

Annual Report
of the
**New York State Coordinating Council
for Services Related to Alzheimer's Disease
and Other Dementias**

to
Governor David A. Paterson
and the
New York State Legislature

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<p><i>It is important to note the report is not intended to address institutional care; rather it focuses on the estimated 75% of people with Alzheimer’s disease who reside in the community and the invaluable network of informal and formal caregivers that allow them to remain there.</i></p>	

Section I. Introduction

New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias

The New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias (Council) was established by Public Health Law § 2004-a (enacted by Chapter 58 of the Laws of 2007, Part B, § 25, and attached hereto as Attachment D). The Council was formed to facilitate interagency planning and policy-making, review specific agency initiatives for their impact on services related to the care of persons with dementia and their families, and provide a continuing forum for concerns and discussions related to the formulation of a comprehensive state policy for Alzheimer's disease (AD). (See Attachment B for a list of the Council members.) The Council is charged with providing reports to the Governor and the Legislature every two years beginning in June 2009. The reports must set forth the Council's recommendations for state policy relating to dementia and include a review of services initiated and coordinated by public and private agencies to meet the needs of persons with Alzheimer's disease and other dementias and their families, this report provides a beginning to this review.

To inform the first report, and as required by Public Health Law § 2004-a, the New York State Department of Health (DOH) and the Council hosted eight community forums in Binghamton, Brentwood (Long Island), Cheektowaga, Manhattan, Rochester, Syracuse, Queensbury, and White Plains. The forums were held during the spring and summer of 2008. Each forum provided an opportunity for community leaders, various providers, local support groups, caregivers, and family members of those with AD to share ideas and challenges in dealing with AD. More than 500 people attended these forums. Many common concerns were expressed at each forum and are outlined in the following pages. The Council also gathered expert advice from Council members and others in the field to inform the development of the report.

This report provides general information about Alzheimer's disease and other dementias, an overview of issues, examples, and recommendations to address challenges faced by patients and their caregivers in the community, and outlines the next steps for the Council, all of which emanated from both the community forums and Council discussions. Future reports will incorporate a strategic plan to address these issues as well as those associated with mild cognitive impairment, and focus on early detection, primary and secondary prevention, and public awareness.

Background

Alzheimer's Disease and Other Dementias

Alzheimer's disease is a brain disorder named for German physician Alois Alzheimer, who first described it in 1906. AD is the most common form of dementia (a general term for the progressive loss of cognitive abilities, including memory, serious enough to interfere with daily life). Scientists have learned a great deal about AD in the century since Dr. Alzheimer first drew attention to it, and today we know that AD is a progressive and fatal brain disorder. AD destroys brain cells, causing problems with memory,

thinking, problem solving, emotional control and behavior severe enough to affect work, activities of daily living (ADL) or relationships. AD gets worse over time and it is fatal. Today it is the sixth-leading cause of death in the United States. Some of the other diseases and disorders that can cause symptoms of dementia are Lewy body dementia, frontotemporal dementia, Parkinson's disease, Huntington's disease, Pick's disease, HIV and Creutzfeldt-Jakob disease. Some dementias or dementia-like symptoms, such as those caused by treatable conditions, are reversible, underscoring the need for early detection.

Scientists do not yet fully understand what causes AD. Age is the most significant known risk factor for AD. While younger people may get Alzheimer's disease, it is much less common. The disease usually begins after age 60, and risk goes up with age. The number of people with the disease doubles every 5 years beyond age 65. People over the age of 85 have a 50% likelihood of developing AD. It is important to note, however, that AD is not a normal part of aging.¹

AD currently has no cure. But early diagnosis and treatments for symptoms, combined with the right services and support, can make life better for the people living with AD and their caregivers and increase the amount of time persons with dementia can remain at home. In recent years both pharmaceutical and behavioral approaches to treat the patient, as well as targeting training and support for caregivers, have been shown to have a significant impact on the health and well-being of both patients and caregivers. Current pharmaceutical interventions include treatment for AD and treatment for co-morbidities (e.g. depression), both of which can improve symptoms.

Moreover, there is an accelerating worldwide effort under way to find better ways to treat the disease, delay its onset, and prevent it from developing. The latest example of this is the United Kingdom's Department of Health February of 2009 publication "The National Dementia Strategy" focusing attention on the National Health Service as well as important community services to address the compelling issues facing people with dementia, their caregivers, and healthcare providers.

Family history is also a significant risk factor for AD. Researchers believe that genetics may play a role in the development of AD. In addition to genetics, researchers are studying education, diet, and environment to learn what role they might play in the development of AD. Scientists are finding increasing evidence that some of the risk factors for heart disease and stroke, such as high blood pressure, high cholesterol, and low levels of the vitamin folate, may also increase the risk of AD. The presence or co-morbidity of other diseases such as type 2 diabetes is also the subject of study.

According to the Centers for Disease Control and Prevention (CDC), AD is one of the top ten leading causes of death in the United States. AD has recently surpassed diabetes as the 6th leading cause of death among American adults. Notably, mortality rates for AD are on the rise, unlike heart disease and cancer death rates which are continuing to decline, and there is growing evidence that death certificate data may not capture a true picture of the disease. For example, a person with AD whose immediate cause of death is a cardiac event or pneumonia may not have AD listed on the death certificate, artificially reducing the mortality rate associated with the disease.

An estimated 5.3 million Americans have Alzheimer's disease. This number has doubled since 1980, and is expected to rise as high as 13.4 million by 2050. Current estimates are that just over 450,000 New Yorkers have this disease. In 2005, total Medicare spending nationwide for individuals with AD was estimated at \$91 billion. Individuals with AD make up less than 13 percent of the Medicare population, yet they account for 34 percent of Medicare spending.² In addition, a 2006 study by the Alzheimer's Association found that nationally the economic burden to industry precipitated by AD and dementia is estimated at \$61 billion annually (\$24.6 billion for healthcare and \$36.5 billion in lost productivity, absenteeism and worker replacement).

Family members and other caregivers provide the majority of care to people with AD, especially for those who remain in the community. According to a recent estimate by the American Association of Retired Persons (AARP), 2.2 million caregivers in New York State are providing \$25 billion in unreimbursed long term care.³ Furthermore, AD patients remaining at home with the help of family caregivers, rather than residing in a facility, provides a more commonly desired and better quality of life for patients and is often less costly for families and the State. Research conducted by Dr. Mary Mittleman of New York University found that with appropriate supports for the spouses of individuals with AD, those suffering from AD can remain in the community significantly longer (557 days) while maintaining quality of life.⁴

Recognizing the importance of family caregivers, DOH also works closely with the New York State Office for the Aging (SOFA) to share information between the Council and the New York State Family Caregiver Council. The Family Caregiver Council was created as part of the 2007-08 enacted state budget. SOFA coordinates the work of the Family Caregiver Council with other state agencies that provide services to caregivers for persons of all ages.

Currently, DOH has two major projects focusing on people with AD and their caregivers in the community: the Alzheimer's Disease Assistance Centers (ADACs) and the Alzheimer's Disease Community Service Programs (ACSPs). (See maps, Attachment C, for locations of ADACs and ACSPs.)

- **Alzheimer's Disease Assistance Centers:** Since 1987, New York State has funded nine ADACs which serve as "centers of excellence" for the diagnosis and management of AD and other dementias and a resource for professionals and community providers.
- **Alzheimer's Disease Community Service Programs:** Since 1988, New York State has funded ACSPs – 19 of them currently – which provide essential family/caregiver support, respite care, information and referral services to patients with AD and their families.

Identification and Prevention

Two of the most common and challenging questions faced by DOH representatives and Council members during the eight community forums were:

1. How will I know to be checked for Alzheimer's disease?
2. What can I do to prevent Alzheimer's disease?

Currently, there are no definitive answers to these questions, although there are several resources (listed in Attachment A hereto) that provide some helpful information, including access to current research and answers to frequently asked questions. The answers to these two questions, however, are important for many reasons, both human and economic. According to a recent paper by researchers at the University of Wisconsin using large scale cost-benefit analysis, "The early diagnosis and treatment of AD are not only socially desirable in terms of increasing economic efficiency, but also fiscally attractive from both state and federal perspectives".⁵ Early diagnosis creates an opportunity for aggressive treatment when it is most effective and essential for planning for anticipated future needs.

Early diagnosis of AD is challenging, but is becoming more routinized through the use of comprehensive history and physical exams, memory assessments, radiological tests and neuropsychological testing. Typically, the first goal of this series of tests is to rule out other conditions that may explain behavioral symptoms. Only when that is complete does AD become a consideration. The possibility of other treatable conditions also raises the priority for early diagnosis. The Alzheimer's Association has developed a list (Attachment E hereto) of the ten warning signs of AD for people to consider when they are concerned about memory loss by themselves or their loved ones.

According to the National Institute on Aging, scientists are rapidly expanding their understanding of the many factors involved in the development of AD. Even though no treatments or pharmaceuticals have yet been proven to prevent AD, people can take some actions that might reduce their risk of developing AD. These actions include:

- Lowering cholesterol levels;
- Lowering high blood pressure levels;
- Controlling diabetes;
- Exercising regularly;
- Engaging in socially and intellectually stimulating activities; and
- Increasing dietary intake of foods believed to lower risk such as fruits, vegetables, fish and olive oil (Mediterranean Diet).

All of these strategies lower the risk of other diseases and help maintain and improve overall health and well-being. However, it is important to remember that pursuing any of these strategies will not necessarily prevent or delay AD in any one individual. Prevention takes many forms; preventing or delaying the onset of disease (primary prevention), as well as preventing complications and minimizing implications in daily life (secondary prevention). Even if the strategies described above are eventually proven to be effective, they might not offset a person's individual genetic and other risk factors enough to prevent AD from developing.

¹ Alzheimer's Association, 2009 Alzheimer's Disease Facts and Figures, published in Volume 4, Issue 2. *Alzheimer's & Dementia*.

² Ibid

³ Across the States 2009: Profiles of Long-Term Care and Independent Living, www.aarp.org

⁴“Improving Caregiver Well-Being Delays Nursing Home Placement of Patients with Alzheimer’s Disease” in *Neurology*, November 14, 2006.

⁵“Early identification and treatment of AD: Social and fiscal outcomes”, Weimer, DL, Sager, MA, *Alzheimer’s & Dementia*, 5 (2009) 215-226

Reference to a particular resource or website does not constitute endorsement by DOH or the Council.

Section II. Issues, Best Practices, and Policy Recommendations

Section II is divided into the priority areas that were described in detail at the community forums and by the Council. Each topic area includes: (1) a list of issues, meaning the challenges and problems that require attention and or action; (2) promising practices, meaning the strategies, programs, or tools presented to the Council that have been shown to work or have promise and might be replicated; and (3) proposed recommendations, meaning the suggestions discussed by the Council to address the issues presented in the forums in the near future.

A. Need To Quantify the Burden of the Disease

All healthcare interventions and strategies for wellness first require good information on which to base decisions. This section addresses the need to understand the prevalence of AD and related dementias among New Yorkers.

Issues

- A lack of reliable, quantifiable data on dementia prevalence makes planning for an adequate system of care difficult.
- The existing AD registry, created for this purpose, does not adequately capture state data related to this disease.
- Resources to expand data collection to include other available sources of data are lacking.
- Studies show that death certificate (vital records) reporting is incomplete⁸

Promising Practices

- The Alzheimer's Association annually publishes a statistical abstract, "Alzheimer's Disease Facts and Figures." The 2009 report contains information about the prevalence of AD, family caregiving, the use and costs of care, and lifetime risks in the United States.
- The New York State Interagency Geriatric Mental Health and Chemical Dependency Planning Council funds geriatric physical/mental health integration pilot projects. Early evidence shows improved care and economies of scale with some models where single records are maintained rather than duplicative records for each system.
- The Behavioral Risk Factor Surveillance Survey (BRFSS), a telephone survey that tracks health risks in the United States, now has a caregiver's module which in future years will provide valuable trend data.

⁸ *Sensitivity and specificity of death certificates for diabetes*, Wingard D, Cheng, W, Presentation on Meta Analysis, www.naphsis.org/NAPHSIS/files/ccLibraryFiles

Proposed Recommendations

- Other available data sets should be utilized to estimate numbers and costs associated with dementia policy and planning, such as data available through the Statewide Planning and Research Cooperative System (SPARCS), Medicaid, or the Outcome and Assessment Information Set (OASIS).
- Physicians should be educated on the benefits of early diagnosis for more complete medical records, especially when using electronic records.
- State agencies should assess the function and value of data systems, discontinue those with low value, and better utilize those with value or achievable potential.

B. Caregiver Economic Burden

One problem of caring for a person with AD is finding ways to continue to meet personal financial commitments while having to devote a significant amount of time to caregiving. The issues, promising practices, and recommendations in this section address this challenge.

Issues

- Caregivers may experience lost employment, premature retirement, and difficulty working full time due to caregiving responsibilities, including attending medical appointments, covering for home health aides that are unavailable at certain times, and spending time locating resources.
- Caregivers may have problems getting or keeping health insurance due to job loss.
- Caregivers' responsibilities and job absences may negatively affect the quality of their work.
- The assumption of payment for patient services and other expenses, including home modifications and medical equipment, can cause family financial strain.
- AD and dementia pose a burdens to the economy in terms of both healthcare costs and lost worker productivity.

Promising Practices

- The Alzheimer's Association website has many examples of educational materials for caregivers. This information should be more readily available to caregivers through healthcare and community groups.
- Other internet tools can be found through AARP, National Council on Aging (NCOA), and SOFA's web sites <http://www.aarp.org>, <http://www.ncoa.org> , and <http://www.aging.ny.gov>.

Proposed Recommendations

- Educate caregivers and patients about the Family Medical and Leave Act, long term care insurance, the benefits of advanced legal and financial planning, and existing support programs through agency websites, educational forums, service networks, and the media.
- Educate employers about caregiving responsibilities and how they can be responsive to these employees through partnerships with trade organizations.
- Increase medical and social adult day care options with staff specifically trained to meet the needs of persons with dementia. These programs can also help meet the needs of working caregivers by extending their daily, weekend, and evening hours.
- Increase case management for families to improve planning for services and access to available services.
- Gradually expand ACSPs that provide multiple activities such as support groups and caregiver helplines until they are available statewide over the next three years.

C. Caregiver Health Burden (Mental and Physical)

The process of caregiving itself is a risk factor for several chronic conditions. The mental and physical toll that caregiving places on caregivers puts them at risk for health problems and can undermine the tremendous value that family caregivers bring to the patient and the system. This section focuses on identifying and reducing the risks associated with providing care for individuals with AD.

Issues

- Caregivers often neglect their own physical and mental health, leading to an increased risk and incidence of chronic disease, depression, and death.
- Caregiver health problems can lead to the premature nursing home placement of the individual with dementia.
- Both minor and adult children who are members of caregiving families dealing with dementia need appropriate training, information about the disease, and referral for support.
- Caregivers need to be made aware of the support services that are available in their community and how to access them.
- Caregivers may have other stresses based on employment status, residence location, race or ethnicity, or other family obligations for which they need support.

Promising Practices

- The American Academy of Family Practice calls for a model which includes caregivers in primary care visits as a “partner in care.”
- The National Family Caregiver Support Program, funded by the federal Older Americans Act, helps persons of any age who serve as a caregiver to a person 60 years of age and older. Services, available through area agencies on aging, include screening and assessment, respite, and counseling.
- The Alzheimer’s Association, DOH ACSPs, and area agencies on aging provide training for caregivers of dementia patients.
- The National Alliance for Caregiving (NAC) has a website about “Family Caregiving 101” at <http://www.familycaregiving101.org/>.
- The United Hospital Fund has a “Next Step in Care” website, www.nextstepincare.org, to improve the working relationship between family caregivers and healthcare providers.

Proposed Recommendations

- Increase access to respite provided by both volunteer and paid providers to allow caregivers regular access to support, physical activity, and healthy nutrition through better awareness of available services and more innovative and aggressive recruitment of respite providers.
- Increase awareness of and access to dementia adult day services (both social and medical models).
- Provide in-person, phone, and web-based support for caregivers through existing mechanisms (e.g., ACSPs).
- Partner with community-based organizations such as the Alzheimer’s Association to train volunteers and educate caregivers about appropriate strategies to deal with ongoing legal, financial, medical, behavioral, and emotional challenges.
- Gradually expand ACSPs that provide multiple support and training activities until they are available statewide over the next three years.

D. Healthcare Provider and Human Services Workforce

The quantity and quality of the workforce available to address AD, both healthcare professionals and paraprofessionals, was raised at every community forum and every Council meeting. Each of the forums highlighted the need for more healthcare workers who are better trained to meet the unique needs of AD patients.

Issues

- Many providers are insufficiently trained for the early detection, diagnosis, and management of dementia patients. Delays in accurate diagnosis result in lost opportunities for individuals to receive early treatment and to access advanced legal and financial planning which is essential to plan for their long term care needs.
- Providers require significant time to provide appropriate diagnosis of and care to individuals with dementia.
- There are anticipated shortages in the specialized workforce essential to individuals with dementia, including professionals educated and specializing in geriatric services, such as physicians, psychiatrists, psychologists, nurse practitioners, nurses, attorneys, social workers, physical therapists, architects and pharmacists.
- According to the Center for Health Workforce Studies, there is a shortage of medical providers in many communities, especially rural areas.

Promising Practices

- New York Connects is a local program, available in many counties within New York State, that provides access to information and referral services for people who seek long term care or additional information about long term care services that they are already receiving.

Proposed Recommendations

- Develop pre-service and continuing education curricula and specialized training in the early detection, diagnosis, management, and treatment of dementia.
- Draw from the tools and training materials developed by the Coordinated Care Alzheimer Demonstration Project for making the workforce “dementia ready.” This project is implemented by SOFA and funded in New York by the federal Administration on Aging and DOH.
- Develop recruitment strategies to encourage young adults to consider healthcare and social service professions related to care for older adults.
- Partner with medical and other professional associations to provide continuing education opportunities on dementia.
- Partner with primary care providers and dementia care facilities to improve lines of communication within the medical community.

E. Quality of Care and Safety

The relationship between quality of care and safety of formal and informal caregivers as well as people with AD was frequently mentioned in community forums. A number of concerns were raised that impact various aspects of family, community, and public support systems. The suggestions below aim to ameliorate these concerns.

Issues

- There are limitations in options for home and community based services and care due to access, geographic location, or cost.
- There is a lack of availability of home health aides, especially in rural areas, to meet the number of hours needed by individuals with dementia.
- There is a lack of specialty training related to specifically working with persons with dementia.
- There is a need to increase the amount of time for home health and personal care aides to attend trainings.
- There is a need for the appropriate and skill based matching of aides with families.
- There is a need for more staff training to recognize the symptoms of dementia, manage someone with the disease, and understand how a person with dementia might react to changes.
- Persons with dementia may be inappropriately placed in psychiatric hospitals, rather than skilled nursing facilities.
- Persons with dementia may be inappropriately or prematurely placed in nursing facilities.
- Patients may be transferred from a facility to a hospital, including an emergency department without a caregiver who can provide accurate information about or advocate for the patient.
- Patient wandering can lead to risk of injury and death.
- There is a lack of availability for emergency respite services for caregivers who may suffer a health or other emergency.
- There is geographic variation in service availability.
- There is a lack of available/adequate supervision and trained respite care.

Promising Practices

- EDGE Dementia training (Electronic Dementia Guide for Excellence, a DOH product) is a web based resource program. Using the Internet as a mode of access and distribution, EDGE works by giving staff members in dementia care settings the tools they need to help them provide quality care. The program offers guidance to identify

and implement interventions that specifically address care and communication challenges faced in dementia care.

- ACSPs, the Alzheimer’s Association, specialty medical providers, and others provide training programs for providers and caregivers to improve quality of life through behavioral and other interventions.

Proposed Recommendations

- Expand specialized dementia training for home health and personal care aides and others working with individuals with dementia to recognize and address symptoms.
- Create opportunities for increased remuneration for those with specific training.
- Develop and require training for hospital staff, including emergency room staff, to recognize and offer better quality care for persons with dementia.
- Identify patient advocates and case managers (including discharge planners) to ease transitions within and between hospitals, nursing homes and community based care.
- Create a coordinated alert system to more quickly locate individuals with dementia who have wandered from their residence.
- Educate architects and engineers about the impact of architecture and engineering on the design, color, texture, lighting, air change ratio, and sound on the safety, security, and management of persons with dementia through pre-service and in-service training.
- Educate caregivers on the importance of home modifications to prevent injury to individuals with dementia.

F. Gaps in Community Support Services

There are a number of community services that have been shown to be of benefit to patients and caregivers. However, it was clear through the community forums and Council discussions that these vital community support services are not uniformly available across the state, and gaps remain in providing essential support services to maintain AD patients in the community.

Issues

- Families report insufficient transportation to medical appointments, food shopping, and senior center services for individuals with dementia and their caregivers.
- Families report that some AD services are not universally available, affordable or “dementia capable,” or do not meet the needs of working caregivers.

- There are limitations in the availability of respite services provided to caregivers due to lack of respite workers or cost.
- Some persons with dementia have no caregivers, creating difficulty for the patient and community service agencies.
- Families report challenges getting 24-hour companion care for persons with dementia.

Promising Practices

- Adult social or medical day care models hold promise, especially for people in the early stages of AD. These models can provide an appropriate level of supervision and stimulation for the patient and needed respite for caregivers who need to remain in the workforce or tend to other responsibilities.

Proposed Recommendations

- Improve access to community services, such as respite, social and medical model adult day care, and support groups through more outreach and program expansion.
- Investigate feasibility of community health worker program to specialize in working with older adults with chronic diseases including dementia and common co-morbidities (diabetes, cardio-vascular disease, arthritis and depression).
- Develop innovative models to address workforce shortages, including recruitment and retention strategies, through education and training programs.
- Gradually expand ACSPs that provide multiple support and training activities until they are available statewide over the next three years.
- Increase availability of non-medical service providers, such as companions, to assist with activities of daily living through community and religious groups.

G. Continuum of Care Options

Families and providers alike pointed to the uneven availability of different levels of care that are needed at progressive stages of AD from community to community.

Issues

- Caregivers most often prefer that people with dementia remain in community settings as long as possible.
- Families report that housing choices, such as assisted living facilities, are often limited due to income or availability.

- Families report that hospice eligibility guidelines are sometimes not well understood, which can restrict dementia patients from this service.
- Adult day services may not provide care for individuals with progressive symptoms.
- There is often a lack of home visiting doctors and/or nurse practitioners.

Promising Practices

- There has been the incorporation of recommended preventive health services in primary care for both individuals with AD and caregivers (e.g. cancer screening, flu vaccine), along with encouragement of physical activity, better nutrition, and avoidance of tobacco.
- The Alzheimer’s Association Guideline for Disease Management calls for use of adaptive devices, renovations, and technology at congregate sites such as nursing homes, senior centers, and adult day care programs.

Proposed Recommendations

- Promote program opportunities that increase physical activity and good nutrition resulting in better overall health to reduce premature entry into nursing home care.
- Work with hospice to promote a model of care for late stage dementia patients who do not meet the current hospice criteria for terminal illness of six months or less.
- Promote service models that integrate and coordinate health and social services to help people with dementia remain safely in community settings as long as appropriate.
- Promote increased awareness of the availability of hospice and palliative care for AD patients through all state programs.
- Train formal and informal caregivers to appropriately manage medications to improve quality of life and facilitate avoidance of nursing home placement.

H. Public Education/Awareness of Dementia

Council members were clear that one of the greatest challenges is debunking myths and demystifying AD. The immediate need to provide accurate, up-to-date information and outreach to the public and healthcare professionals was identified at every meeting and community forum.

Issues

- There is a myth that the characteristic memory loss found in dementia is a normal part of aging.

- The signs and symptoms of dementia are often unclear to the general public and the early stages of dementia may go unrecognized and untreated.
- There is a perceived stigma among individuals with dementia, caregivers, the general public, employers, and healthcare providers related to a dementia diagnosis.
- There is a need to promote awareness of the risk factors associated with the disease, both to the individual with dementia and the caregiver.
- The benefits and results of early detection related to treatment and caregiver support need to be emphasized to the public.
- The public, including young people, healthcare workers, law enforcement, first responders, should be educated about the existence of the disease and sensitized to the behaviors associated with it.

Promising Practices

- “The Alzheimer’s Project”, a collaborative effort of Home Box Office (HBO) Films, the Alzheimer’s Association, the National Institute on Aging and others, provides new and up-to-date multi-media resources for various populations to learn about dementia.
- There are encouraging training opportunities, such as that given by the ADAC based at the State University of New York Plattsburgh, which offers an option to nursing students to be trained in dementia and its related conditions.
- The Alzheimer's Association, area agencies on aging programs, ACSPs, and ADACs all have demonstrated strategies for educating the public and specific groups.

Proposed Recommendations

- Utilize “The Alzheimer’s Project” as a comprehensive multi-media approach to raise awareness among the public, healthcare providers, and caregivers about dementia and to provide direction on available services.
- Link multi-media educational tools (e.g., “The Alzheimer’s Project”) across state agencies so that people seeking information on any relevant state agency website have access to current information.
- Expand pre-service and in-service training opportunities for first responders, including police, emergency medical technicians and firefighters, as well as court officials and others in the community to assure sensitive, appropriate interactions with those who may have dementia and their caregivers.

- Integrate developmental education, including a geriatric component, in the elementary through secondary curricula to increase the level of awareness of normal aging and AD in young people.

I. Healthcare System Issues

This section is divided into two parts because of the large number of concerns related to healthcare systems for AD patients and caregivers.

1. Interaction Between Caregiver and the Healthcare System

Because of the nature of AD, communication between caregivers and healthcare providers is essential for the safety and well-being of AD patients. Obstacles to this communication negatively impact all involved and potentially increase the costs of care.

Issues

- Advocacy by caregivers helps ensure that individuals with dementia receive better diagnosis and appropriate treatment.
- Caregivers are an important source of information about the dementia patient's status for healthcare providers when diagnosing and treating this disease, but are often not part of the patient/physician interaction.
- Misunderstood privacy laws often prohibit the caregiver from participating in medical appointments.
- Caregivers often lack understanding of health systems and legal avenues for planning or problem resolution.

Promising Practices

- "The Alzheimer's Project" (www.hbo.com/alzheimers) has numerous caregiver resources and links to others.
- The Alzheimer's Association's instructional booklet and training program, "Coach Broyles Playbook for Alzheimer's Caregivers," offers supportive advice and empowers caregivers and dementia patients who are dealing with the healthcare system.
- The SOFA website (www.aging.ny.gov) offers practical tools and ideas for caregivers and links to other tool kits. These provide practical tools and ideas for caregivers to deal with the daily challenges they face.
- AARP's website tools

http://assets.aarp.org/external_sites/caregiving/planahead/index.html provides information and checklists for consumers to use when interacting with healthcare system providers.

- United Hospital Fund's new tool at <http://www.nextstepincare.org> provides consumers with valuable information to plan the safe and smooth transition for patients as they move from one care setting to another.

Proposed Recommendations

- Educate caregivers, persons with dementia, and providers about state and federal privacy and confidentiality laws and the advisability of consulting an attorney to plan for the authorization of confidential communications with providers.
- Educate caregivers and providers about resources to assist with property and financial concerns.
- Offer information for caregivers on how to keep records and present information to medical providers.
- Collaborate with the New York State Family Caregiver Council, overseen by SOFA, to develop future recommendations related to healthcare systems issues for persons with dementia and their families.

2. Health Insurance, Medicaid and Medicare Coverage and Reimbursement Issues

Families reported that the coverage and reimbursement issues they dealt with in relation to AD were the most complicated and confusing of any they had ever seen. This complexity creates another challenge to the public cost of maintaining the system.

Issues

- Loss of employment can lead to loss of health insurance for caregivers and dementia patients.
- Services covered as medical for other diseases are often seen as “custodial” for dementia and are therefore not reimbursable by health insurance.
- Medicaid reimburses for medical model day care, while Medicare and private insurance companies may not.
- Even though New York State provides a 20 percent tax credit for premiums, long term care insurance remains underutilized, is unaffordable for many, is inaccessible to those unable to pass strict underwriting by insurers, and often lacks coverage for essential supervision and informal care.

Promising Practices

- Certain costs related to the care of a person with AD may be tax-deductible and caregiver planning assists in addressing the financial challenges of caregiving (see http://www.alz.org/living_with_alzheimers_financial_matters.asp).

Proposed Recommendations

- Expand access to legal and financial information through links on state agency websites.
- Enhance and expand access to adult day care through state programs. Reimbursement for adult day care by various payment sources was frequently mentioned as a strategy to allow people with AD to reside in the community longer.

J. Research

The need for more research about AD and utilizing the lessons learned through research to better meet the needs of AD patients and caregivers was discussed at several forums and in Council meetings.

Issues

- There is often a delay in putting lessons learned from research into practice.
- There is a need for pharmaceutical research to develop medication to better deal with behavioral problems and symptoms.
- Research on non-pharmacologic treatments has been limited.
- There is a lack of awareness of clinical trials among dementia patients and their caregivers. Clinical trials can offer benefits to people with AD and their caregivers that they may not be able to access otherwise .

Promising Practices

- The Synthesis Project, sponsored by the Robert Wood Johnson Foundation, integrates research findings on long-standing health policy questions and addresses the needs of policy makers for concise, strategy-focused information. This problem-solving strategy helps to accelerate the review and decision-making process for public policy makers, potentially including research direction at the National Institutes of Health.

Proposed Recommendations

- Promote research related to strategies to improve patient behavior (i.e., non-traditional therapies, psychosocial interventions, and non-pharmacological treatments).
- Promote collaboration between state research institutes and academia to accelerate drug discovery and clinical trials to validate innovative drug treatments for the behavioral symptoms of dementia that impede patient management.
- Increase awareness and benefits of clinical trials.
- Develop strategies for translating research findings into community practice.
- Collect and evaluate cognitive and behavioral outcomes from participation in dementia adult day programs.
- Consider applying for future federal funding when appropriate.

K. Cultural Competency

The breadth of diversity in New York State creates some unique challenges related to AD. In addition to barriers posed by language differences, attitudes about aging, memory, and healthcare, the role of caregivers vary considerably by cultural group. These cultural differences need to be recognized in treating AD and providing support to caregivers.

Issues

- Each culture views dementia from a culturally-specific perspective which impacts diagnosis, treatment, and caregiving.
- The role of caregiving has culturally-assigned values and prescribed behaviors.
- Language and cultural barriers can impede access to home health aides, support services, and medical treatment.
- Undocumented immigrants experience limited access to care.

Promising Practices

- Nazareth Regional High School (Brooklyn) trains volunteer high school students who are matched culturally and linguistically with dementia patients in all stages of the disease to provide recreational activities.
- The New York City Department for the Aging offers personal care aide training in Spanish, English, and Chinese.
- Bilingual Alzheimer's Association social work staff in NYC educates providers and increases sensitivity to Latino clients with dementia.
- The Alzheimer's Association's 24/7 helpline at http://www.alz.org/we_can_help_24_7_helpline.asp serves people with memory loss, caregivers, healthcare professionals, and the public and has access to a translation service that features over 140 languages and dialects.

Proposed Recommendations

- Conduct an inventory of existing culturally-appropriate strategies and educational programs that address culture-specific beliefs and approaches to dementia within state agencies. DOH should post this information on its website and in other appropriate places.
- Incorporate specific needs of minority populations with dementia into existing training programs for social service and healthcare providers.
- Increase pool of culturally appropriate social service and healthcare providers and home health aides using evidence-based training programs.

- Encourage professional education programs in all health professions to include a course in cultural competency within the required curricula.

L. Special Populations

This topic is divided into four distinct subsections pertaining to: (1) early stage patients, who have typical dementia in the earliest stages; (2) early onset patients, who experience symptoms at significantly earlier ages, sometimes as early as the 30s and 40s, which creates unique issues (child care, etc); (3) dementia patients with behavioral symptoms whose behavioral symptoms may interfere with their safety or that of their caregivers, or require decisions about placement or treatment that are unnecessary in other cases; and (4) individuals with intellectual or developmental disabilities, who face special challenges and risks associated with AD and may require special strategies to address these challenges.

1. Early Stage Patients (people with typical dementia in the earliest stages)

Issues

- Timely/early detection and diagnosis are essential to allow for medical and social support, legal and financial planning for individuals, caregivers, and family, and to permit early intervention.
- Services for early stage individuals are not always available or appropriate to meet the unique needs of this population.
- Information about clinical trials is often not offered to individuals in the early stage of the disease.
- Early detection is complicated by family perception of dementia vs. “normal aging.”

Promising Practices

- The Alzheimer’s Association and some other groups provide opportunities for workshops, education, and support directed at early stage patients and their caregivers.
- “Meet Me at MoMA” (Museum of Modern Art in New York City) offers weekly opportunities for early stage AD patients and their caregivers to tour the art galleries and enjoy a social outing, during a time when the museum is closed to the general public.

Proposed Recommendations

- Design programs specifically directed to individuals in the early stages of AD which help them to continue as productive members of society.

- Request state agencies to post on their websites current, accurate, culturally-aware information for healthcare professionals, including physicians, nurse practitioners, psychologists and social workers, to detect and diagnose dementia in its earliest stages.
- Raise public awareness, especially for family members of those at risk, about the earliest symptoms of dementia and the difference between dementia and normal aging through announcements to the press, promotion of media tools (e.g. “The Alzheimer’s Project”), and links on state agency websites.
- Advise that individuals with a strong family history of AD should be observed by healthcare providers for evidence of mild cognitive impairment, which may be an indicator for the development of AD.

2. Early Onset Patients *(about 3 percent of patients have a type of dementia that strikes significantly earlier in life)*

Issues

- Early onset dementia often affects persons in their working years (as young as the 30s and 40s).
- Loss of employment to those younger patients leads to a loss of health insurance and, because of the diagnosis, difficulty finding affordable replacement insurance.
- Self-awareness of debilitation can lead to a loss of self-esteem and depression.
- Those with early onset dementia have difficulty finding age-appropriate programming.
- Individuals with early onset dementia may be reluctant to self-identify for fear of losing employment.
- Early onset dementia leads to familial concerns related to genetic risk factors.

Promising Practices

- The Sid Jacobs Recreation Center in East Hills, Long Island, provides programming for those in their 30s, 40s, and 50s with early onset dementia. The center offers recreation, aerobics, support groups, and discussion and a “Let’s Do Lunch” program with music, art, exercise, and socialization.

Proposed Recommendations

- Because of the unique needs of this population (and their caregivers who may also be responsible for younger children), programming that is intellectually and cognitively

stimulating, including a physical activity component should be considered in areas of the state where there is a critical mass of patients with this condition.

3. Dementia Patients with Behavioral Issues

Issues

- Poor identification of behavioral issues related to the disease can lead to poor care and/or premature or inappropriate nursing home placement.
- Lack of understanding among caregivers and healthcare providers can escalate problematic behavior.
- Persons with dementia-related behavioral issues may be overmedicated or incorrectly medicated.
- Behavioral issues may jeopardize the safety of the caregiver and complicate admission or retention in programs.

Promising Practices

- The Alzheimer's Association and other groups educate providers and caregivers to manage the behavioral changes caused by dementia.
- Flushing Hospital offers mental health services for older adults in a primary care setting, reducing stigma and improving ease of access.
- The New York State Veterans' Home at Oxford developed a therapeutic biking program for the treatment of depressed nursing home residents with dementia that results in reduced dependence on pharmaceuticals.

Proposed Recommendations

- Train caregivers and providers so they are better equipped to handle behavioral problems, using both proper pharmaceutical and psycho-social interventions.
- Increase integration of the mental and physical health systems using models like the one implemented by Flushing Hospital.
- Encourage dementia-capable adult day programs to be physically designed and programmatically structured to decrease behavioral problems through information sharing and website dissemination.

4. People with Intellectual and Developmental Disabilities

Issues

- Adults with Down syndrome are at a dramatically increased risk of developing AD, beginning in their mid- to late 40s.
- The population of individuals with intellectual and developmental disabilities not due to Down syndrome appear to develop dementia at age-specific rates similar to the rest of the population. However, the growth of the number of adults with Downs syndrome, their lifelong impairments, and a virtually invisible but substantial sub-population of these individuals who are relatively mildly affected, all contribute to concerns associated with AD.
- It is difficult to diagnose dementia in this population, especially during its early stages due to the symptoms already present in these individuals.

Promising Practices

- Access to care and training through professionals with dual experience in developmental disabilities and dementia is important. Recent pilot projects in Rochester and the Capital Region clearly showed that providers with dual experience and knowledge provided advantages to patients and caregivers.

Proposed Recommendations

- Share information regarding existing screening and diagnostic tools through state agency websites.
- Promote research related to behavioral strategies to reduce maladaptive behavior.

Section III. Conclusions and Next Steps

As a large number of New Yorkers reach the ages when dementia is most common, state agencies and partner groups must continue to improve collaboration to address the needs of people with AD and their caregivers. This first report of the Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias is just a beginning. The issues and recommendations outlined in this report set the stage for the Council to continue gathering information that will inform the development of a comprehensive strategic plan to address AD and other dementias. The Council will encourage state agency members to review this report and incorporate the recommendations into current programming, as well as seek expert advice on refining these recommendations for the future.

One focal point of the Council as it begins to develop a strategic plan will be on the maintenance of brain health and function and the prevention or delay of AD and other dementias. The growing body of research about AD and other dementias has identified a list of risk factors including diabetes, cardiovascular disease, hypertension, glucose intolerance, obesity, and other conditions that increase risk for dementia. These conditions can often be better controlled in those already diagnosed and prevented in those who are at risk, in many cases reducing the risk for or postponing the onset of dementia. Additionally, as Dr. Ralph Nixon of the Nathan Kline institute shared with the Council, there is research “in the pipeline” that may lead to entirely new approaches to both the treatment and prevention of AD.

The Council will also continue to address the need for increasing the early identification of mild cognitive impairment and dementia. This is a substantial goal that will take nothing less than a paradigm shift in cultural and professional attitudes. However, there are both human and economic reasons to pursue this goal, and reason to be hopeful that this is achievable. Early identification is essential to receive the maximum benefit from treatment options and to allow planning time for family members. The available treatments for AD have been shown to be most effective when utilized as early as possible in the progression of the disease, and families report that having as much time as possible to plan for the patient's care and for the life changes that result from providing care to an AD patient (e.g., balancing caregiving with jobs, housing, education, children) relieves significant stress. Families also report that a diagnosis of AD causes sadness, but it is also a relief to know what is causing a loved one to act differently, and what they can reasonably expect.

The economic reasons to increase early diagnosis and treatment were best stated in the recent study by researchers at the University of Wisconsin using large scale cost-benefit analysis, “[T]he early diagnosis and treatment of AD are not only socially desirable in terms of increasing economic efficiency, but also fiscally attractive from both state and federal perspectives”.

Family caregivers play an essential role in the system. These caregivers report that they are doing what they want and choose to do, that they want their loved ones to remain at home in the community as long as possible, but the challenges are daunting. The state has a direct interest in caregiver support. Dr. Mittleman's research on this subject shows that

with small investments in caregiver support services, AD patients are able to remain in their homes longer. Incorporating these successful strategies across state agencies and thoughtful expansion when fiscally viable can blunt the impact of the increasing numbers of people with AD.

All of these goals require a greater understanding of AD, mild cognitive impairment, the earliest symptoms of dementia, and the difference between dementia and normal aging. The Council, through the state agencies and outside partners, must focus on common messages to providers and the public so that New Yorkers have the most current information and tools necessary to encourage early detection of AD. This can be accomplished through collaborative efforts that utilize and build upon existing program communications, announcements to the press, promotion of media tools (e.g., “The Alzheimer’s Project”), and links on state agency websites.

The Council will address these and other important AD-related issues in more detail in future meetings and annual reports.

Resources:

New York State Department of Health

<http://www.health.state.ny.us/diseases/conditions/dementia/>

Alzheimer's Association

<http://www.alz.org/>

CDC Healthy Brain Initiative

<http://www.cdc.gov/aging/healthybrain/index.htm>

Lane, J. (2005). Down Syndrome and Alzheimer Dementia-Some Common Medical Issues and Implications for Palliative and End-of-Life Care. *The Frontline of Learning Disability*, 22-23.

New York State Education Department and Office of the Professions www.nysed.gov;

www.op.nysed.gov

New York State Office for the Aging <http://www.aging.ny.gov/>

Project: Caregivers Connect http://www.alz.org/rochesterny/in_my_community_12119.asp

The Alzheimer's Disease Education and Referral (ADEAR) Center

<http://www.nia.nih.gov/Alzheimers/>

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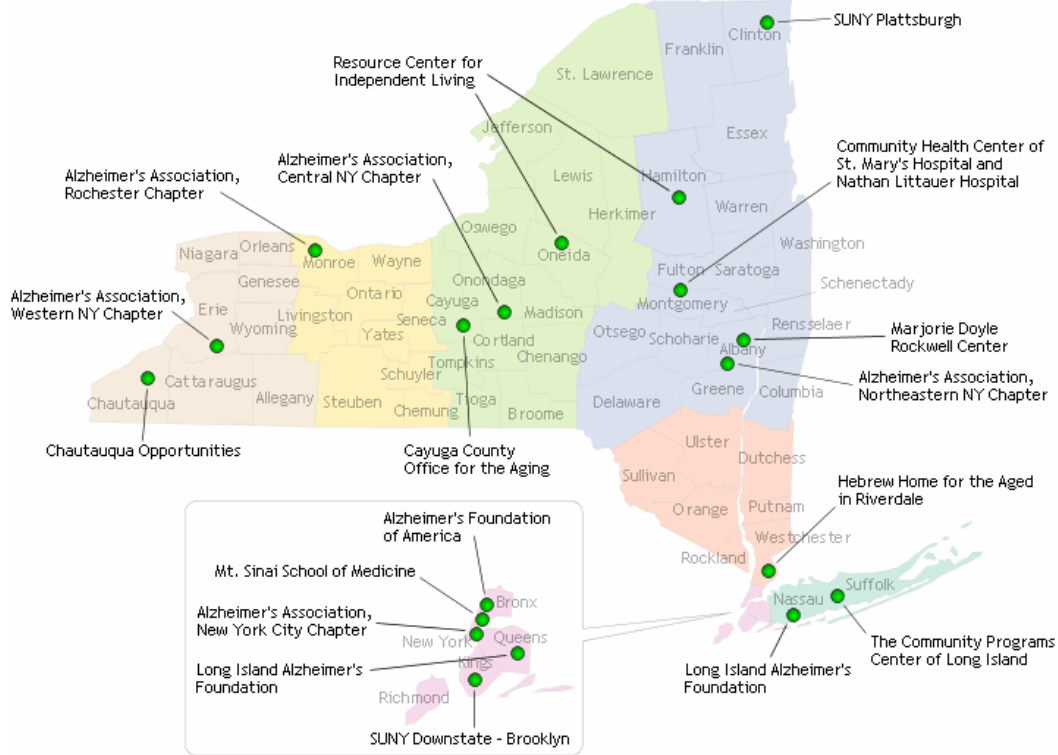
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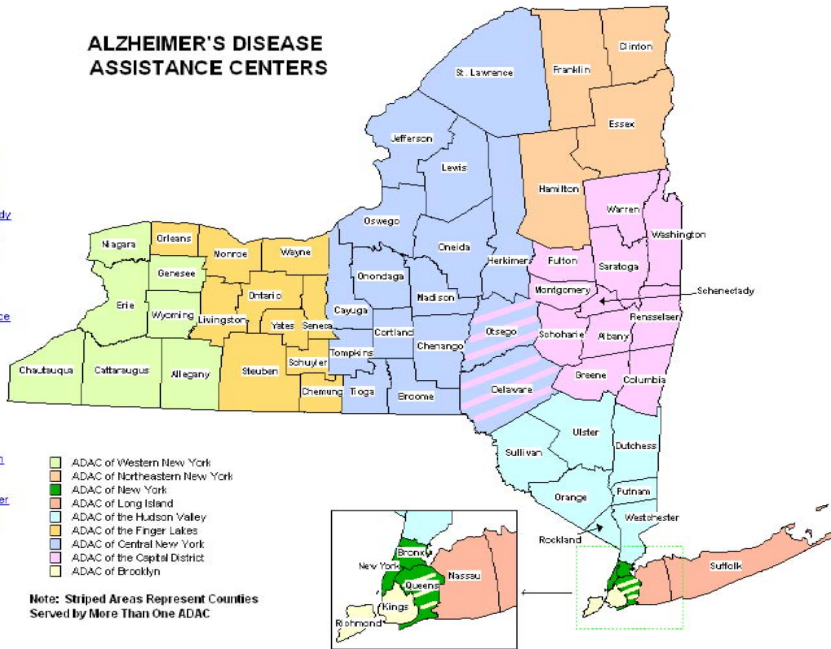
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Alzheimer's Disease Community Service Programs



ALZHEIMER'S DISEASE ASSISTANCE CENTERS

- Albany: Herkimer, Richmond
- Allegany: Jefferson, Rockland
- Bronx: Kings, Saratoga
- Broome: Lewis, Schenectady
- Cattaraugus: Livingston, Schoharie
- Cayuga: Madison, Schuyler
- Chautauqua: Monroe, Seneca
- Chemung: Montgomery, Steuben
- Chenango: Nassau, St. Lawrence
- Clinton: New York, Suffolk
- Columbia: Niagara, Sullivan
- Cortland: Oneida, Tioga
- Delaware: Onondaga, Tompkins
- Dutchess: Ontario, Ulster
- Erie: Orange, Warren
- Essex: Orleans, Washington
- Franklin: Oswego, Yates
- Fulton: Otsego, Westchester
- Genesee: Putnam, Wyoming
- Greene: Queens, Yates
- Hamilton: Rensselaer



Public Health Law Section 2004a

§ 2004-a. Coordinating Council for services related to Alzheimer's disease and other dementia. 1. There is hereby created in the department of health a coordinating council for services related to Alzheimer's disease and other dementia, to facilitate interagency planning and policy, review specific agency initiatives for their impact on services related to the care of persons with dementia and their families, and provide a continuing forum for concerns and discussion related to the formulation of a comprehensive state policy relating to Alzheimer's disease and services for persons with incurable dementia.

2. The council shall be comprised of twenty-one members as follows: the commissioner of health, the director of the state office for the aging, the commissioner of children and family services, the commissioner of education, the commissioner of mental health and the commissioner of mental retardation and developmental disabilities who shall serve ex officio and who may designate representatives to act on their behalf. The governor shall appoint seven other members with expertise in Alzheimer's disease, other dementia or elder care issues, at least two of whom shall represent not-for-profit corporations whose primary purpose is to provide access to experts in the care of persons with Alzheimer's disease and related dementia, that are part of a statewide network of not-for-profit corporations established specifically to respond at the local and regional level to the needs of this population and that provide family intervention services related to Alzheimer's disease in order to postpone or prevent nursing home placements of individuals with Alzheimer's disease or other dementia. Eight members shall be appointed by the governor on the recommendation of the legislative leaders as follows: the temporary president of the senate and the speaker of the assembly shall each recommend three members to the council. One of the three members recommended by the temporary president and one of the three members recommended by the speaker shall be a clinical or research expert in the field of dementia and one of the three members appointed by each shall be a family member or caregiver of a person suffering from Alzheimer's disease or other dementia. One member shall be appointed on the recommendation of the minority leader of the senate and one member shall be appointed on the recommendation of the minority leader of the assembly. The commissioner of health and the director of the office for the aging shall serve, ex officio, as co-chairs of the council. Administrative duties shall be the responsibility of the department. The members of the council shall receive no compensation for their services.

3. Within one year after the effective date of this section, the council shall establish community forums to gain input from consumers, providers, key researchers in the field and other interested parties to provide input and direction on developing a New York state plan for the identification and treatment of Alzheimer's disease in the community. A community forum shall be established in each of the following regions of the state: Long Island, New York city, Northern Metropolitan New York, Northeastern New York, Utica area, Central New York, Rochester area and Western New York. Such state plan shall include but not be limited to identifying best practices in working with persons with Alzheimer's disease, best interventions for

caregivers to help reduce caregiver burnout, best approaches to training doctors, nurses and other medical and non-medical professionals and paraprofessionals to identify Alzheimer's disease, a community assessment of strengths and gaps in community support services, ways in which to coordinate services among various systems, different financing approaches to pay for community support services and any other recommendations.

4. (a) The council shall meet quarterly or more frequently if its business shall require. The community forums in the first year of implementation count as a formal meeting of the council. The members of the council shall receive no compensation but shall be reimbursed for travel and other expenses actually and necessarily incurred in the performance of their duties. The council shall provide reports to the governor and the legislature on or before June thirtieth, two thousand nine and by June thirtieth of every other year thereafter. Such reports shall include recommendations for state policy relating to dementia and a review of services initiated and coordinated among public and private agencies to meet the needs of persons with Alzheimer's disease and other dementia and their families.

(b) The council shall additionally review and report upon the use of clinically recognized, scientifically based, cognitive impairment screening tools used to identify signs of and individuals at-risk for cognitive impairment, including Alzheimer's disease or other dementias, in all settings of the health continuum. Such tools shall include but not be limited to tools approved and/or recognized by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), Agency for Healthcare Research and Quality (AHRQ), the Centers for Medicare and Medicaid Services (CMS), and others as determined by the council which are used by health care providers, across all settings of the health continuum. The council shall also review and report on best practices of providers concerning early identification of at-risk individuals and referral practices, the range of interventions and services available for the cognitively impaired, and shall report its assessment of the need and presence of such tools and practices in each sector of the health continuum. The council shall further include in its reports any findings concerning potential gaps of identification and intervention for the cognitively impaired, the need for public education about cognitive impairment, and recommendations to address that education need.

5. The department shall serve as the focal point to develop comprehensive coordinated responses of the various state agencies with regard to Alzheimer's disease and related dementia and thus help to assure timely and appropriate responses to issues and problems. The department shall collaborate with the state office for the aging on issues related to nonmedical support services for individuals with Alzheimer's disease and other dementia and their caregivers. The department shall collaborate with other appropriate state agencies to establish a simplified coordinated assessment procedure for obtaining needed services for persons with Alzheimer's disease and other dementia.

6. The department, in consultation with the council, shall utilize data and information compiled and maintained pursuant to this article to coordinate state funded research efforts to ensure the most efficient use of funds available for this purpose.

Ten Warning Signs of Alzheimer's Disease (reprinted with permission from the Alzheimer's Association; www.Alz.org)

1. Recent memory loss that affects your job skills; It's normal to occasionally forget an assignment, deadline or friend's name, but frequent forgetfulness or unexplainable confusion at home or in the workplace may signal problems.
2. Difficulty performing familiar tasks; Busy people frequently get distracted. For example, you might leave something on the stove too long or not remember to serve part of a meal. People with AD might prepare a meal and not only forget to serve it, but forget they made it.
3. Problems with language; Everyone has trouble finding the right word sometimes, but a person with AD may forget simple words or substitute inappropriate words, making his or her sentences difficult to understand.
4. Disorientation of time and place; It's normal to momentarily forget the day of the week or what you need from the store. But people with AD can become lost on their own street, not knowing where they are, how they got there or how to get home.
5. Poor or decreased judgment; Choosing not to bring a sweater or coat along on a chilly night is a common mistake. A person with AD, however, may dress inappropriately in more noticeable ways, wearing a bathrobe to the store or several blouses on a hot day.
6. Problems with abstract thinking; Balancing a checkbook can be challenging for many people, but for someone with AD, recognizing numbers or performing basic calculations may be impossible.
7. Misplacing things; Everyone temporarily misplaces a wallet or keys from time to time. A person with AD may put these and other items in inappropriate places, such as an iron in the freezer, or a wristwatch in the sugar bowl, then not recall how they got there.
8. Changes in mood or behavior; Everyone experiences a broad range of emotions, its part of being human. People with AD tend to exhibit more rapid mood swings for no apparent reason.
9. Changes in personality; People's personalities may change somewhat as they age. But a person with AD can change dramatically, either suddenly or over a period of time. Someone who is generally easy going may become angry, suspicious or fearful.
10. Loss of initiative; It is normal to tire of housework, business activities, or social obligations, but most people retain or eventually regain their interest. The person with AD may remain disinterested and uninvolved in many or all of her usual pursuits.