

# CALIFORNIA Health Care Almanac



JUNE 2020

## Long-Term and End-of-Life Care in California: Is California Meeting the Need?

# Executive Summary

As the baby boom generation ages, California’s population of adults age 65 and older continues to rise and is projected to represent 20% of the state’s population in 2030. The aging of California’s population coupled with the projected growth of seniors living with limitations in activities of daily living will likely increase the need for long-term care services.

*Long-Term and End-of-Life Care in California: Is California Meeting the Need?* describes the state’s supply and use of long-term care services, Medicare and Medi-Cal spending on services, and quality of care.

**KEY FINDINGS INCLUDE:**

- Medicare and Medi-Cal accounted for the majority of spending on long-term care services.
- Medi-Cal offers a variety of home and community-based programs to help seniors and persons with disabilities and chronic illnesses live independently outside institutions by assisting with daily needs.
- California nursing facilities performed similarly or better than the national average on a number of quality measures.
- California nursing facilities averaged a higher number of deficiencies than nursing facilities nationwide, and nearly one in five received a deficiency for actual harm or jeopardy of residents in 2017.
- In California, both assisted living beds and users increased from 2012 to 2016, 30% and 28%, respectively.
- Between 2008 and 2018, the number of home health agencies in California increased by 50%, while home health visits increased by 40%.
- The number of hospice agencies licensed in California quadrupled from 2008 to 2018, and the number of hospice days doubled.
- In a 2019 survey of Californians, 65% of respondents reported that their loved ones would have preferred to die at home, while only 39% were able to do so.

See current and past editions of *Long-Term Care in California* at [www.chcf.org/collection/long-term-care-almanac](http://www.chcf.org/collection/long-term-care-almanac).

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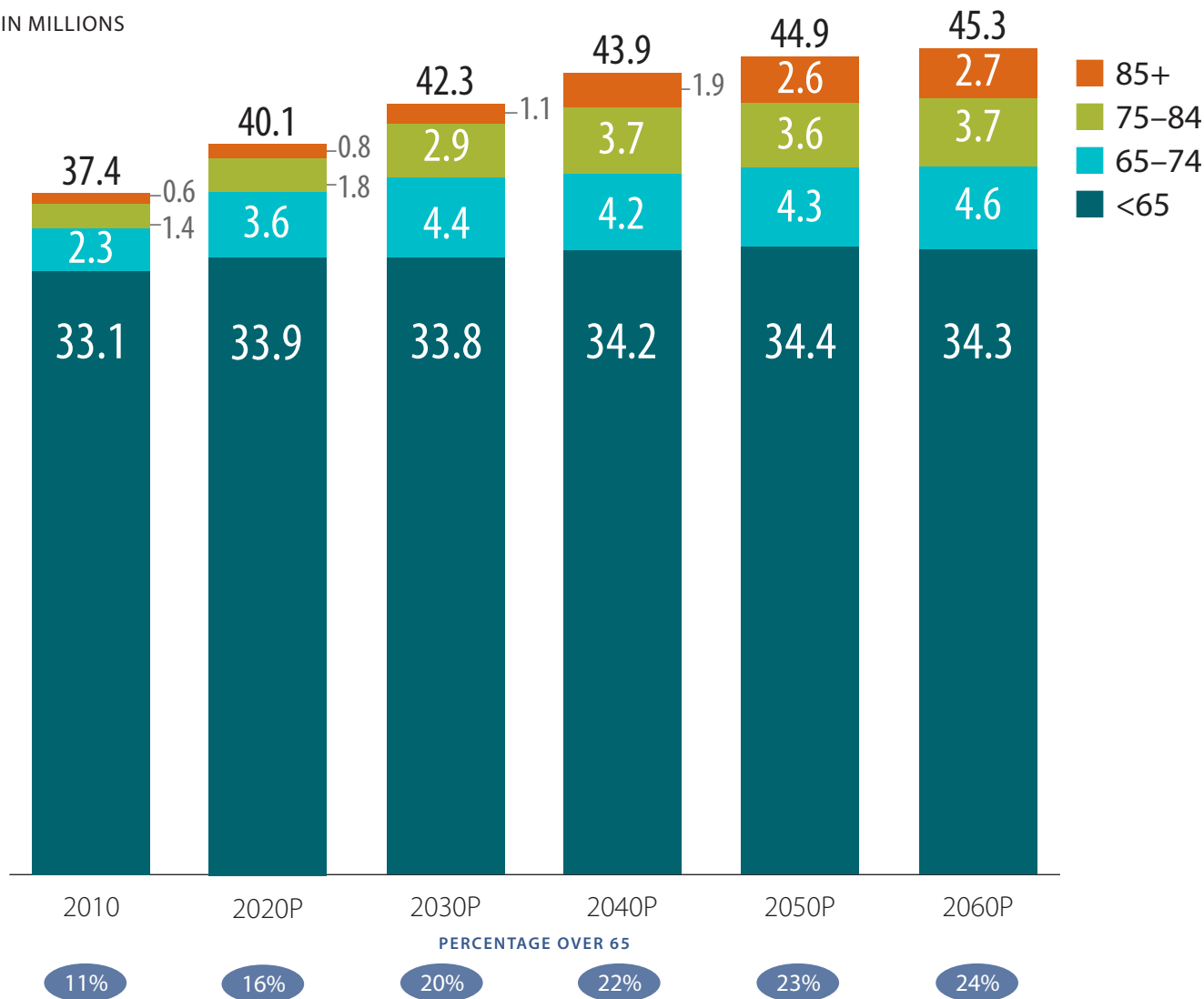
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\*HCBS is Home and Community-Based Services

# Projected Population by Age Group

California, 2010 to 2060, Selected Years

IN MILLIONS



Note: Projections are shown as P.

Source: *State Population Projections (2010–2060): Total Population by Age*, California Dept. of Finance, January 10, 2020.

## Long-Term and End-of-Life Care in California

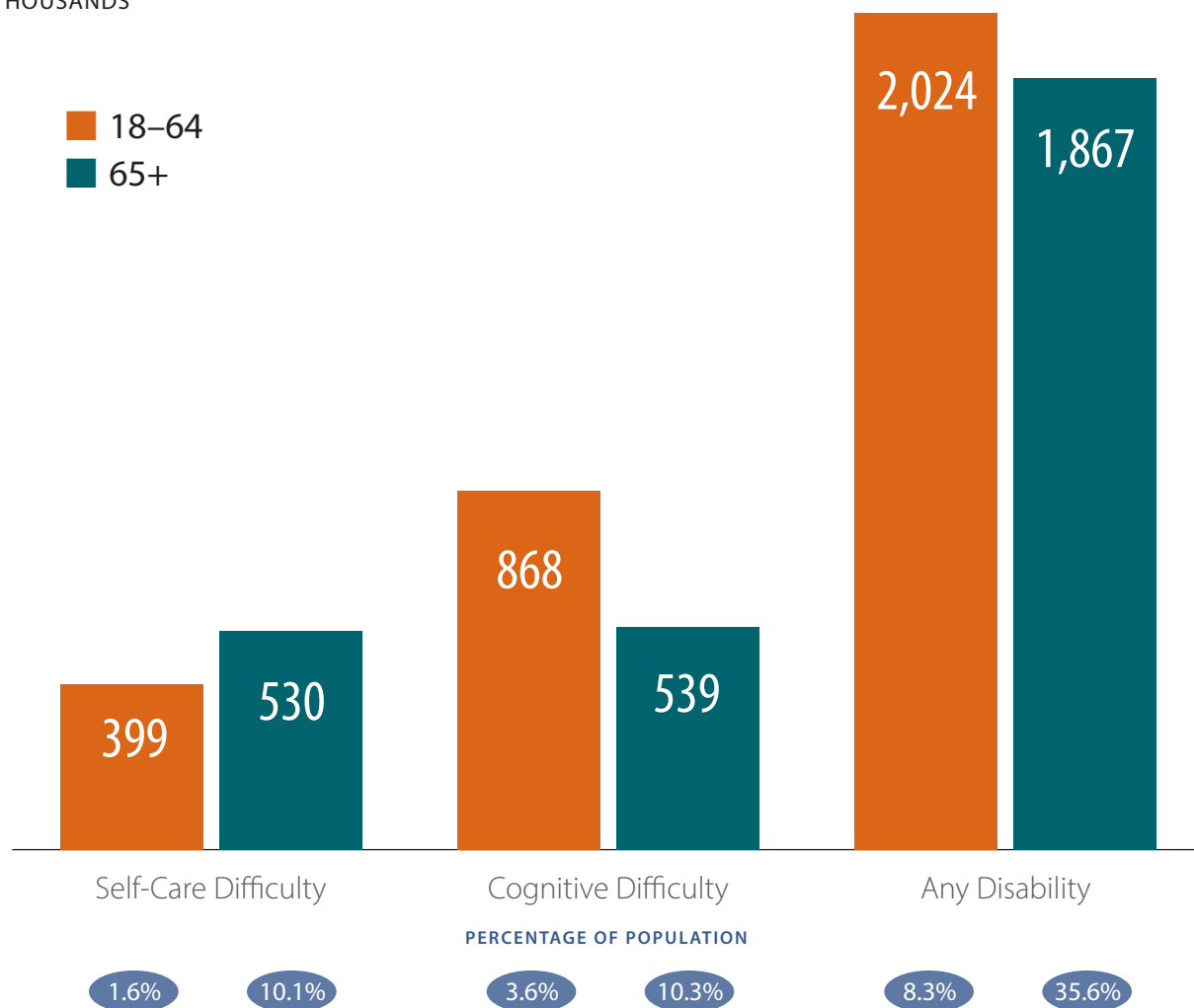
### Overview

California's population is projected to increase by 20% from 2010 to 2060. The most significant growth is projected in those age 65 and older, who will represent nearly one in four Californians by 2060. As the population ages, the need for long-term care services will likely increase.

# Adults with Disability

## by Age Group, California, 2016

IN THOUSANDS



Note: Any disability includes adults with one or more of six types of disability — hearing, vision, cognitive, ambulatory, self-care, and independent living.

Source: Ari Houser, Wendy Fox-Grage, and Kathleen Ujvari, *Across the States 2018: Profile of Long-Term Services and Supports in California*, AARP Public Policy Institute, August 27, 2018.

### Long-Term and End-of-Life Care in California

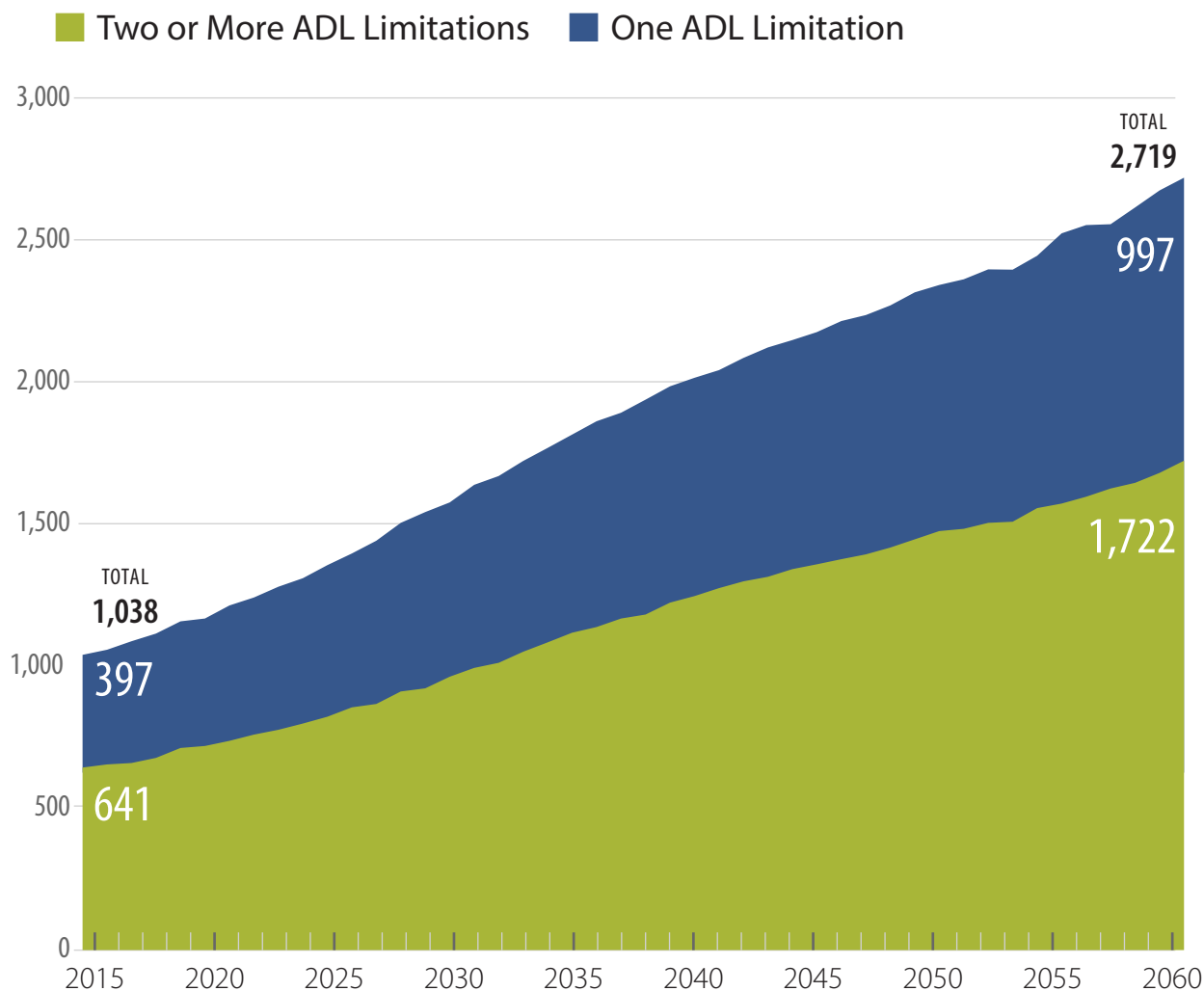
#### Overview

Nearly four million Californians were living with a disability in 2016, representing 1 in 12 adults age 18 to 64 and over 1 in 3 adults age 65 and older.

# Projected Population of Seniors with ADL Limitations

## California, 2015 to 2060

IN THOUSANDS



Notes: Projections produced in fall 2016. Activities of daily living (ADL) are self-care activities performed without assistance on a daily basis such as eating, bathing, dressing, grooming, toileting, and transferring into and out of bed or a chair without assistance.

Source: Special data request, California Legislative Analyst's Office, received February 4, 2020.

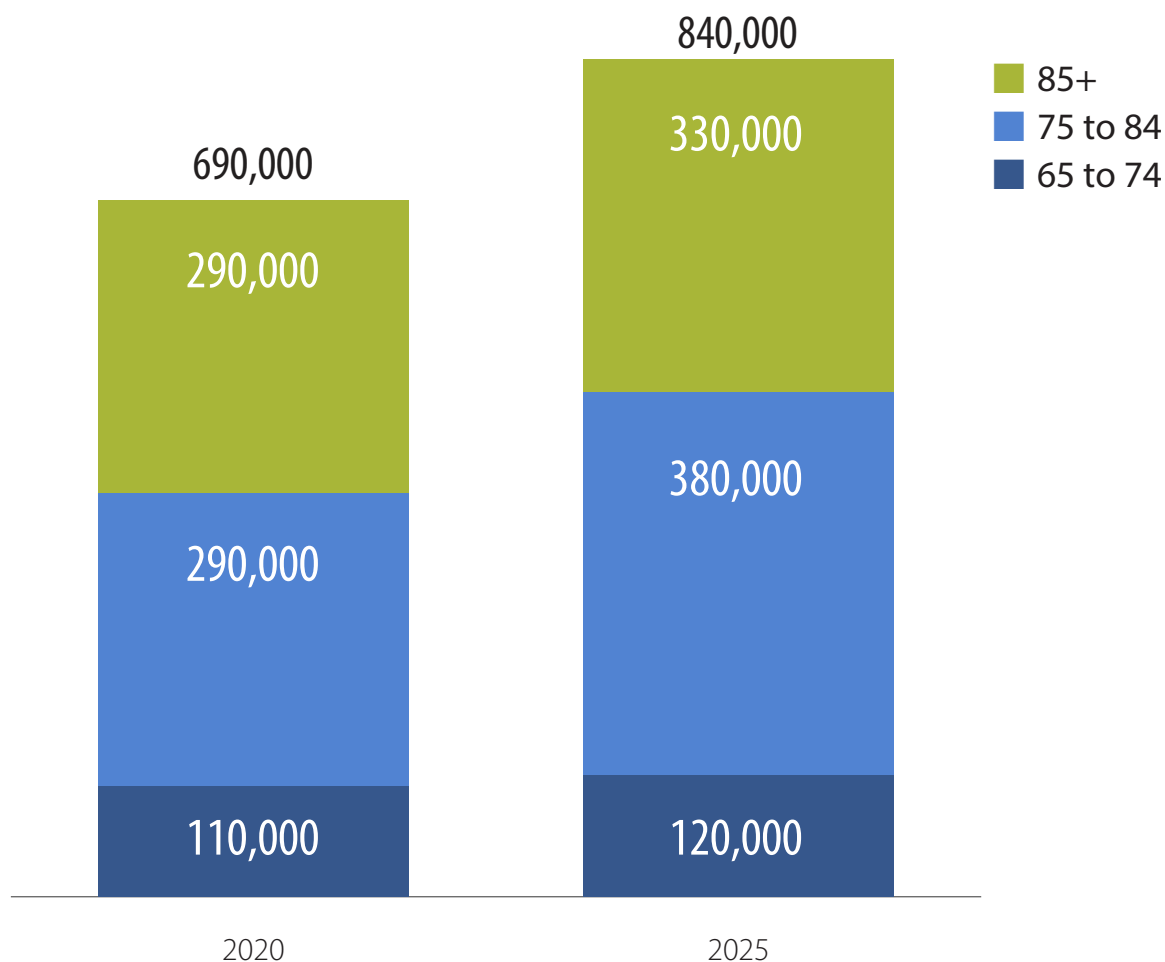
### Long-Term and End-of-Life Care in California

#### Overview

The number of California seniors with one or more limitations in activities of daily living (ADL) is projected to increase from 1 million in 2015 to 2.7 million in 2060. Seniors living with ADL limitations are likely to require long-term care services.

# Projected Prevalence of Alzheimer's Disease, by Age Group

## California, 2020 and 2025



Note: Segments may not sum due to rounding.

Source: *2020 Alzheimer's Disease Facts and Figures*, Alzheimer's Association, n.d.

### Long-Term and End-of-Life Care in California

#### Overview

The number of California seniors living with Alzheimer's disease is projected to increase from 690,000 in 2020 to 840,000 in 2025. Older people living with Alzheimer's or other dementias have more skilled nursing facility stays and home health care visits per year than other older people.

# Overview of Long-Term Care Services

## California, 2020

SERVICE	DESCRIPTION
Skilled Nursing Facility	Skilled nursing facilities provide room and board and round-the-clock nursing care and related services on a continuing basis. A registered professional nurse must be on duty or on call at all times.
Assisted Living Facility / Residential Care Facility	Residential care facilities, also known as assisted living facilities or board and care facilities, provide residents with room and board, assistance with personal care, and any necessary supervision.
Home Health Care	Home health care provides assistance with medications, wound care, intravenous therapy, and help with basic needs such as bathing, dressing, and mobility, which are delivered at a person's home. Home health patients may be elderly, disabled, sick, or convalescing, but they do not need institutional care.
Medicaid Home and Community-Based Services (HCBS)	HCBS are designed to help seniors and persons with disabilities and chronic illnesses live independently outside institutions by assisting with daily needs. HCBS can include case management, homemaker services, home health aide services, personal care, adult day health care, habilitation, and respite care.
Hospice Care	Hospice programs provide supportive care for terminally ill patients and their families, either directly or on a consulting basis with the patient's physician or another community agency. The whole family is considered the unit of care, and care extends through the family's period of mourning.

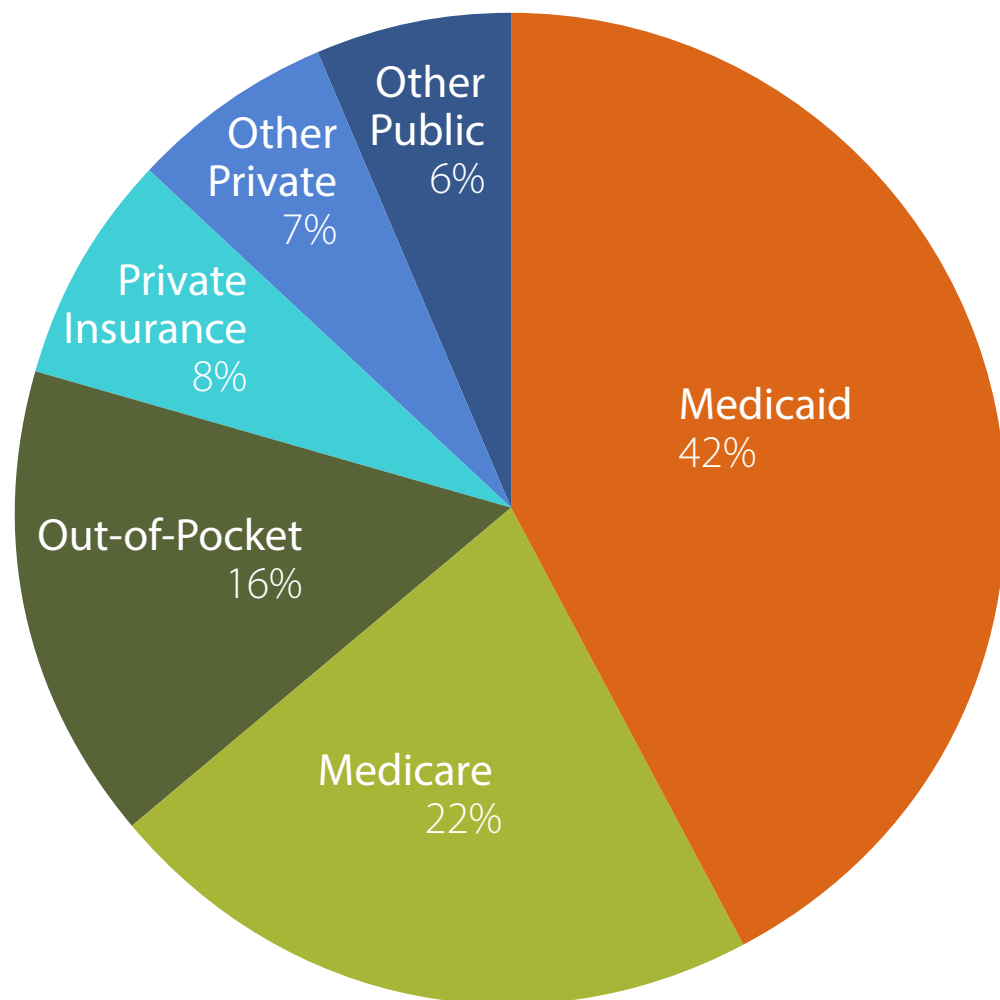
### Long-Term and End-of-Life Care in California

#### Overview

Long-term care services provide essential support to frail seniors and individuals with chronic illness and/or disability who require assistance with essential activities of daily living. Long-term care is provided via both institutional settings, including skilled nursing and assisted living facilities, and home-based care. In addition, many patients and families avail themselves of hospice care at the end of life.

Sources: Molly O'Malley Watts, MaryBeth Musumeci, and Priya Chidambaram, *Medicaid Home and Community-Based Services Enrollment and Spending*, KFF, February 4, 2020; and Leslie Ross, Edwina Newsom, and Charlene Harrington, *Long-Term Care in California: Ready for Tomorrow's Seniors?*, California Health Care Foundation, August 2013.

# Long-Term Services and Supports Spending by Payer, United States, 2016



Notes: Long-term services and supports spending includes services in nursing facilities and in residential care facilities for people with intellectual and developmental disabilities, mental health conditions, and substance use issues, as well as payments for services provided in a person's home (e.g., personal care and homemaker/chore services) and other community-based services (e.g., adult day health care services). Segments may not total 100% due to rounding.

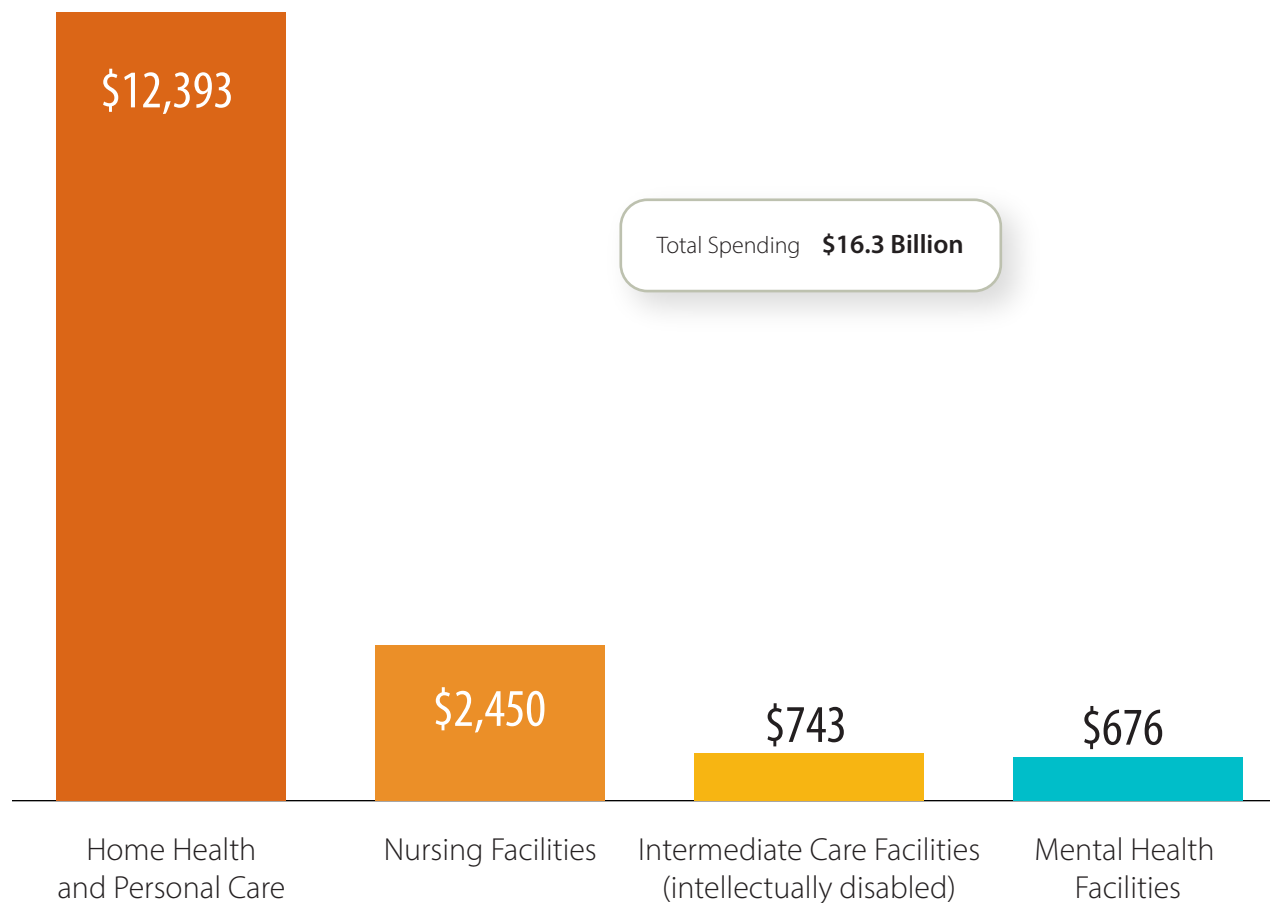
Source: [Who Pays for Long-Term Services and Supports?](#) (PDF), Congressional Research Service, August 22, 2018.

Public payers accounted for 70% of spending on long-term services and supports nationally in 2016. Medicaid covered 42% of spending, while Medicare covered 22% of spending.



# Medi-Cal Fee-for-Service Spending on Long-Term Care by Type, California, 2018

IN MILLIONS



Notes: *Mental health facilities* includes inpatient psychiatric services for people age 21 and under, and other mental health facilities for people age 65 and older. *Home health and personal care* includes standard home health services, personal care, home and community-based care for the functionally disabled elderly, and services provided under home and community-based services waivers.

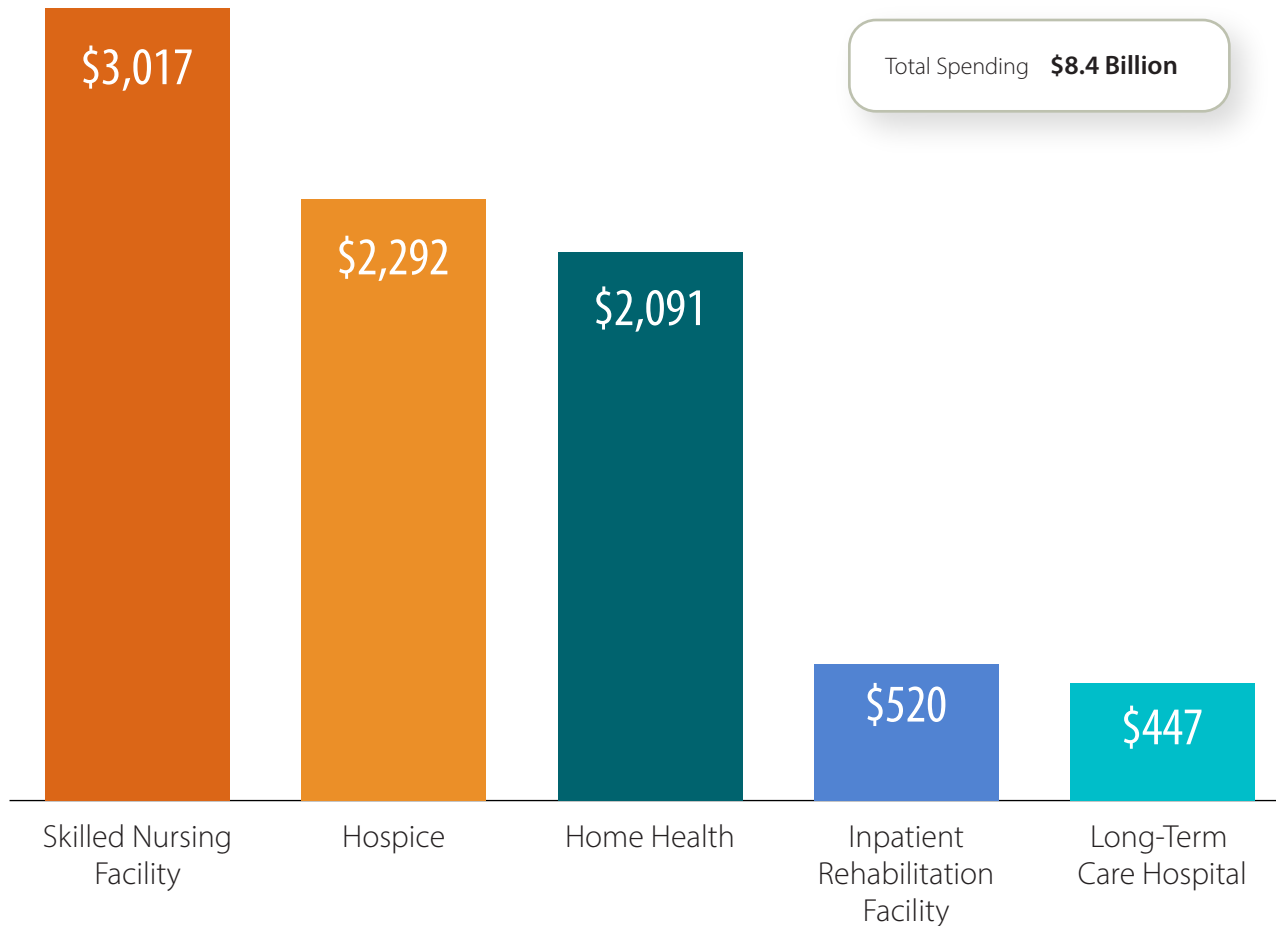
Source: "State Health Facts: Distribution of Fee-for-Service Medicaid Spending on Long Term Care," KFF, accessed March 3, 2020.

## Long-Term and End-of-Life Care in California Overview

Medi-Cal has long been an important payer for long-term care. In 2018, 19% of Medi-Cal spending was on fee-for-service long-term care services (not shown). The vast majority of Medi-Cal fee-for-service spending on long-term care, \$12.4 billion, was on home health and personal care in 2018. Only 24% of Medi-Cal's fee-for-service spending on long-term care covered institutional care.

# Medicare Spending on Long-Term Care by Type, California, 2017

IN MILLIONS



Notes: Data represent the total that Medicare paid after deductibles and coinsurance were deducted. Data contain limited information for beneficiaries enrolled in a Medicare Advantage (MA) plan, such as when MA beneficiaries receive out-of-network care that is paid under the Medicare fee-for-service program, as well as hospice claims for MA beneficiaries.

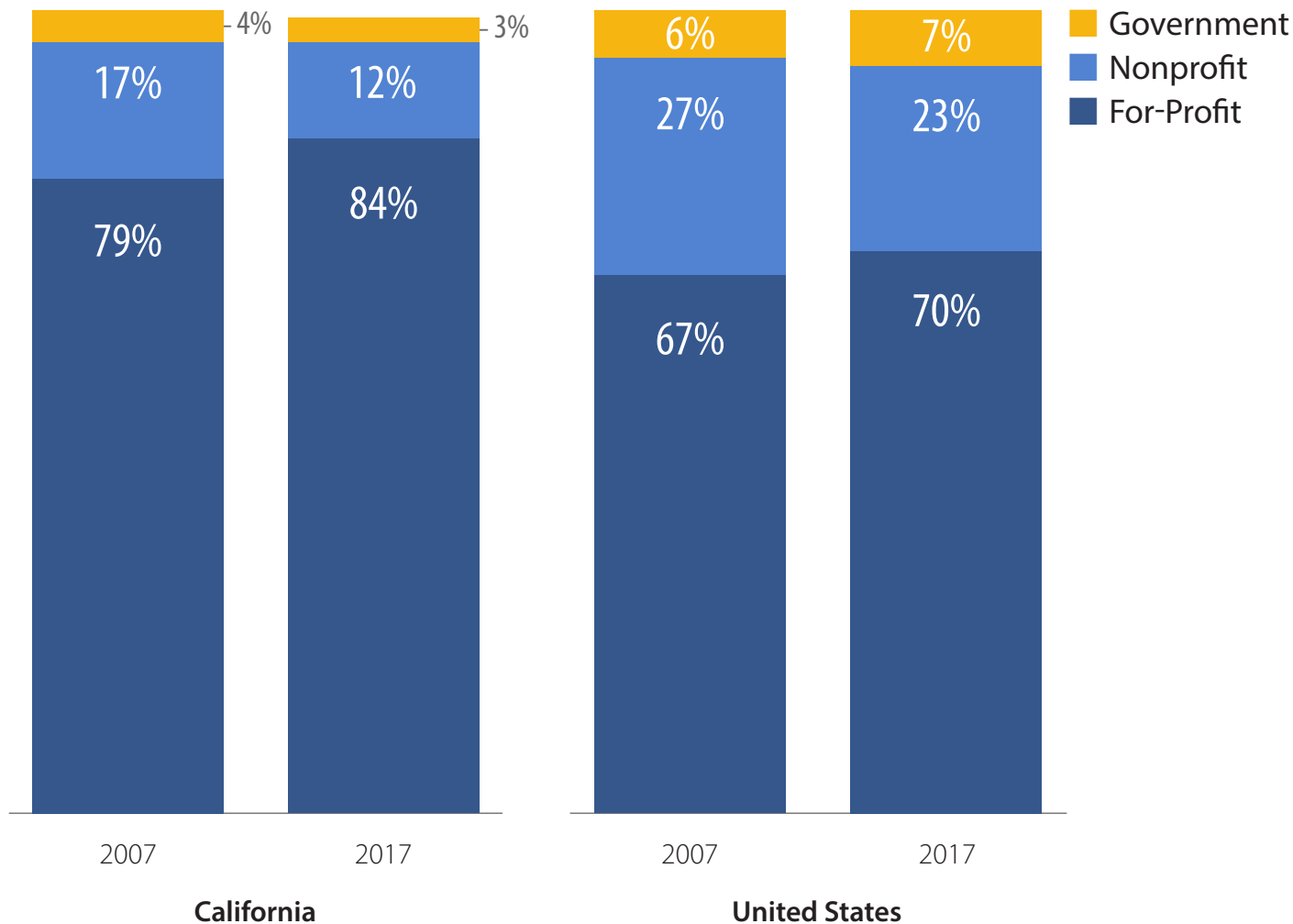
Source: [Post-Acute Care and Hospice Provider Utilization and Payment Public Use Files](#), Centers for Medicare & Medicaid Services, 2017.

## Long-Term and End-of-Life Care in California Overview

In 2017, Medicare spent \$8.4 billion on long-term care in California (including only partial spending for Medicare Advantage patients). Over one-third of the spending was on skilled nursing facilities (SNFs). Medicare covers up to 100 days of SNF care after a medically necessary hospitalization of at least three days.

# Nursing Facilities by Ownership Type

California vs. United States, 2007 and 2017



## Long-Term and End-of-Life Care in California Nursing Facilities

The vast majority of California's certified nursing facilities are for-profit. In 2017, 84% of the state's nursing facilities were for-profit, compared to 70% nationally.

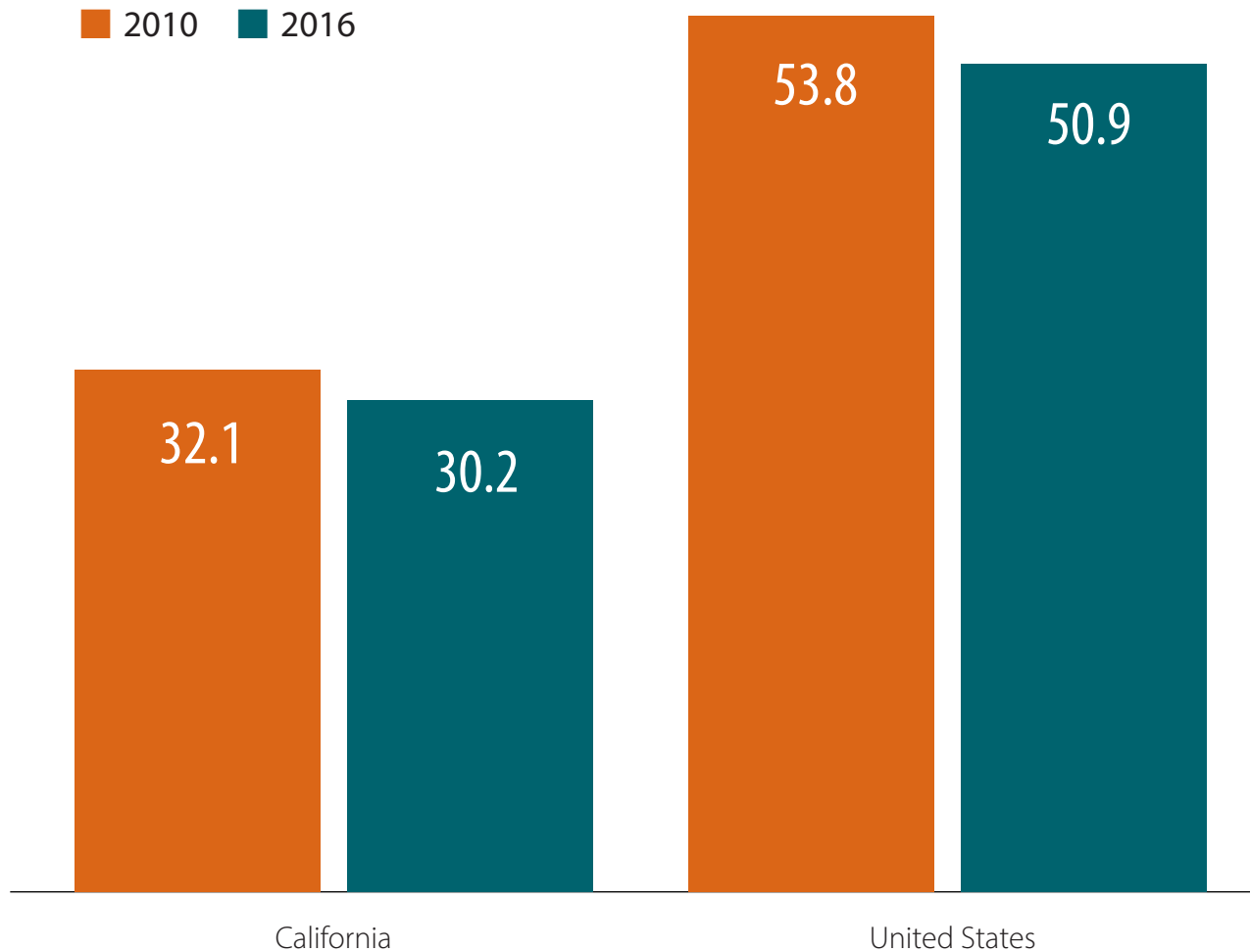
Notes: Data are for certified nursing facilities surveyed in the US. Segments may not total 100% due to rounding.

Source: "State Health Facts: Distribution of Certified Nursing Facilities by Ownership Type," KFF, accessed March 5, 2020.

# Nursing Facility Beds

## California vs. United States, 2010 and 2016

NUMBER PER 10,000 POPULATION



Note: Population data are one-year estimates from the American Community Survey.

Sources: Author calculations based on Charlene Harrington et al., *Nursing Facilities, Staffing, Residents and Facility Deficiencies, 2009 Through 2016*, KFF, April 3, 2018; and *American Community Survey*, US Census Bureau, accessed March 3, 2020.

### Long-Term and End-of-Life Care in California

#### Nursing Facilities

California has a smaller supply of nursing facility beds per capita than the nation. Total nursing facility beds declined slightly from 2010 to 2016 in both California and the United States (not shown).

# Skilled Nursing Facility Beds, Admissions, and Patient Days

## California, 2008 and 2018

SERVICE	2008	2018	% CHANGE (2008 vs. 2018)
Beds	104,690	104,668	0.0%
Admissions	304,534	364,754	19.8%
Patient Days	33,015,390	33,326,637	0.9%

### Long-Term and End-of-Life Care in California Nursing Facilities

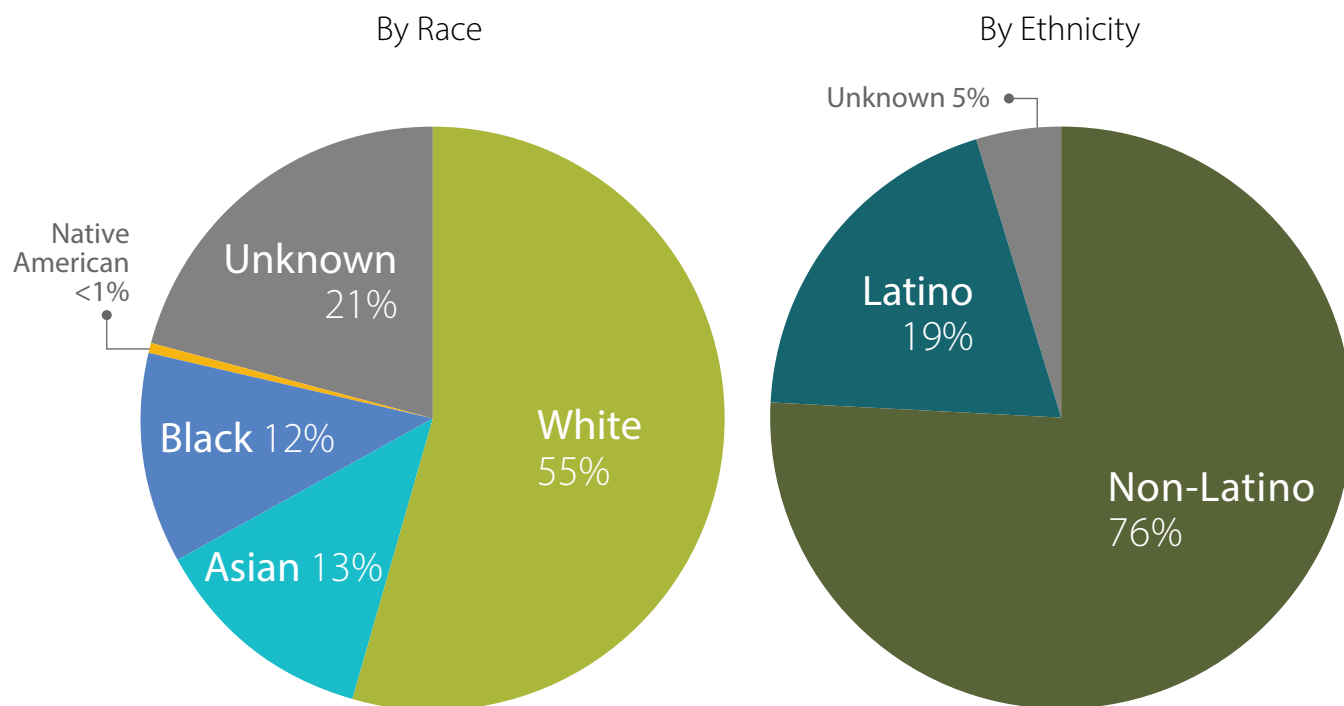
Over the last decade, admissions to California's skilled nursing facilities increased by 20%, while beds and patient days remained flat. In 2018, 65% of discharges were for stays of less than one month, compared to 59% in 2008 (not shown).

Note: Data limited to facilities licensed as skilled nursing facilities.

Source: *Long-Term Care Facilities Annual Utilization Data* (2008, 2018), CHHS Open Data Portal.

# Skilled Nursing Facility Patients by Race and Ethnicity, California, 2018

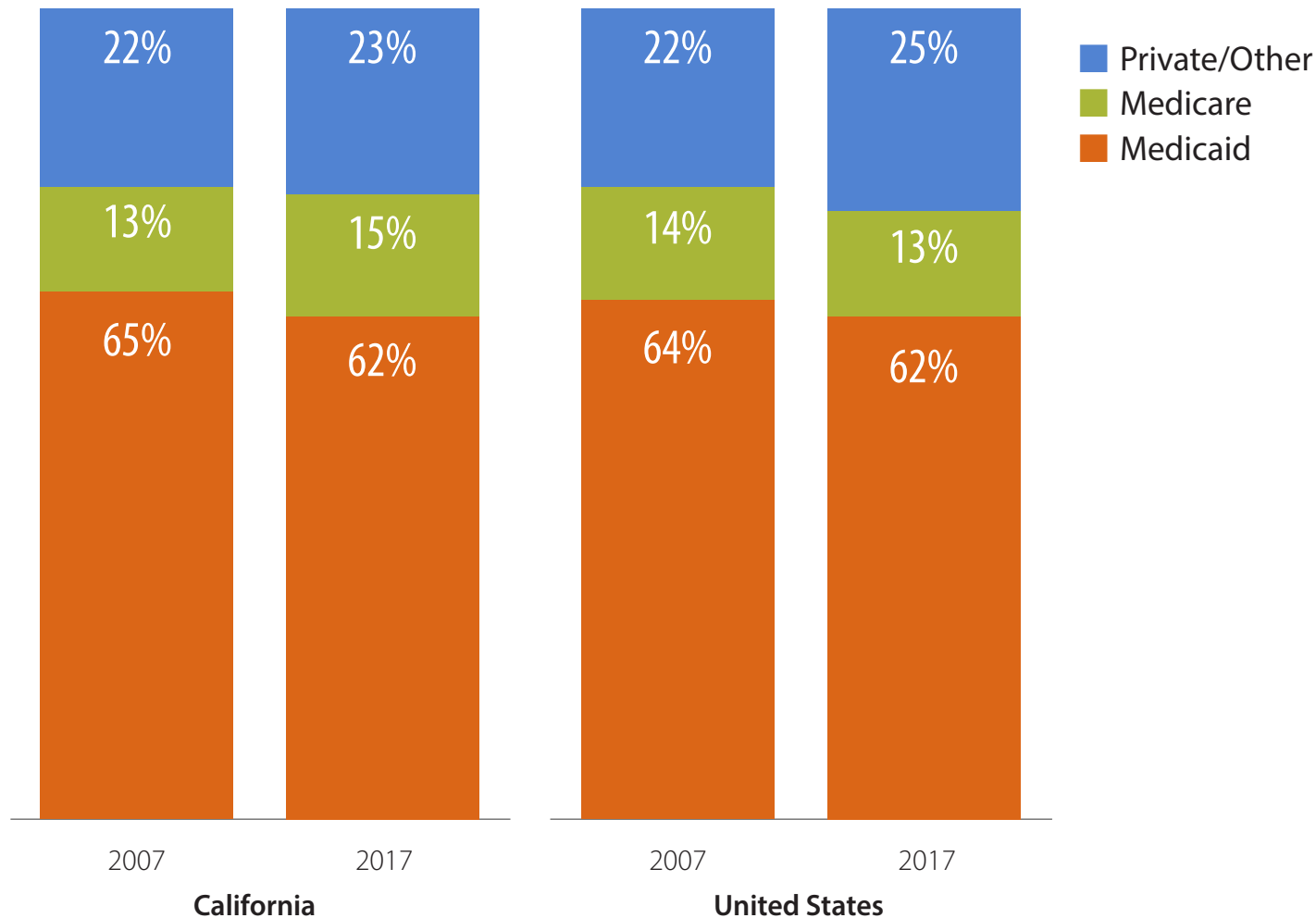
In 2018, the majority of skilled nursing facility patients in California were white and non-Latino.



Note: Data limited to facilities licensed as skilled nursing facilities. Segments may not total 100% due to rounding.  
Source: [Long-Term Care Facilities Annual Utilization Data](#) (2018), CHHS Open Data Portal, last updated January 28, 2020.

# Nursing Facility Residents by Primary Payer

California vs. United States, 2007 and 2017



## Long-Term and End-of-Life Care in California Nursing Facilities

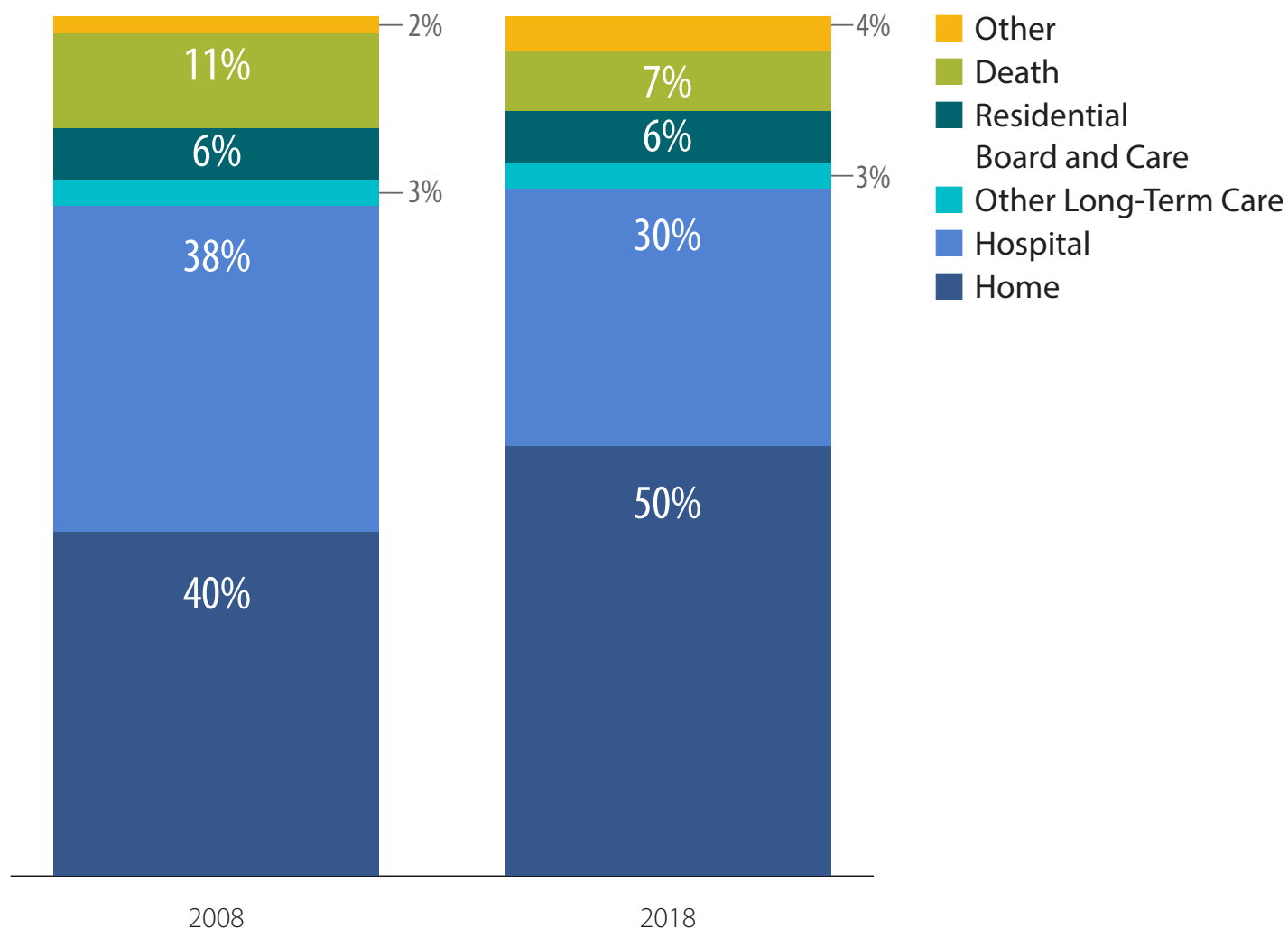
Medicaid has been the dominant payer for nursing facility residents over the last decade in both California and the United States, covering over 6 in 10 nursing facility residents.

Notes: Data are for certified nursing facilities surveyed in the US. Figures represent number of residents by payer at the time the certified nursing facility was surveyed. Segments may not total 100% due to rounding.

Source: "State Health Facts: [Distribution of Certified Nursing Facility Residents by Primary Payer Source](#)," KFF, accessed March 5, 2020.

# Skilled Nursing Facility Discharges by Disposition

California, 2008 and 2018



Notes: Data limited to facilities licensed as skilled nursing facilities. *Hospital* includes state hospital. *Residential board and care* includes residential care facilities for the elderly, adult care facility, other assisted living facilities, or a secured facility such as an Alzheimer's unit, jail, or prison. *Other* includes both other and absent without official leave / against medical advice (the patient left without prior approval of the physician or facility).

Source: [Long-Term Care Facilities Annual Utilization Data](#) (2008, 2018), CHHS Open Data Portal.

## Long-Term and End-of-Life Care in California Nursing Facilities

In 2018, 50% of California's skilled nursing facility patients were discharged home, up from 40% in 2008. Across the same period, the portion of patients discharged to the hospital or who died declined.



# Nursing Home Quality Measures

## California vs. United States, 2019

PERCENTAGE OF LONG-STAY RESIDENTS WHO...

Had Increased Need for Help with Daily Activities



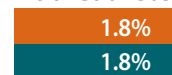
Had Pressure Ulcers



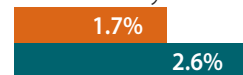
Lost Too Much Weight



Had Catheter Inserted and Left in Bladder



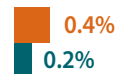
Had Urinary Tract Infection



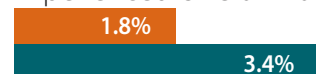
Had Depressive Symptoms



Were Physically Restrained



Experienced One or More Falls with Major Injury



Received Antipsychotic Medication



California  
United States

### Long-Term and End-of-Life Care in California Nursing Facilities

In 2019, California nursing homes performed similarly or better than the national average on a number of quality measures monitored by the Centers for Medicare & Medicaid Services.

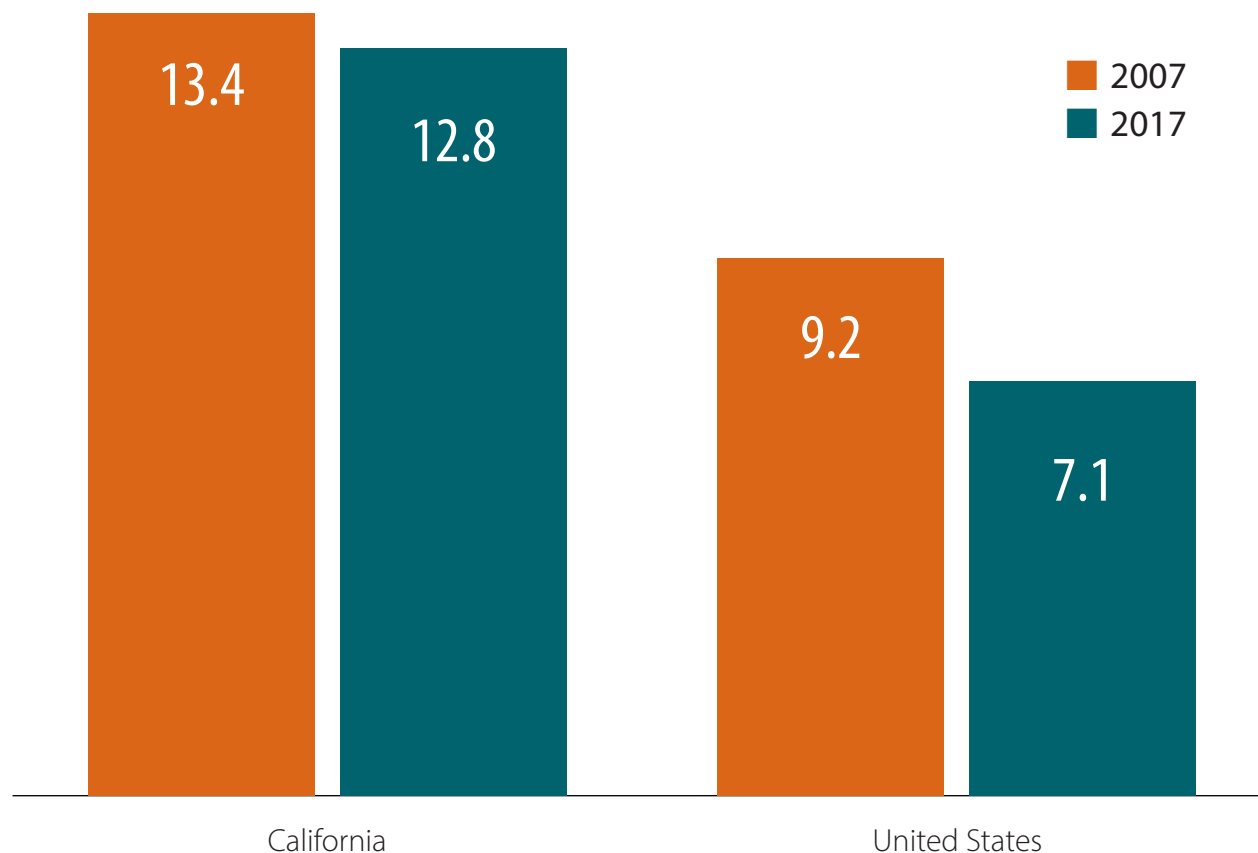
Note: Lower percentages are better.

Source: "Nursing Home Compare Datasets," Centers for Medicare & Medicaid Services, accessed April 29, 2020.

# Nursing Facility Deficiencies

## California vs. United States, 2007 and 2017

AVERAGE NUMBER PER FACILITY



PERCENTAGE WITH DEFICIENCY FOR ACTUAL HARM OR JEOPARDY OF RESIDENTS

16%

19%

27%

19%

Notes: Deficiencies are given for problems which can result in a negative impact on the health and safety of residents. The Centers for Medicare & Medicaid Services defines *actual harm* as a "deficiency that results in a negative outcome that has negatively affected the resident's ability to achieve the individual's highest functional status." *Immediate jeopardy* is defined as a deficiency that "has caused (or is likely to cause) serious injury, harm, impairment, or death to a resident receiving care in the nursing home."

Source: "State Health Facts: [Average Number of Deficiencies per Certified Nursing Facility](#)" and "State Health Facts: [Percent of Certified Nursing Facilities Receiving a Deficiency for Actual Harm or Jeopardy](#)," accessed April 3, 2020.

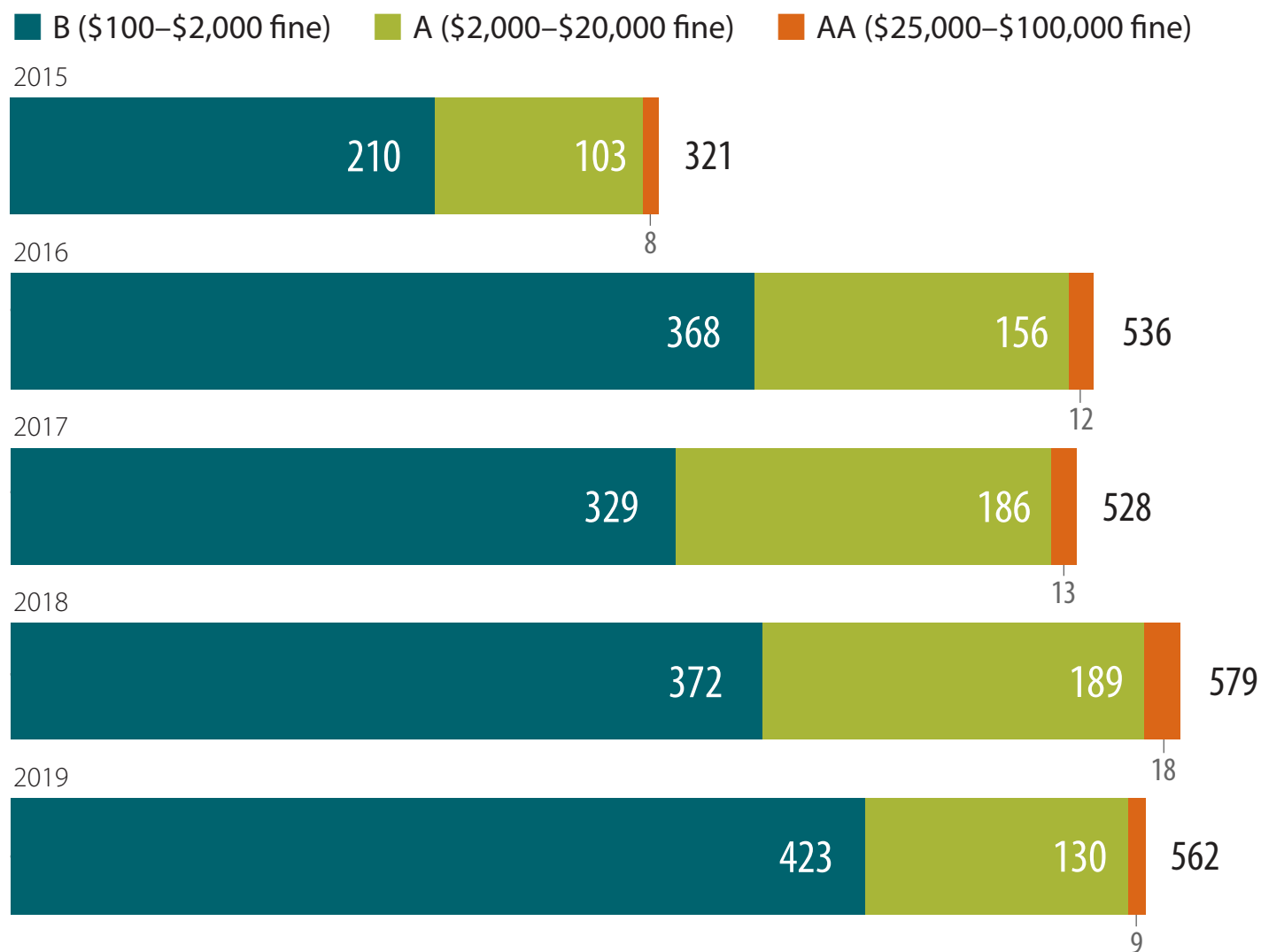
### Long-Term and End-of-Life Care in California

#### Nursing Facilities

Over the last decade, California nursing homes have averaged a higher number of deficiencies than nursing homes nationwide. In 2017, nearly one in five nursing homes in California and nationwide received a deficiency for actual harm or jeopardy of residents.

# Skilled Nursing Facility State Citations

California, 2015 to 2019



Notes: Data limited to facility type, "Skilled Nursing Facility." Class B citations have a direct or immediate relationship to patient health, safety, or security. Class A citations are imminent danger of death or serious harm to patients, or a substantial probability of death or serious physical harm to patients. Class AA citations meet the definition of a Class A violation and are issued when the state determines that a facility's violation was a direct proximate cause of death of a patient or resident.

Source: "State Enforcement Actions Dashboard," California Dept. of Public Health, last updated May 12, 2020.

## Long-Term and End-of-Life Care in California Nursing Facilities

Each year from 2016 to 2019, California issued more than 500 state citations to skilled nursing facilities, the majority of which were for lesser violations. The number of the most serious violations ranged from a low of 8 in 2015 to a high of 18 in 2018.

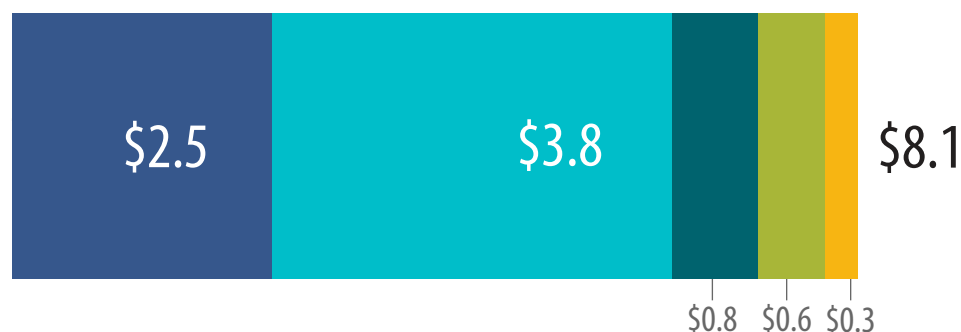
# Skilled Nursing Facility Net Patient Revenue, by Payer

## California, 2008 and 2018

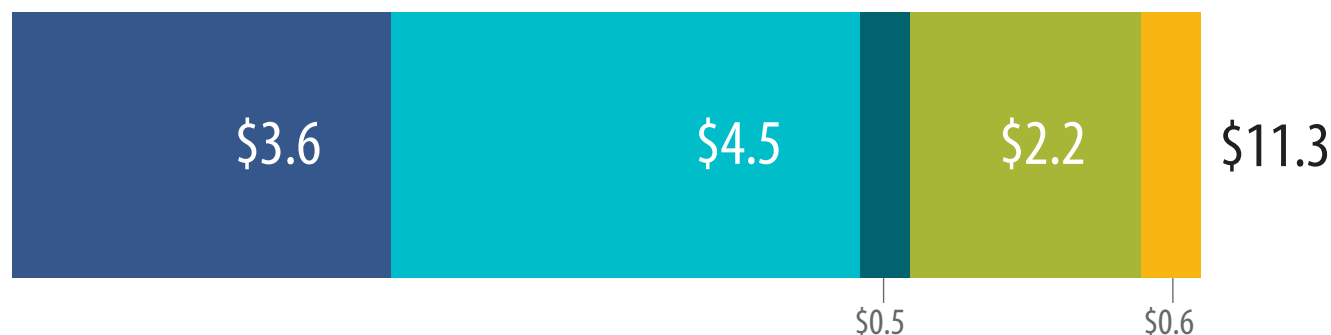
IN BILLIONS

■ Medicare FFS ■ Medi-Cal FFS ■ Self-Pay ■ Managed Care ■ Other Payers

2008



2018



Notes: FFS is fee for service. Data limited to facilities licensed as skilled nursing facilities. Managed care includes commercial, Medicare, and Medi-Cal managed care health plans. Net patient revenue is gross revenue minus deductions (e.g., contractual adjustments).

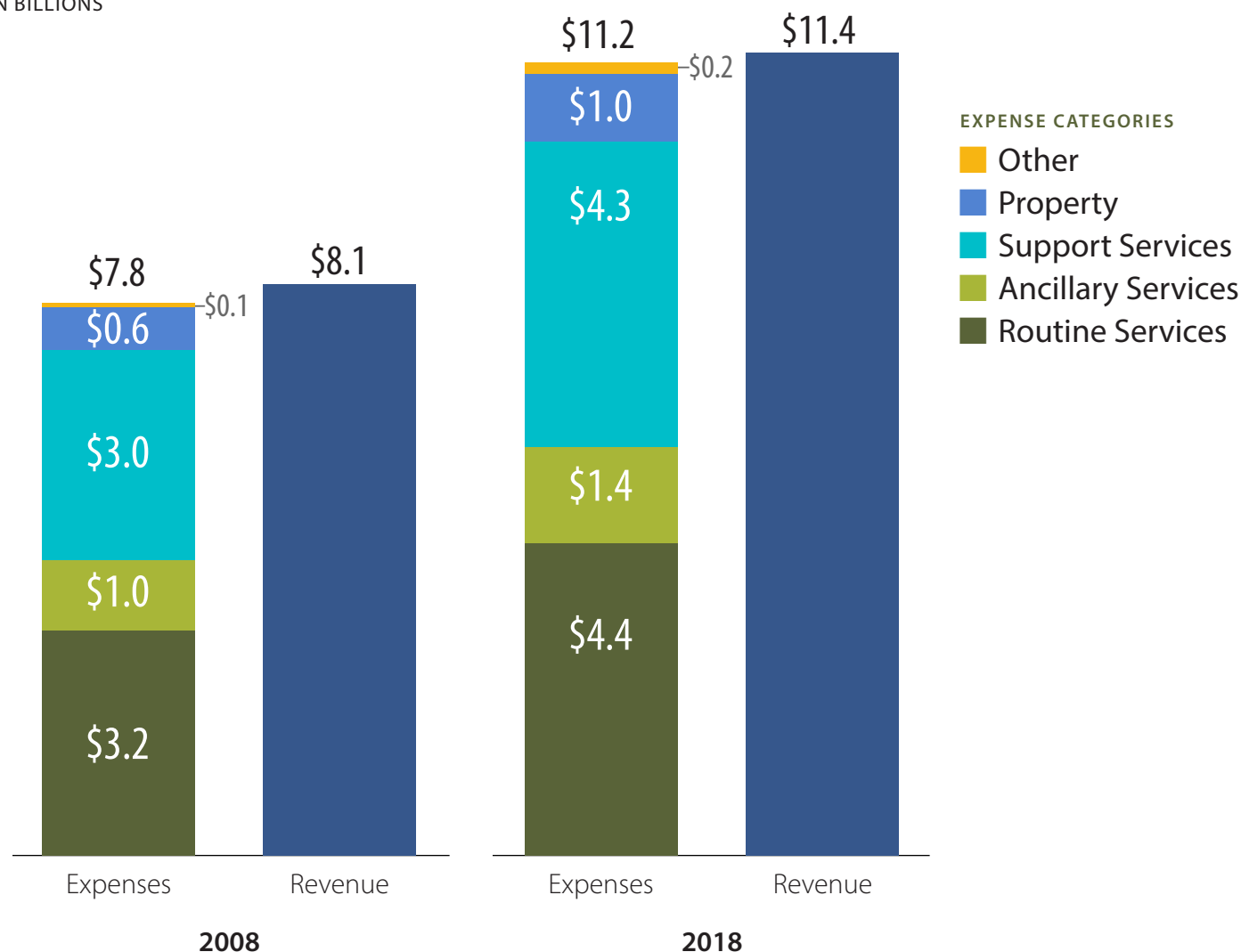
Source: [Long-Term Care Annual Financial Data](#) (2008, 2018), CHHS Open Data Portal.

Skilled nursing facilities' total net patient revenue increased by 40% from \$8.1 billion in 2008 to \$11.3 billion in 2018. In both years, the Medi-Cal fee-for-service program was the largest payer, and the Medicare fee-for-service program was the second-largest payer.

# Skilled Nursing Facility Expenses and Revenue

## California, 2008 and 2018

IN BILLIONS



Notes: Data limited to facilities licensed as skilled nursing facilities. *Revenue* is total health care revenue (net patient revenue plus other operating revenue).

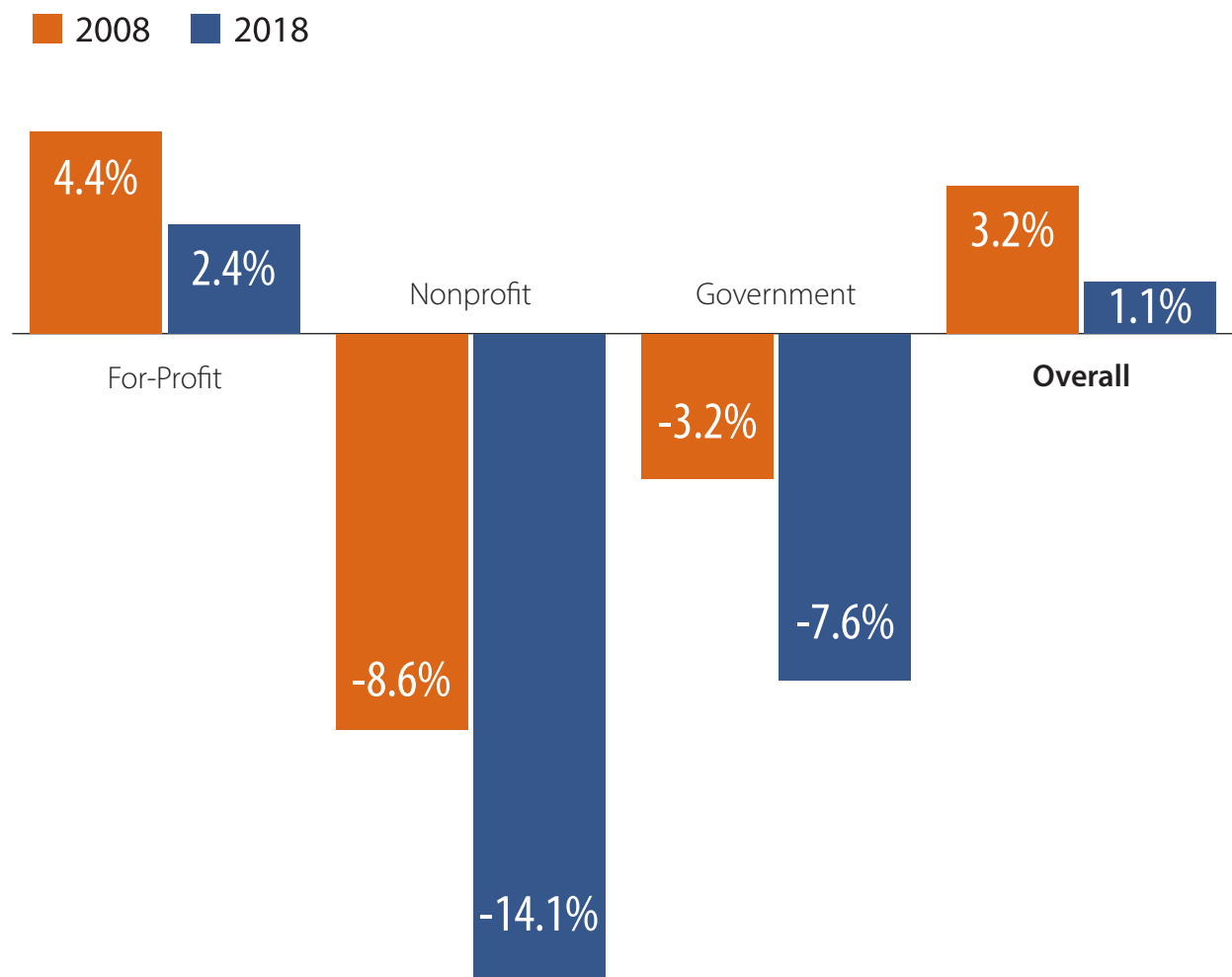
Source: [Long-Term Care Annual Financial Data](#) (2008, 2018), CHHS Open Data Portal.

### Long-Term and End-of-Life Care in California Nursing Facilities

From 2008 to 2018, total expenses for California's skilled nursing facilities increased slightly more than total health care revenues (43% versus 40%, respectively).

# Skilled Nursing Facility Operating Margin by Ownership

## California, 2008 and 2018



### Long-Term and End-of-Life Care in California

#### Nursing Facilities

The operating margin for California's skilled nursing facilities decreased from 3.2% in 2008 to 1.1% in 2018. While for-profit facilities in total posted a positive 2.4% operating margin in 2018, nonprofit facilities posted a negative 14.1% operating margin.

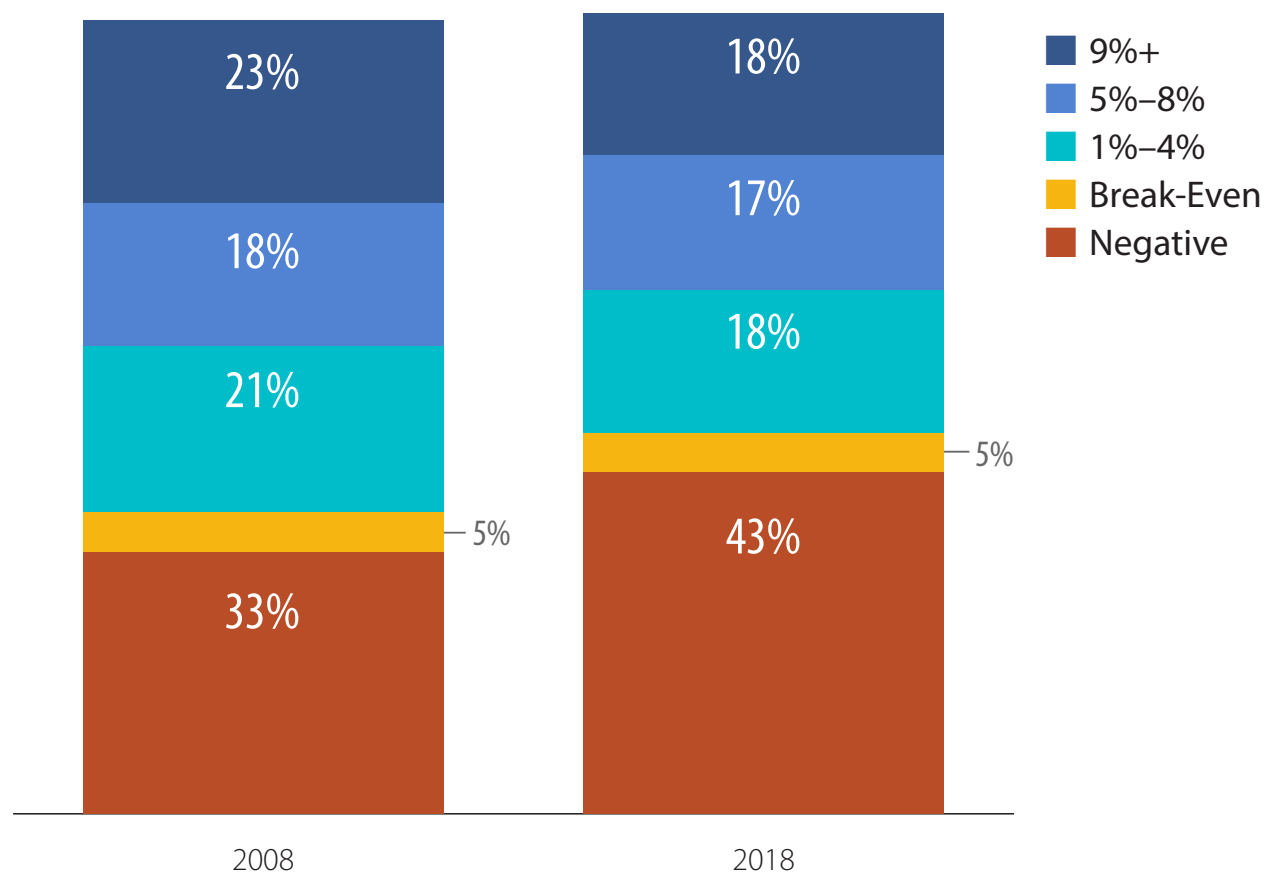
Notes: Data limited to facilities licensed as skilled nursing facilities. *Operating margin* indicates the percentage of health care revenue (net patient revenue and other operating revenue) that remains as income after operating expenses have been deducted.

Source: [Long-Term Care Annual Financial Data](#) (2008, 2018), CHHS Open Data Portal.

# Skilled Nursing Facilities by Operating Margin

## California, 2008 and 2018

PERCENTAGE OF FACILITIES



### Long-Term and End-of-Life Care in California

#### Nursing Facilities

Between 2008 and 2018, the percentage of California skilled nursing facilities with a negative margin increased from 33% to 43%. In 2018, 35% of skilled nursing facilities had an operating margin of 5% or higher.

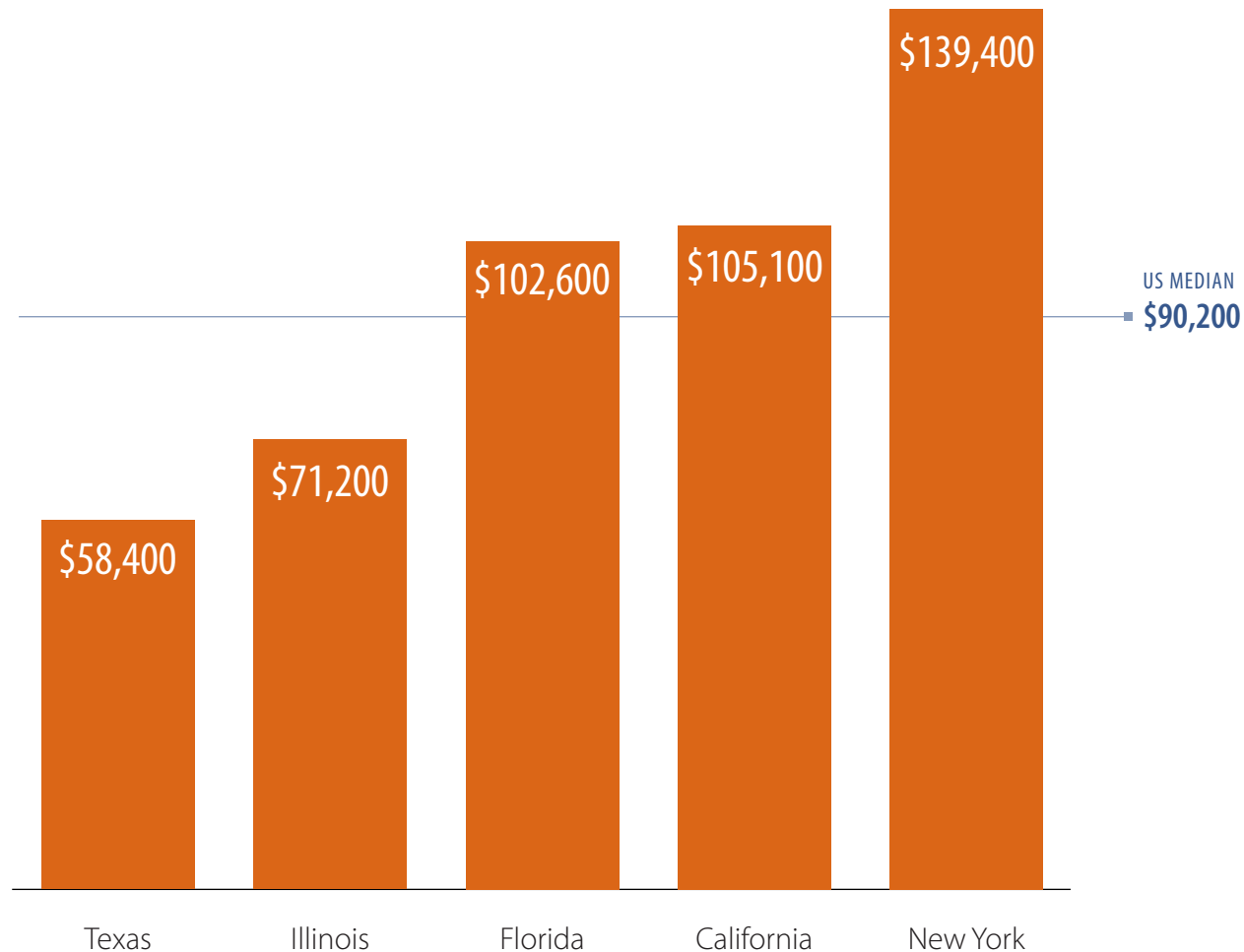
Notes: Data limited to facilities licensed as skilled nursing facilities. *Operating margin* indicates the percentage of health care revenue (net patient revenue and other operating revenue) that remains as income after operating expenses have been deducted. Segments may not total 100% due to rounding.

Source: Author calculations based on [Long-Term Care Annual Financial Data](#) (2008, 2018), CHHS Open Data Portal.

# Nursing Facility Cost, Semiprivate Room

## Selected States, 2019

ANNUAL MEDIAN COST



Note: Based on 365 days of care.

Source: *Cost of Care Survey 2019*, Genworth, October 8, 2019.

### Long-Term and End-of-Life Care in California

#### Nursing Facilities

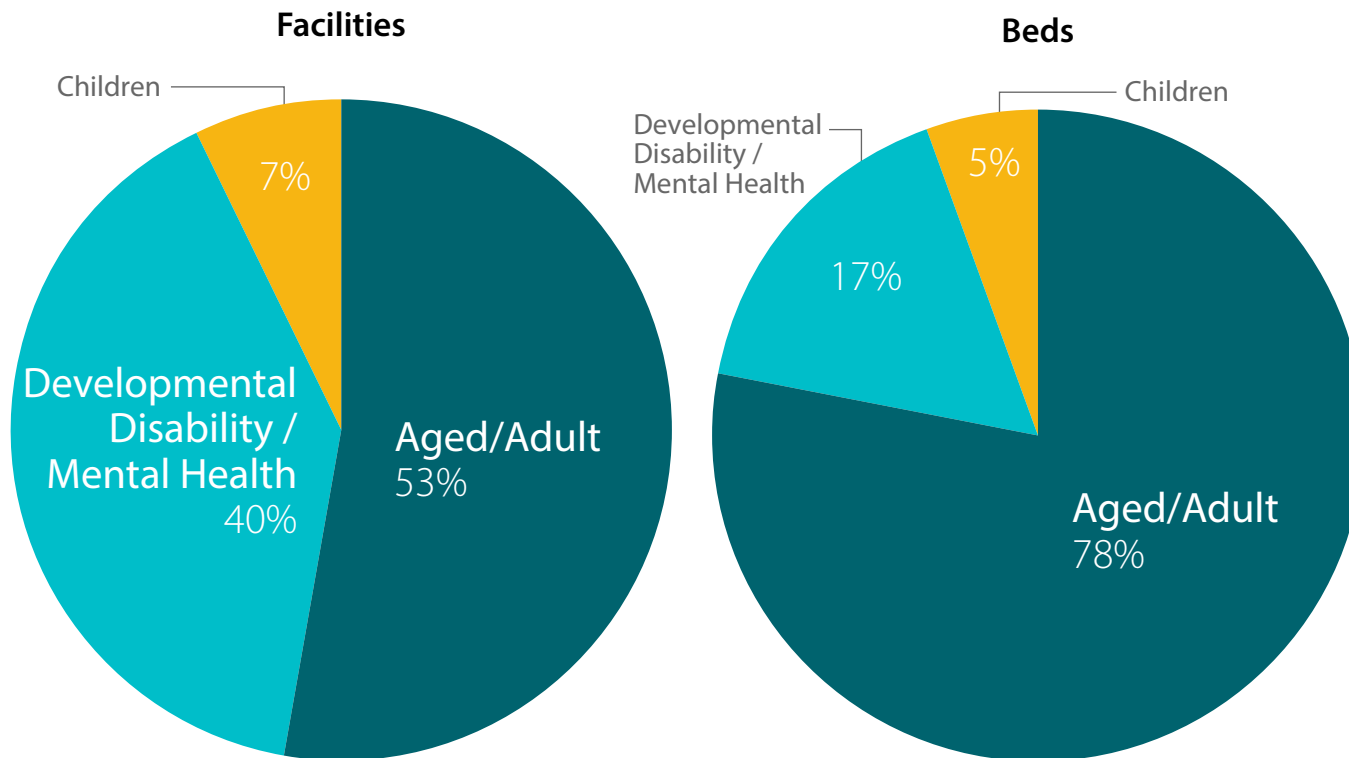
The median cost in 2019 of a semiprivate room in a nursing facility was 17% higher in California than nationally.



# Assisted Living Capacity, by Client Group

## California, 2019

The majority of assisted living facilities and beds in California were licensed to serve aged and adult clients. A large proportion of facilities served Californians with developmental disabilities or mental health conditions.

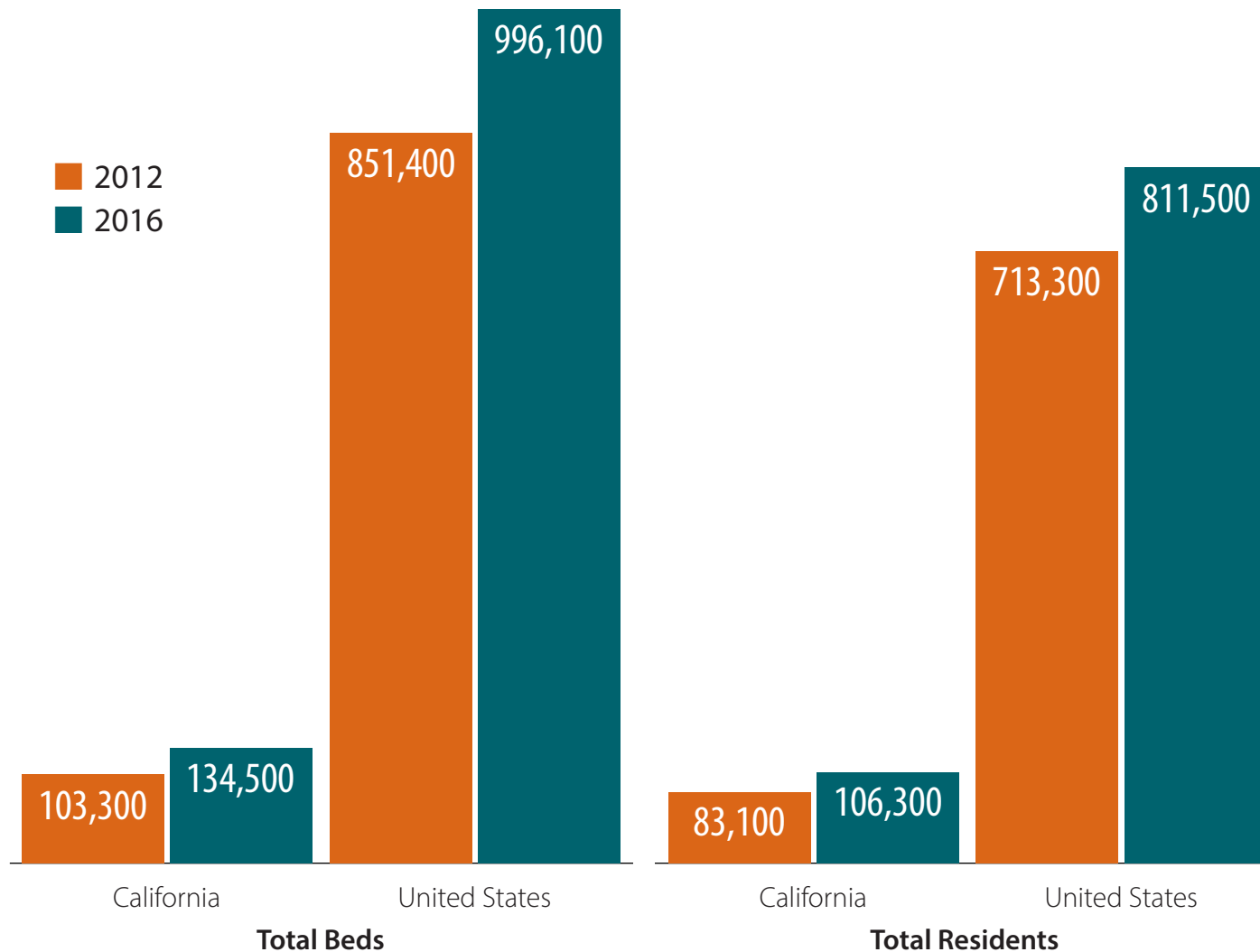


Note: Data for licensed facilities only; excludes facilities with pending licenses, on probation, or closed.

Source: Author analysis of community care licensing data (adult residential facilities, residential elder care facilities, 24-hour residential care for children), [CHHS Open Data Portal](#), accessed February 18, 2020.

# Assisted Living Beds and Residents

California vs. United States, 2012 and 2016



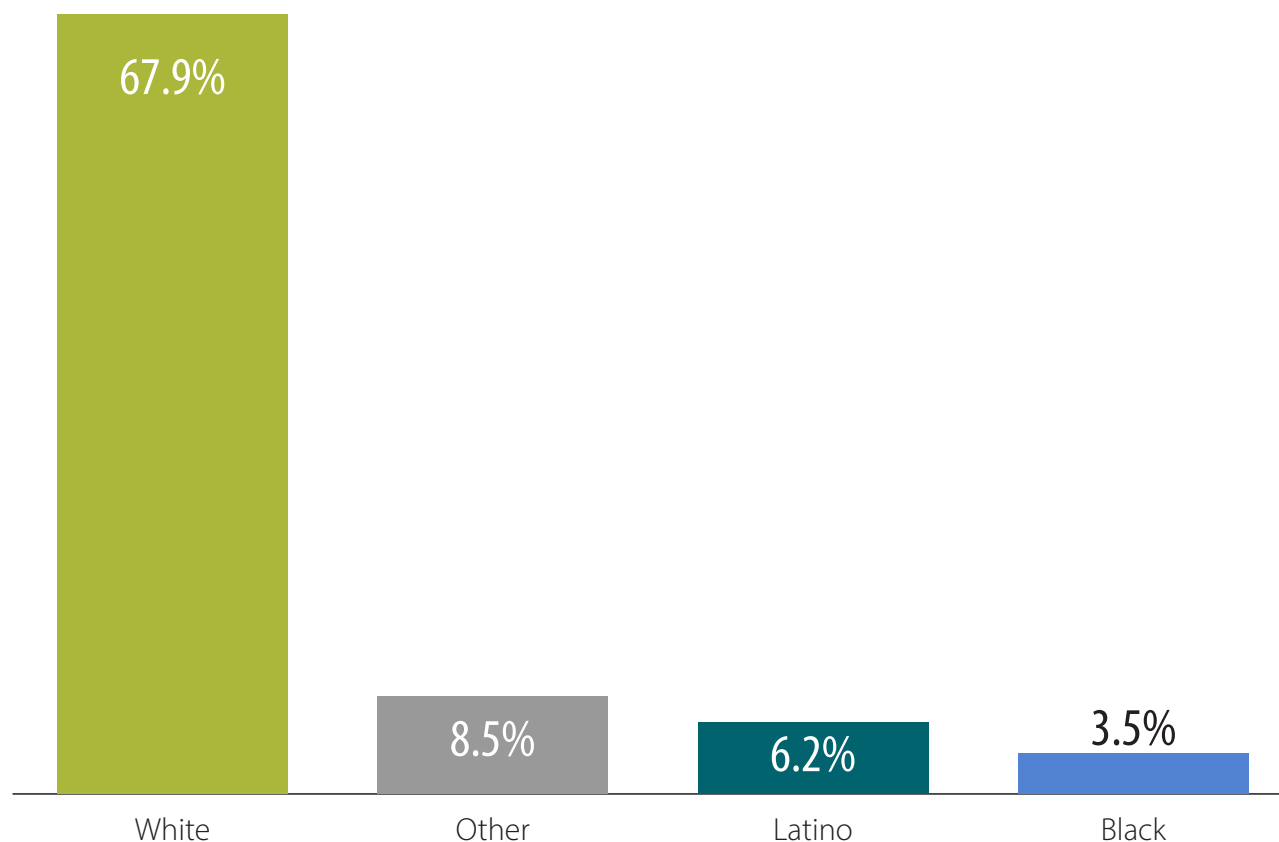
Notes: Number of beds and residents (source uses *service users*) is rounded to nearest 100. *Service users* reflects number of assisted living residents on the day of data collection (as opposed to the total number of service users who lived in these settings at some point during the calendar year). Source uses *residential care community*, which includes assisted living and similar residential care communities.

Source: [National Study of Long-Term Care Providers](#), Centers for Disease Control and Prevention.

Both California and the United States experienced double-digit growth in the number of assisted living beds and residents from 2012 to 2016.

# Assisted Living Residents by Race/Ethnicity, California, 2016

In 2016, about two-thirds of California's assisted living facility residents were white.



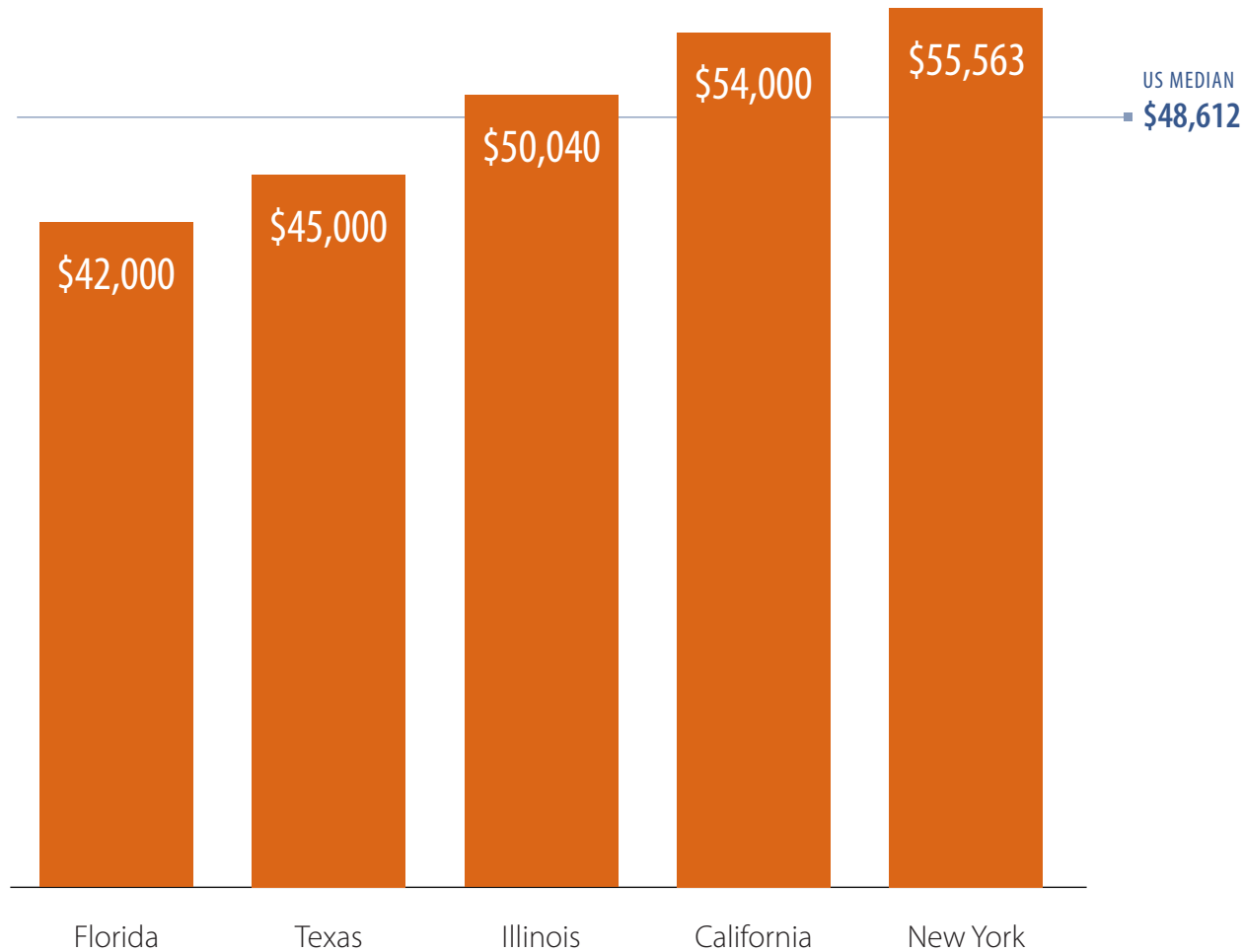
Notes: *Residents* (source uses *service users*) reflects number of residents on the day of data collection (as opposed to the total number of service users who lived in these settings at some point during the calendar year). *Other* includes non-Latino American Indian or Alaskan Native, non-Latino Asian, non-Latino Native Hawaiian or other Pacific Islander, non-Latino of two or more races, and other races. Data source uses *Hispanic*.

Source: J. P. Lendon et al., *Long-Term Care Providers and Services Users in the United States—State Estimates Supplement: National Study of Long-Term Care Providers, 2015–2016*, Centers for Disease Control and Prevention, 2019.

# Assisted Living Facility Cost

## Selected States, 2019

ANNUAL MEDIAN COST



Note: Rates are for 12 months of care in a private one-bedroom.

Source: *Cost of Care Survey 2019*, Genworth, October 8, 2019.

### Long-Term and End-of-Life Care in California

#### Assisted Living

The annual median cost of an assisted living unit was higher in California than nationally. Compared to similar states, only New York had a higher cost.

# Medicaid Home and Community-Based Services, by Authority California, 2018

PROGRAM AUTHORITY	DESCRIPTION	ENROLLMENT	SPENDING (IN THOUSANDS)
STATE PLAN OPTIONS			
Home Health Services	Provides part-time or intermittent nursing services, home health aide services, optional therapy services and medical supplies, equipment, and appliances suitable for use in the home. Only federally required HCBS service.	37,500*	\$153,900*
Personal Care Services: Section 1915(j)	Provides help with self-care (e.g., bathing, dressing) and household activities (e.g., preparing meals).	273,800	\$2,960,800
Community First Choice: Section 1915(k)	Provides attendant services and supports for beneficiaries who would otherwise require institutional care.	228,200	\$5,562,600
State Plan Home and Community-Based Services: Section 1915(i)	Provides homemaker / home health aide / personal care services, adult day health, respite, day treatment / partial hospitalization, psychosocial rehabilitation, and chronic mental health clinic services to beneficiaries with intellectual and developmental disabilities who are at risk of institutional care.	55,800	\$494,600
WAIVERS			
Home and Community-Based Services Waivers: Section 1915(c)	Provides same services as Section 1915(i) to beneficiaries who would otherwise require institutional care; services must be delivered at same or lower average per enrollee cost than institutional care. Waivers can target specific populations or geographies. California has six Section 1915(c) waivers.	149,500	\$3,810,300

\*Home health data are from 2016.

Notes: Various HCBS services have been authorized by Congress in specific sections of the Social Security Act. For more information, see [www.medicaid.gov](http://www.medicaid.gov). *Personal Care Services* and *Community First Choice* are part of California's In-Home Supportive Services Program. For more information on California's Medicaid HCBS waivers, see [www.dhcs.ca.gov](http://www.dhcs.ca.gov).

Sources: Molly O'Malley Watts, MaryBeth Musumeci, and Priya Chidambaram, *Medicaid Home and Community-Based Services Enrollment and Spending*, KFF, February 4, 2020; MaryBeth Musumeci, Molly O'Malley Watts, and Priya Chidambaram, *Key State Policy Choices About Medicaid Home and Community-Based Services*, KFF, February 4, 2020; and Jennifer Ryan and Julie Stone, *Medi-Cal Explained Fact Sheet: Medicaid Waivers in California* (PDF), California Health Care Foundation, October 2019.

While Medi-Cal is required to cover nursing facility care, coverage of most home and community-based services (HCBS) is optional, with the exception of home health services. HCBS programs are designed to help seniors and persons with disabilities and chronic illnesses live independently outside institutions by assisting with daily needs. California offers many HCBS programs, with varying eligibility criteria and enrollment levels.

# Medicaid HCBS Spending per Enrollee, by Authority

## California vs. United States, 2018

### STATE PLAN OPTIONS

Home Health Services\*



Personal Care Services: Section 1915(j)



Community First Choice: Section 1915(k)



State Plan Home and Community-Based Services: Section 1915(j)



### WAIVERS

Home and Community-Based Services Waivers: Section 1915(c)



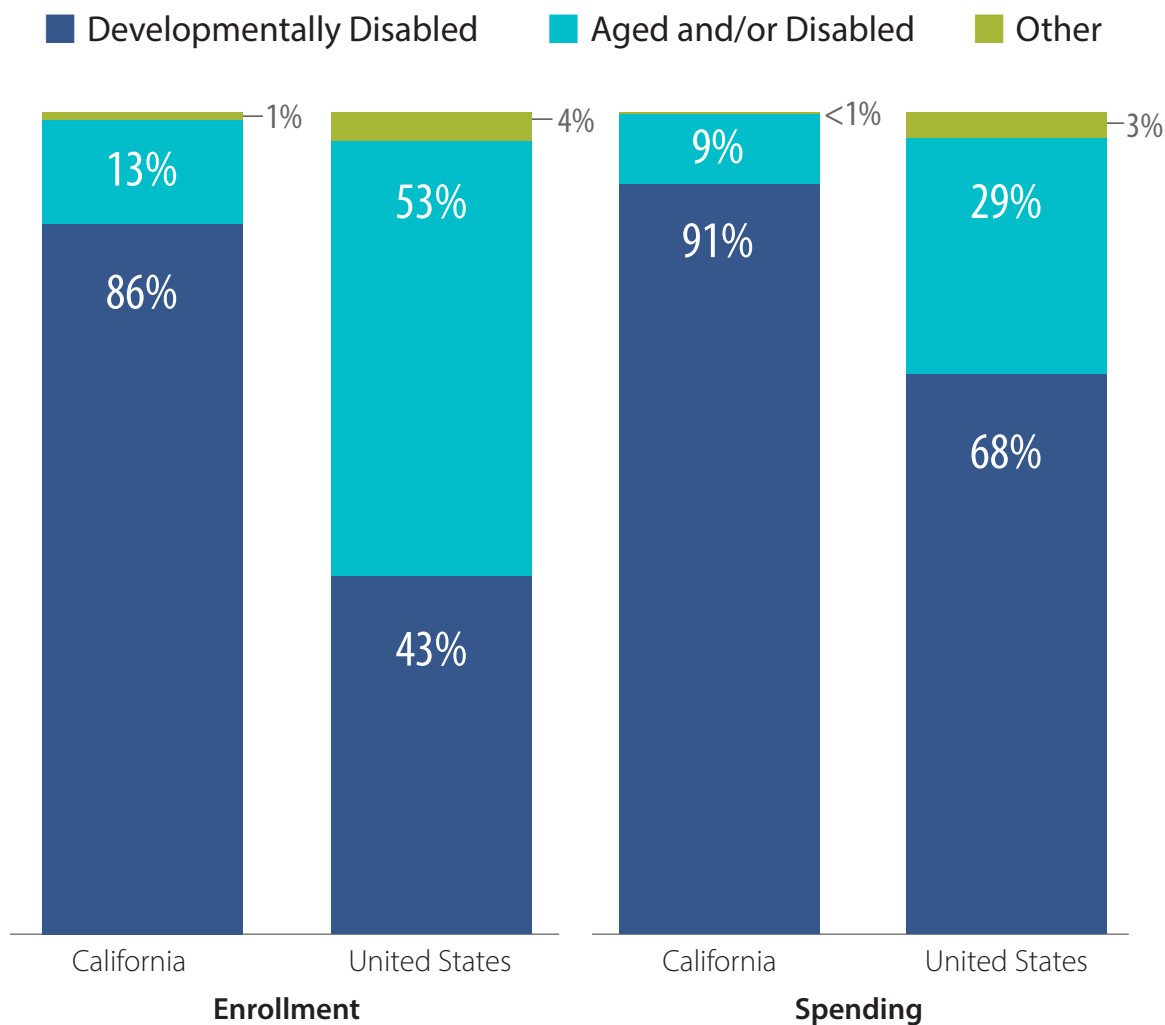
\*California home health data are from 2016.

Notes: HCBS is home and community-based services. The number of states that offer each HCBS varies (except for home health, which is required and offered by all 50 states and the District of Columbia).

Source: Molly O'Malley Watts, MaryBeth Musumeci, and Priya Chidambaram, *Medicaid Home and Community-Based Services Enrollment and Spending*, KFF, February 4, 2020.

Looking across Medicaid's home and community-based services, California spent less per enrollee on home health services, personal care services, and HCBS Waivers than the US average. California spent more per enrollee on Community First Choice and State Plan Home and Community-Based Services than the US average.

# Medicaid HCBS Waivers: 1915(c) Enrollment and Spending by Target Population, California vs. United States, 2018



In California, HCBS Section 1915(c) waiver enrollment and spending is heavily weighted toward people with developmental disabilities. In 2018, California's HCBS Section 1915(c) waivers had a waiting list of 8,510, the vast majority of which (99%) were beneficiaries who were aged and/or had disabilities (not shown).

Notes: HCBS is home and community-based services. Medicaid HCBS Section 1915(c) waivers are designed to provide community-based options for people who would otherwise require care in a nursing facility, hospital, or other institution. *Developmentally disabled* includes intellectual and developmental disabilities. *Aged and/or disabled* includes seniors, seniors and adults with physical disabilities, and adults with physical disabilities. *Other* includes children, and individuals with HIV/AIDS, mental health disabilities, and traumatic brain injury / spinal cord injury.

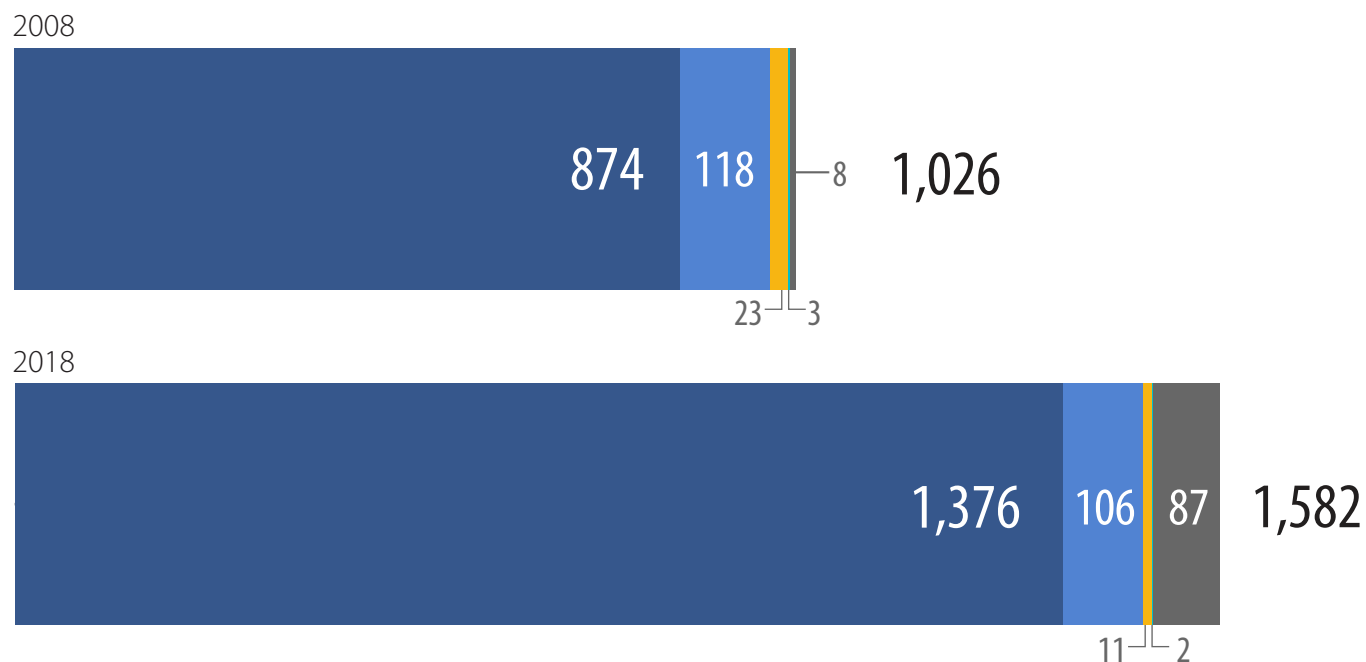
Sources: Molly O'Malley Watts, MaryBeth Musumeci, and Priya Chidambaram, *Medicaid Home and Community-Based Services Enrollment and Spending*, KFF, February 4, 2020; and MaryBeth Musumeci, Molly O'Malley Watts, and Priya Chidambaram, *Key State Policy Choices About Medicaid and Home and Community-Based Services*, KFF, February 4, 2020.

# Home Health Agencies, by Ownership Type

## California, 2008 and 2018

NUMBER OF AGENCIES

■ For-Profit   
 ■ Nonprofit   
 ■ Government   
 ■ University of California   
 ■ Nonresponse



Notes: Data limited to agencies with entity type "Home Health Agency Only." There were an additional 38 agencies in 2008 and 39 agencies in 2018 with entity type "Home Health Agency with Hospice Program." *Government* includes city or county, district, and state. Excludes closed agencies and those in suspense.

Source: Author analysis based on [Home Health Agencies & Hospice Annual Utilization Report](#) (2008, 2018), CHHS Open Data Portal.

From 2008 to 2018, the number of home health agencies licensed in California increased by 50%, from 1,026 to 1,582. In 2018, 87% of the state's home health agencies were for-profit, a slight increase from 2008.

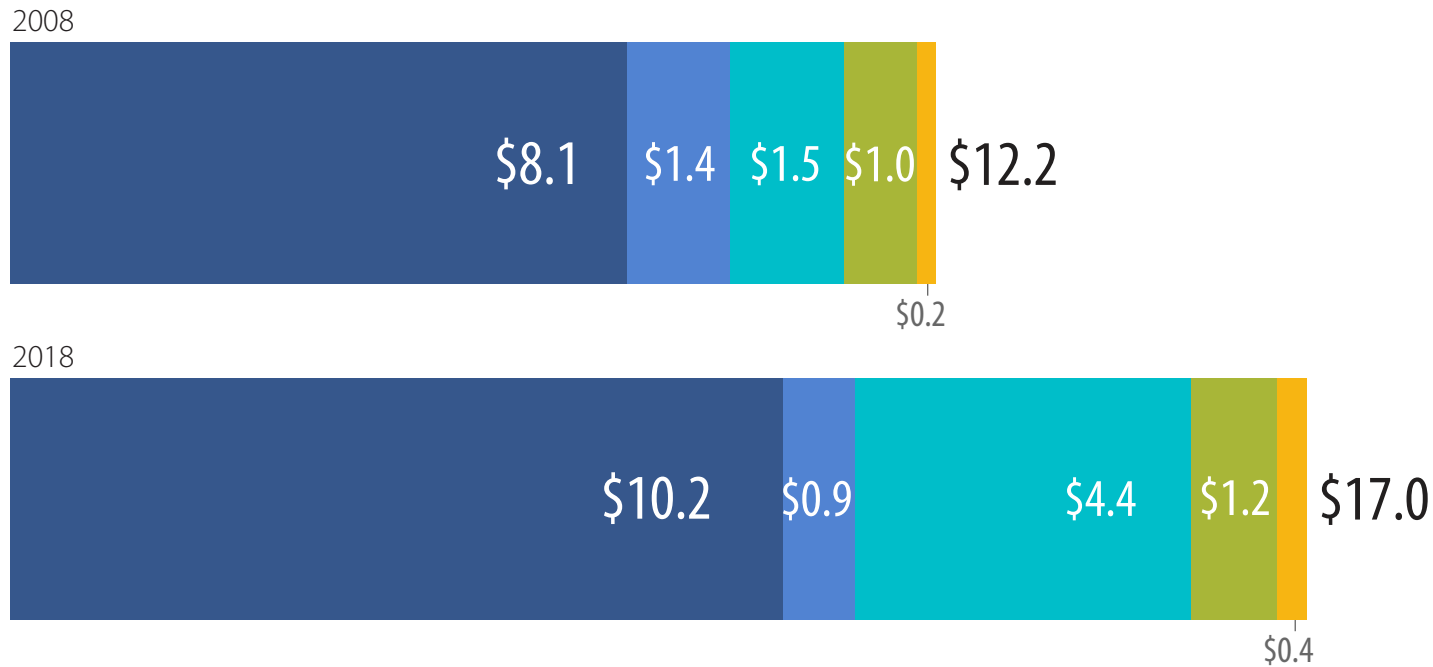


# Home Health Visits, by Payer

## California, 2008 and 2018

IN MILLIONS

■ Medi-Cal FFS ■ Medicare FFS ■ HMO/PPO ■ Private ■ Other



Notes: *FFS* is fee for service. Includes home health visits for all agency entity types and license status. *HMO/PPO* includes Medicare and Medi-Cal HMOs, as well as private HMO and PPO plans. *Private* includes self-pay and other third-party reimbursement. *Other* includes TriCare, no reimbursement, and other. Figures may not sum due to rounding.

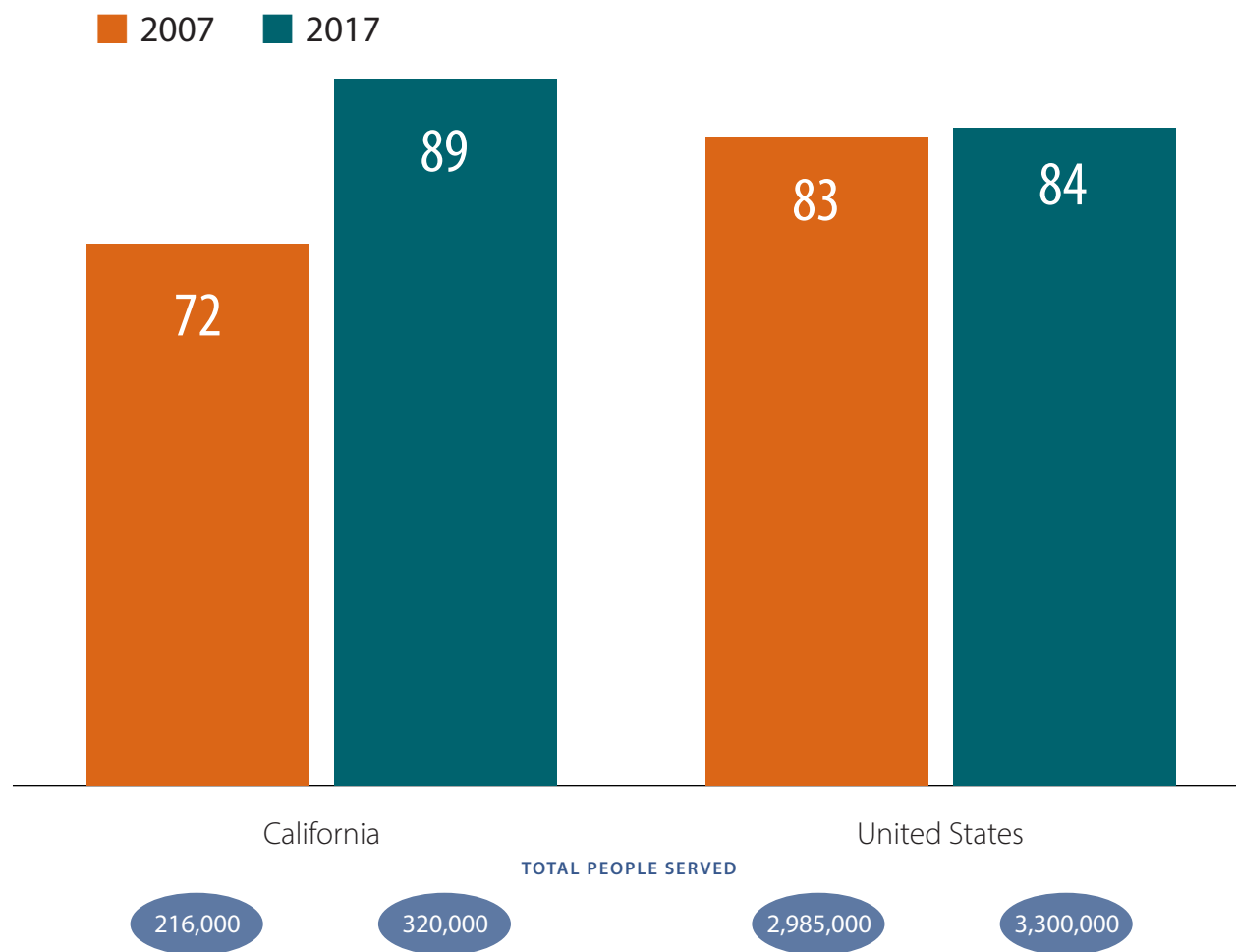
Source: *Home Health Agencies & Hospice Annual Utilization Report* (2008, 2018), CHHS Open Data Portal.

Home health visits in California increased 40% from 2008 to 2018, with the majority of the increase attributable to growth in managed care and Medi-Cal fee-for-service visits.

# Medicare Beneficiaries Receiving Home Health Services

## California vs. United States, 2007 and 2017

PEOPLE SERVED PER 1,000 ENROLLEES



Notes: Excludes Medicare Advantage beneficiaries. Data are as of July 1.

Source: "State Health Facts: Medicare Service Use: Home Health Services," KFF, accessed February 11, 2020.

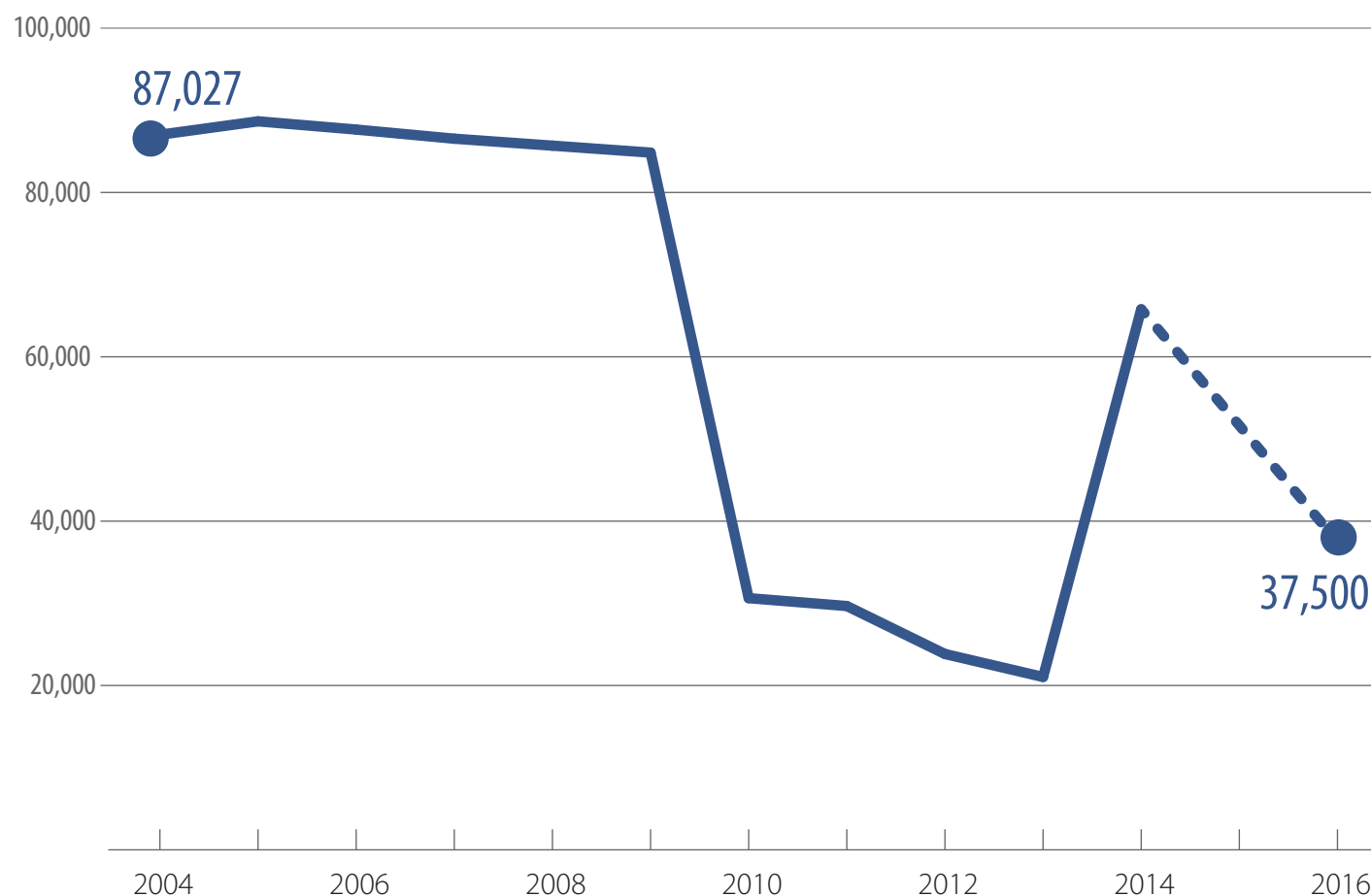
### Long-Term and End-of-Life Care in California

#### Home Health

From 2007 to 2017, California saw a significant growth in the number of Medicare fee-for-service beneficiaries receiving home health services. In 2017, California's Medicare fee-for-service beneficiaries were more likely to receive home health services than beneficiaries nationally.

# Medi-Cal Home Health Patients

California, 2004 to 2016



Note: Data are not available for 2015.

Sources: Molly O'Malley Watts, MaryBeth Musumeci, and Priya Chidambaram, *Medicaid Home and Community-Based Services Enrollment and Spending*, KFF, February 4, 2020; and Molly O'Malley Watts and MaryBeth Musumeci, *Medicaid Home and Community-Based Services: Results from a 50-State Survey of Enrollment, Spending, and Program Policies* (PDF), KFF, January 2018.

## Long-Term and End-of-Life Care in California

### Home Health

The number of Medi-Cal enrollees using home health services decreased sharply between 2009 and 2010.

With the exception of 2014, less than half as many Medi-Cal enrollees used home health from 2010 to 2016 than did from 2004 to 2009. This change in utilization may be largely due to the existence of other Medi-Cal home and community-based services (see page 29).

# Home Health Agency Quality Measures

## California vs. United States, 2019

### HOW OFTEN PATIENTS...

Improved at Walking or Moving Around



Improved at Getting In and Out of Bed



Improved at Bathing



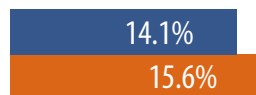
Improved Breathing



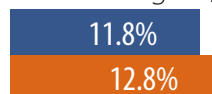
Got Better at Taking Drugs Correctly by Mouth



Had to be Admitted to the Hospital\*



Needed Urgent, Unplanned Care in ER\*



■ California  
■ United States

\*Lower percentages are better. Data are from calendar year 2018.

Note: Data are from July 1, 2018, through June 30, 2019. Higher percentages are better.

Source: "Home Health Compare Datasets," Centers for Medicare & Medicaid Services, accessed May 6, 2020.

### Long-Term and End-of-Life Care in California

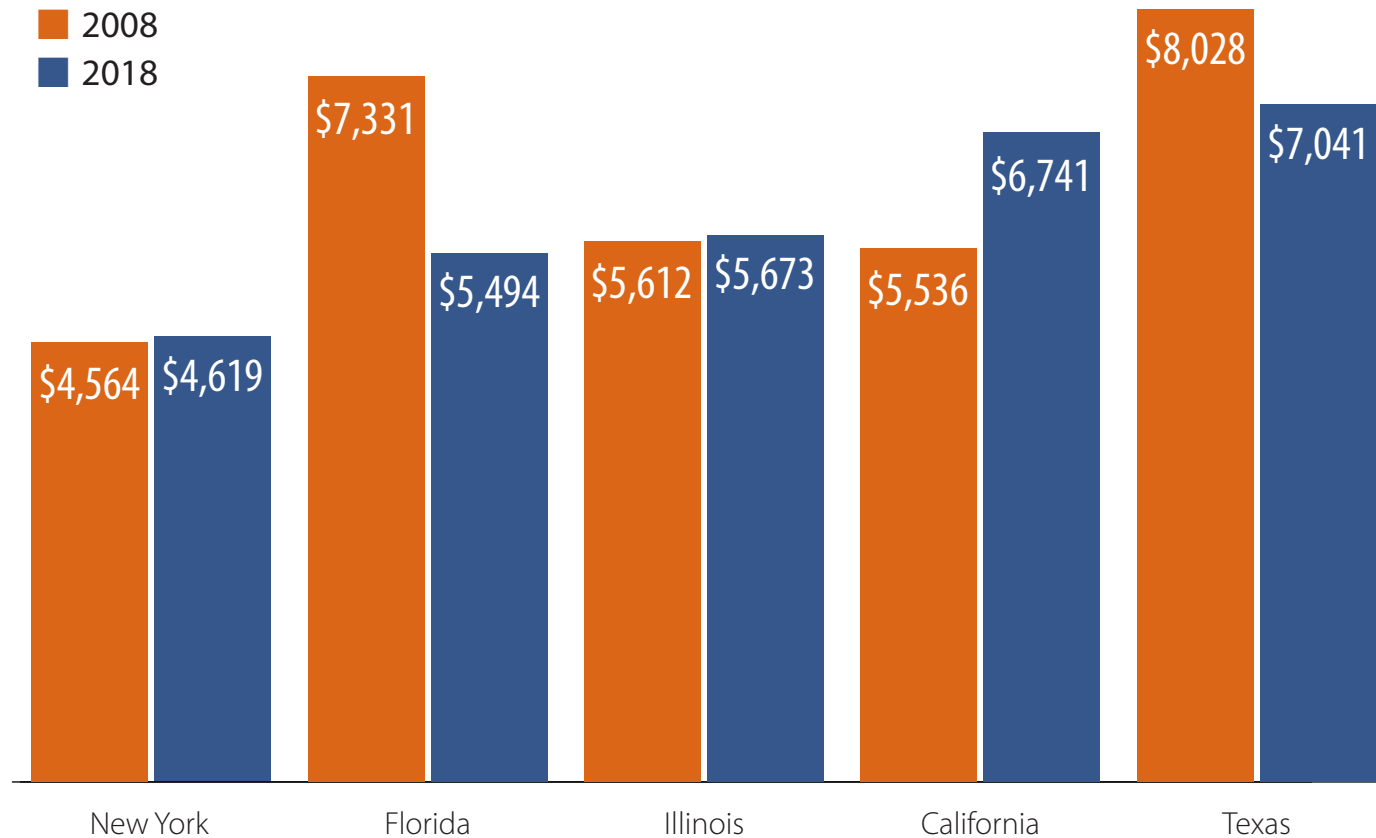
#### Home Health

California home health agencies, on average, performed similarly to or slightly worse than the national average in 2019 on a number of quality measures related to patient function. On two measures related to needing higher-level care, California performed better than the national average.

# Medicare Home Health Spending per Patient

## California vs. Selected States, 2008 and 2018

AVERAGE SPENDING PER HOME HEALTH PATIENT



Note: Fee-for-service patients only.

Source: *Medicare Home Health Utilization by State* (2008, 2018), Centers for Medicare & Medicaid Services.

### Long-Term and End-of-Life Care in California

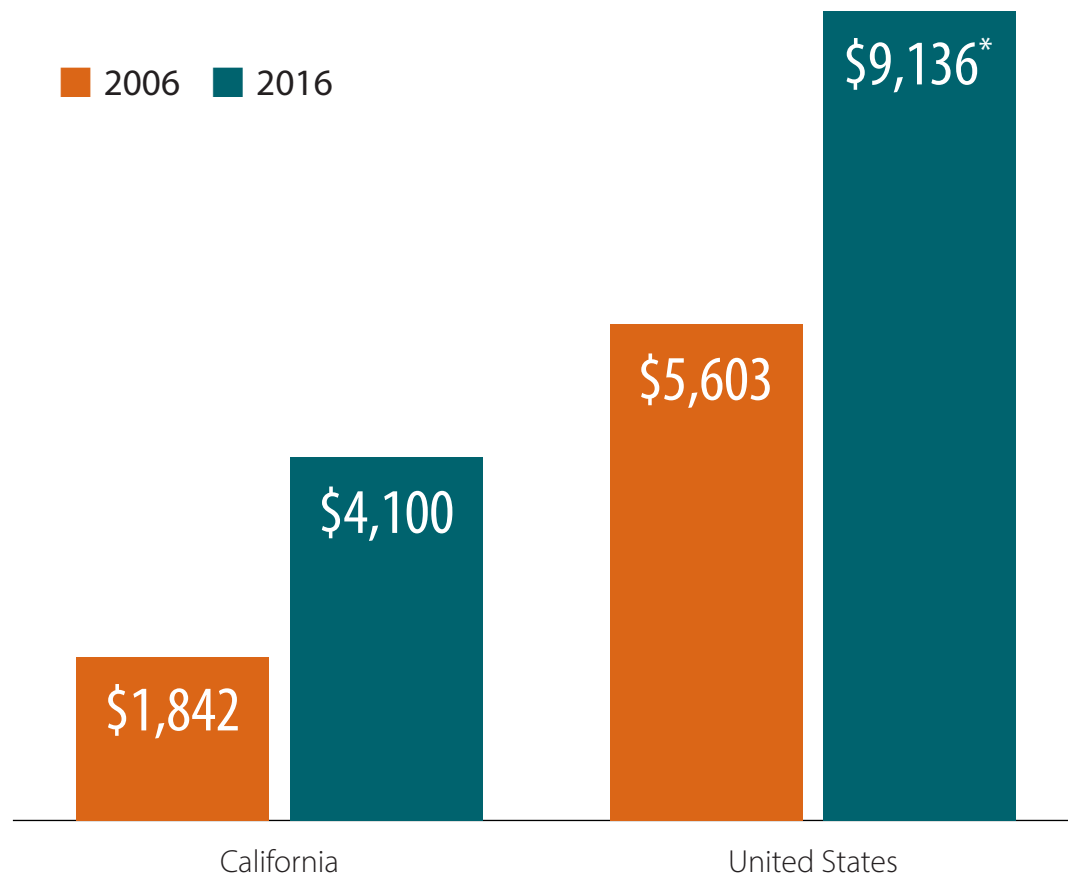
#### Home Health

Average Medicare spending per home health patient increased by 22% for California patients from 2008 to 2018, while spending declined or stayed relatively flat for similar states.

# Medicaid Home Health Spending per Enrollee

## California vs. United States, 2006 and 2016

AVERAGE SPENDING PER HOME HEALTH ENROLLEE



\*Data are 2017.

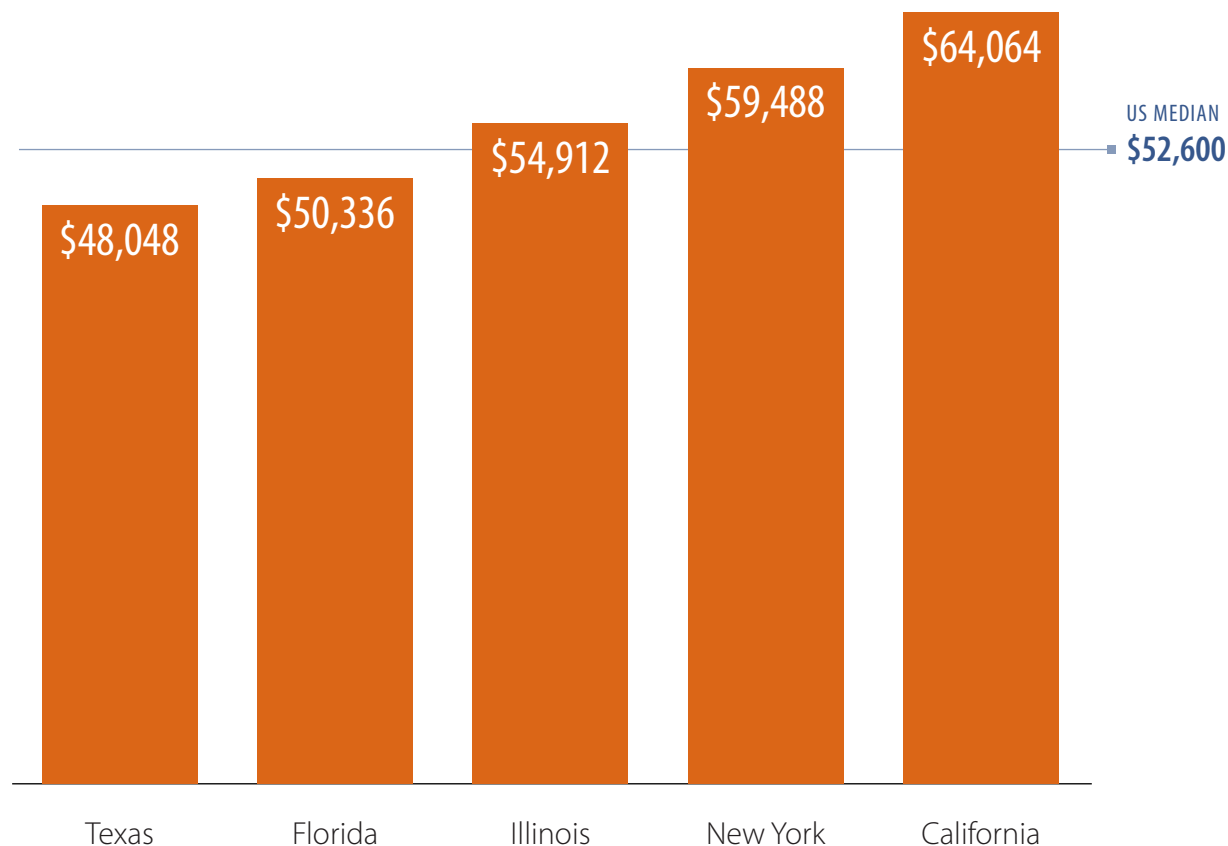
Sources: Molly O'Malley Watts, MaryBeth Musumeci, and Priya Chidambaram, *Medicaid Home and Community-Based Services Enrollment and Spending*, KFF, February 4, 2020; and Molly O'Malley Watts and MaryBeth Musumeci, *Medicaid Home and Community-Based Services: Results from a 50-State Survey of Enrollment, Spending, and Program Policies* (PDF), KFF, January 2018.

Over the last decade, Medicaid spending per home health enrollee increased in California and the nation. Average Medicaid spending remained more than twice as high for the nation than for California.

# Home Health Aide Services, Annual Cost

## California vs. Selected States, 2019

ANNUAL MEDIAN COST



### Long-Term and End-of-Life Care in California

#### Home Health

Home health aide services cost more in California than in similar states. In 2019, California's annual median cost was more than \$10,000 higher than the national median.

Note: Based on 44 hours per week for 52 weeks, and based on the rate charged by a non-Medicare certified, licensed agency.

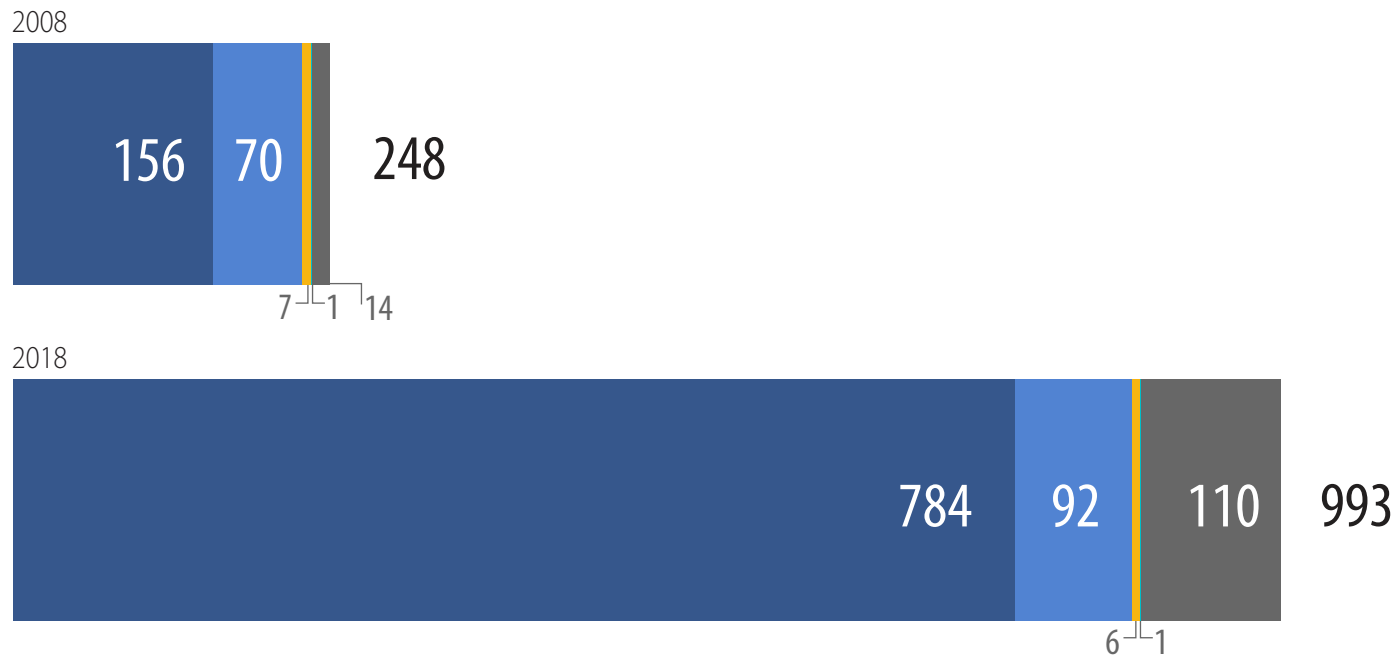
Source: *Cost of Care Survey 2019*, Genworth, October 8, 2019.

# Hospice Agencies, by Ownership Type

## California, 2008 and 2018

NUMBER OF AGENCIES

■ For-Profit ■ Nonprofit ■ Government  
■ University of California ■ Nonresponse



Notes: Data are limited to agencies with entity type "Hospice Only." There were an additional 38 agencies in 2008 and 39 agencies in 2018 with entity type "Home Health Agency with Hospice Program." Excludes closed agencies and those in suspense. *Government* includes city or county, district, and state.

Source: Author analysis based on [Home Health Agencies & Hospice Annual Utilization Report](#) (2008, 2018), CHHS Open Data Portal.

### Long-Term and End-of-Life Care in California

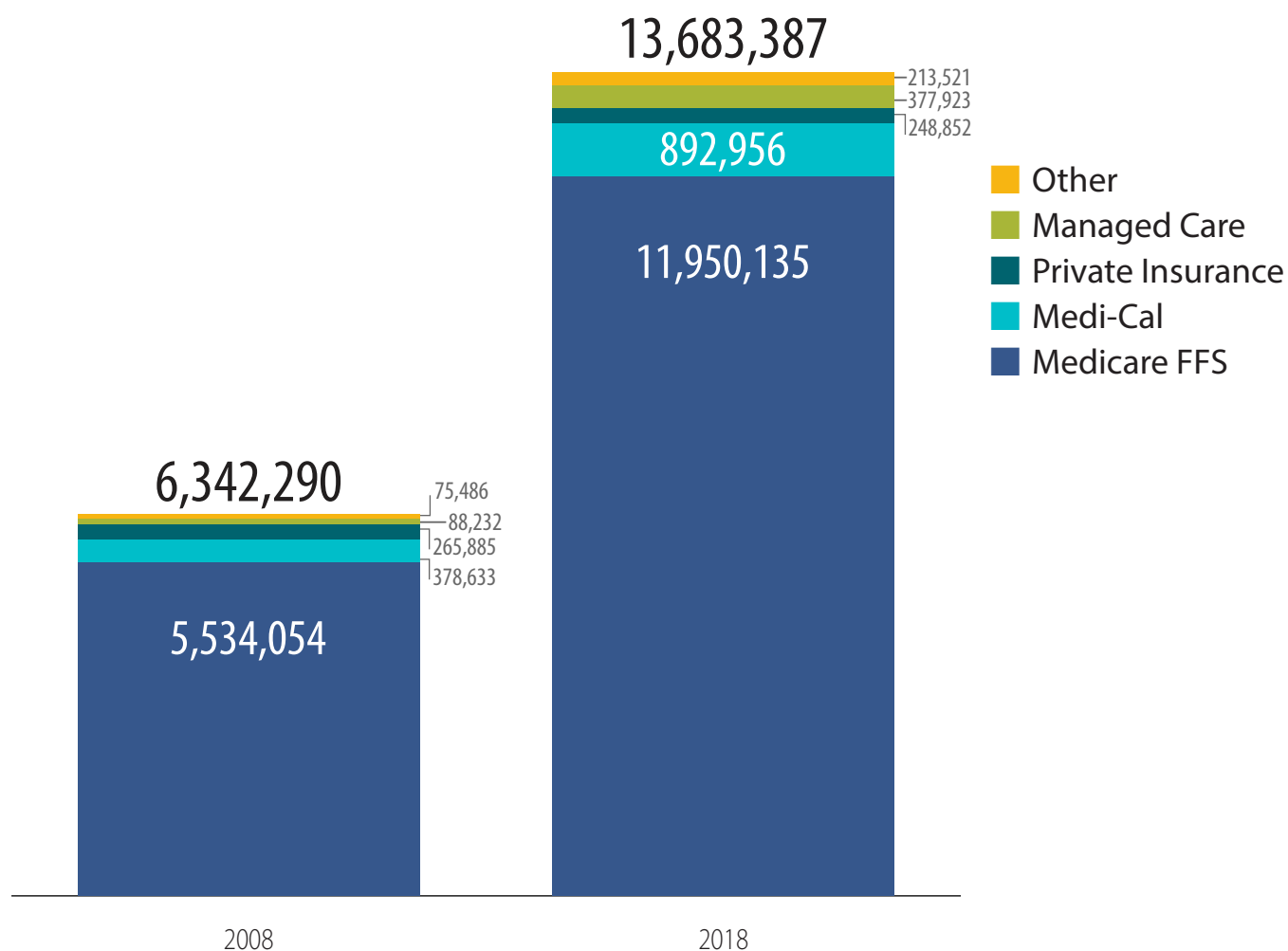
#### Hospice

The number of hospice agencies licensed in California increased by 400% from 2008 to 2018, with growth largely driven by for-profit agencies. In 2018, more than three in four hospice agencies in the state were for-profit.



# Hospice Patient Days, by Payer

## California, 2008 and 2018



Notes: FFS is fee for service. Includes hospice days for all agency entity types and license status. *Medi-Cal* includes Medi-Cal managed care. *Managed care* includes private HMO and PPO plans, as well as Medicare managed care plan. However, *Medicare FFS* covers hospice care for beneficiaries enrolled in Medicare managed care plans. *Private* includes private insurance and self-pay. *Other* includes charity, Dept. of Veterans Affairs, workers' compensation, and home health benefit.

Source: Author analysis based on [Home Health Agencies & Hospice Annual Utilization Report](#) (2008, 2018), CHHS Open Data Portal.

### Long-Term and End-of-Life Care in California

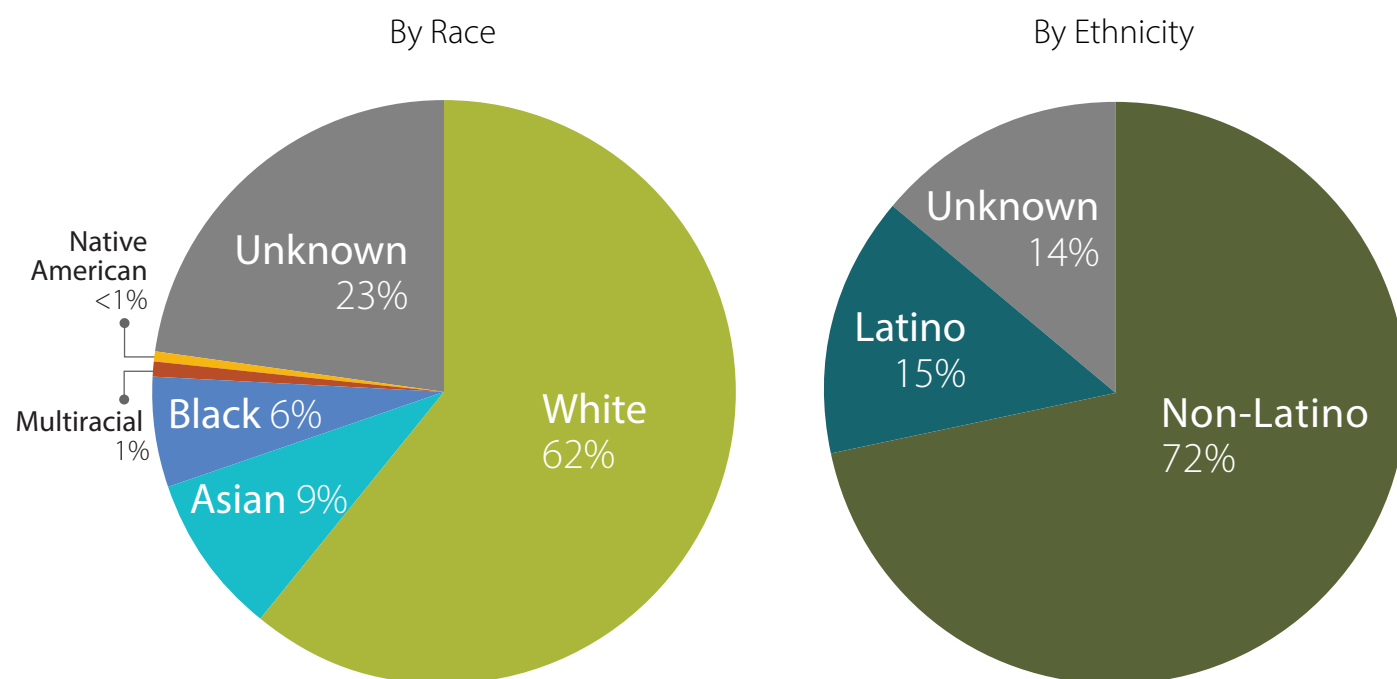
#### Hospice

Hospice days in California more than doubled from 2008 to 2018. The Medicare fee-for-service program was the dominant payer for hospice care in California, paying for nearly 9 in 10 hospice patient days in 2008 and 2018.

# Hospice Patients, by Race and Ethnicity

## California, 2018

Fewer than one in six hospice patients in California in 2018 were non-white or were Latino.



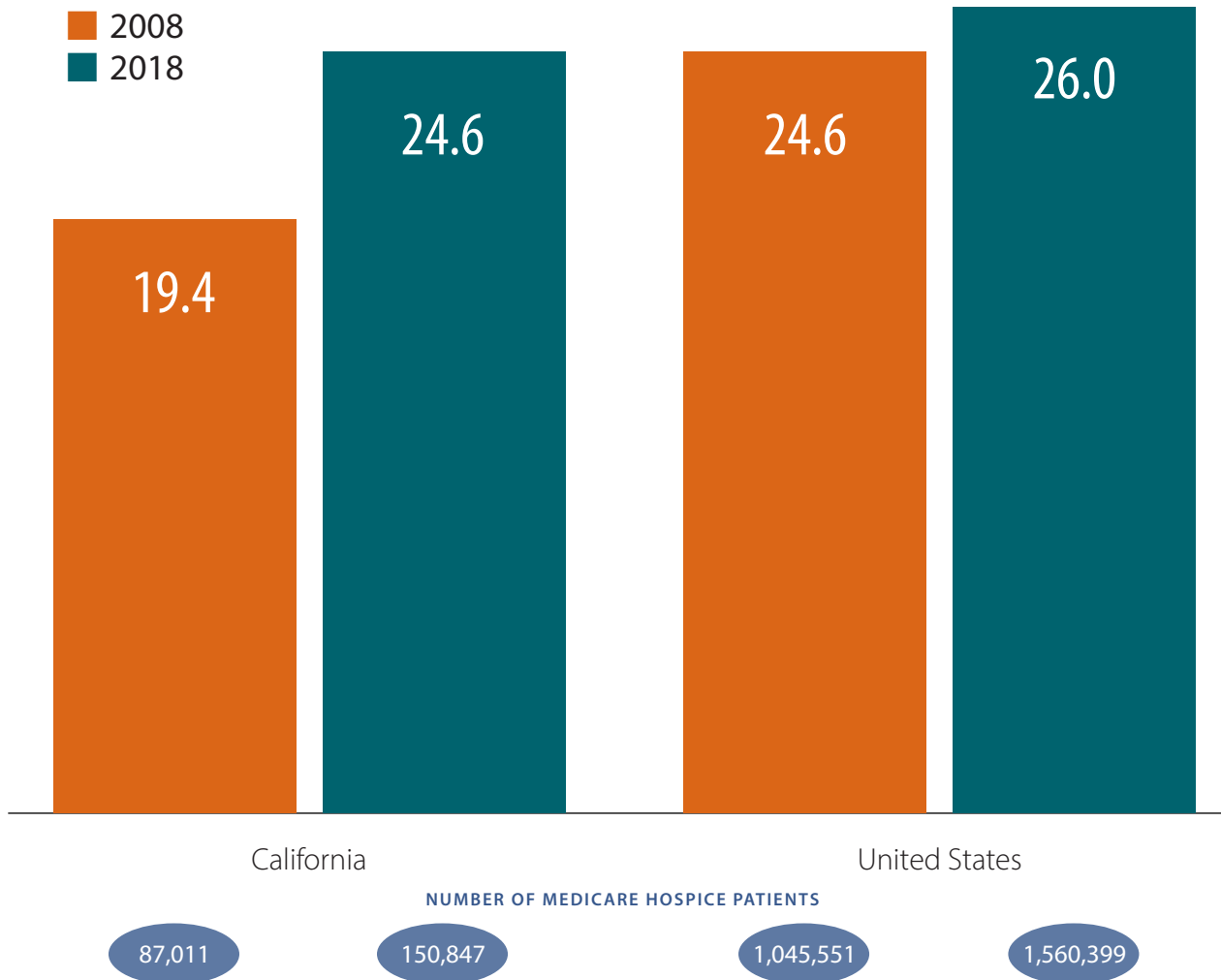
Note: Data include hospice patients for all agency entity types and license status. Segments may not total 100% due to rounding.

Source: Author analysis based on [Home Health Agencies & Hospice Annual Utilization Report](#) (2018), CHHS Open Data Portal, last updated December 4, 2019.

# Medicare Beneficiaries Receiving Hospice Services

## California vs. United States, 2008 and 2018

HOSPICE USERS PER 1,000 BENEFICIARIES



### Long-Term and End-of-Life Care in California

#### Hospice

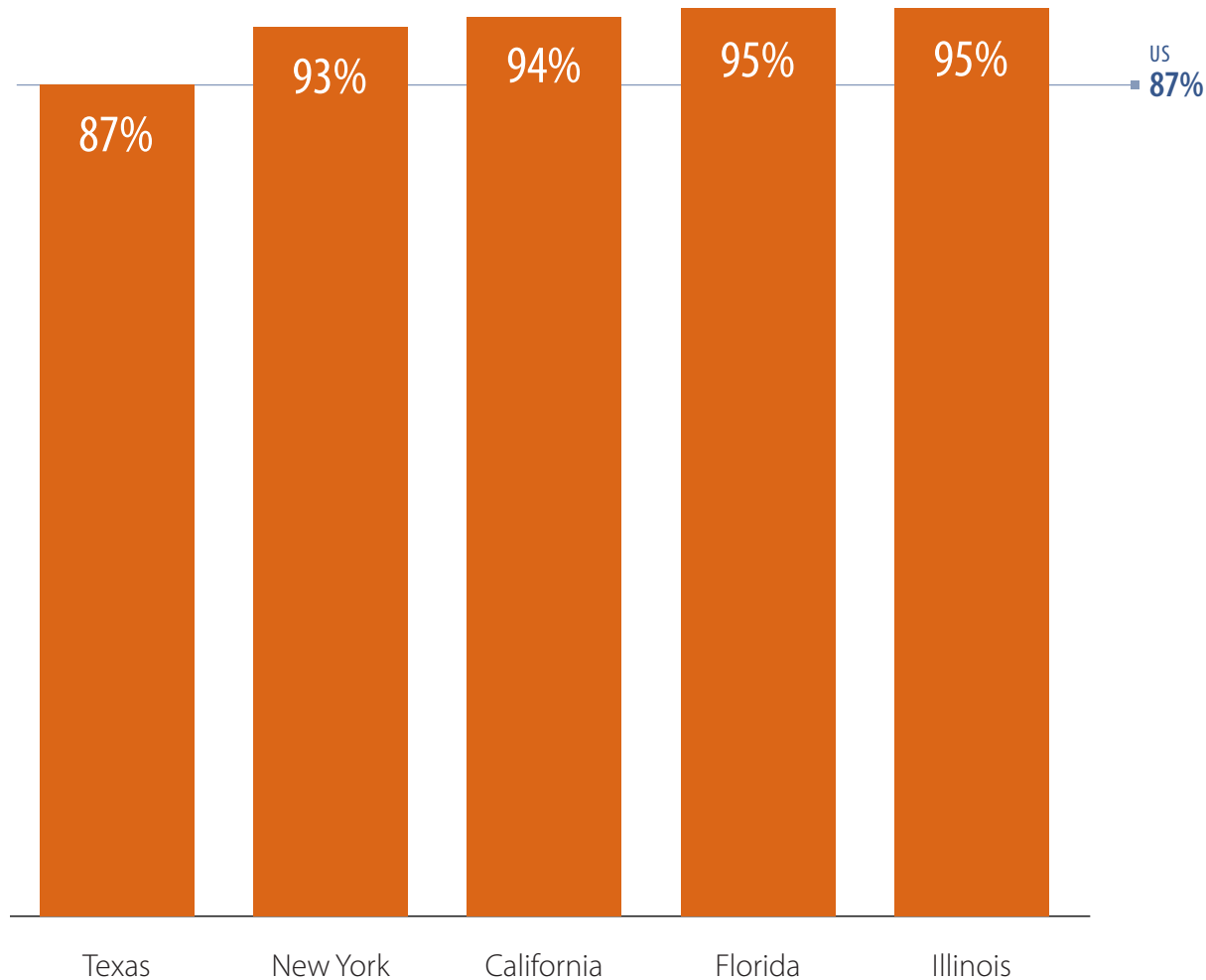
The rate of Medicare beneficiaries receiving hospice services increased by 27% from 2008 to 2018 in California, compared to only a 6% increase in the nation. Despite this increase, California's Medicare beneficiaries used hospice services at a slightly lower rate than the nation in 2018.

Sources: Author calculations based on *Medicare Hospice Utilization by State* (2008, 2018), Centers for Medicare & Medicaid Services; and "Medicare Enrollment Dashboard: Medicare Enrollment Trend by State," Centers for Medicare & Medicaid Services, accessed February 12, 2020.

# Hospice Deficiencies

## California vs. Selected States, 2012 to 2016

PERCENTAGE WITH AT LEAST ONE DEFICIENCY



Notes: Based on the number of hospices surveyed between 2012 and 2016; 95% of hospices that provided care to Medicare beneficiaries were surveyed at least once. A deficiency is issued if a hospice fails to meet at least one requirement for participating in the Medicare program.

Source: *Hospice Deficiencies Pose Risks to Medicare Beneficiaries* (PDF), US Dept. of Health and Human Services, July 2019.

### Long-Term and End-of-Life Care in California

#### Hospice

A recent Office of Inspector General (OIG) review raised concerns that hospices did not always provide needed services and sometimes provided poor-quality care. More than 9 in 10 hospices in California had one or more deficiencies. In addition, the OIG identified 313 poor performers in 2016 (at least one serious deficiency or one substantiated severe complaint), including 39 in California (not shown).

# Hospice Quality Measures

## California vs. United States, 2017

FAMILY CAREGIVERS WHO REPORTED...

■ California ■ United States

Receiving Training About Taking Care of Their Family Member



Family Member Always Received Enough Help for Pain and Other Symptoms\*



Always Receiving Help as Soon as Needed



Hospice Team Always Communicated Well



Family Member Always Treated with Dignity and Respect



Receiving Right Amount of Emotional and Spiritual Support



\*Including sadness, breathing, and constipation.

Note: Data are based on the CAHPS Hospice Survey, which is administered to the primary informal caregiver of the decedent who died while receiving hospice care. Higher percentages are better.

Source: "National Healthcare Quality and Disparities Reports: California — State Snapshot for Home Health-Hospice," Agency for Healthcare Research and Quality, 2018.

## Long-Term and End-of-Life Care in California

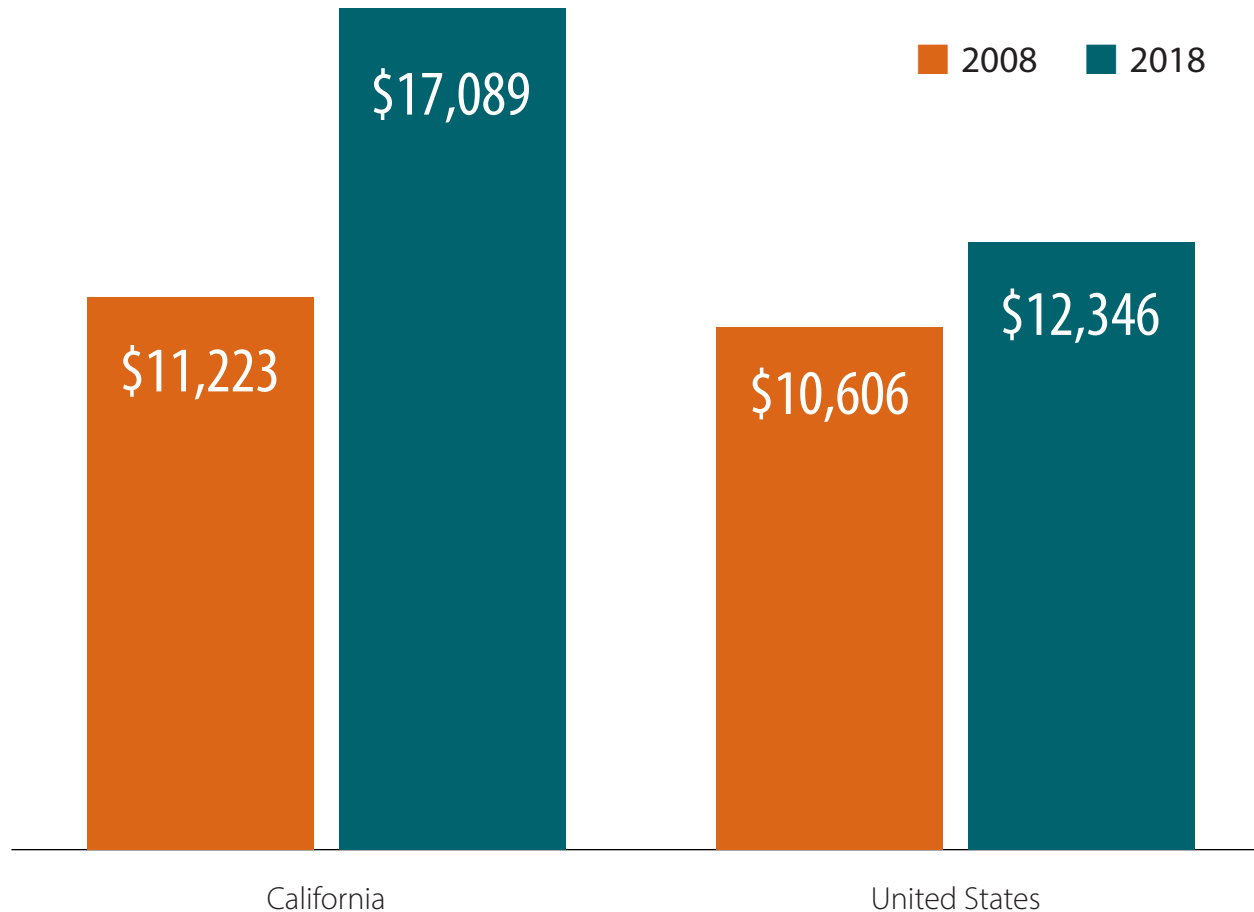
### Hospice

California hospice agencies performed slightly worse than the national average on a number of quality measures related to patient care and support, based on surveys of the hospice patient's primary caregiver.

# Medicare Hospice Spending per Patient

## California vs. United States, 2008 and 2018

AVERAGE SPENDING PER HOSPICE PATIENT



Note: Source uses reimbursement.

Source: *Medicare Hospice Utilization by State* (2008, 2018), Centers for Medicare & Medicaid Services.

### Long-Term and End-of-Life Care in California

#### Hospice

Average Medicare hospice spending per patient increased by 52% in California and 16% in the United States from 2008 to 2018. At the same time, the number of Medicare beneficiaries receiving hospice services increased by 70% in California and 50% nationally (not shown).

# Preferences Around Prolonging Life, by Race/Ethnicity, and Income, California, 2019

If you had an advanced illness, which would you prefer? Base: all respondents (n = 2,588)

- Dying a natural death if my heart should stop beating or I should stop breathing
- Doctors and nurses using everything available to attempt to prolong my life
- I'm not sure

Asian / Pacific Islander



Black



Latino



White



<150% FPL



150%–399% FPL



400%+ FPL



Overall



Notes: Statewide survey of 2,588 adult Californians, PerryUndem, 2019. In 2019, the federal poverty level (FPL) was \$12,490 for a single person and \$25,750 for a household of four. Nonresponders not shown. Segments may not total 100% due to nonresponse or rounding.

Source: *Help Wanted: Californians' Views and Experiences of Serious Illness and End-of-Life Care*, California Health Care Foundation, October 2019.

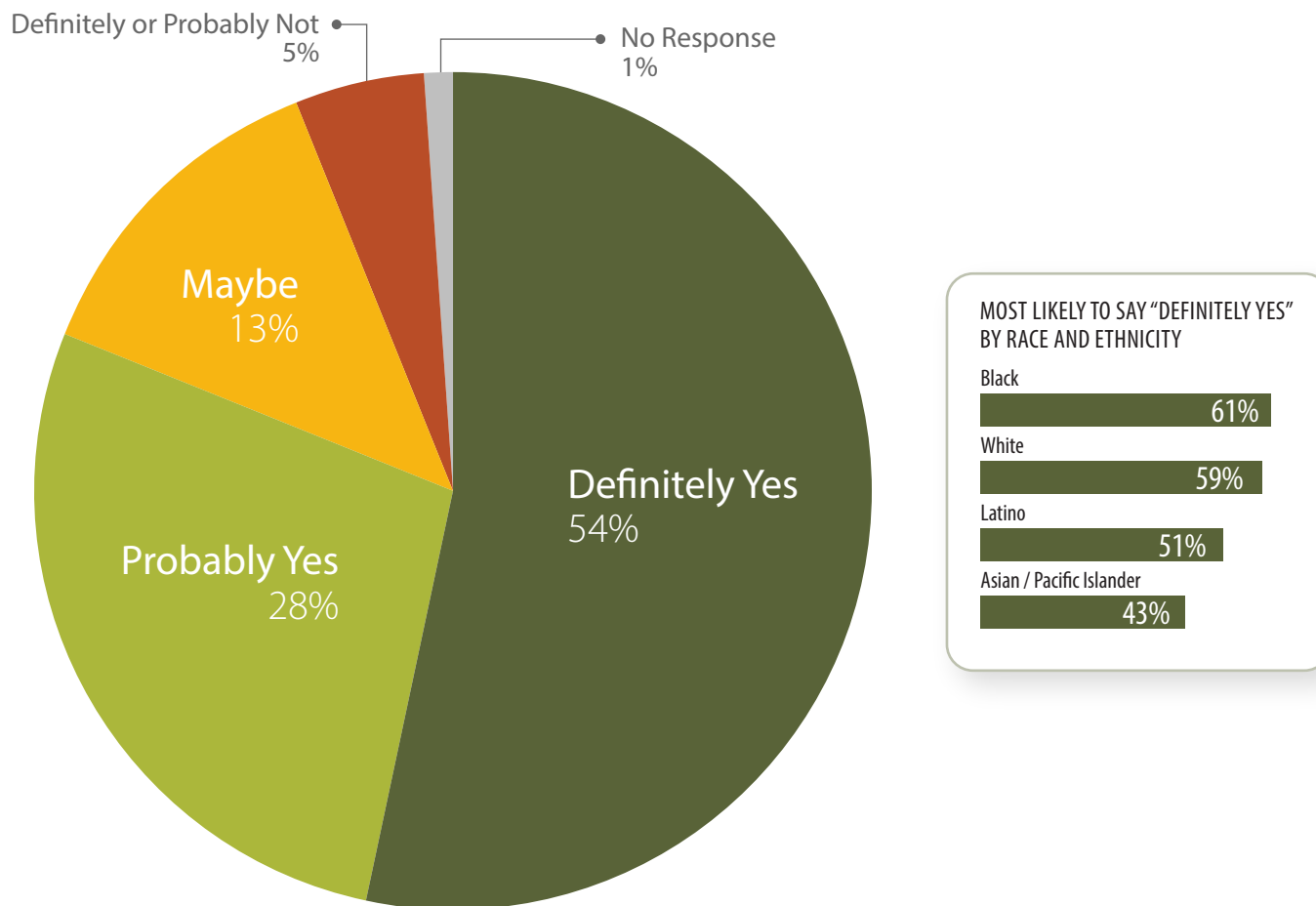
## Long-Term and End-of-Life Care in California End-of-Life Preferences

More than 6 in 10 Californians in a recent survey preferred dying a natural death, compared to about 1 in 10 who would want to receive all possible care to prolong life. Black respondents were more likely to prefer prolonging life (22%) than other racial/ethnic groups. Across all racial/ethnic groups, at least 1 in 4 were not sure. Respondents with incomes less than 150% of the federal poverty level were less likely to want to die a natural death than respondents with higher incomes.

# Would Like to Talk to Doctor About End-of-Life Wishes

## California, 2019

*If you were seriously ill, would you like to talk with your doctor about your wishes for medical treatment towards the end of your life?* Base: all respondents (n = 2,588)



Notes: Statewide survey of 2,588 adult Californians, PerryUndem, 2019. Segments may not total 100% due to rounding.

Source: *Help Wanted: Californians' Views and Experiences of Serious Illness and End-of-Life Care*, California Health Care Foundation, October 2019.

### Long-Term and End-of-Life Care in California

#### End-of-Life Preferences

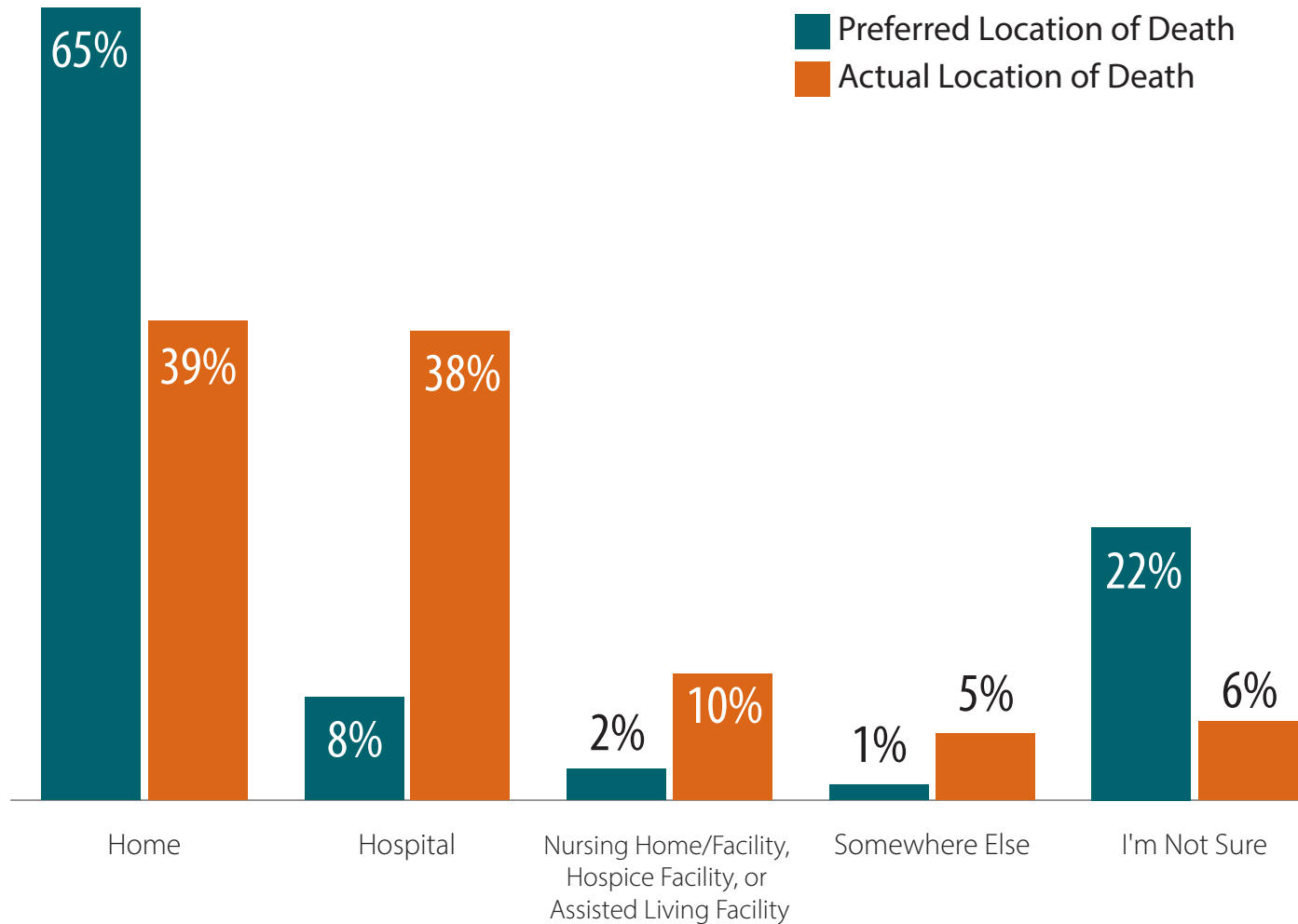
About four in five Californians in a recent survey said they would definitely or probably want to talk with their doctor about their wishes for medical treatment toward the end of life. Black and white respondents were more likely than other races/ethnicities to say they would definitely want to talk with their doctor about their wishes.



# Preferred vs. Actual Location of Death

California, 2019

*As far as you know, where do you think your loved one would have wanted to die if given the choice? Where did your loved one die? Base: respondents who lost a close loved one within the past two years (n = 1,276)*



Notes: Statewide survey of 2,588 adult Californians, PerryUndem, 2019. Nonresponders not shown. Segments may not total 100% due to nonresponse or rounding.

Source: *Help Wanted: Californians' Views and Experiences of Serious Illness and End-of-Life Care*, California Health Care Foundation, October 2019.

A recent survey found that many people did not die in their preferred location. While 65% of respondents reported that their loved ones would have preferred to die at home, only 39% were able to do so. In contrast, 38% died in the hospital, which was the preferred location for only 8% of loved ones.

# Data Resources

## Centers for Medicare & Medicaid Services

Various data resources for supply, use, and quality of long-term care services.

- **Post-Acute Care and Hospice Provider Utilization and Payment Public Use Files (PAC PUF).** Includes utilization, charge and payment data on services provided to Medicare beneficiaries by home health agencies, hospices, skilled nursing facilities, inpatient rehabilitation facilities, and long-term care hospitals.
- **Medicare Utilization for Part A.** Includes annual data on Medicare hospice utilization by state.
- **Nursing Home and Home Health Quality Data.** Data sets providing quality information for all certified nursing homes and home health agencies, as well as state and national averages.

## Kaiser Family Foundation

Data resources and reports on long-term care services by state.

- **State Health Facts.** Provides state data on a variety of long-term care spending and utilization measures.
- **Medicaid Home and Community-Based Services (HCBS)** reports. Provides Medicaid HCBS enrollment and spending data from KFF's annual 50-state survey.

## National Post-Acute and Long-Term Care Study

Formerly known as the National Study of Long-Term Care Providers, this biennial national study monitors trends in the supply and use of the major sectors of long-term care services.

## Office of Statewide Health Planning and Development

Provides annual utilization reports for skilled nursing facilities, home health agencies and hospices licensed in California.

## Long-Term and End-of-Life Care in California Data Resources

### ABOUT THIS SERIES

The California Health Care Almanac is an online clearinghouse for data and analysis examining the state's health care system. It focuses on issues of quality, affordability, insurance coverage and the uninsured, and the financial health of the system with the goal of supporting thoughtful planning and effective decisionmaking. Learn more at [www.chcf.org/almanac](http://www.chcf.org/almanac).

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