



2020 Biennial Update for the Texas State Plan for Alzheimer's Disease

As Required by

**Health and Safety Code,
Section 99.004**



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Executive Summary

Texas Health and Safety Code, Section 99.001, directs the Department of State Health Services (DSHS) to develop and implement a state plan for education on and treatment of Alzheimer's disease and other dementias. In conjunction with a state plan, Texas Health and Safety Code, Section 99.004, requires DSHS to submit a report to the Legislature not later than September 1 of each even-numbered year on the "...development and implementation or the review or modification of the state plan." To comply with this requirement, DSHS presents this report on the progress the DSHS Alzheimer's Disease Program (ADP) has made in the development, implementation, and review of the Texas State Plan for Alzheimer's Disease 2019-2023 (state plan) from September 1, 2019, to April 30, 2020.

The ADP is responsible for developing a state plan, convening stakeholder meetings, and preparing legislative reports. The state plan was published in October 2019. The state plan is publicly available at the [ADP website](#).

To date, funding has not been allocated to implement the state plan, except for a one-time appropriation for an Alzheimer's disease awareness campaign in the 2020-21 General Appropriations Act (2019). The state plan encourages a coordinated effort among Texas stakeholders to address the needs of those with Alzheimer's disease and other dementias.

The following are highlights of ADP activities.

- The ADP disseminated the state plan at the ADP website, by email, and through in-person stakeholder meetings.
- The ADP encouraged stakeholders to share the state plan with diverse populations and throughout the health service regions across Texas.

- The ADP considered strategies for state plan implementation and ways to convene stakeholder workgroups based on the capacity of the ADP to support activities with the staff and resources currently available.
- The 2020-21 General Appropriations Act, House Bill 1, 86th Legislature, Regular Session, 2019 appropriated \$1 million over the biennium for DSHS to produce an Alzheimer's disease awareness campaign. Campaign materials will be ready for release in August 2020.
- The ADP began enhancing the program website with information organized to help family caregivers, healthcare providers, stakeholders, and other interested parties find useful information quickly.
- The DSHS Chronic Disease Epidemiology Branch supported state plan evaluation through surveys to determine participation of the volunteer-based, statewide Texas Alzheimer's Disease Partnership (Partnership) and progress on state plan goals.
- The ADP convened the Partnership to provide input for state plan dissemination and implementation activities. The Partnership is made up of more than 200 individuals and includes physicians; other healthcare providers licensed in Texas; advocate organizations; and other interested parties as outlined in [Texas Health and Safety Code, Section 99.002](#).

1. Introduction

[Texas Health and Safety Code, Section 99.001](#), directs the Department of State Health Services (DSHS) to develop and implement a state plan for education on and treatment of Alzheimer's disease and other dementias. In conjunction with a state plan, [Texas Health and Safety Code, Section 99.004](#), requires DSHS to submit a report to the Legislature not later than September 1 of each even-numbered year on the "...development and implementation or the review or modification of the state plan."

[Texas Health and Safety Code, Chapter 99](#) also requires DSHS to consult with physicians, other healthcare providers, and interested parties when developing the state plan. DSHS must 1) meet with interested parties to collect comment on the state plan at least two times per year and 2) review and modify the state plan every five years.

In consultation with stakeholders, DSHS published the *Texas State Plan for Alzheimer's Disease 2019-2023* (state plan) in October 2019. To comply with the requirements of the aforementioned statutes, DSHS presents this report on the progress the Alzheimer's Disease Program has made in the development, implementation, and review of the state plan from September 1, 2019, to April 30, 2020.

2. Background

Alzheimer's disease is an irreversible brain disease that slowly damages memory, thinking ability, and, eventually, the ability to carry out daily activities. Dementia is a general term for memory loss and changes to other mental abilities and behavior that are severe enough to interfere with daily life.¹

Alzheimer's disease is a major public health issue in Texas. According to the Alzheimer's Association, an estimated 5.8 million Americans age 65 and older are living with Alzheimer's disease in 2020 - approximately 400,000 of which are Texans.² Without a cure or a way to prevent it, the number of Americans age 65 and older with Alzheimer's disease may increase to nearly 14 million people by 2050.²

For more information on Alzheimer's disease in Texas, please see the Department of State Health Services (DSHS) [Alzheimer's Disease Program \(ADP\) website](#).

In 2019, the Legislature directed DSHS to develop and implement a state plan for the education on and treatment of Alzheimer's disease and other dementias. To develop a state plan, the ADP consulted with the following interested parties as outlined by [Texas Health and Safety Code, Section 99.002](#):

- Members of the public with, or who care for persons with, Alzheimer's disease or related disorders;
- Each state agency that provides services to persons with Alzheimer's disease or related disorders;
- Any advisory body that addresses issues related to Alzheimer's disease or related disorders;
- Public advocates concerned with issues related to Alzheimer's disease or related disorders;

¹ Alzheimer's disease fact sheet. National Institute on Aging website. <https://www.nia.nih.gov/health/alzheimers-disease-fact-sheet>. Accessed May 26, 2020.

² Alzheimer's Association. Alzheimer's disease facts and figures. <https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf>. 2020. Accessed May 26, 2020.

- Physicians and healthcare providers licensed in this state who have clinical training and experience in caring for persons with Alzheimer's disease or related disorders; and
- Researchers of issues affecting persons with Alzheimer's disease or related disorders.

Once input was sought from these groups, DSHS published and submitted the state plan in the form of a report to the Legislature in October 2019. Known as the *Texas State Plan for Alzheimer's Disease 2019-2023* (state plan), the state plan serves as a resource for diverse stakeholders across the state and describes a public health approach to address Alzheimer's disease and other dementias with recommended goals and strategies in eight priority areas. For the state plan executive summary, see ([Appendix A](#)). The report is available to the public at the [ADP website](#).

To date, funding has not been allocated to implement the state plan, except for a one-time appropriation for an Alzheimer's disease awareness campaign in the 2020-21 General Appropriations Act (2019). As such, the state plan is not the action plan or strategic plan for any one entity, and the recommended actions in the state plan are not specific to any one organization. Instead, the state plan encourages a coordinated effort among Texas stakeholders to address the needs of those with Alzheimer's disease and other dementias.

In addition to developing the state plan, statute requires DSHS to regularly seek input on the implementation, review, and modification of the state plan. To do so, DSHS must seek input from the aforementioned interested partners at least two times per year. The following report describes the steps DSHS has taken to implement the state plan and seek input on plan dissemination, implementation, and review.

3. State Plan Dissemination and Implementation

The following section describes actions taken by the Department of State Health Services (DSHS) Alzheimer's Disease Program (ADP) to disseminate the *Texas State Plan for Alzheimer's Disease 2019-2023* (state plan) among stakeholders and to begin implementation. Each activity description includes the corresponding state plan Priority Area, numbered as outlined below.

1. Education and awareness
2. Coordinated systems of care and support
3. Partnerships and engagement
4. Training
5. Quality care and support
6. Family inclusion
7. Importance of data collection and evaluation
8. Advance research and collaboration

Activities described in this report took place between September 1, 2019, and April 30, 2020.

Dissemination Activities

The ADP convened the volunteer-based, statewide Texas Alzheimer's Disease Partnership (Partnership) to provide input for state plan dissemination and implementation activities.³ The Partnership is made up of more than 200 individuals and includes physicians; other healthcare providers licensed in Texas; advocate organizations (such as the Texas Medical Association); and other interested parties as outlined in [Texas Health and Safety Code, Section 99.002](#). The ADP maintains a roster of Partnership volunteers who want to receive information on the state plan and attend meetings. As new stakeholders are identified, they are added to the roster.

³ Although DSHS refers to these stakeholders as partners, the term partner is used broadly to indicate the stakeholder's interest in participating and does not imply that there is any formal agreement between DSHS and the stakeholder or that a consensus of partners is required for state plan content.

On November 19, 2019, the ADP convened the Partnership for a kick-off meeting to introduce the state plan and receive input regarding dissemination and implementation ideas. The ADP provided updates on the Alzheimer's disease awareness campaign and state plan evaluation. Likewise, on April 30, 2020, the ADP convened the Partnership for a state plan meeting via webinar to provide updates on ADP implementation activities and seek further input. (Priority Area: 3)

The ADP also disseminated the state plan on the ADP website, by email to the Partnership, and through in-person meetings of the Partnership, the Texas Council on Alzheimer's Disease and Related Disorders, the Aging Texas Well Advisory Committee, and Area Agency on Aging representatives. (Priority Areas: 1, 2, 3)

The ADP encouraged partners to share the state plan with diverse populations and throughout the health service regions across Texas. (Priority Areas: 1, 2, 3)

The Partnership shared the state plan within their networks and used the state plan to support and provide justification for their own work plans and funding opportunity applications. (Priority Areas: 2, 3)

Implementation Activities

The ADP considered strategies for state plan implementation based on the capacity of the ADP to support activities with the staff and resources currently available. With input from the Partnership, the ADP began laying the groundwork to track member expertise; use in-person meetings, webinars, and engagement calls; help members share success stories, strategies, and resources; have more diverse and regional representation; and learn about practical methods to bring partners together for workgroups and information-sharing groups. The state plan emphasizes the need for stakeholders to use the state plan strategies and actions within their own organizations and networks. (Priority Area: 3)

Alzheimer's Disease Awareness Campaign

The 2020-21 General Appropriations Act, House Bill 1, 86th Legislature, Regular Session, 2019, appropriated \$1 million over the biennium for DSHS to produce an Alzheimer's disease awareness campaign. (Priority Areas: 1, 2, 3, 5, 6, 7)

Sherry Matthews Group (SMG) was selected in November 2019 to design and develop the campaign. SMG conducted market research that included English- and Spanish-language focus groups and message testing. The campaign includes culturally competent images with messages in English and Spanish. The primary

audience of the campaign are individuals between 40-60 years of age, with an emphasis on female caregivers.

SMG developed public service announcement messages for paid media to include statewide television, radio, digital, and print ads. SMG also created ADP website landing pages and content to support the awareness campaign message of "See the signs, start a conversation." The website includes information and resources for caregivers.

The campaign was originally scheduled to launch in June 2020, but, due to delays related to COVID-19, radio production did not begin until June 2020, and television production did not begin until July 2020. Campaign materials will be ready for release in August 2020.

ADP Website Update

The ADP began enhancing the program's website with information organized to help family caregivers, healthcare providers, stakeholders, and other interested parties find useful information quickly. This is an ongoing process as the ADP adds information over time. (Priority Areas: 1, 2, 3, 5, 6)

4. State Plan Evaluation

Existing data sources to track statewide progress toward achieving the goals outlined in the *Texas State Plan for Alzheimer's Disease 2019-2023* (state plan) are limited. The state plan encourages stakeholders to collaborate in a coordinated and systematic way to identify and address ongoing data needs for all the Priority Areas. The Department of State Health Services (DSHS) Alzheimer's Disease Program (ADP) is taking steps to develop data collection tools that will provide baseline measurements and targets to determine progress in achieving state plan goals.

Evaluation Activities

In support of the ADP, the DSHS Chronic Disease Epidemiology Branch (CDE) is collecting data related to state plan goals to measure progress and inform the next iteration of the state plan. The following surveys represent the CDE's evaluation activities to date. (Priority Area: 7)

Partnership Member Survey

The CDE conducted the [2019 Texas Alzheimer's Disease Partnership Member Survey](#) with the goal of providing the ADP with foundational information on the work of Texas Alzheimer's Disease Partnership (Partnership) members across the state. (Priority Area: 3)

The ADP used the results of this survey to understand who is actively participating in the Partnership, begin development of a database of member expertise, and begin identifying new stakeholders from health regions across Texas to increase the diversity of the Partnership and the range of disciplines and organizations represented.

The ADP began working with the diverse membership of the Partnership through an in-person meeting, a webinar, and emails to identify interested parties as prescribed in statute to provide input on state plan dissemination and implementation.

Unpaid Caregiver Survey

The CDE will conduct a pre- and post-survey of unpaid caregivers to 1) assess caregivers' experiences providing care and 2) measure progress of Partnership members and stakeholders in achieving state plan goals outlined in Priority Areas 1, 2, 3, and 6. The pre-survey will be conducted in 2020, and the post-survey will be conducted in 2023. A survey link will be provided to Partnership members and stakeholders that have access to networks within the unpaid caregiver population. Those Partnership members and stakeholders will disseminate the survey link to their unpaid caregiver network via email. In addition, survey respondents will have the opportunity to forward the survey link to anyone else they think should complete the survey (snowball sampling).

5. State Plan Review and Modification

[Texas Health and Safety Code, Section 99.003](#) requires the Department of State Health Services (DSHS) to conduct a review and modify the *Texas State Plan for Alzheimer's Disease 2019-2023* (state plan) as necessary. DSHS is to gather information to inform review and future modification of the state plan through consultation with interested parties at least two times per year.

As previously mentioned, one of the methods the Alzheimer's Disease Program (ADP) is using to seek input on the state plan is the Texas Alzheimer's Disease Partnership (Partnership). The expertise of the Partnership is critical to identifying areas of improvement ahead of the next iteration of the state plan in 2024. At both the November 19, 2020, and April 30, 2020, Partnership meetings, the ADP sought input and documented feedback from members that will be used to assess future modifications to the state plan. Through these meetings with the Partnership, the ADP has met the requirement set in [Health and Safety Code, Section 99.002](#), to seek input from interested parties regarding state plan implementation, review, and modification.

As the state plan enters its next revision, the ADP will continue to encourage the participation of Texas stakeholders and seek input from required interested parties. The ADP will build processes and timelines to effectively manage more complex input from stakeholders. The ADP will use this input to make modifications as needed for a 2024-2028 state plan update.

The ADP will determine when smaller meetings with specific stakeholders are needed to fulfill statutory requirements. Texas Health and Safety Code, Section 99.001 requires DSHS to specifically solicit input from healthcare professionals when making updates to the state plan, which can be done more effectively in smaller groups. Smaller meetings with specific stakeholders will enable the ADP to focus on specific topic areas, strategies, and activities of the plan to accurately identify next steps.

6. Conclusion

The *Texas State Plan for Alzheimer's Disease 2019-2023* (state plan) provides recommended Priority Areas and actions regarding education on and treatment of Alzheimer's disease and other dementias. Developed with stakeholder input, the state plan describes a public health approach to address these conditions.

The following are activities of the Alzheimer's Disease Program (ADP) from September 1, 2019, to April 30, 2020:

- Sought input from interested parties regarding state plan dissemination, implementation, and review by convening meetings of the Texas Alzheimer's Disease Partnership (Partnership) and encouraged dissemination through partner networks, diverse populations, and health service regions across Texas;
- Disseminated the state plan through in-person stakeholder meetings, email, and at the ADP website;
- Began developing a statewide Alzheimer's disease awareness campaign for release in August 2020;
- Laid the groundwork for keeping track of who is participating in the Partnership and ways to encourage collaboration among partners;
- Began enhancing the ADP website with information organized to help family caregivers, healthcare providers, stakeholders, and other interested parties; and
- Worked with the Department of State Health Services Chronic Disease Epidemiology Branch regarding state plan evaluation through surveys to determine Partnership participation and progress on state plan goals.

List of Acronyms

Acronym	Full Name
ADP	Alzheimer's Disease Program
CDE	Chronic Disease Epidemiology Branch
DSHS	Department of State Health Services
SMG	Sherry Matthews Group

Appendix A. Texas State Plan for Alzheimer's Disease 2019-2023 - Executive Summary

[Senate Bill 999, 86th Legislature, Regular Session, 2019 \(SB 999\)](#), adds Health and Safety Code, Section 99.001, to direct the Department of State Health Services (DSHS) to develop and implement a state plan for education on and treatment of Alzheimer's disease and other dementias.

The Texas State Plan for Alzheimer's Disease 2019-2023 (state plan) includes emerging issues and trends identified by the volunteer-based Texas Alzheimer's Disease Partnership (Partnership), the [Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map](#)⁴ (developed by the Alzheimer's Association and the Centers for Disease Control and Prevention [CDC]), subject matter experts, and other national and state plans.

The state plan serves as a resource for diverse stakeholders across the state. The state plan describes a public health approach to address Alzheimer's disease and other dementias with recommended actions in eight priority areas:

- Education and awareness;
- Coordinated systems of care and support;
- Partnerships and engagement;
- Training;
- Quality care and support;
- Family inclusion;
- Importance of data collection and evaluation; and
- Advance research and collaboration.

The state plan encourages coordinated effort among Texas stakeholders to address the needs of Alzheimer's disease and other dementias and ensure the health and well-being of Texans.

⁴ 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. <https://www.cdc.gov/aging/pdf/2018-2023-Road-Map-508.pdf>. 2018. Accessed August 19, 2019.