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

December 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
Find your local number: https://educationne.zoom.us/u/avQempuQZ

Meeting Minutes

Link to the recorded meeting:
https://educationne.zoom.us/rec/share/K2eh1Ad74mJlk3zF_BDzsxBxv0MvY56Tur3Xf5c9P_E1OeP83uAap5ZRtSTZjnu0.9EaBmoCjmE6pcGNB
Passcode: *8#4au*9

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, Ashley Davis, Karen Houseman, RaLynn Jacobsen, Carla Lasley, Amy Levering, Terry Levering, Brooke Murtaugh, Judy Nichelson, Darsha Pelland, Michelle Ploeger, Peggy Reisher, Jennifer Swanson, Shawna Thompson, Madison Wurtele

MEMBERS ABSENT: Sarvinoz Kadyrova, Peg Ogea-Ginsburg, Tamara Snider, Dennis Thompson

STAFF PRESENT: Keri Bennett, Nancy Noha, Alexa Krueger

VISITORS/PRESENTERS: Liz Gebhart-Morgan – PIE, Naomi Rolofson-NE VR

The meeting of the Nebraska Brain Injury Advisory Council commenced at 10:03 a.m.

Introductions – *Judy Nichelson and all members*
New member, Jennifer Swanson was introduced and all members briefly introduced themselves.

Approval of September 13, 2024 Minutes:
The minutes of September 13, 2024 were reviewed. **A motion was made by Darsha Pelland and seconded by Carla Lasley to approve the minutes. There were no objections, motion carried by unanimous consent.**

Approval of Agenda:
The agenda was reviewed. **A motion was made by Ashley Davis and seconded by Michelle Ploeger to approve the agenda. There were no objections, motion carried by unanimous consent.**

2024 Brain Injury Needs Assessment Report Part 1–*Liz Gebhart-Morgan of Partners for Insightful Evaluation (PIE)*
This topic was broken into three parts; 1. Individuals with brain injury, 2. Family Members and Informal Caregivers and 3. Service Providers. The small group discussion questions for all three breakout sessions are: Based on the data you just heard, 1. What seems to be going well? 2. What gaps or barriers are still a concern?

Liz Gebhart-Morgan (PIE) discussed the ongoing evaluation of brain injury needs in the state. This year, the focus has been on three surveys conducted to better understand the experiences of individuals with brain injuries, their needs, and service gaps. The comprehensive report summarizing all findings is expected by January and will include aggregate data from the surveys, the TBI registry, and other interviews, amounting to around 40 to 50 pages. In addition to the full report, an executive summary and infographic summaries for each survey will be developed to present key findings in a digestible format. The draft infographics may include highlights but are open for Council member feedback on whether more or less information would be beneficial. The surveys aimed to identify specific symptoms experienced by individuals with brain injuries and their ongoing needs for services. The data revealed that 96% of respondents reported cognitive challenges, often experienced after their injuries. Additionally, a notable proportion indicated they still require medical and therapeutic services, with many expressing unmet needs in social or recreational support. Liz also highlighted that a significant number of respondents desired assistance in their daily lives, but many were not receiving the necessary level of support. Optional questions at the end of the survey explored difficulties in accessing services, indicating that challenges persist throughout the recovery process. Preliminary outcomes indicate that some individuals are utilizing more prescription medications post-injury compared to before, while the use of substances like alcohol has decreased.

Breakout groups discussions:
The groups expressed difficulty in identifying positives related to the survey findings, mainly due to a demographic issue, with half of the respondents from the Omaha and Lincoln areas potentially skewing the data. A significant point raised was that 39% of participants reported being 30 minutes or less away from services, prompting concerns about the accuracy of this information for rural areas and the accessibility of specialized services like neuropsychology and therapy.
They noted challenges with telehealth, as many felt it wasn't a viable option for them, and the importance of understanding the relationship between travel time and the quality of medical services available, especially in the context of limited pain clinics. It was noted the lack of comprehensive understanding among medical personnel regarding brain injuries. The groups also considered the idea of sending surveys to school districts for insight but ultimately decided against it, noting that students generally receive prompt services for concussions and sports injuries, unlike adults in the community. Two questions were raised: first, regarding the number of survey respondents who answered independently versus those who received assistance. It was noted that of the 82 respondents, 85% (n=70) experienced a brain injury themselves, while others filled out the survey on behalf of someone with a brain injury. The second question involved whether the current survey included any historical comparisons from 2009. The groups reflected on the trends observed, highlighting a lower reported need for substance abuse support compared to national averages and an unexpectedly low demand for behavioral health services. They noted the importance of comparing rural versus urban access. The need for a more detailed examination of assistance requirements, particularly in medical needs, was emphasized to identify gaps. They viewed the survey as user-friendly and valuable for discussions with legislators and payers, providing significant data specific to Nebraska to support advocacy efforts. The groups also focused on issues faced by individuals with brain injuries, highlighting the strengths of a graphic that presented information in a structured and readable way. The groups appreciated the graphic's clarity but also identified challenges, such as color accessibility that made it difficult for some members to engage. They discussed the need for deeper exploration of medication-related topics and emphasized the importance of distributing the survey more widely, particularly among medical professionals like speech-language pathologists. A point of discussion was raised by a group member who shared her emotional experience post-traumatic brain injury. She expressed a fear stemming not from physical or emotional safety, but rather from a loss of independence and familiarity with her environment. The groups found this perspective valuable but struggled with how to frame a question that accurately captures this sense of safety. The conversation centered on gathering insights into these feelings and how to articulate them effectively for broader understanding.

2024 Brain Injury Needs Assessment Report Part 2 *- Family Members and Informal Caregivers*
Liz focused on insights gathered from the survey aimed at understanding the knowledge and challenges faced by family members and caregivers of individuals with brain injuries. Key findings indicate that approximately half of the respondents felt knowledgeable about the needs of those with brain injuries, but many lacked awareness of available services and resources. Notably, 39% reported being unfamiliar with the risks of opioid use in this population. The most significant challenges identified were coordinating care, attending to personal care needs, and financial issues. Among major challenges, caregivers indicated that finding paid caregivers and maintaining personal relationships were particularly difficult. To support caregivers, survey participants expressed a need for educational events, financial assistance, support groups, respite care, and social opportunities. Specific desires included resources and support focusing on brain injury care, emotional and cognitive changes, and training that would enhance their understanding and coping strategies. Perceived gaps in services were identified, particularly in respite care, care coordination, independent living supports, and transportation assistance, with significant proportions of caregivers reporting these as unmet needs within their areas. To improve services for individuals with brain injuries, the respondents prioritized greater public awareness, trained providers, financial assistance, and enhanced education for healthcare professionals about brain injury. Overall, the findings highlighted areas of both support and significant gaps, suggesting a need for continued discussion and problem-solving to enhance services for affected families.

Breakout groups discussion:

The groups expressed a desire for a comprehensive "dream survey" to gather specific information about brain injury awareness and support. They noted that a small percentage of individuals feel knowledgeable about brain injuries, with 42% and 47% indicating some awareness. There was a strong interest in increasing educational events, as attendees recognized the need for more educational resources despite existing opportunities. They also called for a better understanding of the care and emotional support services needed by caregivers, particularly concerning how these needs change with the severity of brain injuries. They emphasized the importance of comparing the experiences of individuals with brain injuries and their caregivers using sophisticated statistics to gain valuable insights. They pointed out the lack of a consistent support system in the U.S., which complicates the comparison of data and individual experiences, as each pathway to support is unique. They shared insights about differences between individual and caregiver surveys regarding gaps in awareness and resource accessibility for brain injury support. While individuals did not identify transportation as a significant issue, caregivers viewed it as a notable barrier. They noted the need to differentiate between actual resource gaps and a lack of awareness about available support, such as brain injury support groups and case management resources. The groups emphasized the importance of community awareness, noting that effective awareness campaigns for other health crises (like breast cancer) tend to be more prominent. They discussed challenges related to stigma and misconceptions about brain injuries and concussions, which hinder broader understanding. They suggested increased focus on behavioral health needs, particularly around substance use, as caregivers perceived a greater demand for these. They expressed satisfaction with the participation of caregivers in the survey, emphasizing the importance of soliciting their insights. They noted the existence of support groups for caregivers of individuals with traumatic brain injuries but that many caregivers may be unaware of these resources unless they are attending support groups for the persons they care for. This raises the necessity of better disseminating information about caregiver support options. They identified the need for financial assistance for respite care and acknowledged barriers related to Medicaid waivers, which require caregivers to become financially dependent to qualify. They discussed the importance of recognizing other causes of traumatic brain injuries, such as strokes, and the need to reach out to these individuals. Additionally, they appreciated a specific graphic from the survey data that visually represented areas of need, suggesting it could effectively communicate these issues to legislators and advocate for additional support.

2024 Brain Injury Needs Assessment Report Part 3 - *Service Providers*

Liz discussed the next steps following the results from the three surveys. She noted that by January, comprehensive reporting will be available, which will include an in-depth analysis of geographic differences, TBI registry data, Nebraska VR data, and infographics. She welcomed feedback on the infographics, particularly regarding the amount of data presented and the inclusion of demographic information from the surveys. Looking ahead, additional reporting needs will be identified early next year, with potential one-pagers covering topics like causes of brain injury and employment barriers. In early 2025, a smaller workgroup will be convened to evaluate the data's relevance to the brain injury state plan and consider updates to the plan based on priority areas. Liz expressed gratitude for the participants' feedback, which informs revisions to survey methodologies and future data collection approaches. All feedback is appreciated as it contributes to improving the initiative. Judy, Shawna, Carla and Tiffany volunteered to look deeper into the data.

Liz summarized the findings from the Service Provider survey. The survey was designed with skip patterns to efficiently gather information from various types of agencies, including community-based organizations, state agencies, and medical organizations. It was available only online and aimed to assess the availability of materials related to brain injury that agencies could provide to individuals they support. Approximately half of the respondents indicated they have general brain injury information, while only 35% had lists of support groups. Notably, 46% of respondents expressed a need for support group information. The survey also revealed insights into brain injury screenings, with about half of respondents conducting screenings, but mostly using informal questions rather than formal tools. Respondents' perceived knowledge about brain injury was measured, showing that 59% felt somewhat knowledgeable, while 31% felt very knowledgeable. Supervisory staff expressed varying levels of confidence in their employees' ability to assist individuals with brain injury. Additionally, the survey identified significant and moderate service gaps in areas like behavioral health, counseling, and case management. To address these gaps, respondents indicated that education, training, and greater public awareness about brain injury would be beneficial. The survey reached out to 283 organizations across the state to ensure a diverse sample.

Breakout groups discussion:

The groups discussed the positive outcomes regarding healthcare providers' response rates, indicating strong community demand for information and resources. The high response rate suggests that providers are eager to gain knowledge to support their patients effectively. However, it highlights a need for improvement, particularly in ensuring that providers have access to updated procedures and educational materials, as outdated information could hinder patient care.

The survey identifies low awareness and education concerning respite care among providers, which suggests a gap in informing patients about available resources. It also points out that employee turnover within organizations may affect the consistency and quality of information provided to both providers and patients. Emphasized the need to address gaps in behavioral health services. Raised concerns about the integration of mental health care with physical health conditions, such as treating anxiety in patients with brain injuries without considering the interaction between the two.

The discussion revolved around the challenges related to provider education and awareness regarding brain injury, particularly among specialty providers who might feel ill-equipped to address such issues. There is a noted lack of representation from behavioral health providers in the context of brain injury discussions. Many providers, even those who could potentially be experts, lack awareness of the educational resources available to them concerning brain injuries. This raises questions about their reluctance to engage with these issues and whether it's due to their specialization or a lack of recognition of their educational needs. They mentioned insufficient staffing across various sectors, including a scarcity of home caregivers and transportation resources, which complicates the provision of necessary services. Efforts are underway to create educational curricula for providers on brain injuries. However, the need to balance this with other educational priorities for rural and primary care providers is emphasized. The necessity for effective prioritization of educational content for providers is critical to ensure they can incorporate brain injury education without overwhelming them with additional responsibilities. There was discussion on the consistent need for financial assistance, public awareness, and training for medical professionals regarding traumatic brain injuries (TBIs). They highlighted concerns about the adequacy of information and education available to health professionals, questioning whether current training effectively meets their needs. There was a specific focus on the importance of communicating with providers at their professional level to enhance their understanding and knowledge. The groups noted a gap in follow-up questions when patients disclose a TBI, suggesting that medical assessments should include more comprehensive inquiries into the specific challenges patients face, such as balance issues or color vision problems. This could help healthcare providers better understand and support individuals with TBIs.

Final Brain Injury + COVID-19 literature review - *Keri Bennett and Liz Gebhart-Morgan of Partners for Insightful Evaluation (PIE)*
Liz presented findings from a Covid study funded by the Administration for Community Living (ACL) focused on the intersection of Covid-19 and brain injury in Nebraska. The state received supplemental funding to explore how Covid-19 has impacted individuals with brain injuries, leading to the formation of a dedicated workgroup. This team conducted a literature review to assess health impacts, the effects of the pandemic, long Covid symptoms, and service access during this time. From this research, the group developed three "plain language" documents aimed at summarizing their findings for broader understanding. These documents address the impact of Covid-19 on individuals with brain injuries, their family caregivers, and service providers. Data collection included a needs assessment survey with Covid-related questions and interviews with individuals affected by brain injuries and long Covid. Issues identified included worsening symptoms, challenges in accessing services, feelings of isolation, and financial strains. Recommendations from the interviews suggested creating a comprehensive resource website, guides for individuals coping with memory issues, sample accommodation plans for schools, and training for employers on supporting employees with brain injuries or long Covid. This initiative aims to improve support and understanding for affected individuals in Nebraska, reflecting the workgroup's commitment to addressing the pandemic's ongoing impact.

Committee and Contractor Reports (written reports)
Written reports were sent out with the meeting agenda. No questions or concerns were raised.

Public Policy – *No Report*

Membership – ***Carla Lasley and Keri Bennett***
Carla noted that Lisa Kent-Scheer has been accepted as a member but was not able to attend today.

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

New Chair Appointment and Vice Chair Election – *Keri Bennett and Carla Lasley*
Judy Nichelson's Chair and Tiffany Armstrong's Vice Chair second terms are expiring and we will vote by anonymous poll for a new Vice-Chair by the Council members.
It was noted that Judy has served six years. Gratitude was expressed to Judy for her service and she was presented with a plaque in appreciation.
It was announced that Nebraska VR has appointed Emaly Ball as the new Chair for the next three year term.
Gratitude was expressed to Tiffany for her six years serving as Vice-Chair.
The Vice-Chair is to be filled by a Council member who is an individual with a brain injury per the Operating Procedures. The duties of the Vice-Chairperson shall be to conduct meetings of the BIAC and the Executive Committee in the event the Chairperson is not available. The Vice-Chairperson shall be responsible for regularly interfacing with the Committee Chairpersons to ensure that they are supported in their duties. He or she is to perform such other duties as may be delegated.
Judy Nichelson and Tiffany Armstrong were the only two of the eligible individuals who wished to be considered. The members then voted via Zoom poll. A total of 13 members voted. When the votes were tallied, Judy received five votes and Tiffany received eight votes. Tiffany Armstrong was voted in for a third term as Vice-Chair.

A motion was made by Emaly Ball and seconded by Karen Houseman to accept the voting results appointing Tiffany Armstrong as Vice-Chair. There were no objections, motion carried by unanimous consent.

Recent Federal News and Initiatives

BIAA & NASHIA Brain Injury Awareness and Advocacy – *Keri Bennett*

There was a recent email from The National Association of State Head Injury Administrators (NASHIA) of a compilation of all of the different events that are going to be going on in Washington, DC, in March. Keri emphasized events being planned around brain injury, awareness, and advocacy at the Federal level and National level. March 3rd and 4th the Brain Injury Association of America is going to be hosting a National Brain Injury Conference at the Hilton Arlington National Landing. Keri will send links to this national conference on brain injury, specifically geared for survivors of brain injury and family members. On March 4th, NASHIA is going to host an intensive meeting for states and their partners to learn more about certified community behavioral health clinics, and this meeting will also take place at the Hilton Arlington National Landing. March 5th will be Brain Injury Awareness day on Capitol Hill, and that's a good time to do some in-person advocacy with our Senators and Congressmen in Washington, DC. NASHIA and the Brain Injury Association of America do a great job of putting together materials and helping schedule those appointments and meetings for this great opportunity. NASHIA is hosting an invitation only lunch meeting on Medicaid administrative claiming on Capitol Hill.
On March 6th ACL is hosting our TBI Grantee Partners Day, and anyone may join that meeting as well.
Keri will forward the NASHIA email to the Council, so they may register for any of those events if they plan to attend.

Report on the September 2024 NASHIA conference – *Keri Bennett and Karen Houseman*

The NASHIA Conference held in Eugene, Oregon, provided insights into the challenges and developments related to brain injury care and support at both national and state levels.
Karen Houseman expressed her appreciation for being able to attend the conference and noted several key topics, including:
Lack of Diagnosis and Gap in Services: Many patients with brain injuries do not receive proper diagnoses after hospital visits, and there is a significant gap in cognitive rehabilitation services, which are often limited or unavailable.
Differentiating Treatment: Treatment for traumatic brain injuries often follows a medical model, neglecting the behavioral and cognitive aspects that require tailored interventions for recovery.
Innovative Resources: The nonprofit B.E.S.T (Best Education Strategies and Technology) offers useful applications and free webinars aimed at assisting individuals with brain injuries in relearning skills and receiving instant tech-based feedback.
Peer Support Challenges: While there was a focus on the importance of peer support for individuals dealing with brain injuries, some areas, such as Alaska, reported limited success in peer engagement and preference for non-injury-related topics.
Reclassifying Brain Injuries: There was a push to update brain injury classifications similar to cancer diagnoses to improve understanding and treatment approaches. MRIs were highlighted for providing better diagnostic capabilities than CT scans.
Substance Abuse Intersection: Sessions discussed how to accommodate individuals with both brain injuries and substance abuse issues, including personalized support strategies.

Keri Bennett shared about the integration of Medicaid with criminal justice systems, indicating that reforms now allow for Medicaid assistance prior to release, so that eligible, incarcerated youth or adults can get 30 to 90 days of Medicaid assistance prior to their release, to help with transition to the community. Important for those that serve our youth and adults in criminal and juvenile justice systems to be aware of and need to take advantage of as they are helping people transition back into the community that might be Medicaid eligible because of brain injury. She noted that approximately 29 States now have specific brain injury waivers, and of course, here in Nebraska we have our enhanced waiver that will serve people all over the state. Regarding our public policy committee, suggests taking a deeper look at how to approach Medicaid about that. Another thing to discuss would be something that we've reported on in previous meetings, the centers for Medicaid and Medicare and the chronic disease designation for traumatic brain injury. A recent publication by NASHIA gives good guidance and ideas for states to follow up on with their Medicaid and Medicare programs to see if we can't push that through a little bit further. The National Institutes of Health, like Karen mentioned have a big project underway to reclassify traumatic brain injury. We have all learned about mild, moderate, and severe brain injury based on loss of consciousness and a few other kinds of things that are used to classify, but they are really taking a different tack on that now and looking at better ways to classify brain injury that is more helpful in terms of outcomes and rehabilitation moving forward. Dr. John Corrigan is involved with this, along with many other researchers. It will take several years, but it's a great endeavor to maybe make a big difference for individuals with brain injury moving forward. There were also great employment support presentations that she kept the PowerPoints on. Keri reiterated what Karen said about BEST, the Brain Education Strategies and Technology, that they gave a great presentation, and they offer free webinars and low cost online courses around cognitive rehabilitation.

Peggy Reisher along with Maggie Ferguson from Iowa co-presented on the use of Salesforce for data collection within the brain injury community to better articulate their needs and advocate for collective progress. This was part of a broader effort to expand the brain injury community's voice in national conversations. This is a database they are using at BIA-NE. There are 10 other states using it, and BIAA, the national organization, is considering using it going forward. We can do a better job compiling information about the needs of people in the community. The model systems programs that have funding do a good job getting medical information, but we as a brain injury community need to explain the story from a national perspective much better about what brain injury is. One of the reasons BIA-NE wanted to join BIAA again is to see if they could get that bigger voice going for brain injury across the United States. Salesforce was definitely one of the areas as a starting spot for collecting that data across the nation. Liz is also a huge part of helping make sense of all the data.

Set 2025 Meeting Dates: *All Members*
Proposed dates are: March 28, June 13, September 19, and December 12

Meetings will be scheduled from 10:00 am – 2:00 pm and will be held via Zoom unless otherwise indicated.
A motion was made by Ashley Davis and seconded by Carla Lasley to approve the proposed dates. There were no objections, motion carried by unanimous consent.

It was also noted that the Brain Injury Conference is March 13 and 14, 2025.

Roundtable Discussion: *All Members*

Unfinished (Old) Business (if any) – None

New Business (if any) – for inclusion in a future meeting:
Peggy Reisher shared that OBISSS (Online Brain Injury Screening and Support System) is up and running on the BIA-NE website. She offered to demonstrate what that screening tool looks like, and to see the symptom questionnaire results. It can be used by anybody. There's no charge for it, and it gives those that you're working with a little bit of feedback on their symptoms and strategies that might be helpful to them, based on their symptoms.

Peggy Reisher shared that on their website, they have recently updated the REAP (Reduce/Remove, Educate, Accommodate/Adjust, Pace) manual, a community-based concussion management approach protocol that is a multidisciplinary approach to Returning To Learn (RTL) and Returning to Play (RTP). The manual is available to help educate the community, teachers and parents about concussion. She offered to give a short presentation to walk the Council through how to sign up for REAP and other relevant information.

Peggy Reisher shared about their collaboration with Johns Hopkins for training programs aimed at physicians, physician assistants, and nurse practitioners. The focus is on understanding the intersection between brain injury and behavioral health, especially regarding the effects of medications prescribed for behavioral health on individuals with brain injuries. An 8-session course is planned for launch in 2025, offering Continuing Medical Education (CME) credits to participating physicians. The structure includes a didactic lecture followed by case discussions. Efforts are ongoing to train behavioral health providers within juvenile justice settings, with applications for Sherwood funding anticipated. The goal is to improve the understanding and identification of brain injuries in juveniles involved with the justice system, as well as in the broader population.

Karen Houseman (DHHS AD and TBI Waiver Service Coordination**)** shared updates concerning traumatic brain injury (TBI) services, including a goal to eliminate waitlists for home and community-based waivers by October next year, allowing quicker service access. She noted the introduction of a new assessment tool called **interRai** for evaluating care levels and budgeting, and a shift to an electronic claims and authorization system (Therap) is underway, which involves training for service providers. The transition is expected to enhance billing efficiency and data management. Also, upcoming waiver amendments in 2025 will include discussions about compensating legally responsible individuals for caregiving, amidst other changes. Public comment opportunities will be available in the spring.

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

Next Meeting Date: March 28, 2025