



# **Texas State Plan for Alzheimer's Disease 2019-2023**

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**As Required by  
Health and Safety Code, Section  
99.001**



**TEXAS**  
**Health and Human  
Services**

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**Texas Department of  
State Health Services**

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## 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](#)<sup>1</sup> (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.

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<sup>1</sup> 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.

# 1. Introduction

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.

SB 999 requires that this state plan include strategies on the following topics:

- Improving early detection of, reducing disease onset risks for, and improving treatment of Alzheimer's disease and other dementias;
- Educating health care professionals, caregivers, and the public;
- Providing caregiver support;
- Advancing research related to Alzheimer's disease and other dementias; and
- Collecting and evaluating information on efforts to prevent and treat Alzheimer's disease and other dementias.

Statute also requires DSHS to consult with physicians, other health care providers, and interested parties when developing the state plan. DSHS is to 1) meet with interested parties to collect comment on the state plan at least two times per year, and 2) review and modify every five years. The state plan is to be published and submitted to the Legislature in the form of a report.

This report, known as the Texas State Plan for Alzheimer's Disease 2019-2023 (state plan), describes a public health approach to address Alzheimer's disease and other dementias with recommended goals and strategies 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.

## 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>2</sup>

Though Alzheimer's disease is the most common cause of dementia, there are many other types, including Creutzfeldt-Jakob disease, Lewy body dementia, frontotemporal dementia, Huntington's disease, mixed dementia, normal pressure hydrocephalus, Parkinson's disease, vascular dementia, and Korsakoff syndrome.<sup>3</sup>

For more information on the signs and symptoms of Alzheimer's disease, go to [alz.org/alzheimers-dementia/10\\_signs](http://alz.org/alzheimers-dementia/10_signs).

Alzheimer's disease is a major public health issue in Texas. According to the Alzheimer's Association, more than 5 million Americans of all ages are living with Alzheimer's disease in 2019 - approximately 390,000 of which are Texans.<sup>4</sup> Without a cure or a way to prevent it, the number of Americans age 65 and older with Alzheimer's disease may triple to a projected 14 million people by 2050.<sup>4</sup> In 2018, approximately 1.4 million unpaid caregivers provided care to Texans with Alzheimer's disease, which equates to 1.6 billion hours of unpaid care at a cost of approximately \$20.6 billion per year.<sup>4</sup> Nationally, the economic burden of Alzheimer's disease is estimated at over \$290 billion.<sup>4</sup>

In addition to the impact on individual health and its prevalence, Alzheimer's disease presents other challenges:

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<sup>2</sup> Alzheimer's disease fact sheet. National Institute on Aging website. <https://www.nia.nih.gov/health/alzheimers-disease-fact-sheet>. Accessed August 19, 2019.

<sup>3</sup> Types of dementia. Alzheimer's Association website. <https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia>. Accessed August 19, 2019.

<sup>4</sup> Alzheimer's Association. Alzheimer's disease facts and figures. <https://www.alz.org/media/Documents/alzheimers-facts-and-figures-2019-r.pdf>. 2019. Accessed August 19, 2019.

- There is currently no cure or treatment to prevent or slow the progression of the disease;
- There is stigma and fear of the disease;
- Personal and long-term care for those with Alzheimer's disease is costly;
- The health and well-being of the family of those with Alzheimer's disease is impacted;
- There is insufficient data on the economic and societal impact; and
- There is insufficient funding to address the needs of those with the disease and their family.

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*<sup>1</sup> (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 Partnership includes individuals with diverse backgrounds from state, local, and community organizations, academic and research institutions, for-profit and non-profit sectors, businesses, the health care sector, and family members of individuals affected by Alzheimer's disease and other dementias. The Texas Department of State Health Services (DSHS) gathered stakeholder input for the state plan through two in-person meetings of the Partnership, a state plan survey, and a webinar.

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. The intended audiences for the state plan are professionals and stakeholders connected to health care and related services such as health care providers, health systems, public health professionals, state agencies, community-based organizations, and academic and research institutions. Although the focus of the state plan is on professionals, learning about the priority areas will be empowering for people with Alzheimer's disease and other dementias, family caregivers, and members of the community to know how to take part in care planning and to provide quality care.

In 2010, DSHS and the Texas Council on Alzheimer's Disease and Related Disorders developed the first state plan with input from the Partnership. The 2019-2023 state plan sets the groundwork for moving forward on priority issues and opportunities for coordinated action.

## 3. The State Plan

### A Public Health Approach

Communities across the nation are moving toward a public health approach to address Alzheimer's disease and other dementias. To provide information about this approach, the Alzheimer's Association and the Centers for Disease Control and Prevention (CDC) developed the *Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map*<sup>1</sup> (Road Map). The Road Map provides a comprehensive description of a public health approach that includes definitions, diagrams, and actions for a national audience.

The Texas Department of State Health Services (DSHS) joins this effort by using a public health approach based on the Road Map to address Alzheimer's disease and other dementias in the Texas State Plan for Alzheimer's Disease 2019-2023 (state plan). The state plan is for all types of dementia and addresses similar challenges in finding appropriate and necessary medical and supportive care.

Stakeholders can use the state plan and Road Map together to have a comprehensive public health approach to inform activities; determine how to fulfill the priority needs through their organizations and available resources; and share ideas with others, encourage collaboration and partnership, and provide education to decision makers.

Public health involves organized efforts to prevent, detect, and respond to health risks at a community level. For Alzheimer's disease and other dementias, this means addressing challenges among aging individuals and the wider population. Alzheimer's disease and other dementias are a public health issue because of the large financial impact on society, the burden on families and facilities to provide care, and because there are ways to intervene over the lifespan regarding risk reduction and promoting brain health.<sup>5</sup>

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<sup>5</sup> Public health. Alzheimer's Association website. <https://www.alz.org/professionals/public-health>. Accessed August 19, 2019.

A community-based public health approach has several intended outcomes: reduce risk; improve early detection and diagnosis; reduce stigma; ensure safety and quality care; improve health outcomes and promote health and well-being; ensure the health and well-being of family caregivers; respond to the needs of diverse populations; and prevent avoidable hospitalizations.

To address the needs of Alzheimer's disease and other dementias, the state plan uses a comprehensive public health approach with recommended actions in eight priority areas: 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; and 8) advance research and collaboration.

Addressing the burden of Alzheimer's disease and other dementias in Texas requires the collective action of the entire public health system: state agencies, health care providers and systems, public health professionals, hospitals, care facilities, service and support organizations, research universities, and the general public, to name a few. DSHS is one partner in this collective effort. It is the responsibility of all Texas stakeholders to implement this state plan.

## **Priority Areas and Actions**

The state plan offers recommended priority areas, goals, sectors, and actions developed from stakeholder input. Priority areas emphasize important topics and emerging trends for Alzheimer's disease and other dementias. Sectors include stakeholders commonly associated with the priority areas. Actions are suggested activities and interventions.

The goals are general in nature and reflect the intent of the priority areas. Existing data sources to track statewide progress toward achieving the goals outlined in the 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 of the priority areas. DSHS will begin developing a survey during the first year of the state plan to provide baseline measurements and targets to measure progress in achieving state plan goals.



## Priority Area 1: Education and Awareness

Professionals in the health care community can educate and empower Texans with information needed to reduce the risk of Alzheimer’s disease and other dementias, identify signs and symptoms to increase early detection, reduce stigma around dementia, learn about maintaining brain health, and connect with community resources.

### Goal

Increase the percentage of people with Alzheimer’s disease and other dementias and their family caregivers receiving culturally and linguistically appropriate information and referrals to community resources from health care providers.

### Sectors

Health care providers, state agencies, community-based organizations, public health professionals

### Actions

- 1.1 Provide culturally and linguistically appropriate education on a range of topics to people with Alzheimer’s disease and other dementias and their family caregivers to enhance their health, well-being, and independence. Priority education topics include the following:
  - ▶ Changes in memory, thinking, or behavior that should be discussed with a health professional;
  - ▶ Disease management and coexisting conditions;
  - ▶ The importance of care planning for people with all stages of Alzheimer’s disease and other dementias that includes family caregivers;
  - ▶ Family caregiver health and well-being;
  - ▶ Local caregiver resources and support;
  - ▶ Clinical trials; and
  - ▶ Prevention of abuse, neglect, and exploitation.
- 1.2 Promote culturally and linguistically appropriate awareness and education campaigns (through television, radio, print, and social media) with common messages to help the general public better understand Alzheimer’s disease and other dementias, provide suggestions on steps to reduce the risk of cognitive decline, and reduce disease stigma. Topics for awareness and education campaigns include, but are not limited to, the following:

## Priority Area 1: Education and Awareness

- ▶ Differences between memory changes related to aging and warning signs of Alzheimer's disease and other dementias;
  - ▶ Evidence-based brain health and cognitive aging;
  - ▶ Risk factors, benefits of early detection, and effective strategies for getting a diagnosis;
  - ▶ Populations that are at greater risk;
  - ▶ The role of family caregivers in providing care, participating in care planning with health care providers, and finding support services;
  - ▶ The health and well-being of family caregivers; and
  - ▶ Real stories of people living with Alzheimer's disease and other dementias.
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## Priority Area 2: Coordinated Systems of Care and Support

Health care providers and organizations must continue to find ways to work together and improve systems of care to ensure access to services, quality health care, support over the lifespan, and improved outcomes. A systems approach for care also includes family caregivers, insurance companies, employers, and first responders.

### Goal

Increase collaboration between entities and individuals involved in the care of people with Alzheimer's disease and other dementias to ensure better access to services, quality health care, and support over the lifespan.

### Sectors

Health care providers, hospitals, state agencies, public health professionals, community health workers, community-based organizations, insurance companies, health maintenance organizations, first responders, family caregivers

### Actions

- 2.1 Identify and address services gaps and priority needs in the care and support of people with Alzheimer's disease and other dementias, for instance:
  - ▶ Establish mechanisms that result in better coordination between service providers;
  - ▶ Establish mechanisms that increase access to services at the point of diagnosis and throughout the lifespan regarding diagnosis, treatment and disease management, connection to community supports and education, and family caregiver support;
  - ▶ Build capacity to improve access to community support services such as respite care, adult day care (social and medical models), and support groups through outreach and program expansion;
  - ▶ Identify ways to address the needs of people who are uninsured, underinsured, and people who do not qualify for financial assistance; and
  - ▶ Ensure that services are culturally and linguistically appropriate and available in urban and rural communities.
- 2.2 Identify and support existing or emerging best practice models of care coordination between physicians, hospitals, and other providers that have

## Priority Area 2: Coordinated Systems of Care and Support

long-term facility care professionals to reduce errors and duplication of services, improve outcomes, and minimize hospital readmissions for people with Alzheimer's disease and other dementias and/or behavioral health conditions.

- 2.3 Identify family caregivers in the medical record and include them in care planning to ensure the plan is being followed and to regularly assess their well-being and need for support services in the community.
  - 2.4 Expand the role of community health workers in providing education on care for Alzheimer's disease and other dementias to reach underserved communities.
  - 2.5 Work with social services providers and health care providers across the range of interdisciplinary care to improve the capacity and supply of community-based case management services to help families navigate care needs for Alzheimer's disease and other dementias.
  - 2.6 Work with insurance plan navigators to help people with Alzheimer's disease and other dementias and their family caregivers identify and access services.
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## Priority Area 3: Partnerships and Engagement

Taking action on the diverse issues of Alzheimer’s disease and other dementias requires professionals and organizations to find innovative ways to partner and collaborate. Communities must also work together to support people living with Alzheimer’s disease and other dementias and their families. Dementia friendly approaches within a community help people diagnosed with Alzheimer’s and other dementias remain in their communities for as long as possible and maintain a life of dignity and value. For more discussion on dementia friendly communities see [Appendix C](#).

### Goal

Increase collaborative, diverse partnerships to better support and improve access to resources for people diagnosed with Alzheimer’s disease and other dementias and their family caregivers.

### Sectors

State agencies, community-based organizations, public health professionals, health care providers, hospitals, health maintenance organizations, insurance companies, academic institutions, decision makers, community leaders, local businesses, first responders, charitable organizations, libraries, faith-based groups

### Actions

- 3.1 Educate decision makers on the basics of cognitive health and impairment, the impact of Alzheimer’s disease and other dementias on family caregivers and communities, and the role of public health to make policy recommendations that improve the state’s infrastructure and better respond to the public health need.
- 3.2 Establish mechanisms that result in better coordination between state and local agencies, government departments, and community-based organizations to enable Texas to better service its aging population and people living with Alzheimer’s disease and other dementias.
- 3.3 Partner with state agencies, community-based organizations, and first responders to participate in the following activities:

## Priority Area 3: Partnerships and Engagement

- ▶ Create public health plans that guide emergency preparedness and emergency response that address the special needs of people with Alzheimer’s disease and other dementias and their family caregivers;
  - ▶ Support access to critical health information during crises; and
  - ▶ Prepare emergency professionals for situations involving people with Alzheimer’s disease and other dementias.
- 3.4 Partner with first responder agencies to ensure adequate training on how to respond to people with Alzheimer’s disease and other dementias, increase awareness of safety issues, and promote the [Texas Department of Public Safety’s Silver Alert Program](#)<sup>6</sup> for people at risk for wandering.
- 3.5 Partner with community sectors to promote the concepts of dementia friendly communities.
- 3.6 Engage community-based organizations and local businesses in distributing educational materials and resources that foster public awareness of Alzheimer’s disease and other dementias and available services in the community.
- 3.7 Engage and collaborate with community and cultural leaders to provide education and referrals to resources for diverse communities and rural populations.
- 3.8 Engage with people living with Alzheimer’s disease and other dementias and their family caregivers to share their stories with decision makers and to serve on committees or councils that make decisions for populations with these conditions.
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<sup>6</sup> Silver Alert. Texas Department of Public Safety website. <https://www.dps.texas.gov/dem/Operations/Alerts/SilverAlertOverview.htm>. Accessed August 19, 2019.

## Priority Area 4: Training

Health care professionals must have knowledge of Alzheimer's disease and other dementias, best practices for treatment and care over the lifespan, and the impact on family caregivers. To meet the demands of Alzheimer's disease and other dementias and ensure access to the best care possible, the health care and related services workforce must be committed and well-trained.

### Goal

Increase the percent of health care professionals and students receiving quality training regarding best practices for the treatment and care of people with Alzheimer's disease and other dementias over the lifespan, as well as training on the impact of the disease on family caregivers.

### Sectors

Academic programs, professional associations, accreditation and certification organizations, health care providers, state agencies, community-based organizations, public health professionals, care facilities, social workers, community health workers/promotores

### Actions

- 4.1 Educate health care providers and foster continuing education on the following topics:
- ▶ Using validated standards of diagnosis according to national guidelines;
  - ▶ The importance of early diagnosis and explaining the diagnosis to families;
  - ▶ Providing effective care planning at all stages of Alzheimer's disease and other dementias that includes counseling, referrals, and engaging family caregivers in care management;
  - ▶ The importance of treating coexisting conditions and addressing injury risks;
  - ▶ Attending to behavioral health needs among people at all stages of Alzheimer's disease and other dementias;
  - ▶ The appropriate use of non-pharmacologic and pharmacologic interventions to treat cognitive, behavioral, and psychological symptoms;
  - ▶ Populations that are at greater risk such as African Americans, Hispanics, and women;

## Priority Area 4: Training

- ▶ Assessment and diagnosis of Alzheimer’s disease and other dementias in people with intellectual disabilities and developmental disabilities;
  - ▶ The essential role of family caregivers, health risks for family caregivers, and the importance of maintaining their health and well-being;
  - ▶ Available caregiving information, support programs, and services that are culturally and linguistically appropriate; and
  - ▶ Sources of reliable information about brain health and ways to use the information to inform the people they serve.
- 4.2 Incorporate the best available science about brain health, cognitive impairment, and caregiving for Alzheimer’s disease and other dementias into training for the current and future public health workforces.
- 4.3 Use best practice standards for care of people with Alzheimer’s disease and other dementias and the training of physicians, nurses, and allied health professionals.
- 4.4 Educate public health professionals (social workers, community health workers/promotores) about the best available evidence on brain health, Alzheimer’s disease and other dementias, warning signs, getting a diagnosis, caregiving, the role of public health, and sources of information, tools, and assistance to support public health action.
- 4.5 Strengthen the competencies of professionals who deliver health care and other care services to people with Alzheimer’s disease and other dementias through inter-professional training and other strategies.
- 4.6 Improve behavioral health services for people who are covered through Medicare, Medicaid, and/or private insurance through the recruitment and specialized training of physicians, nurses, and therapists to provide such services.
- 4.7 Mandate competency-based training for employees in specific settings (e.g., hospitals, nursing homes, home care workers, and first responders).
- 4.8 Promote training opportunities for Alzheimer’s disease and other dementias offered by the Health and Human Services Commission (HHSC) for care facility staff.
- 4.9 Build capacity to increase medical and social adult day-care options with staff specifically trained to meet the needs of people with Alzheimer’s disease and other dementias.
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## Priority Area 4: Training

- 4.10 Support efforts within state universities to encourage professionals to enter careers in geriatric health care education.
  - 4.11 Collect accurate and relevant data on the current need for professionals in the workforce regarding Alzheimer's disease and other dementias, and develop future workforce projection models to support these professionals.
  - 4.12 Develop models to address workforce shortages, including recruitment and retention strategies through education and training programs.
  - 4.13 Create incentives (e.g., tuition assistance, housing subsidies, and stipends) to increase the number of health care professionals who pursue education and training to specialize in gerontology and geriatrics, particularly people who make a commitment to work in underserved communities.
  - 4.14 Support certification, licensure, and degree programs that encourage working with older adults and people with Alzheimer's disease and other dementias and their family caregivers.
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## Priority Area 5: Quality Care and Support

Providing quality health care requires commitment by health care professionals and related services providers to understand the best practices for diagnosis, treatment, and care over the lifespan, as well as the role of family caregivers in care planning and maintaining quality of life. Early diagnosis gives the opportunity to participate in clinical trials and is critical to helping families plan for the future.

### Goal

Increase the use of best practices and care standards for the diagnosis, treatment, and care of people with Alzheimer's disease and other dementias over the lifespan, as well as to provide for the needs of family caregivers.

### Sectors

Health care providers, care facilities, hospitals, insurance companies, in-home care services, universities, state agencies, community-based organizations, public health professionals

### Actions

- 5.1 Use validated standards of diagnosis based on national guidelines.
- 5.2 Include screening for cognitive function and mood using validated assessment tools as a regular part of [Medicare Annual Wellness Visits](#),<sup>7</sup> and ensure that screening tools are culturally and linguistically appropriate.
- 5.3 Develop and sustain care coordination, care planning, education, and support for people with mild cognitive impairment, younger-onset and late-onset Alzheimer's disease, and other dementias in ways that are culturally and linguistically appropriate.
- 5.4 Improve access to neuropsychologists and standard laboratory and diagnostic imaging, and use technology such as telemedicine to expand patient access in remote rural areas to highly trained neurologists, neuropsychologists, and other specialists.

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<sup>7</sup> Yearly wellness visits. Medicare.gov website. <https://www.medicare.gov/coverage/yearly-wellness-visits>. Accessed August 19, 2019.

## Priority Area 5: Quality Care and Support

- 5.5 Dedicate health care staff support to coordinate care, develop care plans, and develop formal mechanisms for referral to care facilities and community-based agencies that offer specialized expertise, social supports, and mental health services such as driving guidelines, home modifications, insurance options, legal resources, and respite care.
- 5.6 Discuss personal safety, and refer to programs such as [MedicAlert® + Alzheimer's Association Safe Return®](#)<sup>8</sup> and the Texas Department of Public Safety's Silver Alert Program.<sup>6</sup> Ensure that family caregivers are provided the required diagnosis documentation.
- 5.7 Provide health care consistent with the person's needs, values, and preferences across the lifespan including palliative, hospice, and end-of-life care.
- 5.8 Address the emotional, psychological, and spiritual needs of newly-diagnosed patients and family caregivers.
- 5.9 Make referrals to clinical trials, explain their purpose and value, and what participation in a clinical trial includes.
- 5.10 Include coexisting conditions into the care plan and manage cognitive, behavioral, and psychological symptoms with best practices guidelines to maintain quality of life, maximize function in daily activities, foster a safe environment, and promote social engagement.
- 5.11 As appropriate, incorporate non-pharmacologic and pharmacologic interventions to treat cognitive, behavioral, and psychological symptoms, and promote behavior modification techniques in care facilities for staff and family caregivers to reduce the use of pharmacological interventions.
- 5.12 Avoid the use of antipsychotic medications unless clinically necessary and the inappropriate diagnosis of schizophrenia, or other mental disorders, to justify the use of an antipsychotic medication.

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<sup>8</sup> MedicAlert and Safe Return. Alzheimer's Association website. <http://www.alz.org/care/dementia-medic-alert-safe-return.asp>. Accessed August 19, 2019.

## Priority Area 5: Quality Care and Support

- 5.13 Adopt and encourage the use of the [Alzheimer's Association's Dementia Care Practice Recommendations](#),<sup>9</sup> and increase awareness of the recommendations among families, paid caregivers, and providers.
  - 5.14 Promote the use of Medicare coding to reimburse physicians and allied health professionals for family conferences and care planning meetings that educate and support family caregivers.
  - 5.15 Establish protocols for community-based systems of care to meet the needs of people with Alzheimer's disease and other dementias who exhibit behaviors requiring interventions.
  - 5.16 Evaluate and modify guidelines of inpatient behavioral health services to ensure that the models address the specific treatment of people with Alzheimer's disease and other dementias.
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<sup>9</sup> Dementia care practice recommendations. Alzheimer's Association website. [https://www.alz.org/professionals/professional-providers/dementia\\_care\\_practice\\_recommendations](https://www.alz.org/professionals/professional-providers/dementia_care_practice_recommendations). Accessed August 19, 2019.

## Priority Area 6: Family inclusion

Family caregivers are a vital part of helping people with Alzheimer’s disease and other dementias live life well for as long as possible and get the ongoing care they need over time. Most people diagnosed with Alzheimer’s disease can live in their homes in the early to middle stages of the disease. Families typically provide most of the care in the home. Health care providers must help caregivers understand their role in providing care, know what support and resources are available to them, and stress the importance of maintaining their own health and well-being.

### Goal

Increase the inclusion of family caregivers for people with Alzheimer’s disease and other dementias in the development of care plans, and ensure they receive resources, information, and support regarding diagnosis, treatment, long-term care, and caregiver wellness.

### Sectors

Health care providers, state agencies, universities, community-based organizations, public health professionals, employers, workplace sites.

### Actions

- 6.1 Include the family in all aspects of care planning, and encourage them to connect with other people living with Alzheimer’s disease and other dementias and their families to ask questions, share experiences, and assist with navigating services.
- 6.2 Provide educational resources at the time of diagnosis about the diagnosis, treatment, stages of Alzheimer’s disease and other dementias, financial and legal information, clinical trials, community support resources, and respite services. Resources should be culturally and linguistically appropriate, written in plain language, and meet health literacy guidelines.
- 6.3 Enhance state agency websites to support family caregivers and help them find state resources including [Area Agencies on Aging](https://apps.hhs.texas.gov/contact/aaa.cfm)<sup>10</sup> caregiver programs,

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<sup>10</sup> Area Agencies on Aging directory. Texas Health and Human Services website. <https://apps.hhs.texas.gov/contact/aaa.cfm>. Accessed August 19, 2019.

## Priority Area 6: Family inclusion

the [Aging and Disability Resource Center](#),<sup>11</sup> and community-based organizations.

- 6.4 Recognize caregiving as a health risk factor that deserves public health attention, and include caregiving in public health campaigns and programs.
- 6.5 Recognize and address the range of needs of family caregivers and the best ways to support them over time including financial support, respite, access to health care, and support for psychological and emotional needs.
- 6.6 Encourage hospitals to design and make available care models that include family caregiving in discharge planning and specific discharge instructions to the family.
- 6.7 Encourage employers to adopt recommendations for family caregivers from national reports such as the National Academy of Medicine's [Families Caring for an Aging America](#).<sup>12</sup>

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<sup>11</sup> Aging and Disability Resource Center. Texas Health and Human Services website. <https://hhs.texas.gov/services/aging/long-term-care/aging-disability-resource-center>. Accessed August 19, 2019.

<sup>12</sup> National Academies of Sciences, Engineering, and Medicine. Families caring for an aging America. Washington, DC: The National Academies Press. 2016. [https://www.johnhartford.org/images/uploads/reports/Family\\_Caregiving\\_Report\\_National\\_Academy\\_of\\_Medicine\\_IOM.pdf](https://www.johnhartford.org/images/uploads/reports/Family_Caregiving_Report_National_Academy_of_Medicine_IOM.pdf). Accessed August 19, 2019.

## Priority Area 7: Importance of Data Collection and Evaluation

Surveillance and evaluation are the foundation of an effective public health approach for addressing Alzheimer’s disease and other dementias. Data collected through surveillance and evaluation helps public health programs focus on populations most in need, ensuring that interventions are based on the best available evidence and inform program improvements. There are significant barriers to the collection of population-based data related to Alzheimer’s disease and other disorders at both the national and state levels. Some of these barriers include underreporting on death certificates, misclassification in diagnosis, and methodological differences when reporting statistics. Systematic data collection from the various sectors involved with services and support for Alzheimer’s disease and other dementias is also limited.

### Goal

Increase surveillance of Alzheimer’s disease, other dementias, and related issues, as well as the evaluation and sharing of effective programs.

### Sectors

State agencies, community-based organizations, public health professionals, health care providers, academic programs, universities

### Actions

- 7.1 Support the collection and use of data from the Behavioral Risk Factor Surveillance System (BRFSS) optional module for Cognitive Decline and the BRFSS optional module for Caregiving.
- 7.2 Collaborate with relevant agencies and organizations in a coordinated and systematic way to identify ongoing data needs, surveillance gaps, population trends, service needs for diverse populations, the capacity of the health care system, common data elements, uniform collection methods, and reporting formats for the range of priority areas for Alzheimer’s disease and other dementias.
- 7.3 Determine methods for surveillance of incidence, prevalence, and the impact of Alzheimer’s disease and other dementias on people living with dementia and their family caregivers.

## **Priority Area 7: Importance of Data Collection and Evaluation**

- 7.4 Use the cognitive assessment that is part of Medicare Annual Wellness Visits<sup>7</sup> as a means of developing better statewide prevalence data on cognitive impairment.
  - 7.5 Ensure accuracy in reporting a diagnosis of Alzheimer's disease or another dementia and cause of death.
  - 7.6 Include evaluation and sustainability into training and caregiving support programs to determine program accessibility, effectiveness, and impact.
  - 7.7 Share knowledge of effective programs at regional and national conferences and key stakeholder meetings for replication.
  - 7.8 Collect data on Alzheimer's disease and other dementias to track progress on the goals of the state plan.
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## Priority Area 8: Advance Research and Collaboration

Ongoing Alzheimer's disease research and collaboration are vital to finding a cure and discovering ways to reduce risk and prevent dementia. Research also helps the health care community understand the impact on family caregivers, improve disease management and treatment, and how to best use education and community support services.

### Goal

Support ongoing research efforts, increase opportunities for collaboration among researchers, and share the results of Alzheimer's disease research with the public.

### Sectors

Research institutions, health care providers, decision makers, health organizations, academic programs, community-based organizations

### Actions

- 8.1 Sustain and support ongoing coordinated Alzheimer's disease research in Texas.
- 8.2 Support clinical and non-clinical research on Alzheimer's disease that focuses on early detection, the difference between Alzheimer's disease and other disorders, treatment, and lifelong care.
- 8.3 Encourage research on the costs of health care and long-term care for Alzheimer's disease and other dementias.
- 8.4 Encourage research on the impact of Alzheimer's disease and other dementias on family caregivers.
- 8.5 Increase the number of opportunities to convene local researchers and promote collaboration among scientists by promoting existing research symposiums and hosting additional symposiums and conferences.
- 8.6 Collaborate with private, state, and federal partners to increase participation of diverse populations in research studies.
- 8.7 Educate the public on the availability, purpose, and value of research, as well as encourage participation in clinical trials and other studies.

## **Priority Area 8: Advance Research and Collaboration**

- 8.8 Translate research findings into useful information for the general public, services, and community practice.
  - 8.9 Conduct research to identify, evaluate, and disseminate effective methods of providing educational materials to people with Alzheimer's disease and other dementias, their families, and the public.
  - 8.10 Promote research related to strategies to improve patient quality of life (e.g., non-traditional therapies, psychosocial interventions, non-pharmacological treatments).
  - 8.11 Support increased federal and state funding to support research studies and programs.
  - 8.12 Support efforts to attract junior scientists and young professionals to the area of research in Alzheimer's disease and other dementias.
  - 8.13 Ensure that active research studies are accessible to eligible people living with Alzheimer's disease and other dementias and their family caregivers.
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## 4. 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 challenges of daily life with Alzheimer’s disease and other dementias, the growing economic burden, and the burden on family caregivers require the collective action of many partners. The state plan serves as a resource for Texas stakeholders to use for determining the role and direction of their organizations as part of a coordinated effort to ensure the health and well-being of all Texans.

## **List of Acronyms**

<b>Acronym</b>	<b>Full Name</b>
BRFSS	Behavioral Risk Factors Surveillance System
CDC	Centers for Disease Control and Prevention
DSHS	Texas Department of State Health Services
HHSC	Texas Health and Human Services Commission

## **Appendix A. Definitions**

The definitions are from the *Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map*.<sup>1</sup>

**Alzheimer’s Disease:** an irreversible, progressive brain disorder that slowly destroys memory and thinking skills and, eventually, the ability to carry out the simplest tasks. Symptoms usually develop slowly and get worse over time, becoming severe enough to interfere with daily tasks.

**Alzheimer’s Dementia:** the dementia stage in the Alzheimer’s continuum.

**Brain Health:** a concept that involves making the most of the brain’s capacity and helping to reduce some risks that occur with aging. Brain health refers to the ability to draw on the strengths of the brain to remember, learn, play, concentrate, and maintain a clear, active mind.

**Caregiver:** spouses, partners, adult children, other relatives, and friends providing unpaid help to people living with dementia who have at least one limitation in their activities of daily living and reside in the community. Caregivers often assist with diverse activities of daily living such as personal care, household management, medication and healthcare management, and coordination of financial matters.

**Cognition:** the mental functions involved in attention, thinking, understanding, learning, remembering, solving problems, and making decisions. Cognition is a fundamental aspect of an individual’s ability to engage in activities, accomplish goals, and successfully negotiate the world. It can be viewed along a continuum—from optimal functioning to mild cognitive impairment to Alzheimer’s and severe dementia.

**Cognitive Impairment:** trouble remembering, learning new things, concentrating, or making decisions that affect everyday life.

**Dementia:** the loss of cognitive functioning—thinking, remembering, and reasoning—and behavioral abilities to such an extent that it interferes with a person’s daily life and activities. These functions include memory, language skills, visual perception, problem solving, self-management, and the ability to focus and pay attention. Alzheimer’s is the most common cause of dementia. Other types include vascular dementia, dementia with Lewy bodies, and frontotemporal dementia.

**Mild Cognitive Impairment:** a slight but measurable decline in cognitive abilities that includes memory and thinking. A person with mild cognitive impairment is at an increased risk of developing Alzheimer's or another dementia.

## **Appendix B. Diversity and Underserved Populations**

Person-centered care involves understanding an individual's ethnic and cultural backgrounds. Learn about the different experiences of people with Alzheimer's and other dementias.

Some examples:

- Older African Americans and Hispanics are more likely to develop Alzheimer's disease and other types of dementia than older whites.<sup>4</sup>
- Women have higher rates of Alzheimer's disease and other dementias.<sup>4</sup>
- People with younger-onset Alzheimer's disease have unique needs as they may be parenting children or be the primary provider of the household income.
- Lesbian, gay, bisexual, transgender populations often struggle to find resources that are culturally appropriate and accepting.
- People with intellectual disabilities and developmental disabilities, such as Down syndrome, who develop Alzheimer's disease and other dementias may present symptoms such as personality and behavior changes more commonly than symptoms of memory loss and forgetfulness.<sup>13</sup>
- People living in rural areas may not have access to diagnostic facilities, regular doctor visits, or care facilities.
- Mental health concerns such as depression and anxiety must be carefully assessed as Alzheimer's disease and other types of dementia may cause some of the same symptoms.<sup>14</sup>
- Lack of insurance or being underinsured may prevent people from seeking diagnosis and care.
- Grandparents who are legal guardians of their grandchildren may begin to have memory concerns.

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<sup>13</sup> Down syndrome and Alzheimer's disease. Alzheimer's Association website. <http://www.alz.org/dementia/down-syndrome-alzheimers-symptoms.asp>. Accessed on August 19, 2019.

<sup>14</sup> Depression. Alzheimer's Association website. <https://www.alz.org/help-support/caregiving/stages-behaviors/depression>. Accessed August 19, 2019.

## **Learn about diversity and cultural awareness**

- Learn about the needs and concerns of diverse populations to avoid making assumptions. Help diverse populations describe what they need and the barriers they encounter.
- Learn about the cultural norms and expectations of diverse populations and their attitudes toward health and the medical community.
- Recognize that diverse populations may have different points of view regarding working with health care providers, sharing personal information with others, and asking for help from community organizations.
- Address the stigma. Diverse populations may have different ways of accepting Alzheimer's disease and other dementias and approaches to managing care.
- Recognize that access to services and compliance with care plans can be affected by such things as socioeconomic concerns, education and reading levels, language, family and work obligations, geographic location, and transportation.
- Diverse populations may be under-represented in research and clinical trials.
- Learn about the role of community health workers and promotores (community health workers in Spanish-speaking communities) and how they can promote education and the importance of getting a diagnosis.
- Learn the principles of writing about health topics in plain language and for lower-literacy audiences to make materials easy to read and understand.

## **Learn from diverse populations.**

- Conduct focus groups and use surveys.
- Collaborate with community and cultural leaders.
- Have diverse groups provide feedback on education materials and messaging.



## **Appendix C. Dementia Friendly Communities**

Dementia friendly initiatives are developing in communities in the United States and around the world. The initiatives aim to improve the lives of people with Alzheimer's disease and other dementias and their family caregivers. This movement encourages the general public, non-traditional partners, and long-standing organizations and health care systems to work together and be more effective in their communities. In the United States, Dementia Friendly America® provides education, information, and tools about dementia friendly practices to a national audience. Learn about the dementia friendly movement at [dfamerica.org](http://dfamerica.org).

### **Dementia Friendly Approaches**

- Know that people living with Alzheimer's disease and other dementias in the early stages can live lives with meaning and purpose.
- Help people with dementia live in their homes and communities longer. They have much to offer their communities.
- Make the community more inviting and supportive of people with Alzheimer's disease and other dementias, and their family and friend caregivers.
- Adopt a person-centered approach that is based on respect, kindness, and dementia friendly communication skills.
- Acknowledge the dignity of people living with Alzheimer's disease and other dementias, and reduce stigma and social isolation.
- Create pathways for better diagnosis, treatment, transportation, housing, and community services.
- Recognize the important role of family caregivers, and support their health and well-being.
- Make resources easier to understand and access.
- Find ways for everyone in the community to play a part.
- Encourage businesses to adopt responsive and respectful services.
- Understand the role of research and transferring knowledge to the community.
- Encourage community discussion, understanding, and involvement.
- Recognize and accommodate the needs of diverse populations including culture, language, and economic background.