

**State of New Hampshire
Brain & Spinal Cord Injury
Advisory Council**

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



2019 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 two years, since its establishment by statute in 1997.

In 2019, two public hearings were held: On **Tuesday, May 14, 2019** at Catholic Medical Center located in Manchester, New Hampshire; and on **Tuesday, October 15, 2019** at Southwest Community Services located in Keene, New Hampshire. The testimony at the hearings indicated that significant unmet needs continue to persist in the State.

Lack of 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.

Quote from audience participants:

(The struggle that educators have is that there is a lot of things that come at you, the difference between a brain injury and a learning disability is that they not the same as it often tends to be lumped into the same category it also happens with categories of speech and physically impaired)

(the frustration of having some kind of coordination to help students access services that students are eligible for are nonexistent)

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

Quote from audience participants:

“It’s giving people the smaller amount of community based services they need and also benefiting us as a state because we are able to demonstrate that community service is less expensive than institution level of care”

“Right now we do everything for our son, we make the doctor’s appointments, and we fill out the forms that we need to reapply for Medicaid every year. Who is going to do that for him when we die? Am I responsible for finding someone?”

Discharge Planning and Support. Survivors 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.

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.

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 Secretary Ellen Edgerly at 603-225-8400. Prior reports are available on the New Hampshire Brain Injury Website. <http://www.bianh.org/bsciac.html>.

Respectfully submitted,

James C. Piet, MS

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Brain and Spinal Cord Injury Advisory Council
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