

# ENGAGE. INTEGRATE. INSPIRE.

The mission of the BIAC is to engage, integrate and inspire brain injury stakeholders to help achieve the Statewide Vision for Brain Injury Policies and Services.

## Brain Injury Advisory Council (BIAC) Meeting

**September 13, 2024 - 10:00 a.m. – 2:00 p.m. CT**

**Zoom information for connecting:** <https://educationne.zoom.us/j/94166263913>

To Join By Phone, dial +1 312 626 6799 US (Chicago) - Meeting ID: 941 6626 3913

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## Draft Meeting Minutes

### Link to the recorded meeting:

[https://educationne.zoom.us/rec/share/BQtC6dB0dOJH1\\_sahN419HqdoL15lr4zt9io1WiR758y60ihnyNVT44jPIV\\_ghNU.FTYugu0kQLdTQIPN](https://educationne.zoom.us/rec/share/BQtC6dB0dOJH1_sahN419HqdoL15lr4zt9io1WiR758y60ihnyNVT44jPIV_ghNU.FTYugu0kQLdTQIPN)

Passcode: .r67Q\$i8

*Public notice of upcoming meetings will be available on the Department of Education website under “conferences & meetings” at least 10 days prior to each meeting.*

**MEMBERS PRESENT (and substitutes):** Tiffany Armstrong, Emaly Ball, Jodi Bodnar, Karen Houseman, Carla Lasley, Amy Levering, Terry Levering, Brooke Murtaugh, Judy Nichelson, Michelle Ploeger, Peg Ogea-Ginsburg, Peggy Reisher, Nicole Weaver (substitute for Tamara Snider,) Shawna Thompson, Madison Wurtele

**MEMBERS ABSENT:** Ashley Davis, RaLynn Jacobsen, Sarvinoz Kadyrova, Darsha Pelland, Dennis Thompson

**STAFF PRESENT:** Keri Bennett, Nancy Noha

**VISITORS/PRESENTERS:** Cole Boyle–PIE, Andrew Ngochoch-DHHS, Naomi Rolofson, Jason Kerkman-DHHS, Paula Dodds–BIA-NE

The meeting of the Nebraska Brain Injury Advisory Council commenced at 10:02 a.m.

### Approval Of June 14, 2024 Minutes:

The minutes of June 14, 2024 were reviewed. Judy Nichelson noted that Andrew Ngochoch was marked as present at the June meeting when he was not. **A motion was made by Peggy Reisher and seconded by Carla Lasley to have Andrew removed from the Visitors/Presenters and to approve the minutes with the correction. There were no objections, motion carried, with one abstaining.**

### Approval Of Agenda:

The agenda was reviewed and Peggy noted to add to the agenda, that she would also be reporting on the Brain Injury Association of America (BIAA) and United States Brain Injury Alliance (USBIA) partnership. **A motion was made by Tiffany Armstrong and seconded by Peggy Reisher to approve the agenda with the change. There were no objections, motion carried by unanimous consent.**

### TBI Registry Report and Presentation – Andrew Ngochoch, DHHS Division of Public Health

Andrew presented on the Nebraska Traumatic Brain Injury Registry Annual Report – 2023. The report included descriptive statistics for Count of Cases, Age-Adjusted TBI Rates, Admission Type, Primary Payer, TBI ED Visit & Inpatient Rates, Discharge Status, TBI Rates by Local Health Department, Cause of Injury and Primary Diagnosis.

## **TBI Registry Mailing Materials – Keri Bennett and Nancy Noha**

Keri shared the latest drafts of the registry letter and plans for a new rack card, as well as data from the most recent mailings. A small group of volunteers (Judy, Paula and Terry) met with Nancy, Tresa, Keri and Liz to review a revised letter and new rack card we can use to replace the nine brochures we have been sending out with the letter. We looked at feedback we had received from people who had received a letter via survey questions we ask during those calls around the materials and letter, the needs assessment survey data, feedback from a family member who works in media, and sample letters from other states – CA, TN and VA. Liz also did a literature review and resource search for materials that would be sent out to similar populations. Key takeaways from the small group were that some individuals received the letter in error due to a coding error at the hospital and some individuals not having been told at the time of the ER visit that they had received a brain injury. The survey results indicated that there is value in having both a letter and some sort of enclosure, i.e. brochure or rack card, but the other states we looked at only send a letter. Changes made in response to all this data were to 1. make the registry letter a bit more personal in reaching out to the individual, clearly stating the information will not be shared as that is a primary concern to individuals who called, 2. we went back to using the term “head injury” instead of “brain injury” because sometimes it is only an injury to the head and doesn’t impact the brain but gets coded in a way that places them on the registry. We felt this would soften the message for an individual receiving the letter. The rack card includes some symptoms of a brain injury and resources available. It was suggested we need to reference the state statute on the follow-up mailings, and Keri took note to look at adding this wording back to the letter. Suggestions were made to soften the first sentence, i.e. “You are receiving this letter because of...” A more empathetic first sentence. Nancy noted she is still working on the rack card, and currently planning to have four major contacts for information; BIA-NE, Hotline for Disability Services, 211 and the Aging and Disability Resource Center (ADRC). Suggestions were made to use Chat GPT for language ideas and use a QR code either in the letter or rack card.

## **Brain Injury Needs Assessment Survey and BI State Plan –Cole Boyle of Partners for Insightful Evaluation (PIE)**

Cole reported on the preliminary Needs Assessment Survey data and impact on the BI State Plan. The purpose of the needs assessment was to identify progress, areas for improvement, and unmet needs. The goal is to have all the reporting complete for use by August 2024. Cole highlighted the results from the Service Provider Survey. PIE, along with the brain injury data work group members, is working on developing a methodology guide that highlights key survey questions to ask, outreach approaches and other considerations. The surveys were promoted to 232 organizations by direct communication from someone from the BIAC. There were different sets of questions for the organization affiliation of the respondents. We had different questions for people who worked in Behavioral Health, for those who part of a medical organization like a clinic or hospital or rehab center and for community based organizations, nonprofits and state agencies. We had 112 respondents from 58 different organizations to the survey. The top 3 services with significant gaps include Behavioral Health counseling and substance abuse services, transportation assistance and respite care.

Breakout groups were asked to consider questions:

- 1) What jumped out to you about the TBI Registry or service provider survey data?
- 2) Also considering the preliminary results presented in June: What’s working well in Nebraska? What stands out as something that should be addressed for brain injury in Nebraska?
- 3) What else do we need to know or understand?

Group 1:

### **1. What jumped out to you about the TBI Registry or service provider survey data?**

Service Provider Data Survey.

Services used - Support groups and respite care not used as much as expected. Attributed to provider network for respite. Perceived gaps – Transportation is a national issue. behavioral health needs were not unexpected, but it’s unfortunate that it’s difficult to access. Respite was also on the perceived gaps. Pleasantly surprised to see not as high a gap for the provision of academic accommodations in school settings.

### **2. Also considering the preliminary results presented in June: What’s working well in Nebraska? What stands out as something that should be addressed for brain injury in Nebraska?**

The physical health services are being addressed but mental health and behavioral health needs not as well. This is reflected in many of our roles when we are supporting individuals. Finding safe places for individuals to receive care is challenging with the unmet behavioral and mental health needs. There are limited options for those with disabilities with these needs. This is a need across the lifespan across disabilities. If you add the percentage of moderate and significant gaps together for the categories the results are typically always more than 70% which is alarming.

### **3. What else do we need to know or understand?**

Is there data on when information is received information versus when the data is used? Parents don’t know how to access services for their teenagers and children. It appears teenagers aren’t getting services as soon as they should because of lack of information and the time it takes to get through process to access services.

Group 2:

**1. What jumped out to you about the TBI Registry or service provider survey data?**

The gap in providers and some of those available resources.

**2. Also considering the preliminary results presented in June: What's working well in Nebraska? What stands out as something that should be addressed for brain injury in Nebraska?**

The survey was easier and a better format, yielding better results.

**3. What else do we need to know or understand?**

Little availability of financial resources. The hardships for caregivers. Need for available respite care. Improvements in Medicaid for those that are working.

Group 3:

**1. What jumped out to you about the TBI Registry or service provider survey data?**

Good to see an increase in respondents. Noted behavioral health needs.

**2. Also considering the preliminary results presented in June: What's working well in Nebraska? What stands out as something that should be addressed for brain injury in Nebraska?**

Noticed fewer individuals with brain injury took the survey this time. Noted a lack of diversity and wonder if the language is a barrier. Talked about the challenges around emotional health tying back to behavioral health providers not always having brain injury training. Discussion around employment and related issues, VR resources and whether individuals with brain injury are accessing those services.

**3. What else do we need to know or understand?**

Discussion about case management and care coordination results and if people understood case management care. And the need for more public education and more trained providers

**DHHS Injury Prevention Office presentation - Jason Kerkman of DHHS Injury Prevention Office**

Jason presented on the Injury Prevention Program's projects and TBI work and shared his PowerPoint with the Council. Mission: A safe and injury free life for all Nebraskans. Programs: -Rape and Prevention Education (RPE) – CDC Grant -Nebraska Coalition to End Sexual and Domestic Violence -Motor vehicle related injuries -ACES (Adverse Childhood Experiences) -Traumatic Brain Injury -Nebraska Brain Injury Alliance and Concussion Coalition -Return to Learn/Return to Play -DV/TBI- addressing domestic violence survivors with TBI -Safe Kids Nebraska -Overdose to Action (OD2A) -Prescription Drug Overdose and -MEDS Project- Drug Disposal.

Peggy Reisher encouraged those unfamiliar with the "Forever Shaken" video to go to the BIA-NE website to learn more.

**ACL's Strong Infrastructure Components for Brain Injury (BI): State Self-Assessment Tool – Keri Bennett**

Keri reported on the BI State Plan component of the tool. According to the TBI Technical Assistance and Resource Center (TBI TARC) document, these are the most important features of a state plan. It will help us determine how best to improve services and supports for people living with brain injury. It includes goals for addressing unmet needs, for sustaining current initiatives and ongoing oversight. Nebraska has a long history of state plans, and Keri was involved with creating the first one in 2002 – The NE State Plan for Systematic Services for Individuals with Brain Injuries and Their Families. Keri will send anyone who is interested a PDF of that comprehensive report. It included very similar goals and objectives as our current state plan. Our most recent version includes smart goal language, updated to plainer language and made more accessible for the reader. We also have the executive summary and full plan 508 compliant for people who use screen readers due to a visual impairment. There is a need for improved cultural competence and outreach to diverse communities, as past efforts have faced challenges in engaging these populations effectively; a need for enhanced collaboration among agencies, and a need to explore more digital methods for gathering feedback regularly. Discussion about the importance of showing interagency support for the state plan, possibly through letters of commitment and a better-defined collaborative structure. The state plan is considered a 'living document', with Nebraska VR's commitment to continual evaluation and updates. We may possibly move to a three-year review cycle instead of scheduling annual updates.

**Membership – Carla Lasley**

Carla reported on recent recruitment efforts from the input collected in the June Council meeting, including outreach efforts to identify potential members with lived experience related to support groups. We are following up with representatives from various organizations and ask for assistance from current members in contacting individuals who may be interested in joining. We engaged with the BIA's Resource Facilitators and support group leaders to help identify interested candidates. It was recommended to offer potential members the opportunity to participate in a meeting to get a feel for what the Council does before applying. Carla is following up with Aubrey Guterres, who had previously suggested names of several individuals. It was suggested to continue further outreach, particularly in underrepresented areas like the Panhandle.

## **Contractor reports and ACL Workgroup Updates (written reports only) – Keri Bennett**

Written reports were sent out with the meeting agenda. No questions or concerns were raised.

### **Recent Federal News and initiatives**

#### Proposed Centers for Disease Control funding cuts for TBI data collection – **Tiffany Armstrong**

The TBI Act was up for reauthorization this year. It funds the National Institutes of Health (NIH), the Administration for Community Living (ACL), and the Protection and Advocacy systems in the states. The House Appropriations Committee proposed a cut to the CDC funding instead of an increase for funding which we were hopeful for. But the last update that from NASHIA is that it's unlikely that the House will consider the bill with the cuts that were proposed from the Appropriations Committee. They will most likely put an extension on the funding at current levels.

#### Advisory Board/Council Outreach & Recruitment, TBI Technical Assistance & Resource Center – **Judy Nicholson**

The Technical Assistance and Resource Center, led by Maria Crowley and Judy Dettmer from NASHIA, are developing a guide for states to use in recruiting members for advisory boards or councils focused on individuals with traumatic brain injury (TBI) and other partners. The aim is to finalize the document by the end of September. The guide will cover topics such as recruitment profiles, marketing applications, onboarding new members, and more.

Judy also noted that Congressman Bill Pascrell of New Jersey passed away on August 21 at the age of 87. He was a great leader and legislative ally for the brain injury community. He co-founded the Congressional Brain Injury Taskforce and served as co-chair for many years with Rep. Don Bacon of Nebraska. He will be missed!

#### BIAA: [Centers for Medicare and Medicaid Services Officially Recognizes Brain Injury as a Chronic Condition](#) – **Keri Bennett**

The Centers for Medicare and Medicaid Services (CMS) has officially recognized brain injury as a chronic condition, which may lead to additional funding and programs for states. This recognition is part of ongoing research and dialogue about the broader impacts of brain injury, which can lead to earlier onset of various health conditions. The National Institutes of Health (NIH) is facilitating this initiative through the TBI Model Systems, proposing a chronic healthcare model that emphasizes prevention, extended rehabilitation, and evidence-based recommendations for living with brain injury. It's not yet known just how this recognition will affect future funding and services. There is a webinar sponsored by the Brain Injury Association of America (BIAA) for those looking to learn more about the implications for individuals with brain injuries and their families.

#### [Resource Facilitation Consensus Report](#) and report on BIA and NASHIA partnership – **Peggy Reisher, BIA-NE**

Peggy shared the PowerPoint about the development of resource facilitation for brain injury support across the U.S. Nebraska was at the forefront, hosting a summit on resource facilitation as early as 2013 or 2015. The report highlights the disagreement and confusion surrounding the terminology used—some refer to it as neuro-resource facilitation or resource navigation. The group, funded by the Moody organization, utilized the Delphi process to gather insights from approximately 45 participants, including service providers, individuals with lived experience, and researchers, in order to reach a consensus on definitions and best practices. The consensus emerged that "brain injury resource facilitation" is the preferred term for this activity. Key components identified for resource facilitation include connecting individuals to community resources, assessing their strengths and challenges, setting goals, and coordinating support. Additionally, initiatives for outreach, education for individuals and families, policy advocacy, emotional support, and system changes were emphasized. The group acknowledged the need for common definitions, data collection measures, and consistent outcome measurements to assess effectiveness and inform service delivery. The discussions are part of broader efforts to establish a best practice guide for states involved in resource facilitation, aiming to standardize approaches, methodologies, and guidelines for policy and practice over the next two years. Overall, the text reflects on several years of collaborative efforts toward enhancing resource facilitation for brain injury support, transitioning from ad-hoc practices to a more structured, consensus-driven framework to better serve affected individuals in the community.

Peggy also shared that at the national level, the USBIA voted recently to dissolve. As a result, the Brain Injury Association of America (BIAA) and the United States Brain Injury Alliance (USBIA) will be merging under the auspices of the BIAA. The BIA-NE will return to using the name "Association" instead of "Alliance" in 2025, which is where they began. They will not be changing the way they do things, but their logo, colors and name will change. Overall, it's felt this is a positive change and will strengthen national and state BI advocacy efforts.

### **Roundtable Discussion:**

Peggy shared several initiatives by the BIA-NE aimed at improving the understanding and treatment of brain injuries in various settings. This summer, a training program was completed for staff at the Lincoln and Norfolk Regional Centers,

with the goal of screening patients for brain injuries. There are plans for collaboration with Johns Hopkins to provide education for psychiatrists and other medical professionals on medication management for individuals with brain injuries. Significant progress has also been made in screening children at Douglas County and Lancaster County Youth Treatment Centers, revealing high rates of potential brain injuries (75%-86%). This has led to discussions about systemic changes involving judges and probation officers to incorporate screenings in the legal system, particularly for veterans. An online brain injury screening tool will soon be made available for free, and there are updates planned for concussion resources aimed at supporting children in schools. Efforts are underway to educate Behavioral Health specialists about the importance of recognizing brain injury symptoms to better meet the needs of affected individuals, rather than labeling their problems solely as behavioral issues. Legislation passed in 2015 mandates that schools develop protocols to assist students with brain injuries, but guidance coming from the Department of Education has been limited. Recently, the Department of Education has begun to support these initiatives by including information on their general education website.

**Unfinished (Old) Business** (if any) - None

**New Business** (if any) – The BIA-NE prepares an annual report for the Brain Injury Oversight Committee, which serves to share statistics and insights regarding the populations served. Peggy would be glad to share that at the next meeting. Judy suggested a possible presentation on Worker’s Compensation and its components would be informative and useful.

**Adjourn – A motion to adjourn the meeting at 1:55 p.m. was made Peggy Reisher and seconded by Madison Wurtele, motion carried by unanimous consent, there were no objections.**

**Next Meeting Date:** December 13, 2024