

# **Alzheimer's Disease Illinois State Plan**

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

2014-2017 Report and Recommendations  
January 2014

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## Introduction

In 2010, there were 210,000 persons with Alzheimer's disease living in Illinois. This figure is projected to reach 240,000 in 2025, a 14 percent increase. If all of the persons with Alzheimer's disease in Illinois lived in one city, it would be the state's second largest city. Alzheimer's 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 and other dementias is estimated to total \$203 billion in 2013, increasing to \$1.2 trillion (in today's dollars) by mid-century. Medicare and Medicaid cover about 70 percent of the costs of care. This dramatic rise includes a 500 percent increase in combined Medicare and Medicaid spending.

To put in to perspective the personal and economic impact of Alzheimer's disease and related dementias on persons with the disease, their families and caregivers, and state and federal governments, statistics about Alzheimer's disease and related dementias are presented in this state plan. A much more extensive compilation of facts and figures is published by the Alzheimer's Association every year at [www.alz.org](http://www.alz.org)

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 persons with dementia;
- access to appropriate services for persons 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 persons 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 persons with dementia and their caregivers; and
- expanded research for Alzheimer's and other dementias through state revenue and disbursement.

The Illinois Alzheimer Legislators 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 persons 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, the Illinois Department of Public Health (Department) 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 the Department; 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 the Alzheimer's 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 the Department, in partnership with the ADAC, to prepare a report addressing the impact of Alzheimer's disease and related dementias in Illinois; and, resources and services 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 needs 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, meets the requirement of the act.

Other legislation addressing living arrangements for persons with Alzheimer's, information gathering and autopsies, quality incentives and respite programs have been enacted. Most recently, the state Adult Protective Services Act was amended to include persons with Alzheimer's disease and Illinois created specialty license plates for Alzheimer's 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 at 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. 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 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 who survives 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, may be 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 citizens 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 patients and their caregivers. The law 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 to 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 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 plan identified challenges that face the nation, as well as some specific to Illinois. These include:

- Research on Alzheimer's disease has made steady progress, however, 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 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 to 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 address improved 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 state's Alzheimer's Disease Assistance 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 persons with Alzheimer's disease, their families, caregivers and professionals; and advocate for the needs of persons with Alzheimer's disease.
- Public/private partnerships, such as that of the Department and the Alzheimer's Association, are beneficial to assess the needs of persons with cognitive impairment and caregivers using Illinois BRFSS data.
- The Illinois Alzheimer Legislative Alliance is comprised of members of the General Assembly supportive of making Illinois a dementia-capable state.

### **Impact and Trends of Alzheimer's Disease**

Today, more than 5 million Americans are living with Alzheimer's disease, the sixth leading cause of death in the country and the fifth leading cause of death for those older than age 65. Projections are that the number of persons with this disease may double or even triple by 2050, barring a major medical breakthrough.

Approximately 500,000 persons develop Alzheimer's disease each year in the United States and by 2050, that number could reach 1 million a year. Alzheimer's 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 2010, about 3,000 people in Illinois died from Alzheimer's.

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 persons with Alzheimer's, 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 much 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 patients is the realization that Alzheimer's disease is the most costly of all diseases with respect to the cost to society. Patients often require nursing home placement or assisted living facilities and their family members may have to leave the work force to provide care. Although most Alzheimer's patients are of retirement age, some are younger than 65, necessitate 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 that suffers the most, dealing with the behavioral and caregiving requirements of the patient who may be unaware of his/her impairment and resistive 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**

The BRFSS is a data system that provides information on behaviors and conditions related to the leading causes of death, injury and disability. The 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 were related to cognitive impairment and caregiver activity for persons with Alzheimer's disease.

#### *Cognitive Impairment*

In 2011, BRFSS cognitive impairment module questions were included on the Illinois survey.

- 11.4 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; nearly 80 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:

- 39.1 percent reported confusion or memory loss that always, usually, or sometimes interfered with their ability to work, volunteer or engage in social activities, and/or caused them to give up household activities or chores.
- 63.9 percent reported they needed assistance in some area.
- 5.7 percent reported they always or usually received help from a family member or friend because of their confusion or memory loss.
- 33.4 percent lived alone, with no other adults or children in the household.
- 21.5 percent discussed their confusion or memory loss with a health care provider.

### *Caregiver Activities*

The 2009 Illinois BRFSS caregiver data demonstrates 147,960 persons reported providing an average 3,682,626 hours of caregiving *per week* to a family, friend or neighbor with Alzheimer's disease. 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 linkages can be made to accurate information and 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 added to the 2013 survey and results will be available in 2014.

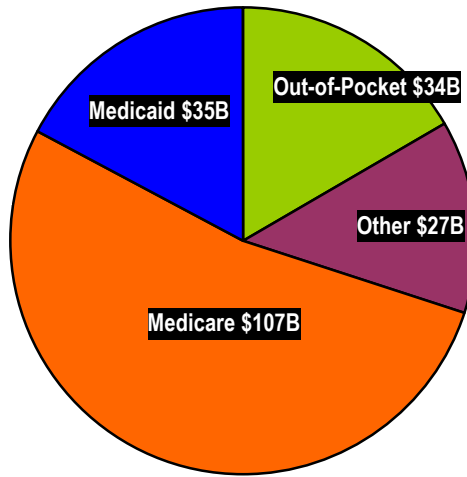
### **Economics of Alzheimer's Disease**

Alzheimer's disease poses a substantial financial burden on society. As the number of people with Alzheimer's disease and other dementias grows, spending for their care will increase dramatically. The total aggregate payments for health care, long-term care and hospice are projected to jump from \$203 billion in 2013 to \$1.2 trillion in 2050 (in 2013 dollars). Medicare and Medicaid cover about 70 percent of the costs of care. This rise includes a 500 percent increase in combined Medicare and Medicaid spending. These national dementia care costs are comparable to, if not greater than, those for heart disease and cancer.

**2013 Costs of Alzheimer's = \$203 Billion**

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

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, 2013 Alzheimer's Disease Facts and Figures, *Alzheimer's & Dementia*, Volume 9, Issue 2; and Unpublished data from the Medicare Current Beneficiary Survey for 2008.

Formal and informal unpaid costs of caring for people older than age 70 with dementia in the United States in 2010 were between \$159 billion and \$215 billion. These costs could rise dramatically with the increase in the numbers of older adults in coming decades. Care costs per person with dementia in 2010 ranged from \$41,000 to \$56,000 depending on how informal care costs were estimated.

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	\$20,638	\$18,380	\$23,792	\$7,832
Medicaid	10,538	232	24,942	549
Uncompensated	284	408	112	320
Private Insurance	2,355	2,588	2,029	1,584
Other Payer	943	171	2,029	149
Out of Pocket	9,754	3,297	18,780	2,378
Total*	45,657	26,869	71,917	14,452

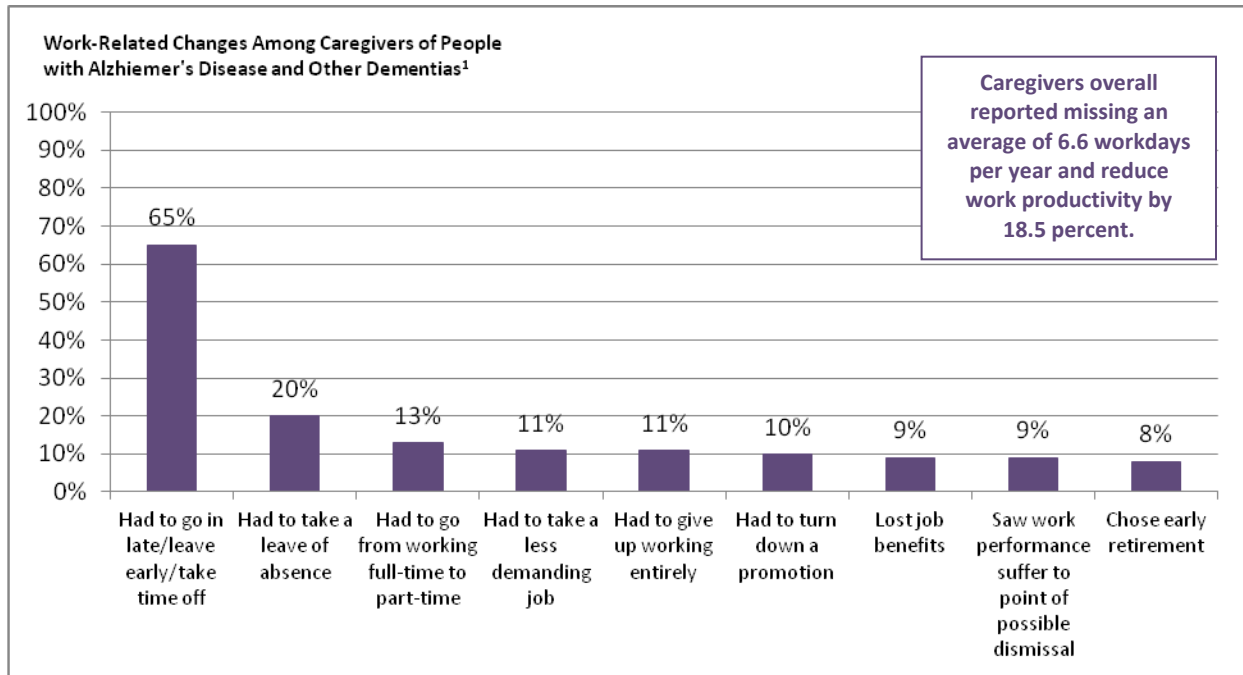
Source: Unpublished data from the Medicare Current Beneficiary Survey for 2008. \*Payments from sources do not equal total payments exactly due to the effect of population weighting. Payments for all beneficiaries with Alzheimer's disease and other dementias include payments for community-dwelling beneficiaries.

Caring for people with Alzheimer's disease also strains health and long-term care systems. Individuals with Alzheimer's disease use a disproportionate amount of health care resources; for instance, they are hospitalized 2-3 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*

The cost of Alzheimer’s disease and related dementias to businesses is profound. Of Illinois’ 584,000 caregivers for someone with dementia, 350,000 are employed in Illinois. Among caregivers of people with Alzheimer’s disease and other dementia, about 60 percent reported being employed full- or part-time. The negative effects of caregiving are the greatest for those aged 18-29, followed by 30- to 40-year-olds, individuals who are still early in their careers.



Source: Alzheimer’s Association, 2013 Alzheimer’s Disease Facts and Figures, *Alzheimer’s & Dementia*, Volume 9, Issue 2; Gallup Healthways Wellbeing Survey, More Than One in Six American Workers Also Act as Caregivers, July, 2011; and Coughlin, J., (2010). Estimating the Impact of Caregiving and Employment on Well-Being: Outcomes and Insights in Health Management, Vol 2; Issue 1.

Caregiver absenteeism costs the U.S. economy an estimated \$25.2 billion in lost productivity (based on the average number of work days missed per working caregiver, assuming \$200 in lost productivity per day). Of those providing care, 24 percent say caring for an aging family member, relative or friend has an impact on their work performance and it keeps them from working more hours. The cost of informal (unpaid) caregiving in terms of lost productivity to U.S. business is \$17.1 billion to \$33 billion annually.

*Costs to Illinois Citizens*

**In 2013, out-of-pocket spending for individuals with Alzheimer’s and other dementias is expected to total an estimated \$34 billion.**

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 \$9,754 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 \$3,297 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 as great – averaging \$18,780.

## **Services and Recommendations 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, educational specialists and research scientists with expertise in dementia care and research.

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 discoveries. 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 funded by the state of Illinois.

In fiscal year (FY) 2013, the NADAC served 1,741 patients, of which 484 were newly diagnosed and 1,257 were returning. NADAC members provided 72 lectures, published 41 papers, produced 12 abstracts and 4 book chapters/invited papers in the field of aging, dementia and cognitive impairment. A total of 466 active research participants participated in the clinical core activities, including 22 projects. The tissue bank has obtained 91 new blood samples for DNA extraction and plasma banking; and fixed and frozen tissue, paraffin blocks, unstained sections, and plasma from 240 cases were distributed to seven investigators resulting in 24 journal articles. A newsletter was published and mail to over 7,500 patients, families, professionals and community residents. NADAC hosted 9 Alzheimer’s disease seminars.

The NADAC has an affiliated faculty of approximately 40 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 FY 2013, the RADAC conducted more than 3000 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 100 manuscript publications; the Alzheimer's Family Care Center provided care to an average of 40 clients per day; 1,733 telephone contacts were made with Data Repository participants to request study participation, schedule study visits, collect study data, and provide study information; over 27,500 persons participated in 577 educational activities including community leadership networking, community engagement, community research presentations, community giving, and media presentations, including 43 percent White, 51 percent African-American, and six percent other with 10 percent identifying their ethnicity as being Hispanic.

A 12 hour training course was developed to meet the needs of the state regulation administered through the Department. An additional 12 hours of curriculum was utilized for sites that already completed the initial 12 hour training course and required ongoing state mandated training. Five courses were offered in FY2013 and reached approximately 200 health professionals in a variety of locations from continuing care communities to nursing homes.

- *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 loco motor 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 2013, CADRD serviced 2,628 patients, of which 1,877 reside in rural communities with populations of less than 50,000. CADRD provided 421 educational and training sessions with 10,736 attendees. Over 20 publications were produced.

The PPS system organized by SIU consists of 37 sites located in 31 different counties to serve the primarily rural portion of Illinois, and is addressed in this plan.

#### **Recommendation 1**

Improve the current funding formulas for the ADA centers to make funding comparable to states demographically similar to Illinois. Utilize new state funding for collaborative efforts among the ADA centers and other academic institutions throughout the state.

#### **Recommendation 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.

#### **Recommendation 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.

#### **Recommendation 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.

### **Recommendation 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.

#### ADA Center Primary Provider Sites

PPS are community-based medical programs that work directly with ADA center staff with 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 37 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 2013, these sites assessed 1,446 different individuals with cognitive problems and provided 301 education programs in 58 different communities with 5,592 people in attendance.

The following recommendations are made to improve PPS delivery of services to patients with Alzheimer disease and their families and caregivers.

### **Recommendation 1**

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.

### **Recommendation 2**

Improve the quality of local care available for persons with Alzheimer's disease by providing training for 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, including, but not be 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.



## *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, a lack of state funding to support an analysis of this makes it 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 the Department the responsibility of establishing a program that included the award of grants to encourage research on Alzheimer's disease. The state income tax check-off donation is the primary source of this funding. The Department 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 also can be used for grant awards.

State support of Alzheimer's disease research has positively impacted total research funding in Illinois. The state's investment in the three ADA centers has resulted in significant benefits that affect public health internationally. However, the various non-monetary dimensions of the impact are not easy to quantify.

In 2012, funding levels for states 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 2003, Illinois received \$3.3 million in state grant funds, in addition to state income tax-check off dollars, to support the ADA centers to provide diagnostic evaluation, treatment, referral and research. This amount was reduced to \$1.7 million when the funding mechanism was changed to include a federal match. And, in federal FYs 2013-2014, funds were cut by an additional 1.75 percent. If the original \$3.3 million had been left intact and matched with federal dollars, Illinois would be on par with other states.

### **Recommendation 1**

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.

### **Recommendation 2**

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 persons at risk or living with Alzheimer's disease.

### **Recommendation 3**

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.

### **Recommendation 4**

Promote Illinois as a competitive location for conducting research associated with Alzheimer's disease and increase local participation in clinical trials and studies on cognitive health and impairment.

#### *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 nonvoting members appointed by the director of the Illinois Department of Public Health. 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.

#### *Public Health, Aging and Guardianship and Advocacy Programs and Support*

The following agency recommendations were made by state agencies providing services to persons with Alzheimer's disease, their families and/or caregivers.

#### Illinois Department of Public Health

The Department 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).

### **Recommendation 1**

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.

**Recommendation 2**

Provide links from the Department's website to the state's ADA Centers, Alzheimer's Association and to [www.alz.org](http://www.alz.org) to improve Illinois citizen's access to information and assistance.

**Recommendation 3**

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); and develop state "Burden Briefs" related to Alzheimer's disease.

**Recommendation 4**

Integrate Healthy People 2020 objectives on "Older Adults" and "Dementias, including Alzheimer's disease" into topic areas in the State Health Improvement Plan.

**Recommendation 5**

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.

**Recommendation 6**

Promote strategies to help ensure the state public health department has awareness of, and develops expertise in, cognitive health and impairment.

**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, facility 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.

### **Recommendation 1**

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.

### **Recommendation 2**

Support the work of the Department of Healthcare and Family Services to implement the Balancing Incentives Program (BIP). The BIP was authorized under the Affordable Care Act to assist states with improving 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 care by shifting individuals into home and community-based services and away from long-term institutional care. The BIP requires three structural changes:

1. A uniform assessment process for access and eligibility to services.
2. A "no-wrong-door" entry into state services.
3. Conflict-free case management.

### **Recommendation 3**

Seek federal grant opportunities to promote the development of a dementia-capable state and to implement programs that benefit persons with Alzheimer's disease and related disorder, and their family caregivers.

**Recommendation 4**

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.

**Recommendation 5**

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 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 FY13, 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.

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.

**Recommendation 1**

Strengthen health care practices at the point of diagnosis by encouraging dedicated staff support or by providing referrals to appropriate entities such as the ADA centers, Alzheimer's Association or the state's aging and disability resource centers to assist in planning care or to provide case management, and to develop formal mechanisms for education and referral to

health care homes and community-based agencies that offer specialized expertise, social supports and mental health services.

### **Recommendation 2**

Work with stakeholders to preserve the elements of Medicaid essential to those living with Alzheimer's disease and their families, and 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.

### **Recommendation 3**

Provide physical, emotional and financial assistance to unpaid caregivers of people with dementia, including respite and support services.

### **Recommendation 4**

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.

### **Recommendation 5**

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*

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 facilities (SLFs) 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). While there is no one approved curriculum for CNA training, 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).

Overall, the state should provide 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.

**Recommendation 1**

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.

**Recommendation 2**

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 and public safety departments.

**Recommendation 3**

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 should be identified and tracked. 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.

**Recommendation 4**

Standardize the training program for CNA's requiring use of evidence-based quality training to satisfy the minimum required training hours in dementia care.

*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 SLFs, 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)

There are approximately 1,200 SNFs in Illinois. Of those, 156 have licensed SCUs. However, there are SNFs that have opted not to pursue SCU licensing, but have developed and advertised programs that appear similar to those that are licensed. Rather than calling these programs “special care units” they may be called “memory support programs” or “memory care wings.” This is confusing to family caregivers, and serves as a disincentive to facilities to seek licensure under Subpart U.

### **Recommendation 1**

SNFs with “look-alike” dementia special care programs or units that have not pursued dementia SCU licensure should be regulated as SCUs.

### **Recommendation 2**

Provide annual training to all long term care (LTC) surveyors and LTC ombudsmen on Subpart U, providing examples of licensed SCUs that are implementing best practices in dementia care into their programs. Part of this training should be assisting surveyors to identify look-alike programs and to encourage them to survey these programs appropriately.

### **Recommendation 3**

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.

### **Recommendation 4**

Re-examine and update rules for facilities that must, or should, comply with the Alzheimer’s Disease and Related Disorders Special Care Disclosure Act (210 ILCS 4/), which includes ALFs, SNFs and SLFs. Mandate full disclosure to potential consumers or their designees the first time marketing materials are offered to the consumer or designee and prior to contracting with the facility for services.

### **Recommendation 5**

Advocate for the appropriate use of comfort care and hospice services within licensed nursing facilities.

## Assisted Living Facilities/Supportive Living Facilities (ALF/SLF)

### **Recommendation 1**

Convene a panel of experts to replace the basic dementia care provisions in the ALF and SLF regulations with comprehensive provisions that reflect current best practices and evidence-based research in dementia care, similar to those found in Subpart U.

### **Recommendation 2**

Utilize data from the SLF pilot; expand the availability of SLF dementia care units in the state.



### **Recommendation 3**

Reassess and update ALF and Shared Housing Administrative Rules to ensure resident's rights for ALF residents and update rules for facilities that must or should comply with the Alzheimer's Disease and Related Disorders Special Care Disclosure Act (210 ILCS 4/), which includes ALFs, SNFs and SLFs. Mandate full disclosure to potential consumers or their designees the first time marketing materials are offered to the consumer or designee and prior to contracting with the facility for services.

### **Recommendation 4**

Create standardized mandatory licensing requirements to ALFs providing care to any resident with a dementia diagnosis.

### Other Residential Settings

#### **Recommendation 1**

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.

#### **Recommendation 2**

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.

#### **Recommendation 3**

Develop and mandate effective training in behavioral interventions (using evidence-based practices) for personnel working with people with dementia in residential care settings.

#### *Geriatric-Psychiatric Services*

Due to the sometimes challenging behaviors associated with Alzheimer's disease and other dementias, individuals or facility 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 and, if appropriately used. 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, is 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 be capable of meeting the current or future needs of persons 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.

**Recommendation 1**

Create a standardized definition of a geriatric psychiatric unit, including acceptable and appropriate admission criteria to be followed by admitting facilities.

**Recommendation 2**

Mandate education of long-term care staff on appropriate behavioral interventions, such as redirection to manage problematic behaviors and minimize escalation of persons with Alzheimer's and related dementias, as well as standards that qualify an individual for psychiatric hospitalization, and enforce appropriate hospitalization practices through annual state survey of licensed long-term care facilities.

**Recommendation 3**

Establish evidence-based care practices for individuals with Alzheimer's disease and other dementias within a psychiatric hospital setting and ensure direct care staff is trained on such care practices. Explore the concept of linking hospital diagnostic codes with reimbursement and level of training.

**Recommendation 4**

Establish long-term care facility transfer/discharge regulations on a state level and ensure persons with Alzheimer's or related dementia are not transferred or discharged solely because they exhibit disruptive behavior.

**Recommendation 5**

Collaborate with state agencies, nursing homes and home- and community-based providers to increase the capacity of the long-term care system to serve people with neuropsychiatric symptoms associated with Alzheimer's or related dementia to optimize patient care and help decrease incidences of hospitalization and inappropriate placement.

*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 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 are 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.

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

**Recommendation 1**

Support the efforts of existing community-based infrastructures (such as the Balancing Incentive Program), that provide greater access to services and to support for persons with dementia; and, develop a state wide public education program to enable informed consumer choice of home and community-based providers. Support the implementation of a coordinated point of entry process that includes a standardized assessment and a two step case management and referral process that minimizes conflicts of interest.

**Recommendation 2**

Equalize the service package for every person with Alzheimer’s disease, whether they are younger or older than age 60. Seek the necessary waivers to consolidate home and community-based services for persons with any stage of Alzheimer’s disease, regardless of the age of onset, to allow a family member, including a spouse, to receive some form of financial incentive for their services and for the additional costs incurred in caring for a person with Alzheimer’s disease at home.

**Recommendation 3**

Identify and expand use of evidence-based best practices within settings designed specifically for individuals with early stage dementia, including adult day services, and provide incentives to extend daily, weekend and evening hours to meet the needs of working caregivers.

**Recommendation 4**

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.

**Recommendation 5**

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*

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 have dementia units.

The need for affordable SLFs 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.

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.

#### **Recommendation 1**

Create more assisted living-level of care for persons with Alzheimer's disease who cannot pay privately for their care and increase availability of residential care, including Medicaid funded, for people with young-onset.

#### **Recommendation 2**

Inventory and evaluate the state's current long-term care facility infrastructure across settings to identify gaps and shortages in service delivery. Gaps and shortages to be assessed by region, income eligibility and level of service provided (i.e. low availability of Medicaid beds in rural areas in facilities that will accept people with behavioral symptoms of dementia).

#### **Recommendation 3**

Work with industry and other stakeholders to identify strategies that would provide appropriate reimbursement and/or other incentives to increase the number of dementia care units and qualified workforce.

#### **Recommendation 4**

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.

#### **Recommendation 5**

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*

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. Persons 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 6 out of 10 individuals with Alzheimer's disease will wander, either on foot or by vehicle, creating safety concerns in the community and on roadways. Being knowledgeable of 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 exists to assert that driving ability decreases 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 assure 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 3 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 legislation<sup>1</sup> 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 must 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, the General Assembly should pass legislation to extend this program beyond law enforcement.

#### **Recommendation 1**

Ensure first responders are knowledgeable in recognizing and interacting with persons with Alzheimer's disease or related dementias through annual state mandated and regulated dementia training within law enforcement and fire safety departments. Minimum training standards should be included.

#### **Recommendation 2**

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.

#### **Recommendation 3**

Implement a coordinated protocol for swift and appropriate action by law enforcement, the news media and other entities upon a report of a missing endangered senior who is incapable of returning to their residence without assistance. Most persons with Alzheimer's disease or a related dementia will meet these criteria. The protocol should include funding for the training of law enforcement personnel in methods for the search and rescue of such persons.

#### **Recommendation 4**

Ensure financial assistance through the Department on Aging 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.

#### **Recommendation 5**

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.

## References

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- 3 The 2011 Illinois Behavioral Risk Factor Surveillance System, Cognitive Impairment Module Data, Illinois department of Public Health
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- 5 Data are in 2013 dollars; created from data from the application of The Lewin Model, which reflects more recent estimates and projections of the prevalence of Alzheimer's disease, created for the Alzheimer's Association by The Lewin Group, to data from the Medicare Current Beneficiary Survey for 2008. "Other" payment sources include private insurance, health maintenance organizations, other managed care organizations and uncompensated care.
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## **Illinois Alzheimer's Disease Advisory Committee**

**Chair:** Rhonda Clancy

Tom Ala

David Bennett

Judy Buchanan

Jeff Christiansen

Erna Colborn

Jerome Epplin

Nancy Flowers

Theresa Gowin

Judith Hertz

Samuel Hill

Kathleen Knope

Lori Kerns

Dennis McManus

Mary Mayes

M.-Marsel Mesulam

Mary Milano

Conny Moody

Darby Morhardt

Mary Nagy

June Ninnemann

Melvin Siegel

John Smith

Orlinda Speckhart

Robert Struble

## **Additional Partners:**

Jennifer Belkov

Melanie Chavin

Danielle Dodson

Susan Frick

Karen Graham

Stephanie Herro

Bryan James

Chuck Johnson

Greg Kyrouac

Cindy Marsden

Sandra Mollahan

Raj Shah

Wayne Smallwood

Jane Stansell

Bruce Steiner

Melissa Tucker

Jennifer Weuve