



# STATE of MISSISSIPPI

## Strategic Plan for Alzheimer's Disease and Related Dementias

2015 — 2020



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# INTRODUCTION

The Mississippi State Strategic Plan to address Alzheimer’s Disease and Related Dementias is a collaborative project led by the Department of Mental Health, Division of Alzheimer’s Disease and Other Dementias; the Alzheimer’s Association Mississippi Chapter; and The MIND Center at the University of Mississippi Medical Center; in partnership with stakeholders from across the state including the Department of Human Services, Division of Aging and Adult Services; and the Department of Health, Office of Preventive Services; and other organizational stakeholder industries and occupations including long term care, hospice, clinical research, social work, nursing, public safety and pharmacy. The plan was developed in recognition of the enormous social, emotional, and economic impact of Alzheimer’s and the need to have a strategic plan to address the needs of individuals and families impacted by the disease in Mississippi. The term “Alzheimer’s” or “Alzheimer’s disease” used in this plan refers to Alzheimer’s disease and related disorders. Consistent with the definition used in the National Alzheimer’s plan, related disorders include frontotemporal, Lewy body, mixed, and vascular dementia.

State Government Alzheimer’s Disease Plans create an infrastructure and accountability necessary to build dementia-capable programs, services and systems for the growing number of people affected by Alzheimer’s disease and other dementias. The Mississippi State Plan will outline a comprehensive and inclusive strategy to plan for the current and impending issues facing the state by quantifying the number of individuals affected by Alzheimer’s and determining the level of services available and needed at all stages of the disease by patients, families and caregivers. Using this approach, Mississippi can address the Alzheimer’s epidemic with an integrated and cost-effective approach.

The Mississippi plan represents a major step forward in bringing together advocates, caregivers, and professionals from healthcare, education, and social services to identify ways to more effectively address current and future needs related to Alzheimer’s disease. Individuals with diverse backgrounds and areas of expertise converged to offer their energy and talents in the development of the plan. The plan identifies five goals, each with accompanying objectives and strategic priorities. Broadly speaking, the plan outlines actions to: increase awareness of and understanding about Alzheimer’s disease; bring focused attention to the quality of care and services for persons with Alzheimer’s disease while improving the capacity of Mississippi’s workforce to respond to the needs of persons with Alzheimer’s disease; strengthen support for caregivers; increase Mississippi’s capacity for Alzheimer’s disease-related research and data collection; and inform Mississippians about ways to promote or improve brain health.

## **Overview of Alzheimer’s disease**

Dementia is an umbrella term for diseases and conditions characterized by a decline in cognitive skills that affect a person’s activities of daily living. Dementia is caused by damage to nerve cells in the brain called neurons. The damage causes neurons to function improperly and they eventually may die. This in turn can lead to changes in memory and behavior and problems with reasoning and judgment.

The Diagnostic and Statistical Manual of Mental Disorders (DSM) is often utilized by physicians to define dementia. In 2013 the American Psychiatric Association released the fifth edition of the DSM-5 which incorporates dementia into the diagnostic categories of major and mild neurocognitive disorders. Major neurocognitive disorders are generally characterized by an individual having cognitive decline that interferes with everyday activities and that may require assistance. Mild neurocognitive disorders are evidenced by modest cognitive decline that does not interfere with everyday activities.

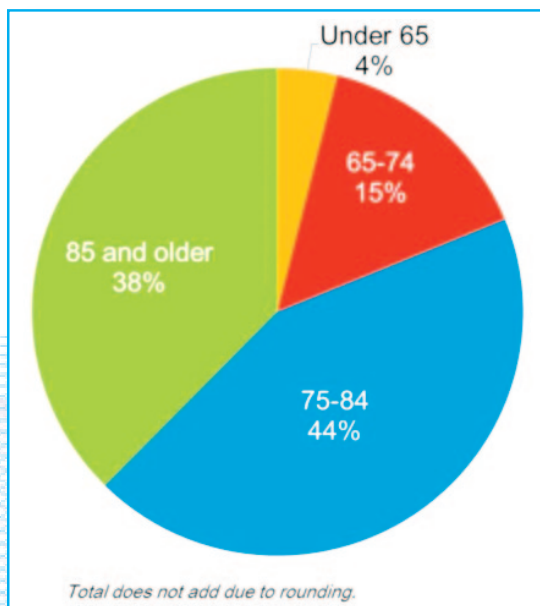
There are multiple types of dementia including, but not limited to, Alzheimer’s disease, vascular dementia, dementia with Lewy bodies, Frontotemporal lobar degeneration, mixed dementia and Parkinson’s disease. Each type of dementia is associated with distinct symptom patterns and brain abnormalities. Some conditions result in behaviors that mimic dementia but are in fact reversible if treated. Common causes are depression, thyroid problems, effects of medications and vitamin deficiencies.

Alzheimer’s disease is the most common form of dementia and accounts for an estimated 60% to 80% of cases. Eventually the person with Alzheimer’s disease will require complete care as their ability to carry out basic bodily functions such as walking and swallowing will be impaired. Alzheimer’s disease is ultimately fatal.

## Prevalence

The impact of Alzheimer’s disease is far-reaching. It is estimated that over five million Americans currently have the disease. While many cases of younger-onset Alzheimer’s disease exist (there are approximately 200,000 cases of persons under age 65 with the disease today), the majority of persons with the disease are aged 65 and over.

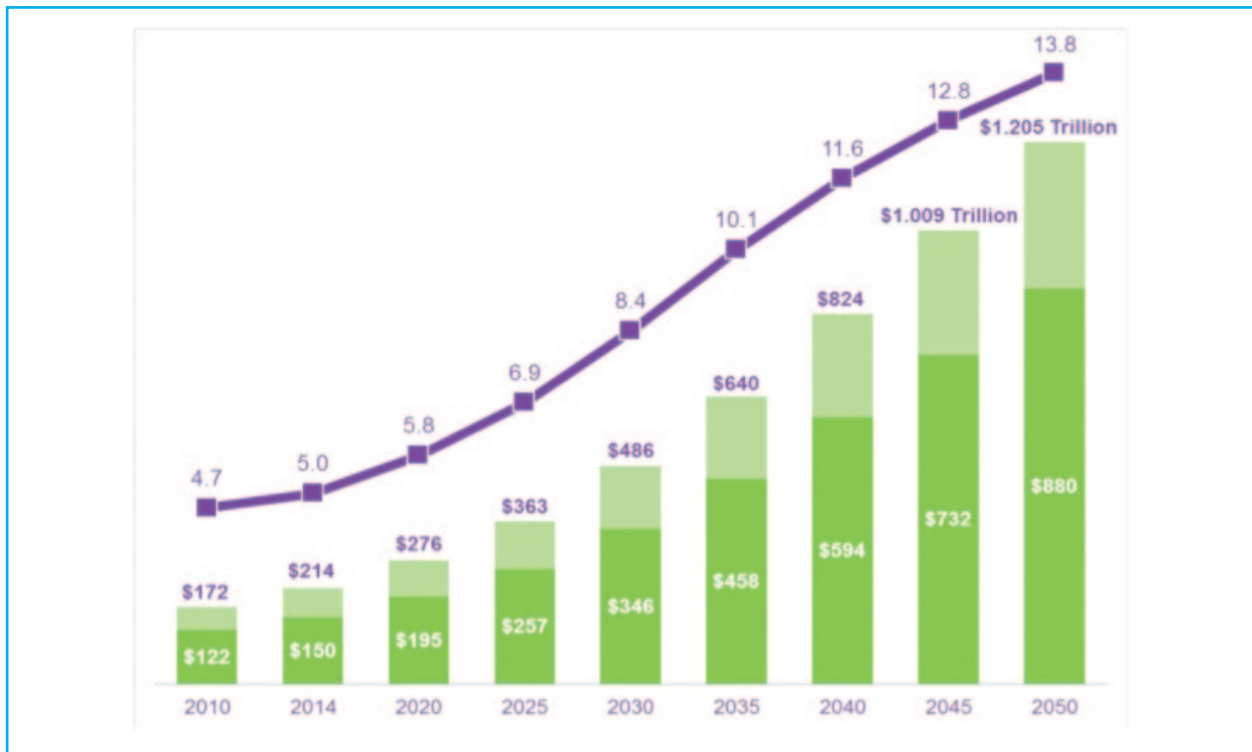
## 2014 Alzheimer’s Disease Age Breakdown



Among Americans aged 65 and over, 1 in 9 persons is currently living with Alzheimer’s, and among those aged 85 and over, the ratio is 1 in 3. In 2010, over 83,000 Americans died of Alzheimer’s disease, making it the country’s sixth leading cause of death. Unlike some of the other top causes of death in this country, at this time there is no proven way to prevent it, cure it, or slow its progression. Moreover, the incidence of Alzheimer’s disease is skyrocketing in proportion to the growth in the older population. It has been estimated that by 2050, nearly 14 million Americans will have Alzheimer’s disease.

In Mississippi, the incidence of the disease is equally daunting. It is estimated that in 2014, 51,000 Mississippians aged 65 and older are living with Alzheimer’s disease. This number does not include the many thousands more with younger-onset Alzheimer’s disease or those with related dementias. Mississippi, like the rest of the country, is in the midst of an unprecedented growth in the older population. Between 2014 and 2025, the number of persons aged 65 and over with Alzheimer’s disease in Mississippi is expected to grow by 27% (from 51,000 people to 65,000 people).

**Predicted Increase in Alzheimer’s Prevalence and Cost  
(In millions of people; in billions of dollars)**

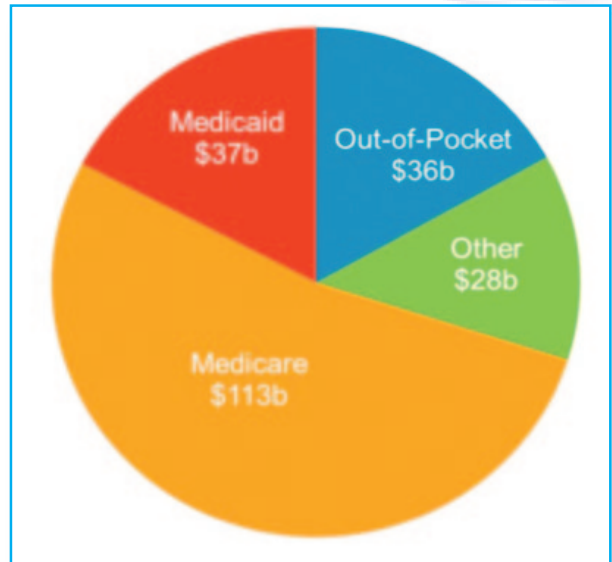


The prevalence of Alzheimer’s disease has a significant impact on the health care system and on health care costs. It is estimated that in 2014, the direct costs of caring for Americans with Alzheimer’s disease will total \$214 billion, including \$37 billion and \$113 billion in costs to Medicaid and Medicare respectively.

The average per-person costs for Medicare beneficiaries with Alzheimer’s and other dementias are three times higher than for those without those conditions. For Medicaid, the cost differential is staggering: the average per-person Medicaid spending for seniors with Alzheimer’s and other dementias is 19 times higher than the average per-person costs for all other seniors.

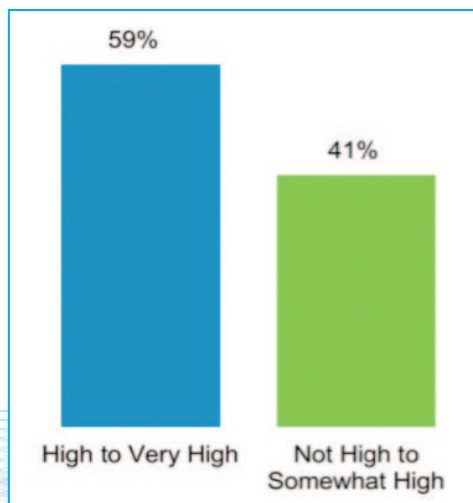
## 2014 Cost of Alzheimer's Disease

The growth in the incidence of Alzheimer's disease has important implications for health care providers. The expansion of the older population nationally and in Mississippi has created an increased demand for health care services, including importantly, the demand for long term care services. Nursing homes, assisted living facilities, home health agencies, personal assistance services agencies, adult day services agencies and other providers require staff to support a growing population with long term care service needs. Beyond that, all health care providers must rely increasingly on the availability of a workforce that has been trained to support the specific care needs of individuals with Alzheimer's disease and related disorders.



The impact of Alzheimer's disease is experienced perhaps most intensely by family caregivers. As a group, family members caring for persons with Alzheimer's disease tend to experience a tremendous amount of emotional stress and often sacrifice their own physical well-being. In addition, many family caregivers carry an economic burden related to their caregiving.

## Emotional Stress of Alzheimer's Caregiving



It has been estimated that in the U.S. in 2013, 15.5 million informal caregivers (family and friends) provided an estimated 17.7 billion hours of unpaid care to persons with Alzheimer's disease and other dementias, a contribution to the nation valued at more than \$220 billion. Fifty-nine percent of caregivers rated the emotional stress of caregiving as high or very high, and over one-third (39%) reported symptoms of depression.

The physical and emotional stress of caregiving resulted in an additional \$9.3 million in health care expenditures in 2013 for caregivers themselves. In addition, caregivers have other out-of-pocket expenditures. Long-distance caregivers (those who live an hour or more away) tend to incur about twice as many out-of-pocket costs.

Mississippi is home to a very large number of caregivers. In 2013, approximately 205,000 Mississippians provided 233 million hours of unpaid care to person's with Alzheimer's disease and other dementias. Additional healthcare costs for Mississippi caregivers in 2013 were an estimated \$117 million.

# HISTORY



In 1998, the Mississippi Alzheimer's Association aggressively lobbied for and secured passage of legislation, which for the first time, recognized and provided a means to address the critical issues related to Alzheimer's disease and dementia as a matter of state public policy. The genesis of the 1998 effort began in 1996 when Alzheimer's Association volunteers first appeared before the Public Health Committees of the Mississippi House of Representatives and Senate for support. In 1997, Senate Committee Chairman, Jim Bean, and House Committee Chairman, Bobby Moody, requested that the Association provide specific legislative recommendations.

Those specific recommendations were made in 1998. The Department of Mental Health, under the leadership of Director Randy Hendrix, PhD, supported legislation which required that

the Department of Mental Health develop a state plan for two key reasons:

- 1) To provide education and training to service providers, family caregivers, and others who deal with Alzheimer's disease and other dementia;
- 2) To develop adult day care, family respite care, and counseling programs to assist families who maintain persons with Alzheimer's disease and other dementias in the home setting.

This legislation, codified at Mississippi Code of 1972, § 41-4-7 (ee), remains a critical piece of the manner in which Mississippi addresses Alzheimer's and dementia needs. The Mississippi Department of Mental Health, Division of Alzheimer's Disease and Other Dementia, implements the legislation by:

- Supporting family members who provide care for persons with dementia at home through adult daycare programs;
- Publishing and distributing, "Living With Alzheimer's: A Resource Guide";
- Providing training and other resources for caregiver support groups;
- Enhancing knowledge and training of health care professionals with respect to dementia;
- Orchestrating the Annual Conference on Alzheimer's Disease and Psychiatric Disorders in Older Adults and The Annual Mississippi Physicians' Conference on Alzheimer's Disease;
- Participating in and supporting public awareness events regarding Alzheimer's;
- Maintaining current and relevant information regarding Alzheimer's disease on the Department of Mental Health website;
- Developing models for respite services for individuals with Alzheimer's and dementia.

Presently the Division employs Master's level trainers and operates three field offices outside of the Department of Mental Health's Central office. Field offices are located in Tupelo, Magee and Long Beach. Through field offices, the Division provides statewide education and training and makes resource materials available to the public at no cost. A caregiver liaison was added to the Division in FY 2013.



The Division partially funds and certifies two adult day centers: Garden Park Adult Day Center in Greenwood, and Footprints Adult Day Services in Newton. Adult Day Centers provide a structured environment for individuals with Alzheimer's disease and related dementias. In addition, respite, counseling, education and training, is provided for family members and other caregivers of individuals facing this devastating disease.

A second major focus of the 1998 – 1999 legislative initiative was to provide incentives to state nursing home facilities to create additional facilities and beds for the treatment of Alzheimer's patients. The legislation, codified as Mississippi Code of 1972, § 43-13-117(4)(e), required that the Division of Medicaid develop and implement a case-mix payment add-on based on statistical data, that would reimburse nursing facilities for the additional cost of caring for patients with Alzheimer's. Also required was the development and implementation of an enhanced fair rental reimbursement system for conversion of beds and construction of facilities for the care of Alzheimer's patients. This payment structure began July 1, 2002.

The 1998 – 1999 initiative also resulted in passage of legislation which removed the moratorium on construction of nursing home facilities or conversion of beds to provide care for Alzheimer's patients in each long-term planning district in the state up to a total of 60 beds in each district. The legislation required that the State Department of Health develop criteria which must be met to qualify nursing facility beds as suitable for Alzheimer's patients. The legislation, which included lifting the moratorium on the addition of nursing home beds beyond Alzheimer's, was vetoed by the Governor. The veto message on April 20, 1998 from Governor Kirk Fordice, however, made special mention of Alzheimer's; "I regret that the 240 nursing home beds that were designated in the bill for Alzheimer's patient cases will not become law. However, Senate Bill 2200 which I signed on March 17, 1998, authorizes the Department of Mental Health to develop and implement state plans for the care and treatment of persons with Alzheimer's disease. The more comprehensive approach of S.B. 2200 is likely to lead to the implementation of education programs, adult day care facilities, family respite care, and counseling of family members."

The 1998 effort provided a springboard for action in 1999. The 1999 legislature authorized the 240 beds over a two-year period, and the Governor approved the legislation codified at Mississippi Code of 1972, § 41-7-191 (2) (r). The Department of Health was authorized to grant certificates of need for conversion or construction of facilities devoted exclusively to Alzheimer's patients. The Department of Health, in consultation with the Department of Mental Health, was directed to develop criteria for Alzheimer's facilities, including standards for staffing levels, space requirements and other necessary enhancements for Alzheimer's care.



Over the next several months the following criteria were developed which included:

- Minimum number of nurses required per shift for each Alzheimer's/dementia care unit;
- Minimum number of aides per Alzheimer's/dementia care unit residents;
- Minimum number of staff members present at Alzheimer's/dementia care units at all times;
- Therapeutic recreation specialists assigned to each Alzheimer's/dementia care unit;
- Licensed social worker, counselor, or therapist assigned to Alzheimer's/dementia care units;
- Training and education of staff of Alzheimer's/dementia care units;
- Individual care plans for each resident;
- Interaction with family members of residents;
- Required therapeutic activities including, but not limited to, exercise, self-care, social activities, crafts, and outdoor activities;
- Physical plant standards for each Alzheimer's/dementia care unit, including a multi-purpose room for dining, activities and family visits;
- Nurses station located within the Alzheimer's/dementia care unit;
- Secure exterior walking pathway, lighted and with seating available;
- Security controls at all entrances and exits and solid exterior fencing.

These regulations are maintained and enforced by the Mississippi State Department of Health. To date, there are Alzheimer's Disease/Dementia Care Unit designations in 18 Nursing Homes with 361 beds and 17 Personal Care homes with 505 beds statewide.

In 2010, the University of Mississippi Medical Center (UMMC) launched The MIND (Memory Impairment Neurodegenerative Dementia) Center which is a major research initiative to help understand the causes and develop new treatments for Alzheimer's disease and related dementias. Partially funded by a \$26 million competitive research grant from the National Institutes of Health which was awarded to Dr. Tom Mosley, founding director, The MIND Center is the lead institution for the ARIC (Atherosclerosis Risk in Communities) Neurocognitive Study, the most comprehensive long-term study on dementia risk ever undertaken and the largest study in the United States to address racial disparities in dementia risk.

Collaborating with The MIND Center are four leading academic medical centers including (1) Johns Hopkins, (2) University of Minnesota, (3) Wake Forest University, and (4) University of North Carolina – Chapel Hill. The MIND Center also uses state-of-the-art brain imaging and powerful new genetic technologies to elucidate the causes of Alzheimer's. In 2011, The MIND Center and UMMC secured a powerful PET Scanner, the eighth of its kind in the world, which allows for visualization of brain plaques that develop in Alzheimer's patients.

The MIND Center Clinic was opened on UMMC's campus in October 2013 to offer physician-based, outpatient treatment for individuals experiencing memory loss and cognitive impairment. Staffed by a team of geriatricians, consulting neurologists and psychiatrists, nurse practitioners and a social worker, the clinic provides comprehensive evaluation and treatment for Alzheimer's and dementia as well as support and guidance for families and caregivers.

In 2014, The MIND Center received \$3 million in dedicated state funding in the 2015 UMMC appropriations bill (S.B. 2860). The support of the state legislature is accelerating The MIND Center's research and allowing for the expansion of dementia clinical services to remote and underserved regions of the state through TeleHealth technology.

Today, the Alzheimer's Association Mississippi Chapter provides a core set of programs, all free to families, including the following:

**The 24/7 Helpline** provides expert advice and referral to local services such as assisted living and long-term care facilities, adult day health centers, and support groups. Helpline staff follows up with callers as a standard practice.

**Care Consultation** provides in-depth assessment and counseling. Care Consultants help families develop a plan for care throughout the disease process, educate them about coping strategies for day to day living, connect them with resources, and empower them by providing the tools to support informed decision making.

**Education Programs for families** cover a variety of topics including the 10 warning signs of dementia, communication and behavior, legal and financial issues, and essential skills training for caregivers.

**Education Programs for professionals** through an annual "Confidence in Caregiving" conference and through medical education programs, reaching out to medical providers throughout the year.

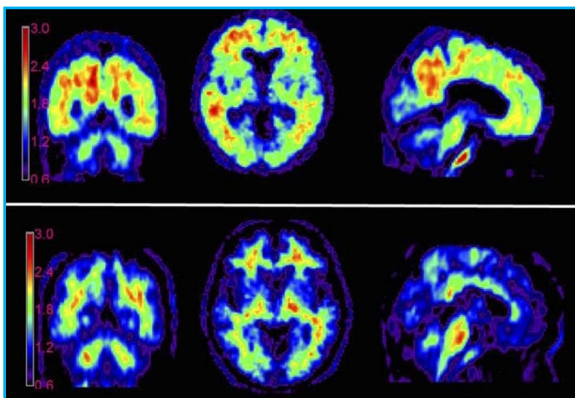
**Support Groups** are a vital mechanism for family caregivers to connect to other caregivers trying to cope with a loved one who has dementia.

**Advancing Research** through partnerships with colleagues in government, academia, industry and other nonprofit organizations and through the promotion of participation in clinical trials particularly through TrialMatch® a clinical studies matching service.

The Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's care, support and research whose mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health. The National Alzheimer's Association is the largest private nonprofit funder of Alzheimer's research. Nationally and locally, the Alzheimer's Association advocates for public policy issues and critical research funding.

# RESEARCH INTRODUCTION

Alzheimer's is officially the 6th leading cause of death in the United States and the 5th leading cause of death for those aged 65 and older<sup>1</sup>. However, recent studies show that it may cause even more deaths than official sources recognize. We now know that it kills more than prostate cancer and breast cancer combined<sup>2</sup>.



Deaths from Alzheimer's disease actually increased by 68 percent between 2000 and 2010, while deaths from other major diseases decreased. Alzheimer's disease is the only cause of death among the top 10 in America that cannot be prevented, cured or even slowed.

Alzheimer's and related dementias currently affect an estimated 5.2 million Americans and more than 51,000 Mississippians. Unless effective treatments can be found, the number of people with Alzheimer's is expected to double by 2030 and triple by 2050\*.



Since life expectancy after an Alzheimer's diagnosis can span from 2 to 20 years<sup>3</sup>, the overall financial burden to both families and society can be staggering. Mississippi spends roughly \$700 million on nursing home care each year. Alzheimer's is the #1 reason for nursing home placement. Research has uncovered important links between Alzheimer's and cardiovascular risk factors including high blood pressure, diabetes and obesity, which are particularly prevalent in Mississippi. In light of the state's high rate of these conditions, Mississippians may experience a disproportionate burden of disability and death from Alzheimer's and other dementias.

The good news is that research currently underway in Mississippi is steadily adding to our understanding of the aging brain and is closing in on more effective ways to prevent and treat Alzheimer's and related diseases. Partially funded by a competitive research grant from the National Institutes of Health, state appropriations and private support, The MIND Center is a major research and clinical care initiative at the University of Mississippi Medical Center (UMMC) aimed at elucidating the causes and developing treatments for Alzheimer's disease and related forms of dementia through innovative research.

The MIND Center's ARIC Neurocognitive Study (ARIC NCS) is the most comprehensive and long-term neuro-epidemiologic study on dementia risk ever undertaken and one of the largest studies in the nation in African Americans to address racial disparities in dementia risk. The ARIC NCS has been ongoing for more than 25 years and is a collaborative effort among five leading academic medical centers including The MIND Center at UMMC, Johns Hopkins, University of Minnesota, Wake Forest University, and University of North Carolina – Chapel Hill.

Current MIND Center research projects support the salaries of 40 staff and scientists at UMMC and include active collaborations with leading medical research institutions around the United States and Europe. The MIND Center brings together leading-edge research, state-of-the-art brain imaging and powerful new genetic technologies to accelerate the pace of discovery in the search for treatments to slow or prevent Alzheimer's and other forms of cognitive decline and dementia.

Precise Research Centers in Flowood is currently conducting a phase III research study of the 5-HT<sub>6</sub> receptor antagonist LU AE58054, in male and female patients aged at least 50 years with mild to moderate Alzheimer's disease (AD) treated with donepezil. The aim of the study is to test how well this new type of drug works and how safe it is in patients with Alzheimer's disease.

The treatment being investigated by Precise Research Centers, helps nerve cells in the brain work together, which is very important for memory, reasoning and thinking. In this study, patients will be selected to receive either 30mg or 60mg of the investigational treatment drug or a placebo. Comparing drugs with placebo is the only way for the doctors to tell if the study treatment is having an additional effect on the patient's mental function.

At the end of the Precise Research study, patients may be offered to continue in a 6-month extension study, if eligible. All patients in the extension study will receive LU AE58054 and a drug containing donepezil, so those on placebo during the initial study will be switched to the active drug.

The Neurological Research Center at the Hattiesburg Clinic is currently enrolling patients in a Phase II, open-label, multicenter study which will evaluate the long-term safety and tolerability of crenezumab in patients with mild to moderate Alzheimer's disease who have participated in and completed the treatment period of the Phase II Study ABE4869g or ABE4955g.

Patients will receive crenezumab at the same dosing frequency, dose level and route of administration they were assigned to after the Week 73 visit of Study ABE4869g or ABE4955g. Patients who received placebo in the initial study will now receive the active drug. Anticipated time on the study treatment is 94 weeks.



The Research Department of Olive Branch Family Medical is currently recruiting participants for an upcoming clinical trial at their Olive Branch location in Desoto County. The purpose of this drug study is to determine the safety and efficacy of TRx0237 in the treatment of subjects with mild Alzheimer's disease.

The unprecedented growth in the number of individuals with Alzheimer's coupled with the tremendous human and societal costs, underscores the urgency of research efforts. In the past, when the investment has been made in research to find ways to prevent and treat major diseases such as breast and prostate cancer, heart disease, stroke and HIV/AIDS, disease outcomes have been dramatically improved. The same must be done with Alzheimer's and dementia.

Mississippi's sustained investment in Alzheimer's disease research will promote innovative technologies and attract increased external economic investments in the state. It will also enhance the ability of state researchers to compete for federal research dollars and ensure Mississippi is at the forefront of this rapidly expanding field of discovery. A commitment to Alzheimer's and dementia research is critical to addressing one of the most severe public health challenges facing Mississippi and the nation today.

## References

<sup>1</sup> Alzheimer's Association, 2014 Alzheimer's Disease Facts and Figures report at [alz.org/facts](http://alz.org/facts) (retrieved March 2014).

<sup>2</sup> James, B.D. (2014), Study: Alzheimer's Disease A Much Larger Cause of Death Than Reported, *Neurology* (the medical journal of The American Academy of Neurology) at [aan.com/PressRoom/Home/PressRelease/1253](http://aan.com/PressRoom/Home/PressRelease/1253) (retrieved March 2014).

<sup>3</sup> Alzheimer's Foundation of America, About Alzheimer's Life Expectancy at [alzfdn.org/AboutAlzheimers/life\\_expectancy](http://alzfdn.org/AboutAlzheimers/life_expectancy) (retrieved April 2014).

<sup>4</sup> Alzheimer's Association, Mississippi Alzheimer's Statistics, 2014 Alzheimer's Disease Facts and Figures report at [alz.org/facts](http://alz.org/facts) (retrieved March 2014).

<sup>5</sup> National Institutes of Health, National Institute on Aging, U.S. Department of Health and Human Services, Publication No. 12-5503, Preventing Alzheimer's Disease – What Do We Know? (September 2012).

<sup>6</sup> Mississippi Chronic Illness Coalition (MCIC), Mississippi State Department of Health, Chronic Illnesses in Mississippi, Risk Factors for Chronic Disease at [msdh.ms.gov/msdhsite/\\_static/](http://msdh.ms.gov/msdhsite/_static/) (retrieved March 2014).

<sup>7</sup> MIND Center at the University of Mississippi Medical Center at [ummhealth.com/mindcenter](http://ummhealth.com/mindcenter) (retrieved May 2014).

<sup>8</sup> Research Department of Olive Branch Family Medical at [obfmc.com](http://obfmc.com) (retrieved June 2014).

# GOAL 1: RESEARCH

Support research in Alzheimer's disease and related dementias.

## OBJECTIVE 1

Identify researchers actively engaged in the areas of Alzheimer's disease and related disorders and strengthen the state's infrastructure to advance research priorities.

### STRATEGIC PRIORITIES:

1. Ensure the most promising research projects are promoted and made sustainable, including research on risk factors and prevention, early diagnosis, treatment and cures for Alzheimer's disease and related dementias.
2. Establish a consortium to include academic institutions, relevant state and local agencies and representation from private and lay stakeholder organizations to serve as an umbrella structure to coordinate and foster research efforts on Alzheimer's disease and other dementias in Mississippi.
3. Survey state universities, hospitals, clinics and physician practices to assess what research is currently being conducted in the areas of Alzheimer's disease and dementia as well as any studies planned in the future.
4. Contact public and private organizations, such as the Alzheimer's Association, to identify what plans they have for research initiatives such as pending grants or clinical trial match.
5. Develop an authoritative list of all active Alzheimer's disease and dementia researchers (including basic and clinical research, behavioral research, and cognitive investigators) and their affiliated research institutions; publish and maintain the list in a centralized location or website which is accessible to the public.



## OBJECTIVE 2

Facilitate the coordination of Alzheimer’s disease and dementia research initiatives in Mississippi and promote collaboration between state research institutions and academia to accelerate treatment discovery and clinical trials.

### STRATEGIC PRIORITIES:

1. Establish research priorities based on Mississippi’s unique demographics and the national priorities outlined in the National Alzheimer’s Project Act (NAPA).
2. Develop and support programs that encourage therapeutics and clinical trials for Alzheimer’s disease and dementia by scientists from Mississippi, including basic research efforts and sponsoring biotechnology incubators to attract businesses to the state.
3. Develop collaborative relationships between researchers involved in ongoing health outcome studies already enrolling ethnic minorities and remote populations to facilitate recruitment of medically underserved individuals into aging and Alzheimer’s disease studies.
4. Contact clinical professionals to determine their interest in research and encourage their participation in research-related activities.
5. Develop and distribute data and informational materials to educate public corporations and state policymakers about the need for interdisciplinary and collaborative Alzheimer’s disease research.

## OBJECTIVE 3

Develop strategies to attract and increase research funding through various sources including state and federal government, universities, colleges, public and private individuals and organizations, and other stakeholders.

### STRATEGIC PRIORITIES:

1. Identify organizations involved in fundraising for Alzheimer’s and dementia research and coordinate efforts through regular communication to limit duplication of efforts while expanding the state’s collective donor base.
2. Quantify the current level of research funding for Alzheimer’s disease in Mississippi and prepare a comprehensive list to identify the funding source and amount for each investigator.
3. Create a centralized location or website to compile information for key stakeholders regarding current Alzheimer’s disease/dementia researchers, studies and funding sources in Mississippi.
4. Explore opportunities to promote competitive funding through Mississippi special funds.



5. Align strategies to capitalize on the Mississippi Healthcare Industry Zone Act which aims to expand access to high-quality medical care for Mississippi residents and increase the number of health care jobs in the state through a business incentive program to encourage health care-related businesses to locate or expand within a qualified Health Care Zone in the state.
6. Create a database of research opportunities from governmental and non-governmental funding sources and identify those grants which address our state's needs; establish a research work group to encourage researchers in Mississippi to apply for grants and provide support for new researchers in grant writing.
7. Develop a program to leverage resources among Mississippi investigators and affiliated researchers for joint applications for federal research funding through various agencies and institutions such as the Veteran's Administration, Centers for Disease Control and Prevention, the Administration on Aging, the Agency for Healthcare Research and Quality, and the National Institutes of Health.
8. Encourage development of an Alzheimer's Disease Research Center (ADRC) in Mississippi that can more effectively compete for federal funding and support.

#### **OBJECTIVE 4**

Educate the public on the availability, purpose and value of Alzheimer's disease and dementia research and encourage participation in current and future studies and clinical trials.

#### **STRATEGIC PRIORITIES:**

1. Create and distribute culturally sensitive and appropriately tailored informational materials and educational programs for the public on aging and Alzheimer's disease research studies to promote study participation.
2. Collaborate with private, state, and federal partners to increase participation of diverse and medically underserved populations in research studies.
3. Engage community physicians to encourage referral to and participation in Alzheimer's disease/dementia research projects and clinical studies.
4. Promote the Alzheimer's Association's TrialMatch as a resource for increasing participation in clinical trials.
5. Expand the use of the University of Mississippi Medical Center's telemedicine technology applications in research protocols to reach rural populations and remote communities.

# COMMUNITY AWARENESS INTRODUCTION

As the prevalence of dementia grows, many myths and inaccurate information regarding Alzheimer's disease and other dementias persist. Public misperceptions about dementia not only lead to stigma, but persons with dementia and those who care for them are often unaware of how to meet care needs. It is estimated that about half a million Americans younger than age 65 have some form of dementia, including Alzheimer's disease; this is referred to as young or early onset.<sup>1</sup>

As approximately 51,000 Mississippians have been diagnosed with Alzheimer's disease alone<sup>2</sup>, the need to understand dementia and how to provide care is paramount. Priorities of this Plan include increasing public awareness across the state regarding Alzheimer's disease and dementia, delivering community education, enhancing community partnerships, and strengthening available resources for citizens and care partners dealing with the disease.

## References

<sup>1</sup> Alzheimer's Foundation of America, About Alzheimer's Life Expectancy at [alzfdn.org/AboutAlzheimers/statistics](http://alzfdn.org/AboutAlzheimers/statistics) (retrieved April 2014).

<sup>2</sup> Alzheimer's Association, Mississippi Alzheimer's Statistics, 2014 Alzheimer's Disease Facts and Figures report at [alz.org/facts](http://alz.org/facts) (retrieved March 2014).

# GOAL 2: COMMUNITY AWARENESS

Increase public awareness of Alzheimer's disease and related dementias.

## OBJECTIVE 1

Educate the public through dissemination of materials through a variety of venues including, but not limited to schools, civic and faith-based organizations, media events and public service announcements.

### STRATEGIC PRIORITIES:

1. Develop content for public awareness campaigns to address a wide range of issues and audiences including, but not limited to, identifying early warning signs and effective strategies for obtaining appropriate diagnosis; recognizing the stages of the disease; and accessing available resources.
2. Determine appropriate venues for outreach and education.
3. Promote the use of social media such as Facebook and Twitter as well as traditional media including print, radio and television, when disseminating public education campaign messages.
4. Ensure information and educational materials are offered at appropriate literacy, language, and legibility (font size) levels for a diverse population.

## OBJECTIVE 2

Identify and develop essential community partnerships across the state.

### STRATEGIC PRIORITIES:

1. Identify potential community partners.
2. Conduct needs assessment with potential community partners.
3. Develop and implement collaborative projects and initiatives based on needs assessment.
4. Explore educational program models to assist community gatekeepers such as clergy, bank tellers, and members of the general public with identifying individuals with cognitive impairments who are at risk in the community.

## OBJECTIVE 3

Develop standardized message tools based on the needs and strengths of community partnerships.

### STRATEGIC PRIORITIES:

1. Determine the requirements and expertise of stakeholder organizations.
2. Determine topics to be addressed by message tools.
3. Create message tools for each topic area to be addressed.
4. Identify individuals who are qualified and willing to present on the topic areas.

## **OBJECTIVE 4**

Establish dedicated regional resource sites across the state to provide information and service listings.

### **STRATEGIC PRIORITIES:**

1. Identify established information and referral clearinghouses.
2. Review existing resource and service listings for accuracy and breadth of information.
3. Update and expand information regarding topics related to dementia, resources and services.
4. Develop resource sites with comprehensive information and resource listings.
5. Develop system to maintain current resource listings.

# COORDINATED CARE INTRODUCTION

Improved quality of life for individuals affected by Alzheimer's disease and other dementias can be achieved through a collaborative statewide system that addresses the complex and individualized care needs of the patient. Over the course of Alzheimer's disease, the affected individual will encounter the full spectrum of care providers from the least skilled and untrained to the most specialized in the medical field. The reliance on paid caregivers and health professionals at every stage of the disease will require accurate information and education on detection, diagnosis, care, treatment, and coordination among providers that spans every level of licensure.

There is currently a dementia knowledge gap that leaves patients and families to their own devices to educate themselves and navigate a varied, complex, and sometimes lacking, system of services and supports at a time when they most need professional guidance and direction. Activities outlined in this section seek to address gaps in services across the state and to promote a culturally sensitive and competent healthcare workforce to improve the quality of life for individuals and families facing the devastation of Alzheimer's disease.

## Reference

Alzheimer's Association, 2014 Alzheimer's Disease Facts and Figures report at [alz.org/facts](http://alz.org/facts) (retrieved March 2014).

# GOAL 3: COORDINATED CARE

Improve the quality of life for persons with Alzheimer's disease and related dementias, as well as their families and caregivers, through coordinated, competent and comprehensive dementia care.

## OBJECTIVE 1

Create and implement structured educational programs in order to develop a workforce that is competent, culturally sensitive, and efficient in dementia care.

### STRATEGIC PRIORITIES:

1. Determine the target audience for dementia programs such as professionals, caregivers, law enforcement, clergy and teachers.
2. Investigate and identify currently available education and training programs relative to dementia care.
3. Collaborate and coordinate with other entities to modify or establish state specific education programs to insure inclusion and focus on dementia care.
4. Create awareness about dementia care programs with target audiences and determine incentives for program completion such as a specific certification or designation.

## OBJECTIVE 2

Improve the management and coordination of care for persons with Alzheimer's disease and dementia from presentation of illness through end of life.

### STRATEGIC PRIORITIES:

1. Coordinate with key strategic partners to disseminate health care professional information packets and training on dementia care to licensed providers.
2. Update licensed healthcare providers on the latest research and science of neurocognitive disorders.
3. Implement dementia care guidelines across all health care settings (such as home health, hospitals, rehabilitation, Department of Motor Vehicles and long term care) regarding the management and transition of care for persons with Alzheimer's and other dementias and their families/caregivers.

## OBJECTIVE 3

Expand access to dementia care through enhanced awareness and availability of dementia care services and resources.

### STRATEGIC PRIORITIES:

1. Identify locations and services of current health care providers and gaps in accessibility to dementia care.
2. Promote awareness of current telemedicine initiatives and potential state wide access to dementia care for medically underserved and rural communities.
3. Create collateral materials to distribute to providers, health departments and pharmacists regarding available dementia care resources and "need to know" information including the Medicare Annual Wellness visit for dementia screenings.

## **OBJECTIVE 4**

Expand collaborative efforts between providers, advocacy groups, and government agencies for enhanced dementia care.

### **STRATEGIC PRIORITIES:**

1. Identify affected providers, advocacy groups and government agencies to create communication networks and encourage continual and consistent relationships relevant to dementia care issues.
2. Provide meeting opportunities at the annual “Conference on Alzheimer’s Disease and Psychiatric Disorders in Older Adults” for continuing discussions of best practices in dementia care among the groups with vested interests.

# CAREGIVER SUPPORT INTRODUCTION

In the state of Mississippi there are over 200,000 caregivers of persons with Alzheimer's disease and other related dementias who provide 233 million hours of unpaid care at a value of almost \$3 billion dollars.<sup>1</sup> Those numbers are expected to significantly increase as our population ages and baby boomers become seniors in need of help. Unpaid caregivers (often family members and women) are a valuable resource to guard our most vulnerable and largest growing population from being at even greater risk of institutionalization and exploitation. Unpaid caregivers prevent healthcare systems from being overloaded with patients suffering from Alzheimer's disease and related dementias.

Identifying current support resources and closing resource gaps is necessary to ensure caregivers receive the help and support they need. The most critical services for caregivers include respite care, adult day care, and home- and community-based services. These services provide adjunctive care so family caregivers get a break, may continue to work, and can take care of themselves as well as their loved one. The support of these caregiver services is vital to prevent caregiver burnout and institutional placement.

A key priority is to provide education for family members who provide care, either in the home or other settings. Family caregivers are at a much higher risk than the general population to report high stress levels, be on antidepressant medications, and develop medical issues of their own; these issues then interfere with caregiving responsibilities. Research has shown that if caregivers are informed and educated, they are better able to manage stress and have fewer medical illnesses of their own. Also if caregivers work in a long term care setting, research indicates they have less turnover and higher job satisfaction.

Supporting caregivers is an essential piece of the complicated puzzle of Alzheimer's disease and related dementias. Caregivers and professionals share a common goal of maintaining an individual's independence and dignity by enabling them to age at home or "in place" for as long as possible.

## Reference

<sup>1</sup> Alzheimer's Association, 2014 Alzheimer's Disease Facts and Figures report at [alz.org/facts](http://alz.org/facts) (retrieved March 2014).



# GOAL 4: CAREGIVER SUPPORT

Enhance the availability of and access to support services for caregivers and family members of individuals with Alzheimer's disease and dementia.

## OBJECTIVE 1

Identify all available caregiver support services and resources across the state and assess and address any gaps or barriers to their delivery.

### STRATEGIC PRIORITIES:

1. Conduct an internet and literature review of available caregiver support information from public and private resources at both the state and national levels.
2. Conduct a needs assessment of caregivers and health care professionals to identify opportunities to enhance awareness of caregiver support services as well as available informational resources.
3. Develop a website to function as a centralized clearinghouse of information regarding available caregiver support services from both online and printed sources.
4. Promote collaboration and involvement of all community partners, both public and private, in centralizing information regarding available caregiver support services.

## OBJECTIVE 2

Provide educational programs to enhance public awareness of available support services to communities, faith-based services, caregivers, family members, and health care providers.

### STRATEGIC PRIORITIES:

1. Identify and collaborate with organizations and agencies that are currently providing educational information and training programs for communities, faith based services, caregivers, family members, and health care providers to expand availability as well as identify underserved areas or groups. Assist with providing materials to community groups, caregivers and health care providers and facilities.
2. Provide focus training with continuing education to health care providers and the medical community that enhances knowledge of resources and support services for caregivers.
3. Engage for-profit and non-profit foundations, the business community, and the state and federal government, to provide funding for caregiver support materials and services.

### **OBJECTIVE 3**

Increase the access and availability of caregiver support services with a focus on the delivery of (1) respite care; (2) adult daycare; and (3) home and community based services across the state including rural and urban areas with underserved populations.

#### **STRATEGIC PRIORITIES:**

1. Identify available resources in the areas of respite care, daycare and home/community based services, and promote expansion to remote and underserved areas.
2. Pursue appropriation of state and federal funding for the expansion of respite care, adult daycare, and home/community based services as well as ancillary services such as transportation.

# BRAIN HEALTH INTRODUCTION

More than 51,000 Mississippians are currently living with Alzheimer's<sup>1</sup> and that number may triple by 2050<sup>2</sup> unless strategies are implemented to prevent, slow or stop this devastating and costly disease. Promising prevention and brain health research is focused on eliminating risk factors that contribute to the development of Alzheimer's disease and dementia, and promoting behaviors which encourage brain health.

The latest research shows a correlation between the risk for Alzheimer's disease and conditions that damage the heart or blood vessels<sup>3</sup> such as high blood pressure, stroke, diabetes, or other metabolic conditions, high cholesterol, elevated blood homocysteine (an amino acid in plasma) and heart disease. Scientific studies are now finding a positive relationship between preventing and treating these risk factors and increased brain health. In other words, "a healthy heart can promote a healthy brain."

According to the 2014 America's Brain Health Index, Mississippi ranks No. 51 and holds the lowest position among the brain-healthiest geographies in the nation.<sup>4</sup> Mississippi has many health challenges including some of the highest rates of chronic diseases such as obesity, diabetes and cardiovascular disease.<sup>5</sup> While there's no cure for Alzheimer's yet, there are lifestyle changes and positive habits that can reduce the risk of developing the disease such as getting regular exercise, maintaining a healthy diet, reducing environmental toxins such as cigarette smoke, avoiding head trauma, staying socially active and keeping the mind challenged.<sup>6</sup>

The objectives and strategies outlined in the following section are aimed at changing this trajectory and improving brain health in Mississippi by focusing on (1) assessing the severity and impact of cognitive decline in the state; (2) including brain health in strategic planning for all Mississippi public health efforts; (3) mobilizing community partners and stakeholders to join forces to promote brain health; and (4) increasing community awareness and educating health care providers about the prevention and treatment of Alzheimer's disease and dementia, the correlation between Alzheimer's and chronic conditions (such as heart disease), and the benefit of early diagnosis and intervention.

## References

<sup>1</sup> Alzheimer's Association, Mississippi Alzheimer's Statistics, 2014 Alzheimer's Disease Facts and Figures report at [alz.org/facts](http://alz.org/facts) (retrieved March 2014).

<sup>2</sup> Alzheimer's Association, 2014 Alzheimer's Disease Facts and Figures report at [alz.org/facts](http://alz.org/facts) (retrieved March 2014).

<sup>3</sup> National Institutes of Health, National Institute on Aging, U.S. Department of Health and Human Services, Publication No. 12-5503, Preventing Alzheimer's Disease – What Do We Know? (September 2012).

<sup>4</sup> National Center for Creative Aging, 2014 America's Brain Health Index, part of a national health education campaign, Beautiful Minds: Finding Your Lifelong Potential at [beautiful-minds.com/AmericasBrainHealthIndex](http://beautiful-minds.com/AmericasBrainHealthIndex) (retrieved March 2014).

<sup>5</sup> Mississippi Chronic Illness Coalition (MCIC), Mississippi State Department of Health, Chronic Illnesses in Mississippi, Risk Factors for Chronic Disease at [msdh.ms.gov/msdhsite/\\_static/](http://msdh.ms.gov/msdhsite/_static/) (retrieved March 2014).

<sup>6</sup> Alzheimer's Association and Centers for Disease Control and Prevention (CDC), The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013 – 2018: Chicago, IL: Alzheimer's Association (2013).

# GOAL 5: BRAIN HEALTH

Inform Mississippians about ways to promote or improve brain health through research-based strategies.

## OBJECTIVE 1

Incorporate measures concerning brain function into existing statewide surveillance to assess the public health impact of declining brain function, inform public health policy and strategies, and monitor progress toward promoting improved quality of life.

### STRATEGIC PRIORITIES:

1. Recommend use of the Behavioral Risk Factor Surveillance System (BRFSS) to collect health outcomes data for persons with impaired brain function, Alzheimer's disease and related dementias, including the impact of cultural variances.
2. Review surveillance data on an ongoing basis to identify trends in brain health within the state.
3. Utilize surveillance data to inform the public and state government regarding the scope of brain function impairment in Mississippi.



## OBJECTIVE 2

Identify and promote culturally sensitive strategies designed to promote brain health and increase public awareness about Alzheimer's disease and related dementias.

### STRATEGIC PRIORITIES:

1. Promote community awareness through the implementation of health promotion campaigns including culturally sensitive messaging.
2. Tailor educational programs to eliminate the stigma associated with Alzheimer's disease and dementia.
3. Perform outreach education on early signs and symptoms of Alzheimer's disease and dementia and promote the benefits of early detection and diagnosis.
4. Evaluate the benefit of establishing a centralized clearing house of brain health information and educational resources.

### **OBJECTIVE 3**

Include brain health as a major consideration in strategic planning for all public health efforts, chronic diseases and issues related to aging and caregiving in Mississippi; engage and mobilize public and private community partners at both the national and state level to promote brain health.

#### **STRATEGIC PRIORITIES:**

1. Leverage strategies outlined in “The Healthy Brain Initiative: The Public Road Map for State and National Partnerships” to develop, implement and maintain an Alzheimer’s State Plan to promote brain health in Mississippi.
2. Integrate brain health strategies and recommendations into state and local public health.
3. Establish and mobilize a broad network of partners in the areas of business, education, manufacturing, and other community-based employers and organizations to implement and promote brain health and wellness programs.

### **OBJECTIVE 4**

Support educational strategies that give health care providers the information required to implement current and emerging research findings in the areas of brain health promotion, prevention, and early diagnosis of Alzheimer’s disease and dementia.

#### **STRATEGIC PRIORITIES:**

1. Develop and implement continuing education programs that improve the ability of health care providers to: (1) promote brain health, (2) recognize early signs and symptoms of Alzheimer’s disease and other dementias utilizing brain health screening and assessment tools in a variety of clinical settings, and (3) provide guidance to patients and families on where to seek treatment and support.
2. Develop strategies to insure health care professionals recognize the role of families in the delivery of care for individuals with Alzheimer’s disease and the importance of caregiver stress management and promotion of their health and well-being.

## NEXT STEPS

The same level of collaboration among individuals and organizations that went into developing the 2015 – 2020 Mississippi State Plan for Alzheimer’s Disease and Related Dementias is anticipated as Mississippi moves forward with the Plan’s implementation. As part of the process of creating the Plan, it became clear that many Alzheimer’s-related resources already exist in Mississippi and that significant benefit will be derived from examining the existing industries, services and resources that address the needs of persons with Alzheimer’s disease, their families and caregivers. Coordinating, combining, and leveraging identified resources will be critical to the Plan’s success. Expanded state policies and responses to the provision of clear and coordinated services will be addressed through community and government partnerships.



Project partners have already expressed eagerness to begin working on various tasks identified in the Plan, and these efforts will begin immediately upon the plan’s completion. The Department of Mental Health, Division of Alzheimer’s; the Alzheimer’s Association, Mississippi Chapter; and The MIND Center at the University of Mississippi Medical Center; will coordinate implementation activities and track progress in meeting goals and objectives outlined in the Plan.

Full implementation and timely execution of the Plan will be dependent on the involvement and contributions of a broad constituency of community partners. Given the high level of interest and commitment among individuals and organizations involved in the process thus far, it is expected that the Plan can achieve results that will have a significant and positive impact on Mississippi’s caregivers, service professionals, and population living with Alzheimer’s disease and related dementias.

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