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.

Projected Population by Age Group
California, 2010 to 2060, Selected Years

IN MILLIONS

2010 2020P 2030P 2040P 2050P 2060P
37.4 40.1 42.3 43.9 44.9 45.3

Note: Projections are shown as P.

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.
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.

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

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 Population of Seniors with ADL Limitations
California, 2015 to 2060

IN THOUSANDS

<table>
<thead>
<tr>
<th>Year</th>
<th>Two or More ADL Limitations</th>
<th>One ADL Limitation</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>2015</td>
<td>641</td>
<td></td>
<td>1,038</td>
</tr>
<tr>
<td>2020</td>
<td>1,722</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2025</td>
<td>2,098</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2030</td>
<td>2,409</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2035</td>
<td>2,719</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2040</td>
<td>2,911</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2045</td>
<td>3,113</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2050</td>
<td>3,315</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2055</td>
<td>3,517</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2060</td>
<td>3,720</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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.
Projected Prevalence of Alzheimer’s Disease, by Age Group
California, 2020 and 2025

<table>
<thead>
<tr>
<th>Age Group</th>
<th>2020</th>
<th>2025</th>
</tr>
</thead>
<tbody>
<tr>
<td>65 to 74</td>
<td>110,000</td>
<td>120,000</td>
</tr>
<tr>
<td>75 to 84</td>
<td>290,000</td>
<td>330,000</td>
</tr>
<tr>
<td>85+</td>
<td>290,000</td>
<td>840,000</td>
</tr>
</tbody>
</table>

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.

Note: Segments may not sum due to rounding.
**Overview of Long-Term Care Services**

**California, 2020**

<table>
<thead>
<tr>
<th>SERVICE</th>
<th>DESCRIPTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Skilled Nursing Facility</td>
<td>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.</td>
</tr>
<tr>
<td>Assisted Living Facility / Residential Care Facility</td>
<td>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.</td>
</tr>
<tr>
<td>Home Health Care</td>
<td>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.</td>
</tr>
<tr>
<td>Medicaid Home and Community-Based Services (HCBS)</td>
<td>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.</td>
</tr>
<tr>
<td>Hospice Care</td>
<td>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.</td>
</tr>
</tbody>
</table>

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.

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.

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.

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

IN MILLIONS

<table>
<thead>
<tr>
<th>Service Type</th>
<th>Spending (Millions)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home Health and Personal Care</td>
<td>$12,393</td>
</tr>
<tr>
<td>Nursing Facilities</td>
<td>$2,450</td>
</tr>
<tr>
<td>Intermediate Care Facilities</td>
<td>$743</td>
</tr>
<tr>
<td>Mental Health Facilities</td>
<td>$676</td>
</tr>
</tbody>
</table>

Total Spending $16.3 Billion

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.

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.

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.
Nursing Facilities by Ownership Type
California vs. United States, 2007 and 2017

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.
Nursing Facility Beds
California vs. United States, 2010 and 2016

NUMBER PER 10,000 POPULATION

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).

Note: Population data are one-year estimates from the American Community Survey.
## Skilled Nursing Facility Beds, Admissions, and Patient Days
California, 2008 and 2018

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Beds</td>
<td>104,690</td>
<td>104,668</td>
<td>0.0%</td>
</tr>
<tr>
<td>Admissions</td>
<td>304,534</td>
<td>364,754</td>
<td>19.8%</td>
</tr>
<tr>
<td>Patient Days</td>
<td>33,015,390</td>
<td>33,326,637</td>
<td>0.9%</td>
</tr>
</tbody>
</table>

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.

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

Nursing Facility Residents by Primary Payer
California vs. United States, 2007 and 2017

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.

Skilled Nursing Facility Discharges by Disposition
California, 2008 and 2018

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.

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).

### Nursing Home Quality Measures
#### California vs. United States, 2019

<table>
<thead>
<tr>
<th>Event</th>
<th>California</th>
<th>United States</th>
</tr>
</thead>
<tbody>
<tr>
<td>Had Increased Need for Help with Daily Activities</td>
<td>9.2%</td>
<td>14.5%</td>
</tr>
<tr>
<td>Had Pressure Ulcers</td>
<td>6.9%</td>
<td>7.3%</td>
</tr>
<tr>
<td>Lost Too Much Weight</td>
<td>4.5%</td>
<td>5.5%</td>
</tr>
<tr>
<td>Had Catheter Inserted and Left in Bladder</td>
<td>1.8%</td>
<td>1.8%</td>
</tr>
<tr>
<td>Had Urinary Tract Infection</td>
<td>1.7%</td>
<td>2.6%</td>
</tr>
<tr>
<td>Had Depressive Symptoms</td>
<td>1.0%</td>
<td>5.1%</td>
</tr>
<tr>
<td>Were Physically Restrained</td>
<td>0.4%</td>
<td>0.2%</td>
</tr>
<tr>
<td>Experienced One or More Falls with Major Injury</td>
<td>1.8%</td>
<td>3.4%</td>
</tr>
<tr>
<td>Received Antipsychotic Medication</td>
<td>10.4%</td>
<td>14.2%</td>
</tr>
</tbody>
</table>

Note: Lower percentages are better.

Nursing Facility Deficiencies
California vs. United States, 2007 and 2017

AVERAGE NUMBER PER FACILITY

<table>
<thead>
<tr>
<th></th>
<th>2007</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>California</td>
<td>13.4</td>
<td>12.8</td>
</tr>
<tr>
<td>United States</td>
<td>9.2</td>
<td>7.1</td>
</tr>
</tbody>
</table>

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."


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

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.

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.

Skilled Nursing Facility Net Patient Revenue, by Payer
California, 2008 and 2018

IN BILLIONS

2008

- Medicare FFS: $2.5
- Medi-Cal FFS: $3.8
- Self-Pay: $0.8
- Managed Care: $0.6
- Other Payers: $0.3

Total: $8.1

2018

- Medicare FFS: $3.6
- Medi-Cal FFS: $4.5
- Self-Pay: $0.5
- Managed Care: $0.6
- Other Payers: $0.5

Total: $11.3

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).

Skilled Nursing Facility Expenses and Revenue
California, 2008 and 2018

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

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

Skilled Nursing Facilities by Operating Margin
California, 2008 and 2018

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.

PERCENTAGE OF FACILITIES

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

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

Note: Based on 365 days of care.
Source: Cost of Care Survey 2019, Genworth, October 8, 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.

Assisted Living Capacity, by Client Group
California, 2019

Note: Data for licensed facilities only; excludes facilities with pending licenses, on probation, or closed.
Assisted Living Beds and Residents
California vs. United States, 2012 and 2016

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

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.

Note: Rates are for 12 months of care in a private one-bedroom.
Source: Cost of Care Survey 2019, Genworth, October 8, 2019.
# Medicaid Home and Community-Based Services, by Authority

## California, 2018

<table>
<thead>
<tr>
<th>PROGRAM AUTHORITY</th>
<th>DESCRIPTION</th>
<th>ENROLLMENT</th>
<th>SPENDING (IN THOUSANDS)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>STATE PLAN OPTIONS</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home Health Services</td>
<td>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.</td>
<td>37,500*</td>
<td>$153,900*</td>
</tr>
<tr>
<td>Personal Care Services: Section 1915(j)</td>
<td>Provides help with self-care (e.g., bathing, dressing) and household activities (e.g., preparing meals).</td>
<td>273,800</td>
<td>$2,960,800</td>
</tr>
<tr>
<td>Community First Choice: Section 1915(k)</td>
<td>Provides attendant services and supports for beneficiaries who would otherwise require institutional care.</td>
<td>228,200</td>
<td>$5,562,600</td>
</tr>
<tr>
<td>State Plan Home and Community-Based Services: Section 1915(i)</td>
<td>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.</td>
<td>55,800</td>
<td>$494,600</td>
</tr>
<tr>
<td><strong>WAIVERS</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home and Community-Based Services Waivers: Section 1915(c)</td>
<td>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.</td>
<td>149,500</td>
<td>$3,810,300</td>
</tr>
</tbody>
</table>

*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).


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

Medi-Cal HCBS

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.
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.

*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).

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:
Home Health Agencies, by Ownership Type
California, 2008 and 2018

NUMBER OF AGENCIES

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

### 2008

- 874 For-Profit
- 118 Nonprofit
- 23 Government
- 3 University of California
- 8 Nonresponse
- Total: 1,026

### 2018

- 1,376 For-Profit
- 106 Nonprofit
- 11 Government
- 2 University of California
- 87 Nonresponse
- Total: 1,582

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.


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

<table>
<thead>
<tr>
<th>Year</th>
<th>Medi-Cal FFS</th>
<th>Medicare FFS</th>
<th>HMO/PPO</th>
<th>Private</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>2008</td>
<td>$8.1</td>
<td>$1.4</td>
<td>$1.5</td>
<td>$1.0</td>
<td>$12.2</td>
</tr>
<tr>
<td>2018</td>
<td>$10.2</td>
<td>$0.9</td>
<td>$4.4</td>
<td>$1.2</td>
<td>$17.0</td>
</tr>
</tbody>
</table>

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.

Medicare Beneficiaries Receiving Home Health Services
California vs. United States, 2007 and 2017

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.

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

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.
Home Health Agency Quality Measures
California vs. United States, 2019

HOW OFTEN PATIENTS...

**Improved at Walking or Moving Around**
- California: 76.7%
- United States: 78.6%

**Improved at Getting In and Out of Bed**
- California: 76.3%
- United States: 79.4%

**Improved at Bathing**
- California: 79.5%
- United States: 80.9%

**Improved Breathing**
- California: 81.6%
- United States: 81.3%

**Got Better at Taking Drugs Correctly by Mouth**
- California: 69.5%
- United States: 72.1%

**Had to be Admitted to the Hospital**
- California: 14.1%
- United States: 15.6%

**Needed Urgent, Unplanned Care in ER**
- California: 11.8%
- United States: 12.8%

*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.

Medicare Home Health Spending per Patient
California vs. Selected States, 2008 and 2018

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.

Note: Fee-for-service patients only.
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.

*Data are 2017.

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

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.

Notes: Data are limited to agencies with entity type “Hospice Only.” There were 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.

Hospice Patient Days, by Payer
California, 2008 and 2018

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.

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.

Hospice Patients, by Race and Ethnicity
California, 2018

By Race
- White: 62%
- Asian: 9%
- Black: 6%
- Non-Latino: 72%
- Multiracial: 1%
- Native American: <1%
- Unknown: 23%

By Ethnicity
- Latino: 15%
- Non-Latino: 72%
- Unknown: 14%

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.

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.

**Medicare Beneficiaries Receiving Hospice Services**

California vs. United States, 2008 and 2018

**HOSPICE USERS PER 1,000 BENEFICIARIES**

<table>
<thead>
<tr>
<th></th>
<th>2008</th>
<th>2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>California</td>
<td>19.4</td>
<td>24.6</td>
</tr>
<tr>
<td>United States</td>
<td>24.6</td>
<td>26.0</td>
</tr>
</tbody>
</table>

**NUMBER OF MEDICARE HOSPICE PATIENTS**

<table>
<thead>
<tr>
<th></th>
<th>2008</th>
<th>2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>California</td>
<td>87,011</td>
<td>150,847</td>
</tr>
<tr>
<td>United States</td>
<td>1,045,551</td>
<td>1,560,399</td>
</tr>
</tbody>
</table>

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).

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.
## Hospice Quality Measures
### California vs. United States, 2017

<table>
<thead>
<tr>
<th>Family Caregivers Who Reported…</th>
<th>California</th>
<th>United States</th>
</tr>
</thead>
<tbody>
<tr>
<td>Receiving Training About Taking Care of Their Family Member</td>
<td>71.1%</td>
<td>72.7%</td>
</tr>
<tr>
<td>Family Member Always Received Enough Help for Pain and Other Symptoms*</td>
<td>72.7%</td>
<td>74.6%</td>
</tr>
<tr>
<td>Always Receiving Help as Soon as Needed</td>
<td>72.8%</td>
<td>77.2%</td>
</tr>
<tr>
<td>Hospice Team Always Communicated Well</td>
<td>77.3%</td>
<td>79.6%</td>
</tr>
<tr>
<td>Family Member Always Treated with Dignity and Respect</td>
<td>87.7%</td>
<td>89.7%</td>
</tr>
<tr>
<td>Receiving Right Amount of Emotional and Spiritual Support</td>
<td>87.8%</td>
<td>89.0%</td>
</tr>
</tbody>
</table>

*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.


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 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).

Note: Source uses reimbursement.
### 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

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Dying Natural Death</th>
<th>Prolong Life</th>
<th>Not Sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asian / Pacific Islander</td>
<td>61%</td>
<td>13%</td>
<td>26%</td>
</tr>
<tr>
<td>Black</td>
<td>53%</td>
<td>22%</td>
<td>25%</td>
</tr>
<tr>
<td>Latino</td>
<td>60%</td>
<td>8%</td>
<td>31%</td>
</tr>
<tr>
<td>White</td>
<td>67%</td>
<td>6%</td>
<td>25%</td>
</tr>
<tr>
<td>&lt;150% FPL</td>
<td>53%</td>
<td>12%</td>
<td>33%</td>
</tr>
<tr>
<td>150%–399% FPL</td>
<td>61%</td>
<td>9%</td>
<td>30%</td>
</tr>
<tr>
<td>400%+ FPL</td>
<td>68%</td>
<td>8%</td>
<td>23%</td>
</tr>
<tr>
<td>Overall</td>
<td>63%</td>
<td>9%</td>
<td>28%</td>
</tr>
</tbody>
</table>

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.

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.

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.
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)

65% Preferred Location of Death
39% Actual Location of Death

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.

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.

AUTHOR
Jennifer Joynt, Independent Consultant

FOR MORE INFORMATION
California Health Care Foundation
1438 Webster Street, Suite 400
Oakland, CA 94612
510.238.1040
www.chcf.org