June | 2019

# Nebraska's Brain Injury State Partnership Program Mentor State Grant

**Annual Evaluation Report**JUNE 2018 – MAY 2019





#### Dear Reader:

Traumatic brain injury (TBI) is a serious public health problem in the United States. The Centers for Disease Control (CDC) reports approximately 2.5 million people sustain a TBI annually, and each year TBI contributes 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. Most TBIs are mild and their effects diminish over time, but even a mild TBI can result in permanent cognitive, physical, and behavioral changes. Individuals experiencing moderate to severe injuries may require life-long supports for housing, work, and community living.

Many Nebraskans impacted by TBI still struggle to access appropriate services to meet their needs. Nebraska Vocational Rehabilitation (VR) and the Brain Injury Advisory Council remain committed to building a comprehensive, multidisciplinary, easily accessible system of care for individuals experiencing brain injury and to ensuring awareness and training for partners in the system.

Nebraska VR serves as lead agency for a U.S. Department of Health and Human Services, Administration for Community Living TBI Implementation Partnership Grant which provides funding for states to build infrastructure and create systems change to better serve their citizens with brain injuries. The Brain Injury Advisory Council advises Nebraska VR, the Department of Education, Special Education, and the Department of Health and Human Services (DHHS) in implementing grant objectives and goals under the Nebraska State Plan for Systematic Services for Individuals with Brain Injuries.

For more information about the Nebraska State Plan for Systematic Services for Individuals with Brain Injuries, please visit the Brain Injury Advisory Council's website at <a href="https://www.braininjury.ne.gov">www.braininjury.ne.gov</a>.

This report summarizes grant-funded project outcomes for FY 2018-2019. Nebraska VR and the Brain Injury Advisory Council look forward to working with our partners and stakeholders to build better futures for Nebraskans with brain injury and their families.

Sincerely,

Keri Bennett, M.S.Ed, CBIS

Kei Bennett

Nebraska VR Program Director for ABI

**TBI Grant Project Director** 

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Report prepared by



#### **Executive Summary**

In FY 2018-2019 Nebraska was awarded a brain injury partnership grant by the Administration for Community Living (ACL), U.S. Department of Health and Human Services. This fiscal year marked the beginning of a new grant cycle with ACL. The overarching goal for Nebraska's brain injury partnership grant is to strengthen Nebraska's system of services and supports that maximizes the independence, well-being and health of people with traumatic brain injuries (TBIs) across the lifespan and all other demographics, their family members and support networks by building a statewide, voice-driven Network of individuals with TBI and their family members that are engaged and equipped to shape policies, programs, and services.

Activities from year 1 of the grant (June 2018-May 2019) are summarized below.

#### **Brain Injury Network Capacity-Building**

- Activities began in February 2019 to form a voice-driven organization of individuals with a brain injury and their family members who will advocate for and serve other individuals with a brain injury. This organization is called the Association of Nebraskans with an Injured Brain (ANIB). ANIB will be headquartered in Kearney.
- Surveys conducted among a small group of individuals interested in forming ANIB
  indicate the lack of a voice-driven approach around brain injury in Nebraska and the
  opportunity for ANIB's members to become more engaged in advocacy through
  involvement in the organization.

#### **Dissemination of Information**

- 5,292 letters were delivered to individuals on the TBI Registry.
- 2,902 website sessions occurred on the Nebraska Brain Injury Advisory Council's website.
- Numerous materials distributed at the Annual Brain Injury Conference.
- 6 information campaigns conducted through Constant Contact with 255 to 270 recipients for each campaign.

#### **Resource Facilitation Case Management**

- The Resource Facilitation program managed by the BIA provided services to 376 individuals (33 received case management services, 98 received intake and referral services, and 53 received information and referral services).
- A total of 376 referrals were made by Resource Facilitation staff.
- Barriers are documented across numerous areas for all Resource Facilitation clients. So far, 23.8% of barriers have been documented as having a successful outcome.
- Concerns in the areas of health and self-direction/care are documented for case management clients. So far, 59.7% of all concerns are documented as showing improvement.

#### **TBI Trainings and Conferences**

- A total of 58 individuals were trained at two brain injury trainings this year.
- Participants of the Living with Brain Injury Summit reported generally positive feedback regarding their increased understanding of needs of individuals with a brain injury and learning strategies for effective advocacy.

#### **Living with Brain Injury Survey**

- The Living with Brain Injury Survey was conducted in January and February of 2019 to provide data on the needs around brain injury. The results were presented and discussed at the Living with Brain Injury Summit.
- A total of 228 individuals with a brain injury, family members, and service providers responded to the survey.

#### TBI Screenings

Nebraska VR conducts approximately 475 screenings per year.

#### Nebraska Association of Service Providers (NASP) Capacity-Building Project

The NASP capacity-building project was completed this grant year. Five organizations
received training and technical assistance on how to provide services to individuals with
a brain injury. The organizations reported mixed overall improvements in their abilities
to serve individuals with a brain injury with some organizations reporting moderate
improvements and others reporting no change. Satisfaction with the project was also
mixed.

#### **TBI Registry Data**

- Since the establishment of new ICD-10 coding in the fourth quarter of 2015, there has been an average of 3,274 individuals entering the TBI registry per quarter.
- TBIs appear to occur in the Western area of the state at substantially higher rates compared to all other areas in Nebraska.

# PROGRAM MENTOR STATE PARTNERSHIP ANNUAL EVALUATION REPORT June 1, 2018 through May 31, 2019

#### **Project Purpose**

In FY 2018-2019 Nebraska was awarded a brain injury partnership grant by the Administration for Community Living (ACL), U.S. Department of Health and Human Services. This fiscal year marked the beginning of a new grant cycle with ACL. The overarching goal for Nebraska's brain injury partnership grant is to strengthen Nebraska's system of services and supports that maximizes the independence, well-being and health of people with traumatic brain injuries (TBIs) across the lifespan and all other demographics, their family members and support networks by building a statewide, voice-driven Network of individuals with TBI and their family members that are engaged and equipped to shape policies, programs, and services.

#### **Grant Objectives**

Nebraska's brain injury grant project focuses on four core areas which provides the basis for the grant objectives:

- Build capacity within the existing TBI support groups by providing leadership and capacity-building coaching to support group leaders and members in at least 10 of the 13 support groups.
- 2. Equip the Network of people with TBI and their families to advocate for policy, program and service changes by making data, resources, tools and strategies accessible to leaders and members of all 13 support groups across the state.
- 3. Engage Network members from all 13 support groups in shaping policies, programs and services by providing education in advocacy strategies and offering opportunities to advocate.
- 4. Connect newly-injured individuals with TBI and their family members to the Network and the existing system of services and supports in underserved, rural areas of the state by training a TBI Peer Resource Navigator from 6 of the 13 support groups.

#### **Brain Injury Network Capacity-Building**

An important part of Nebraska's brain injury grant focuses on network capacity-building. A contract was put in place with a facilitator (John M. Ferrone Management Consulting, Inc.) on February 12<sup>th</sup>, 2019 to begin work on building a new network of individuals with a brain injury and their family members. Recruitment for membership to the network will initially be drawn from brain injury support groups. However, recruitment is not solely limited to the support groups. In the first three and a half months of the project, it was determined that a new non-profit organization will be established with a headquarters located in Kearney to serve as the central organization for the network. This organization will be called the Association of Nebraskans with an Injured Brain (ANIB) and is a "voice-driven" organization — meaning it is comprises of individuals with a brain injury and their family members serving and advocating for other individuals with a brain injury and their family members. Chapters will be formed across the state. A chapter is currently under development in North Platte.

Following is a brief summary of activities and achievements of the brain injury network capacity-building project as outlined by the facilitator of the project:

- 1. Contract began February 12th, 2019, but weather and other setbacks delayed the progress.
- 2. Initial plan/approach was to work in collaboration with the Support Groups; however, only two were interested: North Platte and Kearney.
- 3. Because the Kearney group had the original idea of creating a voice-driven Association of people who have an injured brain and their family members, the effort to start an Association is beginning there. In North Platte, a Chapter will be formed by the people of the Support Group.
- 4. The Association and its Chapters will form the infrastructure for networking. And, these will not replace or usurp the existing Support Groups.
- 5. In Kearney, there are a dozen people participating in the planning phase. This Kearney Planning Group will work to plan the new Association while at the same time the North Platte Support Group will explore what it could mean to be a Chapter.
- 6. The Kearney Planning Group hopes to have a plan completed by the end of the summer so that it can pursue incorporation and a 501c3 status in the Fall.
- 7. An Oversight Committee consisting of BIAC members was formed and has met with John via GoToMeeting twice.
- 8. Overall, there is a very high level of enthusiasm for the initiative. And, everyone is looking forward to collaborating with the BIAC and the BIA-NE, as well as other stakeholders.

#### **Statewide Voice Assessment**

The key component of the brain injury network capacity-building project is to create a voice-driven organization to represent individuals with a brain injury. In order to ascertain the perception of such an organization among those whom the organization intends to serve, the facilitator for the project created the Statewide Voice Assessment Tool, which is a brief eight-question survey. The survey was administered in June 2019, which is technically outside of the grant year for this report. However, the results from the survey reflect the new nature of the project and serve as a sort of baseline from which to determine improvement.

The Statewide Voice Assessment Tool was administered to 13 individuals in Kearney who are involved in the early stages of creating a non-profit voice-driven organization, which is called the Association of Nebraskans with an Injured Brain (ANIB). As can be seen from the results of the survey in Figure 1, respondents gave the voice-driven organization low ratings across all seven of the eight questions due to the fact that the organization is just beginning to get started. Respondents gave higher ratings to survey item #8 regarding funding from grants, due to the project being funded by Nebraska VR's current grant.

Fig	Figure 1 Statewide Voice Assessment Tool Results by Question:  Baseline Results from the Kearney ANIB Meeting – June 2019				
VPE	3I stands	for Voice of People with a Brain Injury	Average rating (0=low, 5=high)		
1.	How w	ell is the VPBI represented in your state? (n=13)	1.5		
2.	-	ple with a brain injury across the state have an organized and ed means of communicating with each other? (n=13)	1.2		
3.	have an	ncy leaders, community leaders, and other people who may interest in the collective VPBI have a point of contact to the collective VPBI, and is that point of contact able to ent a collective opinion or perspective? (n=13)	1.1		
4.		e an entity among the people who have a brain injury that they or support, training, access to programs, etc.? (n=13)	1.2		
5.		PBI organized to the extent that it benefits from revenue ?? (n=13)	0.9		
6.	policies input, a	ne VPBI have the ability to collectively interact and discuss and programs that affect the VPBI, determine response and and contribute such responses and input through appropriate Is? (n=13)	0.9		
7.	To wha (n=13)	t extent is the general public aware of the collective VPBI?	0.9		
8.		t extent is the VPBI included in grant applications and other n funding requests? State block grant planning? (n=13)	2.8		

#### **Advocacy Activity Scale**

Another measurement that is an important part of the brain injury capacity-building project to form a voice-driven organization is the Advocacy Activity Scale. This scale measures the extent of the advocacy activities around brain injury. As with the Statewide Voice Assessment tool, the Advocacy Activity Scale was administered to the 13 individuals in Kearney at the June ANIB meeting. Again, although the survey was technically administered outside of the grant year which this report covers, it was felt that the results serve as a baseline and are pertinent information to include in this report.

Figure 2 presents the results from the Advocacy Activity Scale. The vast majority of the participants had not done any type of public advocacy (public speaking, contacting political representatives, raising money for organizations, etc.) in the past 12 months. However, most of the participants reported that they have worked with a group to improve the lives of people with brain injury and discussed social changes (see items 5 and 6 below). This would seem to indicate that, despite the lack of public engagement, the ANIB group has individuals who are prepared and informed to engage in broader activities related to public advocacy when given the opportunity.

Advocacy Activity Scale Results by Question:  Baseline Results from the Kearney ANIB Meeting – June 2019						
In the last 1	2 months, how many times have you	Not at all	1-3 times	More than 3 times		
	ed a public meeting or rally to improve the lives ple with brain injuries? (n=13)	92.3%	7.7%	0.0%		
-	at a public meeting or forum to support people rain injuries? (n=13)	92.3%	7.7%	0.0%		
3. Called, wrote, or e-mailed a political representative or someone else who has a role in deciding about services for people with brain injuries or funding for these services? (n=12)		91.7%	8.3%	0.0%		
about	in-person someone who has a role in deciding services for people with brain injuries or funding se services? (n=12)	91.7%	8.3%	0.0%		
	d with a group to improve the lives of people rain injuries? (n=13)	38.5%	38.5%	23.1%		
	sed social changes to help people with brain swith family or friends? (n=13)	30.8%	46.2%	15.4%		
	d to elect a political candidate who supported with brain injuries? (n=13)	100%	0.0%	0.0%		
	outed money to help organizations or people upport people with brain injuries? (n=13)	84.6%	7.7%	7.7%		
	money to help organizations or people who t people with brain injuries? (n=13)	100%	0.0%	0.0%		
other c	a letter to the editor, gave an interview, or had contact with the media to support people with njuries? (n=13)	92.3%	7.7%	0.0%		

Figure 2 continued

11. Overall, how much time are you involved in the types of advocacy activities described in items 1-10? (n=13)	Not at all	Less than 25% of my time 69.2%	More than 25% of my time 0.0%
	For self and/or significant other with BI	For self, sig. other, and for people in town, state, or region with BI	On a national level
12. Please check one choice below that best describes the focus of your advocacy activities. (n=13)	61.5%	38.5%	0.0%
	Do not belong	Member	On board or employed
13. Check one choice below that best describes your involvement with the Brain Injury Alliance during the last 12 months. (n=13)	100%	0.0%	0.0%
	Advocacy is not effective	Advocacy is a part of my life	Advocacy is a central prat of my life
14. Check one below that best describes your opinion of advocacy for people with brain injuries. (n=8)	50.0%	37.5%	12.5%

(Note the relatively small number of respondents to item 14.)

#### **Dissemination of Information**

The dissemination of information conducted by the NE VR TBI program is organized under four main areas: Nebraska Brain Injury Registry Letters, Nebraska Brain Injury Advisory Council Website, materials distributed at the Brain Injury Conference, and Constant Contact. Figure 3 contains a summary of the information disseminated under each of these four areas.

Figure 3	Dissemination of Information Summary: June 1, 2018 – May 31, 2019			
Nebraska Brain Injury Registry Letters		<ul> <li>Registry letters mailed: 5,684</li> <li>Letters returned undeliverable: 392</li> <li>Total registry letters delivered: 5,292</li> </ul>		
Nebraska Brain Injury Advisory Council Website		<ul> <li>Website visits: 2,902</li> <li>Between 95 and 411 unique visitors per month</li> <li>(see below for more details)</li> </ul>		
Materials Distributed at Brain Injury Conference (March 2019)		<ul> <li>BI and Opioid Overdose Fast Facts: 75</li> <li>Accommodating the Symptoms of TBI booklets: 50</li> <li>Fact Sheet on VR and BIAC: 50</li> <li>Business cards for Council Chairperson: 25</li> </ul>		
Constant (	Contact Statistics	<ul> <li>Conducted 6 distinct information campaigns through Constant Contact during the grant year.</li> <li>There were between 309 and 359 recipients for each Constant Contact campaign that was sent out.</li> </ul>		

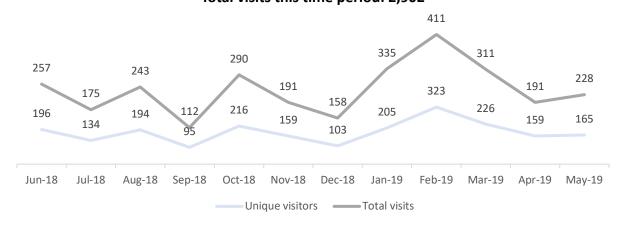
#### Nebraska Brain Injury Advisory Council (BIAC) Website Analytics

Figure 4 below shows the monthly number of visits and unique visitors to the BIAC website.

Figure 4. Nebraska Brain Injury Advisory Council Monthly Website Traffic:

January - May, 2018

Total visits this time period: 2,902



The most common drivers to the BIAC website are direct and search engine, comprising nearly three-fourths of all traffic. Referrals from other sites make up nearly one-fourth (the most consistent number of referrals come from biane.org and traumaticbraininjury.com) Referrals from social media comprise a very small fraction of all visits (Figure 5)

Referral from another site 24% (689 visits)

Social media (Facebook and Twitter) 2% (68 visits)

Search engine 30% (858 visits)

Figure 5. Traffic Drivers to the BIAC Website

#### **Information and Referral**

Information and referral services for survivors of TBI are conducted by four organizations: The Brain Injury Alliance of Nebraska (BIA), Disability Rights Nebraska, the Hotline for Disabilities, and the Aging and Disability Resource Center (ADRC). Between these four organizations, 510 individuals received information and referral services during this grant year (Figure 6). Note that case management clients are included in this total.

Figure 6	Information and Referral Summary: June 1, 2018 – May 31, 2019			
Brain Injury Alliance of Nebraska (BIA) Resource Facilitation		Served  > 53 information and referral clients  > 98 intake and referral clients  > 33 case management clients  A total of 376 referrals were made for these clients this year.		
Disability I	Rights Nebraska	Provided 49 information and referral services for 40 individuals with a TBI.		
Hotline for Disabilities		Provided information and referral services to 18 individuals with a TBI.		
Aging and Center (AE	Disability Resource DRC)	Served  > 190 information and referral clients  > 69 Options Counseling clients  A total of 197 referrals were made for these clients this year.		
Total		Provided information and referral services to 510 individuals with a TBI.		

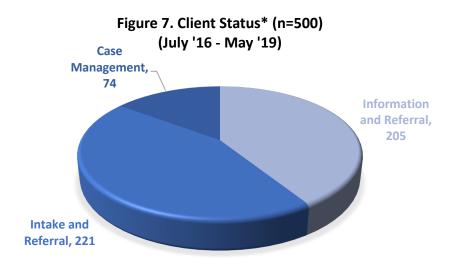
#### Resource Facilitation Case Management (July 2016 through May 2019)

Resource Facilitation conducted by Brain Injury Alliance of Nebraska (BIA) involves close, potentially long-term, one-on-one interaction between a brain injury survivor and a resource facilitator. The Resource Facilitator assists the survivor in navigating resources in their community, evaluating progress with the survivor and family/caregivers, and setting and achieving goals.

The data in this report cover the time period of July 2016 through May 2019 (2 years, 11 months). In July 2016, the Resource Facilitation transferred to a more sophisticated data collection system designed specifically for TBI Resource Facilitation. During this time period, the Resource Facilitation program served 500 individuals. It is important to note that not all data variables are collected for these 500 individuals. There are some variables that are not collected for clients with a lower level of involvement in the program. **Note: for the count of those who were served in this fiscal year alone, see the "Information and Referral" section above.** 

#### **Client Status**

Services can be a fairly simple interaction (Information & Referral) to something more complex (Intake & Referral). Figure 7 below displays the status of the 500 clients served from July 2016 through May 2019.



<sup>\*</sup>Includes all cases that were active during this time period. Some of these cases are now closed.

#### **Intakes Over Time**

Figure 8 documents the number of intakes to the Resource Facilitation program by time period. The number of intakes by time period has remained fairly constant since January 2017.

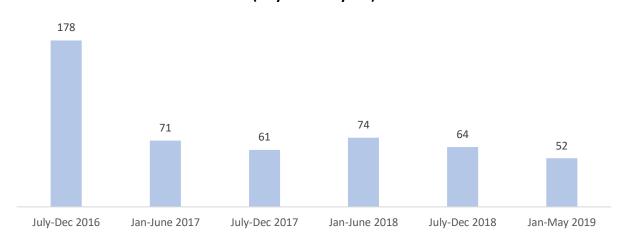


Figure 8. Intakes to the RF Program by Six-Month Time Period (n=500) (July '16 - May '19)

#### **Client Demographics**

Figure 9 details the time between brain injury and intake by the Resource Facilitation Program. There is a wide range among clients in terms of time between brain injury and intake by the Resource Facilitation Program. The average time between brain injury and intake is 9.0 years.

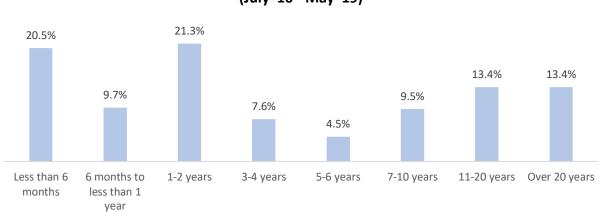


Figure 9. Time between Brain Injury and Intake by the Resource Facilitation Program (n=380)

(July '16 - May '19)

Figure 10 outlines additional client demographics.

Figure 10	Figure 10 Basic Demographics (July '16 – May '19)				
0 / ( 554)		Male	55.1%		
Gen	der (n=454)	Female	44.9%		
		Under 20	12.4%		
		20-39	29.6%		
_	Age at time of intake (n=355)	40-59	39.4%		
		60 and over	18.6%		
		Average Age	43.2		
Paco/ot	hnicity (n=405)	White/Caucasian	86.7%		
Ruceyet	milicity (II–403)	Non-White/Caucasian	13.3%		
		Omaha Area*	40.8%		
llows la	Home location (n=360)	Lincoln Area°	24.4%		
поте к		Greater Nebraska	30.3%		
		Out-of-State	4.4%		

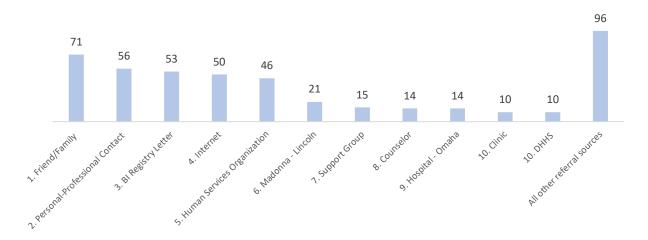
<sup>\*</sup>Omaha Area includes Douglas and Sarpy Counties and Council Bluffs.

<sup>°</sup>Lincoln Area includes Lancaster and Seward Counties.

#### Source of Referral to Resource Facilitation

The top 10 sources for referrals to Resource Facilitation are detailed below in Figure 11.

Figure 11. Top 10 Sources for Referrals to the Resource Facilitation
Program (n=456)
(July '16 - May '19)



#### **Cause of Brain Injury**

The top 10 causes of brain injury for Resource Facilitation clients are detailed below in Figure 12.

Figure 12. Top 10 Causes of Brain Injury (n=393) (July '16 - May '19) 121 76 48 31 28 18 17 14 11 11 9 9 1. Motor 2. Fall 3. Assault 4. Stroke 5. Medical/ 6. Sports/ 7. Anoxia 8. Bicycle 8. Tumor 10. 10. All other Vehicle disease rec Gunshot Motorcycle causes of Crash brain injury

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#### **Barriers**

A strong majority (79.3%) of Resource Facilitation clients have physical and mental health barriers at time of intake. More than half of clients have barriers in the areas of housing, TBI awareness, vocation, and finances at time of intake (Figure 13). On average, clients have barriers in 5.5 of the 12 domains listed below in Figure 6 at time of intake.

Figure 13. Percentage of Clients Experiencing Barriers in the Following Areas at Intake (n=376)
(July '16 - May '19)

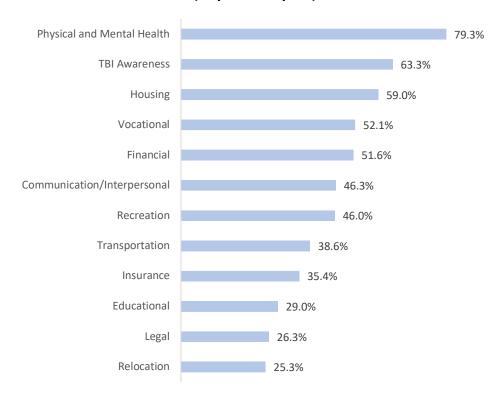


Figure 14 documents successful outcomes for barriers among all clients. The highest success rates are seen in the areas of insurance, TBI awareness, financial, and relocation, among other areas. It is important to note that Figure 14 contains data for all clients. Many clients only have barriers documented at one initial intake point.

Figure 14	Successful Outcomes for Barriers (n=376) (July '16 – May '19)				
	ntake, experienced a ne following areas:	Number of clients experiencing a barrier	Number of clients with a successful outcome	Success rate	
Insurance	e	133	72	54.1%	
TBI Awar	eness	238	95	39.9%	
Financial		194	55	28.4%	
Relocation	on	95	23	24.2%	
Physical a	and Mental Health	298	63	21.1%	
Housing		222	44	19.8%	
Legal		99	19	19.2%	
Recreation	on	173	33	19.1%	
Education	nal	109	19	17.4%	
Vocation	al	196	34	17.3%	
Commun	ication/Interpersonal	174	26	14.9%	
Transpor	tation	145	11	7.6%	
Total Bar	riers	2,076	494	23.8%	

Note: Many clients are still active, and therefore barriers are still being reduced.

#### **Employment and Financial**

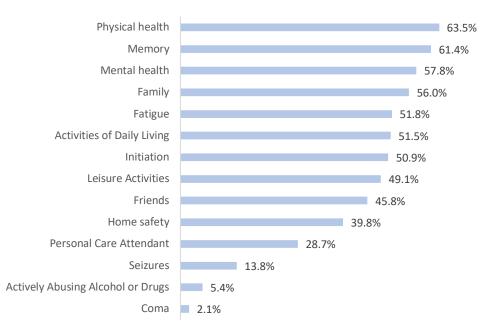
Approximately two-in-five (39.4%) Resource Facilitation clients are reportedly unable to work due to their brain injury. Slightly less than one-in-three (30.0%) are employed (Figure 15).

Figure 15	Employment Summary (as of most recent update)* (n=330) (July '16 – May '19)				
		Number of clients	Percentage of total		
Employed (part-time or full-time) 99 30.0%			30.0%		
In job training or job search 23 7.09			7.0%		
Volunteer		14	4.2%		
Support to perform job (job coach)		7	2.1%		
Unemployed		26	7.9%		
Unable to work		130	39.4%		
Retired		31	9.4%		

#### Concerns Related to Health and Self-Direction/Care

Concerns at intake related to health and self-direction/care are displayed below in Figure 16. Memory is the top concern, documented for nearly two-thirds (65.5%) of clients.

Figure 16. Percentage of Clients with Concerns in the Following Areas at Intake (n=334)
(July '16 - May '19)



Among clients for whom concerns and improvements in health areas have been indicated across at least two time points, 60.5% of all concerns in the domains related to health have been documented as showing improvement (Figure 17). Again, it is important to note that many clients still active and these are still being worked on.

Figure 17	Concerns and Improvements in Health Areas* (n=59) (July '16 – May '19)				
		Clients with a concern in this area at intake	Clients with an improvement in this area	Improvement rate	
Physical	health	28	21	75.0%	
Fatigue		28	18	64.3%	
Home safety		17	10	58.8%	
Mental health		36	18	50.0%	
Seizures		5	2	40.0%	
Total		114	69	60.5%	

<sup>\*</sup>Includes clients who have concerns/improvements indicated at two or more time points. Note: Many clients are still active, and therefore areas of concern are still being improved.

Among clients for whom concerns and improvements in areas related to self-direction/care have been indicated across at least two time points, 59.1% of all concerns in the domains related to self-direction/care have been documented as showing improvement (Figure 18).

Figure 18	Concerns and Improvements in Self-Direction/Care* (n=61) (July '16 – May '19)				
		Clients with a concern in this area at intake	Clients with an improvement in this area	Improvement rate	
Activities of Daily Living		22	20	90.9%	
Leisure Activities		27	20	74.1%	
Initiation		30	21	70.0%	
Personal Care Attendant		11	7	63.6%	
Family	Family		14	48.3%	
Friends		26	11	42.3%	
Memory		36	14	38.9%	
Total		181	107	59.1%	

<sup>\*</sup>Include clients who have concerns/improvements indicated at two or more time points. Note: Many clients are still active, and therefore areas of concern are still being improved.

#### **Mayo-Portland**

The Mayo-Portland Adaptability Inventory ("short version") is a tool used to ascertain needs of individuals who have suffered a brain injury. The tool measures self-care, residence, transportation, employment, and other basic needs. The "short-version" of the Mayo-Portland includes eight inventory items with a minimum score of 0 and maximum of 30. The lower the score on the Mayo-Portland, the greater the independence, and the lesser interference from injuries, for an individual with a TBI. The average, healthy adult, would likely have a score of zero or near zero.

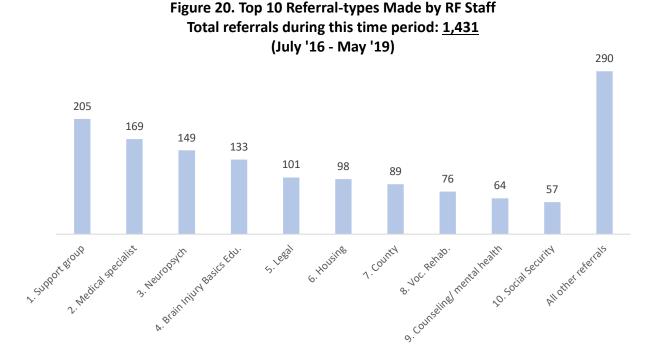
While numerous Mayo-Portland assessments have been completed, a total of 18 clients have a pre and a post Mayo-Portland. The average Mayo-Portland score for these 18 clients has improved (decreased) by 25.6% from pre to post (Figure 19).

Figure 19	Mayo-Portland Pre and Post Summary (n=18) (July '16 – May '19)				
with a Pre	Number of clients with a Pre and Post Mayo-Portland  Average Score at Pre Post Post Improvement				
18	3	16.8	12.5	25.6%	

Note: Decrease in score indicates improvement.

#### Referrals Made by Resource Facilitators

The top 10 referral-types made by Resource Facilitation staff are displayed below in Figure 20. A total of 1,431 referrals have been made by staff during this time period. This makes for an average of 2.9 referrals per client. Of course, clients with a more intensive involvement will receive a greater number of referrals than information and referral clients.



## **TBI Trainings**

Two TBI trainings were offered this grant year. The dates and participants of these trainings are detailed below in Figure 21.

Figure 21	gure 21 TBI Trainings: Dates and Participants									
		Date	Participant Description	Number of Participants						
Brain Injury Summit		March 2019	Individuals with a brain injury, their family members, and service providers.	51						
TBI Modules		Ongoing	Various professionals and family members serving individuals with TBI	7 (unique) Intro training: 3 Pediatric training: 3 Adult training: 3 Substance training: 3						
Total		-	-	58						

#### Living with Brain Injury Summit

A total of 33 surveys were completed by participants in the Living with Brain Injury Summit. Figure 22 below presents the results from the evaluation survey. In general, most participants in the Summit reported an overall positive experience.

**Figure 22. Living with Brain Injury Summit Results** 

				Neither			
<u>A</u>	s a result of today's summit	Strongly disagree (1)	Disagree (2)	agree nor disagree (3)	Agree (4)	Strongly agree (5)	Average (1-5)
1.	I have a good understanding of the "Voice Generated Statewide Vision" for brain injury. (n=31)	9.7%	12.9%	12.9%	58.1%	6.5%	3.4
2.	I believe the "voice generated" approach will be effective in meeting the diverse needs of individuals with a brain injury. (n=31)	3.2%	3.2%	22.6%	51.6%	19.4%	3.8
3.	I have a good understanding of the needs of individuals living with a brain injury as a result of the presentation of survey results and discussion of those results. (n=33)	0.0%	3.0%	18.2%	63.6%	15.2%	3.9
4.	I have a good understanding of current legislative efforts related to brain injury. (n=33)	6.1%	0.0%	15.2%	57.6%	21.2%	3.9
5.	I have a good understanding of strategies for effective advocacy. (n=33)	3.0%	3.0%	6.1%	60.6%	27.3%	4.1
6.	An effective action plan for advocacy was developed. (n=30)	3.3%	13.3%	40.0%	36.7%	6.7%	3.3
7.	There is positive momentum in meeting the needs of individuals with a brain injury. (n=32)	6.3%	3.1%	9.4%	53.1%	28.1%	3.9
8.	I feel like I was able to be a valuable participant in today's summit. (n=33)	9.1%	3.0%	6.1%	54.5%	27.3%	3.9
		Strongly disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Strongly agree (5)	Average (1-5)
9.	Overall, how satisfied are you with today's summit? (n=33)	3.0%	3.0%	3.0%	57.6%	33.3%	4.2

Participants were asked to describe what they believe to be the most valuable outcome of the Living with Brain Injury Summit. A selection of responses is displayed below.

- "Voice to be heard. We look normal but when we have TBI we struggle. Need to be listened to. Believed."
- "I just get rejuvenated every year talking and learning more about my life with a BI and learn about services that will hopefully be available as my issues progress and change."
- "Learning that people with brain injuries feel so much that people don't understand them need them to teach us how to understand so we can do a better job supporting them."
- "Passion relit. Advocacy needs to continue. Keep pushing."
- "Got to meet and work with people from all over the state working with brain injury with the same goals - educate the public and legislature."
- "I felt more comfortable asking for help. I learned about advocacy and this it isn't as hard as it thought it might be."
- "It brought survivors together to discuss common goals and learn about major initiatives."

#### **Living with Brain Injury Survey**

In the Fall of 2018 Nebraska VR and Schmeeckle Research developed the Living with Brain Injury Survey and the survey was administered in January and February of 2019. The Living with Brain Injury Survey is comprised of three unique surveys for (1) individuals with a brain injury, (2) their family members/caregivers, and (3) brain injury service providers. Numerous partners provided feedback on the survey and assisted in the administration of the online survey by distributing the link to potential participants.

The purpose of the Living with Brain Injury Survey is to answer questions such as...

- What services are individuals with a brain injury and their family members needing right now?
- What are the barriers to those services?
- And ultimately, how can we address the needs, gaps, and/or barriers facing individuals with a brain injury, their family members, and service providers?

Results from the survey were presented at the Living with Brain Injury Summit in March 2019 and contributed to a fruitful conversation on the needs of around brain injury in Nebraska. The survey link is posted on the Brain Injury Advisory Council's website and responses continue to be collected. Through February 2019, the number of respondents to the survey is as follows:

- 114 individuals with a brain injury
- <u>68</u> family members/caregivers of individuals with a brain injury
- 46 brain injury service providers (includes those whose organization provides a variety of services, including services to brain injury)

Key findings of the survey include the following:

- Regardless of the service, individuals with a brain injury feel that service providers do not understand brain injury.
- Care coordination services are the most needed types of services as reported by individuals with a brain injury.
- Family members of individuals with a brain injury experience significant financial and emotional hardships and are in need of support services.
- Brain injury service providers perceive considerable gaps in most services for individuals with a brain injury.
- Brain injury service providers are prepared to provide those services that are most needed for individuals with a brain injury if more funding is made available.

#### **TBI Screenings**

Since 2008, Nebraska VR has incorporated brain injury screening in its intake and assessment practices. VR now screens approximately 475 applicants each year for acquired brain injury (ABI). A pre-screening question on the agency application form alerts staff to follow up with an individual who indicates he or she may have experienced a brain injury from a traumatic or non-traumatic event (or both). To date, the top five challenges noted by those screening positive for potential brain injury incidents are:

- 1. Repeating myself because I don't remember what I told someone.
- 2. Feeling exhausted or overwhelmed by my memory problems.
- 3. Struggling to complete paperwork or steps to get the services I need.
- 4. Fearing memory problems will make finding the job I want difficult.
- 5. Struggling to remember what people have said to me.

Nebraska VR applicants and clients that screen positive for potential brain injury incidents are provided with more information on brain injury and where to locate resources close to home.

#### Nebraska Association of Service Providers (NASP) – Capacity-Building Project

The NASP Capacity Building Project was carried over from the previous year. This project involved hiring two consultants to work with five service providing agencies in Nebraska to enhance their capacity to serve individuals with TBI. In FY 2017-2018 and initial two day training was conducted. Following that, one-on-one consultation was conducted to assist the five agencies to better serve and be compensated for working with individuals with brain injury.

The five agencies that received consultation on improving capacity to provide services to individuals with a brain injury were:

- Employment Works
- Integrated Life Choices
- North Star Services
- Ollie Webb Center
- Omni Behavioral Health

At the conclusion of the project in early 2019, each of the five agencies received an opportunity to provide feedback and their assessment of the project. Four of the five agencies completed their assessment. Two of the four organizations reported that they have been able to at least moderately improve their organizations' capacity to serve individuals with a brain injury in such areas as screening, providing services, and developing institutional policies and infrastructure. The other two organizations reported no changes in their organizations' capacity to work with individuals with a brain injury. All of the organizations created three goals at the beginning of the project. At the time of the close of project, all of these goals were documented as either not being completed at all or only being partially completed. No goals were documented as being fully completed.

#### **TBI Registry Data**

This section presents TBI Registry Data from 2013 through 2017. Beginning in October 2015, medical coding switched from ICD-9 to ICD-10 coding systems. When the code for "open wound of head" is excluded, the switch to ICD10 has led to a slight decrease in the number of cases reported to the TBI Registry as shown in Figure 23. However, excluding these "open wound of head" cases has led to a more accurate representation of brain injury within the TBI Registry. Since the establishment of ICD-10 in the fourth quarter of 2015, there has been an average of 3,274 individuals entering the TBI registry per quarter.

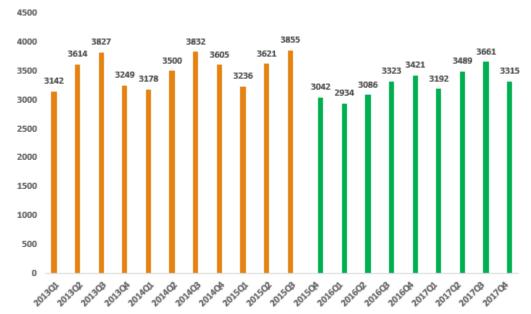


Figure 23. Number of Individuals Entering the TBI Registry by Quarter\* (2013-2017)

\*Does not include the primary diagnosis "open wound of head" (S01.0-S01.9)

Figures 24 and 25 present data on TBI rates per 100,000 population. TBI's are most prevalent among those 85 and over. Males under the age of 25 have notably higher rates of TBI than females of comparable age.

■ICD9CM ■ICD10CM 171 173 

Figure 24. Age-adjusted TBI Rates per 100,000 by Quarter (2013-2017)

(Source: Nebraska Traumatic Brain Injury Registry)



Figure 25. Gender and Age-specific TBI Rates (2013 – 2017)

Local health districts in the Western region of the state (Panhandle and West Central) have the highest rates of TBI in Nebraska (Figure 26). Figure 27 below shows a map of Nebraska's Local Health Districts.

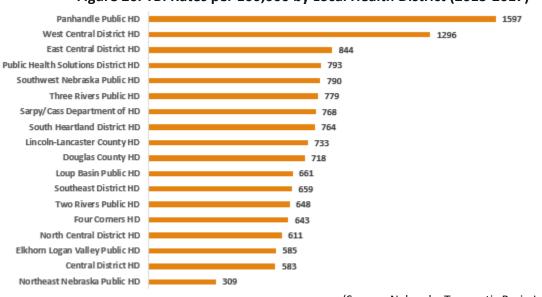


Figure 26. TBI Rates per 100,000 by Local Health District (2013-2017)

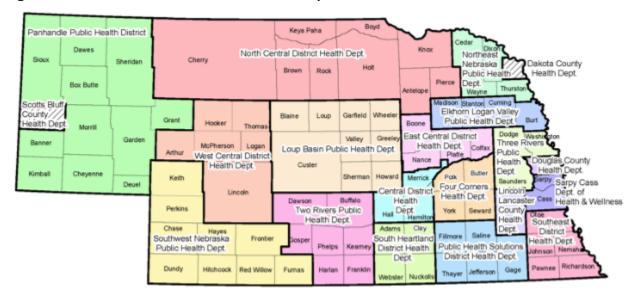


Figure 27. Nebraska's Local Health Districts Map

The leading cause of unintentional TBI-related injuries is falls, accounting for nearly half (47%) of cases in the registry (Figure 28).

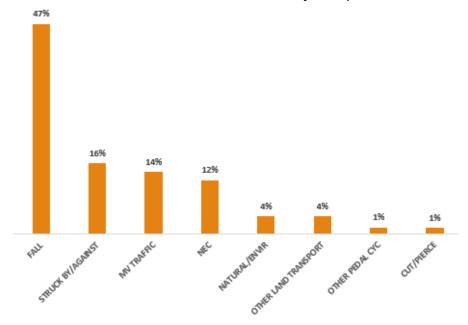


Figure 28. Unintentional Causes of TBI-Related Injuries (October 2015 –2017)