2021 Report

of the

New York State Coordinating Council

for Services Related to Alzheimer’s Disease

and Other Dementia

to

the Governor

and the

New York State Legislature

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Introduction: Executive Summary

Section I. Background

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

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

Coronavirus, COVID-19

On March 11, 2020, the World Health Organization declared COVID-19 a global pandemic. Subsequently, the US Department of Health and Human Services has a National Plan to Address Alzheimer's Disease. This plan indicates that COVID-19 significantly complicates the health and safety of older adults, particularly those experiencing cognitive impairment, and their caregivers. Chronic conditions such as Alzheimer's Disease and related dementias are risk factors of greater morbidity and mortality due to COVID-19, making people with dementia one of the most at-risk groups. In response to this threat and in an effort to secure the safety and well-being of those living with dementia and their caregivers, much needed treatment, services, and supports were either adapted, placed on hold, or eliminated.

Dementia

Dementia is an umbrella term that refers to a group of degenerative neurocognitive disorders. AD/D reflects an impairment of 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.[1]

Alzheimer’s Disease

Alzheimer’s disease (AD) is the most common form of dementia: 60-80% of individuals with dementia have AD.[2] AD is a degenerative and ultimately fatal condition characterized by diagnostic brain abnormalities, amyloid plaques and neurofibrillary tangles, and extensive loss of synapses (the connections between neurons that maintain circuits subserving memory and other brain functions). Amyloid plaques and neurofibrillary tangles contribute to this disruption in neuronal communication in the brain, which eventually causes brain 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. Recently a vaccine that targets removal of amyloid from the AD brain was given FDA approval for use in patients with early stage AD. Early results indicate modest efficacy in slowing progression of the disease, however, the long-term outcome and benefits of the drug remain in dispute.

AD typically occurs in a progressive sequence of stages. According to the 2011 diagnostic guidelines for AD published by the National Institute on Aging (NIA), AD begins before the emergence of observable symptoms.

The NIA identifies three stages of AD that occur on a spectrum: preclinical/presymptomatic Alzheimer’s, mild cognitive impairment (MCI), and dementia due to AD.[3] More information on the diagnostic guidelines can be viewed at: 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.[3] AD affects individuals in different ways, meaning that their presentation of the disease, symptoms they experience, and progression through these stages will be unique. These stages are a guideline. It may be difficult to place an individual in a specific stage because stages blend and may overlap.[4]

Both of these organizations identify these stages as follows:

Preclinical/Presymptomatic Alzheimer’s Disease

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

Mild Cognitive Impairment (MCI)

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

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

MCI is significant to the risk assessment and early 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.[7] 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.[5] Limited information exists on the relationship between MCI and other dementias.

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

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.[5] The Alzheimer's Association describes the following ten warning signs that may strongly indicate AD:

- memory loss that affects/disrupts daily life
- challenges in planning or solving problems
- difficulty completing familiar tasks at home, work, or at leisure
- confusion with time or place
- trouble understanding visual images and spatial relationships
- new problems with words in speaking or writing
- misplacing things and losing the ability to retrace steps
- decreased or poor judgment
- withdrawal from work or social activities
- changes in mood or behavior

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

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.[10, 11]

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). Schizophrenia is an under-recognized cause of dementia. In a recent study of 8,011,773 individuals (tracked from the national Medicare database), who were 66 years of age, 27.9% of the individuals living with schizophrenia also had a dementia diagnosis. (*JAMA Psychiatry.* 2021;78(6):632-641).

Causes and symptoms of the various types of dementia vary, although some of the neurodegenerative processes have common pathways.[1] In terms of clinical presentation and diagnosis, it is often difficult to distinguish between the different forms of dementia. (See Attachment B for additional information related to AD/D.)

In many cases, abnormalities characteristic of more than one type of dementia are found. This can lead to the clinical diagnosis of mixed dementia. Many researchers and experts in the field believe mixed dementia deserves more attention. 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-morbidity 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 6.2 million Americans live with AD, approximately 72% of these individuals are over age 65.[2] The number of Americans over the age of 65 living with AD may grow to 12.7 million by 2050.[2] The rate of AD increases with age, and approximately 34.6% of people over age 85 have AD.[2] 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."[12] 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).[2] One in three seniors in the United States dies from AD.[2] 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. According to data from the CDC, 121,404 people died from Alzheimer's disease in 2017.[13] 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.[14]

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.[15]

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.[16] 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 410,000 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.[2] This number of cases of the disease has far exceeded early expectations.

Centers for Disease Control and Prevention (CDC), Alzheimer's Disease and Healthy Aging Program utilize the Behavioral Risk Factor Surveillance System (BRFSS) to obtain data on the disease. Similar to national figures, in NYS, one (1) in nine (9) individuals aged forty-five (45) and over reported confusion or memory loss in the 2017 Behavioral Risk Factor Surveillance System (BRFSS) and only fifty-four point four percent (54.4%) indicated that they reported the condition to their health care provider.[16] Additional NYS-related BRFSS data is located at: https://www.cdc.gov/brfss/annual_data/annual_2017.html

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.[17] The Task Force issued an updated report with recommendations for these populations in 2018.

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.[2] 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.[18]

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.[2] These conditions include, but are not limited to, cardiovascular disease, diabetes, chronic kidney disease, and higher hemoglobin levels.[19, 20] Increased risk of cardiovascular disease due to diabetes and heart disease also increases the risk of vascular dementia.[2] 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.[2]

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.[21] There is evidence that missed diagnoses of AD/D are more common among African-Americans and Hispanics than non-Hispanic Caucasicans.[2] 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.)[2, 19]

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.[2] Longevity alone might not be the only explanation for the higher prevalence of dementia among women.[23, 24] Researchers are exploring this disparity by examining risk factors related to genetics (brain structure, disease progression, estrogen, and depression.[24] 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. [25, 22, 23]

Women provide sixty-five percent (65%) of all paid and unpaid caregiving for individuals with AD/D.[26] Women are two point three (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. [26, 27] 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 (20%) of female care partners have gone from working full-time to part-time, while only three percent 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.[22, 23, 28]

Early/Younger Onset Dementia

Early (also known as younger) onset dementia occurs when a person under the age of sixty-five (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 five point five percent (5.5%) of individuals with dementia have an early onset form.[29] 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.[12] 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.[30] Individuals with Down syndrome are at a strikingly increased risk of developing early onset AD.[31] Other early onset dementias, such as Huntington's disease, FTD, and vascular dementia, also have familial forms. Huntington's disease is exclusively hereditary.[33] In addition, there are rare dementias caused by neuronal ceroid lipofuscinoses that affect children and young adults.[33, 34]

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.[12]

Down Syndrome

Individuals with Down syndrome (DS), an intellectual and developmental disability (ID/DD), are at increased risk for developing AD, particularly the early onset form of the disease. This is due to the accelerated aging process experienced by this population. Also, these individuals have a partial or full-third copy of chromosome 21. Chromosome 21 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.[35]

Despite the wide ranges reported for dementia prevalence in individuals with Down syndrome, a consistent feature of aging is the progressive accumulation of AD brain pathologies. By the age of forty (40) years, virtually all have sufficient senile plaques and neurofibrillary tangles for a neuropathological diagnosis of AD. Thus, there is dissociation between the age of onset of AD neuropathology (40 years) and increasing signs of clinical dementia." Eur J Neurodegener Dis. 2012 Dec; 1(3): 353–364. PMCID: PMC4184282 Alzheimer's Disease in Down Syndrome Elizabeth Head,[1,5] David Powell,[2,5] Brian T. Gold,[3,5] and Frederick A. Schmitt.[4,5]

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 cognitive 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.[37] For this population, cognitive decline occurs more rapidly and can be aggressive, making early diagnosis crucial to providing better support.[39] Individuals with Down syndrome are more prone to co-morbid conditions such as sensory loss, hypothyroidism, obstructive sleep apnea, osteoarthritis, atlantoaxial instability, osteoporosis, and celiac disease. The presence of multiple co-morbidity conditions makes diagnosis of and treatment for this population difficult because many dementia symptoms are associated with other conditions.[37]

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

Risk Factors

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

Old age is the most significant risk factor for AD. Five point three percent (5.3%) of individuals between the ages of sixty-five to seventy four (65-74), thirteen point eight percent (13.8%) of individuals between the ages seventy-five to eighty-four (75-84), and thirty-four point six percent (34.6%) of individuals aged eighty-five (85) or older have AD.[2]

Genetics research suggests that certain combinations of apolipoprotein enzyme (APOE ε2, ε3, or ε4) genes, inherited from both parents, increase an individual's risk of developing AD.[2, 40] These gene(s) is responsible for providing the blueprint for a protein that transports cholesterol through the blood stream. Researchers estimate that as many as sixty-seven percent (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.[41]

A report issued by the Lancet Commission in 2020 updated recommendations made by that group in 2017, highlighting twelve potentially modifiable risk and protective factors for dementia. These risk factors now include: less education, hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes, low social contact, excessive alcohol consumption, traumatic brain injury, and air pollution. [79] The Commission proposes that up to forty percent (40%) of dementias worldwide could be impacted by addressing these twelve factors.

Further research continues, 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.[42 ,2](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."[43] 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.[44]

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

A study conducted in Denmark supports the theory that lifestyle and health factors can play a significant role in acquiring AD/D.[45] 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 ninety-five (95) than those born in 1905 did at age ninety-three (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 aged sixty-five (65) and older in the same geographic areas.[46] The rate of AD/D in this study dropped twenty-five percent (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 and other potentially harmful waste materials during deep sleep. Individuals should target seven to eight (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 forty percent (40%.) Feelings of social connectedness and fulfillment can help to reduce this risk.[47]

Identification and Diagnosis

The National Institute of Aging's (NIA's) 2011 diagnostic guidelines encourage the early detection of AD/D by recognizing the preclinical/presymptomatic stage of the disease.[48]

Biomarker tests have the potential to identify changes twenty (20) years before noticeable cognitive decline at the preclinical/presymptomatic stage, and these tests are a possible future method of detecting AD/D.[2, 48] 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 tau and certain other disease-related proteins in cerebrospinal fluid and blood and/or detection of 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 mild cognitive impairment (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.

Overall, there are more than forty (40) screening tools available to assess cognition and identify potential impairment. [49] 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. Several of these tools are particularly suited to primary care offices and can be administered during annual physicals by physicians or other health and clinical professionals.[50] 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 cognitive assessment and the recommendations for clinical practice 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.)[51] 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.[2]

The 2019 Alzheimer's Facts and Figures included a *Special Report Alzheimer's Detection in The Primary Care Setting: Connecting Patients with Physicians*.[2] This report explored the state of cognitive assessment, termed "brief cognitive assessment," in the primary care setting and identified potential solutions for ongoing 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.[2] Without such directives, families must make decisions based on what they believe the person would want. Making the decision to withhold or withdraw treatment is difficult, often leaving caregivers with a sense of guilt.[52]

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.[33] In addition, other conditions mimic AD/D and may be reversible (e.g., normal pressure hydrocephalus and delirium).

Early detection is important and necessary for finding more effective treatments and developing prevention strategies.[2] Researchers are exploring early detection through brain imaging, biomarkers, and genetic testing during the preclinical stage before signs and symptoms appear.[53] 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.[54] Barriers also include the public's lack of knowledge about the difference between normal aging and the early signs of MCI/dementia. Additionally, there is a lack of awareness/understanding among some primary care doctors who dismiss the patient/family when they raise concerns about the warning signs of the disease(s). Strategies to overcome these barriers include educating the public and health care providers about the disease and its progression, the benefits of early detection, and the impact of cultural norms on its diagnosis and treatment. As such, this report addresses recommendations related to increased provider education in the diagnosis and treatment of the disease.

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 & Relate*d *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. [55] 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.[53]

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.[55] Large scale clinical trials involving this approach in individuals with mild clinical symptoms of AD have not shown therapeutic efficacy. Recently, one vaccine targeting amyloid removal from the brain (Aducanumab) has been given FDA approval for use in patients with early stage AD. Based on the Aducanumab trial results, efficacy of this treatment in slowing progression of clinical disease is modest and controversial. Its impact as a therapeutic of meaningful clinical value will need to be assessed more fully in a large phase 4 (post-approval) trial involving extended use and monitoring of safety. The recent focus in these "amyloid vaccine" trials has 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 using a tau antibody vaccine or other approaches to reduce tau levels in AD or other tauopathies are ongoing.

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 has continued focus on non-pharmacological and pharmacological interventions that can decrease or slow symptoms associated with AD/D. The recent approval of Aducanumab (Aduhelm) is the first drug approved by the Food and Drug Administration (FDA) that is proposed, although not proven, to slow the progression of the disease. There are several additional medications with the FDA that are being scientifically tested including the use of computational methodologies to identify drugs already approved by the FDA that could be used as potential therapies for Alzheimer's disease.

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.[56, 57]

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.[58] 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 childcare, 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.[2, 25, 59] 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.[59]

Pharmacological

The most commonly used medications on the market 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.

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.[2] 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.

Other avenues being explored by pharmaceutical companies are the development of drugs that mitigate the brain of amyloid or tau, as discussed in a previous section. In June 2021, the FDA approved Aducanumab (Aduhelm) as a medication that may slow the progression of early stage Alzheimer's disease by reducing amyloid. The well-publicized controversy surrounding the approval has created public uncertainty and has strongly increased the need for a public education campaign to address the need for early diagnosis and clinical trial participation. The effectiveness of this medication is still being evaluated. 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.[25] More information on medications can be found at: http://www.nia.nih.gov/Alzheimers/publication/Alzheimers-disease-medications-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.[2, 60] Therefore, medications should be used judiciously for a short period of time. They are likely to be most effective at earlier stages of AD/D and frequent assessment is important to ensure that the benefits of using and continuing these drugs outweigh the risks. The effectiveness and/or spectrum of adverse effects of a given psychotropic agent in treating behavioral/psychiatric symptoms may varying considerably in different dementing disorders. 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.[53] 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 (measurement made on an electrocardiogram used to assess some of the electrical properties of the heart). 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

The National Institute on Health (NIH) indicates that palliative care should be initiated from the time of diagnosis and may have a substantial impact on improving the quality of life. [52] Palliative*, or comfort care, aims to keep an individual comfortable and pain-free until life ends naturally.*[61] 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.[52] 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.[61] Palliative care is not limited to the advanced stages of illness or the end of life, although for people with even the most advanced dementia, comfort matters and is possible. Going forward planning should include evaluating the efficacy of including palliative care interventions in the treatment of individuals with AD/D.

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/.

Impacts of Caregiving

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 fifteen point three (15.3) billion hours of unpaid care.[2] The Alzheimer's Association reports that caregivers' unpaid care was valued at $257 billion in 2020. This is nearly equal to the estimated cost of direct medical and long-term care for AD/D.[2] In NYS, over five hundred eighty-six thousand (586,000) caregivers provided seven hundred seventy-four (774) million hours of unpaid care for individuals with AD/D, valued at $14.62 billion.[2] Studies have found that as many as twenty-five percent (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.[2]

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 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 impacts of caring for an individual living with AD/D disproportionately affects women and minorities.[62] Women represent sixty-five percent (65%) of caregivers of individuals with AD and report taking on a higher burden of caregiving responsibilities. According to the *2021 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.[2, 63] Other research identifies non-Hispanic Caucasian caregivers as experiencing increased depression and perceived stress when compared to caregivers of other races and ethnicities.[64]

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.[65, 66, 67] 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.[66]

Formal Caregivers

Formal caregivers are paid staff who provide in-home or residential care. This workforce includes direct care staff and supporting professionals. Additionally, there are care partners who work with paid/professional supports as a team to provide daily caregiving. These roles/duties may change as the person moves through the stages of Alzheimer's/dementia. The role of the care partner is not limited to spouses, partners or close family members. They may serve as a primary, secondary, or remote support network. One of their greatest challenges is to know where, when, and how to provide assistance. As a result, these caregivers and professionals often experience high levels of stress depression or anxiety, leading to high turnover rates for paid staff in this field and overwhelmed care givers. 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.[68] 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 training for *all* caregivers. It is important to develop effective strategies to attract and retain a more qualified workforce.[69] Workers, family members, and support providers who receive enhanced AD/D training are more likely to have a person-centered attitude and report more job satisfaction and work to maintain a family member in their home. This need is addressed in the goals of this report.

Cost of Alzheimer's Disease and Other Dementia

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 (5) 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.[70] The *2021 Alzheimer's Disease Facts and Figures* pinpoints the cost of care for Americans with AD/D at $355 billion nationally. This includes an estimated $181 billion covered by Medicare, $59 billion covered by Medicaid, $76 billion in-out-of-pocket expenses paid by individuals with AD/D and/or their caregivers, and $39 billion covered by other sources, including private insurance and health organizations.

Nationally, almost four million individuals who have AD/D also have at least one other chronic condition. These individuals are five point five (5.5) times more likely to have six or more chronic conditions than a person without AD/D. According to the 2017 NYS BRFSS, eighty-three percent (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, thirty-eight percent (38%) of Medicare beneficiaries aged sixty-five (65) and older with dementia also had coronary artery disease, thirty-seven percent (37%) also had diabetes, twenty-eight percent (28%) also had congestive heart failure, twenty-nine percent (29%) also had chronic kidney disease, and twenty-five percent (25%) also had COPD.[2]

The average Medicare costs for seniors with AD/D and other chronic conditions are significantly higher than those individuals on Medicare who have a chronic condition without AD/D. According to a 2013 study, a senior with AD/D and diabetes costs Medicare eighty-one percent (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 seventy-five percent (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, twenty-five percent (25%) more than a senior with three chronic conditions but no AD/D ($27,097 compared to $21,581).[71]

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, forty-two percent (42%) of individuals age sixty-five (65) and older with AD/D lived in long-term care facilities as compared with two percent (2%) of individuals age sixty-five (65) and older without AD/D.[71] 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.[1, 72] 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.[73]

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.[74] 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.

Elder Justice for Individuals Living with AD/D

Elder justice is a broad term that, at its essence, means assuring those 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 Federal 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 Adult Protective Services (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 twenty-four (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.[76] 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.[76, 77] 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

Financial exploitation is not only the most common form of elder abuse and is the most underreported. The 2011 *Under the Radar* study found that only one (1) in forty-four (44) cases of financial abuse is reported, compared to one (1) in twenty-four (24) cases overall.[76] 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 four-point seven percent (4.77%) increase in financial exploitation from 2017. Outside of New York City (NYC), financial exploitation risks were the highest percentage of the perpetrator-related risks referred: forty point eight percent (40.8%) for all ages and forty-four point one percent (44.1%) for clients sixty (60) and older. In NYC the rates were thirty percent (30%) for all ages and thirty-two percent (32%) for ages sixty (60) and older.

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.[77, 78]

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

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 more prevalent 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.[77] 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%2005%2012%2011%20final%20report.pdf

National and New York State Public Policy Initiatives

National

The Public Health Road Map

The Alzheimer’s Association and Centers for Disease Control (CDC) have developed The Healthy Brain Initiative’s (HBI) https://www.cdc.gov/aging/healthybrain/roadmap.htm to advance cognitive health as an integral component of public health. It outlines how state and public health agencies and their partners can continue to promote brain health, address cognitive impairment for people living in the community, and help meet the needs of caregivers. This HBI Road Map informs the means by which policies, systems, and environments can further promote brain health.

Alignment of the Road Map actions with essential services of public health insures 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 Health and Human Services (HHS) to create and maintain a national plan to address AD. *National Plan to Address Alzheimer’s Disease* (National Plan) was released in May 2012, with the most recent update published in 2020. 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. To see how the actions have progressed, changed, and expanded since 2012, see the side-by-side index at: https://aspe.hhs.gov/report/national-plan-action-side-side.

In 2020, focus was placed on how to respond effectively to the global pandemic due to the outbreak of the Novel Coronavirus, COVID-19, which significantly complicates the health and safety of older adults, particularly those experiencing cognitive impairment, and their caregivers. Age, multiple chronic conditions, and disability are risk factors of greater morbidity and mortality due to COVID-19, making people with dementia one of the most at-risk groups. In particular, COVID-19 impacts people in congregate care facilities, such as nursing homes, where residents live in confined spaces and receive personal care from staff who support many residents.

In late 2021, a sixth goal was added to the NAPA specific to the promotion of healthy aging and the reduction of risk factors for Alzheimer's disease and related dementias. This new goal will guide research, public health, and clinical practice toward evidence-based lifestyle changes that may mitigate the development of disease.

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

The National Institutes of Health (NIH) and other entities use large research Summits to engage with the research community and stakeholders to solicit perspectives on research gaps and opportunities relevant to cognitive aging and Alzheimer’s disease and Alzheimer’s disease-related dementias (AD/ADRD).

The goals of the Summits are 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 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: Building Our Largest Dementia Infrastructure for Alzheimer's Act

The federal government has advanced funding in support of a public health approach to the prevention, treatment, and care of AD/D, under new legislation passed on December 31, 2018. The BOLD Act authorized the CDC to spend $20 million a year for five years to establish a public health framework across the country, similar to that currently supported in New York State, focusing on early detection and diagnosis of AD/D, the promotion of brain health through the reduction of risks to cognitive decline, and supports for caregiving of those living with Alzheimer's.

Notices of Funding Opportunities (NOFO) were released in March 2020, and contractors began implementing BOLD initiatives on September 30, 2020. This funding established:

- Public Health Centers of Excellence (PHCOE) for dementia risk reduction, early detection of dementia, and dementia caregiving, with the National Alzheimer's Association, the New York University School of Medicine, and the University of Minnesota, respectively.
- Support for 16 state, local, and tribal public health departments to either create strategic plans and the coalition to implement services associated with those plans or to expand current AD/D services and operations.

Information about BOLD can be found at: BOLD Infrastructure for Alzheimer's Act (cdc.gov)

Related Public Policy Initiatives:

New York State Initiatives

Nationally Recognized Health Across All Policies (HAAP), Age-Friendly New York. In January 2017, New York launched an initiative to advance Health Across All Policies in the State. Health Across All Policies is a collaborative approach that integrates health considerations into policymaking across all sectors, including NYS agencies, 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 State's Public Health and Planning Council lead the Prevention Agenda. The 2019-2024 Prevention Agenda furthers New York State's health improvement plan, which is the blueprint for state and local action to improve the health and well-being of all New Yorkers. Incorporated within the Prevention Agenda, is Health Across All Policies/Age Friendly NY initiative, whereby state agencies work together to identify and strengthen the ways that their policies and programs can have a positive impact on health.

New York State Department of Health (NYSDOH) is the first health department to be recognized by the Trust for America's Health (TFAH) as an Age-Friendly Public Health System. To achieve this designation, the NYSDOH completed all of the requirements of TFAH's Age-Friendly Public Health Systems (AFPHS) Recognition Program.

Working caregivers is one of the areas of focus when planning and developing cross systems supports and services. In the United States today, one (1) in six (6) employees spends on average more than twenty (20) hours a week providing care for a loved one. https://www.caregiver.org/resource/caregiver-statistics-work-and-caregiving/ Caregiving costs U.S. businesses an estimated $50 billion a year in lost productivity. https://hr.ucdavis.edu/departments/worklife-wellness/events/caregivers
To respond to the needs of working caregivers, the New York State Office for the Aging, the New York State Department of Labor, and the New York State Department of Health joined with businesses in 2021 to better understand and support working caregivers.

These state agencies launched a public-private partnership to survey businesses and their employees. Responses to the survey will help identify the number of employees who are caregiving for a loved one and to assess working caregiver intensity and connect them to supports and information.

The success of these efforts is based upon the ongoing commitment to embed supportive policies and programs in all elements of the New York public health system, which is embracing the many roles and collaborations necessary to improve and sustain the health and well-being of older New Yorkers.

New York State Department of Health (NYSDOH)

The 2021-2022 NYS budget dedicated $26,600,000 for AD/D programs, representing the largest single-state investment of its kind. With these funds, the NYSDOH has continued to expand and strengthen existing 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 (4) 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.

COVID-19 Response

With the declaration of a worldwide pandemic and in response to COVID-19 closures in March 2020, contractors under the NYSDOH Alzheimer's Disease Caregiver Support Initiative were required to adapt to delivering services differently. Contractor staff across all funded programs quickly established systems to engage in telehealth patient and family visits, or virtual service delivery. Most staff continued to operate within their assigned roles, with mostly all staff working remotely.

Caregiver support programs and the Centers of Excellence for Alzheimer’s Disease (CEADS) quickly transitioned programming to ensure there were no gaps in services, particularly given that caregivers of those living with Alzheimer's disease experience unique levels of caregiver burden and depend on the supports offered by this initiative. This included establishing remote access for caregivers in their homes through electronic medical records at respective hospital systems, ensuring that caregivers had appropriate connectivity, equipment, and technical assistance to access programs and services, and providing program staff with appropriate equipment for home use.

Caregiver support services were offered through virtual means such as Blue Jeans, WebEx, Teams, Zoom, and telephone. Outreach efforts on behalf of the caregiver and person living with dementia resulted in stronger communication and collaboration among other community-based organizations.

The Centers of Excellence were able to transition to telehealth services with waiving of regulatory barriers to this service and the expansion of reimbursement for this service. This allowed for diagnostic services conducted by physicians and ongoing patient care management with social work staff, while also expanding the ability of the CEADs to communicate with and support caregiver families. All Centers reported a significant amount of involvement by the social workers and outreach staff to connect with existing patients to follow-up, to know about the changing community resources, and to provide the linkages to programs that were being moved to virtual platforms (telephone support groups, Zoom joint enrichment events, virtual training opportunities). Overall, virtual programming offered more flexibility in scheduling and could better accommodate the needs of family caregivers. It also allowed clinicians to observe and assess patients in their familiar home surroundings, and all Caregiver Support Initiatives continued to operate during the pandemic, with minimal disruption to service delivery.

All contractors, community services providers, and CEADs, would like to continue to provide some services virtually, such as support groups and education programs in order to ensure safety for caregivers, persons with dementia, and staff, to reduce fear of COVID, continue accessibility for caregivers with access concerns, and decrease travel time so that staff can dedicate more time to clients.

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 (CSI) provides $15 million to fund a network of ten (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 provided $1.5 million to fifteen (15) community-based organizations to provide caregiver support services for targeted underserved communities. Each organization received $100,000 annually to reach caregivers of individuals living with AD/D, either or both of whom are members of underserved communities.

The programs recognized and addressed the need for culturally competent support strategies. Program models were designed to serve individuals who may have experienced 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. This initiative concluded on April 30, 2021. Beginning in 2022, funds allocated for this initiative will be included in the Regional Caregiver Support Initiative. The Request for Applications for the Regional Alzheimer’s Disease Caregiver Support Initiative includes a program component to identify, engage, and provide targeted outreach and services to members of underserved communities. As these services are implemented, data will be collected to assess the efficacy of these services.

The services and supports include:

- 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 ten (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 leaders in the field 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, care management, and medications available for the treatment 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 $4.8 million statewide program, provided through eight (8) 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 two hundred (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.[65, 66] Dr. Mittelman's research studies provide evidence that caregiver support and counseling can delay nursing home placement by a median of one point five (1.5) years.[65] 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."[67] Dr. Mittelman's newer research demonstrates that the New York University

Caregiver Intervention can result in seventeen percent (17%) fewer AD/D deaths in nursing homes, and up to $178.9 million in Medicaid savings over a fifteen (15) year period.[78]

Researchers at the School of Public Health, University of Albany, State University of New York have completed a comprehensive, statewide, multi-level evaluation of the Alzheimer's Disease Caregiver Support Initiative from 2016-2021. This evaluation examined 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 demonstrated significant contributions to the national evidence-base related to Alzheimer's disease support services. It generated important evidence for future programmatic and policy decisions at both the state and national levels.

The net estimated cost savings due to the delay in nursing home placement, using the most conservative estimates, was in excess of $1.9 billion over the course of the Initiative. Over the 5-year period of the Initiative, contractors provided over 1.19 million units of service to caregivers, which averages to an approximate cost of $90 per unit of service. Based on this per-unit cost, the average cost of service per caregiver who said that services kept their loved one home longer was approximately $786.

The unduplicated totals of caregivers that received services through AlzCAP, Regional and Underserved Communities Support Initiatives from 2016-2021 was 211,874. The totals of a few of the services provided to caregivers during that time included: 167,648 Consultation Services, 19,126 Support Group Sessions, and 617,120 hours of Respite Care. The totals of just several of the services that the CEADS provided during the same time period included: 49,247 New Diagnostic Assessments, 135,923 Referrals to Community Supports, 4,098 Clinical Trials and 98,652 Trainings to Health Professionals and Students.

A survey of informal caregiver participants, conducted in the third year of the Initiative, assessed outcomes such as the impacts on caregiving, benefits of services, positive aspects of caregiving, self-reported healthcare utilization, and reported nursing home delay. The survey reflects caregivers who participated in programs and services funded through the NYS ADCSI between January 2018 and July 2019. Caregivers reported a wide range of benefits from ADCSI services. These included improved knowledge and skills and increased quality of life for both the care recipient and care receiver. Caregivers reported that their overall health and well-being improved. Results also indicated that a greater number of benefits and stronger endorsement of benefits is associated with participation in a greater number of services provided through the Initiative.

Other NYSDOH Initiatives

Healthy Brain Initiative Consumer Education Campaign

The Healthy Brain Initiative Consumer Education Campaign mirrors the National Health Brain Initiative (HBI) Road Map, specific to public education and awareness in NYS.

The Healthy Brain Initiative Consumer Education Campaign promotes brain health and risk reduction strategies to address the approaching epidemic of Alzheimer's disease and other dementia across the country. The intended demographic for this education campaign includes New Yorkers in the forty-five to sixty-five (45-65) age group, and the African American and Latin communities. Included in this multimedia campaign are topics such as dispelling the myths of Alzheimer's disease, what it is and what it isn't, ways to adopt a healthy lifestyle that promotes brain health, warning signs and where to get diagnosis, treatment, supports and services, as needed.

Public Health Live!
https://www.albany.edu/cphce/phlchron.shtml

Educational webcasts were 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 were available for professionals including physicians, nurses, and social workers. Webcasts related to AD/D for 2020 -2021 were:

- *Caregiver and Patient Health in Alzheimer's Disease Policy and Systems Change -*
  David Hoffman, DPS, CCE
  Associate Dean and Associate Professor of Ethics and Health Policy, Maria College
  Clinical Professor, Department of Health Policy Management and Behavior, University at Albany School of Public Health
  Adjunct Assistant Professor, Albany Medical College Alden March Bioethics Institute

- *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

- *Sex, Guns and Driving: Considerations in Dementia Care -*
  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 Study

  Andrea Sullivan, OT/L
  Outpatient Occupational Therapy Supervisor
  Burke Rehabilitation Hospital

The Public Health Live! Webcasts were discontinued in later 2021 in favor of the Healthy Brain Initiative Consumer Education Campaign.

Behavioral Health and Dementia Workgroup

The healthcare system in NYS has been lacking in its ability to support people with dementia who need behavioral health services. Although not all people diagnosed with AD/D experience behavioral symptoms, those who do often face difficulty accessing timely and appropriate acute care, episodic medical management, or long-term care services. Many are at a higher risk of hospitalization and placement outside of NYS.

The NYSDOH ADP explored issues related to behavioral health services for those living with AD/D in 2019 with a plan to inform interagency policy, as well as the 2020 budget process. A workgroup was convened to identify barriers to accessing appropriate and timely behavior health services and to identify best practice approaches that address these barriers. Discussion participants represented the NYSDOH, NYSOMH, National Alzheimer's Association, Center for Elder Law and Justice, and several behavioral health providers from St. Peter's Health Partners, University of Rochester, and SUNY Downstate.

Three factors were identified that contribute to systematic gaps in behavioral health services: barriers to admission across all levels of care, a lack of specialized facilities within NYS, and a shortage of skilled workers equipped to care for this population. The use of technology such as telemedicine and ECHO consultations were found to be useful in enhancing access to services and expertise in several regions of NYS. This initiative was in discussion in early 2020 but further action was delayed by the priorities of COVID.

Special Needs Assisted Living Residence (SNALR)

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 when a higher level of care is not needed, the State of New York enacted the Special Needs Assisted Living Residence Voucher Program for Persons with Dementia.

The 2018-19 State Budget Agreement authorized the NYSDOH to establish this voucher program to subsidize the cost of a SNALR for eligible individuals with Alzheimer's disease and/or dementia living in a participating residence. Funding continued in the 2020-21 budget. As of June 23, 2021 the SNALR voucher program instituted a waiting list for new applicants to the program. As vouchers are available wait-listed applicants will move into the program. It is expected that this program will continue, based upon the availability of future state funding. Through the program, the Department is authorized to issue up to two hundred (200) vouchers and subsidize up to seventy-five percent (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 workday, or leaving employment entirely. In-person sessions were placed on hold due to the pandemic

Dementia Friendly America

New York State has been designated as an active member of the Dementia Friendly America national network. Several counties in NYS have been designated as a Dementia Friendly America Community. Additional counties and agencies have placed their efforts on hold during the pandemic. 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.

The COVID-19 pandemic forced the closure of many congregate sites, social adult day services, programs, and other community sites where older adults (including individuals with AD/D) would receive services, supports, nutrition, evidence-based programs, application and assistance support, caregiver supports and respite, information and assistance, and much more. The impact of these closures had a troubling impact on program participants.

Due to the COVID-19 pandemic, NYSOFA, and AAA funded Social Adult Day Service (SADS) programs transitioned service delivery from on-site to virtual models. SADS continued to meet their participants' needs through the use of telephonic, virtual, and in-home programming. In this manner, the programs were able to keep individuals with AD/D stimulated, while also providing needed respite to caregivers. State respite grantees continued to support caregivers with telephone and virtual support groups, delivery of caregiver comfort baskets, and individualized caregiver supports. For SFY 2019, NYSOFA reporting showed seventy-five percent (75%) of SADS participants and sixty percent (60%) of state respite care receivers have cognitive impairments.

The network of Area Agencies on Aging (AAA) and their providers changed their methods of providing services. Both the federal Major Disaster Declaration (MDD) and the state's Executive

Orders gave the network maximum flexibility to meet needs as they arose and did so based on the unique needs of individuals and their caregivers in the community. The network employed strategies, such as the use of technology, services in the home, delivering groceries and supplies, expanding home delivered meals, expanding transportation to critical medical appointments, combating social isolation, and delivering prescriptions. Through NYSOFA's network, approximately three thousand (3,000) animatronics pets were distributed socially isolated older adults (many with AD/D). This has proven to be successful as a low-tech/low-cost innovative way to combat loneliness and improve health conditions for this population.

Two federally funded programs administered by NYSOFA directly serve caregivers: The National Family Caregiver Support Program 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 such as 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.
- 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 is funded through the Administration for Community Living (ACL) grants. It assists family caregivers supporting care recipients across the age and disability spectrum to gain access to needed respite services, trains and recruits respite workers and volunteers, and enhances coordinated systems of community-based services for individuals of all ages. The NYS Caregiving and Respite Coalition (NYSCRC) is helping to build volunteer respite capacity using a respite care provider core competency training curriculum. NYSOFA and NYSCRC have expanded the NYS Volunteer Respite Program 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 volunteer respite training.

NYSCRC built a Virtual Resource Center (VRC) that makes available a suite of evidence-informed/evidence-based training services. The aim of the VRC is to further coordinate information about caregiving and respite training, technical assistance, and related materials. NYSOFA's NY Connects Resource Directory is an online long-term services and supports directory that includes respite and support services listings of programs and services that provide relief for caregivers. The NY Connects Resource Directory (https://www.nyconnects.ny.gov/) includes an ongoing updating process and regular data feeds for long-term services and supports programs from the NYS Department of Health, NYS Office for People with

Developmental Disabilities, NYS Office of Mental Health, NYS Office of Addiction Services and Supports, and the Food Pantries, including a statewide map of Food Pantries locations. Additionally, the NYSCRC web site provides an array of information in its virtual resource center (VRC) for caregivers and caregiving professionals, and also links to the NY Connects Resource Directory: (http://www.nyscrc.org/ny-connects).

The NY Connects No Wrong Door System 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 aging network and other long-term services and supports

NYSOFA Elder Justice programs, services, and activities include:

- Legal assistance funded under the OAA assists older adults with addressing 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) has 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 fifteen (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 sixty-two (62) counties across New York State within the next two (2) 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.

- The 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. NYSOFA administers elder abuse programs that protect and provide services to vulnerable adults, including individuals living with AD/D.

Elder Abuse Interventions and Enhanced Multi-Disciplinary Team Initiative

In 2017-18, NYSOFA partnered with the NYS Office of Victim Services (OVS) to establish and implement the Elder Abuse Interventions and Enhanced Multidisciplinary Team (E-MDT) Initiative. Elder Abuse E-MDTs reviews cases across professions and identifies recommended action steps for interventions 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. The enhancement comes with access to forensic accountants, geriatric psychiatrists/mental health professionals, and civil legal services. The Elder Abuse E-MDT Initiative is funded with a Federal grant received by OVS from the United States Department of Justice, Office for Victims of Crime, under the Victim of Crime Act (VOCA), and with state funding provided by NYSOFA. It is overseen by NYSOFA and coordinated statewide by Lifespan of Greater Rochester Inc. Lifespan and the New York City Elder Abuse Center at Weill Cornell Medicine (NYCEAC) work in concert to provide technical assistance and training to E-MDTs across New York State and with NYSOFA to provide strategic planning for the Initiative. Starting in 2017, the New York City Department for the Aging (DFTA) also began funding NYCEAC to operate Elder Abuse E-MDTs in all five boroughs in New York City. As of July 14, 2021, there are fifty-three (53) counties with operational E-MDTs funded through this Initiative.

Elder Abuse Education and Outreach Program (EAEOP):

The Elder Abuse Education and Outreach Program (EAEOP) provides education and outreach to the public, including older persons and their families and caregivers. The program includes grants to local agencies to establish or expand upon existing local elder abuse education and outreach programs, and grants that are broad-based and have statewide focus, designed to support a statewide effort to increase awareness and prevention of elder abuse. NYSOFA continues to administer the statewide Elder Abuse Education and Outreach Program via Monroe County and Lifespan of Greater Rochester Inc. (Lifespan).

Lifespan operates the Upstate Elder Abuse Center at Lifespan with these funds. Over the years, EAEOP funding support has made it possible for Lifespan to continue efficiently and effectively to expand critical services to benefit professionals and vulnerable older adults throughout New York State. Many innovative local and statewide initiatives over the years are directly or indirectly related to recommendations the NYS Elder Abuse Summits convened by Lifespan in 2004 and 2010 with federal and other funding support. These summits include the: (1) creation of the NYS Coalition on Elder Abuse in 2004 to help implement the statewide elder abuse action agenda developed during the Summit and support collaborative initiatives throughout New York State; (2) the NYS Elder Abuse Prevalence Study; (3) increased professional trainings and public awareness initiatives throughout NYS; (4) Monroe County Fatality Review Team; (5) multiple local coalitions throughout NYS; (6) Office of Violence Against Women Domestic Violence in Later Life Law Enforcement Training; (7) Enhanced Multidisciplinary Teams expansion and additional related financial exploitation services and programs; (8) several Lifespan Scam and ID Theft expanded initiatives; (9) the NYS Coalition on Elder Abuse website; (10) Lifespan's unique Elder Abuse Shelter Program; (11) an outreach and direct services initiative focusing on health care and Latino communities; (12) the Trauma-Informed Care Project; (13) the Elder Justice Advocate Program; and (14) an LGBTQ+ caregiver and older adult multi-program collaborative.

New York State Office of Child and Family Services OCFS

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

On June 18, 2021, the Governor announced a $2.5 million expansion of the first-in-the-nation Enhanced Multidisciplinary Teams (E-MDTs) Initiative, which protects vulnerable adults who may have experienced financial exploitation and other co-occurring forms of abuse. The funding, which will be provided annually through September 2022, assists adults sixty (60) years and older who are at risk due to physical limitations, cognitive impairment or dementia, and social isolation, and expands access to forensic accountants, geriatric psychiatrists/mental health professionals, and civil legal services. The initiative, developed by the NYS Office for the Aging (NYSOFA) and the NYS Office of Victim Services (OVS), currently serves fifty-one (51) counties, covering ninety-two percent (92%) of older adults in the state, making NYS's program the first of its kind in the nation and tripling the number of teams targeting elder abuse. The OCFS Bureau of Adult Services, which oversees APS in all sixty-two (62) counties, worked with a forensic accountant in consultation with a multi-agency advisory board to develop new investigative tools and templates for Adult Protective Services (APS) workers. The grant also enables APS in the pilot areas to forward referrals to a forensic accounting consultant in complex cases.

The initial three-year investment that launched the E-MDT Initiative in 2017 totaled $8.4 million. This investment consisted of federal Victims of Crime Act funds provided by OVS combined with a state investment provided by NYSOFA. NYSOFA partnered with Lifespan of Greater Rochester and Weill Cornell Medicine's New York City Elder Abuse Center to manage, monitor, and distribute the funding. OVS is providing an additional $2 million in Victims of Crimes Act (VOCA) funding annually and NYSOFA has allocated an additional $500,000 annually for continued support of the E-MDT Initiative from October 1, 2020 through September 30, 2022.

Teams now cover fifty-one (51) counties in ten (10) regions, and development of teams in the eleven (11) remaining counties in NYS is ongoing. Services provided to abuse victims through E-MDT interventions include information about and referral to other types of services, such as victim service programs or legal services, and individual advocacy, such as return of personal property, or assistance with applying for public benefits. E-MDT Coordinators provide case consultation on cases, as well as access to consultation services, such as a forensic accountant, geriatric psychiatrist/mental health professional, and civil legal attorney, as appropriate and available. Lifespan of Greater Rochester also holds monthly webinars for professionals on financial exploitation. During the COVID-19 public health crisis, E-MDTs continued to meet virtually, ensuring continued interventions in elder abuse cases and protections for NYS's older adults during a time when many other programs were paused.

Since 2017, E-MDT coordinators have received approximately sixteen hundred (1,600) referrals and six hundred seventy (670) victims have received advocacy services. In that same time period, E-MDT interventions resulted in approximately $645,000 in restitution being ordered by the courts for victims of financial exploitation cases.

In April 2021, OCFS received $5,306,382 in federal funds under the Grants to Enhance Adult Protective Services to Respond to COVID-19. These funds were allocated to APS units within the local departments of social services to enhance, improve, and expand the ability of APS to investigation allegations of abuse, neglect, and exploitation in the context of COVID-19. Counties will be using the funding, in part, to provide goods and services to APS clients, provide education and public awareness of scams and frauds targeted toward vulnerable adult populations, and community awareness related to adult abuse reporting and prevention.

OCFS is partnering with the Alzheimer’s Association of Northeastern New York, State Education and Outreach and Office of Government Affairs with providing updated dementia-specific training designed specifically for APS workers. The training will provide guidance on the differences between aging and levels of cognitive impairment, identifying warning signs, ways to communicate, and understanding the impacts of dementia on the ability to live independently.

OCFS supports continual training opportunities for agency professionals working with the aging population, law enforcement, attorneys, and APS workers at the Annual Adult Training Institute (AATI) conference. The 2020 conference, hosted virtually, included over 900 participants statewide and included several workshops focused on dementia related topics including physiological aspects of aging and recognizing dementia and preventing scams. The 2021 conference planning team includes representation from the Alzheimer's Association of Northeastern New York and will include workshops on cognitive impairments and aging.

OCFS also oversees the Family Type Home for Adults program (FTHAs). FTHAs are a small adult care facility of one (1) to four (4) 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 activities of daily living (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 residents with Alzheimer's and dementia in community-based settings, with individualized care. OCFS, through its local departments of social services, continues to facilitate trainings of FTHA operators by Alzheimer's Association staff to improve quality-of-care given to residents in FTHA. In March 2021, OCFS held three (3) separate "Townhalls" with local departments of social services and FTHA operators to gather input on proposed regulatory amendments to improve services and supervision to the dependent adults residing in these community-based homes. OCFS will include feedback from these Townhalls in the updates to New York Codes, Rules and Regulations 18 CRR-NY II D 489 expected to be published in late 2021/2022.

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 in NIH research funding during the last three years. These awards include the renewal in 2017 of a five (5) 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 Neurofilament Light (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-two 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 three hundred (300) peer reviewed publications in the past ten (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 forty-thousand (40,000) times. Attesting to the influence of CDR research in the research community, NKI has ranked in the top one percent (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 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 an 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 forty (40) to over seventy (70) years of age. It is expected that this grant will be extended for a sixth year while the agency submits a completive 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 continues to make progress on the specific aims of the study which are to:

- 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.
- 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.
- Identify neuroimaging-based changes that occur over the course of progression from normal aging to MCI to dementia in adults with Down syndrome.
- 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, Cerebrospinal Fluid (CSF) and imaging biomarkers that are found to be associated with clinical disease progression.
- 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.
    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 (NYSED)

The New York State Education Department (NYSED), under the authority and direction of the New York State Board of Regents, regulates more than fifty (50) professions licensed under Title VIII of the Education Law. NYSED oversees requirements for professional education, continuing education, and professional practice for each of these professions. NYSED serves a vital function in ensuring that NYSED licensed professionals provide professional services safely and competently to the public, including individuals living with AD/D.

NYSED evaluates and registers (approves) professional education programs, which prepare students for safe, competent entry level practice in a specific profession. Successful completion of a professional education program is often a requirement licensure in a 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 professional education requirements for each profession 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. NYSED provides practice guidance for licensed health professionals through Practice Alerts, Practice Guidelines, webinars for professionals, and recommendations to programs during the approval of course content for the degrees. Some licensed professionals are required by law to complete continuing education. Many associations, employers, and schools offer mandatory continuing education courses through various means, including online offerings. In professions with no mandatory continuing education, such as medicine or nursing, non-mandated continuing education is offered to address professional competence that may specifically focus on the healthcare, social, and behavioral needs of persons living with AD/D. Regardless of whether it is legally required, many professionals complete continuing education that covers issues relevant to AD/D. This education helps to ensure that persons with AD/D receive relevant, competent professional services. 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.

NYSED and NYSDOH oversee training programs for personal care workers, such as home health aides and personal care aides, and certified nurse aides, in accordance with federal regulations. These personal care workers provide services to persons with AD/D, and most training program curriculums cover care for persons with memory issues.

Section II.

2022-2023 Recommendations of the New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementia (AD/D)

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, businesses, and philanthropies to come together with a common set of goals and activities.

Goal 1: Enhance Public Awareness and Advance Early Detection of AD and All Other Dementia

1. 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.

    - Promote brain health and 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.

- Provide funding for a public awareness campaign, that includes the warning signs, referral information for supports and services, and adopting healthy brain habits.

2. Increase public awareness about evolving treatments for AD/D , including new existing and disease modifying drugs.

3. Identify barriers to persons with AD/D accessing appropriate medical and psychiatric treatment for behavioral symptoms accompanying their disease.

Goal 2: <u>Improve Clinical Care for Alzheimer's Disease and Other Dementia</u>

4. Train primary care providers to utilize best-practice approaches for the screening, diagnosis, and care management/treatment of individuals presenting with AD/D and their caregivers. Expand this to include training the medical community in general.

5. Increase public awareness about evolving treatments for AD/D, including new, existing, and evolving disease modifying drugs, and train primary care physicians in the appropriate management of these evolving new treatments for AD/D.

6. Enhance identification of cognitive impairment when patients present in opportunistic settings, such as the emergency room and urgent care centers, by promoting the use of appropriate assessment tools and providing educational materials.

7. 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.

8. 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.

9. 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.

10. Train primary care physicians in the appropriate management of the evolving new treatments and disease modifying drugs for AD/D.

11. 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.

12. Support the availability of, and reimbursement for, tele-health services for diagnostic and care management services to improve access to and timeliness of an accurate diagnosis.

Goal 3: Ensure Access to Housing and Supports that Promote Living in the Least Restrictive Environment. Support Formal Caregivers in These Settings

13. 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:

    - Identify, offer meaningful assistance, and to communicate effectively with individuals with AD/D.
    - Appropriately prepare for and respond to hazards and emergencies.
    - Make physical environment modifications that support dementia friendly communities.
    - Ensure access to housing, community based supports, and/or high quality long term care settings.
    - Promote living in the least restrictive environment whenever possible.

14. 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.

15. Promote efforts to expand use of telemedicine/telepsychiatry in the home to facilitate physician care, cognitive assessments, and monitoring of treatment effectiveness.

16. Support the development of a dementia-capable workforce by advancing evidenced based/informed professional education across the professions and supporting ongoing training of formal caregivers across all settings.

17. Develop effective strategies to recruit and retain medical providers, professionals, and formal caregivers.

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

18. Promote the importance of identifying and assessing the health and well-being of informal caregivers. Ensure the existence of in-person and virtual 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.

19. Train informal 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.

20. Educate informal caregivers on how to effectively navigate the healthcare system, which includes long-term care, and to access AD/D resources and services.

21. Ensure that the financial and justice system recognize and support persons with AD/D by:

    - Providing an on-line AD/D training for law enforcement personnel.
    - Educating financial services personnel on how to identify and report financial exploitation.
    - Providing training for judges, court personnel, attorneys, and other legal professionals on protecting the legal rights of individuals with AD/D.

22. Provide continuing education opportunities on AD/D for all healthcare providers.

23. 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.

24. Increase the requirements for evidence-based AD/dementia education and training in all long-term care settings.

25. Utilize public health data collection systems such as BRFSS, and health data from the National Institute on Health, the NYSDOH Alzheimer's Disease Program, and from the Alzheimer's Association Facts and Figures document to highlight caregiver health and stress and to more accurately quantify the burden of AD/D through aggregate data,

Goal 5: <u>Address Disparities and Improve Health Equity</u>

26. Provide support services that target underserved communities, including education on normal aging versus AD/D and the importance of timely diagnosis of AD/D.

27. Increase awareness and understanding among providers about cultural patterns related to family roles and caregiving in underserved communities.

    - Ensuring that educational programs and support services are culturally and linguistically appropriate (e.g., available in multiple languages).
    - Ensuring that care providers consider staffing patterns that reflect the target underserved community, both culturally and linguistically.

28. 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.

29. Improve the availability of aging network services to support individuals with early onset AD/D.

30. 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.

Goal 6: Promote Research, Prevention, and Risk Reduction Strategies

31. 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.

32. Increase awareness regarding the importance of enrolling in AD/D research and clinical trials.

33. Promote research on the connection between Down syndrome and AD/D in NYS research institutes/OPWDD/NYSDOH initiatives.

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Attachment B - Summary of Alzheimer's Disease and Other Dementia (AD/D)

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

Attachment B - **Summary of Alzheimer's Disease and Other Dementia (AD/D)**

Diagnosis	Diagnostic Criteria
Alzheimer's disease (AD) *(continued)*	a physical and neurological examination; interviews of the patient and family member; mental status tests; functional assessments; and examinations to establish any differential diagnoses.
	Known risk factors: • Advancing age • Family history • Genetics, specifically the presence of the APOE-e4 gene or Down syndrome.

Diagnosis	Diagnostic Criteria
Chronic Traumatic Encephalitis (CTE)	**Characteristics:** CTE is a progressive degenerative brain disease associated with repetitive brain trauma and mild TBI. CTE can occur as a result of concussions often received in contact sports or non-concussive hits to the head over time.
	Symptoms: • Characteristics of dementia - memory loss, impaired judgment, confusion and agitation – appearing years after trauma • Depression and suicidal thoughts • Behavioral and mood changes • Impulse control problems and aggression
	Brain changes: The repetitive brain trauma triggers a progressive degeneration of brain tissue and the build-up of the abnormal protein called tau. These changes in the brain can begin months, years, or even decades after the last episode of trauma.
	Diagnosing: CTE is diagnosed through a physical and neurological examination, as well as a personal history that includes an assessment of past head trauma and involvement in contact sports. Brain imaging is also recommended.
	Known risk factors: • Repeated brain trauma • History of head injuries/TBIs

Diagnosis	Diagnostic Criteria
Creutzfeldt-Jakob disease (CJD)	**Characteristics:** CJD is the most common human form of a group of rare disorders categorized as Prion diseases. Prion diseases occur when prion proteins, found throughout the body and brain, begin misfolding into an abnormal three-dimensional shape. Cognitive changes with CJD are uncharacteristically rapid and severe. There are three main types of CJD: sporadic, familial, and transmitted/infectious. The most common form of CJD is sporadic.

Attachment B - Summary of Alzheimer's Disease and Other Dementia (AD/D)

Diagnosis	Diagnostic Criteria
Creutzfeldt-Jakob disease (CJD) *(continued)*	**Symptoms:** • Confusion and rapid decline in all areas of cognition • Involuntary muscle movements, twitches and/or stiffness • Difficulty walking • Apathy, agitation and mood changes • Depression
	Brain changes: Results from misfolded prion protein throughout the body that progresses to the brain and leads to a destruction of brain cells.
	Diagnosing: CJD is diagnosed through a medical and personal history; a neurological exam; and spinal fluid testing via lumbar puncture to test for the presence of prion protein. Testing should also include an electroencephalogram and brain MRI. There is no known cause for sporadic CJD.
	Known risk factors: • Genetic variations • Exposure to external sources of abnormal prion protein (poorly sterilized medical equipment or infected meat)
Diagnosis	**Diagnostic Criteria**
Frontotemporal dementia (FTD)	**Characteristics:** FTD is an umbrella term that refers to a group of disorders that involve the frontal and temporal areas of the brain controlling personality, language, and movement. These diseases include behavioral variant FTD, temporal/frontal FTD, progressive non-fluent aphasia, semantic dementia, primary progressive aphasia, Pick's disease, corticobasal syndrome, progressive supranuclear palsy, FTD with parkinsonism, and FTD with amyotrophic lateral sclerosis (ALS). Persons with FTD are typically diagnosed in their 40s to 60s.
	Symptoms: • Behavior changes, such as impulsivity and inappropriateness, are often noted first. • Early difficulty with understanding speech or reading • Changes in personality and emotional reactions • Decline in motor function
	Brain changes: There is no distinguishing microscopic abnormality linked to all types of FTD. FTD primarily affects the frontal (forehead) and temporal (behind the ears) lobes of the brain. High levels of tau and Transactive Response Deoxyribonucleic Acid Protein-43 (TDP-43) have been found on autopsy. Individuals with FTD generally develop symptoms at a younger age than those with other forms of

Attachment B - **Summary of Alzheimer's Disease and Other Dementia (AD/D)**

Diagnosis	Diagnostic Criteria
Frontotemporal dementia (FTD) *(continued)*	dementia and survive for anywhere between 18 months to 20 years, with an average life expectancy of seven years.
	Diagnosing: The diagnosis of FTD requires an examination by a professional knowledgeable about this disorder. Evaluations should include a history of issues being experienced by the patient and a comprehensive neurological examination. Brain imaging, particularly MRIs and glucose PET scans, are helpful in determining the diagnosis of FTD.
	Known risk factors: • Family history (accounts for 1/3 of the cases)
Diagnosis	**Diagnostic Criteria**
HIV associated neurocognitive disorder (HAND)/Acquired immune deficiency syndrome (AIDS) dementia complex (ADC)	**Characteristics:** HAND is an umbrella term for HIV-related dementias that include: Asymptomatic Neurocognitive Impairment, Mild Neurocognitive Disorder and HIV-Associated Dementia. The virus enters the central nervous system early in the course of the infection and causes several cognitive changes over the course of the disease.
	Symptoms: • Forgetfulness, confusion, and other changes in cognition • Behavioral and personality changes • Headaches • Weakness and loss of sensation in arms and legs • Progressive motor dysfunction • Extremity pain due to nerve damage
	Brain changes: The HIV virus penetrates the blood-brain barrier and affects subcortical brain structures below the cerebral cortex. HIV has also been shown to alter brain size in the areas specific to learning and information processing. Although the virus doesn't directly invade or damage nerve cells in the brain, it impacts the health and function of these cells, causing an encephalitis (inflammation of the brain). Persons with advanced HIV infections are likely to develop ADC or HAND, leading to behavioral changes and a gradual decline in cognitive function.
	Diagnosing: HAND/ADC is diagnosed through a complete neurological examination, brain imaging, and potentially a lumbar puncture to assess cerebrospinal fluid. Cognitive testing is also recommended.
	Known risk factors: • HIV Infection

<u>Attachment B</u> - Summary of Alzheimer's Disease and Other Dementia (AD/D)

Diagnosis	Diagnostic Criteria
Huntington's disease	**Characteristics:** Huntington's disease is a progressive brain disorder caused by a single defective gene on Chromosome 4. This defect is hereditary and "dominant" meaning that if an individual has the gene then he/she will eventually develop the disease. Symptoms develop typically between the ages of 30 and 50.
Huntington's disease *(continued)*	**Symptoms:** • Unsteady gait and involuntary movements (chorea) involving all extremities • Forgetfulness and impaired judgment • Decline in thinking and reasoning skills including memory, concentration, judgment and ability to plan or organize • Personality changes, mood swings, anxiety, depression and uncharacteristic anger or irritability • Obsessive-compulsive tendencies
	Brain changes: The gene defect influences the abnormal production of "huntingtin" protein that, over time, leads to worsening symptoms.
	Diagnosing: A medical examination completed by a medical professional that includes a personal and family medical history, physical examination and neurological examination. Genetic testing and counseling is strongly recommended.
	Known risk factors: • Heredity and family history
Diagnosis	**Diagnostic Criteria**
Lewy body dementia (LBD)	**Characteristics:** LBD presents with cognitive symptoms similar to AD and movement symptoms typical of Parkinson's disease (muscle rigidity, shuffling gait, stooped posture, and difficulty initiating movement). Most experts estimate that LBD is the third most common cause of dementia after AD and vascular dementia.
	Symptoms: • Cognitive difficulties similar to AD, although memory loss of less severity • Periods of confusion and alertness that vary from one time of the day to another, or from one day to the next • Sleep disturbances, often acting out dreams • Well-formed visual hallucinations and delusions • Muscle rigidity or other Parkinsonian movement features • Autonomic nervous system changes • Difficulty with visual interpretations
	Brain changes: Lewy bodies are abnormal aggregations (or clumps) of the protein alpha-synuclein. When they develop in

Attachment B - Summary of Alzheimer's Disease and Other Dementia (AD/D)

Diagnosis	Diagnostic Criteria
Lewy body dementia (LBD) *(continued)*	a part of the brain called the cortex, dementia can result. Alpha-synuclein also collects in the brains of people with Parkinson's disease, but the masses may appear in a pattern that is different from LBD.
	Diagnosis: A diagnosis of LBD is based on a medical evaluation completed by a medical professional that includes a physical, cognitive and neurological examination. Cognitive changes will be more significant in the areas of judgement, planning, and visual perception, likely less significant for memory. Well-formed hallucinations and delusions are likely. Movement symptoms typical of Parkinson's disease will be present, along with changes in autonomic nervous system function leading to drops in blood pressure, dizziness or repeated falls.
	Known risk factors: • Advanced age • Male gender • Family member with history of LBD • Parkinson's disease diagnosis
Diagnosis	**Diagnostic Criteria**
Mild Cognitive Impairment (MCI)	**Characteristics:** MCI is characterized by cognitive changes that are significant enough to be noticeable by the person experiencing them and/or others, but not severe enough to interfere with daily life or independence. MCI is not cognitive decline related to normal aging. Individuals diagnosed with amnestic MCI are at a greater risk of developing AD/D but not all individuals with MCI progress to a dementia. The symptoms of other conditions, such as depression or a Vitamin B12 deficiency, may mimic those of MCI.
	Symptoms: • MCI primarily affecting memory ("Amnestic") o Short-term memory and re-call problems o Difficulty learning new information • MCI primarily affecting thinking ("Non-amnestic") o Losses in executive thinking (planning, organization) o Lack of judgment o Difficulty completing complex tasks o Changes in visual perception • Presence of depression, irritability, anxiety, and/or apathy
	Brain changes: Brain imaging has shown overall reductions in brain volume in persons with MCI, particularly in the area of the hippocampus, and an enlargement of the ventricles. Abnormal presences of beta-amyloid protein and microscopic

Attachment B - Summary of Alzheimer's Disease and Other Dementia (AD/D)

Diagnosis	Diagnostic Criteria
	clumps of tau may be found but in less significant amounts than seen with AD/D.
	Diagnosing: MCI is a clinical diagnosis based on a medical professional's best judgment after considering the individual's medical history, functional and ADL assessment, input from family, and/or mental status testing. Diagnosis may be enhanced with the use of biomarker testing (cerebrospinal fluid examinations and imaging).
	Known risk factors: • Advancing age • Family history of AD/D • Conditions that increase a person's risk of cardiovascular disease (e.g., hypertension, smoking, lack of exercise, or diabetes)
Diagnosis	**Diagnostic Criteria**
Mixed Dementia **Mixed Dementia** *(continued)*	**Characteristics:** Mixed dementia is characterized by the simultaneous occurrence of the signs and symptoms of different types of dementia. The most common forms of mixed dementia are AD with vascular dementia, AD with LBD, or characteristics of AD mixed with vascular and LBD.
	Symptoms: Symptoms vary and depend on the type of brain changes involved and regions affected. In many cases, symptoms may be similar to or even indistinguishable from those of AD or another type of dementia. In other cases, a person's symptoms may suggest that more than one type of dementia is present.
	Brain changes: An individual 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.
	Diagnosing: Mixed dementia is diagnosed based on a medical evaluation that includes a physical and neurological examination, interviews of the patient and family member, mental status tests, functional assessments, and examinations to establish any differential diagnoses. Although mixed dementia is infrequently diagnosed, researchers believe it deserves more attention because the combination of two or more types of dementia-related brain changes may have a greater impact on individuals and increase their chances of developing symptoms.

Attachment B - Summary of Alzheimer’s Disease and Other Dementia (AD/D)

Diagnosis	Diagnostic Criteria
	Risk Factors: • Risk factors are consistent with the types of dementia that comprise the mixed dementia diagnosis.
Parkinson’s disease	**Characteristics:** Parkinson’s disease occurs when abnormal aggregations (or clumps) of the protein alpha-synuclein occur in the brain. This protein forms Lewy bodies similar to those seen with LBD. As Parkinson's disease progresses, the brain changes gradually spread. These changes often begin to affect mental functions including memory, the ability to pay attention, make sound judgments, and plan the steps needed to complete a task. As Parkinson's disease progresses, it may result in a progressive dementia.
Parkinson’s disease	**Symptoms** • Memory impairment with disruptions in judgment and ability to concentrate • Parkinsonian motor changes, such as: o Bradykinesia (slowed movements) o Tremors, mostly at rest o Muscle rigidity o Gait disturbances (shuffling, forward propelling, difficulty initiating movement) o Mask-like fascial expression o Abnormal posture o Micrographia • Delusions and paranoid ideations • Sleep disturbances • Depression and anxiety • Overall fatigue Low volume and muffled speech
Parkinson’s disease *(continued)* **Diagnosis**	• **Brain changes:** Parkinson's disease begins in a region of the brain that plays a key role in movement. Alpha-synuclein clumps are likely to begin in an area deep in the brain called the substantia nigra; the deposits are called Lewy bodies. These clumps are thought to cause degeneration of the nerve cells that produce dopamine.
	Diagnosing: Parkinson’s disease is diagnosed by a medical professional trained in nervous system disorders and will include a medical history, complete physical and neurological examination, and a thorough assessment of cognitive function. Evaluation may include the use of a specialized imaging technique called a dopamine transporters scan (DaTscan) that captures dopamine in the brain.

Attachment B - **Summary of Alzheimer's Disease and Other Dementia (AD/D)**

Diagnosis	Diagnostic Criteria
	Known risk factors: - Age 60 or older - Heredity - Male gender Exposure to toxins (particularly herbicides and pesticides)
	- **Diagnostic Criteria**
Vascular dementia	**Characteristics:** Vascular dementia results from conditions that decrease or alter blood flow to the brain and leads to brain cell damage. Previously known as multi-infarct dementia, post-stroke or "mini-stroke" dementia, vascular dementia accounts for about 10% of dementia cases. Vascular dementia is the second most common dementia after AD.
Vascular dementia	**Symptoms:** Symptoms of vascular dementia can vary depending on the area of the brain affected and the extent of damage caused by changes in blood flow to the brain. They may include: - Decrease in ability to organize thoughts and actions - Confusion, disorientation, and poor attention span - Impaired judgment and reasoning skills - Difficulty with decision making - Inability to complete complex, multiple step tasks - Communication challenges related to losses in expressive and/or receptive language - Changes to vision Impairments in mobility and/or extremity weakness specific to the area of the brain affected
Vascular dementia *(continued)* **Diagnosis**	**Brain changes:** The location of vascular change in the brain and the extent of the damage will determine how the individual's thinking and physical functioning are affected. There are three criteria necessary for a vascular dementia diagnosis: - A diagnosis of dementia or MCI; - Evidence of a stroke or other blood vessel changes that affect cause damage in the brain; and - No evidence that factors other than vascular changes caused the decline.
	- **Diagnosing:** Because vascular dementia may often go unrecognized, many experts recommend screening for everyone considered to be at high risk for this disorder. A diagnosis of vascular dementia is made after the completion of a professional screening to assess

Diagnosis	Diagnostic Criteria
	memory, thinking ability, and reasoning, in conjunction with a thorough neurological examination. Brain imaging may detect blood vessel changes that can relate to vascular dementia.
	Known risk factors: • History of heart disease and stroke • Smoking • Poorly managed diabetes • Obesity and lack of exercise Hypertension and high cholesterol
	• **Diagnostic Criteria**
Wernicke-Korsakoff syndrome (WKS)	**Characteristics:** WKS is a chronic memory disorder caused by severe deficiency of thiamine (vitamin B-1). It is most often associated with alcoholism but can be associated with AIDS, chronic infections, malnutrition, or other medical conditions. WKS is conceptually closely related to two syndromes: Wernicke encephalopathy, which is an acute phase of disease and potentially reversible, and Korsakoff dementia, which results from more chronic disease and is irreversible.
Wernicke-Korsakoff syndrome (WKS)	**Symptoms:** • Memory problems, both recent recall and long term, accompanying intact higher level cognitive and social skills • Difficulty learning new information Tendency to confabulate and make up information that can't be recalled
	• **Brain changes:** Thiamine helps brain cells produce energy from sugar. When thiamine levels fall too low, brain cells cannot generate enough energy to function properly.
Wernicke-Korsakoff syndrome (WKS) *(continued)*	**Diagnosing:** 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 neuroimaging procedures to confirm that a person has this disorder. Symptoms may be masked by other conditions associated with alcohol misuse. A complete medical workup for cognitive changes should include questions about an individual's alcohol use.
	Known risk factors: • Alcohol misuse • Poor nutrition related to stringent dieting, fasting or anorexia Presence of other diseases that lead to malnutrition such as AIDS, kidney dialysis, chronic infection, or cancer.

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	Traumatic Brain Injury
WHO	World Health Organization
WKS	Wernicke-Korsakoff syndrome