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PHOTOCOPY
PRESERVATION

FROM:
ATKINSON
2 Gunnarson Rd
Worcester 01606

TO: PRESIDENT CLINTON
Re- National Service Plan
The White House
1600 Pennsylvania Ave.
Washington D.C.

May 17, 1993

Dear President Clinton,

This is a copy of a proposal I have just submitted to the US Department of Health and Human Services for the Secretary's Award for Innovations in Health. My recommendation involves using your idea for National Service volunteers and because of this I thought that you might be interested in it. I have been a registered nurse for eight years with a great interest in geriatric issues in this country. Currently I am a first year medical student at the University of Massachusetts Medical School. Thank you for your time in examining this proposal. I have great faith in your ideals and hopes for this country and hope that Americans can work with you in seeing your objectives met.

Sincerely,

Katherine J. Atkinson

2 Gunnarson Road
Worcester, MA 01606
508-853-3878

PROPOSAL FOR COMMUNITY ALZHEIMER'S TRAINERS

Katherine J. Atkinson
University of Massachusetts
Medical School
April 1993

ABSTRACT

As the percentage of elderly within our population increases, we are forced to examine new ways to deal with their health care needs. Among the elderly, Alzheimer's patients have a unique set of problems associated with their progressively debilitating disease. With specially-trained workers providing respite care these patients are often able to remain at home with less physical and emotional stress on the family caregivers, which is cost-effective and beneficial both to the patients and their family members and can prevent the need for institutionalization.

College graduates who received educational loans through the National Service would be educated to meet two important goals: 1) to provide direct care in patient homes and 2) to train and supervise other Alzheimer's home health aides. After the initial training period these 'Alzheimer's Trainers', because of client reimbursements, would require incremental additional cost to the National Service budget. Initially the program targets a segment of the affected population in Massachusetts where this community-based program could effect savings of $600,000 yearly in health care dollars by reducing inpatient care. The model can be applied to other geographic areas, using this training and certification process within the framework of other Alzheimer's Association chapters.

President Clinton's landmark proposal of a National Service Corps suggests the enlistment of young people to provide public service to areas of great social need in exchange for college loans. "I challenge a new generation of young Americans to a season of service: to act on your idealism by helping troubled children, keeping company with those in need, reconnecting our torn communities." One segment of the population needing care and frequently overlooked in our society, particularly by the young, is the elderly. As medical science has advanced, people have come to live longer lives, and the percentage of Americans over the age of sixty-five is rising rapidly. The National Service volunteers would be well utilized as health care workers to the elderly within their community. This would fill a need as well as raising the consciousness of the college-aged individuals.

STATEMENT OF THE PROBLEM

Although there are many populations of elderly needing care, undoubtedly one of the most stressful for caregivers is that of people with Alzheimer's disease. Over ten per cent of people over age sixty-five in the United States are diagnosed with Alzheimer's disease, which remains idiopathic and incurable. In Massachusetts an estimated 130,000 individuals suffer

from this disease. The inevitable gradual cognitive deterioration of these patients demands continual supervision and functional support. Patients often remain physically strong while becoming increasingly unaware. Caregivers eventually must perform all the daily tasks of living for them, including dressing, feeding, and bathing. They also have to cope with behavioral problems like wandering and combativeness. Over half of those afflicted with the disease remain in their homes with a family member, usually a child or spouse, providing around the clock care. Clearly the caregivers face emotional and physical strain ultimately leading to deterioration of their own health and coping skills. More and more of these patients are being placed in nursing homes as family capabilities become taxed. Intervention before this point of family collapse is key to prevent further illness and the need for hospitalization both for patient and provider.

An organization that has emerged to help patients and families cope with this devastating disease is the Alzheimer's Association, a privately-funded non-profit organization with chapters nationwide. The Eastern Massachusetts chapter, located in Boston, services the greater part of the state from the capitol to the farthest border of Worcester county and extending to the Cape Cod canal. This area contains approximately 90,000 individuals suffering from Alzheimer's disease. Paul Raia, Ph. D., Director of Patient Care and Family Support at the Association, states that there are twenty-seven homecare agencies in Massachusetts but none typically handle

Alzheimer's care. "Occasionally Medicaid will cover home care and even less often Medicare will on a very short-term basis, but most of the costs of care are borne by the families." The average annual cost to families is $18,000.

Dr. Raia notes that most families wish to keep the patient at home, to which end most need respite help: a skilled provider able to come into the home and perform patient care, giving the caregiver a much-needed break. Currently the Alzheimer's Association coordinates such help by contracting for respite care to patients' homes. Families use twenty-six hours a week, on average, at a cost of $13 an hour. The home health aides receive approximately $7 an hour for their services with the remainder used to cover administrative costs. The Association is in the process of developing its own curriculum on the training of respite care workers. Generally these employees are high-school graduates eager to learn but lacking skills. Such aides require a great deal of emotional support and supervision. Dr. Raia notes that there are only three doctorally-qualified Alzheimer's Behavioral Specialists like him in the state, and there is a great need for more help in the oversight and training of the 'hands-on' staff.

LITERATURE SUMMARY

The literature on Alzheimer's disease is rapidly proliferating; a review of it suggests the size of the problem. Perhaps the most staggering statistics pertain to the economic burden of this disease on our society. Approximately $90 billion is

spent annually on the care of Alzheimer's patients in the United States; Massachusetts' costs have been estimated at $41 billion [1,2]. Nursing home care alone accounts for expenditures of $5.1 billion annually[4]. Forty per cent of diagnosed Alzheimer's patients are in nursing homes at any one time[22]. The total cost of the disease per patient ranges from $39,000 to $493,277, depending upon the patient's age and stage of the disease at diagnosis[8,22]. Much of these costs fall on government health care insurance, such as Medicare and Medicaid, and strains these programs. Medicaid covers inpatient nursing home care for debilitated patients, and thus has been the hardest hit. Hay and Ernst calculate the cost of Alzheimer's disease to a family providing homecare at approximately $18,000 annually[8]. This contrasts significantly with inpatient annual expenses ranging from $35,000 to $52,000 (these costs include medications and physician bills). Long-term care factors are the most significant determinant in the costs of Alzheimer's care[22]. Clearly a program that helps the family to keep the patient at home would be in the economic best interest of society.

A hidden health care cost of Alzheimer's disease is the negative effect on the health of the family caregiver. The stresses associated with caring for someone with Alzheimer's disease have now been clearly documented with significant increases seen in the family providers' number of days of illness and rates of depression[9,7]. These effects were noted with higher incidences in family members who had lower levels of

social support and who institutionalized the patient[9].

Different forms of respite care have been used within communities, all of which have been found to profoundly benefit the caregiver. These include day-care programs, in-home respite workers, and residential and hospital respite programs[6,10,11,12,14]. Overall the programs that do not require relocation of the patient have the greatest short-term benefits, since the cognitive stresses related to change in setting are avoided[19]. A program that provides care in the patient's home avoids the added burden of relocation, but day-care programs enable better socialization which may partially delay cognitive deterioration[11,12]. Probably a combination of two such programs would be most beneficial, with an emphasis on community day-care at earlier stages of the disease and more home involvement as the disease progresses.

Many different training models exist for home health workers, some specific to Alzheimer's disease, while others, such as those at most visiting nursing organizations, teach non-specific skills for the care of the elderly. The behavioral problems associated with dementias need much more attention than what is customarily provided in geriatric training programs. There are still few programs targeted specifically to patients with senile dementias despite the large patient population[10,13,20]. Those in use have been quite effective, with the greatest deficit being lack of qualified supervision for the workers. Well-trained support is needed to oversee those directly working with patients and their families because

of the unusual forms of behavioral problems associated with the disease [1,20].

PROJECT OBJECTIVES

Ten college graduates will be trained as Alzheimer's Disease Trainers. They will train and supervise home respite workers who will spell family caregivers of Alzheimer's patients; the overall rate of institutionalization is projected to decrease as a result of this indirect intervention. The degree of morbidity among caregivers will decline as a direct result of this intervention.

METHODOLOGY

A college graduate enrolled in the National Service Corps could best be used as an Alzheimer's Disease Trainer. Dr Paul Raia suggests that he could train ten such college-educated young people to become Alzheimer's Trainers in a period of five weeks: two weeks of classroom training by Dr Raia, followed by a two week placement at an adult day-care center for Alzheimer's patients, with a final followup week to review and pull together the experience for participants and give hands on home visit training. These ten Trainers could then each train ten individual respite workers. In addition the Trainers would oversee and support these employees in their placement in patients' homes. Dr Raia would continue as a resource for the Trainers to supervise and mentor their work. Thus the training of 10 National Service Corps volunteers would ultimately pro-

vide 110 respite workers in each two year period for Massachusetts families in need.

National Service Corps volunteers, who are completing college programs, would apply for different positions available to them. Applicants for Alzheimer's Trainer positions would be selected for responsibility and communication skills as well as previous experience in geriatrics. Degrees in the Liberal Arts or Psychology would be desirable, although the specific criteria would be selected by the Alzheimer's Association's executive staff. Presumably an essay and interview would be used in the selection process. Part of this process could include viewing a video of severe dementia clients for the applicant to experience before making a decision. Upon selection, the training process would begin in the late summer or early fall, and the individuals would begin their two-year service commitment.

The training would include education on the nature of the disease, its causes, and medical management. Specific subjects discussed would be common medications and their effects and side-effects, nutrition, and the natural progression of the disease. Behavioral management techniques teach effective ways to deal with wandering, belligerence and combativeness. There would be training on therapeutic communication and helping the caregiver cope through stress reduction and relaxation techniques. Basic principles of 'hands-on' care and the physical needs of patients would cover such topics as skin care and incontinence. Some medical emergency training such as care for

choking would be taught. In addition, a segment on death and dying would help the Trainer come to terms with the ultimate outcome of the disease process. Part of the day-care experience would include instruction on appropriate patient activities and how to encourage participation.

Once fully trained the Trainers would have their own assignments to patients' homes for half of their working hours. The rest of their time they would train other respite home health aides and supervise and support them in their tasks. In this way the Trainers would fill a needed function already budgeted for by the Alzheimer's Association, while also meeting an organizational need. After successful completion of the mandatory two years of service as Trainers, the Alzheimer's Association could then certify them as Alzheimer's Disease Specialists, professionals with a marketable skill in a specialty much needed in this country. Their wages would certainly increase, and they would be able to oversee groups of Trainers and Aides in much the way Dr Raia did for them. Ultimately this could create a workforce of young people attuned to the needs of the elderly. This model could be used, revised and honed at other chapters of Alzheimer's Associations throughout the country.

SIGNIFICANCE OF THE PROJECT

Effective implementation of this proposal would decrease the incidence of institutionalization of Alzheimer's patients while improving the health status and quality of life of family care-

givers. While clearly homecare is not the answer for all such patients, particularly for those who do not have family members willing to expend the time and energy involved in care, it addresses a large segment of the population suffering from this disease. This project would increase awareness of the health care needs of the elderly especially within the younger college graduates typical of the program and would create a new field of employment. In this way the economy would be stimulated by creating new jobs in an area which is currently underserved.

WAYS IN WHICH PROJECT IS INNOVATIVE

The National Service Corps is an emerging plan. The program can utilize young energetic people in public service to their communities. This project is one recommendation of a cost-effective and efficient implementation to benefit an underserved and needy population.

SUMMARY OF EVALUATION METHODS

A long-term evaluation method would compare family coping mechanisms before and after the use of home respite aid. Factors to be evaluated include emotional and health status of the caregivers as well as a comparison of the rate of institutionalization of Alzheimer's patients who participate in this program versus a control group that does not. It would also be interesting to follow the career paths of the Trainers in the ensuing years to observe how many stay in human service employment.

BUDGET ESTIMATE AND JUSTIFICATION

The training process would cost approximately $4000 for the ten Trainers, including the cost of Dr Raia's time and books and supplies. This cost would be covered by the National Service Corps. The Trainers would each then receive $18,000 a year in salary. Half of this amount should be directly reimbursable by either the family or the third party insurer. There would also be a savings to the health care agency in supervisory costs met by these employees. In short it looks feasible for the Alzheimer's Trainers to be partially self-sustaining within the agency with modest additional cost for the National Service budget. The Trainers would earn only a small amount more than the home health aides receive, since their service is part of their repayment of college education loans.

The savings to society would be realized longterm with diminished costs of acute hospitalizations and nursing home placement. These savings could be considerable, since an average eight-day admission for Alzheimer's disease causes a claim for $6,500 to Medicare Part A(22]. With effective, well-supervised care in the home there should be a decline in acute hospitalizations. Projected for 100 Alzheimer's patients this yields an annual savings of $600,000 in acute care admissions. In addition, one might anticipate decreased morbidity of the family caregivers as their stress is relieved by the program. In this way, as families are helped to help themselves with problems of chronic illness, the benefits to society are substantial.

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