



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)
2023 –2026 Report and Recommendations

January 2023

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	10
Funding Opportunities	13
Economics of Alzheimer’s Disease and Related Disorders	16
Coordination of Dementia Care Services	19
Services to Address the Needs of Persons with Alzheimer’s Disease and Related Disorders, Their Families, and Caregivers	20
State of Illinois Alzheimer’s Disease Plan	34
Workforce and Training	35
Public Education and Awareness	36
Service Delivery	39
Community Engagement, Safety, and Support	41
Data	43
Research	44
Acknowledgements	45
References	45

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 (ARD). This plan can also be useful for policy and decision makers to gauge what is happening in Illinois around ARD 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 2023-2026 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

In 2020, there were 230,000 people over 65 years of age living with Alzheimer's disease or a related dementia in Illinois. This figure is projected to reach 260,000 in 2025, a 13% increase. Simultaneously, there is an increasing shortage of direct care providers in the aging, disability, and public health networks. In 2021, approximately 383,000 Illinois caregivers provided more than 486 billion hours of care to someone living with a dementia. That unpaid value of care is more than \$8.8 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 general public on the importance of ensuring a dementia-capable Illinois. 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 to 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 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.

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 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

Today, approximately 6.5 million Americans are living with ADRD, including 230,000 in Illinois (projected to reach 260,000 in 2025, a 13% increase). About 1 in 9 people (10.7%) age 65 or older has 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.

The Alzheimer's Association's 2022 Facts and Figures Report found differences and disparities in the prevalence of Alzheimer's and other dementias. Highlights include:

- 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.
- Of the 6.5 million people aged 65 and older with Alzheimer's in the United States, 4 million are women and 2.5 million are men.

The Alzheimer's Association's 2021 Facts and Figures Special Report, "Race, Ethnicity, and Alzheimer's in America," revealed that health disparities, health care disparities, and discrimination impact Alzheimer's and dementia care. It also found 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.
- Half of Blacks report they have experienced health care discrimination; more than 2 in 5 Native Americans and one-third of Asian Americans and Hispanics report having experienced discrimination when seeking health care.
- Among non-White caregivers, half or more say they have faced discrimination when navigating health care settings for their care recipient, with the top concern being that providers or staff do not listen to what they are saying because of their race, color, or ethnicity. This concern was especially high among Black caregivers, followed by Native American, Asian American, and Hispanic caregivers. Fewer than 1 in 5 White caregivers expressed this view.

- 2 in 5 caregivers who provide unpaid care to a Black person say that race makes it harder for them to get excellent health care. Nearly 1 in 3 caregivers of Hispanic people say the same.

While the number of deaths attributed to most major diseases saw little change and some even declined between 2000 and 2019 – breast cancer (increased by 1.1%), prostate cancer (increased by 1.8%), heart disease (declined by 7.3%), stroke (declined by 10.5%), and HIV (declined by 65.2%) – ADRD deaths climbed, increasing 145.2%. In 2019, there were 3,954 deaths from ADRD in Illinois. ADRD kills more Americans than breast cancer and prostate cancer combined.

With appropriate resources, researchers believe they will be able to develop treatments that slow the progression of ADRD and, as a result, improve the quality of life for people with ADRD, their families, and their caregivers. Of course, the ultimate goal is a cure or prevention for the disease.

The need to diagnose ADRD earlier, even before individuals experience symptoms, has spawned research interest into "biomarkers" – tests such as a brain scan or blood test that would conclusively prove someone has ADRD, independent of the person's cognitive functioning. Such a biomarker could be a more reliable indicator of a treatment response in drug studies and not subject to the inherent variability of cognitive testing.

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 work force 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 work force as well.

There also is 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 families attempts to provide assistance. The ADRD research community is making greater investments into methods to identify and to address caregiver stress, and to improve the quality of life for both the person living with dementia and the caregiver.

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 particular 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.

IDPH used BRFSS state and county data in 2022 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 annual statewide survey that included cognitive questions has a sample size of around 2,400 for adults aged 45 years and older. The county survey, which included cognitive questions, has a sample size of 25,000 for adults 45 years and older. Given the larger sample size, the county data was used for the cognitive brief. The second brief is specific to caregiver characteristics and commitments, and the 2021 statewide BRFSS caregiver data was used for this report. Burden briefs are published and accessible on 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 that go missing. The Silver Search program strives to bring awareness to the increasing incidences of people with Alzheimer's or other dementias that 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 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 scheduled to be 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.

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 opportunities to improve its ability to meet the needs of persons with ADRD because of an increased focus at the federal level. Since the last state plan, there have been significant advancements at the national level as far as funding for ADRD research. Consequently, there is a competitive space for states and others to attract those funds. While these new opportunities exist, there is the challenge on how to organize and to present innovative ideas to compete for these federal dollars most effectively. Some of the state plan recommendations lay the groundwork to support ideas to help Illinois be more competitive to apply for federal funding.

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 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. NAPA is set to expire in 2025 but legislation is currently being worked on in Congress (The NAPA Reauthorization Act) to extend the project. When passed, this bill will continue the work of the national plan through 2035. Additionally, the December 2021 update to the plan added a new national goal for the first time since 2012. This goal focuses on healthy aging and reducing risk factors for cognitive decline and dementia.

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 December 2021. 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 bi-partisan 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 Bold Act authorized \$100 million 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, there will be opportunities within the next three years for the state to apply and to become a recipient of BOLD Public Health Program funding, and/or Center of Excellence funding.

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

- Over the last decade, the Alzheimer’s Association has successfully advocated for dramatic increases to the research appropriations at NIH - now \$3.4 billion annually.
- 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 FY23 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 grow, spending for their care will increase dramatically. The total aggregate payments for ADRD health care, long-term care, and hospice in the United States are projected to jump from \$321 billion in 2022 to approximately \$1 trillion in 2050 (in 2022 dollars), not including the value of unpaid care provided by family and friends. This rise includes a three-fold increase in both government spending under Medicare and Medicaid and out-of-pocket spending.

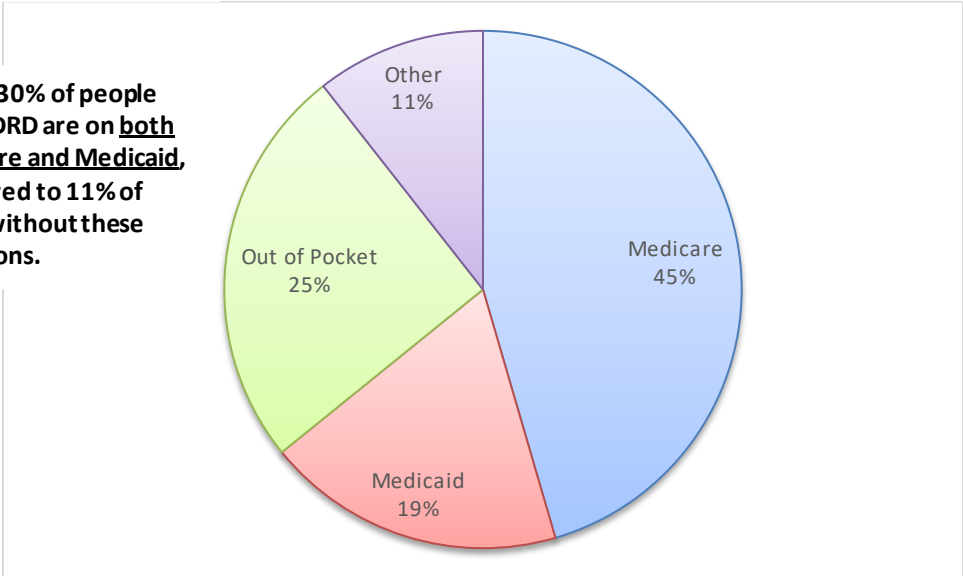
2022 Costs of Alzheimer's = \$321 Billion in the U.S.

Nearly 30% of people with ADRD are on both Medicare and Medicaid, compared to 11% of those without these conditions.

The average per person Medicaid costs for those with ADRD are 22 times higher than for those without these conditions.³

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

Nearly 30% of people with ADRD are on both Medicare and Medicaid, compared to 11% of those without these conditions.



Source: Alzheimer's Association, 2022 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.

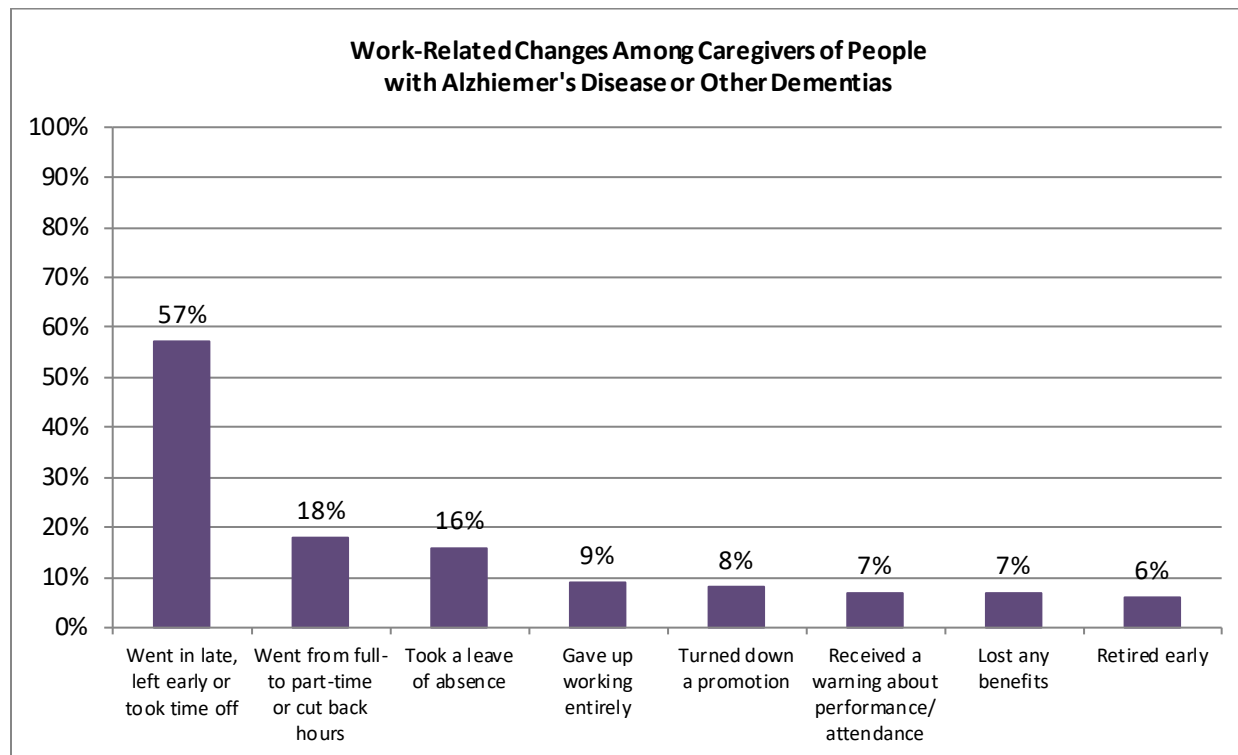
Caring for people living with ADRD also strains health and long-term care systems. Individuals with ADRD use a disproportionate number of health care resources. For instance, ADRD individuals are hospitalized twice as often as people the same age who do not have dementia. Similarly, while people living in nursing homes are a small percentage of the older population, 50% of nursing home residents have ADRD. 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 2021, per capita Medicare spending on a person living with ADRD in Illinois was \$30,672. Additionally, in 2020, total Medicaid payments for Illinoisans aged 65 and older living with ADRD was \$1.8 billion. This Medicaid cost is expected to rise 23.1% to \$2.2 billion by 2025.

In addition to strain on health care and long-term care systems, ADRD requires significant caregiving resources. 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 2021, caregivers of people with ADRD provided an estimated 16 billion hours of informal (i.e., unpaid) assistance, a contribution to the nation valued at \$271.6 billion. The total lifetime cost of care for someone with dementia in 2021 dollars was estimated at \$377,621. The costs associated with family care, including unpaid care and out-of-pocket expenses, make up 70% of lifetime dementia care costs. In 2021, there were 383,000 caregivers in Illinois who provided 483 million hours of unpaid care, with a total value of unpaid care estimated at \$8.8 billion.

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.

Caregiving does not only take a financial toll on caregivers. Health and well-being of caregivers is also negatively impacted. In Illinois 53.5% of caregivers have chronic health conditions, 21.4% have depression, and 16.7% are in poor physical health.

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. In 2018, Medicare beneficiaries aged 65 and older with Alzheimer's disease paid \$9,844 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 of 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 (ADAC) is considered the top tier of dementia care providing diagnostic evaluation, treatment, referral, and research. An ADAC must be a postsecondary higher educational institution having a medical school affiliated with a medical center and having a NIH and NIA sponsored Alzheimer's Disease Core Center. Any regional ADAC that previously was designated as having a National Alzheimer's Disease Core Center but no longer carries such designation can continue to serve as a regional ADAC. ADACs are staffed by a network of physicians, medical specialists, social workers, nurses, educational specialists, and research scientists with expertise in dementia care and research. ADACs 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 regional ADACs, 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*

NADAC serves the Chicago metropolitan area, Cook County, and eight collar counties. The Neurobehavior and Memory Clinic, an essential component of NADAC, attracts patients throughout Illinois, the Midwest region, nationally, and internationally.

NADAC has an affiliated faculty of approximately 50 clinicians and basic scientists from 13 departments at Northwestern University who engage in research and clinical practice related to brain aging, cognitive function, and dementia. The mission of NADAC is to investigate the causes and clinical characteristics of neurodegenerative diseases, to explore the neural foundations of behavior and cognition in health and disease, to discover causes and treatments for dementia disorders, to transfer the benefits of research to persons

living with dementia and their caregiving families, and to train future scientists and clinicians. Areas of clinical emphasis include Alzheimer's disease, primary progressive aphasia, frontotemporal degeneration, and mild cognitive impairment.

The Northwestern Neurobehavior and Memory Clinic environment is multidisciplinary and includes behavioral neurologists, neuropsychologists, neuropsychiatrists, and social workers. In fiscal 2022, there were 905 new and 2,382 return patients seen in the Neurobehavior and Memory Clinic for a total of 3,287 patient visits. The clinic provides state-of-the-art diagnostic and treatment services and ongoing care for patients and families. The clinic treats the whole patient and offers education, counseling, and support services for both patients and their families.

NADAC provides dementia education to clinicians, research scientists, persons living with dementia, family caregivers, and the general community through a variety of modalities. Bi-monthly Alzheimer's disease seminars reach more than 600 clinicians, scientists, and students per year. The annual Alzheimer Day consistently reaches more than 400 people.

While NADAC searches for new and better treatments for dementia disorders, a primary aim is to provide persons living with dementia and their families' opportunities for education, support, and social engagement. These include support and education programs for newly diagnosed patients and families, a mentorship program for persons living with dementia paired with first-year medical students, and creative arts and music interventions.

During FY2022, NADAC contributed to the advancement of scientific research and published 46 peer reviewed papers, four book chapters/invited papers, delivered 11 extramural presentations, and obtained seven new grants. A monthly e-newsletter and annual print newsletter are distributed to more than 8,500 persons living with dementia, family caregivers, clinicians, scientists, and other professionals, in addition to the general community. NADAC maintains a website (www.brain.northwestern.edu) directed to professionals as well as the public, in addition to active Facebook and Twitter accounts. The website contains pages for caregivers, health care providers, investigators, and patients.

NADAC is also focused on raising awareness on Alzheimer's disease and related dementias through community lectures and symposia. NADAC community engagement includes partnering with Black and African American community stakeholders to promote access to education and awareness, family support services, and research opportunities. NADAC is a leader within the Illinois Cognitive Resources Network, in collaboration with all Illinois ADACs; the Alzheimer's Association; and aging, disability, and public health networks with a focus on the development and sustainability of dementia friendly Illinois communities.

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

The Rush Alzheimer’s Disease Assistance Center primarily serves the communities of northeastern Illinois, including persons living with or at risk of dementia due to Alzheimer’s disease and related dementias, and the families that support them. However, the region-focused clinical care programs, patient and family support programs, professional support programs, educational programs, and research programs serve as models that impact persons living with or at risk of dementia due to Alzheimer’s disease and the families who support them. The research programs directly involve study participants from across the country. The data and biospecimens generated by Rush Alzheimer’s Disease Center (RADC) studies are used to the Alzheimer’s disease worldwide.

In 2017, the RADC applied for and received recognition for ICRN as a statewide resource for the Dementia Friends initiative to support grassroots level activities that align with Dementia Friendly Communities in Illinois. At the end of this fiscal year, 7,734 people had become a Dementia Friend across the state. This includes 6,017 Dementia Friends through in-person or virtual talks and 1,717, who signed up online. Since January 2018, RADAC has offered Dementia Champions training to help increase the reach of the Dementia Friends program. We offer the Dementia Champions training virtually to allow for people across the state to attend. Currently, 159 people have gone through the training.

In FY22, the RADC was supporting 16 active clinical research studies, with 10 being intervention trials, funded by the NIH, foundation, and industry partners. Some of these trials are treatment trials of patients with Alzheimer’s disease (AD) or mild cognitive impairment (MCI) that seek care at the Rush Memory Clinic. Others are community-based diagnostic or prevention studies of pre-clinical Alzheimer’s disease, cognitive impairment, and other common chronic conditions of aging, such as disability-free survival. RADC opened enrollment of one trial testing if a wearable audio device can reduce agitation in persons with Alzheimer’s disease and related dementias (ADRD) and another trial that continues to test if an investigational medicine is safe and beneficial to persons with AD. Enrollment for two investigational medication trials for MCI and mild-to-moderate AD are ongoing with one testing if an investigational drug can prevent AD and a different trial examining if statin use in older adults can prevent dementia, disability, or heart disease.

RADC 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, the Rush Memory and Aging Project, the Minority Aging Research Study, the African American Clinical Core, and the Latino Core. Together, these studies have enrolled and followed more than 5,000 older persons, including more than 1,400 African American adults and more than 400 Latinos. In addition to Alzheimer’s disease, RADC studies stroke and

cerebrovascular disease, Parkinson’s and Lewy body disease, TDP-43, and hippocampal sclerosis, as well as resilience to these diseases. RADC also studies gait and disability, sensory loss, sleep and circadian rhythms, diet and nutrition, traumatic brain injury, immune function, menopause, metabolic diseases, pollution, behavioral and neuroeconomics, decision making, literacy, and intensive care unit-dementia.

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

The Dale and Deborah Smith Center for Alzheimer’s Research and Treatment, now known as the Smith Alzheimer’s Center, is a division of SIU School of Medicine. This program was formerly known as the Center for Alzheimer’s Disease and Related Disorders (CADRD). The center was established as a Regional Alzheimer’s Disease Assistance Center by the state, pursuant to Public Act 90-0404. The center is dedicated to assisting patients and families who may be affected by Alzheimer’s disease and Parkinson’s disease. This is accomplished through:

1. Patient care
2. Education, both to professionals and to the community
3. Research
4. Service to the community in “Beyond the Medical Center” programs

The Smith Alzheimer’s Center mission is to integrate patient care, education, and research to better understand the biological aspects of:

1. Aging
2. Cognition
3. Neurodegenerative disorders

The Smith Alzheimer’s Center is a state-supported center with eight aims:

- Provide diagnostic services, treatment, and case management to patients and families throughout Illinois, excluding the Chicago area (special attention is directed to rural areas).
- Provide training, consultation, and continuing education to the community, medical students, residents, practicing physicians, and other health care professionals.
- Maintain a centralized patient database for monitoring patients and controls evaluated at the Smith Alzheimer’s Center and the Memory and Aging Network, also known as, the primary provider sites (PPS). See the paragraph below for further explanation and recommendations relevant to PPS.
- Support clinical and basic research in the fields of dementia and associated locomotor disorders of older people, through the provision of research support staff, carefully diagnosed patients, and non-patient controls.

- Provide legislators, the community, social media, and news media, information pertaining to the latest developments and services in the field of aging.
- Enhance the recruitment of neurologically healthy older people and persons with very early dementia for participation in aging research, including the brain bank program.
- Enlist the participation of PPSs into one or more areas of research.
- Support improvement of activities of daily living for persons with dementia and their caregivers through the “Beyond the Medical Center” programs.

In fiscal year 2022, the Smith Alzheimer’s Center completed 761 new patient assessments and 2,417 follow-up assessments of individuals with cognitive problems. The center provided 128 educational and training sessions. The center participated in 13 investigator-initiated trials, 10 industry sponsored studies, and three grant studies in FY 2021-22. Faculty and staff had six publications and eight posters, abstracts, and presentations.

In fiscal year 2022, the Smith Alzheimer’s Center increased its commitment to diversity and inclusion in the “Beyond the Medical Center” programs by hiring a program coordinator for Diverse Communities. The goal of this position is to develop and to manage non-pharmacological intervention and prevention programs in minoritized communities traditionally underrepresented in medicine, while expanding outreach in underserved and ethnically diverse communities.

Also in fiscal years 2021-22, the Smith Alzheimer’s Center began partnering with AgeLinc, the local Area Agency on Aging, which covers 12 counties in central Illinois. The center is collaborating with AgeLinc on a Dementia Friendly Community plan, with several public presentations being held. The collaboration enables patient referrals to be given back and forth for resources that are needed for those suffering with memory loss and their caregivers.

ADA Center Primary Provider Sites (PPS)

PPS are community-based medical programs that work directly with RADAC staff who have the expertise to diagnose, to treat, and to 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 that 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 a number of 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 has been shown 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. There are an estimated 230,000 people 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 family 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 12 SLP dementia care settings with approximately 300 apartments. Another 32 communities with 1,329 apartments are in various stages of development. Currently, there are 524 total ALFs in Illinois, 320 that have Alzheimer’s care, with 8,313 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 and Advocacy Commission safeguards the rights of persons with disabilities through the work of three distinct programs: the Office of State Guardian (OSG), the Legal Advocacy Service, and the Human Rights Authority. The commission is governed by a board of 11 commissioners who are appointed by the governor and confirmed by the Senate.

The OSG serves as guardian for adults with disabilities as appointed by courts and when there is no one else available to serve as guardian. The Legal Advocacy Service provides legal advice and representation for both children and adults with disabilities most often providing representation for individuals facing involuntary mental health admission or treatment. The Human Rights Authority investigates allegations of disability rights violations committed against persons with disabilities by disability service providers.

The commission works with individuals with Alzheimer's Disease and Related Disorders through its OSG when the OSG is court-appointed to serve as guardian of last resort, when individuals have encounters with the mental health service system and may need legal advice or representation from the commission's Legal Advocacy Service, or when individuals experience rights violations by a service provider, such as a nursing home, hospital, or home health agency, that may warrant an investigation by the Human Rights Authority.

The commission maintains an intake unit that provides referrals to commission services as well as information about adult guardianship, advanced directives, and advocacy resources for persons with disabilities. The commission is also mandated to provide guardianship training for newly appointed guardians. The on-line guardianship training and other commission and resource information is available through the commission's [website](#). The commission's toll-free intake number is 866-274-8023 (TTY: (866-333-3362)).

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.

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 relicensure 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 are 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 are 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 training officers across the state. (50 ILCS 705/10.10)

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 504 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 156 certified SLP providers with 13,161 apartments. Another 39 projects with 2,217 apartments are in various stages of development. There are 12 dementia sites with 316 apartments.

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.

While historically, dementia training has not been part of the curriculum for first responders, 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 in 2022. This requirement became effective January 1, 2023 (P.A. 102-0772). These first responders will now learn best practices for identifying 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 that 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 in-patient 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 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, nor the stabilizing 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 to 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 placement of individuals with Alzheimer’s disease or other dementia into appropriate care facilities at 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

2023-2026

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.
 2. Analyze if the acknowledgement of the dementia-capable workforce as essential workers would incentivize retention and reduce the workforce capacity gap.
- 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, taking into account 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.
 - 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 to 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, to mobilize, or to 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 benefits of early detection and diagnosis.
 - a. Implement an early detection campaign statewide, with a particular focus in 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 Behavioral Risk Factor Surveillance System (BRFSS) caregiver module data to develop and to 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. 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 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. Improve and enhance quality of care for persons living with dementia in residential settings.
1. Increase inclusion of 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 under treatment 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 states 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 prevention and mitigation of possible exploitation.
 2. Provide 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 state’s 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 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 family 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. Implement the BRFSS cognitive and caregiver optional modules.
 1. Implement 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 personalized 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.

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References

- Alzheimer's Association. (2022). *Alzheimer's disease facts and figures*. Alzheimer's Association. <https://pubmed.ncbi.nlm.nih.gov/35289055/>
- 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.alzheimersfactsandfigures.org/)
- Alzheimer's Association. (2021). *Special report: race, ethnicity and alzheimer's in America*. Alzheimer's Association. [alzheimers-facts-and-figures-special-report-2021.pdf](https://www.alzheimersfactsandfigures.org/special-report-2021.pdf)
- Alzheimer's Association and Centers for Disease Control and Prevention. (2018). *Healthy brain initiative, state and local public health partnerships to address dementia: the 2018-2023 road map*. Alzheimer's Association and Centers for Disease Control and Prevention. [Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map \(alz.org\)](https://www.alz.org/healthy-brain-initiative-state-and-local-public-health-partnerships-to-address-dementia-the-2018-2023-road-map)
- BOLD Infrastructure for Alzheimer's Act. Pub. L. No. 115-406 132 Stat. 5362 2018 [PUBL406.PS \(house.gov\)](https://www.congress.gov/bills/115/406/ps)
- 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.
- Couglin, J., (2010). *Estimating the impact of caregiving and employment on well-being: outcomes and insights in health management*. Vol 2, Issue 1.
- Gallup Healthways Wellbeing Survey. (2011) *Caregiving costs U.S. economy \$25.5 billion in lost productivity*. Gallup.
- Gallup Healthways Wellbeing Survey. (2011). In U.S., caregivers suffer from poor physical health. Gallup.
- Gallup Healthways Wellbeing Survey. (2011). *More than one in six american workers also act as caregivers*. Gallup.
- Hebert, L. E., Beckett, L. A., Scherr, P. A., & Evans, D. A. (2001). Annual incidence of alzheimer disease in the United States projected to the years 2000 through 2050. *Alzheimer Disease and Associated Disorders*, 15(4), 169–173. <https://doi.org/10.1097/00002093-200110000-00002>
- Hurd, M. D., Martorell, P., Delavande, A., Mullen, K. J., & Langa, K. M. (2013). Monetary costs of dementia in the United States. *New England Journal of Medicine*, 368(14), 1326–1334. <https://doi.org/10.1056/nejmsa1204629>
- 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.ida.org/state-plan-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.state.il.us/alzheimers-disease-il-state-plan-2020-2023).
- Illinois Department of Public Health. (2021) *The 2020 and 2021 illinois behavioral risk factor*

- surveillance system, cognitive Impairment*. Illinois Department of Public Health Module Data, Caregiver Module, Illinois Department of Public Health.
- 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.
- Magaziner, J., German, P., Zimmerman, S. I., Hebel, J. R., Burton, L., Gruber-Baldini, A. L., May, C., & Kittner, S. (2000). The prevalence of dementia in a statewide sample of new nursing home admissions aged 65 and older. *The Gerontologist*, 40(6), 663–672. <https://doi.org/10.1093/geront/40.6.663>
- Metlife. (2010) *Metlife study of working caregivers and employer health costs: national alliance for caregiving*. Metlife.
- National Alliance for Caregiving and AARP. (2009). *Caregiving in the U.S. unpublished data analyzed under contract for the alzheimer's association*. National Alliance for Caregiving and AARP.
- National Institute of Health. Research Portfolio Online Reporting Tools. Available at <https://projectreporter.nih.gov/reporter.cfm> . Accessed July 5, 2019.
- U.S. Department of Health and Human Services. (2021). *National plan to address alzheimer's disease: 2021 update*. U.S. Department of Health and Human Services. <https://aspe.hhs.gov/sites/default/files/documents/66904c18bb1f0843c3c113d7099e98c1/napa-national-plan-2021-update.pdf>