Turtle Mountain Reservation. Before any focus groups could be convened, the CRH received study approval from the UND Institutional Review Board and obtained signed resolutions from each of the state's five tribal councils. Prior to the sessions, researchers obtained information on community resources, such as human service centers and social service agencies, which were available to participants in the event they experienced any negative emotions or feelings during the focus group sessions.

Since there is no registry for individuals with TBI, assistance with recruitment of subjects was necessary. A list of community and reservation contacts who work in the field of TBI assisted UND project personnel to distribute flyers and invitation letters to potential participants in each community. Community contacts were chosen based on their ability to identify and contact individuals with TBI and caregivers in their area. They were offered a \$100 stipend to assist in the project. Once contact persons from each targeted community were identified, the CRH required that they each sign and return a letter of agreement which pledged their willingness to assist in disseminating invitation packets to individuals with TBI, caregivers, service providers and agency

representatives. Each of the packets contained an invitation letter, focus group schedule, response card, and an informed consent form. Invitation letters were written in partnership with, signed by, and distributed by the community and reservation contacts. Once the researchers received the confirmation of participant interest, follow-up phone calls were made by the researchers to confirm the focus group's location and ascertain needs for special accommodations. Research staff spoke with each community/reservation contact person at least one day prior to the scheduled focus group meeting and verified numbers of participants and any special accommodations. As an incentive for participating in the focus group discussion sessions, a \$25 stipend was offered to those persons whose attendance was not part of his or her professional responsibility. In addition, financial reimbursement of travel expenses, such as mileage, meals, lodging, and child care, was available.

The focus group sessions were conducted in closed-door meeting rooms (for participant privacy) that were booked in advance by the community and reservation contact person(s). At each site, the two focus groups were conducted simultaneously but in separate meeting rooms. Each focus group session included 1-14 participants. The total number of participants/attendees for all focus groups was 184 (55 individuals with TBI, 46 caregivers, 65 service providers and 15 agency representatives). All individuals under the age of sixteen years of age were excluded from participation. Meals or snacks were served at each focus group meeting.

The researchers initiated each focus group session by discussing the study's purpose assuring attendees that their participation was voluntary and they may choose to not answer any questions or leave the group at any time during the discussion. Next, participants were asked to sign consent or assent forms. These signed forms were a requirement of the UND Institutional Review Board (IRB) when research studies involved special populations, such as persons with TBI. The forms were read to participants if necessary and were asked if they had any questions. Any

participant who had a legal guardian present was asked to sign an assent form and the guardian was asked to sign the informed consent form for the person for whom they safeguarded. After the forms were completed, researchers conducted the group discussions, which were typically two hours in length. A 15-minute refreshment break occurred at approximately one hour into the group discussion. At the conclusion of each focus group session, the participants were given a follow-up survey which solicited participants' demographic information and their most prominent unmet TBI service needs.

A tape recorder and microphone were used to record the content of the focus group discussions. The audiotapes were later transcribed by Center for Rural Health personnel in a manner that protected the anonymity of participants. Consistent with UND IRB policies, the tapes will be kept for a three-year period in a locked storage cabinet in the Center for Rural Health office. Upon completion of this time period, the tapes will be destroyed.

Focus Group Findings

The North Dakota TBI focus group data were analyzed by a core group of three researchers at the UND Center for Rural Health. Results of the analyses yielded four prominent TBI themes: increased access to information and resources; increased education and awareness; enhancement of services; and increased support.

Increased Access to Information and Resources

Participants from both focus groups shared the need for improved access to TBI information, including the availability of state resources and services for persons TBI and their families. At the initial onset of the injury, family members stated they were thrown into a new world, yet very little TBI information was readily available to assist them in understanding the

situation at hand. This issue appeared to be a significant problem in all regions of North Dakota, urban and rural alike. However, participants reported that urban-based hospitals provided TBI-affected families with TBI informational packets, whereas those patients and families in rural-based hospitals did not receive such information.

Service providers also expressed the desire and the need to be knowledgeable about the resources and services available to individuals and their families. Participants shared that individuals with TBI are often referred to services designed for developmental disabilities since those are the only services known to the providers. Some service providers and family members indicated they were attending the focus group to learn more about TBI-specific resources that were available.

Two prominent TBI resources in the state are the North Dakota Head Injury Association and the Indigenous People's Brain Injury Association. Some respondents felt these associations were important forces for improving services for North Dakotans with TBI; however, they stated the groups must increase their level of activity throughout the state. Some participants were unaware or confused about the roles and functions of these associations. Frequently mentioned by participants was the development of a centralized resource center with a toll-free number for quick and immediate access to information on general TBI issues, and the availability and location of TBI services in North Dakota. Some participants suggested that efforts should be made to ensure that all state-specific TBI information is socially and culturally sensitive/appropriate for persons with TBI and their families, especially Native Americans.

Increased Training, Education, and Awareness

A consistent message across all 20 focus groups was the need for training and education on TBI. Family members shared their frustrations in the lack of understanding of TBI by the

community, schools, medical professionals, law enforcement. and others. Individuals shared the same frustrations, especially as it related to their injury being misunderstood and not accepted by many individuals they encountered along their path to recovery. Service providers and agency representatives expressed the need for training that is specific to TBI since much of their training had been focused on meeting the needs of persons with developmental disabilities.

The suggested training content focused on many topics including the following categories: overall general information about TBI to include characteristics related to the injury and the effects based on the location of the injury, cognitive changes, changes in behavior as it relates to TBI, physical limitations, ongoing cycle of emotions for the individual and family, evidence based interventions and the differences between TBI, developmental disabilities, and other related disabilities. Among tribal focus groups, suggested issues for additional TBI training mirrored the aforementioned topics, but also these included the areas of dual diagnosis, alcohol abuse, and assistive technology.

When participants were asked to indicate which groups they thought needed additional TBI training, a wide range of responses were elicited. The most commonly mentioned groups included community residents in general, professionals, employers, vocational rehabilitation counselors, physical therapists, occupational therapists, speech pathologists, nurses, physicians, hospital staff, paramedics, teachers, case managers, teachers, tribal court officials, and judges. Also, focus group participants consistently mentioned that family members, spouses, siblings, parents and caregivers had a strong need to have increased access to information and ongoing training in order to better understand TBI.

Increased awareness of TBI was important message that was voiced in all focus groups. Many participants stated that public educational campaigns are needed throughout the state, as the

public generally does not have any knowledge of TBI and its associated impact on affected individuals; limited knowledge and understanding of TBI means there is limited tolerance and acceptance for persons with TBI and their families.

Enhancement of Services:

Medical

Overall participants shared that in order to get the best continuum of medical care, someone needs to advocate for the individual with TBI. As one participant stated, “TBI is not a medical problem but a life long problem.” Over time, increased sophistication of technology and advances in biomedical research will likely produce improved survival rates among persons incurring serious TBIs; thus, it is likely that the need for life-long care among persons with TBI will increase in the future.

Throughout all of the focus groups, participants spoke frequently and candidly about medical services as they relate to individuals with TBI. In the acute stage of care, participants expressed satisfaction with the care received. In the majority of instances this care was provided in urban health facilities. During this time, families shared that they were in “survival mode” where the focus was on getting the individual through the crisis stage. However, the need for information about TBI was frequently mentioned yet there was not a consistent manner in which that information was made available. Participants explained that the hospital social worker shared information packets with them while other participants stated that they had to search for information on their own. One frequent message heard from family members was how they became irritated when physicians would tell them, “There is no hope.” At the initial onset of the injury families shared that they clung to every ounce of hope and hearing such a message created feelings of anger and dissatisfaction with the medical care.

After the acute stage of care, family members and caregivers of persons with TBI expressed frustration with the lack of medical services that were locally available, especially in the rural areas. This frustration was due to several factors including the lack of understanding of TBI by generalist physicians, the inability for family members to get medical information due to HIPAA regulations and the fact that mild TBI was not being diagnosed or being addressed as part of a dual diagnosis. In the tribal communities, the high turnover rate of physicians and the inability to access services through the Indian Health Service System also contributed to frustration of family members. Participants stated that this high turnover rate prevented individuals with TBI from establishing rapport with a physician. Family members reported the resulting discontinuity of care has led to feelings of distrust and missed doctor appointments among persons with TBI and their families.

In regard to rehabilitation services (e.g., physical therapy and speech pathology) for TBI, family members spoke positively about their experiences. In the tribal communities, a consistent message was a lack of specialists who understand TBI and a lack of health providers in the areas of mental health, neurology, and chemical dependency counseling. The same sentiment was echoed during focus group discussions occurring in rural areas. The absence of these services creates a breakdown in the continuum of care for individuals and, thus, the recovery process is hindered. When these services are accessed off the reservation, participants shared that information necessary for the recovery of the individual is not shared with educators, other agencies working with the individual, family members, or the individual themselves. This also is an obstacle in the recovery process and contributes to the problem of having an uncoordinated system of care.

Some participants expressed concerns regarding medications taken by or administered to persons with TBI. The effectiveness of some medications can be reduced over time, emphasizing the importance of having regular checkups with a physician. Also, participants reported that some

individuals with TBI refuse to take their medications, and, as a result, can experience setbacks in their recovery process. In sum, participants believed that some individuals with TBI need additional assistance concerning medication monitoring and compliance.

Employment and Vocational Rehabilitation (VR)

In all of the twenty focus groups the topic of employment was discussed. There was a strong consensus that employment among persons with TBI leads to a rise in self-worth, increases self-esteem, generates personal income, and provides them a reason to believe in themselves. Participants felt that employment was important to the successful recovery of the individual. However, some persons with TBI are unable to obtain and/or keep a job due to several noted barriers, including physical/cognitive challenges (i.e., inappropriate behaviors, impulsivity, short attention span, memory loss, general fatigue), a shortage of employment opportunities in their area, lack of TBI knowledge/understanding among employers, employers' unwillingness to hire persons that cannot work a full day, and a shortage of public transportation to get individuals to job sites. As one participant stated, "Employers who accommodate individuals with TBI are the exception rather than the norm."

Even when individuals were employed, their assigned tasks were often viewed as demeaning. The need for long-term job coaching or supportive employment was frequently mentioned as a need for successful employment. Participants suggested in tribal and non-tribal focus groups alike that the ideal setting would be for individuals to work in a business established for the purpose of employing individuals with TBI. Another suggestion was to increase volunteering opportunities for persons with TBI, as this would be an additional avenue for increasing their self-worth and contributions to society.

Since vocational rehabilitation is an important step in the process of obtaining employment, participants were asked about their perceptions of and satisfaction with these services. In general, the services provided by VR were not always known to family members and other service providers. This lack of awareness was especially apparent within the tribal communities. There appeared to be confusion as to the eligibility requirements for services and the types of “testing” required to receive services. Participants stated that training for individuals provided through vocational rehabilitation was often focused on a developmental disabilities training model which did not meet the specific training needs for individuals with TBI. In several groups, participants voiced that VR caseloads were frequently quite large and their funding was limited for providing long-term supportive employment.

Three of the five tribal focus groups reported barriers to accessing employment, such as the vocational rehabilitation staff member not being a full-time employee, long wait times before VR services were received, limited vocational options, and a lack of extended support. An important aspect of VR shared in the tribal communities was the availability to provide assistive technology. However, the concern has been the lack of technical assistance provided to individuals and their family members on the use of assistive equipment.

Housing

The issues surrounding housing were consistent throughout all focus groups. A concern among many participants was that there are only two TBI-related residential facilities with 21 beds in the state. These two facilities, the HI Soaring Eagle Ranch and Dakota Pointe, are both specifically designed for individuals with TBI. Another facility, Dacotah Alpha, serves both individuals with TBI and developmental disabilities. As one facility is located in southcentral North Dakota and the other two facilities are situated in western North Dakota, some participants felt their

location was inconvenient for individuals with TBI who have to be taken out of their home communities. The facility locations were also viewed as inconvenient for family members and friends who often account for a substantial amount of support provided to persons with TBI. Another noted problem related to these TBI facilities is their paucity of support services for family members.

Participants who were familiar with characteristics of the residential facilities described their model to be more of a group training approach rather than training focused on individual needs. Thus, there is a need for additional training in the area of understanding TBI for those who work in these facilities. Currently, training modules required for employment in a residential setting have focused on developmental rather than TBI-related disabilities.

Various housing needs were expressed by focus group participants. These needs included the following: more residential facilities throughout the state and on the reservations, especially for persons with TBI who are beyond the acute care stage; transitional housing for the different levels of needed care; increased support for those persons with TBI living in the community; and more accessible housing. Some participants said that some North Dakotans with TBI are placed in nursing homes. On a positive, placement in a nursing home can mean they are closer in proximity to family and friends; however, nursing home services are not designed to meet the needs of persons with TBI. A participant characterized the issue of housing for persons with TBI by stating, “You need to find the balance between providing a safe and supportive living environment and an environment that is too structured so the individual does not have an opportunity to develop independence.”

Education-Related Services

Although focus group participation from the educational sector was limited, both family members and service providers did share their thoughts on TBI as it relates to services in the school system. Whether non-tribal or tribal communities, the general message was that there is a shortage of educators who understand TBI and the challenges it presents to affected children. There is a need to have educators better understand behaviors and learning difficulties related to TBI. Participants stated that much of an educators training is focused on developmental disabilities rather than TBI-specific characteristics. There was a sentiment that because of the nature of TBI-appropriate services, the schools would let kids “slide through the cracks” rather than provide appropriate education services. Participants stated that some children with TBI are mislabeled (e.g., learning disabled, ADHD). However, some participants indicated they had very positive experiences with the school system, and spoke highly of the array of services their child received. Others mentioned that the delivery of special education services for TBI did not seem to be consistent throughout the state.

Social and Recreational

Participants shared that the lack of social and recreational activities for individuals led to boredom and withdrawal from family and social activities. Participants indicated that for some persons with TBI, attending a support group was the only outlet for social interaction and meeting new friends. A major concern for family members and individuals was the loss of friendships due to the inability or unwillingness among some persons to accept physical, cognitive and/or behavioral changes in the TBI-affected person. In all of the focus groups, participants shared that the loss of friendships and the challenge of establishing new friendships was one of the most difficult adjustments for persons with TBI.

Eligibility for Services

Participants indicated there was a lack of awareness and understanding regarding criteria for receipt of services and a concern that the eligibility criteria for many services was too focused on developmental disabilities and not TBI-specific. Family members also expressed their frustration with the application process, indicating that it was cumbersome and inconvenient due to long travel distances. A consistent message from participants was that many individuals with TBI were currently receiving services under various systems such as mental health or alcohol rehabilitation, yet these systems/programs were not addressing the TBI.

TBI Waiver

It appeared that the TBI Waiver and its intended functions were not well known among family members and professionals. There seemed to be confusion as to what it is and how to qualify for benefits/services associated with the waiver. Those who were familiar with it stated that the eligibility requirements were too restrictive, denying needed services to some or many North Dakotans with TBI.

Social Security

Participants expressed frustration over the eligibility requirements of Social Security benefits in that they were too restrictive and it often required several attempts to qualify for benefits. There appeared to be frustration with the amount of time (one year) that needed to elapse from injury occurrence to when an individual would qualify for Social Security benefits. In summary, participants felt that there were many TBI-affected persons in need of these benefits throughout the state that were unable to receive them due to these untenable criteria for eligibility.

Medical Assistance

Medical Assistance was another program that was mentioned throughout the focus groups. The same frustrations were expressed. The paperwork is cumbersome, the eligibility restrictions of age were too restrictive and it took too long from the time of the injury to when the assistance was received. Having to travel long distances to apply in person was also viewed as a barrier to receiving needed medical assistance among persons with TBI.

Funding

Participants indicated the lack of funding for comprehensive services and decreased access to health insurance for North Dakotans with TBI. Throughout the focus groups, participants shared the frustration that there appears to be a lack of resources to fund programs to be comprehensive in meeting the specific needs for individuals with TBI and their families. This includes programs and services to address transition, vocational rehabilitation, family support, and TBI Waiver services. Service providers shared that limited funding restricted their ability to offer sufficient salary and benefits packages to recruit and retain qualified staff, particularly night shift personnel.

The process to acquire health insurance for coverage of necessary TBI services and rehabilitation was described as a “nightmare.” Participants shared how they had been repeatedly denied health insurance coverage, but persevered in the application process until they received it. The presence of barriers to health insurance access and difficulties in understanding which services were covered by insurance was a consistent message heard in the tribal communities. There was strong consensus that “source of payment” determines the plan of recovery. One attendee stated, “If you can afford to pay, you can get the best of the best rehabilitation out of North Dakota.”

Support

Many participants expressed the need for additional support groups in both tribal and non-tribal communities for individuals with TBI, their families, and caregivers. Increased access to support groups would give individuals with TBI and their families an opportunity to share and validate their stories, realize they are not alone, and assist in coping with the brain injury. These support groups can also serve as an outlet for disseminating TBI information.

Another support-related issue was the need for a mentor or “buddy” to be there for persons for TBI from the time of the initial injury and extending throughout their lifetime. Having someone there to talk to who understands what the individual with TBI and families are going through could assist to validate their emotions and feelings. A mentor could also serve to educate individuals and families about expectations and potential pitfalls on the journey toward recovery.

Some participants indicated they felt that vocational support could be improved in North Dakota. Specific areas that would be of most benefit included long-term job coaching, in-home supports, and support for transition to independence. Participants felt that these improvements would be needed in all regions of the state, including rural, urban, and tribal areas.

One participant stated that support can be either a positive or negative influence on a person’s recovery process. If a person with TBI has too much support it may reinforce a passive approach to life, which could decrease opportunities for growth and independence. If there is too little support it can hinder progress and rehabilitation as they may give up when faced with challenges, the participant stated. When there is the appropriate level of support, the individual with TBI can and will grow, face challenges, and will be willing to take risks in their life.

Caregivers expressed frustration and a lack of support in dealing with a number of challenges associated with their role, including: how to deal with the changes in family dynamics

and structure as a result of the injury; a lack of understanding of TBI; difficulties in addressing the wide-range needs of the individual with TBI; not knowing the nature and extent of available TBI services and assistance; not having enough time to spend with the individual with TBI; and difficulties in maintaining their resourcefulness and persistency for accessing services needed by the individual with TBI. Participants stated that additional mechanisms of support throughout the state would assist them in coping with the various challenges of providing care to persons with TBI.

Survey Methodology

Target Population - A primary focus of the North Dakota TBI Needs and Resources Assessment involved the creation of a list of persons with TBI in North Dakota. Prior to this assessment effort, the state did not have the capacity to identify and/or contact individuals with TBI, caregivers, service providers or agencies. As a first step, the Center for Rural Health (CRH) solicited state agencies and service providers to provide information related to individuals with TBI and those entities serving this population. The CRH also utilized the media to draw attention to this planning grant. Multiple newspaper articles and radio announcements were delivered throughout the state. The purpose of these announcements was two-fold: recruitment of individuals with TBI and their caregivers for focus group participation; and development of a contact list to be utilized for distributing surveys to individuals with TBI and their caregivers. The resulting lists provided researchers with contact information for 404 individuals with TBI and 370 agencies. In addition, a list of 36 persons providing care to an individual with TBI was developed through focus group participation.

Instruments - The CRH researchers utilized a modified version of the federal TBI survey template to develop North Dakota-specific questionnaires for: 1) individuals with TBI; 2) their caregivers; 3)

TBI agency representatives; and 4) TBI service providers. During the process of survey development, drafts of the questionnaires were reviewed by a variety of expert groups: individuals with TBI; caregivers of persons with TBI; North Dakota agency representatives, and service providers; North Dakota TBI Advisory Committee members; and federal TBI program personnel.

The questionnaires were designed to achieve the following objectives:

- Identify the demographic characteristics of North Dakotans with TBI and their caregivers
- Discover the perceived behavior problems and barriers faced by North Dakotans with TBI and their caregivers
- Determine the assistance and support available to persons with TBI and their caregivers
- Determine the services provided by North Dakota agencies and service providers
- Identify training needs of North Dakota agencies and service providers

An important component of the survey design was the identification of perceived barriers to services among individuals with TBI. Each of the four surveys contained a block of identical questions that measured the presence or absence of perceived barriers to services for persons with TBI. Across all survey efforts, respondents provided the following definition of TBI (as defined in public law 104-166 [H.R. 248]): "...an acquired injury to the brain (e.g., motor vehicle crashes, falls, and assaults). Such term does not include brain dysfunction due to congenital or degenerative disorders, nor birth trauma, but may include brain injuries due to anoxia caused by near drowning."

Individual Survey - As previously mentioned, the state of North Dakota did not maintain a comprehensive list of individuals with TBI. Thus, researchers relied on a convenience sample derived from makeshift lists developed specifically for this project. CRH researchers were dependent upon agencies and support groups to provide lists of individuals known to have sustained a TBI. In some cases the lists were turned over to the CRH which then assumed the primary

responsibility of distributing surveys to the respondents. In other instances, participating entities preferred to manage the lists on their own and assumed the responsibility of distributing the surveys to the persons on their list. In all cases, the individuals were provided with a self-addressed stamped envelope to return their completed questionnaire. In addition, each individual with TBI was asked to distribute a caregiver survey to the individual they identified as their primary caregiver. Distribution of the survey for persons with TBI was initiated on January 13, 2005. Those that did not respond within 30 days were given a second survey. Overall, 425 individuals were provided with an opportunity to complete and return the questionnaire. Twenty-one invalid contacts were recorded. A total of 117 completed surveys were returned, resulting in a response rate of 29 percent.

Caregiver Survey - A caregiver survey was included with each of the surveys for persons with TBI. Again, the person with TBI was asked to provide the caregiver questionnaire to the person who was their primary caregiver. Those caregivers that did not respond within 30 days were given a second survey via the person with TBI for whom they provided care. Overall, 425 surveys were distributed to TBI caregivers. Nineteen invalid contacts were recorded. A total of 94 completed caregiver surveys were returned, resulting in a response rate of 23 percent.

Agency Survey - CRH researchers developed a comprehensive list of agencies believed to provide services to individuals with TBI through a variety of sources, including telephone directories, websites, local/state/federal contacts, and North Dakota TBI Advisory Committee members. Each identified TBI agency was mailed a packet containing a cover letter, an agency questionnaire, and a self-addressed, postage-paid envelope. In addition, a minimum of two service provider questionnaires and cover letters were included for distribution within the agency. The service providers were also provided with a self addressed stamped envelope to return their completed survey. The agency survey mailing was initiated on February 4, 2005. Those agencies that did not

respond within 30 days were mailed a second survey. The second mailing occurred on March 7, 2005. Overall, there were 370 surveys mailed to North Dakota. A total of five invalid contacts were recorded. There were 117 surveys returned, resulting in a response rate of 32 percent.

Service Provider Survey - For this statewide assessment, TBI service providers were accessed through the TBI agency representatives. The cover letter to the agency representatives indicated they should distribute the enclosed 'service provider' surveys to a minimum of two employees who were involved in providing services to persons with TBI. The service provider survey was distributed for the first time on February 4, 2005. Those that did not respond within 30 days were mailed a second survey. Overall, 859 service providers were given an opportunity to participate in the study. There were 173 surveys returned to the CRH for a response rate of 20 percent.

Survey Findings

The following section presents and discusses results summaries for each of the four survey efforts. First, the general demographic information will be addressed for each of the four surveyed groups (i.e., individuals with TBI; caregivers, agency representatives, and service providers). Second, the most frequently cited barriers to accessing and providing TBI services will be presented and discussed for each group.

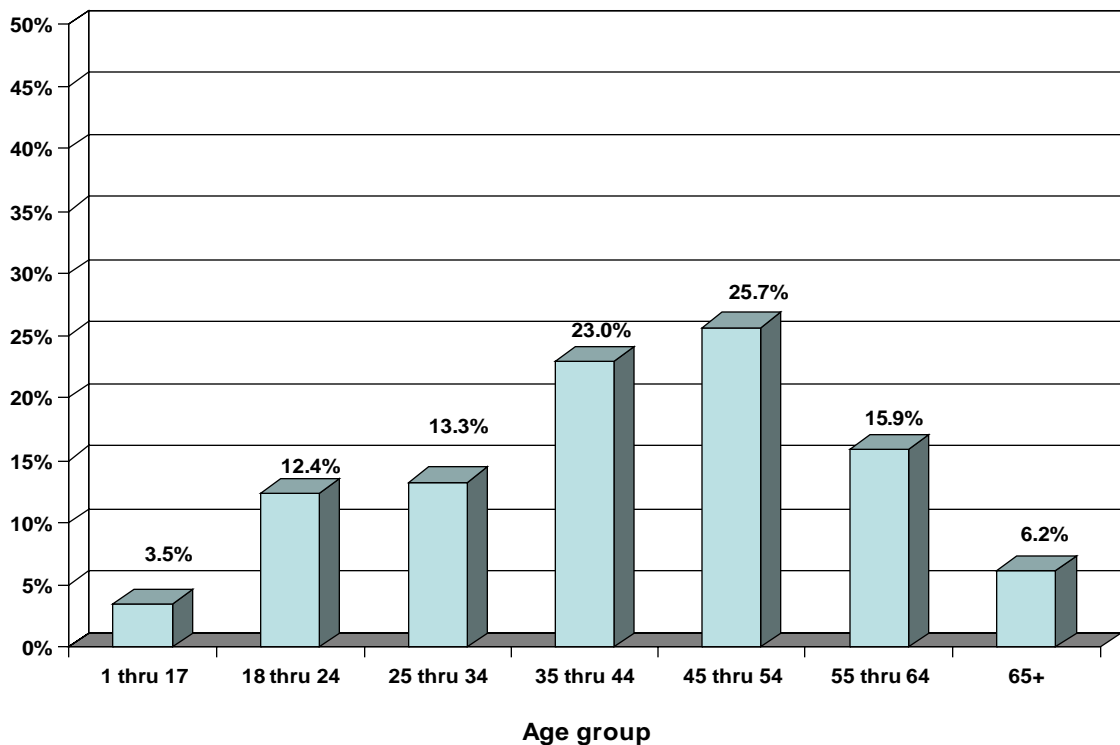
Individuals With TBI - Results

Gender - Males represented 62.8% of the sample.

Age - The mean age of individuals with TBI was 43.8 years. Age of respondents ranged from 5 to 76 years (Note: a proxy aided in completing the questionnaire for respondents who needed assistance). One-half (49.1%) of individuals with TBI were between the ages of 35 and 54 years at

the time of the survey. Approximately one-fourth (25.5%) were aged 18 to 34 years; 22.1 percent of individuals with TBI were 55 years or older (Chart 1).

Chart 1. Age of Individuals with TBI



Race - Survey results indicated that nearly 75 percent of the individuals with TBI were white, followed by Native Americans at 18.1 percent.

Assistance completing survey - Nearly two-thirds (61.7%) of individuals with TBI indicated they completed the survey without assistance.

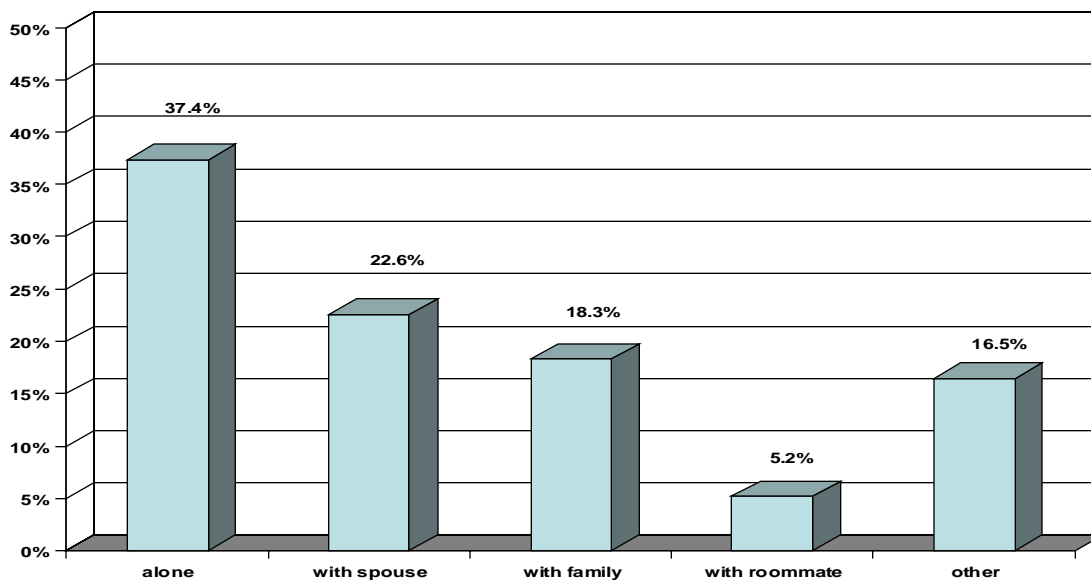
Income – Among individuals with TBI, the most frequented category for personal income was ‘less than \$5,000’ (43.1%) in 2004. Of the remainder, 45.9 percent earned from \$5,000 to \$24,999, and 11.0 percent earned \$25,000 or more in 2004.

Health Insurance - When asked about current health insurance status, 83.5 percent of the respondents indicated they possessed some type of insurance coverage.

Neuropsychological exam – About three-fourths (72.6%) of the respondents indicated they had received a neuropsychological exam after sustaining a TBI.

Amount of Necessary Care - Individuals with TBI were asked to indicate how much care they needed from caregivers due to the TBI. Slightly more than one-half (56.6%) of respondents indicated they needed no care, followed by ‘can be left alone for most of the day ‘(21.2%), ‘left alone for a few hours’ (8.0%), and ‘cannot be left alone’ (14.2%).

Chart 2. Living Arrangement of Persons with TBI



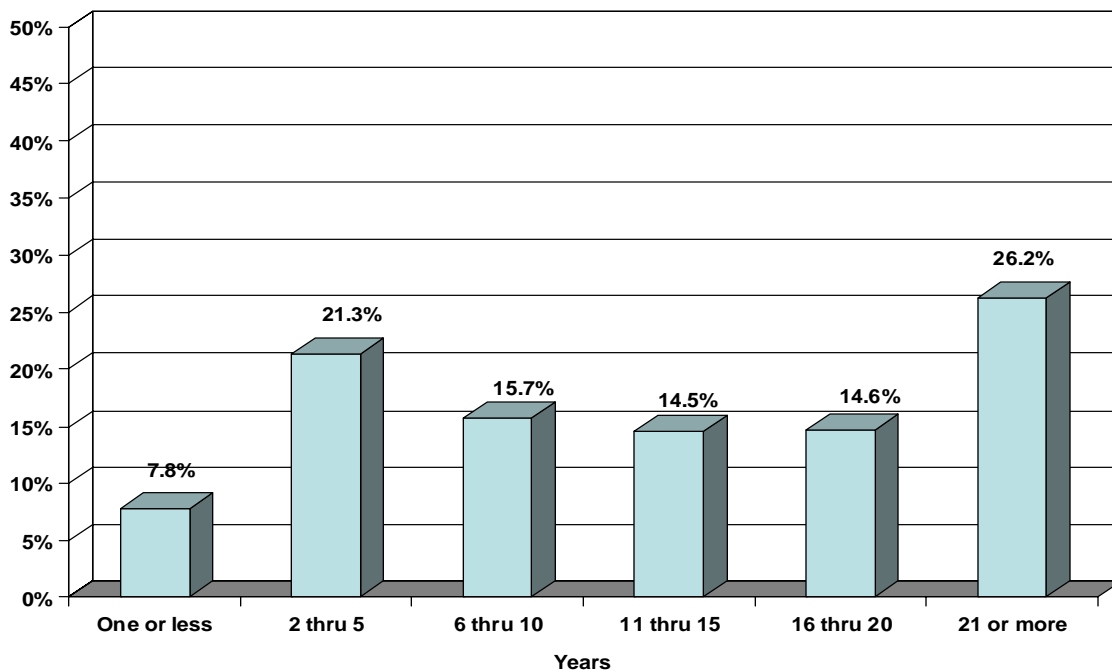
Living Arrangements - More than one-third (37.4%) of individuals with TBI indicated they lived alone, while 40.9 percent indicated they lived with a spouse or family (Chart 2).

Cause of TBI – Slightly more than two-thirds (69.9%) of the respondents indicated that a motor vehicle crash was the cause of their initial TBI. Individuals’ TBIs were also the result of assault/abuse (10.8%) and pedestrian incidents (9.6%).

Number of TBIs - Approximately 12 percent of the respondents had incurred more than one TBI prior to completing the survey.

Years since TBI - The number of years since one’s last TBI ranged from 0 to 44 years and averaged 14.1 years. Slightly more than two-thirds (70.9%) of the respondents indicated they incurred their last TBI more than five years ago. About one-fourth (26.2%) of the respondents reported their last TBI occurred more than 20 years ago (Chart 3).

Chart 3. Number of Years since Last TBI

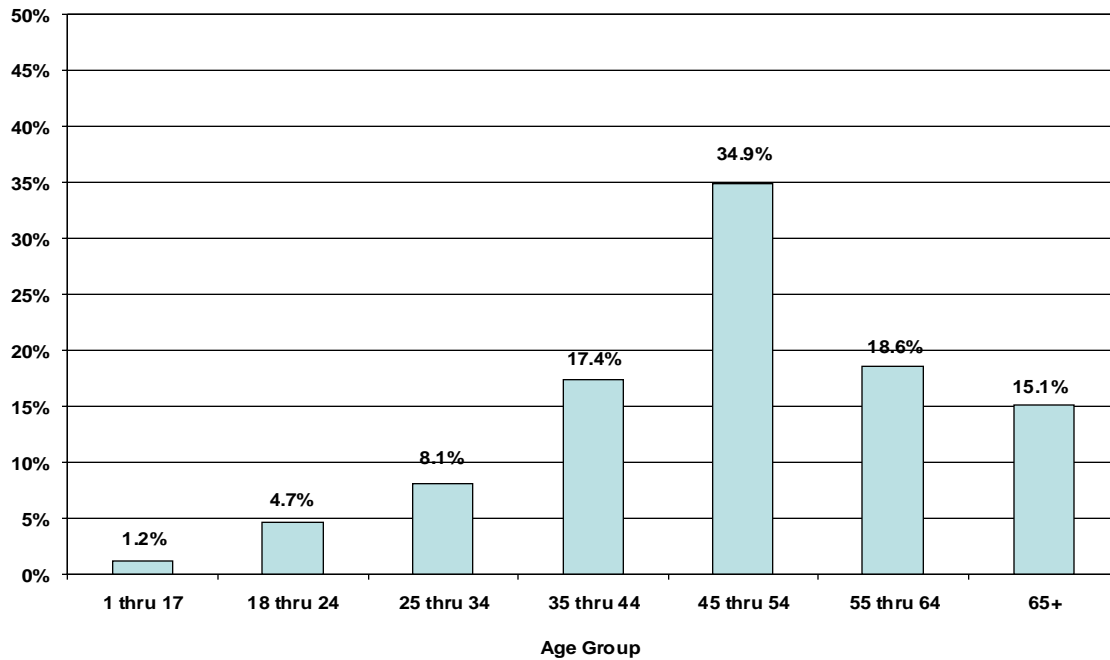


TBI Caregiver Survey - Results

Gender - In contrast to the 'individuals with TBI' survey results, females greatly outnumbered males, comprising four-fifths (80.0%) of the sample.

Age - The mean age of caregivers to individuals with TBI was 50.1 years. The range of respondents' age was 13 to 81 years. Overall, 52.3 percent of the respondents were between the ages of 35 and 54 at the time of the survey. Respondents aged 18 to 34 years accounted for 12.8 percent. About one-third (33.7%) of the respondents were 55 years or older (Chart 4).

Chart 4. Age of Caregivers

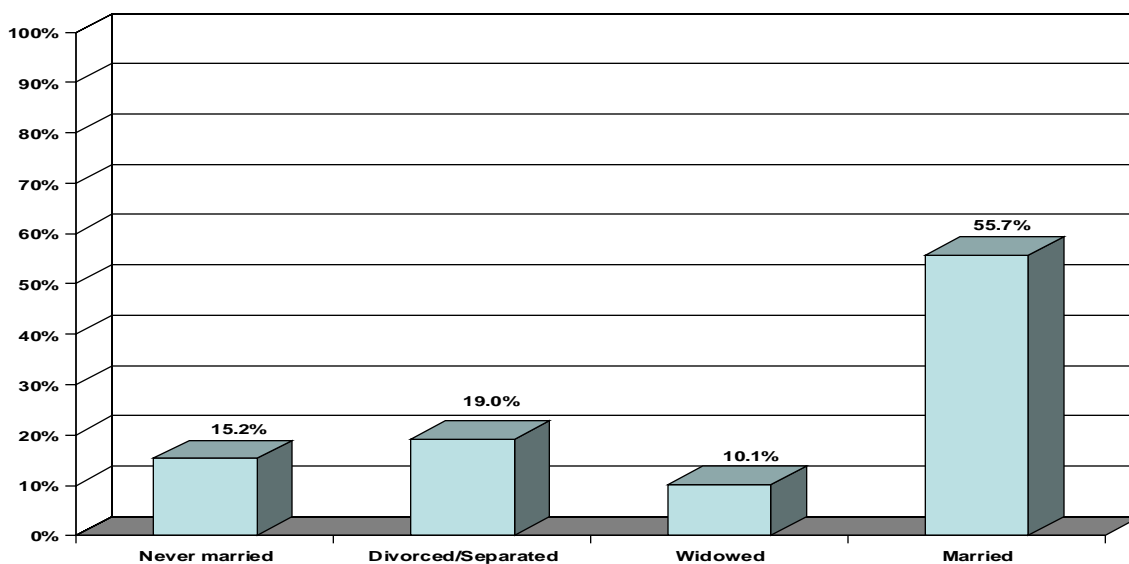


Race - Survey results indicated that 76.7 percent of respondents were white, followed by Native American (18.9%), and more than one race (4.4%).

Health Care Access - When caregivers were asked their perceptions of health care access for their own health needs, 80.5 percent indicated they had 'adequate' access to care. The remainder (19.5%) said their access was inadequate.

Marital status - Chart 5 indicates more than one-half (55.7%) of the caregivers were married; of the remainder, 19.0% were followed by divorced or separated, 15.2% were never married, and 10.1% were widowed.

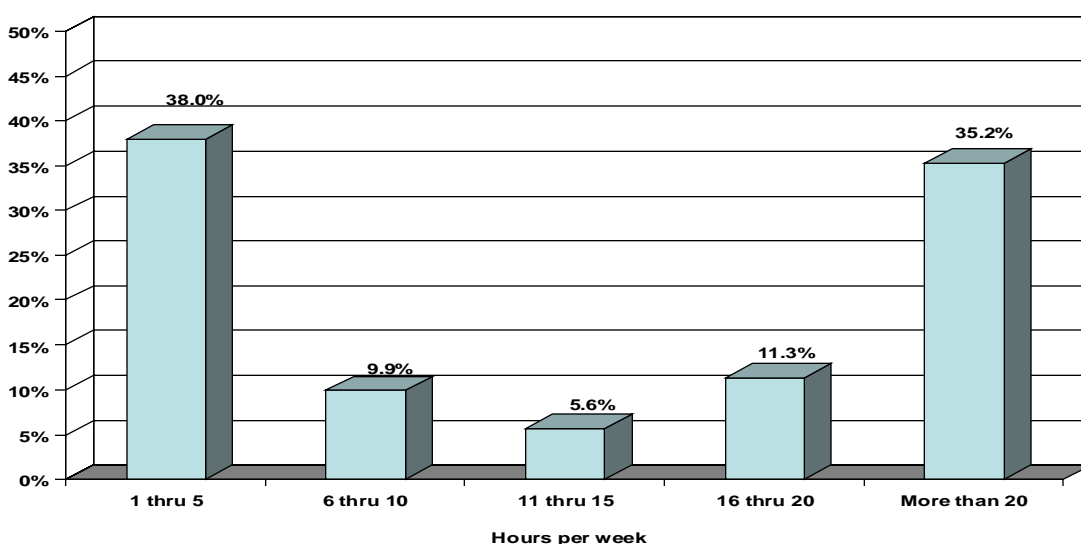
Chart 5. Caregivers' Marital Status



Relationship to individual with TBI - When asked to list their relationship to the individual with TBI, 30.7 percent of caregivers indicated they were a parent, while 17.3 percent indicated they were a spouse, and 20.0 percent were either a sibling or child. Sixteen percent were direct contact providers.

Number of hours providing care - Caregivers were asked to indicate the number of hours per typical week they provided care to the individual with TBI. The most common response was five or fewer hours per week (38.0% of respondents). Approximately one-third (35.2%) of caregivers provided care for more than 20 hours per week (Chart 6).

Chart 6. Number of Hours per Week for Providing Care to Persons with TBI



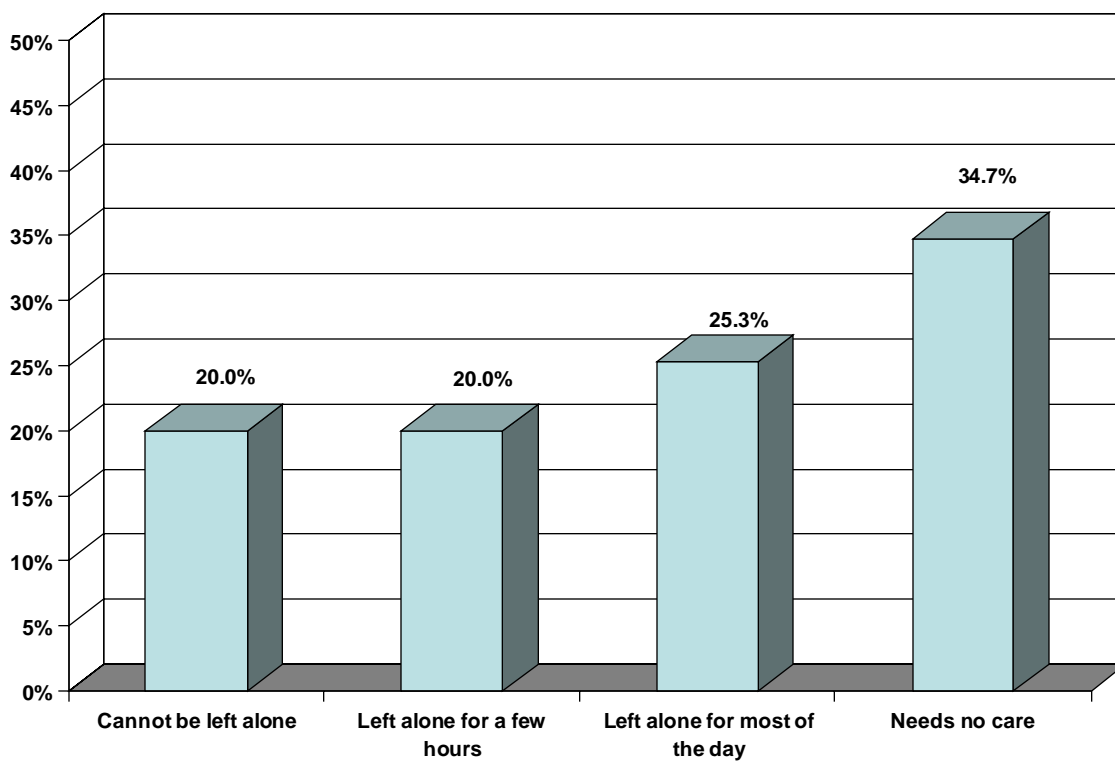
Caregiver living arrangements – Approximately one-third (33.3%) of respondents said they lived with the person they were providing care. Of the remainder, 40.0 percent traveled less than 20 minutes to provide care to the individual with TBI. Caregivers traveling one or more hours to provide care accounted for 14.6 percent.

Number of years providing care – The number of years spent by caregivers tending to the needs of a person with TBI ranged from 0 to 37 years. Approximately one-half (53.4%) of caregivers indicated

they had provided care for more than five years. Those persons providing care for 20 years or more accounted for 12.3 percent of the sample.

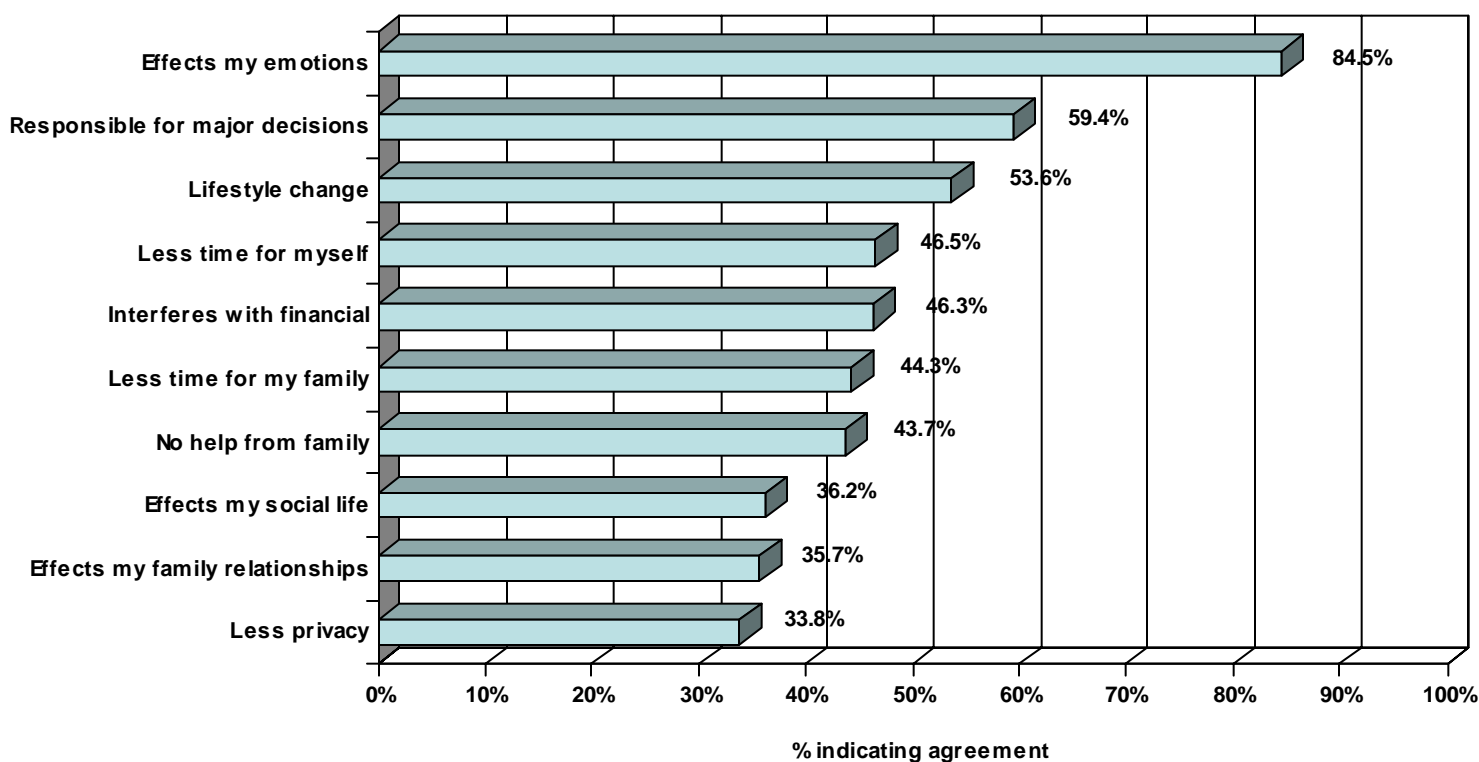
Amount of Necessary Care - When asked how much care is necessary for the person with TBI, about one-third (34.7%) of respondents said they do not require care. Of the remainder, one-quarter (25.3%) said they could be left alone for most of the day, 20.0 percent indicated they could be alone for a few hours, and 20.0 percent said they could not be left alone (Chart 7).

Chart 7. How Much Care is Necessary for the Person with TBI, as Perceived by Caregivers



Caregiver Difficulties - When asked to share the difficulties experienced by caregivers, 84.5 percent indicated that their caregiver role effected their emotions. In addition, responsibility for major decisions (59.4%), lifestyle change (53.6%), less time for themselves (46.5%), interferes with financial obligations (46.3%), and less time for family (44.3%) caused some difficulty among caregivers attempting to complete their role (Chart 8).

Chart 8. TBI Caregiving Difficulties



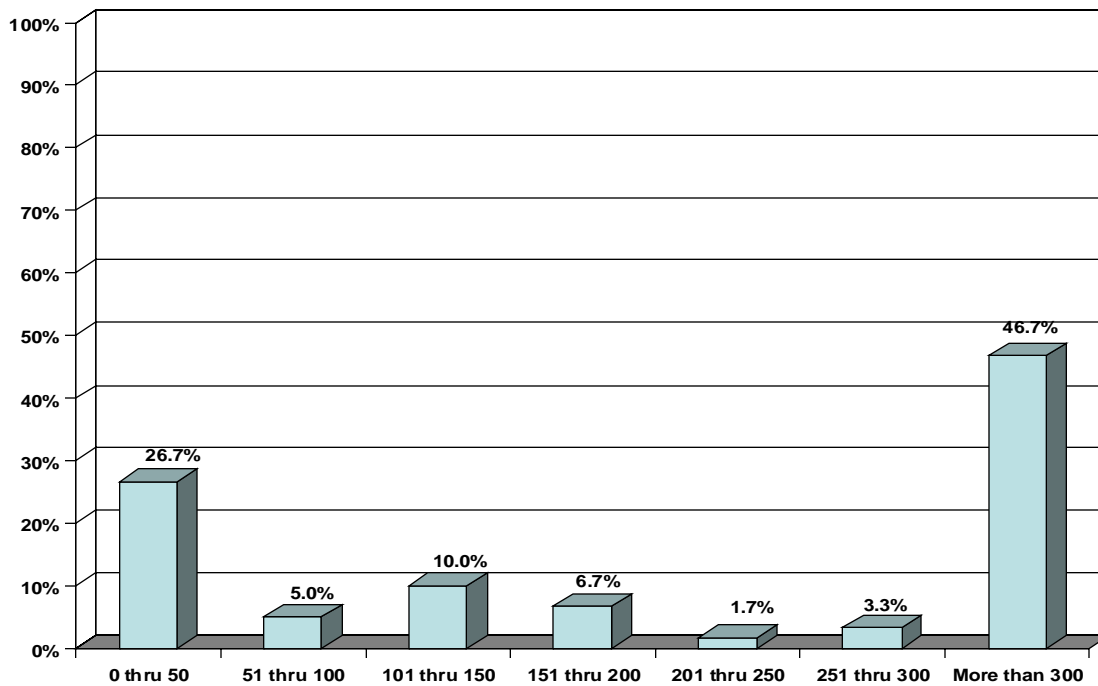
TBI Agency Survey - Results

Of the 114 agency surveys returned, a total of 68 indicated they provided services, funding, or administered programs for individuals with TBI. Thus, the remaining 46 surveys were excluded from analysis.

Agency Type - The responding representatives were predominantly with public agencies (67.7%), with private agencies accounting for one-third (32.3%).

Number of individuals served - Nearly one-half (46.7%) of the responding agencies indicated they served more than 300 persons. In addition, more than one-fourth (26.7%) of the responding agencies indicated they served 50 or fewer persons (Chart 9).

Chart 9. Number of Individuals Served by Your Agency



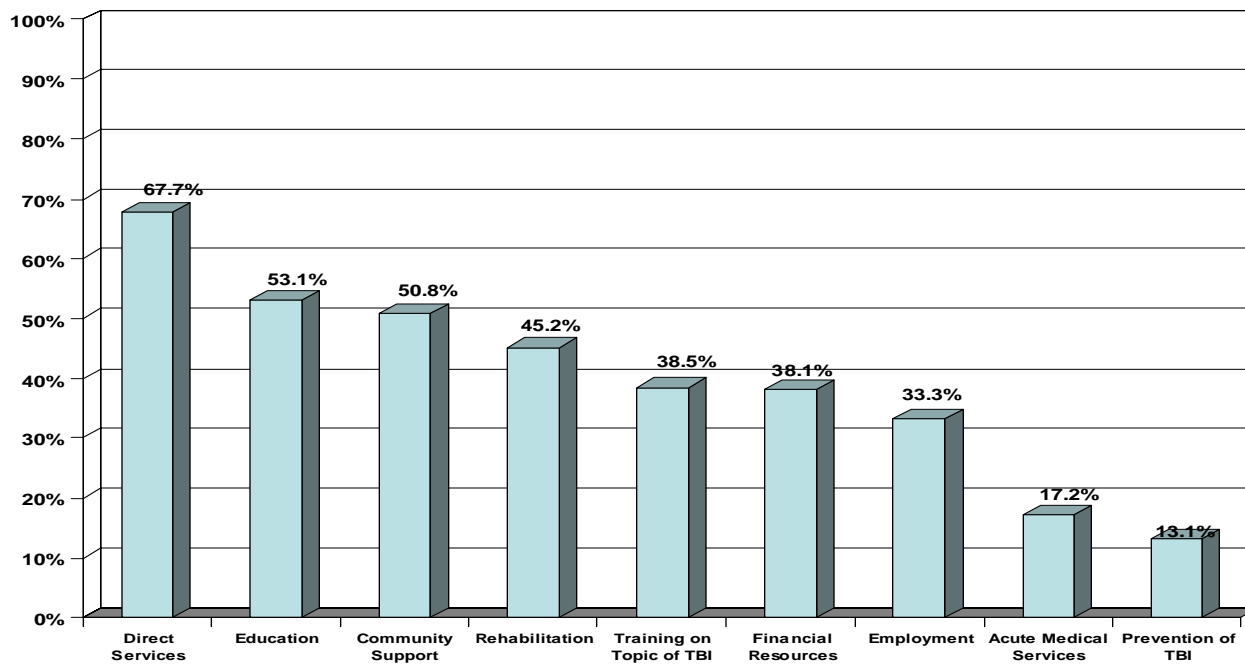
Number of individuals with TBI served - More than three-quarters (75.4%) of the responding agencies indicated they served ten or fewer persons with TBI. In addition, 16.4 percent of responding agencies indicated they serve 21 or more persons with TBI.

Number of staff providing direct care for persons with TBI - Results indicated that 58.6 percent of responding agencies employed five or fewer staff members to provide direct care to persons with TBI. Agencies employing more than 20 providers of direct care for TBI accounted for 10.3 percent.

Training – Regarding level of TBI training, only 7.7% of agency representatives indicated their staff personnel were ‘highly trained.’ Of the remainder, three-fourths (76.9%) characterized the level of TBI training as ‘moderate,’ and 15.4 percent said their staff had no training in TBI. When asked if their staff needed additional training on TBI issues, 83.1 percent responded in the affirmative.

Agency provided services - Chart 10 indicates that polled agencies most commonly provided the following types of services: direct services (67.7%); education (53.1%); community support (50.8%); and rehabilitation (45.2%).

Chart 10. Does Your Agency Provide services Related to...



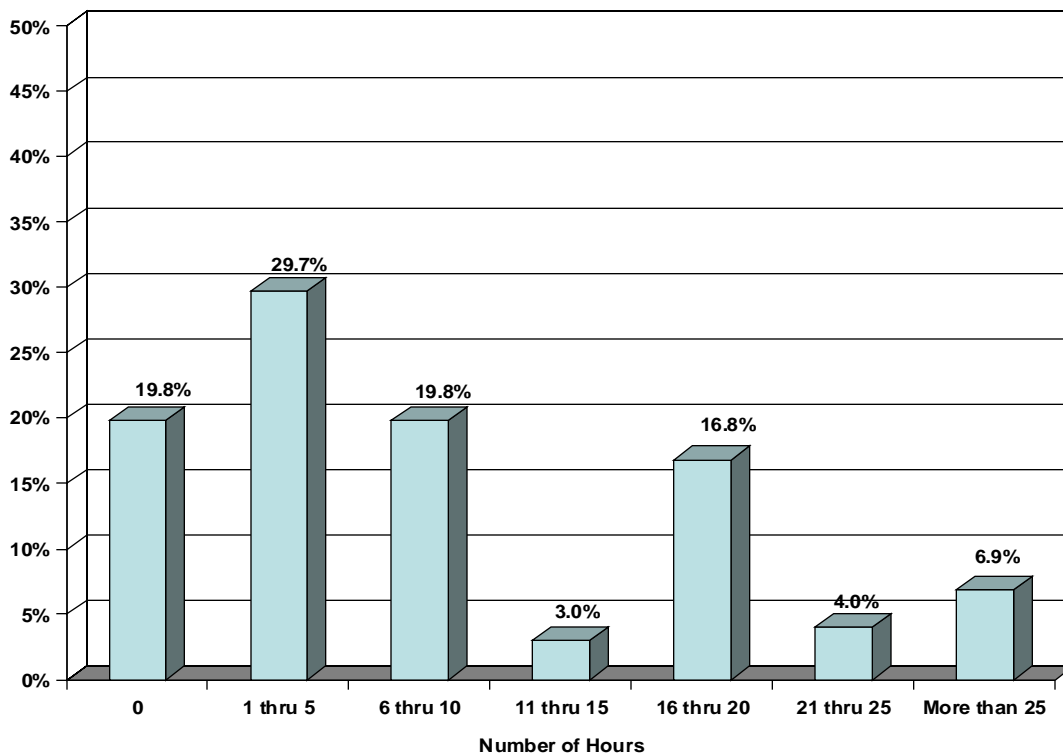
TBI Service Provider - Results

Of the 170 provider surveys returned, a total of 108 respondents indicated they provided direct services for individuals with a brain injury or to their families. Thus, the remaining 62 surveys were excluded from analysis.

Number of individuals with TBI served - Nearly three-quarters (74.7%) of respondents indicated they provided direct care to ten or fewer persons with TBI. In addition, 13.2 percent indicated providing services to more than 20 persons with TBI.

Training – Approximately one-half (49.5%) of service providers indicated they had received five or fewer hours of TBI-related training in the past year (Chart 11). More than three-quarters (78.3%) of respondents indicated a need for additional training on TBI issues.

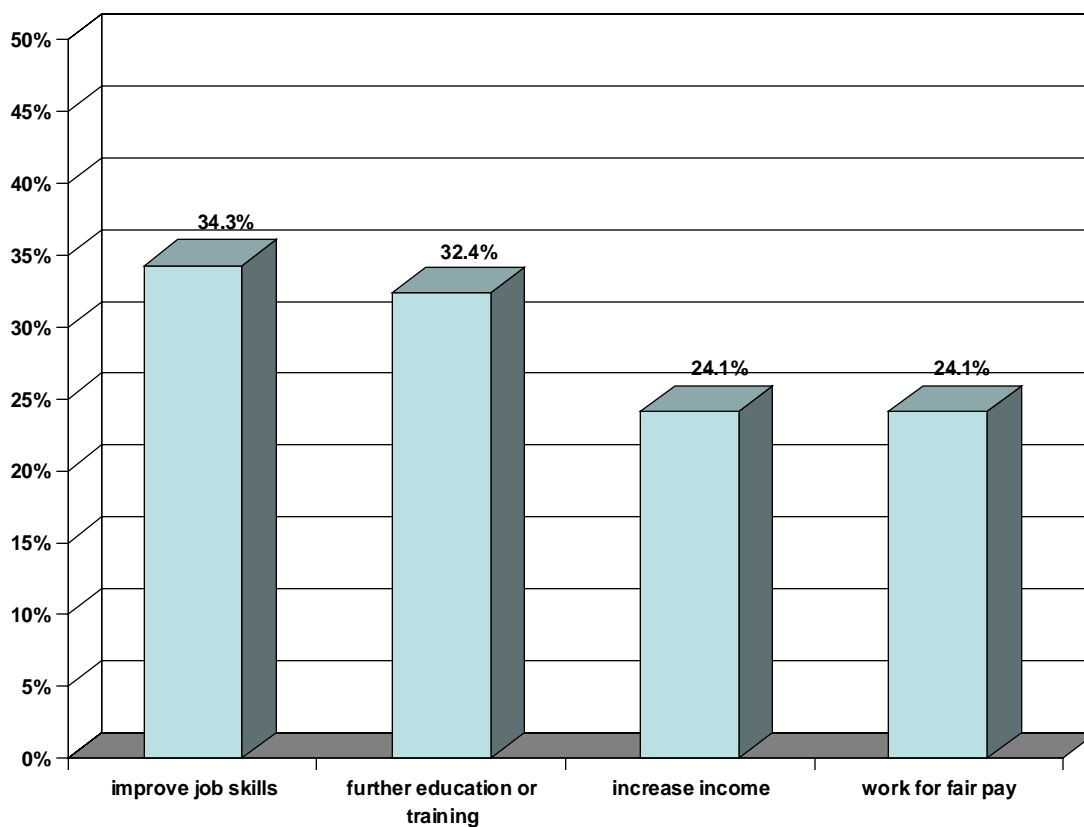
Chart 11. Number of Hours Spent Training for TBI



TBI specific training programs - When respondents were asked if they provided or offered any TBI-specific educational and/or training programs, more than three-fourths (79.2%) indicated they did not.

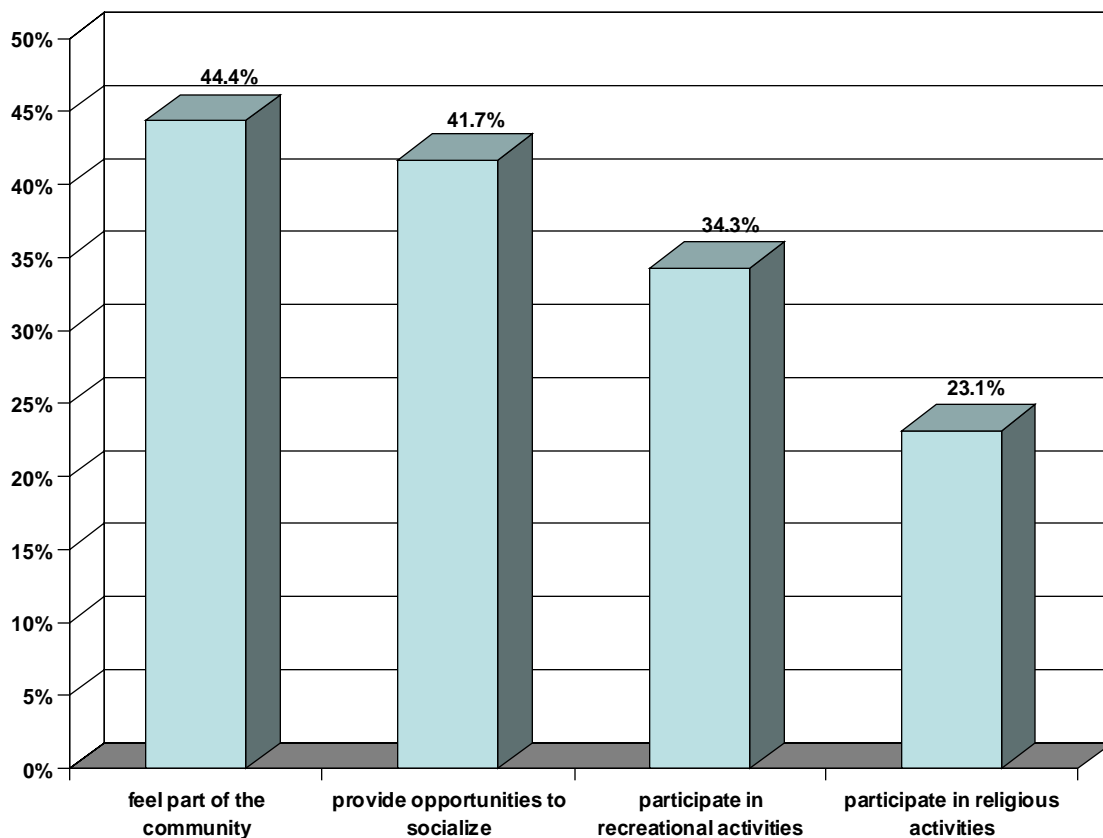
Employment services - Chart 12 indicates that providers delivered employment services for persons with TBI to improve job skills (34.3%), further their education or training (32.4%), increase income (24.1%), and work for fair pay (24.1%).

Chart 12. Do You Provide Employment Services to Individuals with TBI to...



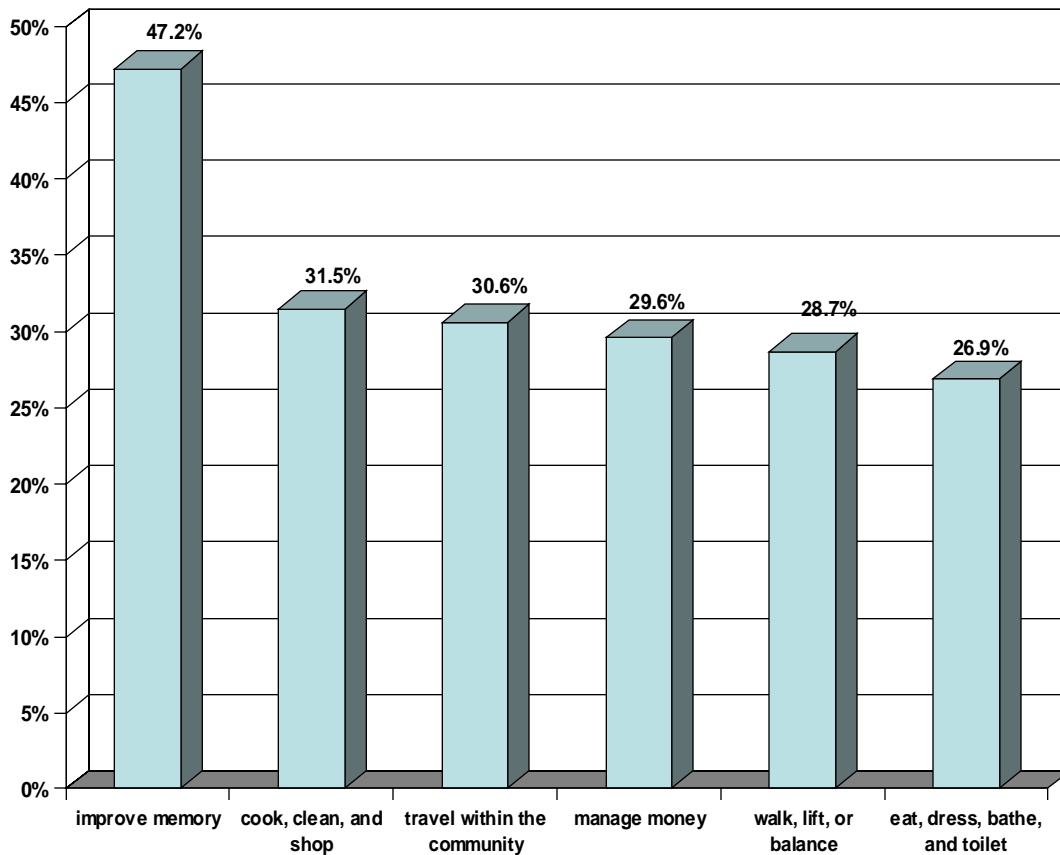
Socialization services - Chart 13 indicates that providers were most likely to deliver socialization services to persons with TBI to make them feel a part of the community (44.4%), provide them opportunities to socialize (41.7%), provide opportunities to participate in recreational activities (34.3%), and provide opportunities to participate in religious or spiritual activities (23.1%).

Chart 13. Do You Provide Socialization Services to Individuals with TBI to...



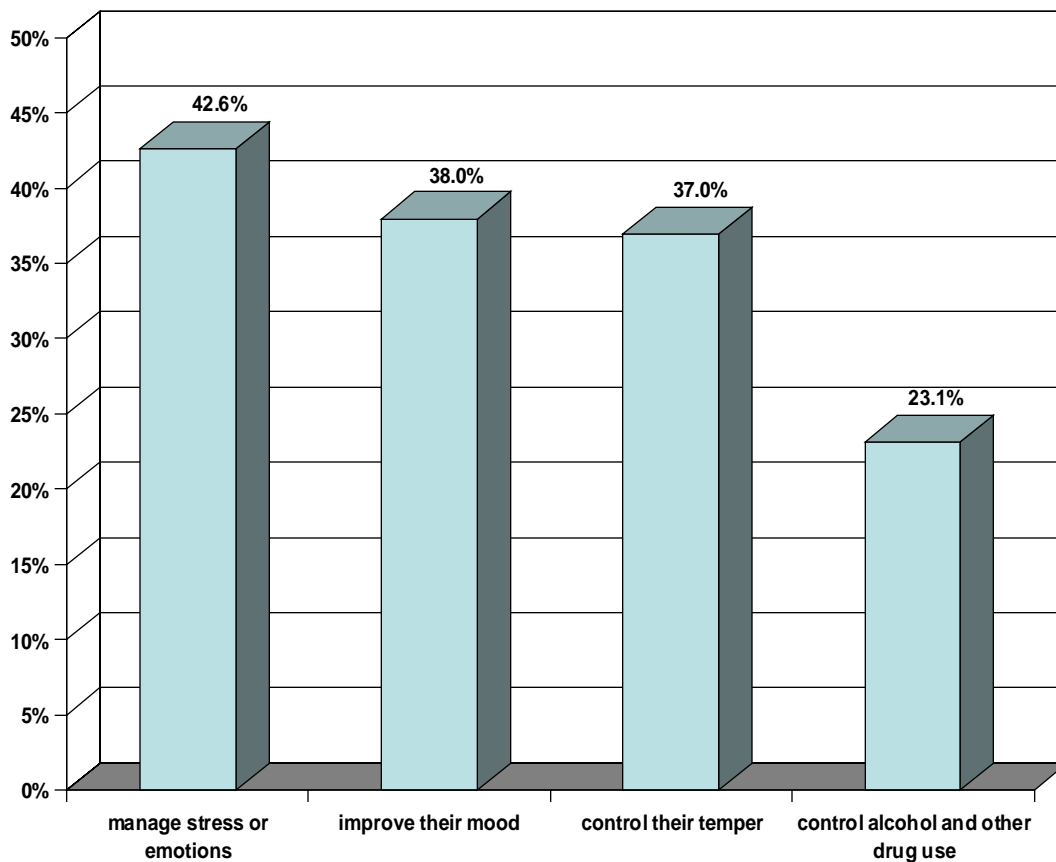
Independent living skills - Chart 14 indicates that providers delivered services related to independent living skills for persons with TBI to improve memory (47.2%); cook, clean and shop (31.5%); travel within the community (30.6%); manage money (29.6%); walk, lift or balance (28.7%); eat, dress, bathe, and toilet (26.9%); obtain housing they can use (20.4%); and obtain personal attendant services (19.4%).

Chart 14. Do You Provide Independent Living Skills to Individuals with TBI to...



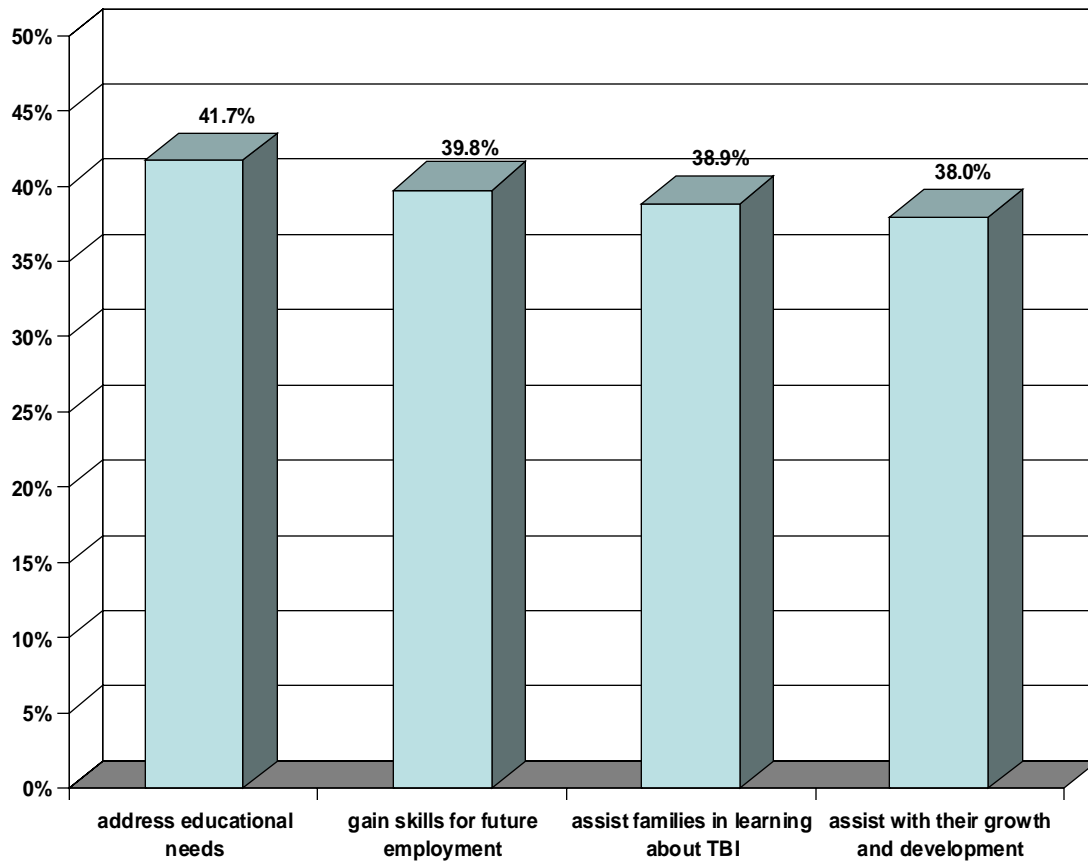
Mental health services - Chart 15 indicates that providers delivered mental health services to persons with TBI to manage their stress or emotion (42.6%); improve their mood (38.0%); control their temper (37.0%); and control their alcohol/drug use (23.1%).

Chart 15. Do You Provide Mental Health Services to Individuals with TBI to...



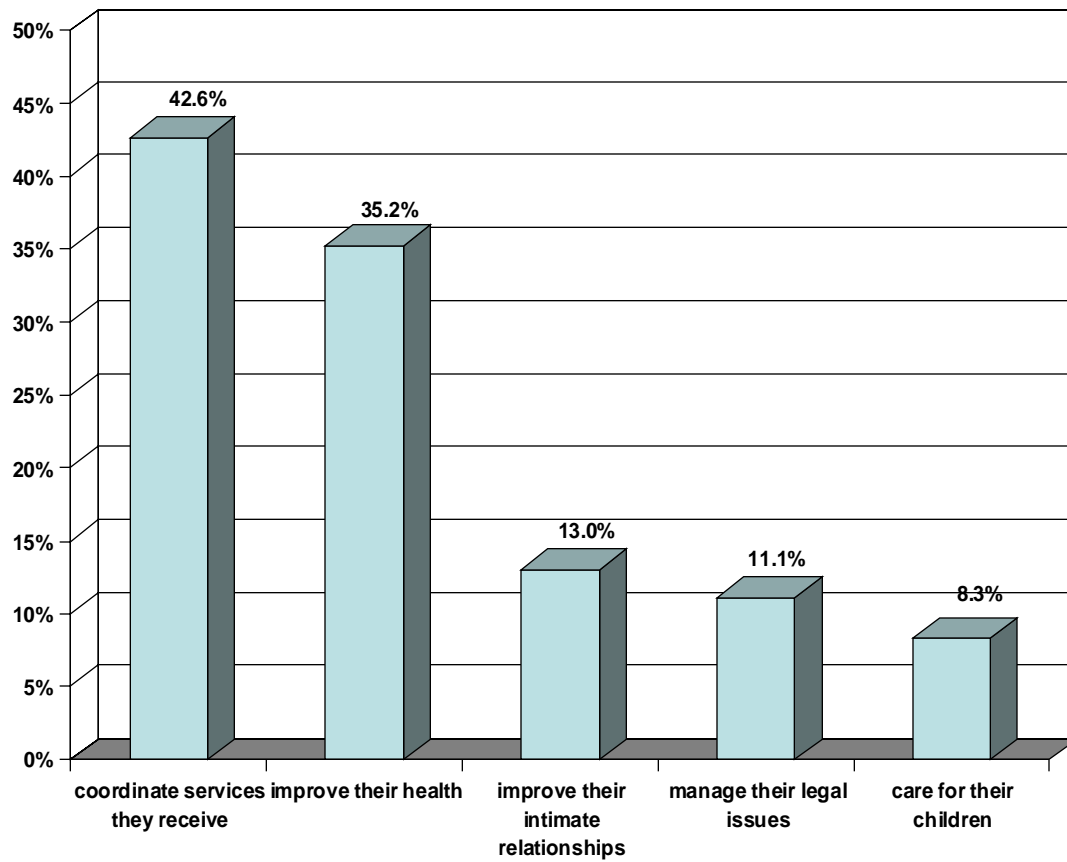
Educational services - Chart 16 indicates that providers delivered services persons with TBI to address educational needs (41.7%); gain skills for future employment (39.8%); assist families in learning about TBI (38.9%); and assist with their growth and development (38.0%).

Chart 16. Do You Provide Educational Services to Individuals with TBI to...



General services - Chart 17 indicates that providers delivered general services to persons with TBI to coordinate services they receive (42.6%); improve their health (35.2%); improve their intimate relationships (13.0%); manage their legal issues (11.1%); and care for their children (8.3%).

Chart 17. Do You Provide General Services to Individuals with TBI to...



Behavioral Issues among Persons with TBI, as Reported by Persons with TBI and Caregivers

Individuals with TBI and their caregivers were asked to identify negative behaviors experienced by persons with TBI. Chart 18 provides a list of behaviors most frequently listed by individuals with TBI. These behaviors included depression/low mood (48.7%); difficulty becoming interested (45.3%); impatient (44.4%); anxious, tense (38.5%); and difficulty controlling temper (38.5%).

Chart 18. Behavioral Issues Identified by Individuals with TBI

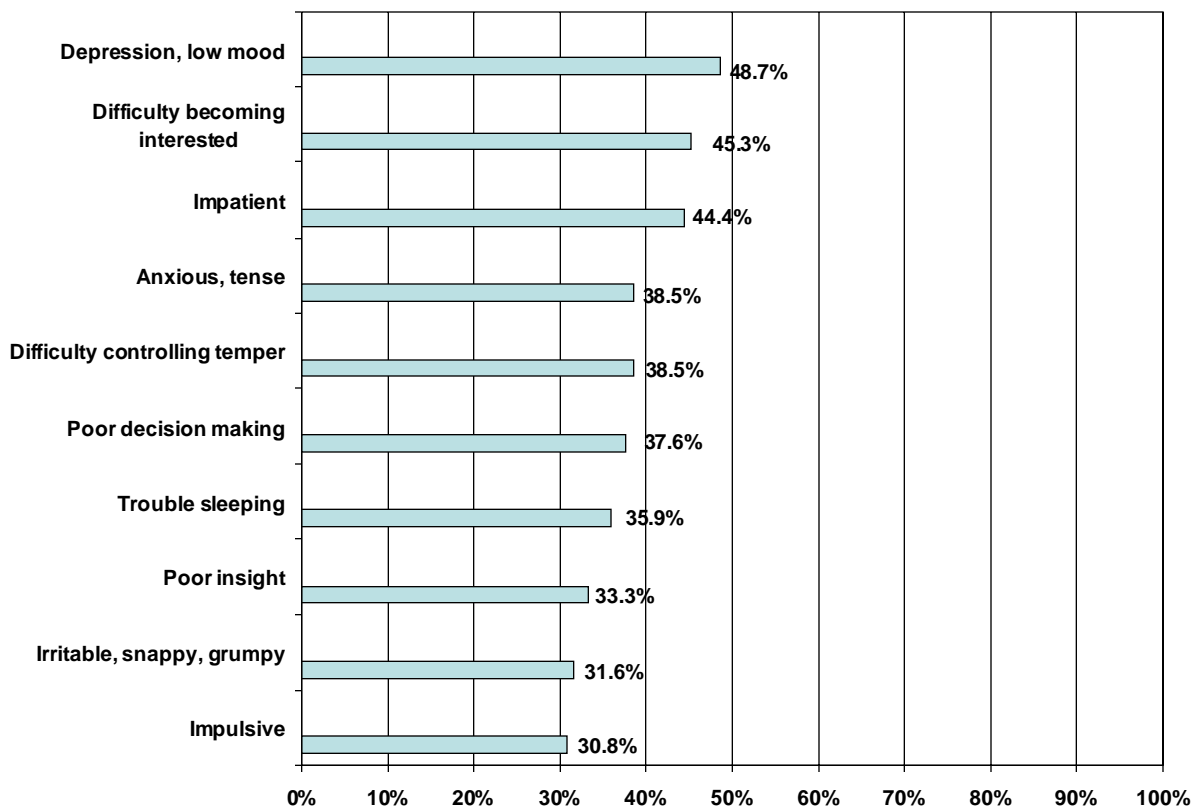
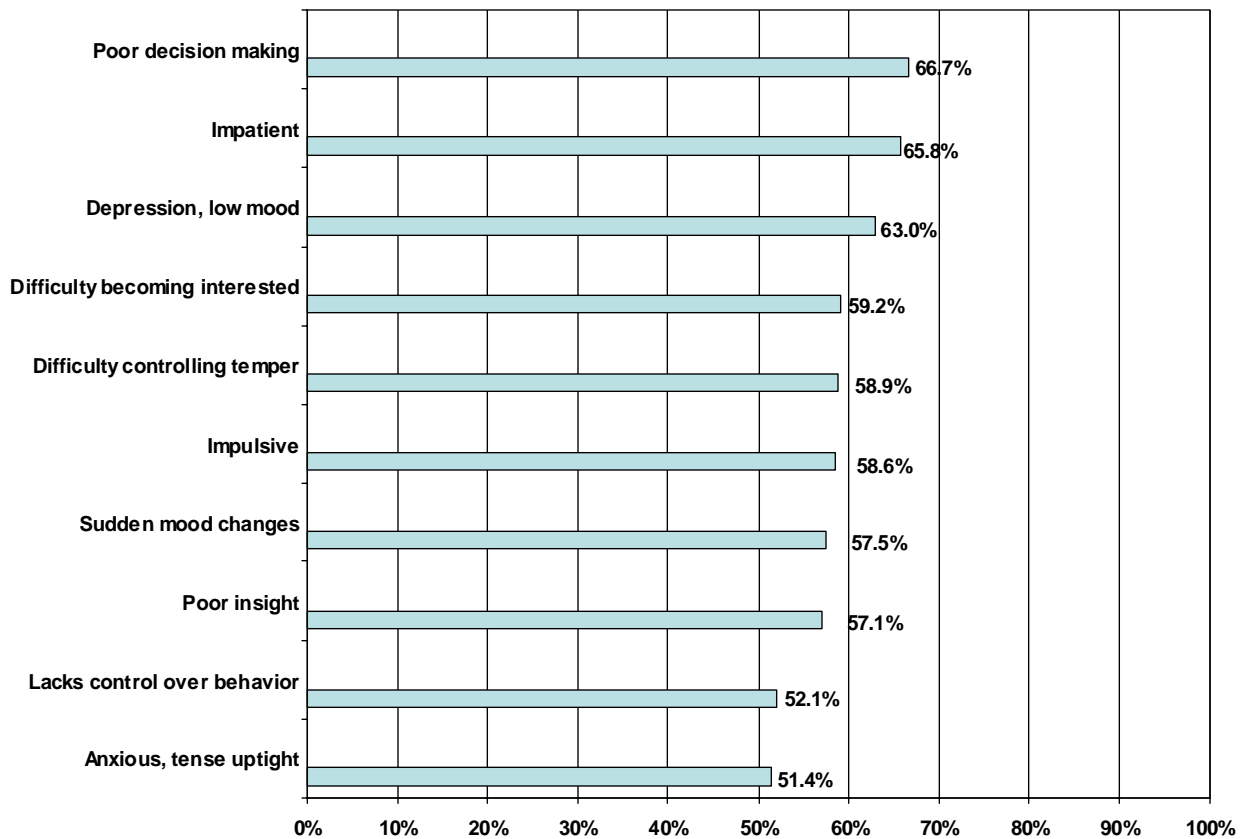


Chart 19 provides a list of negative behaviors that caregivers have noted among persons with TBI. The most frequently listed behaviors included poor decision making (66.7%); impatient (65.8%); depression or low mood (63.0%); difficulty becoming interested (59.2%); difficulty controlling temper (58.9%); impulsive (58.6%); sudden mood changes (57.5%); and poor insight (57.1%).

Chart 19. Behavioral Issues for Individuals with TBI, as Identified by Caregivers



Perceived Barriers to TBI Services: Individuals, Caregivers, Agency Representatives, and Service Providers

Individuals with TBI and their caregivers were asked to identify barriers encountered by individuals with TBI in accessing and using services. The barriers most frequently listed by individuals with TBI (Chart 20) included a shortage of strong TBI advocates (47.0%), no centralized source of TBI information (46.2%), inadequate knowledge of TBI services (46.2%), inadequate financial resources (45.3%), lack of individualization of TBI services (41.9%), and lack of understanding of TBI by providers (38.5%).

Chart 20. Service Barriers Identified by Individuals with TBI

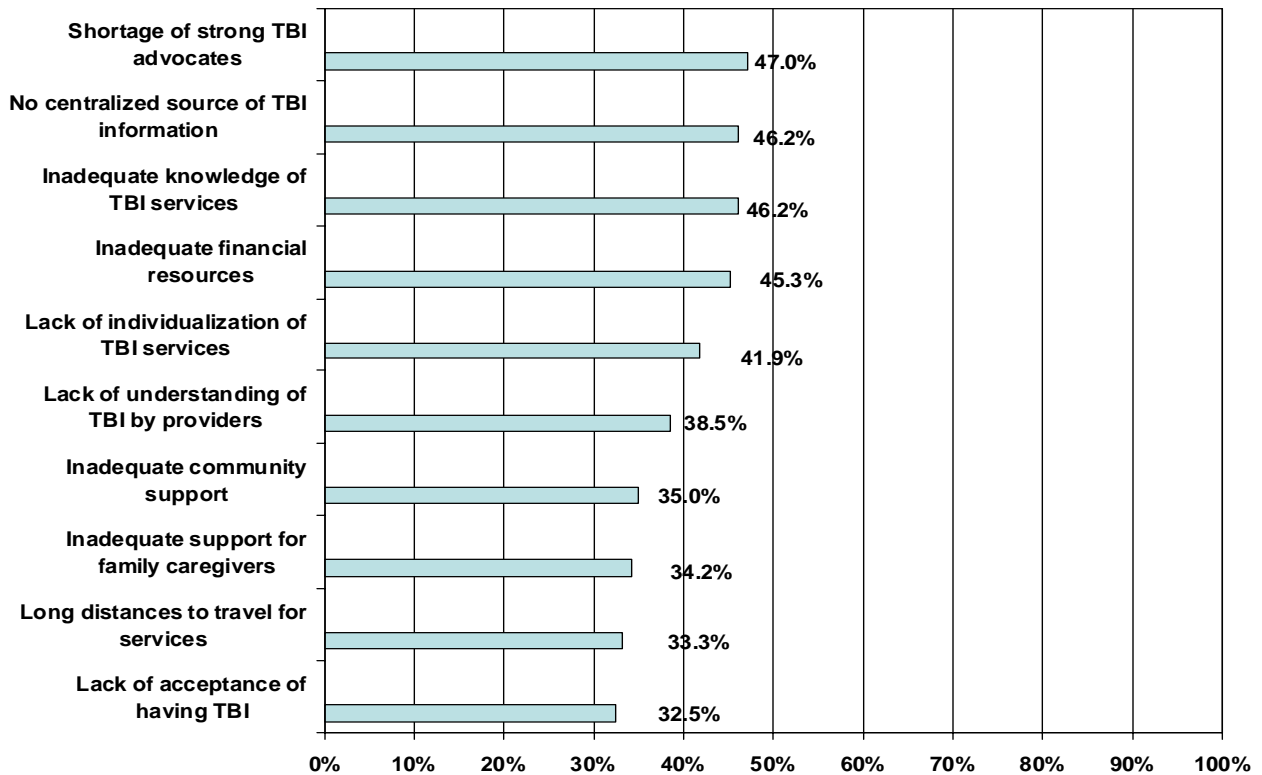
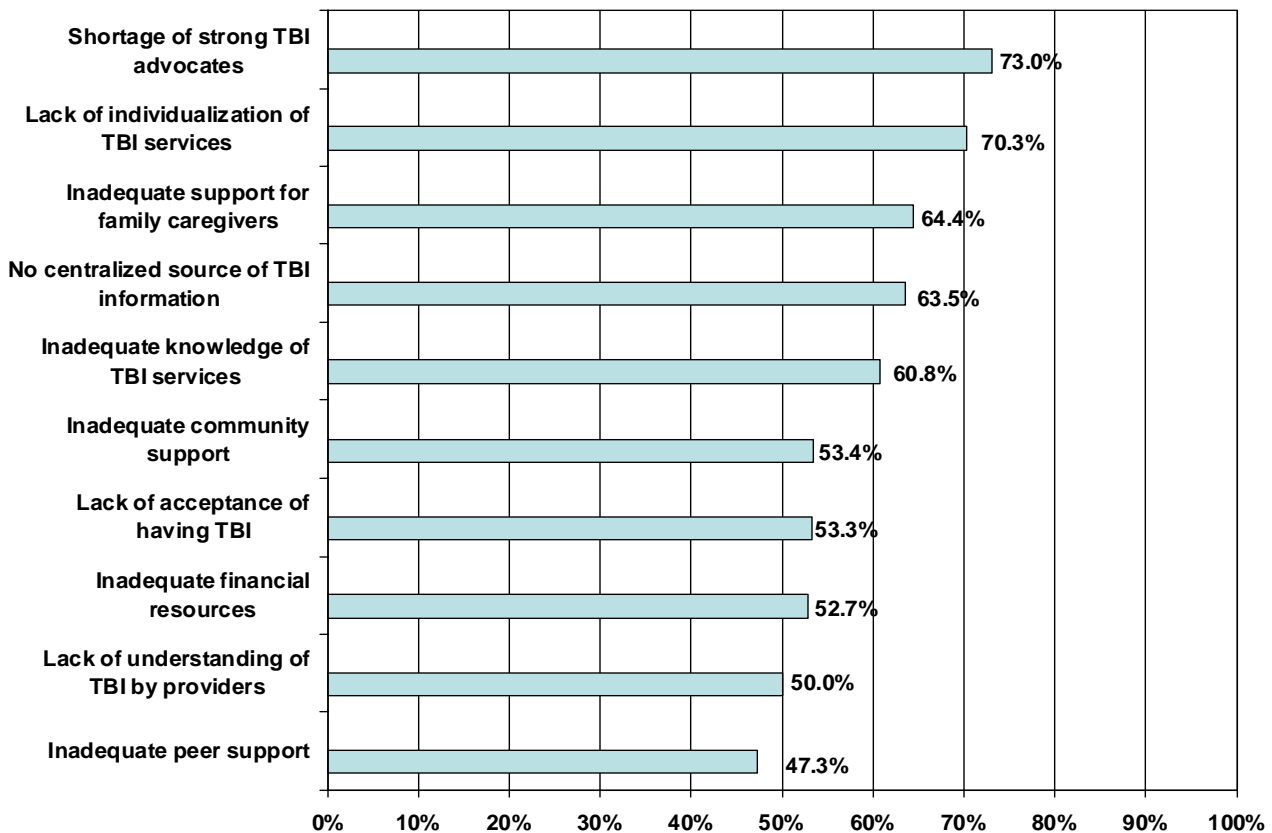


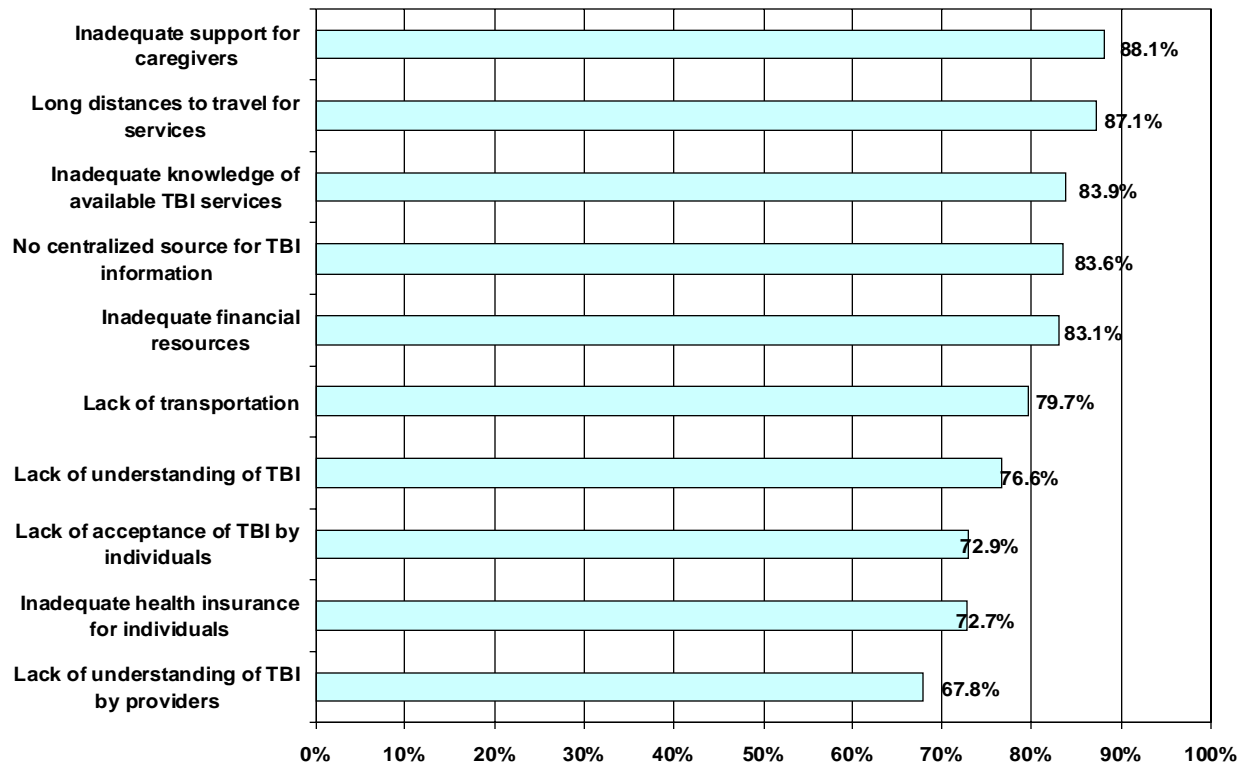
Chart 21 illustrates the most commonly mentioned TBI service barriers, as indicated by TBI caregivers. These barriers included a shortage of strong TBI advocates (73.0%), lack of individualization of TBI services (70.3%), inadequate support for family caregivers (64.4%), no centralized source of TBI information (63.5%), and inadequate knowledge of TBI services (60.8%).

Chart 21. Barriers to Services for Persons with TBI, as Perceived by TBI Caregivers



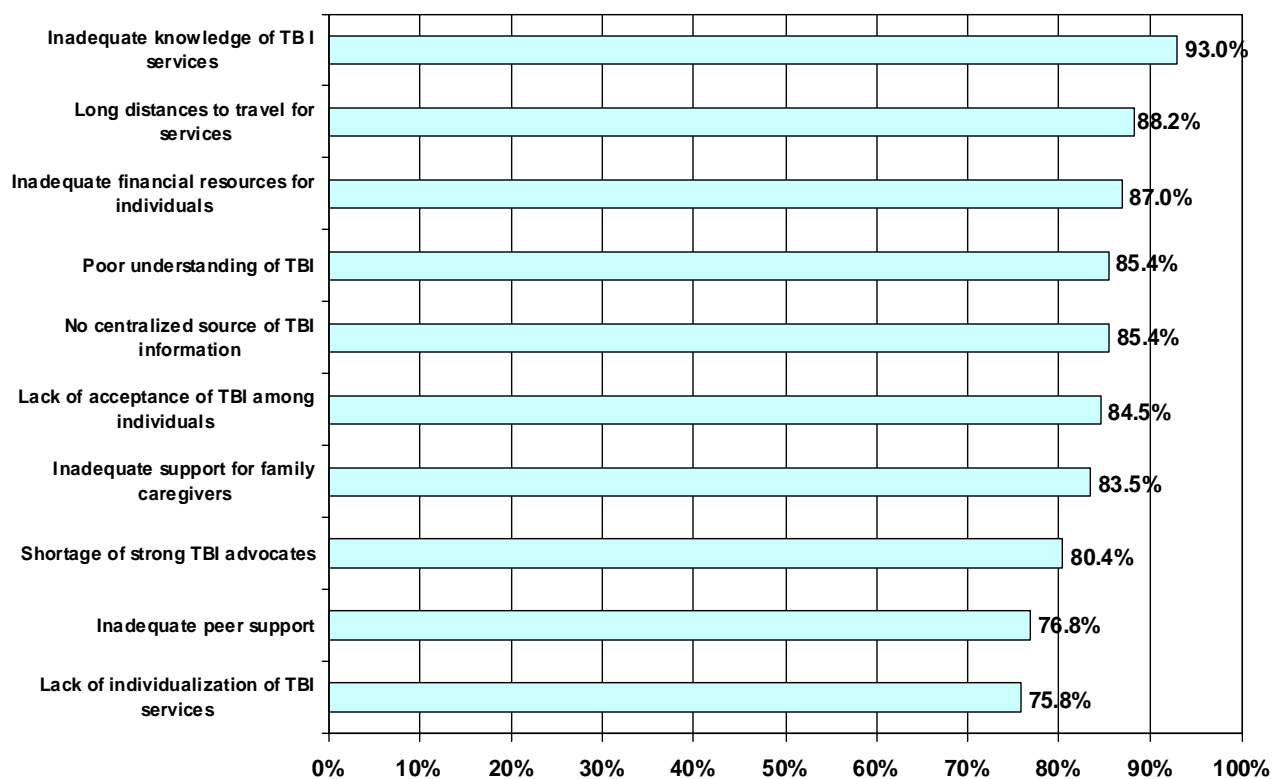
Agency representatives were also asked to identify barriers encountered by individuals with TBI in accessing and using services (Chart 22). The barriers most frequently listed include inadequate support for caregivers (88.1%), long distances to travel for services (87.1%), inadequate knowledge of available TBI services (83.9%), no centralized source for TBI information (83.6%), and inadequate financial resources for individuals (83.1%).

Chart 22. Barriers to Services for Persons with TBI, as Perceived by Agency Representatives



Service providers were asked to identify barriers faced by individuals with TBI for accessing and using services (Chart 23). The most frequently mentioned barriers included inadequate knowledge of TBI services (93.0%), long distances to travel for services (88.2%), inadequate financial resources for individuals (87.0%), poor understanding of TBI issues (85.4%), no centralized source of TBI information (85.4%), and lack of acceptance of TBI among TBI-affected individuals (84.5%).

Chart 23. Barriers to Services for Persons with TBI, as Perceived by Service Providers



Conclusion

Traumatic brain injury is an important public health problem that afflicts the citizens of North Dakota. Through the North Dakota Department of Health's federally-funded TBI Planning grant, UND Center for Rural Health (CRH) researchers and project staff used focus groups and surveys to conduct a needs and resources assessment for persons with TBI and their families in the state. Twenty focus groups, involving (1) persons with TBI, (2) their caregivers, (3) agency representatives, and (4) service providers, were conducted across North Dakota in 2004. Analysis of focus group discussions yielded four prominent themes: increased access to TBI information and resources; increased TBI education, training, and awareness; enhancement of TBI services; and increased support for persons with TBI and their families/caregivers.

A statewide survey effort involving these same four groups was conducted in 2005. Results indicated that persons with TBI and families encountered numerous barriers in accessing and using needed health and social services. The most frequently mentioned barriers cited by persons with TBI were a shortage of strong TBI advocates (47.0%), no centralized source of TBI information (46.2%), inadequate knowledge of TBI services (46.2%), inadequate financial resources (45.3%), lack of individualization of TBI services (41.9%), and lack of understanding of TBI by providers (38.5%). TBI caregivers were polled about the presence of barriers to services for the person with TBI that they provided care. This group's most commonly mentioned barriers included a shortage of strong TBI advocates (73.0%), lack of individualization of TBI services (70.3%), inadequate support for family caregivers (64.4%), no centralized source of TBI information (63.5%), and inadequate knowledge of TBI services (60.8%). Thus, compared to persons with TBI, caregivers indicated the presence of barriers at higher rates, and noted many of the same barriers.

Using the assessment findings as a framework, TBI staff and members of the state TBI Advisory Committee developed a plan of action to address the needs of North Dakotans with TBI and their families. This plan (Appendix B) serves as a blueprint for improving the life circumstances of these persons through sustainability, increased education and awareness, enhancement of services, and increased support.

The state Action Plan, designed to be executed during the three-year Implementation Phase of the TBI federal grant program, sets forth a number of intended outcomes and steps for their achievement. The first intended outcome is for TBI to have a presence in the state with accessible, available, appropriate, and affordable services and supports for individuals with TBI and their families. The actions steps for achieving this outcome include creating a state office of TBI, and securing dedicated funding for TBI programs. The second intended outcome is for individuals with TBI, family members, significant others, and providers of support and services to have timely information, resources, and education regarding TBI. This outcome is to be achieved through the development and implementation of a centralized source for TBI information and referral services, increased awareness of TBI, and increased training on TBI issues.

The third intended outcome of the state action plan is to ensure a coordinated system for individuals with brain injuries and their families to access and receive services and supports. This outcome is to be achieved through several action steps, including the following: provide access to comprehensive and coordinated services to meet their needs; increase opportunities for competitive employment, job retention, and career building; safe, affordable, and accessible place to live that is of their choosing; access to case management services; increase the use of technology to expand service availability; develop TBI screening tools; and assess the status of returning North Dakota National Guard men and women and the effects of the war in relation to TBI.

The fourth intended outcome is increased quality and availability of key supports for individuals with TBI and their families. This outcome is to be achieved by developing resources to assist individuals with brain injuries and their families in coping with the consequences and impact of brain injury throughout the course of their lives. The fifth and final intended outcome is for Native Americans with TBI and their families to have access to culturally appropriate TBI information, services, and supports. This outcome is to be achieved through increasing Native American participation in the process of planning and implementing TBI services in the state, and ensuring that all TBI materials are culturally relevant to Native Americans.

In sum, results of this assessment indicate that much work needs to be done to increase access to needed health and social services for persons with TBI. The next step toward achieving a comprehensive, coordinated system of care is to apply for and secure a federal Implementation grant; these funds will initiate and facilitate state efforts to achieve the goals and objectives of the TBI Action Plan, and build upon the statewide momentum and interest in TBI issues generated by activities conducted in the Planning Phase.

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APPENDIX A.
North Dakota TBI Advisory Committee

TBI Advisory Committee and Work Group

**indicates Work Group member*

The North Dakota Traumatic Brain Injury (TBI) State Action Plan is a product of the work conducted for the North Dakota TBI State Planning Grant. It was completed by the contracted agency, the University of North Dakota Center for Rural Health, in conjunction with the North Dakota State Health Department and the TBI Advisory Committee. This publication was funded by the Department of Health and Human Services (DHHS) Health Resources and Services Administration, Maternal and Child Health Bureau.

***LorRaine Anderson**- Kathryn
Individual with TBI

Tim Huseth- Harvey
HAV-IT

Center for Rural Health

Susan Offutt- Associate Director
TBI Project Coordinator

Shelly Arnold-Bismarck
ND Department of Health

Evelyn Klimpel- Minot
Family Member

Robin Medalen-Research Assistant

Mike Cogan-Assistant Professor

Kyle Muus-Assistant Professor

Brendan Beauclair-Valley City
Individual with TBI

Germaine Keepseagle- Fort Yates
Family Member

Alta Bruce- Belcourt
Injury Prevention Specialist

***Patrick Konewko**- Fargo
Neuropsychologist

***Michelle Clayton**- Grafton
Individual with TBI

***Diana Medicine Stone**- Bismarck
Center for Independent Living

***Larry Dauphinais**- Minot
Indian Health Services
District Sanitarian

Skipp Miller- Williston
Individual with TBI

***Chris Frier**- Grafton
Family Member

***Bruce Murry**- Bismarck
Protection & Advocacy

Diane Gates- Fort Yates
Standing Rock Social Services

Allen Newman- Mandaree
Family Member

Wanda Gier- Bismarck
Vocational Rehabilitation

Shelly Peterson- Bismarck
ND Long Term Care Association

***Rodney Gilmore**- Bismarck
TBI Grant Coordinator
ND Department of Health

***Robin Schumacher**- Bismarck
Division of Aging

Kirk Greff- Mandan
HIT, Inc.

***Mary Simonson**- Valley City
Open Door Center

Darryl Hall- Fort Berthold
Injury Prevention Specialist

Leslie Stastny- Grand Forks
ND Association for Disabled

Colleen Hokanson- Trenton
Injury Prevention Specialist

***Gerry Teevens**-Bismarck
ND Department of Public Instruction

Rodger Wyman- Grand Forks
Individual with TBI

APPENDIX B.
North Dakota TBI Action Plan

Statewide TBI Action Plan for North Dakota

Sustainability

OUTCOME: TBI will have a presence in ND with accessible, available, appropriate, and affordable services and supports for individuals with TBI and their families

Objective 1: Creation of a North Dakota Office of Traumatic Brain Injury

Strategies:

- *Create and adopt unique vision and mission statements
- *Create a Governor's Committee on TBI with tribal representation from both reservations and urban American Indians
- *Review advisory committee membership and sub-committees for representation from key stakeholders, (including populations to be served, taking into consideration culturally diverse and historically under-represented groups) to review the action plan activities
- *Partnership with State, Head Injury Association, Indigenous People's Brain Injury Association and Protection & Advocacy, Indian Health Services, Bureau of Indian Affairs social services and tribal social services
- *Provide coordination and communication across and within service sectors and with Indian Health Services
- *Explore and secure funding sources to sustain office of TBI

Objective 2: Secure Dedicated Funding for TBI Programs

Strategies:

- *Explore the best practices and models of other states
- *Conduct TBI cost basis analysis within existing state systems of services and supports and other data sources
- *Develop source of funding for long-term services
- *Identify legislative processes for implementing the system and key legislative stakeholders
- *Explore and secure funding sources for TBI programs (grants, private, and third party)
- *Coordinate with Head Injury Association, Indigenous People's Brain Injury Association, Protection & Advocacy, Indian Health Services, Bureau of Indian Affairs social services, tribal social services and other interested groups
- *Implement user tax to cover funding for population with brain injury (Trust Fund)

Education and Awareness

OUTCOME: Individuals with TBI, family members, significant others, and providers of support and services will have timely information, resources, and education regarding TBI.

Objective 1: Develop and implement a single point of contact for information and referral services

Strategies:

- *Explore the best practices and models of other states
- *Create a North Dakota 1-800 number
- *Provide information and resource services specific to North Dakota
- *Develop training, resource library, website, etc.
- *Revisit and revise training material, resource library, website, etc.
- *Respond to and follow up on requests for information
- *Coordinate with Perspective Partners
- *Evaluate program
- *Coordinate with the Single Point Entry Agency

Objective 2: Increase awareness about TBI

Strategies:

- *Explore the best practices and models of other states
- *Develop an awareness campaign
- *Develop fact sheets, brochures, presentations on special topics, etc
- *Develop American Indian fact sheets, brochures, presentations on specific topics, etc
- *Develop speaker's bureau (for schools, senior centers, sports organizations, prisons, social security, fire/police dept., homeless shelters, domestic violence shelters, etc.)
- *Develop brochure for distribution to hospitals, schools, and other service agencies
- *Submit general press release on TBI to weekly newspapers
- *Publicize TBI Information, Resources, and Awareness services (radio, local cable access television stations, newspaper, etc.)
- *Present information on TBI as it relates to ethnic and racial minorities

Objective 3: Increase Training on TBI

Strategies:

- *Explore the best practices and models of other states
- *Develop standardized training materials
- *Develop materials specific to American Indian
- *Provide statewide/regional training for educators, school personnel, state employees, job service, juvenile justice system, law enforcement, judicial system, penitentiary, mental health, emergency medical systems, Bureau of Indian Affairs, Tribal services, etc.
- *Present information at relevant in-state conferences
- *Provide joint conference planning across disciplines (Head Injury Association, Indigenous People's Brain Injury Association, Protection & Advocacy and other disciplines)
- *Develop core curriculum and training delivery plan
- *Increase TBI training into Health and Human Service agencies orientation procedures, continuing education, and in-service training
- *Arrange for presentations at TBI conferences on unique issues impacting American Indian individuals with TBI and their families

Enhancement of Services

OUTCOME: Ensure a coordinated system for individuals with brain injuries and their families to access and receive services and supports.

Objective 1: Individuals with TBI will have access to comprehensive and coordinated services to meet their needs

Strategies:

- *Initiate a process for systems to develop partnerships and collaborate more effectively
- *Increase level of collaboration between brain injury, developmental disabilities, behavioral health, substance abuse services, and from acute care to long term care
- *Develop pre-discharge model for use beginning with acute care settings
- *Develop post-discharge follow-up models
- *Explore the best practices and models of other states

Objective 2: Individuals with TBI will have increased opportunities for competitive employment, job retention, and career building

Strategies:

- *Provide education for employers, vocational rehabilitation counselors, and other employment service providers
- *Develop mechanism(s) that promote integrated services to include education, vocational rehabilitation, and employment services
- *Develop mechanism(s) that promote integrated services to include On the Job Training, supported employment, assistive technology, job modification, and employer education

Objective 3: Individuals with TBI will have a safe, affordable, and accessible place to live that is of their choosing

Strategies:

- *Research and develop final report on the availability of current housing
- *Develop solutions to address the housing needs
- *Continue conversations with agencies and tribal governments that have expressed interest in the TBI specific facilities and transitional living programs
- *Coordinate with North Dakota Fair housing Authority

Objective 4: Individuals with TBI will have access to case management services

Strategies:

- *Explore models for case management
- *Research models of other states
- *Explore sources of funding for case management
- *Conduct a cost analysis pertaining to the effectiveness of case management

Objective 5: Increase use of Technology to expand service availability

Strategies:

- *Research models of other states
- *Use technology for telemedicine/support in rural, frontier areas
- *Collaborate with Assistive Technology services- IPAT and University systems, human services, vocational educations, adult education

Objective 6: Develop screening tools

Strategies:

- *Research models of other states
- *Adapt/build screening instruments used by the targeted disciplines to include questions about TBI
- *Develop and conduct training on how to use tool
- *Implement statewide

Objective 7: Assess the status of returning North Dakota National Guard and the effects of the war in relation to TBI

Strategies:

- * Research national data for National Guard and TBI
- * Assess what is currently in place to assess TBI for returning ND National Guard members

Supports

OUTCOME: Increase quality and availability of key supports needed for individuals with TBI and their families

Objective 1: Develop resources to assist individuals with brain injuries and their families in coping with the consequences and impact of brain injury throughout the transition of their life

Strategies:

- *Obtain and study examples from other state's models of mentoring, peer support, and resource facilitation networks
- *Strengthen statewide and local brain injury support groups and talking circles on the reservations and urban settings in North Dakota
- *Increase outreach and technical assistance to support groups and talking circles regarding member recruitment, training, information, and sustainability
- *Strengthen family support initiatives for families of individuals with brain injuries
- *Explore the creation of a mentoring program to provide one-to-one support to a person with brain injury or a member of their family.
- *Social/recreational activities
- *Daycare/family care
- *Entities that offer volunteer opportunities

Tribal Issues

OUTCOME: Native Americans with TBI and their families will have access to culturally appropriate TBI information, services, and supports.

Objective 1: Increasing Native American participation in the process of planning and implementing TBI services

Strategies:

- *Recruit a representative from each reservation for the advisory committee
- *A support group (talking circle) for individuals with TBI and family members on each reservation and urban settings in North Dakota
- *Arrange for presentations at TBI conference on unique issues impacting Native American individuals with TBI and their families

Objective 2: Ensuring that all TBI Materials are culturally relevant to Native Americans

Strategies:

- *Develop Native American TBI specific training materials
- *Develop Native American TBI specific brochures, fact sheets, presentation on specific topics, etc.
- *Ensure Native American representation on TBI material review committee

APPENDIX C.
Focus Group Questions and Prompts

North Dakota Focus Group Questions

Welcome to Our Interview Session

We are very appreciative that you are able to attend today's interview session and we look forward to hearing your thoughts and ideas on ways we can improve the system of care for individuals with traumatic brain injury (TBI).

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

We will gather these sheets upon completion of the interview session as a backup for notes taken during the session. Please do not place your name on this sheet.

What is the name of the town where you reside? _____

What role are you in here? Individual with TB Caregiver
 Service Provider Agency Representative
 (*Direct care provider*) (*Indirect care provider*)

1. Tell us who you are: What is your experience with brain injury?

2. What is your experience with **service** for brain injured persons? Service is inclusive of such areas as, housing, medical care, rehabilitation, disability payments, and social service.
 - a. Think about your experience from the beginning to the present.
 - b. Tell us what stands out most in your experience.

3. **Medical services:** What was your experience with medical services? What was most frustrating? What was the most useful?

North Dakota Focus Group Questions

4. **Transition services:** Please describe the services that you (or the individual you care for) utilized while transitioning from your least independent state to your most independent status. What agencies or practices have been helpful?

5. **Employment:** What services have been most helpful in preparing you (or the individual you care for) for your current employment or what services have helped you to prepare for vocational goals?

6. Imagine that a person you know has just sustained a brain injury: What advice would you give them about the changes they will be experiencing? In your answer, please describe the emotions that they will feel during their first year after becoming brain injured.

7. Removing all barriers, money, travel, etc., what would the best system of services for individuals with brain injuries look like? Please take a moment to reflect on this and then give us your best answer.

We really appreciate you coming here to help us better understand the experience of brain injury from your point of view. We would like to give each of you the opportunity to tell us if there is anything we missed. Please tell us anything that you would like to about the services for brain injured persons in ND? Is there anything that you wanted to say that you did not get the chance to say?

APPENDIX D.
Individual with TBI Questionnaire

We are asking you to volunteer for our study about the needs of persons with traumatic brain injuries (TBI) in North Dakota. You do not have to provide us any information; however, we hope that you will participate. Please provide the following about **YOURSELF**. Your name will be kept confidential.

Q1 YOUR Name:

Q2 Today's Date:

Q3 YOUR Age:

Q4 YOUR Race (check all that apply):

- African American
- Asian
- Hispanic.....
- American Indian
- White
- Other (please specify): _____

Q5 How much money did YOU make in 2004?

- less than \$5,000
- \$5,000 to \$9,999.....
- \$10,000 to \$14,999.....
- \$15,000 to \$24,999.....
- \$25,000 to \$34,999.....
- \$35,000 to \$49,999.....
- \$50,000 to \$74,999.....
- \$75,000 or more

Q6 What sources of income did you have in 2004 (Check all that apply)?

- Employment.....
- Legal settlement from disability
- Public assistance (TANF)
- Retirement income or pension.....
- Supplemental Security Income (SSI).....
- Unemployment compensation
- Workers compensation or other injury benefit.....
- Social Security Income (SSDI)
- Child Support.....
- Spouse, family, friends
- Military benefits.....
- Other (Please specify) _____

Q7 Zip code where YOU live:

Q8 I am completing this survey:

- With assistance
- Without assistance

Q9 Have you ever had a neuropsychological evaluation?

- Yes.....
- No
- Do not know

In your answers, please use the definition of Traumatic Brain Injury (TBI) used in public law 104-166 [H.R. 248]: "...an acquired injury to the brain (e.g., a motor vehicle crashes, falls, assaults, etc). Such term **does not** include brain dysfunction due to congenital or degenerative disorders, nor birth trauma, **but may include** brain injuries due to anoxia caused by near drowning."

Please answer all questions to the best of your ability:

Q10 How old were you when you were first brain injured (in years)?

Q11 What caused your first brain injury (check one)?

- Motor vehicle crash
- Bicycle crash
- Pedestrian
- Near drowning
- Fall
- Assault/Abuse.....
- Firearm (gun shot)
- Other (please specify) _____

Q12 How many brain injuries have you had?

Q13 How long has it been since your last brain injury (in years)?

Q14 Do you have any health insurance now?

- Yes
- No
- Do not know.....

Q15 If so, what type of health insurance do you have (check all that apply)?

- Private or commercial health insurance (e.g. Blue Cross/Blue Shield)
- Medicaid
- Medicare
- CHAND
- Healthy Steps
- Other (please specify) _____

Q16 How much care do you need (check one)?

- I cannot be left alone
- I can be left alone for a few hours at a time.....
- I can be left alone for most of the day
- No care needed

Q17 Please indicate any disabilities you may have now (check all that apply).

- Mental Illness.....
- Aging-related disability
- Developmental disability (autism, down syndrome, cerebral palsy, etc)
- Dementia
- Sensory disability (blindness, deafness, etc).....
- Traumatic brain injury
- Physical disability
- Other (please specify) _____

Q18 Which one of your disabilities impacts your life the most (check one)?

- Mental Illness.....
- Aging-related disability
- Developmental disability (autism, down syndrome, cerebral palsy, etc)
- Dementia
- Sensory Disability (blindness, deafness, etc)
- Traumatic brain injury
- Physical disability
- Other (Please specify) _____

Q19 Do you live (check one)?

- Alone
- With your spouse.....
- With your family (not including spouse).....
- With a roommate
- Other (Please specify) _____

Q20 Do you live in a (check one)?

- Group home.....
- House or apartment.....
- Hospital.....
- Dacotah Alpha
- TBI Residential Facility (e.g. Dakota Pointe or H.I. Soaring Eagle Ranch)
- Nursing Home.....
- Basic Care Facility.....
- Other (please specify) _____

Do you currently **RECEIVE** any assistance in the following areas?

Q21 Employment (check all that apply)

- To increase your income
- To improve your job skills
- To work for fair pay

Q22 Recreational (check all that apply)

- To provide you with opportunities to socialize
- To participate in recreational activities
- To feel a part of the community
- To participate in religious services or spiritual programs

Q23 Independent Living Skills (check all that apply)

- To walk, lift, or balance independently
- To cook, clean, and shop independently
- To manage money and pay bills
- To travel within the community
- To manage your personal attendant services
- To eat, dress, bathe, or toilet independently
- To communicate your needs and wishes to others

Q24 Mental Health (check all that apply)

- To manage your stress or emotion
- To improve your mood
- To control your temper

Q25 General (check all that apply)

- To further your education or training
- To improve your intimate relationships
- To coordinate services you receive (e.g. case management)
- To obtain housing you can use
- To manage your legal issues
- To control your alcohol and other drug use
- To care for your children
- To improve your health
- To improve your memory or problem solving

Do you currently **NEED** any (additional) assistance in the following areas?

Q26 Employment (check all that apply)

- To increase you income
- To improve your job skills
- To work for fair pay

Q27 Recreational (check all that apply)

- To provide you with opportunities to socialize
- To participate in recreational activities
- To feel a part of the community
- To participate in religious services or spiritual programs

Q28 Independent Living Skills (check all that apply)

- To walk, lift, or balance independently
- To cook, clean, and shop independently
- To manage money and pay bills
- To travel within the community
- To manage your personal attendant services
- To eat, dress, bathe, or toilet independently
- To communicate your needs and wishes to others

Q29 Mental Health (check all that apply)

- To manage your stress or emotion
- To improve your mood
- To control your temper

Q30 General (check all that apply)

- To further your education or training
- To improve your intimate relationships
- To coordinate the services you receive (e.g. case management)
- To obtain housing you can use
- To manage your legal issues
- To control your alcohol and other drug use
- To care for your children
- To improve your health
- To improve your memory or problem solving

Please answer the following question by checking **YES** or **NO** for each response

Q31 Are these behaviors a problem for YOU?

	Yes	No
Difficulty controlling my temper	<input type="checkbox"/>	<input type="checkbox"/>
Impatient when my needs are not met easily	<input type="checkbox"/>	<input type="checkbox"/>
Frequent complaining	<input type="checkbox"/>	<input type="checkbox"/>
Aggression; violent behavior	<input type="checkbox"/>	<input type="checkbox"/>
Impulsive; I often dispute topics	<input type="checkbox"/>	<input type="checkbox"/>
Lack control over behavior; my behavior is inappropriate for social situations	<input type="checkbox"/>	<input type="checkbox"/>
Overly dependent; I rely upon others unnecessarily	<input type="checkbox"/>	<input type="checkbox"/>
Poor decision making; I do not think of consequences	<input type="checkbox"/>	<input type="checkbox"/>
Childish; at times I am immature	<input type="checkbox"/>	<input type="checkbox"/>
Poor insight; I refuse to admit difficulties	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty becoming interested in things	<input type="checkbox"/>	<input type="checkbox"/>
Lack of initiative; I do not think for myself	<input type="checkbox"/>	<input type="checkbox"/>
Irritable; snappy; grumpy	<input type="checkbox"/>	<input type="checkbox"/>
Sudden/rapid mood change	<input type="checkbox"/>	<input type="checkbox"/>
Anxious; tense; uptight	<input type="checkbox"/>	<input type="checkbox"/>
Depression; low mood	<input type="checkbox"/>	<input type="checkbox"/>
Irresponsible; can't always be trusted	<input type="checkbox"/>	<input type="checkbox"/>
Trouble sleeping	<input type="checkbox"/>	<input type="checkbox"/>

In your opinion, do you consider these situations as **BARRIERS TO ACCESSING/USING** services for yourself?

Q32

	Yes	No
Inadequate financial resources	<input type="checkbox"/>	<input type="checkbox"/>
Long distances to travel for services	<input type="checkbox"/>	<input type="checkbox"/>
Lack of transportation	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate knowledge of available services for TBI	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate support from family	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate peer support	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate community support	<input type="checkbox"/>	<input type="checkbox"/>
Lack of acceptance of having a TBI	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate health insurance	<input type="checkbox"/>	<input type="checkbox"/>
Lack of individualization of TBI services	<input type="checkbox"/>	<input type="checkbox"/>
Shortage of strong TBI advocates	<input type="checkbox"/>	<input type="checkbox"/>
No centralized source for TBI information	<input type="checkbox"/>	<input type="checkbox"/>
Lack of understanding of TBI by providers	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate support for family caregivers	<input type="checkbox"/>	<input type="checkbox"/>

APPENDIX E.
TBI Caregiver Questionnaire

Because you provide care to someone with a traumatic brain injury (TBI), we are asking for your voluntary participation in our study. The survey is designed to assess the needs of North Dakotans with TBI and their caregivers. You do not have to provide us any information; however, we hope that you will participate. Please provide the following demographic information about **YOURSELF**. Your identity will be kept confidential.

Q1 Today's Date:

Q2 YOUR Age:

Q3 YOUR Race (check all that apply):

- African American
- Asian
- Hispanic
- American Indian
- White
- Other (Please specify) _____

Q4 YOUR Name:

Q5 Zip code where YOU live:

Q6 Are YOU providing care for an individual who has experienced a Traumatic Brain Injury?

- Yes
- No

If you do not care for anyone with TBI, this completes your participation. Please return the survey in the prepaid envelope provided. Thank you.

In providing your information, please use the definition of Traumatic Brain Injury (TBI) as defined in public law 104-166 [H.R. 248]: "...an acquired injury to the brain (e.g., a motor vehicle crashes, falls, assaults, etc). Such term **does not** include brain dysfunction due to congenital or degenerative disorders, nor birth trauma, **but may include** brain injuries due to anoxia caused by near drowning."

Section 1: Questions Q7 - Q12 are asking for information about **YOU** as a caregiver to a person with Traumatic Brain Injury (TBI).

Q7 YOUR relationship to the individual with TBI (check all that apply):

- Spouse
- Sibling
- Parent.....
- Legal Guardian.....
- Child
- Significant other
- Direct Contact provider.....
- Other (please specify) _____

Q8 How far do YOU travel to provide care to him or her?

- I live with the person.....
- Less than 20 minutes away.....
- Between 20 & 59 minutes away
- Between one & two hours away
- More than two hours away

Q9 How long have YOU been providing care to a person with TBI?

- One year or less
- If more than one year, how many years _____

Q10 How many hours per week do YOU provide care to the person with TBI (check one)?

- 1-5 hours a week.....
- 6-10 hours a week.....
- 11-15 hours a week.....
- 16-20 hours a week.....
- More than 20 hours a week.....

Q12 What is YOUR marital status (check one)?

- Never married.....
- Divorced.....
- Widowed.....
- Separated.....
- Married.....

Q11 Do YOU feel you have access to adequate health care for YOUR own health concerns?

- Yes.....
- No.....

Instructions: Below is a list of difficulties commonly experienced by caregivers. If **YOU** experience any of these difficulties, we would like to know how serious a problem this is for you. Please tell us of the difficulties **YOU** have experienced since becoming a caregiver for a person with TBI. Please indicate the seriousness of each difficulty **YOU** have encountered by checking the box in the scale below.

Q13 Caregiving difficulties

	<i>Strongly disagree</i>	<i>Disagree</i>	<i>Neither agree nor disagree</i>	<i>Agree</i>	<i>Strongly agree</i>
Less time for myself (shopping, hobbies, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Less time for my family (shorter vacations, missed events, etc)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
No consistent help from other family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Adversely effects my marital relationship	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Adversely effects my family relationships (siblings, in-laws, children, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Conflicts with my social life (eating out, movies, visiting friends, etc)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emotional aspects (frustration, sadness, anxiety, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Less privacy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Interferes with my job	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Financial obligations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lifestyle change	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having the responsibility for making major decisions for loved ones	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My physical health is deteriorating due to providing care for the person with TBI	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am unable to get the sleep I need due to providing care for the person with TBI	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section 2: Questions 14 - 25 in this section are about the person with TBI.

Q14 At what age did the person with TBI experience their first brain injury (in years)?

Q15 How was the individual with TBI first brain injured (check one)?

- Motor vehicle crash.....
- Bicycle crash
- Pedestrian
- Near drowning
- Fall.....
- Assault/abuse
- Firearm (gun shot)
- Other (Please specify) _____

Q16 How many traumatic brain injuries have they had?

Q17 How long has it been since their last brain injury (in years)?

Q18 Please indicate any disabilities the person you provide care for may have now (check all that apply).

- Mental illness
- Aging-related disability
- Developmental disability (autism, down syndrome, cerebral palsy, etc)
- Dementia
- Sensory disability (blindness, deafness, etc).....
- Traumatic brain injury
- Physical disability
- Other (please specify) _____

Q19 Which one of their disabilities impacts their life the most (check one)?

- Mental illness
- Aging-related disability
- Developmental disability (autism, down syndrome, cerebral palsy, etc)
- Dementia
- Sensory disability (blindness, deafness, etc).....
- Traumatic brain injury
- Physical disability
- Other (please specify) _____

Q20 Does the person with TBI currently have any type of health insurance?

- Yes.....
- No
- Do not know.....

Q21 If you answered yes, what type of health insurance do they have (check all that apply)?

- Private or commercial health insurance (e.g. Blue Cross/Blue Shield)
- Medicaid
- Medicare
- CHAND
- Healthy Steps
- Other (please specify) _____

Q22 Does the person with TBI live (check one)?

- Alone
- With a spouse.....
- With family
- With a roommate
- Other (please specify) _____

Q23 Does the person with TBI live in a (check one)?

- Group home.....
- House or apartment.....
- Hospital.....
- TBI Residential Facility (Dakota Pointe or H.I. Soaring Eagle Ranch).....
- Dacotah Alpha
- Nursing Home.....
- Basic Care Facility.....
- Other (please specify) _____

Q24 How much care, from you and/or others, does the person with TBI require (check one)?

- They cannot be left alone
- They can be left alone for a few hours at a time.....
- They can be left alone for most of the day.....
- They need no care.....

Q25

Do YOU believe that the following BEHAVIORS are a problem for the INDIVIDUAL you provide care for?

	Yes	No
Difficulty controlling temper	<input type="checkbox"/>	<input type="checkbox"/>
Impatient when their needs are not met easily	<input type="checkbox"/>	<input type="checkbox"/>
Frequent complaining	<input type="checkbox"/>	<input type="checkbox"/>
Aggression; violent behavior	<input type="checkbox"/>	<input type="checkbox"/>
Impulsive; often disputes topics	<input type="checkbox"/>	<input type="checkbox"/>
Lacks control over behavior; behavior is inappropriate for social situations	<input type="checkbox"/>	<input type="checkbox"/>
Overly dependent; relies upon others unnecessarily	<input type="checkbox"/>	<input type="checkbox"/>
Poor decision making; <u>Does not</u> think of consequences	<input type="checkbox"/>	<input type="checkbox"/>
Childish; at times immature	<input type="checkbox"/>	<input type="checkbox"/>
Poor insight; refuses to admit difficulties	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty becoming interested in things	<input type="checkbox"/>	<input type="checkbox"/>
Lacks initiative; <u>Does not</u> think for self	<input type="checkbox"/>	<input type="checkbox"/>
Irritable; snappy; grumpy	<input type="checkbox"/>	<input type="checkbox"/>
Sudden/rapid mood change	<input type="checkbox"/>	<input type="checkbox"/>
Anxious; tense; uptight	<input type="checkbox"/>	<input type="checkbox"/>
Depression; low mood	<input type="checkbox"/>	<input type="checkbox"/>
Irresponsible; can't always be trusted	<input type="checkbox"/>	<input type="checkbox"/>
Trouble sleeping	<input type="checkbox"/>	<input type="checkbox"/>

Q26

In your opinion, do you consider these situations as BARRIERS TO ACCESSING/USING services for the individual you provide care for?

	Yes	No
Inadequate financial resources	<input type="checkbox"/>	<input type="checkbox"/>
Long distance to travel for services	<input type="checkbox"/>	<input type="checkbox"/>
Lack of transportation	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate knowledge of available services for TBI	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate support <u>from</u> family	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate peer support	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate community support	<input type="checkbox"/>	<input type="checkbox"/>
Lack of acceptance of having a TBI	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate health insurance	<input type="checkbox"/>	<input type="checkbox"/>
Lack of individualization of TBI services	<input type="checkbox"/>	<input type="checkbox"/>
Shortage of strong TBI advocates	<input type="checkbox"/>	<input type="checkbox"/>
No centralized source for TBI information	<input type="checkbox"/>	<input type="checkbox"/>
Lack of understanding of TBI by providers	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate support <u>for</u> family caregivers	<input type="checkbox"/>	<input type="checkbox"/>

APPENDIX F.
TBI Agency Representative
Questionnaire

We are asking for your participation in our study assessing the needs of persons with traumatic brain injury (TBI) in North Dakota. You are under no obligation to provide us any information; however, we hope that you will participate. Please provide the following information about your agency.

Q1 Today's Date:

Q2 Name of Agency:

Q3 Your Name:

Q4 Your Title:

Q5 Your Department/Division:

Q6 Phone:

Q7 Fax:

Q8 E-Mail:

Q9 Agency Type:

Public

Private (for profit)

Private (not for profit)

Q10 Mailing Address (street, city and zip):

In providing your information, please use the definition of Traumatic Brain Injury (TBI) as defined in public law 104-166 [H.R. 248]: "...an acquired injury to the brain (e.g., motor vehicle crashes, falls, assaults). Such term **does not** include brain dysfunction due to congenital or degenerative disorders, nor birth trauma, **but may include** brain injuries due to anoxia caused by near drowning."

Please answer questions pertaining to the time period **January 1, 2004 to December 31, 2004.**

Q11 Does your agency provide services, funding, or administer programs for individuals with TBI?

Yes.....

No.

Q12 What is the total number of individuals served by your agency?

Q13 What is the number of individuals with TBI served by your agency?

If you answered "no" to Q11, this concludes the survey. Please return the survey in the prepaid envelope.

Q14 In your agency, what is the number of staff who provide direct services to individuals with TBI?

Q15 To what extent do you feel your staff personnel are educated/trained to serve persons with TBI?

Not at all.....

Moderately.....

Highly.....

Q16 Do you feel that your staff personnel need additional training or education specific to TBI?

Yes.....

No.....

Additional Comments:

Q17 Does your agency provide Direct Services (e.g., treatment, therapy, transportation and housing) for or related to persons with TBI?

Yes.....

No.....

Additional Comments:

Q18 Does your agency provide services for the Prevention of TBI?

Yes.....

No.....

Additional Comments:

Q19 Does your agency provide Acute Medical Services for or related to persons with TBI?

Yes.....

No.....

Additional Comments:

Q20 Does your agency provide Education Services for or related to persons with TBI?

Yes.....

No.....

Additional Comments:

Q21 Does your agency provide Employment Services for or related to persons with TBI?

Yes.....

No.....

Additional Comments:

Q22 Does your agency provide Community Support Services for or related to persons with TBI?

Yes.....

No.....

Additional Comments:

Q23 Does your agency provide Rehabilitation Services for or related to persons with TBI?

Yes.....

No.....

Additional Comments:

Q24 Does your agency provide Financial Resources for persons with TBI?

Yes.....

No.....

Additional Comments:

Q25 Does your agency offer Educational and/or Training Programs on the topic of TBI?

Yes.....

No.....

Additional Comments:

In your opinion, do you consider these situations as **BARRIERS to ACCESSING/USING SERVICES** among persons with TBI in **YOUR SERVICE AREA** (e.g., community, region or state)?

Q26 In relation to Agencies and Service Providers:

	Yes	No
Lack of understanding of TBI	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate screening/protocol to identify TBI	<input type="checkbox"/>	<input type="checkbox"/>
Lack of involvement in treatment plan for an individual following discharge from the hospital	<input type="checkbox"/>	<input type="checkbox"/>
Lack of coordination with other services	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate TBI-specific eligibility criteria for services	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate financial resources for your agency	<input type="checkbox"/>	<input type="checkbox"/>

Q27 In relation to individuals with TBI and their families:

	Yes	No
Inadequate financial resources for individuals	<input type="checkbox"/>	<input type="checkbox"/>
Long distances to travel for services	<input type="checkbox"/>	<input type="checkbox"/>
Lack of transportation	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate knowledge of available services for TBI	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate support from family	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate peer support	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate community support	<input type="checkbox"/>	<input type="checkbox"/>
Lack of acceptance of having a TBI by individuals	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate health insurance for individuals	<input type="checkbox"/>	<input type="checkbox"/>
Lack of individualization of TBI services for individuals	<input type="checkbox"/>	<input type="checkbox"/>
Shortage of strong TBI advocates	<input type="checkbox"/>	<input type="checkbox"/>
No centralized source for TBI information	<input type="checkbox"/>	<input type="checkbox"/>
Lack of understanding of TBI by providers	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate support for family caregivers	<input type="checkbox"/>	<input type="checkbox"/>

APPENDIX G.
TBI Service Provider Questionnaire

We are asking for your participation in our study assessing the needs of persons with traumatic brain injury (TBI) in North Dakota. You are under no obligation to provide us any information; however, we hope that you will participate. Please provide the following information about you and your organization.

Q1 Date:

Q2 Name of Organization:

Q3 Your Name:

Q4 Your Position:

Q5 Your Department/Division:

Q6 Phone:

Q7 Fax:

Q8 E-Mail:

Q9 Mailing Address (street, city and zip):

Q10 Site Address (if different from above):

In providing your information, please use the definition of Traumatic Brain Injury (TBI) as defined in public law 104-166 [H.R. 248]: "...an acquired injury to the brain (e.g., motor vehicle crashes, falls, assaults). Such term **does not** include brain dysfunction due to congenital or degenerative disorders, nor birth trauma, **but may include** brain injuries due to anoxia caused by near drowning."

Please answer questions pertaining to the time period January 1, 2004 to December 31, 2004.

Q11 Do YOU personally provide direct services (e.g., treatment, therapy, transportation, housing, or case management) for individuals with a brain injury, or to their families?
Yes.....
No.....

If you answered "no" to Q11, this concludes the survey.
Please return the survey in the prepaid envelope.

Q12 What is the total number of individuals served by YOU personally?

Q13 What is the number of individuals with TBI served by YOU personally?

Q14 What is the number of hours YOU have spent in continuing education and training specific to TBI (e.g., conferences, workshops, classes, etc.)?

Q15 Do YOU have a need for additional education or training specific to TBI?
Yes.....
No.....

Q16 Do YOU provide Direct Services (e.g., conferences, workshops, classes, etc.) for or related to persons with TBI?
Yes.....
No.....
Additional Comments:

Q17 Do YOU provide services for the Prevention of TBI?
Yes.....
No.....
Additional Comments:

Q18 Do YOU provide Acute Medical Services for or related to persons with TBI?
Yes.....
No.....
Additional Comments:

Q19 Do YOU provide Educational Services for or related to persons with TBI?
Yes.....
No.....
Additional Comments:

Q20 Do YOU provide Employment Services for or related to persons with TBI?
Yes.....
No.....
Additional Comments:

Q21 Do YOU provide Community Support Services for or related to persons with TBI?
Yes.....
No.....
Additional Comments:

Q22 Do YOU provide Rehabilitation Services for or related to persons with TBI?

Yes.....

No

Additional Comments:

Q23 Do YOU provide Financial Resources for persons with TBI?

Yes.....

No

Additional Comments:

Q24 Do YOU offer Educational and/or Training Programs on the topic of TBI?

Yes.....

No

Additional Comments:

Please indicate whether **YOU** provide the services listed below by checking all that apply.

Q25 Employment (check all that apply)

To increase their income

To improve their job skills

To provide opportunities for them to work for fair pay

To further their education or training.....

Q26 Recreational (check all that apply)

To provide them with opportunities to socialize

To participate in recreational activities.....

To feel a part of their community

To participate in religious services or spiritual programs.....

Q27 Independent Living Skills (check all that apply)

To walk, lift, or balance independently.....

To cook, clean, and shop independently

To manage money and pay bills.....

To travel within the community

To provide personal care attendant services.....

To eat, dress, bathe, or toilet independently.....

To obtain housing they can use.....

To improve their memory or problem solving.....

Q28 Mental Health (check all that apply)

To manage their stress or emotions

To improve their mood.....

To control their temper.....

To control their alcohol and other drug use

Q29 General (check all that apply)

To improve their intimate relationships

To care for their children.....

To improve their health

To manage their legal issues.....

To coordinate the services they receive (e.g., case management)

Q30 Education (check all that apply)

To address their educational needs.....

To assist with their growth and development.....

To gain skills for future employment.....

To assist the family in working with individuals with TBI they care for

In your opinion, do you consider these situations as **BARRIERS to ACCESSING/USING SERVICES** among persons with TBI in **YOUR SERVICE AREA** (e.g., community, region, or state)?

Q31 In relation to Agencies and Service Providers:

	Yes	No
Lack of understanding of TBI	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate screening/protocol to identify TBI	<input type="checkbox"/>	<input type="checkbox"/>
Lack of involvement in treatment plan for an individual following discharge from the hospital	<input type="checkbox"/>	<input type="checkbox"/>
Lack of coordination with other services	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate TBI-specific eligibility criteria for services	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate financial resources for your agency	<input type="checkbox"/>	<input type="checkbox"/>

Q32 In relation to individuals with TBI and their families:

	Yes	No
Inadequate financial resources for individuals	<input type="checkbox"/>	<input type="checkbox"/>
Long distances to travel for services	<input type="checkbox"/>	<input type="checkbox"/>
Lack of transportation	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate knowledge of available services for TBI	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate support from family	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate peer support	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate community support	<input type="checkbox"/>	<input type="checkbox"/>
Lack of acceptance of having a TBI by individuals	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate health insurance for individuals	<input type="checkbox"/>	<input type="checkbox"/>
Lack of individualization of TBI services for individuals	<input type="checkbox"/>	<input type="checkbox"/>
Shortage of strong TBI advocates	<input type="checkbox"/>	<input type="checkbox"/>
No centralized source for TBI information	<input type="checkbox"/>	<input type="checkbox"/>
Lack of understanding of TBI by providers	<input type="checkbox"/>	<input type="checkbox"/>
Inadequate support for family caregivers	<input type="checkbox"/>	<input type="checkbox"/>

