



**Putting  
the  
Pieces  
Together**

*A Comprehensive Plan  
for Addressing the Burden of  
Alzheimer's Disease in Texas*

**2010 – 2015**

**Texas State Plan on  
Alzheimer's Disease**



# Foreword

In July 2007, the Alzheimer's Study Group was established under the auspices of the Congressional Task Force on Alzheimer's disease and was charged with creating a National Alzheimer's Strategic Plan to address the "looming crisis" of Alzheimer's disease in the United States. In March 2009, the group released its report, *"A National Alzheimer's Strategic Plan: The Report of the Alzheimer's Study Group."* This report was the first national account of its kind, and provided core recommendations for addressing the current and future burden of Alzheimer's disease.

Similarly, development of a plan to advance statewide, coordinated action to address Alzheimer's disease in Texas became paramount as disease prevalence continues to climb, exacting huge human and economic burdens on state residents and resources. In March 2009, the Texas Council on Alzheimer's Disease and Related Disorders and the Department of State Health Services (DSHS) Alzheimer's Disease Program began formal discussions around development of the first, coordinated Texas state plan on Alzheimer's disease. A steering committee was formed, comprised of distinguished leaders and professionals working in the field of Alzheimer's disease. This committee was charged with identifying the plan's priority goals, while taking into account the Alzheimer's Study Group recommendations and unique issues facing Texas.

Five goals were identified as essential plan elements. These goals are believed to represent a comprehensive approach to addressing Alzheimer's disease in Texas: Science, Prevention and Brain Health, Disease Management, Caregiving, and Infrastructure. Each goal within this plan contains targeted actions that Texas needs to take to comprehensively address Alzheimer's disease.

To garner statewide input for plan development, partners were recruited, and the Texas Alzheimer's Disease Partnership (partnership)

was officially formed; its first meeting was held in Austin, Texas, in June 2009. The partnership is comprised of individuals with diverse backgrounds from state, local and community level organizations; academic and research institutions; for-profit and non-profit sectors; businesses; the healthcare sector; and family members of individuals afflicted with Alzheimer's disease. The rich and varied experiences of partnership members provided the synergy and expertise that created a strategic blueprint for formulating and implementing a comprehensive and coordinated statewide plan.

It was determined that the scope and range of this process was sufficiently large enough to call for development of five committees that would address an assigned goal and/or field of focus. Each of the five Alzheimer's Association chapters in Texas were invited and agreed to chair and guide the actions of an assigned committee. The committees met on an ongoing basis to further refine objectives and strategies of their respective goals. Through their efforts, a myriad of voices and perspectives were incorporated into the process and laid the foundation for a working framework of informed and knowledgeable stakeholders.

This plan was designed to present an overview of the state of Alzheimer's disease in Texas, while providing realistic and thoroughly achievable actions and strategies that can be implemented over the next five years. The plan presents a compelling case and provides a clear roadmap for increased and coordinated action among all partners. It is hoped that this plan will benefit Texans by guiding statewide coordinated efforts to reduce the burden of this disease on Texas citizens and those who care for them. Some strategic efforts will be coordinated at the state level, but others can only be effectively coordinated at the local or organizational level. Success of this plan depends on all partners in all sectors and at all levels working collaboratively to achieve what one cannot accomplish alone.

# Acknowledgements

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# Table of Contents

Forward . . . . .	3
Acknowledgements . . . . .	4
Executive Summary . . . . .	7
Goals of the Plan . . . . .	8
Call to Action . . . . .	8
Introduction . . . . .	9-10
Science . . . . .	11-14
Goal I: Texas will support Alzheimer’s disease research.	
Objective 1 . . . . .	15
Objective 2 . . . . .	16
Objective 3 . . . . .	17
Objective 4 . . . . .	18
Objective 5 . . . . .	19
Prevention and Brain Health . . . . .	20-21
Goal II: Texans will experience improved cognitive health throughout the life span.	
Objective 1 . . . . .	22
Objective 2 . . . . .	23
Objective 3 . . . . .	24
Objective 4 . . . . .	25
Objective 5 . . . . .	26
Objective 6 . . . . .	27
Disease Management . . . . .	28
Goal III: Texans with Alzheimer’s disease will experience improved quality of life through better disease management.	
Objective 1 . . . . .	29
Objective 2 . . . . .	30
Objective 3 . . . . .	31
Objective 4 . . . . .	32-33
Objective 5 . . . . .	33
Caregiving/Caregivers . . . . .	34-35
Goal IV: Caregivers will experience enhanced levels of support through improved access to Alzheimer’s disease/dementia care information and services.	
Objective 1 . . . . .	36-37
Objective 2 . . . . .	38
Objective 3 . . . . .	39
Objective 4 . . . . .	40-41
Objective 5 . . . . .	42-43
Infrastructure . . . . .	44-45
Goal V: Texas will improve state and local capacity to address Alzheimer’s disease.	
Objective 1 . . . . .	46
Objective 2 . . . . .	46
Objective 3 . . . . .	47
Objective 4 . . . . .	47
Objective 5 . . . . .	48
References . . . . .	49-50
Plan Contributors/Partners . . . . .	51-56

At least 14 million baby-boomers, those born between 1946 and 1964, will develop Alzheimer's disease or a related disorder in their lifetime, doubling the number of persons with this disease today.

# Executive Summary

Every 70 seconds, someone in the United States develops Alzheimer's disease.

There are now more than 5.3 million Americans living with this disease, including 5.1 million Americans 65 and older and approximately 200,000 under 65 with younger-onset Alzheimer's disease. It is the seventh leading cause of death in the U.S. and fifth leading cause of death for those over 65. At least 14 million baby-boomers, those born between 1946 and 1964, will develop Alzheimer's disease or a related disorder in their lifetime, doubling the number of persons with this disease today. By mid-century, it is estimated that someone in the United States will develop Alzheimer's disease every 33 seconds, or 2,618 new cases of Alzheimer's disease every day or 955,636 new cases every year (*2010 Alzheimer's Disease Facts and Figures, Alzheimer's Association*).

There is no cure for Alzheimer's disease and every person who develops this disease will die from its complications. Unlike other forms of dementia, it is progressive in nature and continues through cognitive and functional decline to total disability and death. The financial impact of Alzheimer's exceeds \$172 billion annually. Its impact in suffering and anguish defies calculation. The primary at-risk factor for Alzheimer's disease is advanced age, but contrary to popular misconception, it is not a normal part of aging. More women than men have Alzheimer's disease, but this is a consequence of their longer life expectancy. There is a growing body of research indicating that African Americans and Hispanic Americans may be at higher risk. Increasing prevalence of Alzheimer's disease is related directly to increasing human life expectancy rates in the United States. A person with Alzheimer's disease or a related dementia will live an average of five to eight years after diagnosis, but may live as many as 20 years or more following onset of symptoms.

The impact of Alzheimer's disease presents many challenges that cannot be dismissed or ignored:

- Clinicians are challenged to treat individuals with Alzheimer's disease at the earliest stage possible to delay its progression, while also helping individuals remain independent for longer periods of time.
- Researchers are challenged to work towards Alzheimer's disease prevention and cure, while also finding ways to delay onset of symptoms until later in life.
- Caregivers are challenged to provide appropriate care and support to family members living with Alzheimer's disease, while also finding ways to manage competing financial, physical, and emotional needs.
- Prevention is challenged by the widely-held belief that declines in brain health and cognitive function are a normal part of aging, when in fact such declines may possibly be delayed and have the potential to be mitigated with early detection and treatment.
- Infrastructure is challenged to meet the societal and economic impact of Alzheimer's disease, while also providing optimal, coordinated care and support systems for affected individuals.

The 2010-2015 Texas State Plan on Alzheimer's Disease was developed in direct response to increasing rates of Alzheimer's disease. Plan objectives provide specific recommendations for addressing the burden of this devastating disease on Texans and those who care for them. Ongoing coordination, information and resource sharing, partnership development, and capacity building are essential for creating a sustained and resourced statewide system to promote and advance recommendations of this plan.

## Goals of the Plan

- Goal I: Texas will support Alzheimer's disease research.
- Goal II: Texans will experience improved cognitive health throughout the life span.
- Goal III: Texans with Alzheimer's disease will experience improved quality of life through better disease management.
- Goal IV: Caregivers will experience enhanced levels of support through improved access to Alzheimer's disease/dementia care information and services.
- Goal V: Texas will improve state and local capacity to address Alzheimer's disease.

## Call to Action

Understanding the current and future burden of Alzheimer's disease in Texas and working collaboratively to implement the 2010-2015 Texas State Plan on Alzheimer's Disease is a pressing charge that cannot be taken lightly. Partners and stakeholders at local, state and regional levels are called upon now to adopt and incorporate activities outlined in this plan. By working together on a unified set of ambitious but thoroughly realistic and achievable goals and objectives, the effect of Alzheimer's disease across the state can be reduced and the quality of life of Texans with Alzheimer's disease and their families can be improved.



# Introduction

Alzheimer's disease (AD) is a progressive and irreversible brain disorder that is characterized by a steady decline in cognitive, behavioral, and physical abilities severe enough to interfere with daily life. Hallmark symptoms of Alzheimer's disease are memory loss, disorientation, and diminished thinking ability followed by a downward spiral that includes problems with verbal expression, analytical ability, frustration, irritability, and agitation. With disease progression, physical manifestations include loss of strength and balance, inability to perform simple tasks and physical activities, and incontinence. As more of the brain is affected, areas that control basic life functions like swallowing and breathing become irreversibly damaged, leading to death. The course of Alzheimer's disease and rate of progression vary from person to person, ranging from an average of five to eight years to more than 20 years from onset of symptoms (*Texas Council on Alzheimer's Disease and Related Disorders, 2008 Biennial Report*).

Alzheimer's disease is the seventh leading cause of death in the United States and has an economic burden that exceeds \$172 billion annually. Currently, 5.3 million people in the United States have Alzheimer's disease, including approximately 340,000 Texans. Nationally, Texas ranks third in Alzheimer's disease cases and second in Alzheimer's disease deaths. A new person develops Alzheimer's disease every

70 seconds, and current projections indicate that this rate will increase to one new case every 33 seconds by 2050. In 2009, there were an estimated 10.9 million unpaid caregivers of individuals with Alzheimer's disease in the United States, most of who were family members. These individuals were confronted day-in day-out with the enormous challenges of caring for a loved one with Alzheimer's disease. In Texas, 852,820 unpaid caregivers are providing care to an estimated 340,000 individuals with Alzheimer's — this equates to 971,191,823 hours of unpaid care at a cost of \$11,168,705,965 per year (*2010 Alzheimer's Disease Facts and Figures, Alzheimer's Association*).

By 2050, without prevention or cure, individuals 65 and older with Alzheimer's disease is projected to reach between 11 and 16 million  
*(2010 Alzheimer's Disease Facts and Figures, Alzheimer's Association)*.

Although Alzheimer's disease is not a normal part of aging, it is considered an age related disorder, affecting up to 13 percent of people 65 and older and increasing to 50 percent at 85 and older. These rates take on increasing significance with the

U.S. population older than 65 expected to increase from its present 13 percent to 18 percent by 2025. It is estimated that the number of people 65 and older with Alzheimer's disease will reach 7.7 million in 2030, almost a 50 percent increase from the 5.3 million who are currently affected. By 2050, without prevention or cure, individuals 65 and older with Alzheimer's disease is projected to reach between 11 and 16 million (*2010 Alzheimer's Disease Facts and Figures, Alzheimer's Association*).

With the first of the 76 million baby boomers reaching 65 in 2011, Alzheimer's disease and other age-related diseases will rank among the leading causes of morbidity and mortality. This will have significant economic and human ramifications (*Texas Council on Alzheimer's Disease and Related Disorders, 2008 Biennial Report*).

While the exact cause of Alzheimer's is not yet known, most experts agree that the disease probably develops much like other chronic conditions and probably results from multiple risk factors. Since the greatest risk factor for Alzheimer's disease is increasing age, many scientists consider the emerging field of prevention an exciting research area. A growing body of evidence suggests that brain health is closely linked to overall heart health. Some data indicate that management of cardiovascular risk factors such as high cholesterol, overweight, diabetes, and high blood pressure may help delay declines in cognitive function. Additional research points to the significant role physical activity and diet play in maintaining lifelong cognitive health (*2010 Alzheimer's Disease Facts and Figures, Alzheimer's Association*).

Currently there is no treatment to stop the deterioration of brain cells in individuals with Alzheimer's disease. Five drugs are approved by the Food and Drug Administration (FDA) that temporarily slow worsening of symptoms for an average of six to 12 months, for about half the individuals who take them. Researchers have identified treatment strategies that may potentially change the course of Alzheimer's disease, and a number of experimental therapies are currently in clinical trials (*2010 Alzheimer's Disease Facts and Figures, Alzheimer's Association*).

Despite a lack of disease-modifying therapies, studies consistently show that active medical management of individuals with Alzheimer's disease significantly improves their quality of life through all disease stages. Active medical management includes appropriate use of available treatment options, effective management of coexisting conditions, and use of supportive services such as counseling and activity and support groups (*2010 Alzheimer's Disease Facts and Figures, Alzheimer's Association*).

The human toll of Alzheimer's disease on patients and the informal network of family and friends in charge of their care is inestimable. Of the more than five million Americans with Alzheimer's disease, approximately 76 percent live at home and receive most of their care from family members. Each caregiving experience presents its own special circumstances and challenges.

Alzheimer's disease exacts an enormous toll on the healthcare system, American businesses, families, and individuals. Until it can be prevented, controlled, and/or cured, the impact of Alzheimer's disease will only continue to intensify (*Texas Council on Alzheimer's Disease and Related Disorders, 2008 Biennial Report*).

In response to these challenges, this plan was developed to comprehensively address Alzheimer's disease in Texas, and contains goals, objectives and strategies essential to reducing the impact and burden of Alzheimer's disease in Texas.

# Science

The aging population is dramatically increasing the incidence of Alzheimer's disease. More than 5.3 million Americans are already living with this disease, which is the seventh leading cause of death in the United States and the fifth leading cause of death for those over age 65. While other causes of death have been declining in recent years, those due to Alzheimer's disease have risen. Between 2000 and 2006, deaths due to heart disease, stroke, and prostate cancer declined by 12 percent, 18 percent, and 14 percent, respectively, whereas deaths attributable to Alzheimer's disease increased by 47 percent. By 2050, Alzheimer's disease is expected to strike nearly a million additional persons per year in the United States and affect an estimated 11 to 16 million Americans.

While these trends are similar in all states, the impact is particularly acute in Texas. Today, Texas ranks third in the nation (behind

California and Florida) in the estimated number of Alzheimer's cases and second in the number of Alzheimer's disease deaths. According to the National Alzheimer's Association, 340,000 Texans will be living with Alzheimer's disease by the end of 2010. In addition, individuals providing care for Alzheimer's patients in Texas grew from 690,058 to 852,820 between 2005 and 2009. Most of these care providers are unpaid family members. The estimated total value of this unpaid care in Texas increased from \$5.8 billion in 2005 to \$11.2 billion in 2009, the second highest in the nation. Texas businesses are also impacted by Alzheimer's disease, losing over \$14 billion annually in healthcare costs and lost productivity.

Therefore, there is a great need for Texas

to develop an infrastructure equal to the challenge and capabilities commensurate with the state's increasing burden imposed by Alzheimer's disease and related disorders. This requires establishing a greater capacity in Texas to provide leadership in the global fight against Alzheimer's disease. The Texas Legislature made a significant investment in Alzheimer's disease research to begin meeting this challenge. The Texas Alzheimer's Research Consortium (TARC) was established in 1999 by the 76th Texas Legislature. This legislative action mandated the Texas Council on Alzheimer's Disease and Related Disorders (Texas Council) to establish a Consortium of Alzheimer's Disease Centers among four state institutions:

Texas Tech University Health Sciences Center (Texas Tech), University of North Texas Health Science Center (UNTHSC), the University of Texas Southwestern Medical Center at Dallas (UT Southwestern), and

Baylor College of Medicine (BCM).

In 2005, Texas lawmakers approved the first appropriation for Alzheimer's disease research. This \$2 million investment provided start-up funding for TARC. In 2007, the 80th Texas Legislature nearly doubled the state's initial investment in TARC making it possible to recruit 500 Texans with Alzheimer's disease and 300 healthy control participants into the Texas Harris Alzheimer's Study to participate in cutting edge biomedical research.

These study volunteers undergo a battery of tests and provide blood and DNA samples annually at TARC member sites. The resulting wealth of uniformly collected clinical, neurocognitive and laboratory data is

Texas-based  
Alzheimer's disease  
research benefits the state  
in many ways.

combined in the new centralized Texas Alzheimer's Data Bank, based at UT Southwestern. TARC also has used state funding to establish the first Texas bio-bank of stored blood, tissue and DNA to support current and future Alzheimer's disease research studies. Researchers across Texas are able to utilize these unique resources to answer specific questions about Alzheimer's disease, both now and in the future, as new information leads to new ideas.

In September 2008, the Texas Council voted to add the University of Texas Health Science Center at San Antonio (UTHSC-SA) to TARC. This addition, coupled with the 2009 state appropriation of \$6.85 million, enabled TARC to begin recruiting a large number of Hispanic individuals into the Texas Harris Alzheimer's Study and extended TARC's reach to South Texas. Inclusion of underrepresented Hispanics significantly strengthens Texas Alzheimer's disease research efforts. More than one-third of Texans are Hispanic, and, according to the Texas State Data Center, Texas will become a majority Hispanic state between 2025 and 2035. With its sizeable Hispanic population, Texas is uniquely positioned to assume a national leadership role in this largely untapped area of Alzheimer's disease research.

There are important interactions between Alzheimer's disease and heart disease, diabetes and other health conditions that are common in Hispanics. In its report, *Hispanics/Latinos and Alzheimer's Disease*, the national Alzheimer's Association predicts that Alzheimer's disease and related dementias among Hispanics could "increase more than six-fold" to as many as 1.3 million by 2050—and calls this development "a looming but unrecognized public health crisis."

Hispanic participation in Alzheimer's disease research has historically been low across

the nation. Texas is presented with the unique opportunity to assemble the nation's only large-scale, well-characterized group of Non-Hispanic and Hispanic Alzheimer's disease research participants with considerable genetic, blood, clinical and cognitive markers, making possible comparative research to advance detection, treatment and prevention of Alzheimer's disease. In addition to TARC's efforts at the UTHSC-SA, there are a number of projects in Texas that enroll Hispanic individuals for aging studies. For example, UTHSC-SA has also participated for many years in the San Antonio Longitudinal Study of Aging (SALSA). This study has tracked development of diabetes, heart disease and stroke in Hispanic research participants of all income levels. Having historical data on these participants' diabetes and related conditions makes their recruitment for Alzheimer's disease research all the more valuable. In addition to SALSA, Project Frontier, led by Texas Tech researchers, enroll Hispanic and rural Texans into a longitudinal study of aging. Furthermore, BCM has several projects underway to understand how to measure cognition in Spanish-speaking patients with Alzheimer's disease and how to understand those particular risks associated with the high rate of diabetes among Hispanics. These are but a few examples of the many projects across the state. In addition, both Texas Tech and UT Southwestern are using telemedicine technology to explore use of this cutting-edge research tool to expand diagnostic services to rural populations. These projects present important opportunities for collaboration between Texas researchers and institutions to capitalize on Texas' unique position to increase participation of underserved groups in Alzheimer's research.

Texas-based Alzheimer's disease research benefits the state in many ways that include, but are not limited to the following:

- **Advances in detection.** Using a



multi-disciplinary/translational approach, that includes blood biomarkers, genetic material, imaging and neurocognitive data, as well as psychological, neuropsychological, behavioral and general medical information, Texas researchers are developing new methods for early Alzheimer's detection.

- **Ability to predict risk.** Recruitment and follow-up of normal elders, along with patients with Alzheimer's disease, will enable scientists to better understand factors leading to increased risk for this disease. TARC researchers have begun this process by looking at information on biomarkers, lipid metabolism, genetics and clinical testing as they relate to the disease. However, many more factors remain to be examined. Early identification of Alzheimer's disease risk will make it possible to create therapies to prevent or delay disease onset.
- **Better tracking of Alzheimer's disease progression.** By leveraging Texas' medical and university infrastructure, Texas-based scientists can identify individual differences among patients that influence the disease progression rate. Data gathered from these studies will help identify new therapies to slow its development and improve quality of life.
- **The best in personalized medicine.** Texas scientists can use advances created by these Texas-based research initiatives to develop new treatments that address a patient's individual Alzheimer's disease "profile," as defined by specific genetic, blood biomarker, general medical, behavioral, psychiatric, and other risk factors.
- **Advances in basic science.** While great progress has been made, researchers are still searching for definitive answers to questions about basic mechanisms of Alzheimer's disease. Advancing understanding of these mechanisms through basic research can benefit Texas by

expanding scientific discovery and identifying additional treatment targets.

Sustaining a competitive edge in Alzheimer's research will benefit Texas. Ongoing research support will help Texas meet two of its four major goals for improving higher education by 2015. The Texas Higher Education Coordinating Board noted in its landmark report entitled "*Closing the Gaps: The Texas Higher Education Plan*" that the state's economy could be adversely affected unless steps are taken to create centers of excellence at the state's institutions of higher education and increase Texas' share of federal research funding, while also increasing competitive state-funded research grants.

A sustained investment in Alzheimer's disease research also increases Texas researchers' ability to leverage this commitment and obtain funding from the National Institutes of Health (NIH) as well as other public and private groups for both clinical research using human participants and basic laboratory research.

Texas' commitment to Alzheimer's disease research will foster scientific excellence at state health science centers and medical schools and promote innovative technologies that can potentially attract increased external economic investments in Texas. Evidence of this effect is already beginning. Since 2005, there has been a substantial increase in Alzheimer's disease research at the majority of Texas universities and health science centers. "Over the last five years, Texas-based investigators have continually increased their portion of highly cited Alzheimer's disease papers within the context of U.S. based Alzheimer's disease research as well as within the context of the global effort to better understand Alzheimer's disease" (*Aaron Sorensen, Scientometrics Editor, Journal of Alzheimer's Disease*).

Historically, most Alzheimer’s disease research occurred at BCM and UT Southwestern. Building upon these anchors, a broad-based expansion of Alzheimer’s disease research has occurred across Texas over the past five years. Texas now leads in a number of areas of research. Working together through TARC mechanisms can align and build a formidable research enterprise, increasing research funding and educational opportunities for all Texans. Boosting state capacity as a center for biotechnology and pharmaceutical development can positively impact hundreds of thousands of Texans with Alzheimer’s disease.

Sustained support for Alzheimer’s research makes Texas an attractive partner for national research projects and will attract more research funding to Texas. Texas has both private sector partnerships and the collaborative TARC structure necessary to begin streamlining transfer of research breakthroughs into drug trials and patented therapies to better treat Texans suffering from Alzheimer’s disease. Sustaining momentum in Alzheimer’s disease research is critical to addressing one of the largest public health challenges facing Texas and the nation, while enabling Texas to become a national leader. Achieving the Texas research goal to delay and ultimately prevent Alzheimer’s disease, as recommended by the National Alzheimer’s Study Group, requires a concerted focus on combining clinical and basic studies to yield effective treatments resulting from laboratory bench work. This approach will facilitate transfer of research discoveries into clinical practice improvements. While progress has been made toward this goal, researchers are still searching for definitive answers to questions about basic mechanisms of Alzheimer’s. In order to accelerate basic

scientific discovery and develop additional targets for treatment, Texas should encourage and support funding in all these areas.

Development of research programs that cut across disciplines is another approach needed to quicken discovery. For example, exploring potentially significant lifestyle modifications, such as diet and exercise alone, is insufficient — pharmacological and behavioral interventions must be integrated in order to develop therapies aimed at Alzheimer’s disease prevention. Texas scientists, through collaboration between behavioral sciences and biomedical research, are developing prevention tools and interventions for those coping with Alzheimer’s disease. This kind of multi-disciplinary research, typically not funded by national health and science foundations, offers significant opportunities to study disease progression and advance therapeutic strategies. Establishing outcome-oriented projects backed by appropriate funding mechanisms and active collaboration with other stakeholders is important. Working with a variety of stakeholders to clarify and streamline pathways for increasing preventive and risk-reducing therapies is a critical task.

Almost everyone knows someone whose life, including a lifetime of memories, has been unraveled by Alzheimer’s disease. Continuing support of Alzheimer’s research will position Texas as a leader in the race to find new ways to detect, delay, treat and ultimately prevent this devastating disease. The following objectives have been developed to strengthen Texas’ commitment to continued Alzheimer’s disease research.

## GOAL I: Texas will support Alzheimer's disease research.

**Objective 1: By August 31, 2015, increase funding to the Texas Alzheimer's Research Consortium to further understanding of the biology of Alzheimer's disease for improved early detection and novel approaches for prevention and treatment.**

### **Rationale:**

Increased funding for the TARC is critical to Texas' efforts to conduct Alzheimer's disease research and will result in a number of important initiatives. These funds will enable creation of an administrative core (a Translational Research Core) within TARC to conduct human clinical trials. This core would translate TARC discoveries into potential new therapies that would benefit Texans suffering from Alzheimer's. Although a large number of clinical trials have been conducted, virtually all have failed to produce effective therapies. TARC Translational Research Core is to find ways to speed up clinical trials of new drugs by identifying novel clinical and biological markers for disease that could be used to evaluate effectiveness of drugs being tested. These markers would also be useful for selecting patients who are more likely to benefit from the investigative treatment, thereby increasing trial sensitivity to demonstrate efficacy. In addition, increased funding could result in creation of a pilot grant program aimed at supporting academic Texas researchers conducting innovative clinical and basic research. These pilot grants will focus primarily on junior researchers and are intended to increase access and utilization of TARC resources by investigators at both TARC and non-TARC institutions.

### **Strategies:**

1. Support efforts to increase funding by ten percent to maintain patient enrollment in the Texas Harris Alzheimer's Study.
2. Develop and distribute data and informational materials to inform potential funders about possible benefits of increased Alzheimer's disease research.
3. Make available detailed information regarding progress and discoveries made by TARC investigators.
4. Compile a compendium of ongoing state-funded projects and future TARC research efforts.
5. Present TARC's specific plan for translating basic scientific discoveries into improved methods for diagnosis, treatment, and prevention of Alzheimer's disease to the scientific community.
6. Create a state-level committee to identify Alzheimer's disease research priorities in Texas.
7. Improve targeted funding opportunities to increase interdisciplinary, multi-institutional collaborations in Alzheimer's disease research.

## GOAL I: Texas will support Alzheimer's disease research.

**Objective 2: By August 31, 2015, increase funding by 25% for non-TARC Alzheimer's disease research in Texas.**

### **Rationale:**

Additional funding is needed to expand non-TARC Alzheimer's disease research in Texas. Creation of an organized plan to acquire these funds is the first important step in achieving this objective. While these efforts will begin with NIH, the largest single source of medical research funding, additional public and private funding sources should be targeted.

### **Strategies:**

1. Quantify the current level of research funding for Alzheimer's disease in Texas and prepare a comprehensive list of all active Texas-based Alzheimer's disease investigators, funded and non-funded.
2. Establish a system for Texas research institutions to annually report research projects and funding sources to the Texas Council on Alzheimer's Disease and Related Disorders.
3. Utilize available information to profile productivity of Alzheimer's disease research in Texas, relative to other states.
4. Develop a program to leverage resources among Texas investigators and affiliated researchers for joint applications for federal research funding through 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.
5. Create an on-line clearinghouse of external, non-state supported research funding opportunities available for any Texas researcher working in Alzheimer's disease and dementia.
6. Establish a research work group to identify funding sources to improve researchers' capacity to attract external research dollars.
7. Encourage development of Alzheimer's disease centers of excellence that can compete for federal support.
8. Promote private funding of Alzheimer's disease projects by disseminating research results of Texas-based scientists among lay communities.
9. Convene an annual forum for Alzheimer's disease researchers from across the nation to meet, discuss, and plan future collaborations.
10. Expand research areas and disciplines engaged in Alzheimer's disease research via funded, collaborative trans-disciplinary grant applications.



## GOAL I: Texas will support Alzheimer's disease research.

**Objective 3: By August 31, 2015, establish a minimum of two non-state funded research projects with special emphasis on the impact of Alzheimer's disease and cognitive aging on the state's underserved individuals, including African Americans, Hispanic Americans, Native Americans, and rural Texas seniors.**

### Rationale:

Hispanic Americans and African Americans, among other minorities, may be at increased risk for developing Alzheimer's disease at a younger age, possibly because many risk factors for Alzheimer's disease, such as high blood pressure, diabetes, and high cholesterol, are much more prevalent within these ethnic groups, who are also underrepresented in medical research. Although 20 percent of the nation resides in rural locations, there is very little information on occurrence of risk factors, presentation, and prevalence of Alzheimer's disease among rural elders. Different environmental exposures may lead to disproportionate risk among these elders. Texas' ethnic and geographic diversity provides a unique opportunity to address Alzheimer's disease among these underserved groups. There are ongoing Texas studies that can, and should, collaborate to begin systematic study of Alzheimer's disease among Hispanic-American, African American, and rural Texans. Use of telemedicine technology is but one example of expanding research and clinical services to these populations. Increased research funding will make it possible for Texas to expand its efforts and thereby assume a national leadership role in these Alzheimer's disease research areas.

### Strategies:

1. Develop collaborative relationships between ongoing Texas-based health outcome studies already enrolling elderly ethnic minorities and medically underserved populations to facilitate recruitment of underserved individuals into aging and Alzheimer's disease specific studies.
2. Create and distribute appropriately tailored informational materials on aging and Alzheimer's disease research studies to underserved Texas communities for volunteer recruitment.
3. Expand use of telemedicine technology applications in research protocols to reach rural populations and communities.
4. Investigate collaborations with Latin-American, bi-national colleagues to embark in lifestyle risk assessment of Hispanics.

## GOAL I: Texas will support Alzheimer's disease research.

**Objective 4: By August 31, 2015, increase utilization of TARC's database by non-TARC Texas researchers to a minimum of three new projects per year.**

### **Rationale:**

TARC is a state asset. As such, resources developed through TARC must be shared with other Texas researchers interested in Alzheimer's disease research. Further, progress toward achieving TARC's goals can best be made by organizing, nurturing and promoting a greater interest in Alzheimer's disease research across the state. This can be realized only if medical as well as other Texas researchers are aware of TARC and available resources to further Alzheimer's disease research. Information distribution about TARC and its resources to Texas medical researchers is a priority.

### **Strategies:**

1. Generate and distribute information describing available TARC data and procedures for requesting data for analysis.
2. Disseminate information to the Office of Research at each Texas-based university, including university media contacts, and selected personnel within institutions.
3. Create a working group/taskforce to interact with TARC's data coordinating center to ensure a user-friendly process for requesting and obtaining data.
4. Develop a Texas list of present and potential Alzheimer's disease researchers by institutions.
5. Assess the feasibility of establishing TARC-funded pilot research grants that support new Texas-based Alzheimer's disease research.
6. Develop a multi-institutional resource sharing system/database that promotes collaborative sharing of information and resources between researchers at all Texas institutions.
7. Identify researchers at existing TARC sites to serve as collaborators and/or mentors for non-TARC Texas-based junior researchers and those who may be new to Alzheimer's disease research.
8. Convene an annual statewide research symposium to highlight Alzheimer's disease research within Texas as well as promote collaboration and resource sharing.
9. Promote awareness of Alzheimer's disease research at academic institutions, hospitals and disease-related businesses.

## GOAL I: Texas will support Alzheimer's disease research.

**Objective 5: By August 31, 2015, advance one recommendation of the Alzheimer's Study Group Strategic Plan by encouraging Texas researchers to collaborate across the scientific spectrum of developmental science and basic research.**

### Rationale:

A disciplined and comprehensive strategy, backed with sufficient public and private investment, is essential for realizing this objective. By promoting research collaboration among institutions and across disciplines, Texas can accelerate the quest for improved diagnosis, treatment, and ultimately, prevention of Alzheimer's disease. These collaborations can only be achieved by integrating cognitive and behavioral research directed towards greater understanding of lifestyle, socioeconomic, psychological, and behavioral risk factors with currently existing biomedical research objectives. Actively supporting Texas researchers in obtaining public and private funding for projects that encourage, support, and promote research across the scientific spectrum of dementia research interventions is required.

### Strategies:

1. Support increased funding for collaborative dementia research across Texas.
2. Develop and distribute data and informational materials to educate public corporations and policymakers about the need for interdisciplinary Alzheimer's disease research.
3. Develop an authoritative list of all active Alzheimer's disease researchers (including basic and clinical research, behavioral research, and cognitive investigators) and their affiliated research institutions.
4. Facilitate acquisition of funding by Texas researchers from the Veteran's Administration, Centers for Disease Control and Prevention, and other federal and private funding sources for multi-disciplinary and multi-institutional collaborative projects.
5. Develop, maintain, and distribute a compendium of ongoing funded Alzheimer's research projects, multi-institutional collaborations, and multi-disciplinary studies within Texas.

## Prevention and Brain Health

Many adults believe that aging is a time of irreversible mental decline and that dementia is inevitable. Factually, declines in cognitive function do not necessarily correlate with the normal aging process. Much like physical health, cognitive health can be viewed along a continuum – from optimal functioning to mild cognitive impairment to severe dementia.

The human brain contains over 100 billion nerve cells (neurons) that work together in networks to perform specific functions. These networks have very specific purposes. Some are involved in forming new memories, recalling old memories, thinking and learning. Others are tasked with controlling the five senses and telling muscles when to move. Alzheimer's disease destroys brain cells, causing these networks to cease normal functioning. As these networks begin to fail, the brain is able to re-route networks to maintain function for a limited period of time. Progression of Alzheimer's disease will ultimately accelerate beyond the brain's ability to recover function.

Alzheimer's disease typically unfolds slowly in patients. Therefore, it is easy to ignore until significant symptoms appear. By the time there are symptoms, treatments that exist may not alter the disease's course. While the ultimate solution to the Alzheimer's crisis is cure, there are steps that can be taken with hope of reducing cognitive decline. Promising prevention and brain health research is now focused on eliminating risk factors that are known to damage the

brain, and increasing those behaviors which promote good brain health. Although there is no proven link between controlling these measures and cognitive performance for Alzheimer's disease prevention, the current body of research indicates a strong correlation between risk for Alzheimer's disease and conditions that damage the heart and/or blood vessels. These conditions include high blood pressure (hypertension), heart disease, stroke, diabetes and metabolic syndrome, elevated blood homocysteine, and high cholesterol

*(2010 Alzheimer's Disease Facts and Figures, Alzheimer's Association).*

Keeping physically, mentally and socially active have been hypothesized to be key factors in reducing one's risk of Alzheimer's disease. Just as Dr. Kenneth Cooper's theories about the positive relationship between aerobic exercise and higher

levels of cardiovascular health have been validated throughout the past three decades, scientific studies are now demonstrating a positive relationship between prevention or treatment of risk factors and increased brain health. Researchers have suggested the beneficial effects of a Mediterranean-type diet – fruits, nuts, legumes, fish rich in omega-3 fatty acids, and olive oil as the major source of monounsaturated fat – in reducing the rate of cognitive decline as measured by the Mini-Mental Status Exam (MMSE) (Knopman, 2009). The Mediterranean type diet can also have a positive impact on lowering blood cholesterol, which can lead to better heart health.

A person's physical health can now easily outlast his or her cognitive and mental abilities. Advancing age presents a classic paradox: people want to live as long as they can, but do not want to experience a decline in their cognitive abilities  
*(AARP's Educator Community).*

Keeping the total cholesterol level below 200 also may reduce the risk of developing dementia later in life. A longitudinal study lasting over 40 years found that even borderline to moderately high cholesterol detected in forty year old individuals greatly increased the chances of having Alzheimer's disease or other dementias later in life. Persons with borderline cholesterol had a 52 percent higher risk of vascular dementia. While this study demonstrated a strong link between borderline to moderate cholesterol and risk for Alzheimer's disease and other dementias, the relationship between the two remains unclear. The implication is quite clear, however, reducing cholesterol through improved diet, lifestyle changes and physical activity improves your heart health and may reduce risk of Alzheimer's and other dementias (Solomon et al., 2009).

Medical technology has exponentially increased lifespan during the 20th century, from 46 to 78 years at present. Advances in medicine have led to cures and treatments of many diseases, such as cancer, heart disease, and tuberculosis. These diseases were not survivable a century ago. Yet, Alzheimer's disease and other dementias create problems on a scale never before imagined. A person's physical health can now easily outlast his or her cognitive and mental abilities. Advancing age presents a classic paradox: people want to live as long as they can, but do not want to experience a decline in their cognitive abilities (*AARP's Educator Community*).

Public health initiatives for improving early detection for many diseases have greatly improved the public's knowledge and access to routine screenings for various chronic conditions, such as high blood pressure and diabetes. Efforts to provide education on primary prevention, such as not smoking and proper nutrition and

physical activity have added years to the American lifespan and enhanced quality of life in later years. However, a significant problem in the current healthcare system is a lack of coordination and payment for preventive healthcare.

Physicians and other primary care providers are presently not reimbursed to deliver appropriate preventive measures. Under current reimbursement methods, physicians and other primary care providers are paid for episodic treatment and management of disease states. Current reimbursement policy effectively discourages valuable between-visit care and support for people with dementia and their family caregivers.

Many primary care practitioners are not prepared to screen and diagnose Alzheimer's disease and other dementias. Some of these issues may stem from a lack of education and understanding of Alzheimer's disease and treatment options. Or, they may result from insufficient resources required to adequately provide a screening and diagnostics program. An obvious consequence is that larger numbers of people go without a proper diagnosis of Alzheimer's disease or other dementias at the earliest stage possible, when the patient is most likely to benefit from treatment.

Objectives and strategies that follow were designed to strengthen and advance awareness of the relationship between prevention and brain health fitness. These activities are developmental in nature, as there are no current established national or state performance measures from which to begin this work. It is believed that these recommendations will serve as a starting place for changing the way Texans think and behave regarding brain health.

## GOAL II: Texans will experience improved cognitive health throughout the life span.

**Objective 1: Ongoing, the Texas Alzheimer’s Disease Partnership will submit proposals to the Behavioral Risk Factor Surveillance System to obtain Texas-specific data related to brain health fitness.**

### **Rationale:**

Having accurate surveillance data helps states measure the burden of disease, guide public health priorities, target interventions, and set healthcare policy. Surveillance data help us understand who is affected by a particular disease, what health behaviors may increase risk, and how this disease affects the person and his or her quality of life. In order to obtain data needed to assess brain health fitness, reliable surveillance is needed. The Behavioral Risk Factor Surveillance System (BRFSS) is a state-based system of health surveys that collects information on health risk behaviors, preventive health practices, and healthcare access primarily related to chronic disease and injury. Established in 1984 by the Centers for Disease Control and Prevention (CDC), the BRFSS is the largest telephone health survey in the world. BRFSS data is collected monthly in all 50 states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, and Guam, and more than 350,000 adults are interviewed each year (CDC).

At present, there are no state or national population-based measures for assessing brain health fitness. For years, the burden of cognitive impairment has been expressed in terms of incidence, prevalence, and mortality for dementias such as Alzheimer’s disease.

Therefore, taking the lead role on developing and implementing new surveillance measures to identify and provide baseline and trend data is essential. As outlined in the following strategies, a workgroup will be established to develop key recommendations relevant to brain health fitness surveillance as well as questions to include on BRFSS surveys. This objective serves as an important first step to increasing the number of measures to accurately describe brain health fitness.

### **Strategies:**

1. Explore and secure funding sources to support BRFSS survey questions.
2. Establish a workgroup to identify, develop, or use existing standardized BRFSS questions.
3. Work with the Department of State Health Services to prepare and submit BRFSS proposals to BRFSS Coordinator.
4. Monitor status of BRFSS proposals and make necessary changes to questions based on feedback from BRFSS Coordinator.



## GOAL II: Texans will experience improved cognitive health throughout the life span.

**Objective 2: By August 31, 2015, increase resources needed to advance and elevate brain health fitness and prevention awareness and education efforts in Texas.**

### **Rationale:**

Texans are living longer with greater physical health status than ever before. This extension of physical vitality is marred by increased impairment in cognitive and mental abilities. The majority of Texans will suffer from declining brain health fitness with increasing age. But this condition may be able to be avoided. The potential for Texans to experience improved brain health fitness as they enjoy longer life spans must be anticipated now.

The brain is highly modifiable. New brain discoveries suggest that more can be done to strengthen brain health fitness than almost any other organ. Appropriate mental and physical activities can potentially offset some types of mental decline in later adulthood (Elias & Wagster, 2007). Even in Alzheimer's disease, it is possible to extend brain health fitness with early detection and early treatment (Chapman et al., 2005). The earlier brain health fitness is addressed, the greater the potential to make progress against sources of reduced mental activity such as: aging, chemotherapy, general anesthesia, silent strokes, and diseases that impair brain health – even Alzheimer's disease.

This initiative calls for a comprehensive effort to advance and elevate brain health fitness in Texas. Major resources are required and will involve partnerships across all segments of public and private society

including corporate Texas, insurers, businesses promoting healthy aging, food industry, and pharmaceuticals and related resources. Through public education and other awareness programs, Texans can free themselves of the stigma and fears associated with assessments of brain health status and reduce the gap between brain health span and lifespan.

### **Strategies:**

1. Identify and support funding opportunities to address and advance brain health fitness.
2. Establish a brain health fitness consortium to provide compelling data on emerging science and translation of research into practice.
3. Develop white papers to educate policymakers on brain health fitness.
4. Support efforts to increase funding and/or legislation for brain health fitness, prevention, awareness, and education.
5. Maintain brain health fitness partnership activities and convene bi-yearly meetings.

## GOAL II: Texans will experience improved cognitive health throughout the life span.

**Objective 3: By August 31, 2015, develop a compendium of targeted preventive brain health fitness screening recommendations and education for healthcare professionals in Texas to establish brain health fitness benchmarks and promote brain health fitness.**

### Rationale:

Medical research is confirming the connection between physical health and brain health. It is now known that a life-time of healthy living has a direct impact on brain health. Just as physical exercise strengthens the body, mental activities strengthen brain health. Just as regular medical check-ups are the foundation for physical health, similarly, assessments of the brain are essential to brain health. Unfortunately, assessment of brain health is not a routine part of the lifestyle of even people who may otherwise be conscientious regarding health maintenance. The result is that by the time most individuals receive a diagnosis of deteriorating brain health fitness, significant, possibly preventable damage has already occurred.

Increasing public awareness of the potential to maximize brain health fitness and lessen cognitive decline with aging is a critical step. But more needs to be done by the medical community as well. It is imperative that primary care providers begin to screen baseline brain health fitness. Initial screening at 50 years of age provides an excellent benchmark. The following strategies address development of effective clinical tools and protocols for measuring brain fitness. These tools, when utilized as part of a regular plan of preventive healthcare, can significantly impact long-term preservation of memory, critical thinking, and decision-making.

### Strategies:

1. Establish a workgroup to identify effective screening tools and brain health fitness recommendations for all Texans.
2. Create a compendium of identified screening tools and brain fitness recommendations.
3. Develop multimedia education programs to promote recommendations for healthcare professionals and the public.
4. Determine best processes for dissemination of screening tools and brain health fitness recommendations for healthcare professionals.
5. Establish brain health fitness continuing education credits for all healthcare professionals.



## GOAL II: Texans will experience improved cognitive health throughout the life span.

**Objective 4: By August 31, 2015, develop one web-based clearinghouse that provides comprehensive information and resources on Alzheimer's disease and overall brain health for the Texas public and healthcare sectors.**

### **Rationale:**

Individuals seeking health information often turn to the internet. Here they find no shortage of information. Literally, millions of articles and websites expound on different aspects of diseases, including Alzheimer's. This abundance of information, rather than being helpful, can actually be a source of confusion and uncertainty. News about Alzheimer's disease and brain health comes from two primary sources: scientific and non-scientific. Scientific information is published after a scientific study or research project. This information is useful and can help Texans understand why preventing Alzheimer's disease is important. Non-scientific information is generally anecdotal and although interesting may be inaccurate or misleading.

Telling the difference between scientific information and anecdotal information can be difficult. It is important that individuals have access to information about Alzheimer's disease that is accurate, science/evidence-based, and reliable. Consequently, creation of an internet-based Alzheimer's disease and brain health "clearinghouse" website that contains accurate, relevant and timely information is required. On this website, Texans will find information on: disease facts; prevention research and brain health fitness; treatment options; state and community resources; and frequently asked questions. The clearinghouse will be shaped by a team of information management and technical experts.

### **Strategies:**

1. Establish a Clearinghouse Steering Committee to develop the conceptual framework, including vision, design, implementation, and evaluation plans.
2. Secure funding to support clearinghouse design, development, implementation, and evaluation.
3. Establish a workgroup to identify information and resources to be included within the clearinghouse.
4. Bring together technical experts to plan and implement clearinghouse technical aspects.
5. Establish an oversight/monitoring workgroup to update and assimilate new data into the clearinghouse bi-annually.

## GOAL II: Texans will experience improved cognitive health throughout the life span.

**Objective 5: By August 31, 2015, one annual assessment will be completed to measure the effectiveness, satisfaction, relevance, and utilization of the Texas Alzheimer's/brain health fitness clearinghouse.**

### **Rationale:**

In this era of technological advancement and instantaneous access to electronic information, an annual clearinghouse review will ensure that information contained is accessible, appropriate, and relevant to current concepts within the Alzheimer's/brain health field. A workgroup of experts across an array of disciplines will be established with the primary responsibility of completing an annual clearinghouse review and providing improvement recommendations.

### **Strategies:**

1. Establish a workgroup to develop metrics for clearinghouse criteria, such as reach, relevance, access, best evidence, quality operations, adherence to budget/return on investment and other metrics as identified by the Clearinghouse Steering Committee.
2. Identify yearly assessment timelines and reporting mechanisms and initiate assessment action with the designated evaluative entity.
3. Develop an annual written assessment of findings and recommendations and present to the Clearinghouse Steering Committee.

## GOAL II: Texans will experience improved cognitive health throughout the life span.

**Objective 6: By August 31, 2015, increase the number of Texas organizations by one per year that will promote information on the relationship between brain health fitness and overall health in their programs' communications and activities.**

### Rationale:

Unfortunately, the general public remains uninformed of how physical health directly impacts cognitive health. This lack of awareness stems from unavailability of print and other materials designed to educate the public of this important relationship. Many barriers confront this public education effort. One of these is geographical. Texas is the second largest state in the nation. Reaching the far corners of this huge area will require efforts of multiple partners and stakeholders working collectively to create awareness. Texas is also an ethnically diverse state. Ensuring that content and means of informing this diverse public requires close alliances among representatives of all ethnic groups.

Members of the Texas Alzheimer's Disease Partnership will build an alliance with one organization per year to promote information on the relationship between brain health fitness and overall health in their programs' communications and activities. By targeting one key organization per year, the partnership can focus on maintaining a growing and stable relationship, ultimately ensuring long-term success. Joint collaboration and promotional efforts with various organizations around Texas will not only allow the partnership to reach and educate a larger population on brain health, but it will increase participation and awareness for future partner agencies as well. Strategies that follow call for a strategic effort to educate Texans of the critical interplay of a healthy lifestyle and cognitive abilities.

### Strategies:

1. Identify organizations and programs to target (i.e. Texas Medical Association, Texas Nurses Association, Texas Academy of Family Physicians, Texas Nurse Practitioners).
2. Establish a development workgroup to identify and prepare materials for promotion to organizations (white papers, briefing papers, etc.).
3. Initiate meetings with organizations to discuss the importance and urgency of promoting current information on brain health fitness.
4. Secure participation for collaborative promotional efforts with organizations.
5. Maintain ongoing relationships with partner organizations and actively work to increase numbers of partner agencies.
6. Publish all materials, including slide presentations, to the Alzheimer's/brain health fitness clearinghouse for use by partnering organizations.

## Disease Management

The term “disease management” grew out of managed care and generally refers to a range of activities focused on returning people with chronic illnesses to a healthier state and helping them to effectively deal with disease complications. More recently, the term has been used to encompass the whole system of coordinated healthcare interventions integrated into an overall continuum of care for the chronically ill. Effective and comprehensive Alzheimer’s disease management on a statewide level will require rethinking previous disease management practices in an Alzheimer’s disease setting. New approaches will be required, bringing together disease managers with all facets of disease management practices.

Redefining disease management as it relates to an Alzheimer’s setting begins with identifying key players, such as those individuals and organizations that can most directly improve quality of life for people with Alzheimer’s disease and their families. Primary stakeholders are those who are engaged in direct provision of healthcare related treatments and therapies, including the patient, family members and or primary caregivers, primary care physicians, specialists, researchers, and other healthcare workers. Secondary stakeholders are those who are similarly involved in providing treatment and services, and include noncaregiver family members, physician networks/organizations, related healthcare workers/networks/organizations, not-for-profit healthcare service providers, faith-based personnel, and law-enforcement and first responder personnel. The third level of disease

managers includes employers, elected officials, healthcare insurance providers (public and private), the pharmaceutical industry, and the general public.

Improved quality of life for persons with Alzheimer’s disease can be achieved through an all-inclusive, statewide system of disease managers, employing better disease management practices and initiatives.

Alliances must be formed, and institutions, organizations, agencies, and private business must join together as a statewide disease-management team. The impact of Alzheimer’s disease is far reaching, extending to all aspects of public and private enterprise. All sectors of society are invited to voluntarily participate in and/or support development and implementa-

tion of a comprehensive, statewide system of an enhanced and expanded Alzheimer’s disease management initiatives in Texas.

The following objectives and strategies are comprehensive in scope and are designed to support effective disease management. Any initiative developed and implemented under a statewide plan will impact not only the patient with Alzheimer’s, but also family members who are frequently the primary caregiver and generally considered to be the secondary casualties of Alzheimer’s disease. These recommendations, when implemented, will elevate and advance comprehensive Alzheimer’s disease management in Texas on an unprecedented level and provide a framework from which to evaluate present initiatives, launch future interventions, and provide for quantifiable improvements.

Improved quality of life for persons with Alzheimer’s disease can be achieved through an all-inclusive, statewide system of disease managers, employing better disease management practices and initiatives.

## Goal III: Texans with Alzheimer's disease will experience improved quality of life through better disease management.

**Objective 1: By August 31, 2015, Texas will increase by 1,000 the number of healthcare professionals who integrate clinical best practices into the early detection, diagnosis and pharmaceutical treatment of persons with Alzheimer's disease.**

### Rationale:

No treatment is available to slow or stop deterioration of brain cells in Alzheimer's disease. Five drugs are currently approved that temporarily slow worsening symptoms for on average, six to 12 months, and for about half of the individuals who take them. Despite current lack of disease-modifying therapies, studies consistently show that active medical management of Alzheimer's disease can significantly improve quality of life through all disease stages for individuals and their caregivers. Active management includes appropriate use of available treatment options, effective integration of coexisting conditions into the treatment plan, and use of supportive services such as counseling, activity and support groups, and adult day center programs.

It is recommended that clinical guidelines be developed in order to promote best practices for recognizing, diagnosing, and providing treatment to individuals with Alzheimer's disease or a related dementia. These guidelines should be targeted to primary healthcare professionals, including physicians, nurse practitioners, physician assistants, social workers, nurses, and other professionals providing primary care to patients with Alzheimer's and their families. Recommendations for management of associated neuropsychiatric symptoms and coexisting medical conditions often seen in persons with Alzheimer's disease will be incorporated into these guidelines. Patients with Alzheimer's disease often need concomitant medication for treatment of diverse central nervous system disorders associated with

progressive brain dysfunction (Cacabelos). Suggestions for easily administered and scored appraisal tools will be incorporated when possible, as well as diagnostic and treatment pearls.

### Strategies:

1. Establish a statewide workgroup to develop and disseminate best practices guidelines.
2. Identify educators to provide continuing medical and nursing education approved presentations on clinical best practices.
3. Work with speaker's bureau on outreach activities in rural areas.
4. Identify opportunities to present at local healthcare professional meetings (i.e. county medical societies, nursing district meetings).
5. Promote inclusion of best practices curriculum into medical schools, nurse practitioner and physician assistant programs.
6. Provide guidelines to medical schools and hospital education through Grand Rounds, continuing medical and nursing education.
7. Develop an on-line educational series for healthcare professionals.
8. Collaborate with a broad spectrum of professional organizations to promote guidelines at conferences and other functions.

## Goal III: Texans with Alzheimer's disease will experience improved quality of life through better disease management.

**Objective 2: By August 31, 2015, increase by 1,000 the number of persons with Alzheimer's disease who participate in new and experimental clinical/research trials in Texas.**

### **Rationale:**

Critical to Alzheimer's disease research is willingness on the part of persons with Alzheimer's disease, at various stages of disease progression, to voluntarily participate in clinical trials and studies. Prior to utilization of therapies or pharmacological interventions in clinical practice, rigorous testing is required. Clinical trials are vital to testing possible interventions to diagnose, prevent, treat and hopefully result in a cure for Alzheimer's disease. They require long-term observation and analysis in large groups and require broad participation by both persons with Alzheimer's disease and those who have not been affected. In order to be effective, clinical trials examine possible interventions to diagnose, prevent, treat, and hopefully cure the disease.

While the benefits of participating in clinical trials and studies are many, there continues to be a shortage of individuals who volunteer to participate. As seen in other disease aspects, a lack of awareness and access contributes to difficulty in recruiting research participants. New therapies and pharmacological interventions can only be confidently and safely applied in practice after they have undergone rigorous scientific testing. Therefore, promoting importance of clinical trials and also recruiting participants for study participation is an essential plan element.

### **Strategies:**

1. Promote greater awareness of existing and new opportunities for participation in Alzheimer's disease-related clinical studies and trials to health and service-related entities.
2. Promote awareness of the Alzheimer's Association's "Emerging Med" website to establish a data base of clinical studies and trials that match patients to clinical trials based on survey information.
3. Ensure that volunteer recruiting activities and measures are published in multiple languages and formats with high degrees of cultural sensitivity.
4. Explore the potential of securing funding for subsidizing costs in providing clinical trials to patients who live in rural areas.
5. Investigate the possibility of obtaining funding to conduct a statewide awareness campaign on the value of clinical trials and studies.



## Goal III: Texans with Alzheimer's disease will experience improved quality of life through better disease management.

**Objective 3: By August 31, 2015, increase access to training and education programs for persons with Alzheimer's disease, their families, and caregivers to improve communication and management of the disease.**

### Rationale:

Critical to this objective is a dedication and commitment to providing accurate and reliable information about Alzheimer's disease to individuals and families so that they may, when properly informed about the disease and its impact on families, adopt and develop strategies to combat the many challenges presented by this disease. This will enhance their ability to lead more fulfilling, less dependent lives over longer periods of time, within constraints of disease symptoms and progression.

While a diagnosis of Alzheimer's disease is often devastating, families who are adequately informed about this disease, its symptoms and long-term progression can often better manage the illness and its impact. Without accurate information, persons with Alzheimer's disease and their families are limited in their capacity to make informed decisions regarding in-home care, legal matters, finances, and other critical issues. Increasing access to training and education is a critical component for the overall goal of enhancing disease management across the state.

While few families are adequately prepared for an Alzheimer's disease diagnosis, it is critical that greater efforts and resources be focused on provision of accurate and reliable disease information through multiple information dissemination venues. The process of informing and education should begin when a person is first diagnosed with Alzheimer's disease. Therefore, the number one support

mechanism provided in fulfillment of this objective is providing accurate and reliable disease information and contact information for local and statewide sources of support and assistance.

### Strategies:

1. Partner with state, local and community agencies to disseminate Alzheimer's educational materials to patients and families (physician offices, Area Agencies on Aging, faith-based organizations, Alzheimer's Associations, for profit and not-for-profit health services agencies, and social services providers serving the elderly).
2. Conduct research to identify, evaluate and deploy effective and efficient methods of providing Alzheimer's disease educational materials to individuals and families.
3. Explore potential funding sources to support a statewide media campaign on resources available to individuals with Alzheimer's disease and their family caregivers.
4. Establish protocols for state and local agencies and cross training to address needs of individuals and families impacted by Alzheimer's disease and related dementias.
5. Look into the feasibility of using large-scale public presentations, mass media outlets, information kiosks, and associated businesses (both public and private) as a way to increase training and educational opportunities.

## Goal III: Texans with Alzheimer's disease will experience improved quality of life through better disease management.

**Objective 4: By August 31, 2015, promote the integration of Dementia Care Practice Recommendations for persons with Alzheimer's disease/related dementias into 250 nursing homes and long-term care facilities in Texas.**

### Rationale:

Dementia is the most significant risk factor for institutionalization and currently there are more than 1.5 million Americans residing in nursing homes. The most common form of dementia is Alzheimer's disease and most of those institutionalized with dementia are of this type. This number is expected to more than triple by the year 2030. It is recommended that quality of life be improved by integrating Dementia Care Practice Recommendations (the Recommendations) for disease management within those facilities.

The Alzheimer's Association developed the Recommendations in 2006 for nursing homes and assisted living facilities. The Recommendations have been adopted by the U.S. Department of Health and Human Services. Several current resources include Acute Care of Vulnerable Elders study (ACOVE) recommendations, American Medical Directors Association (AMDA) clinical practice guidelines, the Texas Department of Aging and Disability Services (DADS) Quality Matters Web (QMWeb), the National Guideline Clearinghouse summary on dementia care practice recommendations for nursing homes, and the Center for Health Systems and Research and Analysis (CHSRA). Quality of life can be significantly improved by integrating the Recommendations for disease management within Texas nursing homes and long-term care (LTC) facilities.

Data supporting this objective include, but are not limited to the following:

- Dementia is the most significant risk factor for institutionalization.

- Alzheimer's disease is the most common form of dementia and accounts for 60 to 80 percent of persons with dementia.
- More than 1.5 million Americans with dementia reside in nursing homes and related facilities and are expected to more than triple by the year 2030.

Distribution of the Recommendations should be provided in multiple venues. Facilities identified as not currently integrating the Recommendations in their disease management plans should be strongly encouraged to do so. Facility administrative and professional medical staff will be advised of opportunities to participate in in-service training to help educate and maintain the Recommendations.

Collaboration with professional organizations will be encouraged as well as strong support to link dissemination of the Recommendations with continuing education credit efforts. The Recommendations will be posted along with hyperlinks on the Alzheimer's Association website and other websites. Ongoing and interim follow-up is suggested to determine any challenges that are encountered during implementation. Hence, continued support of facility integration efforts and working relations through collaborative efforts especially with professional organizations should be maintained over the years.

### Strategies:

1. Survey nursing homes and LTC facilities to identify those facilities which are currently integrating the Recommendations into Alzheimer's/dementia disease management.



2. Review, identify, and promote approaches to effectively integrate the Recommendations within identified facilities.
3. Collaborate with facility administrative and professional medical staff on integration of the Recommendations.
4. Conduct interim survey to determine facility needs on integration of the Recommendations and provide assistance where needed.
5. Continue support of facility integration efforts and maintain working relationships through collaboration.
6. By early 2015, re-survey to determine the numbers of nursing homes and LTC facilities that have integrated the Recommendations and identify implementation challenges and report improvement suggestions.
7. Propose rules changes for integration of the Recommendations to the Department of Aging and Disability Services, if needed.

**Objective 5: By August 31, 2015, Texas will promote Alzheimer’s disease personal safety awareness, measures, and guidelines to 5,000 persons with Alzheimer’s disease and their family members/caregivers.**

**Rationale:**

Safety for all older Americans is of increasing concern. The elderly face many challenges, including falls, accessibility issues, and community hazards. The Centers for Disease Control and Prevention estimate that 35-40 percent of adults 65 and older fall at least once each year. Persons affected with Alzheimer’s disease have even greater safety concerns due to cognitive deficits. Individuals with Alzheimer’s are also at greater risk for wandering, accidents in the home and community, and problems with driving. These individuals are found to be more prone to home injuries, mostly due to falling. One study showed that patients with dementia have a decreased awareness of danger. Consequently, safety concerns are frequently cited by caregivers as a reason for seeking institutional care. Since the extent of risk to Alzheimer’s patients is not easily discernable, addressing these safety issues will allow them to lead healthier lives and remain in their community longer.

**Strategies:**

1. Partner with law enforcement agencies to increase awareness of safety issues (specifically wandering).
2. Investigate conducting a pilot project in a mid-sized city to train police force and first responders about the MedicAlert-Safe Return and Comfort Zone Programs.
3. Partner with Texas Area Agencies on Aging to increase safety awareness for patients with Alzheimer’s.
4. Encourage physicians to incorporate safety in the patient treatment plan.
5. Identify and partner with other safety-related organizations to promote safety awareness and measures.

## Caregiving/Caregivers

An estimated 76 percent of people with Alzheimer's disease live at home. Families are the caregiving heart and soul for the 5.3 million people in the United States whose futures have been so dramatically altered by this disease. In 2009, 10.9 million family members, friends and neighbors provided unpaid care for persons with Alzheimer's disease or other dementias. Current medical interventions may provide symptomatic relief, but cannot delay underlying Alzheimer's disease progression (*2010 Alzheimer's Disease Facts and Figures, Alzheimer's Association*).

Currently more than 852,820 unpaid caregivers, mostly family members, confront overwhelming challenges daily with providing care for an estimated 340,000 Texans with Alzheimer's disease and other forms of dementia. Care provided for an Alzheimer's patient can be extremely stressful. Caregivers frequently become isolated, over-burdened and depressed. One study noted that a person providing care to someone with dementia is twice more likely to have a significant adverse experience than someone who cares for a person who isn't suffering dementia. The same study noted caregivers' frequent need for assistance in both providing direct care and in managing patient needs. Caregivers were also found to have more health problems than others do at their age due to the physical and emotional demands of caregiving. Caregiving is also known to have negative effects on employment, income and financial security.

As Alzheimer's progresses and cognitive decline ensues, individuals with this disease

often experience changes in personality and behavior; while becoming increasingly dependent on others for their needs. On a daily basis, families must deal with loved ones with Alzheimer's disease who are unable to cooperate or are actively resistant to the array of active care services provided. *Families Care: Alzheimer's Caregiving in the United States 2004*, a report by the Alzheimer's Association and National Alliance for Caregiving, found that "Caregivers of persons with Alzheimer's disease and other dementias shoulder a

particularly heavy burden of care. Compared with other caregivers, the type of care they provide is more physically and emotionally demanding and more time consuming, and it takes a heavier toll on work and family life."

Even if a person with Alzheimer's enters an assisted living facility or nursing home, family members maintain their caregiver status by overseeing medical care, legal and financial matters. Duration of Alzheimer's disease is typically five to eight years, but has been known to last over 20 years, making the toll on caregivers prolonged and difficult. The *2010 Alzheimer's Disease Facts and Figures* found that at any one time, 32 percent of family and other unpaid caregivers of people with Alzheimer's and other dementia had been providing help for five years or longer. In addition to the taxing demands of providing constant care, families caring for someone with Alzheimer's often experience great frustration in attempting to locate and access supportive community services. Primary caregivers

Families are the caregiving heart and soul for the 5.3 million people in the United States whose futures have been so dramatically altered by this disease.

of those with Alzheimer's disease are often compelled to take on the job of care manager. Families and those with the disease ordinarily prefer home care, but are not always capable, knowledgeable or adequately skilled in planning, accessing and coordinating services. In part, this is because there is significant fragmentation in the service delivery system. Services vary greatly and are offered by both public and private agencies. Eligibility varies by program sponsor. Some programs have income criteria, some age criteria and others geographic exclusions. This is confusing to the average person and can be overwhelming for those already burdened with the continual care persons with Alzheimer's disease require.

Most often, families turn to their primary care physician for information about Alzheimer's disease, managing difficult and symptomatic disease behaviors, and identifying available community resources to help with caregiving tasks. Unfortunately, primary care physicians are often not able to meet the families' needs in securing medical information and support. Physicians try to convey needed information, but caregivers report it is not adequate to address their questions and concerns. Still the primary care physician and broader

healthcare system can be instrumental with identifying and reaching Alzheimer caregivers and aiding them in accessing services.

Enhancing support for Alzheimer caregivers throughout Texas requires efforts on two fronts: (1) improving access to existing services and (2) developing new services to address gaps in state information, referral and service delivery systems. A brief evaluation of provider reach and effectiveness reveals some limitations. While key service providers reach thousands of Texans annually, consumer awareness of available services is still lacking. After families have identified needed services, they frequently state they could have used assistance months or even years before it was obtained.

Given Texas' geography, diversity of its population, and wide range of long-term needs for the growing number of Texans with Alzheimer's disease, focusing on access to a multitude of existing statewide resources becomes even more critical. Meeting needs of family caregivers is central to this plan. However, many Texans with Alzheimer's will spend some time in a residential care facility. Thus, needs of residential care staff must also be addressed.

## Goal IV: Caregivers will experience enhanced levels of support through improved access to Alzheimer's disease/dementia care information and services.

**Objective 1: By August 31, 2015, develop and promote recommendations for key Texas service providers that enhance current distribution practices of Alzheimer's disease/dementia care information and services.**

### Rationale:

A recent study employed Internet research methods and 2-1-1 resources across the state to identify major providers of Alzheimer information and services. This work was an initial step to: (1) identify major statewide providers, (2) determine services and protocols offered by these providers, and, (3) specify barriers to access. The statewide study found many existing strengths among providers of Alzheimer information and services. Forty-eight business and organizations were identified, offering a broad array of services and a variety of ways to access their services. The following key statewide providers were identified:

The Alzheimer's Association - the oldest and largest national voluntary health organization committed to combating Alzheimer's disease. The Association's mission is to eliminate Alzheimer's disease through research advancement; provide and enhance care and support for all affected; and, reduce risk of dementia through promotion of brain health. The Association carries out its mission through a federation of 76 chapters across the United States and there are five Alzheimer's Association chapters in Texas; autonomously incorporated and based in Austin, Dallas, El Paso, Fort Worth and Houston.

Area Agencies on Aging (AAAs) - AAAs work within their communities to help seniors, their family members and caregivers receive information and assistance on locating and accessing community services. There are 28 AAAs with their

respective service delivery areas covering Texas and reporting to the Texas Department of Aging and Disability Services.

Aging and Disability Resource Centers (ADRCs) - ADRCs endeavor to be the first stop for questions about Texas aging and disability programs and services. Eight ADRCs in Texas work collaboratively with public and private service organizations and their collective service areas within 34 Texas counties. These providers were identified as important resources because of their professional interactions with agencies. Providers were found to frequently offer their services in multiple languages, particularly in Spanish as a secondary language, and a majority of providers interviewed indicated they are satisfied with caregiver services available in their communities. Two issues were immediately clear from this assessment of services for families and professional Alzheimer caregivers across the state: 1) caregivers do not know where to find information about services; and 2) information about caregiver services available throughout Texas is inconsistent and varies widely. Geographically, the state is covered by services provided through the five chapters of the Alzheimer's Association and the Area Agencies on Aging. Core services are similar among the five chapters but, some offer additional services not available statewide. Funding varies and services are locally determined among the Area

Agencies on Aging. Aging and Disability Resource Centers are relatively new in Texas and limited in their current geographic coverage. The Aging and Disability Resource Centers are emerging as a useful referral source and effective collaborator among local agencies. The committee's recommendation is to work with existing key providers to enhance service protocols, materials and distribution practices based on study findings. It is hoped that that key providers are receptive to a mutual effort to enhance statewide service delivery. A public or publicly funded entity may likely need to coordinate this task.

**Strategies:**

1. Establish a workgroup to identify key urban and rural organizations involved in the distribution of Alzheimer's disease information and services.
2. Work with organizations to identify current distribution practices.
3. Assess caregivers on their experiences in obtaining access to needed information and services.
4. Develop recommendations to enhance protocols for distribution of Alzheimer's disease and dementia care information/services.
5. Present findings and recommendations to key Texas service providers.
6. Collaborate with service providers to promote and implement recommendations.
7. Adapt or develop new materials to enhance protocols as needed.
8. Promote technical assistance as needed.

## Goal IV: Caregivers will experience enhanced levels of support through improved access to Alzheimer's disease/dementia care information and services.

**Objective 2: By August 31, 2015, identify and engage the support of a minimum of 20 non-traditional partners in disseminating educational materials and resources that foster public awareness of Alzheimer's disease and services available through the Alzheimer's Association.**

### **Rationale:**

Families often do not know where to find needed information and services, even when resources are available. Current efforts focus on effectiveness of service providers in reaching their targeted audience. This initiative adds further value by expanding outreach efforts to additional community partners. Non-traditional partners such as businesses or other entities primarily focused on non-Alzheimer's services would be invited to go beyond the network of health and social service providers. Non-traditional partners bring extensive infrastructure resources to publicize or promote some aspect of Alzheimer's information and services, preferably on a statewide basis. Non-traditional partners are those who could help reach caregivers at atypical points of contact. This will be particularly helpful in reaching caregivers who are not already connected to any health or social service provider. The five Texas-based Alzheimer's Association chapters have regional and satellite offices throughout the state. As part of a national organization, the Alzheimer's Association offers a toll-free 24/7 telephone helpline. This availability ensures a knowledgeable professional is always available to respond to immediate questions and concerns from caregivers. The Association also has a wide array of quality educational materials available in print and on-line about Alzheimer's disease and caregiving issues. It is recommended that the Alzheimer's Associations play a key role in forging non-traditional partnerships where possible, on a state-wide

basis. Other traditional and non-traditional partners will be needed to promote collaborations and secure needed funding.

### **Strategies:**

1. Identify non-traditional partners with statewide reach to disseminate materials and resources. Such partners may include utility companies, code enforcement officers, public safety officials, billboard companies, banks, public/private businesses, agricultural extension offices, and others.
2. Adapt or develop educational materials and resources that support the education message.
3. Where practicable, establish formal agreements with partners (based on size of organization and level of commitment), which may include subsidizing printing of materials, disseminating educational materials and resources to customers, educating employees about Alzheimer's signs and symptoms and sources of support for persons with Alzheimer's.
4. Expand collaboration and connectivity among non-traditional partners and Alzheimer's Associations in Texas.
5. Monitor the Alzheimer's Association 1-800 telephone helpline to identify and evaluate increases in referrals from non-traditional entities.
6. Maintain partnerships through in-person meetings, conference calls, and other means.



## Goal IV: Caregivers will experience enhanced levels of support through improved access to Alzheimer's disease/dementia care information and services.

**Objective 3: By August 31, 2015, streamline consumer information on rules and regulations governing assisted living and nursing home facilities providing dementia care in Texas.**

### **Rationale:**

Confusion exists when navigating the network of Texas long-term care services. While there is much information on Alzheimer's disease/dementia, it is not always easy to find, and the content's accuracy and validity varies widely among service providers. Streamlining information related to long-term care is vital to consumers when faced with challenges of choosing long-term residential care for a family member. Consumers need accurate and timely information on a variety of topics surrounding Alzheimer's disease care and long-term care placement options.

To make an informed placement decision, consumers need a basic understanding of what assisted living is, how this type of care differs from skilled nursing, and regulations and standards of each. Therefore, streamlining information and developing more uniform materials on long-term care options is critical to this objective.

Partners and stakeholders are called to work together to identify consumer needs around long-term care, develop appropriate materials, and design a comprehensive distribution network. While most of this

information exists in various forms, efforts should be centered on compiling information in a standardized format with consistent delivery and dissemination practices. The following strategies are recommended to begin this process and help consumers with navigating long-term care placement when their family member can no longer be cared for at home.

### **Strategies:**

1. Establish a workgroup to identify and collect educational materials on long-term care services for consumers.
2. Assess and evaluate accuracy and uniformity of materials.
3. Collaborate with long-term care organizations to identify opportunities and develop recommendations for improving and streamlining materials.
4. Work with organizations on materials revision/development and dissemination.
5. Identify funding mechanism(s) to support needed development/dissemination costs.
6. Disseminate materials to consumer organizations and their stakeholders.

## Goal IV: Caregivers will experience enhanced levels of support through improved access to Alzheimer's disease/dementia care information and services.

**Objective 4: By August 31, 2015, require by rule, increased role-appropriate dementia care training requirements of all staff working in any licensed facility housing persons with Alzheimer's disease/dementia.**

### Rationale:

In the 25-year period (2000 to 2025) Texas will experience a 74 percent increase in individuals 65 and older living with Alzheimer's disease. With this increase, the need to ensure quality care for people with Alzheimer's disease becomes increasingly important. This issue needs to be addressed not only in Texas, but across the country, particularly in residential care settings.

Nationally, 69 percent of all nursing home residents have some degree of cognitive impairment. Of these, nursing home records indicate approximately 47 percent of residents are diagnosed with Alzheimer's disease or another dementia. As for assisted living residents, studies indicate that 45-67 percent have Alzheimer's or another dementia. It is undeniable that people with dementia often turn to residing in assisted living and nursing facilities, as physical and mental declines associated with this disease invariably lead to need for such supportive care. Currently, dementia specific training requirements in Texas range from zero to twelve hours annually, depending on the type of facility:

- Facilities licensed as assisted living are not required to provide any training in dementia care.
- Certified Alzheimer's assisted living facilities are required to provide 12 hours of dementia care training annually.
- Licensed nursing homes are required to provide one hour of dementia care training annually.
- Nursing homes certified for care of

persons with Alzheimer's must have four hours of annual continuing education in Alzheimer's disease or related disorders.

Research shows that dementia care training directly correlates to factors impacting patient quality of care. In a study involving 124 nursing facilities in Minnesota, nursing assistants who received more dementia-specific training experienced an increase in knowledge and skills needed to work more effectively with dementia residents. An increase in knowledge and skills also positively impacted workers' job satisfaction and reduced turnover (Grant). In another study on dementia care in assisted living settings, it was found that dementia-specific training provided caregivers (direct care staff) "with the skills to insure resident safety, comfort and quality of life," (McKenzie). These studies highlight many positive benefits resulting from an increase in dementia care training in residential care facilities: increased staff confidence and job satisfaction; less turnover; and most importantly, higher quality of care for residents.

According to the Paraprofessional Healthcare Institute, "Good training ensures that direct-care workers can perform their jobs with competence and confidence. When workers feel well-prepared for their jobs, research shows that they are more likely to stay on the job," (PHI). As indicated in these studies, there is a cascade affect that comes with increased dementia care training. It not only results in better care for residents but also in another matter of



critical importance – reducing staff turnover. The high turnover rate among frontline staff in long-term care poses serious concerns not only as a workforce issue, but as a policy issue, as well; staff turnover is expensive. According to a 2004 report from Institute for the Future of Aging Services, direct turnover cost is conservatively estimated at \$2,500 per incident. Direct costs include the cost of separation, vacancy, replacement, training and increased worker injury. In addition, there are also indirect costs such as productivity losses, penalties resulting from reduced service quality, lost client revenues from losing clients to other agencies and poor morale.

The long-term care industry is not alone in shouldering the burden of these direct and indirect costs. The financial impact on federal, state and local government is staggering. Turnover costs taxpayers roughly \$2.5 billion annually. These negative impacts are further compounded by lower quality care for consumers and higher injury-related medical costs for workers. As author and labor economist Dorie Seavey notes, “Elders pay the heaviest cost of all, in quality of care they receive from too few, too new or temporary staff.” With the numbers of Texans with Alzheimer’s disease and other dementias living in assisted living and nursing facilities, it is imperative that the state work to raise the bar for dementia caregiver staff training requirements for all residential care settings.

**Strategies:**

1. Provide a detailed body of evidence-based data to justify and support increased dementia care training.
2. Present information on the need, evidence and benefit of dementia care training to appropriate policy makers and organizations.
3. Identify and make contact with residential care trade associations and appropriate regulatory agencies to establish partnering relationships.
4. Send out a comprehensive call for partners to collaborate on development of training recommendations.
5. Establish a formal workgroup to develop training curricula, based on roles and functions within facilities.
6. Work with appropriate entities to obtain legislative support of rules revisions as required.
7. Seek cooperation with appropriate rule-making entities for rule enactment.
8. Disseminate dementia care training curricula to affected licensed facilities.
9. Collaborate with appropriate entities to support implementation of training requirements.

## Goal IV: Caregivers will experience enhanced levels of support through improved access to Alzheimer's disease/dementia care information and services.

**Objective 5: By August 31, 2015, partner with at least one Texas healthcare system or group of primary care physicians to pilot test an evidence-based approach to identification, assessment and support of Alzheimer's disease caregivers within healthcare settings.**

### **Rationale:**

One-quarter of all hospitalized patients 65 and older have Alzheimer's disease or another form of dementia (Maslow). Compared to the general hospital population, those with dementia are often older, have a higher burden of chronic illness, and are at higher risk of nursing home placement (Bynum). Chronic illness coupled with dementia contributes to complexity of patient care and increases care burdens on family caregivers. Disease management is especially challenging for the patient and caregiver during care transitions: hospital to home (Jerant, Bayliss). Lack of communication during care transitions between different settings puts the patient at risk for medication errors, unrecognized worsening of disease symptoms, incomplete understanding of discharge instructions, and lack of coordinated follow-up with an outpatient provider (Coleman). Rapid hospital readmission following a hospital discharge is linked to patient inability to self-manage chronic illnesses, adequately report symptoms, and actively participate in their own care. Even though readmissions may seem as separate, acute events, readmissions have been shown to be associated with nursing home placement, a consequence that older adults prefer to avoid (Bishop, Mattimore). Placing a loved one in a nursing home introduces stresses and burdens not only on the patient but also on the patient's caregiving family (Nolan).

Since individuals with dementia are compromised in their ability for self-care, family caregivers are critical for preventing

negative outcomes following hospitalizations, including nursing home placement, and are essential to daily management of the patient's chronic illnesses (Bynum). Caring for a family member with dementia can, however, lead to decreased quality of life and an increase in depressive symptoms in caregivers. Caregiving can also be detrimental to one's health (Schulz, Haley, Kiecolt-Glaser, Pruchno, and Vitaliano) and, if associated with burden, leads to higher rates of caregiver mortality (Schulz). In Texas, 852,820 unpaid caregivers provide care valued at \$11.2 billion in uncompensated care making Texas the second highest in the nation in costs.

Evidence-based interventions are available to address risks associated with care transitions of older adults and to address negative consequences associated with caring for a loved one with dementia. Translation of one such evidence-based intervention, REACH II Intervention, has been implemented within Scott & White's integrated healthcare system in Texas to become the Scott & White Family Caregiver Program (S&W FCP). In 2007, Scott & White Healthcare created the S&W FCP, with funding from the Rosalyn Carter Institute/Johnson & Johnson Caregivers Program. The project was refunded in September 2008 for an additional year. The goal of this project is to identify high-risk patients and provide effective support to family caregivers by providing nursing staff developmental instruction, integration of caregiving risk appraisal measures

(REACH II RAM) into standard practices of care, and a family support program that coordinates hospital-based interventions and community-based formal supports services. The project targets individuals with dementia who are hospitalized, as this is a time in which the patient and family caregiver are at high risk for poor outcomes, including institutionalized long-term care for the patient and high levels of stress for the family caregiver.

To facilitate successful implementation, use of existing information technology was leveraged within the S&W healthcare system. Furthermore, collaboration occurred with the nursing staff, nurse educators, and nurse managers to facilitate integration within existing nursing protocols. To date, the S&W FCP has identified 1,702 Alzheimer's or dementia patients. Of these, 100 caregivers (23 percent) were enrolled in the S&W FCP. Caregiver burden, stress and patient problem behaviors significantly decreased and care recipient safety significantly increased during follow-up.

The healthcare system is frequented by patients with dementia, and provides an ideal contact point for caregivers who would otherwise remain anonymous in the community. Caregivers may also be more apt to receive care and treatment during the high stress of hospitalization (Schulz, Covinsky). Implementing an evidence-based program for caregivers within a healthcare system made up of numerous clinics and hospitals, and comprised of healthcare providers across all settings (physicians, nurses, social workers, and

discharge planners) increases potential identification for caregivers and increases the program's value. Consequently, this plan proposes initiating a pilot project, similar to or modeled after the S&W FCP. By supporting caregivers during these critical times, it is hoped that their burden and stress will be lessened, and the patient's risk of hospitalizations or poor outcomes will be greatly decreased.

#### **Strategies:**

1. Establish a translational research work-group to explore opportunities for implementing an evidence-based caregiver support program into a large healthcare system or within a group of primary care physicians in Texas.
2. Promote integration of Alzheimer's disease caregiver support services into Texas healthcare system(s), providers and other healthcare-related organizations.
3. Encourage partnerships between Alzheimer's disease support service organizations, such as Alzheimer's Associations and local Area Agencies on Aging and healthcare systems to facilitate caregiver access to support services.
4. Identify potential sources of financial support for healthcare systems or physicians who provide support services to Alzheimer's disease caregivers (e.g., Centers for Medicare and Medicaid Services (CMS) demonstration projects, CMS waivers, Medicaid Waiver programs).

## Infrastructure

Improving capacity means enhancing a community's ability to better identify needed resources and meet their needs and to participate more fully in society. Capacity can be defined as an organization's ability to successfully apply skills and resources toward identified goals. Capacity permits organizations to do their work, and is often closely linked to another term — infrastructure. In its broadest sense, infrastructure is viewed as those parts of a system that organize, inform, and support efforts of a group, organization or community in achieving its goals.

Improving and strengthening Texas' capacity to address Alzheimer's disease is essential to improving the health of Texans and creation of

effective formal and informal partnerships are vital to this objective. The vast scope of Alzheimer's issues requires a multi-disciplinary system that includes community-based organizations, academia, state and local governments, along with for-profit and not-for-profit healthcare service industry. Partners and stakeholders at all levels are encouraged to identify where their organization fits into a coordinated effort to reduce the burden of Alzheimer's disease on Texans and volunteer their participation where it will best meet plan objectives.

In Texas, there are many formal and informal networks of concerned professionals representing public, private and civil sectors

committed to dealing with the problems associated with Alzheimer's disease. Among these individuals and organizations, there is no lack of enthusiasm or dedication to the task. Weaving these parts together toward a coordinated effort is therefore a major step towards improving state capacity to address Alzheimer's disease in Texas. The 2010-2015 Texas State Plan on Alzheimer's Disease was developed to begin that coordinated,

mobilization process of engaging all of Texas in collectively addressing Alzheimer's disease.

Improving statewide capacity will require a coordinated, collaborative effort among all partners, at all levels, and within all sectors.

Existing partnerships will need to be reinforced, new partnerships with planning agencies and public officials will need to be developed, and media organizations will need to be engaged in ways not previously used. Progress in the battle against Alzheimer's disease can best be achieved through an infrastructure that links resources in an informed and coordinated manner.

The five objectives that follow are designed to strengthen infrastructure in key areas. Some strategies were designed to engage the media industry in a more active role and brings to the table extensive resources for public education and promotion of state plan initiatives. A diverse community consortium

Improving statewide capacity will require a coordinated, collaborative effort among all partners, at all levels, and within all sectors. Existing partnerships will need to be reinforced, new partnerships with planning agencies and public officials will need to be developed, and media organizations will need to be engaged in ways not previously used.

will take the lead in developing educational materials for elected officials to provide them with information on which to base public policy decisions. These efforts will yield initial benefits as follows:

- More effective concentration of partners/ stakeholder's collective energies, resources, knowledge bases, and innovations.
- Attraction of important new resources and skill sets added to an already impressive mix of talent.
- Greater visibility to the overall effort as partnerships expand.
- Most importantly, achievement of an overall sense of coherence and unity.

Another set of initiatives is geared towards ensuring that information is relevant, accurate, and timely. Information enhances collaboration and enables education, facilitates an open, free exchange of experiences among professionals, and promotes planning innovations. Conducting a large scale effort for a five-year period as called for in the 2010-2015 Texas State Plan on Alzheimer's Disease requires organization. A key element is centralizing coordination at the Texas Department of State Health Services. In this way, a single, central body

becomes the primary conduit for fostering and convening partnerships and networks, orchestrating efforts across multiple agencies and organizations, tracking progress, and measuring the impact against established goals.

Centralizing focus and accountability at the state level has another benefit. Too often, goals are looked at as discrete, disconnected parts with little understanding of their interrelatedness. While progress or slowdowns in one area are rarely viewed as impacting others, practitioners all too often experience the end result of this disconnect. A statewide approach, therefore, greatly reduces the possibility of scarce resources being uncoordinated and expenditures of time, money and resources being exhausted. This perspective enhances efficiency as the entire landscape of the campaign against Alzheimer's disease is monitored and managed. The result is a state-level impetus fully capable and resourced to sustain efforts over time. The following section lays out specific objectives and strategic actions designed to develop a solid infrastructure for a comprehensive and coordinated approach to addressing Alzheimer's disease in Texas.



## Goal V: Texas will improve state and local capacity to address Alzheimer's disease.

### Objective 1: By August 31, 2015, increase communications, collaborations, and coordination among statewide partners to implement state plan activities.

#### Rationale:

Strengthening partner and stakeholder relations and reaching out to form new partners is essential to statewide plan implementation. Effective collaborative efforts by partners and stakeholders will provide new resources and skills that will sustain the synergy that fosters continued plan implementation.

#### Strategies:

1. Identify opportunities to increase partnerships with stakeholders to strengthen and expand state plan implementation.
2. Continue to expand and advance the Texas Alzheimer's Disease Partnership to impact change in Texas.
3. Develop a consortium to spearhead public official education on Alzheimer's disease and promote policies and plans that support it.
4. Identify opportunities to foster partnerships with planning areas (i.e., Governor's State Planning Regions) for plan implementation.
5. Engage the media in state plan implementation activities via town hall meetings, press releases, and other events.

### Objective 2: By August 31, 2015, convene one annual, in-person partnership meeting to review progress made on state plan implementation and identify priority areas for future action.

#### Rationale:

While ongoing information sharing provides tools for a clearer understanding of common interests, it must be accessible and timely to be useful. Coordinated information sharing is one strategy to enhance exchange of experiences, successes, and barriers to plan implementation.

#### Strategies:

1. Identify funding sources to support and coordinate partnership meetings and activities.
2. Establish a workgroup to assist with meeting planning coordination and logistics.
3. Explore use of web-based technology to increase meeting accessibility and participation.
4. Collaborate with partners to identify and increase statewide information sharing and reporting.
5. Develop reporting mechanisms to document progress in implementing initiatives (e.g. survey monkey, semi-annual progress reports).
6. Promote ongoing communication and collaboration among partners and stakeholders to advance the Texas Alzheimer's Disease Partnership (e.g., list serves, newsletters).



## Goal V: Texas will improve state and local capacity to address Alzheimer's disease.

### Objective 3: By August 31, 2015, improve statewide monitoring and surveillance of Alzheimer's disease in Texas.

#### Rationale:

Projections indicate that the Alzheimer's disease burden is expected to significantly increase in coming years. This will have a profound impact on families, healthcare systems, and state resources. For states to plan for the rapidly growing population of persons with Alzheimer's disease, reliable information about the demographics and needs of Texans who are coping with Alzheimer's disease is needed. To more accurately describe the impact of Alzheimer's disease in Texas, it is proposed that investigation, development, and implementation of surveillance measures to better assess the true burden of this disease in Texas begin now.

#### Strategies:

1. Create a statewide, multi-disciplinary group to identify Alzheimer's disease data and surveillance gaps in Texas.
2. Collaborate with partners to identify on-going data needs, collection methods, reporting formats, and funding sources.
3. Continue to assimilate current data, monitor trends, track programs and policies, and recommend actions for improvement.
4. Support ongoing use of the Texas Behavioral Risk Factor Surveillance System to collect and analyze Alzheimer's disease data.
5. Disseminate data and encourage partners/stakeholders to promote Alzheimer's disease data collection in their program activities.

### Objective 4: By August 31, 2015, develop one comprehensive, state sanctioned web-based repository that contains the most current information on prevention, risk factors, disease management, translational research and science, and family caregiver resources.

#### Rationale:

A key component of infrastructure is development and maintenance of a comprehensive web-based repository of Alzheimer's disease/dementia-related information. Emerging information in the field of Alzheimer's is at an all time high, and technology offers an unprecedented ability to access information in a timely manner. Therefore, consolidating this information into one accessible location and maintaining its accuracy will provide valuable resources to professionals and non-professionals alike.

#### Strategies:

1. Form a workgroup to identify information and resources for inclusion in the repository.
2. Identify opportunities for web-based collaborations with other organizations.
3. Pursue potential funding sources for design, development, implementation, and ongoing maintenance of the repository.
4. Establish a volunteer-based oversight/monitoring workgroup to recommend bi-annual repository updates.
5. Promote the repository to partners and stakeholders for use in their organizations.

## Goal V: Texas will improve state and local capacity to address Alzheimer's disease.

**Objective 5: By August 31, 2015, increase by 20 the number of organizations that include activities outlined in the 2010-2015 Texas State Plan on Alzheimer's Disease into their organizational programming.**

### **Rationale:**

Increasing numbers of agencies and organizations that include this plan's activities into their strategic planning will foster a resourced, capable, statewide infrastructure that increases the visibility of Alzheimer's disease in Texas. Through additional visibility and knowledge about Alzheimer's, a broader spectrum of partners and stakeholders will be encouraged to actively identify where their respective resources and potential contribution to better address Alzheimer's disease statewide and subsequently participate in its implementation.

### **Strategies:**

1. Identify new and cost-effective ways to promote and disseminate the plan.
2. Identify system-level organizations and programs for state plan sponsorship.
3. Initiate meetings with state, local, and regional organizations to promote the state plan in fostering a comprehensive and coordinated approach to addressing Alzheimer's disease in Texas.
4. Facilitate formal and informal participation in joint collaborative promotional efforts with all appropriate organizations.
5. Maintain ongoing relationships with Texas organizations and actively work to increase the number that access and utilize the plan.
6. Encourage partners and partnerships to promote the plan in their program's activities and communications.

## Invitation to Participate

**If you are interested in joining the partnership as it moves forward on implementation of the 2010-2015 Texas State Plan on Alzheimer's Disease, please refer to staff contact information at:**  
**[www.dshs.state.tx.us/alzheimers/default.shtm](http://www.dshs.state.tx.us/alzheimers/default.shtm).**

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