



**Texas Council on Alzheimer's Disease
and Related Disorders
Biennial Report 2016**

**As Required By
H.B. 1066, 70th Legislature, Regular Session, 1987**



**Department of State Health Services
September 2016**

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Executive Summary

This report documents the progress of the Texas Council on Alzheimer's Disease and Related Disorders (Council) during fiscal years 2015 and 2016, as follows:

- Coordinated with the Alzheimer's Disease Program (ADP) of the Texas Department of State Health Services (DSHS) to begin updating the *Texas State Plan on Alzheimer's Disease* for 2016-21. The updated plan is based on the concepts of dementia-friendly communities.
- Coordinated the activities of the Texas Alzheimer's Disease Partnership, a volunteer group of more than 150 individuals who actively participate in state planning and promotion of Alzheimer's disease (AD) strategies in Texas.
- Advanced strategies within the *2010-15 Texas State Plan on Alzheimer's Disease*.
- Directed state-appropriated funds to the Texas Alzheimer's Research and Care Consortium (TARCC), as mandated, for AD research in Texas.
- Expanded the scope of statewide research efforts through the inclusion of the University of Texas at Austin as a TARCC member institution.
- Established and implemented the inaugural [Texas Alzheimer's Research and Care Consortium Investigator Grant Program](#) and awarded \$1.2 million in grant funding to seven Texas-based AD researchers.
- Redesigned the TARCC [website](#) to effectively serve the informational needs of the general public and the needs of the elite cadre of Ph.D. and M.D. researchers who are interested in hard science, research studies, and publications.
- Approved funding for the development and implementation of the TARCC, Texas Model for Memory Capable Care Initiative.
- Conducted the biannual performance review of TARCC.
- Provided testimony regarding activities of the Council and TARCC at the October 2, 2014, Joint Committee on Aging.
- Requested that ADP produce a [report](#) on data and barriers to population-level data collection on AD, provided by the Health Promotion and Chronic Disease Prevention Section's (HPCDPS) Office of Surveillance, Evaluation and Research (OSER) on July 31, 2015.

Council Recommendations, Fiscal Years 2017 and 2018

The Council has identified the following priorities:

- Sustain and support ongoing coordinated AD research
- Increase collaborative research among Texas AD researchers
- Continue support for quality long-term care
- Expand community-based programs and services
- Update the *Texas State Plan on Alzheimer's Disease* for 2016-21 to reflect dementia-friendly concepts
- Engage in strategic collaborations
- Expand local caregiver services and supports

Introduction

Pursuant to H.B. 1066, 70th Legislature, Regular Session, 1987, which was codified in [Texas Health and Safety Code, Title 2, Subtitle E, Chapter 101](#), the Council shall:

- Advise the department and recommend needed action for the benefit of persons with Alzheimer's disease and related disorders and for their caregivers
- Coordinate public and private family support networking systems for primary family caregivers
- Disseminate information on services and related activities for persons with Alzheimer's disease and related disorders to the medical and health care community, the academic community, primary family caregivers, advocacy associations, and the public
- Coordinate a volunteer assistance program primarily for in-home and respite care services
- Encourage research to benefit persons with Alzheimer's disease and related disorders
- Recommend to the Department disbursement of grants and funds available for the Council
- Facilitate coordination of state agency services and activities relating to persons with Alzheimer's disease and related disorders

Before September 1 of each even-numbered year, the Council shall submit a biennial report of the Council's activities and recommendations to the Governor, Lieutenant Governor, Speaker of the House of Representatives, members of the Legislature, the Long-Term Care Coordinating Council for the Elderly, and the Board.

Background

Alzheimer's disease is the fastest-growing health threat in the country.¹ Out of the more than five million Americans with AD, 350,000 are Texans.² Recognizing this threat, the Legislature established the Council to serve as the state's advocate for persons with AD, their caregivers, and related professionals.

The Council increases awareness about AD and its impact on Texans, participates as a strategic partner and coordinating body for statewide education, provides supervision and direction on state-funded AD research, and supports policies and programs that benefit people with AD and their caregivers.

For additional information about the AD burden in Texas, see Appendix C (page 11).

¹ Global Burden of Disease Study 2010, *Lancet*, 2012.

² Alzheimer's Association. *Alzheimer's Disease Facts and Figures 2016*.

Council Activities

Awareness and Education

Websites

The DSHS Alzheimer's Disease Program (ADP) maintains a website containing information on AD, warning signs, diagnosis, treatment, legal and financial issues, options for care, and information on licensed nursing and assisted living facilities certified for AD care. Council meeting agendas and minutes, and helpful toll-free phone numbers and internet links, are also available on the ADP website located at www.dshs.state.tx.us/alzheimers/default.shtm.

Under the supervision of the Council, the Texas Alzheimer's Research and Care Consortium (TARCC) maintains a website with information and updates on research activities, information on TARCC institutions and committees, publications, research recruitment opportunities, contact information, and AD statistics and resources. This website can be accessed at <http://www.txalzresearch.org/>.

Toll-Free Information Helpline

Since its inception in 1987, the Council has developed a growing awareness of the tremendous impact AD and related disorders have on individuals, families, and society. DSHS maintains a toll-free information helpline (1-800-242-3399) to provide information, support, and referrals to local community services.

Advocacy

The Council, in its continued efforts to advocate on behalf of individuals with AD and their families, provides guidance to community and state agencies on program and policy development.

Statewide Strategic Planning

Recognizing that AD is a growing public health concern, the Council and the ADP began formal work in 2009 on the development of the [*2010-2015 Texas State Plan on Alzheimer's Disease*](#), the first comprehensive state plan to address the current and future burden of AD on Texas.

The Council and DSHS formed the Texas Alzheimer's Disease Partnership (Partnership) to gather input from partners and stakeholders from state, local, and community level organizations; academic and research institutions; for-profit and non-profit sectors; businesses; the health care sector; and family members of individuals afflicted with AD.

This Partnership is a volunteer group comprised of individuals with diverse backgrounds and experiences that provides the expertise needed to create a strategic blueprint for Texas. Activities include caregiver education materials, disease management guidelines, TARCC research, and promotion of the state plan.

The Council and the ADP are updating the *Texas State Plan on Alzheimer's Disease* for 2016-21. The updated plan is based on the concepts of dementia-friendly communities. The goal is to empower the Partnership and all Texans with tools and strategies to implement dementia-friendly activities in their own communities.

The Council and the ADP continue to promote the AD management guidelines of [*Clinical Best Practices for the Early Detection, Diagnosis, and Pharmaceutical and Non-Pharmaceutical Treatment of Persons with Alzheimer's Disease*](#), which are an objective of the 2010-15 Texas State Plan on Alzheimer's Disease.

The Council requested that the ADP produce a [report](#) on Texas data and barriers to population-level data collection on AD. DSHS's Office of Surveillance, Evaluation and Research (OSER) published this report on July 31, 2015.

Partnership Development

The Council, in its efforts to support AD services and programs, develops partnerships with service and health care organizations, commissions, and aging-related agencies, including:

- Texas Department of Aging and Disability Services (DADS)³
- Texas Respite Coalition
- Silver Alert Program
- Aging Texas Well Advisory Committee

The Council encourages partners to implement the state plan to increase caregiver access to resources and services. Additionally, Council members and DSHS staff serve on boards and advisory and planning committees to help guide the direction of AD assistance programs.

Coordinated Alzheimer's Disease Research

In October 2012, Council members unanimously voted to rename all funded AD efforts under their purview as the Darrell K Royal Texas Alzheimer's Initiative. This initiative is committed to:

- Fostering excellence in research and care through the legislatively-mandated TARCC (see appendix B on page 8 for information about TARCC activities)
- Addressing the burden of AD in Texas through statewide strategic planning
- Promoting AD research and collaboration on projects among Texas researchers
- Coordinating/supporting other state-funded Texas activities as they relate to AD

³ DADS's 28 Area Agencies on Aging (AAAs) form a statewide network that provides comprehensive services for caregivers.

Conclusions

Council Recommendations, Fiscal Years 2017 and 2018

As the state's appointed advocate for persons with AD, their caregivers, and related professionals, the Council respectfully submits the following recommendations:

- **Coordinated Alzheimer's Disease Research**
The Council requests continued recognition and support of coordinated statewide research, as was demonstrated by the Texas Legislature when it passed H.B. 1504, 76th Legislature, Regular Session, 1999, (Chapter 154 of the Texas Education Code) establishing the Texas Consortium of Alzheimer's Disease Centers. The Consortium, later named the Texas Alzheimer's Research and Care Consortium by the Council, provides Texas with the infrastructure for sharing vital AD research and clinical outcomes. It provides a framework for expanding and expediting the search for answers about the causes and methods to delay onset, stop disease progression, and prevent and/or cure AD.
- **Increased Collaborative Research among Texas AD Researchers**
Increasing collaboration in AD research across public, private, state, and federal sectors that cut across disciplines will quicken discovery. Behavioral modifications, such as diet and exercise, and pharmacological interventions must be integrated in order to develop therapies aimed at AD prevention. This type of multi-disciplinary research, typically not funded by national health and science foundations, offers significant opportunities to study disease progression and advance therapeutic strategies. The Council supports using outcome-oriented research projects backed by appropriate funding mechanisms and active collaboration among Texas researchers to identify preventions and therapies.
- **Continued Support for Quality Long-Term Care**
The Council supports maintaining or increasing current levels of nursing-facility eligibility for people with cognitive impairments, specifically AD and other related dementias. The Council requests maintaining or increasing Resource Utilization Groups (RUGs), based on the level of need, to accommodate higher levels of reimbursement for facilities that care for persons with cognitive impairments.
- **Expanded Community-Based Programs and Services**
The Council recommends expansion and optimization of home and community-based programs and services for individuals with AD and their caregivers as well as the expanded availability of affordable respite care, training for caregivers, and other resources to maintain the integrity of the family caregiving system. Family caregivers provide most care. Expanding these resources will afford family caregivers much needed services to assist them in caring for their loved ones with AD.
- **Update the *Texas State Plan on Alzheimer's Disease* for 2016-21**
The Council and the ADP are updating the *Texas State Plan on Alzheimer's Disease* for 2016-21. The updated plan is based on the concepts of dementia-friendly communities. Texas requires greater capacity to address the huge economic and human toll AD places on our

valuable resources and citizens. Limited and competing resources must be carefully directed at comprehensive and coordinated statewide strategic planning. The state of Texas must remain proactive in the face of the burgeoning epidemic of AD.

- **Engage in Strategic Collaborations**

The Council recognizes the importance of establishing and maintaining collaborative relationships with AD experts. The Council and the ADP will continue to engage in strategic collaboration with Texas researchers, clinicians, directors of AD research centers and centers on aging, medical schools, medical professionals, state public health experts, and community partners.

- **Expand Local Caregiver Services and Supports**

The Council recognizes the difficulty and complexity of accessing local services and support that promote the health and well-being of individuals living with AD and their family caregivers. In 2016, the Council approved funding for the development and implementation of the TARCC, Texas Model for Memory Capable Care initiative. This initiative will include:

- Caregiver education and referral information
- Statewide confidential support for family caregivers in the workforce
- Counseling, support groups, and programs that build caregiving skills
- Wellness programs to support memory health
- Responsible transportation planning
- Engaging the person with dementia in meaningful activities
- Residential settings tailored to the needs of persons with dementia and inclusion of family caregivers in decision-making

Appendix A: Council Roster

The Texas Council on Alzheimer’s Disease and Related Disorders (Council) is composed of 17 members including 12 voting members who are appointed by the Governor, Lieutenant Governor, and Speaker of the House. Five non-voting members represent the Health and Human Services Commission (HHSC), Department of State Health Services (DSHS), and Department of Aging and Disability Services (DADS).

Texas Council on Alzheimer’s Disease and Related Disorders 2015-16 Member Roster

Kathlene E. Camp, P.T., M.S.P.T.

Fort Worth

Laura DeFina, M.D.

Dallas

Ronald Devere, M.D.

Austin

Marc Diamond, M.D.

Dallas

Carlos Escobar, M.D.

San Angelo

Melissa L. Edwards

Houston

Francisco González-Scarano, M.D.

San Antonio

The Honorable Clint Hackney

Austin

Debbie Hanna, Chair

Austin

Rita Hortenstine

Dallas

Susan Rountree, M.D.

Houston

Kate Allen Stukenberg

Houston

Valerie J. Krueger

Texas Department of
State Health Services

Lisa B. Glenn, M.D.

Texas Department of
Aging and Disability Services

Patricia Moore, M.Ed., Ph.D.

Texas Department of
State Health Services

Nancy Walker

Texas Health and Human
Services Commission

Toni Packard

Texas Department of
Aging and Disability Services

Staff

Lynda Taylor, M.S.W.

Texas Dept. of State Health Services

Appendix B: Coordinated Alzheimer’s Disease Research

Texas Alzheimer’s Research and Care Consortium

The Texas Alzheimer’s Research and Care Consortium (TARCC) is a collaborative Alzheimer’s disease (AD) research effort directed and funded by the Texas Council on Alzheimer’s Disease and Related Disorders (the Council), as part of the Darrell K Royal Texas Alzheimer’s Initiative. Established in 1999, initial Consortium members included Baylor College of Medicine (BCM), Texas Tech University Health Sciences Center (TTUHSC), University of North Texas Health Science Center (UNTHSC), and UT Southwestern Medical Center at Dallas (UTSW).

In 2005, the Texas Legislature made history by approving an unprecedented first state appropriation for AD research in the nation, providing an initial \$2 million investment in start-up funding for TARCC. In June 2006, the four TARCC members, with the approval of the Council, began work on establishing a comprehensive research study cohort of well characterized subjects (500 AD participants and 300 normal controls) to address early diagnosis, treatment, and ultimately prevention of AD.

In 2008, the Council expanded the reach of AD research into South Texas by adding the University of Texas Health Science Center-San Antonio to TARCC. This move, coupled with the 2009 state appropriation of \$6.85 million, enabled TARCC to begin including Hispanic individuals into the research study (the Texas Harris Alzheimer’s Research Study). The inclusion of underrepresented Hispanics significantly strengthened AD research efforts in Texas and uniquely positioned Texas to assume a national leadership role in this largely untapped area of AD research.

The Council further increased TARCC membership in 2014 with the approval of Texas A&M University Health Science Center (TAMHSC) as a TARCC participating member, and again, in 2015, by adding the University of Texas at Austin (UT Austin) as a TARCC member site.

The expansion of TARCC, coupled with increased funding, has greatly increased Texas’ capacity to advance research and discovery to improve early diagnosis, treatment, and prevention of AD.

The Texas Harris Alzheimer’s Research Study

TARCC maintains a richly characterized and robust multi-institutional, longitudinal cohort of participants (the Texas Harris Alzheimer’s Research Study). To date, TARCC has enrolled more than 3,278 study participants diagnosed with AD or mild cognitive impairment (MCI), as well as cognitively healthy controls subjects (NC).

TARCC enrollment is ongoing and includes replacement of participants who are lost to follow up or death. Active participants (1,730) are seen annually at TARCC member sites, where they undergo a battery of neuropsychological tests and provide blood samples. The resulting uniformly-collected clinical, neurocognitive, and laboratory data are combined in the centralized data file housed at UTSW. Participants are assigned a unique number at the TARCC site when

enrolled. Central data are de-identified in a manner compliant with the Health Insurance Portability and Accountability Act (HIPAA).

Novel and unique strengths of TARCC include:

- **The longitudinal nature of the study, where participants are followed annually.** Analysis of the longitudinal data enables TARCC investigators to model changes in cognitive function over time, allowing for the identification of factors that not only affect risk but also disease progression. The inclusion of individuals diagnosed with Mild Cognitive Impairment (MCI) into the research study is critical to understanding the sequence of neurodegenerative changes that occur as AD develops.
- **The enrollment of the largest number of Mexican American participants in an ongoing AD research study.** Mexican Americans are the fastest growing ethnic group in Texas and are projected to represent a majority of the state's population by 2020. Very little is known about AD in this population.

TARCC sites are expected to use study data in their individual research projects and seek collaborative research opportunities with colleagues. Researchers across the state are also encouraged to use these unique Texas resources for research projects.

TARCC's Current Research Objectives

The goal of TARCC is to advance research efforts in Texas that lead to better diagnosis, treatment, and prevention of AD. TARCC researchers are currently examining the role of biological and clinical markers for inflammation, cardiovascular disease, cardiovascular risk factors, and hyperinsulinemia in the development and progression of AD. These factors are investigated longitudinally and with regard to how they may differ between Mexican American and non-Hispanic White citizens of Texas.

TARCC's research activities are reviewed biannually by an external advisory committee convened by the Council. This committee is comprised of four internationally recognized leaders in AD research who ensure that TARCC adheres to the highest quality research standards and pursues a direction with the greatest potential to break new ground in AD research.

TARCC Achievements

TARCC is enriching the Texas Harris Alzheimer's Research Study with additional biomarkers of interest, particularly cardio-metabolic proteins. This will create a valuable opportunity for increased utilization of TARCC resources in collaborative scientific investigations and aid current investigations into the links between inflammation, vascular risk factors, and insulin resistance with the age at onset, risk for development, and progression rate of AD.

TARCC is also enriching the Texas Harris Alzheimer's Research Study with genotyping data on all TARCC participants for whom a DNA sample currently exists. This study will facilitate opportunities for increased utilization of TARCC resources in collaborative scientific studies.

TARCC researchers have been busy producing and reporting important scientific discoveries. During 2015 and 2016, TARCC researchers published studies describing:

- The link between testosterone and behavioral symptoms in AD
- Markers of cognitive functioning and AD
- Depression and diabetes as a risk factor for mild cognitive impairment and AD in elder Mexican Americans
- The identification of three novel AD risk genes
- The role of elevated vascular inflammation and homocysteine in risk for AD
- Validating the accuracy of a blood-protein based screener for AD across multiple assay methods as well as in serum and brain micro-vessels from mice

These studies provide novel insights into Alzheimer's risk and pathophysiology.

During 2015 and 2016, numerous data requests were submitted by researchers across the state seeking access to TARCC data/samples for research projects. These projects, approved by the TARCC Steering Committee, range from large, multinational studies of AD genetics to the genetic architecture of memory and executive functioning in AD, to neuropsychiatric behaviors as predictors of AD progression.

An Early Return on the State's Investment

The creation of TARCC has set a standard for collaborative scientific endeavors. The synergy of seven institutions bringing clinicians and scientists together to focus on AD has resulted in enhanced research output and increased research infrastructure devoted to AD. These accomplishments are critical to Texas' role as a leader in AD research.

TARCC-based research benefits the state by contributing to new advances in AD diagnosis, risk assessment, and therapeutic interventions.

- **New advances in AD diagnosis.** Using a multidisciplinary/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 working to develop new methods for early detection of AD.
- **New approaches to risk assessment.** TARCC scientists are using advances created by Texas-based research initiatives to address a patient's individual AD "profile," as defined by specific genetic, blood biomarkers, and general medical, behavioral, psychiatric, and other risk factors.
- **New insights into therapeutic interventions.** While great progress has been made, researchers are still searching for definitive answers to questions about the basic mechanisms underlying AD. TARCC researchers are at the forefront of defining how inflammatory proteins can be used for diagnosing AD. Advancing greater understanding of these mechanisms through basic research can benefit Texas by expanding the pipeline of scientific discovery and identifying additional targets for treatment.

Appendix C: Alzheimer's Disease Background

Alzheimer's Disease - An Urgent National Health and Research Priority

The Burden of Alzheimer's Disease

Alzheimer's disease (AD) is an age-related, progressive and irreversible brain disease characterized by a steady decline in cognitive, behavioral, and physical abilities severe enough to interfere with daily life. Hallmark symptoms of AD 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. As the disease progresses, physical manifestations include loss of strength and balance, and the inability to perform simple tasks and physical activities. As cognitive and functional abilities decline, individuals are rendered totally dependent on others for all of their care. As more of the brain becomes affected, areas that control basic life functions like swallowing and breathing become irreversibly damaged, eventually leading to death. Currently, there is no effective prevention, treatment, or cure for AD. New criteria and guidelines for diagnosing AD were proposed and published in 2011, recommending that AD be considered a disease that begins well before the development of symptoms.⁴

AD affects over five million Americans today - 350,000 are Texans. It is the sixth leading cause of death in the U.S. and has an economic burden of \$221.3 billion annually. Texas ranks fourth in the number of AD cases and second in the number of AD deaths. A new person develops AD every 66 seconds, and current projections indicate that this rate will increase to one new case every 33 seconds by 2050. According to the 2014 Alzheimer's Association, Women and Alzheimer's poll, women are at the epicenter of AD. Nearly 3.3 million of the estimated five million individuals with AD are women, and women are more likely to have other dementias.⁵

In 2015, there were an estimated 15.9 million unpaid caregivers in the U.S., most of whom were family members. In Texas, 1.4 million unpaid caregivers provided care to the 350,000 individuals with AD in 2015. This equates to 1.5 billion hours of unpaid care at a cost of \$18.9 billion per year.⁶ Total payments for healthcare, long-term care, and hospice care for individuals with AD and other dementias are projected to increase from \$236 billion in 2016 to \$1 trillion in 2050 (in 2016 dollars).⁷

Progress Through Research and Advocacy

Research continues to expand our understanding of the causes of, treatments for, and prevention of AD.⁸ Scientists have identified genetic and biological changes that occur with AD, allowing them to pinpoint possible targets for treatment. Advances in pharmacologic treatment may stabilize and delay progression of AD symptoms. This delay in progression helps contain costs

⁴ Alzheimer's Association. *Alzheimer's Disease Facts and Figures 2016*.

⁵ Alzheimer's Association. *Alzheimer's Disease Facts and Figures 2016*.

⁶ Alzheimer's Association. *Alzheimer's Disease Facts and Figures 2016*.

⁷ Alzheimer's Association. *Alzheimer's Disease Facts and Figures 2016*.

⁸ National Plan to Address Alzheimer's Disease, U.S. Department of Health and Human Services, 2015 Update.

associated with medical and long-term care, eases caregiver burden, and allows the individual with AD the opportunity to participate more fully in life and postpone inevitable dependency.

Public Health Challenge and Research Priority

AD is a major public health and research challenge because of its detrimental effects on the health and well-being of the nation's population. Because there is no cure for AD, the importance of early detection becomes even more critical—the earlier the diagnosis is made, the more likely the individual may respond to treatment. Despite its importance, significant barriers remain to early detection. A missed or delayed diagnosis of AD can lead to unnecessary burdens on the individual and their caregivers.

Ongoing research efforts to find causes and identify risk factors to delay onset and prevent and cure AD are imperative. As methodologies are refined, scientists and clinicians will be able to investigate and understand the earliest pathological and clinical signs of AD, perhaps 10 to 20 years before a clinical diagnosis is made. Drug development to block the progression of symptoms and eventually prevent AD is critical to decreasing disability and death, containing healthcare costs, and protecting individuals and families.

Increased support for individuals with AD and their caregivers is crucial. Stakeholders must continue to advocate for community and home-based care and community supports for caregivers because these programs give caregivers the assistance they need to help care for their loved ones at home.

Expediting statewide, coordinated action to address AD in Texas remains critical as the prevalence of the disease continues to climb, exacting huge human and economic burdens on Texas citizens and resources. The *2010-2015 Texas State Plan on Alzheimer's Disease* makes a compelling case for increased and coordinated statewide action and provides a clear roadmap for addressing the significant issues AD imposes on Texas. Continued implementation of the state plan, along with a robust focus on care for 2016-2021, will greatly benefit Texans by guiding the state in its efforts to reduce the burden of AD on our citizens and those who care for them.