



# **State Plan for Alzheimer's Disease and Other Related Dementias in Alabama**



**Created by the Alzheimer's Disease Task Force  
2012 -2015**

**Submitted by:**

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# Acknowledgements

**The Alzheimer’s Disease Task Force wants to thank the individuals from across Alabama who gave information about the challenges facing them due to the impact of Alzheimer’s disease and other related dementias. Their input was critical in shaping this state plan (For a list of these individuals See Appendix A on page 26).**

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# Executive Summary

The first efforts to study the impact of Alzheimer’s disease and related dementias on Alabamians began in the early 1990s when the Dementia Education and Training Act (DETA) was passed. Funded by the Education Trust Fund, DETA’s charge was to encourage state and local agencies to work with health care providers to improve services to individuals with Alzheimer’s disease and related dementias and their caregivers, and to provide statewide dementia education and training for caregivers, professionals and members of the general public.

In the ensuing years, it has been noted that there continues to be a rapid increase in the incidence of the disease, causing a tremendous social and economic impact on the citizens of Alabama. It has also been noted that there are an inadequate number of service delivery options and health care professionals who specialize in treating the aging population.

As a result of these and other factors, the Alabama Alzheimer’s Disease Task Force was created by House Joint Resolution 433 on May 2012. It was charged to address the following issues:

- Assess the impact of Alzheimer’s disease and other related dementias on Alabamians
- Examine the service delivery system including health care manpower and resources for those Alabamians with Alzheimer’s disease and other related dementias disease
- Develop strategies to respond to the crisis caused by Alzheimer’s disease and other related dementias.

The membership of the task force included clinical and administrative professionals from public and private health care organizations, representatives from state agencies, and individuals and family members directly affected by Alzheimer’s disease and other related dementias. The findings and recommendations are included in the form of this State Plan for Alzheimer’s Disease and Other Related Dementias in Alabama to be submitted to the Governor and the Legislature. The work was accomplished by established workgroups in the following categories:

- Public Feedback
- Policy Response
- Public Safety
- Alzheimer’s Disease Prevention, Training and Research
- Facility-Based Care
- Community-Based Services

The detailed work of these groups is found in the body of this plan. The task force recommendations are presented in four areas:

- Service Delivery System
- Education
- Certification
- Financial

# Executive Summary

## Background on Alabama's Alzheimer's Disease Task Force

### Purpose

The Alzheimer's Disease Task Force was created by House Joint Resolution 433 in May 2012 to:

- Assess the current and future impact of Alzheimer's disease and other related dementias on the residents of Alabama
- Examine the existing long-term care industries, services, health care manpower, and resources addressing the needs of individuals with Alzheimer's and other related dementias, their families and caregivers
- Develop a strategy to mobilize a state response to the crisis produced by Alzheimer's disease and other related dementias

The task force was instructed to submit its findings and recommendations to the Governor and Legislature in the form of a State Plan for Alzheimer's Disease and Other Related Dementias in Alabama. The timeframe for submission was extended to April 2015 (10<sup>th</sup> Legislature). The accompanying report and recommendations represent the final product of the task force's efforts.

### Context

- Research and technological advances in the health care industry, coupled with public health efforts to promote widespread adoption of healthier lifestyles has resulted in a significant increase in the number of Alabamians who survive into old age. The greatest risk factor for Alzheimer's disease is age. There has been a corresponding increase in the incidence of this disease in the state's population, particularly within the past two decades.

Between 1990 and 1999, the Alabama Legislature made initial efforts to study the impact of Alzheimer's disease on the state's population, and to encourage state and local agencies to work with health care providers to improve services to individuals with Alzheimer's disease and their caregivers. One product of these efforts was the creation of the Dementia Education and Training Act (DETA) in 1993. This legislation provided for an appropriation from the Educational Trust Fund for statewide dementia education and training for caregivers, professionals and members of the general public.

A number of widely divergent factors have led to the realization that development and implementation of a State Plan for Alzheimer's Disease and Other Related Dementias in Alabama is not only possible, but necessary. These factors include:

# Executive Summary

- The rapid increase in the number of Alabamians affected by Alzheimer’s disease and other related dementias
- The tremendous social and economic impact of Alzheimer’s disease and other related dementias on Alabamians
- Deficits in the numbers of health care professionals who specialize in treating populations typically affected by Alzheimer’s disease and other related dementias
- Broad changes in Medicare and other third-party funding occurring as a result of the Affordable Care Act, as well as efforts within Alabama to shift the state’s Medicaid reimbursement system from a fee-for-service to a managed care model
- Technological advances that allow access to educational and training information as well as technical support and direct health care services by virtually every citizen of the state

## Description

Appointees to the task force included clinical and administrative representatives from a broad variety of public and private health care organizations, representatives of state agencies that administrate and provide Alzheimer’s disease and other related dementias services to the public, and individuals and family members directly affected. Please see Appendix A for a full listing of the representatives of groups who participated in the work of the task force.

The task force was charged with examining:

- Changing populations of individuals with Alzheimer’s disease and other related dementias
- The state role in long-term care, family caregiver support, and assistance to persons with early-stage and early onset of Alzheimer's disease and other related dementias
- The state policy regarding persons with Alzheimer's disease and other related dementias
- Type, cost and availability of dementia services
- Dementia-specific training requirements for long-term care staff
- Quality care measures for residential care facilities
- Capacity of public safety and law enforcement to respond to persons with Alzheimer's disease and other related dementias
- Availability of home-based and community-based resources for persons with Alzheimer's disease and other related dementias, and respite care to assist families
- Inventory of long-term care dementia care units for persons with significant behavioral problems
- Adequacy and appropriateness of geriatric-psychiatric units for persons with behavior disorders associated with Alzheimer's disease and other related dementias

# Executive Summary

- Adequacy of community hospitals to provide appropriate health services to persons with Alzheimer's disease and other related dementias
- Adequacy of the probate system to approve and monitor guardians for persons with Alzheimer's disease and other related dementias
- Adequacy of existing resources within the criminal justice system to protect the civil and financial rights of persons with Alzheimer's disease and other related dementias
- Availability of appropriate resources for persons under the age of 60 with dementia
- Availability of memory screening service for early detection and treatment
- Availability of Alzheimer's disease and other related prevention programs
- Assisted living residential options for persons with Alzheimer's disease and other related dementias
- State support of Alzheimer's disease and other related dementias research through universities and other resources
- Health care disparities for minority populations with Alzheimer's disease and other related dementias
- Needed state policies, responses and/or directions for the provision of clear and coordinated services and supports to persons and families affected by Alzheimer's disease and other related dementias, and strategies to address any identified gaps in services
- The level of integration of efforts by responsible state and county agencies to address current and future challenges to good care, including the state universities' capacity to produce critical health care professionals

The task force responsibilities included:

- Hold public meetings and utilize technological means to gather feedback on the recommendations from the general public, as well as individuals and families affected by Alzheimer's disease and other related dementias
- Submit its findings and recommendations to the Governor and the Legislature in the form of a State Plan for Alzheimer's Disease and Other Related Dementias in Alabama no later than April 2015, at which time the task force shall terminate

## Organization

The task force met five times between June 2013 and February 2015. The work of the task force was accomplished by dividing responsibilities across six separate workgroups. These workgroups were charged with gathering the information defined by House Joint Resolution 433 and develop recommendations based on the information. Initial reports and recommendations were subsequently reviewed by the entire task force and consolidated into the final report.

Each workgroup focused on several broad topics:

- Alzheimer's Disease Prevention, Training and Research
- Community-Based Services

- Facility-Based Care
- Public Safety
- Current State Services and State Policy Response
- Public Feedback

## **Service Delivery System**

- The Alabama Department of Mental Health, through its DETA office, should be designated to facilitate and coordinate a service delivery system. The Alabama legislature passed the Dementia Education & Training Act (DETA) to develop an educational program and an array of services concerning Alzheimer's disease and other related dementias for caregivers. Through education, the DETA Program encourages community-based services for persons with Alzheimer's disease and other related dementias. DETA trains family caregivers and professionals in existing community programs and agencies about dementia to ensure persons with dementia live with dignity, independence, and respect. This office should assist in coordinating efforts among the state agencies that service those affected by Alzheimer's disease and other related dementias to build and identify components of the existing system of care and recommend needed components for a comprehensive continuum of care.
- Ways to support and expand existing community-based services should be explored to include the development of partnerships with community-based organizations that assist families who choose to care for their loved one at home.
- Respite and adult day care should be a component within the continuum of care.
- Regulatory barriers that restrict the use of specialized facilities and that prevent or limit use of day facilities for respite and adult day care services should be removed.
- Innovative, non-pharmacologic, person-centered approaches for behavioral management in long-term care facilities (such as those which employ creativity and the arts) should be developed, studied and implemented.
- There should be legislative action to charge the Alabama Department of Public Health to amend the Rules of the State Board of Health for Nursing Facilities, Chapter 420-5-10, to determine the staffing and other services necessary to define an Alzheimer's/dementia specialty care unit in any licensed nursing home.
- All nursing home employees who provide direct patient care should be required by legislative action to successfully complete a DETA training course in the understanding of dementia and care of persons with dementia.
- Telehealth in nursing homes and community care settings should be encouraged and reimbursed by insurance companies or other third party payers to provide support in underserved areas.



## Education

- The DETA program should be a primary point of contact for information, education, referral, and public information for Alzheimer’s disease and other related dementias.
- Financial support from the state budget for DETA should be increased in order to meet the growing demands for education and training of caregivers and health care professionals.
- DETA would be updated on services or new programs developed by all agencies throughout the state. The DETA website [www.alzbrain.org](http://www.alzbrain.org) will have links to all agencies. Each agency is responsible for providing and updating their information.
- All appropriate hospital, emergency medical, law enforcement, home health, hospice, nursing home and other long-term care staff should have initial or updated training through the DETA program or can be directed to online training.

DETA needs more certified dementia trainers; therefore, we need to find persons who are capable of doing Alzheimer training. The budget would need to be increased for reimbursement to these individuals.

- The DETA website should be expanded to include a centralized portal for educational resources and online programs, including information regarding Alzheimer’s disease and other related dementias prevention through diet, exercise, management of chronic illnesses like diabetes, hypertension, cessation of smoking, social engagement and other lifestyle modifications.
- DETA information needs to be updated and a host for the [www.alzbrain.org](http://www.alzbrain.org) website identified.
- Students in health care majors as well as professionals within state universities should be encouraged to pursue careers in geriatric care.

## Certification

- Accrediting agencies should, working with DETA, make Continuous Medical Education (CME) and Continuous Educational Units (CEU’s) available for online completion of courses offered through DETA’s website.
- The Alabama Department of Public Health should be required by legislative action to certify all Alzheimer’s/dementia specialty care units in licensed nursing facilities which meet the requirements under the amended Rules of the Alabama State Board of Health for Nursing Facilities.
- The frequency of surveys (inspections) for Specialty Care Assisted Living Facilities (SCALFs) by the Alabama Department of Public Health should be increased to an annual survey to encourage patient care in an environment that best meets their needs.

- The legislature should provide additional funding to the Alabama Department of Public Health to allow for increased staff to accomplish annual inspection of all SCALFs.
- Cost effective ways to certify adult day care centers should be developed.

## **Financial**

- Certification of adult day care centers should offer opportunities for financial coverage under private long-term care insurance standards.
- Opportunities should be explored through Medicaid to fund adult day care.
- A previously approved Medicaid waiver for SCALFs should be fully funded and expanded by increasing the number of slots available.
- Medicaid should provide an increase in per diem reimbursement for residents in certified dementia care units in nursing homes.
- Increase funding for DETA in the state budget for additional labor and supplies.

The implementation of the recommendations included in this plan represents the beginning of developing a robust continuum of care for Alabamians with Alzheimer’s disease and other related dementias and their families. An ideal continuum of care would offer these individuals an opportunity to reside in the least restrictive, least expensive and most dignified environment for as long as possible, while supporting their families through the issues involved with the disease.

# **Alzheimer’s Disease in Alabama**

Alzheimer’s disease, which is a syndrome characterized by deterioration in cognitive function of such severity to impair activities of daily living, is the most common cause of dementia. Alzheimer’s disease most often affects the brains of older people. Alabamians, as a group, are getting older.

- In 2013, 721,166 Alabamians were aged 65 or older. By 2050, this number is projected to increase by 77 percent to 1,240,000 individuals.
- In 2013, 81,976 Alabamians were aged 85 or older. This number is projected to increase by 224 percent to 283,000 Alabamians by the year 2050.
- One in nine older Americans has Alzheimer’s disease.
- One-third of all seniors who die in a given year have been diagnosed with Alzheimer’s or other related dementia.

### **Alabamians and Alzheimer’s disease**

- In 2013, 86,000 Alabamians had Alzheimer’s disease. By 2020, this number is projected to increase by 12 percent, to 96,000. By 2025, this numbers is projected to increase by 28% to 110,000.
- In Alabama, 12% of seniors have Alzheimer’s disease.

### **Alzheimer’s disease is a deadly illness**

- In 2013, (Brandi) Alzheimer’s disease ranked as the 6<sup>th</sup> leading cause of mortality in Alabama, accounting for nearly 1,523 deaths, which is a 70% increase in Alabama deaths since 2000. Out of the top 10 causes of death in the U.S., Alzheimer’s disease is the only one that cannot be prevented, treated or even slowed down.
- Per 2010 statistics, the Alzheimer’s disease death rate among Alabamians is significantly higher than the U.S. rate. The death rate is 27 percent per 100,000 in the U.S. and 31.8 percent per 100,000 in Alabama.

### **The Social and Economic Costs of Alzheimer’s disease are high**

- In 2013 in Alabama, 299,000 caregivers, usually family members, provided 341,000,000 hours of unpaid care at a cost of \$4,240,000,000.
- The cost of care to Medicaid recipients with Alzheimer’s disease as a primary or secondary diagnosis averages \$146,160 annually.

## **Alzheimer’s Disease Task Force Workgroups**

### **1. Alzheimer’s Disease Prevention, Training And Research Workgroup**

**Chair:** Dr. Daniel Potts

**Members:** DETA (Dr. Timothy Stone, Anne Mathis, Phillis Myers)

- Availability of dementia prevention programs
- State support of AD research through universities and other resources
- Dementia-specific training requirements for long-term care staff
- State university's capacity to produce critical healthcare professionals

### **2. Community-Based Services Workgroup (Home and Community Health)**

**Chair:** Miller Piggott

**Members:** Frank Holden, Gayle Boswell, Nancy McLain, Elaine Brackin, Brandi Medina, Kay

Jones, Anna Pritchett, Doris Ball, Sue Brantley

- Availability of respite care to assist families of persons with dementias such as AD
- Assisted living residential options for persons with dementia
- Quality care measures for residential care providers

### **3. Facility-Based Care Workgroup (Hospitals, Residential Care Facilities, Nursing Care Facilities, and Institutions)**

**Chair:** Dr. Tom Geary

**Members:** Beverly White, Dr. Sabin Sebastian, Kim Justice, Dr. Tom Geary, Bobby Stephenson, Clare Hays, Virginia Moore-Bell

- Adequacy of community hospitals to provide appropriate health services to persons with dementia
- Number of long-term care dementia care units for persons with significant behavioral problems
- Adequacy and appropriateness of geriatric psychiatry units for persons with behavior disorders associated with AD and related dementias

### **4. Public Safety - Legal Workgroup**

**Chair:** Chanda Crutcher

**Members:**

Capacity of public safety and law enforcement to respond to persons with dementias such as Alzheimer's disease

- Adequacy of probate system to approve and monitor guardians for persons with dementia
- Adequacy of existing resources within the criminal justice system to protect the civil and financial rights of persons with dementia

### **5. Current State Services + State Policy Response Workgroup**

**Chair:** Frank Holden

**Members:** Miller Piggott, Dr. Robert Moon, Anna Pritchett, Virginia Moore Bell, Doris Ball

- State role in long-term care, family, and caregiver support
- State role in assistance to persons with early diagnosis state and early onset AD
- Examine the level of integration of efforts by responsible state and county agencies to address current and future challenges to good care
- Strategies to identify gaps in services
- Directions for provision of clear and coordinated services and supports to persons and families living with dementias like AD

### **6. Public Feedback Workgroup**

**Chair:** Brandi Medina

**Members:** Chanda Crutcher, Bobby Stephenson, Anna Pritchett  
Hold public meetings (town meetings) and use technological means (such as webcasts) to gather feedback on the recommendations from the general public, and persons and families affected by AD

## Alzheimer’s Disease Task Force Reports

### Public Feedback Workgroup

#### Task

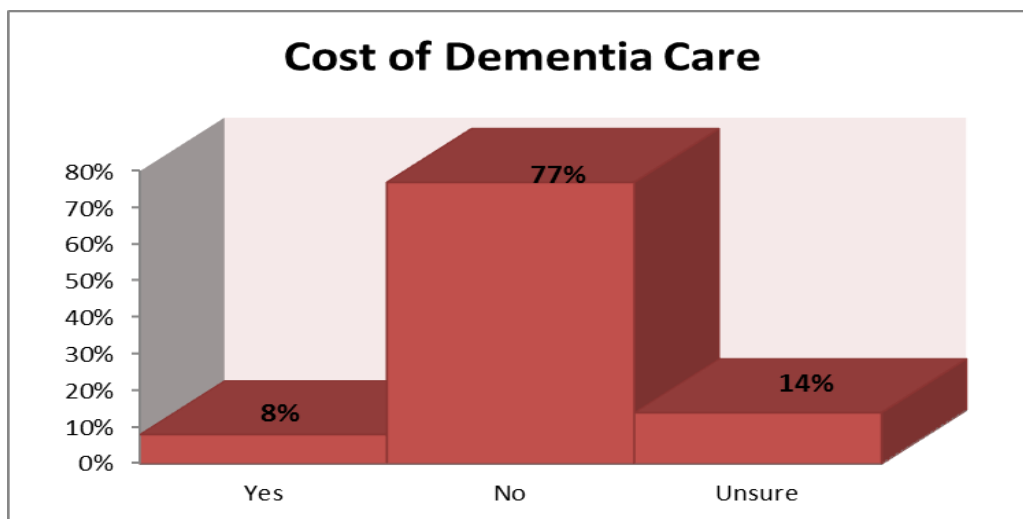
- Use state-wide town hall meetings and online surveys to determine public perception of current quality and accessibility of Alzheimer’s disease and other related dementias services in Alabama

#### Public Survey

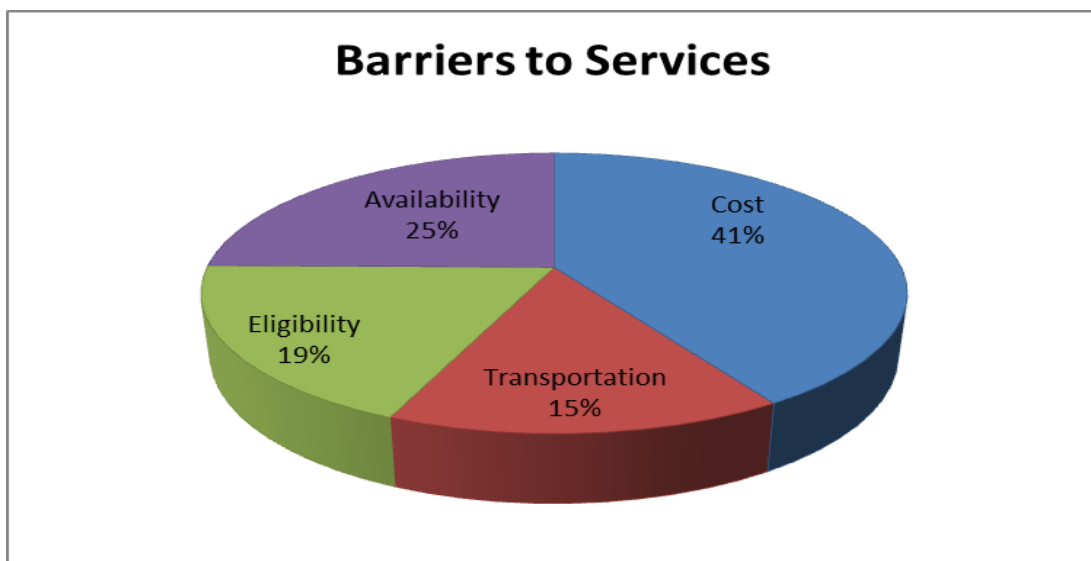
The workgroup created and administered a survey to determine, in a quantitative manner, the public perception regarding quality and accessibility of Alzheimer’s disease and other related dementias services in Alabama. Please see Appendix B for the survey from this workgroup.

#### Sample Questions & Answers:

- **Do you feel that the cost of dementia care services in Alabama is reasonable?**  
*Most families are unable to afford dementia services “out of pocket,” particularly in regards to paying for assisted living or caring for their loved one in their homes, both of which are not reimbursed, in large part, by third party payers, Medicare and Medicaid.*



- **What is your perception of how our state universities are doing in terms of helping fight the burden of Alzheimer’s disease, both in terms of research, caregiver support, professional training, and producing critical health care professionals?**
  - *Universities should be doing more in all areas*
  - *Need to increase funding to the Dementia Education and Training Act (DETA)*
  - *Train more physicians to care for individuals with Alzheimer’s disease and other related dementias*
  - *More research is needed*
  - *More geriatric specialists are needed*
- **What barriers prevent you from receiving the services you need?**



### Town Hall Meetings

The workgroup held 12 town hall meetings throughout the state, in which 342 individuals participated. Online survey was open to the public during the month of August 2014, in which there were 79 completed online surveys. Of this number, 40 percent were family caregivers and 60 percent were health care professionals. The purpose of the town hall meetings was to gather qualitative and descriptive information regarding the public perception of Alzheimer’s disease and other related dementias services in Alabama.

Key concerns identified in the town hall meetings included:

- The need for a statewide clearinghouse of Alzheimer’s disease and other related dementias information (educational information, links to information about available services in every part of our state, training information, etc.) for professionals and for the general public
- The need for easily accessible, high quality, up-to-date Alzheimer’s disease and other related dementias specific training for family members, first responders, nursing home and assisted living staff, as well as a variety of other health care professions

- The need for increased numbers of trained geriatric professionals
- The need to develop innovative funding programs that will allow family members to care for their loved ones in their homes, as an alternative to nursing home placement

## **Policy Response Workgroup**

### **Tasks**

- Gather all available information to determine:
  - State role in long-term care, family and caregiver support
  - State role in assistance to individuals with early diagnosis and early onset of Alzheimer’s disease and other related dementias
- Examine the following:
  - The level of integration of efforts by responsible state and county agencies to address current and future challenges to good care
  - Strategies to identify gaps in service
  - Directions for provision of clear and coordinated services and supports to persons and families affected by Alzheimer’s disease and other related dementias

### **Findings**

- There is no state policy supporting individuals or caregivers dealing with Alzheimer’s disease and other related dementias
- There are virtually no state-supported programs specifically designed for individuals with Alzheimer’s and other related dementias. Programs that do exist are community based, faith based, or academically driven and private pay.
- While state agencies may provide services to individuals with Alzheimer’s disease and other related dementias, they qualified for these services based on other criteria.
- Programs like Alzheimer’s of Central Alabama and other regional Alzheimer’s support groups, the Alzheimer’s Disease Research Center, adult day care and respite care are largely ad-hoc, community based and not widely publicized.
- There are 87 Specialty Care Assisted Living Facilities (SCALFs) that are specifically designed and licensed to provide care for seniors with dementia. SCALFs account for 2,475 residential assisted living units. All assisted living care is private pay.
- Skilled nursing facilities (nursing homes) provide some dementia care. There are 56 nursing homes with designated Alzheimer’s disease units. Medicaid is available for qualifying applicants.
- DETA provides training for professional caregivers and others. Assisted living administrators, nurses and care staff are required by regulation to have DETA training prior to resident contact.

- The Alabama Department of Mental Health’s Mary Starke Harper Geriatric Psychiatry Center provides inpatient geriatric psychiatric care. Approximately half the patients at the Harper Center have Alzheimer’s disease or other related dementias with behavioral disturbances.
- The Alabama Department of Public Health collects statistical data on Alzheimer’s disease deaths.
- The Alabama Department of Rehabilitation does not provide services specifically for individuals with Alzheimer’s disease and other related dementias. The Independent Living program and waiver may serve some individuals with Alzheimer’s disease and other related dementias who otherwise meet the program criteria.
- The Alabama Department of Human Resources provides adult protective services to elderly and disabled adults at risk of neglect, abuse and exploitation. Case management, adult day care, adult foster care, emergency shelter, and other services are designed to prevent or remedy abuse. The department does not specifically provide care for individuals with Alzheimer’s disease and other related dementias or their families.
- The Alabama Medicaid Agency pays for long-term care services for persons with disabilities or needs requiring around the clock nursing care in nursing homes, but does not have any specific programs for individuals with Alzheimer’s disease and other related dementias. Clients in Medicaid must meet income eligibility and other requirements. Medicaid does capture some statistics for clients who have secondary diagnosis of Alzheimer’s disease.

## **Recommendations**

1. Designate single source of information, education, and referral for families and caregivers. Since DETA is already the only unified training resource specifically attuned to Alzheimer’s disease and other related dementias, it would seem likely that DETA could be redirected to provide single-source point of contact for education and public information. This likely would require additional funding for DETA, but would be much less costly than starting a new agency.
2. Promote respite and adult day care services by including adult day care in the continuum of care policy. Develop a resource list of adult day care services.
3. Remove regulatory barriers to skilled nursing facilities and SCALFs that prevent/limit use of day facilities for respite and adult day care.
4. Look at ways to extend Medicaid to cover adult day care services, in addition to existing waiver programs, and explore previously approved Medicaid waiver for SCALF level assisted living.



## Public Safety Workgroup

### Tasks

- Evaluate the following:
  - The capacity of public safety and law enforcement to respond to persons with Alzheimer's disease and other related dementias
  - The adequacy of the probate system to approve and monitor guardians for persons with dementia
  - The adequacy of existing resources within the criminal justice system to protect the civil and financial rights of persons with dementia

### Findings

- Currently there is no specific training that focuses on working with individuals with Alzheimer's disease and other related dementias for public safety employees or law enforcement. This definitely has a negative impact on their capacity to respond. It is recommended that training opportunities be provided to this group through expansion of the DETA program.
- The Alabama Department of Public Safety has implemented Project LifeSaver, a tracking program for persons who have cognitive impairment and wandering tendencies. The program is available in most counties of the state through the sheriff's office.
- The progressive driving impairment caused by Alzheimer's disease and other related dementias is well documented in current literature, and is a significant threat to public safety. Accurate assessment of driving and prediction of degree of impairment can be a difficult task. The determination to restrict driving should be made by a healthcare provider. Legislative action is necessary to require physicians and other licensed professions who are involved in the care of persons with dementia to report suspected impairment in the ability to drive to the State Department of Public Safety. The evaluation of capacity to drive should be based, in part, upon objective assessment. Such assessments can be performed by some physical and occupational therapists and rehabilitation facilities. These assessments currently must be paid for out-of-pocket. It is recommended that advocacy efforts be supported to have such assessments covered by third party payers.
- Legislation is needed for Alzheimer's disease victims who try to buy guns. If an Alzheimer's disease patient wants to buy a gun, he/she can't be stopped if they don't have some criminal record. This poses a threat to caregivers when the patient no longer recognizes friends and family and/or becomes frustrated with the caregiver who is now managing their money and taking away their perceived independence. After a diagnosis, the doctor needs to document. The doctor should also send a letter to police department to do a driving assessment for this person.
- The Alabama Department of Human Resources (DHR) has statutory authority to receive and investigate reports of adults who are suspected of being abused, neglected, or

exploited and arranging protective services. DHR received 6,149 referrals of adult abuse, neglect, and exploitation in FY 2013 and 6,720 referrals in FY 2014. It is estimated that approximately 70% of those referrals involved persons with dementia. DHR files petitions to arrange protection when there is immediate danger to health or safety and the person is unable to protect themselves. These emergency services may include treatment, evaluation, placement, preservation of assets, or other protective services. In addition, when the person is unable to protect themselves and has no one who can protect them, DHR may petition for authority to arrange protective services, placement, and appointment of a guardian or conservator.

- The Adult Protective Services Act provides penalties for abuse, neglect, and exploitation of adults in need of protective services. The Protecting Alabama's Elders Act provides penalties for abuse, neglect, and exploitation of persons age 60 and older.
- The number of elderly individuals who are being victimized financially through technological means, such as scams via the internet, has increased significantly in recent years.
- There is a lack of identified individuals willing to serve as guardians and conservators for incapacitated persons. Few counties have county guardians and conservators. While the law provides for a general conservator or sheriff for the county to be appointed as conservator when no other person applies for appointment and qualifies, few sheriff's offices are equipped to do so. Although there are a few volunteer guardianship programs in the state, guardians through these programs do not generally handle financial affairs.

## **Recommendations**

1. *Develop dementia training programs for all first responders, including Adult Protective Services staff and law enforcement staff, to enable them to better assess individual's capacity to protect themselves*
2. *Strengthen the judicial system's ability to monitor guardians and conservator once appointed.*
3. *Develop means of recruiting qualified persons to serve as guardians and conservators*
4. *Develop dementia specific training especially for guardians and conservators as well as training related to the powers, duties, and responsibilities of guardians and conservators.*
5. *Project Lifesaver programs should be available in all counties.*
6. *Develop training for law enforcement and public safety employees on Alzheimer's disease and buying of guns.*

## **Alzheimer's Disease Prevention, Training, and Research Workgroup**

### **Tasks**

- To evaluate:
  - Availability of dementia prevention programs

- State support of Alzheimer’s disease and other related dementias research through universities and other resources
- Dementia-specific training requirements for long-term care staff
- State universities’ capacity to produce critical health care professionals

## Findings

### *Availability of Dementia Prevention Programs*

- General resources focusing on dementia prevention are readily available on the internet. Websites that provide information about dementia prevention include:
  - [www.alzbrain.org](http://www.alzbrain.org)
  - [www.webmd.com](http://www.webmd.com)
  - [www.prevention.com](http://www.prevention.com)
  - [www.alz.org](http://www.alz.org)
  - [www.alzfdn.org](http://www.alzfdn.org)
  - [www.alzprevention.org](http://www.alzprevention.org)
  - [www.alzheimersprevention.org](http://www.alzheimersprevention.org)
  - [www.usatoday.com](http://www.usatoday.com)
  - [www.helpguide.org](http://www.helpguide.org)
  - [www.mayoclinic.org](http://www.mayoclinic.org)
  - [www.alzca.org](http://www.alzca.org)
  - [www.wesharethecare.org](http://www.wesharethecare.org)
  - [www.alzheimersers.org](http://www.alzheimersers.org)
  - [www.mhainmc.net](http://www.mhainmc.net)
  
- Internet resources that focus specifically on the needs of Alabama’s citizens in regards to dementia are available. The website, [www.alzbrain.org](http://www.alzbrain.org), was created by DETA to focus specifically on the needs of our state citizens to includes information on dementia prevention for family and physicians, SCALF training material (psychotropic medication booklet and managing behavioral symptoms for Alzheimer’s disease booklet), family guides and facts sheets on Alzheimer’s and other related dementias, and a Healthy Hospital program for physicians and caregivers. Currently, this website’s information is in need of updating.
  
- Programs that frame early detection, treatment, and lifestyle modifications in the context of dementia prevention, and that actively and broadly engage Alabama health care providers and state residents are lacking.
  
- Determining the degree that state support has played in advancing Alzheimer’s research is extremely difficult due to the complex nature of state, federal and private funding streams to Alabama’s academic institutions. However, it is clear that these institutions are committed to the work of significant and ongoing dementia research and that these efforts must continue if the state is to ultimately reduce the massive physical, social and fiscal costs associated with these illnesses.

### *Dementia specific training requirements for long-term care staff*

- SCALFs:
  - Registered nurses and unit coordinators must complete specific DETA training resources or equivalent training approved by the state health officer
  - All staff having contact with patients must complete the DETA Brain Series training
- Nursing homes:
  - Certified nursing assistants must complete the CMS Hand in Hand Toolkit training module
  - There are no dementia-specific training requirements for other professional staff in nursing care facilities
- Considering all of the treatment settings in which individuals with dementia receive services and all of the professionals and caregivers who provide those services, there are significant gaps in training requirements for long-term care staff, as well as first responders, emergency department personnel, nursing staff on hospital wards and intensive care units, etc.

### *State universities' capacity to produce critical health care professionals*

- Education of lay and professional caregivers, as well as physicians and other providers regarding Alzheimer's disease prevention, early detection and treatment, behavioral management, psychosocial support and caregiver resources is of paramount importance.
- Continued support of our state universities in their mission of Alzheimer's disease and other related dementias research, education and training is crucial. State financial support for DETA should continue and be increased if we are to meet growing demands for education and training of caregivers and health care professionals.

### *Supporting universities in their research, education and training efforts*

- There are significant deficits in the numbers of trained geriatric primary care and geriatric specialty providers in Alabama. Causes for these deficits include:
  - Professional and economic disincentives that serve as barriers to professionals adopting geriatric health care-focused career paths
  - Difficulties, either real or presumed, associated with meeting the health care needs of Alabama's underserved populations (rural, indigent), of whom geriatric patients represent a significant number

## **Recommendations**

1. The state should encourage students pursuing degrees in a healthcare field to focus their studies in geriatrics, by raising awareness of resources available to such students.
2. Efforts should be supported within our state universities to encourage professionals to pursue careers in geriatric health care education in order to increase the access of healthcare students to geriatric oriented training programs

3. Expand the DETA website and develop it into a centralized portal to make educational and support resources available for all stakeholders, including lay caregivers, long-term care staff, first responders and emergency personnel, nursing staff in hospitals, physicians and other providers. It should make use of webinars, podcasts, SlideShare and other technologies for the dissemination of information. Work with accrediting agencies to make CME and CEU's available for successful completion of online educational programs.

DETA needs staff to develop educational and support resources for first responders and emergency personnel. DETA also needs someone who is knowledgeable of webinars, podcasts, SlideShare and other technologies for the dissemination of information.

4. Explore Telehealth as a means to provide education and support to Alabama's underserved regions, and collaborate with state centers of higher education, the Alabama Partnership for Telehealth, the Alabama Department of Public Health, Alabama Medicaid Agency and other stakeholders.
5. Support collaboration between entities in developing and researching innovative, non-pharmacologic, person-centered approaches for behavioral management (such as those which employ creativity and the arts) in our state's dementia care facilities.

## Facility-Based Care Workgroup

### Tasks

- To evaluate:
  - Adequacy of community hospitals to provide appropriate health services to persons with Alzheimer's disease and other related dementias
  - Number of long-term, dementia care units for persons with significant behavioral problems
  - Adequacy and appropriateness of geriatric psychiatry units for individuals with behavior disorders associated with Alzheimer's disease and other related dementias

### Findings

- Specialized care for younger people with dementia:
  - Inpatient care at the Alabama Department of Mental Health's Mary Starke Harper Geriatric Psychiatry Center is available only for those ages 65 and over
- Residential facility placement for those over age 65:
  - This is problematic if the patient does not have a family that can provide care in the home and they do not have medical problems in addition to dementia such that they qualify for nursing home placement
  - Lack of a requirement for and availability of standardized training for all staff in dementia care, especially in Alzheimer's disease specialty care units

- Geriatric psychiatry inpatient unit care is not well aligned with nursing home care:
  - A prerequisite for Medicare and insurance reimbursement is medication management. This is a disincentive for behavioral management
  - The second disincentive is the allowed length of stay, which is not long enough to develop and evaluate a behavioral management program

## Recommendations

1. Legislative action to provide additional funding for DETA with the goal on updating and upgrading the dementia training for all hospital and nursing home staff.

DETA needs a clinical/medical staff person to develop and update information for training hospital and nursing home staff.

2. There should be legislative action to instruct the Alabama Department of Public Health to amend the Rules of the State Board of Health for Nursing Facilities, Chapter 420-5-10, to determine the staffing and other services necessary to define an Alzheimer's/dementia specialty care unit in any licensed nursing home.
3. All nursing home employees who provide direct patient care should be required by legislative action to successfully complete a DETA training course in the understanding of dementia and care of persons with dementia.

DETA needs additional certified trainers and increase in budget to implement this training around the state.

4. The Alabama Department of Public Health should be required by legislative action to certify all Alzheimer's/dementia specialty care units in licensed nursing facilities which meet the requirements under the amended Rules of the Alabama State Board of Health for Nursing Facilities.
5. Medicaid should provide an increase in per diem reimbursement for residents in certified dementia care units in nursing homes.
6. The frequency of surveys (inspections) for Specialty Care Assisted Living Facilities (SCALFs) by the Alabama Department of Public Health should be increased to an annual survey to encourage patient care in an environment that best meets their needs.
7. Encourage and reimburse telemedicine in the nursing home setting by Alabama Department of Mental Health psychiatry staff as well as other public and private geriatric psychiatry hospital staff to enhance the dementia care in referring nursing homes pre- and post-discharge.
8. Provide state only Medicaid funding for a waiver program for community placement of those dementia patients who need extensive observation and assistance but do not meet federal Medicaid nursing home admission criteria.

# Community-Based Services Workgroup

## Tasks

- To evaluate:
  - Availability of respite care to assist families of persons with Alzheimer's disease and other related dementias
  - Assisted living residential options for persons with Alzheimer's disease and other related dementias
  - Quality care measures for residential care providers

## Findings

- Home and community-based care is usually preferable to institutional care. However, community-based services for dementia patients are mostly private pay and cost prohibitive for many Alabama families. Family caregivers' access to services is restricted by affordability, availability, knowledge of services and lack of transportation.
- The current annual cost of dementia care nationwide is estimated to be \$209 billion ([www.alz.org/downloads/facts\\_figures\\_2013.pdf](http://www.alz.org/downloads/facts_figures_2013.pdf)), more than the cost of cancer care or heart disease care. The need for long-term care and community-based services is critical for dementia patients because of the nature and duration of the disease. Most patients require care for between four to eight years after a diagnosis.
- According to Genworth's 2013 Cost of Care Survey for community-based services in Alabama, a family can expect to pay:
  - \$36,608 annually for homemaker services or home health aides
  - \$6,500 annually for adult day care
  - \$31,200 for assisted living care
  - \$65,700 for nursing home (semi-private room)
- Dementia caregivers incurred \$9.1 billion in healthcare costs of their own (2012 data). Sixty percent reported high levels of stress and 33 percent reported symptoms of depression. The cost of Alzheimer's disease and other related dementias takes many forms including the employment impact for the caregiver and their family in terms of short-term impact on jobs, long-term effects on careers and reductions in savings for the future, particularly for retirement and college savings.
- For the purpose of this workgroup, home and community-based services include training the family caregiver, support groups, sitter and respite services, adult day care, home health care and assisted living care. These services are essential for family caregivers to prevent burnout and to allow the caregiver to perform essential functions. Individuals with Alzheimer's disease and other related dementias benefit from the socialization and structure often provided by these services. These services do not include the entire spectrum of patient services. Nursing home care and hospitalization are not included.

## Recommendations

1. Coordination of the state's Dementia Response System:
  - a. Dementia care requires a continuum of care. The continuum of care in Alabama is far from seamless. Funding, access and availability all work to create a fractured system. Because leadership is needed, one agency should be designated to craft the state's Dementia Response System.
  - b. There should be a coordinated effort by the state agencies that serve the elderly (elderly at least 60+, but preferably 55+ in order to account for early onset of dementia) to examine and identify the continuum of care currently offered through the state's programs and services. DETA could provide the leadership needed to map the state's dementia response system with adequate funding and resources. The Alabama Department of Human Resources, Alabama Department of Senior Services, Alabama Department of Public Health, Alabama Department of Mental Health and Alabama Medicaid Agency all have a stake in the Dementia Response System. Each agency should help identify challenges and gaps in the state's dementia continuum of care. The Dementia Response System should address the continuum of needs families have from education to community-based services to nursing care.
  
2. Foster relationships with community service providers:
  - a. By identifying community resources, the state can more effectively assist families in the community and delay more costly nursing home placement. Efforts should be made to foster and develop partnerships with community-based organizations whose services assist families who choose to care for their loved one at home. The Dementia Response System should explore ways to support and expand existing services and develop new community services that help families with home care.
  
3. Expand the Dementia Education Training Program:
  - a. A family's first line of defense when faced with a diagnosis of dementia is education. The Dementia Education Training Program should be revamped and revised by adding additional staff as needed, such as for updating materials, hosting website, training the trainers, etc. The model for the program has a proven track record and gives the state an opportunity to build on existing resources. Helping families learn the basics of care can improve quality of life for both caregivers and patients.
  - b. A refresher course with updates should be given to existing trainers. Many of the existing trainers have been active community Alzheimer's disease advocates and could offer suggestions and feedback about how to best use available resources to craft the states' Alzheimer's disease educational program. Additional trainers should be included in the network to provide community training and to ensure coverage across the state. The Brain Series training and other material developed by DETA continue to be relevant teaching tools.
  - c. DETA should work with local support group leaders, Alzheimer's disease advocates and others to develop a guide to explain Alzheimer's disease and other related dementias care, local services and eligibility requirements. Training and



resources like the Hand In Hand Program offered by the Alabama Quality Assurance Foundation and the Red Cross could be utilized. DETA trainers should be able to assist dementia caregivers seeking:

- i. Disease course and symptoms
  - ii. Where to go for diagnosis and care
  - iii. Services provided by the Alabama Department of Senior Services: Meals on Wheels, Alabama Cares, Senior Rx, etc.
  - iv. Basic legal and financial considerations
  - v. Research opportunities
  - vi. Support groups
  - vii. Community resources: home health, adult day care centers, assisted living facilities and specialty care assisted living, nursing homes
  - viii. Mental health services for patients with behavioral issues
  - ix. Veteran's benefits – must call local VA
  - x. Hospice care
  - xi. Protective services through the Department of Human Resources to prevent, detect, and remedy abuse, neglect, and exploitation
  - xii. Website links and contact numbers
4. Medicaid waiver slots should be expanded and fully funded:
- a. Community-based services provided by Medicaid waiver can prevent more costly institutionalization of patients and should be fully funded to include adult day care, respite and homemaker services. Currently the length of the application process is too long for some patients to actually receive services. Programs that offer personal choice options with funding that can be used to pay family member wages for providing care should be expanded.
5. Medicaid should be expanded to include funding for qualified persons receiving care at SCALFs:
- a. SCALF care is cost prohibitive for most Alabama families. This level of care is currently private pay. Medicaid funding of SCALF care would provide more options for patients who do not qualify for nursing home care, but who can no longer remain at home.
6. Increase the frequency of SCALF surveys annually by the Alabama Department of Public Health:
- a. Because of Alzheimer's disease progressive nature, ensuring patients are cared for in an environment that best meets their needs requires surveys every 12 to 18 months.
7. Improve access to adult day care services:
- a. Many counties, particularly in rural areas, do not offer adult day care services which are the most cost efficient way to provide respite care. Currently many private insurance companies do not recognize and reimburse for adult day care, because the state does not license this level of care. The Alabama Department of Public Health should work with the state's leaders to develop cost effective ways

to certify adult day care centers that will minimally impact cost, but fulfill private long term care insurance standards.

8. Provide availability for use of state-funded Medicaid waiver for community placement of those that did not meet nursing home criteria.

# Appendix A

## Members of the Alzheimer's Disease Task Force

Ball, Doris S.	Alabama Department of Human Resources
Bell-Shambley, Dr. Beverly	Alabama Department of Mental Health
Boswell, Gayle	Alabama Silver Haired Legislature
Brackin, Elaine	Alzheimer's Caregiver
Buckner, Nancy T.	Alabama Department of Human Resources
Crutcher, Chandra	Member-at-large
Figures, Senator Vivian Davis (Co-chair)	Alabama Senate
Geary, Dr. Walter	Alabama Department of Public Health
Hall, Representative Laura (Co-chair)	House of Representatives
Hays, Dr. Clare	UAB
Holden, Frank	Assisted Living Association of Alabama
Jones, Kay	Alzheimer's Resource Center
Justice, Kim	Alabama Department of Veterans Affairs
Kerr, Vicki	Caring Days Adult Day Care
King, Alan	Judge of Probate, Place 1, Jefferson County
Kinney, Dr. Cleveland	UAB Department of Psychiatry
McClain, Nancy	Autauga, Montgomery, Elmore Seniors, Inc.
McClendon, Senator Jim	Vice-Chair, Senate Health & Human Services Committee
Medina, Brandi	Alzheimer's Association of North Alabama
Miller, Julie	Alabama Department of Senior Services
Moore-Bell, Virginia	Alabama Department of Senior Services
Morrison, Neal	Alabama Department of Senior Services
Patterson, Ozenia	Alabama Medicaid Agency
Piggott, Miller	Alzheimer's of Central Alabama
Potts, Dr. Daniel	Cognitive Dynamics; Dementia Dynamics, LLC
Powers, Dr. Richard	Member-at-large
Pritchett, Anna Merrill	Alabama Association of Retired Persons
Reddoch, Jim	Alabama Department of Mental Health
Reed, Senator Greg	Senate Majority Leader
Sebastian, Dr. Sabin	Mary Starke Harper Geriatric Psychiatry Center, Alabama Department of Mental Health
Stephenson, Bobby	Schmidt Wallace Health Care Management Co.
Sutton, Kellie	Alzheimer's Foundation of the South
Waggoner, Senator Jabo	Chair, Senate Rules Committee
Wallace, Bill	Member-at-large
Wells, Carter	Hudson Alpha Institute for Biotechnology
White, Beverly	Mary Starke Harper Geriatric Psychiatry Center, Alabama Department of Mental Health

# Appendix B

## Public Feedback Workgroup's Survey

### Survey for the Alabama Alzheimer's Disease Task Force (created by Legislative Act 2012-597)

Link to the survey: <http://www.surveymonkey.com/s/T2DWNWK>.

1. Do you feel that the cost of dementia services is reasonable?
2. Do you feel that there are sufficient resources to aid patients and family members for persons under the age of 60 with dementia?
3. How do you feel our state universities are doing in terms of helping fight the burden of Alzheimer's disease, both in terms of research, care giver support, and training and producing critical health care professionals? Do you feel the state should provide support to universities for this purpose
4. Do you have an adequate awareness of preventive methods to reduce the likelihood of developing Alzheimer's disease and other dementias, and to promote brain health? Should the state support educational programs to improve awareness of Alzheimer's disease/dementia prevention and promotion of brain health?
5. What services is your patient receiving? (Check all that apply)

- Home health care
- Adult day care
- Volunteers
- Alabama Cares
- Meals on Wheels
- Veteran's benefits
- Medicaid waiver
- Assisted living
- Specialty care assisted living
- Nursing home
- Hospice

Other (please specify)

6. What barriers prevent you from receiving the services you need? (Check all that apply)

- Cost
- Transportation
- Eligibility
- Availability

Other (please specify)

7. Are there any of the following personnel at your local hospital? (Check all that apply)

\_\_\_\_\_ Geriatrician physician on staff

\_\_\_\_\_ Nurse or CRNP with a certificate of training in geriatric care

\_\_\_\_\_ A designated geriatric unit in the hospital

8. Does your community have inpatient care facilities available for treatment of people with dementia and significant or dangerous behavioral problems?
9. Does law enforcement in your community respond adequately when persons with Alzheimer's/dementia elope (wander) in a way that potentially exposes them to personal harm?
10. Is the probate system in your county adequate at approving and monitoring guardians for persons with dementia?
11. What role do you believe the state should play in long-term care, family and caregiver support?
12. What strategies would you use to identify gaps in services to the families and dementia patients?