The Governor's Advisory Council on Alzheimer's Disease and Related Disorders

2001 Annual Report

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Executive Summary

The Governor's Advisory Council on Alzheimer's Disease and Related Disorders was convened in September 1998 to provide the Governor, state secretariats and agencies, and the Legislature with recommendations regarding the provision of care to Massachusetts' residents with Alzheimer's disease or related disorders (ADRD). A part of the mandate for the Council is to examine the capacity of the long-term care system to adequately serve the approximately 130,000 people with ADRD in the state.

In its general meetings, the Council invited representatives from a number of state agencies to present an overview of the services available to individuals with ADRD. The Department of Mental Retardation, the Department of Mental Health, the Department of Public Health, the Division of Medical Assistance, and the Massachusetts Commission for the Blind all attended meetings of the Council, and provided Council members with information about the services that are available, and, perhaps more importantly, where there are gaps in the system.

These gaps can exist due to eligibility criteria, duplicative services, or lack of information on the part of the public about the services available. Recognizing this fact, the Commonwealth has developed a number of current initiatives, and is looking at how to improve access to community-based services for all individuals with physical or cognitive disabilities. These efforts, which include the release of the Executive Order #421 Report, the creation of an Olmstead Task Force, and the creation of a Commission on Long-Term Care, will generate recommendations related to increasing the capacity of the long-term care system. These efforts, however, will not be specific to those Massachusetts residents with ADRD. The Council feels it is especially important for this population that elders and their caregivers know where to go to receive education, training, support and services. Families need to feel sure that competent and knowledgeable professionals will provide the care they receive. And they need to know that those professionals will make the best decisions about the elder's transition from one form of care to another.

In fiscal year 2001, the Governor's Advisory Council on Alzheimer's Disease focused on three specific issues, all of which are related to the capacity of the long-term care system to provide adequate and appropriate care to individuals with ADRD. These three issues were the training curricula of nursing programs in the Commonwealth, the inappropriate transfers of residents with dementia from nursing facilities to geriatric-psychiatric units in hospitals, and the development of the Springfield Multicultural Alzheimer's Services project. All three speak to the need for the health care and long-term care systems being better prepared to care for individuals with ADRD currently, and for those of the future.

Introduction

In the last few months the focus of the nation has been rightly turned to new internal and external concerns. There remain, however, millions of elders in the country that grapple daily with the effects of Alzheimer's disease and related disorders (ADRD). And with the aging of the Baby Boomer generation, the numbers of people searching for answers and help with caring for individuals with ADRD will be growing. In the next five to ten years, Massachusetts has the opportunity to examine the gaps and flaws in the system that delivers care to its more vulnerable and needy residents. This opportunity is manifesting itself in a number of ways. The Commonwealth of Massachusetts is looking at the care that all people with disabilities and their caregivers are receiving, in a variety of settings. State agencies are reviewing how to improve access to services, the choices individuals can make in receiving care, and how agencies currently work together to provide the care. Initiatives include the release of the Executive Order Report on long-term care, the Olmstead Advisory Task Force convened by the Governor, and the Commission on Long-Term Care, created by the Legislature in the budget for fiscal year 2002. The Council's work is a natural extension of these initiatives, albeit focused on a smaller population.

A report released by the Governor in August 2001, the *Executive Order #421: Report on Long-Term Care,* states that in an ideal long-term care system, "an elder would be able to receive the appropriate combination of services that best meets his or her needs in community-based settings if appropriate and desired by the elder. In addition, an increase in need would not necessarily mean an irreversible change of provider, but perhaps just the addition of another service." While the *Report* is referring to services, it is equally important that elders and their caregivers know where to go to receive education, training, support and services. They need to feel sure that competent and knowledgeable professionals will provide the care they receive. And they need to know that those professionals will make the best decisions about the elder's transition from one form of care to another.

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Alzheimer's Disease and Related Disorders

Alzheimer's disease (AD) is an irreversible, progressive disease of the brain. AD occurs gradually and results in memory loss, unusual behavior, personality changes, and a decline in thinking abilities. As the disease progresses, individuals' loss of memory results in dementia, which is a loss of the capacity to reason, communicate, and carry out activities of daily life. The disease is the result of the death of brain cells and the breakdown of connections between them. People with AD are not just losing information already learned, but are unable to learn and store new information.

According to the Alzheimer's Association, AD is the fourth leading cause of death among adults after heart attacks, cancer, and strokes. Symptoms of the disease usually begin between the ages of 40 and 90, with the majority of cases in people over the age of 65. The noticeable symptoms span a great period of time, usually four to eight years, but in some cases the illness may last 20 years or more. There is no known cause, although age and family history are identified as primary risk factors for the disease. According to the National Institute on Health in its 2000 *Progress Report on Alzheimer's Disease,* "some diseases, like tuberculosis, have clear-cut causes. Others, such as diabetes or arthritis, result from many interrelated factors, including genetic, environmental, and other factors. AD fits into this latter group of diseases....AD develops as a result of a complex cascade of events that take place over many years inside the brain. The disease may be triggered by any number of small changes in this cascade, probably as a result of the interaction of different genetic and non-genetic factors in different individuals."[*]

It is important to note that dementia is not a natural part of the aging process. Unfortunately, there is still considerable public misconception about this fact. As the federal Institute on Aging and the National Institutes on Health have said, "in normal aging, nerve cells in the brain are not lost in large numbers. In contrast, AD causes many nerve cells to stop functioning, lose connections with other nerve cells, and die."[**]

While Alzheimer's disease is the most common form of dementia, representing 56% of cases, it is not the only one. Many other conditions and disease also cause the confusion and behaviors that can be mistaken for AD. These related disorders include Creutzfeldt-Jakob disease, multi-infarct dementia, Pick's disease, Parkinson's disease, Lewy Body disease, and conditions like depression, drug interaction, and thyroid problems. In light of these many similar conditions, all of which have different treatments and some of which can be cured, accurate diagnosis is crucial.

Council Activity in Fiscal Year 2001

Brief History of the Council

The Governor's Advisory Council on Alzheimer's Disease and Related Disorders was convened in September 1998. It was first authorized in Section 379 of Chapter 194 of the Acts of 1998, and the reauthorized in Section 80 of Chapter 236 of the Acts of 2000. The Council is charged by the legislation with the following goals:

- ➢ To recommend the delivery of services in the most effective and efficient manner possible, including identifying means of coordination and cooperation among different state agencies and departments in order to achieve cost savings and to facilitate meeting the needs of people with dementia or their caregivers;
- ➢ To identify additional sources of federal and private sector funding with which the Commonwealth may provide additional services and programs for people with dementia and their caregivers;
- ➢ To promote public and professional awareness and education relative to dementia and access to dementia services and programs;

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[*] National Institute on Aging and National Institutes of Health. Progress Report on Alzheimer's Disease. 2000. NIH Publication No. 00-4859. Silver Spring, MD (2000): 9.

[**] Ibid, 6

- To identify service delivery mechanisms that enhance the quality of life for people with dementia and their caregivers; and
- To evaluate and coordinate implementation of recommendations made in 1994 by the Governor's Conference on Alzheimer's Disease.

Members of the Council, according to the legislation, are to be appointed by the Governor, the President of the Senate, the Speaker of the House, and the Minority Leaders of the House and Senate. There are seventeen appointed members. They are:

Chair: Lillian Glickman, Secretary of the Executive Office of Elder Affairs
Sandra Albright, Executive Director, Kit Clark Senior Services, Dorchester;
Judith Antonangeli, The Birches at Concord, Concord, NH;
Vincent Ciampa, State Representative, Somerville;
Carol Cleven, State Representative, Chelmsford;
Dr. Joan Garity, Ed.D., RN, Associate Professor, UMass Boston, Boston;
Barbara Gloss, Elder Affairs' Citizens' Advisory Council, Winthrop;
Kathryn Hedgepeth, Regional Director, Alzheimer's Association, Massachusetts Chapter, Easthampton;
Joanne Koenig-Coste, M.Ed., President, Alzheimer's Consulting Associates, Framingham;
Ruth Moy, Executive Director, Greater Boston Chinese Golden Age Center, Boston;
Douglas Petersen, State Representative, Marblehead;
Paul Raia, PhD., Director of Patient Care and Family Support, Alzheimer's Association, Massachusetts Chapter, Cambridge;
Diane Sibley, Community Advocate, Boston;
Ralph Stefanelli, Community Advocate, Norton;
Virginia Tierney, Elder Affairs' Citizens' Advisory Council, Quincy;
Marian Walsh, State Senator, Boston; and
Kathleen Walsh, Community Advocate.

Other people who have attended meetings are Ann Hartstein, Ellen Birchander, and Eliza Lake of the Executive Office of Elder Affairs; Ruth Palombo and Rick Kaffenberger of the Department of Public Health; Patricia Baumer of Representative Vincent Ciampa's office; Matt Havens of Senator Walsh's office; Deborah Thomson, James Wessler, Susan Kelly-Grasso, and Ginny Bannas of the Alzheimer's Association, Massachusetts Chapter; Cathy Pastva of the Alzheimer's Association of the Cape and Islands; Ann Hurley of the Boston University Alzheimer's Center; Roberta Rosenberg of the Multicultural Coalition on Aging; Daniel O'Leary of Mystic Valley Elder Services; Linda Connor-Lacke, an Alzheimer's consultant; and Stephanie Bronson, an Elder Affairs Intern.

In addition to covering the information provided below, every meeting of the Council served as a roundtable discussion of the most recent information in the field of Alzheimer's care. Information shared included updates about educational opportunities, the latest research findings, regional events, agency activities, policy changes, and upcoming conferences. In this way, the Council has served as a statewide forum for the dissemination of information and as a brainstorming arena, a function that will contribute to achieving the goal of improving services to people with ADRD across the state.

Council Activities

In fiscal year 2001, the subcommittees carried out the majority of the Council's work. The full Council met five times in meetings that are summarized below.

September 21, 2000

As an acknowledgement of the Council's reauthorization, the Council decided to invite various state agencies, many of who had presented to the Council in the fall of 1999, to present anew their efforts on behalf of people with Alzheimer's disease and their families. The Department of Mental Retardation (DMR), the Department of Mental Health (DMH), and the Department of Public Health (DPH) gave presentations at this meeting.

Department of Mental Retardation: DMR serves adults with mental retardation and the families of children with developmental disabilities. DMR's service system is in the process of evolving from an institutional system to one of broad home- and community-based services that support people in place. In this process, DMR is also changing the focus of services; the focus is no longer on the clinical or medical aspects of care, and ADRD is considered a "medical" issue for DMR clients. A balance needs to be achieved between the clinical and non-clinical modes of care, in order to allow those DMR clients that are developing clinical conditions to age in place. For instance, DMR is developing handouts for providers and families to help them identify behaviors that may point to causes other than the known diagnoses. This can be difficult for staff that have been previously trained to think of behavior as a manifestation of an individual's personality, and that will resist having to think in a clinical manner about behavior.

There is some expertise in the DMR system on ADRD. In the Metro Region of DMR, nurse practitioners and support staff are working to identify DMR clients with ADRD and to work with and educate families about how to address the special challenges a dual diagnosis can present. There are also eight beds dedicated to individuals with ADRD in DMR facilities. The understanding, however, is that there should be better connections built between the DMR system and those already in place, including those of Elder Affairs.

In the discussion following the presentation, the Council made the following points:

- The system needs to be flexible enough to adopt new ways of thinking about people with AD and their unique challenges. For instance, there is a conflict between emphasizing "dignity with choice" and preserving the individual's safety, although one must be careful to maintain a balance between the two concerns. Also, behavior management plans, a commonly used tool in the DMR system, do not work for people with ADRD.
- As people with Down Syndrome develop AD, there are difficulties with obtaining adult day care services for them. The average age of this population tends to be around 50 years old, which means that if they receive dementia day care services, their providers cannot obtain the new higher dementia day care reimbursement rate from Medicaid because their age disqualifies them.
- People with Down Syndrome are not the only DMR population at risk; those with other forms of MR/DD develop ADRD at four times the rate of the rest of the population. In 1990, there were an estimated 780 people in the Commonwealth with a dual diagnosis, a number that may have tripled by now.

Department of Mental Health: DMH's population is defined as "adults with serious and persistent mental illness and children and adolescents with severe emotional disturbance." In general, the Department does not serve those people with "organic" or structural brain disorders. Rather, the focus is on individuals with biochemical or neurotransmitter disorders, such as schizophrenia. Therefore, people with ADRD do not qualify for DMH services.

Council members suggested that there might be a role to DMH to serve caregivers who are suffering from the stresses of caring for a person with ADRD. Efforts could be made to ensure that this population, and all elders, have access to DMH services, and are not told that they should go to Medicare. Finally, there was a discussion of the fact that the Mental Health Parity Law does cover Alzheimer's disease and other dementias, but its implications are limited. It requires that insurance companies provide the same level of coverage for the assessment and treatment of ADRD.

The Department of Public Health: DPH is concerned with preserving the health of the Commonwealth's residents, with a focus on prevention and education. This includes screenings, licensing health care providers, and information and advice on injury prevention, among many other services. While there are currently no services that directly target individuals with ADRD. DPH is sure that they benefit from many of its activities. These include statewide surveys that would include information about the behaviors, and functional and mental status of caregivers.

DPH also runs three state hospitals that provide services to people with dementia: Western Massachusetts, Lemuel Shattuck, and Tewksbury Hospitals. In addition, the Bureau of Family and Child Health is currently working on education programs that could help caregivers, especially in disadvantaged communities. The Bureau is also involved in the Massachusetts Genetic Planning Program, and has received a grant through its Division for Special Needs to do community assessments, which would include looking at ADRD in the community.

October 26, 2000

As a continuing acknowledgement of the Council's reauthorization, the Council invited the Division of Medical Assistance (DMA) and the Massachusetts Commission for the Blind to give presentations at this meeting.

Division of Medical Assistance: DMA is the agency that administers the state Medicaid or MassHealth program, which was created in 1993. Formerly part of the Department of Public Welfare, DMA serves 950,000 clients. For elderly enrollees, MassHealth functions as a wrap-around service, covering those services that are not covered by Medicare, which is the primary insurer for all elders.

While there are no specific services targeted to the families of individuals with ADRD, many are recipients of DMA services. MassHealth pays for institutional services provided in acute care hospitals, chronic/rehab facilities, nursing facilities and the Department of Public Health's public hospitals. As ADRD is very common in nursing facility residents, and is often the reason for admission to the facility, MassHealth is a major payer for services for this population.

In terms of community based long term care for individuals with ADRD, MassHealth pays for personal care attendant (PCA) services, assisted living payments through the Group Adult Foster

Care program (GAFC), the Adult Foster Care (AFC) program, adult day health (including dementia day care), and day habilitation, which is primarily for younger people with a dual diagnosis of ADRD and mental retardation. For people with cognitive impairment, the PCA program has the surrogate model, in which an individual has a designated surrogate to hire and supervise the personal care worker. In addition, the home and community-based waiver offers primarily the same package of services as the state Home Care program administered by Elder Affairs. Finally, DMA and Elder Affairs increased the reimbursement rate for dementia day programs, due to an increase in the budget passed by the Legislature in the FY2001 budget.

Massachusetts Commission for the Blind: The Massachusetts Commission for the Blind (MCB) is the state agency mandated to provide services to the 40,000 registered individuals with sight impairment. MCB has six regions, and a multi-handicap unit that handles the cases of people over the age of 14 who are blind and deaf or have mental retardation. Individuals with Alzheimer's disease or a related disorder would fall into this unit's population. In doing an assessment, MCB will consider the individual's sight, cognitive and functional status, in order to create the best possible care plan. MCB works closely with both immediate and extended family members, as well as with the institutions in which individuals may live. The main focus of any care plan is assuring the individual's safety. Once a care plan has been implemented, the case is "closed," which means that there is no active contact between MCB and the individual. The client is still registered; if the situation changes, MCB can be called back in to retrain or develop a new care plan, and the client and his or her formal and informal caregivers can still call MCB for information and assistance.

MCB is seeing more elderly referrals, many of which suffer from macular degeneration, and therefore are seeing an increase in the number of referrals with ADRD. Occasionally MCB will be called in to see an elder for vision loss, only to discover that the real referral issue is the presence of dementia, especially in referrals for people in nursing facilities. Those referrals with dementia will not retain cane training and facility orientation, which is the usual training approach. In these cases, attempts are made to use a multi-sensory approach to familiarize the resident with his or her surroundings, but it is very difficult.

MCB is a rehabilitation agency; the primary responsibility of its workers is to address the individual's sight loss, and any other diagnosis is considered secondary. That being said, MCB staff work with local long-term care providers such as Aging Services Access Points, other providers of home care services, and home health providers. Staff members have given in-service trainings to these providers and at nursing facilities.

<u>February 15,2001</u>

The Council met to discuss a number of issues, which included:

- Subcommittee reports on meetings regarding transfers of people with ADRD from nursing facilities to geriatric-psychiatric units in hospitals and on the results of a survey of nursing programs geriatric and dementia curricula. These issues are discussed in greater detail in the "Subcommittee Activities" section, below.
- Approval of the Council's fiscal year 2000 annual report.
- Submission of another application for a grant through the Alzheimer's Disease Demonstration Grants to State Program, which is administered by the federal Administration on Aging. The Council, through the Executive Office of Elder Affairs,

applied unsuccessfully for funding from this program in the spring of 2000. There was general agreement that the proposal must be much more specific as to the population that will be served. The group discussed which of the various ethnic groups in the state are underserved. Suggestions included the Latino, Southeast Asian, Russian, or Chinese communities. The resulting application is discussed in greater detail below.

- Allocation of $2.7 million to the Commonwealth from the Administration on Aging through the National Family Caregiver Support Program. The funds from this program, which is part of the reauthorization of the Older Americans Act, are being used to develop the Massachusetts Family Caregiver Program. The program will develop new models of caregiver support while building on the efforts that the elder network currently makes to support family caregivers. In addition to using the funding from AoA, the program will be funded by a $2 million in fund balances from the ASAP purchased services accounts.

April 9, 2001

Fire Safety Codes in Dementia Special Care Units: There has been concern expressed to the Council about nursing facilities being penalized for camouflaging exit doors in dementia units. Camouflaging has been shown to have a positive impact on the residents as well as staff. Hiding egress also causes a decrease in Alzheimer's disease medication and negative reinforcement. Findings also suggest that by improving the environmental quality of these long-term care units, the staff turnover and burnout rate may significantly diminish.

The invited representative from the Department of Public Health's Life Safety Unit gave a presentation on the laws and regulations relevant to this issue. The Unit's only interest is in making the nursing facilities safe and that it is willing to work with the industry to make it so. Regulations state that the door must be easily recognized in a smoke filled room. When exit signs get covered, the doorknob has to be familiar and easily accessible. In accordance to the fire codes, nothing can interfere with the door looking like a door. However, it is possible that the Unit will accept letters requesting waivers for specific situations. In some cases a waiver can be granted for 6 months or a year, with possible renewals to pilot a different system. The system must be in place for a year and it is suggested that during the trial period that a record is kept of its efficacy and safety. However, the federal Health Care Financing Administration (now called the Centers for Medicare and Medicaid Services) has to approve any waivers that the Unit wishes to grant.

During the discussion that followed the presentation, the Council members and other meeting attendees raised concerns regarding the training of long term care surveyors in issues related to dementia care, so that they understand different perspectives and treatment modalities.

June 22, 2001

Massachusetts' Nursing Programs and Dementia: The Council was presented with the results of the Survey of Massachusetts' Nursing Programs. Council members, Elder Affairs, and the Board of Registered Nurses (BORN) developed the survey last summer and the BORN sent it out to those nursing programs that it certifies. In comparison to the survey sent in 1992 that only produced a 23% response rate, the 2000 survey had an overwhelming response rate of 71%.

The most interesting finding was the result of a question that asked whether there is a need for a nursing specialization in geriatrics or dementia care. Of the responses received, 79% agreed that there is the need for specialization, while 17% said that there is no need for it. More importantly, of those responses, 25% saw the need only at the highest levels of education. A representative from BORN attended the meeting to discuss the implications of these findings, and to assist the Council in developing recommendations related to nursing education. For more information about this subject, see the discussion below.

Building the Capacity of the Long-Term Care System

The Governor's Council on Alzheimer's Disease is required, under the terms of its legislative mandate, with looking at professional and public education, with the coordination and enhancement of services, and with finding new sources of funding for Alzheimer's related activities in the Commonwealth. These activities could all be described as *capacity building;* increasing the ability of the health and long-term care systems to serve individuals with ADRD in the most appropriate and effective manner. In its activities of fiscal year 2001, the Council addressed a number of issues that are related to the capacity of the system. This activity was largely conducted in the Subcommittees, with the input of the full Council. Nursing education, inappropriate transfers from nursing facilities to geriatric-psychiatric units in hospitals, and culturally competent outreach, education, and services are all issues that could improve the system's ability to react to the growing population of individuals with ADRD.

Nursing Education

The Professional Education Subcommittee's objective is to ensure that health care professionals across the spectrum understand the medical, social, and functional needs of dementia patients and their families, and that they have knowledge of those services available to this population. Nurses, in particular, are at the forefront of care provision for people with ADRD. They work in all settings of the long-term care system, and provide critical care. Without appropriate training, however, nurses cannot be expected to know intuitively how to care for individuals with dementia, any more than they could care for someone with any other chronic illness.

As was described in the Council's fiscal year 2000 Annual Report, few elders in our current health care system do not require the skilled care of at least an LPN or RN at some point in their aging process, and this is especially true for those with dementia. It is vital that these health care workers be able to respond in an informed, appropriate manner to the needs of this vulnerable population. Developing and promoting a curriculum that trains nursing professionals at all level to provide this care would create a more flexible and responsive health care system. The Council, therefore, conducted a survey of those nursing programs certified by the Board of Registration in Nursing in the fall of 2000. The Council developed the survey instrument, and BORN mailed out and received the responses.

The objective of the survey was to study not only the gerontological content in basic nursing education programs, but to gather data on the inclusion of dementia specific curriculum content. The survey was sent to a total of 57 institutions with nursing programs approved by BORN. There were 52 responses received, analyzed and incorporated in this report, which is a 91% response rate. These responses represented 41 institutions and 73 nursing education programs.

The survey results demonstrated that there is limited availability of courses strictly devoted to geriatric nursing. Integration of gerontological material into other courses, however, was found in 100% of the nursing programs. *Of the 73 programs that were surveyed, none of them had courses devoted to dementia.* The vast majority of the programs, 98%, claimed that dementia was integrated into their curriculum but the vagueness of the responses prohibited a clear understanding of the course content. In addition, the lack of consistency in course hours reported involving geriatric nursing and dementia care made it highly difficult to develop valid conclusions.

An encouraging outcome of the survey was the overwhelming number of institutions that offer clinical experience in geriatrics through their nursing programs. Out of the fifty-two responses received, 92% of them claimed to have clinical experience supporting geriatrics. Approximately 75% of the clinical placements were completed at skilled nursing facilities throughout the Commonwealth.

The final question of the survey, which elicited the perceived need for specialization in geriatric and/or dementia care nursing, yielded the most valuable results. Of the 52 responses received, 41 or 79% of the respondents believe that there is a need for specialization. Nine or 17% of the respondents thought that there was no need for specialization in geriatric/dementia care nursing. Of the original 52 responses, 13 or 25% commented that specialization of this kind is only needed at the graduate level of study, not at the LPN or ADN level.

It is the responses to this last question that concerned the Council in its discussion with BORN; how could the Commonwealth create a specialization in gerontology for nurses at the LPN or AND level of training? After discussion, it was decided that those programs that expressed the most interest in specialization should be brought together to discuss the creation of a pilot project. This project could be funded through grant funds, or could be developed as an initiative at one of the schools. The Council agreed that in fiscal year 2002 they would pursue this issue, in the hopes of creating a nursing workforce that is well-trained in gerontological issues, including dementia care.

Transfers between Nursing Facilities and Geriatric-Psychiatry Units

Adequate and appropriate training of nurses translates into appropriate care decisions, including decisions about which long-term care setting would provide the most appropriate care. According to the Alzheimer's Association and the Long-Term Care Ombudsman Program, there has been an increase in families questioning the appropriateness of their demented elderly family member's transfer from a nursing facility to the geriatric psychiatry unit of a hospital. The Subcommittee on Coordination and Enhancement of Services decided to convene a series of meetings to discuss this subject. The first meeting was with representatives of geriatric psychiatry hospitals, and the second with representatives of nursing facilities.

The Alzheimer's Association and the Long-term Care Ombudsman Program both presented the concerns that they have heard from families, and the experiences that they have had with inappropriate transfers. These included:

- An increase in the number of calls about inappropriate transfers, including cases where a resident has been transferred multiple times.
- Hospitals are sending residents back to nursing facilities with care plans that the facility does not have the capacity to carry out.

- To relieve the pressure on their workers, some facilities are sending their most difficult residents to the hospital, rather than trying to deal with their behaviors in-house.
- Some facilities are refusing to accept the residents back once they have been sent to the hospital, which is in violation of the Omnibus Budget Reconciliation Act of 1987.

Both meetings had very animated discussions, with many of the same conclusions about what may be the cause of the situation, and what should be done about it. Issues that arose in the course of the discussions included:

- The primary concern was communication; without better information, hospitals, nursing facilities, psychiatric consulting services, and families all find fault with each other. Some of these issues could be alleviated by established mechanisms for communication.
- Hospitals and nursing facilities both face enormous financial pressures and regulatory constraints, which can keep them from being able to provide the care that patients may most need in special care units.
- While hospitals feel that nursing facilities are inappropriately resistant to taking back residents who had been transferred to the hospital, facilities feel that hospitals send back residents with care plans that are entirely infeasible.
- Both hospitals and nursing facilities are coping with tremendously difficult staffing situations and with the attendant problems of turnover, training, and care issues.
- Many of the residents that are being transferred have other, acute medical problems that need to be addressed adequately by both the hospital and the nursing facilities.

The two meetings both generated lists of possible future actions that the Council or the participants could facilitate. These included:

- Create better mechanisms for communication, on both the community and statewide level.
- Establish protocols, agreed to by the nursing facility and hospital communities, for transfers both from and to the community.
- Review the funding mechanisms for both hospital and nursing facility reimbursement, and recommend changes that would ensure better care for individuals with ADRD.

The Springfield Multicultural Alzheimer's Services Project

Ultimately, any improvements to the long-term care system will only be as effective as the degree to which they are known about and used. If elders and their caregivers do not know that they can receive care from state systems, if they do not feel that the services meet their needs, the system will have failed them. This is particularly true when one considers multicultural populations. Issues of cultural competency and linguistic barriers can be larger obstacles for families trying to get help than any eligibility requirement.

In the interests of addressing these barriers, the Council submitted an application to the federal Administration on Aging (AoA) for funding under the Alzheimer's Disease Demonstration Grants to States Program (ADDGS) in May 2001. AoA required that proposed programs address two priority program objectives: 1) develop models of assistance for persons with Alzheimer's disease and their families; 2) improve the responsiveness of the existing home and community based care systems for persons with Alzheimer's disease and related disorders and their families.

The Governor's Advisory Council, through the Massachusetts Executive Office of Elder Affairs' application to ADDGS, proposed the Springfield Multicultural Alzheimer's Services Project (SMAS). The SMAS proposal was designed to ensure that Latino and African American individuals with Alzheimer's disease and their families and caregivers have access to appropriate information and services. SMAS will create a link between the Alzheimer's Association, the Spanish American Union, the VNA and Hospice of Western New England, and Greater Springfield Senior Services, Inc., which is the local Aging Services Access Point. The application requested $350,000 a year for three years.

SMAS will conduct outreach to the target populations through the Spanish American Union and the Alzheimer's Association, will assess and train participants through the VNA, and will provide direct services to identified individuals through the state Massachusetts Respite Care Program. SMAS will create new programs for these populations, including education, training, support, and respite for clients' families/caregivers. In addition, all providers will be given cultural competency training. Finally, SMAS will establish monitoring mechanisms to allow accurate evaluation.

SMAS will increase the capacity of the elder service system in the Springfield area to provide for individuals with ADRD and their families. More specifically, these system improvements will include:

- Enhancement of the existing Respite Program's services by adding a targeted outreach plan, a home assessment, and training for family members/caregivers;
- Extension of respite and support services to underserved populations by making the services more responsive to the needs of the culturally diverse aging population.
- Creation of a formal process to provide training and resources for ASAP, VNA, and community agency staff members regarding appropriate outreach and services to minorities with dementia and their families, including in-home support; and
- Development of a partnership between Elder Affairs, the Department of Public Health, the Governor's Advisory Council on Alzheimer's Disease, the Massachusetts Chapter of the Alzheimer's Association, and local service providers.

In June 2001 the Council learned that it had been awarded funding under the ADDGS Program. As Elder Affairs and its partners work to implement SMAS, the Council will continue to serve in an advisory role to the project.

Other Council Activities

The funding for the Council also provides for other activities done under the aegis of the Council. The Council's staff person, Eliza Lake, served as a liaison between Elder Affairs and Alzheimer's patients and their families, providers, and the interested public. She has served as an information resource for Massachusetts' family members and providers, and for interested parties from outside the state. In fiscal year 2001, Ms. Lake attended the Alzheimer's Association's national conference on public policy in Washington, DC, where she was one of only a few state employees devoted to ADRD issues.

Ms. Lake attended and served as the staff person for all of the meetings of the Council and its subcommittees. In addition, she developed and wrote the successful application for funding under the ADDGS grant, and will serve as the Project Director. She attended many other organizations' meetings in order to present the work of the Council, including meetings of the Alzheimer's Association's Advocacy Committee, at which she gave updates on state policies and activities related to ADRD. She also attended meetings of the Multicultural Coalition on Aging, and gave presentations at a meeting of the state's nursing facilities' special care units directors and a conference of the Massachusetts Association of Councils on Aging.