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ALZHEIMER'S PROGRAMS

House Bill 4562 (Substitute H-1) RECEIVED
Sponsor: Rep. Shirley Johnson

House Bill 4563 (Substitute H-1) MAY 05 1988
Sponsor: Rep. Victor C. Krause

House Bill 5159 (Substitute H-1)
Sponsor: Rep. Sharon Gire

Committee: Public Health
First Analysis (4-13-88)

THE APPARENT PROBLEM:

A special subcommittee in the House of Representatives, the Joint Subcommittee on Alzheimer's Disease and Related Disorders, composed of members of the standing committees on Public Health and Mental Health, has issued its recommendations for legislation aimed at dealing with problems associated with Alzheimer's and about 70 related dementing disorders. Public health officials describe Alzheimer's as a progressive, irreversible, neurologic disorder that produces in its victims confusion, personality change, impaired judgment, and an inability to complete thoughts, find words, and follow directions. Experts project that by 1990 about 118,000 older Michigan residents will have Alzheimer's, and nearly 100,000 more will suffer from related dementing disorders. Among the problems addressed by the subcommittee were the lack of access for patients and families to accurate diagnoses and appropriate multidisciplinary treatments; the need for more research opportunities and more brain tissue for use in research; and the difficulty of gathering information about the prevalence of dementing diseases and about the effectiveness of the health care system in meeting the needs of the affected population. The legislation produced by the subcommittee to deal with those problems is based on the comprehensive report issued by the 58-member Michigan Task Force on Alzheimer's Disease and Related Conditions in July of 1987 after a year-long study.

THE CONTENT OF THE BILL:

The bills would amend the Public Health Code to put in place programs directed toward problems associated with Alzheimer's disease and related disorders. House Bill 4562 would create a brain autopsy network and require the development of a subsidy program to help defray autopsy costs. House Bill 4563 would establish a registry to record cases of Alzheimer's disease and related disorders in the state. House Bill 5159 would require the development of a state plan for a network of regional, multidisciplinary diagnostic and assessment centers.

House Bill 4562

The bill would require the Department of Public Health to identify an Alzheimer's disease and related disorders autopsy network. The network would have to include individuals qualified to extract, preserve, transport, and examine tissue, and to prepare reports on the results of examinations, as well as individuals qualified to provide information about autopsies to families and obtain consent for brain autopsies. The department would have to identify one or more tissue repositories for the receipt and storage of tissue. Any participating tissue repository would have to allow equitable access to tissue to people performing

medical research and education and could collect a fee for use of tissue. A repository would have to report annually to the department on the collection and distribution of tissue and on the amount and use of fees collected.

The department would have to provide to physicians, hospitals, nursing homes, medical examiners, funeral directors, victims of Alzheimer's and related disorders and their family members, and other appropriate people written information describing the critical role that autopsies play in the diagnosis of and research into the causes, treatment, and cure of Alzheimer's disease and related disorders.

If a person diagnosed or identified as having Alzheimer's disease or a related disorder or a family representative of such a person requested an autopsy, a representative of the network would have to provide information about the costs, purposes, and benefits of an autopsy, and about the benefits of using the tissue for medical research and education. The network representative would also have to request that the affected person or family representative sign a written consent to the autopsy and a separate written consent to use of the tissue for research and education. The bill specifies that the authority of a family representative would be given first to the legal guardian of the affected person, then to his or her spouse, then to an adult child or children, then to a parent, and then to other family members.

Within one year after the bill's effective date, the department must develop and recommend to the legislature a subsidy program to help defray a portion of the cost of an autopsy to an affected individual or his or her family.

The department would have to adopt guidelines pursuant to the Administrative Procedures Act to administer the bill's provisions, and the Chronic Disease Advisory Committee would advise the department on the adoption of guidelines and oversee the implementation of the bill's provisions.

MCL 333.5525 et al.

House Bill 4563

The bill would require the Department of Public Health to establish a registry to record cases of Alzheimer's Disease and related disorders that occur in the state and to record information necessary and appropriate to conduct epidemiologic surveys. Physicians would be required to report each case of Alzheimer's or a related disorder they diagnosed to the department, and the department would be required to maintain comprehensive records of all reports, which would be subject to the confidentiality

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standards in the health code for medical research projects. Reporting of cases would have to begin the January 1st following the bill's effective date. Within two years after the effective date, the department would have to begin evaluating reports, and no later than 180 days later the first summary report of information would be due. Subsequent annual reports would be due no later than 180 days after the end of each year. The department director would be required to promulgate rules to provide for: the related disorders other than Alzheimer's to be reported; the quality and manner of reporting; the terms and conditions governing release of records disclosing the name and medical condition of a specific individual; the collection of information describing the characterization of the progression, symptoms, and behavior patterns of the relevant disorders. The department could contract for the collection and analysis of the epidemiologic data, as well as for related research.

The bill says that it would not compel an individual to submit to medical or department examination or supervision.

MCL 333.5501

House Bill 5159

The bill would require the development of a state plan for a network of regional, multidisciplinary diagnostic and assessment centers for individuals diagnosed or identified as having Alzheimer's disease or a related disorder. The plan would have to be completed and submitted to the governor and legislature within one year after the bill's effective date. The Department of Public Health would have to develop the plan in consultation with the Department of Social Services, the Department of Mental Health, the Office of Services to the Aging, and the Office of Health and Medical Affairs. In developing the plan, consideration would have to be given to locating centers so as to minimize transportation problems; operating centers in conjunction with existing related services and programs; making sure centers have the capacity to be reimbursed for the diagnostic and assessment process by third-party payers, including Medicare and Medicaid. Consideration would also have to be given to methods of payment for people without sufficient health insurance coverage and with a limited income who are not eligible for Medicaid.

MCL 333.5511

FISCAL IMPLICATIONS:

According to the special joint subcommittee's report, the total cost of the bills would be about \$100,000 through fiscal year 1988-89. The funding recommendations for the bills in fiscal year 1988-89 are as follows: House Bill 4562, \$10,500 to develop consensus plan; House Bill 4563, \$55,500 to develop one-year plan; House Bill 5159, \$29,500 to staff one-year plan (and \$5,746 in fiscal year 1987-88). All figures were recommendations of the Department of Public Health. (3-16-88)

ARGUMENTS:

For:

These three bills are all based on recommendations of a special task force that spent one year studying how best to organize and use the health care resources of the state to deal with the many problems associated with the growing number of Michigan residents afflicted with Alzheimer's and other dementing disorders. The bills were

developed by a special joint subcommittee in the House. In its final report issued in July, 1987, subtitled "Reducing Uncertainty", the task force said:

All that we know about the dementias has come from research using clinical observation, diagnostic tests, and postmortem examinations of the brain. If we are to learn enough to prevent or to cure the dementias, we must have greater activity in all those areas. One way to achieve this, while at the same time serving patients and their families, is to organize the existing health care facilities, agencies, and organizations in such a way that patient care, family support, teaching and research are all performed within the same system and reinforce one another.

The different components of the health care system which deal with dementia patients must become more organized and coordinated. Primary care physicians, regional hospitals, and sophisticated diagnostic centers should become linked in a consistent reliable way, so that patients throughout the state can receive a thorough diagnosis. The health care system should provide a multidisciplinary assessment of the needs of the dementia patient and the family, so that referrals to therapies, counseling, support groups, and support services are immediately available.

The bills are a step toward achieving those goals. One would create a statewide autopsy network to make autopsies more available and accessible to families of victims of dementia so that confirmations of diagnoses can be obtained. Brain tissue for research would also be more available and repositories of such tissue would be established for use in research and education. A proposal for future subsidization of autopsies would have to be developed. Another bill would mandate the development of a plan to create a network of comprehensive diagnostic and treatment centers. A third would establish a register to gather useful information about the incidence of dementing diseases to inform program planning and research.

Against:

While creating a brain autopsy network is important, many families need financial assistance if they are to make use of it. Autopsies, and the results of autopsies, can cost as much as \$1,000. For families already hard hit by the burdens of caring for members with dementia, this is a significant disincentive. A state subsidy would be a great help.

POSITIONS:

The Alzheimer's Disease and Related Disorders Association, Michigan Council, supports the bills. (3-13-88)