

EXECUTIVE ORDER NO. EO 01 – 02

OREGON TASK FORCE ON BRAIN INJURY

The Center for Disease Control estimates that approximately 5.3 million Americans suffer from disabilities related to brain injury, a total exceeding that of each of the following: persistent mental illness, Alzheimer's, stroke, epilepsy, cerebral palsy or spinal cord injury.

The Health Division of the Oregon Department of Human Services analyzed hospital discharge data for the years 1997 and 1998 which identified 6,791 cases of persons hospitalized in Oregon for Traumatic Brain Injury (TBI). These data indicate that the largest number of brain injuries were caused by motor vehicle traffic crashes followed by falls. Oregon Trauma Registry data from the years 1995 and 1996 identified 5,598 persons admitted to hospitals for TBI. The annual average incidence rate of moderate and severe TBI, calculated using Oregon Hospital Discharge Index and the Oregon Trauma Registry data is 60-65 per 100,000.

As recently as 1970, approximately half of all persons suffering from TBI ultimately died as a result of their injuries. However, as a result of improved emergency response, quicker transport to trauma centers, and improved medical technology and techniques, as well as more prevalent use of safety equipment such as seat belts, child safety seats and air bags, that mortality rate has fallen to nearly 22%.

The resultant increase in persons living with TBI creates a need for long term care and rehabilitation that require a concentrated effort to better understand the nature of TBI. At present once patients are discharged from the hospital, there are very few service options to help address the variety of challenges these patients face. As a result, most TBI patients face a post-hospitalization landscape lacking in adequate support systems and viable care options. What makes the situation more difficult is that many individuals with TBI look outwardly normal, but still are significantly impaired in ways that affect their everyday functioning. In this sense, TBI is a "silent epidemic".

At present, available data regarding brain injuries in Oregon are very limited. They do not provide sufficient detail to enable targeting of additional TBI prevention measures or planning for post-hospital service care and service system needs based on functional outcome information. Consideration should be given to establishing a comprehensive TBI tracking system to collect data on incidence,

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patient demographics, nature of injury, cause of injury, injury locale, details on severity of injury, and functional outcomes. Such a system would make an important contribution to the prevention of brain injury and provide information to help improve the system of long-term support services to meet the needs of those who survive brain injury.

In Oregon, no State agency is charged with lead responsibility for programs to address the problems of persons with brain injury. This contrasts with the situation for persons who are developmentally disabled and persons with mental illness. Persons with brain injury and their families express frustration over the lack of services and the perceived fragmentation in delivery of services that do exist. Most of all, they express a desire for greater understanding and awareness of brain injury and its consequences on the part of agency staff, other professionals and the public generally. Overwhelmingly, they express the desire to work or participate in meaningful activity.

In an attempt to respond to the need for more services for persons with brain injury, the Oregon Department of Education in 1997 applied for and received a grant from the federal Bureau of Maternal and Child Health (MCH) of the Health Resources and Services Administration. Grant monies have been used to 1) create teams of experts on brain injury to support educators in Oregon school districts; 2) conduct training of survivors and families in self advocacy; and 3) to create an Oregon Brain Injury Resource Network (OBIRN) so that survivors and family members can call an 800 number or use the internet to obtain information about brain injury and referral to resources which may be able to help them. The grant project will end in August 2001, and with it an Advisory Council on Brain Injury formed to advise on the grant will disband.

Recognizing the need for greater attention to brain injury, 26 states have formally established brain injury advisory or coordinating councils, by executive order or legislation. These councils typically advise the Governor and legislature on the planning, coordination and development of services related to brain injury. They also promote the prevention of brain injury. Establishment of an advisory body on brain injury within the State government, whether by Executive Order or legislation, would be an important step toward creating greater awareness of brain injury as a major public health problem.

Approximately 12 states have established brain injury trust funds to provide services to persons with brain injury which were not being adequately funded from other sources. The source of funding in most cases has been surcharges on motor vehicle violations, and particularly drunk driving. Typically, utilization of trust

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fund monies is overseen by a board appointed by the governor. Most boards also have advisory functions in addition to their trust fund responsibilities.

The Brain Injury Association of Oregon has suggested that the State of Oregon establish such a TBI trust fund trust fund. An obvious issue related to the proposal is whether a state appropriation is to be made and the source of funding for such appropriation. Trust funds are also frequently authorized to seek and accept other private and public sources of funding. These issues, as well as the relationship of the suggested Brain Injury Advisory Council and the body which would oversee the trust fund should be examined by the Task Force.

THEREFORE, IT IS HEREBY ORDERED AND DIRECTED:

1. The Governor's Task Force on Traumatic Brain Injury is hereby created.
2. The Task Force shall consist of the following members, appointed by the Governor to serve indefinitely:
 - a. Two TBI survivors;
 - b. Two relatives of TBI survivors;
 - c. Two representatives of organizations which advocate for persons with brain injuries;
 - d. A representative from the insurance industry; and
 - e. Four representatives of the Oregon Department of Human Services, selected by that agency's Director, to include the following areas of expertise:
 - 1) Epidemiology, public health surveillance and injury prevention;
 - 2) Provision of social services to the disabled;
 - 3) Provision of vocational rehabilitation services; and
 - 4) Provision of mental health services and/or persons with developmental disabilities.

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- f. A representative of the Oregon Department of Education, selected by the Superintendent of Public Instruction;
 - g. two members of the Legislative Assembly or their designees; and
 - h. two medical professionals with experience in treating TBI.
3. The Task Force shall appoint a Chair and Vice-Chair by majority vote.
4. The Task Force shall:
 - a. Analyze and make recommendations regarding a coordinated state agency response to brain injury which focuses on the needs of persons with brain injury. This task should take special note of the results of input provided by brain injury survivors, family members and services providers during town meetings conducted jointly by the Department of Education and the Brain Injury Association of Oregon.
 - b. Explore sources of funding for a TBI Trust Fund to be used to provide support and assistance to survivors which will help them in their efforts to reclaim their lives, develop their abilities to function more independently and enable them to be integrated into and make their contribution to society.
 - c. Review the costs and benefits of establishing an Oregon TBI Registry and TBI Surveillance Program. The review shall include consideration of the experience of other states with similar programs.
 - d. Review and make recommendations regarding the establishment of a Brain Injury Advisory Council in order to advise the Governor and the Legislative Assembly on the needs of persons with brain injuries, and the coordination of the delivery of services to persons with brain injuries and their families.
 - e. Propose such legislation as may be necessary to implement the recommendations of the Task Force.

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- f. The Task Force may submit an interim report and recommendation on one or more of the preceding tasks if it determines it to be necessary or desirable.
- 5. Members of the Task Force are entitled to no compensation or reimbursement of expenses.

Done before me at Salem, Oregon this _____ day of April, 2001.

John A. Kitzhaber, M.D.
GOVERNOR

ATTEST:

Bill Bradbury
SECRETARY OF STATE