
2nd Annual
Living with an Injured
Brain Summit



Welcome to the 2nd Annual Living with an Injured Brain Summit

A Virtual Event to Engage You on Your Recovery Journey

Brought to you by Nebraska VR in collaboration with the Brain Injury Advisory Council and the Nebraska Injured Brain Network

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Zoom Housekeeping

- ❑ Closed captioning: To turn it on go to bottom toolbar and select Closed Captioning, and then Show Subtitles. There are other settings.
- ❑ Camera view: We will spotlight the presenters, and you can choose your view using the icons in the video section.
- ❑ Your microphone is automatically muted by the host. If you have questions, please type in the chat box. All questions will be answered either during the session, or in writing and sent via a document after the Summit.
- ❑ This presentation is being recorded. It will be available in the near future on the BIAC website.
- ❑ If you are having trouble with your internet, you can use your phone to call in and listen (and follow along with the presentation that was sent via email).
- ❑ Use this number: 1 (408) 638-0968, ext: 6967605011

The Purpose of this Summit

- ❑ The **Purpose of this Summit** is to **come together as the Injured Brain Community**—those living with an Injured Brain (Peers), family members, and caregivers, as well as providers, agency representatives and other community champions.
- ❑ Our goals in coming together are to **foster discussion** regarding important topics, to **hear directly** from Peers and family members, and to establish **connectivity** among people who are on the Recovery Journey together.
- ❑ Additional information will be sent out to registrants after the Summit, including **written answers to the questions** that were submitted by attendees, **resources fact sheets**, and instructions for joining the **Learning Communities** that will be launched by this Summit.

Today's Focus: The Statewide Voice-Generated Vision (VGSV) for Brain Injury Policies and Services—and, the Partners Who will Lead Us There

- ❑ **Overview of the VGSV**, by John Ferrone, Summit Moderator
- ❑ **Nebraska VR**, by Keri Bennett, Program Director for Acquired Brain Injury
- ❑ **Brain Injury Advisory Council**, (BIAC), by Judy Nichelson, BIAC Chair
- ❑ **Brain Injury Alliance of Nebraska** (BIA-NE), by Peggy Reisher, Executive Director, and Chris Stewart, Resource Facilitator
- ❑ **Nebraska Injured Brain Network** (NIBN), by Emaly Ball, Board President

An Overview of Our Guiding Vision

- ❑ Voice-Generated Statewide Vision for Brain Injury Policies and Services

- ❑ What do we mean by the word “Vision”?

- ❑ Gives everyone involved (organizations and individuals) a common set of goals to pursue

Key Questions: What is the Vision, and who is involve in helping to achieve it?

What is Our Vision?

Voice-Generated Statewide Vision for Brain Injury Policies and Services:

<https://braininjury.nebraska.gov/council/statewide-vision-brain-injury-policies-and-services>

[DRAFT] 5 Parts to the Vision—In the next 5-7 years, the future of brain injury in Nebraska will have evolved such that the following statements will accurately characterize the realm of brain injury:

1. Nebraskans with a brain injury, regardless of **geographic** location or **financial** means, will have **access** to the necessary resources that they require to **pursue** their **recovery journey**.
2. The Voice of people with a brain injury and their family members will exist as a **unified Voice of solidarity and advocacy**, and will be engaged to shape policies and programs.

What is Our Vision? (continued)

3. All **stakeholders** in the brain injury realm will understand their unique role as well as how they **complement each** other towards making the future of brain injury better; subsequently, people with a brain injury will have an easier time navigating available resources with the help of specialized assistance from **Peer Support** and **Resource Facilitation** programs.
4. The **Nebraska Legislature** will be informed about the nature of brain injury and its ongoing impact on Nebraskans, and will be **supportive of funding and policies** to support the necessary statewide resources for those with brain injury.
5. The complex nature of an injured brain and the recovery journey will be understood by everyone, such that **stigma will be eliminated** and the public will be more supportive of efforts to improve overall brain injury support and resources.

Who is Pursuing Our Vision?

- Nebraska VR
- Brain Injury Advisory Council (BIAC)—which includes many collaborating partners from other State agencies as well as providers, in addition to representatives of the Injured Brain Community.
- Brain Injury Alliance of Nebraska (BIA-NE)
- Nebraska Injured Brain Network (NIBN)

There are many other people and entities that are important to the pursuit of the Vision. The above four entities are the key leaders.

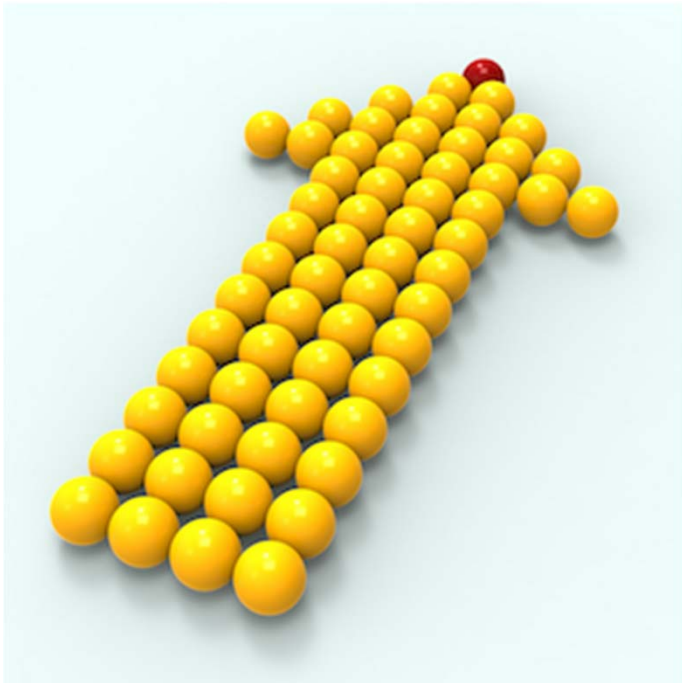
Let's hear from each of them about what their organization is and how it is striving to achieve the Vision.

Who is Nebraska VR?

- ❑ We are the state employment program for people with disabilities, housed in the Nebraska Department of Education (NDE), Office of Vocational Rehabilitation, known as Nebraska VR.
- ❑ We help people with disabilities prepare for, find and keep jobs. We also help businesses recruit, train, and retain employees with disabilities.



Our Role in the Injured Brain Community



- ❑ Nebraska VR received designation as the lead state agency for Traumatic Brain Injury (TBI) from Governor Heineman in 2008. Prior to that, NDE's Office of Special Education had been the designated lead agency.
- ❑ As lead agency, we apply for and manage the federal TBI Grant from the Administration for Community Living (ACL) TBI State Partnership Grant Program.

Our Role in the Injured Brain Community (continued)

- ❑ Nebraska VR sponsors and supports the statewide Brain Injury Advisory Council (BIAC), which is a required core component for all states who wish to compete for the grants.
- ❑ We also ensure that Nebraska maintains the other required core components; a State Plan for Brain Injury Services and Supports, a periodic Needs and Resources Survey, and state matching funds for the grant.

How We Collaborate

- ❑ By building relationships with the BIAC member organizations, looking to them for input and recommendations for TBI grant goals and objectives, and helping them advocate for policies, services and programs that will positively impact people with injured brains and their families and caregivers.
- ❑ By working with other ACL TBI grantee states on projects that have impact at the national level. Nebraska currently co-leads workgroups focused on *Transition and Employment* and *Using Data to Connect People to Services*. All grantee states are also working on core competencies and professional TBI workforce development.

How We Collaborate (continued)

- ❑ Educating our own staff and those in other state agencies who serve people with injured brains.
- ❑ Contracting with organizations and businesses to carry out the activities related to our TBI grant goals and objectives in building our state's capacity.



Past Successful TBI Grant Initiatives

- ❑ Supported creation and growth of the Brain Injury Alliance of Nebraska (BIA-NE).
- ❑ Funded a successful pilot and initial support for the BIA- NE's Resource Facilitation program.
- ❑ Supported the BIA-NE's Annual Brain Injury Conference until it became self-sustaining.
- ❑ Created the TBI Registry Follow-Up Mailing of letters and brochures that reach over 10,000 newly injured people each year.
- ❑ Provided many years of data and education to support legislation for a state TBI Trust Fund, which will be implemented soon.

Current TBI Grant Initiatives

- ❑ Building a comprehensive, accessible toolkit for orienting new BIAC members with help from the National Association of State Head Injury Administrators (NASHIA).
- ❑ Building a statewide network of people with injured brains and family members through the Nebraska Injured Brain Network (NIBN) and providing funding for their website.

Current TBI Grant Initiatives (continued)

- ❑ Disseminating a needs survey focused on brain injury and behavioral health challenges.
- ❑ Sponsoring this Summit, to build and amplify the voice of people with injured brains and their family members and caregivers.
- ❑ Funding a pilot of Peer to Peer Supports just for people with injured brains and their family members (coming soon).

Accomplishing the Vision



- ❑ Nebraska VR and the BIAC adopted the Vision in December 2017.
- ❑ The Vision served as the foundation for our current TBI grant goals and objectives (FY 2018 – 2021).
- ❑ The Annual Living with Brain Injury State Plan for 2019 – 2020 goals and objectives represent tangible steps toward achieving the Vision.
- ❑ Adding more people with injured brains to the BIAC to at least 50% of the membership.

What is the BIAC?

Here to present: Judy Nichelson, Council Chair

The Brain Injury Advisory Council is the forum for all brain injury stakeholders in the state to collectively identify needs and service gaps, and to recommend policy and system changes consistent with the federal TBI program's purpose.

- ❑ Membership includes people with the lived experience of brain injury, family members and professionals.
- ❑ The Council's mission is to “engage, integrate and inspire brain injury stakeholders to help achieve the Statewide Vision for Brain Injury Policies and Services.”

Purpose

- ❑ To advise Nebraska VR on matters that include (but are not limited to) implementation of the Annual Brain Injury State Plan and the federal TBI grant.

How We Collaborate

- ❑ We are expanding our membership to be consistent with the federal TBI program's commitment to independent living and person-centered planning, to ensure that people with the lived experience of brain injury make up at least 50% of the Council's membership.

How We Accomplish the Vision Together

- Judy's Story
- Registered Nurse/Survivor
- How I found the BIAC
- BIAC Chair, and how my experience with Aphasia affects it
- BIAC Operating Procedures state the Chair and Vice Chair must be people with BI
- Accommodations for people with injured brains to join, lead and participate in the BIAC
- Nebraska Injured Brain Network (NIBN)



BIA-NE Presentation

NIBN Board Members

- Emaly Ball, President
- Sara Kadyrova, VP
- Michelle Janicek, Treasurer
- Susie Bonde, Secretary
- Frank Bonde
- June Collison
- Larry Janicek



Presentation Overview

- ❑ The Nebraska Injured Brain Network, or NIBN, including its History, Mission, Vision, Status, and the role of Chapters.
- ❑ What NIBN is planning to do for you and others in the injured brain community in Nebraska.
- ❑ The Nebraska Vocational Rehabilitation (VR) grant and the technical assistance provided by this grant.

History of NIBN

- ❑ In 2017, 6 Brain Injury Support Groups provided more than 300 comments about the need for more services.
- ❑ In 2017, the Kearney Brain Injury Support Group suggested the creation of a new organization that would be of the people with an injured brain, and for the people with an injured brain. This was the “birth” of the NIBN concept.
- ❑ Nebraska VR applied for a federal grant, explaining the need to connect people living with an injured brain.

History of NIBN, continued

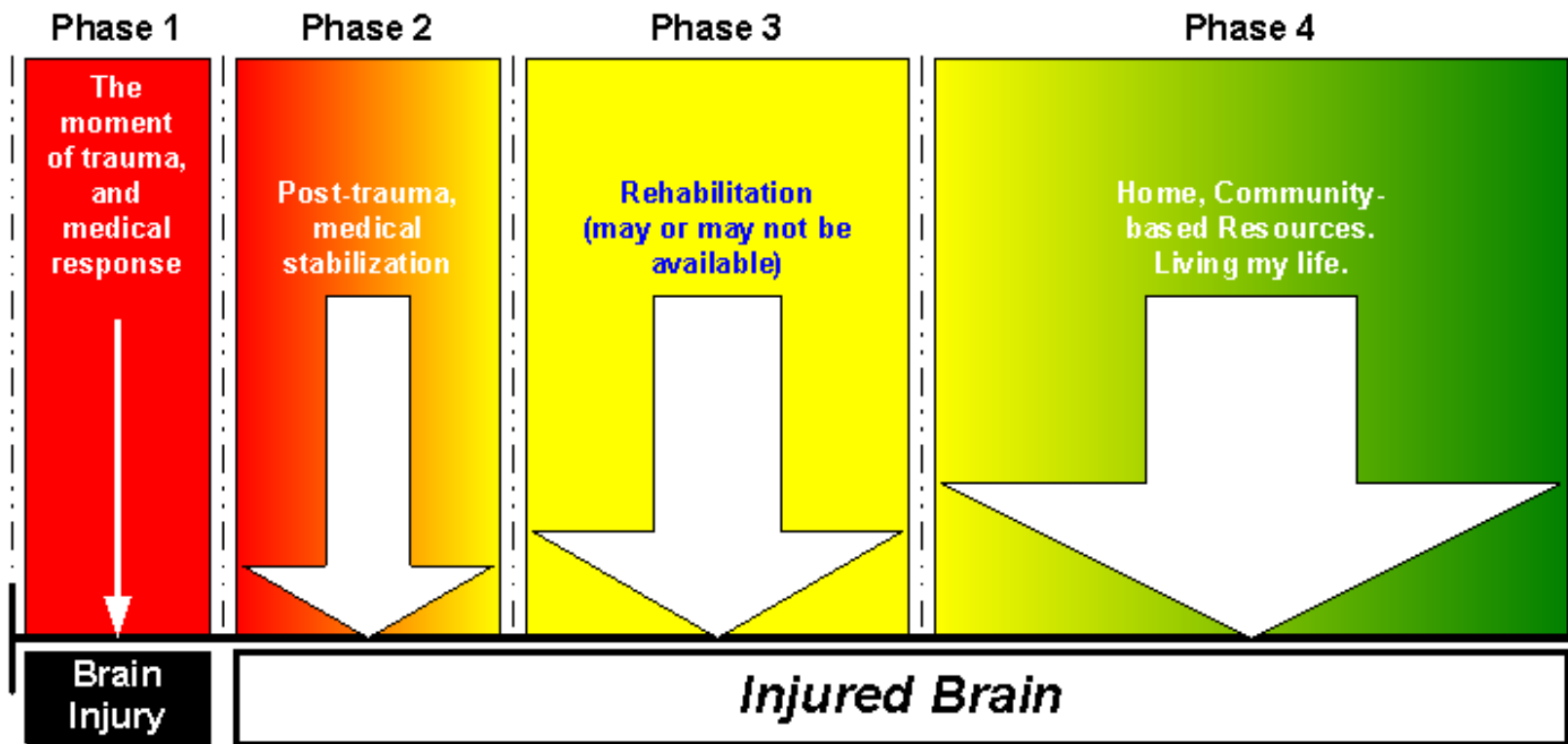
- ❑ The Brain Injury Alliance (BIA-NE) already exists, and provides valuable training and education.
- ❑ In 2018, Nebraska VR solicited proposals for its initiative to connect people living with an injured brain.
- ❑ In 2019, Nebraska VR launched an initiative to create a voice-driven organization, which resulted in the creation of NIBN.

NIBN's Mission

- ❑ The NIBN Board has been working to create the Nebraska Injured Brain Network, which is designed to serve the people of the injured brain community, and to complement and collaborate with the BIA-NE.
- ❑ The Mission of NIBN, then, is to be a life line for people with an injured brain, uniting and empowering us and our families.

“Injured Brain” Definition

The Different Phases of a Brain Injury versus an Injured Brain, and Recovery



Our Unique Voice, the Heart of NIBN

- When we come together as a unified group of people living with an injured brain (along with our family members and caregivers), ***we have...***
 - ❖ **Strength**, to advocate
 - ❖ **Solidarity**, to withstand challenges
 - ❖ **Support**, to help each other
 - ❖ **Connection**, to combat isolation
 - ❖ **Identity**, to feel part of something bigger than me
 - ❖ **Familiarity**, to form bonds with each other
 - ❖ **Understanding**, to be patient with one another
 - ❖ **Trust**, to take risks with each other
 - ❖ **Fun**, because we can

NIBN's Vision

- Our Vision is based on the phrase “Injured Brain” which we discussed above.
- Our Vision is also closely aligned with the Voice-Generated Statewide Vision.
- Our Vision currently has seven (7) components...

NIBN's Vision, continued

- Nebraskans living with an injured brain and their family members will be the unified Voice of NIBN.
- We will have access to the resources we need, regardless of geographic location.
- We will build a community of our peers.
- We will be assisted by Peer Supporters who can help us on our recovery journey.

NIBN's Vision, continued

- We will be active in shaping policies and programs to improve our recovery journey.
- Those who assist us with our recovery journey will understand their unique role and collaborate with each other such that there is no wrong door to the services and resources we need.
- We will decrease the stigma associated with living with an injured brain.

NIBN's Current Status

- Incorporated as a non-profit in the State of Nebraska (effective October 30, 2019).
- NIBN has an Employee Identification Number (EIN) with the Federal IRS.
- NIBN has applied for 501c3 status (expected to receive by February of 2021).
- Has contracted with Nebraska VR for outreach and development purposes.
- Currently contracted for branding services such as our logo and website.

The Role of Chapters

- ❑ NIBN in Kearney is the statewide “hub of the wheel”.
- ❑ The Chapters are the spokes of the wheel, reaching out to communities across Nebraska.
- ❑ The Chapters, connected through the hub, will form the network of people living with an injured brain—the Injured Brain Community.
- ❑ The Chapters will be led by local people living with an injured brain and their family members.
- ❑ The Chapters will have a local purpose, as well as a role with the statewide initiatives.

Types of Supports NIBN Plans to Deliver

- A robust website with resources and links, especially to help you find resources close to you.
- Peer Support, meaning a person who has been living with an injured brain and who can meet with you to help you along with your own recovery journey (organized through the Chapters).
- Advocacy that involves you—helping you tell your story to those who need to hear it, and creating opportunities for you to tell your story on a statewide level.
- Marketing support, to assist Chapters to develop local injured brain communities.

We are Launching a Learning Community on This Topic

- You've heard a lot of information today.
- You probably have many questions, and you might like to participate in further discussion.
- You might have insights you'd like to share.

You'll have an opportunity to do these things in our upcoming Learning Communities!

- A Learning Community is an online forum with a facilitator where you can participate in further discussions of this topic
- During the second half of January you will receive an invitation with instructions as to how to sign up and participate in this Learning Community

Contact Information for Today's Presenters

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- ❑ John Ferrone, Ferrone Associates, jferrone@ferroneassociates.com