



**House
Legislative
Analysis
Section**

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SPINAL CORD/BRAIN INJURY REGISTRY

**Senate Bill 450 (Substitute H-3)
First Analysis (3-29-88)**

**Sponsor: Senator Vernon J. Ehlers
House Committee: Appropriations
Senate Committee: Health Policy**

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THE APPARENT PROBLEM:

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 deaths in the 1-44 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. At present, the Department of Public Health can receive statistics on these patients by extrapolating figures for Michigan from national statistics. It can also receive data from the Hospital Discharge Data Base. This system, however, has limitations, primarily in the areas of accuracy and quality control. For example, a patient may be admitted to a hospital, operated on, and discharged. He or she may later be admitted again for corrective surgery, and discharged. However many times the patient was admitted to the hospital and then discharged, he or she would appear on the hospital's discharge data as a separate case, since the data base uses no personal identifiers. Some people believe that Michigan should establish a registry of these debilitating conditions, 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.

THE CONTENT OF THE BILL:

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, and to create an advisory committee within the department. The bill would:

- 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 as a standing subcommittee of the Chronic Disease Advisory Committee within the department, and specify its responsibilities.
- require the legislature to appropriate sufficient funds to implement the registry and the advisory committee.
- provide for these provisions to expire at the end of three years.

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 department had contracted for data collection, maintenance, storage, retrieval, and quality control. A report or record could not be released to a person authorized by the director if it allowed identification of the subject of the report.

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

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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.
- 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, Public Health; the Michigan Rehabilitation Services within the Department of Education; and the Office of Health and Medical Affairs.

The committee would be required biannually 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 the registry, and provide advice and expertise to the department to carry out its duties in establishing a registry.
- 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 biannually to the legislature on the committee's activities, and make that report available to the public.

MCL 333.2633 et al.

HOUSE COMMITTEE ACTION:

The House Appropriations Committee adopted a substitute which amended the bill as it passed the Senate. Its major provisions include requirements that the advisory committee be created in the Department of Public Health as a standing subcommittee of the Chronic Disease Advisory Committee; that the advisory committee determine the elements, scope, and quality of the registry, as well as providing advice and expertise to the department on research and other activities related to the prevention of spinal cord and traumatic brain injury, and support for patients; and that these provisions expire after three years. The committee also amended the bill to allow the department to release information to persons with whom the department had contracted for data collection, maintenance, storage, retrieval, and for quality control.

FISCAL IMPLICATIONS:

The House Fiscal Agency estimates that the fiscal implications of the bill to the state would be \$46,000, with the assumption that the department contract out the data

collection, maintenance, storage, quality control, and retrieval to the Southeast Michigan Spinal Cord Injury System (SEMISCIS). Of the \$46,000, \$26,000 would be incurred by the department itself for a half-time position and related costs to support the advisory committee, analyze the data and prepare reports, and \$20,000 would go to SEMISCIS, which currently receives a federal grant to operate a spinal cord injury registry for Southeastern Michigan. (3-21-88)

ARGUMENTS:

For:

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 so that the occurrence of these conditions 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. This bill would add two important categories to the existing registries. Further, by collecting data on spinal cord injuries and traumatic brain injuries, the state will be able to contribute more reliable data to national data systems and receive more reliable demographic, incidence and characteristic information from those sources.

For:

The costs of spinal cord and traumatic brain injuries in Michigan are borne by insurance carriers, workers' compensation, Medicaid, rehabilitation services, the 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 and allow studies of regions of the state where traumatic brain and spinal cord injuries occur most frequently. The state could then develop appropriate prevention strategies, target treatment and educational services, and enhance advocacy services for victims.

For:

Disability that results from spinal cord or traumatic brain injuries imposes costs on the individual, his or her family, and society. The cost of caring for a severely injured person, over their lifetime, could well exceed \$1 million. There can also be a major reduction in productivity of others who are less severely injured. Thus, if there is even a small reduction in these types of injuries, it may result in a savings to the state. By providing interested parties with a comprehensive and annually updated list of health care providers that specialize in treatment of these injuries, and acting as an advocate, in government decisions, for persons with these types of injuries, the provision of the bill would allow many to lead more productive lives.

For:

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

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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.

Against:

The legislation suggests creation of a registry for two purposes: 1) the identification of trends in spinal cord and traumatic brain injuries in order to design prevention programs; and 2) the identification of individuals with such injuries who may need to be targeted for specialized treatment and rehabilitation services. It is questionable whether a single registry is the most cost effective means of addressing both purposes. The subcommittee proposed in the legislation should be given the opportunity to explore the epidemiology of these kinds of injuries in a comprehensive way and then decide whether or not a comprehensive registry, a more limited registry in combination with periodic surveys and better use of existing data sources, or other methods of gathering the data will best address the objectives outlined by the legislation.

Against:

The bill is ambiguous in its provisions for maintaining the confidentiality of the records collected in the registry. While it states that "these reports shall be confidential," and "shall be released by the department only upon written request of the person who is the subject of the report," it also states that the information recorded in the registry "shall be supplied to persons seeking to apply appropriate preventive and control measures." Also, since an agency other than the Department of Public Health will be collecting the data, how can the department ensure the confidentiality of the maintenance of the data? Who will be liable if data is released inappropriately or illegally?

Response: Liability for breach of confidentiality would fall first on the contracting agency, the Southeastern Michigan Spinal Cord Injury System (SEMISCIS), whose protocol met the standards required for federal approval in order to receive a federal grant. SEMISCIS's first procedure is to assign a patient a case number. The information containing patient number and corresponding name is entered into the computer by one of two SEMISCIS research librarians. From that point on, the patient's name is blackened out on all information sheets used to enter research information on the patient. Only the two research librarians responsible for entering the initial data on the patient have access to the name. The agency would be liable for any breach of confidentiality by its employees.

POSITIONS:

A representative from the Michigan Hospital Association testified before the House Appropriations Committee in support of the bill, but expressed concern about hospital administrative problems and costs involved in ever-increasing requests for information associated with the many registry proposals made in recent months. Concern was also expressed over the future of the project in the next few years, since budget dollars are dwindling. (3-28-88)

Representatives from the Department of Public Health testified before the House Appropriations Committee in support of the bill. (3-28-88)

The Michigan Head Injury Alliance supports the bill. (3-28-88)

The Michigan Developmental Disabilities Council supports the bill. (3-28-88)

The Department of Education supports the bill. (3-28-88)

The Department of Social Services supports the bill. (3-28-88)

The Department of Mental Health has no position on the bill. (3-28-88)

The Department of Management and Budget (DMB) does not support the bill. In testimony before the House Appropriations Committee, the department's representative stated that DMB does support the creation of the Spinal Cord Injury and Traumatic Brain Injury Committee as a standing subcommittee of the Chronic Disease Advisory Committee, but does not support having a mandate to establish a registry prior to study of the issues by the proposed committee. (3-25-88)