



**Texas Council on
Alzheimer's Disease and
Related Disorders
Biennial Report 2020**

**As Required by
Texas Health and Safety Code,
Section 101.010**

**Texas Council on Alzheimer's
Disease and Related Disorders**

September 2020

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Executive Summary

The Texas Council on Alzheimer's Disease and Related Disorders (Council) was established in 1987. [Texas Health and Safety Code, Section 101.010](#) requires the Council to submit to the Governor, Lieutenant Governor, Speaker of the House of Representatives, and members of the Legislature a biennial report of activities and recommendations.

This report documents the activities of the Council during fiscal years 2019-2020, as well as recommended actions for 2021-2022.

The following are highlights of the Council's activities.

- In fiscal year 2019, the Council voted to approve the University of Texas Health Rio Grande Valley for membership to the Texas Alzheimer's Research and Care Consortium, and elect Eddie Patton Jr. as Council Vice Chair.
- In fiscal year 2019, the Council Chair appointed Byron Cordes, Vaunette Fay, and Ana Guerrero Gore to a three-person biennial report workgroup to be convened by the Department of State Health Services (DSHS) in early fiscal year 2020.
- In fiscal year 2020, Council members provided input for the biennial report via individual email. DSHS convened the three-person workgroup via conference call on February 25, 2020, to condense duplicate recommendations and consolidate the Council member input to send to the Council for review. The workgroup did not have a quorum of the Council and did not vote on any matter.

In June 2020, the Council identified the following recommendations for fiscal years 2021-2022.

- Sustain and support ongoing coordinated Alzheimer's disease (Alzheimer's) research and research into improving the lives of families and caregivers of persons with Alzheimer's or related disorders.
- Continue support for quality care for persons with Alzheimer's and related dementias and their caregivers.
- Engage in strategic collaborations.
- Expand local caregiver services and supports.

1. Introduction

As directed by [Texas Health and Safety Code, Section 101.007](#), the Texas Council on Alzheimer's Disease and Related Disorders (Council) shall engage in the following activities:

- 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 of State Health Services disbursement of grants and funds available for the Council; and
- 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, and members of the Legislature.

This report outlines the activities of the Council in fiscal years 2019-2020 and their recommendations for 2021-2022.

2. Background

In 2020, an estimated 5.8 million Americans age 65 and older are living with Alzheimer’s disease (Alzheimer’s). In Texas, approximately 400,000 people age 65 and older have Alzheimer’s.¹ Recognizing this threat, the Texas Legislature established the Texas Council on Alzheimer’s Disease and Related Disorders (Council). For additional information about the Alzheimer’s burden in Texas, see [Appendix A](#).

As directed by statute, the Council is composed of 15 members including 12 voting members who are appointed by the Governor, Lieutenant Governor and Speaker of the House. Three non-voting members are appointed by the Health and Human Services Commission and the Department of State Health Services. For a list of Council members, see [Appendix B](#).

¹ Alzheimer’s Association. Alzheimer’s disease facts and figures. <https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf>. 2020.

3. Council Activities – Fiscal Years 2019-2020

The Texas Council on Alzheimer’s Disease and Related Disorders (Council) is required to meet at least twice each calendar year. The Council met on January 30, 2019; October 28, 2019; and June 4, 2020. The second meeting of calendar year 2020 will occur in the fall.

Rita Hortenstine’s term as Council Chair expired in December 2019 and Marc Diamond was subsequently appointed to the position.

The following new Council members were appointed over the 2019-2020 biennium:

- November 2018: Sudha Seshadri
- July 2019: Jessica R. Hyde
- September 2019: Michael Gayle
- December 2019: Angela Turner and Laura DeFina (reappointed)

The following describes Council activities in fiscal year 2019.

- The Council voted to include the University of Texas Health Rio Grande Valley as a member of the Texas Alzheimer’s Research and Care Consortium.
- The Council voted to elect Eddie Patton, Jr. as Council Vice Chair.
- The Council Chair appointed Byron Cordes, Vaunette Fay, and Ana Guerrero Gore to a three-person biennial report workgroup to be convened by the Department of State Health Services (DSHS) in early fiscal year 2020.

The following describes Council activities in fiscal year 2020.

- Council members provided input for the biennial report via individual email. DSHS convened the three-person workgroup via conference call on February 25, 2020, to condense duplicate recommendations and consolidate the Council member input to send to the Council for review. The workgroup did not have a quorum of the Council and did not vote on any matter.
- In June 2020, the Council voted on four recommendations for the Biennial Report 2020.

4. Council Recommendations – Fiscal Years 2021-2022

The Texas Council on Alzheimer’s Disease and Related Disorders (Council) respectfully submits the following recommendations.

Recommendation 1: Sustain and support ongoing coordinated Alzheimer’s disease (Alzheimer’s) research and research into improving the lives of families and caregivers of persons with Alzheimer’s or related disorders.

- Continue recognition and support of coordinated statewide research, as the Texas Legislature demonstrated in passing House Bill 1504, 76th Legislature, Regular Session, 1999 (Texas Education Code, Chapter 154), to establish the Texas Consortium of Alzheimer’s Disease Centers.
- Support research on Alzheimer’s, both basic science research and clinical research, focusing on
 - ▶ early detection,
 - ▶ differentiation between Alzheimer’s and related dementias,
 - ▶ differentiation between diverse biological and environmental factors that contribute to cognitive dysfunction, and
 - ▶ treatment and care for persons living with dementia and their caregivers.
- Support the incorporation of the Alzheimer’s optional modules in the annual Texas Behavioral Risk Factor Surveillance System. The two Alzheimer’s modules are the *Caregiver Optional Module* and the *Cognitive Decline Optional Module*.
- Support efforts to bring to Texas one or more National Institute on Aging funded Alzheimer’s Disease Research Centers, and other similar national organizations.
- Establish a statewide brain banking system.

Recommendation 2: Continue support for quality care for persons with Alzheimer’s and related dementias and their caregivers.

- Promote interdisciplinary education of health professionals, first responders, and other essential personnel on how to interact with persons with dementia, management of behaviors (e.g., anxiety, aggression, wandering, etc.) through behavior modification, environmental

modifications and medication use, and promoting dementia friendly concepts.

- ▶ Work with city and county officials to promote the concept of dementia friendly cities and communities.
- ▶ Support programs that center on education of police, first responders, and other essential personnel on how to deal with persons with dementia.
- Support the development of quality care tailored to the needs of persons with dementia and the inclusion of family caregivers in decision making. Recognize and accommodate the needs of diverse populations including the effects of culture, language, and socioeconomic background.
- Promote the [Alzheimer's Association's 2018 Dementia Care Practice Recommendations](#).² The *Dementia Care Practice Recommendations* outline recommendations for quality care practices based on a comprehensive review of current evidence, best practices, and expert opinions.
- Promote the Alzheimer's awareness campaign as funded by the [2020-21 General Appropriations Act, House Bill \(HB\) 1, 86th Legislature, Regular Session, 2019](#). HB 1 allocated \$1 million in funding specifically for the development and implementation of a public awareness campaign for Alzheimer's.
- Enhance the Department of State Health Services (DSHS) Alzheimer's Disease Program website by providing additional resources specifically for health care professionals.

Recommendation 3: Engage in strategic collaborations.

- Encourage partnerships between state and county medical organizations and other stakeholders to promote research and awareness campaigns with an emphasis on geographic areas with the greatest need.
- Promote the Alzheimer's Association and Centers for Disease Control and Prevention's [Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map](#), to promote brain health as a vital component of public health, and to increase the

² Fazio S, Pace D, Maslow K, Zimmerman S, Kallmyer B. Alzheimer's Association Dementia Care Practice Recommendations. *The Gerontologist*. 2018;58(Supplement 1):S1-S9. <https://www.alz.org/media/Documents/alzheimers-dementia-care-practice-recommendations.pdf>.

number of Texans who recognize the direct impact physical health can have on brain/cognitive health.³

- Support and promote the [Texas State Plan for Alzheimer's Disease 2019-2023](#) (state plan).⁴ [Texas Health and Safety Code, Section 99.001](#) directs DSHS to develop and implement a state plan for education on and treatment of Alzheimer's and other dementias. The state plan will be reviewed and modified as necessary every five years.
- Invite local representatives to speak at Council meetings about how they are implementing the state plan.

Recommendation: 4: Expand local caregiver services and supports.

- Strengthen the DSHS Alzheimer's Disease Program and its role in providing support and resources for persons living with the disease, caregivers, and health care professionals.
- Enhance the DSHS Alzheimer's Disease Program website by making it more user-friendly with links and references to Alzheimer's state and community services.

³ Alzheimer's Association and Centers for Disease Control and Prevention. Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map. *Centers for Disease Control and Prevention*. <https://www.cdc.gov/aging/pdf/2018-2023-Road-Map-508.pdf>. Published 2018.

⁴ Texas Department of State Health Services. Texas State Plan for Alzheimer's Disease 2019-2023. *Texas Department of State Health Services*. <https://www.dshs.texas.gov/legislative/2019-Reports/Alzheimers-Disease-State-Plan-2019-2023.pdf>. Published September 2019.

5. Conclusion

The Texas Council on Alzheimer’s Disease and Related Disorders (Council) continues to dedicate time and effort to highlighting the needs of persons living with Alzheimer’s disease (Alzheimer’s) and other dementias, their family caregivers, and related professionals.

The Council’s recommendations for fiscal years 2021-2022 include sustaining and supporting ongoing coordinated Alzheimer’s research and research into improving the lives of families and caregivers of persons with Alzheimer’s or related disorders, continuing support for quality care for persons with Alzheimer’s and related dementias and their caregivers, engaging in strategic collaborations, and expanding local caregiver services and support.

List of Acronyms

Acronym	Full Name
DSHS	Department of State Health Services

Appendix A. Alzheimer's Disease – An Urgent National Health and Research Priority

Appendix A was updated by the Alzheimer's Disease Program at the Department of State Health Services.

The Burden of Alzheimer's Disease

Alzheimer's disease (Alzheimer's) 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 Alzheimer's 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 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 Alzheimer's. Alzheimer's is thought to begin 20 years or more before symptoms develop.

In 2020, an estimated 5.8 million Americans age 65 and older are living with Alzheimer's. In Texas, approximately 400,000 people aged 65 and older have Alzheimer's. It is the sixth leading cause of death in the U.S. and has an economic burden of an estimated \$305 billion annually. Texas ranks fourth in the number of Alzheimer's cases and second in the number of Alzheimer's deaths. Nearly 3.6 million of the estimated 5.8 million people age 65 and older with Alzheimer's are women and 2.2 million are men. Women are more likely to have other dementias.

In 2019, there were more than 16 million unpaid caregivers in the U.S., most of whom were family members. In Texas, approximately 1.45 million unpaid caregivers provided care to the approximately 400,000 individuals with Alzheimer's in 2019. This equates to an estimated 1.65 billion hours of unpaid care at a cost of approximately \$21.6 billion per year. Total payments for health care, long-term care, and hospice care for individuals with Alzheimer's and other dementias are projected to increase from \$305 billion in 2020 to more than \$1.1 trillion in 2050 (in 2020 dollars).

Progress Through Research and Advocacy

Research continues to expand our understanding of the causes of, treatments for, and prevention of Alzheimer's.⁵ Scientists have identified genetic and biological changes that occur with Alzheimer's, allowing them to pinpoint possible targets for treatment. Advances in pharmacologic treatment may stabilize and delay progression of Alzheimer's symptoms. This delay in progression helps contain costs associated with medical and long-term care, eases caregiver burden, and allows the individual with Alzheimer's the opportunity to participate more fully in life and postpone inevitable dependency.

Public Health Challenge and Research Priority

Alzheimer's 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 Alzheimer's, 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 Alzheimer's 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 Alzheimer's are imperative. As methodologies are refined, scientists and clinicians will be able to investigate and understand the earliest pathological and clinical signs of Alzheimer's, perhaps 10 to 20 years before a clinical diagnosis is made. Drug development to block the progression of symptoms and eventually prevent Alzheimer's is critical to decreasing disability and death, containing health care costs, and protecting individuals and families.

Increased support for individuals with Alzheimer's 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 Alzheimer's in Texas remains critical as

⁵ U.S. Department of Health and Human Services. National plan to address Alzheimer's disease: 2019 update. <https://aspe.hhs.gov/report/national-plan-address-alzheimers-disease-2019-update>

the prevalence of the disease continues to climb, exacting huge human and economic burdens on Texas citizens and resources.

Appendix B. Texas Council on Alzheimer’s Disease and Related Disorders Member Roster

Byron Cordes, LCSW, C-ASWCM San Antonio	Laura DeFina, MD Dallas
Marc Diamond, MD, Chair Dallas	Joe A. Evans, Jr. Beaumont
Vaunette Fay, PhD Houston	Ana Guerrero Gore Galveston
Char Hu, PhD Austin	Eddie L. Patton, Jr., MD, Vice-Chair Sugar Land
Mary Ellen Quiceno, MD, FAAN Dallas	Sudha Seshadri, MD, DM San Antonio
Terrence Sommers Amarillo	Angela Turner Normangee
Jessica R. Hyde, MS, CHES Texas Department of State Health Services	Valerie J. Krueger Texas Health and Human Services Commission
Michael Gayle, PT, DPT, MA, OCS Texas Health and Human Services Commission	<u>Staff</u> Lynda Taylor, MSW Texas Department of State Health Services