

**Bobby Jindal**  
GOVERNOR



**Alan Levine**  
SECRETARY

**State of Louisiana**  
Department of Health and Hospitals  
Office of the Secretary

October 1, 2009

The Honorable Bobby Jindal  
Governor of Louisiana  
State Capital  
P.O. Box 94004  
Baton Rouge, LA 70804

Dear Governor Jindal:

In response to Senate Concurrent Resolution No. 80 (SCR 80) of the 2008 Regular Session, the Louisiana Department of Health and Hospitals (DHH) submits the enclosed report. The resolution created the Louisiana Alzheimer's Disease Task Force to study and make recommendations to the Legislature of Louisiana concerning the current and future impact of Alzheimer's disease and related dementias on Louisiana citizens.

DHH is available to discuss the enclosed report and recommendations with you. Please contact Hugh Eley, assistant secretary of the DHH office of aging and adult services, at (225) 219-0230 with any questions or comments that you may have.

Sincerely,

A handwritten signature in black ink, appearing to read "Alan Levine".

Alan Levine  
Secretary

Enclosures

Bobby Jindal  
GOVERNOR



Alan Levine  
SECRETARY

**State of Louisiana**  
Department of Health and Hospitals  
Office of the Secretary

October 1, 2009

The Honorable Willie Mount, Chair  
Senate Health and Welfare Committee  
State Capital  
P.O. Box 94183  
Baton Rouge, LA 70804

Dear Senator Mount:

In response to Senate Concurrent Resolution No. 80 (SCR 80) of the 2008 Regular Session, the Louisiana Department of Health and Hospitals (DHH) submits the enclosed report. The resolution created the Louisiana Alzheimer's Disease Task Force to study and make recommendations to the Legislature of Louisiana concerning the current and future impact of Alzheimer's disease and related dementias on Louisiana citizens.

DHH is available to discuss the enclosed report and recommendations with you and the members of the Senate Health and Welfare Committee. Please contact Hugh Eley, assistant secretary of the DHH office of aging and adult services, at (225) 219-0230 with any questions or comments that you may have.

Sincerely,

A handwritten signature in black ink, appearing to read "ALV", with a long, sweeping horizontal stroke extending to the right.

Alan Levine  
Secretary

Enclosures

**Bobby Jindal**  
GOVERNOR



**Alan Levine**  
SECRETARY

**State of Louisiana**  
Department of Health and Hospitals  
Office of the Secretary

October 1, 2009

The Honorable Kay Katz, Chair  
House Health and Welfare Committee  
State Capital  
P.O. Box 44486  
Baton Rouge, LA 70804

Dear Representative Katz:

In response to Senate Concurrent Resolution No. 80 (SCR 80) of the 2008 Regular Session, the Louisiana Department of Health and Hospitals (DHH) submits the enclosed report. The resolution created the Louisiana Alzheimer's Disease Task Force to study and make recommendations to the Legislature of Louisiana concerning the current and future impact of Alzheimer's disease and related dementias on Louisiana citizens.

DHH is available to discuss the enclosed report and recommendations with you and the members of the House Health and Welfare Committee. Please contact Hugh Eley, assistant secretary of the DHH office of aging and adult services, at (225) 219-0230 with any questions or comments that you may have.

Sincerely,

A handwritten signature in black ink, appearing to read "Alan Levine".

Alan Levine  
Secretary

Enclosures

DEPARTMENT OF HEALTH AND HOSPITALS

# THE IMPACT OF ALZHEIMER'S DISEASE IN LOUISIANA

---

A REPORT OF THE LOUISIANA  
ALZHEIMER'S DISEASE TASK FORCE

REPORT PREPARED IN RESPONSE TO SCR 80  
OF THE 2008 REGULAR SESSION

OCTOBER 2009

**Contact:**

Louisiana Department of Health and Hospitals  
HUGH ELEY  
Office of Aging and Adult Services  
PO Box 2031  
Baton Rouge, LA 70821  
225-219-0223  
[hugh.eley@la.gov](mailto:hugh.eley@la.gov)

**Table of Contents**

EXECUTIVE SUMMARY ..... 3  
INTRODUCTION..... 6  
TRENDS IN POPULATIONS and NEEDS:..... 7  
THE FACE OF THE DISEASE..... 7  
LOUISIANA: THE STATE OF OUR STATE ..... 12  
TASK FORCE RECOMMENDATIONS..... 44  
CONCLUSION ..... 59  
BIBLIOGRAPHY ..... 60

---

## EXECUTIVE SUMMARY

---

Alzheimer's disease is a progressive, irreversible condition that leads to a loss of memory, cognition, judgment, orientation, ability to understand and communicate effectively and, frequently, changes in personality and behavior. Other forms of dementia bring similar changes.

The burden for dementia care falls mainly on families. About 10 million Americans provide unpaid, "informal" care each year for adult family members and friends with Alzheimer's disease and related dementias (ADRD's).<sup>1</sup> In Louisiana, over 160,000 persons provide \$1.5 billion of informal care to people with ADRD's.

As the "baby boomer" population ages, Alzheimer's disease will be a growing problem in the United States and Louisiana. By 2010, there will be an estimated 83,000 people in our state who have been diagnosed with the disease. By 2035 that number is expected to rise by 37 percent. When compared to other states, Louisiana had the third highest aged-adjusted death rate from ADRD's. While commonly seen as a disease of the elderly, a significant number of persons with ADRD's are under the age of 60, with diagnoses having even been made for people in their 20's.

People with ADRD's and their families access a wide array of services, including medical care, day care, personal care at home, specialized housing, and nursing facility care to supplement what families can do on their own. Much of this is paid for out of pocket, with lesser amounts coming from Medicare and private insurance, including long-term care insurance. Public funding supplements this care primarily through services provided under Medicaid and the Older Americans Act. These services are generally not directed solely to persons with ADRD's, but are generally available to older persons and persons with disabilities.

Residents of Louisiana who are affected by Alzheimer's disease report serious difficulties in obtaining the level of care they need to support themselves and their loved ones. Fear and denial cause individuals to refuse care, fail to ask the right questions, and fail to plan. Publically funded services are fragmented and difficult to find. Furthermore, services are underfunded, leading to long waiting lists for what does exist. Financial eligibility criteria for publically funded services leave Louisiana with a large number of persons who don't qualify for assistance, but can't afford the services they need either.

The Louisiana Alzheimer's Disease Task Force has made 27 recommendations in the areas of coordination, programs and services, caregiver support, public awareness, health care and health services, professional workforce, surveillance and data collection, advanced planning, and research. Full implementation will require the cooperation of multiple state agencies and non-governmental organizations. Of these 27 recommendations, the most important are in the area of coordination. Implementing the coordination recommendations will provide Louisiana with a framework that will make possible steady progress in achieving workable solutions for people with ADRD's. These recommendations are as follows:

### **Recommendation 1**

**Create a permanent Advisory Council on ADRD consisting of the current Task Force**

---

<sup>1</sup> [www.alz.org](http://www.alz.org)

**designations plus additional designations to ensure balance and expertise to include such functions as:**

- Monitor benchmarks for implementation of the Task Force Report.
- Update recommendations of the Task Force Report, as appropriate.
- Monitor progress of implementation of the dementia-training regulations for nursing facilities and assisted living communities.
- Report annually to the Legislature.

**Recommendation 2**

**Establish and fund a Program Manager for Alzheimer's disease and related dementias in the Office of Aging and Adult Services (OAAS) to include functions such as:**

- Coordinate interagency policy, programs, and services.
- Gather information and resources about dementia, both public and private, and serve as a clearinghouse.
- Coordinate with the Office of Public Health (OPH) on surveillance and data collection.
- Staff the Advisory Council on ADRD's.
- Identify and pursue grant opportunities.
- Coordinate quality management initiatives.
- Monitor programs that serve persons with ADRD's.
- Monitor implementation of the Plan for Choice
- Monitor all workgroups convened to address issues touching the lives of persons with ADRD's, their caregivers and families.
- Oversee implementation of the Task Force Report.
- This would not replace or duplicate any services currently offered by the Area Agencies on Aging, the Alzheimer's Association or other agencies, but would act as a referral source to local services

**Recommendation 3**

**Develop and/or implement, building on existing resources, a dementia-branded toll-free number and website to act as a clearinghouse for programs, services and educational information serving persons with ADRD's that takes advantage of existing information and referral services such as Aging and Disability Resource Centers and the Long-term Care Options Help Line.**

## Alzheimer's Disease Task Force Members

Pursuant to SCR 80 the Louisiana Alzheimer's Disease Task Force was formed. The members of this task force with their affiliations are as follows:

Patricia DeMichele, J.D., Chair  
The Advocacy Center

Mary Norris  
Medicaid/DHH

Jodi Guidry  
LA Nursing Home Association.

John Ford  
LA Adult Day Service Association

Karen Contrenchis  
Gulf States Association of Homes & Services  
for the Aging

Yvette Williams-Jones  
PACE-LA

Marie Brown-Mercadel  
Dept. of Social Services

Ruth Fontenot  
Alzheimer's Association of LA

Jo Huey  
LA Assisted Living Association.

Dr. Jay Bulot  
Governor's Office of Elderly Affairs

Linda Beauvais  
Capital Area Agency on Aging

Debbie Thompson  
LA Home Care Association

Dr. Susan Nelson  
LA State Medical Society

Dr. Nancy Bologna  
Louisiana Geriatrics Society

Angela Shockley  
Office for Citizens with Dev.  
Disabilities/DHH

Cynthia Prestholdt  
LA State Nurses Association

Cathy Castille  
Office of Mental Health/DHH

Verda Gates  
Community and Residential Services  
Association

Jamey Boudreaux  
LA/MS Hospice and Palliative Care  
Organization

Susan Pinder  
Consumer, appointed by the Governor

Marianne White  
Consumer, appointed by the Governor

Nicole Kilgore  
LA State Police

Kerry Everitt  
AARP Louisiana

Julia Kenny  
Department of Health and Hospitals

Dr. Jeffrey Keller  
Pennington Biomedical Research Center

Mark Perry  
Bureau of Primary Care and Rural  
Health/DHH

Hugh Eley  
Office of Aging and Adult Services/DHH



---

## INTRODUCTION

---

The Louisiana Alzheimer's Disease Task Force was established by SCR 80 of the 2008 Regular Legislative Session. This report addresses those topics listed in the resolution and is organized as determined by SCR 80.

As the work of the Task Force proceeded, an overarching theme began to emerge. While not quite a vision statement, it is a hopeful view of the future.

Louisiana public policy will promote dignity and quality of life for Louisianians with Alzheimer's disease and related dementias at any age and at any stage of the disease by:

- Increasing public awareness
- Promoting prevention
- Ensuring early detection and diagnosis
- Coordinating policy, programs, services and funding
- Providing programs, services and support appropriate to persons of all ages, across all stages of dementia
- Providing support, education and training for caregivers, both paid and unpaid
- Promoting advance planning
- Preventing secondary problems arising from cognitive impairments
- Increasing public health surveillance
- Attracting research to Louisiana

The Task Force assessed the needs of persons with Alzheimer's disease and related dementias (ADRD's) and of their caregivers and families, and then identified programs and services that might currently address those needs. The group then looked for gaps between needs and services and found that nine themes emerged as challenges across all stages and at all ages of the disease. Those themes became the basis for the nine areas in "Task Force Recommendations" below.

Once challenges were identified, Task Force members met with people in six communities at public forums hosted by Alzheimer's Services of the Capital Area in Baton Rouge, and by the Alzheimer's Association Louisiana Chapter in Shreveport, Lake Charles, Monroe, Alexandria and New Orleans. Through a series of exercises, the 146 participants had an opportunity to tell their stories, to describe the most important challenges facing persons with dementia, and to prioritize the issues most important to them personally.

---

## TRENDS IN POPULATIONS AND NEEDS: THE FACE OF THE DISEASE

---

### **BACKGROUND**

Alzheimer's disease is the most common form of the brain diseases listed under the major category of dementia. Dementia occurs in people with Alzheimer's disease because healthy brain tissue degenerates, causing a steady decline in memory, mental abilities, and daily living skills. Alzheimer's is a progressive, degenerative disease that causes more than simple forgetfulness. It may begin with slight memory loss and confusion, but eventually it leads to irreversible mental impairment that destroys a person's ability to remember, reason, learn and imagine.

Persons with Alzheimer's disease or other dementias exhibit different levels of physical and cognitive abilities at different stages. Symptoms common in early stages include memory loss, lapses in judgment, changes in personality, and inability to follow through with common life tasks. Families often notice these changes but attribute them to "normal aging." Physicians may also miss these early warning signs. At this point, individuals usually require minimal assistance with regular tasks such as cooking, dressing and cleaning. By the time a medical diagnosis is made, the individual is usually past the early stages. The needs of persons with Alzheimer's disease, their caregivers and families vary by stage and increase dramatically in the later stages.

Delay in diagnosis is unfortunate. While there is currently no cure for Alzheimer's disease and related dementias, researchers continue to make progress in identification and treatment. Many available medications appear to work best in the early stages by providing some symptomatic relief and potentially delaying further deterioration. Treatments primarily improve the quality of life and, as more drugs are studied, researchers have discovered several genes associated with Alzheimer's disease which may lead, in turn, to new treatments to block progression.

### **CHANGING POPULATION WITH DEMENTIA**

#### **Prevalence**

- ***National***

In a statistical report released in 2009, the Alzheimer's Association estimated that 5.3 million Americans have Alzheimer's disease and related dementias (ADRD's). Moreover, approximately 500,000 Americans *under age 65* have ADRD's, with about 40 percent of them having Alzheimer's disease.<sup>2</sup>

---

<sup>2</sup> (Alzheimer's Association, *Alzheimer's Disease Facts and Figures 2008* Washington, D.C.: 2008. ([www.alz.org](http://www.alz.org))). ["Alzheimer's Report"].

According to the Alzheimer’s Report, every 70 seconds someone in America develops ADRD. By mid-century, someone will develop dementia every 33 seconds. By 2050, as the baby boomer generation ages, the number of Americans age 65 and older with ADRD’s could range from 11 million to 16 million. By that date, more than 60 percent of those with will be age 85 or older.

The Alzheimer’s Report states that 28 percent of Medicare beneficiaries age 65 and older with ADRD’s were also eligible for Medicaid in 2004. Of that total, about half were nursing facility residents, with the rest living in communities. The Alzheimer’s Report further notes that, in 2005, 65 percent of older people living in communities and 84 percent of those at high risk of needing nursing home care do not have enough assets to cover even *one month* of nursing home care.

Alzheimer’s disease is the seventh leading cause of death for people of all ages, and is the fifth leading cause for those aged 65 and older. Death rates increase with age and have been increasing over time. More than two-thirds of those dying from dementia did so in nursing facilities, compared with roughly 80 percent of cancer patients who died at home or in hospitals.

Deaths attributed to Alzheimer’s disease or other dementias have continued to increase despite the decrease in the number of deaths due to other major diseases. According to the Alzheimer’s Report, deaths attributed to Alzheimer’s disease increased 47.1 percent while those attributed to heart disease – the number one cause of death – decreased by 11.5 percent.

Deaths attributed to ADRD’s are substantially underreported on death certificates, leading to a significant underestimation of the public health impact of these conditions. Both studies and anecdotal reporting by researchers indicate that the underreporting extends even to contributory causes of death. This is true whether death occurs in the community or in a nursing facility.

The burden for financing long-term care falls primarily on public resources. Nationally long-term care spending totaled \$177.6 billion in 2006; Medicaid accounted for the largest share (40 percent) followed by Medicare and out-of-pocket (20 percent and 22 percent respectively).<sup>3</sup>

- **Louisiana**

The Alzheimer’s Report reflects nearly 73,000 Louisianians with a diagnosis of Alzheimer’s disease in 2000, with a potential 14 percent increase by 2010 to 83,000, and a staggering rise to 100,000 people in 2025, only 16 years away.

**Table 1: Projections for Total Numbers of Louisianians Age 65 and Older with ADRD’s**

Year	65 – 74	75 – 84	85+	Total	% change from 2000
2000	5,100	38,000	30,000	73,000	
2010	4,700	41,000	37,000	83,000	14 %
2020	6,000	43,000	43,000	92,000	26%
2025	7,000	51,000	46,000	100,000	37%

<sup>3</sup> Kaiser Commission on Medicaid and the Uninsured, Medicaid and Long-Term Care Services and Supports, February 2009. Available at [http://www.kff.org/medicaid/upload/2186\\_06.pdf](http://www.kff.org/medicaid/upload/2186_06.pdf). These data do not include services financed primarily through Medicaid HCBS waivers.

In 2005, Louisiana had the third highest age-adjusted death rate attributed to Alzheimer's disease – 34.2 per 100,000 or 1,405 deaths.

### **STATE ROLE IN LONG-TERM CARE**

In 2007, 1.6 percent of Louisiana's population was age 85 or older, a figure expected to climb to 2.6 percent by 2030 for a 74 percent increase in the population segment having the highest disability rate. In that same year, 4.1 percent of Louisiana's population was between the ages of 75 and 84. This figure is expected to climb to 6.6 percent by 2030 for an 84 percent increase.<sup>4</sup> Advancing age is well-recognized as an important risk factor for Alzheimer's disease and related dementias.

An AARP Louisiana-specific survey demonstrated that 88 percent of Louisianians feel it is very important to have long-term care services in place to enable them or their family members to stay at home as long as possible if long-term care were needed.<sup>5</sup>

Nationally the Medicaid program accounts for the majority of public expenditure for all long-term care services. Historically, the majority of publically financed long term care has been provided in facilities, as institutional care is an entitlement under federal law, where community-based care usually is not. In recent years states have undertaken efforts to shift more resources into community-based services. In the past few years, Louisiana has seen a large increase in spending on community-based services. In State Fiscal Year 2008, 26 percent of the approximately \$1 billion in Medicaid expenditures on long term care services targeted for the elderly or those with adult-onset disabilities went into community based services. For State Fiscal Year 2009 that percentage rose to about 32 per cent. This increase has been driven primarily by expansion of the number of persons served as nearly 13,000 persons receiving Medicaid long-term care now receive it in the community. Nevertheless, demand for these services continues to grow, with over 12,000 people currently on registries (waiting lists). The Department of Health and Hospitals (DHH) is currently implementing changes in the community-based programs intended to reduce the per-person costs, allowing more persons to be served at a given level of expenditure. Nursing home expenditures have also grown. Expenditures for nursing facility care have risen in five years from \$604 million to \$716 million, while utilization has decreased by nine percent.

- **Louisiana's Plan for Choice In Long Term Care**

On October 22, 2004, Governor Blanco issued Executive Order KBB 2004-43 which required a two-stage process to reform the administration and delivery of long-term care supports and services within Louisiana. During the first stage, the "Plan for Immediate Action" was developed. The second stage resulted in the development of the "Louisiana's Plan for Choice in Long-term Care: Comprehensive Long-Term Care Reform Plan"<sup>6</sup> (Plan for Choice) which described initiatives that could be completed by 2010.

---

<sup>4</sup> AARP, *Across the States: Profiles in Long-term Care and Independent Living*. Washington, D.C.: 2009. [AARP State Profiles"].

<sup>5</sup> (AARP, *Louisiana Long-term Care: A Survey of AARP Members*. Washington, D.C. AARP Knowledge Management 2005.

<sup>6</sup> <http://www.dhh.state.la.us/offices/publications/pubs->

The Plan for Choice was developed by a consortium with DHH, as the lead agency, in collaboration with the Department of Social Services, the Department of Transportation and Development, the Department of Public Safety, the Department of Labor, the Department of Education, the Department of Veterans Affairs, the Department of Economic Development, the Governor's Office of Elderly Affairs, the Governor's Office of Disability Affairs, the Louisiana Housing Finance Agency, and the Louisiana State Board of Nursing as well as a diverse group of non-governmental stakeholders. The Plan for Choice addressed many areas of interest to persons with ADRD's and their families. However, it did not mandate the development of dementia-specific competence or the development of dementia-specific programs for Louisiana.

### **FAMILY CAREGIVER SUPPORT**

Nearly ten million people across the country provide unpaid care to persons with ADRD's, including families, friends and neighbors. In 2008, they provided 8.5 billion hours of unpaid care at a value of \$94 billion.<sup>7</sup> In Louisiana in 2008, 160,915 unpaid caregivers delivered a total of 138,900,565 hours of unpaid care at a value of more than \$1.5 billion.<sup>8</sup>

About 60 percent of unpaid caregivers are women and most are relatives. Unpaid caregivers range in age from very young to very old, with an average age of 48. Ten percent of the unpaid caregivers live more than two hours away from the person with dementia.

Unpaid caregivers perform a variety of tasks: grocery shopping, meal preparation, transportation, administering medication, managing finances, supervising to ensure safety, personal care, making arrangements for medical care and managing behavioral symptoms. Many unpaid caregivers continue to perform some of these tasks even after the person with dementia moves into a residential care setting.

People with ADRD's do not simply suffer loss of memory. There is a loss of judgment, orientation, ability to understand and communicate effectively and, frequently, there are changes in personality and behavior. As the levels of supervision and personal care rise, many caregivers experience high levels of stress and negative effects on their health, employment, income and financial security.

Some persons with ADRD's may qualify for public programs offered primarily by the Governor's Office of Elderly Affairs (GOEA) and the Office of Aging and Adult Services (OAAS). Their programs include information and referral, home and community based respite care, homemaker services, personal care, meal preparation and the like. GOEA sponsors the National Family Caregiver Support Program<sup>9</sup> (NFCSP) which provides individual counseling, support groups, respite

---

**[77/LA%20Plan%20for%20Choice%20in%20Long-term%20Care%20 Full%20document web.pdf](#)**

<sup>7</sup> Care was valued at \$11.10 per hour, which is the average of the minimum wage (\$5.85 per hour) and the average wage of a home health aide in July 2008 (\$18.35 per hour). Alzheimer's Report at p.34.

<sup>8</sup> 2008 *Alzheimer's Disease Facts and Figures* , The Alzheimer's Association p. 19

<sup>9</sup> [http://www.aoa.gov/AoARoot/AoA\\_Programs/HCLTC/Caregiver/index.aspx](http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/Caregiver/index.aspx) , September 9,2009.

care, personal care, home repair and modifications to any person caring for an individual with Alzheimer's disease – regardless of age. Faith-based organizations and other private providers offer an array of services for a fee, which is often an out-of-pocket cost for an unpaid caregiver.

### **HELP FOR THOSE WITH YOUNGER ONSET**

The term “younger onset dementia” refers to dementia that first occurs in a person under age 65 and may be caused by Alzheimer's disease or other related diseases or conditions. People with younger onset dementia may be at any stage of the disease.<sup>10</sup> It is estimated that six to ten percent of all people with Alzheimer's disease may have onset of symptoms before age 65.

ADRD's are devastating conditions that take a huge emotional, financial, and physical toll on the person, the caregivers and the families. When they occur in people under age 65, these conditions cause additional and unique problems because they are unexpected and because most of the potentially helpful programs and services are designed for, and targeted to, older persons. For example, few families would realize that the NFCSP, under the Councils on Aging would offer services to anyone regardless of age – even if both caregiver and patient are younger than 60.

In the Alzheimer's Early Onset Report, experts identified six problems common to persons with younger onset dementia and their families. Not all persons with younger onset dementia experience each of these problems and many persons over the age of 65 with dementia face similar issues. These common problems include:

- Difficulty getting an accurate diagnosis because it is unexpected in younger persons as an explanation for symptoms of dementia.
- Loss of employment and job-related income since symptoms of dementia in younger workers may not be formally recognized as a work disability.
- Difficulty obtaining Social Security Disability Insurance (“SSDI”), Supplemental Security Income (“SSI”) and other disability benefits.
- Lack of health insurance and high out-of-pocket expenditures for medical care because they are not yet eligible for Medicare and often lose job-related health coverage.
- High out-of-pocket costs for long-term care since most publicly-funded programs only serve the very poor who qualify for SSI or persons over the age of 60.
- Lack of appropriate medical care, residential care, and community services which are typically designed for and targeted to older persons.

Problems facing all persons with ADRD's are magnified for those who experience younger onset. Physicians, employers and health and long-term care policymakers need to become more aware of younger onset dementia and the importance of tailoring diagnosis, treatment, work accommodations, health insurance and long-term care programs and services to the unique needs of this group.

---

<sup>10</sup> Maslow, K., Langa, K.M., Kabeto, M.U., and Weir, D.R. “Early Onset Dementia: A National Challenge, A Future Crisis” The Alzheimer's Association.  
[http://www.alz.org/national/documents/report\\_earlyonset\\_summary.pdf](http://www.alz.org/national/documents/report_earlyonset_summary.pdf). September 29, 2009.

## **STATE POLICY REGARDING PERSONS WITH ALZHEIMER'S DISEASE and DEVELOPMENTAL DISABILITIES**

Studies demonstrate a significant link between Down syndrome and the onset of Alzheimer's disease. In fact, some show a nearly 100 percent correlation. As this population continues to live longer lives, the numbers of people with such a dual diagnosis will increase. Diagnosis of Alzheimer's disease in persons with developmental disabilities is also difficult. The Office of Citizens with Developmental Disabilities (OCDD) has a Center on Aging and Developmental Disabilities and is developing competency in this area to address the growing needs of older persons with developmental disabilities. OCDD provides consultation and training to staff that encounter individuals with dementia in the course of their work.

---

### **LOUISIANA: THE STATE OF OUR STATE**

---

As the work of the Task Force progressed, it was clear that individuals with Alzheimer's disease and related dementias (ARD's) and their families in Louisiana struggle to obtain appropriate support. While further in this report there will be descriptions of many available services, many persons report that the system is fragmented, making services hard to find. Of even greater importance is that most publically funded systems and services are underfunded, leading to long waiting lists. Not all services are available everywhere, meaning that optimal care is often unavailable to many. Finally, publically funded services are often means-tested, leaving a large group of consumers who do not qualify for assistance, and who are also unable to purchase the care that they need.

#### **DEMENTIA SERVICES**

Three state agencies offer publicly-funded services for persons with ARD's, their families and caregivers: GOEA, OAAS in the Department of Health and Hospitals (DHH), and the Department of Veterans Affairs (LDVA). While all of these agencies may design their services with the needs of people with ARD's and their families in mind, no agency targets services specifically to persons with ARD's, although many clients using the services may fall into that category.

Both GOEA and OAAS use a combination of state and federal funding to provide long-term care services and supports that may benefit persons with ARD's. GOEA combines funds from Title III of the Older Americans Act<sup>11</sup> with state appropriations to deliver home- and community-based services across the state. OAAS utilizes federal Medicaid dollars along with the state match to fund both nursing facility care and home and community-based services. The LDVA funds dementia services only with state general funds.

The specific cost of dementia services is difficult to assess since services generally serve older Louisianians without regard to diagnosis. For example, a person may need in-home services because of a chronic medical condition but have no cognitive impairment whatsoever. Overall spending by GOEA and OAAS on long-term care would likely overstate the cost for these services to persons

---

<sup>11</sup> The Older Americans Act, Title III, Grants to State and Community Programs. Available at [http://www.aoa.gov/AoA/Root/AoA\\_Programs/OAA/oa\\_full.asp#\\_Toc153957659](http://www.aoa.gov/AoA/Root/AoA_Programs/OAA/oa_full.asp#_Toc153957659). Sept. 9, 2009.

with dementia.

The Alzheimer's Association Louisiana Chapter, Alzheimer's Services of the Capital Area and Alzheimer's Services of the Crescent City provide support groups for caregivers; support groups for Younger Onset Alzheimer's disease patients; dementia care conferences for professionals and caregivers; free informational programs for family caregivers; law enforcement and first responder training; dementia training for providers, professionals and in-home caregivers; referral services, MedicAlert/Safe Return program; 24 hour toll-free helpline; care consultations; public advocacy; efforts; and research funding. These organizations primarily rely on donations to support their work. Some faith-based organizations and other not-for-profit entities offer various services that support this population. The costs of these efforts are unknown.

Nationally, Medicaid is the largest single payer for long-term care expenses (40 percent). While Medicare is not seen as a provider of long-term care services, its post-acute hospital benefits provide for an additional 20 percent of long-term care expenditures. Private pay accounts for an additional 22 percent.<sup>12</sup>

The Task Force developed a Chart of Stages, Current Services and Gaps in Services (Table 2) to identify, as best we could, services available to persons with dementia whether or not targeted to that group.

---

<sup>12</sup> Kaiser Foundation. February 2009.



**THIS PAGE HAS BEEN INTENTIONALLY LEFT BLANK**

Table 2: Gaps in services, challenges to access, and current services arranged by stages of ADRD's

STAGES and CHARACTERISTICS	CURRENT SERVICES	GAPS IN SERVICES and CHALLENGES TO ACCESS
<p>Stage 1: Normal Aging</p> <p>No deficits whatsoever</p>	<p><b>Public Information &amp; Education</b></p> <ul style="list-style-type: none"> <li>● Wellness &amp; prevention                             <ul style="list-style-type: none"> <li>○ Alzheimer's Association</li> <li>○ Alzheimer's Services of the Capital Area</li> <li>○ GOEA through Councils on Aging/ Area Agencies on Aging (AAA)/ Senior Centers</li> <li>○ Faith-based organizations</li> </ul> </li> <li>● Community education                             <ul style="list-style-type: none"> <li>○ Alzheimer's Association</li> <li>○ Alzheimer's Services of the Capital Area</li> <li>○ Medicare</li> <li>○ Aging &amp; Disability Resource Centers (ADRCs)</li> </ul> </li> </ul> <p><b>Advance Planning</b></p> <ul style="list-style-type: none"> <li>● Legal</li> <li>● Financial</li> <li>● Long-term care insurance</li> <li>● Health care planning</li> </ul> <p><b>Professional Direct Care Workforce</b></p> <ul style="list-style-type: none"> <li>● Provider education                             <ul style="list-style-type: none"> <li>○ GOEA through Councils on Aging/AAA/Senior Centers</li> <li>○ Aging &amp; Disability Resource Centers (ADRCs)</li> </ul> </li> </ul>	<p><b>Coordination</b></p> <ul style="list-style-type: none"> <li>● Widely scattered programs, services, &amp; policy decisions</li> <li>● Lack of single policymaking authority</li> <li>● Lack of comprehensive &amp; coordinated public funding</li> </ul> <p><b>Public Awareness</b></p> <ul style="list-style-type: none"> <li>● Prevention/wellness/brain health</li> <li>● Risk factors</li> <li>● Culturally competent &amp; easily understood information</li> <li>● Marketing strategies tailored to unique cultural differences &amp; designed to be available where people are when the need for information arises (the teachable moment)                             <ul style="list-style-type: none"> <li>○ Urban &amp; rural</li> <li>○ Ethic &amp; cultural attitudes</li> </ul> </li> </ul> <p><b>Advance planning</b> – health, end of life &amp; financial</p> <ul style="list-style-type: none"> <li>● Denial of need</li> <li>● Lack of awareness of need</li> <li>● Lack of tools &amp; services</li> <li>● Lack of information about tools &amp; services that are available</li> <li>● Lack of understanding about long-term care insurance</li> </ul> <p><b>Professional Direct Care Workforce</b></p> <ul style="list-style-type: none"> <li>● Academic curricula do not address dementia-specific training</li> <li>● Continuing education requirements do not address dementia-specific training</li> <li>● Professional certification requirements do not address dementia-specific training</li> <li>● DHH/DSS provider licensing requirements do not address dementia-specific training</li> </ul> <p><b>Health Care &amp; Related Services</b></p> <ul style="list-style-type: none"> <li>● Lack of public education regarding risk factors, prevention, wellness, and brain health</li> </ul>

STAGES and CHARACTERISTICS	CURRENT SERVICES	GAPS IN SERVICES and CHALLENGES TO ACCESS
<p><b>Stage 2: Possible Mild Cognitive Impairment</b></p> <p>Personal awareness of some functional decline</p> <p>Complains of forgetting location of objects</p> <p>Subjective work difficulties</p>	<p><b>Public Information &amp; Education</b></p> <ul style="list-style-type: none"> <li>● Wellness activities <ul style="list-style-type: none"> <li>○ Alzheimer’s Association</li> <li>○ Alzheimer’s Services of the Capital Area</li> <li>○ GOEA through Councils on Aging/Area Agencies on Aging (AAA)/ Senior Centers</li> </ul> </li> <li>○ Faith-based organizations</li> <li>● Community education <ul style="list-style-type: none"> <li>○ Alzheimer’s Association</li> <li>○ Alzheimer’s Services of the Capital Area</li> <li>○ Medicare</li> <li>○ ADRCs</li> </ul> </li> </ul> <p><b>Advance Planning</b></p> <ul style="list-style-type: none"> <li>● Legal</li> </ul>	<ul style="list-style-type: none"> <li>● Lack of public health surveillance &amp; data collection</li> </ul> <p><b>Surveillance &amp; data collection</b></p> <ul style="list-style-type: none"> <li>● Lack of widespread &amp; consistent public health surveillance <ul style="list-style-type: none"> <li>○ Incidence</li> <li>○ Prevalence</li> <li>○ Identify risk factors</li> <li>○ Need to develop strategies to reduce risk</li> </ul> </li> <li>● Rapidly evolving knowledge of ADRD</li> <li>● Inconsistent data for research</li> <li>● Lack of data for effective policy development <ul style="list-style-type: none"> <li>○ Caregiver health</li> <li>○ Diseases of cognitive impairments</li> </ul> </li> </ul> <p><b>Coordination</b></p> <ul style="list-style-type: none"> <li>● Widely scattered programs, services, &amp; policy decisions</li> <li>● Lack of single policy making authority</li> <li>● Lack of comprehensive &amp; coordinated public funding</li> </ul> <p><b>Public Awareness</b></p> <ul style="list-style-type: none"> <li>● Prevention/wellness/brain health</li> <li>● Risk factors</li> <li>● Culturally competent &amp; easily understood information</li> <li>● Marketing strategies tailored to unique cultural differences &amp; designed to be available where people are when the need for information arises (the teachable moment) <ul style="list-style-type: none"> <li>○ Urban &amp; rural</li> <li>○ Ethic &amp; cultural attitudes</li> </ul> </li> </ul> <p><b>Advance Planning</b> – health, end of life, &amp; financial</p> <ul style="list-style-type: none"> <li>● Denial of need</li> <li>● Lack of awareness of need</li> <li>● Lack of tools &amp; services</li> </ul>

STAGES and CHARACTERISTICS	CURRENT SERVICES	GAPS IN SERVICES and CHALLENGES TO ACCESS
<p><b>Stage 3: Mild Cognitive Impairment</b></p> <p>Objective functional deficit interferes with a person's most complex</p>	<ul style="list-style-type: none"> <li>• Financial</li> <li>• Long-term care insurance</li> <li>• Health care planning</li> <li>• <b>Professional Direct Care Workforce</b></li> <li>• Provider education <ul style="list-style-type: none"> <li>○ Councils on Aging/AAA/Senior Centers</li> <li>○ Aging &amp; Disability Resource Centers (ADRCs)</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Lack of information about tools &amp; services that are available</li> <li>• Lack of understanding of LTC insurance</li> <li>• <b>Professional Direct Care Workforce</b></li> <li>• Academic curricula do not address dementia-specific training</li> <li>• Continuing education requirements do not address dementia-specific training</li> <li>• Professional certification requirements do not address dementia-specific training</li> <li>• DHH/DSS provider licensing requirements do not address dementia-specific training</li> <li>• <b>Health Care &amp; Related Services</b></li> <li>• Lack of public education regarding risk factors &amp; brain health</li> <li>• Lack of coordinated public health surveillance &amp; data collection</li> <li>• <b>Surveillance &amp; Data Collection</b></li> <li>• Lack of widespread &amp; consistent public health surveillance <ul style="list-style-type: none"> <li>○ Incidence</li> <li>○ Prevalence</li> <li>○ Identify risk factors</li> <li>○ Develop strategies to reduce risk</li> <li>○ Health effects on caregivers</li> </ul> </li> <li>• Rapidly evolving knowledge of ADRD</li> <li>• Inconsistent data for research</li> <li>• Lack of data for effective policy development <ul style="list-style-type: none"> <li>○ Caregiver health</li> <li>○ Diseases of cognitive impairments</li> </ul> </li> </ul>
<p><b>Stage 3: Mild Cognitive Impairment</b></p> <p>Objective functional deficit interferes with a person's most complex</p>	<p><b>Health Care</b></p> <ul style="list-style-type: none"> <li>• Early detection &amp; benefits</li> <li>• Drug therapies</li> <li>• <b>Programs &amp; Services</b></li> <li>• Information &amp; referral <ul style="list-style-type: none"> <li>○ GOEA through Councils on</li> </ul> </li> </ul>	<p><b>Coordination</b></p> <ul style="list-style-type: none"> <li>• Widely scattered programs, services, &amp; policy decisions</li> <li>• Lack of single policymaking authority</li> <li>• Lack of comprehensive &amp; coordinated public funding</li> <li>• <b>Public Awareness</b></li> <li>• Prevention/wellness/brain health</li> </ul>

STAGES and CHARACTERISTICS	CURRENT SERVICES	GAPS IN SERVICES and CHALLENGES TO ACCESS
<p>tasks, including the ability to plan or organize, reading retention, performance issues in work &amp; social setting</p>	<ul style="list-style-type: none"> <li>○ Aging &amp; AAAs</li> <li>○ Alzheimer's Association</li> <li>○ Alzheimer's Services of the Capital Area</li> <li>○ Louisiana Assisted Living Association (LALA)</li> <li>○ Gulf States Association of Homes and Services for the Aging (GSAHSA)</li> <li>○ Louisiana Nursing Home Association (LNHA)</li> <li>○ ADRC's</li> <li>● Safety programs</li> <li>○ Medic Alert Safe Return (Alzheimer's Association)</li> <li>○ Alzheimer's Services of the Capital Area</li> <li>○ Project Life Saver (825/month)</li> <li><b>Caregiver Support</b></li> <li>● Alzheimer's Association</li> <li>○ 24-hour hotline</li> <li>○ Support groups</li> <li>○ Care consultation</li> <li>● Alzheimer's Services of the Capital Area</li> <li>○ In-home or on-site respite care</li> <li>○ Support groups</li> <li>● LALA</li> </ul>	<ul style="list-style-type: none"> <li>● Risk factors</li> <li>● Culturally competent &amp; easily understood information</li> <li>● Marketing strategies tailored to unique cultural differences &amp; designed to be available where people are when the need for information arises. (the teachable moment) <ul style="list-style-type: none"> <li>○ Urban &amp; rural</li> <li>○ Ethic &amp; cultural attitudes</li> </ul> </li> <li><b>Advance planning</b> – health, end of life, &amp; financial</li> <li>● Denial of need</li> <li>● Lack of awareness of need</li> <li>● Lack of tools &amp; services</li> <li>● Lack of information about tools &amp; services that are available</li> <li>● Lack of understanding of LTC insurance</li> <li><b>Professional Direct Care Workforce</b></li> <li>● Academic curricula do not address dementia-specific training</li> <li>● Continuing education requirements do not address dementia-specific training</li> <li>● Professional certification requirements do not address dementia-specific training</li> <li>● DHH/DSS provider licensing requirements do not address dementia-specific training</li> <li><b>Health Care &amp; Related Services</b></li> <li>● Lack of public education regarding risk factors &amp; brain health</li> <li>● Lack of coordinated public health surveillance &amp; data collection</li> <li>● Lack of access to clinical trials</li> <li><b>Caregiver support</b></li> <li>● General lack of support &amp; services</li> <li>● Lack of support &amp; services is exacerbated in rural areas</li> <li>● Lack of public awareness of supports &amp; services that <i>are</i> available</li> <li>● Lack of human resource policies to address on-the-job issues for employees who are caregivers</li> </ul>

STAGES and CHARACTERISTICS	CURRENT SERVICES	GAPS IN SERVICES and CHALLENGES TO ACCESS
	<ul style="list-style-type: none"> <li>• Faith-based organizations</li> <li><b>Professional Direct Care Workforce</b></li> <li>• Provider Education <ul style="list-style-type: none"> <li>○ LALA</li> <li>○ GSAHSA</li> <li>○ LNHA</li> </ul> </li> </ul>	<p><b>Programs &amp; Services</b></p> <ul style="list-style-type: none"> <li>• No resources for persons with younger-onset diagnosis <ul style="list-style-type: none"> <li>○ Public programs usually age-related</li> <li>○ No programs to help maintain employment &amp; financial independence</li> </ul> </li> <li>• Resource network &amp; statewide single point of entry are not dementia-specific &amp; target primarily older persons</li> <li>• OAS LTC Options Help Line is not marketed in a way that would attract persons with dementia or their caregivers</li> <li>• Over reliance on institutional long-term care services because of lack of widely available HCBS</li> <li>• Adequacy of LTC assessment tool for persons with dementia</li> <li>• Lack of funding for respite, adult day care, adult day health care, &amp; other HCBS services</li> <li>• Medicaid HCBS waiting lists</li> <li>• Urban – rural disparities in all programs &amp; services across the state</li> <li>• Regulatory restrictions in licensing adult residential care facilities preventing expansion of respite &amp; other day or other short-stay programs</li> <li>• Housing alternatives <ul style="list-style-type: none"> <li>○ Little or no availability of supportive housing</li> <li>○ Affordability is a barrier</li> <li>○ No public financing of assisted living or any adult residential care facility</li> <li>○ Issues surrounding transfer/discharge for difficult or dangerous behaviors</li> </ul> </li> <li>• No central planning authority for policies &amp; programs</li> <li>• Public safety <ul style="list-style-type: none"> <li>○ No dementia-specific requirements for renewing a driver's license</li> <li>○ First responders do not universally receive dementia-specific training</li> <li>○ Emergency preparedness <ul style="list-style-type: none"> <li>▪ Facilities</li> <li>▪ Community based</li> </ul> </li> </ul> </li> </ul>

STAGES and CHARACTERISTICS	CURRENT SERVICES	GAPS IN SERVICES and CHALLENGES TO ACCESS
		<ul style="list-style-type: none"> <li>▪ Shelter readiness &amp; adequately trained staff               <ul style="list-style-type: none"> <li>• General shelters</li> <li>• Critical transportation needs shelters</li> </ul> </li> <li>▪ Transportation</li> </ul> <p><b>Advance Planning</b> – health, end of life, &amp; financial</p> <ul style="list-style-type: none"> <li>• Denial of need</li> <li>• Lack of awareness of need</li> <li>• Lack of tools &amp; services</li> <li>• Lack of information about tools &amp; services that are available</li> <li>• Lack of understanding of LTC insurance</li> </ul> <p><b>Professional Direct Care Workforce</b></p> <ul style="list-style-type: none"> <li>• Academic curricula do not adequately address dementia-specific training</li> <li>• Continuing education requirements do not address dementia-specific training</li> <li>• Professional certification requirements do not address dementia-specific training</li> <li>• DHH/DSS provider licensing requirements do not address dementia-specific training</li> </ul> <p><b>Health Care &amp; Related Services</b></p> <ul style="list-style-type: none"> <li>• Lack of appropriate mental health services for those with ADRD exhibiting difficult or dangerous behaviors</li> <li>• No publicly-available screening</li> <li>• Lack of public education regarding risk factors &amp; brain health</li> <li>• Lack of coordinated public health surveillance &amp; data collection</li> <li>• Genetic testing issues</li> <li>• Medically underserved rural areas across all medical specialties</li> <li>• Health disparities generally statewide</li> </ul> <p><b>Surveillance &amp; Data Collection</b></p> <ul style="list-style-type: none"> <li>• Lack of widespread &amp; consistent public health surveillance               <ul style="list-style-type: none"> <li>○ Incidence</li> </ul> </li> </ul>

STAGES and CHARACTERISTICS	CURRENT SERVICES	GAPS IN SERVICES and CHALLENGES TO ACCESS
<p><b>Stage 4: Mild Dementia</b></p> <p>Instrumental activities of daily living (ADLs) become affected</p> <p>Difficulty with such things as bill paying, managing finances, cooking, cleaning, traveling</p> <p>Reduced memory of personal history</p>	<p><b>Health Care</b></p> <ul style="list-style-type: none"> <li>● Some early diagnosis</li> <li>● Drug therapies</li> </ul> <p><b>Advance Planning</b></p> <ul style="list-style-type: none"> <li>● Legal</li> <li>● Financial</li> <li>● Long-term care insurance</li> <li>● Health care planning</li> </ul> <p><b>Programs &amp; Services</b></p> <ul style="list-style-type: none"> <li>● Information &amp; referral <ul style="list-style-type: none"> <li>○ GOEA through Councils on Aging &amp; AAAs</li> <li>○ Alzheimer's Association</li> <li>○ Alzheimer's Services of the Capital Area</li> <li>○ Louisiana Assisted Living Association (LALA)</li> <li>○ Gulf States Association of Homes and Services for the Aging (GSAHSA)</li> <li>○ Louisiana Nursing Home Association (LNHA)</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>○ Prevalence</li> <li>○ Identify risk factors</li> <li>○ Develop strategies to reduce risk</li> <li>● Rapidly evolving knowledge of AD/DRD</li> <li>● Inconsistent data for research</li> <li>● Lack of data for effective policy development <ul style="list-style-type: none"> <li>○ Caregiver health</li> <li>○ Diseases of cognitive impairments</li> </ul> </li> </ul> <p><b>Coordination</b></p> <ul style="list-style-type: none"> <li>● Widely scattered programs, services, &amp; policy decisions</li> <li>● Lack of single policymaking authority</li> <li>● Lack of comprehensive &amp; coordinated public funding</li> </ul> <p><b>Public awareness</b></p> <ul style="list-style-type: none"> <li>● Culturally competent &amp; easily understood information</li> <li>● Marketing strategies tailored to unique cultural differences &amp; designed to be available where people are when the need for information arises. (the teachable moment) <ul style="list-style-type: none"> <li>○ Urban &amp; rural</li> <li>○ Ethic &amp; cultural attitudes Build on community partnerships</li> </ul> </li> </ul> <p><b>Caregiver Support</b></p> <ul style="list-style-type: none"> <li>● General lack of support &amp; services</li> <li>● Lack of support &amp; services is exacerbated in rural areas</li> <li>● Lack of public awareness of supports &amp; services that <i>are</i> available</li> <li>● Lack of human resource policies to address on-the-job issues for employees who are caregivers</li> </ul> <p><b>Advance Planning</b> – health, end of life, &amp; financial</p> <ul style="list-style-type: none"> <li>● Denial of need</li> <li>● Lack of awareness of need</li> <li>● Lack of tools &amp; services</li> </ul>



STAGES and CHARACTERISTICS	CURRENT SERVICES	GAPS IN SERVICES and CHALLENGES TO ACCESS
	<ul style="list-style-type: none"> <li>○ ADRCs</li> <li>● Safety programs <ul style="list-style-type: none"> <li>○ Medic Alert Safe Return (Alzheimer’s Association)</li> <li>○ Alzheimer’s Services of the Capital Area</li> <li>○ Project Life Saver (825/month)</li> </ul> </li> <li><b>Caregiver Support</b> <ul style="list-style-type: none"> <li>● Alzheimer’s Association <ul style="list-style-type: none"> <li>○ 24-hour hotline</li> <li>○ Support groups</li> <li>○ Care consultation</li> </ul> </li> <li>● Alzheimer’s Services of the Capital Area <ul style="list-style-type: none"> <li>○ In-home or on-site respite care</li> <li>○ Support groups</li> </ul> </li> <li>● LALA/GSAHSA/LNHA</li> <li>● Faith-based organizations</li> </ul> </li> <li><b>Professional Direct Care Workforce</b> <ul style="list-style-type: none"> <li>● Provider Education <ul style="list-style-type: none"> <li>○ LALA</li> <li>○ GSAHSA</li> <li>○ LNHA</li> </ul> </li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>● Lack of information about tools &amp; services that are available</li> <li>● Lack of understanding of LTC insurance</li> <li><b>Programs &amp; Services</b> <ul style="list-style-type: none"> <li>● Resource network &amp; statewide single point of entry</li> <li>● Overreliance on institutional long term care services</li> <li>● Adequacy of LTC assessment tool for persons with ADRD</li> <li>● Lack of funding for respite, adult day care, adult day health care, &amp; other Medicaid HCBS waiver services</li> <li>● Medicaid HCBS waiting lists</li> <li>● Urban – rural disparities in all programs &amp; services across the state</li> <li>● Regulatory restrictions in licensing adult residential care facilities preventing expansion of respite &amp; other day or short-stay programs</li> <li>● Housing alternatives <ul style="list-style-type: none"> <li>○ Availability of supportive housing</li> <li>○ Affordability</li> <li>○ Public financing of assisted living</li> <li>○ Issues around discharge for difficult or dangerous behaviors</li> </ul> </li> <li>● No central planning authority for policies &amp; programs</li> <li>● Public safety <ul style="list-style-type: none"> <li>○ Driving</li> <li>○ Programs to address wandering</li> <li>○ First respyonder</li> <li>○ Emergency preparedness <ul style="list-style-type: none"> <li>■ Facilities</li> <li>■ Community based</li> <li>■ Shelter readiness &amp; adequately trained staff</li> <li>■ Transportation</li> </ul> </li> </ul> </li> </ul> </li> <li><b>Professional Direct Care Workforce</b> <ul style="list-style-type: none"> <li>● Academic curricula do not adequately address dementia-specific training</li> </ul> </li> </ul>

STAGES and CHARACTERISTICS	CURRENT SERVICES	GAPS IN SERVICES and CHALLENGES TO ACCESS
<p><b>Stage 5: Moderate Dementia</b> Needs help choosing proper clothes, but not</p>	<p><b>Public Information &amp; Education</b></p> <ul style="list-style-type: none"> <li>• Alzheimer’s Association</li> <li>• Alzheimer’s Services of the Capital Area</li> <li>• Alzheimer’s Services of the</li> </ul>	<ul style="list-style-type: none"> <li>• Continuing education requirements do not address dementia-specific training</li> <li>• Professional certification requirements do not address dementia-specific training</li> <li>• DHH/ DSS provider licensing requirements do not address dementia-specific training</li> </ul> <p><b>Health Care &amp; Related Services</b></p> <ul style="list-style-type: none"> <li>• Lack of appropriate mental health services for those with ADRD’s &amp; co-morbid mental health diagnoses</li> <li>• No public availability of screening</li> <li>• Lack of coordinated public health surveillance &amp; data collection</li> <li>• Genetic testing issues</li> <li>• Medically underserved rural areas across all medical specialties</li> <li>• Health disparities generally statewide</li> <li>• Lack of access to clinical trials</li> </ul> <p><b>Surveillance &amp; Data Collection</b></p> <ul style="list-style-type: none"> <li>• Lack of widespread &amp; consistent public health surveillance <ul style="list-style-type: none"> <li>○ Incidence</li> <li>○ Prevalence</li> <li>○ Identify risk factors</li> <li>○ Develop strategies to reduce risk</li> </ul> </li> <li>• Rapidly evolving knowledge of ADRD</li> <li>• Inconsistent data for research</li> <li>• Lack of data for effective policy development <ul style="list-style-type: none"> <li>○ Caregiver health</li> <li>○ Diseases of cognitive impairments</li> </ul> </li> </ul> <p><b>Coordination</b></p> <ul style="list-style-type: none"> <li>• Widely scattered programs, services, &amp; policy decisions</li> <li>• Lack of single policymaking authority</li> <li>• Lack of comprehensive &amp; coordinated public funding</li> </ul> <p><b>Public Awareness</b></p>
<p><b>Stage 5: Moderate Dementia</b> Needs help choosing proper clothes, but not</p>	<p><b>Public Information &amp; Education</b></p> <ul style="list-style-type: none"> <li>• Alzheimer’s Association</li> <li>• Alzheimer’s Services of the Capital Area</li> <li>• Alzheimer’s Services of the</li> </ul>	<ul style="list-style-type: none"> <li>• Continuing education requirements do not address dementia-specific training</li> <li>• Professional certification requirements do not address dementia-specific training</li> <li>• DHH/ DSS provider licensing requirements do not address dementia-specific training</li> </ul> <p><b>Health Care &amp; Related Services</b></p> <ul style="list-style-type: none"> <li>• Lack of appropriate mental health services for those with ADRD’s &amp; co-morbid mental health diagnoses</li> <li>• No public availability of screening</li> <li>• Lack of coordinated public health surveillance &amp; data collection</li> <li>• Genetic testing issues</li> <li>• Medically underserved rural areas across all medical specialties</li> <li>• Health disparities generally statewide</li> <li>• Lack of access to clinical trials</li> </ul> <p><b>Surveillance &amp; Data Collection</b></p> <ul style="list-style-type: none"> <li>• Lack of widespread &amp; consistent public health surveillance <ul style="list-style-type: none"> <li>○ Incidence</li> <li>○ Prevalence</li> <li>○ Identify risk factors</li> <li>○ Develop strategies to reduce risk</li> </ul> </li> <li>• Rapidly evolving knowledge of ADRD</li> <li>• Inconsistent data for research</li> <li>• Lack of data for effective policy development <ul style="list-style-type: none"> <li>○ Caregiver health</li> <li>○ Diseases of cognitive impairments</li> </ul> </li> </ul> <p><b>Coordination</b></p> <ul style="list-style-type: none"> <li>• Widely scattered programs, services, &amp; policy decisions</li> <li>• Lack of single policymaking authority</li> <li>• Lack of comprehensive &amp; coordinated public funding</li> </ul> <p><b>Public Awareness</b></p>

STAGES and CHARACTERISTICS	CURRENT SERVICES	GAPS IN SERVICES and CHALLENGES TO ACCESS
<p>with toileting or eating</p> <p>May not know date, year, telephone number or where he/she lives</p> <p>Increased difficulty with serial subtraction</p>	<p>Crescent City</p> <ul style="list-style-type: none"> <li>• GOEA through Councils on Aging/AAA/Senior Centers</li> <li>• Faith based organizations</li> </ul> <p><b>Programs &amp; Services</b></p> <ul style="list-style-type: none"> <li>• Personal Care <ul style="list-style-type: none"> <li>○ GOEA</li> <li>○ Medicaid State Plan &amp; Waiver services</li> <li>○ Private long-term care insurance coverage</li> <li>○ Private pay providers</li> <li>○ Veterans Affairs</li> </ul> </li> <li>• Information &amp; Referral <ul style="list-style-type: none"> <li>○ ADRC's</li> <li>○ GOEA through Councils on Aging/AAA/Senior Centers</li> <li>○ Alzheimer's Association</li> <li>○ Alzheimer's Services of the Capital Area</li> <li>○ Alzheimer's Services of the Crescent City</li> <li>○ LALA</li> <li>○ National Family Caregiver Services Program (NFCSP)</li> </ul> </li> <li>• Housing <ul style="list-style-type: none"> <li>○ Assisted Living <ul style="list-style-type: none"> <li>▪ LALA</li> <li>▪ Gulf States Homes &amp; Services for the Aging</li> </ul> </li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Prevention/wellness/brain health</li> <li>• Risk factors</li> <li>• Culturally competent &amp; easily understood information</li> <li>• Marketing strategies tailored to unique cultural differences &amp; designed to be available where people are when the need for information arises. (the teachable moment) <ul style="list-style-type: none"> <li>○ Urban &amp; rural</li> <li>○ Ethic &amp; cultural attitudes</li> </ul> </li> </ul> <p><b>Advance planning</b> – health, end of life, &amp; financial</p> <ul style="list-style-type: none"> <li>• Denial of need</li> <li>• Lack of awareness of need</li> <li>• Lack of tools &amp; services</li> <li>• Lack of information about tools &amp; services that are available</li> <li>• Lack of understanding of LTC insurance</li> </ul> <p><b>Professional Direct Care Workforce</b></p> <ul style="list-style-type: none"> <li>• Academic curricula do not adequately address dementia-specific training</li> <li>• Continuing education requirements do not address dementia-specific training</li> <li>• Professional certification requirements do not address dementia-specific training</li> </ul> <p>DHH/ DSS provider licensing requirements do not address dementia-specific training</p> <p><b>Health Care &amp; Related Services</b></p> <ul style="list-style-type: none"> <li>• Lack of public education regarding risk factors &amp; brain health</li> <li>• Lack of coordinated public health surveillance &amp; data collection</li> </ul> <p><b>Caregiver support</b></p> <ul style="list-style-type: none"> <li>• General lack of support &amp; services</li> <li>• Lack of support &amp; services is exacerbated in rural areas</li> <li>• Lack of public awareness of supports &amp; services that <i>are</i> available</li> <li>• Lack of human resources policies to address on-the-job issues for employees who</li> </ul>

STAGES and CHARACTERISTICS	CURRENT SERVICES	GAPS IN SERVICES and CHALLENGES TO ACCESS
	<ul style="list-style-type: none"> <li>○ Nursing Facilities</li> <li>○ Other adult residential care facilities</li> <li>● Adult Day Health Care</li> <li>○ Faith-based organizations</li> <li>○ Private pay providers</li> <li>○ Councils on Aging (varies by parish)</li> <li>○ Older American's Act Title III Programs (GOEA)</li> <li>○ Medicaid Waiver</li> <li>○ Veterans Affairs</li> <li>● Respite Care</li> <li>○ GOEA through Parish Councils on Aging</li> <li>○ NFCSP/GOEA</li> <li>○ VA</li> <li>● Safety Programs</li> <li>○ Medic Alert Safe Return (Alzheimer's Association)</li> <li>○ PERS</li> <li>○ Alzheimer's Services of the Capital Area</li> <li>○ Project Life Saver (825/month)</li> <li><b>Caregiver Support</b></li> <li>● Alzheimer's Association</li> <li>○ 24-hour hotline</li> <li>○ Support groups</li> <li>○ Care consultation</li> </ul>	<p>are caregivers</p> <p><b>Programs &amp; Services</b></p> <ul style="list-style-type: none"> <li>● No resources for persons with early diagnosis</li> <li>○ Public programs usually age-related</li> <li>○ No programs to help maintain employment &amp; financial independence</li> </ul> <p><b>Programs &amp; Services</b></p> <ul style="list-style-type: none"> <li>● Resource network &amp; statewide single point of entry</li> <li>● Over reliance on institutional long-term care services</li> <li>● Adequacy of LTC assessment tool for persons with ADRD</li> <li>● Lack of funding for respite, adult day care, adult day health care, &amp; other Medicaid HCBS waiver services</li> <li>● Medicaid HCBS waiting lists</li> <li>● Urban – rural disparities in all programs &amp; services across the state</li> <li>● Regulatory restrictions in licensing adult residential care facilities preventing expansion of respite &amp; other day or short-stay programs</li> <li>● Housing alternatives <ul style="list-style-type: none"> <li>○ Availability of supportive housing</li> <li>○ Affordability</li> <li>○ Public financing of assisted living</li> <li>○ Issues around discharge for difficult or dangerous behaviors</li> </ul> </li> <li>● Central planning authority for policies &amp; programs</li> <li>● Public safety <ul style="list-style-type: none"> <li>○ Driving</li> <li>○ Programs to address wandering</li> <li>○ First responders</li> <li>○ Emergency preparedness <ul style="list-style-type: none"> <li>■ Facilities</li> <li>■ Community based</li> <li>■ Shelter readiness &amp; adequately trained staff</li> </ul> </li> </ul> </li> </ul>

STAGES and CHARACTERISTICS	CURRENT SERVICES	GAPS IN SERVICES and CHALLENGES TO ACCESS
<p><b>Stage 6: Moderately Severe Dementia</b></p>	<ul style="list-style-type: none"> <li>● Alzheimer’s Services of the Capital Area</li> <li>● Faith-based organizations</li> <li>● LALA</li> <li>● GSAHSA</li> <li>● LNHA</li> <li>● NFCSP/GOEA</li> <li>● Private pay or other respite care services</li> </ul>	<ul style="list-style-type: none"> <li>▪ Transportation</li> </ul> <p><b>Professional Direct Care Workforce</b></p> <ul style="list-style-type: none"> <li>● Academic curricula do not adequately address dementia-specific training</li> <li>● Continuing education requirements do not address dementia-specific training</li> <li>● Professional certification requirements do not address dementia-specific training</li> <li>● DHH/ DSS provider licensing requirements do not address dementia-specific training</li> </ul> <p><b>Health Care &amp; Related Services</b></p> <ul style="list-style-type: none"> <li>● Lack of appropriate mental health services for those with ADRD’s &amp; co-morbid mental health diagnoses</li> <li>● No public availability of screening</li> <li>● Lack of coordinated public health surveillance &amp; data collection</li> <li>● Genetic testing issues</li> <li>● Medically underserved rural areas across all medical specialties statewide</li> <li>● Health disparities generally statewide</li> </ul> <p><b>Surveillance &amp; Data Collection</b></p> <ul style="list-style-type: none"> <li>● Lack of widespread &amp; consistent public health surveillance <ul style="list-style-type: none"> <li>○ Incidence</li> <li>○ Prevalence</li> <li>○ Identify risk factors</li> <li>○ Develop strategies to reduce risk)</li> </ul> </li> <li>● Rapidly evolving knowledge of ADRD</li> <li>● Inconsistent data for research</li> <li>● Lack of data for effective policy development <ul style="list-style-type: none"> <li>○ Caregiver health</li> <li>○ Diseases of cognitive impairment</li> </ul> </li> </ul> <p><b>Coordination</b></p> <ul style="list-style-type: none"> <li>● Widely scattered programs, services, &amp; policy decisions</li> <li>● Lack of single policy making authority</li> </ul>
<p><b>Stage 6: Moderately Severe Dementia</b></p>	<p><b>Public Information &amp; Education</b></p> <ul style="list-style-type: none"> <li>● Alzheimer’s Association</li> <li>● Alzheimer’s Services of the</li> </ul>	

STAGES and CHARACTERISTICS	CURRENT SERVICES	GAPS IN SERVICES and CHALLENGES TO ACCESS
<p>Memory difficulties continue to worsen, significant personality changes may emerge, &amp; people may need extensive help with customary phone activities</p> <p>Decreased ability to dress, bathe, &amp; toilet independently</p> <p>May experience urinary &amp; fecal incontinence</p> <p>May begin to forget names of family members &amp; friends</p> <p>Tend to wander &amp; become lost</p>	<p>Capital Area</p> <ul style="list-style-type: none"> <li>● Alzheimer's Services of the Crescent City</li> <li>● GOEA through Councils on Aging/AAA/Senior Centers</li> <li>● Faith-based organizations</li> </ul> <p><b>Programs &amp; Services</b></p> <ul style="list-style-type: none"> <li>● Personal Care <ul style="list-style-type: none"> <li>○ GOEA</li> <li>○ Medicaid State Plan &amp; Waiver services</li> <li>○ Private long-term care insurance coverage</li> <li>○ Private pay providers</li> <li>○ Veterans Affairs</li> </ul> </li> <li>● Information &amp; Referral <ul style="list-style-type: none"> <li>○ ADRCs</li> <li>○ LTC Options Help Line/OAAS</li> <li>○ GOEA through Councils on Aging/AAA/Senior Centers</li> <li>○ Alzheimer's Association</li> <li>○ Alzheimer's Services of the Capital Area</li> <li>○ Alzheimer's Services of the Crescent City</li> <li>○ LALA</li> <li>○ National Family Caregiver Services Program (NFCSP)</li> </ul> </li> <li>● Housing</li> </ul>	<ul style="list-style-type: none"> <li>● Lack of comprehensive &amp; coordinated public funding</li> </ul> <p><b>Public Awareness</b></p> <ul style="list-style-type: none"> <li>● Culturally competent &amp; easily understood information</li> <li>● Marketing strategies tailored to unique cultural differences &amp; designed to be available where people are when the need for information arises (the teachable moment) <ul style="list-style-type: none"> <li>○ Urban &amp; rural</li> <li>○ Ethic &amp; cultural attitudes</li> <li>○ Build on community partnerships</li> </ul> </li> </ul> <p><b>Caregiver Support</b></p> <ul style="list-style-type: none"> <li>● General lack of support &amp; services</li> <li>● Lack of support &amp; services is exacerbated in rural areas</li> <li>● Lack of public awareness of supports &amp; services that <i>are</i> available</li> <li>● Lack of human resource policies to address on-the-job issues for employees who are caregivers</li> </ul> <p><b>Programs &amp; Services</b></p> <ul style="list-style-type: none"> <li>● Resource network &amp; statewide single point of entry</li> <li>● Over reliance on institutional long-term care services</li> <li>● Adequacy of LTC assessment tool for persons with ADRD</li> <li>● Lack of funding for respite, adult day care, adult day health care, &amp; other Medicaid HCBS waiver services</li> <li>● Medicaid HCBS waiting lists</li> <li>● Urban – rural disparities in all programs &amp; services across the statewide</li> <li>● Regulatory restrictions in licensing adult residential care facilities preventing expansion of respite &amp; other day or short-stay programs</li> <li>● Housing alternatives <ul style="list-style-type: none"> <li>○ Availability of supportive housing</li> <li>○ Affordability</li> <li>○ Public financing of assisted living</li> </ul> </li> </ul>

STAGES and CHARACTERISTICS	CURRENT SERVICES	GAPS IN SERVICES and CHALLENGES TO ACCESS
	<ul style="list-style-type: none"> <li>○ Assisted Living <ul style="list-style-type: none"> <li>▪ LALA members</li> <li>▪ GSAHSA members</li> </ul> </li> <li>○ Nursing Facilities</li> <li>● Adult Day Health Care</li> <li>○ Faith-based organizations</li> <li>○ Private pay providers</li> <li>○ Councils on Aging (varies by parish)</li> <li>○ Older American's Act Title III Programs (GOEA)</li> <li>○ Medicaid Waiver</li> <li>○ Veterans Affairs</li> <li>● Respite Care <ul style="list-style-type: none"> <li>○ GOEA through parish Councils on Aging</li> <li>○ NFCSP</li> <li>○ VA</li> </ul> </li> <li>● Safety Programs <ul style="list-style-type: none"> <li>○ Medic Alert Safe Return (Alzheimer's Association)</li> <li>○ PERS</li> <li>○ Alzheimer's Services of the Capital Area</li> <li>○ Project Life Saver (825/month)</li> </ul> </li> <li>● <b>Caregiver Support</b> <ul style="list-style-type: none"> <li>● Alzheimer's Association <ul style="list-style-type: none"> <li>○ 24-hour hotline</li> <li>○ Support groups</li> </ul> </li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>○ Issues surrounding discharge for difficult or dangerous behaviors</li> <li>● Central planning authority for policies &amp; programs</li> <li>● Public safety <ul style="list-style-type: none"> <li>○ Driving</li> <li>○ Programs to address wandering</li> <li>○ First responders</li> <li>○ Emergency preparedness <ul style="list-style-type: none"> <li>▪ Facilities <ul style="list-style-type: none"> <li>▪ Community based</li> <li>▪ Shelter readiness &amp; adequacy trained staff</li> <li>▪ Transportation</li> </ul> </li> </ul> </li> </ul> </li> <li>● <b>Professional Direct Care Workforce</b> <ul style="list-style-type: none"> <li>● Academic curricula</li> <li>● Continuing education requirements</li> <li>● Professional certification requirements</li> <li>● DHH/DSS provider licensing requirements</li> </ul> </li> <li>● <b>Health Care &amp; Related Services</b> <ul style="list-style-type: none"> <li>● Lack of appropriate mental health services for those with ADRD's &amp; co-morbid mental health diagnoses</li> <li>● No public availability of screening</li> <li>● Lack of coordinated public health surveillance &amp; data collection</li> <li>● Genetic testing issues</li> <li>● Medically underserved rural areas across all medical specialties statewide</li> <li>● Health disparities are generally statewide</li> </ul> </li> <li>● <b>Surveillance &amp; Data Collection</b> <ul style="list-style-type: none"> <li>● Lack of widespread &amp; consistent public health surveillance <ul style="list-style-type: none"> <li>○ Incidence</li> <li>○ Prevalence</li> <li>○ Identify risk factors</li> </ul> </li> </ul> </li> </ul>

STAGES and CHARACTERISTICS	CURRENT SERVICES	GAPS IN SERVICES and CHALLENGES TO ACCESS
<p><b>Stage 7: Severe Dementia</b></p> <p>Progressive loss of ability to speak, walk, sit up, smile &amp; hold head up</p>	<ul style="list-style-type: none"> <li>○ Care consultation</li> <li>● Alzheimer’s Services of the Capital Area</li> <li>● Alzheimer’s Services of the Crescent City</li> <li>● Faith-based organizations</li> <li>● LALA</li> <li>● GSAHSA</li> <li>● LNHA</li> <li>● NFCPS</li> <li>● Private pay or other respite care services</li> </ul> <p><b>Public Information &amp; Education</b></p> <ul style="list-style-type: none"> <li>● Alzheimer’s Association</li> <li>● Alzheimer’s Services of the Capital Area</li> <li>● Alzheimer’s Services of the Crescent City</li> <li>● GOEA through Councils on Aging/AAA/Senior Centers</li> <li>● Faith-based organizations</li> </ul> <p><b>Programs &amp; Services</b></p> <ul style="list-style-type: none"> <li>● Personal Care <ul style="list-style-type: none"> <li>○ GOEA</li> <li>○ Medicaid State Plan &amp; Waiver services</li> <li>○ Medicare/Medicaid Hospice benefit</li> <li>○ Private long-term care</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>○ Develop strategies to reduce risk</li> <li>● Rapidly evolving knowledge of ADRD</li> <li>● Inconsistent data for research</li> <li>● Lack of data for effective policy development <ul style="list-style-type: none"> <li>○ Caregiver health</li> <li>○ Diseases of cognitive impairments</li> </ul> </li> </ul>
		<p><b>Coordination</b></p> <ul style="list-style-type: none"> <li>● Widely scattered programs, services, &amp; policy decisions</li> <li>● Lack of single policy making authority</li> <li>● Lack of comprehensive &amp; coordinated public funding</li> </ul> <p><b>Public Awareness</b></p> <ul style="list-style-type: none"> <li>● Culturally competent &amp; easily understood information</li> <li>● Marketing strategies tailored to unique cultural differences &amp; designed to be available where people are when the need for information arises (the teachable moment) <ul style="list-style-type: none"> <li>○ Urban &amp; rural</li> <li>○ Ethic &amp; cultural attitudes</li> <li>○ Build on community partnerships</li> </ul> </li> </ul> <p><b>Caregiver Support</b></p> <ul style="list-style-type: none"> <li>● General lack of support &amp; services</li> <li>● Lack of support &amp; services is exacerbated in rural areas</li> <li>● Lack of public awareness of supports &amp; services that <i>are</i> available</li> <li>● Lack of human resource policies to address on-the-job issues for employees who</li> </ul>



STAGES and CHARACTERISTICS	CURRENT SERVICES	GAPS IN SERVICES and CHALLENGES TO ACCESS
	<ul style="list-style-type: none"> <li>insurance coverage</li> <li>○ Private pay providers</li> <li>○ Veterans Affairs</li> <li>● Information &amp; Referral <ul style="list-style-type: none"> <li>○ ADRCs</li> <li>○ GOEA through Councils on Aging/AAA/Senior Centers</li> <li>○ Alzheimer's Association</li> <li>○ Alzheimer's Services of the Capital Area</li> <li>○ Alzheimer's Services of the Crescent City</li> <li>○ LALA</li> <li>○ National Family Caregiver Services Program (NFCSP)</li> <li>○ LMHPCO (hospice)</li> </ul> </li> <li>● Housing <ul style="list-style-type: none"> <li>○ Assisted Living <ul style="list-style-type: none"> <li>▪ LALA members</li> <li>▪ Gulf States Homes &amp; Services for the Aging members</li> </ul> </li> <li>○ Nursing Facilities/LNHA</li> <li>● Adult Day Health Care <ul style="list-style-type: none"> <li>○ Faith-based organizations</li> <li>○ Private pay providers</li> <li>○ Councils on Aging (varies by parish)</li> <li>○ Older American's Act Title III Programs (GOEA)</li> <li>○ Medicaid Waiver</li> </ul> </li> </ul> </li> </ul>	<p>are caregivers</p> <p><b>Programs &amp; Services</b></p> <ul style="list-style-type: none"> <li>● Resource network &amp; statewide single point of entry</li> <li>● Over reliance on institutional long-term care services</li> <li>● Adequacy of LTC assessment tool for persons with ADRD</li> <li>● Lack of funding for respite, adult day care, adult day health care, &amp; other Medicaid HCBS waiver services</li> <li>● Medicaid HCBS waiting lists</li> <li>● Urban – rural disparities in all programs &amp; services across the statewide</li> <li>● Regulatory restrictions in licensing adult residential care facilities preventing expansion of respite &amp; other day or short-stay programs</li> <li>● Housing alternatives <ul style="list-style-type: none"> <li>○ Availability of supportive housing</li> <li>○ Affordability</li> <li>○ Public financing of assisted living</li> <li>○ Issues surrounding discharge for difficult or dangerous behaviors</li> </ul> </li> <li>● Central planning authority for policies &amp; programs</li> <li>● Public safety <ul style="list-style-type: none"> <li>○ Driving</li> <li>○ Programs to address wandering</li> <li>○ First responders</li> <li>○ Emergency preparedness <ul style="list-style-type: none"> <li>▪ Facilities</li> <li>▪ Community based</li> <li>▪ Shelter readiness &amp; adequacy trained staff</li> <li>▪ Transportation</li> </ul> </li> </ul> </li> <li><b>Professional Direct Care Workforce</b> <ul style="list-style-type: none"> <li>● Academic curricula</li> <li>● Continuing education requirements</li> </ul> </li> </ul>

STAGES and CHARACTERISTICS	CURRENT SERVICES	GAPS IN SERVICES and CHALLENGES TO ACCESS
	<ul style="list-style-type: none"> <li>○ Veterans Affairs</li> <li>● Respite Care <ul style="list-style-type: none"> <li>○ GOEA through parish Councils on Aging</li> <li>○ NFCSP/GOEA</li> <li>○ Hospice</li> <li>○ DVA</li> </ul> </li> <li>● Safety Programs <ul style="list-style-type: none"> <li>○ Medic Alert Safe Return (Alzheimer's Association)</li> <li>○ PERS</li> <li>○ Alzheimer's Services of the Capital Area</li> <li>○ Project Life Saver (825/month)</li> </ul> </li> <li>● <b>Caregiver Support</b> <ul style="list-style-type: none"> <li>● Alzheimer's Association <ul style="list-style-type: none"> <li>○ 24-hour hotline</li> <li>○ Support groups</li> <li>○ Care consultation</li> </ul> </li> <li>● Alzheimer's Services of the Capital Area</li> <li>● Alzheimer's Services of the Crescent City</li> <li>● Faith-based organizations</li> <li>● LALA/GSAHSA/LNHA</li> <li>● NFCPS/GOEA</li> <li>● Private pay or other respite care services</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>● Professional certification requirements</li> <li>● DHH/DSS provider licensing requirements</li> <li>● <b>Health Care &amp; Related Services</b> <ul style="list-style-type: none"> <li>● Lack of coordinated public health surveillance &amp; data collection</li> <li>● Lack of uniform interpretation of hospice qualifying events by hospice medical directors</li> <li>● Lack of appropriate &amp; timely referrals to hospice</li> <li>● Medically underserved rural areas across all medical specialties statewide</li> <li>● Health disparities, generally, statewide</li> <li>● Lack of access to clinical trials</li> </ul> </li> <li>● <b>Surveillance &amp; Data Collection</b> <ul style="list-style-type: none"> <li>● Lack of widespread &amp; consistent public health surveillance <ul style="list-style-type: none"> <li>○ Incidence</li> <li>○ Prevalence</li> <li>○ Identify risk factors</li> <li>○ Develop strategies to reduce risk</li> </ul> </li> <li>● Rapidly evolving knowledge of ADRD</li> <li>● Inconsistent data for research</li> <li>● Lack of data for effective policy development <ul style="list-style-type: none"> <li>○ Caregiver health</li> <li>○ Diseases of cognitive impairments</li> </ul> </li> </ul> </li> </ul>

## **DEMENTIA-SPECIFIC TRAINING REQUIREMENTS**

Academic curricula in health care and social services do not adequately address dementia-specific content even though health care and social service professionals will often see people with dementia and their families in the course of their practices.

Currently there are no dementia-specific training requirements for those working with persons with Alzheimer's or other dementias. The Legislature passed Act 571 (2008 Regular Session) requiring workers in nursing facilities and adult residential care facilities receive dementia-specific training as part of facility licensing standards. Regulations are proceeding through rulemaking and the requirements will likely become effective in early 2010, with full compliance required of providers by January 1, 2011.<sup>13</sup>

These dementia-specific training requirements apply to all nursing facilities and residential care facilities. They require more training for staff in facilities "that segregate or provide a special program or unit for residents with probable Alzheimer's disease or a related disorder so as to prevent or limit access by residents to areas outside designated or special areas."<sup>14</sup> The type and length of training varies with the amount of time workers come into contact with residents with ADRD's.

Nursing facility staff who provide nursing or nursing assistant services must be trained on an overview of the diseases, communicating with persons with dementia, behavioral management, promoting independence in activities of daily living and understanding and dealing with family issues. The same training will be required of workers who provide direct face-to-face care in adult residential care facilities.

## **QUALITY CARE MEASURES FOR PROVIDERS**

Pursuant to the Plan for Choice, OAAS began a robust quality management initiative for all licensed service providers, many of which serve persons with Alzheimer's disease or other dementias. However, no quality measures are dementia-specific at this time.

## **PUBLIC SAFETY and LAW ENFORCEMENT**

Public safety and law enforcement officials may interact with people with ADRD's and their families in a variety of ways. These may include, but are not limited to, people with ADRD's who are

- Crime Victims
- Witnesses
- Perpetrators
- People who are incarcerated
- Missing persons
- Drivers
- Accident victims

---

<sup>13</sup> LAC 48:I.6803, 6851 and 6867 and LAC 48:I.9701 and 9727

<sup>14</sup> RS 40:1300.123

- Emergency Evacuees

Law enforcement officers will be best served in accomplishing their mission with training in communication with persons living with an ADRD in all of these roles.

The Louisiana Department of Public Safety's mission is to provide safety services by upholding and enforcing the laws, administering regulatory programs, managing records, educating the public and managing emergencies, both directly and through interaction with other agencies. Furthermore, the Department is to act with integrity and professionalism, maintaining an environment that is responsive to the needs of its personnel and the citizens of Louisiana by providing essential public safety services efficiently and effectively through education, prevention, and the use of technology.

The Alzheimer's Disease Task Force members specifically examined two agencies within the Department of Public Safety: the Louisiana State Police and the Louisiana Office of Motor Vehicles.

The Louisiana State Police is a statutorily mandated, statewide law enforcement agency charged with ensuring the safety, order, and security of the people in the state through enforcement, regulation, education, and providing other essential public safety services. The Louisiana State Police endeavors to communicate and coordinate activities with all local law enforcement jurisdictions in the state. The Traffic Enforcement Program is dedicated to improving public safety through public education, training, and enforcement. The Program administers homeland security initiatives.

The Louisiana Office of Motor Vehicles serves people through the administration of vehicle registration and driver licensing laws.

## **HOME and COMMUNITY-BASED RESOURCES and RESPITE CARE**

- **Types of Home and Community-based Care**

Home and Community-Based Services (HCBS) is a term used to describe a broad array of long-term care services that can be provided in a person's home or in group settings. Examples of HCBS include personal care, housekeeping, lawn maintenance, minor home repairs, shopping assistance, and adult day care. Such services may be purchased by individuals and families out-of-pocket, funded through long-term care insurance, subsidized by private donations (such as through United Way) or provided through government sources (primarily Medicaid, Medicare and the Older Americans Act).

- **The Governor's Office of Elderly Affairs (GOEA)**

GOEA offers services such as caregiver support, respite care, education, meals, and protective services, adult day care, care coordination, homemaking and chore services, socialization activities, home health and personal care, and nutrition programs primarily through support provided under the Older Americans Act (OAA). While none of these programs are limited to individuals with ADRD's, the OAA does provide a specific focus on individuals with ADRD'S within its titles. The OAA is the only source of publically funded services that is not means tested. However, these

services are mostly limited to persons age 60 and older.

GOEA delivers its services through a network of Parish Councils on Aging that are local not-for-profit organizations. Services vary by parish but can include caregiver support, respite care, education, care coordination, homemaker and chore services, socialization activities, health promotion initiatives, in-home personal care, and information and referral. The federal OAA funds that support these programs are matched with state dollars and enhanced with locally generated funds.

Under a grant from the Administration on Aging (AoA), GOEA also offers the National Family Caregiver Services Program (NFCSP) which was established in 2000 to fund a range of supports that assist family and informal caregivers to care for their loved ones at home for as long as possible. The NFCSP offers five types of services: information to caregivers about available services; assistance to caregivers in gaining access to the services; individual counseling, organization of support groups, and caregiver training; respite care and supplemental services, on a limited basis. Last year NFCSP served nearly 3,300 caregivers. Of these just over half reported that their family members were diagnosed with some form of dementia.

GOEA also operates Aging and Disability Resource Centers (ADRC) statewide, offering a single point of entry for information and referral in long-term care. The ADRC is a collaborative effort of Administration on Aging and the Centers for Medicare & Medicaid Services (CMS), and is designed to streamline access to long-term care. GOEA and OAAS are piloting a single point of entry in one part of the state that combines the information and referral activity with application and enrollment for Medicaid community based services.

- ***The Office of Aging and Adult Services(OAAS)/Department of Health and Hospitals***

OAAS provides services through the Medicaid program. The Medicaid State Plan covers personal care services, home health care, hospice services and non-emergency medical transportation for all persons who meet eligibility requirements. Medicaid waiver programs offer adult day health care (which includes personal care, health promotion, and socialization activities among other services) support coordination, companion services and home modifications. Unlike State Plan services, waiver services are limited to a capped number of clients and operate registries (formerly known as waiting lists) to prioritize services. None of the programs or services is targeted specifically to persons with AD/DRD's, their caregivers and families. However, based on 2008 data, 73 percent of adult day health care waiver participants show some degree of cognitive impairment. Similarly 70 percent of elderly and disabled adult waiver participants and 79 percent of participants in the long-term personal care services state plan program are similarly impaired. Additionally, assessments conducted for Medicaid funded long-term care programs (both institutional and HCBS) include cognitive deficits among the criteria that will allow individuals to meet level of care requirements for these services.

OAAS is currently developing new waiver options, which would provide a broader range of services, including but not limited to adult residential care (assisted living), assistive technology, and more skilled services such as physical therapy. The new waivers would provide more cost-effective alternatives to one-on-one personal care in the home, while still helping persons to remain in communities as long as possible.

OAAS offers a Long-term Care Help Line toll-free number to help people locate available long-term care services and supports.

- **Louisiana Department of Veterans Affairs (LDVA)**

Services may be provided by the LDVA to veterans with Alzheimer's disease and related dementias but it does not appear that the LDVA sponsors any programs specifically for veterans with dementia. LDVA assists Louisiana veterans in obtaining federal and state benefits for which they qualify. LDVA also operates five veterans' homes that provide assisted living and skilled nursing services.<sup>15</sup>

### **LONG-TERM CARE DEMENTIA CARE UNITS**

State law provides for disclosure by an Alzheimer's special care unit<sup>16</sup> of additional care provided in a number of areas.<sup>17</sup> The disclosure law does not require a specific license in order to provide specialized services. However, a covered facility or program that meets the statutory definition must keep a record of its disclosure forms which are then reviewed for accuracy as part of the licensing renewal process.<sup>18</sup>

- **Adult Residential Care Facilities**

Neither the Department of Social Services (DSS) nor any other state agency tracks persons with dementia who are served in adult residential care facilities of any size. However, trade associations provide rough estimates of the percent of their members who have specialized dementia care units.

The Louisiana Assisted Living Association (LALA) conducted a survey of its 60 members in April 2009. Fifty nine percent of those responding indicated that they had a "special care unit" for residents with dementia. A survey of members of the Gulf States Homes and Services for the Aging, which includes not-for-profit assisted living communities, continuing care residential

---

<sup>15</sup> [www.vetaffairs.com](http://www.vetaffairs.com)

<sup>16</sup> "An 'Alzheimer's special care unit' means any nursing facility, residential care/assisted living facility, adult congregate living facility, home health agency, home- and community-based service provider which provide adult day care services, hospice, or continuing care retirement community that segregates or provides a special program or special unit for residents with a diagnosis of probably Alzheimer's disease or a related disorder so as to prevent or limit access by a resident to areas outside the designated or separated area; and that advertises, markets, or otherwise promotes the facility as providing specialized Alzheimer's/dementia care services." RS 40:1300.123(1).

<sup>17</sup> These areas include: (1) a written statement of philosophy and missions reflecting the needs of persons with dementia, (2) process for placement in, transfer or discharge from the unit, (3) process for assessment, care planning, and implementation, (4) staffing patterns and training, (5) physical environment and design features appropriate to the population, (6) resident activities, (7) family's role in care and (8) program fees. RS 40:1300.124B

<sup>18</sup> RS 40:1300.124 A.

communities and small group homes, indicates approximately 50 percent of the residents have diagnoses of Alzheimer's disease or other dementias. However, this estimate increases to 80 to 90 percent when undiagnosed residents exhibiting symptoms of dementia are added.

- **Nursing Facilities**

Nursing facility licensing does not distinguish by resident diagnosis. The number of nursing facilities operating special care units for persons with ADRD's is unknown.

Cognitive Impairment in Nursing Home Residents 2007 – AA Facts/figures

- Total Nursing home residents – 42,425
- No cognitive impairment – 24 percent
- Very mild/mild cognitive impairment – 28 percent
- Moderate/severe cognitive impairment – 48 percent

## **GERIATRIC-PSYCHIATRIC UNITS and OTHER MENTAL HEALTH CARE**

There are 40 licensed psychiatric hospitals and 43 other licensed hospitals (acute care and critical access hospitals) that have psychiatric units. Louisiana's hospital licensing system does not track the differentiation as to whether the services are for children, adults or geriatrics. There is no license or outcome measures for geriatric-psychiatric units.

The Task Force relied on anecdotal evidence of available units and found them scattered sparsely around the state. However, the problem of care for persons with ADRD's who exhibit difficult or dangerous behaviors is much broader than the use of these specialized units could, or should, address. This designation becomes a misnomer as we recognize the prevalence of younger-onset dementias and the likelihood that persons with dementia of *any* age may require mental/behavioral health care services.

There are a number of both public and private hospitals that likely treat persons with ADRD's in general psychiatric units. It is unclear whether staff in these units receive any dementia-specific training to address the unique needs of this population. Most who deal with psychiatric facilities agree that there is no dementia-specific training offered, in all likelihood.

The Office of Mental Health (OMH) currently focuses on providing services to persons with serious mental illness. However, persons with ADRD's who exhibit difficult or dangerous behaviors usually do not have a diagnosis of serious mental illness. It is thought that this focus resulted largely from the specific parameters included in various funding initiatives. It is unknown how the merger of OMH with the Office for Addictive Disorders (OAD) into the Office of Behavioral Health (OBH) pursuant to Act 384 (2009 Regular Session) will impact the mission of the two offices with respect to providing care to this subgroup of persons with dementia.

As far as the Task Force could discern, there are no specific public or private programs or services targeted to persons with dementia who exhibit difficult or dangerous behaviors.

## **ASSISTED LIVING and OTHER RESIDENTIAL CARE OPTIONS**

The Department of Social Services (DSS) licenses Adult Residential Care facilities. Within that license are three modules: assisted living, personal care homes, and shelter care. The key differences are as follows:

Assisted living is a home or facility distinguished by residents living in individual living units including a kitchenette and private bathroom. To date, there are 75 licensed assisted living communities. There is no separate license required for those that provide dementia-specific care.

Personal care homes are small facilities housing eight or fewer residents. While residents get a private or semi-private bedroom, there is no requirement for private baths. Currently, 34 personal care homes are licensed. Most, if not all, of these facilities that accept older residents accept clients with dementia. A few facilities in this category accept only persons with dementia. Evidence from the field indicates that many persons with dementia, even those with difficult behaviors, will function well in smaller scale homes.

Shelter care facilities are essentially large personal care homes serving nine or more residents. Twenty-five facilities are licensed for shelter care.

Neither DSS nor any other state agency tracks persons with ADRD's who are served in adult residential care facilities of any size. However, trade associations provide rough estimates of the percent of their members who have specialized dementia care units. The Louisiana Assisted Living Association (LALA) conducted a survey of its 60 members in April 2009. Fifty nine percent of those responding indicated that they had a "special care unit" for residents with dementia.

Congregate or independent living facilities are available both in the private pay market and with rent-subsidies provided by the U.S. Department of Housing and Urban Development (HUD). Such facilities usually provide either no services or minimal services such as light housekeeping and some meals. Many residents of these facilities are people with early stages of ADRD's. There have been numerous pilot projects, including a few in Louisiana, to bring additional services into HUD sponsored properties that would extend the time that people with ADRD's can continue to reside in independent living. Currently OAAS is the local lead agency for a Permanent Supportive Housing (PSH) project in Region 1 that supports frail elders, as well as other special needs populations, in HUD subsidized, independent apartments.

## **STATE SUPPORT FOR RESEARCH**

The extent of dementia related research in Louisiana is unknown. Research on Alzheimer's disease or other dementias is conducted at Pennington Biomedical Research Center and LSU/Shreveport. The University of Louisiana-Monroe Institute of Gerontology does on research on dementia as well as on the broader issues of aging. Louisiana State University, Tulane University, and the University of Louisiana at Lafayette and others all employ faculty whose research interests encompass topics related to Alzheimer's disease.

According to the Institute for Dementia Research and Prevention, part of the Pennington Biomedical Research Center, "Louisiana has a number of talented scientists, and many of these individuals are working on research projects which have the potential to be therapeutics which



prevent dementia and promote healthy brain aging. What does not currently exist in Louisiana is the infrastructure to promote world class basic and clinical research on dementia, and access to infrastructure investigators new to dementia research to test their potential therapeutics for dementia and brain pathology.”<sup>19</sup>

Most researchers in Louisiana depend on federal or private funding for specific research even if they are faculty at state-funded universities and other institutions.

**PUBLIC COMMENT**

As directed by SCR80, the Task Force attended a series of public forums to listen to comments on the work of the Task Force, to date, from people with ADRD’s, families affected by ADRD’s, providers of services to people with ADRD’s, and the general public. The public hearings, sponsored by the Alzheimer’s Association of Louisiana were held in Lake Charles, Shreveport, Monroe, Alexandria, and New Orleans. Alzheimer’s Services of the Capital Area sponsored an additional public hearing in Baton Rouge. Observations from the forums are summarized in the Table 3. Further, forum participants had the opportunity to identify what they saw as challenges and to prioritize them, as reflected in Table 4.

**Table 3: Summary of observations at public forums by location.**

<b>BATON ROUGE</b>	<b>SHREVEPORT</b>	<b>LAKE CHARLES</b>	<b>MONROE</b>	<b>ALEXANDRIA</b>	<b>GREATER NEW ORLEANS</b>
<ul style="list-style-type: none"> <li>• Lift moratorium on respite care licensing</li> <li>• Develop tips to stay patient</li> <li>• Frustration</li> <li>• Human resources departments need this information</li> <li>• Develop incentives for nursing homes to diversify services</li> <li>• Give this session for legislators</li> </ul>	<ul style="list-style-type: none"> <li>• Providers asked to do more with less money, e.g., ADHC</li> <li>• Constitutionally protected funding leaving health &amp; education as only places to cut</li> <li>• 3-year EDA waiting period</li> <li>• Develop nursing school credit for student volunteering in-home respite care</li> <li>• Lack of awareness and understanding of hospice care</li> <li>• No training for unpaid caregivers</li> </ul>	<ul style="list-style-type: none"> <li>• LAnswers.com</li> <li>• Step-by-step support group</li> <li>• EPS finds self neglect &amp; caregiver stress &amp; denial</li> <li>• Long EDA waiting list</li> <li>• Seeing more alcohol-induced dementia</li> <li>• Need more public awareness before need arises</li> <li>• COA can help while on waiting list</li> <li>• Training for neighborhood gatekeepers, e.g., law enforcement, postman, utility workers</li> <li>• Address revocation of driving privileges</li> <li>• Capacity to continue to drive should be part of routine medical exam</li> </ul>	<ul style="list-style-type: none"> <li>• NII regs make it hard to deliver respite care; just like regular resident admission</li> <li>• NII dementia locked units distinguish between ambulatory &amp; those using wheelchairs</li> <li>• NII’s often won’t take combative patients</li> <li>• Budget cuts</li> <li>• Day care provider: why do NII’s get all</li> </ul>	<ul style="list-style-type: none"> <li>• Need resources for EPS to help keep people at home</li> <li>• Direct-care staff training for in-home paid caregivers</li> <li>• Education, information, guidance</li> <li>• Family compensation</li> <li>• Develop natural supports, e.g., neighbors, friends, church; teach them how to help</li> <li>• Need to reduce perceived stigma on family</li> <li>• Lack outpatient MII</li> <li>• NII’s can’t deal so they just sedate</li> <li>• Hospice information for</li> </ul>	<ul style="list-style-type: none"> <li>• Need supported housing &amp; housing subsidies</li> <li>• Need to help caregivers get through emotional barriers</li> <li>• Educate public before reach crisis stage</li> <li>• Preparedness is critical</li> <li>• Project Safe Return</li> <li>• Caregiver training</li> <li>• Weekend adult day care</li> <li>• Address caregiver denial</li> <li>• Promote more networking</li> <li>• Affordability across the board</li> <li>• Access to information</li> </ul>

<sup>19</sup> [www.idrp.pbrc.edu/aboutus](http://www.idrp.pbrc.edu/aboutus)

BATON ROUGE	SHREVEPORT	LAKE CHARLES	MONROE	ALEXANDRIA	GREATER NEW ORLEANS
	<ul style="list-style-type: none"> <li>• Family doctors need to understand ADOD</li> <li>• How do we attract clinical trials?</li> <li>• Financial problems when caregiver must quit job</li> <li>• Lack of publicity for support groups</li> <li>• Lack of participation in support groups</li> <li>• Need quick and easy-to-read tips for caregivers</li> <li>• Who will police new dementia training regulations and hold providers accountable?</li> <li>• Nursing homes are warehouses; better services at home</li> <li>• Need to pay people who give care</li> <li>• Educate judges about dementia</li> <li>• Financial stress on families &amp; the state "It's expensive!"</li> <li>• Long distance caregiving issues</li> <li>• Gov. &amp; legislators need to have conversations with caregivers</li> <li>• Need more activities and services for younger onset, as well as research</li> <li>• Legal training for [unpaid] caregivers</li> </ul>	<p>protocol</p> <ul style="list-style-type: none"> <li>• Families in denial: educate, accept, act</li> <li>• Financial exploitation</li> <li>• "Don't take it personally"</li> <li>• Need respite care so can attend support group</li> </ul>	<p>the money?</p>	<p>families</p> <ul style="list-style-type: none"> <li>• Develop a hospice-like design for treating dementia</li> <li>• Support volunteers</li> <li>• Answer family questions when MD's can't/won't</li> <li>• Use more volunteers</li> <li>• Caregiver gives up life elsewhere</li> <li>• Need more LTC insurance info</li> <li>• VA checks have information stuffers about LTC insurance, etc.</li> <li>• Ideal system is a continuum</li> <li>• NIFs provide substandard care</li> <li>• Patients are subject to Medicaid treatment in NH</li> <li>• NH staff aren't trained for dementia patients</li> <li>• NIFs lock up and sedate</li> <li>• 70% NH residents have dementia</li> <li>• Need in-home &amp; community services for earlier stages &amp; use NH for late stages</li> <li>• Provide habilitation care</li> </ul>	<ul style="list-style-type: none"> <li>• Doctor should be jumping-off point for information</li> <li>• MD's need education about dementia</li> <li>• Need HIPPA exemption to confidentiality rules</li> <li>• Need more Rx information</li> <li>• MD's are not keeping up to date on latest drugs</li> <li>• Develop partnership with LaCPAs re: advance planning issues</li> <li>• Some LTC insurance covers dementia care</li> <li>• Alzheimer's Services of the Crescent City created web-based virtual community for support</li> <li>• Coordination function should be in Alzheimer's Association</li> <li>• Approach from social marketing point of view</li> <li>• Need newsletter about medical and research advances</li> </ul>

**Table 4. Most important challenges for people with dementia**

<b>MOST SIGNIFICANT ISSUES FACING PEOPLE WITH ALZHEIMER'S DISEASE and RELATED DEMENTIAS IN LOUISIANA</b>	<b>MOST IMPORTANT ISSUE TO YOU</b>
<ul style="list-style-type: none"> <li>• What new treatments are available</li> <li>• Cost of medication</li> <li>• Limited facilities to help people</li> <li>• Preventive treatment if available</li> <li>• Limited services being offered to help keep people in homes with their families</li> <li>• More in-home services to help caregivers</li> <li>• Special training for caregivers in NH's and other caregiving services</li> <li>• Better equip facilities to make them more comfortable &amp; safer</li> <li>• More facilities (NH's, sitter services, etc.) with security systems</li> <li>• More caregiving support groups for sharing &amp; learning</li> <li>• Lack of preparedness to manage the situation . . . in crisis . . . no idea where to access services or what is needed</li> <li>• Financially affording cost of care</li> <li>• Evacuation</li> <li>• Family understanding complexity of situation</li> <li>• How to handle current situation</li> <li>• Most people don't know where to go to find care</li> <li>• Lack of education</li> <li>• Education</li> <li>• Support</li> <li>• Access to care &amp; resources</li> <li>• Accurate diagnosis</li> <li>• Least restrictive residential care services such as Alzheimer's Residential Care Homes &amp; Assisted Living for people who receive Medicaid</li> <li>• Reliable caregivers/caregiver system especially in middle &amp; later stages . . . caregiver burnout more than adequacy of care</li> <li>• Resources, resources, resources</li> <li>• Research, research, research</li> <li>• Weekend adult day for family caregivers</li> <li>• Standardized training for caregivers</li> <li>• Affordable housing for those requiring secure facility</li> </ul>	<ul style="list-style-type: none"> <li>• Need more information</li> <li>• Why doctors cannot have an exemption to confidentiality . . . would help more families understand . . . would help caretakers be better prepared for changes</li> <li>• Finding a geriatrician familiar with vascular dementia</li> <li>• Respite time</li> <li>• Help with day care</li> <li>• Caregiver support groups . . . to get through the tough times . . . get rid of stress</li> <li>• Empowerment of patients, families, friends to be knowledgeable, skilled, financially prepared, to have equipment &amp; supplies . . . to manage life well with Alzheimer's</li> <li>• Living in New Orleans at hurricane season &amp; evacuating person with AD. . . current system is a farce &amp; undependable</li> <li>• Promoting LTC insurance policies that cover AD &amp; other dementias</li> <li>• People be able to know that good care is available</li> <li>• Education</li> <li>• Support</li> <li>• Access to care &amp; resources</li> <li>• Accurate diagnosis</li> <li>• Less restrictive housing options who can't afford assisted living</li> </ul>

<b>MOST SIGNIFICANT ISSUES FACING PEOPLE WITH ALZHEIMER'S DISEASE and RELATED DEMENTIAS IN LOUISIANA</b>	<b>MOST IMPORTANT ISSUE TO YOU</b>
<ul style="list-style-type: none"> <li>• Increased awareness of disease process</li> <li>• Cost of care – medicines, inpatient housing in good quality facilities</li> <li>• Medicare to pay for adult day care</li> <li>• Help more doctors study the problems</li> <li>• Cost of LTC</li> <li>• Cost of insurance (Medicare/Medicaid)</li> <li>• Two-year [Medicaid] wait</li> <li>• Early diagnosis &amp; treatment</li> <li>• Research</li> <li>• Medications</li> <li>• Support groups</li> <li>• Putting AD/EOAD on death certificates</li> <li>• Caregiver support &amp; training</li> <li>• Education of professionals</li> <li>• Limited access to appropriate care . . . before patient is chair/bed bound, there is gap in available services for person with stage 5/6 AD</li> <li>• Younger onset . . . difficulty with MD's supporting diagnosis . . . can present well for short periods . . . dismissive of attempt to educate re: new treatments</li> <li>• LTC insurance</li> <li>• Finding out about available resources – home health, LTC</li> <li>• Lack of accessible resources for poor people, rural areas, cities with no programs</li> <li>• Lack of awareness about disease &amp; available resources</li> <li>• Replicating services &amp; resources provided by Alzheimer's Services in BR</li> <li>• Lack of services or long waiting lists</li> <li>• Lack of specific training/education regarding dementia to general public, medical providers, <i>etc.</i></li> <li>• Transportation for patient &amp; caregivers to services</li> <li>• Public/private funding for services</li> <li>• Early diagnosis &amp; treatment</li> <li>• Care of the caregiver</li> <li>• Listing of providers (public &amp; private pay) on LouisianaAnswers.com</li> </ul>	<ul style="list-style-type: none"> <li>• Affect of caregiver burnout on quality of care</li> <li>• That those who have it and those who take care of them have support . . . quality of life</li> <li>• Cost of care!</li> <li>• To keep my spouse in our home</li> <li>• Education</li> <li>• Early diagnosis &amp; treatment</li> <li>• Cost of care</li> <li>• Providing care for growing population</li> <li>• Need for Medicare/Medicaid supported programs to care for growing population with dementia</li> <li>• That programs be designed to create a lifestyle that is conducive with normal life for patients . . . increase assisted living &amp; decrease NH admissions until nearing final stages</li> <li>• "Live With Alzheimer's With Dignity"</li> <li>• Appropriate medical care . . . best, most appropriate, treatment possible to extend quality of life</li> <li>• Supporting the caregiver by keeping up with information about care of patient &amp; caregiver &amp; available resources – home help, LTC</li> <li>• Marketing information to homebound patients &amp; caregivers about available services</li> </ul>

<b>MOST SIGNIFICANT ISSUES FACING PEOPLE WITH ALZHEIMER'S DISEASE and RELATED DEMENTIAS IN LOUISIANA</b>	<b>MOST IMPORTANT ISSUE TO YOU</b>
<ul style="list-style-type: none"> <li>• Day Care</li> <li>• Meaningful activities for person with Alzheimer's</li> <li>• Family counseling . . . getting past denial</li> <li>• Cost of care for younger onset patients</li> <li>• Benefits for early onset</li> <li>• Need regional support groups</li>   <li>• Competent care from those who will be faced with caring for AD patients</li> <li>• Public awareness</li> <li>• Trained personnel in NH's</li>   <li>• Proper identification &amp; treatment in early stages</li> <li>• Assuring that family &amp; paid caregivers receive training about behaviors &amp; how to cope</li> <li>• Support groups</li> <li>• Respite</li> <li>• Identify those who should not be driving</li>   <li>• Accessing services</li> <li>• Affordability</li> <li>• Awareness of information/education</li> <li>• Training certification/standardization</li>   <li>• Caregiver support</li> <li>• Availability of resources</li> <li>• Research</li>   <li>• Trained caregivers whether family or professional</li> <li>• Keeping people in their homes as long as possible</li> <li>• Increased numbers</li> <li>• Research, research, research</li> <li>• Money for meds &amp; housing (assisted living, NH's)</li> <li>• Public awareness of available services</li>   <li>• Isolation . . . believe they are social &amp; active but are not</li> <li>• Remembering the past</li>   <li>• Health care</li> <li>• Understanding</li>   <li>• Lack of testing &amp; diagnosis</li>   <li>• Correct diagnosis</li> </ul>	<ul style="list-style-type: none"> <li>• Care</li>   <li>• Having someone understand what it is really like . . . having them understand that I will be someone they do not know</li>   <li>• Proper identification &amp; treatment in early stages</li> <li>• Assuring that family &amp; paid caregivers receive training about behaviors &amp; how to cope</li> <li>• Support groups</li> <li>• Respite</li> <li>• Identify those who should not be driving</li> <li>• Training caregivers to deal with aggressive behaviors</li>   <li>• Accessing services</li>   <li>• Marketing &amp; training &amp; public awareness beginning with doctors</li>   <li>• Patient's refusal to get medical attention</li>   <li>• Respite</li>   <li>• Caregiver support</li> <li>• Programs &amp; services – specifically coordination &amp; awareness</li> <li>• Research</li>   <li>• Caregiver support &amp; programs to aid the caregiver &amp; the patient</li>   <li>• Support for caregivers</li>   <li>• Helping caregivers get some needed respite</li> </ul>

<b>MOST SIGNIFICANT ISSUES FACING PEOPLE WITH ALZHEIMER'S DISEASE and RELATED DEMENTIAS IN LOUISIANA</b>	<b>MOST IMPORTANT ISSUE TO YOU</b>
<ul style="list-style-type: none"> <li>• Early intervention</li> <li>• Education</li> <li>• Dementia training</li>   <li>• Organized activities for younger onset, <i>i.e.</i>, outings, brain building strategies &amp; games</li>   <li>• Caregiver support &amp; tools to aid in care of loved one</li> <li>• Early detection</li> <li>• Need to know when to seek medical attention</li> <li>• Rural areas sometimes do not know what is normal seniors' forgetfulness &amp; what is Alzheimer's</li>   <li>• Lack of knowledge for caregiver, family member, etc.</li> <li>• Denial by patient</li> <li>• Taking control without offending patient – finances, health care</li> <li>• Inconsistencies from day to day with brain power</li> <li>• How to educate others when offended by patient that it is the disease talking rather than the patient</li> <li>• Availability of assistance, services, etc.</li> <li>• How caregiver can go on with life &amp; not feel guilty</li>   <li>• Awareness</li> <li>• Funding</li>   <li>• Lack of knowledge</li>   <li>• Stigma</li> <li>• Lack of information, support &amp; hopelessness</li> <li>• Misleading information on current research causes yo-yo emotional effect on caregivers</li> <li>• Financial &amp; legal issues, especially Medicare coverage is huge issue</li> </ul>	<ul style="list-style-type: none"> <li>• Knowledge/awareness of disease by caregivers, patient &amp; family</li> </ul>

---

## TASK FORCE RECOMMENDATIONS

---

The Task Force was charged with providing time-specific recommendations to the Legislature. The Task Force targeted recommendations to the areas of coordination, programs and services, caregiver support, public awareness, health care and health services, professional workforce, surveillance and data collection, advance planning, and research.

The scope of these recommendations is beyond the abilities of a single state agency or other organization to implement. The Task Force recommends that the Legislature create an advisory group to work with state agencies and non-governmental organizations to fully implement these recommendations. The Task Force recognizes that Louisiana is in difficult budgetary times. However, the need for services for people with ADRD's will only grow. Where recommendations call for new or expanded programs, the Task Force recognizes that providing necessary resources will require spending existing resources more wisely as well as identifying new resources as they become available.

### **COORDINATION**

#### **Introduction**

Lack of coordination is the most pressing challenge across all aspects of meeting the needs of persons with ADRD's, their caregivers and families. Lack of coordination makes it difficult, and sometimes impossible, to assess the availability of services in order to identify gaps and make recommendations. Indeed, improved coordination is *the* essential first step in filling many of the needs of persons whose lives are touched by dementia.

#### **Recommendation 1**

**Create a permanent Advisory Council on ADRD consisting of the current Task Force designations plus additional designations to ensure balance and expertise to include such functions as:**

- Monitor benchmarks for implementation of the Task Force Report.
- Update recommendations of the Task Force Report, as appropriate.
- Monitor progress of implementation of the dementia-training regulations for nursing facilities and assisted living communities.
- Report annually to the Legislature.

#### **Recommendation 2**

**Establish and fund a Program Manager for Alzheimer's disease and related dementias in the Office of Aging and Adult Services (OAAS) to include functions such as:**

- Coordinate interagency policy, programs and services.
- Gather information and resources about dementia, both public and private, and serve as a clearinghouse.
- Coordinate with the Office of Public Health (OPH) on surveillance and data collection

- Staff the Advisory Council on ADRD's.
- Identify and pursue grant opportunities.
- Coordinate with quality management initiatives.
- Monitor programs that serve persons with ADRD's.
- Monitor implementation of the Plan for Choice.
- Monitor all workgroups convened to address issues touching the lives of persons with ADRD's, their caregivers and families.
- Oversee implementation of the Task Force Report.

This would not replace or duplicate any services currently offered by the Area Agencies on Aging, the Alzheimer's Association or other agencies, but would act as a referral source to local services.

### **Recommendation 3**

**Develop and/or implement, building on existing resources, a dementia-branded toll-free number and website to act as a clearinghouse for programs, services and educational information serving persons with ADRD's that takes advantage of existing information and referral services such as ADRC's, the Alzheimer's Association, and the LTC Options Help Line.**

### **Rationale**

The Task Force found that programs, services, and policy decisions are widely scattered among a variety of state agencies, as well as private providers, and there is no single policymaking authority for persons with ADRD's. Such fragmentation made it difficult to evaluate what programs and services currently exist, let alone what supports might be needed. More importantly, it is difficult for some and impossible for other consumers to navigate the disparate sources of information and resources to meet their needs. California, Florida, Illinois, Kentucky, New York, Tennessee, Texas and Vermont have all found benefit in establishing an Alzheimer's advisory council or commission to oversee the development of Alzheimer's policy in their states. A permanent body ensures that on-going attention is paid to this issue and that there is a vehicle for making changes when appropriate.

Kentucky, Vermont and New York have staff devoted to developing state-specific programming for Alzheimer's disease. Louisiana's DHH already has disease-specific units in the areas of diabetes, asthma, heart disease and hypertension, obesity and smoking cessation. Such programs have been effective in promoting behavior modification that reduces the incidence disease, and thereby saves state dollars. An advisory council tied to a permanent staff person will provide a focal point for activity that can best coordinate services, develop new services, connect consumers to necessary services, and assist providers with evidence based care.

Coordinated public policy requires consistent input from all stakeholders across the state who are involved in the lives of persons with ADRD's, their caregivers and families. The recommended advisory council should be inclusive and extend beyond the current Task Force membership in order to frame more accurately the policy decisions that must be made.



## **PROGRAMS and SERVICES**

### **Introduction**

The Task Force catalogued all programs and services that could be identified as being of assistance to persons with ADRD's whether in-home, community-based or delivered in a residential care or nursing facility.

### **Recommendation 4**

**Ensure that all state-funded and/or regulated services and programs are designed to meet the specific needs of persons with ADRD's, at any age and at any stage of the disease including, but not limited to, actions that:**

- Ensure that the study of adult day health care programs pursuant to HCR 190 (2009 Regular Session) includes consideration of the specific needs of persons with ADRD's, at any age and at any stage of the disease.
- Simplify and/or develop laws and regulations that encourage development of social model adult day care programs.
- Ensure that all programs and services have the capacity to address the unique needs of persons with ADRD's exhibiting difficult or dangerous behaviors.
- Strictly enforce facility transfer/discharge regulations to ensure that persons with Alzheimer's disease or other dementias are not transferred or discharged solely because they exhibit disruptive behavior.
- Improve access to the full array of home and community-based services for persons with ADRD's through public education, dedicated toll-free number, and branded website.
- Develop and implement affordable accessible housing alternatives across the full spectrum of residential care settings including, but not limited to, funding and implementation of the Medicaid assisted living waiver and extending Medicaid to subsidized housing.
- Develop and implement effective programs to help younger onset Alzheimer's patients remain in the work force as long as possible.

### **Recommendation 5**

**Convene a workgroup to study alternative financing for the funding, including but not limited to the Medicaid state match, necessary to meet the need for programs and services for persons with ADRD's.**

- Fund statewide expansion of the Program for All-inclusive Care of the Elderly (PACE) as it is designed to meet the specific needs of persons with ADRD's.

### **Recommendation 6**

**In implementing the Plan for Choice, ensure that goals, objectives and action steps address the specific needs of persons with ADRD's, their caregivers and families including, but not limited to:**

- Quality management goals for the collection and analysis of dementia-specific quality measures and initiate quality improvements, as indicated.
- Dementia-specific objectives and action steps to provide persons with access to affordable transportation statewide.

### **Recommendation 7**

**Develop and implement public safety programs to address the needs of persons with ADRD's, their caregivers and families which may include:**

- Monitor implementation of Silver Alert wandering alert system
- Promote the enhancement of initial and continuing training requirements to address the needs of persons with dementia who may or may not exhibit difficult or dangerous behaviors, as it applies to first responders, including but not limited to: law enforcement personnel, fire fighters, the Louisiana National Guard, emergency medical personnel, and search and rescue organizations, to include dementia-specific training and education appropriate to their functions.
- Ensure that plans implemented by the Emergency Management Disability and Aging Coalition include dementia-specific training for workers in general shelters and those staffing critical transportation needs shelters.
- Explore best practices for ensuring that persons with ADRD's cannot retain their drivers' licenses when their cognitive impairments interfere with their ability to drive.

### **Recommendation 8**

**Investigate the elimination of the current prohibition against receiving Long-term Personal Care Services and Hospice Services concurrently.**

### **Rationale**

Participants in the six public forums overwhelmingly expressed the need for, and importance of, access to high quality programs and services across all settings. They pointed to the critical need for available and accessible home and community-based services that would ensure that persons with ADRD's can remain in their homes as long as possible to meet their wishes, as well as to control the cost of health care.

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

- Persons with ADRD's, their caregivers and families, most often request these services so that they can live in their homes as long as possible.
- The federal government is encouraging states to focus on home and community care rather than institutional care.
- Home and community-based care is more economical (in most cases) than institutional care at a time when state and federal budget dollars are strained.

Even when programs and services are available, caregivers and families expressed frustration at finding them. Persons with younger-onset dementias do not typically look to programs for the elderly as a source of help for them. Often caregivers of persons with dementia of any age look for resources for the *condition* rather than the *type of services* or the *age group* served. While the ADRC's and the LTC Options Help Line offer some guidance, there are no publicly-sponsored dementia-specific information and referral resources in the state.

Waiting lists for home and community-based services are even more frustrating for caregivers who

locate available programs and supports. Persons with younger onset dementia face an almost complete lack of programs and services since many that are available are age related.

The Task Force and public forum participants identified the lack of appropriate adult non-medical day care, particularly for those with younger-onset dementias, but lacking at all stages and all ages of the disease. Providers pointed to the lack of a simplified licensing process as a barrier to providing such services within existing programs, both residential and community-based.

Affordable, accessible housing was cited by both the Task Force and forum participants as a critical need. While legislation permits public financing of Medicaid services delivered in assisted living communities, the program has never been funded. One solution to the shortage of viable housing options is to fund the Medicaid waiver for assisted living and expand participation in that waiver to other adult residential care settings.

Task Force members and the public expressed concerns involving public safety issues including wandering, driving, and encounters with first responders, and emergency (hurricane) preparedness. While some strides have been made in first responder training for encounters with persons with mental illness or developmental disabilities,<sup>20</sup> dementia-specific training is not required as either a prerequisite for employment or as a continuing education requirement. Emergency preparedness plans have also improved to meet the needs of persons with disabilities in both general and critical transportation needs shelters. However, none of the planning specifically addresses the needs of persons with dementia in either shelter setting. Many states have explored ways to address the need to curtail driving at some point in the progression of dementias and Louisiana should look for best practices and amend motor vehicle licensing laws accordingly.

## **CAREGIVER SUPPORT**

### **Introduction**

The Task Force examined the needs of unpaid caregivers, as well as the programs and services that might meet those needs.

### **Recommendation 9**

**Increase the availability and affordability of in-home, community-based, and multi-day respite care.**

- Revise regulations to eliminate barriers to providing adult day care in adult residential care communities.
- To the extent permitted by Federal law, revise regulations to simplify short-stay admission to any residential facility for respite care.

### **Recommendation 10**

**Develop and implement, building upon existing resources, a public awareness campaign to**

---

<sup>20</sup> RS 40:2405.5. “Training for law enforcement interaction with mentally ill and developmentally disabled persons.”

increase knowledge about, and use of, existing Federal and state tax exemptions, deduction, and credits for caregivers of persons with ADRD's.

### **Recommendation 11**

**Encourage development of services that support caregivers remaining in the workforce through efforts such as:**

- Partnering with stakeholders such as the Chamber of Commerce, Society of Human Resource Managers, small business owners and others, and caregivers to explore employer implementation of a “cafeteria plan” state income tax benefit for caregivers of persons with ADRD's.
- Partnering with the state Society of Human Resource Managers and caregivers to develop and implement employee assistance programs for employees who are caregivers for persons with ADRD's.

### **Recommendation 12**

**Explore opportunities to increase funding for the National Family Caregiver support Program (NFCSP).**

#### **Rationale**

Louisiana generally lacks sufficient affordable, accessible supports and services for unpaid caregivers who care for most of the persons with ADRD's in the state. This gap in services is exacerbated in rural areas where often *no* services are available. And even where services exist, public comments at forums across the state revealed a general lack of awareness of supports and services that *are* available.

Public input reported a general need for respite services for all unpaid caregivers, whether delivered in the home, in a community setting or as a short stay in a residential setting. Moreover, caregivers who want or need to remain in the workforce have few on-the-job resources to assist them. Louisiana caregivers echo the concerns facing caregivers nationwide: high levels of stress and negative effects on their health, employment, income and financial security. Innovative employers in other states offer employee assistance programs that include information and referral about dementia resources, flexible scheduling and even on-site adult day care.

NFCSP already offers significant support to families of persons with Alzheimer's disease, regardless of the age of the patient or the caregiver. Currently approximately half of the caregivers receiving assistance through this program care for a loved one with an ADRD diagnosis. Expansion of this program could be done quickly, without promulgation of additional legislation, federal approval or new rules.

## **PUBLIC AWARENESS**

### **Introduction**

As the Task Force catalogued current Louisiana policies and program, lack of public awareness – among Task Force members themselves – presented a significant barrier to addressing the needs of persons with ADRD's. Public comments reinforced that conclusion.

### **Recommendation 13**

**Build strategic public/private partnerships to develop and implement a statewide public awareness campaign addressing issues across the entire ADRD spectrum including, but not limited to:**

- Prevention, wellness and brain health
- Risk factors
- Importance of early diagnosis
- Available treatments
- Available information and resources to support persons with ADRD's, their caregivers and families

### **Recommendation 14**

**Build on existing public/private partnerships to develop and implement social marketing strategies tailored to the unique cultural differences across the state and designed to make information and resources available where people are when they need that information.**

### **Rationale**

The theme of public awareness arises in many aspects of dementia policy and programs. It begins with the lack of knowledge and publicity about prevention, wellness and risk factors, unlike other major illnesses such as cancer and heart disease. This lack of awareness leads to a failure to seek, or an inability to obtain, the early diagnosis so critical to maintaining dignity and quality of life. It appears in the continued stigma attached to ADRD's which prevents people from accessing services. And when services are needed, they often cannot be found.

Louisiana implemented a successful social marketing campaign to increase enrollment of children in the state's children's health insurance program by creating easy-to-understand information, emphasizing the concept of insurance rather than welfare, which was perceived as a stigma, and disseminating information where parents of eligible children were likely to find it – in grocery stores, Head Start facilities, schools and the like. Louisiana must make a similar effort to address the lack of understanding about the nature, scope, and treatment of ADRD's.

## **PROFESSIONAL DIRECT CARE WORKFORCE**

### **Introduction**

The Task Force looked at workers who likely would encounter persons with ADRD's, across all programs, to evaluate current training programs and ongoing training needs.

### **Recommendation 15**

**In implementing the Plan for Choice, ensure that goals, objectives and action steps relating to workforce development address the need for dementia-specific competency including, but not limited to:**

- Including dementia-specific requirements in the development of a competent direct service worker (DSW) workforce.

- Requiring dementia-specific training and education as part of OAAS's initiative to expand opportunities for DSW's.
- Developing dementia-specific strategies in efforts to promote culture change, including the components of workforce practices and person-centered care approaches, across all care settings.

### **Recommendation 16**

**Extend dementia-specific training requirements to include all licensed and unlicensed providers serving persons who may have ADRD's.**

#### **Rationale:**

Louisiana does not currently require dementia-specific training for workers most likely to serve persons with ADRD's. Studies demonstrate that workers who understand dementia and associated behaviors are less frustrated and more likely to remain in their jobs. Providers experience reduced turnover among direct care workers and clients experience a better quality of life and exhibit fewer difficult behaviors.

Regulations requiring dementia-specific training for certain staff of nursing facilities and adult residential care facilities will likely go into effect in January 2010 with full compliance required by January 2011. These requirements should be extended to all providers serving persons who may have ADRD's.

Louisiana's initiative to develop a competent direct service worker workforce offers another opportunity to include dementia-specific training. Early and ongoing training for DSW's across all care settings will ensure that persons with ADRD's are treated with dignity and that DSW's will have more positive work experiences.

## **HEALTH CARE and RELATED SERVICES**

### **Introduction**

The Task Force studied the allied health care needs of persons with ADRD's including mental health, speech, occupational and physical therapy, and non-dementia related medical care.

### **Recommendation 17**

**Convene a workgroup of gerontologists, geriatric psychiatrists, advanced practice nurses, and psychologists, others specializing in behavioral health care, dementia specialists, staff from the Office of Mental Health (OMH), OAAS, GOEA, persons with dementia, and caregivers to develop best practices to address the needs of persons with dementia who exhibit dangerous or difficult behaviors by examining such issues as:**

- The adequacy of geriatric-psychiatric hospitals, general psychiatric hospitals and acute care hospitals with psychiatric units, by number and location statewide.
- Establish parameters for the type and length of treatment for persons with Alzheimer's disease or other dementias in in-patient settings.
- Determine and implement protocols for placement of persons with Alzheimer's disease and related dementias in, and release from, psychiatric in-patient hospitalization.

- Establish protocols for community-based systems of care to meet the needs of persons exhibiting behaviors requiring intervention.

### **Recommendation 18**

**Work with universities and other professional schools to develop dementia-specific training and recruitment options such as:**

- Optimal training content standards for licensed health professional integrated into curricula relevant to ADRD's
- Creation of a program to recruit and train geriatric psychiatrists, geriatricians, advanced practice nurses, and other geriatric specialists
- Residencies or fellowships for geriatric specialists
- Specific academic track for medical students, residents and other students who do not specialize in geriatrics

### **Recommendation 19**

**Work with professional licensing and certification entities to require dementia-specific training in relevant licensing, certification and continuing education initiatives for providers such as nurses, certified nursing assistants, physicians not specializing in geriatrics, occupational therapists, physical therapists, dentists, and the like.**

### **Rationale**

Few, if any, outpatient mental health programs serve persons with ADRD's who exhibit difficult or dangerous behaviors, nor would many such services be appropriate. Inpatient mental health services, while more available, often do not have staff with dementia-specific training. Public comments suggest that persons with ADRD's are being transferred to psychiatric inpatient facilities from residential care settings then denied readmission on the basis that the person poses a danger. Whether that is true or not, it raises the question of what Louisiana will do to meet the needs of this group. Several states have instituted promising practices which should be explored once the scope of the issue has been defined by the workgroup.

It is also important that health care providers and providers of allied services understand the unique needs of persons with ADRD's even though their services are not targeted solely to that population. Experts recognize that the patient will have better care and the provider will have a more rewarding experience by avoiding the frustration that sometimes accompanies treating a patient with dementia.

## **SURVEILLANCE and DATA COLLECTION**

### **Introduction**

As the Task Force studied issues raised for consideration in SCR 80, it was readily apparent that most of the information could not be collected in ways that would be useful in informing our deliberations.

### **Recommendation 20**

**Establish, a dementia-specific initiative in the Office of Public Health (OPH) to develop**

**and implement the most effective system to collect data regarding prevalence, population trends, service needs and impact of ADRD's on the person, their caregivers and families.**

### **Rationale**

In Louisiana, as in many other states, there is a lack of widespread and consistent public health surveillance on the incidence and prevalence of ADRD's or identifying risk factors. This lack of data hampers valuable research to identify risk factors unique to Louisiana and to develop strategies to reduce those risks. Inconsistent data for research also effects research into new treatments for the disease.

Lack of data makes it difficult to develop effective, coordinated public policy to address the needs of persons affected by dementia. Caregiver health is increasingly noted as a public health concern of enormous proportions yet Louisiana is just beginning a pilot to track their health status.

## **ADVANCE PLANNING**

### **Introduction**

The Task Force studied the need for advance planning in the areas of health, long-term care, and finances to evaluate the role of such planning in meeting expressed needs of persons with ADRD's, their caregivers and families.

### **Recommendation 21**

**Convene a workgroup to explore options for funding and development of a public awareness campaign regarding the importance of advance health care, long-term care and financial planning, including resources available to help with such planning.**

### **Recommendation 22**

**Support implementation of Louisiana Physicians Order for Scope of Treatment (LaPOST)**

- LaPOST represents a model of care that results in an easily identifiable document that translates a patient's end of life wishes and goals of care into a physician order. This document transfers with the patient across care settings (*e.g.*, from hospital to home to nursing home to hospice).

### **Recommendation 23**

**Encourage the use of long-term care insurance, including Long-Term Care Partnership Program, as an important tool in enabling consumers to be personally responsible for financing their own long-term care.**

### **Rationale**

Beyond traditional estate planning, use of advance planning tools does not appear to be widespread among persons with ADRD's. It appears that many Louisianians do not take advantage of advance planning tools including long-term care insurance, advance financial planning for incapacity and health care powers of attorney.



Lack of planning often requires judicial intervention into health and financial decision-making which may or may not reflect the wishes of the subject of the interdiction. Even without court action, lack of planning leads to family frustration and even dissention. There are several reasons for this phenomenon including denial of the need to plan in advance, lack of awareness of the need to plan, lack of tools for planning and services to inform the planning process, and a lack of information about the tools and services that actually are available. It is important that the public is informed about advance planning tools and encouraged to use them.

## **RESEARCH**

### **Introduction**

The Task Force did a cursory review of research in the state. Without any coordinating body, it is difficult to know precisely what is being done. However, anecdotally the Task Force identified work at Pennington Biomedical Research Center, LSU/Shreveport, and the University of Louisiana at Monroe.

### **Recommendation 24**

**Support dementia research by increasing the sharing of scientific knowledge among scientists, through stand-alone conferences, as well as by incorporating dementia research topics into other conferences that meet in Louisiana.**

### **Recommendation 25**

**Support the development of a Center of Excellence for dementia research to promote collaboration, share knowledge, and offer education and services throughout Louisiana.**

### **Recommendation 26**

**Develop strategies to attract, grow and track research funding through universities, colleges, not-for-profit organizations and other stakeholders.**

### **Recommendation 27**

**Develop and support programs that encourage therapeutics and clinical trials for dementia by scientists from Louisiana, including basic research efforts and sponsoring biotechnology incubators to attract businesses to the state.**

### **Rationale**

Although Louisiana provides funds to universities to support faculty positions in various capacities, monies are not designated for use in specific areas of research. Furthermore, Louisiana does not have any targeted funds to specifically support dementia research through universities or other research and evaluation activities and there is no coordination of ongoing research and little routine sharing of information across the state. As far as could be determined, Louisiana lacks dementia research at nearly every level.

Pennington Biomedical Research Center recently created the Institute for Dementia Research & Prevention to generate world class research programs focused on dementia prevention and

providing vital educational opportunities for individuals affected by dementia. One of the goals of the Institute will be to promote clinical trials in Louisiana.<sup>21</sup>

Many states have Centers of Excellence for dementia research, often located in a university or among a consortium of institutions. Typically such Centers conduct state of the art research, serve as a central site for coordinating and facilitating the state's various efforts to diagnose, treat and prevent dementias, act as a clearinghouse for information about dementia and lead partnerships to educate, research, advocate and develop service programs that will improve the current practices in the state. A Louisiana Center for Excellence in Dementia could act as a source of information, as a facilitator of collaboration and as a catalyst to substantially improve the quality of life for persons and families affected by the disease.

Increased support for dementia research as recommended would also act as a catalyst for economic development in many areas of the state where research is already underway. Biomedical incubators would serve to attract business, infusing our state's economy spearheading development of innovative treatments and services.

---

<sup>21</sup> [www.idrp.pbrc.edu](http://www.idrp.pbrc.edu)

---

---

## **PART 4 TIMELINES**

### **By the end of Year One**

#### **Recommendation 1: Coordination**

Create a permanent Advisory Council on ADRD consisting of the current Task Force designations plus additional designations to ensure balance and expertise.

#### **Recommendation 2: Coordination**

Establish and fund a Program Manager for Alzheimer's disease and related dementias in the Office of Aging and Adult Services (OAAS).

#### **Recommendation 3: Coordination**

Develop and/or implement, built on existing resources, a dementia-branded toll-free number and website to act as a clearinghouse for programs, services and educational information serving persons with Alzheimer's disease and related dementias.

#### **Recommendation 8: Programs & Services**

Investigate the elimination of the current prohibition against receiving Long-Term Personal Care Services and Hospice Services concurrently.

#### **Recommendation 9: Caregiver Support**

Increase the availability and affordability of in-home, community-based, and multi-day respite care.

#### **Recommendation 15: Professional Direct Care Workforce**

In implementing the Plan for Choice, ensure that goals, objectives and action steps relating to workforce development address the need for dementia-specific competency.

#### **Recommendation 17: Health Care and Related Services**

Convene a workgroup of gerontologists, geriatric psychiatrists and psychologists, others specializing in behavioral health care, dementia specialists, Office of Mental Health (OMH), OAAS, GOEA, persons with dementia, and caregivers to develop best practices to address the needs of persons with dementia who exhibit dangerous or difficult behaviors.

#### **Recommendation 20: Surveillance and Data Collection**

Establish, a dementia-specific initiative in the Office of Public Health to develop and implement the most effective system to collect data regarding prevalence, population trends, service needs and impact of Alzheimer's disease and related dementias on the person, caregivers and families.

#### **Recommendation 22: Advance Planning**

Support implementation of LaPOST.

#### Recommendation 12

Explore opportunities to increase funding for the National Family Caregiver Support Program (NFCSP).

### Years Two to Five

#### Recommendation 4: Programs and Services

Ensure that all state-funded and/or regulated services and programs are designed to meet the specific needs of persons with Alzheimer's disease and related dementias, at any age and at any stage of the disease.

#### Recommendation 5: Programs and Services

Convene a workgroup to study alternative financing for the funding, including but not limited to the Medicaid state match, necessary to meet the need for programs and services for persons with Alzheimer's disease and related dementias.

#### Recommendation 6: Programs and Services

In implementing the Plan for Choice, ensure that goals, objectives and action steps address the specific needs of persons with ADRD's, their caregivers and families.

#### Recommendation 10: Caregiver Support

Develop and implement, building on existing resources, a public awareness campaign to increase knowledge about, and use of, existing Federal and state tax exemptions, deduction, and credits for caregivers of persons with Alzheimer's disease and related dementias.

#### Recommendation 11: Caregiver Support

Encourage development of services that support caregivers remaining in the workforce.

#### Recommendation 13: Public Awareness

Build strategic public/private partnerships to develop and implement a statewide public awareness campaign addressing issues across the entire ADRD spectrum.

#### Recommendation 14: Public Awareness

Build on existing public/private partnerships to develop and implement social marketing strategies tailored to the unique cultural differences across the state and designed to make information and resources available where people are when they need that information.

#### Recommendation 16: Professional Direct Care Workforce

Extend dementia training requirements to include all licensed and unlicensed providers serving persons who may have Alzheimer's disease and related dementias.

#### Recommendation 18: Health Care and Related Services

Work with universities and other professional schools to develop dementia-specific training and recruitment options.

#### Recommendation 19: Health Care and Related Services

Work with professional licensing and certification entities to require dementia-specific training in all licensing, certification and continuing education initiatives.

Recommendation 21: Advance Planning

Convene a workgroup to develop a public awareness campaign regarding the importance advance health care, long-term care and financial planning, including resources available to help with such planning.

Recommendation 23: Advance Planning

Encourage the use of Long-Term care Insurance, including Long-Term Care Partnership Program, as an important tool in enabling consumers to be personally responsible for financing their own long-term care.

Recommendation 24: Research

Support dementia research by increasing the sharing of scientific knowledge among scientists, through stand-alone conferences, as well as by incorporating dementia research topics into other conferences that meet in Louisiana.

Recommendation 26: Research

Develop strategies to attract, grow and track research funding through universities, colleges, not-for-profit organizations and other stakeholders.

**By Year Five and Ongoing**

Recommendation 7: Programs and Services

Develop and implement public safety programs to address the needs of persons with Alzheimer's disease and related dementias, their caregivers and families.

Recommendation 25: Research

Support the development of a Center of Excellence for dementia research to promote collaboration, share knowledge, and offer education and services throughout Louisiana.

Recommendation 27: Research

Develop and support programs that encourage therapeutics and clinical trials for dementia by scientists from Louisiana, including basic research efforts and sponsoring biotechnology incubators to attract businesses to the state.

---

## CONCLUSION

---

Alzheimer's disease and related dementias (ADRD's) pose a serious problem for our nation and our state. As the population ages, it is likely to become the *real* epidemic of the 21<sup>st</sup> century. Louisiana will have no choice but to provide more services at greater cost to its citizens. This is especially true because of the significant dependence on public resources to finance long-term care in Louisiana.

Currently Louisianans affected by ADRD's report that services are difficult to find and access. Even when people find out about useful services that exist, there are often long waiting lists. A large segment of the population may not qualify for publically funded services but is clearly unable to afford the amount of care that is necessary.

The combination of system inefficiencies and rising demand means that the current service delivery system is unsustainable over the long haul. Significant re-design coupled with new resources from private as well as public sources will be necessary to provide adequate care for those with Alzheimer's disease. Research provides the only hope that this situation might change significantly.

As a first step in dealing with the Alzheimer's crisis more realistically, the Task Force recommends that the Legislature create a permanent Advisory Council on Alzheimer's Disease and Related Dementias to continue its work in cataloguing current services, identifying national best practices and coordinating statewide efforts across all disciplines. Subgroups of the Advisory Council could be called upon to lead workgroups called for in the Task Force recommendations, monitor progress on all recommendations, amend recommendations as appropriate, and report annually to the Legislature.

The Task Force further recommends that the Legislature create and fund a program manager in OAAS whose job is to coordinate policies and programs affecting persons with Alzheimer's disease and related dementias, their caregivers and their families. Such staff would be responsible for implementing dementia-branded toll-free numbers and website that, while utilizing existing information and referral resources, appears and is marketed to the public as specific to Alzheimer's disease and related dementias.

Louisiana's best chance to prepare for the coming epidemic is to put in place an infrastructure to coordinate current services, identify future needs and monitor all Task Force recommendations. Without a permanent Advisory Council and dedicated staff, it is unlikely that much progress will be made on the remaining recommendations.

---

## BIBLIOGRAPHY

---

ADRCs: [www.aoa.gov/AoARoot/AoA\\_Programs/HCLTC/ADRC/index.aspx](http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/ADRC/index.aspx)

*Families Care: Alzheimer's Caregiving in the United States 2004*, The Alzheimer's Association and National Alliance for Caregiving  
[www.alz.org/national/documents/report\\_familiescare.pdf](http://www.alz.org/national/documents/report_familiescare.pdf)

[www.alz.org/documents/national/report\\_ASG\\_alzplan.pdf](http://www.alz.org/documents/national/report_ASG_alzplan.pdf)

Early onset report

[www.alz.org/alzheimers\\_disease\\_publications\\_reports.asp](http://www.alz.org/alzheimers_disease_publications_reports.asp)

Across the States 2009

[http://assets.aarp.org/rgcenter/ill/d19105\\_2008\\_atl\\_la.pdf](http://assets.aarp.org/rgcenter/ill/d19105_2008_atl_la.pdf)

2005 LA LTC member survey

[http://www.aarp.org/research/surveys/care/ltc/costs/articles/la\\_member.html](http://www.aarp.org/research/surveys/care/ltc/costs/articles/la_member.html)

### FOOTNOTES

<sup>1</sup> [www.alz.org](http://www.alz.org)

<sup>2</sup> (Alzheimer's Association, *Alzheimer's Disease Facts and Figures 2008* Washington, D.C.: 2008. ([www.alz.org](http://www.alz.org)). ["Alzheimer's Report"].

<sup>3</sup> Kaiser Commission on Medicaid and the Uninsured, *Medicaid and Long-Term care Services and Supports*, February 2009. Available at [http://www.kff.org/medicaid/upload/2186\\_06.pdf](http://www.kff.org/medicaid/upload/2186_06.pdf). These data do not include services financed primarily through Medicaid HCBS waivers.

<sup>4</sup> AARP, *Across the States: Profiles in Long-term Care and Independent Living*. Washington, D.C.: 2009. [AARP State Profiles"].

<sup>5</sup> (AARP, *Louisiana Long-term Care: A Survey of AARP Members*. Washington, D.C. AARP Knowledge Management 2005

<sup>6</sup> <http://www.dhh.state.la.us/offices/publications/pubs-77/LA%20Plan%20for%20Choice%20in%20Long-term%20Care%20Full%20document%20web.pdf>

<sup>7</sup> Care was valued at \$11.10 per hour, which is the average of the minimum wage (\$5.85 per hour) and the average wage of a home health aide in July 2008 (\$18.35 per hour). Alzheimer's Report at p.34.

<sup>8</sup> 2008 *Alzheimer's Disease Facts and Figures* The Alzheimer's Association p. 19

<sup>9</sup> [http://www.aoa.gov/AoARoot/AoA\\_Programs/HCLTC/Caregiver/index.aspx](http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/Caregiver/index.aspx) . Sept. 9, 2009

<sup>10</sup> Maslow, K., Langa, K.M., Kabeto, M.U., and Weir, D.R. "Early Onset Dementia: A National Challenge, A Future Crisis" The Alzheimer's Assn.  
[http://www.alz.org/national/documents/report\\_earlyonset\\_summary.pdf](http://www.alz.org/national/documents/report_earlyonset_summary.pdf). Sept. 9, 2009

<sup>11</sup> The Older Americans Act, Title III, Grants to State and Community Programs. Available at [http://www.aoa.gov/AoARoot/AoA\\_Programs/OAA/oa\\_full.asp#\\_Toc153957659](http://www.aoa.gov/AoARoot/AoA_Programs/OAA/oa_full.asp#_Toc153957659)

<sup>12</sup> Kaiser Foundation. February 2009.

<sup>13</sup> LAC 48:I.6803, 6851 and 6867 and LAC 48:I.9701 and 9727

<sup>14</sup> RS 40:1300.123

<sup>15</sup> [www.vctaffairs.com](http://www.vctaffairs.com)

<sup>16</sup> “An ‘Alzheimer’s special care unit’ means any nursing facility, residential care/assisted living facility, adult congregate living facility, home health agency, home- and community-based service provider which provide adult day care services, hospice, or continuing care retirement community that segregates or provides a special program or special unit for residents with a diagnosis of probably Alzheimer’s disease or a related disorder so as to prevent or limit access by a resident to areas outside the designated or separated area; and that advertises, markets, or otherwise promotes the facility as providing specialized Alzheimer’s/dementia care services.” RS 40:1300.123(1).

<sup>17</sup> These areas include: (1) a written statement of philosophy and missions reflecting the needs of persons with dementia, (2) process for placement in, transfer or discharge from the unit, (3) process for assessment, care planning, and implementation, (4) staffing patterns and training, (5) physical environment and design features appropriate to the population, (6) resident activities, (7) family’s role in care and (8) program fees. RS 40:1300.124B

<sup>18</sup> RS 40:1300.124 A.

<sup>19</sup> [www.idrp.pbrc.edu/aboutus](http://www.idrp.pbrc.edu/aboutus)

<sup>20</sup> RS 40:2405.5. “Training for law enforcement interaction with mentally ill and developmentally disabled persons.”

<sup>21</sup> [www.idrp.pbrc.edu](http://www.idrp.pbrc.edu)



SENATE CONCURRENT RESOLUTION NO. 80

BY SENATOR MOUNT AND REPRESENTATIVES ABRAMSON, BOBBY BADON, BALDONE, BARRAS, BARROW, BILLIOT, BURFORD, TIM BURNS, CARMODY, CHANDLER, DOERGE, DOWNS, FRANKLIN, GALLOT, GISCLAIR, HARDY, HILL, HINES, HOFFMANN, HOWARD, JOHNSON, KATZ, LABRUZZO, LEBAS, LEGER, PETERSON, POPE, RITCHIE, SIMON, ST. GERMAIN, TRAHAN, TUCKER, WILLIAMS AND WILLMOTT

A CONCURRENT RESOLUTION

To create the Louisiana Alzheimer's Disease Task Force to study and make recommendations to the Legislature of Louisiana concerning the current and future impact of Alzheimer's disease and related dementias on Louisiana citizens.

WHEREAS, Alzheimer's disease is a progressive, fatal disease of the brain that destroys mental and physical functions, that is not a part of normal aging and for which there is no known cure; and

WHEREAS, every seventy-one seconds someone in America develops Alzheimer's disease, and an estimated five million two hundred thousand Americans now live with the disease; and

WHEREAS, it has been estimated that by mid-century, someone will develop Alzheimer's every thirty-three seconds; and

WHEREAS, between 2000 and 2010, Louisiana will have experienced a fourteen per centum growth rate of people with this devastating disease, and Louisiana will soon have eighty-three thousand citizens diagnosed with Alzheimer's.

THEREFORE, BE IT RESOLVED that the Legislature of Louisiana does hereby create the Louisiana Alzheimer's Disease Task Force to assess, evaluate, and review the impact on Louisiana citizens of Alzheimer's disease.

BE IT FURTHER RESOLVED that the task force shall be comprised of the following members:

- (1) The secretary of the Department of Health and Hospitals, or his designee.
- (2) The secretary of the Department of Social Services, or his designee.

- (3) One person who suffers from Alzheimer's disease appointed by the governor.
- (4) One person who serves as a care giver to a person with Alzheimer's disease appointed by the governor.
- (5) One person representing the nursing facility industry appointed by the Louisiana Nursing Home Association.
- (6) One person representing the assisted living industry appointed by the Louisiana Assisted Living Association.
- (7) One person representing the adult day services industry appointed by the Louisiana Adult Day Health Care Association.
- (8) One person representing the home health care industry appointed by the Louisiana Home Health Care Association.
- (9) One person representing the medical care provider community appointed by the Louisiana Geriatric Society.
- (10) One person representing patient care assistants appointed by the Community and Residential Services Association.
- (11) One person who engages in research related to Alzheimer's disease appointed by the Alzheimer's Association.
- (12) One person representing and appointed by the AARP.
- (13) The director of the Bureau of Primary Care and Rural Health in the office of the secretary of the Department of Health and Hospitals.
- (14) One person representing and appointed by the Louisiana State Medical Society.
- (15) The assistant secretary of the office of aging and adult services within the Department of Health and Hospitals, or his designee.
- (16) The assistant secretary of the office for citizens with developmental disabilities within the Department of Health and Hospitals, or his designee.
- (17) The Medicaid director within the Department of Health and Hospitals, or his designee.
- (18) One person representing and appointed by the Program for All Inclusive Care of the Elderly of Louisiana.
- (19) One member representing law enforcement appointed by the secretary of the

Department of Public Safety and Corrections.

(20) One person representing and appointed by the Alzheimer's Association.

(21) The executive director of the Governor's Office of Elderly Affairs, or his designee.

(22) One person representing and appointed by The Advocacy Center.

(23) One person representing and appointed by the Louisiana and Mississippi Hospice and Palliative Care Organization.

(24) The assistant secretary of the office of mental health within the Department of Health and Hospitals, or his designee.

(25) One person representing and appointed by Gulf States Homes and Services for the Aging.

(26) One person representing the Area Agency on Aging and appointed by the executive director of the Governor's Office of Elderly Affairs.

(27) One person representing and appointed by the Louisiana State Nurses Association.

BE IT FURTHER RESOLVED that the Louisiana Alzheimer's Disease Task Force shall include an examination of the following in its assessment and recommendations:

(1) Trends in the state Alzheimer's population and needs, including the changing population with dementia, the state's role in long-term care, family caregiver support, assistance to persons with early-stage and early onset of Alzheimer's disease, and the state policy regarding persons with Alzheimer's disease and developmental disabilities.

(2) The type, cost and availability of dementia services.

(3) Dementia-specific training requirements for those working with persons with dementia.

(4) The quality care measures for providers who deliver services to persons with Alzheimer's disease.

(5) The capacity of public safety and law enforcement to respond to persons with Alzheimer's disease.

(6) The availability of home and community-based resources for persons with Alzheimer's disease and respite care to assist families.

(7) The inventory of long-term care dementia care units.

(8) The adequacy and appropriateness of geriatric-psychiatric units for persons with behavior disorders associated with Alzheimer's disease and related dementia.

(9) Assisted living options for persons with dementia.

(10) The state support of Alzheimer's disease research through Louisiana universities and other resources.

(11) The needed state policies or resources, including but not limited to directions for the provision of clear and coordinated services and supports to persons and families living with Alzheimer's disease and related disorders and strategies to address any identified gaps in services.

BE IT FURTHER RESOLVED that by October 1, 2008, the secretary of the Department of Health and Hospitals, or his designee, shall convene the Louisiana Alzheimer's Disease Task Force, and the Department of Health and Hospitals shall provide the necessary facilities and administrative support which are necessary.

BE IT FURTHER RESOLVED that the Louisiana Alzheimer's Disease Task Force shall hold public meetings and utilize technological means, such as web casts, to gather feedback on the recommendations from the persons and families affected by Alzheimer's disease and from the general public.

BE IT FURTHER RESOLVED that the members of this task force shall serve without compensation, except per diem or expenses reimbursement to which they may be individually entitled as members of the constituent organizations.

BE IT FURTHER RESOLVED that the members of the task force shall elect one member to serve as chairman and one member to serve as vice-chairman of the task force.

BE IT FURTHER RESOLVED that the Louisiana Alzheimer's Disease Task Force shall submit a report of its findings and date-specific recommendations to the Senate and House committees on health and welfare and to the governor in the form of a State Alzheimer's Plan prior to October 1, 2009.

BE IT FURTHER RESOLVED that the Louisiana Alzheimer's Disease Task Force shall terminate upon the delivery of the State Alzheimer's Plan to the House and Senate committees on health and welfare or on October 1, 2009, whichever occurs earlier.

**SCR NO. 80**

**ENROLLED**

BE IT FURTHER RESOLVED that a copy of this Resolution be transmitted to each official or organization responsible for serving on the task force or selecting a person to serve on the task force.

---

PRESIDENT OF THE SENATE

---

SPEAKER OF THE HOUSE OF REPRESENTATIVES