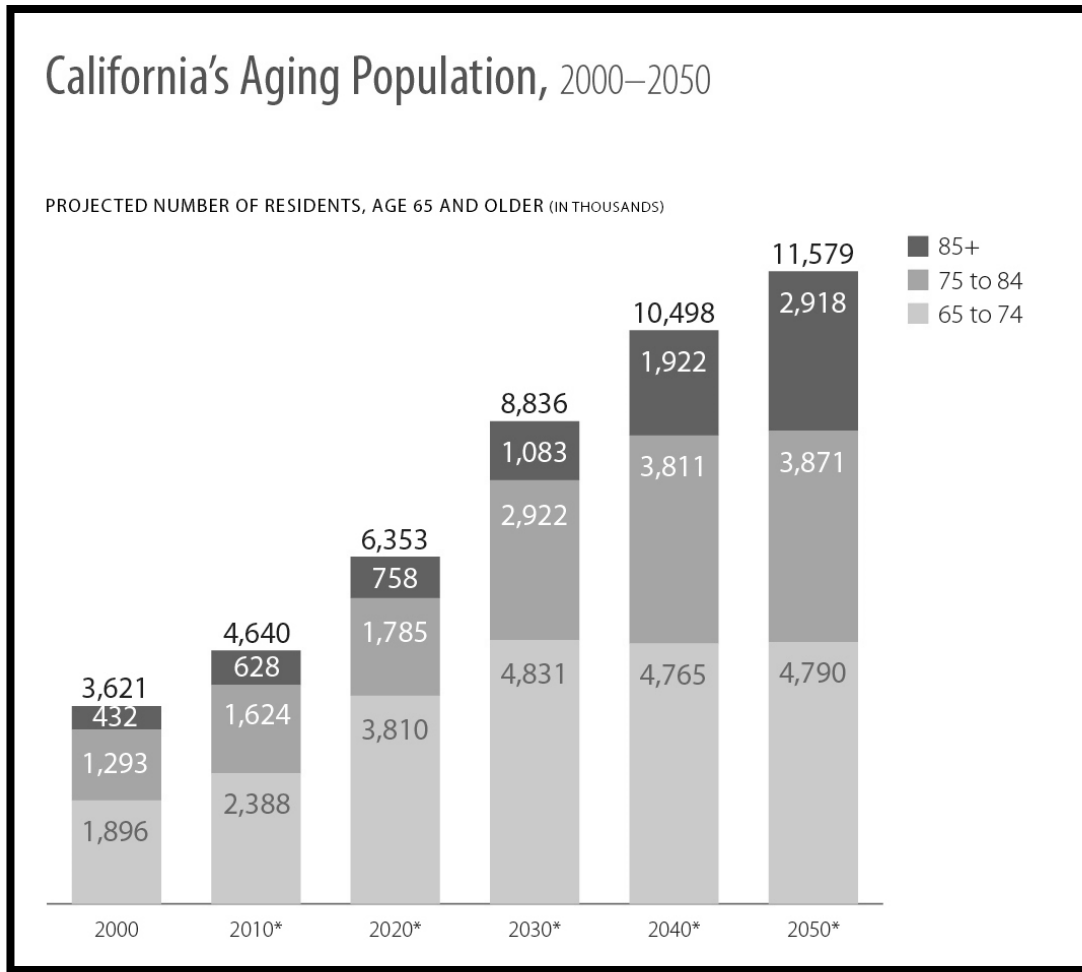
SENATE SELECT COMMITTEE ON AGING AND LONG-TERM CARE



CALIFORNIA AGING POLICY IN BRIEF

May 20th, 2014

INTRODUCTION

California is the most populous state in the nation with just over 38.3 million residents. It is anticipated that this number will increase by 27% in the next 20 years, in part due to the size and longevity of the aging population. [1] In 2011, the largest generation in history – the Baby Boomers – started turning 65, resulting in a rapid increase in the number of older Americans in the United States. In California, the number of individuals age 65 and older is projected to increase almost 100% in the next 20 years, from 4.41 million in 2010 to 8.4 million in 2030. [2] In addition to the aging population, the number of working-age adults between the ages of 18-64 with disabilities is expected to grow by approximately 20% in the next 20 years. [3] All told, the increase in both the aging population and the working-age adults with disabilities compounds the need for a comprehensive system of long-term care services.

Alzheimer's disease and other dementias are increasing in prevalence and California will see a doubling of the number of residents with these conditions by 2030, from 588,208 Californians in 2009 to more than 1.1 million in 2030. [4]

Not only is the California population aging, but it is also becoming more racially and ethnically diverse. At the time of the 2000 census, 70% of seniors were white, 13% were Latino, 10% were Asian, and 5% were African- American. By 2020, white seniors will be 50% of the aging population, with Latinos at 27%, Asians at 15%, and African-Americans at 5%.[5]

The increasing diversity of the state's senior population will have important implications for how long term care (LTC) services will need to be organized and delivered to ensure that they are culturally appropriate and available in local communities across the state.

In 2010, the projected average life expectancy was almost 81 years for women and almost 76 years for men. [6] Not only is the population aging, but it is also living longer, often with disabling conditions. In 2000, 125 million, or 45.4% of Americans had one or more chronic conditions. By 2030, it is anticipated that this number will increase by 37% to 171 million, thereby increasing the demand for Long-Term Care services. [7]

AGING IN CALIFORNIA

Successful aging in California requires a paradigm shift in attitudes towards aging; the aging process which is often portrayed in negative stereotypes that leave society fearful of aging altogether. This

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[1] "Across the States: Profiles of Long Term Care and Independent Living" AARP, 8th edition. 2009.
[2] "Population with Age and Sex Detail 2000-2050." California Department of Finance. 2007.
[3] "California Healthcare Almanac: Long Term Care Facts and Figures" California Healthcare Foundation. 2009.
[4] "Alzheimer's Disease: Facts and Figures in California" Alzheimer's Association. 2009.
[5] "California Healthcare Almanac: Long Term Care Facts and Figures" California Healthcare Foundation. 2009.
[6] "Statistical Abstract of the US; Table 102 Expectation of Life at Birth" US Census. 2010.
[7] Wu Sy, Green A "Projection of Chronic Illness Prevalence and Cost Inflation" Rand Corp. 2000.

process should be viewed as part of the continuum of life, rather than as an experience to be feared. The aging experience is unique for each person with some people aging with disabilities and functional needs, and others remaining functionally independent. Some individuals may require minimal functional support in order to maintain their independence, whereas others may require a more significant level of services and supports. Successful aging requires there be access to a range of services that enable older adults to live life to the fullest whether through employment, retirement, volunteerism, health care and wellness services, or long-term care services.

What is long-term care and how is need defined?

Long-term care refers to a broad range of services provided by paid or unpaid providers that can support people who have limitations in their ability to care for themselves due to a physical, cognitive, or chronic health condition that is expected to continue for an extended period of time. These care needs may arise from an underlying health condition as is most common among older adults, an inherited or acquired disabling condition among younger adults, and/or a condition present at birth.

LTC services can be provided in a variety of settings including one's home (e.g., home care or personal care services), in the community (e.g., adult day care), in residential settings (e.g., assisted living or board and care homes), or in institutional settings (e.g., intermediate care facilities or nursing homes). The term home-and-community-based services (HCBS) refer collectively to those services that are provided outside of institutional settings.

Generally, a person needing LTC is one who requires assistance with activities of daily living (ADLs), including bathing, dressing, eating, transferring, walking or instrumental activities of daily living (IADLs), this may include meal preparation, money management, house cleaning, medication management, transportation.

The aging population, increasing longevity, and a corresponding increase in disability prevalence will amplify the need for LTC services. Given that public dollars fund a substantial amount of paid LTC services, it is likely that this projected increase in demand will place significant fiscal pressure on federal, state, and local governments.

What is the likelihood of an individual needing long-term care services?

The likelihood of using LTC services increases with age. The likelihood of becoming disabled in two or more ADLs or of developing cognitive impairment is 68% among those age 65 and older, meaning that almost 7 out of 10 seniors will have substantial needs for supportive care.[8] Almost half of all seniors will enter a nursing home at some point in their lives, even if only for a short rehabilitative stay. And the likelihood of any use of HCBS is 71.3 % among those age 65 and older, representing over 7 out of

[8] "Beyond 50: A Report to the Nation on Independent Living and Disability" AARP. 2003.

10 seniors.[9] Among those who use any LTC services, the average person will require at least three years of care.[10]

Who provides long-term care in California?

INFORMAL CAREGIVERS

More than 6 million Californians age 18 and older provided informal care for a family member or friend with a long-term illness or disability during 2009.[11] Almost 47 % of those are between the ages of 18 and 44 years old.[12] The majority (about 57%) of informal caregivers in California are women.[13] Among adults age 18 and older, approximately 25% of African-American adults, 25 % of White adults, 20% of Hispanic adults and 17% of Asian, Hawaiian or Pacific Islander adults are informal caregivers.[14]

One in every six households in California contains at least one informal caregiver for someone age 50 or over.[15] The majority (73.2%) of informal caregivers in California provide care for a family member. Caregivers age 65 and older are more likely to be caring for a spouse or partner, while younger caregivers are more likely to be caring for a parent/parent-in-law or other relative.[16] In 2011, over 1.5 million Californians provided unpaid care to someone with Alzheimer's disease or other dementia.[17] Forty-four percent of California's informal caregivers provide care to someone with mental health or emotional problems, and 56 % provide care to someone with more than two physical health problems.[18]

Informal caregivers in California provide care for over three years on average and spend over 21 hours per week providing care.[19] Approximately one-third of caregivers live with care recipients and spend an average of 36 hours per week on caregiving responsibilities.[20]

More than half of California's informal caregivers are also employed outside the home; 52% of caregivers work full-time and another 11% work part-time, in addition to their caregiving

[9] Alecxih, L.M. "Long Term Care; What is it, Who Needs it, and Who Provides it?" Health Insurance Association of America. 1997.
[10] Alecxih, Kemper, and Komisar "Longterm Care over and Uncertain Future; What can current retirees expect?" Inquiry. 2005.
[11] Hoffman, Mendez-Luck "Stressed and Trapped: Caregivers in California" 2011.
[12] Ibid
[13] Ibid
[14] Ibid
[15] A Profile of Family Caregivers: Results of the CA Statewide Survey of Caregivers. Center for the Advanced Study of Aging Services. 2003.
[16] Mendez-Luck, Interview, August 16th 2012.
[17] CA Alzheimer's Statistics, Alzheimer's Association. 2012.
[18] A Profile of Family Caregivers: Results of the CA Statewide Survey of Caregivers. Center for the Advanced Study of Aging Services. 2003.
[19] Hoffman, Mendez-Luck "Stressed and Trapped: Caregivers in California" 2011.
[20] Ibid

responsibilities.[21] In 2009, the estimated economic value of unpaid caregiving in California was $47 billion.[22]

FORMAL CAREGIVERS

California is home to the largest direct care workforce in the country.[23] In 2009, the state's direct care workforce totaled 579,630 workers.[24] Of these direct care workers, 203,630 were employed as certified nursing assistants, home health aides or personal care aides.[25] An estimated 376,000 independent providers were employed in California in public programs that provide personal care services. Independent providers are employed directly by consumers.[26]

The majority of California's direct care workers are women (85%) and their average age is 44 years.[27] Roughly 75% of California's direct care workers are employed in home-and community-based settings and 80% of personal care aides provide care in private homes.[28]

Who pays for long-term care in California?

PUBLIC FINANCING

Medicaid, referred to as Medi-Cal in California, is the Medi-Cal assistance program jointly funded by California and the federal government to cover health services for low-income individuals including seniors, persons with disabilities, families with children, pregnant women, and selected others. The amount of the federal contribution to Medicaid relative to state dollars is termed the federal Medi-Cal assistance percentage, or FMAP. In California, the FMAP is 50%, meaning that the federal government pays half of the bill for Medi-Cal services rendered.

Medi-Cal long-term care expenditures for 2010 totaled about $11.8 billion. This represents approximately 31% of total Medi-Cal spending. California spends approximately 57% of its Medi-Cal long-term care funding on home-and community-based services, such as personal assistance with eating, bathing or dressing provided in one's home. Forty-three percent is directed toward institutional long-term care, which includes nursing homes, intermediate care facilities for people with

[21] Hoffman, Mendez-Luck "Stressed and Trapped: Caregivers in California" 2011.
[22] Feinberg, Reinhard, Houser, Choula "Valuing the Invaluable: 2011 Update: The Growing Contributions and Costs of Family Caregiving. 2011.
[23] State Facts: CA Direct Care Workforce. Public Health Institute. 2010.
[24] Data Center, Public Health Institute. 2011.
[25] Eiken, Sredl, Burwell, Gold "Medicaid Expenditures for Long Term Services and Supports" 2011.
[26] State Facts: CA Direct Care Workforce. Public Health Institute. 2010.
[27] Data Center, Public Health Institute. 2011.
[28] State Facts: CA Direct Care Workforce. Public Health Institute. 2010.

developmental disabilities that do not need continuous nursing care but require supervision and personal assistance, and mental health facility services.[29]

GOVERNMENT ORGANIZATION OF LONG-TERM CARE

FEDERAL LONG-TERM CARE SERVICES

At the federal level, LTC services are administered by the U.S. Department of Health and Human Services (HHS), specifically the Centers for Medicare and Medicaid Services (CMS) and the Administration on Aging (AoA). CMS is the federal agency responsible for the day-to-day operation of the Medicare program and the federal portion of the Medicaid program. The AoA is the federal agency responsible for advancing the interests and concerns of older adults and their caregivers, and funding supportive services through the Older Americans Act of 1965 and its subsequent amendments and reauthorizations.

CALIFORNIA LONG-TERM CARE SERVICES

In California, most LTC services are administered under the auspices of the California Health and Human Services Agency (CHHS). Many of the departments within the Agency administer a range of health care services, social services, mental health services, alcohol and other drug treatment services, income assistance, and public health services. (Appendix A presents California's Departments and Programs for Long-Term Care followed by a Program Compendium with a description of both Federal and State Programs that provide Long-Term Services and Supports).

SYSTEM CHALLENGES

California was once a leader in providing services to support the full integration of seniors and persons with disabilities into community life. Despite these initial advancements, the long-term care system has been negatively impacted by system fragmentation, lack of system-wide data or planning, capacity issues, and fiscal pressures.

CHALLENGE #1: SYSTEM FRAGMENTATION

California's LTC system provides important services that serve as alternatives to institutionalization. Yet program development and expansion has occurred in silos and without an overall system strategy, thereby leading to significant fragmentation across programs and services. Not only is there fragmentation among individual HCBS programs; there is also fragmentation among programs across

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[29] Eiken, Sredl, Burwell, Gold "Medicaid Expenditures for Long Term Services and Supports" 2011.

the health and social service continuum. The Little Hoover Commission's 2004 report "Real Lives: Real Reforms" states the following:

> *The organization of California's health and human service departments is largely the product of piecemeal evolution. As new programs have been authorized, they have been housed in various departments, often based on compromises, without periodic reorganization necessary to make the multitude of programs work in concert. As a result, the missions of these departments are incongruent, some responsibilities overlap and there are unintended gaps in authority and responsibility.*

Despite California's array of home and community based services, multiple funding streams and varied eligibility criteria have created "silos" of services, making it difficult for the consumer to move with ease from one service or program to another. As the Little Hoover Commission notes, this confusion and difficulty in accessing services results in over-utilization of unnecessary and costly care, such as emergency room services or longer-than-necessary nursing home stays. The process for transitioning clients from institutional to community care is inconsistent.

System Restructuring

Since 1996, several entities have called for a restructuring of aging and long-term care services. Numerous studies and reports were issued, led by The Little Hoover Commission (2004 and 2011) and the Assembly Committee on Aging and Long-Term Care (2004).

The following common themes were identified among these efforts:

1. The administration of California's long-term care programs reflect a piecemeal approach in program development and funding
2. The complexity of the system is the greatest barrier to improving services and the current system is impossible for consumers to access in a seamless way. In 2004, there were 38 programs housed in five different departments.

The Assembly Committee on Aging and Long-Term Care noted the one common denominator across all Health and Human Services Agency programs is the aging consumer. It is this consumer group that will, because of the aging baby boomers, dominate the political landscape in the coming years and demand that the right services are provided at the right time in the most appropriate setting. Reliance upon coordination to achieve these changes will not be sufficient. Fundamental structural change is essential and will require substantial political will to bring about. This means the Administration, the Legislature and a broad array of stakeholders must all be engaged and find common ground. Structural change should ensure that a high quality continuum of care is provided to older Californian's and establish a focal point for all of California's aging population. The various restructuring reports present the following components as critical to system restructuring:

1) Access to care coordination/case management services

2) Delivering services based on functional need rather than age
3) Maximizing administrative efficiency through data collection and tracking systems
4) Access to federal waivers that allow for innovation and flexibility
5) Enhancing private pay options for individuals who can afford to finance services but who currently lack access to such services.

Past proposals have sought to reorganize the state structure and consolidate programs serving seniors and persons with disabilities into a single department structure. The intent was to allow for more coordinated programming, data collection, and policy development. The proposals were not adopted for a number of reasons, including the fiscal costs as well as questions as to whether consolidating administrative structures at the state level would translate into improved care and coordination for the consumer at the local level.

CHALLENGE #2: FISCAL DISINCENTIVES LIMIT ACCESS TO HCBS

Not all home and community-based (HCBS) programs are available on a statewide basis, nor are they funded at a level to adequately meet total demand in the communities that are served. Consumers often remain on long waiting lists before receiving services.

Deficiencies in HCBS system capacity can be attributed to the federal Medicaid institutional bias. Medicaid law provides an entitlement to institutional care and therefore requires states to cover the costs of nursing home care for Medicaid beneficiaries. However, there is no similar guarantee for HCBS since these services are optional and permissible but not mandatory. As a result, California's HCBS include a patchwork of Medi-Cal optional State Plan services and Medi-Cal waiver programs that provide community-based alternatives for individuals who would otherwise require care in a nursing facility or hospital. The waiver programs serve a limited number of individuals and often have long waiting lists. A number of HCBS programs operate outside of the Medi-Cal program using either state General Fund or other federal funds, but these programs often lack the capacity and funding to meet the community's need.

CHALLENGE #3: LACK OF DATA AND SYSTEM-WIDE PLANNING

In addition to its fragmented funding and service delivery system, California lacks comprehensive data to evaluate program effectiveness and identify needs and gaps in service delivery. No single department or agency uniformly collects and reports long-term care data. Without comprehensive, consistently collected and reported data, it is difficult to evaluate the cost-effectiveness of HCBS and to determine how to best meet the needs of the population. The aging of the state's population and growth of the working-age population of adults with disabilities makes it all the more important for California to adequately prepare for an increased demand in LTC services. Data and planning are essential components to preparation. In 1999, the U.S. Supreme Court ruled in the case of Olmstead v. L.C., finding that the unnecessary institutionalization of people with disabilities is a violation of the Americans with Disabilities Act of 1990. In 2003, the state released the California Olmstead Plan, which

included a number of recommendations on how to build upon the state's HCBS to meet the intent of the U.S. Supreme Court's *Olmstead* decision.. However, the California Olmstead Plan did not set timeframes or specific deliverable action items. And while some individual departments have developed strategic plans, there is no system-wide, long-range strategic plan that would set priorities and maximize the use of limited resources.

CHALLENGE #4: FISCAL PRESSURE AND BUDGET REDUCTIONS

As the demographics have changed and people have sought to remain in their homes and communities, HCBS caseload has increased. This fact, coupled with a difficult fiscal climate, and the Medicaid institutional bias, has made most HCBS programs the target of significant budget reductions. These reductions continue to threaten the progress the state has made in providing community-based alternatives to institutionalization. Over the past several years, a number of critical long-term care programs have either been eliminated and/or experienced major reductions in funding. Programs eliminated include: Linkages; Adult Day Health Care; Alzheimer's Resource Day Care Centers and Low-income Senior Rental Assistance and Homeowners Tax Credit. Programs that experienced major funding reductions include: In-Home Support Services (IHSS); SSI/SSP; Community Care Licensing; Adult Protective Services; Caregiver Resource Centers; Adult Day Care; Caregiver Services; Respite Services; Medi-Cal; and Nutrition.

EMERGING INITIATIVES

FEDERAL INITIATIVES

The Patient Protection and Affordable Care Act (ACA) laid the groundwork for wide-ranging continuum of care reform by establishing a framework for coordination and integrated services across providers and settings. The ACA presents opportunities to improve LTC, concurrently creating and strengthening linkages between Medi-Cal care and supportive services.

Critical reforms spelled out in the ACA include the establishment of the Center for Medicare and Medicaid Innovation and the Federal Coordinated Health Care Office (informally known as the "Office of the Duals") both within the Centers for Medicare and Medicaid Services (CMS). These ACA provisions create the space to test ideas that can lead to improvements in coordination across the multiple payment and delivery systems, including mechanisms to break through regulatory barriers and integrate funding sources, a major contributor to the fragmentation in the current system. Efforts to transform payment and delivery system models of care and pilots to bundle payment for acute and post-acute care services also offer the promise to expand beyond a narrow Medi-Cal scope of practice toward connecting older adults in need of LTC to supportive services in their community. The ACA also provides funding to expand the base of direct care workers needed to deliver LTC services, for which

the demand is projected to increase by 34% over the next decade.[30] The ACA will also provide funding for Aging and Disability Resource Centers (ADRCs) to help people with disabilities more easily navigate the LTC system. Finally, the ACA will offer states incentives to expand Medicaid-funded home-and community-based services.

CALIFORNIA COORDINATED CARE INITIATIVE (CCI)

The Coordinated Care Initiative (CCI) changes the way the Medi-Cal care and long-term services and supports (LTSS) work together to serve low-income older adults and people with disabilities. The main components of the CCI include:

1. Provisions for California's Dual Eligible Integration Demonstration referred to as CAL MediConnect
2. Mandatory enrollment of dual eligible individuals, covered under both Medicare and Medi-Cal, into Medi-Cal managed care.
3. Integration of Medi-Cal funded LTSS into managed care.

The CCI will be implemented in eight counties starting with San Mateo, which began on April 1, 2014. Counties include: Alameda, Los Angeles, Orange, Riverside, San Bernardino, San Diego, San Mateo, and Santa Clara). In total, the CCI impacts 456,000 dual eligible consumers through CAL MediConnect and approximately 600,000 individuals enrolled in mandatory Medi-Cal managed care with managed LTSS.

RURAL MANAGED CARE EXPANSION

Prior to 2013, Medi-Cal managed care operated in 30 of California's 58 counties, with the 28 rural counties maintaining a fee-for-service infrastructure. The 2012-13 budget expanded Medi-Cal managed care into the 28 rural counties. Seniors and people with disabilities who are on Medi-Cal and reside in these rural managed care counties are not required to enroll in managed care, but may choose to do so on a voluntary basis. The state will likely require this population to enroll in Medi-Cal managed care sometime in the future.

THE IDEAL SYSTEM[31]

In the ideal person-centered system, individuals would have access to a readily-available network of affordable options that provides high- quality care and supports, allowing these individuals to live well and safely in their homes and communities. The needs, values, and preferences of these individuals and their family caregivers would be regularly honored by the providers, organizations and delivery

[30] "Occupational Projections for Direct Care Workers 2006-2016" Public Health Institute. 2008.
[31] "Achieving Person Centered Care: the Five Pillars of System Transformation" Policy Brief 7. Scan Foundation. 2012.

systems that serve them. Health care providers would be knowledgeable about long-term services and supports, connecting people with available options to help them live functional lives.

An array of community service providers would exist to help individuals navigate options for care and provide the tangible services. Community service providers, acting as the eyes and ears for health care professionals, would link accurate and timely information back to health care providers to enable individuals to use all services in the most appropriate and cost-effective manner.

All providers would focus on making and maintaining key integrated connections among the main service platforms – primary, acute, behavioral, and rehabilitative care with LTC – and place the individual in the center of the care experience. Overall, the right providers would engage with individuals at the right time and right place, involving family as appropriate and creating a rational plan of care that puts the person's preferences, values, and desires first.

Envisioning the Ideal System

The Select Committee on Aging and Long Term Care in its initial research and hearings will explore the current deficiencies in California's Aging and Long Term Care system and what the Ideal System should look like.

THE FIVE KEY QUESTIONS TO BE ANSWERED ARE:

1) What is the ideal system?
2) What values underlie the ideal system?
3) What are the necessary components of an ideal system?
4) What are the major challenges and barriers?
5) How do we achieve the ideal system?