ALZHEIMER'S DISEASE AND RELATED DEMENTIAS FACTS AND FIGURES IN CALIFORNIA:

CURRENT STATUS AND FUTURE PROJECTIONS

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TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

State of California—Health and Human Services Agency
California Department of Public Health

TOMÁS J. ARAGÓN, M.D., Dr.P.H
Director and State Public Health Officer

GAVIN NEWSOM
Governor

MESSAGE FROM THE DEPARTMENT DIRECTOR AND STATE PUBLIC HEALTH OFFICER

The State of California is dedicated to building a “Healthy California for All” and improving the lives of California’s most vulnerable. In 2018, the California Legislature called upon the California Department of Public Health to update the 2009 *Alzheimer’s Disease and Related Dementias Facts and Figures in California: Current Status and Future Projections* report.[1] This report is a vital update providing an accounting of the dramatic impacts and effects of Alzheimer’s disease and related dementias (ADRDs), that includes essential data by race, ethnicity, gender, sexual orientation, and socioeconomic status.

California is among the most ethnically and culturally diverse states in the United States. ADRDs have rippling socioeconomic effects (e.g., caregiving, living arrangements, family structure, economic impact on family and communities). These effects are far reaching and hard to appreciate until the disease’s progressive impact on society is described. ADRDs grow in prevalence and severity as we age. Our population is graying rapidly and as a result, the number of people living with ADRDs in California is rising exponentially and disproportionately impacting women and communities of color.

The first step to addressing ADRDs is assessment – this report aims to provide the foundation for our collective understanding of the issue. Next, we will continue to integrate our State services and will be striving to implement in the coming years segments of the Master Plan for Aging’s five bold goals, driven by 23 Strategies and powered by 100+ action-ready initiatives, as well as areas of the ten final

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[1] Senate Bill 1292 (Hueso) - California Health and Safety Code Section 125283

recommendations provided by the Governor's Task Force on Alzheimer's Disease Prevention, Preparedness, and Path Forward. Finally, we have invested in a network of ten California Alzheimer's Disease Centers, ADRDs research with a focus on women and communities of color, and six California Healthy Brain Initiative State and Local Public Health Partnerships to begin a meaningful response in the coming years. Together we must work with counties, cities, and communities, as well as our public, private, faith, and educational partners to make California a healthy, vibrant, inclusive place to live, play, work, and learn. For more information please visit our Alzheimer's Disease Program website at: https://www.cdph.ca.gov/Programs/CCDPHP/DCDIC/CDCB/Pages/AlzheimersDiseaseProgram.aspx

Sincerely,

Tomás Aragón

Tomás J. Aragón, M.D., Dr.P.H.
Director and State Public Health Officer
California Department of Public Health

EXECUTIVE SUMMARY

The impact of dementia is being felt across all sectors of society. This report offers information to help California better meet the growing demand for support and services that meaningfully address the needs of individuals living with Alzheimer's disease and related dementias (ADRDs) and their caregivers.

Over the next 20 years, the impact of ADRDs on the State of California will increase dramatically. Longer life expectancies and the aging of the large baby boom cohort will lead to an increase in the number and percentage of Californians who will be 65 years of age and older. Since the primary risk factor for ADRDs is older age, substantial increase is anticipated in the numbers of people who will be living with the disease.

Dementia is an overall term for a group of symptoms that have several causes, but its characteristics are often pervasive, affecting a person's ability to perform everyday activities because of impairments with memory, language, problem-solving, and other cognitive skills. It is a degenerative brain disease, meaning that it worsens over time. Alzheimer's disease (AD) is the most common cause of dementia. Other common causes of dementia include cerebrovascular disease and Lewy body disease. More detailed information about ADRDs can be found in **Appendix A** at the end of this report.

This report details the broad and significant implications that the impending increased prevalence of ADRDs will have on California's businesses, public programs, and affected families. In different sections of this report AD and ADRDs (also referred to as dementia) might be discussed separately and is dependent on the availability of data. However, since more information is available about AD, a subtype of dementia that is the most common cause of dementia (accounting for 60-80% of all causes of dementia), there is an emphasis on the implications of AD in this report.

Prevalence of Alzheimer’s Disease in California

In 2019, approximately 660,000 Californians over 65 years of age lived with AD, which accounted for approximately 11% of the nation’s AD prevalence (5.8 million people). Between 2019 and 2040 a doubling in the number of Californians living with ADRDs is expected. This increase will affect all regions of the state across various demographic groups. Current estimates reveal that between 2019 and 2040:

- The population of California will expand by 16%, whereas the population of people living with AD will expand by 127%;
- The number of Californians over 75 years of age living with AD will more than double, growing to over 1.3 million;
- The number of Californians between 55 and 74 years of age living with AD will increase 26%, growing to 194,975 people;
- The number of people living with AD in California’s fifteen most populous counties (those with a population of 700,000 or more) will at least double;
- The number of Californians living with AD will increase 11% for women, growing to 917,482 people; and increase 8% for men, growing to 609,197 people;
- The number of people living with AD will more than triple for Californians who identify as Latino/Latina/Latinx (Latino/a/x) American, growing to 431,982 people; nearly triple for Californians who identify as Black/African American, growing to 91,071 people; and more than double for Californians who identify as Asian American/Pacific Islander, growing to 241,106 people;

- The number of people living with AD will more than double for Californians who identify as lesbian, gay, or bisexual, growing to 74,522 people.
- People with Down syndrome have an increased risk of developing AD. Estimates show that AD affects about 30% of people living with Down syndrome who are between 50 and 59 years of age and closer to 50% of people living with Down syndrome who are 60 years of age and older.

Lifetime Risk of Alzheimer's Disease in California

Among California's baby boomers who live to be 65 years of age and older, estimates suggest:

- One in six people will develop AD.
- One in five people will develop dementia.

Deaths from Alzheimer's Disease in California

- As of 2018, AD was the third leading cause of death in California.
- California's AD mortality rate was 27 deaths per 100,000 people, compared to the United States' (U.S.) AD mortality rate of 31 per 100,000 people, in 2018.
- AD showed the greatest increase as the cause of death compared to other leading causes of death in California, growing 28% between 2014 to 2017.
- The population of Californians who identified as Asian American/Pacific Islander had the greatest increase in deaths reported due to AD, growing by almost ten-fold between 2000 and 2018.
- The population of Californians who identified as Black/African American had the highest death rate among those in the age ranges of 65 to 74 years and 75 and 84 years, in 2018.

- The California counties with the highest number of deaths due to AD were Los Angeles (3,994 people), Orange (1,432 people), and San Diego (1,425 people).

Living Arrangements for People Living with Alzheimer's Disease in California

- The number of Californians living with AD who reside in community settings will more than double between 2019 and 2040 – growing to 908,730 who will live in the community with others; 382,623 who will live alone in the community; 95,656 who will live in residential care settings, such as an assisted living facility; and 207,254 who will live in nursing homes.
- California anticipates an increase in the number of women 65 years of age and older who will live alone, which reflects national trends.
- Californians 50 years of age and older who experience homelessness have higher rates of geriatric concerns than the general population, including difficulty performing activities of daily living, mobility and cognitive impairments, frailty, and depression. In a small sample of Californians 50 years of age and older who experienced homelessness, approximately 26% had cognitive impairments in 2017.
- The California Department of Veteran's Affairs (CalVet) provides veterans long-term residential care in the Veteran Home Care Program, with some offering specialized memory care programs. The number of veterans living with ADRDs was estimated to be 74,778 in 2017.
- The number of prisoners in California 55 years of age and older, living with ADRDs, was estimated to be 1,698 in 2018.

Caregiving for People with Alzheimer’s Disease in California

AD results in a progressive decline in a person’s ability to care for themselves. Ultimately, the person with AD will need the help of others with basic activities of daily living. Caring for a person with AD is often very difficult and poses physical, emotional, and economic challenges. This is particularly true because most care is delivered at home by families. While the majority of information concerning caregiving refers to caregivers of individuals living with AD, given the progressive nature of all dementias, caregivers of individuals with a dementia other than AD, may also experience similar challenges.

Traditionally, most caregivers have been the wives or adult daughters of the individual with AD. However, family structure changes and women participating in the workforce are major trends that have significant implications for the way families and society at large care for people living with AD.

Dementia caregivers assume a wide range of responsibilities and provide more extensive assistance to people living with dementia compared to caregivers of people with other health conditions. Caregivers of people living with AD are more likely to provide help with emotional and mental health problems, such as confusion or belligerence; behavioral issues such as wandering; intimate activities of daily living, such as bathing and toileting; instrumental activities of daily living, such as housekeeping and handling finances; and more likely to perform medical/nursing tasks, such as catheter care or tube feedings. Dementia caregivers experience high levels of burden, which can take significant mental, physical, and even financial tolls on them.

- More than 1.6 million Californians provide unpaid care for a person with AD, which amounts to 1,849 million hours of care and has an estimated value of over $24 billion in 2020.
- Most unpaid caregivers provide 20 or more hours of care per week to a friend or family member living with AD.
- California's caregivers of people 50 years of age and older are, on average, 60 years of age.
- California's caregivers are 60% female.
- Approximately 67% of California family caregivers use their own money to care for a loved one, spending it on transportation (81%), assistive technology (51%), home modifications (48%), home health aide (28%), respite care (21%), or adult day care (12%).
- Approximately 520,000 In-Home Supportive Services (IHSS) caregivers provided paid care to over 550,500 recipients in California who are low-income older adults and people with disabilities in 2019. Among these IHSS recipients, approximately 30,000 have ADRDs, based on conservative estimates.

Cost of Caregiving in California

- The 2008 total cost of caring for community-residents and institutionalized individuals 55 years of age and older, living with AD in California, is estimated to increase 126%, growing to over $153 billion by 2040.
- The 2008 total cost of caring for people living with AD who live in the community is estimated to increase 124%, growing to over $144.1 billion by 2040.
- The 2008 total cost of caring for people living with AD who live in institutions is estimated to increase 63%, growing to over $9.2 billion by 2040.

- The 2008 total unpaid and paid care costs for people with AD is estimated to more than double, growing to over $103 billion and $48 billion, respectively by 2040.
- The cost to Medi-Cal (California's Medicaid Program) programs for individuals with AD or related dementias is 2.5 times greater than the cost for individuals who do not have these diagnoses. Cost differences are largely due to skilled nursing facility expenditures, in 2019 dollars.
- Long-term care costs in California are expected to more than double between 2019 and 2040, which includes skilled nursing facilities, assisted living facilities, adult day health care facilities, and home care.
- The cost of long-term care in California tends to be higher than the national averages, with skilled nursing facility costs and home costs approximately 20% higher than national averages.
- The number of geriatricians needed in California to meet demand given the prevalence of AD for people 65 years of age and older will more than double, growing to a need of 2,278 geriatricians between 2019 and 2040.
- Specialty physicians, and providers such as those located at the ten California Alzheimer's Disease Centers, are most often relied on to provide dementia work-up and diagnosis. However, the number of these specialists is not sufficient to meet the overwhelming need.
- The total end of life health care costs for decedents diagnosed with dementia is significantly greater than other diseases, with much of those expenses not covered by health insurance, thus placing a large financial burden on families.

- The estimated cost to California employers in lost productivity annually from full-time and part-time employed caregivers is $48.3 billion. The majority of these costs, estimated in excess of $5.3 billion annually, are attributable to attempting to replace caregivers who leave the workforce.
- While the burden of care falls primarily on families, the rapid growth in the prevalence of AD will also impact California's healthcare costs, causing them to rise significantly. In particular, ADRDs are a major contributor to Medi-Cal costs.

SECTION I –ALZHEIMER’S DISEASE AND RELATED DEMENTIAS IN CALIFORNIA

INTRODUCTION[2]

Dementia is an overall term for a group of symptoms. The symptoms of dementia have several causes, but its characteristics are often pervasive, affecting a person’s ability to perform everyday activities because of impairments with memory, language, problem-solving, and other cognitive skills. AD is the most common cause of dementia, accounting for 60-80% of all causes of dementia (Alzheimer’s Association, 2019). It is a degenerative brain disease, meaning that it worsens over time. Other common causes of dementia include cerebrovascular disease and Lewy body disease, each accounting for 5-10% of all causes of dementia (Alzheimer’s Association, 2019). The majority of individuals with dementia with Lewy bodies also have AD pathology (Alzheimer’s Association, 2019). When an individual shows the brain changes of more than one cause of dementia, mixed pathologies are considered the cause. Studies suggest that mixed dementia is more common than previously recognized, with about 50% of people living with dementia who were studied at Alzheimer's Disease Centers having pathologic evidence of more than one cause of dementia (Brenowitz et al., 2017). Other types of dementia include frontotemporal degeneration and Parkinson’s disease. More detailed information about ADRDs can be found in **Appendix A** at the end of this report.

This report details the broad and significant implications that the impending increased prevalence of ADRDs will have on California’s businesses, public programs,

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[2] Portions of this report contain information reprinted and/or adapted with permission from Alzheimer’s and Dementia, 2019, Volume 15, Pages 321–387, Alzheimer’s Association, 2019 Alzheimer’s Disease Facts and Figures. https://www.sciencedirect.com/science/article/pii/S1552526019300317, last accessed 7/8/2019.

and affected families. At times AD and ADRDs (also referred to as dementia) might be discussed separately and is dependent on the availability of data. However, since more information is available about AD, a subtype of dementia that accounts for 60-80% of all causes of dementia, there is an emphasis on the implications of AD in this report. Given this bias of information, it should be noted that if all individuals living with dementia were considered, the estimated costs and burden discussed in this report are probably underestimates.

PREVALENCE[3]

Dementia can afflict anyone. Age, however, is the most significant risk factor for developing dementia, and more specifically AD. Because the number of older persons will grow dramatically as the baby boomer population, those born between 1946-1964, reach 65 years of age, the number of new cases of AD is projected to soar. Approximately one in ten people 65 years of age and older has AD, and that prevalence increases with age (Alzheimer's Association, 2019). The initial baby boomers reached 65 years of age in 2011 and will continue to expand through 2049, significantly impacting the prevalence of AD. While this is true for the nation, the state of California will experience some of the largest percentage growth of individuals with AD (Jennifer Weuve, Herbert, Scherr, and Evans, 2015). These increases will have a marked impact on health care systems, as well as the Medi-Cal program (California's Medicaid Program), which covers the cost of long-term care and support for low-income older people living with dementia.

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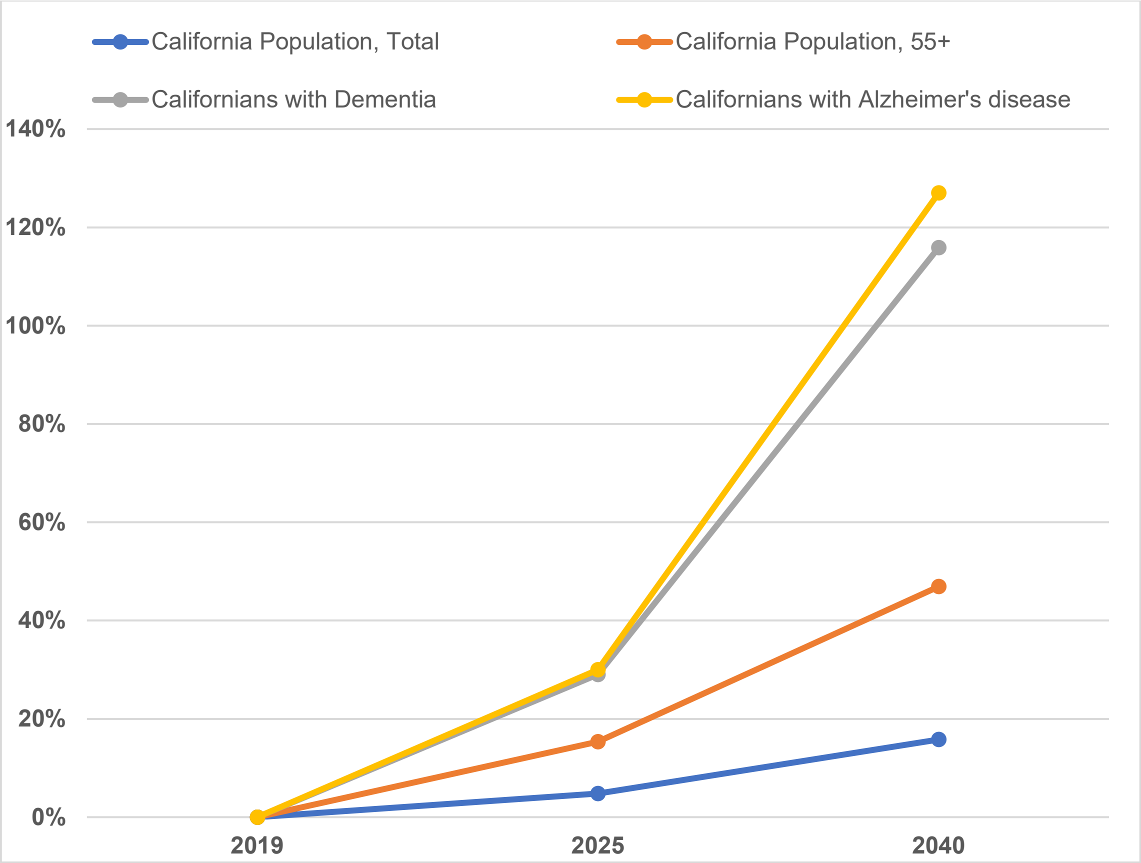
In California, approximately 660,000 people over 65 years of age lived with AD in 2019. By 2025, projections indicate there will be 866,000 people, a 31% rise, and by 2040 there will be a 127% increase in the number of individuals over 65 years of age living with AD (see **Appendix B**). The population of older adults with AD will increase at a pace that exceeds the total population growth, resulting in a greater demand on health care resources. The rapid growth of an aging population will affect all race, ethnicity, and culturally diverse groups and all regions of this diverse state.

Figure 1 highlights the growth in the number of people living with AD or dementia compared to overall growth of the population in California (i.e., total population and in those 55 years of age and older). Relative to the 2019 population, by 2040, the population of the state will expand by 16%, whereas people living with dementia will increase by 116% and people living with AD will increase by 127%. In other words, by 2040, the number or people living with dementia or AD in California will more than double, compared to an overall population growth of 16%.

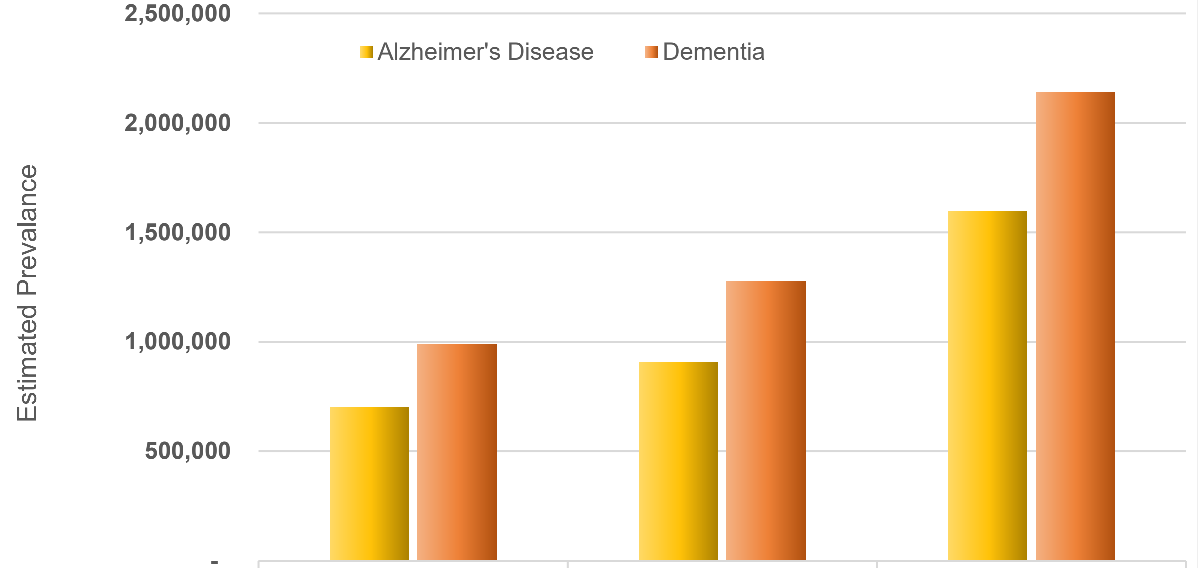
FIGURE 1: ESTIMATED PERCENT INCREASE IN THE POPULATION OF CALIFORNIA AND IN CALIFORNIANS AGE 55+ WITH DEMENTIA OR ALZHEIMER'S DISEASE: 2019, 2025, 2040.



Source: State of California, Department of Finance, *E-1 Population Estimates for Cities, Counties and the State with Annual Percent Change — January 1, 2019 and 2020.* Sacramento, California, May 2019. Accessed July 2, 2019. Please see Appendix B for methodology used to estimate California Alzheimer's disease prevalence.

As shown in ***Figure 2***, the expected increase in people with AD or dementia will grow exponentially between 2019, 2025, and 2040. The percentage of Californians 55 years of age and older with AD or dementia is projected to increase by 30% between 2019 to 2025. Between 2025 and 2040, the percent of individuals 55 years of age and older living with dementia is projected to increase by 67% and individuals with AD is projected to increase by 74%. In summary, between 2019 and 2040, the number of Californians 55 years of age and older who are projected to acquire AD or dementia will more than double. A similar projection from 2019-2040 is anticipated for individuals 65 years of age and older (see **Appendix C, Table C6**).

FIGURE 2: ESTIMATED NUMBER OF CALIFORNIANS 55+ WITH ALZHEIMER'S DISEASE OR DEMENTIA - 2019, 2025, 2040

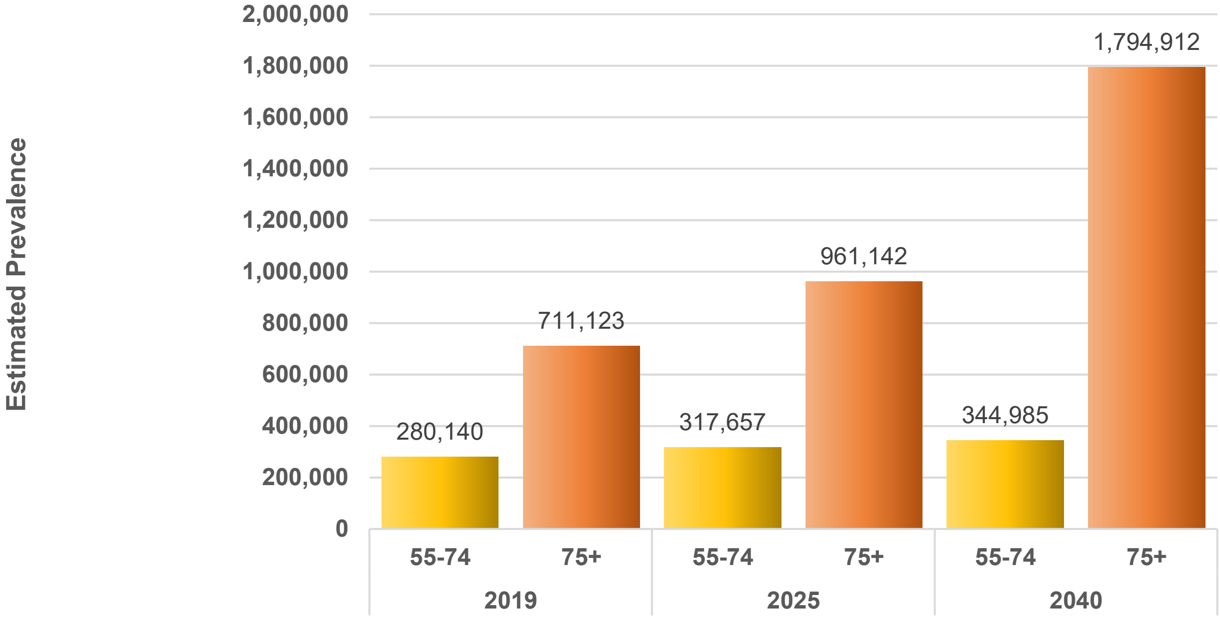


	2019	2025	2040
🟨 Alzheimer's Disease	702,556	907,080	1,594,264
🟧 Dementia	991,263	1,278,799	2,139,896

Source: State of California, Department of Finance, *E-1 Population Estimates for Cities, Counties and the State with Annual Percent Change — January 1, 2019 and 2020.* Sacramento, California, May 2019. Accessed July 2, 2019. Please see Appendix B for methodology used to estimate California Alzheimer's disease prevalence.

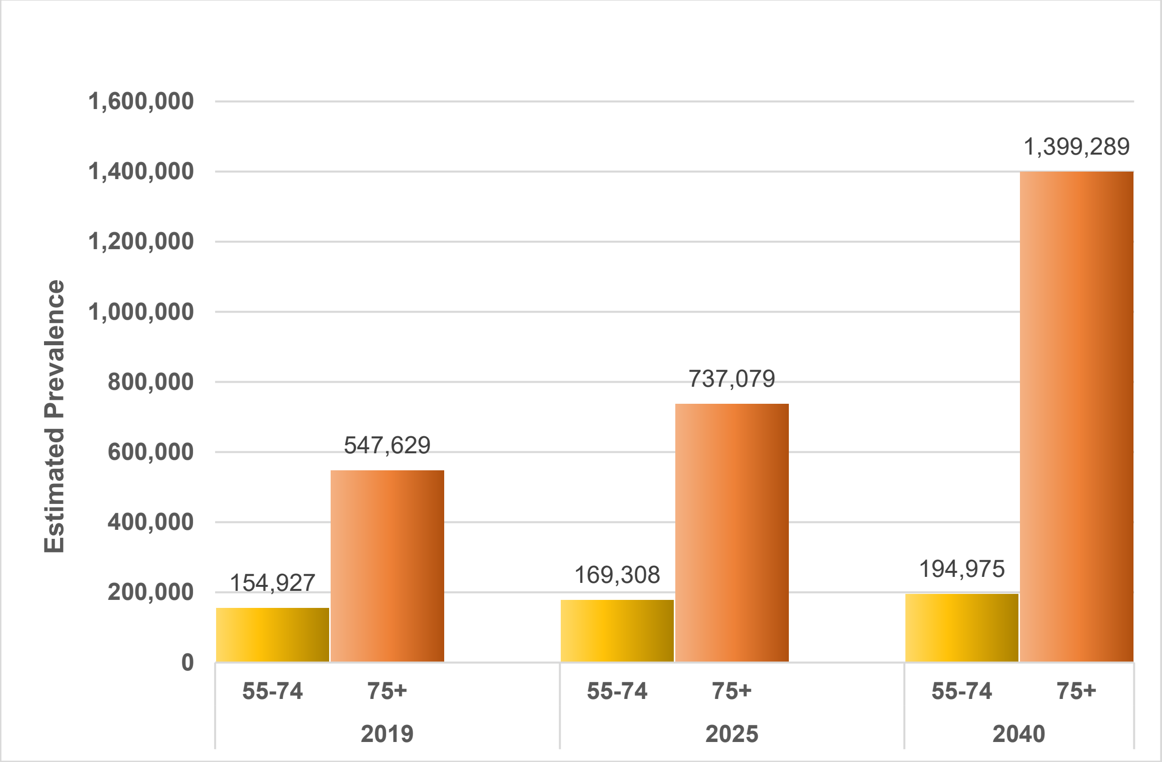
Factors that are likely to increase the number of people living with ADRDs in California include the growth in the state's older population and reduced mortality from other causes. With advances in medical technology and clinical interventions, the number of individuals living into their 80s and 90s are expected to grow, which will be reflected in the number or people living with ADRDs. As displayed in ***Figure 3** and* ***Figure 4***, the majority of people living with dementia or AD are 75 years of age and older. In 2019, this age group constituted 72% and 78% of the total number of people over the age of 55 years who had dementia or AD, respectively. By 2040, more than twice as many persons 75 years of age and older will have dementia or AD, amounting to over 1.8 million and 1.3 million persons, respectively. The growth in the number of people living with dementia or AD, however, is not limited to older adults. For example, we also project increases in the number of individuals with AD between 55 and 74 years of age. In 2019, there were 154,927 persons within the age 55-74 group who had AD. By 2040 this number is estimated to increase by 26% to 194,975 people.

FIGURE 3: ESTIMATED AGE DISTRIBUTION OF CALIFORNIANS WITH DEMENTIA; 2019, 2025, 2040



Source: State of California, Department of Finance, *E-1 Population Estimates for Cities, Counties and the State with Annual Percent Change — January 1, 2019 and 2020.* Sacramento, California, May 2019. Accessed July 2, 2019. Please see Appendix B for methodology used to estimate California Alzheimer's disease prevalance.

FIGURE 4: ESTIMATED AGE DISTRIBUTION OF CALIFORNIANS WITH ALZHEIMER'S DISEASE; 2019, 2025, 2040



Source: State of California, Department of Finance, *E-1 Population Estimates for Cities, Counties and the State with Annual Percent Change — January 1, 2019 and 2020.* Sacramento, California, May 2019. Accessed July 2, 2019. Please see Appendix B for methodology used to estimate California Alzheimer's disease prevalence.

ESTIMATED NUMBER OF PEOPLE WITH ALZHEIMER'S DISEASE IN SELECT CALIFORNIA COUNTIES: 2019, 2025, 2040

The number of older people living in California's counties differs greatly. Consequently, the number and proportion of people in each county with AD varies significantly. As shown in ***Table 1***, by 2040, the number of people living with AD in California's fifteen largest counties, (those with a population of 700,000 or more) are estimated to double.

TABLE 1: ESTIMATED NUMBER AND PERCENT CHANGE IN PEOPLE 55+ WITH ALZHEIMER'S DISEASE IN CALIFORNIA COUNTIES WITH A POPULATION OF 700,000 OR MORE, 2019, 2025, 2040

County	2019	2025	2040	% increase 2019 - 2025	% increase 2025-2040	% increase 2019-2040
Los Angeles	177345	230167	416531	30%	81%	135%
Orange	59339	76730	131906	29%	72%	122%
San Diego	58616	76204	133257	30%	75%	127%
Riverside	44694	59020	108287	32%	83%	142%
Santa Clara	35314	46342	82336	31%	78%	133%
San Bernardino	28925	38387	69614	33%	81%	141%
Alameda	28045	37791	69264	35%	83%	147%
Sacramento	24885	32569	56525	31%	74%	127%
Contra Costa	21857	29557	54073	35%	83%	147%
San Francisco	18749	23222	37153	24%	60%	98%
San Mateo	16289	20924	34612	28%	65%	112%
Ventura	15807	20627	36445	30%	77%	131%
Fresno	14643	18641	31085	27%	67%	112%
Kern	11487	14545	23793	27%	64%	107%
San Joaquin	10999	14601	26484	33%	81%	141%

Source: State of California, Department of Finance, *E-1 Population Estimates for Cities, Counties and the State with Annual Percent Change — January 1, 2019 and 2020.* Sacramento, California, May 2019. Accessed July 2, 2019. Please see Appendix B for methodology used to estimate California Alzheimer's disease prevalence.

MODIFIABLE RISK FACTORS

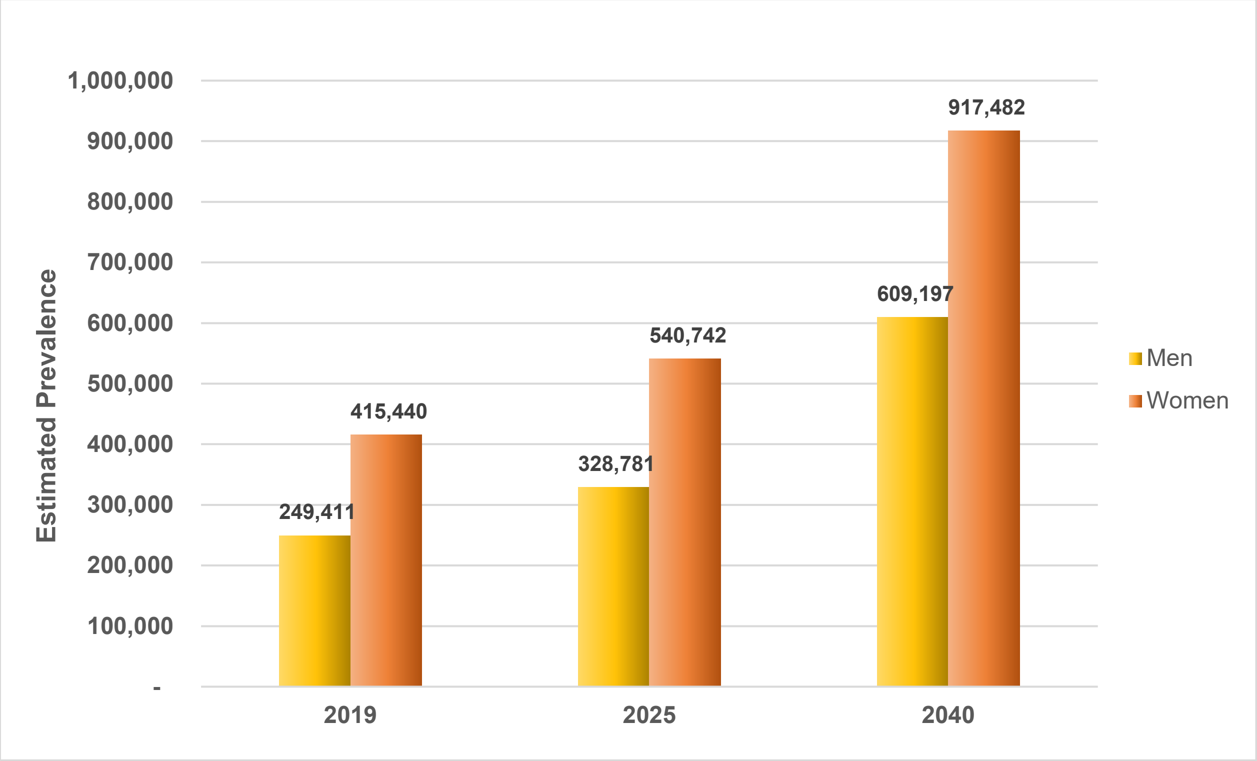
While risk factors such as age and genetics cannot be changed, there are other risk factors that can be modified and have an impact on the likelihood of cognitive decline and dementia. Risk factors include low education, hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes, low social contact, excessive alcohol consumption, traumatic brain injury, and air pollution (Livingston et al., 2020). Modifying the 12 risk factors listed above may prevent or delay up to 40% of dementias (Livingston et al., 2020). For instance, a healthy diet, lifelong learning, and cognitive training may be associated with reduced risk of cognitive decline. Additionally, studies show that regular physical activity and management of cardiovascular risk factors (especially diabetes, obesity, smoking, and hypertension) are associated with reduced risk of cognitive decline and may be associated with reduced risk of dementia (Baumgart et al., 2015; Blazer, Yaffe, and Liverman, 2015).

It is never too early and never too late throughout the life span for dementia prevention. The potential for prevention is high and might be higher in low-income and middle-income countries where more dementias occur (Livingston et al., 2020). In high-income countries (e.g., the U.S., the United Kingdom, and France) age-specific incidence rates of dementia have been found to be lower in more recent cohorts compared with cohorts from previous decades (Livingston et al., 2020). If Californians engage in healthy behaviors associated with decreased risk of cognitive impairment, this may slow the increase in total number or people with dementia. More research is needed to fully understand the biological mechanisms by which these factors reduce risk.

ALZHEIMER’S DISEASE AND DEMENTIA AMONG WOMEN

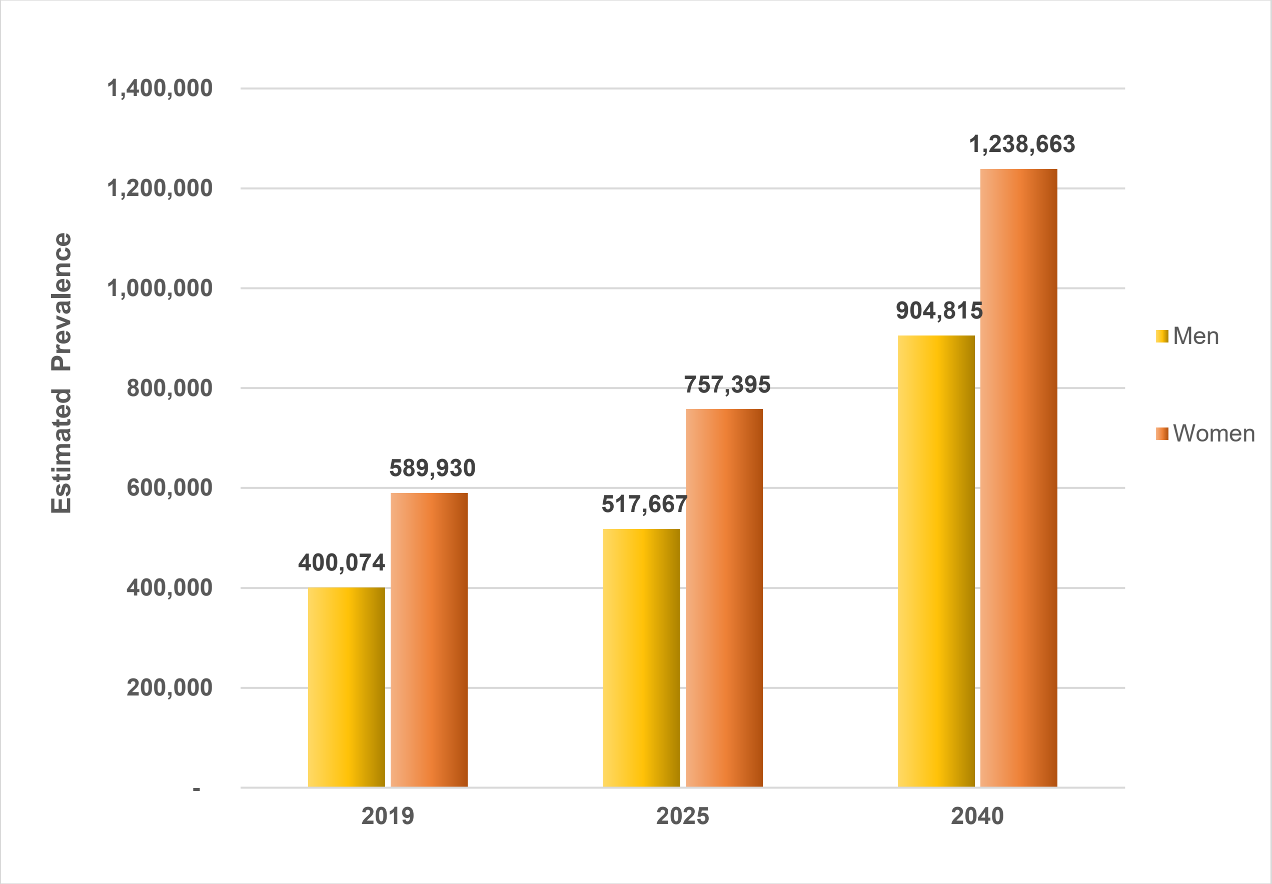
AD and dementia is deeply impacted by gender. More women than men have AD or dementia. Almost two-thirds of Americans with AD are women. Of the 5.6 million people 65 years of age and older with AD in the U.S., an estimated 3.5 million are women and 2.1 million are men (Alzheimer's Association, 2019a). California prevalence estimates for AD are similar to the national estimates. In 2019, approximately 63% of Californians 55 years of age and older with AD were women (415,440 people). Of the total population of Californians over 55 years of age in 2019, 7% of women had AD compared to an estimate of 5% of men. By 2040, the total population of Californians older than 55 years of age who will have AD is estimated to grow to approximately 11% for women and 8% among men. ***Figures 5 and 6*** display the current and projected number of women and men who will develop AD or dementia.

FIGURE 5: ESTIMATED ALZHEIMER'S DISEASE PREVALENCE AMONG CALIFORNIANS AGED 55+ BY SEX; 2019, 2025, 2040



Sources:
1. State of California, Department of Finance, *E-1 Population Estimates for Cities, Counties and the State with Annual Percent Change — January 1, 2019 and 2020.* Sacramento, California, May 2019. Accessed July 2, 2019. Please see Appendix B for methodology used to estimate California Alzheimer's disease prevalence.
2. Plassman BL, Langa KM, Fisher GG, Heeringa SG, Weir DR, Ofstedal MB, et al. Prevalence of dementia in the United States: The Aging, Demographics, and Memory Study. *Neuroepidemiology* 2007;29(1-2):125-32.

FIGURE 6: ESTIMATED DEMENTIA PREVALENCE AMONG CALIFORNIANS AGE 55+ BY SEX; 2019, 2025, 2040



Sources:
1. State of California, Department of Finance, *E-1 Population Estimates for Cities, Counties and the State with Annual Percent Change — January 1, 2019 and 2020.* Sacramento, California, May 2019. Accessed July 2, 2019. Please see Appendix B for methodology used to estimate California Alzheimer's disease prevalence.
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Several social and biological reasons provide possible explanations of why more women than men have AD. While numerous studies have explored this gender difference, none have been conclusive, and more research is warranted. One common explanation has been that women live longer than men, on average; thereby heightening their risk of developing AD. Studies looking at the incidence of developing AD, however, have found no significant differences between men and women in the proportion who develop AD at any given age (Alzheimer's Association, 2019a). Other studies have attributed the difference to other related health factors, such as a “survival bias.” For instance, men who manage to live to older ages and are included in studies may tend to represent healthier men; and, as a result, may have a lower risk of developing AD than men who died earlier from other conditions, such as cardiovascular disease (Alzheimer's Association, 2019a). Other researchers are examining whether the risk of AD could be higher for women at any age due to biological or genetic variations or differences in life experiences, such as an interaction between the APOE-e4 genotype (the best-known genetic risk factor for AD) and the sex hormone estrogen. Studies, however, are inconclusive on finding differences between men and women in the association between APOE genotype, except for a slightly elevated risk for women with the APOE-e3/e4 genotype compared with men with the same genotype between 65 and 75 years of age (Alzheimer's Association, 2019a) (see **Appendix A**). Finally, because low education is a risk factor for dementia, it is possible that lower educational attainment in women than in men born in the first half of the 20th century could account for a higher risk of AD in women (Alzheimer's Association, 2019a).

ALZHEIMER’S DISEASE AND DEMENTIA AMONG CALIFORNIA’S ETHNIC AND CULTURALLY DIVERSE POPULATION

California is among the most ethnically and culturally diverse states in the U.S. (McCann, 2019a). Six of California’s counties rank in the top twenty most racially and ethnically diverse counties in the U.S., with three counties in the top ten (Alameda, Solano, and Sacramento) and three additional counties among the top 20 (San Joaquin, Orange, Contra Costa) (Niche, 2019; Olson, 2014). As such, it is important to examine how current and future population trends among the state's racially, ethnically, linguistically, and culturally diverse population will change the face of dementia over the next three decades. As demonstrated in the revised "Ten Essential Public Health Services" framework, systematic change is taking place to achieve equitable health outcomes in diverse populations (Centers for Disease Control and Prevention, 2020). To enable optimal health for all, focus is being placed on removal of systemic and structural barriers within policies, systems, and overall community conditions. Such barriers include poverty, racism, gender discrimination, ableism, and other forms of oppression. (Centers for Disease Control and Prevention, 2020).

Studies of dementia in underrepresented race and ethnic groups are relatively sparse. This reflects the urgent need for current and future research to include increased numbers of people who are Latino/Latina/Latinx (Latino/a/x) American,[4] Black/African American, Asian American/Pacific Islander, and Native American in studies and investigations so everyone benefits from advances in dementia science (Alzheimer's Association, 2020). Several biological and social factors including social determinants of health[5] provide possible explanations of why race, ethnicity, and culture have substantial influences on the impact of dementia in California's communities. Although some scientific evidence suggests genetic risk factors for

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[4] Latinx can be defined as 'an inclusive term that recognizes the intersectionality of sexuality, language, immigration, ethnicity, culture and phenotype' of people who are labeled Hispanic according to U.S. Census categories (Salinas Jr and Lozano, 2019). People have come to use Latinx as a political identity to signal a rejection of U.S. colonial naming practices and Chicano patriarchy, instead embracing Indigenous and queer identities that move beyond the binary (a/o) identity (Torres, 2018).

[5] Social determinants of health are conditions in which people are born, grow, live, work, and age that affect a wide range of health and quality of life risks and outcomes. Social determinants of health can be grouped into five domains: economic stability, education access and quality, health care access and quality, neighborhood and built environment, and social and community context. Retrieved 3/10/2021, from https://www.who.int/teams/social-determinants-of-health and https://www.cdc.gov/socialdeterminants/about.html

dementia may differ by race/ethnicity, genetic factors do not appear to account for the large differences in prevalence or incidence among racial/ethnic groups (Chin, Negash, and Hamilton, 2011; Yaffe et al., 2013). Likely culprits for an increased risk for dementia in underrepresented racial and ethnic groups are the presence of other health conditions, such as cardiovascular disease and diabetes. Social determinants of health for dementia include socioeconomic characteristics, such as lower levels of education, higher rates of poverty, and greater exposure to adversity and discrimination, which are also more prevalent in underrepresented racial and ethnic groups. Moreover, some studies suggest that differences based on race and ethnicity do not persist in rigorous analyses that account for such factors (Alzheimer's Association, 2019a).

Cultural biases in cognitive testing and inadequate translation of diagnostic tools to other languages may also influence the identification of dementia in ethnically and culturally diverse populations. While significant progress has been made to develop culturally sensitive tools, they have not been standardized or normalized across diverse populations, nor are they being widely used outside of academic or specialized research settings. As a consequence, underreporting and obtaining a diagnosis at a later stage of dementia often occurs among ethnically and culturally diverse populations. This missed and delayed diagnosis not only limits the scientific understanding of dementia’s impact within California’s racially, ethnically, linguistically, and culturally diverse communities; it directly impacts the individual living with dementia, since the effectiveness of medications, psychological, or social interventions depends upon early diagnosis. Coupled with a dementia workforce shortage of bilingual professionals nationwide, testing and diagnosis of non-English speaking older adults is especially challenging. Although these disparities are well known, little is known about the effectiveness of various strategies to improve diagnosis and access to quality care, such as cultural humility or cultural competence training, to address cultural differences and few studies evaluate possible interventions (Lines, Sherif, and Wiener, 2014).

Figure **7** displays the current and projected number of Californians who have and will develop AD in the future among White/Caucasian American, non-Latino/a/x, Latino/a/x American, Black/African American, Asian American/Pacific Islander, Native American, and multiracial population groups. ***Figure 8*** displays the current and projected number of Californians who have and will develop dementia in the future among White/Caucasian American, non-Latino/a/x, Latino/a/x American, Black/African American, Asian American/Pacific Islander, Native American, and multiracial population groups. ***Figure 9*** displays the current and projected number of women in California who have and will develop AD in the future among White/Caucasian American, non-Latino/a/x, Latino/a/x American, Black/African American, Asian American/Pacific Islander, Native American, and multiracial population groups.

When and how people arrive in the U.S. varies, and helps explain the diversity of people and its implications for dementia research and practice. This report uses the following overarching terms: White/Caucasian American, non-Latino/a/x, Latino/a/x

American, Black/African American,[6] Asian American/Pacific Islander,[7] and Native American. However, it is crucial to understand the diversity of these heterogeneous groups, which includes many groups of people and their descendants from many countries with widely varying histories, cultures, traditions, religions, languages, migration histories, and settlement in California. Differences in migration history require culturally and linguistically appropriate services.

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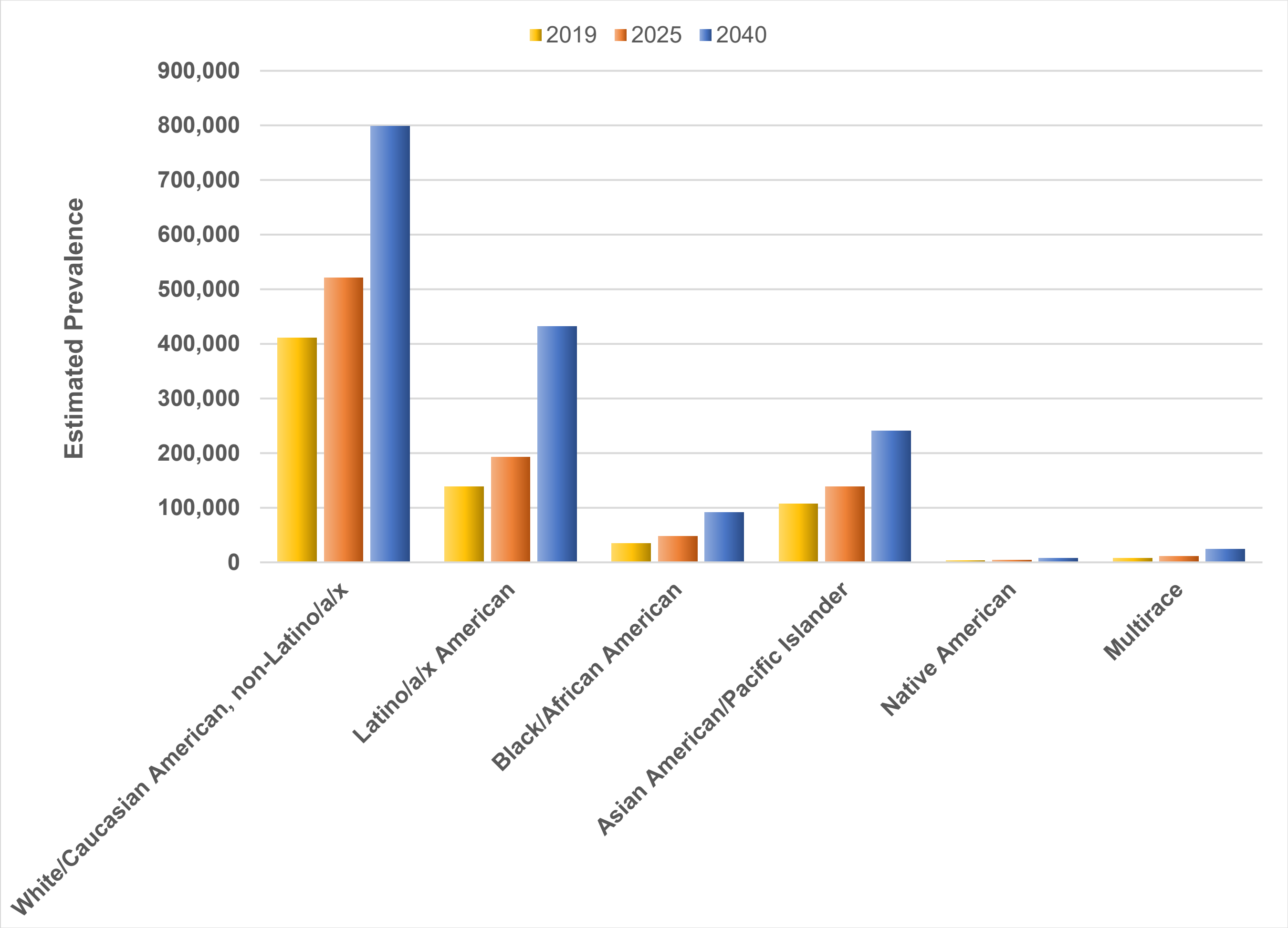
[6] Racial categories, which have been included on every U.S. census since the first one in 1790, have changed from decade to decade, reflecting the politics and science of the times. It was 1960 when people could select their own race. It was 2000 when people could choose more than one race to describe themselves, allowing for an estimate of the nation's multiracial population. In 2020, for the first time, the U.S. census form asks respondents who choose white or black for their race to give more information about their origins (A. Brown, 2020).

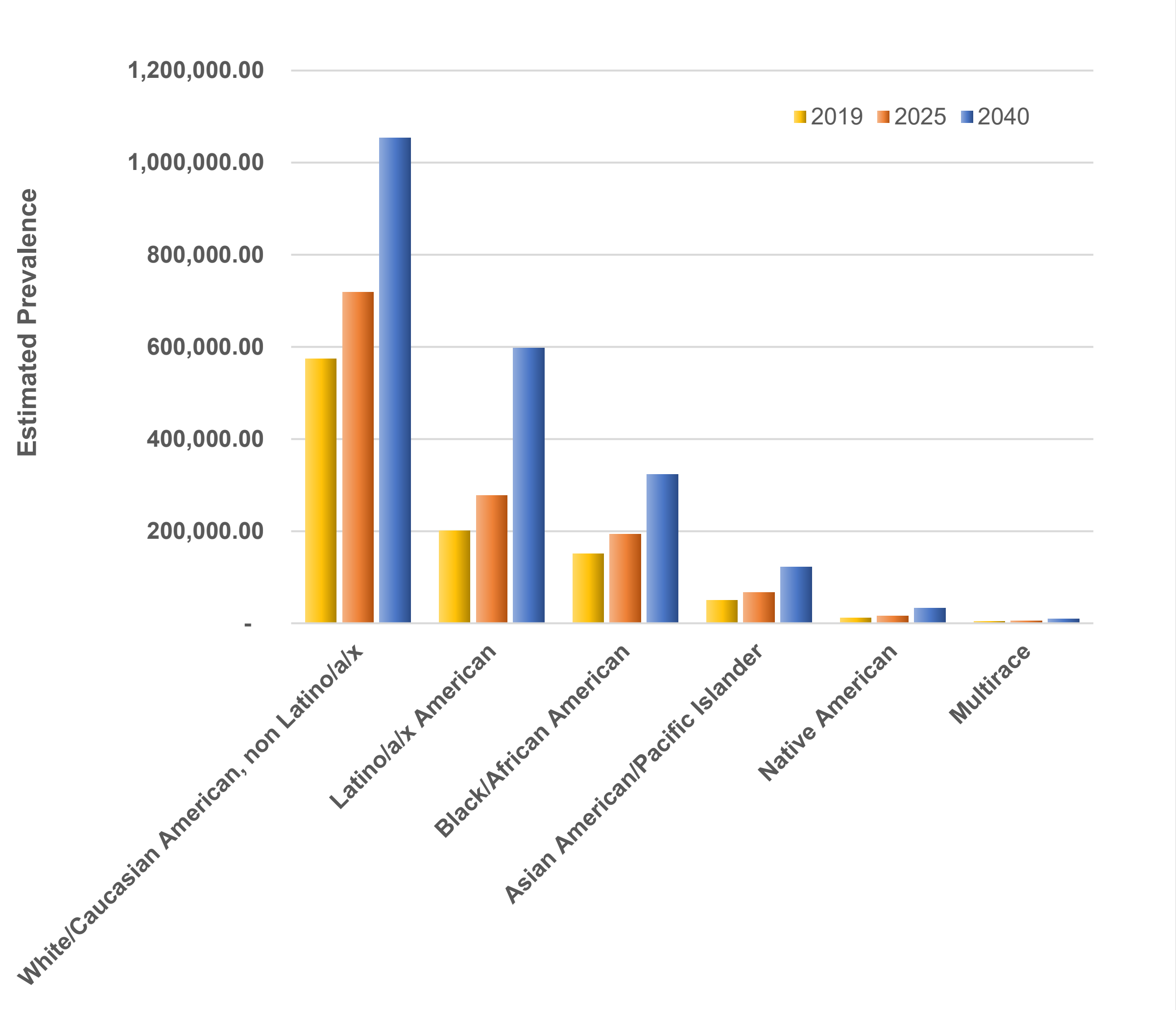
[7] Government definitions of racial categories do not always correspond with Americans' understanding of these racial categories. J. Lee and Ramakrishnan (2019) found a disjuncture in racial assignment between those the U.S. government assigns as Asian American and those that Americans include in the category, which bias the narratives of Asian Americans. College-educated, younger Americans are more inclusive in who counts as Asian American, indicating that the social norms of racial assignment are mutable. The term Asian American/Pacific Islander can describe the diaspora of people who self-identify as being indigenous to or have ancestry from countries in the East or Southeast parts of the Asia continent, the Indian subcontinent, and the Pacific Islands in any of the three sub-regions of Oceania (Micronesia, Melanesia, and Polynesia). When and how people from Asia and the Pacific Islands arrived in the U.S. varies, which helps explain why some groups have greater shares of U.S.-born or foreign-born among their population. Immigration from Asia and the Pacific Islands has outpaced immigration from Latin America every year since 2010. Almost 40% of the new immigrant arrivals were from Asia and the Pacific Islands in 2017 (New American Economy Research Fund, 2019).

FIGURE 7: ESTIMATED PREVALENCE OF ALZHEIMER’S DISEASE AMONG CALIFORNIANS AGE 55+ BY RACE/ ETHNICITY; 2019, 2025, 2040



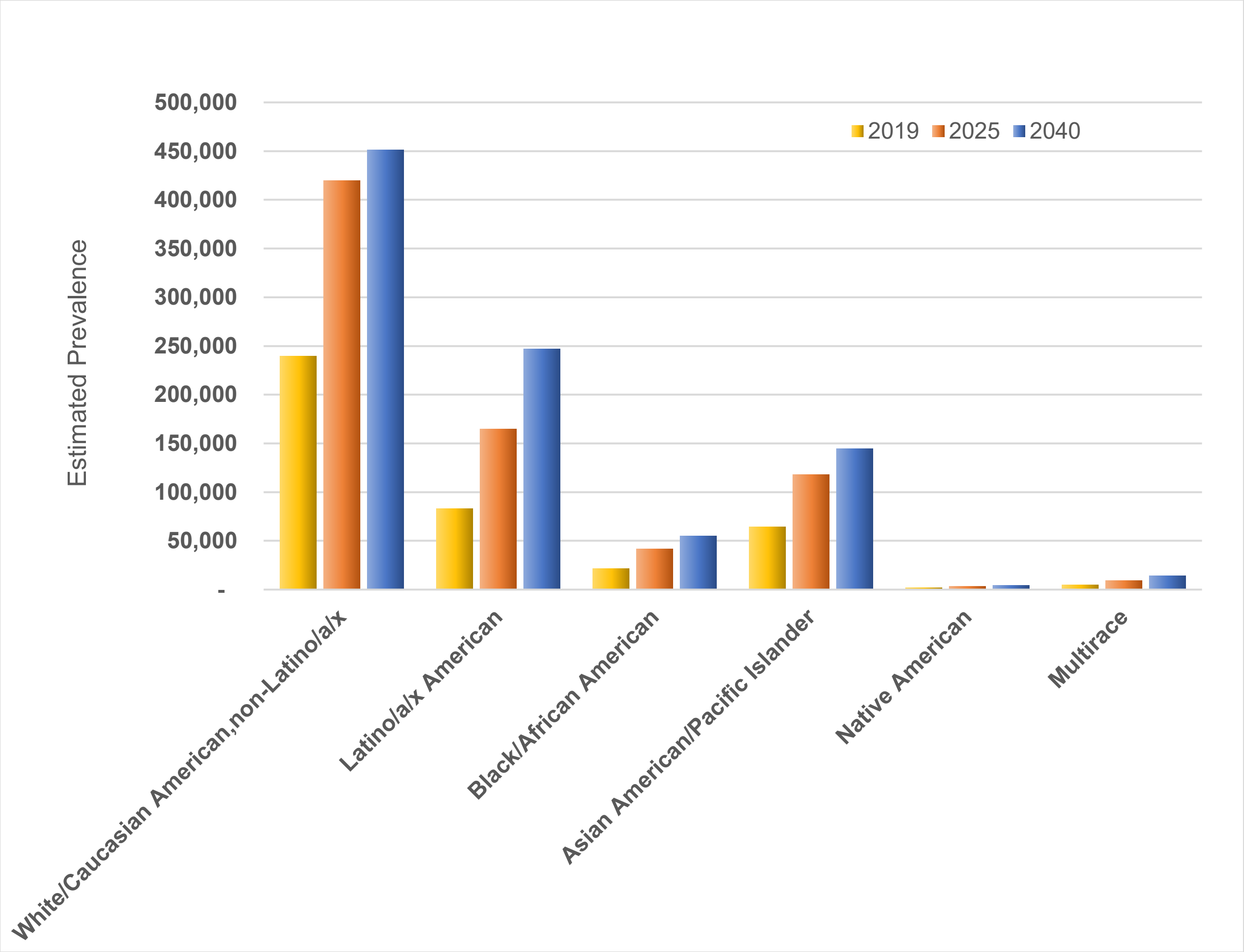
Source: State of California, Department of Finance, *E-1 Population Estimates for Cities, Counties and the State with Annual Percent Change — January 1, 2019 and 2020.* Sacramento, California, May 2019. Accessed July 2, 2019. Please see Appendix B for methodology used to estimate California Alzheimer's disease prevalence.

FIGURE 8: ESTIMATED PREVALENCE OF DEMENTIA AMONG CALIFORNIANS AGE 55+ BY RACE/ ETHNICITY; 2019, 2025, 2040



Source: State of California, Department of Finance, *E-1 Population Estimates for Cities, Counties and the State with Annual Percent Change — January 1, 2019 and 2020.* Sacramento, California, May 2019. Accessed July 2, 2019. Please see Appendix B for methodology used to estimate California Alzheimer's disease prevalence.

FIGURE 9: ESTIMATED PREVALENCE OF ALZHEIMER'S DISEASE AMONG CALIFORNIAN WOMEN AGE 55+ BY RACE/ ETHNICITY; 2019, 2025, 2040



Sources:
1. State of California, Department of Finance, *E-1 Population Estimates for Cities, Counties and the State with Annual Percent Change — January 1, 2019 and 2020.* Sacramento, California, May 2019. Accessed July 2, 2019. Please see Appendix B for methodology used to estimate California Alzheimer's disease prevalence.
2. Plassman BL, Langa KM, Fisher GG, Heeringa SG, Weir DR, Ofstedal MB, et al. Prevalence of dementia in the United States: The Aging, Demographics, and Memory Study. *Neuroepidemiology* 2007;29(1-2):125-32.

WHITE/CAUCASIAN AMERICANS, NON-LATINO/LATINA/LATINX

Based on calculated prevalence estimates in this report, in 2019 59% of older Californians who identified as White/Caucasian American, non-Latino/a/x are estimated to be living with AD. This population will experience the largest absolute growth in the number of people living with AD between 2019 and 2040, due to the aging of the baby boomers who predominately identify as White/Caucasian American, non-Latino/a/x . The proportional increase, however, relative to the entire population of people who identify as White/Caucasian American, non-Latino/a/x will not be as steep compared to California’s other ethnic populations, primarily due to lower fertility rates among the baby boomers and increased immigration of Latino/a/x American and Asian American/Pacific Islander groups. Other related reasons include, but are not limited to, lower risks associated with developing AD because of higher educational levels; associated health factors (e.g., lower rates of diabetes and vascular disease than other population sub-groups); and generally better access to, and use of, health services among this population.

LATINO/LATINA/LATINX AMERICANS

The words “Latino/a/x” and “Hispanic” are often used interchangeably, though they mean two different things. Latino/a/x American refers to people who are from or descended from people from Latin America, whereas Hispanic refers to people who speak Spanish and/or are descended from Spanish-speaking populations, including countries such as Argentina, Colombia, Cuba, Dominican Republic, Ecuador, El Salvador, Guatemala, Honduras, Mexico, Nicaragua, Panama, Peru, Puerto Rico, Spain, and Venezuela, to name a few. Depending upon the specific subgroup of people who identify as American, the risk, prevalence, and severity of dementia may vary. For example, there is a pronounced increase in life expectancy among certain nationalities and regions (Mexicans, Central Americans and South Americans), middle years of age and older age groups, and first-generation immigrants. Researchers call this a “Latino/a/x” mortality advantage, but do not know what accounts for it and have hypothesized a mix of attributors that include a combination of social supports, diet, and limited smoking (Vega, Cabrera, Wygant, et al., 2017).

People who identify as Mexican American comprise the largest subgroup of people who identify as Latino/a/x American in the U.S. As migration patterns from Latin America change, the origins of U.S. Hispanics are beginning to shift. For instance, since 2010, people who identified as Venezuelan, Dominican, and Guatemalan saw the fastest population growth. The socioeconomic conditions of people who identify as Latino/a/x American vary widely by origin, which helps explain differences in resources access and need.

People who identify as Latino/a/x American comprise the second largest ethnic group in California and are quickly becoming the state's majority group. In 2019, 20% of Californians living with AD were people who identified as Latino/a/x American. Similar to national trends, older adult Californians who identify as Latino/a/x American are more likely than older adult Californians who identify as White/Caucasian American, non-Latino/a/x to have AD, on a per-capita basis. Between 2019 and 2040, the estimated number of Californians living with AD who identify as Latino/a/x American will more than triple, from 138,725 to 431,982 (see ***Figure 7***).

While research is beginning to uncover the impact of dementia among Californians who identify as Latino/a/x American, current scientific knowledge suggests that this population may be at greater risk of developing dementia than other ethnic groups due to increasing life expectancy, health conditions, and socioeconomic factors (Alzheimer's Association, 2019a; Latino Coalition for a Healthy California, n.d.; Us Against Alzheimer's, n.d.; Vega, Cabrera, Wygant, Valez-Ortiz, and Counts, 2017). The life expectancy of people who identify as Latino/a/x American is projected to increase to age 87 by 2050, surpassing all other ethnic groups in the U.S. (Alzheimer's Association, 2004). Because age is the most significant risk factor for developing dementia, the gains in life expectancy among Californians who are Latino/a/x American will likely contribute to the growing number and proportion of those with dementia as well.

Dementia prevalence is also substantially explained by socioeconomic status, which helps explain differential access to resources and need for the diversity of people who identify as Latino/a/x American. In 2017, households headed by people who were 65 years of age and older and identified as Latino/a/x American reported a median income of $40,512, compared to $61,946 for all American households headed by people 65 years of age and older. In 2017, the median personal income for men and women 65 years of age and older who identified as Latino/a/x American was $19,179 and $12,758, respectively; compared to $32,654 and $19,180 for all American men and women 65 years of age and older, respectively. The poverty rate for people 65 years of age and older who identified as Latino/a/x American was 17%, compared to 9% for all Americans 65 years of age and older (Administration for Community Living, 2018c).

Racial/ethnic inequalities are widely observed for many health outcomes. In the case of dementia, the most compelling explanations relate to established risk factors for dementia, such as low education, hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes, low social contact, excessive alcohol consumption, traumatic brain injury, and air pollution (Livingston et al., 2020). It is important to remember that more socially disadvantaged groups, including Latino/a/x American are particularly at risk. A mounting body of evidence indicates that vascular disease risk factors, such as diabetes, high blood pressure, heart disease, hypertension and stroke, may also be risk factors for dementia among people who identify as Latino/a/x American. A recent study found that people who identified as Latino/a/x American and diagnosed with dementia were more likely to have cerebrovascular disease than people who identified as White/Caucasian American, non-Latino/a/x or people who identified as Black/African American. The study also found that people who identified as Latino/a/x American were more likely to have mixed pathologies (such as a combination of AD and cerebrovascular disease) than people who were White/Caucasian American, non-Latino/a/x (Filshtein et al., 2019). Prior studies suggest dementia risk differs between subgroups of people who identify as Latino/a/x American. For instance, an elevated risk was observed among people who identified as “Caribbean Latinos” in New York City, but not among people who identified as “Mexican Americans” in California, compared to people who identified as “White” (Haan et al., 2007; Haan et al., 2003; Plassman et al., 2007). The Hispanic/Community Health Study/Study of Latinos (HCHS/SOL) provided additional evidence that dementia risk likely varied across subgroups of people who identified as Latino/a/x American in the U.S. For instance, people who identified as Dominican and Puerto Rican had significantly higher odds of low performance on a neuropsychological test battery than people who identified as having “Mexican” origin. Although the study did not assess dementia, low performance on neuropsychological tests in population samples strongly predicts future dementia risk (Elias et al., 2000; Gonzalez et al., 2015).

BLACK/AFRICAN AMERICANS

While this report uses the umbrella term Black/African American, it is important to understand that this term encompasses many groups of people and their descendants from many countries with widely varying histories, cultures, traditions, religions, languages, migration histories, and settlement in California. When and how people arrive in the U.S. varies, which helps explain the diversity of people who identify as Black/African American and its implications for dementia research and practice.

California is among the main states where immigrants from Africa are concentrated (Public Broadcasting Service, n.d.). California was among the top ten states with the largest population of people who identified as Black/African American in 2017 (U.S. Department of Health and Human Services Office of Minority Health, 2019). The metropolitan areas in California with the largest population of people who identified as Black/African American were Los Angeles, San Francisco-Oakland, Riverside-San Bernardino, Sacramento, San Diego, Vallejo-Fairfield, and Fresno.

In 2019, 5% of Californians living with AD were people who identified as Black/African American. The number of Californians living with AD who identify as Black/African American will nearly triple by the year 2040, with an estimated increase from 34,591 to 91,071 people. This may be underestimated because screening and assessment tools and the design of clinical trials do not address the unique expression or presentation of AD in people who identify as Black/African American (Clark et al., 2005).

Some population-based or memory clinic cohorts report an AD incidence among people who identify as Black/African American as twice that of people who identify as White/Caucasian American, non-Latino/a/x (Tang et al., 2001; J. Weuve et al., 2018).

Other recent data, however, suggest racial differences may not be as large as previously thought. In a study that leveraged 14 years of prospective data on a large, diverse cohort of older adults in northern California with equal access to healthcare, dementia incidence was highest among people who were Black/African American; however, the difference in incidence rate between people who were Black/African American (26%) and White/Caucasian American, non-Latino/a/x (19%) was smaller than expected (Mayeda, Glymour, Quesenberry, and Whitmer, 2016).

There is substantial evidence of under-reporting of dementia among people who identify as Black/African American. Given cultural differences in expectations for healthy aging and the potential for differential underdiagnosis by clinicians, it is possible there are differences in diagnosis patterns by race/ethnicity, which could contribute to the observed trends of delayed and more missed diagnoses in people who identify as Black/African American (Clark et al., 2005). Older adults who identify as Black/African American also tend to perform more poorly on cognitive tests on average than older adults who identify as White/Caucasian American, non-Latino/a/x. The use of dementia diagnosis of cognitive testing against population norms may skew prevalence numbers of dementia on people who identify as Black/African American, some of whom under perform on those tests as a result of growing up with educational disparities. As a result, people who identify as Black/African American tend to have a much higher false-positive result for cognitive impairment or dementia (Alzheimer's Association, 2002; Barnes and Bennett, 2014).

Several factors help explain why people who identify as Black/African American may be hard hit by AD. For instance, socioeconomic characteristics, including lower levels of education, higher rates of poverty, and greater exposure to adversity and discrimination may increase the risk of developing AD among people who identify as Black/African American. In 2017, households containing families headed by people who were 65 years of age and older and identified as Black/African American reported a median income of $43,705, compared to $61,946 for all American households headed by people 65 years of age and older. In 2017, the median personal income for men and women 65 years of age and older who identified as Black/African American was $22,485 and $15,817, respectively; compared to $32,654 and $19,180 for all American men and women 65 years of age and older, respectively. The poverty rate for people 65 years of age and older who identified as Black/African American was 19%, compared to 9% for all Americans 65 years of age and older (Administration for Community Living, 2018a).

Lack of physician contact is also likely to be widespread in families caring for people who identify as Black/African American with dementia. Clark et al. (2005) found a lag time of about seven years between the time a caregiver who identifies as Black/African American notices symptoms in the person with dementia they are caring for and seeking physician consultation. Forgetfulness was the symptom most likely to make caregivers think that something might be wrong and was also the reason most often given for having the patient see a physician. More than half the caregivers attributed delays in consulting a physician to thinking that the observed changes were normal aging, being unsure how severe the problem was, and finding it difficult to discuss the problem with the patient; more than one-third also found it challenging to face the possibility of dementia, and they experienced anger on the part of the patient about a possible physician visit. While physician contact was more characteristic of more highly educated families, it still may not yield a correct diagnosis for the patient.

Income and poverty also play a role in the differences to resource access and care for the diversity of people who identify as Black/African American (Clark et al., 2005).

Health conditions, such as cardiovascular disease and diabetes, are considered to be risk factors for dementia. These risk factors are more prevalent in people who identify as Black/African American (Alzheimer's Association, 2019a; Barnes and Bennett, 2014; Barnes et al., 2005; George, Duran, and Norris, 2014).

While racial groups may have genetic differences, a number of studies suggest that genetic factors do not appear to account for the significant differences in prevalence or incidence among racial groups (Chin et al., 2011; Yaffe et al., 2013). There is inconclusive evidence to suggest that genetic and environmental factors and the associated risk for dementia works differently in people who identify as Black/African American. A recent study using several cohorts of people who identify as Black/African American confirmed that the APOE-e4 allele, along with a new gene called ABCA7, is related to an increased risk of AD among people who identify as Black/African American (Reitz, Jun, and Naj, 2013). The study is noteworthy because it represents the largest genome-wide association study to date involving people who identify as Black/African American. Another study found a greater familial risk of AD among people who identified as Black/African American, where the cumulative risk of dementia among first-degree relatives of persons with AD was 43.7% (Green et al., 2002). While APOE-e4 allele increases risk of clinical AD (see **Appendix A**), it is inconsistently related to AD or cognition among people who identify as Black/African American (Logue, Schu, and Vardarajan, 2011).

ASIAN AMERICAN/PACIFIC ISLANDERS

California has the largest population of people who identify as Asian American/Pacific Islander in the U.S., with the number projected to grow significantly in coming decades. In 2018, the largest Asian American/Pacific Islander groups of California included people who identified as Chinese (1,721,461), Filipino (1,596,476), Indian (815,421), Vietnamese (758,908), Korean (529,208), and Japanese (455,900). California counties with the largest percentage of people who identified as Asian American/Pacific Islander were Santa Clara (34%), Orange County (19%), and Los Angeles (14%) (Asian and Pacific Islander American Vote, 2018). The growth of the Asian American/Pacific Islander population in California will have a corresponding increase in the number of individuals living with dementia. In 2019, 15% of Californians with AD were Asian American/Pacific Islander. The number of Californians living with AD who are Asian American/Pacific Islander will more than double between 2019 and 2040, increasing from approximately 107,268 to 241,106 (see ***Figure 7***). These numbers might be an underestimation for several reasons. For instance, studies have indicated that people who are, or identify as, Asian American/Pacific Islander may not report symptoms of dementia to a medical professional unless family caregivers require medical assistance with behavioral issues (Jones, Chow, and Gatz, 2006).

Prior research on dementia has been limited to examining Asian American/Pacific Islanders as one group or Japanese Americans alone (Borenstein et al., 2014; Mayeda et al., 2016; White et al., 1996). In a 14-year study of dementia incidence among subgroups of people who identified as Asian American/Pacific Islander, Mayeda, Glymour, Quesenberry, and Witmer (2017) found moderate differences in dementia incidence across subgroups in a large usual-care setting in

Northern California. Age-adjusted dementia incidence rates were higher among people who identified as “White” than “All Asian-Americans” or any subgroup of people who identified as Asian American/Pacific Islander. Compared with people who identified as Chinese, dementia incidence was slightly higher among people who identified as Japanese and Filipino, and lower among people who identified as South Asian. More studies are needed to help understand dementia risk in the growing and diverse population of Californians who identify as Asian American/Pacific Islander.

Several factors help explain the heterogeneity in dementia risk between groups of people who identify as Asian American/Pacific Islander, as well as the barriers to seeking information, assistance, or professional care. For instance, the entwined influence of language and cultural beliefs may be related to the later stage of dementia at which people who identify as Asian American/Pacific Islander get a diagnosis from healthcare providers. Language plays an important role in shaping cultural beliefs, which may, in turn, shape understandings about dementia. To provide a specific example, the literal translation of the word “dementia” conveys the meaning of “crazy catatonic” in Chinese, and the signs and symptoms of dementia can be interpreted as a mental illness with shame attached. This sense of shame can extend beyond the individual to their entire family. As such, the stigma of dementia may trigger negative responses that deter people from seeking information, assistance, or a diagnosis until the disease has progressed to later stages (Alzheimer's Association, n.d.-b, n.d.-c; Eller and Belza, 2018; Jones et al., 2006; Yoo, Musselman, Lee, and Yee-Melichar, 2015). Since people who identify as Asian American/Pacific Islander are so diverse, language and cultural beliefs may play very different roles in their knowledge and understanding about dementia. Moreover, due to a relatively more recent immigration history to the U.S., people who are Asian American/Pacific Islander have a high rate of limited English proficiency when compared to other groups. Some languages, like Chinese, have multiple dialects, making the dissemination of culturally and linguistically appropriate information about dementia more complex.

Another aspect impacting the ability of people who identify as Asian American/Pacific Islander from obtaining a diagnosis of dementia may be due to the medical community's lack of available interpretation services coupled with a limited understanding of health practices and beliefs held by the diversity of people who identify as Asian American/Pacific Islander. People who are Asian American/Pacific Islander may also opt for an integrative approach to health care based on cultural beliefs about the interconnectedness of mind, body, and spirit. When coping with dementia, evidence has shown that tailored services and tools can help the diversity of people who identify as Asian American/Pacific Islander overcome these challenges (Chao et al., 2011).

Though healthcare utilization could contribute to differences in dementia diagnosis rates for people who identify as Asian American/Pacific Islander, Mayeda et al. (2017) found high healthcare utilization rates in all subgroups of people who identified as Asian American/Pacific Islander in a large usual-care setting in Northern California, when examining the heterogeneity of dementia incidence between these groups. Evaluating differential validity of diagnosis for subgroups of people who identify as Asian American/Pacific Islander, however, remains an important area for future research.

Socioeconomic predictors of dementia, such as income, occupational conditions, or education, also differ on average between subgroups of people who identify as Asian American/Pacific Islander, which may impact dementia risk differently (Mayeda et al., 2017). For instance, Asian American/Pacific Islander households have higher median incomes than many other comparable groups (New American Economy Research Fund, 2019). These earnings, however, also do not unveil differences when examining variables such as age and gender, which help explain socioeconomic differences in resource access and need. In 2017, households containing families headed by people who were 65 years of age and older and identified as Asian American/Pacific Islander reported a median income of $67,627, compared to $61,946 for all American households headed by people 65 years of age and older. However, in 2017, the median personal income for men and women 65 years of age and older who identified as Asian American/Pacific Islander was $26,692 and $14,418, respectively; compared to $32,654 and $19,180 for all American men and women 65 years of age and older, respectively. The poverty rate for people 65 years of age and older who identified as Asian American/Pacific Islander was 11%, compared to 9% for all Americans 65 years of age and older (Administration for Community Living, 2018b). Aggregate data on household earnings also do not account for the distinct historical trajectories of the different groups of people who identify as Asian American/Pacific Islander, which help explain socioeconomic differences between groups. In 2019, among Californian's Asian American/Pacific Islander population who were working and struggling with poverty, 44% identified as Hmong, 36% identified as Native Hawaiian and Pacific Islander, 26% identified as Cambodian, 26% identified as Vietnamese, 23% identified as Chinese, 22% identified as Filipino, 22% identified as Japanese, and 20% identified as Indian (Ramakrishnan et al., 2019).

Moreover, links between education and dementia, which are strongly inversely associated in most populations (Beydoun et al., 2014), may not be the same for people who identify as Asian American/Pacific Islander. According to Mayeda et al. (2017), the average level of education was lower among older adult Californians who identified as Asian American/Pacific Islander overall than older adult Californians who identified as White/Caucasian American, non-Latino/a/x. Therefore, the lower dementia in people who were Asian American/Pacific Islander overall compared to people who were White/Caucasian Americans, non-Latino/a/x was inconsistent with the overall educational patterns. Furthermore, their study found that people who identified as Filipino American had the highest levels of education and the highest dementia incidence among all the subgroups that they examined of people who identified as Asian American/Pacific Islander. This surprising finding of higher dementia risk in a highly educated population may reflect differences in the quality of education, differences in the resources that education provided for people who identified as Filipino American, or the education advantage may simply be overwhelmed by some risk factor that is more common in people who identify as Filipino American (Mayeda et al., 2017).

Finally, genetic variants linked to dementia, such as APOE-e4, may have different prevalence across subgroups of people who identify as Asian American/Pacific Islander. National data on prevalence of APOE genotypes in subgroups of people who identify as Asian American/Pacific Islander to verify this is limited. Some studies, however, have reported lower prevalence of APOE-e4 genotype in people who identify as Japanese American and Chinese American, compared with typical estimates for the U.S. population (Borenstein et al., 2014; Havlik et al., 2000;

Liang et al., 2013). These pathways may be partially mediated by known cardiometabolic risk factors, such as obesity and diabetes.

LESBIAN, GAY, BISEXUAL, TRANSGENDER, AND QUEER, OR QUESTIONING

The U.S. older adult population includes millions of people who identify as gender and sexual minorities. This is an umbrella term that encompasses the broad population of people who identify as lesbian, gay, bisexual, transgender, queer, or questioning (LGBTQ) as well as those whose sexual orientation and gender identity varies. Furthermore, the population of older adults who identify as LGBTQ are racially, ethnically, and culturally diverse. An estimated one in five (20%) older adults who identifies as LGBTQ is a person of color. Researchers estimate that nationally there are more than 2.7 million people who identify as LGBTQ over 50 years of age, and that number is increasing rapidly as the baby boomers age and more people self-identify as LGBTQ. Current estimates suggest that more than 200,000 people who identify as sexual minorities in the U.S. are living with dementia (Alzheimer's Association, 2018). Unfortunately, information on dementia prevalence impacting all sexual minorities is limited. The majority of data focuses on lesbian, gay, and, at times, the bisexual communities. While advances in LGBTQ rights and LGBTQ acceptance have begun gaining momentum in recent decades, this population continues to face discrimination, marginalization, and invisibility in society.

In California, AD is expected to more than double between 2019 and 2040, from approximately 16,790 to 36,705, for people who identify as lesbian, gay, or bisexual (LGB)[8] and are 55 years of age and older. For dementia in the population of people

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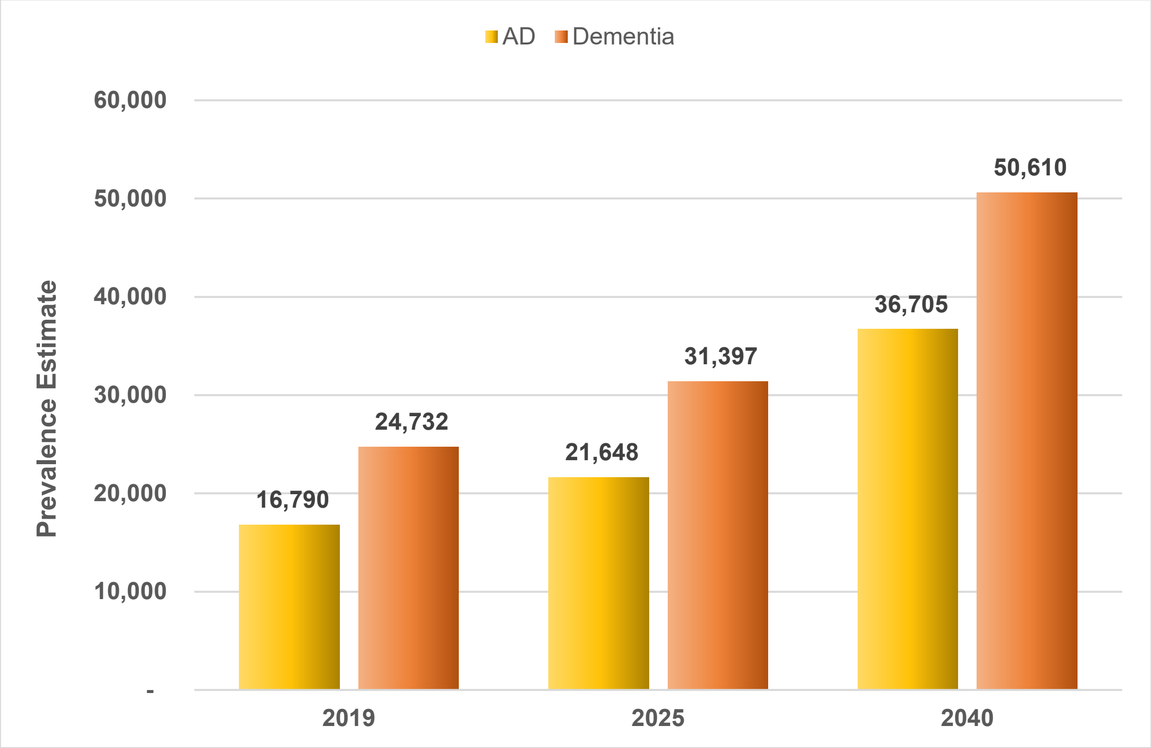
[8] Unfortunately, the available data is limited for prevalence of ADRDs among the aging transgender, queer, and questioning community, therefore, the California data in this report is for the combined LGB community.

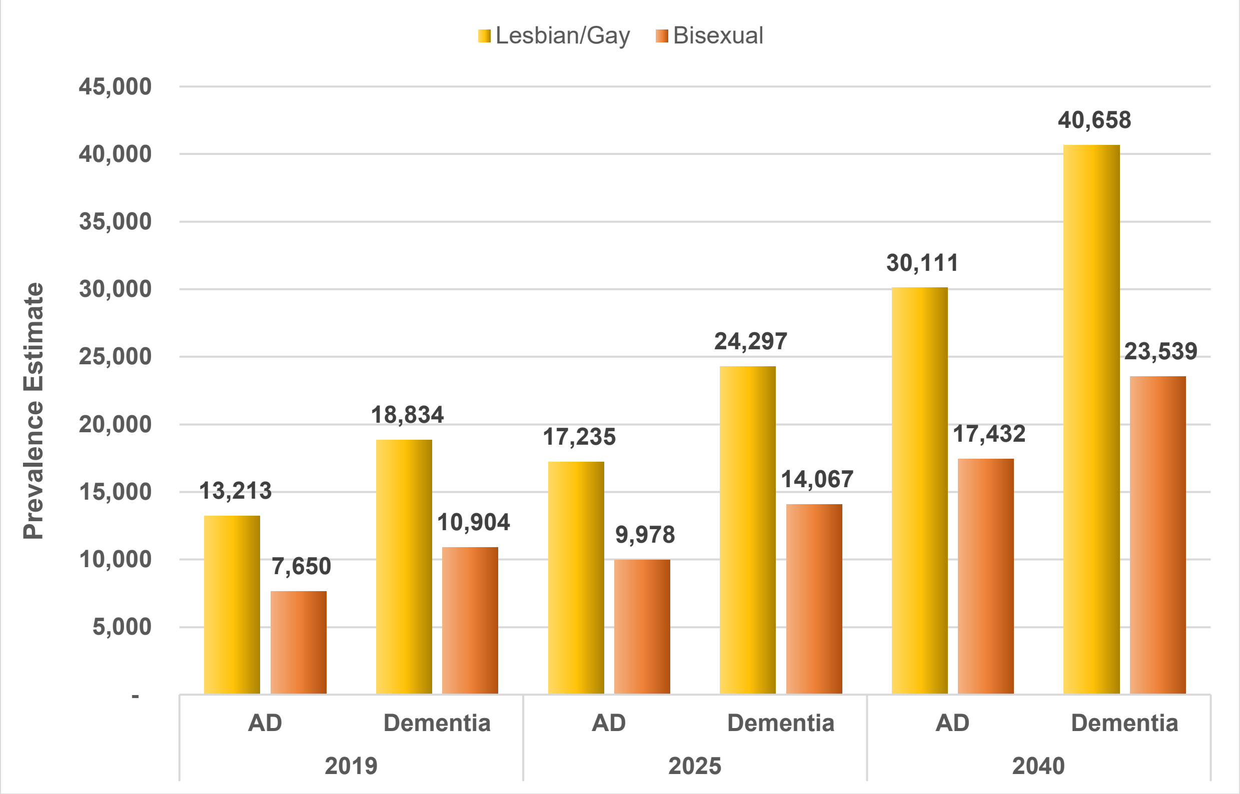
who identify as LGB and are 55 years of age and older, the growth in prevalence from 2019 to 2040 will also more than double from an estimated 24,732 to 50,610 LGB individuals (see ***Figure 10***). ***Figure 11*** shows the estimated increase number of LGB individuals living with dementia between 2019 and 2040 separately for lesbian and gay individuals, and for individuals who are bisexual. These numbers are most likely underestimations because data on sexual orientation and gender identity are not consistently gathered or reported, making it difficult to know or to predict the exact prevalence of ADRDs among this population. An estimated 40% of older adults who identify as LGBTQ say that their health care providers are unaware of their sexual orientation (Movement Advancement Project, 2017).

FIGURE 10: ESTIMATED PREVALENCE OF ALZHEIMER’S DISEASE AND DEMENTIA AMONG LESBIAN, GAY, OR BISEXUAL (LGB) CALIFORNIANS AGE 55+ BY SEXUAL ORIENTATION, 2019, 2025, 2040



Sources:
1. State of California, Department of Finance, *E-1 Population Estimates for Cities, Counties and the State with Annual Percent Change — January 1, 2019 and 2020.* Sacramento, California, May 2019. Accessed July 2, 2019. Please see Appendix B for methodology used to estimate California Alzheimer's disease prevalence.
2. 2015, 2016, 2017, 2018 California Health Interview Survey

FIGURE 11: ESTIMATED PREVALENCE OF ALZHEIMER'S DISEASE AND DEMENTIA AMONG LGB CALIFORNIANS AGE 55+ BY SEXUAL ORIENTATION, 2019, 2025, 2040



Sources:
1. State of California, Department of Finance, *E-1 Population Estimates for Cities, Counties and the State with Annual Percent Change — January 1, 2019 and 2020.* Sacramento, California, May 2019. Accessed July 2, 2019. Please see Appendix B for methodology used to estimate California Alzheimer's disease prevalence.
2. 2015, 2016, 2017, 2018 California Health Interview Survey

While age is a key risk factor for ADRDs, additional health care and socioeconomic risk factors may influence disparities for people who identify as LGBTQ (Allen, 2018; Alzheimer's Association and Sage, n.d.; Fredriksen-Goldsen, Jen, Bryan, and Goldsen, 2018; Movement Advancement Project, 2017). For example, older adults who identify as LGBTQ have a greater amount of health disparities when compared to their peers who do not identify as LGBTQ. Some of these health disparities include increased rates of depression, higher rates of tobacco and alcohol use, and higher rates of obesity and cardiovascular disease have been found among women who identify as being a lesbian, and higher rates of HIV/AIDS has been found among men who identify as gay or bisexual. Many of these health conditions have been linked to an increased risk of AD and vascular dementias. Also, older adults of color who identify as LGBTQ face greater health disparities than their counterparts who identify as White/Caucasian American, non-Latino/a/x and LGBTQ (Emlet and Fredriksen-Goldsen, 2017).

ALZHEIMER’S DISEASE AMONG PEOPLE WITH TRISOMY 21 (DOWN SYNDROME)

Down syndrome is the most common chromosomal disorder. Individuals born with three copies of chromosome 21 (called trisomy 21) instead of two copies are known to have Down syndrome. In the U.S. each year, about 6,000 babies are born with Down syndrome (Mai et al., 2019). The estimated number of people with Down syndrome, in 2014, was 213,841, with a population prevalence of 6.7 per 10,000 inhabitants (or one in 1,490). This included 138,019 “non-Hispanic Whites;” 27,141 “non-Hispanic Blacks;” 32,933 “Hispanics;” 6,747 “Asian Pacific Islanders;” and 1,527 Native Americans (de Graff, Buckley, and Skotko, 2020). An estimated 250,000 people with Down syndrome live in the U.S. today, though data are limited (Buckley, n.d.).

The California Birth Defects Monitoring Program (CBDMP) has been an active ascertainment, population-based registry since 1983. The registry currently monitors birth defects in a ten-county subset of California. These counties (San Joaquin, Stanislaus, Merced, Madera, Fresno, Kings, Tulare, Kern, Orange and San Diego) represent approximately 30% of the state’s births and are representative of the state’s population. The most recent data from the National Birth Defects Prevention Network (2019) report using 2012-2016 data indicates a 15.7 prevalence for every 10,000 live births. Unfortunately, the CBDMP does not extend beyond birth information for individuals living with Down syndrome in California, such as age, gender, and ethnicity and race.

A combination of community living rather than institutional care, early and continuing access to medical interventions, and overall improvements in population health has had a positive impact on the lives of people with Down syndrome, resulting in increased longevity. The estimated life expectancy of persons with Down syndrome has increased from an average of 12 years of age in the 1940s to 60 years of age in the present population of developed countries (Bittles, Bower, Hussain, and Glasson, 2006). Some individuals live into their 70s and, rarely, into their 80s (Alzheimer's Association, n.d.-a).

People with Down syndrome have an increased risk of developing AD, and this is believed to be related to chromosome 21, which carries a gene that produces one of the key proteins involved with changes in the brain caused by AD. It is believed that trisomy 21 may increase the production of beta-amyloid fragments in the brain, making AD a more acute concern for people with Down syndrome than other forms of intellectual disability (National Down Syndrome Society, n.d.)

People with Down syndrome develop AD at an earlier age than people without Down syndrome. By 40 years of age, most people with Down syndrome have significant levels of beta-amyloid plaques and tau tangles in their brain (Lott and Dierssen, 2010). Estimates show that AD affects about 30% of people with Down syndrome in their 50s and closer to 50% of people with Down syndrome in their 60s (National Down Syndrome Society, n.d.). AD is a common cause of death in people with Down syndrome, along with leukemia, respiratory illnesses, congenital circulatory defects, disease of the digestive system, and epilepsy (Day, Strauss, Shavelle, and Reynolds, 2005).

As with all adults, advancing age increases the likelihood that a person with Down syndrome will exhibit symptoms of AD. While all people with Down syndrome are at risk, many will not manifest changes of AD in their lifetime. This is why it is especially important to be careful and thoughtful about assigning an AD diagnosis without looking at all other possible causes for why changes are taking place with aging. The initial presentation of AD symptoms differs for individuals with Down syndrome. Most adults with Down syndrome will not self-report concerns about memory. Changes in overall function, personality and behavior may be more common early signs of AD rather than memory loss and forgetfulness. While the early AD symptoms may differ for Down syndrome individuals, AD is suspected when there is a series of changes seen in an individual, compared to their previous level of functioning (Alzheimer's Association, n.d.-a; National Down Syndrome Society, n.d.).

Diagnosing dementia in a person with Down syndrome can be difficult because of the challenges involved in assessing thinking-skill changes in those with intellectual disabilities. Formal screenings for memory concerns and diagnosis depends largely on an accurate history of the individual, detailing progressive changes in daily functioning and memory loss. This is why it is vitally important for a caregiver who knows the person well to be involved. It is worth the effort not to rush a diagnosis and ensure the assessments are thorough so that all other possibilities are given careful consideration.

Experts recommend the following principles as key to person-centered diagnosis in those with Down syndrome (Alzheimer's Association, n.d.-a). The first is to document baseline adult function by 35 years of age. By 35 years of age, each individual's medical record should ideally include detailed information on his or her adult abilities. The person with Down syndrome, family members, and other reliable individuals are helpful sources for this information. Second, watch for changes in day-to-day function. Reduced enthusiasm for daily activities, loss of interest in social interactions, and changes in personality and behavior are often early signs of an underlying decline in thinking skills. Third, consider professional assessment by a dementia expert. A variety of cognitive tests have been used to evaluate thinking changes in adults with Down syndrome. However, experts caution that cognitive tests should never be used as the only benchmark to diagnose dementia. Fourth, rule out other causes of symptoms that influence changes in thinking and function, including thyroid problems, depression, chronic ear and sinus infections, vision loss, and sleep apnea. After a dementia diagnosis is made, proactively building a support network of people will be important for the person with Down syndrome (National Down Syndrome Society, n.d.).

LIFETIME RISK OF ALZHEIMER’S DISEASE AND DEMENTIA

“Lifetime risk” is the probability that a person of a given age who does not have a particular disease or condition will develop the disease or condition at any time in his or her life. Lifetime risk calculations are useful because they can provide guidance as to whether biomarker screening would provide clinically useful prognostic information for clinicians, patients, and their families regarding the likelihood that a preclinical condition detected by biomarker screening will ever actually manifest itself with clinical symptoms during a person’s natural lifespan. If interventions could slow disease progression rates even modestly, lifetime risks of ADRDs could be appreciably reduced.

Based on data from the Framingham Heart Study, conservative national estimates of lifetime risk show that one in five women and one in ten men who live to be at least 45 years of age will develop AD in their remaining lifetime. Slightly higher proportions of women and men who reach 45 years of age will develop some type of dementia, including AD (Chene et al., 2015). These same trends continue for women and men who live to be at least 65 years of age, but with slightly higher risks for developing some type of dementia, including AD: one in four women and one in six men. The lifetime risk of dementia, including AD did not differ between women and men when starting the observation at midlife. The significantly higher cardiovascular mortality among men compared with women between 45 and 65 years of age may explain a selection of men at the lowest risk for dementia, including AD and account at least partly for the difference between genders, though this observation needs further replication. Many studies have also found notable gender differences exist in the prevalence of cardiovascular risk factors and incidence of cardiovascular deaths. The difference between cardiovascular risk factors and disease could partly explain why the risk of dementia and especially AD occurs more strongly for women than men at older ages. The cardiovascular link would benefit from additional research. Finally, extrapolation to other populations is cautioned. The study on which the lifetime risk factors are based, the Framingham Heart Study, used a relatively high threshold for including an individual as a person with dementia. People who had very early or mild dementia and individuals with moderate dementia of less than six months duration were not counted as having dementia. Also, the Framingham Heart Study was mainly composed of White/Caucasian American, non-Latino/a/x individuals. These findings need replication on other large databases with standardized ascertainment of dementia and AD in persons of other race/ethnicities, in different countries with genetic and cultural differences, and alternative profiles of cause-specific mortality (Chene et al., 2015).

Another study reported the estimates of the lifetime risk of AD based on age, gender, and biomarker tests for preclinical disease (Brookmeyer and Abdalla, 2018). The study found that lifetime risks for AD vary considerably by age, gender, and preclinical disease state. For example, the lifetime risks for a female with only asymptomatic amyloidosis are 8.4% for a 90-year old and 29.3% for a 65-year old. The lifetime risk increases if an individual’s preclinical state includes asymptomatic amyloidosis, neurodegeneration, and mild cognitive impairment. In this situation, persons younger than 85 years of age have a lifetime risk of at least 50% for developing AD.

As deaths from other causes are expected to decrease in the future, the average lifespan for the U.S. population will increase. As a result, people will be living longer, increasing their probability of developing ADRDs. True lifetime risk may be greater because the number of deaths due to heart disease, cancer, and stroke (the three leading causes of death) is decreasing while the number of deaths due to ADRDs is increasing (refer to the next section of this report, Mortality, for additional discussion of ADRDs and other leading causes of death).

LIFETIME RISK AND CALIFORNIA’S BABY BOOMER POPULATION

The baby boomers are people born between 1946 and 1964. In 2019, the oldest baby boomers, people born in 1946, were 73 years of age. The youngest baby boomers, people who were born in 1964, were 55 years of age.

The remaining lifetime risks of ADRDs apply to all the baby boomers who are already 65 years of age and older. The remaining lifetime risks of ADRDs also apply to baby boomers who are under 65 years of age, assuming that they live to be at least 65 years of age.

As of 2019, California's baby boomer population includes approximately 8.3 million people, of whom over 4.1 million are 55 to 62 years of age and approximately 4.3 million are 63 to 73 years of age (see **Appendix B**). Applying the national proportions from the Framingham Heart Study to California's population, it is estimated that 1.4 million Californian baby boomers can expect to develop AD in their remaining lifetime (Chene et al., 2015). Similarly, about 1.7 million can expect to develop dementia, including AD. The lifetime risk for developing AD for a California baby boomer who lives to be 65 years of age is one in six. The lifetime risk is one in five for developing dementia, including AD, for people who live to be 65 years of age (see **Appendix D** for county-specific rates).

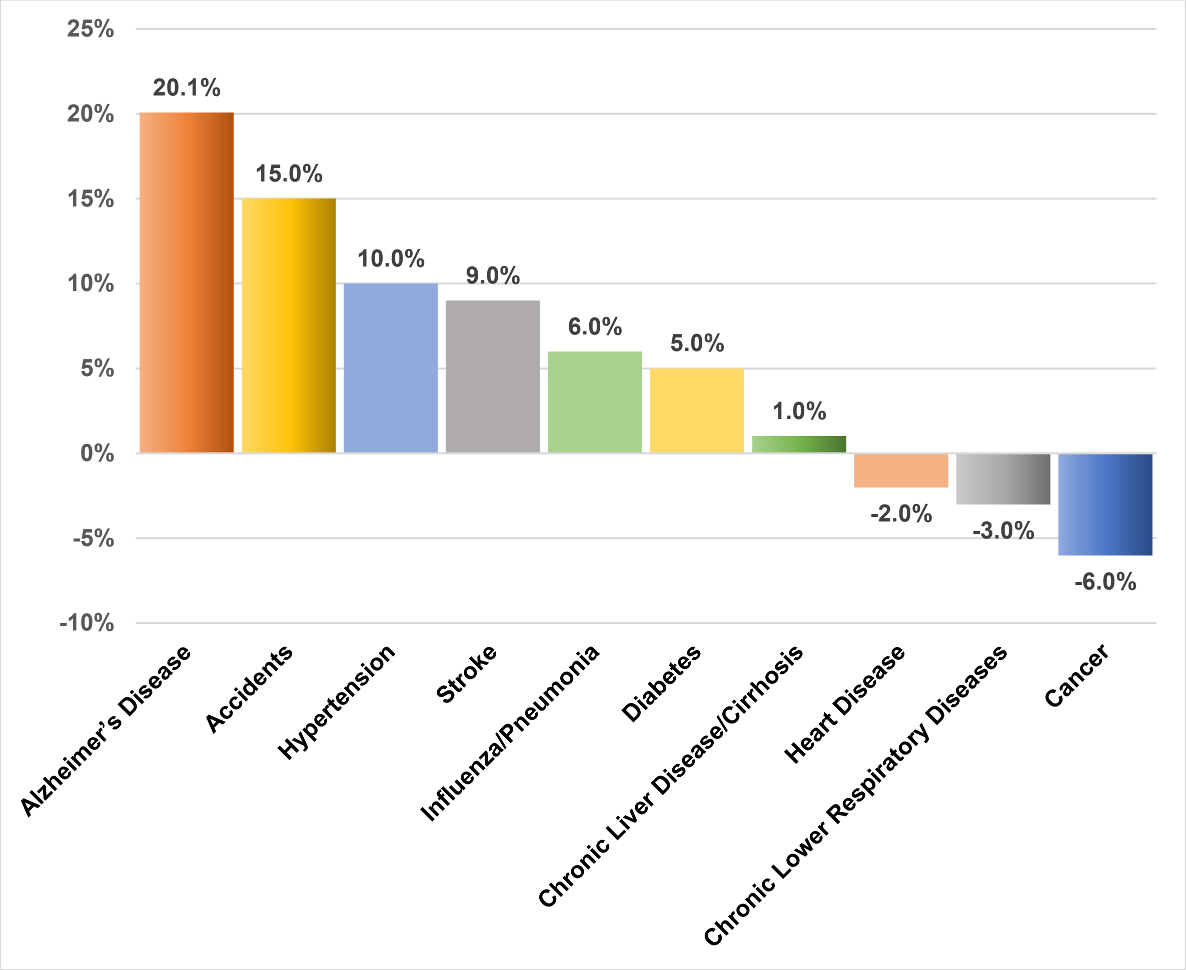
LIFETIME RISK AMONG CALIFORNIA'S ETHNIC AND CULTURALLY DIVERSE POPULATION

A study conducted by Kaiser Permanente Northern California members, observed rates of dementia and mortality to cast predictions of the lifetime risk of developing AD and dementia from all causes, among individuals who survived dementia-free to 65 years of age. They predicted that 36%–39% of Black/African Americans; 32%-36% of Native Americans; 31%–33% of Latino/a/x Americans; 15%--31% of Pacific Islanders; 29%–30% of White/Caucasian Americans, non-Latino/a/x; and 27%–29% of Asian Americans would be diagnosed with dementia over the next 25 years (Mayeda et al., 2016).

MORTALITY

As of 2018, AD was recognized as the third leading cause of death in California; up from number five in 2014. As shown in ***Figure 12*** and ***Table 2***, comparing AD to other leading causes of death in California between 2014 and 2018, AD showed the greatest increase in the number of deaths (20%, age-adjusted). While the other leading causes of death – hypertension, stroke, influenza/pneumonia, and diabetes – also show increases between 2014 and 2018, the increase is less precipitous compared to AD. Since 2000 the number of deaths attributable to AD has almost quadrupled, no other leading cause of death has experienced this type of increase. With an aging population and as people live longer, the deaths due to AD may continue to increase relative to other illnesses. Also, contributing to the increased number of reported AD deaths are more accurate protocols for its diagnosis (Alzheimer's Association, 2019).

FIGURE 12: PERCENTAGE CHANGE IN AGE-ADJUSTED RATES FOR THE LEADING CAUSES OF DEATH IN CALIFORNIA, 2014 TO 2018



Source: Centers for Disease Control and Prevention, National Center for Health Statistics, https://www.cdc.gov/nchs/pressroom/states/california/california.htm, last accessed June 17, 2020

TABLE 2: NUMBER OF DEATHS AND CHANGE IN LEADING CAUSE OF DEATH RANKING IN CALIFORNIA: 2014 TO 2018

Leading Cause of Death in California	2014		2018		Rank Change from 2014 to 2018
	# of Deaths	Rank	# of Deaths	Rank	
Heart Disease	58,189	2	62,547	1	⬆
Cancer	58,412	1	59,962	2	⬇
Alzheimer’s Disease	12,644	5	16,627	3	⬆
Stroke	13,731	3	16,457	4	⬇
Accidents	11,804	6	14,153	5	⬆
Chronic Lower Respiratory Diseases	12,780	4	13,634	6	⬇
Diabetes	8,249	7	9,506	7	⟷
Influenza/Pneumonia	5,970	8	6,917	8	⟷
Hypertension	4,573	10	5,511	9	⬆
Chronic Liver Disease/Cirrhosis	5,013	9	5,390	10	⬇

Source: Centers for Disease Control and Prevention, National Center for Health Statistics, https://www.cdc.gov/nchs/pressroom/states/california/california.htm, last accessed June 17, 2020

Even though deaths attributed to AD have increased over time, this number probably underestimates the disease’s public health impact because of the procedures for recording causes of death. The Centers for Disease Control and Prevention considers a person to have died from AD if the death certificate lists AD as the underlying cause of death, defined as “the disease or injury which initiated the train of events leading directly to death.” However, people with ADRDs often have other coexisting medical conditions, such as a heart disease or cancer. Additionally, severe ADRDs frequently causes physical complications that increase the risk of serious acute medical conditions that can cause death, such as immobility, swallowing disorders, and malnutrition. One autopsy study found that respiratory system diseases were the immediate cause of death in more than half of people with AD, followed by circulatory system disease in about a quarter (Alzheimer's Association, 2019a). Consequently, a “blurred distinction” (Ganguli and Rodriguez, 1999) exists between death *with* dementia and death *from* dementia. In cases where the medical record fails to reflect an dementia diagnosis, it is also possible that the certifying physician did not even know the individual had the disease.

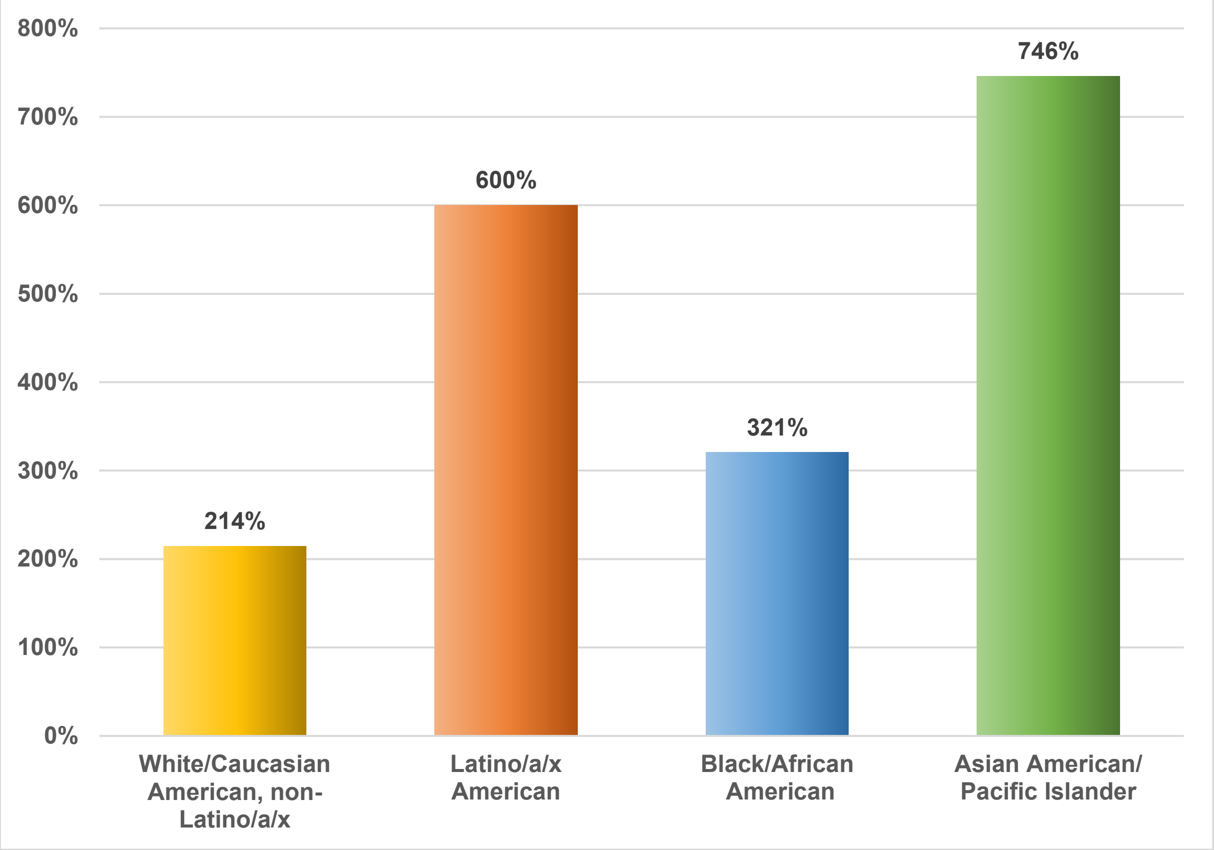
A 2017 national review of mortality attributable to various diagnosed dementias that included unspecified dementia, AD, vascular dementia, and other degenerative disease of nervous system not elsewhere classified, showed that deaths attributed to AD were highest (46%) (Kramarow and Tajada-Vera, 2019). Irrespective of the cause of death, for individuals with onset of AD by 70 years of age, 61% of are expected to die before 80 years of age compared with 30% of people 70 years of age without AD. Of the AD survivors, nearly 70% will be in a nursing home (Arrighi, Neumann, Lieberburg, and Townsend, 2010).

ALZHEIMER’S DISEASE MORTALITY AMONG CALIFORNIA’S ETHNIC AND CULTURALLY DIVERSE POPULATION

Given California’s aging population and the projected increase in the number of people living with AD who identify as Black/African American, Latino/a/x American, and Asian American/Pacific Islander over the next 21 years, deaths due to AD within these groups will increase. As displayed in ***Figure 13***, between 2000 and 2018, the population of people who identified as Asian American/Pacific Islanders showed the greatest increase in the number of reported deaths due to AD, by almost ten-fold.

FIGURE 13: PERCENT CHANGE IN ALZHEIMER'S DISEASE CRUDE DEATH RATES BY RACE/ETHNICITY, 2000 TO 2018

(Crude death rates[9])



Source: Centers for Disease Control and Prevention (CDC), National Center for Health Statistics: CDC WONDER Online Database. (2020). Underlying Cause of Death data 1999-2018. Retrieved from https://wonder.cdc.gov/wonder/help/ucd.html.
Note: Rates are per 100,000 population. ICD-10 codes G30 were used. White/Caucasian American, non-Latino/a/x, African American, Asian American/Pacific Islander, and Native American exclude Latino/a/x American ethnicity. Latino/a/x American includes any race category, accounting for higher than 100% totals for percentage of AD deaths in Appendix E Table E2.

In 2018, California's AD mortality rate was 42 deaths per 100,000 people, higher than the U.S. rate of 37.3 deaths (Alzheimer's Association, 2019a). The population of people who identified as White/Caucasian American, non-Latino/a/x had the highest reliable death rate (48.4), followed by the population of people who identified as

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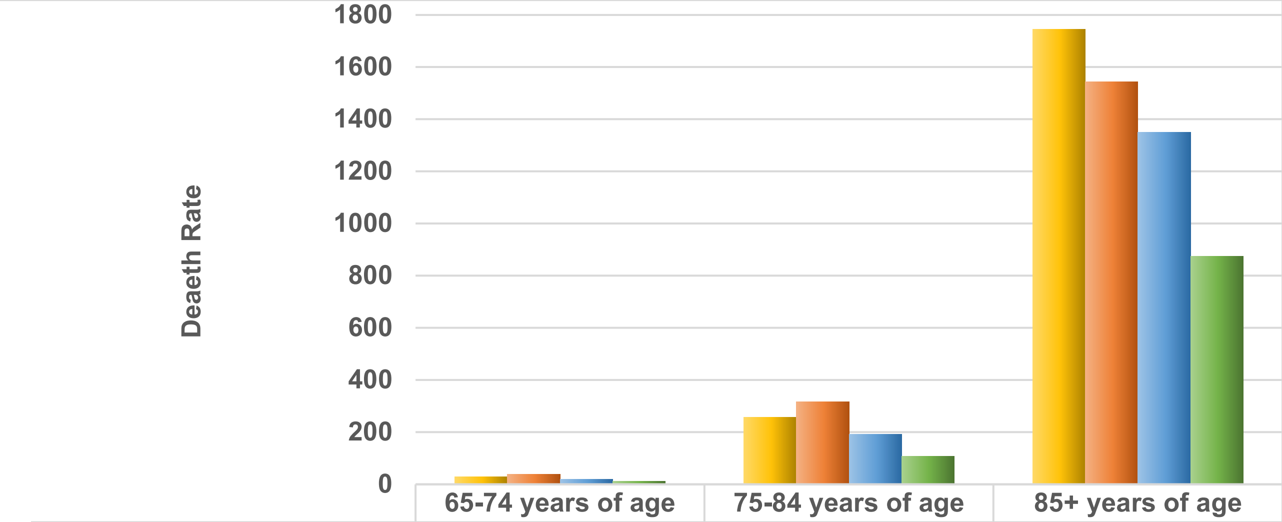
[9] The **crude death rate** is the number of **deaths** occurring among the population of a given geographical area during a given year, per 1,000 mid-year total population of the given geographical area during the same year.

Black/African American (32.8), Asian American/Pacific Islander (22), and Latino/a/x American (16.8).

In 2018, the population of people who identified as Black/African American had the highest death rate in the 65 to 74 and 75 to 84 years of age groups, while the population of people who identified as White/Caucasian American, non-Latino/a/x had the highest death rate in the 85 years of age and older age groups (see ***Figure 14***). The population of people who identified as Asian American/Pacific Islander had the lowest death rate in all the age groups. The generally low death rate among the population of people who identify as Asian American/Pacific Islander may be due to under-reporting of AD on death certificates due to its either being diagnosed later in the course of the disease, not reporting dementia symptoms to medical professionals unless needing assistance with behavioral issues, or health providers under-reporting (Alzheimer's Association, 2019; Ayalon and Aréan, 2004; Yoo, Musselman, Lee et al., 2015).

FIGURE 14: ALZHEIMER'S DISEASE CRUDE DEATH RATES BY RACE/ ETHNICITY AND AGE GROUP, 2018

(Death Rates Per 100,000 Population)



	65-74 years of age	75-84 years of age	85+ years of age
🟨 White/Caucasian American, non-Latino/a/x	29.9	257.9	1746
🟧 Black/African American	38.2	316.3	1544.6
🟦 Latino/a/x American	20.4	191.7	1350.2
🟩 Asian American/ Pacific Islander	11.2	107.2	874.2

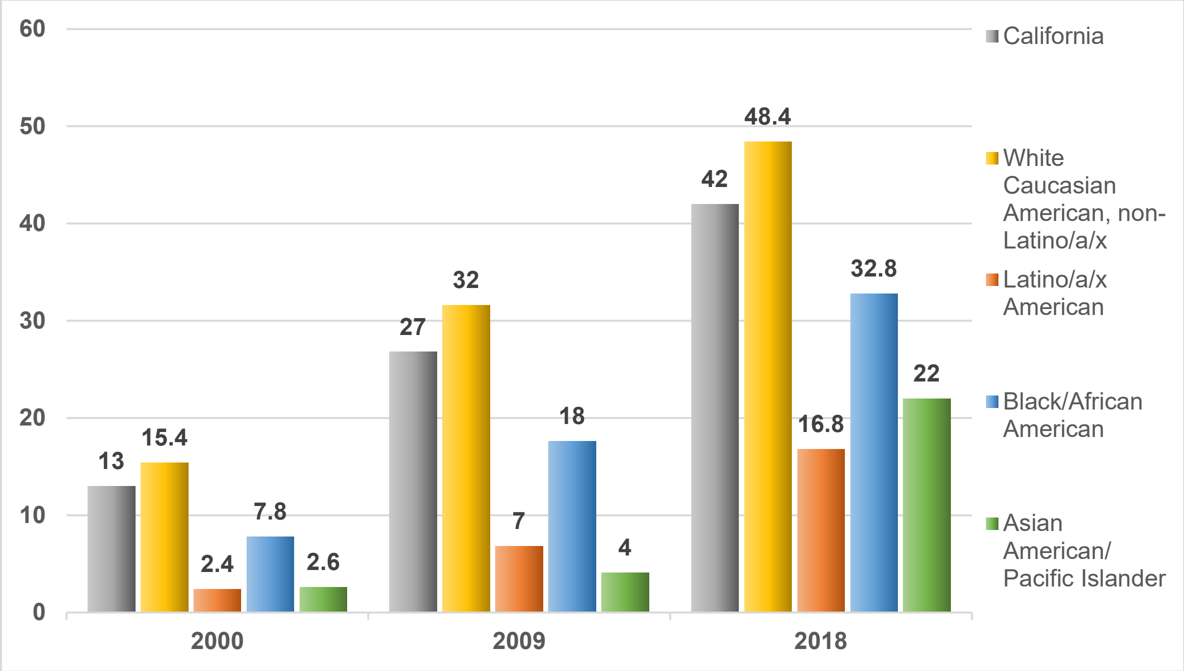
Source: Centers for Disease Control and Prevention (CDC), National Center for Health Statistics: CDC WONDER Online Database. (2020). Underlying Cause of Death data 1999-2018. Retrieved from https://wonder.cdc.gov/wonder/help/ucd.html.

Note: Rates are per 100,000 population. ICD-10 codes G30 were used. White/Caucasian American, non-Latino/a/x, Black/African American, Asian American/Pacific Islander, and Native American exclude Latino/a/x American ethnicity. Latino/a/x American includes any race category, accounting for higher than 100% totals for percentage of Alzheimer's Disease deaths in Appendix E Table E2.

AD death rates for California residents over the past eighteen years have increased from 13 deaths per 100,000 in 2000 to 42 deaths in 2018, an increase of 223% (see ***Figure 15***). All population groups showed increases in rates over this time period. However, the Asian American/Pacific Islander population had the largest increase in death rates (746%), followed by the Latino/a/x American population (600%), the Black/African American population (321%), and the White/Caucasian American, non-Latino/a/x population (214%). The reasons for increased death rates due to AD might be due to fewer people dying from other illness, such as heart disease and the fact that individuals are living longer, as increased age is the most significant risk factor for developing the disease. Improvements in culturally appropriate dementia evaluations, resulting in improved diagnostic accuracy, may have also contributed to the larger increase in death rates among communities of color.

FIGURE 15: ALZHEIMER'S DISEASE DEATH RATES BY RACE/ETHNICITY: 2000, 2009, 2018

(Age-Adjusted Death Rates per 100,000 population)



Source: Centers for Disease Control and Prevention (CDC), National Center for Health Statistics. Underlying Cause of Death 1999-2018 on CDC WONDER Online Database, released in 2020 Note: Rates are per 100,000 population. ICD-10 codes G30 were used. White/Caucasian, non-Latino/a/x, African American, Asian American/Pacific Islander, and Native American exclude Latino/a/x American ethnicity. Latino/a/x American includes any race category, accounting for higher than 100% totals for percentage of Alzheimer's Disease deaths in Appendix E Table E2.

ALZHEIMER'S DISEASE MORTALITY IN CALIFORNIA COUNTIES

As displayed in ***Table 3***, Los Angeles, Orange, and San Diego have the highest number of deaths due to AD. Complete county information for AD from 2015 to 2017 can be found in **Appendix E**. The county AD death rates were calculated using the mid-year population, 2016 as the denominator and are presented as rates per 100,000 population.

TABLE 3: CALIFORNIA COUNTIES WITH THE GREATEST THREE-YEAR AVERAGE NUMBER OF ALZHEIMER'S DISEASE DEATHS, 2015 - 2017

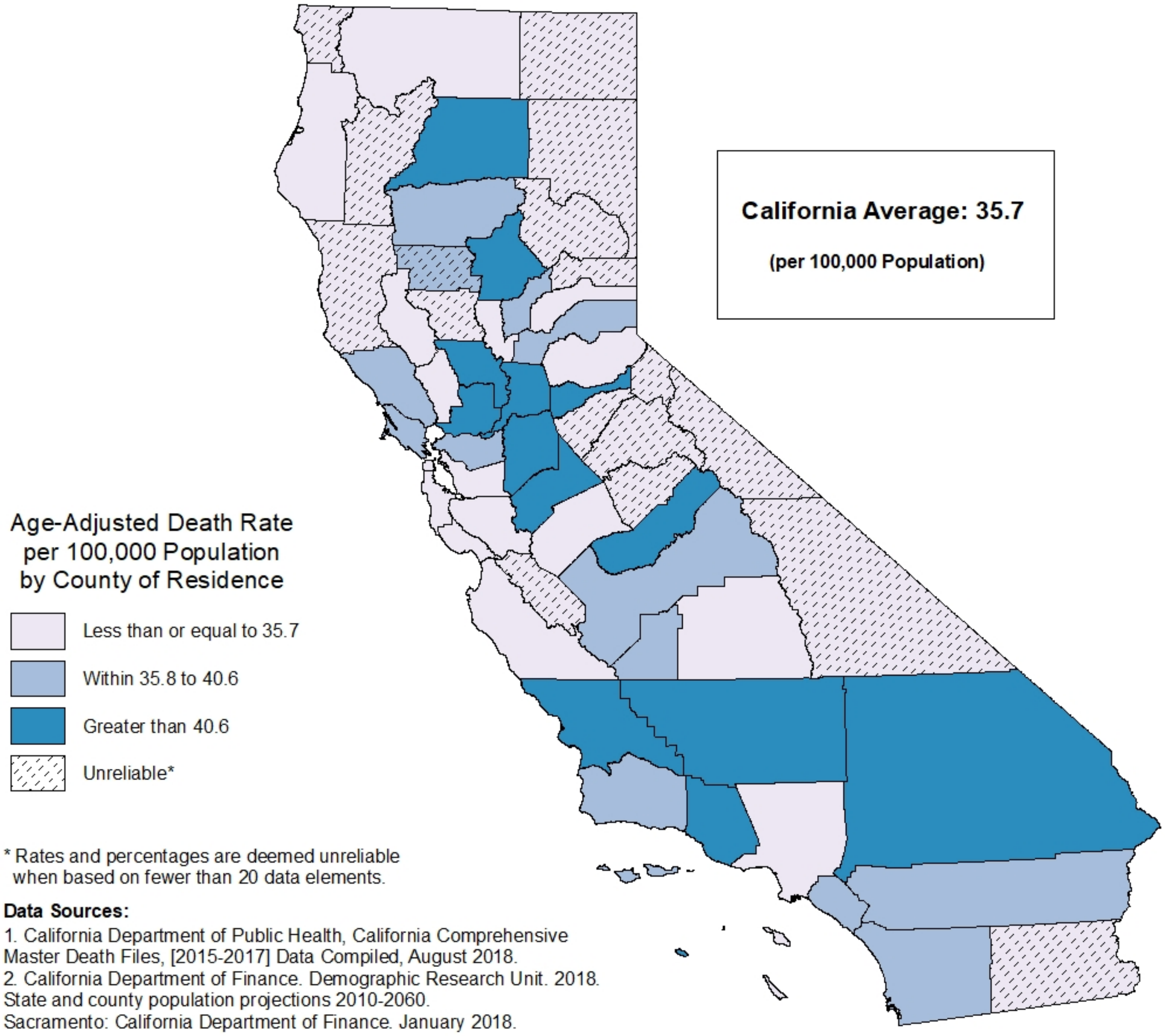
County of Residence	2015-2017 Alzheimer's Deaths (Average)	Percent of Total 2016 CA Population	2016 Population	Age Adjusted Death Rate per 100,000 Population
CALIFORNIA	**15,603**	**-**	**39,312,207**	**35.7**
Kern	349	2.2	887,922	53.4
San Joaquin	345	2.2	738,343	51.6
San Bernardino	716	4.6	2,143,578	43.3
Ventura	419	2.7	853,673	42.6
Sacramento	656	4.2	1,503,536	42.1
Orange	1,432	9.2	3,179,122	38.6
Contra Costa	519	3.3	1,129,332	38.3
Fresno	351	2.2	988,072	38.1
San Diego	1,425	9.1	3,295,816	38
Riverside	1,003	6.4	2,359,588	37.8
Los Angeles	3,994	25.6	10,215,103	35.6
Alameda	587	3.8	1,637,176	33.8
San Francisco	342	2.2	872,463	26.4

Source: County Health Status Profiles 2019, California Department of Public Health Center for Health Statistics

The reasons for this difference are unclear and there are likely to be many reasons that contribute to the variability in AD death rates between counties in California. One influence is the large numbers of older adults. Another reason might be the differences in the racial/ethnic composition of the counties. The diversity between counties of different risk factors associated with AD, such as level of education, health status, and access to health care, may also contribute to the variability in death rates. As noted earlier, variability among counties in reporting AD as a cause of death may also be a factor.

Five of the counties listed in ***Table 3*** are considered to be in the top twenty for racial/ethnic diversity, based on U.S. census data (Alameda – 1st, Sacramento – 8th, San Joaquin – 14th, Orange – 16th, Contra Costa – 19th) (Niche, 2019). ***Figure 16*** shows a thematic map of the AD death rates for all California counties. **Appendix E** lists the death rates by county.

FIGURE 16: AVERAGE ALZHEIMER'S DISEASE DEATH RATES FOR ALL CALIFORNIA COUNTIES: 2015-2017



* Rates and percentages are deemed unreliable when based on fewer than 20 data elements.

Data Sources:
1. California Department of Public Health, California Comprehensive Master Death Files, [2015-2017] Data Compiled, August 2018.
2. California Department of Finance. Demographic Research Unit. 2018. State and county population projections 2010-2060.
Sacramento: California Department of Finance. January 2018.

SECTION II – LIVING ARRANGEMENTS FOR PEOPLE LIVING WITH ALZHEIMER’S DISEASE

California’s older adult population live in a variety of settings that affect their quality of life, health, and well-being. While many people prefer to age in place in their own home and community, changes in their cognitive and physical capacities may require them to need more care, assistance, or supportive services over time. The typical course of AD is progressive over a seven to ten-year duration that results in increasing dependency and then death. From 70 to 80 years of age, a typical individual with AD spends approximately three years in the mild stage of the disease, three years in the moderate stage and four years in the severe stage. At 80 years of age, 75% of surviving individuals with AD (but only 4% of the general population) are expected to be in a nursing home. By 74 and 76 years of age, approximately 29% and 48% of AD patients, respectively, are nursing home residents (Arrighi et al., 2010). During the earlier stages of the illness, a majority of individuals with AD will be in living arrangements other than a nursing home. Also, for individuals with an onset of AD at 70 years of age who survive for ten years, approximately four of the ten years will be spent in a nursing home (Arrighi et al., 2010).

Several social and family structural trends affect our understanding of the unique living arrangement needs of older adults and individuals living with AD. These trends will influence policy on how best to provide the appropriate level of support and living situation for individuals with dementia.

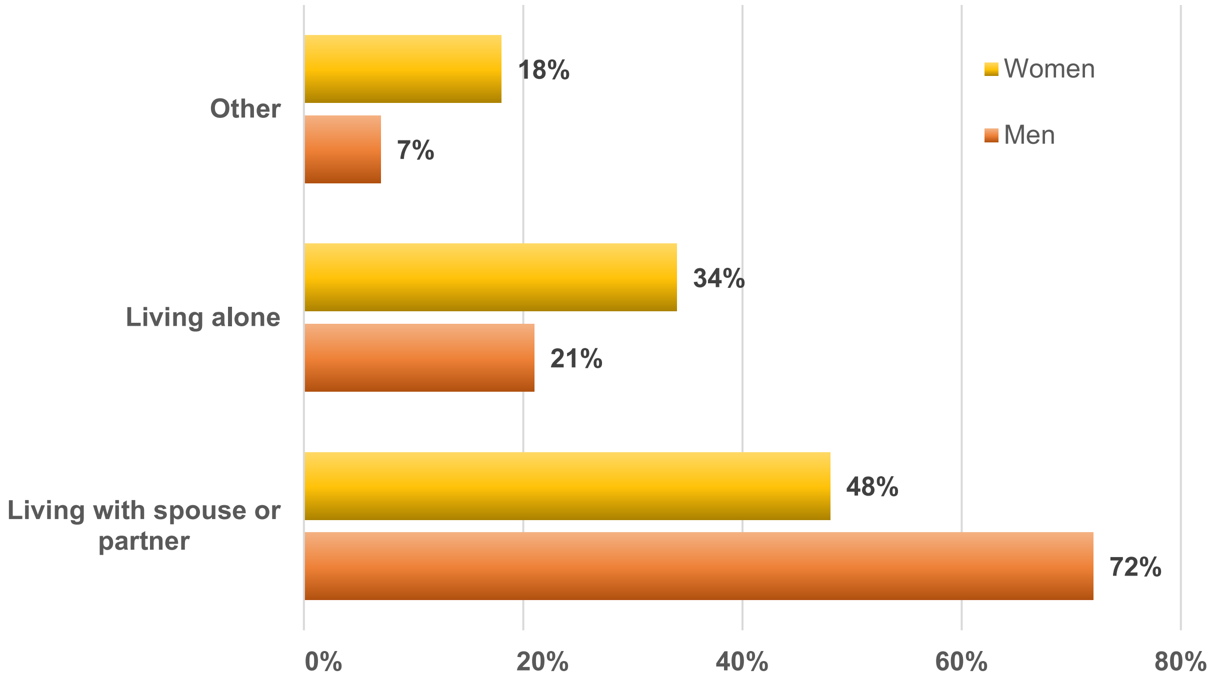
Changes to Family Structure

Within California it is anticipated that there will be significant changes to the family structure with the fastest projected rates of growth among the divorced, separated, or never married groups. A 2015 Public Policy Institute report estimated that between 2012 and 2030 the number of individuals who are divorced or separated will increase by 115%, whereas the number who are never married will increase by 210%. The number of married people 65 years of age and older will increase only by 75% (Beck and Johnson, 2015).

The changes in family structure will also impact the number of children who might provide care to parents. Those who have never been married are less likely to have children than those who have been married at some point. The 2015 Public Policy Institute report estimated that by 2030, 20% of 75-year-old women will be childless, compared to just 12% in 2012 (Beck and Johnson, 2015). Furthermore, baby boomers had much lower birth rates than their parents and are more likely to have never had children (Colby and Ortman, 2015; Colby and Ortman, 2014). Older individuals without children will be more likely to live alone.

More women over 65 years of age tend to live alone compared to men (Administration on Community Living, 2018; Reher and Requena, 2018). National 2018 census data for individuals 65 years of age and older showed that approximately 34% of women and 21% of men lived alone (see ***Figure 17***). Furthermore, with advancing age the proportion of individuals living alone increases with 44% of women 75 years of age and older living alone.

FIGURE 17: LIVING ARRANGEMENTS OF PERSONS AGE 65 AND OVER, UNITED STATES, 2018



Source: Administration on Community Living,

<u>Homelessness</u>

Homelessness is another issue that will have significant policy implications for caring for both an aging population and individuals living with ADRDs. Nationally, adults 50 years of age and older are among the fastest growing population of homeless people (Brown et al., 2016; Henry et al., 2018; U.S. Interagency Council on Homelessness, n.d.). California has the highest rates of people experiencing sheltered or unsheltered homelessness in the country. Baby boomers, who have experienced chronic homelessness throughout their lives or become homeless for the first time in their lives, drive the increase in an aging homeless population (Brown et al., 2016). The 2008 recession significantly impacted baby boomers who may have been financially stable but then lost wealth from investments or lost their homes, which increased the risk of homelessness for this population. California's housing crisis and high cost of living, along with stagnant wages, pensions declining, and healthcare costs increasing, make it difficult for people to save money for retirement. This leaves people with little money left for emergencies, resulting in older adults who are at a greater risk of homelessness than any time in recent history (Goldberg, Lang, and Varrington, 2016).

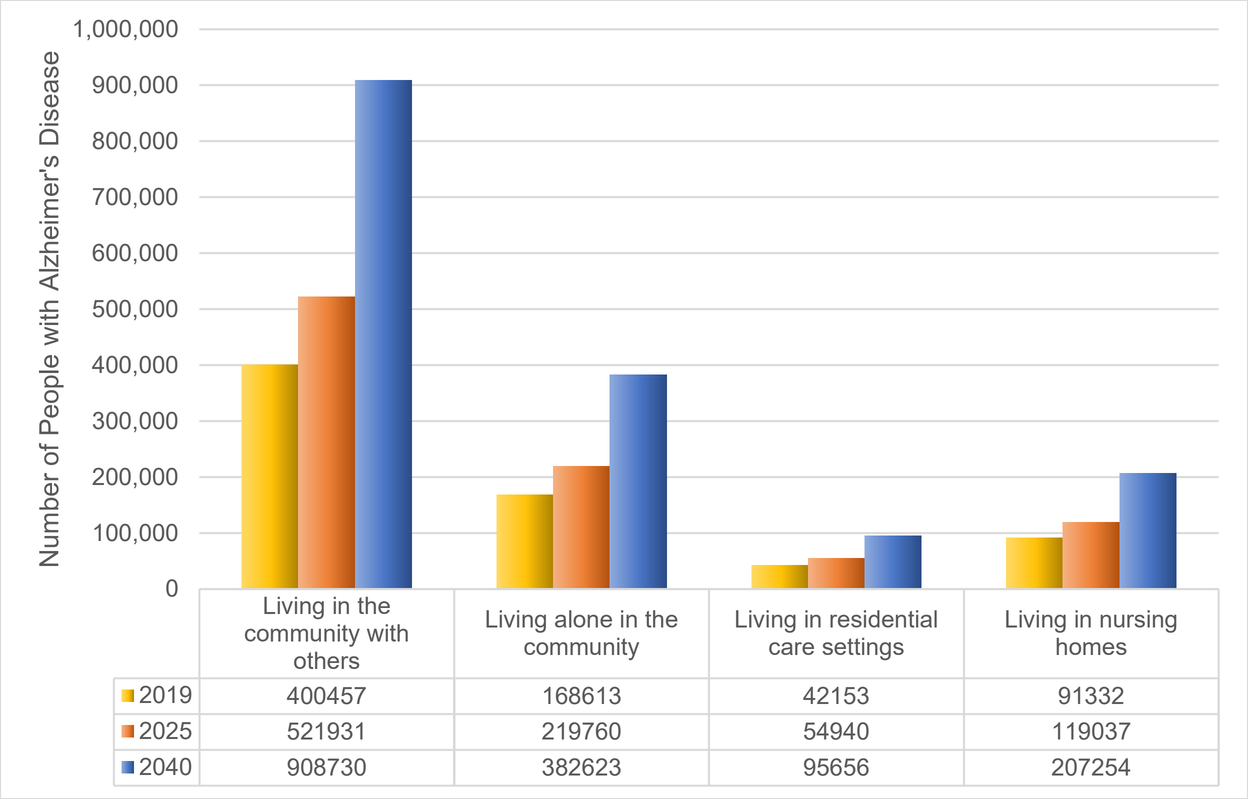
In San Francisco between 1990-2003, the proportion of people 50 years of age and older who were homeless increased from 11% to 32% (Hahn, Kushel, Bangsberg, Riley, and Moss, 2006). This increase in the proportion of aging homeless population exceeded the aging rate in the general population. The trend implies that the homeless population is not a stable cohort. Rather, it suggests that homelessness becomes more chronic over time, with age.

When compared to members of California's general population, homeless adults 50 years of age and older have significantly higher rates of geriatric concerns including difficulty performing activities of daily living (ADLs), mobility and cognitive impairment, frailty, and depression compared to the general population (Brown, Kiely, Bharel, and Mitchell, 2012). In a sample of 350 homeless adults 50 years of age and older, residing in Oakland, CA, it was found that 25.8% had cognitive impairments (Brown et al., 2017). For health care providers who serve an aging homeless population addressing ADRDs will become more prominent.

COMMUNITY LIVING ARRANGEMENTS

According to 2017 estimates, 81% of people living with AD reside in the community, which can include living in their own home with caregivers (57%) or alone (24%). The remaining 19% of individuals living with AD reside in a residential care setting (6%) such as an assisted living facility; or in a nursing home (13%) (Lapore, Farrell, and Wiener, 2017). Based on these estimates, ***Figure 18*** approximates the number of Californians living with AD in these various community settings. In each setting it is estimated that the number of individuals living with AD will more than double between 2019 and 2040.

FIGURE 18: ESTIMATED DISTRIBUTION OF LIVING ARRANGEMENTS FOR PEOPLE WITH ALZHEIMER'S DEMENTIA IN CALIFORNIA: 2019, 2025, 2040



	Living in the community with others	Living alone in the community	Living in residential care settings	Living in nursing homes
2019	400457	168613	42153	91332
2025	521931	219760	54940	119037
2040	908730	382623	95656	207254

Source: Lepore, M., Ferrell, A., and Wiener, J. M. (2017). Living Arrangements of People with Alzheimer's Disease and Related Dementias: Implications for Services and Supports, 1–23.

Home-Based Living

Home-based living arrangements for people living with AD include single-family homes, apartments, and other private residences. Most people who live at home reside with others, typically a spouse or other family members. The majority of care provided to people living with AD comes from family members, friends, or other unpaid caregivers. However, the current trends toward smaller families, in part due to higher divorce rates and more geographic dispersion of families, means that the availability of family caregivers is expected to decline, while the number of people living with AD is increasing (Lapore et al., 2017; Roth, Fredman, and Haley, 2015). Although federal and state policy promotes home and community-based services over institutional care, almost no data are available about the quality of these services, especially as they are provided to people living with AD and their caregivers (National Quality Forum, 2016).

In general, people with dementia need more support from caregivers. Studies have shown that it is not unusual for people living with dementia in home-based living arrangements to have many unmet care and service needs to help them cope with cognitive impairment, including environmental and safety challenges such as being at high fall risk or wandering, and having unmanaged behavioral and health symptoms such as sleep disturbances and pain (Black, Johnston, Reuland, Lyketsos, and Samus, 2018; Gitlin, Hodgson, Verrier Piersol, Hess, and Hauck, 2014). These unmet needs might contribute to individuals with dementia living in the community having higher hospitalizations and emergency department use than others in the community without dementia, when controlling for other medical conditions (Daras, Feng, Wiener, and Kaganova, 2017; Feng, Coots, Kaganova, and Wiener, 2014).

Another area of focus in caring for individuals in the community with dementia, is the growing number of individuals with dementia who live alone. These individuals present with additional challenges since the decline in cognition and their ability to care for themselves may go unnoticed until a crisis or emergency occurs. People living alone who have dementia are at high risk of self-neglect, which is when a vulnerable adult is unable to practice basic self-care, including but not limited to provision of food, clothing, or shelter, and management of health care needs; physical and mental health maintenance, emotional well-being, and general safety; or management of financial affairs. Although people who live alone with dementia tend to report fewer unmet care needs and underuse long-term services and supports, this is often related to the severity of their dementia and lack of knowledge of existing services (Gould et al., 2015).

Congregate Community-Based Living

Some people living with dementia reside in congregate community-based living arrangements, such as various residential care facilities for the elderly (RCFE)[10] and continuum of care facilities that are licensed and certified by a state. Some RCFEs have special care units for people living with dementia, with architecture designed to address their needs and staff trained in dementia care (Khatutsky et al., 2016). Nationally, only a small percentage, 7% of RCFEs exclusively serve people living with a dementia, however, it has been estimated, that the proportion of RCFE residents living with a dementia to be about 40% (Harris-Kojetin et al., 2016; Khatutsky et al., 2016; Zimmerman et al., 2013; Zimmerman, Sloan, and Reed, 2014).

While the majority of California's residential facilities and beds are licensed to serve older adult clients, little is known about the quality of care that is provided in RCFEs to people living with dementia, though facilities are regulated at the state level (Harrington, Wiener, Ross, and Musumeci, 2017; Ross, Harrington, and Newsom, 2013). In California, as of January 2019 all RCFEs are inspected annually. While

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[10] RCFEs are housing arrangements for persons, 60 years of age and over, where 24-hour non-medical care and supervision is provided. RCFEs are often referred to as assisted living facilities, or board and care homes. (Adult and Senior Care Program. (n.d.). California Department of Social Services. Retrieved January 28, 2021, from https://cdss.ca.gov/inforesources/community-care/ascp-centralized-application-units)

California requires an agency review of facilities that will provide dementia care, licensing requirements do not mandate staffing levels or ratios in facilities providing dementia care. Staffing level is frequently correlated with quality of care.

NURSING HOMES. Both cognitive and functional impairment are common among nursing home residents. In 2014, 40.7% of nursing home residents in California had mild or no cognitive impairment, 23% had moderate cognitive impairment, and 36.3% had severe cognitive impairment (Centers for Medicare and Medicaid Services, 2015).

On many nursing home quality measures, people with severe cognitive impairment do worse than people with mild or moderate cognitive impairment, such as having pressure ulcers, the use of restraints, episodes of incontinence, the use of feeding tubes, unintended weight loss, and were more likely to be prescribed antipsychotics (Centers for Medicare and Medicaid Services, 2015). While the rates of hospitalization and emergency department use among nursing home residents are high, they do not appear to differ substantially for people living with AD (Feng et al., 2014).

OTHER LIVING ARRANGEMENTS

Veteran-centered living arrangements

The California Department of Veterans Affairs (CalVet) offers long-term care to California veterans and, under certain circumstances, to the spouses and domestic partners of veterans. CalVet's mission is to provide veterans long-term residential care in the Veteran Home Care (VHC) Program with rehabilitative, residential, medical, and support services in a home-like environment. Some of the VHCs also offer specialized memory care programs. These services are located at eight Veterans Homes throughout the state in Redding, Yountville, Barstow, Fresno, Lancaster, Ventura, West

Los Angeles, and Chula Vista. The capacity for the VHCs skilled nursing facilities is 1,027 beds and the capacity for the RCFEs is 634.

As of 2017, California's veteran population over the age of 65 was 849,750, representing approximately 51% of the veteran population in California (Department of Veteran Affairs, 2017). A conservative estimate of the number of veterans in 2017 living with ADRDs was estimated to be 74,778. This probably underestimates the number of veterans living with ADRDs, given the unique and added risk factors for the disease such as traumatic brain injury, posttraumatic stress disorder, and/or other service-related injuries.

Prisons

Older adults are the fastest growing group in the prison population. In California, between 2000 and 2017, the share of prisoners 50 years of age and older more than quintupled, from 4% to 23% (Harris, Goss, Hayes, and Gumbs, 2019). Improved medical care, long sentences from tougher crime laws, and a steady increase of older adults entering prison has contributed to the extraordinary rise of aging inmates. According to the California Department of Corrections and Rehabilitation, in 2018, there were over 19,300 inmates older than 55 years of age (Bernstein, 2018).

Older adults aging in the prison system may be more likely to develop ADRDs given poor health and lifestyle choices prior to and during a prison sentence, along with mental health issues and prevalence of traumatic brain injury (Brooke, Diaz-Gil, and Jackson, 2018; Maschi, Kwak, Ko, and Morrissey, 2012). A conservative estimate of the number of California prisoners over 55 years of age in 2018 living with ADRDs was estimated to be 1,698. This probably underestimates the number of prisoners due to a higher prevalence of severe health and mental health issues. Also, the National

Commission on Correctional Health Care defines the care of an “older adult” as beginning at 50 years of age as opposed to the traditional retirement age of 65 because the average prisoner is often described as experiencing premature aging in disease, disability, and overall health. Their health condition may also approximate the health condition of nonincarcerated people who are 10 to 15 years older (Reimer, 2008). Concerns of this growing population has led authorities to take the first steps toward creating a dementia unit at the state’s main prison medical facility in the San Joaquin Valley City of Stockton (Bernstein, 2018).

SECTION III – CAREGIVING FOR PEOPLE WITH ALZHEIMER'S DISEASE

CAREGIVERS

WHO ARE THE CAREGIVERS?

A dementia caregiver is anyone who aids someone else who is, in some degree, unable to care for themselves and needs help due to having a dementia. Caregiving often includes assistance with ADLs, such as bathing or dressing, as well as instrumental activities of daily living (IADLs), such as paying bills, shopping, or using transportation. Caregivers also provide emotional support to people with dementia, as well as other forms of help, such as communicating and coordinating care with other family members and health care providers. Compared with other caregivers, dementia caregivers provide more help with daily activities and experience more disruption of social activities, interrupted sleep, and depressed and hopeless feelings (Moon and Dilworth-Anderson, 2014). More than 16 million Americans provide an estimated 18.6 billion hours of unpaid care for people with AD or other dementias (Alzheimer's Association, 2020).

There are several sources of caregiving – paid, paid "hidden," unpaid, and volunteers. "Paid caregiver" is a term that refers to professional caregivers, such as a provider associated with a healthcare or social system. Direct care workers, nursing assistants, home health aides, personal care aides, domestic workers, and personal attendants provide most of the paid long-term care to older adults living at home or in residential settings (Khatutsky, Wiener, Anderson, Akhmerova, and Jessup, 2011; Stone, 2012). Nursing assistants make up the majority of staff who work with cognitively impaired residents in nursing homes and help with bathing, dressing, housekeeping, food preparation and other activities. Most nursing assistants are women who come from diverse ethnic, racial, and geographic backgrounds (Alzheimer's Association, 2019a). Turnover rates are high among paid caregivers, and recruitment and retention are persistent challenges (Institute of Medicine, 2008). The challenging work environments contribute to higher turnover rates among nursing staff across care environments (Stone, 2015).

Live-in caregivers constitute a distinctive sector of the in-home paid care workforce. Their work schedules typically involve multiple consecutive days at clients' homes providing round the clock care, returning home only after having completed their extended shifts. In some cases, caregivers may live-in fulltime. In all cases, private homes constitute the caregivers' primary workplace, and the wide range of support services they provide mirror those available in nursing homes and board and care facilities (Poo, 2015). Live-in caregivers may be employed through home care agencies, caregiver referral websites, or hired directly by clients or family members. Many of these workers are immigrant and racial/ethnic minority women, often Filipino women (Guevarra and Lledo, 2013; Parrenas, 2015).

In California, the Home Care Services Protection Act, which took effect in January 2016, requires all in-home caregivers to pass a state and federal background check (California Department of Social Services, n.d.-a). A state-run registry website (https://www.ccld.dss.ca.gov/hcsregistry/about.aspx) is available for the public to check whether a caregiver meets the screening requirements. Anyone affiliated with a home care agency must be registered. Registration is optional for independent operators.

Caregivers who are hired directly by clients or family members constitute paid "hidden" caregivers. These are individuals who are paid for caregiving services but are not affiliated with a health agency.

“Unpaid caregiver” is a term that refers to unpaid individuals who provide care, such as family members, friends, or neighbors. Notably, the definition of a family caregiver includes family members of choice, not just the families that people are born into. People with ADRDs are commonly cared for by family members or friends. For example, a spouse who must help their spouse to dress and bathe; a partner who takes over bill paying and other chores that their significant other can no longer complete; a daughter who brings one of her parents to live in her home because the parent is no longer safe living alone. The ranks of unpaid caregivers are projected to grow due to population aging, increasing longevity, the growing number of people with chronic conditions associated with an aging population, such as ADRDs, and the increasing cost of long-term services and supports (LTSS) (Meyer et al., 2018; National Academies of Sciences Engineering and Medicine, 2016).

Also, emerging are volunteer programs that help older adults remain in their homes in the community, such as the services provided by the Council on Aging in Southern California (www.coasc.org) or Lavender Seniors located in northern California East Bay (https://lavenderseniors.org/). While the volunteer programs may not provide assistance with bathing or dressing, they assist individuals who have caregiving needs and cognitive impairments to access important supportive services, provide companionship, and may provide case management.

In the discussion of caregivers and caregiving, it is important to be cognizant that some caregivers might be disadvantaged when it comes to seeking relevant information, education and training. Caregivers who identify as coming from racial/ethnic, cultural minority groups, people with limited English proficiency, and caregivers who identify as being LGBTQ do not access information services to the same extent as other caregivers. For instance, a study about caregivers in California by Scharlach et al. (2006) found that participants who identified as Native American, Filipino, and Russian did not know about available existing services to caregivers; whereas participants who identified as Latino/a/x American did, but not how to access them. Lack of awareness among some groups may indicate poor targeted outreach by providers. In some cases, caregivers from racial/ethnic minority groups may be reluctant to approach services, due to lack of trust in government services, culturally or linguistically appropriate services, or the belief that the information would not be useful (Browne, 2014; Scharlach et al., 2006).

For instance, people who identify as Asian American/Pacific Islander are more likely to assume caregiving roles to an older adult compared to the general population.[11] Additionally, people who identify as Asian American/Pacific Islander are more likely to live in multigenerational households, compared to the general population. With strong cultural values placed on family, deference to older generations, and larger households, Asian American/Pacific Islander caregiving often involves multiple family members playing a role and taking part in decision-making, rather than a single person who is the primary caregiver or decision-maker. Even with multiple caregivers, families that identify as Asian American/Pacific Islander may underestimate the physical and emotional toll of daily caregiving. Culturally and linguistically appropriate guidance and support to find professional resources, like adult day services and respite, may help

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[11] It is important to note the cultural nuances in each Asian American/Pacific Islander ethnic group that relate to their traditional cultures, beliefs, attitudes, and practices in relation to caregiving. Unfortunately, when national health data are reported for Asian American/Pacific Islander subjects, it is often reported for the aggregated group. This aggregation may mask differences between Asian American subgroups, such as the Southeast Asian population, and result in heterogeneity among Asian American/Pacific Islander subgroups when interpreting data.

people who identify as Asian American/Pacific Islander maintain their caregiving system (Alzheimer's Association, n.d.-b).

Likewise, caregivers who identify as LGBTQ or caring for someone who identifies as LGBTQ have unique experiences that providers need to consider. Caregivers and recipients who identify as LGBTQ are significantly less likely to access medical and social services than their peers who do not identify as LGBTQ (Stewart and Kent, 2017). Furthermore, it has been shown that people who identify as LGBTQ become caregivers at a slightly higher rate than their peers who do not identify as LGBTQ. One in five people who identify as LGBTQ provide care for another adult, compared to one in six people who do not identify as LGBTQ (National Alliance for Caregiving and American Association of Retired Persons [AARP], 2015). Of organizations serving caregivers in California, nearly half indicate there is little or no outreach and materials targeting caregivers who identify as LGBTQ (Fredriksen-Goldsen et al., 2018; Meyer et al., 2018). Classes such as Savvy Caregiver and Powerful Tools for Caregivers are exceptions when it comes to serving minority ethnic caregivers and LGBTQ caregivers (California Task Force on Family Caregiving, 2017). California has been a leader in provider training for older adults who identify as LGBTQ and their families, passing the Older Californian Equality and Protection Act in 2006 as well as passing legislation in 2008 that requires health care staff in long-term care settings to be trained in preventing discrimination based on sexual orientation and gender identity. However, there is some indication that long-term care settings have not embraced the training and broaden the messaging of the importance of supporting older adults in the community who identify as LGBTQ (Romero, 2016). A multi-state survey, that included California, inquired about the experiences of older adults who identify as LGBTQ in long-term care settings. The study found that nearly half of the older adults who identified as LGBTQ had experienced mistreatment in a care facility (Center, Force, and SAGE, 2011). As with many issues facing older adults who identify as LGBTQ and their caregivers, more can be learned about their experiences.

UNPAID CAREGIVERS

The primary reasons caregivers provide care and assistance to a person with ADRDs are the desire to keep a family member or friend with ADRDs at home, their proximity to the person with ADRDs, and the caregiver's perceived obligation to the person with ADRDs (Alzheimer's Association, 2019a). Many people living with ADRDs will have more than one unpaid caregiver. For example, people who live with their primary caregiver may also receive help from another relative, friend, or neighbor, known as a secondary caregiver. Only a small percentage of older adults with ADRDs do not receive help from family members or other unpaid care providers. These include people who live alone, perhaps because it is more difficult to ask for and receive unpaid care, and people from certain subgroups, such as LGBTQ individuals who may experience greater isolation for reasons ranging from living alone to social stigma to a diminished social network of available care providers (Movement Advancement Project, 2017; Wallace, Cochran, Durazo, and Ford, 2011; Yang, Chu, and Salmon, 2018).

In the U.S., the majority of caregivers are women (60%) and more than 60% of caregivers are married, living with a partner or in a long-term relationship. The average caregiver is 49 years of age with a third of caregivers 65 years of age or older. One-quarter of caregivers are "sandwich generation" caregivers, meaning they care for an aging parent and a child under 18 years of age. One in six millennial caregivers (adults who were born between 1980 and 1998) assists someone living with ADRDs. Among millennial caregivers, 7% are “Asian,” 22% are Black/African American, 30% are “Latino,” and 41% are “White” (Vega, Aranda, and Rodriguez, 2017). Among primary caregivers (individuals who indicate having the most responsibility for helping their relative) of people with dementia, over half take care of their parents (Alzheimer's Association, 2019a; Kasper, Freedman, and Spillman, 2014; National Alliance for Caregiving and Alzheimer's Association, 2017; Rabarison et al., 2018; W. A. Vega, Aranda, and Rodriguez, 2017).

It is not uncommon within communities of color that individuals live in multigenerational family households, suggesting that within households of color they might be more likely to have care responsibilities for older adults. In 2016, 29% of the population that identified as “Asian American” lived in multigenerational family households, compared to 27% and 26% of the population who identified as “Hispanic/Latino” and Black/African American, respectively. A smaller percentage of the population that identified as “White/Caucasian, not Hispanic or Latino” (16%) lived with multiple generations of family members (Cohn and Passel, 2018).

Caregiving is challenging emotionally, physically, and financially. Caregivers spend an average of 24 hours a week providing care and 55% of female caregivers work full-time (National Alliance for Caregiving and AARP, 2015). Much of the caregiving responsibilities are shouldered by women. On average, female caregivers spend more time caregiving than male caregivers. According to the 2014 Alzheimer’s Association Women and Alzheimer’s Poll, which surveyed both men and women, of those providing care for 21 to more than 60 hours per week, 67% were women (Alzheimer's Association, 2014). Similarly, the 2015-17 Behavioral Risk Factor

Surveillance System (BRFSS) surveys found that of all dementia caregivers who spend more than 40 hours per week providing care, 73% were women (Alzheimer's Association, 2019a; Centers for Disease Control and Prevention). Two and a half times as many women reported living with the person with dementia full time (Alzheimer's Association, 2014). Of those providing care to someone with dementia for more than five years, 63% are women (Alzheimer's Association, 2019a; Centers for Disease Control and Prevention). Given the intensive caregiving provided by women, it is not surprising that female caregivers may experience slightly higher levels of burden, impaired mood, depression, and impaired health than men. Of dementia caregivers who indicate a need for individual counseling, support groups or respite care, the large majority are women (individual counseling, 83% versus 17%; support groups, 73% versus 27%; and respite care, 71.5% versus 28.5%) (Alzheimer's Association, 2019a).

An individual living with dementia may experience changes in memory, personality, and behavior, such as wandering or asking questions repeatedly, which can be difficult for family caregivers. Research has shown that the stress of family caregiving for people with dementia is associated with high emotional strain, poor physical health outcomes, and increased mortality (Alzheimer's Association, 2019a; National Poll on Healthy Aging, 2017; Reinhard, Friss Feinberg, Choula, and Houser, 2015; Reinhard, Friss Feinberg, Houser, Choula, and Evans, 2019). There is also evidence that spouses are at increased risk of dementia themselves (Kara Bottiggi Dassel, Carr, and Vitaliano, 2015) and significantly more are likely to experience increased frailty over time, as compared to non-dementia caregivers (Kara B. Dassel and Carr, 2016).

While the emotional and social well-being of a caregiver can be impacted, this does not mean that there will no longer be times of joy, shared laughter, and companionship. Dementia develops gradually, which means there is time to plan ahead, time to adjust to the diagnosis, and time to enjoy being with each other. In a national poll, 85% of respondents indicated that caring for someone with AD was very or somewhat rewarding (National Poll on Healthy Aging, 2017). For more information on the impact of caregiving, including available resources, go to the Alzheimer's Association website at https://www.alz.org/help-support/caregiving.

CALIFORNIA CAREGIVERS

Among unpaid caregivers, about 1,624,000 Californians provide care for a person with AD, amounting to more than 1.8 billion hours of unpaid care, which has a total value of $24,245,000,000 in unpaid care, and over $1.1 billion dollars in higher health care costs of caregivers (Alzheimer's Association, 2020; Alzheimer's Association, 2019). Among those who provide unpaid care to family and friends living with AD, more than 60% provide 20 or more hours of care per week. More than 40% of AD caregivers have been providing care for at least two years (Alzheimer's Association, 2012).

Predominantly the role of California family caregivers are held by women (59%), who are married (68%), are 58 years of age, have graduated from college with at least a four-year degree (51%), live in a household with an income under $100,000 (55%), and provide care to a parent or parent-in-law (60%) (AARP, 2018a, 2018b; Guengerich, 2018, 2019).

CAREGIVING SUPPORT SERVICES

With the impending increase in the number of people with dementia, there will be a simultaneous increase in the need for appropriate home care services and support services. However, it is also important to note that these crucial support services have experienced significant reductions in their budgets (e.g., Caregiver Resource Centers (CRCs)) or their budgets have been eliminated (e.g., Alzheimer’s Day Care Resource Centers). Improving availability of and access to caregiver support and home care services may reduce the need for individuals with dementia to need care in more costly institutionalized settings. Studies evaluating the effectiveness of enhanced support services for caregivers of people with dementia have been shown to improve caregivers' capabilities and well-being and delay institutionalization of individuals with dementia (Long, Moriarty, Mittelman, and Foldes, 2014; Mittelman, Haley, Clay, and Roth, 2006). Furthermore, enhancing caregiver supports could be cost-effective and potentially ease the economic burden of dementia (Long et al., 2014). Support programs for unpaid caregivers should be considered as a cost-effective way to manage dementia while researchers continue to seek effective treatments.

California has a number of support services for caregivers and individuals living with dementia. CRCs and Alzheimer’s organizations are located throughout California, ideally providing a single point of entry for support services for caregivers and individuals with dementia. **Appendices F and G** provide a list of Alzheimer organizations and CRCs.

California was the first state in the nation to establish a statewide network of support organizations for caregivers and all residents have access to CRCs in their area (see **Appendix G**). California's statewide network of 11 CRCs serves more than 14,000 families and caregivers of adults affected by chronic and debilitating health conditions including dementia, cerebrovascular diseases (such as stroke or aneurysms), degenerative diseases such as Parkinson's, Huntington's and multiple sclerosis, or traumatic brain injury, among many others. While each center tailors its services to its geographic area, all centers provide core services to families and caregivers ranging from counseling and care planning to legal/financial consulting and respite, at low or no cost. After several years of funding cuts, the 2019-2020 California budget approved a onetime ask of $10M per year over the next three years for the CRCs. These funds will be used to expand and improve caregiver support services across the state of California among the eleven CRCs. This increase in funding is notable since the budget of the CRCs had been reduced by 74% in 2009 when the budgets was $10.5 million. In 2015, a $2 million recovery restored some of these funds (Meyer et al., 2018).

The most recent annual report available on CRC services took place in 2008, reporting that in 2008 13,143 caregivers received family consultations. Caregivers expressed high satisfaction with these services, with 94% of caregivers reporting that CRC staff provided them with information and resources to best manage their caregiving situation, and 96% found the educational programs they attended to helpful (California Task Force on Family Caregiving, 2017; Meyer et al., 2018). The annual 2007 CRC report indicated that the average caregiver served by the program is a 59-year-old woman who has been caring for her father or husband with AD for three to four years. Most caregivers are women (77%) and nearly half are 60 years of age or older—those who are at highest risk of health problems themselves. Caregivers are most often an adult child of the care receiver (47%) or, spouses (35%), and a small percentage of caregivers have a non-family relationship (9%) with the care recipient. Most caregivers served by the CRC system are likely to live with the care recipient (71%).

Prior to their defunding in 2009 by the State of California the Alzheimer's Day Care Resource Centers (ADCRCs) had also been an important resource for caregivers. While some ADCRCs continue to operate, their services are no longer free to qualified individuals living with dementia. The ADCRCs provided important care service role for individuals living with ADRDs in the mid to late stages of the illness and support for their caregivers. These services could help prevent or delay costly institutionalization of individuals living with ADRDs. While the services of the ADRCs are not replaceable, caregivers caring for an individual living with dementia are now referred to their local Area Agency on Aging to discuss whether they have funds available for subsidized adult day care through a program made possible by the Older Americans Act. Another option for Medi-Cal eligible individuals living with dementia would be to consider whether the Medi-Cal Community Based Adult Services (CBAS) Program would meet their needs.

There are several Alzheimer's organizations located throughout CA (see **Appendix F**) with service offices meeting the needs of family caregivers and the growing number of people living with dementia. These organizations provide disease education, early stage support programs, activity programs for individuals living with dementia, family care consultations, information and referral, support groups, adult day programs, and a wanderer's identification programs.

PAID CAREGIVING

Direct care workers, such as nurse aides, home health aides, and personal and home care aides, provide most of the paid long-term care to older adults living at home or in residential settings (Alzheimer's Association, 2019a). Predominantly direct care workers are female (87%) and people of color (59%) (Scales, 2020). Just over a quarter (27%) of direct care workers are immigrants, and educational attainment is fairly low across the workforce (53% have a high school education or less) (Scales, 2020).

Direct care workers' jobs are challenging, and they frequently do not receive the necessary training to provide dementia care. The salary provided to direct care workers is also low (Institute of Medicine, 2008). These factors likely contribute to the high turnover rates among paid caregivers. Among home health aides, turnover in the first year is estimated to be between 40% to 60% and 80% to 90% within the first two years. Assisted-living staff experience a turnover rate of 21% to 135%. The certified nursing assistant turnover rate is 71% on average. These high turnover rates are a significant cost to employers which is estimated to be $4.1 billion annually (Institute of Medicine, 2008). Recruitment and retention are persistent challenges (Warshaw and Bragg, 2014).

In California, In Home Supportive Services (IHSS) provide people with low income who are blind, disabled, or 65 years old or older with personal assistance and in-home services so they can safely stay in their homes or continue working. Approximately 520,000 IHSS caregivers provide care to over 550,500 recipients who include low-income older adults and people with disabilities, to help them remain safely in their homes (California Department of Social Services, n.d.-c). IHSS allows care recipients and their families to choose who to hire to provide services, including relatives or friends. Services range from assistance with household chores to personal care and paramedical services. IHSS is often seen as an alternative to assisted living or nursing facilities. The majority of IHSS recipients are older adults: 15% are 85 years of age or older and 41% are 65 to 84 years of age (California Department of Social Services, 2019). Based on conservative estimates, approximately 30,000 of these older adults could have ADRDs.

LONG-DISTANCE CAREGIVERS

Long-distance caregiving is a term describing a caregiver who lives more than one hour away from the person receiving care. While the majority of caregivers live with or are within 20 minutes from the care recipient, national estimates report that about 12% live more than an hour away from the person for whom they provide care and 15% live between 20 minutes to an hour away (National Alliance for Caregiving and Alzheimer's Association, 2017). Among the long-distance dementia caregivers, national estimates indicate they are, on average, 51 years old, 65% are employed while caregiving, 68% care for a parent who is on average 80 years old (National Alliance for Caregiving and Alzheimer's Association, 2017). Long distance caregivers are more educated (67%) and have higher household incomes (87%) than dementia caregivers who live closer. Long distance caregivers provide significantly fewer hours of care (17.7 hours) per week but a significant majority (59%) report high levels of emotional stress. The person with dementia that the long-distance caregiver is caring for typically lives in their own home (53%) or some care facility or community (31%) (National Alliance for Caregiving and Alzheimer's Association, 2017).

CHARACTERISTICS OF CARE RECIPIENTS

In California, those with AD who receive care from family and friends are predominately female (70%), age 85+ (56%), and nearly half of them are the parent or parent-in-law of the caregiver (46%) (Alzheimer's Association, 2012).

National estimates indicate that more than a third of dementia care recipients are 85 years of age or older (37%) which is double the share of non-dementia care recipients (18%). Dementia caregivers caring for the “oldest old (age 85+) are more likely to have paid assistance from aids or housekeepers (57%) than do other dementia caregivers (39%); however, there are few other significant differences between the two groups. This suggests that the increased dementia caregiver burden relates more to the demands of caring for someone with dementia than to the advanced age of the care recipient (National Alliance for Caregiving and Alzheimer's Association, 2017).

People with dementia receive help with a wide variety of activities from their caregivers. A national estimate indicates that, on average, dementia care recipients receive approximately 28 hours of care per week which is about four hours more than a non-dementia recipient (National Alliance for Caregiving and Alzheimer's Association, 2017). As displayed in ***Table 4 and Table 5*****,** people living with AD need more help with ADLs and IADLs. Individuals living with dementia need more assistance from their caregivers in routine activities (ADLs) such as, eating, bathing, getting dressed, toileting, transferring, and continence. They also require assistances with those activities that allow an individual to live independently in a community (IADLs).

TABLE 4: ASSISTANCE WITH ACTIVITIES OF DAILY LIVING BY CAREGIVERS FOR DEMENTIA OR NON-DEMENTIA RECIPIENTS

Activities	Dementia Caregiver	Non-Dementia Caregiver
Get in and out of beds and chairs	45%	43%
Get dressed	38%*	30%
Bathe or shower	34%*	23%
By feeding him or her	33%*	20%
Get to and from the toilet	32%*	25%
By dealing with incontinence/diapers	32%*	12%
Helps with three or more ADLs	*38%**	*28%*
Helps with all six ADLs	*12%**	*3%*
Average number of ADLs	*2.1**	*1.5*

Source: Dementia Caregiving the U.S., National Alliance for Caregiving, February 2017
Note: An asterisk (*) indicates a significant difference (p<.05) in care activities provided by caregivers for dementia recipients compared to non-dementia recipients.

TABLE 5: ASSISTANCE WITH INSTRUMENTAL ACTIVITIES OF DAILY LIVING PROVIDED BY CAREGIVERS FOR DEMENTIA OR NON-DEMENTIA RECIPIENTS

Activities	Dementia Caregiver	Non-Dementia Caregiver
Transportation	83%*	76%
Grocery or other shopping	80%	75%
Housework	70%	73%
Managing finances	68%*	50%
Preparing meals	64%	60%
Giving medicines, pills, or injections	61%*	43%
Arranging outside services	46%*	27%
Helps with four or more IADLs	*71%**	*61%*
Helps with all seven IADLs	*24%**	*10%*
Average number of IADLs	*4.7**	*4.1*

Source: Dementia Caregiving the U.S., National Alliance for Caregiving, February 2017
Note: An asterisk (*) indicates a significant difference (p<.05) in care activities provided by caregivers for dementia recipients compared to non-dementia recipients.

Among people living with dementia who live alone and those who live with others, some use paid care, however, most rely upon unpaid care, such as family members and friends, to help meet their needs. This is, in part, because paid care is expensive, especially if the person with dementia is not eligible for and enrolled in Medicaid. Harris-Kojetin et al. (2016) found that home health agencies and adult day service centers are used by many people living with AD – approximately one-third of Medicare home health agency patients and one-third of adult day service center clients.

CAREGIVING TASKS

Dementia caregivers tend to provide more extensive assistance to people living with dementia compared to caregivers of people living with other conditions (National Alliance for Caregiving and Alzheimer's Association, 2017). The problems are multifaceted and are physical, emotional (e.g., anxiety, apathy and lack of inhibition) and behavioral. Caregivers of people living with dementia are more likely than family caregivers of people without dementia to help with emotional or mental health problems (41% versus 16%) and behavioral issues (15% versus 4%) (National Alliance for Caregiving and Alzheimer's Association, 2017). A common symptom like wandering can be a regular source of anxiety for caregivers. Nearly half of those with dementia will wander at one point (McShane et al., 1998).

Dementia caregivers are more likely to help their loved one with more intimate activities of living (ADLs), including incontinence issues, bathing, and feeding. National estimates indicate that dementia caregivers helps with 2.1 of 6 ADLs, compared with 1.5 by the average non dementia caregiver. More than one in ten caregivers help with all six ADLs, four times the rate among non-dementia caregivers. (National Alliance for Caregiving and Alzheimer's Association, 2017). Moreover, two-thirds of dementia caregivers say they perform medical/nursing tasks, which include skilled activities such as administering injections, tube feedings, and catheter care. More than half of dementia caregivers do these medical/nursing tasks with no prior training or preparation, which is notably higher than the rate of non-dementia caregivers.

Some family members and other unpaid caregivers who live with a person who has dementia provide supervision and help 24 hours a day, seven days a week, getting up with the person at night and assisting with all of the individual’s needs. Such around-the-clock care is needed when a person can no longer be left alone because of risk of wandering, getting lost, and other unsafe activities. These additional needs result in caregivers of people living with dementia providing more hours of help, on average, than caregivers for physically impaired individuals. In California, more than 60% of unpaid dementia caregivers provide 20 or more hours of care per week (Alzheimer's Association, 2012). This information is consistent with more national information provided by the AARP in 2015 reporting on caregiving for care recipients over 50 (Alzheimer's Association and National Alliance for Caregiving, 2015).

Dementia caregivers also provide assistance with more IADLs, such as transportation, shopping, administering medicines, using the telephone, housekeeping, preparing food, handling finances. National estimates indicate that the average dementia caregiver helps with four point seven of seven IADLs, compared with four point one by the average non-dementia caregiver. Nearly one in four dementia caregivers helps with all seven IADLs, more than double the rate of non-dementia caregivers. A 2012 AARP report found that family caregivers provide care with medication management (78%), help with assistive devices (43%), preparation of food for special diets (41%), and wound care (35% (Reinhard, Levine, and Samis, 2012)). The extent of caregiving responsibilities suggests a sizable portion of dementia caregivers manage nearly all of their loved one’s household in addition to their other care responsibilities (National Alliance for Caregiving and Alzheimer's Association, 2017). Not surprisingly, given these additional needs, the annual cost of caring for an individual living with AD at home in the US is estimated at $56,000 (National Alliance for Caregiving and Alzheimer's Association, 2017).

DURATION OF CAREGIVING

Because dementia often progress slowly, most caregivers spend many years in the caregiving role. The course of AD progresses over a seven to ten-year period. National estimates indicate that 86% of dementia caregivers have provided care and assistance for at least the past year, nearly 70% for more than a year, 30% for more than five years, and more than 14% for over a decade. More than 60% of dementia caregivers expect to continue to have caregiving responsibilities for some adult over the next five years, compared to 49% among non-dementia caregivers (Alzheimer's Association, 2019a; National Alliance for Caregiving and Alzheimer's Association, 2017).

In addition to the disease duration, the immediate demands of caregiving are also time intensive. National estimates indicate that caregivers of people living with dementia report providing 27 hours more care per month on average (92 hours vs. 65 hours) than non-dementia caregivers, with over half providing more than 21 hours of care per week (Alzheimer's Association, 2019a). A 2017 national poll found that 42% of dementia caregivers provided care for an average of nine hours per day (National Poll on Healthy Aging, 2017). An analysis of national caregiving trends from 1999 to 2015 found that care per week increased from 35 hours on average in 1999 to 48 hours on average in 2015. The weekly hours of care for non-dementia caregivers decreased from 34 to 25 hours, over the same time period (Alzheimer's Association, 2019a; Wolff et al., 2018).

The duration of caregiving for California families and other unpaid caregivers are consistent with the national averages. At least 25% have been providing care for six years or more to someone 50 years of age or older, and 75% have been providing care for five years or less. California caregivers as a whole typically spend 14 hours a week (median) and get about 10 hours of help weekly from other unpaid family members, friends, or volunteers (median, with average not available) (Scharlach et al., 2003).

Both state and national figures highlight the greater amount of time caregivers spend caring for people living with dementia compared to other individuals without dementia.

IMPACTS OF CAREGIVING

Most family and other unpaid caregivers are proud of the help they provide, and some manage caregiving tasks with little difficulty. However, there is substantial evidence that caregiving can exact a toll on emotional health and cause stress and depression, especially for caregivers of people living with dementia. Caring for a person with dementia poses special challenges for the caregiver. Individuals with dementia require increasing levels of supervision and personal care, and many caregivers experience high levels of stress and negative effects on their health, employment, income and financial security. As previously described, dementia caregivers assume a wide range of responsibilities and assist in significantly more tasks than do non-dementia caregivers.

EMOTIONAL WELL-BEING

While it is not uncommon to hear about the “burden” of caregiving, there is indication that families are better managing the care they provide to relatives than in the past. National estimates indicate that from 1999 to 2015, dementia caregivers were reporting fewer physical difficulties (from 30% in 1999 to 17% in 2015) and financial difficulties (from 22% in 1999 to 9% in 2015). In addition, use of respite care by dementia caregivers increased (from 13% in 1999 to 27% in 2015) (Alzheimer's Association, 2019a; Wolff et al., 2018).

Although there are indications that dementia caregivers are better managing the care provided, dementia caregivers are one of the more burdened groups of caregivers which is not surprising considering all the responsibilities dementia caregivers manage. National estimates indicate that nearly half of dementia caregivers are in a high-burden situation, and dementia caregivers have a significantly higher average burden than do non-dementia caregivers due to the longer duration of caregiving (National Alliance for Caregiving and Alzheimer's Association, 2017).

As shown in ***Table 6**,* more caregivers of people living with cognitive impairment felt the negative impacts of emotional stress, physical strain, and poorer health (National Alliance for Caregiving and Alzheimer's Association, 2017).

TABLE 6: IMPACT OF CAREGIVING ON EMOTIONAL AND PHYSICAL HEALTH ON CAREGIVERS CARING FOR INDIVIDUALS WITH DEMENTIA OR NON-DEMENTIA

	Dementia Caregivers	Non-Dementia Caregivers
High Emotional Stress	49%*	35%
Excellent/Very Good Health	42%*	50%
Caregiver Health Made Worse by Impact of Caregiving	35%*	19%
High Physical Strain	29%*	17%
Fair/Poor Health	21%	16%
Average Burden of Care[1]	3.1*	2.8

Source: Dementia Caregiving the U.S., National Alliance for Caregiving, February 2017.
Note: [1] "Burden of Care" is an index based on the number of hours of care provided by the caregiver, the number of Activities of Daily Living performed, and the number of Instrumental Activities of Daily Living. Points are assigned for each of these, and ultimately, these points are consolidated into three burden categories: low (values 1 and 2), medium (3), and high (values 4 and 5). See *Caregiving in the U.S. 2015* Appendix B, Detailed Methodology for the details of creating the index.
*An asterisk (*) indicates a significant difference (p<.05) between caregivers for dementia recipients compared to caregivers of non-dementia recipients.

HEALTH

The high burden of care provided over a long period can take a significant mental and physical toll on dementia caregivers. National estimates indicate that nearly half of dementia caregivers say providing care is emotionally stressful, and three in ten say that providing care often involves physical strain. This physical and emotional stress has a negative impact on the health of many dementia caregivers. About four in ten (42%) say their health is "excellent" or "very good"—statistically significantly lower than the share among non-dementia caregivers (50%). Dementia caregivers are nearly twice as likely to say that their health has gotten worse as a result of their caregiving responsibilities. More than one in three dementia caregivers says their health has declined (35%), versus just one in five non-dementia caregivers (National Alliance for Caregiving and Alzheimer's Association, 2017).

INCOME AND FINANCIAL SECURITY

Caregiving is expensive and many families experience financial stress. This is often due to high out-of-pocket costs related to caregiving which on average can exceed $10,000 a year. Approximately 67% of California family caregivers use their own money to care for a loved one and they use it on: transportation (81%), assistive technology (51%), home modifications (48%), home health aide (28%), respite care (21%), and adult day care (12%) (AARP, 2018c).

Compounding the high cost of care, is that many caregivers of people living with dementia have to quit work, reduce their work hours, or take time off because of caregiving responsibilities (MetLife, 2011). Significantly more California caregivers who provide care to someone 50 years of age or older with memory problems or dementia changed their work schedules (reduced the number of work hours) than did those not dealing with this condition (Scharlach et al., 2003). In the two weeks before the 2003 survey, 21% of employed caregivers had missed work—from arriving late or leaving early to taking three or more days off. One half of these employees missed at least 16 hours of work during this two-week period (Scharlach et al., 2003). Although California has family leave benefits for eligible workers, few caregivers know about this (Andrew Chang and Company LLC, 2015; California Legislative Information, 2016).

The financial cost and stress of caring for an individual with dementia poses dilemmas with respect to broader family needs and decisions. For example, a family can be confronted with questions of where to allocate their funds, hiring in home care or paying for a child to attend college. Caregiving and its consequences impact all members of a family, regardless of whether they are providing direct care. A comprehensive national survey found that the individuals most financially strained tend to be lower income, “non-White,” “non-Asian” family caregivers, and caring for someone who needs assistance with at least one ADL (Rainville, Skufca, and Mehegan, 2016).

SECTION IV – COSTS OF CARING FOR PEOPLE WITH ALZHEIMER’S DISEASE AND RELATED DEMENTIAS IN CALIFORNIA

Because dementia is a chronic disease that requires comprehensive medical and social services health and long-term care for people with dementia is one of the costliest conditions to society (Hurd, Martorell, Delavande, Mullen, and Langa, 2013). Nationally direct health care expenditures on dementia care are similar to heart disease and significantly higher than cancer (Hurd et al., 2013). Estimating costs attributable to dementia is challenging because individuals with dementia frequently have more coexisting chronic health problems than those without dementia.

National estimates of total payments in 2019 (in 2019 dollars) for all individuals with ADRDs are estimated at $290 billion. Medicare and Medicaid are expected to cover $195 billion, or 68%, of the total health care and long-term care payments for people with ADRDs. Out-of-pocket spending is expected to be $63 billion, or 22% of total payments (Alzheimer's Association, 2019a). In 2010, the yearly monetary cost per person that was attributable to dementia was either $56,290 or $41,689, depending on the method used to value unpaid care. The total societal costs of dementia are expected to increase nearly 80% by 2040 (Hurd et al., 2013).

Reducing the costs associated with hospitalizations is important to bring down the cost of dementia care. Of importance are the functional and cognitive deficits, not simply a dementia diagnosis, that are significantly associated with higher risks for hospitalizations, longer hospital stays, higher Medicare expenditures, higher incidence of delirium compared to individuals without cognitive impairment (Fogg, Griffiths, Meredith, and Bridges, 2018; Zhu et al., 2015). It is important to identify when hospitalized if older individuals have cognitive impairment or an existing diagnosis of dementia, in order to be aware of their increased susceptibility to adverse events in the hospital environment, and to provide appropriate surveillance for intermediate outcomes to prompt preventative action. Hospitalizations and expenditures can be impacted if strategies are developed that take into consideration cognitive and functioning deficits. Furthermore, there are conditions associated with increased hospitalization risk which are potentially preventable, such as urinary tract infections, dehydration, diabetes, and hypertension, if outpatient care is improved through education among individuals who provide care, unpaid and paid (Agency for Healthcare Quality and Research, 2001; Fogg et al., 2018).

THE COST AND PROVISION OF CARE FOR PEOPLE WITH ALZHEIMER'S DISEASE AND RELATED DEMENTIAS

UNPAID AND PAID CARE COSTS

Unpaid care services refer to assistance rendered outside of the traditional medical and social service markets and for which providers are not reimbursed – they are usually provided by family members. Paid services refer to those rendered for a price in the traditional medical and social service marketplace.

The value of unpaid care, primarily shouldered by families, is enormous, and its replacement by paid service providers would be extremely costly. For instance, in 2018, caregivers of people living with dementia provided an estimated 18.5 billion hours of unpaid care, a contribution to the nation valued at $233.9 billion. This total lifetime cost of care for someone with dementia was estimated at $350,174 (2018 dollars). Families bear 70% of the total lifetime dementia care costs burden

(Alzheimer's Association, 2019a; Jutkowitz et al., 2017; Official Data Foundation, n.d.). Costs for caring for a loved one with AD averages well over $10,000 a year in out-of-pocket costs (Meyer et al., 2018). Across different race/ethnicity groups, Black/African American and Latino/a/x American caregivers, generally, spend a higher proportion of their income on out-of-pocket costs to provide care than White/Caucasian American, non-Latino/a/x and Asian American/Pacific Islander caregivers (Meyer et al., 2018).

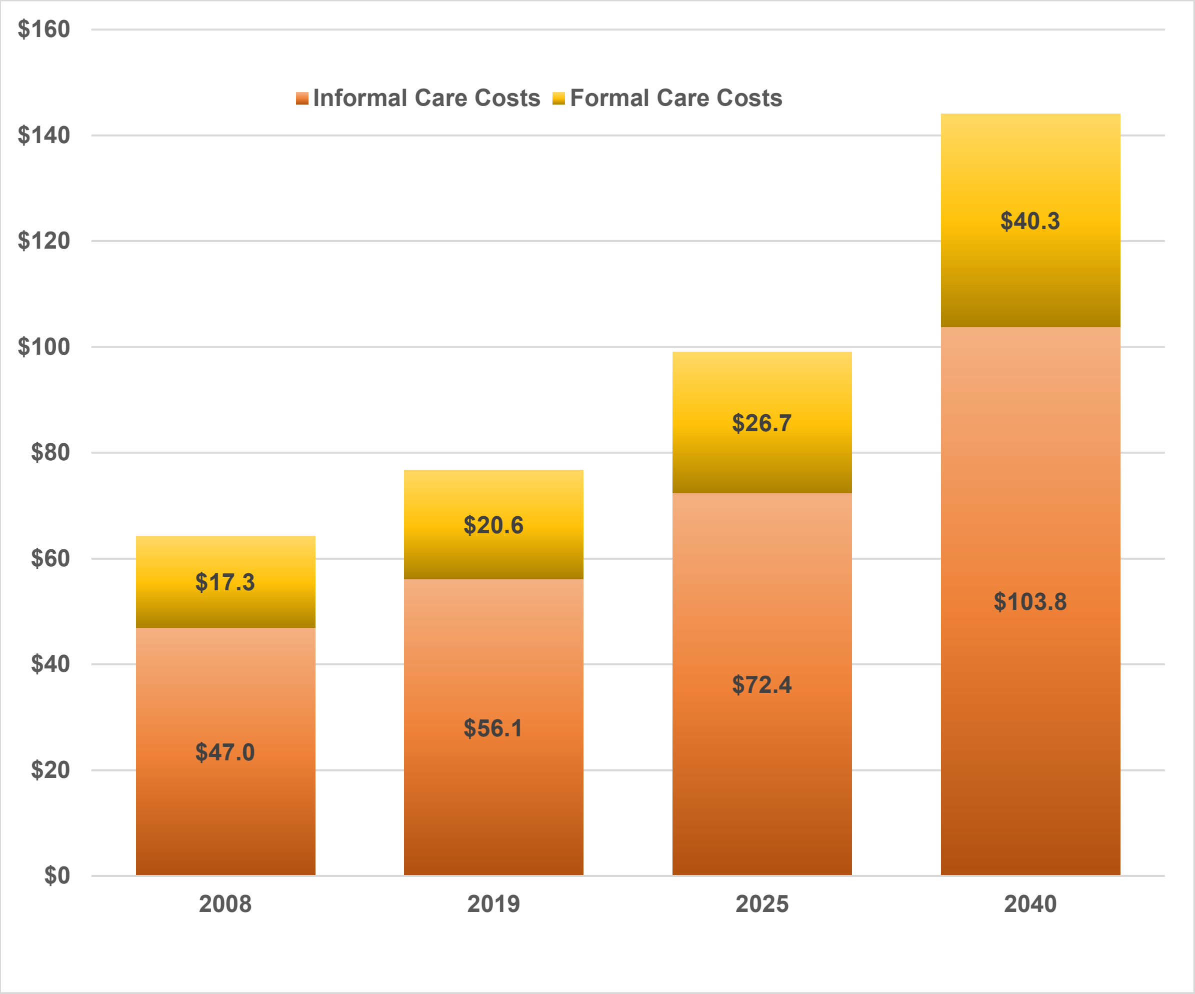
Estimates of the economic value of unpaid caregiving provide a way to quantify this enormous societal contribution by answering the question: “If unpaid caregivers were not available, what would it cost to substitute paid services for the care provided?” To answer this question, estimates of the unpaid cost of caring for individuals with AD who live in the community or reside in institutions were calculated based on original data provided by Dorothy Rice et al. (1993), using 2019 dollars (which assumes no inflation from 2008-2040) and AD prevalence estimates.

The following cost estimates represent the total social costs of caring for people living with AD in California for years 2008, 2019, 2025, and 2040. We use the term “social costs” to emphasize the fact that we include both the unpaid value of unpaid caregivers’ labor in addition to out-of-pocket expenditures by families for paid services. Both of these costs are associated with caregiving to address the needs of a person having AD.

In thinking about the economic value (or cost) of unpaid care and the cost of paid care, it is prudent to keep in mind that a reduction in costs in one type of care will reflect an increase in costs in the other type of care. For example, if we reduce paid care costs, we increase unpaid care costs, and vice versa. This is because the care needs of people living with AD will remain, regardless of which long-term care sector (i.e., unpaid or paid) provides the assistance. Since the value of unpaid care is imputed, it therefore represents a social cost rather than an actual out-of-pocket expenditure for the care of people living with AD.

As displayed in ***Figure 19 and 20*** between 2008 and 2040, it is estimated that the total cost of caring for community-residents (***Figure 19***) and institutionalized (***Figure 20***) individuals 55 years of age and older living with AD in California will increase from $67.7 billion to $153.3 billion. This more than doubling in cost parallels the change in the number of people 55 years of age and older who will be living with AD, largely due to the aging of the baby boomers. Family members' labor will contribute almost three-quarters of the total cost of care for community-resident and institutionalized individuals living with AD.

FIGURE 19: ESTIMATED AND PROJECTED PAID AND UNPAID COMMUNITY CARE COSTS FOR PEOPLE WITH ALZHEIMER'S DISEASE, AGE 55+: 2008, 2019, 2025, 2040 (COSTS IN BILLIONS OF DOLLARS)



Source: Rice, D., Fox, P. J., Max, W., Webber, P. A., Lindeman, D. A., Hauck, W. W., and Segura, E. (1993). The economic burden of Alzheimer's disease care. *Health Affairs, 12*(2), 164-176. The figures reported in this article were updated using 2019 dollars. The 2018 Survey of 1,152 California Voters aged 40-plus was used for their percentage of full-time and part-time caregivers.

FIGURE 20: ESTIMATED AND PROJECTED PAID AND UNPAID INSTITUTIONAL CARE COSTS FOR PEOPLE WITH ALZHEIMER'S DISEASE, AGE 55+: 2008, 2019, 2025, 2040 (COSTS IN BILLIONS OF DOLLARS)

Source: Rice, D., Fox, P. J., Max, W., Webber, P. A., Lindeman, D. A., Hauck, W. W., and Segura, E. (1993). The economic burden of Alzheimer's disease care. *Health Affairs, 12*(2), 164-176. The figures reported in this article were updated using 2019 dollars. The 2018 Survey of 1,152 California Voters aged 40-plus was used for their percentage of full-time and part-time caregivers.

By 2040, the total cost of caring for people with AD in California who live in the community are estimated to increase 124%, from $64.3 billion in 2008 to $144.1 billion in 2040. A similar increase will occur for individuals living in institutions, such as skilled nursing facilities, from $3.4 billion in 2008 to $9.2 billion in 2040. However, compared to community-resident individuals, the majority of costs for institutionalized individuals with AD are due to skilled nursing facility expenditures.

Given the projected increases in the number of Californians living with AD, the economic impact of the disease in the future will be substantial in terms of paid costs alone. Since a high proportion of costs for institutional care are borne by the federal and state governments, the cost to taxpayers will be high. The impact on families will be even more dramatic, since the majority of care for individuals is provided through unpaid sources. The unpaid and paid costs are estimated to more than double between 2008 and 2040. Unpaid care costs were $47 billion in 2008 and are estimated to exceed $103.8 billion by 2040; whereas paid care costs are estimated to increase from $20.4 billion in 2008 to $48.6 billion by 2040.

As would be expected, there is a higher total cost of caring for people living with severe AD. The relative increased cost of unpaid care for individual with AD living in the community with severe cognitive impairment compared to those having mild or moderate impairment is 14%; whereas the cost increase for providing paid care services is significantly greater, a more than doubling in estimated costs for the paid care for a person with severe AD compared to someone with mild or moderate impairments (see **Appendix H**).

Although unpaid care costs represent an imputed value rather than an actual dollar expenditure, if unpaid caregivers were not available, caregiving services would probably be purchased from paid providers, or else people living with AD now cared for in the community would be placed in institutions such as skilled nursing facilities. Smaller family size coupled with the increasing labor force participation of those who provide more of the care – women – will result in fewer available unpaid caregivers for people living with AD in the future. Therefore, more of these imputed costs may become actual expenditures.

COSTS TO THE MEDI-CAL PROGRAM

The care of people living with ADRDs is a significant contributor to Medi-Cal[12] costs. People living with ADRDs are high users of long-term care services, and Medi-Cal pays for skilled nursing facility and other long-term care services. For individuals with the onset of AD at the age of 70 years and who survive for ten years, it is estimated that four of these ten years will be spent in a nursing home (Arrighi et al., 2010). Contributing to nursing home placement and increased hospitalizations are the lack of community-based services. In addition to nursing home care, other services are often needed when caring for people living with ADRDs, such as psychiatric visits, adult day health care, home health, hospice, psychological services, durable medical equipment, lab and x-ray, and ambulance services.

Nationally, total Medicaid spending for people living with ADRDs has been projected to be $49 billion in 2019 (in 2019 dollars) (Alzheimer’s Association, 2019a). One quarter of individuals 65 years of age or older live in California, Florida and Texas, and ***Figure 21*** compares the estimated Medicaid spending among these three states (Alzheimer’s Association, 2019a; Himes, 2019). Between 2019 and 2025 there will be an estimated 32% increase in cost to California’s Medi-Cal program for individuals living with ADRDs. The total per-person Medicaid payments for Medicare beneficiaries 65 years of age and older with ADRDs were 23 times as great as Medicaid payments for other Medicare beneficiaries (Alzheimer’s Association, 2019a). The majority of this cost difference is accounted for by long-term care expenditures (e.g., nursing homes and other residential care facilities, such as assisted living facilities) and the greater

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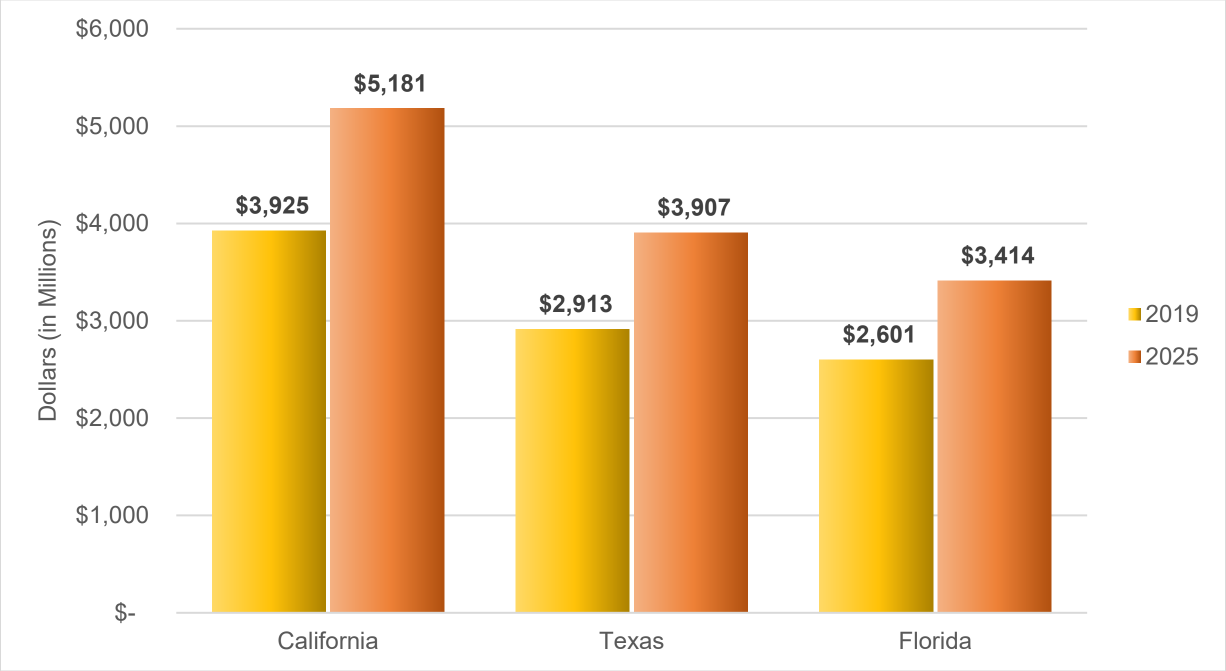
[12] Medi-Cal is California's Medicaid health care program that pays for a variety of medical services for children and adults with limited income and resources, and that it is supported by federal and state taxes. https://www.dhcs.ca.gov/services/medi-cal/pages/whatismedi-cal.aspx

percentage of people with dementia who are eligible for Medicaid (Alzheimer's Association, 2019a).

FIGURE 21: TOTAL MEDICAID PAYMENTS FOR AMERICANS AGE 65+ WITH ALZHEIMER'S DISEASE AND RELATED DEMENTIAS IN CALIFORNIA, TEXAS AND FLORIDA: 2019 DOLLARS*



Source: Alzheimer's Association. (2019a). 2019 Alzheimer's Disease Facts and Figures. *Alzheimer's and Dementia, 15*(3), 321-387.

TRENDS IN PAID LONG-TERM CARE PROVISION AND COSTS

Most people with dementia who live at home receive unpaid help from family and friends. Typically, these caregivers provide more help to their loved ones than caregivers of people with physical disabilities. As the dementia progresses, caregivers provide more and more care until they can no longer manage care responsibilities on their own, often because of their own health decline.

When caregiving responsibilities exceed capacity, families begin to explore long-term care options ranging from paid home- and community-based services, such as hiring home care workers or placing their loved ones in adult day care, assisted living residences, or skilled nursing facilities. The following are some of the types of long-term care services available (Genworth, 2019a).

Homemaker services allow people to continue to live in their own homes or to return to their homes by helping them complete household tasks that they can no longer manage alone. Homemaker service aids may clean clients' houses, cook meals, or run errands.

Home health aides, personal, and home aids, provide more extensive personal care than family or friends are able to or have the time or resources to provide. They help those who are older, disabled, or ill to continue living in their own homes or in residential care facilities instead of in skilled nursing facilities. There are two categories of licensed home health aides: Medicare certified, and non-Medicare certified. Medicare certified agencies can accept Medicare reimbursements while non-Medicare certified agencies cannot.

Community Based Adult Services (CBAS) are state licensed adult day care/health care facilities that provide interdisciplinary health, social, and mental health services. This type of care provides services at a community-based congregate center for adults who need assistance or supervision during the day, but who do not need around the clock care. In California 54% of CBAS participants were older than 65 years of age and 24% have a dementia diagnosis (Lendon and Rome, 2018). The CBAS are an important component of care in helping to prevent avoidable hospitalizations, emergency room visits, readmissions, and other costly services.

Assisted Living Facilities, known in California as Residential Care Facilities, are living arrangements that provide personal care and health services for people who may need assistance with ADLs, but who wish to live as independently as possible and who do not need the level of care provided by a skilled nursing facility. Assisted living is not an alternative to a nursing home, but an intermediate level of long-term care. In California 97.1% of residents are older than 65 years of age and 35.3% have ADRDs (National Center for Health Statistics (U.S.), 2019). Nationally it is reported that small residential care facilities (four to 25 beds) have a larger proportion of residents with ADRDs (51%) compared to mid-size (44%) and larger facilities (39%) (Caffrey, Harris-Kojetin, and Sengupta, 2015). Fifty-eight percent of residential care facilities offer programs for residents with ADRDs (Suehs et al., 2013).

Skilled Nursing Facility is for people who may need nursing care or a higher level of supervision and personal care than in an assisted living facility. They offer residents personal care, room and board, supervision, medication, therapies, and rehabilitation, as well as skilled nursing care 24 hours a day. In California, for 2019, there were approximately 37,388 individuals living with dementia who spent some time in a nursing home, approximately 3% of all people with AD (American Health Care Association, 2019a, 2019b). Nursing home population demographics reflect the racial diversity of California. Since 2004, the number of residents who identified as White/Caucasian American, non-Latino/a/x declined by 11% as of 2014 (to 58%) while there was an increase in the percentage of residents who identified as Asian American/Pacific Islander and other unknown races of 3% and 7% (to 11% and 19%). Between 2004 and 2014 the percentage of Latino/a/x American residents increase by 5% to 18% (Gibson, 2015).

Since 2004, Genworth Financial, Inc. has conducted a cost of care survey that has become the foundation for long-term care planning. The survey covers 441 regions and is based on data collected from more than 15,178 completed surveys of nursing homes, assisted living facilities, adult day health facilities, and home care providers. Potential respondents were selected randomly from a nationwide database of providers in each category of long-term care services. Survey respondents represent all 50 states, the District of Columbia and Puerto Rico. It is the most comprehensive cost analysis in the industry and the only one that provides comparative data since 2004 (Genworth, 2019c).

Based on Genworth survey results, some trends have emerged across the long-term care services landscape. Overall, the cost of care within facility-based providers has steadily increased. What was unexpected in 2019 was the substantial increase in the cost of receiving care at home. This includes the cost of both homemaker services, that is assistance with “hands off” everyday tasks, such as cooking, cleaning, laundry, and providing companionship, as well as home health aides who provide “hands on” assistance with activities like bathing, eating, going to the bathroom, and getting dressed. Homemaker services rose 7.14% in just a single year, which translates to an annual national median cost of $51,480 (based on 44 hours of care per week). Home health aide services rose 4.55% during that same period, which translates to an annual median cost of $52,624 (based on 44 hours per week) (Genworth, 2019c). The increasing cost of care provided at home is due to a variety of factors, including low unemployment, wage pressures, regulatory changes, labor shortages, sicker patients, and employment retention challenges (Genworth, 2019b). Long-term care costs in California are expected to more than double between 2019 and 2040 (see ***Table 7***). The cost of long-term care in California tends to be significantly higher than the national averages, with skilled nursing facility cost and home care cost approximately 20% higher than national averages.

While there are a number of long-term care options available to people living with dementia and their families, paying for these services for very long is not affordable for most people. As shown in ***Table 7***, in California, home care can cost between $64,018 and $64,064 annually, and assisted living averages $54,000 annually. Skilled nursing facility care is even more expensive, ranging between $105,120 and $127,750 annually (Genworth, 2019a, 2019c). While most people prefer to stay in their homes and the cost of home care or assisted living is almost half the cost of a skilled nursing facility, the financial feasibility of individuals remaining in their homes will be a challenge for most families.

TABLE 7: ANNUAL COST OF LONG-TERM CARE IN CALIFORNIA: ASSUMING 5% ANNUAL INFLATION*

Skilled Nursing Facility [1]	**2019**	**2025**	**2040**
Private Room	$127,750	$171,197	$355,907
Semi-Private room	$105,120	$140,871	$292,860
Assisted Living Facility [2]			
Private, 1-Bedroom	$54,000	$72,365	$150,442
Adult Day Health Care Facility [3]			
Adult Day Health Care	$20,020	$26,829	$55,775
Home Care [4]			
Home Health Aide	$64,064	$85,852	$178,480
Homemaker Services	$64,018	$85,790	$178,352

Source: https://www.genworth.com/aging-and-you/finances/cost-of-care.html

Accessed December 20, 2019

Notes:

[1] Based on 365 days of care

[2] Based on 12 months of care, private, on bedroom

[3] Based on 5 days per week by 52 weeks

[4] Based on 44 hours per week by 52 weeks

Typically, Medi-Cal covers skilled nursing facility stays that most people with dementia will need because Medicare only covers care in a skilled nursing facility for up to 100 days if it is associated with an illness that required hospitalization of at least three days. In order to qualify for Medi-Cal benefits, beneficiaries need to be poor (i.e., income to not exceed 138% of the Federal Poverty Level (FPL)) in order to receive coverage. For an individual diagnosed with ADRDs who is single the FPL maximum income is $17,609 and if the diagnosed individual has a spouse or significant other their income would need to be less than $23,792 to qualify for Medi-Cal. Although the Medicare coverage is narrow, a significant number of adults either believe that Medicare covers the cost of nursing home care or they are unsure of whether Medicare covers the cost (Alzheimer's Association, 2016).

While private long-term care insurance is an option, this is costly, and few can afford purchasing policies before developing dementia. In 2014, approximately 11% of adults 65 years of age and older had long-term care insurance (Johnson, 2016). For individuals with incomes greater than $100,000, 19% had long-term care insurance (Doty and Shipley, 2012). There are also racial disparities for who has long-term care insurance with White/Caucasian Americans, non-Latino/a/x being four times more likely than Black/African Americans and six times more likely than Latino/a/x Americans to have private long-term care insurance (Johnson and Park, 2011).

In California, for a single male 55 years of age the annual long-term care insurance premium estimate is $3,249 and for women this estimate increases to

$4,220 (Genworth, n.d.).[13] Annual long-term care insurance coverage for a couple can be $5,818. The cost of long-term care is expected to rise over the years, simply due to inflation. While the Patient Protection and Affordable Care Act passed in 2010 included a provision to create a federal long-term care insurance program, the Community Living Assistance Services and Support (CLASS) Act, because of financially sustainability concerns, the program was terminated in 2011.

THE GERIATRIC AND DEMENTIA WORKFORCE AND EFFORTS TO BOLSTER CARE

What the long-term care estimates do not take into consideration are market forces that may contribute to the rising cost of care. The U.S. will experience an imminent shortage of paid caregivers who provide direct care for the growing aging population and physicians who are certified in geriatric medicine or have dementia training. By 2030, an estimated 3.4 million direct care workers will be needed to work in LTSS settings to meet the future demand of growing diversity of the U.S. older adult population and greater use of home and community-based services (Spetz, Trupin, Bates, and Coffman, 2015; U.S. Department of Health and Human Services, Health Resources and Services Administration, and National Center for Health Workforce Analysis, 2017).

Since 1996 there has been decline in the number of certified geriatricians (American Board of Medical Specialties, 2018); (W.-C. Lee and Sumaya, 2013). In 2018 California had 736 certified geriatricians (American Board of Medical Specialties, 2018). Research shows that 30% of people 65 years of age and older need care from a geriatrician, and that each geriatrician can care for up to 700 patients (American

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[13] This assumes a $300 daily maximum of care expenses for two years. The daily maximum of care benefit was based on the daily cost of a semi-private room in a nursing home.

Geriatrics Healthcare Profesionals, n.d.). This translates to a demand for geriatricians that will most likely exceed supply. Additionally, specialty physicians, such as those located at the ten California Alzheimer's Disease Centers,[14] are most often relied on to provide work-up and diagnosis (see **Appendix I**). However, the number of these specialists is not sufficient to meet the overwhelming need (California Alzheimer's Disease Centers, 2018).

Table 8 shows the number of geriatricians needed in California to meet demand given the prevalence of AD for individuals 65 years of age and older compared to the prevalence of individuals 65 years of age or older without AD. Although the shortfall in the number of geriatricians is based on the number of certified geriatricians in 2018 (736), given the past history of a decline in the number of geriatricians, it is unlikely that there will be a significant increase that will meet the needs of the aging California population or those individuals with AD.

TABLE 8: ESTIMATED AND PROJECTED NUMBER OF GERIATRICIANS NEEDED TO CARE FOR CALIFORNIANS AGE 55+ WITH ALZHEIMER'S DISEASE AND FOR CALIFORNIANS AGE 65+ WITHOUT ALZHEIMER'S DISEASE, 2019, 2025, 2040

	2019		2025		2040	
	Demand	Shortfall	Demand	Shortfall	Demand	Shortfall
Californians with AD, 65+	1,004	-28%	1,308	-70%	2,278	-201%
California Population, 65+	2,625	-257%	3,331	-353%	4,728	-542%

*Note: Geriatricians needed for individuals 55+ years of age with AD is based on population prevalence estimates reported in this report. Geriatricians needed for individuals 65+ years of age without AD is based on 30-35% of the patient population over age 65 years will require the care of a geriatrician (Fried and Hall, 2008; Reuben, Bradley, Zwangziger, and Beck, 1993). The geriatrician shortfall was calculated based on the 2018 level of 736 Geriatricians.

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[14] The CADCs are a statewide network of ten dementia care Centers of Excellence at university medical schools, established by legislation in 1984 and funded by CDPH. The CADCs focus on reducing the burden of ADRDs in California by developing comprehensive diagnosis, treatment, education, and support services to with ADRDs and their caregivers (see **Appendix I**).

The shortage of the caregiver workforce and physicians with geriatric training will potentially negatively impact Californians and the health care system in two ways: the cost of health care may rise significantly as the workforce supply diminishes, and the quality and availability of care providers may decrease, placing adding pressures on family members and friends caring for loved ones who will experience additional financial pressures and may consider nursing home placements earlier in the disease process. Leaders in the field of geriatrics have suggested alternative approaches to achieve geriatric competency, other than attempting to train more geriatricians (Kotek, Bates, and Spetz, 2017; Petriceks, Olivas, and Srivastava, 2018; Tinetti, 2016). One approach is to view the existing certified geriatricians as an elite workforce whose mission is to ensure that every clinician caring for older adults is competent in geriatric principles and practices. With this strategy geriatrics is considered as a "metadiscipline" that transcends and informs all other disciplines and guiding all care (Tinetti, 2016).

In 2000, California responded to this worker shortage by funding the Caregiver Training Initiative (CTI), as part of the Governor's Aging with Dignity Initiative. The goals of the CTI project were to address urgent caregiver workforce shortages through innovative approaches for recruiting, training, and retaining caregivers in the healthcare industry and to enhance the earning potential of these workers to ensure that:

- California's communities have well-trained caregivers necessary for all levels of care for the older adult population;
- Communities have caregivers necessary for continuity of long-term care; and
- Caregivers have opportunities for entry-level employment, and for career advancement.

Twelve Regional Collaborators throughout California were awarded grants and the primary participants in the program were Workforce Investment Act clients and Welfare-to-Work clients. The initiative demonstrated that a long-term care worker shortage can be addressed by supporting programs to recruit, train, and retain individuals not currently in the workforce or who are underemployed (Matthias et al., 2003). However, these programs may be costly due to pre-training preparation, training, and supportive services needed for the individual and program success, thus, a greater focus is needed on the study of the factors leading to increasing retention of this workforce.

In 2011, through the Affordable Care Act, the federal government awarded about $15 million in grants to California and five other states to recruit and train qualified caregivers for older adults and people with disabilities (State of Health, 2015). The California Long-Term Care Education Center received a grant to train over 6,000 IHSS caregivers in Los Angeles, San Bernardino, and Contra Costa Counties. IHSS providers are in direct and frequent contact with the consumers they care for and are in the unique position to positively impact consumers' health. IHSS providers were trained to serve in an enhanced caregiving role and to be effective members of their consumers' care teams by bridging quality in-home care with the health care delivery system. IHSS consumers also received training to help them self-direct their own care. The training of home care workers was associated with better care, stronger health outcomes and at lower costs through reductions in consumers' use of the Emergency Department and hospitalizations, particularly repeat visits to the Emergency Room and readmissions to the hospital (California Long-Term Care Education Center, 2016). The cost saving implications to Medicare and Medicaid could be significant.

In 2018, the California Department of Social Services (CDSS) awarded a three-year contract to California State University, Sacramento, College of Continuing Education to administer the In-Home Supportive Services Training Academy (IHSSTA) (Sacramento State University, 2018). The IHSSTA serves all 58 counties and is California's statewide training provider for all aspects of the IHSS program, the largest in the U.S. Training participants include county social services workers, social work supervisors, quality assurance staff, administrative law judges, CDSS staff, and other staff designated by CDSS and the counties. The IHSSTA designs and delivers competency-based training to increase the quality and outcomes of care for those served. Throughout the year, Core Curriculum training courses are offered throughout the state (California Department of Social Services, n.d.-b).

Federally, the Administration on Aging/Administration for Community Living (AoA/ACL) has been funding grants under the Alzheimer's Disease Initiative – Specialized Support Services and Alzheimer's Disease Support Services Program. These programs work to establish dementia-capable care systems, provide services to special populations and training to staff serving persons living with dementia, and offer consultation and training for family caregivers. These grants support efforts at the state and local level to expand the availability of home and community-based services for people with dementia and their caregivers. Several projects within California have been recipients of the AoA/ACL grants. Also funded through the AoA/ACL is the National Alzheimer's and Dementia Resource Center which provides individualized technical assistance and other resources to projects that work to improve services for people with dementia and their caregivers (National Alzheimer's and Dementia Resource Center, n.d.; RTI International, n.d.).

Nationally, in 2015, the Geriatric Workforce Enhancement Program (GWEP) was created to improve the health outcomes for older adults by developing a healthcare workforce that maximizes patient and family engagement, and by integrating geriatrics and primary care. The goals of this program are to: 1) educate and train the primary care and geriatrics workforce to care for older adults in integrated geriatrics and primary care models, and 2) partner with community based organizations to address gaps in healthcare for older adults, promote age-friendly health systems and dementia-friendly communities, and address the social determinants of health. California is home to four GWEP Programs at the: University of Southern California; University of California, Irvine; San Diego State University Foundation; and The Regents of the University of California, San Francisco (American Geriatrics Healthcare Professionals, n.d.). The GWEPs work toward:

- Developing partnerships between academia, primary care delivery sites/systems, and community-based organizations.
- Training geriatrics specialists, primary care providers, and health professions students, residents, fellows, and faculty to assess and address the primary care needs of older adults.
- Delivering community-based programming that provides patients, families, caregivers, and direct care workers with the knowledge and skills to improve health outcomes for older adults.
- Providing training to patients, families, caregivers, direct care workers, healthcare providers, and health professions students, residents, fellows, and faculty on ADRDs and how cognitive and behavioral impairments impact medical care throughout the course of illness.

HOSPICE/PALLIATIVE CARE USE OR END OF LIFE CARE COSTS

While hospice care and palliative care are often provided together, they do differ. Both palliative care and hospice care provide comfort. But palliative care can begin at diagnosis, and at the same time as treatment. Hospice care begins after treatment of the disease is stopped and when it is clear that the person is not going to survive the illness.

Medicare and Medi-Cal cover palliative care services but do not use the word "palliative." Medicare has a hospice benefit that has four levels depending on the needed care: Routine Home Care, General Inpatient Care, Continuous Home Care, and Inpatient Respite Care. More than 90% of the hospices in the U.S. are certified by Medicare. Surprisingly, the hospice benefit is grossly underutilized. Although 51% of Medicare beneficiaries who died in 2018 were enrolled in hospice at the time of death, 40% of patients received care for 14 days or less, while those receiving care for more than 180 days accounted for 14% (National Hospice and Palliative Care Organization [NHPCO], 2020). Receiving hospice care for 14 days or less is insufficient to maximize the available services of hospice care. The *National Hospice and Palliative Care Organization* (NHPCO) *Facts and Figures* report (2020) indicated the percentage of California Medicare decedents enrolled in hospice at the time of death in 2018 was 46%. California ranked 36 among all states for decedent enrollment in Medicare hospice. Utah had the highest enrollment of 61% and Alaska the lowest enrollment of 23%.

According to 2016 Medicare hospice use data for California, 19% of individuals who used hospice had a diagnosis of dementia. Individuals diagnosed with cancer or diagnosed with circulatory/heart disease had a higher hospice use, 27% and 20%, respectively (Centers for Medicare and Medicaid Services, 2018). Since 2014 the use of hospice care among individuals with dementia has essentially remained unchanged.

Nationally, the *NHPCO Facts and Figures* report (2020) found that individuals with a principal diagnosis of dementia had the largest number of days of care on average (105 days) and differed in hospice use from those with other diseases. Individuals with a dementia diagnosis tended to be either enrolled in hospice for a very short (one week or less) or a very long (longer than six months) period of time (De Vleminck, Morrison, Meier, and Aldridge, 2018).

Having a diagnosis of dementia also led Medicare hospice spending for beneficiaries at 25%, compared to 18% for beneficiaries having a cancer diagnosis (NHPCO, 2020). The higher Medicare hospice spending for individuals might be attributable to multiple considerations such as the duration of the illness and utilizing a large number of hospice days of care. Also, because of the slow and unpredictable progression of dementia, it is not unusual for individuals with dementia to have several episodes of enrollment and disenrollment in hospice care.

Costs at the end of life are significant, regardless of cause and whether hospice is used. However, the total costs for decedents diagnosed with dementia is significantly greater than other diseases, with much of those expenses uninsured, thus placing a large financial burden on families. These burdens are particularly pronounced among demographic groups least prepared for financial risk (Alzheimer's Association, 2019a; Kelley, McGarry, Gorges, and Skinner, 2015).

In the last five years of life for individuals with dementia the total cost was $357,650 per person compared to $228,020 per person for individuals without dementia (translated to 2018 dollars), a difference of 57%. Additionally, out-of-pocket costs represented a substantially larger proportion of total wealth for those with dementia than for people without dementia (32% vs. 11%) (Alzheimer's Association, 2019a; Kelley et al., 2015). While Medicare expenditures were similar across groups, it was the average out-of-pocket spending and unpaid care costs for dementia patients ($61,522 and $83,022, respectively) that was significantly higher than for non-dementia patients ($34,068 and $38,272, respectively). The out-of-pocket expenses for individuals diagnosed with dementia is 81% higher compared to non-dementia causes. The difference in costs for unpaid care is even greater for individuals diagnosed with dementia versus other causes, 116%. Not only was absolute out-of-pocket spending significantly higher within the dementia group, but out-of-pocket spending as a proportion of total household wealth five years prior to death was also substantially higher, median of 32% for dementia and 11% for other diseases. This proportion was greater for Black/African Americans (84%), those with less than high school education (48%), and unmarried/widowed women (58%) (Alzheimer's Association, 2019a; Kelley et al., 2015).

COST TO CALIFORNIA BUSINESSES

PRODUCTIVITY LOSSES TO CALIFORNIA BUSINESSES

Much of the onus for providing care to people living with AD will fall on the working-age population. Employees older than 50 years of age are often in their peak earning years which is also the time period for that an individual is at the greatest risk of being a caregiver for an older relative (MetLife, 2011). Employed caregivers provide care for an average of three point seven years (National Alliance for Caregiving and AARP, 2015). As discussed in the previous section, workers trying to balance caregiving and work responsibilities are experiencing greater and greater stress because of rising health care and professional caregiving costs. Furthermore, employee workdays can be subject to unplanned interruptions, which undermines their productivity and inhibit their longer-term career prospects, or trigger turnover because they must leave the workforce altogether. Because of substantial caregiving obligations, employees often arrive on the job physically drained and emotionally distracted. While the cost of caregiving on businesses due to employee turnover, loss of institutional knowledge, and temporary hiring, in addition to substantial productivity costs such as absenteeism and presenteeism[15] is difficult to measure, studies suggest the costs to be massive and underestimated (Fuller and Raman, 2019). Nationally, the total estimated aggregate lost wages, pension, and Social Security benefits of these caregivers of parents is nearly $3 trillion (MetLife, 2011). For an individual female caregiver, the cost impact of caregiving on lost wages and Social Security benefits amounts to $324,044. For a male caregiver the impact of lost wages and benefits equals $283,716 (MetLife, 2011).

The issue of how caregiving impacts a business is both neglected by employers and hidden by employees. Employers rarely account for how caregiving responsibilities might be affecting their workforce, nor do they factor in such costs while evaluating potential investments to enhance worker productivity. Many employees hide the growing burden of caregiving responsibilities. They struggle to balance the responsibilities of work and caregiving and when the emotional and physical stress becomes too much, some respond by reining in their ambitions, such as, reducing their working hours or

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[15] Presenteeism is when workers are present for work but may be distracted, thus not optimizing their capacity. (*Supporting Caregivers in the Workplace: A Practical Guide for Employers*. (2017, September). AARP. Retrieved January 28, 2021, from https://www.aarp.org/content/dam/aarp/work/job-search/2019/02/NEBGH-caregiving-practical-guide.pdf)

dropping out of the workforce altogether. This leaves employers often paying another major cost, the loss of talented and trained employees.

It is estimated that the number of caregivers of people living with ADRDs in California is 1,621,000 (Alzheimer's Association, 2019a). As shown in ***Table 9***, the estimated cost to California employers in lost productivity annually from full-time and part-time employed caregivers is $8.3 billion. The majority of these costs is attributable to attempting to replace caregivers who leave the workforce. The loss of these workers costs California businesses an estimated loss in economic productivity in excess of $5.3 billion annually. This figure is based on an estimate of 22% of employed caregivers who leave the workplace (AARP, 2018a, 2018b; Guengerich, 2018, 2019).

In addition to replacing employee caregivers who leave the work force, absenteeism is particularly costly to California businesses. Approximately 33% of employed caregivers (230,020) miss work from arriving late to taking three or more days off, and half of these employees missed at least 16 hours of work during a two-week period (Scharlach et al., 2003). This resulted in an estimated 400 hours of work missed annually by caregivers. Using the median wage of $20.40, this resulted in $1.8 billion in caregiver absenteeism costs to California businesses.

TABLE 9: TOTAL ESTIMATED COST TO CALIFORNIA BUSINESSES OF FULL-TIME EMPLOYED CAREGIVERS:2018[16]

	# of Caregivers	Cost per Employee	Total Employer Cost
Replacing Employees	153,347	$7,657	$5,337,151,740
Absenteeism	230,020	$2,693	$1,876,962,384
Workday Interruptions	312,269	$457	$318,514,829
Elder Crisis	313,664	$220	$153,569,650
Supervisor Time	320,564	$124	$86,321,500
Unpaid Leave	83,664	$196	$136,506,355
Full-Time to Part-Time	141,149	$813	$424,734,765
TOTAL		**$12,160**	**$8,333,761,223**

Note: Refer to **Appendix B** for a description of the methodology.

In the coming years, as the baby boomers' age and life expectancy increases, more workers will be taking on the responsibility of caregiving for loved ones, the costs to California businesses will continue to rise. Unfortunately, at this time there is a misalignment between what employers offer and what employees need among those who are caregivers (Fuller and Raman (2019)). This is partly due to employers being unaware of the magnitude and impact caregiving can have on their employees and business. Based on existing studies, several researchers have offered suggestions towards easing the undesired impact caregiving responsibilities has on businesses, such as (Fuller and Raman, 2019; Metlife, 2006, 2011; Schulz and Eden, 2016; Vega et al., 2017):

- Improved acknowledgement and recognition of the responsibilities of family caregivers;

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[16] To estimate the productivity losses to California businesses, several sources of data were used. Refer to Appendix B for an explanation of the methodology used for these calculations. The *2019 Alzheimer's Facts and Figures* (Alzheimer's Association, 2019a) reported 1,621,000 caregivers of recipients with AD or dementia in California. The California median hourly wage used in these calculations was obtained from the May 2018 United States Department of Labor Bureau of Labor Statistics. Productivity losses are based on percent of California caregivers who are employed which translates to 697,030 caregivers. To calculate the different components effecting businesses, we followed the model used in "The MetLife Caregiving Cost Study: Productivity Losses to U.S. Business" (2006).

- More flextime and flexible work arrangements, such as telecommuting and job-sharing;
- Employee and/or employer funded long-term care insurance;
- Increased access and improved communication with health care providers;
- Increased access to information, referral, and educational programs; and
- Increased access to affordable and tailored services and programs that provide respite care, adult day services, and caregiver support groups.

California was the first state to create a paid family leave program (PFL) in July 2004. In July 2020, Senate Bill (SB) 83, that was passed by the Legislature and approved by Governor Newsom, extended from six to eight weeks the maximum duration of PFL benefits individuals may receive from California's State Disability Insurance program to care for a seriously ill child, spouse, parent, grandparent, grandchild, sibling, or domestic partner; or to bond with a minor child within one year of the birth or placement of the child via foster care or adoption. The PFL program does not provide job protection unless employees are covered by the federal Family and Medical Leave Act and the California Family Rights Act.

Additionally, the California Family Rights Acts was expanded through SB 1383. Passed by the California Legislature and approved by California Governor Newsom, beginning January 2021, SB 1383 made it an unlawful employment practice for any employer with five or more employees to refuse to grant a request by an employee to take up to 12 work weeks of unpaid protected leave during any 12-month period to bond with a new child of the employee or to care for themselves or a child, parent, grandparent, grandchild, sibling, spouse, or domestic partner, as specified.

CONCLUSION

The impact of dementia is being felt across all sectors of society. This report offers information to help California better meet the growing demand for support and services that meaningfully address the needs of individuals living with ADRDs. It will allow California constituents, legislators, and health advocates to develop policies and programs to address the needs and improve the quality of care available to individuals living with ADRDs and their families.

California has the largest older adult population in the nation and the most people living with ADRDs. These numbers are projected to double over the next decade, requiring critical investments today to prepare our state for future growth. Governor Newsom demonstrated his commitment to prioritizing Californians directly impacted by ADRDs through significant new investments such as the Master Plan for Aging (https://mpa.aging.ca.gov/) as well as key ten final recommendations provided by the Governor's Task Force on Alzheimer's Disease Prevention, Preparedness, and Path Forward (http://caalztaskforce.org/). Additionally, the State has invested in a network of ten California Alzheimer's Disease Centers, ADRDs research with a focus on women and communities of color, and six California Healthy Brain Initiative State and Local Public Health Partnerships (https://www.cdph.ca.gov/). These targeted initiatives demonstrate the State's shared commitment to improving health outcomes and reducing disparities in California through meaningful response to ADRDs in the coming years.

APPENDICES

APPENDIX A – OVERVIEW OF ALZHEIMER'S DISEASE AND RELATED DEMENTIAS[17]

This section provides information about the definition of dementia, the characteristics of specific types of dementia, and the symptoms and risk factors for, and treatment of, Alzheimer's disease (AD). AD is the most common cause of dementia. More detailed information on these topics is available from the Alzheimer's Association (https://www.alz.org/) as well as the California Department of Public Health, Alzheimer's Disease Program (https://www.cdph.ca.gov/Programs/CCDPHP/DCDIC/CDCB/Pages/AlzheimersDiseaseProgram.aspx).

Dementia: Definition and Specific Types

Dementia is an overall term for a particular group of symptoms. The characteristic symptoms of dementia include a decline in memory as well as impairment in at least one of the following cognitive abilities that is severe enough to interfere with daily life:

- language, such as ability to generate coherent speech and understand spoken or written language;
- recognition, such as the ability to identify objects, assuming intact sensory function;
- movement, such as the ability to execute motor activities, assuming intact motor abilities, sensory function and comprehension of the required tasks; and

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[17] Portions of this report contain information reprinted and/or adapted with permission from Alzheimer's and Dementia, 2019, Volume 15, Pages 321–387, Alzheimer's Association, 2019 Alzheimer's Disease Facts and Figures. https://www.sciencedirect.com/science/article/pii/S1552526019300317, last accessed 7/8/2019.

- problem-solving, such as the ability to think abstractly, make sound judgements and plan and carry out complex tasks.

Different types of dementia have been associated with distinct symptom patterns and distinguishing microscopic brain abnormalities. Increasing evidence from long-term epidemiological observation and autopsy studies suggest that many people have microscopic brain abnormalities associated with more than one type of dementia. The symptoms of different types of dementia also overlap and can be further complicated by coexisting medical conditions. **Table A1** provides information about the most common types of dementia.

TABLE A1: COMMON TYPES OF DEMENTIA AND THEIR TYPICAL CHARACTERISTICS[18]

Type of Dementia	Characteristics
Alzheimer's disease	• The most common type of dementia; accounts for 60% to 80% of cases. • Difficulty remembering recent conversations, names or events is often an early clinical symptom; apathy and depression are also often early symptoms. Later symptoms include impaired communication, disorientation, confusion, poor judgment, behavioral changes and, ultimately, difficulty speaking, swallowing and walking. • Hallmark pathologies are accumulation of protein fragment beta-amyloid (plaques) outside neurons in the brain and twisted strands of the protein tau (tangles) inside neurons. • Slowly progressive brain disease that begins many years before symptoms emerge.
Cerebrovascular disease	• Considered the second most common type of dementia. • Blood vessels in brain are damaged and/or brain tissue is injured from not receiving enough blood, oxygen or nutrients, leading to areas of dead tissue or bleeding in the brain. • Commonly a mixed pathology, with most people living with dementia showing the brain changes of cerebrovascular disease and AD. • Impaired judgment or impaired ability to make decisions, plan or organize may be the initial symptom, but memory may also be affected, especially when the brain changes of other causes of dementia are present. In addition to changes in cognitive function, people with vascular dementia commonly have difficulty with motor function, especially slow gait and poor balance.
Mixed dementia	• When an individual shows the brain changes of more than one cause of dementia. • Mixed dementia is more common than previously recognized.

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[18] Portions of this report contain information reprinted and/or adapted with permission from Alzheimer's and Dementia, 2020, Volume 16, Pages 391-460, Alzheimer's Association, 2020 Alzheimer's Disease Facts and Figures. DOI: 10.1002/alz.12068, last accessed 5/1/2020.

	• The likelihood of having mixed dementia increases with age and is highest in people age 85 or older.
Lewy body disease	• Lewy bodies are abnormal clumps of the protein alpha-synuclein in neurons. When they develop in a part of the brain called the cortex, dementia can result. • People with Lewy body disease have some of the symptoms common in Alzheimer’s but are more likely to have initial or early symptoms of sleep disturbances, well-formed visual hallucinations and visuospatial impairment. These symptoms may occur in the absence of significant memory impairment, but memory loss often occurs, especially when the brain changes of other causes of dementia are present. • Most people with Lewy body disease also have AD pathology.
Parkinson’s disease	• Problems with movement are common symptoms. • Cognitive symptoms develop either just before movement symptoms or later in the disease. • As Parkinson’s disease progresses, it often results in dementia secondary to the accumulation of alpha-synuclein in the cortex (similar to dementia with Lewy bodies).
Frontotemporal dementia	• Symptoms include changes in personality and behavior and/or difficulty with producing or comprehending language. Unlike Alzheimer’s, memory is typically spared in the early stages of disease. • Nerve cells in the front and side regions of the brain are affected, and these regions become shrunken. In addition, the upper layers of the cortex typically become soft and spongy and have abnormal protein inclusions. • Possibly the most common cause of dementia in people younger than 60. • Pick’s disease (“Pick’s bodies”) is one type of frontotemporal dementia.
Creutzfeldt-Jakob disease	• Rapidly fatal disorder that impairs memory and coordination and causes behavior changes. • “Variant Creutzfeldt-Jakob disease” is believed to be caused by consumption of products from cattle affected by “mad cow disease.” • Caused by the misfolding of prion protein throughout the brain.
Normal pressure hydrocephalus	• Caused by the buildup of fluid in the brain. • Symptoms include difficulty walking, memory loss and inability to control urine. • Can sometimes be corrected with surgical installation of a shunt in the brain to drain excess fluid.

Causes of Dementia

AD is the most common type of dementia. Nationally, AD accounts for 60% to 80% of cases. About 5% to 10% of individuals with dementia show evidence of vascular dementia alone. About 5% of individuals with dementia show signs of Lewy body disease alone. Frontotemporal dementia accounts for about 3% of dementia cases in people 65 years of age and older and about 10% of dementia cases in studies of people younger than 65 (Alzheimer's Association, 2020).

Mild cognitive impairment is a condition in which a person has problems with memory, language, or other essential cognitive function that is severe enough to be noticeable to others and show up on psychometric tests, but not severe enough to interfere with daily life. Some people with mild cognitive impairment go on to develop dementia. For others, the symptoms of mild cognitive impairment do not progress to dementia, and some people who have mild cognitive impairment at one point in time later revert to normal cognitive status. Due to differences in how mild cognitive impairment is defined, the incidence and prevalence is not yet understood – research actively continues in this area.

Alzheimer's Disease

In AD, as in other types of dementia, increasing numbers of nerve cells deteriorate and die. A healthy adult brain has 1000 billion nerve cells, or neurons, with long branching extensions connected at 100 trillion points. At these connections, called synapses, information flows in tiny chemical pulses released by one neuron and taken up by the receiving cell. Different strengths and patterns of signals move constantly through the brain's circuits, creating the cellular basis of memories, thoughts and skills.

In AD, information transfer at the synapses begin to fail, the number of synapse declines and eventually cells die. In a brain with advanced AD, there is dramatic shrinkage from cell loss and widespread debris from dead and dying neurons.

Scientists do not yet fully understand the processes that result in the catastrophic brain damage associated with AD. According to a leading theory, called "amyloid hypotheses," the prime suspect is a tiny protein fragment called beta-amyloid. Trouble begins when yet-to-be-identified factors trigger overproduction of beta-amyloid and reduce the brain's ability to dispose of it. The excess jams signaling at the synapses, blocking information flow and leading to a cascade of damaging events ending in cell death.

Beta-amyloid fragments gradually accumulate into the microscopic “plaques” considered to be one pathological hallmark of AD. The other hallmark is “tangles,” formed when a different protein called tau twists into strands inside dead and dying neurons. Other abnormalities seen in AD brain tissue include inflammation and oxidative damage due to highly reactive oxygen-containing products of cellular metabolism.

Symptoms of Alzheimer’s Disease

Individuals typically live with AD symptoms for years. The pace at which symptoms advance from mild to moderate to severe varies from person to person; however, as the disease progresses, cognitive and functional abilities decline. Over time, symptoms tend to increase and start interfering with individuals' ability to perform everyday activities. At this point, the individual is said to have dementia due to AD, or Alzheimer's dementia.

Age is the most significant risk factor for developing AD. One in 10 people (10%) 65 years of age and older has Alzheimer’s dementia. The percentage of people with Alzheimer’s dementia increases with age: 3% of people age 65-74, 17% of people 75-84, and 32% of people age 85 years and older have Alzheimer’s dementia (Alzheimer's Association, 2020). It is important to note that Alzheimer’s dementia is not a normal part of aging, years of age and older age alone is not sufficient to cause Alzheimer’s dementia (Herbert, Weuve, Scherr, and Evans, 2013)

In the mild stage of Alzheimer's dementia, most people are able to function independently in many areas but are likely to require assistance with some activities to maximize independence and remain safe. They may still be able to drive, work and participate in favorite activities. As the disease progresses, neurons in other parts of the brain are damaged or destroyed. Activities that used to be core to the individual's identity, such as planning family events or participating in sports, may no longer be possible. In the moderate stage of Alzheimer's dementia, which is often the longest stage, individuals may have difficulties communicating and performing routine tasks, including activities of daily living (ADLs) (such as bathing and dressing); become incontinent at times; and start having personality and behavioral changes, including suspiciousness and agitation.

Eventually, neurons in parts of the brain that enable a person to carry out basic bodily functions, such as walking and swallowing, are affected. In the severe stage of Alzheimer's dementia, individuals need help with ADLs and are likely to require around-the-clock care. Individuals who lose their ability to control swallowing are at heighten vulnerability to malnutrition and dehydration. People in the final stages of AD are bed-bound and the disease is, ultimately, fatal.

The effects of AD on an individual's physical health become especially apparent in the severe stage of Alzheimer's dementia. Because of damage to areas of the brain involved in movement, individuals become bed-bound. Being bed-bound makes them vulnerable to conditions including blood clots, skin infections and sepsis, which triggers body-wide inflammation that can result in organ failure. Damage to areas of the brain that control swallowing makes it difficult to eat and drink. This can result in individuals swallowing food into the trachea (windpipe) instead of the esophagus (food pipe). Food particles may be deposited in the lungs and cause lung infection. This type of infection is a contributing cause of death among many individuals with AD.

It is important to note that some individuals have dementia-like symptoms without the progressive brain changes of AD or other degenerative brain diseases.

Common causes of dementia-like symptoms are depression, untreated sleep apnea, delirium, side effects of medications, thyroid problems, certain vitamin deficiencies and excessive alcohol consumption. Unlike AD and other dementias, these conditions often may be reversed with treatment. Those with AD live an average of eight years after their symptoms become noticeable to others, but survival can range from four to twenty years, depending on age and other health conditions. On average, a person with AD will spend more years in the most severe stage of the disease than in any other stage. Much of this time may be spent in a nursing home, as nursing home admission by age 80 is expected for 75% of people with AD compared with only 4% of the general population.

APPENDIX B – METHODOLOGICAL NOTES AND DATA SOURCES

B1. Alzheimer’s Disease Prevalence Projection Methods

The prevalence of AD in residents aged 65 years of age and older in California and its counties was calculated using prevalence rates published by the Alzheimer's Association (2019a) that were based upon estimates by Hebert, Weuve, Scherr, and Evans (2013) using the 2010 census – refer to p. 17 of the *2019 Alzheimer’s Disease Facts and Figures*. The age breakdown of the prevalence rates is: (a) 3% for age 65-74, (b) 17% of people age 75-84, and (c) 32% for age 84 years of age and older. These prevalence rates were applied to California Department of Finance population projections for race/ethnicity and sex for the years 2019, 2025, and 2040. Estimates of lesbian, gay, and bisexual populations in California were calculated using the AskCHIS tool and applied to the California Department of Finance population projections for the years 2019, 2025, and 2040. Estimates of prevalence by sex were arrived at using prevalence estimates from Plassman et al. (2007).

For California residents under the age of 65, estimates of AD were calculated using prevalence rates published by the Alzheimer's Association (2006) report *Early Onset Dementia*: *A National Challenge, A Future Crisis* and the Alzheimer's Association (2019a) *2019 Alzheimer’s Disease Facts and Figures*. An estimate of the number of individuals with dementia was first calculated and then the number of individuals with AD was computed. The Alzheimer’s Association (2006) *Early Onset Dementia*: *A National Challenge, A Future Crisis* report indicates the proportion of people between the ages of 55-59 with disabling cognitive impairment was 1.9% and the prevalence increased to 2.2% for people aged 60-64. The California prevalence for individuals age 55-59 and 60-64 were determined using these figures on the California Department of Finance population projections for the years 2019, 2025, and 2040. The Alzheimer's Association (2007) report, *Alzheimer’s Disease Facts and Figures 2007,* indicated that a conservative estimate of the number of individuals younger than 65 with dementia who are likely to have AD ranges between 40% to 50%. To arrive at an approximation of the number of Californians with AD between 55-64 of age, we applied the lower range of this estimate, 40%, to the previously calculated dementia frequencies (Alzheimer's Association, 2009).

B2. Lifetime Risk of Alzheimer’s Disease and Dementia Projection Methods

The estimate of lifetime risk of dementia and AD for California baby boomers, individuals born between 1946 through 1964, was calculated using figures published by Chene et al. (2015). Estimates of adjusted cumulative incidence were applied to Californians by sex. The breakdown of cumulative incidence by sex and age are: Dementia - (a) 22.7% for women age 45 years of age and older, (b) 13.8% for men age 45 years of age and older, (c) 24.6% for women 65 years of age and older, (d) 15.5% for men 65 years of age and older, and AD – (a) 19.5% for women age 45 years of age and older, (b) 10.3% for men age 45 years of age and older, (c) 21.1% for women 65 years of age and older, (d) 11.6% for men 65 years of age and older. These figures were applied to the California Department of Finance population projections for the years 2019, 2025, and 2040. Estimates of cumulative incidence for dementia and AD for age 45 years of age and older were applied to men and women age 55-62 and estimates of cumulative incidence for dementia and AD 65 years of age and older were applied to men and women age 63-73.

B3. Mortality and Alzheimer's Disease Death Rates

Data on the death rates of AD by race/ethnicity in California were collected from the *WONDER Online Database* administered by the U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, and National Center for Health Statistics (n.d.). Data was categorized by race and year, with the addition of ethnicity for Latino/Latina/Latinx (Latino/a/x) American. Rates were per 100,000 population. ICD-10 codes G30 were used. White/Caucasian, not Hispanic or Latino, African American, Asian/Pacific Islander, and Native American excluded Latino/a/x American ethnicity. Latino/a/x American includes any race category, therefore accounting for higher than 100% totals for percentage of AD deaths in **Table D2**.

Data on the death rates of AD by county were collected from the County Health Status Profiles 2019 created by the California Department of Public Health (Greene et al., 2019).

B4. Paid and Unpaid Caregiving Costs

To calculate the paid and unpaid costs of caregiving for people with AD, we used the same framework from the 2009 report, *Alzheimer's Disease Facts and Figures in California* (Ross, Brennan, Nazareno, and Fox, 2009). The following is the description of the 2009 methodology which was updated with 2019 dollars.

Data on the paid and unpaid costs of caregiving for people with AD were derived using figures from a California study by Rice et al. (1993). Paid and unpaid costs of caring were calculated separately for people with mild/moderate AD and severe AD (MMSE <=17 is severe; above 17 mild/moderate).

Total annual costs for each category were converted to 2019 dollars using the Consumer Price Index inflation calculator comparing May 2009 to May 2019 (1.27), as reported by the United States Department of Labor and the United States Census Bureau (U.S. Bureau of Labor Statistics. CPI Inflation Calculator. https://www.bls.gov/data/inflation_calculator.htm. Accessed on 4/7/20.)

Unpaid costs were converted using changes in the hourly compensation in the business sector. Each component of costs from the Rice et al. (1993) study was converted into categories of the Consumer Price Index for All Urban Consumer as follows (U.S. Bureau of Labor Statistics. Consumer Price Index for All Urban Consumers CPI-U: U.S. city average, by expenditure category. https://www.bls.gov/news.release/cpi.t01.htm. Accessed on 4/7/20):

- Hourly compensation in the business sector – unpaid services
- Hospital – hospital and related services
- Nursing Home – medical care services
- Physician visits – professional services
- Medications – medical care commodities

- Medical items – medical care commodities
- Social services – medical care services
- Other – medical care services

After a review of the literature, we did not find contemporary research on distinguishing the prevalence of mild/moderate AD and severe AD in the United States of America. Because the cost of care for early and late stages of AD vary, we used the 2009 report distribution of individuals with mild/moderate AD and severe AD. In 2009 the mild/moderate and severe AD categories were derived using data from the California Department of Public Health's AD Research Centers of California (ARCCs) Minimum Uniform Data Set for the years 1998-2008 for patients 65 years of age and older who were diagnosed with AD. The ARCCs are state-funded clinics located primarily at university medical centers within California.

The various severity cost components were applied to the California prevalence rates as follows: severely impaired patients evaluated—30.9% of the total; mild/ moderately impaired patients—69.01% of the total.

B5. Cost to the Medi-Cal Program

Menzin et al. (1999) published a study looking at California Medi-Cal administrative claims data for the purposes of evaluating the costs to the Medi-Cal program for individuals with ADRDs compared to individuals without dementia. To obtain the Medi-Cal estimates discussed in this report, we extracted the costs reported by Menzin et al. (1999), that were in 1995 dollars, and updated the costs to 2019 dollars using economic indices reported by the United States Department of Labor and the United States Census Bureau (US Bureau of Labor Statistics. CPI Inflation Calculator. https://www.bls.gov/data/inflation_calculator.htm. Accessed on 4/7/20, — see method note F3 for the listing of indices used.)

B6. Costs to California Businesses

To calculate the different components effecting businesses, we followed the model used in The Metlife (2006) *Caregiving Cost Study: Productivity Losses to U.S. Business* report. To estimate the productivity losses to California businesses, several sources of data were used (California Employment Development Department, n.d.; Metlife, 2006; Payscale.com, n.d.; Scharlach et al., 2003; U.S. Bureau of Labor Statistics, n.d.-b). Productivity losses are based on the *2018 AARP California Caregiver Survey* (AARP, 2018a; Guengerich, 2018) which found 43% of caregivers who are employed outside of the home. Using the *2019 Alzheimer's Facts and Figures* (Alzheimer's Association, 2019a) report of 1,621,000 caregivers of recipients with AD or dementia in California. Based in information from the *2018 AARP California Caregiver* report (AARP, 2018a), we estimated there were 697,030 caregivers in California. The *2018 AARP California Caregiver* (AARP, 2018a; Guengerich, 2018) survey also found that 75% of caregivers are employed full-time and 25% are employed part-time.

Replacement Costs

To estimate the number of caregivers who leave the workplace on an annual basis, we used the *2018 AARP California Caregiver* (AARP, 2018a; Guengerich, 2018) survey which estimates that approximately 22% of caregivers leave the workplace over the course of caregiving. Scharlach et al. (2003) found the average length of time providing care for employed caregivers is 3.7 years. Thus, the estimated number of caregivers leaving the workplace on an annual basis is 5.64%. The median income was based on information from the California Department of Finance website, http://www.dof.ca.gov/Forecasting/Economics/Indicators/Income/ (Accessed 1/21/20). The year for median income used was May 2018 when the median income was $69,609—50% of this salary was used to calculate replacement cost. Source: U.S. Census Bureau, American Community Survey 1-Year Estimates, Deflated by CA Department of Finance using the Personal Consumption Expenditures Deflator (2012=100).

Absenteeism Costs

To estimate absenteeism costs, we used the figures reported by the *2018 AARP California Caregiver* (AARP, 2018a; Guengerich, 2018) survey that 33% of employed caregivers missed work from arriving late to taking 3 or more days off. Scharlach et al. (2003) found that 50% missed at least 16 hours of work in 2 weeks prior to the study interview. This resulted in 230,020 employed caregivers missing approximately 400 hours per year. The costs were then derived by applying the California median hourly wage, $20.40, obtained from the May 2018 United States Department of Labor Bureau of Labor Statistics. Source: U.S. Department of Labor Bureau of Labor Statistics, https://www.bls.gov/oes/current/oes_ca.htm#00-0000, Accessed on January 21, 2020

Workday Interruptions

The Metlife (2006) *Caregiving Cost Study: Productivity Losses to U.S. Business* report estimates that 44.8% of employed caregivers experience workday interruptions and the number of interrupted hours is 50 per year.29 The costs were then derived by applying the California median hourly wage, $20.40, obtained from the May 2018 United States Bureau of Labor Statistics.

Elder Crisis

The MetLife (2006) *Caregiving Cost Study: Productivity Losses to U.S. Business* report estimates that 60% of employed caregivers experience an occasional crisis when they have to take off a few days to make arrangements for services, move a loved one to a different living situation, or deal with a hospitalization which results in an estimated 3 days (24 hours) per year loss of work. The costs due to elder crisis were then derived by applying the California median hourly wage, $20.40, obtained from the May 2018 United States Bureau of Labor Statistics.

Reducing Time from Full-time to Part-time Status

These costs were estimated separately for small businesses (0-499 employees) and large businesses (500+ employees). The *2018 AARP California Caregiver* survey (AARP, 2018a; Guengerich, 2018) found that 27% of caregivers need to reduce their hours of employment. The California Employment Development Department estimates that 79.1% of Californians are employed in small businesses and approximately 20.8% are employed in large businesses (https://www.labormarketinfo.edd.ca.gov/LMID/Size_of_Business_Data.html Accessed 1/21/20). Using these estimates results in 111,507 caregivers employed in small businesses and 29,641 caregivers in large businesses who will likely reduce the amount of time that they work due to caregiver responsibilities. 50% of the average monthly salary for small and large businesses was obtained to calculate the costs associated with going from full- to part-time employment—$2,661 for small businesses and $4,318 for large businesses https://www.labormarketinfo.edd.ca.gov/LMID/Size_of_Business_Data.html (Accessed 1/21/20)

Supervision Costs

The MetLife (2006) *Caregiving Cost Study: Productivity Losses to U.S. Business* report estimates that 45.9% of employed caregivers have supportive supervisors. This resulted in 320,563 caregivers with supportive supervisors. Similar to the procedures in The MetLife (2006) *Caregiving Cost Study: Productivity Losses to U.S. Business* report, we took the California median hourly wage and increased this by 10% to estimate a supervisors' wage. It is estimated that supervisors spent one hour per month (12 hours per year) supervising these employees.

Unpaid Leave Costs

The MetLife (2006) *Caregiving Cost Study: Productivity Losses to U.S. Business* report estimates that 16% of employed caregivers take unpaid leave—83,644 California care- givers—for a total of 10 days per year. The California median hourly wage was used to calculate the cost of unpaid leave based on a seven-hour day.

TABLE C1: ESTIMATED NUMBER AND PERCENT CHANGE IN PEOPLE AGE 55+ WITH ALZHEIMER'S DISEASE: 2019, 2025, AND 2040 – CALIFORNIA AND COUNTIES

County	2019	2025	2040	% change 2019-2025	% change 2025-2040	% change 2019-2040
Alameda	28,045	37,430	69,264	35	83	147
Alpine	28	42	67	54	57	142
Amador	1,190	1,545	2,282	31	46	92
Butte	4,861	5,806	8,041	21	37	65
Calaveras	1,450	1,955	2,997	36	52	107
Colusa	402	487	763	22	55	90
Contra Costa	21,857	29,265	54,073	35	83	147
Del Norte	589	685	910	17	32	55
El Dorado	4,484	6,080	10,153	37	65	126
Fresno	14,643	18,461	31,085	27	67	112
Glenn	548	648	954	20	46	74
Humboldt	2,686	3,384	5,109	27	49	90
Imperial	3,117	3,858	6,547	25	68	110
Inyo	490	606	992	25	62	102
Kern	11,487	14,390	23,793	27	64	107
Kings	1,847	2,281	3,493	25	52	89
Lake	1,656	2,021	2,620	23	29	58
Lassen	556	702	1,044	28	47	88
Los Angeles	177,345	228,012	416,531	30	81	135
Madera	2,707	3,435	5,244	28	51	94
Marin	7,117	9,395	14,520	33	53	104
Mariposa	605	755	1,135	26	49	88
Mendocino	2,002	2,682	3,959	35	46	98
Merced	3,666	4,700	8,102	29	71	121
Modoc	301	373	456	25	21	52
Mono	175	313	745	81	135	325
Monterey	7,406	9,408	16,202	28	71	119
Napa	3,086	4,005	6,246	31	55	102
Nevada	3,112	4,082	5,965	32	45	92
Orange	59,339	76,035	131,906	29	72	122
Placer	9,760	12,869	20,777	33	60	113
Plumas	664	839	1,033	27	22	56
Riverside	44,694	58,470	108,287	32	83	142
Sacramento	24,885	32,244	56,525	31	74	127
San Benito	937	1,258	2485	36	95	165

County	2019	2025	2040	% change 2019-2025	% change 2025-2040	% change 2019-2040
San Bernardino	28,925	37,973	69,614	33	81	141
San Diego	58,616	75,491	133,257	30	75	127
San Francisco	18,749	23,037	37,153	24	60	98
San Joaquin	10,999	14,448	26,484	33	81	141
San Luis Obispo	6,885	9,029	14,968	32	64	117
San Mateo	16,289	20,740	34,612	28	65	112
Santa Barbara	8,505	10,256	16,758	22	62	97
Santa Clara	35,314	45,924	82,336	31	78	133
Santa Cruz	4,895	6,822	12,403	41	80	153
Shasta	4,153	4,930	6,689	20	34	61
Sierra	113	142	176	27	22	56
Siskiyou	1,318	1,593	1,983	22	23	50
Solano	8,220	11,135	19,566	37	74	138
Sonoma	11,545	15,693	27,443	37	73	138
Stanislaus	8,398	10,594	17,743	27	66	111
Sutter	1,787	2,170	3,342	23	53	87
Tehama	1,454	1,747	2,328	21	32	60
Trinity	460	570	690	25	20	50
Tulare	6,427	8,104	13,261	27	62	106
Tuolumne	1,605	2,028	2,908	27	42	81
Ventura	15,807	20,425	36,445	30	77	131
Yolo	3,285	4,357	7,496	34	70	128
Yuba	1,075	1,349	2,301	27	69	114
CALIFORNIA	702,556	907,080	1,594,262	30	74	127

Source: State of California, Department of Finance, *E-1 Population Estimates for Cities, Counties and the State with Annual Percent Change — January 1, 2019 and 2020.* Sacramento, California, May 2019. Accessed July 2, 2019. Please see Appendix B for methodology used to estimate California Alzheimer's disease prevalence.

TABLE C2: ESTIMATED NUMBER AND PERCENT CHANGE IN PEOPLE AGE 55+ WITH ALZHEIMER'S DISEASE BY RACE/ ETHNICITY 2019, 2025, AND 2040 – CALIFORNIA

Race	2019	2025	2040	% change 2019-2025	% change 2025-2040	% change 2019-2040
White/Caucasian American, Non-Latino/a/x	411,138	516,559	798,695	27	53	94
Latino/a/x American	138,725	190,580	431,982	39	124	211
Black/African American	34,591	47,187	91,071	38	91	163
Asian American/Pacific Islander	107,268	137,730	241,106	30	73	125
Native American	3,031	4,050	7,468	35	82	146
Multirace	7,802	10,974	23,941	42	116	207

Source: State of California, Department of Finance, *E-1 Population Estimates for Cities, Counties and the State with Annual Percent Change — January 1, 2019 and 2020.* Sacramento, California, May 2019. Accessed July 2, 2019. Please see Appendix B for methodology used to estimate California Alzheimer's disease prevalence.

TABLE C3: ESTIMATED NUMBER OF PEOPLE AGE 55+ WITH ALZHEIMER’S DISEASE BY RACE/ ETHNICITY AND BY COUNTY – 2019

County	White/Caucasian American, Non-Latino/a/x	Latino/a/x American	Black/ African American	Asian American/ Pacific Islander	Native American	Multirace
Alameda	13,062	3,210	3,248	8,025	77	423
Alpine	23	1	0	0	3	0
Amador	1,097	53	3	11	11	14
Butte	4,308	292	45	97	55	62
Calaveras	1,305	88	9	17	12	19
Colusa	272	105	6	10	5	3
Contra Costa	14,227	2,456	1,504	3,325	57	287
Del Norte	518	25	1	12	23	10
El Dorado	3,980	241	24	157	29	54
Fresno	8,220	4,287	538	1,360	101	137
Glenn	433	87	3	11	9	5
Humboldt	2,393	96	13	40	96	47
Imperial	809	2,160	43	57	32	18
Inyo	415	36	1	5	28	4
Kern	7,222	2,961	441	603	113	147
Kings	1,041	605	61	113	15	13
Lake	1,441	108	41	18	22	26
Lassen	487	33	7	6	14	9
Los Angeles	75,600	51,537	14,921	32,952	414	1,920
Madera	1,815	692	62	57	44	36
Marin	6,295	323	89	337	9	64
Mariposa	544	30	3	5	12	11
Mendocino	1,742	139	7	34	53	26
Merced	2,001	1,198	142	264	23	38
Modoc	273	13	2	3	6	3
Mono	155	13	1	3	3	1
Monterey	4,512	1,839	196	742	33	84
Napa	2,448	363	31	204	13	28
Nevada	2,927	101	4	28	21	31
Orange	37,462	9,056	632	11,411	153	625
Placer	8,377	674	70	502	53	84
Plumas	619	22	2	4	8	9
Riverside	30,233	9,283	1,898	2,691	212	378
Sacramento	15,968	2,639	1,815	3,949	131	383
San Benito	552	333	5	33	4	9

County	White/Caucasian American, Non-Latino/a/x	Latino/a/x American	Black/ African American	Asian American/ Pacific Islander	Native American	Multirace
San Bernardino	15,322	8,621	2,076	2,430	170	306
San Diego	38,862	10,042	1,928	6,973	221	590
San Francisco	7,245	1,831	1,073	8,380	30	190
San Joaquin	6,074	2,325	624	1,772	51	154
San Luis Obispo	5,968	609	44	169	32	63
San Mateo	9,465	2,152	487	3,976	24	186
Santa Barbara	6,240	1,644	136	378	41	65
Santa Clara	18,330	4,938	654	10,938	79	373
Santa Cruz	3,899	690	33	201	18	53
Shasta	3,790	156	17	68	60	62
Sierra	103	6	0	0	2	1
Siskiyou	1,173	65	12	12	27	30
Solano	4,405	980	945	1,723	42	125
Sonoma	9,866	947	129	434	62	107
Stanislaus	5,687	1,885	155	476	57	139
Sutter	1,168	245	30	301	17	26
Tehama	1,267	119	6	15	26	21
Trinity	411	17	1	2	16	13
Tulare	3,760	2,199	62	285	52	68
Tuolumne	1,481	75	5	10	17	17
Ventura	10,774	3,346	218	1,279	50	140
Yolo	2,256	599	69	301	20	40
Yuba	815	132	21	62	23	22

Source: State of California, Department of Finance, *E-1 Population Estimates for Cities, Counties and the State with Annual Percent Change — January 1, 2019 and 2020.* Sacramento, California, May 2019. Accessed July 2, 2019. Please see Appendix B for methodology used to estimate California Alzheimer's disease prevalence.

TABLE C4: ESTIMATED NUMBER OF PEOPLE AGE 55+ WITH ALZHEIMER'S DISEASE BY RACE/ ETHNICITY AND BY COUNTY – 2025

County	White/ Caucasian, Non-Latino/a/x	Latino/a/x American	Black/ African American	Asian American/ Pacific Islander	Native American	Multirace
Alameda	17,405	4,439	4,407	10,445	232	619
Alpine	37	1	0	0	0	0
Amador	1,406	80	4	16	2	21
Butte	5,075	382	64	123	7	92
Calaveras	1,743	131	12	22	2	29
Colusa	319	140	6	11	2	4
Contra Costa	18,520	3,482	2,207	4,534	91	440
Del Norte	591	38	2	13	1	12
El Dorado	5,346	337	33	242	7	80
Fresno	9,985	5,765	712	1,682	25	188
Glenn	498	117	4	14	0	6
Humboldt	3,014	125	18	51	3	67
Imperial	925	2,739	57	72	2	22
Inyo	501	53	1	9	0	6
Kern	8,710	3,994	570	776	15	196
Kings	1,234	787	84	139	3	16
Lake	1,738	146	43	24	3	40
Lassen	618	40	7	7	1	11
Los Angeles	93,037	70,676	19,844	41,354	462	2,574
Madera	2,221	950	88	72	2	52
Marin	8,233	480	123	446	14	98
Mariposa	675	38	3	10	1	15
Mendocino	2,321	201	9	41	2	38
Merced	2,450	1,661	172	330	9	55
Modoc	336	19	1	3	1	5
Mono	275	25	1	4	0	3
Monterey	5,551	2,612	227	850	43	127
Napa	3,103	523	45	276	6	41
Nevada	3,802	160	7	37	2	46
Orange	46,649	12,599	930	14,830	168	842
Placer	10,927	910	115	723	15	115
Plumas	780	28	3	6	1	13
Riverside	37,353	13,549	2,785	3,919	109	566
Sacramento	20,441	3,594	2,505	4,939	242	576

County	White/ Caucasian, Non-Latino/a/x	Latino/a/x American	Black/ African American	Asian American/ Pacific Islander	Native American	Multirace
San Benito	732	453	9	44	1	14
San Bernardino	19,380	11,764	2,911	3284	88	425
San Diego	48,906	13,664	2,693	9,099	291	833
San Francisco	9,363	2,244	1,347	9,776	60	267
San Joaquin	7,686	3,181	925	2,341	75	234
San Luis Obispo	7,715	905	55	220	5	85
San Mateo	11,603	2,880	620	5337	230	267
Santa Barbara	7,286	2,189	166	469	15	93
Santa Clara	23,157	6,766	958	14405	135	533
Santa Cruz	5,408	1,010	46	254	7	77
Shasta	4,462	197	22	83	6	86
Sierra	130	8	0	1	0	1
Siskiyou	1,406	82	16	16	1	37
Solano	5,873	1,388	1,342	2297	76	177
Sonoma	13,256	1,395	190	592	36	162
Stanislaus	6,921	2,533	223	649	61	185
Sutter	1,407	317	35	352	6	37
Tehama	1,501	159	7	22	2	30
Trinity	507	21	0	4	0	18
Tulare	4,503	3,011	85	354	7	83
Tuolumne	1,849	101	7	17	2	29
Ventura	13,723	4,501	306	1627	35	199
Yolo	2,956	815	106	391	16	58
Yuba	1,010	172	30	77	3	34

Source: State of California, Department of Finance, *E-1 Population Estimates for Cities, Counties and the State with Annual Percent Change — January 1, 2019 and 2020.* Sacramento, California, May 2019. Accessed July 2, 2019. Please see Appendix B for methodology used to estimate California Alzheimer's disease prevalence.

TABLE C5: ESTIMATED NUMBER OF PEOPLE AGE 55+ WITH ALZHEIMER'S DISEASE BY RACE/ ETHNICITY AND BY COUNTY – 2040

County	White/ Caucasian American, Non-Latino/a/x	Latino/a/x American	Black/ African American	Asian American/ Pacific Islander	Native American	Multirace
Alameda	29,404	10,663	8,356	19,124	216	1,501
Alpine	53	3	0	1	9	1
Amador	1,990	183	8	36	29	35
Butte	6,689	716	112	230	112	182
Calaveras	2,620	236	14	40	38	50
Colusa	412	312	6	15	11	8
Contra Costa	30,638	8,582	4,688	8,904	175	1,086
Del Norte	732	74	4	27	52	22
El Dorado	8,591	778	62	481	75	167
Fresno	14,094	12,112	1,341	2,925	232	381
Glenn	642	257	6	22	16	10
Humboldt	4,375	280	44	87	193	131
Imperial	1,229	5,016	93	115	61	35
Inyo	770	125	4	15	66	12
Kern	12,072	8823	1,086	1,253	230	328
Kings	1,611	1,448	159	202	34	39
Lake	2,148	272	42	41	54	63
Lassen	900	71	11	11	27	23
Los Angeles	145,609	158,654	36,150	69,825	985	5,309
Madera	2,773	2,065	140	106	77	83
Marin	11,941	1,253	236	838	27	226
Mariposa	993	75	6	15	24	22
Mendocino	3,185	492	16	68	126	73
Merced	3,579	3,513	297	561	50	102
Modoc	386	40	2	4	15	9
Mono	613	99	1	12	13	8
Monterey	7,667	6,462	415	1,314	70	275
Napa	4,258	1,265	90	523	31	79
Nevada	5,390	342	12	74	56	91
Orange	70,917	30,906	2,095	25,849	336	1,802
Placer	16,753	1,891	240	1,465	154	275
Plumas	927	55	6	8	17	20
Riverside	59,108	32,905	6,242	8,113	611	1,308
Sacramento	3,2874	8,231	5,176	8,488	391	1,365

County	White/ Caucasian American, Non-Latino/a/x	Latino/a/x American	Black/ African American	Asian American/ Pacific Islander	Native American	Multirace
San Benito	1,294	1,039	22	87	13	30
San Bernardino	30,160	26,568	5,826	5,806	359	895
San Diego	77,790	30,938	5,732	16,191	581	2,025
San Francisco	15,925	4,355	2,128	14,029	86	630
San Joaquin	12,219	7,182	2,077	4,367	166	473
San Luis Obispo	12,117	2,077	104	408	92	171
San Mateo	17,347	6,226	944	9,454	67	575
Santa Barbara	10,229	5,084	289	848	95	212
Santa Clara	36,262	15,185	1,987	27,483	210	1,209
Santa Cruz	9,013	2,533	105	509	51	191
Shasta	5,800	401	41	151	141	155
Sierra	160	11	0	1	2	2
Siskiyou	1,678	141	21	35	58	50
Solano	9,689	3,129	2,559	3,641	109	439
Sonoma	21,554	3,630	446	1,237	186	392
Stanislaus	10,282	5,398	469	1,115	134	345
Sutter	1,991	662	61	526	35	68
Tehama	1,841	336	12	29	50	60
Trinity	602	30	1	4	28	25
Tulare	5,918	6,340	176	567	115	146
Tuolumne	2,559	207	10	35	46	51
Ventura	22,109	10,224	634	2,857	133	487
Yolo	4,646	1,693	200	777	56	125
Yuba	1,568	395	65	160	43	70

Source: State of California, Department of Finance, *E-1 Population Estimates for Cities, Counties and the State with Annual Percent Change — January 1, 2019 and 2020.* Sacramento, California, May 2019. Accessed July 2, 2019. Please see Appendix B for methodology used to estimate California Alzheimer's disease prevalence.

TABLE C6: ESTIMATED NUMBER AND PERCENT CHANGE IN PEOPLE AGE 65+ WITH ALZHEIMER'S DISEASE: 2019, 2025, AND 2040 – CALIFORNIA AND COUNTIES

County	2019	2025	2040	% change 2019-2025	% change 2025-2040	% change 2019-2040
Alameda	26,323	36,037	67,368	37	92	163
Alpine	26	41	66	59	63	159
Amador	1,139	1,515	2,247	33	51	100
Butte	4,648	5,681	7,842	22	42	73
Calaveras	1,387	1,921	2,960	38	56	116
Colusa	380	471	743	24	62	101
Contra Costa	20,521	28,200	52,683	37	92	164
Del Norte	558	667	890	20	36	63
El Dorado	42,31	5,928	9,995	40	71	140
Fresno	13,769	17,773	30,078	29	75	126
Glenn	518	629	927	21	52	84
Humboldt	2,536	3,295	4,968	30	55	101
Imperial	2,949	3,729	6,388	26	76	122
Inyo	463	590	972	28	68	114
Kern	10,695	13,778	22,904	29	73	122
Kings	1,735	2,205	3,379	27	58	101
Lake	1,577	1,975	2,568	25	33	66
Lassen	523	681	1,029	30	53	100
Los Angeles	166,857	219,258	405,382	31	90	150
Madera	2,573	3,332	5,070	30	57	104
Marin	6,798	9,156	14,283	35	59	114
Mariposa	578	741	1,120	28	53	96
Mendocino	1,902	2,621	3,875	38	51	108
Merced	3,433	4,505	7,817	31	80	136
Modoc	289	366	449	27	24	57
Mono	156	300	728	92	149	377
Monterey	7,002	9,101	15,737	30	78	131
Napa	2,927	3,890	6,101	33	61	113
Nevada	2,984	4,013	5,876	34	49	100
Orange	55,933	73,138	128,533	31	80	136
Placer	9,320	12,540	20,299	35	66	123
Plumas	638	827	1,020	30	25	62
Riverside	42,306	56,427	105,563	33	92	156
Sacramento	23,330	31,005	54,703	33	82	142
San Benito	872	1,205	2,423	38	106	185
San Bernardino	26,838	36,301	67,425	35	92	159
San Diego	55,280	72,909	129,784	32	83	141
San Francisco	17,895	22,307	35,843	25	67	108

County	2019	2025	2040	% change 2019-2025	% change 2025-2040	% change 2019-2040
San Joaquin	10,250	13,796	25,609	35	92	158
San Luis Obispo	6,563	8,837	14,716	35	69	128
San Mateo	15,421	20,018	33,678	30	73	124
Santa Barbara	8,067	9,936	16,305	23	69	108
Santa Clara	33,284	44,169	79,990	33	86	147
Santa Cruz	4,584	6,610	12,146	44	88	171
Shasta	3,951	4,803	6,520	22	39	69
Sierra	108	140	174	30	25	63
Siskiyou	1,263	1,565	1,950	24	27	57
Solano	7,731	10,772	19,116	39	82	153
Sonoma	10,938	15,268	26,845	40	80	151
Stanislaus	7,873	10,179	17,194	29	74	125
Sutter	1,691	2,090	3,233	24	60	98
Tehama	1,383	1,699	2,274	23	37	68
Trinity	442	561	681	27	23	56
Tulare	6,037	7,782	12,788	29	70	120
Tuolumne	1,538	1,992	2,861	30	46	89
Ventura	14,843	19,702	35,613	33	85	146
Yolo	3,099	4,214	7,292	36	78	142
Yuba	999	1,289	2,213	29	78	130
CALIFORNIA	661,952	874,482	1,551,236	32	82	141

Source: State of California, Department of Finance, *E-1 Population Estimates for Cities, Counties and the State with Annual Percent Change — January 1, 2019 and 2020.* Sacramento, California, May 2019. Accessed July 2, 2019. Please see Appendix B for methodology used to estimate California Alzheimer's disease prevalence.

TABLE C7: ESTIMATED NUMBER AND PERCENT CHANGE IN PEOPLE AGE 65+ WITH ALZHEIMER'S DISEASE BY RACE/ ETHNICITY – 2019, 2025, AND 2040, CALIFORNIA

Race	2019	2025	2040	% change 2019-2025	% change 2025-2040	% change 2019-2040
White/Caucasian American, Non-Latino/a/x	391,374	503,410	783,137	29	56	100
Latino/a/x American	127,126	178,677	414,466	41	132	226
Black/African American	32,081	45,187	88,715	41	96	177
Asian American/Pacific Islander	101,393	132,903	234,671	31	77	131
Native American	2,824	3,902	7,294	38	87	158
Multirace	7,153	10,402	22,952	45	121	221

Source: State of California, Department of Finance, *E-1 Population Estimates for Cities, Counties and the State with Annual Percent Change — January 1, 2019 and 2020.* Sacramento, California, May 2019. Accessed July 2, 2019. Please see Appendix B for methodology used to estimate California Alzheimer's disease prevalence.

TABLE C8: ESTIMATED NUMBER OF PEOPLE AGE 65+ WITH ALZHEIMER'S DISEASE BY RACE/ ETHNICITY AND BY COUNTY – 2019

County	White/ Caucasian American, Non-Latino/a/x	Latino/a/x	Black/ African American	Asian American/ Pacific Islander	Native American	Multirace
Alameda	12,346	2,934	3,032	7,556	72	383
Alpine	22	1	0	0	3	0
Amador	1,054	48	2	10	11	14
Butte	4,135	271	43	91	52	57
Calaveras	1,251	83	8	16	11	18
Colusa	261	96	6	10	5	3
Contra Costa	13,470	2,235	1,387	3,117	52	259
Del Norte	494	22	1	11	21	9
El Dorado	3,765	221	23	147	26	49
Fresno	7,844	3,928	496	1,281	94	127
Glenn	413	79	3	10	8	4
Humboldt	2,268	87	11	37	90	43
Imperial	779	2,029	40	54	30	17
Inyo	395	33	1	5	26	4
Kern	6,828	2,663	401	562	105	136
Kings	992	557	54	107	14	12
Lake	1,377	99	39	16	20	24
Lassen	460	30	6	6	13	8
Los Angeles	72,055	47,422	13,962	31,245	388	1,785
Madera	1,746	637	58	54	42	35
Marin	6,039	293	82	318	8	59
Mariposa	521	28	2	5	11	10
Mendocino	1,664	126	7	32	50	24
Merced	1,901	1,094	133	249	22	35
Modoc	264	12	1	3	6	3
Mono	139	10	1	2	3	1
Monterey	4,337	1,667	182	709	31	76
Napa	2,343	328	27	192	12	26
Nevada	2,812	94	4	26	20	29
Orange	35,656	8,224	573	10,762	143	575
Placer	8,023	634	64	474	50	76
Plumas	596	20	2	4	7	9
Riverside	29,042	8,463	1,736	2,520	197	348
Sacramento	15,075	2,406	1,661	3,724	120	343
San Benito	519	306	5	31	3	8

County	White/ Caucasian American, Non-Latino/a/x	Latino/a/x	Black/ African American	Asian American/ Pacific Islander	Native American	Multirace
San Bernardino	14,431	7,807	1,893	2,270	158	278
San Diego	36,967	9,217	1,766	6,591	205	534
San Francisco	6,893	1,723	1,015	8,061	28	176
San Joaquin	5,727	2,115	562	1,660	46	140
San Luis Obispo	5,715	562	39	159	30	58
San Mateo	9,034	1,989	463	3,742	22	170
Santa Barbara	5,982	1,505	128	355	39	58
Santa Clara	17,429	4,552	602	10,288	74	340
Santa Cruz	3,680	621	30	188	17	48
Shasta	3,616	144	16	63	55	57
Sierra	99	6	0	0	2	1
Siskiyou	1,127	61	11	11	25	28
Solano	4,165	899	872	1,644	40	111
Sonoma	9,402	856	119	407	57	97
Stanislaus	5,388	1,721	139	444	53	129
Sutter	1,112	225	27	286	16	24
Tehama	1,211	108	6	14	24	19
Trinity	395	16	1	2	15	13
Tulare	3,591	2,008	57	269	48	63
Tuolumne	1,422	70	4	9	16	16
Ventura	10,197	3,069	200	1,204	46	126
Yolo	2,143	554	63	283	19	37
Yuba	763	120	19	57	21	19

Source: State of California, Department of Finance, *E-1 Population Estimates for Cities, Counties and the State with Annual Percent Change — January 1, 2019 and 2020.* Sacramento, California, May 2019. Accessed July 2, 2019. Please see Appendix B for methodology used to estimate California Alzheimer's disease prevalence.

TABLE C9: ESTIMATED NUMBER OF PEOPLE AGE 65+ WITH ALZHEIMER’S DISEASE BY RACE/ ETHNICITY AND BY COUNTY – 2025

County	White/ Caucasian American, Non-Latino/a/x	Latino/a/x American	Black/ African American	Asian American/ Pacific Islander	Native American	Multirace
Alameda	16,920	4,143	4,243	10,040	111	581
Alpine	36	1	0	0	3	0
Amador	1,383	77	3	16	15	21
Butte	4,981	364	62	118	67	89
Calaveras	1,715	127	12	21	18	28
Colusa	313	131	6	11	7	4
Contra Costa	18,005	3,241	2,110	4,353	78	414
Del Norte	579	35	1	12	29	12
El Dorado	5,225	319	32	234	41	76
Fresno	9,750	5,423	677	1,619	124	179
Glenn	487	109	3	13	10	6
Humboldt	2,943	118	17	48	105	64
Imperial	909	2,633	54	69	42	21
Inyo	491	50	1	9	35	6
Kern	8,470	3,697	539	744	140	188
Kings	1,206	750	78	136	20	15
Lake	1,705	138	42	23	28	39
Lassen	602	38	6	6	19	11
Los Angeles	90,567	66,537	19,087	40,104	508	2,455
Madera	2,181	895	85	70	50	51
Marin	8,058	445	117	429	14	93
Mariposa	664	36	3	10	14	15
Mendocino	2,283	186	9	39	68	36
Merced	2,385	1,554	166	317	32	52
Modoc	331	18	1	2	9	4
Mono	266	22	1	4	5	3
Monterey	5,456	2,438	217	828	40	122
Napa	3,039	486	42	267	17	39
Nevada	3,743	153	7	36	29	44
Orange	45,384	11,649	882	14,249	179	796
Placer	10,678	872	111	697	75	108
Plumas	770	26	3	6	9	13
Riverside	36,536	12,655	2,640	3,771	287	538
Sacramento	19,810	3,345	2,379	4,751	181	540

County	White/ Caucasian American, Non-Latino/a/x	Latino/a/x American	Black/ African American	Asian American/ Pacific Islander	Native American	Multirace
San Benito	709	427	9	42	6	13
San Bernardino	18,831	10,940	2,767	3,159	203	401
San Diego	47,680	12,823	2,562	8,778	285	781
San Francisco	9,020	2,137	1,308	9,552	38	250
San Joaquin	7,434	2,952	868	2,243	78	221
San Luis Obispo	7,583	861	51	213	48	81
San Mateo	11,290	2,708	601	5,135	33	252
Santa Barbara	7,138	2,047	160	452	51	88
Santa Clara	22,527	6,354	916	13,769	101	502
Santa Cruz	5,280	943	44	244	26	73
Shasta	43,57	186	21	80	77	83
Sierra	129	8	0	1	2	1
Siskiyou	1,386	79	16	15	34	36
Solano	5,717	1,304	1,288	2,241	56	165
Sonoma	12,974	1,293	182	569	96	154
Stanislaus	6,721	2,367	211	623	80	176
Sutter	1,365	297	33	338	21	35
Tehama	1,466	148	7	21	28	28
Trinity	500	20	0	4	20	17
Tulare	4,394	2,820	80	343	66	79
Tuolumne	1,819	98	6	16	25	28
Ventura	13,365	42,23	293	1,567	66	187
Yolo	2,884	769	101	374	31	55
Yuba	972	160	28	71	26	32

Source: State of California, Department of Finance, *E-1 Population Estimates for Cities, Counties and the State with Annual Percent Change — January 1, 2019 and 2020.* Sacramento, California, May 2019. Accessed July 2, 2019. Please see Appendix B for methodology used to estimate California Alzheimer's disease prevalence.

TABLE C10: ESTIMATED NUMBER OF PEOPLE AGE 65+ WITH ALZHEIMER'S DISEASE BY RACE/ ETHNICITY AND BY COUNTY – 2040

County	White/ Caucasian American, Non-Latino/a/x	Latino/a/x American	Black/ African American	Asian American/ Pacific Islander	Native American	Multirace
Alameda	28,812	10,177	8,155	18,578	211	1,436
Alpine	52	3	0	1	8	1
Amador	1,964	178	8	36	28	34
Butte	6,543	684	110	221	110	174
Calaveras	2,589	231	14	39	37	49
Colusa	406	299	5	15	11	7
Contra Costa	30,085	8,189	4,559	8,641	172	1,039
Del Norte	718	70	3	27	50	21
El Dorado	8,473	751	61	473	73	163
Fresno	13,805	11,567	1,294	2,822	226	366
Glenn	629	245	6	22	16	10
Humboldt	4,265	264	42	84	187	126
Imperial	1,209	4,884	89	113	59	34
Inyo	757	121	4	15	64	11
Kern	11,757	8,354	1,043	1,212	224	314
Kings	1,570	1,390	152	198	33	37
Lake	2,112	260	42	40	53	61
Lassen	889	69	11	11	26	23
Los Angeles	142,764	152,980	35,341	68,225	966	5,106
Madera	2,719	1,958	134	103	75	81
Marin	11,802	1,187	229	820	26	219
Mariposa	981	73	5	15	24	21
Mendocino	3,132	468	15	67	123	71
Merced	3,499	3,344	288	539	49	98
Modoc	380	39	2	4	15	8
Mono	602	93	1	12	13	8
Monterey	7,551	6,159	405	1,288	69	266
Napa	4,189	1,207	88	511	30	77
Nevada	5,317	332	11	73	55	89
Orange	69,649	29,596	2,038	25,186	330	1,734
Placer	16,406	1,819	232	1,428	151	263
Plumas	916	53	6	8	17	19
Riverside	58,120	31,599	6,073	7,914	597	1,259
Sacramento	32,020	7,808	5,008	8,187	381	1,300

County	White/ Caucasian American, Non-Latino/a/x	Latino/a/x American	Black/ African American	Asian American/ Pacific Islander	Native American	Multirace
San Benito	1,274	1,001	21	85	13	29
San Bernardino	29,511	25,408	5,654	5,647	350	855
San Diego	76,213	29,757	5,566	15,760	565	1,922
San Francisco	15,251	4,153	2,080	13,688	84	587
San Joaquin	11,932	6,827	2,008	4,230	161	452
San Luis Obispo	11,949	2,013	100	399	91	166
San Mateo	17,036	5,938	919	9,168	66	551
Santa Barbara	10,046	4,859	282	822	93	203
Santa Clara	35,609	14,497	1,928	26,596	206	1,154
Santa Cruz	8,877	2,432	103	499	50	185
Shasta	5,666	383	39	145	137	149
Sierra	158	10	0	1	2	2
Siskiyou	1,653	136	21	34	57	49
Solano	9,518	3,003	2,500	3,569	107	420
Sonoma	21,194	3,451	433	1,208	182	376
Stanislaus	10,054	5,140	455	1,081	132	333
Sutter	1,940	628	60	506	34	65
Tehama	1,805	322	11	28	49	58
Trinity	595	29	1	4	28	24
Tulare	5,788	6,026	171	551	112	140
Tuolumne	2,521	202	9	34	45	50
Ventura	21,794	9,802	621	2,794	131	471
Yolo	4,549	1,628	195	747	55	119
Yuba	1,518	373	63	151	41	66

Source: State of California, Department of Finance, *E-1 Population Estimates for Cities, Counties and the State with Annual Percent Change — January 1, 2019 and 2020.* Sacramento, California, May 2019. Accessed July 2, 2019. Please see Appendix B for methodology used to estimate California Alzheimer's disease prevalence.

APPENDIX D– STATE AND COUNTY ALZHEIMER’S DISEASE AND DEMENTIA LIFETIME RISK ESTIMATES

TABLE D1: LIFETIME RISK FOR BABY BOOMERS BORN BETWEEN 1946 THROUGH 1964 TO DEVELOP DEMENTIA AND ALZHEIMER’S DISEASE BY GENDER: CALIFORNIA AND COUNTIES

	Population 55-73 Who Will Develop Dementia and Alzheimer’s Disease					
County	**Dementia Females**	**Alzheimer’s Disease Females**	**Dementia Males**	**Alzheimer’s Disease Males**	**Dementia Total**	**Alzheimer’s Disease Total**
Alameda	43,500	37,338	24,589	18,379	68,089	55,716
Alpine	47	40	32	24	78	64
Amador	1,454	1,247	866	647	2,320	1,895
Butte	6,262	5,375	3,427	2,562	9,690	7,937
Calaveras	1,879	1,613	1,070	800	2,949	2,413
Colusa	533	457	341	255	874	712
Contra Costa	34,332	29,468	19,144	14,309	53,476	43,777
Del Norte	793	681	459	343	1,253	1,024
El Dorado	6,558	5,629	3,869	2,892	10,427	8,521
Fresno	21,910	18,806	12,441	9,299	34,351	28,105
Glenn	733	629	454	339	1,187	969
Humboldt	4,116	3,533	2,357	1,762	6,473	5,294
Imperial	4,290	3,682	2,268	1,695	6,558	5,377
Inyo	695	597	434	324	1,129	921
Kern	18,927	16,246	11,073	8,276	30,000	24,522
Kings	2,658	2,281	1,699	1,270	4,357	3,551
Lake	2,198	1,886	1,255	938	3,453	2,824
Lassen	826	709	534	399	1,360	1,108
Los Angeles	260,955	223,987	145,594	108,819	406,549	332,807
Madera	3,538	3,036	2,039	1,524	5,577	4,561
Marin	9,221	7,914	4,984	3,726	14,205	11,640
Mariposa	724	621	436	326	1,160	947
Mendocino	2,988	2,565	1,673	1,251	4,661	3,815
Merced	5,617	4,821	3,296	2,463	8,913	7,285
Modoc	332	285	193	144	525	429
Mono	450	386	291	217	741	604
Monterey	10,264	8,810	6,028	4,506	16,292	13,316
Napa	4,191	3,597	2,395	1,790	6,586	5,387
Nevada	3,895	3,343	2,163	1,617	6,058	4,960
Orange	83,417	71,600	47,956	35,843	131,373	107,443
Placer	11,940	10,248	6,647	4,969	18,587	15,216
Plumas	783	672	455	340	1,238	1,012
Riverside	60,054	51,545	34,403	25,714	94,457	77,260

	Population 55-73 Who Will Develop Dementia and Alzheimer’s Disease					
County	**Dementia Females**	**Alzheimer’s Disease Females**	**Dementia Males**	**Alzheimer’s Disease Males**	**Dementia Total**	**Alzheimer’s Disease Total**
Sacramento	39,954	34,294	21,574	16,125	61,528	50,419
San Benito	1,548	1,329	932	697	2,480	2,025
San Bernardino	50,453	43,307	28,408	21,232	78,861	64,539
San Diego	84,114	72,197	48,079	35,937	132,194	108,134
San Francisco	21,213	18,207	13,780	10,300	34,993	28,507
San Joaquin	18,218	15,637	10,492	7,841	28,709	23,478
San Luis Obispo	9,122	7,829	5,212	3,896	14,334	11,725
San Mateo	22,137	19,000	12,572	9,397	34,709	28,398
Santa Barbara	11,038	9,474	6,348	4,745	17,386	14,219
Santa Clara	48,355	41,506	29,000	21,674	77,355	63,180
Santa Cruz	8,174	7,015	4,837	3,616	13,010	10,631
Shasta	5,645	4,845	3,086	2,307	8,732	7,153
Sierra	138	118	81	61	219	179
Siskiyou	1,612	1,384	900	673	2,512	2,057
Solano	12,572	10,790	7,001	5,233	19,573	16,024
Sonoma	16,896	14,501	9,238	6,906	26,134	21,407
Stanislaus	13,092	11,238	7,387	5,521	20,479	16,759
Sutter	2,411	2,069	1,400	1,046	3,811	3,116
Tehama	1,896	1,627	1,072	801	2,968	2,429
Trinity	534	459	318	238	853	697
Tulare	9,785	8,399	5,629	4,207	15,414	12,606
Tuolumne	2,022	1,735	1,159	867	3,182	2,602
Ventura	23,830	20,454	13,747	10,275	37,577	30,729
Yolo	5,411	4,644	3,184	2,381	8,595	7,025
Yuba	2,062	1,770	1,266	947	3,328	2,716
CALIFORNIA	1,022,313	877,476	581,569	434,690	1,603,882	1,312,166

Source: State of California, Department of Finance, *E-1 Population Estimates for Cities, Counties and the State with Annual Percent Change — January 1, 2019 and 2020.* Sacramento, California, May 2019. Accessed July 2, 2019. Please see Appendix B for methodology used to estimate California Alzheimer's disease prevalence.

TABLE E1: ALZHEIMER'S DISEASE DEATHS IN CALIFORNIA BY COUNTY OF RESIDENCE, 2015-2017

County of Residence	2015-2017 Deaths (Average)	%	2016 Population	Age-Adjusted Death Rate	95% Confidence Limit	
					Lower	Upper
Santa Clara	119	0.8	1,932,827	†	4.5	6.5
Del Norte	3	0.0	26,956	*	1.8	25
Imperial	19	0.1	186,520	*	6.1	15.7
Inyo	3	0.0	18,658	*	2.5	30.4
Mendocino	15	0.1	88,779	*	6.5	19.5
Modoc	2	0.0	9,506	*	1.4	43.1
San Benito	7	0.0	58,010	*	4.7	25.2
Tuolumne	13	0.1	54,291	*	6.6	21.1
Lassen	5	0.0	30,599	*	4.9	35.6
Mariposa	7	0.0	18,057	*	7.1	38.1
Plumas	7	0.0	19,535	*	8.7	42.8
Alpine	0.3	0.0	1,128	*	<0.1	283.2
Calaveras	19	0.1	44,747	*	14	36
Mono	1	0.0	13,801	*	1.4	115.3
Sierra	1	0.0	3,141	*	1.4	117.5
Nevada	49	0.3	98,300	26	19.2	34.3
Humboldt	44	0.3	135,884	26.1	19	35
San Francisco	342	2.2	872,463	26.4	23.6	29.3
Lake	26	0.2	64,712	26.5	17.4	38.8
Monterey	129	0.8	439,945	26.9	22.1	31.6
Merced	60	0.4	272,286	27.7	21.2	35.7
El Dorado	69.0	0.4	184,085	27.9	21.7	35.3
San Mateo	300	1.9	768,507	27.9	24.7	31.2
Trinity	7	0.0	13,492	*	11.4	58.3
Colusa	8	0.0	22,428	*	12.8	60.8
Napa	64	0.4	141,569	31.2	24	39.9
Siskiyou	26	0.2	44,373	31.6	20.6	46.4
Santa Cruz	94	0.6	275,754	32.2	26	39.4
Tulare	125	0.8	467,960	32.3	26.6	38
Sutter	36	0.2	98,208	32.3	22.6	44.8
Alameda	587	3.8	1,637,176	33.8	31	36.6
Los Angeles	3,994	25.6	10,215,103	35.6	34.5	36.7
Glenn	13	0.1	29,084	*	19.2	62.6
Yuba	23	0.1	76,138	36.7	23.2	55
Tehama	33	0.2	64,158	37	25.5	52
Kings	41	0.3	149,172	37.2	26.7	50.5
Riverside	1,003	6.4	2,359,588	37.8	35.5	40.2
San Diego	1,425	9.1	3,295,816	38	36	40
Fresno	351	2.2	988,072	38.1	34	42.1
Contra Costa	519	3.3	1,129,332	38.3	34.9	41.6

County of Residence	2015-2017 Deaths (Average)	%	2016 Population	Age-Adjusted Death Rate	95% Confidence Limit	
					Lower	Upper
Placer	222	1.4	375,805	38.4	33.3	43.4
Santa Barbara	226	1.4	447,309	38.5	33.4	43.7
Orange	1,432	9.2	3,179,122	38.6	36.6	40.6
Marin	176	1.1	262,706	39.4	33.5	45.3
Sonoma	285	1.8	503,152	40	35.3	44.7
San Luis Obispo	178	1.1	278,080	41.1	35	47.2
Amador	31	0.2	37,181	41.6	28.2	59.2
Sacramento	656	4.2	1,503,536	42.1	38.9	45.4
Madera	68	0.4	155,518	42.4	32.9	53.8
Ventura	419	2.7	853,673	42.6	38.5	46.7
San Bernardino	716	4.6	2,143,578	43.3	40.1	46.4
Solano	201	1.3	433,412	43.7	37.6	49.7
Yolo	96	0.6	216,726	48.3	39.1	58.9
San Joaquin	345	2.2	738,343	51.6	46.1	57
Butte	179	1.1	224,761	53.2	45.2	61.1
Kern	349	2.2	887,922	53.4	47.8	59
Stanislaus	287	1.8	543,592	55.1	48.6	61.5
Shasta	149	1.0	177,631	55.7	46.7	64.7
CALIFORNIA	15,603	100.0	39,312,207	35.7	35.2	36.3

*Rates are deemed unreliable when based on fewer than 20 data elements.
† Data and rates for Santa Clara County may not provide the true reflection of Alzheimer's deaths due to reporting inconsistencies.
See technical notes for more information.
<0.1 Indicates lower confidence limit is less than 0.1 but greater than 0.0.
Note: Counties were rank ordered first by increasing age-adjusted death rate (calculated to 15 decimal places), second by decreasing size of population.
Sources: 1. California Department of Public Health, California Comprehensive Master Death Files, [2015-2017] Compiled, August 2018.
2. California Department of Finance. Demographic Research Unit. 2018. State and county population projections 2010-2060. Sacramento: California Department of Finance. January 2018.

TABLE E2: ALZHEIMER'S DISEASE DEATHS IN CALIFORNIA: 2018 BY RACE/ ETHNICITY

	Latino/a/x American Origin	2018 Deaths	% of Total Deaths	Age-Adjusted Rate	2018 Population	% of CA Population
White/Caucasian American	Latino/a/x	2,574	15.5	32.6	14,186,310	35.9
	Not Latino/a/x	11,592	69.7	43.4	15,115,515	38.2
Black/African American	Not Latino/a/x	926	5.6	42.8	2,446,372	6.2
Asian American/ Pacific Islander	Latino/a/x	15	0.1	*	378,549	1.0
	Not Latino/a/x	1,443	8.7	19.3	6,247,617	15.8
American Indian or Alaska Native	Latino/a/x	12	0.1	*	570,560	1.4
	Not Latino/a/x	43	0.3	21.6	207,399	0.5
CALIFORNIA		16,627	100%	37.1	39,557,045	100.0

Source: Centers for Disease Control and Prevention (CDC), National Center for Health Statistics. Underlying Cause of Death 1999-2018 on CDC WONDER Online Database, released in 2020. Data are from the Multiple Cause of Death Files, 1999-2018, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Accessed at http://wonder.cdc.gov/ucd-icd10.html on Oct 2, 2020 4:21:53 PM
Note: Rates are per 100,000 population. ICD-10 codes G30 were used. White/Caucasian American, non-Latino/a/x, African American, Asian American/Pacific Islander, and Native American exclude Latino/a/x American ethnicity. Latino/a/x American includes any race category. Category for Black/African American and Latino/a/x American was not available.
*Rate is statistically unreliable

APPENDIX F – ALZHEIMER'S ORGANIZATIONS

Several organizations exist throughout California to provide education, support and advocacy for the Alzheimer's disease and related disorders community. These fall into two primary categories: the nationwide Alzheimer's Association with chapters in many communities and independent community-based organizations throughout the state including Alzheimer's Los Angeles, Alzheimer's Orange County and Alzheimer's San Diego.

Alzheimer's Association, Their Chapters, and the Regions They Serve

The Alzheimer's Association (www.Alz.org) is a voluntary health organization based in Chicago, IL providing Alzheimer's care, support, and research. Their mission is to eliminate Alzheimer's disease and all other dementia through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health. Six strategic objectives guide their efforts. Core programs and support services to connect people with peers and professionals include:

- Free and confidential 24/7 Helpline at (800) 272-3900 or TDD: (866) 403-3073.
- Local resources at local Alzheimer's Association offices.
- Support programs, including face-to-face support groups and ALZConnected, an online support community.
- Education programs, both in the community or online.
- Early-stage social engagement programs for those living in the beginning stage of Alzheimer's or other dementias to get out, get active, and get connected to others.

- 24/7 wandering support for a safe return (https://www.alz.org/help-support/caregiving/safety/medicalert-with-24-7-wandering-support)
- Online tools, including:
    - ALZConnected (https://www.alzconnected.org/)
    - Alzheimer's Navigator (https://www.alzheimersnavigator.org/),
    - Alzheimer's Association TrialMatch® (https://www.alz.org/alzheimers-dementia/research_progress/clinical-trials/about-clinical-trials)
    - Community Resource Finder (https://www.communityresourcefinder.org/)
    - Live Well Online Resources (https://www.alz.org/help-support/i-have-alz/live-well/live_well_online_resources)
    - Virtual Library (https://www.alz.org/help-support/resources/virtual_library)

Alzheimer's Association Chapters and the Regions They Serve

NORTHERN CALIFORNIA AND NORTHERN NEVADA
Website:
https://www.alz.org/norcal/about_us/contact_us

Greater San Francisco Bay Area
San Jose Office, Headquarters
2290 North First Street, Suite 101
San Jose, CA 95131
Phone: (408) 372-9900

East Bay Office
3675 Mt. Diablo Blvd., Suite 250
Lafayette, CA 94549

San Francisco Office
100 Pine Street, Suite 2150
San Francisco, CA 94111
Phone: (415) 463-8500

North Bay
San Rafael Office
4340 Redwood Hwy., Suite D314
San Rafael, CA 94903
Phone: (415) 472-4340
Santa Rosa Office
1450 Neotomas Avenue, Suite 140
Santa Rosa, CA 95405
Phone: (707) 573-1210

Northern Nevada
Reno Office
639 Isbell Road, Suite 240
Reno, Nevada 89509
Phone: (775) 786-8061

California Central Valley
Chico
150 Amber Grove Drive, Suite 154 Chico, CA 95973
Phone: (530) 895-9661

Fresno Office
550 West Alluvial, Suite 106
Fresno, CA 93711
Phone: (559) 753-8200

Sacramento Office
1455 Response Road, Suite 190
Sacramento, CA 95815
Phone: (916) 930-9080

CALIFORNIA SOUTHLAND

Website:
https://www.alz.org/socal?set=1

Main office
9606 S. Santa Monica Blvd., Suite 200
Beverly Hills, CA 90210
Phone: (323) 309-8821

San Fernando Valley
16600 Sherman Way, Suite 276
Van Nuys, CA 91406
Phone: (818) 875-9928

Coachella Valley
74020 Alessandro Drive, Suite A
Palm Desert, CA 92260
Phone: (760) 996-0006

Inland Empire
3200 Inland Empire Blvd., Suite 280
Ontario, CA 91764
Phone: (909) 406-5376

Bakersfield Office
1401 Commercial Way, Suite 210
Bakersfield, CA 93309
Phone: (661) 912-3053

Central Coast
Monterey Office
21 Lower Ragsdale Drive
Monterey, CA 93940
Phone: (831) 647-9890
Santa Cruz Office
550 Water Street, Suite L-2
Santa Cruz, CA 95060
Phone: (831) 647-9890

CALIFORNIA CENTRAL COAST

Website:
https://www.alz.org/cacentralcoast/about_us/contact_us

Headquarters
1528 Chapala Street, Suite 204
Santa Barbara, CA 93101

Santa Maria Office
120 East Jones Street, Suite 113
Santa Maria, CA 93454

Ventura County Office
2580 E. Main Street., Suite 201
Ventura, CA 93003

San Louis Obispo County Office
3232 S. Higuera Street, Ste. 101A
San Luis Obispo, CA 93401

ORANGE COUNTY CHAPTER

Website:
https://www.alz.org/oc/about_us/contact_us

770 The City Drive South, Suite 7400
Orange, CA 92868
Phone: (949) 426-8544

SAN DIEGO/IMPERIAL CHAPTER
Website: https://www.alz.org/sandiego/about_us/contact_us

5075 Shoreham Pl #240
San Diego, CA 92122
Phone: (619) 678-8322

Independent Community-Based Alzheimer's Organizations

Independent community-based organizations are deeply embedded in local communities and focus on providing free localized care, support and education to people living with Alzheimer's disease and related disorders, their family caregivers and the professionals who serve them. Each organization is unique and reflective of the community they serve but they all provide extensive offerings of programs and services including:

- Toll free Helpline 844.HELP.ALZ (844-435-7259)
- Social Work Dementia Care Specialists who partner with families over the course of the disease, providing home visits when necessary (pre-COVID-19)
- Caregiver education and evidence-based caregiver skills training proven to reduce depression and anxiety and improve tolerance for difficult behavioral symptoms
- Support programs for people in the early stages of ADRDs and their care partners
- Extensive community outreach to increase awareness and understanding of ADRDs and combat stigma, including culturally and linguistically competent education and outreach to diverse communities
- In-person, online, and telephone-based support groups in multiple languages
- Activity programs to engage both the person living with ADRDs and their family caregivers

- Professional training programs for health and long-term care providers

Most activities are delivered in English and Spanish; some in other languages. In some locations, these organizations also offer adult day care and other services.

Community-Based Alzheimer's Organizations

ALZHEIMER'S LOS ANGELES

Website: https://www.alzheimersla.org/

The mission of Alzheimer's Los Angeles is to improve the lives of families affected by Alzheimer's and dementia by increasing awareness, delivering effective programs and services, providing compassionate support, and advocating for quality care and a cure.

Headquarters
4221 Wilshire Blvd. Ste 400
Los Angeles, CA 90010
(323) 938-3379
info@alzla.org

EAST LOS ANGELES OFFICE
133 North Sunol Dr, Ste 237
Los Angeles, CA 90063
323.881.0574

SAN FERNANDO VALLEY OFFICE*
**Temporarily closed, will be relocated after the COVID-19 pandemic*
21515 Vanowen St, Ste 120
Canoga Park, CA 91303
818.830.8590

ALZHEIMER'S ORANGE COUNTY

Website: https://www.alzoc.org/

The mission of Alzheimer's Orange County is to provide hands-on care and support, information, referrals, education and resources for individuals and families in Orange County and surrounding areas who experience memory loss, Alzheimer's and other dementias, while advancing critical research for a cure.

2515 McCabe Way, Suite 200
Irvine, CA 92614
(949) 955-9000
info@alzoc.org

South County Adult Day Services
24260 El Toro Road
Laguna Woods, CA 92637
Phone: (949) 855-9444

Acacia Adult Day Services
2515 McCabe Way, Suite 200
Irvine, CA 92614
(714) 530-1566

Irvine Cottages
12 locations in Irvine, Mission Viejo and Newport Beach.
(949) 533-5938

ALZHEIMER'S SAN DIEGO

Website: https://www.alzheimersla.org/

The mission of Alzheimer's San Diego is helping families today, finding a cure for tomorrow.

6632 Convoy Court
San Diego, CA 92111
858.492.4400
info@alzsd.org

APPENDIX G – CAREGIVER RESOURCE CENTERS IN CALIFORNIA

California has 11 Caregiver Resource Centers (CRCs) that provide core services to families and caregivers ranging from counseling and care planning to legal/financial consulting and respite, at low to no cost. Website: https://www.caregiver.org/californias-caregiver-resource-centers

Other Alzheimer's Organizations and the Regions They Serve

FAMILY CAREGIVER ALLIANCE/BAY AREA CAREGIVER RESOURCE CENTER
Statewide Resource Consultant
101 Montgomery Street, Suite 2150
San Francisco, CA 94104
Phone: 415-434-3388 or 800-445-8106 (toll-free)
Website: https://www.caregiver.org/
Email: info@caregiver.org
Alameda, Contra Costa, Marin, San Francisco, San Mateo, and Santa Clara Counties

CAREGIVER RESOURCE CENTER OF ORANGE
(a program of St. Jude Medical Center)
130 W. Bastanchury Road
Fullerton, CA 92835
Phone: 714-446-5030 or 800-543-8312 (regional)
Website: http://www.caregiveroc.org/
Email: ocrcuser@stjoe.org
Orange County

COAST CAREGIVER RESOURCE CENTER
(a program of Cottage Rehabilitation Hospital)
2415 De La Vina Street
Santa Barbara, CA 93105
Phone: 803-569-8950
Website: https://www.cottagehealth.org/services/rehabilitation/caregiver-services/
Email: info@coastcrc.org
San Luis Obispo, Santa Barbara, and Ventura Counties

DEL MARE CAREGIVER RESOURCE CENTER
1537 Pacific Avenue, Suite 300
Santa Cruz, CA 95060
Phone: 831-459-6639 or 800-624-8304
Website: http://www.hpcn.org/
Email: info@hpcn.org
Monterey, San Benito, and Santa Cruz Counties

DEL ORO CAREGIVER RESOURCE CENTER
8421 Auburn Boulevard, Suite 265
Citrus Heights, CA 95610
Phone: 916-728-9333 or 800-635-0220 (regional)
Website: http://www.deloro.org/
Email: crc@deloro.org
Alpine, Amador, Calaveras, Colusa, El Dorado, Nevada, Placer, Sacramento, San Joaquin, Sierra, Sutter, Yolo, and Yuba Counties

INLAND CAREGIVER RESOURCE CENTER
1430 East Cooley Drive, Suite 124
Colton, CA 92324
Phone: (909) 514-1404, (800) 675-6694 (California)
Website: www.inlandcaregivers.com
Email: info@inlandcaregivers.org
Inyo, Mono, Riverside, and San Bernardino Counties

PASSAGES CAREGIVER RESOURCE CENTER
(formerly Mountain Caregiver Resource Center)
25 Main Street, Suite 202
Chicago, CA 95929
Phone: (530) 898-5925, (800) 822-0109 (regional)
Website: www.passagescenter.org
Email: MCRC@csuchico.edu
Butte, Glenn, Lassen, Modoc, Plumas, Shasta, Siskiyou, Tehama, and Trinity Counties

REDWOOD CAREGIVER RESOURCE CENTER
1140 Sonoma Avenue, Suite 1B
Santa Rosa, CA 95405
Phone: (707) 542-0282, (800) 834-1636 (regional)
Website: www.redwoodcrc.org
Email: nps@redwoodcrc.org
Del Norte, Humboldt, Lake, Mendocino, Napa, Solano, and Sonoma Counties

SOUTHERN CAREGIVER RESOURCE CENTER
3675 Ruffin Road, Suite 230
San Diego, CA 92123
Phone: (858) 268-4432, (800) 827-1008 (toll-free)
Website: www.caregivercenter.org
Email: scrc@caregivercenter.org
San Diego and Imperial Counties

UCSF FAMILY CAREGIVER SUPPORT CENTER
(formerly Los Angeles Caregiver Resource Center)
USC School of Gerontology
371 McClintock Avenue
Los Angeles, CA 90089
Phone: (855) 872-6060 (toll free)
Website: fcscgero.org
Email: fcspgero@usc.edu
Los Angeles County

VALLEY CAREGIVER RESOURCE CENTER
3845 North Clark Street, Suite 201
Fresno, CA 93726
Phone: (559) 224-9154, (800) 541-8614 (regional)
Website: www.valleycrc.org
Email: info@valleycrc.org
Fresno, Kern, Kings, Madera, Mariposa, Merced, Stanislaus, Tulare, and Tuolumne Counties

APPENDIX H – STATE PAID AND UNPAID ALZHEIMER'S DISEASE COST OF CARE PROJECTIONS

TABLE H1: PROJECTIONS OF THE COST OF CARING FOR COMMUNITY-RESIDENT AND INSTITUTIONALIZED PEOPLE WITH ALZHEIMER'S DISEASE IN CALIFORNIA AGE 55+ (2019 U.S. DOLLARS): 2019, 2025, 2040

Projections of Paid Costs and the Value of Unpaid Care for Alzheimer Patients in California 55+ (2019 $US)

				Unpaid Care		Paid Care		
	# of Patients		**# of Patients**	**Cost per Patient**	**Total cost ($ Billions)**	**Cost per Patient**	**Total cost ($ Billions)**	**TOTAL COST ($Billions)**
Community								
2019	672,597	mild-mod impairment	467,748	$79,991	$37.4	$22,803	$10.7	**$76.7**
		severe impairment	204,848	$91,142	$18.7	$48,706	$10.0	
2025	868,505	mild-mod impairment	602,996	$79,991	$48.2	$22,803	$13.8	**$99.1**
		severe impairment	265,509	$91,142	$24.2	$48,706	$12.9	
2040	1,526,739	mild-mod impairment	763,429	$79,991	$61.1	$22,803	$17.4	**$144.1**
		severe impairment	469,333	$91,142	$42.8	$48,706	$22.9	
Institutionalized								
2019	29,959			$13,881	$0.4	$122,913	$3.7	**$4.1**
2025	38,575			$13,881	$0.5	$122,913	$4.7	**$5.3**
2040	67,523			$13,881	$0.9	$122,913	$8.3	**$9.2**
All Settings								
2019	702,556				$56.5		$24.3	**$80.8**
2025	907,080				$73.0		$31.4	**$104.4**
2040	1,594,262				$104.8		$48.6	**$153.4**

NOTE: An assumption of these calculations is that the distributions will remain constant into the future. We applied the 2019 per capita AD paid and unpaid cost estimates to AD prevalence estimates by residence. We made all cost projections in 2007 dollars which assumes no inflation from 2008-2030. The value of unpaid care is based on the replacement cost approach and therefore does not represent an actual expenditure, but rather the cost to replace unpaid caregivers' labor.

References: Rice, DR, Fox, P J, Max, W, Webber, P, Lindeman, D, Hauck, W, and Segura, E (1993). The Economic Burden of Alzheimer's Disease Care. *Health Aff.*, 12, 165-76.

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TABLE H2: PROJECTIONS OF THE COST OF CARING FOR COMMUNITY-RESIDENTS AND INSTITUTIONALIZED PEOPLE WITH ALZHEIMER'S DISEASE IN CALIFORNIA AGE 65+ (2019 U.S. DOLLARS): 2019, 2025, 2040

Projections of Paid Costs and the Value of Unpaid Care for Alzheimer Patients in California 65+ (2019 $US)

				Unpaid Care		Paid Care		
	# of Patients		# of Patients	Cost per Patient	Total cost ($ Billions)	Cost per Patient	Total cost ($ Billions)	TOTAL COST ($Billions)
Community								
2019	634,084	mild-mod impairment	437,581	$79,991	$35.0	$22,803	$10.0	**$72.5**
		severe impairment	196,502	$91,142	$17.9	$48,706	$9.6	
2025	829,440	mild-mod impairment	572,397	$79,991	$45.8	$22,803	$13.1	**$94.8**
		severe impairment	257,043	$91,142	$23.4	$48,706	$12.5	
2040	1,485,929	mild-mod impairment	1,025,439	$79,991	$82.0	$22,803	$23.4	**$169.8**
		severe impairment	460,489	$91,142	$42.0	$48,706	$22.4	
Institutionalized								
2019			27,868	$13,881	$0.4	$122,913	$3.4	**$3.8**
2025			36,454	$13,881	$0.5	$122,913	$4.5	**$5.0**
2040			65,307	$13,881	$0.9	$122,913	$8.0	**$8.9**
All Settings								
2019			661,952		$5.3		$23.0	**$76.2**
2025			865,894		$69.7		$30.1	**$99.8**
2040			1,551,236		$124.9		$53.8	**$178.7**

NOTE: An assumption of these calculations is that the distributions will remain constant into the future. We applied the 2019 per capita AD paid and unpaid cost estimates to AD prevalence estimates by residence. We made all cost projections in 2007 dollars which assumes no inflation from 2008-2030. The value of unpaid care is based on the replacement cost approach and therefore does not represent an actual expenditure, but rather the cost to replace unpaid caregivers' labor.

References: Rice, DR, Fox, P J, Max, W, Webber, P, Lindeman, D, Hauck, W, and Segura, E (1993). The Economic Burden of Alzheimer's Disease Care. *Health Aff.*, 12, 165-76.

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US Department of Labor. Bureau of Labor Statistics. CPI Inflation Calculator. https://www.bls.gov/data/inflation_calculator.htm. Access 4/7/20.

APPENDIX I – CALIFORNIA ALZHEIMER’S DISEASE CENTERS

The California Alzheimer’s Disease Centers (CADCs) comprise a network of 10 Centers of Excellence, located at university medical schools, to effectively and efficiently:

- Improve dementia health care delivery
- Provide specialized training and education to healthcare professionals
- Advance the diagnosis and treatment of ADRDs.

The CADCs attract fiscal resources to meet the growing needs of Californians affected by dementia. These include industry and federal support for clinical trials and research; foundation and federal support for training programs, fellowships, and research grants; and private philanthropy. Each CADC plays a critical role in building a vital workforce for the growing needs of the state through training physicians, nurses, physician assistants, healthcare professionals, and research investigators. They also serve California’s diverse population by providing an array of linguistically and culturally appropriate care, as well as community education and outreach such as lectures, workshops, forums, and support groups that are open to the public. Website: https://www.cdph.ca.gov/Programs/CCDPHP/DCDIC/CDCB/Pages/CaliforniaAlzheimersDiseaseCenters.aspx

What are the services are provided by the CADCs?

CADC patients receive a comprehensive assessment which may include medical, neurological, psychological, and psychosocial evaluations; as well as laboratory and neuroimaging tests, such as magnetic resonance imaging (MRI), computerized tomography (CT) scan, or positron emission tomography (PET) scan.

Who provides these services at the CADCs?

The services are provided by an interdisciplinary care team, which may include neurologists, psychiatrists, physician assistants, psychologists, nurse specialists, neuropsychologists, and social workers. Once a clinical team has determined the diagnosis, a conference will be scheduled for the patient, family members, and others involved in the patient's health care. Staff will discuss the evaluation results and treatment recommendations. Patients continue to see their private physician for primary care and treatment.

Who is eligible for these services?

Any individual with symptoms of memory loss, disorientation, and confusion may contact one of the CADCs for an evaluation. Patients may be self-referred or referred by a family member, private physician, or community agency.

Who is eligible for these services?

Most of the costs of the services and diagnostic tests are covered by insurance. Medicare, Medi-Cal, and supplemental or private insurance are accepted. Unless prior arrangements for financial assistance are made with the CADC, patients or their families are responsible for fees not covered by insurance.

Location of the California Alzheimer's Disease Centers

UNIVERSITY OF CALIFORNIA, DAVIS – SACRAMENTO
Lawrence J. Ellison Ambulatory Care Center
4860 Y Street, Suite 3900
Sacramento, CA 95817
Phone: 916-734-5496
Fax: 916-703-5290
Website:
https://health.ucdavis.edu/alzheimers/

UNIVERSITY OF CALIFORNIA, DAVIS – EAST BAY
100 North Wiget Lane, Suite 150
Walnut Creek, CA 94598
Phone: 925-357-6515
Fax: 925-988-0697
Website:
https://health.ucdavis.edu/alzheimers/

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO – SAN FRANCISCO
Memory and Aging Center
1500 Owens Street, Suite 320
San Francisco, California
Clinic appointments: 415-353-2057
Research inquiries: 415-476-3722
Website:
https://memory.ucsf.edu/about/contact-memory-and-aging-center

STANFORD UNIVERSITY – PALO ALTO
Stanford/VA Alzheimer's Center
Palo Alto VA Health Care System
Mail Code: 116F-PAD
3801 Miranda Avenue
Bldg. 4, 1st Floor, Rm. C151A
Palo Alto, CA 94304
Direct Line: 650-858-3915
Fax: 650-849-0183
Website:
http://med.stanford.edu/svalz.html

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO – FRESNO
UCSF Fresno Alzheimer and Memory Center
2335 E. Kashian Ln, Suite 301
Fresno, CA 93701
Phone: 559-227-4810
Fax: 559-227-4167
Email: alz@fresno.ucsf.edu
Website:
http://www.fresno.ucsf.edu/alzheimer-memory-center/

UNIVERSITY OF CALIFORNIA, LOS ANGELES – LOS ANGELES
710 Westwood Plaza, Room C-224
Los Angeles, CA 90095-1769
Phone: 310-794-3655 / 310-794-6191 [Clinical Trials] / 310-794-8580 [Español]
Fax: 310-794-3148
Website: https://eastonad.ucla.edu/

UNIVERSITY OF SOUTHERN CALIFORNIA – LOS ANGELES
Keck Hospital of USC
1500 San Pablo St,
Los Angeles, CA 90033

USC Healthcare Center 2 (Licensed by Keck Hospital of USC)
1520 San Pablo Street Suite 3000
Los Angeles, CA 90033

USC Norris Comprehensive Cancer Center (Licensed by USC Kenneth Norris Jr. Cancer Hospital)
1441 Eastlake Ave
Los Angeles, CA 90033

Keck Medicine of USC – Beverly Hills (Licensed by Keck Hospital of USC)
9033 Wilshire Blvd, Suite 400
Beverly Hills, CA 90211

La Cañada – USC Healthcare Center (Licensed by Keck Hospital of USC)
1751 Foothill Blvd., Suite 2
La Cañada Flintridge, CA 91011

LAC+USC Medical Center
1100 N. State St.
Clinic Tower, 4th Floor
Los Angeles, CA 90033

Phone: 800-USC-CARE (800-872-2273)
Website:
https://neuro.keckmedicine.org/treatments-services/memory-and-aging-center/

UNIVERSITY OF SOUTHERN CALIFORNIA – RANCHO LOS AMIGOS
Rancho Los Amigos National Rehabilitation Center
7601 E. Imperial Highway
Downey, CA 90242
Phone: 800-USC-CARE (800-872-2273)

Website:
https://neuro.keckmedicine.org/treatments-services/memory-and-aging-center/

UNIVERSITY OF CALIFORNIA, IRVINE – IRVINE

Administration
2642 Biological Sciences III
Irvine, CA 92697-4545
Phone: 949-824.3253
Fax: 949.24.0885
Research Clinic
1100 Gottschalk Medical Plaza
Irvine, CA 92697-4285
Phone: 949-824.2382
Fax: 949-824.3049
Website: https://www.mind.uci.edu/

UNIVERSITY OF SAN DIEGO – SAN DIEGO

UC San Diego Health
200 West Arbor Drive
San Diego, CA 92103
Main Line: 858-657-7000
New Patient Line: 800-926-8273Website:
https://health.ucsd.edu/specialties/psych/senior/general/memory-aging-resilience/Pages/default.aspx

APPENDIX J – REFERENCES

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APPENDIX K – LIST OF CALIFORNIA AREA AGENCIES ON AGING

The California Department of Aging contracts with and provides leadership and direction to 33 Area Agencies on Aging (AAA) throughout California that coordinate a wide array of services to seniors and adults with disabilities at the community level and serve as the focal point for local aging concern.

You can locate a AAA in your area by calling 1-800-510-2020 or by going to the California Department of Aging website and selecting your county from the provided map or using the county table at the bottom of the page to find your county phone number - https://aging.ca.gov/Find_Services_in_My_County/

APPENDIX L – 2017 CALIFORNIA GUIDELINE FOR ALZHEIMER'S DISEASE MANAGEMENT

The 2017 California Alzheimer's Clinical Care Guideline reflects new evidence, improved practice and changes in Law. This is the 4th edition of the California Alzheimer's Clinical Care Guideline, first published in 1998 and revised in 2002 and 2008. The 2017 update specified in statute (SB 613, Chapter 577, 2015) addresses changes in scientific evidence, clinical practice, and state and federal law. The 2017 California Alzheimer's Clinical Care Guideline is available through the California Department of Public Health website: https://www.cdph.ca.gov/Programs/CCDPHP/DCDIC/CDCB/CDPH%20Document%20Library/Alzheimers'%20Disease%20Program/ALZ-CareGuidelines.pdf