Introduction

The era of long term care in nursing homes may slowly be ending.

In 2005, about 1.5 million Californians used long term care services. That number is expected to skyrocket as 6.5 million Californians will be age 65 and older by 2025. Nearly a million of those will be 85 and older, and many will need long term care. But nursing homes may not be the default standard for care; many frail elderly will be cared for at home.

This report highlights the changes taking place within California’s long term care system. Among the findings:

- From 1990 to 2002, residential care capacity increased nearly 67 percent, while nursing home capacity and occupancy fell.
- In 2002, nearly four times as many Californians received long term care outside of nursing homes, compared to only 2.5 times as many in 1999.
- In 2002, Californians receiving care outside of nursing homes (77%) accounted for only 49 percent of long term care expenses, underscoring the cost effectiveness of home- and community-based services.

Individuals served by long term care include adults and children with disabilities, the elderly, and individuals needing temporary assistance while recovering from an illness or injury. Alternatives to institution-based care include: residential, home health, hospice, and personal care services programs.

See appendix for an explanation of long term care options and government programs that help pay for HCBS care.

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California’s Population Is Aging

Projected Number of Residents, Age 65 and Older (in millions), 1990–2025

As the population ages, the demand for long-term nursing care will increase. The number of California residents age 65 and older is projected to nearly double by 2025—a larger growth rate than any other state or the United States overall (75 percent).

Americans are living longer. In 2001, the life expectancy was 77.2 years, compared to 75.5 just ten years earlier. The number of California residents age 85 and older — those who are most likely to need extended care at home or in nursing homes — is likely to more than double by the year 2030, when the bulk of baby boomers will come of advanced age.

Population with Work-Related Disabilities*

Number (in millions) of Californians, Age 18 and Older, 1992–2006

Although the rate of work-related disabilities for Californians has remained about the same since 1992, the total number is increasing. Many of these individuals may require long term care in the future.

*Data does not include individuals with severe disabilities and those currently receiving long term care.

Number of Californians Served by LTC, Estimates for 2005*

- Nursing Homes: 316,532 admissions, 115,000 clients at a point in time
- Residential Care: 182,000 admissions, 153,000 clients at a point in time
- Home Health: 521,151 clients at a point in time
- Hospice: 102,539 admissions, 8,000 clients at a point in time
- Waivers†: 72,653 admissions, 72,653 clients at a point in time
- Personal Care: 327,000 admissions, 327,000 clients at a point in time
- TOTAL: 1,521,875 admissions, 718,653 clients at a point in time

*Estimates may include duplicates: individuals served by multiple programs or admitted to the same program more than once. Estimates include only individuals whose services were paid for by public payers.
†Estimates for waivers are for 2004. The waivers and personal care categories reflect only those covered by Medicaid. Individuals being served by intermediate care are included in the nursing home category.

Source: Estimates by UCSF, 2006. Based on state reports from the Office of Statewide Health Planning and Development, the California Department of Social Services, and the California Department of Health Services Medi-Cal Program.

Of the approximately 1.5 million Californians served by long term care in 2005, 34 percent received care through home health agencies, 42 percent were evenly split between nursing homes and personal care services, and 12 percent lived in some form of residential care. Medicaid’s Home- and Community-Based Services (HCBS) waivers were allotted to only 5 percent.
Throughout California and the United States, the supply of institution-based beds has declined since 1990. In contrast, the supply of residential care beds rose dramatically, growing by nearly 67 percent in California and 76 percent nationally. This trend reflects the growing preference, based on financial and personal considerations, for home- and community-based care.

Note: Nursing home and intermediate care facilities provide traditional institution-based care.

*See appendix for definitions of residential and intermediate care.

From 1998 to 2004, nursing home occupancy rates in California decreased by 3.5 percent even as the size of the older population increased. This decline corresponds to the increased use of residential care and home- and community-based services.

In 2005, 56 percent of California’s residential care facilities and 76 percent of the residential beds in the state were licensed to serve adult and elderly clients. The residential care facilities licensed to serve developmentally and/or mentally disabled clients (44 percent) represent 24 percent of the residential beds in the state.

Note: “MD/DD/O” stands for mentally disabled (those with mental illness), developmentally disabled, and other (e.g., children). Facilities serving only the developmentally disabled are included in the DD category; those serving all three groups are included in the MD/DD/O category. The DD and MD/DD/O categories may include elderly individuals with developmental or mental disabilities.

Source: California Department of Social Services, Community Care Licensing Division, Sacramento, CA. Data as of December 2005.
Licensed Home Health Agencies, California vs. the U.S., 1995–2002

Number per 100,000 Population

<table>
<thead>
<tr>
<th>Year</th>
<th>United States</th>
<th>California</th>
</tr>
</thead>
<tbody>
<tr>
<td>1995</td>
<td>4.8</td>
<td>2.6</td>
</tr>
<tr>
<td>1998*</td>
<td>5.1</td>
<td>3.4</td>
</tr>
<tr>
<td>1999</td>
<td>4.6</td>
<td>2.6</td>
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<tr>
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<td>2001</td>
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<td>2.4</td>
</tr>
<tr>
<td>2002</td>
<td>3.9</td>
<td>2.5</td>
</tr>
</tbody>
</table>

*Numbers of home health agencies dropped significantly after government oversight increased in 1998.


Although the number of licensed home health agencies in California increased 11 percent compared to a 13 percent decrease nationally from 1996 to 2002, the number of agencies per 100,000 is still a third lower than the national average.
From 1998 to 2002, the number of Medicare-certified hospices per 100,000 declined by 6 percent and 21 percent in the United States and California, respectively. Increased regulation and low Medicare reimbursement rates may be contributing to the decline in California.
Medicare Beneficiaries Receiving LTC, California vs. the U.S., 1999–2002

Number per 1,000 Population, by Type of Care

<table>
<thead>
<tr>
<th>Year</th>
<th>California (CA)</th>
<th>U.S.</th>
<th>Hospice</th>
<th>Home Health</th>
<th>Nursing Homes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1999</td>
<td></td>
<td></td>
<td>1.3</td>
<td>4.4</td>
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<tr>
<td></td>
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<td>1.7</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>U.S.</td>
<td></td>
<td>1.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2000</td>
<td>1.5</td>
<td>4.1</td>
<td>5.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>CA</td>
<td>1.9</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>U.S.</td>
<td></td>
<td>1.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2001</td>
<td>1.6</td>
<td>4.2</td>
<td>5.0</td>
<td></td>
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</tr>
<tr>
<td></td>
<td>CA</td>
<td>2.1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>U.S.</td>
<td></td>
<td>2.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2002</td>
<td>1.7</td>
<td>4.5</td>
<td>5.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>CA</td>
<td>2.3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>U.S.</td>
<td></td>
<td>2.3</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>


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From 1999 to 2002, fewer Medicare beneficiaries in California received nursing home, home health, or hospice services than the national average. Medicare does not pay for residential or personal care.
Long Term Care
Number Served

By 2002, Medicaid recipients participating in the personal care program in California outstripped the national average by a factor of four, reflecting the state legislature’s large appropriation for personal care. In contrast, national participation in waiver programs was double that for California, where the appropriation was much smaller.

*Stands for home- and community-based services. Medicaid data for hospice care is not available from CMS.

Personal Care Services Comparison, Highest/Lowest States vs. the U.S. Average, 2002

Participants per 1,000 Population

- **California**: 8.4
- **Missouri**: 8.0
- **Arkansas**: 6.7
- **U.S. Average**: 3.9
- **Tennessee**: 0.6
- **Mississippi**: 0.3
- **Connecticut**: 0.3


**Long Term Care**

Number Served

In 2002, California ranked first in the nation in personal care services per 1,000 participants. Personal care includes services received through HCBS waivers, the state’s Medi-Cal benefits for personal services, and the Older Americans Act Title III program. Only 30 states, including California, offer optional personal care services programs, while others include personal care in their waiver programs.
**Estimated Cost of LTC, by Payer Source, United States, 2004**

*Institutional Care*

Total: $115.2 billion

- **Self Pay**: 27.7%
- **Medicare**: 13.9%
- **Medicaid/Other Public**: 46.9%
- **Other Private**: 11.5%

†HCBS Care

Total: $43.2 billion

- **Self Pay**: 11.3%
- **Medicare**: 38.0%
- **Medicaid/Other Public**: 36.3%
- **Other Private**: 14.4%

*Institutional care includes freestanding nursing homes (not hospital-based), rehabilitation facilities, and intermediate care facilities for the aged, physically disabled, and developmentally disabled.

†HCBS includes home health, personal care, waivers, and other long term care services at home and in the community. Figures do not include care received by those paying for residential and personal care out-of-pocket or through private insurance.

Notes: See appendix for an explanation of long term care options. There are no estimates for total expenditures for California.


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**Long Term Care Financial Picture**

Many individuals, especially those in institutions, receiving long term care have exhausted their savings, private insurance, and Medicare benefits, leaving Medicaid to fund their ongoing care. Medicaid pays the lion’s share for institutional care, while Medicaid and Medicare split the majority of costs for home- and community-based care.
Nursing Home Revenue, by Primary Payer Source, California vs. the U.S., 2004

California
- Total: $7.6 billion
- Medi-Cal: 50%
- Medicare: 26%
- Self Pay: 17%
- Other: 7%

United States
- Total: $115.2 billion
- Medicaid: 47%
- Medicare: 28%
- Self Pay: 14%
- Other: 12%

Note: “Other” includes private insurance, managed care, and other sources such as charity.


Long Term Care
Financial Picture

Many patients in California are sent to nursing homes for post-hospital care, resulting in shorter hospital stays. This practice accounts for Medicare’s higher share of revenue paid to nursing homes in California.
Medicare and Medicaid Home Health Agency Payments (in millions), California vs. the U.S., 1999–2002

In line with the decrease in the number of home health agencies, total Medicare and Medicaid payments to home health agencies fell 18 percent from 1999 to 2001. However, as the cost of home health care and the number of home health agencies increase, total payments are once again on the rise.


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Annual Medicare and Medicaid Home Health Payments per Recipient, California vs. the U.S., 1999–2002

<table>
<thead>
<tr>
<th>Year</th>
<th>CA Medicaid</th>
<th>U.S. Medicaid</th>
</tr>
</thead>
<tbody>
<tr>
<td>1999</td>
<td>$2,330</td>
<td>$4,138</td>
</tr>
<tr>
<td>U.S.</td>
<td>$3,571</td>
<td>$4,196</td>
</tr>
<tr>
<td>2000</td>
<td>$2,757</td>
<td>$3,958</td>
</tr>
<tr>
<td>CA</td>
<td>$3,135</td>
<td>$3,880</td>
</tr>
<tr>
<td>U.S.</td>
<td>$3,135</td>
<td>$3,880</td>
</tr>
<tr>
<td>2001</td>
<td>$3,714</td>
<td>$3,763</td>
</tr>
<tr>
<td>CA</td>
<td>$3,475</td>
<td>$3,425</td>
</tr>
<tr>
<td>U.S.</td>
<td>$3,475</td>
<td>$3,425</td>
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<tr>
<td>2002</td>
<td>$3,923</td>
<td>$4,234</td>
</tr>
<tr>
<td>CA</td>
<td>$3,689</td>
<td>$3,581</td>
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</tbody>
</table>


Long Term Care
Financial Picture

In 2002, Medicare’s home health agency payment per enrolled beneficiary in California was 18 percent higher than the U.S. average. From 1999 to 2002, Medicaid’s home health agency payment per participant increased 68 percent compared to a 3 percent increase nationally.
In 2002, Medicare paid $4.5 billion for hospice care compared to the $706 million paid by Medicaid. From 1990 to 2002, Medicaid expenditures for hospice services grew 35-fold compared to Medicare’s 15-fold increase.

Medicare and Medicaid Hospice Expenditures per Capita, California vs. the U.S., 2002

<table>
<thead>
<tr>
<th></th>
<th>Medicare</th>
<th>Medicaid</th>
</tr>
</thead>
<tbody>
<tr>
<td>California</td>
<td>$11.60</td>
<td>$1.80</td>
</tr>
<tr>
<td>United States</td>
<td>$15.70</td>
<td>$2.40</td>
</tr>
</tbody>
</table>

Note: Expenditures per capita = total expenditures / total population.

Medicaid Participants vs. Expenditures, by Type of Care, California vs. the U.S., 2002

<table>
<thead>
<tr>
<th></th>
<th>Home- and Community-Based Services (HCBS)</th>
<th>Institutional Care (IC)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Participants</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>California</td>
<td>2.40 (56%)</td>
<td>1.90 (44%)</td>
</tr>
<tr>
<td>United States</td>
<td>.41 (77%)</td>
<td>.13 (23%)</td>
</tr>
</tbody>
</table>

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Expenditures</strong>*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>California</td>
<td>3.4 (49%)</td>
<td>3.5 (51%)</td>
</tr>
<tr>
<td>United States</td>
<td>25.3 (31%)</td>
<td>57.7 (69%)</td>
</tr>
</tbody>
</table>

*Although room and board is included in institutional care expenditures, HCBS waivers cannot pay for these expenses, by law.

Note: See appendix for a complete explanation of HCBS programs. Institutional care includes short or long term care at freestanding nursing homes (not hospital-based), rehabilitation facilities, and intermediate care facilities for the aged, physically disabled, and developmentally disabled.


Long Term Care Financial Picture

In 2002, Medicaid paid $83.1 billion in long term care expenses for 4.3 million people in the United States compared to California’s $6.9 billion for 540,000 people. California spent a greater share on home-and community-based services than the nation, although the majority of expenditures are still used for facility-based care, which is much more expensive per participant.
Total Medicaid Expenditures, by HCBS Program, California vs. the U.S., 2002

in billions

- Home Health
- Personal Care
- HCBS Waiver

California

- Home Health: $0.58
- Personal Care: $1.80
- HCBS Waiver: $0.97

United States

- Home Health: $16.94
- Personal Care: $3.11
- HCBS Waiver: $5.38


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## Annual Expenditures per Participant for Medicaid HCBS Programs, California vs. the U.S., 1999–2002

<table>
<thead>
<tr>
<th>Year</th>
<th>CA</th>
<th>U.S.</th>
<th>1999</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Home Health</td>
<td>Personal Care</td>
<td>$5,479</td>
<td>$6,777</td>
<td>$7,712</td>
<td>$8,061</td>
</tr>
<tr>
<td></td>
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<td>$3,481</td>
<td>$7,023</td>
<td>$3,638</td>
<td>$8,815</td>
</tr>
<tr>
<td></td>
<td>HCBS Waiver</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>$13,145</td>
<td>$13,073</td>
<td>$13,073</td>
<td>$15,355</td>
</tr>
</tbody>
</table>

### Long Term Care

**Financial Picture**

In comparison to the national average, California spends 66 percent more per participant receiving home health care and less per participant for personal care and HCBS waivers. Expenses for HCBS waivers reflect participants’ greater need for skilled nursing care.


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Annual Expenditures per Capita for Medicaid HCBS Programs, California vs. the U.S., 1999–2002

<table>
<thead>
<tr>
<th>Year</th>
<th>Home Health</th>
<th>Personal Care</th>
<th>HCBS Waiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>1999</td>
<td>CA: $11.60</td>
<td>CA: $16.40</td>
<td>$35.80</td>
</tr>
<tr>
<td></td>
<td>U.S.: $8.40</td>
<td>U.S.: $14.60</td>
<td>$39.60</td>
</tr>
<tr>
<td>2000</td>
<td>CA: $11.40</td>
<td>CA: $17.10</td>
<td>$43.70</td>
</tr>
<tr>
<td></td>
<td>U.S.: $8.70</td>
<td>U.S.: $16.10</td>
<td>$44.50</td>
</tr>
<tr>
<td>2001</td>
<td>CA: $16.50</td>
<td>CA: $22.50</td>
<td>$51.90</td>
</tr>
<tr>
<td>2002</td>
<td>CA: $16.50</td>
<td>CA: $27.80</td>
<td>$51.40</td>
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</tbody>
</table>

Personal Care Expenditures* per Capita, Highest/Lowest States vs. the U.S. Average, 2002

<table>
<thead>
<tr>
<th>State</th>
<th>Expenditure</th>
</tr>
</thead>
<tbody>
<tr>
<td>New York</td>
<td>$84.23</td>
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<tr>
<td>New Mexico</td>
<td>$81.22</td>
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<tr>
<td>Maine</td>
<td>$63.62</td>
</tr>
<tr>
<td>California</td>
<td>$51.67</td>
</tr>
<tr>
<td>U.S. Average</td>
<td>$31.45</td>
</tr>
<tr>
<td>Mississippi</td>
<td>$3.41</td>
</tr>
<tr>
<td>Kentucky</td>
<td>$3.32</td>
</tr>
<tr>
<td>Connecticut</td>
<td>$2.48</td>
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</tbody>
</table>

*Sources of funding include HCBS waivers for personal care, Medi-Cal benefits for personal services, and the Older Americans Act Title III program services.


Long Term Care
Financial Picture

In 2002, California ranked 4th in the nation in expenditures per capita for personal care services. Expenditures are related to the generosity of state appropriations for select programs. New York, New Mexico, and Maine, were ranked 1st through 3rd, respectively.
Medicaid 1915 (c) Waiver* Participants and Expenditures, by Type of Waiver, California vs. the U.S., 2002

<table>
<thead>
<tr>
<th></th>
<th>Participants</th>
<th>Expenditures</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>California</td>
<td>United States</td>
</tr>
<tr>
<td>Developmentally Disabled</td>
<td>71.1%</td>
<td>73.5%</td>
</tr>
<tr>
<td>Aged and Disabled</td>
<td>39.0%</td>
<td>89.9%</td>
</tr>
<tr>
<td>HIV/AIDS†</td>
<td>1.8% / 1.5%</td>
<td>2.0%</td>
</tr>
<tr>
<td>Other‡</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*See appendix for an explanation of 1915(c) waivers.
†HIV/AIDS expenditures for both California and the United States were less than 1 percent.
‡“Other” includes children and mental health programs.


Long Term Care
Financial Picture

The cost of providing home- and community-based services is less for the aged and disabled than for those with developmental disabilities.
Definitions and Explanations

Home Health Care
Individuals who need skilled nursing and other professional services may receive home health care from trained workers who visit the home to help with care needs. To be eligible for home health services, an individual must have a doctor’s orders for either skilled nursing care or therapy services (such as physical, occupational, or speech therapy).

Home Health Care Agency
To operate as a home health agency and provide skilled nursing, an agency must be licensed by and meet the minimum standards set by the State of California.

Hospice
An approach to caring for terminally ill clients that stresses palliative care (relief of pain and uncomfortable symptoms). The goal of hospice care is to minimize pain and suffering, not to cure illness. Hospice clients are cared for by a team of professionals and volunteers who specialize in different types of care. Hospice programs provide care in a variety of settings including: the client’s home, skilled nursing facilities, special units in hospitals, or stand-alone hospice facilities.

Intermediate Care Facilities (ICF)
Serving only the developmentally disabled, ICFs provide less intensive nursing care than skilled nursing, and also provide dietary, pharmacy, personal care, and social and activity services. People entering an ICF may need occasional, but not continuous, nursing care.

Personal Care Services
Used by individuals who require assistance with the activities of everyday living such as dressing, eating, or bathing. Services do not include skilled nursing care, and providers do not need to be certified as home health caregivers.

Residential Care Facilities (RC)
Also called community care, assisted living, board and care, or independent living facilities. These facilities help people who do not need skilled nursing and are able to live independently with limited assistance.

Skilled Nursing Facilities (SNF)/Nursing Homes
Provide skilled and therapeutic nursing care by licensed nurses (RNs and LVNs/LPNs) on a continuous basis for an extended period of time.

MEDICAID’S ALTERNATIVES TO INSTITUTIONAL CARE
Medicaid is a primary payer of long term care services for people with disabilities whose need for care has become a financial burden. To receive funding, states can develop long term care programs and may apply for waivers from the traditional Medicaid program.

Medicaid Home- and Community-Based Services (HCBS)
Innovative long term care programs designed by states to help people with disabilities receive care at home or in their communities so they do not have to rely on institutional care.

HCBS Waivers
States receive waivers of certain Medicaid requirements under Section 1915 (c) of the Social Security Act to set up the programs, which vary from state to state, and are aimed at helping people with disabilities live independently. The HCBS waiver programs provide services to people with disabilities under age 65 (including children with disabilities) and the elderly whose need for long term care has become a financial burden. The HCBS also allows the state to limit services, eligibility, and spending in ways that are not allowed by the traditional Medi-Cal program.
Definitions and Explanations, cont.

California has established the following six home- and community-based service 1915 (c) waiver programs:

1) The Acquired Immune Deficiency Syndrome (AIDS) waiver — for people with HIV or AIDS (generally mid- to late-stage) who would otherwise need to be in a nursing facility or hospital. Patients must require skilled nursing or observation on an ongoing, intermittent basis and 24-hour supervision.

2) The developmentally disabled waiver — for developmentally disabled persons who are regional center (centers that provide community-based services and supports for individuals with developmental disabilities) clients and live in the community as an alternative to care provided in an intermediate care facility for the developmentally disabled.

3) The In-Home Medical Care waiver — for the severely disabled who are wheel chair and/or technology dependent and who would otherwise need to be in the hospital for a minimum of 90 days. This group includes drug-exposed infants. The program intends to move these individuals home with support and appropriate medical care.

4) The Multipurpose Senior Services Program waiver — for Medi-Cal beneficiaries who are 65 or over and are medically needy and would otherwise need to reside in a nursing facility. This program allows individuals to live independently in their homes.

5) The Nursing Facility A/B waiver — for physically disabled Medi-Cal beneficiaries, who would otherwise need to be in nursing facility care (either a skilled nursing facility or an intermediate care facility).

6) The Nursing Facility Subacute waiver — for physically disabled Medi-Cal beneficiaries who would otherwise require at least 180 days or more of nursing facility services at the adult or pediatric subacute (non-emergency) level of care.

Personal Care Services

California offers a program of personal care services for people with low incomes called In Home Supportive Services or Personal Care Services Program (IHSS/PCSP).

IHSS/PCSP is a federal-, state-, and county-funded program that pays home care services for people who are 65 years or older, disabled, or blind. Disabled children are also eligible. IHSS/PCSP does not provide skilled nursing care or therapy services. The amount of services and type of services authorized are based on the needs of each individual. Providers may be formal personal care attendants from an agency or independent providers (including family members or friends that meet certain conditions). No medical supervision is required for the IHSS/PCSP program and the workers do not need to be certified as home health caregivers.
Authors

Charlene Harrington, Ph.D., R.N., Professor, Sociology and Nursing, University of California, San Francisco

Janis O’Meara, M.P.A., Theodore Tsoukalas, Ph.D., and Terence Ng, M.A., Department of Social & Behavioral Sciences, University of California, San Francisco

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