FINAL REPORT

GOVERNOR'S TASK FORCE

ON ALZHEIMER'S DISEASE

STATE OF CONNECTICUT

GOVERNOR
WILLIAM A. O'NEILL

COMMISSIONER
MARY ELLEN KLINCK

JANUARY 1989
November, 1988

The Honorable William A. O'Neill
Governor, State of Connecticut
Executive Chambers
State Capitol
Hartford, Connecticut 06106

Dear Governor O'Neill:

In the Interim Report of January, 1987, the Governor's Task Force on Alzheimer's Disease estimated the number of Connecticut elderly with measurable signs of cognitive impairment to be approximately 69,000, including approximately 28,000 older persons with moderate to severe impairment. The Task Force also projected that "the overall number of elderly with measurable signs of cognitive impairment would increase to nearly 100,000 by the end of the century and the number of moderate to severe cases to 39,000."

Since the publication of the Interim Report, the Task Force has taken heed of your words when you charged us to "pursue our important work and report back to me.... We know that Alzheimer's disease is an increasingly significant problem in our society and we look forward to receiving reports so that we in state government can build upon the foundation already established to provide even more responsive and compassionate care to victims and their families."

As Chairman and on behalf of the Governor's Task Force on Alzheimer's Disease, I am pleased to present you with our Final Report. This report summarizes activities of the Task Force, presents findings and our recommendations, and includes important research commissioned by the Task Force. We believe these recommendations are an integral part of a comprehensive program to address the problems connected with Alzheimer's disease.
The Task Force is well aware of the current budget crisis, is very concerned about the shortfall and its potential effects on programs and services, realizes that there are many state functions that compete for fiscal priority, recognizes that efforts to deal with the problems of Alzheimer's disease can be costly, yet continues to stress that there is an imperative need to come to grips with the problems and economic impact of the disease. The magnitude of the problem and its future impact require that the Task Force advocate for continued and effective initiatives. Therefore, we have set forth strong recommendations in this Final Report.

I am grateful to the members of the Task Force for their commitment and efforts during this lengthy period. Their level of interest and support never faltered, and in fact, has grown. The Task Force will disband officially with the publication of this report, but the devotion they manifest to helping those victims and family caregivers who live the sorrowful "thirty-six hour day" will continue. Rising phoenix-like from the dissolution of the Task Force, a new coalition of Alzheimer's-involved organizations will appear. Working with all committed Connecticut citizens, we anticipate a better future for Alzheimer's victims and their families in our state.

Sincerely,

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Final Report
Governor's Task Force on Alzheimer's Disease and Related Dementias

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Executive Summary

Alzheimer's disease kills. Every one of the 2.5 million Americans who suffer from it dies. Alzheimer's is a continuous, irreversible degeneration of the brain. The cause of it is still unknown. While several scientists are beginning to unravel some of its mysteries, unless a cure is found, within fifty years well over seven million Americans may fall victim to Alzheimer's disease and related disorders.

Alzheimer's disease doesn't just kill. It costs. We don't have to look fifty years ahead to see that society is already facing a crisis, as Alzheimer's families struggle to care for their loved ones. The Office of Technology Assessment's report, Losing a Million Minds, states that dementing disorders are among the most costly public health problems the nation is likely to face in the next fifty years.

In an article in the "American Journal of Public Health" discussing the economic costs of Alzheimer's disease, Joel Hay, Ph.D., and Richard L. Ernst, Ph.D., estimated the economic costs of Alzheimer's disease to individuals and to society. Their analysis was derived from epidemiological projections and cost information for the U.S. population in 1983. Estimated costs include both direct medical care and social support costs, as well as indirect costs, such as support services provided by family volunteers, and the value of lost economic productivity in Alzheimer's patients. Mid-range estimates of net annual expected costs for an Alzheimer's patient, excluding the value of lost productivity, are nearly $20,000 a year. Most often the victim's family must carry the weight of this expense. Under base case assumptions, the total cost of disease per patient was $48,544 to $493,277, depending on the patient's age at disease onset. The estimated present value of total net costs to society for all persons first diagnosed with Alzheimer's disease in 1983 was $27.9 to 31.2 billion. When the value of lost labor output is considered, the social burden of Alzheimer's is much greater still. Due to the omission of such costs as emotional stress, these figures probably understate the actual economic costs of Alzheimer's disease.

The current lack of long term care assistance means that families are shouldering the majority of caregiving and financial responsibilities. When the family's endurance and savings give
way, they must depend on the only other source available, which is Medicaid-funded institutional care. As the number of elderly reaching 65 exceeds the number of young people facing maturity, fewer and fewer working people will be supporting more and more individuals subject to Alzheimer's disease.

In Connecticut approximately $240 million is spent to care for the estimated 9,000 dementia patients in residential settings (GSU Report, Appendix). Sixty per cent of those patients are Medicaid recipients. Since neither Medicare nor private health insurance covers the costs of long term care for this or other chronic diseases, Connecticut citizens are facing a potential financial time bomb.

Why are all these depressing statistics important? Statistics on diseases that afflict a population can have a major influence on the distribution of health-related resources. The problems presented in the following report are significant, and will increase in years to come, as people over 65 constitute a greater percentage of Connecticut's population.

On the other hand, much has been done in Connecticut and much can be done to improve the situation of the victims and their families, by making good use of facilities and programs already in existence, by expanding useful programs, and by implementing new ideas and projects.

With this in mind the Governor's Task Force on Alzheimer's Disease has adopted the following recommendations:

- Increase the availability of care in the community.
- Maintain access to extended care facilities.
- Improve patient care skills relevant to dementia.
- Expand funding mechanisms for long term dementia care.
- Promote greater public awareness of Alzheimer's issues and existing services.
I. Background

Alzheimer's disease is a disease of unknown cause which usually affects adults over age 60. It is not a normal consequence of aging. The onset is usually slow and gradual. In time, it follows a progressive deteriorating course marked by problems in communication, recent short-term memory, long-term memory, loss of spontaneity and tendencies to withdraw from social settings. Problems in abstract thinking and behavior disturbances such as agitation and quarrelsomeness are also characteristic of the disease. These symptoms are progressive and followed by disorientation and wandering. Although Alzheimer's disease is by far the most common cause of irreversible dementia in the aged, there are others such as multi-infarct dementia (the cumulative effect of minor strokes), Pick's disease and Parkinson's disease. The recommendations of the Task Force are meant to apply to all persons suffering from irreversible dementias no matter what the cause.

The most common characteristic of dementia is cognitive dysfunction (best described in layman's terms as chronic confusion) which can be measured with some degree of accuracy by screening tests such as the mental status quotient (MSQ). The most recently available data suggests that approximately 16,000 non-institutionalized elderly Connecticut residents are currently suffering from moderate to severe cognitive impairments (in most cases resulting from an irreversible dementia) and an additional 41,000 are suffering from a mild form of cognitive disorder (frequently a sign of the early stages of Alzheimer's disease). These numbers are expected to increase to 22,000 and 53,000 respectively by the year 2000. Department of Health Services data indicates that an additional 14,000 elderly nursing home residents show signs of moderate-to-severe cognitive impairment. Taken all together it appears that approximately 71,000 elderly Connecticut residents are now experiencing some level of cognitive impairment and that this number will increase to over 100,000 by the end of the century.

II. Recommendations

The following are recommendations of the Governor's Task Force on Alzheimer's Disease and Related Dementias. This Task Force is an expanded version of the Task Force to Study the Needs of Persons Suffering from Alzheimer's Disease which issued its preliminary report to the Legislature in February of 1986. In
January of 1987, the expanded Governor's Task Force issued its recommendations; those recommendations and budget were adopted unanimously by the Task Force at the December 17, 1986 meeting. The following recommendations are based on deliberations, studies and activities which have taken place between August 26, 1986, and December, 1988. They represent the Task Force's best judgement at this stage in its deliberations on the types of services needed by Alzheimer's victims and their families. They should not be considered a blueprint for the establishment of a new service network but rather a description of the constellation of services and service linkages that would provide the optimal measure of relief from the suffering caused by this disease.

A. Task Force Statement of Intent

The Governor's Task Force on Alzheimer's Disease supports the establishment of an independent Alzheimer's Coalition in Connecticut.

The Task Force has established an important identity, providing both advocacy on behalf of disease victims and families, as well as specific professional expertise in discussions of clinical care and research. The Task Force becomes even more useful to the State of Connecticut as programs develop and priority decisions concerning their evaluation and funding are required. As the Task Force completes its three-year appointed term in December, 1988, its members, drawn from leaders of professional, state and civic groups in Connecticut, remain committed to the recommendations drawn from its studies and deliberations which were submitted to the Governor.

In expression of that commitment, it has been proposed that a coalition of Task Force members and others be established to continue necessary work. The goals of the Alzheimer's Coalition of Connecticut are:

1. Review systems/programs that are the direct result of Task Force recommendations.

2. Promote recommendations of the Task Force that remain unaddressed.

3. Pursue findings of Task Force studies that have important implications for care, and promote further studies that advance this cause.

4. Advocate legislation that will advance care, research, diagnosis and treatment of dementia.

5. Advocate education about dementia and its implications for patients, caregivers, professionals and related social systems.
6. Promote the development of care systems in Connecticut, particularly long term care, that meet the needs of both patients and caregivers.

7. Act as a source for advice and counsel to state, civil and professional groups/individuals who want to improve care to dementia victims and their families.

B. Recommendations

1. Increase the Availability of Care in the Community.

The majority of the victims of Alzheimer's disease and related dementias are cared for in the community by relatives, most commonly spouses or children. The progressive nature of the disease presents caregivers with a series of challenges. These require a series of individual responses that depend on the caregiver's own skills and resources and the services available in the immediate vicinity. Task Force members felt that after Alzheimer's is diagnosed, caregivers and victims could best be served by local experts who would be familiar with and could refer people to local resources. In 1987, the Task Force recommended and continues to recommend that the state establish a network of regional Alzheimer's centers staffed by professionals to provide that service. These Alzheimer's specialists would be able to develop individualized care plans for victims and provide either advice or case management to families as the condition of the patient progresses.

In order to provide the broadest range of coverage, the Task Force recommended that five such centers be established, one in each of the five health planning areas. These centers would be staffed by a minimum of two professionals with case management, community nursing or social work backgrounds and previous experience with Alzheimer's disease. They would be established on a competitive basis through RFP's directed toward case management, community health and Alzheimer's support organizations.

Adult day care is one of the community services most frequently used by victims of Alzheimer's disease. A 1984 survey of adult day care centers conducted by the Department on Aging found that approximately one-quarter of all adult day care users were diagnosed as suffering from Alzheimer's disease or a related dementia and a third of all users showed signs of moderate to severe cognitive impairments. The same study found that the staff ratio in most centers was too low to provide adequate care to Alzheimer's patients. This gave rise to the Department's program to support additional staff in day care centers so as to increase the number of Alzheimer's victims the centers can care for. Based on the Department's experience with this program we estimate that it costs approximately $5.00 per day over the usual
fees to provide appropriate service. Centers operate for approximately 200 days a year. Given the importance of adult day care in the treatment of community-dwelling Alzheimer's victims, the Task Force supports expanding the availability of adult day care services to Alzheimer's victims.

The Task Force also recommends initiatives in the area of community care which emphasize respite care admissions to residential care facilities, companion services and other services which provide temporary relief from caregiving. These services should be linked to counseling and psychological services capable of addressing emotional difficulties. To minimize cost and transportation problems, and to ensure geographic accessibility, special emphasis should be placed on the development of decentralized in-home respite care. Such services might, for example, be organized through the regional centers, or town basis through Area Agencies on Aging, senior centers and local support groups. Training local volunteers and/or retirees as caregivers would help keep such services economically feasible for both self-pay clients and third-party payors. In communities unable to support this level of organization, periodic or regional programs designed to train individuals in the provision of respite care as "paid assistants" might be developed. Innovative means of providing respite care should be investigated. Additional efforts should be made to improve access to more traditional home care services such as home health care, homemaker services, meal preparation and chore services. Where the use of multiple services must be negotiated to maintain the dementia patient in the community, case management should play a central role in delivering services; this could be done by the regional centers.

Funding requested in FY 1987 was $500,000 for expanded adult day care services. Funding requested in FY 1987 for the regional centers was $500,000. The Task Force continues to recommend this level of request for funding.

2. Maintain Access to Extended Care Facilities.

The Task Force recommends the promotion of options for ensuring access to skilled nursing facilities for those dementia patients whose medical conditions require such care. The Task Force suggests that residential care providers, regulatory agencies and fiscal intermediaries tie the construction of an appropriate number of new skilled nursing beds to dementia care, preferably in the context of specialized dementia care units. Given the labor- and space-intensive nature of dementia care, the feasibility of supplementary reimbursement for the care of dementia patients in such units should be considered. Movement in this direction would need to be accompanied by a search for less intensive and less costly options for residential care of dementia patients whose medical conditions do not require skilled nursing care but who, in the absence of informal care, are unable
to remain in the community because of behavioral problems or who live alone. Intermediate care facilities and homes for the aged might serve as useful starting points in such a search. A group home model might also be considered as a minimal care option for patients in the earliest stages of the disease. Under such a multilevel care approach, procedures for ensuring continuing placement at an appropriate level of supervision would have to be implemented.

National data suggests that the cost differential in caring for dementia patients in institutions is approximately $14.00 a day. Assuming the GSU estimate of 9,000 dementia patients in residential settings is correct, the introduction of a differential rate for the care of dementia patients would increase overall institutional care costs by approximately $46 million a year, 60% of which, or $28 million would be paid for by Medicaid.

3. Improve Patient Care Skills Relevant to Dementia.

The Task Force's current initiative involving the creation of specialized diagnostic centers should be pursued vigorously, complemented by new initiatives in the area of professional and paraprofessional training. These educational initiatives should encompass the spectrum of health and social service personnel involved in the diagnosis and management of dementia, and target training activities at all levels of practice. One strategy would be to work with health professional schools in the state to update and expand the coverage of dementia in their curricula, and to develop appropriate educational materials for in-service training. For health and social service professionals, continuing education efforts should emphasize the early signs and symptoms of dementia, appropriate referral for diagnosis, and the range of services available to assist in managing the dementia patient. In the case of paraprofessionals, such training should emphasize management of the agitated patient and effective communication with dementia patients and family members. Training for both groups would benefit from basic information on the nature and course of the disease.

In addition, the Education Subcommittee of the Task Force has recommended:

1) Further statewide or regional symposia for professionals and family caregivers should be developed and presented at least annually, under the auspices of the Department on Aging, the two chapters of Alzheimer's Association, the Alzheimer's coalition, the state's two medical schools and other appropriate agencies.

2) Development of a specialized component on Alzheimer's disease and other dementias should be considered as part of the curriculum for all colleges and universities in Connecticut which offer professional and paraprofessional training in the medical and related fields.
The Task Force requested $100,000 in FY 1987 for education. It continues to recommend this level of request for funding.

4. Expand Funding Mechanisms for Long Term Dementia Care.

Reimbursement restrictions on the social services required to maintain dementia victims in the community, on related home care and home health services, and on the extra staffing and environmental costs associated with residential care of dementia victims represent major obstacles to effectively and efficiently meeting the needs of such individuals and their families. The Task Force recommends funding options for these services and advocates for needed changes in reimbursement policies. In this regard, a thorough review of existing funding mechanisms, and those under development, may be in order. Such a review, if conducted, should include an examination of the financial and organizational arrangements of programs in the state which have been successful in delivering needed services to dementia patients despite reimbursement limitations, and consideration of service delivery incentives which might be incorporated into existing reimbursement structure. Staff at the State Office of Policy and Management engaged in formulating long term care insurance are presently considering the issue.


The Task Force supports the Department of Human Resources' efforts to provide additional funding for Info-Line for statewide twenty-four-hour coverage. Other outreach mechanisms designed to disseminate service information directly to caregivers are encouraged and promoted. The Task Force recommends that the Department on Aging should expand its collection and distribution of educational materials, tapes, etc., which inform the public on Alzheimer's disease. The Task Force also recommends an additional $90,000 in funding for the Department on Aging to cover additional staff and materials to assist the Alzheimer's unit in coordinating Alzheimer's public information and outreach, promoting long term care information and developing and distributing educational materials.
III. History, Pathology, and Etiology

Today, in many thousands of Connecticut households, someone will forget to turn off the stove or be at a loss to name a familiar object. This someone will look well and show no sign of serious depression, overt neurological deficit, stroke, brain tumor or any other specific disease. Yet this person is very sick. Within three to ten years, he or she will become severely demented. He or she will not be able to do the simplest task, such as eat or dress; then he or she will die often from some complication that afflicts bedridden patients.

Most of these patients are elderly, but their symptoms are not the normal course of "aging". These people have a specific disease: Alzheimer's. The diagnosis can only be inferred during the patient's lifetime; no unique pattern of behavioral abnormalities has been established and there is no satisfactory laboratory test short of a brain biopsy. An autopsy, however, shows highly characteristic pathologic changes in the brain.

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 proportionately, with age (Emr and Schneider, 1985).

Diagnosis of Alzheimer's disease is by exclusion, as mentioned above, since definite diagnosis can only be confirmed through examination of brain tissue. There is a loss of neurons (nerve cells), particularly in regions essential for memory and cognition. There are accumulations of twisted filaments (neurofibrillary tangles) and other abnormal structures within neurons. There are amorphous aggregates of protein adjacent to and within blood vessels. And there are scattered focuses of cellular debris and amyloid called neuritic plaques.

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

How is it that this devastating disease attracted so little attention until recently and that its prevalence was not recognized? For a long time people with these symptoms were said to be "senile" or suffering from "hardening of the arteries." Within recent years, however, it has been clear that the brains of most old people with dementia show all the characteristic signs of Alzheimer's disease if examined at autopsy. Now it is estimated that Alzheimer's disease afflicts from 1.5 to two million Americans and that at least 100,000 of them die of it every year. Yet no one knows what causes it, how its characteristic changes are brought about or how to treat it.
IV. 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 theory of "stages of cognitive decline" is one of several about the progression of the disease; not all persons with dementia progress in the same manner.

V. Demographics

Evidence from epidemiologic studies and projections of the growth of Connecticut's over-65 population lead to the conclusion that, barring medical breakthroughs in prevention and treatment, dementing illness will affect increasing numbers of Connecticut's elderly population each year. It is inescapable.

Unfortunately, this is an easier conclusion to reach than to quantify. As McDonnell et al. (1983) have pointed out, "there is considerable variation among estimates of rates of dementia and absolute numbers of people so afflicted. This variation is understandable in view of differences in populations included in the studies (institutional or community), the degree of dementia being assessed (mild, moderate, severe), the variety and definition of dementia (Alzheimer's disease, multi-infarct dementia, unspecified dementias), the age groups (total population, the 65 and older group), as well as differences in methodologies which are followed to identify and diagnose dementia and to derive the estimates." The most recently available data on the prevalence of dementing illness among Connecticut's elderly can be found in a newly published study by the National Institute on Aging. Completed in 1986 and based on data collected in 1983 and 1984, this study (Established Populations for Epidemiologic Studies of the Elderly: Resource Data Book) presents baseline data collected from representative...
samples of the noninstitutionalized population age 65 and over in three communities: East Boston, Massachusetts; Iowa and Washington counties in Iowa; and New Haven, Connecticut. Clinical diagnoses of Alzheimer's disease and related dementias were not reported in the published data; the presence of dementia was instead indicated by declines in cognitive functioning measured by an item modification of the Mental Status Quotient (MSQ) questionnaire.

For purposes of analysis, scores from the New Haven study were grouped as follows: 0-2 errors - no impairment, 3-4 errors - mild impairment, 5 errors or more - moderate to severe impairment (Kane and Kane, 1981). In general, moderate to severe impairment scores on the MSQ can be taken as a good indicator of the presence of dementia or some other form of organic brain disorder. The mild scores are somewhat more difficult to interpret in the absence of clinical data, although they are often one indicator of the early stages of Alzheimer's disease. Overall, the instrument is reported to have a greater bias toward false negatives than false positives when used as a screening tool for organic brain dysfunctions.

Assuming for the moment that moderate to severe cognitive impairment can be taken as a reasonable indicator of dementia and mild impairment as an indicator of the need for further assessment, application of the age-specific impairment rates from the New Haven study to the estimated Connecticut population for 1984 yield an estimate of 57,000 persons in the community age 65 and over showing signs of some level of cognitive impairment with 16,000 of these being moderately to severely impaired.

The institutional population must be added to these estimates to give a complete picture of the problem. According to McDonnell et al., estimates of the institutionalized population afflicted with dementia range from a low of 50% to a high of 75% with the majority of the studies quoted being in the 50% to 60% range. The annual census of Connecticut nursing home patients asks nursing home administrators to report whether each of their patients is confused or disoriented. The confused or disoriented category is defined as "significant or substantial inability to remember dates, familiar events or people to the degree that patient is impaired nearly every day in basic activities of daily living" (Connecticut Department of Health Services, 1986). The intent is to identify patients who would fall roughly into the moderate to severe category, and supplementary instructions indicate that comatose patients are to be included in this category. The September 30, 1984 census showed a total of 13,683 confused or disoriented patients in Connecticut nursing homes. This was 53% of the total nursing home population, a figure comfortably within the range of estimates reviewed by McDonnell et al. Assuming the comparability of the nursing home census data to the moderate to severe estimates in the community data, the total of moderate to severe cases would increase to 28,000, and the total number of elderly suffering would increase to 69,000.
The age-specific rates that resulted from these combined data sources were applied to the Office of Policy and Management's series of age-specific population projections for the years 1980 through 2000 to produce a rough estimate of the potential growth in dementia cases over that period. These estimates show the overall number of elderly with measurable signs of cognitive impairment increasing to nearly 100,000 by the end of the century and the number of moderate to severe cases to 39,000.

Shortly before the release of the New Haven data, Preston (1986) completed a review of the international literature on the prevalence of dementia. He concluded that much of the variation within these studies was due to differences in methodology and operational definition of the disease. He felt that studies which used similar methodologies and definitions produced reasonably consistent findings. After examining seven such studies, he was able to construct a formula for predicting age-specific prevalence rates for moderate to severe dementia that fit closely with the observed rates. His formula was:

\[ R(a) = \exp[0.1258(a-42.1008)] \]

where \( R \) = rate per thousand

\( a \) = the lower limit of the age interval \( a \) to \( a + 5 \)

When this formula is applied to the OPM population estimates for 1985 to 2000, it yields estimates of 29,000 elderly persons with moderate to severe dementia in Connecticut in 1985 to 41,000 in the year 2000. These estimates are not too dissimilar from those developed earlier using the Connecticut data from 1984.

Although they show a tendency to agree, the tentative nature of these estimates is most striking. Incidence estimates, i.e., estimates of the number of new cases that occur, or at least are identified in a given time period, are even less concrete. McDonnell et al. were only able to identify four such studies in their review and these were based on relatively limited and specialized samples. The most detailed of the studies reported--life tables constructed by Sluss, Gruenberg and Kramer to predict the incidence of senile dementia in males over 65--would, when applied to both sexes in Connecticut, yield an estimated incidence of approximately 5,000 cases in 1984.
VI. History of the Task Force

In 1985, as a result of an act of the General Assembly (Special Act No. 85-81), a Task Force to Study the Needs of Persons Suffering from Alzheimer's Disease was established. The act was to take effect on July 1, 1985. This group submitted an initial report to the Legislature in February, 1986, recommending that the State of Connecticut develop an Alzheimer's disease information program and expand respite care programs for victims and their families.

The Task Force also recommended that the Task Force be continued until February, 1987, for the purpose of conducting "analyses and feasibility studies and to allow time to identify solutions for the needs that this Task Force has identified." This preliminary report also recommended that the Task Force be expanded to include the following: the Commissioners of Income Maintenance, Mental Health, and Hospitals and Health Care, or their designees; a representative of the insurance industry; a legislator from each party; a member of the legal profession; a representative of the Alzheimer's Disease and Related Disorders Association; and two representatives from the home care sector.

In the fall of 1987, Governor O'Neill announced that the Task Force would become his designated "Governor's Task Force on Alzheimer's Disease" and charged its members to "continue to study the service needs of victims of Alzheimer's and related disorders as well as the needs and concerns of the family members who provide care for these patients."

Governor O'Neill said, in a news release at that time, "I am disappointed that the 1986 General Assembly failed to do more with the Task Force proposals," and "that is why I am pleased to adopt another of its recommendations--that the Task Force be continued and expanded to include members whose programs and policies impact on Alzheimer's and related problems. I was truly impressed with the work of that group, and I am asking the members and their new colleagues to pursue their important work and report back to me early next year."

"We already know that this is an increasingly significant problem in our society, and I look forward to receiving the report of the Task Force so that we in state government can build upon the foundation already established to provide even more responsive and compassionate care and assistance to victims and their families."

With this charge in mind, the expanded Task Force met frequently. At the first meeting it was decided to establish four subcommittees: Information and Referral, Training and Education, Diagnostic and Research Centers, and Caregiving. Each of the subcommittees was to study the problems related to Alzheimer's disease and that particular topic, develop findings in that regard, report on them, and make recommendations as to the future course of action to respond to that problem.
In addition to research, the Task Force requested reports from Task Force members with special expertise, ranging from legal problems facing Alzheimer's patients to descriptions of the Geriatric Education Center at the University of Connecticut and the Braceland Center at the Institute of Living.

Invited guests also shared information with the Task Force; one speaker reported on the Governor's Commission on Private and Public Responsibilities for Financing Long Term Care for the Elderly, and another provided material on Yale New Haven Hospital/Yale University efforts regarding Alzheimer's victims.

The Task Force published an Interim Report in February, 1987. Included in the Interim Report were recommendations based on the initial report and on activities and deliberations which took place between August 26, 1986, and December 17, 1986. These recommendations and budget were adopted unanimously by the Task Force at the December 17, 1986 meeting. They are:

1. Continuation of the Governor's Task Force to Study Alzheimer's Disease and Related Dementias.
   Funding requested in FY 1987: $50,000

2. Establish a statewide Information and Referral center on Alzheimer's disease and related dementias.
   Funding requested in FY 1987: $200,000

3. Establish a focus of responsibility within state government for monitoring Alzheimer's disease and related dementias and coordinating state policy for dealing with these conditions.
   Funding requested in FY 1987: $119,290

4. Expand the availability of adult daycare services to the victims of Alzheimer's disease and related dementias.
   Funding requested in FY 1987: $500,000

5. Increase the availability of respite care to families caring for the victims of Alzheimer's disease and related dementias in the community.
   Funding requested in FY 1987: $500,000

   Funding requested in FY 1987: $500,000
7. Provide education for paid professionals, papaprocessionals and family caregivers.

Funding requested in FY 1987: $100,000

8. Assure the availability of expertise in the management of Alzheimer's disease at the regional level.

Funding requested in FY 1987: $500,000

Since the publication of the Interim Report of January, 1987, the Governor's Task Force on Alzheimer's Disease has addressed those recommendations. The recommendations led to a series of partnerships with other state agencies and organizations. The recommendations were addressed and implemented in the following manner:

1. The very first recommendation in the Interim Report was for the continuation of the Task Force. During Task Force deliberations many issues were raised by members which required further study. Two areas of study were identified as most important to the care of the Alzheimer's victims: respite care and institutional care. Respite services currently include adult day care, short term institutional care, and home care from a variety of formal and informal providers.

Many questions still remain about the concept of respite care for the Alzheimer's victim. The focus of respite care must be to relieve the primary caregiver who provides care twenty-four hours a day, seven days a week. The need for respite will recur frequently and individual programs must be planned for intervals suitable for individual caregivers. Quantitative formulae need to be developed which represent the true need for respite, and alternative funding arrangements should be investigated. A voucher system or a predetermined formula for service reimbursement are two possible considerations. Most importantly a new definition of respite care must be arrived at that is relevant to the specialized care required by the Alzheimer's victim.

The second area of concern which the Task Force felt required more study was institutional care standards. Present estimates suggest that anywhere from 50-60% of institutionalized persons suffer from Alzheimer's or related dementias. Many of these persons may be in a terminal or dependent state but a certain percentage are experiencing the agitated, restless stage of the disease, which presents specific caregiving dilemmas to institutions.

Allocations to continue the Task Force were used to pay for consulting services and to conduct studies. Between August of 1987 and June of 1988, the University of Connecticut Gerontology Studies Unit (GSU) carried out a series of research and
educational activities for the Task Force. A survey commissioned by the Task Force, with Task Force members directing research, resulted in a joint project of the Department on Aging, the Travelers Center on Aging and the Gerontological Studies Unit of the Department of Community Medicine at the University of Connecticut Health Center. The Survey of Professional and Informal Care of Connecticut Residents with Alzheimer's Disease and Related Disorders, a Final Research Report, June 1988, directed by Richard A. Lusky, Ph.D., was a product of this research. A Directory of Resources for Connecticut Residents with Alzheimer's Disease and Related Disorders, 1988, is a second publication resulting from the survey. Dr. Lusky said that the survey was designed to provide sound information on the numbers of dementia victims receiving formal services in Connecticut, the gaps in services and the barriers that limit adequate care. (n.b., the Survey and Directory are available for study at the Alzheimer's unit, Department on Aging.)

2. The second recommendation was fully accomplished with the cooperation and partnership of the State Department of Human Resources and its funding for Info-Line. The Task Force saw the glaring need for an Alzheimer's disease information program. With funds channeled to Info-Line, an Alzheimer's disease information and crisis phone service was established. In January of 1988, Info-Line, with six regional offices around the state, launched expanded services. Although Info-Line had always received and answered calls about Alzheimer's in the past, caseworkers began getting special training for this project. They are now better equipped to answer questions, explain treatment options, refer callers to available services and collect pertinent data. Publicity campaigns were undertaken, special brochures were printed, and educational videotapes were made. A Professional Advisory Board to Info-Line was established for ongoing input and cooperation. Members represent the Department on Aging, the Department of Human Resources, the Task Force, and the Alzheimer's Association chapters.

3. The third recommendation has been implemented; an Alzheimer's unit is now established within the Department on Aging in the Research and Planning Division. Two staff positions have been funded. Since December, 1987, a Planning Analyst has been planning activities inherent in responsibilities related to Alzheimer's, performing staff functions to the Task Force (and similar bodies that may be established to study problems associated with Alzheimer's and related dementias) and coordinating programs within other state government entities which meet the needs of Alzheimer's patients.

4. Recommendation number four concerning adult day care has not been fully implemented. The Department on Aging has continued channeling funds to the five Area Agencies on Aging to help support adult day care for Alzheimer's victims. In fiscal year 1987 -1988, the Department funded twenty-two of the fifty centers to help pay for aides to take care of Alzheimer's
victims. Funding for adult day care continues to be recommended by the Task Force and is included in recommendation number one of this report.

5. The fifth recommendation to increase the availability of respite care to families caring for the victims of Alzheimer's disease and related dementias in the community has been addressed through a relationship with the Department of Health Services. The Department received increased funding which allowed it to contract with agencies to provide respite care in all 169 towns. The Respite Care Program is operated through the Community Nursing and Home Health Division of the Department of Health Services.

6. The sixth recommendation was realized in the Governor's Recommended Budget for the 1988-1989 fiscal year when the Department on Aging received monies to support the development of Alzheimer's disease diagnostic and research centers. A request for proposal was sent out inviting agencies, institutions and coalitions of organizations to apply. The diagnostic centers will fill a much needed gap in the spectrum of services for Alzheimer's victims in the state. The funding for these centers will be used as "seed money." In the light of the demands regarding Alzheimer's populations and the inadequate numbers of those skilled in gerontology and geriatrics, innovative approaches must be developed to increase expertise in diagnosing Alzheimer's disease. Most physicians are not familiar with the diagnostic techniques which are appropriate for determining the causes of cognitive impairment. These frequently require expertise from multiple disciplines. Connecticut residents faced with a suspected diagnosis were frequently referred to Boston or New York to have that diagnosis confirmed. National Alzheimer's Association officials have stated that obtaining the diagnostic centers is an outstanding achievement of the Task Force. (Announcement of awards will have been made by the time this report goes to press.)

7. Providing education for paid professionals, paraprofessionals and family caregivers was the seventh recommendation of the Task Force. This recommendation has been addressed and will continue to be addressed in a number of ways. Education is the key to sensitizing those who come into contact with Alzheimer's victims and their families. Educational programs are needed at many different levels, including education for the general public; education for professional caregivers such as doctors, nurses, occupational therapists, physical therapists, social workers, recreational therapists, nutritionists, speech therapists, and neurologists; education for paraprofessionals such as homecare personnel, police, EMT staff, acute care hospital personnel; attorneys and clergy; and education for families caring for the Alzheimer's victim.
In the fall of 1987, Task Force members, GSU staff and Department on Aging staff worked closely to plan an innovative one-day conference designed to unite and mobilize family and professional caregivers serving dementia victims throughout the state. The Education subcommittee of the Task force developed a conference format which included a keynote address by Nancy Mace, M.A., co-author of *The Thirty-six Hour Day*, a presentation by Dr. Richard Lusky of the provider and informal caregiver survey results, small group information and sharing sessions, workshops conducted by invited experts and Task Force members and presentation of sharing group results. Entitled "Partners and Pioneers," the conference was held on April 6, 1988, under the sponsorship of the Task Force, the Connecticut chapters of the Alzheimer's Disease and Related Disorders Association, the Department on Aging and the University of Connecticut Travelers Center on Aging. Evaluation forms and comments were extremely positive; planners were praised for bringing together professional and informal caregivers for the purposes of mutual learning, information sharing and problem solving.

The Final Project Report, Research and Education in Alzheimer's Disease and Related Disorders, prepared for the Task Force by Dr. Lusky and project staff, and included as Appendix to this report, describes each of these activities—the conference, the findings of the two surveys, and the resources directory.

The Education subcommittee continues to recommend educational initiatives encompassing the spectrum of health and social service personnel. Recommendation number three of this Final Report reemphasizes training for all who would benefit from information on the nature and course of the disease and management techniques.

8. Recommendation number eight, assuring the availability of expertise in the management of Alzheimer's disease at the regional level, has not been addressed and continues to be recommended as recommendation number one in this Final Report.

The Task Force continued to meet during the summer and fall of 1988. All minutes of general meetings, subcommittee meetings, ad hoc subcommittee meetings, and the "Steering Committee for Continuation" meetings are available at the Department on Aging.

An organization of Task Force members and others will continue in some form such as a coalition, as all members feel very strongly about their commitment. As one member stated, "The Governor's Task Force on Alzheimer's Disease has established an important identity, providing both advocacy on behalf of disease victims and families as well as specific professional expertise to discussions of clinical care and research. The Task Force becomes even more useful to the State of Connecticut as programs develop and priority decisions concerning their evaluation and funding are required. At a minimum, the Task Force should remain active as an Advisory Committee to SDA and as a resource group.
statewide. Members of the Task Force have stated they will not take the easy way out and have already pledged themselves to tackle the unaddressed problems facing Alzheimer's victims and their families.
RESEARCH AND EDUCATION IN
ALZHEIMER'S DISEASE AND RELATED DISORDERS

FINAL PROJECT REPORT

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I. INTRODUCTION

Between August 1, 1987 and June 30, 1988, the University of Connecticut Gerontology Studies Unit (GSU) carried out a series of research and educational activities for the Governor's Task Force on Alzheimer's Disease. These activities included surveys of organizations and individuals providing formal and informal care to Connecticut residents with Alzheimer's Disease and other dementias, the development of a resource directory of service providers, and the organization of a statewide conference designed to bring professional and informal caregivers together for the purposes of mutual learning, information sharing, and problem solving. The activities were funded under a multipurpose contract from the Connecticut State Department on Aging. This final project report describes each of these activities, presents the key findings of the two surveys and the conference, identifies the major challenges associated with meeting the needs of Connecticut's dementia victims and their families, and offers recommendations for further action by the Task Force based on the results of the entire project. A more detailed description of the two surveys and their findings can be found in the project's final research report, "Survey of Professional and Informal Care of Connecticut Residents with Alzheimer's Disease and Related Disorders," concurrently submitted to the Task Force with the present report.

II. PROVIDER SURVEY

Procedures

The first survey, a return-mail survey of Connecticut health and social service providers, was conducted in the Fall of 1987. The survey focused on key service delivery issues identified by the Task Force during its first two years, including: 1) the numbers and types of formal caregivers assisting dementia patients, 2) the size and nature of the dementia population under care, 3) the types of services available to such patients in various residential and community care settings, 4) major gaps in service and barriers to optimizing care for such patients, and 5) providers’ staff training needs in the area of dementia care.

Information in each of these areas was sought by means of a seven-part questionnaire. The instrument summarized the Task Force's working definition of dementia, emphasizing its organic basis, irreversible nature, and manifestation in the form of progressive cognitive dysfunction including: "disorientation, confusion, short or long-term memory loss, impairment of abstract thinking, and/or behavioral disturbance such as withdrawal, wandering, agitation, or disruptive behavior." A series of structured, semi-structured, and unstructured questions were then used to elicit: 1) organizational information about the providers, 2) "census" data on patients who, in the providers’ estimation, met the survey definition of dementia, and 3) providers’ views on the care of dementia patients.

In October, 1987, questionnaires were sent to all licensed residential care facilities, homes for the aged, home health agencies, homemaker programs, and adult day care centers. Acute care and chronic disease hospitals equipped for the care of dementia patients, the state's two licensed CAM (coordinating, *Governor's Task Force on Alzheimer's Disease, "Interim Report," January 1987, pp 12-13.*
assessment and monitoring) agencies, and social service agencies reporting the management of dementia cases were also surveyed. In all, 626 providers received the questionnaire accompanied by explanatory letters from the Commissioner on Aging and the Director of the GSU, and by a return-addressed postage-paid reply envelope.

A total of 531 facilities, agencies, and programs returned their questionnaires by 1/20/88 for an overall response rate of 85%. Responding providers included 285 residential care facilities, 159 community agencies, 34 adult day care centers, 30 hospital inpatient units, and 23 hospital outpatient units. Further analysis showed that those returning the questionnaires were broadly representative of those surveyed. Individual response rates were 84% for residential facilities, 86% for community agencies, 97% for adult day care centers, 77% for hospital inpatient units, and 97% for hospital outpatient units. As a result, the distribution of the responding providers, by provider type, was nearly identical to the original mailing list. The geographic distribution and organizational size of those responding also paralleled the universe of providers.

Findings

Key findings from the provider survey include the following:

A total of 341 of the 531 responding providers (64%) reported caring for dementia patients. The proportion varied from 57% among hospital outpatient units to 97% among adult day care centers.

Together, the providers reported serving 9,575 dementia patients. Approximately three out of every four (74%) of those identified by the survey as receiving formal services were receiving such care in long-term care facilities. The vast majority of these individuals (92%) resided in skilled nursing facilities.

Another 3% of the dementia patients identified were reported by hospital inpatient units, leaving less than one-fourth of those identified (23%) residing in the community.

The dementia victims reported by responding providers were very old, and, more often than not, female. Among cases identified through the survey, 98% were over the age of 60, with 38% of these individuals over the age of 85. About 75% of those over the age of 60 were female.

The majority of dementia patients identified through the survey did not appear to represent persistent behavioral problems. Providers characterized 57% of residential dementia patients and 53% of dementia patients in the community as predominately "passive."

According to responding providers, the majority of their dementia patients required professional care. In all, 81% of residential and 69% of community-residing patients identified by the survey required such care.

Medicaid appears to be the major payment mechanism for the formal services received by dementia patients. It was the primary payment source for 53% of the dementia patients identified (64% of residential patients and 13% of community-residing patients).
About 99% of skilled nursing facilities reported caring for dementia patients. In contrast, only 61% of intermediate care facilities and 8% of homes for the aged reported caring for such patients. About 75% of home care agencies did so.

Patients with dementia, as defined by the survey, occupied 33% of the beds in residential facilities. In contrast, they constituted only 6% of the combined caseload of community agencies. Adult day care centers, however, reported the highest proportion of patients meeting the survey criteria for dementia (42%).

A wide range of services were reportedly available to dementia patients from both residential and community-based providers. A number of key services, including segregated dementia care units, consulting psychologists and geriatricians, respite care admissions, family support groups, and chore services were, however, absent or very limited in availability.

While hospital-based programs were more likely to provide access to specialized professional staff such as psychiatrists and psychologists, they were (as noted above) in contact with very few of the dementia patients identified through the survey.

The major barriers to optimal care of dementia patients, as reported by residential facilities, hospitals, and community-based providers, centered on financial constraints. Residential care facilities tended to emphasize their inability to recover the extra staffing and space costs associated with dementia care, while hospital-based programs emphasized limited family finances and insurance. Community agencies were somewhat more likely to show concern with the "denial of covered services" and the exclusion of needed services from most reimbursement mechanisms.

Staffing problems, including staff shortages and limited availability of staff with special training in dementia care, constituted a second set of barriers to optimal dementia care among all three types of providers.

Providers uniformly identified their most pressing staff training needs as improved management of agitated patients, better understanding of dementia and its progression, and more effective communication with dementia patients and their families.

Resource Directory

While the primary purpose of the provider survey was to gather data needed for evaluating and improving Connecticut's services for dementia victims and their families, an attempt was also made to make the information supplied by respondents more immediately useful to service providers and informal caregivers. To this end, GSU staff extracted survey data on the availability of dementia-relevant services from survey respondents reporting the care of one or more dementia patients. This information was then organized by provider type (eg. residential facilities, home care agencies, hospital units) and provider location (eg. by town). The resulting "Directory of Resources for Connecticut Residents with Alzheimer's Disease and Related Disorders" provides formal and informal caregivers with detailed information on the availability of thirty-three specialized services from 341 residential and community-based providers located in 98 towns throughout the state. Accompanying text explains the rationale for the inclusion of services and providers in the directory and guides the reader in its use. Appendices provide the information required to contact all providers included in the directory, the state's InfoLine service, public health nursing associations,
CAM (coordinating, assessment and monitoring) agencies, and Alzheimer’s Disease Support Groups. As part of the overall project, one-hundred and fifty copies of the directory were provided to the State Department on Aging in June, 1988.

III. INFORMAL CAREGIVER SURVEY

Procedures

In the Winter of 1988 a second survey, involving telephone interviews with 100 informal caregivers managing dementia patients in the community, was conducted to obtain data which would complement and expand upon the information obtained from formal care providers. This survey focused on the characteristics of informal caregivers and those for whom they cared, activities associated with informal care, the use of formal services, obstacles to caregiving, and the possible consequences of caregiving for the caregiver. The one-half hour semi-structured interviews were conducted by experienced GSU interviewers. To obtain better insight into the special problems associated with the informal care of dementia patients, an additional 100 interviews were conducted with caregivers assisting those disabled by conditions other than dementia. To ensure that those interviewed would be similar to those identified in the provider survey, additional criteria for inclusion in the survey were that either the caregiver or the care recipients be aged 60 or older and that they live in Connecticut.

Family support groups and adult day care centers cooperated in identifying and securing the participation of both types of informal caregivers. As a result, much less is known about the representativeness of those participating in the informal care survey. About three-fourths of those caring for dementia patients were supplied by support groups, with the remaining individuals coming from adult day care centers. A somewhat larger proportion of the 100 comparison cases came to the study by way of adult day care centers. Given the relatively low level of service contact suggested by the formal care provider survey, both groups must be considered somewhat unusual in that all individuals were receiving some level of organized assistance with their caregiving. While there is no apparent reason to believe that the participants were atypical of those informal caregivers in contact with services, the results of the informal caregivers survey must clearly be considered subject to selection bias and the other limitations associated with “convenience samples.”

Findings

Key findings from the informal caregiver survey include:

Virtually all informal caregivers were caring for their spouse (48%) or parent (43%), and were living with the recipient of care (96%). About 60% lived alone with the care recipient, about 29% identified themselves as the only source of assistance and less than one-quarter (24%) relied on any assistance from professional caregivers.
As a group, care recipients with dementia were younger than other care recipients, more often married, less likely to live alone, and in comparatively better health. Only 11% compared to 30% of other care recipients, were characterized as being in "less than good health" by their caregivers. Those caring for dementia patients were correspondingly younger than other caregivers and more likely to be a spouse than a grown child.

Obtaining an appropriate diagnosis of dementia and referral to useful services was often cited as problematic. Thirty-three percent of those caring for dementia patients reported difficulty in obtaining a satisfactory diagnosis and 13% percent of the care recipients were reportedly still without a firm diagnosis. More than three-quarters (78%) of informal caregivers reported that there was no referral to support services at the time of diagnosis.

Despite their better physical health, care recipients with dementia exhibited high levels of functional dependence. Substantial numbers required help with such basic activities of daily living as getting in and out of bed (23%), eating (32%), using the toilet (41%), dressing (71%), and bathing (78%). Eighty-five percent or more were dependent in more complex activities, such as using the telephone (85%), taking medications (94%), or preparing meals (99%). Care recipients with dementia were, in fact, more likely than other care recipients to be dependent in every area covered by the survey except walking and transferring.

Such dependence among care recipients was tied to extensive cognitive deficits. Virtually all (99%) experienced difficulties with short-term memory, three-fourths (74%) with long-term memory, and 71% reportedly had difficulty recognizing close family members at least some of the time. Behavioral problems were similarly prevalent, with 70% reportedly experiencing bouts of restlessness, 62% periods of passivity, 47% wandering, and 44% engaging in abusive behavior. Nearly two-thirds (62%) had experienced one or more of these symptoms for at least three years and 45% for five years or more.

Caregiving represented a central, important, and time consuming role for those managing dementia victims at home. Over one-third (38%) had been providing such care for three to four years and 29% for five years or more. Virtually all (97%) provided such care daily. Moreover, 9% reported caring for at least one additional person disabled due to illness.

Those caring for dementia patients were less likely to report using home care services than other caregivers (17% vs. 25%), and somewhat more likely to draw upon the assistance of other family, friends, and neighbors (62% vs. 56%).

Of 18 potentially useful services covered in the interview, caregivers managing dementia patients cited medical evaluation, support groups, adult day care, respite care, companion services, and friendly visitors as the most useful and, with the exception of medical evaluation, the most difficult to obtain.

In all, 84% of those caring for dementia patients, compared to 64% of other caregivers, identified useful services which they were not using. "Lack of availability" was the reason most often given for not using a needed service (26% of reasons given), followed by "never having heard of the service before" (18% of reasons given), and "rejection of the service by the care recipient" (15% of the reasons given). While "affordability" was a less important reason for failing to use a needed service, it was more likely to be mentioned by those caring for dementia patients than by other caregivers (10% vs. 6%).

Those interviewed were readily able to distinguish between serious problems associated with caregiving and less important problems. Difficulties cited by at least one-half of the respondents included the limitations which caregiving responsibilities impose on social
activities and friendships (84%), dealing with their own (78%) or the care recipient’s (77%) emotional state, getting help from relatives and friends (52%), finding qualified paid help (42%), and paying for useful services or assistance (51%).

Compared to other caregivers, those caring for dementia patients were about twice as likely to report feelings of frustration (45% vs. 25%), emotional exhaustion (32% vs. 18%), sleeplessness (26% vs. 12%), anxiety (25% vs. 15%), helplessness (25% vs. 7%), and depression (21% vs. 11%).

IV. CONFERENCE ON ALZHEIMER’S DISEASE

Activities

Beginning in the Fall of 1988, GSU staff worked closely with Task Force members and Department on Aging staff in planning an innovative one-day conference designed to unite and mobilize family and professional caregivers serving dementia victims throughout the state. With this goal in mind, the Education Subcommittee of the Task Force developed a conference format combining: 1) a “Welcome” by Mary Ellen Klinck, Commissioner on Aging and Chairman of the Task Force, 2) presentation of the provider and informal caregiver survey results by Dr. Lusky of the GSU, 3) a keynote address by Nancy Mace, M.A., co-author of The Thirty-Six Hour Day, 4) small group information and sharing sessions, 5) a series of afternoon workshops conducted by Task Force members and invited experts, 6) the presentation of sharing group results by John Cooper, M.P.A., chairman of the Education Subcommittee, and 7) a closing reception for all attendees.

Preparation for the conference included site selection, the formulation of workshop curricula, and the creation, printing, and distribution of 2000 conference brochures to survey participants, support groups, senior centers, libraries, universities, relevant professional associations, the media, and other interested groups. Additional preparation included confirmation of registration, provision for audiovisual equipment, selection of materials for distribution at the conference, and related details. Task Force members and GSU staff were assisted in these tasks by the University of Connecticut Health Center’s Office of Continuing Education.

Entitled “Partners and Pioneers,” the conference was held on April 6, 1988, under the sponsorship of the Governor’s Task Force on Alzheimer’s Disease, the Connecticut chapter of the Alzheimer’s Disease and Related Disorders Association, the Connecticut State Department on Aging, and the University of Connecticut’s Travelers Center on Aging. A total of 340 individuals traveled to the Sheraton Hotel in Waterbury, Connecticut to participate in the conference. Another 100 individuals seeking registration could not be accommodated because of space limitations on site. Registration materials show that nearly one-fourth (23%) of the conference participants were informal caregivers. Twenty-two of these individuals attended the conference under the financial sponsorship of a Connecticut long-term care facility. Formal caregivers in attendance included a wide range of health and social service professionals, attorneys, administrators, educators, and clergy.
Afternoon workshops included: 1) "A Psychosocial/Medical Update on Alzheimer's Disease," by Alan Siegal, M.D., 2) "Loving Care: Making Contact with the Alzheimer's Patient," by Mildred Ross, O.T.R. and Karen MacDonald, 3) "Creative and Positive Care in the Nursing Home," a panel discussion of residential care moderated by Tom Fulton, 4) "Stages of Dementia and Strategies for Care," by Harry Morgan, M.D., and Harold Maphet, Ph.D., and 5) "The Family: Partners and Pioneers in Alzheimer's Care," by Nancy Gustafson, R.N., and Jack Gesino, Ph.D.

Evaluation forms submitted by conference participants were positive about the underlying theme of the conference and its content. Ninety-five percent of those returning forms indicated that they had obtained new information that would enhance their caregiving activities. Speakers, workshops, and overall conference were uniformly well received. Spontaneous comments on the evaluation forms typically emphasized the value of an opportunity for formal/informal caregiver interaction and expressed hope that similar conferences might be held in the future.

Findings

Apart from its educational and integrative functions, the "Partners and Pioneers" conference provided an opportunity to gather additional qualitative information from informal caregivers and providers about the needs and problems of both groups. This was particularly true of the "caring and sharing groups" which met during the morning session. Review of notes taken by assigned "recorders" in each group shows that discussion centered on four topics: "barriers to care," "education and training needs," "needed services," and "workable care strategies."

In general, discussions of "barriers to care," "education and training needs," and "needed services" tended to confirm and expand upon the findings of the provider and informal care surveys. The most frequently discussed "barriers to care" proved to be financial/reimbursement problems, "spend-down" requirements for receiving public assistance, limits and gaps in service, minimal knowledge of available resources, lack of respite care and trained aides, limited knowledge of the disease process on the part of key professionals such as physicians and attorneys, fire code restrictions on locked treatment units, refusal of many long-term care facilities to accept dementia patients, and a similar reluctance of family members to seek or accept assistance. In the area of "education and training," discussion typically focused on the need to improve training of physicians, nurses, and other staff in such areas as the diagnosis of dementia, use of coping strategies, communication with patients and families, patient safety, medication, and the legal and ethical dimensions of dementia care. Discussion of "needed services" centered on the need for more home-based respite care, more attractive pay scales for nurses, aides and other home care workers, 24-hour crisis intervention and emergency coverage, and locked nursing home units with specialized programs for Alzheimer's Disease patients. Participants frequently noted that more publications on dementia care were needed for reference and self-study.

Among the most "workable care strategies" described by participants were use of support groups, case management, respite care from friends and neighbors, and family conferences with professionals. The importance of remaining tolerant and flexible, of retaining one's sense of humor, and of "using your imagination" in problem solving was also frequently mentioned.
V. CHALLENGES IN DEMENTIA CARE

Based on the findings of the two surveys described here, it is evident that health and social service providers in Connecticut are facing, and will continue to face, serious challenges in meeting the needs of dementia victims and their families. These challenges are not likely to be overcome without major initiatives on the part of providers and support from federal, state, and local authorities. Failure to at least partially meet these challenges will surely increase the already heavy burden of care confronting the families and friends of dementia victims in Connecticut, and indirectly extend the burden to even larger numbers of state residents, service providers, and public programs.

Reaching Dementia Patients and Their Families

In its Interim Report of January, 1987, the Governor’s Task Force on Alzheimer’s Disease, estimated the number of Connecticut elderly with measurable signs of cognitive impairment resulting from dementia to be approximately 69,000, including approximately 28,000 older persons with moderate to severe impairment. Findings of the surveys described here and discussions at the conference in April confirm the continuous and demanding attention required by individuals at advanced stages of this progressive disease. Among the very old dementia patients found in long-term care facilities, progressive cognitive deterioration is often accompanied by significant physical deterioration. Despite comparatively better physical health, younger dementia victims in the community often exhibit levels of functional impairment rivaling or exceeding those of much older individuals disabled by chronic physical disease. From the dementia census figures supplied by participants in the provider survey, and from the service utilization data offered by participants in the informal care survey, it is clear that the majority of Connecticut’s dementia patients and their families face the ravages of the disease without the benefit of supportive services. In all, only 9,575 dementia patients were reported by the residential, community, and hospital care providers surveyed. While careful application of observed rates of dementia care to nonresponding providers yielded an estimate of 2,211 additional cases in contact with providers, it appears that no more than 41% of the 28,000 elderly with moderate to severe cognitive impairment, cited by the Task Force, are receiving formal care as recognized dementia patients. Given the extent of unmet service needs found among participants in the informal care survey, it is likely that the remaining 69% who are not receiving services experience comparable or greater service needs. Failure to respond to these needs can only compromise the well-being of these dementia victims and their informal caregivers, and increase future demand for more costly care.

Providing Institutional Care

At present, the receipt of formal care by dementia victims in Connecticut depends almost exclusively on access to residential care facilities. Estimates derived from the provider survey suggest that approximately 79% of those dementia victims receiving formal services in Connecticut receive such services in long-term care facilities, with skilled nursing facilities accounting for about 95% of dementia patients in residential care settings. With community-based service for dementia patients in short supply, residential care is likely to remain a critical element in meeting the needs of the state’s dementia patients in the foreseeable

future. Will residential care facilities be able to accommodate the rapidly expanding numbers of dementia victims associated with continued aging of the state's population? In the same Interim Report noted above, the Governor's Task Force on Alzheimer's Disease projected the "...overall number of elderly with measurable signs of cognitive impairment increasing to nearly 100,000 by the end of the century and the number of moderate to severe cases to 39,000."* These projected 40% increases in the number of dementia victims far exceed expected growth in the state's older population as a whole. Under conditions of normal demand for nursing home care and a moderate growth in the number of long-term beds in the state, residential care providers would still be hard pressed to accommodate such increases in the number of dementia victims. Given recent cost containment initiatives which have stabilized the number of long-term care beds in the state and increased the demand for residential care among hospital discharges, it is likely that even severely impaired dementia victims will find access to residential care increasingly difficult. With approximately one-third of their beds occupied by patients with dementia, skilled nursing facilities are already evidencing concern about admitting labor and space intensive dementia patients at existing reimbursement rates. When asked about their "capacity to care for dementia patients," 86% of the skilled nursing facilities participating in the provider survey indicated that they were already at, or above, their capacity to care for such patients. Under these circumstances, it is essential that steps be taken to ensure that residential care remains available to the growing numbers of dementia victims in the state who will continue to require it.


Developing Community Services

While it is clear that steps must be taken to provide residential care to a growing number of dementia victims in the state, it is also evident that community-based care can, and should, play a greater role in meeting the service needs of dementia victims and their informal caregivers. Extending the ability of informal caregivers to manage dementia victims in the community is essential if the number of institutionalized dementia patients is to be minimized. Findings from the provider and informal caregiver surveys show that relevant supportive services for community-residing dementia victims and their families are in critically short supply. In the informal caregiver survey, 71% of those managing dementia victims at home reported going without paid assistance of any kind. Of the remaining 29%, nearly half relied exclusively on paid assistance from an individual rather than agency personnel. While about 75% of home care agencies participating in the provider survey reported caring for dementia patients, such patients accounted for no more than 6% of their combined caseloads. Census data and service utilization information obtained from the two surveys suggest that, of the 18,680 moderately to severely impaired dementia victims believed to be residing in the community, only one in nine (about 2100 individuals) receive formal services as recognized dementia patients. The types of services most desired by those caring for dementia victims are temporary relief from caregiving, opportunities for social interaction, and a chance to share caregiving experiences. For the most part, these either do not exist in the community or are unknown to caregivers. The affordability of such services (where they do exist), caregiver reluctance to seek formal services, and refusal of services by care recipients also appear to play less frequent but nonetheless important roles in minimizing the receipt of needed community services.
Survey and conference data also identified a number of areas in which the formal care currently being provided to dementia patients could, and should, be improved. With nearly one-third of informal caregivers reporting difficulty in obtaining a timely diagnosis of dementia, improving diagnostic techniques and procedures should be high on the list of areas to be addressed. Misdiagnosis by primary care physicians, repetitious diagnostic tests, referrals to inappropriate specialists, and a reluctance on the part of physicians to commit to an "unpleasant" and "unchangeable" diagnosis were frequently described by the informal caregivers surveyed. While diagnostic problems may be expected with a condition as complex, comparatively rare, and destructive as dementia, the implementation of new diagnostic techniques, improved training of physicians in the area of dementia, and more effective organization of health care resources could minimize such problems. Efficient and appropriate referral at the time of diagnosis deserves similar attention. While appropriate referral at the time of diagnosis could provide dementia victims and their families with an efficient and uniform route to supportive services, only 30% of informal caregivers interviewed reported receiving any referral for services at the time of diagnosis. At the same time, residential, community, and hospital care providers report a need for professional and paraprofessional staff with special skills in the management of dementia patients. Survey responses from all three types of providers suggest that even if funding for dementia care were to be substantially increased, staff shortages and the absence of specialized skills would seriously limit the expansion of needed services. Since it is unlikely that individuals with the required skills would be found readily in the marketplace, upgrading staff skills in dementia care is likely to depend (in the long run) on more thorough professional and paraprofessional training programs and (in the short run) on innovative in-service training programs.

Financing Long-Term Dementia Care

An obvious but sometimes overlooked fact, constantly reaffirmed by the research described in this report, is that dementia victims are long-term care patients. In this regard they face all of the obstacles to obtaining needed care and supportive services which confront physically disabled elderly. Burdened by a chronic, progressively debilitating disease, they must turn to a system of health and social services oriented to acute care and recovery. Successfully coping with the disease requires that they, or their informal caregivers, marshal diverse and considerable resources at a time in life when personal resources (social and financial) are typically limited or on the decline. Complex and variable eligibility requirements for insurance benefits and public programs make negotiating access to such help difficult even when eligibility requirements can be met, particularly in the context of social and emotional disruption which surrounds the disease. In addition, dementia victims and their caregivers face special problems in obtaining useful long-term care. Those services most needed to remain in the community, being primarily social rather than medical in nature (e.g., respite care, adult day care, companion services) are covered only by public assistance programs which require impoverishment before help can be obtained. Moreover, while "availability" rather than "affordability" emerged as the major barrier to obtaining such services in the caregiver survey, their exclusion from traditional forms of health insurance may well account for their being in such short supply. Neither residential or community care providers are likely to organize special dementia care programs when the costs of such programs exceed revenues or
if reliable sources of reimbursement for such services cannot be identified. While current efforts directed to containing public and private health and social service expenditures make dramatic increases in the funding of dementia care unlikely, some increase in the dollars directed to dementia victims will undoubtedly accompany their growing numbers. It is essential that such increases, even if they are modest, be tied to innovative service delivery concepts and "creative financing" if significant headway is to be made in addressing the needs of the state's dementia victims and their families.

VI. RECOMMENDATIONS

Based on the survey and conference results described in this document and the project's final research report, Task Force activities promoting the welfare of the state's dementia victims and their families should give priority to the following issues:

1. Maintaining Access to Residential Care

To this end the Task Force should explore and promote options for ensuring access to skilled nursing facilities for those dementia patients whose medical conditions require such care. The Task Force could, for example, work with residential care providers, regulatory agencies, and fiscal intermediaries to tie the construction of an appropriate number of new skilled nursing beds to dementia care, preferably in the context of specialized dementia care units. Given the labor and space intensive nature of dementia care, the feasibility of supplementary reimbursement for the care of dementia patients in such units should be considered. Movement in this direction would need to be accompanied by a search for less intensive and less costly options for residential care of dementia patients whose medical conditions do not require skilled nursing care but who, in the absence of informal care, are unable to remain in the community. Intermediate care facilities and homes for the aged might serve as a useful starting points in such a search. While few of the ICFs and homes for the aged surveyed currently care for dementia patients, about one-third of those who do so report that they could care for more cognitively impaired patients. A group home model, similar to the one employed by the Department of Mental Health might also be considered as a minimal care option for patients in the earliest stages of the disease. Under such a multilevel care approach, procedures for ensuring continuing placement at appropriate level of supervision would have to be implemented.

2. Increasing the Availability of Community Care

Task Force initiatives in the area of community care should emphasize respite care admissions to residential care facilities, adult day care, companion services and other services which provide temporary relief from caregiving. These services should be linked to counseling and psychological services capable of addressing the emotional difficulties found among participants in the project's caregiver survey. To minimize cost and transportation problems, and to ensure geographic accessibility, special emphasis should be placed on the development of decentralized in-home respite care. With assistance from the State such services might, for example, be organized on a regional or town basis through Area
Agencies on Aging, senior centers, and local support groups. Training local volunteers and/or retirees as caregivers would help keep such services economically feasible for both self-pay clients and third-party payers. In communities unable to support this level of organization, periodic or regional programs designed to train individuals in the provision of respite care as "paid assistants" might be developed. Additional efforts should be made to improve access to more traditional home care services such as home health care, homemaker services, meal preparation, and chore services. Where the use of multiple services must be negotiated to maintain the dementia patient in the community case management should play a central role in delivering services.

3. Improving Patient Care Skills Relevant to Dementia

Given the prevalence of diagnostic difficulties and staffing problems uncovered in the provider and caregiver surveys, the Task Force should sponsor programs designed to bring about improvements in each of these areas. Its current initiative involving the creation of specialized diagnostic centers should be pursued vigorously, complimented by new initiatives in the area of professional and paraprofessional training. These educational initiatives should encompass the spectrum of health and social service personnel involved in the diagnosis and management of dementia, and target training activities at all levels of practice. One strategy would, for example, be to work with health professional schools in the state to update and expand the coverage of dementia in their curricula, and to develop appropriate educational materials for continuing and in-service training. For health and social service professionals, continuing education efforts should emphasize the early signs and symptoms of dementia, appropriate referral for diagnosis, and the range of services available to assist in managing the dementia patient. In the case of paraprofessionals, such training should emphasis the key direct care skills identified in the provider survey: managing the agitated patient and effective communication with dementia patients and family members. Training for both groups would benefit from basic information on the nature and typical course of the disease. Task Force cooperation with the Department of Health Services (which licenses health care professional, facilities, and programs) and with state and regional professional associations (which often sponsor continuing education) might be useful in implementing such educational programs.

4. Promoting Greater Awareness of Existing Services

The project’s informal caregiver survey suggests that limited knowledge of service options on the part of caregivers remains a central barrier to the receipt of useful services. The Task Force should continue to support the special dementia referral service conducted by the state’s InfoLine program. While this effort and the resource directory prepared as part of this project should help inform caregivers about available services, the Task Force should continue to explore and promote additional outreach mechanisms designed to disseminate service information directly to caregivers.
5. Expanding Funding Mechanisms for Long-Term Dementia Care

Reimbursement restrictions on the social services required to maintain dementia victims in the community, on related home care and home health services, and on the extra staffing and environmental costs associated with residential care of dementia victims represent major obstacles to effectively and efficiently meeting the needs of such individuals and their families. The Task Force should continue to examine funding options for these services and to advocate for needed changes in reimbursement policies. In this regard, a thorough review of existing funding mechanisms, and of those under development, may be in order. Such a review, if conducted, should include an examination the financial and organizational arrangements of programs in the state which have been successful in delivering needed services to dementia patients despite reimbursement limitations, and consideration of service delivery incentives which might be incorporated into the existing reimbursement structure. In addition, Task Force members may wish consult with, and advise, Office of Policy and Management staff engaged in formulating long-term care insurance options involving public and private participation. Some consideration of the costs associated with inadequate funding of needed services might also strengthen the Task Force in its advocacy role.
# Financial Expenditure Report

**Dr. R. Lusky**  
Task Force on Alzheimer's Disease

Report Period: 8/1/87-6/30/88  
Contract Period: 8/1/87-6/30/88

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Certification: I certify that the above data is correct, based on an official accounting system and records, consistently applied and maintained, and that expenditures shown have been made for the purpose of, and in accordance with, applicable contract terms and conditions.

Project Director’s Signature:  
Dr. R. Lusky  
Project Director

Financial Officer’s Signature:  
Kenneth R. Landorf, Manager  
Date
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 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.

Autopsy - the post mortem examination of a body.

Biopsy - a diagnostic examination of a piece of tissue removed from a living subject.

Cognitive impairment - a deterioration of the mental processes of thought, memory, comprehension, and reasoning.

Computerized tomography (CT or CAT scan) - a new diagnostic technique using a computer and x-rays to obtain a highly detailed image of the section of the body being studied.

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.

Electroencephalography (EEG) - the recording of the electric activities of the brain by means of wires placed painlessly on the scalp; useful in detecting tumors, epilepsy, and brain damage.

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.

Nerve cell - a neuron, the basic unit of the nervous system consisting of a cell body and its threadlike extensions for receiving and transmitting impulses.

Neurofibrillary tangle - tangled threadlike nerve fibers lying in the cell bodies of the neurons.

Neuritic (senile) plaques - deposits of starch-like protein on the nerve fibers that interfere with transmission of information between the nerve cells. A localized abnormal area found in the brain of a person with Alzheimer's disease.

Respite care - arrangements for a specific period of relief from the regular responsibilities of care of another.
Alzheimer's disease is a progressive disorder of the brain that affects more than two and one-half million Americans. This disease is the fourth leading cause of death among older Americans.

It is vital that the services of government, concerned citizens and organizations, and health care officials be coordinated to combat the overwhelming physical, emotional and financial hardships associated with Alzheimer's disease.

Family and community support groups are essential, because providing care often changes from a mild inconvenience to severe hardship as the disease progresses and the victim's condition deteriorates. These groups also focus public attention on the problems confronted by Alzheimer's patients, families and friends, and foster a greater understanding and awareness of the "silent epidemic."

The Governor's Task Force on Alzheimer's Disease, the state Department on Aging, the two Connecticut chapters of the Alzheimer's Association, and other public and private agencies and organizations are to be commended for their excellent work and continuing commitment to ease the burdens and ramifications of Alzheimer's disease for our people.

Therefore, in recognition and appreciation of the work being done by countless dedicated men and women, and to increase public awareness and support of their efforts, I am pleased to designate November, 1988 as Alzheimer's Disease Awareness Month in Connecticut.

Governor.
October 6, 1986

Mrs. Mary Ellen Klinck
Commissioner
Department on Aging
175 Main Street
Hartford, Connecticut 06106

Dear Mrs. Klinck:

It is my pleasure and privilege to appoint you as Chairman of the Task Force to Study the Needs of Persons Suffering from Alzheimer's Disease, effective October 6, 1986, to serve at the pleasure of the Governor.

Your commission will be mailed to you under separate cover.

With best regards,

Sincerely,

WILLIAM A. O'NEILL
Governor

cc: The Honorable Julia H. Tashjian
Secretary of the State
cc: The Honorable J. Edward Caldwell
Comptroller
cc: Messrs. Henry J. Becker and Leo V. Donohue
Auditors of Public Accounts
cc: Commissioner Douglas S. Lloyd, M.D.
Department of Health Services
cc: Audrey M. Wasik, Coordinator
Commission on Long Term Care
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