

2013 Report

of the

New York State Coordinating Council

For Services Related to Alzheimers Disease and

Other Dementias

to

Governor Andrew M. Cuomo

and the

New York State Legislature

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Section I. Background

NYS Coordinating Council for Services Related to Alzheimers Disease & Other Dementias

The New York State Coordinating Council for Services Related to Alzheimers 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).

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 Alzheimers disease. (See Attachment A 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 Alzheimers disease and other dementias and their families particularly to make recommendations on the use of cognitive screening tools.

This is the third report by the New York State Coordinating Council for Services Related to Alzheimers Disease and Other Dementias. The Council has gathered expert advice from Council members and others in the field to inform the development of this report.

(Throughout this document the term "AD" is used to refer to Alzheimers disease and other related dementias.)

Council Activity

2012-2013 Council meeting dates:

May 3rd, 2012 – The Council met to discuss the release of the 2011 Report of the Coordinating Council for Services Related to Alzheimers Disease and Other Dementias. The Council made recommendations for topics to be included in the 2013 report. State agency members reported on related activity in their agency.

August 14th, 2012 – The Council members discussed new research findings and clinical trials and also discussed the 2nd National Alzheimers Plan. State agency members reported on related activity in their agency.

December 7th, 2012 – The Council members met to discuss priority areas of the 2013 Council report, and also discussed the implications of super storm Sandy and the need for emergency preparedness. State agency members reported on related activity in their agency.

March 15th, 2013 – The Council met to discuss the use of cognitive screening tools and review a drafted item for the 2013 Council report. State agency members reported on related activity in their agency.

June 10th, 2013 – The Council discussed issues related to mortality data, cognitive screening, early detection, and dissemination of information about AD. State agency members reported on related activity in their agency.

September 9th, 2013 – The Council met to discuss this report in draft form.

Alzheimers Disease & Other Dementias

Dementia is a term that refers to the loss of cognitive function including memory, thinking, language, judgment, and behavior. Although there are several types, 50-80% of individuals with dementia have Alzheimers disease, making it the most common form. Alzheimers disease is a fatal, degenerative condition that most commonly occurs in older adults and is characterized by specific brain abnormalities including amyloid plaques and neurofibrillary tangles. Amyloid plaques and neurofibrillary tangles cause a disruption in neuronal communication in the brain, which ultimately causes cell death. There is currently no cure for Alzheimers disease.

Alzheimers disease occurs in a progressive sequence of stages. The Alzheimers Association (2013b) refers to seven stages of AD: no impairment, very mild decline, mild decline, moderate decline, moderately severe decline, severe decline, and very severe decline. These stages are more commonly referred to as early-stage, middle-stage, and late/final-stage. According to new diagnostic guidelines for AD published by the National Institute on Aging (NIA) in 2011, AD begins before the emergence of observable symptoms. The NIA identifies three stages of AD that occur on a spectrum: preclinical/presymptomatic, mild cognitive impairment (MCI), and final stage Alzheimers. More information on the 2011 diagnostic guidelines can be viewed at [http://www.alz.org/research/diagnostic_criteria/].

Symptoms of AD get progressively worse over time. Individuals in the early stages of AD may have trouble remembering recent information including places, names, events, and some

personal information. Individuals in the moderate stages of AD often develop challenging behaviors, such as wandering or personality changes that result in aggression or agitation. There is often a decrease in language abilities, increase in confusion and memory loss, unstable mood, and decreased ability to complete daily tasks. The late stages of AD are extremely debilitating for the individual and devastating for the family. Individuals in the late stages will eventually require total care and dependence on caregivers. The disease will ultimately lead to death.

The Alzheimers Association (2013b) describes ten warning signs that may strongly indicate AD as follows: memory loss that affects/disrupts daily life; challenges in planning or solving problems; difficulty completing familiar tasks at home, work, or at leisure; confusion with time or place; trouble understanding visual images and spatial relationships; new problems with words in speaking or writing; misplacing things and losing the ability to retrace steps; decreased or poor judgment; withdrawal from work or social activities; and changes in mood or behavior.

Other types of dementia include vascular dementia, dementia with Lewy bodies, mixed dementia, Parkinson's disease, Frontotemporal dementia (FTLD), Creutzfeldt-Jakob disease, normal pressure hydrocephalus, Huntington's disease, and Wercknicke's-Korsakoff syndrome. Causes and symptoms of the various types of dementia vary, and some symptoms of dementia can be prevented or treated. Many dementias are caused by a mixed dementia, with elements of Alzheimers, vascular and Lewy Body pathology present.

Prevalence & Mortality

The United States currently has an estimated 5.2 million Americans living with AD. Less than half of these individuals are even aware that they have the disease. Ninety-six percent of Americans with AD are over the age of 65. The number of Americans age 65 and over with AD is expected to triple by the year 2050 as the population of elderly Americans from the baby boom generation ages (Alzheimers Association, 2013a). Individuals over 90 years old are referred to as the "oldest old", and these individuals have extremely high rates of AD (NIA, 2012). Americans over the age of 65 are not the only individuals at risk for AD. There are a number of individuals who are diagnosed with AD in their 30s-50s, which is known as "younger/early onset." Early onset AD is rare, but still affects roughly 200,000 Americans. The vast number of Americans with AD makes this fatal disease the 5th leading cause of death among individuals 65 and older in the United States and the 6th leading cause of death overall (CDC, 2010). According to the latest figures from the Alzheimers Association (2013a), care for individuals with AD costs \$203 billion nationally, including an estimated \$107 billion covered by Medicare and \$35 billion covered by Medicaid. This report can be viewed at [http://www.alz.org/downloads/facts_figures_2013.pdf]. New data suggest that when factoring in the cost of informal care, dementia cost the nation \$215 billion in 2010 (Hurd, Martorell, Delavande, Mullen, & Langa, 2013).

The number of women in the United States with AD is significantly higher than men, with women making up two-thirds of the total number of Americans with AD. Although the number of women with AD is higher than the number of men, most research has shown that women are no more likely to develop AD and that this difference may be due to a longer life expectancy for women (Alzheimers Association, 2013a). Other researchers speculate that this difference could be due partly to women having higher rates of depression/anxiety and other health problems than men (NIA, 2012).

There are differences in the development of AD among racial and ethnic groups. African Americans are two times more likely than whites to have AD. Hispanics are one and a half times more likely than whites to have AD. Research has shown that these differences are likely due to the higher number of individuals in these groups who have certain health conditions associated with AD, such as high blood pressure and diabetes. Socioeconomic status and education levels also might play a role in the development of the disease, which could partly explain racial/ethnic differences (Alzheimers Association, 2013a). Recent research has demonstrated that Hispanics may have earlier onset than whites, and African Americans may have an older onset than whites (National Institute on Aging, 2012). This research also showed that upon initial diagnosis, African Americans and Hispanics had higher levels of cognitive impairment, but more research is needed to determine the cause, for example, differing cultural views regarding medical care and cognitive decline.

Individuals with Down syndrome are at an increased risk for developing AD, particularly early onset Alzheimers, due to the accelerated aging process experienced by this population. Individuals with Down syndrome have an extra copy of the 21st chromosome, which may explain the accelerating aging in this population and the increased risk of developing AD because many genes associated with aging and AD are located on this chromosome. Individuals with Down syndrome have a 30% chance of developing AD in their 50s and a 50% chance in their 60s. Although individuals with Down syndrome develop the pathology of AD, not all exhibit the typical symptoms and decline associated with the disease. Individuals with Down syndrome are also more likely to have additional co-occurring conditions such as sensory loss, hypothyroidism, obstructive sleep apnea, osteoarthritis, atlantoaxial instability, osteoporosis, and celiac disease. The presence of multiple co-occurring conditions makes diagnosis and treatment for this population difficult because many symptoms of dementia are present in other conditions (Alzheimers Association, 2013a; National Down Syndrome Society, 2013). More information on the connection of Down syndrome and AD can be found at [\[http://www.ndss.org/Resources/Aging-Matters/Alzheimers-Disease/Anesthesia-Down-Syndrome1/\]](http://www.ndss.org/Resources/Aging-Matters/Alzheimers-Disease/Anesthesia-Down-Syndrome1/) and [\[http://aadmd.org/NTG\]](http://aadmd.org/NTG).

The U.S. Department of Health and Human Services (HHS) recognizes that the previously mentioned populations are more likely to develop AD and have created a task force to address

the needs of these specific populations. This task force has issued a report with recommendations for these populations. The report can be found at [\[http://aspe.hhs.gov/daltcp/reports/2013/AlzSpPop.pdf\]](http://aspe.hhs.gov/daltcp/reports/2013/AlzSpPop.pdf).

The Center for Disease Control (CDC) conducts a survey each year called the Behavioral Risk Factor Surveillance System (BRFSS). There are two modules related to AD: the perceived cognitive impairment module and the caregiver module. National data from perceived cognitive impairment module from the most recent BRFSS indicate that one in eight Americans over the age of 60 is experiencing confusion or memory loss. Of those who reported cognitive impairment, one in three reported functional difficulties related to their confusion or memory loss. Eighty-one percent of those with cognitive decline have not reported it to their health care providers (Alzheimers Association, 2013c). In New York, 11% of individuals aged 60 and over reported confusion or memory loss in the most recent BRFSS, and 78% of these individuals have not reported it to their health care provider. Additional BRFSS New York State data can be found at [\[http://www.alz.org/documents_custom/public-health/newyork.pdf\]](http://www.alz.org/documents_custom/public-health/newyork.pdf).

The number of individuals with AD in New York State is currently estimated at 320,000, and is expected to increase to 350,000 by 2025 (Alzheimers Association, 2013a). Prevalence and mortality rates for New York State are not an accurate representation of actual figures due to the lack of early detection/diagnosis and under-reporting on death certificates. Death certificates often list the immediate cause of death rather than indicating AD as an underlying condition. Many individuals with AD develop other conditions, such as pneumonia, as a result of the disease, and the cause of death is often listed as one of these conditions.

In 1984 the prevalence of AD in New York State was estimated to rise to 155,000 by 2010 (New York Academy of Medicine & the New York State Health Planning Commission, 1984). Current prevalence rates are more than double the predicted rates from 1984, and the actual numbers very likely even exceed these rates, demonstrating the vast underestimation of the prevalence of AD.

Identification & Diagnosis

The NIA's 2011 diagnostic guidelines are helping to encourage early detection of AD by recognizing the presymptomatic stage of the disease and by acknowledging biomarker tests as a potential way of detecting AD in the future. These tests would utilize brain imaging technology, such as magnetic resonance imaging (MRIs) and computed tomography scans (CTs) to examine blood and cerebrospinal fluid for biomarkers and mutations associated with AD. Current research is also examining the use of positron emission tomography (PET) scans and molecular imaging technology to detect AD (Alzheimers Association, 2013a).

Cognitive screening tools are used to help determine the need for further assessment for cognitive impairment or dementia. Cognitive screening tools alone do not provide enough

information for diagnosis, and a more extensive assessment and evaluation is required for diagnostic purposes. There is no one cognitive screening used universally, and over 40 screenings have been established to assess cognition and identify potential impairments (Cullen et al., 2007). Currently, there are several validated cognitive screening tools, and the Alzheimers Association, the National Institutes of Health, and the Centers for Medicaid and Medicare Services (CMS) have recommended several cognitive screening tools that could be used in primary care settings, particularly in the Medicare Annual Wellness Visit. The cognitive screening tools recommended by CMS, NIH, and Alzheimers Association have been identified as being fast and easy to implement and free to use. More information on the CMS/NIH recommendations can be found at [<http://aspe.hhs.gov/daltcp/napa/101512/Mtg6-Slides1.pdf>], and more information on the Alzheimers Association's recommendations can be found at [http://www.alz.org/professionals_and_researchers_14899.asp]. Additional cognitive screening tools can be found at [<http://www.nia.nih.gov/research/cognitive-instrument>].

Early Detection

New York State, along with the National Plan to Address Alzheimers Disease, the Alzheimers Association, and the Public Health Road Map issued by the CDC, recommends early detection of AD. Early detection is important for several reasons. Symptoms of some dementias can be treated and the overall progression of others can be slowed if detected early in the disease process. Some conditions mimic dementia and are sometimes reversible (i.e. normal pressure hydrocephalus). For research purposes, early detection is important and necessary for finding treatments and preventions before the disease has progressed too far. Individuals with AD that have been diagnosed early would have the opportunity to participate in clinical trials that could be beneficial to treating or slowing the disease early on. Individuals with AD would also have the ability to access services that require a diagnosis earlier. Another major benefit of early diagnosis for individuals with AD is the ability to plan ahead and prepare for the future while they still have mental capacity.

One example of the benefits of early detection are demonstrated in an article from the Alzheimers Association (2010) which described a study called the "Dementia Demonstration Project" conducted at the Minneapolis Veteran (VA) Medical Center. In this study, a sample of veterans 70 years old and older was screened for dementia. Those diagnosed with dementia received case management and education. The health care costs for the individuals diagnosed with dementia in this study decreased by 29% in the year following their diagnosis, demonstrating that early detection and intervention can dramatically reduce health care costs and also improve quality of care. In addition to reducing health care costs, those who were diagnosed early were able to access services early that help them and their caregivers to cope and reduce stress.

Risk Factors & Prevention

There currently is no exact known cause of AD, but researchers have discovered several risk factors associated with the disease. Age is the greatest risk factor for AD, although there are still some individuals with early onset diagnoses. Family history plays a role in AD indicating that there is a genetic component to the disease. Research has shown support for genetic involvement in individuals with early onset AD and the disease for these individuals always runs in families and is caused by a mutation in a gene inherited from a parent (NIA, 2012). There are several other genetic mutations that are involved in the onset of AD, including a mutation on the 21st chromosome (NIA, 2012).

Other risk factors involved in AD that are currently being examined are lifestyle choices and health conditions. There has been research supporting the importance of cardiovascular health because there are high rates of AD in individuals with cardiovascular problems. Risk factors for cardiovascular problems include high cholesterol, obesity, diabetes, lack of physical activity, poor diet and smoking. There has been research supporting the premise that a higher level of education and larger brain size lowers the risk for or slows the progression of AD (NIA, 2012). Some researchers believe that the role of education is less important to brain function and explain this connection by the impact of lower socioeconomic status on access to medical care. Individuals with head injury or traumatic brain injury (TBI) are at an increased risk for AD (Alzheimers Association, 2013a).

A recent study in Denmark supports that lifestyle and health factors can play a significant role in acquiring AD (Span, 2013). This study compared two generations; those born in 1915 and 1905, and found that those born in 1915 scored higher on two different cognitive tests at age 95 than the group of those born in 1905 did at age 93. The only major differences found among these two groups were better diets and living conditions, including access to health care through a national health care system, higher incomes, and better access to housing and nursing care. This study suggests that individuals that are healthier will be less likely to have some of the risk factors associated with AD, and therefore will be less likely to develop the disease. A similar study in England and Wales compared two generations of randomly selected individuals 65 and older in the same geographic areas (Kolata, 2013a). The rate of dementia in this study dropped 25% in the second generation studied. The later generation better controlled for cardiovascular risk factors and was better educated, reiterating again the influence of education and health in the development of AD.

Further research regarding these risk factors is needed. However, based on the risk factors identified at this time, there are several preventative actions that individuals can take that may potentially lower the risk of having AD. These preventive strategies include: lowering cholesterol levels; lowering high blood pressure levels; controlling diabetes; engaging in regular

physical activity; engaging in socially and intellectually stimulating activities; increasing dietary intake of healthy foods; and engaging in safe practices to avoid head injuries. Research on risk factors is ongoing and yielding positive findings that increase the hope that the disease will be understood and treatments uncovered.

Existing Treatments & Ongoing Research

Although there is no cure for AD, there are some existing treatments to help decrease or slow symptoms associated with the disease and many more are being researched. Existing treatments address the cognitive or behavioral symptoms of AD. Cholinesterase inhibitors are medications used to treat the cognitive symptoms of AD, and include Donepezil (Aricept), Rivastigmine (Exelon), and Galantamine (Razadyne). Memantine (Namenda) is another medication used to reduce symptoms. Donepezil treats symptoms associated with all stages of AD, while Rivastigmine and Galantamine only treat symptoms associated with the mild-moderate stages, and Memantine treats the moderate-severe stages (Alzheimers Association, 2013b). More information on these medications can be found at [\[http://www.nia.nih.gov/alzheimers/publication/alzheimers-disease-medications-fact-sheet\]](http://www.nia.nih.gov/alzheimers/publication/alzheimers-disease-medications-fact-sheet).

Individuals with AD and one or more additional chronic condition(s) are common, and these individuals are referred to as having multiple chronic conditions. Managing co-occurring conditions makes treatment for AD more effective, although this is often a challenge within the health care system.

There are pharmaceutical treatments and non-drug treatments available for treating some of the behavioral symptoms associated with AD. Pharmaceutical treatments include the use of anti-depressants, anxiolytics, and antipsychotics (Alzheimers Association, 2013b). Non-drug treatments include a variety of interventions that often involve support services for individuals with AD. It is important to fully assess behavioral and psychological symptoms of AD as they are often secondary symptoms or responses to unmet needs or pain (Kovach, Noonan, Schlidt & Wells, 2005; Algase, Beck, Kolanowski, Whall, Berent, Richards & Beattie, 1996). Individuals with AD are often unable to communicate their needs or express that they are in pain, so their needs are often manifested in disruptive behaviors. When pain or unmet needs are unresolved, the problem often results worsening behavioral and psychological symptoms.

The NIA's 2011-2012 Alzheimers disease progress report reviewed some of the most promising treatments under current investigation. Researchers are looking at ways to reduce the build-up of two proteins: beta-amyloid and Tau. Build-up of beta-amyloid causes a disruption in cell communication. Beta-amyloid can be reduced by inhibiting a protein involved in its build-up called gamma-secretase and decreasing levels of another protein called ApoE. Tau is a protein that causes tangles within the neurons that block the transport of nutrients through microtubules

in the cells. Treatments aimed at reducing “Tau tangles” could include the use of microtubule-stabilizing drugs. Allopregnanolone hormone treatment is also being examined to promote neurogenesis (NIA, 2011; Alzheimers Association, 2013a).

Current research focuses on the prevention of AD or treatment in the early stages, as research that has attempted to intervene in the later/clinical stages has been unsuccessful at changing the course of the disease. A unique research opportunity exists in a small village in Colombia where AD is genetically linked through several generations. Almost everyone in this community has a certain genetic mutation causing them to develop early onset AD. Examining this population and involving these individuals in clinical trials can provide a great deal of knowledge to researchers since their chances of developing AD are very high. In this study, researchers will provide a drug treatment to 300 individuals in this community with a certain genetic marker for an early-onset form of AD that affects many members of this family (Belluck, 2012).

Since many of the treatments under investigation would be most effective during the earliest stages of AD, early detection is especially important so that individuals can be involved in clinical trials and receive treatments and services in the early stages. The Food and Drug Administration has recognized the need to accelerate the research process for AD and have changed their rules for approving drugs for treatment or prevention (Kolata, 2013b). Research is critical to finding a prevention or cure for AD, and with the growing number of individuals diagnosed with AD, time is vitally important.

Role of Caregivers

Millions of Americans are providing unpaid care for individuals with AD. The Alzheimers Association (2013a) reports that caregivers’ unpaid care saved the nation \$216 billion in 2012. Caring for individuals with AD, especially in the later stages of the disease, can be emotionally and physically demanding. The National Alliance for Caregivers (NAC) and the American Association of Retired Persons (AARP) conducted a study in 2009 to examine the prevalence and characteristics of caregivers and the impact of caregiving on these individuals. In this study, sixty-one percent of caregivers believe the emotional stress of caregiving to be high/very high. Data from the caregiver module in the BRFSS indicate that AD caregivers are 3.5 times more likely to have difficulties with their own health (Alzheimers Association, 2013e). The stress that caregivers endure can lead to several negative outcomes for their own well-being, the workforce, and the health care system. In 2012 there were over 1 million caregivers in New York State, and 15.4 million caregivers nationally (Alzheimers Association, 2013a). Caregivers for individuals with AD spend on average 23 hours per week on caregiving duties (Alzheimers Association, 2013e).

Caregivers in the direct care workforce in nursing homes, home care, or other residential facilities experience high levels of stress, leading to high turnover rates in this field. One study examined attitudes of direct care workers in dementia settings and found that stress levels are particularly high in facilities with specialized dementia units (Zimmerman et al., 2005). Stress levels were also higher among male workers, younger workers, and staff working less than 2 years. An important finding of this study is that workers who had more dementia training were more likely to have a person-centered attitude and report more job satisfaction.

Current Projects – National and New York State

The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships

The Alzheimers Association and Centers for Disease Control and Prevention (CDC) have created a Public Health Road Map, as part of the Healthy Brain Initiative, outlining recommendations related to cognitive decline and AD for local and state public health agencies and their partners. The two main objectives of the Road Map are to reduce the number of individuals who have undiagnosed AD and to reduce the number of avoidable hospitalizations due to AD. The newest version of the Public Health Road Map for State and National Partnerships includes recommendations in four major areas for action: monitoring and evaluating; educating and empowering the nation; developing policy and mobilizing partnerships; and assuring a competent workforce. The Road Map can be found at [<http://www.alz.org/publichealth/2013-report/index.html>].

National Plan to Address Alzheimers Disease

The National Alzheimers Project Act (NAPA) was signed into law in early 2011 by President Barack Obama. NAPA requires the Secretary of the U.S. Department of Health and Human Services (HHS) to create and maintain a national plan to address Alzheimers disease. The first national plan was released in May 2012 and was updated in June 2013. The National Alzheimers Project also coordinates federal research on AD; works to improve diagnosis, treatment, and care for AD, including health care services and long term services and supports; and coordinates internationally on the fight on Alzheimers disease (U.S. Department of Health and Human Services, 2013a). The most recent version of the National Plan to Address Alzheimers Disease can be viewed at: [<http://aspe.hhs.gov/daltcp/napa/NatlPlan2013.pdf>].

New York State Department of Health

The New York State Department of Health (DOH) has funded nine Alzheimers Disease Assistance Centers (ADACs) located throughout New York State. ADACs serve as “Centers for Excellence” for diagnosing and caring for individuals with Alzheimers disease and provide training for medical professionals and resources for the community. In addition to diagnosing, ADACs provide services for individuals with AD and their caregivers, including counseling, support groups, referrals to community resources, etc. Additional information and locations of ADACs can be found at [<http://www.health.ny.gov/diseases/conditions/dementia/help.htm>].

The New York State Alzheimers Community Assistance Program (AlzCAP), carried out by The Coalition of New York State Alzheimers Association Chapters, funded by DOH provides a variety of support services for individuals with AD and their caregivers. Services include a 24/7 helpline, education for families and caregivers, care consultation, support groups, and respite.

While not a direct replication, these projects reflect the evidence developed by Dr. Mary Mittelman at NYU. Dr. Mittelman describes the key factors of her successful approach in Neurology (2006). In the article she indicates "The intervention consisted of six sessions of individual and family counseling, support group participation, and continuous availability of ad hoc telephone counseling". These key factors are provided by a combination of interventions through the ADACs and AlzCAP (along with other important services) and include: Caregiver counseling, training, support activities (including facilitated peer support groups for caregivers and family members; a caregiver hotline; and community education). In communities where ADACs and AlzCAP are present, New Yorkers have access to key elements of the supportive approach demonstrated by Dr. Mittelman's research. Other important additional services provided by the ADACs are early identification of AD (early diagnosis) and medical management of AD and co-morbid conditions. This array of services are based on the evidence provided through over 20 years of research; tailored to meet the needs of communities where ADACs are located; and can reasonably be expected to achieve positive outcomes for the people receiving program services.

The NY State Office for the Aging (NYSOFA) has received a Systems Integration Grant from the U.S. Administration on Aging called Part B -“*Creating Dementia Capable, Sustainable Service Systems for Persons with Dementia and Their Family Caregivers*”. Through the work of this grant, NYSOFA and its partners, will be adding questions to the NY Connects intake screen to assist in identifying individuals who may not yet be diagnosed, those diagnosed with AD and their caregivers in order to help link them to services of the ADACs, AlzCAP and other community based service providers. NYSOFA and DOH are working together with the Alzheimers partners funded under the grant to help provide support for implementation of Dr.

Mittelman's intervention. NY Connects is an online resource inventory for long term services and supports in New York State. NY Connects can be accessed at [<http://www.nyconnects.ny.gov/nyprovider/consumer/indexNY.do>].

Section II. Issues & Recommendations

Section II is divided into priority areas in which issues and challenges exist within the healthcare and long-term care systems and for individuals with AD and their caregivers and families. Each topic area includes a list of the issues and proposed recommendations for addressing these issues.

A. Need for Early Detection and to Quantify the Burden of the Disease

This section addresses the need and importance of better understanding the prevalence of AD in New York State. Quantifying the burden of the disease is essential for making decisions regarding interventions, research, and funding.

Issues:

- New York State data related to AD prevalence is not adequately represented in national reports due to the lack of early diagnosis by physicians and under-reporting of AD on death certificates.
- Many healthcare providers do not understand the importance of early diagnosis of AD, and therefore many individuals with AD lack time to plan and prepare while they still have mental capacity.
- Public health surveillance systems (e.g. Behavioral Risk Factor Surveillance System) provide only limited incidence measurements.

Recommendations:

- **A.1:** Healthcare providers should be educated about the importance and benefits of early detection and diagnosis as well as the NIA 2011 diagnostic guidelines for AD.
- **A.2:** DOH should utilize public health surveillance systems to more accurately quantify burden of the disease.

- **A.3:** Health care providers should screen individuals over age 65 for cognitive impairment as part of regular care using one of the validated cognitive screening tools recommended by the Alzheimers Association, NIH, and CMS.
- **A.4:** As part of primary and emergent care, healthcare providers should utilize a sentinel question similar to that used by the National Health Service (NHS) in the UK. This question asks, “Have you (has the person) been more forgetful in the last 12 months to the extent that it has significantly affected your (their) daily life?”
- **A.5:** DOH and partners should meet with the State Education Department, professional boards, and medical and nursing school representatives to encourage inclusion of the NIA 2011 diagnostic guidelines and importance of early detection in the curriculum of registered programs in these and other relevant professions.
- **A.6:** DOH should require ADACs to develop a training module to educate providers on the importance of accurate use of death certificates.

B. Caregiver Economic Burden

This section describes issues and recommendations related to the economic burden that many caregivers experience due to balancing caregiving responsibilities and maintaining personal employment.

Issues:

- Caregivers’ work performance and attendance can be impacted from the stress of caregiving responsibilities, which could ultimately result in loss of employment due to termination or resignation.
- Lost worker productivity can be extremely costly to the economy.
- Caregivers may have problems obtaining or keeping health insurance due to job loss.
- Caregivers may experience economic stress if undertaking financial responsibilities for medical services and other expenses for the individual with AD or themselves.
- Caregivers in the “sandwich generation” that care for both children and an individual with AD often experience economic stress.

Recommendations:

- **B.1:** DOH and partners should educate individuals with AD and caregivers about long term care insurance, particularly the Partnership for Long Term Care.
- **B.2:** DOH and partners should educate individuals with AD and caregivers about the benefits of advanced legal and financial planning.
- **B.3:** DOH should work with business groups to educate employers about caregiving responsibilities and how they can be responsive to employees through partnerships with organizations, such as the Alzheimers Association and local aging offices.
- **B.4:** DOH and partners should increase awareness and access to services for caregivers and patients (i.e. adult day care or respite) through case management and online resource inventories.
- **B.5:** The State should explore tax incentives for caregivers to ease their economic burden.

C. Caregiver Health Burden (Mental and Physical)

This section describes the mental and physical health risks associated with caregiving of individuals with AD and provides several recommendations for reducing these risks.

Issues:

- Caregivers, including those with multiple chronic conditions, often neglect their own physical and mental health, leading to an increased risk and incidence of chronic disease, anxiety/depression, and death.
- Caregivers' stress can lead to premature placement of individuals with AD in nursing homes.
- Caregivers are often unaware of services and supports in their area.
- Children and teenagers who provide care for individuals with AD may lack adequate support.

Recommendations:

- **C.1:** Providers should encourage health promotion for caregivers.
- **C.2:** DOH and partners should encourage employers to offer caregiver support services or referrals through Employee Assistance Programs.
- **C.3:** Health care providers of the individual with AD should regularly assess caregivers' physical and psychological well-being through informal assessments or refer them to their health care provider.
- **C.4:** Healthcare providers should be aware of available resources and refer caregivers to services.
- **C.5:** Programs with AD services should add support services for children and teenagers who provide care for individuals with AD.
- **C.6:** An online resource directory should be available and should include respite and support services to provide relief for caregivers.

D. Healthcare Provider and Human Services Workforce

This section describes issues related to AD in the healthcare and human services workforce including the need for better trained professionals. Several recommendations are proposed for improving dementia care in the healthcare and human services workforce.

Issues:

- There are anticipated shortages in the specialized workforce essential to individuals with AD, including professionals educated and specializing in geriatric services, such as physicians, psychiatrists, psychologists, nurse practitioners, nurses, attorneys, social workers, physical therapists, architects, accountants and pharmacists.
- Many providers are insufficiently trained for early detection, diagnosis, and management of individuals with AD.
- Public service professionals including first responders and public safety personnel may not have appropriate information about AD.

Recommendations:

- **D.1:** Specialized education and training curricula for AD should be utilized, and current/updated information should be made available for all professions in various media forms (i.e. the CMS Hand in Hand nursing home training series, found at <http://www.cms-handinhandtoolkit.info/>).
- **D.2:** Require continuing education credits for healthcare providers, including licensed social workers working with individuals with AD, such as the continuing education credits offered by ADACs.
- **D.3:** Paraprofessional caregivers should be adequately trained and compensated.
- **D.4:** Practice recommendations for appropriate care and management of AD in every setting should be embedded in all systems.
- **D.5:** Individuals who serve the public (i.e. mail carriers, meter readers, meals on wheels volunteers, etc.) should be trained to identify individuals with AD and know how to appropriately prepare for and respond to all-hazards emergencies.
- **D.6:** Explore the use of stipends or scholarships for students studying geriatrics as a recruitment strategy and incentive for entering a specialized workforce.

E. Quality of Care and Safety

This section describes issues related to quality of care and safety concerns for individuals with Alzheimers disease or other dementias in both formal and informal care settings. Recommendations are proposed to improve these concerns.

Issues:

- There is a lack of advance planning for individuals with AD during the early stages of dementia.
- Individuals with AD are at increased risk for wandering and injuries.
- There is a lack of availability for emergency respite services for caregivers who may suffer a health or other emergency.

- Individuals with AD often experience avoidable stress and confusion during and after transitions to emergency rooms, hospitals, primary care, and/or residential facilities due to poor communication and lack of staff understanding.
- Individuals with AD often experience long wait times both for available appointments and while in patient waiting rooms. Both types of waits are detrimental to this population and may reflect workforce shortages.

Recommendations:

- **E.1:** Providers should encourage individuals with AD, families, and caregivers to plan ahead regarding health care, finances, and legal issues so that the individual with AD can fully participate in the process. This includes designating a health care proxy and power of attorney, drafting a will, filling out a living will, and communicating about the NYS Medical Order for Life Sustaining Treatment (MOLST) form for when this becomes necessary.
- **E.2:** ADACs and providers should educate caregivers on the importance of home modifications and strategies to prevent injury and limit wandering, including enrolling in the Alzheimers Association’s Medic Alert + Safe Return Program.
- **E.3:** Healthcare providers should consider ways to reduce the number of transitions for individuals with AD.
- **E.4:** Healthcare providers should be trained to communicate effectively with individuals with AD during and after transitions to ensure that they are as comfortable as possible.
- **E.5:** The State should explore increasing availability of emergency respite services for caregivers.

F. Gaps in Community Support Services

This section describes accessibility issues and gaps in services within the community for individuals with AD. Recommendations are proposed to increase accessibility to services for individuals with AD.

Issues:

- There is a lack of public knowledge about available services, and it is often difficult to access these services.
- Limitations and access issues for services and supports are greater in some geographic areas.
- Many healthcare providers are unaware of available services or how to access them and therefore cannot adequately refer individuals with AD or their caregivers.

Recommendations:

- **F.1:** Assure availability of a resource directory for individuals with AD, their families, and caregivers including state and privately supported programs, and populate DOH website and the Office of Professions website with linkages to this directory and program websites. One example is the NY Connects website which can be found at: [\[http://www.nyconnects.ny.gov/programs.php\]](http://www.nyconnects.ny.gov/programs.php).

G. Continuum of Care Options

This section describes the issues related to remaining in the community and accessing residential care facilities. Recommendations are proposed to increase awareness of housing options and assist individuals with AD who wish to remain at home.

Issues:

- Home health care and adult day services might be difficult to access for individuals with progressive AD, especially if the individual has behavioral issues.
- Geographical location and housing situations can limit access to services and/or transportation.
- Housing choices, such as assisted living facilities and nursing home facilities may not be affordable for individuals or their families.
- There is a lack of advance planning for health and other services.
- Many individuals with AD need supervision/custodial care.

Recommendations:

- **G.1:** Promote increased awareness of the availability of end-of-life and palliative care for individuals with AD through all state programs.
- **G.2:** Providers should train formal and informal caregivers to appropriately manage medications to improve quality of life and facilitate avoidance of nursing home placement.
- **G.3:** Home health aides should be trained to primarily utilize appropriate social interventions to improve the quality of life for those with AD.
- **G.4:** Individuals and families of those that need nursing home care should be aware of issues related to choosing a quality facility and should access the nursing home directory on the DOH webpage (<http://www.health.ny.gov/facilities/nursing/>)

H. Public Education/Awareness of Dementia

This section describes the need for the public to be provided with accurate and up-to-date information and education about AD. Recommendations are proposed to increase public education and awareness.

Issues:

- A stigma associated with AD is still very prevalent in society.
- Misperceptions about the causes and symptoms of AD still exist in the public including providers and policy makers.
- The benefits and results of early detection related to treatment and caregiver support need to be emphasized to the public.

Recommendations:

- **H.1:** Integrate a geriatric component to developmental curricula in elementary through secondary education to increase the level of awareness of normal aging versus AD.
- **H.2:** Create a public/private partnership to bring awareness of AD to the public.

- **H.3:** Partner with organizations for other chronic conditions associated with AD to help disseminate information (i.e. organizations for heart disease and diabetes).

I. Healthcare Systems Issues

This section describes issues related to the caregivers' interactions with the healthcare system, such as communication difficulties with healthcare providers. Issues with health insurance are also discussed in this section. Recommendations are proposed to open communication between caregivers and healthcare providers and to assure access to services that require health insurance.

1. Interaction Between Caregiver and the Healthcare System

Issues:

- Caregivers are an important source of information about the individual's status for healthcare providers, but are often not part of the patient/physician interaction due to privacy laws.
- Privacy laws are often misunderstood by providers and caregivers, which inhibits useful communication.
- There is a lack of awareness of advance directives.

Recommendations:

- **I-1.1:** Offer information for caregivers on how to keep records and present information to medical providers.
- **I-1.2:** Educate caregivers on the importance of obtaining health care proxy forms and keeping copies available for emergency room or hospital visits.
- **I-1.3:** DOH and partners should educate providers about HIPAA guidelines that relate to family members and caregivers being present for and participating in appointments.
- **I-1.4:** DOH and partners should educate caregivers and the public on advance care directives, including health care proxy, living will, and MOLST forms.

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

Issues:

- Loss of employment can lead to loss of health insurance for caregivers and individuals with AD.
- Medicaid reimburses for medical adult day care, while Medicare and private insurance companies may not.

Recommendations:

- **I-2.1:** The Council should investigate sliding scale fees or tax credits for adult day care, which could allow individuals with AD to reside in the community longer.
- **I-2.2:** The Council should investigate increasing access to social and medical model adult day care.
- **I-2.3:** DOH should educate individuals under the age of 65 who are not eligible for Medicare or Medicaid about New York State of Health to ensure access to health insurance.

J. Research

This section describes the need for more research and more individuals participating in clinical trials. Recommendations are proposed to increase research on AD.

Issues:

- There is often a delay in applying research into practice.
- Most individuals with AD and their caregivers are unaware of existing and new clinical trials that could benefit them now or in the future.
- There is an ongoing need for AD research to develop treatments and prevention strategies.
- There are differences among racial and ethnic groups with AD, and more research is needed on these groups.

Recommendations:

- **J.1:** Evidence-based research on drug free treatments has demonstrated effectiveness, and should be utilized for treating individuals with AD. NYS research institutes should continue to research drug free treatments.
- **J.2:** DOH and partners should increase awareness on benefits of clinical trials.
- **J.3:** NYS research institutes should collaborate to accelerate progress in AD research, and apply for federal funding as needed.
- **J.4:** The Council should identify strategies to increase enrollment of racial and ethnic groups in AD studies and clinical trials.
- **J.5:** The Council should educate the public about the latest research findings through future council reports.
- **J.6:** DOH and partners should educate the public, individuals with AD, and their families about the benefits of brain donation for research purpose through public web pages and other means.

K. Health Disparities

The breadth of diversity in New York State creates some unique challenges related to AD across cultural groups. This section describes these challenges and proposes recommendations to increase services and supports for individuals in different cultural groups.

Issues:

- Cultures have different perspectives regarding AD, which impacts diagnosis, treatment, and caregiving.
- African Americans are two times more likely than whites to have AD, and Hispanics are one and a half times more likely to have AD than whites. Missed diagnoses are also common in these groups.
- Those with lower socioeconomic status and education levels have a higher risk of developing AD.

Recommendations:

- **K.1:** Incorporate specific needs of cultural groups with AD into existing training programs for social service and healthcare providers.
- **K.2:** ADACs should continue to implement outreach educational programs for racial and cultural groups.
- **K.3:** The Council should encourage professional education programs in all health professions to include cultural competency.
- **K.4:** DOH should create a program to educate primary care providers in high risk communities.

L. Special Populations

This section describes issues and recommendations related to four populations: (1) individuals in the early stages of AD; (2) individuals with early onset AD; (3) individuals with AD who experience behavioral and psychological symptoms; and (4) individuals with intellectual and developmental disabilities and AD. There are challenges and risks unique to each of these populations that will be addressed through several recommendations.

1. Early Stage AD

Issues:

- Lack of early detection and diagnosis leads to a lack in planning and services available for individuals with early stage AD.
- Services are not always appropriate to meet the unique needs of this population.

Recommendations:

- **L-1.1:** Design programs and support services for individuals with early stage AD.
- **L-1.2:** Raise public awareness regarding earliest symptoms of dementia and difference between AD and normal aging, while encouraging individuals with these symptoms to be examined by healthcare providers.

- **L-1.3:** Health care providers should routinely assess cognitive impairment as part of normal primary care.

2. *Early (Young) Onset AD*

Issues:

- Individuals with early onset AD often experience loss of employment, which can also lead to a loss of health insurance.
- Self-awareness of debilitation can lead to loss of self-esteem and depression.
- Some individuals with early onset AD with young children experience difficulty caring for their children and communicating about the disease.
- There is a need for individuals with early onset AD to plan ahead regarding employment/finances, family plans, legal plans, and new safety needs.
- Many individuals with early onset AD are not age-eligible for services in some systems, and many services are not age-appropriate for younger individuals.

Recommendations:

- **L-2.1:** Increase programming that is intellectually, cognitively, and physically stimulating.
- **L-2.2:** Individuals with early onset AD should be educated about early retirement, government assistance programs (Social Security, Medicare, and Medicaid), and personal disability insurance.
- **L-2.3:** DOH should educate providers on the importance of individuals with early onset AD applying for Social Security Disability benefits.
- **L-2.4:** Support groups should be created in as many geographical areas as possible so that individuals in this population can have reasonable access.
- **L-2.5:** Individuals in this population should be encouraged to seek additional services to manage psychological problems.

- **L-2.6:** Aging network services should be available whenever possible to individuals with early onset AD.

3. Behavioral Issues and Psychological Symptoms of AD

Issues:

- Individuals with AD related behavioral issues may be overmedicated, incorrectly medicated, prematurely sent to nursing homes, or sent to psychiatric institutions due to lack of understanding and poor identification of behavioral symptoms of AD.
- Individuals with AD exhibiting behavioral symptoms may have unmet needs or pain and may be inappropriately medicated with antipsychotics.
- Behavioral issues may complicate admission or retention in programs or nursing home facilities.
- Behavioral issues present significant challenges to caregivers in the community and in long term care facilities.
- Behavioral issues are often transient, but labels sometimes persist and have negative consequences.
- Due to the risk of cerebrovascular events and death associated with the use of antipsychotics in individuals with AD, the FDA has placed warnings on the use of these drugs.

Recommendations:

- **L-3.1:** Caregivers, paraprofessionals, and professionals should be trained in appropriate interventions.
- **L-3.2:** DOH and partners should educate health care providers about unmet needs or pain as causes of behavioral symptoms of AD to avoid unnecessary medications.
- **L-3.3:** DOH and partners should educate health care providers about the dangers associated with antipsychotic use and encourage drug free interventions as a first line approach to treating behavioral symptoms of AD.

- **L-3.4:** Nursing homes should work with individual patients with AD to decrease behavioral issues.

4. Individuals with Intellectual and Developmental Disabilities and AD

Issues:

- Many individuals with Down syndrome eventually develop AD and experience symptoms of AD at an earlier age than the general population.
- Diagnosis in this population is especially difficult.
- Individuals in this population do not often self-report their memory problems.

Recommendations:

- **L-4.1:** DOH should work with The Office of People With Development Disabilities (OPWDD) to promote research on the connection between Down syndrome and AD in NYS research institutes.
- **L-4.2:** DOH and partners should train professionals and paraprofessionals that work with individuals with developmental disabilities to be aware of the connection between Down syndrome and AD and to identify indicators of AD.
- **L-4.3:** DOH and partners should encourage families and caregivers of individuals with Down syndrome who suspect memory problems to communicate this concern to the individual's health care provider.
- **L-4.4:** Families of individuals with intellectual and developmental disabilities should be encouraged to engage in early planning regarding AD.

M. Emergency Preparedness

Preparing for disasters can be extremely difficult for individuals with AD. These individuals often experience a significant amount of anxiety and distress due to their confusion about the event, and they are at an increased risk for physical and emotional harm during disasters. This section describes several recommendations to increase planning and safety for individuals with AD during disasters.

Issues:

- There is a need for specific disaster preparedness planning for individuals with AD and their caregivers.
- There is a lack of awareness of AD among emergency respondents, which makes assisting and communicating with individuals with AD more difficult.

Recommendations:

- **M.1:** Emergency shelters, hospitals, and residential care facilities should have disaster plans in place that include specific identification measures for individuals with AD with medical information for each individual.
- **M.2:** Emergency shelter staff members should be educated about AD and how to specifically help individuals with AD both physically and emotionally.
- **M.3:** Caregivers should be educated about how to prepare for emergencies by utilizing an emergency kit for the individual with AD that includes identification information, medical information, prescriptions, clothing, etc.
- **M.4:** Healthcare providers should recommend identification systems for individuals with AD, such as the Medic Alert + Safe Return Program.
- **M.5:** Individuals residing in communities should be encouraged to have redundant back-up plans in place to anticipate for interruptions in services (e.g. electricity, water, transportation).

Section III. A Call to Action

As global, national, and state awareness of dementia has increased, so has the urgency for public health, human service, long-term care and health systems to come together through public and private partnerships to actively address AD. The New York State Coordinating Council for Services Related to Alzheimers Disease and Other Dementias has created a framework that Council members will utilize to exercise accountability for the recommendations made in this report. This serves as both a roadmap for progress and a call for diverse groups to work together to achieve the recommendations included here. What we know now is that AD poses one of the greatest risks to our physical and economic futures. These recommendations provide

opportunities for government, healthcare and human service professionals and institutions, business and philanthropies to come together with a common set of goals and activities. Attachment C provides an outline of the recommendations indicating the responsible parties and suggested timelines for completion and will serve as a tool to track progress and challenges moving forward.

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**Attachment A: New York State Coordinating Council for Services Related to Alzheimers
Disease and Other Dementias Council Members List**

Louis R. Belzie, MD
Director
Behavioral Health
Long Term and Palliative Care
Brookdale University
One Brookdale Plaza
Brooklyn, NY 11212
Ph: (718) 240-6981
Email: mdart@aol.com

Elizabeth Smith-Boivin
Executive Director & CEO
Alzheimers Association Northeastern
New York
4 Pine West Plaza, Suite 405
Albany, NY 12205
Ph: (518) 867-4999
Email: esmith-boivin@alz.org

Sharon Boyd
631 Plank Road
Macedon, NY 14502
Ph: (315) 524-9047
Email: sboyd2@rochester.rr.com

W. Ted Brown, MD, Ph.D.
Director
Institute for Basic Research in
Developmental Disabilities
1050 Forest Hill Road
Staten Island, NY 10314
Ph: (718) 494-5117
Email: Ted.Brown@opwdd.ny.gov

David Cascio, RN, BSN
Past President
Alzheimers Association
Western New York Chapter
40 Daisy Lane
Amherst, NY 14228
Email: djcascio@roadrunner.com

Hon. Barbara C. Donno
Mayor, Incorporated Village
of Plandome Manor
53 Manhasset Avenue
Manhasset, NY 11030
Ph: (516) 627-3701
Email: boardmom@aol.com

Kathleen Doyle, Ph.D.
Executive Secretary
NYS Education Department
89 Washington Avenue
Albany, NY 12234
Ph: (518) 474-3817 (ext. 150)
Email: kdoyle2@mail.nysed.gov

Deborah Greenfield
Family and Children's Services
Specialist II
Office of Children and Family Services
52 Washington Street 336 N
Rensselaer, NY 12144
Ph: (518) 402-3895
Email:
deborah.greenfield@ocfs.state.ny.us

William Higgins, MD
1985 Crompond Road
Cortlandt Manor, NY 10567
Ph: (914) 739-3597
Fax: (914) 739-4575
Email: Whigginsmd@aol.com

Catherine J. James
Chief Executive Officer
Alzheimers Association
Central New York Chapter
441 West Kirkpatrick Street
Syracuse, NY 13204
Ph: (315) 472-4201 (ext. 105)
Email: cjames@alz.org

Mark Kissinger , Director
Division of Long Term Care
NYSDOH
Corning Tower, Room 1417
Albany, NY 12237
Ph: (518) 402-5673
Email: mlk15@health.state.ny.us

Jed A. Levine
Executive Vice President
Director, Programs and Services
Alzheimers Association
New York City Chapter
360 Lexington Avenue 4th Floor
New York, NY 10017
Ph: (646) 744-2902
Email: JLevine@alznyc.org

Ralph Nixon, MD, Ph.D.
Director of Research
Nathan Kline Institute
140 Old Orangeburg Rd.
Orangeburg, NY 10962
Ph: (845) 398-5423
Email: Nixon@NKI.RFMH.org
Alternate: rosdil@nki.rfmh.org

Greg Olsen
Acting Director
New York State Office for the Aging
Two Empire State Plaza
Albany, NY 12223-1251
Ph: (518) 474-4425
Email: greg.olsen@ofa.state.ny.us

Mary Ann Malack-Ragona
Executive Director/CEO
Alzheimers Disease Resource Center
of Long Island
45 Park Avenue
Bayshore, NY 11706
Ph: (631) 580-5100 (ext. 306)
Email: maryann.ragone@adrcinc.org

Paula Rice
316 West 116th Street, Apt. 3A
New York, NY 10026
Ph: (212) 280-0641
Email: Pjrice13@aol.com

Mollie A. Richards
Director
Rehabilitation Programs at Jewish
Senior Life
2021 Winton Road South
Rochester, NY 14618
Ph: (585) 427-7760
Email: mrichards@jewishhomeroch.org

David Hoffman
NYS Department of Health
Division of Long Term Care
ESP, Corning Tower, Room 1970
Albany, NY 12237
Ph: (518) 474-0662
Email: dph01@health.state.ny.us

Attachment B: Acronym List

ADAC	Alzheimers Disease Assistance Center
AlzCAP	Alzheimers Community Assistance Program
BCNYS	The Business Council of New York State, Inc.
DOH	New York State Department of Health
LTSS	Long-term services and supports
MCO	Managed Care Organization
MSSNY	Medical Society of the State of New York
NYSBA	New York State Bar Association
OCFS	New York State Office of Child and Family Services
OEM	New York State Office of Emergency Management
OHE	New York State Office of Higher Education
OPWDD	New York State Office of People With Developmental Disabilities
SED	New York State Education Department
SOFA	New York State Office for Aging

Attachment C: Recommendation Timeline

Recommendation	Description	Responsible Parties	Suggested Timeline
Need for Early Detection and to Quantify Burden of the Disease			
A.1	Healthcare providers should be educated about the importance and benefits of early detection and diagnosis as well as the NIA 2011 diagnostic guidelines for AD.	DOH; OHE; ADACs; AlzCAP	2014 and ongoing
A.2	DOH should utilize public health surveillance systems to more accurately quantify burden of the disease.	DOH	2014 and ongoing
A.3	Health care providers should screen individuals over age 65 for cognitive impairment as part of regular care using one of the validated cognitive screening tools recommended by the Alzheimers Association, NIH, and CMS.	DOH; OHE; ADACs; AlzCAP; MSSNY; professional organizations	2015 and ongoing
A.4	As part of primary and emergent care, healthcare providers should utilize a sentinel question similar to that used by the National Health Service (NHS) in the UK. This question asks, “Have you (has the person) been more forgetful in the last 12 months to the extent that it has significantly affected your (their) daily life?”	DOH; OHE; ADACs; AlzCAP; MSSNY; professional organizations	2014 and ongoing
A.5	DOH and partners should meet with the State Education Department, professional boards, and medical and nursing school representatives to encourage inclusion of the NIA 2011 diagnostic guidelines and importance of early detection in the curriculum of registered programs in these and other relevant professions.	DOH; SED; advocates	2014-15 and ongoing
A.6	DOH should require ADACs to develop a training module to educate providers on the importance of accurate use of death certificates.	DOH; ADACs	2014

Caregiver Economic Burden			
B.1	DOH and partners should educate individuals with AD and caregivers about long term care insurance, particularly the Partnership for Long Term Care.	DOH; DFS; SOFA; insurers	2014 and ongoing
B.2	DOH and partners should educate individuals with AD and caregivers about the benefits of advanced legal and financial planning.	DOH; DFS; SOFA; insurers; NYSBA	2014 and ongoing
B.3	DOH should work with business groups to educate employers about caregiving responsibilities and how they can be responsive to employees through partnerships with organizations, such as the Alzheimers Association and local aging offices.	DOH; BCNYS	2014 and ongoing
B.4	DOH and partners should increase awareness and access to services for caregivers and patients (i.e. adult day care or respite) through case management and online resource inventories.	DOH; SOFA; OCFS; AlzCAP	2014 and ongoing
B.5	The State should explore tax incentives for caregivers to ease their economic burden.	The Council	2014
Caregiver Health Burden (Mental & Physical)			
C.1	Providers should encourage health promotion for caregivers.	DOH; OHE; ADACs; AlzCAP; MSSNY; professional organizations	2014 and ongoing
C.2	DOH and partners should encourage employers to offer caregiver support services or referrals through Employee Assistance Programs.	DOH; BCNYS	2014
C.3	Health care providers of the individual with AD should regularly assess caregivers' physical and psychological well-being through informal assessments or refer them to their health care provider.	DOH; OHE; ADACs; AlzCAP; MSSNY; professional organizations	2014 and ongoing

C.4	Healthcare providers should be aware of available resources and refer caregivers to services.	DOH; OHE; ADACs; AlzCAP; MSSNY; professional organizations	2014 and ongoing
C.5	Programs with AD services should add support services for children and teenagers who provide care for individuals with AD.	DOH; OHE; ADACs; AlzCAP; MSSNY; SED; professional organizations	2014 and ongoing
C.6	An online resource directory should be available and should include respite and support services to provide relief for caregivers.	DOH; SOFA	2014
Healthcare Provider & Human Service Workforce			
D.1	Specialized education and training curricula for AD should be utilized, and current/updated information should be made available for all professions in various media forms.	DOH; SED; OHE; professional organizations	2016 and ongoing
D.2	Require continuing education credits for healthcare providers, including licensed social workers working with individuals with AD, such as the continuing education credits offered by ADACs.	DOH; SED; OHE; professional organizations	2016 and ongoing
D.3	Paraprofessional caregivers should be adequately trained and compensated.	DOH; provider groups; groups representing LTSS employees	Ongoing process
D.4	Practice recommendations for appropriate care and management of AD in every setting should be embedded in all systems.	The Council	2014 and ongoing
D.5	Individuals who serve the public (i.e. mail carriers, meter readers, meals on wheels volunteers, etc.) should be trained to identify individuals with AD and know how to appropriately prepare for and respond to all-hazards emergencies.	DOH; SOFA; SED; ADACs; AlzCAP	2015 and ongoing
D.6	Explore the use of stipends or scholarships for students studying geriatrics as a recruitment strategy and incentive for entering a specialized workforce.	The Council; OHE; professional groups	2014-15 and ongoing

Quality of Care & Safety			
E.1	Providers should encourage individuals with AD, families, and caregivers to plan ahead regarding health care, finances, and legal issues so that the individual with AD can fully participate in the process. This includes designating a health care proxy and power of attorney, drafting a will, filling out a living will, and communicating about the NYS Medical Order for Life Sustaining Treatment (MOLST) form for when this becomes necessary.	DOH; OHE; ADACs; AlzCAP; MSSNY; professional organizations	2014-15 and ongoing
E.2	ADACs and providers should educate caregivers on the importance of home modifications and strategies to prevent injury and limit wandering, including enrolling in the Alzheimers Association's Medic Alert + Safe Return Program.	DOH; ADACs; AlzCAP; DCJS	2014-15 and ongoing
E.3	Healthcare providers should consider ways to reduce the number of transitions for individuals with AD.	DOH; SOFA; hospitals; home care providers; nursing homes	2014-15 and ongoing
E.4	Healthcare providers should be trained to communicate effectively with individuals with AD during and after transitions to ensure that they are as comfortable as possible.	DOH; ADACs; SOFA; professional organizations	2014-15 and ongoing
E.5	The State should explore increasing availability of emergency respite services for caregivers.	DOH; ADACs; AlzCAP	2014-15 and ongoing
Gaps in Community Support Services			
F.1	Assure availability of a resource directory for individuals with AD, their families, and caregivers including state and privately supported programs, and populate DOH website and the Office of Professions website with linkages to this directory and program websites. One example is the NY Connects website.	The Council	2014

Continuum of Care Options			
G.1	Promote increased awareness of the availability of end-of-life and palliative care for individuals with AD through all state programs.	DOH; SOFA; ADACs; AlzCAP; other Council members	2014-15 and ongoing
G.2	Providers should train formal and informal caregivers to appropriately manage medications to improve quality of life and facilitate avoidance of nursing home placement.	DOH; ADACs; provider groups	2014-15 and ongoing
G.3	Home health aides should be trained to primarily utilize appropriate social interventions to improve the quality of life for those with AD.		2014 and ongoing
G.4	Individuals and families of those that need nursing home care should be aware of issues related to choosing a quality facility and should access the nursing home directory on the DOH webpage.	DOH	2014 and ongoing
Public Education & Awareness of Dementia			
H.1	Integrate a geriatric component to developmental curricula in elementary through secondary education to increase the level of awareness of normal aging versus AD.	DOH; SED	2016
H.2	Create a public/private partnership to bring awareness of AD to the public.	All Council members	2014-15 and ongoing
H.3	Partner with organizations for other chronic conditions associated with AD to help disseminate information (i.e. organizations for heart disease and diabetes).	DOH; ADA; AHA; ACS, AF; AARP	2014-15 and ongoing
Healthcare System Issues			
I-1.1	Offer information for caregivers on how to keep records and present information to medical providers.	DOH; SOFA; SED; ADACs; AlzCAP; professional organizations	2014-15 and ongoing

I-1.2	Educate caregivers on the importance of obtaining health care proxy forms and keeping copies available for emergency room or hospital visits.	DOH; SOFA; SED; ADACs; AlzCAP; professional organizations	2014-15 and ongoing
I-1.3	DOH and partners should educate providers about HIPAA guidelines that relate to family members and caregivers being present for and participating in appointments.	DOH; SOFA; SED; ADACs; AlzCAP; professional organizations	2014-15 and ongoing
I-1.4	DOH and partners should educate caregivers and the public on advance care directives, including health care proxy, living will, and MOLST forms.	DOH; SOFA; SED; ADACs; AlzCAP; professional organizations	2014-15 and ongoing
I-2.1	The Council should investigate sliding scale fees or tax credits for adult day care, which could allow individuals with AD to reside in the community longer.	The Council	2015-16 and ongoing
I-2.2	The Council should investigate increasing access to social and medical model adult day care.	The Council	2014-15 and ongoing
I-2.3	DOH should educate individuals under the age of 65 who are not eligible for Medicare or Medicaid about New York State of Health to ensure access to health insurance.	DOH	2014 and ongoing
Research			
J.1	Evidence-based research on drug free treatments has demonstrated effectiveness, and should be utilized for treating individuals with AD. NYS research institutes should continue to research drug free treatments.	DOH; SOFA; ADACs; AlzCAP; research organizations	2014 and ongoing
J.2	DOH and partners should increase awareness on benefits of clinical trials.	DOH; SOFA; ADACs; AlzCAP; research organizations	2014 and ongoing
J.3	NYS research institutes should collaborate to accelerate progress in AD research, and apply for federal funding as needed.	DOH; SOFA; ADACs; AlzCAP; research organizations	2014 and ongoing

J.4	The Council should identify strategies to increase enrollment of racial and ethnic groups in AD studies and clinical trials.	The Council	2014 and ongoing
J.5	The Council should educate the public about the latest research findings through future council reports.	Council members	2015
J.6	DOH and partners should educate the public, individuals with AD, and their families about the benefits of brain donation for research purpose through public web pages and other means.	DOH & partners	2014 and ongoing
Health Disparities			
K.1	Incorporate specific needs of cultural groups with AD into existing training programs for social service and healthcare providers.	ADACs; AlzCAP; Council members; groups representing diverse populations	2014 and ongoing
K.2	ADACs should continue to implement outreach educational programs for racial and cultural groups.	ADACs	2014 and ongoing
K.3	The Council should encourage professional education programs in all health professions to include cultural competency.	The Council	2015
K.4	DOH should create a program to educate primary care providers in high risk communities.	DOH	2015
Special Populations			
L-1.1	Design programs and support services for individuals with early stage AD.	DOH; SOFA; ADACs; AlzCAP; professional organizations	2014-15 and ongoing
L-1.2	Raise public awareness regarding earliest symptoms of dementia and difference between AD and normal aging, while encouraging individuals with these symptoms to be examined by healthcare providers.	Council members & partners groups	2014-15 and ongoing

L-1.3	Health care providers should routinely assess cognitive impairment as part of normal primary care.	DOH; provider groups; MCOs; professional organizations	2015 and ongoing
L-2.1	Increase programming that is intellectually, cognitively, and physically stimulating.	All Council members with constituent partners	2014 and ongoing
L-2.2	Individuals with early onset AD should be educated about early retirement, government assistance programs (Social Security, Medicare, and Medicaid), and personal disability insurance.	DOH; DFS; SOFA; insurers; NYSBA	2014-15 and ongoing
L-2.3	DOH should educate providers on the importance of individuals with early onset AD applying for Social Security Disability benefits.	DOH	2014-15 and ongoing
L-2.4	Support groups should be created in as many geographical areas as possible so that individuals in this population can have reasonable access.	DOH; SOFA; AlzCAP; CBOs	2014-15 and ongoing
L-2.5	Individuals with early onset should be encouraged to seek additional services to manage psychological problems.	DOH; SED; professional organizations	2014-15 and ongoing
L-2.6	Aging network services should be available whenever possible to individuals with early onset AD.	SOFA	2014-15 and ongoing
L-3.1	Caregivers, paraprofessionals, and professionals should be trained in appropriate interventions.	DOH; SED; OMH; SOFA; ADACs; AlzCAP; professional organizations	2014 and ongoing
L-3.2	DOH and partners should educate health care providers about unmet needs or pain as causes of behavioral symptoms of AD to avoid unnecessary medications.	DOH; SED; OMH; SOFA; ADACs; AlzCAP; professional organizations	2014-15 and ongoing
L-3.3	DOH and partners should educate health care providers about the dangers associated with antipsychotic use and encourage drug free interventions as a first line approach to treating behavioral	DOH; SED; OMH; SOFA; ADACs; AlzCAP; professional organizations	2014 and ongoing

	symptoms of AD.		
L-3.4	Nursing homes should work with individual patients with AD to decrease behavioral issues.	DOH; professional organizations	2014 and ongoing
L-4.1	DOH should work with The Office of People With Development Disabilities (OPWDD) to promote research on the connection between Down syndrome and AD in NYS research institutes.	DOH; OPWDD	2014 and ongoing
L-4.2	DOH and partners should train professionals and paraprofessionals that work with individuals with developmental disabilities to be aware of the connection between Down syndrome and AD and to identify indicators of AD.	DOH; OPWDD; partner groups	2014 and ongoing
L-4.3	DOH and partners should encourage families and caregivers of individuals with Down syndrome who suspect memory problems to communicate this concern to the individual's health care provider.	DOH; OPWDD; partner groups	2014 and ongoing
L-4.4	Families of individuals with intellectual and developmental disabilities should be encouraged to engage in early planning regarding AD.	DOH; OPWDD; partner groups	2014 and ongoing
Emergency Preparedness			
M.1	Emergency shelters, hospitals, and residential care facilities should have disaster plans in place that include specific identification measures for individuals with AD with medical information for each individual.	DOH; local health departments; OEM	2015 and ongoing
M.2	Emergency shelter staff members should be educated about AD and how to specifically help individuals with AD both physically and emotionally.	DOH; local health departments; OEM	2015 and ongoing

M.3	Caregivers should be educated about how to prepare for emergencies by utilizing an emergency kit for the individual with AD that includes identification information, medical information, prescriptions, clothing, etc.	DOH; SOFA; ADACs; AlzCAP	2014 and ongoing
M.4	Healthcare providers should recommend identification systems for individuals with AD, such as the Medic Alert + Safe Return Program.	DOH; professional organizations; provider groups	2014 and ongoing
M.5	Individuals residing in communities should be encouraged to have redundant back-up plans in place to anticipate for interruptions in services (e.g. electricity, water, transportation).	DOH; local health departments; OEM	2014 and ongoing