

STUDY OF FAMILY CAREGIVER SUPPORTS AND SERVICES

Section 1 of 2015 House Bill No. 1279 ([appendix](#)) provides for a Legislative Management study of family caregiver supports and services. The study must identify policies, resources, and programs available for family caregivers and encourage additional innovative and creative means to support family caregivers so they are able to continue to provide in-home support for older adults. The study must include input from stakeholders, including representatives of hospitals, social and clinical providers, advocacy organizations, tribal governments, state and local agencies and institutions, and caregivers in this state. The committee may receive testimony on the needs of family caregivers, including designation of caregivers, training, respite services, medical leave policies, and delegation of tasks to non-medical aides. The study must include an inventory of the resources available to family caregivers and may make any recommendations for administrative actions to support family caregivers. The Legislative Management may contract for consulting and coordination of study services.

PREVIOUS LEGISLATIVE STUDIES 2007-08 Interim

Dementia-Related Services Study

During the 2007-08 interim, the Long-Term Care Committee studied dementia-related services. The committee learned, according to national estimates, North Dakota had 16,000 individuals diagnosed with dementia, including Alzheimer's, which is the most common form of dementia. By 2010 the number was expected to increase to 18,000. Approximately 10 percent of individuals diagnosed with Alzheimer's have early onset of the disease which is before age 65. The committee learned that about 50 percent of nursing home residents have some type of dementia. Thirty percent of the victims of abuse, neglect, self-neglect, and exploitation assisted by adult protective services have dementia.

The committee learned that in 2000, Medicare spent nearly three times as much, on average, for people with Alzheimer's and other dementias as for beneficiaries without dementias. Estimated nursing home and other costs for Alzheimer's and dementia patients for calendar year 2007 totaled \$104 million in North Dakota.

The committee learned 70 percent of individuals with Alzheimer's and other dementias live at home where they are cared for by family and friends. Information on caregivers and the economic value of caregiving by state in 2006 indicated the total annual economic value of caregivers in North Dakota was estimated at \$550 million and nationally it was \$350 billion.

The committee learned county social services are often unable to provide assistance to individuals with dementia because they exceed certain income levels or are below certain age requirements. In addition, some individuals choose not to seek assistance because of the perceived stigma attached to the disease.

The committee learned the primary reasons individuals with dementia enter skilled nursing facilities are caregiver exhaustion and lack of resources.

The committee recommended House Bill No. 1043 that:

- Directed the Department of Human Services to contract for a dementia care services program in each area of the state served by a regional human service center to provide personalized care consultation services, training, and education regarding dementia;
- Provided for a \$1.2 million general fund appropriation for the program; and
- Provided for a report to the Legislative Management regarding the outcomes of the program.

2009-10 Interim

Dementia-Related Services Report

During the 2009-10 interim, the Long-Term Care Committee received reports from the Department of Human Services and learned that the department entered a contract with the Alzheimer's Association Minnesota-North Dakota Chapter for provision of a dementia care services program in each area of the state served by a regional human service center. The association hired five regional care consultants to provide services in the state. The consultants were fully trained and have been networking with other agencies and organizations to coordinate efforts, develop referral processes, and assure that services were not duplicated. Preliminary outcomes included:

- The number of citizens completing intake into the program continued to grow each month.
- Services were being provided in all eight Department of Human Services regional service areas.

- An estimated 56 percent of those living with Alzheimer's disease remained in their own home.
- Families caring for the family member in their own home were those needing the greatest assistance.

PROGRAMS

Dementia Care Services Program

Dementia is the condition of an individual involving loss of memory and impairment of cognitive functions severe enough to interfere with the individual's daily life. During the 2007-08 interim, the Long-Term Care Committee studied the availability of and future need for dementia-related services and funding for programs for individuals with dementias. The committee determined that it is difficult to access dementia-related services for individuals under the age of 60 and assistance with legal-related services is generally available to older individuals but may not be available to those under age 65. The committee recommended and the Legislative Assembly approved 2009 House Bill No. 1043, which appropriated \$1.2 million from the general fund and directed the Department of Human Services to contract with a private provider for a dementia care services program in each human service region.

The Department of Human Services Division of Aging Services - Dementia Care Services Program is a state funded program that provides care consultation and training to caregivers to address the unique and individual needs that arise throughout the various stages of dementia. Eligibility is not based on diagnosis, age, or income and anyone may participate in educational sessions on dementia. The program includes the following:

- Identifying available services within the region.
- Providing information to medical professionals, law enforcement, and the public regarding the symptoms of dementia, the benefits of early detection and treatment, and the services available to individuals with dementia and their caregivers.
- Assessing the needs of individuals with dementia and their caregivers.
- Training care providers to manage and provide for the care of individuals with dementia.
- Providing consultation services to individuals with dementia and their caregivers.
- Facilitating the referral of individuals with dementia and their caregivers to appropriate care and support services.

Family Caregiver Supports and Services

The Department of Human Services Division of Aging Services receives federal funds under the federal Older Americans Act to provide support and services to caregivers in the state. The North Dakota Family Caregiver Support Program is designed to provide training, supportive services, and respite care to caregivers who provide unpaid care on a 24-hour basis to enable an older adult to remain in their own home. The program also assists grandparents or relative caregivers who are caring for a child age 18 or younger or an adult child with a disability.

The program provides a system of support services to unpaid caregivers including the following:

- Individuals who are caring for an adult age 60 or older.
- Grandparents or other relative caregivers who are 55 years of age or older and who are caring for a child age 18 or younger.
- Grandparents or other relative caregivers who are 55 years of age or older caring for an adult child with a disability between age 19 and 59.
- Individuals who are caring for a person with Alzheimer's or a related dementia regardless of their age.

In addition, the program enables caregivers to continue to provide care in their homes and community for as long as they choose, and to provide support and services that safeguard the caregiver's own health and emotional well-being, which includes the following support and services:

- Information about local services and supports in the community.
- Assistance from a trained caregiver coordinator from a human service center to help caregivers assess needs and access support services.
- Counseling, support groups, and training services to meet caregiver individual needs for assistance.
- Respite care for temporary relief to caregivers who provide 24-hour care.

- Supplemental services to assist with the cost of incontinence supplies and assistive devices such as a shower bench or safety rails.

During fiscal year 2013, 285 unpaid caregivers received 24,856 respite care hours of service. A survey conducted during the fall of 2014 revealed that the respite care program helps keep older adults at home an average of 24 months longer than they could have without the support. In addition, caregivers report that the program assists a caregiver with coping with the challenges of providing 24-hour care in their homes.

FUNDING

Dementia Care Services Program

The 2015 Legislative Assembly provided funding as follows for programs and services relating to the dementia care services program:

	General Fund	Other Funds	Total
Department of Human Services			
Division of Aging Services	\$1,200,000	\$0	\$1,200,000
Human service centers	0	0	0
Total Department of Human Services	\$1,200,000	\$0	\$1,200,000

Family Caregiver Supports and Services

The 2015 Legislative Assembly provided funding as follows for programs and services relating to family caregiver and support services:

	General Fund	Other Funds	Total
Department of Human Services			
Division of Aging Services	\$0	\$1,048,424	\$1,048,424
Human service centers	274,072	513,505	787,577
Total Department of Human Services	\$274,072	\$1,561,929	\$1,836,001

PROPOSED STUDY PLAN

The following is a proposed study plan for the committee's consideration:

1. Receive information from the Department of Human Services regarding family caregiver support and services policies, resources, and programs available for family caregivers.
2. Receive testimony from stakeholders, including representatives of hospitals, social and clinical providers, advocacy organizations, tribal government, state and local agencies and institutions, and caregivers in this state.
3. Consider hiring a consultant to assist with the study.
4. Receive comments by interested persons regarding the study of family caregiver supports and services.
5. Develop recommendations and any bill drafts necessary to implement the recommendations.
6. Prepare a final report for submission to the Legislative Management.

ATTACH:1