

Nebraska Traumatic Brain Injury

Needs and Resources Assessment

Executive Summary

The 2010 Nebraska Needs and Resources assessment purpose was to 1) describe the current traumatic brain injury (TBI) population, incidence rates, and prevalence rates; 2) identify the service needs of individuals with brain injury and their families; and to 3) describe existing services and supports, service gaps and system barriers.

TBI is defined as an insult to the brain, not of a degenerative or congenital nature, but caused by an external physical force that may produce a diminished or altered state of consciousness, which results in an impairment of cognitive abilities or physical functioning. It can also result in the disturbance of behavioral or emotional functioning. These impairments may be either temporary or permanent and cause partial or total functional disability. TBI is a subset of Acquired Brain Injury (ABI), which also includes injuries of a non-traumatic nature, such as stroke, near drowning, hypoxic or anoxic brain injury, tumor, neurotoxins, or electric shock.

ABI (including TBI) may result in mild, moderate or severe levels of impairment in attention, learning and memory, organization, communication, and executive functioning. Any of these impairments may permanently affect an individual's ability to live and work independently. In general, the TBI needs assessment results and recommendations are partial to severe and moderate TBIs as a majority of survey respondents had severe brain injuries. Further, stakeholder and provider feedback focused primarily on more severe TBI cases and services and services are more frequently funded and received for more severe brain injuries. However, service needs, gaps and barriers that are addressed in the needs assessment are also relevant to mild brain injuries.

Data was obtained from Nebraska's TBI Registry and other data sources and stakeholder feedback was obtained through numerous research methods. The full report provides limitations and qualifications of the data presented in this executive summary.

TBI Population Description

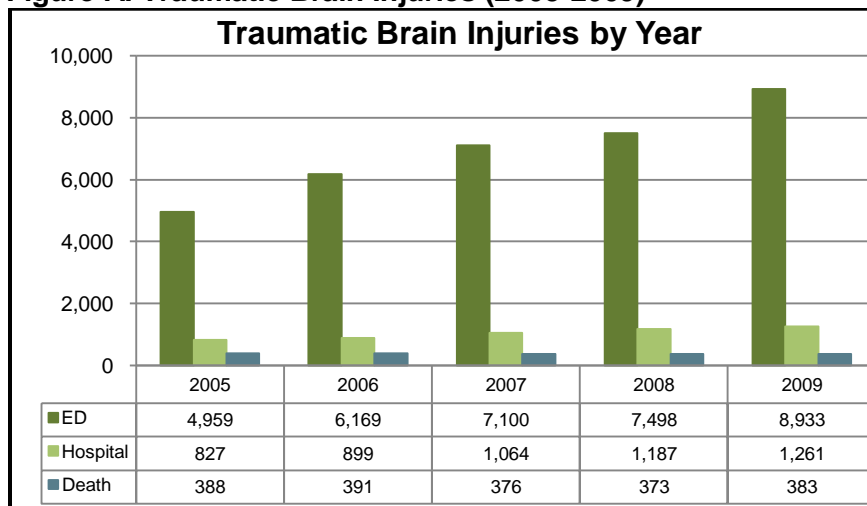
Prevalence

The CDC's National Center for Injury Prevention and Control estimates that 5.3 million U.S. citizens (2% of the population) are living with disability as a result of a traumatic brain injury. The CDC's estimated 2% prevalence rate applied to Nebraska's 2010 population provides a conservative estimated prevalence for Nebraska of **36,527** individuals living with a traumatic brain injury related disability.

Incidence

Nebraska's TBI Registry was analyzed to describe characteristics of individuals with a TBI and to calculate incidence rates for various populations. Figure A shows that from 2005 to 2009 there has been a steady increase in the number of TBI related Emergency Department (ED) visits and hospitalizations, while the number of deaths remained relatively unchanged.

Figure A. Traumatic Brain Injuries (2005-2009)



While prevalence measures the number of individuals living with a TBI, incidence measures the number of TBIs per year. The number of TBI injuries or deaths per 100,000 population (incidence rate) adjusted for differences in age distributions between Nebraska and the U.S. are shown in Figure B. The Nebraska hospitalization rates were below the U.S. average while the death rates and 2009 emergency department rates were above U.S. averages.

Figure B. Nebraska and U.S. Age-Adjusted Incidence Rates

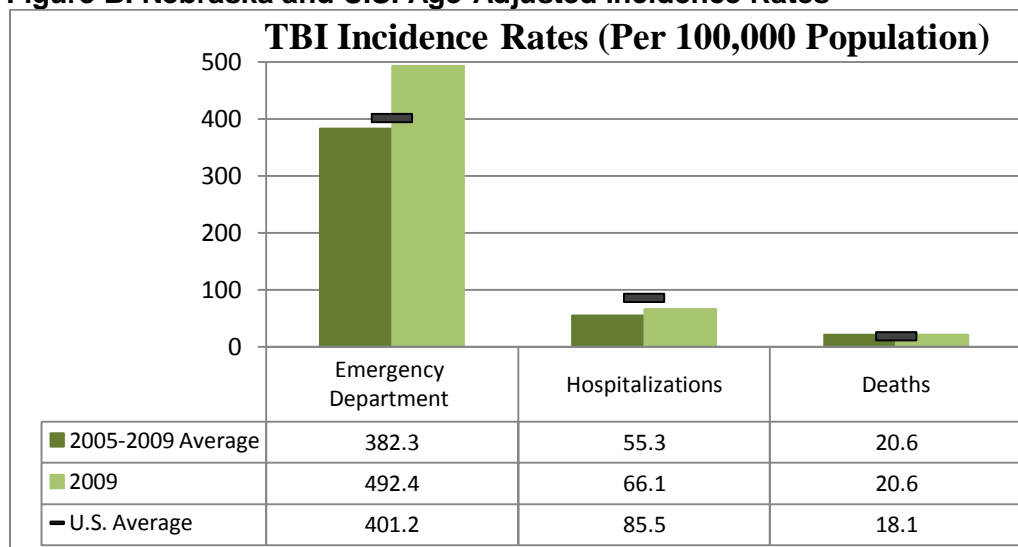


Figure C depicts the 2005-2009 average **number** of TBIs for each Nebraska county, while Figure D shows the **incidence rate**, number of TBIs per 100,000 population, for each county. The figures show that some of the counties with the highest overall number of TBIs do not necessarily have the highest incidence rates.

Figure C. TBI Emergency Department Visits by County (2005-2009)

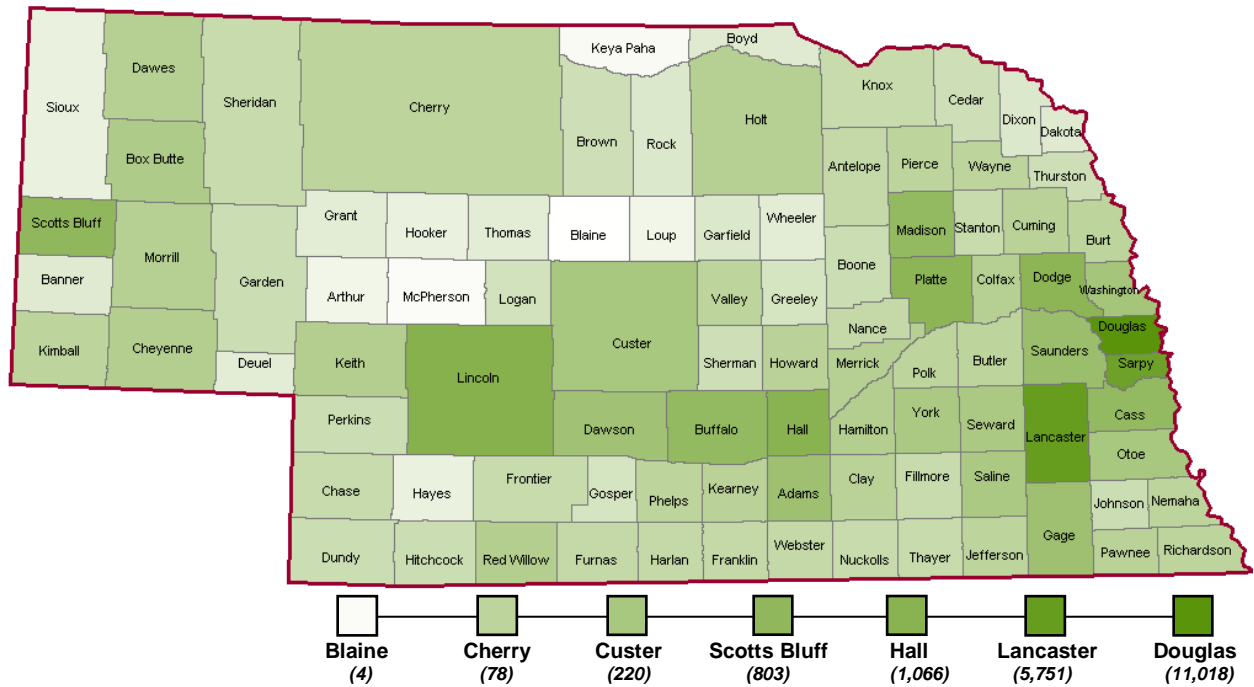
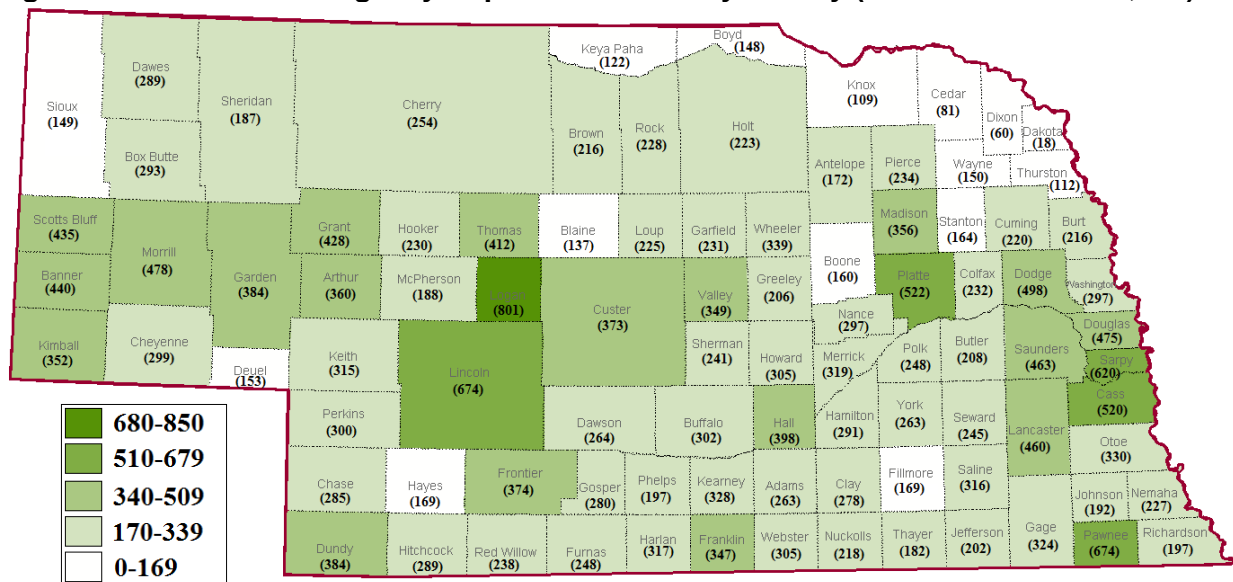


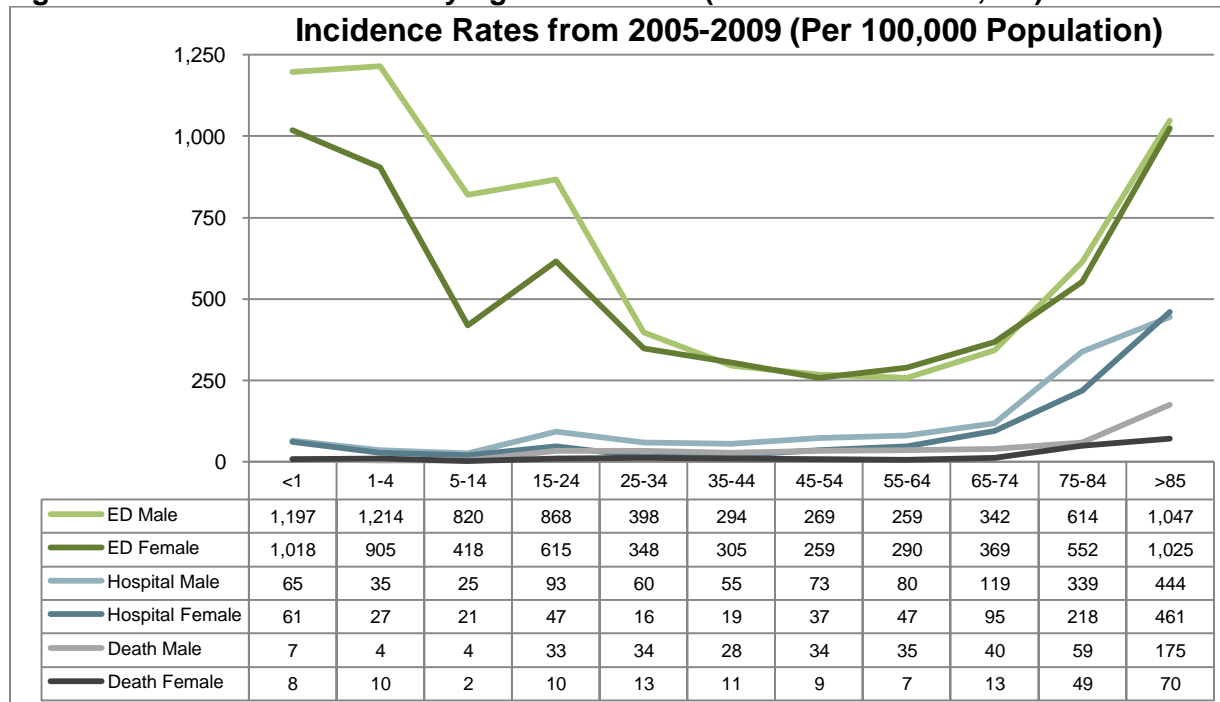
Figure D. 2005-2009 Emergency Department Visits by County (Incidence Rate/100,000)



Age and Gender Incidence

From 2005-2009 the nominal and age adjusted TBI rate per 100,000 population was greater for males. Percentages also suggest that the proportion of brain injuries that are male increases with severity. Figure E shows that the incidence rate for hospitalizations and deaths increases with age; however, the incidence rate for emergency department visits is highest among both those under 4 years old and over 85 years old.

Figure E. TBI Incidence Rates by Age and Gender (Incidence Rate/100,000)



Causes

The 3 most frequent causes of TBI related emergency department visits, hospitalizations, and deaths are listed in Table A, with falls being the most frequent cause of injury and motor vehicle incidences the most frequent cause of death. In further analysis, the incidence rate for falls as the cause of injury is higher for individuals under 1 and over 65 for emergency department and hospital visits and higher for individuals over 65 for deaths. Incidence rates involving motor vehicles or being struck by/against was highest for 25-44 year olds for all three registries.

Table A. 2009 Top causes of injury or death

Causes	Emergency Department	Hospital	Death
Falls	50%	52%	28%
Struck By/Against	24%	7%	1.3%
Motor Vehicle	13%	24%	35%
Firearm	0.1%	1.2%	26%

Females had a lower incidence rate for almost every cause of injury. However, the rate of falls was similar between genders as it was 260 emergency department visits per 100,000 for both males and females in 2009. Males had a notably higher incidence rate for TBIs resulting from being struck by or against, firearms, and pedal cyclist. For example, 11 out of 100,000 males had a TBI related firearm death in 2009 compared to 1 in 100,000 females.

Description of Service Needs, and Gaps and Barriers

The surveys, key informant interviews, and focus groups provided a comprehensive picture of the barriers to service, the most needed/important services, and the gaps in service. The following results include all acquired brain injuries (ABI), with traumatic brain injuries (TBI) representing a majority of the ABIs. The service needs are similar for both groups. Key results are highlighted such as the strengths of the system; individual/caregiver's satisfaction with services and needed services; and perceived gaps and barriers to needed services.

Barriers

Barriers that prevented or limited appropriate access or use of services were identified by service providers, agencies, and key informants. Currently, the state is lacking a resource facilitator, or central access point, to assist individuals with brain injuries and their families to access appropriate resources. The need was confirmed from the collected data from stakeholders and was presented to the state legislature in the spring of 2011 as funding for a resource facilitator for veterans was proposed.

The top barriers indicated by individuals and families included general lack of awareness and knowledge of TBI and a lack of service awareness. The lack of case management and resource facilitation was, also, consistently reported as a barrier.

Service providers listed financial resources, lack of understanding of brain injury, inadequate knowledge of available services, and lack of individualization of brain injury services as the largest barriers to services.

Lack of available funding resources for services and the lack of awareness of funding resources were identified by all stakeholders as a major barrier to receiving services. Geographic barriers, such as distance from services, were also mentioned most often by key informants as many individuals must travel to the eastern part of the state for services. To summarize, the most frequently mentioned critical barriers in order of importance include:

1. Awareness and advocacy
2. Funding sources - financial resources
3. Knowledge of services and resources
4. Case management/resource facilitation
5. Training for service professionals (primary care, therapists)
6. Education at all levels: community, service provider staff, families and caregivers
7. Geographic barriers - transportation
8. Early intervention

Strengths

Many services identified by individuals/caregivers as important were being provided with high satisfaction, such as primary medical care, rehabilitation, occupational therapy, and physical therapy. In some instances, services may be ongoing and may still be needed but individuals/caregivers are currently satisfied with the level of service they are receiving. Respondents also felt they were listened to by the hospital and medical staff, service coordinators and case managers. Specific strengths of the system include

1. Primary health care services
2. Acute and hospital based rehabilitation
3. Therapy (physical therapy, speech language therapy, and occupational therapy)

Service Needs and Gaps

Overall, the research indicates that there is a system gap in long-term residential and community-based services for some populations in Nebraska. Some of the most important services listed may be provided to satisfaction and some of the largest gaps may involve "relatively" unimportant services or have a small percentage of TBI individuals utilizing the service. Analyzing these results collectively, following is the list of the most important needs that are currently not being provided at the desired level:

Gaps in Most Needed Services

1. Cognitive training
2. Counseling
3. Behavioral supports
4. Community skills training
5. Employment support
6. Educational services

Looking solely at the importance rating of TBI needs, which may include services currently being received or received in the past, the most important service needs indicated by individuals with brain injuries and their caregivers were:

Most Important Needs

1. Cognitive training
2. Sources of funding
3. Primary medical care
4. Physical therapy
5. Counseling (individual and family)
6. Information resources
7. Occupational therapy

Although there is overall satisfaction with medical services, collected information from stakeholders also indicate there is still a lack of knowledge and awareness of TBI by some medical professionals and service providers.

Service providers indicated lack of specialized service (i.e., neurobehavioral services), limited range of funds for service needs and lack of brain injury training among professionals as the top gaps in services. In aggregate from all sources, the following areas appear to be the most

prevalent service gaps, which are ranked by the percentage of individuals who need/needed the service but are currently not receiving/did not receive the service:

Most Prevalent Gaps

1. Employment support
2. Community based services and supports
3. Behavioral supports
4. Counseling
5. Assistive technologies
6. Dental
7. Cognitive training
8. Educational services
9. Housing with supports
10. Social and emotional support/resources

Note that some of the most prevalent gaps listed above may have been ranked as "relatively" unimportant when compared to for instance cognitive services or primary medical care.

Individual survey respondents reported many changes to their lives since the injury, most often indicating that things have worsened. The most adversely affected areas were:

- Physical health
- Emotional well-being
- Income

TBI Costs and Funding Mechanisms

Total estimated annual costs for the U.S., based on a rate of 2% of the population, related to traumatic brain injury are estimated at \$60 billion. This includes severe, moderate, and mild brain injury. This total cost estimate includes both fatal and nonfatal injuries and medical costs and productivity losses.

Using national research and the estimated 2% cited above, the total estimated brain injury costs for Nebraska in 2009 is **\$413,513,208**.

It is estimated that the lifetime costs for:

- Mild brain injury - \$85,000
- Moderate brain injury - \$941,000
- Severe brain injury - \$3 million

TBI Waivers

There are 15 states with a TBI waiver and 8 other states with an ABI waiver; Nebraska is one of the 15 states with a TBI waiver. Nebraska waiver capacity (40 waivers) and utilization (21 waivers) have remained constant from 2005 to 2010 despite an increasing number of TBI injuries. The average expenditure per waiver recipient has decreased slightly from \$32,272 in 2005 to \$31,663 in 2010.

Table B compares Nebraska's waiver program to comparable states' waiver programs. The proportion of Nebraska's population served and TBI waiver funding are lower than comparable states. However, individuals with a TBI in Nebraska have also received Aged & Disabled waivers, which have increased for TBI survivors from 37 waivers in 2005 to 62 in 2010.

Table B. TBI Medicaid Waiver Programs by State (2006)

State	Waiver Name	Number Served	Participants Per 1,000 Population	Total Annual Expenditures	Expenditures Per Participant
Nebraska	TBI	21	.01	\$614,777	\$29,275
Colorado	Brain Injury	293	.06	\$9,027,735	\$30,811
Iowa	Brain Injury	774	.20	\$11,048,583	\$14,275
Kansas	Head Injury	240	.09	\$5,602,952	\$23,346
Wyoming	ABI	143	.28	\$4,327,485	\$30,262

Table C shows what services are funded for the TBI waiver programs listed in Table B. Surrounding states have a notably larger array of services funded. The TBI waiver programs in other states cover a range of community based supports and rehabilitation services; in this respect the Nebraska TBI waiver is limited.

Table C. TBI Medicaid Waiver Services Funded by State (2006)

State	Services Covered
Nebraska	Specialized assisted living*
Colorado	Day care/treatment, behavioral, skills training, home modifications, special equipment, personal care
Idaho	Personal care services, rehabilitation, community and supported living
Iowa	Case management, consumer directed attendant care, supported community living, respite care
Kansas	Personal assistance services, medical equipment, home modifications, AT, rehabilitation services, transitional living skills
Utah	Case management, supported living, supported employment, transportation
Wyoming	Case management, rehabilitation, psychological services, occupational services, adaptive equipment, personal care

*Specialized assisted living includes assistance with daily living and personal care activities for individuals in the assisted living facility.

One limitation of the TBI waiver is that not all individuals with a brain injury qualify for Medicaid and, therefore, few would be eligible for the waiver program. A traumatic brain injury trust fund would be a possible resource to bridge the funding gap for those who are not eligible for a waiver or for those who are not receiving adequate funds through the waiver program to provide for the needed services.

TBI Trust Funds

A TBI trust fund represents a possible funding source for providing services for individuals with a TBI. There are 24 states with a brain injury related trust fund with amounts ranging from \$800,000 to \$17 million and the number served ranging from 160 to 21,000. For existing brain injury trust funds the primary revenue sources have been from all traffic violations, DUI's, car registration, speeding violations, and reckless driving.¹⁵

When asked about potential uses of a Nebraska TBI trust fund, individuals and caregivers most frequently selected:

- Rehabilitation
- Brain injury research
- Counseling
- Assessment and identification of TBI

Service providers most frequently selected the following as their preferred use of potential trust funds:

- Community based services and supports
- Rehabilitation
- Job services

Proposed Recommendations

Based on the identified needs, gaps, of the current system of services for individuals with a brain injury, the following items are recommended as possible actions or changes:

1. Increase awareness of TBI in the system and throughout the community. This includes increased advocacy for individuals where there are important gaps such as with career and educational services.
2. Increase TBI education and training for medical professionals and service provider staff. There needs to be broader awareness and training for professionals, some within the medical field but more importantly outside of the medical field.
3. Build off existing system and expand access to service coordination, resource facilitation, and case management. Increase distribution of information on available resources, address specific needs, and recommend services individualized to the TBI survivor's needs. This may include:
 - A central database of service providers and agencies with contact information
 - A designated contact person for service coordination and referrals including those services outside the medical community
 - A focus on case management at the point of release from rehabilitation and within the following 1-2 years, including during long-term community based services
 - A record keeping and follow-up system that would track individual for ongoing issues and inform individuals on resources that are typically needed throughout the "community reintegration" process.
 - Contact upon release from the hospital or rehabilitation facility either providing family education and counseling or referring individuals and families to available services they may need in the future.
 - Improve system collaboration
4. Conduct a Nebraska specific cost analysis. Collaborate with appropriate agencies and providers to track the average annual cost of TBI in Nebraska throughout the system and make projections based on the TBI Registry population.

5. Establish a TBI Trust Fund:
 - The TBI waiver is limited due to eligibility requirements; a traumatic brain injury trust fund would be a possible resource to bridge the funding gap for those who are not eligible for a waiver or for those who are not receiving adequate funds through the waiver program to provide for the needed services.
 - Possible sources of funding for the trust fund include traffic violations or DUI fines.
 - Recommended uses of the trust fund include community based services and supports, rehabilitation services, counseling, employment supports, and funds for TBI identification and assessment.

6. Modify and expand the existing TBI waiver program in Nebraska:
 - Expand the services funded under the TBI waiver. Currently, Nebraska only funds assisted living services. Comparable states have brain injury waivers that fund a range of community based supports and rehabilitation services, which were indicated as service gaps in Nebraska.
 - Increase the number of waivers and total waiver funding for individuals with a brain injury.
 - Modify the TBI waiver requirements to expand eligibility to underserved groups, which would be an extension of increasing the range of funded services.