

**SFA**

BILL ANALYSIS

Senate Fiscal Agency

Lansing, Michigan 48909

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**Senate Bill 450 (as enrolled)(Public Act 122 of 1988)****Sponsor: Senator Vern Ehlers****Senate Committee: Health Policy****House Committee: Public Health**

Mich. State Law Library

**Date Completed: 8-10-88****RATIONALE**

Approximately 8,000 traumatic spinal cord injuries occur in the United States each year. Spinal cord injuries affect public health through the high cost of acute care; the relatively young age of the victims—primarily 15-24 years of age; the causes of these injuries, such as car accidents, gun shot wounds, and sports, which often are preventable; and the permanence of the disability. Spinal cord injuries are responsible for more illnesses and deaths in the one-to-44 years age group than all communicable diseases and other health conditions combined. Similarly, head injuries kill 100,000 Americans a year, and send more than 700,000 victims to the hospital. Head injury is the number one killer of persons under the age of 44, and kills more Americans under the age of 34 than all other diseases combined. Estimates place the number of head injury cases in Michigan between 18,000 and 20,000 a year. Some people believe that Michigan should establish a registry of these debilitating conditions, rather than merely extrapolating figures for Michigan from national statistics, in order to study and better understand where and how these injuries occur, whether they can be prevented, and how victims and their families can be helped to cope with the results of these kinds of injuries.

**CONTENT**

The bill would amend the Public Health Code to:

- Require the Department of Public Health to establish a registry to record cases of spinal cord and traumatic brain injuries that occur in the State.
- Require hospitals to report these cases, as well as information on the recognition, prevention, or control of these injuries.
- Provide for the confidentiality of these reports, and specify circumstances under which the reports could be released.
- Provide that the release of these reports, either voluntarily or as required by the Code, would not subject a person or agency furnishing the information to liability in a court action and would not be considered a willful betrayal of a professional secret or violate a confidential relationship.
- Create the Spinal Cord Injury and Traumatic Brain Injury Committee within the Department as a standing subcommittee of the Chronic Disease Advisory Committee and specify its responsibilities.
- Require the Legislature to appropriate "sufficient funds" to implement the registry and advisory committee.
- Specify that the bill's provisions on the registry, the committee, and funding would be repealed three years after the bill's effective date.

**Registry**

The Department would be required to establish a registry of spinal cord or traumatic brain injury cases, and information concerning these cases, that occur in the State. The information would have to be supplied to persons seeking to apply appropriate preventive and control measures. "Traumatic brain injury" would mean an "insult to the brain, not of a degenerative or congenital nature, that may produce a diminished or altered state of consciousness, and which results in impairment of cognitive abilities or physical functioning".

The Director would have to require by rule that hospitals report cases of these injuries and submit specified additional information on reported cases or control populations, as the Director considered necessary and appropriate for the recognition, prevention, or control of spinal cord and traumatic brain injury.

The bill specifies that it would not compel a person to submit to medical or Departmental examination or supervision.

**Confidentiality**

The Department would be required to maintain comprehensive records of all reports submitted pursuant to the bill. These reports would be confidential and could be released by the Department only upon written request of the person who was the subject of the report, or his or her guardian, executor, or attorney, or other person designated in writing by the person who was the subject of the report.

Reports and records or information contained in the reports also could be released by the Department to persons authorized by the Director to conduct research studies or to other persons with whom the Director entered into a contract for data collection, data maintenance, data storage, data retrieval, and quality control.

The Director would be required to promulgate rules to implement these provisions.

**Committee**

The Spinal Cord Injury and Traumatic Brain Injury Committee would be created in the Department as a standing subcommittee of the Chronic Disease Advisory Committee. Members would be appointed by the Director. The committee would consist of the following 16 members:

- Five health care professionals with expertise in areas of treatment, rehabilitation, and transportation of individuals with spinal cord or traumatic brain injuries, or both.

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- One person with a spinal cord injury and one person with a traumatic brain injury.
- Two public members who represented purchasers of health care services.
- One representative of a health care corporation that provides third-party reimbursement services or benefits.
- One representative of the Michigan Hospital Association.
- The Directors, or their designees, of the Departments of Social Services, Mental Health, and Public Health; the Michigan Rehabilitation Services within the Department of Education; and the Office of Health and Medical Affairs.

The committee would be required biennially to elect a chair and other officers as the committee considered appropriate and to meet at least quarterly at the call of the chair. Members would be reimbursed for necessary travel or other expenses, or both, pursuant to provisions in the Code.

#### Committee Responsibilities

The committee would be required to do all of the following:

- Determine the elements, scope, and quality of a spinal cord injury and traumatic brain injury registry and provide advice and expertise to the Department regarding research and other activities related to the prevention of spinal cord injury and traumatic brain injury and support for individuals suffering from these injuries, or both.
- Review compiled epidemiological data regarding spinal cord and traumatic brain injuries and recommend and advocate appropriate prevention and control measures.
- Provide interested parties with a comprehensive and annually updated list of health care providers and health facilities that specialize in treatment of spinal cord and traumatic brain injuries, and other appropriate services.
- Serve as an effective and visible advocate for individuals with spinal cord injuries or traumatic brain injuries, or both, in all governmental decisions.
- Report biennially to the Legislature on the committee's activities, and make that report available to the public.

MCL 333.2633 et al.

### **FISCAL IMPACT**

The cost to the Department of Public Health of developing and maintaining a registry in accordance with the provisions of Senate Bill 450 would be less than \$50,000 per year. The following assumptions were used to achieve this estimate:

- The average cost per report to the registry would be equivalent to the average cost per report to the existing cancer registry.
- The conditions to be reported to the registry would not include a primary diagnosis of concussion.
- The number of reports to the registry would be less than 8,000 annually.

The costs associated with the Spinal Cord Injury and Traumatic Brain Injury Committee proposed in the bill are indeterminate and would depend on the number of meetings of the committee; the distances each member of the committee would travel in order to attend committee meetings; and the extent to which existing Department efforts and information could be used by the committee to meet the reporting and advocacy obligations outlined in the bill.

### **ARGUMENTS**

#### ***Supporting Argument***

Currently, the Department of Public Health maintains registries on cancer and the effects of Agent Orange exposure and supports a kidney registry maintained by the University of Michigan. Registries usually are established to collect data on diseases and health conditions of sufficient importance to the public health that their occurrence must be reported to public health officials. Registries serve as sources of accurate information as to the source, duration, fatality, incidence and prevalence of the disease or condition. Currently, some private organizations and associations collect data on these injuries, but they contend that a number of cases go unreported. Spinal cord and traumatic brain injuries have an impact on the public health of the State because of the costs associated with treatment, the relatively young age of the victims, and the disabilities that result. A registry of these injuries would lead to a better understanding of the nature of these injuries and preventive measures that could be taken to reduce their impact on the public health.

#### ***Supporting Argument***

The costs of spinal cord and traumatic brain injuries in Michigan are borne by insurance carriers, workers' compensation, Medicaid, rehabilitation services, State Departments of Public Health, Mental Health, Education, and Social Services, as well as the victims and their families. Local school districts, hospitals, and State agencies need a sound basis of information on which to plan for programs and services. The bill would provide a base for developing incidence and prevalence data, allow studies of regions of the State where traumatic brain and spinal cord injuries occur most frequently, and aid in developing preventive and educational services to these areas.

#### ***Supporting Argument***

Disability that results from spinal cord or traumatic brain injuries imposes costs on the individual, his or her family, and society. Families of injured persons need to know what type of rehabilitation services and support groups are available. A large number of people with spinal cord and traumatic brain injuries are relatively young in age. Rehabilitation could help these people to lead long and productive lives. The bill would require that the Spinal Cord and Traumatic Brain Injury Committee provide interested parties with a comprehensive and annually updated list of health care providers and facilities that specialize in treatment of these injuries.

#### ***Opposing Argument***

It is not certain that establishing a registry on spinal cord and traumatic brain injuries is the most economical method to collect data on these injuries. Establishment and maintenance of a registry can be expensive. The costs and benefits of a registry should be weighed against the costs and benefits of alternative approaches, such as periodic surveys, before any registry is established. The Spinal Cord Injury and Traumatic Brain Injury Committee should be given the opportunity to explore the epidemiology of these kinds of injuries in a comprehensive manner and then decide whether a comprehensive registry, a more limited registry in combination with periodic surveys and better use of existing data sources, or other methods of gathering data would best address the objectives outlined in the bill.

**MORE**

***Opposing Argument***

There are numerous severely disabling conditions with effects that could be ameliorated with improved trend analysis, prevention planning, and treatment referral services. There are no registries proposed for such diseases as Lupus Erythematosus, Myasthenia Gravis, Multiple Sclerosis, Ileitis and Colitis. The estimated 125,000 persons in Michigan who suffer from such diseases have needs that are as great as those of persons covered by registries in place or proposed, and should not be ignored.

***Opposing Argument***

The bill is ambiguous in its provisions for maintaining the confidentiality of the records collected in the registry. The bill specifies that the reports would be confidential and could be released by the Department of Public Health only upon written request of the person who was subject of the report and by other specified individuals. Yet, the bill also would permit the reports, records, or information contained in the reports to be released to persons authorized by the Director of the Department to conduct research studies or to those persons who contracted for data collection, maintenance, storage, retrieval, and quality control. The version of the bill as passed by the Senate would not have permitted the release of a report or record whose subject could have been identified. It is not certain if the enrolled bill would ensure the confidentiality of the subject of the report or record.

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This analysis was prepared by nonpartisan Senate staff for use by the Senate in its deliberations and does not constitute an official statement of legislative intent.