

Disability Rights New Jersey (DRNJ) is the designated protection and advocacy system for people with disabilities in New Jersey, which includes the Protection and Advocacy for Individuals with Traumatic Brain Injury program (PATBI), 42 U.S.C. § 300d-53.<sup>1</sup> Services provided to individuals with traumatic brain injury under the PATBI program include: (1) information, referral, and advice; (2) individual and family advocacy; (3) legal representation; and (4) assistance in self-advocacy.

On behalf of DRNJ, I wish to express our concerns about the change in the definition of “traumatic brain injury” in the proposed amendment to N.J.A.C. 10:141-1.2.

DRNJ is making the following three recommendations:

- prioritize services not people
- increase dedicated revenue if needed to provide the highest priority service to all in need
- provide more robust reporting to inform policy makers

While the major causes of brain injuries can be placed in categories that can be easily distinguished, it is just as often the case that the most frequently used terms – “traumatic brain injury” and “acquired brain injury” – are used imprecisely and sometimes interchangeably.

In order for me to understand the current debate, I found it helpful to impose the following definitions.

An **acquired brain injury** is brain damage that is **not** caused by genetic or congenital disorders, or by trauma during birth. Degenerative disorders, while occurring later in life are also generally excluded from the definition of acquired brain injury.

Acquired brain injuries can be divided into three major causal categories:

**Traumatic Brain Injury**, which results from a blow or jolt to the head or a penetrating head injury that disrupts the function of the brain.

**Non-traumatic Brain Injury**, which can be derived from either an internal or external source such as strokes, brain tumors, infections, poisoning, or substance abuse.

**Anoxia Due to Trauma**, which is the loss of blood flow to the brain due to a traumatic event.

Today's debate is, therefore, occasioned by the proposal of the Department of Human Services to amend its current regulation, which can, and apparently has been, read to include all three of the above categories, and restrict the definition to only the most narrow definition of "traumatic brain injury."

This proposal has caused concern because not only is this a major departure from the fund's current practice, but also these distinctions, based on the **cause** of the brain injury, are not useful in categorizing the severity of the injury or the unmet needs of the individual. Individuals who experience brain injuries resulting from any of the three listed causes experience similar problems in accessing appropriate services, maximizing independence, and avoiding unnecessary institutionalization. So, while the uniqueness of brain injuries makes the need for a dedicated fund necessary, to condition assistance on the cause of the injury rather than the effect of the injury is excessively arbitrary.

The proposed elimination of individuals who have experienced anoxia due to trauma, which is specifically included in the federal definition of traumatic brain injury in the legislation establishing state grants for traumatic brain injury, 42 U.S.C. § 300d-52(i)(2), as potential beneficiaries of the fund is particularly troublesome.

Suppose two young men are sailing off the Jersey shore, and an unusually large wave nearly capsizes the boat. One of the young men is thrown to the deck of the boat, while the other young man is tossed overboard and nearly drowns. If both young men sustain a head injury, only the young man whose head strikes the deck of the boat will be eligible for assistance from the fund.

Or, suppose a young girl and a young boy are playing baseball. The young girl's pitch hits the young boy in the head. The next batter hits a line drive right back to the pitcher, striking her in the chest and causing her heart to stop beating until she can be revived. If both the young girl and the young boy sustain a head injury, only the young boy will be eligible for assistance from the fund.

Similarly, two young women are in a car that is in a collision. One young woman is not wearing her seatbelt and is thrown into the windshield. The other young woman is wearing her seatbelt, but receives a major cut from a piece of metal thrust into the passenger compartment resulting in a severe loss of blood. If both young women sustain a head injury, only the young woman whose head strikes the windshield will be eligible for assistance from the fund.

Unfortunately, this example also holds for two service members who are victims of the same hostile improvised explosive device (IED). The service member who sustains a head injury from the concussion would be eligible for assistance from the fund, while the service member who sustains a head injury as a result of the loss of blood from a shrapnel wound would not.

If the fund is unable to meet all the reasonable needs of everyone who has sustained a brain injury, we would prefer that the fund prioritize the services to be funded rather than the people receiving the funds.

In any of the examples above, the individual eligible for services from the fund can potentially receive assistance for cognitive therapy, transportation, a tutor, assistive technology, and home management; while the other individual who sustains a similar injury during the same event receives no assistance for any of these. We would suggest that the more equitable response would be to assist both individuals to meet their greatest need.

If the fund is unable to meet this basic undertaking with its current funding, then I have no problem supporting an increase in the dedicated funding for the fund. Since I commute to work on New Jersey Transit and have been told to anticipate a fare increase well over \$0.50 twice a day for less service, an additional \$0.50 increase in annual automobile registration fees<sup>2</sup> to ensure that individuals with severe head injuries receive basic services is a real bargain by comparison.

I would, however, couple a funding increase with more robust reporting by the fund. In fact, I would encourage the fund to voluntarily provide, or the legislature to request, more comprehensive reporting now. I have no reason to question the legitimacy of any of the fund's expenditures or its practices. More detailed information about the applications received by the

fund by causal category, its expenditures by cause and service, as well as its current balances, would allow policy makers not only to assess the operations of the fund (for example, I suspect that including anoxia due to trauma within the definition of traumatic brain injury would have negligible impact on the fund), but also to determine whether there are other parts of the system that need to be examined or fixed.

DRNJ urges the legislature to ensure that the fund continues to assist the greatest number of individuals with head injuries to receive necessary services needed to maximize independence and avoid unnecessary institutionalization.

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<sup>1</sup> Other programs incorporated within the protection and advocacy system include:

- Protection and Advocacy for Individuals with Developmental Disabilities (PADD), 42 U.S.C. §§ 15041 to 15045
- Protection and Advocacy for Individuals with Mental Illness (PAIMI), 42 U.S.C. §§ 10801 to 10851
- Protection and Advocacy of Individual Rights (PAIR); 29 U.S.C. § 794e
- Client Assistance Program (CAP); 29 U.S.C. § 732
- Protection and Advocacy for Assistive Technology (PAAT); 29 U.S.C. § 3004
- Protection and Advocacy for Beneficiaries of Social Security (PABSS); 42 U.S.C. § 1320b-21
- Protection and Advocacy for Voter Access (PAVA); 42 U.S.C. §§ 15461 and 15462.

<sup>2</sup> According to the Brain Injury Association of America, motor vehicle or traffic crashes account for only 20% of the narrow definition of traumatic head injuries. (<http://www.biausa.org/aboutbi.htm>, viewed February 18, 2009) Therefore, even with the proposed restricted definition, four out of every five individuals receiving assistance from the revenue derived from automobile registration will have acquired a traumatic head injury from something other than an auto or traffic accident.