

State of New Hampshire  
Brain & Spinal Cord Injury  
Advisory Counsel

C/o Brain Injury Association of New Hampshire  
52 Pleasant Street  
Concord, NH 03301



## 2020 ANNUAL REPORT

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 three years, since its establishment by statute in 1997.

Due to the 2020 COVID-19 quarantine, the first public hearing scheduled for the spring was replaced with an Advisory Council Survey on Unmet Needs mailed out to individuals listed in the Brain Injury Association of New Hampshire (BIANH) database. In addition, the Advisory Council placed a survey monkey link on the BIANH website, placed in the Headway Newsletter, distributed to individuals with brain and spinal cord injuries and to the organizations that support them. The second public hearing was held through a ZOOM virtual platform on October 22, 2020. Results from the survey and testimony at the virtual public hearing indicated that significant unmet needs continue to persist in the State.

### **Lack of Medical and General Public Education and Awareness.**

Survivors report that there can be misunderstanding by employers and even by primary care health professionals, particularly when the survivor appears normal. Access to resources is more complicated because many people do not understand how brain injuries affect survivors, families and caregivers.

***Survivor Statement: “I live independently, one of the things that I struggle with most is that I find out that I am too high functioning to receive services because I can do a lot for myself.”***

**Community Programs.** Post rehabilitation programs, such as the program at the Krempels Center, are not available to survivors who do not live in the Portsmouth area. There is unanimity among survivors regarding the benefits of the Krempels Center. Some survivors travel from as far away as Keene to participate. Transportation issues are significant. There should be more programs like that.

**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 is not intuitive, even when services are available. Pertinent information should be more available at discharge. Resource directories and assistance in obtaining services are important.

***Family Member Statement: “During the first year of the brain injury as a family member it is almost like you are in the middle of the ocean waiting for a buoy to come so you can grab on to it and hope everything is going to be ok.”***

**Employment.** Survivors describe loss of employment and lack of supports needed to return to work, misunderstanding about their abilities and deficits, and difficulty finding employers receptive to their disabilities.

***Taken from survivor survey: “My employer didn’t help with work recovery, 4 years of legal battles with my employer insurance and denials of medical treatment.”***

**Transportation.** There is a lack of public transportation for a population that is frequently unable to drive. Survivors describe numerous impacts including difficulties getting to medical appointments, difficulty accomplishing basic life responsibilities, and isolation from activities in the community.

Due to the chronic and continuing nature of unmet needs presented at hearings over the years, and the need for funding to address such needs, the Advisory Council determined in 2016 to create a task force pursuant to RSA 137-K to determine the feasibility of establishing a brain injury trust fund. Stakeholders were invited. The task force included persons with knowledge about brain injury, including providers and survivors and representatives from the Department of Safety and from the Department of Health and Human Services. Four meetings with presentations were held in September and October. Enclosed please find a copy of the BRAIN INJURY TRUST FUND TASK FORCE REPORT dated June 6, 2016. The Brain and Spinal Cord Injury Advisory Council continues to support the establishment of a trust fund.

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

Respectfully submitted,

*James C. Piet, MS*

James C. Piet, Chair  
Brain and Spinal Cord Injury Advisory Council  
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