

ACL Traumatic Brain Injury State Partnership Grants Performance Measurement Reporting Tool

Updated June 9, 2020 for Grantee Completion

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A. Grant Activities (all grantees respond)

1. Which activities did you carry out as part of your ACL project using program funding during this reporting period? (Check all that apply)

- a. Partnership Development** - identifying and reaching out to new partners, coordinating and aligning activities, information exchange, collaboration on grant activities, collaboration on activities related to the grant
- b. Planning and Infrastructure Development** - state planning, policy and procedures development, state councils, needs assessment, surveillance, registry, IT systems
- c. Information and Referral/Assistance (I&R/A)** - bringing people and services together, answering questions from individuals and families about human service resources, helping people get connected to public benefits, sharing information about available services like home care and adaptive equipment. Note: I&R is about bringing people and services together. Individuals may reach out once or many times, but I&R typically does not involve ongoing engagement of individuals like Resource Facilitation. If the description provided here does not align with how your program defines this activity, please provide your definition here:

Click or tap here to enter text.

- d. Screening** - using a standardized procedure, structured interview, or tool to elicit the lifetime history of TBI for an individual. Screening can be used for clinical, research, programmatic, eligibility determination, service delivery or treatment purposes. If the description provided here does not align with how your program defines this activity, please provide your definition here:

Click or tap here to enter text.

- e. Resource Facilitation** – this category of activity could include development of resources such as databases, resource directories, and communications tools to improve service delivery. It could also mean providing assistance through an accessible, holistic, and person-centered process that engages individuals in decision making about their options, preferences, values, and financial resources and helps connect them with programming, services and supports they choose. In some states this may be called service coordination, service navigation, case management, options counseling, or person centered counseling. Resource facilitation could be of short term or long term duration. If the description provided here does not align with how your program defines this activity, please provide your definition here:

Click or tap here to enter text.

- f. Training, Outreach and Awareness** - continuing education for professionals who may work with or provide services for people who have experienced a TBI, training for individuals who have experienced a TBI, public education and awareness, training for caregivers, on-the-job training for agency staff, cross-training with partnering agencies. If the description provided here does not align with how your program defines this activity, please provide your definition here:

Click or tap here to enter text.

- Other 1 (Describe):** Click or tap here to enter text.

- Other 2 (Describe):** Click or tap here to enter text.

- Other 3 (Describe):** Click or tap here to enter text.

2. Did you target or limit some or all of your grant activities to support people in a particular setting or particular population during this reporting period? If yes, please select all that apply.

[NOTE: IF ALL OF THE ACTIVITIES ARE DESIGNED TO MORE GENERALLY SUPPORT ALL TBI SURVIVORS IN YOUR STATE, **DO NOT CHECK 'YES, ALL' OR 'YES, SOME' FOR ANY SETTING/POPULATION. ONLY CHECK 'NO' BELOW AND DO NOT FILL OUT THE REST OF THE TABLE.**]

- NO, all of our activities are designed to more generally support all TBI survivors in our state**

Setting/Population	YES, ALL of our activities were primarily targeted to this group	YES, SOME of our activities were primarily targeted to this group
a. Athletes	<input type="checkbox"/>	<input type="checkbox"/>
b. Children and youth (younger than 22)	<input type="checkbox"/>	<input type="checkbox"/>
c. Adults (22-59)	<input type="checkbox"/>	<input type="checkbox"/>
d. Older adults (60 or over)	<input type="checkbox"/>	<input type="checkbox"/>
e. People who are homeless	<input type="checkbox"/>	<input type="checkbox"/>
f. People who are hospitalized	<input type="checkbox"/>	<input type="checkbox"/>
g. People who are incarcerated or formerly incarcerated	<input type="checkbox"/>	<input type="checkbox"/>
h. Medicaid home and community-based services participants	<input type="checkbox"/>	<input type="checkbox"/>
i. Native Americans	<input type="checkbox"/>	<input type="checkbox"/>
j. Other ethnic, racial or linguistic minorities	<input type="checkbox"/>	<input type="checkbox"/>
k. Residents of nursing facilities, rehab facilities or ICFs/MR	<input type="checkbox"/>	<input type="checkbox"/>

Setting/Population	YES, ALL of our activities were primarily targeted to this group	YES, SOME of our activities were primarily targeted to this group
l. Rural populations	<input type="checkbox"/>	<input type="checkbox"/>
m. People who experience unhealthy substance use or a substance use disorder	<input type="checkbox"/>	<input type="checkbox"/>
n. Students	<input type="checkbox"/>	<input type="checkbox"/>
o. Veterans or current service members	<input type="checkbox"/>	<input type="checkbox"/>
p. People who are victims of crime, domestic violence, or intimate partner violence	<input type="checkbox"/>	<input type="checkbox"/>
q. Other 1 (describe)	<input type="checkbox"/>	<input type="checkbox"/>
r. Other 2 (describe)	<input type="checkbox"/>	<input type="checkbox"/>
s. Other 3 (describe)	<input type="checkbox"/>	<input type="checkbox"/>

3. Percent of your state’s counties (parishes or boroughs) targeted and reached through your grant’s activities during this reporting period:

- a. Total number of counties in state #Click or tap here to enter text.
- b. Counties targeted for this project #Click or tap here to enter text.
- c. Counties reached this reporting period #Click or tap here to enter text.

4. For each of your grant activities, please provide how much of your total program funding you spent in the last completed grant year in support of each of the different activities listed below, rounded to closest \$1,000. [NOTE: THIS QUESTION WILL BE ASKED ONCE A YEAR ABOUT THE LAST COMPLETED GRANT YEAR. THE AMOUNT IN ROW ‘j’ SHOULD TOTAL THE AMOUNTS IN ROWS ‘a’ THROUGH ‘i’].

- a. Partnership Development \$Click or tap here to enter text.
- b. Planning and Infrastructure Development \$Click or tap here to enter text.
- c. Information and Referral/Assistance \$Click or tap here to enter text.
- d. Screening \$Click or tap here to enter text.
- e. Resource Facilitation \$Click or tap here to enter text.
- f. Training, Outreach and Awareness \$Click or tap here to enter text.
- g. Other 1 (Describe): \$Click or tap here to enter text.
- h. Other 2 (Describe): \$Click or tap here to enter text.
- i. Funds not yet spent including any carryover funds from last fiscal year \$Click or tap here to enter text.
- j. **Total Program Funding** \$Click or tap here to enter text.

5. Did your project use any evidence-based practices, interventions, or programs as part of your grant activities during this reporting period?

YES NO

If yes, please describe:

Click or tap here to enter text.

B. Partnership Activities (all grantees respond)

6. Which organizations in your state received funding through the ACL State Partnership Program to carry out and/or support grant activities (primary awardee and sub-awarded partners) in this reporting period?

a. Lead Grantee Agency

i. **Name of organization:** Click or tap here to enter text.

ii. **Type of organization (select all the designations below that apply to this organization):**

- State Medicaid Agency
- State Vocational Rehabilitation Agency,
- State Department of Education
- State Department of Criminal Justice/Corrections
- State Unit on Aging
- State Department for Developmental Disabilities
- State Behavioral and/or Mental Health Agency
- State Department of Public Health
- Tribal Council
- Other State Agency
- University Center on Excellence for Developmental Disabilities
- University
- Other (Specify): Click or tap here to enter text.

b. Funded Partner 1 (If applicable complete; if not go to Question 7)

i. **Name of organization:** Click or tap here to enter text.

ii. **Type of organization (select all the designations below that apply to this organization):**

- State Medicaid Agency
- State Vocational Rehabilitation Agency,
- State Department of Education
- State Department of Criminal Justice/Corrections
- State Unit on Aging
- State Department for Developmental Disabilities
- State Behavioral and/or Mental Health Agency
- State Department of Public Health
- Tribal Council/Organization
- Other State Agency
- University Center on Excellence for Developmental Disabilities.
- University
- State Independent Living Council
- State I/DD Council
- Affiliate of National Brain Injury Organization
- County or Local Government Entity,
- Community-Based Services Organization (e.g. CAA, ADRC, AAA, CIL),
- Public Health Department or Clinic
- Recovery or Substance Abuse Treatment Center
- VA Medical Center
- Other Health Care Provider
- University
- Private Business/Employer
- Other (Specify): Click or tap here to enter text.

iii. **Is this partner new this reporting period?** Yes No

Funded Partner 2 (If applicable complete; if not go to Question 7)

i. **Name of organization:** Click or tap here to enter text.

ii. **Type of organization (select all the designations below that apply to this organization):**

- State Medicaid Agency
- State Vocational Rehabilitation Agency,
- State Department of Education
- State Department of Criminal Justice/Corrections
- State Unit on Aging
- State Department for Developmental Disabilities
- State Behavioral and/or Mental Health Agency
- State Department of Public Health
- Tribal Council/Organization
- Other State Agency
- University Center on Excellence for Developmental Disabilities.
- University
- State Independent Living Council
- State I/DD Council
- Affiliate of National Brain Injury Organization
- County or Local Government Entity,
- Community-Based Services Organization (e.g. CAA, ADRC, AAA, CIL),
- Public Health Department or Clinic
- Recovery or Substance Abuse Treatment Center
- VA Medical Center
- Other Health Care Provider
- University
- Private Business/Employer
- Other (Specify): Click or tap here to enter text.

iii. **Is this partner new this reporting period?** Yes No

Funded Partner 3 (If applicable complete, if not go to Question 7)

i. **Name of organization:** Click or tap here to enter text.

ii. **Type of organization (select all the designations below that apply to this organization):**

- State Medicaid Agency
- State Vocational Rehabilitation Agency,
- State Department of Education
- State Department of Criminal Justice/Corrections
- State Unit on Aging
- State Department for Developmental Disabilities
- State Behavioral and/or Mental Health Agency
- State Department of Public Health
- Tribal Council/Organization
- Other State Agency
- University Center on Excellence for Developmental Disabilities.
- University
- State Independent Living Council
- State I/DD Council
- Affiliate of National Brain Injury Organization
- County or Local Government Entity,
- Community-Based Services Organization (e.g. CAA, ADRC, AAA, CIL),
- Public Health Department or Clinic
- Recovery or Substance Abuse Treatment Center
- VA Medical Center
- Other Health Care Provider
- University
- Private Business/Employer
- Other (Specify):Click or tap here to enter text.

iii. **Is this partner new this reporting period?** Yes No

LIST ADDITIONAL FUNDED PARTNERS, AND ORGANIZATION TYPE, AS NEEDED IN THE FIELD BELOW:

7. Which types of organizations are program partners and support program activities but *did not* receive program funds during this reporting period?

a. Types of Unfunded Partners

Select all the types of organizations that are unfunded partners and indicate if this type of organization is new (as of this reporting period) or a continuing partner.

- State Medicaid Agency
- State Vocational Rehabilitation Agency,
- State Department of Education
- State Department of Criminal Justice/Corrections
- State Unit on Aging
- State Department for Developmental Disabilities
- State Behavioral and/or Mental Health Agency
- State Department of Public Health
- Protection and Advocacy Programs
- Tribal Council/Organization
- Other State Agency
- University Center on Excellence for Developmental Disabilities.
- University
- State Independent Living Council
- State I/DD Council
- Affiliate of National Brain Injury Organization
- County or Local Government Entity
- Community-Based Services Organization (e.g. CAA, ADRC, AAA, CIL),
- Public Health Department or Clinic
- Recovery or Substance Abuse Treatment Center
- VA Medical Center
- Other Health Care Provider
- University
- Private Business/Employer
- Other (Specify): [Click or tap here to enter text.](#)

8. Is there anything else you would like to let ACL know about your Partnership activities during this reporting period? *This question is not mandatory.*

[Click or tap here to enter text.](#)

C. Planning and Infrastructure Development (all grantees respond)

9. Please list your advisory council members for this project period and place a check by their affiliations. You may check all that apply if a person represents two or more affiliated entities.

GRANTEES CAN ADD THE NAMES BELOW OR UPLOAD AN ATTACHMENT WITH THE ROSTER OF NAMES. GRANTEES CAN ADD AS MANY ADVISORY COUNCIL MEMBERS AS THEY NEED.

Advisory Council Member Name	Person who has experienced a TBI (Survivor)	Family member of person who has experienced a TBI	Center for Independent Living/State Independent Living Council representative	Aging and Disability Resource Center representative	Protection & Advocacy agency representative	Long-term care ombudsman representative	TBI Model Systems representative	Representative from an Affiliate of National Brain Injury Organization	Other (describe)
Example: John Smith	<input checked="" type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	Click or tap here to enter text.
Click or tap here to enter text.	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	Click or tap here to enter text.
Click or tap here to enter text.	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	Click or tap here to enter text.
Click or tap here to enter text.	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	Click or tap here to enter text.

Advisory Council Member Name	Person who has experienced a TBI (Survivor)	Family member of person who has experienced a TBI	Center for Independent Living/State Independent Living Council representative	Aging and Disability Resource Center representative	Protection & Advocacy agency representative	Long-term care ombudsman representative	TBI Model Systems representative	Representative from an Affiliate of National Brain Injury Organization	Other (describe)
Click or tap here to enter text.	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	Click or tap here to enter text.
Click or tap here to enter text.	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	Click or tap here to enter text.
Click or tap here to enter text.	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	Click or tap here to enter text.
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Click or tap here to enter text.	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	Click or tap here to enter text.
Click or tap here to enter text.	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	Click or tap here to enter text.

Advisory Council Member Name	Person who has experienced a TBI (Survivor)	Family member of person who has experienced a TBI	Center for Independent Living/State Independent Living Council representative	Aging and Disability Resource Center representative	Protection & Advocacy agency representative	Long-term care ombudsman representative	TBI Model Systems representative	Representative from an Affiliate of National Brain Injury Organization	Other (describe)
Click or tap here to enter text.	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	Click or tap here to enter text.
Click or tap here to enter text.	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	Click or tap here to enter text.
Click or tap here to enter text.	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	Click or tap here to enter text.
Click or tap here to enter text.	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	Click or tap here to enter text.
Click or tap here to enter text.	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	Click or tap here to enter text.
Click or tap here to enter text.	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	Click or tap here to enter text.
Click or tap here to enter text.	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	Click or tap here to enter text.

Advisory Council Member Name	Person who has experienced a TBI (Survivor)	Family member of person who has experienced a TBI	Center for Independent Living/State Independent Living Council representative	Aging and Disability Resource Center representative	Protection & Advocacy agency representative	Long-term care ombudsman representative	TBI Model Systems representative	Representative from an Affiliate of National Brain Injury Organization	Other (describe)
Click or tap here to enter text.	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	Click or tap here to enter text.
Click or tap here to enter text.	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	Click or tap here to enter text.
Click or tap here to enter text.	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	Click or tap here to enter text.
Click or tap here to enter text.	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	Click or tap here to enter text.
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Click or tap here to enter text.	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	Click or tap here to enter text.

Advisory Council Member Name	Person who has experienced a TBI (Survivor)	Family member of person who has experienced a TBI	Center for Independent Living/State Independent Living Council representative	Aging and Disability Resource Center representative	Protection & Advocacy agency representative	Long-term care ombudsman representative	TBI Model Systems representative	Representative from an Affiliate of National Brain Injury Organization	Other (describe)
Click or tap here to enter text.	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	Click or tap here to enter text.
Click or tap here to enter text.	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	Click or tap here to enter text.
Click or tap here to enter text.	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	Click or tap here to enter text.
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Click or tap here to enter text.	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	Click or tap here to enter text.

Advisory Council Member Name	Person who has experienced a TBI (Survivor)	Family member of person who has experienced a TBI	Center for Independent Living/State Independent Living Council representative	Aging and Disability Resource Center representative	Protection & Advocacy agency representative	Long-term care ombudsman representative	TBI Model Systems representative	Representative from an Affiliate of National Brain Injury Organization	Other (describe)
Click or tap here to enter text.	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	Click or tap here to enter text.
Click or tap here to enter text.	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	Click or tap here to enter text.
Click or tap here to enter text.	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	Click or tap here to enter text.
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Click or tap here to enter text.	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	Click or tap here to enter text.
Click or tap here to enter text.	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	<input type="checkbox"/> Yes	Click or tap here to enter text.

10. Estimate the number of people in your state who have experienced a TBI and are getting some kind of Medicaid Home and Community Based Services or supports.

a. Estimate how many people living in your state have experienced a TBI: Click or tap here to enter text.

i. Of the total in 'a' above, estimate how many people who have experienced a TBI are currently receiving HCBS through a Medicaid TBI waiver: Click or tap here to enter text.

ii. Of the total in 'a' above, estimate how many people who have experienced a TBI are in your grant's target population (e.g. based on where they live in the state, their age, setting in which they live or some other demographic or criteria): Click or tap here to enter text.

(a) Of the total in 'a' above, estimate how many people in your target population are currently receiving services or supports that help them live in a home or community setting through a Medicaid waiver or some other kind of publicly funded program (e.g. state HCBS program, Rehabilitation Services Act, Older Americans Act): Click or tap here to enter text.

b. Notes about data provided (e.g., unknown because none of our partners collect this information, data are incomplete because only some of our partners collect this information. Please describe.):

Click or tap here to enter text.

11. What planning and infrastructure accomplishments or activities of the last six months do you think have been or will be most impactful? Consider how you are working toward systems change and what progress you are seeing.

Click or tap here to enter text.

12. Is there anything else you would like to let ACL know about your planning and infrastructure activities during this reporting period? These activities may include needs assessments, state plans, and registries *This question is not mandatory.*

Click or tap here to enter text.

D. Information and Referral/Assistance (if applicable to grant activities)

13. How many I&R/A contacts were made in this reporting period (across all funded partners providing grant-related I&R/A)?

a. How many people live in the collective service areas of the organization or organizations providing I&R/A with grant funding?:[Click or tap here to enter text.](#)

Total number of contacts made to organizations that use program funds to support some or all of their I&R/A activities: [#Click or tap here to enter text.](#)

Total number of contacts made to these funded partners regarding TBI in reporting period: [#Click or tap here to enter text.](#)

b. Notes about data provided (e.g., unknown because none of our partners collect this information, data are incomplete because only some of our partners collect this information. Please describe.):

[Click or tap here to enter text.](#)

14. How often are different types of services referred for I&R/A callers who have experienced a TBI, their family members, or other professionals and service providers during this reporting period across all funded partners providing grant-related I&R/A? Please select an option for each type of referral.

Type of Referral	COMMONLY	OCCASIONALLY	NEVER	UNKNOWN
a. Grant-funded resource facilitation, service coordination	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Other type of resource facilitation, service coordination (provided by other unfunded partners or other organizations such as an affiliate of national brain injury organization, ADRC, CIL, other ABI association, or other organization)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Older Americans Act services (e.g., nutrition services, LTC Ombudsman)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Behavioral health services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Brain injury support groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Caregiver supports	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Independent living services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Domestic violence help services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Employment counseling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Type of Referral	COMMONLY	OCCASIONALLY	NEVER	UNKNOWN
j. Educational counseling or school disability services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. Health insurance information or counseling (e.g. SHIP, Medicaid eligibility)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. General medical services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m. Specialized TBI/ABI services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n. Homeless services provider	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o. Housing supports	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p. Medicaid waiver services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
q. Physical, occupational, recreational or speech therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
r. Legal or advocacy services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
s. Transportation services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
t. Social Security	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
u. Veteran's hospital or clinic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
v. Vocational rehabilitation services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
w. In-home services and supports	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
x. Other 1 (Specify) Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
y. Other 2 (Specify) Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
z. Other 3 (Specify) Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

15. Is there anything else you would like to let ACL know about your I&R/A activities during this reporting period? *This question is not mandatory.*

Click or tap here to enter text.

E. Screening (if applicable to grant activities)

16. How many unduplicated people did you and your funded partners screen to identify a history of TBI during this reporting period (across all funded partners providing grant-related screening)? Please enter a number, or select zero or unknown, for each row.

SCREENING	NUMBER	ZERO	UNKNOWN
a. Total number of unduplicated people screened this reporting period	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
b. Number of people screened who were identified as having a history of TBI	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
Number of people under age 22	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
Number of people between 22-59	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
Number of people 60 or older	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
Number of veterans of any age	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>

17. Select which standardized instruments you or your partners used for screening procedures during this reporting period. (Select all that apply)

Instrument	Yes	No
a. The Ohio State University Traumatic Brain Injury Identification Method (OSU TBI-ID)	<input type="checkbox"/> YES	<input type="checkbox"/> NO
b. A modified version of the OSU TBI-ID	<input type="checkbox"/> YES	<input type="checkbox"/> NO
c. The Brain Injury Screening Questionnaire (BISQ)	<input type="checkbox"/> YES	<input type="checkbox"/> NO
d. Defense and Veterans Brain Injury Center TBI Screening Tool (DVBIC TBI), also called The Brief Traumatic Brain Injury Screen (BTBIS)	<input type="checkbox"/> YES	<input type="checkbox"/> NO
e. The Traumatic Brain Injury Screening Instrument (TBISI)	<input type="checkbox"/> YES	<input type="checkbox"/> NO
f. HELPS	<input type="checkbox"/> YES	<input type="checkbox"/> NO
g. Military Acute Concussion Evaluation (MACE)	<input type="checkbox"/> YES	<input type="checkbox"/> NO
h. Automated Neuropsychological Assessment Metrics (ANAM)	<input type="checkbox"/> YES	<input type="checkbox"/> NO
i. Other 1 (Specify): Click or tap here to enter text.		
j. Other 2 (Specify): Click or tap here to enter text.		
k. Other 3 (Specify): Click or tap here to enter text.		

18. Of the people who have experienced a TBI whom you screened in this reporting period, how many were living in these following settings at the time of their screening? Please enter a positive number, or select zero or unknown, for each row.

LIVING SETTING	NUMBER	ZERO	UNKNOWN
a. On their own/independent	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
b. Homeless	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
c. With parent or grandparent	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
d. With immediate family	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
e. With friends or other extended family	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
f. Group home	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
g. Prison or Jail/Justice involved setting	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
h. Transitional living program or temporary housing	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
i. Community Based Neurobehavioral Rehabilitation Services	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
j. Nursing facility or in-patient rehab setting	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
k. Supervised living program	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
l. Assisted-living settings	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
m. Other 1 (Specify): Click or tap here to enter text.	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
n. Other 2 (Specify): Click or tap here to enter text.	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
o. Other 3 (Specify): Click or tap here to enter text.	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>

Notes about data provided (e.g., unknown because none of our partners collect this information, data are incomplete because only some of our partners collect this information. Please describe.):
Click or tap here to enter text.

19. Of the people who have experienced a TBI whom you screened during this reporting period, how many were in competitive, integrated employment and/or in school at the time of the screening? Please enter a number, or select zero or unknown, for each row.

	NUMBER	ZERO	UNKNOWN
a. Competitive, integrated employment	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
b. In school or training	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>

Notes about data provided (e.g., unknown because none of our partners collect this information, data are incomplete because only some of our partners collect this information. Please describe.):
Click or tap here to enter text.

20. Is there anything else you would like to let ACL know about your screening activities this reporting period? *This question is not mandatory.*
Click or tap here to enter text.

F. Resource Facilitation (if applicable to grant activities)

21. For how many unduplicated people who have a TBI did you or your partners provide resource facilitation in this reporting period (across all funded partners providing grant-related resource facilitation)? Please enter a number, or select zero or unknown, for each row.

RESOURCE FACILITATION	NUMBER	ZERO	UNKNOWN
Total number of unduplicated people who have experienced a TBI who were provided with resource facilitation in this reporting period	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
Number of people under age 22	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
Number of people between 22-59	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
Number of people 60 or older	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
Number of veterans of any age	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>

Notes about data provided (e.g., unknown because none of our partners collect this information, data are incomplete because only some of our partners collect this information. Please describe.):
Click or tap here to enter text.

22. What types of referrals did those providing Resource Facilitation make for people who have experienced a TBI and who received resource facilitation during this reporting period? Please select a response for each type of referral.

Type of Referral	COMMONLY	OCCASIONALLY	NEVER	UNKNOWN
a. Grant-funded resource facilitation, service coordination	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Other type of resource facilitation, service coordination (provided by other unfunded partners or other organizations such as an affiliate of national brain injury organization, ADRC, CIL, other ABI association, or other organization)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Older Americans Act services (e.g., nutrition services, LTC Ombudsman)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Behavioral health services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Brain injury support groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Caregiver supports	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Independent living services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Domestic violence help services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Type of Referral	COMMONLY	OCCASIONALLY	NEVER	UNKNOWN
i. Employment counseling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Educational counseling or school disability services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. Health insurance information or counseling (e.g. SHIP, Medicaid eligibility)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. General medical services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m. Specialized TBI/ABI services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n. Homeless services provider	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o. Housing supports	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p. Medicaid waiver services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
q. Physical, occupational, recreational or speech therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
r. Legal or advocacy services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
s. Transportation services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
t. Social Security	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
u. Veteran's hospital or clinic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
v. Vocational rehabilitation services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
w. In-home services and supports	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
x. Other 1 (Specify): Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
y. Other 2 (Specify): Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
z. Other 3 (Specify): Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

23. Of the people who have experienced a TBI for whom you provided resource facilitation this reporting period, how many were living in these different settings at the time you worked with them? Please enter a number, or select zero or unknown, for each row.

LIVING SETTING	NUMBER	ZERO	UNKNOWN
a. On their own/independent	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
b. Homeless	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
c. With parent or grandparent	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
d. With immediate family	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
e. With friends or other extended family	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
f. Group home	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
g. Prison or Jail/Justice involved setting	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
h. Transitional living program or temporary housing	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
i. Community Based Neurobehavioral Rehabilitation Services	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>

LIVING SETTING	NUMBER	ZERO	UNKNOWN
j. Nursing facility or in-patient rehab setting	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
k. Supervised living program	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
l. Assisted-living settings	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
m. Other (Specify): Click or tap here to enter text.	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>

Notes about data provided (e.g., unknown because none of our partners collect this information, data are incomplete because only some of our partners collect this information. Please describe.):
Click or tap here to enter text.

24. Of the people who have experienced a TBI for whom you provided resource facilitation this reporting period, how many were in competitive, integrated employment and/or in school while receiving resource facilitation? Please enter a number or select zero or unknown, for each row.

	NUMBER	ZERO	UNKNOWN
a. Competitive, integrated employment	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
b. In school or training	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>

Notes about data provided (e.g., unknown because none of our partners collect this information, data are incomplete because only some of our partners collect this information. Please describe.):
Click or tap here to enter text.

25. Of the people who have experienced a TBI for whom you provided resource facilitation this reporting period, how many did you support through a transition from an institutional setting (e.g. criminal justice system, nursing facility) into the community? Please enter a number—or select zero, unknown, or not applicable—for each row.

	NUMBER	ZERO	UNKNOWN	N/A
a. Number transitioning from criminal justice system to community (with or without HCBS)	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Number transitioning from nursing facility/medical facility to community (with or without HCBS)	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Number transitioning from another setting to community (with or without HCBS) Describe: Click or tap here to enter text.	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Notes about data provided (e.g., unknown because none of our partners collect this information, data are incomplete because only some of our partners collect this information. Please describe.):
Click or tap here to enter text.

26. Is there anything else you would like to let ACL know about your resource facilitation efforts during this period? *This question is not mandatory.*

Click or tap here to enter text.

G. Training, Outreach and Awareness (if applicable to grant activities)

27. How many different types of people received grant-supported training in this reporting period (across all funded partners that provide training with program funds)? Please enter a number—or select zero, unknown, or not applicable—for each row.

	NUMBER	ZERO	UNKNOWN	N/A
a. Staff providing grant-related services	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Staff providing, I&R/A	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Staff conducting Screenings	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Staff providing Resource Facilitation	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Clinical/medical providers	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physicians	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emergency medical services providers/first responders	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other clinical/medical providers	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Coaches or other athletics personnel	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Domestic violence services staff	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Family, friends, informal caregivers	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Homeless services organization staff	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Individuals who have experienced a TBI	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. In-home services and supports staff	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Law enforcement personnel	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Prison or criminal justice system staff	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. Protection and advocacy staff	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. Residential rehabilitation center staff	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m. Nursing home staff	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	NUMBER	ZERO	UNKNOWN	N/A
n. Universities, colleges, or school staff (excluding school coaches)	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o. Veterans & military organization staff	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p. Other 1 (Describe): Click or tap here to enter text.	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
q. Other 2 (Describe): Click or tap here to enter text.	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
r. Other 3 (Describe): Click or tap here to enter text.	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Notes about data provided (e.g., unknown because none of our partners collect this information, data are incomplete because only some of our partners collect this information. Please describe.):
Click or tap here to enter text.

28. Please provide the number of grant-sponsored trainings that took place this reporting period, by topic area and include the number of attendees. Please enter either a positive number, zero (0), unknown, or not applicable in every field.

Note: “grant-sponsored trainings” refers to those using program funds or state matching funds.

Topic Area	Number of Trainings	Number of Attendees
a. TBI Basics	Click or tap here to enter text.	Click or tap here to enter text.
b. Aging and TBI	Click or tap here to enter text.	Click or tap here to enter text.
c. Assistive technology	Click or tap here to enter text.	Click or tap here to enter text.
d. Athletics	Click or tap here to enter text.	Click or tap here to enter text.
e. Behavioral health and TBI	Click or tap here to enter text.	Click or tap here to enter text.
f. Caregiving	Click or tap here to enter text.	Click or tap here to enter text.
g. Children and TBI	Click or tap here to enter text.	Click or tap here to enter text.
h. Concussions & mild TBI	Click or tap here to enter text.	Click or tap here to enter text.
i. Criminal justice and TBI	Click or tap here to enter text.	Click or tap here to enter text.
j. Diagnosis	Click or tap here to enter text.	Click or tap here to enter text.
k. Educational issues	Click or tap here to enter text.	Click or tap here to enter text.
l. Employment and training of people with TBI	Click or tap here to enter text.	Click or tap here to enter text.
m. Identification, screening, assessment	Click or tap here to enter text.	Click or tap here to enter text.
n. Independent living	Click or tap here to enter text.	Click or tap here to enter text.
o. Substance Use and TBI	Click or tap here to enter text.	Click or tap here to enter text.
p. Neurobehavioral aspects of TBI	Click or tap here to enter text.	Click or tap here to enter text.
q. Public Policy	Click or tap here to enter text.	Click or tap here to enter text.
r. Person Centered Planning/Counseling	Click or tap here to enter text.	Click or tap here to enter text.
s. Community-based services and support resources	Click or tap here to enter text.	Click or tap here to enter text.
t. Treatment and therapies	Click or tap here to enter text.	Click or tap here to enter text.
u. Other 1(Specify): Click or tap here to enter text.	Click or tap here to enter text.	Click or tap here to enter text.
v. Other 2(Specify): Click or tap here to enter text.	Click or tap here to enter text.	Click or tap here to enter text.
w. Other 3(Specify): Click or tap here to enter text.	Click or tap here to enter text.	Click or tap here to enter text.

Notes about data provided (e.g., unknown because none of our partners collect this information, data are incomplete because only some of our partners collect this information. Please describe.):
Click or tap here to enter text.

29. Please list and describe any training materials, outreach materials, fact sheets or other products you produced during this reporting period.

Click or tap here to enter text.

30. Is there anything else you would like to let ACL know about your training activities during this reporting period? *This question is not mandatory.*

Click or tap here to enter text.

H. Other (if applicable to grant activities)

31. Describe what activities you undertook in this area this reporting period.

Click or tap here to enter text.

32. How many unduplicated people did you work with or support through the activity identified in 31 during this reporting period? Please enter a number, or select zero or unknown, for each row.

OTHER	NUMBER	ZERO	UNKNOWN
Total number of people who have experienced a TBI who participated in the activity identified in 31	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
Number of people under age 22	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
Number of people between 22-59	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>
Number of people 60 or older	Click or tap here to enter text.	<input type="checkbox"/>	<input type="checkbox"/>

Notes about data provided (e.g., unknown because none of our partners collect this information, data are incomplete because only some of our partners collect this information. Please describe.):

Click or tap here to enter text.

List "Other" activities, as needed, in the field below:

I. Narrative Responses (all grantees respond)

33. Please describe the TBI mentoring and work group activities your program led or participated in during this reporting period.

Click or tap here to enter text.

34. Please describe the extent to which the mentoring and work group activities you participated in added value to your program, the national program, and/or any other aspect of your TBI work.

Click or tap here to enter text.

35. Did you use the services of the TBI Technical Assistance and Resource Center (TARC) during this reporting period? [Yes/No] *If yes, please describe these services. If you did not use the services of the TBI TARC during this reporting period, please explain why not.*

Click or tap here to enter text.

36. How would you describe the quality of services you received from the TBI TARC during this reporting period?

Click or tap here to enter text.

37. Is there anything else you would like to let ACL know about your project or the TBI State Partnership Program?

Click or tap here to enter text.

Public Burden Statement:

According to the Paperwork Reduction Act of 1995, no persons are required to respond to a collection of information unless such collection displays a valid OMB control number (OMB 0985-NEW). Public reporting burden for this collection of information is estimated to average [8] hours per response, including time for gathering and maintaining the data needed and completing and reviewing the collection of information. The obligation to respond to this collection is required to retain or maintain benefits under the statutory authority [Traumatic Brain Injury Reauthorization Act of 2018 (P.L. 115-377)].

ACL Traumatic Brain Injury State Partnership Grants Performance Measurement Reporting
Nebraska VR Supplemental Narrative Responses for June – November, 2020

Due to space limitations in the Reporting Tool, narrative responses are included here as noted.

Section A. Grant Activities

5. Did your project use any evidence-based practices, interventions, or programs as part of your grant activities during this reporting period?

Yes, to some extent. Peer Support is recognized as an evidence-based practice in the field of mental health recovery. The common lived experiences between people create a bond of trust and respect that forms the foundation for one person to guide, support and coach another person to recovery. The goal for Nebraska VR's TBI grant is to build an infrastructure that will foster this type of connectivity among people living with a brain injury. The Nebraska Injured Brain Network (NIBN) is the peer-run organization creating the network infrastructure through new chapters that are forming across the state. The technical assistance provided to NIBN with grant funding empowers them to become familiar with the concepts of peer support, and in turn, the NIBN members support each other as peers while this project evolves.

8. Is there anything else you would like to let ACL know about your Partnership activities during this reporting period?

Nebraska VR and the Brain Injury Advisory Council (BIAC) were pleased to collaborate with the Nebraska Injured Brain Network (NIBN) in hosting the 2nd Annual Living with An Injured Brain Summit in November, 2020. The Summit spotlighted individuals with the lived experience of brain injury and family members who shared their stories and strategies for living well and thriving after brain injury. Nebraska VR was also able to include our TBI grant objective to build a voice-driven network of individuals with TBI and family members with the state's Olmstead plan this year.

Section C. Planning and Infrastructure Development

10. b. Notes about data provided:

Data are incomplete because very little is collected or available. Regarding the figure in 10.a., an estimated 39,051 people living in Nebraska have experienced a TBI. This number represents 2% of Nebraska's 2020 population of 1,952,570 and very likely falls short of the number of actual injuries that have occurred. Actual data are not available on the prevalence of TBI in Nebraska. According to the National Center for Injury Prevention and Control, an estimated cumulative 5.3 million individuals are living with a TBI-related disability in the United States, representing a prevalence of approximately 2% of the U.S. population.

Regarding the figure in 10.a.i., this figure is the number of people with TBI currently receiving HCBS through the state's TBI Waiver. No data are available on the number of people with TBI receiving HCBS through the state's other Waivers.

Regarding the figure in 10.a.ii., although some of Nebraska's TBI grant activities target rural and underserved populations, most are statewide in scope, thus targeting every person in the state with TBI, which was estimated to be 39,051.

Regarding the figure in 10.a.ii.(a), data for all publicly funded programs are not available, as few of our state agencies and programs collect data specific to people with TBI. Data for the three programs that capture this data are as follows:

- Nebraska VR (Vocational Rehabilitation) = 126
- Aging & Disability Resource Center (ADRC) = 5
- Medicaid TBI Waiver = 20
- Total estimate = 151

11. What planning and infrastructure accomplishments or activities of the last six months do you think have been or will be most impactful?

A number of planning and infrastructure activities were accomplished in the last six months. Under a contract with the National Association of State Head Injury Administrators (NASHIA), Nebraska VR finalized content for the Brain Injury Advisory Council (BIAC) new member toolkit, which will "live" on the BIAC website. Content is designed to help new members gain a basic knowledge of Nebraska's public programs and system of services for people with brain injury, and to help them participate fully in BIAC meetings, committee work and decision-making. The toolkit includes a Mentor curriculum for more seasoned Council members to mentor new members. Nebraska VR and the BIAC look forward to launching the toolkit and Mentor activities in early 2021. The 2021 *Living with Brain Injury Needs Survey* was launched with a focus on the mental and behavioral health needs of individuals with brain injury. When analysis is complete, the results will be used to inform future State Plan and TBI grant activities. A competitive request for proposals (RFP) was released for Phase 1 of a three-phase pilot of Peer to Peer Supports for individuals with brain injury. The Nebraska Injured Brain Network (NIBN) was chosen as the contractor for this phase, which includes assessment and planning activities to develop a proposed model for the pilot. Phases 2 and 3 of the pilot will be launched in 2021. Despite the challenges imposed by the COVID-19 pandemic, Nebraska VR and the BIAC were successful in maintaining our quarterly meeting schedule and continuing committee work by moving to a completely virtual environment.

12. Is there anything else you would like to let ACL know about your planning and infrastructure activities during this reporting period? These activities may include needs assessments, state plans and registries.

Nebraska VR engaged the TBI Technical Assistance and Resource Center (TARC) to facilitate a review of our Living with Brain Injury State Plan for 2019-2020 with the BIAC for any needed updates or edits. The revised Plan is submitted with this report to show the minor revisions that were agreed upon for 2021-2022.

Section D. Information and Referral/Assistance

13. b. Notes about data provided:

The 20 contacts made to funded partners regarding traumatic brain injury (TBI) were made to the Brain Injury Alliance of Nebraska (11) and to Nebraska VR (9). These were calls received in response to TBI Registry mailings. A number of unfunded partners provide TBI-related I&R/A services to individuals with brain injury, family members and professionals. They include the Hotline for Disabilities, Disability Rights Nebraska, the League of Human Dignity and Independence Rising, among others. No data are available on contacts made to these unfunded partners.

Each month, Nebraska VR partners with the Department of Health and Human Services (DHHS), Division of Public Health to mail a letter and brochure to all individuals reported by the Nebraska Hospital Association in that month as having been diagnosed with a TBI. This is how Nebraska VR uses the TBI Registry data to connect people to services. During this reporting period, 1,218 letters were mailed, 113 letters were returned, and 1,105 letters were delivered to newly injured individuals placed on the TBI Registry. These numbers do not include a mailing for November 2020 as that mailing has been delayed by DHHS until late December or early January 2021.

A total of nine different brochures are utilized; for ages 0-21, 22-59 and 60+, across three regions of the state (western, central and eastern). Each brochure lists statewide resources along with regional and local organizations that provide assistance “close to home”. The purpose of customizing the brochures is to more quickly connect individuals with TBI to resources in their region or in their community.

15. Is there anything else you would like to let ACL know about your I&R/A activities during this reporting period?

An email is sent to each of the organizations listed in the brochures when the monthly letters and brochures are mailed. The email includes the number of letters sent for each of the three geographic regions of the state, but of course does not list the names or addresses of individuals receiving the mailings. The email may also include information on upcoming training events and new resources. Our objective is to call attention to the number of individuals in each area of the state who were diagnosed with a brain injury, and to prepare the organizations to respond to callers. The email also provides an opportunity to continue building awareness of TBI.

During this reporting period, we negotiated a new process with our state printing department for printing and distribution of the monthly letters and brochures that will increase our efficiency and reduce costs for the mailings. Our state printing department will print our letters and brochures on demand beginning January 1, 2020. This will ensure distribution of the most up to date brochures as revisions can be made to the documents prior to each mailing. The state printing department will also collate and insert the letters and brochures in envelopes, affix postage and mail the materials, expediting delivery to newly injured individuals placed on the TBI Registry.

Section E. Screening

18. Notes about data provided:

Data on the individual's age and living setting are not collected on the screening instrument used in this activity. Data are available, however it would require a review of each individual's application form to glean, and that task is too time-consuming to complete.

19. Notes about data provided:

Data on employment and school status are not collected on the screening instrument used in this activity. Data are available, however it would require a review of each individual's application form to glean, and that task is too time-consuming to complete.

20. Is there anything else you would like to let ACL know about your screening activities this reporting period?

The Nebraska VR Acquired Brain injury (ABI) Screen is conducted with individuals who apply for services with Nebraska VR and indicate a history of possible ABI. The agency application form includes the following pre-screening question; "In your lifetime (including childhood) have you ever injured your head, face or neck, or experienced repeated impacts to your head (e.g. from shaking, car accident, fall, fight, gunshot, explosion, contact sports or military service, etc.) OR have you ever experienced an illness that affected your brain (e.g. cancer, stroke, meningitis, tumor, drowning, poisoning, etc.)? __ Yes __ No __ Not sure." Nebraska VR staff are instructed to schedule a follow-up conversation with applicants who answer "Yes" or "Not Sure" to that question, using the ABI Screen as an interview guide to document a lifetime history of possible brain injury incidents and resulting functional challenges that may pose barriers to employment.

Section G. Training, Outreach and Awareness

27. Notes about data provided:

Data are included for seven training events conducted by the Brain Injury Alliance of Nebraska (BIA-NE) under a contract with Nebraska VR, and for four 2nd Annual Living with An Injured

Brain Summit sessions, for total of 11 events. A total of 208 people attended these events. A large number of attendees (93) did not identify their role at registration and did not complete the post-training evaluation forms for these training events.

29. Please list and describe any training materials, outreach materials, fact sheets or other products you produced during this reporting period.

Following is a list with descriptions for training and outreach materials that were produced during this reporting period:

- 2nd Annual Living with an Injured Brain Summit event items, including a flyer, several slide presentations and a Question and Answer document shared with all attendees. All of these items are posted to the Brain Injury Advisory Council (BIAC) website, along with links to the recorded Summit sessions at <https://braininjury.nebraska.gov/second-annual-living-injured-brain-summit-2020>
- “Brain Talks” Speaker’s Bureau items, including a sample flyer and slide presentation. These materials were produced by the Brain Injury Alliance of Nebraska (BIA-NE) under contract with Nebraska VR.
- Nebraska’s *Living with Brain Injury State Plan for 2019-2020*, including revisions that will be incorporated for the *2021-2022 Plan*.

Section H. Other

31. Describe what activities you undertook in this area this reporting period.

The centerpiece of Nebraska VR’s TBI grant is the Voice-driven Network Capacity Building project. The goal for this project is to build leadership capacity across a statewide Network of people with the lived experience of brain injury and their family members. Network members will be connected with each other to provide support, and they will be equipped to advocate with one voice for policy, program and service changes that will benefit Nebraskans impacted by brain injury. With technical assistance provided by a contracted consultant, the Nebraska Injured Brain Network (NIBN) noted several accomplishments during the reporting period:

- Partnered with Nebraska VR and the BIAC to plan, promote and deliver the 2nd Annual Living with An Injured Brain Summit.
- Formed local Chapters in two new communities in central and western Nebraska.
- Proposed a winning approach to pilot Peer to Peer Supports for individuals with acquired brain injury (ABI) in answer to Nebraska VR’s request for proposals (RFP).
- Strengthened their Board of Directors leadership capacity through monthly Board meetings and work sessions.
- Drafted and approved a set of financial policies to guide the NIBN organization.
- Drafted content for the organization’s website, which will be launched in early 2021. The website will host individual web pages for each local NIBN Chapter.

32. Notes about data provided.

Figures listed are for participants with TBI. The NIBN Chapters also include family members. Following are the Chapter member totals (individuals with TBI and family members):

- Kearney Chapter, 7 members (including the NIBN Board of Directors)
- North Platte Chapter, 34 members
- Hastings Chapter, 4 members
- Grand Island Chapter, 2 members
- Ogallala Chapter, 2 members

Per request from Dana Fink with ACL, we are providing the following data on the NIBN Chapter members with TBI:

Participant Living Setting (Individuals with TBI only)	Number	Zero	Unknown
On their own/independent	13		
Homeless		x	
With parent or grandparent	2		
With immediate family	2		
With friends or other extended family		x	
Group Home		x	
Prison or Jail/Justice involved setting		x	
Transitional living program or temporary housing		x	
Community Based Neurobehavioral Rehabilitation Services		x	
Nursing facility or inpatient rehabilitation setting		x	
Supervised living setting		x	
Other (Specify):			
Other (Specify):			
Other (Specify):			
Employment/School setting	Number	Zero	Unknown
Competitive, integrated employment	2		
In school or training	1		

Section I. Narrative Responses

33. Please describe the TBI mentoring and work group activities your program led or participated in during this reporting period.

The *Transition and Employment* work group met monthly in an on-line forum, making good progress on group goals. Mentor grantee states, Indiana and Nebraska, facilitated each

meeting. The work group includes Partner state representatives from North Carolina and Vermont. Representatives from Iowa and Colorado also participated in work group activities. All meetings were recorded and archived for the benefit of members who could not attend. The group is small, but extremely productive.

Much of our work during this reporting period centered on creating a competency self-assessment tool for VR Counselors (VRCs) based on our VRC Core Competencies, originally drafted in Year 1 and revised in Year 2. Once again, the group collaborated with Nebraska's contracted grant evaluator, Will Schmeckle to develop the tool in SurveyMonkey®. Several competency measurement scales were reviewed in the process. Once the self-assessment tool was finalized, we identified several strategies for promoting the tool to state VR programs; explaining its usefulness for identifying education and training gaps among front-line VR staff and increasing VR success rates with clients who experience TBI. The group collaborated with Dr. Christina Dillahunt-Aspillaga to draft a sample letter for VR Administrators to introduce the tool to staff. Our goal is to deploy the tool in our work group states, collect, analyze and report the data by the end of this grant cycle.

The work group completed several additional activities during this reporting period:

- Mentor states drafted work group summaries on behalf of the group to use in their reports.
- Shared work group product information with the TBI TARC representatives and other Mentor states.
- Deployed a work group member survey to select SME speaker for the NASHIA SOS Conference.
- Indiana sponsored Dr. Christina Dillahunt-Aspillaga as a speaker for the NASHIA SOS Conference in September, 2020 and as a guest for our work group meeting following her presentation.
- Reviewed our WIOA state plans for objectives that would support introduction of the VRC self-assessment to VR staff to increase success rate (rehab rate) with clients who experience TBI and to support education and training objectives for front-line staff. Identified key points of entry for all four states in the work group.
- Requested legacy training materials and documents from the TBI TARC on TBI and employment topics to organize into a "repository".
- Indiana shared links to their webinars created for the Florida Vocational Rehabilitation TBI Curriculum.
- Invited Dana Fink, Program Analyst with the Office of Disability Service Innovations in ACL to share information on the new AoD Disability Employment Task Force/TA Center and collaborate on promoting the VRC Core Competencies and self-assessment tool to the Rehabilitation Services Administration.
- Drafted a workplan to prioritize short and long-term action steps to complete before the TBI grant cycle is done, and identify work that needs to be carried forward into the future.

Mentor states Indiana and Nebraska and will submit Year 3 products on behalf of the work group with the year-end report in June, 2021.

The *Using Data to Connect People to Services* work group met monthly in an on-line forum, making good progress on group goals. Mentor grantee states, Virginia and Nebraska, facilitated each meeting. The work group includes Partner state representatives from Alabama, Alaska, California, Georgia, Idaho, Kansas, Maine, Maryland, Minnesota, Missouri, North Carolina, Ohio, Rhode Island, Utah and Vermont. All meetings were recorded and archived for the benefit of members who could not attend. The total number of active states in the work group is seventeen (17). The group is very large, but very productive.

The work group completed several activities during this reporting period:

- Work group discussion topics covered during the reporting period included; state plans, outcome measures, BRFSS, measuring BI incidence/prevalence.
- Distributed the TBI Registry questionnaire link to the remaining TBI grantee states, and collaborated with NASHIA to distribute it to unfunded states.
- Mentor state Virginia contracted with NASHIA to write a TBI Registry whitepaper based on our questionnaire results, and Mentor state Nebraska contracted with Virginia to reimburse them for a portion of the costs.
- Collaborated with HSRI/TBI TARC on shaping the literature review for the white paper.
- Mentor state Virginia sponsored a speaker for the work group at NASHIA's Annual State of the States conference; C.B. Eagye, Research Associate at Craig Hospital in Denver, CO.
- Work group members from Virginia, Alaska and Nebraska met with Matthew Breiding of the CDC and NASHIA staff regarding the possibility of including standard TBI questions in state BRFSS surveys.
- Submitted "Outcomes" questions for a future TBI SPP grantee meeting agenda item.
- Mentor states drafted a work group summary on behalf of the group to use in their reports.
- Shared information and tips with each other on 508 Compliance for grantee products.
- Shared work group product information with the TBI TARC representatives and other Mentor states.

The work group anticipates submitting several products with the next report for Year 3.

The *TBI Workforce Development* work group of Mentor grantee states met monthly via videoconference to collaborate on development of workforce competencies for the given domains (1) Return-to-Learn/Return-to-Play, (2) Criminal and Juvenile Justice, (3) Opioid Use and Mental Health, (4) Transition and Employment (VRC) and (5) Underserved Populations. Each of the five work groups reported on progress and supported the collective effort by sharing strategies to accomplish tasks.

During this reporting period the *Return-to-Learn/Return-to-Play* competency work group completed their set of competencies and will finalize them with subject matter experts (SMEs)

in December 2020. The *Transition and Employment* work group members created a Vocational Rehabilitation Counselor (VRC) Competency Self-Assessment Survey and is working with ACL on methods, collaborations and messaging to survey vocational rehabilitation program staff in their respective states before the close of the grant cycle. The *Criminal and Juvenile Justice* work group is in the second SME review phase and is on track to complete their competencies before the close of the grant cycle. The *Opioid Use and Mental Health* work group completed a literature review and are working with HSRI to review coding of the literature. The work group members are finalizing a survey that will be sent out to states. The survey is slated to launch in January 2021. The *Underserved Populations* competency work has been put on hold due to the time limits associated with this grant cycle. The diversity of underserved populations does not lend itself to one set of professional competencies. For example, there is great variability of needs among veterans, Native American populations and victims of domestic violence who experience TBI. Identifying appropriate professional competencies for serving each group is quite challenging.

The group of Mentor states welcomed Technical Assistance Support Center (TARC) staff into the monthly Mentor state meetings. The group worked with TARC staff to identify needs for assistance which included literature reviews, survey edits and implementation strategies, grantee portal orientation, webinar/ training suggestions and product development and review.

34. Please describe the extent to which the mentoring and work group activities you participated in added value to your program, the national program and/or any other aspect of your TBI work.

Once again, the work group experiences offered an excellent venue for states to share information, resources, strategies and best practices with each other. In particular, Nebraska benefitted from discussions in the *Using Data to Connect People to Services* work group to identify new TBI data sources that will help us “tell the story” of TBI in Nebraska. The work group’s meeting and consultation with C.B. Eagye of Craig Hospital was most informative in identifying strategies to estimate TBI prevalence in the state. The *Transition and Employment* work group’s collaboration on vocational rehabilitation counselor (VRC) Competencies has been most rewarding, and a great contribution to development of a national TBI workforce training program. The accompanying self-assessment survey for VRCs will be a tangible tool for state VR programs to use in building their capacity to successfully serve their clients with TBI.

35. Did you use the services of the TBI Technical Assistance and Resource Center (TARC) during this reporting period (Yes/No). If yes, please describe these services.

Yes, Nebraska VR utilized the services of the TBI TARC during this reporting period. Following our TARC plan that was developed during the last reporting period, we received assistance with the following activities:

- We invited TARC staff to review and provide feedback on our draft 2020 Needs Assessment Survey, which focused on the intersection of TBI and mental or behavioral health challenges. Feedback was incorporated into the final draft.
- Maria Crowley with the TARC facilitated a discussion among Nebraska’s Brain Injury Advisory Council (BIAC) members to review and revise the *Living with Brain Injury State Plan for 2019-2020*.
- Maria also provided several public service announcement examples from other states for our future efforts in building TBI awareness.
- TARC staff supported the activities of the *Using Data to Connect People to Services* work group, coordinating a literature review for use in drafting a white paper on TBI Registries, and a conversation with Matthew Breiding of the Centers for Disease Control and Prevention (CDC) on the Behavioral Risk Factor Surveillance System.
- TARC staff combed the TBI grantee “legacy” collection for training and educational materials on TBI and employment for the *Transition and Employment* work group.

2nd Annual Living with an Injured Brain Summit



A Virtual Event to Engage You
on Your *Recovery Journey*

Connect with a computer or device:

<https://zoom.us/j/6967605011>

Or connect via telephone: 1-408-638-0968 -- ext: 6967605011

PROGRAM SCHEDULE

**November 9th, 10th, 12th and 13th – 9 am – 11 am CT
(recorded and re-presented 6 pm – 8 pm CT)**

The **Purpose of this Summit** is to bring together the people of 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.

- Monday, Nov. 9: An Overview of the Statewide Vision for Brain Injury Policies and Services, and the Organizations Helping to Accomplish the Vision**
- Learn what Nebraska VR, the Brain Injury Advisory Council (BIAC), the Brain Injury Alliance of Nebraska (BIA-NE) and NIBN are, and how they are collaborating to create more resources and supports for Peers across the state.
 - *Presenters: Keri Bennett (Nebraska VR), Peggy Reisher (BIA-NE), Chris Stewart (BIA-NE), Judy Nichelson (BIAC), and Emaly Ball (NIBN)*
- Tuesday, Nov. 10: Living with an Injured Brain...You are Not Alone on Your Recovery Journey**
- As Peers we are unique, but we are not alone. Listen to the Recovery Journeys of three Peers. Listen for what feels familiar, and recognize that people all over the state are experiencing a similar journey as yours. Come away finally feeling connected to a community that understands you and that you can contribute to.
 - *Presenters: Roy Stutz, Sara Kadyrova, Shawna Thompson*
- Thursday, Nov. 12: Coping, Managing, and Living with an Injured Brain**
- Tune in to hear how some Peers have managed to cope with their injured brains and the many challenges that they encounter. Learn some new techniques that may help you. Feel validated that your hardships are shared by others. Help build the tools and resources that can be useful to others.
 - *Presenters: Emaly Ball, Roy Stutz, Pam Cody (Assistive Technology Partnership)*
- Friday, Nov. 13: So, Your Loved One has an Injured Brain... The Family Member and Caregiver's Journey**
- As Family Members and Caregivers, we experience a unique type of stress. We are not alone. Listen to others in the same role, and come to know that you are part of a community that needs to find and help each other.
 - *Presenters: June Collison, Dennis Thompson, Susie Bonde*
-

Learning Communities

The fun doesn't stop! **After this Virtual Summit, we will host Learning Communities** online (and

perhaps in-person someday) to continue to learn from one another, build new relationships and supports, and increase our knowledge and skills. Each Topic will become a Learning Community that will meet virtually throughout the year, and we hope you consider participating and becoming part of the Injured Brain Community.

To participate in a [Learning Community](#), please send an email expressing your choices from the topics below, to: trisa.christensen@nebraska.gov

- Continued discussion about the Vision and partner organizations
- Continued discussion about the Recovery Journey and Tools and Resources
- Continue discussion about the Family Members and/or Caregiver's journey

You will be contacted about the date and time for the first meeting which will occur sometime in mid-January 2021.

Thank you for attending! This Virtual Summit is *by* people living with an injured brain (Peers) *for* people living with an injured brain, and their family members and caregivers. The Summit experience is designed to be both empowering and inclusive, not only of the people who are in the Injured Brain Community, but for all partners and stakeholders as well.

Please let us know how we did and any suggestions you have for our 2021 Summit by completing the Online Evaluation at:

<https://www.surveymonkey.com/r/BIsummit2020>

Thank you to the Presenters! This includes the Brain Injury Alliance of Nebraska (BIA-NE), along with several individuals who are sharing their stories so that attendees can recognize that they are not alone in their Recovery Journey, as well as to learn new strategies and perspectives that can be helpful.

This Virtual Summit is brought to you by the teams at Nebraska VR, The Brain Injury Advisory Council (BIAC), and the Nebraska Injured Brain Network (NIBN).

This project was supported, in part by grant number 90TBSG0036-03-00, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.



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

This project was supported, in part by grant number 90TBSG0036-03-00, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.



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 Polices 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.

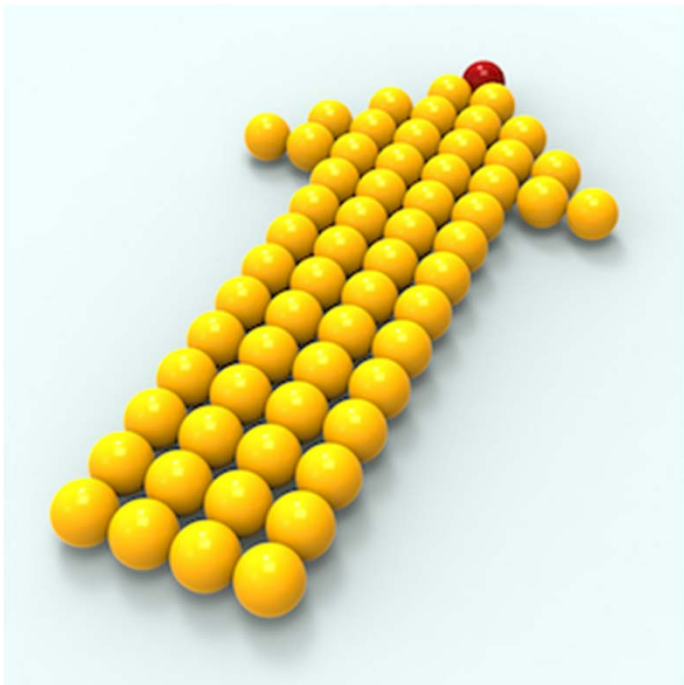
Let's hear from each of them about what their organization is and how it is striving to achieve the Vision.

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

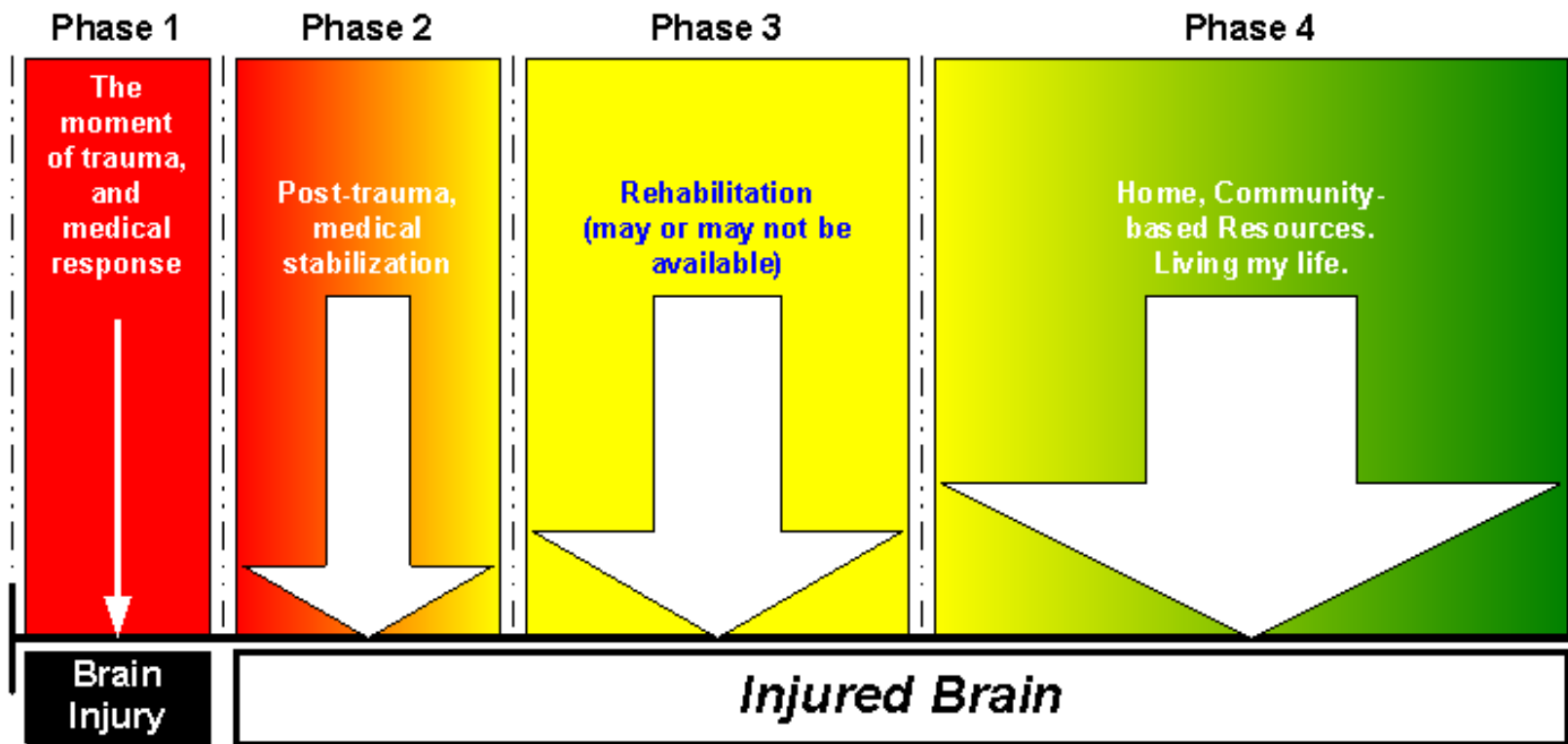
- ❑ The Brain Injury Alliance (BIA-NE) already exists, and provides valuable training and education.
- ❑ In 2018, Nebraska VR solicited proposals for its initiative to connect people living with an injured brain.
- ❑ In 2019, Nebraska VR launched an initiative to create a voice-driven organization, which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

- ❑ Keri Bennett: keri.bennett@nebraska.gov
- ❑ Judy Nichelson, BIAC, judy_nichelson@outlook.com
- ❑ Peggy Reisher, BIA-NE, peggy@biane.org
- ❑ Chris Stewart, BIA-NE, chris@biane.org
- ❑ Emaly Ball, NIBN, emalyball@gmail.com
- ❑ John Ferrone, Ferrone Associates, jferrone@ferroneassociates.com

Brain Injury Alliance of Nebraska

Peggy Reisher, MSW, Executive Director

Chris Stewart, BS, Resource Facilitator

Nov. 2020



**Brain Injury
Alliance**

N E B R A S K A



combined health
agencies drive
MEMBER CHARITY



Mission and Vision



- **Mission:** To create a better future for all Nebraskans through brain injury prevention, education, advocacy and support
- **Vision (adopted by board in 2018):**
 - Individuals with brain injury have the necessary resources to pursue their recovery.
 - Individuals with brain injury and their families have a statewide unified voice.
 - Providers collaborate with statewide peer support for individuals with brain injury.
 - Individuals with brain injury have support from a variety of state agencies.
 - There is an elimination of stigma related to brain injury.



BIA-NE History and Board

- **History**

- 2009- Brain Injury Group of Nebraska
- 2010- Brain Injury Association of Nebraska
- 2016- Brain Injury Alliance of Nebraska

- **Board**

- Currently 13-member board of directors
- 8 board members are individuals with a brain injury or family member of an individual with a brain injury



Staff



Peggy Reisher
Executive Director



Chris Stewart
Resource Facilitator



Gina Simanek
Resource Facilitator



Elle Stecher
Program and Marketing Associate



Core Programs and Services



- **P**revention
- **E**ducation
- **A**dvocacy
- **S**upport





Prevention

- Forever Shaken Documentary
 - Over 20 million views on YouTube

- Promotion of Seatbelt/Occupant Restraint
 - Six billboards for 12 weeks
 - 3.5 million views





Education

Building systems capacity

- 20+ Trainings
- Juvenile Justice, Aging, Corrections, Veterans, Behavioral Health, Domestic Violence Programs
- 4 Programs are screening for brain injury
- **Annual Brain Injury Conference**
 - Virtual on March 18 and 19, 2021



Education continued...



Get Schooled on Concussions

Brain Injury Alliance
NEBRASKA

Are you ready to Get Schooled on Concussions?

Enhance your Return To Learn (RTL) plan with a 4-week strategy delivered directly to your inbox *based on your teaching style*.

- **Nebraska Concussion Coalition**

- Every Nebraska teacher has access to GSOC/TACT
- getschooledonconcussions.com/nebraska
- Password: TACTnebraska2020



Advocacy

Legislative Activity

- Brain Injury Trust Fund Bill- Funds available as of 7-15-20
- 14 Bills in 2020

Advocacy Events

- Brain Injury Awareness Month- March
- BI Advocacy Day- 3-12-20
- Disability Pride/ADA Anniversary Webinar Series
- Voter Registration and Get out to Vote



Support

Promote Support Groups

- 18 support groups across the state
- 3 new virtual support groups

Engagement Committees

- Monthly meetings
- Peer support
- Creating and expanding statewide resources

Resource Facilitation

- Help identify and access supports to build personalized teams to achieve individualized goals
- Over 700 unique clients



BE the CHANGE

- Brain Talks
- Survivor Stories
- Advocacy events
- Leadership opportunities
- Brain injury awareness events



Call us or Sign up now!

- **Call Chris Stewart-844-423-2463 to learn about how you can get involved**
- Join the other 2,800 Nebraskans to get our newsletter to be kept informed of:
 - Survivor Stories
 - Events happening across the state and nation
 - Research opportunities
 - Training/educational opportunities
 - News about brain injury
- **<https://biane.org/about/signupnewsletter.html>**





Thank You!

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**combined health
agencies drive**
MEMBER CHARITY



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

This project was supported, in part by grant number 90TBSG0036-03-00, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.



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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.
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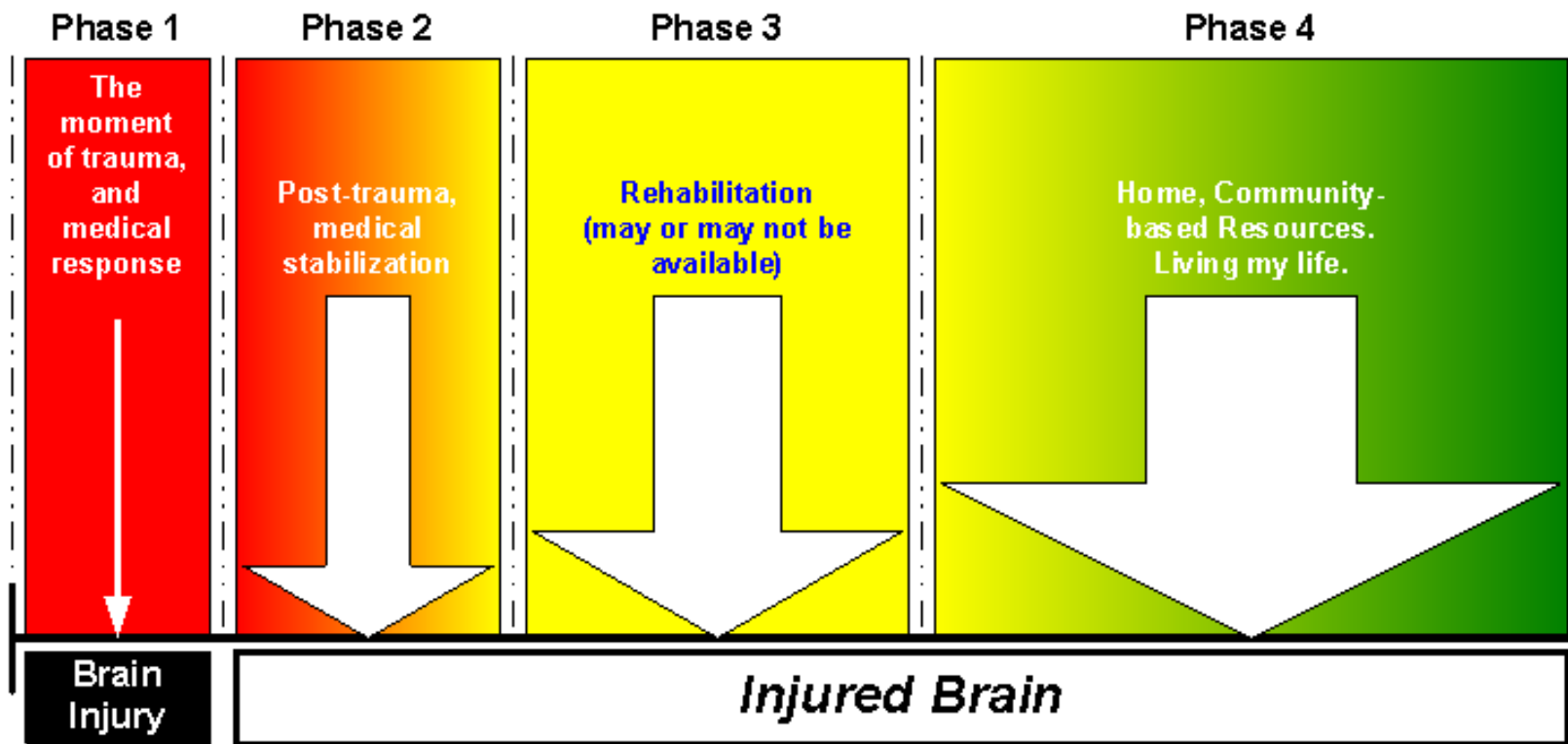
Today's Focus:

Living with an Injured Brain... You are *Not Alone* in Your Recovery Journey

- ❑ **Definition of Injured Brain**, by John Ferrone, Summit Moderator
- ❑ **Sara Kadyrova**, a person living with an injured brain
- ❑ **Shawna Thompson**, a person living with an injured brain
- ❑ **Roy Stutz**, a person living with an injured brain

“Injured Brain” Definition

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



My name is Sarvinoz “Sara” Kadyrova, and I am a person living with an injured brain

- ❑ I acquired my brain injury as a result of carbon monoxide poisoning and anoxia to the brain resulting from a house fire while working as a caretaker in my client’s home. (July 23, 2012)
- ❑ Recovery journey was/is difficult, as I was trying to recover from burns and complications from it, physically, emotionally and I didn’t realize extent of my brain injury well until after discharge from hospital, which was 5+ months.

Before my brain injury, people who knew me described me as “Brainiac”

- Excellent memory... read a book once (especially textbooks) and get A's on tests.
- Recognized for scholastic achievements (deans lists, gold medal, etc.) .
- Last job was working as noninvasive cardiac assistant in the hospital (did EKGs, stress tests, holter monitors).
- Translator.

Physically, I was like the Energizer Bunny



- Worked
- School full time
- Mother of 3 children in different activities (soccer, violin, swim)
- Volunteered
- Very social with friends and attended gatherings/celebrations routinely

After my brain injury for few years in a row, I felt like I could never get enough rest

- Slept 15-20 hours a day.
- Depression as a result of physical and cognitive challenges.
- There are days that I still fight with those challenges.
- (But life is much better than the first few years post injury... I am still on my Recovery Journey).

Returned to perform all my ADLs/IADLS independently including more complex activities:

- Driving
- Going back to school
- Working
- Caring for my family with 3 children

Started college over from prerequisites

- I was 2 semesters away from getting my BSN degree prior to my brain injury.
- Now in nursing program again.
- Worked with VR getting support throughout my journey back to school, work, now part of NIBN and BIAC.

Life has its challenges but we have to face it,
work towards our goal and move forward and
never give up.



I have had so many wonderful people to walk beside me throughout my recovery journey

- My family of course
- Very exceptional friends/neighbors
- Nebraska VR and the Mentor they provided
- Kearney community: Kearney Volunteer fire department, GSH, VR, KPS, YMCA

Main hardship is my health



- My lungs are more susceptible to illnesses
- Memory
- Fatigue
- Depressed... black hole
- And, I missed a lot of milestones with my children as they were starting different schools

I was able to cope with help from...

- Family and friends and community
- Therapist
- Nebraska VR and Mentor
- Instructors
- Medication for depression

Create awareness about brain injury and living with an injured brain

- Reduce stigmatization related to it.
- An injured brain should be treated like any other chronic condition (diabetes, HTN etc.) you manage it day to day and proper collaboration is vital to the health of individuals effected by it without stereotypes and discrimination.

For others living with an injured brain

- There is light at the end of tunnel or midway.
- Do not to get discouraged but always have hope which is very important for your brain's health.
- Don't give up! Live your life one day at a time or even few hours at the time.
- No matter what keep moving!

For family members and providers

- Listen to the person effected.
- Not everyone has same experiences.
- Do what is best for your family member/patient.
- I want to feel connected, understood and not judged.



Want to thank everyone who has walked the walk with me and my family, cleared the path for me, and showered us with support and love.

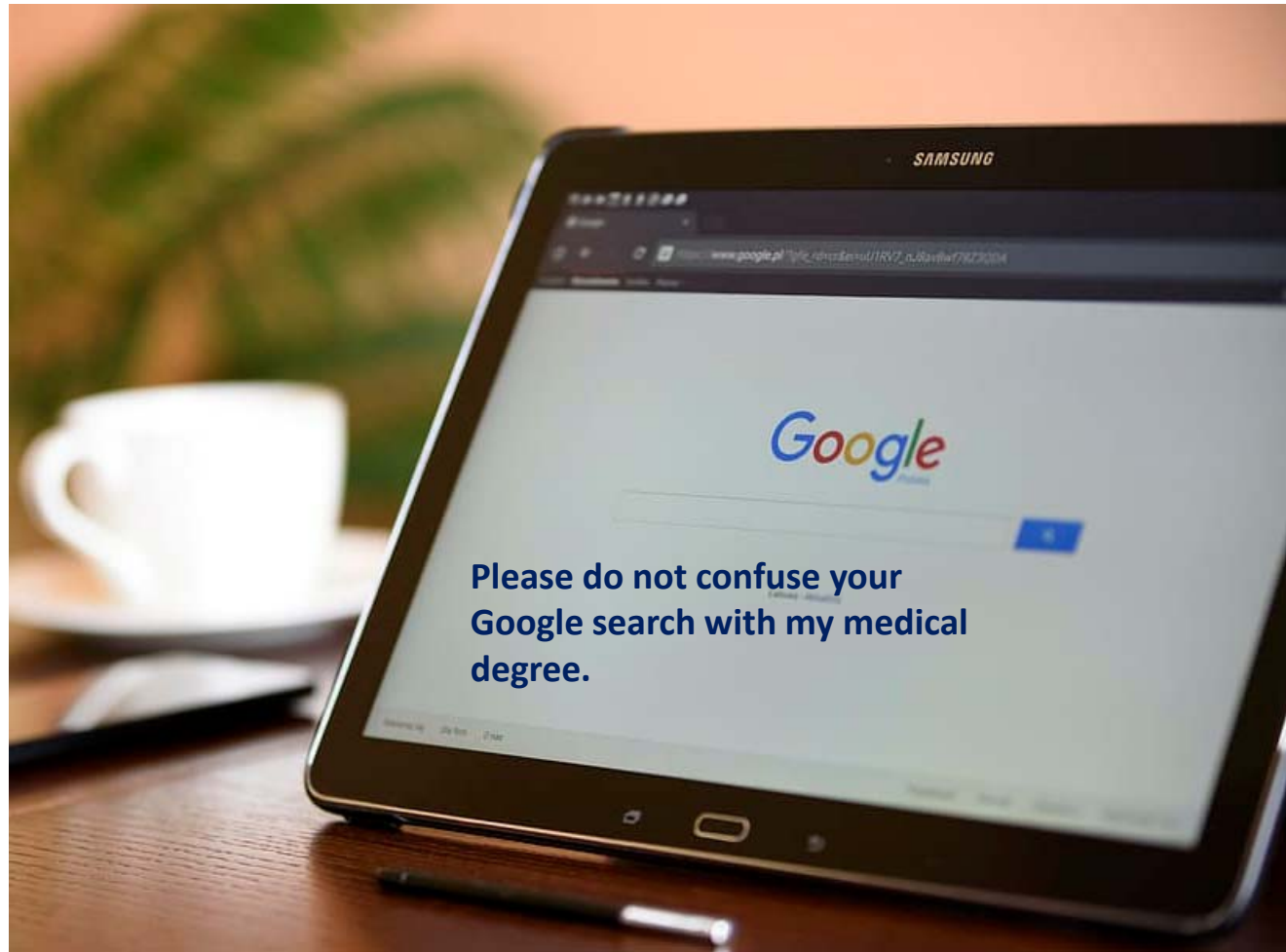
My Story

I am Shawna Thompson and I am living with an
Injured Brain.

Injury

- ❑ I have a Coup-contrecoup brain injury (my brain bounced against the inside of my skull on one side, and then back against the other side).
- ❑ I was the restrained passenger in an ambulance, the driver fell asleep and drove off the interstate.
- ❑ This accident occurred on January 24, 2017 just before midnight.

My recovery has been a rollercoaster! One Doctor to another Doctor. No one seems to have a grasp of treatment as a whole.



The journey has been and feels more like a game of *Whack-A-Mole* with symptoms rather than a cohesive plan of attack and treatment!



I thought I was going crazy, Drs. & lawyers kept telling me this just couldn't be. My family didn't believe me!

Everyone just kept saying "go back to work, you are fine".

I knew something was wrong...

But I knew I wasn't fine and I was **Scared**, and then Judy said *yep*, I do that! I feel like that! Oh yeah & do you do this or that?

I knew I wasn't crazy, I hadn't slipped into ***WTF land!***
Somebody gets it & I can get help!

Keep reaching out...

- Reach out for help! If one person doesn't believe you go on to the next! You know your injury, you know yourself.
- Find a support group, they are your best resource for finding help!
- Find God and hold on !

Before...

- ❑ Before the injury? I was a nurse, mom, grandma, I was decisive, busy, knew what I was good at!
- ❑ An advocate for myself & others! I fought hard for what I believed in!

I was very social, loved people! I never met a stranger. I was loud, probably too loud!

I always had a book.



I felt too much, scared of water!

I ***Loved, Loved, Loved.***



After the brain injury incident?

- I'm indecisive, I don't want to be around people, I love the quiet!
- I'm less tolerant of people.
- When I'm done I'm done!
- I can't cry, I don't feel much!

Milestones

- Dr. Mistry!
 - Dr. Mistry has been a Godsend!
 - He get's it! He has a plan!
 - He is a Proponent!
- Coordinated Care
- Glasses
- Trike

Supportive People

There are a number of people who have been a part of my journey: Dennis, my boys, our injured brain group!

Joys

It's funny the small things that bring joy.
Time with grandchildren, peace, doing
something, accomplishing something that
I've struggled with!

Hardships/Setbacks

- Workers Compensation – Financial
- Driving
- Lack of resources
- Facing the fact that things- “Wont Be The Same”*

Mental Health

- Depression is common, we have holes in our head, chemicals can't move appropriately and medications don't either!

- Suicidal, every person I've talked to has that running through the back of their brains!
 - I think chemical imbalance causes these feelings.

 - How many Mental Health patients are really **Brain Injury Patients?**

HOPE

- I used to hope for a normal life.
- Now I hope for *Acceptance* of this life.
- I hope for joy, laughter, happiness and peace, love, the same things everyone wants.
- We aren't different in our hopes!

Damaged, not dumb!

- It is important to know that you can *Deny* it all you want! I did.
- I searched for any other answer!
- It was still a brain injury and I never hit my head! (I Think).
- Shaking was enough to damage me forever and that is what I am... *Damaged not dumb!*

The old me...

- Life is different. Not better, not worse. Just different this way. Acceptance takes time. Some days I kick and scream and that's OK.
- Some days I'm OK with it.
- Do I want the old me back? Most days. I miss her, I grieve her! But I'm learning to like this woman, she's more thoughtful, less judgmental (sometimes).

You can do it!

Give yourself time, it will be OK. We just don't know what OK looks like and that can be scary! So find someone to hold your hand (I'm good at that), turn on the light and take that first step into the scary. We can tackle it together!

My Name is Roy Stutz

- I work at University of Nebraska at Kearney.
- Bachelor's in Education with a minor in Athletic Training.
- Master's in Education.
- 20+ years I have worked in the Athletic Training world.
 - Three team National Championships, numerous individual National Champions.
 - Worked with every sport in the NCAA as well as high school events and club events.
- I have an Athletic Trainer Certified (ATC), Performance Enhancement Specialist (PES), and Corrective Exercise Specialist (CES) from the National Academy of Sports Medicine (NASM).

The day my life changed...

- On February 07, 2019...
- Wrestling team finished practice.
- I was going to workout.
- Around 7:00 pm my world changed forever; I had a stroke.
- Never really had a headache.
- I remember things in bits and pieces, but I don't remember the whole thing.

Major stroke...

- ❑ They say that you need to have the medication within three hours to give you the most successful opportunity to recover. Flown to Omaha.
- ❑ The Neurologist said that I had a Medial Cerebral Artery, Ischemic stroke.
- ❑ When the Neurologist says that it was “impressive” that’s code for “you had a major stroke”.
- ❑ The bits and pieces that I remember were not being able to move my right side, all I could say was “what happened?”.

-
- When I got to see the CT Scan of my brain (months later) I could see why he said that.
 - The initial CT Scan showed NO blood to the left side of my brain.
 - After the Thrombectomy, you could see blood going all though the left side of my brain.
 - Dr. Gonzalez my neurologist in Omaha was able to predict exactly what kind of symptoms I would have based on where the stroke happened.
 - Some orthopedic in the right foot, more sever in the right arm, but most of all I would have trouble with Aphasia or word finding issues.
 - He was right!!!!

Physical recovery path

- I spent 1 week in the hospital in Omaha.
- 1 week in an in-patient hospital in Grand Island.
- Then the rest of the time at home going through rehab here in Kearney.
- Dr. Gonzalez said that I would make a full recovery.
- But he didn't go into what it would be like or how long it would take.

Progress, and then disappointment

- ❑ Amber Dugan was my speech language therapist here in Kearney: therapist, a counselor, my biggest fan, and my advocate.
- ❑ The first 4 months were awesome.
 - ❑ I recovered well.
 - ❑ I overcame the orthopedic issues in my foot and my arm.
 - ❑ Cognitive was a bit of a struggle, but I was coming along well.
- ❑ The next 3 months were a struggle.
 - ❑ I learned that I wasn't going to be asked back as an Athletic Trainer at UNK.
 - ❑ Since I was a sophomore in high school, I wanted to be an Athletic Trainer, now it was gone just like that.

-
- The next 6 months were awful.
 - I was re-assigned at UNK.
 - I took a pay cut.
 - I didn't do what I loved, and didn't have any of those relationships any more.
 - I pushed me into a dark and tough depression.
 - I was never suicidal, but I didn't want one impulsive moment to change everything for me or my family.
 - The next 11 months.
 - Here I am.
 - I don't know what I am doing, but I am doing it.
 - Come to accept the fact that Athletic Training won't ever be a part of me anymore.

Comparisons... before and after

- When I look back on who I was before the stroke I was intense, bordering on.
 - Now I am more laid back and don't take stuff so serious.
- I would go and go and go with no regard for my self or others around me.
 - Now I take time to be present in every conversation and really focus on what the other person is saying and engaged in them completely.
- I used to think I was a good dad to my son and daughter.
 - Today I am fully invested in them both.
 - Time, talents, and treasures are for them.

Today...

- Currently I am taking classes for my Mental Health and Counseling Master's at UNK.
- Working with different students, but still having the same connection.
- There were milestones along the way that lead to my recovery of my body, my mind, or my spirit.
 - The one thing that I know is that I am recovering every day. I don't think I will ever stop recovering.
 - Things I can't do well, but I am still trying.
 - It's frustrating but it helps me know that I am alive.
 - I don't think I ever was fighting for my life, but I was fighting for my way of life.

If there is one thing that I can say to anyone who has an injured brain:

- Don't Give Up!!!
 - You may not live the life you once had, and it stinks, but there is more to life than what you lost.
 - Your body may not work the way it once did, but it still works, and that means that it can still be healed.
 - No like it was, but more than it could be.
 - You may not think or speak like you used to.
 - But you still have a voice and that means that there is someone who needs to hear your story.
 - Your loved one might only be able to say, "what happened?"
 - They can still communicate, and tell you that they love you and appreciate what you do, if you let them.

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- ❑ Sara Kadyrova: sarvanoz04@yahoo.com
- ❑ Shawna Thompson, sugarbabysweets41@hotmail.com
- ❑ Roy Stutz, stutzrj@unk.edu
- ❑ John Ferrone, Ferrone Associates, jferrone@ferroneassociates.com

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Living with an Injured
Brain Summit



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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.
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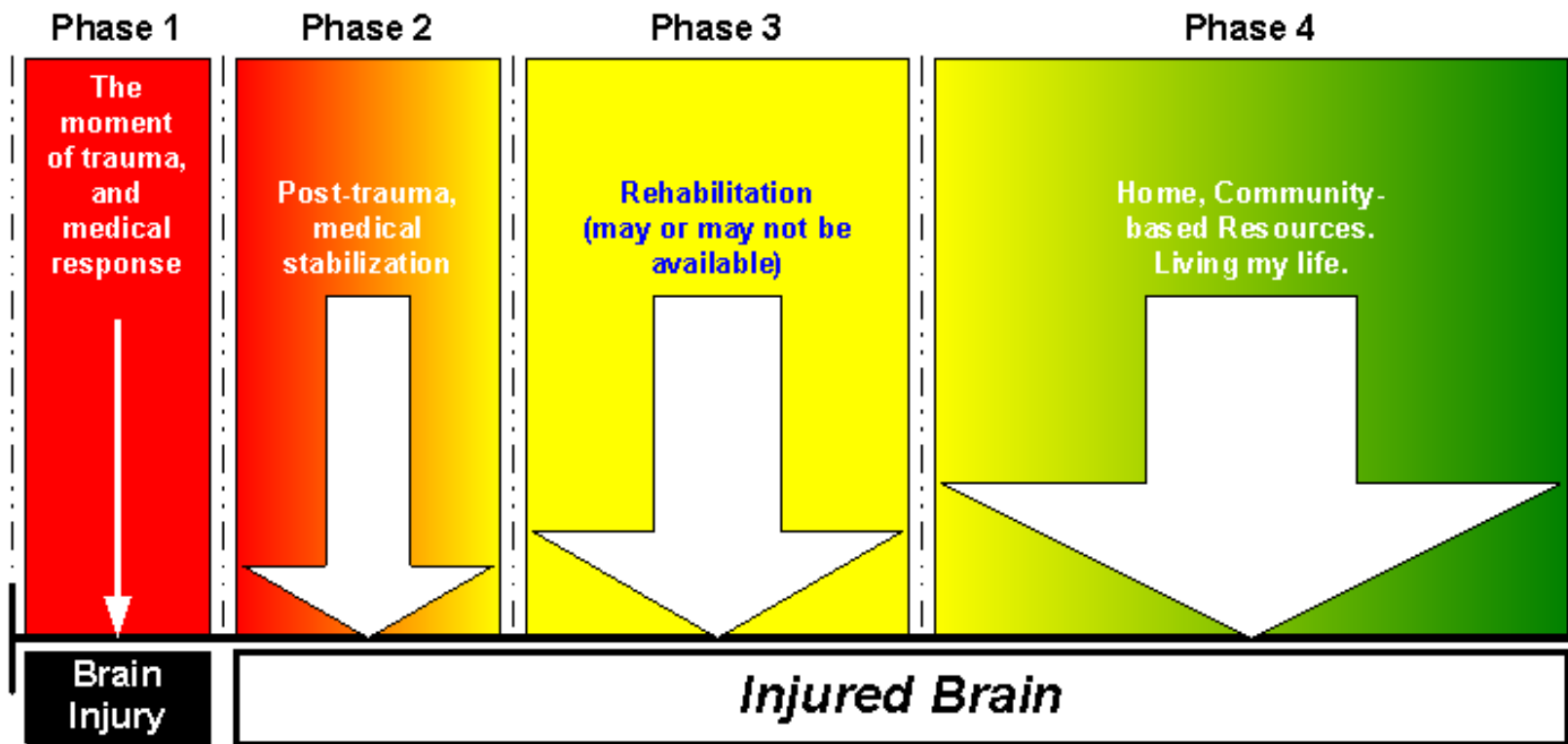
Today's Focus:

Coping, Managing and Living with an Injured Brain

- ❑ **Definition of Injured Brain**, by John Ferrone, Summit Moderator
- ❑ **Roy Stutz**, a person living with an injured brain
- ❑ **Pam Cody**, a person living with an injured brain
- ❑ **Emaly Ball**, a person living with an injured brain

“Injured Brain” Definition

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



My name is Roy Stutz, and I'm living with an injured brain

- You've heard my story on Tuesday
- Today I want to talk to you more about how and why I was able to get to where I am now
- So much of how I got through all of this is because of my faith; I will not tell anyone that they need a faith or that without a faith you can't recover
- Immediately when I had a stroke there were people around me who cared for me
 - My wife and my kids, my mom and dad, my mother-in-law, and my life group from church
 - The paramedics were people that I had worked with for years
 - The flight nurse was someone who we went to church with

- ❑ Dee my wife
- ❑ Dawson 15 (when I suffered a stroke)
- ❑ Eliza 11 (when I suffered a stroke)



So many people played a role in helping me through

- People in the waiting room that I never saw but were there
- ICU nurse who specialized in strokes in special population
- My mom and dad drove all night to get to Omaha from Denver
- In GI, I was visited by a ton of people at the hospital
- When I got home there were a ton of people who came to see me

-
- ❑ I started speech and language therapy
 - ❑ Autumn Ambler, SLP
 - ❑ She took the time to meet me right where I was. She cared about me and getting my job back.
 - ❑ Ultimately it didn't work out to have my old job back, but there is no way that I would have recovered the way I have



Role Models...

- My injury came with two major issues
 - One is the word finding issues
 - Two is the depression
- Word Finding is something that can be overcome with therapy, accommodations, and special services
 - Pastor Adrian has a stuttering problem: God doesn't care about it, why should anyone else.
 - George Springer is the center fielder for the Astros and has a speech impediment. He doesn't shy away from the interviews
- If it works for them it can work for me

Focus on Depression

- Those who have not had a brain injury do not know what it's like to have an injured brain
 - Times when you can't explain how you feel
 - Emotionally
 - Physically
 - Times when you don't know how you feel
 - Sad
 - Angry
 - Suicidal (even for those who never thought about suicide)
 - Tears for no reason
- Many times those people with an injured brain have such a shift in their daily life
 - Loss of a job
 - Loss of function in an extremity
 - Loss of identity

Overcoming Isolation

- It becomes easy to isolate ourselves
- This was the beginning of being stripped of everything
 - My job (my identity)
 - My friends (what I thought were my friends)
 - Athletics (I couldn't throw a ball, for someone who coached it was tough)
 - Finances (took a major pay cut to stay at the University)
- I suffered from depression for sure
- What got me out of it?
 - Family
 - True friends
 - Doctors and medications
 - Small group of men that wouldn't let me isolate myself

Take the wins

- Some days I just had to live from one minute to the next
 - Getting up and going to work was a win
- It was by surrounding myself with great people
- I really don't think there was a technique or strategy that I used
 - It was by the grace of God

YOU ARE NOT ALONE!!!!

- No matter what the circumstance is, there are people who care
- They don't have to have the exact circumstance to care about YOU!!!
- You have to find one or two people who will just sit with you
- Sometimes the best of intention is the worst thing that we want to hear
 - We just need someone who will just sit with us
 - Cry when we cry
 - Let us be angry without judgement
 - Don't tell us that "everything's going to be alright."

Suicide is not the answer

- ❑ If you don't feel like you have anyone who is willing to be that friend, PLEASE call me, text me e-mail me. I remember how impactful that was for me, and I will do it for anyone who needs it.

Roy Stutz

308-440-8841

stutzrj@unk.edu

My Name is Pam Cody

- ❑ I suffered a brain injury in October 2012, and I want to share some of the tools and techniques that have been helpful to me as I manage my day to day challenges.
- ❑ Assistive Technology Partnership (ATP)—accessed via Nebraska VR.



How did my life change?

- Different personality
- Aphasia
- Cannot spell/grammar usage as well as I used to
- Cannot put together papers or blocks of information like I used to
- Sleep patterns
- Focus
- Weight gain

Specific challenges I face...

- Challenges include attending Master Program
- Ability to process what is being said
- Replying in a professional manner

How I have dealt with these challenges...

- ❑ Using software and apps to assist me in preparing papers for school (Read and Write Gold/Grammarly/Citationsy); repeat, repeat, repeat steps;

How do I manage my day to day life?

- Through apps/software to remind me what needs to be done that day

What tools, strategies, techniques, do I use?

- MyBionicBrain – costly and only iOS platform;
- BEST Suite: 4 in 1 app – less costly but needs smartphone;
- Reminders on smartphone;
- Calendar;
- Notes on smartphone

This is the New Me!

My Name is Emaly Ball, and This is
My Recovery Journey and How I
Manage/Cope with My Challenges

Injury Time Line

- ❑ May 2012 – Main Injury event – Car wreck
 - ❑ Moderate to Severe traumatic brain injury
 - ❑ Several broken bones
 - ❑ Partially collapsed lung
- ❑ 2014 - secondary injury – Car wreck
 - ❑ Mild traumatic brain injury
- ❑ 2016 – secondary injury – head hit by a faulty handicap door
 - ❑ Concussion

Challenges from my Injured Brain

- Changes in emotion and emotional response
 - Irritability
 - Depression
 - Post-traumatic stress disorder
 - Chronic anxiety

- Sleeping challenges
 - Insomnia
 - Multiple sleep disruptions

- Physical challenges
 - Frequent headaches
 - Nausea
 - Sensitivity to light and sound
 - fatigue

Challenges from my Injured Brain

- Cognitive challenges
 - Inability to think clearly
 - Inability to follow conversations
 - Memory problems
 - Easily distracted
 - Easily confused
 - Comprehension difficulties
- Chronic pain makes my symptoms worse

Daily Coping Strategies

- Planning plays a key role in my daily and weekly routine
- Creating *Goal lists* as well as to-do lists
 - A Goal list – a list of tasks I can reasonably get done in one day/week
 - The to-do list – everything that must get done eventually
- Pain management techniques
 - Medications and Herbal Supplements
 - Stretching and Yoga

Tools, Strategies, Techniques

- Accommodations
- Goal-lists and to-do lists
- Color coding activities on lists
 - By priority
 - When in college – I color coded based on class, work, home, etc.
- Adding due dates and “goal dates”
 - Goal date – when I want to have something done, but it may not be due yet

Tools, Strategies, Techniques

- Automated systems of reminders
 - Pre-sent/Scheduled emails
 - Amazon Alexa Dot announcements
 - Calendar reminder emails/notifications

- Automated financial systems
 - Automatic Bill-Pay services
 - Excel Finance Sheet with automatic calculations

Tools, Strategies, Techniques

- Stretching and yoga
- Intentionally scheduling in free time
 - Making rest and relaxation a priority
- Having an Emotional Support Animal (ESA)
 - Tip: there are laws to enable you to have an ESA even if you rent



Developing Tools and Strategies

- It's important to find out what works best for you
- Talk about your struggles with someone; brainstorm
- Try new things

How could you begin?

- Identify problems or stressors in your daily life
 - Perhaps keep a journal of when you begin feeling drained or stressed, so you can identify a pattern

- Brainstorm ways to alleviate the problem or stressor
 - Can you do something new or differently?
 - Can someone else do something to help?
 - Do you need an accommodation?

How could you begin?

- Search for accommodations
 - Institutional accommodations
 - education settings
 - workplace settings
 - In-home accommodations
 - getting assistive technology
 - altering existing items

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

- ❑ Roy Stutz, stutzrj@unk.edu
- ❑ Pam Cody: pam.cody@nebraska.gov
- ❑ Emaly Ball, emalyball@gmail.com
- ❑ John Ferrone, Ferrone Associates, jferrone@ferroneassociates.com

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

This project was supported, in part by grant number 90TBSG0036-03-00, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.



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.

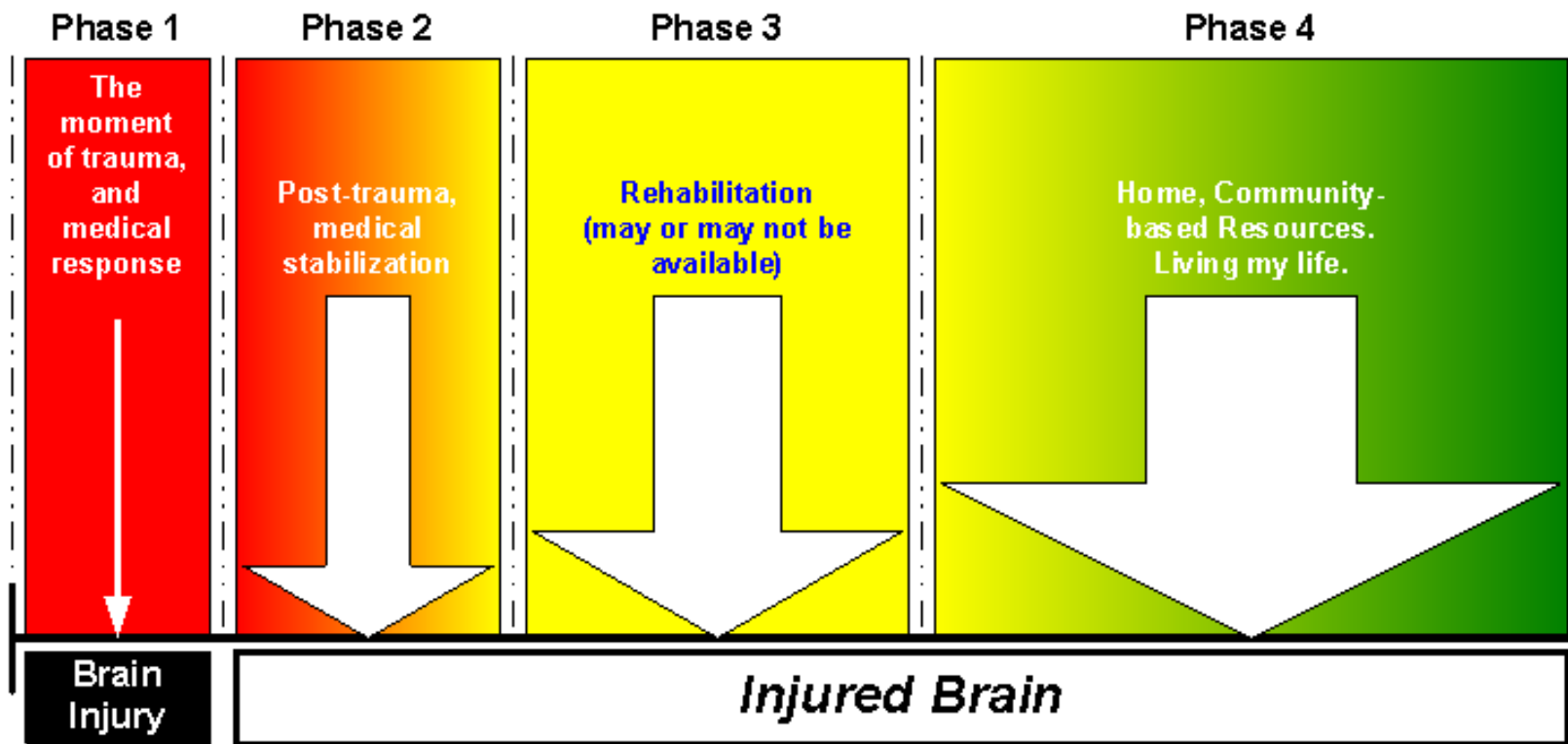
Today's Focus:

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

- ❑ **Definition of Injured Brain**, by John Ferrone, Summit Moderator
- ❑ **Dennis Thompson**, spouse of a person living with an injured brain
- ❑ **Susie Bonde**, spouse of a person living with an injured brain
- ❑ **June Collison**, a coach and mentor of a person living with an injured brain

“Injured Brain” Definition

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





I'm Dennis
Thompson, and I'm
the husband of a
person living with an
inured brain. My
wife's name is
Shawna.

Our Connection

- Each of us have a different story, a different circumstance that brings us together, but we share a common denominator.....

***T**raumatic **B**rain **I**njury*

Perhaps it is just me, the term or title “Caregiver” seems to denote a rather one sided or burdensome responsibility.



In fact it can be quite the opposite, might I suggest it is a blessing? A blessing in disguise, but a blessing none the less.

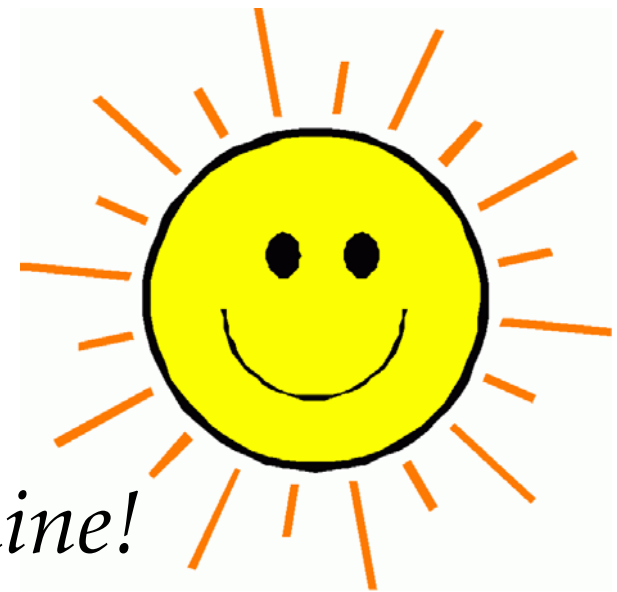
The Invisible Challenge

After a brain injury heals on the outside, outward appearances don't always tell the story. The uninformed or miss-informed look at a victim of TBI and conclude that "there is nothing wrong, look at them, they look just like you and I" The absence of deformities, scars or other outward differences can indeed act as a master disguise!

-
- ❑ In fact all too often society assigns value or worth to an individual by outward appearance or behavior.
 - ❑ I think it's a scapegoat for looking in the mirror!
 - ❑ Aren't we all created in the image of God?
 - ❑ Aren't we all worthy of consideration?
 - ❑ 1 Corinthians 15:9-10: "For I am the least of the apostles and do not deserve to be called an apostle...But by the grace of God *I am what I am*, and his grace to me was not without effect."

-
- You see, our worth is connected to our creator. If God is of great and inestimable worth, then we as human beings made in his image must be of great value, too!

*God made you
beautiful – so shine!*



LET ME COUNT MY BLESSINGS

- ❑ My phone rang just before midnight January 24, 2017
- ❑ It's Shawna, my wife
- ❑ She had left earlier in the day for work, providing RN care for a patient being transported to Denver via ambulance.
- ❑ "We've been in an accident, my driver fell asleep, we drove off the Interstate over an embankment. We are shaken up but no apparent significant injuries."

My wife called, that call could have just as easily been from a Colorado Highway Patrolman with much different news!

Blessings...

I watch as she tosses and turns in her sleep, as she reaches out to brace herself for impact, tears running down her cheeks, some times she awakens screaming, other times complete collapse from exhaustion as she relives the accident!

My wife is alive. She's is able to toss and turn, to scream!

Blessings...

- ❑ She's sound asleep on our way to another Dr.'s appointment, this time in Colorado
- ❑ She awakens startled as we pass the accident site... it's not a one time occurrence—each time we travel that direction, the same reaction.

My wife feels... she senses!

Blessings...

- Can you get me to a hair appointment?
- A nail appointment?

I can help bring a bit of “normal” back into her life!

Blessings...

- Can you just sit for a minute?
- Spend your time with me?

I selfishly deal with stress by staying busy, any kind of busy! But my wife is still with me and desires my company.

Blessings...

- When will this end? Jumping through hoops, Dr. appointment after Dr. appointment, every trip past the accident site a Re-injury!
- Will someone just acknowledge that it was an accident? Take responsibility? Let her begin to heal!
- Nearly 4 years since the accident and the only one fighting for Shawna is Shawna!

My wife can still fight for herself!

I'm More Than a Caregiver...

- ❑ You see, I'm more than Shawna's caregiver...
I'm her husband, and she's my best friend!
- ❑ 38 years ago we made a commitment to each other, entered into covenant with each other and God!

Parallel Challenges...

- Did I sign up for “This” 38 years ago? You bet I did, this and whatever else life might throw at me!
- Did I expect “This” to happen to us? NO!
- Am I'm I happy about it? NO!
- Somedays I'm down right angry! I'm mentally drained, I'm physically drained, I'm emotionally drained! So is Shawna!
- I ache all over, but guess what so does Shawna!

All these things I get to do
and be **with my wife!**



I Count My Blessings!

Faith is Key to My Journey...

- ❑ As you all know, a *TBI* isn't temporary; it is most certainly a journey!
- ❑ There will be good days, there will be days that lead us to ask *WHY* ?
- ❑ But these are days we have been given, not because we deserve them but because God loves us!

For I know the plans I have for you, declares the Lord, plans for welfare and not for evil, to give you a future and a hope.

Jeremiah 29:11



How do we move forward?

- Together!
- Your local NIBN Chapter
- The Injured Brain Community
(all of us together)
- Supporting one another



Spread The Word

You each have a story to tell, tell it! TBI's aren't a new thing, there isn't a vaccine to prevent or cure them! Living with an Injured Brain is a lifelong journey.



Our Stories have an Impact...

- ❑ Raising awareness and educating others, including Doctors and Lawmakers is crucial to advancing care and research.
- ❑ Your future depends on it and the future of an entire Injured Brain Community depends on it!

My name is Susie Bonde.

I am a wife and caregiver to my husband, Frank Bonde, who is living with an injured brain.

Frank's Accident...

- December 21, 2015
- Semi-truck ran into his tractor on the highway about 6 am in the morning
- Cold and foggy

Frank's Accident...

- ❑ Ejected from the tractor, landed on the highway, able to roll over enough to not drown in fluids but unable to get himself up.
- ❑ Transported to Good Samaritan Hospital.
- ❑ The next day had surgery to place 2 rods, 10 screws, and 2 plates in his back and neck.
- ❑ He does not remember much more than it being very cold and long bumpy ride, and waking up he thought he was in the basement.

Power of Community and Prayer...

- There were a lot of people praying for his recovery-- being from the small town of Callaway, Nebraska the word spread quickly.
- Word spread via the Internet.
- Church has a prayer chain set up for these type of incidents.

I have known Frank all my life since we grew up in the same town. He was actually my first high school date, when we went to the Valentines Sweetheart dance put on by the FHA, (Future Homemakers of America).

Our Beginning...

- ❑ Well when I heard word of his accident I put him in my prayers, then on February 14, 2016, sent him a text message asking him how he was doing, and that I was praying for him.
- ❑ He responded thanks, and said he was at least up right and moving, but going slow.
- ❑ We then kept communication going thru the spring.
- ❑ Then when he was able to drive he came to see me, and told me more of his accident, and we caught up on old times.

Communication and Help...

- ❑ Doctor visits
- ❑ Paperwork needed to start his disability, which for those with injured brain this can be very overwhelming.
 - ❑ It has been helpful that I work as a secretary/office manager, and I was aware of a lot of forms that needed completing.
 - ❑ For those who don't have someone with this talent, this can be a very tough task.
- ❑ Finding out more that was needed to assist him on this journey.

Commitment...

- Then we started talking more of our relationship, and in the fall he asked me to marry him.
- On February 3, 2017 we got married.
- Life made change for both of us.

Beyond the Obvious Injuries....

- As his physical recovery progressed, we found out he had more injuries that were missed while in the hospital.
- He needed to have more surgery, on his forehead where he still had gravel rocks that were imbedded.
- Elbow had nerve damage.
- Tear 4 rotator cuff, which was worst the doctor had seen.
- Evaluated at Madonna in Lincoln and he has a traumatic brain injury.

Coping...

- 6 weeks of intensive therapy to learn how to cope with the injured brain.
- Since then learned a lot about how to handle day to day living.
- See a counselor to help both of us with communication so that we can see how each other need to communicate.
- This just helps us grow with each other cause you do need an outlet at times.

The Invisible Challenge...

People can look at Frank and think there is nothing wrong, that he looks normal on the outside, but what they don't know is what is on the inside of a person and how they have challenges with their brain just to function.

Different Techniques to Handle What Comes Our Way

- We use a lot of notes to jot down what things need to be handled.
- We ask each other how our day went, what took place.
- We discuss what the plans are for the next day.
- We also keep in touch with each other throughout the day to make sure we are both doing ok, and how the day is going.
- We learned to keep the line of communication going so that he/we both know what is going on and helps jog our memory.

Things Can Affect Us Mentally and Physically...

- Challenges take a toll on a person. We keep an eye out for each other: we know when each other gets tired quickly and need to give ourselves time outs to rest and regroup.
- Find activities that are relaxing--we really like to go to this place Paint Paradise and paint items, very good outlet to find our creative side, and relax.
- Things are not readily available in this rural area, so we learned that you have to push to find it, also to keep good track of details when things come up.
- We learned to take one day at a time.



We hope that by sharing our journey we are on that we can help those who don't know where to start regarding one's health, doctor visits, paperwork, and finding others in this area with an injured brain to support one another.

I am a Mentor

- June Collison
- I'm a mentor/friend of a brain injured individual.
- This information that I will be sharing is in regards to Sara Kadyrova. She is a very special person to me, beyond me assisting her as a mentor.

Sara is a Hero

- Sara was a nursing student taking care of a disabled individual in their home.
- During her time taking care of the individual a fire erupted.
- Everyone escaped except the disabled person. Sara went back in to get her!
- She was overcome by smoke and collapsed while trying to carry her (she was twice her size).
- Sara suffered burns on 75% of her body, as well as a brain injury from smoke inhalation.
- She also suffered sadness, as the woman did not survive.

My Initial Role

- ❑ Approximately 7 years ago the accident happened.
- ❑ My life didn't change till I met her 4 year ago.
- ❑ I knew of her from the hospital and had assisted in some fundraisers for her, but that is all I knew of her situation.
- ❑ Then I was contacted by Vocational Rehab to see if I could help a nursing student who had a brain injury with some skills and this is where our adventure began.

The True Challenge

- ❑ I thought I was just to train her on skills and I would be done.
- ❑ I didn't realize how much time it may take when working with a brain injured individual. So I have learned a LOT!
- ❑ We started off with simple skills and simple moments of sharing of our life. Then one day after watching her for 90 minutes attempt to apply sterile gloves and still doing it wrong, was when I had to stop and reflect.

A Tool We Used

- ❑ From here we started spending more time on the brain injury and how to help her with this.
- ❑ That is when I became a semi expert with the use of the Bionic Brain, it's a computer program that was developed specifically for those with brain injuries.
- ❑ NOW Sara had this, but she wasn't using it in its full capacity. So we started making cheat sheets or cliff note versions of skills and things that she needed to remember.

Mentoring Takes Determination by Both!

- ❑ Just so you know that Sara is super determined and super “stubborn” about things.
- ❑ There were several arguments and disagreements through all of this training and several tears that were shed by both of us.

Emotionally...

- I truly have been impacted emotionally I see that how much she wants to be a nurse and how much she struggles with how she was before the fire to how she is now.
- I hate to see her struggle like this and be so down and depressed.
- So we try to have several laughs and hugs and try not to focus on the past, but rather the future and the good things that are happening.

Mentally...

- ❑ The mental impact has been what I would call a challenge.
- ❑ I love to find solutions and love changes and so we are constantly trying to find ways to make the bionic brain and other things assist her in her success.

Spiritually...

- ❑ Spiritual impact at times has been hard, as we both have our religious preference and beliefs but it is in different forms.
- ❑ “Fasting” for Ramadan.
- ❑ Sara needs nutrition to feed her brain and give her body energy to perform and so we had to reflect on the importance of this vs her beliefs and values.
- ❑ Sara decided to make some changes to this fasting in order to have her brain function but yet practice her beliefs and things did improve.

Looking Forward

- ❑ Remember the successes and not focus on the failures.
- ❑ Sara has a hard time staying positive and I totally get that, as she has been through a LOT but the growth she has made over the last 4 years has been amazing.

Consider This...

- Take a moment and think of those routines you have in your life.
- Brushing your teeth after a meal.
- Putting your socks on a certain way before your shoes.
- NOW stop and imagine that you got up and were in a hurry and forgot to brush your teeth, forgot to put your socks on, and just left the house with no shoes or socks, AND it's 2:00 in the morning.
- How do you feel? Confused, upset, disoriented, frustrated, any of those emotions? Well that is how a brain injured person feels every day.

We are Launching a Learning Community on This Topic

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- You probably have many questions, and you might like to participate in further discussion.
- You might have insights you'd like to share.

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- ❑ Dennis Thompson, npfdchief35@yahoo.com
- ❑ Susie Bonde: scoonsup@hotmail.com
- ❑ June Collison, junecoll89@gmail.com
- ❑ John Ferrone, Ferrone Associates, jferrone@ferroneassociates.com

**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:

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



**Brain Injury
Alliance**
N E B R A S K A



You're Invited: BRAIN Talks

(Basics, Resources, Advocacy, Innovation, Networking)

Come together to share a meal and experiences of overcoming challenges together.

Tuesday, September 15, 2020

5:30-7:30 p.m.

**At: Christian Church of Waterloo
23720 Cedar Dr., Waterloo, NE**

5:30 - 6:00 pm - Complimentary Dinner: RSVP to 402-650-7132 or 402-890-7126

6:00 - 6:30 pm - "Improving the 'New Normal'": Have you ever been told, "This is your new normal?" Tammy Storer is an innovator in search of therapies to improve the "New Normal" for her daughter, herself, and as a Speech/Language Pathologist working at a TBI Outpatient Clinic.

6:30 - 6:45 pm - Dessert, Table Talks

6:45 - 7:30 pm - "It is Easier to Give than to Receive'": Ruth and Pastor Mike Bitter were on separate journeys that came together as they learned the best way to take care of themselves is by caring for others.

Hosted by:

- Christian Church of Waterloo
- Brain Injury Alliance of Nebraska
- Martinwood International

About BIA-NE:

Brain Injury Alliance of Nebraska works to create a better future for all Nebraskans through brain injury prevention, education, advocacy, and support.

Contact:

Chris Stewart, Resource Facilitator
Brain Injury Alliance of Nebraska
chris@biane.org
402-423-2463

biane.org | (844) 423-2463 | (402) 423-2463 | info@biane.org



This project was supported, in part by grant number 90TBSG0036-02-00, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.



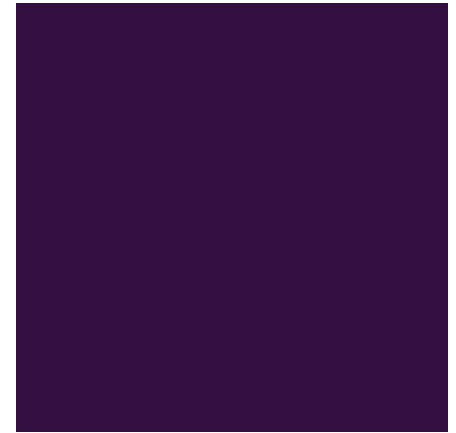
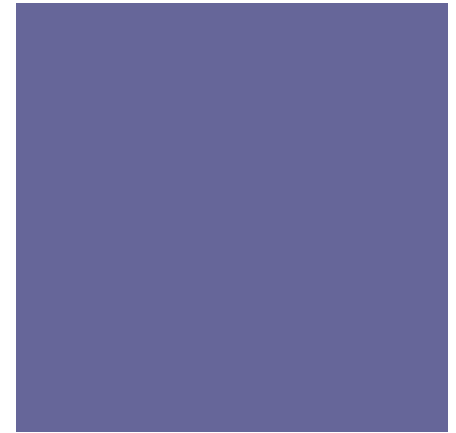
Nina's slides for
October 21, 2020
12 – 1 p.m. and 8:30 – 9:30 p.m



- Family to Family Health Information Center
- At PTI Nebraska
- 1941 S 42nd St, Ste 205
- Omaha, NE 68105
- 402-403-3908
- nbaker@pti-nebraska.org

- Nina Baker introductions and announcements

- Please take a minute to complete brief, anonymous survey at:
www.surveymonkey.com/r/BIAEvaluation



BRAIN Talks – Basic Resources, Advocacy, Innovation and Networking

Amanda Wells, LIMHP, PLADC, NCC

Chris Stewart, BS



A Brain Injury can Happen to Anyone, Anywhere at Any Time



- **Brain Injury – May be referred to as:**
 - Acquired Brain Injury (ABI) includes anoxia (lack of oxygen) aneurysms, stroke and infections (Lyme, Meningitis, COVID, etc.) that may affect cognition.
 - Traumatic Brain Injury (TBI) caused by an external force, bump, blow or hit to the head from vehicle accident, fall, sports, playing, etc. or a penetrating head injury.
- CDC - Most frequent causes of TBI are resulting from a fall, especially in those under one year old and over 65.
- Brain Injury Alliance of Nebraska demographics are mostly adults, 18-65; typically they are 6 months to 20 years post injury.
- Lives are changed by a brain injury, most notably physical health, emotional well-being and loss of income and insurance. The entire family is affected.



We All Need to be Educated about Brain Injury

“A major problem for survivors of TBI (traumatic brain injury) is that they pass rehabilitation but fail life” (Hux, 2003).



+ Who is affected by TBI?

Everyone!

- Everyday in Nebraska: at least one person dies from a traumatic brain injury (TBI), three people are hospitalized and over 24 people a day visit the emergency department because of TBI.
- The monetary cost associated with TBIs in Nebraska was over \$413,000,000 in 2009. Includes fatal/nonfatal injuries, medical costs and productivity losses.
- In the last five years, steady increase in emergency department visits, hospitalizations and deaths caused by a traumatic brain injury. Emergency visits for brain injury in Nebraska are higher than national average.

The Journey Starts with an Injury, and HOPEFULLY, Receiving an Accurate Diagnosis and Available Treatment:

■ Go with your gut.

- Symptoms of a brain injury may not appear immediately.
- Or the child may not report/remember a hit to the head.
- Person may not be aware or able to describe symptoms.
- If co-occurring with other conditions, keep asking -

■ If you see unusual or new symptoms including:

- Mood Swings/changes in personality
- Changes in attention or thinking abilities
- Greater anxiety, depression, or difficulty handling stress
- Indicating having headaches, problems with vision or balance
- Increased difficulty in expressing their thoughts or feelings
- Changes in sleep or level of fatigue when doing typical tasks



Now for the Rest of the Story - Brain Injury is Multifaceted...



- Every injury and individual is different
- Same symptoms, but different ways to approach them
- Everyone does not have the same resources/
rehabilitation/socio-economic status/culture/coping
strategies/family-friend support/education/age
- Neuropsychiatric and mental health
- Insurance needs
- Lifetime of different concerns





Contact Brain Injury Alliance at biane.org



- Please contact Brain Injury Alliance of Nebraska for support through:
Increase awareness, education and supports
- BRAIN Talks – for community groups to increase awareness
- Resource Facilitation – to provide options for care & support
- TACT – an online educational resource that helps teachers provide differentiated instruction to students with TBI in the classroom when they need it. <https://www.getschooledonconcussions.com/nebraska/>
- Remove/Reduce, Educate, Adjust/Accommodate, Pace (REAP) Manuel for parent, students, teachers and medical
- Peer to Peer Support – Advocate and assist each other through sharing experiences
- **For resources & networking opportunities please go to: biane.org or contact: Chris, 402-890-7126 or chris@biane.org**



“When your greatest heartache becomes your greatest ministry, grace comes full circle.”
-Bethany Haley Williams



+ In helping others we heal ourselves



- Amanda Wells:
- Parent
- Advocate for her children and others
- Mental Health Therapist
- Using personal and professional experiences to support families

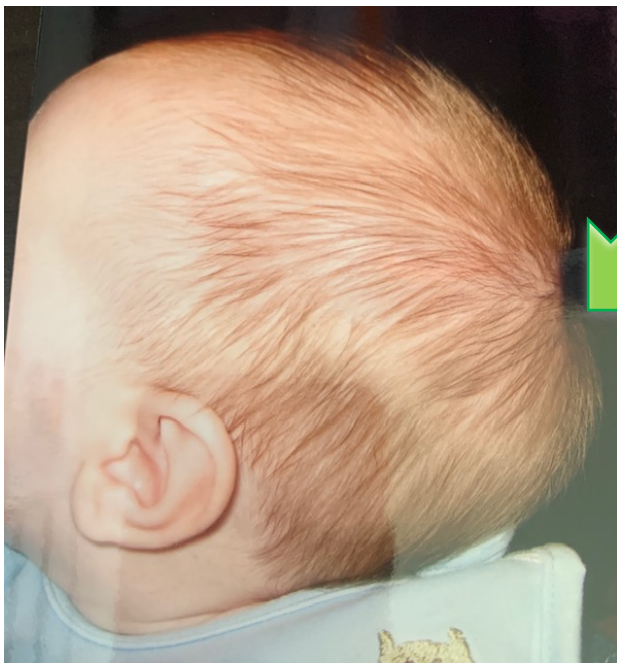


Along the Willowed Path, P.C.

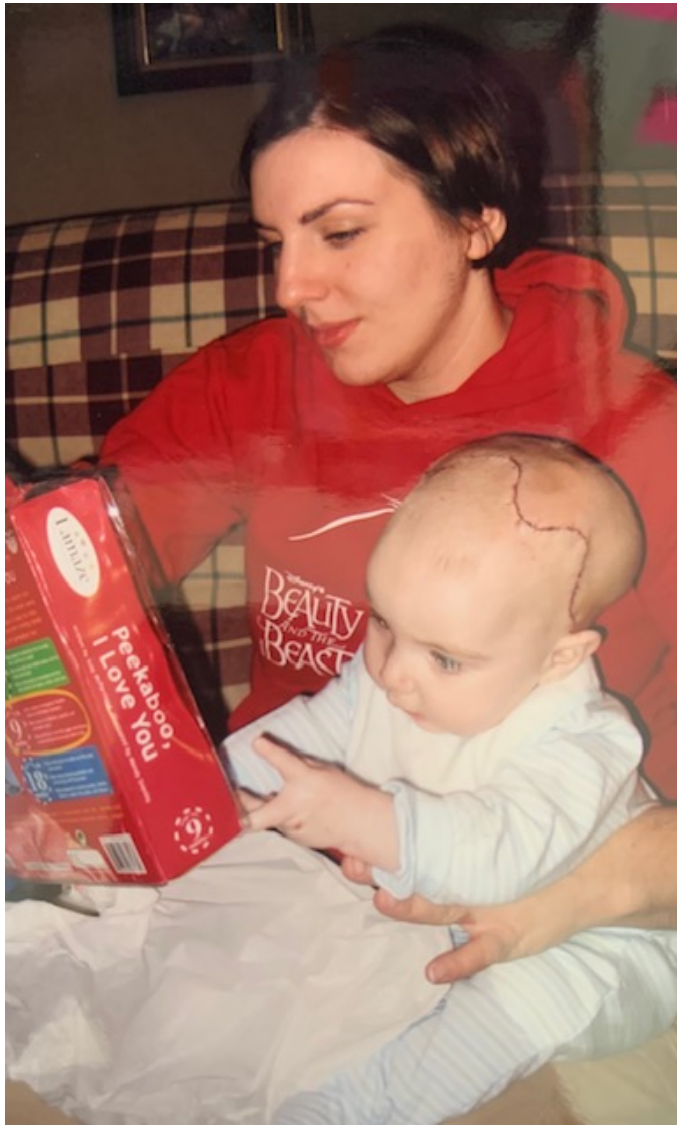
- The Journey – Our Story
- Mom, Clinician, and Advocate
- Hope
- Healing
- Empowerment

Our Path

- Craniosynostosis
- Daniel's Symptoms:
 - Constipation
 - High Pain Tolerance
 - Funny Bump
 - Pediatrician Explanation
 - Neurologist and Next Steps
 - ICP



The Frist Surgery – 2nd TBI



- 7 hours later
- Findings
- The Road Ahead
 - Doctors' Orders
- Swelling
- Developmental Milestones
- Pre-School
- Kindergarten
 - Sherriff Syndrome
- Elementary School
 - Discipline
 - Parental Shame and Guilt
 - Beginning of a Stigma

2nd Surgery – Concussion #1 – Concussion #2

- Change in Personality
- Back to Neurologist
 - Choices
- 2nd Surgery
 - Trauma
- Fall at School – Concussion #1
- Elementary School Challenges
 - Bullying
 - Depression, Suicidal Ideations
 - Fixation
 - Sherriff Syndrome 2.0
 - Supports and Lack of Supports
- Concussion #2
- Lack of Understanding
 - Lazy, Unmotivated
 - Angry
 - Annoying/Blurts Out



Hope - Healing

- Neurospsych evaluation and answers
- Moving forward/change of scenery
- Frustrations
- The Bottom Line Is Love/Caring/Patience
- Stop – BI or Something Else?
- Acceptance and Mindfulness
- Therapy
- Neuroplasticity
 - Youth
 - Adults
- “I’m doing the best I can!”



Empowerment

- Caregivers – Individuals – Service Providers - Teachers
 - Self-care
 - Grace
 - Ask for Support
 - LISTEN
- The Helping Exchange: PEARL (Brown & Woodworth 2017/McMorrow 2005)
 - Positive – What might a positive interaction look/sound like?
 - Early – What would an early interaction look like?
 - All – What might all mean when thinking about interaction?
 - Reinforce – What might a reinforced interaction look like? (intrinsic/extrinsic)
 - Look – What are we looking for in this interaction?
 - How can I support you?

Experience

- Brain injury can happen to anyone
- It looks different in each person
 - Worst Part of BI
 - “I remember what I used to be able to do. It is so frustrating.”
 - “What is wrong with me?” – Nothing...different, not less.
 - “I really am trying!”
 - “I hope when you’re talking to or working with someone and they have a quick reaction that you will stop and think maybe it’s because they have a brain injury. So many people do. Maybe it’s just a symptom and not who they are.”



Amanda Wells, LIMHP, PLADC, NCC

President

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Chris Stewart,

Resource Facilitator

Brain Injury Alliance of Nebraska

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THANK YOU!

Please take a moment to complete survey

www.surveymonkey.com/r/BIAevaluation

Living with Brain Injury



Nebraska Annual State Plan 2019-2020

August 2019



This project was supported, in part by grant number 90TBSG0036-01-00, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.

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Introduction

Welcome to Nebraska's *Annual Living with Brain Injury State Plan for 2019-2020*, developed by the Nebraska Department of Education, Office of Vocational Rehabilitation (Nebraska VR) and the statewide Brain Injury Advisory Council (BIAC). The *Plan* is intended as a guide to improve the state's system of services and supports for people with brain injury and their families.

Nebraska VR serves as the lead state agency for brain injury, providing the required state match and full-time staff to administer the state's federal Traumatic Brain Injury (TBI) grant from the Administration for Community Living (ACL). Grant funds are used for projects aimed at closing the gap of unmet and insufficiently met needs of Nebraskans of all ages who are impacted by brain injury, and to support the work of the BIAC.

The BIAC acts as the forum for all brain injury stakeholders in the state to collectively identify unmet needs and service gaps, and to recommend policy- and service system-based solutions. Its members include individuals and family members directly impacted by brain injury, medical providers, service organizations, state agency representatives and advocates. The BIAC's mission is to "engage, integrate and inspire brain injury stakeholders to help achieve the *Statewide Vision for Brain Injury Policies and Services*." The *Vision* was created in 2017 by over 225 individuals with brain injury and their family members. It inspires a better future, and better outcomes for Nebraskans impacted by this oftentimes devastating injury.

The *Statewide Vision for Brain Injury Policies and Services* states that, 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:

- 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.
- 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.
- 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 Resource Navigators.
- 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.
- 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.

The goals and objectives described in the *Plan* represent tangible steps toward achieving this *Vision*. Nebraska VR and the BIAC do not expect to take these steps alone, but seek instead to actively engage *all* brain injury stakeholders in improving the state's system of services and supports for people with brain injury and their families.

About Brain Injury

Depending on the cause, a brain injury is considered traumatic or non-traumatic. A traumatic injury can be caused by a bump, blow or jolt to the head, or a penetrating head injury that disrupts the normal function of the brain. Non-traumatic injuries can be caused by stroke, lack of oxygen to the brain, drug overdose, illness or infection. Even a mild brain injury can result in permanent cognitive, physical, emotional and behavioral changes that impact daily function. Individuals who experience more moderate to severe injuries may require life-long services and supports for housing, work and community living. Each year, over 10,000 Nebraskans of all ages are diagnosed with traumatic brain injuries. Countless more are injured, yet are not diagnosed or treated. The number of non-traumatic injuries that occur each year is unknown. Many who are injured, especially those living in rural areas, have limited or no access to the services and supports they need to recover, return to school or work, or to live as independently as possible. People with brain injury and their families are often unaware of existing services and supports in their areas and how to access them.

How This Plan Was Developed

Members of the BIAC reviewed data from the *2019 Living with Brain Injury Survey* and many other sources to identify the most urgent and prevalent unmet and insufficiently met needs of people with brain injury and their families to address in the *Annual Living with Brain Injury State Plan for 2019-2020*. Nebraska VR and the BIAC also gathered input on the *Survey* results from participants attending the 1st Annual Living with Brain Injury Summit, held in March 2019. To obtain public input, the *Plan* was disseminated via electronic mailing lists and social media. Printed copies were mailed to each of the local Brain Injury Support Groups across the state. The *Plan* was also posted for public review and comment at the Nebraska VR and BIAC websites. In August 2019, Nebraska VR and the BIAC will host a statewide, public meeting via videoconference at all Nebraska VR offices, inviting questions and comments from the public.

An Invitation

As stated previously, the *Plan* is intended as a guide to improve the state's system of services and supports for people with brain injury and their families. There are countless dedicated advocates, professionals, agencies and organizations across the state doing incredible work to help people reclaim their lives after brain injury. The *Plan* is an invitation for us all to share accountability for the same vision; to become engaged, integrated and inspired brain injury stakeholders.

The Merriam Webster dictionary defines a stakeholder as "one who is involved in or affected by a course of action." If your life or the life of someone you know or care for is affected by brain injury, then you are a brain injury stakeholder, and your input is vital. To become involved in BIAC activities, contact Nebraska VR and the BIAC by email at vr.infobiac@nebraska.gov or by phone at (308) 865-5012. You can learn more about us at our websites:

Nebraska VR: <http://www.vr.nebraska.gov>

Brain Injury Advisory Council: <https://braininjury.nebraska.gov>

Nebraska Brain Injury Advisory Council

Tiffany Armstrong, Gretna

Jerry Bryan, Hotline for Disabilities Services/Client Assistant Program, Lincoln

Nancy Coffman, Nebraska Commission for the Blind and Visually Impaired, Lincoln

Tania Diaz, Disability Rights Nebraska, Lincoln

Mark C. Draper, Draper Education Consulting, and NDE Office of Special Education, Lincoln

Michelle Hawley-Grieser, Lincoln

Brett Hoogeveen, Quality Living, Inc., Omaha

Dale Johannes, Lincoln

Kristen Larsen, Nebraska Council on Developmental Disabilities, Lincoln

Carla Lasley, Nebraska VR, Lincoln

Brooke Murtaugh, Madonna Rehabilitation Hospital, Lincoln

Judy Nichelson, Council Chair, North Platte

Peg Ogea-Ginsburg, Department of Health and Human Services, Injury Prevention, Lincoln

Zoe Olson, Blue Rivers Area Agency on Aging, Beatrice

Vaishali Phatak, University of Nebraska Medical Center, Omaha

Peggy Reisher, Brain Injury Alliance of Nebraska, Lincoln

Kathy Scheele, Department of Health and Human Services, Medicaid and Long Term Care, Lincoln

Frank Velinsky, Omaha

Staff

Keri Bennett, Nebraska VR, Kearney

Tresa Christensen, Nebraska VR, Kearney

Liz Lohse, Assistive Technology Partnership, Lincoln

Nancy Noha, Assistive Technology Partnership, Lincoln

Annual Living with Brain Injury State Plan for 2019-2020

Access Services

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.

<p>Goal 1: Improvements to Nebraska’s system of care and community-based services for people with brain injury will be driven by the collection and analysis of meaningful data.</p>	<ul style="list-style-type: none"> • Revise the Annual <i>Living with Brain Injury</i> Needs Survey and the survey process with input from people with brain injury, family members, the Brain Injury Alliance of Nebraska (BIA-NE) and other stakeholders, to increase participation. • Advocate for amendments to the Traumatic Brain Injury (TBI) Registry follow-up statute to allow for multiple contacts with individuals placed on the Registry, and other improvements to connect them with appropriate services for their recovery, using data from the BIA-NE’s Resource Facilitation program and other sources. • Create and implement a plan to systematically collect meaningful data and statistics on Nebraskans impacted by brain injury, including data on the long-term outcomes of people with brain injury.
<p>Goal 2: Paid caregivers and professionals in medicine and healthcare, education, behavioral health, law enforcement, vocational rehabilitation, and other disciplines will receive information, training, and education to understand and address the physical, cognitive, emotional and behavioral needs of people with brain injury.</p>	<ul style="list-style-type: none"> • Prioritize professional groups for training and education, and develop training curriculum in collaboration with the BIA-NE, utilizing Annual <i>Living with Brain Injury</i> Needs Survey results.
<p>Goal 3: People with brain injury and their family members will access affordable housing, and home and community-based service options in all parts of the state.</p>	<ul style="list-style-type: none"> • Advocate to amend the current TBI Waiver level of care and services. • Advocate to provide Independence Skills Training services to people with brain injury served under the Aged and Disabled Waiver. • Advocate in the development and implementation of Nebraska’s Olmstead Plan.
<p>Goal 4: People with brain injury and their family members will be made aware of the dangers of Opioid medication misuse, and know where to seek assistance and treatment of substance abuse concerns. (HHS-wide Public Health Goal)</p>	<ul style="list-style-type: none"> • A BIAC Committee will consult with state Opioid experts and resources and develop action steps for an education plan.
<p>Goal 5: People with brain injury and co-occurring serious mental illness will receive effective treatment and community-based services to meet their needs. (HHS-wide Public Health Goal)</p>	<ul style="list-style-type: none"> • A BIAC Committee will consult with Behavioral Health experts, the BIA-NE, and people with brain injury and co-occurring serious mental illness to develop action steps for the provision of effective treatment and services.

Build the Voice

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.

<p>Goal 1: People with brain injury and their family members will have the leadership capacity and resources to effectively advocate for policy, program and service improvements.</p>	<ul style="list-style-type: none">• Build the foundation for a statewide, voice-driven association of people with brain injury and their family members by providing leadership and capacity-building coaching.• Equip the association to advocate for policy, program and service changes by making data, resources, tools and strategies accessible to its leaders and members.• Engage association members in shaping policies, programs and services by providing education in advocacy strategies and offering opportunities to advocate, such as an Annual <i>Living with Brain Injury</i> Summit.• The association, Nebraska VR, the BIAC and the BIA-NE of Nebraska will define complementary roles to foster a unified front for brain injury, and to avoid competition and duplication of effort.
<p>Goal 2: The Brain Injury Advisory Council will be engaged and fully representative of the statewide population of people with brain injury.</p>	<ul style="list-style-type: none">• Develop onboarding, orientation, and mentoring materials to ensure new members are able to fully participate in BIAC activities.• Add new members with brain injury representing each region of the state to reach 50% of the total BIAC membership.

Connect to Resources

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;~~ **in helping Nebraskans with brain injury live full and productive lives;** subsequently, people with a brain injury will have an easier time navigating available resources with ~~the help of~~ specialized assistance from Peer Support ~~Resource Navigators,~~ **and Resource Facilitation Programs.**

<p>Goal 1: People of all ages who have experienced brain injury will be connected to resources in their region of the state.</p>	<ul style="list-style-type: none"> • In the TBI Registry follow-up mailing, include customized brochures for recipients in three age groups and three regions to connect them to resources closer to their home. • Disseminate customized brochures via the Aging and Disability Resource Centers and other agencies and organizations to ensure outreach to older persons and individuals with disabilities is achieved. • Collaborate with the BIA-NE’s Resource Facilitators to ensure individuals with brain injury of all ages in each region of the state are connected to available resources.
<p>Goal 2: People with brain injury will receive help from trained Peer Support Resource Navigators to locate and access available resources have access to trained Peer Support mentors.</p>	<ul style="list-style-type: none"> • Implement a Peer Support Resource Navigation demonstration pilot using evidence-based Peer to Peer Support practices (such as those from the Centers for Medicare & Medicaid Services (CMS) and the Substance Abuse and Mental Health Services Administration (SAMHSA)). The demonstration pilot will prioritize underserved, rural areas of the state. • Define the role of the Peer Support Resource Navigator mentor role to complement existing brain injury programs and supports in collaboration with such as the BIA-NE’s Resource Facilitators Facilitation program to avoid competition and maximize collaboration and minimize duplication of effort. • When established, Peer Support Resource Navigators will serve people with brain injury living in underserved, rural areas of the state as first priority.
<p>Goal 3: Nebraska’s statewide capacity to provide comprehensive and coordinated services to people with brain injury and their families will be enhanced through active participation in federal brain injury grant and technical assistance programs.</p>	<ul style="list-style-type: none"> • Nebraska VR will co-lead federal grantee workgroups on “Transition and Employment”, and “Using Data to Connect People to Services” topics, and will share workgroup products with the BIAC and other stakeholders. • Nebraska VR will participate in the development of national Brain Injury Workforce Competencies with other Mentor grantee states.

Shape Policy

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.

<p>Goal 1: The Annual Brain Injury State Plan will reflect the Voice-Generated Statewide Vision, and will serve as a structured approach to communicate the needs of Nebraskans with brain injury and their families to the Legislature and other stakeholders.</p>	<ul style="list-style-type: none">• Obtain public input on the draft Annual Brain Injury State Plan.• Share the Annual Brain Injury State Plan with the new Brain Injury Trust Fund Oversight Committee.• Implement the Annual Brain Injury State Plan with measurable outcomes.
<p>Goal 2: Nebraska VR will serve as the state’s lead agency, providing administrative leadership for the Brain Injury Advisory Council, and collaborating with brain injury stakeholders and other state agencies to build and sustain a statewide, comprehensive, coordinated system of brain injury services.</p>	<ul style="list-style-type: none">• Nebraska VR will provide state match funds and full time staff for the federal TBI grant application and administration.• Nebraska VR will provide frequent updates on BIAC and TBI grant activities to the Nebraska Department of Education Commissioner who will serve on the Brain Injury Trust Fund Oversight Committee.
<p>Goal 3: The Brain Injury Advisory Council’s messaging and advocacy plans will be fully implemented based on meaningful data that drives ongoing voice-driven advocacy efforts.</p>	<ul style="list-style-type: none">• The BIAC’s Public Policy Committee will research barriers to the provision of community-based services and draft recommendations.• The BIAC’s Public Policy Committee will review Annual <i>Living with Brain Injury</i> Needs Survey and other data to recommend BIAC advocacy and public policy priorities on an annual basis.

Increase Public Awareness

The complex nature of an injured brain and the recovery journey will be understood by all Nebraskans, such that stigma will be decreased and the public will be more supportive of efforts to improve overall brain injury support and resources.

<p>Goal 1: Ensure that families receive information, education and support to address their financial, social and emotional needs associated with caring for someone with brain injury.</p>	<ul style="list-style-type: none"> • Prioritize information and education topics and supports, and plan action steps utilizing Annual <i>Living with Brain Injury</i> Needs Survey results and input from Annual <i>Living with Brain Injury</i> Summit attendees.
<p>Goal 2: The Brain Injury Advisory Council will be seen as a credible, statewide leader, and the forum for all brain injury stakeholders to pursue the Voice-Generated Statewide Vision.</p>	<ul style="list-style-type: none"> • Launch public awareness activities to increase BIAC visibility, strengthen connections with other disability organizations and increase outreach to brain injury stakeholders across the state (to include social media and BIAC website enhancements). • Identify supplemental revenue for BIAC sustainability. • BIAC committees will be established, functioning, active and providing directions. • Submit a proposal to host the National Association of State Head Injury Administrators (NASHIA) conference in Omaha, NE in 2021.

To comment on the *Annual Living with Brain Injury State Plan for 2019-2020*, contact Nebraska VR and the BIAC by email at vr.infobiac@nebraska.gov or by writing to us at Nebraska VR/BIAC, 315 W 60th Street, Ste 400, Kearney, NE 68845.

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