

U.S. Administration for Community Living
Traumatic Brain Injury State Partnership Program Mentor State Grant
Semi-Annual Performance Report

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Project Title: Nebraska Builds a Statewide, Voice-Driven Traumatic Brain Injury Network

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Activities and Accomplishments

Nebraska's project goal is to increase state and national capacity to provide access to comprehensive and coordinated services for individuals with traumatic brain injury (TBI) and their families 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.

1. What did you accomplish during this reporting period and how did these accomplishments help you reach your stated project goal(s) and objective(s)? Please note any significant project partners and their role in project activities.

Project objective #1 is to build the foundation for a statewide, voice-driven Network with 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 during Years 1-3 of the project. A request for proposals (RFP) was released in late 2018, and a qualified contractor was chosen. The contractor began leadership coaching with 13 members from two support groups located in the more rural, south central part of the state in February, 2019. The local Area Agency on Aging (AAA) and Aging and Disability Resource Center (ADRC) site provided free meeting space for the group. A committee of Brain Injury Advisory Council (BIAC) members and Nebraska Vocational Rehabilitation (VR) staff provided oversight and support for the project. Although work began only a few months ago, project participants have already learned how powerful and effective a voice-driven association of individuals with brain injury and their family members can be. The project has provided the infrastructure needed for networking and building leadership capacity, and outreach to include additional support groups is ongoing. Overall, there is a high level of enthusiasm for the project.

Nebraska VR and the BIAC began revising the BIAC bylaws and operational procedures to clarify and strengthen the relationship between the two entities, and to support the addition and full inclusion of many more individuals with brain injury. Nebraska VR consulted with the **Advisory Boards and Survivor Engagement** workgroup Mentor states (Tennessee and West Virginia) on best practices for including conflict of interest policies in advisory board bylaws. The revisions will be completed during the next reporting period, along with revisions to the BIAC membership application and associated orientation and meeting materials.

Project objective #2 is to 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 during Years 1-3 of the project. New support group leader email addresses were added to the BIAC mailing list. When the *2019 Living with Brain Injury Survey* was launched, all support group leaders were notified and provided a tip sheet for helping their group members complete the survey. Paper copies of the survey were provided upon request. Monthly support group meetings were added to the BIAC website calendar, and meeting agendas were posted when available. Nebraska VR pursued a contract with the Department of Health and Human Services (DHHS), Division of Public Health to add optional questions regarding life-time history of TBI incidents to the annual *Behavioral Risk Factor Surveillance System (BRFSS) Survey*, conducted in early 2019. *BRFSS Survey* data will be available in 2020. The final *2019 Living with Brain Injury Survey* results and other reports were disseminated via the BIAC mailing list and posted to the BIAC website.

Project objective #3 is to 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 during Years 1-3 of the project. The BIAC Public Policy committee

partnered with the BIA-NE, individuals with brain injury, and their family members from across the state to advocate for passage of LB481, the Brain Injury Trust Fund Bill. After many attempts over nearly two decades, the bill was passed to create the Brain Injury Trust Fund, which will receive \$500,000 per year, appropriated from the state's Health Care Cash Fund for brain injury resource facilitation and other services and supports. This landmark legislation is a key step in creating a sustainable, responsive, statewide system of services and supports for individuals with brain injury, their families and caregivers.

The *2019 Living with Brain Injury Survey*, a needs assessment survey of individuals with brain injury, family members, caregivers and service providers, was conducted in early 2019, primarily in an online format. The survey questions were drafted with input from the BIAC, the BIA-NE and several support group leaders. Some support group members completed printed copies of the survey, and BIA-NE staff assisted some individuals in completing the survey online. The survey link is maintained on the BIAC website for individuals to complete at any time. Additional survey results are collected and analyzed quarterly, and will be reported in next year's data. Feedback from advocates, individuals with brain injury and their family members will be used to redesign the survey questions and process for next year. The report, titled *2019 Living with Brain Injury Survey Results: A Nebraska Needs Assessment* is attached as Appendix A.

Nebraska's *1st Annual Living with Brain Injury Summit* was held on March 27, 2019. It was scheduled on the day before the *Annual Brain Injury Conference* to encourage attendance for both events. The event was located in the south-central part of the state, permitting better attendance from rural communities. The venue offered remote access to event proceedings for those who could not attend in person. Fifty-one participants attended, including individuals with brain injury, family members and service providers. Participants provided input on solutions to

address the unmet and insufficiently met needs, service gaps and barriers identified in the *2019 Living with Brain Injury Survey Results*. The agenda also included presentations on advocacy and public policy from the BIA-NE, Disability Rights Nebraska (DRN) and the Statewide Independent Living Council (SILC). The *1st Annual Living with Brain Injury Summit* promotional flyer, agenda, small group discussion summary and evaluation are attached as Appendix B.

Nebraska VR and the BIAC reviewed the *2019 Living with Brain Injury Survey Results*, BIA-NE Resource Facilitation program data, TBI Registry data, *Summit* small group discussion summary, and other data sources to draft initial objectives for an *Annual Brain Injury State Plan*. Nebraska VR requested and was granted an extension from the Administration for Community Living (ACL) to submit the *State Plan* by August 15, 2019 to allow adequate time for public review and input. The additional time will be used to disseminate the draft *State Plan*, and to hold statewide public meetings via videoconference to obtain input from stakeholders. The *State Plan* will address the unmet and insufficiently met needs, service gaps and barriers identified by the individuals with brain injury and family members from across the state, along with objectives to pursue the *Voice-Generated Statewide Vision*, adopted by the BIAC in 2017.

Project objective #4 is to 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 during Years 2 and 3 of the project. Grant staff requested and received technical assistance from the TBI Coordinating Center on “Disability Peer Navigators” that will inform development and implementation of Nebraska’s TBI Peer Resource Navigator model. A committee of BIAC

members and other stakeholders will review research, request technical assistance and draft a model for statewide TBI Peer Resource Navigator development in Year 2.

During this reporting period, letters and brochures were delivered to 2,526 individuals placed on the TBI Registry with newly diagnosed brain injuries. Nebraska VR contracted with the DHHS, Office of Injury Surveillance (OIS) to provide names and demographic data on individuals reported to the registry, sorted by age group (birth-21, 22-59 and 60+) and by region (western, central and eastern Nebraska) so that the mailings could be customized. Brochures listing state and local resources specific to each age group in the rural western area are titled *TBI Registry Western Area Brochures* and attached as Appendix C. The color-coded brochures will assist individuals and their families to locate age appropriate resources in their area. The brochures will also be distributed to the listed agencies and local support groups as resources to hand to individuals and families impacted by TBI. Grant staff continued listing monthly local support group meetings and agendas on the BIAC website calendar to help connect individuals with brain injury and their families to others in their area.

Project Objective #5 is to increase national capacity to provide comprehensive and coordinated services to individuals with TBI by providing mentorship and technical assistance to Partner State Grantees in Years 1-3 of the project. Nebraska VR serves as a co-Mentor for the **Transition and Employment** and **Using Data to Connect People to Services** workgroups. Nebraska VR's grant staff provided leadership, and administrative, communications, and technical support for online workgroup meetings and maintained the contact lists for each group. The **Transition and Employment** Mentor and Partner state representatives met online each month during the reporting period. The group included representatives from Indiana, Nebraska, North Carolina, Vermont, and a non-grantee participant from Iowa. Workgroup members

brainstormed a list of core competencies (specialized knowledge, skills and abilities) thought to be essential for Vocational Rehabilitation Counselors (VRCs) to effectively support people with brain injury in their employment endeavors. The workgroup's product for Year 1 is the document titled *Proposed VRC Core Competencies for Serving Individuals with Brain Injury*, submitted by Nebraska VR on behalf of the workgroup and attached as Appendix D. Plans for Year 2 include a review and request for feedback from subject matter experts, and additional edits as needed. An associated set of draft survey questions is in development, and will be used to poll VRCs in selected states on the legitimacy of the proposed core competencies in Year 2.

The **Using Data to Connect People to Services** Mentor and Partner state representatives met online each month during the reporting period. Mentor states Virginia and Nebraska hosted and facilitated the meetings. The group included Partner state representatives from Alaska, California, Georgia, Idaho, Kansas, Minnesota, Missouri, Rhode Island, Utah, and Vermont, and non-grantee participants from Iowa and North Carolina. Workgroup members found that by sharing details about each state's TBI data sources and practices, we enriched our own knowledge and understanding, and also created the foundation for a national TBI data model. The workgroup's products for Year 1 are; *Our Common Language*, a glossary of brain injury data sources and commonly used terminology, a *Data Matrix* of workgroup member state data sources, and a PowerPoint slide presentation titled *TBI Registries: Two Models*, describing the TBI registry models in Virginia and Georgia. All three products were submitted by Virginia on behalf of the workgroup. Plans for Year 2 include an update to the *Our Common Language* document with state-specific data sources. Nebraska VR provided individualized assistance to the Indiana representative on TBI Registries and to the Vermont representatives on adding brain injury screening questions to the BRFSS survey.

Nebraska also participated in the Mentor state workgroup to address professional TBI Workforce Development. The **Brain Injury Workforce Training Development** workgroup, comprised of representatives from all Mentor states, met monthly to discuss and collaborate on this project. Each month, the states rotated the responsibilities for facilitating the work group meeting and taking notes. Collectively, the workgroup decided to focus workforce training and competency development efforts on five key areas represented in five of the nine Mentor-Partner work groups, determining that this would be an efficient and effective way to amplify and complement the work being conducted in these groups. These five areas or domains are (1) Return-to-Learn/Return-to-Play, (2) Criminal & Juvenile Justice, (3) Opioid Use and Mental Health, (4) Transition and Employment, and (5) Underserved Populations.

The workgroup selected Return to Learn (RTL) as the first area to address. Laura Beck of Oregon sent Tim Williams of the TBI Coordinating Center key references and articles on “Return-to-Learn” based on the National Collaborative on Children’s Brain Injury (NCCBI). In turn, Tim created draft workforce competencies addressing this domain.

Workgroup members also determined it would be important to have at least two to three subject matter experts (SMEs) review the competencies to ensure they align with best practices before the competencies are finalized. Laura Beck completed a search and found examples of SME surveys for other domains. The workgroup drafted a list of questions based on the examples and reviewed them with a questionnaire for knowledge, skills, and abilities. Dana Fink, ACL Project Coordinator, reviewed and provided feedback on the draft SME questions. The SME survey and RTL competencies will be updated prior to pilot testing with at least two to three SMEs. Based on their feedback, the workgroup will modify this approach with the remaining domains listed above during Years 2 and 3 of the project. The Mentor group

developed several products, including a *Competency Task List*, *Competency Spreadsheet* and an *SME Survey* which were submitted by Colorado on behalf of the entire workgroup. These workgroups are excellent forums for states to provide mentorship and technical assistance in order to increase national capacity to serve individuals with TBI.

2. What, if any, challenges did you face during this reporting period and what actions did you take to address these challenges? Please note in your response changes, if any, to your project goal(s), objective(s), or activities that were made as a result of challenges faced.

Responses to the *2019 Living with Brain Injury Survey* were fewer than expected; only 114 individuals with brain injury, 68 family members/caregivers and 46 service providers participated. This impacted both the amount and quality of data collected on the unmet and insufficiently met needs of Nebraskans with brain injury in 2019. Nebraska VR staff collected feedback from attendees during the *Summit* about the survey format and distribution process. To address this challenge, a committee of Nebraska VR staff, BIAC members, and other stakeholders will meet with the TBI grant external evaluation contractor to review the feedback received and adjust the survey instrument, format, and distribution process accordingly for the next year. No changes to project goals, objectives or activities were made during the reporting period due to this challenge.

3. How have the activities conducted during this project period helped you to achieve the measurable outcomes identified in your project proposal?

Reporting period activities contributing to achievement of each measurable outcome are listed in Table 1, beginning on page 9.

Table 1	Measurable Outcome	Contributing Activities
	<p>1. At least 7 of 10 support group leaders and 15 support group members will report increased leadership skills in support group facilitation, outreach to individuals with TBI, families and caregivers, and building collaborative efforts among local TBI stakeholders, as measured by a pre- and post-questionnaire, documentation of outreach activities and an increase in support group membership numbers compared to Year 1 baseline numbers. The pre- and post-questionnaire will be developed in partnership with the project external evaluation contractor.</p>	<ul style="list-style-type: none"> • The TBI Network Capacity Building project was launched in February, 2019. • Support group leader email addresses were maintained on the BIAC mailing list, ensuring that the support groups will receive timely invitations and updates on the project. • The Statewide Voice Assessment Tool was developed in partnership with the contractor and external evaluation team, and administered by the contractor with the core TBI Network Capacity Building project participants. Year 1 results are described in Figure 1 on page 14.
	<p>2. People with TBI and their family members will report increased advocacy activities at the local, regional, state and national level compared to Year 1 baseline levels, as measured by the Advocacy Activity Survey (AAS), and documentation of the number of advocacy and educational presentations reported each year. The AAS is a validated</p>	<ul style="list-style-type: none"> • The <i>2019 Living with Brain Injury Survey</i> was launched in early 2019. A total of 114 individuals with brain injury, 68 family members/caregivers and 46 service providers participated. Survey results informed development of the draft <i>Annual Brain Injury State Plan</i> and advocacy efforts at all levels.

<p>questionnaire which measures involvement in a range of advocacy activities, developed by James F. Malec, Ph.D., L.P.</p>	<ul style="list-style-type: none"> • The <i>1st Annual Living with Brain Injury Summit</i> was held on March 27, 2019 with 51 participants. The agenda included advocacy and educational presentations by BIA-NE, SILC and DRN representatives. • The BIAC Public Policy Committee and BIA-NE successfully advocated for passage of LB 481, the Brain Injury Trust Fund Bill. • Educational materials were disseminated at the <i>2019 Annual Brain Injury Conference: Brain Injury and Opioid Overdose Fast Facts, Accommodating the Symptoms of TBI, Nebraska VR-BIAC Summary</i>, and BIAC Chairperson business cards. • The AAS was administered by the contractor with the core TBI Network Capacity Building project participants. Year 1 results are described in Figure 2 on page 15.
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	<ul style="list-style-type: none"> • When available, the BRFSS survey data will also be used to inform advocacy efforts at all levels.
<p>3. The number of individuals with TBI and family members from rural areas joining the Network will increase by 20% of Year 1 baseline numbers in Years 2 and 3. Baseline Network membership numbers will be based on Year 1 support group membership numbers.</p>	<ul style="list-style-type: none"> • Year 1 baseline Network membership numbers include 13 members from two rural support groups. • A new contract with DHHS, OIS was negotiated. Names of newly-injured individuals with TBI were reported by age group and region so individuals with TBI and family members may be connected to local resources and support groups directly. • A total of 2,526 individuals newly diagnosed with TBI and placed on the TBI Registry received letters and brochures from December 1, 2018 to May 31, 2019. The brochures include information on how to join the BIAC mailing list. (Letters mailed: 2,754, letters returned undeliverable: 228, letters delivered: 2,526).

	<ul style="list-style-type: none"> • The <i>2019 Living with Brain Injury Survey</i> included an invitation to join the BIAC mailing list. There were 55 additions to the list as a result.
<p>4. People with TBI and their family members receiving assistance from a TBI Peer Resource Navigator will report increased access and reduced barriers to needed services and supports as measured by the Mayo-Portland Adaptability Inventory (MPAI-4) and data on the numbers of individuals needing, referred for, and receiving services. The MPAI-4 is a tool used to understand long-term outcomes from brain injury. It is currently in use by the BIA-NE Resource Facilitation program to identify unmet needs and barriers to needed services.</p>	<ul style="list-style-type: none"> • Grant staff requested and received technical assistance from the TBI Coordinating Center on “Disability Peer Navigators” that will inform development and implementation of Nebraska’s TBI Peer Resource Navigator model. • The <i>2019 Living with Brain Injury Survey Results</i> provided region-specific data on the needs of individuals with TBI, their families and caregivers, including barriers they experience in accessing needed services and supports. • Further TBI Peer Resource Navigator activities were postponed to Year 2.
<p>5. Designated Partner State Grantees will report an annual increase in their capacity to provide employment services for people with TBI, as measured by annual benchmarks in their work plan. Partner State Grantees will</p>	<ul style="list-style-type: none"> • Nebraska VR facilitated the Transition and Employment workgroup with co-Mentor state, Indiana. Partner state participants expressed satisfaction with the direction, pace and outcomes of the

<p>report an annual increase of 5% from Year 1 baselines in the number of successful employment outcomes for individuals with TBI.</p>	<p>workgroup thus far. The workgroup drafted proposed VRC core competencies for serving clients with brain injury who are seeking employment as its product for Year 1.</p> <ul style="list-style-type: none">• Nebraska participated in the Mentor state TBI Workforce Development workgroup, facilitated meetings and provided administrative support as needed.
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Figure 1	Statewide Voice Assessment Tool Results by Question: Baseline Results	
VPBI stands for Voice of People with a Brain Injury		Average rating (0=low, 5=high)
1.	How well is the VPBI represented in your state? (n=13)	1.5
2.	Do people with a brain injury across the state have an organized and sustained means of communicating with each other? (n=13)	1.2
3.	Do agency leaders, community leaders, and other people who may have an interest in the collective VPBI have a point of contact to access the collective VPBI, and is that point of contact able to represent a collective opinion or perspective? (n=13)	1.1
4.	Is there an entity among the people who have a brain injury that they go to for support, training, access to programs, etc.? (n=13)	1.2
5.	Is the VPBI organized to the extent that it benefits from revenue sources? (n=13)	0.9
6.	Does the VPBI have the ability to collectively interact and discuss policies and programs that affect the VPBI, determine response and input, and contribute such responses and input through appropriate channels? (n=13)	0.9
7.	To what extent is the general public aware of the collective VPBI? (n=13)	0.9
8.	To what extent is the VPBI included in grant applications and other program funding requests? State block grant planning? (n=13)	2.8

The key component of the TBI Network Capacity Building project is to create a voice-driven organization and network of individuals with brain injury, their family members and caregivers. To ascertain the perception of such an organization among those whom the organization intends to serve, the project contractor created the Statewide Voice Assessment Tool, which is a brief eight-question survey. The tool was administered to the 13 core project participants. Survey results in Figure 1 reflect the new nature of the project and serve as a baseline from which to determine improvement.

Figure 2 Advocacy Activity Scale Results by Question: Baseline Results			
In the last 12 months, how many times have you...	Not at all	1-3 times	More than 3 times
1. Attended a public meeting or rally to improve the lives or people with brain injuries? (n=13)	92.3%	7.7%	0.0%
2. Spoke at a public meeting or forum to support people with brain 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%
4. Visited in-person someone 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%
5. Worked with a group to improve the lives of people with brain injuries? (n=13)	38.5%	38.5%	23.1%
6. Discussed social changes to help people with brain injuries with family or friends? (n=13)	30.8%	46.2%	15.4%
7. Worked to elect a political candidate who supported people with brain injuries? (n=13)	100%	0.0%	0.0%
8. Contributed money to help organizations or people who support people with brain injuries? (n=13)	84.6%	7.7%	7.7%
9. Raised money to help organizations or people who support people with brain injuries? (n=13)	100%	0.0%	0.0%
10. Wrote a letter to the editor, gave an interview, or had other contact with the media to support people with brain injuries? (n=13)	92.3%	7.7%	0.0%

Figure 2 presents the results from the AAS with the same project participants. This scale measures the extent of the advocacy activities the participants have conducted on brain injury issues as a baseline for Year 1. Results indicate that, despite the lack of public engagement to date, the group includes participants who are prepared and informed to engage in broader activities related to public advocacy when given the opportunity.

4. What was produced during the reporting period and how have these products been disseminated? Products may include articles, issue briefs, fact sheets, newsletters, survey instruments, sponsored conferences and workshops, websites, audiovisuals, and other informational resources.

Nebraska produced and disseminated several products during this reporting period. All products are attached as appendices to this report, and will be uploaded to the Max.gov website. The *2019 Living with Brain Injury Survey Results* were published in May, 2019. The report was shared initially with the BIAC members and Nebraska VR staff for use in drafting objectives for the *Annual Brain Injury State Plan* before being posted to the BIAC website and disseminated via email. The *1st Annual Living with Brain Injury Summit* flyer was posted to the BIAC website and disseminated widely via the BIAC mailing list and member organizations. The *Summit Agenda* was provided to on-site and remote attendees. The *Summit* small group discussion summary and evaluation documents were distributed to BIAC members for review in drafting goals and objectives for the *State Plan*. The *TBI Registry Western Area Brochures* were shared with the agencies and organizations listed as resources to solicit feedback before including them with the monthly TBI Registry mailings to individuals placed on the Registry. The *Proposed VRC Core Competencies for Serving Individuals with Brain Injury* document is submitted to ACL on behalf of the Transition and Employment workgroup as its Year 1 product. The document titled *Nebraska VR-BIAC Summary* was created for distribution during the *TBI Awareness Day* events in Washington D.C. in March, 2019. It was also distributed later that month to attendees of Nebraska's *Annual Brain Injury Conference*. A list of product appendices appears on page 17 of this report.

APPENDICES

Appendix A: 2019 Living with Brain Injury Survey Results: A Nebraska Needs Assessment

Appendix B: 1st Annual Living with Brain Injury Summit Flyer, Agenda, Summary, Evaluation

Appendix C: TBI Registry Western Area Brochures

Appendix D: Proposed VRC Core Competencies for Serving Individuals with Brain Injury

Appendix E: Nebraska VR-BIAC Summary