



State of Illinois
Illinois Department of Public Health

State of Illinois Alzheimer's Disease Plan

Pursuant to Alzheimer's Disease Assistance Act (410 ILCS 405)
2026–2029 Report and Recommendations

January 2026

Table of Contents

Overview	3
A Call To Action	4
Goals Overview	5
Introduction	5
Alzheimer’s Disease and Related Disorders: Conventions	6
Impacts and Trends of Alzheimer’s Disease and Related Disorders	8
Behavioral Risk Factor Surveillance System	10
Legislative History	11
Funding Opportunities	14
Economics of Alzheimer’s Disease and Related Disorders	17
Coordination of Dementia Care Services	20
Services to Address the Needs of Persons with Alzheimer’s Disease and Related Disorders, Their Families, and Caregivers	21
State of Illinois Alzheimer’s Disease Plan	35
Workforce and Training	36
Public Education and Awareness	37
Service Delivery	40
Community Engagement, Safety, and Support	42
Data	44
Research	45
Acknowledgements	46
References	48

What is the State of Illinois Alzheimer's Disease Plan?

The State of Illinois Alzheimer's Disease Plan was established in January 2014 and is required to be revised every three years in accordance with the Alzheimer's Disease Assistance Act. The current plan is a revision of the original plan and reflects new initiatives, goals, objectives, and strategies to help strengthen dementia capability in Illinois over the next three years. Although Alzheimer's disease is the most common form of dementia, the plan is intended to include all dementias, such as vascular, Lewy body, and frontotemporal, within the recommendations.

The plan is produced by the Illinois Department of Public Health (IDPH) in conjunction with the Alzheimer's Disease Advisory Committee (ADAC), other state agencies, and relevant Alzheimer's disease stakeholders. The intent of the plan is to guide research, diagnosis, referral, support, and treatment services within each of the following areas:

- Illinois' Alzheimer's Disease Network (Regional Alzheimer's Disease Assistance Centers and Primary Provider Sites)
- State Supported Alzheimer's Disease Research
- Illinois Alzheimer's Disease Advisory Committee
- Illinois State Agencies' Alzheimer's Programs and Support (Illinois Department of Public Health, Illinois Department on Aging, Illinois Department of Human Services, and Illinois Department of Healthcare and Family Services)
- Dementia Care Services
- Dementia Specific Training Requirements
- Quality Care Measures (Skilled Nursing Facilities, Assisted Living Facilities/Supportive Living Facilities, and Other Settings)
- Geriatric-Psychiatric Services
- Home and Community-Based Resources
- Residential Options for Persons with Dementia
- Public Safety and Law Enforcement

Who is the Plan For?

The State of Illinois Alzheimer's Disease Plan is for any person, community, agency, institution, or organization that has the means and interest in helping implement recommendations outlined in the plan. The goal is to help serve persons living with dementia and caregivers impacted by Alzheimer's disease and related dementias (ADRD). This plan can also be useful for policy and decision makers to gauge what is happening in Illinois around ADRD and what still needs to be done. This plan is not a substitute for individualized work or action plans

developed by organizations or persons interested in addressing the needs of people impacted by ADRD.

How to Use This Plan?

This plan is meant “to guide” ADRD-related efforts within the state. It should be viewed as a compass shared by all the stakeholders that will give a unifying direction to their programs. The recommendations can be used to formulate specific goals, objectives, and strategies that can be pursued by individual stakeholders. Collaboration is encouraged among stakeholders to increase the effectiveness of their individual efforts.

A Call To Action

The updated goals and recommendations in the 2026-2029 State of Illinois Alzheimer’s Disease Plan are a considerable undertaking. Collaborative efforts among state agencies, community partners, and stakeholders are integral to the coordinated approach that is needed to address ADRD and increase dementia capability in Illinois. It is imperative to include the voices of individuals, care partners and families living with dementia, professionals, and stakeholders from across sectors, and those representing underserved communities. The intention of the plan is to strategize approaches that are equitable, culturally, and linguistically responsive, create meaningful change, and reduce health disparities. All Illinoisians are invited and encouraged to join in this endeavor.

Goals Overview

Workforce and Training

Develop, expand, and sustain a dementia-capable, culturally responsive workforce in Illinois.

Public Education and Awareness

Increase public awareness about brain health, risk reduction, and early detection of Alzheimer's Disease and Related Dementias with a particular emphasis in underserved communities.

Service Delivery

Increase equitable access to person-centered, coordinated, and culturally competent care, support, and therapeutic interventions for persons living with dementia, their families, and caregivers.

Community Engagement, Safety, and Support

Ensure that Illinois communities are dementia capable and prepared to respond to the needs of diverse persons living with dementia, their families, and caregivers.

Data

Identify, collect, and utilize data to assess the impact of dementia in Illinois and improve public health outcomes.

Research

Promote opportunities to expand dementia-related research and support the translation and dissemination of research findings with an emphasis on maintenance of cognitive health, prevention of dementia, early diagnosis, and personalized intervention.

Introduction

According to the 2024 Illinois Alzheimer's statistics, there were 250,000 people over 65 years of age living with Alzheimer's disease or a related dementia in Illinois. Simultaneously, there is an increasing shortage of direct care providers in the aging, disability, and public health networks. This same source cites approximately 311,000 Illinois caregivers provided more than 480 billion hours of care to someone living with dementia. The unpaid value of care is more than \$9.8 billion.

Alzheimer’s disease and related dementias are not limited to a particular race, marital status, country of origin, religion, or sexual preference. Nationally, the cost of caring for those with ADRD in 2022 is estimated to total \$321 billion (including \$206 billion in Medicare and Medicaid payments combined) and is expected to increase to \$1 trillion (in today’s dollars) by mid-century. This dramatic rise includes a three-fold increase both in government spending under Medicare and Medicaid and in out-of-pocket spending.

Throughout this plan, recommendations are provided for new policies to address Illinois’ response to ADRD. These recommendations can be achieved through close collaboration among both private and public partnerships. Regulatory changes can be made to better support those living with dementia and their caregivers, as well as to support and continue developing the state’s essential dementia infrastructure. These action steps are designed to ensure Illinois becomes a “dementia-capable state,” as defined in the Alzheimer’s Disease Assistance Act (410 ILCS 405), meaning Illinois and its long-term care services, community-based services, and dementia-support systems have:

- The ability to identify people with dementia and their caregivers.
- Information, referral, and service coordination systems that provide person-centered services to persons living with dementia and their caregivers.
- Eligibility criteria for public programs that are equitable for persons living with dementia.
- Coverage of services that persons living with dementia and their caregivers are likely to use.
- A professional caregiving workforce that is knowledgeable about ADRD and how to serve that population and their caregivers.
- Quality assurance systems that consider the unique needs of people living with dementia and their caregivers.

The Alzheimer’s Disease Advisory Committee (ADAC) recognizes that continuing to work closely with members of the General Assembly will be critical to educate the legislature and the people of Illinois on the importance of ensuring a dementia-capable state. Together, strategies will be identified to move the state forward in crafting a better response to the growing public health crisis of ADRD.

Alzheimer’s Disease and Related Disorders: Conventions

In this plan, Alzheimer’s disease is often used as shorthand for the term “Alzheimer’s disease and related disorders,” or “Alzheimer’s Disease and Related Dementias (ADRD).” Alzheimer’s disease also includes mild cognitive impairment. As the field is rapidly advancing, the definitions are evolving because of scientific learning. For consistency with the intent of the General

Assembly through the implementation of the Alzheimer’s Disease Assistance Act and for the greatest impact on the residents in Illinois, the recommendations in this State of Illinois Alzheimer’s Disease Plan are for ADRD and not just Alzheimer’s disease.

ADRD are the conditions leading to the constellation of signs and symptoms described by the term dementia. As defined in the Alzheimer’s Disease Assistance Act, dementia is a “general term for cognitive decline caused by various diseases and conditions that result in damaged brain cells or connections between brain cells.” There is a decline in cognitive function, along with physical function and behavior, from a previous level of functioning. Dementia represents the transition when cognitive function prevents an individual from carrying out customary activities at work or home.

Alzheimer’s disease is one of many conditions that can result in dementia. It happens to be the most common dementia seen in old age. It is an irreversible, progressive brain disease and is fatal. Eventually, the person with Alzheimer’s disease is completely reliant on others for assistance with the most basic activities of daily living, such as eating. It is characterized by cognitive decline (e.g., memory loss, confusion, and poor reasoning), behavioral and psychiatric disorders (e.g., depression, delusions, agitation), and declines in functional status (e.g., ability to perform activities of daily living and self-care). The hallmarks of Alzheimer’s disease are the accumulation of abnormal proteins in the brain: clumps of beta-amyloid (called amyloid plaques) and tangled bundles of tau fibers (called neurofibrillary tangles). Most experts now agree that the accumulation of plaques and tangles in the brain may begin 20 or more years before the symptoms of dementia appear.

The causes of Alzheimer’s disease are not completely understood, but researchers believe they include a combination of inherited risk factors, environmental influences, medical conditions (such as heart disease or diabetes), and lifestyle circumstances. The importance of any one of these factors in increasing or decreasing the risk of developing Alzheimer’s disease may differ from person to person. In more than 90% of people living with Alzheimer’s disease, symptoms do not appear until after age 60 and the incidence of the disease increases with age. In rare cases, known as early or younger-onset Alzheimer’s disease, people develop symptoms in their 30s, 40s, or 50s. In a still smaller group, the disease is inherited through a genetic mutation and almost always starts during early to mid-adulthood. The proportion of Alzheimer’s disease caused by genetic mutations is less than 5%. Many current studies are investigating the benefits of exercise, diet, and other lifestyle modifications that may prevent or delay the onset of Alzheimer’s disease, including the recently published US Pointer Study that performed a randomized trial of over 2000 at-risk adults that showed lifestyle interventions slowed the progression of cognitive decline.

Dementia is also caused by other known and yet undefined diseases and conditions in the brain. Three common neurodegenerative causes are vascular disease, Lewy body dementia, and frontotemporal degeneration. Some of these, such as frontotemporal degeneration, start at a

much younger age when a person is in their 50s and early 60s, and can impair language or behavior, while leaving memory intact. Determining whether a dementia is caused by Alzheimer's disease, or another cause used to be difficult. There are now biomarkers obtained through blood draw, spinal tap, or brain imaging that can make these distinctions and determine the major cause of the dementia. Researchers now also recognize that many of these diseases and conditions can co-occur in the brain and work together to influence the onset of dementia.

Impacts and Trends of Alzheimer's Disease and Related Disorders

Approximately 6.7 million Americans were living with ADRD in 2023, including approximately 200,000 people under the age of 65. There are approximately 250,000 individuals with Alzheimer's in Illinois. The Alzheimer's Association estimates 7.2 million individuals live with Alzheimer's in 2025, with 74% of those being age 75 or over. Of these 7.2 million, over 60% are women. About 12% of people aged 65 or older have Alzheimer's dementia. It is projected that the number of people with this disease may double or even triple by 2060, barring a major medical breakthrough. ADRD are not diseases limited to a particular race, marital status, country of origin, religion, or sexual preference; however, there are disparities in incidences that are known.

The US Department of Health and Human Services' 2024 National Plan to Address Alzheimer's Disease identifies that:

- Older Blacks are about twice as likely to have Alzheimer's or other dementias as older Whites.
- Older Hispanics are about one and one-half times as likely to have Alzheimer's or other dementias as older Whites.
- 54% of American Indian and Alaska Native (AI/AN) populations age 70 and older experience cognitive impairment.

In addition to these at-risk populations, the Health Brain Initiative 2023-2027 Road Map lists women, lower socioeconomic status, and lower education levels are more impacted populations. It also reveals that health disparities, health care disparities, and discrimination impact Alzheimer's and dementia care, as well as the following:

- More than one-third of Blacks, and nearly one-fifth of Hispanics and Asian Americans, believe discrimination would be a barrier to receiving Alzheimer's care.
- Just under half (49%) of Native Americans believe they have access to culturally competent care.
- Those experiencing racism have led to a decline in cognition and delayed diagnosis, resulting in loss of benefits from early diagnosis and intervention.

- LGBTQ+ individuals also face discrimination and barriers to care and support, with transgender and non-binary individuals having 4.5 times increase likelihood of cognitive decline.
- Most caregivers are women, with 73% caregiving for more than 40 hours a week and 63% of women who are providing caregiving services for more than 5 years. This gives women a disproportionate burden of lost employment, income, and stress.
- Individuals with intellectual and developmental delays face barriers in care and are many times underdiagnosed or misdiagnosed while developing Alzheimer's at an earlier and greater rate than other adults.

Data collected through the 2023 Cognitive Decline module of the Illinois Behavioral Risk Surveillance Survey showed nearly 15% of Illinoisans have worsening difficulties with thinking and memory and of those, 60% were worried about it but only 40% have discussed this with their healthcare provider. This discussion rate is only slightly higher than the 36% who say their impaired cognition interferes with their day-to-day activities; it matches those reporting that they experience functional disability due to cognitive decline. Demographic information for those reporting difficulties with thinking and memory verifies that cognitive impairment impacts all groups. There are slightly higher rates in the Black, Non-Hispanic population. Females are also impacted at a slightly higher rate, 15% over 14% of males. There does seem to be a stronger incidence in lower income, with 42% of those reporting making less than \$35,000 per year and 22% having less than a high school education.

While the number of deaths attributed to most major diseases saw little change and some even declined between 2000 and 2022 – breast cancer (increased by 0.9%), prostate cancer (increased by 7.4%), heart disease (declined by 1.1%), stroke (declined by 1.4%), and HIV (declined by 65.9%) – ADRD deaths climbed, increasing 142.4%. Deaths related to Alzheimer's or Dementia are difficult to tally due to differences in the way deaths are recorded. Nationally, there were over 290,000 deaths listing dementia as a cause of death, with 120,000 of those specifically listing Alzheimer's. In 2021, Alzheimer's was the seventh leading cause of death nationwide, with 4,025 deaths from ADRD in Illinois. ADRD kills more Americans than breast cancer and prostate cancer combined. Nationwide Alzheimer's deaths fell to seventh in 2020 and 2021 due to the COVID-19 pandemic.

In recent years, extensive research has led to the FDA approval of therapeutics to be used by individuals in the early stages of Alzheimer's to slow the progression of symptoms and improve the quality of life for people with ADRD, their families, and their caregivers. With appropriate resources, research will be needed to determine efficacy in later stages and in diverse populations. Even with the development of therapeutics, the goal is a cure or prevention for the disease.

The need to diagnose ADRD earlier, even before individuals experience symptoms, has spawned research and development of blood testing that checks for biomarkers that are known

to be present in individuals with Alzheimer's. Testing for biomarkers could be a more reliable indicator of a treatment response in drug studies and is not subject to the inherent variability of cognitive testing and reduces additional radiation exposure from brain scans.

Another profound development in the care of persons living with dementia is the realization that compared to all diseases, ADRD incurs the highest societal cost. Persons living with dementia often require transitions to nursing homes or assisted living facilities and family members may have to leave the workforce to provide care. Although most persons living with dementia are of retirement age, some are younger than 65 years of age, and a diagnosis of dementia often necessitates dropping out of the workforce as well.

There is also a greater emphasis on the health and well-being of the caregivers of persons living with ADRD. ADRD often claims two individuals: the person living with dementia and their caregiver, particularly if the caregiver is the spouse or partner. It is often the spouse/partner that suffers the most, dealing with the behavioral and caregiving requirements of the person living with dementia, who may lack awareness of their impairment (a common symptom of dementia) and, as a result, may challenge the family's attempts to provide assistance. The ADRD research community is making greater investments into methods to identify and address caregiver stress, and to improve the quality of life for both the person living with dementia and the caregiver.

The 2021 Illinois Behavioral Risk Factor Surveillance System Caregiver module estimates that over 16% of Illinois residents provide regular care for a family member or friend. The majority of these caregivers are caring for a family member, either a spouse or partner (19%) or another family member (67%). Most of those reporting are caring for individuals without dementia, with only 7% of those surveyed caring for someone with dementia or other cognitive impairment. Because of the small number caring for dementia, it is difficult to apply demographic information specific to cognitive impairment caregivers.

Behavioral Risk Factor Surveillance System

The Behavioral Risk Factor Surveillance System (BRFSS) is a data system that provides information on behaviors and conditions related to the leading causes of death, injury, and disability. BRFSS is a joint effort of the Centers for Disease Control and Prevention (CDC) and state health departments. In Illinois, BRFSS surveys are conducted as random-dialed telephone interviews of adult residents throughout the state. BRFSS questions are scripted and conducted by trained interviewers. BRFSS data are used to identify the need for services, to target populations at greatest risk, to evaluate past efforts, and to guide health policy decisions.

A unique feature of BRFSS is the ability to generate specific data related to specific question responses. Two "optional" BRFSS modules are related to cognitive impairment and caregiver

activity. The BRFSS Cognitive Decline module measures subjective cognitive decline (SCD) and its associated effects on function and daily living. The BRFSS Caregiver module is designed to provide information about persons who self-identify as caregivers and provide some form of care to another person with a health problem or disability. The BRFSS Cognitive Decline module was included on the Illinois statewide survey in 2020. It was also asked on the Illinois County Behavioral Risk Factor Survey (IL BRFS) between 2015-2019. In addition, the caregiving module was completed in the statewide 2021 BRFSS survey and the cognitive decline module was completed in the statewide 2023 survey.

IDPH used BRFSS state and county data in 2024 to develop two burden updates. One burden brief focuses on those reporting Subjective Cognitive Decline (SCD), including characteristics of prevalence, general health measures, impact on daily living, and status of talking with a health professional. The county survey data from 2015-2019, which included cognitive questions, was used for this Burden brief had a sample size of just over 23,000 for adults 45 years and older. The second brief is specific to caregiver characteristics and commitments, and the 2021 statewide BRFSS caregiver data were used for this report. Burden briefs are published and accessible on the Publications section of the Illinois Department of Public Health's [Alzheimer's Disease webpage](#).

Legislative History

Illinois has been a leader for many years in addressing Alzheimer's disease and related dementias (ADRD). In 1984, the House Appropriations Committee and the Legislative Research Unit collaborated on a major conference that generated an 11-bill legislative package, which became known as the "Alzheimer's Initiative" and was approved unanimously in 1985. A key component of the legislative initiative was the Alzheimer's Disease Assistance Act (410 ILCS 405). The legislation required that by January 1, 1987, and every three years thereafter, IDPH prepares an Illinois Alzheimer's Disease Assistance Plan in consultation with the Illinois Alzheimer's Disease Advisory Committee (ADAC) to guide research, diagnosis, referral, and treatment services within each service area described by IDPH; provide oversight of three regional Alzheimer's disease assistance centers (ADA centers), including their primary provider sites (PPS); and coordinate Alzheimer's Disease Research Fund (ADRF) grants.

In 2003, a legislative task force on Alzheimer's disease was created (HJR 14) to obtain a snapshot of the current status of Alzheimer's disease activities and to receive updated information and recommendations for ensuring Illinois would be able to respond to the rise in the number of people affected by the disease.

In 2007, the General Assembly passed Senate Joint Resolution 43 (SJR 43), recommending IDPH, in partnership with the ADAC, prepare a report addressing the impact of Alzheimer's disease

and related dementias in Illinois and the resources and services needed to improve the state's capacity to address the disease.

In 2012, the Alzheimer's Disease Assistance Act was amended (P.A. 97-0768) to include revised state plan requirements to reflect a more dementia capable state. The plan was submitted to the Office of the Governor and the General Assembly by January 1, 2014, as required by the act.

Additionally, the State Adult Protective Services Act was amended to include people living with Alzheimer's disease (P.A. 99-143) and Illinois created specialty license plates for Alzheimer's disease awareness (P.A. 98-0259).

In 2015, the Illinois General Assembly passed legislation (P.A. 99-0322) to create the Silver Search program, as part of the Endangered Missing Persons Advisory statutes. The program, which began in 2016, is a coordinated effort to bring awareness, education, and resources to help find and safely return people with Alzheimer's or other dementias who go missing. The Silver Search program strives to bring awareness to the increasing incidences of people with Alzheimer's or other dementias who get lost and ways in which the public can help law enforcement return them home safely.

In 2016, the General Assembly passed the Alzheimer's Disease and Related Dementia Services Act (P.A. 99-0822) that established minimum training requirements for employees of organizations and facilities that provide Alzheimer's and other dementia-related services. Rules implementing this act were promulgated in 2019. The sunset provision of the act was eliminated in 2022 with the passage of P.A. 102-0747.

The enacted 2018 hospital assessment legislation (P.A. 100-0581) approximately tripled funding available for Alzheimer's research at the three Illinois regional ADA centers to \$10 million annually. This \$10 million in annual Alzheimer's disease research funding was renewed in subsequent hospital assessment legislation in 2020 (P.A. 101-0650) and 2022 (P.A. 102-0886).

In 2019, the General Assembly passed legislation (P.A. 101-0588) authorizing the creation of a dementia coordinator position within IDPH. This position is responsible for the implementation of the State of Illinois Alzheimer's Disease Plan and coordinates resources for Alzheimer's and other dementias across state agencies. The first dementia coordinator started work in February 2021. The act also changed the membership structure for the Alzheimer's Disease Advisory Committee from 16 to 17 members and redirected ADRF funding to support the work of the new dementia coordinator in administering data collection and implementing the state plan.

In 2021, legislation was enacted to require at least one hour of dementia training for health care providers who have direct patient interactions with adults aged 26 and older, including physicians, nurses, and other health care providers licensed through the Illinois Department of Financial and Professional Regulation (P.A. 102-0399). Training must be completed as part of

existing continuing education requirements for license renewals beginning January 1, 2023. A similar one-hour dementia training requirement is part of re-licensure requirements for paramedics and emergency medical technicians (EMTs) licensed by the Illinois Department of Public Health was enacted in 2022 and was implemented beginning January 1, 2023 (P.A. 102-0772).

Additional professional training requirements were also enacted through legislation, including those for Adult Protective Services (APS) caseworkers in 2021 (P.A. 102-0004) and Community Care Program (CCP) direct services staff in 2022 (P.A. 102-1020). Both APS and CCP workers are required to take two hours of dementia training annually.

In 2023, the General Assembly passed legislation (P.A. 103-0064) to further expand dementia training mandates to all guardians. The legislation requires public guardians to take one hour of annual dementia training. Existing required training upon appointment for private guardians must also include content on dementia.

Medicaid coverage for the Alzheimer's diagnosis and care planning billing code CPT 99483 was also enacted legislatively in 2023 (P.A. 103-0102). This ensures that financial limitations no longer prevent families from receiving diagnostic and care planning services.

The General Assembly acted in 2024 (P.A. 103-0908) to create an advance directives registry, which would include POLST forms. This registry will be hosted by the Secretary of State and will be operational by January 1, 2027, allowing paramedics and healthcare professionals to have access to an individual's advance directive form in an emergency, regardless of healthcare setting.

With FDA-approved Alzheimer's treatments to slow the progression of the disease now available and many more on the horizon, the General Assembly acted to expand access to these treatments. In 2024, legislation (P.A. 103-0975) was passed requiring insurance coverage in state employee health insurance plans starting January 1, 2026.

This coverage mandate was expanded by 2025 legislation (P.A. 104-0001) to include all state-regulated insurance plans starting January 1, 2027. Illinois is the first state in the nation to require insurance coverage for Alzheimer's treatments.

Illinois Alzheimer's Disease Advisory Committee

The Alzheimer's Disease Advisory Committee (ADAC) was established through the Alzheimer's Disease Assistance Act and consists of 17 voting members and five non-voting members appointed by the IDPH director. The directors of the following state agencies, or their designees, serve as nonvoting members: Department on Aging, Department of Healthcare and

Family Services, Department of Public Health, Department of Human Services, and the Guardianship and Advocacy Commission.

Appointed members include persons experienced in research and the delivery of services to individuals with Alzheimer's disease or a related disorder and their families. Per the act, the membership structure shall include:

- (1) One individual from a statewide association dedicated to Alzheimer's care, support, and research.
- (2) One individual from a non-governmental statewide organization that advocates for seniors.
- (3) Dementia coordinator of the Illinois Department of Public Health, or the coordinator's designee.
- (4) One individual representing the Community Care Program's Home and Community Services Division.
- (5) One individual representing the Adult Protective Services Unit.
- (6) Three individuals from Alzheimer's Disease Assistance Centers.
- (7) One individual from a statewide association representing an adult day service organization.
- (8) One individual from a statewide association representing home care providers.
- (9) One individual from a statewide trade organization representing the interests of physicians licensed to practice medicine in all of its branches in Illinois.
- (10) One individual representing long-term care facilities licensed under the Nursing Home Care Act, an assisted living establishment licensed under the Assisted Living and Shared Housing Act or supportive living facilities.
- (11) One individual from a statewide association representing the interests of social workers.
- (12) One individual representing Area Agencies on Aging.
- (13) Medicaid director of the Illinois Department of Healthcare and Family Services, or the director's designee.
- (14) One individual from a statewide association representing health education and promotion and public health advocacy.
- (15) One individual with medical or academic experience with early onset Alzheimer's disease or related disorders.

The ADAC reviews programs and services provided by state agencies directed toward persons with ADRD, and, by consensus, recommends changes to improve the state's response. ADAC's recommendations are reflected throughout this state plan.

Funding Opportunities

Illinois has had opportunities to improve its ability to meet the needs of persons with ADRD

because of an increased focus and advancements at the federal level during the last state plan. Consequently, Illinois has capitalized on this competitive space to attract those funds and expand Dementia capacity in the State of Illinois. After being granted the BOLD grant from CDC, three Dementia partners have been funded to improve education about Alzheimer’s Disease and Related Dementias, as outlined in the 2023-2026 plan and this current plan. Some of the state plan recommendations lay the groundwork to support ideas to help Illinois be more competitive in applying for federal funding.

In January 2025, potential payment freezes on current contracts threatened the continuation of funding these vital programs. Delayed notice of grant continuations for FFY26 also pose challenges of uncertainty for the longevity and financial support of these projects moving forward.

In March 2022, Congress finalized and President Joseph Biden signed into law a \$289 million increase for Alzheimer’s research funding at the National Institutes of Health (NIH) for the federal fiscal year 2022, bringing the total funding to more than \$3.5 billion. Congress also finalized \$25 million for implementation of the BOLD Infrastructure for Alzheimer’s Act at CDC, which is a \$10 million increase over the FFY2021 level. NIH is requesting an additional \$226 million for Alzheimer's research in FFY2023. Over the last decade, these increases have been advocated for by the Alzheimer’s Association and the Alzheimer’s Impact Movement (AIM) and reflect an eight-fold increase. Billions of dollars are also being spent through other United States funding streams and biotech companies. These funds will allow the NIH to accelerate investment in collaborations that speed discovery, groundbreaking prevention trials, and the testing of new therapeutics.

The federal government has become more invested in ADRD research and the optimal treatment and care of both ADRD patients and their caregivers with the passage of the National Alzheimer’s Project Act of 2011 (NAPA). The first National Plan to Address Alzheimer’s Disease was published in May 2012. The goals of the plan have been to prevent and to effectively treat ADRD by 2025, to enhance care quality and efficiency, to expand support for people with the disease and their families, to enhance public awareness and engagement, to track progress, and to drive improvement. The federal government has committed more than \$50 million to achieve these goals. The national plan was updated in 2013 to include new federally supported programs available to states and organizations to foster research and to improve the care of patients and caregivers and was updated again in December 2021, adding a new national goal focusing on healthy aging and risk factor reduction for cognitive decline and dementia. HHS released another update in 2024 that prioritizes support for individuals with Dementias and their caregivers. In 2024, Congress passed the NAPA Reauthorization Act, as well as the Alzheimer’s Accountability and Investment Act, to continue the work of the National Plan to Address Alzheimer’s Disease to support Alzheimer’s research. This reauthorization extends the legislation through 2035.

In addition to the creation of the National Plan to Address Alzheimer’s Disease, NAPA also directed the U.S. Department of Health and Human Services (HHS) to create and convene the Advisory Council on Alzheimer’s Research, Care, and Services, which includes a combination of federal agency representatives and non-federal members, to oversee implementation of the national plan. The advisory council released the most recent update in 2024. Over the years, there have been additional achievements that have been supported by the national plan and advisory council. These include the HOPE for Alzheimer’s Act, the BOLD Infrastructure for Alzheimer’s Act (P.L. 115-406), the Younger Onset Alzheimer’s Disease Act, the Promoting Alzheimer’s Awareness to Prevent Elder Abuse Act (P.L. 116-252), and the Improving HOPE for Alzheimer’s Act. There has been progress, but there is more to be done.

In 2018, the bipartisan BOLD Infrastructure for Alzheimer’s Act (P.L. 115-406) was unanimously passed with the intention of establishing a public health infrastructure across the country to implement effective Alzheimer’s interventions focused on public health issues, such as increasing early detection and diagnosis, reducing risk, and preventing avoidable hospitalizations. The act established the Related Dementias Public Health Centers of Excellence; provided funding to state, local and tribal public health departments; and increased data analysis and timely reporting. The Centers for Disease Control has offered funding to support the Bold Act over five years to carry out various public health activities addressing Alzheimer’s and other dementias. While Illinois was not a recipient of BOLD funding initially, it was awarded the grant in 2023, giving opportunities to expand dementia capabilities in the State of Illinois.

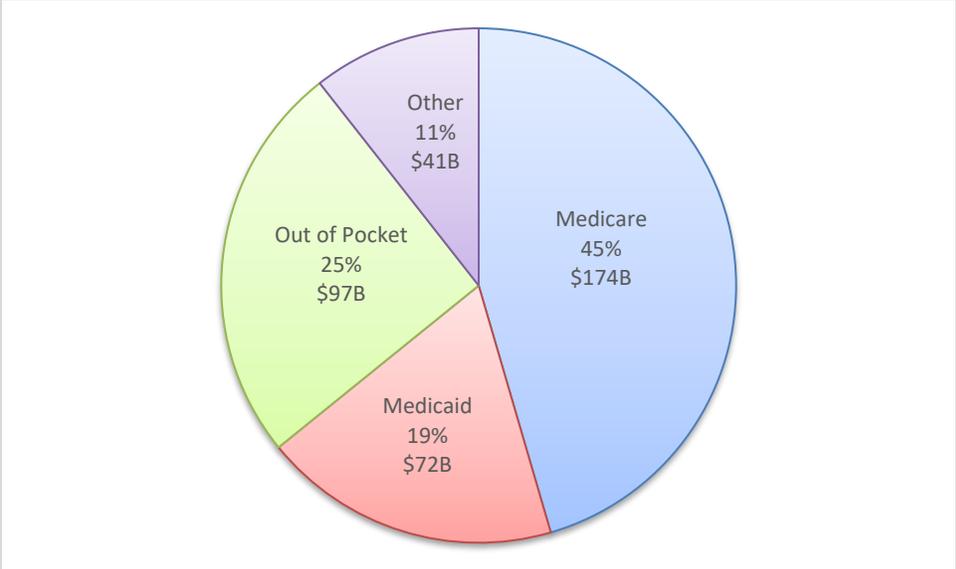
In addition to BOLD funding, other opportunities exist, including:

- Over the last decade, the Alzheimer’s Association has successfully advocated for dramatic increases in the research appropriations at NIH.
- Billions of dollars are also being spent on dementia research from biotech companies.
- The state’s Regional Alzheimer’s Disease Assistance Centers (RADAC) are uniquely placed to provide guidance regarding improvements to respond to ADRD and to support those dealing with Alzheimer’s disease.
- The state’s regional ADACs address clinical needs and enhance the awareness of the disease through research activities.
- Organizations, such as the Alzheimer’s Association, provide information, resources, support, and other services to people with ADRD, to their families, to caregivers, and to professionals. The organizations also advocate for the needs of people with Alzheimer’s disease.
- Public/private partnerships, such as that of IDPH and the Alzheimer’s Association, are beneficial to assess the needs of people with cognitive impairment and caregivers using Illinois BRFSS data.
- The General Assembly allocated \$2 million in FY26 general revenue funds for the Illinois Department of Public Health Alzheimer’s Disease Research, Care, and Support program.

Economics of Alzheimer's Disease and Related Disorders

ADRD poses a substantial financial burden on society. As the number of people living with ADRD and other dementias grows, spending for their care will increase dramatically. The total aggregate payments for ADRD health care, long-term care, and hospice in the United States in 2023 are estimated to be \$345 billion and expected to reach approximately \$1 trillion in 2050. This does not include the value of unpaid care provided by family and friends.

2025 Costs of Alzheimer's = \$384 Billion in the U.S.



The average per person Medicare costs for those with ADRD are nearly three times higher than for those without these conditions.

Source: Alzheimer's Association, 2025 Alzheimer's Disease Facts and Figures.

The table below describes the average annual per-person payments for health care and long-term care services for Medicare beneficiaries aged 65 and older with and without Alzheimer's or other dementias.

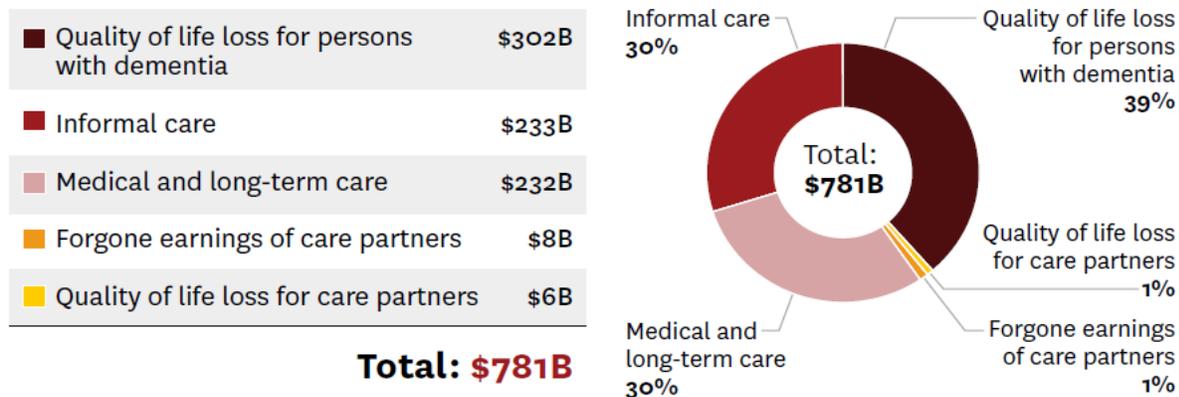
Average Annual Per-person Payments for Health Care and Long-Term Care Services, Medicare Beneficiaries Aged 65 and Older, With and Without Alzheimer’s Disease and Other Dementias, in 2021 Dollars.		
Payment Source	Beneficiaries with Alzheimer’s Disease and Other Dementias	Beneficiaries without Alzheimer’s Disease and Other Dementias
Medicare	\$21,024	\$7,576
Medicaid	\$6,478	\$291
Uncompensated	\$184	\$229
HMO	\$1,867	\$2,193
Private Insurance	\$1,468	\$916
Other Payer	\$893	\$401
Out of Pocket	\$9,844	\$2,420
Total*	\$41,757	\$14,026

Source: Unpublished data from the Medicare Current Beneficiary Survey for 2018. *Payments from sources do not equal total payments exactly due to the effect of population weighting. Payments for beneficiaries with Alzheimer’s or other dementias include payments for community-dwelling beneficiaries and beneficiaries living in residential care settings.

Caring for people living with ADRD also strains health and long-term care systems. Individuals with ADRD use a disproportionate number of health care resources. For instance, ADRD individuals are hospitalized 2-3 times as often as people the same age who do not have dementia, with 1 in 4 dementia patients having a preventable hospitalization. Similarly, while people living in nursing homes is 4% percentage of the general population age 80 and older, 75% of individuals with ADRD who are age 80 and older are nursing home residents. As the number of people with ADRD grows over the next two decades, dementia will place a major strain on these care systems, as well as on Medicare and Medicaid, the major funders of this care. In 2023, per capita Medicare spending on a person living with ADRD in Illinois was \$34,637. Additionally, in 2020, total Medicaid payments for Illinoisans aged 65 and older living with ADRD was almost \$1.8 billion. This Medicaid cost is expected to rise 23.1% to \$2.2 billion by 2025.

In 2025, AARP and The National Alliance for Caregiving partnered to create a report on caregiving in the US. It was found that 11% of the 63 million American caregivers care for someone with Alzheimer’s or dementia. In addition to the strain on health care and long-term care systems, ADRD requires significant caregiving resources. The Healthy Brain initiative of 2023-2027 cites that more than 11 million Americans provide unpaid care for people with Alzheimer’s disease and other dementias. More than two-thirds of these unpaid caregivers are women. Eighty-three percent of the help provided to older adults in the United States comes from family members, friends, or other unpaid caregivers. In 2022, caregivers of people with ADRD provided an estimated 18 billion hours of informal (i.e., unpaid) assistance, a contribution to the nation valued at \$339.5 billion. The total lifetime cost of care for someone with dementia in 2024 dollars was estimated at \$405,262. The costs associated with family care, including unpaid care and out-of-pocket expenses, make up 70% of lifetime dementia care costs, but may be underestimated compared to other expenses that may not be easily captured. In 2024, there were 311,000 caregivers in Illinois who provided 480 million hours of unpaid care, with a total value of unpaid care estimated at \$9.8 billion.

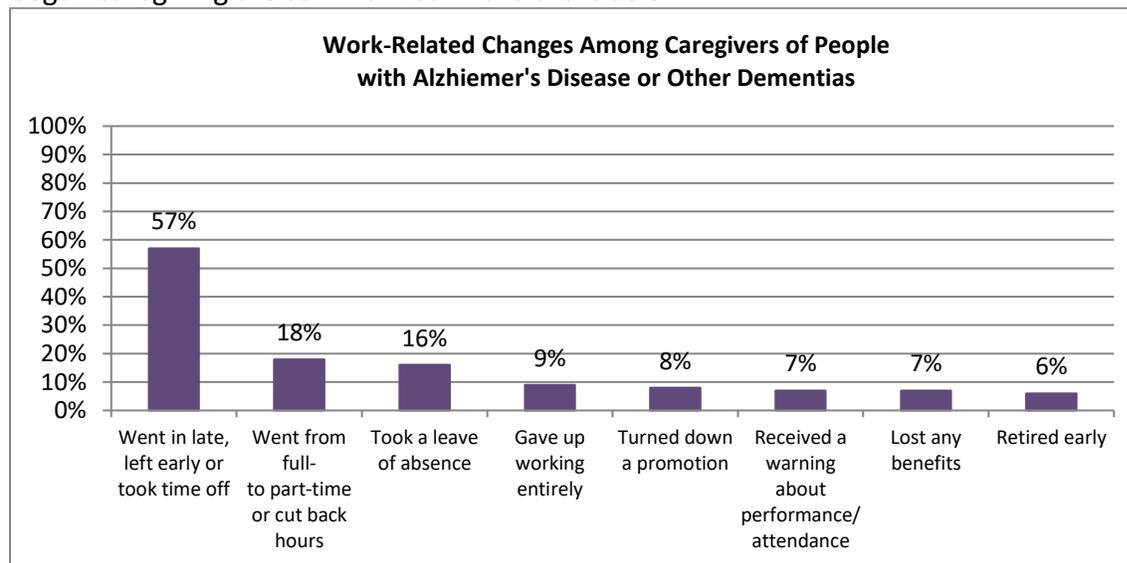
USC released an Issue Brief in April 2025 that outlined the current cost of dementia in the United States. This included multiple areas of expense for the 5.6 million Americans living with dementia and reaches an astounding \$781 billion.



Source: USC Leonard D. Schaeffer Institute for Public Policy and Government Services, The Cost of Dementia in 2025.

Effects of Caregiving on Employees and Employers

Many care contributors for people living with ADRD experience disruptions to employment because of the demands of caregiving. Among people employed at any time since they became caregivers of someone with ADRD, 9% ultimately quit their jobs to continue providing care, 57% had to go in late to work or leave early, and 16% had to take a leave of absence. Other work-related challenges for dementia caregivers who had been employed at any time since they began caregiving are summarized in the chart below.



Source: Alzheimer's Association, 2022 Alzheimer's Disease Facts and Figures.

In addition to employment disruptions, caregivers of persons living with dementia face a significant financial impact of caregiving. In 2021, caregivers reported nearly twice the average out-of-pocket costs (e.g., medical, personal care, and household expenses for the person with dementia; personal expenses and respite services for the caregiver) of caregivers of persons not living with dementia (\$12,388 versus \$6,667). Survey data from 2016 indicates 48% of caregivers reduced spending and 43% cut back on saving due to the out-of-pocket costs of providing help to someone with dementia.

Not only does caregiving take a financial toll on caregivers, but their health and well-being are also negatively impacted. In Illinois, 64.2% of caregivers have chronic health conditions and 29.0% have depression. Nationally, 74% of caregivers are concerned with maintaining their own health while they are a caregiver.

Costs to Illinois Citizens

High out-of-pocket costs are a reality for individuals living with ADRD and their caregivers, despite other sources of financial assistance. Caregivers spend \$240,000-\$280,000 out-of-pocket in the last 7 years of life for someone with Alzheimer's. Medicare beneficiaries aged 65 and older with Alzheimer's disease paid \$10,564 out-of-pocket on average for health care and long-term care services not covered by other sources.

Coordination of Dementia Care Services

Access to, and coordination of, dementia care resources are critical to ensure people living with Alzheimer's disease can experience the highest quality of life possible, to support caregivers, and to control health care costs. Often, those who are just diagnosed are not presented with information about available care options. Those living with ADRD under the age of 65 experience an especially acute need for resources. Persons living with dementia who receive care from a multitude of providers often suffer from the lack of coordination among providers, or the lack of dementia knowledge in the people treating them. This lack of knowledge leads to unnecessary emergency department visits and overuse of antipsychotic and other sedative medications. The provision of clear and coordinated services and supports is an integral part of making Illinois more dementia capable.

Public Health's Response to Alzheimer's Disease and Related Dementias

Public health is uniquely positioned to respond to ADRD. ADRD has become a growing public health crisis as the burden of dementia becomes larger and the far-reaching impacts of the disease expand. Public health protects and promotes the health of all people in all communities. Public health practices and activities offer strengths that make a public health approach to addressing ADRD important.

According to the CDC’s Alzheimer’s Disease Healthy Brain Initiative, public health has a critical role to play in promoting the cognitive functioning of adults across the life course and addressing soaring costs to health care, social, and economic systems. By applying a broad community-based approach, public health can accelerate risk reduction, advance early detection and diagnosis, and ensure safety and quality of care. The Healthy Brain Road Map provides an action agenda for the public health community by utilizing traditional tools of public health. The roadmap actions align with Essential Services of Public Health: educate and empower the nation, develop policies, mobilize partnerships, assure a competent workforce, and monitor and evaluate.

Illinois has joined a nationwide movement to mobilize a public health response to ADRD. In 2019, the General Assembly passed legislation (P.A. 101-0588) authorizing the creation of a dementia coordinator position within the Illinois Department of Public Health (IDPH). In February 2021, a full-time dementia coordinator joined the IDPH Office of Health Promotion, Division of Chronic Disease. The coordinator’s top priorities are to implement activities related to the strategies and recommendations of the State of Illinois Alzheimer’s Disease Plan, coordinate resources across state agencies, strengthen partnerships with community stakeholders and partners, and coordinate statewide efforts that increase awareness of ADRD with improved access to high-quality services. Additionally, promoting and supporting consistent, collaborative efforts between state agencies, community partners, and stakeholders is integral to the coordinated approach that is needed to address ADRD and increase dementia capability in Illinois.

Services to Address the Needs of Persons with Alzheimer’s Disease and Related Disorders, Their Families, and Caregivers

Illinois’ Alzheimer’s Disease Network

Regional Alzheimer’s Disease Assistance Centers

A Regional Alzheimer’s Disease Assistance Center (RADAC) is considered the top tier of dementia care, providing diagnostic evaluation, treatment, referral, and research. A RADAC must be a postsecondary higher educational institution having a medical school affiliated with a medical center and having an NIH and NIA sponsored Alzheimer’s Disease Core Center. Any regional ADAC that was previously designated as having a National Alzheimer’s Disease Core Center but no longer carries said designation, can continue to serve as a RADAC. RADACs are staffed by a network of physicians, medical specialists, social workers, nurses, educational specialists, and research scientists with expertise in dementia care and research. RADACs provide comprehensive diagnosis and treatment facilities and services; consultation and referral service for individuals living with ADRD and their families; research programs and facilities; training, consultation, and continuing education for caregivers; centralized data collection, processing, and storage; and ADRD scientific and medical research programs.

The RADACs, funded by the Illinois Department of Healthcare and Family Services (HFS), in Illinois are:

- *Northwestern Alzheimer’s Disease Assistance Center (NADAC) for Northern Illinois, Northwestern University Feinberg School of Medicine, Chicago*

In 2024, the clinic is staffed by a multidisciplinary team of 6 behavioral neurologists, 6 neuropsychologists, 2 neuropsychiatrists, 3 social workers, 1 social work fellow, and 1 nurse. There were 851 new and 2,990 return patients seen in the Neurobehavior and Memory Clinic for a total of 3,841 patient visits. NADAC offered three monthly online care partner support groups: Younger Onset, Primary Progressive Aphasia (PPA), and Frontotemporal Dementia (FTD). The Younger-Onset sees an average of 8 care partners per month and FTD sees an average of 10 participants per month. The PPA group had an average of 31 participants each month and is divided into early, moderate, and advanced stage breakout rooms.

Fourteen CME-approved Roundtable Series were offered, with an estimated 35-40 participants each session. The 30th Annual Alzheimer Day was held May 3, 2024. The Northwestern University Mesulam Center for Cognitive Neurology and Alzheimer’s Disease News produces an annual 25+page print newsletter directed to over 8,000 patients, families, health and social service professionals and the general community; during FY24, the e-newsletter *Connections* reached 4,875 recipients. The Northwestern ADAC/Mesulam Center maintains a website directed to professionals as well as the public. The site contains pages for caregivers, healthcare providers, investigators, and patients. Scheduled educational events are listed, center research is described, and funding opportunities are highlighted and the Neurobehavior and Memory Clinic is featured, and contact information is provided. During this fiscal year, there were over 63,000 users and over 79,000 sessions accessed in total. The Northwestern ADAC/Mesulam Center holds active Twitter(X) and Facebook accounts. There are 2,100 total followers and during this fiscal year, there were over 4,600 total engagements with our social media accounts. During this reporting period, the Mesulam Center Seminar Series held 7 seminars reaching 107 clinicians, research scientists, staff and students.

- *Rush Alzheimer’s Disease Center (RADC) for Northern Illinois, Rush University Medical Center, Chicago*

In 2024, RADC currently supported 17 active clinical trials, with 11 being intervention trials, funded by federal, foundation, and industry partners. Some of these are treatment trials of patients with Alzheimer’s disease (AD) or Mild Cognitive Impairment (MCI) who sought care at the Rush Memory Clinic. Rush has five ongoing community-based cohort studies that enroll older persons without dementia and focus on the prevention of Alzheimer’s disease and other common chronic conditions of aging through identification of risk factors. These include the Religious Orders Study, which is conducted across the USA, and the Rush Memory and Aging

Project, the Minority Aging Research Study, the African American Clinical Core, and the Latino Core, all of which cover Cook and the collar counties. Together, these studies have enrolled and followed more than 5,550 older persons, including about 1,330 non-Latino Black adults and 490 Latinos. To enhance diversity, the RADAC also runs a research project in Brazil, the Pathology Alzheimer's and Related Dementias Study. To date, we have collected more than 4200 brains from persons aged 18-105, 40% Black and 47% female, with a mean education of 6 years.

- *Southern Illinois University (SIU), School of Medicine, Smith Center for Alzheimer's Research and Treatment, Springfield*

The Smith Alzheimer's Center serves 93 counties, the average percentage of people with Alzheimer's disease per county is 11.0%, which is slightly higher than the national average of ~10.7%, according to the Alzheimer's Association 2023 Alzheimer's disease Facts & Figures. In FY24, the Smith Alzheimer's Center saw 571 new patients. The number of dementia patients seen after the first evaluation during this year was 1671. In FY24, the Memory and Aging Network primary partner sites performed assessments with 68 new patients with 173 follow-up visits. During FY24, the Smith Alzheimer's Center researchers were involved in 24 studies. Of these, 14 were investigator-initiated bench science and clinical studies supported by the Smith Alzheimer's Center, the Alzheimer's Association, and the National Institutes of Health. The remaining 10 studies were industry-sponsored clinical trials. The Smith Alzheimer's Center team produced 18 peer-reviewed publications in well-respected journals and 14 abstracts resulting in posters and oral presentations at regional, national, and international conferences and meetings. The research team consisted of 9 faculty/staff and 32 research members. The Beyond the Medical Center programs offer non-pharmacological programs and support services for people with dementia and their caregivers. Current offerings include Art Express, Dementia Caregiving 101, Stepping Up, Minds in Motion, Early-Stage Memory Loss Support Group, Music and Memory, MIND Diet Cooking Classes, and Building Moments Lego Program. In FY24, 1,372 people with memory loss, 1,347 caregivers attended Beyond the Medical Center programs (Note: Touchpoints consist of the total number of attendees, not necessarily unique individuals). The Memory and Aging ECHO project offers community professionals virtual education and access to the Smith Alzheimer's Center dementia and gerontology experts, primarily targeting those living and practicing in rural areas that often experience decreased access to specialized care. There were 73 distinct participants in ECHO in FY24. The Smith Alzheimer's Center's team provides dementia related presentations throughout the year for a variety of audiences at various conferences and events. This includes health care professionals, social service providers, clinicians, patients, caregivers and families. In FY24, the Smith Alzheimer's Center provided 83 educational opportunities.

ADA Center Primary Provider Sites (PPS)

PPS are community-based medical programs that work directly with RADAC staff who have the expertise to diagnose, treat, and make referrals for patients with dementia symptoms, and to provide supportive services to their families. The concept of PPSs evolved because of the need for accessible diagnostic and treatment centers throughout the state, in addition to the three

regional ADACs. Rush and Northwestern serve the Chicago metropolitan area, which includes Cook, DuPage, Grundy, Kane, Kankakee, Lake, McHenry, Kendall, and Will counties. The Smith Alzheimer’s Center serves the remaining 93 counties.

State Supported Alzheimer’s Disease Research

State law requires the Illinois Alzheimer’s Disease State Plan to address the “level of state support of Alzheimer’s research through Illinois universities or other institutions, and the results of such investments reflected both in research outcomes and subsequent federal investment in research.” However, it is difficult to provide specific, quantifiable data. Historically, research dollars were provided through the Alzheimer’s Disease Research Act (410 ILCS 410). The act gave IDPH the responsibility of establishing a program that awarded grants to encourage research on Alzheimer’s disease.

In 2019, the General Assembly passed legislation that amended both the Alzheimer’s Disease Research, Care, and Support Fund Act (410 ILCS 410) and the Alzheimer’s Disease Assistance Act (410 ILCS 405) with changes effective January 1, 2020. These changes authorized the creation of a dementia coordinator within IDPH. In addition to establishing and defining responsibilities of the full-time coordinator position, other significant changes to these acts included restructuring the Alzheimer’s Disease Advisory Committee membership, re-naming the fund to include “Care and Support,” adding promotion of the fund and defining use of moneys in the fund, to be directed primarily to support the dementia coordinator position and, if further funding remains, to then execute BRFSS cognitive and caregiver surveys and other data projects, and lastly to implement state plan recommendations. The state income tax check-off donation remains the source of this fund.

Home and Community-Based Resources

Home and community-based services for people with ADRD are essential for several reasons:

- These are the services preferred by most persons with ADRD and their families.
- The federal government is encouraging states to focus on home and community-based care rather than on institutional care. This has been a priority in Illinois.
- In most cases, home and community-based care is proven to be more economical than institutional care.
- In Illinois, there are growing numbers of Memory Cafés intended to provide social support for individuals living with early-stage dementia within their local community.
- Adult day care services that allow respite for caregivers during the week and increase the quality of life for the individual with dementia.
- Palliative and hospice care programs are becoming more sensitive and skilled at providing care for individuals in late and final stages of dementia.

To allow a person with Alzheimer’s disease to reside in a home or community-based living situation for as long as possible, services must be available to:

- Enable individuals diagnosed in the early stages to function safely and independently for as long as possible.
- Support caregivers – functionally, financially, educationally, and emotionally – with the provision of in-home care.

In order to provide sufficient home and community-based services that achieve these goals, it is recommended that services be standardized across human services agencies and better coordinated between publicly and privately funded entities. Furthermore, the evaluation, development, and expansion of both established and unique service models (e.g., early-stage adult day services, volunteer respite models) should be encouraged.

Residential Options for Persons with Dementia

The need for quality residential care for people with dementia greatly exceeds the current capacity for such care in Illinois. An estimated 250,000 people are living with Alzheimer’s disease in Illinois; however, Illinois only has approximately 1,200 long-term care facilities serving more than 100,000 residents and few facilities have dementia units.

People living in independent sections of a continuing care facility who later develop dementia, and their families are often reluctant to transfer to higher levels of care because of the stigma and costs involved.

The need for affordable Supportive Living Program (SLP) settings that are appropriate for people with dementia is especially acute and the availability of even costly assisted living facilities (ALFs) with dementia care does not meet the demand. There are currently 20 SLP dementia care settings with approximately 520 apartments. Another 40 communities are in various stages of development, with 33 being Dementia Care sites. Currently, there are nearly 502 total ALFs in Illinois, with approximately 69 that have Alzheimer’s care, providing 2,028 total Alzheimer’s units.

Evidence suggests people with dementia do best in the least restrictive environment that is appropriate for them. However, because most people cannot afford or obtain assisted living, they may be forced to receive care within a skilled nursing facility.

Illinois State Agencies Programs and Support

Illinois Department of Public Health (IDPH)

IDPH is responsible for implementing activities of the Alzheimer’s Disease Assistance Act (410 ILCS 405) and the Alzheimer’s Disease Research, Care and Support Fund Act (410 ILCS 410). The IDPH Dementia Program promotes dementia capability in the state through the coordination of high-quality statewide services that support the needs of people in Illinois with Alzheimer’s

Disease and Related Disorders, their families, and caregivers. The Dementia Program is housed within IDPH's Office of Health Promotion, Division of Chronic Disease. The program facilitates the director-appointed Alzheimer's Disease Advisory Committee (ADAC), which oversees the development and implementation of the Alzheimer's Disease State Plan. In 2019, the General Assembly passed legislation (P.A. 101-0588) authorizing the creation of a dementia coordinator position within IDPH.

Illinois Department on Aging (IDoA)

An important factor in Illinois' response to Alzheimer's disease has been the efforts of the IDoA to develop an infrastructure to aid persons living with dementia and their caregivers.

The Senior Help Line connects older adults, caregivers, and professionals to information and to services, including community-based services, caregiver resources, and information about how to access important services.

Adult Protective Services addresses questions of alleged abuse in domestic (non-institutional) settings, including physical abuse, sexual abuse, emotional abuse, confinement, passive neglect, willful deprivation, and financial exploitation. Changes to the Adult Protective Services Act in 2013 ensure adults with Alzheimer's disease are included in the protections afforded by this law.

The *Long-Term Care Ombudsman Program* protects and promotes the rights and quality of life for people who reside in long-term care facilities (nursing homes). This program advocates for residents by informing residents and their families of their rights; resolving complaints; providing information on residents' needs/concerns to their families, program staff, and their community; and advocating for improved standards of care.

The *Senior Health Insurance Program* is a free counseling service that answers questions regarding Medicare, Medicare supplemental insurance, Medicare advantage plans, prescription drug coverage through Medicare and other resources, prescription costs from Social Security, long-term care insurance, Medicare claims and appeals, and Medicare beneficiary rights and guarantees.

Area Agencies on Aging (AAAs) primary task is planning and coordinating services and programs included in the federal Older Americans Act and funded by the Administration for Community Living. Funding is distributed by IDoA throughout Illinois in 13 planning and service areas (PSAs). Each AAA is responsible for planning, coordinating, and advocating for the development of a comprehensive and coordinated system of services for older adults and caregivers within the boundaries of each PSA. These services include legal services, congregate meals, home modification, home-delivered meals, options counseling, family caregiver services, senior health assistance, and supportive services. This local expertise is important due to the considerable heterogeneity in services available in the various regions.

Care Coordination Units (CCUs) help older adults and caregivers determine what their specific needs are and what services are available to meet those needs. The CCUs also coordinate and integrate home and community-based services into care plans as appropriate. Care coordinators employed by CCUs assess older individuals' needs, determine eligibility for specified services, develop care plans with the consent of the older person and/or their family, coordinate service delivery, and generally manage service needs on a regular basis. The CCUs are supported through a combination of state general revenue funds and Title III federal funds.

Illinois Guardianship and Advocacy Commission

The Illinois Guardianship & Advocacy Commission (GAC) is composed of three divisions: Office of State Guardian, Legal Advocacy Service, and Human Rights Authority. Although GAC does not have programs that are specific to dementia, by the nature of the services GAC provides, GAC provides significant services to persons with dementia.

The Office of State Guardian (OSG) serves as the court-appointed guardian for adults with disabilities under the Illinois Probate Act. OSG has over 5400 wards statewide. Although OSG wards have a variety of disabilities resulting in a need for guardianship, a significant number of wards have dementia or dementia-related conditions. The guardianship services (which include making healthcare and financial decisions) provided are not specific to dementia, but when OSG is providing guardianship services for a ward with dementia, the guardianship representative will cater the services to meet the needs of the ward with dementia.

The Human Rights Authority (HRA) conducts investigations of complaints of violations of the rights of persons with disabilities. Complaints submitted to HRA relate to people with a variety of disabilities, including dementia.

OSG's goal is to provide court-appointed guardianship services. Individuals who receive guardianship services meet the requirements of the Illinois Probate Act, as determined by a circuit court. OSG is the guardian of last resort, meaning that no other person or entity is willing and able to serve as guardian. OSG serves as guardian throughout the State. OSG is authorized by the Guardianship and Advocacy Act (20 ILCS 3955/1 et seq.) and provides services pursuant to the Illinois Probate Act, primarily Article 11a on Guardians for Adults with Disabilities (755 ILCS 5/112-1 et seq.), as well as other related acts, such as the Health Care Surrogate Act (755 ILCS 40/1 et seq.), among others.

HRA's goal is to investigate complaints related to the rights of eligible recipients who receive services from certain service providers, such as mental health services. HRA is authorized by the Guardianship and Advocacy Act (20 ILCS 3955/1 et seq.). HRA operates statewide.

Illinois Healthcare and Family Services

The Illinois Healthcare and Family Services Department (HFS) administers Home and Community Based Services (HCBS) waivers that allow HFS to pay for Medicaid services in an individual's own home or a community setting, instead of an "institution," such as a skilled nursing facility. Other state agencies operate the HCBS waivers, including the Illinois

Department on Aging (IDoA), the Illinois Department of Human Services (DHS) Division of Rehabilitation Services, and the DHS Division of Developmental Disabilities. In addition, Illinois's three Regional Alzheimer's Disease Assistance Centers are funded by HFS.

HFS oversees the Supportive Living Program (SLP), an approved HCBS waiver for assisted living services. Illinois developed SLP as an alternative to nursing home care for low-income older people and people with physical disabilities ages 22-64. The goal of the program is to provide support and services to residents to enable them to maintain their independence and delay skilled nursing home admission. By combining personal care and other services, residents can live independently and take part in decision-making. Personal choice, dignity, privacy, and individuality are emphasized. The SLP operates statewide. The SLP dementia care setting program was developed in response to requests by providers and families for an affordable assisted living model for residents with dementia.

Illinois Department of Human Services (IDHS)

The Division of Rehabilitation Services operates three Medicaid Waivers collectively referred to as the Home Services Program (HSP), Persons with Disabilities, Persons with HIV/AIDS, and Persons with Brain Injury. The HSP provides services to individuals with severe disabilities so they can remain in their homes and be as independent as possible. Individuals with Alzheimer's disease and/or related dementia are not eligible for services based solely upon those diagnoses alone unless there is a clinical diagnosis of acquired brain injury and/or they receive the minimum scoring on the Determination of Need Tool used to assess an individual's functional limitations and unmet needs.

The Division of Rehabilitation Services offers additional services to individuals with severe disabilities, including vocational rehabilitation, services for people who are blind or visually impaired, and Educational Services, including the Illinois Schools for the Deaf and Visually Impaired, the Illinois Center for Rehabilitation and Education, and the Next Steps program for parents of children with disabilities. The goal of the Home Services Program is to provide support and services to individuals with severe disabilities that will enable them to maximize their independence so they can remain in their homes and not be placed in nursing facilities. Eligibility requirements include:

- Be under age 60 at the time of application, unless in the AIDS or Brain Injury 1915c HCBS Medicaid Waiver.
- Have a significant disability lasting 12 months or longer, or for the duration of life.
- Be at imminent risk of nursing facility placement.
- Have applied, cooperated and obtained a decision on Medicaid eligibility unless already on Medicaid or spend-down.
- Require services in the home costing the same or less than nursing facility costs.

- Be a State of Illinois resident with U.S. citizenship or show proof of legal entry into the United States.
- Have assets under the asset limit, which is different for individuals under age 18 and those 18 and older.
- Score the required points on the Determination of Need (DON).

HSP Medicaid Waiver Programs are authorized by the Disabled Persons Rehabilitation Act (20 ILCS 2405/3(f) and the federal Centers for Medicare and Medicaid Services (42 CFR 440.180). The goal of the Vocational Rehabilitation Program is to assist persons with disabilities in locating and retaining quality employment. Eligibility requirement:

- Between the ages of 16-64
- Must have a significant physical or mental impairment that makes it difficult to go to work.

The Vocational Rehabilitation Program is authorized by Section 3 of the Disabled Persons Rehabilitation Act [20 ILCS 2405/3(b)].

All services are available statewide. Additional training is completed for HSP staff, although not yet mandatory, and is also available to help educate people on the warning signs and effective communication strategies for individuals with Alzheimer's Disease.

Dementia-Specific Training Requirements

Many dementia-specific training requirements and recommendations have been enacted in recent years by the General Assembly.

Staff serving clients with ADRD within a skilled nursing facility, assisted living facility, home health provider, or hospice program providing Alzheimer's or dementia services are required to take six hours of initial dementia training and three hours of annual dementia training thereafter. Alzheimer's services supervisors in skilled nursing facilities and assisted living facilities are required to take 12 hours of annual dementia training and Alzheimer's services supervisors at home health providers or hospice programs are required to take eight hours of annual dementia training. Training topics are prescribed in statute and associated rules. (410 ILCS 406)

Certified nursing assistants (CNAs) are also required to take 12 hours of dementia training on the care and treatments of residents with ADRD at the start of their employment as part of their initial instruction. CNAs working in special care units are required to have an additional 12 hours of dementia-specific continuing education training each year. (210 ILCS 45/3-206(g))

Health care providers licensed through the Illinois Department of Financial and Professional Regulation (IDFPR), including physicians, nurses, physician assistants, and social workers, who have direct interaction with adult patients aged 26 and over are required to take at least one hour of training on the diagnosis, treatment, and care of individuals with ADRD as part of their continuing education requirements to renew their licenses. (20 ILCS 2105/2105-365)

Additionally, paramedics and EMTs licensed through IDPH are required to take one hour of training on the diagnosis, treatment, and care of individuals with ADRD as part of their re-licensure requirements. (20 ILCS 2310/2310-710)

Any person employed or contracted by IDoA to provide Adult Protective Services or otherwise respond to and prevent adult abuse, neglect, or exploitation is required to take two hours of annual dementia training with topics including identifying the signs and symptoms, risks, and communication best practices. (320 ILCS 20/3.1) Additionally, any person employed or contracted by IDoA to provide direct care services to individuals participating in the Community Care Program is required to take two hours of annual dementia training with topics, including ADRD, safety risks, and communication. (20 ILCS 105/4.02h)

The Illinois State Police (ISP) is required to create training on the Silver Search program to find people with dementia who wander. While this training is not mandatory for police officers, it has been incorporated into training at police academies and ISP has run a mobile unit to train officers across the state. (50 ILCS 705/10.10)

Like the Adult Protective Services training that the Alzheimer's Association helped IDoA to develop, the association collaborated in 2022 with IDoA to develop the newly mandated dementia training for providers of the Community Care Program.

In 2022, the Alzheimer's Disease Physician Early Detection Training Program launched, supporting dementia training for physicians and health care professionals, including continuing education units to fulfill the new licensure requirements. An early detection virtual live webinar was held in November 2022, with approximately 133 attendees and 117 continuing medical education requests. The Brain Trust podcast series was released in early 2023 with the aim of equipping family physicians with best practices for ADRD early detection methods, efficient clinic procedures, and referral procedures to increase early detection. More details for this project are described in the following section.

In 2024, Public Act 103-0064 became effective on January 1, 2024. The law, which was passed by the Illinois General Assembly in 2023, requires that the guardianship training program for all guardians include content regarding Alzheimer's disease and dementia. Additionally, it requires that a public guardian annually complete a one-hour course on Alzheimer's disease and dementia. The Alzheimer's Association collaborated with the Guardianship & Advocacy Commission to ensure this additional content was launched as part of the training in 2024.

Quality Care Measures

Illinois has an Alzheimer's Disease and Related Dementias Special Care Disclosure Act that requires licensed residential care settings that provide specialized care to individuals with dementia to disclose information about their program to the state agency responsible for licensing of that setting, as outlined in the act.

In addition, Special Care Unit (SCU) regulations exist for skilled nursing and intermediate care facilities (77 IL Adm. Code 300.7000-7080; “Subpart U”). There are basic dementia provisions in the regulations for ALFs (77 IL Adm. Code 295.4060). For Supportive Living Programs, there are basic special regulations that apply to the dementia care settings (89 IL Adm. Code 146.600-710).

Skilled Nursing Facilities

These facilities provide skilled nursing care, continuous observations, restorative services, and other services with frequent medical supervision. Skilled nursing and rehabilitation staff manage, observe, and evaluate care. These facilities also provide for residents who need care and treatment required in the post-acute phase of illness or during reoccurrences of symptoms in long-term illness. Medicare certifies these facilities to ensure they have the staff and equipment to give skilled nursing care, rehabilitation services, and other related health services. These facilities are Medicare, Medicaid, and private pay.

Assisted Living Facilities

The IDPH Division of Assisted Living oversees nearly 570 licensed establishments regulated under the Assisted Living and Shared Housing Establishment Code (77 Illinois Administrative Code 295). This division is responsible for conducting and processing annual and complaint survey investigations, incident report investigations, and follow-up surveys, when applicable. This is a state licensure program with no federal oversight, as the residents in both assisted living and memory care areas are private pay through an establishment contract. Renewal applications and licensure fees are required yearly.

Supportive Living Program Settings

Illinois developed the Supportive Living Program (SLP) as an alternative to nursing home care for low-income older people and people with physical disabilities ages 22-64.

By combining personal care and other services, residents can live independently and take part in decision-making. Personal choice, dignity, privacy, and individuality are emphasized.

HFS has obtained a "waiver" to allow payment for services not routinely covered by Medicaid. These include personal care, homemaking, laundry, medication supervision, social activities, recreation, and 24-hour staff to meet residents scheduled and unscheduled needs. The resident is responsible for paying the cost of room and board to the SLP provider.

Currently, there are 160 certified SLP providers with 13,400 apartments. Among these are 20 dementia sites with 520 apartments, an increase of 8 sites and 184 units. Another 40 projects are in various stages of development, of which 33 are Dementia Care Sites.

Public Safety and Law Enforcement

In considering public safety and law enforcement as they pertain to individuals living with Alzheimer’s disease or related dementia, the state considers the safety of the individual and the safety of the public. People with ADRD comprise a growing portion of the population and the number of individuals living in the community (versus long-term care facilities) who are experiencing cognitive decline. As a result, the likelihood of public safety officials who serve the community interacting with persons with cognitive decline or dementia will continue to grow.

While not required by statute, dementia training for law enforcement officers is now part of police academy training because of a recommendation by the Silver Search Advisory Committee and adoption by the training board. Existing officers who have completed the academy are trained by mobile units throughout the state, so eventually all police officers will be trained with basic information about Alzheimer’s and dementia.

Historically, dementia training was not part of the curriculum for first responders. In 2022, a one-hour dementia training requirement as part of re-licensure requirements for all paramedics and emergency medical services personnel licensed by IDPH was enacted. This requirement became effective January 1, 2023 (P.A. 102-0772). These trainings offer best practices for first responders to identify individuals with dementia, communication techniques, or strategies for diffusing challenging behaviors.

About 3 million Americans with ADRD go missing each year. If an elderly person is not found within 24 hours, there is a 50% chance he/she will suffer serious injury or die. Additionally, it is estimated that 60% of people living with Alzheimer’s or dementia will wander at some point during the diagnosis. Several years ago, Illinois passed legislation¹ adding “missing endangered seniors” to the list of individuals who require the Illinois State Police to initiate immediate action through the statewide Law Enforcement Agencies Data System (LEADS). In 2015, the General Assembly passed legislation to create Silver Search in Illinois, a coordinated effort to bring awareness, education, and resources to help find and safely return people with Alzheimer’s and dementia who go missing. Silver Search focuses on providing proactive training and reactive technology to locate quickly and efficiently someone who has Alzheimer’s or dementia who goes missing.

The Silver Search law, which went into effect in 2016, created an Endangered Missing Person Advisory to notify the public about a missing and endangered person when they wander. An Endangered Missing Person Advisory is a voluntary partnership with law enforcement, local broadcasters, and other partners to notify the public about a missing and endangered person. The advisory is initiated by the local law enforcement agency. The purpose of the advisory is to get as many people looking for the missing person as possible. Emails, faxes, radio and television broadcasts, text messages, and law enforcement bulletins are all means to disseminate the information about the missing person. Because of the partnership with the

Illinois Department of Transportation and the Illinois Tollway Authority, the dynamic message signs on the interstates and tollways are now utilized during advisories when a person is missing while driving in a vehicle. The Illinois Lottery also utilizes digital lottery terminals in lottery retail outlets to display advisories as another way to spread information about an endangered person.

Geriatric-Psychiatric Services

Due to the sometimes-challenging behaviors associated with ADRD, individuals or program staff caring for someone living with dementia may seek assistance through psychiatric hospitalization. Admission to inpatient psychiatric units should be limited to extreme cases and implemented only after all behavioral interventions are explored. With optimal management methods, many individuals can be effectively treated and stabilized through medication management and observation within the safe and secure environment of the home or facility in which they reside.

For psychiatric hospitalization to occur, an individual must meet the basic mental health code criteria of being deemed harmful to themselves or others, being unable to provide for their basic needs or guard themselves from harm, or, due to their lack of understanding of their illness and its treatment, requiring treatment on an inpatient basis. Common behaviors that may be associated with ADRD can include delusions, hallucinations, paranoia, agitation or aggression, depression, anxiety, sexual inappropriateness, and self-harming behaviors.

The current system for admission to behavioral care relies on the hospital emergency department as the access point for evaluation and admission to the psychiatric unit for behavioral treatment. The system is inadequate, inefficient, and inappropriate, as many emergency departments do not have the expertise, staff, time, or a stabilized environment to respond adequately to the challenging behaviors exhibited by the person with dementia.

Also, the availability of hospital geriatric-psychiatric beds is low, particularly outside Cook County, resulting in many individuals spending 2-3 days receiving inadequate or even counterproductive care in the emergency department, waiting for beds to become available. Furthermore, emergency departments are not able to provide the long-term, holistic nursing support that is an important component of dementia care. While some psychiatric hospitals have begun to address the challenge of caring for individuals living with dementia in their facilities by creating geriatric units, what defines such a unit is not addressed on a state level to ensure consistency.

Additionally, after receiving psychiatric treatment and stabilization, facilities are often reluctant to accept or re-admit individuals with a behavioral history due to their dementia. Such denial of care creates challenges in the placement of individuals with Alzheimer's disease or other dementia into appropriate care facilities at the time of discharge.

The current model is not capable of meeting the current or future needs of people living with ADRD who exhibit advanced behavioral issues. Assuming that the current model could be improved, it is necessary to design incentives to encourage changes to meet the needs of persons living with ADRD with behavioral issues requiring intervention.

The concerns discussed above highlight the complexity of the issue. It is recommended, over the three-year period of this strategic plan, to set a priority to review the scope of the problem and identify solutions to gain a better understanding of the type of care needed to improve the model.

State of Illinois Alzheimer's Disease Plan

2026-2029

Goal One

Workforce and Training

Develop, expand, and sustain a dementia-capable, culturally responsive workforce in Illinois.

- A. Quantify the essential value of a dementia-capable workforce on the economic productivity of Illinois.
 1. Gather information regarding the workforce supply and demand in Illinois to estimate the impacts of the current workforce capacity gap on economic output in Illinois.
- B. Identify and examine strategies that have been effective in addressing workforce shortages for dementia care.
 1. Examine nationwide and international strategies that have been effective in advancing the workforce recruitment and retention of direct care workers.
 - a. Collaborate with the Illinois Department on Aging to examine potential opportunities to advance technology that supports individuals, professional caregivers, and family caregivers impacted by Alzheimer's disease and other dementias.
- C. Identify, develop, and mobilize multi-sector partnerships to expand the number of potential ADRD workforce members.
 1. Identify existing stakeholders, programs, and resources in Illinois that support entry and advancement within the direct care field.
 2. Develop a strategy to coordinate efforts with partners, such as creating dementia specific geriatric or aging interest groups for workforce development.
 3. Mobilize partners to identify and to implement strategies that can make entry into the dementia care field more appealing.
- D. Identify and develop sector-specific training modules, which include the dementia-capable core competencies created by the IDPH Alzheimer's Disease Advisory Committee, considering the cultural background and literacy level of the trainee.
 1. Monitor the implementation and effectiveness of mandated training for professionals.
 2. Identify gaps in training that are needed for additional professional sectors and groups with the potential to enhance the lives of persons living with dementia and their caregiving families.

Goal Two

Public Education and Awareness

Increase public awareness about brain health, risk reduction, and early detection of Alzheimer's Disease and Related Dementias (ADRD) with a particular emphasis in underserved communities.

- A. Promote healthy aging, brain health, and risk reduction for ADRD.
 1. Educate communities about healthy cognitive aging, cognitive decline, and warning signs of ADRD.
 2. Examine best practices and identify methods for promoting brain health education across the lifespan.
 3. Integrate brain health and ADRD risk information into the health promotion messaging and risk reduction activities of other chronic disease prevention programs.
 - a. Establish partnerships with other chronic disease programs to strategize how to collaboratively promote shared lifestyle and health behaviors that support both brain health and physical health.
 - b. Identify and disseminate shared risk factors for both brain and physical health diseases, such as hypertension, diabetes, lack of physical activity, sleep problems, smoking, substance use, hearing impairment, social connectedness, and mental health issues.
 - c. Identify and implement best practices or evidence-informed strategies that reduce modifiable risk factors for brain, heart, and overall health.
 - d. Disseminate brain health infographics and messaging widely through partner networks and social media.
 4. Reduce the burden of risk in groups that have a disproportionately higher prevalence of risk factors for ADRD.
 - a. Identify effective ways to widely disseminate ADRD risk reduction and brain health messaging that is culturally appropriate and accessible to underserved communities, including mobilization of trusted partners.
 - b. Identify, develop, or adapt culturally and linguistically appropriate health messaging materials about risk reduction strategies for improved brain and physical health.
 - c. Develop partnerships with community-based organizations that serve underserved communities to promote awareness of ADRD and healthy aging.
 - d. Partner with the Illinois Department on Aging (IDoA) and Illinois Department of Human Services (DHS) to identify social determinants of health and other barriers that hinder access to health promotion and chronic disease services in underserved areas or populations.

- e. Support the IDoA to identify effective methods for linking members of underserved communities and higher-risk groups to resources that are focused on improving the social determinants of health.
- 5. Increase access to health promotion, chronic disease prevention, and chronic disease management services that can assist in managing the chronic conditions known to increase risk for cognitive impairment. **[see NAPA 6.D.3 & 6.D.4]**
 - a. Identify and utilize effective communication models for disseminating knowledge of and implementing practice of current health promotion and prevention opportunities.
 - b. Ensure that health promotion and chronic disease interventions include messaging for health care providers that underscores the essential role of caregivers and the importance of maintaining their health and well-being.
 - c. Partner with IDoA and DHS and the aging network to assess and address gaps in falls prevention, chronic disease education, and other health promotion programs or activities, particularly in underserved areas.
 - d. Partner with IDoA, DHS, community-based organizations, and other stakeholders to introduce, deliver, and expand the reach of evidence-based chronic disease self-management education (CDSME) and self-management support programs within underserved areas to improve the confidence of older adults in managing their chronic condition(s).
- B. Accelerate dissemination of ADRD risk reduction information to local public health departments and other public health partners.
 - 1. Educate public health professionals about the best available evidence on dementia, the role of public health, and sources of information, tools, and assistance to support public health action.
 - a. Educate local health departments about the importance of brain health, risk reduction, and ways to use this information to address brain health.
 - b. Collaborate with other public health organizations, schools of public health, and other public health partners to identify shared goals and priorities regarding brain health promotion and risk reduction for ADRD.
 - 2. Develop and mobilize partnerships between the public health and aging networks to increase their collaboration toward healthy brain efforts.
 - a. Connect local health departments with Area Agencies on Aging for increased awareness of the dementia-specific services and supports that each offers in their respective areas.
 - b. Strategize with local health departments and Area Agencies on Aging about collaborating to promote, mobilize, or develop evidence-based disease prevention and health promotion services for the older adults where there are gaps in their service areas.
 - 3. Engage other IDPH offices, state agencies, Area Agencies on Aging, and community-based organizations about brain health, ADRD, and ways to collaborate for making Illinois more dementia-capable.

- C. Advance early detection of ADRD.
 - 1. Educate the public about cognitive changes that should be discussed with a health professional and the benefits of early detection and diagnosis.
 - a. Implement an early detection campaign statewide, with a particular focus on underserved and high-risk communities.
 - b. Raise awareness about less common forms of dementia, such as primary progressive aphasia, that commonly occur under the age of 65.
 - c. Raise awareness that Alzheimer’s dementia can be a young-onset disease.
 - 2. Train family physicians and other health care providers about the importance of ADRD early detection, effective implementation strategies for incorporating early detection methods into practice, and effective ways to disclose ADRD diagnoses.
 - 3. Identify and promote culturally and linguistically responsive strategies designed to reduce conflicting messages, to decrease stigma, and to increase ADRD awareness in underserved communities.
 - a. Mobilize community-based organizations and trusted partners (e.g., health educators, community health workers) into underserved and high-risk communities to provide ADRD education and promote linkage to local screening, evaluation, and resources.
- D. Promote early planning for persons living with dementia, their families, and caregivers, including, but not limited to:
 - 1. Legal and financial planning.
 - 2. Guardianship, powers of attorney, and other alternatives.
 - 3. Advanced directives.
 - 4. Educate people with ADRD and their families about safe driving practices and alternatives for transportation.
- E. Increase and enhance messaging about the importance of family caregiving and family well-being.
 - 1. Educate the public about the importance of caregivers and how caregivers can recognize being in a caregiving role.
 - 2. Educate physicians, health care systems, and other professionals about the essential role of family caregiver well-being and the risks to mental and physical health.
 - 3. Utilize the Behavioral Risk Factor Surveillance System (BRFSS) caregiver module data to develop and publish a burden brief that provides valuable insights about caregivers in Illinois.
 - 4. Disseminate information and increase access to resources and supports for unpaid family caregivers, including those that help the caregiver build the skills they need to provide care.
 - 5. Collaborate with the Illinois Family Caregiver Coalition to ensure that campaign messaging and materials developed include the unique needs of unpaid family caregivers and individuals living with dementia.

6. Identify and partner with community-based organizations to assist in the dissemination of culturally responsive caregiving resources and support.

Goal Three

Service Delivery

Increase equitable access to person-centered, coordinated, and culturally competent care, support, and therapeutic interventions for persons living with dementia, their families, and caregivers.

- A. Enhance dementia care coordination and increase effective person-centered care planning for persons living with dementia and their families.
 1. Develop a coordinated approach to utilizing state resources for all Illinois residents.
 2. Establish statewide programs that provide support to informal caregivers of individuals living with dementia through a pilot program that includes care consultations and service coordination to assist care partners and family members.
 3. Continue conversations with state agencies and the administration to find and implement effective methods for acquiring services no matter what state agency an individual living with dementia and their family enters, at any age and any point along the continuum of the disease.
 4. Increase awareness of the importance of care planning for persons living with dementia and their families.
 5. Promote the use of tools that assist person-centered planning for people and families in all stages of dementia and at any age.
- B. Expand the accessibility and availability of Medicaid programs and other state-administered services.
 1. Promote and advance Medicaid Home and Community Based Services and ensure they are dementia-capable and accessible for persons living with dementia, caregivers, and families in all stages of dementia.
 - a. Support the expansion and availability of the Supportive Living Program (SLP) waiver that promotes community integration for persons living with dementia.
 - b. Provide dementia training to all providers and direct-care workers of the Persons who are Elderly HCBS waiver and Community Care Program (CCP) waiver to increase the dementia-capability of these services.
 - c. Increase visibility and awareness of all components of the Persons who are Elderly waiver and Community Care Program (CCP) available for persons aged 60 and older.

- d. Partner with IDoA to align services and promote a coordinated transition for adults under 60 who are utilizing the DHS Division of Rehabilitation Services Home Services waiver and intend to continue waiver services and supports with IDoA.
 - e. Partner with the DHS Division of Rehabilitation Services Home Services waiver to provide quality person-centered services and care for persons living with dementia under the age of 60 and their caregiving families.
 - f. Partner with HFS to expand coverage of Supportive Living Services for those under 65.
 - g. Provide dementia training to all providers and direct-care workers of the DHS Division of Rehabilitation Services (DRS) HCBS waivers to increase the dementia-capability of these services for individuals living with early-onset dementia.
2. Increase visibility and awareness of the IDoA’s Older American Services programs that can benefit persons living with dementia and their family caregivers.
- C. Identify and reduce barriers to accessing services, including transportation challenges, financial impediments, location of services, and other social determinants of health, particularly in underserved areas.
- 1. Collaborate with IDoA to strategize outreach methods for addressing these social determinants of health for people and caregivers living with dementia, potentially through supportive gap-filling services or linkage to state and local community resources.
- D. Assess and address caregiver health and well-being.
- 1. Publish and utilize BRFSS data and burden briefs to provide valuable insights regarding the challenges for ADRD caregivers.
 - 2. Increase awareness of Caregiver Assessment Tools to screen for stress levels, depression, health, and quality of life.
 - 3. Increase access to evidence-based or evidence-informed caregiving programs.
 - a. Promote awareness and use of evidence-based caregiver education, including, but not limited to, Savvy Caregiving and Stress Busting for Caregivers.
 - b. Host an informational webinar for Area Agencies on Aging (AAAs), local health departments (LHDs), managed care organizations (MCOs), aging providers, and other community-based organizations to inform them of credible national databases or online resource tools that provide access to evidence-based practices and reliable resources for planning caregiver programming.
 - c. Host a webinar for medical practitioners about resources for caregivers and person-centered planning for persons living with dementia and their families.

4. Collaborate with the Illinois Family Caregiver Coalition and other unpaid caregiver support programs to ensure that the strategies developed include the unique needs of unpaid family caregivers and individuals living with dementia.
 5. Increase accessibility and availability of services that give families a break from providing daily care, such as respite, in-home care, adult day services, and residential care.
 6. Increase awareness of adult day services that reduce isolation, promote social health and community integration, and serve as a vital support to families and unpaid caregivers of persons living with dementia.
- E. Assess and monitor the quality of care for persons living with dementia in residential care settings.
1. Assess and monitor health care quality measures that address cognitive assessments, the delivery of care planning to people with diagnosed dementia, and improved outcomes.
- F. Palliative Care
1. Educate persons living with dementia, care partners, family members, and professionals about using palliative care services for persons living with dementia. Palliative care focuses on the quality of life for persons living with dementia to improve symptoms, to prevent undertreatment of symptoms and overtreatment with unnecessary and burdensome treatment, and to enhance caregiver quality of life.
- G. Hospice
1. Educate persons living with dementia, care partners, family members, and professionals about hospice services for people living with advanced dementia. Hospice care focuses on the comfort and dignity at the end of life and provides care and support services to the individual and family in the final stages of dementia (for people expected to live less than six months).

Goal Four

Community Engagement, Safety, and Support

Ensure that Illinois communities are dementia capable and prepared to respond to the needs of diverse persons living with dementia, their families, and caregivers.

- A. Assure the safety and protection of people living with cognitive decline and dementia who are at risk for abuse, neglect, and exploitation.
1. Enhance financial and legal protections for persons living with dementia.
 - a. Educate financial professionals, legal professionals, and other community groups about the signs of cognitive decline and dementia, as well as risks and indicators for possible exploitation by others for persons living with dementia.

- b. Provide “warning signs” of abuse or exploitation due to cognitive decline and the necessary resources for these professionals to report suspected abuse or exploitation to Adult Protective Services.
 - c. Make recommendations for the prevention and mitigation of possible exploitation.
 - 2. Monitor dementia-specific training for providers of public guardianship services, as well as other guardians.
 - 3. Advocate for the expansion of supported decision-making in Illinois to include persons living with Alzheimer’s disease and other related dementias.
 - 4. Increase financial assistance and access to safety locator programs that are tailored to the needs of persons living with dementia, their caregivers, and families.
- B. Support and promote the expansion of Dementia Friendly communities and Dementia Friends in Illinois.
 - 1. Promote the expansion of dementia friendly communities that are supportive for persons living with dementia, their caregivers, and families.
 - 2. Promote the development of Dementia Friends throughout Illinois, including within state agencies, Area Agencies on Aging, local health departments, aging network service providers, local community-based organizations, faith communities, and community members.
 - 3. Assess collaborative efforts for dementia friendly and age-friendly efforts in Illinois.
 - 4. Collect community success stories that highlight the impact of the dementia-friendly movement in Illinois and create a Dementia Friendly and Dementia Friends brief to disseminate.
- C. Assure public health plans that guide emergency preparedness and emergency response address the unique needs of people with dementia and their caregivers, support access to critical health information during crises, and prepare emergency professionals for the unique needs of persons living with dementia, their families, and caregivers.
 - 1. Engage stakeholders from state and local emergency management agencies to discuss the opportunity to integrate dementia-inclusive information into existing plans and develop guidance for emergency management agencies.
 - 2. Review best practices and plans from other states’ emergency preparedness plans that include procedures tailored to the unique needs of persons living with dementia, their families, and caregivers.
 - 3. Meet with partners and subject matter experts to develop guidance for state and local emergency management agencies, and to recommend changes to emergency management plans that will address the needs of individuals living with cognitive decline and dementia during emergency situations and disasters.

4. Identify communities where there are disparities in emergency planning and response to strategize outreach efforts to educate persons living with dementia, their families, and caregivers about emergency preparation.
 5. Provide dementia-specific resources to all first responders.
 6. Promote and encourage caregivers and the families of persons living with dementia to develop a disaster and emergency response plan.
- D. Improve access to geriatric-psychiatric services that are dementia capable, take into consideration the unique behavioral needs of persons living with dementia, and seek to stabilize community living arrangements.
1. Assess the current state of both inpatient and outpatient geriatric-psychiatric care in Illinois, including the availability of hospital geriatric-psychiatric beds, access to geriatric-psychiatric outpatient services, and availability of telehealth services.
 2. Identify and examine nationwide and international strategies that have been effective in responding to and stabilizing crisis situations that involve cognitive and behavioral challenges for persons living with dementia.
 3. Identify key state agency and community stakeholders.

Goal Five

Data

Identify, collect, and utilize data to assess the impact of dementia in Illinois and improve public health outcomes.

- A. Continue the BRFSS cognitive and caregiver optional modules.
 1. Continue the optional cognitive and caregiver BRFSS modules per national frequency recommendations.
 2. Utilize BRFSS data to develop and publish burden briefs for both subjective cognitive decline and caregiving.
- B. Examine other surveillance strategies for dementia-related data collection in Illinois that can inform policy response and public health programming.
 1. Examine nationwide and global strategies to effectively identify persons living with dementia in Illinois.
 2. Examine nationwide and global strategies that are effective for identifying who ADRD caregivers are in Illinois.
 3. Identify existing data collection systems and sources in Illinois.
 4. Partner with IDoA to collect data that assists in determining what regions of the state need increased access to dementia specific care.
- C. Examine methods and strategies of collecting data that can help identify health disparities and social determinants of health that put older adults at higher risk for cognitive decline and ADRD.

1. Examine national frameworks, methods, or strategies for collecting data to address social determinants of health.
 2. Strategize collection methods to identify where the greatest disparities exist in Illinois for access to chronic disease management, health promotion activities, dementia services, and caregiver supports.
- D. Support national data collection on dementia and caregiving.
- E. Embed evaluation into training and programs to determine program accessibility, effectiveness, and impact.

Goal Six

Research

Promote opportunities to expand dementia-related research and support the translation and dissemination of research findings with an emphasis on maintenance of cognitive health, prevention of dementia, early diagnosis, and patient-centered intervention.

- A. Pursue opportunities to support state funding for dementia-related research of the Regional Alzheimer's Disease Assistance Centers.
- B. Seek federal or private matches to leverage state funding for projects that capitalize on the Alzheimer's Disease Assistance Centers' strengths.
- C. Foster research collaborations and networking opportunities among professionals.
 1. Alzheimer's Disease Assistance Center staff should continue facilitating meetings with institutes of higher education and care providers within the state to encourage an exchange of ideas and to foster research collaborations.
- D. Promote awareness of clinical trials and studies on cognitive health and impairment, particularly in diverse communities that are underserved and underrepresented in research.
- E. Promote the advancement of translational research and the dissemination of key findings that stand to impact prevention, accurate diagnosis, and appropriate intervention.
 1. Expand translational research on risk factors for ADRD.
 2. Train researchers how to effectively translate the scientific content of research findings into information that is meaningful, applicable, and capable of being quickly and efficiently put into practice.
 - a. Identify and mobilize the professionals or experts equipped to train researchers about effective translation methods.
 - b. Plan and deliver a seminar or workshop about methods for research translation.
 - c. Facilitate translation of risk reduction research findings into clinical practice.

- d. Identify avenues in addition to scientific journals and peer sharing that can promote and disseminate translational research findings.

Acknowledgements

The Illinois Alzheimer’s Disease State Plan was prepared by the Alzheimer’s Disease Advisory Committee, partners from public health and aging service organizations, and academic institutions.

Illinois Alzheimer’s Disease Advisory Committee

(Appointed and nominated members)

- Jen Belkov Alzheimer’s Association
- Vicki Ortiz American Association of Retired Persons
- Elizabeth Simonton Illinois Department of Public Health
- Kelly Rice Illinois Department of Aging
- Brian Pastor Illinois Department on Aging
- Erin Hascup Southern Illinois University Smith Center for Alzheimer’s Disease
- Darby Morhardt Northwestern University Mesulam Center for Alzheimer’s Disease
- David Bennett Rush Alzheimer’s Disease Assistance Center
- (vacant) Illinois Adult Day Services Association
- (vacant) National Association of Social Workers-Illinois Chapter
- David Lowitzki Illinois Association of Community Care Program Homecare Providers
- Cristina Diaz Age Options Area Agency on Aging
- Smita Patel Illinois Association of Family Physicians
- Jane Williams Prairie Living Supportive Living Facility
- Lisa Gregory Illinois Department of Healthcare and Family Services
- Tom Hughes Illinois Public Health Association
- James Mastrianni University of Chicago
- Becky Dragoo Illinois Department on Aging
- Sarah Smith Illinois Guardianship and Advocacy Commission
- Molly Chapman Illinois Department of Human Services
- Melissa Stalets Illinois Department of Public Health

Additional Contributors

- Rush Alzheimer's Disease Assistance Center
- Southern Illinois University Smith Center for Alzheimer's Disease
- Alzheimer's Association-Illinois Chapter—David Olsen
- Illinois Department on Aging
- Northwestern University Mesulam Center for Alzheimer's Disease

References

- Alzheimer's Association. (2025). *Alzheimer's disease facts and figures*. Alzheimer's Association. <https://www.alz.org/getmedia/ef8f48f9-ad36-48ea-87f9-b74034635c1e/alzheimers-facts-and-figures.pdf>
- Alzheimer's Association. (2022). *2022 Alzheimer's disease facts and figures special report more than normal aging: understanding mild cognitive impairment*. Alzheimer's Association. [alzheimers-facts-and-figures.pdf](https://www.alz.org/getmedia/ef8f48f9-ad36-48ea-87f9-b74034635c1e/alzheimers-facts-and-figures.pdf)
- Alzheimer's Association and Centers for Disease Control and Prevention. (2023). *Healthy brain initiative, state and local public health partnerships to address dementia: the 2023-2027 road map*. Alzheimer's Association and Centers for Disease Control and Prevention. <https://www.cdc.gov/aging-programs/media/pdfs/2024/06/HBI-State-and-Local-Road-Map-for-Public-Health-2023-2027-508-compliant.pdf>
- Alzheimer's Association. (2024). *2024 Illinois Alzheimer's Statistics*. Alzheimer's Impact Movement. [2024 Illinois Alzheimer's Statistics](https://www.alz.org/getmedia/ef8f48f9-ad36-48ea-87f9-b74034635c1e/alzheimers-facts-and-figures.pdf)
- Baker LD, Espeland MA, Whitmer RA, et al. (July 28, 2025). Structured vs Self-Guided Multidomain Lifestyle Interventions for Global Cognitive Function: The US POINTER Randomized Clinical Trial. *JAMA*. 2025;334(8):681–691. doi:10.1001/jama.2025.12923 [Structured vs Self-Guided Multidomain Lifestyle Interventions for Global Cognitive Function: The US POINTER Randomized Clinical Trial | Dementia and Cognitive Impairment | JAMA | JAMA Network](https://doi.org/10.1001/jama.2025.12923)
- BOLD Infrastructure for Alzheimer's Act. Pub. L. No. 115-406 132 Stat. 5362 2018 [PUBL406.PS \(house.gov\)](https://www.congress.gov/115/plaws/publ/406/2018/plaws-publ-406-132-stat-5362-2018)
- Centers for Medicare and Medicaid Services. (2018). *Unpublished tabulations based on data from the Medicare current beneficiary survey for 2018*. Centers for Medicare and Medicaid Services.
- Illinois Department on Aging. (2022). *Illinois department on aging state plan*. Illinois Department on Aging. [state-plan-2022-2024-july2021-final-version.pdf \(illinois.gov\)](https://www.idph.illinois.gov/~/media/IDPH/2022-2024-july2021-final-version.pdf)
- Illinois Department of Public Health. (2020). *Alzheimer's disease state plan*. Illinois Department of Public Health. [Alzheimer's Disease - IL State Plan 2020 - 2023 \(illinois.gov\)](https://www.idph.illinois.gov/~/media/IDPH/2020-2023-alzheimers-disease-il-state-plan.pdf)
- Illinois Department of Public Health. (2025) *The 2021 Illinois Behavioral Risk Factor Surveillance System, Caregiver module*. Illinois Department of Public Health Module Data, Caregiver Module, Illinois Department of Public Health. <https://idph.illinois.gov/brfss/statedata.asp?xtabFile=CAREGIVERREGCARE&area=il&yr=2021&selTopic=CAREGIVER&form=strata&show=xtab>
- Illinois Department of Public Health. (2025) *The 2023 Illinois Behavioral Risk Factor Surveillance System, Cognitive Decline module*. Illinois Department of Public Health Module Data, Cognitive Decline Module, Illinois Department of Public Health.

<https://idph.illinois.gov/brfss/statedata.asp?selTopic=COG&area=il&yr=2023&form=strata&show=freq>

Maslow K. (2006) How many hospital patients have dementia? In Silverstein N and Maslow K, eds. *Improving hospital care for people with dementia*. New York, NY: Springer.

Metlife. (2010) *Metlife study of working caregivers and employer health costs: national alliance for caregiving*. Metlife. <https://www.kff.org/wp-content/uploads/sites/2/2010/09/mmi-working-caregivers-employers-health-care-costs.pdf>

National Alliance for Caregiving and AARP. (July 2025). *Caregiving in the U.S. Research Report*. National Alliance for Caregiving and AARP. <https://www.caregivingintheus.org/wp-content/uploads/2025/07/caregiving-in-us-2025.doi .10.26419-2fppi.00373.001.pdf>

USC Leonard D. Schaeffer Institute for Public Policy and Government Services. (April 23, 2025). Issue Brief. *The Cost of Dementia in 2025*. USC Leonard D. Schaeffer Institute for Public Policy and Government Services. <https://schaeffer.usc.edu/research/the-cost-of-dementia-in-2025/>

U.S. Department of Health and Human Services. (2024). *National plan to address Alzheimer’s disease: 2024 update*. U.S. Department of Health and Human Services. <https://aspe.hhs.gov/sites/default/files/documents/dc2ff0be0e08df15971fce57cb8e5c7a/napa-national-plan-2024-update.pdf>