



State of Illinois
Illinois Department of Public Health

Alzheimer's Disease State Plan

Pursuant to Alzheimer's Disease Assistance Act (410 ILCS 405)

January 1, 2017 – January 1, 2020 Report and Recommendations

December 2016

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What is the Alzheimer’s Disease Illinois State Plan?

The Alzheimer’s Disease Illinois State Plan (State Plan) was established in January 2014 and is required to be revised every three years thereafter in accordance with the Alzheimer’s Disease Assistance Act. The current plan is a revision of the original plan and reflects new initiatives implemented over the last three years, including the prioritization of recommendations, Healthy Brain Initiative, Illinois Cognitive Resources Network, and state requirements for staff training and health care facilities advertising.

The plan is produced by the Illinois Department of Public Health (IDPH) in conjunction with the Alzheimer’s Disease Advisory Committee (ADAC) 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; and
- Public Safety and Law Enforcement.

Who is the Plan for?

The Alzheimer’s Disease Illinois State Plan is for any person, community, agency, institution, or organization that has the means to and interest in helping implement recommendations outlined in the plan. This plan can also be useful for policy and decision makers to gauge what is happening in Illinois around Alzheimer’s disease and what still needs to be done.

How to Use this Plan?

This plan is meant “to guide” the Alzheimer’s disease efforts within the State of Illinois. This plan is not a substitute for individualized work or action plans developed by organizations or persons interested in addressing the needs of people with Alzheimer’s disease and related

dementias. Rather, the State Plan should be viewed as a compass shared by all the Alzheimer’s disease stakeholders that will give a unifying direction to all 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.

*2017 – 2020 Recommendations to Address the
Needs of People with Alzheimer’s Disease, Their Families, and Caregivers*

SHORT-TERM RECOMMENDATIONS

The Alzheimer’s Disease Advisory Committee identified the following recommendations as feasible to accomplish during the three-year reporting time.

Illinois’ Alzheimer’s Disease Network

- **Short-term recommendation (ST) 1** - Improve the current funding formulas for the regional Alzheimer’s Disease Assistance (ADA) Centers to assure funding is sustainable. The ADA Centers are described on pages 18-20. *(Assign to the Regional ADA Centers.)*
- **ST 2** - Improve the quality of local care available for people with Alzheimer’s disease by providing training for primary provider sites (PPS) staff, families, and stakeholders; and expanding the PPS program to include additional primary care providers by building linkages with organizations representing primary care physicians and internists. Organizations include, but not limited to, the Illinois Academy of Family Physicians, the Illinois Chapter of the American College of Physicians (for general internists), the Illinois Primary Health Care Association (for primary physicians in federally qualified health centers), and local health departments. The PPS program is described on page 20. *(Assign to the ADA Center PPS.)*

State Supported Alzheimer’s Disease Research

- **ST 3** - ADA center staff should facilitate meetings with other research entities (institutes of higher education and care providers) within the state to encourage exchange of ideas and to foster research collaborations. Federal and foundation research grants could be developed to address ways to impact the public health burden and health disparities, and to develop a roadmap to increase a diverse research workforce interested in careers to address the issues faced by people at risk or living with Alzheimer’s disease.
- **ST 4** - Continue increasing local participation in clinical trials and studies on cognitive health and impairment.

Illinois State Agencies Programs and Support

- **ST 5** - Provide links from IDPH’s website to the state’s ADA Centers and to the Alzheimer’s Association (www.alz.org) to improve access to information and assistance. *(Assign to IDPH.)*
- **ST 6** – Develop additional state “Burden Briefs” related to Alzheimer’s disease. A description of the burden brief can be found on page 14. *(Assign to IDPH.)*
- **ST 7** - Integrate Healthy People 2020 objectives on “Older Adults” and “Dementias, including Alzheimer’s disease” into topic areas in the State Health Improvement Plan. *(Assign to IDPH.)*
- **ST 8** - Seek federal grant opportunities to promote the development of a dementia-capable state and to implement programs that benefit people with Alzheimer’s disease and related disorders, and their family caregivers. Illinois Department on Aging (IDoA) programs are described on page 22. *(Assign to IDoA.)*
- **ST 9** - Support the expansion and availability of speech-language pathology (SLP) dementia care units in the state as initiated by the Illinois Department of Healthcare and Family Services (HFS). *(Assign to HFS.)*
- **ST 10** - Support the implementation of the final home and community-based services (HCBS)

regulations so that individuals have the opportunity to receive these services in a manner that protects individual choice and promotes community integration. Support programs that will further this recommendation even if it's not covered by Medicaid or Medicare. *(Assign to HFS.)*

Dementia Care Services

- **ST 11** - Continue to strengthen health care practices at the point of diagnosis by encouraging dedicated staff support or by providing referrals to appropriate entities such as ADA centers, the Alzheimer's Association or the state's aging and disability resource centers. Assist in planning care or providing case management, and developing formal mechanisms for education and referral to health care institutions and community-based agencies that offer specialized expertise, social supports, and mental health services.
- **ST 12** - Work with stakeholders to preserve the elements of Medicaid essential to those living with Alzheimer's disease and their families. Evaluate the use of Medicaid and Medicare waivers that would strengthen care coordination and management to reduce the use of more expensive facility-based long-term care services when cost efficient home- and community-based services are appropriate.
- **ST 13** - Provide physical, emotional, education, and financial assistance to unpaid caregivers of people with dementia, including respite and support services.

Dementia-Specific Training Requirements

- **ST 14** - Provide incentives to develop partnerships between and among various providers, centers of excellence, educational and vocational programs, community colleges and universities, both to provide better models of dementia education and training, and to attract individuals to careers in dementia care.

Quality Care Measures

- **ST 15** - Develop and mandate effective training in behavioral interventions (using evidence-based practices) for personnel working with people with dementia in residential care settings.
- **ST 16** - Require residential care facilities, as a condition of licensure, to institute an approved protocol for dealing with behavioral issues of individuals with Alzheimer's and other dementias, and ensure all staff members are trained in implementing protocol.

Residential Options for Persons with Dementia

- **ST 17** - Create a tiered structure of Medicaid reimbursement for all residential care facilities to compensate for the higher cost of caring for individuals with Alzheimer's disease and related dementias, both early onset and diagnoses after 65 years of age.

Other

- **ST 18** - Make it a criminal offense for an individual to financially exploit a cognitively impaired individual.

Introduction

In 2016, there were 220,000 people with Alzheimer’s disease living in Illinois. This figure is projected to reach 230,000 in 2025, an 18.2 percent increase. If all of the people with Alzheimer’s disease in Illinois lived in one city, it would be the state’s second largest city. Alzheimer’s disease is not a disease that limits itself to a particular race, marital status, country of origin, religion, or sexual preference.

Nationally, the cost of caring for those with Alzheimer’s disease and other dementias is estimated to total \$236 billion in 2016, increasing to \$1.1 trillion (in today’s dollars) by mid-century. Medicare and Medicaid cover about 68 percent of the total health care and long-term payments. In 2016, the Medicaid cost of caring for people with Alzheimer’s disease in Illinois was \$1,531 million.

Throughout this plan, recommendations are provided for new policies to address Illinois’ response to Alzheimer’s disease and related dementias. These recommendations can be achieved through close collaboration among partner and public input to advocate for appropriate legislative action and regulatory change, and facilitate public-private partnerships. 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;
- person-centered information, referral, safety, and service coordination;
- eligibility criteria for public programs that are equitable for people with dementia;
- access to appropriate services for people with dementia and their caregivers;
- a variety of quality home- and community-based service and nursing care options;
- a health care workforce knowledgeable about dementia, and serving people with dementia and their caregivers;
- a coordinated public health system in which cognitive health is a priority;
- quality assurance systems considering the unique needs of people with dementia and their caregivers; and
- expanded research for Alzheimer’s disease and other dementias through state revenue and disbursement.

The Illinois Alzheimer’s Legislators Alliance (Alliance), comprised of 66 members of the General Assembly, has recognized the importance of ensuring Illinois is dementia-capable and stands ready to move the state forward in crafting a better response to the growing public health crisis of Alzheimer’s disease and related dementias. The Alliance was instrumental in coordinating three public hearings to gain broad input into the content of this plan. The public hearings were held in southern, central, and northern areas of Illinois. Community members and staff of

agencies providing programs and services to people with Alzheimer’s disease and related dementias, their families, and caregivers offered suggestions for the plan.

Legislative History

Illinois has been involved in addressing Alzheimer’s disease and related dementias for many years. 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 prepare 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 (AD 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. This plan, due to the Office of the Governor Office and the General Assembly by January 1, 2014, met the requirement of the act.

Other legislation addressing living arrangements for people with Alzheimer’s disease, information gathering and autopsies, quality incentives, and respite programs have been enacted. The State Adult Protective Services Act was amended (P.A. 99-143) to include people with Alzheimer’s disease and Illinois created specialty license plates for Alzheimer’s disease awareness.

Alzheimer's Disease: A Definition

Dementia is a term used to designate brain diseases that progressively and permanently undermine cognitive function and behavior to the point where the individual is no longer able to carry out customary activities at work or home. Alzheimer's disease is one of many dementias. It happens to be the most common dementia seen in old age. It is an irreversible, progressive brain disease and is fatal. It slowly destroys brain function and leads to dementia. 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).

Alzheimer's disease is a specific disease of the brain that was identified more than 100 years ago, but research into its causes, risk factors, and potential treatments has gained momentum only in the last 30 years. The hallmarks of Alzheimer's disease are the accumulation of abnormal proteins in the brain: clumps of beta-amyloid (called amyloid plaques) and tangled bundles of tau fibers (called neurofibrillary tangles). Most experts now agree that the accumulation of plaques and tangles in the brain may begin 20 or more years before the symptoms of dementia appear. Many current studies are investigating the benefits of exercise, diet, and other lifestyle modification that may prevent or delay the onset of Alzheimer's disease.

The causes of Alzheimer's disease are not completely understood, but researchers believe they include a combination of genetic, environmental, and lifestyle factors. 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 rare cases, known as early or younger-onset Alzheimer's disease, people develop symptoms in their 30s, 40s, or 50s.

The first symptom of Alzheimer's disease is often memory impairment. As the disease progresses, memory continues to decline and other functions, like language skills and decision-making, become more difficult. Personality and behavior changes also may occur. A person with the disease may no longer recognize family and friends.

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. In more than 90 percent of people with Alzheimer's disease, symptoms do not appear until after age 60 and the incidence of the disease increases with age.

However, there are other types of dementia caused by other diseases and conditions in the brain, such as frontotemporal, Lewy Body, and vascular dementias. Some of these, such as frontotemporal, 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. Distinguishing between Alzheimer's disease and other dementias, in terms of clinical presentation and diagnosis, is

challenging and may require extensive testing in specialized centers. Researchers now recognize that many of these diseases and conditions can co-occur in the brain and work together to influence the onset of dementia. Therefore, in this plan, the term “Alzheimer’s disease and related dementias” will often be used to refer to Alzheimer’s disease and related neurodegenerative disorders.

Opportunities and Challenges

Illinois has opportunities to improve its ability to meet the needs of persons with Alzheimer’s disease because of an increased focus at the federal level. With the passage of the National Alzheimer’s Project Act of 2011 (NAPA), the federal government has become more invested in Alzheimer’s disease research and the optimal treatment and care of both Alzheimer’s disease patients and their caregivers. NAPA established the Advisory Council on Alzheimer’s Research, Care and Services and required the secretary of U.S. Department of Health and Human Services, in collaboration with the advisory council, to create and maintain a *National Plan to Address Alzheimer’s Disease*, which was published in May 2012. The goals of the plan are preventing and effectively treating Alzheimer’s disease by 2025, enhancing care quality and efficiency, expanding support for people with the disease and their families, enhancing public awareness and engagement, tracking progress, and driving 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 improve the care of patients and caregivers.

The Alzheimer’s Association and the U.S. Centers for Disease Control and Prevention (CDC) Healthy Aging Program developed a *National Public Health Road Map to Maintaining Cognitive Health* outlining how state and local public health agencies and their partners can promote healthy cognitive functioning and help meet the needs of caregivers. Similar recommendations are included in this State Plan. Additionally, CDC developed two Behavioral Risk Factor Surveillance System (BRFSS) modules to assess cognitive impairment and caregiver activity. Illinois has administered both modules and data is included in this plan.

The National Institutes of Health (NIH) provides funding for Alzheimer’s disease research and significant dollars have been awarded to Illinois research institutions. Increased partnerships between the state and research institutions may lead to increased federal funding in Illinois.

The national Alzheimer’s disease plan identified challenges the nation faces, as well as some specific to Illinois. These include:

- While research on Alzheimer’s disease has made steady progress, there are no pharmacological or other interventions to definitively prevent, treat, or cure the disease.

- While many groups have taken steps to develop quality measures to assess Alzheimer's disease care and to improve training of the health and long-term care workforce, there is room for improvement.
- Family members and other informal caregivers who take on the responsibility of caring for a loved one with Alzheimer's disease need support. The majority of people with Alzheimer's disease live in the community and their families provide most of their care. The toll of caregiving can have major implications for caregivers and families; about one-third of caregivers report symptoms of depression.
- Stigmas and misconceptions associated with Alzheimer's disease are widespread and profoundly impact the care provided to, and the isolation felt by, people with Alzheimer's disease and their families.
- Public and private sector progress is significant, but coordination and tracking are limited; as is data to assess the incidence, prevalence, trends, and costs.
- Illinois has no state-funded office designated to oversee and coordinate state-based programming of Alzheimer's disease. While many state agencies support a specific aspect of Alzheimer's disease service or care, better understanding of programs and coordination of efforts through one lead agency is needed.
- Illinois' fiscal limitations affect the ability to improve Alzheimer's programs and services. Strong partnerships could lead to increased federal funding to the state.

Opportunities exist, including:

- The state's ADAC is uniquely placed to provide guidance regarding improvements to respond to Alzheimer's disease and assistance for those dealing with Alzheimer's disease. The ADAC is described on page 21.
- The state's regional ADA Centers 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 Alzheimer's disease, their families, caregivers, and 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 Alliance is comprised of members of the General Assembly who are supportive of making Illinois a dementia-capable state.
- The Healthy Brain Initiative (HBI), funded by the National Association of Chronic Disease Directors, allowed IDPH and partners to successfully expand implementation of priority action items of the *The Public Health Road Map for State and National Partnerships, 2013-2018*. Additional information about the HBI can be found on pages 14 and 32.
- There is an opportunity to build upon the following accomplishments:
 - Developed "Burden Updates" addressing the impact of cognitive impairment and the specific needs of caregivers.

- Established a minimum set of core competencies for providers and care partners who work directly with dementia patients and their care partners as a foundation for more profession-specific competencies in the future.
- Completed a prioritization process resulting in five long-term and four short-term priorities out of the 63 recommendations offered in the *Illinois Alzheimer's Disease State Plan: 2014-2017*.
- Presented a webinar September 29, 2015, targeted to local health departments, area agencies on aging and other local agencies to inform them how they can use and access data and evidence-based practices to address the needs of people with cognitive impairment and their care partners in their geographic areas. There were a total of 182 health and aging network participants from across the state registered for this training, making the impact far-reaching.

Impact and Trends of Alzheimer's Disease

Today, more than five million Americans are living with Alzheimer's disease, including 220,000 in Illinois (projected to reach 230,000 in 2025, an 18.2 percent increase), the sixth leading cause of death in the country and the fifth leading cause of death for those older than age 65. It is projected that the number of people with this disease may double or even triple by 2050, barring a major medical breakthrough.

Approximately 500,000 people develop Alzheimer's disease each year in the United States. By 2050, that number could reach one million a year. Alzheimer's disease is not a disease that limits itself to a particular race, marital status, country of origin, religion, or sexual preference.

This disease leaves no survivors. While the number of deaths attributed to most major diseases declined between 2000 and 2010 -- heart disease (by 16 percent), breast cancer (by 2 percent), prostate cancer (by 8 percent) and stroke (by 23 percent) -- Alzheimer's disease deaths climbed, increasing 68 percent. In 2013, there were 2,919 deaths from Alzheimer's disease in Illinois.

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

The need to diagnose Alzheimer's disease earlier, even before patients have symptoms, spawned research interest into "biomarkers"— tests such as a brain scan or blood test that would conclusively prove someone has Alzheimer's disease, independent of the patient'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 Alzheimer’s disease patients is the realization that compared to all diseases, Alzheimer’s disease incurs the highest societal cost. Patients often require placement in nursing homes or assisted living facilities and their family members may have to leave the work force to provide care. Although most Alzheimer’s disease patients are of retirement age, some are younger than 65; diagnosis 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 with Alzheimer’s disease. Alzheimer’s disease often claims two individuals: the patient and his/her caregiver, particularly if the caregiver is the spouse. And it is often the spouse/partner that suffers the most, dealing with the behavioral and caregiving requirements of the patient who may be unaware of his/her impairment and resistant to caregiving. The Alzheimer’s disease research community is making greater investments into methods to identify and to address caregiver stress, and to improve the quality of caregiving for the benefit of both the patient and the caregiver.

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 CDC and state health departments. BRFSS surveys are conducted as random-dialed telephone interviews of adult residents throughout Illinois. BRFSS questions are scripted and conducted by trained interviewers. BRFSS data are used to identify the need for services, target populations at greatest risk, evaluate past efforts, and 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 for persons with Alzheimer’s disease.

Cognitive Impairment

In 2015, BRFSS cognitive impairment module questions were included on the Illinois survey.

- 9.6 percent of Illinois adults aged 60 or older self-reported confusion or memory loss that is happening more often or getting worse over the past 12 months; 53.5 percent of them have not talked to a health care professional about it.

Among Illinois adults aged 60 or older with confusion or memory loss:

- 43 percent reported always, usually, or sometimes interfered with their ability to give up household activities or chores.
- 30.2 percent reported always, usually, or sometimes interfered with their social lives.

- 34.7 percent reported always, usually, or sometimes needing help with day-to-day activities. 7.2 percent reported they never received help with day-to-day activities from a family member or friend.

As a result of HBI efforts, IDPH and partners used BRFSS state and county data to develop two Burden Updates, one focusing on increased confusion or memory loss and the challenges faced by caregivers (for the state and regionally for 13 Planning and Service Areas [PSAs]); and a second specific to caregiver demographic and socioeconomic characteristics, time spent providing care, and health problems of both individuals who receive care and caregivers. A statewide webinar to showcase the Burden Updates was conducted March 25, 2015 for area agencies on aging, local health departments, and other groups to increase awareness of cognitive health issues and offer tips for using the data in local planning to address the needs of persons with cognitive impairment and caregivers.

Caregiver Activities

The 2015 Illinois BRFSS caregiver data demonstrate that 131,800 persons reported providing care to a family, friend, or neighbor with dementia and other cognitive disorders. The majority of caregivers have been providing care for 2 to 5 years (37.2%) or more than 5 years (27%). An additional 22.5 percent have been providing care for 6 months to less than 2 years and only 13.2 percent are relatively new caregivers providing care less than 6 months. Half (49.9%) provide up to 8 hours of care each week on average, About 15 percent provide 9 to 19 hours per week, about 17 percent provide 20 to 39 hours a week and another 17 percent provide 40 hours of more a week. In calculating the economic value of care provided by unpaid caregivers, the Alzheimer's Association used a methodology that, in 2012, valued care at \$12.33 per hour.

However, it is much more expensive if families have to buy care in the marketplace. The most recent data showed the national average cost of a non-medical home health aide was \$21 per hour (or \$168 for an eight-hour day). The Illinois average was the same, although the average was slightly higher in Chicago and in the Highland Park area at an average of \$22 per hour.

The surveillance data denote the extent of self-reported confusion or memory loss among non-institutionalized adults aged 60 or older who may require services and support now or in the future. This underscores the need for increased awareness about changes in memory and confusion that may warrant discussions with health care and service providers so that patients can be provided with accurate information and linked to needed services. In addition, caregiver services must be more accessible and comprehensive in all areas of Illinois to address the needs of persons with Alzheimer's disease and their family, friends, and neighbors serving as caregivers.

The cognitive impairment module and the caregiving module were included in the 2013 and 2015 survey.

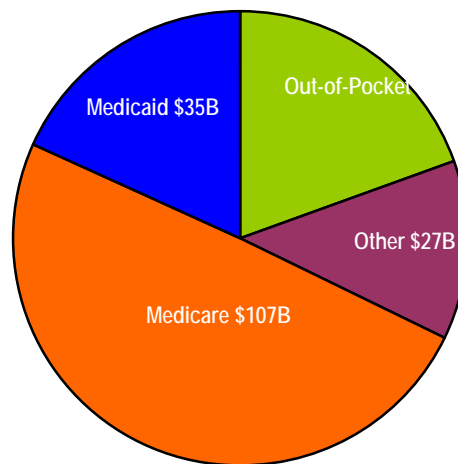
Economics of Alzheimer's Disease

Alzheimer's disease poses a substantial financial burden on society. As the number of people with Alzheimer's disease and other dementias grow, spending for their care will increase dramatically. The total aggregate payments for health care, long-term care, and hospice are projected to jump from \$236 billion in 2016 to \$1 trillion in 2050 (in 2016 dollars). This dramatic rise includes a nearly five-fold increase in government spending under Medicare and Medicaid and a nearly five-fold increase in out-of-pocket spending.

2016 Costs of Alzheimer's = \$236 Billion in the U.S.

The average per person **Medicaid** costs for those with Alzheimer's and other dementias are **19** times higher than for those without these conditions³

Nearly **30%** of people with Alzheimer's and other dementias are on **both Medicare and Medicaid**, compared to **11%** of those without these conditions.



The average per person **Medicare** costs for those with Alzheimer's and other dementias are **3** times higher than for those without these conditions.

Source: Alzheimer's Association, 2016 Alzheimer's Disease Facts and Figures, *Alzheimer's & Dementia*, Volume 12, Issue 4;

More than 15 million Americans provide unpaid care for people with Alzheimer's disease and other dementias. Eighty-three percent of the help provided to older adults in the United States comes from family members, friends, or other unpaid caregivers. In 2015, caregivers of people with Alzheimer's and other dementias provided an estimated 18.1 billion hours of informal (i.e., unpaid) assistance, a contribution to the nation valued at \$221.3 billion. Considering all sources of unpaid care (for example, help from multiple family members) among people who receive such care, individuals with dementia receive an average of 171 hours of care per month, which is over 100 hours more care per month than those without dementia (66 hours per month, on average).

Average Annual Per-person Payments For Health Care and Long-Term Care Services, Medicare Beneficiaries Age 65 and Older, With and Without Alzheimer’s Disease and Other Dementias and By Place of Residence, in 2015 Dollars.

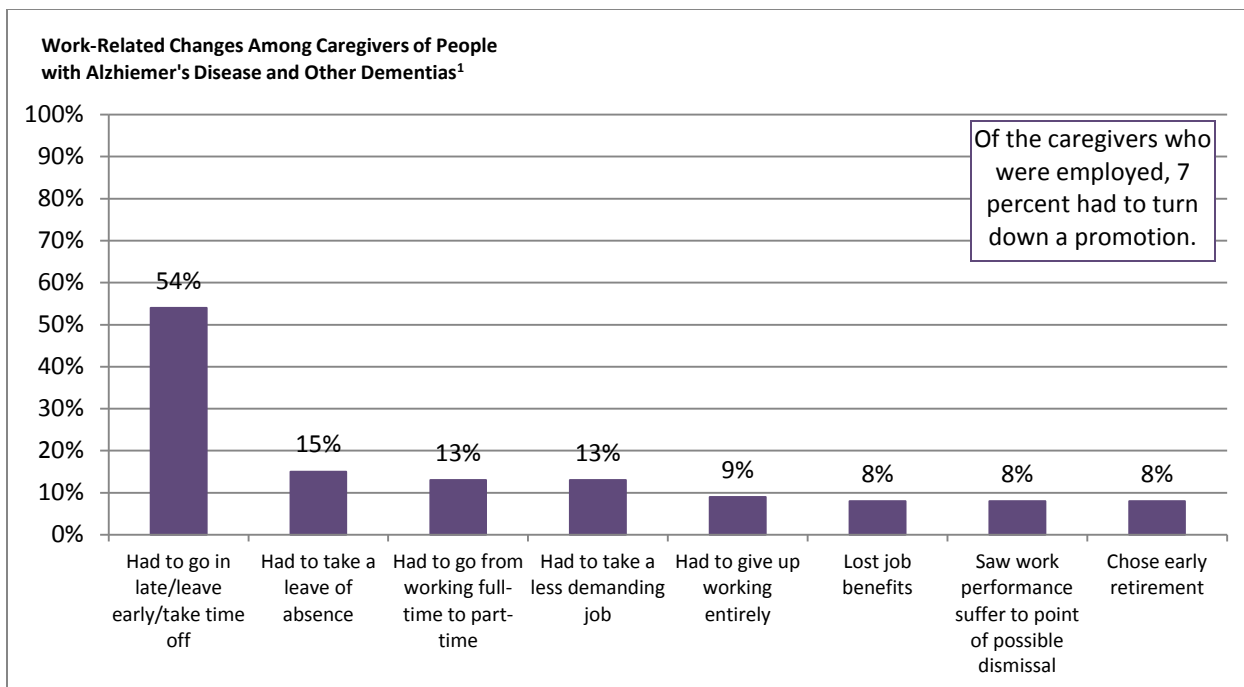
Payment Source	Beneficiaries with Alzheimer’s Disease and Other Dementias By Place of Residence			Beneficiaries without Alzheimer’s Disease and Other Dementias
	Overall	Community- Dwelling	Residential Facility	
Medicare	\$22,206	\$19,776	\$25,600	\$8,427
Medicaid	\$11,338	\$249	\$26,837	\$590
Uncompensated	\$306	\$439	\$120	\$345
HMO	\$1,114	\$1,729	\$254	\$1,625
Private Insurance	\$2,534	\$2,784	\$2,183	\$1,704
Other Payer	\$1,015	\$183	\$2,176	\$161
Out of Pocket	\$10,495	\$3,548	\$20,207	\$2,559
Total*	\$49,126	\$28,911	\$77,381	\$15,550

Source: Unpublished data from the Medicare Current Beneficiary Survey for 2008. *Payments from sources do not equal total payments exactly due to the effect of population weighting. Payments for all beneficiaries with Alzheimer’s disease and other dementias include payments for community-dwelling beneficiaries.

Caring for people with Alzheimer's disease also strains health and long-term care systems. Individuals with Alzheimer's disease use a disproportionate number of health care resources; for instance, they are hospitalized 2 to 3 times as often as people the same age who do not have the disease. Similarly, while people living in nursing homes are a small percentage of the older population, nearly half (48 percent) of nursing home residents have Alzheimer's disease. As the number of people with Alzheimer’s disease grows over the next two decades, this disease will place a major strain on these care systems, as well as on Medicare and Medicaid, the major funders of this care.

Effects of Caregiving on Employees and Employers

Among people who were employed at any time since they became caregivers of someone with Alzheimer’s or another dementia, nine percent ultimately quit their jobs to continue providing care. Fifty-four percent had to go in late or leave early, and 15 percent 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 below:



Source: Alzheimer's Association, 2016 Alzheimer's Disease Facts and Figures, *Alzheimer's & Dementia*,

Many care contributors for people with Alzheimer's disease and other dementias experience disruptions in employment as a result of the demands of caregiving. According to the *Alzheimer's Association Family Impact of Alzheimer's survey*, many care contributors reported that they had to work fewer hours or stop working entirely to support the person with dementia. Thirty-five percent of care contributors reported household income losses as a result of these employment changes. Care contributors and their families who experienced income losses lost an average of \$15,194 compared with their income the year before employment changes. Among those who reported income losses, 41 percent lost 20 percent or more of their household income. An additional 23 percent lost 10 to nearly 20 percent of their household income. In contrast to most studies and surveys on how caregiving affects one's employment, the Alzheimer's Association survey found that some care contributors had to increase work — increase the number of hours worked, take an additional job, go back to work, or postpone retirement — to help pay expenses for their relative or friend with dementia.

Costs to Illinois Citizens

High out-of-pocket costs are a reality for individuals with Alzheimer's disease and their caregivers despite other sources of financial assistance. In 2008, Medicare beneficiaries age 65 and older with Alzheimer's disease paid \$10,495 out-of-pocket on average for health care and long-term care services not covered by other sources. Averages per person out-of-pocket payments were \$3,548 per person for community-dwelling individuals. For individuals living in nursing homes and other residential facilities, per-person out-of-pocket expenses were almost 6 times higher — averaging \$20,207.

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

Illinois’ Alzheimer’s Disease Network

Regional Alzheimer’s Disease Assistance Centers

A regional Alzheimer's disease assistance center (ADA center) is considered the top tier of dementia care providing diagnostic evaluation, treatment, referral, and research. An ADA center must be a postsecondary higher educational institution having a medical school affiliated with a medical center and having a National Institutes of Health and National Institutes on Aging sponsored Alzheimer's Disease Core Center. Any regional ADA center 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 ADA center. ADA centers are staffed by a network of physicians, medical specialists, social workers, nurses, educational specialists, and research scientists with expertise in dementia care and research.

In 2012, funding levels for states with senior populations similar to Illinois to support their ADA center programs were much larger than that of Illinois—with Florida at \$16.6 million, California at \$5.9 million, and Arizona at \$4 million. In FY2003, Illinois provided \$3.3 million of state funds. In FY2004 this annual amount was reduced to \$1.7 million when the funding mechanism was changed to include a federal match, while in fiscal years 2013 and 2014, funds were cut by an additional 1.75 percent. If the original \$3.3 million per year had been left intact and matched with federal dollars, Illinois would be on par with other states.

The regional Alzheimer’s Disease Assistance Centers, funded by the Department of Healthcare and Family Services, in Illinois are:

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

The mission of NADAC is to investigate the neurological basis of cognitive function, to elucidate causes of dementia, and to ensure the patients and their families are the beneficiaries of resultant advances. The components of the NADAC are: 1) the Alzheimer’s Disease Core Center funded by the National Institute on Aging, 2) The Cognitive Brain Mapping Group, 3) the Neurobehavior and Memory Clinic and 4) the Regional Alzheimer’s Disease Assistance Center designated by the state of Illinois.

In fiscal year (FY) 2016, the NADAC served 2,541 patients, of which 1,054 were newly diagnosed and 1,487 were returning, through the Northwestern Neurobehavior and Memory Clinic, a multidisciplinary team of neurologists, neuropsychologists, neuropsychiatrists and social workers. NADAC members continue to provide dementia education to clinicians, research scientists, patients, families, and the general community

through a variety of modalities which include Alzheimer’s disease seminars which reach over 500 clinicians, scientists, and students per year, their annual Alzheimer’s Day which consistently reaches over 425 people; quality of life enrichment programs, including the Buddy Program, support and education programs and other innovative interventions that serve over 400 patients and families per year. NADAC members continue to contribute to the advancement of scientific research and publish an annual average of 40 peer reviewed papers, six book chapters/invited papers, and 24 abstracts in the field of aging, dementia and cognitive impairment. A total of 543 patients are currently active participants in the Alzheimer’s Disease Core Center which supports 35 collaborative studies, including clinical drug trials and non-pharmacological interventions. An annual newsletter is distributed to over 7,500 patients, families, professionals and community residents.

The 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.

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

The overall goal of the RADAC is to provide an infrastructure to support high quality clinical care, community-wide education, and research into the causes, prevention, and treatment of Alzheimer’s disease. These activities foster the independence and wellbeing of Illinois citizens and reduce disability and other common chronic age-related conditions. The RADAC has four cores carefully designed to provide this infrastructure: 1) Administrative, 2) Clinical and Patient-Oriented Research, 3) Population Research and Laboratory Studies and 4) Education.

In fiscal year 2016, the RADAC conducted more than 2000 clinical evaluations including evaluations on new and return patients at the RADAC clinic and evaluations as part of an ongoing study funded by sources other than State funds; produced more than 75 manuscript publications; 3339 telephone contacts were made with Data Repository participants to request study participation, schedule study visits, collect study data, and provide study information; over 16,725 persons participated in 694 educational activities including community leadership networking, community engagement, community research presentations, community giving, and media presentations, including 58 percent White, 37 percent African-American, and five percent other with 32 percent identifying their ethnicity as being Hispanic.

- *Southern Illinois University (SIU), School of Medicine, Center for Alzheimer’s Disease and Related Disorders (CADRD), Springfield*

CADRD is a state-supported center with the following seven 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 public, students, residents, practicing physicians and other health care professionals
- Maintain a centralized patient database for monitoring patients and controls evaluated at CADRD and the primary provider sites (PPS – see 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 public 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

In FY 2014-2016, CADRD completed 1,433 Initial and 5,865 Follow-up assessments of individuals with cognitive problems. CADRD provided 333 educational and training sessions in 43 different communities with 13,618 attendees. Ninety-four publications were produced.

The PPS system organized by SIU consists of 32 sites located in 27 different counties to serve the primarily rural portion of Illinois, and is addressed in this plan.

ADA Center Primary Provider Sites (PPS)

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

In populous areas, PPSs may include dementia specialists, social workers, psychologists, nurse practitioners and educational specialists. In rural areas, a minimal staff of a nurse, a social worker and a supervising physician may comprise the PPS.

The 32 PPS follow SIU assessment guidelines and coordinators attend training biannually in Springfield. As each community has different needs, some examples of additional services offered by PPS are transportation, respite care, support groups; and Tai Chi, exercise, art appreciation and other non-pharmacological interventions for those with dementia. In FY 2014-2016, these sites completed 2,037 Initial and 1,918 Follow-up assessments of individuals

with cognitive problems and provided 758 education programs in 81 different communities with 22,645 people in attendance.

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 in Illinois.” However, it is difficult to provide specific, quantifiable data.

The most direct state source of research dollars are those 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. The state income tax check-off donation is the source of this funding. IDPH has promulgated rules to establish criteria for the determination of awards and distribution of grants. Under the Alzheimer’s Disease Research Act, additional donations to this fund received by the state of Illinois also can be used for grant awards.

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 23 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 Guardianship and Advocacy Commission.

The ADAC reviews programs and services provided by state agencies directed toward persons with Alzheimer’s disease and related dementias, and, by consensus, recommend changes to improve the state’s response. ADAC’s recommendations are reflected throughout this state plan.

ADAC also is responsible for reviewing and recommending grant awards to Illinois researchers under the Illinois Alzheimer’s Disease Research Act.

Illinois State Agencies Programs and Support

Illinois Department of Public Health

IDPH is responsible for implementing activities of the Alzheimer’s Disease Assistance Act (410 ILCS 405) and the Alzheimer’s Disease Research Act (410 ILCS 407).

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 with dementia and their caregivers.

The Senior Help Line connects 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 (AAA) act as a gatekeeper for federal funds from Title III of the Older Americans Act. These programs are distributed 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 the elderly 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) function as gatekeepers to the state long-term care system by coordinating and integrating community-based long-term care services available throughout the entire aging network for and on behalf of frail and vulnerable older persons. 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 (Commission)

Created in 1979, the Commission protects the rights and promotes the welfare of persons with disabilities. A board of eleven Commissioners, who serve without compensation, govern the agency. The Commission is an executive state agency created to safeguard the rights of persons with disabilities. By providing legal representation, investigating complaints of rights violations and providing state guardianship for Illinois' population with disabilities, the Commission has given voice to those who have previously gone unheard.

The Commission's Intake Unit provides information to citizens about guardianship, powers of attorney, the Health Care Surrogate Act and other resources for individuals with disabilities, including Alzheimer's. More than 5,000 inquiries are received each year. The toll-free Intake number is 866-274-8023. The Commission's Office of State Guardian (OSG) is appointed "guardian of last resort" when there are no family members or friends willing or able to serve as guardian. OSG received 450 new cases in FY2013; 26 percent were individuals diagnosed with Alzheimer's related dementia.

Dementia Care Services

Access to, and coordination of, dementia care resources are critical to ensure people with Alzheimer's disease can experience the highest quality of life possible, to support caregivers, and to control health care costs. Often the just-diagnosed are not presented with information of available care options. Those with a diagnosis under the age of 65 experience an especially acute need for resources. People with dementia who receive care from a multitude of providers often suffer from the lack of coordination between providers, or the lack of dementia knowledge in the people treating them. This lack of knowledge leads to unnecessary emergency room visits, overuse of antipsychotic and other sedative medications.

Dementia-Specific Training Requirements

In Illinois, there are specific dementia training requirements for skilled nursing facilities (SNFs) and assisted living facilities (ALFs) with dementia care programs (77 IL Adm. Code 300.7000-7080 and 77 IL Adm. Code 295.4060). There are also training requirements listed for supportive living programs (SLPs) with dementia care pilots (89 IL Adm. Code 146.600-710).

In Illinois, Certified Nursing Assistants (CNA) receive 120 hours of initial instruction. Of those 120 hours, 12 hours at minimum are required to be dementia-specific (IL Adm. Code, 77, 395.300, r - z). The statute includes a thorough list of topics to be covered as part of the training. CNAs working in special care units (SCU) are required to have an additional 12 hours of dementia specific continuing education training each year (IL Adm. Code, 77, 300.7050 (e), 1 - 10).

In Illinois, Senate Bill 2301, enacted August 15, 2016, created the Alzheimer's Disease and Related Dementias Services Act requiring Alzheimer's disease and related dementias services programs to provide materials defining the philosophy of the program, specific services offered, and behavior management tactics employed at admission, enrollment, or earlier upon request.

The Act specifies training requirements for staff with direct access to clients with Alzheimer's disease or a related dementia and requires employers to maintain records of such training and the curriculum used. IDPH must provide information about Alzheimer's disease and related dementias training on its website and must promulgate rules to implement the Act by January 1, 2017

It is recommended that the state should ensure adequate funding and other incentives to ensure dementia care training is available for, and accessible to, family/friends of those with dementia and other unpaid caregivers; staff of state agencies; the health care workforce providing caregiver respite and support services; in-home and community-based services; and staff in licensed residential care settings.

Quality Care Measures

Illinois has an Alzheimer's Disease and Related Dementias Special Care Disclosure Act which requires all 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, 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 SLPs, there are basic special regulations that apply to the dementia care pilot that the Department of Healthcare and Family Services is implementing (89 IL Adm. Code 146.600-710).

Skilled Nursing Facilities (SNFs)

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 Division of Assisted Living oversees 418 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 AL and Memory Care areas are private pay through an establishment contract. Renewal applications and licensure fees are required yearly.

Supportive Living Programs (ALF/SLP)

Illinois developed the Supportive Living Program as an alternative to nursing home care for low-income older people and people with disabilities under Medicaid.

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

The Department of Healthcare and Family Services has obtained a "waiver" to allow payment for services that are 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 at the facility.

Currently, there are 146 certified SLP providers with 11,930 apartments. Another 17 projects with 1,842 apartments are in various stages of development. There are five dementia sites with 119 apartments.

Geriatric-Psychiatric Services

Due to the sometimes challenging behaviors associated with Alzheimer's disease and other dementias, individuals or program staff caring for someone with memory loss 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 facility in which they reside.

In order for psychiatric hospitalization to occur, an individual must meet basic mental health code criteria of being deemed harmful to him or herself or others. Common behaviors that may be associated with Alzheimer's disease and related dementias 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, because many emergency departments do not have the expertise, staff, time, and stabilizing environment to deal with a dementia patient whose behavior may be out of control.

Also the availability of hospital geriatric-psychiatric beds is low, particularly outside Cook County, resulting in many individuals spending two- to three-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 with memory loss in their facilities by creating geriatric units, what defines such a unit is not addressed on a state level to ensure consistency.

Staff in the geriatric psychiatric units of hospitals, are not currently receiving standardized training to ensure the best evidence-based care practices are utilized when treating individuals with cognitive challenges associated with dementia. These care practices differ from those implemented in the treatment of individuals without the cognitive challenges.

Additionally, after receiving psychiatric treatment and stabilization, facilities are often reluctant to accept or re-admit individuals with a behavioral history. Such denial 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 with Alzheimer's disease and related dementias who exhibit advanced behavioral issues. Assuming that the current model could be improved, it may be necessary to design incentives to encourage changes to meet the needs of persons with Alzheimer's disease and related dementias with behavioral issues requiring intervention.

Home and Community-Based Resources

Home and community-based services for people with Alzheimer's disease and related dementias are essential for a number of reasons:

- These are the services preferred by most persons with Alzheimer's disease and related disorders 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.

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, and
- 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 210,000 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; 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 transferring to higher levels of care because of the stigma and costs involved.

The need for affordable SLPs appropriate for people with dementia is especially acute and the availability of even costly ALFs with dementia care does not meet the demand. There are only 55 ALFs with freestanding dementia care buildings and 78 with dementia 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 SNF.

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 takes into account the safety of the individual and the safety of the general public. People with Alzheimer's disease or related dementia 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 is also increasing. 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.

Currently, standardized, statewide dementia training is not part of the curriculum for new or existing law enforcement officers, firefighters, or ambulance personnel. First responders and other public safety personnel do not learn best practices for identifying individuals with dementia, communication techniques, or strategies for diffusing challenging behaviors. Additionally, due to lack of knowledge, emergency personnel may not understand that six out of ten individuals with Alzheimer's disease will wander, either on foot or by vehicle, creating safety concerns in the community and on roadways. Being knowledgeable about dementia and how it may affect the memory, communication abilities, and judgment of those with varying degrees of dementia will greatly benefit both the service provider and the person with dementia. Ignorance of how dementia may impair the functioning of the person may lead to ineffective or even counterproductive interactions and results.

Research shows driving ability declines with age and/or declining cognitive ability. The addition of the written exam to the driver's license renewal process for older adults adds a cognitive dimension and increases the likelihood that those who may have Alzheimer's disease or another dementia will be recognized. Older drivers in Illinois are already tested according to an

age-determined schedule, so adding the written exam as a routine requirement is a logical, reasonably low-cost method, to screen for drivers who may have dementia. This will strengthen the state's ability to ensure its drivers are driving safely. Additionally, motor vehicle service facility personnel should be trained not to assist any person completing any part of the driving test, including vision, sign identification, the written test, and behind the wheel. To do so may allow an otherwise unqualified person to receive a license.

About three million Americans with Alzheimer's disease and related dementias go missing each year. If an elderly person is not found within 24 hours, there is a 50 percent chance that he/she will suffer serious injury or die. 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). With respect to missing endangered seniors, however, the law does not extend beyond notification to law enforcement entities. An effective statewide emergency alert program should be established to aid in the identification and recovery of missing endangered adults. Several states have implemented legislation that broadens the notification system. To be truly effective, this program should be extended beyond law enforcement.

Acknowledgements

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Appendix A

Overview of 2014 – 2015 Illinois Alzheimer’s Disease State Plan Prioritization Process

In January 2014, Illinois Department of Public Health (IDPH) published the *Illinois Alzheimer’s Disease State Plan*. From 2014 – 2015, partners prioritized recommendations and identified next steps. IDPH contracted with the Illinois Public Health Institute (IPHI) to develop a plan and formal prioritization process for working with the Alzheimer’s Disease Advisory Committee (ADAC) members and partners to prioritize top short and long-term recommendations from the 63 overall recommendations for service and activity in the *Illinois Alzheimer’s Disease State Plan* and develop future action steps.

In collaboration with IDPH, IPHI designed a highly interactive consensus-based facilitation process which included multiple interventions for providing information, soliciting feedback, discussing and working towards consensus, reaching consensus and building upon the decisions made with incremental consensus building discussions and decisions. Surveys, webinars and in-person meetings were used throughout the process, each with a detailed facilitation plan. Technology of Participation and nominal group process techniques were used during the in-person meetings to reach consensus and ultimately prioritize top short and long-term issues.

Final Priorities - The final results for the facilitated prioritization process resulted in five long-term priorities and four short-term priorities out of the 63 recommendations offered in the 2014-2017 *Illinois Alzheimer’s Disease State Plan*. These 2014-2017 long-term priorities primarily served as a basis for many of the new 2017-2020 recommendations and many of the short-term priorities were accomplished.

Long-term Priorities	Short-term Priorities
Provide support to health care providers to offer coordinated care for persons with dementia	Utilize state and local data to identify trends in cognitive impairment and needs of care givers.
Identify standard basic core competencies for all health and social service providers and develop dementia specific training based on core competencies	Integrate Healthy People 2020 Objectives into State Health Improvement Plan .
Equalize and standardize all public benefits regardless of age of onset	Advocacy for Palliative Care, Comfort Care and Hospice so that patients who are eligible get the services for which they are eligible.
Create standards of care for all dementia patients in institutional care	Require long-term care facilities posing as a “ look-alike ” Special Care Unit to adhere to authentic SCU regulations.
Review and update all facility regulations	

Appendix B

2017 – 2020 Recommendations to Address the Needs of Persons with Alzheimer’s Disease, Their Families and Caregivers

LONG-TERM RECOMMENDATIONS

Illinois’ Alzheimer’s Disease Network

- **Long-term recommendation (LT) 1** - Utilize new state funding for collaborative efforts among the ADA centers and other academic institutions throughout the state. (*Regional Alzheimer’s Disease Assistance Centers.*)
- **LT 2** - Utilize the strengths of each of the three ADA centers, including epidemiology studies (Rush), non-AD related dementias (Northwestern) and rural outreach (SIU) to collaborate with the Illinois Department of Healthcare and Family Services and other state agencies; seek federal or private matches to leverage state funding for projects that capitalize on ADA center strengths; and foster partnerships among the Aging and Disability Resource Network, the Alzheimer’s Association and members of the Illinois Cognitive Resource Network. (*Regional Alzheimer’s Disease Assistance Centers.*)
- **LT 3** - Develop database repository mechanisms that facilitate the use of de-identified state data for research projects on the prevalence and incidence of Alzheimer’s disease, and share access among ADA centers to permit patient and caregiver recruitment for research to improve their quality of life. (*Regional Alzheimer’s Disease Assistance Centers.*)
- **LT 4** - As required by the Alzheimer’s Disease Assistance Act, ADA centers should demonstrate instances of referral to consultation and/or additional community services to ensure informed consent for treatment and to assist them in obtaining necessary assistance and support services through PPS and various private and public agency programs. (*Regional Alzheimer’s Disease Assistance Centers.*)
- **LT 5** - Streamline support of patients with Alzheimer disease by assigning an individual(s) in each ADA center to act as a point person to coordinate local care delivery or to guide Alzheimer’s patients and caregivers to available services. This person(s) would supervise distribution of new funds to local communities to further efforts for locally developed initiatives. (*Regional Alzheimer’s Disease Assistance Centers.*)
- **LT 6** - Integrate and expand the coordination between ADA centers and PPS to coordinate with other entities, such as local hospitals, community-based organizations, or care groups to identify and to engage additional stakeholders. (*ADA Center Primary Provider Sites.*)

State Supported Alzheimer’s Disease Research

- **LT 7** - Improve research funding in Illinois by expanded promotion of the state income tax check-off fund; increase the overall level of State funding for ADA Centers to support research, care and treatment; evaluate strategies to improve partnerships with private entities; and identify strategies used by other states to leverage additional research dollars.
- **LT 8** - Illinois research data regarding programs, demonstration projects and services supported by federal and state dollars involving older persons should be collected in a transparent data base (data.illinois.gov) to enable researchers and other stakeholders to access information in order to identify the needs of older persons with, or at risk for, dementia and to assist in developing and implementing grant proposals.

- **LT 9** - Promote Illinois as a competitive location for conducting research associated with Alzheimer’s disease.

Illinois State Agencies

- **LT 10** - With appropriate funding, identify and promote culturally-appropriate strategies designed to increase public awareness about dementia, including Alzheimer’s disease, to reduce conflicting messages, decrease stigma and promote early diagnosis. (*Illinois Department of Public Health*)
- **LT 11** - Include Alzheimer’s disease as a data point in IPLAN and urge inclusion of Alzheimer’s disease in local health needs assessments, as well as integration of Alzheimer’s disease awareness and education into local health department’s community health plans. (*Illinois Department of Public Health*)
- **LT 12** - Promote strategies to help ensure the state public health department has awareness of, and develops expertise in, cognitive health and impairment. (*Illinois Department of Public Health*)
- **LT 13** - Continue to administer the BRFSS cognitive impairment and caregiver modules in Illinois and use this and other surveillance data to enhance awareness of public health programming (e.g., link between BRFSS questions on cognition to health-related quality of life or falls prevention). Approximately \$68,000 is needed to implement both modules.
- **LT 14** - Train ombudsman, CCU and AAA service providers, adult protective services staff and managed care organizations to be knowledgeable about Alzheimer’s disease and related dementias. (*Illinois Department on Aging*)
- **LT 15** - Continue the work of the Department of Healthcare and Family Services to implement structural changes that will improve access to Medicaid-funded home and community-based long-term services and supports (LTSS), and streamline program eligibility and service delivery to consumers between state agency programs. The primary objective to achieve a rebalancing of Long Term Services and Supports (LTSS) by shifting individuals into home and community-based services and away from long-term institutional care. The structural changes include:
 - a. A uniform assessment process for access and eligibility to services.
 - b. A “no-wrong-door” entry into state services.
 - c. Conflict-free case management. (*Illinois Department on Aging*)
- **LT 16** - Provide grants to eligible Illinois organizations and institutions to improve service delivery, to develop evidence-based programs and to address unmet needs for individuals with Alzheimer’s and related dementias. (*Illinois Department on Aging*)
- **LT 17** - Enhance IDoA’s website to include information about specific resources available to individuals with Alzheimer’s disease and related dementias, such as the Illinois Alzheimer’s disease assistance centers, Alzheimer’s Association and alz.gov. (*Illinois Department on Aging*)

Dementia Care Services

- **LT 18** - Equalize and standardize public benefits for all persons with Alzheimer’s disease where funding is provided by the Illinois Division of Rehabilitation Services (for those in the program before age 60, including persons with younger-onset Alzheimer’s), the Illinois Department on Aging, the Medicaid program or some other source.
- **LT 19** - Improve the coordination and delivery of care by emphasizing strong links and relationships among hospital systems, medical, mental health, other home- and community-based services, long-term care facilities, emergency medical services and other health care agencies. This should include working with regional medical centers and community hospitals to improve assessment, referral and care coordination for people with dementia who are treated in hospital emergency

departments.

Dementia-Specific Training Requirements - The following recommendations are intended to improve access to care and consumer knowledge of care options, equalize benefits for people with young onset Alzheimer's disease, and improve care coordination across health settings.

- **LT 20** - Require periodic training for those employed in settings in which they are highly likely to encounter persons with dementia. This includes state agencies and departments (e.g., Department of Human Services, Department of Aging); programs; and subcontractors. Settings may include, but are not limited to emergency department and hospital personnel, licensed residential care settings, senior centers, senior housing, primary care physician offices, first responders, and public safety departments.
- **LT 21** - Standardize the training program for CNA's and care companion requiring use of evidence-based quality training to satisfy the minimum required training hours in dementia care.
- **LT 22** - In order to assure consistency in training, dementia-specific curricula should be developed, adapted or recommended for various professional caregiving audiences, taking into account the cultural background and literacy level of the trainee(s), and should include an assessment to learning, and outcomes measures (including how the training impacts the quality of care) should be identified and tracked. Dementia specific care expectations should be integrated into agencies policies and procedures and performance reviews. The curricula should be reviewed periodically to assure it is up to date and reflects current research and practice. Training should be accessible through a variety of formats, including, but not limited to, classroom, webinars, online, video conferencing and audio conferencing.

Quality Care Measures

- **LT 23** - Convene a panel of experts to review and update the SNF special care unit regulations, assuring they reflect current best practices and evidence-based research in dementia care. (*Skilled Nursing Facilities*)
- **LT 24** - Advocate for the appropriate use of comfort care/palliative and hospice services within licensed nursing facilities. (*Skilled Nursing Facilities*)
- **LT 25** - Convene a panel of experts to replace the basic dementia care provisions in the ALF and SLP regulations with comprehensive provisions that reflect current best practices and evidence-based research in dementia care, similar to those found in Subpart U. (*Assisted Living Facilities/Supported Living Programs.*)
- **LT 26** - Form a task force to examine the possibility of establishing standards for dementia SCUs specializing in serving those with severe behavioral issues. The task force would consist of experts in the field of dementia care, particularly experts in frontotemporal dementia (FTD) and other atypical dementias; experts in medical *and* non-pharmaceutical behavior management; family members of those with FTD or other atypical dementias; and care providers who currently have programs in place and are able to provide care for the most challenging dementia residents. Note: A subset of individuals with dementia experience severe behavior changes that can be difficult to care for in traditional long term care settings. This is especially true for people with atypical dementias, such as FTD. Families of these individuals are often challenged with finding appropriate placement, and even then may find themselves needing to find another placement if their family member acts out. Staff may not receive adequate training and may not understand how to best work with these individuals. (*Other residential settings*)
- **LT 27** - Form a task force to examine current services offered across state agencies. This task force will make recommendations as to how these various agencies may be able to work together to provide appropriate services for those with younger onset dementia. Those with younger-onset

dementias (diagnosed prior to age 65) find a lack of appropriate programs and services. Adult day programs and residential care are generally focused at persons 65 years of age or older. (*Other residential settings*)

Geriatric-Psychiatric Services

- **LT 28** - Create a standardized definition of a geriatric psychiatric unit, including acceptable and appropriate admission criteria to be followed by admitting facilities.
- **LT 29** - Explore the concept of linking hospital diagnostic codes with reimbursement and level of training

Home and Community-Based Resources - The following efforts are recommended to facilitate increased availability and informed utilization of home and community-based services.

- **LT 30** - Increase access to home and community based services for those with Alzheimer’s and other dementias who are not eligible for Medicare or Medicaid (including those under 65).
- **LT 31** - Coordinate efforts between public and social service transportation providers to improve community mobility, regardless of age, including expansion and reimbursement of transportation services for people with Alzheimer’s disease. Support should be included for an “arm to arm” model (driver walks the individual to the door and waits for a caregiver to answer and guide the individual inside) and implement dementia training for transportation providers.
- **LT 32** - Develop and implement strategies for recruitment of volunteer respite providers through a variety of sources, including nursing and other allied medical science schools’ intern programs, volunteer organizations, AARP, school volunteer placement offices and religious groups, and expand resources for caregivers of individuals with dementia.

Residential Options for Persons with Dementia - In order to improve quality, quantity and access to care, the following should be addressed: disparities in care, consumer education and empowerment, innovations in care, and the well-being of people with dementia in residential facilities.

- **LT 33** - Within the state’s aging and disability resource centers, inform the public on how to plan for the financing, insuring and legal issues associated with meeting long-term care needs. Develop and promote educational resources for better understanding of long-term care financing options. Create a network of patient navigators to assist with LTC planning and placement.
- **LT 34** - Test new models and expand evidence-based best practices in alternative care facilities caring for individuals with dementia. Explore the option of developing a pilot program of small group homes for those with a diagnosis of dementia. Many states have licensed small group homes as a care option for individuals with dementia. These settings, which are similar to the center for independent living model, are small, homelike and community-based. Given that most individuals with dementia require custodial care, this may be a better and more cost-effective option than large, institutional-based settings.

Public Safety and Law Enforcement

- **LT 35** - Ensure financial assistance through the Department on Aging and the Department of Rehabilitation Services to family caregivers for programs, such as Medic Alert/Safe Return and Comfort Zone, through the Alzheimer’s Association or other safety locator programs to help lower the incidences of wandering/missing person reports for those with dementia. Lower reports of wandering and lost individuals will also result in lower costs to first responder agencies, as there will be less need for response to missing and endangered person calls. Emergency home response systems are inappropriate for this population.
- **LT 36** - All older drivers who seek driver’s license renewal should be tested with the existing written test when they present for license renewal. Currently, older drivers who seek driver’s license

renewal must present to a state driver's license facility for vision and behind-the-wheel testing according to a schedule determined by their age and last renewal date. This recommendation adds the standard written test to the existing renewal process.

- **LT 37** - Ensure those who practice law in Illinois and serve the elderly are knowledgeable in recognizing and interacting with persons with Alzheimer's disease or related dementias. The Illinois State Bar Association should develop appropriate accreditation and continuing legal education requirements in this regard.