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Legacy Health Endowment

A Data Report to Help Better Understand Long-Term Care in California and Beyond

Prepared for: Legacy Health Endowment

California Health Policy Strategies, LLC

Marianna Yamamoto, Researcher
Jaemie Anne Abad, Researcher
David Panush, President
David Maxwell-Jolly, Senior Advisor

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From the President of Legacy Health Endowment

In California and across the nation, far too many professionals struggle with finding accurate data and information regarding long-term care. As a result, we asked the team of professionals at California Health Policy Strategies to provide Legacy Health Endowment with a definitive report where everything we want to know about long-term care could be found.

As the rural California Central Valley struggles with finding community-based long-term care services to assist both Medi-Cal and non-Medi-Cal eligible people over 55, understanding the basic challenges facing the middle class is extremely important.

America and rural Californians share many things, one, in particular, is the fact that we are a rapidly aging society. Long-term care represents a huge gaping hole in the country's safety net. And, as it applies to the middle class the hole widens even more.

As you read through the data report, you will quickly realize that our long-term care system is patched together and leans heavily on Medicaid (Medi-Cal in California) and the heroic and often unrecognized work of unpaid family caregivers.

California's long-term care system is fragile, and for the middle class that is aging in place, it is teetering on the verge of collapse. Without a long-term care infrastructure, most Americans face high costs, undue burdens, and threats to their well-being in older adulthood.

The data report that follows was created to help inform and educate. But, to also begin to underscore a story of neglect – if we do not address the long-term care needs of the growing aging middle class, families young and old will be impacted both emotionally and financially.

As you read through the report, please feel free to email any questions or comments.

Jeffrey Lewis
President & CEO
Legacy Health Endowment
jeffrey@legacyhealthendowment.org
209/250-2315

Key Data Points

Population Data

- **California's older adult population (ages 60 and above) is expected to grow to 10.8 million people**, or 25% of the state population, by 2030 (California Department of Aging, 2021).
- **An estimated 7.09 million adults (1 in 4) in California are living with a disability** (CDC, 2021).
- **The 65+ population in Merced County is expected to grow 159% and 110% in Stanislaus County** from 2019 to 2060 (California Department of Finance, 2021).
- **7% of people aged 65 to 79 living in Merced and Stanislaus Counties live alone**, compared to **over 46% of individuals ages 80 and older**. In comparison, 32% of individuals aged 80 and older live alone statewide (California Health Interview Survey, 2020).
- **65% and 63% of the 65+ population in Merced and Stanislaus Counties, respectively, reported being in "excellent," "very good," or "good" health** (California Health Interview Survey, 2020).

Populations of Focus

- **6.5 million Californians were enrolled in Medicare in 2021**, including dual-eligible individuals and individuals enrolled in Medicare Advantage plans (Department of Health Care Services & ATI Advisory, 2022).
    - 5.07 million Californians (78% of total California Medicare population) were enrolled in Medicare without Medi-Cal (Department of Health Care Services & ATI Advisory, 2022).
- **663,352 seniors and people living with a disability enrolled are in Medi-Cal only** (Department of Health Care Services, 2022).
    - 1.58 million individuals are dual eligible for both Medi-Cal and Medicare (Department of Health Care Services, 2022).

Long-Term Services and Supports (LTSS)

- In 2018, **$379 billion was spent nationally on LTSS** (Watts et al., 2020).
- **Over half (52%) of national LTSS expenditures was paid for by Medicaid**, while 18% was paid out-of-pocket, and 11% paid by private insurance (Watts et al., 2020).

Long Term Care (LTC)

- In California, **LTC facilities had an average revenue of $355 per patient day** across all payers in 2020 (Department of Health Care Access and Information, 2022). On average, Medicare paid $359.57 per patient day and Medi-Cal paid $329.47 per patient day (Department of Health Care Access and Information, 2022).

- **In California, a semi-private room in a nursing home facility costs an average of $117,530 per year**. This is a nearly 6% increase in cost since 2020 (Genworth, 2021).
- **Nationally, a semi-private room in a nursing home facility costs an average of $94,900 per year.** This cost has increased by nearly 2% since 2020 (Genworth, 2021).

Home and Community Based Services (HCBS)

- **California accounted for 19% ($17.6 billion) of national Medicaid HCBS spending** in 2018 (Watts et al., 2020).
- During February 2022, approximately **666,700 people received a caregiver from In-Home Supportive Services (IHSS) in California**. On average, an IHSS caregiver was paid $1,806 per participant per month (Department of Social Services, 2022).
- In 2018, California spent **$25,500 per enrollee across all Section 1915(c) HCBS waiver programs** (California Health Care Foundation, 2020). California spent an average of $45,800 per adult enrollee living with a physical disability, $26,900 per enrollee living with a developmental disability, and $3,800 per enrollee who is a senior (Watts et al., 2020).

Hospice

- California spent **$3.5 billion on hospice services in 2020**, serving close to 247,000 patients across all payer sources (California Department of Health Care Access and Information, 2021).
- In 2020, **Medicare paid for 80.2% of hospice patients**, 6.3% had Medi-Cal or Medi-Cal Managed Care, and 4% were Self Pay (California Department of Health Care Access and Information, 2021).

Caregivers

- Unpaid labor provided by family caregivers is estimated to amount to **$470 billion nationally and $63 billion in California** (Tan et al., 2021).
- In California, **one in four family caregivers provided 20+ hours of care per week**, yet only 1 in 11 received any payment (Tan et al., 2021). At IHSS wage rates, this amounts to at least $315.80 in unpaid wages per week or $16,421 annually (Guengerich, 2020).
- On average, **family caregivers spend approximately $7,000 annually in out-of-pocket costs t**hat account for 20% of their incomes (California Task Force on Family Caregiving, 2018). In a 2020 survey, 67% of caregivers reported using their own money to help provide care (Guengerich, 2020).
- In California, 13.5% of caregivers reported a physical or mental health problem due to caregiving (Tan et al., 2021).

I. Introduction

According to the California Department of Aging (2021), **California expects the population of adults over the age of 60 to grow to 10.8 million people by 2030**, or 25% of the total state population. Furthermore, **an estimated 1 in 4 adults (7.09 million adults) in California are living with a disability**[1] (CDC, 2021). However, there are insufficient affordable options for long-term services and supports (LTSS) to adequately support older adults, people living with a disability, and their families.

LTSS are accessed by older adults and people with disabilities to receive clinical and non-clinical services and support for daily living activities. In 2018, $379 billion was spent nationally on LTSS (Watts et al., 2020). Medicaid is the primary payer for LTSS nationally, accounting for over half (52%) of national LTSS expenditures (Watts et al., 2020), covering institutional and home- and community-based services. In contrast, Medicare coverage of LTSS is limited to acute and post-acute services and temporary home health services for patients in certain circumstances. As a result, 18% of the national spending on LTSS, or $68.22 billion, was paid out-of-pocket and 11% by private insurance (Watts et al., 2020). Driven by the limited coverage of LTSS services provided by Medicare, the eligibility restrictions of Medicaid, and the high cost of LTSS, there is a gap in coverage and access to quality and affordable LTSS services for seniors and people living with disabilities that are unable to qualify for Medi-Cal.

Legacy Health Endowment proposes to establish the Person-Centered Pilot Program to address the gap in affordable and quality LTSS services for individuals over the age of 60 and individuals living with a disability who do not qualify for Medi-Cal. This memorandum outlines LTSS cost and utilization data for California and nationally to showcase the need for the Person-Centered Pilot Program.

County Data

Merced County

- The 65+ population is expected to grow 159% from 2019 to 2060 (California Department of Finance, 2021). The 65+ share of the population is expected to grow to 18.5% in 2060 from 11.5% in 2019 (California Department of Finance, 2021).
- 65% of the 65+ population in Merced County reported being in “excellent,” “very good,” or “good” health (California Health Interview Survey, 2020)

Stanislaus County

- The 65+ population is expected to grow 110% from 2019 to 2060 (California Department of Finance, 2021).

[1] Includes mobility, cognition, independent living, hearing, vision, and self-care disabilities.

- The 65+ share of the population is expected to grow to 20.2% in 2060 from 13.4% in 2019 (California Department of Finance, 2021).
- 63% of the 65+ population in Stanislaus County reported being in "excellent," "very good," or "good" health. (California Health Interview Survey, 2020)

Merced & Stanislaus Counties Combined Data

- Over 41% of the 65-79 population in Merced and Stanislaus Counties is Latinx, compared to 25% of the 65 to 79 population statewide (California Health Interview Survey, 2020).
- 7% of people aged 65 to 79 living in Merced and Stanislaus Counties live alone, compared to over 46% of individuals ages 80 and older. In comparison, 32% of individuals aged 80 and older live alone statewide (California Health Interview Survey, 2020).

II. Populations of Focus

Given that the cost and availability of LTSS varies by payer, the number of enrolled individuals in Medicare, Medi-Cal (California's Medicaid program), and both Medicare and Medi-Cal are listed below.

Medicare

Medicare is the federal insurance program for people over the age of 65 and people living with disabilities. Medicare includes hospital insurance (Part A), medical insurance (Part B), and optional prescription drug coverage (Part D). Medicare coverage of LTSS is limited to transitional care services post-hospitalization or after a period of illness, with predetermined benefit periods. Medicare covers up to 100 days for short-term physical rehabilitation care in a skilled nursing facility and up to 100 visits for home health services. Hospice services are covered with a physician's certification that the patient has a life expectancy of 6 months or less, and services can be extended beyond this period with a recertification.

- California
    - 6.5 million Californians were enrolled in Medicare in 2021, including dual-eligible individuals and individuals enrolled in Medicare Advantage plans (Department of Health Care Services & ATI Advisory, 2022).
    - 5.07 million Californians (78% of total California Medicare population) were enrolled in Medicare without Medi-Cal (Department of Health Care Services & ATI Advisory, 2022).
    - 3.12 million (48%) Medicare members in California were enrolled in a Medicare Advantage plan (Department of Health Care Services & ATI Advisory, 2022). Medicare Advantage plans (Part C) are offered by private

insurance companies who deliver Medicare Part A, Part B, and oftentimes Part D services to individuals.

- National
    - 63.5 million people in the U.S. were enrolled in Medicare in 2021 (Department of Health Care Services & ATI Advisory, 2022).
    - 11.43 million (18%) Medicare members nationally were dual eligible for Medicare and Medi-Cal in 2021 (Department of Health Care Services & ATI Advisory, 2022).

Medi-Cal

Medi-Cal is California's Medicaid program. Medi-Cal is a joint federal and state health coverage program that covers low-income individuals, pregnant women, children, people over 65, and people living with a disability. Medicaid is the largest source of health coverage nationally, where each state sets its own income and asset eligibility limits. Medi-Cal covers LTSS through long-term care and home- and community-based services (HCBS).

- Merced County
    - 9,692 individuals aged 65 years and older were enrolled in Medi-Cal in 2020 (Department of Finance, 2020).
    - 11,989 individuals aged 65 years and older are expected to be enrolled in Medi-Cal by 2030.[2]
- Stanislaus County
    - 17,027 individuals aged 65 years and older were enrolled in Medi-Cal in 2020 (Department of Finance, 2020).
    - 20,809 individuals aged 65 years and older are expected to be enrolled in Medi-Cal by 2030.[3]
- California (As of November 2021)
    - 14,405,711 individuals are enrolled in Medi-Cal (Department of Health Care Services, 2022).
    - 663,352 (4.6%) seniors and people living with a disability enrolled are in Medi-Cal only (Department of Health Care Services, 2022).
    - 1.58 million individuals (11%) are dual eligible for both Medi-Cal and Medicare (Department of Health Care Services, 2022).
- National (As of November 2021)

[2] Projections calculated using the California Department of Finance population projections (2020) and Medi-Cal Certified Eligibility data (2022). Assumes that the pace of growth in Medi-Cal enrollment by county remains constant.

[3] See footnote 2.

- 78.9 million people are enrolled in Medicaid (Centers for Medicare & Medicaid Services, 2021).

III. Financial Impact

Long Term Care Facilities
Long Term Care (LTC) facilities include skilled nursing facilities, hospice facilities, intermediate care facilities, and congregate living facilities. The U.S. spends approximately 1.6% of its GDP on LTC, a rate marginally higher than the average of 1.5% of GDP across OECD countries (OECD, 2020).

- California
  - A total of 1,069 long-term care (LTC) facilities [4] operated in California with a capacity of 106,341 beds in 2020 (Department of Health Care Access and Information, 2022).
  - LTC facilities had over 286,800 discharges and generated a total net patient revenue of over $12 billion (Department of Health Care Access and Information, 2022).
  - Medi-Cal accounted for over 39% of total net patient revenue in LTC facilities, followed by Medicare at nearly 36% (Department of Health Care Access and Information, 2022).
  - On average, LTC facilities had a revenue of $355 per patient day across all payers in 2020 (Department of Health Care Access and Information, 2022). On average, Medicare paid $359.57 per patient day and Medi-Cal paid $329.47 per patient day (Department of Health Care Access and Information, 2022).
  - A semi-private room in a nursing home facility costs an average of $117,530 per year. This is a nearly 6% increase in cost since 2020 (Genworth, 2021).

- National
  - In 2018, the U.S. had approximately 31 beds per 1,000 people aged 65 years and older (OECD, 2022).
  - In FY 2019, Medicaid spent $67.1 billion in institutional LTSS (Murray et al., 2021).
  - A semi-private room in a nursing home facility costs an average of $94,900 per year. This cost has increased by nearly 2% since 2020 (Genworth, 2021).

[4] Long Term Care facilities include facilities that deliver skilled nursing, intermediate care, care for individuals who are mentally disordered, care for individuals who have a developmental disability, sub-acute care, and sub-acute pediatric care.

Service		Average Daily Cost in California	Average Daily Cost Nationally	% Difference
Assisted Living Facility	Private, One Bedroom	$173	$148	17%
Nursing Home Care	Semi-Private Room	$322	$260	24%
Nursing Home Care	Private Room	$400	$297	35%

Figure 1: Average Daily Cost of LTC in 2021 (Genworth, 2021)

Home and Community Based Services

Home and Community Based Services (HCBS) programs deliver clinical and non-clinical services to patients in home or community settings. HCBS is an alternative to receiving LTSS in an institutional setting. California offers 12 HCBS programs through Medi-Cal, including Community-Based Adult Services (CBAS), Multipurpose Senior Services Program, In-Home Supportive Services, and Home Health Care, among others (Christ & Huyenh-Cho, 2021). HCBS programs are authorized via demonstration waivers, Section 1915(c) waivers, and State Plan Amendments.

- California accounted for 19% of national Medicaid HCBS spending in 2018. California spent over $17.6 billion on HCBS in Medi-Cal in 2018 (Watts et al., 2020).

State Plan HCBS Programs include In-Home Supportive Services (IHSS) and Home Health Care.

- During February 2022, approximately 666,700 people received IHSS in California (Department of Social Services, 2022). On average, 113 hours per recipient were authorized per month (Department of Social Services, 2022), costing approximately $1,806 per month in IHSS caregiver wages.[5]

[5] Calculated from the average authorized hours per month multiplied by the average hourly wage ($15.96) of IHSS workers.

Service		Average Daily Cost in California	Average Daily Cost Nationally	% Difference
Home Health Care	Homemaker Services	$201	$163	23%
Home Health Care	Homemaker Health Aide	$201	$169	19%

Figure 2: Average Daily Cost of Home Health Care in 2021 (Genworth, 2021)

Section 1915(c) Waiver HCBS Programs include the Assisted Living Waiver, Home and Community Based Services Alternatives Waiver, AIDS Waiver, Home and Community-Based Services for the Developmentally Disabled, and the Multipurpose Senior Services Program (MSSP).

- In 2018, California served approximately 149,500 individuals through the Section 1915(c) waiver programs, spending approximately $3.81 billion (Watts et al., 2020).
- In 2018, California spent $25,500 per enrollee across all Section 1915(c) waiver programs. (California Health Care Foundation, 2020). California spent an average of $45,800 per adult enrollee living with a physical disability, $26,900 per enrollee living with a developmental disability, and $3,800 per enrollee who is a senior (Watts et al., 2020).

Section 1115 Demonstration Waiver HCBS Programs include California Community Transitions, Community-Based Adult Services (CBAS), Cal MediConnect (CMC), Managed Long-Term Services and Supports (MLTSS), and Program for All-Inclusive Care for the Elderly (PACE).

- California spent $4.67 billion on Section 1115 HCBS Programs to serve 474,300 enrollees in 2018, spending approximately $9,900 per enrollee (Watts et al., 2020).
- In 2020-2021, California projected spending approximately $6.05 million in CBAS (a benefit provided by licensed Adult Day Health Centers) at an approximate cost of $158 per person (California Department of Aging, 2021). CBAS expects to serve approximately 38,198 people, which includes 37,122 people with Medi-Cal and 1,076 who are private pay participants (California Department of Aging, 2021).

Service	Average Daily Cost in California	Average Daily Cost Nationally	% Difference
Adult Day Health Care	$85	$78	9%

Figure 3: Average Daily Cost of Adult Day Health Care in 2021 (Genworth, 2021)

Palliative and Hospice Care

Palliative Care Agencies focus on reducing a patient's physical suffering and addressing the symptoms of disease using a supportive, multidisciplinary approach. Patients may use life-prolonging medications, and do not have to be terminally ill to receive services.
Hospice Agencies provide services to patients nearing end-of-life, focusing on keeping patients comfortable and supporting their families during this transition. Patients may receive services from a hospice nurse, social worker, chaplain, hospice physician, and more (Centers for Medicare & Medicaid Services, n.d.).

- California spent $3.5 billion on hospice services in 2020, serving close to 247,000 patients across all payer sources (California Department of Health Care Access and Information, 2021).
- 80.2% of hospice patients had Medicare as payer, 6.3% had Medi-Cal or Medi-Cal Managed Care, 2.4% had Managed Care or Private Insurance, 4% were Self Pay, and 0.2% received charity care (California Department of Health Care Access and Information, 2021).
- 82.3% of hospice patients received services at home, rather than in skilled nursing facilities, hospitals, etc.(California Department of Health Care Access and Information, 2021).

Medication Management Services

Service	Cost	Description
Pill Organizer	$5 to $30	Pillboxes range in price depending on features (number of compartments, compartment size, easy-open tabs, etc.).
Electronic Pill Dispenser	$70 to $500 one-time, or $30 to $150 monthly subscription (Hipp & Hall, 2021)	Electronic pill dispensers have features such as alarms, missed dose alerts to caregivers, and other telemedicine features. However, the patient/caregiver must load the dispenser.
ALF Medication Management	$300 to $500 per month (Paying for Senior Care, 2020)	Residents of Assisted Living Facilities may need to pay monthly medication management fees on top of their other monthly ALF costs.
Home Health Nurse	$150+ per visit (based on Medicare rates) (Centers for Medicare & Medicaid Services, 2020)	Home Health Nurses may provide medication management and fill pillboxes. Some may even request and pick up prescriptions on behalf of the patient.
Home Care Aide	$201 in daily costs	Aides may provide medication reminders but cannot administer medications. They may instruct a patient to fill a pillbox but cannot fill the pillbox on the patient's behalf (California Department of Social Services, 2017).
Pre-Sorted Pill Packs by Date/Time	Usually no additional costs (divvydose, n.d.; PillPack, n.d.; CVS Pharmacy, n.d.)	A combined mail-order pharmacy and pill packaging service, these programs sort medications into packs labeled with dates and times. Patients pay their usual prescription copays.

Figure 4: Estimated Cost of Medication Management Services, Equipment, and Staff

Durable Medical Equipment

DME Type	Medicare Part B (Average Patient's Responsibility in 2019) (Centers for Medicare & Medicaid Services, n.d., 2019; Department of Health and Human Services & Centers for Medicare & Medicaid Services, 2006)	Medi-Cal (Patient's Responsibility 2019/2020) (Department of Health Care Services, 2020)	Average Supplier Submitted Charges (2019)
Single Point Cane	$6.54 one-time	$0	$28.27 one-time
Front Wheeled Walker	$12.30 one-time	$0	$111.07 one-time
Manual Wheelchair with Leg Rests	$8.56 per month, until fully paid after 13 months	$0	$83.09 per month
Bedside Commode	$13.13 one-time	$0	$119.23 one-time
Semi-Electric Hospital Bed with Side Rails and Mattress	$14.32 per month, until fully paid after 13 months	$0	$184.37 per month
Patient Lift with Sling	$12.66 per month, until fully paid after 13 months	$0	$122.81 per month
Oxygen Concentrator	$20.41 per month, until fully paid after 36 months	$0	$454.16 per month

Figure 5: Estimated Cost of Durable Medical Equipment in California

Caregivers

Informal caregivers are family members or friends who provide care and assistance with daily activities. In 2020, one in five Americans in the U.S. or approximately 55 million family caregivers were caring for an adult or a child with special needs (AARP & National Alliance for Caregiving, 2020). There are an estimated 4.5 million family caregivers in California who care for an adult (California Task Force on Family Caregiving, 2018).

- In California, one in four family caregivers provided 20+ hours of care per week, yet only 1 in 11 received any payment (Tan et al., 2021). At IHSS wage rates, this

amounts to at least $315.80 in unpaid wages per week or $16,421 annually (Guengerich, 2020). Unpaid labor provided by family caregivers is estimated to amount to $470 billion nationally and $63 billion in California (Tan et al., 2021)

- In addition to providing unpaid labor, 54% of caregivers surveyed reported working full time and 9.7% part time (Tan et al., 2021). In addition 71% of caregivers report changing their work schedule (Guengerich, 2020). It is possible that there are employment or social opportunities that caregivers are foregoing due to their caregiving responsibilities (Tan et al., 2021).
- On average, family caregivers spend approximately $7, 000 annually in out-of-pocket costs that account for 20% of their incomes (California Task Force on Family Caregiving, 2018). 67% of caregivers surveyed reported using their own money to help provide care (Guengerich, 2020)
- More than 20% of family caregivers in California reported experiencing financial stress, with higher rates among African American, Asian, and Latinx respondents compared to White respondents (Tan et al., 2021).

IV. Socioemotional Impacts

Aging in Place

"Aging in place" is an approach that allows older adults to stay in their home and community. Among older adults engaged in the study, staying in their community brought a sense of attachment, safety, and security (Wiles et al., 2012). Furthermore, preserving existing attachments to environmental surroundings and community that have been shown to support patient wellbeing (Wiles et al., 2012). Aging in place is connected to identity, autonomy, and independence for the older person. Older adults have reported a preference for remaining at home as long as possible. Aging in place has been promoted as a cost-effective alternative to institutional care and to prevent avoidable hospitalizations (Moody et al., 2022).

Caregivers

Caregiving for a family member or loved one can have emotional impacts on the caregiver.

- In California, 13.5% of caregivers reported a physical or mental health problem due to caregiving (Tan et al., 2021).
- 68% of respondents who are caregivers in California reported feeling emotionally stressed because of caregiving responsibilities (Guengerich, 2020).
- 74% of respondents who are caregivers in California reported feeling stressed trying to balance job and family responsibilities (Guengerich, 2020).
- Given the gender differences in caregiving, the mental and physical strain of caregiving disproportionately impacts women (Tan et al., 2021).

V. Limitations

Publicly available data on the cost of services in California and national level was not consistently available or directly comparable. Comparability may be limited due to differences in reporting year, reported measure, and population.

Data on caregiver burden and responsibility is collected by agencies like the California Health Interview Survey and the AARP through surveys. Survey data is most informative to capture respondent's self-reported identity and experiences from the sample of respondents. The reliability and generalizability of survey data could be impacted by selection bias in the sample of respondents. Census data that does outline personal assistance needs and caregiver characteristics was published in 1990.

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