BACKGROUND PAPER 89-2

ALZHEIMER'S DISEASE

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Research Division
Legislative Counsel Bureau
# Alzheimer's Disease

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ALZHEIMER'S DISEASE

I

BACKGROUND

Alzheimer's disease is a degenerative neurological disorder, characterized by ever-increasing dementia (deteriorating mentality) that can strike even middle-aged adults. The disease knows no economic or social boundaries and affects men and women almost equally. It is a disease that has only been recognized in the last few decades as a distinct illness but has been with us for centuries. In the past, it commonly was referred to as acute senility.

Between three and four million people in the United States now have Alzheimer's disease, more than double the estimated number of people who are believed to be carrying acquired immune deficiency syndrome (AIDS) antibodies. The Alzheimer's case load is expected to spiral upwards as the population in America ages. While those 60 years and younger have very little chance of developing Alzheimer's, the risk increases to one-in-three for those who are in their 80's. Almost half of the patients now in continuous-care facilities are Alzheimer's victims.

In 1983, the cost of Alzheimer's disease was approximately $38 billion per year—current costs are estimated at $80 billion a year and are expected to reach a staggering $160 billion by the year 2000. The two diseases are similar in effect: both are terminal, but with Alzheimer's, the victims lose the use of their minds long before their bodies cease to function properly. Both are slow, progressive diseases, but Alzheimer's is slower, usually stretching costly care over 5 or 10 years, compared to less than 2 years for AIDS. Both place a tremendous burden on care givers as the patients become less and less able to care for themselves.

According to the United States Congress' Office of Technology Assessment, the number of persons with Alzheimer's is expected to reach seven million within a
50-year period. In America, Alzheimer's disease causes over 150,000 deaths annually and is the fourth leading cause of death in adults, after heart disease, cancer and stroke.

Over the past 2 years, researchers have developed several potential diagnostic tests for Alzheimer's, including neurological examinations, psychological tests and special X-ray procedures. One drug, tetrahydroaminoacridine (THA), is undergoing clinical trials, but shows early promise in reducing some of the symptoms of the disease. There is still no cure for Alzheimer's disease.

II

FEDERAL ACTIVITIES

A. Federal Statutes

In 1986, the U.S. Congress enacted Public Law 99-660 which included the Alzheimer's Disease and Related Dementias Services Research Act. This law established the Council on Alzheimer's Disease within the U.S. Department of Health and Human Services, an advisory panel on Alzheimer's Disease; a new group of awards for achievement in research to be bestowed by the National Institute of Aging (NIA); and an information clearinghouse to disseminate data concerning Alzheimer's disease--also administered by the NIA.

The act authorizes various federal research programs and mandates educational programs for Medicare regarding disability policies relating to dementia.

The Alzheimer's Disease and Related Dementias Service Research Act of 1986, and Title 42, Section 285e-2, of the United States Code Annotated, 1988, "Alzheimer's Disease Centers," are the only current federal statutes specific to Alzheimer's. Alzheimer's is occasionally referenced within other federal statutes concerning a broader group of persons, such as the elderly, or the disabled.

Specific federal research funds currently available are discussed in part V of this report.
B. Proposed Legislation

In 1988, by a vote of 169 to 243, the U.S. House of Representatives rejected a measure (H.R. 3436) that would have extended Medicare home health coverage to millions of Americans who suffer from Alzheimer's or other chronic illnesses or disabilities. However, key House leaders pledged to take up the issue in 1989.

According to the Alzheimer's Disease and Related Disease Association, Inc. (ADRSA), there are 24 bills pending before the current Congress (two new bills and 22 carry-overs from the previous session) which would affect Alzheimer's patients or their families. (See Appendix A.)

In addition, U.S. Representative Edward R. Roybal introduced a bill on March 20, 1989, that would increase funding for Alzheimer's research from the present $120 million to $500 million annually by 1992.

III

PROGRAMS AND ACTIVITIES IN OTHER STATES

Until the Federal Government alters the Medicare program, the states have been left to fill the gaps in the provision and financing of specialized services for victims of Alzheimer's. Much of the pressure for these programs has come from families, agencies and providers struggling to cope with difficulties in caring for patients with the disease.

A few states have funded joint research and service programs geared to Alzheimer's, patterned after a 1985 Illinois statute--now a model act of The Council of State Governments (See Appendix B, "Alzheimer's Disease Assistance Act).

In recognition of the actual and potential impact upon a state's health care delivery system, Arizona, California, Colorado, Indiana and New Hampshire have established Alzheimer's disease task forces or made changes to existing ones to study the problem. Many of these groups are expected to report recommendations to their respective legislatures for action during 1989 legislative sessions.
The majority of those caring for individuals afflicted with the disease are family members, and there are few, if any, reimbursement mechanisms for the expenses they incur. Recently, concern has focused upon the emotional support required by these family care givers.

A. Service Programs

As of 1987, at least 12 states were reported to have created distinct service programs geared to Alzheimer's disease patients and their families: California, Connecticut, Delaware, Florida, Illinois, Indiana, Kentucky, Massachusetts, New Jersey, New York, Ohio and Virginia. Three others--Hawaii, Maryland and Wisconsin--have required existing community-based service programs to be extended to Alzheimer's patients.

Most of the services fall into one of the following categories: adult day care, specialized diagnostic and treatment centers, respite for family care givers, and other home- and community-based services.

In addition, in 1988 Maryland revised eligibility requirements to include those with Alzheimer's in adult day care services. In recognition of the different service requirements of nursing home residents with dementia, Missouri added 45 classroom hours to training requirements for nursing assistants hired to work in nursing homes. The hours must include instruction on the handling of Alzheimer's patients and those with mental disorders.

B. Respite Care Programs

Several states have approved legislation within the last year addressing the need for respite care and other support services. Delaware, Maine, Oregon and Washington have expanded their community support programs to include services for persons caring for individuals with dementia. The State of Texas has established a special council to provide such services, and New Jersey has established a "statewide respite program" to provide this type of support on an emergency or intermittent basis. Virginia is developing a clearinghouse for identifying victims of dementia and is developing support systems to help delay or deter institutionalization.
C. Public Information Activities by Other States

Appropriations of money also have been made by some states to disseminate information concerning Alzheimer's disease. The listing which follows was obtained from the January 1987 issue of Advocacy Update by the Alzheimer's Disease and Related Disorders Association, and from the 1987 Health Care Legislation by David Landes of the National Conference of State Legislatures. The following states have allocated funds for the purpose of public information:

1. Kansas - Kansas Session Laws of 1986 (S.B. 690) authorizes the Kansas Department on Aging to establish an information and referral service on Alzheimer's disease;

2. Texas - The 1987 Texas General Laws (SCR 85), encourages banking, insurance and legal communities to provide public information on the value of estate planning for victims of Alzheimer's disease;

3. Wisconsin - The 1985 Wisconsin Laws (AB 29) authorizes the ADRDA-Greater Milwaukee Chapter to establish a statewide clearinghouse. The Wisconsin Alzheimer's Information Center provides training and technical assistance, develops training curricula, and coordinates public awareness activities statewide;

4. The 1987 Wisconsin laws, chapter 27 (S.B. 100), authorizes the department of health and social services to provide outreach and other activities to develop public awareness of Alzheimer's disease.

For an overview of all legislative activity by the states in 1987, see Appendix C, "'Alzheimer's Disease,' 1987 Health Care Legislation." Various other funded programs are discussed in the following section of this report.

IV

FUNDING FOR RESEARCH AND SERVICES

Neither Medicare nor most private insurance plans cover the costs of long-term care. Therefore, families usually have
no choice but to "spend down" to exhaust existing resources in order to qualify for state Medicaid assistance. A 1986 study by the U.S. Congress found that elderly persons living alone will, on the average, exhaust their resources after 13 weeks in a nursing home. More than half of these elderly couples, will become impoverished if one spouse is in a nursing home for more than 6 months.

Other than state Medicaid and one federal Medicare pilot program, funding for services for Alzheimer's disease patients takes the form of either state appropriations for special programs or grants. On the other hand, the Federal Government appears to be funding the majority of the research activity concerning Alzheimer's.

A. Federal Activities

According to an article in Newsweek (March 6, 1989), the Federal Government now devotes $120 million annually to Alzheimer's research. Until 1987, the Federal Government's principal activities in dealing with Alzheimer's disease have been to support biomedical and clinical research and to assist in the creation of specialized diagnosis and treatment centers. However, the 99th Congress directed the Health Care Financing Administration to conduct a demonstration program designed to determine the effectiveness and impact on health status of providing a comprehensive care approach to Medicare beneficiaries afflicted with Alzheimer's.

This program represents the first attempt by the Federal Government to link Alzheimer's care to Medicare, rather than the more limited grant programs or funding provided through state Medicaid programs. An evaluation of this demonstration project, expected in 1991, will help Congress decide whether to include additional services--particularly community-based care--under the Medicare program. Until that time, however, the Federal Government's activities center primarily upon biomedical and health services research.

1. Biomedical Research

Biomedical research includes basic biological, clinical and public health research. Clinical research applies basic scientific techniques to search for effective treatments,
methods of diagnosis, and preventative measures. Public health research uses both basic and clinical research and applies it to specific population groups.

Alzheimer's disease cannot be prevented, nor may its symptoms be reversed with current knowledge and techniques. It is hoped that research activities will lead to effective treatments for the disease.

Federal support for biomedical research (excluding health services delivery) has gone from less than $4 million in 1976 to over $65 million for 1987 (see Table No. 1 on page 8). Appendix D, titled "National Institute of Aging Research Centers," lists those research facilities devoted primarily to biomedical research on Alzheimer's disease.

2. Health Services Research

Health services research is the multidisciplinary study of those with dementia and of the systems that serve them. It is estimated that federal spending in health services research related to Alzheimer's ranged from $1.3 million to $2 million in 1986. This level of research corresponds to about 1/200th of 1 percent of the estimated national cost of this illness. It also represents about 3 percent of the biomedical research being conducted on Alzheimer's and other severe dementias.

There are many federal grants available for Alzheimer's research related to health services. The more significant of these include:

- **Persistent Viral Infections-Alzheimer's Disease Research Grants from the National Institutes of Health.**
- **NINCDS Alzheimer's Disease Diagnosis Research Grants by the National Institute of Allergy and Infectious Diseases.**
- **Family Stress and the Care of Alzheimer's Disease Victims Research Grants from the National Institute of Mental Health.**
- **Alzheimer's Disease and Other Related Dementias of Aging Research Grants.**
Table 1  Federal Funding for Research on Dementia, 1976-87 (thousand dollars)

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<td>50,779</td>
<td>57,280</td>
<td>54,697</td>
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<sup>a</sup>NIA (National Institute on Aging); NINCDS (National Institute on Neurological and Communicative Disorders and Stroke); NIMH (National Institute of Mental Health);
<sup>b</sup>NIAID (National Institute on Allergy and Infectious Diseases); DRR (Division of Research Resources, National Institutes of Health); AOA (Administration on Aging), and HCFA (Health Care Financing Administration).
<sup>c</sup>All agencies are in the U.S. Department of Health and Human Services.
<sup>d</sup>Appropriated by Congress in Public Law 99-178.
<sup>e</sup>Estimates following sequestration of funding under the Deficit Reduction Act of 1985.
<sup>f</sup>Estimates based on Continuing Resolution appropriations for Fiscal Year 1987 (P.L. 99-500), with individual figures taken from agency budget offices and direct appropriations.


B. State Activities

The bulk of state funding for Alzheimer's has been in the provision of direct services, either through Medicaid or for special programs. Although state Medicaid eligibility requirements vary from state to state, most Alzheimer's victims become eligible to receive Medicaid reimbursement for long-term care after all financial resources have been exhausted.

Eligibility criteria for state-financed programs for long-term care can often determine whether and to what extent Alzheimer's patients may receive services. Several states have enacted legislation specifically prohibiting discrimination against Alzheimer's patients by providers of state supported adult day care, respite services and other long-term care programs. Many states have expanded existing programs or made provisions for "special needs" patients. However, some states have funded either research or service programs specifically for Alzheimer's patients.

1. Research

Several states have been active in funding research activities with regard to Alzheimer's disease. Missouri's legislature designated $200,000 last year for research projects focusing of the cause, diagnosis, management and provision of care and services relevant to the disease. In Ohio, the legislature appropriated $258,000 for a pilot project establishing a Alzheimer's research and service center.

2. Direct Services

There has also been some funding activities on the part of states for direct services. The State of New Jersey has appropriated $95,000 to establish a training program for health care providers of Alzheimer's patients in nursing homes.
New York added $300,000 to its state budget to allow permanent centers created in 1987 to perform diagnosis, assessment, case management and referral for Alzheimer's patients, plus another $300,000 to support local initiatives. North Carolina earmarked $850,000 for a new Alzheimer's disease facility.

C. Private Sector Activities

In the private sector, there are currently 168 entries concerning Alzheimer's research in the computerized database, "Foundation Grants." The following are available or have become available recently:

- Dementia care and respite services program - this grant will support 19 nonprofit day centers nationwide in providing affordable care for adults with an illness related to dementia, including Alzheimer's disease, and in providing respite for their family care givers ($4.45 million over 4 years funded by the Robert Wood Johnson Foundation, plus $1.25 million over 4 years cofunded by ADRDA and the U.S. Administration on Aging).

- Ralph M. Parsons Foundation/ADRDA Research Grants.

- Allied Corporation/ADRDA Faculty Scholar Awards.

- ADRDA Research Grants.

A list of potential grant sources may be found in Appendix E titled, "Government and Private Source Grants for Alzheimer's Disease Projects."

V

HEALTH INSURANCE ISSUES

Alzheimer's disease has been one of the driving forces in state efforts to encourage the availability of private long-term care insurance. The provision of such insurance has been seen as a method to spread the financial costs of long-term care across a wider pool of contributors. While most families are the primary providers of care during the early
stages of Alzheimer's, nearly all eventually turn to nursing home care for the final years of the disease's progress. Such care may be required for several years.

A. Classification of Alzheimer's Disease

One difficulty with Alzheimer's disease is the lack of uniform agreement as to its medical (and hence insurance-based) classification. The current edition of the International Classification of Diseases (ICD-9-CM), which is used to code diagnoses for billing and other purposes, classifies Alzheimer's in two different sections—290.10, under "Mental Disorders", and in 331.0 under "Other Cerebral Degeneration".

According to the report by the U.S. Congress' Office of Technology Assessment, disorders causing dementia lie on the border between traditional conceptions of mental disorders and organic diseases. Concepts of mental disorders are based upon observed behavior, whereas concepts of organic disease tend to focus on conditions where a distinct physical disability can be identified. There has always been a broad ill-defined gray zone between mental disorder and organic disease.

The dual nature of Alzheimer's disease is also reflected in the diagnosis and treatment of persons with the disease and other dementing disorders. Alzheimer's patients will often be treated by a neurologist, a psychiatrist or both. Due to the dual nature of the disease, it may be difficult to legislate a definition of the disease for the purpose of requiring insurance coverage.

B. Coverage Restrictions

Many insurance entities have inserted exclusions for conditions classified as mental disorders from coverage in their health insurance policies. This would effectively exclude those persons from the services required without liquidation of assets—the so-called "spend down"—to be eligible for a state's Medicaid program. This process shifts the financing burden from the private sector to the states.
C. Public Policy Options

Many states have recognized the shift promoted by insurers and have responded with legislation. While most of the state's activities have involved either regulation of long-term care insurance or mandating mental health benefits, other related activities have taken place recently. In 1988, Colorado revised its state requirements for long-term care insurance by requiring that those policies which cover institutional care also provide home care without any prerequisite hospital or nursing home care. California also amended its statutes concerning long-term care insurance to require mandatory coverage of Alzheimer's disease and other degenerative, dementing illnesses.

Recently, many states have sought to use private insurance as a mechanism to help provide for long-term care. By the beginning of 1988, over 21 states had adopted the Long-Term Care Insurance Model Act (see Appendix G) and its companion model regulation, from the National Association of Insurance Commissioners (NAIC). For those states that have adopted the models, long-term care policies are prohibited from excluding Alzheimer's from the conditions of coverage, and cancellation of the policy on the grounds of deteriorating mental or physical health is prohibited.

For the most part, increased mental health coverage in private insurance over the last decade has been largely the result of state mandated benefits. Approximately 27 states have mandated that health insurance sold in-state include mental health and mental disorders benefit coverage. Many of these state legislatures believe that adequate mental health coverage would relieve some of the demand for public services.

The major opponents of mandated coverage have been the insurance industry and employers. Both argue that added benefits increase costs and stifle competition. Some critics of mandated benefits claim that such laws discourage employers (especially small employers) from providing any insurance benefits for their employees, thereby increasing the ranks of the uninsured. Many states are now requiring a cost-benefit analysis for any mandated insurance benefit.
Of the 27 states mandating mental health benefits in private insurance policies, 14 have mandatory coverage statutes that require insurers to pay for mental health care in certain types of policies. Of these 14 states, five require this coverage for individual policies as well as for group policies. The remaining states require that insurance policies offer mental health coverage at the policyholder's option. Three states—Connecticut, Maryland and Virginia—have both mandatory and optional provisions (see Figure No. 1).

Figure 1

States with Mandated Private Mental Health Insurance Benefits

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States that mandate mental health insurance
States that require insurance policies to offer mental health coverage at the policyholder's option
States with mandatory and optional provisions
States have increased insurance coverage for Alzheimer's using two basic methods:

1. Mandating that all private insurance sold within a state include mental health benefits;

2. Requiring that long-term care insurance sold within a state cover Alzheimer's disease.

An additional option might be to require all health policies sold within a state to cover Alzheimer's disease and related dementing disorders.

VI

PROGRAMS AND ACTIVITIES IN NEVADA

Activities concerning Alzheimer's disease have been limited in Nevada, although the increasing average age of Nevadans is expected to bring the issue into sharper focus over the next few decades.

A. Nevada Statistics

Since Alzheimer's disease can be diagnosed only upon autopsy, it is difficult to determine the precise number of active cases within Nevada. However, an estimate for the state can be made based upon national projections. According to the 1987 study by the U.S. Congress' Office of Technology Assessment, 5 to 7 percent of the American population over the age of 65 years is afflicted with the disease. The study uses 6.5 percent as the median for its estimates.

Using the 6.5 percent figure, and based upon Nevada population estimates, there are approximately 7,400 persons in Nevada currently afflicted with Alzheimer's disease. Using projected population data, that number will grow to about 13,700 by the year 2000.

As with most states, the majority of the funding for Nevada's citizens with Alzheimer's comes from families, then through Nevada Medicaid once assets are exhausted. In 1987, the Nevada legislature enacted Assembly Bill 456
(chapter 434, Statutes of Nevada, 1987, which allowed the
division of assets to prevent the impoverishment of the
spouse of an Alzheimer's victim for Medicaid eligibility.

B. Facilities with Special Services

State facilities in Nevada do not offer special services for
Alzheimer's patients. People diagnosed as having
Alzheimer's disease do not qualify for admission to a mental
health facility, so they are placed in private nursing
homes. Wards of the state who have Alzheimer's also are not
admitted to mental health facilities.

Currently, there are three nursing homes in the state that
offer special services for Alzheimer's patients. Following
is a discussion of these facilities and their services.

Sierra Convalescent Center in Carson City (telephone:
883-3622) opened a separate locked unit for Alzheimer's
patients in 1986. Recently expanded to a 46-bed capacity,
the Alzheimer's section currently houses 38 patients. This
unit offers a higher ratio of care delivery than the rest of
the facility and an activity director is specifically
assigned to the unit. Some respite care is also available.

Opened in August of 1988, Manor Care in Reno (telephone:
829-7220) maintains a separate wing under a full-time
manager for Alzheimer's patients. The wing has a 30-bed
capacity and currently houses 15 patients. An activities
director manages 9 hours per day of structured programs for
the residents of this wing. These programs, distinct from
the activities programs in the rest of the facility, seek to
keep the patients functioning at the highest level possible.
The wing also has a higher ratio of care delivery than the
other units.

Cosada Delmar in Las Vegas (telephone: 361-6111) opened its
Alzheimer's unit on February 8, 1989. This section of the
nursing home is secured and structured--emphasizing a home­
like atmosphere--and is self-contained (dining and
recreational areas are separate from the rest of the
facility). The Alzheimer's program is directed by a
physician consultant and includes a full-time activities
director. The unit has a higher ratio of care delivery than
the rest of the facility and can house 22 patients; 18 were scheduled to arrive when it opened.

C. Research Activities

There is little research activity concerning Alzheimer's within the State of Nevada. John Peacock, M.D., of the school of medicine at the University of Nevada-Reno, is conducting one research project as part of a 5-year $750,000 grant from the Veterans Administration. The project concerns transplantation of fetal brain tissue of mice to other mice with an Alzheimer's-like condition. He has also received $20,000 per year over the last 6 years from the Robert Hawkins Foundation for his research.

D. Private Sector Activity

The Alzheimer's Disease and Related Disorders Association maintains two chapters within Nevada. Their addresses are:

ADRDA - Northern Nevada Chapter
4280 Truckee River Trail
Reno, Nevada 89523
Telephone: 702-786-8061

ADRDA - Southern Nevada Chapter
913 East Ogden Avenue
Las Vegas, Nevada 89101
Telephone: 702-366-0899

The northern chapter includes 12 counties, and the southern chapter includes the remaining five counties. Although both chapters serve primarily a support role for Alzheimer's families, the northern Nevada chapter is funding a limited program of respite care for some of its members. Both groups operate using membership fees and donations. Nevada's office of community services (through Clark County's Economic Opportunity Board) recently provided a one-time grant of $6,000 to the southern chapter for operating expenses.

E. Insurance Issues

The State of Nevada does not mandate that all health insurance policies (either individual or group policies)
sold within the state cover mental health disorders. According to staff of the Nevada’s insurance division in the department of commerce, some group and individual policies within the state do exclude mental disorders, thereby conceivably excluding Alzheimer's.

However, the insurance division has recently adopted the NAIC's "Long-Term Care Insurance Model Regulation" which prohibits the exclusion of Alzheimer's from this type of health insurance policy. The model act is being incorporated into the Nevada Administrative Code under chapter 687B titled "Contracts of Insurance." Other options could be pursued to extend coverage to additional Alzheimer's patients (see "Policy Options" in the previous section for a discussion of insurance coverage options).

VII

CONCLUDING REMARKS

At the national level, serious legislative efforts with regard to the problems posed by Alzheimer's disease began around 1986. The current focus in Congress concerns long-term care issues, and the possibility of extending some Medicare home health coverage to some Alzheimer's patients. In addition, should Congress address the overall question of federal funding for long-term care, many of the financial difficulties faced by Alzheimer's victims and their families could be solved.

Much of the activity concerning Alzheimer's disease research is taking place at the federal level, although some states have funded research projects from general revenues. Approximately 97 percent of the federal funds available for Alzheimer's programs are for biomedical research; the remaining 3 percent is directed toward health services research.

For the most part, states are providing funds for direct services, either indirectly through state Medicaid, or for programs designed specifically for Alzheimer's patients. Many states have begun to focus upon revision of eligibility requirements, to allow Alzheimer's patients to participate in long-term care programs; specialized diagnostic treatment
centers; public information initiatives; and respite care programs for family care givers. Various grants are available to states from federal and private sources for research programs and direct services.

Long-term care insurance has been proposed as one solution to providing care for Alzheimer's patients. Many states have adopted the NAIC's model legislation which effectively requires the inclusion of Alzheimer's as a condition to be covered by long-term care policies. Other states have, in effect, mandated coverage of Alzheimer's by requiring health insurance policies (mostly group policies) to include coverage for mental health conditions. In states without such a mandate (including Nevada), many insurers exclude mental disorders from coverage. Since medical science treats Alzheimer's as both an organic problem and as a mental condition, it may be difficult to legislate a definition of the disease for the purpose of requiring insurance coverage.

In Nevada, approximately 7,400 persons currently suffer from the disease. The state itself does not provide a direct service program specifically for Alzheimer's patients, although several private nursing homes have set up specialized units. Most of the treatment occurs through the state Medicaid program. Although Nevada has not adopted the NAIC model act, its insurance division has recently adopted the NAIC's model regulations which require coverage for Alzheimer's disease under any long-term care policy sold within the state.

From the broad perspective, it appears that there are various initiatives at the federal level which have the potential for addressing direct care problems for Alzheimer's patients. However, it appears likely that the states will continue to be both the innovators and the primary source of financing in the direct care arena for some time to come.
SELECTED REFERENCES


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APPENDIX A

Listing of Bills Pending Before The 101st Session of the United States Congress as compiled by the Alzheimer's Disease and Related Disease Association, Inc.
Provide that a demonstration project be conducted to determine the feasibility and desirability of providing benefits and benefits relating to certain social and longterm health services under the Federal employees health benefits program.

STATUS:
1/03/89 INTRODUCED. To HOUSE Committee on POST OFFICE AND CIVIL SERVICE

Improve the provision of services under the Medicare and Medicaid Program to individuals with Alzheimer's disease or related disorders and to amend the Public Health Service Act to provide assistance for education, research, and treatment programs relating to such disease and disorders.

STATUS:
3/16/88 INTRODUCED. To SENATE Committee on LABOR AND HUMAN RESOURCES.

Requires the Director of the National Institute on Aging to provide for the conduct of clinical trials on the efficacy of the use of tetrahydroaminoacridine in the treatment of Alzheimer's disease.

STATUS:
4/09/87 INTRODUCED. To SENATE Committee on LABOR AND HUMAN RESOURCES.
US S 818

AUTHOR: Matsenbaum

TOPIC: HEALTH AND SOCIAL SERVICES

SUBTOPIC: DISEASES- OTHER

SUMMARY:
Amends the Older Americans Act of 1965 to establish the Alzheimer's Disease and related dementias home and community based services block grant.

STATUS:
1/06/87 INTRODUCED. To SENATE Committee on LABOR AND HUMAN RESOURCES.

US H 3130

AUTHOR: Roybal Waxman

TOPIC: HEALTH AND SOCIAL SERVICES

SUBTOPIC: HEALTHCARE FINANCING

SUMMARY:
Improves the provision of services under the medicare and medicaid programs to individuals with Alzheimer's disease or related disorders and to amend the Public Health Service Act to provide assistance for education, research, and treatment programs relating to such disease and disorders.

STATUS:
8/06/87 INTRODUCED. Jointly to HOUSE Committees on ENERGY AND COMMERCE and WAYS AND MEANS.

US H 397

AUTHOR: Pepper

TOPIC: HEALTH AND SOCIAL SERVICES

SUBTOPIC: DISEASES- OTHER

SUMMARY:
Provides for the designation of 10 regional centers for the treatment of Alzheimer's disease and related dementia.

STATUS:
1/07/87 INTRODUCED. Jointly to HOUSE Com. on WAYS AND MEANS, to HOUSE Com. on ENERGY AND COMMERCE, and HOUSE Com. on EDUCATION & LABOR.
US H 2075  
**AUTHOR:** Snowe, Biaggi  
**TOPIC:** HEALTH AND SOCIAL SERVICES  
**SUBTOPIC:** SOCIAL SERVICES

**SUMMARY:**  
Amends the Older Americans Act to require area agencies on aging to coordinate their services with the activities of community-based organizations established for the benefit of victims of Alzheimer's disease and their families.

**STATUS:**  
4/09/87 INTRODUCED. To HOUSE Committee on EDUCATION AND LABOR.

US H 2979  
**AUTHOR:** Snowe, et al  
**TOPIC:** TAXATION  
**SUBTOPIC:** PERSONAL TAXES

**SUMMARY:**  
Amends the Internal Revenue Code to allow a deduction from gross income for home care and adult day and respite care expenses of individual taxpayers with respect to a dependent of the taxpayer who suffers from Alzheimer's disease or related organic brain disorders.

**STATUS:**  
7/21/87 INTRODUCED. To HOUSE Committee on WAYS AND MEANS.

US H 388  
**AUTHOR:** Solomon  
**TOPIC:** FINANCIAL INSTITUTIONS  
**SUBTOPIC:** COMMERCIAL BANKS AND BANKING

**SUMMARY:**  
Provides for the establishment of and limited deduction of contributions to long-term care savings accounts.

**STATUS:**  
1/04/89 INTRODUCED. To HOUSE Committee on WAYS AND MEANS.
US H 158

AUTHOR: Gallo

TOPIC: HEALTH AND SOCIAL SERVICES

SUBTOPIC: HEALTHCARE FINANCING

SUMMARY:
Amends Social Security Act. Permits State coverage of persons requiring extensive home care under a home-or-community-based waiver, and related provisions.

US H 550

AUTHOR: Panetta et al

TOPIC: HEALTH AND SOCIAL SERVICES

SUBTOPIC: HEALTHCARE FINANCING

SUMMARY:
Amends the Social Security Act to provide for coverage of adult day care under the Medicare Program.

STATUS:
1/08/87 INTRODUCED. Jointly to HOUSE Committee on WAYS AND MEANS and to HOUSE Committee on ENERGY AND COMMERCE.

US H 407

AUTHOR: Roe

TOPIC: HEALTH AND SOCIAL SERVICES

SUBTOPIC: SOCIAL SERVICES

SUMMARY:
Establishes within the Department of Health and Human Services a Home Health Clearinghouse to provide elderly persons with a single place where they can obtain complete information on the Federal home health programs available to them.

STATUS:
1/07/87 INTRODUCED. To HOUSE Committee on ENERGY AND COMMERCE.

1/07/87 INTRODUCED. To HOUSE Committee on ENERGY AND COMMERCE.
US H 616  
**AUTHOR:** Gilmour  
**TOPIC:** HEALTH AND SOCIAL SERVICES  
**SUBTOPIC:** SOCIAL SERVICES  

**SUMMARY:**  
Amends the Internal Revenue Code to allow a credit against tax for expenses incurred in the care of elderly veterans.  

**STATUS:**  
1/20/87 INTRODUCED. To HOUSE Committee on WAYS AND MEANS.  

US H 1626  
**AUTHOR:** Rinaldo  
**TOPIC:** HEALTH AND SOCIAL SERVICES  
**SUBTOPIC:** MEDICAL SPECIALTIES AND SERVICES  

**SUMMARY:**  
Establishes a program to make grants to States to provide home health services to older individuals.  

**STATUS:**  
3/16/87 INTRODUCED. To HOUSE Committee on EDUCATION AND LABOR.  

US H 200  
**AUTHOR:** Roybal  
**TOPIC:** HEALTH AND SOCIAL SERVICES  
**SUBTOPIC:** HEALTH- MISC  

**SUMMARY:**  
Amends the Social Security Act. Establishes a U.S. health program to insure access for all Americans to quality health care while containing the costs of the health care system.  

**STATUS:**  
1/07/87 INTRODUCED. To HOUSE Committees on WAYS AND MEANS and ENERGY AND COMMERCE.  

US H 65  
**AUTHOR:** Pepper  
**TOPIC:** HEALTH AND SOCIAL SERVICES  
**SUBTOPIC:** SOCIAL SERVICES  

**SUMMARY:**  
Amends title XVIII of the Social Security Act to provide for a part C program to furnish comprehensive catastrophic and preventive benefits through prepaid plans.  

**STATUS:**  
1/06/87 INTRODUCED. To HOUSE Committee on WAYS AND MEANS and Committee on ENERGY AND COMMERCE.
SUMMARY:
Amends the Internal Revenue Code to allow a deduction from gross income for home care and adult day and respite care expenses of individual taxpayers with respect to a dependent of the taxpayer who suffers from Alzheimer's disease or related organic brain disorders.

STATS:
7/21/87 INTRODUCED. To HOUSE Committee on WAYS AND MEANS.

SUMMARY:
Improves the provision of services under the Medicare and Medicaid programs to individuals with Alzheimer's disease or related disorders and to amend the Public Health Service Act to provide assistance for education, research, and treatment programs relating to such disease and disorders.

STATS:
8/06/87 INTRODUCED. Jointly to HOUSE Committees on ENERGY AND COMMERCE and WAYS AND MEANS.

SUMMARY:
Amends the Social Security Act to protect the welfare of spouses of institutionalized individuals under the Medicaid Program.

STATS:
2/26/87 INTRODUCED. To SENATE Committee on FINANCE.

SUMMARY:
Amends the Social Security Act. Provides that in case of an institutionalized spouse, income and resources required under court order to be used for the support of a non-institutionalized spouse are not considered to be available to the institutionalized spouse.

STATS:
3/18/87 INTRODUCED. To SENATE Committee on FINANCE.
SUBTOPIC: MEDICAL SPECIALTIES AND SERVICES

SUMMARY:
Establishes a quality assurance system for homecare services provided under Medicare and Medicaid programs, the Social Services Block Grant Program, and the Older Americans Act of 1965.

STATUS:
3/18/87 INTRODUCED. To HOUSE Committee on WAYS AND MEANS.

US H 631

AUTHOR: Conte
TOPIC: TAXATION
SUBTOPIC: PERSONAL TAXES

SUMMARY:
Amends the Internal Revenue Code to allow a credit against income tax for expenses incurred in the care of certain elderly family members.

STATUS:
1/21/87 INTRODUCED. To HOUSE Committee on WAYS AND MEANS.

US S 454

AUTHOR: Sasser
TOPIC: HEALTH AND SOCIAL SERVICES
SUBTOPIC: SOCIAL SERVICES

SUMMARY:
Amends the Social Security Act to provide for part C program to furnish comprehensive catastrophic and preventive benefits through prepaid plans.

STATUS:
2/04/87 INTRODUCED. To SENATE Committee on FINANCE.

US S 997

AUTHOR: Pell
TOPIC: HEALTH AND SOCIAL SERVICES
SUBTOPIC: HEALTH- MISC

SUMMARY:
Requires the Director of the National Institute on Aging to provide for the conduct of clinical trials on the efficacy of the use of tetrahydroaminoacridine in the treatment of Alzheimer's disease.

STATUS:
4/09/87 INTRODUCED. To SENATE Committee on LABOR AND HUMAN RESOURCES.
Alzheimer's Disease Assistance Act

Growing concern over Alzheimer's disease, and other related medical conditions which destroy certain vital brain cells, has prompted many states to explore the need for legislation addressing the problems associated with these disorders and services for the victims and their families.

According to the Intergovernmental Health Policy Project, by mid-1987, six states (Indiana, Maryland, Nevada, New Jersey, New Hampshire and Virginia) had enacted legislation specifically addressing the disease. Prior to 1987, at least 24 states had established a state-level task force or study commission to examine problems stemming from the disease to assess the availability of services and to determine the need for new or modified programs.

At least 10 states had initiated service programs geared to Alzheimer's disease patients and families (California, Connecticut, Delaware, Florida, Illinois, Kentucky, Massachusetts, New Jersey, New York and Ohio). Other states (Hawaii, Maryland and Wisconsin) explicitly required existing community-based programs to extend services to these patients.

This act, based on 1985 Illinois legislation, establishes a program for the conduct of research regarding the cause, cure and treatment of Alzheimer's disease and related disorders, and through a statewide system of regional and community-based services, provides for the identification, evaluation, diagnosis, referral and treatment of victims. The act also requires that the state's department of public health prepare a state Alzheimer's Disease Assistance (ADA) plan every three years in consultation with the ADA advisory committee also established in the act.

For additional information on Alzheimer's disease legislation across the states, the reader may wish to consult the major national contacts in the area: the Intergovernmental Health Policy Project, 2011 Eye St., NW, Suite 200, Washington, DC 20006. 202/872-1445; Alzheimer's Disease and Related Disorders, 70 East Lake St., Suite 600, Chicago, IL 60601. 312-853-3060; the National Association of State Units on Aging, 600 Maryland Ave., SW, Suite 208, Washington, DC 20024. 202/484-7182.

Suggested Legislation

(Title, enacting clause, etc.)

1  Section 1. [Short Title.] This act may be cited as the Alzheimer's Disease Assistance Act.

1  Section 2. [Legislative Findings and Declaration.] The legislature finds that Alzheimer's disease and related disorders are devastating health conditions which destroy certain vital cells of the brain and which
affect an estimated [insert number] Americans. This means that approximately [insert number] citizens of [insert state name] are victims. The legislature also finds that [insert percentage] of all nursing home admissions in the state may be attributable to the Alzheimer's disease and related disorders and that these conditions are the fourth leading cause of death among the elderly. It is the opinion of the legislature that Alzheimer's disease and related disorders cause serious financial, social and emotional hardships on the victims and their families of such a major consequence that it is essential for the state to develop and implement policies, plans, programs and services to alleviate such hardships. The legislature recognizes that there is no known cause or cure for Alzheimer's disease at this time, and that it can progress over an extended period of time and to such a degree that the victim's deteriorated condition makes him or her susceptible to other medical disorders that generally prove fatal. It is the intent of the legislature, through implementation of the act, to establish a program for the conduct of research regarding the cause, cure and treatment for Alzheimer's disease and related disorders; and through the establishment of Regional Alzheimer's Disease Assistance Centers and community-based services, to provide for the identification, evaluation, diagnosis, referral and treatment of victims of such health problems.

Section 3. [Definitions.] As used in this act:

1. "Alzheimer's disease and related disorders" means a health condition resulting from significant destruction of brain tissue with resultant loss of brain function, including, but not limited to, progressive, degenerative and dementing illnesses including presenile and senile dementias, including Alzheimer's disease and other related disorders.

2. "Regional Alzheimer's Disease Assistance center" or "regional ADA center" means a postsecondary higher educational institution having a medical school in affiliation with a medical center, and designated as such by the [state department of public health] under Section 4 of this act.

3. "Primary Alzheimer's provider" means a licensed hospital, a medical center under the supervision of a physician licensed to practice medicine in all of its branches, or a medical center that provides medical consultation, evaluation, referral and treatment to persons who may be or who have been diagnosed as victims of Alzheimer's disease or related disorders pursuant to policies, standards, criteria and procedures adopted under an affiliation agreement with a regional ADA center under this act.

4. "Alzheimer's Disease Assistance network" or "ADA network" means the various health, mental health and social services agencies that provide referral, treatment and support services under standards and plans adopted and implemented in conjunction with a regional ADA center.

5. "ADA Advisory Committee" or "advisory committee" or "committee" means the Alzheimer's Disease advisory committee created under Section 6 of this act.

34
Section 4. [Development of Standards for a Service Network and Designation of Regional Centers and Primary Providers.] By [insert date], the [department], in consultation with the advisory committee, shall develop standards for the conduct of research and for the identification, evaluation, diagnosis, referral and treatment of victims of Alzheimer’s disease and related disorders and their families through the ADA network of designated regional centers and other providers of service under this act. Such standards shall include:

(1) A description of the specific populations and geographic areas to be served through ADA networks that may be established under this act;

(2) Standards, criteria and procedures for designation of regional ADA centers, which ensure the provision of quality care to a broad segment of the population through on-site facilities and services and through a network of primary Alzheimer’s providers and other providers of service that may be available within the service area defined by the [department]. The regional ADA centers shall provide at least the following:

(i) Comprehensive diagnosis and treatment facilities and services which have (A) professional medical staff specially trained in geriatric medicine, neurology, psychiatry and pharmacology, and the detection, diagnosis and treatment of Alzheimer’s disease and related disorders, (B) sufficient support staff who are trained as caregivers to victims of Alzheimer’s disease and related disorders, (C) appropriate and adequate equipment necessary for diagnosis and treatment, (D) transportation services necessary for outreach to the service area defined by the [department] and assuring access of patients to available services, and (E) such other support services, staff and equipment as may be required;

(ii) Consultation and referral services for victims and their families to ensure informed consent to treatment and to assist them in obtaining necessary assistance and support services through primary Alzheimer’s providers and various private and public agencies that may otherwise be available to provide services under this act;

(iii) Research programs and facilities to assist faculty and students in discovering the cause of and the diagnosis, cure and treatment for Alzheimer’s disease and related disorders;

(iv) Training, consultation and continuing education for caregivers, including families of those who are affected by Alzheimer’s disease and related disorders;

(v) Centralized data collection, processing and storage that will serve as a clearinghouse of information to assist victims, families and ADA resources, and to facilitate research; and

(vi) Programs of scientific and medical research in relation to Alzheimer’s disease and related disorders that are designed and conducted in a manner that may enable such center to qualify for federal financial participation in the cost of such programs.

(3) Procedures for recording and reporting research and treatment results by primary Alzheimer’s providers and other affiliated providers of service that are within the ADA network to the regional ADA center.
(4) Policies, procedures and minimum standards and criteria to be included in affiliation agreements between primary Alzheimer's providers and the regional ADA center in the conduct of any research and in the diagnosis, referral and treatment of victims of Alzheimer's disease and related disorders and their families; and

(5) Policies, procedures, standards and criteria, including medical and financial eligibility factors, governing admission and utilization of the programs, facilities and services available through the ADA network by persons who may be or who have been diagnosed as victims of Alzheimer's disease and related disorders, including forms and procedures for obtaining necessary patient consents to participation in research, and in the reporting and processing of appropriate information in a patient's medical records in relation to consultations, referrals and treatments by the various providers of service within the ADA network.

Section 5. [State ADA Plan.] By [insert date], and every [three] years thereafter, the [department] shall prepare a state Alzheimer's disease assistance plan in consultation with the advisory committee to guide research, diagnosis, referral and treatment services within each service area described by the [department]. Such plan shall indicate any research programs being conducted and the status, results, costs and funding sources of such programs. The plan shall also indicate the number of persons served, the extent of services provided, and the resources required for the delivery of services. Such plan shall identify and describe the duties and accomplishments of each regional ADA center, the primary Alzheimer's providers and other various providers of service within the ADA network of the described service area. The [department] shall consult with and take into consideration the plans of local and state comprehensive health planning agencies recognized under the [insert citation for state health planning statute, as applicable].
Section 6. [ADA Advisory Committee.] There is created the Alzheimer's disease advisory committee consisting of [21] voting members appointed by the [director] of the [department], as well as [five] nonvoting members as hereinafter provided in this section. The [director] or his designee shall serve as one of the [21] voting members and as the chairman of the committee. Those appointed as voting members shall include persons who are experienced in research and the delivery of services to victims and their families. Such members shall include [four] physicians licensed to practice medicine in all of its branches, [one] representative of a postsecondary educational institution which administers or is affiliated with a medical center in the state, [one] representative of a licensed hospital, [one] registered nurse, [one] representative of a long term-care facility, [one] representative of an area agency on aging, [one] social worker, [one] representative of an organization established under the [state insurance code] for the purpose of providing health insurance, [five] family members or representatives of victims of Alzheimer's disease and related disorders, and [four] members of the general public. Among the physician appointments shall be persons with specialties in the fields of neurology, family medicine, psychiatry and pharmacology. Among the general public members, at least [two] appointments shall include persons [65] years of age or older.

In addition to the [21] voting members, the [directors] or their designees of the following state agencies shall serve as nonvoting members: [department on aging], [department of mental health and developmental disabilities], [department of rehabilitation services], [department of public aid], and [guardianship and advocacy commission]. Each voting member appointed by the [director of public health] shall serve for a term of [two] years, and until his successor is appointed and qualified. Members of the committee shall not be compensated but shall be reimbursed for expenses actually incurred in the performance of their duties. No more than [11] voting members may be of the same political party. Vacancies shall be filled in the same manner as original appointments.

Section 7. [Regional ADA Center Grants-in-Aid.] Pursuant to appropriations enacted by the legislature, the [department] shall provide grants-in-aid to regional ADA centers for necessary research and for the development and maintenance of services for victims of Alzheimer's disease and related disorders and families in accordance with the state Alzheimer's assistance plan. The [department] shall promulgate rules and procedures governing the distribution and specific purposes for such grants, including any contributions of recipients of services toward the cost of care.
1987 HEALTH CARE LEGISLATION

By

David Landes

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ISBN 1-55516-678-4
Alzheimer's Disease

CA 1987 Cal. Stats., Chap. 945 (AB 1865) establishes the California Alzheimer's Disease and Related Disorders Research Fund and allows taxpayers to designate a specified amount in excess of their tax liability to be transferred to this fund; requires funds to be allocated to state departments for contracts or research grants relating to the care, treatment, and cure of Alzheimer's disease.

CA 1987 Cal. Stats., Chap. 1038 (SB 1166) prohibits all individual or group disability insurance group self-insured employee welfare benefit plans and non-profit hospital services plans that offer coverage for long-term care facility or in-home services from excluding benefits from persons with Alzheimer's disease or other related dementing illnesses.


IL 1987 Ill. Laws, P.A. 85-940 (SB 147) requires nurses' aides employed in nursing homes that admit persons with Alzheimer's disease or related disorders to complete 12 hours of in-house training in the care and treatment of these patients.

IN 1987 Ind. Acts, P.L. 40 (HEA 1012) requires the Department of Aging and Community Services to: develop training programs for persons who care for persons with Alzheimer's disease or related senile dementias, establish pilot programs for the provision of respite care and other supportive services for Alzheimer's disease and related senile dementia patients and their families, and administer a grant program for Alzheimer's disease and related senile dementia activities; establishes an 11-member Alzheimer's disease and related senile dementia task force.

MD 1987 Md. Laws, SJ 10 continues a coordinating council to advise the Interagency Committee on Services to the Aging on the review, coordination, formulation, and implementation of programs concerning Alzheimer's disease, related disorders, and other diseases and conditions afflicting the elderly; requires reports of findings and recommendations to be made to the Governor and General Assembly; requires a study of Alzheimer's disease as a psychiatric disorder.

MO 1987 Mo. Laws, p. 576 (SB 200) appropriates $200,000 to the Board of Curators of the University of Missouri for grants for original research in the area of Alzheimer's disease and related disorders; requires the Division of Aging to encourage development of services for persons having Alzheimer's disease and related disorders; authorizes the division to make one-year grants to entities sponsoring pilot projects that prevent or postpone admission to an institution, offer services tailored to the Alzheimer's and related disease groups, or offer temporary relief for family caregivers.

NV 1987 Nev. Stats., Chap. 431 (AB 437) requires the Board of Health to adopt separate regulations governing licensing and operation of adult day care centers and residential facilities that provide care to Alzheimer's disease victims.
NM 1987 N.H. Laws, Chap. 237 (HB 376) establishes a respite care program to relieve primary caretakers (family members or other persons) of the victims of Alzheimer's disease and related disorders.

NY 1987 N.Y. Laws, Chap. 586 (S 1475) establishes at least two geographically dispersed Alzheimer's Disease Assistance Centers to provide comprehensive and coordinated services to Alzheimer's disease victims and their families, including patient diagnosis and case management and training and education for caregivers and families of Alzheimer's disease victims.


OR 1987 Or. Laws, Chap. 692 (SB 827) provides that persons under 60 years of age with Alzheimer's disease or related disorders qualify for Oregon's Project Independence.

OR 1987 Or. Laws, Chap. 902 (HB 2238) provides a "checkoff" on Oregon income tax returns for contributions to the Alzheimer's Disease Research Fund and eliminates the checkoff if $50,000 or less is contributed in each of two consecutive years.

TX 1987 Tex. Laws, Chap. 74 (HB 420) directs the Department of Health to include training in the care of persons with Alzheimer's disease in their required employee orientation and training for certain personnel employed in nursing homes.

TX 1987 Tex. Gen. Laws, Chap. 114 (SB 1134) directs the Department of Health to establish an optional system to certify institutions that meet certain standards for the specialized care and treatment of persons with Alzheimer's disease.


TX 1987 Tex. Gen. Laws, (SCR 75), recognizes Alzheimer's disease as a physical disease rather than a mental disorder and encourages health service providers and reimbursement sources to do likewise.

TX 1987 Tex. Gen. Laws, (SCR 85) encourages the legal, banking, and insurance communities to provide public information on the value of estate planning for victims of Alzheimer's disease.

VA 1987 Va. Acts, Chap. 403 (S. 560) establishes a statewide Alzheimer's Disease and Related Disorders Registry to collect medical records, tissue samples, and other data on Alzheimer's disease victims as aid to scientific research; establishes an advisory committee; requires a contract with a medical school for quality assurance review of the registry's materials to ensure that they meet standards for medical research.

VA 1987 Va. Acts, Chap. 699 (H. 1250) creates a 18-member Alzheimer's Disease and Related Disorder Commission to advise the Department of Mental Health
and Mental Retardation in developing a plan for funding local initiatives for services to Alzheimer's disease victims and in developing funding priorities and evaluation criteria for such programs.

WI 1987 Wis. Laws, Chap. 27 (SB 100) authorizes the Department of Health and Social Services to provide outreach and other activities to develop public awareness of Alzheimer's disease.
Government Research Directory
FIFTH EDITION

A Descriptive Guide to Approximately 3,700 U.S. Government Research and Development Centers, Institutes, Laboratories, Bureaus, Test Facilities, Experiment Stations, Data Collection and Analysis Centers, and Grants Management and Research Coordinating Offices in Agriculture, Business, Education, Energy, Engineering, Environment, the Humanities, Medicine, Military Science, and Basic and Applied Sciences

Kay Gill and Susan E. Tufts, Editors

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National Institute on Aging

DEPARTMENT OF HEALTH AND HUMAN SERVICES
PUBLIC HEALTH SERVICE
NATIONAL INSTITUTES OF HEALTH
NATIONAL INSTITUTE ON AGING (NIA)
NIH Bldg. 31, Rm. SC35
900 Rockville Pike
Bethesda, MD 20892

Established: 1974

Established: 1974

Research Description: NIA conducts and supports research relating to the biomedical, social, and behavioral aspects of aging. The Intramural Research Program is primarily conducted at the Gerontology Research Center in Baltimore, MD. In addition, the Institute's Neurosciences Laboratory operates basic and clinical research programs from the NIH Clinical Center in Bethesda. The principal NIA extramural programs are the Behavioral and Social Research Program, Biomedical Research and Clinical Medicine Program, and Neurosciences and Neurophysiology of Aging Program. The extramural programs support studies on aging at universities, hospitals, medical centers, and nonprofit institutions throughout the United States, with funds made available through a variety of grants and contracts. The Institute also supports the training of scientists for research careers in aging. Other important NIA components are the Epidemiology, Demography, and Biometry Program and the Office of Extramural Affairs.

Publications and Information Services: Research results and activities are published in journals, as reports and proceedings, and in NIH publications. A list of publications is available by writing to the NIA Information Center, 2209 Distribution Circle, Silver Spring, MD 20910.

Remarks: NIA currently funds 10 Alzheimer's Disease Research Centers (ADRCs). The ADRCs studies range from the basic mechanisms of Alzheimer's Disease, to what can be done to treat it, and helping families to cope. The centers are located at Duke University, Durham, NC; Harvard Medical School/Massachusetts General Hospital, Boston, MA; Johns Hopkins Medical Institutions, Baltimore, MD; Mount Sinai School of Medicine/Bronx VA Medical Center (see separate entry); University of California—San Diego (see separate entry); University of Kentucky, Lexington, KY; University of Pittsburgh, Pittsburgh, PA; University of Southern California—Los Angeles, CA; University of Washington, Seattle, WA; and Washington University, St. Louis, MO. In addition, the NIA Teaching Nursing Home awards program supports research by academic medical centers and nursing homes on geriatric health problems in nursing homes and other clinical settings. Areas included in the program are diagnostic assessment of the geriatric patient, dementia, incontinence, falls, injuries, and musculoskeletal disorders producing functional disability in the geriatric population, among others.

ALZHEIMER'S DISEASE RESEARCH CENTER
Mail Code H-204
225 Dickinson St
San Diego, CA 92103

Established: 1984

Research Description: Center's research efforts focus on the clinical and cognitive changes associated with Alzheimer's disease and other dementing illnesses. Activities involve obtaining epidemiological data and medical histories, analyzing blood and sera, and administering
batteries of neuropsychological tests and neurological exams of patients. Center also conducts clinical drug testing and studies memory and language dysfunction, the possibility of a genetic or metabolic basis for Alzheimer’s disease, and the chronobiology of the disease.

Publications and Information Services: Research results are published in primary journals and as research reports. Center sponsors an annual conference on caring for Alzheimer’s disease victims for health care and legal professionals.

ALZHEIMER’S DISEASE RESEARCH CENTER (ADRC)
Mount Sinai School of Medicine
c/o Veterans Administration Medical Center
Psychiatry Service (116A)
Bronx, NY 10468
Kenneth L. Davis, Director
Phone: (212) 933-2121
FTS 663-1825
Established: 1984
Staff: 15 research professionals, 10 supporting professionals, 8 technicians, and 2 others.

Research Description: Center provides care facilities (administrative, autopsy, data management, recruitment and diagnosis, and neurochemistry) for clinical and pre-clinical studies relating to Alzheimer’s disease. Research includes investigations of new diagnostic tests, proposed drug treatments, possible animal models, neurochemical changes in the brain, and studies of genetic and other etiologic factors. Another important aspect of this work is the study of the natural course of aging in persons who do not have significant memory problems. In addition to research, the Center provides family support programs as well as clinical evaluations in which individuals are screened for diagnosis by the staff of the Center’s Memory Disorders Clinic. Services of the Memory Disorders Clinic and the ADRC are available to men and women (both veterans and nonveterans) over the age of 55 who have memory problems or cognitive difficulties. Professional services provided by the ADRC are generally free of charge.

Special Facilities: Clinical Research Center, animal laboratories, and a data processing group, all located at the Bronx VA Medical Center; and a gas chromatograph/mass spectrometry laboratory, located at Mount Sinai School of Medicine.

Publications and Information Services: Research results are published in primary journals. Monthly Research Meetings and weekly Journal Club meetings are held for ADRC staff. In addition, ADRC research is presented regularly at annual meetings of relevant professional societies.
APPENDIX E

Government and Private Source Grants for Alzheimer's Disease Projects, Dialog Computerized Database Retrieval dated March 1989

Ralph M. Parsons Foundation ADRAH Research Grants

There grants, partially funded by the Ralph M. Parsons Foundation and administered by ADRAH, are intended to bring new investigators into research on Alzheimer's disease and related disorders and to help established investigators develop new approaches to etiology, pathogenesis, treatment, management, and prevention. Awards are granted in the areas of epidemiology, molecular biology, cellular and molecular genetics, and caregiving. Four awards will be made, one in each of the areas of program interest, renewable for one additional year. Funds will be awarded to the investigator's administrative unit and are to be used toward the investigator's salary and other research expenses.

Maximum of $50,000 annually

PROFILE: PRIVATE

LIMITATION: Applicants with no other current funding for the proposed research are given priority.

DATE DUE: Jul 9 (RECEIPT OF PROPOSAL SATISFIES)
REFERENCE: Grants Administrator, (312) 853-3060
SOURCE: Alzheimer's Disease and Related Disorders Association, 340 N Michigan Ave., Chicago, IL 60601

KEY WORDS: Alzheimer's Disease; Geriatrics; Epidemiology; Cellular and Molecular Biology; Genetics

2/5/2 (Item 2 from file: 85)
0005788

Persistent Viral Infections-Alzheimer's Disease Research Grants--U.S.

The National Institute of Allergy and Infectious Diseases, the National Institute of Neurological and Communicative Disorders and Stroke and the National Institute on Aging made special emphasis for regular research grants on the subject of persistent viral infections possibly associated with or models for chronic human diseases such as Alzheimer's disease. The National Institute of Aging particularly supports research on infectious diseases that involve the aging process or that present problems for the aging and research to identify biological markers that are predictive of or diagnostic of specific chronic diseases such as Alzheimer's, for which a transmissible etiologic agent may be suspected, but not yet known.

$15,808-$1,275,0471 average grant $70,280

PROFILE: FEDERAL

DATE DUE: Feb 1, Jun 1, Oct 1 (RECEIPT OF PROPOSAL SATISFIES)
REFERENCE: Dr. Richard L. Smroka, Biomedical and Clinical Research, (301) 496-4096
SOURCE: National Institute on Aging, 5600 Fishers Lane, Rockville, MD
CATALOG OF FEDERAL DOMESTIC ASSISTANCE: PH-461 (13,866)
KEY WORDS: Alzheimer's Disease; Viral Infections; Geriatrics; Infectious Diseases/Agents
Persistent Viral Infections-Alzheimer's Disease Research Grants

The National Institute of Allergy and Infectious Diseases, the National Institute of Neurological and Communicative Disorders and Stroke, and the National Institute on Aging invite applications for new research grants on the subject of persistent viral infections. These genes may be associated with or models for chronic human diseases such as Alzheimer's disease. The programmatic interests of NIMCD include infectious diseases of neurological disorders with particular emphasis upon persistent infections of cells and tissues of the nervous system and the biology of viral neurotropism. Another goal of this research program is to identify biological markers that are predisposing to diagnostic of specific chronic diseases such as Alzheimer's disease. No strain of a transmissible etiological agent may be suspected but not yet known.

$120,000-$300,000; average grant $150,000

PROFILE: FEDERAL

LIMITATION: Universities, medical colleges, hospitals, and laboratories; other public, private, or nonprofit institutions are eligible.

DATE DUE: Feb 1, Jun 1, Oct 1 (RECEIPT OF PROPOSAL SATISFIES)

REFERENCE: Dr. John C. Dalton, Division of Extramural Activities (301) 496-9248

SOURCE: National Institute of Neurological and Communicative Disorders and Stroke, Federal Bldg, Rm 1016, Bethesda, MD, 20892-4200

CATALOG OF FEDERAL DOMESTIC ASSISTANCE: PAGES: 13,354

KEY WORDS: Alzheimer's Disease; Viral Diseases; Geriatrics; Infectious Diseases; Agents; Neurologic Diseases and Disorders

MINCD Alzheimer's Disease Diagnosis Research Grants

The NIMCDs, together with the National Institute on Aging and the National Institute of Mental Health, wishes to stimulate further research focusing on early and accurate diagnosis of Alzheimer's disease. Progress in understanding and diagnosing Alzheimer's disease will most likely come about through assembling, evaluating, and combining data at many different levels of experimental and clinical research. Because the collection, analysis, and evaluation of data from such sources will be maximally useful only so long as they are carefully screened for accuracy of diagnosis, relevance, and reliability and are comparable across studies. Although not limiting the following are some of the topics that are of particular programmatic interest: diagnostic screening, neuropsychological diagnostic and behavioral measures, biological and chemical markers, neuroimaging, and neuropathological markers.

PROFILE: FEDERAL

DATE DUE: Feb 1, Jun 1, Oct 1 (RECEIPT OF PROPOSAL SATISFIES)

REFERENCE: Eugene J. Oliver, Ph.D., Demielinating Atrophic and Lenticular Disorders Program, (301) 496-1431

SOURCE: National Institute of Neurological and Communicative Disorders and Stroke, Federal Bldg, Rm 710, Bethesda, MD, 20892-4200

CATALOG OF FEDERAL DOMESTIC ASSISTANCE: PAGES: 13,354

KEY WORDS: Geriatrics; Alzheimer's Disease

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NIMH Alzheimer's Disease Diagnosis Research Grants

The NIMH, together with the National Institute on Aging and the National Institute of Neurological and Communicative Disorders and Stroke, wishes to stimulate further research focusing on the early and accurate diagnosis of Alzheimer's disease. Progress in understanding and diagnosing Alzheimer's disease will most likely come about through accumulating, evaluating, and comparing data and material from many sources. All data collected—both retrospective and prospective—will be maximally useful only so long as they are carefully screened for accuracy of diagnosis, relevance, and reliability and are comparable across studies. Although not limiting, the following are some of the topics that are of particular programmatic interest: diagnostic screening; neuropsychological diagnosis and other behavioral measures; biological and chemical markers; neuroimaging; and neuropathological markers.

PROFILE: FEDERAL

DATE DUE: Jun 1; Oct 1 (RECEIPT OF PROPOSAL SATISFIED)

REFERENCE: Nancy Miller, Ph.D., Mental Disorders of the Aging Research Branch, (301) 496-1185.

SOURCE: National Institute of Mental Health, 5600 Fishers Ln., Parklawn Bldg., Rockville, MD 20857

KEYWORDS: Geriatrics; Alzheimer's Disease

NIHID Persistent Viral Infections—Alzheimer's Disease Research Grants

The National Institute of Allergy and Infectious Diseases, the National Institute of Neurological and Communicative Disorders and Stroke, and the National Institute on Aging invite applications for regular research grants on the subject of persistent viral infections possibly associated with, or models for chronic human diseases such as Alzheimer's disease. Of particular interest to the NIHID is understanding the molecular mechanisms by which viruses can persist within tissue or cells and influence immune-competent and immunocompetent individuals and cause alterations of specialized cell functions: autoimmune reactions or cytology. Another goal is to identify biological markers that are predisposing to or diagnostic of specific chronic diseases, such as Alzheimer's, for which a transmissible etiology may now be suspected but not yet known. $1,000-$1,616,854; average grant $205,796

PROFILE: FEDERAL

LIMITATIONS: Universities; medical colleges; hospitals; and laboratories of other public or private, profit or non-profit institutions are eligible.

DATE DUE: Jun 1; Oct 1 (RECEIPT OF PROPOSAL SATISFIED)

REFERENCE: Gary Tomlinson, Grants Management Branch, (301) 496-7074.

SOURCE: National Institute of Allergy and Infectious Diseases, 9 Westwood Pl., Bethesda, MD 20892-4201

CATALOG OF FEDERAL DOMESTIC ASSISTANCE: PAGE (C) 13,856

KEYWORDS: Alzheimer's Disease; Viral Diseases; Geriatrics; Virology; Neurologic Diseases and Disorders
NIA Alzheimer's Disease Diagnosis Research Grants

The NIA, together with the National Institute of Mental Health and the National Institute of Neurological and Communicative Disorders and Stroke, wishes to stimulate further research focusing on the early and accurate diagnosis of Alzheimer disease. Progress in understanding and diagnosing Alzheimer disease will most likely come about through a combination of evaluating and comparing data and material from many sources. All data collected, both retrospective and prospective, will be maximally useful only so long as they are carefully screened for accuracy, relevance, and reliability and are comparable across studies. Although not limiting the following are some of the topics that are of particular programmatic interest: diagnostic screening, neuropsychological diagnosis and other behavioral measures, biological and chemical markers, neuroimaging, and neuropathological markers.

$15,000-$15,000 average grant $17,000
PROFILE: FEDERAL
DATE DUE: Feb 1, Jun 1, Oct 1 (RECEIPT OF PROPOSAL SATISFIES)
REFERENCE: Dr. Zaven Khachaturian, Neuroscience and Neuropsychological Research, (301) 496-9350
SOURCE: National Institute on Aging, 9999 Rockville Pike, Bldg 31, Rm 5C35, Bethesda, MD 20892-4200
CATALOG OF FEDERAL DOMESTIC ASSISTANCE: PAGE(S) 13, 246
KEY WORDS: Geriatrics; Alzheimer's Disease

Family Stress and the Care of Alzheimer's Disease Victims Research Grants

NIMH seeks applications for studies which will increase knowledge and improve research methodologies on family stress related to the care of individuals with Alzheimer's disease (AD) and the development of family care and service delivery models. Applications should address the generation of systematic information on the nature, consequences, and interplay of stress associated with caregiving factors associated with understanding and enhancing family support; the identification, treatment, and management of excess disability in AD patients and strategies to maximize their functional level at all stages of the disease; the prevention of psychopathology and the promotion of mental health among family caregivers; and research aimed at improving the delivery of services which provide treatment and clinical interventions for individuals with AD and for the family members who care for them.

$10,000-$10,000 average grant $16,000
PROFILE: FEDERAL
LIMITATION: Private, nonprofit, or for-profit and public institutions, such as units of state or local government and authorized units of the federal government including Veterans Administration hospitals and other facilities, are eligible to apply for these grants.
DATE DUE: Feb 1, Jun 1, Oct 1 (RECEIPT OF PROPOSAL SATISFIES)
REFERENCE: Dr. Darrel Regier, Director, Mental Disorders of the Aging Research Branch, Division of Clinical Research, (301) 496-3848
SOURCE: National Institute of Mental Health, 5600 Fishers Ln, Rm 11303, Rockville, MD 20857
CATALOG OF FEDERAL DOMESTIC ASSISTANCE: PAGE(S) 13, 248
KEY WORDS: Alzheimer's Disease; Family Care; Stress; Mental Health; Health Care Delivery; Nursing
Cross-National Investigations of the Epidemiology of Alzheimer's Disease and Other Dementias of Later Life

The long-range goal of this program is the elucidation of new risk factors, combinations, or sequences of risk factors. While the program is independent of the World Health Organization Special Program for Research on Aging (WHO SPRA), the research goals and scope were formulated to be in accord with the goals of the WHO SPRA efforts in demetizing diseases. Both the NIA and the WHO SPRA are particularly interested in research which will lead to testable hypotheses regarding the etiology of Alzheimer's disease. In order to meet the specific goals of this program, clear operationally defined and nonreducible diagnostic criteria are required for cases very early in the course as well as for those with more advanced disease. Screening instruments for cognitive disorders are required. The instruments should be able to be used by paraprofessionals and trained nonprofessionals in a variety of settings. These instruments must be culturally, socioeconomically, and educationally nonbiased for use in cross-cultural and cross-national studies. Reliable, valid, and culturally fair risk factor assessment interview methods and instruments are needed for determining exposure to putative risk factors (e.g., parental age, affected pedigreed thyroid disease, head trauma). Prospective applicants are encouraged to consult with the project officer regarding the scientific goals, design, and subject population of the proposed study.

PROFILE: FEDERAL LIMITATION: While the program is directed toward U.S. investigators, applications from foreign institutions will also be accepted. It is highly desirable that foreign applicants should explore and establish collaborative scientific relationships with U.S. investigators to build stronger links in the instruments, methods, and hypotheses employed in epidemiological research. The NIA and the WHO SPRA will assist investigators in establishing collaborative relationships.

DATE DUE: Feb 1, Jun 1, Oct 1 (RECEIPT OF PROPOSAL SATISFIED)

REFERENCE: Teresa Sluss Radebaugh (Ed.), Chief, Epidemiology and Diagnostics, Neuroscience and Neuropsychology of Aging Program (301) 496-9959

SOURCE: National Institute on Aging 9000 Rockville Pike, Bldg 31, Rm 5C35, Bethesda, MD 20892-4200

CATALOG OF FEDERAL CHARTERED ASSISTANCE PAGE(S): 14, 866.

KEY WORDS: Epidemiology; Alzheimer's Disease; Psychosocial; Mental Health

53
Alzheimer's Disease and Other Related Dementias of Aging Research Grants

NIA and MINDS support research to elucidate the etiology of pathogenesis of Alzheimer's disease, improve diagnosis, and eventually provide sound basis for effective therapy. The following topics are of particular interest: differential diagnosis, clinical and pathological studies, cerebral circulation and metabolism, neurochemistry, neuroendocrinology, genetics—population studies, immunology—virology, and animal and other model systems. Program project grants (P01) deadlines are January 1, June 1, and October 1. Individual research project grants (R01) deadlines are March 1, July 1, and November 1. Receipt of proposal satisfies deadline requirements.

PROFILE: FEDERAL
LIMITATION: Prior to submitting a proposal the applicant is requested to send a brief letter of intent to both project officers. Project officers and contact at NIA is Dr. Zaven S. Khachaturian, Head, Neuroscience of Aging Programs, Biomedical Research and Clinical Medicine, National Institute on Aging, Bethesda, MD 20892-1033. Reference: Dr. John C. Dalton, Division of Extramural Activities, (301) 496-9248.

SOURCE: National Institute of Neurological and Communicative Disorders and Stroke, National Institute of Aging, Biomedical Research and Clinical Medicine, National Institute on Aging, Bethesda, MD 20892-1033.

CATALOG OF FEDERAL DOMESTIC ASSISTANCE: PAGE(S) 13,853-13,854

KEY WORD(S): Alzheimer's Disease; Geriatrics; Geriatric Medicine; Virology.

5/3/19 (Item 11 from File: 85)
00006.04

Alzheimer's Disease Research Center Grants

NIA is inviting grant applications for the establishment of centers of excellence devoted to the study of Alzheimer's disease and related dementia disorders of the aged. A center will be expected to foster the following related functions: conducting interdisciplinary research training scientists and clinicians; and teaching and/or transferring new information concerning Alzheimer's disease and related disorders. The intent is to fund up to three new grants per year. The initial support period is for 5 years. Applications received after deadline date will be returned without review.

PROFILE: FEDERAL
LIMITATION: Institution applicants eligible for these grants are those in which there are at least 3 principal investigators, with any PH1 agency or comparable peer reviewed research project grants on Alzheimer's disease or in related areas. Each of which has at least 2 years of committed support remaining at the time of application or one more program project grants which also have at least 2 years of committed support remaining. Institution applicants that can demonstrate the ability to launch such a research effort are also eligible.

GRANT STATUS: REVISED
DATE DUE: Jan 18 (RECEIPT OF PROPOSAL SATISFIES)
REFERENCE: Associate Director, NIA, (301) 496-9350
SOURCE: National Institute on Aging, 9000 Rockville Pike, Bethesda, MD 20892-1033.
CATALOG OF FEDERAL DOMESTIC ASSISTANCE: PAGE(S) 13,853-13,854
KEY WORD(S): Geriatrics; Alzheimer's Disease.
Allied Corporation/ADRDA Faculty Scholar Awards

These awards, partially supported by the Allied Corporation and administered by ADRDA, provide sustained support for individual investigators at the junior faculty level who have a commitment to basic or clinical research relevant to degenerative brain disorders such as Alzheimer's. The proposed research need not involve direct studies of Alzheimer's disease but it must have the potential to add to our knowledge of relevant issues. Investigators may conduct research in the biological, behavioral, or social sciences. Three awards are made annually, renewable for a second and third year depending upon satisfactory progress. Further information on the program or applications may be requested at any time from the foundation.

$33,000 plus maximum of $5,000 for expenses

PROFILE: PRIVATE

LIMITATIONS: Investigators at the junior academic level (instructor or assistant professor or equivalent in nonacademic research institutions) are eligible. Applicants should have completed at least 3 years of postdoctoral research training prior to receipt of the award and should have demonstrated research achievement and a high potential for further scientific productivity.

DATE DUE: Feb 15 (RECEIPT OF PROPOSAL SATISFIES)

REFERENCE: Faculty Scholar Awards Program, (312) 853-3060

SOURCE: Alzheimer's Disease and Related Disorders Association, 330 N Michigan Ave, Chicago, IL 60601

KEY WORDS: Geriatrics; Alzheimer's Disease

ADRDA Research Grants

One-year pilot grants are intended to bring new investigators into research on Alzheimer's disease and other degenerative brain disorders and to help established investigators develop new approaches to etiology, pathogenesis, treatment, management, and prevention. Application information is available on request.

Maximum of $12,000

PROFILE: PRIVATE

LIMITATIONS: Nonprofit institutions may apply on behalf of individual investigators. Funds are awarded to the administrative unit and are to be used toward the investigator's salary, supplies, travel and other related research expenses.

DATE DUE: Feb 15 (RECEIPT OF PROPOSAL SATISFIES)

REFERENCE: Research Grants Administrator, (312) 853-3060

SOURCE: Alzheimer's Disease and Related Disorders Association, 330 N Michigan Ave, Chicago, IL 60601

KEY WORDS: Geriatrics; Alzheimer's Disease

Memphis Plough Community Foundation, Memphis, TN

$6,560 to Alzheimer's Day Care, Memphis, TN, 1987

PROFILE: Agency (direct service)

LIMITATIONS: Giving limited to Memphis and Shelby County, western TN, northern MS, and the surrounding vicinity

POPULATION GROUP: Aged

SOURCE: 1987 AR. D

FIELD OF ACTIVITY: Medical care/welfare, general

KEY WORDS: Alzheimer's Disease; 1A-care; Day care; Alzheimer's disease/Aged, day care
Hillman Foundations Inc., The, PA
$10,000 to Council Care Senior Adult Day Care Center, Pittsburgh, PA. To establish day care center for adults afflicted with Alzheimer's Disease to be used as educational and research model in cooperation with University of Pittsburgh Graduate Schools of Social Work and Public Health and Alzheimer's Research Project at Western Psychiatric Institute and Clinic. 6/26/86
PROFILE: Agency (direct service).
LIMITATION: Pittsburgh and southwestern PA
POPULATION GROUP: Aged
TYPE OF SUPPORT: Program development
SOURCE: 6/26/86 GL + D
FIELD OF ACTIVITY: Medical care/medical research/welfare: general/mental health
KEY WORDS: Aged, day care, day care, aged/Alzheimer's disease, research/Psychiatry, research/Medical research, Alzheimer's disease/Social work school, research

6/5/3
2691964
Memphis-Plowman Community Foundation, The, TN
$5,000 to Alzheimer's Day Care, Memphis, TN, 1985
PROFILE: Agency (direct service).
LIMITATION: Giving limited to Memphis and Shelby County, western TN, northern MS, and the surrounding vicinity
POPULATION GROUP: Aged
SOURCE: 1985 AR + D
FIELD OF ACTIVITY: Welfare: general
KEY WORDS: Alzheimer's disease, services/Aged, Alzheimer's disease, Day care/Aged, day care

6/5/4
2661540
Reynolds (Kate B.) Charitable Trust, NC
$110,052 to Alzheimer's Disease and Related Disorders Association of Western North Carolina, Asheville, NC. To develop support network in 15 counties for families with members afflicted with such diseases. 1984
PROFILE: Association or professional society Agency (direct service).
LIMITATION: Giving limited to NC, with emphasis on Winston-Salem and Forsyth County.
POPULATION GROUP: Aged
TYPE OF SUPPORT: Program development
SOURCE: 1984 AR + D
FIELD OF ACTIVITY: Health: general
KEY WORDS: Alzheimer's disease, family services/family services

6/5/5
2672626
Sierra Foundation for Health, CA
$35,000 to California Alzheimer's Disease and Related Disorders Association, Sacramento, CA. For start-up funds for center for care of Alzheimer's patients. 6/85
PROFILE: Association or professional society
LIMITATION: Giving limited to the following CA counties: El Dorado, Nevada, Placer, Sacramento, San Joaquin, and Yolo
POPULATION GROUP: Aged
TYPE OF SUPPORT: Program development
SOURCE: 6/85 GL + D
FIELD OF ACTIVITY: Medical care
KEY WORDS: Alzheimer's disease, services/Aged, Alzheimer's disease
Length and Time Phasing of Assistance: Grant awards are made annually with a project period not to exceed 7 years in duration.

POST ASSISTANCE REQUIREMENTS:
Reports: Annual progress reports and reports of expenditures are required.
Audits: In accordance with the provisions of OMB Circular No. A-128, "Audits of State and Local Governments." State and local governments that receive financial assistance of $100,000 or more within the State's fiscal year shall have an audit made for that year. State and local governments that receive between $25,000 and $100,000 within the State's fiscal year shall have an audit made in accordance with Circular No. A-128, or in accordance with Federal laws and regulations governing the programs in which they participate. For nongovernmental grant recipients, audits are to be carried out in accordance with the provisions set forth in OMB Circular No. A-110. In addition, grants are subject to inspection and audits by DHHS and other Federal officials.
Records: Expenditures and other financial records must be retained for 3 years from the day on which the grantee submits the last expenditure report for the report period.

FINANCIAL INFORMATION:
Obligations: (Grants) FY 87 $0, FY 88 est $3,000,000, and FY 89 est $5,000,000.
Range and Average of Financial Assistance: To be determined.

PROGRAM ACCOMPLISHMENTS: None.

REGULATIONS, GUIDELINES, AND LITERATURE: 42 CFR 52; Public Health Service Grants Policy Statement.

INFORMATION CONTACTS:
Regional or Local Office: None.
Headquarters Office: Dr. Andrew Morgan, Acting Deputy Associate Director, Neuroscience and Neuropsychology of Aging Program, National Institute on Aging, National Institutes of Health, Room 1C-27, Building 31, Bethesda, MD 20892. Telephone: (301) 496-9350 (Use same 7-digit numbers for FTS.)

RELATED PROGRAMS: 13 866, Aging Research.

EXAMPLES OF FUNDED PROJECTS: None.

CRITERIA FOR SELECTING PROPOSALS: The major elements in evaluating proposals include assessments of: (1) scientific merit of the research; (2) background, productivity, and commitment of the applicant in the area of aging, and Alzheimer's Disease (AD) and related dementias; (3) likelihood of award to foster expansion and break new ground in AD research; (4) likelihood of continued productivity and innovation; (5) ability to foster development of junior faculty and researchers; (6) plan of development of the junior investigator(s); (7) commitment of the institution to strengthening its research and other activities in AD and other dementias of aging; and (8) scope and nature of activities to enhance research and development of researchers in these areas.
13.148 LEADERSHIP AND EXCELLENCE IN
ALZHEIMER'S DISEASE AND RELATED
DEMENTIAS

FEDERAL AGENCY: NATIONAL INSTITUTES OF HEALTH.
PUBLIC HEALTH SERVICE: DEPARTMENT OF HEALTH
AND HUMAN SERVICES

AUTHORIZATION: Title IX, Section 911, Public Law 99-660.

OBJECTIVES: To make awards to distinguished senior investigators
who have made significant contributions to biomedical research
related to Alzheimer's Disease and related dementias. The objective
is to support the recipient's research program and to assist in
the development of outstanding junior investigators to conduct re-
search in such areas.

TYPES OF ASSISTANCE: Project Grants.

USES AND USE RESTRICTIONS: Research grants are intended to
support the direct costs of a project in accordance with an ap-
proved budget, plus an appropriate amount for indirect costs.
Grantees must agree to administer the grant in accordance with
the regulations and policies governing the research grants program
of the Public Health Service. (1) It is required that the Principal
Investigator commit at least 70 percent of his/her time and effort
to research efforts supported by this instrument. No more than 20
percent of the award may be used for salary support for the senior
investigator. (2) Salary support will be provided for at least one,
but no more than three junior researchers who demonstrate ex-
ceptional promise to conduct research in the area of aging and
Alzheimer's Disease and related dementias. Support will be pro-
vided for up to 80 percent of salary and related fringe benefits,
consistent with time and effort. No more than 30 percent of the
award may be used for this component. (3) Support of the re-
search program(s) of the recipient senior investigator may be used
in the following ways: (a) expansion of the scope of currently
funded research into new lines of inquiry through novel tech-
iques or approaches and by addition of personnel; (b) support or
expansion of the research of the junior investigator(s) for up to 1
year; or (c) support of innovative or opportunistic research on
aging and Alzheimer's Disease and related dementias as pilot stud-
ies for no more than 2 years.

ELIGIBILITY REQUIREMENTS:

Applicant Eligibility: Universities, colleges (including schools
public health, medical, dental, and nursing schools) labora-
tories, hospitals, State and local health departments, other public or
private institutions (both for-profit and nonprofit), and individuals
Beneficiary Eligibility: Any nonprofit or for-profit organiza-
tion, company, or institution engaged in biomedical research.

Credentia1s/Documentation: Costs will be determined in accord-
ance with OMB Circular No. A-87 for State and local govern-
ments for-profit organizations; costs are determined in accordance
with Subpart 31.2 of the Federal Acquisition Regulations. For or-
grantees, costs will be determined by HHS Regulations 45 C.
Part 74, Subpart Q.

APPLICATION AND AWARD PROCESS:

Preapplication Coordination: This program is excluded from con-
age under E.O. 12372.

Application Procedure: The standard applications forms, as for-
mal, by PHS and required by OMB Circular No. A-102 for State
local governments, must be used for this program. Also, con-
sumption is available from the NIA staff. An application form, PI
398, may be requested from the Division of Research Grants, Na-
tional Institutes of Health, Bethesda, MD 20892, and should
submitted to the same address when completed. Proposals are
reviewed for scientific merit, evaluation of applicant qualifications,
adequacy of the research environment, and significance of the pro-
posed problem to be studied. This program is subject to the pro-

Award Procedure: Each application receives an initial science
review by a panel of non-NIH scientists and a secondary review
by the National Advisory Council on Aging Awards are made
by the NIA to the grantee institution.

Deadlines: Future deadline dates will be announced in the N
GUIDE FOR GRANTS AND CONTRACTS. Contact Her-
quar ters Office listed below.

Range of Approval/Disapproval Time: From 6 to 9 months.

Appeals: A principal investigator (P.I.) may question the substan-
tial or procedural aspects of the review of his/her application by co-
municating with the staff of the Institute and, subsequently, the
P.I. and applicant institution may formally appeal to the Dep.
Director for Extramural Research, Office of the Director, NIH.

Renewal: Awards are not renewable.

ASSISTANCE CONSIDERATIONS:

Formula and Matching Requirements: This program has no statuto-
formulas or matching requirements.
Audit: Grantees are subject to audit. In accordance with the provisions of OMB Circular No. A-122, "Audits of State and Local Governments," State and local governments that receive financial assistance of $100,000 or more within the State’s fiscal year shall have an audit made for that year. State and local governments that receive between $25,000 and $100,000 within the State’s fiscal year shall have an audit made in accordance with Circular No. A-128, or in accordance with Federal laws and regulations governing the programs in which they participate. These audits shall be made in accordance with the General Accounting Office guidelines, “Standards for Audit of Government Organizations, Program, Activities, and Functions,” and additional OMB guidance.

Records: Records must be maintained for 3 years.

FINANCIAL INFORMATION:
Account Identification: 75-1636-0-1-506
Obligations: (Grants) FY 87-90; FY 89-est $4,787,000; and FY 89 est $4,787,000.
Range and Average of Financial Assistance: $3,272 to $4,410,000; $3,983,592.

PROGRAM ACCOMPLISHMENTS: None.

INFORMATION CONTACTS:
Regional or Local Office: Regional Aging Program Directors, Administration on Aging, Office of the Secretary, Department of Health and Human Services, Regional Office. (See Appendix IV of the Catalog for addresses.)
Headquarters Office: Associate Commissioner for State and Tribal Programs, Administration on Aging, Department of Health and Human Services, Washington, DC 20201. Contact: Dr. Joyce Berry. Telephone: (202) 245-0011.

RELATED PROGRAMS: 13.633, Special Programs for the Aging—Title III, Part B—Grants for Supportive Services and Senior Centers; 13.635, Special Programs for the Aging—Title III, Part C—Nutrition Services; 13.655, Special Programs for the Aging—Title VI, Part A—Indian Programs; 13.668, Special Programs for the Aging—Title IV—Training, Research and Discretionary Projects and Programs; 72.001, Foster Grandparent Program; 72.002, Retired Volunteer Program.

EXAMPLES OF FUNDED PROJECTS: None.

CRITERIA FOR SELECTING PROPOSALS: Non-competitive State grants are awarded upon approval of State Plan.

APPLICATION AND AWARD PROCESS:
Preapplication Coordination: No preapplication is required. This program is excluded from coverage under E.O. 12372.
Application Procedure: No Federal forms are required, but certain assurances and information described in the Annual Report Instruction must be included. This program is excluded from coverage under OMB Circular No. A-102 and No. A-110.
Award Procedure: Applications will be reviewed against all eligibility requirements contained in the authorizing legislation. All eligible State and territorial governments will receive funding.

Deadlines: Deadlines will be contained in the notice sent to each State and other eligible entities announcing the availability of funds under this program.

Range of Approval/Disapproval Times: From 30 to 90 days.
Appeals: None.

Renewals: Grants are made annually. A new application is required each year.

ASSISTANCE CONSIDERATIONS:
Formula and Matching Requirements: There is no matching requirement. The statistical factor used for fund distribution is the population of children under age 18 in each State.

Length and Timing of Assistance: Grants are made for a 1-year period.

POST ASSISTANCE REQUIREMENTS:
Reports: Reporting requirements will be described in program guidelines.

Audit: In accordance with the provisions of OMB Circular No. A-122, "Audits of State and Local Governments," State and local governments that receive financial assistance of $100,000 or more within the State’s fiscal year shall have an audit made for that year. State and local governments that receive between $25,000 and $100,000 within the State’s fiscal year shall have an audit made in accordance with Circular No. A-128, or in accordance with Federal laws and regulations governing the programs in which they participate.

Records: Records must be retained for 3 years.
13.441 SPECIAL PROGRAMS FOR THE AGING—
TITLE III, PART D—IN-HOME SERVICES FOR
FRAIL OLDER INDIVIDUALS
(In-Home Services for Frail Older Individuals)

FEDERAL AGENCY: ADMINISTRATION ON AGING, DEPARTMENT OF HEALTH AND HUMAN SERVICES

AUTHORIZATION: Older Americans Act of 1965, Public Law 94-73, as amended, Public Law 100-175

OBJECTIVES: To provide grants to States for in-home services to frail older individuals, including in-home supportive services for older individuals who are victims of Alzheimer's disease and related disorders with neurological and organic brain dysfunctions, and to the families of such victims.

TYPES OF ASSISTANCE: Formula Grants.

USES AND USE RESTRICTIONS: Funds are awarded to States to carry out a program for providing in-home services to frail older persons. Each State shall develop eligibility criteria which take into account age, greatest economic need, non-economic factors contributing to frailty, and non-economic and non-health factors contributing to the need for in-home services. A State plan covering 2, 3, or 4 years, with annual revisions as necessary, must be submitted for approval to the Commissioner on Aging. Area plans are to be submitted to State agencies for approval.

ELIGIBILITY REQUIREMENTS:
Applicant Eligibility: All States and U.S. Territories which have State agencies on aging designated by the Governors.
Beneficiary Eligibility: Older individuals, especially those with the greatest social and economic needs.
Credentials/Documentation: Costs will be determined in accordance with OMB Circular No. A-87 for State and local governments.

APPLICATION AND AWARD PROCESS:
Preapplication Coordinations: State Plans are covered under E.O. 12372, but Intergovernmental Consultation Review is excluded. This program requires coordination with the policies of OMB Circular No. A-102. Standard application forms, as furnished by DHHS and required by OMB Circular A-102, must be used for this program.
Application Procedure: Consult the appropriate Regional Office for State application instructions. This program is excluded from coverage under OMB Circular No. A-110.
Award Procedure: State agencies approve and award funds to sub-state level organizations whom they have designated.
Deadlines: Deadlines are determined by State agencies on an annual basis, usually 45 days before the beginning of the budget period.
Range of Approval/Disapproval Time: From 30 to 45 days.
Appeals: Appeals may be applied for through prescribed appeal procedures as provided in Section 307 of the Older Americans Act of 1965, as amended.
Renewals: Applications are submitted for a 2-, 3-, or 4-year period and revised as necessary.

ASSISTANCE CONSIDERATION:
Formula and Matching Requirements: Older Americans Act of 1965, as amended, Section 304(a) and (d). This program is funded on a Federal/State matching basis at a ratio of 85-15. For each fiscal year, State resources must provide not less than 25 percent of the nonfederal share of each State's total Title III expenditures from State or local public resources. The statistical factor used for fund allocation is the population in a state over 60 years and source is the "1980 Decennial Census," as revised.
Length and Time Planning of Assistance: State agencies must obligate funds within the fiscal year for which funds are appropriated.

POST ASSISTANCE REQUIREMENTS:
Reports: Quarterly SF-269 Expenditure Reports, and Annual Performance Reports.
LONG-TERM CARE INSURANCE MODEL ACT

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Section 1. Purpose

The purpose of this Act is to promote the public interest, to promote the availability of long-term care insurance policies, to protect applicants for long-term care insurance, as defined, from unfair or deceptive sales or enrollment practices, to establish standards for long-term care insurance, to facilitate public understanding and comparison of long-term care insurance policies, and to facilitate flexibility and innovation in the development of long-term care insurance coverage.

Comment: The purpose clause evidences legislative intent to protect the public while recognizing the need to permit flexibility and innovation with respect to long-term care insurance coverage.

Section 2. Scope

The requirements of this Act shall apply to policies delivered or issued for delivery in this state on or after the effective date of this Act. This Act is not intended to supersede the obligations of entities subject to this Act to comply with the substance of other applicable insurance laws insofar as they do not conflict with this Act, except that laws and regulations designed and intended to apply to Medicare supplement insurance policies shall not be applied to long-term care insurance. A policy which is not advertised, marketed or offered as long-term care insurance or nursing home insurance need not meet the requirements of this Act.

Comment: This section makes clear that entities subject to the Act must continue to comply with other applicable insurance legislation not in conflict with this Act.

Section 3. Short Title

This Act may be known and cited as the "Long-Term Care Insurance Act."

Section 4. Definitions

Unless the context requires otherwise, the definitions in this section apply throughout this Act.

A. "Long-term care insurance" means any insurance policy or rider advertised, marketed, offered or designed to provide coverage for not less than twelve consecutive months for each covered person on an expense incurred, indemnity, prepaid or other basis; for one or more necessary or medically necessary diagnostic, preventive, therapeutic, rehabilitative, maintenance or personal care services, provided in a setting other than an acute care unit of a hospital. Such term includes group and individual policies or riders whether issued by insurers; fraternal benefit societies; nonprofit health, hospital, and medical service corporations; prepaid health plans; health maintenance organizations or any similar organization. Long-term care insurance shall not include any insurance policy which is offered primarily to provide basic Medicare supplement coverage, basic
Long-Term Care Insurance Model Act

hospital expense coverage, basic medical-surgical expense coverage, hospital confinement indemnity coverage, major medical expense coverage, disability income protection coverage, accident only coverage, specified disease or specified accident coverage, or limited benefit health coverage.

B. “Applicant” means:

(1) in the case of an individual long-term care insurance policy, the person who seeks to contract for benefits, and

(2) in the case of a group long-term care insurance policy, the proposed certificate holder.

C. “Certificate” means, for the purposes of this Act, any certificate issued under a group long-term care insurance policy, which policy has been delivered or issued for delivery in this state.

D. “Commissioner” means the insurance commissioner of this state.

Drafting Note: Where the word “Commissioner” appears in this Act, the appropriate designation for the chief insurance supervisory official of the state should be substituted.

E. “Group long-term care insurance” means a long-term care insurance policy which is delivered or issued for delivery in this state and issued to:

(1) One or more employers or labor organizations, or to a trust or to the trustees of a fund established by one or more employers or labor organizations, or a combination thereof, for employees or former employees or a combination thereof or for members or former members or a combination thereof, of the labor organizations: or

(2) Any professional, trade or occupational association for its members or former or retired members, or combination thereof, if such association:

(a) Is composed of individuals all of whom are or were actively engaged in the same profession, trade or occupation: and

(b) Has been maintained in good faith for purposes other than obtaining insurance: or

(3) An association or a trust or the trustee(s) of a fund established, created or maintained for the benefit of members of one or more associations. Prior to advertising, marketing or offering such policy within this state, the association or associations, or the insurer of the association or associations, shall file evidence with the Commissioner that the association or associations have at the outset a minimum of 100 persons and have been organized and maintained in good faith for purposes other than that of obtaining insurance; have been in active existence for at least one year; and have a constitution and by-laws which provide that:

(a) the association or associations hold regular meetings not less than annually to further purposes of the members:

(b) except for credit unions, the association or associations collect dues or solicit contributions from members: and

(c) the members have voting privileges and representation on the governing board and committees.

Thirty days after such filing the association or associations will be deemed to satisfy such organizational requirements, unless the Commissioner makes a finding that the association or associations do not satisfy those organizational requirements.
(4) A group other than as described in Subsections E(1), E(2) and E(3), subject to a finding by the Commissioner that:

(a) The issuance of the group policy is not contrary to the best interest of the public;

(b) The issuance of the group policy would result in economies of acquisition or administration; and

(c) The benefits are reasonable in relation to the premiums charged.

F. "Policy" means, for the purposes of this Act, any policy, contract, subscriber agreement, rider or endorsement delivered or issued for delivery in this state by an insurer: fraternal benefit society; nonprofit health, hospital, or medical service corporation: prepaid health plan; health maintenance organization or any similar organization.

Drafting Note: This Act is intended to apply to the specified group and individual policies, contracts, and certificates whether issued by insurers; fraternal benefit societies; non-profit health, hospital, and medical service corporations; prepaid health plans; health maintenance organizations or any similar organization. In order to include such organizations, each state should identify them in accordance with its statutory terminology or by specific statutory citation. Depending upon state law, insurance department jurisdiction and other factors, separate legislation may be required. In any event, the legislation should provide that the particular terminology used by these plans and organizations may be substituted for, or added to, the corresponding terms used in this Act. The term "regulations" should be replaced by the terms "rules and regulations" or "rules" as may be appropriate under state law.

The definition of "long-term care insurance" under this Act is designed to allow maximum flexibility in benefit scope, intensity and level, while assuring that the purchaser's reasonable expectations for a long-term care insurance policy are met. The Act is intended to permit long-term care insurance policies to cover either diagnostic, preventive, therapeutic, rehabilitative, maintenance or personal care services, or any combination thereof, and not to mandate coverage for each of these types of services. Pursuant to the definition, long-term care insurance may be either a group or individual insurance policy or a rider to such a policy, e.g., life or accident and sickness. The language in the definition concerning "other than an acute care unit of a hospital" is intended to allow payment of benefits when a portion of a hospital has been designated for, and duly licensed or certified as a long-term care provider or swing bed.

Section 5. Extraterritorial Jurisdiction - Group Long-Term Care Insurance

No group long-term care insurance coverage may be offered to a resident of this state under a group policy issued in another state to a group described in Section 4E(4), unless this state or another state having statutory and regulatory long-term care insurance requirements substantially similar to those adopted in this state has made a determination that such requirements have been met.

Drafting Note: By limiting extraterritorial jurisdiction to "discretionary groups," it is not the drafters' intention that jurisdiction over other health policies should be limited in this manner.

Section 6. Disclosure and Performance Standards for Long-Term Care Insurance

A. The Commissioner may adopt regulations that include standards for full and fair disclosure setting forth the manner, content and required disclosures for the sale of long-term care insurance policies, terms of renewability, initial and subsequent conditions of eligibility, nonduplication of coverage provisions, coverage of dependents, preexisting conditions, termination of insurance, continuation or conversion, probationary periods, limitations, exceptions, reductions, elimination periods, requirements for replacement, recurrent conditions and definitions of terms.

Comment: This subsection permits the adoption of regulations establishing disclosure standards, renewability and eligibility terms and conditions, and other performance requirements for long-term care insurance. Regulations under this subsection should recognize the developing and unique nature of long-term care insurance and the distinction between group and individual long-term care insurance policies.

B. No long-term care insurance policy may:

(1) Be cancelled, nonrenewed or otherwise terminated on the grounds of the age or the deterioration of the mental or physical health of the insured individual or certificate holder; or
(2) Contain a provision establishing a new waiting period in the event existing coverage is converted to or replaced by a new or other form within the same company, except with respect to an increase in benefits voluntarily selected by the insured individual or group policyholder; or

(3) Provide coverage for skilled nursing care only or provide significantly more coverage for skilled care in a facility than coverage for lower levels of care.

C. Preexisting condition:

(1) No long-term care insurance policy or certificate other than a policy or certificate thereunder issued to a group as defined in Section 4E(1) shall use a definition of "preexisting condition" which is more restrictive than the following: Preexisting condition means a condition for which medical advice or treatment was recommended by, or received from, a provider of health care services, within six months preceding the effective date of coverage of an insured person.

(2) No long-term care insurance policy or certificate other than a policy or certificate thereunder issued to a group as defined in Section 4E(1) may exclude coverage for a loss or confinement which is the result of a preexisting condition unless such loss or confinement begins within six months following the effective date of coverage of an insured person.

(3) The Commissioner may extend the limitation periods set forth in Sections 6C(1) and (2) above as to specific age group categories in specific policy forms upon findings that the extension is in the best interest of the public.

(4) The definition of "preexisting condition" does not prohibit an insurer from using an application form designed to elicit the complete health history of an applicant, and, on the basis of the answers on that application, from underwriting in accordance with that insurer's established underwriting standards. Unless otherwise provided in the policy or certificate, a preexisting condition, regardless of whether it is disclosed on the application, need not be covered until the waiting period described in Section 6C(2) expires. No long-term care insurance policy or certificate may exclude or use waivers or riders of any kind to exclude, limit or reduce coverage or benefits for specifically named or described preexisting diseases or physical conditions beyond the waiting period described in Section 6C(2).

D. Prior institutionalization:

No long-term care insurance policy which provides benefits only following institutionalization shall condition such benefits upon admission to a facility for the same or related conditions within a period of less than thirty days after discharge from the institution.

E. The Commissioner may adopt regulations establishing loss ratio standards for long-term care insurance policies provided that a specific reference to long-term care insurance policies is contained in the regulation.

F. Right to return - free look:

(1) Individual long-term care insurance policyholders shall have the right to return the policy within ten days of its delivery and to have the premium refunded if, after examination of the policy, the policyholder is not satisfied for any reason. Individ-
ual long-term care insurance policies shall have a notice prominently printed on the first page of the policy or attached thereto stating in substance that the policyholder shall have the right to return the policy within ten days of its delivery and to have the premium refunded if, after examination of the policy, the policyholder is not satisfied for any reason.

(2) A person insured under a long-term care insurance policy issued pursuant to a direct response solicitation shall have the right to return the policy within thirty days of its delivery and to have the premium refunded if, after examination, the insured person is not satisfied for any reason. Long-term care insurance policies issued pursuant to a direct response solicitation shall have a notice prominently printed on the first page or attached thereto stating in substance that the insured person shall have the right to return the policy within thirty days of its delivery and to have the premium refunded if after examination the insured person is not satisfied for any reason.

G. An outline of coverage shall be delivered to an applicant for an individual long-term care insurance policy at the time of application for an individual policy. In the case of direct response solicitations, the insurer shall deliver the outline of coverage upon the applicant's request, but regardless of request shall make such delivery no later than at the time of policy delivery. Such outline of coverage shall include:

(1) A description of the principal benefits and coverage provided in the policy;
(2) A statement of the principal exclusions, reductions and limitations contained in the policy;
(3) A statement of the renewal provisions, including any reservation in the policy of a right to change premiums; and
(4) A statement that the outline of coverage is a summary of the policy issued or applied for, and that the policy should be consulted to determine governing contractual provisions.

H. A certificate issued pursuant to a group long-term care insurance policy which policy is delivered or issued for delivery in this state shall include:

(1) A description of the principal benefits and coverage provided in the policy;
(2) A statement of the principal exclusions, reductions and limitations contained in the policy; and
(3) A statement that the group master policy determines governing contractual provisions.

I. No policy may be advertised, marketed or offered as long-term care or nursing home insurance unless it complies with the provisions of this Act.

Comment: The above provisions are deemed appropriate due to the particular nature of long-term care insurance and are consistent with group insurance laws. Specific standards would be contained in regulations implementing this Act.

Section 7. Administrative Procedures

Regulations adopted pursuant to this Act shall be in accordance with the provisions of [cite section of state insurance code relating to the adoption and promulgation of rules and regulations or cite the state's administrative procedures act, if applicable].

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Section 8. Severability

If any provision of this Act or the application thereof to any person or circumstance is for any reason held to be invalid, the remainder of the Act and the application of such provision to other persons or circumstances shall not be affected thereby.

Section 9. Effective Date

This Act shall be effective [insert date].

Legislative History (all references are to the Proceedings of the NAIC):