

# 2022 Biennial Update for the Texas State Plan for Alzheimer's Disease

As Required by Health and Safety Code, Section 99A.004

Department of State Health Services
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## **Executive Summary**

Texas Health and Safety Code, Section 99A.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 addition to a state plan, Texas Health and Safety Code, Section 99A.004 requires DSHS to submit a report to the Legislature by September 1 of each even-numbered year on the development and implementation or the review or modification of the state plan. This report describes DSHS' actions to disseminate, implement, and evaluate the Texas State Plan for Alzheimer's Disease 2019-2023 (state plan) from May 1, 2020, to March 31, 2022.

DSHS is responsible for developing and implementing the state plan, convening stakeholder meetings, and preparing legislative reports. The current state plan was first created and published in October 2019 and is available on the <a href="DSHS website">DSHS website</a>. The state plan encourages a coordinated effort among Texas stakeholders to address the needs of those with Alzheimer's disease and other dementias.

To date, funding has not been specifically allocated to implement the state plan. However, in the 2022-23 General Appropriations Act (Senate Bill 1, 87th Legislature, Regular Session, 2021), the Legislature appropriated \$1 million to DSHS for the Alzheimer's Disease Program.

The following are highlights of DSHS activities.

- DSHS disseminated the state plan through the DSHS website, email, and inperson stakeholder meetings.
- DSHS encouraged stakeholders to share the state plan with diverse populations and throughout Texas' health service regions.
- DSHS developed a process for collaborating with the Texas Alzheimer's Disease Partnership (Partnership) on new educational resources for the public.
- DSHS sought input from the Partnership on potential revisions to the state plan.
- Using funds from the 2022-23 General Appropriations Act, DSHS is enhancing the existing Alzheimer's disease awareness campaign to better reach African American and Asian American populations.
- DSHS updated its website with new educational resources and reorganized website content to help stakeholders find useful information more quickly.

- DSHS conducted a survey among unpaid caregivers in Texas to learn more about the experiences of current and former unpaid caregivers. DSHS will use the survey results to estimate the progress made towards implementing the recommendations in the state plan. DSHS published the survey results in the <u>2021 Texas Alzheimer's Disease and Related Dementias Caregiver Survey Report</u>.
- DSHS held virtual meetings with the Partnership to collect input on state plan dissemination and implementation activities.

DSHS will publish the next iteration of the state plan (for 2024-2028) on September 1, 2024.

#### 1. Introduction

Texas Health and Safety Code, Section 99A.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 addition to a state plan, Texas Health and Safety Code, Section 99A.004 requires DSHS to submit a report to the Legislature by September 1 of each even-numbered year on the development and implementation or the review or modification of the state plan.

Statute also requires DSHS to consult with physicians, other health care providers, and interested parties when developing the state plan. DSHS must 1) meet with interested parties to collect comments on the state plan at least twice a year and 2) review and modify the state plan at least once every five years.

In consultation with stakeholders, DSHS published the <u>Texas State Plan for Alzheimer's Disease 2019-2023</u> (state plan) in October 2019. To comply with statutory requirements, this report describes DSHS' actions to disseminate, implement, and evaluate the state plan from May 1, 2020, to March 31, 2022.

## 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.<sup>1</sup>

Alzheimer's disease is a major public health issue in Texas. According to the Alzheimer's Association, approximately 400,000 Texans age 65 and older were living with Alzheimer's disease in 2020. An estimated 6.5 million Americans age 65 and older are living with Alzheimer's disease in 2022. Without a cure or a way to prevent it, the number of Americans age 65 and older with Alzheimer's disease is projected to reach 12.7 million people by 2050.<sup>2</sup>

For more information on Alzheimer's disease in Texas, please see the <u>Department</u> of State Health Services (DSHS) 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, DSHS consulted with the interested parties required by <u>Texas</u> Health and Safety Code, Section 99A.002.

Once input was sought, DSHS published and submitted the <u>Texas State Plan for Alzheimer's Disease 2019-2023</u> (state plan) as a report to the Legislature in October 2019. The state plan describes a public health approach to address Alzheimer's disease and other dementias and provides recommended goals and strategies in eight priority areas.

To date, funding has not been specifically allocated to implement the state plan. However, in the 2020-21 General Appropriations Act (House Bill 1, 86th Legislature, Regular Session, 2019), the Legislature appropriated \$1 million to DSHS to implement an Alzheimer's disease awareness campaign. In the 2022-23 General Appropriations Act (Senate Bill 1, 87th Legislature, Regular Session, 2021), the

<sup>&</sup>lt;sup>1</sup> Alzheimer's Disease Fact Sheet. National Institute on Aging website. https://www.nia.nih.gov/health/alzheimers-disease-fact-sheet. Accessed February 17, 2022.

<sup>&</sup>lt;sup>2</sup> Alzheimer's Association. Alzheimer's Disease Facts and Figures. https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf. Accessed March 28, 2022.

Legislature again appropriated \$1 million to DSHS but for general operations of the Alzheimer's Disease Program.

In addition to developing the state plan, statute requires DSHS to regularly seek input on the implementation, review, and modification of the state plan from stakeholders at least twice a year. To satisfy this requirement, DSHS convenes and consults the Texas Alzheimer's Disease Partnership (Partnership), a stakeholder group of more than 300 individuals, including: health care providers, advocates, researchers, members of the public, and state agency representatives (such as the Health and Human Services Commission).

DSHS 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. State Plan Dissemination and Implementation

The following section describes actions taken by the Department of State Health Services (DSHS) to disseminate the <u>Texas State Plan for Alzheimer's Disease 2019-2023</u> (state plan) and implement its recommendations. 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 May 1, 2020, and March 31, 2022.

DSHS convened meetings of the volunteer-based, statewide Texas Alzheimer's Disease Partnership (Partnership) to provide updates and receive input regarding state plan dissemination and implementation activities.<sup>3</sup> Due to COVID-19 precautions, DSHS held Partnership meetings virtually on December 8, 2020, June 2, 2021, and December 9, 2021.

#### **Dissemination Activities**

DSHS disseminated the state plan through its <u>website</u> and encouraged partners to share the state plan with diverse populations and across Texas' health service regions. (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)

<sup>&</sup>lt;sup>3</sup> 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.

### **Implementation Activities**

DSHS considered strategies for state plan implementation based on the department's capacity to support activities with the staff and resources currently available. 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)

#### Stakeholder Meetings

DSHS completed the following activities during Partnership meetings.

- DSHS provided an opportunity for stakeholders to offer input on the *Education and Awareness* priority area of the state plan to learn about new trends and other helpful updates to inform the eventual revision of the state plan. (Priority Areas: 1, 3)
- Sherry Mathews Group (SMG), the marketing communications agency contracted by DSHS to create the Alzheimer's disease awareness campaign, provided a presentation on how the campaign was developed, the materials in the <u>Alzheimer's Campaign Toolkit</u>, and ideas the Partnership could use for dissemination. (Priority Areas: 1, 2, 3, 5, 6, 7)
- DSHS presented data from the <u>2021 Texas Alzheimer's Disease and Related Dementias Caregiver Survey Report</u>. DSHS encouraged Partnership members to share the data and use it to inform their own organizations' activities. (Priority Areas: 1, 2, 3, 5, 6, 7)
- DSHS outlined a process to organize Partnership workgroups. Partnership workgroups are topic-specific and tasked with either developing issue briefs or highlighting regional resources. These activities will expand the educational resources available to caregivers and health care professionals. DSHS will post new content on its website. (Priority Areas: 1, 2, 3, 5, 6)
- DSHS presented the results of surveys conducted among Partnership members. DSHS surveys sought member input on what issue briefs should be developed for the website. The Partnership identified three topics for issue briefs: 1) types of care and how to locate them, 2) support groups, and 3) technology resources for caregivers. DSHS will convene Partnership workgroups to develop the issue briefs and identify dementia resources in health service regions. (Priority Areas: 1, 2, 3, 5, 6)
- A representative from the Health and Human Services Commission's Office of Aging and Disability Services presented on the services and resources

available in Texas through the Area Agencies on Aging and the Aging and Disability Resource Centers. This information is intended to inform the activities of individual Partnership organizations and encourage collaboration. (Priority Areas: 1, 2, 3, 5, 6)

#### 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)

DSHS contracted with SMG in November 2019 to design and develop the campaign. SMG conducted market research through focus groups and message testing in English and Spanish. SMG then developed public service announcement messages for paid media, including statewide television, radio, digital, and print ads. In August 2020, DSHS launched the media campaign. The goal of the campaign is to help Texans recognize the signs of Alzheimer's disease in their loved ones and start a conversation on seeking care. The primary audience for the campaign is individuals between 40-60 years of age, with an emphasis on female caregivers.

DSHS updated and refreshed its website to support the "See the signs. Start a conversation" message of the campaign. The DSHS website includes updated information and resources for caregivers and the Alzheimer's Campaign Toolkit.

The campaign generated more than 21 million impressions in fiscal year 2020 and 31 million impressions in fiscal year 2021 (via television, radio, print, digital, social media, webpage, email).<sup>4</sup> The campaign was also featured nationally in the American Association of Retired Persons' (AARP's) magazine online and in print.

Using funding appropriated to DSHS in the 2022-23 General Appropriations Act (Senate Bill 1, 87th Legislature, Regular Session, 2021), DSHS contracted with SMG in October 2021 to enhance the existing 2020-2021 campaign with additional public service announcement messages for paid media, including statewide television, radio, digital, and print ads.

The Partnership provided input on campaign enhancements and recommended an increased focus on reaching diverse populations of different racial, ethnic, and national backgrounds, specifically African American and Asian American

<sup>&</sup>lt;sup>4</sup> A media impression is a measure of the number of times content is consumed.

populations. As such, SMG conducted market research that included Asian American and African American focus groups and message testing. The 2022-2023 campaign will have an emphasis on these populations.

Through the contract with SMG, DSHS is also developing an educational booklet for the public that includes information on getting a diagnosis and how to find community resources. Community support organizations and health care providers can use this booklet to encourage early diagnosis and make referrals to community resources. Once completed, DSHS will post the booklet on the website.

#### **DSHS** Website Update

DSHS updated its website with new educational resources and reorganized website content to help stakeholders find useful information more quickly. This is an ongoing process as DSHS develops additional materials. (Priority Areas: 1, 2, 3, 5, 6)

Examples of new website content include the following.

- A flyer highlighting the connection between heart health and brain health, titled <u>Healthy Heart, Healthy Brain. Steps for Protecting the Heart, Brain, and Body</u>.
- Materials from the Alzheimer's disease awareness campaign. The goal of these materials is to encourage individuals to start a conversation with their loved ones after noticing possible signs of Alzheimer's disease (<u>Warning</u> <u>Signs and Next Steps</u>; <u>Early Intervention Protects Quality of Life</u>; <u>Alzheimer's</u> <u>Campaign Toolkit</u>; <u>Alzheimer's disease See the Signs. Start a Conversation</u>).
- The <u>2021 Texas Alzheimer's Disease and Related Dementias Caregiver</u> <u>Survey Report</u> and a one-pager summarizing the results, titled <u>2021</u> <u>Caregiver Survey Results</u>.

#### 4. State Plan Evaluation

Because existing data sources are limited, it is difficult for the Department of State Health Services (DSHS) to track the state's progress toward achieving the goals outlined in the <u>Texas State Plan for Alzheimer's Disease 2019-2023</u> (state plan). As such, DSHS encourages stakeholders to use the state plan to collaborate in a coordinated and systematic way to identify and address ongoing data needs for all priority areas. DSHS 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**

The following describes DSHS' evaluation activities. (Priority Area: 7)

#### Unpaid Caregiver Survey and Report

In collaboration with the Partnership, DSHS created and conducted the *2021 Texas Alzheimer's Disease and Related Dementias Caregiver Survey.* The goals of the survey were to learn more about the experiences of current and former unpaid caregivers and determine progress made towards the strategies and activities listed in the state plan. The Partnership assisted DSHS with question development, survey methodology, piloting, and survey distribution.

DSHS has limited access to the caregiver population; therefore, DSHS used the networks of Partnership organizations and a snowball sampling method to recruit respondents. DSHS emailed the survey to Partnership members and other key stakeholders with instructions to forward the email with the survey link to unpaid caregivers or to people who might know unpaid caregivers. Recipients were then encouraged to forward the survey link to other unpaid caregivers they knew. To increase the reach of the survey, DSHS also posted the survey link to the Department's LinkedIn and Twitter social media pages. The survey was open from January 4 to March 5, 2021. A total of 360 respondents were included in the analysis.

From the survey, DSHS confirmed that caregiving can have a negative overall impact on unpaid caregivers' health, work, and finances. Although this is an important start, more data is needed to better understand similarities and

differences in the caregiving experience in Texas based on race, culture, linguistic capability, socioeconomic status, and geographic area.

Survey development, methodology, and results are provided in the <u>2021 Texas</u> <u>Alzheimer's Disease and Related Dementias Caregiver Survey Report</u>. DSHS will develop a manuscript for publication in a peer-reviewed journal and plans to conduct the survey among Spanish-speaking unpaid caregivers.

#### 5. State Plan Review and Modification

Texas Health and Safety Code, Section 99A.003 requires the Department of State Health Services (DSHS) to review and modify the state plan at least once every five years. Additionally, DSHS is required to gather information to inform the review and future modification of the state plan through consultation with interested parties at least twice a year.

DSHS will develop the next iteration of the state plan in 2023 (year five of the current state plan) ahead of publication on September 1, 2024.

The expertise of the Partnership is critical to identifying areas of improvement for the next iteration of the state plan. At the Partnership meetings listed in this report, DSHS sought and documented input from members that will be used to assess future modifications to the state plan. Through these meetings with the Partnership, DSHS has met the statutory requirement to seek input from interested parties regarding state plan implementation, review, and modification.

As DSHS begins the process of revising the state plan, DSHS will continue to encourage the participation of Texas stakeholders and seek input from required interested parties. DSHS will build processes and timelines to effectively manage more complex input from stakeholders. DSHS will use this input to inform the development of the 2024-2028 state plan.

DSHS will determine when smaller meetings with specific stakeholders are needed to fulfill statutory requirements. <u>Texas Health and Safety Code, Section 99A.001</u> requires DSHS to solicit input from health care professionals when making updates to the state plan, which can be done more effectively in smaller groups. Doing so will enable DSHS to focus on specific state plan topic areas, strategies, and activities to accurately identify next steps.

#### 6. Conclusion

The <u>Texas State Plan for Alzheimer's Disease 2019-2023</u> (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 Department of State Health Services (DSHS) conducted the following state plan dissemination, implementation, and evaluation activities from May 1, 2020, to March 31, 2022.

- Sought input from stakeholders regarding state plan dissemination, implementation, review, and modification by convening the Texas Alzheimer's Disease Partnership (Partnership).
- Disseminated the state plan through in-person stakeholder meetings, email, and the <u>DSHS website</u>.
- Enhanced the existing statewide Alzheimer's disease awareness campaign to better reach African American and Asian American populations.
- Developed processes for organizing Partnership workgroups tasked with creating issue briefs and identifying regional resources.
- Updated and reorganized the DSHS website with new educational resources to help family caregivers, health care providers, stakeholders, and other interested parties.
- Worked with the Partnership to evaluate the state plan by creating and conducting a survey to learn more about the experiences of current and former unpaid caregivers.

## **List of Acronyms**

Acronym	Full Name
DSHS	Department of State Health Services
SMG	Sherry Matthews Group
AARP	American Association of Retired Persons