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FINAL REPORT NEW JERSEY ALZHEIMER'S DISEASE STUDY COMMISSION



SUBMITTED TO
GOVERNOR THOMAS H. KEAN
JULY 1986

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FINAL REPORT

NEW JERSEY ALZHEIMER'S DISEASE STUDY COMMISSION

SUBMITTED TO GOVERNOR THOMAS H. KEAN

JULY 1986

Alzheimer's Disease Study Commission

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Department of Health, Trenton,
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State of New Jersey
DEPARTMENT OF HEALTH

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J. RICHARD GOLDSTEIN, M.D.
COMMISSIONER

July 25, 1986

Honorable Thomas H. Kean, Governor
State of New Jersey
State House
Trenton, New Jersey 08625

Dear Governor Kean:

As Chairman of the Alzheimer's Disease Study Commission, I am pleased to present you with a summary of the Commission's findings and our recommendations which we believe to be an integral part of a comprehensive program to address the problems connected with Alzheimer's disease.

We estimate that approximately 230,000 residents of New Jersey suffer from cognitive impairment. Studies based on small samples indicate that 10% - 20% of the elderly with symptoms of dementia have reversible conditions. Alzheimer's disease and multi-infarct dementia account for 80% of the irreversible dementias.

Several of the Commission's primary recommendations, such as the development of an Alzheimer's Disease and Related Disorders Resource Center and the establishment of a diagnostic center for the cognitively impaired, have already been accomplished. Another recommendation is for the increase of adult day care and respite programs in New Jersey. Legislation has been introduced in both the Senate and the Assembly for the expansion of these services.

The members of the Alzheimer's Disease Study Commission appreciate and share your concerns for the problems faced by victims of this devastating disease. We believe the adoption of the recommendations contained in this report will be beneficial to both the victims of Alzheimer's disease and related disorders and their families.

Sincerely,

A handwritten signature in black ink, appearing to read "J. Richard Goldstein".

J. Richard Goldstein, M.D.
State Commissioner of Health

ACKNOWLEDGEMENT

The Alzheimer's Disease Study Commission would like to thank all of the people who shared their experiences, knowledge and emotions with us while we conducted the public hearings and surveys.

The Alzheimer's Disease Study Commission acknowledges with appreciation the efforts of personnel from the Department of Health, Gerontology Program who assisted in preparing the report: Rickey Greene, Coordinator, Helena Meade, Elizabeth Ferraro, Dierdre Fisher, and Joan Wagner. Special recognition is given to Deborah Reeves and Karla Tucillo for secretarial support.

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Executive Summary

Alzheimer's disease is a degenerative, irreversible disease characterized by intellectual deterioration, disorganization of the personality and the inability to carry out activities of daily living. While there is great variability between Alzheimer's patients, it is generally accepted that they progress through a process of cognitive decline. Each level of cognitive function is marked by recognizable clinical characteristics that affect the functional capacity of the patient. The disease may last anywhere between two and twenty years. There is no cure for the disease at this point in time.

Recognizing the impact Alzheimer's disease has on both the victim and the caretaker, Governor Thomas H. Kean signed Assembly Bill 3638 on September 29, 1983, establishing an Alzheimer's Disease Study Commission. The responsibilities of the Commission included examining the incidence of Alzheimer's disease in New Jersey, the needs of victims and their families and the availability and affordability of services.

The Commission membership consisted of the Commissioners of the Departments of Health, Human Services, and Community Affairs, two State Senators and two members of the General Assembly, as well as seven citizen members.

The first meeting of the Commission was held on July 12, 1984. Dr. J. Richard Goldstein, Commissioner of Health, was elected Chairman of the Commission. One of the first actions of the Commission was to convene a series of three public hearings to which professionals and family members were invited.

As a result of the public hearings, the devastating impact on the individual and family members was brought to the attention of the Commission.

Obtaining an early diagnosis of Alzheimer's disease was identified as a major problem encountered by victims and their families. A diagnostic tool specific for Alzheimer's disease does not currently exist. Therefore, physicians treating clients with a suspected dementia work by a process of elimination. Many reversible conditions can mimic Alzheimer's disease and the ramification of mislabeling a client can be catastrophic to all those involved. Family caregivers and professionals alike expressed the need for a more informed medical community.

Despite the burdens of caregiving the desire to keep the Alzheimer's disease victim at home for as long as possible was well affirmed by many giving testimony. Successful home care, however, can be draining and requires community resources which assist and support the primary care providers. The caretaker, usually a family member, must constantly monitor the Alzheimer victim's activity. The constant monitoring does not leave much

personal time for the caregiver; this in turn leads to an increase in the level of stress for caregivers.

A problem identified by almost every individual providing testimony was the financial strains which are inflicted on the victims and their families. The long-term effects of Alzheimer's disease most often require support such as custodial care, social services, counseling and support and respite for family caregivers. Subsidized funding for the chronically ill individual who requires these services but does not require "skilled care" is currently non-existent for a large portion of the United States population.

As a result of the poignant testimony at these hearings, the Commission adopted the following recommendations:

- . The State of New Jersey should support the establishment of a statewide resource directory for family caregivers and health and human service providers.
- . The State of New Jersey should develop an Alzheimer's Disease and Related Disorder Resource Center which will link Alzheimer's victims and their families with appropriate programs and services to meet their complexity of needs.
- . The State of New Jersey should support the establishment of a diagnostic center for the cognitively impaired. The first diagnostic center would be affiliated with the University of Medicine and Dentistry of New Jersey - Robert Wood Johnson Medical School.
- . The State of New Jersey should provide support for the expansion of adult day care programs and should provide for and coordinate the utilization of existing services for both in home and out of home respite care in order to furnish relief and support to family and other unpaid care providers of those afflicted with Alzheimer's disease or a related disorder.
- . The State Department of Health in collaboration with the various health related professional associations (i.e., physicians, nurses, social workers and occupational therapists), members of the clergy, the Departments of Community Affairs and Human Services, and the Alzheimer's Disease Support Network should develop and implement seminars and/or workshops on issues relevant to Alzheimer's disease and related disorders. Continuing education programs should be targeted towards a multidisciplinary audience and should, when appropriate, include family or other nonpaid caregivers.
- . A study should be undertaken by the Department of Insurance on developing a long-term private insurance product for Alzheimer's disease patients.

- . The New Jersey Department of Health should develop a brochure to give information to caretakers of Alzheimer's patients about autopsy costs, brain banks and other resources available to them.
- . The New Jersey Department of Health should develop guidelines for the care of Alzheimer patients in nursing homes. These guidelines would include methods to deal with the specific problems encountered in the care of Alzheimer patients.
- . Efforts should be taken to expand Medicare to cover chronic illness.
- . The Department of Higher Education should work with the various professional schools in New Jersey (medical, nursing and allied health professionals) to see that information related to Alzheimer's disease and related disorders be included in the curricula. The Department of Higher Education should further use its influence to have questions concerning Alzheimer's disease and related disorders included on state licensing board examinations.
- . We encourage both federal and private research into the etiology and treatment of Alzheimer's disease and related disorders.

PURPOSE OF COMMISSION

With the passage of Public Law 1983, Chapter 352 (see Appendix I) the Alzheimer's Disease Study Commission was formed. This legislation was sponsored by Assemblyman David Schwartz and signed by Governor Thomas H. Kean on September 29, 1983. The responsibilities of the Study Commission included examining the incidence of the disease in New Jersey, the needs of the victims and their families and the availability and affordability of services. The contents of this report contain the work of the Commission up to this point in time.

INTRODUCTION

History, Pathology and Etiology of Alzheimer's Disease

Alzheimer's disease is a degenerative, irreversible disease characterized by intellectual deterioration, disorganization of the personality and inability to carry out activities of daily living. A number of terms and disease processes have been used to describe the changes that occur with Alzheimer's disease, including, but not limited to, "senility," "senile dementia," "hardening of the arteries," and "organic brain syndrome."

The condition was first described in Germany in 1907 by Dr. Alois Alzheimer, for whom the disease was named. Onset can occur in middle or later life, however, the risk of having the disease increases exponentially with aging (Emr & Schneider, 1985). Diagnosis of Alzheimer's disease is one of exclusion, since definitive diagnosis can only be confirmed through examination of brain tissue. The pathologic findings include:

1. Neurofibrillary tangles: tangles of threadlike nerve fibers tangled upon themselves and laying in the cell bodies of the neurons.
2. Neuritic (senile) plaques: deposits of starch-like protein on the nerve fibers that interfere with transmission of information between the nerve cells.
3. Atrophy of the brain: due to neurofibrillary tangles that develop in the cerebral cortex.

The etiology of the disease is still unknown, although a number of theories have been postulated as possible factors: heredity, aluminum deposits, an auto immune response, a neurotransmitter deficiency, trauma (Katzman, 1986), and slow growing viruses (Butler & Emr, 1982).

Disease Progression

While there is great variability between Alzheimer's patients, it is generally accepted that they progress through a series of cognitive declines. Dr. Barry Reisberg, M.D., Clinical Director of the Geriatric Study and Treatment Program at the New York University Medical Center has identified seven stages of cognitive decline which include:

1. normal
2. normal age forgetfulness
3. early confusional
4. late confusional
5. early dementia
6. middle dementia
7. late dementia

Each level of cognitive function is marked by recognizable clinical characteristics that affect the functional capacity of the patient. It should be noted that Dr. Reisberg's stages of cognitive decline is one of several theories about the progression of the disease; not all persons with dementia progress in the same manner. (See Appendix II).

Affect of Alzheimer's Disease on Caretakers

As the cognitive ability of the Alzheimer's disease victim begins to decline, the caretaker role becomes more complex. Early in the disease, the associated symptoms such as memory loss are often more troubling to the patient, and often the family is not aware of any change in the patient's behavior. As the disease progresses and the patient begins to lose the ability to do routine tasks such as marketing and managing personal finances, the caretaker must assume these responsibilities and check on the patient regularly. Care and supervision become a full time responsibility. At this time caretakers may need, at the minimum, part time help to care for the patient. Eventually, the responsibility for caring for the Alzheimer's patient in advanced stages becomes overwhelming. The caretakers must devote their life to someone who can't even remember their name. If no help is available, institutionalization may be the only alternative. Both Alzheimer's patients and their caretakers need sustained, long-term, comprehensive, appropriate and affordable services during all stages of the illness.

Prevalence of the disease

New Jerseyans 65 and older represented 12.3% of the state's population, or about 1 in every 8 persons in 1983. Nationally, residents over 65 years were 11.7% of the population in that year. (Aging in New Jersey, p.3).

There are considerable numbers of old people entering the ranks of New Jersey's senior population yearly. In 1980, 67,812 persons reached the age of 65 and 47,490 persons in the over 65 group died, a net increase of 20,314 older New Jerseyans (56 per day) (Aging in New Jersey, p.5). New Jersey is the ninth highest ranking state in numbers of older people, and the overall older population has been increasing five times faster than the total state population (Aging in New Jersey, p.6-7). Within ranks of New Jersey's older population, those 75 and older are projected to increase more than 13% by year 2000. The over 85 group is growing the fastest and is expected to double in number and population between 1980 and 2000. The growth of this age group is important in relation to Alzheimer's disease since the risk of having cognitive impairments increases with age.

The recent Report of the Secretary's Task Force on Alzheimer's Disease, 1984, considered the issues of the incidence and prevalence of dementia. It identified the difficulty of recognizing the early stages of Alzheimer's disease as a major problem in determining the incidence. This report avoids presenting one incidence rate, recognizing that the existing studies which venture estimates are not comparable. For example, one study conducted in Rochester, Minnesota, reported an annual incidence of 110 new cases per 100,000 residents over the age of 29 years. A Swedish study, estimated the annual incidence of "senile psychosis" to be 380 per 100,000 persons age 60 and older.

Likewise, there is no concensus regarding estimates of the prevalence of dementia. Research studies conducted in Europe yield estimates ranging from 2.9 to 21.6 percent in the elderly, using various criteria.

Essentially, the lack of conclusive data on dementia is due to the difficulty in obtaining a definitive diagnosis. The Task Force Report addresses this problem:

At the present time, the definitive diagnosis of Alzheimer's disease is based upon the observation at autopsy or biopsy of large numbers of neurofibrillary tangles and senile plaques in the cerebral cortex of clinically demented individuals. The clinical diagnosis is made in progressively dementing individuals in whom other known causes for the cognitive and memory impairment have been excluded. . . Nevertheless, even with the best information available, it is often difficult to distinguish the specific Alzheimer's disease patient, particularly early in the course of the disease, from multi-infarct dementia, depression, or other functional states.

Another factor contributing to the difficulty in diagnosing the disease and in accumulating accurate data is the lack of mental

status tests that are not biased by "social class, motivation, attention, communication problems, emotional disorders, physical health, and reaction to the test situation itself". Therefore, the Task Force cautions that a diagnosis of dementia should not be made on the basis of any single test.

The National Institute of Mental Health is currently funding a five site Epidemiologic Catchment Area Study (ECA) of the prevalence of mental disorders in six major categories. Persons with Alzheimer's disease and related disorders are included under the category labeled cognitive impairment. Preliminary findings, which were reported in a recent volume of the Archives of General Psychiatry, (Myers, et al., 1984), reveal the prevalence of cognitive impairment to be as follows for the population age 65 years and older in three of the sites:*

	<u>Severe</u>		<u>Mild</u>	
	Males %	Females %	Males %	Females %
New Haven	6.3	4.2	11.5	11.6
Baltimore	5.7	4.8	14.2	16.6
St. Louis	4.6	3.6	18.4	15.0

*Note The ECA study assessed cognitive impairment with a widely-used screening instrument. It should be noted, however, that the instrument does not differentiate Alzheimer's disease and other disorders from other cognitive dysfunctions, some of which are treatable. Because prevalence in other sites may not strictly apply to New Jersey, the prevalence of cognitive impairment found in the three ECA study sites should be viewed as providing no more than a likely range for New Jersey.

Because the prevalence of cognitive impairment increases sharply with age beyond age 75, less rough estimates are obtained from prevalence rates by smaller age groups than age 65+ considered all together. This takes into account any important differences in the age structure of the populations. Table I, based on prevalence rates for ten-year age groups in the New Haven site, reports the estimation of 43,162 residents of New Jersey with severe cognitive impairment and 189,298 residents with mild cognitive impairment.

The National Institute on Aging's Consensus Task Force on Senility, 1980, determined that "intellectual impairment in the elderly may be due to conditions that can be cured, to conditions that with our current state of knowledge show an inexorable downhill course, or to conditions that can be ameliorated with

treatment". Studies based on small samples indicate that 10%-20% of the elderly with symptoms of dementia have reversible conditions. As many as 100 reversible conditions can present symptoms of dementia (depression, head injury, high fever, poor nutrition, adverse drug reaction, etc.) (United States Department of Health and Human Services, 1981). Alzheimer's disease and multi-infarct dementia account for approximately 80% of the irreversible dementias (Task Force, 1980). Other causes of irreversible dementia include Pick's disease, Huntington's disease, Parkinson's disease, Creutzfeldt-Jakob disease, etc.

TABLE I

Estimated Number of New Jersey Residents
With Cognitive Impairment

<u>Age Range</u>	<u>1985 Projected Population^a</u>	<u>Severely Impaired %^b</u>	<u>N</u>	<u>Mildly Impaired %^b</u>	<u>N</u>
45-54	779,400	0.6	4,676	5.8	45,205
55-64	814,200	1.0	8,142	3.2	26,054
65-74	573,600	1.1	6,310	8.2	47,035
75-84	283,600	4.0	11,344	17.4	49,346
85+	84,600	15.0	<u>12,690</u>	25.6	<u>21,658</u>
			43,162		189,298

- Notes:
- a. New Jersey Department of Labor, Division of Planning and Research, Office of Demographic and Economic Analysis, "New Jersey Revised Total and Age and Sex Population Projections, 1985-2000," July, 1983.
 - b. Prevalence of cognitive impairment, New Haven site of the Epidemiological Catchment Area Study, Charles E. Holzer, III et al, An Epidemiologic Assessment of Cognitive Impairment in a Community Population, in Research in Community and Mental Health, Vol. 4, Greenwich, Conn.: JAI Press, 1984.

HISTORY OF THE COMMISSION

Recognizing the impact Alzheimer's disease has on the victim and caretaker, Governor Thomas H. Kean signed Assembly Bill 3638 on

September 29, 1983 establishing an Alzheimer's Disease Study Commission.

The Commission membership consists of the Commissioners of the Departments of Health, Human Services, and Community Affairs, two State Senators and two members of the General Assembly, as well as seven citizen members (See Appendix III).

The duties of the Commission are:

- . To study the extent and severity of the incidence of Alzheimer's disease in New Jersey with consideration of the specialized needs and facilities for the care of those afflicted.
- . To study the needs of the victims and their families, the availability and affordability of long-term care arrangements, including in home care and other alternatives to institutionalization.
- . To gather and disseminate data and information regarding the care and treatment of persons with the disease, to stimulate awareness and provide accurate data for health professionals and governmental policy-makers having responsibilities relevant to this problem.

The first meeting of the Commission was held on July 12, 1984. Dr. J. Richard Goldstein, Commissioner of Health, was elected Chairman of the Commission. At the initial meeting of the Commission it was decided to establish three task forces composed of Commission members to pursue the objectives of the Commission. The three task forces were to study the problems related to Alzheimer's disease in New Jersey, develop findings in this regard and make recommendations as to future courses of action to respond to this problem.

One of the recommendations of the Task Force on Resources was that public hearings be held in various places throughout the state to hear testimony regarding the needs and problems of Alzheimer's patients and their families in New Jersey. As a result of the public hearings and the Task Force findings in general, recommendations were made to improve the diagnosis, treatment and care of Alzheimer's patients in the state. In addition, Commission members have continued to participate in a number of professional and educational programs throughout the state regarding Alzheimer's disease.

SUMMARY OF TASK FORCES

Needs Assessment Task Force

Commission Members:

Barbara Wolfson - Chairperson
Deborah Piggins

Others:

Mary Breckenridge, Ph.D - UMDNJ - Robert Wood Johnson
Medical School
John Toner, Ph.D - Columbia University, Long Term Care
Gerontology Center
Angela Waff - Department of Human Services
Rickey Greene - Department of Health
Dierdre Fisher - Department of Health
Joan Wagner - Department of Health

The purpose of the Needs Assessment Task Force was to determine the incidence, prevalence and mortality associated with Alzheimer's disease and related disorders in New Jersey.

After much discussion concerning the scarcity of reliable data in New Jersey, it was decided to extrapolate from the findings of previous studies and apply these estimates to New Jersey's population. (See pp. 5 for prevalence of dementia in New Jersey.)

In addition, the Task Force developed the following recommendations:

- . The State should set aside funding for a research study to be conducted to determine the incidence and prevalence of dementing illness among New Jersey's population.
- . The State should develop regional centers for the diagnosis and management of Alzheimer's disease. These centers should include a data collection component.
- . Legislation should be introduced mandating that insurance companies operating within New Jersey include coverage for the diagnosis and management of Alzheimer's disease and related disorders.
- . The State should develop specialized training programs on dementia and offer them at the local level to community workers.

- . The State should establish demonstration programs to test the cost effectiveness of various treatment modalities (day care, respite care, etc.) on patients with dementing disease. In addition to providing assistance to the patient and the caregiver, the staff of these programs could share their experience and train additional professionals in the most appropriate methods of managing this population.
- . The State should compensate the family for the cost of an autopsy to verify the diagnosis of Alzheimer's disease.

Resource Task Force

Commission Members:

Assemblyman David Schwartz - co-chairperson
 Deborah Piggins - co-chairperson
 Assemblyman Nicholas Felice
 Hugh Koops
 Helena Meade
 Donna Rooney
 Terry Tanenbaum

Others:

Hadijah Carlyle - Aide to Assemblyman Schwartz
 Dierdre Fisher - Department of Health
 Rickey Greene - Department of Health
 Lorraine Lesiak - Department of Health
 Angela Waff - Department of Human Services

The purposes of the Resource Task Force were to:

- . Identify health and social service resources available to the victims of Alzheimers disease and related disorders and barriers to effective treatment.
- . Examine problems faced by Alzheimer's disease and related disorders victims and their families.

Initial recommendations were:

- . The Department of Health should conduct a survey of licensed health facilities to determine admission policies, treatment cost, training of personnel and the utilization rates. (See Appendix IV)
- . To conduct public hearings which would enable the Task Force to inform the Legislature and Governor of the findings regarding the resources and problems relating to Alzheimer's disease.

Medical Task Force

Commission Members:

Frank Snope, M.D. - Chairman
Helena Meade
Donna Rooney
Terry Tanenbaum
Joan Mintz - Deputy Director, Division on Aging
Martin Epstein, M.D. - Chief Medical Consultant, Department
of Human Services

Others:

Rickey Greene - Department of Health
Leslie Marter - Department of Health
Dierdre Fisher - Department of Health
Joan Wagner - Department of Health

The purpose of the Medical Task Force was to assess the diagnostic, evaluation and treatment criteria appropriate for Alzheimer's disease and related disorders victims.

The Task Force developed the following recommendations:

- . The State of New Jersey should consider establishing three regional centers for the diagnosis, study and management of Alzheimer's disease and related disorders. The centers should be affiliated with the campuses of the University of Medicine and Dentistry of New Jersey.
- . The State of New Jersey should immediately undertake a series of educational activities for health professionals in the diagnosis and management of Alzheimer's disease and related disorders.
- . Alzheimer's disease and related disorders should be designated a reportable disease for a period of five years.

SUMMARY OF TESTIMONY GIVEN AT THE PUBLIC HEARINGS

The following summary highlights the concerns of 63 individuals who gave testimony at the three public hearings of the Alzheimer's Disease Study Commission. Approximately 150 people, including both interested professionals and family caregivers, were in attendance throughout the hearings which were held on:

November 7, 1984, at Essex County College, Newark,
New Jersey;

November 28, 1984, at UMDNJ Robert Wood Johnson Medical School, New Brunswick, New Jersey and

December 5, 1984, at Stockton State College, Pomona, New Jersey.

Of the 63 individuals providing testimony, thirty-eight were family caregivers and twenty-five represented interested professionals.

The following enumerates the major concerns voiced at these public inquiries. These concerns emphasized the need for improved:

- . Education of Health Care Providers and the General Public
- . Financial Assistance/Availability of Insurance
- . Legal Counseling
- . Accurate Diagnosis
- . Community Based Services
- . Coordination of Care
- . Respite Care
- . Day Care
- . Family Support and Counseling
- . Nursing Home Policies
- . Research

Education

Family caregivers were adamant about the need for improved education of both professional and nonprofessional individuals caring for victims of Alzheimer's disease. Physicians, nurses, social workers, therapists, clergy, homemaker-home health aides, and family care providers were specifically identified as priorities for improved education.

Physicians, it was reported, often lack knowledge about the disease, appropriate diagnostic workup, and the availability of community resources which may be of benefit to the client and/or the family.

Medical and nursing personnel in acute care hospitals and long-term care institutions, on numerous occasions, readily

acknowledged to family members their lack of knowledge about Alzheimer's disease.

Likewise, during the home stage of care, a stage which is desirable by most for as long as feasible, nurses and home health aides admittedly lacked training concerning specific interventions for the Alzheimer disease victim.

Family caregivers voiced reluctance to allow home health care providers in their home with limited, if any, knowledge about Alzheimer's disease. One gentleman utilized a video-taped program about the disease for the numerous aides coming to care for his wife. A lack of continuity in aide assignment was identified as a common occurrence within home health agencies, a situation which creates additional stress on the victim and their family.

Specific geriatric/gerontological course content is not clearly identifiable in the curriculum of many health-related professional schools. The elderly population is the most rapidly growing segment of our population and accounts for a disproportionate percentage of the clientele serviced by the health care system. Hence, it was recommended that specific training related to the needs and health problems of the older adult should be mandated by the Department of Higher Education and/or various disciplines. Furthermore, specific training about Alzheimer's disease should be required for those presently involved in the care of geriatric clients via continuing education programs throughout the health care system.

The availability of effective educational programs on Alzheimer's disease was another area of concern. One suggestion for meeting this need for information statewide and which warrants consideration by the Alzheimer's Disease Study Commission was the development of regional training centers. Attracting instructors and/or speakers with expertise in the management of Alzheimer's disease is at best difficult. The development of regional multi-purpose training centers would be a positive step towards making accurate, updated information available to care providers about this devastating disease and the specialized approaches necessary to manage the symptoms and behavior imposed by the disease.

Financial Assistance

A problem identified by almost every individual providing testimony, both family caregivers and professionals alike, was the financial strains which Alzheimer's disease all too often inflicts on its victims and their families. The long term effects of a chronic illness such as Alzheimer's disease requires, most often, support in terms of custodial care, social services, counseling, and support and respite for family care providers. Subsidized funding for the chronically ill individual who

requires these services but does not require "skilled care" is currently non-existent for a large portion of the United States population.

Only those who are extremely wealthy or qualify for Medicaid can afford the necessary care to maintain the client at home or in an institution (i.e., the 15,000-40,000 or more dollars per year needed to care for the Alzheimer's disease victim who, once diagnosed or exhibiting behavioral symptoms, generally has a life expectancy up to 10 years or greater).

One alternative is to apply for municipal welfare, an action providing additional trauma for many individuals, and in the end, financial aid still may be infeasible.

Professionals from long term care institutions, home health agencies, and day care facilities shared the financial concern of family care providers. While their goal is to provide quality high level care, reimbursement constraints for "non-skilled" care make admission of Alzheimer's victims a financially draining situation. One speaker recommended that it was time for the "arbitrary and restrictive" interpretation of the terminology "skilled" versus "custodial" care to be reassessed; current definitions of these terms and current policy disqualifies Alzheimer's victims from benefits from most private insurance plans and Medicare. Even Medicaid reimbursement is based on the level of "skill" required to care for the individual. Hence, those agencies accepting clients receiving Medicaid are reimbursed for the lower rate of "non-skilled" care despite the reality that specialized skill is required to care for the individual with Alzheimer's disease and his/her family.

Legal counseling for the elderly is available and can help avert some of these problems if initiated early in the course of the the disease or preferably as a part of routine planning for advancing age. Legal counseling should be a part of the referral process.

Clearly, the message provided by those individuals making statements at these public hearings is that a need exists for the Legislature to explore and support measures to assist families in meeting the exorbitant costs inflicted by this devastating disease.

Diagnosis

Obtaining an early diagnosis of Alzheimer's disease has been identified as a major problem encountered by victims and their families. A diagnostic tool specific for Alzheimer's disease does not currently exist; therefore, physicians treating clients with a suspected dementia work by a process of elimination. Many reversible conditions can mimic Alzheimer's disease and the

ramifications of mislabeling a client can be catastrophic for all those involved.

Family caregivers and professionals alike expressed the need for a more informed medical community. Physicians responsible for providing a diagnosis should have knowledge of and access to those having the expertise and equipment necessary to adequately assess those individuals presenting the symptoms congruent with dementia.

At the time of the public hearings, New Jersey did not have a diagnostic center designed to meet the needs of those affected by Alzheimer's disease. Family members reported traveling to Philadelphia, New York, and Maryland in order to obtain a comprehensive diagnostic evaluation. The creation of one or more diagnostic centers in New Jersey may mean an earlier and more accurate diagnosis. Early diagnosis is essential to the effective and efficient long range planning required by those affected by this disease. In addition, these diagnostic centers have the potential to provide a secondary gain of being established training sites for health care professionals.

Community Services

Despite the burdens of caregiving, the desire to keep the Alzheimer's disease victim at home for as long as possible was well affirmed by many providing testimony. Successful home care, however, can be draining and requires community resources which assist and support the primary care providers.

Unfortunately, many family caregivers and professionals are unfamiliar with the mechanism of receiving information about available community resources. Individuals are all too often passed from one potential information source to another without obtaining answers and/or help in identifying specific local resources.

Several viable suggestions were proposed by those providing testimony to help bridge this information gap. Many participants thought that a statewide clearinghouse for information and referral would be beneficial. Likewise, improved dissemination of information pertinent to Alzheimer's disease and better utilization of the existent network serving the older population in New Jersey were suggested as perhaps the "best possible" resource for a standardized information and referral system.

A plea for improved availability of community-based services was also expressed by those testifying. The need for day care programs designed for Alzheimer's disease victims and other forms of in-home and/or institutional respite care for family care providers was clearly identified as a desirable community service. Most day care centers operate Monday through Friday between the hours of 9:00 A.M. to 4:00 P.M. Family care

providers expressed the hope that new programs be developed to meet the needs of those care providers who must work. Effective day care has the potential to reap multiple benefits such as improved functional level, self-esteem and dignity for the victims and provide a period of rest or reprieve for stressed family caregivers.

Support within the community is perhaps best exemplified by the work being done by the various Alzheimer's disease support groups which have emerged throughout the state and the nation. Advocacy for these support groups was requested as they currently provide the vast majority of counseling provided to family caregivers.

Nursing Home Concerns

The decision to place the Alzheimer's victim in a nursing home is difficult at best and often comes about as family or friends gradually realize the long-term consequences of mental decline. A curious blend of grief, guilt, and relief is associated with the decision to relinquish the direct responsibility of care to professionals in a nursing home.

Choosing a desirable institution to provide for the multiple and specialized needs of the Alzheimer victim has been identified as a time consuming and frustrating process by many. Families are confronted with long waiting lists, institutions who have only a limited number of beds for confused individuals, and all too often, nursing homes who refuse to accept patients with dementia. Even if one finds a home which will accept an Alzheimer's disease victim, many institutions will not accept Medicaid clients. Some nursing homes in New Jersey will refuse to keep a client who has exhausted all of his/her private pay funds.

Legislation which will prohibit some of these current policies and practices was requested by those concerned individuals present at the public hearings.

Support for the development of special units or programs designed to meet the specific needs of the Alzheimer's disease victims within existing nursing homes, was also requested. Several programs currently exist in New Jersey long term care institutions and may eventually serve as role models towards quality care.

Research

Finally, there was a plea for continued research into the causes, treatment, and day to day management of Alzheimer's disease. Those providing testimony expressed a desire and willingness to participate in clinical studies if available. Victims and care providers alike are desperate in their need to find and do something which may promote a positive change in the quality of their lives. (For excerpts of actual testimony, see Appendix V.)

ROLE OF THE HEALTH DEPARTMENT

Staff from the Gerontology Program of the New Jersey State Department of Health were assigned the responsibility of acting as resource persons to the Commission. They planned the Commission meetings, identified and obtained resources, and answered numerous public inquiries concerning the Commission's activities and resources available for persons with dementia in New Jersey.

The first activity performed by staff was to design and mail a survey on Alzheimer's disease and related disorders to all state directors of aging, leading medical and social researchers in the field of dementia and the various federal agencies that serve the elderly. They were asked to provide information concerning the following:

- . incidence of Alzheimer's disease
- . financial impact of Alzheimer's disease on health and social service systems
- . financial assistance currently available to victims and their caregivers
- . needs of the victims and caregivers
- . state legislation or special studies pertaining to Alzheimer's disease
- . model programs addressing needs of the victim and caregiver
- . current research
- . specialized training for professionals and/or caregivers.

The survey, which was disseminated in August, 1984, yielded considerable technical information concerning research in progress. However, it was disappointing to discover that most states did not have any specialized services or statistics on Alzheimer's disease. Many indicated that they worked closely with affiliates of the Alzheimer's Disease and Related Disorders Association and referred inquiries to them.

The next task that was undertaken was to conduct a literature search. Contact was also initiated between staff and the regional Long Term Care Gerontology Centers funded by the United States Administration on Aging. From the Centers,

information was received concerning their training activities and research.

Contact was initiated between the Department and the national office of the Alzheimer's Disease and Related Disorders Association (ADRDA). They provided us with copies of their newsletter which identified new legislation being considered in other states.

The ADRDA lobbyist in Washington, D.C. informed staff of new federal legislation which would impact on Alzheimer's disease. Subsequently, copies of all state and federal legislation were obtained, analyzed and a summary was prepared and distributed to the members of the Commission.

Staff from the Gerontology Program visited the COPSA Day Hospital at the University of Medicine and Dentistry - Robert Wood Johnson Medical School, Community Mental Health Center. COPSA staff have been extremely generous with their time and expertise. They and representatives of the Alzheimer's Disease Support Network, a statewide organization of self-help support groups for caregivers, helped staff identify existing resources for victims and family caregivers. Additional assistance was obtained from the New Jersey Self-Help Clearinghouse. As a result, lists of self-help groups for family caregivers and day care centers that would accept persons with dementia were developed and widely distributed. These ultimately were expanded into Alzheimer's Disease: A New Jersey Directory of Services for Family Caregivers and Health and Human Service Providers, which was developed in collaboration with the New Jersey Division on Aging.

The Commission, on July 12, 1984, convened for the first time and formulated three task forces:

1. Needs Assessment
2. Resources
3. Medical

The first task force attempted to obtain New Jersey specific data on incidence and prevalence. Staff were unable to identify any one data base that had reliable information on persons with dementia. One problem identified was the fact that most insurance policies will not reimburse for chronic care. Thus many persons with Alzheimer's disease are not eligible for care, unless they are also being treated for an acute condition (eg., pneumonia, falls, etc.). Thus, we were unable to obtain any reliable data from the Hospital Discharge Abstracts, since the primary and secondary diagnosis most usually involves an acute condition. Staff conducted a survey of Long Term Care Facilities (See Appendix IV) to determine the incidence of dementia in nursing homes and residential health care facilities. One problem we experienced was that although we provided appropriate codes from the Diagnostic and Statistic Manual III, and

the International Classification of Diseases, 9th revision, many residents had been admitted prior to these revised manuals, and the codes for their admitting diagnoses were not necessarily compatible. Finally, staff reviewed Vital Statistics for 1982 in the hope of identifying deaths from various forms of dementia. In that year, a total of 46,899 persons who were age 65 or older expired in New Jersey. Only 86 death certificates (.18%) indicated that the primary cause of death was a form of dementia. Most physicians will not list dementia as a cause of death unless a brain autopsy is performed.

To determine the prevalence of Alzheimer's disease and related disorders in New Jersey, consultation was sought from from Mary Breckenridge, Ph.D. of the University of Medicine and Dentistry and John Toner, Ph.D. of the Columbia Long Term Care Gerontology Center. It was decided to apply the preliminary findings from the National Institute of Mental Health funded Epidemiologic Catchment Area Study to New Jersey's population (See p. 4).

The Task Force on Resources decided to convene three public hearings to allow family caregivers and health professionals an opportunity to identify problems they encounter and to offer recommendations. A letter was sent from Commissioner Goldstein to most professional organizations in the state informing them of the public hearings and inviting them to testify. Among those invited included: New Jersey Medical Society, New Jersey State Nurses Association, Home Health Agency Assembly of New Jersey, Home Care Council of New Jersey, Offices on Aging, New Jersey Hospital Association, National Association of Social Workers, the two nursing home associations, and pharmaceutical and insurance companies. Invitations were also sent to Alzheimer's Disease and Related Disorders Association and leading gerontologists in the tri-state area. The various self-help groups were contacted and encouraged to attend. Finally, the Office of the Commissioner issued a press release which was widely covered by the media. See p. 10 for a summary of the testimony at the three public hearings.

The Medical Task Force examined the availability of medical personnel with expertise to diagnose dementia and the training needs of caregivers and health professionals. This task force recommended the establishment of three diagnostic centers affiliated with the University of Medicine and Dentistry and that the Department of Health develop a training program for caregivers and health professionals on the management of the patient with dementia.

Staff from the Gerontology Program subsequently contacted all dementia diagnostic centers in the tri-state area to learn more about their testing procedures, staffing patterns, and their operational costs. This information was summarized, presented to the Commission, and later incorporated into the resource directory.

A site visit was conducted to the New York City Alzheimer's Resource Center, which is operated by the New York City Department for the Aging. This program functions as a clearinghouse for information and referrals for family caregivers and the professional community. Staff from the Alzheimer's Resource Center were extremely cooperative and provided valuable assistance.

Dr. Goldstein, Commissioner of Health and Ann Zahora, Director of New Jersey Division on Aging met with representatives of the Brookdale Foundation of New York City to discuss plans to educate the public and professional community in the diagnosis and management of dementia. The Department of Health (Gerontology Program) and the Department of Community Affairs (Division on Aging) submitted a grant application to the Brookdale Foundation which was funded for \$53,000. These funds were used to develop and publish Alzheimer's Disease: A New Jersey Directory of Services for Family Caregivers and Health and Human Service Providers, to sponsor the Governor's Conference on Alzheimer's disease and related disorders which was held on November 19, 1985, at the Hyatt Regency Hotel in Princeton, New Jersey (See Appendix VI), and for specialized educational seminars for physicians and homemaker-home health aides.

Another training conference was held on June 17, 1985. This conference, which was co-sponsored by the Home Care Council of New Jersey, was titled Home Management of Patients with Dementia (See Appendix VII). This conference, which was attended by 200 persons, was specially designed to meet the needs of staff from home health agencies and visiting homemaker agencies.

Gerontology Program staff worked closely with Commission members and the New Jersey Alzheimer's Disease Support Network in participating in numerous educational programs through-out the state. Among the presentations were: Adult Day Care Association, Garden State AHEC, New Jersey State Nurses Association (Constituency 3), Storer Cable Network, 3 seminars to train the trainers of homemaker-home health aides, and various other audiences, including support groups. Finally, the Department of Health, Gerontology Program, and the Home Health Agency Assembly of New Jersey were successful in obtaining a grant from the United States Public Health Service to train public health nurses in gerontology. Seven hours of the 35 hour curriculum are devoted to the diagnosis and management of the patient with dementia. In the first year, approximately 400 nurses will be trained under this project.

Legislation was introduced in the General Assembly (A-2463) which would appropriate \$1,000,000 to the Department of Health for the purchase of adult day care services for individuals with dementia. The Department supports this legislation and believes that day care may promote a better quality of life for the victim by maintaining an optimal level of functioning for a longer

period of time. As a result of this bill, the Gerontology Program staff met with representatives of the Adult Day Care Association on several occasions to discuss the need for licensure of adult day care centers.

On April 30, 1985, Dr. Goldstein appeared before the Joint Appropriations Committee of the New Jersey Legislature. He testified in support of a resolution introduced to allocate monies to the Department to establish an Alzheimer's Disease Diagnostic Center and an Alzheimer's Disease Resource Center. As a result of the Department's support and advocacy from the Alzheimer's Disease Support Network, the Department of Health received an appropriation of \$500,000 for Fiscal Year 1986.

The Department of Health awarded a contract of \$500,000 to the University of Medicine and Dentistry - Rutgers Medical School CMHC to develop the COPSA Institute for Alzheimer's Disease and Related Disorders. The institute includes an Alzheimer's Disease Resource Center as well as a Diagnostic Center (See Appendix VIII).

On October 28, 1985, Congressman Matthew Rinaldo convened a hearing of the House Select Committee on Aging in Elizabeth, New Jersey to discuss the problems encountered by victims of Alzheimer's disease. Commissioner Goldstein attended and informed the Committee of the activities of the Alzheimer's Disease Study Commission and the needs that were identified at the Commission's public hearings.

Two final staff activities were working with the Governor's Office to proclaim November, 1985, as Alzheimer's disease and related disorders month (See Appendix IX), and preparation of the feature article on Alzheimer's disease in Healthline for January/February, 1986. Healthline is the Department of Health's newsletter and has a distribution of almost 2,000 health care providers (See Appendix X).

RECOMMENDATIONS, RATIONALE AND ACCOMPLISHMENTS

Recommendation #1

The State of New Jersey should support the establishment of a statewide resource directory for family caregivers and health and human service providers.

Rationale

A statewide resource directory would be a valuable instrument in providing information to family care providers and the health care community about existent resources and community or institutional services which may help families cope with the problems

imposed by the disease. Linking the victims to appropriate resources can be vital in maintaining their dignity and optimal level of functioning.

Accomplishment

In November 1985, the Alzheimer's Disease Directory of Services for Family Caregivers and Health and Human Service Providers was published and subsequently distributed at the Governor's Conference on Alzheimer's Disease and Related Disorders. It was developed co-jointly by the New Jersey Department of Health, Gerontology Program and the New Jersey Department of Community Affairs, Division on Aging. It includes current information about the types of resources available in specific geographic areas which might be of assistance to families and victims of Alzheimer's disease and related disorders. The project was funded with monies from the Brookdale Foundation Grant. The original printing consisted of 2,000 copies which were distributed throughout the state. The Resource Directory is presently being updated and an additional 2,000 copies will be printed.

Recommendation #2

The State of New Jersey should develop an Alzheimer's Disease and Related Disorder Resource Center which will link Alzheimer's victims and their families with appropriate programs and services to meet their complexity of needs. The Commission recommends that \$150,000 be appropriated for this purpose.

Rationale

Family care providers and professionals alike are often unfamiliar with the mechanism of obtaining required knowledge about available health and social services for those affected by Alzheimer's disease. Individuals are all too often passed from one potential information source to another without obtaining answers and/or in identifying specific local resources.

The establishment of a statewide resource center would augment the valuable efforts of the caregiver support groups and result in improved access and utilization of community based services (i.e., day care, respite care). The development of educational materials and programs focused towards assisting those persons, family or otherwise, requesting help from the resource center will lead to an increased awareness and understanding of the problems associated with Alzheimer's disease and related disorders and hopefully to a reduction in stress related to the altered lifestyle imposed by the disease.

The expertise of those at the resource center would also be further utilized by direct involvement in training workshops and seminars for professionals. This will lead to improved diagnosis

and management of persons with irreversible dementias and a better plan for service delivery.

Recommendation #3

The State of New Jersey should support the establishment of a diagnostic center for the cognitively impaired. The first diagnostic center would be affiliated with UMDNJ - Robert Wood Johnson Medical School.

A multidisciplinary approach to the assessment process is deemed most appropriate and will facilitate effective and efficient long-range planning for the victim and family affected by Alzheimer's disease or a related dementia. The Commission recommends that \$600,000 be appropriated for the diagnostic center.

Rationale

Obtaining an early diagnosis of Alzheimer's disease has been identified as a major problem encountered by victims and their families. A diagnostic tool or test specific for Alzheimer's disease does not currently exist. Therefore, physicians treating clients with a suspected dementia work by a process of elimination. Many reversible conditions can mimic Alzheimer's disease and the ramifications of mislabeling a client can be catastrophic for all those involved.

Family care providers and professionals alike express the need for a more informed medical community. Physicians responsible for providing a diagnosis should have knowledge of and access to those having the expertise and equipment necessary to adequately assess those individuals presenting with symptoms congruent with dementia. Hence the diagnostic center would not only provide an invaluable service to dementia victims and their families, but would also have the potential of becoming an established training site for health care professionals who deal with the cognitively impaired.

The State of New Jersey does not currently have a diagnostic center designed to meet the needs of those affected by Alzheimer's disease. Family members are forced to travel to neighboring states in order to obtain this specialized evaluation. Long trips are difficult for dementia victims and their families.

Accomplishment

In October 1985, the Institute for Alzheimer's Disease and Related Disorders was established at the University of Medicine and Dentistry of New Jersey, Robert Wood Johnson Medical School in Piscataway, New Jersey. This project was funded by a supplemental appropriation of \$500,000 in the State budget for Fiscal Year 1986, to the University of Medicine and Dentistry of

New Jersey, Robert Wood Johnson Medical School, through the Department of Health. A total of \$600,000 was appropriated for the Institute for Fiscal Year 1987. The Institute provides the following services:

a. Resource Center

The Resource Center maintains a current directory of services available to Alzheimer's victims and their families and disseminates this information throughout the state. It has an 800-toll free number which enables family caregivers, professionals and the general public to obtain information relevant to all aspects of Alzheimer's disease through a central clearinghouse. It also provides crisis counseling and education of family caregivers and health professionals.

b. Diagnostic Clinic

The Diagnostic Clinic utilizes a multidisciplinary approach to evaluate and plan appropriate methods of treatment for Alzheimer's victims. The evaluation includes a comprehensive work-up to differentiate reversible from irreversible dementias.

c. Day Care

The Day Care program is designed specifically for dementia patients. It evaluates the ability of the dementia patient to perform activities of daily living and provides rehabilitation and constant monitoring of the patient's status. In addition it offers support services and education to both formal and informal caretakers.

d. Consultation and Training

It provides a training site for hands on professional education, as well as consultation, education and training for family members, health professionals and others who work with dementia patients.

Recommendation #4

The State of New Jersey should provide support for the expansion of adult day care programs and should provide for and coordinate the utilization of existing services for both in home and out of home respite care in order to furnish relief and support to family and other unpaid care providers of those afflicted with Alzheimer's disease or a related disorder. The Commission

recommends that \$3,000,000.00 be appropriated for day care and respite care services.

Rationale

Family or other caregivers who provide care in the home are frequently under substantial stress, physically, emotionally, and financially.

The demands and responsibilities of the caregiving role may be overwhelming to the individual who may also be coping with their own aging. The caregiver often has failing health, and may rapidly be depleting their financial resources. Younger or middle age caregivers also suffer the strains inherent in caring for the progressively declining victim of Alzheimer's disease or a related disorder. The concurrent roles of being a spouse, parent, and/or full or partial breadwinner can result in turmoil for all family members. Respite care and other community based supportive services such as adult day care could relieve some of these stresses, maintain and strengthen the family unit, and postpone or prevent institutionalization.

Day care programs can provide relief from the steadily increasing responsibilities of caring for the dementia victim at home. Unfortunately, many existent programs limit or deny admission to victims of dementia. The physical and behavioral manifestations of the disease may necessitate greater staff - client ratios and a specialized program of activities.

Only a few day care programs designed to meet the special needs of dementia victims and their families currently exist in New Jersey. Experience has shown, however, that two to three days of attendance each week not only lightens the emotional and physical burdens experienced by family members but may also promote a better quality of life for the victims by maintaining an optimal level of functioning for a longer period of time.

Day care centers which recognize the unique needs of the client with dementia and their families also provide an avenue for family members to gain mutual support and exchange ideas for coping with and managing the behaviors characteristic of dementia.

The formulation of demonstration projects in day care for the cognitively impaired adult will furnish a valuable service to New Jerseyans. These model programs should also serve as training sites for those providing care in a variety of settings to individuals with Alzheimer's disease or a related disorder. Hence, they have the potential to perpetuate a service which may postpone nursing home placement and provide a better quality of life for both the victims and their families.

Accomplishment

Legislation has been introduced in both the Senate (S-2252) and the Assembly (A-2463) which would appropriate 1,050,000.00 from the General Fund to the Department of Health to be used for the purchase of adult day care services for persons with Alzheimer's disease. An appropriation of \$50,000.00 is included to contract for the development of the training program required under this act.

These bills also require:

- (a) that family support groups should be established by each grantee;
- (b) individuals who cannot afford the entire cost of the program should be assisted in accordance with a sliding fee scale;
- (c) services should be provided to assist family members, including counseling and referral to other resources.

Legislation (S-2167) has also been introduced in the Senate which would appropriate \$1,000,000.00 to the Department of Human Services which would establish in-home and out-of-home respite care services for functionally impaired persons. Caregivers of individuals with a form of dementia would be eligible to receive respite care services.

Recommendation #5

The State Department of Health in collaboration with the various health related professional associations (i.e., physicians, nurses, social workers and occupational therapists), members of the clergy, the Departments of Community Affairs and Human Services, and the Alzheimer's Disease Support Network should develop and implement seminars and/or workshops on issues relevant to Alzheimer's disease and related disorders. Continuing education programs should be targeted towards a multidisciplinary audience and should, when appropriate, include family or other nonpaid caregivers. The Commission recommends that \$50,000.00 be appropriated to the Department of Health for the development of a training program for nursing home staff on the management of dementia.

Rationale

Individuals providing testimony at the three Alzheimer's Disease Study Commission public hearings were adamant about the need for improved education of both professional and nonprofessional care providers for victims of Alzheimer's disease.

Information about the disease process, appropriate diagnostic workup, the availability of community resources, and concrete strategies for managing the behaviors characteristic of a dementing illness were identified as major knowledge deficits among care providers.

Educational attention to Alzheimer's disease is most deserving as this disease is reaching catastrophic proportions. While experts formerly believed that the incidence of Alzheimer's disease was low and only occurred in individuals under 65, this disorder is now recognized as the most common cause of severe intellectual impairment in older adults.

Educating those who care for older adults or an elderly family member is a priority and can occur in a variety of settings.

Accomplishment

In June 1985, the Home Care Council of New Jersey and New Jersey State Department of Health, Gerontology Program co-sponsored a seminar on home management of patients with dementia. This conference focused on issues related to the day to day management of noninstitutionalized individuals with a dementing illness. Those attending the seminar included nurses, social workers, homemaker/home health aides, therapists, nutritionists, and family members, who provide care in the home. This conference was attended by approximately 200 people.

In November 1985, the New Jersey Department of Health, the New Jersey Department of Community Affairs and the Brookdale Foundation co-sponsored the New Jersey Statewide Conference on Alzheimer's Disease. The funding was made available through the Brookdale Foundation. The conference focused on the dissemination of information about Alzheimer's disease and related disorders to professionals and the public. It brought together national and state experts on Alzheimer's disease. It also gave an opportunity to discuss the state's plan for services to Alzheimer's disease victims and their families. This conference was attended by more than 400 people, including health care professionals and family caretakers.

Through funds from the Brookdale Grant, education and training programs will be offered to homemaker-home health aides in the care and management of dementia. In addition plans are currently being formulated to provide physician training through roving symposia and day long seminars.

Recommendation #6

A study should be undertaken by the Department of Insurance on developing a long-term private insurance product for Alzheimer's disease patients.

Rationale

Alzheimer's disease is a chronic condition and most insurance policies only cover acute/skilled care. The need for investigation into long-term insurance is important because of the financial burden placed on the Alzheimer's victims and their caretakers. The cost of institutional care for patients with dementia has been estimated to exceed \$25 billion a year (Katzman, 1986). It is only after a person becomes impoverished, can they obtain any type of assistance, such as medicaid.

Recommendation #7

The New Jersey Department of Health should develop a brochure to give information to caretakers of Alzheimer's patients about autopsy costs, brain banks and other resources available to them.

Rationale

Many families wish to have autopsies done in order to aid research programs that would identify the causes and treatment methods for Alzheimer's disease. Arrangements for the autopsy procedure should be made in advance. However, there is little information available to the public regarding autopsy costs, brain banks, and the procedures involved in utilizing these services (See Appendix XI).

Accomplishment

The New Jersey Department of Health's Gerontology Program has begun to investigate the costs and problems entailed in having autopsies performed on people tentatively diagnosed as having Alzheimer's disease. In Fiscal Year 1987, the Gerontology Program will develop a brochure regarding autopsy costs, brain banks and the resources available to families who wish to have autopsies performed.

Recommendation #8

The New Jersey Department of Health should develop guidelines for the care of Alzheimer patients in nursing homes. These guidelines would include methods to deal with the specific problems encountered in the care of Alzheimer patients.

Rationale

Many nursing homes will not accept Alzheimer's disease patients because of behavioral changes which result in the need for a higher number of nursing care hours. These guidelines would assist nursing homes in developing programs and/or services to adequately care for Alzheimer patients and potentially reduce the nursing care hours needed to care for these patients.

Recommendation #9

Efforts should be taken to expand Medicare to cover chronic illness.

Rationale

Alzheimer's disease is a chronic illness and Medicare only reimburses for acute care. The cost of caring for an Alzheimer's disease victim can financially destroy a family. The cost of care increases as the disease progresses. In the later stages, custodial services such as bathing, dressing and feeding are needed which are not covered by Medicare. Consequently, if the caregiver must continue to work, a paid helper must be hired and be paid by the victim or by the caregiver. Other non-covered expenses include respite care, day care services and medical surgical supplies.

Recommendation #10

The Department of Higher Education should work with the various professional schools in New Jersey (medical, nursing and allied health professionals) to see that information related to Alzheimer's disease and related disorders be included in the curricula. The Department of Higher Education should further use its influence to have questions concerning Alzheimer's disease and related disorders included on state licensing board examinations.

Rationale

If this information is included in the curriculum, it would sensitize health professionals to the various facets of Alzheimer's disease and would result in better diagnosis and treatment plans.

Recommendation # 11

We encourage both federal and private research concerning the etiology and treatment of Alzheimer's disease and related disorders.

Rationale

This research is necessary in order to prevent the proliferation of Alzheimer's disease and to reduce the economic, social and psychological effects associated with this illness.

GLOSSARY

Activities of Daily Living:

Those actions performed on a day to day basis in order to maintain a level of functioning.

Adult Day Care:

The provision of medical care and treatment and/or socially supportive services to older persons in one site, usually during work hours when the primary caregiver is otherwise occupied.

Alzheimer's Disease:

A progressive brain disease of unknown causes which results in global cognitive impairment.

Autopsy:

The post mortem examination of a body.

Biopsy:

A diagnostic examination of a piece of tissue removed from a living subject.

Caretaker:

A family member or significant other who assists another person in managing their activities of daily living.

Cognitive Impairment:

A deterioration of the mental processes of thought, memory, comprehension, and reasoning.

Conservatorship:

A limited form of guardianship where the conservator is only responsible for financial matters of the person involved.

Diagnosis:

The act or process of deciding the nature of a disease by examination and observation.

Guardianship:

A legal process by which another person assumes total responsibility for the welfare of another. The person involved becomes a ward of the guardian.

Homemaker-Home Health Aide:

An individual certified by the State Department of Health as having satisfactorily completed a training course approved by the Department and employed by a public or private agency licensed as a Homemaker-Home Health Aide Agency in the state of New Jersey.

Medicaid:

A federal and state program for health care costs for those low income persons who qualify. Limits are set on the cash and non-cash resources a person may have.

Medicare:

An entitlement program under Social Security for persons 65 and older eligible for Social Security and for permanently disabled younger persons. Part A covers some of the costs associated with hospital and post-hospital nursing home or home health care. Part B, purchased with a monthly premium, is a supplemental insurance covering physician and other non-hospital costs.

Mental Status Test:

Usually a standardized procedure (e.g. Falstein MMSE) with the primary purpose of gathering data to determine etiology, diagnosis, prognosis and treatment of mental status disorders.

Neurofibrillary Tangle:

Tangled threadlike nerve fibers lying in the cell bodies of the neurons.

Neuritic (Senile) Placques:

Deposits of starch-like protein on the nerve fibers that interfere with transmission of information between the nerve cells.

Respite Care:

Arrangements for a specific period of relief from the regular responsibilities of care of another.

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APPENDIX I

PUBLIC LAW 1983, CHAPTER 352

Chapter heading editorially supplied.

Section

- 26:2M-1. Legislative findings and declarations.
- 26:2M-2. Alzheimer's disease study commission; membership; vacancies; compensation.
- 26:2M-3. Chairman.
- 26:2M-4. Duties of commission.
- 26:2M-5. Employees.
- 26:2M-6. Hearings; findings and recommendations.

Chapter heading editorially supplied

26:2M-1. Legislative findings and declarations

The Legislature finds and determines:

- a. In recent years Alzheimer's disease has come to be recognized as presenting a medical and social problem of grave dimensions.
- b. A degenerative and fatal brain disease of undetermined origin, Alzheimer's disease currently affects four million people in the United States, some as young as 40, causing progressive memory loss, confusion, inability to communicate, extreme personality change, and eventual inability to perform the most basic tasks.
- c. No effective treatment for this disease is at present known, and proper care for persons afflicted with it is difficult and expensive to procure; coping with the needs of those afflicted becomes more arduous as the disease progresses; and adequate care for those afflicted is beyond the means of many families.
- d. It is appropriate that State Government take due cognizance of this significant problem in the field of public health and social welfare; that it take such measures as may be feasible and appropriate to ease the burdens of the afflicted and their families; and that it facilitate the study and awareness of means to care for the victims of Alzheimer's disease and of present or prospective approaches to the treatment of the disease.

L.1983, c. 352, § 1, eff. Sept. 29, 1983.

Assembly Committee On Aging Statement

Assembly, No. 3638—L.1983, c. 352

This bill creates a commission to study Alzheimer's disease and the social and medical needs which result from it. Members of the commission would include the Commissioners of Health, Human Services and Community Affairs, ex-officio, two Senators, two Assemblymen and seven citizens including three health professionals, and family members or legal guardians of persons afflicted with the disease.

The bill directs the commission to promptly prepare an initial report and other reports as its studies progress, and requests it to report to the Governor and the Legislature recommendations for governmental action or proposed legislation to assist and alleviate the needs of victims of Alzheimer's disease and their families.

Two technical amendments were adopted by the committee.

Title of Act:

An Act to create the Alzheimer's Disease Study Commission. L.1983, c. 352.

26:2M-2. Alzheimer's disease study commission; membership; vacancies; compensation

a. There is created the Alzheimer's Disease Study Commission, which shall consist of:

- (1) The Commissioners of the Departments of Health, Human Services and Community Affairs, who shall serve during their continuance in their respective offices;
- (2) Two members of the Senate, who shall not be of the same political party, to be appointed by the President of the Senate, and who shall serve during their continuance in office as Senators;
- (3) Two members of the General Assembly, who shall not be of the same political party, to be appointed by the Speaker of the General Assembly, and who shall serve during their continuance in office as members of the General Assembly;
- (4) Seven citizen members, including no more than three health professionals who are currently involved in direct services to victims of Alzheimer's disease, to be appointed by the Governor, who shall be chosen from among persons who by reason of family relationship or legal guardianship bear, or have borne, responsibility in caring for victims of Alzheimer's disease.

b. Vacancies in the membership of the commission shall be filled in the same manner as the original appointments were made.

c. Members of the commission shall serve without compensation, but shall be entitled to reimbursement for actual expenses necessarily incurred in carrying out their duties as members of the commission.

L.1983, c. 352, § 2, eff. Sept. 29, 1983.

Statement: Committee statement to Assembly, No. 3638—L.1983, c. 352, see § 26:2M-1.

26:2M-3. Chairman

The commission shall organize as soon as may be practicable after the appointment of its members and shall select a chairman from among its members and a secretary who need not be a member of the commission.

L.1983, c. 352, § 3, eff. Sept. 29, 1983.

Statement: Committee statement to Assembly,
No. 3638—L.1983, c. 352, see § 26:2M-1.

26:2M-4. Duties of commission

It shall be the duty of the commission:

a. To study the extent and severity of the incidence of Alzheimer's disease in this State, with due consideration to the consequent need for specialized modes and facilities for the care of those afflicted;

b. To study the needs of both the victims of the disease and their families, the availability and affordability of long-term care arrangements, including in-home care and other alternatives to institutionalization;

c. To gather and disseminate data and information relative to the care and treatment of persons afflicted with this disease, so as to stimulate awareness and provide accurate data for health care professionals and governmental policymakers having responsibilities relevant to this problem.

L.1983, c. 352, § 4, eff. Sept. 29, 1983.

Statement: Committee statement to Assembly,
No. 3638—L.1983, c. 352, see § 26:2M-1.

26:2M-5. Employees

The commission shall be entitled to call to its assistance and avail itself of the services of such employees of any State, county or municipal department, board, bureau, commission or agency as it may require and as may be available to it for the purposes of carrying out its duties under this act, and to employ such stenographic and clerical assistants and incur such traveling and other miscellaneous expenses as it may deem necessary in order to perform its duties, and as may be within the limits of funds appropriated or otherwise made available to it for those purposes.

L.1983, c. 352, § 5, eff. Sept. 29, 1983.

Statement: Committee statement to Assembly,
No. 3638—L.1983, c. 352, see § 26:2M-1.

26:2M-6. Hearings; findings and recommendations

The commission may meet and hold hearings at such place or places as it shall designate during the sessions or recesses of the Legislature, and shall report its findings and recommendations to the Governor and the Legislature, accompanying the same with any legislative bills which it may desire to recommend for adoption by the Legislature, as soon as may be practicable after its appointment and organization, and from time to time thereafter as it may deem appropriate in the development of its studies pursuant to section 4 of this act.¹

L.1983, c. 352, § 6, eff. Sept. 29, 1983.

¹ Section 26:2M-4.

Statement: Committee statement to Assembly,
No. 3638—L.1983, c. 352, see § 26:2M-1.

APPENDIX II

THE GLOBAL DETERIORATION SCALE FOR
ASSESSMENT OF PRIMARY DEGENERATIVE DEMENTIA

Global Deterioration Scale (GDS) for Age-Associated
Cognitive Decline and Alzheimer's Disease*

GDS stage	Clinical phase	Clinical characteristics	Psychometric concomitants
1 No cognitive decline	Normal	No subjective complaints of memory deficit. No memory deficit evident on clinical interview.	Average or above average performance for age and WAIS vocabulary score on 3 of 5 Guild (4) memory subtests.
2 Very mild cognitive decline	Forgetfulness	Subjective complaints of memory deficit, most frequently in following areas: (a) forgetting where one has placed familiar objects; (b) forgetting names one formerly knew well. No objective evidence of memory deficit on clinical interview. No objective deficits in employment or social situations. Appropriate concern with respect to symptomatology.	Below average performance for age and WAIS vocabulary score on 3 of 5 Guild subtests.
3 Mild cognitive decline	Early Confusional	Earliest clear-cut deficits. Manifestations in more than one of the following areas: (a) patient may have gotten lost when traveling to an unfamiliar location; (b) co-workers become aware of patient's relatively poor performance; (c) word and name finding deficit become evident to intimates; (d) patient may read a passage or a book and retain relatively little material; (e) patient may demonstrate decreased facility in remembering names upon introduction to new people; (f) patient may have lost or misplaced an object of value; (g) concentration deficit may be evident on clinical testing. Objective evidence of memory deficit obtained only with an intensive interview conducted by a trained geriatric psychiatrist. Decreased performance in demanding employment and social settings. Denial begins to become manifest in patient. Mild to moderate anxiety accompanies symptoms.	One standard deviation or greater below average performance for age and WAIS vocabulary score on 3 of 5 Guild memory subtests. Often no errors on the Mental Status Questionnaire (MSQ) (5)
4 Moderate cognitive decline	Late Confusional	Clear-cut deficit on careful clinical interview. Deficit manifest in following areas: (a) decreased knowledge of current and recent events; (b) may exhibit some deficit in memory of one's personal history; (c) concentration deficit elicited on serial subtractions; (d) decreased ability to travel, handle finances, etc. Frequently no deficit in following areas: (a) orientation to time and person; (b) recognition of familiar persons and faces; (c) ability to travel to familiar locations. Inability to perform complex tasks. Denial is dominant defense mechanism. Flattening of affect and withdrawal from challenging situations occur.	Frequent mistakes on 3 or more items on MSQ.
5 Moderately severe decline	Early dementia	Patient can no longer survive without some assistance. Patient is unable during interview to recall a major relevant aspect of their current lives: e.g., their address or telephone number of many years, the names of close members of their family (such as grandchildren), the name of the high school or college from which they graduated. Frequently some disorientation to time (date, day of week, season, etc.) or to place. An educated person may have difficulty counting back from 40 by 4s or from 20 by 2s. Persons at this stage retain knowledge of many major facts regarding themselves and others. They invariably know their own names and generally know their spouses and children's names. They require no assistance with toileting or eating, but may have some difficulty choosing the proper clothing to wear and may occasionally clothe themselves improperly (e.g., put shoes on the wrong feet, etc.).	Deficits evident on brief MSQ assessment.
6 Severe cognitive decline	Middle dementia	May occasionally forget the name of the spouse upon whom they are entirely dependent for survival. Will be largely unaware of all recent events and experiences in their lives. Retain some knowledge of their past lives but this is very sketchy. Generally unaware of their surroundings, the year, the season, etc. May have difficulty counting from 10, both backward and sometimes forward. Will require some assistance with activities of daily living, e.g., may become incontinent, will require travel assistance but occasionally will display ability to travel to familiar locations. Diurnal rhythm frequently disturbed. Almost always recall their own name. Frequently continue to be able to distinguish familiar from unfamiliar persons in their environment. Personality and emotional changes occur. These are quite variable and include: (a) delusional behavior, e.g., patients may accuse their spouse of being an impostor; may talk to imaginary figures in the environment, or to their own reflection in the mirror; (b) obsessive symptoms, e.g., person may continually repeat simple cleaning activities; (c) anxiety symptoms, agitation, and even previously nonexistent violent behavior may occur; (d) cognitive abulia, i.e., loss of willpower because an individual cannot carry a thought long enough to determine a purposeful course of action.	5-10 errors on MSQ.
7 Very severe cognitive decline	Late dementia	All verbal abilities are lost. Frequently there is no speech at all—only grunting. Incontinent of urine; requires assistance toileting and feeding. Lose basic psychomotor skills, e.g., ability to walk. The brain appears to no longer be able to tell the body what to do. Generalized and cortical neurologic signs and symptoms are frequently present.	

* Reisberg, B., Ferris, S.H., de Leon, M.J., and Crook, T., Am. J. Psychiatry, 139: 1136-1139, 1982.

APPENDIX III

MEMBERS OF THE COMMISSION

Alzheimer's Disease Study Commission

Membership

J. Richard Goldstein, M.D., Chairman
Commissioner, New Jersey State
Department of Health, Trenton,
New Jersey

George Albanese, Commissioner
New Jersey Department of Human
Services, Trenton, New Jersey
(Replaced by Geoffrey Perseley, 1985)
(Replaced by Drew Altman, 1986)
Represented by: Martin Epstein, M.D.
Chief Medical Consultant

John P. Renna, Commissioner
New Jersey Department of
Community Affairs
Trenton, New Jersey
(Replaced by Leonard S. Coleman, Jr., 1986)
Represented by: Joan Mintz, M.S.S.W.,
Deputy Director, New Jersey Division
on Aging

Nicholas R. Felice
Assemblyman, District 40
Fairlawn, New Jersey
Represented by: Doris Sasadi
Ramsey, New Jersey

David C. Schwartz
Assemblyman, District 17
New Brunswick, New Jersey

Garrett W. Hagedorn
(deceased August 9, 1985)
Senator, District 40
Midland Park, New Jersey

Joseph Hirkala
Senator, District 36
Passaic, New Jersey

Hugh A. Koops, Ph.D.
New Brunswick, New Jersey

Frank C. Snope, M.D.
North Brunswick, New Jersey

Helena M. Meade, M.S.W.
Pennington, New Jersey

Terry Tanenbaum
Edison, New Jersey

Deborah H. Piggins
New Brunswick, New Jersey

Ex-officio:

Dolores G. Cooper
Assemblywoman, District 2
Atlantic City, New Jersey

Barbara Wolfson, A.C.S.W.
Lakewood, New Jersey

Carol Knopka, R.N.
Office of the Ombudsman
Trenton, New Jersey

Donna Rooney
Linden, New Jersey

APPENDIX IV
LONG TERM CARE SURVEY

The New Jersey State Department of Health was requested to determine the incidence and prevalence of Alzheimer's Disease and related disorders in New Jersey. The Department was further requested to survey the state's long-term care facilities to determine as accurately as possible the number of patients affected by these disorders, treatment costs and specialized training of personnel.

The Department mailed approximately 400 survey forms to Skilled Nursing Facilities (SNF), Intermediate Care Facilities (ICF), Residential Health Care Facilities (RHCF), and Medical Day Care Centers (MDC). We received 221 returns of which 26 were unusable for various reasons. Of those returned, the number of facilities by level of care showed that 117 were SNF; 97 were ICF-A; 95 were ICF-B; 82 were RHCF and 9 were MDC. The discrepancy in the results reflects that one facility often incorporates several levels of care.

The surveyed facilities were questioned regarding their admission policies. Most facilities indicated that they do have an admission policy; the only exceptions were from the Residential Health Care Facilities. No one acknowledged having an admission policy specific to Alzheimer's Disease. In response to the question "Do you restrict the number of patients with a diagnosis of Alzheimer's Disease?", five of the SNF/ICF group responded "yes" and 15 of the RHCF/MDC "yes". When asked if the agency differentiated care for Alzheimer's Disease, 19 of the SNF/ICF group indicated they do, as did 12 of the RHCF/MDC group.

The responding facilities had a total patient census of 18,027 of which 3230 (17.9) persons had a diagnosis of Alzheimer's Disease or a Related Disorder. Looking at each category by type of facility and source of payment, SNF had a total of 4,865 patients of which 1,059 (21.8%) had a diagnosis of Alzheimer's Disease or a Related Disorder. Medicaid and Self-pay represented the largest source of payment (4,428 or 24.5%) had a diagnosis of Alzheimer's Disease or Related Disorder. The ICFA & B had a total of 10,092 patients of which 1906 (18.9%) had a diagnosis of Alzheimer's Disease or related disorder. Medicaid and Self-pay again represented the largest source of payment for this category (9,561 or 94.7%). The RHCF had a total of 2,564 patients of which 215 (8.4%) had a diagnosis of Alzheimer's Disease or Related Disorder. Self-pay represented the largest source of payment for this group (1,721 or 67.1%). The MDC had a total of 551 patients of which 50 (9.1%) had a diagnosis of Alzheimer's Disease or Related Disorder. Medicaid represented the largest source of payment for the MDC category.

The breakdown of patients by age and gender (See Table II) shows that there were 3,116 patients involved in this section of the survey. Of these, 20% were males while 80% were females. The SNF/ICF category had a total of 93.9% of the patients (585 males and 2,343 females). The RHC/MDC category had a total of 6.03% of patients (36 males and 152 females). There is a discrepancy in the total because agencies did not always provide a breakdown by age and gender.

The survey requested that information be provided on per diem charges. Many facilities did not comply with the request, or the information provided indicated they did not understand what was wanted. The following information is based on the data provided by respondents to this section of the survey. The Self-pay and Medicare patients residing in Skilled Nursing Facilities had the highest per diem costs; they ranged from \$50.00 to \$75.00. There were some Self-pay and Medicare patients who fell outside of this range. The Self-pay and Medicare patients in the Intermediate Care Facilities showed a wider range of patient care costs (\$30.00 to \$60.00). The Residential Health Care Facilities' charges averaged in the \$20.00 to \$30.00 range. The Medical Day Care costs were about the same for all reimbursements (\$27.00 - \$30.00). Medicaid fees under Skilled Nursing Facilities fell within the same range as Self-pay, but in many instances were about \$5.00 to \$8.00 less than the Self-pay category. In the ICF category, the per diem costs for Medicaid are less than the Self-pay; sometimes \$6.00 to \$12.00 less. Medical Day Care under Medicaid is slightly less costly, averaging about \$27.00. It should be noted that many facilities indicated a flat fee irregardless of funding source. A few facilities indicated that besides the flat fee they charge patients for such things as dressings, laundry services and special equipment, while others stated they will charge more for those clients who require greater care, i.e., feeding, incontinence care, etc.

One section of the survey requested information about staff training on Alzheimer's Disease. We again ran into the problem of the form not being completed properly, i.e., instead of providing the numbers requested, many facilities simply checked the selected category. Also, from the comments, it seemed that the person completing the form did not understand that we were gathering information about Alzheimer's Disease only (i.e., the State requires 8 inservices a year; 'x' number of hours monthly, etc.). The general impression seems to indicate that the staff of most facilities are lacking in specialized training about Alzheimer's Disease. Many agencies, it must be noted, indicated they had received no training, nor had they provided any training to staff.

In summary, based on the information from the returns in long-term care facilities, 17.8% of the total institutionalized population have a diagnosis of Alzheimer's Disease

or a related disorder. Of this population, the age distribution shows that patients under age 70 totaled 6.1%. The 70-79 age group was 24.1 and the 80+ age group amounted to 69.5% of the patients with dementia.

The most significant finding confirmed testimony from caregivers at the public hearings. There is a lack of training for employees working in long-term health care facilities, especially in relation to Alzheimer's Disease. This finding is consistent in all staffing categories (administration, nursing, aides, recreation, social service and other).

We believe that these findings should be viewed as a conservative estimate of the population with dementia in health care facilities. Many facilities indicated that a significant number of their patients had been admitted with diagnoses from previous diagnostic manuals.

Survey of Long-Term Care Facilities

Patient Census

Type of Facility

Type Patient	Category	Skilled Nursing Facility (SNF)	Intermediate Care Facility-A (ICF-A)	Intermediate Care Facility-B (ICF-B)	Residential Health Care Facility (RHCF)	Medical Day Care MDC)	Totals
Self-Pay	Total Patients	2,142	2,475	895	1,721	160	7,393
	Alzheimer's Patients	494	623	151	156	21	1,445
Medicare	Total Patients	219	42	20	//////	////////	281
	Alzheimer's Patients	40	13	4	//////	////////	57
Medicaid	Total Patients	2,286	4,675	1,516	//////	357	8,834
	Alzheimer's Patients	488	909	146	///	24	1,567
SSI	Total Patients	11	//////	//////	545	//////	556
	Alzheimer's Patients	—	//////	//////	48	//////	48
Other	Total Patients	207	337	132	298	34	1,008
	Alzheimer's Patients	37	53	7	11	5	113
	Total Patients	4,865	7,529	2,563	2,564	551	
	Alzheimers's Patients	1,059	1,598	308	215	50	

Source of Payment

Survey of Long-Term Care Facilities

Number of Alzheimer's Patients by Age and Gender

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	Age Group	Under 60	60-64	65-69	70-74	75-79	80-84	85 +	
Gender	Male	SNF	17	19	26	82	112	151	178
		ICF	0	4	1	3	11	8	9
	Female	RHCF	17	32	65	168	331	629	1,101
		MDC	1	7	6	13	34	45	46
Total		35	62	98	266	488	833	1,334	
Percent		1.1	1.9	3.1	8.5	15.6	26.7	42.8	

**Diagnostic Criteria for Classification
as Alzheimer's Disease**

For the purpose of this survey, please consider any patient with one of the following primary or secondary diagnoses as having Alzheimer's Disease or a Related Disorder:

ICD - 9	DSM III
290.0 Senile Dementia, Simple Type	290.00 Primary Degenerative Dementia, Senile Onset, Uncomplicated
290.1 Presenile Dementia	290.10 Primary Degenerative Dementia, Presenile Onset, Uncomplicated
	290.11 Primary Degenerative Dementia, Presenile Onset with Delirium,
	290.12 Primary Degenerative Dementia, Presenile with Delusions
	290.13 Primary Degenerative Dementia, Presenile Onset with Depression
290.2 Senile Dementia, Depressed or Paranoid Type	290.20 Primary Degenerative Dementia, Senile Onset with Delusions
	290.21 Primary Degenerative Dementia, Senile Onset with Depression
290.3 Senile Dementia with Acute Confusional State	290.30 Primary Degenerative Dementia, Senile Onset with Delirium
290.4 Arteriosclerotic Dementia	290.40 Multi-Infarct Dementia
331.0 Alzheimer's Disease	Nothing comparable in DSM-III
331.1 Picks Disease	Nothing comparable in DSM-III
331.1 Senile Degeneration of the Brain	Nothing comparable in DSM-III
331.3 Communicating Hydrocephalus	Nothing comparable in DSM-III

SURVEY OF NURSING HOMES
WITH ALZHEIMER'S DISEASE CLIENTS

Name of Facility

Address of Facility

Name of Administrator

Name of Contact Person

Telephone No.

Do you have an admission policy? Yes No

Do you have an admission policy specific to Alzheimer's Disease and Related Disorders? Yes No

If Yes, please attach your current policy.

Do you restrict number of patients with a diagnosis of Alzheimer's Disease and Related Disorders? Yes No

Do you differentiate care for patients with a diagnosis of Alzheimer's Disease and Related Disorders? (If Yes, explain under additional comments.) Yes No

Do you wish to receive a copy of the results of this survey? Yes No

Additional Comments

Attach add'l sheets if necessary.

PATIENT CENSUS

Type Patient	Category	Skilled Nursing Facility (SNF)	Intermediate Care Facility A (ICF-A)	Intermediate Care Facility B (ICF-B)	Residential Health Care Facility (RHCF)	Medical Day Care (MDC)
Self-Pay	Total Patients					
	Alzheimer's Patients					
Medicare	Total Patients				/ / / / / / / /	/ / / / / / / /
	Alzheimer's Patients				/ / / / / / / /	/ / / / / / / /
Medicaid	Total Patients				/ / / / / / / /	
	Alzheimer's Patients				/ / / / / / / /	
SSI	Total Patients		/ / / / / / / /	/ / / / / / / /		/ / / / / / / /
	Alzheimer's Patients		/ / / / / / / /	/ / / / / / / /		/ / / / / / / /
Other	Total Patients					
	Alzheimer's Patients					

If you have other levels of care, please provide appropriate data.

Attach add'l sheets if necessary.

AVERAGE LENGTH OF STAY (DAYS)

Category	Skilled Nursing Facility (SNF)	Intermediate Care Facility A (ICF-A)	Intermediate Care Facility B (ICF-B)	Residential Health Care Facility (RHCF)	Medical Day Care (MDC)
Total Patient Population					
Alzheimer's Patients					

NUMBER OF ALZHEIMER'S PATIENTS BY AGE AND GENDER

Gender \ Age Group	Under 60	60 - 64	65 - 69	70 - 74	75 - 79	80 - 84	85 +
Male							
Female							

PER DIEM CHARGES

Type Patient	Category	Skilled Nursing Facility (SNF)	Intermediate Care Facility A (ICF-A)	Intermediate Care Facility B (ICF-B)	Residential Health Care Facility (RHCf)	Medical Day Care (MDC)
Self-Pay	Total Patients					
	Alzheimer's Patients					
Medicare	Total Patients					
	Alzheimer's Patients					
Medicaid	Total Patients					
	Alzheimer's Patients					
SSI	Total Patients					
	Alzheimer's Patients					
Other	Total Patients					
	Alzheimer's Patients					

Are there any additional charges for patients diagnosed with Alzheimer's Disease and Related Disorders?

Yes No

If Yes, please explain.

STAFF TRAINING ON
ALZHEIMER'S DISEASE AND RELATED DISORDERS

NUMBER OF STAFF TRAINED BY TYPE OF TRAINING

Staff Category	On-Site Inservice	Educational Curriculum	Off-Site Inservice	Other	None
Administration					
Nursing					
Aides					
Recreation					
Social Services					
Other					

NUMBER OF STAFF TRAINED BY LENGTH OF TRAINING

Staff Category	4 Hours or Less	1-5 Day Seminar/ Workshop	Semester	Other	None
Administration					
Nursing					
Aides					
Recreation					
Social Services					
Other					

APPENDIX V
EXCERPTS OF ACTUAL TESTIMONY

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MR. H : Thank you, Commission, for allowing me to speak this morning. My name is E of Fanwood, New Jersey. I have a wife that is an Alzheimer's victim. I am also in the insurance business. I understand what everybody says when they say there is no insurance to cover this particular disease. I am presently on disability leave myself, because of the pressure and stress of this particular disease.

In 1982, around June of 1982, my wife suddenly started to do strange things. She is only 50 years old. Since that time I have gone through all the pains that everyone has spoke about here, especially Mr. P , who I have known before, in trying to understand exactly what was wrong with her. We initially went to her family doctor, as you normally would do. the only reason that he was able to determine that there was something wrong that was not physical was because she was physically in great shape, and when he saw her come back for

1 her blood test, he noticed how agitated she was,
2 and he immediately called me at my office and said,
3 "I think you should take your wife to a neurologist."

4 I proceeded to do so, and was told by the
5 neurologist at that time that she had senile dementia.
6 We then proceeded to go to several other persons,
7 one psychiatrist and a psychologist. And we still
8 got the same kind of diagnosis.

9 We also then were told by the doctor that
10 there were more tests necessary. We also at that
11 time did have a CAT scan done. And this CAT scan,
12 again, showed there was some atrophy taking place
13 within the brain. But they always say that we lose
14 our brain cells every day. But hers were just
15 being lost a little quicker. I never knew what
16 this meant, and I didn't understand that at that
17 time.

18 I proceeded to do as the doctor suggested,
19 and put her in the hospital and have her done again.
20 So we had second opinions on everything. Again,
21 the second opinions proved that she had this
22 Alzheimer's disease.

23 At that point, since the family physician
24 had set up all the contacts for me, I left it to
25 him in a sense, to tell me where to go. He was

1 stymied at that point, because he didn't know what
2 you did with Alzheimer's disease, except that we
3 had her on Haldol and hydrogen and a couple of other
4 drugs they had to counteract one of the others.

5 Anyway. I then proceeded to get involved
6 with a support network. At that time it was in
7 Westfield, New Jersey. At the support network I
8 did learn about The 36 Hour Day, which to me has
9 been the Bible in taking care of my wife.

10 I have also videotaped several programs on
11 Alzheimer's disease. I have used that videotape
12 as a training process for the aides that I have had
13 to get to come into the home. for my being here
14 today, I have an aide at home. These aides, of
15 course, are very expensive, and nobody can really
16 afford them. I couldn't afford them. However, my
17 particular insurance contract allows me to pay for
18 them. Not everybody's does, but I have one set up
19 that allows me to pay for it. And I am having
20 trouble with the company to get them to fulfill
21 that part of it. But that's something else.

22 I have used these training tapes that I
23 have videotaped on Alzheimer's disease programs
24 to show these particular aides what to do. The
25 reason for that is -- and I have gone through all

1 of them -- I contacted every agency, as has Mr.
2 P , that you can want to know, from P
3 through U I think I have a list of them
4 here. There are a number of them, and every one that
5 has sent me an aide has sent me someone who knows
6 nothing about Alzheimer's disease. All they know
7 about is, as I said, taking care of cooking, cleaning
8 and taking care of the patient as you normally would
9 take care of any other patient.

10 But an Alzheimer's disease patient is not
11 any other patient. An Alzheimer's disease patient
12 is one that demands your care and your guidance
13 and your love.

14 We have been married 32 years now, so that
15 I have given her, basically, all the possible love
16 I can and could, to the point now that I can't
17 physically, mentally, handle the situation. I am
18 in the process now of trying to get her in a nursing
19 home, because she has become completely, almost
20 fetal position. Really, you have to do everything
21 for her. She does nothing for herself.

22 This caused -- and I have a 17-year old
23 daughter. Of course, this has caused a lot of
24 problems with us trying to understand what's going
25 on, and still trying to make a living for ourselves.

1 It has also caused my son, who recently graduated
2 from Lehigh University to take off, because he
3 couldn't understand this. At the time that he
4 thought his life was supposed to get together, all
5 of a sudden, he's got a mother now completely off
6 the wall. And he left and went to Boulder,
7 Colorado. But, he is now earning a living out in
8 Boulder, Colorado.

9 It has caused a tremendous effect familywise.
10 We are now still dealing with this problem, as I
11 said, only because I am able to provide the care
12 for her through my particular situation. However,
13 there is a tremendous need to have these home health
14 aides, and that's what I have been using, or anyone
15 in a particular position, but home health aides are
16 what I have been using, to be trained. They are
17 not trained. And this is, to me, appalling, that
18 you're paying out dollars to these so-called State
19 licensed agencies who get a license in New Jersey
20 to say that they are going to provide care for you,
21 and they send you someone who knows nothing about
22 your particular situation.

23 I have to now, in a sense, take off time
24 to stay home and, basically, give the whole training
25 course to an individual before I can allow her to

1 touch my wife.

2 We have a desperate need to have these
3 individuals trained, and a Commission such as this,
4 I think, it's darn good that we have now available
5 to us. Yes, I think, in some of the other areas
6 that were spoken of this morning, we have need to
7 have facilities.

8 I am about to put her into P Hospital
9 in Berkeley Heights, which is one of the institutions
10 that have been rated very good for nursing home care
11 for Alzheimer's patients. But it's been a tremendous
12 effort, not only that, but a tremendous waiting list.
13 We initially started out 300 on the waiting list.

14 I just want to say again that the agencies --
15 and I really have a problem with them, because I
16 have paid a lot of money being somewhat reimbursed,
17 but I have paid a lot of money out, and I felt I
18 was not getting my dollars' worth for the kind of
19 service that they had to give.

20 And we should stress here, the Commission
21 should stress providing this particular agency.
22 If they are going to be State licensed or take the
23 license away from them. And don't let them send
24 anybody to an Alzheimer's patient who are not
25 strictly qualified to do so.

1 BY MS. R :

2 Q After your wife was diagnosed, were you
3 informed that there are centers such as the Albert Einstein
4 Hospital in New York that is doing research with patients,
5 and with some, quite successfully?

6 A Unfortunately, no. I had at that time, tried to
7 ascertain just where and what I might do to get some help.
8 I say, all my help, initially, came from a support group,
9 because nobody else knew anything. And I started with that.
10 And I kind of built up. New, I tried to , and I just a
11 few weeks ago, I took her to New York again for the last
12 time for a neurologist. And he just says at this point
13 that she has -- her curve has gone so fast, so quickly.
14 He had never seen one so fast and so quickly, that my
15 best bet for her now was a nursing home.

16 We had tried the Muhlenberg Hospital Day Care at
17 the time that that initially got opened, really. I'm
18 glad to hear now that they are in a better position to
19 handle Alzheimer's because at that time they were not. She
20 just couldn't do the things that they had everybody else
21 doing. At that period of time, she was in that wandering
22 stage. I had to take her off the transportation, because
23 she would get off at stops and wander off, and they would
24 have to go get her and bring her back. And they became
25 frightened being liable for that situation. I, therefore,

H - Direct

1 had to start dropping her off myself and bringing her back
2 home. So, as I said, at that time they were not really
3 prepared for Alzheimer's. I am glad to here, as I heard
4 this morning, apparently, that center is better now with
5 Alzheimer's disease. It's a good center, but they just
6 weren't good for Alzheimer's disease at that time.

7 Q My mother is at F Hospital, and she's
8 been there for four years. If it's any consolation, the
9 care has been very good.

10 A I have heard very good things about Runnells and the
11 care there. I have to thank the Freeholders for helping me
12 to get her in, because that's a very difficult place to get
13 into.

14

15 BY MS. P :

16 Q How is her nursing home care going to be paid
17 for?

18 A I have become pauperised, as someone said this
19 morning. Now I have Medicaid coming in. I have mortgaged
20 everything to the hilt, just paying bills that fall upon
21 this. And Medicaid now says she qualifies for the nursing
22 home.

23 MS. P : Are there any other questions
24 for Mr. H ?

25 Thank you very much.

19 MS. P : Okay. Thank you very much.
20 M and D can speak
21 next because I know you've left Mrs. D at
22 home.

23 And I wonder if you could, you have a
24 rather unusual circumstance here. If you could
25 explain, why you both have to go home to the same

1 person.

2 MS. M : My name is M

3 I'm a widow with seven children. And my husband
4 was a victim of Alzheimer's. He died in July.

5 And the reason why is I am now helping
6 R by sitting with his wife during the day.
7 And I had come earlier but things were running
8 late.

9 My husband was 61 when he passed away. He
10 wasn't diagnosed until '79. And looking back
11 we have come across evidence that he had Alz-
12 heimer's for 14 years. I had thought maybe
13 around ten, but I have talked to people and they
14 felt that he had problems way back then.

15 Before that he was being treated for
16 nerves and tension and stress and everything
17 else, and finally I just said to the doctor,
18 there's got to be something else wrong. So he
19 was put in the hospital and I was happy because
20 they told me that it was not mental. I figured,
21 oh, how do I get this man for treatment, you
22 know, a very strong healthy man all his life,
23 worked hard to support his children. But that
24 same evening I got a call from a neurologist who
25 said I think your husband has Alzheimer's

1 disease, which was Greek to me because I had
2 never heard of it. And he said, well, we'll run
3 tests and find out for sure. They did tests and
4 that's what it was. He said there's nothing
5 really we can do. It's just going to take its
6 toll.

7 I didn't know what to expect. I mean he
8 told me as much as he knew. And I guess there
9 wasn't much that he knew about it himself. My
10 husband worked for another year after he was
11 diagnosed, but it got to be too hard. They were
12 very lenient with him. And finally he had to
13 retire. He went on Social Security and a pension
14 And things were rough because of bills. I was
15 trying to work a part-time job, but then it was
16 getting too hard because -- my daughter was at
17 home with him, but it got where he was just
18 taking off. He was looking for me. That's what
19 we realized after a while, that every time I'd
20 come home I'd find him uptown wandering around
21 and as soon as he saw me, of course, he said, oh,
22 there you are.

23 I eventually had to stop working because
24 it was just too much. It was only four hours a
25 day, but I looked forward to going to work I tell

1 you. But he got worse. He used to have anxiety
2 attacks. He used to get violent, but at least
3 then I knew what it was from. I heard of a
4 support group and I got involved with them and
5 then the day hospital, which was a big help to
6 me, at Rutgers. He went for a year. And I had
7 a problem too, I didn't realize that my husband
8 couldn't write his name anymore, because I took
9 care of all the finances even before he quit
10 work. And all of a sudden it dawned on me he
11 couldn't even sign his name and -- of course
12 he couldn't talk anymore. Where he worked they
13 kept saying, well, you'll have to get legal
14 guardianship. So I went looking and I wasn't
15 familiar with the system. I went to Legal Aid,
16 which I was not eligible for because of his
17 income was just a little above what they would
18 help. So I had to get a lawyer and then they
19 had to appoint another lawyer for him. So it
20 cost me over a thousand dollars to take him to
21 court and have him proved incompetent, which was
22 very hard on me. And what -- the money was
23 rough too, but I mean I managed to get through
24 it. And he started to go where I couldn't leave
25 him at all. I used to be able to go to the

1 store and leave him with maybe the younger child
2 you know, the youngest one. But he got to be
3 a handful. He became incontinent. He had to be
4 bathed, he had to be dressed, he had to be fed
5 eventually. He was on medication and we did try
6 to regulate it at home, but he had gotten a
7 side affect from one of the medications. So
8 they suggested that, the doctor from R
9 had suggested that we put him on the waiting
10 list for Just put him in like for three
11 or four weeks, maybe, to regulate his medication.
12 So I agreed with that. I figured well that
13 would give him -- that it would give me a chance
14 to get some rest because I was with him constant-
15 ly.

16 Well, all of a sudden in March he got very
17 violent. The medication he was on wasn't help-
18 ing. And constantly every time I went near him
19 he was swinging. And then he started throwing
20 things. He went after his grandson who he did
21 not know was his grandson. And finally I called
22 up the day hospital on Monday and I said I can-
23 not bring J in, he's too bad. I cannot take
24 him in a car and I wouldn't expect them to take
25 care of him. I was afraid somebody would get

1 hurt. So they called and they pushed
2 through and they got him a bed right away. Well,
3 to this day I still feel guilty that I did that.
4 Because once he went into they told me
5 to come back in about three or four days, just
6 let him get accustomed to the place. Well, I
7 left him and I went back in about three days.
8 He no longer knew me. He was sitting in a
9 geri-chair, constantly screaming. I tried to
10 help feed him, he constantly swung at me. And
11 I was going back like every other day. And
12 some days he looked a little quieter, but he
13 was constantly in that chair. He got where he
14 couldn't walk anymore. And this went on for
15 six and a half weeks. Finally they said, well,
16 I'm sorry, there's nothing more we can do for
17 him.

18 His insurance would only cover ten weeks
19 of mental health, you know, hospitals. And they
20 felt that it was time now for me to try and find
21 a place to put him. And I felt that if I hadn't
22 put him there, if I had waited a little longer,
23 maybe he would have got over this anxiety. Maybe
24 he wouldn't have got so violent. But the only
25 alternative was -- he wasn't eligible for

1 Medicaid and they said even if he was they
2 probably wouldn't get a nursing home to take him
3 so he had to go into . So they trans-
4 ported him to and I signed the papers.
5 He was there for eight weeks. I went every other
6 day to see him and watch him deteriorate. And
7 one day I'd go in he'd be sleeping, another day
8 he'd be strapped down, another day he'd be con-
9 stantly screaming. And finally, June 30th, he
10 was rushed to Medical Center where -- he
11 had pneumonia, a very bad infection in the blood
12 from bedsores. And I sat and watched him day
13 and night for a week. And he passed away.

14 Not only that I had a lot of problems with
15 my children, the younger one. I had one child
16 who is 16 now who had contemplated suicide. I
17 found out it was because he felt that he could
18 not come to me because I had so many problems
19 with his father. He had the fear of his father
20 dying and I guess the fear of someone else get-
21 ting the disease in the family. So he had to go
22 for help. The younger one was constantly in
23 trouble with school, so he missed the whole year
24 at school. Although the school was very sympa-
25 thetic and they helped him and they said no sense

1 pressuring them. You know, let them lose the
2 year, they'll pick it up.

3 My children were all very devastated with
4 their father's death and watching him. And I
5 feel that if I had some help where he could have
6 been kept home, it would have been much easier.
7 And once he's out of his home environment he
8 just went down.

9 MS. P Do we have any questions?

10 MS. W : What could we do to help
11 you now?

12 MS. M My tragedy is over. The only
13 reason I consented to come here was to try and
14 help others. I don't like to see them go through
15 what I had to go through. Right now my children
16 and I are picking up the pieces. I have the six
17 boys at home. And we are trying to help each
18 other. I do have a good family, which is good
19 and good friends, and a support group which was
20 a great help. And the day hospital, I can't
21 thank them enough because even at the end -- I
22 used that time to do grocery shopping and things
23 that I couldn't do before that.

24 MS. P Thank you very much.

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MS. R My name is B R And
I'm from Millville, New Jersey. And I have a
very short testimony. This was a very emotional
thing for me to write down.

My name is B R and I am here to
testify in two roles. Number one, my husband is
a victim of Alzheimer's disease and also I am
president of the Cumberland County Alzheimer's
Support Group. H and I started the group.
And thank God I found H

I found it a very difficult assignment
to spell out in words my feelings about Alzheim-
er's disease. To the victim of this dreadful
illness life is at best intolerable, but to the
caregiver it is a total devastation. We drive
ourselves to the point of physical and emotional
exhaustion. We are caregivers 24 hours a day,
seven days a week. We have to watch our loved
ones turn into total strangers month by month or
sometimes even week by week.

My husband was a freeholder in Cumberland
County for six years. He had been on the Board
of Directors of United Jersey Bank for over 20³
years. And in 1957 he was nominated citizen of
the year in Millville for his community work.

1 And look at him today, he's starting to be a
2 living vegetable. This is not my first encounter
3 with a catastrophic illness. My first husband
4 died of cancer 15 years ago, leaving me a widow
5 with five children to raise. However, in his
6 case his medical bills were very well covered by
7 medical insurance. But now dealing with an
8 Alzheimer's victim, I have no assurance that I
9 will be so fortunate. It scares me to contemplate
10 what is ahead of me financial. Because my hus-
11 band can no longer work, our financial situation
12 has changed drastically in the past two years.
13 And because he can no longer function as head of
14 the household, I have had to take over as manager
15 of all our finances. Another added burden to
16 my role as caregiver.

17 Neither Medicare nor most private health
18 insurance programs pay for the custodial care
19 victims need. My health insurance premiums per
20 year are atrociously high and in return I feel
21 I am getting very little.

22 As a caregiver to a husband, I feel there
23 is a great need for male homemakers. Perhaps in
24 some way we could attract men into the homemaker
25 field. I'm sure my husband would be much more

1 comfortable with a man helping him in the bath-
2 room, rather than a strange woman other than
3 myself. The need for some type of respite care
4 is dire, especially for someone in the position
5 I now find myself in. All my children live in
6 various other states and unable to get to me for
7 even one full day. So I am literally going it
8 alone. However, the cost of such respite day
9 care centers should not be so high we cannot
10 afford to use them. Maybe some of the casino
11 and lottery funds which I understand were to be
12 used for senior citizens could be allotted to
13 offset the cost of running day care centers for
14 the elderly.

15 Alzheimer's disease is now one of the
16 major health problems in the United States. And
17 as the baby boom population ages, it will become
18 an ever increasing problem. I think we must do
19 something -- do some drastic planning and preparã
20 tion right now in order to take care of the
21 elderly in the future.

22 Thank you so much for listening to me.

23 MS. P Thank you.

24 Do you have any specific suggestions about
25 what kind of better coordinated care and better

1 subsidized care we might get?

2 MS. R : Oh, I'm into this so early.
3 I really don't know where to go. At the point
4 I am now my husband would -- I tried a day care
5 center. And I just took him there to look at it
6 and I had 24 hours of upset that he just wouldn't
7 take kindly to the idea of being in a large room
8 with a lot of other people like that. He wants
9 me continually. I am looking more for homemaker
10 care right now. That's not to say I wouldn't
11 use a day care center later. And, of course,
12 I'm looking into nursing home care eventually.

13 But I'm at the point where he's still
14 lucid enough to know when I leave him. And he
15 gets upset, a little bit when I do leave him. So
16 I'm not so sure, perhaps, like this Mr. H
17 said, a day care center wasn't for him, but it
18 would be for me, you see, the respite for me.

19 MS. P ,: Will he accept a stranger
20 in the home?

21 MS. R : Not very well. I had a little
22 trouble with that. But I think gradually he's
23 getting over the fact that I have -- do bring
24 different people in. I have to. You can't live
25 this 24 hours a day, seven days a week and not

1 go beserk. You really can't. Especially going
2 without sleep for weeks on end. One never knows
3 what the night is going to bring.

4 MS. P Would you describe what
5 nights are like.

6 MS. R Well, one night I made the
7 bed six times completely. The pillows were gone
8 I mean I had to start from scratch six times I
9 counted between one o'clock and six o'clock.
10 And another night I had a real problem. He had
11 a -- I don't know whether he had a nightmare. I
12 have no idea. And I had a night table and I had
13 pushed it as far away from the bed as possible.
14 He must have somehow slipped out, hit his head
15 here on the night table and I jump up and he's
16 just flowing blood down, his whole face was just
17 covered with blood. I do not remember getting a
18 robe on him. I do not remember putting my
19 clothes on. All I remember was I was in the
20 car and the next thing I was at the hospital.
21 And he had seven stitches in his head.

22 Well, for four days you can imagine. I
23 wish the hospital would have kept him for at
24 least 24 hours. I thought it was rather unfair.
25 And when I told them he was an Alzheimer victim,

1 because they told me to watch for concussion.
2 I said how can I watch for concussion when he
3 drowzes all day long. Well, then watch that his
4 eyes don't dialate. So here I am going around
5 peering at him all day long to see if his eyes
6 were dialating, you know. The nights are pretty
7 bad. I got pretty well bruised one night. He
8 had -- I don't know. He talks about they. They
9 are fighting.

10 MS. P : Hallucinating.

11 MS. R Yes. And I couldn't -- that
12 night I just couldn't budge him at all. So, it's
13 a trauma to live with.

14 MS. P : Any other questions?

15 MS. T : One more question. You
16 took your husband to the day care center one time

17 MS. R : Just to visit, just to look
18 at it.

19 MS. T , : Was there an Alzheimer's
20 there, care center or was it just for aged.

21 MS. R : They said they took Alzheimer
22 patients.

23 MS. T : I see.

24 MS. R . But I thought it interesting
25 that they were only ever filled 50 percent of

1 their capacity. And when I got there I could
2 see why. It was very institutionalized and very
3 I just wouldn't put him there.

4 MS. T Okay.

5 MS. R The atmosphere was not right
6 for him.

7 MS. T Because my experience
8 with the day care center, which was at COPSA,
9 was a very positive one. And I'm sad to hear
10 that you don't have a similiar kind of a place
11 to take him --

12 MS. R They were very nice. Don't
13 misunderstand me.

14 MS. T I know that it would
15 give you a big help.

16 MS. R They were very nice. But he-

17 MS. T But not the right kind
18 of environment.

19 MS. R The environment was not for
20 him, no.

21 MS. P Thank you.

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APPENDIX VI

BROCHURE OF STATEWIDE CONFERENCE
ON ALZHEIMER'S DISEASE

**NEW JERSEY
STATEWIDE CONFERENCE
ON
ALZHEIMER'S
DISEASE**

**TUESDAY, NOVEMBER 19, 1985
HYATT REGENCY OF PRINCETON
Route One North at Alexander Road
Princeton, New Jersey**



STATE OF NEW JERSEY
Honorable Thomas H. Kean, Governor

Sponsored By:

NEW JERSEY DEPARTMENT OF HEALTH
J. Richard Goldstein, M.D., Commissioner

**NEW JERSEY DEPARTMENT OF
COMMUNITY AFFAIRS**
John P. Renna, Commissioner

THE BROOKDALE FOUNDATION
New York, New York

**Alzheimer's Conference
New Jersey Department of Community Affairs
Division on Aging
CM 807
Trenton, New Jersey 08625-0807**

Registration - \$15 per person, which includes lunch and materials
 November 19, 1985 - Hyatt Regency of Princeton, Princeton, New Jersey

NAME _____ TELEPHONE # _____
 ORGANIZATION AFFILIATION (if any) _____
 ADDRESS _____ ZIP _____

Checks payable to: Treasurer, State of New Jersey Amount enclosed _____

RETURN REGISTRATION TO:

Alzheimer's Conference
 New Jersey Department of Community Affairs
 Division on Aging
 CN 807
 Trenton, New Jersey 08625-0807
 Phone: (609) 292-3766

List workshop preferences by letter:

	1st	2nd
1:30 (A,B,C)	_____	_____
2:45 (D,E,F)	_____	_____

CONFERENCE PROGRAM

8:30 REGISTRATION

9:00 WELCOME AND REPORT ON THE NEW JERSEY ALZHEIMER'S DISEASE STUDY COMMISSION

J. Richard Goldstein, M.D.
 Commissioner
 New Jersey Department of Health

9:30 PAST, PRESENT AND FUTURE OF ALZHEIMER'S DISEASE

Carl Eisendorfer, Ph.D., M.D.
 Professor, Department of Psychiatry and Medicine
 Albert Einstein College of Medicine
 New York, New York

10:15 BREAK

10:30 FAMILY PERSPECTIVE OF ALZHEIMER'S DISEASE

Marion Roche, Author
Another Name for Madness

11:15 DIAGNOSIS OF ALZHEIMER'S FOR THE PRACTITIONER

Cynthia D. Steele, BSN, RN
 Dementia Research Clinic
 Johns Hopkins Hospital, Baltimore, Md.

12:00 LUNCHEON

Remarks
 John P. Renna, Commissioner
 N.J. Department of Community Affairs

ALZHEIMER'S PROJECTS OF THE ADMINISTRATION ON AGING

Carol Fraser Fisk
 Acting Commissioner
 Administration on Aging, Washington, D.C.

1:30 WORKSHOPS/SEMINARS

● **SESSION ONE**

A. Ethical Issues

Jack D'Ambrosio
 State of New Jersey
 Ombudsman for the
 Institutionalized Elderly
 Moderator

B. Design for Institutional Care of Alzheimer's Patients

Nancy Peppard
 Nancy Peppard and Associates
 Washington, D.C.

C. Working with Families

Lee Joslin
 Director
 COPSA Institute for Alzheimer's Disease and Related Disorders
 UMDNJ-Rutgers Medical School-CHMC
 Piscataway, New Jersey

2:30 BREAK

● **SESSION TWO**

2:45 D. Community Care Programs

Hugh A. Koops, Ph.D.
 New Brunswick Theological Seminary
 Moderator

E. Day-To-Day Management of the Alzheimer's Patient in the Community

Larry Tune, M.D.
 Director, Dementia Research Clinic
 Assistant Professor, Psychiatry and Behavioral Sciences, Neuroscience, and Medicine
 Johns Hopkins Hospital, Baltimore, Md.

F. Alzheimer's Disease: The Personal Story of Caring

Werner Boehm, Ph.D.
 Professor Emeritus in Social Work
 Rutgers the State University
 Moderator

3:45 ADJOURNMENT

APPENDIX VII

BROCHURE OF CONFERENCE ON HOME MANAGEMENT
OF PATIENTS WITH DEMENTIA

**HOME MANAGEMENT
OF
PATIENTS WITH DEMENTIA**

Monday, June 17, 1985

RAMADA INN
US 1 and Ridge Road
Princeton, NJ



Sponsored by:
**HOME CARE COUNCIL
OF NEW JERSEY**
and
**NEW JERSEY STATE
DEPARTMENT OF HEALTH
GERONTOLOGY PROGRAM**



Home Care Council of New Jersey

The State Association of Homemaker-Health Aide Agencies
60 South Fullerton Ave.
Montclair, New Jersey 07042

REGISTRATION FORM

AGENCY _____
ADDRESS _____ PHONE _____
CITY _____ STATE _____ ZIP _____

FEE: \$15.00 per person (includes coffee break and luncheon)

NAMES OF ATTENDEES	FEE	SEMINAR SESSION I	SELECTIONS SESSION II
_____	\$ _____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
TOTAL		_____	_____

Enclosed is a check (no cash please) for \$ _____ for _____ reservations.

RETURN TO: Home Care Council of New Jersey
ATTENTION: JEAN HOLTZ (201) 744-5524
60 S. Fullerton Avenue
Montclair, New Jersey 07042

RSVP before June 7, 1985

PROGRAM

- 8:15 Registration
- 9:00 Welcome and Introductory Remarks
- 9:15 "Alzheimer's Disease: An Overview"
Miriam Aronson, Ed.D.
Assistant Professor of Neurology
and Psychiatry
Albert Einstein College of
Medicine, N.Y.
- 9:45 "Dementia: Home Care Issues"
(a) Home Health Agency Perspective
Nancy Grippe, R.N., M.P.H.
Coordinator, Home Health Care
NJ State Department of Health
- (b) Family Perspective
Deborah Hanwell Piggens
Legislative Chair
Alzheimer's Disease Support
Network of New Jersey
- 10:15 Coffee Break
- 10:30 "Day to Day Management in the Home"
(a) Structuring the Day
Isabel Levow, A.C.S.W. —
Program Director
Service Programs for the Aged
International Center for the
Disabled, N.Y.
- (b) Techniques for Bathing, Grooming,
Feeding, and Toileting
Teddy Kern, M.S., OTR
Occupational Therapist and
Medical Coordinator
Center for Independent Living,
N.Y.
- (c) Personal Experiences of a Family
Careprovider
Helena Meade, M.S.W.
Pennington, NJ
- 2:00 Lunch — Poolside
- 1:00 Luncheon Address
"Problems of Behavior and Mood"
Nancy Mace, M.A.
Co-Author, "The 36-Hour Day"

- AFTERNOON SEMINARS**
(choice of two)
- 2:00 Session I (select one)
- (a) "How Caring for an Impaired Person
Affects Family Careproviders"
Moderator:
Werner W. Boehm, Ph.D.
Emeritus Professor of
Social Work
Rutgers University
- Panel:
Maryanne Benson
Family Careprovider
Newark, NJ
- Louise Saunders
Family Careprovider
Newark, NJ
- Florence Meyers
Family Careprovider
Milltown, NJ
- Ralph Dey
Family Careprovider
Milltown, NJ
- (b) "Helping Families Cope with
Alzheimer's Disease
Mildred Potenza, B.S.
President, Alzheimer's Disease
Support Network, N.J.
- (c) "Respite Care"
Patricia A. Henry
Executive Director
Visiting Homemaker and
Health Services, Inc.
Mt. Holly, NJ
- Susan McGibney, R.N.
Assistant Director
Visiting Homemaker Service of
Hudson County
Jersey City, NJ

- 3:00 Session II (select one)
- (d) "Adult Day Care"
Moderator:
Carol Kurland, M.S.W.
Administrator, Office of Home
Office of Home Care Programs
Division of Medical Assistance
and Health Services
NJ Department of Human Services
- Panel:
Eileen Puree
Program Supervisor,
COPSA Day Hospital for the
Cognitively Impaired
Piscataway, NJ
- Ann Reeves
Executive Director
Summit-Area Association for
Gerontological Endeavor
New Providence, NJ
- Joyce Spielberger
Program Coordinator
Bergen County Adult Day Care
Paramus, NJ
- (e) "Supervision of Home Health Staff"
Mary Hahn, R.N.,C., Ed.M.
Resource Coordinator
ADRDA Tri-County NJ Affiliate
- (f) "Nursing Issues: Advanced Stage
Dementia"
Linda Fein, R.N.
COPSA Day Hospital for the
Cognitively Impaired
Piscataway, NJ

**HOME MANAGEMENT
OF PATIENTS WITH DEMENTIA**

Monday, June 17, 1985

Providing care to individuals with a dementing illness and support for their families is a growing challenge facing home health care providers. This conference will focus on issues related to the day to day management of non-institutionalized individuals with a dementing illness.

OBJECTIVES:

1. To identify strategies for structuring the day for the dementia victim in the home.
2. Examine approaches for providing a safe environment within the home.
3. Explore techniques for assisting client's with activities of daily living.
4. Provide insights into the affects of a dementing illness on the family.
5. Discuss resources to help dementia victims and their families cope with the ramifications of the illness.
6. Share information to help supervisors provide instruction, support and guidance to those providing direct care in the home.

WHO SHOULD ATTEND:

Nurses, Homemaker/Home Health Aides, Social Workers, Therapists, Nutritionists and other health care workers providing care in the home.

FEE \$15.00

APPENDIX VIII

COPSA INSTITUTE BROCHURE

The COPSA Institute for Alzheimer's Disease and Related Disorders provides services statewide to persons with dementia, their families and the professionals who work with them. Dementia is a general mental deterioration due to organic factors. Manifestations include loss of recent memory, difficulty with new experiences, unstable emotions, and a decline in intellectual ability with gradual loss of judgment and social skills.

The following assistance is available through Institute programs:

RESOURCE CENTER

- Statewide information and referral for families and professionals
- Ongoing phone counseling
- Family education and counseling
- Liaison to family support groups and professional service providers

DIAGNOSTIC CLINIC

- Diagnostic work-ups for persons with memory problems or confusion.
- Second opinions
- Coordination of follow-up recommendations

DAY HOSPITAL PROGRAM

- Rehabilitation and treatment for dementia patients
- Education and ongoing support for families
- Training site for hands-on education in dementia management

CONSULTATION & EDUCATION SERVICES

- Training and seminars on dementing illnesses for professionals.
- Technical assistance on developing Alzheimer's programs

Fees vary according to the type of service and can be adjusted based upon income. There are no fees for the Resource Center. Health insurance plans help to cover some Diagnostic Clinic and Day Program services.

**FOR FURTHER INFORMATION ABOUT SERVICES CALL:
1-(800) 424-2494 or (201) 463-4430
Monday through Friday
8:30 a.m. to 4:30 p.m.**

APPENDIX IX
PROCLAMATION



STATE OF NEW JERSEY
EXECUTIVE DEPARTMENT

Proclamation

WHEREAS, the State Department of Health estimates that 200,000 residents of New Jersey have a form of intellectual impairment called dementia and as many as 50,000 of these may be severely impaired; and

WHEREAS, Alzheimer's disease is responsible for 50 to 60 percent of all cases of dementia; and

WHEREAS, this disease is irreversible in nature and its cause or causes remain unknown; and

WHEREAS, every family member is affected in some way by the devastating changes that occur in the victims of Alzheimer's disease;

NOW, THEREFORE, I, THOMAS H. KEAN, Governor of the State of New Jersey, do hereby proclaim

NOVEMBER, 1985

as

ALZHEIMER'S DISEASE AND RELATED DISORDERS MONTH

in New Jersey, and urge all residents to learn as much about the disease as possible, to seek a thorough diagnostic evaluation and physician's advice if an intellectual impairment is suspected, and if a diagnosis is confirmed, to obtain the counsel and support currently available through the numerous family self-help groups functioning within the State.

GIVEN, under my hand and the Great Seal of the State of New Jersey, this twelfth day of November in the year of Our Lord one thousand nine hundred and eighty-five and of the Independence of the United States, the two hundred and tenth.

GOVERNOR

BY GOVERNOR:

JANE BURGIO, SECRETARY OF STATE

APPENDIX X
HEALTHLINE

A Matter of Lifestyle

This month, "A Matter of Lifestyle" looks at a health issue which is not caused by lifestyle choices but which does affect the lives of an estimated 130,000 New Jerseyans and their families: Alzheimer's disease.

Alzheimer's Disease

Getting older does not mean getting "senile."

Most people experience an occasional episode of forgetfulness—which is a normal part of the aging process. In fact, the word "senile" is derived from a Latin root that simply means "to grow old." For generations it has been inappropriately linked to mental decline in old age. While neuroscientists agree that changes do occur in the brain as we reach advanced age, they emphasize that these changes do not seriously affect mental capacities.

There are however, patterns of memory loss that indicate that a real and potentially serious problem exists. When memory loss affects a person's work or social life—a secretary who cannot remember the names of people she has worked along side of for many years, or a lawyer who forgets to show up in court—it may be an indication of progressive-intellectual decline. This disease process can occur, unfortunately, at any age, but early evaluation and diagnosis are essential because under the umbrella description of "senility" are many treatable and potentially reversible causes of confusion and/or mental impairment.

Between 50 and 60% of progressive intellectual impairment in the elderly is attributable to Alzheimer's disease, an irreversible change in the structure and function of the brain.

There are however, several potentially reversible causes of confusion and intellectual impairment. As many as 15% of all mentally impaired elderly have reversible conditions which may be caused by developing heart or lung disease, diabetes, inadequate nutrition, dehydration, an acute infection, depression or the effects of multiple medications. Their reversible states of confusion generally appear rather suddenly—over the course of a few days or months. Even when the cause is not specifically correctable, appropriate medical attention may be helpful in another 20 to 25% of the cases.

Irreversible causes of intellectual impairment on the other hand, usually occur slowly over a period of many months and years.

What is Alzheimer's Disease?

Alzheimer's disease, first described in 1906 by a German physician Alois Alzheimer, usually affects the elderly (those age 65 and older), but it can strike victims in their late 40's and 50's as well.

At first, individuals experience only minor and—often almost imperceptible symptoms. As the condition progresses, however, there are increasing signs of memory loss, confusion, a loss of time or place, reduction in interest, irritability, restlessness, and failing attention to personal hygiene. Later stages of the illness may reveal impairment in speech or an inability to recognize common shapes or to follow simple directions. Impaired judgement, decreased attention span, and a total inability to care for oneself eventually occur.

For some time, experts have recognized two structural abnormalities found in the brain tissue of individuals who have been victims of Alzheimer's disease. One is an unusual tangle of nerve filaments in the outer layers of the brain (cerebral cortex). These filaments (called neurofibrillary tangles) appear in pairs and are twisted around each other like braids. The second abnormality is a clumping of deteriorating nerve endings called plaque. This plaque disrupts the passage of certain chemicals (acetylcholine) responsible for conveying nerve impulses within the brain. Both of these abnormalities are found in areas of the brain that are associated with memory and attention. The larger the number of plaques and tangles, the greater the disturbance in intellectual function and memory. But, of course, this medical proof of Alzheimer's is only available in an autopsy and, therefore, of no value in diagnosing this disease.

Research on the hereditary aspects of the disease and its possible relationship to high aluminum concentrations in the brain, nutritional impairments and/or slow acting transmissible viruses is ongoing. About 25% of early onset cases appear to be hereditary but there is as yet no way to identify susceptible people genetically.

According to several sources the risk of developing Alzheimer's disease increase with age: 65-74 a 4 or 5% risk; 75-84, a 10 or 15% risk; 85 and over, a 20% risk.

Misdiagnosis is a problem

Despite a growing awareness of Alzheimer's disease among health professionals, misdiagnosis is still a problem.

Most people experience an occasional episode of forgetfulness.

Alzheimer's Risk By Age
65-74 3 or 4% risk
75-84 10 or 15% risk
85 + 20% risk

First, it is essential that other reversible illnesses which cause memory loss be excluded before making a diagnosis of Alzheimer's disease. Each individual suspected of Alzheimer's disease should have thorough physical, neurological and psychiatric evaluations. Computerized tomography (CAT scan), electroencephalography and studies of the spinal fluid system are often required for an accurate diagnosis, as well as urinalysis, chest x-ray, blood studies, thyroid gland functions studies and tests to detect nutritional deficiencies.

After other diseases have been eliminated as the possible causes for the symptoms, a firm diagnosis of Alzheimer's disease can usually be made. Periodic neurological examination and psychological testing are useful in evaluating the progress of the disease.

Help for the Caregiver

"The thirty-six hour day" is the way caregivers have described the impact of taking care of an Alzheimer's patient. The caregiver's (usually a spouse or child) burden is physical, psychological, financial and emotional. A detailed study at Duke University provided insights into the burden of caregivers, and into the differences between spouse caregivers and child caregivers: spouses were in poorer health, had more financial problems, less leisure time and were more likely to take psychotropic drugs. Children reported more stress and more unhappiness.

Surprisingly, putting the Alzheimer's patient in a nursing home or long-term care facility didn't ease the emotional, physical, financial or psychological burden. The only advantage it offered was giving the caregiver more time for social or recreational activities. Many caregivers spent nearly as much time visiting the patient in the nursing home as they did in caretaking, and all of them experienced the stress of watching a loved one deteriorate no matter where that loved one was living.

There are, however, things that can be done to enhance the well-being of caregivers: —community groups that offer day care respite programs

- emotional support groups for caregivers to share emotions and information
- shared responsibility for caregivers by family members and friends

Caregivers can learn how to manage the Alzheimer patients behavior in order to reduce their own stress by establishing regular times for meals, chores, bedtime; providing a calm environment; keep the patient reality oriented with clocks, calendars, reminders; speaking to the patient in short simple sentences and, of paramount importance, taking care of themselves.

When is it time to consider nursing home care?

- When the home environment is more restrictive than a nursing home—with the right facility and therapy—would be.
- When the patient would not know the difference between home and institution.
- When the patient no longer recognizes the caregiver and only responds to the care.
- When the care is more than the caregiver can physically give.

For additional information regarding Alzheimer's disease contact:

Alzheimer's Disease and Related Disorders Association, Inc.
360 North Michigan Avenue
Chicago, Illinois 60601
phone: (312) 853-3060

The Institute for Alzheimer's Disease and Related Disorders of the
Community Mental Health Center
Rutger's Medical School
P.O. Box 101
Piscataway, New Jersey 08854
phone: (201) 463-4442

The Department of Health in conjunction with the Department of Community Affairs has just issued a county-by-county guide to services for the Alzheimer patient entitled: *Alzheimer's Disease, a New Jersey Directory of Services for Family Care Givers and Health and Human Service Providers*. For a copy contact:

The New Jersey Department of Health
Gerontology Program
120 Stockton Street
Trenton, NJ 08625
(609) 292-8106

The caregiver needs help in what is called "the thirty-six hour day."

Four criteria help in deciding when a patient should be in a nursing home.

State directory of services is available.

APPENDIX XI

AUTOPSY REPORT

The New Jersey Department of Health's Gerontology Program was requested to investigate the costs and problems entailed in having autopsies performed on people tentatively diagnosed as having Alzheimer's Disease and of reimbursement to families.

Literature suggests that autopsies are very important in that it is the only way a definitive diagnosis of Alzheimer's Disease can be made. However, the literature is lacking information concerning the particulars of obtaining an autopsy.

At a recent conference at the National Institutes of Health, Dr. Neal Cutler stated that 60-70% of the time, the diagnosis of Alzheimer's Disease has been confirmed upon autopsy. At the same conference Linda Nee, MSW stated that in Maryland, the findings indicate that 20-50% of the people diagnosed with Alzheimer's Disease show no evidence at autopsy. She further indicated that this has resulted in physicians being hesitant to order autopsies for fear of law suits resulting from misdiagnosis.

In New Jersey, the president of the Pathologist Association, Dr. Campos, stated that the national autopsy rate has dropped to about 10%. As a result, there has been decreased confirmation of diagnosis for those people suspected of having Alzheimer's Disease.

The Medical Examiner's office may be requested to perform an autopsy on any and all unusual or suspicious deaths, occurring within 24 hours of admission to a hospital and those listed as "dead on arrival". The county of residence covers the cost of these autopsies. There is no charge to the family.

Several area hospitals were contacted. Staff pathologists indicated that they perform autopsies if so requested by the attending physician and there is no charge. When families request an autopsy, one of two approaches are taken. (1) The hospital may perform the autopsy if the family signs a permission form and the physician orders the autopsy. In this case the charge will vary depending upon hospital policy from \$100 to \$1,000. (2) The family may sign the request and the physician will order the autopsy. However, according to the pathologist, the family will not be charged, and the cost of the autopsy will be included as part of the hospitalization. When families request the autopsy, they are billed for services which are made payable to the hospital and the pathologist. It was learned that pathologists may work on a fee for service basis independent of hospitals and in these cases they bill family directly. We were unable to ascertain the costs for this service or the procedure followed or the facilities used.

One neuropathologist who has recently begun employment in this area (Dr. Douglas Miller) was previously employed as a pathology-related researcher in the brain bank at Massachusetts General in Boston. Viewing the autopsy as one looking at brain pathology in Alzheimer's Disease, he indicated that a neuropathologist performing the autopsy would result in greater cost - from \$1,000 to \$3,000 per case. He gave a general breakdown of time and people utilized which would increase the cost: 2½-4 hrs. of gross time for removal and preparation of brain; 1-1½ hrs. for tissue preparation; about 1 hour for a histologist to view slides; 2-2½ hrs. for typing and tissue reports and 2-2½ hrs. for

other related duties.

The Alzheimer's Disease and Related Disorders Association Autopsy Assistance Network has a brain bank located at Albert Einstein Medical Center. It serves people from New York, New Jersey and Connecticut who wish to have their brain tissue submitted for research. The cost for this program is borne by the family. There are two options which are utilized. First, the family can have the entire body shipped to New York by the undertaker. The pathologist will remove the brain and the remains will be returned to the family for funeral arrangements and burial. This is costly to the family since they must pay for the transportation. The second option involves the family, contracting with a local pathologist/hospital for brain removal, preparation and shipment. The Network has a policy procedure about how to prepare and ship the brain which must be frozen at -70 c. Shipments can only be done on Monday and Tuesday since the dry ice preparation will not keep over the weekend. In this area Federal Express will transport the tissue. It is also important to follow the procedure since brain tissue can be useful if extracted within 24 hrs. of death.

The brain bank prepares the slides so they can be used in research. The slides are made available to others doing research.

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