2015 Report

of the

New York State Coordinating Council

for Services Related to Alzheimer's Disease

and Other Dementias

to

Governor Andrew M. Cuomo

and the

New York State Legislature

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Section I. Background

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).

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 Alzheimer's disease and other dementias (AD/D) and their families, and provide a continuing forum for concerns and discussions related to the formulation of a comprehensive state policy for AD/D. (See Attachment A for a list of 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 AD/D and include a review of services initiated and coordinated by public and private agencies to meet the needs of persons with AD/D and their families. This is done particularly to make recommendations on the use of cognitive screening tools.

This is the fourth report by the Council. The Council has gathered expert advice from Council members and others in the field to inform the development of this report.

Council Activity

The following is a list of 2013-2015 Council meeting dates and topics of discussion:

December 9, 2013: *2013 Council Report*, The National Advisory Council (NAC) Report, Administration on Aging (AOA) grant, and guardianship issues

March 11, 2014: *2013 Council Report*, AOA Grant Update, and Reaching Older Adults Research, and New York State (NYS) member agency updates

June 10, 2014: Discussion related to disparities in AD and AOA *Alzheimer's Disease Supportive Services Program: Dementia Capability for Persons with Alzheimer's Disease and Related Dementias* Request for Application (RFA) updates, and NYS member agency updates

September 9, 2014: Program updates, ethical issues, New York State Department of Health (NYSDOH) *Addressing Disparities in Alzheimer's Disease and Other Dementias* RFA; research updates, and NYS agency updates

December 9, 2014: NAC updates, new Diagnostic and Statistical Manual of Mental Disorders 5 (DSM-5) nomenclature, NYSDOH Falls Prevention Demonstration Project, and NYS member agency updates

March 3, 2015: Discussion of 2015 *Report of the New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias*, proposed recommendations, and NYS agency updates

June 8, 2015: Discussion of *2015 Report of the New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias*, proposed recommendations, and NYS agency updates

October 1, 2015: Discussion of *2015 Report of the New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias*, proposed recommendations, and NYS agency updates

Dementia

AD/D or dementia are umbrella terms that refer to a group of degenerative neurocognitive disorders. Alzheimer's disease and other dementias damage brain functioning leading to cognitive decline (e.g., memory loss, language difficulty, poor executive functioning), behavioral and psychiatric disorders (e.g. depression, delusion, agitation), and declines in activities of daily living (ADL) and independent functioning.[1]

Alzheimer's Disease

Alzheimer's disease (AD) is the most common form of dementia; 60-80% of individuals with dementia have AD.[2] AD is a degenerative and ultimately fatal condition characterized by specific brain abnormalities, including amyloid plaques and neurofibrillary tangles. AD primarily occurs in adults with progressively increased frequency at older ages. Amyloid plaques and neurofibrillary tangles reflect a disruption in neuronal communication in the brain, which eventually causes cell death. There is currently no cure for AD/D. Treatments that may temporarily improve or slow worsening symptoms do not alter the overall disease progression of AD/D. Symptoms of AD progressively worsen over time.

AD typically occurs in a progressive sequence of stages:

- According to the 2011 diagnostic guidelines for AD published by the National Institute on Aging (NIA), AD begins before the emergence of observable symptoms. The NIA identifies three stages of AD that occur on a spectrum: preclinical/presymptomatic Alzheimer's, mild cognitive impairment (MCI), and dementia due to AD.[3] More information on the diagnostic guidelines can be viewed at http://www.alz.org/research/diagnostic_criteria. The Alzheimer's Association identifies three stages of dementia due to AD: early-stage, middle-stage, and late/final-stage.[3] AD affects individuals in different ways, meaning that their presentation of the disease, symptoms they experience, and progression through these stages will be unique. These stages are a guideline and it may be difficult to place an individual in a specific stage because stages blend and may overlap.[4]

Descriptions of the stages identified by these two organizations follow:

Preclinical/Presymptomatic Alzheimer's Disease

Preclinical AD occurs before symptoms are present and an individual has measurable biomarkers for the disease. The preclinical stage can begin years, or even decades, before the symptoms of early-stage AD begin to occur. Studies suggest the possibility of subtle cognitive changes that could be detectable years before meeting the criteria for MCI.[3]

Mild Cognitive Impairment

MCI is a clinical diagnosis that is determined by the judgment of a medical professional based on a medical evaluation that includes mental status screening, medical history, input from the patient and close family members, and assessment of daily activities. MCI causes cognitive changes that can affect memory, completion of tasks, reasoning, etc. "Amnestic MCI" affects memory and "non-amnestic MCI" affects thinking skills outside of memory, such as judgment.[5] Individuals being evaluated for MCI should be screened and assessed for depression because this condition can exacerbate cognitive decline or its symptoms may mirror cognitive impairment.

The symptoms of MCI are significant enough to be noticed by the individual experiencing the change and/or by other people. However, these symptoms are typically not severe enough to interfere with daily life or independence.[2, 5] MCI symptoms can be described as a range between the expected cognitive decline of normal aging and the more significant changes of AD/D.[6]

MCI is significant in the development and diagnosis of AD, but some individuals with MCI never develop AD. Studies indicate that as many as 10% to 20% of people over age 65 have MCI, and as many as 15% of people with MCI progress to AD each year. People with amnestic MCI are at greater risk of developing AD. If an individual presents with both MCI and the biomarkers for AD, then there is a degree of certainty that the individual will develop AD.[5] Limited information exists on the relationship between MCI and other dementias.

The causes of MCI are not fully understood, but there is significant evidence that MCI can be exacerbated by depression, certain medications, and/or co-occurring medical conditions, such as diabetes.[6] For those individuals with MCI caused by a treatable condition, managing these conditions can eliminate the presence of MCI-like symptoms. This is particularly true among older adults with acute depression.[8] Evidence indicates that people older than 70 years of age with MCI and untreated depression are at twice the risk of developing AD than people with MCI without depression. While a correlation exists between depression, MCI, and AD/D, there is no definitive evidence that this is a causal relationship.[9]

Early-Stage Alzheimer's Disease

Individuals in the early stage of AD may have difficulty remembering recent information including places, names, events, and some personal information as the stage progresses; these symptoms are consistent with MCI progressing to AD.[5] The Alzheimer's Association describes the following ten warning signs that may strongly indicate AD:

- 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.

When a person exhibits these warning signs, he or she should consult with a physician who will conduct tests to rule out the possibility of other reversible conditions with similar symptoms, such as delirium, depression, drug interactions, and normal pressure hydrocephalus.[2]

Middle-Stage Alzheimer's Disease

Individuals in the middle stage of the AD progression exhibit more pronounced symptoms of the disease. This stage generally begins with the development of more pronounced cognitive decline and difficulties. Individuals may develop challenging behaviors such as wandering, personality changes, and increased agitation and/or aggression. Other changes in this stage include progressively increasing language difficulties, confusion, further memory loss, unstable mood, and difficulties with ADLs.

Late/Final-Stage Alzheimer's Disease

Individuals in the late stages of AD experience extremely debilitating symptoms which can be devastating for their caregivers and family. The time frame from the onset of the disease until death can last for two to three years.[10] Between 20% and 30% of patients will "linger" as long as 10 years in the advanced stage of AD.[11]

During the final stage of AD's progression, individuals lose awareness of recent experiences and surroundings and physical functioning. They have difficulty communicating, have difficulty with and eventually lose the ability to swallow, and are vulnerable to infections such as pneumonia. Individuals in this stage will eventually require total care and dependence on caregivers. The disease will ultimately lead to death.

Other Types of Dementia

Other types of dementia include: vascular dementia; Lewy body dementia (LBD); Parkinson's disease; Frontotemporal dementia (FTD); Huntington's disease; Creutzfeldt-Jakob disease (CJD); Wernicke-Korsakoff syndrome (WKS); chronic traumatic encephalitis (CTE); and human immunodeficiency virus (HIV) associated neurocognitive disorders (HAND). Causes and symptoms of the various types of dementia vary, with some of the neurodegenerative processes having common pathways.[1] In terms of clinical presentation and diagnosis, it is often difficult to distinguish between the different forms of dementia. (See Attachment B for additional information related to AD/D.)

In many cases, abnormalities characteristic of more than one type of dementia are found. This can lead to the clinical diagnosis of mixed dementia. Many researchers and experts in the field believe mixed dementia deserves more attention. According to an autopsy-based study conducted by the Rush Memory and Aging Project, more than 50% of people with AD experience a mixed presentation of dementia symptoms and pathology where abnormalities characteristic of more than one type occur concurrently.[4, 12]

Despite evidence from autopsy studies of the high prevalence of mixed pathologies in older adults, mixed dementia is infrequently diagnosed, but has a significant impact on the development of the pathologies. The combination of two or more types of dementia-related brain changes may have a greater impact on the brain than one type alone and requires more complicated diagnostic procedures and treatments.

Mixed dementia is expressed differently in every patient. The most common form of mixed dementia exhibits the pathology of AD co-existing with blood vessel complications associated with vascular dementia. AD symptoms can also co-occur with Lewy bodies, the abnormal protein deposits characteristic of LBD. In some cases, a person may have brain changes linked to all three conditions: AD, vascular dementia, and LBD. For more information on mixed dementia; see https://www.alz.org/dementia/downloads/topicsheet_mixed.pdf.

Prevalence and Mortality

National

An estimated 5.3 million Americans live with AD; approximately 5.1 million are over age 65 and 200,000 are under age 65.[2, 13] One in nine Americans over the age of 65 has AD. This number is expected to triple by the year 2050 as the baby boom generation ages.[13] The rate of AD increases with age, with approximately one-third of people over 85 years-old diagnosed with AD.[14] Although AD is typically diagnosed in people over age 65, there are also an estimated 200,000 Americans between 30 to 60 years old diagnosed with "younger/early onset."[15] There is currently limited data addressing the prevalence and mortality of other dementias.

AD is the fifth leading cause of death among individuals ages 65 and older and the sixth leading cause of death overall in the United States (US).[16] However, prevalence and mortality rates for AD are not an accurate representation of actual figures due to the lack of early detection and diagnosis and underreporting of AD on death certificates.[17] Similarly, limited data related to other dementias could also contribute to their underrepresentation on death certificates. The Centers for Disease Control and Prevention (CDC) recognizes the cause of death based on what is listed on death certificates. Death certificates often list the acute illness, rather than the underlying cause of that illness, as the cause of death. For example, pneumonia may be listed as the cause of death when this acute illness resulted from complications from AD.[17, 18]

The CDC, in collaboration with state health agencies, conducts the annual Behavioral Risk Factor Surveillance System (BRFSS) survey. The BRFSS has two modules related to AD: the perceived cognitive impairment and caregiver modules. National data from the perceived cognitive impairment module from the 2011 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. The Alzheimer's Association estimates that 81% of those with cognitive decline have not reported this condition to their health care providers. In NYS, 11% of individuals aged 60 and over reported confusion or memory loss in the 2011 BRFSS; 78% of them indicated that they have not reported the condition to their health care provider.[19, 20] Additional NYS-related BRFSS data is located at http://www.alz.org/documents_custom/public-health/newyork.pdf.

New York State

The scope of AD has been difficult to project for a number of reasons including the following: many people remain undiagnosed because they do not share their symptoms with their medical providers; medical providers may be reluctant to give this diagnosis; cultural barriers influence the decision to seek a diagnosis; the occurrence of delayed diagnosis and misdiagnosis; and individuals have increasingly longer lifespans.

The current estimate of the number of individuals with AD in NYS is 380,000 and that number is expected to increase to 460,000 by 2025. Comparable data for other dementias is not available.[2, 18] The rise of the number of cases of the disease has far exceeded early expectations. Current rates of AD are more than double the 1984 prediction made by the New York Academy of Medicine and the NYS Health Planning Commission. These data indicated that the prevalence of AD in NYS would be 155,000 by 2010. [2, 21]

Special Populations

The United States Department of Health and Human Services (HHS) recognizes that AD/D disproportionately impacts racial and ethnic minorities, individuals with younger onset AD/D, and those with Down syndrome. HHS has created the Task Force on Specific Populations to address the needs of these specific populations.[22] The Task Force has issued a report with recommendations for these populations. This report is located at http://aspe.hhs.gov/daltcp/reports/2013/AlzSpPop.pdf.

Racial and Ethnic Minorities

Disparities are associated with the risk of developing of AD/D among certain racial, ethnic, and socioeconomic groups. Compared to whites, African Americans are two times and Hispanics are one and a half times more likely to have AD.[2, 14] 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/D.[2] These conditions include, but are not limited to, cardiovascular disease, diabetes, chronic kidney disease, and higher hemoglobin levels.[23, 24] Increased risk of cardiovascular disease due to diabetes and heart disease also increases the risk of vascular dementia.

In addition to life style risk factors, researchers at Columbia University Medical Center and the Alzheimer's Disease Genetics Consortium have identified a variant of a gene (ABCA7) involved in cholesterol and lipid metabolism. This gene appears to be a stronger risk factor for late-onset AD in African Americans than in non-Hispanic Caucasians of European ancestry.[25] Another study demonstrated that Hispanics, as compared to Caucasians, may have an earlier onset, while African Americans may have a later onset of the disease.[14] This research also found that upon initial diagnosis, African Americans and Hispanics had higher levels of cognitive impairment and dementia than non-Hispanic whites, and suggested that more research is required to determine the reason (e.g., differing cultural views regarding medical care and cognitive decline).[2, 23]

Women

The number of women in the US with AD is significantly higher than that of men, with women comprising 3.2 million of the 5.3 million Americans with AD. Women with MCI experience a more rapid decline in cognition than men and are therefore at an increased risk of developing AD.[2, 26] Researchers are exploring this disparity by examining risk factors related to genetics (e.g., Apolipoprotein E (APOE)-ε4 genome), brain structure, disease progression, estrogen, and depression.[2, 26] There is currently no definitive evidence of a causal relationship between these risk factors and AD/D.

Early Onset Dementia

Early onset dementia occurs when a person under the age of 65 is diagnosed with AD/D. Between 3% and 6% of individuals with AD/D have an early onset form. The Alzheimer's Association calculates that between 200,000 and 640,000 individuals currently live with early onset AD/D in the US; this discrepancy is due, in part, to limited information about the number of individuals with early onset of dementias other than AD, and delayed diagnosis.[15] In addition, other types of dementias mimic early-onset AD including vascular dementia; Huntington's disease; Parkinson's disease; FTD; LBD; CTE; and HAND.

Many forms of early onset dementia are a type of familial disease that is inherited from a biological parent. Most cases of early onset familial AD result from inherited mutations on specific genes.[27] Individuals with Down syndrome are at a strikingly increased risk of developing early onset AD.[28] Other early onset dementias, such as Huntington's disease, FTD, and vascular dementia, also have familial forms; Huntington's disease is exclusively hereditary.[29] In addition, there are rare dementias caused by neuronal ceroid lipofuscinoses that affect children and young adults.[30, 31]

Individuals with early onset AD/D and their caregivers face unique challenges when planning and managing the disease progression. Since AD/D is more prevalent in older individuals, obtaining an accurate diagnosis for a younger person can be difficult unless the individual has a known family history of a hereditary dementia. Delayed diagnosis and misdiagnosis limit access to research studies and mitigating interventions. Most individuals are not prepared for the negative financial impact of early-onset AD/D due to job loss, cost of healthcare, difficulty obtaining Social Security Disability benefits, ineligibility for Medicare, and high cost of long-term care. Resources and community supports are limited because AD/D programs are typically designed for older adults. Individuals with early onset AD/D frequently have dependent children living at home. These factors exacerbate the financial demands and stress on their caregivers.[15]

Down Syndrome

Individuals with Down syndrome, an intellectual and developmental disability (ID/DD), are at increased risk for developing AD, particularly the early onset form, due to the accelerated aging process experienced by this population. These individuals have a partial or full third copy of the 21st chromosome. The 21st chromosome carries genes that are involved in the aging process and in producing the proteins that contribute to the development of AD. The particular properties of this chromosome set make AD a more acute concern for this population.[32] Individuals with Down syndrome almost invariably develop the brain pathology of AD (e.g., amyloid plaques and neurofibrillary tangles) by the time they are 30 years old[33]; more than 70% will develop AD and AD-related cognitive decline when they are in their 60s.[28]

Although most individuals with Down syndrome develop the pathology of AD, not all exhibit the typical symptoms and decline associated with the disease. Researchers are focusing on individuals with Down syndrome who do not develop AD in order to identify differences and protective qualities.[34] For this population, cognitive decline occurs more rapidly and can be aggressive, making early diagnosis crucial to providing better support for them.[35] Individuals with Down syndrome are more prone to 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 of and

treatment for this population difficult because many dementia symptoms are associated with other conditions.[34]

Due to the unique presentation of AD in individuals with Down syndrome, this population requires specialized care from formal and informal caregivers.[36] The National Task Group on Intellectual Disabilities and Dementia Practices recommends specific caregiver training, the use of respite services, environmental modifications, and collaboration with service agencies.[35] More information on the connection of Down syndrome and AD can be found at: http://www.ndss.org/Resources/Aging-Matters, http://aadmd.org/sites/default/files/NTG-communitycareguidelines-Final.pdf and http://aadmd.org/NTG.

Risk Factors

There currently is no exact known cause of AD; research to understand the biological origins of the disease is critically needed. However, researchers have discovered several risk factors associated with AD: older age, family history and heredity, and lifestyle.

Old age is the most significant risk factor for AD. One of nine individuals age 65 and older and one in three of those age 85 and older are diagnosed with AD.[37]

Genetics research suggests that certain combinations of APOE ε2, ε3, or ε4 genes, inherited from both parents, increase an individual's risk of developing AD.[2, 14, 38] This gene is responsible for providing the blueprint for a protein that transports cholesterol through the blood stream. Researchers estimate that as many as 65% of individuals with AD have at least one copy of APOE-ε4. Research also supports the conclusion that mutations of several specific genes cause AD/D.[14]

Researchers are exploring the influence of lifestyle choices and health conditions on AD. For example:

- Research supports the importance of cardiovascular health, citing the high rates of AD in individuals with cardiovascular disease. Risk factors for cardiovascular disease include high cholesterol, obesity, diabetes, lack of physical activity, poor diet, and smoking.[39]
- Research has supported the hypothesis that a higher level of education, which may increase or strengthen neural pathways, lowers the risk for, or slows the progression of, AD by creating a "cognitive reserve."[40] Other researchers believe the role of education is less important to brain function and explain this connection by the impact lower socioeconomic status has on access to medical care.[41]
- Individuals with head injuries or moderate to severe traumatic brain injury (TBI) are at an increased risk for developing AD/D.[2, 42]

A study conducted in Denmark supports the theory that lifestyle and health factors can play a significant role in acquiring AD/D.[43] This study compared two generations born in 1915 and 1905. Those born in 1915 scored higher on two different cognitive tests at age 95 than those born in 1905 did at age 93. The only major differences found between these two groups were that the 1915 cohort had 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 research suggests that healthier individuals are less likely to have some of the risk factors associated with AD/D, and will therefore be less likely to develop the disease. A similar study in England and Wales compared two generations of randomly selected individuals age 65 and older in the same geographic areas.[44] The rate of AD/D in this study dropped 25% in the second generation studied. Individuals in the later generation presented reduced cardiovascular risk factors and were better educated, emphasizing the influence of education and health in the development of AD/D.

Further research regarding risk factors is essential to better understand causal relationships and to improve opportunities for the prevention of AD/D. Based on known risk factors, individuals can pursue a number of preventative life style changes to potentially lower their risk of developing AD/D. These strategies include:

- lowering high cholesterol;
- lowering high blood pressure;
- controlling diabetes;
- quitting smoking;
- maintaining a healthy weight;
- engaging in regular physical activity;
- engaging in socially and intellectually stimulating activities;
- choosing to eat healthier foods; and
- engaging in safe practices to avoid head injuries.

Identification and Diagnosis

The NIA's 2011 diagnostic guidelines encourage the early detection of AD/D by recognizing the preclinical/presymptomatic stage of the disease.[45] Biomarker tests have the potential to identify changes 20 years before noticeable cognitive decline at the preclinical/presymptomatic stage and these tests are a possible future method of detecting AD/D.[2, 45] A biomarker is a biological factor that can be measured which detects the presence, absence, or risk of a disease, (e.g., beta-amyloids and tau in cerebrospinal fluid), and certain proteins and/or mutations in blood tests.

Another form of brain biomarker analysis involves brain imaging technology. Magnetic resonance imaging (MRIs) and computed tomography scans enable brain structural abnormalities, including tumors and regional brain shrinkage, to be detected. Positron emission tomography (PET) scans involve a tracer molecule injected into the blood that detects the abnormal presence of a specific pathological protein (amyloid or tau) in the brain or identifies brain regions with abnormal metabolic activity.

Combinations of these methods may be used to distinguish AD from other forms of dementia with more precision. These new biomarker analyses may eventually enable definitive AD/D diagnoses to be made in the clinic setting.

AD/D cognitive screening tools are assessments that can determine a person's cognitive abilities, detect impairments, track functional/ADL decline, and monitor progression of MCI and AD/D. Cognitive screening tools alone do not provide enough information for formal diagnosis, but support the need for further, more extensive assessment and evaluation for diagnostic purposes. The Alzheimer's Association, the National Institutes of Health (NIH), and Centers for Medicare and Medicaid Services (CMS) have recommended validated tools that are applicable

in a range of settings. For example, these tools may be used in primary care offices and administered during annual physicals or used by other health and clinical professionals.[46] More than 40 screening tools are utilized to assess cognition and identify potential impairments.[47] Many of the recommended cognitive screening tools are easily accessed, implemented, and free to administer; however they should be used only by those persons who have reason to know that they are competent to do so.

Additional information on the CMS/NIH recommendations is located at http://aspe.hhs.gov/daltcp/napa/101512/Mtg6-Slides1.pdf*.*

Additional information on the Alzheimer's Association's recommendations is located at http://www.alz.org/professionals_and_researchers_14899.asp *or* http://www.alz.org/documents_custom/The%20Cognitive%20Assessment%20Toolkit%20Copy_v1.pdf.

Additional cognitive screening tools are located at http://www.nia.nih.gov/research/cognitive-instrument*.*

Early Detection

NYSDOH, in addition to the *National Plan to Address Alzheimer's Disease*, the Alzheimer's Association, and *The Healthy Brain Initiative: the Public Health Road Map for State and National Partnership, 2013-2018 (*Public Health Road Map*)*, issued by the CDC and the Alzheimer's Association, recommend early detection of AD/D.[48] Early detection is important for the individual with AD/D for a number of reasons including, but not limited to: accessing support services; planning and preparing for the future while they still have the capacity to do so; accessing treatments; and participating in clinical trials.[2]

Support services, including support groups, care consultation, and educational programs help individuals with AD/D connect with peers, and increase knowledge of the disease, caregiving options, and community resources.[49] Individuals diagnosed with early-stage AD/D have the opportunity to engage in financial and advanced care planning, and to determine and clearly express their wishes for the future.[2] Without such directives, families must make decisions based on what they believe the person would want. Making the decision to withhold or withdraw treatment is difficult, often leaving caregivers with a sense of guilt.[10]

Early detection of AD/D allows for more effective management of some symptoms and the overall advancement of other symptoms can possibly be slowed with medication. With early detection, other conditions can be ruled out or treated including depression, abnormal thyroid function, Wernicke encephalopathy, and vitamin B12 deficiencies which can intensify MCI.[29] In addition, other conditions mimic AD/D and may be reversible (e.g., normal pressure hydrocephalus and delirium).

Early detection is important and necessary for finding more effective treatments and developing prevention strategies.[2] Researchers are exploring early detection through biomarkers and genetic testing during the preclinical stage, before signs and symptoms appear.[50] Early detection provides individuals with the opportunity to participate in clinical trials that could be beneficial for treating or slowing AD/D in its early stages.

Barriers to early detection include the social stigma associated with AD/D and denial of observed changes and symptoms.[51] Social stigma persists despite the many attempts to reduce it. Strategies to overcome this barrier include educating the public on the disease and its progression, the benefits of early detection, and the impact of cultural norms on its diagnosis and treatment.

Research

Prevention

Research is a critical component of finding a method to prevent or cure AD/D and, given the growing number of individuals diagnosed with AD/D, time is of vital importance. Focus is on the prevention of AD/D and treatment in early stages, as research that has attempted to intervene in the later/clinical stages has been unsuccessful at changing the course of the disease. Currently, there are no clear prevention strategies for AD/D. However, there are steps that can be taken to recognize and mitigate risk factors.

The NIH's report *Researching for a Cure: Alzheimer's Disease and Related Dementias Research at NIH Bypass Budget Proposal for Fiscal Year 2017* suggests that some of the most promising treatments under current investigation are those focused on prevention by mitigating risk factors. Prevention strategies being studied focus on addressing risk factors such as cardiovascular health, physical activity, emotional well-being, intellectual stimulation, and social connections. Research suggests that improving an individual's vascular health has the potential to affect the development of AD/D.[50] Other unique and promising prevention research trials are exploring gene therapies and the influence of the endocrine system on preventing AD/D.

Researchers are exploring ways to prevent or delay 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 the cleavage process that generates this small protein from a larger precursor. Inhibitors of the two cleaving enzymes involved in this process, BACE-1 and gamma-secretase, are being developed as a strategy to prevent or delay the onset of AD. Tau is a protein found in neurons where it stabilizes the shape and function of a cell. In many neurodegenerative diseases, the normal function stops and these malfunctioning proteins begin to accumulate in the neuron preventing normal cellular function. Current trials include testing an anti-amyloid drug. Ongoing clinical trials are testing whether antibodies to beta-amyloid can reduce the accumulation of beta-amyloid plaque in the brains of individuals with such genetic mutations to reduce, delay, or prevent symptoms.[50]

Treatments

Although there is no cure for AD/D, research focuses on non-pharmacological and pharmacological interventions that can decrease or slow symptoms associated with AD/D.

Non-pharmacological

Behavioral symptoms commonly associated with AD/D and early losses in functional independence are not always directly attributable to the underlying physiology of the disease. Precipitating factors of behavioral or psychological symptoms associated with AD/D must be understood, especially if symptoms are new onset. Careful history and assessment may reveal an underlying medical cause for behavioral symptoms which can be addressed and treated by a

medical provider. Behavioral and psychological symptoms exhibited by individuals with AD/D should be fully assessed given that communication with the patient is often difficult. Behavioral changes, including aggression, are often responses to unmet needs such as thirst, constipation, need to use the bathroom, fatigue, hunger, pain, or secondary symptoms.[52, 53]

If there is no apparent underlying medical cause, basic, non-pharmacological approaches to AD/D care should be the first consideration for all medical and support personnel and formal or informal caregivers. Evidence shows that individuals living with AD/D are influenced significantly by fatigue, changes in routine, overwhelming sensory input, the need to integrate and respond to a demanding and busy environment and/or the misperceptions about that environment that are associated with disease-associated perceptual losses.[75] Often these situations can be prevented or reversed by focusing on caregiver approach and the environment of care as a first priority. This may avoid the use of medication and the risk for adverse events related to those medications.

Non-pharmaceutical interventions may require creativity and trial and error, but there are a number of suggested interventions that should be considered to alleviate behavioral symptoms for individuals with AD/D. Shortening activities (90 minutes or less), providing rest periods, and interspersing high stimulus activities with quieter moments will combat fatigue and mitigate adverse reactions. Caregivers can minimize an individual with AD/D's reactions to change by creating clear and consistent daily routines, minimizing environmental changes and unnecessary travel, and/or maintaining consistent caregivers and caregiver routines. Awareness of an individual with AD/D's response to large groups and noise and the importance of ensuring appropriately functioning glasses and hearing aids further reduce inappropriate sensory input. In addition, consistent use of a non-confrontational approach by caregivers that integrates positive use of body language and verbal instructions promotes positive understanding by the individual with AD/D.

Additional non-pharmacological treatments of AD/D include music therapy, reminiscence therapy, physical exercise, cognitive training, and collaborative care.[2, 27, 55] The goal of these interventions is to maximize cognitive functioning and the individual's ability to perform ADL's, and/or enhance overall quality of life throughout the disease process. Best practices for AD/D care include care models that are team-based and coordinate care across settings, including medical.[55]

Pharmacological

Existing pharmacological treatments address the cognitive symptoms of AD and some other dementias by temporarily increasing neurotransmitter chemicals to the brain. These treatments do not stop the damage to neurons that causes AD, but may temporarily improve symptoms. Cholinesterase inhibitors are medications used to treat individuals with mild to moderate symptoms; these medications include Donepezil (Aricept), Rivastigmine (Exelon), and Galantamine (Razadyne). Memantine (Namenda) is a medication used to reduce symptoms for those with moderate to severe AD and is believed to moderate glutamate levels in the brain that may lead to brain cell death.[2] Namzaric has been approved to treat moderate to severe AD and combines memantine hydrochloride extended-release (Namenda) and donepezil hydrochloride (Aricept), which are often prescribed in tandem.

Another avenue being explored by pharmaceutical companies is to develop drugs that rid the brain of amyloid antibodies. However, at this time clinical trials have not yielded positive results.[50, 55] An alternative intervention under exploration by the NIH is testing existing drugs

that may yield positive results for AD/D that were originally developed to address other diseases.[27] More information on medications can be found at http://www.nia.nih.gov/Alzheimers/publication/Alzheimers-disease-medications-fact-sheet.

Behavior management through non-pharmacological interventions may not be sufficient for every individual's plan of care. Pharmaceutical therapies are also available for treating some of the mental health, behavioral symptoms and co-occurring chronic conditions associated with AD/D. Psychotropic medication (e.g., anti-depressants, anxiolytics, and antipsychotics) can be used to address behavioral and emotional symptoms including, but not limited to, agitation, aggression, hallucinations, and delusions. There are health risks associated with the off-label use of some of these medications in individuals with AD/D.[2, 57] Therefore, medications should be used judiciously for a short period of time and frequent assessment is important. Individuals with AD/D frequently have one or multiple chronic conditions (e.g., AD and hypertension). Managing co-occurring conditions improves the effectiveness of AD/D treatment.[50]

Palliative Care

Palliative care should be initiated from the time of diagnosis and may have a substantial impact on improving the quality of life for the individual with AD/D as well as the caregiver.[10] Palliative or comfort care aims to keep an individual comfortable and pain-free until life ends naturally.[58]

Once the decision is made to pursue comfort care or palliative care, clinicians should discuss treatment options with caregivers for the inevitable medical decline that will follow. Despite available treatments, there is currently no cure for AD/D, and the disease results in death.[10] Most individuals with end-stage AD/D are at an increased risk of aspiration pneumonia, development of pressure sores, recurrent urinary tract infections and possible urosepsis, poor oral intake affecting weight and nutrition, constipation, and delirium. Advanced care decisions should respect the person's values and wishes while maintaining comfort and dignity.[58]

Caregiver Burden

Informal Caregivers

Millions of Americans are informal caregivers who provide unpaid care for individuals with AD/D. Nationally, informal caregivers for individuals with AD/D provide an estimated 17.9 billion hours of unpaid care. The Alzheimer's Association reports that caregivers' unpaid care was valued at $217.7 billion in 2014. This is nearly equal to the estimated cost of direct medical and long term care for AD/D. Studies have found as many as one-third of individuals cared for by "sandwich generation caregivers" (caregivers who care for both an aging person and a dependent child), are individuals with AD/D.[2, 19]

The role of an informal caregiver for a person with AD/D is intensely stressful. Caring for individuals with AD, especially in the later stages of the disease, can be extremely demanding. The chronic stressors of caregiving often affect the caregiver's financial stability, physical health, and emotional well-being. Caregivers are tasked with a wide range of responsibilities including, but not limited to, assisting with ADL's, advocacy, managing physical and behavioral symptoms, caring for other family members, identifying support services, paying for services, and, eventually, providing total care for the person with AD/D.

Most of the contemporary research indicates that the burden of caring for an individual with AD/D disproportionately affects women and minorities.[59] Women represent 65% of caregivers of individuals with AD and report taking on a higher burden of caregiving responsibilities. According to the *2015 Alzheimer's Association Facts and Figures* and a study conducted by AARP, Hispanic and African American caregivers report more time caregiving and higher intensity of caregiving burden compared to non-Hispanic white caregivers.[2, 60] However, other research disputes this claim and identifies non-Hispanic white caregivers as experiencing increased depression and perceived stress when compared to caregivers of other races and ethnicities.[61]

Research also demonstrates that providing caregivers with an array of support services alleviates caregiver burden, enhances the quality of life for both the individual with AD and the caregiver, delays institutional placement, and lowers healthcare costs. The most effective caregiver support strategies strive to improve the well-being of caregivers and consequently the outcomes for individuals with AD/D.[62, 63, 64] The Alzheimer's Association recommends case management, psychoeducation, counseling, support groups, respite, psychotherapeutic approaches, multicomponent approaches, and training for caregivers of individuals with AD/D. Caregivers who receive support services are able to stave off negative impacts on their own health.[63]

Formal Caregivers

Formal caregivers are paid staff who provide in-home and residential care. These caregivers often experience high levels of stress, leading to high turnover rates in this field. One study, which examined attitudes of direct care workers in AD/D settings, found that stress levels are particularly high in facilities with specialized AD/D units.[65] Stress levels were also higher among male workers, younger workers, and staff working for less than two years,

The growing number of individuals with AD/D has created an urgent need for additional trained professional caregivers. Strategies for expanding this workforce include improving compensation and training to retain and attract a more qualified workforce.[66] Workers who receive more AD/D training are more likely to have a person-centered attitude and report more job satisfaction.

Cost of Alzheimer's Disease and Other Dementias

Individuals with AD/D use a disproportionate amount of healthcare resources. A study funded by NIH found that health care costs for AD/D are greater than for any other disease. NIH reported that in the last five years of life, total health care spending for an individual with AD/D is more than $280,000, greater than costs associated with death from other diseases, including cancer and heart disease.[67]

The cost of health care, long-term care, and hospice services for individuals with AD/D makes this one of society's most costly chronic conditions.[68] According to the *2015 Alzheimer's Association Facts and Figures*, the cost of care for Americans with AD/D is $226 billion nationally. This includes an estimated $113 billion covered by Medicare; $41 billion covered by Medicaid; $44 billion in-out-of-pocket expenses paid by individuals with AD/D and/or caregivers; and $29 billion covered by other sources, including private insurance and health organizations. It is also more common for a person with AD/D to be dually enrolled in Medicaid and Medicare; 29% of seniors with AD/D are dually enrolled, as compared to 11% of those without the disease.

Average annual Medicaid payments for people with AD/D are 19 times greater than average Medicaid payments for dual enrollees who do not have this condition.[2]

Almost four million individuals who have AD/D also have at least one other chronic condition. These individuals are 5.5 times more likely to have six or more chronic conditions than a person without AD/D. According to the 2012 NYS BRFSS, 12.4% of respondents who reported memory problems also reported having the following conditions: arthritis, asthma, chronic obstructive pulmonary disease, diabetes and/or cancer.

Other common chronic conditions associated with individuals with AD/D are heart disease, strokes, and kidney disease. The combination of AD/D and chronic health conditions complicates treatment and increases the cost of care. In 2009, 30% of Medicare beneficiaries age 65 and older with dementia also had coronary artery disease, 29% also had diabetes, 22% also had congestive heart failure, 17% also had chronic kidney disease and 17% also had COPD.[2]

The average Medicare costs for seniors with AD/D and other chronic conditions are significantly higher than those individuals on Medicare who have a chronic condition without AD/D. A senior with AD/D and diabetes costs Medicare 81% more than a senior with only diabetes. Individuals with multiple chronic conditions are more expensive to the Medicare system; this is true for those with and without AD/D. A senior with one chronic condition and AD/D costs Medicare an average of 75% more than a senior with one chronic condition but no AD/D; this equates to $16,775 compared to $9,523. Seniors with three chronic conditions and AD/D cost Medicare, on average, 25% more than a senior with three chronic conditions but no AD/D; $27,097 compared to $21,581.[69]

Individuals with AD/D require more care (e.g., home care, long-term skilled nursing, etc.) than those experiencing normal aging: 42% of individuals with AD/D live in long-term care facilities as compared with 2% of individuals without AD/D.[69] Individuals with AD/D are hospitalized two to three times more frequently than individuals of the same age without AD/D.[1, 70]

In addition to increased health care costs, the cost of AD/D to business and industry is substantial when considering lost wages and productivity from absenteeism and the effects of presenteeism (the issue of workers' being present on the job but, because of illness or other medical conditions, not fully functioning) for those caregivers who are able to remain in the workforce.[71] Many are forced to reduce hours or quit altogether due to their caregiving responsibilities. Loss of wages may also contribute to financial burden when an individual with AD/D needs to exit the workforce prematurely due to symptoms of AD/D, particularly early onset. More information is available at https://www.alz.org/facts/downloads/facts_figures_2015.pdf.

The value of unpaid caregiving is also significant. Caregivers for individuals with AD/D spend an average of 92 hours per month fulfilling caregiving duties.[72] In 2014, there were 15.7 million caregivers of individuals with AD/D. Nationally, NYS has the fourth highest number of unpaid caregivers in the nation. According to data from the *2015 Alzheimer's Disease Facts and Figures*, over one million caregivers in NYS provided an estimated 1,100,000 hours of unpaid care valued at over $14 billion dollars.

Elder Justice for Individuals with AD/D

Elder justice is a broad term that, at its essence, means assuring that vulnerable older adults are protected from crime, abuse, neglect and financial exploitation. Elder justice also involves ensuring that vulnerable older adults have access to legal interventions and networks that provide or refer them to services and supports to address their needs. The Elder Justice Act (42 USCS § 3002) defines "elder justice" as follows: (A) used with respect to older individuals, collectively, means efforts to prevent, detect, treat, intervene in, and respond to elder abuse, neglect, and exploitation and to protect older individuals with diminished capacity while maximizing their autonomy; and (B) used with respect to an individual who is an older individual, means the recognition of the individual's rights, including the right to be free of abuse, neglect, and exploitation."

Abuse is a term that refers to knowingly, intentionally, or negligently acting in a manner that causes harm or a serious risk of harm to a susceptible person. Elder abuse occurs when a person is targeted due to vulnerabilities related to advanced age. This harm can by inflicted by anyone including a formal or informal caregiver, a family member, a friend, an acquaintance, a gatekeeper, or a stranger.

There is currently no mechanism for formally tracking elder exploitation. The number of individuals suffering from elder abuse is severely underreported. According to a 2011 study conducted in NYS, for every one reported case of abuse, as many as 24 cases are unreported. The most common forms of abuse are financial, emotional, physical, and neglect. While sexual abuse does occur, is not as common as these other forms.[73] It is fairly common for an abuser to inflict multiple types of abuse on a victim (e.g., a perpetrator is financially exploiting an elderly person, but also employs emotional and physical abuse to keep that person subservient).

Individuals with AD/D are especially susceptible to exploitation due to their difficulty recognizing, communicating, and/or defending themselves. In addition, perpetrators will exploit their cognitive impairment for personal gain at the expense of the victim. One of the most effective ways to protect an individual with AD/D from abuse is when an advocate, friend, family member, or caregiver recognizes the warning signs and intervenes or contacts NYS Adult Protective Services (APS) for assistance.[73, 74] More information about recognizing elder abuse can be found at: http://www.aoa.gov/AoA_programs/elder_rights/EA_prevention/whatisEA.aspx.

Financial Exploitation

As seen nationally, the number of financial exploitation cases in NYS is on the rise and is the most common form of elder abuse. Financial abuse is a broad term that includes, but is not limited to, the theft of money or property; coercing a person to adjust a will; using property without given permission; subjecting an individual to fraud and scams; overcharging for a service; or forging signatures. Poor cognition and increased dependence on others can create situations where the individual with AD/D is more vulnerable to this exploitation. In general, financial exploitation is difficult to prove due to underreporting and, often, lack of proof.

The gap in reporting is vast; one study based on analysis of self-reports found that only one in 44 cases of financial abuse is reported to authorities (i.e., APS or law enforcement).[73] Gatekeepers at banks and other financial institutions are in the unique position of being able to recognize suspicious activity. Financial institutions and states recognize this growing problem and have developed policies and procedures to identify and address exploitation. In NYS, APS

has the authority to examine bank records if financial abuse is reported.[73, 74] More information is available at:
http://www.nij.gov/topics/crime/elder-abuse/pages/financial-exploitation.aspx,
http://NYSOCFS.ny.gov/main/publications/pub4664text.asp and
http://www.preventelderabuse.org/elderabuse/fin_abuse.html.

Physical Abuse, Emotional Abuse, and Neglect

Individuals with AD/D are more vulnerable to abuse due to their limited ability to communicate, self-advocate, and recognize maltreatment. Correlations exist between caregiver stress and abuse. Physical abuse, emotional abuse (also referred to as psychological abuse), and neglect are the other most common forms of abuse. Physical abuse is physical force or violence that results in bodily injury, pain, or impairment. It includes assault, battery, and inappropriate restraint. Emotional abuse is the willful infliction of mental or emotional anguish by threat, humiliation, or other verbal or nonverbal conduct. Neglect is the failure of caregivers to fulfill their responsibilities to provide needed care. "Active" neglect refers to intentionally withholding care or necessities. "Passive" neglect refers to situations where caregiving is withheld as a result of illness, disability, stress, ignorance, lack of maturity, or lack of resources.

As with financial abuse, the best way to prevent physical or emotional abuse and neglect is to recognize the warning signs and intervene or contact APS.[74] More information is available at http://www.preventelderabuse.org/.

Public Policy Initiatives: International and National

International

World Health Organization

The World Health Organization (WHO) recognizes AD/D as a priority condition and global public health challenge. WHO supports and encourages international efforts to address this growing issue by directing efforts to: develop health and social systems; support informal care and caregivers; raise awareness and advocacy; and plan a way forward through strategic action by the international community to address the gaps in the previously mentioned areas.[75] In March 2015, WHO hosted the first Ministerial Conference on Global Action against Dementia. The goal of this conference was to raise awareness of the socioeconomic burden of AD/D and to place AD/D high on the global health agenda.[76]

National

The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships 2013-2018

The Alzheimer's Association and CDC have created *The Healthy Brain Initiative: The Public Health Road Map for the State and National Partnership* (The Public Health Road Map), which outlines recommendations related to cognitive decline and AD for state and local public health agencies and their partners. The two main objectives of The Public Health 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 Public Health Road Map 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.[48] The Public Health Road Map can be accessed at http://www.alz.org/publichealth/2013-report/index.html.

National Plan to Address Alzheimer's Disease

The National Alzheimer's Project Act (NAPA) was signed into law in early 2011 by President Barack Obama. NAPA requires the Secretary of HHS to create and maintain a national plan to address AD. The first *National Plan to Address Alzheimer's Disease* (National Plan) was released in May 2012, with the most recent update published in 2015. The National Plan coordinates federal research on AD; works to improve prevention, diagnosis, treatment, and care for AD, including health care services and long-term services and supports; and coordinates internationally on the fight against AD.[57] The most recent version of the National Plan can be accessed at http://aspe.hhs.gov/daltcp/napa/NatlPlan2014.pdf.

Public Policy Initiatives: New York State

New York State Department of Health

The 2015-2016 NYS budget included Governor Cuomo's proposal for increased funding for services directed to individuals with AD/D and their caregivers and dedicated $25 million for AD/D programs, the largest single state investment of its kind. With these funds, NYSDOH will expand and strengthen AD/D programs and develop new initiatives using evidenced-based strategies to support caregivers of and individuals with AD/D. This new initiative, one of many Medicaid Redesign Team (MRT) projects, will address a myriad of needs of this community including a focus on improving early detection, quality of life, and quality of care including palliative care; educating health care providers; and reducing unnecessary emergency department visits, hospitalizations, and nursing home placements. The investment will be primarily carried out through competitive procurements.

Three major caregiver support initiatives will result from the increased state appropriation. The goal of these initiatives is to expand the safety net for caregivers of individuals with AD/D by recognizing and addressing the need for day-to-day caregiver supports and stress reduction. Benefits of these services will include improved health and quality of life for both individuals with AD/D and their caregivers, reduced hospitalizations, and increased ability to maintain individuals with AD/D in the community. The first RFA will provide $15 million for 10 large regional awards to provide caregiver services across the state. The second RFA will provide $1.5 million to be disbursed to 15 community-based organizations in order to target traditionally underserved communities.

NYSDOH funds the Coalition of Alzheimer's Association Chapters (AlzCAP), which in turn oversees subcontracts covering every region of the state. The increased state appropriation will enable expanded services to be available through this initiative. The goal of AlzCAP is to reduce the enormous toll that individuals with AD/D and their families experience by promoting effective patient management, education, and appropriate support for individuals with AD/D, caregivers, health care personnel, volunteers, community agencies, and first responders. These Chapters provide essential family/caregiver training and support; information and referral services; support groups for individuals with AD/D, caregivers, and family members; and a 24-hour hotline for individuals with AD/D and their families. The AlzCAP and ADAC programs

which serve similar geographic regions collaborate with and reciprocally refer individuals with AD/D and caregivers to each other for appropriate diagnosis, treatment, and support services.

Although not a direct replication, these projects reflect the evidence developed by Dr. Mary Mittelman at New York University and others.[62, 63] Dr. Mittelman describes the key factors of her successful approach in *Health Affairs*. In the article, she explains, "The intervention consisted of individual and family counseling, support group participation, and continuous availability of ad hoc telephone counseling."[64]

The increased funding will also enable the strengthening and rebranding of existing programs funded by NYSDOH. The NYSDOH currently funds nine Alzheimer's Disease Assistance Centers (ADACs) located throughout NYS. ADACs serve as "Centers for Excellence" for diagnosing and caring for individuals with AD/D. These Centers provide training for medical professionals and resources for the community. In addition to diagnosis and treatment, ADACs provide services for individuals with AD/D and their caregivers, including care management, support groups, and information and referrals to community resources. A competitive RFA, issued in 2015, will rebrand and enlarge this program. Additional information, including ADAC locations can be found at http://www.health.ny.gov/diseases/conditions/dementia/help.htm.

The ADACs and AlzCAP providers currently provide these key factors through a combination of interventions including caregiver counseling, training, and support activities such as facilitated peer support groups for caregivers and family members, a caregiver hotline, and community education. In communities where both ADACs and AlzCAP programs are present, New Yorkers have access to key elements of the supportive approach demonstrated by Dr. Mittelman's research.[62, 63] Additional services provided by the ADACs include early identification and diagnosis of AD/D and medical management of AD/D and co-morbid conditions. This array of services is based on the evidence provided through over 20 years of research. They have been tailored to meet the needs of communities being served and are expected to achieve positive outcomes for the individuals receiving program services.

In 2016, NYSDOH is also funding a two-year disparities demonstration initiative. One contractor has been selected to address disparities in AD/D throughout the mid-Hudson Valley by implementing an AD/D referral and outreach demonstration project in primarily African American and Hispanic communities.

Additional long-term care programs within NYSDOH, the Office of Health Insurance Programs, and Division of Long Term Care offer support for individuals with AD/D and their caregivers. Under the Affordable Care Act, the Balancing Incentive Program (BIP) provides financial incentives to participating states, including NYS, to offer Long Term Services and Supports (LTSS) as an alternative to institutional care. BIP aligns with the state's ongoing efforts to improve access to home and community based long-term care services through grants. Identified targets of the structural requirements of this program are the No Wrong Door/Single Entry Point System, the Core Standardized Assessment instrument, and Conflict-Free Case Management. These structures support the coordination of services for identified populations, including those with AD/D.

In addition, the Uniform Assessment System for New York is a web-based system that utilizes a comprehensive assessment within eight Medicaid home and community-based LTSS. This assessment helps providers identify the type of services and programs to deliver to individuals with AD/D. Support services for individuals with AD/D and their caregivers include: adult day health care, assisted living programs, and long-term home health care. The goal is to improve

providers' ability to connect individuals with AD/D to appropriate care. New York Connects: Choices for Long Term Care distributes information and assistance about long-term services and supports whether an individual utilizes self-pay, has health insurance, or is eligible for a government program.

New York State Office for the Aging (NYSOFA)

NYSOFA partners with state agencies and community based organizations on projects and activities concerning elder justice. These initiatives are described below:

In September 2012, Governor Andrew Cuomo announced the New York State Legal Services Initiative. The ultimate goal of this statewide, collaborative initiative is to increase access to affordable legal assistance and to ensure equal access to justice for three targeted population groups: older adults, individuals of all ages with all types of disabilities, and the caregivers of these population groups. This initiative led to a partnership among NYSOFA, the New York State Office of Court Administration, the New York State Office for Persons with Developmental Disabilities, and the New York State Bar Association, with facilitation assistance from Robert Abrams, Esq., a private attorney, and guidance from a 113-member Think Group. Information on the New York State Legal Services Initiative can be found at http://www.aging.ny.gov/LivableNY/LegalServices.

The Elder Abuse Prevention Intervention (EAPI) initiative is a three-year grant project established to pilot an intervention to prevent and address financial exploitation and elder abuse. Funded through the Affordable Care Act under the 2012 Prevention and Public Health Fund (PPHF), EAPI is also a resource for professionals serving individuals within the target population (adults aged 60 and older) who show signs of financial exploitation, and have at least one of the following characteristics: (1) health or mental health problems and/or physical impairments; (2) possible cognitive impairment issues and/or AD/D; and/or (3) social isolation and/or inadequate social support.

EAPI project partners include NYSOFA (project lead) and New York State Office for Child and Family Services (NYSOCFS) – Adult Protective Services (trainers of financial professionals). The two pilot areas include Manhattan and the Finger Lakes (counties of Monroe, Cayuga, Livingston, Ontario, Seneca, Wayne, and Yates). The EAPI initiative brings together entities with unique resources and skills, to form coordinated, enhanced multi-disciplinary teams. A unique component of the pilot intervention is the use of forensic accountants, as well as specialists from a variety of disciplines with unique skills. These individuals will consult and share expertise and organize active joint investigations and interventions to stop potential and existing financial exploitation and other forms of elder abuse.

NYSOFA collaborates with the Department of Financial Services to provide guidance to the financial industry on recognizing and reporting financial exploitation. It also participates in multiple interagency activities on elder abuse awareness, training, and prevention.

NYSOFA operates adult abuse programs that protect and provide services to vulnerable adults, including individuals with AD/D. The Long Term Care Ombudsman Program provides advocacy and serves as a resource for the more than 160,000 older adults and persons with disabilities who reside in NYS long-term care facilities, including nursing homes and adult care facilities. Ombudsmen help residents and their families understand and exercise their rights to quality care and a high quality of life.

NYSOFA also manages the Elder Abuse Education and Outreach Program (EAEOP) which provides information and outreach to the general public, including older persons and their families and caregivers specific to identifying and preventing elder abuse, neglect, and exploitation. The program consists of two components: 1) grants that allow local agencies to establish or expand existing elder abuse education and outreach programs in their distinct communities; and 2) grants that are more broad-reaching and designed to support statewide efforts to increase awareness and prevention of elder abuse.

In 2011, AOA awarded NYSOFA a Systems Integration Part B, "*Creating Dementia Capable, Sustainable Service Systems for Persons with Dementia and Their Family Caregivers*" grant. System Integration partners include the Area Agencies on Aging (AAA), NY Connects (New York's Aging and Disability Resource Center), six chapters of the Alzheimer's Association, and a community-based Alzheimer's provider. The partners worked together create a dementia capable, sustainable service system for persons with dementia and their family caregivers. This initiative is expected to end on September 30, 2016.

Systems Integration Work Groups were formed to undertake the various activities of this Dementia Capable initiative and included representatives from participating AAAs, local NY Connects, Alzheimer's disease partners, and other state agencies. Activities are ongoing to develop implementation mechanisms to heighten awareness, sensitivity, and response to individuals with or suspected of having AD/D and caregivers.

The Work Groups developed a definition for dementia capability within the NYS's aging services network which reflects elements in both the "Consumer Directed Care Toolkit: Home and Community-Based Services for People with Dementia and their Caregivers,"[77] and the 2011 Administration on Aging Systems Integration Program Announcement and Grant Application Instruction. To be dementia-capable, individuals who help consumers access home and community-based services (HCBS) must be 1) skilled at identifying and effectively communicating with individuals who have or may have dementia, including AD, and their caregiver; 2) knowledgeable about the kinds of services that help individuals with dementia and their caregivers; and 3) capable of providing linkages to other organizations that can help.[77, 78] Dementia-capable services are tailored to the unique needs of persons with dementia and their caregivers.

To date, as a result of these collaborative efforts, the following grant activities have been accomplished: 1) cross-training with AAAs and NY Connects; 2) formalized referral procedures with AAAs and NY Connects; 3) standardized web-based dementia training for AAAs and NY Connects; 4) expansion of referrals to chronic disease self-management programs; and 5) provision of direct services of care consultation and respite.

Other activities of the Work Groups include:

- In anticipation of a new No Wrong Door Screening Tool, currently being developed through the Balancing Incentive Program, the Dementia Capable workgroups have focused on incorporating two questions that will help identify individuals with dementia.

- Redesigning, expanding, and enhancing the NY Connects statewide resource directory to identify services for individuals with dementia and their caregivers.

- Web-based training for AAAs and NY Connects staff and specific training for case managers.

Information on NYSOFA's programs, services and initiatives for older New Yorkers can be found at http://www.aging.ny.gov/NYSOFA/Final_State_Plan_2015_2019.pdf.

New York State Education Department

The New York State Education Department (NYSED) regulates education throughout the lifespan and oversees the 54 professions licensed under Title VIII of the Education Law. NYSED has a vital function in providing a wide range of services to the public, including those individuals with AD/D. Many of these professions, including medicine, psychology, social work, physical therapy, occupational therapy, dentistry, accountancy, engineering, and architecture, address the needs of persons with AD/D and their caregivers.

While the core education requirements for these professions differ, all licensed professionals who provide services to persons with AD/D are required to ensure they are competent to provide the services before doing so. In addition to the education, training, and experiential opportunities to gain such competence offered by associations and employers, the NYSED Office of the Professions facilitates such education through a number of mechanisms. These include Practice Alerts, Practice Guidelines, approval of mandated continuing education courses, webinars for professionals, and recommendations to programs during the approval of course content for the degrees.

Within the broad services of NYSED, other offices provide oversight of education and the provision of services. These include the Office of Adult Career and Continuing Education Services, which encompasses the areas of Vocational Rehabilitation (including Independent Living Administration); Adult Education; and the Bureau of Proprietary School Supervision. Several of the 16 Independent Living Centers (ILC) in NYS operate as fiscal intermediaries under NYSDOH Medicaid Consumer Directed Personal Care Assistance Program (CDPAP) and provide self-directed services through surrogates. Surrogate-directed CDPAP for Medicaid eligible individuals helps individuals with AD/D remain at home, typically with family members and/or family caregivers. In addition, ILCs participate in providing New York State Office for Persons with Developmental Disabilities (NYSOPWDD) with family support services and NYSOFA with self-directed personal care services. ILCs also offer limited respite options for family caregivers.

The Bureau of Proprietary School Supervision (BPSS) oversees the programs that follow the curriculum determined by NYSDOH. To the extent that AD/D is included in the Home Health Aide-Core Curriculum established by NYSDOH, BPSS ensures that the programs include these educational requirements and are presented by qualified instructors. These programs are also overseen by the Office of the Professions' Professional Education and Review Unit.

New York State Office for Child and Family Services (NYSOCFS)

NYSOCFS serves NYS by promoting the safety, permanency, and well-being of children, families, and communities.

With recent support from state and federal government legislative actions, the issue of financial exploitation of elderly and vulnerable adults is receiving increased attention. Changes in law, together with strong community involvement against this growing social and economic problem, will hopefully reverse the trend of elder abuse.

The NYSOCFS Bureau of Adult Services is conducting the New York State Cost of Financial Exploitation Study, a research study to determine the cost of financial exploitation among vulnerable adults in NYS. The one-year time period for gathering information spanned from October 2012 through September 2013. Case information on 928 APS cases across NYS that were identified as having financial exploitation as a risk factor was provided by 31 participating counties and Lifespan of Greater Rochester, a non-profit elder services agency.

In this study, NYSOCFS examined the cost of funds and other property stolen from vulnerable elderly and dependent adults. In addition, the agency analyzed the cost of providing government benefits and services to victims of financial exploitation as well as the cost to agencies for the financial exploitation investigation and other related activities. In order to get a comprehensive picture of victims' situations, NYSOCFS examined other social factors including characteristics and relationships between perpetrators and victims.

Results of the study are not yet finalized, but preliminary numbers from the analyzed cases indicate that over $23.5 million was stolen from victims. The most frequent methods used were misappropriation of funds, larceny and Power of Attorney abuse. The cost of new or additional benefits that were put into place to keep the adult safe totaled over $1 million; Food Stamps and Medicaid were the most common benefits. The cost to involved agencies, including APS and law enforcement, totaled nearly $1.2 million. The total figure of almost $26 million is a mere fraction of the actual cost based on the 1:44 ratio of reported cases as discussed above. Therefore, final study results will most likely indicate a much higher number. NYSOCFS is expected to release the final results of this study by the end of 2015.

The social characteristics found in this this study were not surprising. For example, family members/spouses made up 61% of cases (36% were adult children). Eighty percent (80%) of victims were age 60 or older and 46% were age 81 or older. Seventy-six percent (76%) of all victims had one or more health concerns and 30% of them had signs of AD/D. Fifty-eight percent (58%) of the victims required assistance with ADL's.

Most victims do not want to involve law enforcement. This is due in part to feelings of shame or guilt, especially when a member of their family is the perpetrator. However, in about 24% of the cases criminal action was taken and only 1% of those cases saw the perpetrators convicted. A much lower percentage of cases (7%) sought civil action and the victim saw some type of settlement in only 1% of those cases.

On October 1, 2015 Governor Andrew M. Cuomo announced that NYS will use a $300,000 federal grant to crack down on the financial exploitation of older and vulnerable adults. The funding will support a two-year pilot program to expand APS in Onondaga County and Queens. This model will serve as a blueprint for the rest of the state. The NYSOCFS Bureau of Adult Services, which oversees APS in all 62 counties, will work with these local agencies to develop new investigative tools and templates for APS workers. The grant will also enable APS to confer with a forensic accounting consultant on complex cases, and to improve data collection systems. This pilot program will have an immediate impact in Onondaga County and Queens, while helping to develop the tools and resources needed to reduce this kind of abuse statewide.

New York State Office of Mental Health

The New York State Office of Mental Health (OMH) provides support for two psychiatric research institutes which study severely disabling mental disorders, the Nathan Kline Institute for Psychiatric Research (NKI) and the New York State Psychiatric Institute (NYSPI), both of which conduct research programs on the causes, early diagnosis, and treatment of AD and related neurodegenerative diseases. The major concentration of AD research within OMH is conducted at the Center for Dementia Research (CDR).

Recognized internationally for influential advances toward innovative AD therapies, CDR researchers have been awarded over $25 million in external research funding since 2011, mostly from the NIH. These awards include the renewal of a five-year, $10.3 million NIH Program Project grant in 2011 supporting collaborative research by four NKI investigators and several other NYS scientists to continue their pioneering investigations on the causes of AD and the earliest stages of AD development. The goal of current research is to identify biomarkers of AD at stages before these earliest clinical symptoms so that treatments can begin sooner. The further understanding of the biology underlying the earliest changes in the disease have identified new targets for drug intervention at these early stages. This has contributed to the development of drug therapies currently undergoing clinical testing in secondary prevention trials.

Researchers in NKI's Center for Brain Imaging and Modulation are investigating abnormal brain function, possibly heralding the future onset of Alzheimer's, in symptom-free elderly individuals who are at higher genetic risk to develop the disease. Other new imaging techniques, initially perfected in Alzheimer's model systems, are now being applied in patient populations with the goal of widening the window of prevention opportunity even further. Innovative lines of drug discovery, including recently patented approaches, are under development in the CDR, some in partnership with major pharmaceutical companies to accelerate the identification of new therapy candidates.

CDR programs have yielded over 140 peer reviewed publications in the past five years, including reports in the most prestigious scientific journals (Cell, PNAS, Science, Nature Medicine, and others), which have been cited by other investigators world-wide over 15,000 times. Attesting to the influence of CDR research in the research community, NKI ranks in the top 1% of all research institutions nationwide in citations per publication.

Ongoing programs include research to uncover mechanisms by which mutant genes accelerate the onset of AD. Major advances, for example, have been made at NKI in understanding the biology and possible treatment of AD in individuals with Down Syndrome, a population representing the most common form of early onset AD. Recent publications on AD in Down syndrome with implications for therapy have received national press attention. Additional patented technology is enabling an active program of genomic studies on individual neurons in the human brain with AD, an area of research pioneered in the CDR.

Individuals with AD decline faster if they also have vascular-related brain damage. Research in this area was catalyzed by the findings of an NKI scientist, who identified the first gene that causes a form of dementia related to AD and affects primarily the blood vessels. Subsequently, NKI scientists have developed unique laboratory models of the disease for drug screening and understanding further this important interaction of blood vessel disease with AD. Another major program is investigating the higher incidence of epilepsy in AD and its contribution to AD progression.

An important mission of OMH AD programs is to optimize the management of both memory and behavioral symptoms of people with AD/D. The elderly are highly prone to developing psychiatric disorders, probably because of age-related changes in the brain, physical disorders, as well as increased stress in later life. Besides trials of new memory-enhancing medications, these efforts at NKI's Geriatric Psychiatry Division and at the NYSPI's Memory Disorders unit have included research into effective treatments for agitation, the most common symptom leading to hospitalization and residential nursing care of individuals with AD/D. Additional clinical research is addressing the adverse effects of commonly used medicines when used in individuals with AD/D.

Both facilities offer access to cutting-edge clinical trials of diverse experimental compounds for the prevention and treatment of AD. An ongoing NKI program is designed to address important clinical needs of the elderly such as providing free cognitive assessments to individuals with memory complaints through the Memory Education and Research Initiative program. Clinical research studies at the Taub Institute at Columbia, involving investigators from the NYSPI, consist of investigational treatment studies for MCI and AD; brain imaging studies utilizing MRI and PET scanning with state-of-the-art technique and new radioactive tracers; genetic and family studies involving specific risk factors; and new approaches to make an early diagnosis of AD/D.

Section II. A Call to Action

As global, national, and state awareness of AD/D 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/D.

The New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias has developed the following recommendations that Council members will use as both a roadmap for progress and a call for diverse groups to work together to achieve them.

AD/D poses one of the greatest threats to our physical and economic futures. The following 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.

Section III. Recommendations

Recommendations for the 2015 Report of the New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias

Recommendation	Responsible Parties	Description
Caregiver Wellness and Supports		
Ensuring quality of life and quality of care for persons living with AD/D and their families across care settings		
A-1.1	NYSDOH Initiatives, NYSOFA, NY Connects	Make available an online resource directory that includes respite and support services which provide relief for caregivers.
A-1.2	NYSDOH Initiatives, NYSOFA	Improve individual and family awareness of support services.
A-1.3	NYSDOH, NYSOFA	Promote volunteer based respite models.
Caregiver Education		
A-2.1	NYSDOH Initiatives	Train informal caregivers to appropriately manage medications and to implement behavioral strategies and non-pharmacological approaches that will improve quality of life for individuals with AD/D and facilitate maintenance of home placement in the community.
A-2.2	NYSDOH Initiatives, Primary Care Providers, Healthcare Providers, Support Services Providers, Hospital Discharge Planners, AAAs	Educate caregivers on the importance of home modifications and strategies to prevent injury and limit wandering, including enrolling in the Alzheimer's Association's Medic Alert + Safe Return Program.
A-2.3	NYSDOH Initiatives, Primary Care Providers, Healthcare Providers, Support Services Providers, AAAs	Educate caregivers on how to effectively navigate the healthcare system and the importance of emergency preparedness; components would include: • Explaining Medicare/Medicaid/managed care options • Maintaining medical records • Effectively presenting information to medical providers • Completing advanced care planning documents • Keeping copies of advanced directives available for emergency room or hospital visits • Utilizing an emergency kit for the individual with AD/D that includes information such as identification, medical diagnoses, prescriptions, clothing, etc. • Assuring backup plans • Explaining long term services and supports

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Recommendation	Responsible Parties	Description
Work Force		
B-1.1	NYS Governor's Office of Employee Relations Business Council of NYS	Educate employers to recognize the economic cost of AD/D to the workplace and encourage them to offer caregiver support services and referrals through Employee Assistance Programs and personnel policies.
B-1.2	NYSDOH Initiatives	Develop and/or intensify public/private partnerships to increase public awareness of AD/D.
Training		
B-2.1	NYSDOH Initiatives, NYSOFA	Train individuals ("gatekeepers") who serve the public (i.e., mail carriers, meter readers, Meals on Wheels volunteers, etc.) on how to identify individuals with AD/D and how to appropriately prepare for and respond to hazards and emergencies.
B-2.2	NYSDOH Initiatives, NY CONNECTS, NYSOFA	Ensure that paraprofessional caregivers in both home and care settings are trained to ensure that mechanisms exist to link trained caregivers to families needing services.
B-2.3	NYSED	Provide continuing education opportunities for all healthcare providers who take AD/D training classes as a part of their mandated continuing education in accordance with their scope of practice.
B-2.4	NYSED	Provide licensed professionals the opportunity to take an online examination that would require licensees to correctly answer questions on AD/D and, when all are correct, issue some credit toward mandated continuing education in their professions.
B-2.5	NYSDOH Initiatives, NYSED	Provide training and education to medical providers and other healthcare professionals on the following topics and tools: • Understanding diagnostic guidelines • Working with people with AD/D • Working with caregivers • Understanding the importance and benefits of early detection and diagnosis • Communicating effectively with individuals with AD/D and caregivers during and after care transitions to ensure that they are as comfortable as possible • Using appropriate social interventions to improve the quality of life for those with AD/D • Understanding and communicating hospice and palliative care best practices

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Recommendation	Responsible Parties	Description
		• Recognizing how unmet needs or pain result in behavioral symptoms • Avoiding unnecessary medications and understanding the dangers associated with psychotropic medications • Effectively using non-pharmacological approaches as an alternative to psychotropic medication use • Understanding Health Insurance Portability and Accountability Act guidelines, and the NYS laws, rules and regulations, related to family members and caregivers including releasing patient information to them, and their right to be present for and participate in medical appointments • Identifying high-risk communities • Recognizing the unique needs of special populations (e.g., those individuals with early onset Alzheimer's disease, down syndrome and ID/DD, and dementias other than AD/D) • Incorporating the specific needs of cultural groups and cultural competency • Completing and coding death certificates accurately • Training emergency room staff to recognize and appropriately respond to the behavior of individuals with AD/D • Diagnosing in the emergency room and appropriately applying International Classification of Diseases-10 codes to record both the immediate cause of death and the presence of AD/D • Care planning • Understanding best practice and model dementia programs • Understanding Dementia Capable Communities
Public Awareness		
C-1.1	NYSED	• Integrate a geriatric component into developmental curricula in elementary through secondary education in order to increase the level of awareness of differences between normal aging and AD/D. • Include the opportunity for certified teachers to obtain coursework that addresses AD/D and is approved for continuing education.

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Recommendation	Responsible Parties	Description
		• Stress the full field of employment opportunities that provide care and services to the AD/D population in the joint efforts of the P-12 Education Office and the Office of the Professions to inform all students about future work and careers.
C-1.2	NYSDOH Initiatives	Bring attention to risk factors, prevention strategies, and early diagnosis.
C-1.3	NYSDOH Initiatives, Primary Care Providers	Promote increased awareness of the availability of palliative care for individuals with AD/D.
C-1.4	NYSDOH Centers of Excellence for Alzheimer's Disease (CEADs)	Educate the public, individuals with AD/D, and their families about the benefits of brain donation for research purpose through public web pages and other means.
C-1.5	NYSDOH Initiatives	Raise public awareness about the difference between AD/D and normal aging, while encouraging individuals with AD/D symptoms to be examined by healthcare providers when they experience the earliest symptoms.
C-1.6	NYSDOH Initiatives, NYSOFA	Promote early diagnosis, increase access to support services, and show people where to go for help.
C-1.7	NYSDOH Initiatives	Implement a public awareness campaign promoting the benefits of an early AD/D diagnosis.
C-1.8	NYSDOH Initiatives, Primary Care Providers	Promote primary and secondary prevention by more clearly linking the relationship between a healthy lifestyle and brain health.
Clinical Care		
Improving clinical care for persons with dementia		
D-1.1	NYSDOH Initiatives, Health Care Providers, Primary and Specialty Care Providers, Support Services Providers, Hospitals	Reduce avoidable emergency department visits, hospitalizations, and nursing home placements.
D-1.2	NYSDOH Initiatives, NYSED, Primary Care Providers, Health Care Providers, Support Services Providers	Quality clinical care should include the following components: • Reducing the number of transitions for individuals with AD/D • Screening individuals over age 65 for cognitive impairment as part of regular and emergent care with their consent, using one of the validated cognitive screening tools and/or a sentinel question similar to that used by the National Health Service in the United Kingdom: "Have you (has the person) been

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Recommendation	Responsible Parties	Description
		more forgetful in the last 12 months to the extent that it has significantly affected your (their) daily life?" • Encouraging those affected by early onset AD/D to seek additional services to manage both physical and behavioral co-occurring conditions • Utilizing evidence-based drug-free treatments that demonstrate effectiveness for treating individuals with AD/D • Implementing outreach educational programs for racial and cultural groups • Assessing cognitive impairment as part of routine primary care • Increasing programming that is cognitively and physically stimulating • Addressing behavioral challenges through neurobehavioral rehabilitation • Promoting the use of tele psychiatry and telemedicine for brief cognitive assessments • Increasing options to care for individuals with AD/D in the primary care setting • Providing care management at the time of diagnosis to all individuals with AD/D
D-1.3	Health Care Providers	Offer continuing education credits to providers to learn about AD/D screening, diagnosis, and treatment options in order to reduce misdiagnoses and inappropriate use of psychotic medicines.
D-1.4	NYSDOH Initiatives	Embed appropriate care and management of AD/D in every setting where NYSDOH has regulatory authority: homecare, adult care facilities**,** nursing homes, hospitals, and medical adult day program settings.
D-1.5	NYSDOH Initiatives, Primary Care Providers	Assess caregivers' physical and psychological well-being through informal assessments, encourage health promotion, and refer them to their healthcare provider and support services.
Clinical Trials		
D-2.1	NYSDOH Initiatives	Increase awareness regarding the importance of research and clinical trials.
D-2.2	Centers of Excellence for Alzheimer's Disease	Identify strategies to increase enrollment of racial and ethnic groups in AD/D studies and clinical trials.
Planning		
E-1.1	NYSDOH Initiatives, Health Care Providers, NYS Bar Association,	Encourage individuals with AD/D, families, and caregivers to plan ahead regarding healthcare, finances, and legal issues so that the individual with

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Recommendation	Responsible Parties	Description
	Legal Community, Hospital-based Medical/legal Partnerships, NYSOFA	AD/D can fully participate in this process. This includes advanced care planning; financial planning; selection of a power of attorney; drafting a will; and communication about these documents for when this becomes necessary.
Dementia Friendly Communities		
F-1.1	NYS Division of Criminal Justice Services (NYSDCJS)	Offer an on-line AD/D training for law enforcement.
F-1.2	NYSDOH Initiatives, NYSOFA	Train individuals ("gatekeepers") who serve the public (i.e., mail carriers, meter readers, Meals on Wheels volunteers, etc.) on how to identify individuals with AD/D and how to appropriately prepare for and respond to hazards and emergencies.
F-1.3	NYSDOH	Expand awareness of social and medical model adult day programs.
F-1.4	NYSDOH	Promote dementia capability in local long term services and support networks.
Special Populations		
Early Onset		
G-1.1	NYSDOH Initiatives	Educate individuals with early-onset AD/D about early retirement, government assistance programs (Social Security, Medicare, and Medicaid), and personal disability insurance.
G-1.2	NYSDOH Initiatives	Educate providers on the importance of individuals with early onset AD/D applying for Social Security Disability benefits.
G-1.3	NYSDOH Initiatives	Create support groups in as many geographical areas as possible so that individuals can have reasonable access to them.
G-1.4	NYSOFA	Improve the availability of aging network services to individuals with early onset AD/D.
Underserved Populations		
G-2.1	NYSDOH Initiatives	Explore effective support mechanisms for individuals with dementias other than AD.
G-2.2	NYSDOH Initiatives	Create support services that target underserved populations and that provide education on normal aging, improve timely diagnosis of AD/D, and provide effective support mechanisms for individuals with AD/D and their caregivers.
Down Syndrome and Intellectual Disability		
G-3.1	NYSOPWDD	Encourage families and caregivers of individuals with Down syndrome who suspect memory problems to

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Recommendation	Responsible Parties	Description
		communicate this concern to the individual's healthcare provider.
G-3.2	NYSOPWDD	Encourage families and caregivers of individuals with AD and Down syndrome or Intellectual Disability/Developmental Disability to engage in early planning regarding AD/D.
G-3.3	NYSDOH Initiatives	Collect data and valid research on the relationship between concussion/acquired brain injury and AD/D for use in recognizing the effects of such injuries for treatment planning, the importance of developing injury avoidance measures, and the importance of such events in the diagnosis, behavior and treatment needs at a later stage in life.
Elder Justice		
H-1.1	Office of Court Administration (OCA), NYS Bar Association, NYSOPWDD,NYSOFA	Increase access to affordable legal assistance for people with dementia and their caregivers.
H-1.2	NYSOFA, NYSOCFS	Educate Expanded In-home Services for the Elderly and Protective Services for Adults (PSA) staff on the AD/D population and the risks of adult abuse.
H-1.3	NYSDOH, NYSOCFS	Educate financial services personnel on how to identify and report financial exploitation.
H-1.4	NYSDOH, OMBUDSMAN	Advocate for enhanced quality of care and quality of life for individuals with AD/D who reside in skilled nursing and assisted living facilities.
H-1.5	NYSDOH	Provide training for judges, court personnel, attorneys, and other legal professionals on protecting the legal rights of individuals with AD/D.
H-1.6	NYSOCFS	Expand the use of forensic accountants and multidisciplinary teams to prevent elder abuse
H-1.7	NYSOCFS,OCA	Research bill paying/money management programs for individuals with AD/D who do not have family caregivers to prevent financial exploitation and abuse.
H-1.8	NYSDOH Initiatives, NYSOFA, NYSOCFS, NYSDCJS,	Participate in interagency activities on elder abuse awareness, training and prevention (e.g., the Alzheimer's Association First Responder Training and PSA Training) released by the Coordinating Council on Police Services for the Elderly to its law enforcement network.
Research		
I-1.1	NYS Research Institutes	Collaborate to accelerate progress in AD/D research, as follows:

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Recommendation	Responsible Parties	Description
		• Expanding research programs on the causes, diagnosis, and treatment of AD and related dementias to match the urgent need • Continuing collaborative research across institutes and incentivize development of cooperative inter-institutional programs • Promoting drug discovery initiatives and industry partnerships for drug discovery • Continuing to research biological effects of life style and drug-free approaches to lowering AD risk • Developing a new generation of young investigators through training and seed grant opportunities • Applying for federal funding
I-1.2	The Council, NYSDOH Initiatives, NYSED	Educate the public about the latest research findings and clinical trials, using multi-media opportunities, public presentations, social networks and public television.
I-1.3	NYSOPWDD	Promote research on the connection between Down syndrome and AD/D in NYS research institutes.
I-1.4	NYSDOH	Utilize public health surveillance systems to more accurately quantify burden of AD/D through aggregate data from electronic records, the BRFSS, and the Alzheimer's Association Facts and Figures document.
I-1.5	NYS Research Institutes	Maintain and facilitate research at a state and federal level to accelerate progress toward effective treatments for AD/D. • Leverage programs for early evaluation and care to expand knowledge and access to clinical trials and related clinical research • Leverage state data bases for epidemiological and outcome research • Interface with local Alzheimer's Association Chapters to synergize in research, awareness, and treatment efforts
I-1.6	NYS Research Institutes	Identify recognized and approved research studies throughout NYS on AD/D and maintain an updated inventory for use by educators and researchers.
I-1.7	NYSDOH Initiatives, NYS Research Institutes	Identify and promote valid and effective non-pharmaceutical interventions for individuals with AD/D.

References

1. U.S. Department of Health and Human Services (2015). National Plan to Address Alzheimer's disease: 2015 update. Retrieved from http://aspe.hhs.gov/daltcp/napa/NatlPlan2015.pdf.
2. Alzheimer's Association (2015a). Alzheimer's Disease Facts and Figures. *Alzheimer's & Dementia* 2015; 11(3)332+.
3. Reisa A. Sperling,[a,*] Paul S. Aisen,[b] Laurel A. Beckett,[c] David A. Bennett,[d] Suzanne Craft,[e] Anne M. Fagan,[f] Takeshi Iwatsubo,[g] Clifford R. Jack, Jr.,[h] Jeffrey Kaye,[i] Thomas J. Montine,[j] Denise C. Park,[k] Eric M. Reiman,[l] Christopher C. Rowe,[m] Eric Siemers,[n] Yaakov Stern,[o] Kristine Yaffe,[p] Maria C. Carrillo,[q] Bill Thies,[q] Marcelle Morrison-Bogorad,[r] Molly V. Wagster,[r] and Creighton H. Phelps. Toward defining the preclinical stages of Alzheimer's disease: Recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. Alzheimers Dement. 2011 May; 7(3): 280–292.
4. Schneider J.A., Arvanitakis Z, Bang W, & Bennett D.A. (2007). Mixed brain pathologies account for most dementia cases in community-dwelling older persons. *Neurology 69*(24) 2197–2204.
5. Alzheimer's Association (2012) Mild Cognitive Impairment (MCI) http://www.alz.org/dementia/downloads/topicsheet_mci.pdf
6. Mayo Clinic (2015). Diseases and Conditions. Retrieved from http://www.mayoclinic.org/diseases-conditions/.
7. Marilyn S. Albert,,a*, Steven T. DeKosky,,b, c, Dennis Dickson, d, Bruno Dubois, e, Howard H. Feldman, f, Nick C. Fox, g, Anthony Gamst, h, David M. Holtzman, i,,j, William J. Jagust, k,Ronald C. Petersen, l, Peter J. Snyder, m, n, Maria C. Carrill, o, Bill Thies, o, Creighton H. Phelps, p. The diagnosis of mild cognitive impairment due to Alzheimer's disease: Recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease Alzheimer's & Dementia 7 (2011) 270–279.
8. Lee, J. S., Potter, G. G., Wagner, H. R., Welsh-Bohmer, K. A., & Steffens, D.C., (2007), Persistent mild cognitive impairment in geriatric depression. *International Psychogeriatric 19*(1) 125-135.
9. Modrego P. J., Ferrández, J. (2004). Depression in patients with mild cognitive impairment increases the risk of developing dementia of Alzheimer's type: a prospective cohort study. *Archive of Neurology, 61*(8) 1290-1293.
10. Yeaman, P.A., Ford, J.L., & Kim, K.Y. (2012) Providing Quality Palliative Care in End-State Alzheimer Disease. *American Journal of Hospice & Palliative Medicine 30 (5),* 499-502.
11. Alzheimer's Disease Education and Referral Center (2003). Retrieved from https://www.nia.nih.gov/alzheimers/features/alzheimers-disease-and-end-life-issues.
12. Alzheimer's Association (2015c) Mixed Dementia; http://www.alz.org/dementia/mixed-dementia-symptoms.asp.
13. Hebert, L. E., Weuve, J., Scherr, P. A., & Evans, D. A. (2013) Alzheimer's disease in the United States (2010-2050) estimated using the 2010 census. *Neurology 80*(19) 1778-1783.
14. United States Health and Human Services: National Institute on Aging (2012). 2011-2012 Alzheimer's Disease Progress Report. Retrieved from http://www.nia.nih.gov/Alzheimers/publication/2011-2012-Alzheimers-disease-progress-report/

15. Alzheimer's Association. Early-Onset Dementia: A National Challenge, a Future Crisis. Washington, D.C.: Alzheimer's Association; 2006.
16. Centers for Disease Control and Prevention (2010). 10 Leading Causes of Death by Age Group. Retrieved from http://www.cdc.gov/injury/wisqars/pdf/10LCID_All_Deaths_By_Age_Group_2010-a.pdf.
17. U.S. Department of Health and Human Services. National Institute on Aging May 22, 2014. Retrieved from https://www.nia.nih.gov/research/announcements/2014/05/number-alzheimers-deaths-found-be-underreported
18. Weuve, J., Hebert, L. E., Scherr, P. A., Evans, D. A. Prevalence of Alzheimer's Disease in U.S. Epidemiology 2015; 26(1): e4-e6.
19. Alzheimer's Association (2013c) Alzheimer's Caregiver: Data from the Behavioral Factors Surveillance System (BRFSS). http://act.alz.org/site/DocServer/2013_BRFSS_Caregiving_Data.pdf?docID=18763.
20. Alzheimer's Association (2013e). Cognitive Decline in New York Fact Sheet. Retrieved from http://www.alz.org/documents_custom/public-health/newyork.pdf.
21. New York Academy of Medicine & the New York State Health Planning Commission (1984). Alzheimer's Disease: Implications for Public Policy in New York State, *1-17*.
22. U.S. Department of Health and Human Services (2013). Improving Care for Populations Disproportionately Affected by Alzheimer's Disease and Related Dementias: Report from the Task Force on Specific Populations. Retrieved from http://aspe.hhs.gov/daltcp/reports/2013/AlzSpPop.pdf.
23. Barnes, L. L., & Bennett, D. A. (2014). Alzheimer's Disease in African Americans: Risk Factors and Challenges for the Future. *Health Affairs*. *33*(4) 580-586.
24. Howard, G., Peace, F., Howard, V. J. The Contributions of Selected Diseases to Disparities in Death Rates and Years of Life Lost for Racial/Ethnic Minorities in the United States, 1999–2010. Prev Chronic Dis 2014;11:140138. DOI: http://dx.doi.org/10.5888/pcd11.140138.
25. Reitz, C.; Jun, G.; Naj, A.; Rajbhandary, R.; Vardarajan, B. N.; Wang, L. S.; Valladares, O.; Lin, C. F.; Larson, E. B.; Graff-Radford, N. R.; Evans, D.; DeJager, P. L.; Crane, P. K.; Buxbaum, J. D.; Murrell, J. R.; Raj, T.; Ertekin-Taner, N.; Logue, M.; Baldwin, C. T.; Green, R. C.; Barnes, L. L.; Cantwell, L. B.; Fallin, M. D.; Go, R. C.; Griffith, P.; Obisesan, T.O.; Manly, J. J.; Lunetta, K. L.; Kamboh, M. I.; Lopez, O. L.; Bennett , D. A.; Hendrie, H.; Hall, K. S.; Goate, A. M.; Byrd, G. S.; Kukull, W. A.; Foroud, T. M.; Haines, J. L.; Farrer, L. A.; Pericak-Vance, M. A.; Schellenberg, G. D.; Mayeux, R.; Alzheimer Disease Genetics Consortium. (2013). Variants in the ATP-Building Cassette Transporter (ABCA7) apolipoprotein E ϵ4, and the Risk of Late-Onset Alzheimer's Disease in African Americans. *The Journal of the American Medical Association. 309 (14); 1483-92.* http://jama.jamanetwork.com/article.aspx?articleid=1677372.
26. Alzheimer's Association; International Conference 2015. https://www.alz.org/aaic/_downloads/tues-8am-women-risk.pdf.
27. National Institute on Aging (2015). *Alzheimer's Disease Genetics (August, 2015)* NIS No. 15-6424
28. Lai, F. and Williams, R. S., (1989). A Prospective Study of Alzheimer's Disease in Down Syndrome. *Archive of Neurology 46,* 849-853.
29. Alzheimer's Association (2015) Types of Dementia. Retrieved from: http://www.alz.org/dementia/types-of-dementia.asp.
30. Kuruppu, D. K.; Mathews, B. R., (2013). Young-Onset Dementia. *Seminars in Neurology 33* (04), 365-885. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4033406/.
31. Retrieved from http://www.thearc.org/learn-about/intellectual-disability on 7/30/15.

32. National Down Syndrome Society (2012). Alzheimer's Disease & Down Syndrome. http://www.ndss.org/Resources/Health-Care/Associated-Conditions/Alzheimers-Disease--Down-Syndrome/.
33. Mann, D. M. (1988). The Pathological Association Between Down Syndrome and Alzheimer's Disease. *Mechanisms of Aging and Development 43* 99-136.
34. National Down Syndrome Society (2013). Aging and Down Syndrome: A Health and Well-Being Guidebook. New York, NY: Moran, J.
35. National Task Group on Intellectual Disabilities and Dementia Practices (2013). http://aadmd.org/sites/default/files/NTG-communitycareguidelines-Final.pdf.
36. http://healthaffairs.org/blog/2015/08/03/a-more-cohesive-home-integrating-primary-and-palliative-care-for-seriously-ill-patients/.
37. Alzheimer's Association (2015). Risk Factors. www.alz.org/alzheimers_disease_causes_risk_factors.asp
38. Loy, C. T.; Schofield, P. R.; Turner, A. M.; Kwok, J. B. J. Genetics of Dementia. Lancet 2014; 383:828–40.
39. Matthew Baumgart, a; Heather M. Snyder,b*; Maria C. Carrillo, b; Sam Fazio, c; Hye Kima, Harry Johns, d; Summary of the Evidence on Modifiable Risk Factors for Cognitive Decline and Dementia: A Population-Based Perspective Alzheimer's & Dementia 11 (2015) 718-726.
40. Stern, Yokov, Alzheimer Dis Assoc Disord. 2006 Jul-Sep; 20(3 Suppl 2):S69-74.
41. Alzheimer's Association, (2013a). 2013 Alzheimer's Disease Facts and Figures. *Alzheimer's and Dementia: The Journal of the Alzheimer's Association, 9,* 208-245.
42. Boston University, CTE Center 2009. http://www.bu.edu/cte/about/what-is-cte/.
43. Span, P. (2013, July 17). In Europe, Dementia Rates May be Falling. New York Times. Retrieved from http://newoldage.blogs.nytimes.com/2013/07/17/in-europe-dementia-rates-may-be-falling/?_r=0.
44. Kolata, G. (2013). Dementia rate is found to drop sharply, as Forecast. *New York Times* Retrieved from http://www.nytimes.com/2013/07/17/health/study-finds-dip-in-dementia-rates.html
45. Alzheimer's Association (2015b) 32and Guidelines for Alzheimer's Disease; http://www.alz.org/research/diagnostic_criteria/.
46. Cordell, C. B.; Boroson, S.; Boustani, M.; Chodosh, J.; Reuben, D.; Verghese, J.; Thies, W.; & Fried, L. B. (2013) Alzheimer's Association Recommendations for Operationalizing the Detection of Cognitive Impairment During the Medicare Annual Wellness Visit in a Primary Care Setting, *Alzheimer's & Dementia* 9, 141-150.
47. Cullen, B.; O'Neill, B.; Evans, J. J.; Coen, R. F.; & Lawlor, B. A. (2007). A Review of Screening Tests for Cognitive Impairment. *Journal of Neurology, Neurosurgery, & Psychiatry, 78*(8), 790-799.
48. Centers for Disease Control and Prevention (2013). The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018. Retrieved from http://www.cdc.gov/aging/pdf/2013-healthy-brain-initiative.pdf.
49. Alzheimer's Association (2015). Care Consultation. Retrieved from http://www.alz.org/oc/in_my_community_10847.asp.
50. National Institute on Aging (2014). 2013-2014 Alzheimer's Disease Progress Report Insights and Challenges. Retrieved from http://www.nia.nih.gov/Alzheimer's /publication/2013-2014-_Alzheimer's-disease-progress-report.
51. Batsch, N. L., Mittelman, M. S. & Alzheimer's Disease International (2012). World Alzheimer's Report 2012: Overcoming the Stigma of Dementia. Retrieved from http://www.alz.org/documents_custom/world_report_2012_final.pdf.

52. Kovach, C. R., Noonan, P. E., Schlidt, A.M. & Wells, T. (2005). A model of consequences of need-driven, dementia-compromised behavior. *Journal of Nursing Scholarship, 37*(2), 134-140.
53. Algase, D. L., Beck, C. Kolanowski, A., Whall, A., Berent, S., Richards, K. & Beattie, E. (1996). Need-driven dementia-compromised behavior: An alternative view of disruptive behavior. *American Journal of Alzheimer's Disease*, 10-19.
54. Resources for Integrated Care (2015). http://event.on24.com/r.htm?e=1038360&s=1&k=82CA3393D54B8EB5D4FA440D29FC4038
55. Iglehart, J.K. (2014). The elusive search for solutions to Alzheimer's. *Health Affairs, 33*(4) 526.
56. Bor, J. S. (2014). The search for affective Alzheimer's therapies: a work in progress. *Health Affairs 33*(4) 527-533.
57. Taiple, H., Koponen, M., Tansknen, A., Tolppanen, A. M., Tiihonen, J., Hartikainen, S., (2014) Antipsychotic polypharmacy among a nationwide sample of community-dwelling persons with Alzheimer's Disease. *Journal of Alzheimer's Disease. 41* p. 1223-1228. U.S. Department of Health and Human Services (2014a). National plan to address Alzheimer's disease: 2014 update. Retrieved from http://aspe.hhs.gov/daltcp/napa/NatlPlan2014.pdf.
58. Alzheimer's Association (2015). End-of-life Decisions. https://www.alz.org/national/documents/brochure_endoflifedecisions.pdf
59. Lynda A. Anderson, PhD; Valerie J. Edwards, PhD; William S. Pearson, PhD; Ronda C. Talley, PhD, MPH; Lisa C. McGuire, PhD; Elena M. Andersen, PhD. Adult Caregivers in the United States: Characteristics and Differences in Well-being, by Caregiver Age and Caregiving Status http://www.cdc.gov/pcd/issues/2013/13_0090.htm.
60. National Alliance for Caregiving & AARP (2009). Caregiving in the U.S. in 2009. Retrieved from http://www.caregiving.org/data/Caregiving_in_the_US_2009_full_report.pdf.
61. Janevic, M.R. and Commell, C.M. Racial, Ethnic, and Cultural Differences in the Dementia Caregiving Experience Recent Findings *The Gerontologist 41*(3) 334-347.
62. Mittelman, M,S., Haley, W.E., Clay, O.J. & Roth, D.L. (2006). Improving Caregiver Well-Being Delays Nursing Home Placement of Patients with Alzheimer's Disease. *Neurology*, *67,* 1592-1599.
63. Mittelman, M,S., Haley, W.E., Clay, O.J. & Roth, D.L. (2006). *Mary S. Mittelman, Dr.P.H., David L. Roth, Ph.D., Olivio J. Clay, M.A., William E. Haley, Ph.D.* Preserving Health of Alzheimer Caregivers.
64. Mittelman, M. & Bartels, S. (2014). Translating research into practice: case study of a community-based dementia caregiver intervention. *Health Affairs, 33*(4), 587-95.
65. Zimmerman, S., Williams, C. S., Reed, P. S., Boustani, M., Preisser, J. S., Heck, E. & Sloane, P. D. (2005). Attitudes, Stress, and Satisfaction of Staff Who Care for Residents with Dementia. *The Gerontologist, 45*(1), 96-105.
66. Warshaw, G. A. & Bragg, E. J., (2014). Preparing the Health Care Workforce to Care for Adults with Alzheimer's Disease and Related Dementias. *Health Affairs 33*(4) 633-641.
67. National Institute on Aging (2015). Retrieved from http://www.nih.gov/news/health/oct2015/nia-27.htm
68. Hurd, M. D., Martorell, P., Delavande, A., Mullen, K. J. & Lange, K. M. (2013). Monetary Costs of Dementia in the United States. *The New England Journal of Medicine, 368*(14), 1326-1334.
69. Bynum, J. (2011). Tabulations based on data from the Medicare current beneficiary survey for 2008. Unpublished manuscript. Dartmouth Institute for Health Policy and Clinical Care, Dartmouth Medical School

70. Bynum, J. P.; Rabins, P. V.; Weller, W.; Niefeld, M.; Anderson, G. F.; Wu, A. W.; (2004). The Relationship Between Dementia, Diagnosis, Chronic Illness, Medicare Expenditures, and Hospital Use. *Journal of American Geriatrics Society. 52 (2) p. 187-194.*
71. Hemp, P. (2004). Presenteeism: at work – but out of it. *Harvard Business Review*. October 2014. Retrieved from https://hbr.org/2004/10/presenteeism-at-work-but-out-of-it/ar/1
72. Kasper, J. D.; Freedman, V. A.; Spillman, B. C. (2014) Disability and Care Needs of Older Americans by Dementia Status: An Analysis of the 2011 National Health and Aging Trends Study. Available at http://aspe.hhs.gov/pdf-report/disability-and-care-needs-older-americans-analysis-2011-national-health-and-aging-trends-study.
73. Lachs, M., Berman, J. (2011). *Under the Radar: New York State Elder Abuse Prevalence Study.* Retrieved from: http://NYSOCFS.ny.gov/main/reports/Under%20the%20Radar%2005%2012%2011%20final%20report.pdf.
74. National Committee for the Prevention of Elder Abuse (2008). http://www.preventelderabuse.org/.
75. World Health Organization & Alzheimer's Disease International (2015). http://www.who.int/mental_health/neurology/dementia/en/.
76. Alzheimer's Association, RTI International (2012). *Consumer-Directed Care Toolkit: Home and Community-Based Services for People with Dementia and Their Caregivers – A Toolkit for the Aging Network.* Retrieved from http://www.aoa.acl.gov/AoA_Programs/HPW/Alz_Grants/docs/Toolkit1_ConsumerDirectedCare.pdf
77. U.S. Administration on Aging (2011). *Program Announcement and Grant Application Instructions **PART A** - Accelerating Integrated, Evidence-Based, and Sustainable Service Systems for Older Adults, Individuals with Disabilities and Family Caregivers; **PART B** – Creating Dementia-Capable, Sustainable Service Systems For Persons With Dementia And Their Family Caregivers*: *Attachment G Definitions* (OMB Approval No. 0985-0018). Retrieved from http://www.adrc-tae.acl.gov/tiki-index.php?page=SysInt.
78. National Institute of Medicine (2015): http://www.nlm.nih.gov/medlineplus/ency/article/001613.htm.

Attachment A:

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

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Ralph Nixon, MD, Ph.D.
Nathan Kline Institute

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New York State Office for the Aging

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Alzheimer's Association, New York City Chapter

Elizabeth Smith-Boivin
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Attachment B:

Summary of Alzheimer's Disease and Other Dementias (AD/D)

Diagnosis	Diagnostic Criteria
Alzheimer's disease (AD)	**Characteristics:** AD is a slowly progressive brain disease that begins well before symptoms emerge and is fatal. There is no known cure or vaccine for this disease. AD is the most common type of dementia, accounting for an estimated 60 to 80% of cases.
	Symptoms: • Early-stage: o Difficulty remembering recent conversations, names, or events o Confusion with time and place o Word finding issues o Difficulty performing familiar tasks in home, social, or work settings o Misplacing valuable items o Losses in planning, problem solving, and organizational abilities o Changes in mood or behavior o Withdrawal from work or social activities o Impaired judgment • Middle-stage: o Forgetting events in one's personal history o Mood changes (apathy, depression, irritability) o Behavioral changes (agitation, wandering, aggression) o Increasing confusion related to date, time, and place o Difficulty maintaining continence o Disturbances in sleep, disruptions in sleep patterns o Increasing difficulties with ADLs, mobility, and functional independence • Late-stage: o Lack of awareness of recent experiences, surroundings, and physical functioning o Difficulty swallowing o At risk for infections, especially pneumonia o Further decline in physical ability and mobility o Significant dependence on caregivers for ADLs and personal care o Impaired verbal and receptive communication skills
	Brain changes: Hallmark abnormalities are deposits of the protein fragment beta-amyloid (plaques) and twisted strands of the protein tau (tangles) as well as evidence of nerve cell damage and death in the brain.
	Diagnosing: An AD diagnosis is based on a medical evaluation completed by a medical professional that includes a physical and neurological examination; interviews of the

Summary of Alzheimer's Disease and Other Dementias (AD/D)

Diagnosis	Diagnostic Criteria
Alzheimer's disease (AD) *(continued)*	patient and family member; mental status tests; functional assessments; and examinations to establish any differential diagnoses.
	Known risk factors: • Advancing age • Family history • Genetics, specifically the presence of the APOE-e4 gene or Down syndrome.
Diagnosis	**Diagnostic Criteria**
Chronic Traumatic Encephalitis (CTE)	**Characteristics:** CTE is a progressive degenerative brain disease associated with repetitive brain trauma and mild TBI. CTE can occur as a result of concussions often received in contact sports or non-concussive hits to the head over time.
	Symptoms: • Characteristics of dementia - memory loss, impaired judgment, confusion and agitation – appearing years after trauma • Depression and suicidal thoughts • Behavioral and mood changes • Impulse control problems and aggression
	Brain changes: The repetitive brain trauma triggers a progressive degeneration of brain tissue and the build-up of the abnormal protein called tau. These changes in the brain can begin months, years, or even decades after the last episode of trauma.
	Diagnosing: CTE is diagnosed through a physical and neurological examination, as well as a personal history that includes an assessment of past head trauma and involvement in contact sports. Brain imaging is also recommended.
	Known risk factors: • Repeated brain trauma • History of head injuries/TBIs
Diagnosis	**Diagnostic Criteria**
Creutzfeldt-Jakob disease (CJD)	**Characteristics:** CJD is the most common human form of a group of rare disorders categorized as Prion diseases. Prion diseases occur when prion proteins, found throughout the body and brain, begin misfolding into an abnormal three-dimensional shape. Cognitive changes with CJD are uncharacteristically rapid and severe. There are three main types of CJD: sporadic, familial, and transmitted/infectious; the most common form of CJD is sporadic.
	Symptoms: • Confusion and rapid decline in all areas of cognition • Involuntary muscle movements, twitches and/or stiffness • Difficulty walking

Summary of Alzheimer's Disease and Other Dementias (AD/D)

Diagnosis	Diagnostic Criteria
Creutzfeldt-Jakob disease (CJD) *(continued)*	• Apathy, agitation and mood changes • Depression
	Brain changes: Results from misfolded prion protein throughout the body that progresses to the brain and leads to a destruction of brain cells.
	Diagnosing: CJD is diagnosed through a medical and personal history; a neurological exam; and spinal fluid testing via lumbar puncture to test for the presence of prion protein. Testing should also include an electroencephalogram and brain MRI. There is no known cause for sporadic CJD.
	Known risk factors: • Genetic variations • Exposure to external sources of abnormal prion protein (poorly sterilized medical equipment or infected meat)
Diagnosis	**Diagnostic Criteria**
Frontotemporal dementia (FTD)	**Characteristics:** FTD is an umbrella term that refers to a group of disorders that involve the frontal and temporal areas of the brain controlling personality, language, and movement. These diseases include behavioral variant FTD, temporal/frontal FTD, progressive non-fluent aphasia, semantic dementia, primary progressive aphasia, Pick's disease, corticobasal syndrome, progressive supranuclear palsy, FTD with parkinsonism, and FTD with amyotrophic lateral sclerosis (ALS). Persons with FTD are typically diagnosed in their 40s to 60s.
	Symptoms: • Behavior changes often noted first; may be impulsive and inappropriate • Early difficulty with understanding speech or reading • Changes in personality and emotional reactions • Decline in motor function
	Brain changes: There is no distinguishing microscopic abnormality linked to all types of FTD. FTD primarily affects the frontal (forehead) and temporal (behind the ears) lobes of the brain. High levels of tau and Transactive Response Deoxyribonucleic Acid Protein-43 (TDP-43) have been found on autopsy. Individuals with FTD generally develop symptoms at a younger age than those with other forms of dementia, and survive for anywhere between 18 months to 20 years, with an average life expectancy of seven years.
	Diagnosing: The diagnosis of FTD requires an examination by a professional knowledgeable about this disorder. Evaluations should include a history of issues being experienced by the patient and a comprehensive neurological examination. Brain imaging, particularly MRIs and glucose PET scans, are helpful in determining the diagnosis of FTD.

Summary of Alzheimer's Disease and Other Dementias (AD/D)

Diagnosis	Diagnostic Criteria
Frontotemporal dementia (FTD) *(continued)*	**Known risk factors:** • Family history (accounts for 1/3 of the cases)
Diagnosis	**Diagnostic Criteria**
HIV associated neurocognitive disorder (HAND)/Acquired immune deficiency syndrome (AIDS) dementia complex (ADC)	**Characteristics:** HAND is an umbrella term for HIV-related dementias that include: Asymptomatic Neurocognitive Impairment, Mild Neurocognitive Disorder and HIV-Associated Dementia. The virus enters the central nervous system early in the course of the infection and causes several cognitive changes over the course of the disease.
	Symptoms: • Forgetfulness, confusion, and other changes in cognition • Behavioral and personality changes • Headaches • Weakness and loss of sensation in arms and legs • Progressive motor dysfunction • Extremity pain due to nerve damage
	Brain changes: The HIV virus penetrates the blood-brain barrier, and affects subcortical brain structures below the cerebral cortex. HIV has also been shown to alter brain size in the areas specific to learning and information processing. Although the virus doesn't directly invade or damage nerve cells in the brain, it impacts the health and function of these cells, causing an encephalitis (inflammation of the brain). Persons with advanced HIV infections are likely to develop ADC or HAND, leading to behavioral changes and a gradual decline in cognitive function.
	Diagnosing: HAND/ADC is diagnosed through a complete neurological examination, brain imaging, and potentially a lumbar puncture to assess cerebrospinal fluid. Cognitive testing is also recommended.
	Known risk factors: • HIV Infection
Diagnosis	**Diagnostic Criteria**
Huntington's disease	**Characteristics:** Huntington's disease is a progressive brain disorder caused by a single defective gene on Chromosome 4. This defect is hereditary and "dominant" meaning that if an individual has the gene then he/she will eventually develop the disease. Symptoms develop typically between the ages of 30 and 50.
	Symptoms: • Unsteady gait and involuntary movements (chorea) involving all extremities • Forgetfulness and impaired judgment • Decline in thinking and reasoning skills including memory, concentration, judgment and ability to plan or organize

Summary of Alzheimer's Disease and Other Dementias (AD/D)

Diagnosis	Diagnostic Criteria
Huntington's disease *(continued)*	• Personality changes, mood swings, anxiety, depression and uncharacteristic anger or irritability • Obsessive-compulsive tendencies
	Brain changes: The gene defect influences the abnormal production of "huntingtin" protein that, over time, leads to worsening symptoms.
	Diagnosing: A medical examination completed by a medical professional that includes a personal and family medical history, physical examination and neurological examination. Genetic testing and counseling is strongly recommended.
	Known risk factors: • Heredity and family history
Diagnosis	**Diagnostic Criteria**
Lewy body dementia (LBD)	**Characteristics:** LBD presents with cognitive symptoms similar to AD and movement symptoms typical of Parkinson's disease (muscle rigidity, shuffling gait, stooped posture, and difficulty initiating movement). Most experts estimate that LBD is the third most common cause of dementia after AD and vascular dementia.
	Symptoms: • Cognitive difficulties similar to AD, although memory loss of less severity • Periods of confusion and alertness that vary from one time of the day to another, or from one day to the next • Sleep disturbances, often acting out dreams • Well-formed visual hallucinations and delusions • Muscle rigidity or other Parkinsonian movement features • Autonomic nervous system changes • Difficulty with visual interpretations
	Brain changes: Lewy bodies are abnormal aggregations (or clumps) of the protein alpha-synuclein. When they develop in a part of the brain called the cortex, dementia can result. Alpha-synuclein also collects in the brains of people with Parkinson's disease, but the masses may appear in a pattern that is different from LBD.
	Diagnosis: A diagnosis of LBD is based on a medical evaluation completed by a medical professional that includes a physical, cognitive and neurological examination. Cognitive changes will be more significant in the areas of judgement, planning, and visual perception, likely less significant for memory. Well-formed hallucinations and delusions are likely. Movement symptoms typical of Parkinson's disease will be present, along with changes in autonomic nervous system function leading to drops in blood pressure, dizziness or repeated falls.
	Known risk factors: • Advanced age

Summary of Alzheimer's Disease and Other Dementias (AD/D)

Diagnosis	Diagnostic Criteria
Lewy body dementia (LBD) *(continued)*	• Male gender • Family member with history of LBD • Parkinson's disease diagnosis
Diagnosis	**Diagnostic Criteria**
Mild Cognitive Impairment (MCI)	**Characteristics:** MCI is characterized by cognitive changes that are significant enough to be noticeable by the person experiencing them and/or others, but not severe enough to interfere with daily life or independence. MCI is not cognitive decline related to normal aging. Individuals diagnosed with amnestic MCI are at a greater risk of developing AD/D but not all individuals with MCI progress to a dementia. The symptoms of other conditions, such as depression or a Vitamin B12 deficiency, may mimic those of MCI.

	Symptoms:
	• MCI primarily affecting memory ("Amnestic"):
	  ○ Short-term memory and re-call problems
	  ○ Difficulty learning new information
	• MCI primarily affecting thinking ("Non-amnestic")
	  ○ Losses in executive thinking (planning, organization)
	  ○ Lack of judgment
	  ○ Difficulty completing complex tasks
	  ○ Changes in visual perception
	• Presence of depression, irritability, anxiety, and/or apathy

	Brain changes: Brain imaging has shown overall reductions in brain volume in persons with MCI, particularly in the area of the hippocampus, and an enlargement of the ventricles. Abnormal presences of beta-amyloid protein and microscopic clumps of tau may be found but in less significant amounts than seen with AD/D.
	Diagnosing: MCI is a clinical diagnosis based on a medical professional's best judgment after considering the individual's medical history, functional and ADL assessment, input from family, and/or mental status testing. Diagnosis may be enhanced with the use of biomarker testing (cerebrospinal fluid examinations and imaging).
	Known risk factors: • Advancing age • Family history of AD/D • Conditions that increase a person's risk of cardiovascular disease (e.g., hypertension, smoking, lack of exercise, or diabetes)
Diagnosis	**Diagnostic Criteria**
Mixed Dementia	**Characteristics:** Mixed dementia is characterized by the simultaneous occurrence of the signs and symptoms of different types of dementia. The most common forms of

Summary of Alzheimer's Disease and Other Dementias (AD/D)

Diagnosis	Diagnostic Criteria
Mixed Dementia *(continued)*	mixed dementia are AD with vascular dementia, AD with LBD, or characteristics of AD mixed with vascular and LBD.
	Symptoms: Symptoms vary and depend on the type of brain changes involved and regions affected. In many cases, symptoms may be similar to or even indistinguishable from those of AD or another type of dementia. In other cases, a person's symptoms may suggest that more than one type of dementia is present.
	Brain changes: An individual with mixed dementia will have the pathology of the presenting combination of AD/D. For example, in an individual with both AD and vascular dementia, abnormal protein deposits associated with AD co-exist with blood vessel changes problems linked to vascular dementia.
	Diagnosing: Mixed dementia is diagnosed based on a medical evaluation that includes a physical and neurological examination, interviews of the patient and family member, mental status tests, functional assessments, and examinations to establish any differential diagnoses. Although mixed dementia is infrequently diagnosed, researchers believe it deserves more attention because the combination of two or more types of dementia-related brain changes may have a greater impact on individuals and increase their chances of developing symptoms.
	Risk Factors: • Risk factors are consistent with the types of dementia that comprise the mixed dementia diagnosis.
Diagnosis	**Diagnostic Criteria**
Parkinson's disease	**Characteristics:** Parkinson's disease occurs when abnormal aggregations (or clumps) of the protein alpha-synuclein occur in the brain. This protein forms Lewy bodies similar to those seen with LBD. As Parkinson's disease progresses, the brain changes gradually spread. These changes often begin to affect mental functions including memory, the ability to pay attention, make sound judgments, and plan the steps needed to complete a task. As Parkinson's disease progresses, it may result in a progressive dementia.

	Symptoms
	• Memory impairment with disruptions in judgment and ability to concentrate
	• Parkinsonian motor changes, such as:
	  ○ Bradykinesia (slowed movements)
	  ○ Tremors, mostly at rest
	  ○ Muscle rigidity
	  ○ Gait disturbances (shuffling, forward propelling, difficulty initiating movement)
	  ○ Mask-like fascial expression

Summary of Alzheimer's Disease and Other Dementias (AD/D)

Diagnosis	Diagnostic Criteria
Parkinson's disease *(continued)*	○ Abnormal posture ○ Micrographia • Delusions and paranoid ideations • Sleep disturbances • Depression and anxiety • Overall fatigue • Low volume and muffled speech
	Brain changes: Parkinson's disease begins in a region of the brain that plays a key role in movement. Alpha-synuclein clumps are likely to begin in an area deep in the brain called the substantia nigra; the deposits are called Lewy bodies. These clumps are thought to cause degeneration of the nerve cells that produce dopamine.
	Diagnosing: Parkinson's disease is diagnosed by a medical professional trained in nervous system disorders and will include a medical history, complete physical and neurological examination, and a thorough assessment of cognitive function. Evaluation may include the use of a specialized imaging technique called a dopamine transporters scan (DaTscan) that captures dopamine in the brain.
	Known risk factors: • Age 60 or older • Heredity • Male gender • Exposure to toxins (particularly herbicides and pesticides)
Diagnosis	**Diagnostic Criteria**
Vascular dementia	**Characteristics:** Vascular dementia results from conditions that decrease or alter blood flow to the brain and leads to brain cell damage. Previously known as multi-infarct dementia, post-stroke or "mini-stroke" dementia, vascular dementia accounts for about 10% of dementia cases. Vascular dementia is the second most common dementia after AD.
	Symptoms: Symptoms of vascular dementia can vary depending on the area of the brain affected and the extent of damage caused by changes in blood flow to the brain. They may include: • Decrease in ability to organize thoughts and actions • Confusion, disorientation, and poor attention span • Impaired judgment and reasoning skills • Difficulty with decision making • Inability to complete complex, multiple step tasks • Communication challenges related to losses in expressive and/or receptive language • Changes to vision

Summary of Alzheimer's Disease and Other Dementias (AD/D)

Diagnosis	Diagnostic Criteria
Vascular dementia *(continued)*	• Impairments in mobility and/or extremity weakness specific to the area of the brain affected
	Brain changes: The location of vascular change in the brain and the extent of the damage will determine how the individual's thinking and physical functioning are affected. There are three criteria necessary for a vascular dementia diagnosis: • A diagnosis of dementia or MCI; • Evidence of a stroke or other blood vessel changes that affect cause damage in the brain; and • There is no evidence that factors other than vascular changes caused the decline.
	Diagnosing: Because vascular dementia may often go unrecognized, many experts recommend screening for everyone considered to be at high risk for this disorder. A diagnosis of vascular dementia is made after the completion of a professional screening to assess memory, thinking ability, and reasoning, in conjunction with a thorough neurological examination. Brain imaging may detect blood vessel changes that can relate to vascular dementia.
	Known risk factors: • History of heart disease and stroke • Smoking • Poorly managed diabetes • Obesity and lack of exercise • Hypertension and high cholesterol
Diagnosis	**Diagnostic Criteria**
Wernicke-Korsakoff syndrome (WKS)	**Characteristics:** WKS is a chronic memory disorder caused by severe deficiency of thiamine (vitamin B-1). It is most often associated with alcoholism but can be associated with AIDS, chronic infections, malnutrition, or other medical conditions. WKS is conceptually closely related to two syndromes: Wernicke encephalopathy, which is an acute phase of disease and potentially reversible, and Korsakoff dementia, which results from more chronic disease and is irreversible.
	Symptoms: • Memory problems, both recent recall and long term, accompanying intact higher level cognitive and social skills • Difficulty learning new information • Tendency to confabulate and make up information that can't be recalled
	Brain changes: Thiamine helps brain cells produce energy from sugar. When thiamine levels fall too low, brain cells cannot generate enough energy to function properly.
	Diagnosing: WKS is a clinical diagnosis representing a doctor's best professional judgment about the reason for a

Summary of Alzheimer's Disease and Other Dementias (AD/D)

Diagnosis	Diagnostic Criteria
Wernicke-Korsakoff syndrome (WKS) *(continued)*	person's symptoms. There are no specific laboratory tests or neuroimaging procedures to confirm that a person has this disorder. Symptoms may be masked by other conditions associated with alcohol misuse. A complete medical workup for cognitive changes should include questions about an individual's alcohol use.
	Known risk factors: • Alcohol misuse • Poor nutrition related to stringent dieting, fasting or anorexia • Presence of other diseases that lead to malnutrition such as AIDS, kidney dialysis, chronic infection, or cancer

For more information about Alzheimer's Disease and Other Dementias:
http://hivinsite.ucsf.edu/InSite?page=id-01-08
http://www.alz.org/dementia/types-of-dementia.asp
http://www.alz.org/facts/overview.asp#impact
http://www.mayoclinic.org/diseases-conditions
http://www.bu.edu/cte/about/what-is-cte/
https://www.aids.gov/
https://www.nia.nih.gov/alzheimers/publication/
http://www.theaftd.org/life-with-ftd/newly-diagnosed/faq

Attachment C:

Acronyms

AAA	Area Agency on Aging
AD	Alzheimer's disease
AD/D	Alzheimer's disease and other dementias
ADAC	Alzheimer's Disease Assistance Center
ADC	AIDS dementia complex
ADL	Activities of daily living
AIDS	Acquired Immune Deficiency Syndrome
AlzCAP	Coalition of Alzheimer's Association Chapters
AOA	Administration on Aging
APOE	Apolipoprotien E
APS	Adult Protective Services
BIP	Balancing Incentive Program
BPSS	Bureau of Proprietary School Supervision
BRFSS	Behavioral Risk Factor Surveillance System
CDC	Centers for Disease Control and Prevention
CDPAP	Consumer Directed Personal Care Assistance Program
CDR	Center for Dementia Research
CEAD	Centers of Excellence for Alzheimer's Disease
CJD	Creutzfeldt-Jakob disease
CMS	Centers for Medicare and Medicaid Services
Council	New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias
CTE	Chronic Traumatic Encephalitis
FTD	Frontotemporal Dementia
HAND	HIV associated neurocognitive disorder
HHS	U.S. Department of Health and Human Services
HIV	Human Immunodeficiency Virus
ID/DD	Intellectual Disability and Developmental Disability
ILC	Independent Living Centers
LBD	Lewy Body Dementia
LTSS	Long-term services and supports
MCI	Mild Cognitive Impairment
MRI	Magnetic Resonance Imaging
MRT	Medicaid Redesign Team
NAC	National Advisory Council
NAPA	National Alzheimer's Project Act
NIA	National Institute in Aging
NIH	National Institutes of Health
NKI	Nathan Kline Institute for Psychiatric Research
NWD	No Wrong Door
NYS	New York State
NYSDCJS	New York State Division of Criminal Justice Services
NYSDOH	New York State Department of Health
NYSED	New York State Education Department
NYSOCFS	New York State Office for Child and Family Services
NYSOFA	New York State Office for the Aging
NYSOPWDD	New York State Office for Persons with Developmental Disabilities

NYSPI	New York State Psychiatry Institute
OCA	Office of Court Administration
PET	Positron Emission Tomography
PSA	Protective Services for Adults
Public Health Road Map	*The Healthy Brain Initiative: the Public Health Road Map for State and National Partnership, 2013-2018*
RFA	Request for Applications
TBI	Traumatic Brain Injury
US	United States
WHO	World Health Organization
WKS	Wernicke-Korsakoff syndrome