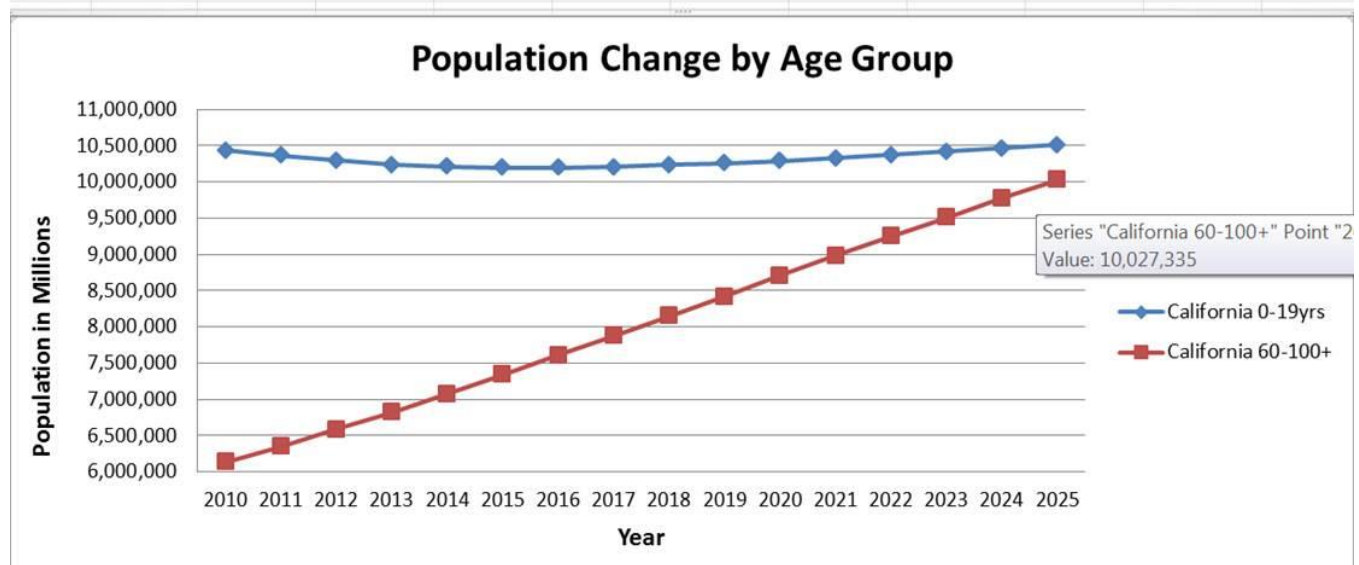


California's State Plan for Alzheimer's Disease: An Action Plan for 2011 – 2021

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 4 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. 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 third 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 is set to release their recommendations in July 2018 at a public hearing at USC. The 1.6 million Californians currently providing unpaid care to a loved one with dementia eagerly await the final report.

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 and is set for release on June 21, 2018.

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). This year, the Commission on the Future of California’s Health Care Workforce was formed with far-reaching recommendations due by year end.

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 \$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 such as SB 547 (Liu) have failed, necessitating further exploration of this goal area to achieve the intended result.

IV. The Path Forward

While progress has been made on many of the Alzheimer’s State Plan priorities, the human toll and economic burden of Alzheimer’s disease requires the State to accelerate its efforts in order to be ready to meet the needs of the growing number of Californians living with Alzheimer’s and their family caregivers.

Fortunately, the Brown Administration, the Legislature and stakeholders have positioned the state to make significant advances in four key areas:

A. Workforce

Recruiting, training and retaining a dementia capable workforce

The demand for high quality care and supportive services across all care settings – from community-based care through skilled nursing facilities - cannot be met without significant attention to the development of a well-trained workforce. This is especially true for those who will be caring for someone with dementia.

Next Steps:

- Analyze the California Future Health Care Workforce Commission Recommendations and adopt strategies specific to Healthy Aging and Care for Older Adults.
- What else??

B. Systems Change

Strengthening health care delivery systems

Improving rates in detection, diagnosis, disclosure, documentation and disease management is critical to individual quality of life, family and caregiver well-being, health outcomes and public costs. The dementia capable system indicators developed through the state’s Dementia Cal Medi-Connect grant project, have been used by participating health plans to change how they manage care for people with dementia who are dually eligible.

Several studies have demonstrated improved health outcomes and potential cost savings by implementing similar standards of care meriting the expansion of these best practices to the broader health care delivery system.

Next Steps:

- Direct the CA Department of Public Health, CA Department of Health Care Services and CA Department of Managed Health Care to jointly convene a workgroup to elevate best practices

within the Medi-Cal program and within the 10 CA Alzheimer's Disease Centers for broad dissemination to consumers, caregivers and providers.

- Ensure the 2017 Alzheimer's Clinical Care Guideline and 2018 Assessing Cognitive Complaint toolkit are disseminated and put into practice.
- Promote new evidence on brain health, including diet, nutrition and exercise, to emphasize lifestyle interventions. Examples such as [Let's Get Healthy California](#) and the [California Wellness Plan](#) demonstrate the value and utility of positive images and messaging throughout the public health network.
- Conduct targeted outreach to communities of color who are at higher risk including Blacks/African Americans and Hispanics/Latinos. In addition, women are at greatest risk of developing Alzheimer's, serving as a family caregiver, and working in direct care.

Behavioral Health

The advisory committee has invested considerable time and resources to better understand and improve access for all persons with Alzheimer's in need of mental health services and/or crisis intervention. This link provides an overview: <http://www.chhs.ca.gov/Alzheimer/Agenda%20Item%203-%20Mental%20Health%20Access%20for%20Persons%20with%20Dementia%20FINAL.pdf>

Next Step:

- Working in collaboration with the CA Department of Health Care Services, develop and disseminate a tool to educate patients, families and providers on available services.

Revision of Residential Care Facilities for the Elderly (RCFE) dementia regulations.

Pressure to update the RCFE model from a system that relied on waivers and exceptions to a system that expects and fully integrates residents with dementia has prompted a thorough review of the Community Care Licensing regulations. This is a current focus of the Department of Social Services with far reaching impact as the state licenses 7500 communities with a majority of residents living with a cognitive impairment.

Next Step:

- Demonstrate program integration by drawing on expertise of other state departments with specialized knowledge of dementia population, e.g. CDPH and DHCS.

C. Home and Community-Based Services

Expand options to meet consumer preferences while avoiding or delaying higher cost institutional placement.

All of us want to remain engaged and active with family, friends and our community throughout our lives. This desire is no different for people living with dementia. With access to quality home and community-based services people with dementia can safely remain in their homes and communities longer.

Next Steps:

- Explore model universal long-term care statutes in other large states, e.g. New York, Hawaii, Washington, promoting access for middle income families at risk of Medicaid eligibility or asset depletion.
- Provide input into the UCLA California Health Interview Survey (CHIS) data collection effort on Long-Term Services and Supports (LTSS) and utilize county-specific data to plan for and build local capacity.
- Highlight and implement the recommendations of the California Task Force on Family Caregiving.

D. Public Awareness

Educate the public on the benefits and value of early detection and accurate diagnosis

Alarmingly, less than half of all persons with Alzheimer’s have been formally diagnosed by a clinician and most patients have not been told of their diagnosis nor has it been documented in the medical record. Lack of critical health information impedes person centered care and prevents patients and families from accessing early and effective interventions.

Next step:

- Examine successful public health campaigns, e.g. smoking cessation; Five a Day; Talk, Sing, Read, etc. Make recommendations on target audience, key messaging and funding sources.

V. Summary

The original state plan, 2011 – 2021, provided an important impetus for action. Now, with 2.2 million Californians living with Alzheimer’s or caring for a loved one with the disease, it’s time to accelerate efforts. 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 a costly and chaotic crisis care model to a risk reduction and health promotion framework. Data indicates Medicaid savings in the billions, if not trillions, of dollars nationwide as a result of early and accurate diagnosis. Empowering consumers and caregivers with health information, community resources and care options will ultimately address each of the goal areas.