
Iowa Legislative Fiscal Bureau

Dennis Prouty
(515) 281-5279
FAX 281-8451



State Capitol
Des Moines, IA 50319
September 15, 1992

Alzheimer's Disease and Related Disorders

ISSUE

An examination of how Alzheimer's Disease and related disorders impact the citizens of the State of Iowa regarding caregiving and nursing home placement

AFFECTED AGENCIES

Department of Elder Affairs (DEA)

Department of Human Services (DHS)

Department of Inspection and Appeals (DIA)

CODE AUTHORITY

Chapter 249D, Code of Iowa

BACKGROUND

The Governor's Task Force on Alzheimer's Disease and Related Disorders in 1989 predicted that by the year 2010 the cost to care for 30,000 to 47,000 Alzheimer's victims would be \$2.0 to \$3.0 billion annually. The Alzheimer's Disease and Related Disorders Association (ADRDA), Inc. in 1991 stated that approximately 10% of all persons over the age of 65 and approximately 47% of persons over 85 are afflicted with Alzheimer's Disease. In Iowa there are currently approximately 40,000 Alzheimer's Disease victims.

Usually, the first symptom is memory loss. As the disease progresses, the victim may begin to have difficulty making decisions, handling finances, grooming, or dressing. Next, social situations become more difficult. Finally, the victim will become totally incapacitated and require 24 hour custodial care usually in a nursing home.

However, while there is a significant number of individuals with Alzheimer's Disease and related disorders, the main thesis of this review is not the victim, but the impact on the caregivers of Alzheimer's Disease patients and ultimately placement in a nursing home. The most common caregiver is the victim's family. The major problem associated with caregiving is the fact that Alzheimer's Disease and other dementia are not predictable. A family does not know whether the disease will last 1 or 20 years. There is no cure with death being the only release.

CURRENT SITUATION

Caring for a victim of Alzheimer's Disease at home can cost a family up to \$22,000 per year. Current programs to finance health care do little to lessen the financial burden of caring for victims. Prescription drugs, respite services, adult day care, and nursing home care are not covered by Medicare or by most private health insurance companies. Therefore, families have a choice: being physically and emotionally exhausted by providing all needed care directly or having a large financial burden by paying others for care, if available.

Approximately 70% of all care of Alzheimer's Disease victims is given by the families. This care may be supplemented by social and health care services. Services such as homemaker/home health, chore services, companion care, respite care, home-delivered meals, and transportation are examples of services provided to assist caregivers in the home. Adult day care, 24 hour respite care, and emergency respite care are all out-of-home services that may be necessary to help the caregivers of dementia victims.

One study conducted by the American Association of Retired Persons stated that approximately 33% of caregivers are employed. Often the responsibilities of the caregivers conflict with job responsibilities. Even with daytime care for the victim, the employed caregiver needs time off from work for such things as taking the victim to medical appointments or to apply for benefits. This affects a caregiver's sick leave, vacation time, time without pay, and leaves of absence. Sometimes the caregiver has to leave employment to care for the victim.

Care of the Alzheimer's Disease victim typically continues at home until the health of the caregiver is threatened. The behavior of the person with Alzheimer's Disease often becomes unmanageable and the family may not be able to continue to care for the victim. Usually a medical complication occurs which, in conjunction with dementia, requires nursing care and the victim can no longer be maintained at home.

Dementia is the major cause of nursing admissions. One national study estimates that 65% of nursing home residents meet clinical and mental status criteria for dementia and 55% of all deceased nursing home patients were found to have Alzheimer's Disease. The cost of nursing home care for an Alzheimer's Disease victim is estimated to be \$50,000 per year. Currently in Iowa the DIA has licensed 654 beds for individuals with Alzheimer's Disease or related disorders.

Studies have shown that it takes, on the average, 13 months of nursing home care to deplete a family's savings and assets. At that point Medicaid subsidizes care. Therefore, the longer a person with Alzheimer's Disease or related disorder can stay at home, the less Medicaid support will be required for the victim's care.

ALTERNATIVES

The following are 4 alternatives which the Legislature may wish to examine.

1. Earlier placement of the Alzheimer's Disease victim. If the family caregiver is being drained physically, emotionally, and financially due to caring for the victim, then earlier placement in an institution is an alternative.
2. Development of more beds in special Alzheimer's Disease units with training for specialized unit staff.
3. Seek additional funds from other public sources and the private sector. However, it needs to be noted that the constituency of the Alzheimer's Disease network is caregivers and professionals who are not likely contributors.

4. Enhancement of service coordination. The DEA has in place a Case Management Program. Enhancing this Program would provide elders with Alzheimer's Disease a more comprehensive approach to accessing services.

BUDGET IMPACT

The Legislature appropriated \$68,933 in FY 1992 and a like amount for FY 1993 to the DEA for the support of Alzheimer's Disease victims and families. These funds are awarded to the 5 State chapters of the ADRDA. During FY 1992, there were 117 active Alzheimer's Disease support groups in 77 counties throughout Iowa and 6 counties with in-home visitation programs. Every county has an initial contact person. The 5 chapters had 5,197 inquiries and made 898 referrals to other agencies in FY 1992. The chapters also made 717 educational presentations with 17,242 attendees, including 4,926 family members of Alzheimer's Disease victims.

The main programmatic components of the 5 ADRDA chapters are support, education, and training. As more in-home services become dementia capable and as more respite services for Alzheimer's Disease victims and families become available, the victim will be able to stay at home longer. As a result, shorter nursing stays would occur and, therefore, less Medicaid funding would be necessary through DHS.

Increased funds for in-home services such as homemaker-home health aide, chore, respite, public health nurses, case management, adult day care, and emergency and institutional respite will enable Alzheimer's Disease victims and the family caregivers to delay nursing home placement. Such a delay has the potential of providing the more desired family caregiving and saving money by providing access to a full range of services.

STAFF CONTACT: Bob Snyder (Ext. 14614)