

LEGAL AND MEDICAL DEFINITIONS USED FOR DEMENTIA-RELATED CONDITIONS - BACKGROUND MEMORANDUM

Senate Concurrent Resolution No. 4027 (attached as an appendix), as passed, provided for a study of the need for dementia-related services, standards, and practices for caregivers and a review of the legal and medical definitions used for dementia-related conditions and the funding for programs and services for individuals with dementia. Testimony in support of Senate Concurrent Resolution No. 4027 indicated that because the number of individuals with Alzheimer's disease and related dementia in the state will continue to increase, there is a need to determine whether North Dakota has adequate services to provide care specifically designed for these individuals.

By Legislative Council directive, the scope of the study is limited to a review of the legal and medical definitions used for dementia-related conditions. The limit in the scope of the study was done in light of a grant that was awarded to the Aging Services Division of the Department of Human Services for the development of a new system for providing a funding rebalancing and single point of entry for the elderly and individuals with disabilities who are considering long-term home and community-based services and institutional care services. The department has awarded the contract for this project to the North Dakota Center for Persons with Disabilities at Minot State University. Additional information regarding this project is discussed later in this memorandum.

DEMENTIA

Dementia is not a specific disease. It is a descriptive term for a collection of symptoms that can be caused by a number of disorders that affect the brain. Individuals with dementia have significantly impaired intellectual functioning that interferes with normal activities and relationships. An individual may also lose the ability to solve problems and maintain emotional control and may experience personality changes and behavioral problems, such as agitation, delusions, and hallucinations. A diagnosis of dementia is made only if two or more brain functions--memory and language skills--are significantly impaired without loss of consciousness. Some of the diseases that can cause symptoms of dementia are Alzheimer's disease, vascular dementia, Lewy body dementia, frontotemporal dementia, Huntington's disease, and Creutzfeldt-Jakob disease. Physicians have identified other conditions that can cause dementia or dementia-like symptoms, including reactions to medications, metabolic problems and endocrine abnormalities, nutritional deficiencies, infections, poisoning, brain tumors, anoxia or hypoxia (conditions

in which the brain's oxygen supply is either reduced or cut off entirely), and heart and lung problems. In some circumstances, dementia may be temporary or is reversible. Some common causes of dementia that may be reversible include brain disease, such as tumors, subdural hematoma, and hydrocephalus; depression; negative drug interactions; drug overdose; alcohol abuse; malnutrition; heart disease; traumas that cause concussions or contusions; metabolic or endocrine disorders; infections; and environmental changes.

ALZHEIMER'S DISEASE AND RELATED DEMENTIA

Well-known diseases that cause dementia include Alzheimer's disease, multi-infarct dementia, Parkinson's disease, Huntington's disease, Creutzfeldt-Jakob disease, Pick's disease, and Lewy body dementia. Description of each of these diseases, as provided by the Alzheimer's Association, are as follows:

- **Alzheimer's disease** - Alzheimer's disease is the most common cause of dementia affecting as many as four million Americans. Alzheimer's disease is a degenerative disease that attacks the brain, begins gradually, and progresses at a variable rate. Alzheimer's disease results in impaired memory, thinking, and behavior and can last from 3 to 20 years from the time of onset of symptoms. Warning signs of Alzheimer's disease are memory loss that affects job/home skills, difficulty performing familiar tasks, problems finding the right words, disorientation as to time and place, poor or decreased judgment, difficulty with learning and abstract thinking, placing things in inappropriate places, changes in mood and personality, and marked loss of initiative. In the last stage of Alzheimer's disease, patients are unable to take care of themselves. Recent research has shown links between particular genes and Alzheimer's disease, but in about 90 percent of Alzheimer's disease cases, there is no clear genetic link. With the help of standardized diagnostic criteria, physicians can diagnose Alzheimer's disease with accuracy of 85 to 90 percent once symptoms occur. However, a definitive diagnosis of Alzheimer's disease is possible only through the examination of brain tissue at autopsy. The Alzheimer's Association has estimated that in 2000 there were 16,000

North Dakotans with Alzheimer's disease.

The association also estimated that the number will grow to 20,000 by 2025.

- **Multi-infarct dementia** - Multi-infarct dementia, or vascular dementia, is a deterioration of mental capacity caused by multiple strokes (infarcts) in the brain. These events may be described as ministrokes, where small blood vessels in the brain become blocked by blood clots, causing the destruction of brain tissue. These strokes may damage areas of the brain responsible for a specific function as well as produce general symptoms of dementia. As a result, multi-infarct dementia is sometimes misdiagnosed as Alzheimer's disease. Multi-infarct dementia is not reversible or curable, but detection of high blood pressure and other vascular risk factors can lead to a specific treatment that may modify multi-infarct dementia progression. Multi-infarct dementia is usually diagnosed through neurological examination and brain scanning techniques, such as a computerized tomography (CT) scan or magnetic resonance imaging (MRI).
- **Parkinson's disease** - Parkinson's disease is a progressive disorder of the central nervous system that affects over one million Americans. In Parkinson's disease certain brain cells deteriorate for reasons not yet known. These cells produce a substance called dopamine, which helps control muscle activity. Parkinson's disease is often characterized by tremors, stiffness in limbs and joints, speech difficulties, and difficulty initiating physical movement. Late in the course of the disease, some patients develop dementia, Alzheimer's, or some other dementia. Conversely, some Alzheimer's patients develop symptoms of Parkinson's. Medications such as levodopa, which converts dopamine inside the brain, and deprenyl, which prevents degeneration of dopamine-containing brain cells, are used to improve diminished or reduced motor symptoms in Parkinson's disease patients but do not correct the mental changes that occur.
- **Huntington's disease** - Huntington's disease is an inherited, degenerative brain disease that causes both physical and mental disabilities and usually begins in midlife. Early symptoms can vary from person to person but include involuntary movement of the limbs or facial muscles, difficulty concentrating, and depression. Other symptoms include personality change, memory disturbance, slurred speech, and impaired judgment. Children born to a person with Huntington's disease have a 50 percent chance of inheriting the gene that causes Huntington's disease. A genetic test is available to confirm a diagnosis of Huntington's disease and to identify carriers of the Huntington's disease gene. There is no treatment to stop the progression of Huntington's disease, but the movement disturbances and psychiatric symptoms can be treated with medication.
- **Creutzfeldt-Jakob disease** - Creutzfeldt-Jakob disease is a rare, fatal brain disorder that causes rapid, progressive dementia and other neuromuscular disturbances. Creutzfeldt-Jakob disease is caused by a transmissible agent. Research suggests that the agent differs significantly from viruses and other conventional agents. The disease can be inherited, but the majority of causes are not. Early symptoms of Creutzfeldt-Jakob disease include failing memory, changes in behavior, and lack of coordination. As the disease advances, usually very rapidly, mental deterioration becomes pronounced, involuntary movements appear, and the patient experiences severe difficulty with sight, muscular energy, and coordination. Like Alzheimer's disease, a definitive diagnosis of Creutzfeldt-Jakob disease can be obtained only through examination of brain tissue at autopsy.
- **Pick's disease** - Pick's disease, also known as frontotemporal dementia, is also a rare brain disorder, characterized by shrinkage of the tissues in the frontal and temporal lobes of the brain and by the presence of abnormal bodies--Pick's bodies--in the nerve cells of the affected areas of the brain. Pick's disease usually begins between the ages of 40 and 60. The symptoms are similar to Alzheimer's disease, with a loss of language abilities, skilled movement, and the ability to recognize objects or people. Initial diagnosis is based on family history, symptoms, tests, and ruling out other cause of dementia. A definitive diagnosis of Pick's disease is usually obtained at autopsy.
- **Lewy body dementia** - Lewy body dementia is an irreversible form of dementia associated with abnormal protein deposits in the brain called Lewy bodies. Symptoms of Lewy body dementia are similar to Alzheimer symptoms and include memory loss, confusion, and difficulty communicating. Hallucinations and paranoia also become apparent in the earlier stages of the disease and often last throughout the disease process. Although initial symptoms of Lewy body dementia may be mild, affected individuals eventually develop severe cognitive impairment. At this time, there is no treatment available for Lewy body dementia.

RECENT PROJECTS REGARDING ALZHEIMER'S DISEASE AND RELATED DEMENTIA

Department of Human Services Alzheimer's and Related Dementia Project

In 1997 the Legislative Assembly directed the Department of Human Services to establish pilot projects for Alzheimer's and related dementia populations in order to explore the financial and service viability of converting existing long-term care facility bed capacity to a specific service environment targeting the Alzheimer's and related dementia populations. During the 1997-98 interim, the department established a 14-bed pilot project with the Baptist Home of Kenmare.

The Department of Human Services monitored the program's costs and services. During the 1999-2000 interim, the Department of Human Services reported to the Budget Committee on Institutional Services that the Alzheimer's and related dementia pilot project accomplished the goals set forth in the original legislation and that the Baptist Home of Kenmare provided appropriate and adequate care to its residents with Alzheimer's and related dementia at a cost of \$15.05 per day less than services of a similar nature provided in a nursing facility. The department also reported that it had approved additional pilot projects, including Edgewood Vista in Bismarck, Edgewood Vista in Minot, and Exner's Basic Care, Inc., in Jamestown.

Senate Bill No. 2034 (1999) repealed North Dakota Century Code Section 50-06-14.4, which authorized the Alzheimer's and related dementia projects.

Alzheimer's Disease Demonstration Grants

The federal Alzheimer's Disease Demonstration Grants to States Program was established under Section 398 of the Public Health Service Act [Pub. L. 78-410], as amended by Public Law 101-157 and by Public Law 105-379, the Health Professions Education Partnerships Act of 1998. The program is administered by the Administration on Aging, an agency within the United States Department of Health and Human Services.

The program's mission is to expand the availability of diagnostic and support services for persons with Alzheimer's disease, their families, and their caregivers, as well as to improve the responsiveness of the home and community-based care system to persons with dementia. The program focuses on serving hard-to-reach and underserved individuals with Alzheimer's disease or related dementia. The program awarded demonstration grants to 38 state government agencies in fiscal year 2005, including the North Dakota

Department of Human Services through the Aging Services Division.

The grant awarded to the Department of Human Services is in the amount of \$261,150 per year for up to three years. The purpose of the North Dakota program is to increase dementia identification, treatment, and caregiver respite with a special focus on rural areas and American Indian reservations. Two medical systems will provide protocols, tools, and training to the medical community to facilitate assessment, treatment, and referral for enhanced respite services. The grant requires a 25 percent nonfederal match the first year, 35 percent the second year, and 45 percent the third year. The Dakota Medical Foundation has committed to providing a portion of the match for each of the three years of the project. The remainder of the match is required of the contractors who will be providing services funded by the grant. No state general funds are budgeted for the grant.

Real Choice Systems Change Grant Program

In September 2004 a grant was awarded to the Aging Services Division of the Department of Human Services. The purpose of the \$315,000 three-year grant is to provide a single point of access to long-term support and care services for the elderly and individuals with disabilities. The Department of Human Services has contracted with the North Dakota Center for Persons with Disabilities at Minot State University to conduct the project. The project, known as the Real Choice Systems Change Grant - Rebalancing Initiative, is working to develop a plan for rebalancing of funds between long-term care services and those services provided in home or community settings. The project is also looking at developing a new system for providing a single point of entry for services for elderly and individuals with disabilities who are considering long-term care and home and community-based services. The project involves bringing together representatives from public and private organizations that play a role or are interested in assuring that North Dakota elderly and persons with disabilities have options and access to the continuum of long-term care services in the state.

2005 LEGISLATION

Legislation enacted in 2005 which may affect the services provided for individuals with Alzheimer's disease or related dementia include:

- **House Bill No. 1190** related to the policy of determining further expansion of basic care facilities in the state. The bill stated the two circumstances under which basic beds may be added between August 1, 2005, and July 31, 2007, provided the process for transferring of basic care beds, and addressed requirements for basic care beds acquired by Indian tribes.

- **House Bill No. 1191** related to the policy of expansion of nursing facilities in the state. The bill retained one exception to limiting expansion of nursing facility beds, allowing a facility to revert a basic care bed to a nursing bed; allowed transfers of beds from one facility to another; provided a nursing bed that is converted to a basic care bed may be transferred as a basic care bed; however, that bed may not then be relicensed as a nursing bed; and addressed requirements for nursing beds acquired by Indian tribes.

SUGGESTED STUDY APPROACH

The committee, in its review of the legal and medical definitions used for dementia-related conditions, may want to consider the following approach:

- Receive information and testimony from the Department of Human Services regarding the Alzheimer's disease and related dementia demonstration grant project as well as other concerns regarding dementia conditions.

- Receive information and testimony from organizations such as the Minnesota-North Dakota Alzheimer's Association, North Dakota Long Term Care Association, and the North Dakota Protection and Advocacy Project regarding dementia issues that need to be addressed, including issues related to the legal and medical definitions for dementia-related conditions.
- Receive information from the North Dakota Center for Persons with Disabilities at Minot State University regarding the Real Choice Systems Change Grant Program and whether legislative changes are necessary to address issues relating to the legal and medical definitions of dementia.
- Develop recommendations and prepare legislation necessary to implement those recommendations.

ATTACH:1

**Fifty-ninth Legislative Assembly of North Dakota
In Regular Session Commencing Tuesday, January 4, 2005**

SENATE CONCURRENT RESOLUTION NO. 4027
(Senator Brown)
(Representative Kreidt)

A concurrent resolution directing the Legislative Council to study the need for dementia-related services, standards, and practices for caregivers and review the legal and medical definitions used for dementia-related conditions and the funding for programs and services for individuals with dementias.

WHEREAS, individuals with dementias need specialized services; and

WHEREAS, there are more than 16,000 individuals in North Dakota with dementias; and

WHEREAS, the training of caregivers needs to be at a high standard to protect these incapacitated individuals; and

WHEREAS, the need for specialized services for demented individuals is unknown and the need appears not to be met; and

WHEREAS, the needs of individuals with dementias may require specialized programs and services to increase their quality of life;

NOW, THEREFORE, BE IT RESOLVED BY THE SENATE OF NORTH DAKOTA, THE HOUSE OF REPRESENTATIVES CONCURRING THEREIN:

That the Legislative Council study the need for dementia-related services, standards, and practices for caregivers and review the legal and medical definitions used for dementia-related conditions and the funding for programs and services for individuals with dementias; and

BE IT FURTHER RESOLVED, that the Legislative Council report its findings and recommendations, together with any legislation required to implement the recommendations, to the Sixtieth Legislative Assembly.