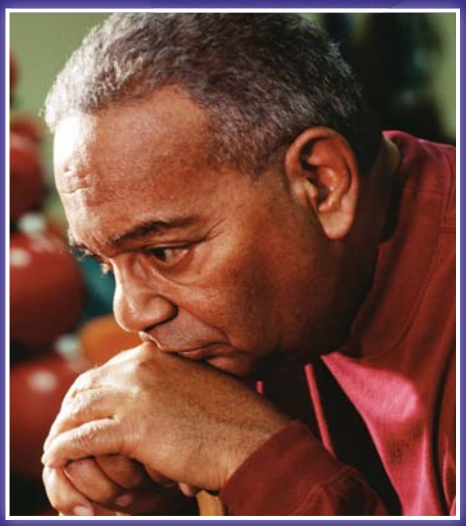

Missouri Alzheimer's State Plan Task Force

Report to Governor Jermiah W. (Jay) Nixon and the Missouri General Assembly

November 2010

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Executive Summary

Alzheimer's is a national crisis, affecting Americans across all walks of life and across all regions of the country. There are 5.3 million Americans with Alzheimer's and another person is added every 70 seconds. Caring for those with Alzheimer's and other dementias costs our country a total of $172 billion, including $122 billion in costs to Medicare and Medicaid. It is estimated that by 2050, 13.5 million Americans aged 65 and older will have Alzheimer's disease and the costs of care will reach over $800 billion annually.

The Missouri Alzheimer's State Plan Task Force was commissioned by the 95th General Assembly to achieve three goals:

1. Assess the current and future impact of Alzheimer's disease and related dementia on residents of the State of Missouri.
2. Examine the existing services and resources addressing the needs of persons with dementia, their families, and caregivers.
3. Develop recommendations to respond to the escalating public health emergency regarding Alzheimer's.

The 19 members of the Task Force include representation from state government composed of the Lieutenant Governor, the state departments of Health & Senior Services, Social Services and Mental Health, the House of Representatives and State Senate, professionals working with persons with Alzheimer's, family caregivers and a person living with Alzheimer's.

Public input was gathered through meetings in five geographic regions of the state. At these community forums the task force listened to the frustrations, concerns and advice of those dealing with the effects of Alzheimer's disease on them and their families. They spoke about the difficulty of getting an appropriate diagnosis; the physical, emotional, and social stress of caregiving; the financial hardships experienced paying for care; and the strong desire to keep their loved ones at home. A summary of these comments is provided in the appendix.

These comments served as a foundation for the recommendations developed. The task force has identified five focus areas with goals and strategies for the State of Missouri to address and respond to the escalating public health crisis regarding Alzheimer's.

Access to early intervention and support

The Alzheimer's State Plan Task Force recommends a concerted effort be made to enhance public awareness about the disease, promote early detection and provide better access to needed information and support.

Goal: Promote access to statewide expert diagnostic services that can lead to early intervention and support.

Strategies

- Promote physician and health care professional educational opportunities to increase detection and diagnostic services and provide access, information and support for newly diagnosed individuals and their families.
- Implement a public awareness campaign to increase early intervention and diagnosis. The Missouri Department of Health & Senior Services and the Alzheimer's Association will seek non-governmental grant funding for a campaign that will be based on best practices in social marketing.
- Pilot statewide dementia assessments with physicians at an early point of contact through the implementation of such tools as the AD8 as called for in Missouri Alzheimer's Innovation Grant from the Administration on Aging.
- Initiate partnerships for the development of endowed residency and geriatric fellowships to increase the number of geriatricians.

Road Map for Care and Support

The Alzheimer's State Plan Task Force recognizes the need for information that will assist individuals throughout the progression of the disease. The information should be comprehensive, easy to understand and access. It should build on statewide resources such as state websites maintained by the Missouri Department of Health and Senior Services, Area Agencies on Aging, and Alzheimer's Association.

Goal: Create a Road Map for care and support that provides quality information on services across the continuum from early diagnosis to end of life.

Strategies

- Identify existing statewide resource databases and evaluate them for inclusion of dementia related resources.
- Create a Road Map including community organizations such as the Alzheimer's Association and Area Agencies on Aging network that provide unbiased information on care planning and in-person consultation.
- Develop a strategy for dissemination of the Road Map to consumers, health care professionals, and community partners.

Services and Support

The Alzheimer's State Plan Task Force supports initiatives to improve services that enable those with Alzheimer's disease and other dementias to live longer in their homes and neighborhoods, if they wish to do so. Families who now bear much of the burden of caregiving should have access to cost effective supports to help them care for their loved ones at home.

Goal: Provide a wide array of community and home based services that may offer more cost-effective options for the rapidly increasing number of Missourians with Alzheimer's or related disorders and their caregivers.

Strategies

- Examine existing MO HealthNet programs for gaps in service that may limit the ability to utilize home and community based care.

- Identify and disseminate information on respite programs and advocate for expanded respite resources.
- Enhance community awareness of the benefits of long term care insurance including Missouri's Long Term Care Partnership Program, the CLASS program and Missouri's new premium refund law.
- Identify the opportunities for the State of Missouri to secure federal and non-federal funding to advance home and community based options for those with Alzheimer's and related dementia.

Delivering Improved Dementia Care

The Alzheimer's State Plan Task Force supports initiatives to ensure an available and adequately trained workforce of health professionals who have the incentive to provide collaborative and person centered care.

Goal: Ensure a sufficient, dementia conscious, quality workforce at all levels of the care continuum.

Strategies

- Review current dementia training requirements and make recommendations designed to strengthen the delivery of quality dementia services across the care continuum including appropriate behavioral interventions and medications.
- Design a structure to review transfers/discharges of persons with Alzheimer's disease or related dementias.
- Advocate for including accredited dementia training for the career ladder workforce.
- Identify guidelines for assessment, diagnosis and treatment of individuals with dementia to assure appropriate location and level of service.
- Identify appropriate standards of care for behavioral health units that treat individuals with dementia.
- Advocate for guidelines of inpatient behavioral health services to assure that the models address the specific treatment of individuals with dementia.
- Recommend ongoing in-service training on Alzheimer's disease and related dementia for first responders through programs such as Missouri Peace Officer Standards & Training.
- Support the development of a pilot demonstration project that incorporates dementia specialists assigned as a treatment team member for all individuals with dementia while inpatient in hospitals and behavioral health settings.

Missouri as a Leader in Alzheimer's Research

Goal: Maintain Missouri's status as a research leader in Alzheimer's disease and related disorders.

Strategies

- Advocate for restoration of state funding to Missouri based researchers for the Alzheimer's Disease and Other Related Disorders Program.
- Partner with academic institutions across the state to develop a research summit with the dual goals of fostering scientific collaboration and disseminating current research to the general public.

Jeremiah W. (Jay) Nixon
Governor

Peter Kinder
Lt. Governor & Chairman

State of Missouri
Alzheimer's State Plan Task Force

November 15, 2010

The Honorable Jay Nixon
Governor
State of Missouri
State Capitol, Room 216
Jefferson City, Missouri 65101

Dear Governor Nixon:

In 2009, the Missouri General Assembly passed HB 272 that created the Missouri Alzheimer's State Plan Task Force charged with addressing the challenges of Alzheimer's disease and related dementia for future generations. We hereby submit to you the Task Force's State Plan as considered and approved by a vote of the task force.

This State Plan includes an assessment of the current and future impact of Alzheimer's and related dementia on residents of Missouri. It examines existing services and resources available for persons with dementia, their families and caregivers. It includes recommendations to respond to this escalating public health situation.

On behalf of the task force members, I submit this report to you and the Missouri General Assembly for your review and consideration. We believe that the following State Plan will provide the necessary roadmap to improve the lives affected by Alzheimer's disease.

It has been an honor to be Chairman of the Missouri Alzheimer's State Plan Task Force and please let me know if I or the other members of the task force can be of additional assistance to you as your consider these recommendations.

Sincerely,

Peter Kinder

Lt. Governor Peter D. Kinder
Task Force Chairman

Missouri Alzheimer's State Plan Task Force Membership

Lt. Governor Peter Kinder
Chairman

Richard AuBuchon, J.D.
Jerry Dowell
(resigned Nov. 1, 2010)
Lt. Governor's Designee

Margaret Donnelly, J.D.
Director, Health & Senior Services
Glenda Meachum-Cain
Health & Senior Services Designee

Keith Schafer
Director, Mental Health
Jan Heckemeyer
Lynn Carter
(retired Aug. 31, 2010)
Mental Health Designee

Ronald Levy
Director, Social Services
Theresa Valdes, Social Services Designee

Representative Maria Chappelle-Nadal
House of Representatives Member

Senator Bill Stouffer
Missouri Senate Member

Gwendolyn Richards
Member with early-stage Alzheimer's or related dementia

VACANT
Maureen Dempsey, M.D.
(resigned Nov. 1, 2010)
Member who is a family caregiver of a person with Alzheimer's or a related dementia

John Morris, M.D.
Member who is a licensed physician with experience in the diagnosis, treatment, and research of Alzheimer's disease

Carol Scott
Julie Ballard
(resigned Oct. 15, 2010)
Member from the office of the state ombudsman for long-term care facility residents

Lisa Baron, J.D.
Member representing the home care profession

Timothy Dolan
Member representing residential long-term care

Deborah Ellis
Member representing the adult day services profession

John Huff, J.D., M.B.A.
Member representing the insurance profession

Jean Leonatti
Member representing the area agencies on aging

Joseph Palm, M.P.H.
Member with expertise in minority health

Lois Zerrer, J.D.
Member who is a licensed elder law attorney

Clara Carroll Rodriguez
Member from the leading voluntary health organization in Alzheimer's care, support, and research

Joan D'Ambrose
Member from the leading voluntary health organization in Alzheimer's care, support and research

Introduction

Alzheimer's disease poses a grave and growing challenge to our Nation.

Many experts already recognize that Alzheimer's will severely affect the lives of millions of Americans who either suffer from this disease or care for someone who does. Less appreciated are the grave economic consequences that Alzheimer's disease, with its cumulative costs, will impose on the country. Unless we take decisive action now, the Alzheimer's crisis could very easily surpass even the current economic crisis in the damage it inflicts on individuals and our economy.

The Report of the Alzheimer's Study Group, 2009, Newt Gingrich and Bob Kerrey, co-chairs

More than 110,000 individuals in Missouri are currently living with Alzheimer's or related dementia. With the aging of the baby boomer population, that number will escalate to more than 130,000 by 2025. In the mid-1980s, Missouri recognized Alzheimer's disease as an emerging issue and established the first Missouri Alzheimer's Task Force. Charged with developing strategies to respond to growing needs, the task force established new programs to support family caregivers and advance research.

What we know about Alzheimer's disease has dramatically changed since the first Alzheimer's Task Force.

In 2009, the General Assembly passed and Governor Nixon signed legislation calling for the establishment of an Alzheimer's State Plan Task Force to address the challenges of Alzheimer's disease both now and for future generations.

For the nineteen members appointed to the task force, gathering input from individuals living with Alzheimer's disease, family caregivers, and stakeholders from across the state was a critically important part of the planning progress. In early 2010, five community forums were held across the state. Four hundred people attended and passionately shared their stories and their ideas to better address the Alzheimer's crisis going forward.

Their voices resonate throughout this plan. The difficulty of getting an appropriate diagnosis; the physical, emotional, and social stress of caregiving; the lack of a road map for care; the financial hardships experienced paying for care; the strong desire to keep loved ones at home.

This plan is in response to the concerns voiced. It strives to enhance support to individuals with the disease and their care partners from early diagnosis to end of life. It is designed to provide the foundation for work that the task force will continue over the next two years.

Missouri is facing one of the most challenging economic times of recent history. In that context, this plan calls for modest funding in areas of critical importance - supports that will help families care for their loved ones at home and support for research that will move us closer to a cure.

Overview of Alzheimer's Disease

Alzheimer's disease is a brain disorder named for German physician Alois Alzheimer who first described it in 1906. Scientists have learned a great deal about Alzheimer's disease in the century since Dr. Alzheimer first drew attention to it. Today we know that Alzheimer's and related dementias:

- **Is a progressive and fatal brain disease.** Alzheimer's destroy brain cells, causing memory loss and problems with thinking and behavior severe enough to affect work, lifelong hobbies or social life. Alzheimer's disease gets worse over time, and can be fatal. Today Alzheimer's is the sixth - leading cause of death in the United States.

- **Has no current cure.** But treatments for symptoms, combined with the right services and support, can make life better for the millions of Americans living with Alzheimer's disease. There is an accelerating worldwide effort under way to find better ways to treat the disease, delay its onset, or prevent it from developing.

- **Is the most common form of dementia**. Dementia is a general term for memory loss and other intellectual disabilities serious enough to interfere with daily life. Alzheimer's disease accounts for 50 to 80 percent of dementia cases.

Types and Causes of Dementia

Types of Dementia	Characteristics
Alzheimer's disease	Most common type of dementia; accounts for an estimated 60–80 percent of cases. Difficulty remembering names and recent events is often an early clinical symptom; apathy and depression are also often early symptoms. Later symptoms include impaired judgment, disorientation, confusion, behavior changes and difficulty speaking, swallowing and walking. Hallmark abnormalities are deposits of the protein fragment beta-amyloid (plaques) and twisted strands of the protein tau (tangles).
Vascular dementia (also known as multi-infarct or post-stroke dementia or vascular cognitive impairment)	Considered the second most common type of dementia. Impairment is caused by decreased blood flow to parts of the brain, often due to a series of small strokes that block arteries. Symptoms often overlap with those of Alzheimer's, although memory may not be as seriously affected.
Mixed dementia	Characterized by the hallmark abnormalities of Alzheimer's and another type of dementia — most commonly vascular dementia, but also other types, such as dementia with Lewy bodies. Recent studies suggest that mixed dementia is more common than previously thought.
Dementia with Lewy bodies	Pattern of decline may be similar to Alzheimer's, including problems with memory and judgment as well as behavior changes. Alertness and severity of cognitive symptoms may fluctuate daily. Visual hallucinations, muscle rigidity and tremors are common. Hallmarks include Lewy bodies (abnormal deposits of the protein alpha-synuclein) that form inside nerve cells in the brain.

Parkinson's disease	Many people who have Parkinson's disease (a disorder that usually involves movement problems) also develop dementia in the later stages of the disease. The hallmark abnormality is Lewy bodies (abnormal deposits of the protein alpha-synuclein) that form inside nerve cells in the brain.
Frontotemporal dementia	Involves damage to brain cells, especially in the front and side regions of the brain. Typical symptoms include changes in personality and behavior and difficulty with language. No distinguishing microscopic abnormality is linked to all cases. Pick's disease, characterized by Pick's bodies, is one type of frontotemporal dementia.
Creutzfeldt-Jakob disease	Rapidly fatal disorder that impairs memory and coordination and causes behavior changes. Variant Creutzfeldt-Jakob disease is believed to be caused by consumption of products from cattle affected by mad cow disease. Caused by the misfolding of prion protein throughout the brain.
Normal pressure hydrocephalus	Caused by the buildup of fluid in the brain. Symptoms include difficulty walking, memory loss and inability to control urination. Can sometimes be corrected with surgical installation of a shunt in the brain to drain excess fluid.

Source: Alzheimer's Association *2010 Alzheimer's Disease Facts and Figures*

Symptoms of Alzheimer's Disease

Alzheimer's disease can affect different people in different ways, but generally begins with gradual worsening with remembering new information. This is because disruption of brain cells usually begins in regions involved in forming new memories. As damage spreads, individuals experience other difficulties.

Warning signs of Alzheimer's:

- Memory loss that disrupts daily life
- Challenges in planning or solving problems
- Difficulty completing familiar tasks at home, at work or at leisure
- Confusion with time or place
- Trouble understanding visual images and spatial relationships
- New problems with words in speaking or writing
- Misplacing things and losing the ability to retrace steps
- Decreased or poor judgment
- Withdrawal from work or social activities
- Changes in mood and personality

Risk Factors for Alzheimer's Disease

Although the cause or causes of Alzheimer's disease are not yet known, most experts agree that Alzheimer's, like other common chronic conditions, probably develops as a result of multiple factors rather than a single cause.

The greatest risk factor for Alzheimer's disease is advancing age, but Alzheimer's is not a normal part of aging. Most Americans with Alzheimer's disease are aged 65 or older, although individuals younger than age 65 can also develop the disease.

A small percentage of Alzheimer's disease, probably less than 1 percent, is caused by rare genetic variations found in a small number of families worldwide. In these inherited forms of Alzheimer's, the disease tends to develop before age 65, sometimes in individuals as young as 30.

A genetic factor in Alzheimer's developing at age 65 or older is apolipoprotein E-e4 (ApoE-e4). ApoE-e4 is one of three common forms of the ApoE gene, which provides the blueprint for a protein that carries cholesterol in the bloodstream. Everyone inherits one form of the ApoE gene from each of his or her parents. Those who inherit one ApoE-e4 gene have increased risk of developing Alzheimer's disease. Those who inherit two ApoE-e4 genes have an even higher risk. However, inheriting one or two copies of the gene does not guarantee that the individual will develop Alzheimer's disease.

Treatment and Prevention of Alzheimer's disease

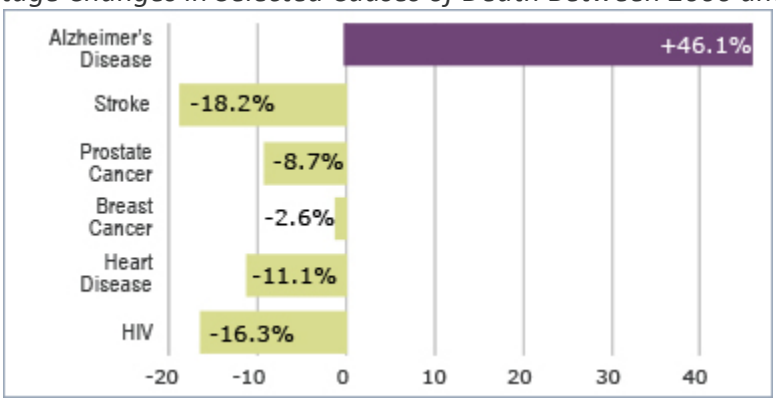
No treatment is available to slow or stop the deterioration of brain cells in Alzheimer's or related dementias. The U.S. Food and Drug Administration has approved five drugs that temporarily slow worsening of symptoms for about half of the individuals who take them. Currently, there are approximately 90 experimental therapies aimed at slowing or stopping the progression of Alzheimer's disease are in clinical testing in human volunteers.

A growing body of evidence suggests that the health of the brain — one of the body's most highly vascular organs — is closely linked to the overall health of the heart and blood vessels. Some data indicate that management of cardiovascular risk factors, such as high cholesterol, Type 2 diabetes, high blood pressure, smoking, obesity and physical inactivity may help avoid or delay cognitive decline. Many of these risk factors are modifiable — that is, they can be changed to decrease the likelihood of developing both cardiovascular disease and the cognitive decline associated with Alzheimer's. More limited data suggest that a low-fat diet rich in fruits and vegetables may support brain health, as may a robust social network and a lifetime of intellectual curiosity and mental stimulation.

Key Facts about Alzheimer's Disease and Related Dementia

- An estimated 5.3 million Americans of all ages have Alzheimer's disease, 110,000 in Missouri. By 2025, the number of Missourians with the Alzheimer's or related dementia is projected to increase to 130,000.
- Without a means of prevention, better treatment, or cure, Alzheimer's is projected to afflict 10 million Americans from the Baby Boom generation and contribute cumulative costs of almost $20 trillion to Medicare and Medicaid between 2010 and 2050. (The Report of the Alzheimer's Study Group, 2009)
- More women than men have dementia, primarily because women live longer on average than men, increasing the time during which women could develop Alzheimer's or other dementia.
- Alzheimer's disease is the sixth-leading cause of death across all ages in the United States. Strategic investments in other diseases have resulted in declines in deaths, while Alzheimer's disease has increased by more than 46%.

Percentage Changes in Selected Causes of Death Between 2000 and 2006



- Source: Alzheimer's Association *2010 Alzheimer's Disease Facts and Figures*
  - *National Center for Health Statistics. Deaths: Final Data for 2000.*
    - *Heron et al*

Supporting Individuals with Alzheimer's and Related Dementias in Missouri

More than 110,000 individuals in Missouri are currently living with Alzheimer's or related dementias. With the aging of the baby boomer population and the increase in life expectancy, that number will escalate to more than 130,000 by 2025. Planning now to address this public health emergency is critically important for the state of Missouri.

Early Stage Alzheimer's Disease

Increasingly, individuals are being diagnosed earlier in the disease process. Receiving an early diagnosis enables individuals to actively participate in making decisions about their current and future needs. There is also a better chance of benefiting from treatment. In recent years, services and resources originally designed only for caregivers have expanded to also address the needs of individuals with early stage Alzheimer's.

In Missouri, grant funding from the Administration on Aging (AoA) has enabled the Department of Health and Senior Services in partnership with the Alzheimer's Association to implement innovative programs for individuals with early stage dementia. These programs are designed to enhance quality of life through involvement in enrichment classes, volunteer opportunities, and support groups for both the person with dementia and their care partner.

Two additional grants from the AoA, Project LEARN and Project LEARN More, have focused on piloting the AD8 assessment tool to better identify individuals with early memory loss and connect them through care consultations to appropriate services and community resources.

Younger-Onset Alzheimer's

Alzheimer's is considered to be younger-onset if the Individual is age 65 or younger when symptoms first appear. Although we do not have statistics for Missouri, nationally there are an estimated 200,000 people.

Younger individuals with Alzheimer's are often confronted with unique challenges including loss of employment and income. In 2010, the Social Security Administration added early-onset Alzheimer's to its Compassionate Allowances Initiative in an effort to improve and expedite the disability determination process. Claims that fall under this initiative are fast tracked and decided within days instead of months and even years.

The Alzheimer's State Plan Task Force is fortunate to have Gwen Richards as a member. Through her actions and her voice, Gwen has stressed the importance of providing individuals with early stage Alzheimer's opportunities to stay engaged in productive and meaningful activities including volunteering, advocating, and educating self as well as others.

Family Caregiving

Alzheimer's disease does not just affect the person with the disease, but it has profound impact on families as well. In Missouri, more than 200,000 family members and friends provide more than 230 million hours of unpaid care, a contribution to the state valued at almost $2.7 billion.

Caring for a person with Alzheimer's or related dementia is often very difficult. As a result, many unpaid caregivers experience high levels of emotional stress and depression. As heard repeatedly at the community forums, the stress of caregiving impacts the health, employment, income and financial security of many caregivers.

Startling facts about women and the stress of caregiving were recently released in a report by Maria Shriver; *A Woman's Nation Takes on Alzheimer's:*

- Four out of ten caregivers say they had no choice in becoming caregivers.
- Women caregivers are stressed and stretched - about a third are caring for someone 24/7, and almost half of female caregivers provide more than 40 hours a week of care.
- Due to the emotional stress and physical strain of caregiving, Alzheimer and dementia spouses were 6 times more likely to develop dementia themselves.
- One-third of female Alzheimer's and dementia caregivers are part of the "sandwich generation" — with children or grandchildren under the age of 18 living in their homes.

Resources for Individuals with Alzheimer's and Their Caregivers

In Missouri, there are an array of services for both individuals with Alzheimer's and caregivers. At the community forums, individuals spoke of the value of support groups, care consultations, helpline, and respite. They also talked about their frustrations with knowing how and when to access services, the difficulty of getting an appropriate diagnosis, and the need for resources in rural communities.

Services available across the state include (See Appendix for Matrix of Services in Missouri):

- Consultations, service navigation and geriatric case management
- Support groups
- Information and assistance
- Education and training
- Legal and financial advise
- Respite assistance

Respite Care Assistance

Caregivers often express that what they need most to continue caring for a person with dementia at home is rest or a break from caregiving. An article published in the *Journal of the American Medical Association* demonstrates that programs offering social support such as respite, caregiver education and counseling enable spouse caregivers to delay nursing home placement of their loved ones an average of 329 days longer than those who did not receive these services.

In Missouri, respite assistance programs are available from the Alzheimer's Association Chapters, the Area Agencies on Aging, and through Mo HealthNet. Unfortunately, the non-Medicaid programs often have waiting lists and the amount of available assistance is minimal. Even with these limitations, at community forums individuals stressed the importance of these programs and the need for additional funding.

Long-Term Care Services

Most people with Alzheimer's, an estimated 70 percent, live at home with help from family and friends. As the disease progresses, they require additional assistance. Many access paid services at home, in the community, or a residential care setting. Often individuals utilize more than one setting over the long course of the disease.

In Missouri, home and community services that are available across the state include personal care assistance, homemaker/chore, home delivered meals, respite, transportation, home health, adult day programs, and hospice.

Licensed residential care options include residential care facilities (RCF and RCFII), assisted living facilities (ALF and ALF**), intermediate care facilities (ICF), and skilled nursing facilities (SNF). Only ALF**, ICF, and SNF are able to care for individuals that need more than minimal assistance to evacuate the facility, including those with Alzheimer's.

Alzheimer's Special Care Units operate either as a facility serving only persons with dementia or a unit within a long-term care facility. Special care units are required to disclose to the state and make available to the public information about the dementia specific services they offer. Currently, there are approximately 3,000 special care unit beds in Missouri.

Private Pay Costs

Missouri's annual average private pay costs, according to the Met Life 2009 Market Survey of Long-Term Care Costs:

- Skilled nursing facility: $48,910 (semi private room) and 55,115 (private room)
- Assisted living facility: $36,408
- Home care: $23,400 (based on home health aide for five hours, five days per week)

Medicaid Costs

Given the high average private pay cost of long term care services, many people cannot afford to pay for services for the duration of the disease. Medicaid plays a critically important role when a person's private resources are exhausted.

MO HealthNet, Missouri's Medicaid program, covers the cost of home and community services as well as care in a nursing home.

Medicaid Average Cost Per Person (2010)	
	Missouri*
Nursing facility expenditures	$38,235
HCBS expenditures for older people	$11,900
HCBS for adults with physical disabilities	$11,691
Personal care services	$9,183
Aged & Disabled waiver services	$7,467

**Missouri Department of Social Services Medicaid Annual Report for FY 2010*
Note: HCBS Expenditures include Home Health, Adult Day Health Care, Aged and Disabled Waiver, Personal Care, Aids Waiver, Physical Disabilities Waiver and Independent Living Waiver.

Home and community based services available to all MO HealthNet participants include personal care, adult day health care, and home health. Other home and community based services are available under the Aged and Disabled Wavier (respite, homemaker, chore, and home delivered meals), the Independent Living Waiver (expanded personal care, specialized medical equipment& supplies, and environmental accessibility adaptation), and the developmental disabilities waivers (respite, expanded personal care, therapies, habilitation, crisis intervention, community transition, communication skills instruction, environmental accessibility adaptations, and specialized medical equipment & supplies).

Access to home and community based waiver services varies by age, cognitive abilities, geographic location, and available funding. Vital respite services which relieve a caregiver are limited to individuals age 65 and older, disabled individuals age 63-64, and individuals who have a developmental disability. The Independent Living Waiver requires the participant to hire and manage their own direct care workers which may not be an option for most individuals with cognitive impairments. The wide array of services under the developmental disabilities waivers may be limited to services provided only in a specific county or based on available funding, which results in waiting lists for access to waiver services.

In 2008, Missouri's Medicaid Assisted Living Waiver was approved by the Center for Medicare and Medicaid Services (CMS). The waiver would cover the cost of services for MO HealthNet clients needing nursing home level of care that want to have their care needs met through assisted living. To date, this waiver has not been funded.

Long-Term Care Insurance

Private long-term care insurance is an option for those who have the foresight and purchase policies before developing dementia. According to 2010 Alzheimer's Disease Facts and Figures, private health and long-term care insurance policies funded only about 9 percent of total long-term care spending in 2006. However, when policies are purchased before individuals develop the disease, long-term care insurance plays a significant role in paying for the care of people with dementia. A study of people filing claims on their long-term care insurance policies shows that about two-thirds of those in assisted living and nursing homes had a cognitive impairment.

The Missouri Long Term Care Partnership Program was launched in 2008 to promote the purchase of long- term care insurance. The program is a dollar for dollar model – for every dollar a policy pays out in benefits, a dollar of personal assets can be protected when applying for MO HealthNet.

In 2012, the Community Living Assistance Services and Support Act (CLASS program), a provision of the Affordable Care Act, is scheduled to be implemented. This new voluntary insurance program will help functionally impaired individuals, including those with substantial cognitive impairment, pay for nonmedical services and supports – to help them remain within their homes and communities for as long as they can. Benefits can be used to pay for such things as home modifications, assistive technology, accessible transportation, homemaker services, respite care, personal assistance services, and home care aides.

Individuals with Alzheimer's as a Result of Down Syndrome

Persons with Down syndrome are at a much higher risk of developing Alzheimer's disease than those in the general population. Today, persons with Down syndrome are living longer and now have a life expectancy that is only 15-20 years less than the general public. This means many persons with Down syndrome are now living long enough for Alzheimer's disease to progress and symptoms to show.

Scientists have found that a gene on chromosome 21 produces amyloid precursor protein (APP). Persons with Down syndrome, therefore, have three copies of APP instead of the normal two. Because of this, virtually all people with Down syndrome will develop Alzheimer's disease if they live into middle age. Changes in personality and behavior, including apathy and decreased interaction, are often the earliest signs of Alzheimer's while memory loss is, interestingly, often not evident until a few years later.

As with dementia-specific care, the goal of providing care to persons with both Down syndrome and Alzheimer's disease are to maintain the individual's quality of life through person-centered care. Persons with Down syndrome can remain in community settings if physical characteristics of the setting are adapted to respond to the individual needs. Strategies developed for persons with Alzheimer's are often inappropriate for persons with Down syndrome. Care guidelines specific to persons with Down syndrome have been developed for this specific reason.

Safety

Alzheimer's disease causes a number of changes in the brain and body that may affect safety. Depending on the stage of the disease, these can include changes in judgment, abstract thinking, sense of time/place, and behavior. As the disease progresses, the person's abilities will change. This means situations that are not of concern today may become potential safety issues in the future.

Driving

Driving demands good judgment, quick reaction times and split-second decision making. A diagnosis of Alzheimer's disease alone is not a reason to take away driving privileges. But due to the progressive nature of Alzheimer's, a person with the disease will eventually be unable to drive.

It is often difficult to decide when to stop or limit driving. To help make this decision, a driving evaluation from a certified professional is helpful. Ideally, families should talk openly about driving soon after a diagnosis.

In situations where a person is considered to be an unsafe driver but they continue to drive, Missouri's impaired driving law enables family members, professionals, and other concerned individuals to submit a confidential report to the Department of Motor Vehicles for a driving evaluation.

Wandering

More than 60 percent of those with Alzheimer's disease will wander. Up to half of all of these persons who are not found within 24 hours will suffer serious injury or death.

All individuals with Alzheimer's are encouraged to enroll in an identification or tracking program designed to assist in the return of those who wander and become lost.

Missouri's Endangered Person Advisory is a voluntary partnership between law enforcement and local broadcasters to rapidly disseminate information about a missing and endangered person to law enforcement agencies, broadcasters, and the public.

First responders play an important role in the lives of people with Alzheimer's disease and their families. Although Missouri does not require dementia training for first responders, many law enforcement agencies across the state receive First Responder training by the Alzheimer's Association.

Quality of Care in Missouri

Dementia Training

Since 2001, Missouri has had in place dementia training requirements for individuals employed by an in-home agency, home health agency, adult day center, assisted living facility, residential care facility, or nursing home providing services to people with dementia. The statute requires individuals be trained on topics including overview of the disease, communicating with persons with dementia, behavioral management, promoting independence with activities of daily living, and understanding and dealing with family issues. Implementation of the training has not been consistent resulting in varied degrees of knowledge and impact on quality of care.

At the community forums, individuals expressed the need for training not just of direct care staff but also for physicians, health professionals, hospital staff, and first responders. Of noted concern was the revolving door for persons with behavioral issues that resulted in being transferred to a gero-psych unit and then to a new facility with this scenario often repeating itself again and again. Families expressed frustration with the lack of appropriate training by the long term care facility staff as well as the staff for the gero-psych units.

Missouri's Alzheimer's Demonstration Project

The intent of the Alzheimer's Demonstration Project was to provide data to the Department of Health & Senior Services about a potential new licensure category for long term care facilities providing special care for persons with Alzheimer's and related dementias. Four facilities participated in the pilot and the University of Missouri conducted an interdisciplinary evaluation of the programs.

The 2005 Alzheimer's Demonstration Project Report by the Department of Health & Senior Services concluded that a special licensure category was not required for the care of individuals with Alzheimer's. It did however highlight a number of positive results demonstrated through the pilots:

- Families reported being very pleased with the facilities and the care their loved ones received;
- Staff were also pleased; turnover was drastically reduced and in facilities where there are other nursing programs, certified nurse aides and certified medication technicians wanted to work on the Alzheimer' units. It had become the unit of choice;
- Quality of life for the elderly residents had been greatly increased;
- Residents showed less signs of agitation, anxiety, and physical and verbal acting out;
- Residents had fewer falls, used fewer psychotropic medications and where hospitalized less; and
- Residents participated in meaningful activities and had more social interaction with each other and with the staff.

Culture Change

The Culture Change movement is shifting the way long term care is being delivered across the country, including in Missouri. The Missouri Coalition Celebrating Care Continuum Change (MC5) is working to create senior living environments where each individual's dignity and value is respected and celebrated. Formed in 2005, MC5 participating facilities are dedicated to reinventing the continuum of care in favor of a more person-centered approach.

Research in Missouri

The Alzheimer's Disease Research and Related Disorders Program, established by legislation in 1987, focused on advancing new research initiatives and bringing new researchers into the field. Since inception, the program administered by the Board of Curators at the University of Missouri has experienced a high return on investment. The program supports an average of eight projects each year. In follow up reports from grant recipients, for each dollar expended on these projects, more than ten dollars in subsequent support comes to the state from national granting agencies. The program has not been funded since 2006.

In 2009, approximately $20 million in federal and foundation grants were awarded to Missouri Alzheimer's researchers. Current research can be divided into four broad categories: longitudinal studies and centers (~$10.5 million), brain imaging (~$2 million), mechanisms of disease (~$7 million), and psychosocial factors (~$0.5 million). Research in each of these categories is driven by the goal of improved and earlier diagnosis of Alzheimer's disease.

Select highlights of Missouri Alzheimer's research:

1) University of Missouri-Columbia: Dr. Grace Sun leads collaborative research to examine the roles of oxidative stress and inflammation in Alzheimer's disease.
2) University of Kansas Medical Center: The Brain Aging Project of the KU Alzheimer and Memory Program led by Dr. Jeff Burns investigates the role of lifestyle factors and cardiorespiratory fitness in promoting healthy brain aging in residents of Kansas City in both Missouri and Kansas.
3) Washington University in St. Louis: The earliest brain changes underlying late-onset and early-onset Alzheimer's disease, which may be therapeutic targets to prevent Alzheimer dementia, are among the multicomponent research projects directed by Dr. John C. Morris at Missouri's only federally funded Alzheimer's Disease Research Center.
4) University of Missouri-St. Louis: Dr. Ann Steffen leads research efforts aimed at reducing depression in dementia caregivers and Dr. Tom Meuser investigates mobility issues, such as driving a motor vehicle, in demented individuals.

Recommendations

Access to Early Intervention and Support

"My mother is a fighter and she had to fight to even get a diagnosis. This is something you shouldn't have to fight for." Daughter of individuals with younger-onset Alzheimer's

At community forums across Missouri people expressed their frustrations with getting an appropriate diagnosis, especially for those with younger-onset Alzheimer's. For others, the concern was with the lack of information and support from their physicians following the diagnosis.

Dr Abhilash Desai in his testimony on behalf of the Missouri State Medical Association said, "There is strong evidence that improving the process through which people are diagnosed and widening access to a high level of support at a relatively early stage of the illness is beneficial." He continued in stating that, "90 percent of suffering of the patient and their family members can be avoided by providing these services starting early and maintaining them through the course of the illness."

In Missouri there are resources to support the individual with the disease and their caregivers; however, assistance is needed from health care professionals to connect people to these services at the time of diagnosis.

The Alzheimer's State Plan Task Force recommends a concerted effort be made to enhance public awareness about the disease, promote early detection and provide better access to needed information and support.

Goal: Promote access to statewide expert diagnostic services that can lead to early intervention and support.

Strategies

- Promote physician and health care professional educational opportunities to increase detection and diagnostic services and provide access, information and support for newly diagnosed individuals and their families.

- Implement a public awareness campaign to increase early intervention and diagnosis. The Missouri Department of Health & Senior Services and the Alzheimer's Association will seek non-governmental grant funding for a campaign that will be based on best practices in social marketing.

- Pilot statewide dementia assessments with physicians at an early point of contact through the implementation of such tools as the AD8 as called for in Missouri Alzheimer's Innovation Grant from the Administration on Aging.

- Initiate partnerships for the development of endowed residency and geriatric fellowships to increase the number of geriatricians.

Road Map for Care and Support

"A person needs to be a lawyer to figure out and understand all these services." Caregiver

The Alzheimer's State Plan Task Force Services Workgroup identified resources and services available across the state to assist both the individual with dementia as well as their caregivers. Although an array of services is available, knowing how and when to access this information was a frustration voiced by both individuals with Alzheimer's and their caregivers.

The Alzheimer's State Plan Task Force recognizes the need for information that will assist individuals throughout the progression of the disease. The information should be comprehensive, easy to understand and access. It should build on statewide resources such as state websites maintained by the Missouri Department of Health & Senior Services, Area Agencies on Aging, and Alzheimer's Association.

Goal: Create a Road Map for care and support that provides quality information on services across the continuum from early diagnosis to end of life.

Strategies

- Identify existing statewide resource databases and evaluate them for inclusion of dementia related resources.

- Create a Road Map including community organizations such as the Alzheimer's Association and Area Agencies on Aging network that provide unbiased information on care planning and in-person consultation.

- Develop a strategy for dissemination of the Road Map to consumers, health care professionals, and community partners.

Services and Support

"This disease costs more than most have ever had to pay for anything in their life." Caregiver

Families often make heroic sacrifices to care for their loved ones but they cannot do it alone. About 70 percent of people with Alzheimer's are living at home with the assistance of uncompensated care provided by families and friends. In Missouri, there are more than 200,000 caregivers providing 230 million hours of uncompensated care at a value of more than $2.6 billion.

Caring for a person with Alzheimer's or another dementia is often very difficult and many unpaid caregivers experience high levels of emotional stress and depression as a result. At the community forums across the state, caregivers shared their stories of declining health, jobs loss, and financial difficulties. They talked about the hardship on the middle class who are not poor enough for Medicaid but struggle to pay privately for care. They spoke about the lack of home and community resources in rural communities. They shared of the need for respite assistance and the barriers that exist with waiting lists for both Alzheimer's Association and Area Agencies on Aging programs. They expressed their desire for Medicaid to cover less costly assisted living.

In Missouri, the average annual private pay cost of a nursing home in 2009 was $48,910 for a semi-private room and $55,115 for a private room as compared to $36,408 for assisted living (Met Life 2009 Market Survey of Long-Term Care Costs). In 2008, CMS approved a Medicaid assisted living waiver for Missouri; however it has not been funded.

For those that qualify, MO HealthNet promotes participant choice and care in the least restricted setting. It covers nursing home care as well as in-home services and adult day care. The consumer directed state plan personal care program and independent living waiver allow individuals to hire and manage their own direct care workers. Although potentially beneficial to individuals in rural communities, this is not an option for most people with cognitive impairments because the person must self direct their care.

The Missouri Long Term Care Partnership Program was launched in 2008 to promote the purchase of long term care. The program is a dollar for dollar model – for every dollar a policy pays out in benefits, a dollar of personal assets can be protected when applying for MO HealthNet.

The Affordable Care Act created a voluntary, enrollment-based insurance program that will be available after October 2012 called the Community Living Assistance Services and Supports (CLASS) Program that will assist people who need help with daily activities. Under this voluntary program, individuals will receive a cash allowance for care and other supports to help them keep their independence.

The Alzheimer's State Plan Task Force supports initiatives to improve services that enable those with Alzheimer's disease and other dementias to live longer in their homes and neighborhoods, if they wish to do so. Families who now bear much of the burden of caregiving should have access to cost effective supports to help them care for their loved ones at home.

Goal: Provide a wide array of community and home based services that may offer more cost-effective options for the rapidly increasing number of Missourians with Alzheimer's or related disorders and their caregivers.

Strategies

- Examine existing MO HealthNet programs for gaps in service that may limit the ability to utilize home and community based care.

- Identify and disseminate information on respite programs and advocate for expanded respite resources.

- Enhance community awareness of the benefits of long term care insurance including Missouri's Long Term Care Partnership Program, the CLASS program and Missouri's new premium refund law.

- Identify the opportunities for the State of Missouri to secure federal and non-federal funding to advance home and community based options for those with Alzheimer's and related dementia.

Delivering Improved Dementia Care

"We have been bounced around to many nursing homes because staff did not understand our needs."
Caregiver

Across the care continuum, from physicians to hospitals to hospice, there is an increasing and urgent need for a workforce trained to deliver quality dementia care. At the community forums, people repeatedly expressed the need for training for physicians, health professionals, hospital staff, first responders, and direct care staff employed by in-home agencies, assisted living facilities, adult day programs and nursing homes.

Of noted concern was the revolving door for persons with behavioral issues that resulted in being transferred to a gero-psych unit and then to a new facility with this scenario often repeating itself again and again. Individuals with Alzheimer's are significantly impacted by sudden displacement and subsequent isolation from familiar surroundings and family when transferred to another setting or one of higher intensity.

Since 2001, Missouri has had in place dementia training requirements for individuals employed by in-home agency, home health agency, adult day center, assisted living facility, residential care facility, or nursing home providing services to people with dementia. Implementation is not consistent resulting in varied degrees of knowledge and impact on quality of care.

Little formal training occurs in medical school or internship/residency regarding dementia, diagnosis and early intervention. Investment in focused education during critical training periods will yield far reaching results in practice.

The Alzheimer's State Plan Task Force supports initiatives to ensure an available and adequately trained workforce of health professionals who have the incentive to provide collaborative and person centered care.

Goal: Ensure a sufficient, dementia conscious, quality workforce at all levels of the care continuum.

Strategies

- Review current dementia training requirements and make recommendations designed to strengthen the delivery of quality dementia services across the care continuum including appropriate behavioral interventions and medications.

- Design a structure to review transfers/discharges of persons with Alzheimer's disease or related dementias.

- Advocate for including accredited dementia training for the career ladder workforce.

- Identify guidelines for assessment, diagnosis and treatment of individuals with dementia to assure appropriate location and level of service.

- Identify appropriate standards of care for behavioral health units that treat individuals with dementia.

- Advocate for guidelines of inpatient behavioral health services to assure that the models address the specific treatment of individuals with dementia.

- Recommend ongoing in-service training on Alzheimer's disease and related dementia for first responders through programs such as Missouri Peace Officer Standards & Training.

- Support the development of a pilot demonstration project that incorporates dementia specialists assigned as a treatment team member for all individuals with dementia while inpatient in hospitals and behavioral health settings.

Missouri as a Leader in Alzheimer's Research

"We need more research money and we need to cure this disease soon before it plagues my entire family." Caregiver

The Alzheimer's Disease Research and Other Related Disorders Program, established by legislation in 1987, focused on advancing new research initiatives and bringing new researchers into the field. Since inception, the program administered by the Board of Curators at the University of Missouri has experienced a high return on investment. The program supported an average of eight projects each year. In follow up reports from grant recipients, for each dollar expended on these projects, more than ten dollars in subsequent support comes to the state from national granting agencies. The program has not been funded since 2006.

Goal: Maintain Missouri's status as a leader in Alzheimer's disease and related disorders research.

Strategies

- Advocate for restoration of state funding to Missouri based researchers for the Alzheimer's Disease and Other Related Disorders Program.

- Partner with academic institutions across the state to develop a research summit with the dual goals of fostering scientific collaboration and disseminating current research to the general public.

Appendix

Summary of Comments from Statewide Community Forums

The Alzheimer's State Plan Task Force held five community forums from January to April 2010 to hear from the residents of Missouri about what their thoughts and concerns were in regards to living with Alzheimer's. The five forums were held in Columbia, St. Louis, Springfield, Cape Girardeau, and Kansas City. In a review of the forum notes, the following themes emerged.

Caregiver Stress

Comments concerning the stress placed on caregivers focused on how Alzheimer's does not affect just the person with dementia but also the physical, mental, social, and financial well-being of the caregiver.

Job-Related Stress
The most frequent comment under Caregiver Stress had to do with the caregiver's need or inability to remain in the workforce while also caring for their loved one. Some workplaces were flexible in allowing time off for caregiving while others were not flexible. The responsibility of caregiving forced many to quit their jobs, and others wanted to quit but could not give up the insurance or benefits. One caregiver pointed out that even after her parents passed away, it has been difficult to re-enter the workforce because of the large gap in her work history. Another person remarked that caregivers not only lose income from not working but also lose social security credit for retirement.

Medical Effects
Stress was linked to medical illnesses, exhaustion, and even death. As one person shared, the stress her father experienced while caring for her mother led to his death. It was suggested that there is empirical research to support this and that the issue deserves greater attention.

Stress from Legal, Financial, and Social Burdens
Legal issues, including obtaining guardianship or establishing power of attorney, were cited as sources of stress. One caregiver brought up the "double whammy" of trying to establish guardianship for her mother who has dementia and transferring guardianship of her developmentally disabled sister from her mother to herself. Caregivers felt socially isolated and abandoned by former supports, and there was stress related to the cost of care.

Services and Resources

Existing services and resources
The most frequently mentioned resource was the Alzheimer's Association and the Association's programs, including Care Consultations, early stage programs, support groups, and respite. The majority of comments were positive towards the organization, but a few caregivers felt that they were not given enough assistance. The Area Agencies on Aging, elder law attorneys, and the resource directories for senior services were also mentioned as useful resources and services. Concerns about budget cuts and waiting lists were voiced about some services and resources.

Getting a Proper Diagnosis
Getting a doctor to give an Alzheimer's diagnosis was sometimes referred to as a fight. There were several stories about being misdiagnosed for several years with a variety of disorders, including depression or adult attention deficit disorder, and there were even doctors who did not believe in Alzheimer's disease. As one person said, a diagnosis of Alzheimer's disease after years of misdiagnoses was a relief because "you can't start living until you have a diagnosis and you know the problem you are facing." Some people were given a diagnosis of Alzheimer's disease when it was really something else, such as medication related.

Respite
Comments about Respite focused on its importance to caregivers, the need for more funding, and the barrier of long waiting lists for both the Alzheimer's Association and Area Agencies on Aging respite programs. Participants also noted that while it was important, the time given to caregivers was minimal and they could use more than just a few hours each month. One volunteer for the Alzheimer's Association Helpline call center said that the number one call they receive is for respite care.

Rural Services
The lack of resources in rural areas was often mentioned as a barrier. Traveling to larger cities added to the cost and burden of the disease.

Waiting Lists
When appropriate or quality services existed, there were often long waiting lists that acted as a barrier. Waiting lists were often cited as barriers to respite care and admittance into assisted living facilities.

Other Barriers
Other barriers included the availability of in-home care workers, services for people with early stage Alzheimer' disease and case management. In Kansas City, Mo., there was comparison of services and quality between the states of Kansas and Missouri, including a lack of memory care in assisted living for those living on the Missouri side.

Cost of Care / Paying for Care

The cost of care was frequently mentioned, and as one participant summarized it, "this disease costs more than most have ever had to pay for anything in their life." A few caregivers cited costs of care as high as $250,000 over 5 years and $70,000 a year.

Cost of Keeping People at Home
Comments frequently focused on the cost of keeping a loved one at home and the need for assistance to do so. These comments typically framed the cost of caring for someone at home as more cost-effective than nursing home placement and encouraged the state to provide more assistance for in-home care and for family caregivers.

Drugs and Other Costs
The cost of prescription drugs was often cited as a burden. Financial assistance for home medical equipment and the cost of seeking needed legal assistance were also mentioned.

Medicaid and Medicare
Participants talked about falling just above the income limit to qualify for Medicaid or being forced to spend-down. Once on Medicaid, it only covered nursing homes and not assisted living or in-home care. Medicare was referenced particularly in relation to the cost of medications in the doughnut hole of Medicare Part D, the hospice benefits, and the homebound restrictions.

Healthcare and Long Term Care Insurance
When people mentioned their health insurance plan, it was typically about how fortunate they were to have one or how they needed to keep working to maintain the plan. Long term care insurance was referenced in terms of how much it costs, the restrictions on what it covers, including a 3-year limit and only nursing home care, not assisted living, and that there should be an employer tax incentive for offering long term care insurance.

Quality of Care / Professional Training

The Quality of Care covered a range of comments about existing high quality services and the need for higher quality in other areas. Increasing the quality of care and responding to the individual's needs were cited as improving the outcomes for the person with dementia. A number of participants expressed a need for more or better professional training across the care continuum, including how it should be mandatory.

Medical Community
Doctors, the medical community, and hospitals were often cited as needing more training in working with persons with Alzheimer's and other dementias. While doctors needed to be better trained in diagnosis, they also needed to know how to better interact with persons with dementia and to know how to refer patients and caregivers to resources. There was a feeling that the diagnosis came without any hope for what could be done.

Some participants explained that doctors and hospital staff would often try to collect information from the person with dementia when they could have consulted with the caregiver to get more accurate information. There were suggestions that this training should be a part of medical school training.

Staffing Quality
The quality of in-home care and long term care facilities was often related to the need for more staff, including lower staff to resident ratios, and better trained staff. While staff who work with persons with dementia are required to receive training, there were comments on how the quality of that training is monitored.

Long Term Care Facilities and In Home Care Workers
Comments about long term care facilities and in home care workers included that they did not know how to approach and work with persons with dementia and that more training was required. A suggestion of monthly in-services was given.

Hospitals
There were comments and stories about how hospitals are not prepared to work with persons with Alzheimer's and how this can negatively affect the health of a person seeking care in a hospital. As one person noted, the hospital trips actually made her loved one's health decline more rapidly. Some of the suggestions included that hospital staff be trained in dementia care, a dementia care specialist be on

staff at the hospital, or the person with dementia have a care history record that travels with them from the long term care facility to the hospital.

Regulations and Standards
Statewide regulations for special care units and staff trainings were recommended. Also, making it easier for families to know how well a facility scored in state inspections was important in selecting quality care. One participant compared it to health department ratings of fast food restaurants, asking why should the quality of long-term care facilities not be just as easy to know.

Veteran's Homes
At least one person at each of the forums mentioned that their loved one was in a Missouri Veteran's Home and that the quality of care they received there was excellent. There was concern that all care facilities should have this same level of person-centered care.

Public Awareness / Education for Individual

Many participants made comments that there needed to be great public awareness about Alzheimer's disease and that families needed to be better educated on the disease and the resources available.

Family Education
According to many of the participants, individuals with Alzheimer's and their families needed more education on the progression of the disease and what resources were available to them. Information on long term care facilities, medications, and legal advice were all areas where there needed to be greater education and awareness among families.

Public Awareness
Participants cited that until they had Alzheimer's in their family, they knew nothing about it. It is still not talked about. As one participant said, we do not have a face for Alzheimer's, and even in a newspaper article that day on "The Face of Alzheimer's," the accompanying photo was of someone's back as they walked away. There was a sense that all Missourians should be aware of Alzheimer's and its impact.

Research

The need for research or the hope that there would someday be a cure was frequently mentioned. Typically, the statement focused on the need for more research funding. There were also comments to lift restrictions on research, recognizing the work of the Alzheimer's Disease Research Center of Washington University in St. Louis, and to increase research outside of these metropolitan areas.

Matrix of Services

Type of Service	Availability	Average Cost in 2009	Funding Sources
General Support for Caregivers and Persons with Dementia – available regardless of where the AD victim resides:			
Early Intervention and Counseling	Scope and access is grant dependent	No fee to consumers; contributions encouraged	Administration on Aging Charitable donations Private pay
Care Consultations, Service Navigation, and Geriatric Case Management	Generally available	Varies from donation basis to $150 per hour	Private pay Charitable donations Older Americans Act
Support Groups	Generally available	No charge to consumers	Charitable donations
Information and Assistance/Referral	Generally available Alzheimer's Association; 211 system; Area Agencies on Aging	No charge to consumer	Charitable donations Older Americans Act
Education/Training	Generally available however limited in rural communities (or by phone only)	No charge to consumers	Charitable donations Private pay
Legal/financial advice	More readily available in larger cities	Varies	Private pay Legal Services

Home and Community Based Services – services may also be available in an institutional setting:			
Respite Care	Generally available for private pay; age, level of care, and financial restrictions for publicly funded services	$17 – 22.00 per hour	MO HealthNet*** Older Americans Act AD Service Grants Charitable donations VA Benefits Private pay
Personal Care	Generally available for private pay; age, level of care, and financial restrictions for publicly funded services	$15-21.00 per hour	MO HealthNet* Older Americans Act Private pay VA Benefits
Homemaker/Chore	Generally available for private pay; age, level of care, and financial restrictions for publicly funded services	$15-19 per hour	MO HealthNet** Older Americans Act Private Pay VA Benefits
Home-delivered meals	Generally available for private pay; age, level of care, and financial restrictions for publicly funded services	$5-9.00 per meal	MO HealthNet** Older Americans Act Private Pay
Adult Day Health Services	Generally available for private pay in larger cities; few in rural areas; age, level of care, and financial restrictions for publicly funded services	$35.60 (3 to 5 hours per day) $70.20 (6 to 10 hours per day)	MO HealthNet* Older Americans Act Private Pay

	Transportation	Group transportation available statewide; but individualized or specialty transportation is spotty	Varies	MO HealthNet (restricted to transportation to MO HealthNet covered services, excluding pharmacy and durable medical equipment.) Older Americans Act Public transit funding Private pay
	Personal Emergency Response System	Generally available	Varies	Charitable donations Private pay
	Hospice Care	Available only if person has terminal illness with prognosis that life expectancy is six months or less and they elect hospice services	Varies – some rates established by Medicare; MO HealthNet follows Medicare rates	Medicare MO HealthNet Charitable donations Private Pay
	Home Modifications	Generally available in larger cities	Varies - $55-65 per hour	Private pay Older Americans Act MO HealthNet****
	Home Health	Generally available	$65-140 per hour	MO HealthNet Medicare Private Pay Private Insurance VA Benefits
	Housing/apartments with services	Not readily available in rural areas	Varies	Private pay HUD/RHA subsidies

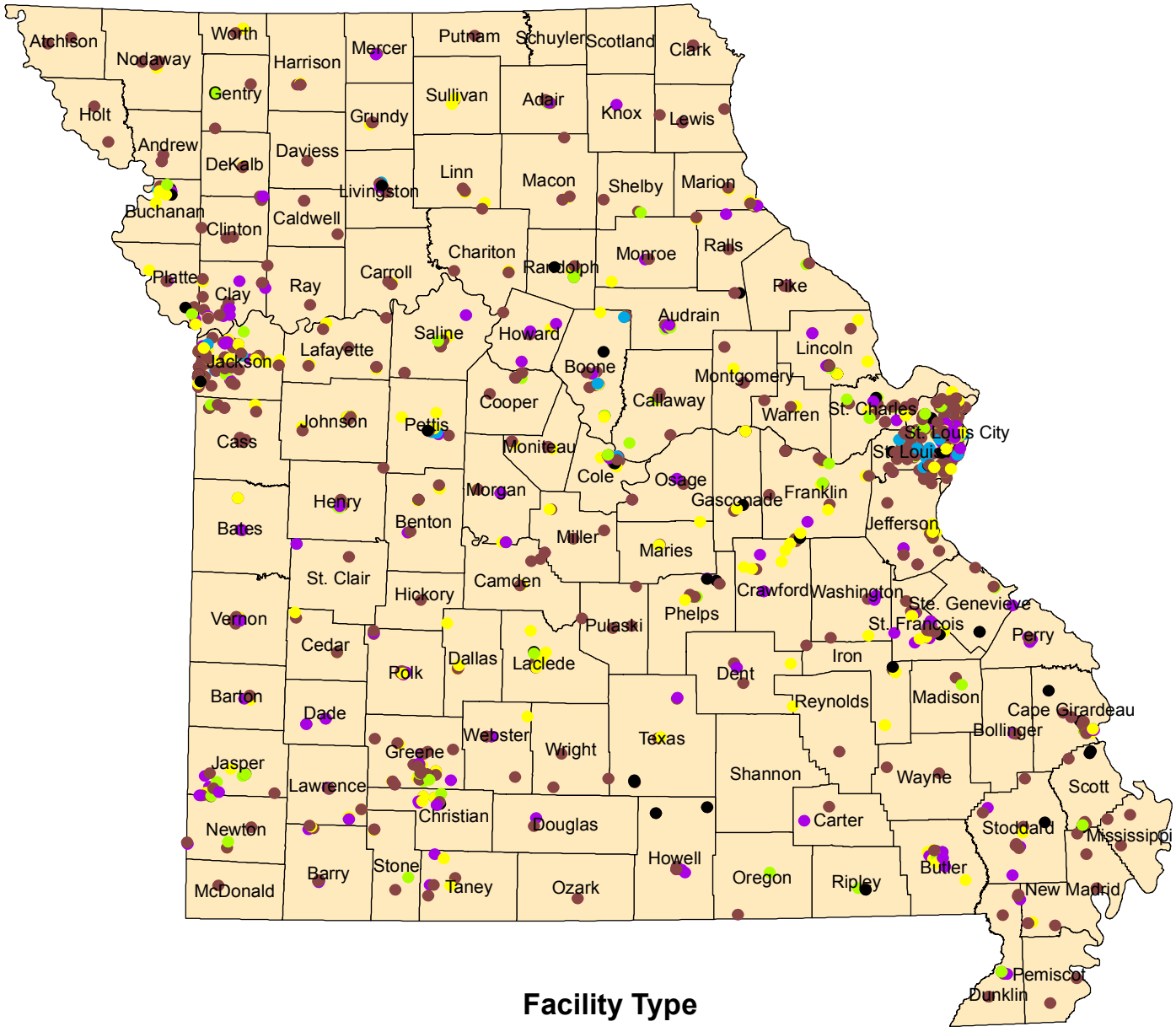
Licensed Residential/Institutional Services:				
	Residential Care Facility (RCF) -24-hour care and services including assistance with medications and care during short term illnesses or recuperation	234 facilities serving approximately 3,500	$24,000 average annual private pay (DHSS website) Maximum $156 per month for supplemental nursing care only	MO HealthNet (personal care) Cash grants Private pay Long Term Care insurance VA Benefits
	Residential Care Facility II (RCFII) - provides additional services including supervision of diets and assistance with person care.	211 facilities serving approximately 5,500	$24,000 average annual private pay (DHSS website) Maximum $292 per month for supplemental nursing care only	MO HealthNet (personal care) Cash grants Private pay Long Term Care insurance VA Benefits
	Assisted Living Facility – option 1 - 24-hour care and services including assistance with medications and personal care. Services are based on the abilities, desires, and functional needs of the individual and delivered in a home like setting.	71 facilities serving 2,500	$36,408 average annual private pay (2009 Met Life Market Survey on Long Term Care Costs) Maximum $292 per month for supplemental nursing care only	MO HealthNet (personal care) Cash grants Private pay Long Term Care insurance VA Benefits
	Assisted Living Facility – option 2 - Similar to ALF option 1, an ALF option 2 may accept or continue to care for people with cognitive or physical impairments that require additional assistance to evacuate in an emergency.	84 facilities serving 2,500	$36,408 average annual private pay (2009 Met Life Market Survey on Long Term Care Costs) Maximum $292 per month for supplemental nursing care only	MO HealthNet (personal care) Cash grants Private pay Long Term Care insurance VA Benefits

	Intermediate Care Facility (ICF) - 24-hour personal care, health, and nursing care services under the daily supervision of a licensed nurse and direction of a licensed physician.	33 facilities serving 1,500	Varies by facility	MO HealthNet Medicare Private pay Long Term Care insurance VA Benefits
	Skilled Nursing Facility (SNF) - 24-hour care including skilled nursing care and treatment services commonly performed by or under the supervision of a registered professional nurse (RN).	498 facilities serving approx 39,000	$55,115 average annual private pay (2009 Met Life Market Survey on LTC Costs) $40,880 average MO HealthNet rate ($112 daily; 2007 per day) $269 per day (2006 average Medicare)	MO HealthNet Medicare Private pay Long term care insurance VA Benefits
	Specialty Gero-psych In-patient Units – in-patient geriatric mental health services	59 facilities with a total capacity of 3,011 beds; irregular distribution across the state	Varies; ranges from $14 – 18,000 dependent on length of stay and services	Medicare MO HealthNet Private pay Some private insurance
	Alzheimer's Special Care Units - SCU are in long term care facilities and provide environments, programs, and staff specifically designed for the care needs of Individuals with Alzheimer's Disease.	213 across the state	Varies by licensure level and facility Same rate as SNF for MO HealthNet – no enhanced payment	MO HealthNet Medicare (very limited/SNF only) Private pay Long term care insurance VA Benefits

*MO HealthNet – public funding available for personal care to all MO HealthNet participants; restricted to those 18 years of age or older for adult day health care.
**MO HealthNet – public funding available through the Home and Community Based Services (HCBS) Aged & Disabled Waiver; restricted to those 63 years of age or older and subject to income and asset limits.

***MO HealthNet – public funding available through the HCBS Aged & Disabled Waiver and the developmental disabilities waivers (DD); available to 63-64 year olds who are disabled, 65+ year olds, and for individuals with developmental disabilities (regardless of age) if they are not on a waiting list for one of the DD waivers.
****MO HealthNet - public funding available through the HCBS Independent Living Waiver (limit of $5,000 every five year), the Developmental Disabilities (DD) Comprehensive, Community Support, and Prevention Waivers (limit of $5000 per year); available to 18-64 year olds who are disabled and capable of self-directing their services, and for individuals with developmental disabilities (regardless of age) if they are not on a waiting list for one of the DD waivers.

Missouri Facilities



Facility Type

- ALF
- ALF**
- ICF
- RCF
- RCF*
- SNF

Some facilities at this map scale may be overlapping.

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RCF June 2010.mxd
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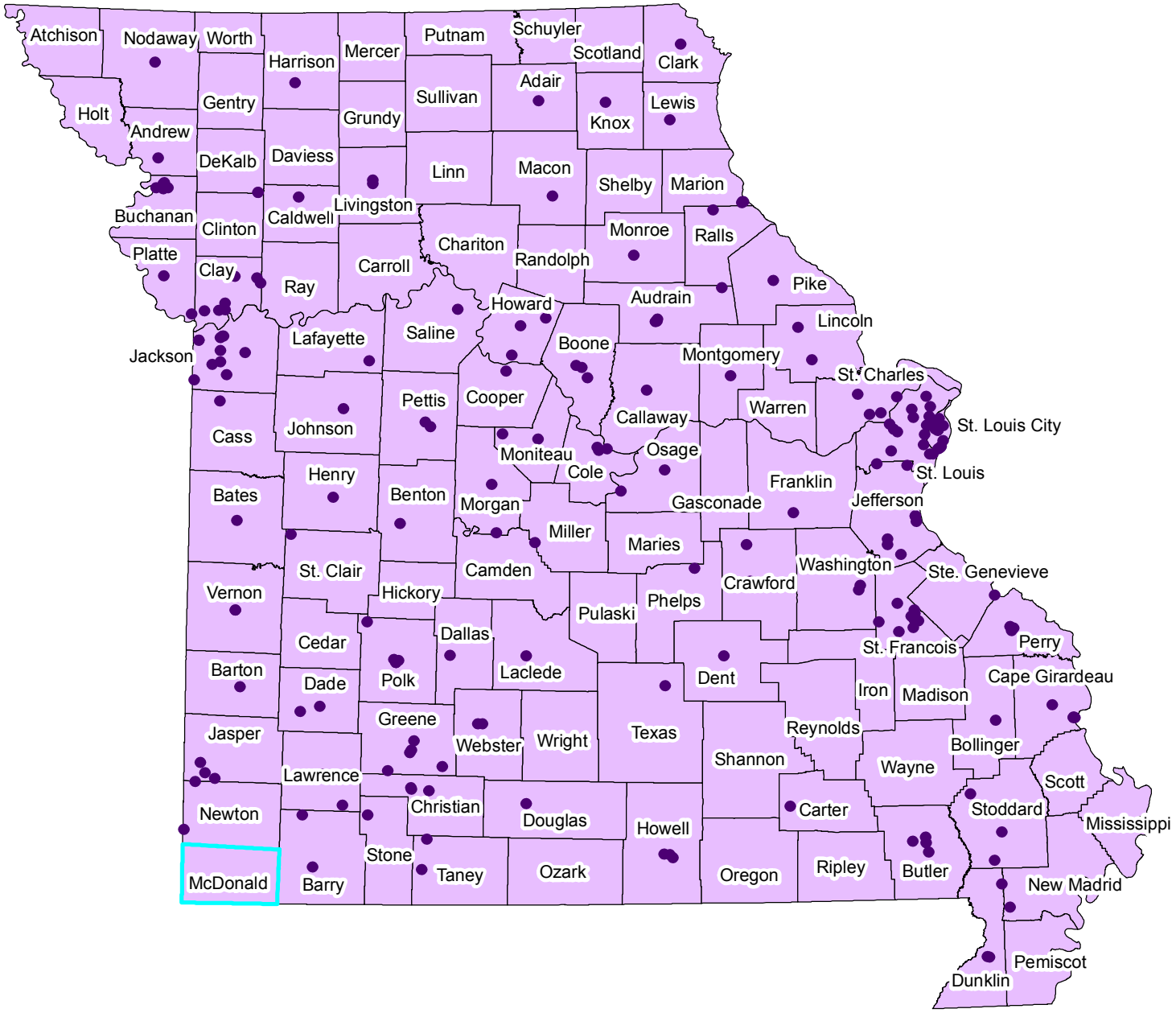
Missouri ALF Facilities



Some facilities at this map scale may be overlapping.

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ALF Facility June 2010.mxd
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Missouri ALF** Facilities

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ALF2 Facility June 2010.mxd
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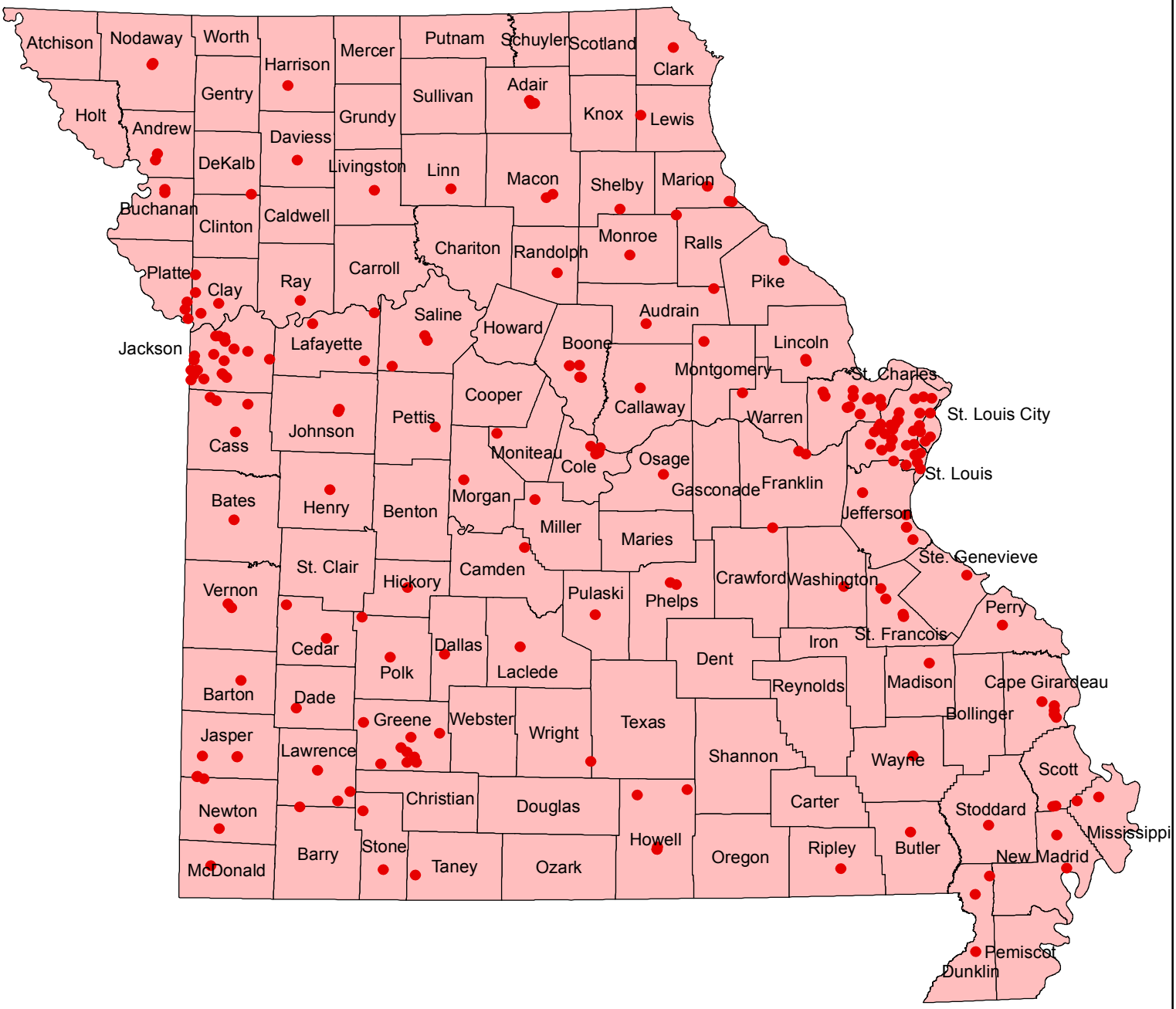
Missouri Alzheimer SCU Facilities



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Missouri SNF Facilities

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alzheimer's association®

Missouri

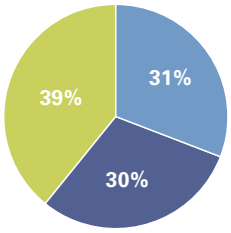
Alzheimer Statistics

In the United States, 5.3 million people are living with Alzheimer's disease, and a new individual is diagnosed with the disease every 70 seconds. Unless something is done, by 2050, up to 16 million Americans will have Alzheimer's, and a new case will be diagnosed every 33 seconds.

Number of People Aged 65 and Older with Alzheimer's and Other Dementias by Age

Year	65–74	75–84	85+	Total	% change from 2000
2000	6,500	55,000	48,000	110,000	
2010	5,600	53,000	55,000	110,000	0%
2020	7,200	53,000	57,000	120,000	9%
2025	8,300	63,000	58,000	130,000	18%

Cognitive Impairment in Nursing Home Residents, 2008



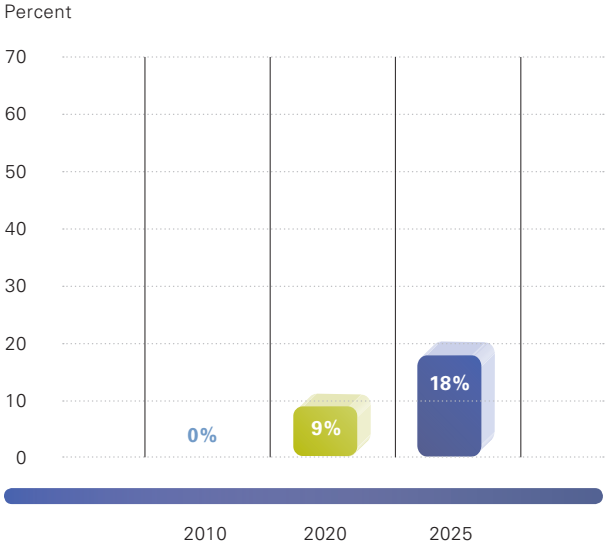
Total Nursing Home Residents
79,422

Level of Cognitive Impairment
- severe/moderate
- mild/very mild
- none

Number of Alzheimer and Dementia Caregivers, Hours of Unpaid Care, and Economic Value of Care

Year	Number of Caregivers	Total Hours of Unpaid Care	Total Value of Unpaid Care
2007	179,524	154,965,127	$1,639,531,039
2008	180,997	156,236,940	$1,734,230,037
2009	202,662	230,791,080	$2,654,097,424

Percentage Change in Number with Alzheimer's Disease Compared to 2000



Number of Deaths Due to Alzheimer's Disease in 2006

1,632

For more information, view the *2010 Alzheimer's Disease Facts and Figures* report at **alz.org/facts**.

FIRST REGULAR SESSION

[TRULY AGREED TO AND FINALLY PASSED]

SENATE COMMITTEE SUBSTITUTE FOR

HOUSE COMMITTEE SUBSTITUTE FOR

HOUSE BILL NO. 272

95TH GENERAL ASSEMBLY

0954S.05T 2009

AN ACT

To amend chapter 191, RSMo, by adding thereto one new section relating to the Alzheimer's state plan task force, with an expiration date.

Be it enacted by the General Assembly of the state of Missouri, as follows:

Section A. Chapter 191, RSMo, is amended by adding thereto one new section, to be known as section 191.115, to read as follows:

191.115. 1. There is hereby established in the department of health and senior services an "Alzheimer's State Plan Task Force". The task force shall consist of nineteen members, as follows:

(1) The lieutenant governor or his or her designee, who shall serve as chair of the task force;

(2) The directors of the departments of health and senior services, social services, and mental health or their designees;

(3) One member of the house of representatives appointed by the speaker of the house;

(4) One member of the senate appointed by the president pro tem of the senate;

(5) One member who has early-stage Alzheimer's or a related dementia;

(6) One member who is a family caregiver of a person with Alzheimer's or a related dementia;

(7) One member who is a licensed physician with experience in the diagnosis, treatment, and research of Alzheimer's disease;

EXPLANATION — Matter enclosed in bold-faced brackets **[**thus**]** in the above bill is not enacted and is intended to be omitted from the law. Matter in **bold-face** type in the above bill is proposed language.

(8) One member from the office of the state ombudsman for long-term care facility residents;

(9) One member representing the home care profession;

(10) One member representing residential long-term care;

(11) One member representing the adult day services profession;

(12) One member representing the insurance profession;

(13) One member representing the area agencies on aging;

(14) One member with expertise in minority health;

(15) One member who is a licensed elder law attorney;

(16) Two members from the leading voluntary health organization in Alzheimer's care, support, and research.

2. The members of the task force, other than the lieutenant governor, members from the general assembly, and department directors, shall be appointed by the governor with the advice and consent of the senate. Members shall serve on the task force without compensation.

3. The task force shall:

(1) Assess the current and future impact of Alzheimer's disease and related dementia on residents of the state of Missouri;

(2) Examine the existing services and resources addressing the needs of persons with dementia, their families, and caregivers; and

(3) Develop recommendations to respond to the escalating public health situation regarding Alzheimer's.

4. The task force shall include an examination of the following in its assessment and recommendations required to be completed under subsection 3 of this section:

(1) Trends in state Alzheimer's and related dementia populations and their needs, including but not limited to, the state's role in long-term care, family caregiver support, and assistance to persons with early-stage Alzheimer's, early onset of Alzheimer's, and individuals with Alzheimer's disease as a result of Down's Syndrome;

(2) Existing services, resources, and capacity, including but not limited to:

(a) Type, cost, and availability of services for persons with dementia, including home and community based resources, respite care to assist families, residential long-term care options, and adequacy and appropriateness of geriatric-psychiatric units for persons with behavior disorders associated with Alzheimer's and related dementia;

(b) Dementia-specific training requirements for individuals employed to provide care for persons with dementia;

(c) Quality care measure for services delivered across the continuum of care;

(d) Capacity of public safety and law enforcement to respond to persons with Alzheimer's and related dementia;

(e) State support for Alzheimer's research through institutes of higher learning in Missouri;

(3) Needed state policies or responses, including but not limited to directions for the provision of clear and coordinated services and supports to persons and families living with Alzheimer's and related dementias and strategies to address any identified gaps in services.

5. The task force shall hold a minimum of one meeting at four diverse geographic regions in the state of Missouri during the calendar year to seek public input.

6. The task force shall submit a report of its findings and date-specific recommendations to the general assembly and the governor in the form of a state Alzheimer's plan no later than November 15, 2010, as part of Alzheimer's disease awareness month.

7. The task force shall continue to meet at the request of the chair and at a minimum of one time annually for the purpose of evaluating the implementation and impact of the task force recommendations and provide annual supplemental reports on the findings to the governor and the general assembly.

8. The provisions of this section shall expire on November 1, 2012.

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Hearing- and speech-impaired citizens can dial 711.
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