2023 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

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 and their families, and provide a continuing forum for concerns and discussions related to the formulation of a comprehensive state policy for Alzheimer's disease and related dementias. (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 Alzheimer's disease and related dementias and include a review of services initiated and coordinated by New York State agencies to meet the needs of persons living with Alzheimer's disease and related dementias and their families. This is the eighth 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.

COVID-19 Response

With the declaration of a worldwide pandemic and in response to COVID-19 closures in March 2020, contractors under the New York State Department of Health 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 the majority of staff working remotely.

Caregiver support programs and the Centers of Excellence for Alzheimer's Disease 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 continue to be offered through various virtual platforms. Outreach efforts on behalf of the caregiver and the 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 allows for diagnostic services conducted by physicians and ongoing patient care management with social work staff, while also expanding the ability of the Centers of Excellence for Alzheimer's Disease to communicate with and support caregiver families. All Centers of Excellence for Alzheimer's Disease 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, virtual joint enrichment and wellness events, and virtual training opportunities). Overall, virtual programming offers more flexibility in scheduling and better accommodates the needs of family caregivers. It also allows clinicians to observe and assess patients in their familiar home surroundings.

Lessons Learned

Studies indicated caregivers of those living with Alzheimer's disease and related dementias experienced higher levels of stress during the pandemic than the rest of the population.[82] Early in the pandemic, studies suggested the removal of supports and services at the onset of the pandemic caused a substantial increase on caregiver workload and stress.[83] [84] As stated above, contractors under the New York State Department of Health, Alzheimer's Disease Caregiver Support Initiative, quickly adapted to virtual and telehealth services to ensure there was no gap in delivery of service. A study conducted by the New York University (NYU) Langone, Alzheimer's Disease and Related Disorders Family Support Program, indicated caregivers were able to transition to online services with little difficulty, which allowed them to benefit from the availability of online services. Some caregivers reported satisfaction with the increased convenience of virtual programming.

With the public health emergency ending on May 11, 2023, contractors, community services providers, and Centers of Excellence for Alzheimer's Disease, 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.

Dementia

Dementia is an umbrella term that refers to a group of degenerative neurocognitive disorders. Alzheimer's disease and related dementia 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 and independent functioning.[1]

Alzheimer's Disease

Alzheimer's disease is the most common form of dementia: 60-80% of individuals with dementia have Alzheimer's disease.[2] Alzheimer's disease 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 Alzheimer's disease. Available treatments that may temporarily improve or slow worsening symptoms do not alter the overall disease progression of Alzheimer's disease. However, in 2021, Aducanumab, a disease modifying therapy that targets removal of amyloid from the Alzheimer's disease brain was given Food and Drug Administration approval for use in patients with early-stage Alzheimer's disease. The efficacy and long-term benefits will continue to be evaluated. Lecanemab, an additional disease modifying therapy to treat Alzheimer's disease in the early, mild stages was approved in July of 2023.

Alzheimer's disease typically occurs in a progressive sequence of stages. According to the 2011 diagnostic guidelines for Alzheimer's disease published by the National Institute on Aging, Alzheimer's disease begins before the emergence of observable symptoms.

The National Institute on Aging identifies three stages of Alzheimer's disease that occur on a spectrum: preclinical/presymptomatic Alzheimer's, mild cognitive impairment, and dementia due to Alzheimer's disease.[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 Alzheimer's disease: mild, moderate, and severe.[3] Alzheimer's disease 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]

Preclinical/Presymptomatic Alzheimer's Disease

Preclinical Alzheimer's disease 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 Alzheimer's disease begin to occur. Studies suggest the possibility of subtle cognitive changes that could be detectable years before meeting the criteria for mild cognitive impairment.[3]

Mild Cognitive Impairment

Mild cognitive impairment 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. Mild cognitive impairment causes cognitive changes that can affect memory, completion of tasks, reasoning, etc. "Amnestic mild cognitive impairment" affects memory, and "non-amnestic mild cognitive impairment " affects thinking skills outside of memory, such as judgment.[5] Individuals being evaluated for mild cognitive impairment should be screened and assessed for depression because this condition can exacerbate cognitive decline, or its symptoms may mirror cognitive impairment.

The symptoms of mild cognitive impairment 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] Mild cognitive impairment symptoms can be described as a range between the expected modest cognitive decline of normal aging and the more significant changes of Alzheimer's disease and related dementia.[6]

Mild cognitive impairment is significant to the risk assessment and early diagnosis of Alzheimer's disease, but some individuals with mild cognitive impairment never develop Alzheimer's disease. Studies indicate that as many as 15% to 20% of people over age 65 have mild cognitive impairment, and a review of 32 studies identified that a median of 31.5% of people with mild cognitive impairment progress to Alzheimer's disease over five years.[7] People with amnestic mild cognitive impairment are at greater risk of developing Alzheimer's disease. If an individual presents with both mild cognitive impairment and the biomarkers for Alzheimer's disease, there is a degree of certainty that he or she will develop Alzheimer's disease.[5] Limited information exists on the relationship between mild cognitive impairment and other dementias.

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

Mild Alzheimer's Disease (Early-Stage)

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

- 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 Alzheimer's disease 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 activities of daily living.

Severe Alzheimer's Disease (Late-Stage)

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

During the final stage of Alzheimer's disease'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 Alzheimer's disease and related dementia.)

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 Alzheimer's disease co-existing with blood vessel complications associated with vascular dementia. Alzheimer's disease symptoms can also have co-morbidity with Lewy bodies, the abnormal protein deposits characteristic of Lewy body dementia. In some cases, a person may have brain changes linked to all three conditions: Alzheimer's disease, vascular dementia, and Lewy body dementia. For more information on mixed dementia, see: https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/mixed-dementia

Behaviors Associated with Dementia

Many individuals living with Alzheimer's disease and related dementia may never exhibit behaviors.[81] However, it is not uncommon for those living with the disease to experience behaviors at some point in their diagnosis. Behaviors may include but are not limited to:

Repetition

A person living with Alzheimer's disease and related dementia may have repetitive behaviors, such as asking the same question repeatedly or repeating words or activities.

Aggression

Aggression may be either physical or verbal. Aggressive behaviors may be caused by a frustrating event or may arise for no apparent reason.

Some common causes of aggressive behaviors are:
- Physical discomfort, including lack of sleep, hunger or thirst, or pain.
- Environmental factors - a noisy room, large groups of people, clutter, etc.
- Difficulty with communication - this can include difficulty understanding instructions, being asked too many questions, or given too many tasks at once. In addition, presentation of aggressive behaviors may be due to the individual living with Alzheimer's disease and related dementia having difficulty communicating their own needs.

Agitation and Anxiety

Agitation may be caused by several factors including:
- Change in environment, including hospital admissions, living environment, even new furniture or decor
- New or unfamiliar caregivers
- Uncertainty and fear
- Fatigue

Sundowning

Sundowning can occur from late afternoon/early evening and can last into the night. During this time of day, individuals living with Alzheimer's disease and related dementia may experience increased confusion and behavioral symptoms.

Wandering

Wandering occurs when an individual living with Alzheimer's disease and related dementia loses their way or becomes confused about their location. It is one of the most concerning behaviors associated with Alzheimer's disease and related dementia.[81] Signs of wandering include forgetting how to get to familiar places or talking about fulfilling former obligations (such as work or picking up their children). The Alzheimer's Association estimates that six in ten people living with Alzheimer's disease and related dementia will wander at least one time. Wandering can be dangerous and increases the risk of emotional strain, physical injury, or even death. Everyone living with Alzheimer's disease and related dementia is at risk for wandering.

More information can be found at: https://www.alz.org/help-support/caregiving/stages-behaviors

Prevalence and Mortality

National

An estimated 6.7million Americans age 65 or older live with Alzheimer's disease, approximately 73% of these individuals are over age 75.[2] The number of Americans over the age of 65 living with Alzheimer's disease may grow to 12.7 million by 2050.[2] The rate of Alzheimer's disease increases with age, and approximately 35.4% of people over age 85 have Alzheimer's disease.[2] Although Alzheimer's disease is typically diagnosed in people over age 65, it is estimated that at least 200,000 Americans between the ages of 30 to 64 are diagnosed with "younger/early onset."[12] There is currently limited data addressing the prevalence and mortality of other forms of dementia. Alzheimer's disease was officially listed as the sixth-leading cause of death in the United States in 2019. In 2020 and 2021, when COVID-19 became the third-leading cause of death, Alzheimer's disease was the seventh-leading cause of death; official counts for 2022 are still being compiled.[2]

A research study conducted by the Centers for Disease Control and Prevention, 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 Alzheimer's disease 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 Centers for Disease Control and Prevention, 132,741 people died from Alzheimer's disease in 2020.[13] However, prevalence and mortality rates for Alzheimer's disease are not an accurate representation of actual figures due to the lack of early detection and diagnosis and underreporting of Alzheimer's disease on death certificates.[14]

Similarly, limited data related to other dementias could also contribute to their under-representation on death certificates. The Centers for Disease Control and Prevention 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 Alzheimer's disease.[15]

The Centers for Disease Control and Prevention, in collaboration with state health agencies, conducts the annual Behavioral Risk Factor Surveillance System (BRFSS) survey. The Behavioral Risk Factor Surveillance System has two modules related to Alzheimer's disease: the perceived cognitive impairment, and caregiver modules. National data from the perceived cognitive impairment module from the 2020 survey indicates that one in ten Americans over the age of 45 are experiencing confusion or memory loss. One in three 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 reported this condition to their health care providers.[16] https://www.cdc.gov/aging/data/infographic/2019-2020/aggregate-scd.html

New York State

The scope of Alzheimer's disease 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.

The Alzheimer's Association estimates 410,000 individuals in New York State have Alzheimer's disease, and that number is expected to increase to 460,000 by 2025. More recently, in an article published in the Alzheimer's & Dementia: The Journal of Alzheimer's and Dementia, the number of individuals living with Alzheimer's disease in New York State is approximated to be 426,000.[87] New York State has the second highest prevalence of Alzheimer's disease in the United States. Comparable data for other dementias is not available.[2]

Also noteworthy from that report, Bronx County is one of the top three counties in the United States with the highest prevalence of Alzheimer's disease, with 16.6% of people over 65 living with Alzheimer's disease.[87]

The Centers for Disease Control and Prevention and the 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 New York State, one (1) in nine (9) individuals aged forty-five (45) and over reported confusion or memory loss in the 2021 Behavioral Risk Factor Surveillance System and less than half indicated that they reported the condition to their health care provider.[16] Additional New York State-related *Behavioral Risk Factor Surveillance System* data is located at: https://www.cdc.gov/brfss/annual_data/annual_2021.html

The United States Department of Health and Human Services recognizes that Alzheimer's disease and related dementia disproportionately impacts racial and ethnic minorities, individuals with younger onset Alzheimer's disease and related dementia, and those with Down syndrome. Health and Human Services 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.

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 Alzheimer's disease and related dementia. 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 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 Alzheimer's disease and related dementia in the United States; this wide range is due, in part, to limited information about the number of individuals with early onset of dementias other than Alzheimer's disease, and delayed diagnosis.[12] In addition, other types of dementias mimic early onset Alzheimer's disease including vascular dementia, Huntington's disease, Parkinson's disease, Frontotemporal Dementia, Lewy body dementia, Chronic Traumatic Encephalitis, and Human Immunodeficiency Virus associated neurocognitive disorder.

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 Alzheimer's disease result from inherited mutations on specific genes.[30] Individuals with Down syndrome are at a strikingly increased risk of developing early onset Alzheimer's disease.[31] Other early onset dementias, such as Huntington's disease, Frontotemporal Dementia, 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 Alzheimer's disease and related dementia and their caregivers face unique challenges when planning and managing the disease progression. Since Alzheimer's disease and related dementia 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 Alzheimer's disease and related dementia 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 Alzheimer's disease and related dementia programs are typically designed for older adults. Individuals with early onset Alzheimer's disease and related dementia 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, an intellectual and developmental disability, are at increased risk for developing Alzheimer's disease, 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 Alzheimer's disease neuropathology. The properties of this chromosome set make Alzheimer's disease 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 Alzheimer's disease brain pathologies. By the age of forty (40) years, virtually all have sufficient senile plaques and neurofibrillary tangles for a neuropathological diagnosis of Alzheimer's disease. Thus, there is dissociation between the age of onset of Alzheimer's disease 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 intellectual/developmental disabilities, Alzheimer's disease or 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 Alzheimer's disease and related dementia.

Although most individuals with Down syndrome develop the pathology of Alzheimer's disease, 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 Alzheimer's disease 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 Alzheimer's disease 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 Alzheimer's disease can be found at: https://www.ndss.org

Risk Factors

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

The percentage of people living with Alzheimer's dementia increases with age. Five percent (5%) of individuals between the ages of sixty-five to seventy-four (65-74), thirteen point one percent (13.1%) of individuals between the ages seventy-five to eighty-four (75-84), and thirty-three point three percent (33.3%) of individuals aged eighty-five (85) or older have Alzheimer's disease.[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 Alzheimer's disease.[2, 40] These gene(s) are 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 Alzheimer's disease have at least one copy of APOE-ε4. Research also supports the conclusion that mutations of several specific genes cause Alzheimer's disease and related dementia.[40]

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.[78] 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 Alzheimer's disease. For example:

- Research supports the importance of cardiovascular health, citing the high rates of Alzheimer's disease 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, Alzheimer's disease 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 are at an increased risk for developing Alzheimer's disease and related dementia.[2]

A study conducted in Denmark supports the theory that lifestyle and health factors can play a significant role in acquiring Alzheimer's disease and related dementia.[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 Alzheimer's disease and related dementia 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.[45] The rate of Alzheimer's disease and related dementia 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 Alzheimer's disease and related dementia.

Further research regarding risk factors is essential to better understand causal relationships and to improve opportunities for the prevention of Alzheimer's disease and related dementia. Based on known risk factors, individuals can pursue many preventative lifestyle changes to potentially lower their risk of developing Alzheimer's disease and related dementia. 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.[46,47]
- Studies have indicated a correlation between hearing loss and Alzheimer's disease and related dementia. A recent study conducted found that hearing intervention may have a significant effect on reducing cognitive decline[86].

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] Studies have indicated a correlation between hypertensive disorders of pregnancy, including both gestational hypertension and preeclampsia, and vascular dementia. One study conducted found that women with a history of hypertensive disorders of pregnancy were more at risk for developing dementia than women who did not have hypertensive pregnancies. The study found that hypertensive disorders of pregnancy was associated with 1.64 times higher risk for vascular dementia.[80] 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]

Racial and Ethnic Minorities

Disparities are associated with the risk of developing of Alzheimer's disease and related dementia 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 Alzheimer's disease.[2] More research is needed to estimate the prevalence of Alzheimer's disease and related dementia 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 Alzheimer's disease and related dementia 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 Alzheimer's disease and related dementia.[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 Alzheimer's disease in African Americans than in non-Hispanic Caucasians of European ancestry.[21] There is evidence that missed diagnoses of Alzheimer's disease and related dementia 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]

Identification and Diagnosis

The National Institute of Aging's 2011 diagnostic guidelines encourage the early detection of Alzheimer's disease and related dementia 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 Alzheimer's disease and related dementia.[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 and computed tomography scans enable brain structural abnormalities, including tumors and regional brain shrinkage, to be detected. Positron emission tomography 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 Alzheimer's disease from other forms of dementia with more precision. These new biomarker analyses may eventually enable definitive Alzheimer's disease and related dementia diagnoses to be made in the clinical setting.

Review and Report on Cognitive Screening Tools

Alzheimer's disease and related dementia cognitive screening tools are assessments that can determine a person's cognitive abilities, detect impairments, track functional/activities of daily living decline, and monitor progression of mild cognitive impairment and Alzheimer's disease and related dementia. 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 National Institute on Health, and Centers for Medicare and Medicaid Services 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.[49] 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

New York State Department of Health, 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, 2023-2027 (*Public Health Road Map*)*, issued by the Centers for Disease Control and Prevention and the Alzheimer's Association, recommend early detection of Alzheimer's disease and related dementia. https://www.cdc.gov/aging/pdf/roadmap/HBI-State-and-Local-Road-Map-for-Public-Health-2023-2027-508-compliant.pdf[50]

Early detection is important for the individual living with Alzheimer's disease and related dementia 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*.[79] 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 Alzheimer's disease and related dementia connect with peers, and increase knowledge of the disease, caregiving options, and community resources. Individuals diagnosed with early-stage Alzheimer's disease and related dementia have the opportunity to engage in financial and advanced care planning and to determine and clearly express their wishes for the future.[79] 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 Alzheimer's disease and related dementia 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 mild cognitive impairment.[33] In addition, other conditions mimic Alzheimer’s disease and related dementia 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 Alzheimer’s disease and related dementia in its early stages.

New Alzheimer’s treatments, including Lecanemab, are indicated for people with mild cognitive impairment, or mild dementia. Early diagnosis will ensure patients will have access to new treatments.

Barriers

Barriers to early detection include:

- The public’s lack of understanding about the difference between normal aging and the early signs of mild cognitive impairment/dementia. The ten warning signs of Alzheimer’s disease/dementia may not be recognized by individuals experiencing cognitive changes and their loved ones.

- 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).

- Social stigma associated with Alzheimer’s disease and related dementia and denial of observed changes and symptoms.[53]

- Fear of being diagnosed with Alzheimer’s disease or a related dementia.

- Lack of an affordable biomarker test for Alzheimer’s/related dementia adds to the complexity of making an early and accurate diagnosis, especially in rural and under-served communities.

Another significant barrier to diagnosis is the shortage of healthcare providers, including but not limited to, neurologists, geriatric psychiatrists, geriatricians, geriatric nurse practitioners, and other providers who are trained in diagnosing Alzheimer’s disease and related dementia. According to the report, “A Shortage of Neurologists – We Must Act Now: A Report From the AAN 2019 Transforming Leaders Program,” there is a large disparity between the need for neurologists and the availability of providers. As the population ages, many with neurogenerative diseases, the gap will continue to widen. One of the most prominent effects of the disparity is longer wait times for an initial appointment with a neurologist.[88]

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. A new era of research, treatment, and available services may help mitigate fear of diagnosis. As such, this report addresses recommendations related to increased provider education in the diagnosis and treatment of the disease.

Research Update

Prevention and Risk Reduction

Research is a critical component of finding a method to prevent or cure Alzheimer’s disease and related dementia and, given the growing number of individuals diagnosed with Alzheimer’s disease and related dementia, time is of vital importance. The focus is on the prevention of Alzheimer’s disease and related dementia 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 Alzheimer’s disease. Currently, there are no clear prevention strategies for Alzheimer’s disease and related dementia. However, there are steps that can be taken to recognize and mitigate risk factors.

The National Institute on Health report titled *Sustaining Momentum: National Institute on Health Takes Aim at Alzheimer’s Disease & Relate*d *at National Institute on Health 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 Alzheimer’s disease and related dementia.[53]

Several unique and promising prevention research trials are exploring gene therapies and the influence of the endocrine system on preventing Alzheimer’s disease and related dementia. 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 Alzheimer’s disease 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 Alzheimer’s disease have not shown therapeutic efficacy. In June 2021, a treatment targeting amyloid removal from the brain (Aducanumab) was approved by the Food and Drug Administration for use in patients with early-stage Alzheimer’s disease. 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 Alzheimer's disease due to genetic mutation or the presence of early amyloid deposits in the brain detected by neuroimaging.

Tau is a second protein implicated in Alzheimer's disease 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 Alzheimer's disease, 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 Alzheimer's disease 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 Alzheimer's disease, inflammation and deficient "cell waste recycling" to name a few. Alzheimer's disease 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 Alzheimer's disease and related dementia, the advancements of biologics, particularly monoclonal antibodies, in drug development has led to significant optimism about potential disease modifying treatments. In addition, research has continued focus on non-pharmacological and other pharmacological interventions that can decrease or slow symptoms associated with Alzheimer's disease and related dementia. The June 2021 approval of Aducanumab, the first drug approved by the Food and Drug Administration that is proposed, although not proven, to slow the progression of the disease. The approval in 2023 of Lecanemab (and the fact that there are several additional medications under consideration with the Food and Drug Administration hold hopes for new treatments that may serve to as potential therapies for Alzheimer's disease.

Non-pharmacological

Behavioral and psychological symptoms exhibited by individuals with Alzheimer's disease and related dementia 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 Alzheimer's disease and related dementia 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 Alzheimer's disease and related dementia 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 Alzheimer's disease and related dementia. Person-centered approaches should be applied that demonstrate an understanding of who the person was before developing Alzheimer's disease and related dementia, 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 Alzheimer's disease and related dementia.

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 Alzheimer's disease and related dementias 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 Alzheimer's disease and related dementias 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 Alzheimer's disease and related dementia.

Additional non-pharmacological treatments of Alzheimer's disease and related dementia 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 activities of daily living, and/or enhance overall quality-of-life throughout the disease process. Best practices for Alzheimer's disease and related dementia care include care models that are team-based and coordinate care across settings, including medical.[59]

Pharmacological

The most used medications on the market only address the symptoms of Alzheimer's disease and related dementia. 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 Alzheimer's disease and related dementia.

These symptom managing medications, called cholinesterase inhibitors are often used to treat mild to moderate symptoms of Alzheimer's disease. These medications include Donepezil, Rivastigmine (Exelon), and Galantamine. Memantine, the second type of medication available, is used for moderate to severe Alzheimer's disease and is believed to mitigate glutamate levels in the brain that may lead to brain cell death.[2] Memantine hydrochloride extended-release and donepezil hydrochloride, a combination drug, has been approved to treat moderate to severe Alzheimer's disease. This agent combines memantine hydrochloride extended-release and donepezil hydrochloride, which are often prescribed in combination.

As previously noted, pharmaceutical companies are exploring new research aimed at the development of drugs that mitigate the brain of amyloid or tau. The first of these disease modifying treatments, Aducanumab was approved in June 2021 by the Food and Drug Administration as a treatment 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 July 2023, the Food and Drug Administration granted full approval of Lecanemab, a disease modifying therapy to treat Alzheimer's disease in the early, mild stages. Lecanemab is a monoclonal antibody medication. It is the first traditionally approved treatment that addresses the underlying course of Alzheimer's, treating the disease.

The Centers for Medicare and Medicaid Services has approved Medicare coverage for a portion of the cost of treatment for patients who have a diagnosis of mild cognitive impairment or mild Alzheimer's disease dementia. To qualify for coverage, the Centers for Medicare and Medicaid Services requires the medication be prescribed by a physician. The prescribing physician is required to enroll patients receiving the treatment in the Centers for Medicare and Medicaid Services National Patient Registry.

Lecanemab treatment is covered by Medicare Part B. Individuals receiving Lecanemab treatment with traditional Medicare will be responsible for the 20% coinsurance for the cost of the treatment. At this time, there is uncertainty whether private insurance will cover the cost of the treatment. Also, in question is whether both Medicare and private insurance will cover the required ancillary testing, including magnetic resonance imaging and blood work.

Another disease modifying treatment under review at the Food and Drug Administration and expected for approval in early 2024 is Donanemab, furthering the advancements currently underway with in Alzheimer's disease and related dementia clinical trials. In addition to the new approaches to therapy being explored, as mentioned above, another alternative intervention under exploration by the National Institute on Health is testing existing drugs originally developed to address other diseases but have pharmacological properties suggesting that they may yield positive results for Alzheimer's disease and related dementia.[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 Alzheimer's disease and related dementia, 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 Alzheimer's disease and related dementia.[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 Alzheimer's disease and related dementia, 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 Alzheimer's disease and related dementia, which are often a greater management problem for caregivers than memory loss. For example, a new class of antipsychotic agent, Pimavanserin, which is currently Food and Drug Administration approved only for Parkinson's dementia with psychosis, is being evaluated for use to treat psychosis, agitation, and aggression in Alzheimer's disease and related dementia. In May 2023, the Food and Drug Administration approved Brexpiprazole, a pharmacological treatment for agitation associated with dementia due to Alzheimer's disease. This is the first Food and Drug Administration-approved treatment option for this indication,

Individuals living with Alzheimer's disease and related dementia 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 Alzheimer's disease and related dementia treatment approach.[53] It should be noted that the drugs used for Alzheimer's disease and other dementias 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 Alzheimer's disease and related dementia.

Palliative Care

The National Institute on Health 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.[60] 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 Alzheimer's disease and related dementia, and the disease results in death.[52] Most individuals with late-stage Alzheimer's disease and related dementia 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.[60] 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 Alzheimer's disease and related dementia.

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 Alzheimer's disease and related dementia. Nationally, informal caregivers for individuals with Alzheimer's disease and related dementia provide an estimated eighteen billion hours of unpaid care.[2] The Alzheimer's Association reports that caregivers' unpaid care was valued at $339.5 billion in 2022.[2] In New York State, five hundred forty-six thousand (546,000) caregivers provided eight hundred eighty-four (884) million hours of unpaid care for individuals with Alzheimer's disease and related dementia, valued at $19,089 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 Alzheimer's disease and related dementia.[2]

The role of an informal caregiver for a person with Alzheimer's disease and related dementia is intensely stressful. Caring for individuals with Alzheimer's disease, 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 activities of daily living, 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 Alzheimer's disease and related dementia.

Most of the contemporary research indicates that the impacts of caring for an individual living with Alzheimer's disease and related dementia disproportionately affects women and minorities.[62] Women provide more than sixty percent (60%) of all paid and unpaid caregiving for individuals with Alzheimer's disease and related dementia.[26] Of those who provide care for more than five years, sixty three percent (63%) of those caregivers are women. This means that much of the financial, emotional, and physical burden of caregiving falls on them.[2, 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 (3%) of the men have had to do the same. This leaves women more vulnerable to being unable to support themselves later in life given a Social Security system based on number of years worked.[22, 23, 28]

According to the *2023 Alzheimer's Disease Facts and Figures* and a study conducted by the American Association of Retired Persons, Hispanic and African American caregivers report more time caregiving and higher intensity of caregiving burden compared to non-Hispanic Caucasian caregivers.[2, 62, 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 Alzheimer's disease 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 Alzheimer's disease and related dementia.[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 Alzheimer's disease and related dementia. 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 Alzheimer's disease and related dementia, found that stress levels are particularly high in facilities with specialized Alzheimer's disease and related dementia 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 Alzheimer's disease and related dementia 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 Alzheimer's disease and related dementia 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 Alzheimer's disease and related dementia use a disproportionate amount of healthcare resources. Until less invasive, more affordable biomarker tests are approved and available, even the cost of diagnosing Alzheimer's disease is disproportionately higher than other diagnoses. A study funded by National Institute on Health found that health care costs for Alzheimer's disease and related dementia are greater than for any other disease. The National Institute on Health reported that in the last five (5) years of life, total health care spending for an individual living with Alzheimer's disease and related dementia 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 Alzheimer's disease and related dementia 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 Alzheimer's disease and related dementia 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 Alzheimer's disease and related dementia and/or their caregivers, and $39 billion covered by other sources, including private insurance and health organizations.

Nationally, almost four million individuals who have Alzheimer's disease and related dementia 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 Alzheimer's disease and related dementia. According to the 2017 New York State Behavioral Risk Factor Surveillance System, 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 Alzheimer's disease and related dementia are heart disease, strokes, and kidney disease. The combination of Alzheimer's disease and related dementia 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 chronic obstructive pulmonary disease.[2]

The average Medicare costs for seniors with Alzheimer's disease and related dementia and other chronic conditions are significantly higher than those individuals on Medicare who have a chronic condition without Alzheimer's disease and related dementia. According to a 2013 study, a senior with Alzheimer's disease and related dementia 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 Alzheimer's disease and related dementia. A senior with one chronic condition and Alzheimer's disease and related dementia costs Medicare an average of seventy-five percent (75%) more than a senior with one chronic condition but no Alzheimer's disease and related dementia. This equates to $16,775 as compared to $9,523. Seniors with three chronic conditions and Alzheimer's disease and related dementia cost Medicare, on average, twenty-five percent (25%) more than a senior with three chronic conditions but no Alzheimer's disease and related dementia ($27,097 compared to $21,581).[71]

Individuals living with Alzheimer's disease and related dementia 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 Alzheimer's disease and related dementia lived in long-term care facilities as compared with two percent (2%) of individuals age sixty-five (65) and older without Alzheimer's disease and related dementia.[71] A 2004 study estimated that individuals living with Alzheimer's disease and related dementia are hospitalized two to three times more frequently than individuals of the same age without Alzheimer's disease.[1, 72] However, a 2013 study showed a decrease in hospital discharges for individuals with Alzheimer's disease and related dementia between 1999 and 2009. This could be due to increasing mortality rates for individuals living with Alzheimer's disease and related dementia, as well as an increase in individuals living with Alzheimer's disease and related dementia who are cared for in residential facilities rather than hospitals.[72]

In addition to increased health care costs, the cost of Alzheimer's disease and related dementia 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 Alzheimer's disease and related dementia needs to exit the workforce prematurely due to symptoms of Alzheimer's disease and related dementia, particularly early onset.

Elder Justice for Individuals Living with Alzheimer's Disease and Other Dementia

Elder justice is a broad term that, at its essence, means assuring that vulnerable older adults are protected from crime, abuse, neglect, and financial exploitation. Elder justice also involves ensuring that vulnerable older adults have access to legal interventions and networks that provide or refer them to services and supports to address their needs. The 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 New York State, elder abuse and exploitation cases are referred to Adult Protective Services and are tracked through the Adult Services Automation Program (ASAP.net) or Adult Protective Services (APS.net) in New York City. In addition, New York State has been participating with the federal government to provide statistical data to the National Adult Maltreatment Reporting System since 2016.

The number of individuals suffering from elder abuse is severely underreported. According to the 2011 New York State Elder Abuse Prevalence study titled *Under the Radar: New York State 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 Alzheimer's disease and related dementia 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 Alzheimer's disease and related dementia from abuse is for an advocate, friend, family member, or caregiver who recognizes the warning signs to intervene or contact New York State Adult Protective Services for assistance. More information about recognizing elder abuse can be found at:

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

Financial Exploitation

Financial exploitation is 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 Alzheimer's disease and related dementia is more vulnerable to this exploitation. In general, financial exploitation is difficult to prove due to underreporting and, often, lack of proof.

Adult Protective Services statistics for 2018 show a four point seven percent (4.77%) increase in financial exploitation from 2017. Outside of New York City, 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 New York City, 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 New York State, Adult Protective Services has the authority to examine bank records when indicated. The New York State Office of Children and Family Services and Division of Financial Services 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 Office of Children and Family Services website.[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://acl.gov/programs/protecting-rights-and-preventing-abuse/elder-justice

Physical Abuse, Emotional Abuse, and Neglect

Individuals living with Alzheimer's disease and related dementia 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 Adult Protective Services. More information is available at: https://aging.ny.gov/programs/elder-abuse

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 "Healthy Brain Initiative" Public Health Road Map
https://www.cdc.gov/aging/healthybrain/roadmap.htm

The Healthy Brain Initiative's State and Local Public Health Partnerships to Address Dementia: the 2018-2023 Road Map (Healthy Brain Initiative Road Map) serves 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, improve diagnosis and care of Alzheimer's disease and related dementia and help meet the needs of caregivers. This Healthy Brain Initiative Road Map forms the means by which policies, systems, and environments can further promote brain health. State Alzheimer's plans are increasingly being guided by the actions outlined in the Road Map.

The 2018-2022 Healthy Brain Initiative Road Map outlined 25 actions centered around four traditional domains of public health, including to Educate and Empower, Develop Policies and Mobilize Partnerships, Assure a Competent Workforce, and Monitor and Evaluate. Alignment of the Road Map actions with essential services of public health ensures that initiatives to address Alzheimer's disease can be incorporated easily and efficiently into existing public health initiatives.

A 2023-2027 version of the Healthy Brain Initiative Road Map was released in 2023. The updated Healthy Brain Initiative Roadmap outlines 24 actions centering around domains of public health. The domains were expanded from the previous report to: Strengthen Partnerships and Policies, Measure, Evaluate and Utilize Data, Build a Diverse and Skilled Workforce, and Engage and Educate the Public. The Roadmap's continued goal is to fully integrate cognitive health and caregiving supports into public health practices.

National Plan to Address Alzheimer's Disease

The National Alzheimer's Project Act was signed into law in early 2011 and requires the Secretary of Health and Human Services to create and maintain a national plan to address Alzheimer's disease. The *National Plan to Address Alzheimer's Disease* (National Plan) was released in May 2012, with the most recent update published in 2022. http://aspe.hhs.gov/sites/default/files/documents/59cefdd628581b48b2e389891a675af0/napa-national-plan-2022-update.pdf The National Plan coordinates federal research on Alzheimer's disease, works to improve prevention, diagnosis, treatment, and care for Alzheimer's disease, including health care services and long-term services and supports, and coordinates internationally on the fight against Alzheimer's disease.

The National Plan focuses on six goals: Prevent and Effectively Treat Alzheimer's disease and related dementia by 2025, Enhance Care Quality and Efficiency, Expand Supports for People with Alzheimer's disease and related dementia and their Families, Enhance Public Awareness and Engagement, and Track Progress and Drive Improvements. In 2021, a new national goal was added 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.

Since 2020, focus has been placed on how to respond effectively to the outbreak of the Novel Coronavirus, COVID-19, which has significantly complicated the health and safety of older adults, particularly those experiencing cognitive impairment, and their caregivers. Age, multiple chronic conditions, and disability are well recognized risk factors for greater morbidity and mortality due to COVID-19, making people with dementia one of the most at-risk groups. Actions under the National Plan are supporting increased research into the impacts of COVID-19 and post-COVID conditions on brain health, cognition and Alzheimer's disease and related dementia. Particularly, efforts are looking at the long-term effects of COVID-19 infections through the Researching COVID to Enhance Recovery (RECOVER) Initiative. This initiative is examining the clinical outcomes seen with long-COVID and these affect both cognition and the risk of developing Alzheimer's disease and related dementia. The National Institutes of Health has been joined by the National Institute on Aging to support research specific to the social, behavioral, and economic impacts of COVID-19 on aging and vulnerable populations, including those with cognitive impairment and dementia.

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

The National Institutes of Health and other entities use large research Summits to engage with the research community and stakeholders and to solicit perspectives on research gaps and opportunities relevant to cognitive aging and Alzheimer's disease and Alzheimer's disease-related dementias. The third Summit on Care, Services and Supports for Persons with Dementia and their Caregivers was held in March 2023.

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.

BOLD: Building Our Largest Dementia Infrastructure for Alzheimer's Act

The federal government advanced support for a public health approach to the prevention, treatment, and care of Alzheimer's disease and related dementia, under new legislation passed on December 31, 2018. The **Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's (BOLD) Act** authorized the Centers for Disease Control and Prevention to 1) establish Public Health Centers of Excellence dedicated to promoting the best ways to effectively manage Alzheimer's disease and related dementia and support caregivers, 2) work with state, local, and tribal public health departments to promote brain health, strategies to reduce cognitive decline and care for individuals with Alzheimer's disease and related dementia, and 3) improve the analysis and timely reporting of data on Alzheimer's disease and related dementia, cognitive decline, caregiving and health disparities at both a state and national level. Efforts under Building Our Largest Dementia Infrastructure (BOLD) have been directed at implementing the **Healthy Brain Initiative 2018-2023 Road map**.

Initial Notices of Funding Opportunities were released in March 2020, focused on early detection and diagnosis of Alzheimer's disease and related dementia, the promotion of brain health through the reduction of risks to cognitive decline, and supports for caregiving of those living with Alzheimer's. Several Building Our Largest Dementia Infrastructure (BOLD) initiatives began on September 30, 2020, including the establishment of Public Health Centers of Excellence for dementia risk reduction, early detection of dementia, and dementia caregiving, with the National Alzheimer's Association, the New York University (NYU) School of Medicine, and the University of Minnesota, respectively, and 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 Alzheimer's disease and related dementia services and operations.

A new Notices of Funding Opportunities was released in January 2023, soliciting additional proposals from public health departments interested in developing or expanding Alzheimer's disease and related dementia services and programs. The New York State Department of Health applied for Building Our Largest Dementia Infrastructure (BOLD) funding to enhance its public health response to Alzheimer's disease and related dementia, build workforce capacity to detect and diagnose Alzheimer's disease and related dementia, in collaboration with currently funded Centers of Excellence for Alzheimer's Disease and extend the promotion of brain health and risk reduction strategies to local public health departments and area Offices of Aging. In August 2023, New York was notified it was one of 43 states and/or territories to receive the award.

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

Related Public Policy Initiatives:

New York State Initiatives

On November 4, 2022, Governor Kathy Hochul directed an unprecedented new level of coordination, planning, and policymaking with Executive Order No. 23 creating the first Master Plan for Aging in New York State, heralding a new era of support for older adults and people of all ages to succeed.

Under the leadership of Governor Hochul, New York State has embarked on New York State's Master Plan for Aging. The Master Plan for Aging is designed to ensure that older adults and individuals of all ages can live healthy, fulfilling lives while aging with dignity and independence.

The New York State Department of Health and New York State Office for the Aging are coordinating the Master Plan for Aging, building on decades of work and partnerships with state agencies, local governments, and stakeholders. First announced in Governor Hochul's State of the State Address and Fiscal Year 2023 State Budget, the Master Plan for Aging process was further directed by Executive Order No. 23, which Governor Hochul signed on November 4, 2022.

In its structure and scope, the Master Plan for Aging is a new and unprecedented opportunity to support older adults and people of all ages. However, the Master Plan for Aging also builds on a longstanding foundation of existing coordinated work in New York. This work has long recognized that the concerns of older adults – and the opportunities to support them – exist across traditional service, infrastructure, and program boundaries.

The Master Plan for Aging's origins extend from several preceding efforts and initiatives. These include Livable New York, in 2011, which helped municipalities better plan for the housing and community needs of older people, younger people with disabilities, families, and caregivers. In addition, the Downtown Revitalization Initiative – now in its sixth round of funding – has invigorated and enlivened smaller and rural downtowns to improve quality-of-life and foster age-friendly community spaces for people of all ages to thrive.

These and related efforts at the state and local levels led to a landmark distinction in 2017: New York became the first state in the nation enrolled into the World Health Organization Global Network of Age-Friendly Cities and the American Association of Retired People Network of Age-Friendly States. This Age-Friendly New York milestone was followed by Executive Order No. 190 (in 2018), which embeds age-friendly and livable principles into state policies, operation, and procurement based on a Health Across All Policies Approach in alignment with New York's Age-Friendly initiatives. 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 the Health Across All Policies/Age Friendly New York 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 is the first health department to be recognized by the Trust for America's Health as an Age-Friendly Public Health System. To achieve this designation, the New York State Department of Health completed all of the requirements of Trust for America's Health's Age-Friendly Public Health Systems, Public Health System 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

In 2021, the New York State Office for the Aging, New York State Department of Labor, and New York State Department of Health joined with businesses to address the needs of working caregivers and to better understand and support them. Together these agencies developed a working caregiver initiative to respond to the impact of caregiving on employed caregivers. The working caregiver initiative aggregates the impact of caregiving on public and private businesses and provides these businesses with helpful resources to help them better understand the perspectives of employed caregivers, the impact that caregiving has on them, and links employed caregivers to resources. The Initiative aims to recognize caregiving as a statewide issue that impacts all systems. The following strategies are being utilized as part of the working caregiver initiative:

- *Employed Caregiver Survey*: The New York State Office for the Aging and the New York State Caregiving and Respite Coalition collaborated with the University of Wisconsin to tailor its web-based employed caregiver survey to the needs of New York State. The survey launched in June 2021 and ended in November 2021, after the University of Wisconsin informed New York State that it could no longer support the survey efforts. In 2022, New York State Office for the Aging modified the Wisconsin survey to continue collecting data. Businesses were encouraged to share the survey with their employees, and the many tools available to help caregivers self-identify. The survey is being promoted on social media and is available on New York State Office for the Aging's website. Preliminary results of the survey showed that:
    - 32 percent of employees assist individuals 22 hours or more per week
    - 16 percent of employees assist individuals 15 hours to 21 hours per week
    - 27 percent of employees assist individuals 8 hours to 14 hours per week
    - 26 percent of employees assist individuals up to 7 hours per week

- *Caregiver Guide for Businesses*: In June 2021, the *Caregiver Guide (The Guide) for Businesses* was issued in a press release. The Guide includes links to programs, supportive services, workplace data, and information about New York State Paid Family Leave (a benefit that provides workers with job-protected, paid time off to care for a family member). All businesses across the state were targeted for dissemination. The Guide is also available on the New York State Office for the Aging, New York State Department of Labor, and the New York State Department of State websites. New York State Office for the Aging developed a resource brochure for working caregivers, which supplemented the Guide. The brochure provides links to important resources that help support working caregivers.

- *Caregiver Intensity Index:* The Caregiver Intensity Index helps caregivers identify with and feel honored in their role, gives them an Intensity Score, and navigates them to free resources for their unique needs.

- *Trualta*: New York State Office for the Aging and the Association on Aging in New York have launched a partnership with Trualta to offer the caregiver education and support platform at no cost to any unpaid caregiver in New York State.

- *The Caregiver's Guide Video*: New York State Office for the Aging developed this informational video to help individuals self-identify as caregivers and learn more about resources available to support them.

New York State Department of Health

The 2023-2024 New York State budget dedicated $26.4 million for Alzheimer's disease and related dementia programs, representing the largest single-state investment of its kind. With these funds, the New York State Department of Health has continued to expand and strengthen existing Alzheimer's disease and related dementia programs and developed new initiatives using evidenced-based strategies to support caregivers of and individuals living with Alzheimer's disease and related dementia.

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 New York State Department of Health Medicaid Redesign Team 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 three (3) major caregiver support initiatives. The goal of these initiatives is to expand the safety net for caregivers of individuals living with Alzheimer's disease and related dementia 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 Alzheimer's disease and related dementia and their caregivers, reduced hospitalizations, and increased ability to maintain individuals living with Alzheimer's disease and related dementia in the community. Programs which serve similar geographic regions collaborate with and reciprocally refer individuals living with Alzheimer's disease and related dementia and their caregivers to each other to ensure the receipt of appropriate diagnosis, treatment, and support services.

More information on these initiatives, including an interactive New York State 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 Alzheimer's Disease Caregiver Support Initiative

The Regional Alzheimer's Disease Caregiver Support Initiative provides $16.5 million annually to fund a network of ten (10) organizations across New York State which deliver programs that support caregivers who care for New Yorkers living with Alzheimer's disease and related dementia across New York State. Beginning in 2022, funds allocated for the former Alzheimer's Disease Caregiver Initiative for Underserved Communities were included in the Regional Caregiver Support Initiative. The Request for Applications for the Regional Alzheimer's Disease Caregiver Support Initiative included a program component to identify, engage, and provide targeted outreach and services to members of underserved communities. As these services are implemented, data is collected to assess their efficacy.

This statewide program provides*:*

- Caregiver Assessments
- Outreach to and Engagement with Underserved communities
- Caregiver Support and Engagement activities, such as

    - Support Groups,
    - Joint Enrichment Activities; and/or
    - Caregiver Wellness Programs
- Caregiver Education
- Respite

Centers of Excellence for Alzheimer's Disease

The Centers of Excellence for Alzheimer's Disease initiative provides $4.7 million annually to a network of ten (10) medical centers and teaching hospitals across New York State, recognized nationally and by New York State as experts in the diagnosis and care of individuals living with Alzheimer's disease and related dementia. The Centers of Excellence for Alzheimer's Disease are leaders in the field of research and clinical trials seeking effective treatments and a cure for Alzheimer's disease and related dementia.

The Centers of Excellence for Alzheimer's Disease program provides:

- Interdisciplinary and comprehensive medical services for the diagnosis of Alzheimer's disease and related dementia.
- Coordinated treatment and care management for individuals living with Alzheimer's disease and related dementia.
- 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 Alzheimer's disease and related dementia.
- 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 Alzheimer's disease and related dementia 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 statewide and in every region of New York State through subcontracts with the seven (7) Alzheimer's Association Chapters, the Alzheimer's Association/Coalition delivers a comprehensive array of community-based services for individuals living with Alzheimer's disease and related dementia and their caregivers.

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 Alzheimer's disease and related dementia.
- Support groups for caregivers and individuals living with Alzheimer's disease and related dementia.
- 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 (NYU) 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."[66] Dr. Mittelman's newer research demonstrates that the New York University (NYU) Caregiver Intervention can result in seventeen percent (17%) fewer Alzheimer's disease and related dementia deaths in nursing homes, and up to $178.9 million in Medicaid savings over a fifteen (15) year period.[77]

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 New York State 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 first 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.

As of June 2023, more than 269,000 unduplicated caregivers received services through the Alzheimer's Disease Community Assistance Program and the Regional Caregiver Support Initiatives from 2016-2022. Since its inception, the Caregiver Support Initiative has provided over 201,000 Consultations/Caregiver assessment services, over 22,000 Support Group sessions, and nearly 819,000 hours of Respite care.

The Centers of Excellence for Alzheimer's Disease initiative has provided more than 66,000 new diagnostic assessments, over 205,000 referrals to Community Supports, and over 116,000 trainings to physicians, health care professionals, and students.

A survey of informal caregiver participants, conducted in the third year of the first 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 New York State Alzheimer's Disease Caregiver Support Initiative between January 2018 and July 2019. Caregivers reported a wide range of benefits from Alzheimer's Disease Caregiver Support Initiative 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 New York State Department of Health Initiatives

Healthy Brain Initiative Consumer Education Campaign

The Healthy Brain Initiative Consumer Education Campaign mirrors the National Health Brain Initiative Road Map, specific to public education and awareness in New York State.

The Healthy Brain Initiative Consumer Education Campaign ran from February 9, 2022 to March 20, 2022. The campaign promoted 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 included New Yorkers in the forty-five to sixty-five (45-65) age group, in the African American and Latin communities. Included in this multimedia campaign were 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 New York State Department of Health 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 Alzheimer’s disease and related dementia for 2020 - 2021 were:

- *Caregiver and Patient Health in Alzheimer's Disease Policy and Systems Change -*
  David Hoffman, DPS, CCE

- *New York State’s Public Health Approach to Alzheimer’s Disease*
  Mary P. Gallant, PhD, MPH
  Meghan Fadel, Director of Evaluation, New York State Department of Health

- *Sex, Guns, and Driving: Considerations in Dementia Care -*
  Jessica Zwerling, MD, MS
  Andrea Sullivan, OT/L

The New York State Department of Health’s participation with the Public Health Live! Webcasts was discontinued in 2021 but, as noted, these programs remain available to the public.

Behavioral Health and Dementia Workgroup

The healthcare system in New York State has been lacking in its ability to support people with dementia who need behavioral health services. Although not all people diagnosed with Alzheimer’s disease and related dementia 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 New York State.

The New York State Department of Health, Alzheimer's Disease Program, explored issues related to behavioral health services for those living with Alzheimer's disease and related dementia 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 New York State Department of Health, New York State Office of Mental Health, 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 State University of New York 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 New York State, and a shortage of skilled workers equipped to care for this population. The use of technology such as telemedicine and the Alzheimer's and Dementia Care ECHO consultations were found to be useful in enhancing access to services and expertise in several regions of New York State. This initiative was in discussion in early 2020 but further action was delayed by the priorities of COVID.

Special Needs Assisted Living Residence

Adults with Alzheimer's disease and/or dementia who can no longer afford to pay privately for a Special Needs Assisted Living Residence 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 New York State Department of Health to establish a demonstration voucher program to subsidize the cost of a Special Needs Assisted Living Residence for eligible individuals with Alzheimer's disease and/or dementia living in a participating residence. Through this program, the Department is authorized to issue up to two hundred (200) vouchers to individuals who are no longer able to pay for their assisted living care but remain appropriate for that level of care. The program can subsidize up to seventy-five percent (75%) of the regional average private pay rate for the monthly cost of a Special Needs Assisted Living Residence for an approved applicant. Funding continued in the 2020-21 budget. As of June 23, 2021, the Special Needs Assisted Living Residence voucher program instituted a waiting list for new applicants to the program. As vouchers are available, wait-listed applicants will move into the program. The Department of Health paused the approval of new applications in July of 2023. As provided in the Council recommendations, in Section II of the Council Report, the Department is encouraged to continue this program in support of those living in Special Needs Assisted Living Residence's, based upon the availability of future state funding.

Dementia Friendly America

New York State has been designated as an active member of the Dementia Friendly America national network. Several counties in New York State 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

New York State Office for the Aging'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 that serve them. These partnerships with community-based organizations and state agencies result in beneficial outcomes for older adults in New York State, including individuals living with Alzheimer's disease and related dementia and their caregivers.

New York State Office for the Aging has actively engaged partner agencies in addressing social determinants of health to improve the daily life and overall health of older adults through work under the Health Across All Policies approach. Through Executive Order 190, all agencies were directed to, where practicable, consider how their actions can address the needs of older adults through programs, policies, and contracting. Reflecting this commitment, New York State Office for the Aging participated in the Age-Friendly Planning Grant, which provided $1M in funding to county-based teams (composed of County Executive, Local Health Department, Planning/Zoning, and Area Agency on Aging staff) to integrate a similar model of collaborative governance recognizing the needs of older adults and to become members of American Association of Retired People's Network of Age Friendly States and Communities – recognizing a commitment to the needs of older adults through community design and governance.

In addition, several multi-sector partnerships to promote preventive health and services, build community connections, and improve the quality-of-life for older adults. The New York State Office for the Aging and the network of Area Agencies on Aging have participated in and promoted the New York State Age-Friendly Action Community initiative, beginning in 2020 led by the Healthcare Association of New York State with support from New York State Department of Health, The John A. Hartford Foundation, and the Institute for Healthcare Improvement. The Action Community helps participant health systems, and other service and support providers, accelerate the adoption of four evidence-based elements to organize the care of older adults, known as the "4Ms:" What Matters, Medication, Mentation and Mobility. To-date, 100 sites across New York State have earned official recognition from the Institute for Healthcare Improvement as Age-Friendly Health Systems.

Similar recognition for the need to access and adapt evidence-based practices into our services and supports for older adults that promote quality-of-life and healthy aging includes the Dementia Friendly Communities framework. New York State Office for the Aging advocates for public-private partnerships, similar to work under Health Across All Policies and Age Friendly Health Systems, that are seeking to ensure communities are equipped to support people living with dementia and their caregivers. Dementia friendly communities foster the ability of people living with dementia to remain in community and engage and thrive in day-to-day living, including ensuring families are being properly informed, communities are safe and respectful of individuals living with dementia, their families, and caregivers, and providing supportive options that foster quality-of-life.

Social Adult Day Services Programs

Social Adult Day Services programs are structured, comprehensive programs that provide functionally impaired adults (those who need help with everyday tasks) with an array of services in a protective setting for any part of the day, but for less than a 24-hour period. Currently, there are 13 Social Adult Day Service programs directly funded by New York State Office for the Aging and 80 Social Adult Day Service programs funded by the local Area Agencies on Aging.

In 2021, the definition of Social Adult Day Service in paragraph (b) of subsection (1) of Section 215 of the New York State Elder Law was amended to allow for the delivery of Social Adult Day Service in congregate, community, or home settings, to combat loneliness and social isolation, support social determinants of health, provide caregivers with needed respite, and support working caregivers.

Caregiver Supports and Services

New York State Office for the Aging also administers two federally funded programs that provide direct supports and services to informal caregivers:

1. *The National Family Caregiver Support Program* was established in 2000 to provide states with funding for a range of supports that assist family and informal caregivers to care for a family member at home for as long as possible (authorizing legislation is Section 373 of the Older Americans Act of 1965, as amended, Title III-E). New York State Office for the Aging administers this program through the Area Agencies on Aging. Area Agencies on Aging that accept The National Family Caregiver Support Program funds from New York State Office for the Aging must establish and operate a caregiver support program that meets the needs of the caregiver and enhances support given to the care receiver; helps the caregiver become a better advocate and more confident in assisting the care receiver with their needs; deters placement in a long-term care facility and promotes continued care within the home or in alternative community settings for older adults for as long as possible; and helps provide support to older relatives who are caregivers of children or individuals with disabilities, if desired. When family caregivers are well supported, receivers of their care are able to stay in their homes longer and can have a better quality-of-life.

   According to the Older American's Act, the following populations of caregivers are eligible for services under the National Family Caregiver Support Program:

   - Adult family members or other informal caregivers 18 years of age and older providing care to individuals 60 years of age and older.
   - Adult family members or other informal caregivers 18 years of age and older providing care to individuals of **ANY AGE** with Alzheimer's disease or related disorder. Related disorders include dementia, traumatic brain injury, mild cognitive impairment, and chronic traumatic encephalopathy.
   - Older relatives (not the parents), 55 years of age and older living with and providing care to a child under the age of 18.
   - Older relatives (including the parents), 55 years of age and older living with and providing care to an adult aged 18 to 59 with disabilities.

   NOTE: Respite and supplemental services must only be provided to the caregivers of "frail" older adults. Caregivers who meet the definition of older relative caregiver are eligible for all five service types.

Caregiver services under the National Family Caregiver Support Program include:

- Information about services available in local communities.
- Assistance in gaining access to services and resources in local communities.
- Individual counseling, support groups, and caregiver training in areas of caregiving, health, nutrition, and financial literacy who assist the caregiver in making decisions and solving problems related to their caregiving role.
- Respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities. Respite care is prioritized to family caregivers providing care to a frail older adult. Services can be provided in the home, adult day service program, or overnight stay in a residential care setting.
- Supplemental services on a limited basis to complement the care provided by caregivers (e.g., assistive technology, home modifications, incontinent supplies, legal assistance, and transportation).

FFY 2021 Caregivers Served:

- 5,427 Caregivers received counseling/support groups/training
- 2,056 Caregivers received respite care
- 4,867 Caregivers received supplemental services

Based on recommendations made by professionals and informal caregivers, New York State Office for the Aging expanded its current caregiver-directed service delivery model under the National Family Caregiver Support Program to include out-of-home respite care and allow vouchers as a payment mechanism. These recommendations were gathered through a professional work group and a series of caregiver focus groups. A formal analysis and report on the caregiver focus groups was developed and summarizes the input process, corresponding research, and key recommendations for developing a flexible model of caregiver-directed respite. New York State Office for the Aging has included the expansion of the caregiver-directed service delivery model in the NFCSP Standards, which were issued in November 2022. The National Family Caregiver Support Program Standards inform Area Agencies on Aging about the expansion of the optional caregiver-directed service delivery model, and the requirements for implementing the model. New York State Office for the Aging developed a Technical Assistance Memorandum that includes tools and resources to help Area Agencies on Aging implement an effective caregiver-directed service delivery model.

Tailored Caregiver Assessment and Referral Pilot Project

New York State Office for the Aging received a technical assistance grant from the National Academy for State Health Policy that focused on family caregiving. A portion of the grant funds was used to test the Tailored Caregiver Assessment and Referral assessment tool and gain important outcomes and metrics on the assessment's impact on caregivers within New York State Office for the Aging's network. The Tailored Caregiver Assessment and Referral is a care management protocol designed to assist informal caregivers who provide care to adults of any age with chronic or acute health conditions. It is based on Caregiver Identity Theory, which views caregiving as a series of transitions caused by changes in both the caregiving context and personal norms based on familial roles and culture. According to the theory, identity discrepancy, defined as a disparity between a caregiver's behavior and their identity standards or personal norms, is a major source of caregiver stress. Identity discrepancy can be seen in three types of burden (objective burden, relationship burden, and stress burden) as well as depression. Tailored Caregiver Assessment and Referral has proven outcomes that reduce stress and depression for family caregivers. It has also been successful in extending aging in place for the one in need of care. The pilot project was conducted over 20 months and focused on the feasibility of implementing Tailored Caregiver Assessment and Referral as the caregiver assessment tool that would be used by all Area Agencies on Aging when providing services to caregivers under the National Family Caregiver Support Program.

New York State Office for the Aging gathered quantitative and qualitative data from pilot participants to provide recommendations on the feasibility of statewide integration. The pilot project concluded in December 2022, with a total of 282 completed assessments. The project provided the New York State Office for the Aging with a better understanding of the criteria for identifying respite needs, the impact on caregiver depression and stress levels, and the effects of delaying nursing home placement, which could result in significant Medicaid savings. One hundred percent of caregivers who were assessed, lowered, or maintained their identity discrepancy and depression rating, and 99 percent of caregivers lowered or maintained their relationship burden, stress burden, and objective burden. A mini-evaluation report of the project is currently being developed. Beginning on October 1, 2023, New York State Office for the Aging will begin using Tailored Caregiver Assessment and Referral under the National Family Caregiver Support Program statewide, based on comments from participants in the pilot project and data gathered throughout the pilot.

2. *The Lifespan Respite Program* is funded through grants from the Administration for Community Living. Lifespan Respite Care programs are coordinated systems of accessible, community-based respite care services for family caregivers of children and adults of all ages with disabilities. Such programs reduce duplication of effort and assist in the development of respite care infrastructures at the state and local levels. The New York State Lifespan Respite Program Core Team includes New York State Office for the Aging, the Monroe County Office for the Aging, Lifespan of Greater Rochester, Inc. (Lifespan), New York State Coalition on Caregiving and Respite, and NY Connects, the No Wrong Door System in New York State.

Lifespan Respite: Project Period 2020-2023

The goal of the 2020-2023 Lifespan Respite Grant is to continue to build upon prior and current Lifespan Respite initiatives by engaging key stakeholders to strengthen New York State’s Lifespan Respite Care System through expanded respite services, new partnerships, and targeted outreach statewide to provide a sustainable, coordinated respite care system to support caregivers across the age and disability spectrum. This is accomplished by increasing the number and types of partnerships to strengthen New York’s Lifespan Respite Care System; expanding volunteer respite care services, training, and oversight across the age and disability spectrum; expanding outreach strategies to address underserved populations with respite care and build emergency respite capacity; and expanding workforce initiative with businesses in supporting working caregivers.

Lifespan Respite Mini-Grants

As a part of the 2020-2023 Lifespan Respite Grant, New York State Coalition on Caregiving and Respite issued a Request for Applications to award additional mini-grants. The purpose of the mini-grants is to provide the opportunity for the development and/or expansion of Volunteer Respite Programs across New York State. Applicants were required to develop or expand innovative, local, or regional community respite programs for caregivers and their care receivers and demonstrate the ability to utilize volunteers to deliver respite. Applicants were required to commit to serving a minimum of 25 caregivers during the year 2 program period (September 2021-August 2022). Five applications were received and awarded. Some of the reported accomplishments of the mini-grants include:

- *Jefferson County Office for the Aging*: Started a drop-in respite program called Respite Haven at two churches in Jefferson County. The programs have a total of 19 care receivers and eight volunteers and provided 1,541 hours of respite care to 65 caregivers.

- *InterFaith Works*: Successfully trained 12 new senior companions, which allowed for an increase in the number of caregivers served from 17 to 22. A total of 4,863 hours of respite care were provided to 66 caregivers. They also sent out a survey that asked, “Have you felt a reduction in caregiving stress because of having respite care?” Six out of seven respondents answered “yes.”

- Senior Citizens Center of Saratoga Springs, Inc.: Recruited and trained 55 respite companions and provided 2,751 hours of respite care to 158 caregivers. One of the caregivers served noted, “Before, I hadn’t been able to do anything. I now feel less caged, and I get relief.”

- *Tompkins County Office for the Aging*: Recruited eight student volunteers and one student coordinator. The students provided 199.5 hours of respite care to seven caregivers. At the end of the project, both the students and the caregivers completed post-surveys regarding the project. The caregivers expressed a desire to participate in future respite programs due to the noticeable positive changes that occurred during their time in the project. The students identified several valuable aspects of participating in the project, including the experience they gained from providing respite to this population, the enjoyment they gained from the time spent providing care, and positive interactions with both the caregiver and care receiver.

- *Colonie Senior Service Centers, Inc*.: Provided 1,240.5 hours of respite care to 270 caregivers. Eight respite companions were trained for the in-home respite program, and three respite companions were trained for the social adult day program.

New York State Coalition on Caregiving and Respite awarded additional mini grants for the year 3 program period (September 2022-August 2023) using a Request for Applications process, and seven applications were received and awarded to:

- Interfaith Works of Central New York
- Tompkins County Office for the Aging
- Colonie Senior Service Centers, Inc.
- Community Caregivers
- The Noyes Caregiver Resource Center
- West Falls Center for the Arts
- Senior Center of Saratoga Springs

New York State Coalition on Caregiving and Respite Voucher Program

In January 2022, New York State Coalition on Caregiving and Respite developed and implemented a caregiver-directed voucher model for respite care. The voucher program serves kinship caregivers, as well as informal caregivers who are not eligible for respite under Medicaid Managed Care programs and who are caring for someone with chronic conditions. Eligible caregivers can receive up to a $600 voucher to pay for respite care and can apply for a voucher twice per year. Applicants must be the primary caregiver and must live in New York State. Since its launch, 330 caregivers (unduplicated) from 48 counties across New York State have applied for and received a respite voucher, totaling $296,100. Caregivers are asked to complete a satisfaction survey after they have spent their voucher. Ninety-eight percent of respondents stated that the respite care they received helped reduce their stress level, and 98 percent of respondents stated that respite had a positive impact on themselves and their families.

Lifespan Respite Project Period 2021-2026

The goal of the 2021-2026 Lifespan Respite grant is to strengthen New York's Lifespan Respite Care System by piloting a New York State Coalition on Caregiving and Respite regional satellite to build capacity for expanded information, education, respite, and other caregiver supports to underserved groups, as well as statewide development of new partnerships, targeted outreach, and advocacy to provide a sustainable, coordinated respite care system to support caregivers across the age and disability spectrum. This will be accomplished by piloting a New York State Coalition on Caregiving and Respite satellite Regional Caregiver Wellness and Respite Center to engage, assess, and provide services to family caregivers in the region; add the LifeCourse Tools for Respite to the NY Connects No Wrong Door trained counselors' caregiver toolbox to improve respite access statewide; develop and implement a respite worker training program; and increase family caregivers' self-identification and awareness of their role.

Caregiver Wellness and Respite Center

The primary goal of the Lifespan Respite Program is to expand New York State Coalition on Caregiving and Respite's reach by piloting a regional satellite center. The Caregiver Wellness and Respite Center officially opened on July 1, 2022 and serves caregivers in a six-county region in northern New York State (Clinton, Essex, Franklin, Hamilton, Warren, and Washington counties). The Caregiver Wellness and Respite Center is operated by the Center for Neurobehavioral Health (the Center), which is an affiliated program of the State University of New York, College at Plattsburgh, and is supported by the State University of New York Research Foundation. The Center was chosen as a partner in the Caregiver Wellness and Respite Center pilot because of the region's rural, underserved population, and because of the Center's established infrastructure and readiness as a service provider under the Alzheimer's Disease Caregiver Support Initiative to expand and serve new caregiver populations. The Caregiver Wellness and Respite Center is engaging, assessing, and providing services to rural family caregivers for better care coordination, respite implementation, and improved social determinants of health for informal caregivers living in the targeted area. The Caregiver Wellness and Respite Center offers respite vouchers, consultation and assessment services, and education and outreach to caregivers across age and disability groups within the satellite's regional area. The newly formed Caregiver Wellness and Respite Center will increase the capacity and quality of respite and other supports for informal caregivers in the six-county region, allowing caregivers to better care for themselves while also providing caring. According to reports, 55 respite vouchers were distributed between January 1, 2023 and June 30, 2023, totaling $28,337. These respite vouchers provided 55 caregivers with 1,423.5 hours of respite care.

Respite Care Provider Training

New York State Coalition on Caregiving and Respite applied for and was accepted to participate in a Respite Care Recruitment, Training, and Retention Pilot project managed by the Respite Care Association of Wisconsin, Access to Respite Care and Help, Respite National Network, and National Academy for State Health Policy. The overall goal of this pilot project was to increase the pool of trained, qualified respite care providers in each state by establishing national core competencies for entry-level respite care providers.

New York State's training curriculum launched in March 2022 and covered online course modules titled: What is Respite?; Disability Basics for Respite Providers; Client Care for Respite Providers; Medication Administration for Respite Providers; Abuse and Neglect for Respite Providers in New York State; Caring for Challenging Moments for Respite Providers; Wellness, Household, and Free Time Activities; Professional Ethics and Interpersonal Skills for Respite Providers; Meeting with the Caregiver and Care Receiver; and Meeting with the Caregiver.

The courses were completed at the learner's own pace, with a minimum final exam score of 75 percent required for each course to earn a certificate of completion. Through this pilot project, the curriculum courses were offered for free for up to 100 New York State learners and reports show that New York State had 82 active learners complete the training.

Now that the pilot project has ended, New York State Coalition on Caregiving and Respite is able to customize the training. For example, they plan to make the medical-focused modules an optional component of the certificate. Those who wish to complete those modules would be given an "advanced" certificate. New York State Coalition on Caregiving and Respite also plans to add modules that support workforce development for those who may wish to market themselves as independent respite care providers. The trainings will also be made available in Spanish. The software company is also working with New York State Coalition on Caregiving and Respite to develop a respite provider registry, which will allow respite care providers to add their information to the registry once they have completed the training. Caregivers throughout the state will then be able to search the online registry when looking for a respite provider.

LifeCourse Tools for Respite

New York State Office for the Aging intends to provide regional training to New York Connects/No Wrong Door counselors trained in Options Counseling/Person-Centered Counseling on how to use the LifeCourse Tools for Respite. The LifeCourse Tools include a respite guidebook, portfolio, and other tools that are designed to assist family caregivers caring for anyone of any age or disability, as well as those who support them, in developing a plan to access respite services both within and outside the formal services system. These resources will be added to the NY Connects Person-Centered Counseling toolbox. This approach will help improve care integration by involving family caregivers in care coordination and transitions across providers and settings, as preferred by the caregiver and care receiver.

New York State Office for the Aging's New York 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 New York 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 New York State Department of Health, Office for People with Developmental Disabilities, Office of Mental Health, Office of Addiction Services and Supports, and the Food Pantries, including a statewide map of Food Pantries locations. There are approximately 18,896 providers and 68,249 programs listed in the New York Connects Resource Directory. Additionally, the New York State Coalition on Caregiving and Respite web site provides an array of information in its virtual resource center with an available suite of evidence-informed/evidence-based training services. The aim of the virtual resource center is to further coordinate information about caregiving and respite training, technical assistance, and related materials, and also links to the New York Connects Resource Directory: (http://www.nyscrc.org/ny-connects).

The New York Connects/No Wrong Door System includes three questions related to memory problems that have been incorporated into the New York Connects screening process. These questions are used to refer to dementia-related services. New York Connects also assists individuals with Medicaid applications and referrals for aging network and other long-term services and supports. In 2022, New York Connects assisted 18,677 informal caregivers who provide care for individuals of all ages and abilities, accounting for nine percent of all calls to New York Connects.

Elder Abuse Interventions and Enhanced Multi-Disciplinary Team Initiative

New York State began piloting Enhanced Multi-Disciplinary Teams in 2012. Building upon the success of the Initiative, New York State Office for the Aging partnered with the New York State Office of Victim Services in 2017, to establish and implement the Statewide Elder Abuse Interventions and Enhanced Multi-Disciplinary Teams Initiative. Currently, there are Enhanced Multi-Disciplinary Teams operational in 59 counties and the remaining three counties will be operational by the end of 2023.

Enhanced Multidisciplinary Teams offer an evidence-based, person-centered response to elder abuse. They bring together professionals from various disciplines and systems (e.g., Adult Protective Services), aging services, mental health, finance, law enforcement, health care, etc.) to locally address cases of elder mistreatment (financial, physical, psychological, sexual, and neglect by others). Teams also have access to the specialty services that make the multi-disciplinary team "enhanced," including forensic accountants, mental health professionals, and civil legal services. Services provided to abuse victims through Enhanced Multi-Disciplinary Teams interventions include referrals to other types of services, return of personal property, and assistance with applying for public benefits. Services provided to abuse victims through Enhanced Multi-Disciplinary Teams interventions include referrals to other types of services, return of personal property, and assistance with applying for public benefits.

Each year of the Enhanced Multi-Disciplinary Teams Initiative has brought a growing number of referrals. From 352 cases in 2017-18 to 1,149 cases in 2021-22. In addition, Enhanced Multi-Disciplinary Teams interventions have led to approximately $4.2 million in court-ordered or agreed-upon restitution in financial exploitation cases. Of this, approximately $1.2 million was returned to the victims.

Elder Abuse Education and Outreach Program:

The Elder Abuse Education and Outreach Program 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. New York State Office for the Aging continues to administer the statewide Elder Abuse Education and Outreach Program via Monroe County and Lifespan of Greater Rochester Inc.

Lifespan operates the Upstate Elder Abuse Center at Lifespan with these funds. Over the years, Elder Abuse Education and Outreach Program 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.

New York State Office of Children and Family Services

The New York State Office of Children and Family Services serves New York State by promoting the safety, permanency, and well-being of children, vulnerable and dependent 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 Initiative, which protects vulnerable adults who may have experienced financial exploitation and other co-occurring forms of abuse. Enhanced Multi-Disciplinary Teams assist 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 New York State Office for the Aging and the New York State Office of Victim Services, was the first of its kind in the nation. In support of the efforts to identify and prevent financial exploitation, the Office of Children and Family Services Bureau of Adult Services, which oversees Adult Protective Services 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 workers referred to as the Financial Exploitation Investigative Suite of Tools.

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

Teams now cover the entire state. Services provided to abuse victims through Enhanced Multi-Disciplinary Teams 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. Enhanced Multi-Disciplinary Teams 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.

In April 2021, Office of Children and Family Services received $5,306,382 in federal funds under the Grants to Enhance Adult Protective Services to Respond to COVID-19. Additional federal funding ($14,059,718) was awarded to Office of Children and Family Services under the American Rescue Plan Act in 2022. These funds were allocated to Adult Protective Services units within the local departments of social services to enhance, improve, and expand the ability of Adult Protective Services to investigation allegations of abuse, neglect, and exploitation in the context of COVID-19. Counties have continued to use the funding, in part, to provide goods and services to Adult Protective Services 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. Further, Office of Children and Family Services allocated almost $600,000 of the federal funds over a three-year period to partner with New York State Office for the Aging and Lifespan to provide Enhanced Multi-Disciplinary Teams-like services to vulnerable adults under the age of 60. The pilot, Augmented Multidisciplinary Teams began reviewing cases in December 2022.

Office of Children and Family Services has continued to partner 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 Adult Protective Services 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. The web-based training for professionals is slated for posting on the Office of Children and Family Services website in 2023.

Office of Children and Family Services supports continual training opportunities for agency professionals working with the aging population, law enforcement, attorneys, and Adult Protective Services workers at the Annual Adult Training Institute conference. The 2021 conference was held virtually while the 2022 conference resumed in-person workshops, with attendance reaching over 300 people. Several workshops focused on dementia related topics, including physiological aspects of aging, and recognizing dementia, and preventing scams. The 2023 conference planning team includes representation from the Alzheimer's Association of Northeastern New York and will include workshops on cognitive impairments and aging as well as a presentation from Dementia Friends New York.

Office of Children and Family Services also oversees the Family Type Home for Adults program. Family Type Home for Adults 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. 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. Office of Children and Family Services, through its local departments of social services, continues to facilitate trainings of Family Type Home for Adults operators by Alzheimer's Association staff to improve quality-of-care given to residents in Family Type Home for Adults. In March 2021, Office of Children and Family Services held three (3) separate "Townhalls" with local departments of social services and Family Type Home for Adults operators to gather input on proposed regulatory amendments to improve services and supervision to the dependent adults residing in these community-based homes. Office of Children and Family Services will include feedback from these Townhalls in any proposed changes to New York Codes, Rules, and Regulations 18 CRR-NY II D 489.

New York State Office of Mental Health

Aging and Dementia Research

The New York State Office of Mental Health provides support for two psychiatric research institutes which study severely disabling mental disorders. The Nathan Kline Institute for Psychiatric Research and the New York State Psychiatric Institute both conduct research programs on the causes, early diagnosis, and treatment of Alzheimer’s disease and related dementias. The major concentration of Alzheimer’s disease research within New York State Office of Mental Health is conducted at the Center for Dementia Research. Center for Dementia Research programs have yielded over three hundred fifty (350) peer reviewed publications in the past ten (10) years, including reports in the most prestigious scientific journals (Proceedings of the National Academy of Sciences, Nature Medicine, Nature Neuroscience, Science, and others). Attesting to the influence of Center for Dementia Research in the research community, these publications have been cited by other investigators world-wide over seventy-thousand (70,000) times.

Recognized internationally for influential advances toward innovative Alzheimer’s disease therapies, Center for Dementia Research researchers have been awarded over $33 million in National Institute on Health research funding during the last five years. This sustained high level of funding has enabled them to continue pioneering investigations on the causes of Alzheimer’s disease and additional related dementias. Their research has defined cellular abnormalities that arise decades before the earliest clinical symptoms and is yielding new biomarkers of Alzheimer’s disease so that treatments can begin sooner. Notably, the neurological roles of Neurofilament Light, the recently discovered first reliable blood biomarker to track the progression of Alzheimer’s disease, is a longstanding focus of Center for Dementia Research studies, which were pivotal in guiding the discovery of this biomarker. Understanding the biology underlying the earliest changes in Alzheimer’s disease and related dementias has identified new drug targets, including a compound against an early disease target yielding promising therapeutic effects in a Phase 2 clinical trial in Lewy body dementia patients and will be the first therapy for this devastating common dementia if ongoing Phase 3 testing confirms Phase 2 results. Innovative lines of drug discovery, including approaches that address a novel molecular target in Alzheimer’s disease which have recently been awarded patents, are being further validated in the Center for Dementia Research.

Additional 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 Alzheimer’s disease, genetic basis, accelerate the onset of Alzheimer’s disease. Major advances, for example, have been made in the Center for Dementia Research in understanding the biology, and possible treatment of Alzheimer’s disease in individuals with Down syndrome, a population representing the most common form of early onset Alzheimer’s disease. Additional patented technology is enabling an active program of genomic studies on individual neurons in the human brain with Alzheimer’s disease, an area of research pioneered in the Center for Dementia Research.

Individuals with Alzheimer’s disease decline faster if they also have vascular-related brain damage. Research in this area was catalyzed by the findings of the Nathan Kline Institute for Psychiatric Research scientist, who discovered the first gene known to cause a form of dementia related to Alzheimer’s disease that affects primarily the blood vessels. Subsequently, Nathan Kline Institute for Psychiatric Research scientists have developed unique laboratory models of the disease for drug screening and understanding further this important interaction of blood vessel disease with Alzheimer’s disease, 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 Alzheimer’s disease and its contribution to initiation and progression of the disease.

Researchers in Nathan Kline Institute for Psychiatric Research’s Center for Brain Imaging and Modulation are investigating abnormal brain function, possibly heralding the future onset of Alzheimer’s disease, 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 Alzheimer’s disease 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. Recent acquisition of a 9.4 T magnetic resonance imager, one of only three in the world, and formation of a world class team of experts in high-field imaging promises to achieve previously impossible detail of human brain anatomy and disease pathology.

An important mission of New York State Office of Mental Health, Alzheimer’s disease programs is to optimize the management of both memory and behavioral symptoms of people with Alzheimer’s disease and related dementia . 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 Nathan Kline Institute for Psychiatric Research’s Geriatric Psychiatry Division and at the New York State Psychiatry Institute’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 Alzheimer’s disease and related dementia, and the detection of loss of smell as a symptom emerging at the earliest stages of Alzheimer’s disease. Additional clinical research is addressing the adverse effects of commonly used medicines when taken by individuals living with Alzheimer’s disease and related dementia.

New York State Office of People with Developmental Disabilities

New York State Institute for Basic Research in Developmental Disabilities, the research arm of New York State Office of People with Developmental Disabilities, is in the seventh year of a research program called, “Alzheimer Biomarker Consortium-Down Syndrome.” This project is a large research initiative to find biomarkers to track Alzheimer's disease in people with Down syndrome. Researchers collect information and blood samples from people with Down syndrome and their siblings. Participants may undergo physical exams, neurological tests, brain scans, and assessments to measure cognition, memory, and movement. Additional information is obtained through personal and family health history, caregiver questionnaires, and genetic studies. Information gained from this initiative may help people with Alzheimer's and Down syndrome, as well as people with only Alzheimer's disease.

Adults with Down syndrome are more likely to develop Alzheimer's disease in middle age compared with most other people. This is an especially important and timely issue, given the dramatic increase in their life expectancy, and we now need to discover the causes of this increased risk. This knowledge will help us to anticipate the amounts and types of supports they will need. In 2020, this grant was extended for another five years, to continue this important research program. This work has been supported by funds from the New York State Office for People with Developmental Disabilities and National Institute on Health grants U19 AG068054-01 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.

The New York State Office of People with Developmental Disabilities 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/Down syndrome and further clinical progression.
- Identify profiles and rates of change in beta amyloid, proteomic, lipidomic and cerebrospinal fluid biomarkers that characterize progression from normal aging to mild cognitive impairment to onset of dementia.
- Identify neuroimaging-based changes that occur over the course of progression from normal aging to mild cognitive impairment 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, 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 mild cognitive impairment/Down syndrome 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 magnetic resonance 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 Alzheimer's disease 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 cerebrospinal fluid biomarkers, imaging measures, and genetic variants will be examined to develop the most valid indicators of preclinical and early stages of Alzheimer’s disease.

New York State Education Department

The New York State Education Department, 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. The New York State Education Department oversees requirements for professional education, continuing education, and professional practice for each of these professions. The New York State Education Department serves a vital function in ensuring that New York State Education Department licensed professionals provide professional services safely and competently to the public, including individuals living with Alzheimer’s disease and related dementia.

The New York State Education Department 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 Alzheimer’s disease and related dementia 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 Alzheimer’s disease and related dementia are required to ensure they are competent to provide the services before doing so. The New York State Education Department 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 Alzheimer’s disease and related dementia. Regardless of whether it is legally required, many professionals complete continuing education that covers issues relevant to Alzheimer’s disease and related dementia. This education helps to ensure that persons with Alzheimer’s disease and related dementia receive relevant, competent professional services.

Within the broad services of the New York State Education Department, other offices provide oversight of education and the provision of services. These include the Office of Adult Career and Continuing Education Services, which encompasses the areas of Vocational Rehabilitation (including Independent Living Administration), Adult Education, and the Bureau of Proprietary School Supervision.

Several of the Independent Living Centers in New York State operate as fiscal intermediaries under New York State Department of Health Medicaid Consumer Directed Personal Assistance Program and provide self-directed services through surrogates. Surrogate-directed Consumer Directed Personal Care Assistance Program for Medicaid-eligible individuals helps individuals living with Alzheimer's disease and related dementia remain at home, typically with family members and/or family caregivers. In addition, Independent Living Centers participate in providing the Office for People With Developmental Disabilities with family support services and New York State Office for the Aging with self-directed personal care services. The New York Association on Independent Living, Inc. is partnered with Independent Living Centers across the state to provide the Open Doors Transition Center and Peer Outreach & Referral programs. This project, funded by the New York State Department of Health 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.

New York State Education Department and New York State Department of Health 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 Alzheimer's disease and related dementia, 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

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 Disease Understanding in order to Advance Early Detection of Alzheimer's Disease and All Other Dementia

1. Implement public awareness and education activities that are designed to enhance health and wellness and their relationship to Alzheimer's disease and related dementia:

    - Encourage individuals with Alzheimer's disease and related dementia symptoms to be examined by healthcare providers when they experience the earliest symptoms and raise awareness about the difference between Alzheimer's disease and related dementia and normal aging.

- Promote brain health and raise awareness of risk factors, prevention strategies, and the importance of early differential diagnosis of Alzheimer's disease and related dementia.

- Reach those individuals most at risk of developing Alzheimer's disease and related dementia.

- Address the impact of Alzheimer's disease and related dementia on women, both as caregivers and persons with the disease.

- Promote increased awareness of the availability of palliative care for individuals living with Alzheimer's disease and related dementia.

- 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 Alzheimer's disease and related dementia, including new existing and disease modifying drugs.

3. Identify barriers to persons with Alzheimer's disease and related dementia accessing appropriate medical and psychiatric treatment for behavioral symptoms accompanying their disease.

Goal 2: Improve Clinical Care for Alzheimer's Disease and Other Dementia

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

5. Increase public awareness about evolving treatments for Alzheimer's disease and related dementia, including new, existing, and evolving disease modifying drugs.

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 New York State Centers of Excellence for Alzheimer's Disease 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 Alzheimer's disease and related dementia.

11. Promote the importance of early planning to individuals with Alzheimer's disease and related dementia, 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 Alzheimer's disease and related dementia 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 age/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 Alzheimer's disease and related dementia.
    - Appropriately prepare for and respond to hazards and emergencies.
    - Make physical environment modifications that support age/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 Alzheimer's disease and related dementia, 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 Alzheimer's Disease and Related Dementia

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 Alzheimer's disease and related dementia.

20. Educate informal caregivers on how to effectively navigate the healthcare system, which includes long-term care, and to access Alzheimer's disease and related dementia resources and services.

21. Ensure that the financial and justice system recognize and support persons with Alzheimer's disease and related dementia by:

    - Providing an on-line Alzheimer's disease and related dementia 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 Alzheimer's disease and related dementia.

22. Provide continuing education opportunities on Alzheimer's disease and related dementia for all healthcare providers.

23. Support employers to better understand the effects of Alzheimer's disease and related dementia by educating them to recognize the economic cost of Alzheimer's disease and related dementia 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 Alzheimer's disease and related dementia education and training in all long-term care settings.

25. Utilize public health data collection systems such as Behavioral Risk Factor Surveillance System, health data from the National Institute on Health, the New York State Department of Health, Alzheimer's Disease Program, and from the Alzheimer's Association Facts and Figures document to highlight caregiver health and stress and to quantify the burden of Alzheimer's disease and related dementia more accurately through aggregate data.

Goal 5: Address Disparities and Improve Health Equity

26. Provide support services that target underserved communities, including education on normal aging versus Alzheimer's disease and related dementia and the importance of timely diagnosis of Alzheimer's disease and related dementia.

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.

    - Ensuring regionally appropriate services for rural areas.

28. Educate individuals with early onset Alzheimer's disease and related dementia 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 Alzheimer's disease and related dementia.

30. Encourage families and caregivers of individuals with intellectual disability/developmental disability who suspect memory problems and other symptoms to communicate this concern and request assessment by the individual's healthcare provider and engage in early planning regarding Alzheimer's disease and related dementia. Ensure coordination with, and support from, current New York State Department of Health Initiatives.

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

31. Using public health data, promote the importance of lifestyle changes to improve the health, wellness, and quality-of-life of individuals with Alzheimer's disease and related dementia and their caregivers, including best practice approaches for implementing strategies to potentially reduce the risk of developing Alzheimer's disease and related dementia.

32. Increase awareness, reaching patients with the disease, as well as health volunteers, regarding the importance of enrolling in Alzheimer's disease and related dementia research and clinical trials.

33. Promote research on the connection between Down syndrome and Alzheimer's disease and related dementia in New York State research institutes/ New York State Office of People with Developmental Disabilities/New York State Department of Health initiatives.

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Attachment A - Members of the New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementia

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<u>Attachment B</u> - Summary of Alzheimer's Disease and Related Dementias

Diagnosis	Diagnostic Criteria
Alzheimer's disease	**Characteristics:** Alzheimer's disease 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. Alzheimer's disease is the most common type of dementia, accounting for an estimated 60% to 80% of cases.
Alzheimer's disease *(continued)*	**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 activities of daily living, 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 activities of daily living 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 Alzheimer's disease diagnosis is based on a medical evaluation completed by a medical professional that includes a physical and neurological examination;

Attachment B - Summary of Alzheimer’s Disease and Related Dementias

Diagnosis	Diagnostic Criteria
	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	**Characteristics:** Chronic Traumatic Encephalitis is a progressive degenerative brain disease associated with repetitive brain trauma and mild traumatic brain injury. Chronic Traumatic Encephalitis 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: Chronic Traumatic Encephalitis 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/traumatic brain injuries
Diagnosis	**Diagnostic Criteria**
Creutzfeldt-Jakob disease	**Characteristics:** Creutzfeldt-Jakob disease 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 Creutzfeldt-Jakob disease are uncharacteristically rapid and severe. There are three main types of Creutzfeldt-Jakob

Attachment B - Summary of Alzheimer's Disease and Related Dementias

Diagnosis	Diagnostic Criteria
Creutzfeldt-Jakob disease *(continued)*	disease: sporadic, familial, and transmitted/infectious. The most common form of Creutzfeldt-Jakob disease is sporadic.
	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: Creutzfeldt-Jakob disease 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 magnetic resonance imaging. There is no known cause for sporadic Creutzfeldt-Jakob disease.
	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	**Characteristics:** Frontotemporal dementia 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 frontotemporal dementia, temporal/frontal frontotemporal dementia, progressive non-fluent aphasia, semantic dementia, primary progressive aphasia, Pick's disease, corticobasal syndrome, progressive supranuclear palsy, frontotemporal dementia with parkinsonism, and frontotemporal dementia with amyotrophic lateral sclerosis. Persons with frontotemporal dementia 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

Attachment B - Summary of Alzheimer’s Disease and Related Dementias

Diagnosis	Diagnostic Criteria
	Brain Changes: There is no distinguishing microscopic abnormality linked to all types of frontotemporal dementia. Frontotemporal dementia 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 frontotemporal dementia generally develop symptoms at a younger age than those with other forms of dementia and survive for anywhere between 18 months to 20 years, with an average life expectancy of seven years.
Frontotemporal dementia *(continued)*	**Diagnosing:** The diagnosis of frontotemporal dementia 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 magnetic resonance imaging and glucose positron emission tomography scans, are helpful in determining the diagnosis of frontotemporal dementia.
	Known Risk Factors: • Family history (accounts for 1/3 of the cases)
Diagnosis	**Diagnostic Criteria**
Human Immunodeficiency Virus associated neurocognitive disorder/Acquired immune deficiency syndrome Acquired Immune Deficiency Syndrome d Dementia Complex	**Characteristics:** Human Immunodeficiency Virus associated neurocognitive disorder is an umbrella term for Human Immunodeficiency Virus-related dementias that include: Asymptomatic Neurocognitive Impairment, Mild Neurocognitive Disorder and Human Immunodeficiency Virus-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 Human Immunodeficiency Virus penetrates the blood-brain barrier and affects subcortical brain structures below the cerebral cortex. Human Immunodeficiency Virus has also been shown to alter brain size in the areas specific to learning and information

Attachment B - Summary of Alzheimer's Disease and Related Dementias

Diagnosis	Diagnostic Criteria
	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 Human Immunodeficiency Virus infections are likely to develop Acquired Immune Deficiency Syndrome dementia complex or Human Immunodeficiency Virus associated neurocognitive disorder, leading to behavioral changes and a gradual decline in cognitive function.
	Diagnosing: Human Immunodeficiency Virus associated neurocognitive disorder Acquired Immune Deficiency Syndrome dementia complex 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: • Human Immunodeficiency Virus Infection
Diagnosis	**Diagnostic Criteria**
Huntington's disease	**Characteristics:** Huntington's disease is a progressive brain disorder caused by a single defective gene on Chromosome 4. This defect is hereditary and "dominant" meaning that if an individual has the gene then he/she will eventually develop the disease. Symptoms develop typically between the ages of 30 and 50.
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**

Attachment B - Summary of Alzheimer’s Disease and Related Dementias

Diagnosis	Diagnostic Criteria
Lewy body dementia	**Characteristics:** Lewy body dementia presents with cognitive symptoms similar to Alzheimer’s disease and movement symptoms typical of Parkinson’s disease (muscle rigidity, shuffling gait, stooped posture, and difficulty initiating movement). Most experts estimate that Lewy body dementia is the third most common cause of dementia after Alzheimer’s disease and vascular dementia.
	Symptoms: • Cognitive difficulties similar to Alzheimer’s disease, although memory loss of less severity • Periods of confusion and alertness that vary from one time of the day to another, or from one day to the next • Sleep disturbances, often acting out dreams • Well-formed visual hallucinations and delusions • Muscle rigidity or other Parkinsonian movement features • Autonomic nervous system changes • Difficulty with visual interpretations
	Brain Changes: Lewy bodies are abnormal aggregations (or clumps) of the protein alpha-synuclein. When they develop in a part of the brain called the cortex, dementia can result. Alpha-synuclein also collects in the brains of people with Parkinson's disease, but the masses may appear in a pattern that is different from Lewy body dementia.
Lewy body dementia *(continued)*	**Diagnosis:** A diagnosis of Lewy body dementia 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 Lewy body dementia Parkinson’s disease diagnosis
Diagnosis	**Diagnostic Criteria**
Mild Cognitive Impairment	**Characteristics:** Mild cognitive impairment 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. Mild cognitive impairment is not cognitive

Attachment B - Summary of Alzheimer's Disease and Related Dementias

Diagnosis	Diagnostic Criteria
	decline related to normal aging. Individuals diagnosed with amnestic mild cognitive impairment are at a greater risk of developing Alzheimer's disease and related dementia but not all individuals with mild cognitive impairment progress to a dementia. The symptoms of other conditions, such as depression or a Vitamin B12 deficiency, may mimic those of mild cognitive impairment.
	Symptoms: • Mild cognitive impairment primarily affecting memory ("Amnestic") o Short-term memory and re-call problems o Difficulty learning new information • Mild cognitive impairment 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 mild cognitive impairment, particularly in the area of the hippocampus, and an enlargement of the ventricles. Abnormal presences of beta-amyloid protein and microscopic clumps of tau may be found but in less significant amounts than seen with Alzheimer's disease and related dementia.
	Diagnosing: Mild cognitive impairment is a clinical diagnosis based on a medical professional's best judgment after considering the individual's medical history, functional and activities of daily living 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 Alzheimer's disease and related dementia • Conditions that increase a person's risk of cardiovascular disease (e.g., hypertension, smoking, lack of exercise, or diabetes)
Diagnosis	**Diagnostic Criteria**
Mixed Dementia	**Characteristics:** Mixed dementia is characterized by the simultaneous occurrence of the signs and symptoms of different types of dementia. The most common forms of

Attachment B - Summary of Alzheimer’s Disease and Related Dementias

Diagnosis	Diagnostic Criteria
	mixed dementia are Alzheimer’s disease with vascular dementia, Alzheimer’s disease with Lewy body dementia, or characteristics of Alzheimer’s disease mixed with vascular and Lewy body dementia.
	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 Alzheimer’s disease 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 Alzheimer’s disease and related dementia. For example, in an individual living with both Alzheimer’s disease and vascular dementia, abnormal protein deposits associated with Alzheimer’s disease 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.
Mixed Dementia *continued*	**Known 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 Lewy body dementia. 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**

Attachment B - Summary of Alzheimer's Disease and Related Dementias

Diagnosis	Diagnostic Criteria
Parkinson's disease *(continued)* **Diagnosis**	• 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
	• **Brain Changes:** Parkinson's disease begins in a region of the brain that plays a key role in movement. Alpha-synuclein clumps are likely to begin in an area deep in the brain called the substantia nigra; the deposits are called Lewy bodies. These clumps are thought to cause degeneration of the nerve cells that produce dopamine.
	Diagnosing: Parkinson's disease is diagnosed by a medical professional trained in nervous system disorders and will include a medical history, complete physical and neurological examination, and a thorough assessment of cognitive function. Evaluation may include the use of a specialized imaging technique called a dopamine transporters scan (DaTscan) that captures dopamine in the brain.
	Known Risk Factors: • Age 60 or older • Heredity • Male gender Exposure to toxins (particularly herbicides and pesticides)
	• **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 Alzheimer's disease.

<u>Attachment B</u> - Summary of Alzheimer’s Disease and Related Dementias

Diagnosis	Diagnostic Criteria
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 mild cognitive impairment • Evidence of a stroke or other blood vessel changes that affect cause damage in the brain • No evidence that factors other than vascular changes caused the decline
	• **Diagnosing:** Because vascular dementia may often go unrecognized, many experts recommend screening for everyone considered to be at high risk for this disorder. A diagnosis of vascular dementia is made after the completion of a professional screening to assess memory, thinking ability, and reasoning, in conjunction with a thorough neurological examination. Brain imaging may detect blood vessel changes that can relate to vascular dementia.
	Known Risk Factors: • History of heart disease and stroke • Smoking • Poorly managed diabetes • Obesity and lack of exercise Hypertension and high cholesterol
	Diagnostic Criteria
Wernicke-Korsakoff syndrome	**Characteristics:** Wernicke-Korsakoff syndrome 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 Acquired Immune Deficiency

Attachment B - Summary of Alzheimer’s Disease and Related Dementias

Diagnosis	Diagnostic Criteria
	Syndrome, chronic infections, malnutrition, or other medical conditions. Wernicke-Korsakoff syndrome 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	**Symptoms:** • Memory problems, both recent recall and long-term, accompanying intact higher level cognitive and social skills • Difficulty learning new information • Tendance 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 *(continued)*	**Diagnosing:** Wernicke-Korsakoff syndrome 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 Acquired Immune Deficiency Syndrome, 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
ADRD	Alzheimer’s disease and related 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
BOLD	Building Our Largest Dementia Infrastructure
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	NAPA
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 Children 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
SNALR	Special Needs Assisted Living Residence
TBI	Traumatic Brain Injury
WHO	World Health Organization
WKS	Wernicke-Korsakoff syndrome