

2019 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

## **Table of Contents**

### **Section I. Background**

New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias.....	3
Dementia.....	3
Prevalence and Mortality.....	6
Risk Factors.....	10
Identification and Diagnosis .....	11
Early Detection.....	12
Research Update.....	13
Caregiver Burden.....	17
Cost of Alzheimer's Disease and Other Dementias.....	18
Elder Justice for Individuals with AD/D.....	19
National and New York State Public Policy Initiatives.....	21
Related Public Policy Initiatives: New York State.....	23
Section II. Recommendations (Under Development).....	35
References.....	36
Attachment A: New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias Member List.....	41
Attachment B: Summary of Alzheimer's Disease and Other Dementias.....	42
Attachment C: Acronym List.....	52

## **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) is established pursuant to Public Health Law § 2004-a as enacted by Chapter 58 of the Laws of 2007, Part B, § 24.

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 living 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 was charged with providing reports to the Governor and the Legislature beginning in 2009 and every two years thereafter. 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 New York State (NYS) agencies to meet the needs of persons living with AD/D and their families.

Since 2011, New York, under Governor Cuomo's leadership, has launched several initiatives to make New York the best place to grow up and grow older, including implementing a [Health Across All Policies](#) approach where state agencies work together to develop policies and programs that positively impact public health; expanding the state's [Prevention Agenda](#) to more comprehensively address the social determinants of health and healthy aging; and adopting the [eight domains](#) of livability for age-friendly communities as defined by the World Health Organization (WHO) and AARP. The domains are designed to encourage both state and local level strategies advancing healthy lifestyles, including exercise and social connectiveness, that have been shown to prevent or delay physical and cognitive decline.

This is the sixth report by the Council. The Council has gathered advice from Council members and other experts in the field to inform the development of this report.

#### **Dementia**

Dementia is an umbrella term that refers to a group of degenerative neurocognitive disorders. AD/D damages 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 an individual's ability to perform activities of daily living (ADL) and independent functioning.<sup>1</sup>

#### **Alzheimer's Disease**

Alzheimer's disease (AD) is the most common form of dementia; 60-80% of individuals with dementia have AD.<sup>2</sup> 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. Available treatments that may temporarily improve or slow worsening symptoms do not alter the overall disease progression of AD. 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.<sup>3</sup> More information on the diagnostic guidelines can be viewed at:  
<https://www.nia.nih.gov/health/alzheimers-disease-diagnostic-guidelines>.

The Alzheimer's Association identifies three stages of dementia due to AD: mild, moderate, and severe.<sup>3</sup> 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. It may be difficult to place an individual in a specific stage because stages blend and may overlap.<sup>4</sup>

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.<sup>3</sup>

#### *Mild Cognitive Impairment (MCI)*

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.<sup>5</sup> 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.<sup>2,5</sup> MCI symptoms can be described as a range between the expected cognitive decline of normal aging and the more significant changes of AD/D.<sup>6</sup>

MCI is significant in the development and diagnosis of AD, but some individuals with MCI never develop AD. Studies indicate that as many as 15% to 20% of people over age 65 have MCI, and a review of 32 studies identified that a median of 31.5% of people with MCI progress to AD over five years.<sup>7</sup> People with amnestic MCI are at greater risk of developing AD. If an individual presents with both MCI and the biomarkers for AD, there is a degree of certainty that he or she will develop AD.<sup>5</sup> 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.<sup>6</sup> For those individuals with MCI caused by treatable conditions, managing these

conditions can eliminate the presence of MCI-like symptoms. This is particularly true among older adults with acute depression.<sup>8</sup> 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.<sup>9</sup>

#### *Mild Alzheimer's Disease (Early-Stage)*

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.<sup>5</sup> 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
- changes in mood or behavior

When an individual 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.<sup>2</sup>

#### *Moderate Alzheimer's Disease (Middle-Stage)*

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 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.

#### *Severe Alzheimer's Disease (Late-Stage)*

Individuals in the late stages of AD experience extremely debilitating symptoms which can be devastating for their caregivers and families. The symptoms of AD worsen over time. However, the rate of the disease's progression varies. A person with AD will live, on average, eight to ten years after diagnosis. However, in some cases, individuals with AD can live as long as 20 years.<sup>10, 11</sup>

During the final stage of AD's progression, individuals lose awareness of recent experiences and surroundings and physical functioning. They have difficulty communicating and are vulnerable to infections such as pneumonia due to the inability to move around during late-stage Alzheimer's disease. They eventually lose the ability to swallow. Individuals in this stage will eventually require total care and dependence on caregivers. The disease will ultimately lead to death. Pneumonia is a common cause of death because impaired swallowing allows food or beverages

to enter the lungs, where an infection can begin. Other common causes of death include dehydration, malnutrition and other infections.

### 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, although some of the neurodegenerative processes have common pathways.<sup>1</sup> 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. Several studies report that a majority of people with Alzheimer's disease also had brain changes associated with another form of dementia upon autopsy. (Kapasi A, DeCarli C, Schneider JA. Impact of multiple pathologies on the threshold for clinically overt dementia.), (Brenowitz WD, Hubbard RA, Keene CD, Hawes SE, Longstreth WT, Woltjer, et al. Mixed neuropathologies and estimated rates of clinical progression in a large autopsy sample. *Alzheimer's Dement*. 2017;13(6):654-62)

Despite evidence from autopsy studies of the high prevalence of mixed pathologies in older adults, mixed dementia is infrequently diagnosed, despite its 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/media/Documents/alzheimers-dementia-mixed-dementia-ts.pdf>.

### **Prevalence and Mortality**

#### National

An estimated 5.8 million Americans live with AD; approximately 5.6 million of these individuals are over age 65.<sup>2</sup> The number of Americans over the age of 65 living with AD may grow to 13.8 million by 2050.<sup>2</sup> The rate of AD increases with age, and approximately 32% of people over age 85 have AD.<sup>2</sup> Although AD is typically diagnosed in people over age 65, it is estimated that at least 200,000 Americans between the ages of 30 to 60 are diagnosed with "younger/early onset."<sup>12</sup> There is currently limited data addressing the prevalence and mortality of other forms of dementia.

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).<sup>2</sup> One in three seniors in the United States dies from AD.<sup>2</sup> A research study conducted by the Centers for Disease Control and Prevention

(CDC), which analyzed all resident death certificates filed from the 50 states and the District of Columbia, found an age-adjusted rate of 25.4 deaths from AD per 100,000 deaths for the year 2014; this is a 54.4% increase from the 1999 rate of 16.5 deaths per 100,000.<sup>13</sup> According to data from the CDC, 121,404 people died from Alzheimer's disease in 2017.<sup>2</sup> 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.<sup>14</sup>

Similarly, limited data related to other dementias could also contribute to their under-representation on death certificates. The 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.<sup>15</sup>

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 2017 survey indicates that one in nine Americans over the age of 45 are experiencing confusion or memory loss. Over a third of those who reported cognitive impairment also reported functional difficulties related to their confusion or memory loss. Less than half of those with cognitive decline have not reported this condition to their health care providers.<sup>16</sup> [https://www.cdc.gov/brfss/annual\\_data/annual\\_2017.html](https://www.cdc.gov/brfss/annual_data/annual_2017.html).

### New York State (NYS)

The scope of AD has been difficult to project for multiple reasons. These include the following: many people remain undiagnosed because they do not share their symptoms with their medical providers; medical providers are reluctant to give this diagnosis; and cultural barriers discourage individuals from seeking a diagnosis.

An estimated 400,000 individuals in NYS have AD and that number is expected to increase to 460,000 by 2025. Comparable data for other dementias is not available.<sup>2</sup> The rise of the number of cases of the disease has far exceeded early expectations.

Similar to national figures, in NYS, 1 in 9 individuals aged 45 and over reported confusion or memory loss in the 2017 BRFSS and only 54.4% of them indicated that they reported the condition to their health care provider.<sup>16</sup> Additional NYS-related BRFSS data is located at: [https://www.cdc.gov/brfss/annual\\_data/annual\\_2017.html](https://www.cdc.gov/brfss/annual_data/annual_2017.html).

### 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.<sup>17</sup> The Task Force issued an updated report with recommendations for these populations in 2018. This report is located at: <https://aspe.hhs.gov/report/national-plan-address-alzheimers-disease-2018-update/strategy-2h-improve-care-populations-disproportionately-affected-alzheimers-disease-and-related-dementias-and-populations-facing-care>.

## Racial and Ethnic Minorities

Disparities are associated with the risk of developing of AD/D among certain racial, ethnic, and socioeconomic groups. Compared to older Caucasians, older African Americans are two times and Hispanics are one and a half times more likely to have AD.<sup>2</sup> More research is needed to estimate the prevalence of AD/D in other racial and ethnic groups. However, a 2016 study which examined electronic health records of individuals from six different racial and ethnic groups found that dementia incidence was highest among African Americans and American Indians, intermediate among Latinos, Pacific Islanders, and Caucasians, and lowest among Asian Americans.<sup>18</sup>

Research has shown that higher prevalence rates of AD/D in the African American and Hispanic populations are likely due to the higher number of individuals in these groups who have health conditions associated with AD/D.<sup>2</sup> These conditions include, but are not limited to, cardiovascular disease, diabetes, chronic kidney disease, and higher hemoglobin levels.<sup>19, 20</sup> Increased risk of cardiovascular disease due to diabetes and heart disease also increases the risk of vascular dementia.<sup>2</sup> Socioeconomic characteristics may also contribute to differences in prevalence or incidence among racial groups. These factors include lower levels of education, higher rates of poverty, and greater exposure to adversity and discrimination.<sup>2</sup>

In addition to lifestyle 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.<sup>21</sup> There is evidence that missed diagnoses of AD/D are more common among African-Americans and Hispanics than non-Hispanic Caucasians.<sup>2</sup> Research has also found that upon initial diagnosis, African Americans and Hispanics had higher levels of cognitive impairment and dementia than non-Hispanic Caucasians, and suggested that more research is required to determine the reason (e.g., differing cultural views regarding medical care and cognitive decline.).<sup>2, 19</sup>

## Women

Dementia disproportionately affects women -- both in disease prevalence and through caregiving burden. The disease contributes to growing rates of disability among women and impacts their emotional, physical, and financial well-being.

Women make up nearly two-thirds of Americans with the disease.<sup>2</sup> Longevity alone might not be the only explanation for the higher prevalence of dementia among women.<sup>23, 24</sup> Researchers are exploring this disparity by examining risk factors related to genetics (brain structure, disease progression, estrogen, and depression).<sup>24</sup> There is currently no definitive evidence of a causal relationship between these risk factors and AD/D. Health behavior, including cognitive development, education and physical activity throughout the lifespan might contribute to the difference in prevalence among men and women.<sup>25, 22, 23</sup>

Women provide 65% of all paid and unpaid caregiving for individuals with AD/D.<sup>26</sup> Women are 2.3 times more likely than men to have provided care to someone with dementia for more than five years; this means that much of the financial, emotional, and physical burden of caregiving falls on them.<sup>26, 27</sup> Women are more likely than men to reduce their work hours to part-time or stop working altogether to be able to provide care. Twenty percent of female care partners have gone from working full-time to part-time, while only 3% of the men have had to do the same. This

leaves women more vulnerable to being unable to support themselves later in life given a Social Security system based on number of years worked.<sup>22, 23, 28</sup>

### Early/Younger Onset Dementia

Early (also known as younger) onset dementia occurs when a person under the age of 65 is diagnosed with AD/D. There is limited data available on the number of Americans in the neurotypical population who are currently living with early onset dementia. A systematic review and meta-analysis published by the National Institutes of Health (NIH) in 2015 estimated that approximately 5.5% of individuals with dementia have an early onset form.<sup>29</sup> In 2006, the Alzheimer's Association calculated a tentative range of 200,000 to 640,000 individuals living with early onset AD/D in the US; this wide range is due, in part, to limited information about the number of individuals with early onset of dementias other than AD, and delayed diagnosis.<sup>12</sup> 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.<sup>30</sup> Individuals with Down syndrome are at a strikingly increased risk of developing early onset AD.<sup>31</sup> Other early onset dementias, such as Huntington's disease, FTD, and vascular dementia, also have familial forms. Huntington's disease is exclusively hereditary.<sup>33</sup> In addition, there are rare dementias caused by neuronal ceroid lipofuscinoses that affect children and young adults.<sup>33, 34</sup>

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.<sup>12</sup>

### 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 of the disease, due to the accelerated aging process experienced by this population. These individuals have a partial or full third copy of the 21<sup>st</sup> chromosome. The 21<sup>st</sup> chromosome carries genes that are involved in the aging process and in producing the proteins that contribute to the development of AD neuropathology. The properties of this chromosome set make AD a more acute concern for this population.<sup>35</sup>

Most people with Down syndrome will develop significant levels of beta-amyloid plaques and tau tangles in their brains by the age of 40 years. According to the National Down Syndrome Disease Society, "Alzheimer's disease is not inevitable in people with Down syndrome. While all people with Down syndrome are at risk, many adults with Down syndrome will not manifest the changes of AD in their lifetime." It is estimated that about 30% of people with Down syndrome have AD in their 50s, and this number rises to 50% when they reach their 60s.<sup>36</sup>

Given this early onset, it is important that families and caregivers of individuals with DD/ID or AD and Down syndrome who suspect memory problems and/or other symptoms communicate their concerns to the individual's healthcare provider and engage in early planning regarding AD/D.

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.<sup>37</sup> For this population, cognitive decline occurs more rapidly and can be aggressive, making early diagnosis crucial to providing better support.<sup>39</sup> 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.<sup>37</sup>

Due to the unique presentation of AD in individuals with Down syndrome, this population requires specialized care from formal and informal caregivers.<sup>39</sup> 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.<sup>38</sup> More information on the connection of Down syndrome and AD can be found at:

<https://www.ndss.org/>

<https://aadmd.org/sites/default/files/NTG-communitycareguidelines-Final.pdf>

<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. Three percent of individuals between the ages of 65-74, 17% of individuals between the ages 75-84, and 32% of individuals age 85 or older have AD.<sup>2</sup>

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.<sup>2,42, 40</sup> This gene is responsible for providing the blueprint for a protein that transports cholesterol through the blood stream. Researchers estimate that as many as 67% 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.<sup>41</sup>

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, excessive alcohol use, and tobacco use.<sup>42</sup> ([https://www.cdc.gov/heartdisease/risk\\_factors.htm](https://www.cdc.gov/heartdisease/risk_factors.htm))
- 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.”<sup>43</sup> 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.<sup>44</sup>

- ⦿ Individuals with head injuries or moderate to severe traumatic brain injury (TBI) are at an increased risk for developing AD/D.<sup>2</sup>

A study conducted in Denmark supports the theory that lifestyle and health factors can play a significant role in acquiring AD/D.<sup>45</sup> This study compared two generations, one born in 1915 and the other in 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.<sup>46</sup> 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 many preventative lifestyle changes to potentially lower their risk of developing AD/D. These strategies include:

- Exercise/physical activity – Physical activity reduces inflammation, encourages generation of stem cells, helps maintain healthy weight, reduces stress and risk of many chronic conditions.
- Sleep – The brain clears excess amyloid during deep sleep. Individuals should target 7-8 hours of sleep per night.
- Diet – The Mediterranean diet has been shown to have multiple benefits, and other approaches (i.e., increasing fruit and vegetable intake) have been shown to reduce inflammation and reduce the risk of many chronic conditions.
- Intellectual Stimulation – Learning something new builds new synapses in the brain – an essential component of an active functioning brain.
- Manage stress – Chronic increased stress produces toxic brain chemicals thought to accelerate dementia symptoms. Stress reducing and managing activities like exercise and meditation help reduce and control those chemicals.
- Social Stimulation and Reduction of Isolation – The subjective experience of social isolation can increase the risk of dementia by up to 40%. Feelings of social connectedness and fulfillment can help to reduce this risk.<sup>47</sup>

## **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.<sup>48</sup> 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.<sup>2, 48</sup> A biomarker is a substance

found in the body that can be measured to detect 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 biomarker analysis involves brain imaging technology. Magnetic resonance imaging (MRI) and computed tomography (CT) 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 diagnostic 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 clinical setting.

### Review and Report on Cognitive Screening Tools

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 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.<sup>49</sup> More than 40 screening tools are utilized to assess cognition and identify potential impairments.<sup>50</sup> 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 Alzheimer's Association's recommendations is located at:  
<https://www.alz.org/professionals/healthcare-professionals/cognitive-assessment>.

Additional information on assessing cognitive impairment is located at:  
<https://www.nia.nih.gov/alzheimers/publication/assessing-cognitive-impairment-older-patients>.

### **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, 2018-2023* (Public Health Road Map), issued by the CDC and the Alzheimer's Association, recommend early detection of AD/D. (<https://www.cdc.gov/aging/pdf/2018-2023-Road-Map-508.pdf>)<sup>51</sup> Early detection is important for the individual living 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.<sup>2</sup>

*The 2019 Alzheimer's Facts and Figures* includes a Special Report *Alzheimer's Detection in The Primary Care Setting: Connecting Patients with Physicians*.<sup>2</sup> This report explores the state of cognitive assessment, termed "brief cognitive assessment," in the primary care setting and

identifies potential solutions for existing barriers to widespread adoption of assessment in primary care settings.

Support services, including support groups, care consultation, and educational programs help individuals living with AD/D connect with peers, and increase knowledge of the disease, caregiving options, and community resources. 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.<sup>2</sup> 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.<sup>52</sup>

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.<sup>33</sup> 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.<sup>2</sup> Researchers are exploring early detection through biomarkers and genetic testing during the preclinical stage, before signs and symptoms appear.<sup>53</sup> 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.<sup>54</sup> 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 Update**

### 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. The 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. Aerobic exercise is presently the mainstay of delaying progression of the mild cognitive impairment stage of AD. 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 report titled *Sustaining Momentum: NIH Takes Aim at Alzheimer's Disease & Related at NIH Bypass Budget Proposal for Fiscal Year 2019* suggests that some of the most promising treatments under current investigation may be those focused on prevention by mitigating risk factors.<sup>55</sup> 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.<sup>53</sup>

Several unique and promising prevention research trials are exploring gene therapies and the influence of the endocrine system on preventing AD/D. Researchers have been exploring ways to prevent or delay the build-up of two proteins: beta-amyloid and Tau. Build-up of beta-amyloid in the brain is associated with 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 among the strategies being tested to prevent or delay the onset of AD although results of large trials thus far have been negative.

Ongoing clinical trials are also testing whether antibodies to beta-amyloid can reduce the accumulation of beta-amyloid plaque in the brains of individuals to reduce, delay, or prevent symptoms.<sup>55</sup> Large scale clinical trials involving this approach in individuals with mild clinical symptoms of AD have not shown therapeutic efficacy. The recent focus in these “amyloid vaccine” trials have been on very early intervention whereby the antibodies (or other anti-amyloid treatments) are administered some years before clinical symptoms arise. The individuals in these trials are selected because they are known to be at risk for AD due to genetic mutation or the presence of early amyloid deposits in the brain detected by neuroimaging.

Tau is a second protein implicated in AD and related “tauopathies,” which is found in neurons where it normally facilitates communication of signals within the cell and between different neurons. In certain neurodegenerative diseases, including AD, these normal functions of tau become corrupted leading to the aggregation of tau into forms that are considered toxic to neurons. Clinical trials are anticipated or underway to use a tau antibody vaccine or other approaches to reduce tau levels in AD.

Most recently, a widening range of therapeutic approaches are in pre-clinical and clinical development to target other brain abnormalities in AD — inflammation and deficient “cell waste recycling” to name a few. AD is increasingly recognized as a multifactorial disease that may require multiple treatment strategies to address optimally, including therapies targeting other brain processes besides tau or amyloid.

### 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 and psychological symptoms exhibited by individuals with AD/D should be fully assessed, given that communication with the patient is often difficult. Careful history and assessment may reveal an underlying medical cause for behavioral symptoms which can be addressed and treated by a medical provider. Behavioral symptoms commonly observed 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 must be understood, especially if symptoms are new onset. 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.<sup>56, 57</sup>

If there is no underlying medical cause, behavioral changes should be approached using non-pharmacological interventions including skilled communication strategies that are used by all medical and support personnel and formal or informal caregivers, and environmental

management. 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 or busy environment and/or the misperceptions about their environment that are related to disease-associated perceptual losses.<sup>58</sup> 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 several suggested interventions that should be considered to alleviate behavioral symptoms for individuals with AD/D. Person-centered approaches should be applied that demonstrate an understanding of who the person was before developing AD/D, acknowledge life experiences that were important to them and support the social roles that the person valued throughout life. Effectively engaging a person in meaningful activities that simulate occupational tasks, such as child care, past work experiences and volunteerism, can enhance caregiving success while maintaining social connections and a sense of “self” for the person living 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 living 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 living 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 living with AD/D.

Additional non-pharmacological treatments of AD/D include music therapy, reminiscence therapy, physical exercise, cognitive training, and collaborative care.<sup>2, 25, 59</sup> The goal of these interventions is to maximize cognitive functioning and the individual’s ability to perform ADLs, 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.<sup>59</sup>

### *Pharmacological*

Current medications only address the symptoms of AD/D. These medications alter chemicals in the brain that are important to learning, mood and memory, if only temporarily in the disease course. These pharmacological treatments do not stop the progression of the disease or offer a cure for AD/D.

There are two types of medications available for use with AD/D. Cholinesterase inhibitors are medications often used to treat mild to moderate symptoms of AD; these medications include Donepezil (Aricept), Rivastigmine (Exelon), and Galantamine (Razadyne). Memantine (Namenda), the second type of medication available, is used for moderate to severe AD and is believed to mitigate glutamate levels in the brain that may lead to brain cell death.<sup>2</sup> Namzaric, a combination drug, has been approved to treat moderate to severe AD. This agent combines memantine hydrochloride extended-release (Namenda) and donepezil hydrochloride (Aricept), which are often prescribed in combination.

Another avenue being explored by pharmaceutical companies is the development of drugs that rid the brain of amyloid or tau, as discussed in a previous section. However, at this time clinical trials of anti-amyloid treatment have not yielded positive results.<sup>53, 59</sup> In addition to the new approaches to therapy being explored, as mentioned above, another alternative intervention under exploration by the NIH is testing existing drugs originally developed to address other diseases but have pharmacological properties suggesting that they may yield positive results for AD/D.<sup>25</sup> More information on medications can be found at:

<http://www.nia.nih.gov/Publication/Alzheimers-disease-medication-fact-sheet>.

As previously described, behavior management using non-pharmacological approaches should be the first goal of treatment. However, avoiding medication use may not be sufficient for every individual. Pharmaceutical therapies are available for addressing behavior symptoms that may occur with AD/D, treating pre-existing mental health disorders and managing co-existing chronic conditions. 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. However, none of these medications were developed for use in managing the behaviors associated with dementia and there are health risks associated with the “off-label” use of some of these medications in individuals with AD/D.<sup>2, 60</sup>

Therefore, medications should be used judiciously for a short period of time and frequent assessment is important to ensure that the benefits of using these drugs outweigh the risks. A variety of agents with novel mechanisms of action compared to current anti-psychotics are under development to treat behavioral symptoms of AD/D, which are often a greater management problem for caregivers than memory loss. For example, a new class of antipsychotic agent, pimavanserin (Nuplazid), which is currently FDA approved only for Parkinson’s dementia with psychosis, is being evaluated for use to treat psychosis, agitation, and aggression in AD/D.

Individuals living with AD/D frequently have one or multiple chronic conditions that also need to be addressed by their primary care providers. Pharmacological treatment of any co-existing medical condition is likely to improve the effectiveness of the AD/D treatment approach.<sup>53</sup> It should be noted that the drugs used for AD/D are associated with significant interactions with other agents particularly those that prolong the QT intervals. In addition, periodic evaluation of pharmacotherapy as the dementia process continues has also shown to reduce common geriatric syndromes (falls, weight loss, unsteady gait) and improve the general well-being for patients with AD/D.

### *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 living with AD/D as well as the caregiver.<sup>52</sup> Palliative, or comfort care, aims to keep an individual comfortable and pain-free until life ends naturally.<sup>61</sup>

Once the decision is made to pursue 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.<sup>52</sup> Most individuals with late-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.<sup>61</sup>

*Palliative Care for People with Dementia: Why Comfort Matters in Long-Term Care*, a guidance document developed by CaringKind, addresses the need for improving the quality-of-life and care for residents diagnosed with advanced dementia who live in nursing homes, through a program that generates the special adaptations needed to make palliative care more effective for persons living with advanced dementia and their families. More information on palliative care can be found at: <https://caringkindnyc.org/palliativecare/>.

## 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 18.5 billion hours of unpaid care.<sup>2</sup> The Alzheimer's Association reports that caregivers' unpaid care was valued at \$234 billion in 2018. This is nearly equal to the estimated cost of direct medical and long term care for AD/D.<sup>2</sup> In NYS, over one million caregivers provided 1.15 billion hours of unpaid care for individuals with AD/D, valued at \$14.59 billion.<sup>2</sup> Studies have found that as many as 25% of individuals cared for by "sandwich generation caregivers" (caregivers who care for both an aging person and a dependent child) are persons living with AD/D.<sup>2</sup>

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 ADLs, 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 living with AD/D.

Most of the contemporary research indicates that the burden of caring for an individual living with AD/D disproportionately affects women and minorities.<sup>62</sup> Women represent 65% of caregivers of individuals with AD and report taking on a higher burden of care giving responsibilities. According to the *2019 Alzheimer's Disease 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 Caucasian caregivers.<sup>2, 63</sup> Other research identifies non-Hispanic Caucasian caregivers as experiencing increased depression and perceived stress when compared to caregivers of other races and ethnicities.<sup>64</sup>

Research also demonstrates that providing caregivers with an array of support services alleviates caregiver burden, enhances the quality of life for both the individual living 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.<sup>65, 66, 67</sup> 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 can stave off negative impacts on their own health.<sup>66</sup>

## Formal Caregivers

Formal caregivers are paid staff who provide in-home or residential care. These caregivers often experience high levels of stress, leading to high turnover rates in this field. A 2005 study, which examined attitudes of direct care workers serving people with AD/D, found that stress levels are particularly high in facilities with specialized AD/D units.<sup>68</sup> 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. It is important to develop effective strategies to attract and retain a more qualified workforce.<sup>69</sup> 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 living 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 living with AD/D is more than \$341,651, greater than costs associated with this period from any other diseases.

The cost of health care, long-term care, and hospice services for individuals with AD/D makes dementia one of society's most costly chronic conditions.<sup>70</sup> The *2019 Alzheimer's Disease Facts and Figures* pinpoints the cost of care for Americans with AD/D at \$290 billion nationally. This includes an estimated \$146 billion covered by Medicare; \$49 billion covered by Medicaid; \$63 billion in-out-of-pocket expenses paid by individuals with AD/D and/or their caregivers; and \$32 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. Twenty-seven percent of seniors with AD/D are dually enrolled, as compared to 11% of those without dementia. Average annual Medicaid payments for people with AD/D are 23 times greater than average Medicaid payments for dual enrollees who do not have this condition.<sup>2</sup>

Nationally, 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 2017 NYS BRFSS, 83% of respondents who reported subjective cognitive decline 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 2014, 38% of Medicare beneficiaries age 65 and older with dementia also had coronary artery disease, 37% also had diabetes, 28% also had congestive heart failure, 29% also had chronic kidney disease and 25% also had COPD.<sup>2</sup>

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. According to a 2013 study, 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 holds 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 as 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).<sup>71</sup>

Individuals living with AD/D require more care (e.g., home care, long-term skilled nursing, etc.) than those experiencing normal aging. In a 2011 report based on data from the Medicare current beneficiary survey, 42% of individuals age 65 and older with AD/D lived in long-term care facilities as compared with 2% of individuals age 65 and older without AD/D.<sup>71</sup> A 2004 study estimated that individuals living with AD/D are hospitalized two to three times more frequently than individuals of the same age without AD.<sup>1,72</sup> However, a 2013 study showed a decrease in hospital discharges for individuals with AD/D between 1999 and 2009. This could be due to increasing mortality rates for individuals living with AD/D, as well as an increase in individuals living with AD/D who are cared for in residential facilities rather than hospitals.<sup>73</sup>

In addition to increased health care costs, the cost of AD/D to business and industry is substantial when considering lost wages and productivity resulting 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 able to remain in the workforce.<sup>74</sup> 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 living 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/media/Documents/alzheimers-facts-and-figures-2019-r.pdf>.

The value of unpaid caregiving is also significant. Caregivers for individuals living with AD/D spend an average of 92 hours per month fulfilling caregiving duties.<sup>77</sup> In 2016, there were 15.7 million caregivers of individuals living with AD/D. Nationally, NYS has the fourth highest number of unpaid caregivers in the nation. According to data from the *2019 Alzheimer's Disease Facts and Figures*, over one million caregivers in NYS provided an estimated 1.15 billion hours of unpaid care valued at \$14.6 billion.

### **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 be inflicted by anyone including a formal or informal caregiver, a family member, a friend, an acquaintance, a gatekeeper, or a stranger.

In NYS, elder abuse and exploitation cases referred to APS are tracked through the Adult Services Automation Program (ASAP.net) or APS.net in New York City. In addition, NYS has been participating with the federal government to provide statistical data to the National Adult Maltreatment Reporting System (NAMRS) since 2016.

The number of individuals suffering from elder abuse is severely underreported. According to the 2011 NYS Elder Abuse Prevalence study titled *Under the Radar: NYS Elder Abuse Prevalence Study*, for each 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, it is not as common as these other forms.<sup>76</sup> It is 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 living 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 living with AD/D from abuse is for an advocate, friend, family member, or caregiver who recognizes the warning signs to intervene or contact NYS APS for assistance.<sup>76, 77</sup> More information about recognizing elder abuse can be found at:

<https://ocfs.ny.gov/main/psa/financial-exploitation.asp>

<https://acl.gov/programs/protecting-rights-and-preventing-abuse/elder-justice>.

### 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 living 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.

APS statistics for 2018 show a 4.77% increase in financial exploitation from 2017. Outside of NYC, financial exploitation risks were the highest percentage of the perpetrator-related risks referred: 40.8% for all ages and 44.1% for clients 60 and older. In NYC the rates were 30% for all ages and 32% for ages 60 and older.

The gap in reporting is likely vast. The NYS Prevalence Study, which is based on an analysis of self-reports, found that only one in 44 cases of financial abuse is reported to authorities (i.e., APS or law enforcement).<sup>76</sup>

<http://ocfs.ny.gov/main/reports/Under%20the%20Radar%2005%2012%2011%20final%20report.pdf>.

Gatekeepers at banks and other financial institutions are in a unique position 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 when indicated. The NYS Office of Children and Family Services (NYSOCFS) and Division of Financial Services (NYSDFS) have continued to conduct numerous trainings on these topics for state and local staff as well as representatives of financial institutions. A recording of one of these 2018 trainings is posted on the OCFS website.<sup>77, 78</sup>

More information is available at:

<http://www.nij.gov/topics/crime/elder-abuse/pages/financial-exploitation.aspx>

<https://ocfs.ny.gov/main/reports/Cost%20of%20Financial%20Exploitation%20Study%20FINAL%20May%202016.pdf>

<https://ocfs.ny.gov/main/psa/defaultdatabaseDetails.asp?ID=1348>

<https://acl.gov/programs/protecting-rights-and-preventing-abuse/elder-justice>

[https://ocfs.ny.gov/main/view\\_article.asp?ID=1514.](https://ocfs.ny.gov/main/view_article.asp?ID=1514.)

### Physical Abuse, Emotional Abuse, and Neglect

Individuals living 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.<sup>77</sup> NYSOCFS and NYSOFA have developed a new Gatekeeper Toolkit which is available to local APS and OFAs to provide local presentations to those in close contact with potential victims. More information is available at: <http://www.preventelderabuse.org>

<https://ocfs.ny.gov/main/reports/Under%20the%20Radar%202005%202012%202011%20final%20report.pdf>

[https://ocfs.ny.gov/main/view\\_article.asp?ID=1514.](https://ocfs.ny.gov/main/view_article.asp?ID=1514.)

### **National and New York State Public Policy Initiatives**

#### National

##### *The Public Health Road Map*

The Alzheimer's Association and CDC have developed The Healthy Brain Initiative's [State and Local Public Health Partnerships to Address Dementia, The 2018-2023 Road Map](#) which charts a course for state and local public health agencies and their partners. The document prepares all communities to act quickly and strategically by stimulating changes in policies, systems, and environments. Alignment of the Road Map actions with Essential Services of Public Health ensures that initiatives to address Alzheimer's disease can be incorporated easily and efficiently into existing public health initiatives. The four traditional domains of public health action items include: Monitor and Evaluate; Educate and Empower the Nation; Develop Policies and Mobilize Partnerships; and Assure a Competent Workforce.

### *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 2018. 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.<sup>1</sup> The most recent version of the National Plan can be accessed at: <https://aspe.hhs.gov/report/national-plan-address-alzheimers-disease-2018-update>.

### *National Research Summit on Care, Services and Supports for Persons with Dementia and Their Caregivers*

The National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers convened a two-day meeting sponsored by the HHS and the Foundation at the National Institutes of Health on October 16-17, 2017, in Bethesda, MD. A follow-up Summit will be held in March 2020.

The goal of this Summit was to identify what is known and what needs to be known to accelerate the development, evaluation, translation, implementation, and scaling up of comprehensive care, services, and supports for persons living with dementia, families, and other caregivers. The Summit was focused on research needed to improve quality of care and outcomes across care settings, including quality of life and the actual experience of persons living with dementia and their caregivers (including family members, neighbors, friends, fictive kin, and formal, paid caregivers).

Information and video footage from the Summit can be found at:  
<https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers>.

### *The Science of Caregiving: Bringing Voices Together* Summit

The National Institute of Nursing Research and partners convened *The Science of Caregiving: Bringing Voices Together* Summit on August 7-8, 2017. Caregiving experts convened at the NIH to gather insight and perspectives across the spectrum of caregiving, including the importance of caregiving across the lifespan as well as current and future directions for research to improve the health of patients and caregivers. Information and video footage from the summit can be found at: <https://www.ninr.nih.gov/newsandinformation/newsandnotes/caregiving-summit-video>.

### *Bold Act*

The federal government has authorized \$100 million to support a public health approach to the prevention, treatment and care of AD/D, under a new law signed in 2018. The Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act unanimously passed the U.S. Senate and was approved by a near-unanimous vote in the House of Representatives on December 31, 2018.

The BOLD Act authorizes the CDC to spend \$20 million a year for five years. The law:

- Establishes centers of excellence across the country dedicated to promoting the best ways to effectively deal with Alzheimer's and to help caregivers better understand and address dementias. The centers will also help educate the public on Alzheimer's disease, cognitive decline and overall brain health.
- Provides for the CDC to work with state health departments to help them promote brain health, reduce the risk of cognitive decline and improve the care for individuals with Alzheimer's.
- Requires improved analysis and timely reporting of data on Alzheimer's cognitive decline, caregiving and health disparities at the state and national level.

The text of the BOLD Act can be found at: <https://www.govtrack.us/congress/bills/115/s2076/text>.

### **Related Public Policy Initiatives: New York State**

#### **Governor's Initiatives: Nationally Recognized Health Across All Policies (HAAP), Age-Friendly New York**

In January 2017, Governor Andrew Cuomo launched a new initiative to advance Health Across All Policies in New York State. Health Across All Policies is a collaborative approach that integrates health considerations into policymaking across all sectors to improve community health and wellness, recognizing that a community's greatest health challenges are complex and often linked with other societal issues that extend beyond healthcare and traditional public health activities. To successfully improve the health of all communities, health improvement strategies must target social determinants of health and other complex factors that are often the responsibility of non-health partners such as housing, transportation, education, environment, parks, and economic development.

[The Governor's announcement](#) specifically called on the state's Public Health and Health Planning Council and its Ad Hoc Committee to Lead the Prevention Agenda, to lead this effort.

This initiative is initially focusing efforts on creating age-friendly communities and policies. Incorporating policies that promote healthy aging will help NYS agencies to consider the needs of all populations and environments in which people live as they develop and implement new programs. The long-term goal is to engage all New York State agencies in a collaborative approach to embed health improvement and healthy aging policies as a focus of decision-making within all agencies.

## New York State Department of Health (NYSDOH)

The 2019-2020 NYS budget dedicated \$27,412,000 for AD/D programs, representing the largest single state investment of its kind. With these funds, the NYSDOH has expanded and strengthened exiting AD/D programs and developed new initiatives using evidenced-based strategies to support caregivers of and individuals living with AD/D.

The initiative is based on evidence that demonstrates providing an array of caregiver services in the community helps avoid unnecessary hospitalizations and emergency department visits, delays nursing home placement and improves caregiver burden and mental health outcomes.

This initiative, one of many NYSDOH Medicaid Redesign Team (MRT) projects, addresses a myriad of needs of this community. A focus on improving early detection, quality of life, and quality of care includes palliative care, education of health care providers, and reduction unnecessary emergency department visits, hospitalizations, and nursing home placements. The investment has been accomplished primarily through competitive procurements.

The increased state appropriation funds four major caregiver support initiatives. The goal of these initiatives is to expand the safety net for caregivers of individuals living with AD/D by recognizing and addressing the need for day-to-day caregiver supports and stress reduction. Benefits of these services include improved health and quality of life for both individuals living with AD/D and their caregivers, reduced hospitalizations, and increased ability to maintain individuals living with AD/D in the community. Programs which serve similar geographic regions collaborate with and reciprocally refer individuals living with AD/D and their caregivers to each other to ensure the receipt of appropriate diagnosis, treatment, and support services.

More information on these initiatives, including an interactive NYS map listing county-specific services can be found at:

<https://www.health.ny.gov/diseases/conditions/dementia/alzheimer/county/>.

A description of each component of the initiative follows:

### *The Regional Caregiver Support Initiative*

The Regional Caregiver Support Initiative provides \$15 million to fund a network of 10 organizations across NYS which deliver programs that support family caregivers who care for New Yorkers living with AD/D across NYS. Each organization receives \$1.5 million annually to provide caregiver support services.

This statewide program provides:

- Care consultations
- Support groups
- Caregiver education and training programs
- Respite
- One or more additional caregiver support services including access services, caregiver companions, care support teams, caregiver wellness programs and joint enrichment opportunities

### *The Caregiver Support Initiative for Underserved Communities*

The Caregiver Support Initiative for Underserved Communities provides \$1.5 million to 15 community-based organizations to provide caregiver support services for targeted underserved communities. Each organization receives \$100,000 annually to reach caregivers of individuals living with AD/D, either or both of whom are members of underserved communities.

The programs recognize and address the need for culturally competent support strategies. Program models are designed to serve individuals who may experience challenges related to geographic isolation; English as a second language; minority or ethnic group membership; sexual orientation and gender identity; low socioeconomic status; or cultural isolation.

These programs offer:

- Extensive outreach to target communities
- Caregiver assessment and referrals
- Support groups
- Education and training
- Caregiver wellness
- Joint enrichment
- Respite

### *Centers of Excellence for Alzheimer's Disease*

The Centers of Excellence for Alzheimer's Disease (CEAD) initiative provides \$4.7 million to a network of 10 medical centers and teaching hospitals across NYS, recognized nationally and by NYS as experts in the diagnosis and care of individuals living with AD/D. Each organization receives \$470,000 annually. The CEADs are at the forefront of research and clinical trials seeking effective treatments and a cure for AD/D.

The CEAD program provides:

- Interdisciplinary and comprehensive medical services for the diagnosis of AD/D.
- Coordinated treatment and care management for individuals living with AD/D.
- Linkages to community-based services for patients and caregivers.
- Expert training for physicians, health care professionals, and students on the detection, diagnosis and management of AD/D.
- Support for primary care providers to promote cognitive screening in community-based settings.
- Information on and access to current research and clinical trials.
- Resources to increase public awareness of AD/D and the importance of early screening.

### *Alzheimer's Disease Community Assistance Program*

The Alzheimer's Association, New York State Coalition is a not-for-profit organization that coordinates the Alzheimer's Disease Community Assistance Program (AlzCAP) in every region of NYS. The \$5 million statewide program, provided through eight subcontracts, delivers a comprehensive array of community-based services for individuals living with AD/D and their caregivers. Subcontractor funding varies depending on the region.

This statewide program provides:

- Professional care consultations conducted in-person, by phone, or virtually, depending on the person's needs.
- Training and education for both caregivers and individuals living with AD/D.
- Support groups for caregivers and individuals living with AD/D.
- A 24-hour Helpline available in more than 200 languages.
- Community education, awareness, and outreach.
- Training for professional caregivers, faith leaders, and gatekeepers, to create dementia-friendly and well-informed communities.

While not a direct replication, these initiatives reflect the evidence developed by Dr. Mary Mittelman at New York University and others.<sup>65, 66</sup> Dr. Mittelman's research studies provide evidence that caregiver support and counseling can delay nursing home placement by a median of 1.5 years.<sup>65</sup> 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."<sup>67</sup> Dr. Mittelman's newer research demonstrates that the New York University Caregiver Intervention can result in 17% fewer AD/D deaths in nursing homes, and up to \$178.9 million in Medicaid savings over a 15-year period.<sup>78</sup>

Researchers at the School of Public Health, University of Albany, State University of New York are conducting a comprehensive, statewide, multi-level evaluation of the Alzheimer's Disease Caregiver Support Initiative. This evaluation will examine process and outcomes with an emphasis on how NYS has changed as a result of this initiative.

In addition to documenting the effect of these expanded caregiver support services on a variety of patient, caregiver, and health system outcomes, the evaluation will significantly contribute to the national evidence base related to Alzheimer's disease support services. It will generate important evidence for future programmatic and policy decisions at both the state and national levels.

### Other NYSDOH Initiatives

#### Public Health Live!

Educational webcasts are produced on current evidenced-based information and interventions through a partnership between the NYSDOH and the University at Albany School of Public Health known as **Public Health Live!** Continuing education credits for viewing webcasts are available for professionals including physicians, nurses and social workers. Webcasts related to AD/D include:

- **Alzheimer's Disease and the Importance of Accurate Death Reporting**  
Jessica Zwerling, MD, MS  
Director, Montefiore Hudson Valley Center of Excellence for Alzheimer's Disease,  
Associate Professor of Neurology, Program Director, UCNS Geriatric Neurology  
Fellowship, Director, Memory Disorders Center at Blondell, Associate Director, Center for  
the Aging Brain Clinical Director, Einstein Aging Study

- **New York State's Public Health Approach to Alzheimer's Disease**  
Mary P. Gallant, PhD, MPH  
Senior Associate Dean for Academic Affairs, Professor of Health Policy, Management and Behavior, University at Albany School of Public Health  
  
Meghan Fadel  
Director of Evaluation and Special Projects, Bureau of Community Integration and Alzheimer's Disease NYS Department of Health
- **Clinical and Ethical Indications for Cognitive Impairment Screening in Primary Care**  
David Hoffman, D.P.S., C.C.E  
Director, Bureau Community Integration and Alzheimer's Disease, NYSDOH
- **Alzheimer's Disease and Advance Directives: A Primer for Primary Care Physicians**  
Wayne Shelton, PhD, MSW  
Professor of Medicine and Bioethics, Alden March Bioethics Institute, Albany Medical College  
  
Kevin Costello, MD  
Assistant Professor of Medicine and Attending, Department of Medicine, Albany Medical College
- **Psychiatric Manifestations of Parkinson's Disease and Its Treatment**  
Guy J. Swartz, MD  
Assistant Clinical Professor of Neurology, Stony Brook University Medical Center
- **The Clinical and Cultural Challenges of Dementia in African American and Hispanic Communities**  
Jennifer J. Manly, PhD  
Associate Professor, Department of Neurology, Columbia University  
  
Teresa Santos, LMSW  
Care Coordinator, CEAD  
Center for the Aging Brain and the Memory Disorder Clinic, Montefiore Medical Center
- **Falls and their Prevention: A Geriatric and Pharmacological Imperative**  
Bruce R. Troen, MD  
Chief of the Division of Geriatrics and Palliative Medicine, Jacobs School of Medicine and Biomedical Sciences, SUNY Buffalo  
  
Michael Brodeur, PharmD  
Associate Professor or Pharmacy Practice, Albany College of Pharmacy and Health Sciences
- **Determining Caregiver Needs and Well Being**  
Elizabeth Smith-Boivin, MSHSA  
Executive Director/CEO, Alzheimer's Association, Northeastern New York Chapter

### *Behavioral Health and Dementia Workgroup*

People with dementia who experience behaviors that require specialized intervention often have trouble accessing timely and appropriate care. The NYSDOH conducted key informant interviews in 2018 and 2019 that helped identify contributing challenges across the continuum of care. These issues include a lack of local neurobehavioral services, challenges with emergency department care, a lack of specialists and generalists equipped to support this population, and barriers to admission to both acute and long-term care settings. To address these challenges, a workgroup comprised of state agency representatives and community stakeholders will develop recommendations for NYSDOH. This workgroup has not yet been started.

### *Special Needs Assisted Living Voucher Demonstration Program for Persons with Dementia*

Adults with Alzheimer's disease and/or dementia who can no longer afford to pay privately for a Special Needs Assisted Living Residence (SNALR) generally have no other option than to enroll in the Medicaid Program. This enrollment often results in a transition from private pay residence in an assisted living facility to a skilled nursing facility. In order to explore options to prevent such transitions and to keep residents in the least restrictive setting possible, the State of New York has enacted the *Special Needs Assisted Living Voucher Demonstration Program for Persons with Dementia*.

The 2018-19 State Budget Agreement authorized the NYSDOH to establish this voucher demonstration program to subsidize the cost of a SNALR for individuals with Alzheimer's disease and/or dementia. This demonstration program has budget authority for two (2) years.

Through the demonstration, the Department may issue up to 200 vouchers and subsidize up to 75% of the regional average private pay rate for the monthly cost of a SNALR for an approved applicant living with a diagnosis of Alzheimer's disease and/or dementia.

### *The Alzheimer's Workplace Alliance*

The Alzheimer's Workplace Alliance (Alliance) is affiliated with the Alzheimer's Association. The Alliance raises awareness about the disease and the importance of early detection while providing help to those who are balancing work and caregiving responsibilities. The Alliance's work is a cost saving measure that supports employee well-being, work-life balance and retention.

The NYSDOH has joined the Alliance to provide critical information and support to employees across NYS who are caring for someone with AD/D. Due to the demands of caregiving, many NYSDOH employees face work-related challenges-depleting their time off accruals, needing to shorten their work day, or leaving employment entirely.

### *Dementia Friendly America*

New York State has been designated as an active member of the Dementia Friendly America national network. One local community (Chautauqua) has been featured on the national website: <https://www.dfamerica.org>

## New York State Office for the Aging (NYSOFA)

NYSOFA's mission is to help older New Yorkers be as independent as possible for as long as possible through advocacy, development and delivery of person-centered, consumer-oriented, and cost-effective policies, programs and services which support and empower older adults and their families, in partnership with the network of public and private organizations which serve them. These partnerships with community-based organizations and state agencies result in beneficial outcomes for older adults in NYS, including individuals living with AD/D and their caregivers.

Informal caregivers are an invaluable resource to their loved ones and to the health care system. Two federally funded programs administered by NYSOFA directly serve caregivers:

- The National Family Caregiver Support Act Title III, Part E, was established in the 2000 amendments and reauthorization of the Older American's Act (OAA) to address the needs of the growing number of informal caregivers. The National Family Caregiver Support Program assists informal caregivers - spouses, adult children, other family members, friends and neighbors - in their efforts to care for older persons who need help with everyday tasks.

Services provided include:

- information about available services and assistance in gaining access to services;
  - individual counseling, support groups, and/or training to assist caregivers in the areas of health, nutrition and financial literacy and to make decisions and solve problems relating to their caregiver roles;
  - respite to temporarily relieve caregivers from their responsibilities by providing a short-term break through home care, overnight care in an adult home or nursing home, adult day care and other community-based care; and
  - supplemental services to complement the care provided by the caregiver, such as a Personal Emergency Response System, assistive technology, home modifications, home delivered meals, and transportation.
- The Lifespan Respite Program, funded through an Administration for Community Living grant, assists family caregivers to gain access to needed respite services, trains and recruits respite workers and volunteers, and enhances coordinated systems of community-based services for individual of all ages. The NYS Caregiving and Respite Coalition (NYSCRC) is helping to build volunteer respite capacity using the Respite Education and Support Tools (REST) model.
  - NYSOFA and NYSCRC have expanded the REST model to include trainers within the past year. Additionally, mini-grants were awarded through the Lifespan Respite Grant, to expand and enhance volunteer respite. Organizations were invited to submit applications for replication and growth of successful volunteer respite programs in NY, as well as to offer REST training to meet training needs of respite volunteers.

NYSOFA has an online resource directory that includes respite and support services which provide relief for caregivers. The NY Connects Resource Directory (<https://www.nyconnects.ny.gov/>) includes an ongoing updating process. Additionally, the NYSCRC web site provides information and links to the NY Connects Resource Directory: (<http://www.nyscrc.org/ny-connects>).

The NY Connects No Wrong Door screening tool now includes three questions related to memory problems that have been incorporated into the NY Connects screening process. These questions are used to refer to dementia-related services. NY Connects also assists individuals with Medicaid applications and referrals for other long-term services and supports.

Area Agencies on Aging (AAAs) contract with 81 Social Adult Day Service (SADS) programs utilizing a variety of federal and state funding. This service provides a safe, stimulating and affirming environment for individuals living with AD/D, with many programs offering evidence-based creative art therapies. The caregivers benefit from respite and caregiver support services. Sixteen SADS programs were directly funded by NYSOFA during State Fiscal Year (SFY) 2017-18 and 1,101 caregivers received services. Eighty-one percent of participants in these programs were cognitively impaired. The State Respite Program awarded 13 grants to 10 agencies during SFY 2017-18, serving 607 caregivers. Sixty-one percent of care receivers were cognitively impaired.

NYSOFA Elder Justice activities include:

- Legal assistance funded under the OAA addresses legal issues related to income, health care, long term care, nutrition, housing, utilities, protective services, defense of guardianship, abuse, neglect, and age discrimination.
- The Office of Court Administration (OCA) convened a NYS Elder Justice Committee. This group, with NYSOFA's participation, has continued to collaborate to improve the way the court system addresses cases involving our state's older population.
- The Remote Access to Temporary Orders of Protection Program has been implemented in 15 counties statewide and new counties are being added each month. The Office of the Statewide Coordinating Judge for Family Violence Cases' goal is to make this program available in all 62 counties across New York State within the next two years. It allows for filing of a family offense petition to be done on-line and initial ex parte hearing can be held via Skype. This is a benefit to older adults who are not able to attend in person.

NYSOFA operates adult abuse programs that protect and provide services to vulnerable adults, including individuals living with AD/D:

- In 2017-18, NYSOFA partnered with the NYS Office of Victim Services (OVS) to establish and implement the OVS/Victims of Crime Act (VOCA) Elder Abuse Interventions and Enhanced Multidisciplinary Team (E-MDT) Initiative. E-MDTs investigate and intervene in complex cases of elder abuse. They bring together professionals in each county of operation from various disciplines, including, but not limited to, Adult Protective Services (APS), local Offices for the Aging (OFA), human services, law enforcement, and health care, to provide an effective and efficient means of addressing complex cases of abuse of older adults (aged 60 and older). The enhancement comes with access to forensic accountants, geriatric psychiatrists, and community legal services. The E-MDT model

was piloted in seven counties from 2012-2016 with federal grant funds and sustained and expanded with NYS funds during State Fiscal Year 2016-17. E-MDTs funded through this Initiative continue to expand across NYS and, as March 1, 2019, are now operational in 34 counties.

- The NYS Long Term Care Ombudsman Program (LTCOP), administered by NYSOFA, assists vulnerable adults, including individuals living with AD/D, in long term care facilities. The Office of the State Long Term Care Ombudsman provides advocacy and resources for people who reside in long-term care facilities including nursing homes, assisted living and adult care facilities.

#### New York State Office of Child and Family Services (NYSOCFS)

NYSOCFS serves NYS by promoting the safety, permanency, and well-being of children, vulnerable adults, 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 conducted 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 information gathering period 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. This study can be found at: <http://ocfs.ny.gov/main/reports/Cost%20of%20Financial%20Exploitation%20Study%20FINAL%20May%202016.pdf>.

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. To obtain a comprehensive picture of victims' situations, NYSOCFS examined other social factors including characteristics and relationships between perpetrators and victims.

Results of the study were issued in 2016. Across the 479 verified cases, over \$24 million was reported in lost assets. The most common loss was monetary, with 42% of verified cases reporting cash losses of nearly \$8 million. A statewide estimate indicates victim losses of about \$109 million. An additional \$14 million in costs were attributed to service agency and public benefit cost. The aforementioned *NYS Elder Abuse Prevalence Study* (2011), funded by NYSOCFS, suggests that there are 10 to 44 unreported incidents of financial exploitation for every case that is reported. Applying the data from the *NYS Cost of Financial Exploitation Study*, low and high-end estimates of actual victim financial loss ranged from \$352 million to \$1.5 billion annually.

The most frequent methods used for financial exploitation 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 in documented costs. The cost to involved agencies, including APS and law enforcement, totaled nearly \$1.2 million. The total figure of \$27

million is a mere fraction of the actual cost based on the 1:44 ratio of reported cases reported in the NYSOCFS-funded NYS Elder Abuse Prevalence Study.

The social characteristics found in this study were not surprising. For example, family members/spouses made up 67% 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 of all victims had one or more health concerns and 30% of them had signs of AD/D. Fifty-eight-percent of the victims required assistance with ADLs. Allegations of abuse/exploitation were more likely to be verified when clients were assessed as having dementia or difficulty managing finances due to dementia.

Most victims do not want to involve law enforcement. This is due in part to feelings of fear, shame or guilt, especially when a member of their family is the perpetrator. However, in approximately 24% of the cases, criminal action was taken. Only 1% of those cases resulted in the conviction of the perpetrators. A 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 would use a \$300,000 federal grant to crack down on the financial exploitation of older and vulnerable adults. The funding initially supported a two-year pilot program in Onondaga County and Queens. In 2018, pilot sites were expanded to include Livingston and Monroe counties, as well as JASA, a NYC APS vendor, in 2108. 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, worked with a forensic accountant in consultation with a multi-agency advisory board to develop new investigative tools and templates for APS workers. The grant also enables APS in the pilot areas to move referrals to a forensic accounting consultant in complex cases.

Training of pilot APS units on the use of the new investigation tools occurred in April 2017. The pilot units are currently field testing the new tools and processes. Revisions based on feedback from the field will result in a more refined tool from which all APS units and EMDTs can benefit. The findings have been shared in national forums such as NAPSA (National Adult Protective Services Association) webinars. The grant also has a component for enhancement of APS data systems to better document the costs of financial exploitation of APS clients and case outcomes on an ongoing basis. In 2018, state and federal funding created an expansion of the EMDT program which will ensure a team to address financial exploitation in every NYS county by 2020.

NYSOCFS, in conjunction with OFA and DOH, is working with the Healthcare Association of New York State (HANYS) and the Home Care Association to develop training on abuse/neglect screening for health care workers, with a focus on physicians and home health care providers.

NYSOCFS also oversees the Family Type Home for Adults program (FTHAs). FTHAs are a small adult care facility of one to four residents who require personal care and/or supervision but not continuous medical care as provided by a nursing home. Most typically, residents reside with the operator in their homes. They receive meals, housekeeping, assistance with medication as well as ADLs. This small setting lends itself to low caregiver/resident ratios and residents receive care in environments similar to their own homes, rather than a facility. This model provides an alternative to institutional care and has been successful in maintaining many AD/D residents in community based settings with individualized care. NYSOCFS, through its local social service districts, continues to facilitate trainings of FTHA operators by Alzheimer's Association staff to improve quality of care for this population.

## New York State Office of Mental Health (OMH)

The New York State Office of Mental Health (NYSOMH) 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 conduct research programs on the causes, early diagnosis, and treatment of AD and related dementias. The major concentration of AD research within NYSOMH is conducted at the Center for Dementia Research (CDR).

Recognized internationally for influential advances toward innovative AD therapies, CDR researchers have been awarded over 30 million dollars in NIH research funding during the last three years. These awards include the renewal in 2017 of a five-year, \$12 million NIH Program Project grant 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. Their research has defined cellular abnormalities that arise decades before the earliest clinical symptoms and is yielding new biomarkers of AD so that treatments can begin sooner. Notably, the neurological roles of "NF-L," the recently discovered first reliable blood biomarker to track the progression of AD is a longstanding focus of CDR studies. Understanding the biology underlying the earliest changes in the disease has identified new drug targets, including a compound against an early disease target currently in a phase 2 clinical trial. Innovative lines of drug discovery, including approaches that have recently been awarded patents, are being validated in the CDR, some in partnership with major pharmaceutical companies to accelerate this validation process.

Researchers in NKI's Center for Brain Imaging and Modulation are investigating abnormal brain function, possibly heralding the future onset of AD, in clinically normal populations across the age spectrum and in symptom-free elderly individuals who are at higher risk genetic risk to develop the disease. Other new imaging techniques, initially perfected in AD model systems, are now being applied in patient populations and in normal volunteers with the goal of widening the window of prevention opportunity even further.

CDR programs have yielded over 300 peer reviewed publications in the past 10 years, including reports in the most prestigious scientific journals (Cell, Proceedings of the National Academy of Sciences, Nature Medicine and others), which have been cited by other investigators world-wide over 40,000 times. Attesting to the influence of CDR research in the research community, NKI has ranked in the top 1% of all research institutions nationwide in the number of citations per publication.

Ongoing programs include research to uncover mechanisms by which mutant genes or alternative gene forms like the APOE4 allele, the most influential risk factor for AD, genetic basis, accelerate the onset of AD. Major advances, for example, have been made in the CDR 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. 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,

including characterizing new forms of communication in the brain via release from brain cells and spread of vesicles containing cell signals. Another major program is investigating the higher incidence of epilepsy in AD and its contribution to AD initiation progression.

An important mission of NYSOMH 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 living with AD/D and the detection of loss of smell as a symptom of the earliest stages of AD. Additional clinical research is addressing the adverse effects of commonly used medicines when taken by individuals living with AD/D.

#### New York State Office of People with Developmental Disabilities (OPWDD)

OPWDD is in the fifth year of a research program called "A Study to Identify Biomarkers of Alzheimer's Disease in Adults with Down Syndrome," which is designed to understand why adults with Down Syndrome are more likely to develop Alzheimer's disease in middle age compared with most other people, and why there is a wide range of age at onset of clinical symptoms from under 40 to over 70 years of age. It is expected that this grant will be extended for a sixth year while the agency submits a competitive renewal which would allow for continuation of the research program. This work is supported by funds from the New York State Office for People with Developmental Disabilities and NIH grant P01 HD035897, U54 HD079123 and U01AG051412.

The specific goals of the study are to:

- Develop methods for early diagnosis of Alzheimer's Disease in adults with Down Syndrome, biological characterization of the preclinical and early phases of Alzheimer's Disease, and identification of risk factors for the development of Alzheimer's Disease.
- Identify sensitive neuropsychological measures of cognitive decline, brain imaging, and blood-based and genetic biomarkers associated with the transition from healthy aging to mild cognitive impairment to clinical dementia.
- Understand the pathways affected by the disease process and their implications for improved prevention and treatment.

OPWDD's continues to make progress on the specific aims of the study which are to:

1. Validate methods for classifying dementia status to and quantify longitudinal changes in neurocognition, adaptive functioning and neuropsychiatric concerns developing with onset of mild cognitive impairment (MCI-DS) and further clinical progression.
2. Identify profiles and rates of change in beta amyloid, proteomic, lipidomic and CSF biomarkers that characterize progression from normal aging to MCI to onset of dementia.
3. Identify neuroimaging-based changes that occur over the course of progression from normal aging to MCI to dementia in adults with Down Syndrome.

4. Examine candidate genes that may modify risk for dementia among adults with Down Syndrome and to determine their association with individual differences in plasma amyloid, proteomic, lipidomic, CSF and imaging biomarkers that are found to be associated with clinical disease progression.
5. Develop resources broadly available to the field including:
  - a. Empirically supported criteria defining MCI-DS and dementia;
  - b. Potentially useful outcome measures for use in clinical trials; and
  - c. Repositories of biological and DNA samples linked to in depth archived assessment data.

Analysis of MRI imaging biomarkers will include longitudinal measures of atrophy, white matter abnormalities, and intrinsic network connectivity paradigms. Amyloid positron tomography will delineate regional and whole brain uptake of amyloid. Polymorphisms in candidate genes for AD and related biomarkers will be studied as potential modifiers of risk and their relation to beta amyloid, proteomic, lipidomic and imaging biomarkers examined. Relationships among demographic, clinical, blood based and CSF biomarkers, imaging measures, and genetic variants will be examined to develop the most valid indicators of preclinical and early states of AD.

#### New York State Education Department

The New York State Education Department (NYSED), under the authority and direction of the New York State Board of Regents, oversees the 54 professions licensed under Title VIII of the Education Law, including their requirements for education, conduct, and practice. NYSED has a vital function in providing a wide range of services to the public, including those individuals living with AD/D.

Essentially all the professions require a generic core education for licensure that includes sufficient breadth and depth of content to enable licensees at entry level to address professional issues throughout the lifespan, as appropriate to the services and activities offered by the profession. Issues related to behavioral, emotional and social needs and ethics are becoming a fundamental requirement of professional education programs through curricular mandates placed in regulation. In addition, many professions, such as medicine, psychology, and the social work and mental health practitioner professions, for example, have specifically included issues of cultural competence and health care disparities in mandated curricula. This is a significant development since, for persons living with AD/D and their caregivers, the cultural customs and beliefs influence the way health and behavior is understood and health care and social living decisions are made.

While the core education requirements for these professions differ, all licensed professionals who provide services to persons living with AD/D are required to ensure they are competent to provide the services before doing so. Many professions that provide services to persons living with AD/D have mandated continuing education requirements approved by the Department that must be met for the licensees to be re-registered for practice. Course content regarding AD/D that is related to the practice of a profession may be accepted in these professions. Programs for Clinical Nurse Specialists in Adult Health may focus on the needs of those with AD/D.

The Department also provides guidance through Practice Alerts, Practice Guidelines, webinars for professionals, and recommendations to programs during the approval of course content for

the degrees. In addition to the education, training, and experiential opportunities to gain such competence that is part of the mandated curriculum of a profession, many associations, employers and schools have recognized this need and offer training through various means, including online offerings. Many other professions, including nursing, offer non-mandated continuing education to licensees to address professional competence that may specifically focus on the healthcare, social, and behavioral needs of persons living with AD/D.

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 (BPSS).

Several of the Independent Living Centers (ILCs) in NYS operate as fiscal intermediaries under NYSDOH Medicaid Consumer Directed Personal Assistance Program (CDPAP) and provide self-directed services through surrogates. Surrogate-directed CDPAP for Medicaid eligible individuals helps individuals living with AD/D remain at home, typically with family members and/or family caregivers. In addition, ILCs participate in providing the OPDD with family support services and NYSOFA with self-directed personal care services. The New York Association on Independent Living, Inc. is partnered with ILCs across the State to provide the Open Doors Transition Center and Peer Outreach & Referral programs. This project, funded by the NYSDOH as part of the federal Money Follows the Person demonstration program, is designed to help Medicaid-eligible individuals who live in nursing homes return to the community. It also assists individuals with developmental disabilities living in large group homes and institutions (Intermediate Care Facilities and Developmental Centers) transition to smaller community settings or more integrated community programs.

The 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.

## **Section II. Recommendations**

---

The Council has developed the following series of recommendations that members will use as both a roadmap for progress and a call for diverse groups to work together to achieve them.

The 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.

## **2019 Recommendations of the New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias (AD/D)**

### **Goal 1: Advance Early Detection of and Improve Clinical Care for Alzheimer's Disease and other Dementias**

1. Train primary care providers to utilize best-practice approaches for the screening, diagnosis, and management of individuals presenting with AD/D and their caregivers.
2. Enhance identification of cognitive impairment when patients present in opportunistic settings, such as the emergency department and urgent care centers, by promoting the use of appropriate assessment tools and providing educational materials.
3. Increase awareness and implementation of cognitive screening during the Medicare annual wellness visit, including assessment of a person's ability to implement a care plan and access services.
4. Increase the number and funding of NYS Centers of Excellence for Alzheimer's Disease (CEAD) to improve the timeliness of, and access to, diagnostic care.
5. Ensure that physicians, hospitals, and diagnostic centers have access to, and implement appropriate coding for, advanced testing and care planning to maximize reimbursement of care.
6. Identify barriers to persons with AD/D accessing appropriate medical and psychiatric treatment for behavioral symptoms accompanying their disease.
7. Increase awareness regarding the importance of enrolling in AD/D research and clinical trials.
8. Promote the importance of early planning to individuals with AD/D, their families and caregivers to plan, including healthcare, finances, and legal issues as early in the disease process as possible, so that the individual with 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, thereby enabling them to be prepared when their use becomes necessary.
9. Support the development of a dementia-capable workforce by advancing professional education across the professions and supporting ongoing training of direct-care staff.

### **Goal 2: Prevention and Risk Reduction Strategies**

10. Promote the importance of lifestyle changes to improve the health, wellness, and quality of life of individuals with AD/D and their caregivers, including best practice approaches for implementing strategies to potentially reduce the risk of developing AD/D.

### **Goal 3: Ensure Access to Housing and Supports that Promote Living in the Least Restrictive Environment**

11. Promote dementia-friendly, well-informed communities that focus on reducing stigma and the inclusion of people living with dementia. Train community members on how to (1) identify, offer meaningful assistance and to communicate effectively with individuals with AD/D; (2) appropriately prepare for and respond to hazards and emergencies; and (3) make physical environment modifications that support dementia friendly communities.
12. Promote policy changes, programs and initiatives that enhance access to, and affordability of, assisted living for those living with AD/D, including expansion of the Dementia Special Needs Assisted Living Residence voucher demonstration program.
13. Promote efforts to expand use of telemedicine/telepsychiatry in the home to facilitate physician care, cognitive assessments, and monitoring of treatment effectiveness.

### **Goal 4: Supporting Caregivers and Persons Living with AD/D**

14. Promote the importance of identifying and assessing the health and well-being of caregivers. Ensure the existence of support services and systems that provide caregivers with a thorough, person-specific assessment and use of valid and evidence-based tools to assess caregiver burden and stress.
15. Train caregivers to appropriately implement evidence-based behavioral strategies and non-pharmacological approaches that will improve quality of life for both themselves and individuals with AD/D.
16. Educate caregivers on how to effectively navigate the healthcare system, which includes long-term care, and to access AD/D resources and services.
17. Ensure that the financial and justice system recognize and support persons with AD/D by:
  - Mandating an on-line AD/D training for law enforcement personnel;
  - Educating financial services personnel on how to identify and report financial exploitation; and
  - Providing training for judges, court personnel, attorneys, and other legal professionals on protecting the legal rights of individuals with AD/D.
18. Provide continuing education opportunities on AD/D for all healthcare providers as a part of their mandated continuing education in accordance with their scope of practice.
19. Support employers to better understand the effects of AD/D by educating them to recognize the economic cost of AD/D to the workplace, and promoting initiatives, including support services and referrals through Employee Assistance Programs and personnel policies.

## **Goal 5: Address Disparities and Improve Health Equity**

20. Provide support services that target underserved communities, including education on normal aging versus AD/D and the importance of timely diagnosis of AD/D.
21. Increase awareness and understanding among providers about cultural patterns related to family roles and caregiving in underserved communities.
  - a. Ensuring that educational programs and support services are culturally and linguistically appropriate (e.g., available in multiple languages).
  - b. Ensuring that care providers consider staffing patterns that reflect the target underserved community, both culturally and linguistically.
22. Educate individuals with early onset AD/D and their providers about early retirement, government assistance programs (Social Security, Medicare, and Medicaid), and personal disability insurance.
23. Improve the availability of aging network services to support individuals with early onset AD/D.
24. Encourage families and caregivers of individuals with DD/ID who suspect memory problems and other symptoms to communicate this concern to the individual's healthcare provider and engage in early planning regarding AD/D. Ensure coordination with, and support from, current NYSDOH Initiatives.
25. Promote research on the connection between Down Syndrome and AD/D in NYS research institutes/OPWDD/NYSDOH initiatives.

## **Goal 6: Enhance Public Awareness and Engagement**

26. Implement public awareness activities that are designed to enhance health and wellness and their relationship to AD/D:
  - Encourage individuals with AD/D symptoms to be examined by healthcare providers when they experience the earliest symptoms and raise awareness about the difference between AD/D and normal aging.
  - Raise awareness of risk factors, prevention strategies, and the importance of early differential diagnosis of AD/D.
  - Reach those individuals most at risk of developing AD/D.
  - Address the impact of AD/D on women, both as caregivers and persons with the disease.
  - Promote increased awareness of the availability of palliative care for individuals living with AD/D.
  - Promote primary and secondary prevention by clearly linking the relationship between a healthy lifestyle and brain health.

27. Utilize public health surveillance systems to highlight caregiver health and stress and 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.
28. Increase awareness and participation in the NYS Alzheimer's disease tax check-off box on personal income tax returns and require quarterly report on funds available and uses.

## References

1. U.S. Department of Health and Human Services (2018). National Plan to Address Alzheimer's disease: 2018 update. Retrieved from <https://aspe.hhs.gov/report/national-plan-address-alzheimers-disease-2018-update>.
2. Alzheimer's Association (2019). Alzheimer's Disease Facts and Figures. *Alzheimer's & Dementia* 2019.
3. Reisa A. Sperling,<sup>a,\*</sup> Paul S. Aisen,<sup>b</sup> Laurel A. Beckett,<sup>c</sup> David A. Bennett,<sup>d</sup> Suzanne Craft,<sup>e</sup> Anne M. Fagan,<sup>f</sup> Takeshi Iwatsubo,<sup>g</sup> Clifford R. Jack, Jr.,<sup>h</sup> Jeffrey Kaye,<sup>i</sup> Thomas J. Montine,<sup>j</sup> Denise C. Park,<sup>k</sup> Eric M. Reiman,<sup>l</sup> Christopher C. Rowe,<sup>m</sup> Eric Siemers,<sup>n</sup> Yaakov Stern,<sup>o</sup> Kristine Yaffe,<sup>p</sup> Maria C. Carrillo,<sup>q</sup> Bill Thies,<sup>q</sup> Marcelle Morrison-Bogorad,<sup>r</sup> Molly V. Wagster,<sup>r</sup> 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) <https://www.alz.org/media/Documents/alzheimers-dementia-mild-cognitive-impairment-ts.pdf>
6. Mayo Clinic (2015). Diseases and Conditions. Retrieved from <http://www.mayoclinic.org/diseases-conditions/>.
7. Ward A, Tardiff S, Dye C, Arrighi HM (2013). Rate of Conversion from Prodromal Alzheimer's Disease to Alzheimer's Dementia: A Systematic Review of the Literature. *Dementia and Geriatric Cognitive Disorders EXTRA.* <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3808216/>
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. Alzheimer's Association. Stages of Alzheimer's & Symptoms. <https://www.alz.org/alzheimers-dementia/stages>
11. Alzheimer's Association (2015c) Mixed Dementia; <http://www.alz.org/dementia/mixed-dementia-symptoms.asp>.
12. Alzheimer's Association. Early Onset Dementia: A National Challenge, a Future Crisis. Washington, D.C.: Alzheimer's Association; 2006.
13. Taylor CA, Greenlund SF, McGuire LC, Lu H, Croft J. Morbidity and Mortality Weekly Report (MMWR). Centers for Disease Control and Prevention.

- <https://www.cdc.gov/mmwr/volumes/66/wr/mm6620a1.htm>. Published July 21, 2017. Accessed September 14, 2017.
14. 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](http://www.cdc.gov/injury/wisqars/pdf/10LCID_All_Deaths_By_Age_Group_2010-a.pdf).
  15. 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.
  16. Alzheimer's Association (2015) Alzheimer's Caregiver: Data from the Behavioral Factors Surveillance System (BRFSS). <https://www.alz.org/media/Documents/factsheet-2016-caregiver-data-from-2018-brfss.pdf>
  17. 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>.
  18. Mayeda ER, Glymour MM, Quesenberry CP, Whitmer RA. Inequalities in dementia incidence between six racial and ethnic groups over 14 years. *Alzheimer's & dementia : the journal of the Alzheimer's Association*. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4969071/>.
  19. 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.
  20. 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>.
  21. 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. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3667653/>.
  22. Alzheimer's Research UK (2015). Women and Dementia: A Marginalized Majority. <http://www.alzheimersresearchuk.org/wp-content/uploads/2015/03/Women-and-Dementia-A-Marginalised-Majority1.pdf>.
  23. Bamford S-M, Hayat SA, Luben R, et al. (2012). Women and Dementia - Not forgotten. [https://www.researchgate.net/publication/230644343\\_Women\\_and\\_dementia\\_-Not\\_forgotten](https://www.researchgate.net/publication/230644343_Women_and_dementia_-Not_forgotten). Alzheimer's Association; International Conference 2015. [https://www.alz.org/aaic/\\_downloads/tues-8am-women-risk.pdf](https://www.alz.org/aaic/_downloads/tues-8am-women-risk.pdf).
  24. National Institute on Aging (2015). *Alzheimer's Disease Genetics* (August, 2015) NIS No. 15-6424.
  25. Women's Health and Equality Consortium (2016). Women and Dementia. [https://www.researchgate.net/publication/308985807\\_Women\\_and\\_Dementia\\_Women's\\_Health\\_Equality\\_Consortium\\_October\\_2016](https://www.researchgate.net/publication/308985807_Women_and_Dementia_Women's_Health_Equality_Consortium_October_2016)
  26. Alzheimer's Association (2015). New Reports From the Alzheimer's International Conference. [https://www.alz.org/aaic/\\_downloads/thurs-1130am-overview.pdf](https://www.alz.org/aaic/_downloads/thurs-1130am-overview.pdf)

27. Alzheimer's Association (2017). Dementia and Caregiving in the U.S. [http://www.caregiving.org/wp-content/uploads/2017/02/DementiaCaregivingFINAL\\_WEB.pdf](http://www.caregiving.org/wp-content/uploads/2017/02/DementiaCaregivingFINAL_WEB.pdf)
28. University of York Social Policy Research Unit (2015). Women and Dementia: All But Forgotten? A Literature Review. [https://www.york.ac.uk/inst/spru/research/pdf/womendementia\\_literature\\_review.pdf](https://www.york.ac.uk/inst/spru/research/pdf/womendementia_literature_review.pdf)
29. Zhu X-C, Tan L, Wang H-F, et al. (2015). Rate of early onset Alzheimer's disease: a systematic review and meta-analysis. *Annals of Translational Medicine*. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4356853/>
30. National Institute on Aging (2015). *Alzheimer's Disease Genetics* (August, 2015) NIS No. 15-6424
31. Lai, F. and Williams, R. S., (1989). A Prospective Study of Alzheimer's Disease in Down Syndrome. *Archive of Neurology* 46, 849-853.
32. Alzheimer's Association (2015) Types of Dementia. Retrieved from: <http://www.alz.org/dementia/types-of-dementia.asp>.
33. 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/>.
34. Retrieved from <http://www.thearc.org/learn-about/intellectual-disability> on 7/30/15.
35. National Down Syndrome Society (2012). Alzheimer's Disease & Down Syndrome. <http://www.ndss.org/Resources/Health-Care/Associated-Conditions/Alzheimers-Disease-Down-Syndrome/>.
36. National Down Syndrome Society. Anesthesia and Down Syndrome. <https://www.ndss.org/resources/anesthesia-down-syndrome/>
37. National Down Syndrome Society (2013). Aging and Down Syndrome: A Health and Well-Being Guidebook. New York, NY: Moran, J.
38. National Task Group on Intellectual Disabilities and Dementia Practices (2013). <http://aadmd.org/sites/default/files/NTG-communitycareguidelines-Final.pdf>.
39. <https://www.healthaffairs.org/do/10.1377/hblog20150803.049733/full/>
40. Loy, C. T.; Schofield, P. R.; Turner, A. M.; Kwok, J. B. J. Genetics of Dementia. *Lancet* 2014; 383:828–40.
41. Ridge, P. G., Ebbert, M. T., & Kauwe, J. S. (2013). Genetics of Alzheimer's disease. *BioMed research international*, 2013, 254954. doi:10.1155/2013/254954 ([https://www.cdc.gov/heartdisease/risk\\_factors.htm](https://www.cdc.gov/heartdisease/risk_factors.htm).)
42. Fryar CD, Chen T, Li X. Prevalence of Uncontrolled Risk Factors for Cardiovascular Disease: United States, 1999–2010. NCHS Data Brief, No. 103. Hyattsville, MD: National Center for Health Statistics, Centers for Disease Control and Prevention, US Dept of Health and Human Services; 2012.
43. Stern, Y. *Alzheimer Dis Assoc Disord*. 2006 Jul-Sep; 20(3 Suppl 2):S69-74.
44. 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.
45. 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](http://newoldage.blogs.nytimes.com/2013/07/17/in-europe-dementia-rates-may-be-falling/?_r=0).
46. 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>.
47. Wilson RS, Krueger KR, Arnold SE, et al. Loneliness and Risk of Alzheimer Disease. *Arch Gen Psychiatry*. 2007;64(2):234–240. doi:10.1001/archpsyc.64.2.234
48. Sutin, Angelina R, et al. "Loneliness and Risk of Dementia." *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, U.S. National Library

- of Medicine, 26 Oct. 2018, <https://www.ncbi.nlm.nih.gov/pubmed/30365023>. Alzheimer's Association (2015b) 32nd Guidelines for Alzheimer's Disease; [http://www.alz.org/research/diagnostic\\_criteria/](http://www.alz.org/research/diagnostic_criteria/).
49. 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.
  50. 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.
  51. for Disease Control and Prevention (2018). The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2018-2023. Retrieved from <https://www.cdc.gov/aging/pdf/2018-2023-Road-Map-508.pdf>.
  52. 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.
  53. National Institute on Aging (2015). 2014-2015 Alzheimer's Disease Progress Report Advancing Research Toward a Cure. Retrieved from [http://www.questri.com/wp-content/uploads/2016/09/2014-2015\\_alzheimers-disease-progress-report.pdf](http://www.questri.com/wp-content/uploads/2016/09/2014-2015_alzheimers-disease-progress-report.pdf).
  54. Batsch, N. L., Mittelman, M. S. & Alzheimer's Disease International (2012). World Alzheimer's Report 2012: Overcoming the Stigma of Dementia. Retrieved from <https://www.alz.co.uk/sites/default/files/pdfs/world-report-2012-summary-sheet.pdf>
  55. *SUSTAINING MOMENTUM: NIH Takes Aim at Alzheimer's Disease & Related Dementias*. National Institutes of Health, 28 July 2017, [https://www.nia.nih.gov/sites/default/files/2017-07/FY19-bypass-budget-report-508\\_0.pdf](https://www.nia.nih.gov/sites/default/files/2017-07/FY19-bypass-budget-report-508_0.pdf).
  56. 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.
  57. 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.
  58. World Health Organization & Alzheimer's Disease International (2015). [http://www.who.int/mental\\_health/neurology/dementia/en/](http://www.who.int/mental_health/neurology/dementia/en/).
  59. Iglehart, J.K. (2014). The elusive search for solutions to Alzheimer's. *Health Affairs*, 33(4) 526.
  60. Taipale, H., Koponen, M., Tanskanen, 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>.
  61. Alzheimer's Association (2015). End-of-life Decisions. [https://www.alz.org/national/documents/brochure\\_endoflifedeцийions.pdf](https://www.alz.org/national/documents/brochure_endoflifedeцийions.pdf)
  62. 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](http://www.cdc.gov/pcd/issues/2013/13_0090.htm).
  63. National Alliance for Caregiving & AARP (2015). Caregiving in the U.S. in 2015. Retrieved from <http://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf>.

64. 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.
65. 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.
66. 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.
67. Mittelman, M. & Bartels, S. (2014). Translating research into practice: case study of a community-based dementia caregiver intervention. *Health Affairs*, 33(4), 587-95.
68. 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.
69. 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.
70. 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.
71. 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.
72. 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.
73. Pinette, A., Obisesan, T.O., Shetty, N., Tchiendji, C.S., Mehari, A. Trends in Hospitalization Associated with Alzheimer's Disease in the United States. *Journal of the American Geriatrics Society*. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3744116/>.
74. 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>.
75. 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>.
76. Lachs, M., Berman, J. (2011). *Under the Radar: New York State Elder Abuse Prevalence Study*. Retrieved from: <http://NYSOCS.ny.gov/main/reports/Under%20the%20Radar%2005%2012%2011%20final%20report.pdf>.
77. National Committee for the Prevention of Elder Abuse (2008). <http://www.preventelderabuse.org/>.
78. Foldes SS, Moriarty JP, Farseth PH, Mittelman MS, Long KH. Medicaid Savings From The New York University Caregiver Intervention for Families with Dementia | The Gerontologist | Oxford Academic. OUP Academic. <https://academic.oup.com/gerontologist/article/doi/10.1093/geront/gnx077/3869333/Medicaid-Savings-From-The-New-York-University?rss=1>. Published July 5, 2017.

**Attachment A**

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

Louis R. Belzie, MD  
Brookdale University

David Cascio, RN, BSN  
Schofield Home Health Care

Carl I. Cohen, MD  
SUNY Health Science Center at Brooklyn

Kathleen Doyle, PhD  
New York State Education Department

Teresa A. Galbier, MPA  
Alzheimer's Association, Rochester and Finger Lakes Region Chapter

Deborah Greenfield  
New York State Office of Children and Family Services

William Higgins, MD, MBA  
New York Presbyterian/Hudson Valley Hospital

Catherine J. James  
Alzheimer's Association, Central New York Chapter

Mark Kissinger  
New York State Department of Health

Jed A. Levine, MA  
CaringKind

Ralph Nixon, MD, PhD  
Nathan Kline Institute

Greg Olsen  
New York State Office for the Aging

Susan Prendergast, RN, BS  
New York State Office for People with Developmental Disabilities

Paula J. Rice  
CaringKind

Elizabeth Smith-Boivin, MSHSA  
Alzheimer's Association, Northeastern New York Chapter

## **Attachment B**

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

<b>Diagnosis</b>	<b>Diagnostic Criteria</b>
<b>Alzheimer's disease (AD)</b>	<p><b>Characteristics:</b> 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.</p> <p><b>Symptoms:</b></p> <ul style="list-style-type: none"><li>• Early-stage:<ul style="list-style-type: none"><li>○ Difficulty remembering recent conversations, names, or events</li><li>○ Confusion with time and place</li><li>○ Word finding issues</li><li>○ Difficulty performing familiar tasks in home, social, or work settings</li><li>○ Misplacing valuable items</li><li>○ Losses in planning, problem solving, and organizational abilities</li><li>○ Changes in mood or behavior</li><li>○ Withdrawal from work or social activities</li><li>○ Impaired judgment</li></ul></li><li>• Middle-stage:<ul style="list-style-type: none"><li>○ Forgetting events in one's personal history</li><li>○ Mood changes (apathy, depression, irritability)</li><li>○ Behavioral changes (agitation, wandering, aggression)</li><li>○ Increasing confusion related to date, time, and place</li><li>○ Difficulty maintaining continence</li><li>○ Disturbances in sleep, disruptions in sleep patterns</li><li>○ Increasing difficulties with ADLs, mobility, and functional independence</li></ul></li><li>• Late-stage:<ul style="list-style-type: none"><li>○ Lack of awareness of recent experiences, surroundings, and physical functioning</li><li>○ Difficulty swallowing</li><li>○ At risk for infections, especially pneumonia</li><li>○ Further decline in physical ability and mobility</li><li>○ Significant dependence on caregivers for ADLs and personal care</li><li>○ Impaired verbal and receptive communication skills</li></ul></li></ul> <p><b>Brain changes:</b> 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.</p> <p><b>Diagnosing:</b> An AD diagnosis is based on a medical evaluation completed by a medical professional that includes a physical and neurological examination; interviews of the</p>

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

<b>Diagnosis</b>	<b>Diagnostic Criteria</b>
<b>Alzheimer's disease (AD) <i>(continued)</i></b>	<p>patient and family member; mental status tests; functional assessments; and examinations to establish any differential diagnoses.</p> <p><b>Known risk factors:</b></p> <ul style="list-style-type: none"> <li>• Advancing age</li> <li>• Family history</li> <li>• Genetics, specifically the presence of the APOE-e4 gene or Down syndrome.</li> </ul>
<b>Diagnosis</b>	<b>Diagnostic Criteria</b>
<b>Chronic Traumatic Encephalitis (CTE)</b>	<p><b>Characteristics:</b> 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.</p> <p><b>Symptoms:</b></p> <ul style="list-style-type: none"> <li>• Characteristics of dementia - memory loss, impaired judgment, confusion and agitation – appearing years after trauma</li> <li>• Depression and suicidal thoughts</li> <li>• Behavioral and mood changes</li> <li>• Impulse control problems and aggression</li> </ul> <p><b>Brain changes:</b> 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.</p> <p><b>Diagnosing:</b> 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.</p> <p><b>Known risk factors:</b></p> <ul style="list-style-type: none"> <li>• Repeated brain trauma</li> <li>• History of head injuries/TBIs</li> </ul>
<b>Diagnosis</b>	<b>Diagnostic Criteria</b>
<b>Creutzfeldt-Jakob disease (CJD)</b>	<p><b>Characteristics:</b> 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.</p> <p><b>Symptoms:</b></p> <ul style="list-style-type: none"> <li>• Confusion and rapid decline in all areas of cognition</li> <li>• Involuntary muscle movements, twitches and/or stiffness</li> <li>• Difficulty walking</li> </ul>

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

<b>Diagnosis</b>	<b>Diagnostic Criteria</b>
<b>Creutzfeldt-Jakob disease (CJD) (continued)</b>	<ul style="list-style-type: none"> <li>• Apathy, agitation and mood changes</li> <li>• Depression</li> </ul> <p><b>Brain changes:</b> Results from misfolded prion protein throughout the body that progresses to the brain and leads to a destruction of brain cells.</p> <p><b>Diagnosing:</b> 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.</p> <p><b>Known risk factors:</b></p> <ul style="list-style-type: none"> <li>• Genetic variations</li> <li>• Exposure to external sources of abnormal prion protein (poorly sterilized medical equipment or infected meat)</li> </ul>
<b>Diagnosis</b>	<b>Diagnostic Criteria</b>
<b>Frontotemporal dementia (FTD)</b>	<p><b>Characteristics:</b> 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.</p> <p><b>Symptoms:</b></p> <ul style="list-style-type: none"> <li>• Behavior changes, such as impulsivity and inappropriateness, are often noted first.</li> <li>• Early difficulty with understanding speech or reading</li> <li>• Changes in personality and emotional reactions</li> <li>• Decline in motor function</li> </ul> <p><b>Brain changes:</b> 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.</p> <p><b>Diagnosing:</b> 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.</p>

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

<b>Diagnosis</b>	<b>Diagnostic Criteria</b>
<b>Frontotemporal dementia (FTD) (continued)</b>	<p><b>Known risk factors:</b></p> <ul style="list-style-type: none"> <li>• Family history (accounts for 1/3 of the cases)</li> </ul>
<b>Diagnosis</b>	<b>Diagnostic Criteria</b>
<b>HIV associated neurocognitive disorder (HAND)/Acquired immune deficiency syndrome (AIDS) dementia complex (ADC)</b>	<p><b>Characteristics:</b> 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.</p> <p><b>Symptoms:</b></p> <ul style="list-style-type: none"> <li>• Forgetfulness, confusion, and other changes in cognition</li> <li>• Behavioral and personality changes</li> <li>• Headaches</li> <li>• Weakness and loss of sensation in arms and legs</li> <li>• Progressive motor dysfunction</li> <li>• Extremity pain due to nerve damage</li> </ul> <p><b>Brain changes:</b> 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.</p> <p><b>Diagnosing:</b> 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.</p> <p><b>Known risk factors:</b></p> <ul style="list-style-type: none"> <li>• HIV Infection</li> </ul>
<b>Diagnosis</b>	<b>Diagnostic Criteria</b>
<b>Huntington's disease</b>	<p><b>Characteristics:</b> 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.</p> <p><b>Symptoms:</b></p> <ul style="list-style-type: none"> <li>• Unsteady gait and involuntary movements (chorea) involving all extremities</li> <li>• Forgetfulness and impaired judgment</li> <li>• Decline in thinking and reasoning skills including memory, concentration, judgment and ability to plan or organize</li> </ul>

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

<b>Diagnosis</b>	<b>Diagnostic Criteria</b>
<b>Huntington's disease <i>(continued)</i></b>	<ul style="list-style-type: none"> <li>• Personality changes, mood swings, anxiety, depression and uncharacteristic anger or irritability</li> <li>• Obsessive-compulsive tendencies</li> </ul> <p><b>Brain changes:</b> The gene defect influences the abnormal production of "huntingtin" protein that, over time, leads to worsening symptoms.</p> <p><b>Diagnosing:</b> 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.</p> <p><b>Known risk factors:</b></p> <ul style="list-style-type: none"> <li>• Heredity and family history</li> </ul>
<b>Diagnosis</b>	<b>Diagnostic Criteria</b>
<b>Lewy body dementia (LBD)</b>	<p><b>Characteristics:</b> 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.</p> <p><b>Symptoms:</b></p> <ul style="list-style-type: none"> <li>• Cognitive difficulties similar to AD, although memory loss of less severity</li> <li>• Periods of confusion and alertness that vary from one time of the day to another, or from one day to the next</li> <li>• Sleep disturbances, often acting out dreams</li> <li>• Well-formed visual hallucinations and delusions</li> <li>• Muscle rigidity or other Parkinsonian movement features</li> <li>• Autonomic nervous system changes</li> <li>• Difficulty with visual interpretations</li> </ul> <p><b>Brain changes:</b> 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.</p> <p><b>Diagnosis:</b> 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.</p> <p><b>Known risk factors:</b></p> <ul style="list-style-type: none"> <li>• Advanced age</li> </ul>

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

<b>Diagnosis</b>	<b>Diagnostic Criteria</b>
<b>Lewy body dementia (LBD) (continued)</b>	<ul style="list-style-type: none"> <li>• Male gender</li> <li>• Family member with history of LBD</li> <li>• Parkinson's disease diagnosis</li> </ul>
<b>Diagnosis</b>	<b>Diagnostic Criteria</b>
<b>Mild Cognitive Impairment (MCI)</b>	<p><b>Characteristics:</b> 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.</p> <p><b>Symptoms:</b></p> <ul style="list-style-type: none"> <li>• MCI primarily affecting memory ("Amnestic")           <ul style="list-style-type: none"> <li>◦ Short-term memory and re-call problems</li> <li>◦ Difficulty learning new information</li> </ul> </li> <li>• MCI primarily affecting thinking ("Non-amnestic")           <ul style="list-style-type: none"> <li>◦ Losses in executive thinking (planning, organization)</li> <li>◦ Lack of judgment</li> <li>◦ Difficulty completing complex tasks</li> <li>◦ Changes in visual perception</li> </ul> </li> <li>• Presence of depression, irritability, anxiety, and/or apathy</li> </ul> <p><b>Brain changes:</b> 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.</p> <p><b>Diagnosing:</b> 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).</p> <p><b>Known risk factors:</b></p> <ul style="list-style-type: none"> <li>• Advancing age</li> <li>• Family history of AD/D</li> <li>• Conditions that increase a person's risk of cardiovascular disease (e.g., hypertension, smoking, lack of exercise, or diabetes)</li> </ul>
<b>Diagnosis</b>	<b>Diagnostic Criteria</b>
<b>Mixed Dementia</b>	<p><b>Characteristics:</b> Mixed dementia is characterized by the simultaneous occurrence of the signs and symptoms of different types of dementia. The most common forms of</p>

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

<b>Diagnosis</b>	<b>Diagnostic Criteria</b>
<b>Mixed Dementia (continued)</b>	<p>mixed dementia are AD with vascular dementia, AD with LBD, or characteristics of AD mixed with vascular and LBD.</p> <p><b>Symptoms:</b> 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.</p> <p><b>Brain changes:</b> An individual living with mixed dementia will have the pathology of the presenting combination of AD/D. For example, in an individual living with both AD and vascular dementia, abnormal protein deposits associated with AD co-exist with blood vessel changes problems linked to vascular dementia.</p> <p><b>Diagnosing:</b> 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.</p> <p><b>Risk Factors:</b></p> <ul style="list-style-type: none"> <li>• Risk factors are consistent with the types of dementia that comprise the mixed dementia diagnosis.</li> </ul>
<b>Diagnosis</b>	<b>Diagnostic Criteria</b>
<b>Parkinson's disease</b>	<p><b>Characteristics:</b> 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.</p> <p><b>Symptoms</b></p> <ul style="list-style-type: none"> <li>• Memory impairment with disruptions in judgment and ability to concentrate</li> <li>• Parkinsonian motor changes, such as: <ul style="list-style-type: none"> <li>◦ Bradykinesia (slowed movements)</li> <li>◦ Tremors, mostly at rest</li> <li>◦ Muscle rigidity</li> <li>◦ Gait disturbances (shuffling, forward propelling, difficulty initiating movement)</li> <li>◦ Mask-like fascial expression</li> </ul> </li> </ul>

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

<b>Diagnosis</b>	<b>Diagnostic Criteria</b>
<b>Parkinson's disease (continued)</b>	<ul style="list-style-type: none"> <li>○ Abnormal posture</li> <li>○ Micrographia</li> <li>● Delusions and paranoid ideations</li> <li>● Sleep disturbances</li> <li>● Depression and anxiety</li> <li>● Overall fatigue</li> <li>● Low volume and muffled speech</li> </ul> <p><b>Brain changes:</b> 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.</p> <p><b>Diagnosing:</b> 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.</p> <p><b>Known risk factors:</b></p> <ul style="list-style-type: none"> <li>● Age 60 or older</li> <li>● Heredity</li> <li>● Male gender</li> <li>● Exposure to toxins (particularly herbicides and pesticides)</li> </ul>
<b>Diagnosis</b>	<b>Diagnostic Criteria</b>
<b>Vascular dementia</b>	<p><b>Characteristics:</b> 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.</p> <p><b>Symptoms:</b> 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:</p> <ul style="list-style-type: none"> <li>● Decrease in ability to organize thoughts and actions</li> <li>● Confusion, disorientation, and poor attention span</li> <li>● Impaired judgment and reasoning skills</li> <li>● Difficulty with decision making</li> <li>● Inability to complete complex, multiple step tasks</li> <li>● Communication challenges related to losses in expressive and/or receptive language</li> <li>● Changes to vision</li> </ul>

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

<b>Diagnosis</b>	<b>Diagnostic Criteria</b>
<b>Vascular dementia (continued)</b>	<ul style="list-style-type: none"> <li>• Impairments in mobility and/or extremity weakness specific to the area of the brain affected</li> </ul> <p><b>Brain changes:</b> 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:</p> <ul style="list-style-type: none"> <li>• A diagnosis of dementia or MCI;</li> <li>• Evidence of a stroke or other blood vessel changes that affect cause damage in the brain; and</li> <li>• No evidence that factors other than vascular changes caused the decline.</li> </ul> <p><b>Diagnosing:</b> 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.</p> <p><b>Known risk factors:</b></p> <ul style="list-style-type: none"> <li>• History of heart disease and stroke</li> <li>• Smoking</li> <li>• Poorly managed diabetes</li> <li>• Obesity and lack of exercise</li> <li>• Hypertension and high cholesterol</li> </ul>
<b>Diagnosis</b>	<b>Diagnostic Criteria</b>
<b>Wernicke-Korsakoff syndrome (WKS)</b>	<p><b>Characteristics:</b> 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.</p> <p><b>Symptoms:</b></p> <ul style="list-style-type: none"> <li>• Memory problems, both recent recall and long term, accompanying intact higher level cognitive and social skills</li> <li>• Difficulty learning new information</li> <li>• Tendency to confabulate and make up information that can't be recalled</li> </ul> <p><b>Brain changes:</b> Thiamine helps brain cells produce energy from sugar. When thiamine levels fall too low, brain cells cannot generate enough energy to function properly.</p> <p><b>Diagnosing:</b> WKS is a clinical diagnosis representing a doctor's best professional judgment about the reason for a person's symptoms. There are no specific laboratory tests or</p>

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

<b>Diagnosis</b>	<b>Diagnostic Criteria</b>
<b>Wernicke-Korsakoff syndrome (WKS) (continued)</b>	<p>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.</p> <p><b>Known risk factors:</b></p> <ul style="list-style-type: none"><li>• Alcohol misuse</li><li>• Poor nutrition related to stringent dieting, fasting or anorexia</li><li>• Presence of other diseases that lead to malnutrition such as AIDS, kidney dialysis, chronic infection, or cancer</li></ul>

## **Attachment C**

### **Acronyms**

AAA	Area Agencies on Aging
AD	Alzheimer's disease
AD/D	Alzheimer's disease and other dementias
ADC	AIDS dementia complex
ADL	Activities of daily living
AIDS	Acquired Immune Deficiency Syndrome
AlzCAP	Coalition of Alzheimer's Association Chapters
APS	Adult Protective Services
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
E-MDT	Enhanced Multi-Disciplinary Teams
FTD	Frontotemporal Dementia
HAND	HIV associated neurocognitive disorder
HIV	Human Immunodeficiency Virus
ILC	Independent Living Centers
LBD	Lewy Body Dementia
MCI	Mild Cognitive Impairment
MRI	Magnetic Resonance Imaging
NAPA	National Alzheimer's Project Act
NIA	National Institute in Aging
NIH	National Institutes of Health
NKI	Nathan Kline Institute for Psychiatric Research
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
NYSCRC	New York State Coalition on Caregiving and Respite
NYSPI	New York State Psychiatry Institute
NYSOMH	New York State Office of Mental Health
OAA	Older American's Act
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
REST	Respite Education and Support Tools
SADS	Social Adult Day Service
SFY	State Fiscal Year

TBI  
WHO  
WKS

Traumatic Brain Injury  
World Health Organization  
Wernicke-Korsakoff syndrome