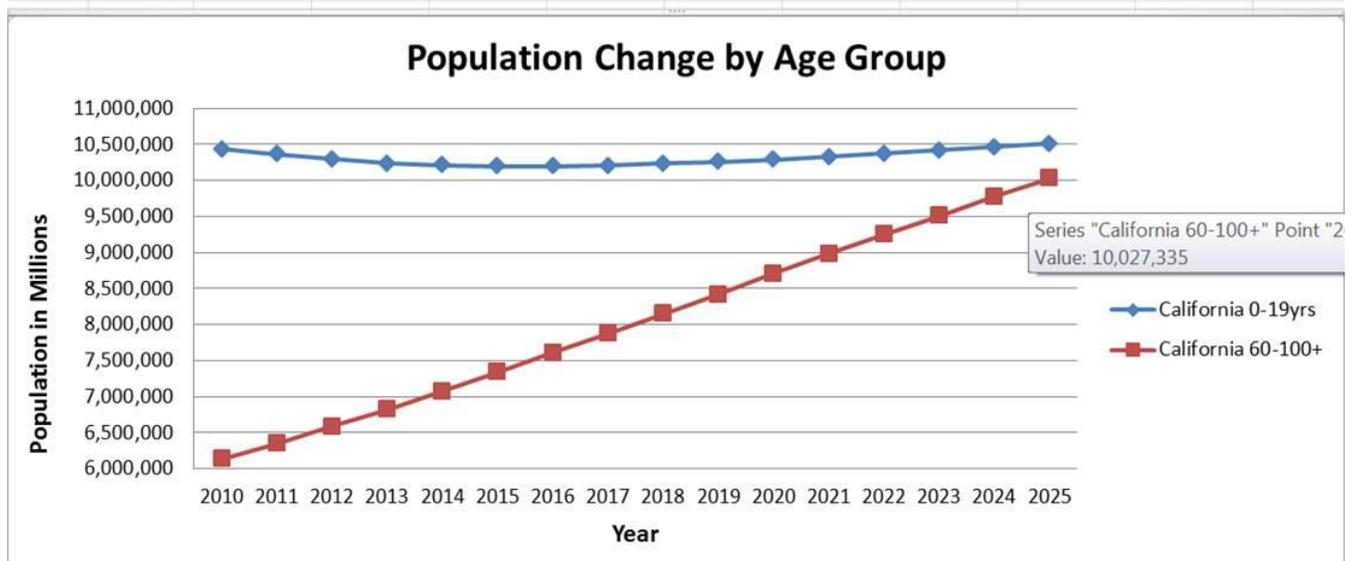


California's State Plan for Alzheimer's Disease: An Action Plan for 2011 – 2021
Transition Document for New Administration

I. A Vision for California

The incoming Administration will experience the first wave of an historic shift in California's population. By 2025, for the first time the older adult cohort will be approximately the same size as the youth population, representing a rapid overall increase of four million Californians aged 60-100 as compared to decades of flat growth among the 0-19 age group. This shift will ultimately disrupt all sectors of our economy, including health care, social services, education, housing and transportation.



California Department of Finance

Despite some progress on modifiable risk factors, age remains the single most reliable predictor of Alzheimer's disease with 1:10 at age 65 and 1:3 at age 85 being affected. The 85+ population is one of the fastest growing demographics in California. Understanding the complex needs of persons with dementia is a critical first step in designing a long-term care delivery system that supports all Californians. A framework exists for undertaking the ambitious planning needed to reform and enhance the existing system of care in California's State Plan for Alzheimer's Disease.

II. Background

In 2008, the Legislature began to address the Alzheimer's crisis when it enacted Senate Bill 491 (Alquist), calling for California to develop an Alzheimer's disease state plan. Under the leadership of the Alzheimer's Disease and Related Disorders Advisory Committee, a statewide task force was appointed. Working with the Alzheimer's Association and the California Health and Human Services Agency, the task force engaged more than 2,500 individuals in plan development, including people living with the disease, family caregivers, under-represented communities, educators, researchers and providers.

The task force made special efforts to address the unique needs of California's culturally diverse population, in particular those who are at greater risk of developing Alzheimer's disease, including African Americans, Latinos and women. Over an 18-month period, the task force developed a 10-year action plan to tackle the enormous challenges Alzheimer's disease presents to individuals, families, communities and the State of California. Three guiding principles influenced the group's work:

- Promote person-centered care responsive to individual needs
- Address the broad cultural, ethnic, racial, socio-economic and demographic diversity of California's population
- Integrate the social and medical needs of this and other aging populations living with multiple chronic and disabling conditions

When the state plan was released in 2011 at the start of Governor Brown's Administration, 588,000 Californians were living with Alzheimer's. At the time, the magnitude of the population affected inspired statewide action. Today, 650,000 Californians are directly impacted. What's more, Alzheimer's has climbed from the sixth leading cause of death in California to the fourth in just seven years. Increased disease prevalence and mortality coupled with explosive growth of the aging population creates a sense of urgency like no other time in California's history.

Under the leadership of the Brown Administration, the Secretary's Alzheimer's Disease and Related Disorders Advisory Committee has taken concrete steps forward. This transition document outlines the key achievements to date and highlights emerging issues in need of greater attention and focus.

III. Key Achievements

The state plan focused on six goal areas, with progress made in all areas. The Brown Administration, together with the Legislature, has enacted a number of legislative, regulatory and budget changes to improve the lives of persons with dementia and their caregivers. In the wake of the 2008 recession, changes have been modest and incremental. Many of the improvements have been time limited or confined to select counties, with opportunities for comprehensive system change still untapped.

1. Eliminate Stigma

Since 2014, the Legislature has recognized June as Alzheimer's and Brain Awareness Month with Assembly Concurrent Resolutions presented on the floor. Beyond these ceremonial gestures, there have been no formal initiatives to raise public awareness or educate consumers.

2. Ensure Access to High Quality, Coordinated Care in the Setting of Choice

In conjunction with passage of the federal Affordable Care Act (ACA), California has expanded coverage options for all populations. For seniors and persons with disabilities, Medi-Cal managed care has been the primary method of coverage expansion with implementation of the Coordinated Care Initiative and its central elements: Managed Medi-Cal Long Term Supports and Services (LTSS) and Cal MediConnect. For many participating health plans, this is the first time they have enrolled seniors and persons with disabilities into

managed care. Strengthening these systems of care – and building direct linkages to community services and supports – is key to meeting the needs of beneficiaries with dementia and their family caregivers. Health plans are instrumental in upholding the Olmstead decision, ensuring that services are provided “in the most integrated setting appropriate to the needs of qualified individuals with disabilities.”

3. Establish a Comprehensive Approach to Support Family Caregivers

In 2015, the Legislature passed The Care Act requiring hospitals to notify and consult with a family caregiver before discharge. In the same year, the California Department of Public Health adopted the optional caregiver burden question on the national Behavioral Risk Factor Surveillance System (BRFSS) survey. Also in 2015, the Legislature approved the creation of a statewide task force on family caregiving. That group released its final recommendations in July 2018 at a public hearing at USC. Today, 1.6 million Californians provide unpaid care to a loved one with dementia.

4. Develop an Alzheimer’s Proficient, Culturally Competent Workforce

This is the area of most significant progress to date, due in large part to the complex and changing needs of this population spanning the full continuum of care from unlicensed to highly specialized personnel.

The California Department of Aging partnered with Alzheimer’s organizations to secure back-to-back federal grants to support a dementia care manager pilot project within Cal MediConnect. Participating health plans in select counties committed to train dementia care specialists within their systems, and to develop new policies, procedures and protocols to better support dual eligible Medicare/caid beneficiaries with dementia, as well as their caregivers.

The California Department of Public Health provided statewide leadership on physician training, adopting the 2017 Alzheimer’s Clinical Care Guideline for post-diagnostic treatment recommendations. In addition, Governor Brown and the Legislature provided one-time funding to CDPH to develop an “Assessing Cognitive Complaints Toolkit” for community physicians. This toolkit was developed in collaboration with the 10 California Alzheimer’s Disease Centers was released in June 2018 and is available to the public on the CDPH website.

In 2014, the Governor and the Legislature approved widespread changes to dementia training in all 7500 licensed Residential Care Facilities for the Elderly (RCFEs) in the state. Finally, the Legislature approved and Governor Brown signed into law SB 449 (Monning), requiring two hours of dementia training for all Certified Nurse Assistants (CNAs). Last year, the Commission on the Future of California’s Health Care Workforce was formed with far-reaching recommendations due by the end of 2018.

5. Advance Research

To date, the voluntary tax check-off fund has raised over \$25 million for Alzheimer’s research. The California Department of Public Health issued its largest competitive Request for Application (RFA) in its history in 2016, awarding \$1.6 million in research grants to

seven awardees. This year, Governor Brown proposed and the Legislature approved \$3.1 million in new General Fund support for Alzheimer’s disease research, ongoing. California’s 10 Alzheimer’s Disease Centers are at the forefront of discovery, investigating contemporary topics such as biomarkers and health disparities.

6. Create a Coordinated State Infrastructure that Enhances the Delivery of Care

Individuals with Alzheimer’s disease and their families rely on services across the continuum of care, interacting over the course of the disease with CDA, CDPH, DHCS, DSS and other departments outside of the Agency, including housing and transportation. Sweeping efforts to consolidate government functions, such as 2016’s Senate Bill 547 (Liu) have failed, necessitating further exploration of this goal area to achieve the intended result.

IV. The Path Forward

While incremental progress has been made on many of the Alzheimer’s State Plan priorities, there is an urgent need to view the population affected more comprehensively. The human toll and economic burden of Alzheimer’s disease requires the State to accelerate its planning efforts in order to meet the diverse needs of the growing number of Californians directly impacted by Alzheimer’s.

We stand at a critical juncture. Due to the population size, range of needs, cost of care and projected growth, it is no longer feasible to “carve out” persons with dementia. Nor is it practical to develop parallel programs given the sheer volume of patients, clients, beneficiaries, enrollees and consumers affected. Consistent with the philosophy of person-centered care, there is a unique opportunity to fully integrate individuals with Alzheimer’s into existing systems of care. Going forward, California is well positioned to adopt a population health model that cuts across departments, breaks down silos and puts the person with the disease at the center of policy and budget decisions.

Individuals with cognitive impairment are served in a wide variety of settings funded by multiple payors, including extraordinarily high out-of-pocket costs. Initially, the incoming Administration is encouraged to leverage the Agency’s leadership role to require each department to adopt actions that increase home and community-based options, enhance care coordination, ease care transitions and promote independence. However, internal leadership alone will not prepare California for what’s to come – there must be an investment in existing infrastructure and infusion of new resources to make the system work in all parts of the state, for all persons affected.

The advisory committee recommends the following:

California Health and Human Services Agency

1. Identify and empower Agency leadership to provide oversight and integration among all departments serving individuals and families impacted by Alzheimer’s. Ensure all departments serving people with dementia are invited to attend all meetings of the Alzheimer’s Disease and Related Disorders Advisory Committee, and encourage active participation/staff leadership representation.

2. Direct the Alzheimer’s Disease and Related Disorders Advisory Committee to develop an overarching mission statement and guiding principles to inform all departments serving individual with Alzheimer’s disease.

California Department of Aging (CDA)

1. Adopt a statewide public awareness campaign in conjunction with the 33 Area Agencies on Aging (AAAs) and partner organizations to reach consumers at risk of dementia with culturally appropriate, evidence-based health information in their local communities.
2. Support administration of the federal Administration on Community Living (ACL) grant award to expand the Cal Medi-Connect pilot to new audiences.
3. Reestablish Alzheimer’s Day Care Resource Center (ADCRC) oversight and support; ensuring community-based daytime respite and engaging, dementia appropriate centers providing for the nutrition, medical, social and daily needs of those with mid-to-late stage Alzheimer’s disease.

California Department of Public Health (CDPH)

1. In partnership with the California Conference of Local Health Officers (CCLHO), adopt the recommendations within the Centers for Disease Control’s 2018 Healthy Brain Initiative.
2. Adopt the Behavioral Risk Factor Surveillance System (BRFSS) optional question regarding subjective cognitive complaints on the 2020 statewide survey.
3. Establish the California Alzheimer’s Disease Program as the statewide expert on detection, diagnosis and disease management and deploy resources and expertise to other state departments.

Department of Health Care Services (DHCS)

1. Promote widespread adoption of the dementia capable system indicators developed through the state’s Cal Medi-Connect grant project to all Medi-Cal managed care health plans.
2. Expand the Medi-Cal Assisted Living Waiver (ALW) slots to additional counties with a demographic rate methodology as well as a rate differential to address the higher costs of dementia care.
3. Educate payors, providers and beneficiaries on the availability, eligibility and accessibility of behavioral health services for individuals with Alzheimer’s and related dementias.
4. Adopt the recommendations within the July 2018 California Task Force on Family Caregivers with respect to the statewide Caregiver Resource Center (CRC) network.

Department of Managed Health Care (DMHC)

1. Engage the department in its oversight role of Medicare Advantage Plans (MAPs) to promote statewide implementation of the federal Chronic Care Act.

Department of Social Services (DSS)

1. Ensure access to Residential Care Facilities for the Elderly (RCFE) for persons with dementia by revising regulations to acknowledge the widespread prevalence of Alzheimer’s and related dementia among residents in all facility types.

2. Coordinate with DHCS to synchronize efforts to expand the Medi-Cal Assisted Living Waiver renewal.
3. Review the In-Home Supportive Services (IHSS) eligibility criteria and approval process to safeguard persons with dementia with adequate protective supervision hours.

Office of Statewide Health Planning and Development (OSHPD)

1. Explore opportunities for pilot projects and demonstrations to implement the final recommendations of the California Future Health Workforce Commission, scheduled for release in November 2018. Specifically, examine avenues to create a universal health worker with dementia training embedded.

V. Summary

The original state plan, 2011 – 2021, provided an important framework for discussion. Now, with 2.2 million Californians living with Alzheimer’s or caring for a loved one with the disease, it is time to accelerate action. The advisory group strongly recommends targeting resources on several priority focus areas to make measured improvement in select areas. Moreover, with overlap between settings, cross-collaboration among departments is emphasized to promote program integration. Finally, these experts encourage greater focus on early detection and diagnosis to shift policies and funding from costly and chaotic crisis care to a risk reduction and health promotion model, as well as adding support for people with dementia and their families. Data indicates Medicaid savings in the billions, if not trillions, of dollars nationwide as a result of early and accurate diagnosis.

In addition, priority must be placed on support for people living with Alzheimer’s disease and related dementias and for their family caregivers. These caregivers are the backbone of our home and community-based supports system. We must prioritize their identification, assessment and support. Only by fully supporting family caregivers can the state avoid unnecessary and costly hospitalizations and nursing home placement. Each department within the Agency has an important role to play in shifting attitudes and opinions regarding persons with dementia and family caregivers, starting with a collective emphasis on early detection, diagnosis and caregiver support.

Helpful Resources:

[California State Plan for Alzheimer’s Disease](#)

[Legislative Analyst Office report on seniors and persons with disabilities](#)

[Caregiver Task Force final report](#)

[SB 547 \(Liu\) proposal](#)

[Senate Aging & Long-Term Care Shattered System report](#)

[California Alzheimer’s Data Report](#)

[Mental Health Services for Persons Living with Alzheimer's](#)
[2018 Alzheimer's Disease Facts & Figures](#)