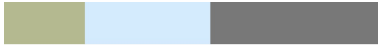


2010 Nebraska Traumatic Brain Injury Needs and Resources Assessment



Schmeckle Research Inc.

Table of Contents

Contributors	1
Executive Summary	2
1. Introduction	12
Needs and Resource Assessment Purpose	12
Methodology	13
2. Nebraska Traumatic Brain Injury Profile	14
Limitations	14
Prevalence of TBI	14
Incidence of TBI	15
TBI Incidence by Year	16
Age Breakdown and Incidence	18
Gender Breakdown and Incidence	20
TBI by Age and Gender	21
TBI by County	24
TBI by Behavioral Health Region	28
TBI by Cause of Injury or Death	30
TBI by Length of Stay	36
TBI by Discharge Status	36
Veteran's Administration TBI Registry Profile	38
Brain Injury Helpline Calls	39
3. Brain Injury Services and Needs	42
NE Traumatic Brain Injury Survey Results	42
Individual/Caregiver Survey	42
Service Provider and State Agency Survey Results	61
Brain Injury Focus Group Results	77
Traumatic Brain Injury Key Informant Interview Results	85
4. Service Coordination	94
Veteran Resource Facilitation Feasibility	94
Nebraska System of Services and Supports	97

5. Funding Mechanisms and Cost of Services.....	100
Brain Injury Waivers.....	100
Brain Injury Trust Funds.....	106
Brain Injury Dedicated Funds.....	108
Cost of Traumatic Brain Injury.....	111
6. Appendices.....	112
Appendix A: 2005-2009 TBI Incidence by County.....	112
Appendix B: 2009 TBI Incidence by County.....	113
Appendix C: 2005-2009 TBI ED Visits by County (Incidence/100,000).....	114
Appendix D: 2005-2009 TBI Hospitalizations by County (Incidence).....	115
Appendix E: 2005-2009 TBI Deaths by County (Incidence/100,000).....	116
Appendix F: Traumatic Brain Injury Registry Age by Region.....	117
Appendix G: Individual, Provider, and Agency Respondents and Location.....	118
Appendix H: Individual Survey System of Services Suggestions.....	121
Appendix I: Goodwill Industries of Greater NE ABI Employment Program.....	126
Appendix J: TBI Key Informant Interview Questions.....	129
Appendix K: Trust Fund Use: Survey and Key Informant Responses.....	130
8. References.....	132

List of Tables

Table 1.	Number of Participants by Method	13
Table 2.	Nebraska Population and Estimate of Known TBI Prevalence	15
Table 3.	Total Estimated Nebraska Prevalence	15
Table 4.	TBI Incidence by Year (Incidence Rate/100,000)	17
Table 5.	TBI's by Age (2009)	18
Table 6.	TBI's by Age (2005-2009)	19
Table 7.	2009 TBI Incidence by Age (Incidence Rate/100,000)	19
Table 8.	2005-2009 TBI Incidence by Age (Incidence Rate/100,000)	20
Table 9.	TBI by Gender (2009)	20
Table 10.	Male TBI's by Year (Incidence Rate/100,000)	20
Table 11.	Female TBI's by Year (Incidence Rate/100,000)	21
Table 12.	Age by Gender (2009)	22
Table 13.	2009 Male TBI Incidence by Age (Incidence Rate/100,000)	24
Table 14.	2009 Female TBI Incidence by Age (Incidence Rate/100,000)	24
Table 15.	TBI ED Visits by Behavioral Health Regions (2005-2009)	28
Table 16.	TBI Hospitalizations by Behavioral Health Regions (2005-2009)	29
Table 17.	TBI Deaths by Behavioral Health Regions (2005-2009)	29
Table 18.	Emergency Department Cause of Injury by Year	31
Table 19.	Hospital Cause of Injury by Year	32
Table 20.	Cause of Death by Year	32
Table 21.	Emergency Department Cause of Injury by Age (2009)	33
Table 22.	2009 ED Cause of Injury by Age (Incidence Rate/100,000)	33
Table 23.	Hospital Cause of Injury by Age (2009)	34
Table 24.	2009 Hospital Cause of Injury by Age (Incidence Rate/100,000)	34
Table 25.	Death Registry Cause of Injury by Age (2009)	34
Table 26.	2009 Death Registry Cause of Injury by Age (Incidence Rate/100,000)	35
Table 27.	Cause by Gender (2009)	35
Table 28.	2009 Cause by Gender (Incidence Rate/100,000)	36
Table 29.	Emergency Department Length of Stay	36
Table 30.	Hospital Length of Stay	36
Table 31.	Emergency Department Discharge Status	37
Table 32.	Hospital Discharge Status	37
Table 33.	VA Brain Injury Screens (April 2007-November 2010)	38
Table 34.	VA TBI by Age (April 2007-November 2010)	38
Table 35.	VA TBI by Gender (April 2007-November 2010)	38
Table 36.	Type of Call to Hotline	39
Table 37.	Hotline Calls by County	40
Table 38.	Type of Calls to BIA-NE (8/10/2010 - 2/11/2011)	40
Table 39.	Awareness of Statewide Information/Resource Phone Lines	41
Table 40.	Use of Statewide Information/Resource Phone Lines	41
Table 41.	Individual/Caregiver Survey Respondents	43
Table 42.	Cause of Brain Injury	44
Table 43.	Brain Injury Type (TBI vs. ABI)	44
Table 44.	Severity of Brain Injury	44
Table 45.	Other Diagnoses or Symptoms	45
Table 46.	Changes to Life Since Injury	45
Table 47.	Age of Individual with Brain Injury	46
Table 48.	Ethnicity/Race of Individual with Brain Injury	46
Table 49.	Marital Status of Individual with Brain Injury	46
Table 50.	Highest Grade Level Completed by Individual with Brain Injury	46
Table 51.	Household Income for Individual with Brain Injury	47

Table 52.	Employment Status.....	47
Table 53.	Length of Employment Since Injury.....	47
Table 54.	Reason for Not Working.....	48
Table 55.	Daily Transportation.....	48
Table 56.	Place of Residence.....	49
Table 57.	Person with Whom Individual Resides.....	49
Table 58.	Type of Housing Preferred.....	49
Table 59.	Supports Needed for Preferred Housing.....	50
Table 60.	Resources for Brain Injury-Related Expenses.....	50
Table 61.	Social/Emotional Supports Available.....	51
Table 62.	Released Early from Health Care Facilities.....	52
Table 63.	Received Appropriate Services Based on Severity of Brain Injury.....	52
Table 64.	Factors Interfering with Receiving Services.....	52
Table 65.	Feel Needs Were Listened to By.....	53
Table 66.	Health Care Facility Services - Satisfaction and Need.....	53
Table 67.	Satisfaction and Need for Health Care Services.....	55
Table 68.	Individual and Caregiver Importance Rating of Health Services Needed.....	55
Table 69.	Satisfaction and Need for Skill Services.....	57
Table 70.	Individual and Caregiver Importance Rating of Skill Services Needed.....	57
Table 71.	Satisfaction and Need for Educational Services.....	57
Table 72.	Satisfaction and Need for Employment Services.....	58
Table 73.	Satisfaction and Need for Support Services.....	59
Table 74.	Individual and Caregiver Importance Rating of Support Services Needed.....	60
Table 75.	Caregiver Satisfaction with Services.....	60
Table 76.	Service Provider Survey Respondent Categories.....	62
Table 77.	Service Providers' Primary Service.....	63
Table 78.	Acute Medical Services and Programs.....	63
Table 79.	Employment Services.....	64
Table 80.	Educational Services and Programs.....	65
Table 81.	Brain Injury Prevention Services.....	65
Table 82.	Brain Injury Education and Training to Whom.....	65
Table 83.	Immediate and Transitional Programs/Services.....	66
Table 84.	Agencies Immediate/Transitional Programs/Services Funded.....	67
Table 85.	Long-term Community Based Services Provided.....	68
Table 86.	Individuals Served.....	69
Table 87.	Financial Resources Provided.....	70
Table 88.	Referral Sources for Individuals with Brain Injury.....	70
Table 89.	Time after Brain Injury Typically Referred.....	71
Table 90.	Tasks for Designated Staff for Brain Injury.....	72
Table 91.	Staff - Total and Dedicated to Brain Injury.....	72
Table 92.	Gaps in Services to Individuals with brain injuries (selected top 3).....	73
Table 93.	Barriers to Access/Use of Services (selected top 5).....	73
Table 94.	Underserved Populations and Service Expansion Needs.....	74
Table 95.	Service Provider Services for Challenging Behaviors.....	76
Table 96.	If Removed, Where Individuals Placements.....	76
Table 97.	Formalized Neurobehavioral Program.....	76
Table 98.	If yes, what types?.....	76
Table 99.	Focus Group Participants.....	77
Table 100.	Key Informant Interview Participants.....	85
Table 101.	Nebraska TBI Waiver Statistics.....	100
Table 102.	Nebraska TBI Waiver by Gender and Age.....	100
Table 103.	TBI/SCI Medicaid Waiver (2006).....	101
Table 104.	TBI/SCI Medicaid Waiver Services Funded (2006).....	102
Table 105.	Brain Injury Aged and Disabled Waiver Funding by Service.....	104
Table 106.	Average Brain Injury A&D Waiver Amount by Service.....	104
Table 107.	Aged and Disabled Waivers by Region and Gender.....	105

Table 108.	Average Age of A&D Waiver Recipients by Region.....	105
Table 109.	Brain Injury Trust Funds by States (August 2006).....	107
Table 110.	Uses of Nebraska TBI Trust Fund (Survey Responses: Multiple Responses).....	107
Table 111.	Resources for TBI-related Expenses (Multiple Responses).....	109
Table 112.	TBI Emergency Department Payer Source.....	110
Table 113.	TBI Hospital Payer Source.....	110
Table 114.	TBI Emergency Department Visits by Region and Payer Source (2009).....	110
Table 115.	TBI Hospital Visits by Region and Payer Source (2009).....	110
Table 116.	Emergency Department Payer Source by Age (2009).....	110
Table 117.	2005-2009 Traumatic Brain Injury Incidence by County.....	112
Table 118.	2009 Traumatic Brain Injury Incidence by County.....	113
Table 119.	TBI Emergency Department Visits by Region and Age (2009).....	117
Table 120.	TBI Hospital Visits by Region and Age (2009).....	117
Table 121.	TBI Deaths by Region and Age (2009).....	117
Table 122.	Individuals City.....	118
Table 123.	Individuals County.....	118
Table 124.	Service Provider Respondents and County.....	119
Table 125.	State Agency Respondents.....	120

List of Figures

Figure 1.	Traumatic Brain Injuries (2005-2009).....	17
Figure 2.	TBI's by Age (2009).....	18
Figure 3.	TBI Injuries and Deaths by Gender (2005-2009).....	21
Figure 4.	TBI Emergency Department Visits by Age and Gender.....	22
Figure 5.	TBI Hospitalization by Age and Gender.....	22
Figure 6.	TBI Deaths by Age and Gender.....	23
Figure 7.	TBI Incidence Rates by Age and Gender (Incidence Rate/100,000).....	23
Figure 8.	TBI Emergency Department Visits by County (2005-2009).....	25
Figure 9.	2005-2009 ED Visits by County (Incidence Rate/100,000).....	25
Figure 10.	TBI Hospitalizations by County (2005-2009).....	26
Figure 11.	2005-2009 TBI Hospitalizations by County (Incidence Rate/100,000).....	26
Figure 12.	TBI Deaths by County (2005-2009).....	27
Figure 13.	2005-2009 TBI Deaths by County (Incidence Rate/100,000).....	27
Figure 14.	TBI Emergency Department Visits by Region (2009).....	28
Figure 15.	TBI Hospitalizations by Region (2009).....	29
Figure 16.	TBI Deaths by Region (2009).....	30
Figure 17.	TBI Top Causes of Injury or Death (2009).....	31
Figure 18.	Individual/Caregiver Survey Respondents by County of Residence.....	43
Figure 19.	Service Coverage by Providers Surveyed.....	62
Figure 20.	Provider TBI Numbers Served.....	69
Figure 21.	Nebraska's Network of Brain Injury Services.....	97
Figure 22.	TBI System Gaps from Individual/Caregiver Survey.....	98
Figure 23.	Brain Injury Waivers by State.....	101
Figure 24.	Nebraska Aged and Disabled Waivers Granted to Individuals with a TBI.....	103
Figure 25.	2008 Brain Injury Trust Funds by State.....	106
Figure 26.	2008 Brain Injury Dedicated Funds by State.....	108
Figure 27.	2005-2009 TBI ED Visits by County (Incidence Rate/100,000).....	114
Figure 28.	2005-2009 TBI Hospitalizations by County (Incidence Rate/100,000).....	115
Figure 29.	2005-2009 TBI Deaths by County (Incidence Rate/100,000).....	116

Contributors

Nebraska Vocational Rehabilitation

Keri Bennett, Program Director - Acquired Brain Injury

Brain Injury Association of Nebraska

Kate Kulesher-Jarecke, Executive Director

Nebraska Department of Health and Human Services, Division of Public Health

Nebraska TBI Advisory Council and Staff

Nancy Noha, *Project Coordinator: Assistive Technology Partnership*

Rose Dymacek, *Special Populations Office: Nebraska Department of Education*

Keri Bennett, *Program Director-Acquired Brain Injury: Vocational Rehabilitation*

Frank J. Velinsky, *Caretech, Inc.*

Lori Terryberry-Spohr, Ph.D., *Madonna Rehabilitation Hospital*

Gary Hausmann, *Brain Injury Survivor*

Margy Hoffmann, *Deputy Director: Vocational Rehabilitation*

Tiffany Armstrong, *Council Chair/Brain Injury Survivor*

Margaret Jensen, *EDN Services Coordinator: Brain Injury Network Area Leader*

Roger Stortenbecker, *Collaborative Industries, Inc.*

Susan Buettner, *Long Term Care Administrator: Division of Medicaid & Long Term Care*

Dale Johannes, *Brain Injury Survivor*

Mike Hon, *Quality Living, Inc.*

Tania Diaz, *Nebraska Advocacy Services*

Peggy Reisher, *Director of Programs and Services: Brain Injury Association of Nebraska*

Michelle Hawley-Grieser, *Family Member of Brain Injury Survivor*

Lori Wardlow, *Nebraska/Iowa VA Health Care Systems*

Pam Kasl, *Recorder*

Karen Hux, *University of Nebraska*

Mark Schultz, *Director: Vocational Rehabilitation*

Mary Gordon, *Developmental Disabilities Planning Council: Nebraska DHHS*

Tiffany Young, *Catholic Health Initiatives*

Jana Maresh, *Web Site Manager*

Victoria Rasmussen, *Client Assistance Program*

Tiffany Verzal, *Family Member of Brain Injury Survivor*

Marylouise Lehman, *SPED Behavior Consultant, ESU #16*

Caroline Helget, *Staff Assistant*

Research Consultant

The report was completed by Schmeeckle Research, Inc., a research and evaluation company located in Lincoln, Nebraska. For further information, contact Joyce Schmeeckle, PhD. [joyce@schmeeckleresearch.com or 402.477.5407]

This project was supported by TBI Implementation Partnership Grant #H21MC06758 from the U.S. Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). The contents are the sole responsibility of the authors and do not necessarily represent the official views of HHS.

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

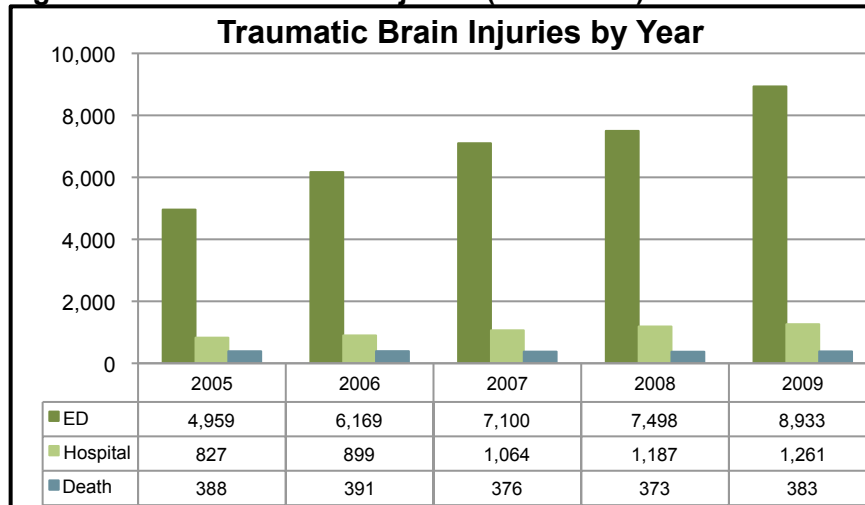
Prevalence

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

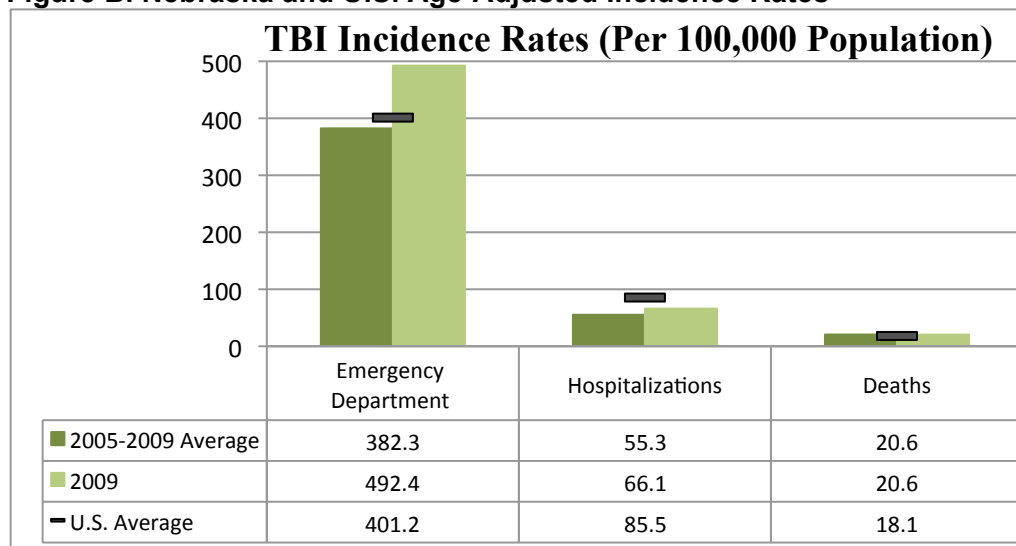


Figure C depicts the 2005-2009 average **number** of TBIs for each Nebraska county, while Figure D shows the **incidence rate**, number of TBIs per 100,000 population, for each county. The figures show that some of the counties with the highest overall number of TBIs do not necessarily have the highest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

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

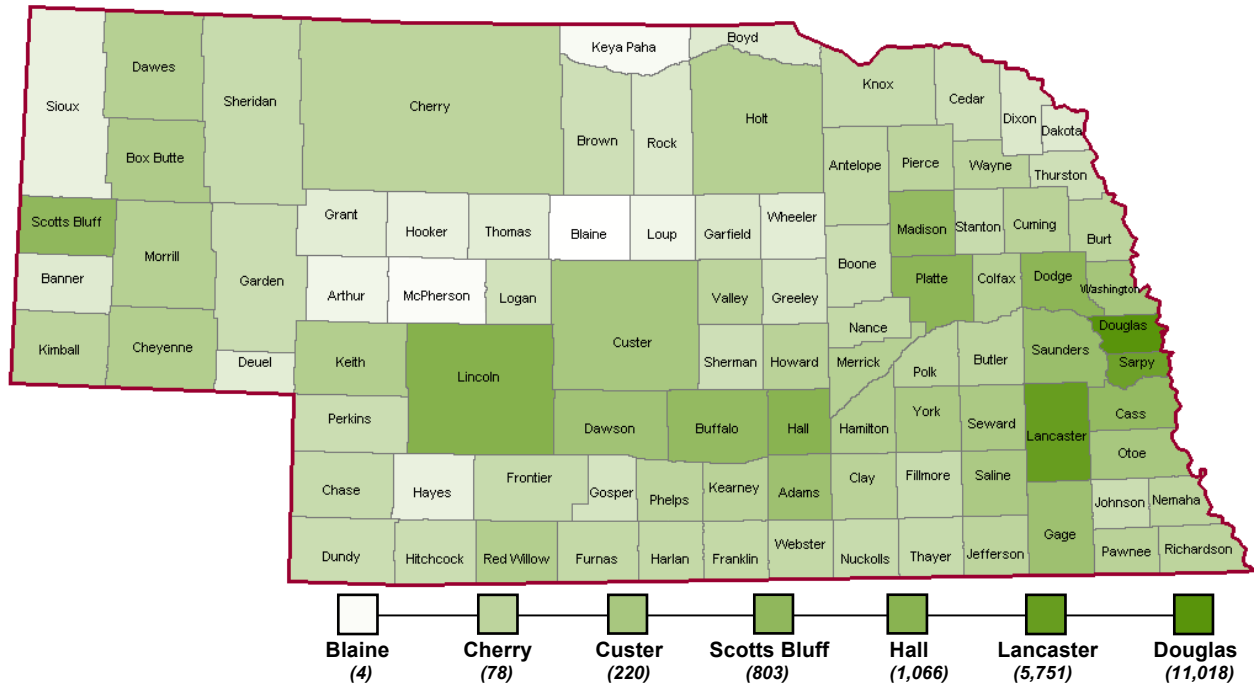
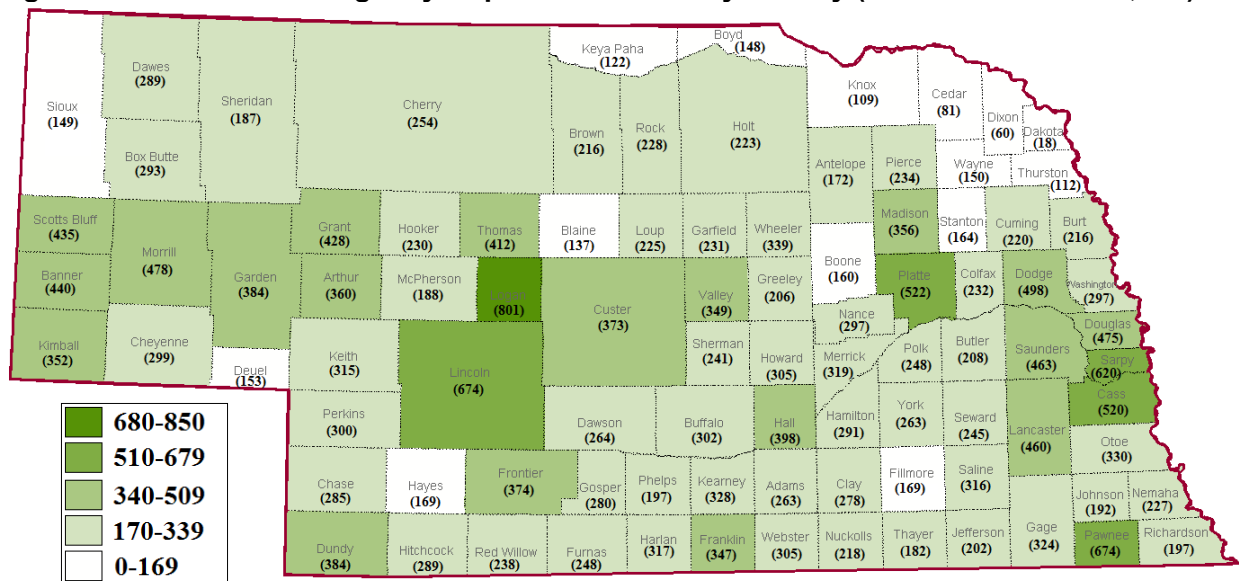


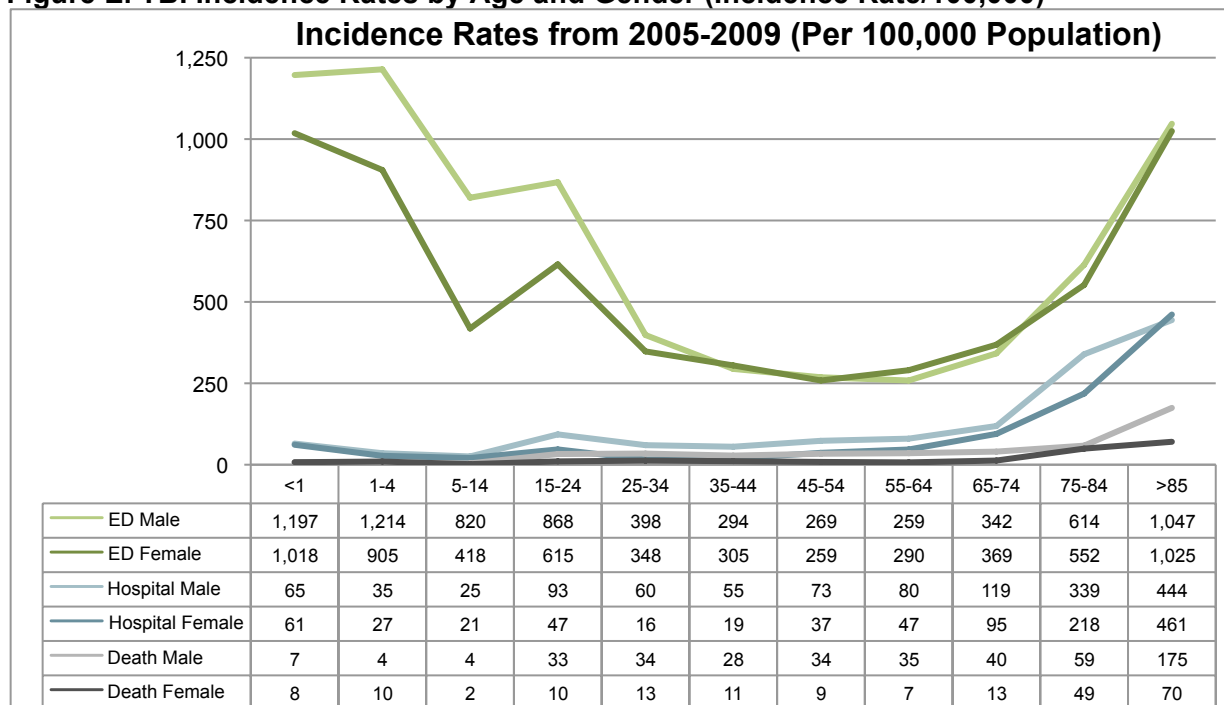
Figure D. 2005-2009 Emergency Department Visits by County (Incidence Rate/100,000)



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.

Nebraska Traumatic Brain Injury

Needs and Resources Assessment

1 Introduction

Based on the Center for Disease Control and Prevention (CDC) estimates from 2002-2006, at least 1.7 million people sustain a traumatic brain injury (TBI) in the United States each year. Of those individuals, about 52,000 die, 275,000 are hospitalized, and 1.365 million are treated and released from an emergency department. Of the 1.7 million injuries, 75% are estimated to be mild traumatic brain injuries.¹

Traumatic Brain Injuries are a contributing factor to a third (30.5%) of all injury-related deaths in the United States.² Direct medical costs and indirect costs of TBI, such as lost productivity, totaled an estimated \$60 billion in the United States in 2000.³

Traumatic brain injury is a serious public health problem in the United States. Each year, traumatic brain injuries contribute to a substantial number of deaths and cases of permanent disability.

A TBI is caused by a bump, blow or jolt to the head or a penetrating head injury that disrupts the normal function of the brain. Not all blows or jolts to the head result in a TBI. The severity of a TBI may range from "mild," i.e., a brief change in mental status or consciousness to "severe," i.e., an extended period of unconsciousness or amnesia after the injury. The majority of TBIs that occur each year are concussions or other forms of mild TBI."¹

An acquired brain injury, which includes TBI, is defined according to the Brain Injury Association of America as an injury to the brain, which is not hereditary, congenital, degenerative, or induced by birth trauma. An acquired brain injury is an injury to the brain that has occurred after birth.

Needs and Resource Assessment Purpose

The purpose of the statewide Needs and Resources Assessment is "to identify the service needs of individuals with brain injury and their families and to describe existing services and supports, service gaps and system barriers in both the public and private sectors. The assessment will be used to guide development of the TBI State Plan, to inform and educate the general public, state agencies and service providers, to promote TBI-favorable policy and the development of appropriate services and supports to meet the needs of individuals with TBI that are comprehensive, coordinated, family and person-centered and culturally sensitive."⁴

Needs and Resource Assessment Methodology

The TBI needs assessment is a HRSA grant-funded project conducted to determine the gaps and barriers in services for caregivers and individuals with TBI's and other brain injuries. As indicated in Table 1, the needs assessment data collection included the following methodologies:

- Focus Groups with individuals with brain injuries and their caregivers
- Stakeholder surveys with state agencies, service providers, and caregivers and individuals with brain injuries
- Key informant interviews

Table 1. Number of Participants by Method

Data Collection Method	N
Individual/ Caregiver Survey	293
Provider Survey	59
Agency Survey	5
Key Informant Interview	17
Lincoln Focus Group	19
Norfolk Focus Group	25

- TBI Data
 - TBI Registry
 - Veterans Administration Brain Injury Data
 - Hotline and BIA-NE Data
 - Medicaid - Aged and Disabled Data
 - National Trust Fund Data

This section describes traumatic brain injury in Nebraska in terms of TBI prevalence and incidence rates. Prevalence refers to the proportion of people within a given population with a traumatic brain injury. Incidence refers to the number of new traumatic brain injuries within a given period for a certain population.

Awareness of the demographics of individuals suffering from brain injuries, the cause of injury, length of hospital stay, payer source, and place of discharge all give insight into the needed services and gaps in service in Nebraska. Prevalence and incidence data support the qualitative information presented throughout the report to identify at-risk populations. Prevalence and incidence rates also present insight to the magnitude of services and funding needed and to the public and private costs of TBI in Nebraska. The following elements were measured based on Nebraska Traumatic Brain Injury Registry data demographics from 2005-2009:

1. The rates and percentages for TBI related emergency department visits, hospitalizations, and deaths in Nebraska.
2. The cause of injury or death for TBI related emergency department visits, hospitalizations, and deaths in Nebraska.
3. The length of stay, discharge status, and payer source (presented in the cost section of the report) for TBI related emergency department visits and hospitalizations in Nebraska.

Limitations

Prevalence estimates of individuals living with a traumatic brain injury are limited in several aspects. First, the prevalence rate was calculated based on United States CDC estimates; Nebraska's prevalence rate may differ from national prevalence rates. Second, the CDC calculation does not account for disability among individuals who visited the emergency department but were not admitted to the hospital; therefore prevalence rates will be underestimated. Finally, prevalence and incidence estimates do not consider individuals who have sustained a mild or moderate brain injury who do not visit an emergency room or hospital or who were not properly diagnosed with a brain injury. A significant number of individuals who suffer a brain injury visit their family physician or do not seek care; therefore, they are not represented in the data. A majority of concussions for sports injuries and brain injuries to veterans are also not reported in the estimations as the individuals may not have been admitted to the emergency department or hospital and veteran incidence data (page 34) was not comparable due to reporting variations and data limitations. Even considering these limitations, the CDC model is the most accurate model available for prevalence estimations.

Prevalence of Traumatic Brain Injury

The CDC's National Center for Injury Prevention and Control estimates that 5.3 million U.S. citizens (2 percent of the population) are living with disability as a result of a traumatic brain injury. This represents the prevalence of TBI disability, defined as the proportion of persons in the population at a given time who have disability resulting from a traumatic brain injury.⁵

The CDC's estimated 2% prevalence rate is applied to Nebraska's behavioral health regions in Table 2 to provide an estimated prevalence for Nebraska. Based on historical national averages, it is estimated that there are **36,527** individuals with a brain injury related disability in Nebraska.

Table 2. Nebraska Population and Estimate of Known TBI Prevalence ⁶

Behavioral Health Region	2010 Population	2010 TBI Prevalence
Region 1	87,789	1,756
Region 2	135,752	2,715
Region 3	226,320	4,526
Region 4	173,444	3,469
Region 5	444,920	8,898
Region 6	758,116	15,162
Nebraska	1,826,341	36,527

According to research reported by the New York Traumatic Brain Injury Model System in *TBI Research Review: Policy & Practice*, for every individual with a known TBI through hospital or emergency department admissions there are 3-5 others who have brain injuries who are not diagnosed or receiving care. ⁷ Based on this estimate, Table 3 shows the estimation of total traumatic brain injuries, both known and unknown, in Nebraska. The estimated prevalence is substantially higher when undiagnosed individuals not receiving care are considered. It should be noted that the estimate of unknown individuals is limited based on geography, sample size, and time frame and is best used as a range measurement. When considering the current services and number of known brain injuries, 36,527 individuals is a more accurate estimate.

Table 3. Total Estimated Nebraska Prevalence ⁶

Behavioral Health Region	2010 Known Prevalence	2010 Total Prevalence (Low Estimate)	2010 Total Prevalence (High Estimate)
Region 1	1,756	7,024	10,536
Region 2	2,715	10,860	16,290
Region 3	4,526	18,104	27,156
Region 4	3,469	13,876	20,814
Region 5	8,898	35,592	53,388
Region 6	15,162	60,648	90,972
Nebraska	36,527	146,108	219,162

When Nebraska's prevalence is referenced elsewhere in the needs and resource assessment it will be inferred that the prevalence is 36,527 as this is the estimation based off "known" incidences and most directly relates to cost of services and the system of existing services.

Incidence of Traumatic Brain Injury

Nebraska Traumatic Brain Injury Registry

Traumatic brain injury incidence rates are calculated for new brain injuries, annually, for specific populations. The CDC estimates that in the United States, an estimated 1.7 million people sustain a TBI annually. ¹ Of them:

- 52,000 are deaths,

- 275,000 are hospitalizations
- 1,365,000 are Emergency Department visits

The Nebraska TBI Registry, maintained by the Nebraska Department of Health and Human Services, receives data from all acute hospitals in the state. Please note TBI's are NOT reported from physicians or clinics in the state that may have diagnosed patients with TBI's. In addition, incidence rate calculations do not include individuals who were undiagnosed or misdiagnosed. Therefore, incidence estimates will be underestimated.

Traumatic brain injury incidence rates are documented through certain codes specific to TBI's within the registry. The registry data consists of individuals who experienced at least one diagnosis relating to a brain injury. The registry was analyzed from 2005 to 2009. At the time of this report, 2010 data was not yet available.

The TBI Registry consists of three databases:

- Emergency Department Database
- Hospital Database
- Death Database

The TBI Registry information in the following sections is measured as rates, which is the number of individuals per measure of population, and also in percentages, which is the distribution of individuals per category. For example, the number of males with a TBI per 100,000 males in Nebraska would be a rate and the number of males with TBI per total number of individuals with TBI would be a percentage.

Rates are calculated based on 2000 census data as 2010 census data was not available by the release of the needs assessment. Certain incidence rates were compared to United State averages; when U.S. averages are used, the rate is calculated using an annual average from 1995-2001 to 2000 census data. While a direct comparison of 2005-2009 Nebraska rates to 1995-2001 U.S. rates will not be unbiased given population growth, the comparison does provide a benchmark for Nebraska.

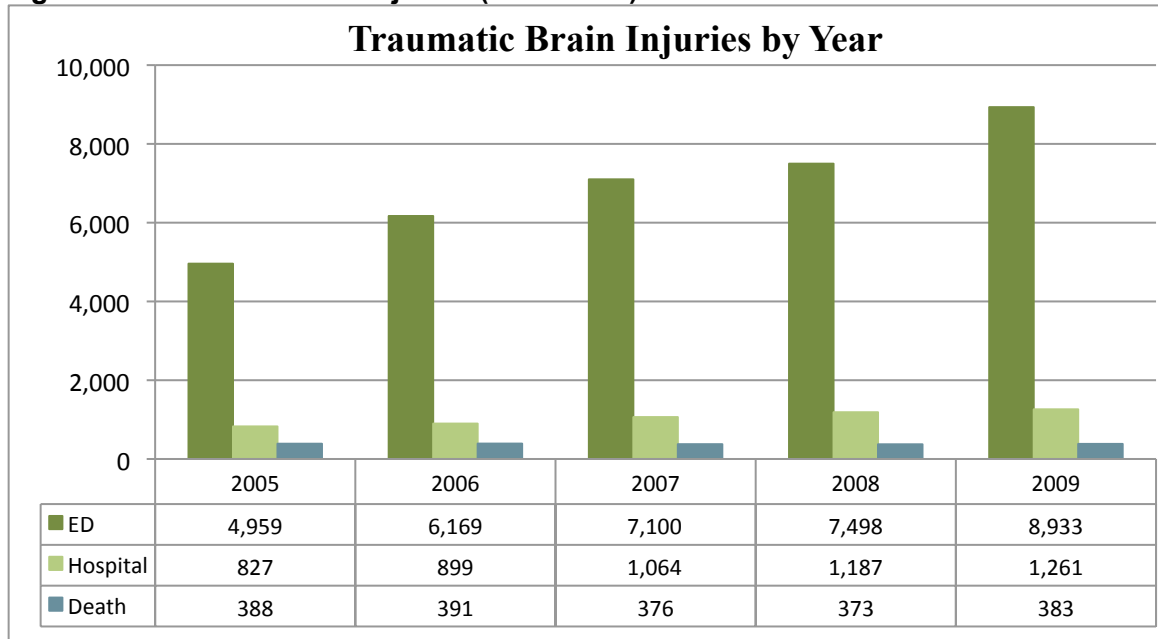
Certain variables such as race and place of occurrence were measured sporadically in the past and were not recorded for a high percentage of incidences; therefore, due to the lack of unbiased measurement and representative data, these variables were excluded from the analysis.

When possible, TBI related data was collected annually from 2005 to 2009. However, in some cases data was not available on an annual basis or as far back as 2005 or forward as 2010, so available data and the data for the most recent year were used in the analysis.

TBI Incidence by Year

The number of Emergency Department and hospital visits related to traumatic brain injuries has steadily increased from 2005 to 2009. However, the number of deaths has slightly decreased overall (see Figure 1).

Figure 1. Traumatic Brain Injuries (2005-2009)



The number of traumatic brain injuries is normalized for comparison by computing the number of injuries or deaths per 100,000 population. Table 4 shows the TBI rate for Emergency Department and hospital visits as well as deaths for 2009 and for an annual average from 2005-2009. As stated previously U.S. rates were computed for an annual average of 1995-2001 traumatic brain injuries per 2000 census population data.

Age-adjusted rates account for differences in age distributions between the populations being compared and allow for an unbiased comparison. Nebraska's age-adjusted hospitalization rate for both 2009 and 2005-2009 were below the U.S. average of 85.5 TBI's per 100,000 population. The 2009 Emergency Department rate was above the 401.2 U.S. average, but the 2005-2009 average was slightly below the U.S. average. However, the death rates were above the 18.1 per 100,000 U.S. average for both time periods.⁸

The later Nebraska time period has some affect on the U.S. comparisons; however, it can be noted that in general the Emergency Department and death rates for Nebraska were higher than the hospital rate when compared to U.S. rates.

Table 4. TBI's by Year (Incidence Rate/100,000)

Year (s)	ED		Hospital		Death	
	Rate	Age Adjusted Rate	Rate	Age Adjusted Rate	Rate	Age Adjusted Rate
2009	500.9	492.4	70.7	66.1	21.5	20.6
2005-2009 Average	388.7	382.3	58.8	55.3	21.4	20.6

Age Breakdown and Incidence

Figure 2 (and Table 5) show that the age makeup of traumatic brain injury related Emergency Department visits consisted of a younger demographic when compared to hospital visits and deaths for 2009.

Figure 2. TBI's by Age (2009)

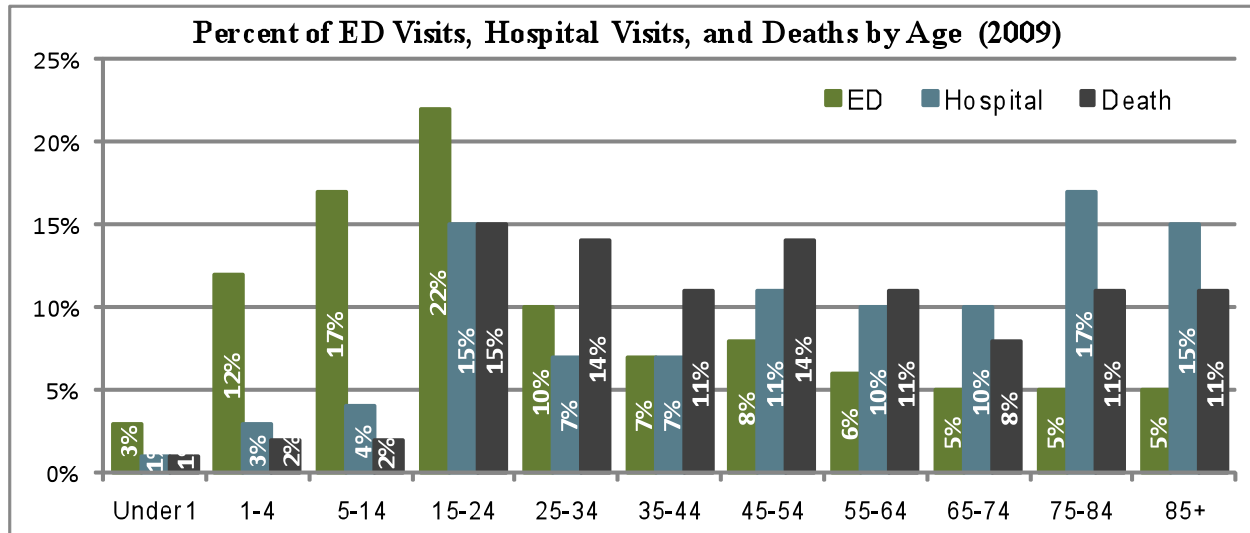


Table 5. TBI's by Age (2009)

Age	ED		Hospital		Death	
	n	%	n	%	n	%
Under 1	299	3%	17	1%	2	1%
1-4	1,118	12%	33	3%	7	2%
5-14	1,492	17%	55	4%	7	2%
15-24	1,952	22%	185	15%	57	15%
25-34	869	10%	90	7%	55	14%
35-44	673	7%	84	7%	44	11%
45-54	677	8%	141	11%	54	14%
55-64	535	6%	123	10%	41	11%
65-74	417	5%	124	10%	30	8%
75-84	478	5%	222	17%	44	11%
85+	423	5%	187	15%	42	11%

A review of age breakdown of traumatic brain injury related ED visits, hospital visits, and deaths have not changed notably from 2005 to 2009 (See Table 6). The only change would be an upward trend in brain injury related deaths for 25 and over when compared to individuals under 25.

Table 6. TBI's by Age (2005-2009)

Age	ED					Hospital					Death				
	05	06	07	08	09	05	06	07	08	09	05	06	07	08	09
Under 1	4%	4%	3%	4%	3%	3%	2%	2%	2%	1%	1%	1%	0%	1%	1%
1-4	12%	13%	12%	12%	13%	4%	3%	2%	2%	3%	1%	1%	1%	1%	2%
5-14	18%	17%	17%	16%	17%	6%	6%	6%	5%	4%	4%	3%	4%	2%	2%
15-24	24%	23%	22%	22%	22%	14%	15%	13%	12%	15%	22%	21%	20%	18%	15%
25-34	9%	9%	10%	10%	10%	7%	7%	8%	7%	7%	11%	9%	10%	12%	14%
35-44	7%	7%	8%	8%	8%	8%	7%	8%	6%	7%	11%	11%	11%	9%	11%
45-54	7%	7%	7%	8%	8%	8%	9%	10%	11%	11%	13%	13%	13%	13%	14%
55-64	5%	4%	5%	6%	6%	7%	9%	7%	8%	10%	10%	12%	8%	8%	11%
65-74	4%	4%	5%	5%	5%	10%	10%	12%	11%	10%	5%	8%	7%	8%	8%
75-84	6%	6%	6%	7%	5%	19%	16%	19%	19%	18%	13%	12%	16%	16%	11%
85+	4%	5%	5%	5%	5%	13%	15%	13%	17%	15%	10%	9%	9%	14%	11%

The incidence rates for ED visits, hospital visits, and deaths by age are shown in Table 7 (for the year 2009) and Table 8 (average rates for 2005 through 2009). The incidence of brain injury related Emergency Department visits was highest for individuals 85 and older and 4 and younger. Hospitalization and death incidence was highest for individuals 65 and older. There was also a higher hospitalization and death incidence for 15-24 years olds compared to Emergency Department visits.

In general, Nebraska had a lower Emergency Department and hospitalization incidence for those younger than 65 when compared to the U.S. average. However, the death rates for almost every age group were higher in Nebraska. This was especially evident for the older populations.

Table 7. 2009 TBI's by Age (Incidence Rate/100,000)

Year (s)	ED		Hospital		Death	
	Rate	U.S. Rate*	Rate	U.S. Rate*	Rate	U.S. Rate*
Under 1	1,110.1	1,035	63.1	79.9	7.4	5.7
1-4	1,063.2		31.4		6.7	
5-14	623.3	586	23.0	55.0	2.9	4.13
15-24	744.5	573	70.6	116.4	21.7	26.0
25-34	373.9	358	38.7	73.6	23.7	18.9
35-44	299.5	291	37.4	66.5	19.6	17.2
45-54	263.5	211	54.9	57.6	21.0	16.4
55-64	274.6	151	63.1	61.6	21.0	17.0
65-74	356.1	158	105.9	86.8	25.6	22.5
75-84	577.7	336	268.3	272.1	53.2	50.6
85+	1,031.5		456.0		102.4	

*U.S. Rates consist of an annual average from 1995-2001 to 2000 Census Data

Table 8. 2005-2009 TBI's by Age (Incidence Rate/100,000)

Year (s)	ED		Hospital		Death	
	Rate	U.S. Rate*	Rate	U.S. Rate*	Rate	U.S. Rate*
Under 1	946.7	1,035	78.0	79.9	7.4	5.7
1-4	807.4		26.6		3.8	
5-14	485.4	586	23.4	55.0	4.6	4.13
15-24	595.4	573	54.2	116.4	28.2	26.0
25-34	281.8	358	32.7	73.6	18.9	18.9
35-44	231.4	291	32.5	66.5	18.2	17.2
45-54	196.2	211	41.3	57.6	19.5	16.4
55-64	189.4	151	45.2	61.6	19.0	17.0
65-74	263.0	158	95.7	86.8	23.1	22.5
75-84	504.0	336	230.8	272.1	62.9	50.6
85+	809.6		380.4		97.5	

*U.S. Rates consist of an annual average from 1995-2001 to 2000 Census Data

Gender Breakdown and Incidence

Tables 9-11 and Figure 3 show that there has been a higher number and percent of male ED visits, hospitalizations, and deaths when compared to female incidences. The nominal and age adjusted rate per 100,000 population was greater for males. Percentages also suggest that the proportion of brain injuries that are male increases with severity.

Table 9. TBI by Gender (2009)

Gender	ED		Hospital		Death	
	n	%	n	%	n	%
Male	4,922	55%	727	58%	266	70%
Female	4,011	45%	534	42%	117	30%

Nebraska males and females both had higher emergency department and death incidence rates when compared on an age adjusted basis with the United States. The hospitalization incidence for both males and females in Nebraska was lower than the United States.

Table 10. Male TBI's by Year (Incidence Rate/100,000)

Year (s)	ED			Hospital			Death		
	Rate	Age Adjusted Rate	U.S. Rate*	Rate	Age Adjusted Rate	U.S. Rate*	Rate	Age Adjusted Rate	U.S. Rate*
2009	556.6	550.3	470	82.2	83.4	110.4	30.1	30.2	28.4
2005-2009 Average	437.0	-	470	70.0	-	110.4	30.1	-	28.4

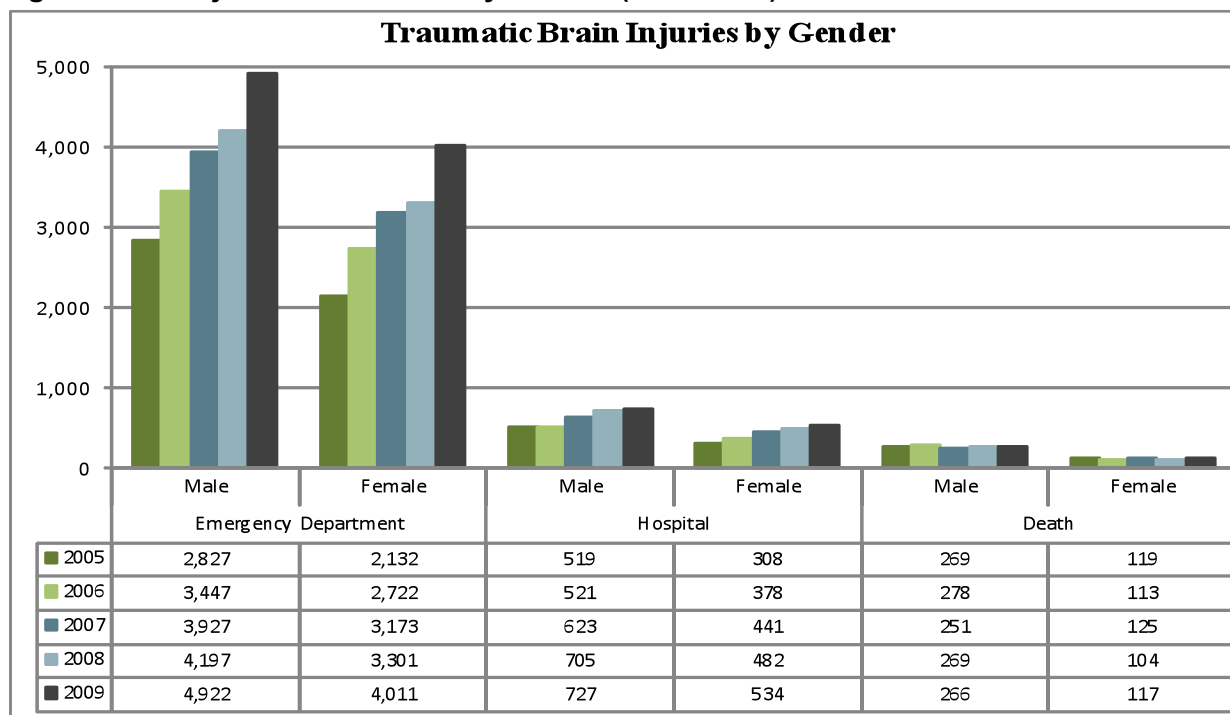
*U.S. Rates consist of an annual average from 1995-2001 to 2000 Census Data

Table 11. Female TBI's by Year (Incidence Rate/100,000)

Year (s)	ED			Hospital			Death		
	Rate	Age Adjusted Rate	U.S. Rate*	Rate	Age Adjusted Rate	U.S. Rate*	Rate	Age Adjusted Rate	U.S. Rate*
2009	446.1	432.2	329	59.4	49.3	61.7	13.0	11.7	8.9
2005-2009 Average	341.2	-	329	47.7	-	61.7	12.9	-	8.9

*U.S. Rates consist of an annual average from 1995-2001 to 2000 Census Data

Figure 3. TBI Injuries and Deaths by Gender (2005-2009)



TBI by Age and Gender

Table 12 separates the data by age and gender. Comparing this TBI data by age group and gender graphically in Figures 4-6 indicates that males have a higher percent of ED visits, hospitalizations, and deaths for younger individuals when compared to females. For example, Figure 5 shows that 25% of female hospitalizations were for individuals 85 years old and over, compared to 8% for males. A majority of this difference is not a reflection of rate differences but a reflection of total population variation for each age group for males and females. However, the data is useful when considering services and funding for demographic populations in Nebraska.

Table 12. TBI's Age by Gender (2009)

Age	ED		Hospital		Death	
	Male	Female	Male	Female	Male	Female
Under 1	166	133	9	8	1	1
1-4	653	465	19	14	2	5
5-14	1,002	490	31	24	5	2
15-24	1,165	787	125	60	44	13
25-34	478	391	72	18	41	14
35-44	336	337	63	21	32	12
45-54	344	333	94	47	43	11
55-64	249	286	77	46	34	7
65-74	187	230	65	59	22	8
75-84	210	268	116	106	20	24
85+	132	291	56	131	22	20

Figure 4. TBI Emergency Department Visits by Age and Gender

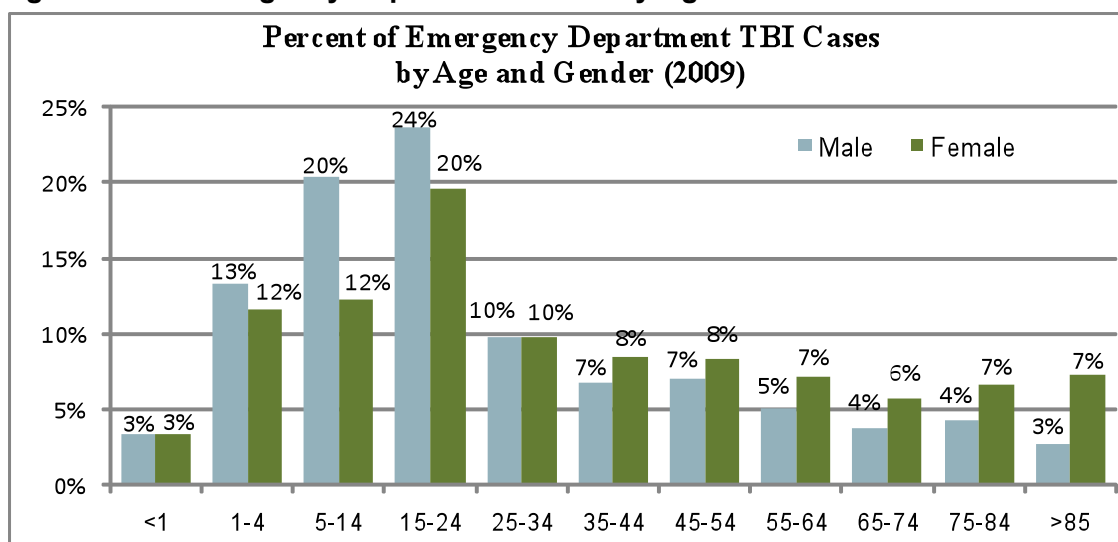


Figure 5. TBI Hospitalization by Age and Gender

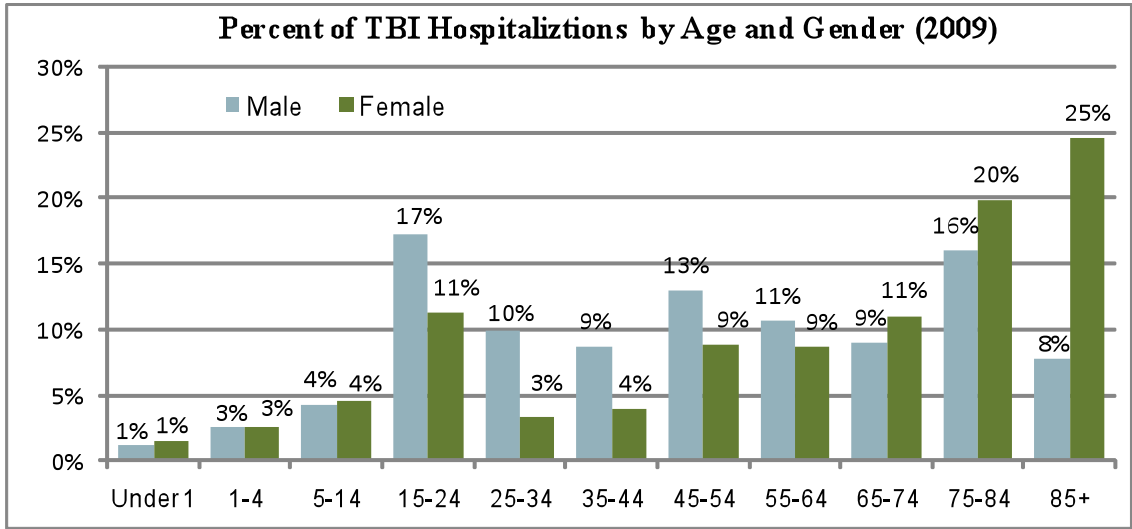
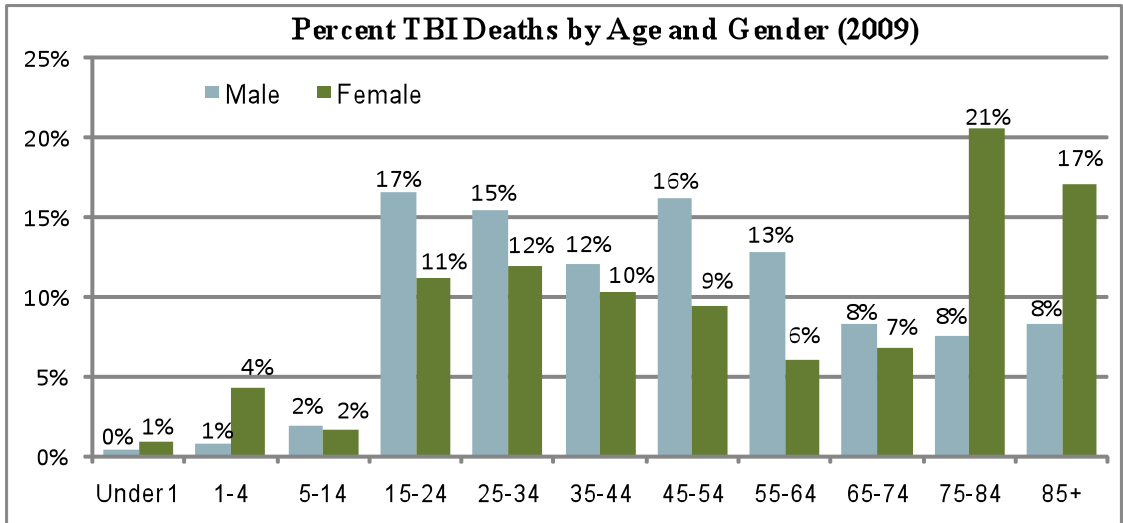
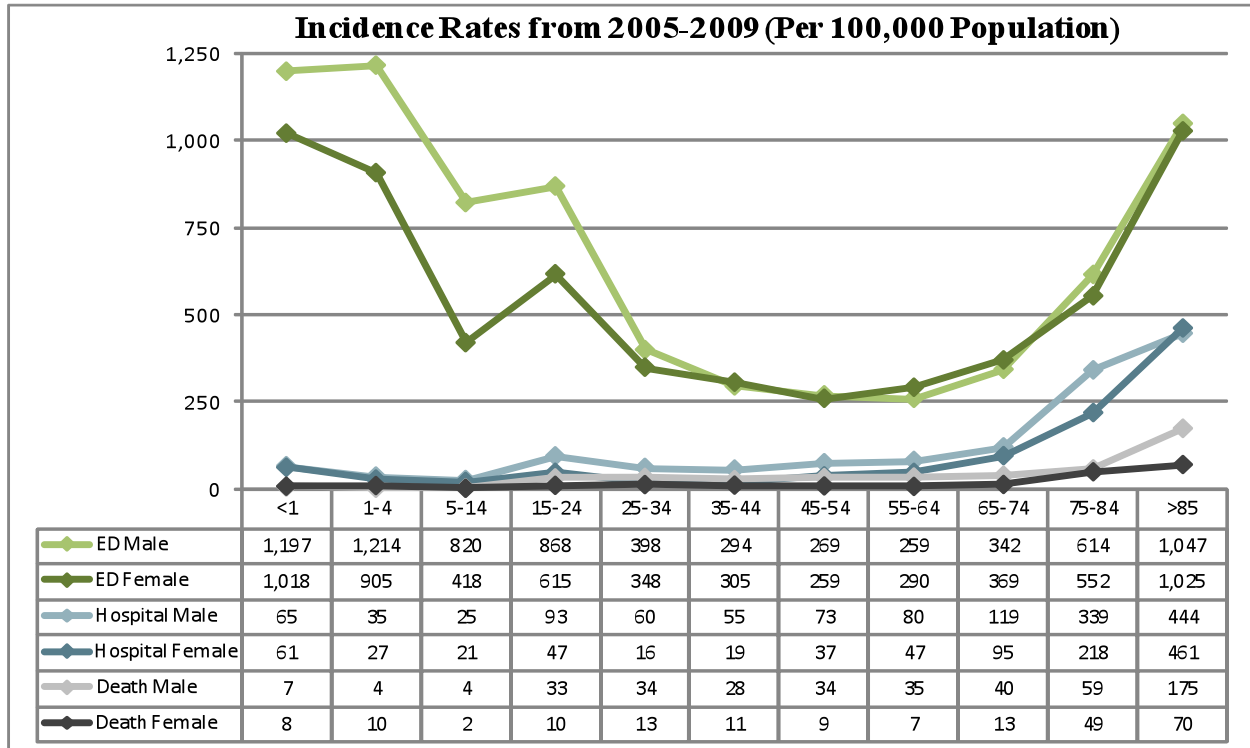


Figure 6. TBI Deaths by Age and Gender



The incidence rates (number per 100,000 people) for ED visits for both males and females were highest for younger and elderly individuals, the two extremes of the age scale. The ED incidence rate for male was much higher for younger age groups when compared to females. Both hospitalization and death incidence rates for males and females were highest for older age groups. The average incidence rates from 2005-2009 for males and females is shown in Figure 7.

Figure 7. TBI Incidence Rates by Age and Gender (Incidence Rate/100,000)



Tables 13 and 14 compare Nebraska's incidence rate to the U.S. for males and females, respectively, per 100,000 population. Nebraska's hospital incidence rate for both males and females is below the United States average for those under 55 years old, but higher for those over 55. For a majority of the age groups for both males and females in Nebraska, the death and emergency department incidence rates are above the United States averages.

Table 13. 2009 Male TBI's by Age (Incidence/100,000)

Year (s)	ED		Hospital		Death	
	Rate	U.S. Rate*	Rate	U.S. Rate*	Rate	U.S. Rate*
Under 1	1,196.7	1,254	64.9	95.4	7.2	6.3
1-4	1,214.2		35.3		3.7	
5-14	820.0	743	25.4	74.6	4.1	5.3
15-24	867.6	647	93.1	159.1	32.8	40.3
25-34	398.2	441	60.0	105.5	34.2	29.8
35-44	294.2	361	55.2	95.7	28.0	26.6
45-54	268.5	205	73.4	81.0	33.6	26.0
55-64	258.6	-	80.0	79.4	35.3	27.5
65-74	341.9	-	118.8	103.6	40.2	36.7
75-84	614.0	323	339.2	276.0	58.5	83.7
85+	1,047.1		444.2		174.5	

*U.S. Rates consist of an annual average from 1995-2001 to 2000 Census Data

Table 14. 2009 Female TBI's by Age (Incidence Rate/100,000)

Year (s)	ED		Hospital		Death	
	Rate	U.S. Rate*	Rate	U.S. Rate*	Rate	U.S. Rate*
Under 1	1,018.1	806	61.2	63.7	7.7	5.0

1-4	905.1		27.3		9.7	
5-14	418.2	432	20.5	34.4	1.7	2.9
15-24	615.3	499	46.9	72.3	10.2	11.4
25-34	347.9	273	16.0	41.4	12.5	7.9
35-44	304.9	222	19.0	37.6	10.9	7.8
45-54	258.6	217	36.5	35.1	8.5	7.1
55-64	290.2	182	46.7	45.3	7.1	7.4
65-74	368.6	-	94.6	73.1	12.8	11.0
75-84	552.1	344	218.4	269.9	49.4	31.6
85+	1,024.6		461.2		70.4	

*U.S. Rates consist of an annual average from 1995-2001 to 2000 Census Data

Breakdown by County

Figures 8,10, and 12 depict brain injury cases by emergency department, hospital inpatient, and death data, respectively. Figures 9,11, and 13 depict brain injury incidence rates (number of TBIs per 100,000 people) by emergency department, hospital inpatient, and death data, respectively. The map is shaded according to county density, with the darkest shades indicating the highest number or incidence of individuals with a brain injury related diagnosis.

Appendix A shows the exact numbers for each county by emergency department, hospital inpatient, and death numbers for the average five year time period, 2005-2009. Appendix B show this data for 2009, exclusively.

Figure 8. TBI Emergency Department Visits by County (2005-2009) ¹

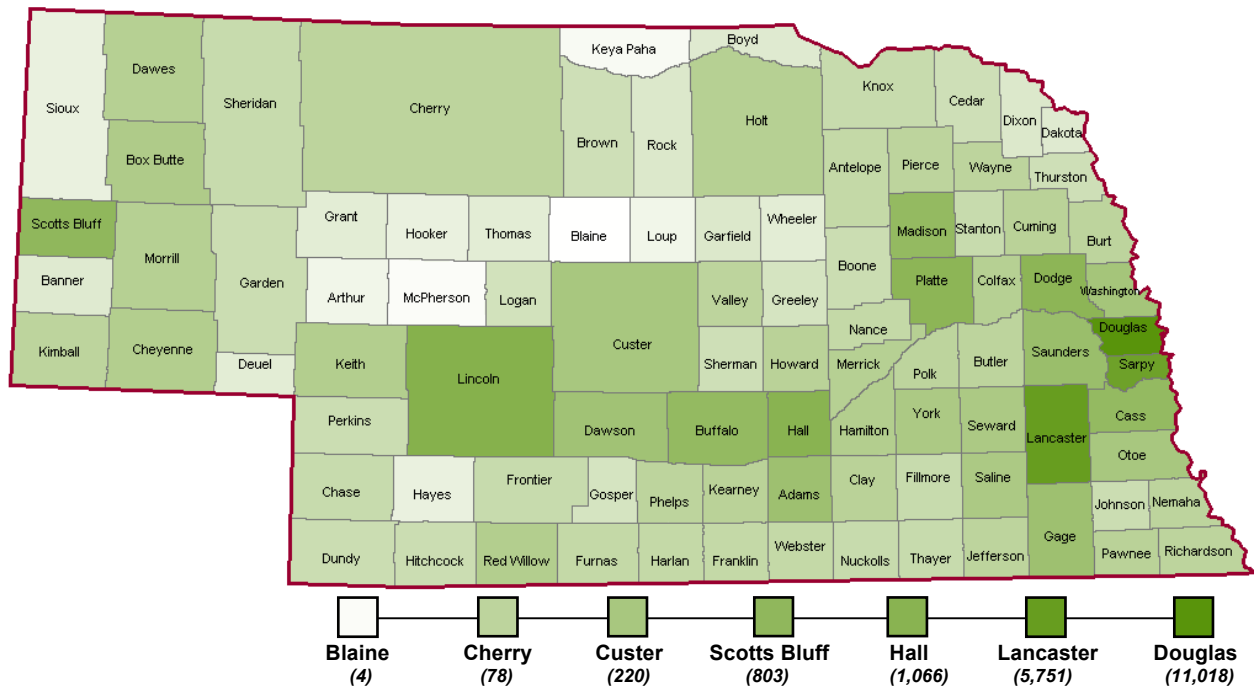


Figure 9 shows that some counties, such as Logan County, that had a relatively small number of TBI related ED visits had a high incidence rate. The Nebraska counties with the highest

¹ Microsoft MapPoint

prevalence rates were Logan, Sarpy, Cass, Lincoln, Platte, and Pawnee counties. Appendix C shows a larger map of Figure 9.

Figure 9. 2005-2009 Emergency Department Visits by County (Incidence Rate/100,000) ^{9,2}

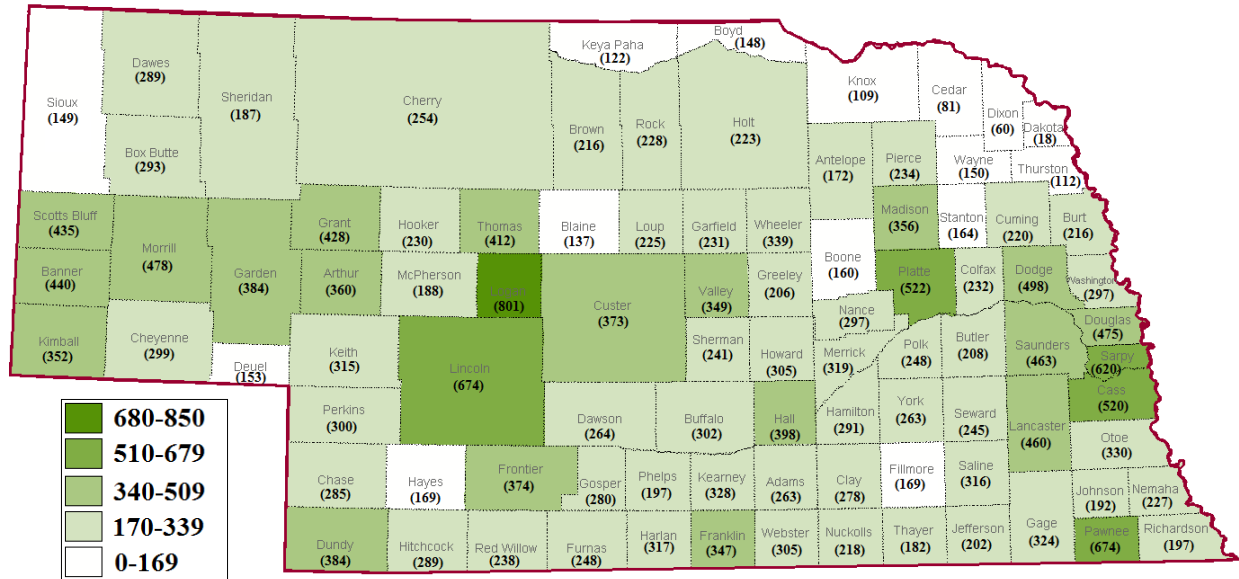
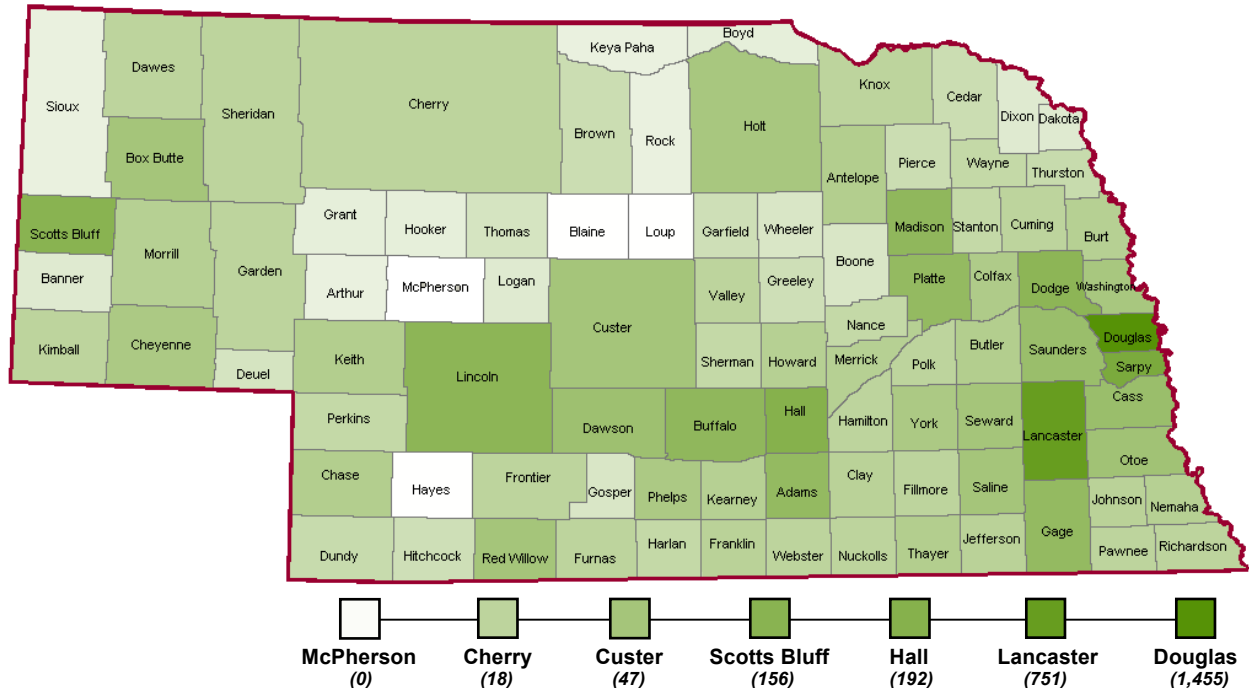


Figure 10. TBI Hospitalizations by County (2005-2009) ³



² Microsoft MapPoint

³ Microsoft MapPoint

The Nebraska counties with the highest hospitalization incidence rates were Thomas, Garden, Chase, Wheeler, Frontier, Franklin, and Pawnee counties. Appendix D shows a larger map of Figure 11.

Figure 11. 2005-2009 TBI Hospitalizations by County (Incidence Rate/100,000) ⁹

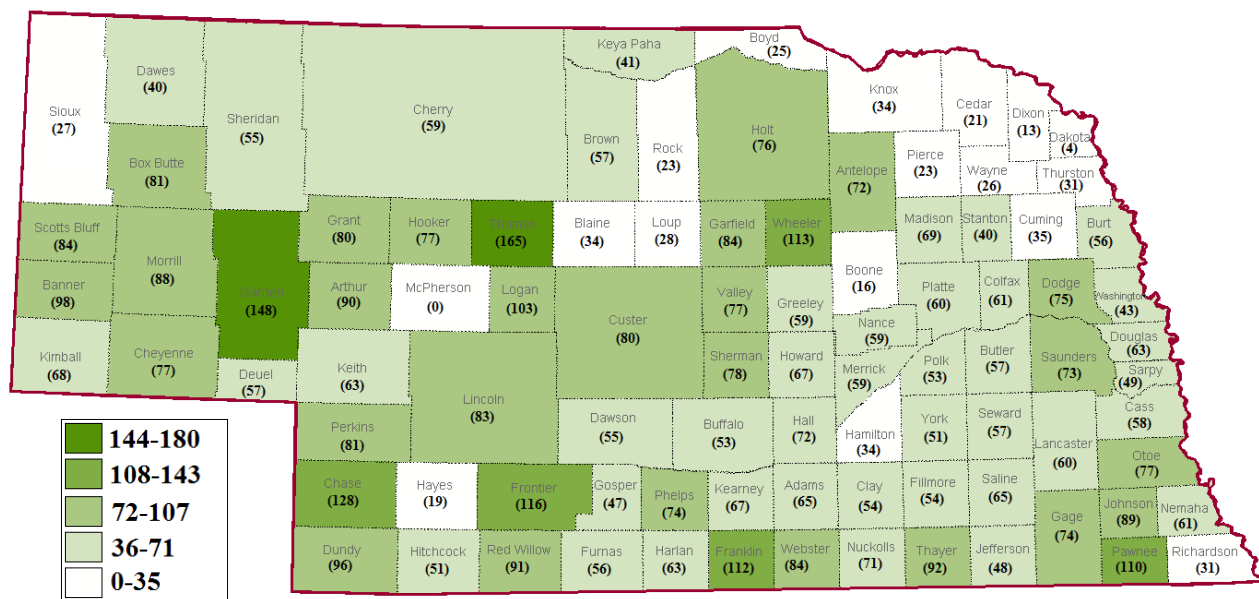
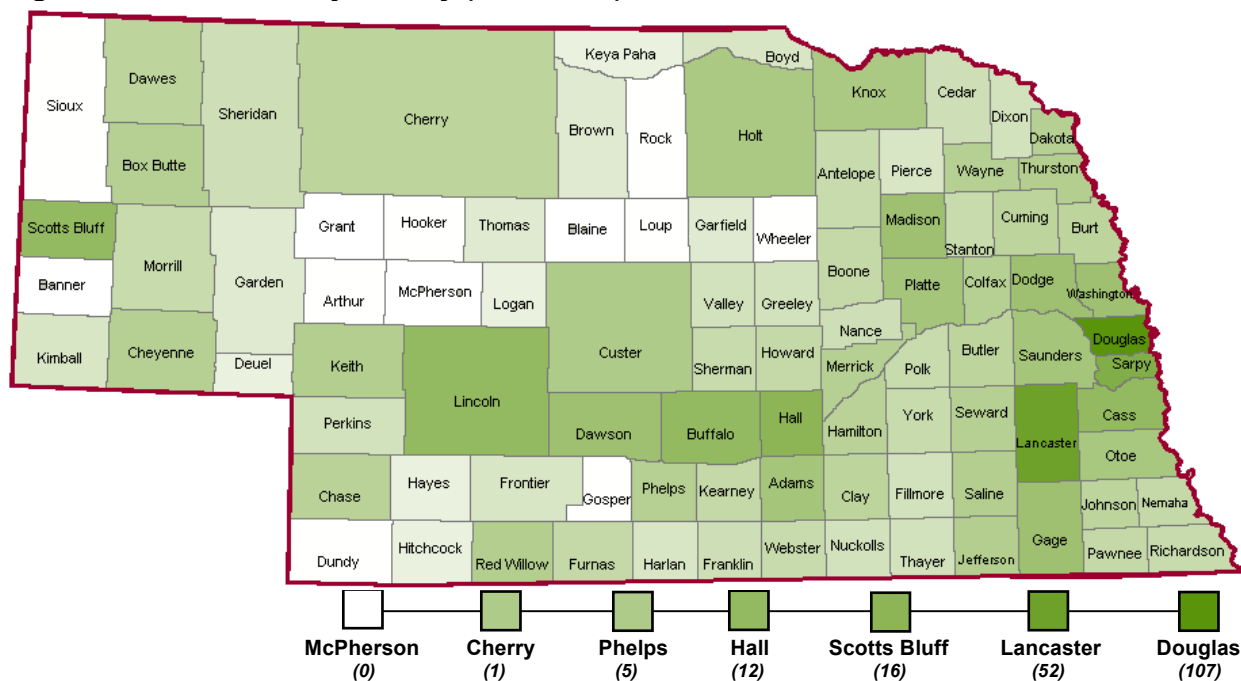
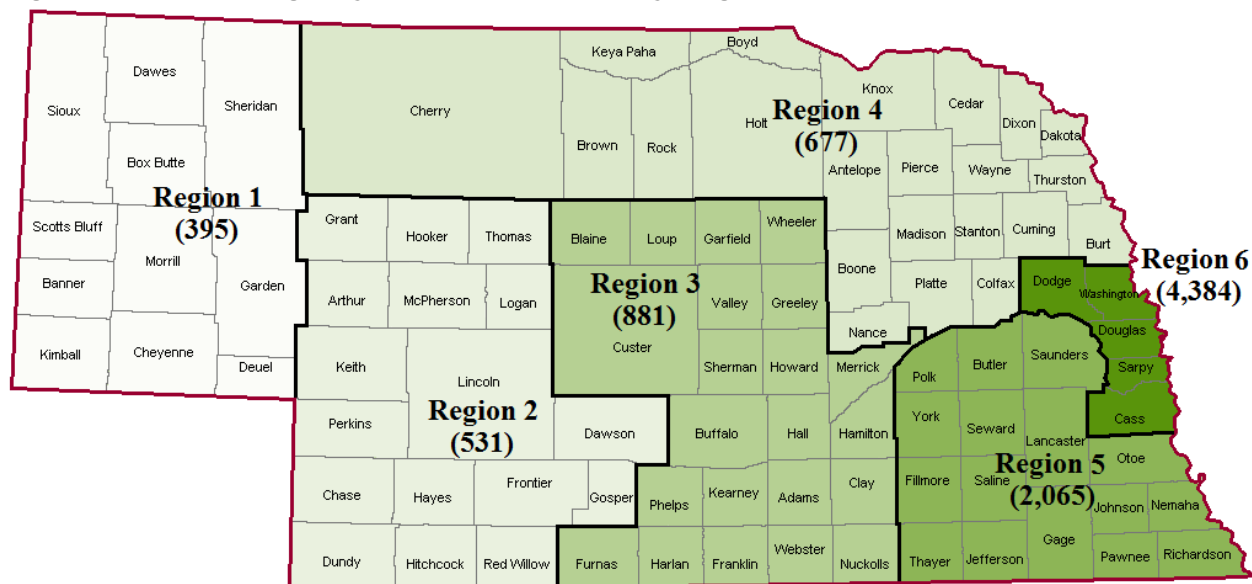


Figure 12. TBI Deaths by County (2005-2009) ⁴



⁴ Microsoft MapPoint

Figure 14. TBI Emergency Department Visits by Region (2009)

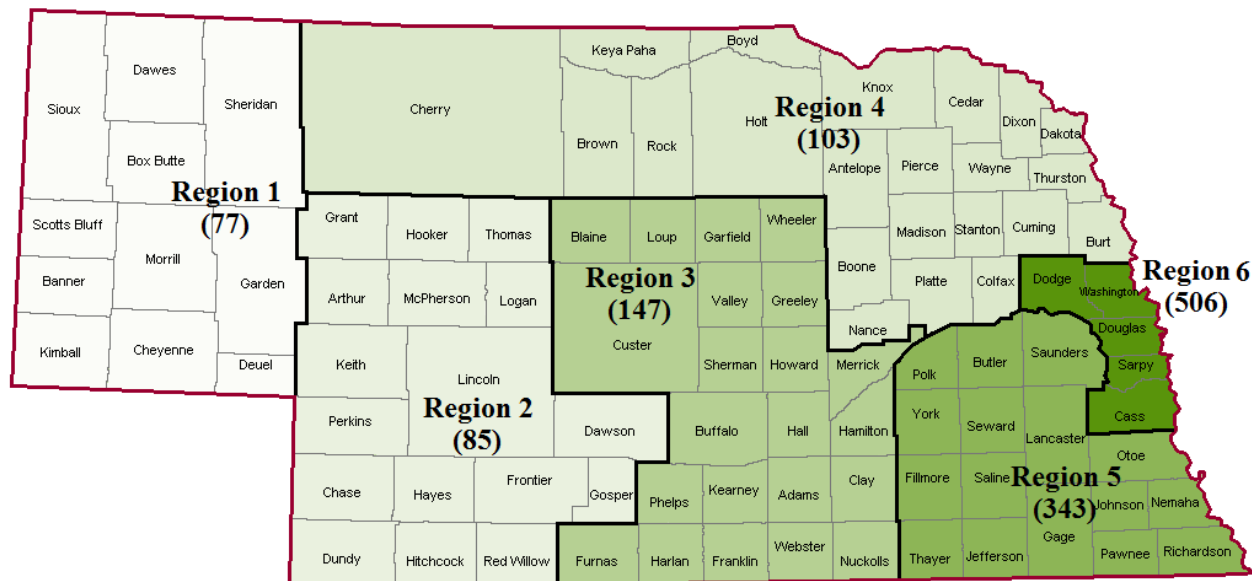


The percent of TBI hospitalization from Region 5 have increased from 2005-2009 while the percent from Region 4 has decreased.

Table 16. TBI Hospitalizations by Behavioral Health Regions (2005-2009)

Regions	2005		2006		2007		2008		2009	
	n	%	n	%	n	%	n	%	n	%
Region 1	61	7.4%	70	7.8%	73	6.9%	77	6.5%	77	6.1%
Region 2	73	8.8%	57	6.3%	83	7.8%	92	7.8%	85	6.7%
Region 3	107	12.9%	127	14.1%	144	13.5%	168	14.2%	147	11.7%
Region 4	87	10.5%	108	12.0%	118	11.1%	100	8.4%	103	8.2%
Region 5	170	20.6%	212	23.6%	242	22.7%	310	26.1%	343	27.2%
Region 6	327	39.5%	323	35.9%	404	38.0%	440	37.1%	506	40.1%
Unknown	2	0.2%	2	0.2%	0	0.0%	0	0.0%	0	0.0%
Total	827		899		1,064		1,187		1,261	

Figure 15. TBI Hospitalizations by Region (2009)

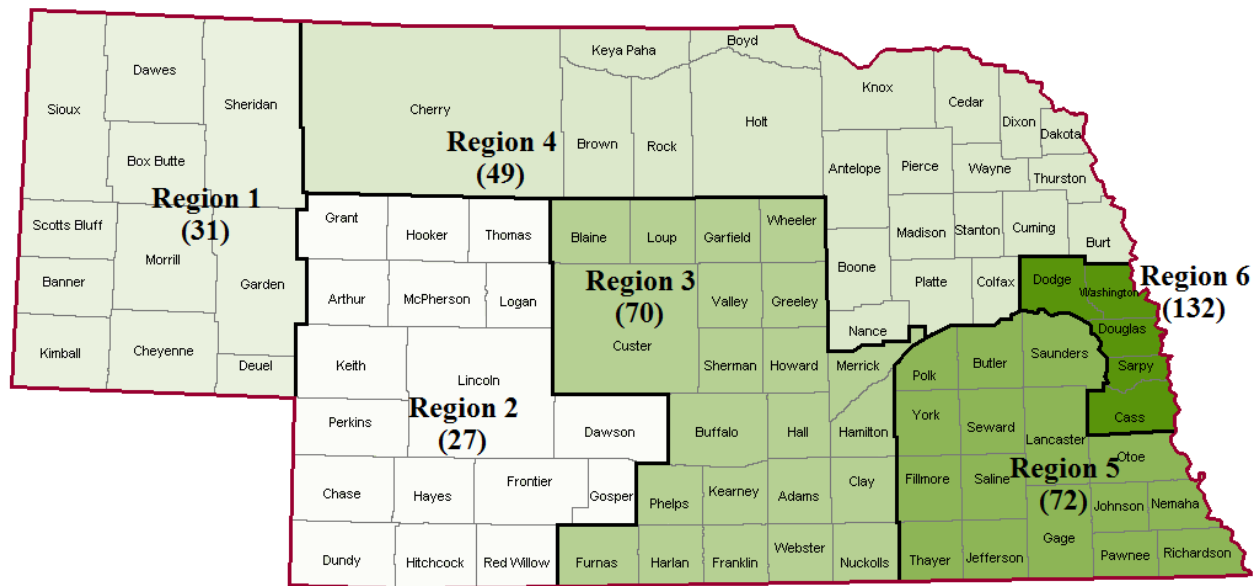


The percent of TBI related deaths from Region 1 and Region 3 have increased from 2005-2009 while the percent from Region 4 has decreased.

Table 17. TBI Deaths by Behavioral Health Regions (2005-2009)

Regions	2005		2006		2007		2008		2009	
	n	%	n	%	n	%	n	%	n	%
Region 1	22	5.7%	23	5.9%	23	6.1%	23	6.2%	31	8.1%
Region 2	32	8.2%	30	7.7%	28	7.4%	33	8.8%	27	7.0%
Region 3	59	15.2%	51	13.0%	50	13.3%	60	16.1%	70	18.3%
Region 4	57	14.7%	51	13.0%	52	13.8%	42	11.3%	49	12.8%
Region 5	78	20.1%	88	22.5%	88	23.4%	81	21.7%	72	18.8%
Region 6	135	34.8%	147	37.6%	135	35.9%	134	35.9%	132	34.5%
Unknown/Outside NE	5	1.3%	1	0.3%	0	0.0%	0	0.0%	2	0.5%
Total	388		391		376		373		383	

Figure 16. TBI Deaths by Region (2009)



Appendix F shows tables that separate ED visits, hospitalizations, and deaths for each region by age group for 2009. In all Regions, youth and young adults (1-24) have the highest visits to the ED but hospitalization and death rates are most prevalent in the over 45 age groups across all regions.

TBI Registry Data by Cause of Injury or Death

Figure 17 depicts an overview of the most frequent, top 5 for each category, causes of brain related injury or death. Falls, being struck by or against, and motor vehicle crashes are the most frequent causes of ED or hospital visits, while brain injury related deaths have a higher percentage of firearm related causes and lower percentage of struck by or against causes.

Tables 18-20 include the cause of injury or death by year and give more detail about injuries and trends. Overall, there was relatively little change in the order of most frequent causes of brain related injury or death over the past 5 years.

Figure 17. TBI Top Causes of Injury or Death (2009)

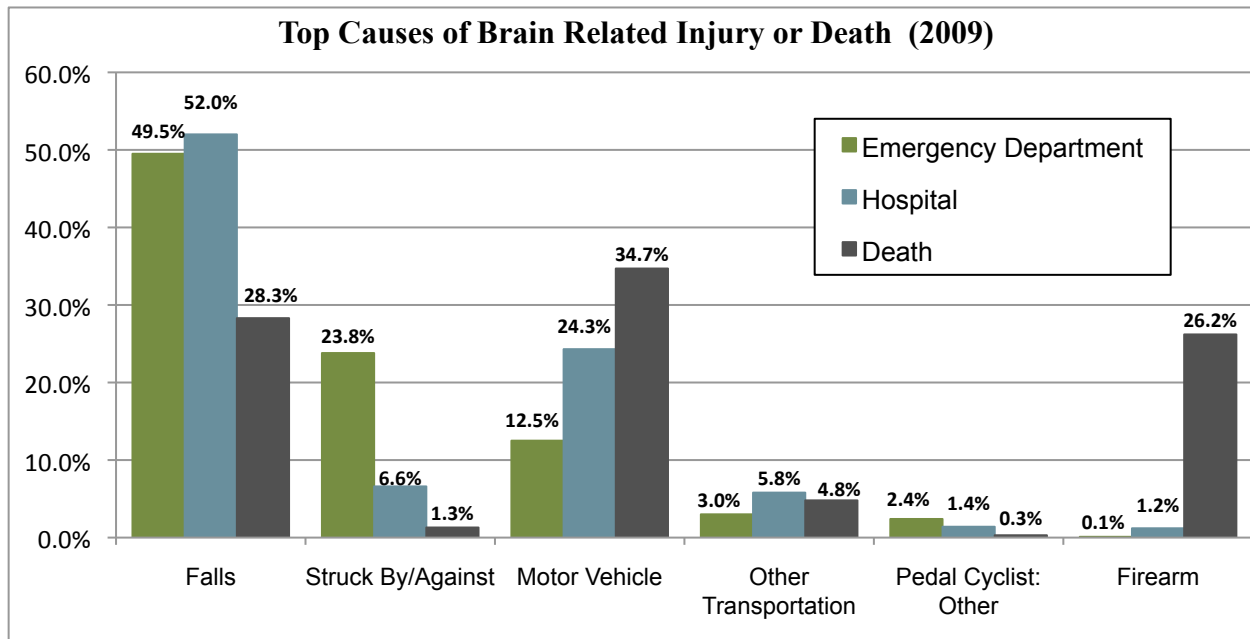


Table 18. Emergency Department Cause of Injury by Year

Emergency Department Cause of Injury	2005		2006		2007		2008		2009	
	n	%	n	%	n	%	n	%	n	%
Falls	2,247	45.3%	2,863	46.4%	3,486	49.1%	3,699	49.3%	4,422	49.5%
Struck By/Against	1,279	25.8%	1,578	25.6%	1,564	22.0%	1,797	24.0%	2,129	23.8%
Motor Vehicle	675	13.6%	798	12.9%	1,027	14.5%	985	13.1%	1,118	12.5%
Other Transportation	199	4.0%	215	3.5%	216	3.0%	218	2.9%	266	3.0%
Pedal Cyclist: Other	161	3.2%	175	2.8%	183	2.6%	183	2.4%	217	2.4%
Cut/Pierce	23	0.5%	19	0.3%	26	0.4%	37	0.5%	28	0.3%
Natural/Environmental	22	0.4%	32	0.5%	36	0.5%	31	0.4%	49	0.5%
Firearm	10	0.2%	19	0.3%	7	0.1%	13	0.2%	7	0.1%
Pedestrian: Other	9	0.2%	5	0.1%	6	0.1%	11	0.1%	9	0.1%
Overexertion	7	0.1%	7	0.1%	9	0.1%	11	0.1%	9	0.1%
Machinery	7	0.1%	5	0.1%	10	0.1%	9	0.1%	17	0.2%
Drowning	4	0.1%	3	0.0%	2	0.0%	1	0.0%	2	0.0%
Fire/Burn	1	0.0%	1	0.0%	2	0.0%	2	0.0%	2	0.0%
Poisoning	0	0.0%	4	0.1%	2	0.0%	4	0.1%	3	0.0%
Suffocation	0	0.0%	3	0.0%	0	0.0%	0	0.0%	7	0.1%
Unspecified/Other Classifiable	315	6.4%	442	7.2%	524	7.4%	497	6.6%	648	7.3%
Total	4,959		6,169		7,100		7,498		8,933	

Table 19. Hospital Cause of Injury by Year

Hospital Cause of Injury	2005		2006		2007		2008		2009	
	n	%	n	%	n	%	n	%	n	%
Falls	422	51.0%	461	51.3%	555	52.2%	673	56.7%	656	52.0%
Motor Vehicle	211	25.5%	187	20.8%	257	24.2%	244	20.6%	306	24.3%
Struck By/Against	61	7.4%	77	8.6%	83	7.8%	96	8.1%	83	6.6%
Other Transportation	32	3.9%	49	5.5%	42	3.9%	52	4.4%	73	5.8%
Pedal Cyclist: Other	16	1.9%	16	1.8%	11	1.0%	19	1.6%	18	1.4%
Firearm	9	1.1%	15	1.7%	3	0.3%	14	1.2%	15	1.2%
Natural/Environmental	7	0.8%	10	1.1%	5	0.5%	10	0.8%	8	0.6%
Pedestrian: Other	3	0.4%	1	0.1%	0	0.0%	1	0.1%	0	0.0%
Poisoning	2	0.2%	3	0.3%	1	0.1%	0	0.0%	1	0.1%
Machinery	1	0.1%	1	0.1%	2	0.2%	3	0.3%	2	0.2%
Overexertion	1	0.1%	1	0.1%	0	0.0%	0	0.0%	0	0.0%
Fire/Burn	0	0.0%	0	0.0%	1	0.1%	0	0.0%	3	0.2%
Cut/Pierce	0	0.0%	0	0.0%	1	0.1%	1	0.1%	3	0.2%
Drowning	0	0.0%	0	0.0%	1	0.1%	0	0.0%	0	0.0%
Suffocation	0	0.0%	0	0.0%	1	0.1%	0	0.0%	3	0.2%
Unspecified/Other Classifiable	62	7.5%	78	8.7%	101	9.5%	74	6.2%	90	7.1%
Total	827		899		1,064		1,187		1,261	

Table 20. Cause of Death by Year

Death Registry Cause of Death	2005		2006		2007		2008		2009	
	n	%	n	%	n	%	n	%	n	%
Motor Vehicle	159	42.0%	156	40.4%	153	41.6%	119	32.2%	131	34.7%
Firearm	101	26.6%	102	26.4%	82	22.3%	96	26.0%	99	26.2%
Falls	79	20.8%	73	18.9%	91	24.7%	114	30.9%	107	28.3%
Other Transportation	6	1.6%	12	3.1%	16	4.3%	6	1.6%	18	4.8%
Pedal Cyclist: Other	4	1.1%	0	0.0%	0	0.0%	1	0.3%	1	0.3%
Struck By/Against	3	0.8%	5	1.3%	2	0.5%	5	1.4%	5	1.3%
Pedestrian: Other	2	0.5%	4	1.0%	2	0.5%	1	0.3%	3	0.8%
Machinery	2	0.5%	1	0.3%	1	0.3%	4	1.1%	0	0.0%
Drowning	2	0.5%	0	0.0%	1	0.3%	0	0.0%	0	0.0%
Cut/Pierce	1	0.3%	1	0.3%	2	0.5%	0	0.0%	0	0.0%
Natural/Environmental	0	0.0%	1	0.3%	1	0.3%	0	0.0%	1	0.3%
Suffocation	0	0.0%	0	0.0%	2	0.5%	3	0.8%	1	0.3%
Poisoning	0	0.0%	2	0.5%	1	0.3%	1	0.3%	0	0.0%
Unspecified/Other Classifiable	20	5.3%	29	7.5%	14	3.8%	19	5.1%	12	3.2%
Total	379		386		368		369		378	

Table 21 through Table 26 show the number and incidence rates (per 100,000 population) for emergency department visits, hospitalizations, and deaths by age group.

The incidence rate for falls 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 21. Emergency Department Cause of Injury by Age (2009)

ED Cause of Injury	Age <1		1-14		15-24		25-44		45-64		65+	
	n	%	n	%	n	%	n	%	n	%	n	%
Falls	233	78%	1,411	54%	432	22%	525	34%	704	58%	1,117	85%
Struck By/Against	44	15%	740	28%	689	35%	427	28%	175	14%	54	4%
Motor Vehicle	5	2%	109	4%	487	25%	296	19%	156	13%	65	5%
Other Transportation	1	0%	72	3%	85	4%	52	3%	47	4%	9	1%
Pedal Cyclist: Other	0	0%	141	5%	30	2%	20	1%	24	2%	2	0%
Cut/Pierce	0	0%	6	0%	9	0%	10	1%	0	0%	3	0%
Natural/Environmental	0	0%	15	1%	7	0%	12	1%	10	1%	5	0%
Firearm	0	0%	0	0%	0	0%	3	0%	2	0%	2	0%
Pedestrian: Other	0	0%	2	0%	3	0%	2	0%	1	0%	1	0%
Overexertion	1	0%	1	0%	3	0%	1	0%	1	0%	2	0%
Machinery	0	0%	1	0%	3	0%	6	0%	5	0%	2	0%
Drowning	0	0%	0	0%	0	0%	2	0%	0	0%	0	0%
Fire/Burn	0	0%	0	0%	1	0%	0	0%	1	0%	0	0%
Poisoning	0	0%	0	0%	1	0%	2	0%	0	0%	0	0%
Suffocation	0	0%	2	0%	1	0%	3	0%	1	0%	0	0%
Unspecified/Other Classifiable	15	5%	110	4%	201	10%	181	12%	85	7%	56	4%
Total	299		2,610		1,952		1,542		1,212		1,318	

Table 22. 2009 Emergency Department Cause of Injury by Age (Incidence Rate/100,000)

Emergency Department Cause of Injury*	Overall	Age <1	1-14	15-24	25-44	45-64	65+
Falls	247.9	865.0	409.5	164.8	114.8	155.8	463.8
Struck By/Against	119.4	163.4	214.8	262.8	93.4	38.7	22.4
Motor Vehicle	62.7	18.6	31.6	185.7	64.7	34.5	27.0
Other Transportation	14.9	3.7	20.9	32.4	11.4	10.4	3.7
Pedal Cyclist: Other	12.2	0.0	40.9	11.4	4.4	5.3	0.8
Natural/Environmental	2.7	0.0	4.4	2.7	2.6	2.2	2.1
Cut/Pierce	1.6	0.0	1.7	3.4	2.2	0.0	1.2
Unspecified/Other Classifiable	36.3	55.7	31.9	76.7	39.6	18.8	23.3
Total	495.3	1,110.1	757.6	706.4	337.3	268.3	547.2

*Rates of less than 1 per 100,000 were excluded from following tables

Table 23. Hospital Cause of Injury by Age (2009)

Hospital Cause of Injury	Age <1		1-14		15-24		25-44		45-64		65+	
	n	%	n	%	n	%	n	%	n	%	n	%
Falls	7	41%	30	34%	20	11%	28	16%	129	49%	432	81%
Motor Vehicle	0	0%	25	28%	105	57%	68	39%	66	25%	42	8%
Struck By/Against	0	0%	6	7%	26	14%	30	17%	11	4%	10	2%
Other Transportation	1	6%	8	9%	18	10%	15	9%	25	9%	6	1%
Pedal Cyclist: Other	0	0%	5	6%	0	0%	3	2%	8	3%	2	0%
Firearm	0	0%	0	0%	8	4%	3	2%	3	1%	1	0%
Natural/Environmental	0	0%	4	5%	1	1%	0	0%	1	0%	2	0%
Cut/Pierce	0	0%	0	0%	1	1%	0	0%	2	1%	0	0%
Machinery	0	0%	0	0%	0	0%	0	0%	1	0%	1	0%
Fire/Burn	0	0%	0	0%	0	0%	1	1%	0	0%	2	0%
Poisoning	0	0%	0	0%	1	1%	0	0%	0	0%	0	0%
Suffocation	0	0%	0	0%	1	1%	1	1%	0	0%	1	0%
Unspecified/Other Classifiable	9	53%	10	11%	4	2%	15	9%	18	7%	34	6%
Total	17		88		185		174		264		533	

Table 24. 2009 Hospital Cause of Injury by Age (Incidence Rate/100,000)

Hospital Cause of Injury	Overall	Age <1	1-14	15-24	25-44	45-64	65+
Falls	36.2	26.0	8.7	7.6	6.1	28.6	179.4
Motor Vehicle	17.2	0.0	7.3	40.0	14.9	14.6	17.4
Struck By/Against	4.7	0.0	1.7	9.9	6.6	2.4	4.2
Other Transportation	4.1	3.7	2.3	6.9	3.3	5.5	2.5
Pedal Cyclist: Other	1.0	0.0	1.5	0.0	0.7	1.8	0.8
Unspecified/Other Classifiable	5.0	33.4	2.9	1.5	3.3	4.0	14.1
Total	70.7	63.1	25.5	70.6	38.1	58.4	221.3

Table 25. Death Registry Cause of Injury by Age (2009)

Death Registry Cause of Death	Age <1		1-14		15-24		25-44		45-64		65+	
	n	%	n	%	n	%	n	%	n	%	n	%
Motor Vehicle	2	18%	37	49%	225	61%	179	42%	161	37%	114	19%
Firearm	0	0%	5	7%	102	28%	150	36%	154	35%	69	12%
Falls	0	0%	3	4%	10	3%	29	7%	66	15%	356	60%
Other Transportation	1	9%	7	9%	15	4%	14	3%	12	3%	9	2%
Struck By/Against	0	0%	2	3%	1	0%	6	1%	7	2%	4	1%
Pedestrian: Other	2	18%	0	0%	1	0%	7	2%	2	0%	1	0%
Pedal Cyclist: Other	0	0%	1	1%	1	0%	1	0%	2	0%	1	0%
Cut/Pierce	0	0%	0	0%	0	0%	2	0%	1	0%	1	0%
Natural/Environmental	0	0%	0	0%	0	0%	1	0%	1	0%	1	0%
Machinery	0	0%	1	1%	1	0%	2	0%	3	1%	1	0%
Drowning	0	0%	0	0%	3	1%	0	0%	0	0%	0	0%
Poisoning	0	0%	0	0%	1	0%	2	0%	0	0%	1	0%
Suffocation	0	0%	0	0%	1	0%	4	1%	1	0%	0	0%
Unspecified/Other Classifiable	6	55%	19	25%	9	2%	25	6%	27	6%	39	7%
Total	11		75		370		422		437		597	

Table 26. 2009 Death Registry Cause of Injury by Age (Incidence Rate/100,000)

Death Registry Cause of Death	Overall	Age <1	1-14	15-24	25-44	45-64	65+
Motor Vehicle	40.3	7.4	10.7	85.8	39.2	35.6	47.3
Firearm	26.9	0.0	1.5	38.9	32.8	34.1	28.6
Falls	26.0	0.0	0.9	3.8	6.3	14.6	147.8
Other Transportation	3.3	3.7	2.0	5.7	3.1	2.7	3.7
Struck By/Against	1.1	0.0	0.6	0.4	1.3	1.5	1.7
Unspecified/Other Classifiable	7.0	22.3	5.5	3.4	5.5	6.0	16.2
Total	107.2	40.8	21.8	141.1	92.3	96.7	247.9

Table 27 and Table 28 show the number and incidence rate for TBI related emergency department visits, hospitalizations, and deaths for males and females. Females had a lower incidence rate for almost every cause of injury; however, the rate of falls was similar between genders. Males had a notably higher incidence rate for brain injuries resulting from being struck by or against, firearms, and pedal cyclist.

Table 27. Cause by Gender (2009)

Cause	ED		Hospital		Death	
	Male	Female	Male	Female	Male	Female
Falls	2,186	2,236	338	318	55	52
Struck By/Against	1,380	749	67	16	5	0
Motor Vehicle	574	544	176	130	89	42
Other Transportation	150	116	45	28	13	5
Pedal Cyclist: Other	146	71	12	6	0	1
Cut/Pierce	20	8	3	0	0	0
Natural/Environmental	29	20	5	3	0	1
Firearm	6	1	14	1	90	9
Pedestrian: Other	7	2	0	0	1	2
Overexertion	5	4	0	0	0	0
Machinery	15	2	2	0	0	0
Drowning	1	1	0	0	0	0
Fire/Burn	1	1	2	1	0	0
Poisoning	1	2	1	0	0	0
Suffocation	4	3	3	0	1	0
Unspecified/Other Classifiable	397	251	59	31	12	5
Total	4,922	4,011	727	534	266	117

Table 28. 2009 Cause by Gender (Incidence Rate/100,000)

Cause	ED		Hospital		Death	
	Male	Female	Male	Female	Male	Female
Falls	259.2	257.6	40.1	36.6	6.5	6.0
Struck By/Against	163.6	86.3	7.9	1.8	0.6	0.0
Motor Vehicle	68.1	62.7	20.9	15.0	10.6	4.8
Other Transportation	17.8	13.4	5.3	3.2	1.5	0.6
Pedal Cyclist: Other	17.3	8.2	1.4	0.7	0.0	0.1
Cut/Pierce	2.4	0.9	0.4	0.0	0.0	0.0
Natural/Environmental	3.4	2.3	0.6	0.3	0.0	0.1
Firearm	0.7	0.1	1.7	0.1	10.7	1.0
Pedestrian: Other	0.8	0.2	0.0	0.0	0.1	0.2
Overexertion	0.6	0.5	0.0	0.0	0.0	0.0
Machinery	1.8	0.2	0.2	0.0	0.0	0.0
Drowning	0.1	0.1	0.0	0.0	0.0	0.0
Fire/Burn	0.1	0.1	0.2	0.1	0.0	0.0
Poisoning	0.1	0.2	0.1	0.0	0.0	0.0
Suffocation	0.5	0.3	0.4	0.0	0.1	0.0
Unspecified/Other Classifiable	47.1	28.9	7.0	3.6	1.4	0.6
Total	583.6	462.1	86.2	61.5	31.5	13.5

TBI by Length of Stay

As reported in Table 29, nearly all individuals were in the emergency department for a day or less; this has been consistent from 2005-2009. Over 80% of TBI hospitalizations were from 0-7 days, with over a third between 1 and 3 days (Table 30).

Table 29. Emergency Department Length of Stay

Emergency Department Length of Stay	2005		2006		2007		2008		2009	
	n	%	n	%	n	%	n	%	n	%
1 Day	4,884	98.5%	6,055	98.2%	6,972	98.2%	7,348	98.0%	8,840	99.0%
1-3 Days	42	1.0%	63	1.0%	71	1.0%	84	1.1%	69	0.8%
4-7 Days	15	0.3%	16	0.3%	22	0.3%	23	0.3%	11	0.1%
8-14 Days	5	0.2%	14	0.2%	15	0.2%	12	0.2%	10	0.1%
15-21 Days	6	0.1%	5	0.1%	6	0.1%	11	0.1%	1	0.0%
22-30 Days	2	0.1%	8	0.1%	8	0.1%	11	0.1%	1	0.0%
31+ Days	5	0.1%	8	0.1%	6	0.1%	9	0.1%	1	0.0%

Table 30. Hospital Length of Stay

Hospital Length of Stay	2005		2006		2007		2008		2009	
	n	%	n	%	n	%	n	%	n	%
1 Day	213	25.8%	213	23.7%	234	22.0%	244	20.6%	273	21.6%
1-3 Days	244	29.5%	293	32.6%	336	31.6%	402	33.9%	417	33.1%
4-7 Days	216	26.1%	238	26.5%	285	26.8%	322	27.1%	350	27.8%
8-14 Days	95	11.5%	95	10.6%	127	11.9%	119	10.0%	132	10.5%
15-21 Days	31	3.7%	31	3.4%	49	4.6%	48	4.0%	52	4.1%
22-30 Days	16	1.9%	19	2.1%	16	1.5%	38	3.2%	19	1.4%
31+ Days	12	1.5%	10	1.1%	17	1.6%	14	1.2%	18	1.4%

TBI Registry Data by Discharge Status

Tables 31 and 32 report discharge statuses for ED and hospitalization patients. A majority of individuals who were in the ED or hospitalized for a brain injury were released to their home.

However, a high percent of hospital patients were released to skilled nursing facilities, inpatient rehabilitation facilities (IRF), or expired.

Table 31. Emergency Department Discharge Status

Emergency Department Discharge Status	2005		2006		2007		2008		2009	
	n	%	n	%	n	%	n	%	n	%
Home	4,125	83%	5,068	82%	5,938	84%	6,274	84%	7,744	87%
Short-Term Hospital	210	4%	249	4%	267	4%	297	4%	297	3%
Left Against Medical Advisement	19	0%	26	0%	21	0%	48	1%	47	1%
Skilled Nursing Facility	17	0%	34	1%	24	0%	29	0%	46	1%
Custodial Care	28	1%	27	0%	21	0%	36	0%	40	0%
Inpatient Hospital	20	0%	34	1%	34	0%	30	0%	33	0%
Expired	27	1%	31	1%	26	0%	27	0%	24	0%
Care of Children	34	1%	19	0%	23	0%	20	0%	23	0%
Critical ACC Hospital	0	0%	2	0%	6	0%	3	0%	10	0%
Psychiatric Hospital	0	0%	2	0%	1	0%	4	0%	7	0%
Home Under Care	3	0%	11	0%	8	0%	12	0%	6	0%
Court Law Enforcement	0	0%	0	0%	0	0%	0	0%	5	0%
IRF	19	0%	10	0%	12	0%	19	0%	5	0%
Med LTCH	2	0%	6	0%	4	0%	11	0%	5	0%
NFC Medicaid	13	0%	9	0%	5	0%	10	0%	4	0%
Reserve Assignment	1	0%	0	0%	3	0%	7	0%	4	0%
Federal Health Facility	1	0%	0	0%	4	0%	2	0%	3	0%
Hospice: Medical Facility	2	0%	0	0%	1	0%	1	0%	3	0%
Still Patient	1	0%	5	0%	3	0%	1	0%	1	0%
Unknown	437	9%	636	10%	699	10%	667	9%	626	7%

Table 32. Hospital Discharge Status

Hospital Discharge Status	2005		2006		2007		2008		2009	
	n	%	n	%	n	%	n	%	n	%
Home	440	53.2%	475	52.8%	563	52.9%	580	48.9%	626	50%
Short-Term Hospital	16	1.9%	28	3.1%	23	2.2%	26	2.2%	17	1%
Left Against Medical Advisement	8	1.0%	5	0.6%	5	0.5%	8	0.7%	12	1%
Skilled Nursing Facility	92	11.1%	116	12.9%	117	11.0%	170	14.3%	172	14%
Custodial Care	20	2.4%	17	1.9%	11	1.0%	17	1.4%	11	1%
Inpatient Hospital	0	0.0%	0	0.0%	0	0.0%	1	0.1%	0	0%
Expired	69	8.3%	77	8.6%	78	7.3%	88	7.4%	89	7%
Care of Children	6	0.7%	3	0.3%	5	0.5%	3	0.3%	3	0%
Psychiatric Hospital	1	0.1%	1	0.1%	5	0.5%	3	0.3%	5	0%
Home Under Care	35	4.2%	26	2.9%	59	5.5%	58	4.9%	63	5%
IRF	107	12.9%	104	11.6%	150	14.1%	169	14.2%	198	16%
Med LTCH	13	1.6%	20	2.2%	15	1.4%	18	1.5%	19	2%
NFC Medicaid	3	0.4%	2	0.2%	0	0.0%	1	0.1%	2	0%
Reserve Assignment	0	0.0%	0	0.0%	0	0.0%	2	0.2%	0	0%
Federal Health Facility	0	0.0%	0	0.0%	1	0.1%	3	0.3%	5	0%
Hospice: Medical Facility	8	1.0%	8	0.9%	9	0.8%	8	0.7%	12	1%
Home-Based Masb	8	1.0%	14	1.6%	22	2.1%	23	1.9%	20	2%
Hospice: Home	0	0.0%	3	0.3%	0	0.0%	5	0.4%	3	0%
Unknown	1	0.1%	0	0.0%	0	0.0%	4	0.3%	4	0%

Veteran's Administration TBI Registry Profile

Brain Injury Screenings and Diagnosis's

The Veteran's Administration provided traumatic brain injury data for individuals the VA serves, which includes veterans who had been deployed to a combat zone dealing with Iraq or Afghanistan. The VA began collecting data in April 2007 and calculated figures on a cumulative basis since this date, so the format and time period reported differ from the TBI Registry analysis. In addition, the data covers all Nebraska except the panhandle, where individuals seek assistance in Rapid City, and includes 12 counties in Iowa.

Veteran's Administration screening and evaluation data in Table 33 goes from April 2007 to November 2010. Approximately 17% of the 4,540 screens were positive and 61% of those who screened positive completed a comprehensive TBI evaluation. Out of the 460 who completed a comprehensive evaluation, 66% were confirmed as having a traumatic brain injury.

Table 33. VA Brain Injury Screens (April 2007-November 2010)

TBI Screens	n	%
Total Screens	4,540	
Screened Positive	759	16.7%
Comprehensive Evaluation Screening Completed	460	60.6%
Confirmed TBI Diagnosis	302	65.6%

Table 34 and Table 35 shows that a majority, approximately 94%, of individuals diagnosed with a TBI through the VA were male and 46% were ages 25-29.

Table 34. VA TBI by Age (April 2007-November 2010)

Age	n	%
18-24	61	20.2%
25-29	138	45.7%
30-34	55	18.2%
35-39	20	6.6%
40-44	18	6.0%
45-49	6	2.0%
50-54	4	1.3%

Table 35. VA TBI by Gender (April 2007-November 2010)

Gender	n	%
Male	283	93.7%
Female	19	6.3%

Brain Injury Helpline Calls

Hotline for Disability and Brain Injury Association Calls

Hotline for Disability Calls

Nebraska provides assistance for individuals with questions regarding their brain injury and the resources available through Nebraska's Hotline for Disability Services. The Hotline provides information and referrals to Nebraskans who have questions or concerns related to a disability. This includes information about rehabilitation services, transportation, special parking permits, legal rights, and any other questions related to a disability.¹⁰

The following hotline data consists of contacts received in response to the TBI Registry letter and contacts around brain injury in general. The data is for calls related to brain injuries, exclusively. The following tables show the call type or reason and the number of calls from each county. The results are for the end of year Brain Injury Report, October 1, 2009 to September 30, 2010.

A majority of the 151 calls during the previous fiscal year were for information and referrals (48%), advocacy and support (11%), or assessment services (8%).

Table 36. Type of Call to Hotline¹⁰

Call Type	n	%
Information and Referral	73	48.3%
Advocacy and Support	16	10.6%
Assessment Services	12	7.9%
Medical	8	5.3%
Assistive Devices	5	3.3%
Housing/Residential	5	3.3%
Vocational Rehabilitation	5	3.3%
Financial	4	2.6%
Family/Individual Resources	4	2.6%
Insurance	3	2.0%
Case Management	3	2.0%
Employment	2	1.3%
Emergency Relief	2	1.3%
Transportation	2	1.3%
Counseling and Guidance	1	0.7%
Other/Unknown	6	4.0%
Total	151	

Table 37. Hotline Calls by County ¹⁰

County	n	%	County	n	%	County	n	%
Douglas	46	30.5%	Morrill	2	1.3%	Keith	1	0.7%
Lancaster	35	23.2%	Otoe	2	1.3%	Valley	1	0.7%
Hall	8	5.3%	Polk	1	0.7%	Dixon	1	0.7%
Platte	5	3.3%	Butler	1	0.7%	Kearney	1	0.7%
Thayer	4	2.6%	Gage	1	0.7%	Pierce	1	0.7%
Sarpy	4	2.6%	Merrick	1	0.7%	Johnson	1	0.7%
Lincoln	4	2.6%	Scotts Bluff	1	0.7%	Chase	1	0.7%
Cass	3	2.0%	Saunders	1	0.7%	Kimball	1	0.7%
Madison	3	2.0%	Phelps	1	0.7%	Box Butte	1	0.7%
Buffalo	3	2.0%	York	1	0.7%	Webster	1	0.7%
Dawson	2	1.3%	Deuel	1	0.7%	Out of State	5	3.3%
Nuckolls	2	1.3%	Seward	1	0.7%			
Dodge	2	1.3%	Cuming	1	0.7%	Total	151	

Brain Injury Association of Nebraska Calls

In 2010, the Brain Injury Association of Nebraska began receiving calls from individuals regarding questions related to brain injuries from the TBI registry letter instead of Nebraska's Hotline for Disability Services. Table 38 lists the types and quantities of calls received from August 20, 2010 to February 11, 2011. Of the 91 calls received, information and referral calls were the most frequent followed by questions regarding why they received a letter giving information about brain injury.

Table 38. Type of Calls to BIA-NE (8/10/2010 - 2/11/2011)

Call Type	n	%
Information and Referral	41	37.31%
Why Letter	19	17.29%
Advocacy and Support	15	13.65%
Financial	5	4.55%
Assessment Services	4	3.64%
Legal	3	2.73%
Counseling and Guidance	2	1.82%
Medical	1	1%
Case Management	1	1%
Total	91	

Phone Line Resource: Provider Survey Results

Select survey questions relating to the phone line use and referral system were taken from the service provider survey, which is analyzed in detail in section three. Service providers were asked to respond to questions regarding awareness and use of the statewide information and resource phone line, Table 39 and Table 40. Almost a third did not respond to the question. Of those providers who responded 51% were unaware of a statewide phone line. This percentage was much lower, 20%, for state agencies. Approximately 2/3 of agencies that responded to the survey question indicated referring people to the phone line compared to 19% of providers.

Table 39. Awareness of Statewide Information/Resource Phone Lines

	Providers		Agencies	
	n	%	n	%
Yes	19	48.7%	4	80%
No	20	51.3%	1	20%

Table 40. Use of Statewide Information/Resource Phone Lines

	Providers		Agencies	
	n	%	n	%
Use the phone line occasionally	2	3%	1	17%
Use the phone line often	1	2%	2	34%
Referred people to the phone line	11	19%	4	66%
Shared the phone line number	7	12%	4	66%

Nebraska Traumatic Brain Injury Survey Results

Individual/Caregiver, Service Provider, and State Agency Surveys

Survey Methodology

Online surveys were developed for individuals and their caregivers as well as service providers and state agencies that may serve individuals with brain injuries. Draft surveys were presented to the TBI Advisory Council and sub-committees for review and revisions. In addition, several providers and individuals with TBI piloted the surveys prior to administering the survey in November 2010 through January 2011.

The individual and caregiver survey asked identical questions with the exception of a few additional questions asked of caregivers. Likewise, the service provider and state agency surveys also asked similar questions. The survey instruments are available upon request to the Nebraska State Vocational Rehabilitation Office at (308) 865-5012.

Service provider surveys were sent to potential providers serving individuals with TBIs in the state and likewise for state agencies. Although the needs assessment is specific to traumatic brain injury, it is recognized that services provided do not differ for individuals whether their brain injury was a result of trauma or acquired in some other way. Therefore, individuals with any acquired brain injury were included in the survey sample. A convenience sampling methodology was used, as one list of all individuals with TBI from which to sample is not available.

The survey links were made available through the TBI support groups, published in local and regional papers and sent out to providers to distribute to their clients and patients. In addition, Quality Living Inc. and Madonna mailed the surveys to individuals they served in the recent past. Surveys in paper format were also made available to support groups to distribute as appropriate.

Individual/Caregiver Survey Results

There were 293 surveys completed by individuals with TBI or other acquired brain injuries (ABI) or by their caregiver. Approximately two-thirds were completed by individuals (see Table 41). However, in some instances the caregiver may have filled out the individual survey for the individual with the brain injury.

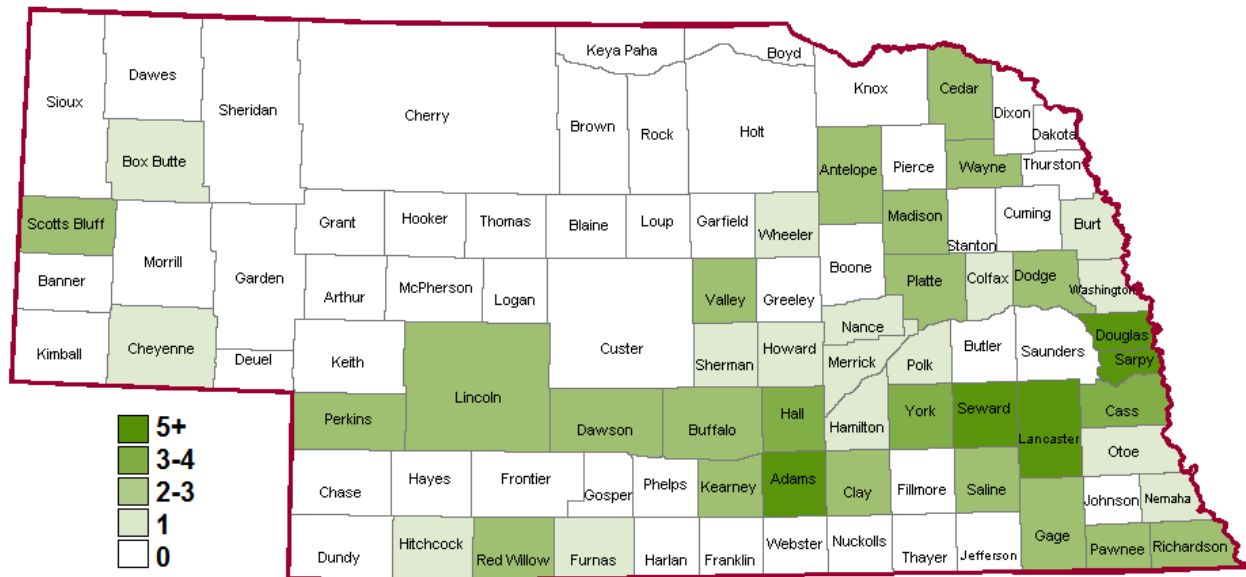
Please note that survey respondents may have chosen not to respond to some questions, therefore the number that responded to a particular question may vary. The number of responses for each question or response is indicated by the letter "n" in each table.

Table 41. Individual/Caregiver Survey Respondents

Individual with TBI	n	%
Individual	181	62%
Caregivers	112	38%
Child	53	18%
Spouse/Significant Other	24	8%
Parent	9	3%
Sibling	7	2%
Friend	2	1%
Other	17	6%
Total	293	100%

Respondents represented 44 of the 93 counties, 47%, in the state with approximately half indicating living in Lincoln or Omaha. Figure 18 shows each county by the number of individuals/caregivers that completed a survey from that county. that a majority of the respondents were from the southeastern part of the state. Appendix G gives a complete list of the number of individuals completing the survey by city and county.

Figure 18. Individual/Caregiver Survey Respondents by County of Residence



Cause of Brain Injury

The primary cause of the brain injury for respondent was motor vehicle crashes with falls second most frequent (see Table 42). Only one injury was a result of military combat or training. The causes of brain injury were categorized into either a traumatic brain injury (TBI) or other type of acquired brain injury (ABI). Table 43 reports respondents by brain injury type. The majority of the survey respondents (81%) had traumatic brain injuries as opposed to other ABIs.

Table 42. Cause of Brain Injury

Cause	n	%
Motorized vehicle crash (car, truck, motorcycle, ATV, etc.)	133	47%
Fall	52	18%
Stroke/Brain Tumor/Aneurysm/Infection/Disease	40	14%
Assault/Abuse/ Firearm/Gunshot	25	9%
Bicycle/Pedestrian injury	11	4%
Sports injury	10	4%
Other	7	2%
Near drowning or anoxia (lack of oxygen)	4	1%
Poisoning/Overdose	3	1%
Total	285	100%

Table 43. Brain Injury Type (TBI vs. ABI)

Type	n	%
Traumatic Brain Injury	231	81%
Other Acquired Brain Injury	54	19%

Severity of Brain Injury

Over half of the respondents classified the brain injury as severe (see Table 44). Further analysis revealed no difference in classification of severity whether the respondent was the individual or the caregiver. There also was little difference in whether the brain injury was categorized as TBI or ABI. The majority of caregivers (72%) responding to the survey provided direct care. About half (49%) of the caregivers indicated some level of independence of the individual they're providing care to as they could be left alone much of the day or did not need direct supervision.

Table 44. Severity of Brain Injury

Severity	Total		Caregiver		Individual	
	n	%	n	%	n	%
Mild (loss of consciousness: 0-30 minutes)	47	17%	12	12%	25	20%
Moderate (loss of consciousness: 30 minutes-24 hrs)	18	6%	7	7%	11	6%
Severe (loss of consciousness: over 24 hrs)	133	48%	62	60%	71	40%
Unsure	82	29%	22	21%	60	34%
Total	280	100%	103	100%	177	100%

Numerous other health diagnosis or symptoms typically accompany brain injuries, as noted in Table 45. The top three "other diagnoses" in addition to the brain injury diagnosis indicated by the respondents were cognitive disability, behavior or mental health, and communication disabilities. These conditions that accompany TBI have implications on service need, coordination of services, and cost and funding sources.

Table 45. Other Diagnoses or Symptoms (Multiple Responses)

Other diagnoses or symptoms	n	%
Cognitive disability (thinking, memory, learning and reasoning)	199	68%
Behavior or Mental Health (Depression, anxiety, personality or mood changes)	148	51%
Communication disorder (speech, expression, understanding)	122	42%
Sleep/Fatigue conditions	109	37%
Physical disability	110	38%
Sensory Disability (sight, hearing, touch, taste, smell)	80	27%
Dementia (impairment of attention, memory, judgment and language skills)	77	26%
Seizures	63	22%
Muscle spasticity (muscle spasms)	59	20%
Attention Deficit Disorder/Attention Deficit-Hyperactivity Disorder	57	20%
No Long-term health conditions	3	1%
Development disability (autism, Down Syndrome, Cerebral Palsy, etc.)	9	3%
Other health conditions: cognitive issues, headaches and migraines, tremors and shakiness, loss of walking and writing skills, energy loss, incontinence, arthritis, bipolar, thyroid, diabetes, balance issues, feeding issues, seizures, vocal cord damage, loss of internal thermostat, initiative, numbness in legs, loss of memories, post-concussion syndrome, stress and fatigue, communication issues		

Respondents' Life Since Injury

Respondents reported many changes to their lives since the injury, most often indicating that things have worsened since the brain injury. As can be seen in Table 46, physical health, emotional well-being, and income were reported by most as having been adversely affected since the brain injury

Table 46. Changes to Life Since Injury

Changes	n	Is better	No change	Has worsened
Physical health	214	7%	21%	72%
Emotional well-being	216	11%	18%	71%
Income	209	5%	26%	69%
Social relationships	216	10%	25%	65%
Employment	201	3%	31%	66%
Education	202	6%	49%	45%
Living situation	207	12%	44%	44%
Marriage	177	7%	53%	41%
Parenting	161	6%	62%	32%
Other: memory loss, decision-making, better long-term relationships, independence, family well-being, child care, ignorance of others, meaning of life, depression, suicidal thoughts, drug and alcohol use, rejection by society, divorce, intimacy issues, ability to re-learning, communication difficulty, less active lifestyle, personality changes, excessive/inadequate sleep, vocational loss.				

Demographics of Individuals with Brain Injury

Tables 47 to 51 include the demographics of the 293 individuals with brain injury as reflected by survey responses. This includes both individuals completing the survey and the surveys completed by caregivers. Of the approximate 60% that responded to the age question, current age of half of the individuals with a brain injury was between 20-59 and approximately 64% were male. The majority of the respondents were White/non-Hispanic and single or married. All levels of education and income were represented in the sample. There was very little difference in marital status before and after the injury.

Table 47. Age of Individual with Brain Injury

Age Category	n	Birth - 10 years	11 years- 19 years	20 years- 39 years	40 years- 59 years	60 years-79 years	80 years or older
Age now	170	8%	19%	24%	26%	21%	4%
Age at 1st Brain Injury	149	9%	22%	27%	22%	18%	3%
Age at 2nd Brain Injury	22	5%	23%	23%	46%	5%	0%
Age at 3rd Brain Injury	10	0%	10%	30%	50%	0%	10%

Table 48. Ethnicity/Race of Individual with Brain Injury

Race	n	%
White: Hispanic/Latino	43	19%
White: Non-Hispanic/Latino	182	78%
Black/African-American	2	1%
Asian	3	1%
American Indian or Alaska Native	2	1%
Missing	61	

Table 49. Marital Status of Individual with Brain Injury

Marital Status	Before Brain Injury	Current
Single	102	98
Married	71	69
Divorced	12	21
Widowed	4	8
Separated	1	5

Table 50. Highest Grade Level Completed by Individual with Brain Injury

Education Level	n	%
Less than 8th grade	13	4%
Some High School	16	5%
High School Diploma	57	19%
Some College	78	25%
College Graduate	46	15%
Graduate Degree	27	9%
Unknown (Missing)	70	23%

Table 51. Household Income for Individual with Brain Injury

Annual Income	n	%
Less than \$5,000	39	13%
\$5,000 - \$9,999	23	8%
\$10,000 - \$19,999	32	10%
\$20,000 - \$34,999	38	12%
\$35,000 - \$49,999	26	9%
\$50,000 - \$74,999	28	9%
Over \$75,000	29	9%
Unknown	92	30%

Employment

Table 52 presents the employment status for those with brain injuries. The majority, 76%, of the respondents do not currently work. Many are retired or are students. However, 65% of the respondents that worked full-time at the time of their injury no longer work full-time. Student status has also decreased but this may be due to the time between the injury and the survey date. Table 53 indicates that of those that work, only 28% have worked for more than a year. The most often cited reason for not working is inability to perform any job (see Table 54).

Table 52. Employment Status

Employment Status	When Injured (n=297)	Current (n=296)
Unemployed, total disability	7%	24%
Employed Full-Time (35 or more hours per week)	33%	12%
Employed Participant-Time	10%	12%
Unemployed but desire work	3%	10%
Student	16%	9%
Volunteer	4%	9%
Retired	7%	5%
Homemaker	5%	4%
Unsure	1%	2%

Table 53. Length of Employment Since Injury

Time period	n	%
No employment since the injury	110	50%
Less than 1 month	3	1%
1 month - 1 year	47	21%
1-3 years	27	12%
More than 3 years	36	16%

Table 54. Reason for Not Working

Reason	n	%
Inability to perform any job	69	24%
Inability to perform a previous job	50	17%
Inability to find work	31	11%
Retired	28	10%
Interference with benefits	26	9%
Student	25	9%
Choose not to work	8	2%
Permanently disabled	4	1%
Other: symptoms make it difficult to be around people, cognitive and physical limitations, chronic pain, inappropriate relating skills, homelessness, lack of emotional control, need help knowing what work they could do, poor decision-making skills, lack of executive functioning, inability to perform job duties, stigma, no drivers license, permanently disabled, why work and lose all benefits, transportation needed, no help from Voc Rehab.		

Transportation

As can be seen in Table 55, over one-third of the respondents drive themselves and approximately another third rely on family or friends for transportation. Others walk, use the bus/train or bicycle for transportation purposes.

Table 55. Daily Transportation (multiple responses)

Transportation	n	%
Drives themselves	120	41%
Rides with family/friends	88	30%
Individual does not travel on a daily basis	46	16%
Walk	36	12%
Public transportation (bus/train)	22	8%
Bicycle	22	8%
Taxi/cab	7	2%
Assisted living/Madonna Van	3	1%
School bus	2	1%

Housing

The majority of respondents reside in a house or apartment with a spouse or significant other. Approximately half of the respondents report the individual with brain injury lives where the individual or caregiver would prefer, although this is more likely to be true for individuals rather than caregivers; 61% of individuals are living where they would prefer to live, whereas only 34% of caregivers report the individual is living where the caregiver would prefer him/her to live. The supports most frequently noted as necessary in order to live in preferred location were financial assistance, home health aids, and information on resources (see Table 56 through Table 59).

Table 56. Place of Residence

Residence	n	%
House or apartment	197	79%
Assisted living	20	8%
Nursing Home	13	5%
Rehabilitation facility	10	4%
Other	8	3%
Group Home	1	< 1%
College	1	< 1%
Hospital	0	0%
Transitional Facility	0	0%
Total	250	100%

Table 57. Person with Whom Individual Resides

Person	n	%
Spouse/significant other	85	45%
Parents/family	54	28%
Alone	41	22%
Roommate	6	3%
Others	1	1%
Care provider	1	1%
Total	188	100%

Table 58. Type of Housing Preferred

Type of Housing	n	%
House or apartment	169	71%
Assisted Living	27	11%
Home of Care Provider	23	10%
Rehabilitation facility	8	3%
Group setting	5	2%
Nursing Home	4	2%
Other	1	1%
Total	237	100%

Table 59. Supports Needed for Preferred Housing (Multiple Responses)

Supports	n	%
Currently live where chosen	149	51%
Financial assistance	69	24%
Home health aids	33	11%
Information on resources	32	11%
Community living services	25	9%
Home modifications (ramps, etc.)	21	7%
Specialized facilities (for needs)	19	7%
Transitional Services	18	6%
More accessible housing	16	6%
Nursing Care	13	4%
More facilities	12	4%
Other: not enough money to pay rent and medical/prescription needs, need more space for rehab equipment, access to MH providers without having to drive for hours, help with cleaning, need supervision for daily living decisions, support for caregiver, transportation, help with modifications to home.		

Financial Resources of Respondents

Financial resources used for brain injury related expenses are reported in Table 60. The majority of respondents used private insurance or personal funds to pay for brain injury-related expenses. Medicare and Medicaid also were used by approximately a third of the respondents.

Table 60. Resources for Brain Injury-Related Expenses (Multiple Responses)

Resources	n	%
Private insurance	122	42%
Personal funds	106	36%
Medicare	93	32%
Medicaid	87	30%
Personal loans from family/friends	30	10%
Legal settlement	24	8%
Vocational rehabilitation	13	4%
Workers compensation	13	4%
TBI waiver	11	4%
Veteran's administration	8	3%
Social security disability/benefits	9	3%
Special education funds	4	1%
Unemployment	3	1%
Children with special health needs	1	1%
Department of labor	1	1%
Other: Debit forgiveness, private insurance, bankruptcy, college insurance, Tricare, workman's comp, family, hospital foundation grant, TBI fund, job, law suit, crime victims compensation.		

Social Supports

Social and emotional supports were available for most of the respondents (see Table 61). Family and friends provide support most often, with churches listed third. Brain injury support groups were listed by 21%, which may be a reflection of the distribution of the survey through support groups. Open ended responses, indicate that although most individuals with brain injuries had some level of support, many feel that more social support is necessary or desirable. Whereas individuals may be getting some social support, the data reported here is not a measure of the adequacy of the support or resources provided.

Table 61. Social/Emotional Supports Available (Multiple Responses)

Supports	n	%
Family	220	75%
Friends	166	57%
Church, synagogue or other place of worship	97	33%
Brain injury support group	61	21%
Other individual with a brain injury	54	18%
Other organization	13	4%
No support/very little	11	4%
Veteran's organization	7	2%
Counseling/Physician/Psychiatrist	4	1%
Caregivers	2	1%
Vocational Rehab	1	1%
Madonna	1	1%

Experiences with and Needs for Health Care Facilities

Overall, respondents indicate positive experiences with health care facilities and providers. Details of the respondents' experiences and the additional needs they reported are detailed in the sections below.

Release and Appropriate Level of Services

Approximately a third of respondents felt the individual was released from services too early. Caregivers were more likely than individuals to believe the individual/they were released too early. In addition, 26% thought the individual did not receive the appropriate level of services (see tables 62-64). The four factors indicated most often that may have interfered with receiving services at the time of need were

- Lack of understanding
- Financial resources
- Shortage of advocacy or awareness
- Not aware of services

Table 62. Released Early from Health Care Facilities

Released Too Early	Total		Individual		Caregiver	
	n	%	n	%	n	%
Yes	77	29%	39	22%	38	40%
No	147	56%	103	62%	44	46%
Unsure	39	15%	26	16%	13	14%
Total	263		168		95	

Table 63. Received Appropriate Services Based on Severity of Brain Injury

Appropriate Services	Total		Caregiver		Individual	
	n	%	n	%	n	%
Yes	161	61%	49	52%	112	66%
No	69	26%	35	37%	34	20%
Unsure	35	13%	11	11%	24	14%
Total	265	100%	95	100%	170	100%

Table 64. Factors Interfering with Receiving Services (Multiple Responses)

Factors	n	%
Lack of understanding of brain injuries by providers	83	28%
Financial resources	68	23%
Shortage of advocacy or awareness	57	20%
Not aware of services	55	19%
Lack of services for my individual needs	48	16%
No central source for information	45	15%
Inadequate community support	43	15%
Inadequate health insurance	42	14%
Long distance travel for services	40	14%
Eligibility requirements/Denied service	32	11%
Not eligible for Medicaid	28	10%
Lack of transportation	28	10%
Inadequate support from family	28	10%
Inadequate prescription coverage	18	6%
Difficulty with English language	11	4%
Other: had to find things out on own, lack of communication with those responsible for testing, TBI doctor canceled so went too long without help, doctors/insurance co. not believing symptoms, incorrect diagnosis, denial of illness by employer, ER too busy, no support team, facility needs greater than available resources, unawareness physical conditions was due to TBI, HIPPA issues, delay of TBI issues, rehab didn't prepare them for life, distance from care facilities, need for specific insurance for brain injuries, need for longer time in rehab with insurance support, the huge amount of paper work for insurance, cost of care from personal finances not covered by insurance, denial by patient, school system failure, money, transportation, family and patient, inadequate medical care at major rehab hospital, lack of information for families to aid in maximizing recovery, abusive situation		

Listened to by Providers

Table 65 represents how respondents felt their needs were listed to by various health care and support providers. In general, respondents felt their needs were listened to by their hospital and medical professionals, rehabilitation professionals, and service coordinators/case managers. Many respondents reported that their needs were not listened to by employment professionals or housing authorities, indicating a need for increased education/awareness of TBI topics for those who may not have often serve individuals diagnosed with a brain injury.

Table 65. Feel Needs Were Listened to By . . .

Provider	Does Not Apply (n)	Of Those Reporting a Need		
		n	Felt Needs Were Listened To	Did Not Feel Needs Were Listened To
Employment professionals	99	119	43%	57%
Housing authorities	155	67	57%	43%
Mental Health and Counseling professionals	65	154	62%	38%
Medicaid	107	113	64%	36%
Education professionals	88	136	71%	29%
Service Coordinator or Case Manager	59	161	75%	25%
Hospital and Medical professionals	10	220	77%	23%
Rehabilitation professionals (Speech Therapy, Physical Therapy, Assistive Therapy, etc.)	20	215	84%	16%

Health Care Facility Services

There were few unmet needs in relationship to health care facilities and there was satisfaction with a majority of facilities (see Table 66). Nursing homes received the highest dissatisfaction ratings, 25%. Assisted living services were the most frequently needed service with 29% of individuals reporting a current or past need and not receiving the service.

Table 66. Health Care Facility Services - Satisfaction and Need

Facility	Indicating Service was Not Needed (n)	Of Those Reporting a Need			
		n	Received & Satisfied	Received & Dissatisfied	Past or Present Need Not Met
Assisted living	99	62	55%	16%	29%
Non hospital-based residential program	92	51	63%	18%	20%
Rehabilitation (Home-based/Hospital outpatient)	40	164	77%	14%	9%
Nursing home	111	36	56%	25%	19%
Hospital/Acute Care	29	184	87%	7%	6%
Emergency Room	21	195	80%	14%	6%
Rehabilitation (Hospital inpatient)	41	151	80%	13%	7%

Health Care Services: Need and Satisfaction

Respondents were asked to indicate their level of satisfaction with health care services and their need for services. As can be seen in Tables 67 and 68, respondents were generally satisfied with the health care services they received. The greatest number of respondents reported satisfaction with the following services:

- Primary medical care
- Nursing
- Physical therapy

Respondents most often reported they were unsatisfied with:

- Substance use evaluation/treatment
- Pain management
- Occupational therapy

The health services for which respondents most reported their needs were unmet are:

- Counseling
- Early intervention
- Dental

When asked to rate the level of current need for services, the following received the highest ratings:

- Primary medical care
- Physical therapy
- Counseling (individual and family)

Taken together, the need and satisfaction ratings suggest that individuals are currently in need of and are receiving primary medical care and physical therapy to their satisfaction. However, individual and family counseling was identified as both highly needed and is the need most often unmet for most individuals with a brain injury. This suggests that present efforts to provide primary medical care and physical therapy to individuals with a brain injury are satisfactory, however, access to counseling services needs to be increased. Further statistical analyses indicate there was a pattern of relationship between need ratings and severity of injury status such that individuals diagnosed with severe brain injuries were more likely than individuals diagnosed with mild or moderate injuries to indicate a high need for occupational therapy. Analyses for individuals with severe brain injuries only indicate that dental, occupational therapy, physical therapy, and primary medical care were the most highly rated. There was no pattern of relationship between any of the need ratings and TBI/ABI injury status.

Table 67. Satisfaction and Need for Health Care Services

Health Care Services	Service Not Needed (n)	Of Those Reporting a Need			
		n	Received & Satisfied	Received & Dissatisfied	Past or Present Need and Not Met
Counseling	34	156	42%	14%	44%
Early Intervention	82	83	43%	17%	40%
Dental	79	103	53%	8%	39%
Mental health counseling	68	117	40%	17%	21%
Pain Management	81	94	51%	21%	12%
Nutrition/Dietary services	89	80	61%	10%	11%
Vision	61	124	68%	8%	10%
Physical therapy	33	170	72%	15%	9%
Speech/Language therapy	66	122	70%	13%	9%
Occupational Therapy	47	149	69%	18%	7%
Primary Medical Care	41	139	78%	13%	4%
Nursing	102	71	75%	8%	1%
Substance Use Evaluation/Treatment	128	32	41%	22%	0%

Table 68. Individual and Caregiver Importance Rating of Health Services Needed

Health Care Services	n	Low Importance of Need	High Importance of Need
Primary medical care	196	25%	64%
Physical therapy	207	26%	63%
Counseling (individual and family)	204	25%	61%
Mental health counseling	192	32%	52%
Occupational therapy	199	33%	52%
Vision	199	36%	51%
Speech/Language therapy	196	38%	48%
Dental	195	37%	46%
Early intervention	187	40%	42%
Pain management	192	41%	41%
Nutrition/Dietary services	192	44%	37%
Nursing	190	51%	33%
Substance use evaluation/treatment	184	63%	22%

Skill Services, Including Educational and Employment Services

Overall, respondents indicate very mixed experiences with skill service facilities and providers. Details of the respondents' experiences and the unmet needs they reported are detailed below and in Tables 69 and 70. Additional detail on specific educational and employment services is also provided.

Skill Services: Need and Satisfaction

Respondents were asked to indicate their level of satisfaction with skill services and their need for such services. In general, respondents were very divided in their satisfaction with skill services they received. The greatest number of respondents reported satisfaction with the following services:

- Cognitive training
- Educational services

However, respondents most often reported they were unsatisfied with:

- Educational services
- Employment support

The skill services for which respondents most reported their needs were unmet are:

- Employment support
- Community skills training
- Behavioral supports

When asked to rate the level of current need for services, respondents gave the following the highest ratings:

- Cognitive training
- Behavioral supports
- Educational services

The conflicting conclusions, especially for educational and employment services, are likely due to a diverse set of experiences across the respondents and age of the individuals with brain injuries, which include children. For example, about one-third of those who reported that educational services were necessary reported that they had received and were satisfied with their educational services, whereas one-third reported dissatisfaction, and the remaining one-third reported an unmet need.

Taken together, the need and satisfaction ratings suggest that individuals are currently in need of and are receiving cognitive training to their satisfaction. However, behavioral support services were identified as an important yet often unmet need for individuals with a brain injury. Employment support services were also rated as highly important by at least half of the respondents, yet many felt their need went unmet or they were unsatisfied with the service they received. This suggests that present efforts to provide cognitive training to individuals with a brain injury are satisfactory, however, more and improved behavioral support, educational, and employment services are necessary.

Table 69. Satisfaction and Need for Skill Services

Skill Services	Service Not Needed (n)	Of Those Reporting a Need			
		n	Received & Satisfied	Received & Dissatisfied	Past or Present Need and Not Met
Employment support	82	98	23%	18%	58%
Community skills training	78	97	36%	9%	55%
Behavioral supports	50	141	33%	16%	51%
Cognitive training	26	173	48%	15%	37%
Educational services	63	111	39%	30%	32%
Money management	96	76	36%	7%	25%

Table 70. Individual and Caregiver Importance Rating of Skill Services Needed

Skill Services	n	Low Importance of Need	High Importance of Need
Cognitive training	211	20%	70%
Behavioral supports	204	33%	52%
Educational services	193	32%	52%
Employment support	196	38%	50%
Community skills training	190	34%	47%
Money management	189	44%	40%

Educational Services

Satisfaction with and need for educational services are detailed in Table 71. Of those respondents of school age or with other interest in educational services, over half were satisfied with regular and special education services but one-fifth were dissatisfied with these same services. There was some need indicated for an interim-program school, university services, and high school to college transition supports.

Table 71. Satisfaction and Need for Educational Services

Educational Services	Service Not Needed (n)	Of Those Reporting a Need			
		n	Received & Satisfied	Received & Dissatisfied	Past or Present Need Not Met
Interim-Program (Rule 18) school	183	14	21%	14%	65%
University Services (services for students with disabilities)	153	57	30%	19%	51%
High School to College transition supports	167	43	35%	14%	51%
Alternative school program	167	41	44%	17%	39%
Special Education Services	162	52	50%	21%	29%
Regular Education Services (Elementary and High School)	162	49	60%	20%	20%

Employment Services

Of those able/interested in employment, almost two-thirds reported an unmet need for job/career training, job placement, and job counseling. Approximately one-fifth of the respondents reported dissatisfaction with the employment services they received whereas an additional one-fifth reported satisfaction with the same services (see table 72).

Table 72. Satisfaction and Need for Employment Services

Employment Services	Service Not Needed (n)	Of Those Reporting a Need			
		n	Received & Satisfied	Received & Dissatisfied	Past or Present Need Not Met
Job or career training	127	85	18%	21%	61%
Job placement	128	81	15%	20%	65%
Job counseling	213	88	23%	18%	59%

Support Services: Experience and Need

Overall, respondents indicate either satisfaction with or an unmet need for support services. Details of the respondents' experiences and the unmet needs they reported are detailed below (see tables 73 and 74).

Support Services: Need and Satisfaction

Respondents were asked to indicate their level of satisfaction with support services and their need for such services. In general, respondents were split between satisfaction for services received or report an unmet need. The greatest number of respondents reported satisfaction with the following services:

- Personal care/Attendant services
- Transportation
- Recreation

For any support service, one-fifth or less of the respondents reported dissatisfaction with the service. Respondents most often reported they were unsatisfied with:

- Sources of funding
- Case management/Service coordination
- Legal services

The health services for which respondents most reported their needs were unmet are:

- Advocacy
- Chore services*
- Housing with supports

It is important to note that although a majority of those indicating that chore services were necessary felt their need was unmet, only approximately one-third of the respondents indicated that chore services were necessary, and less than one-fourth of the respondents rated it as a need of high importance.

When asked to rate the level of current need for services, the following received the highest ratings:

- Sources of funding
- Information/resources
- Case management/Service coordination

Taken together, the need and satisfaction ratings suggest that individuals are currently in need of and are receiving sources of funding; despite being the support service respondents were most dissatisfied with, a majority of the respondents to this question indicated they were satisfied with the sources of funding they have received. However, information/resources and case management/service coordination services were identified as needs of high importance, yet one-third or more participants reported their need for these services was unmet. This suggests that present efforts to provide funding sources to individuals with a brain injury are satisfactory, but that there needs to be increased access to information/resources and case management/ service coordination services.

Further statistical analyses indicate there was a pattern of relationship between need ratings and severity of injury status such that individuals diagnosed with severe brain injuries were more likely than individuals diagnosed with mild or moderate injuries to indicate a high need for the following services: assistive technology, housing with supports, personal care/attendant services, recreation, respite care, sources of funding, and transportation. Analyses for individuals with severe brain injuries only indicate that housing with supports, recreation, and sources of funding were the most highly rated needs. There was no pattern of relationship between any of the need ratings and TBI/ABI injury status.

Table 73. Satisfaction and Need for Support Services

Support Services	Service Not Needed (n)	Of Those Reporting a Need			
		n	Received & Satisfied	Received & Dissatisfied	Past or Present Need and Not Met
Advocacy	55	120	38%	11%	52%
Chore Services	105	52	42%	8%	50%
Housing with supports	107	64	42%	9%	48%
Information/resources	45	128	41%	16%	44%
Assistive Technology	72	96	43%	17%	41%
Case Management/Service Coordination	43	135	47%	17%	36%
In-home help	109	59	32%	12%	25%
Respite Care	120	44	36%	7%	23%
Parenting or Child Care	140	25	36%	12%	20%
Recreation	82	91	52%	11%	20%
Personal care/Attendant Services	108	63	56%	6%	19%

Legal services	85	89	30%	17%	18%
Transportation	86	90	54%	8%	18%
Sources of funding	51	133	52%	20%	11%

Table 74. Individual and Caregiver Importance Rating of Support Services Needed

Services	n	Low Importance of Need	High Importance of Need
Sources of funding	201	25%	65%
Information/resources	192	28%	56%
Case management/Service coordination	194	30%	48%
Advocacy	194	34%	47%
Recreation	186	40%	44%
Legal services	192	40%	43%
Transportation	191	46%	41%
Assistive technology	191	48%	38%
Housing with supports	191	48%	38%
In-home help	192	51%	36%
Personal care/Attendant services	191	52%	31%
Respite care	179	54%	29%
Chore services	183	60%	24%
Parenting or child care	184	63%	23%

Support for Caregivers

Caregivers also reported on their experience with the support they have received. For all services, well over half of the respondents reported unmet needs. This clearly indicates that more support services for the caregivers of individuals with a brain injury are necessary (see table 75).

Table 75. Caregiver Satisfaction with Services

Services	Service Not Needed (n)	Of Those Reporting a Need			
		n	Received & Satisfied	Received & Dissatisfied	Past or Present Need Not Met
Family counseling	17	52	15%	15%	69%
Support group for caregivers	23	45	24%	7%	69%
Relief from care (respite care)	43	20	30%	5%	65%
Training for how to care	32	29	34%	3%	62%
Information on available resources	14	54	24%	15%	61%
Home health aid/ personal care assistant	50	17	41%	0%	59%

Suggestions for Improvement to Services and Supports

Open-ended comments and suggestions were grouped according to the following content themes:

1. Awareness/Information
2. Education/Training
3. Financial/Funding
4. Support
5. Staff/Care/Services/Activities
6. Staff/Care/Services/Activities
7. Other

A complete list of comments and quotations is located in Appendix H. The number of responses related to the improvement concept is listed next to the suggested item. The most often listed suggestions:

- **Awareness:** Community awareness and education/immediate dissemination of information by all providers **(28)**
- **Education/Training:** Better education/training for medical staff and professionals **(18)**
- **Awareness:** Family receiving education and awareness of TBI information **(8)**
- **Facilities:** ABI Community Center **(8)**
- **Services:** Resource facilitation/case management **(8)**

Service Provider and State Agency Survey Results

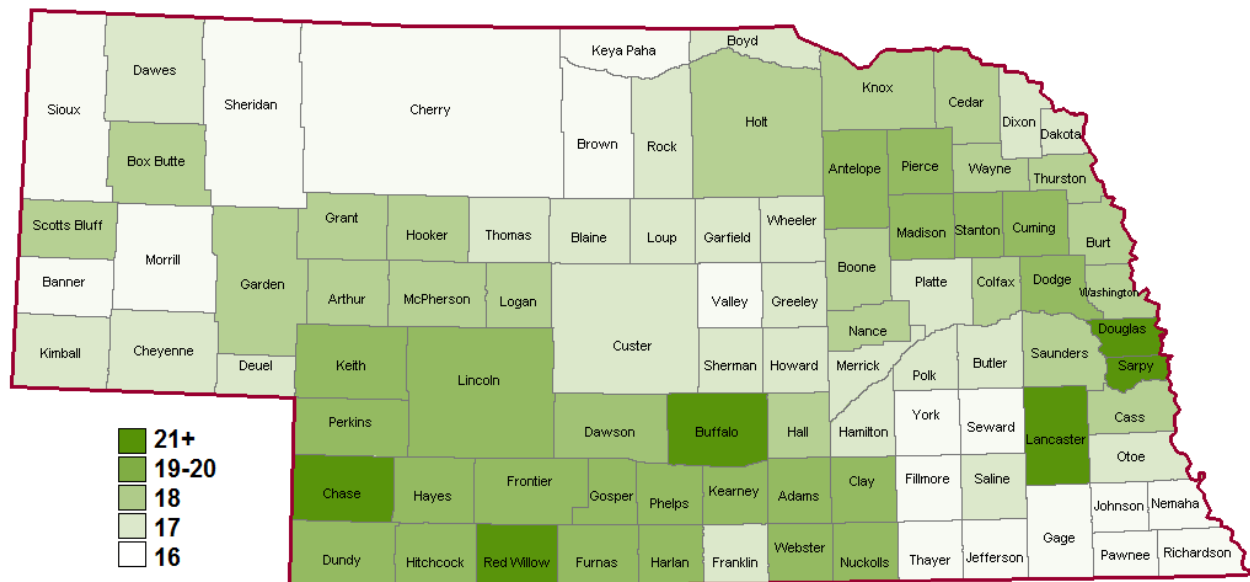
Fifty-nine (N=59) providers across the state responded to the TBI Provider Survey. It is unknown how many providers had access to the survey as the online survey link was e-mailed out by various personnel from various organizations. Therefore, response rates are not available.

Out of the state agencies that would have been appropriate to complete the survey, five agencies completed the survey. As many of the same questions were asked in both the agency and service provider surveys, the results, when appropriate, are reported in the same tables. Due to the small number of agency respondents, the responses are listed by number only and not as a percent.

Of the service providers and agencies that responded to the survey, all but one of the agencies served all Nebraska counties and 16 or 27% of the providers served all counties. The list of respondents is located in Appendix G.

Figure 19 depicts the number of providers who cover each county for the providers that responded to the survey. The lowest coverage is 16 providers as 16 providers indicated providing services to all counties in Nebraska. The southern and eastern parts of Nebraska had the highest number of providers providing services.

Figure 19. Service Coverage by Providers Surveyed



The majority listed their "type" as non-profit. Schools, for-profit organizations, and government were also represented by survey respondents. The primary services by survey respondents listed "other" as often as the checklist provided. However, the list does indicate that most primary services to individuals with brain injuries are represented. Education and community-based services were at the top of the list but all services were presented by at least three organizations. See Tables 76 and 77.

Table 76. Service Provider Survey Respondent Categories

Provider Type	n	%
Non-Profit	37	69%
Schools/Academic	8	15%
For Profit	7	13%
Government	2	4%
Missing (5)		

Table 77. Service Providers' Primary Service

Service	n	%
Educational Programs	23	39%
Community-based (not in home)	15	25%
Acute	9	15%
Community-based (in-home)	8	14%
Outpatient Therapies	7	12%
Post Acute (Residential)	4	7%
Assisted Living	3	5%
Post Acute (Non-Residential)	3	5%
Other: Acute Rehabilitation Unit, Rehabilitation Day Program, Long-Term Care Acute Hospital, Skilled Care, Outpatient Services, Residential for Ventilator-Dependent Patients, Advocacy, Community-Based Employment and Residential Services, Extended Family Houses, Transitional Employment, Domestic Violence Intervention, Sexual Assault Intervention, Stalking Crisis Intervention, Emergency Rent and Utility Assistance, Head Start, Immunizations, Commodity Supplemental Food Program, Recreation, Alternative Financing, Neuropsychological Evaluation, Non-treatment Shelter Setting, Assistive Technology, Vocational, Group Home, among others.	18	31%

Medical, Employment, Education, and Prevention Services

Tables 78 to 81 report the medical, education, employment, and prevention programs and services offered by service providers. The assumption is that services are available to all patients or clients, regardless of their medical history. The services most often provided are:

- Acute Medical: Family Education, Information and Training and Referrals
- Employment: Job Coaching
- Educational: Early Intervention/Preschool and Special Education

Most often, brain injury education and training is offered to the organization's own staff or individuals with brain injuries (see Table 82). Primary and secondary prevention services for TBI were offered by providers by over two-thirds of the respondents. Educational services were mostly provided within the school system. Health related education is also provided.

Table 78. Acute Medical Services and Programs (n=42)

Medical	Providers		Agencies (n)	
	n	%	Fund	Provide
None	24	57%	2	2
Family Education, Information and Training	11	26%	0	0
Referral to Subspecialties	8	19%	1	1
Family Mentoring	7	17%	0	0
Discharge Planning/Service Coordination	5	12%	0	1
Acute Medical Care	4	10%	1	1
Emergency Medical Care	4	10%	1	1
Screening, Identification and Provision of Discharge Protocols	4	10%	1	0

at All Levels of Brain Injury (Mild, Moderate, Severe)				
Substance Abuse Screening	3	7%	1	1
Pre-Hospital Transport and Treatment	2	5%		1
Trauma Systems	2	5%	1	0
Other: Decision-making, Minority health, Immunizations, Nutrition, Every Woman Matters, Visual	4	10%	0	0

Table 79. Employment Services (n=39)

Employment	Providers		Agencies	
	n	%	Fund	Provide
None	14	36%	2	2
Job Coaching	12	31%	1	0
Career Counseling/Guidance	8	21%	0	1
Pre-Vocational Services	8	21%	0	1
Job Placement	7	18%	1	1
Assistive Technology	6	15%	2	1
Job Development	6	15%	1	1
Vocational Evaluation	6	15%	0	1
Job Accommodations	5	13%	1	2
Advocacy (Self-Family)	4	10%	0	1
Special Skills Training (Computer, Data Processing)	4	10%	1	2
Work Adjustment	3	8%	1	1
Supported Employment	0	0%	1	
Work Support	0	0%	1	1
Other: benefits analysis, transportation to work, vocational assessments; defined within the field of developmental disabilities	4	10%	0	0

Goodwill Industries of Greater Nebraska ABI Employment Program

There are vocational rehabilitation programs in Nebraska that have been successful in providing vocational services to individuals with an ABI and serving as a resource for referrals for additionally needed services. One such service is the Goodwill Industries of Greater Nebraska ABI Employment Program (ABI EP) which is:

A partnership between Vocational Rehabilitation and Goodwill Industries of Greater Nebraska to provide supported employment services leading to supported, competitive employment for individuals with Acquired Brain Injury (ABI).

Data from the Goodwill Industries of Greater Nebraska's ABI Employment Program provide evidence of success for programming that serves individuals with a TBI. Specifically, individuals who were aware of and able to access the ABI EP in Kearney, Grand Island, or Hastings report predominantly positive outcomes.

For example, 97% of those enrolled in the ABI EP are employed post-injury, compared to the 24% of those who responded to the state-wide survey (see Table 52). Employment also had a positive effect on the ABI EP participant's ability to find additional supports such as job coaching (100% had job coaching after employment), and community or day support services (also 100%). 71% of ABI EP participants were able to retain their employment, with an additional 14% becoming employed elsewhere after leaving one employer.

Additionally, there may be a slight snowball effect of services, such that those who are receiving vocational rehab may also be aware of and successfully attain other services; many of the unmet needs identified by those in the individual/caregiver surveys (see Tables 67, 69 and 73) are being met for those who have participated in the ABI EP. For example, only 14% of those in the ABI EP report an unmet need for mental health services, compared to the 21% of individuals surveyed state-wide. Similarly, where as 48% of those in the state-wide survey reported housing as a unmet need, only 10% of those in the ABI EP report this as a need.

Please refer to Appendix I for a complete presentation of the Goodwill ABI program data.

Table 80. Educational Services and Programs (n=39)

Educational	Providers		Agencies	
	n	%	Fund	Provide
Early Intervention/Preschool	12	31%	1	2
Special Education	12	31%	1	2
None	10	26%	1	1
Education (Kindergarten -12th Grade)	9	23%	1	3
Health Related Services (i.e., OT, PT, Speech, etc.)	9	23%	1	1
Alternative School	8	21%	1	0
Transitional Services	8	21%	1	0
Higher Education	4	10%	2	2
Interim-Program (Rule 18) School	4	10%	1	2
Charter/Private School	1	3%	0	0
Advocacy (Family/Child)	0	0%	0	0
Other: skills needed to work; Head Start; visual rehab; tutoring; evaluative; vocational and basic living skills; set-up plan for re-entry to school	9	23%	0	0

Table 81. Brain Injury Prevention Services (n=40)

Prevention	Providers	
	n	%
None	18	45%
Primary Prevention of Intentional Injuries (Shaken Baby Syndrome, Violence)	13	33%
Primary Prevention of Unintentional Injuries (Falls, Occupant Protection)	12	30%
Secondary Prevention (of Disabling Conditions)	7	18%
Other	2	5%

Table 82. Brain Injury Education and Training to Whom (n=44)

Receives Training	Providers		Agencies (n)	
	n	%	Fund	Provide
Own Staff	18	41%	1	0
Individuals with a Brain Injury	15	34%	1	0
Educators/Teachers	14	32%	2	1
Families/Significant Others	14	32%	0	0
None	10	23%	2	2
Health Professionals/Rehabilitation Providers	8	18%	1	0
Law Enforcement/Criminal Justice	4	9%	1	0
Brain Injury Statewide Advisory Board/Council	3	7%	1	0

Other: Educational presentations, Program Coordinator/ Voc Manager certified in Brain injuries; Training available to anyone; Training and education is funded for all of these through the federal TBI Implementation Partnership Grant, which VR administers	3	7%	1	0
--	---	----	---	---

Immediate and Transitional Programs and Services

All immediate and transitional services and programs listed are being offered at some level and in some geographic locations (see Tables 83 and 84). Whereas a specific program or service may be offered, financial or geographic access to services may be different. However, due to the fact that not all providers responded to the survey, the exact gaps in services are unknown. If the 16 providers that indicated they provide services for the entire state are separately reviewed, at least one provider indicated they provided services statewide from those services except for emergency care. Logically, this would not be possible for anyone provider but emergency room hospitals are located throughout the state. At least one agency funds all services listed except for neurobehavioral services.

Table 83. Immediate and Transitional Programs/Services (multiple responses; n=39)

Immediate and Transitional	Providers (N=59)								
	Under 18	Over 18	In-Patient	Out Patient	Day Treatment	Community Re-Entry	Residential	Skilled Nursing	Other
Acute Medical Care	4	4	4	4	0	0	0	3	1
Acute Rehabilitation	2	3	3	0	2	2	1	1	1
Assistive Technology	9	7	3	4	2	3	1	1	2
Case Management	6	5	2	1	3	4	2	1	3
Cognitive Therapy	3	2	2	2	2	2	1	1	1
Community Agency/Referral	9	6	3	2	4	6	3	2	2
Crisis Care	4	3	1	0	1	2	1	1	3
Dietary/Nutrition	8	6	4	2	3	4	2	1	1
Discharge Planning	4	4	4	3	2	2	1	2	1
Education/Special Education	12	6	2	3	2	3	3	1	2
Emergency Medical Care	2	2	1	1	0	0	0	2	1
Family Education Training or Counseling	7	6	3	2	2	3	1	2	3
Hearing	4	2	2	0	1	1	1	1	1
Housing Support	3	3	2	1	2	4	1	1	2
Independent Living Skills	4	6	2	3	3	7	4	1	2
In-Home Care	4	4	1	1	1	3	4	1	1
Mental Health	7	4	4	4	2	2	1	1	1
Neurobehavioral Treatment	1	1	1	2	1	1	1	1	1
Neuropsychology	4	4	4	4	2	2	1	1	1
None	3	2	2	2	2	2	2	2	2
Nursing	5	4	4	2	1	1	1	2	1
Orthodontics Prosthetics	1	1	1	1	1	1	1	1	1
Physical Therapy	6	6	5	4	2	2	1	1	1
Post Acute Rehabilitation	2	2	2	4	2	2	1	1	1

Prevention Programs	3	2	2	2	2	2	1	1	1
Psychiatry	2	2	3	1	1	1	1	1	1
Psychology	5	5	3	3	2	2	1	1	1
Screenings	7	3	2	3	2	2	1	1	2
Self Advocacy Training	6	6	2	1	2	3	1	1	3
Immediate and Transitional	Under 18	Over 18	In-Patient	Out Patient	Day Treatment	Community Re-Entry	Residential	Skilled Nursing	Other
Social Work	4	4	4	3	2	3	1	1	1
Speech/Language Therapy	12	7	4	3	3	2	1	1	3
Substance Abuse Evaluation & Treatment	3	2	2	2	1	1	1	1	1
Swallowing	6	5	4	3	2	2	1	1	1
Therapeutic Recreation	2	2	2	1	2	2	1	1	1
Transportation	7	6	3	3	4	5	4	2	1
Trauma Systems	2	1	1	0	0	0	0	0	1
Vestibular Services	4	3	3	3	2	2	1	1	1
Vision	6	3	3	1	2	2	1	1	1
Vocational/Career	3	5	1	1	2	3	2	1	3
Wellness Activities/Promotion	6	5	3	4	3	3	2	1	2

Table 84. Agencies Immediate/Transitional Programs/Services Funded (Multiple Responses)

	Fund		Fund
Assistive Technology	4	Crisis Care	1
Hearing	3	Dietary/Nutrition	1
Physical Therapy	3	Discharge Planning	1
Psychology	3	Emergency Medical Care	1
Vision	3	Family Education Training or Counseling	1
Case Management	2	Family Education Training or Counseling	1
Community Agency/Referral	2	Housing Support	1
Education/Special Education	2	In-Home Care	1
Independent Living Skills	2	Neurobehavioral Treatment	1
Mental Health	2	Nursing	1
Orthodontics Prosthetics	2	Post Acute Rehabilitation	1
Psychiatry	2	Prevention Programs	1
Screenings	2	Self Advocacy Training	1
Speech/Language Therapy	2	Social Work	1
Substance Abuse Evaluation & Treatment	2	Swallowing	1
Transportation	2	Therapeutic Recreation	1
Vocational/Career	2	Trauma Systems	1
Acute Medical Care	1	Vestibular Services	1
Acute Rehabilitation	1	Wellness Activities/Promotion	1
Cognitive Therapy	1	Neurobehavioral	0

Long-term Community-based Services

Whereas some services such as independent living services and transportation, are provided by a limited number of providers on a long-term basis, other services such as medical equipment/supplies, housing, substance abuse treatment and transitional living services are provided only on a minimal basis (see Table 85).

Table 85. Long-term Community Based Services Provided (n=38)

Service	Providers		Agencies	
	n	%	Fund	Provide
None	11	29%	2	2
Independent Living Services	9	24%	1	1
Transportation	8	21%	0	0
Advocacy (Self and Community)	8	21%	0	0
Family Support, Education and Training	8	21%	0	0
Assistive Technology,	8	21%	0	0
Information/Resources	8	21%	1	2
Recreation/Social Programs	8	21%	0	0
Housing (Supervised/Supported)	5	13%	0	0
Peer Support	6	16%	0	0
Case Management/Service Coordination	4	11%	1	1
Nursing Care	4	11%	1	1
Supervision	4	11%	0	0
Home Care/Home Support	3	8%	0	0
Respite Care	4	11%	1	1
Skilled Nursing Care	3	8%	1	1
Day Program	3	8%	0	0
Chores	2	5%	0	0
Housing (Modification)	2	5%	1	1
Legal Services	2	5%	0	0
Mental Health Services	2	5%	1	1
Personal Assistance/Attendant Services	2	5%	0	0
Durable Medical Equipment/Supplies	1	3%	1	2
Housing (Accessible/Affordable)	1	3%	1	1
Substance Abuse Treatment	1	3%	1	1
Transitional Living Services	1	3%	0	0
Primary Care Medical Services		3%	1	1
Assistive Technology	8	21%	1	1
Chronic Neurobehavioral Treatment, Clubhouse, Coma Care,	0	0%	0	0
Other: Assessment and estimates for Assistive Technology, Day vocational services program for 21 & over, Employment, Transportation is limited and expensive, work solutions and loan programs for assistive technology devices.	6	16%		

Number Served

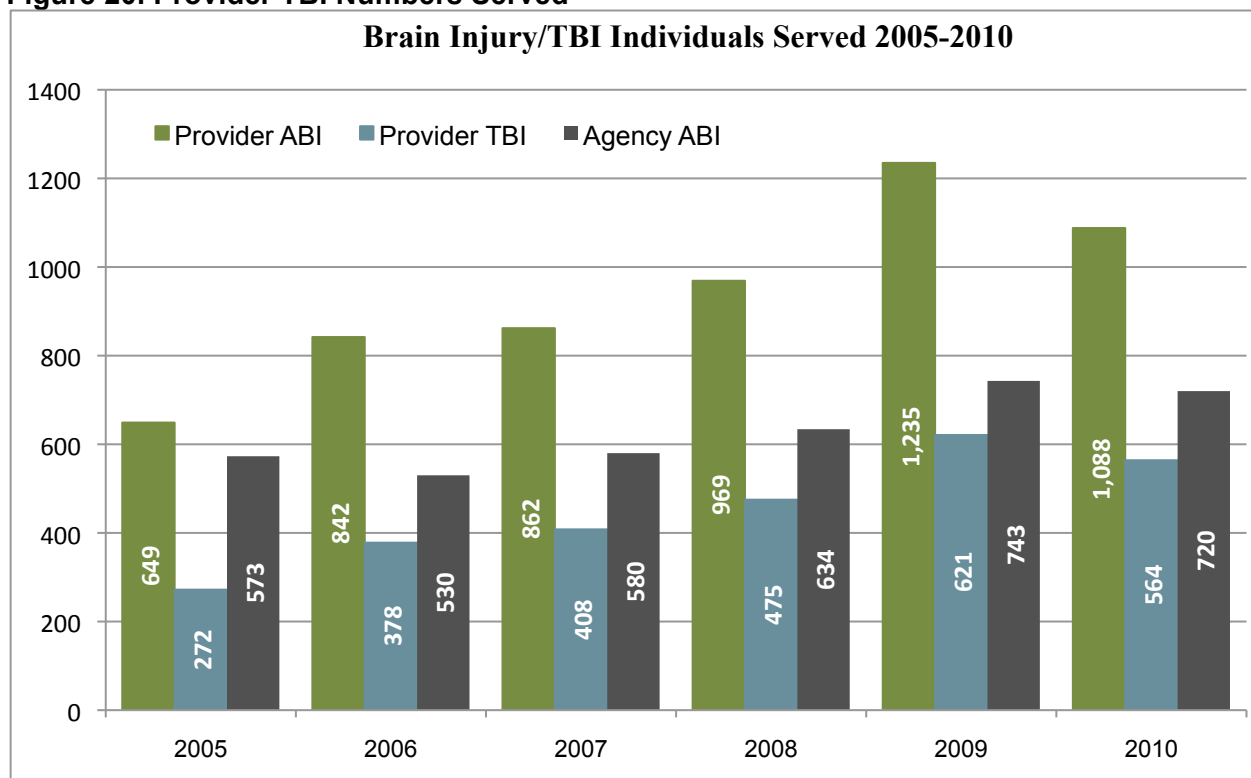
The number served individuals served was completed by 23 of the 59 providers. Overall, there was a general pattern of more individuals with brain injuries and those with TBI being served by providers with approximately half of TBI's of all brain injured individuals. The number of individuals with TBI served remained relatively stable over the 6-year period with a slight

increase in brain injury individuals served by providers. Agency numbers for ABI and TBI were so small they were combined and reported as ABI only. (See Table 86 and Figure 20)

Table 86. Individuals Served (n=23 providers and 5 agencies)

	Providers			Agencies	
	Total	ABI	TBI	Total	ABI
2005	66,385	649	272	53,271	573
2006	64,921	842	378	52,878	530
2007	65,956	862	408	55,269	580
2008	65,104	969	475	55,266	634
2009	71,401	1,235	621	56,073	743
2010	93,697	1,088	564	56,569	720

Figure 20. Provider TBI Numbers Served



Financial Resources

The majority (65%) of the providers responding to the survey do not provide any financial resources to individuals with brain injury (see Table 87). However, a few providers and agencies do provide limited resources for food, housing, medical costs and miscellaneous other expenses.

Table 87. Financial Resources Provided (multiple responses; n=34)

Financial Resources	Providers		Agencies
	n	%	n
None	22	65%	3
Transportation	4	12%	1
Assistive Technology	4	12%	2
Other (funding coordination, in-home repairs, limited resources for all, medical costs)	4	12%	2
Food	3	9%	1
Housing (Mortgage, Rent, Utilities, Etc.)	3	9%	1
Medical Costs	3	9%	0
Attendant Services	1	3%	0
Home Care/Home Support	1	3%	0
Medical Equipment/Supplies	1	3%	0
Personal Attendant Services	1	3%	0
Respite Care	0	0%	0

Referrals and Coordination

Providers and agencies receive referrals for their services from multiple sources. The top three referral sources to providers are family/caregiver, primary care or other physicians, and from state agencies. See Table 88 for a complete list and response rates. Although over half of the respondents did not indicate the time between the injury and the referral, those that did respond indicated the referral happened in the first 30 days or within the first 6 months (see Table 89).

Table 88. Referral Sources for Individuals with Brain Injury (multiple responses; n=45)

Referral Sources	Providers		Agencies
	n	%	n
Family/Caregiver	21	47%	4
Primary Care or Other Physicians	19	42%	4
From Other State Agencies, (Not VR)	17	38%	4
From Rehabilitation Facility	15	33%	4
Self Referral	14	31%	4
Counselor/Mental Health	12	27%	3
From the State's Office of Vocational Rehabilitation	10	22%	2
From Acute Care Hospital	9	20%	2
Referral from BIA or Other Non-Profit Organization	7	16%	4
From Judicial System	5	11%	1
From Protection & Advocacy	5	11%	4
No System Identified	3	7%	1
Resource Line	2	4%	4

Voluntary Registry	1	2%	0
Reporting Regulation/Mandated Registry	0	0%	1
Other: DHHS Developmental Disabilities, Early Development Network, Educational Performance, Family, Local School Districts	6	13%	2

Table 89. Time after Brain Injury Typically Referred (n=23)

Timeframe	n	%
Within 30 days	6	26%
1-6 Months	7	31%
7-12 Months	3	13%
1-3 Years	3	13%
4-6 Years	3	13%
6 Years or more	1	4%

Coordination

When asked about inter-agency agreements with other individuals or agencies, providers listed the following agreements:

- Contract with VR/Goodwill to provide diagnosis of TBI for eligibility to receive VR services.
- DHHS
- Nebraska Dept of Health and Human Services Certain Nebraska and Iowa AAA's Fremont County (Iowa) Case Management League of Human Dignity Iowa Department of Human Services Iowa Medicaid Enterprises
- Nebraska Voc Rehab services - (3)
- The "to be" Acquired Brain Injury Community Center of NE is engaging with other organizations that serve individuals with ABI's so that there is more support and communication amongst professionals about the needs of individuals with ABI's and their caregivers/families. The BIA-NE is the ABI Community Center of Nebraska's fiscal agent!!:) The Nebraska Stroke Association is also a great partner in getting this center set up.
- Transportation to Good Will and employment opportunities.

Staff Designation

Many providers and agencies do not have designated staff specific to brain injury patients but of those that do, dedicated staff tasks focus on assistive technology, education, and case management/care coordination for brain injury patients/clients. About one-fourth dedicate their time to brain injury less than half of their time and the rest more than half of their time. (See Tables 90 and 91).

Table 90. Tasks for Designated Staff for Brain Injury (multiple responses; n=43)

Designated Staff Tasks	Providers		Agencies
	n	%	n
Assistive Technology	16	38%	1
Education	14	33%	2
None	13	31%	2
Case Management/Care Coordination	12	29%	0
Employment	9	21%	1
Family Support	9	21%	0
Mental Health Counseling (Individual and Family)	8	19%	0
Alcohol/Drug Addiction	6	14%	0
Transportation	6	14%	0
Housing	2	5%	1
Other: Cognitive rehab, PT, OT, Speech therapy, Neuropsychological evaluations, Resource/referral information, In-home assistance, Medical coordination			1

Table 91. Staff - Total and Dedicated to Brain Injury

Staff Time	Total	Average
Total Staff - Provider and Agency	8,505	243
1% - 49% of time serving individuals with brain injuries	439	23
50% - 100% of time serving individuals with brain injuries	531	59

Gaps and Barriers

Providers and agencies were asked to indicate the top 3 gaps in services from their perspective (see Table 92). Most agencies identified long-term services as the biggest gap, which differed some from the providers top list. The three most prevalent gaps in services identified by providers were

- Lack of Specialized Services (i.e. Neurobehavioral Services)
- Limited Range of Funds for Service Needs
- Lack of Brain Injury Training Among Professionals

Similarly, providers and agencies selected the top 5 barriers to for individuals with brain injury to access or use services based on their experiences (see Table 93). Again, the agencies' top 5 did vary some from the providers list, however both listed financial resources and lack of understanding of brain injury as top barriers. As one provider commented, " I have found that a lack of awareness of an individual's deficit often leads to many struggles down the road, especially for those that are living independently and have no firm direction on what they are/are not able to do; and how their family perceives the incorrectly as well as the community." Table 93 lists the barriers in rank order from providers, with the top 5 also listed below:

- Financial Resources
- Lack of Understanding of Brain Injury
- Inadequate Knowledge of Available Services
- Lack of Individualization of Brain Injury Services
- Eligibility Requirements

Table 92. Gaps in Services to Individuals with brain injuries (selected top 3)

Gaps	Providers		Agencies
	n	%	n
Lack of Specialized Services (i.e. Neurobehavioral Services)	21	36%	2
Limited Range of Funds for Service Needs	21	36%	3
Lack of Brain Injury Training Among Professionals	19	32%	2
Long-term Services/Support	18	31%	4
Need For Evaluation and Assessment of Brain Injuries	12	20%	0
Limited Case Management	5	9%	1
Limited Program Eligibility	4	7%	0
Other	3	5%	0

Table 93. Barriers to Access/Use of Services (selected top 5)

Barriers	Providers		Agencies
	n	%	n
Financial Resources	20	34%	3
Lack of Understanding of Brain Injury	17	29%	3
Inadequate Knowledge of Available Services	16	27%	2
Lack of Individualization of Brain Injury Services	14	24%	1
Eligibility Requirements	13	22%	0
Inadequate Community Support	12	20%	3
Lack of Neurobehavioral Services	11	19%	2
Lack of Acceptance of Having a Brain Injury	9	15%	2
Inadequate Health Insurance	8	14%	1
Lack of Transportation	8	14%	0
Long Distance Travel for Services	8	14%	3
Shortage of Strong Advocacy	8	14%	0
Lack of Provider Access to Programs/Agencies	7	12%	1
Lack of Choice and/or Length of Services	6	10%	2
Inadequate Support from Family	5	9%	0
No Central Source for Brain Injury Information	5	9%	2
Poor Communication/Referral System	5	9%	0
Difficulty with English Language	2	3%	0
Other: e.g., inadequate use of available community support, lack of well organized long-term system of support	6	10%	0

Service Expansions and Underserved Populations

Table 94 shows the majority of providers and agencies indicate a lack of services for specific populations that are underserved and see a need for an expansion of brain injury services. However, a similar number indicated they were "unsure" of any underserved populations nor the need for additional services.

Table 94. Underserved Populations and Service Expansion Needs

Opinions	Providers			Agencies		
	Yes	No	Unsure	Yes	No	Unsure
There are specific populations that are not receiving services / are underserved	20	0	20	4	1	0
There are brain injury services that need to be expanded or added	20	1	15	4	0	1

Specific comments regarding underserved populations were reviewed. Specifically, individuals not receiving services includes those that may live far from services, those that are homeless, in the criminal justice system, developmentally disabled, or receiving behavioral health services (i.e., mental health or substance abuse) that are undiagnosed. "So many people are walking wounded and have not been diagnosed with an ABI from a fall/car wreck/abused homes; even those individuals that have been diagnosed are still underserved because many of these individuals will have ABI related problems down the road."

There is a population of young adults who need cognitive or physical support. Others that may not be receiving services include the previous employed that are in need of post rehab support, and individuals needing neurobehavioral services or with challenging behaviors that are undiagnosed. "Mild TBI individuals typically are from medical standpoint fully recovered, but from neuropsychological standpoint they have significant dysfunctions that prevent them from living in the community and/or sustaining gainful employment."

Comments: Services Needing Expansion

Comments regarding the need for expansion of services was fairly lengthy. The list of services needing expansion from the providers and agencies includes the following:

- Community-based services (3)
- Development of community-based neurobehavioral long term services, such as brain injury club house approach (3)
- Awareness and education (2)
- Community based life skills service provided by well trained professionals - lack of funding and understanding of what is needed for long term community support
- Screening and coordination of services among multiple agencies and providers
- Community support
- Case management
- Long-term care
- Training and access to training for agencies to provide an expanded array of services (2)
- Consistent and universal screening in ER's with appropriate education and follow-up. Better training of PCP's so they know how to screen appropriately.
- Resource or additional services for a person with a developmental disability/mental health and TBI.

- Job services
- Madonna-type services in other parts of the state
- Placement of individuals always poses a problem when families are unable to care for them at home.
- Private agencies should have access to all state agency programs and be permitted to compete in providing BI services/programs
- Shaken Baby identification
- TBI Trust Fund to fill the gaps and provide community based services 2) Expand the existing TBI Waiver beyond Assisted Living 3) Train service providers on a routine basis to keep them updated and increase their capacity to serve individuals with brain injury
- Increasing independence, functional living, and advocacy skills of ABI survivors; fostering the development and maintenance of peer, family and community relationships; assisting in the development and pursuit of realistic educational and vocational goals with professionals that understand ABI; providing one on one and group based tutoring services for academic challenges; facilitating access to professional and community based resources; educating families and professionals about issues relating to ABI; resource center for dispersal of information about medical, rehabilitation, psychological, housing, transportation, vocational rehabilitation, educational, financial, legal; support of survivors and their families through transitions in the recovery process; providing job coaching and simulated work experiences for survivors.
- Where do I begin? Nebraska is the only state without a trust fund, resource facilitation or other state-funded resource for individuals with brain injury. Nebraska offers top-notch acute care and rehabilitation, however only a small percentage of brain-injured individuals actually receive these services. Nebraska needs expanded resources (outside of Medicaid Waivers and Medicaid) for community re-entry following brain injury and needs long-term case management for individuals returning to their community and attempting independent living and employment, such as cognitive rehabilitation or therapy. Long-term state funding would also allow the development of supported employment providers who can address on and off-site barriers to successful employment. Trust funds and resource facilitation are models that have shown success in other states.

Services for Individuals with Challenging Behaviors

Tables 95 to 98 detail the services providers offer for individuals with challenging behaviors. It is well known that there is a lack of appropriate long-term facilities available for individuals that have suffered brain injury that have challenging behaviors in the state. When asked if they provide services to individuals with challenging behaviors, the majority of providers responded that they do serve these individuals, although close to half indicated they have had to remove individuals due to behavior issues. For those responding they have removed individuals, individuals were typically placed at home, in a skilled nursing facility or in a hospital. Providers also report having difficulty placing individuals with challenging behaviors. As stated by one provider, "We work with individuals with challenging behaviors during acute rehab but not on a long-term placement - great difficulties with appropriate discharge placements who do not recover past the agitated and chronic neurobehavioral difficulties stage."

Four providers indicated they have a specific neurobehavioral program but it is uncertain if this program is at the level needed for some individuals.

Table 95. Service Provider Services for Challenging Behaviors

	Yes		No		Unsure or n/a	
	n	%	n	%	n	%
Serve Individuals with Challenging Behaviors	28	76%	4	11%	5	14%
Difficulty to Place Due to Challenging Behavior	14	42%	9	27%	10	33%
Removed Due to Challenging Behaviors	11	46%	13	54%	0	0%

Table 96. If Removed, Where Individuals Placements

	Yes
Home (With Supervision) Placement	6
Skilled Nursing Facility Placement	4
Hospital (Psychiatric Unit) Placement	4
Neurobehavioral Unit/Facility Placement	3
Home (Independent) Placement	2
Hospital (Other Unit) Placement	0
Other Placement: Removal due to physical aggression, mental health professionals with expertise in TBI, accept referrals from individuals with serve individuals with combination of mental health needs and a development disability	

Table 97. Formalized Neurobehavioral Program

	n
Yes*	4
No	22
N/A	12
Missing (21)	

*Quality Living, Sheridan Lutheran, Boys and Girls Home of NE, Quest Connections

Table 98. If yes, what types?

	Yes
Inpatient Locked Neurobehavioral Program	1
Inpatient Unlocked Neurobehavioral Program	1
Residential Neurobehavioral Program	3
Outpatient, Not Residential Neurobehavioral Program	3

Traumatic Brain Injury Focus Group Results

Survivor and Caregiver Focus Groups

Two focus groups were conducted with traumatic brain injury survivors, their family members, and caregivers to get a broad view of the needs, gaps, and barriers in brain injury related services throughout Nebraska. The first focus group was conducted with the Lincoln TBI Support Group on October 12, 2010 at the 1st United Methodist Church in Lincoln, Nebraska. The second focus group was conducted with the Norfolk TBI Support Group on November 1, 2010 at Faith Regional Health Services in Norfolk, Nebraska. Table 99 reports characteristics of the focus group participants.

Table 99. Focus Group Participants

Group Characteristics	Lincoln Focus Group		Norfolk Focus Group	
	Range	Average	Range	Average
Total Number of Participants	19		25	
Number of Survivors	14		12	
Number of Caregivers	5		8	
Number of Providers	1		5	
Number of Men	7		7	
Number of Women	12		18	
Survivor's Years Since Injury	10-45 Years	28 Years	0.5-42 Years	16 Years
Caregiver's Years Providing Care	5-11 Years	7 Years	2-29 Years	14 Years

Summary of Focus Groups and Key Results

When combining responses from both focus groups, four distinct areas of need were consistently mentioned and often stressed as important.

Respite Care/Adult Day Program

One of the most pressing needs mentioned, especially among caregivers and family members, was the need for respite care or an adult day program to offer relief. The need for these services went beyond the needed emotional and physical rest on behalf of the caregiver. In many cases spouses or family members had to forgo their careers and primary income source to provide full time care for the individual with a brain injury. Adult day programs would provide family members the time needed to meet vocational and financial requirements. In addition, the individual with the brain injury and the caregiver often had far too many household needs that they were unable to spend the time necessary to find a job, to get the therapy and services necessary for the brain injury, or get the emotional supports that they needed. Although several

individuals desired an adult day program, others simply wanted a few hours of respite care to catch up on necessities.

Case Management and Service Coordination

The need for established and effective case management, information/resource, and referral systems was often mentioned as a need during the focus groups. A surprising number of individuals did not know where to go to find information on available services or where to contact someone who could refer them to agencies or providers who may help with their needs. When the individuals did seek help at agencies that could not provide services for their needs, they were seldom referred to another agency or provider who could help. Case managers are needed to evaluate the specific or special needs of the individual and recommend appropriate services. For example, several individuals indicated that they needed more one on one services or needed a longer stay in rehab or extended outpatient services. These case managers are needed to refer and recommend the appropriate services to individuals and to monitor and follow up with individuals who may not develop or recognize their need for services until much later after their injury.

Financial Support

Another pressing need of brain injury survivors and their caregivers is financial support, which included primarily the problems of finding and keeping a job and steady income, the lack of waivers and funds for needed therapies and specialized services, the difficulties of getting on disability, and the high costs of prescriptions. As many individuals and caregivers have had to leave their jobs and careers since the brain injury, financial burdens are constantly on the minds of many survivors and their families.

Awareness and Training

Finally, awareness of TBI, related conditions, limitations, and training for evaluating and providing services to individuals with a TBI were key needs frequently mentioned. Survivors and caregivers often thought providers and physicians were not properly trained to screen or provide services for TBI and often not knowledgeable on TBI issues. However, several of the individuals in the Norfolk focus group indicated that their primary care provider went out of their way to learn about TBI and provide the appropriate services. A notable number of individuals expressed their difficulties when interacting with providers, agencies, therapists, and vocational professionals who were not aware or informed about TBI and were often unsympathetic and patronizing. Focus group members thought providers and agencies should be trained properly on TBI related topics so the appropriate screens, services, and referrals could be made.

Greatest Challenges Since Brain Injury

Lincoln Focus Group:

- Awareness of services
- Eligibility of services and getting accepted for services and

"I have memory problems and throbbing head pain. I haven't had any services since being released from the hospital and I have no idea where to go to get help."

- programs (disability coverage, respite care, etc.)
- Feelings of abandonment and alienation from family and friends
- Being taken advantage of (people dominating them) and a sense of helplessness
- Lack of public awareness of brain injury and the resulting conditions; the public and even providers are uninformed about the unique difficulties of living with a brain injury.
- Dismissive providers who have not experienced the symptoms and effects and are not informed or trained on treating brain injury survivors.
- Lack of services, awareness, and understanding that brain injury conditions are often long term and significantly different than similar symptoms with other injuries (i.e. headaches/migraines, memory loss, anger, depression, compulsiveness, etc.)
- Lack of employment options and appropriate working conditions. Many individuals who have survived a brain injury can't work full days due to fatigue or multitask and remember procedures like they could prior to the injury.
- Behavioral issues such as anxiety, depression, substance abuse issues, anger, and compulsiveness.
- Physical and medical issues such as fatigue, memory loss, and decreased perseverance.

"If doctors realize what your disability is, they will try to help you out and refer you to service, while this has not been as positive of an experience with the state agencies."

Norfolk Focus Group:

- Emotional and behavioral problems such as anger, depression, a sense of isolation, and feelings that no one understands their condition or what they are going through.
- Compulsive behaviors, for example, one individual who suffered a brain injury just quit his job one day without thinking about income or his family.
- The slow transition process
- The slow and difficult re-learning processes
- Memory loss and the confusion of not recognizing people they have known their whole life
- Coming to terms with the limitations of improving conditions and functions
- For caregivers, difficulties in remaining patient with TBI survivors and coming to terms with the slow process of recovery and learning.
- Lack of awareness by doctors and providers and lack of

"As a provider that helps people with brain injuries, it is difficult finding people to provide respite care or chores who understands the condition. When families are trying to find someone to help them in their home, the helper quits because of anger"

understanding of how the results and conditions of individuals with brain injuries are different from other illnesses.

Experiences with Brain Injury Services

Lincoln Focus Group:

- There is a lack of awareness among providers and primary care physicians. One individual stated the doctor will spend 5 minutes with them and give a quick medication without researching brain injuries. The medication prescribed had negative side effects and was not appropriate for an individual suffering from a brain injury.
- There is a gap in disability coverage and eligibility as well as other financial resources for brain injury victims; individuals don't look disabled and often get looked over even though their conditions may be more severe and limiting than other individuals with a physical disability.
- There is a need for advocacy and services relating to education. Resources to assist in transferring classes and the transitioning process after the brain injury are needed, as are services and programs to provide remedial help.
- There is a need for more realistic and appropriate rehabilitation exercises. Several individuals stated that they were doing exercises in rehab that either had nothing to do with their everyday activities or were far too complicated for the degree of their injury.
- There was expressed need for a job coach and for job placements that did not require changing duties every day as individuals did not have the capacity to remember a large list of tasks that changed daily.
- A frequent difficulty with obtaining the appropriate services was financial issues such as the high cost of services and prescriptions, ineligibility for Medicaid waivers, and problems keeping their houses because of limitations on benefits and VA coverage.
- Problems with individuals not being allowed to participate in rehabilitation meetings regarding their outcomes. One individual expressed problems with professionals giving their opinions on worst case scenarios to family members without a best case scenario. Providers should stick strictly to outcomes and results and leave their personal opinions to themselves.
- One individual did not get enough brain injury exercises and thought the providers focused too much on a broken hip.

"An agency said we didn't qualify for chore or housekeeping help because we had children in the house. They didn't tell us where we could go for help or

- Another commented that Lincoln was lucky to have general assistance which was necessary.

Norfolk Focus Group:

- There were problem with physicians and other providers. Providers don't give or get referrals, they are uninformed about TBI, and recommend treatment that is not specific for individuals with a brain injury.
- Several indicated that respite care or adult day services are not available and often needed.
- The paperwork and process to qualify for programs and services are often too time consuming and difficult for individuals with brain injuries.
- There is a need for assistance and services for TBI survivors with disruptive or aggressive behavior, especially for youth who are in schools and interact with teachers and administrators who are uninformed about TBI.
- One individual thought hospital services, outpatient therapies, and speech therapies worked well, but there were no services once they were on their own.
- Others commented that their rehab experiences with Madonna and their physical and occupational therapies were great and also their experience at Quality Living where they re-learned important skills and functions.
- Others commented that it took a long time for therapy to help and it was often hard to get someone to help them gain independence.
- A survivor stated the League of Human Dignity wouldn't help because they had kids and said they couldn't do anything about services for chores.
- Another individual said he experienced memory loss and headaches, but has no idea where to go to get help. He was unaware of supports or assistance.

"One of the biggest needs when you leave the hospital, is the need for follow up. In this system when you're finished your finished. There's just no follow through and no support and we know from research that individuals need that support for on average 2 years."

- Lincoln TBI Provider

Transition Experience

Lincoln Focus Group:

- Individuals were often upset with not being able to do things they could do previously. Job services need to focus on jobs that offer repeated activities instead of ones that give different jobs every day.

- Sometimes agencies think individuals make too much money and don't need assistance, but they don't consider the high costs of medication, which is often thousands of dollars a year.
- There is a great need for follow up when individuals leave the hospital. There is often an unawareness of services or the avenues to get information or help.
- A caregiver was extremely thankful for the adult day program available to her spouse. It offers the kind of therapy they need, and is the caregivers respite.
- Some of the therapies were impractical and would not reflect the individuals average day or behaviors. Therapies need to be specialized to the individual. For example, an individual who has never cooked and will not need to cook would not need to learn these things, instead the time could be spent on re-learning how to drive or read through mail.

"There is no respite care or day program available. I can't work or anything because someone has to watch her all the time. I need a break and there's no help for that. It's

Norfolk Focus Group:

- The group agreed that it was hard to deal with the lack of awareness and sympathy and the uneducated individuals who don't comprehend the condition or needs of survivors.
- They struggled with the difficulty of explaining to others the problems they are having or the feelings they are dealing with.
- Caregivers struggled with the lack of respite care available. One caregiver stated that they can't handle the mood swings and needed education and training for themselves, their families, and their providers.
- Caregivers often want to have the person they knew before the brain injury, but they never will. It is hard for family members and caregivers to be patient and they often need supports.
- Marriages often failed because the spouse couldn't understand the condition or it was too difficult. There is a need for education, training, and counseling for the family and services to help keep them together.
- Individuals struggle with the fact that they can't do the things they did before. It can become isolating because they can't do recreational activities they did with friends before.
- Several individuals stated that when they were released from the hospital, they didn't know where to go to get referrals, they didn't know any names to contact, and they didn't know where or how to get help. They were unaware of the services available.

Most Needed Services

Lincoln Focus Group:

- Immediate and sustained advocacy for TBI individuals
- Health Insurance coverage and affordable medical services
- Assistance and fair processes for disability coverage
- Transportation
- Utilities that they don't have for everyday needs. Some individuals have to spend large amounts of time walking or finding ways of doing things that could be done very quickly with appliances and assistance.
- Assistance with medications and prescriptions.
- Career and job services with employers who understand that they may have to repeat instructions or re-teach skills due to limitations of the individual with the brain injury.
- Financial needs, career and income assistance, and retirement funding and assistance
- Problems with having to give up their homes to qualify for certain programs or assistance.
- Affordability of insurance and high prescription costs
- The group agreed that support groups have been the most helpful and there is a great need for emotional help and support for survivors. Most of the individuals started with their support group through word of mouth not through referrals by agencies or providers.
- Legal services and planning assistance
- One individual could not find health insurance, so she her only option was to take classes to get the university's coverage.
- Additional volunteer programs and mentor programs to assist individuals.
- When in intensive care and rehabilitation, personal and family support is needed. Providers often try to limit contact so the patient can rest, which is not always the ideal action.
- There is a need for more specialized, one on one care.
- Legal assistance. One individual used the Volunteer Lawyer Project, but believed the lawyer did a quick under the table settlement with her husband's lawyer.

Norfolk Focus Group:

- There is a need for respite care, chores, or someone to give the caregiver a break. Some caregivers can't work because the individual with a brain injury can't be left alone.

"I know everyone's experience hasn't been the same, but Vocational rehab helped my son get a job after his injury. This was very helpful and would have been difficult

"There is a big problem, people just aren't aware of services. When my son was injured, we thought this was something we had to deal with on our own. People don't

- Daytime programs to relieve immense demands
- Information on available resources, doctors could let patients know about resources
- References and case management
- Emotional supports, interaction with friends and families, and recreational activities
- Neurologist
- Doctor awareness, education and training
- Need for specialized services. Some doctors spent 5 minutes then recommended treatment like they would for someone without a brain injury.
- Training for schools and professionals, possibly an hour training a year for teachers and bosses/companies that don't understand TBI or the resulting conditions (memory loss, fatigue, anger, compulsion, headaches).
- Awareness and advocacy, especially for children suffering from a brain injury. It's harder for teachers and other kids to understand the condition and children are often bullied.

Service Gaps

Norfolk Focus Group:

- Gaps for elderly individuals
- Gaps for individuals with a behavioral or learning disability
- There are difficulties and obstacles when trying to get disability coverage for brain injuries when compared to other injuries or illnesses.
- Individuals who think they can do it on their own or who are in denial do not get the required services and supports.

Suggestion for the State

Lincoln Focus Group:

- Provide case managers once individuals are released from the hospital.
- More transitional resources and information.
- Have a central place for information, service resources, and referrals for someone to match the services to the needs of the TBI survivors.
- Chores and respite services are needed as well as day programs for individuals so spouses or other family members can work and help pay for treatment and services.
- Emergency respite services
- Additional or enhanced career services that provide a lower stress environment and part time work or work that allows breaks for fatigue.
- Programs for individualized services,

"Not every head injury is alike. Doctors need to learn about each person's head injury. They need to learn the different degrees of injury and emotions."

- especially early on in transition, for specific needs.
- Some survivors won't need services for a while but need them long term, so it would be helpful to have someone to check in on needs in the future, say every 6 months.
- Housing for those at retirement ages to relieve caregiver.
- Assistive technology and appliances.
- Independent living services.
- Social workers do a good job but can't provide continued services, need someone for minor services afterwards.
- New to the system, fall through the gaps. Don't know where to turn.
- Advocacy and awareness to get financial assistance.
- Legal assistance.

Norfolk Focus Group:

- The state needs to look into financial assistance for medications and the criteria for disability.
- TBI awareness for the general public and for providers and agencies.
- State needs specialized treatment services and education on how to evaluate the special needs of individuals who have suffered from a TBI.
- Expand and fund respite care and adult day care
- Supports and programs to help with careers and job finding.
- Case management, information systems, and reference systems need to improve. Doctors and providers need to have a system to get information to patients and give an appropriate referral.
- Doctors could have list of resources available and contacts/referrals to get help.
- Rent assistance.

Traumatic Brain Injury Key Informant Interview Results

Service Providers, State Agencies, and TBI Survivors

Key informants (see Table 100), or stakeholders, were identified by Advisory Council staff for the interviews for the TBI needs assessment. The phone interviews were conducted in December of 2010 using a structured questions, which are located in the Appendix J. The intent of the interviews was to gather more in-depth information regarding the needs of TBI individuals and their families and the questions about the functioning of the system.

Responses from the interviews were aggregated and summarized by themes. When responses were identical or similar, the number of individuals with that response are indicated by a number in parenthesis following the comment. Interview responses to some questions are located in a different section which corresponding to that section, such as the TBI trust fund and feasibility of a resource facilitator.

Table 100. Key Informant Interview Participants

Name	Association
Ellen Spearman	Survivor
Gina Simanek	Survivor
Karen Hux	University of Nebraska – Lincoln "Speech Pathology Instructor/Researcher"
Lori Wardlow	Nebraska/Iowa VA Health Care Systems "OEF/OIF Case Manager"
Marcia Stuckey	Western Nebraska Community College "Veteran's with TBI returning to school"
Margaret Jensen	Early Development Network "Support Group Leader"
Margy Hoffmann	Vocational Rehabilitation
Mike Hon	Quality Living, Inc. CEO
Nancy Noha	Assistive Technology Partnership "TBI Grant Staff"
Peggy Reishner	Madonna Rehabilitation Hospital
Roger Stortenbecker	Collaborative Industries "Developmental Disabilities"
Rose Dymacek	Nebraska Department of Education "Coordinates TBI School Transition"
Susan Buettner	Nebraska DHHS "Long-term Care"
Tania Diaz	Nebraska Advocacy Services
Tiffany Armstrong	Survivor
Tiffany Young	Good Samaritan Hospital: Social Work
Victoria Rasmussen	Hotline for Disability Services "Client Assistance Program"

1. Greatest need/biggest issue facing individuals with TBI and families:

The two primary overarching needs identified by the key informants were financial resources to provide needed services and associated costs, and the need for increased knowledge and awareness. Listed below are the specific needs mentioned.

Financial resources for . . .

- Adequate services (2)
- Lack of resources for adults to live independently (i.e., housing, employment)
- Assisted living care, independent living and long-term care
- Support services for transitions and living, school and employment
- Additional services
- Services for long-term support needs
- Adult daycare
- Community-based services
- Financial needs due to lack of insurance
- Medications
- Transportation issues
- TBI Waivers
- Resource facilitation
- Assessment services
- Expand services similar to those offered by QLI

Knowledge and awareness in relationship to . . .

- Service availability
- Lack of understanding of needs at the community level
- Injury awareness
- Undiagnosed injuries
- Education and training: birth to 21 years of age
- Training for professionals

Other

- Need for flexibility to provide individualized services

2. Strengths and weaknesses in the current system of care for individuals with TBI in Nebraska:

The strengths and weaknesses of the current system listed included more weaknesses than strengths. However, based on the strengths listed, there was an indication that the system is improving in coordination and networking across healthcare and community providers. Acute care services and hospital-based rehabilitation were also mentioned as positive aspects of the system. There is also a sense of commitment by a core group of individuals addressing issues related to TBI. Awareness also seems to be increasing.

Weaknesses of the system were most often associated with the lack and knowledge of services, specific gaps in services or needs, and the need for education and training. Many mentioned the lack of availability for services in western Nebraska.

Strengths and weaknesses described are listed below.

Strengths

- Professionals and agencies have done a good job with hospital based acute care (3)
- Fairly good job with hospital based rehabilitation (4)
- Acute services
- Madonna and QLI's long-term residential program
- Coordination of care: private hospital, community based organizations, vocational rehab, QLI, DSN, and Madonna all communicate to provide best options for individuals
- More collaboration among providers
- Good comodore and coordination between agencies
- Good network forming for what is available - an improvement from the past
- Committed core group of people to develop infrastructure
- Good advocates at vocational rehabilitation and on the TBI council
- Community providers stepped-in to provide evaluation for TBI
- Individuals who have worked with TBI are always ready to help
- More awareness than in the past
- Growing awareness among service providers
- Increased awareness - individuals getting word out, the brain injury association, and a number to call are all important.
- Several active programs in the state
- TBI Registry and letters mailed to individuals
- Support groups

Weaknesses

- Lack of case management (2)
- Gaps in training and education for medical and informational supports (2)
- Overall lack of services
- No services specific to TBI
- Lack of understanding of brain injury by doctors
- Lack of counseling so individuals
- Lack of commitment on the part of the state to commit resources despite legislative proceedings showing the need
- Lack of services for complicated care, assistive resources and rehabilitation
- Lack of expertise in Nebraska
- Lack of long-term employment support
- Gaps in effective support groups
- Need for respite care and networking for respite care
- Lack of adequate programs and resources outside Lincoln and Omaha
- Lack of post-acute services
- Waiting list at QLI and limited access to the facility
- Lack of knowledge of available resources
- System weak in identifying mild brain injuries
- Need for curriculum related to cognitive functioning
- Need for a model program to develop skills for vets
- Services not available in rural settings
- Need for long-term supports
- Limited range of services compared to other states
- Lack of awareness and training for brain injuries

- Need for a center that offers support services (no budget support for concept)
- Poor reintegration of children back to school and of adults back into the community and back into their vocations
- No money for new issues
- Need for training in the community and with providers
- It is difficult to find services out west past Lincoln. Specifically, there is a lack of community care, PT, and OT. Those that need services often don't qualify for resources
- No one in one support group takes advantage of Vocational Rehab and Employment Works
- Lack of specialized services - providers and agencies have to contract out
- Lack of proper diagnosis and holistic treatment

3. Referral and Transitional System Changes

"All individuals are lumped into one group regardless of age. There are 1500 people on the developmental disability list and they must be discharged to a safe environment. The referral services for acute hospital services are limited and QLI referral services are a dead end in some cases. There is also uncertainty in qualifying for the League of Human Dignity and for home health. There is not a good model structure in place."

Suggestions and comments related to the referral and transitional system. There was some mention of the limited help available through the Hotline and the Brain Injury Association but this does not direct individuals directly to services and still there is a need for a better referral process as there is no real coordination or continuum of care after medical treatment. The need for one referral source or one person to coordinate and refer to the appropriate services for the state was suggested. As stated, "the overall path is fragmented. There is a lack of awareness and education for paths of transition and resources available." Another issue is when individuals are referred, they can only be referred to services based on what insurance covers. This is true of using services at Madonna as well. As stated by one individual,

" It is a bigger issue than referrals; there are no community-based services to access home healthcare. Individuals with a TBI are sent back with their family when they require 24-hour care and often have psych issues; they can't find the appropriate help. There is a drop off in available services, so there may not be anyone to refer individuals to."

Lack of information, available transitional resources and adequate follow-up, were also concerns shared, as mentioned in the following statements:

- There needs to be information sharing between medical professionals, schools, and other agencies that are involved with individuals with a TBI
- Lack of information available regarding community-based and transitional services after rehab.
- Lack of transitional services and supports. In appropriate placement in nursing homes
- Transitioning is a huge challenge for survivors and a difficult process for support groups and vocational rehabilitation.
- Lack of transitional and skill-building resources for family
- Transitional services don't exist in the capacity needed and there is very little training.
- A system needs to be developed to address personal and family issues

- Organizations are in place, but there no specific services to help individuals with brain injuries
- There needs to be follow-up after discharge when the needs become apparent
- There is also no coordination of services in the state and survivors in this area usually end up either not receiving services or receiving inappropriate services.
- Madonna has been the exception; they are good at referrals, especially for neurology services that aren't available in Nebraska.

4. Barriers in Medical and/or Transition Services

Primary barriers to services the lack of services and outside of Lincoln and Omaha so geographic barriers to services do exist in the state which result in limited access. "The main services are in Omaha and Lincoln and there are few available in rural communities." This geographic barrier includes the access to rehabilitation facilities both in distance and costs. There is an awareness and information barrier for families and needed support for families. There is also a knowledge issue with professionals, as indicated by this statement. "There is a significant knowledge barrier and a lack of understanding from professionals, providers, doctors, and the lay public in general when it comes knowing what it means to be a survivor and the long-term needs necessary for proper treatment."

"The main barriers are funding and services available." Funding was also mentioned often as a barrier to medical and transitional services, as was general access. " There is a huge barrier in trying to get people into the system." Following are more specific comments relating to barriers.

Geographic Barriers:

- Geographic barriers: gaps in services in rural NE, i.e., housing or independent living facilities, no continuum of options or range of services and support services
- The availability of services geographically especially for families in rural settings is a barrier. There is no access and not enough money to set up one on one support in these areas, the only option may be to relocate to a larger city.
- There are geographic barriers and barriers with providers transitioning individuals into the community.
- There are huge barriers for individuals in western Nebraska. It is challenging for this population to acquire services and transportation. There is no network, a lack of resources, and inadequate knowledge on the issue.
- There is a huge disadvantage the farther central and north an individual is because there are not adequate providers and professionals, especially ones who are trained and aware of TBI. In addition, employment opportunities for this population are more limited in rural areas.
- Distance is a real barrier and support services are lacking; there is a sense of powerlessness for many individuals and there needs to be services available for support.
- There are large barriers in rural areas, funding barriers, lack of expertise in certain areas where individuals have to go out of state, and central Nebraska has a lack of medical knowledge to address TBI.

Access, Funding, Awareness and Support

- Accessibility and awareness/resource facilitation. Not everyone knows about centers and services and there is often no one in place to direct individuals to services. (2)

- Cuts in Medicaid and medical funding will hurt access to services, when specialization for TBI individuals is needed.
- There are no medical barriers, but there are in step down services by providers and there are issues with the availability of providers.
- There is a transportation and access issue where people have to drive to bigger cities for the needed services.
- There is an information barrier where families don't know of and can't get to the resources they need.
- There is a need for support groups and flexible services to address the variability of needs.
- There needs to be better access to services, resources to find the appropriate services, and more specialized services.
- The state needs to address the stigma and fear.
- Overall funding, eligibility for services, a lack of community based services, and inadequate health insurance are all barriers that prevent individuals from receiving the appropriate services.
- The resources are too widespread and there are not enough resources available, especially in rehabilitation and outreach.
- Facilities are lacking, and there is a need for living facilities to take individuals during the day so family members can work.
- There is an overall lack of services and lack of identification of TBI. There should be a screening project, specifically for children 0-4, because of the high incidence for falls.
- There are barriers to emotional support and medication.
- The support groups don't talk about services; it is a place for emotional support.
- There are support groups, but nothing for mild brain injuries and there is a problem when individuals are unaware of their brain injury.
- There is a barrier for developmental disabilities based on behavior modification. Families need to have contact during treatment and individuals need to be closer with their family. There is a barrier in support.
- Suggest screening in behavioral health treatment services for brain injury.

5. Gaps in Services - specific to individuals with aggressive behaviors or co-occurring disorders

All agreed that there is a gap in services and facilities available to individuals with aggressive behaviors or those with co-occurring disorders. "Neuro-behavioral services are extremely lacking in Nebraska." "There is also a gap in levels of expertise. Funding is a concern. " The state of Nebraska does not realize the significance of neuro-behavioral services for individuals with a TBI. There are not enough funds to individuals and there are no experts in Nebraska. "The state tries to piece together services, which results in gaps and individuals not receiving the services they need." Another stated, "There is a lack of neuro-behavioral services for Nebraskans and the length of service is too short. Individuals are not getting the appropriate services. Other states are willing to pay for this needed service and to have that expertise."

In general, there are gaps in housing, long-term support, education and training. On the behavioral health issues, there is a lack of screening and understanding of traumatic brain injury. Other gaps talked about were gaps in community-based services. "Community based services can be developed but there is no leadership from the state." Following are other specific gaps mentioned.

- Neuropsychological evaluations aren't done when they need to be and there needs to be rewards for adaptive replacement for aggressive individuals
- The state needs neurobehavioral funding for programming and to develop a program or Medicaid fund. There was a discontinuation of anger rehab services
- The north/central part of the state does not have adequate screening systems in place, which is necessary - especially from birth to age 5
- There are a large amount of misdiagnosed individuals. There are also gaps in behavioral health services and mental health services
- Brain injury is often co-occurring with mental health or substance abuse issues and there are no facilities in Nebraska to address this diagnosis
- There are gaps in the level of expertise, need for a center, and availability of safe environments
- There is a gap in housing supports and options, specifically for younger individuals
- There is a gap in long-term supervision. There is a financial need for families who take care of individuals who need constant attention. When these supports aren't available and there is no supervision
- Gaps in discharge and follow-up
- Awareness and training for family members to realize what is actually going on
- There is also a gap for students who have a TBI because schools rarely acknowledge or address the issue and the students are often put into other categories such as special education

6. Alternatives for individuals with TBI that are placed in assisted living or nursing homes inappropriately:

There currently are very few options for individuals in the state for long-term placement. More group homes are needed, as QLI provides the only housing and rehab option in the state. Without an options, there is a need to provide additional support to families or increase independent living skills. However, there is a lack of resources to develop independent living skills. "Assisted living and nursing homes don't have rehabilitation services so individuals don't move to a level of independence because they are lacking the appropriate services." Case management or resource facilitation was again mentioned as being beneficial with this issue.

The problem has real impacts as lives, as shared by one individual. "There are a lot of silos for individuals. Medicaid is departmentalized and not flexible, so individuals often don't get the right services. For example, recently we have had 3 individuals around the age of 22 get stuck in a nursing home, when they needed group home services. When individuals go through Medicaid they often don't get the needed services."

Several individuals recommended pursuing a brain injury community center. Specific suggestions and comments include:

- There needs to be additional services and waivers.
- There are no alternatives. The family needs to be resourceful. There has been some progress with Medicaid from Medicaid waivers. It is hard to move forward without an infrastructure, but there needs to be supports for supervision/cognitive re-trainers and education at all levels.
- Services need to address why individuals had to be moved from their families to these facilities; there is no other place for these individuals to go. They need more services

than they could get at home, but the current placement does not address these needs appropriately.

- There are barriers in flexibility of funding, waiver eligibility, developmental disability services, and funding as well as different barriers for those over 21 years old.
- This issue cannot be highlighted enough. All individuals suffering from a brain injury, but especially youth, need everyday stimulation to improve.
- There is a need for an ABI community center with skills training as well as staff at facilities who are trained in neuropsychological PT and OT to help with rehabilitation.
- There is no housing with the exception of Quality Living that can offer the services that individuals need.
- There is a financial and insurance issue that results in inappropriate placement of individuals; too often people are in nursing homes, where staff is not trained in or able to handle brain injury.
- There needs to be more group home type facilities in the state. For assisted living there needs to be a house level instead of nursing home level.
- There are huge burdens on families if there are no options for placement and living. The families need support too, for instance day programs and respite care.
- There are some group homes, Madonna, and some help with independent living that provides help with cooking and chores etc. There is not currently anything else available.
- This is especially a problem for the younger population; if they receive appropriate placement they will thrive, if they do not there is a high probability of depression and a halt in recovery.
- There is a need for assistive technologies, in-home care, and supports to become independent.
- There is a challenge of getting individuals into independent living facilities, they need supports, and often there are not any options or alternatives.
- Individuals need the support of a family and caregiver, which brings up the need for family supports as caregivers.
- Resource facilitator may help direct to appropriate resources. Young people are being placed in nursing homes inappropriately;
- There needs to be a case manager that coordinates local service agencies and someone to access appropriate care. Aged and disabled waivers provide services in home, which would be an option.
- For individuals, and specifically veterans, if there is not a strong family structure they have nowhere to go and no options. There needs to be a residential facility for veterans and regional mental health facilities for veterans. The National Guard has the highest rates of suicides in the military from TBI's.

7. Perception of gaps in training for certain professions, such as physicians, for detecting TBI and for providing appropriate services:

Training is needed for professionals such as primary care providers, family physicians, nurses (particularly discharge nurses), counselors, therapists, speech therapists, teachers and educators, HHS, employment agencies, vocational rehabilitators, law enforcement, higher institutions, outpatient and occupational therapy professionals, occupational therapists, nursing home staff, psychologists, special educators, department of motor vehicles, and at homeless shelters.

Education for detecting brain injuries, referral resources, available resources, general information, transition resources, recognition of symptoms, educating professionals to know when they don't have the expertise to appropriately address issues and then training on how to refer to others.

- There is a need for training for lay people who deliver direct services to individuals, and this information needs to be passed on to new staff and others.
- There is nothing in the core educational curriculum that addresses TBI. There is a great need as there is not any training in medical school.
- Medical professionals expect individuals who have suffered from a TBI to have a full recovery, when in reality they may never fully recover. Professionals sugar coat the effects of the injury and may never see the long-term problems. There may be no solution to this problem.
- There are gaps; people need to talk about the stigma. No one wants to talk about the issue or how to transition these individuals.
- Day programs don't know how to work with individuals with a TBI.
- Doctors have book knowledge on the subject at times, but people are fearful to self advocate with doctors to relay issues and needs that may not align with the doctors knowledge.
- Special education students are too often misplaced.
- Professionals who have a little education on head injuries think they understand it all, which is never the case. It's not necessarily a training issue they may just not work with enough people to make the right calls.
- There is not enough information on the medical side. For instance, professionals don't distinguish between the causes of behavioral problems.

Veteran Resource Facilitation Feasibility

Stakeholder Feedback

Summary

There is consensus that a resource facilitator is greatly needed in the state of Nebraska to provide an access point for individuals with brain injury to call for resources and receive the appropriate services. There is a gap for all individuals with brain injuries to have someone they can call to learn about potential resources for them to access. So although the concept of a resource facilitator for veterans is positive, many believe a resource facilitator is needed for all individuals with brain injuries in the state. Strategically, "it doesn't make sense" one individual commented to have a resource facilitator for only veterans. Whereas the need for veterans is recognized and veterans should be supported, it was also mentioned that they also have other resources, such as the Veteran's Trust Fund, to access. However, it would be the hope if a resource facilitator could be supported for veterans, it would lead to a service for the general population. "It is a great idea and good start with a small population, but all brain injury survivors need case management and service coordination."

Some individuals support one point person in the state that has all of the knowledge of available resources while others believe multiple resource facilitator are needed at a regional level and geographically distributed. It was also mentioned by several that tracking individuals with brain injuries and maintaining a database would be an important aspect of this position so needs can accurately be matched or considered at a later date. Also mentioned was the importance of developing a complete list of resources that would be available to the public. It was recommended by one individual the resource facilitator should be the responsibility of a state agency.

In your opinion, what is the feasibility of creating resource facilitators who would provide ongoing support to veterans with brain injuries? What would be your recommendations?

State Agency Survey Results

- Resource facilitators would be helpful to all individuals with brain injuries.
- Feasible idea, but dependent on funding.
- I am not sure about the available funding to do so, but we would recommend that it would happen. There is a need for a specialist who can guide and assist individuals with brain injury and their families.
- In my experience, this service would be beneficial to veterans with brain injury in Nebraska. There are many services and supports available to veterans, however locating and learning about all of these programs is nearly impossible for most individuals, especially those with brain injury. Also, community-based professionals

serving those veterans need specialized training and support in serving these men and women. Many other states already offer these supports with varying levels of success.

- I think it would be a great idea for all people with brain injury.

Service Provider Survey Results

- Actually, I think only focusing on veterans, although strategic to try to get the bill through doesn't make any sense. It is the population as a whole that needs the services and one person could likely serve both veterans and non-veterans until we could collect data substantiating the need for multiple people in the different districts.
- Currently we deal with "coordinators" who set up appointments, then bills that don't get processed through the VA. We also deal with mental health practitioners through the VA who call in repeatedly after appointments are set and the trip is planned to travel 45 miles one-way for that appointment. This seems like it would add one more layer of people to go through to get one service done from start to finish.
- Do something with telehealth so they do not have travel so far.
- I think it should be a priority. Many of us do not realize what our veterans have gone through, the emotional as well as physical trauma they have experienced and they should be supported to the utmost.

Key Informant Interview Results

- There is an argument against case management for veterans because there is a trust fund to pull out funds for their needs. The state needs one person to coordinate resources across the state for strictly TBI related issues for everyone.
- The hope is that it would lead into something for the general population, because all individuals have a great need for resource facilitation and a case manager. Traveling to services is difficult for many individuals, and a complete resource list would be helpful in finding the most appropriate services. There needs to be services in the locations where there are needs.
- It is a great idea and good to start with a small population, but all brain injury survivors need case management and service coordination.
- It is critical to have someone they can call when they need a service.
- It is key to the issue and how to access services that people don't know about
- Helpful for everyone and could help with aligning services for prevention, mental health, substance abuse, and domestic violence.
- Needs to be a person in each region that is identified to become familiar to coordinate services and respond to needs.
- Iowa has 5 case managers, the whole state of Nebraska needs this service. The individuals can use education and training to increase awareness as a resource for staff.
- Statewide agency, with some understanding of case management. An existing agency should house this responsibility and mandate what coordination includes and doesn't include. Document what needs can't be met, everything is anecdotal at this point, so there need to be records.
- This is a need and beyond veterans as well. There are lots of gaps.
- There is a great need for case managers, especially for military individuals who don't know what is available. The state needs one person who knows everything that is available. Too often people give different advice or direct individuals to different services. If there was one person who had knowledge on all the services available, individuals could be more accurately matched with the appropriate services.
- Resource facilitators and case managers are needed especially for the aged and disables, for those out of nursing homes, and for those needing independent living.

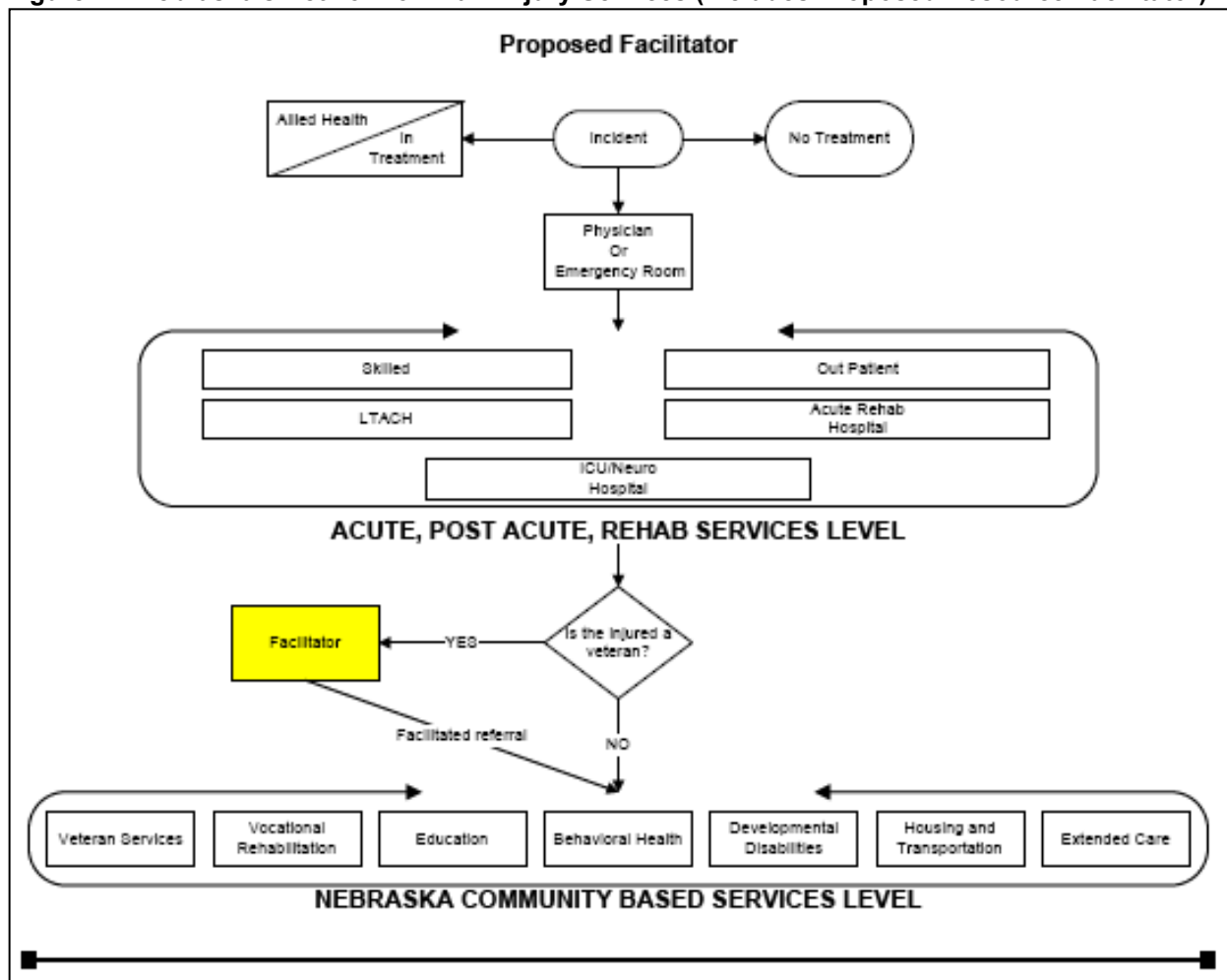
- Case management is a great idea and needed. There are too many people who don't get heard and who don't know what resources they need. Families and individuals need to speak with TBI and ABI staff and others to get the appropriate services and resources.
- Specific military don't know what is available, a resource facilitator is needed so that one person knows everything that is available; however, there is still the issue of knowing what services each individual needs. The second person would be addressed with more education and training for service providers, who can then refer individuals to the resource facilitator.
- Resource facilitators are a great idea, but may need lobbying and statewide initiatives to make progress. There should be a separate pot of money.
- There should be one referral source where individuals can go for referrals, waiver eligibility, and program eligibility. The resource facilitator should track individuals and their needs, so they can be accurately matched or considered at a later date. There has to be a record to individuals are not forgotten or lost in the system and so matches can be made.

Nebraska Systems of Services and Supports

Assessment of System Paths and Gaps

Figure 21 depicts the proposed system and flow of services for traumatic brain injury in Nebraska. The circular arrows in the diagram indicate that an individual may be referred to or utilize several of the services within the enclosed area. For example, an individual may go from acute hospital rehabilitation to a skilled nursing facility.

Figure 21. Nebraska's Network of Brain Injury Services (Includes Proposed Resource Facilitator)



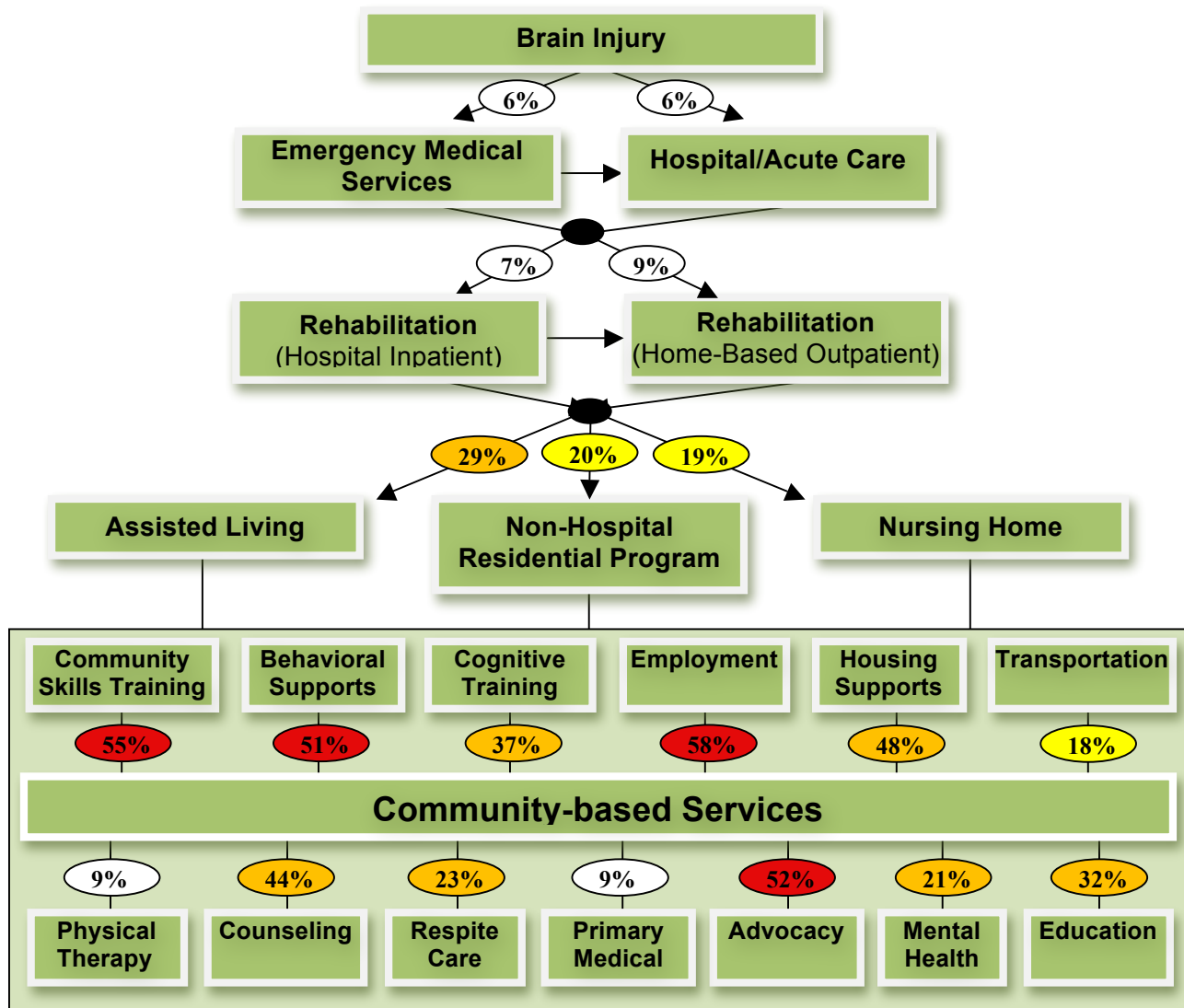
Another diagram was constructed to show service gaps at different levels of care for individuals with a TBI. Figure 22 shows the percentage of individuals/caregivers who indicated that a service was needed in the past and was not received or currently needed and is not being received. The color of the service increases the more the service was needed and not received. For example, the initial primary services such as emergency department or rehabilitation

services all had less than 10% indicating they didn't receive the service when needed and are in "white". Services with 10%-20% such as the need for nursing home assistance or transportation are in "yellow", those 21%-50% are in "orange", and those where over 50% of respondents needed the service but did not receive it are in "red". Advocacy and employment services were the most frequently indicated gaps in the flow of services.

Taking into consideration how individuals and caregivers responded to both the importance of the need for each service and the needs that they need or needed but didn't receive, the top service coordination gaps for individuals with a TBI were:

- Employment support
- Community based services/ community skills training
- Behavioral supports
- Counseling
- Advocacy

Figure 22. TBI System Gaps from Individual/Caregiver Survey



Service Providers and Available Resources

As providers and available services change frequently, information may be obtained through a variety of online sources. The current statewide databases for service and support resources are as follows:

Hotline for Disabilities
http://www.cap.ne.gov:3000/hotline_services

Answers 4 Families
<http://www.answers4families.org/>

Nebraska 211
<http://www.ne211.org/>

Other brain injury support resources include:

Brain Injury Association of Nebraska
www.biane.org

Assistive Technology Partnership
(888)806-6287 atp.ne.gov

In addition, to develop one centralized database of all services and resources in the state, Nebraska received funding to develop Aging and Disability Resource Center (ADRC) services in September of 2009. The grant was awarded to Nebraska's State Unit on Aging at the Nebraska Department of Health and Human Services. The mission of ADRC is "to position Nebraska's network of long-term support service providers for sustainability through facilitating partnerships and collaboration (ultimately helping Nebraskans)."

The ADRC vision for Nebraska is to streamline access to existing long-term support services, by collaborating with existing agencies and partnerships across the state. In addition, the Answers4Families website will be enhanced to help consumers get connected with organizations in their own communities. Partners in local communities will set specific goals based upon issues they see as important, in keeping with the general goals of the grant:

Additional info on the ADRC project in Nebraska:
<http://www.answers4families.org/information-services/adrc-project/adrc-nebraska>

Brain Injury Waivers

Nebraska Waiver Program & State Comparisons

Traumatic Brain Injury Waiver

The objective of the Traumatic Brain Injury Waiver is to provide up to 40 adults with traumatic brain injury client-focused waiver services to strengthen and support informal and formal services to meet the unique cognitive and behavioral needs of each client in a specialized assisted living facility.¹¹

To be eligible for the waiver, individuals must have a medical diagnosis of a traumatic brain injury, which is defined as a traumatically acquired non-degenerative structural brain damage. The term does not apply to brain injuries that are congenital or degenerative or to brain injuries induced by birth trauma.¹¹

Table 101 shows the capacity of TBI waivers from 2006/2007 to 2010/2011 and Table 102 contains the characteristics of individuals funded. The capacity and demographic numbers are for all of Nebraska, while the funding numbers and characteristics are only for Quality Living in Douglas County due to availability of data. The number of individuals funded for 2005 and 2006 could not be accurately determined.¹¹

The average amount received per individual increased from 2007 and is in excess of \$30,000 per individual. The average age of waiver recipient has increased over the past 6 years to 44 years in 2010; men were on average older than women recipients. Since 2005 there have been more capacity for TBI waivers than individuals receiving waiver funding.

Table 101. Nebraska TBI Waiver Statistics

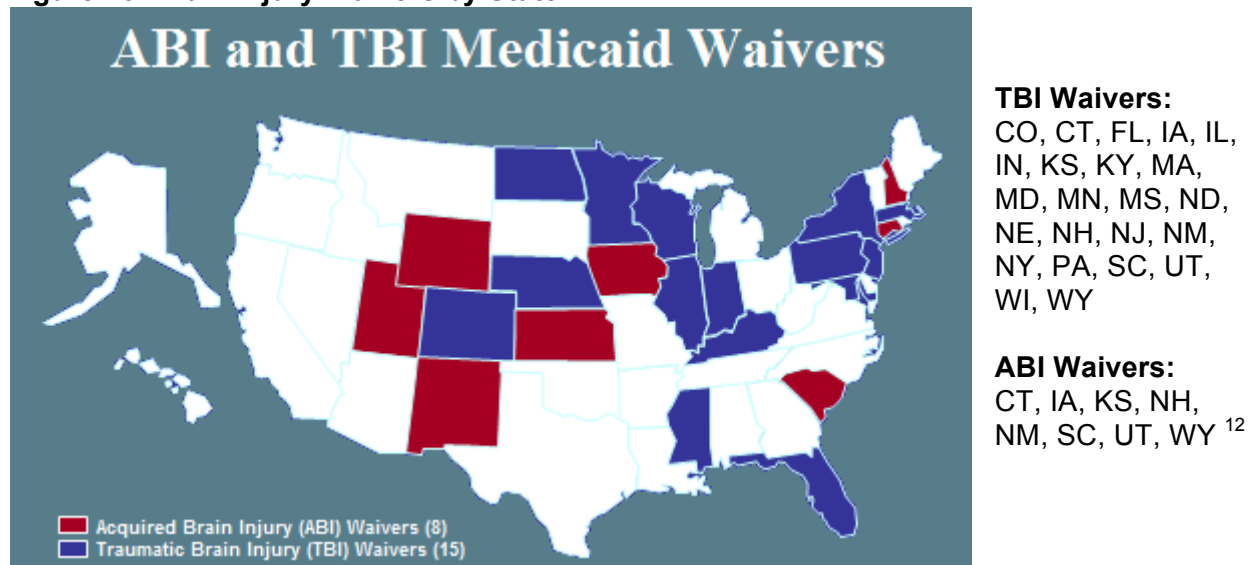
TBI Waiver	2005	2006	2007	2008	2009	2010
Nebraska Capacity	40	40	40	40	40	40
Number of Individuals Funded	20	21	21	21	21	21
Total Amount Funded	\$645,441	\$614,777	\$654,127	\$669,381	\$681,603	\$664,913
Average Amount Per Individual	\$32,272	\$29,275	\$26,801	\$31,875	\$30,982	\$31,663

Table 102. Nebraska TBI Waivers by Gender and Age

TBI Waiver	2005	2006	2007	2008	2009	2010
Individuals Funded	20	21	21	21	21	21
Female	4	5	5	5	5	5
Male	16	16	16	16	16	16
Average Age	40	40	41	42	43	44
Average Age Female	38	35	36	37	38	39
Average Age Male	40	41	42	43	44	46

Figure 23 depicts the states with TBI or ABI waivers as of 2005, which was the most recent year of analysis. Nebraska is one of the 15 states with a TBI waiver; less than 50% of states had a TBI or ABI waiver as of 2005.

Figure 23. Brain Injury Waivers by State ¹²



Other States have non-ABI/TBI-specific waivers that are serving individuals with brain injury and others. (These are not included on this map.) ¹²

Table 103 compares Nebraska's TBI Waiver Program with comparable states traumatic brain injury/spinal cord injury waiver programs. Nebraska offers notably fewer brain injury waivers than comparable states and waiver programs both in number per 1,000 population and in overall annual waiver expenditures. However, there were also comparable states that did not have a brain injury specific waiver in place.

Table 103. TBI/SCI Medicaid Waivers (2006) ¹³

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
Idaho	TBI	19	.01	\$1,277,412	\$67,323
Iowa	Brain Injury	774	.20	\$11,048,583	\$14,275
Kansas	Head Injury	240	.09	\$5,602,952	\$23,346
Utah	TBI	92	.04	\$2,082,364	\$22,634
Wyoming	ABI	143	.28	\$4,327,485	\$30,262
Maine, Missouri, Nevada, New Mexico, and South Dakota have no waivers related to TBI.					

Table 104 shows that the services covered by Nebraska's TBI waiver is limited when compared to related brain injury waivers in surrounding states. The TBI waiver programs in other states cover a range of community based supports and rehabilitation services.

Table 104. TBI/SCI Medicaid Waiver Services Funded (2006)¹³

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

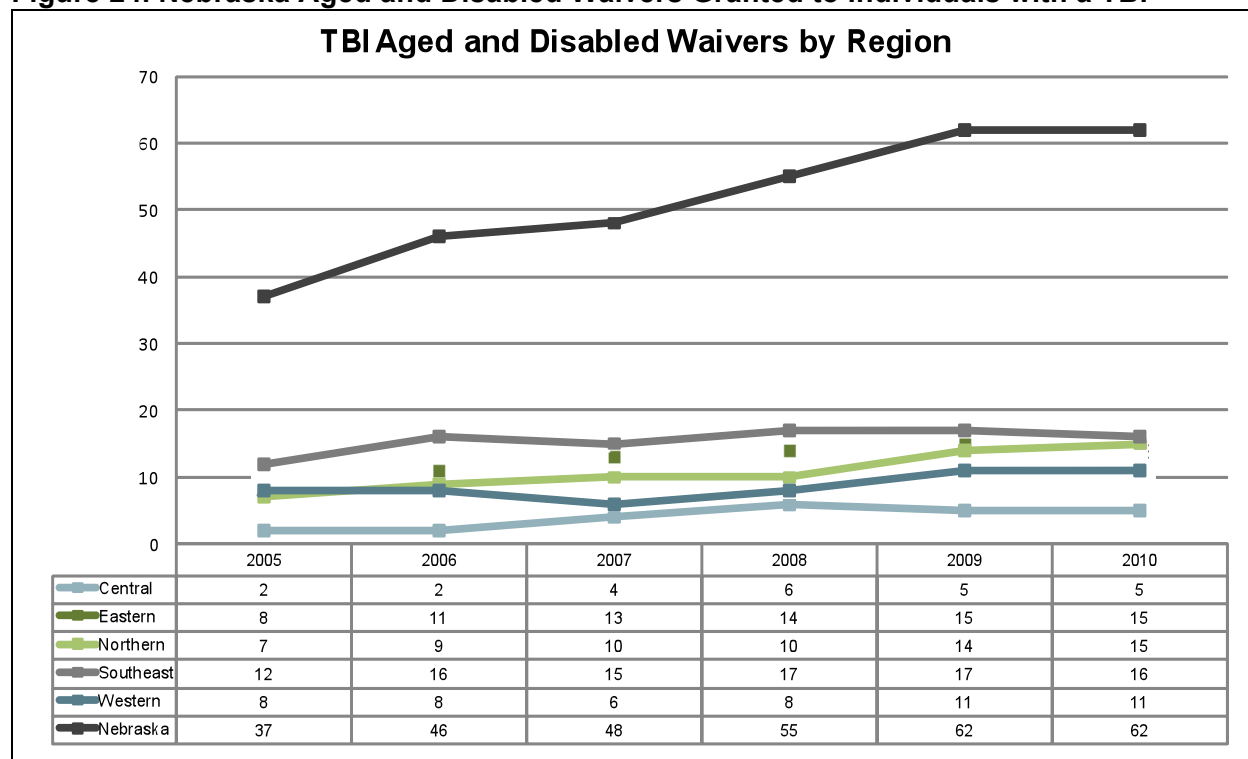
*Specialized assisted living includes assistance with daily living and personal care activities for individuals in the assisted living facility.¹¹

Aged & Disabled Waiver

In addition to specific traumatic brain injury or acquired brain injury waivers, waivers are available through other sources such as Nebraska's Aged & Disabled Waiver Program. The Home and Community-Based Services Waiver for Aged and Adults and Children with Disabilities Waiver program has operated statewide since 1988 to provide options for aged persons and adults and children with disabilities to allow them to live safely in a home or community setting. Waiver services are offered as an alternative to nursing home care and eligible clients have the same level of care needs as nursing home residents. The A&D Waiver is based on a family-centered, client-directed philosophy with an emphasis on the use of informal and natural supports in the community.¹¹

To be eligible for the A&D waiver, clients must be Medicaid eligible, meet the nursing facility level of care criteria and have care needs that can be met through waiver services.¹¹ Figure 24 shows that the number of aged and disabled waivers given to individuals with a TBI has increased for all regions since 2005.

Figure 24. Nebraska Aged and Disabled Waivers Granted to Individuals with a TBI



The brain injury A&D waiver may cover multiple services; Table 105 includes the number of brain injury individuals receiving waiver funds by service. The number of services received and total waiver funds paid out have increased since 2005. Chore services were the most frequent service covered by the waiver, and had the highest average waiver amount (see Table 106). Table 106 also shows that the average amount of funding per waiver service received has generally increased since 2005.

Table 105. Brain Injury Aged and Disabled Waiver Funding by Service

Service	2005		2006		2007		2008		2009		2010	
	n	\$	n	\$	n	\$	n	\$	n	\$	n	\$
Respite care in home	11	\$16,167	8	\$6,707	6	\$3,736	4	\$3,435	5	\$3,956	8	\$4,389
Chore	28	\$480,043	37	\$586,994	42	\$681,335	45	\$823,958	50	\$875,922	54	\$983,744
MV private									7	\$1,295	7	\$3,533
Disability related in home child care	5	\$25,449	4	\$37,501	5	\$38,957	3	\$34,647	3	\$33,764	6	\$50,146
Medical Transportation commercial local	5	\$8,700	5	\$8,485	10	\$18,893	9	\$13,500	8	\$18,542	7	\$8,731
ER system	6	\$1,651	8	\$2,181	7	\$1,900	6	\$1,859	7	\$1,775	5	\$1,039
Medical Transportation commercial distance							1	\$1,714	3	\$5,403	2	\$666
Nutrition services	3	\$560	1	\$105	1	\$275	1	\$105			2	\$713
Escort	4	\$7,955	5	\$7,390	13	\$6,585	16	\$11,751	18	\$9,076	10	\$6,539
MV private medical									7	\$1,144	10	\$2,890
Respite care	2	\$5,734	3	\$7,619	3	\$10,780	5	\$20,752	6	\$16,516	3	\$17,134
Transportation commercial local	5	\$1,450	4	\$1,004	3	\$1,035	3	\$3,972	4	\$6,411	2	\$5,165
Meals home-delivered	3	\$2,746	2	\$1,409	2	\$952	1	\$10	1	\$528	4	\$2,162
Adult day health care	2	\$9,248	2	\$8,416	4	\$21,920	5	\$22,488	4	\$17,035	6	\$19,055
Disability related child care	4	\$38,766	4	\$34,002	2	\$24,351	2	\$30,805	4	\$42,276	4	\$42,673
Escort medical	9	\$5,636	10	\$12,983	19	\$22,439	19	\$22,614	20	\$17,291	13	\$13,304
Total	87	\$604,106	93	\$714,796	117	\$833,158	120	\$991,610	147	\$1,050,934	143	\$1,161,883

*MV – Motor Vehicle

Table 106. Average Brain Injury A&D Waiver Amount by Service

Service	2005	2006	2007	2008	2009	2010
Respite care in home	\$1,470	\$838	\$623	\$859	\$791	\$549
Chore	\$17,144	\$15,865	\$16,222	\$18,310	\$17,518	\$18,217
MV private	-	-	-	-	\$185	\$505
Disability related in home child care	\$5,090	\$9,375	\$7,791	\$11,549	\$11,255	\$8,358
Transportation commercial local medical	\$1,740	\$1,697	\$1,889	\$1,500	\$2,318	\$1,247
ER system	\$275	\$273	\$271	\$310	\$254	\$208
Transportation commercial distance medical	-	-	-	\$1,714	\$1,801	\$333
Nutrition services	\$187	\$105	\$275	\$105	-	\$357
Escort	\$1,989	\$1,478	\$507	\$734	\$504	\$654
MV private medical	-	-	-	-	\$163	\$289
Respite care	\$2,867	\$2,540	\$3,593	\$4,150	\$2,753	\$5,711
Transportation commercial local	\$290	\$251	\$345	\$1,324	\$1,603	\$2,583
Meals home-delivered	\$915	\$705	\$476	\$10	\$528	\$541
Adult day health care	\$4,624	\$4,208	\$5,480	\$4,498	\$4,259	\$3,176
Disability related child care	\$9,692	\$8,501	\$12,176	\$15,403	\$10,569	\$10,668
Escort medical	\$626	\$1,298	\$1,181	\$1,190	\$865	\$1,023
Total	\$6,944	\$7,686	\$7,121	\$8,263	\$7,149	\$8,125

*MV – Motor Vehicle

Table 107 and Table 108 show individuals with a traumatic brain injury who received an aged and disabled waiver for each region by gender and average age, respectively.

Nebraska's Central and Southeast regions had a higher percentage of males receiving a waiver while the percent of waivers granted to females increased for Eastern, Southeast, and overall from 2005 to 2010. On average Southeast Nebraska had the oldest population of waiver recipients and Northern Nebraska had the youngest.

Table 107. Aged and Disabled Waivers by Region and Gender

Region and Gender		2005	2006	2007	2008	2009	2010
Central	Female	0%	0%	25%	33%	40%	40%
	Male	100%	100%	75%	67%	60%	60%
Eastern	Female	38%	27%	38%	50%	60%	60%
	Male	63%	73%	62%	50%	40%	40%
Northern	Female	71%	67%	60%	60%	43%	47%
	Male	29%	33%	40%	40%	57%	53%
Southeast	Female	33%	31%	33%	35%	41%	44%
	Male	67%	69%	67%	65%	59%	56%
Western	Female	63%	75%	50%	50%	45%	55%
	Male	38%	25%	50%	50%	55%	45%
Total	Female	46%	43%	42%	45%	47%	50%
	Male	54%	57%	58%	55%	53%	50%

Table 108. Average Age of A&D Waiver Recipients by Region

Region	2005	2006	2007	2008	2009	2010
Central	39	40	43	44	39	40
Eastern	38	32	36	36	40	41
Northern	29	32	34	35	36	34
Southeast	41	38	44	46	48	49
Western	26	35	31	37	38	45
Total	34	35	38	40	41	42

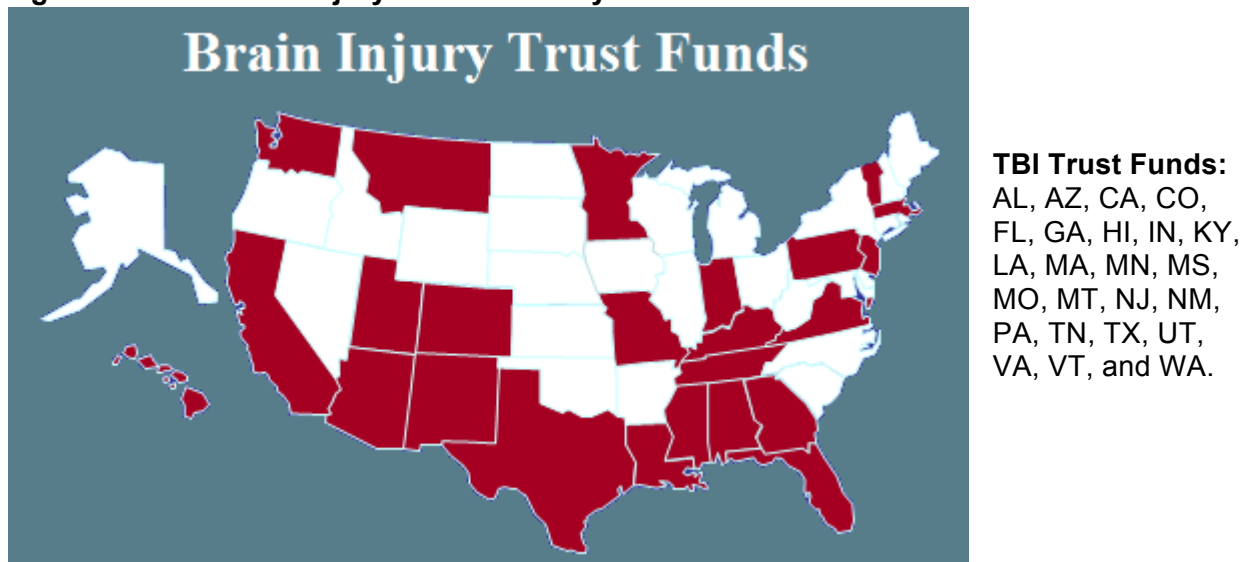
Brain Injury Trust Funds

Nebraska Trust Fund & State Comparisons

Traumatic Brain Injury Trust Funds

Nebraska currently does not have a traumatic brain injury trust fund; however, previous and current legislative bills and resolutions have been introduced addressing the need and feasibility of creating a fund. Figure 25 depicts the states that had brain injury trust funds in place as of 2008. Of the 24 brain injury trust funds that exist, 11 also benefit individuals with spinal cord injuries.

Figure 25. 2008 Brain Injury Trust Funds by State ¹²



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.¹⁴

Table 109 provides data from comparable states with brain injury trust funds. Annual funding for comparable states range from \$800,000 to \$17 million and the number served ranges from 160 to 21,000.

Table 109. Brain Injury Trust Funds by States (August 2006)

State	Annual Revenue	Most Requested Service/Support	Number Served	Average Annual Per-Person Expenditure
Arizona	\$2 million	Cognitive retraining; Vehicle modification	21,000	IL - \$10,766 VR \$4,900 - \$10,874
California	\$1 million	Counseling; Support groups	15,000	Unknown
Colorado	\$1.5 million	Care coordination, services, research and education	215	\$900 - \$1,000
Florida	\$17 million	Inpatient rehabilitation	2,000	-
Massachusetts	\$6.8 million	Private case management	800+	-
Minnesota	\$1 million	Employment assistance	400	-
Missouri	\$800,000	Transitional Home and Community Support Training	540	\$6,000
New Jersey	\$3.8 million	Cognitive Therapy	160	\$4,578
New Mexico	\$1.5 million	Prescription Medication	550	-
Texas	\$10.5 million	Post Acute Rehabilitation	464	\$17,069 - \$44,694

Nebraska individuals associated with traumatic brain injury were asked how they would recommend using funds if a Nebraska trust fund was created through surveys and key informant interviews.

Table 110 shows that individuals and caregivers most frequently wanted the funds used for rehabilitation, brain injury research, counseling, and assessment and identification of TBI. Nebraska providers and agencies differed from individuals and caregivers in their desired use of the trust funds. Providers and Agencies would use the funds for community-based services and support, job services, rehabilitation, and resource and service coordination.

Table 110. Uses of Nebraska TBI Trust Fund (Survey Responses: Multiple Responses)

Trust Fund Uses	Individual/Caregiver	Providers	Agencies
Rehabilitation	65%	47%	25%
Brain Injury research	53%	11%	0%
Counseling	46%	26%	25%
Assessment and Identification of TBI	44%	29%	50%
Job services	39%	45%	50%
Community-Based Services and Support	37%	63%	100%
Acute Care	37%	3%	0%
Education services	32%	42%	25%
Prevention and Awareness of TBI	32%	26%	25%
Case Management	27%	32%	100%
Resource and Service Coordination	26%	37%	75%
Crisis Services	25%	24%	75%
Recreation	18%	8%	0%
Nursing Home transitions	15%	5%	50%
Other: Post-acute care, advocates, outpatient therapy, assistive technologies, daily living needs, respite care, finances for pay loss, retraining, legislation for financial loss protection, housing, general support.	10%	8%	0%

Survey respondents and key informants gave other responses for trust fund use and feasibility. Individuals and caregivers most frequently commented that funds should be used for daily activities and therapies that are needed post rehabilitation. They also commented that funds should be used for educating medical professionals and employers about TBI.

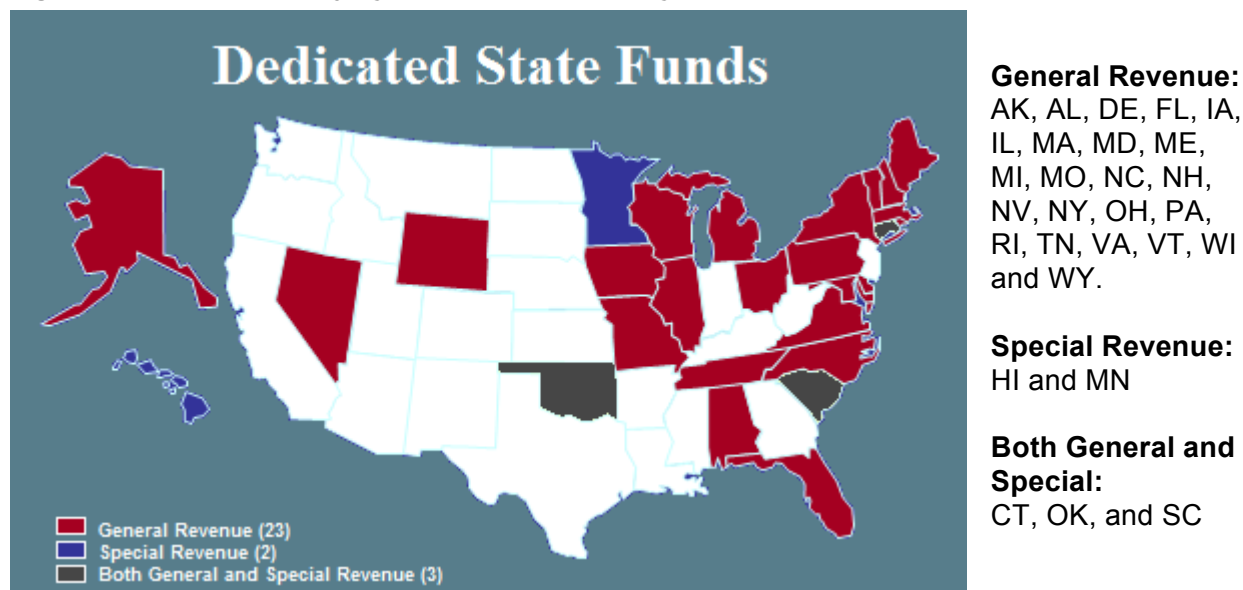
Key informants indicated that there needed to be awareness about TBI before appropriate funds and uses can be established and many felt that funds should be used for advocacy. In addition, medical and service professional TBI training and housing were among the most frequently mention uses for trust funds. Appendix K gives a list of the exact survey responses and key informant responses regarding Nebraska Trust Fund use and feasibility.

Brain Injury Dedicated Funds

General and Special Revenue State Comparisons

Figure 26 depicts the states that offer general revenue, special revenue, or both general and special revenue funds for individuals with a brain injury as of 2008. A majority of the states that offer dedicated funds, apart from waivers and trust funds, are in the eastern part of the U.S.

Figure 26. 2008 Brain Injury Dedicated Funds by State ¹²



Other Brain Injury Funding Mechanisms

Payer Source and Financial Resources

Individual and Caregiver Survey: Financial Resources

Table 111 shows the financial resources that individuals and caregivers used to pay for brain injury related services. The majority of respondents used private insurance or personal funds to pay for TBI-related expenses. Medicare and Medicaid were used by approximately a third of the respondents.

Table 111. Resources for TBI-related Expenses (Multiple Responses)

Resources	n	%
Private insurance	122	42%
Personal funds	106	36%
Medicare	93	32%
Medicaid	87	30%
Personal loans from family/friends	30	10%
Legal settlement	24	8%
Vocational rehabilitation	13	4%
Workers compensation	13	4%
TBI waiver	11	4%
Veteran's administration	8	3%
Social security disability/benefits	9	3%
Special education funds	4	1%
Unemployment	3	1%
Children with special health needs	1	1%
Department of labor	1	1%
Other: Debit forgiveness, private insurance, bankruptcy, college insurance, Tricare, workman's comp, family, hospital foundation grant, TBI fund, job, law suit, crime victims compensation.	33	11%

TBI Registry Breakdown by Payer Source

Tables 112 through 116 show breakdowns of TBI payer source for emergency department and hospital visits. Commercial insurance has been the primary payer source for emergency department visits from 2005-2009; however the percentage has decreased as the percent attributed to self-pay and federal program funding sources have increased. A larger percentage of TBI hospital visits were paid through Medicare when compared to emergency room visits.

Behavioral health regions 3, 4, and 5 has a higher percent of Medicare coverage and Region 4 has a higher percentage of Medicaid payer sources for both emergency department and hospital visits.

Table 112. TBI Emergency Department Payer Source

ED Payer Source	2005		2006		2007		2008		2009	
	n	%	n	%	n	%	n	%	n	%
Commercial Insurance	2,855	57.6%	3,370	54.6%	3,760	53.0%	3,794	50.6%	4,790	53.6%
Medicaid	827	16.7%	1,021	16.6%	1,128	15.9%	1,160	15.5%	1,411	15.8%
Medicare	743	15.0%	985	16.0%	1,182	16.6%	1,309	17.5%	1,403	15.7%
Self Pay	326	6.6%	422	6.8%	587	8.3%	728	9.7%	704	7.9%
Federal Program	208	4.2%	371	6.0%	443	6.2%	507	6.8%	625	7.0%

Table 113. TBI Hospital Payer Source

Hospital Payer Source	2005		2006		2007		2008		2009	
	n	%	n	%	n	%	n	%	n	%
Commercial Insurance	319	38.2%	352	39.2%	391	36.7%	412	34.7%	493	39.1%
Medicaid	94	11.4%	90	10.0%	107	10.1%	100	8.4%	123	9.8%
Medicare	321	38.8%	357	39.7%	431	40.5%	547	46.1%	510	40.4%
Self Pay	39	4.7%	41	4.6%	71	6.7%	69	5.8%	65	5.2%
Federal Program	57	6.9%	59	6.6%	64	6.0%	59	5.0%	70	5.6%

Table 114. TBI Emergency Department Visits by Region and Payer Source (2009)

ED Age	Region 1		Region 2		Region 3		Region 4		Region 5		Region 6	
	n	%	n	%	n	%	n	%	n	%	n	%
Commercial Insurance	211	53%	280	53%	501	57%	360	53%	1,185	57%	2,253	51%
Medicaid	89	23%	113	21%	137	16%	126	19%	438	21%	508	12%
Medicare	54	14%	93	18%	152	17%	149	22%	364	18%	591	13%
Self Pay	11	3%	37	7%	58	7%	23	3%	18	1%	557	13%
Federal Program	30	8%	8	2%	33	4%	19	3%	60	3%	475	11%

Table 115. TBI Hospital Visits by Region and Payer Source (2009)

Hospital Age	Region 1		Region 2		Region 3		Region 4		Region 5		Region 6	
	n	%	n	%	n	%	n	%	n	%	n	%
Commercial Insurance	42	55%	44	52%	54	37%	42	41%	125	36%	186	37%
Medicaid	3	4%	2	2%	13	9%	12	12%	33	10%	60	12%
Medicare	25	32%	30	35%	73	50%	45	44%	160	47%	177	35%
Self Pay	1	1%	4	5%	4	3%	3	3%	1	0%	52	10%
Federal Program	6	8%	5	6%	3	2%	1	1%	24	7%	31	6%

Table 116. Emergency Department Payer Source by Age (2009)

ED Payer Source	Age <1		1-14		15-24		25-44		45-64		65+	
	n	%	n	%	n	%	n	%	n	%	n	%
Commercial Insurance	161	54%	1,659	73%	1,273	65%	847	55%	717	59%	133	10%
Medicaid	120	40%	517	23%	298	15%	156	10%	76	6%	13	1%
Medicare	0	0%	0	0%	13	1%	74	5%	167	14%	1,149	87%
Self Pay	1	0%	32	1%	217	11%	296	19%	117	10%	7	1%
Federal Program	17	6%	72	3%	151	8%	169	11%	135	11%	16	1%

Nebraska's Cost of Traumatic Brain Injury

Public and Private Costs

The estimated annual and lifetime costs of traumatic brain injuries in Nebraska are based on private and public cost research and do not reflect "actual" costs incurred to the state of Nebraska. Estimates are based off combinations of national studies and estimations, Nebraska's Traumatic Brain Injury Registry data, and United States census estimations.

Estimated Annual Costs

The CDC's National Center for Injury Prevention and Control estimates that 5.3 million U.S. citizens (2 percent of the population) are living with disability as a result of a traumatic brain injury. This represents the prevalence of TBI disability, defined as the proportion of persons in the population at a given time who have disability resulting from a traumatic brain injury.⁵

Total estimated annual costs 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.¹⁵

There are several assumptions that limit the validity of the following Nebraska annual estimate:

- Average costs are taken from services throughout the United States; therefore, costs in Nebraska may differ from the average used in the CDC estimates.
- The type of services available differ from state to state, so associated costs will vary.
- Nebraska estimates may be understated as the costs of services have increased from the time studies were undertaken (2000).
- The length of stay for services may differ from estimates used in the national study. For instance, the average length of stay in the emergency department, hospital and other services may differ from national assumptions based on many factors such as severity variations, differences in state guidelines and programs, and varying demographics of individuals injured.
- The cost may be underestimated as it does not include individuals who are receiving services or incurring losses from a brain injury who have not been to the hospital or emergency department or who have not been diagnosed with a TBI.

Using the national estimates listed above, the annual cost of a brain injury per individual is \$11,321. Based on the historical national average of 2%, it is estimated that there are **36,527** individuals with a brain injury related disability in Nebraska.

The total estimated brain injury costs for Nebraska in 2009 is **\$413,513,208** ($\$11,321 * 36,527$). Consider that the \$413,513,208 estimate may have considerable variability from the true annual cost of TBI due to the assumptions listed above.

Estimated Lifetime Costs

It is estimated that the lifetime costs for a mild brain injury is \$85,000, for a moderate brain injury is \$941,000, and for a severe brain injury is \$3 million.¹⁶

Appendix A

Table 117. 2005-2009 Traumatic Brain Injury Incidence by County

County	ER	Hospital	Death	County	ER	Hospital	Death
ADAMS	410	102	16	JOHNSON	43	20	9
ANTELOPE	64	27	7	KEARNEY	113	23	8
ARTHUR	8	2	1	KEITH	140	28	15
BANNER	18	4	0	KEYA PAHA	6	2	2
BLAINE	4	1	0	KIMBALL	72	14	4
BOONE	50	5	8	KNOX	51	16	19
BOX BUTTE	178	49	13	LANCASTER	5,751	751	199
BOYD	18	3	4	LINCOLN	1,167	143	42
BROWN	38	10	3	LOGAN	31	4	2
BUFFALO	639	113	44	LOUP	8	1	1
BURT	84	22	11	MADISON	627	122	34
BUTLER	91	25	9	MCPHERSON	5	0	0
CASS	633	71	42	MERRICK	131	24	13
CEDAR	39	10	6	MORRILL	130	24	7
CHASE	58	26	12	NANCE	60	12	6
CHERRY	78	18	10	NEMAHA	86	23	8
CHEYENNE	147	38	13	NUCKOLLS	55	18	5
CLAY	98	19	10	OTOE	254	59	23
COLFAX	121	32	13	PAWNEE	104	17	8
CUMING	112	18	11	PERKINS	48	13	5
CUSTER	220	47	18	PHELPS	96	36	14
DAKOTA	18	4	14	PIERCE	92	9	4
DAWES	131	18	10	PLATTE	826	95	27
DAWSON	322	67	33	POLK	70	15	7
DEUEL	16	6	2	RED WILLOW	136	52	16
DIXON	19	4	5	RICHARDSON	94	15	7
DODGE	900	136	32	ROCK	20	2	1
DOUGLAS	11,018	1,455	411	SALINE	219	45	16
DUNDY	44	11	1	SARPY	3,800	298	89
FILLMORE	56	18	5	SAUNDERS	459	72	27
FRANKLIN	62	20	6	SCOTTS BLUFF	803	156	41
FRONTIER	58	18	4	SEWARD	202	47	14
FURNAS	66	15	8	SHERIDAN	58	17	6
GAGE	373	85	32	SHERMAN	40	13	7
GARDEN	44	17	3	SIoux	11	2	1
GARFIELD	22	8	3	STANTON	53	13	7
GOSPER	30	5	1	THAYER	55	28	5
GRANT	16	3	0	THOMAS	15	6	3
GREELEY	28	8	5	THURSTON	40	11	15
HALL	1,066	192	62	VALLEY	81	18	5
HAMILTON	137	16	12	WASHINGTON	279	40	32
HARLAN	60	12	4	WAYNE	74	13	13
HAYES	9	1	2	WEBSTER	62	17	7
HITCHCOCK	45	8	2	WHEELER	15	5	1
HOLT	129	44	21	YORK	192	37	7

HOOVER	9	3	1	OUTSIDE NE	0	0	167
HOWARD	100	22	8	TOTAL	34,644	5,234	1,911
JEFFERSON	84	20	15				

Appendix B

Table 118. 2009 Traumatic Brain Injury Incidence by County

County	ER	Hospital	Death	County	ER	Hospital	Death
ADAMS	85	16	4	JOHNSON	15	2	0
ANTELOPE	18	6	1	KEARNEY	28	3	0
ARTHUR	0	0	0	KEITH	44	6	4
BANNER	2	2	0	KEYA PAHA	0	0	0
BLAINE	1	0	0	KIMBALL	21	5	2
BOONE	12	2	1	KNOX	22	3	3
BOX BUTTE	57	11	3	LANCASTER	1,477	224	52
BOYD	6	0	0	LINCOLN	298	32	3
BROWN	12	3	1	LOGAN	3	1	0
BUFFALO	176	19	30	LOUP	5	1	0
BURT	22	4	0	MADISON	179	19	4
BUTLER	33	5	0	MCPHERSON	0	0	0
CASS	180	18	7	MERRICK	25	7	2
CEDAR	11	0	3	MORRILL	27	7	1
CHASE	13	10	2	NANCE	13	1	1
CHERRY	18	3	1	NEMAHA	27	8	1
CHEYENNE	44	8	2	NUCKOLLS	16	3	1
CLAY	31	6	2	OTOE	52	18	4
COLFAX	33	8	1	PAWNEE	18	3	0
CUMING	34	4	2	PERKINS	7	2	1
CUSTER	60	10	1	PHELPS	31	7	5
DAKOTA	7	1	2	PIERCE	22	2	0
DAWES	34	4	0	PLATTE	192	23	4
DAWSON	66	14	6	POLK	18	3	0
DEUEL	5	0	0	RED WILLOW	33	8	1
DIXON	3	0	0	RICHARDSON	16	1	4
DODGE	182	28	4	ROCK	7	0	0
DOUGLAS	2,801	393	107	SALINE	46	11	1
DUNDY	19	0	1	SARPY	1,141	59	9
FILLMORE	8	4	0	SAUNDERS	117	11	6
FRANKLIN	13	7	1	SCOTTS BLUFF	176	28	16
FRONTIER	17	5	2	SEWARD	54	11	3
FURNAS	20	5	2	SHERIDAN	14	6	3
GAGE	94	20	3	SHERMAN	17	2	1
GARDEN	11	4	2	SIOUX	4	0	0
GARFIELD	7	2	0	STANTON	10	4	0
GOSPER	10	1	0	THAYER	9	7	1
GRANT	5	1	0	THOMAS	2	1	0
GREELEY	8	0	0	THURSTON	14	3	2
HALL	242	55	12	VALLEY	24	5	0
HAMILTON	28	2	1	WASHINGTON	80	8	3
HARLAN	20	2	0	WAYNE	15	3	2
HAYES	1	0	0	WEBSTER	13	2	1
HITCHCOCK	11	4	0	WHEELER	4	1	0
HOLT	27	7	7	YORK	62	9	3
HOOVER	2	0	0	OUTSIDE NE	0	0	23

HOWARD	27	1	3	TOTAL	8,933	1,261	383
JEFFERSON	19	6	2				