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GOVERNOR



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SECRETARY

State of Louisiana
Department of Health and Hospitals
Office of Aging and Adult Services

January 4, 2016

President John Alario
Louisiana Senate
P. O. Box 94183
Baton Rouge, LA 70804

Speaker Charles Kleckley
Louisiana House of Representatives
P. O. Box 94062
Baton Rouge, LA 70804

RE: HCR 133

HCR 133 requires the Traumatic Head and Spinal Cord Injury (THSCI) Trust Fund Advisory Board study and make recommendations for policy and procedural changes, including necessary legislation, to expand its services to persons with spinal cord injuries arising from sudden internal medical conditions. This letter presents the results of that study.

Background

The purpose of the THSCI program is to provide Louisiana citizens who survive traumatic head or spinal cord injuries a source of funds for services that will enable them to return to a reasonable level of functioning in their communities. Services eligible for funding include but are not limited to: evaluations, post-acute medical care rehabilitation, therapies, medications, attendant care, and equipment necessary to assist with activities of daily living, provided that such expenses are related to the traumatic spinal cord or head injury. The most requested services and supports are medical supplies, equipment, personal assistance services, and home and vehicle modifications.

The trust fund is a statutorily dedicated fund established in 1993 and is funded exclusively by surcharges on fines for DUI, speeding, and reckless operation of a motor vehicle, the cause of many traumatic head and spinal cord injuries. The Clerks of Court collect the fines and forward the funds to the State Treasurer.

DHH contracts with three case management agencies statewide to assist consumers in developing a plan of care to identify needed goods/services. Case management agencies are the link between individuals and the services and supports they need. Case managers are responsible for assuring that individuals receive goods and services according to the care plan.

Current revenue is \$1.6 million annually—an amount which has been consistent over the length of the program. There is an annual cap of \$15,000 and a maximum lifetime cap of \$50,000 for each individual's use. Costs for the case management function are not included in the amounts available to the individual. The average per person expenditure (excluding case management costs) is \$9,000.

The Trust Fund is currently supporting 689 active cases statewide. Once individuals are approved for services through this program, they stay in the system until they reach the maximum cap, develop an unstable medical condition that precludes participation, fail to cooperate with the service plan, become eligible for the services through a different program, move out of state or pass away.

Members of the Advisory Board include a neuropsychologist, a survivor of a traumatic head injury, a survivor of a traumatic spinal cord injury, a family member of a survivor of a traumatic head injury, and a family member of a survivor of a traumatic spinal cord injury, as well as representatives of statewide and local organizations recognized for their work in advocacy programs for persons with traumatic head and spinal cord injuries such as the Advocacy Center, the state Medical Society, Louisiana Hospital Association, Louisiana Rehabilitation Services and key members of the legislature. The Advisory Board is charged with advising DHH in all phases of administration of the fund.

Diagnosis and Eligibility

As per the statute R.S. §46:2632(4-5), a Spinal Cord Injury is defined “as an insult to the spinal cord; not of a degenerative or congenital nature but caused by an external physical force resulting in paraplegia or quadriplegia”. Traumatic Head Injury is defined as “an insult to the head, affecting the brain, not of a degenerative or congenital nature, but caused by an external physical force that may produce diminished or altered state of consciousness which results in an impairment of cognitive abilities or physical functioning.”

To be determined eligible for funds, the individual must meet ALL the following criteria:

1. Have an injury that meets the statutory definition for traumatic head and/or spinal cord injury.
2. Be a resident of Louisiana, officially domiciled in the State of Louisiana at the time of injury and during provision of services
3. Have a reasonable expectation for improvement in functional outcome

4. Have exhausted all other governmental and private sources
5. Provide proof of denial from other sources
6. Willing to accept services from an advisory board-approved facility/program
7. Be medically stable, and
8. Must complete and submit an appropriate application

Concerns Regarding Expansion of Eligibility:

The Advisory Board met on August 13, 2015 to discuss the whether to expand the program to include spinal cord injuries arising from sudden internal medical conditions. Spinal cord injuries arising from sudden internal medical conditions are nontraumatic (NTSCI). An NTSCI is any damage to the spinal cord that has not been caused by external trauma. The spinal cord is damaged in other ways, such as infection, disease (e.g. multiple sclerosis), and loss of blood supply, compression by cancer or through slow degeneration of the spinal bones (vertebrae) such as in osteoarthritis. After thoughtful consideration, the Advisory Board identified several concerns and developed its recommendations in response to the charge set forth in HCR 133. The Advisory Board's primary concerns with expanding program eligibility are as follows:

1. Definition

Currently, the scope of the THSCI program is easily defined, with injuries to the brain or spinal cord arising from trauma due to external forces applied to the central nervous system (i.e., brain or spinal cord). If the external trauma clearly produced an internal medical event (e.g., stroke; disc herniation), then the subsequent condition might potentially fall within the scope of the program. HCR 133's focus, however, is on an acute internal medical event that is not produced by trauma. While an acute internal medical event may be sudden, it is not within the scope of external forces that may produce trauma. Moreover, internal medical conditions, whether congenital or produced by some disease mechanism, may lead to both insidious and acute onset of symptoms. An aneurysm may be the result of a congenital condition, and it may enlarge over time, but only produce acute (sudden) conditions when it bursts. Degenerative spinal conditions may be insidious until nerve root impingement is achieved, and then there may be a sudden onset of spinal symptoms. The request also specifies that a spinal cord change must occur, either temporary or permanent. By definition (and program scope), temporary changes would not be fundable, as recovery or remitting is implied.

2. Population

It is estimated that 276,000 Americans are survivors of spinal cord injuries (Source: National Spinal Cord Injury Statistical Center). As defined above,

NTSCIs are frequently due to degenerative conditions related to the spinal cord. Spinal cord vascular problems, herniated discs and even aging are considered as etiologies for NTSCI spinal cord injuries. Most NTSCI spinal cord injuries are related to another diagnosis, so injuries are not reported as spinal cord injuries. The current legislative request, lacking clear definition, would potentially open the fund up to thousands more requests. For example, if a sudden onset of a multiple sclerosis condition was to qualify, that would potentially open the fund up to approximately 3000 new cases in Louisiana alone (based upon a rate of 60 cases/ 1000,000 population). Many more potential cases would be added based upon the language of "acute internal medical event." While not all potential cases would qualify, the manpower required to evaluate all the request would be beyond the pale of the program. We estimate the number of people seeking and qualifying for services through the trust fund will quadruple if the fund is expanded to include NTSCIs.

3. Meeting the Need

The program currently has a waiting list of 306 individuals and a wait time of more than three years for services. While approximately 100 people are added to the waiting list every year, the Trust Fund was able to open only 96 new cases between FY 2014-2015. This lag in services occurs in part because individuals often hold on to the balance of their lifetime reserve once their immediate needs are met as a safety net for unforeseen future need. Under current funding, this lag would increase exponentially if the program were expanded.

4. Program Intent

The potential scope of the expansion to serve individuals with a NTSCI is not consistent with the purpose of the THSCI fund in Louisiana or any of the 21 states that have enacted this program. There is no clear linkage of funding source to nontraumatic spinal cord injuries.

Conclusions/ Recommendations:

After studying the issue, the THSCI advisory Board voted unanimously to recommend that no changes be made to the authorizing legislation. A proposed expansion would far exceed the ability to provide any additional services.

OAAS-R-15-006
OCDD-P-15-004
November 2, 2015
Page 5

Sincerely,

A handwritten signature in blue ink, consisting of several loops and a long horizontal stroke, positioned above the printed name.

Andrew Kuyoro
Member, THSCI Board of Directors