

New Hampshire Brain & Spinal Cord Injury Advisory Council Concord, New Hampshire



2023 ANNUAL REPORT

BACKGROUND

The Brain and Spinal Cord Injury Advisory Council (The "Advisory Council") is charged by the New Hampshire Legislature with investigating the unmet needs of New Hampshire residents with brain or spinal cord injuries. See NHRSA 137-K. The Advisory Council has been holding public hearings for twenty-six years, since its establishment by statute in 1997.

Senate Bill 439, AN ACT relative to the advisory council and community based programs was signed into law on July 19, 2022. This law streamlines the council membership from fifteen to eight members, removes the barriers, makes the council more productive and ensures quorums. By having a smaller required number of members, the dedicated members who attend meetings regularly meet or exceed the quorum count for voting on activities.

FINDINGS

Results from the testimony at the public hearings indicate that serious unmet needs continue to prevail in New Hampshire. Unfortunately, most feedback from the public regarding unmet needs has remained largely unchanged for well over twenty years.

Lack of Medical and General Public Education and Awareness.

Persons living with brain injury (survivors) and spinal cord injuries report that there continues to be widespread misunderstanding by employers and even by primary care health professionals regarding these issues, particularly when the individual has no obvious visible disability. Access to resources is more complicated because many people do not understand how brain injuries affect survivors, families and caregivers.

- Several participants testified that agencies seemed to try to push their issues on to some other agency.
- Several participants testified about the extreme efforts needed to fill out extensive paperwork, often very difficult for brain injury survivors, repeat their stories multiple times and getting what they referred to as "The run around".

• One woman reported that it took six months with a lot of roadblocks to get her husband on the ABD waiver.

Home Support for Individuals with Disabilities and Family Members.

Survivors and family members face significant obstacles when they are discharged from acute care. They are frequently unable to negotiate through multiple systems, which are not intuitive, even when services are available, which is definitely not always the case. Pertinent information should be more available at discharge. Resource directories and assistance in obtaining services are important. A lack of long term care community resources continues. As our elected officials are well aware there is a statewide crisis in identifying and securing consistent and responsible direct support personnel, leaving many in the brain injury and spinal cord injury communities with no services or supports at times.

 Many Brain injury and spinal cord injury survivors and family members spoke about the need for long term assistance in the home and for occasional respite. Many survivors who need in home supports do not get them.

Staffing Issues

Many participants spoke about the need for consistent case management, which often does not exist.

As the Department of Health and Human Services is well aware, there is a significant staffing shortage throughout the state in the human service sector. This creates insurmountable barriers for people with significant disabilities.

Employment. Both brain injury and spinal cord Injury Survivors described the loss of employment and lack of supports needed to return to work, misunderstanding about their abilities and deficits, and difficulty finding employers open to supporting them with their disabilities.

Transportation. There is a significant lack of public transportation for a population that is frequently unable to drive. Many described numerous impacts including difficulties getting to medical appointments, difficulty accomplishing basic life responsibilities, and isolation from activities in the community. Social isolation was a consistent theme at the public hearings.

- One survivor spoke of the paradox that if you take an ambulance to go to the emergency room, you have no way to get home.
- Others spoke of the pervasive lack of wheelchair accessible vans for transportation.

• The transportation that does exist for people with disabilities is generally not seen as being affordable.

Housing. As has been reported in many contexts, there is a lack of both affordable and accessible housing for brain and spinal cord injury survivors throughout the state. Our elected officials are well aware of the housing challenges within the state and people with low incomes or accessibility issues experience far greater challenges in this regard.

 Several stories were related about lack of housing, having no place to go, significant difficulties with moving and what sounded like exorbitant rental costs.

Community Programs/Brain Injury Clubhouse. On a positive note, post rehabilitation programs, such as the program at the Krempels Center, have not been available to survivors who do not live in the Portsmouth area. There is unanimity among survivors regarding the benefits of the Krempels Center.

However, earlier this year, the NH DHHS Bureau of Developmental Services, lead state agency for brain injury programs, has dedicated \$750,000 of Federal American Rescue Plan Act funds for the startup of a second brain injury clubhouse. A contract has recently been awarded and the agency that it was awarded to is in the preliminary stages of opening it up.

Behavioral health: Several survivors and family members at the hearings reported a <u>significant lack of behavioral health supports</u> for survivors and family members. There was a reported lack of understanding in the behavioral health community regarding brain injury and an unavailability of therapists in many locations who are available and willing to work with survivors. On a positive note here, the Center for Life Management is actively working on improving supports to brain injury survivors who also have behavioral health issues. The Brain Injury Association has recently been awarded a grant through the National Association of State Head Injury Administrators to enhance the collaboration between behavioral health systems and brain injury services.

It should be noted that feedback from the brain injury community and the spinal cord injury community is eerily similar. The spinal cord injury hearing held in June evoked the following comments:

 Statewide, there is a significant lack of affordable and accessible transportation. When a wheelchair van breaks down there are few, if any, other options and people can be stuck at home, missing work, missing appointments, etc.

- The same can be said of housing. There is a significant lack of affordable and accessible housing.
- Many people are dealing with social isolation.
- As the NH Department of Health and Human Services is well aware, there is a significant lack of direct support staff to provide care.
- In all things, there is a greater need for advocacy, especially in navigating the "system" which puts up many roadblocks and barriers.
- There is a lack of knowledge on the part of many healthcare professionals In terms of supporting people with spinal cord injuries.

Emerging Issues. As the reader is aware, damage from the consequences of the COVID-19 coronavirus created a new level of challenges and further exacerbated the cognitive, physical, emotional and behavioral symptoms associated with a traumatic brain injury or spinal cord injury. At the same time, the experience of limited in-person interaction created a greater level of social isolation, as many support groups and other opportunities had to go virtual.

If you have any questions about this report, feel free to contact Advisory Council Administrator Ellen Edgerly at 603-834-9570. Prior reports are available on the New Hampshire Brain Injury Website at http://www.bianh.org/bsciac.html.

 John Richards
 December 14, 2023

 John Richards, Chair
 Date

Brain and Spinal Cord Injury Advisory Council

Respectfully submitted,

ADDENDUM BRAIN INJURY AND SUBSTANCE ABUSE.

SUD/Brain Injury And Mental Health Interagency Task Force

The Brain Injury Association of NH established an interagency task force, which met from Jan. 2019 through Jan. 2023. The task force included representatives from the neuropsychology industry; the Dept. of Health and Human Services; the Dept. of Education; the Dept. of Safety; NH PBS; the healthcare industry; the brain injury community and the communications industry.

The task force was tasked with 1) raising awareness of the signs of a brain injury and 2) helping to change the behaviors of providers and other frontline medical personnel, as well as family members, so they could make the connection between brain injury and opioid overdose and seek help and resources for the patient with a brain injury more easily.

Key target audiences included: Families & Caregivers; Medical Frontliners (including case workers, social workers, nurses and ER physicians); Schools

Accomplishments:

- Development of educational rack cards (in English & Spanish) for distribution via the ER, physician offices and opioid overdose kits distributed by first responders
- Multiple presentations to target audiences on the connection between SUD and Brain Injury/Mental Health, many made possible by the BDAS grant
- Establishment of the SUD section of the BIANH website
- Completing a 2-year pilot program at St. Joseph Hospital, which involved training medical frontliners to screen opioid overdose patients using the tool developed by Dr. John Corrigan at Ohio State University. This effort was funded by the Foundation for Healthy Communities
- Working with the Dept. of Safety to train EMS/first responders on the SUD/Brain Injury connection
- Working with the NH Providers Association to promote a SUD/Brain Injury website and toolkit
- Working with NH PBS on the concept for a follow-up to the Roads to Recovery documentary that could be used in the schools

Overview of St. Joseph Hospital Pilot Program

- SJH 2-yr. Pilot program ran from June 2021 to June 2023
- The focus was to train medical frontliners so they could identify potential brain injury cases in opioid overdose patients, using the screening tool developed by Dr. John Corrigan
- What differentiated the approach was the presence of a neuro-resource facilitator onsite at the hospital following up with patients
- The pilot program was funded through the Foundation for Healthy Communities and Karen Bradshaw at St. Joseph Hospital was the grant administrator

What We Learned:

- Pre- and post-training surveys showed those who took the training had higher rates of referring patients to BIANH and asking questions about the history of drug and alcohol use
- The number of respondents who felt SJH had a good system for following up with patients who may have sustained a brain injury increased
- Familiarity with the signs of a brain injury were highest among those who took the training
- We had some limitations with budget and lack of staff/staff focused on COVID/turnover impacted the pilot program.
- We were able to expand outreach by training those who worked the Mobile Health Clinic, headed by Dr. Vatti and staffed by nurse practitioners, nurses, patient service repos and drivers with EMT experience

Other Awareness-Raising:

- Ongoing trainings
- Updates in newsletters and SJH annual report
- Distribution of "rack cards" with information on the SUD/Bi connection, distributed in the ED & at Mobile Health Clinic (English/Spanish)
- Information from SUD Resource Page posted on Case Management/Services for Outpatients page
- Presentations by subject matter experts continue on this subject
- BIANH working with Phil Vaughn on the possibility of a follow-up documentary to "Roads to Recovery"
- In conversation with Maria Varanka at DOS about the possibility of putting together a training on this topic for EMTs as part of their CEUs