

**QUESTIONS AND ANSWERS FROM THE
2ND ANNUAL LIVING WITH AN INJURED BRAIN
VIRTUAL SUMMIT
(November 9, 10, 12 and 13, 2020)**

A Virtual Event to Engage You on Your Recovery Journey



An Overview of the Statewide Vision for Brain Injury Policies and Services, and the Organizations Helping to Accomplish the Vision

Presenters: John Ferrone, Ferrone Associates, Keri Bennett, Nebraska VR, Judy Nicholson, Brain Injury Advisory Council, Peggy Reisher and Chris Stewart, Brain Injury Alliance of Nebraska, Emaly Ball, Nebraska Injured Brain Network.

Living with an injured Brain...You are Not Alone on Your Recovery Journey

Presenters: Sara Kadyrova, Shawna Thompson, Roy Stutz

Coping, Managing, and Living with an Injured Brain

Presenters: Roy Stutz, Pam Cody, Emaly Ball

So, Your Loved One has an Injured Brain... The Family Member and Caregiver's Journey

Presenters: Dennis Thompson, Susie Bonde, and June Collison

**A note from the Summit presenters: Many questions were very personal and those who presented have provided comments where they could; however, most feel that the Learning Communities would be a better forum to delve more deeply into such questions so that they can talk about them rather than try to write about their feelings. We hope to see you in our Learning Communities—an informational email will be sent very soon.*

Question: Asking for a friend...What resources are there available for the person with an injured brain when they are elderly, and in outstate Nebraska, when they do not qualify for Medicaid? Are there Respite programs? Day facilities? Adult daycare? Can Area on Aging assist? League of Human Dignity? Does this person have to spend their life resources down to nothing to be able to get assistance with their brain injury? This person feels like they are falling through the cracks and going to have to be broke financially to get any assistance. Any recommendations?

Answer:

BIA-NE Response – If a brain injury is involved, regardless of the individual’s prognosis, location, age or needs, contact the Brain Injury Alliance of Nebraska because ours is not a “one-size fits all” population. Everyone should have choices to overcome their barriers. Call BIA-NE Resource Facilitation at 844-423-2463 or e-mail chris@biane.org. Brain Injury Alliance of Nebraska advocates for individuals in creating person-directed teams of support that evolve with the individual’s needs and goals. BIA-NE collects the data and invites people to engage in system change that better serves our entire population as a growing and more connected community.

Question: How to best function with brain injury during turmoil of pandemic and unknown while establishing new normal for best quality of life?

Answer(s):

BIA-NE Response - The pandemic has introduced our entire country to the conditions that most of our folks’ experience after suffering any kind of brain injury that now includes COVID. In navigating this kind of turmoil, our population become experts. Brain Injury Alliance of Nebraska connects individuals across the state; when people are in fear of the future, we offer each other hope. When isolated, we build connections, and when in need, we find resources. Too often our population is seen as broken because of a diagnosis. When in fact, we are leaders that have been down this kind of hole and have found our way out. If you want to be part of the solution call BIA-NE Resource Facilitation 844-423-2463 or e-mail chris@biane.org.

NE VR & NIBN Response: We have included at the end of this document, a collection of resources that people may be able to use to cope with the pandemic

Question: With the resources and support for Peers, will this be more user friendly, and easy to access?

Answer(s):

BIA-NE Response - Brain Injury Alliance of Nebraska has learned, “no one can know what it is like to live with a brain injury, unless you have experienced a brain injury.” BIA-

NE Resource Facilitation has been offering connections between individuals with similar experiences and their family members for years. BIA-NE Resource Facilitation has collected data on the matches between peers since July 2020. It is organic and holistic the empowerment that comes from sharing learned experiences to help each other. If you want to be connected to a peer from across the state, please contact BIA-NE Resource Facilitation and check out “Survivor’s Stories” on biane.org.

NIBN Response – NIBN is working diligently toward creating a peer to peer support program that will be accessible for as many people as possible. Additionally, our growing Chapter system will be encouraged to incorporate remote access for support group or other activity-based meetings. In fact, this is already being done in the Kearney Area Chapter. Keep an eye out for when we launch our website, www.nibn.org, which is planned for early 2021. We will have information about when our support groups are meeting and how to contact the Chapter leaders.

Question: It would be encouraging to hear from others who have had to deal with various forms of abuse after surviving a brain injury.

Answers(s):

BIA-NE Response - Brain Injury Alliance of Nebraska has spent the last few years working in shelters and corrections completing TBI screenings and referring individuals that have suffered abuse for evaluation, treatment, and community resources. Often the symptoms a person has after abuse are confused by the complicated experiences. Shelter staff, through education, recognize the potential for TBI and the difference with mental health diagnosis. For education and results of the screening tool, please contact 844-423-2463 or info@biane.org.

NIBN Response: Please see the end of this document where we have placed various resources you can utilize.

Question: What additional training could a care giver obtain to better assist?

Answer(s):

BIA-NE Response - BIA-NE Resource Facilitation has extensive experience of collaborating with statewide caregiver groups. Working together to provide empathy, awareness and supports for family members providing care to loved ones that have suffered a TBI. While the journeys may start with the same event, the needs, stressors, and challenges faced by the individual and family member can be different. To strengthen the informal supports of families, on which recovery relies, ensuring the care and well-being of the caregivers is a priority. By offering resources, training, and supports that address the unique needs of the entire team’s needs, the result is everyone feels better.

NIBN Response – We can think of two websites that caregivers could look at for training including <https://www.ilru.org/training-online> and brainline.org. The trainings available at ILRU are extensive, so you may want to browse through the website and see what topics are most important to you, then go from there.

Question: How to support my loved one with an injured brain when no other community supports exists? Needs cognitive therapy options. Help finding easier ways to connect with in home caregivers... any associations?

Answer(s):

BIA-NE Response - There is no doubt that location can be a barrier in accessing needed services, if a “no” is considered as a final answer. The Brain Injury Alliance of Nebraska collaborates with individuals, professionals, and family members across the state to create individual quilts of supports while working on developing whole blankets of wrap around services. Using the turmoil of the pandemic, organizations that were previously unavailable are now offering on-line services. Our population includes innovators that are creating and sharing alternative options, within their communities, that provide the therapeutic care that can help. Nothing about brain injury is seamless or easy, but working together, we can do better and just in collaborating there is healing.

Emaly Ball/NIBN Response – It may be beneficial to call a local department of health and human services office to see if they can provide you with a list of associations or organizations that may be able to help. Additionally, at the end of this document there is a list of various resources that may be beneficial to you. Don’t forget to check out our website, www.nibn.org, when it is launched – which is planned for early 2021.

Question: My son would like to further his education. What resources and assistance might be available for him to attend and is there anything the schools can do to accommodate him?

Answer(s):

BIA-NE Response - BIA-NE Resource Facilitation is connected to the university that work with students on accommodations. Brain Injury Alliance of Nebraska is also collaborating on tools that educators across grade levels can access for accommodations that address specific needs of their individual students, subject, and teaching style. Brain Injury Alliance of Nebraska also works with the BIRSST Teams across the state and offers through Facebook, “Teens and Twenties” with discussions about overcoming barriers in education.

Emaly Ball/NIBN Response – Be sure to check with your school’s guidance counselor or disability services department. Every campus (either high school or college) has someone who can help. You could even just call the main office and they should be

able to direct you to where you need to go! Don't forget to check out the resources listed at the bottom of this document, also.

Roy Stutz's response: Every school has an office that houses Disability Services like Emaly said. The problem is that your son has to advocate for himself. The people there have a wide range of services that they can help him with, but he has to advocate for himself. The process of getting and keeping disability is an ongoing and evolving document. He knows what works for him and what doesn't. He has to develop the relationship between himself and the disability services. The other thing that he should do is email and set up a time at the beginning of each semester and talk to individual professors. This does two things: 1. It helps them get on the same page from the start. When he initializes the conversation it help the professor to know that he is serious about his education. 2. It humanizes him to the professors. They don't seem him as a number, but they see him as a student who will work hard, he just needs a little extra help. All of this is dependent on him being secure with who he is and what he needs to be successful.

Question: Is some of the information also similar to coping strategies, etc. for people with mental illnesses and their family members?

Answer(s):

BIA-NE Response -Brain Injury Alliance of Nebraska is collaborating with our individuals, family members and behavioral healthcare providers statewide to overcome the silos of diagnosis and misunderstanding to increase options for each individual. Expanding understanding for comprehensive inclusion of cognitive challenges involves everyone sharing experiences and best outcomes.

NIBN Response: Please see the end of this document where we have placed various resources you can utilize.

Question: How have you been able to handle emotional rollercoasters (frustration, anger, depression, etc.)? What hurdles did you have and how did you overcome them?

Answer:

Emaly Ball's response – as a person living with an injured brain, it is difficult to handle emotions sometimes. I have to try to remember that I can get frustrated easily and I need to take time to communicate my feelings – and taking your time is OKAY!

Question: What mistakes have you made with communication? Can you share any barriers to communication? How have you been able to overcome this?

Answer:

NIBN Response: This question will be discussed during the Learning Communities.

Question: Perhaps developing good mentors in the community is something to be tackled in a learning community over the next year?

Answer:

NIBN Response – We will be working to launch our learning communities in early 2021. An informational email will be sent out to all participants, and the procedures for signing up will be explained.

Question: What mistakes or assumptions have you had in trying to communicate with someone with a TBI? How did you overcome them?

Answer:

Keri Bennett's response: Communication with someone after a TBI can be challenging for both the person with TBI and those who are trying to communicate with him or her. A TBI can result in various physical and/or cognitive changes that impact a person's ability to speak, read and write, interpret body language, etc. In my opinion, there are two great mistakes we make in trying to communicate with a person who has an injured brain. The first mistake is not taking time to fully understand the person's specific communication challenges so we can alter our own methods of communication to accommodate those challenges. The second great mistake we make is to not allow time for the person with TBI to respond when we have asked a question or provided information. As professionals or caregivers, we need to learn to stop talking, and become comfortable with silence, even if it seems an unbearably long silence. There is good information about how to address communication difficulties after TBI at the Brainline.org website: <https://www.brainline.org/article/communication-effects-after-brain-injury>

Resources for 2nd Annual Living with an Injured Brain Summit Participants

COVID-19

NASHIA COVID-19 Related Resources

Information for Advocates, Consumers and Families, Staff, Educators and Providers, State and Federal Policies:

<https://www.nashia.org/latest-news>

Brain Injury Association of Virginia

Mental Health Strategies and other COVID-19 resources:

<https://www.biav.net/resources-and-information-on-covid-19/>

BRAINSTEPS Strategies for Teaching Educators, Parents & Students of Pennsylvania and Colorado (Specific to virtual education and students with injured brains):

<https://static1.squarespace.com/static/5eb2bae2bb8af12ca7ab9f12/t/5f3c31582db2a8159c1964c3/1597780314855/BrainSTEPS.Online.Learning.Adjustments.ABI.pdf>

Virtual Education & Students With Disabilities Resource Guide: Supporting Student Success in the Time of COVID-19 and Beyond:

<https://www.respectability.org/wp-content/uploads/2020/08/RespectAbility-Virtual-Education-Students-With-Disabilities-Resource-Guide.pdf>

Caregivers and Respite Care

List of Respite Care Resources from Munroe-Meyer Institute website:

<https://www.unmc.edu/mmi/faculty-staff/respite-resources.html>

Nebraska Lifespan Respite Network and Nebraska Caregiver Coalition

<https://respite.ne.gov/partners-and-advocates/nebraska-caregiver-coalition>

Brainline.org, Caregiver Basics

<https://www.brainline.org/caregivers/caregiver-basics>

Hotline for Disability Services

<https://cap.nebraska.gov>

Nebraska Aging & Disability Resource Center (ADRC)

<https://nebraska.arounja.org>

Telehealth and Rehabilitation

Quality Living, Inc. Telerehab Program

<https://qliomaha.com/programs-services/telerehab/>

Neurorestorative Interactive Telehealth Services

<https://www.neurorestorative.com/treatment-approach/supports-services/interactive-telehealth-services/>

Errorless Learning After Brain Injury

<https://www.brainline.org/video/dr-tedd-judd-talks-about-errorless-learning-after-brain-injury>

Assistive Technology, Accommodations and Strategies

Brain Education Strategies Technology (BEST) Suite of Apps

<https://bestconnections.org>

Cognitive Harmonics, Inc. My Bionic Brain application

<https://cognitiveharmonics.com/my-bionic-brain/>

Job Accommodation Network (JAN), brain injury

<https://askjan.org/disabilities/Brain-Injury.cfm>

Job Accommodation Network (JAN), stroke

<https://askjan.org/disabilities/Stroke.cfm>

Nebraska VR Orientation Video

http://vr.nebraska.gov/job_seekers/index.html

Re-useable Notebooks:

Many types exist and you can find them on Amazon.com. The one Emaly uses is called an Elfin Book.

<https://elfinbook.co>

Various Topics Related to Injured Brains

Brainline.org website

<https://www.brainline.org>

Nucleus Medical Media Concussion/TBI YouTube Video (2012)

<https://youtu.be/55u5lvx31og>

Same Video (updated in 2013)

<https://youtu.be/tgChTeALF7g>

Social Security Administration

www.ssa.gov

Brain Injury Alliance of Nebraska Resource Facilitation

<https://biane.org/events/resource-facilitation/>

Counseling Services - Referral Names:

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| A New Day Counseling 308/236-9105 | 3915 N Ave Ste. B |
| Boys Town, NE - Hotline - 800/448-1833 | 14100 Crawford Street |
| Elevate Counseling & Consulting 308/251-2222 | 3710 Central Ave Ste. #9 |
| Gina Smith, Counselor 308/237-6865 | 2811 30 th Avenue |
| Insight Counseling & Recovery 308/237-0391 | 2908 W 39 th St. Ste. B |
| Jane Klosterman 308/236-7790 | 124 W 46 th St. Ste. 106 |
| Live Well Counseling Services 308/234-6029 | 3814 A Avenue |
| Midwest Encouragement Counseling Center 308/224-0596 | 15 W 22 nd St. |
| Richard Young (24 access center) 308/865-2000 | 1755 Prairie View Place |
| Richard Young Physician Office 308/865-2249 | 1755 Prairie View Place |
| Ryan Smith, Counselor 308/455-3435 | 3000 2 nd Ave Ste. 204 |
| Safe Center 308/237-2599 | 620 East 25 th St. Ste. #14 |
| South Central Behavioral Services (24-adult crisis) 308/237-5951 Access Services M, T, Th, F from 8:30 till 12 pm-Walk-ins welcome | 3810 Central Ave |