

# A Shattered System: Reforming Long-Term Care in California.

## **Envisioning and Implementing an IDEAL Long-Term Care System in California**



**A Report by the Senate Select Committee on Aging and Long Term Care**  
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January 5, 2015

Dear Colleagues:

The Members of the Senate Select Committee on Aging and Long-Term Care respectfully seek your partnership in an extraordinary and notable opportunity to advance a new vision for serving the needs of older adults and persons with disabilities in California.

Today, older adults, their families, caregivers, and state and local government suffer from a costly and fragmented "non" system of long-term care services and supports. Why? California has not made development of an efficient and effective long term care system a priority.

Based on a year-long effort to research and conduct public hearings on aging and long term care, the Select Committee has articulated in this report, the need for a person-centered system that provides individualized care in accordance with needs, is easy to navigate, facilitates transitions from levels of care, and overall maximizes the ability of people to age and receive care in the their homes and communities rather than in institutions.

To date, California has not responded to the increase in the aging population or the rich cultural and ethnic diversity of the state. We are plagued by a lack of capacity -- especially in rural areas -- in services, supports, and workforce across a range of disciplines.

The challenge before us is two-fold. First, over 5.1 million persons age 65 and over will call California home by 2015. Due to aging Baby Boomers and migration patterns, that number will grow to 8.4 million by 2030 – or nearly one fifth of the population. Second; as the Baby Boom population ages, it will become more ethnically diverse, driving demand for culturally competent service delivery.

Reliance upon our existing patchwork of programs and services to serve our growing aging and disabled population will result in unnecessary expenditures, inequitable access, and irrelevant services. Furthermore, under the existing fragmented structure there is no leader to oversee or coordinate the entire range of services, and no mechanism for accountability or improvement.

Over the past 20 years, multiple hearings, studies, and reports have raised these concerns in an attempt to capture the attention of policy makers, healthcare providers, and

economists. Consistently governmental leaders have been advised to replace the existing patchwork of competing administrative authorities, programs, services, and personnel to create a coordinated system that operates with respect for the consumer and is grounded in evidence-based policies and practices. In addition to better serving the needs of its residents, such a system would also eliminate inefficient and ineffective state expenditures.

Today, programs to assist dependent adults are spread across at least six major state departments. There is no statewide leader to champion a statewide vision, develop a statewide plan, or implement a statewide strategy. There are no bench marks to measure outcomes or evaluate effectiveness; nor are there clear lines of accountability. Best practices are under-valued and not shared across agencies, departments and programs. The enclosed report is intended to correct these deficiencies and lay out a blue print for achieving an integrated system of care for our aging and disabled population.

We can no longer ignore the intersection of demographics, disability, diversity and longevity. We know what needs to be done, why it needs to be done, and how it needs to be done. Our report, ***"A Shattered System: Reforming Long-Term Care in California: Envisioning and Implementing an IDEAL Long-Term Care System in California,"*** makes over 30 legislative recommendations for immediate action and provides a strategy to achieve improved coordination and a high functioning comprehensive system. We implore you to review the report and the recommendations proposed. We hope you will agree to sponsor, co-sponsor, or support implementing measures in the 2015 Legislative Session. If you are interested in sponsoring one of these bills, please contact Suzanne Reed, CoS, for Senator Carol Liu at 651-4025 or email her at [Suzanne.reed@sen.ca.gov](mailto:Suzanne.reed@sen.ca.gov).

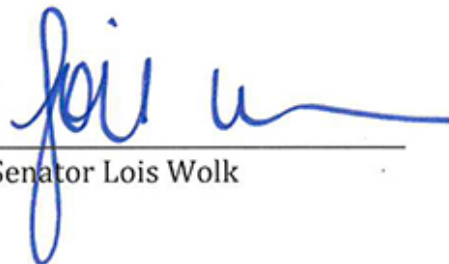
We know that elders and persons with disabilities prefer to remain as independent as possible, in their own homes with support from home and community-based services. How much longer can policy makers ignore this singular responsibility before the cost of inaction and an impending crisis impact equal priorities such as education, public safety, or the environment?

The Select Committee believes we can create an ideal long-term care system, one that enables older adults and persons with disabilities to live with dignity, choice and independence, while shielding society from the costly effects of inaction. The need for long-term care is great and will only become greater. Improvements require vision, a strategy and informed leadership. Let us work together to create a legacy for a population that has been ignored too long.

Respectfully,



Senator Carol Liu



Senator Lois Wolk



Senator Jim Beall

# **A Shattered System: Reforming Long-Term Care in California**

**Envisioning and Implementing an  
IDEAL Long-Term Care System in California**

**FINAL REPORT**

**DECEMBER 2014**

**Senate Select Committee on Aging and Long-Term Care  
Senator Carol Liu, Chair**

**Committee Members: Senators Jim Beall, Tom Berryhill, Ed Hernandez,  
Richard Roth, Lois Wolk**

**Patty Berg, Principal Consultant**

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## EXECUTIVE SUMMARY

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*Our most cruel failure in how we treat [the aged] is the failure to recognize that they have priorities beyond merely being safe and living longer; that the chance to shape one's story is essential to sustaining meaning in life; that we have the opportunity to refashion our institutions, our culture, and our conversations in ways that transform the possibilities for the last chapters in everyone's lives.*

Atul Gawande M.D., *Being Mortal* (2014)

Dr. Atul Gawande, general and endocrine surgeon at Brigham and Women's Hospital and professor in the Department of Health Policy and Management at the Harvard School of Public Health and the Department of Surgery at Harvard Medical School, believes that a person's age or physical or cognitive impairment should not portend a sedentary life of isolation in or out of an institution. The Select Committee on Aging and Long-Term Care agrees.

People prefer to remain at home and avoid institutionalization to every extent possible. This desire is reinforced by the U.S. Supreme Court's 1999 ruling in *Olmstead vs. L.C.*,<sup>1</sup> which established the right of individuals with disabilities -- of any age -- to receive services in the most integrated and least restrictive setting possible.

Ultimately, California needs to value and protect all populations with the wise use of our resources, which in the case of older adults and people with disabilities means accessing long-term care (LTC) services in their own community. As a society, we need to ensure that the financing and delivery of services meets the needs of individuals who want to live to their fullest capacity without being treated like patients or as burdens to society.

Numerous reports, hearings, and legislative proposals have sought to transform California's patchwork of LTC programs, services, and policies into a functioning, efficient, and sustainable system. However, these efforts have not produced a cohesive program due to fragmented jurisdictions, resource constraints, bureaucratic overlap, and diffused accountability. Absent substantial reform of the state's aging and long-term care system, the costs of over-institutionalization, lost productivity, and degraded quality of life will far exceed the cost to implement integrated, evidence-based solutions.

The state's economic recovery now offers an opportunity to address an unanswered call to action to build an LTC infrastructure that meets the needs of older adults and persons with disabilities. The data are clear that a crisis is potentially eminent: older adults currently comprise 12.5% of California's population,<sup>2</sup> with projections showing that 24% of the population will be over age 65 in 2030.<sup>3</sup> Current

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<sup>1</sup> *Olmstead v. L.C.*, 527 U.S. 581 (1999).

<sup>2</sup> United States Census Bureau. "Selected Population Profile in United States, 2013 American Community Survey 1-Year Estimates." 2013. Accessed at: [http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS\\_13\\_1YR\\_S0201&prodType=table](http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_13_1YR_S0201&prodType=table).

<sup>3</sup> State of California, Department of Finance. *Report P-3: State and County Population Projections by Race/Ethnicity, Detailed Age, and Gender, 2010-2060*. January 2013.

demand for home and community-based LTC services and supports is outpacing capacity, causing consumers to depend upon inefficient and poorly coordinated services that only partially meet their needs.

State Senator Carol Liu, Chair of the Senate Select Committee on Aging and Long-Term Care, led a comprehensive effort in 2014 to identify the structural, policy, and administrative changes necessary to realize an "ideal" long-term care delivery system and develop recommendations and a strategy to achieve that vision. The 30 recommendations presented in this report (see pages 16-32) address challenges in the current system identified by the Select Committee and comprise a strategy for creating a sustainable, efficient continuum of care for this and future generations of aging and disabled adults. Recommendations fall into eight issue areas as summarized below.

**State Leadership:** California's fragmented organizational structure leaves the state with a leadership vacuum that complicates any effort to undertake comprehensive LTC reform. Rather than develop a vision and overall strategic plan for LTC system transformation, the state has adopted a piecemeal and reactive approach to change. **Recommendation:** Reform the state-level administrative structure by naming an LTC leader (a "Czar") to organize system-wide planning activities and establishing a Department of Community Living within the Health and Human Services Agency. The Department, in collaboration with other agencies and departments with relevant responsibilities, should develop a state Long-Term Care Plan (LTC Plan) to guide the priorities and implementation of aging and long-term care investments, policies, and programs statewide.

**Legislative Leadership:** Despite various informational and legislative hearings on specific issues, the California State Legislature struggles to advance comprehensive solutions to critical LTC issues. Diffused leadership is due in part to numerous policy issues being deliberated in a budget context, rather than a policy context, as well as various policy committees (Aging, Health, Human Services, Housing, Transportation) sharing jurisdiction over the issues affecting the LTC system.

**Recommendation:** The Senate should establish a standing Committee on Long-Term Care, and the Assembly should expand the jurisdiction of its existing Committee on Aging and Long-Term Care. Each Committee should exercise jurisdiction over the range of LTC programs serving older adults and people with disabilities, including oversight of the Department of Community Living (upon its establishment) and the Coordinated Care Initiative.

**System Integration:** California's Coordinated Care Initiative (CCI) reflects a new approach to delivering services whereby Medi-Cal managed care entities maintain responsibility for delivering both health and LTC services. **Recommendation:** The Legislature should enhance its oversight of the CCI in order to identify and address issues on a real-time basis. The state should establish a more formalized arrangement for stakeholder oversight and feedback through a CCI Implementation Council. The Council would be responsible for reviewing issues and examining access to services. Finally, the state should establish care coordination guidelines and strong accountability standards in statute.

**Fragmentation/Lack of Integrated Data:** The most critical issue facing California's LTC system is the fragmentation of programs at the state, regional, and local levels. This fragmentation results in a lack of meaningful data to inform policy-making and lack of access to coordinated services for consumers. Universal assessment offers a uniform process through which to connect data elements and to

evaluate the consumer's needs in a consistent manner. **Recommendation:** The state should commit to universal assessment as a statewide initiative that can be utilized not only for service delivery purposes, but also to support quality measurements by gathering information that can be used to construct quality measures for LTC. At the state level, universal assessment data can help program planners understand the needs of the population; support allocation of resources at the person, program, and state levels in a standardized way; and evaluate quality. Further, the state needs to develop a data infrastructure with the capacity to collect and integrate data from across programs so that the same information can be used to drive program and policy decisions.

**Infrastructure:** Inadequate funding, lack of information, lack of services and providers, insufficient transportation and housing, and geographic isolation have impacted consumer access to services statewide. California's home and community-based services HCBS infrastructure has struggled to keep up with demand for services, due in part to significant budget cuts during the recession.

**Recommendation:** The California Health and Human Services Agency should establish safety net and access standards for home and community-based services to determine the basic statewide service mix, particularly for each of the 44 rural counties. This will establish a baseline for identifying gaps and investing resources appropriately. Additionally, the state should invest in an LTC information portal by re-establishing the Cal Care Net website as a valuable tool for individuals and families to access information and understand their LTC options.

**Workforce:** The implementation of the Affordable Care Act (ACA) and expansion of Medi-Cal, together with the increase in California's diverse aging population, will increase demand for culturally competent LTC professionals. **Recommendation:** As part of its LTC Plan, the state should outline a strategy that analyzes workforce needs for the LTC population, outlines training and education requirements for the LTC workforce, and aligns resources accordingly. Additionally, the state should consider the needs of family caregivers, the backbone of the LTC workforce. To these ends, the state should expand nurse delegation of health maintenance tasks and implement legislation to help identify the caregiving needs for individuals discharged from hospitals to home settings. Finally, the state should institute full practice authority for nurse practitioners in order to expand access to primary care services across the state.

**Funding:** The impact of years of devastating budget cuts and program eliminations across California's LTC system cannot be underestimated. The state's economic recovery offers the opportunity to strategically reinvest in the system and support services for older adults, persons with disabilities, and their families, who currently rely on a patchwork of services to avoid institutionalization. Continuing to place a low priority on reinvestment in California's home and community-based infrastructure will only force greater reliance on institutionalization and higher costs for the state. **Recommendation:** The Legislature and Administration need to prioritize investment to build a sustainable infrastructure that will meet the needs of California's growing aging and disabled population. Without this support the consumers, families, and, ultimately, society as a whole will bear the brunt of a dysfunctional system.

**Federal Issues:** Federal government policies and initiatives have a direct impact on the state's LTC system. **Recommendation:** The Legislature and Administration need to engage with recommended policies on a number of federal issues, including finding a solution to the nation's LTC financing crisis, reauthorizing the Older Americans Act, and raising the eligibility threshold for Medi-Cal LTC.

## INTRODUCTION

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California's aging population is growing rapidly and also becoming more racially and culturally diverse. The population of individuals over age 65 will increase by 27% for young retirees (aged 65-74) and 10% for mature retirees (aged 75-84) by the year 2017.<sup>4</sup> In addition, the number of adults with disabilities in California is expected to grow by approximately 20% in the next 20 years (see Appendix Tabs 2 and 8, Demographics).

Alzheimer's disease and other dementias are on the rise and projected to affect an estimated 1.1 million Californians by 2030.

Aging disproportionately impacts women; though women comprise roughly half of the population overall, by age 65 the proportion of women to men increases to almost six out of ten, and in the 85+ group, women outnumber men nearly two to one.<sup>5</sup> Moreover, because women's life expectancy is longer than men's, women are more likely to outlive their resources and slip into poverty.

These demographic realities constitute a social and moral imperative to plan thoughtfully for the aging of our population. At stake is the ability to age with dignity, choice, and independence for two key groups: older adults and people with disabilities who depend upon a system of long-term care (LTC) to remain as independent as possible.

Unfortunately, California is not prepared to meet this demographic imperative.

A person-centered, culturally responsive LTC system would enable individuals to receive services in the most affordable, home-like settings available. California was once a leader in providing services to support the full integration of older adults and persons with disabilities into community life. Over the past several years, however, the LTC system has been adversely impacted by system fragmentation, a lack of usable data, poor planning, unaddressed workforce issues, capacity issues, and of course devastating budget cuts during the recession.

### ***What Is Long-Term Care?***

*Long-term care (LTC), also referred to as Long-Term Services and Supports (LTSS), refers to a broad range of services delivered 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. LTC services can be provided in a variety of settings including at home, in the community, in residential care settings, or in institutional settings. The term home and community-based services (HCBS) refers collectively to those services that are provided outside an institutional setting. Generally, LTC includes assistance with activities of daily living (ADLs) such as bathing, dressing, eating, or transferring, and instrumental activities of daily living (IADLs) such as meal preparation, money management, house cleaning, medication management, and transportation (see Appendix Tab 2).*

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<sup>4</sup> State of California, Department of Finance. 2013-14 Governor's Budget, Summary 2013, page 125. Accessed January 10, 2013. <http://www.ebudget.ca.gov/pdf/BudgetSummary/FullBudgetSummary.pdf>.

<sup>5</sup> California Assembly, Committee on Aging and Long-Term Care. "Informational Hearing: Faces of Aging: Aging as a Women's Issue." March 2014.

## A Call to Action

Numerous entities have sought to address the needs of California's older population and LTC system, including the Little Hoover Commission (1996 and 2011), the Senate Health and Human Services Committee's Subcommittee on Aging and LTC (SB 910, Statutes of 1999), and the Assembly Committee on Aging and Long-Term Care (2004, 2011). Despite these efforts, little progress has been made, and California faces many of the same problems that were identified almost 20 years ago, but they are bigger now.

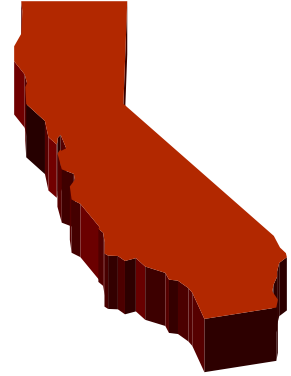
Today, a renewed effort is underway to address the challenges confronting California's LTC system. In February 2014, the California Senate established the Senate Select Committee on Aging and Long-Term Care to articulate a vision for an effective and efficient long-term care system and develop a comprehensive strategy for achieving that vision (see Appendix Tab 1). The committee convened academic, government, labor leaders, and experts in the fields of aging and disability at two public hearings (see Appendix Tabs 4, 5, and 6); held numerous informal stakeholder sessions; and conducted interviews with key informants (see Appendix Tab 7) to document the contemporary challenges and opportunities California faces. This report summarizes findings, identifies the priorities, and recommends specific actions to achieve the ideal vision.

### **The Ideal Person-Centered LTC System**

- *Individuals would have access to a readily available network of affordable options that provides high-quality care and supports, allowing individuals to live well in their homes and communities.*
- *The needs, values, and preferences of individuals and their caregivers would be regularly honored by the system and its providers.*
- *Knowledgeable health care providers would connect individuals with available options.*
- *An array of home and community-based providers would assist in navigating services and linking timely information to health care providers.*
- *Providers would recognize the value of health promotion activities (consisting of exercise, nutritional guidance, and regular preventive services, and including access to mental health services) as vital components of the system of care.*
- *All providers would maintain 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.*
- *Collaboration and coordination at the regional and local level would facilitate access to services and supports in the community.*

## How California Compares

The second *State Scorecard on Long-Term Services and Supports* (Scorecard), produced by the AARP Public Policy Institute, examines state performance relative to a high-performing long-term services and supports (LTSS or LTC) system, which should be affordable, high-quality, and well-coordinated in order to support older adults and people with disabilities in the settings of their choice, with an emphasis on living independently in the community.<sup>6</sup> California ranks higher than most states on overall system performance, largely due to the success of the In-Home Supportive Services program. However, California has several areas in need of substantial improvement, particularly with respect to providing caregiver support and decreasing the burden of care transitions. The Scorecard has initiated a national conversation about system performance, areas of opportunity, and the need for an organized system of care that better coordinates services for LTC consumers. This Select Committee report provides a blueprint to respond to the system issues identified by the 2014 LTSS Scorecard.



## EXAMINING CALIFORNIA'S SHORTFALLS: FIVE CROSSCUTTING ISSUES

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Five key overarching issues pervade the LTC system, impacting the ability to address system shortcomings and plan for the needs of consumers and their caregivers (see Appendix Tab 5).

### 1. Legislative and State Leadership:

- **Legislative Leadership:** The Legislature struggles to advance comprehensive solutions to critical LTC issues. Diffused leadership is due in part to numerous policy issues being deliberated in a budget context rather than a policy context, as well as various policy committees (Aging, Health, Human Services, Housing, Transportation) sharing jurisdiction for the LTC system issues. While the Assembly has a standing policy Committee on Aging and Long-Term Care, its policy jurisdiction is limited to only the programs serving older Californians through the Department of Aging. The Senate Select Committee on Aging and Long-Term Care plays a role in raising policy issues but is not a "standing" committee and thus has no jurisdiction over the LTC system or authority to move legislation.
- **State Leadership:** California's fragmented organizational structure leaves the state with a leadership vacuum that complicates any effort to undertake comprehensive LTC reform. Among state agencies there is no distinct leader who is responsible for establishing and implementing a vision for comprehensive LTC service delivery. Instead,

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<sup>6</sup> S.C. Reinhard, E. Kassner, A. Houser, K. Ujvari, R. Mollica, and L. Hendrickson. for AARP, The Commonwealth Fund, and The SCAN Foundation. *Raising Expectations, 2014: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers*. June 2014. Accessed at: [http://www.longtermscorecard.org/~media/Microsite/Files/2014/Reinhard\\_LTSS\\_Scorecard\\_web\\_619v2.pdf](http://www.longtermscorecard.org/~media/Microsite/Files/2014/Reinhard_LTSS_Scorecard_web_619v2.pdf).

the current structure offers a piecemeal approach to system change; there is no overarching plan for creating an integrated system.

2. **Fragmentation and Lack of Integrated Data:** The most critical issue facing California's LTC system is the fragmentation of programs at the state, regional, and local levels, creating major systems issues, as follows:
  - Consumers struggle to identify and access necessary home and community-based services, resulting in increased likelihood of hospitalization and institutional placements.
  - The state administrative structure lacks coordinated oversight and accountability across programs to monitor and improve system quality.
  - Programs lack consistent and meaningful data across the system. Without data to inform policy direction, the Legislature is left with little capacity to identify issues and trends and, therefore, can respond only to the loudest and most persistent advocates, regardless of system needs.
3. **Crumbling Infrastructure and Lack of Capacity:** Insufficient funding, lack of information, lack of services and providers, insufficient transportation and housing, and geographic isolation have impacted consumer access to services statewide. This is particularly true in California's rural counties, where remote location and the challenges of recruiting, training, and retaining qualified LTC providers thwart service delivery.
4. **Workforce Shortage:** Implementation of the Affordable Care Act (ACA) and expansion of Medi-Cal, together with the growth of California's diverse aging population, will increase demand for LTC professionals. Employment projections estimate that California will need to add 500,000 health care workers within five years -- by 2020 -- as described below (see Appendix Tab 8).
  - Geriatric Competencies: California faces a severe shortage of geriatric-trained professionals and paraprofessionals. In 2011 the state had only 739 geriatricians -- or one for every 5,968 older adults. In addition, less than one percent of all Registered Nurses are certified in gerontology.
  - Cultural Competencies: California entered the era of a "majority-minority" population in 2010, and in 2014 Latinos became the largest population, comprising 38% of California's cultural profile. As the state's population increasingly becomes culturally and ethnically diverse, efficiency and cost benefits demand that the workforce reflect these demographics. Diversifying the state's health care and direct care workforce supports culturally competent care that will reduce disparities in access and improve outcomes.
  - Direct Care Workers: California's direct care workers -- including certified nurse assistants, home health aides, and personal care aides -- are responsible for an estimated 70-80% of the paid hands-on care for older adults and persons with disabilities. Direct care workers have the closest contact with consumers and can most directly influence the quality of the care experience. However, direct care workers are among the lowest paid of all U.S. workers, and approximately 45% live in households earning below 200% of the federal poverty level. Experts note that by increasing

training opportunities, this sector can be stabilized and professionalized to ensure it meets the growing demands of California's older population.

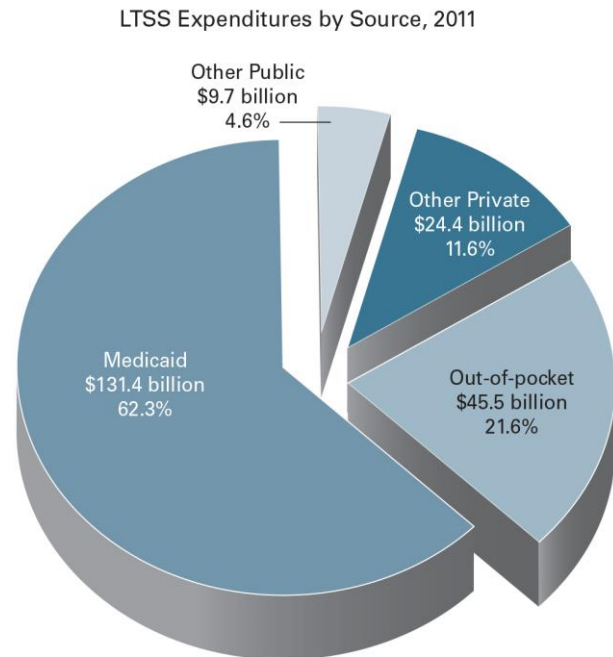
5. **Funding Challenges:** Years of budget cuts at both the state and federal levels have eroded the LTC service system. These reductions continue to threaten the progress the state has made in providing community-based alternatives to institutionalization. Over the past several years, a number of critical LTC programs have been eliminated or endured significant reductions in funding. As a result of the system's chronic underfunding, individuals are left with fewer options for services in the community and an increased likelihood of institutionalization.

## TEN CRITICAL POLICY AREAS

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Policies impacting older adults and people with disabilities are interrelated, making it inadvisable for policymakers to view specific topics and concerns in a vacuum. Each of the following policy areas has a critical impact on the service delivery system serving older adults and people with disabilities.

1. **Health Care:** Ensuring access to culturally competent health care is essential for reducing mortality and disability and improving quality of life for older adults and people with disabilities. Access to health care and rehabilitation services impacts disease risk, disability, and mortality rates. Ultimately, the standard for health care relates not only to an individual's physical health, but also to functional wellbeing, mental health, and overall wellness.
2. **Long-Term Care/Long-Term Services and Supports:** Long-term care (LTC), also referred to as long-term services and supports (LTSS), refers to a broad range of non-medical services provided by paid or unpaid providers in institutional, home, and community-based settings. The aging population, increasing longevity, and a corresponding increase in disability prevalence will amplify the need for culturally competent LTC.
3. **Long-Term Care Financing:** California and the nation face an unprecedented crisis related to the financing of long-term care. Traditionally, LTC responsibility has fallen on unpaid family caregivers, but when paid services are needed, most Californians are not financially prepared. Individuals and their families initially pay for LTC by utilizing their own resources, even though most people do not have the financial wherewithal to cover these costs on an ongoing basis. Most individuals have not set aside the size and scope of savings necessary for ongoing support to meet functional needs. When LTC needs

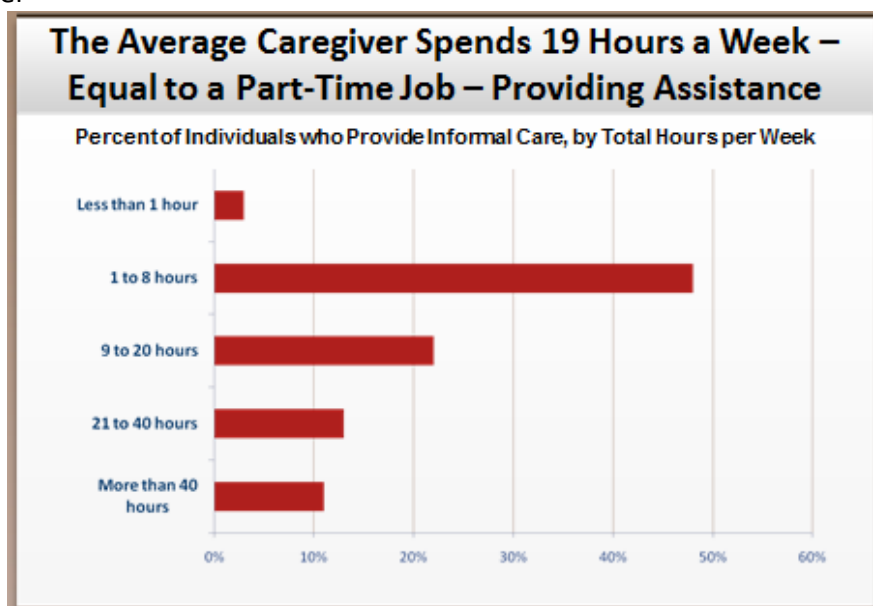


Source: National Health Policy Forum, based on data from 2011 National Health Expenditure Accounts

arise, they often must decrease their standard of living, leave LTC needs unmet, or both.<sup>7 8</sup> Individuals are often forced to spend down to the poverty level in order to qualify for Medi-Cal LTC coverage.

LTC expenditures from all sources combined are projected to increase from \$211 billion in 2010 to \$346 billion in 2040.<sup>9</sup> LTC is funded through a mix of sources, with individuals and their families relying first on personal resources and then on multiple, uncoordinated public sources, all with unique requirements, most notably Medicaid (Medi-Cal). Medicaid is the dominant source of payment for long-term care (62% of LTC expenditures nationally), followed by out-of-pocket payments by individuals and families (22% of LTC expenditures nationally). Other private payers, including LTC insurance, play a minor role (12% of LTC expenditures nationally). Without viable alternatives for financing LTC, individuals and their families will continue to be burdened by the high cost of LTC, while the state and federal government budgets will face ongoing pressure with increased Medicaid (Medi-Cal) expenditures.

4. **Family Caregivers:** Unpaid family caregivers are the forgotten workforce of the LTC system. Nearly six million unpaid caregivers – typically family and friends – provide LTC in California, valued at \$47 billion annually.<sup>10</sup> While a number of programs and policies exist to support family caregivers, most family caregivers are unaware of or unable to access these services. Many have had to sacrifice their jobs and family income to provide care for a loved one. The needs of the family caregivers must be addressed in order to support the population's LTC workforce needs; this is particularly true for women, as they disproportionately bear the burden of caregiving.



<sup>7</sup> The Commission on Long-Term Care. "Report to the Congress." September 2013. Accessed at: <http://ltccommission.lmp01.lucidus.net/wp-content/uploads/2013/12/Commission-on-Long-Term-Care-Final-Report-9-26-13.pdf>.

<sup>8</sup> The SCAN Foundation. "Shaping Affordable Pathways for Aging with Dignity." March 2013. Accessed at: <http://thescanfoundation.org/shaping-affordable-pathways-aging-dignity-current-issues-and-potential-solutions-addressing-america>.

<sup>9</sup> The SCAN Foundation. "Who Pays for LTC in the U.S.?" January 2013. Accessed at: [http://www.thescanfoundation.org/sites/thescanfoundation.org/files/who\\_pays\\_for\\_ltc\\_us\\_jan\\_2013\\_fs.pdf](http://www.thescanfoundation.org/sites/thescanfoundation.org/files/who_pays_for_ltc_us_jan_2013_fs.pdf).

<sup>10</sup> UCLA Center for Health Policy Research, "Stressed and Strapped: Caregivers in California" September 2011. Accessed at: [http://thescanfoundation.org/sites/thescanfoundation.org/files/UCLA\\_CHIS\\_Caregivers\\_2.pdf](http://thescanfoundation.org/sites/thescanfoundation.org/files/UCLA_CHIS_Caregivers_2.pdf)

5. **Transitional Care:** Transitional care refers to both transitions from hospital to home as well as transitions from long-term institutional settings (nursing homes) to home.
- Hospital to Home Transitions: Inadequate planning and lack of access to services and supports in the home setting often lead to repeat hospitalizations and a greater likelihood of long-term institutional placement. Improving an individual's transition from the hospital to the home is vital to creating a more person-centered system of care and reducing rates of hospital readmission.
  - Nursing Home to Home Transitions: Individuals overwhelmingly prefer to receive services in the community as opposed to an institution. Individuals residing in institutional facilities have the right to receive services in the least restrictive environment, which often requires transitioning individuals from long-stay institutional placements back to the community. These transitions are a resource-intensive process, requiring care coordination services to facilitate the transition and assist the individual in accessing services and supports in the community. These efforts frequently are hampered by limited availability of affordable and accessible housing and transportation.
6. **Wellness and Mental Health:** In spite of perceptions to the contrary, aging is not uniformly associated with significant disease and disability. Health promotion activities consisting of exercise, nutritional guidance, and regular preventive services – including access to mental health services and social and intellectual engagement – are vital to maintaining health and containing costs. It is clear that preventing heart disease, diabetes, and obesity is possible and pays long-term dividends. However, most prevention programs (such as the California Active Aging Project, which promotes healthy and active aging) require an upfront and sustained investment to produce long-term savings. To date, however, the state has not committed funding for expanded access to such programs.
7. **Alzheimer's Disease and Related Dementia:** Within the next 20 years, the number of Californians living with Alzheimer's disease is projected to nearly double, growing to over 1.1 million. This demographic reality brings with it significant implications for the health care and LTC service delivery system, including a substantial increase in caregiving and service needs.
8. **Housing:** A significant percentage of older adults and people with disabilities often confront serious housing-related problems, including lack of affordable and disabled-accessible housing. Older adults and people with disabilities are likely to face high housing costs or live in physically unsupportive environments that are disconnected from services. There is an inadequate supply of affordable supportive housing options for people who need more services and support than can be provided in their homes or apartments or who wish to transition out of an institution into the community.
9. **Transportation and Mobility:** Access to transportation is important for an individual to partake of community life and access services and supports. Yet many older adults and people with disabilities struggle with unmet transportation and mobility needs. Those who do not drive or have someone to drive them need low-cost mobility options to access health services, socialize,

volunteer, or participate in physical or intellectual activities. While public transportation is an option in the more urban areas of the state, the transit routes often do not pass close enough to housing and services. In rural areas, public transportation is scarce or nonexistent.

10. **Employment and Retirement:** Employment can be essential for older adults and people with disabilities to remain integrated and engaged in society. Furthermore, many older Californians are remaining in the workforce after 65, either by choice or necessity. Both state and employer policies should enable our aging and disabled population to remain gainfully employed as long as they need or want to work.

## EMERGING TRENDS

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While California today faces many of the same issues it confronted nearly 20 years ago, several trends have emerged in recent years that impact the LTC landscape, adding a new sense of urgency to reform.

### Federal Initiatives

**The Affordable Care Act:** The Patient Protection and Affordable Care Act (ACA) laid the groundwork for wide-ranging reform by establishing a framework for coordinated and integrated services across providers and settings. The ACA presents opportunities to improve LTC, concurrently creating and strengthening linkages between medical 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 and mitigate fragmentation in the current system. Efforts to transform payment and delivery system models 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. Additionally, the ACA provides funding for a number of initiatives, including expanding the base of direct care workers and expanding access to Aging and Disability Resource Centers (ADRCs) to help people with disabilities more easily navigate the LTC system. Finally, the ACA offers states incentives to expand Medicaid-funded home and community-based services.

**The Administration on Community Living (ACL):** The Administration on Community Living was established on April 18, 2012, bringing together the Administration on Aging, the Office on Disability, and the Administration on Developmental Disabilities. This reorganization is designed to reduce fragmentation across community living service and support needs of both the aging and disability populations, enhance access to quality health care and long-term services and supports for all individuals, and promote consistency in community living policy across other areas of the federal government. This federal reorganization presents a model and an opportunity for California to better coordinate service delivery through administrative reorganization.

## State Initiatives

Reflecting a nationwide trend, California is moving away from a fee-for-service delivery system that contracts directly with providers and toward a managed approach that delivers both health care and LTC.

**The Coordinated Care Initiative:** California's Coordinated Care Initiative (CCI) reflects a new approach to delivering services whereby Medi-Cal managed care entities maintain responsibility for delivering both health and LTC services. This new model of care requires the medical community, supportive service providers, and health plans to change how they do business and develop the skills to deliver person-centered, coordinated services. Through the CCI, the state contracts with Medi-Cal managed care plans to administer an array of services across the medical and LTC systems, with an incentive to avoid institutional care whenever possible. The CCI is being implemented in seven counties, starting with San Mateo, which began on April 1, 2014; other counties include Los Angeles, Orange, Riverside, San Bernardino, San Diego, and Santa Clara. The main components of the CCI include:

1. Cal MediConnect: Dual eligible individuals—those that are eligible for both Medicare and Medi-Cal—who reside in CCI counties can voluntarily enroll in the Cal MediConnect program, which provides coordinated medical, behavioral health, long-term institutional, and home and community-based services through a managed care delivery system. This program is voluntary for eligible individuals.
2. Managed Medi-Cal LTSS: All Medi-Cal beneficiaries residing in CCI counties are required to join a Medi-Cal managed care health plan for LTSS (LTC) benefits, including institutional services (e.g., skilled nursing facilities) and home and community-based services, including In-Home Supportive Services (IHSS), the Multipurpose Senior Services Program (MSSP), and the Community-Based Adult Services (CBAS) program.
3. Mandatory enrollment of dual eligible individuals into Medi-Cal managed care: Dual eligible individuals in CCI counties are required to enroll in a Medi-Cal managed care plan.
4. Universal assessment for LTC: A universal assessment (UA) tool will streamline the assessment process, with the goal of better connecting consumers to services in the community. The California Departments of Health Care Services (DHCS), Social Services, and Aging are working with stakeholders to develop the UA tool and process, and it is anticipated that this will be piloted in two CCI counties in 2017.

Several issues have emerged through the course of CCI implementation, including education and outreach, complexity of care transitions, enrollment, and LTSS (LTC) integration/care coordination. The state continues to work with stakeholders to respond to issues as they arise.

**Rural Managed Care:** Prior to 2013, Medi-Cal managed care operated in 30 of California's 58 counties, while 28 rural counties maintained a fee-for-service infrastructure. The 2012-13 budget expanded Medi-Cal managed care into these 28 rural counties. The Community-Based Adult Services (CBAS) program is the only home and community-based LTC program operating as a Medi-Cal managed care LTC benefit in rural counties, whereas the CCI counties include CBAS, MSSP, IHSS, and nursing home care as a Medi-Cal managed care LTC benefit. The Administration has expressed its intention to

eventually transition these same LTC benefits to Medi-Cal managed care entities statewide, but current statute only permits it in the seven CCI counties.

## RECOMMENDATIONS: CREATING THE IDEAL LONG-TERM CARE SYSTEM

Based on research, feedback received through legislative hearings, and numerous discussions with consumers, stakeholders, and experts in the field, the Committee has developed the following recommendations as priority actions for California's policymakers to build the ideal LTC system. While these recommendations alone will not solve all of the system issues, they would represent a significant step forward to developing the infrastructure for a more person-centered, integrated system of care.

### STATE LEADERSHIP: RECOMMENDATIONS

#### Address HCBS Fragmentation: Create California Department of Community Living

System fragmentation is one of the most significant issues impacting both service delivery and state leadership capacity (see Appendix Tabs 3 and 9). ***The state administrative structure should be reorganized to establish a Department of Community Living (DCL) under California's Health and Human Services Agency, replicating the federal government's Administration for Community Living and reflecting the national trend toward service delivery in the least restrictive, most integrated community-based setting.*** This department would consolidate all home and community-based LTC programs, including those serving older adults, persons with disabilities, and persons with developmental and intellectual disabilities. These programs, now scattered across six departments,

Periodic Table of California's Long-Term Care Programs and Services for Older Adults and Adults with Disabilities

Program or Service Name/Acronym/Abbr. Primary Funding Source (if known)																			OAC
AD program																			
CAPP	CBAS CMS																		
PHCA**	CRCs	IMPACT DHCS																	
WISE WOMAN CDC	AIDS waiver CMS	IHO waiver CMS																	
C4P CDC	HCBS-DD waiver CMS	DD-CNC waiver CMS	StatePlan Services CMS	Veteran Homes	RCs	SCCRC	ILCs	SFMNP USDA	CACFP USDA	SD	LTD	WAP DOE	SSDIP SSA	BBP*	SCSEP ACL	FCSP ACL			
AIDS waiver CMS	ALW CMS	NF-AH waiver CMS	MMC CMS	Home Loans	HCBS-DD waiver CMS	CPIS	MEP	Spec. Services	PEL	SOP	DCRA	PC&S	CAP GF	FGP*	SNAP- Ed	HICAP Fed. grant			
HHA Cert.	CCT CMS	IHSS+ CMS	CCI CMS	Pension	DCs	SSS	TTW	SAP	CalJOBS	Senior Savers	HCVP/ AHP HUD	BMFEA	CVCB	Linkages*	Support. Services	Legal Asst. ACL			
NH- L&C	CPLTC	PACE CMS	PDDP	Claims	OPS	CSLB- Contractor Info	TBI	BEP	EU	EDSTP FTA	PRA HUD	ECE	CCLM/ CCRC	RPOS*	MIPPA ACL/CMS	LTCOP ACL			
CBAS L&C	CLSB waiver CMS	SCAN CMS	GHPP	A&A	FGSCP	CFB	AT	LEAP	AJCC	NFT** FTA	MHSA HP MHSA	EOLCP	APS	SCP*	NFT* FTA	EAPP ACL			

\*These programs no longer receive any General Fund support, but remain authorized in statute as part of the Older Californians Act. The local Area Agencies on Aging determine whether and to what extent to fund the programs.

\*\*These programs no longer receive any General Fund support.

would be housed in the newly created DCL. The new department would retain state-level budget authority for home and community-based programs and serve as the single point of state-level contact, providing leadership to local jurisdictions in replicating best practices and overseeing statewide LTC service delivery. The DCL would coordinate efforts across respective local and regional delivery systems, developing statewide standards while maintaining local flexibility to meet needs specific to the population. In establishing the DCL, the state would reach out to stakeholder groups representing older adults and people with disabilities to ensure that the new department effectively meets the population needs while promoting coordinated service delivery and access to home and community-based services.

## **Appoint an LTC “Czar”**

Most of the issues confronting the state administrative structure relate to multiple entities overseeing multiple programs without a clear leader overseeing or coordinating efforts. ***An individual within the Health and Human Services Agency, with extensive background and knowledge of LTC, should be appointed as LTC “Czar” to lead departments and programs across the agency and spearhead establishing the new Department of Community Living. The Czar would lead in developing and implementing a statewide LTC strategic plan, create a statewide vision for LTC service delivery and infrastructure, oversee and coordinate LTC integration efforts across health and LTC services, address issues across departments and sister agencies, manage quality improvement efforts, and maintain accountability for outcomes.*** While the Department of Community Living would focus on issues pertaining to home and community-based LTC, the LTC Czar would focus on issues across the broader LTC continuum. This would include institutional and home and community-based services as well as coordination across sister agencies (Business, Transportation, and Housing) that impact broader service delivery systems. In addition, the LTC Czar would serve as liaison to the federal Administration on Community Living and be responsible for ensuring that the state maximizes the use of available federal funding opportunities.

The LTC Czar would have the authority to consolidate data and programs from multiple departments, initiate state-level program coordination, and facilitate coordination of services at the local level. The Czar would work across rural and urban communities to identify infrastructure capacity issues and lead in the development of access standards for HCBS.

Through a Senate-confirmed appointment, the LTC Czar would be responsible for reporting on an annual basis to the legislative and fiscal policy committees on the current status of LTC in California, the level of state spending across LTC programs, success in leveraging and drawing down federal funds, progress in improving the continuum of services, and the next steps that must be taken to continue to enhance the coordination and delivery of services.

## **Develop a State LTC Plan**

States that have demonstrated successful LTC system transformation have typically based their reforms on a long-term vision and a strategic plan for LTC. California is currently embarking on a number of new initiatives, including the Coordinated Care Initiative and the expansion of managed care and Medicaid Waiver consolidation, without an overall vision and plan for the future of LTC

service delivery. Other states, including Minnesota (the top-ranked state on the 2014 LTSS Scorecard), have shown that developing and implementing an LTC vision and strategic plan is a critical component of LTC system transformation.

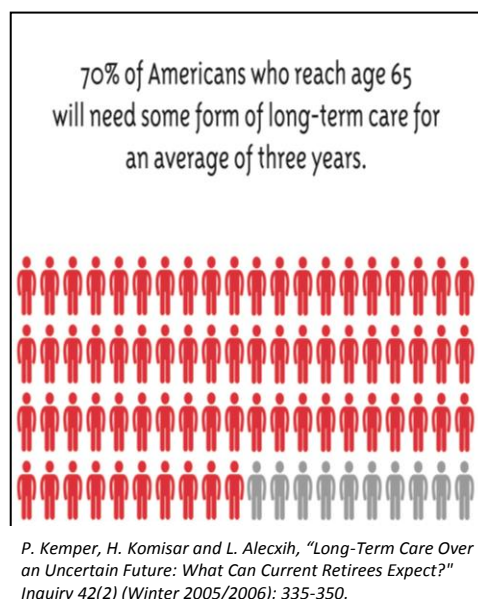
***The Health and Human Services Agency should be charged with developing a system-wide LTC Plan with clear benchmarks and timelines that reflects a vision and serves as a blueprint for setting priorities and maximizing the use of limited resources.*** The LTC Plan should incorporate information gathered from previous studies and other states that have implemented similar plans for LTC system transformation, while engaging a range of stakeholders representing the LTC population, including but not limited to the California Commission on Aging, the State Independent Living Council, consumers, caregivers (paid and unpaid), service providers, and advocates. The plan should develop guiding principles, including those developed through other states' LTC plans, focused on ensuring that all services are consumer-centered, delivered in the most integrated setting possible, and in accordance with individuals' needs, values, and preferences, while promoting a culture that regards older adults and people with disabilities as community assets. Specifically, the plan should address the following:

- **Managed Care Expansion:** The CCI changes the health care and LTC landscape for older adults and people with disabilities in seven of California's counties. However, most of the LTC system still remains in the fee-for-service system. Thus, California is operating two vastly different LTC systems—one in which the seven CCI counties operate through a managed care infrastructure and the other that continues to operate on a fee-for-service basis. The LTC Plan should include a strategy for how the state plans to expand system integration, including budgeting practices that incentivize access to HCBS regardless of where one resides.
- **Family Caregivers:** The plan should articulate a support structure for California's unpaid family caregivers, taking into account current programs, services, and deficiencies to build a sustainable system. In addition, employment-related policies should be reconsidered to better support unpaid caregivers in the workforce. Such policies could include increasing the length of protected leave and expanding the California Family Rights Act to include care for grandparents, siblings, and in-laws to match the Family Paid Leave benefit.
- **Person-Centered Planning:** The plan should develop principles and standards for person-centered service planning in an integrated system of care to ensure that individuals and families have the opportunity to engage in service planning across the health and LTC continuum in a manner that reflect their needs, desires, and preferences.
- **Comprehensive LTC Workforce Strategy:** California has no comprehensive strategy to address the health and LTC workforce needs across the continuum of care, making it difficult to project demand and identify strategies to meet increased needs.
  - The LTC Plan should include a strategy that analyzes workforce needs, outlines training and education requirements for the LTC workforce,<sup>11</sup> and aligns resources accordingly.

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<sup>11</sup> The following disciplines would be included in the LTC workforce: primary care physicians (including osteopathic physicians), geriatricians, registered nurses, nurse practitioners, pharmacists, direct care workers, and social workers.

- The plan should examine the career pathway as defined by the Workforce Investment Board's Health Workforce Development Council; assess community awareness of long-term care career opportunities; examine adequacy of training; and analyze the impact on recruitment, retention, and workforce quality (see Appendix Tab 8).
  - The plan should address the mental health workforce needs for older adults who are currently unable to access services due to limited availability and lack of culturally/linguistically trained professionals.
- **Reducing Nursing Home Placements:** The plan should include directives for ensuring that the integrated system screens individuals prior to placement in a nursing home in order to avoid unnecessary nursing home admissions. The state should consider how Pre-Admission Screening (PAS) can be integrated into a managed care context and look to other states for best practices -- including Oregon's system that screens Medicaid consumers prior to admission to nursing homes -- that are used to determine if an individual is appropriate for community-based care as opposed to institutional placement. The LTC Plan should specify the minimum levels of functional limitations that individuals must have in order for nursing facilities to receive Medi-Cal reimbursement.
  - **Planning for LTC Needs:** The LTC Plan should include a strategy for developing a public/private partnership to raise Californians' awareness of, and engagement in, LTC planning. Most people do not understand that 70 percent of individuals who live beyond the age of 65 will need some form of LTC, on average for three years. Further, most people do not engage in conversations with family about their future desires and preferences for care, services, and supports. This denial about aging and future LTC needs can be a serious detriment to individuals who are not prepared to address and finance their LTC needs. Advance planning is particularly important for disabled adults who will outlive their parents or familial caregivers. The state should address this issue in partnership with advocates, private foundations, and other entities in order to engage the broader population on LTC issues.
  - **Elder Justice/Elder Abuse Prevention:** The LTC Plan should include guidance on enhancing decision-making capacity for impaired individuals, as well as options for supported and surrogate decision-making that are appropriate for various levels of impairment and risk. Additionally, the plan should specify measures to evaluate consumers' capacity to provide or oversee self-care and consent or refuse services. Finally, the plan should address how to



educate LTC consumers and providers, lawyers, courts, and the public about “safe” advance directives,<sup>12</sup> limited conservatorships, and affordable access to conservators.

- **End-of-Life Planning:** The plan should address end-of-life planning issues, emphasizing consumers’ rights to exercise their own decisions about options to die with dignity. Further, the plan should recognize improvements to end-of-life care, while promoting access to quality health and long-term care services, including palliative care, for consumers and their families.
- **Building on Regional Innovations:** The LTC Plan should consider how to expand local and state-level innovations designed to address the challenges related to LTC service delivery. Such efforts include San Francisco’s LTC Strategic Planning and deinstitutionalization efforts; San Diego’s approach to system collaboration and integration; initiatives to develop affordable, accessible housing as a partnership between counties and affordable housing developers (San Mateo Health Plan); local “Villages” modeled on the national Village movement, which focuses on helping older adults remain at home and participate in a mutual aid collaborative; and the community-based health home model<sup>13</sup> that integrates adult day services with Medicare primary care physicians and Medi-Cal managed care plans to provide vulnerable, at-risk elderly beneficiaries with “high touch” care coordination, health and wellness education, supportive services for the participant and caregivers, and referrals to community-based resources (California Association of Adult Day Services).

## LEGISLATIVE OVERSIGHT: RECOMMENDATIONS

### Create Standing Committees on Long-Term Care

***The Senate should establish a standing Committee on Long-Term Care, and the Assembly should expand the jurisdiction of its existing Committee on Aging and Long Term Care.*** Each committee should exercise jurisdiction over the range of LTC programs serving older adults and people with disabilities, including oversight of the Department of Community Living (upon its establishment) and the Coordinated Care Initiative. The committees should monitor implementation of the LTC Plan and system transformation activities, including policy integration of LTC into managed care. Pending creation of a standing committee, the Senate should continue the Select Committee on Aging and LTC.

### Provide Enhanced CCI Oversight

Legislative oversight is critical to the implementation of the CCI and in identifying and addressing issues on a real-time basis. At present, oversight for the CCI spans fiscal committees as well as health and

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<sup>12</sup> Safe advance directives reduce the likelihood that legal authority can be abused. For example, powers of attorney for finances should clearly specify the scope of authority being granted (e.g. to pay bills, as opposed to broad authority that can be used to sign a deed or make large gifts).

<sup>13</sup> The health home model is similar to the medical home model. For more information, see: <http://www.ncsl.org/research/health/the-medical-home-model-of-care.aspx>.

human services policy committees. The relevant policy and fiscal committees of the Legislature should do the following:

- ***Consult with the state agencies and departments to ascertain needs and capacity issues, particularly in relation to the CCI and managed care expansion.*** In addition, the Legislature should research other states to consider the kinds of staffing and content expertise necessary to monitor and oversee managed care plans responsible for delivering the full range of Medi-Cal services.
- ***Engage with members and staff from budget, health, and human services committees in both houses to identify the key issues related to CCI implementation.***
- ***Engage budget staff regarding oversight of managed care rates, particularly regarding rate structure and fiscal incentives for home and community-based services.*** Pending those discussions, recommendations may follow regarding:
  - The need to dedicate one policy committee in each house with oversight responsibilities to review implementation, evaluate the success of the CCI, and identify issues and areas for improvement on an ongoing basis;
  - The need for legislative oversight to examine the rate process and adequacy; and
  - The need for oversight on how home and community-based services, as well as mental health services, are being accessed under the CCI.

## **Engage in 1115 Waiver, 1915(c) Waiver Consolidation, and New HCBS Regulations**

The Legislature needs to enhance engagement in Medi-Cal redesign opportunities via the process to renew the 1115 Medi-Cal waiver, the proposed consolidation of the 1915(c) waivers, and the HCBS State Transition Plan. These initiatives provide the potential to redesign California's medical and LTC system and can bring about significant change without a request for new General Fund dollars.

Under the federal Medicaid program (Medi-Cal in California), states are permitted to provide Medicaid-funded services outside of the established rules and requirements of the Medicaid program through "waivers." In general, a Medicaid waiver grants authority to modify certain requirements to allow for the exploration of new approaches in service delivery.

- **1115 Waiver:** 1115 waivers are intended to demonstrate and evaluate a policy or an approach to providing coverage for medical or LTC services on a widespread basis, offering the broadest form of waiver authority for states to pursue. California's existing Section 1115 "Bridge to Reform" Waiver is in its fourth year of a five-year demonstration that focused on preparing the state for ACA implementation. The Department of Health Care Services (DHCS) is beginning the waiver's renewal process with the goal of reforming the Medi-Cal payment and delivery systems.<sup>14</sup> The 1115 waiver contains provisions impacting how LTC is delivered in California, including managed LTSS (LTC) and other matters.

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<sup>14</sup> California Department of Health Care Services. "Initial Concepts for 2015 Waiver." July 2014. Accessed at: [http://www.dhcs.ca.gov/provgovpart/Documents/Waiver%20Renewal/Initial\\_Concepts\\_for\\_2015\\_Waiver-July\\_2014.pdf](http://www.dhcs.ca.gov/provgovpart/Documents/Waiver%20Renewal/Initial_Concepts_for_2015_Waiver-July_2014.pdf)

- **1915(c) Waiver Consolidation Proposal:** The 1915(c) waivers use Medicaid dollars to fund services aimed at keeping Medicaid beneficiaries out of institutional settings. Services are delivered in a home or community setting and must cost the same or less than the care given to an institutional peer group. California's eight 1915(c) waivers provide critical services including in-home nursing care, case management, respite support, home modification, and others that enable individuals to remain at home and avoid institutionalization. However, the current waiver system is siloed and often unable to meet need, as is evidenced by the long wait lists for the MSSP and Nursing Facility waivers.

At present, DHCS is designing a home and community-based 1915(c) waiver that integrates many of the state's current 1915(c) waivers to consolidate the Multi-Purpose Senior Services Program, Assisted Living Waiver, Nursing Facility/Acute Hospital Waiver, HIV/AIDS Waiver, In-Home Operations Waiver, and San Francisco's Community Living Support Benefit (SF-CLSB), with the following specifications:<sup>15</sup>

- Target population: Individuals who are at a nursing facility-level of care in the community and are at risk of nursing facility admission, as well as beneficiaries residing in nursing facilities or institutional settings who can safely return to the community.
- Services: Includes services in the six waivers that are not duplicative by definition, scope, duration, frequency, and mode of benefits provided through the Medi-Cal State Plan and managed care health plans.
- Case Management: An Organized Health Care Delivery System (OHCDS) will provide case management. For individuals residing in a Residential Care Facility for the Elderly or Adult Residential Facility, the facility will be responsible for providing daily services while contracting with the OHCDS for coordinating waiver services.

This new model has the potential to achieve greater flexibility in service delivery, but it is critical that the consolidated waiver address the multiple shortcomings of the current system.

- **New HCBS Regulations:** The federal government finalized rules that will have a significant impact on how home and community-based services (HCBS) are provided through California's Medi-Cal program.<sup>16</sup> Among other requirements, the new rules expect all Medicaid (Medi-Cal) home and community-based settings to support full access to the community, including implementing a person-centered planning process and developing opportunities for individuals to seek employment, engage in community life, control personal resources, and receive services in the community. Further, residential service providers must offer privacy in units (including lockable doors, choice of roommates, and freedom to furnish and decorate units) and options for individuals to control their own schedules (including access to food at any time and the freedom to have visitors at any time). DHCS is preparing its transition plan to meet these new federal requirements. Individual Waiver Transition Plans are required to be submitted by the state to CMS by March 16, 2015. All impacted waivers must be in full compliance with the new Federal rules by March 17, 2019.

<sup>15</sup> California Department of Health Care Services. "Consolidated Waiver Summary." August 2014.

<sup>16</sup> For more information on these rules, see: <https://www.federalregister.gov/articles/2014/01/16/2014-00487/medicaid-program-state-plan-home-and-community-based-services-5-year-period-for-waivers-provider>.

***Additional legislative engagement on the issue above would help ensure that the waiver renewal processes and new federal HCBS regulations meet the states' intended goals and outcomes. Further, the Legislature should work with the Department of Health Care Services to outline in the 1115 Waiver a Pre-Admission Screening policy for nursing home placement, expand access to Medi-Cal-funded assisted living, and create a new Medi-Cal-reimbursable procedure code to cover discharge planning.***

## **SYSTEM INTEGRATION (COORDINATED CARE INITIATIVE): RECOMMENDATIONS**

### **Establish a CCI Implementation Council**

CCI oversight could be strengthened through a focused dialogue with external stakeholders. To this end, ***the state should develop a more formalized arrangement for stakeholder oversight and feedback in California's Coordinated Care Initiative, through a CCI Implementation Council.*** As a best practice, California could look to Massachusetts' dual eligible demonstration's Implementation Council, comprised of external stakeholders who are charged with reviewing issues, examining access to services, and partnering with the state on outreach and education.<sup>17</sup>

### **Establish Care Coordination Standards for CCI**

Care coordination is a critical component of the CCI. Through effective care coordination, older adults and their families receive information about their options to connect with home and community-based services and avoid unnecessary institutionalization. However, state law lacks specified standards and guidelines for required care coordination services as part of the CCI.

***The state should establish care coordination guidelines and strong accountability standards in statute. Specifically, care coordination should be a required service authorized in statute as part of the CCI, along with the other required LTC/LTSS services authorized in statute*** (health care and LTC, including Community-Based Adult Services, the Multipurpose Senior Services Program, In-Home Supportive Services, and nursing facility care). ***Further, the Legislature should specify an individual's rights to access care coordination, identify which entity(s) is/are responsible for ensuring this access, and establish an appeals process for recourse in the event care coordination service is not delivered.***

### **Establish Guidelines for Dementia Care Management**

There are an estimated 57,000 people with dementia in California's Coordinated Care Initiative. Due to their complex needs and high costs for management, these individuals should be categorized as "high-risk" and assigned to a dementia care manager in the plan. Furthermore, ***the state should require guidelines for dementia care management in the CCI plans. The guidelines should draw on the experience of the "Dementia Cal MediConnect" three-year grant awarded to the California Department of Aging by the federal Administration on Community Living.*** The grant was

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<sup>17</sup> For more information on Massachusetts' Implementation Council, see: <http://www.mass.gov/eohhs/docs/eohhs/healthcare-reform/state-fed-comm/implementation-council-faq.pdf>.

implemented as part of an effort to build a dementia-capable, integrated system of care for people with Alzheimer's disease and related dementias who are enrolled in Cal MediConnect. The findings of the grant should be developed as guidelines for CCI plans and providers serving individuals with dementia.

## **FRAGMENTATION/LACK OF INTEGRATED DATA: RECOMMENDATIONS**

### **Commit to Universal Assessment**

Traditionally, multiple medical and LTC providers assess individuals using different assessment instruments, with information used for different purposes. This serves only to create "assessment fatigue" for the consumer. A person-centered system of care can only exist if the entities that administer and oversee the system know the full scope of need and preferences for all eligible individuals and organize services based on information gathered in a single assessment designed to meet all health and functional needs.

A uniform process with connected data elements (often referred to as "universal assessment") can be used to evaluate the consumer's needs in a consistent manner and create a care plan tailored to each person's strengths, needs, and service/support preferences in an equitable manner. This information can be utilized not only for service delivery purposes, but also to support quality measurement by gathering information that can be used to construct LTC quality measures. At the state level, universal assessment data can help program planners understand the needs of the population; support allocation of resources at the person, program, and state levels in a standardized way; and evaluate quality.

**Current Efforts:** The California Departments of Health Care Services, Social Services, and Aging are working with stakeholders to develop and pilot a universal assessment tool for individuals needing LTC. However, the current universal assessment effort is based on statutory intent language only. There is no assurance that the state will proceed with implementing it beyond the pilot currently operating in two counties.

***The state should change the pilot status of universal assessment to a permanent state initiative. Further, the state should remove the sunset and commit the universal assessment to statute in all seven Coordinated Care Initiative (CCI) counties, with eventual expansion statewide. This process should also include caregiver-specific questions to enable providers to better support the needs of unpaid caregivers. Finally, the state should ensure the necessary resources to facilitate the project's statewide expansion.***

### **Develop Integrated Information Technology Infrastructure**

The universal assessment provides an instrument with which to collect a unified set of data across specific programs serving consumers in the community. However, it is not currently possible for data to be assimilated from across health and LTC programs in order to understand service use, identify gaps in delivery, track outcomes, and improve efficiency in service delivery. The state needs to

develop a data infrastructure with the capacity to collect and integrate data from across programs in a format that enables use of the information to drive program and policy decisions.

***The California Health and Human Services Agency should develop an information technology infrastructure that enables the collection and integration of data; facilitates consumer care coordination; and provides information to state, regional, and local levels that enables effective management of programs and services.*** The Health and Human Services Agency's California Community Choices program commissioned a project in 2011 to analyze the options for such an endeavor.<sup>18</sup> In addition, the federal Centers for Medicare and Medicaid Services (CMS) recently funded an "eLTSS initiative" with pilots in nine states (not California) to develop standards and processes for IT interoperability focused on home and community-based services.<sup>19</sup> Drawing upon the findings of the California IT study and CMS "eLTSS" initiative, California should examine options for developing an IT infrastructure that incorporates current data systems.

## INFRASTRUCTURE: RECOMMENDATIONS

### Establish HCBS Access Standards

California's HCBS infrastructure has struggled to keep up with demand for services – due in part to years of failure to invest in services and recent budget cuts. The transition to managed care offers an opportunity to define a baseline for access to HCBS across the state. While access standards exist for health care providers, no such standards exist for HCBS, making it difficult to ensure consumer access to these services on a statewide basis and eliminate geographic inequities.

***The California Health and Human Services Agency should establish a safety net and access standards for home and community-based LTC services that identifies the basic service mix for each county. The state should then contract with an entity to perform a statewide inventory to assess available services. Particular attention should be paid to the 44 rural counties to identify gaps and where investment is needed to ensure that the basic service mix is in place.***

### Enhance Rural Capacity

California's 44 rural counties are home to 5.2 million people -- just 14% of Californians -- but those counties account for 80% of the state's land mass. The rural county populations tend to be older, poorer, and less healthy than urban area populations. What's more, rural areas have fewer health care and LTC providers – hospitals, home health agencies, hospice organizations, long-term care facilities, primary care clinics, and HCBS services – and less of the human infrastructure that accompanies these institutions. Barriers to overcoming these challenges include:

- Low-rate Medi-Cal reimbursement to primary care physicians in rural areas and statewide,
- A population dispersed across tens of thousands of square miles,

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<sup>18</sup> David Zingmond, Kathleen Wilber, Sutep Laohavanich, and Pelargos Panayiotis. *The Power of Integrated Information: The Benefits and Challenges of Developing a Long Term Care Data Warehouse in California*. Accessed at: [http://www.communitychoices.info/docs/Data%20Warehouse%20Report/Data\\_Warehouse\\_Report\\_Final.pdf](http://www.communitychoices.info/docs/Data%20Warehouse%20Report/Data_Warehouse_Report_Final.pdf)).

<sup>19</sup> For more information, see: <http://wiki.siframework.org/eLTSS+Join+the+Initiative>.

- Difficulty recruiting and retaining qualified professionals in the LTC field to practice in remote areas, and
- Limited HCBS and residential services options outside of institutional care in a nursing facility.

Recommended short-term steps policymakers can take to remedy issues of capacity in rural areas:

- ***Permit California's rural hospitals to employ primary care physicians,***
- ***Provide funding to increase the use of telemedicine and tele-pharmacy services in rural areas, and***
- ***Expand Medi-Cal's Assisted Living Waiver to rural areas. Assisted living provides supportive services and housing to individuals in non-institutional settings. Most assisted living services can be covered only through private pay, with certain exceptions including a small program that offers Medi-Cal coverage for assisted living, referred to as the Assisted Living Waiver (ALW). The ALW gives Medi-Cal-eligible individuals at risk of institutionalization the option to reside in an assisted living setting or public subsidized housing as an alternative to institutionalization. However, the ALW only operates in limited areas of the state and is not available to individuals in rural areas.***

## Revise Mental Health Services Act Funding Formula

***The state should revise the current funding formula of the Mental Health Services Act (MHSA) to ensure that there is funding and programming for older adults within the Act and that funding is allocated equitably statewide.*** Rural counties currently receive a smaller portion of MHSA dollars, while at the same time experiencing a serious lack of access to mental health services.

## Establish LTC Information Portal

Consumers and caregivers struggle to access information about LTC services and options, not knowing where to go for information about choices for how and where to receive services. In 2001 the state launched the CalCareNet website, and this single website enabled Californians to search for state-licensed facilities and LTC programs. The website was expanded to include HCBS and provide greater consumer-focus and was later piloted in select counties through California Community Choices.<sup>20</sup> The project never received additional funding for maintenance and expansion and has since been taken offline.

***The state should invest resources to re-establish the Cal Care Net website as a tool to enable individuals and families to access information and understand options for LTC.***

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<sup>20</sup> For reference:

- California Community Choices. Business Case for CalCareNet Portal. Accessed at: [http://communitychoices.info/docs/CalCareNet\\_Business\\_Case.pdf](http://communitychoices.info/docs/CalCareNet_Business_Case.pdf).
- Cal Care Net Project Charter. Accessed at: <http://communitychoices.info/docs/reports/CalCareNet%20Charter%20Final%20111908.pdf>.
- Cal Care Net Usability Testing Report. Accessed at: [http://communitychoices.info/docs/ccn/CalCareNet\\_Report\\_final\\_July-2011.pdf](http://communitychoices.info/docs/ccn/CalCareNet_Report_final_July-2011.pdf).

## Identify Options for LTC Financing in California

While the responsibility for developing a national solution to LTC financing may lie with the federal government, the state also has the ability to act in response to the LTC financing crisis. ***The Department of Insurance should explore options for financing long-term care in California, including examining options for development of a statewide LTC insurance program that offers alternative financing solutions. To do so, the Department of Insurance should convene a task force in partnership with other state entities, industry experts, and stakeholders.*** This effort could be modeled on legislation introduced by former Senator Elaine Alquist (Senate Bill 1438) in 2012.

## WORKFORCE: RECOMMENDATIONS

### Enable Full Practice Authority for Nurse Practitioners

States have the ability to determine the scope of treatment capacity for nurses. Nurse practitioners (NPs) are registered nurses who, in California, are required to hold a master's degree in nursing and complete advanced coursework. Full practice authority allows for NPs to evaluate and diagnose patients, order and interpret diagnostic tests, manage treatments, and prescribe medications — all of which essentially is care equivalent to that provided by a physician. At present, 18 states allow NPs full practice authority. However, most states, including California, require NPs to work with physicians under a written practice agreement that restricts their activities.

The increase in the number of insured individuals, coupled with the dwindling number of primary care physicians, has left a fairly sizable gap in the number of capable medical professionals available to handle the sudden influx of individuals requiring care. Enabling full practice by NPs addresses this issue in the absence of any state or federal action to reverse the ever-expanding shortfall in primary care.

The Legislature examined this issue in 2013 with Senate Bill 491 (Hernandez), which sought to provide full practice authority for NPs under specified circumstances. Though passed by the Senate, the legislation failed to pass out of the Assembly. ***California should revisit this issue in an effort to increase access to services and help to alleviate workforce shortages, particularly in rural areas of the state.***

### Expand Nurse Delegation of Health Maintenance Tasks

Unpaid family caregivers are often faced with providing challenging care to loved ones, including tube feedings, ventilator care, intramuscular injections, and ostomy care, despite feeling uncomfortable and unprepared to do so. Unpaid family caregivers unwilling or unable to perform these tasks themselves must hire a registered nurse (RN) to minister to their loved one. This is because California law prohibits privately paid home health workers from performing certain health maintenance tasks that

nurses have not delegated.<sup>21</sup> With proper training, home care workers could perform these tasks at a fraction of the cost of a RN – benefitting families needing help and reducing taxpayer expenditures.

As reported in the 2014 LTSS Scorecard, California ranks 40<sup>th</sup> in the nation in permitting privately paid home care workers to perform certain nursing tasks under the direction of a licensed health care professional.<sup>22</sup> California law only allows two of 16 tasks reviewed to be performed by privately paid home care workers, whereas 50% of all states allow paid home care workers to perform ten or more of the 16 tasks. It should be noted that there are specified exceptions to California’s nurse delegation law, including for In-Home Supportive Services.

***The state should revise the statute to permit direct care workers to perform specified health maintenance tasks under the direction of a licensed health care professional, as follows:***

- ***Require nurses to delegate certain tasks to direct care workers who demonstrate such competency, particularly in home and community-based settings;***
- ***Require oversight and training of the direct care workers who perform these tasks; and***
- ***Promote development of training and certification programs that enable direct care workers to develop the skills needed for an expanded scope of practice and pay scales that recognize their increased capabilities.***

## **Require Hospital-to-Home Transition Support for Family Caregivers**

Unpaid family caregivers provide the majority of LTC support, yet the health and LTC system is slow to recognize them as partners. Identifying and meeting the needs of California’s caregivers can help ensure that individuals remain at home and avoid institutionalization.

Hospital-to-home transitions often fail to recognize the caregiver as a partner in the discharge planning process. As a result, consumers return home without considering the role of the caregiver in the process, and caregivers must try to meet the consumer’s needs without appropriate training. Family caregivers should be an integral part of the discharge and transition process. Properly supported, caregivers play a critical role in keeping consumers out of costly institutions and helping to reduce preventable readmissions.

***California should enact legislation requiring hospitals to:***

- ***Record the name of the family caregiver when a loved one is admitted to a hospital or rehabilitation facility,***
- ***Notify the family caregiver when the loved one is to be discharged to another facility or home;***

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<sup>21</sup> List of 16 tasks: administer oral medications; administer medication on an as-needed basis; administer medication via pre-filled insulin or insulin pen; draw up insulin for dosage measurement; administer intramuscular injection medications; administer glucometer test; administer medication through tubes; insert suppository; administer eye/ear drops; gastrostomy tube feedings; administer enema; perform intermittent catheterization; perform ostomy care including skin care and changing appliance; perform nebulizer treatment; administer oxygen therapy; perform ventilator respiratory care.

<sup>22</sup> LTSS Scorecard at:  
[http://www.longtermscorecard.org/~media/Microsite/Files/2014/Reinhard\\_LTSS\\_Scorecard\\_web\\_619v2.pdf](http://www.longtermscorecard.org/~media/Microsite/Files/2014/Reinhard_LTSS_Scorecard_web_619v2.pdf).

- ***Provide an explanation and live instruction of the medical tasks that the family caregiver would perform; and***
- ***Provide telephonic technical assistance to the caregiver when questions arise.***

## **In-Home Supportive Services (IHSS) Training Curriculum**

IHSS is the cornerstone of California's home and community-based services system that enables low-income, aged, blind, and disabled individuals to remain safely in the home and avoid institutionalization. A critical component of the IHSS program is the consumer-directed model that allows consumers to hire, fire, and train caregivers. IHSS consumers typically require assistance with activities of daily living (ADL) such as bathing, eating, or dressing. They also may require services of a paramedical nature, such as bowel and bladder care, tube feeding, and basic medical services. However, no specialized training is required for an IHSS worker to perform services of a paramedical nature – leaving many of them without the core competencies necessary to provide more complex care.

IHSS workers have faced low wages, few benefits, a lack of standardized training, and limited opportunities for advancement. As a result, the home care industry experiences high rates of turnover, reducing the continuity of services to consumers. Studies show that training increases job satisfaction and can be an effective way to retain IHSS workers and enable consumers to receive more consistent, reliable care. With high-quality training in place, career pathways can be built to other related careers such as in health care and social services. Areas to consider for training include: fall prevention, stroke detection, early signs of dementia, CPR, wound care, gerontology, medication management, behavioral health, nutrition, end-of-life care/decision-making, occupational safety, and dispute resolution/family mediation. ***The state should implement a certified, standardized, voluntary training curriculum that offers a career ladder and increased pay for IHSS workers who increase their capacities to deliver care.***

## **Enhance Adult Protective Services Training**

California's laws for investigating and responding to elder abuse are overly complex, resulting in a wide variation in implementation across the state. This translates into inconsistent responses and a lack of information on victims or abusers, all of which impedes efforts to protect victims, track offenders, and reduce recidivism.

Adult Protective Services (APS) provides essential advocacy and services to promote the wellbeing and independence of elders and adults with disabilities. APS social workers carry out complex investigations of abuse, neglect, and exploitation in collaboration with long-term care ombudsmen (ombudsmen), community care licensing, law enforcement, and other key stakeholders. In 2011 fiscal and programmatic control of APS was realigned from the state to the county level, which has brought about increased inconsistencies among counties in training, investigation, and response.

***The state should increase training requirements and support for APS social workers, long-term care ombudsmen, and law enforcement entities that are responsible for investigating and responding to abuse, including how and when to report.***

## **Institute Elder Justice Training for LTC Providers**

LTC providers are often the first to encounter or witness elder abuse or neglect. However, providers currently have limited knowledge of elder rights and limited ability to recognize signs of abuse and exploitation. ***Managed care organizations, medical providers, and LTC providers should incorporate elder justice training into all aspects of service delivery.***

## **Mandate Training on Diagnosing and Treating Alzheimer's and Related Disorders**

The incidence of Alzheimer's disease is under-reported, leaving many individuals without treatment. Only 50% of people with Alzheimer's ever receive a formal diagnosis, and only half of these have the diagnosis documented in their medical charts. This is due in part to the stigma associated with these illnesses and the unwillingness to raise such sensitive issues. Further, medical professionals lack training in identifying and addressing Alzheimer's disease and related disorders. ***Medical education curriculum and continuing education should include training on the screening, diagnosis, treatment, and management of Alzheimer's disease and related disorders.***

## **Establish Minimum Geriatric Competency Standards for Mental Health Providers**

***Mental health professionals should be required to meet minimum standards for geriatric competency in mental health as a requirement to serve older adults.***

## **FUNDING: RECOMMENDATIONS**

Over the past several years, a number of critical LTC programs have been eliminated and/or experienced major reductions in funding: the In-Home Supportive Services Program; Medi-Cal provider rate reduction and benefit eliminations (dental, vision, other ancillary services); Adult Protective Services; the Multipurpose Senior Service Program; Older Californians Act programs (Linkages, Alzheimer's Resource Day Care Centers, respite and caregiver services, Brown Bag and Foster Grandparent Program); Low-Income Senior Rental Assistance and Homeowners Tax Credit; Caregiver Resource Centers; and SSI/SSP payment reductions. The Adult Day Health Care (ADHC) program was eliminated as a Medi-Cal benefit and then re-established as the Community-Based Adult Services (CBAS) program. CBAS continues to struggle with rate issues and access to services. In the wake of these reductions, we have a crumbling state infrastructure that cannot meet the current needs of older adults and persons with disabilities who rely on these services to remain at home and avoid institutionalization, let alone the future needs of this rapidly growing population.

The state's economic recovery offers the opportunity to strategically reinvest in the system, services, and supports older adults and persons with disabilities need to remain at home, in the community, and out of institutions. The time has come to reorganize program administration and service delivery and to put the consumer first, starting with a major reinvestment in California's home and community-based infrastructure. The Legislature and the Administration need to make funding for LTC a priority in

the state budget. Without this commitment, consumers, families, and, ultimately, society as a whole will bear the brunt of a dysfunctional system.

## Commit to Strategic Reinvestment in the LTC System

The Legislature and the Governor need to commit to reinvesting in the LTC infrastructure, particularly in the home and community-based services that are critical to helping people remain in the community and avoid institutionalization. However, simply restoring past cuts is not the answer. A piecemeal, uncoordinated approach to reinvestment would serve only to further fragment the system and would not meet current and future needs. ***Therefore, in its budget deliberations, the Legislature should outline a broad-based strategy for investment in programs and services in the context of what is needed to build an integrated system of care.*** This funding strategy should identify gaps and inequities in service delivery and consider how the actions listed below could fit into an emerging integrated system:

- Restore the 7% across-the-board reduction in IHSS hours;
- Reinvest in Medi-Cal ancillary services for older adults, including vision, hearing, and podiatry;
- Increase reimbursement to Medi-Cal providers, including primary care physicians;
- Address issues related to accessing services under CBAS as a managed care benefit, including rates, eligibility criteria, and assessment;
- Reinvest in Older Californian Act programs;
- Reinvest in Caregiver Resource Centers;
- Examine the rate structure for and access to all HCBS services;
- Restore SSI/SSP purchasing power to levels that bring combined payments current with the inflation that has occurred since 2008 (when payments were frozen); and
- Reinvest in APS and other investigative agencies to provide necessary resources to investigate and respond to elder abuse.

## FEDERAL ISSUES: RECOMMENDATIONS

### Engage in LTC Financing Solutions

The Federal Bipartisan Policy Center introduced its Long-Term Care Initiative<sup>23</sup> in early 2014 and will deliver specific policy recommendations in early 2015. State policymakers should examine the Center's recommendations as they relate to Californians and continue advocating for state and federal solutions to financing future LTC needs. ***Specifically, the Legislature should include long-term care financing as a priority for California and consider the Bipartisan Policy Center's long-term care initiative and forthcoming recommendations.***

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<sup>23</sup> Bipartisan Policy Center. "Long Term Care Initiative Launch." 2014. Accessed at: <http://bipartisanpolicy.org/events/2014/04/long-term-care-initiative-launch>.

## Urge Congressional Delegation Action on LTC Financing

***The Legislature should identify solutions recommended by the Bipartisan Policy Center and write a letter from the leaders of both parties in both houses to the California Congressional Delegation urging them to act on the issue of LTC financing.***

## Increase Financial Eligibility Threshold for Medi-Cal LTC

The ACA enabled California's expansion of Medi-Cal coverage to individuals at or below 138% of Federal Poverty Level without imposing asset tests for this population (meaning that the expansion population does not need to spend down assets to qualify for Medi-Cal). However, confusion surrounds coverage of LTC for this "expansion" population. The state included LTC in the Medi-Cal expansion group, but only if individuals meet the asset requirements (spend down assets to qualify). In other words, California would only offer LTC to the expansion Medi-Cal population if it can also apply an asset test, which has not yet been approved by the federal government.

***The state should work with the federal government to set a Medi-Cal eligibility threshold for LTC consistent with the Affordable Care Act and coverage for up to 138% of the Federal Poverty Level for Medi-Cal LTC, including eliminating asset tests.***

## Reauthorize the Older Americans Act

The federal Older Americans Act (OAA) established a network for programs serving older adults and caregivers through state units on aging, area agencies on aging, tribal organizations, and Native Hawaiian organizations. The OAA authorizes funding for various social and nutrition services to older adults including meals, senior centers, caregiver support, transportation, health promotion, and others. However, the OAA has not been reauthorized since 2006. ***The Legislature should pass a joint resolution urging the California Congressional Delegation to sign on as co-sponsors to bills reauthorizing the Older Americans Act of 1965, as amended in 2006, and as introduced in Congress in 2015.***

## CONCLUSION

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In the perfect storm of health care reform, federal reorganization, economic recovery, and demographic and social imperatives, California has an opportunity to address the longstanding LTC issues stemming from its fragmented, inefficient, and ineffective system. We can no longer ignore the intersection of demographics, disability, and longevity. Many experts, scholars, and advocates have called for reforms to move California's LTC system forward over the years. Now it is time to create an ideal LTC system, one that enables older adults and people with disabilities to live with dignity, choice, and independence.

As one Select Committee hearing expert witness stated, "We have the population. We have the expertise. We know the needs. We know the challenges. We know what has to be done. What we need is the political will to do it."

The Legislature, in collaboration with the Brown Administration, needs to make providing services to older adults and people with disabilities a priority for California. It is time to commit the resources necessary to deliver services efficiently in the least restrictive, most integrated home and community-based settings and in accordance with the needs, values, and preferences of older adults, people with disabilities, and their families. They are valued residents of California, and they deserve no less.

## **APPENDICES – TABS 1-11**

**Tab 1:** Senate Select Committee on Aging and Long-Term Care: Membership, Purpose, and Methodology

**Tab 2:** Background Paper (California Policy in Brief) - Demographics: What Is Long-Term Care, Who Receives It, and Who Provides It?

**Tab 3:** Periodic Table of California’s Long-Term Care Programs and Services for Older Adults and Adults with Disabilities, plus Compendium

**Tab 4:** Hearing Summary – July 8, 2014 – Glendale, California  
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**Tab 6:** Biographies

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**Tab 8:** Senate Office on Research: Demographics and Workforce  
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California Health Interview Survey: Select Data on Californians 60 and Older  
California State and Federal Spending in Agencies and Departments That Provide Aging and Long-Term Care Services, 2013-14  
Facts & Citations: Healthcare Workforce Serving Aging Californians – Needs & Capacity

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**Tab 10:** Background Articles:  
a. America’s Long-Term Care Crisis: Challenges in Financing and Delivery  
b. Policy Brief on AARP Scorecard  
c. Transforming California’s System of Care for Older Adults and People with Disabilities: A Look at the State’s Administrative and Fiscal Organization

**Tab 11:** Common Aging Acronyms

## **Senate Select Committee on Aging and Long-Term Care: Membership, Purpose, and Methodology**

**COMMITTEE MEMBERS:**

**Senator Carol Liu, Chair**

Senator Jim Beall

Senator Tom Berryhill

Senator Ed Hernandez

Senator Richard Roth

Senator Lois Wolk

**COMMITTEE PURPOSE:**

The Committee's purpose is to articulate an IDEAL structural vision for an effective and efficient aging and long-term care support and service delivery system and to develop a comprehensive strategy – both short-term and long-term – to achieve that vision. The Committee plans to establish as well a New Cultural Vision of aging by reshaping the narrative about what aging is and what would it take to change the perception of aging from negative stereotypes to positive prototypes, so that aging and elders are valued by society.

**STRUCTURAL CHANGE METHODOLOGY:**

To create a new and IDEAL Structural Vision, the Senate Select Committee held two hearings:

1. July 8, 2014 in Glendale, CA: Informational Hearing titled, "California's Service Delivery System for Older Adults: Envisioning the IDEAL"  
**Hearing Focus:** Presenters were asked to provide answers to the following five questions: What values underlie an IDEAL system? What is the IDEAL system? What are the essential components? What are the major barriers/challenges to achieving an IDEAL system? How do we achieve the IDEAL?
2. August 12, 2014 in Sacramento, CA: Joint Hearing with the Assembly Committee on Aging and Long-Term Care titled: "Implementing an IDEAL Aging and Long-Term Care System in California"  
**Hearing Focus:** Presented findings and conclusions from the Informational Hearing in response to the five questions, the problems identified with the current system and the recommendations for creating an IDEAL system. In addition, presenters were asked, based on key questions posed, to identify the legislative and/or administrative responses to the five system change priorities for the 2015 Legislative Session.

Invited to participate in both hearings as presenters were some of California's leading experts and scholars in the field of aging and long-term care.

July 8 Hearing: Dr. Kate Wilber; Dr. Steven P. Wallace; Sandi Fitzpatrick; Amber Cutler; Dr. Fernando Torres-Gil; Laura Trejo; Dr. Karen Lincoln; Cheryl Phillips, M.D.; Dr. Gretchen Alkema.

August 12 Hearing: Patty Berg; Dr. Gretchen Alkema; Dr. Fernando Torres-Gil; Sandi Fitzpatrick; Sarah Steenhausen; Laura Trejo.

### **CRITICAL POLICY ISSUES METHODOLOGY:**

A team of individuals in the field of aging and long-term care identified experts in 10 critical policy areas to interview. Thirty individuals were interviewed via one-hour conference calls conducted by Patty Berg, Principal Consultant and Sarah Steenhausen, Senior Policy Advisor, The SCAN Foundation.

Policy Areas Included: Health Care; Long-Term Care/Long-Term Services and Supports; Long-Term Care Financing; Family Caregivers; Transitional Care; Wellness and Mental Health; Dementia and Alzheimer's Disease; Housing; Transportation and Mobility; Employment and Retirement

A standard interview tool was created and emailed to each of the respondents prior to the call. Five key questions were asked:

1. What do you see as the emerging trends (policy or programmatic) related to \_\_\_\_\_?
2. What are the most significant challenges impacting \_\_\_\_\_?
3. What barriers need to be overcome to address those challenges?
4. What legislative and/or regulatory solutions would you recommend?
5. What local, regional or state program models or best practices do you recommend to the Senate Select Committee?

A write-up of each interview was then mailed to the respondents for their edits/additional commentary. If indicated, amendments were made, and the report became a final summary of the interview.

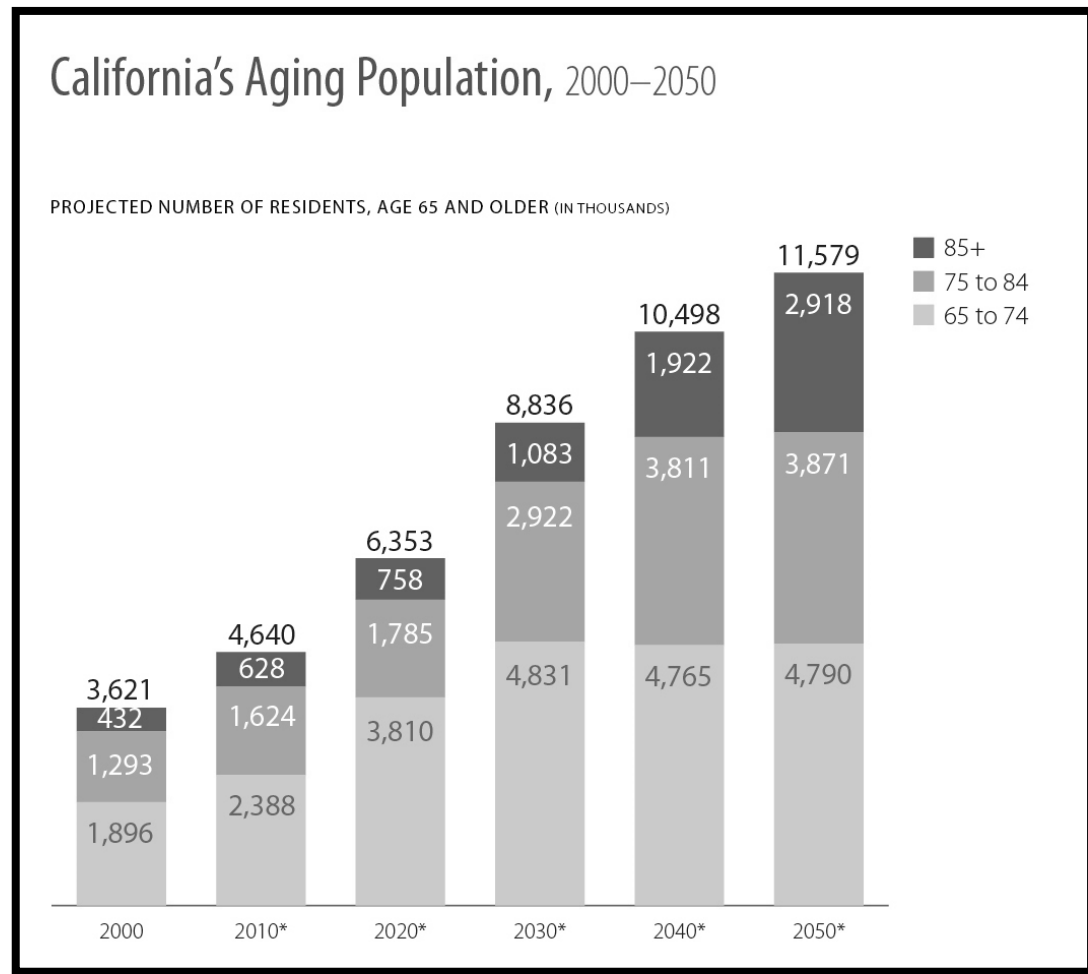
For two of the Critical Policy areas – Transportation and Employment and Retirement – an email letter was sent mid-August to four leaders in Transportation and three leaders in Employment and Retirement requesting their written comments identifying the most significant challenges to overcome and potential legislative/administrative solutions, as well as policy opportunities to consider.

Committee staff also worked closely with the Senate Office on Research on demographics, info graphics and Workforce issues.

Information gathering also took place through individual face-to-face meetings with multiple providers in the field of aging and long-term care and organizations representing elders and people with disabilities.

## **Background Paper: Demographics: What Is Long-Term Care, Who Receives It, Who Provides It?**

# SENATE SELECT COMMITTEE ON AGING AND LONG-TERM CARE



## CALIFORNIA AGING POLICY IN BRIEF

May 20<sup>th</sup>, 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.<sup>1</sup> 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.<sup>2</sup> 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.<sup>3</sup> 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.<sup>4</sup>

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%.<sup>5</sup>

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.<sup>6</sup> 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.<sup>7</sup>

## **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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<sup>1</sup> "Across the States: Profiles of Long Term Care and Independent Living" AARP, 8<sup>th</sup> edition. 2009.

<sup>2</sup> "Population with Age and Sex Detail 2000-2050." California Department of Finance. 2007.

<sup>3</sup> "California Healthcare Almanac: Long Term Care Facts and Figures" California Healthcare Foundation. 2009.

<sup>4</sup> "Alzheimer's Disease: Facts and Figures in California" Alzheimer's Association. 2009.

<sup>5</sup> "California Healthcare Almanac: Long Term Care Facts and Figures" California Healthcare Foundation. 2009.

<sup>6</sup> "Statistical Abstract of the US; Table 102 Expectation of Life at Birth" US Census. 2010.

<sup>7</sup> 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.<sup>8</sup> 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

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<sup>8</sup> "Beyond 50: A Report to the Nation on Independent Living and Disability" AARP. 2003.

10 seniors.<sup>9</sup> Among those who use any LTC services, the average person will require at least three years of care.<sup>10</sup>

## 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.<sup>11</sup> Almost 47 % of those are between the ages of 18 and 44 years old.<sup>12</sup> The majority (about 57%) of informal caregivers in California are women.<sup>13</sup> 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.<sup>14</sup>

One in every six households in California contains at least one informal caregiver for someone age 50 or over.<sup>15</sup> 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.<sup>16</sup> In 2011, over 1.5 million Californians provided unpaid care to someone with Alzheimer's disease or other dementia.<sup>17</sup> 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.<sup>18</sup>

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

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

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<sup>9</sup> Alecxih, L.M. "Long Term Care; What is it, Who Needs it, and Who Provides it?" Health Insurance Association of America. 1997.

<sup>10</sup> Alecxih, Kemper, and Komisar "Longterm Care over and Uncertain Future; What can current retirees expect?" Inquiry. 2005.

<sup>11</sup> Hoffman, Mendez-Luck "Stressed and Trapped: Caregivers in California" 2011.

<sup>12</sup> Ibid

<sup>13</sup> Ibid

<sup>14</sup> Ibid

<sup>15</sup> A Profile of Family Caregivers: Results of the CA Statewide Survey of Caregivers. Center for the Advanced Study of Aging Services. 2003.

<sup>16</sup> Mendez-Luck, Interview, August 16<sup>th</sup> 2012.

<sup>17</sup> CA Alzheimer's Statistics, Alzheimer's Association. 2012.

<sup>18</sup> A Profile of Family Caregivers: Results of the CA Statewide Survey of Caregivers. Center for the Advanced Study of Aging Services. 2003.

<sup>19</sup> Hoffman, Mendez-Luck "Stressed and Trapped: Caregivers in California" 2011.

<sup>20</sup> Ibid

responsibilities.<sup>21</sup> In 2009, the estimated economic value of unpaid caregiving in California was \$47 billion.<sup>22</sup>

## FORMAL CAREGIVERS

California is home to the largest direct care workforce in the country.<sup>23</sup> In 2009, the state's direct care workforce totaled 579,630 workers.<sup>24</sup> Of these direct care workers, 203,630 were employed as certified nursing assistants, home health aides or personal care aides.<sup>25</sup> 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.<sup>26</sup>

The majority of California's direct care workers are women (85%) and their average age is 44 years.<sup>27</sup> 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.<sup>28</sup>

## 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

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<sup>21</sup> Hoffman, Mendez-Luck "Stressed and Trapped: Caregivers in California" 2011.

<sup>22</sup> Feinberg, Reinhard, Houser, Choula "Valuing the Invaluable: 2011 Update: The Growing Contributions and Costs of Family Caregiving. 2011.

<sup>23</sup> State Facts: CA Direct Care Workforce. Public Health Institute. 2010.

<sup>24</sup> Data Center, Public Health Institute. 2011.

<sup>25</sup> Eiken, Sredl, Burwell, Gold "Medicaid Expenditures for Long Term Services and Supports" 2011.

<sup>26</sup> State Facts: CA Direct Care Workforce. Public Health Institute. 2010.

<sup>27</sup> Data Center, Public Health Institute. 2011.

<sup>28</sup> 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.<sup>29</sup>

## **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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<sup>29</sup> 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 Californians 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.<sup>30</sup> 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**<sup>31</sup>

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

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<sup>30</sup> "Occupational Projections for Direct Care Workers 2006-2016" Public Health Institute. 2008.

<sup>31</sup> "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?

**Periodic Table of California's Long-Term Care  
Programs and Services for Older Adults and Adults  
with Disabilities, plus Compendium**



## Glossary of Program Names, Acronyms, and Abbreviations

### Primary Funding Sources

CMS = Centers for Medicare and Medicaid Services

CDC = Centers for Disease Control and Prevention

DHCS = Department of Health Care Services

Fed. grant = Federal Grant

ACL = Administration for Community Living

FTA = Federal Transit Administration

DOE = Department of Energy

HUD = Housing and Urban Development

SSA = Social Security Administration

USDA = United States Department of Agriculture

GF = General Fund (State)

MHSA = Mental Health Services Act

ACF = Administration for Children and Families

## [Department of Public Health](#)

AD = Alzheimer's Disease Program-provides clinical services through California Alzheimer's Disease Centers (ADCs) and research awards to scientist studying Alzheimer's disease and related disorders.

CAPP = California Arthritis Partnership Program-increases access to and use of evidence-based physical activity and self-management interventions to Californians living with arthritis.

PHCA = Preventive Health Care for Adults-"provides chronic disease prevention and free health assessments to adults 50+ in participating counties." Currently participating counties include Humboldt, Kern, Kings, Madera, Orange, San Bernardino, Shasta, Stanislaus, Tulare, and Ventura.

WISEWOMAN = Well-Integrated Screening and Evaluation for Women Across the Nation-"helps underserved women reduce the risk of cardiovascular disease (CVD) through timely, high quality screening, education and intervention." Participating program sites (from 2008-2013) were located in Los Angeles and San Diego County.

C4P = California Colon Cancer Control Program-"provides community outreach and education, professional education for medical providers, and collaboration with health insurers, nonprofit groups, and other stakeholders."

AIDS waiver = Acquired Immune Deficiency Syndrome waiver, a Medi-Cal waiver program which provides home and community based services as an alternative to nursing facility care or hospitalization.

HHA Cert. = Home Health Aide Certification

NH L&C = Nursing Home Licensing & Certification-"CDPH is responsible for ensuring nursing homes comply with state laws and regulations." The Health Facilities Consumer Information System site contains a complaint form where consumers and the general public can file a complaint about a facility.

CBAS L&C = Community-Based Adult Services Facility Licensing & Certification

## [Department of Health Care Services](#)

CBAS = Community-Based Adult Services-"offers services to eligible older adults and/or adults with disabilities to restore or maintain their optimal capacity for self-care and delay or prevent inappropriate or personally undesirable institutionalization. CBAS is a Medi-Cal Managed Care benefit available to eligible Medi-Cal beneficiaries enrolled in Medi-Cal Managed Care."

CRCs = Caregiver Resource Centers-located in regions throughout the state, "serve thousands of families and caregivers of those with Alzheimer's disease, stroke, Parkinson's disease and other disorders."

AIDS waiver = Acquired Immune Deficiency Syndrome waiver, a Medi-Cal waiver program which provides home and community based services as an alternative to nursing facility care or hospitalization.

HCBS-DD = Home and Community-Based Services for the Developmentally Disabled-"administered by the California Department of Developmental Services (DDS) who will authorize home and community-based services for developmentally disabled persons who are Regional Center consumers."

ALW = Assisted Living Waiver-goal is to "facilitate a safe and timely transition of Medi-Cal eligible seniors and persons with disabilities from a nursing facility to a community home-like setting and offer eligible seniors and persons with disabilities, who reside in the community, but are at risk of being institutionalized, the option of utilizing ALW services to develop a program that will safely meet his/her care needs. Today the ALW is operating in Alameda, Contra Costa, Fresno, Los Angeles, Riverside, Sacramento, San Bernardino, San Diego, San Joaquin and Sonoma counties." The program is expected to expand into Kern, Orange, Santa Clara and San Mateo counties in 2014.

CCT = California Community Transitions Project-facilitates and monitors the transition of eligible Medi-Cal beneficiaries, who have continuously resided in state-licensed health care facilities for a period of 90 consecutive days or longer, from those facilities to community settings."

CPLTC = California Partnership for Long-Term Care-educates "Californians on the need to plan ahead for their future long-term care and to consider private insurance as a vehicle to fund that care; offers high quality policies that must meet stringent requirements set by the Partnership and the State of California."

CLSB waiver = Community Living Support Benefit waiver-"assist eligible individuals to move into available community settings and to exercise increased control and independence over their lives." There are various eligibility requirements, including residing in the city and county of San Francisco.

IMPACT = IMProving Access, Counseling & Treatment for Californians with Prostate Cancer-"will pay for prostate cancer treatment for up to 12 months for qualified individuals. Treatment is available throughout California."

IHO waiver = In-Home Operations waiver-"provides home and community-based services to targeted groups of people who would otherwise require long term care in a nursing facility or a hospital."

DD-CNC = Developmentally-Disabled/Continuous Nursing Care Program-"provides 24-hour continuous skilled nursing care in home and community-based residential settings to persons with developmental disabilities who are medically fragile. The program currently assists approximately 45 individuals who reside in homes located in Desert Hot Springs, Fresno, Gardena, San Bruno, San Jose, Santa Rosa and Sylmar."

NH/AF waiver = Nursing Home/Acute Hospital waiver-"provides services in the home to Medi-Cal beneficiaries who would otherwise receive care in an intermediate care facility, a skilled nursing facility, a subacute nursing facility, or an acute care hospital."

IHSS+ = In-Home Supportive Services Plus State Plan Option Program-"pays parents or spouses to provide services to qualified Medi-Cal recipients; allows participants to receive services at home."

PACE = Program of All-Inclusive Care for the Elderly-"provides a comprehensive medical/social service delivery system using an interdisciplinary team approach in a PACE Center that provides and coordinates all needed preventive, primary, acute and long-term care services." There are eligibility requirements for PACE, including residing in service area counties and zip codes.

SCAN = Senior Care Action Network Health Plan-"a Medicare Advantage Special Needs Plan that contracts with the Department of Health Care Services to provide services for the dual eligible Medicare/Medi-Cal population subset residing in Los Angeles, San Bernardino, and Riverside counties."

State Plan Services = includes Home and Community-Based Services including habilitation, respite care, supported employment, prevocational services, homemaker services, home health aide services, etc.

MMC = Medi-Cal Managed Care-"provides high quality, accessible, and cost-effective health care through managed care delivery systems."

CCI = Coordinated Care Initiative-“promotes integrated delivery of medical, behavioral, and long-term care services, and also provides a road map to integrated Medicare and Medi-Cal services for people on both programs, called “Medi-Medi” or “dual eligible beneficiaries.”

PDDP = Prescription Drug Discount Program for Medicare Recipients- “enables Medicare recipients to obtain their prescription drugs at a cost no higher than the Medi-Cal reimbursement rates.”

GHPP = Genetically Handicapped Persons Program-“a health care program for adults with certain genetic diseases.”

### [Department of Veterans Affairs](#)

Veteran Homes = CalVet Veteran Homes include independent living, intermediate nursing care, memory care, outpatient clinic, residential care, skilled nursing care, and transitional housing.

Home Loans = meets veterans’ home loan needs with products that have below market interest rates with low or no down payment requirements.

Pension = a benefit paid to wartime veterans age 65 or older who have limited or no income.

Claims = range from Agent Orange exposure, dependent and indemnity compensation, disability compensation, and various healthcare-related services.

A&A = Advocacy & Assistance; staff trained to provide counseling and referral services to individuals and their families.

### [Department of Developmental Services](#)

RCs = Regional Centers-“nonprofit private corporations that contract with the Department of Developmental Services to provide or coordinate services and supports for individuals with developmental disabilities.”

HCBS-DD = Home and Community-Based Services for the Developmentally Disabled: this waiver “provided a vehicle for California to offer services not otherwise available through the Medi-Cal program to serve people (including the developmentally disabled) in their own homes and communities.”

DCs = Developmental Centers-“provide 24-hour habilitation and treatment services for residents with developmental disabilities.”

OPS = Office of Protective Services- a highly specialized law enforcement organization that works within developmental centers.

FGSCP = Foster Grandparent and Senior Companion Programs: The Foster Grandparent program “establishes person-to-person relationships between low income seniors, age 55 years or older, and children with intellectual disabilities. Senior Companions provide one-on-one mentoring to adults residing at the developmental centers and in various community settings.” Both programs provide volunteers with a number of incentives, including a stipend, meals, travel reimbursement, etc.

## Department of Consumer Affairs

SCCRC = Senior California Consumer Resource Center-links to assistance information for senior consumers, including financial and privacy resources, general consumer tips, health and welfare resources, reporting elder abuse, senior scambuster kit, and the California Senior Gateway.

CPIS = Consumer Protection Information for Seniors- "The California Department of Consumer Affairs has prepared this "Senior Scambuster Kit" to provide older Californians with tips and resources that can help them say "no thanks" to scammers and "no deal" to dishonest dealers."

SSS = Senior Scam Stopper™ Seminars- "In addition to providing information about construction-related scams and how seniors can protect themselves when hiring a contractor, the seminars feature expert speakers from many local, state and federal agencies, who present broader topics, including identity theft, auto repair, and investments."

CLSB-Contractor Info = site contains "What Seniors Should Know" before hiring a contractor.

CFB = Cemetery and Funeral Bureau, site contains a "Consumer Guide to Funeral and Cemetery Purchases".

## Department of Rehabilitation

ILCs = Independent Living Centers-An ILC is "a consumer controlled, community based, cross disability, nonresidential private nonprofit agency that is designed and operated within a local community by individuals with disabilities."

MEP = Mobility Evaluation Program-"provides driving evaluations for qualified individuals to help determine their transportation needs; also provides passenger and wheelchair evaluations."

TTW = Ticket to Work Program-the goal of the program "is to expand the universe of service providers that are available to those individuals between ages 18-64 who are entitled to Social Security benefits based on disability (SSDI) and for those who are eligible for Supplemental Security Income (SSI) based on disability or blindness."

TBI = Traumatic Brain Injury Program-"The Department of Rehabilitation (DOR) is committed to providing services to individuals with disabilities through employment, independence and equality, including those individuals with a traumatic brain injury."

AT = Assistive Technology Program-"provides AT devices and services statewide to assist individuals with disabilities to live independently and participate in the community."

Spec. Services = Specialized Services for the blind, visually impaired, deaf, and hard of hearing.

SAP = Schedule A Program-"a federal government program designed to remove barriers and increase employment opportunities for persons with disabilities."

BEP = Business Enterprises Program- "provides an opportunity for qualified DOR consumers, who are legally blind, to become independent food service professionals."

LEAP = Limited Examination and Appointment Program-"an alternate examination and appointment process for the recruitment and hiring of individuals with disabilities into State service."

## Department of Education

CACFP = Child and Adult Care Food Program-“provides supplemental funding to assist centers (adult day care facilities) in providing a quality nutrition program to functionally impaired adults or adults who are 60 years of age or older.”

## Department of Food and Agriculture

SFMNP = Seniors Farmers' Market Nutrition Program-“provides low-income seniors with check booklets that can be used to purchase fresh fruits, vegetables, cut herb and honey at Certified Farmers' Markets (CFM).”

## Employment Development Department

PFL = Paid Family Leave “insurance provides up to six weeks of benefits for individuals who must take time off to care for a seriously ill child, spouse, parent, or registered domestic partner, or to bond with a new child.”

CalJOBS = included on EDD's “Services for Older Workers” site, CalJOBS is an automated system that helps facilitate the match between a job seeker and an employer based on occupational, geographic, and type of employment (full, part-time, or temporary) factors.

EU = Employment Unlimited Job Clubs primarily serve those who are aged 40 and over.

AJCC = America's Job Center of California system, included on EDD's “Services for Older Workers” site, are local centers/offices that provide employment resources, including specialists that know the labor market and can help in your job search.

## Department of Motor Vehicles

SD = Senior Driver site developed specifically for older drivers.

SOP = Senior Ombudsman Program, which “represents the interest of public safety for all Californians with a special interest in addressing the concerns of senior drivers.” Four ombudsmen are available in Sacramento/Northern California; San Francisco/Oakland; Orange/San Bernardino/San Diego; and Los Angeles/Oxnard.

## Health and Human Services Agency

OAC = Olmstead Advisory Committee-ensures the involvement of people with disabilities and other stakeholders in making recommendations on actions to improve California's long term care system.

ADRDAC = Alzheimer's Disease and Related Disorders Advisory Committee-established to provide advice and assistance to address the program needs and priorities of the Alzheimer's population.

## Department of Aging

AAA = Area Agencies on Aging-through contracts with the Department of Aging, "coordinate a wide array of services to seniors and adults with disabilities at the community level and serve as the focal point for local aging concerns."

CBAS = Community-Based Adult Services-"a community-based day health program that provides services to older persons and adults with chronic medical, cognitive, or mental health conditions and/or disabilities that are at risk of needing institutional care. Under an interagency agreement, the CBAS Program is administered between the Department of Health Care Services (DHCS), the California Department of Public Health (CDPH), and the California Department of Aging (CDA)."

MSSP = Multipurpose Senior Services Program-"provides both social and health care management services for frail elderly clients who wish to remain in their own homes and communities. The California Department of Aging (CDA) administers MSSP under an interagency agreement with the Department of Health Care Services."

DPHP = Disease Prevention and Health Promotion-"provides disease prevention services or health promotion programs."

FCSP = Family Caregiver Support Program-"services, including caregiver information, assistance in gaining access to services, counseling and training support, temporary respite, and limited supplemental services to complement the care provided by caregivers."

HICAP = Health Insurance Counseling and Advocacy Program-"provides personalized counseling, community education and outreach events for Medicare beneficiaries."

Legal Asst. = Legal Assistance, through funded Legal Services Projects provided by local Area Agencies on Aging, "identify legal problems and legal service needs of older individuals and adults with disabilities within their communities."

LTCOP = Long-Term Care Ombudsman Program-investigates and endeavors to resolve complaints made by, or on behalf of, individual residents in long-term care facilities.

EAPP = Elder Abuse Prevention Program-focuses on developing, strengthening, and implementing programs for the prevention, detection, assessment, and treatment of elder abuse.

ALz. CMC = Alzheimer's CalMediConnect, will expand the capacity to serve persons with dementia in managed care plans (9 participating health plans expected by the end of the grant period in Sept. 2016).

*\*\*Note that this is a demonstration project scheduled to occur in eight counties- Alameda, San Mateo, Santa Clara, Los Angeles, Orange, San Diego, Riverside, and San Bernardino.*

CDSME = Chronic Disease Self-Management Education- provides information and teaches practical skills for managing chronic health problems.

Nutr. = Nutrition services include Congregate Nutrition Services (meals in a group setting) and Home Delivered Meal Services to individuals aged 60 years and older.

SCSEP = Senior Community Services Employment Program- "provides part-time work-based training opportunities at local community service agencies for older workers who have poor employment prospects and assists with the transition of individuals to private or other employment opportunities in the community."

Snap-Ed = Supplemental Nutrition Assistance Program-Education, "promotes nutrition education and obesity prevention interventions among low-income older adults."

Suppt. Services = Supportive Services-"provides a variety of services to address functional limitations, maintain health and independence, and promote access to services."

MIPPA = Medicare Improvements for Patients and Providers Act-increases outreach to people with Medicare, especially those with limited incomes and resources, by providing target funding for HICAP, Area Agencies on Aging (AAAs), and Aging and Disability Resource Centers (ADRCs) to assist beneficiaries in enrollment and accessing key benefits.

NFT = New Freedom Transit Program-improved and extended transportation access and services for older adults and adults with disabilities. The program was funded through reimbursements from Caltrans to the Department of Aging and services provided by 33 local Area Agencies on Aging. *\*\* The agreement (funding?) for this program expired on April 30, 2014.*

ADRCs = Aging and Disability Resource Connections-"designed to help individuals learn more about their community LTSS options and get the services they need." *\*\*Note that as of July 1, 2014, oversight of the ADRCs will transfer from the Health and Human Services Agency to the Department of Aging.*

ADRCs = Alzheimer's Day Care Resource Centers-"provides services to persons with Alzheimer's disease and related dementias and their families and caregivers." *\*\*This program no longer receives State General Fund dollars, but is still authorized under the Older Californians Act. It's at the discretion of the local Area Agencies on Aging to fund and offer this service.*

BBP = Brown Bag Program-"provided surplus and donated food to low-income adults aged 60 or older." *\*\*This program no longer receives State General Fund dollars, but is still authorized under the Older Californians Act. It's at the discretion of the local Area Agencies on Aging to fund and offer this service.*

FGP = Foster Grandparent Program-"engaged low-income volunteers aged 60 or older in providing support and one-on-one assistance to children and youth in a variety of community settings. Volunteers served up to 40 hours per week and received a tax-exempt stipend and other benefits." *\*\*This program no longer receives State General Fund dollars, but is still authorized under the Older Californians Act. It's at the discretion of the local Area Agencies on Aging to fund and offer this service.*

Linkages = "a care management program which serves frail older adults and adults with functional impairments who are at risk of being placed in an institutional setting. Linkages professionals, known as care managers, link their clients to services that assist them to remain independent in their own communities." *\*\*This program no longer receives State General Fund dollars, but is still authorized under the Older Californians Act. It's at the discretion of the local Area Agencies on Aging to fund and offer this service.*

RPOS = Respite Purchase of Service-"provides relief and support to caregivers in order to delay premature or inappropriate institutionalization of both the person receiving care and the caregiver." *\*\*This program no longer receives State General Fund dollars, but is still authorized under the Older Californians Act. It's at the discretion of the local Area Agencies on Aging to fund and offer this service.*

SCP = Senior Companion Program-"provides supportive services to adults with physical, emotional or mental health limitations, the majority of whom are elderly, in an effort to achieve and maintain their highest level of independent living." *\*\*This program no longer receives State General Fund dollars, but is still authorized under the Older Californians Act. It's at the discretion of the local Area Agencies on Aging to fund and offer this service.*

### Centers for Medicare and Medicaid Services

Medicare = a federal health insurance program for people age 65 or older, individuals with a disability, and individuals with End-Stage Renal Disease (ESRD).

### Department of Child Support Services

CSS = Child Support Services-may be available to grandparents who are caring for their grandchildren (if they are legal guardians).

## Department of Social Services

IHSS = In-Home Supportive Services-“helps pay for services that can help elderly, disabled or blind individuals remain safely in their own home. Services can include housecleaning, meal preparation, laundry, grocery shopping, personal care services (such as bowel and bladder care, bathing, grooming and paramedical services), accompaniment to medical appointments, and protective supervision for the mentally impaired.”

SSDI = Social Security Disability Insurance-“pays benefits to you and certain members of your family if you are “insured,” meaning that you worked long enough and paid Social Security taxes.”

SSI/SSP = Supplemental Security Income/State Supplementary Payment- “The SSI Program is a federally funded program which provides income support to you if you are aged 65 or older, blind or disabled. The SSP Program is the state program which augments SSI.”

CAP = Cash Assistance Program for Immigrants-“a 100 percent state-funded program designed to provide monthly cash benefits to aged, blind, and disabled non-citizens who are ineligible for SSI/SSP.”

CVCB = California Veterans Cash Benefit-available to certain WWII veterans who are also eligible for SSI/SSP or the Special Veterans Benefit.

CCIL/RF/CCRC = Community Care Licensing-A division that licenses and oversees both day care and residential facilities for children and adults in the State of California; provides information on selecting a facility, including Residential Facilities (RF) and Continuing Care Retirement Communities (CCRC).

APS = Adult Protective Services-“investigate reports of abuse of elders and dependent adults who live in private homes and hotels or hospitals and health clinics when the abuser is not a staff member. County APS staff evaluates abuse cases and arranges for services such as advocacy, counseling, money management, out-of-home placement, or conservatorship.”

KSSP = Kinship Support Services Program-“provides support services to relative caregivers and the children placed in their homes; also provides post permanency services to relative caregivers who have become the legal guardian or adoptive parent of a formerly dependent child.”

CalFresh = also known as the Supplemental Nutrition Assistance Program (SNAP) for California, “CalFresh benefits have the potential to help older adults purchase healthful foods. By offsetting food costs, CalFresh also leaves older adults with more money to pay for other basic needs.”

## Department of Community Services and Development

LIHEAP = Low-income Home Energy Assistance Program-“provides assistance to eligible low-income households (includes households with vulnerable populations including the elderly and/or disabled) to manage and meet their immediate home heating and/or cooling needs.”

WAP = Weatherization Assistance Program-“reduces the heating and cooling costs for low-income families (focusing on those with elderly residents, individuals with disabilities, and families with children) by improving the energy efficiency of their homes and ensuring their health and safety.”

## [Department of Justice/Office of the Attorney General](#)

PC&S = Protecting Children & Seniors-site lists the responsibilities and goals of the Attorney General in protecting children and seniors; includes a Missing and Unidentified Persons Unit and other resources.

BMFEA = Bureau of Medi-Cal Fraud & Abuse-"works aggressively to investigate and prosecute those who would rob taxpayers of millions of dollars each year and divert scarce health care resources from the needy; also works aggressively to protect patients in nursing homes and other long-term care facilities from abuse or neglect."

ECE = Elder Care Employer-"provides criminal history information to employers of persons who are non-licensed and providing non-medical domestic or personal care to an aged or disabled adult in the adult's own home (including In-Home Supportive Services)."

EOLCP = End of Life Care Planning- the Office of the Attorney General offers a checklist and resource guide for consumers.

## [Department of Human Resources](#)

LTD = Long-term Disability Insurance-"helps protect you from loss of income if an illness or injury prevents you from working for six months or more."

DCRA = Dependent Care Reimbursement Accounts-"similar to a medical account except it's for paying daycare expenses; expenses for child care, elder care, and care for a disabled dependent are reimbursable if the care is necessary for you to work or look for work."

## [Housing Finance Agency](#)

HCVF/AHP = Housing Choice Voucher Program (also known as Section 8)/Affordable Housing Program-this HFA site will "give you a listing of Section 8 apartments or apartments where low income housing might be available depending on vacancies. It will note if it is a family or elderly project."

PRA = Project Rental Assistance-"a demonstration program that provides the state the opportunity to proactively implement system changes for Medicaid beneficiaries with disabilities, ages 18-61, who have resided in a long-term health care facility for at least 90 days and desire to return to community living, or are at risk of institutionalization because of loss of housing."

MHSAHP = Mental Health Services Act Housing Program-"offers permanent financing and capitalized operating subsidies for the development of permanent supportive housing, including both rental and shared housing, to serve persons with serious mental illness and their families who are homeless or at risk of homelessness (includes some senior housing projects)."

## [Department of Transportation/Caltrans](#)

Senior Savers = "Amtrak travelers 62 years of age and over are eligible to receive a 15% discount on the lowest available rail fare on Amtrak California trains."

EDSTP = Elderly and Disabled Specialized Transit Program, established to meet "the transportation needs of elderly persons and persons with disabilities in areas where public mass transportation services are otherwise unavailable, insufficient, or inappropriate."

NFT = New Freedom Transit Program, "seeks to reduce barriers to transportation services and expands the transportation mobility options available to people with disabilities beyond the requirements of the Americans with Disabilities Act (ADA) of 1990." \*\* *The agreement (funding?) for this program expired on April 30, 2014.*

*Prepared by Malaika K. Singleton, Ph.D., California State Senate Office of Research, May 31, 2014*

**Hearing Summary – July 8, 2014 – Glendale,  
California**

**SENATE SELECT COMMITTEE ON AGING AND LONG TERM CARE**  
**SUMMARY REPORT: INFORMATIONAL HEARING**

**DATE:** August 4, 2014

**TO:** Senator Carol Liu, Chair, Senate Select Committee on Aging and Long-Term Care and Committee members: Senators Lois Wolk, Richard Roth, Ed Hernandez, Tom Berryhill, Jim Beall

**FROM:** Patty Berg, Principal Consultant

**SUBJECT:** Summary Report: Informational Hearing on “California’s Service Delivery System for Older Adults: Envisioning the Ideal”

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The Senate Select Committee on Aging and Long Term Care held its first informational hearing on July 8, 2014 in Glendale, California. Approximately 150 people representing consumers, service providers, and a variety of stakeholder groups attended to hear the presentations of noted experts in the field of gerontology and aging and long term care policy and services delivery. (*see Agenda, Appendix A*).

Highlights and take-aways from the presentations are summarized below. Presentations can be found at <http://senate.ca.gov/agingandlongtermcare> and a video of the hearing can be found at: [youtube.com/watch?v=BeZ1tge2UiU&feature=youtu.be](http://youtube.com/watch?v=BeZ1tge2UiU&feature=youtu.be)

Committee Chair Carol Liu began the three-hour hearing with recognition that California’s current aging and long-term care system does NOT:

- Provide for person-centered, individualized care or easy transitions between programs;
- Provide statewide access to a range of services, especially in rural areas;
- Respond to the cultural and ethnic diversity of our state;
- Develop a skilled, high quality workforce to meet the growing demand;
- Collect data in a uniform manner that enables it to measure outcomes and identify best practices;
- Use a universal assessment tool for consumers and their caregivers; or
- Support caregivers, many of whom themselves are aging.

The focus of the hearing was to establish a new structural vision for aging and long-term care, answering the following five questions:

1. What values underlie an ideal system?
2. What is the ideal system?
3. What are the essential components?
4. What are the major barriers/challenges to achieving an ideal system?
5. How do we achieve the ideal?

**TOPIC ONE: Who are the consumers and what are their needs?**

**Presenter:** Kate Wilber, Ph.D., Professor of Gerontology, Mary Pickford Foundation, USC School of Gerontology;

Dr. Wilber used two graphics, “Consumer Experience/What is the Current Approach” and “How the Consumer Navigates” to illustrate the navigation nightmare people face when trying to access programs and/or transition from the array of Long Term Services and Supports (LTSS) programs they may need. (See Appendices B and C)

Dr. Wilber described LTSS consumer characteristics as follows:

- Persons of all ages with physical and/or cognitive illness;
- About 60% of Home and Community Based Service (HCBS) users are age 65+;
- 29% live alone;
- Need for LTSS increases with age. Those 85+ have the highest need;
- Racial/ethnic characteristics of HCBS in California
  - 37% white
  - 26.70% Latino
  - 20.10% Asian/PI
  - 15% African American
  - 4.1% other
- All of us are potential consumers. Age is not a proxy for need.
  - 70% of people aged 65+ will need LTSS for an average time of three years;
  - Almost half will spend time in a nursing facility

LTSS needs for (In Home Support Services (IHSS) recipients include:

- Help with Activities of Daily Living (ADL), e.g., bathing, dressing, toileting, eating, transferring;
- Help with Instrumental Activities of Daily Living (IADL), e.g., housework, laundry, shopping/errands, meal preparation;

Unpaid Family Caregivers:

- Most LTSS in CA and in the nation is provided “informally” by family members or friends;
- More than 6 million people 18+ provided informal care in 2009; 1.5 million assisted someone with Alzheimer’s Disease;
- 1 in 6 households included an informal caregiver;
- The average caregiver provides 21 hours/week; 36 hours if they share a household;
- 29% provide assistance with ADL’s
- The majority work outside the home;
- In 2009 estimated contribution in CA was \$47 billion.

## **TOPIC TWO: California’s Current System**

**Presenters: Sandi Fitzpatrick**, M.A., Executive Director, CA Commission on Aging

**Steven P. Wallace**, Ph.D., Chair, Department of Community Health Sciences, UCLA School of Public Health

LTSS Development in California

- 1970’s – a decade of service innovation: CA Commission on Aging; CA Dept. of Aging and 33 Area Agencies on Aging (AAA’s); Independent Living Centers; On Lok and the Family Caregiver Alliance; LTC Ombudsman; Program of All-Inclusive Care for the Elderly (PACE); Adult Day Health Care (ADHC); Multipurpose Senior Services Program (MSSP), In-Home Support Services (IHSS);
- 1980’s - Home and Community Based Services – Linkages; Alzheimer’s Resource Day Care Centers; Health Insurance Counseling and Advocacy Program; Respite Services for caregivers; State Alzheimer’s Task Force; Older California’s Act;

- 1990's – mid 2000: Strategic Planning – State Independent Living Council; Olmstead Decision; Futurist planning – 6 reports highlighting changes anticipated with the baby boomers calling for restructuring. All failed.
- 2008 – forward – Economic downturn/divestment of services

#### The System Today

- LTSS spread over six departments;
- Faltering economic at federal and state levels have diminished funding;
- Policy makers are ignoring the intersection of demographics, disability and longevity;

#### Challenges facing California

- System fragmentation – silos, multiple funding streams, varied eligibility, difficult to navigate;
- State leadership – in creating a vision and goal setting;
- Lack of capacity – programs not available statewide or funded adequately, especially in rural areas;
- Lack of data and system-wide planning to evaluate effectiveness. No single department uniformly collects and reports all LTC data. Multiple state plans that impact the same population;
- Demographics/longevity – older adult population will grow exponentially while the shrinking subsequent generations will translate into a family caregiver crisis;
- Workforce shortage of professionals and paraprofessionals;
- Local level struggles due to chronic underfunding, increase demand for services and an increase in poverty rates for older adults.

#### The Consumer's Experience of LTSS in California (from the HOME Project, "Helping Older Adults Maintain Independence")

- Consumers needs change over time and experience unpredictable changes in care needs;
- Needs are dynamic and so is the system they depend on. The LTSS landscape constantly shifts but consumers can be challenged (physically and mentally) to be proactive in order to maintain needed care;
- Some older adults need a dense network of care, but are unable to create them due to a fragmented care network or non-existent services;
- Older adults with disabilities have unstable and changing needs, confronting an often unstable and changing set of public supports;
- Cuts and changes to LTSS happen as older adults are also experiencing changes in their physical and mental health. Many just "make do" with what they have regardless of what they need to remain independent at home.

#### Policy Recommendations for the Consumer:

- **Advance truly "person-centered care planning";**
- **Maximize efforts to ensure consumers are well informed and supported to exercise real choice;**
- **Develop continuity of care provisions that reflect consumer preferences.**

## **TOPIC THREE: Emerging Policies That Will Impact the Current System**

**Presenter: Amber Cutler**, Staff Attorney, National Senior Citizens Law Center

**Managed Care Expansion** into 28 rural (primarily fee-for-service) counties as of 2014. Seniors and persons with disabilities will be mandatorily enrolled into managed care with some exclusions.

### **California Coordinated Care Initiative (CCI)**

**Implementation and Implications of the 1.2 million involved individuals – Medi-Cal (seniors and persons with disabilities and dual eligible (Medicare and Medi-Cal):**

- Complexity of transitions
- Enrollment issues
- Disruption of care
- LTSS integration/care coordination issues

Senator Liu summarizes the common themes from the first four speakers:

1. The current system fails to organize around the consumer's needs and has been plagued by fragmentation and years of budget cuts;
2. Consumers and caregivers fail to receive necessary services because they don't know they are available or how to access them;
3. New programs such as the CCI attempt to address some of the system's shortcomings through better coordination and access to services; and,
4. The CCI has placed a significant emphasis on budget savings, while attempting to pilot programs in 8 of the state's largest counties with varying degrees of success. We need to step back and consider what it will take to meet to deliver coordinated care so that seniors and people with disabilities can access the right services at the right time in the right place, in accordance with their needs and preferences.

## **TOPIC FOUR: Envisioning the Ideal Aging and Long-Term Care System**

### **Presenters:**

**Fernando Torres-Gil**, Ph.D., Professor of Social Welfare and Public Policy, Director of the Center for Policy Research on Aging Public Policy, UCLA;

**Laura Trejo**, MSG, MPA, General Manager, Los Angeles Department of Aging;

**Karen Lincoln**, Ph.D., Associate Professor, Director of Hartford Center of Geriatric Social Work Excellence, USC School of Social Work;

**Steven P. Wallace**, Ph.D., Chair, Department of Community Health Sciences, UCLA School of Public Health

**Cheryl Phillips**, MD, Senior Vice President Leading Age

Observations and the responses from the five leading experts on aging and long-term care issues in California are summarized below.

### **1) Values of the IDEAL System**

- Age is appreciated as a stage of life, not treated as a social problem or disease-like state.
- Consumer/family focused
- Culturally competent and linguistically accessible
- Community based
- Staff trained in gerontology and geriatrics

- Role and importance of Caregivers is fully appreciated
- Systems support and encourage interagency cooperation, collaboration, and partnerships – requires effort and investments
- Outcome and data driven accountability
- Covering the cost of LTC should not require impoverishment

## **2) What is the IDEAL?**

- Single-point of entry that would allow for navigation
- Strong advocates for consumer (professional, paraprofessional, family)
- Easy transitions between programs
- Available and trained workforce (professional and family)
- Adequate housing and transportation services
- Culturally compatible services
- Built-in protections against fraud and abuse
- Responsive to seniors with disabilities
- Universally available
- Reliable funding sources for senior services
- Any ideal LTSS system must build on the AAA network
- Implement some of the many recommendations that have been made to date
- California needs a strategic and integrated approach to senior services
- Build on the California Department of Aging's expertise by authorizing them to lead and funding them to provide programmatic and policy recommendations to all levels of State government on issues impacting seniors and their family caregivers
- Ensure that California is implementing cost effective and outcomes driven policies, programs and services to meet the needs of California's seniors and their family caregivers.

## **3) What are the Necessary Components?**

- Addressing the health, social, mental health, spiritual, functional, economic and environmental needs of those who are aging
- Pedestrian/disabled friendly outdoor spaces and buildings
- Affordable housing and convenient transportation
- Respect and social inclusion
- Communication and information on available health and social services
- Preventative information and care
- Social participation
- Civic participation and employment
- Adequate and trained workforce
- Support for caregivers
- Cultural, ethnic considerations and linguistically accessible services
- For LTC Insurance, public/private solution; focus on service-enriched housing for all income levels; be flexible in benefits and their application

## **4) What are the Major Barriers and Challenges?**

- Older adult population is here, growing, increasingly diverse and requires tailored approaches
- Speed of change requires a flexible and quick responses
- Elimination of programs and reduction in services and capacity due to cutbacks in funding over the last five years

- Gaps in labor force readiness
- State-level policy changes consistently fail to see that transitions happen at the local level for consumers, not just at the payer source. As a result, AAA's have been consistently excluded as a major stakeholder
- No strong political advocates for making funding for aging programs a priority
- System fragmentation inhibits collaboration and coordination
- Lack of capacity due to program funding
- Lack of uniform data collection and system-wide planning
- Insufficient workforce and local level struggles
- Within the African American community: 81.5% never heard of CCI; 44/6% do not know how to use a computer; 43% have no internet access; 47.7% do not participate in programs for seniors; 35.2% want programs that are missing; 90.9% say more needs to be done to provide quality services to African American seniors
- Workforce issues: By 2030, 3.5 million additional health care professionals and direct care workers will be needed nationwide. Nationally, between 2010 and 2030, women aged 25 to 44 (the typical direct care worker) will increase by only 7%. Over the next two decades, LA County will gain 867,000 older adults and lose 630,000 people younger than 25 years old. The US could have nearly 63,000 fewer doctors than needed by 2015. That number could double by 2025
- Current and future geriatrician shortfall: 4.41 million older adults 65+ in CA. 739: number of certified geriatricians as of 2011 or one geriatrician for every 5,968 older adults. 2813: the number of geriatricians we need to train between now and 2030
- California family caregivers: Currently, 80% of care is provided informally by family members and friends. There are 4,020,000 family caregivers. \$47 billion – the estimated economic value of unpaid contributions in 2009. 7.7 to 1 – family caregiver ratio in 2010; 4.4 to 1 – family caregiver ratio in 2030; 2.7 to 1 – family caregiver ratio in 2050
- Challenges with current LTC financing: managed LTSS moving toward controlling costs and shifting to HCBS; Medicaid cannot be the solution for middle income people; Middle income seniors poorly prepared for LTC costs due to losses in home equity and retirement following recession and Medicaid safety net requires spending down of assets; 41% of Californian's have a "great deal of concern" about paying for care vs. 29% of Americans

## **5) How Do We Achieve the IDEAL?**

- Legislature and Governor need to make aging and long term care a state priority
- We need to raise awareness and build on the idea of shared risk
- We need to shine a light on the current systems dysfunction
- We must have better data, monitoring, and oversight
- We need a focus on prevention
- We need to improve access and quality of older adult services to vulnerable seniors to reduce the cost of LTC and increase the quality of life for seniors and their families
- We need LTC financing reform – following the example of Minnesota's approach on LTC Financing Reform: focus on middle-income individuals; provide LTC planning information for consumers; use the workplace to educate younger workers; develop insurance products that are simplified, affordable, flexible and portable and consider tax credits for LTC insurance premiums.
- We have the population. We have the expertise. We know the needs. We know the challenges. We know what has to be done. What we need is the political will to do it!

- Advocates need to develop a shared agenda so they can effectively influence the aging and long term care reform movement.

## **TOPIC 5: California in Comparison to Other States: A Look at the LTSS Scorecard**

**Presenter: Gretchen Alkema**, Ph.D., Vice President of Policy and Communications, The SCAN Foundation

The Scorecard is a framework for assessing LTSS System Performance among the 50 states and the District of Columbia. California was measured against five indicators. California ranked in the top quartile overall at Number 9. Ranking for the five indicators were as follows:

- Affordability and access – 14
- Choice of setting and provider – 2
- Quality of life and quality of care – 24
- Support for family caregivers – 24
- Effective transitions – 22

There were five policy recommendations for California's consideration:

- 1) Continue action on the Universal Assessment
- 2) Elevate the value of care coordination
- 3) Create a Bill of Rights for dually eligible Californian's
- 4) Bolster support for California's unpaid caregivers
- 5) Improve LTSS affordability

## **PUBLIC COMMENT**

Public comment at the hearing and at the "Seniors Listening Session" hosted by the Committee on the previous day included the following:

- Consumers should be included in the discussions on aging and long term care;
- Voices of consumers need to be heard and respected; elders need a "Consumer Bill of Rights";
- More funding is needed for case management, respite services for caregivers, and transportation;
- Transportation services need to be more reliable and convenient, i.e., on-time and door-to-door;
- There should be greater communication and cooperation among agencies and programs;
- Service delivery and support programs need to be better coordinated;
- Different cohorts of aging need to be recognized as having different needs; but eligibility criteria need to recognize that functionality and needs vary among those of the same age;
- Education on preparing for needs in old age should be made available when people are younger so they can plan ahead. The public, including the aging, families, and caregivers, need more information about how to age well, how to protect their health and safety, how their needs may evolve, what support they might need, what services are available, and how to access them;
- Consumer should have access to a counselor or advisor that can help them navigate the system and the access the appropriate services and supports;
- Consumers need a way to evaluate the quality of services being offered by nursing homes, in home health care providers, and residential care facilities;
- Caregivers need more information and support especially with respect to the care needed during transition periods when patients are discharged to their homes.
- Federal and state government need to fund cost-effective community and volunteer programs like Senior CORPS;

- Low income/rural communities need more services;
- Alzheimer's Disease Research needs much more funding;
- Primary and secondary prevention should be major features of health care delivery, e.g., diet and exercise, home safety to prevent falls, and better care to prevent secondary complications like pressure sores.

**ON August 12, 2014, The Senate Select Committee on Aging and Long Term Care will hold a Joint Hearing with the Assembly Committee on Aging and Long-Term Care in Sacramento, titled: "Moving CA Toward an IDEAL Long-Term Care System: Recommendations and Next Steps." It will be held in Room 113 of the State Capitol from 2:00 PM – 4:00 PM.**

**INFORMATIONAL HEARING  
SENATE SELECT COMMITTEE ON AGING AND LONG-TERM CARE**

**Tuesday, July 8, 2014 10:00 AM – 1:00 PM**

**Glendale Central Library  
222 East Harvard Street  
Glendale, CA 91205**

**CALIFORNIA’S SERVICE DELIVERY SYSTEM FOR OLDER ADULTS:  
ENVISIONING THE IDEAL**

**AGENDA**

**I. Welcome and Opening Remarks**

**Senator Carol Liu**, Chair, Senate Select Committee on Aging and Long-Term Care

**II. Overview: Who Are the Consumers and What Are Their Needs?**

**Kate Wilber**, Ph.D., Professor of Gerontology, Mary Pickford Foundation, USC School of Gerontology

**III. California’s Current System**

**Sandi Fitzpatrick**, M.A., Executive Director, CA Commission on Aging

**Steven P. Wallace**, Ph.D., Chair, Department of Community Health Sciences, UCLA School of Public Health

1. Current Administrative Structure and Range of Services
2. The Consumer’s Experience
3. Why the system as it exists today is broken

**IV. Emerging Policies That Will Impact the Current System**

**Amber Cutler**, Staff Attorney, National Senior Citizens Law Center

1. Rural Managed Care Expansion
2. California Coordinated Care Initiative (CCI)

**V. Envisioning the Ideal System**

**Fernando Torres-Gil**, Ph.D., Professor of Social Welfare and Public Policy, Director of the Center for Policy Research on Aging Public Policy, UCLA

**Steven P. Wallace**, Ph.D.

**Laura Trejo**, MSG, MPA, General Manager, Los Angeles Department of Aging

**Karen Lincoln**, Ph.D., Associate Professor, Director of Hartford Center of Geriatric Social Work Excellence, USC School of Social Work

**Cheryl Phillips**, MD, Senior Vice President Leading Age

1. What is the Ideal System?
2. What Values Underlie the Ideal System?
3. What are the Necessary Components?
4. What are the Major Barriers and Challenges?
5. How Do We Achieve the Ideal?

## **VI. California in Comparison to Other States: A Look at the LTSS Scorecard**

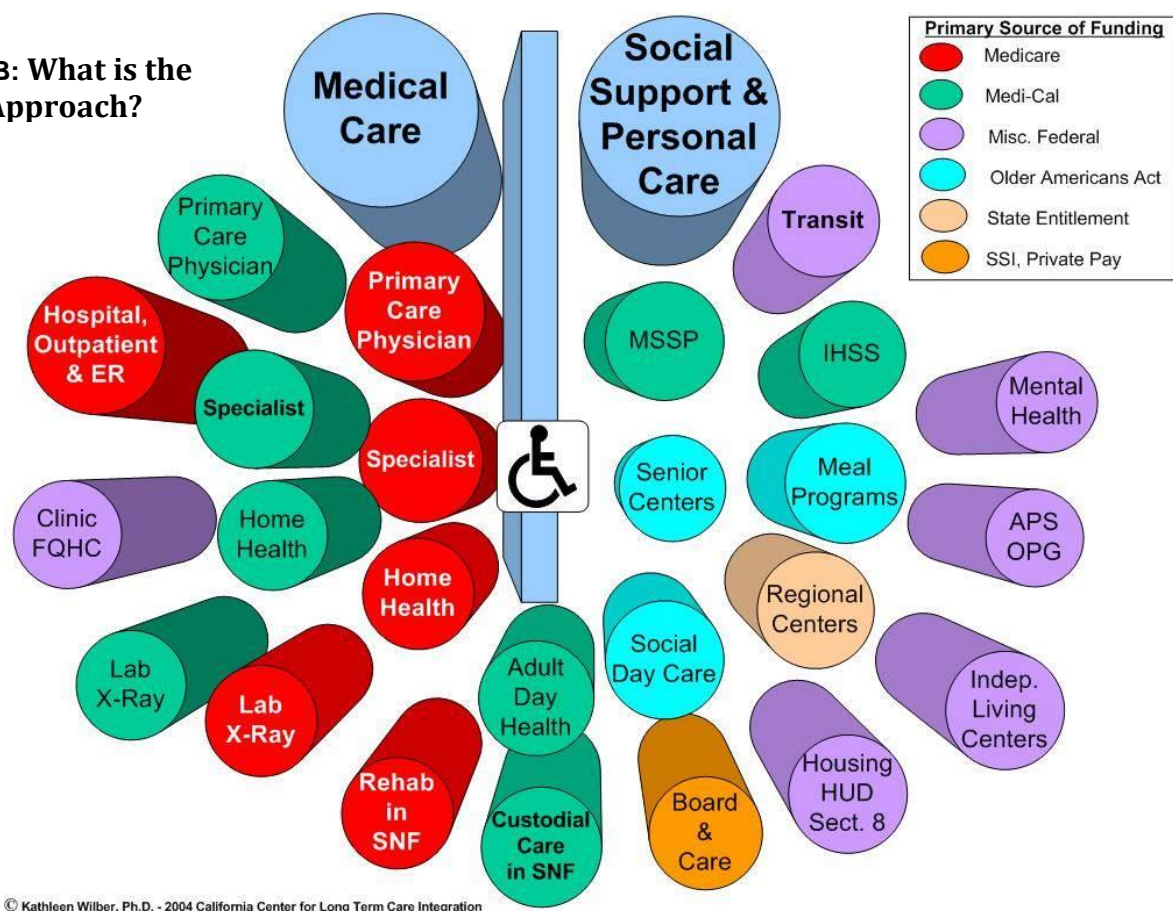
**Gretchen Alkema**, Ph.D., Vice President of Policy and Communications, The SCAN Foundation

## **VII. Public Comment**

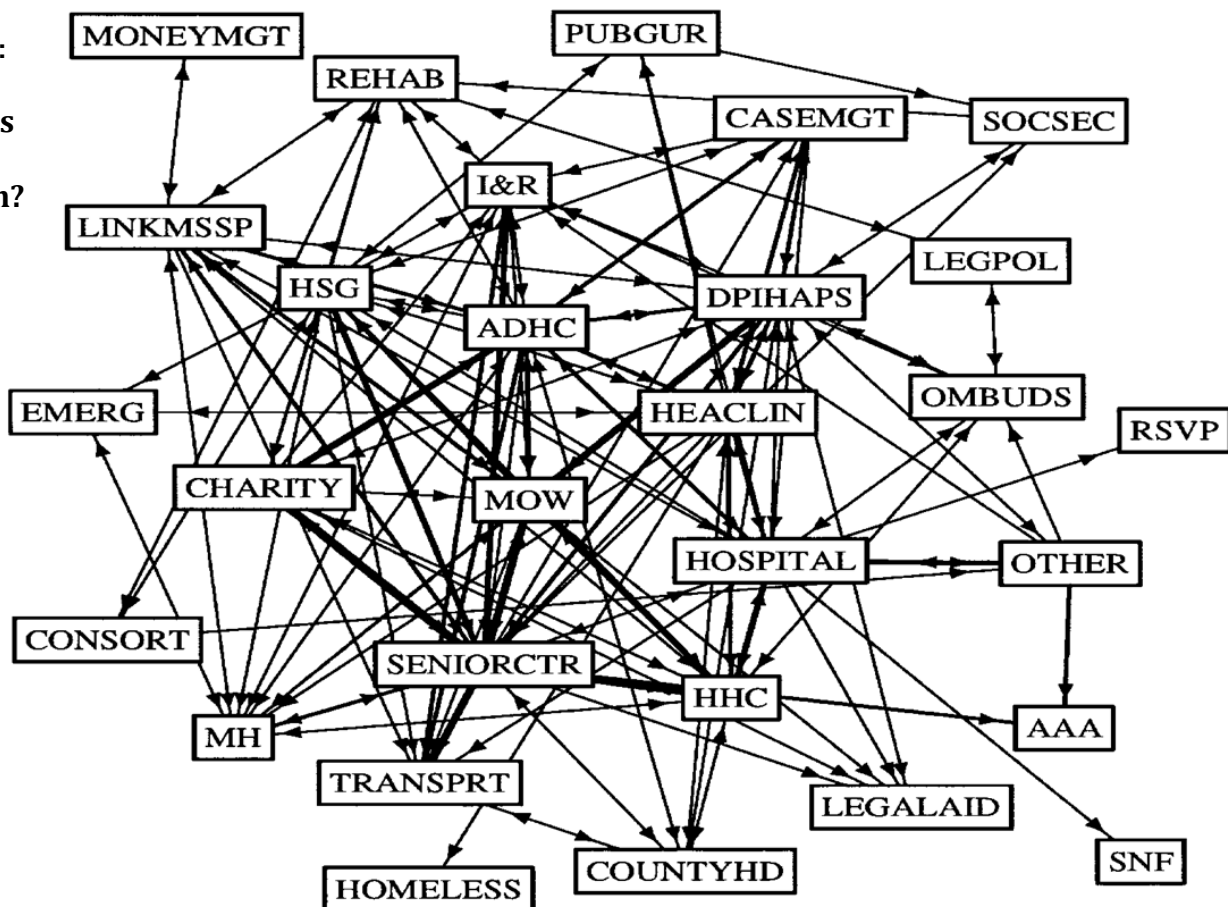
## **VIII. Closing Comments**

**Senator Carol Liu**, Chair, Senate Select Committee on Aging and Long-Term Care

## Appendix B: What is the Current Approach?



## Appendix C: How do Consumers Navigate the System?



**Hearing Summary – August 12, 2014 – Sacramento,  
California**

**SENATE SELECT COMMITTEE ON AGING AND LONG-TERM CARE  
ASSEMBLY COMMITTEE ON AGING AND LONG-TERM CARE**

**SUMMARY REPORT: JOINT COMMITTEE HEARING**

**DATE:** August 22, 2014

**TO:** Senator Carol Liu, Chair, Senate Select Committee on Aging and Long-Term Care and Committee members: Senators Jim Beall, Tom Berryhill, Ed Hernandez, Richard Roth, Lois Wolk, Assemblywoman Mariko Yamada, Chair, Assembly Committee on Aging, And Long-Term Care and Committee members: Assembly members: Cheryl Brown, Tom Daly, Adam Gray, Shannon Grove, Marc Levine, Donald Wagner

**FROM:** Patty Berg, Principal Consultant, Senate Select Committee on Aging and Long-Term Care

**SUBJECT:** Summary Report: Joint Committee Hearing on “Implementing an IDEAL Aging and Long-Term Care System in California”

The Senate Select Committee on Aging and Long-Term Care, chaired by Senator Carol Liu, together with the Assembly Committee on Aging and Long-Term Care, chaired by Assembly Member Mariko Yamada, held a Joint Hearing on August 12, 2014, at the State Capitol in Sacramento, California. Over 200 people representing consumers, service providers and a variety of stakeholder groups attended to hear recommendations from noted experts in the field of gerontology on implementing an IDEAL aging and long-term care system in California. (See Agenda, Appendix A).

This hearing followed an informational hearing held in Glendale, California on July 8, 2014. Recommendations regarding what was needed for structural change from the Informational Hearing were synthesized and prioritized into five major policy areas identified as mandatory first steps in addressing the creation of an IDEAL system: State and Legislative Leadership, Fragmentation and Lack of Integrated Data, Infrastructure - Statewide and Rural Capacity, Workforce, and Funding.

A video of the full hearing can be found at [www.CalChannel.com](http://www.CalChannel.com) “Video on Demand, Joint Legislative Hearing on Implementing an Ideal Aging and Long-Term Care System in California, August 12, 2014.”

Senator Liu opened the two-hour Joint Hearing by referencing an infographic designed by the Senate Office on Research illustrating the 20 different state departments and 112 long-term services or programs that currently attempt to meet the needs of California’s older adults and people with disabilities. The infographic (See Periodic Table, Appendix B) clearly shows the fragmentation and the impossibilities of coordination that not only confound access for consumers but also impedes efficient delivery of services.

Both Senator Liu and Assemblywoman Yamada expressed their optimism that the recommendations made in the five policy areas would help produce both a legislative and administrative roadmap – both in the short-term and the long-term – for designing and implementing a truly responsive and IDEAL Aging and Long-Term Care system for Californians.

**TOPIC ONE: “Envisioning the IDEAL”: Findings and Conclusions from the Informational Hearing Conducted July 8 in Los Angeles**

**Presenter: Patty Berg,** Principal Consultant, Senate Select Committee on Aging and Long-Term Care

Ms. Berg summarized the responses of presenters Dr. Fernando Torres-Gil; Laura Trejo; Dr. Karen Lincoln; Dr. Steven P. Wallace and Dr. Cheryl Phillips, M.D. (See Power Point Presentation, Appendix C) to the five questions posed by the Select Committee:

1. What values underlie and IDEAL system?
2. What is the IDEAL system?
3. What are the essential components?
4. What are the major barriers and challenges?
5. How do we achieve the IDEAL?

She noted the problems with the current system:

- System fragmentation – silos, multiple funding streams, varied eligibility, difficult to navigate
- State leadership – in creating a statewide vision and goals
- Lack of capacity – especially in rural areas, where home and community based services are not available or adequately funded
- Lack of data and system-wide planning - to evaluate effectiveness
- Demographic diversity and longevity
- Workforce shortage
- Local level struggles – due to chronic underfunding, increased demand for services and increase in poverty rates for older adults
- Lack of strong political advocates – to make funding for aging a priority

July 8<sup>th</sup> hearing recommendations for creating an IDEAL system included:

- Make aging and long-term care a state priority
- Raise awareness and build on the idea of shared risk
- Shine a light on the current system’s dysfunction – and the return on investment of providing a better system of services and supports
- Improve data, monitoring and oversight
- Focus on prevention
- Improve access and quality of older adult services to vulnerable seniors – to reduce the costs of long-term care and increase the quality of life for seniors and their families

- Reform long-term care financing
- Advocates develop a shared agenda – so we can wield more clout in the aging and long-term services and supports reform movement

The final take-away from the July 8<sup>th</sup> hearing was:

***We have the population. We have the expertise. We know the needs. We know the challenges. We know what has to be done. What we need is the political will to do it.***

## **TOPIC TWO: From the Long-Term Services and Supports (LTSS) Scorecard: California System Change Recommendations**

**Presenter: Gretchen Alkema, Ph.D.,** Vice President of Policy and Communications, The SCAN Foundation.

**Policy Recommendation 1: Continue Action on Universal Assessment.** The Legislature should change the pilot status of Universal Assessment to a permanent state initiative. Given the importance of Universal Assessment as the cornerstone of an organized system of care that is more responsive to individual's needs, values, and preferences, the Legislature should remove the sunset and commit the Universal Assessment process to statute as a project implemented in all CCI counties, with eventual statewide expansion. Further, the process should include caregiver-specific questions to enable providers to better support the needs of unpaid family caregivers. Finally, the state should commit the necessary resources to facilitate the project's expansion.

**Policy Recommendation 2: Elevate the Value of Care Coordination.** The Legislature should establish clear care coordination guidelines and strong accountability standards in statute. Specifically, care coordination should be a required service authorized in statute as part of the CCI, along with the other required LTSS services authorized in statute (healthcare and LTSS including CBAS, MSSP, IHSS, and Nursing Facility care). Further, the Legislature should specify an individual's rights to access care coordination, which entity(s) is/are responsible for ensuring this access, and appeals processes in the event the care coordination service is not delivered.

**Policy Recommendation 3: Create a Bill of Rights for Dually Eligible Californians.** The Legislature should reframe the dual eligible system change conversation from one of finance and budget issues to one of person-centered care with the needs and desires of the individual at the core of the discussion. To this end, California should establish a "Dual Eligible Bill of Rights" that outlines in statute the rights of dual eligible individuals including access to an array of services in an integrated setting, consumer choice, and empowerment. These rights would establish the foundation of system change efforts, establish accountability for the health plans, and communicate what people can expect from coordinated services that are grounded in meeting the needs, desires, and preferences of consumers.

**Policy Recommendation 4: Bolster Support for California's Unpaid Caregivers.**

The state should develop a strategy/plan to support family caregivers, taking into account the available programs and services and areas to expand and build upon the system. In addition, employment-related policies could be reconsidered to better support California's unpaid caregivers in the workforce. Such policies could include increased length of protected leave, and expanding the California Family Rights Act to include care for grandparents, siblings, and in-laws to match the Family Paid Leave benefit.

**Policy Recommendation 5: Develop a Long-Term Plan for LTSS**

**Transformation.** California leadership should identify a clear long-term vision for LTSS, and develop a strategic plan focused on the vision as a measure for setting priorities and accountability for forward movement.

**Policy Recommendation 6: Establish Legislative Policy committees with LTSS**

**Oversight.** The Senate should follow the Assembly's lead and establish a standing policy committee on Aging and Long Term care with monitoring and oversight responsibilities over those programs and services that would constitute a "system" of LTSS and other health and long-term care programs serving older adults and people with disabilities.

**Policy Recommendation 7: Improve Affordability for the Future. The California Legislature should urge the California Congressional delegation to act on the issue of Long-Term Care financing. The Legislature should make Long-Term Care financing a priority of California and consider the Bipartisan Policy Center's Long-Term Care Initiative [what is this? Need more definition] and forthcoming recommendations.**

**TOPIC 3: System Changes: Priority Policy and Budget Proposals for 2015 Legislative Session**

**Presenters: Fernando Torres-Gil**, Ph.D., Professor of Social Welfare and Public Policy, Director of the Center for Policy Research on Aging Public Policy, UCLA, Member, AARP Board of Trustees

**Laura Trejo**, MSG, MPA, General Manager, Los Angeles Department of Aging

**Sandi Fitzpatrick**, M.A., Executive Director, California Commission on Aging

**Sarah Steenhausen**, M.S., Senior Policy Advisor, The SCAN Foundation

Of the four distinguished leaders in the field of aging, three of them took part in the Senate Select Committee's Informational Hearing in July: Dr. Fernando Torres-Gil, Laura Trejo and Sandi Fitzpatrick. Sarah Steenhausen, the fourth panelist, has been working closely with the Senate Select Committee since its inception.

The panelists spoke to the five System Changes, starting with State and Legislative Leadership. Each of the five System Changes had leadoff speakers, responding to

pre-assigned questions posed by the Senate Select Committee. Other panelist's were invited to also add their comments.

### **System Change Number 1: State and Legislative Leadership**

Leadoff Speakers: Dr. Fernando Torres-Gil and Sandi Fitzpatrick

**Question: What strategies do you recommend to cultivate legislative leadership and the policy expertise necessary to address these critical issues and set key policy priorities?**

#### **Dr. Torres-Gil:**

- The Senate Select Committee and Assembly Committee on Aging are already providing leadership. There is, as well, a robust set of organizations that care about long-term care issues.
- Aging, however, is not a priority at the national or state level or with the public at large.
- Changing demographics and aging of the baby boomers portends a crisis and creates a perfect storm that can catalyze change.
- Identify your leaders and key advocates and bring them together in a critical mass for change.
- Make the Senate Select Committee a permanent policy committee and expand the jurisdiction of both the Assembly and Senate aging committees. They need to be seen as power players.
- The Legislature needs to be yelling and screaming. In order to do that, you need the data and documentation to make the case.
- The Legislature/advocates need to tell the story to the media and public in a different way in order to get them aroused and supportive. Need to develop a new narrative, e.g., choice and independence.
- Charge and involve the UC system to assist the Committees in making the case – to the Legislature at large, the media and the public.
- Change the name of the Department of Aging to the Department of Aging and Long-Term Care.
- Services for long-term care and home and community based services for aging and persons with disabilities need to be consolidated. The head of such a department must report directly to the Governor.
- Litigation is always an option to consider. Work with the National Senior Citizens Law Center and the Olmstead Advisory committee to pursue issues and leverage change.
- Involve the private sector, asking what they want that would also mesh within our framework for change.
- Involve older Californians (consumers and potential consumers) and veterans.
- Need to develop a longevity services plan to educate both youth and middle age folks. It should start with “you will need or provide care one day.”

- California must continue to provide leadership. Aging and long term care are historically a low a priority of the Executive branch and the Legislature. The message must be plan, prepare and invest for the inevitable. It will be worth it.

**Sandi Fitzpatrick:**

- California should look to the federal Administration for Community Living as a potential model for state integration.
- Integration efforts must be adequately resourced – both backfill dollars and new dollars must be a priority for aging programs.
- Expand the jurisdiction of the Assembly Aging and Long-Term Care Committee and establish a like policy committee in the Senate.
- The transformation towards integrated care in California is predicated on the expansion of managed care. If managed care is the ultimate service system for older Californian's in all counties – then we need to ask ourselves how will the core LTSS be integrated and further how should the existing home and community based service programs be incorporated into this new model.

**Sara Steenhausen (The SCAN Foundation) added:**

- Significant policy proposals (such as the Coordinated Care Initiative) should be considered as part of the policy process, rather than as budget initiatives, which often lack the opportunity for thoughtful policy deliberation.

**System Change Number 2: Fragmentation and Lack of Integrated Data**

Leadoff Speaker: Sarah Steenhausen

**Question: What should the legislature do, a) in the near-term and b) in the long-term, to eliminate the silos and inconsistencies among programs and also promote collaboration and coordination of services at the state, regional and local levels?**

- Structure services and programs more effectively at the state level.
- Develop a long-term plan for LTSS development in an integrated system of care. Create a long-term plan that outlines priorities for developing a statewide infrastructure needed to develop an integrated system of care in all California counties.
- Examine State Capacity. Examine other state programs, to consider the kinds of staffing and content expertise necessary in this evolving role of the state monitoring and oversight of managed care plans responsible for delivering the full range of Medi-Cal services.
- Enhance the role of external evaluation and stakeholder oversight. The Legislature should consider developing a more formalized arrangement for stakeholder oversight feedback in California's Coordinated Care Initiative.

- The Legislature should enhance oversight of CCI on an ongoing basis, dedicating one policy committee in each house to review implementation and evaluate the success of the CCI to identify issues and areas for improvement.
- Develop networks of individual-level data that, when connected and effectively analyzed, create a comprehensive picture of the needs and service use patterns of individuals in the system and allow for the evaluation of the quality of care they receive at a specific point in time as well as across points in time.
- An integrated information system can support provider access to appropriate information in a timely fashion and can reduce perennial problems individuals experience with multiple assessments.
- Information should be automated electronically and organized centrally enabling the universal assessment, which is embodied by a uniform set of questions gathered for each participating individual, can be used to evaluate their needs in a consistent manner and create a care plan tailored to each person's strengths, needs, and service/support preferences.
- At the state level, universal assessment data can help program planners understand the needs of the population, support allocation of resources at the person, program, and state levels in a standardized way, and enable evaluation of quality.

**Laura Trejo added:**

- There is a cost to data. It requires discipline. The Health and Human Services Agency must set the standards. It must own it and use it. Consistency in data collection is required for both statewide planning and effective service delivery

**System Change Number 3: Infrastructure: Statewide and Rural Capacity**

Leadoff Speakers: Laura Trejo and Sandi Fitzpatrick

**Questions: 1) What short and long-term actions do you recommend to develop and expand California's LTSS infrastructure? And, 2) What specifically should be done to expand services in rural communities?**

**Laura Trejo:**

- There is a pressing need to work with other state agencies that also provide services in a variety of settings to an aging population.
- Look for efficiencies and opportunities to leverage partnerships and resources.
- Access the UC system to identify ways to improve systems.
- Redirect existing resources and repurpose programs.
- Infuse geriatric competencies within the education system.
- Decide how to select funding priorities for LTSS by way of investment and redirect reinvestment of resources. **[needs a little further explanation]**

**Sandi Fitzpatrick:**

- The 44 rural counties in California lack the necessary infrastructure of LTSS. Improving rural older adults' access to care requires a combination of creativity, flexibility, and merit a public commitment of dollars.
- The minimum necessary set or basic service mix of LTSS must be determined at the state level. Next, each of the 44 rural counties would be assessed to establish gaps and then resources should be invested to ensure the basic service mix is in place statewide.
- Medi-Cal reimbursements to primary care physicians must be increased from the current rate. Low rates are especially detrimental in rural areas.
- Rural hospitals must be able to employ primary care physicians but recruiting and retaining these professionals are particularly difficult in rural settings.
- Increase the use of telemedicine and telepharmacy services in rural counties.

**System Change Number 4: Workforce**

Leadoff Speakers: Dr. Torres-Gil and Laura Trejo

**Question: How can California prepare to meet the workforce needs for aging and long-term care?**

**Dr. Torres-Gil:**

- The question on everyone's mind should be: **who will take care of us?**
- Need to involve the CSU's and community colleges. Higher education has an important role to play, majoring in gerontology is not an easy sell to young people.
- How to entice students to enter the field of gerontology is the Big Question. We need to develop a sound strategy to do this, involving educational leaders.

**Laura Trejo:**

- Fund higher education for gerontology.
- Invest in creative financing for students to enter the field, e.g., loan forgiveness if you work in the field for two years following graduation (similar to MSW degrees); internships, paid field placements, etc.
- Partner with foundations to offer scholarships.
- Work with the California Council on Gerontology and Geriatrics to assist in addressing workforce issues, including identifying successful models employed by other states.

**Sarah Steenhausen (of The SCAN Foundation) added:**

- Identify what is needed to expand and support the direct care workforce.
- Provide greater support to California's unpaid family caregivers.

- Expand nurses' ability to delegate. California should revise scope of practice to broaden opportunities for professional and direct care workers with demonstrated competency to perform essential aging and long term care tasks. Specifically, the state should permit nurses to delegate and supervise certain tasks to direct care workers with sufficient training and demonstrated competency to perform them, particularly in home and community based settings that do not have regularly scheduled registered nurses, subject to sufficient consumer protections.

### **System Change Number 5: Funding**

Leadoff Speaker: Laura Trejo

**Questions: 1) What can policymakers do in the short-term to provide adequate funding for aging and long-term care services? And 2) What programs and funding should California advocate for at the federal level?**

**Laura Trejo:**

- Target funding on health care models that work.
- Invest in Family Caregiver network.
- Invest in mental health suicide prevention programs for older adults.
- Legislature must support the reauthorization of the Older Americans Act, sending a letter to the California Congressional Delegation urging their support and requesting action on behalf of California's seniors.
- Strategically examine how California can leverage dollars through the 1115 federal waiver.
- Within California's Coordinated Care Initiative is a new system – how will the legislature oversee rates and services? There are built-in incentives for home and community based services, which signifies a major shift in how California has done business previously.

**Sarah Steenhausen (of The SCAN Foundation) added:**

- Focus on developing a person-centered system, not program-centered. Ensure that the system adequately funds services and supports – across both health and human services – that meet a range of needs for the person through a more holistic approach to service delivery.
- Examine financial incentives and access to a range of services in the new system of care. It is critical that the new system of care be adequately funded through rate development, to ensure appropriate funding of the entire range of services.
- Dedicate resources for state oversight capacity. With more of the service delivery system devolving to managed care plans, the Legislature should ensure there is adequate funding for the state infrastructure to perform high-quality monitoring and oversight of Coordinated Care Initiative plans.
- Develop a budgeting plan for statewide LTSS system integration. The state should develop a plan and blueprint for how it will proceed with an

integrated system of care and includes budgeting practices that incentivize access to home and community based services, regardless of where one resides.

- The Legislature should closely evaluate the extent to which the current rate structures for both Cal MediConnect and Managed LTSS incentivizes the use of home and community based services vs. institutionalization, and what policies could be instituted to increase access to a range of services.
- Using the 1115 Waiver renewal, the California should pursue the potential to bring additional resources into the LTSS system by developing additional integrated models of care that can be tested through the waiver, while also considering all of the components that fall under jurisdiction of the existing waiver, including managed LTSS.

## **PUBLIC COMMENT**

- We need to fully fund service for senior citizens. We remain a low priority and our advocacy is crummy. We need to focus on Legislative Caucuses, not just committees, starting with the Women's Caucus. We need to work with leadership and push a model that the Governor will support.
- We need to reinvest in naturalization service programs and in housing and transportation.
- Support HICAP programs. Long term care financing – the majority of the middle class has been left out and cannot purchase long-term care insurance. How will we pay for their care? Public benefits are good to talk about, but the middle class is not served by these programs.
- The average person is ill prepared to face long-term care. We need a longevity education plan. The system is too fragmented. We need single point of entry – like 211.
- We need more support for younger disabled individuals. Their need is longer.
- We must professionalize the workforce for both the worker and the employer.
- Unpaid caregivers are the backbone of long-term care. Nurse practitioners should have independence in their scope of practice. Universal assessment is critical. Caregivers need training before a family member is discharged from hospital.
- Integrate home and community based providers. More protections need to be in place. There needs to be a process in place to assist the transfer of MediCal beneficiaries from plans.
- We are over-assessed. Area Agencies on Aging have a proven track record of success. They need support and funding to face the challenges ahead. We must all work together for solutions.
- Need to integrate services from beginning to end. Rural areas do not know about services. Need culturally appropriate information, training and services. Need media education

- Set standards and educate people to meet people's needs. Mental health services are cut off at age 59 in many counties.
- The Elder Justice Coalition stressed the importance of considering elder justice concerns when looking at service integration and called for statutory changes to improve the state's response to elder and dependent adult abuse.
- Sacramento lacks good mental health services for the disabled. Adequate housing and transportation are huge issues.
- The long-term care ombudsman is the only health and human services program required to maintain presence in assisted living and skilled nursing facilities. We need systems we can be proud of that secure the safety and well being of seniors.
- Consider serious mental health issues in the aging population.
- Support system integration and universal design. Encourage people to receive subsidies to modify their homes before they become disabled. We need more funding.
- Infrastructure will be important. Support what works well, restore what used to work with funding. This year we tried to get funding back to 2008 levels. It did not happen. The good parts of our system are under threat right now.
- Be aware that people do not have advocates for them. We need more ombudsmen to speak up for those who have no advocates.

# Senate Select Committee on Aging and Long Term Care

July 8<sup>th</sup> Hearing Summary:  
California's Service Delivery System  
for Older Adults: Envisioning the Ideal

Patty Berg, Principal Consultant



## Problems:

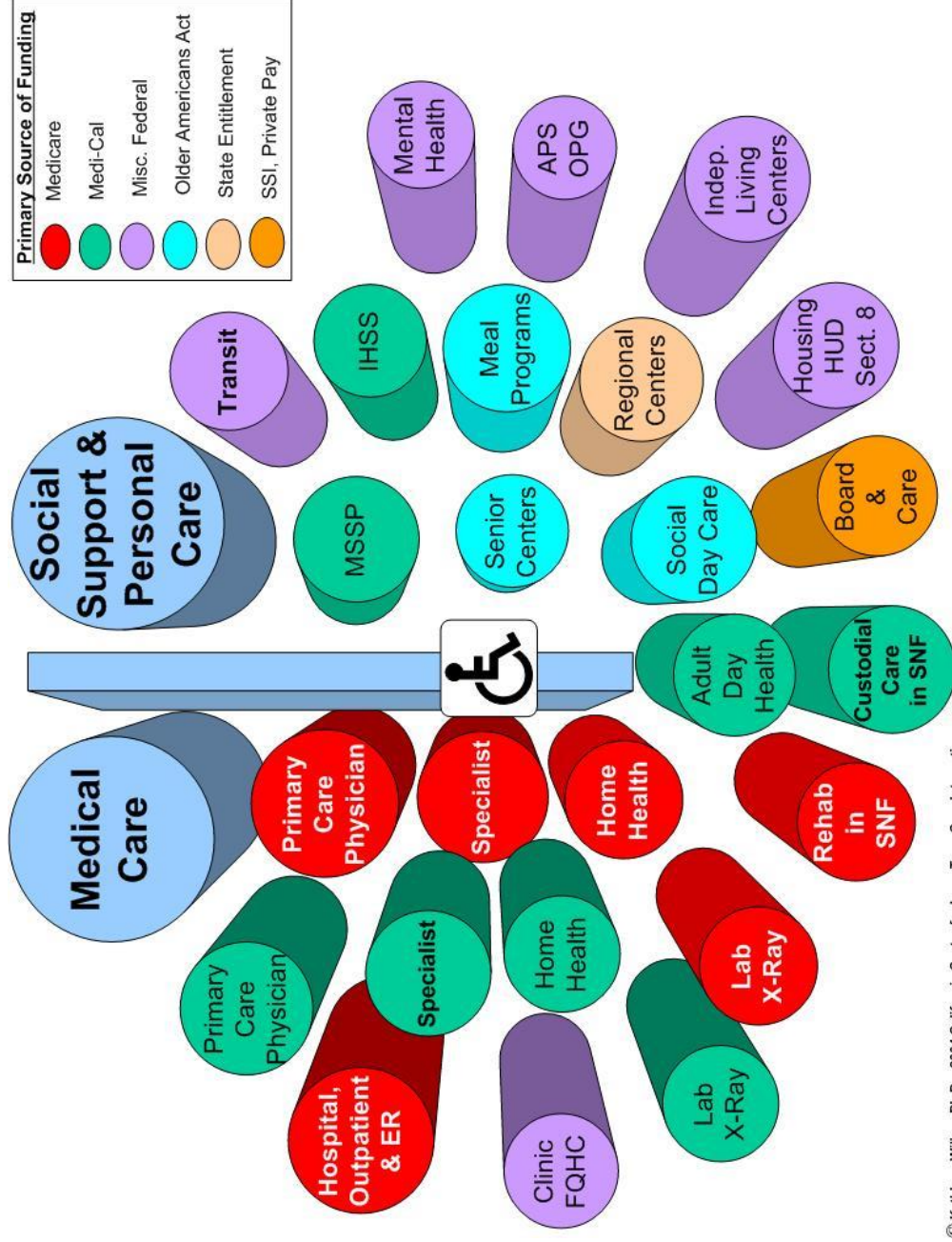
- No person-centered, individualized care
- Poor transitions
- Limited access to a range of services, especially in rural areas
- Lack of cultural competency
- Lack of high skilled workforce to meet demand
- No Uniform Data
- No Universal Assessment tool
- Limited Caregiver supports



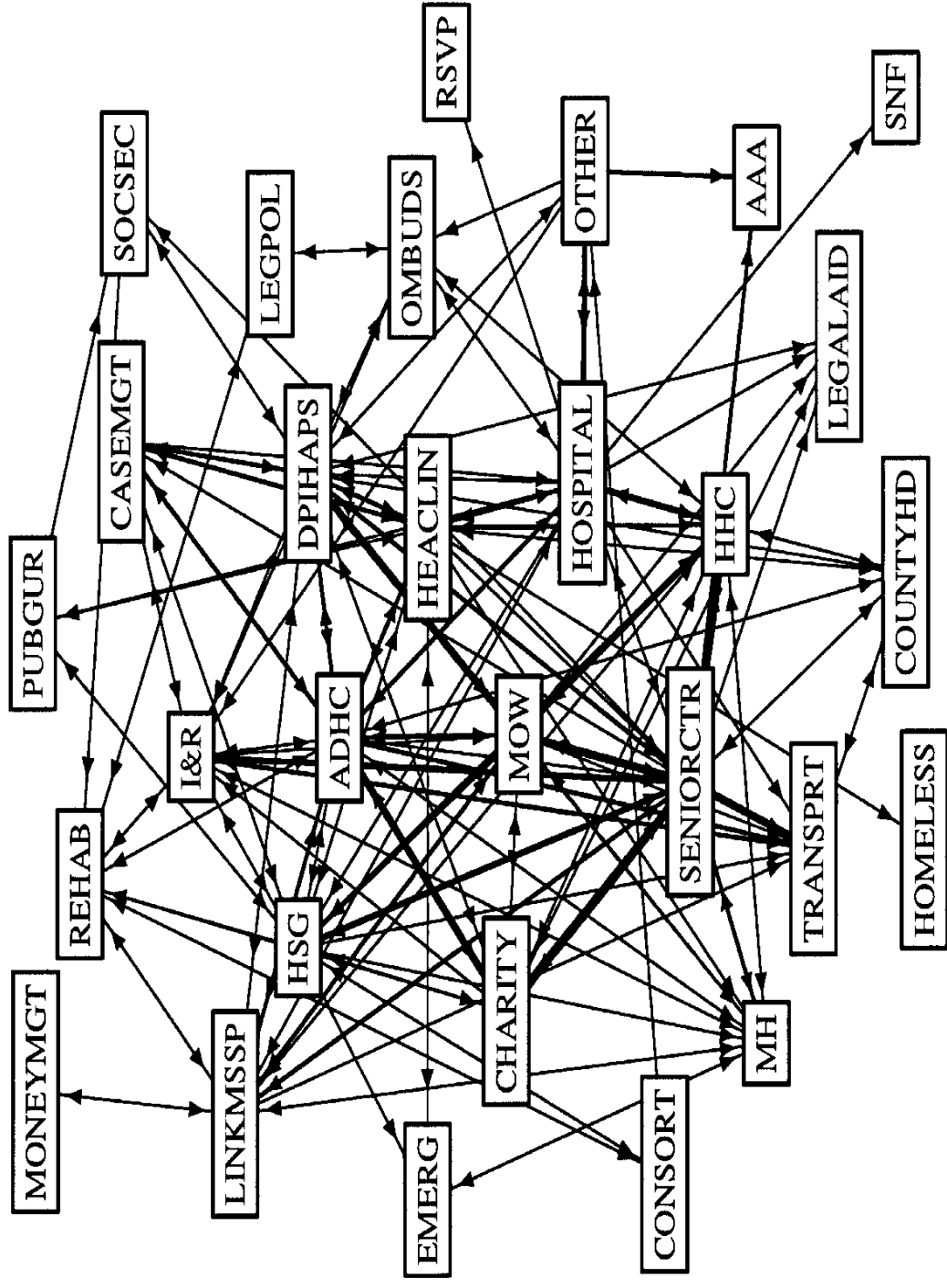
# The Current System

- Fails to organize around consumer needs
- Is plagued by fragmentation and years of budget cuts
- Is difficult, if not impossible, to navigate and access
- Lacks systematic and integrated data collection and evaluation

# What is the Current Approach?



# How do Consumers Navigate the System?





# Establishing a New Structural Vision

- What values underlie an IDEAL system?
- What is the IDEAL system?
- What are the essential components?
- What are the major barriers & challenges?
- How do we achieve the IDEAL?



# Underlying Values:

- Age appreciated as a stage of life, not a social problem or disease
- **Consumer centered/family focused**
- Culturally competent and linguistically accessible
- **Community based**
- Workforce trained in gerontology and geriatrics
- **Systems that support interagency cooperation, collaboration, and partnerships**
- Outcome and data driven accountability
- **Caregivers recognized and supported as part of the system**
- Long-term care should not require impoverishment



# The IDEAL:

- Strategic, integrated approach to senior services
- Department of Aging leads and coordinates system change
- Cost effective and outcome-driven policies, programs and services
- Universally available and sustainably funded system
- A single-point of entry
- Smooth and easy transitions
- Protections against fraud and abuse
- Culturally sensitive and compatible
- Services in urban and rural settings
- Area Agencies on Aging network as the foundation of a statewide infrastructure
- A trained aging and long-term care workforce funded through public/private partnerships
- Caregiver support
- Strong advocates for the consumer
- Senior affordable housing and transportation needs reflected in state, regional and local plans.



# Essential Components:

- Holistic approach through a continuum of care
- Respect and social inclusion
- Communication and information on available health and social services
- Civic participation and employment
- Adequate and trained workforce
- Caregiver support services
- Cultural and ethnic considerations and linguistically accessible services
- Preventative information and care
- Public/private solutions for long-term care insurance
- Affordable housing, transportation oriented development, and transportation services
- Universal design of outdoor spaces and buildings



# Major Barriers & Challenges:

- System fragmentation
  - Demographic diversity and longevity
- State leadership
  - Workforce shortage
- Lack of capacity
  - Local level struggles
- Lack of data and system-wide planning
  - Lack of strong political advocates



# Achieving the IDEAL:

- Make aging and long term care a state priority
- **Raise awareness and build on the idea of shared risk**
- Shine a light on the current system's dysfunction
- **Improve data, monitoring, and oversight**
- Focus on prevention
- **Improve access and quality of older adult services to vulnerable seniors**
- Reform Long-term care financing
- **Advocates develop a shared agenda**

*We have the population. We have the expertise. We know the needs. We know the challenges. We know what has to be done. **What we need is the political will to do it..***

## Biographies

**SENATE SELECT COMMITTEE ON AGING AND LONG-TERM CARE  
ASSEMBLY COMMITTEE ON AGING AND LONG-TERM CARE**

**Expert Panelists' Biographies**

**GRETCHEN ALKEMA**

Gretchen E. Alkema serves as Vice President of Policy and Communications for The SCAN Foundation. Prior to joining the Foundation, she was the 2008-09 John Heinz/Health and Aging Policy Fellow and an American Political Science Association Congressional Fellow, serving in the office of Senator Blanche L. Lincoln (D-AR). Dr. Alkema collaborated with legislative staff to advise Senator Lincoln on aging, health, mental health, and long-term care policy.

Dr. Alkema holds a PhD from the University of Southern California's Davis School of Gerontology and was awarded the John A. Hartford Doctoral Fellow in Geriatric Social Work and AARP Scholars Program Award. She completed post-doctoral training at the VA Greater Los Angeles Health Services Research and Development Center of Excellence and was a research associate for the California Fall Prevention Center of Excellence. Her academic research focused on evaluating innovative models of chronic care management and translating effective models into practice.

Dr. Alkema also earned a master's in social work with a specialist in aging certificate from the University of Michigan and a bachelor's degree in psychology from the University of Colorado, Boulder. As a Licensed Clinical Social Worker, she practiced in government and non-profit settings including community mental health, care management, adult day health care, residential care and post-acute rehabilitation.

**AMBER CUTLER**

Amber Cutler is a staff attorney with the National Senior Citizen's Law Center. She joined NSCLC's Health Care team in February 2013 and is based in NSCLC's Los Angeles office. Amber primarily focuses on California's Coordinated Care Initiative and other changes under the Affordable Care Act impacting low-income seniors and persons with disabilities. Amber formerly worked for Legal Aid of Western Missouri as Director of the Medical Legal Partnership at St.Luke's Hospital in Kansas City, Missouri. Amber is admitted to the California, Missouri, and Illinois bars and is a 2006 graduate of Washington University School of Law.

**SANDI FITZPATRICK**

Sandra Fitzpatrick has nearly 35 years of experience in the administration, development and evaluation of senior and volunteer services with an expertise in rural service delivery. She is a respected statewide advocate for older adults. Since 2004, Ms. Fitzpatrick has been the Executive Director of the California Commission on Aging, an independent state entity that serves as the principal advocate for over six million older Californians. The 18 member Commission serves in an advisory capacity to the Governor, the State Legislature, and the California Department of Aging.

Her work at the Commission has included advancing the cause of elder justice, taking a lead role in helping the state understand the implications of Medi-Cal Managed Care expansion to rural counties, and promoting community based services transformation through a multiyear senior center initiative. Under her direction the California Commission on Aging has successfully secured policy bills related to senior housing, older adult mental health, culturally appropriate services, and for increased funding for the long-term care ombudsman.

Ms. Fitzpatrick worked with the Governor's office to coordinate California's White House Conference on Aging delegation in 2005. She is a Board Member of the California Foundation on Aging and a member of the Model Approaches Senior Legal Advisory Group.

Formerly, she was the Executive Director of the Area 1 Agency on Aging in northern California and a member of the Executive Committee of the California Association of Area Agencies on Aging. She was a national Policy Committee delegate to the 2005 White House Conference on Aging. Fitzpatrick earned a master's degree in organizational communication from Humboldt State University.

#### **KAREN LINCOLN**

Karen D. Lincoln is an associate professor in the School of Social Work and the associate director of the USC Edward R. Roybal Institute on Aging. She graduated with honors from the University of California, Berkeley, where she received a BA in Sociology with a minor in African American Studies, and is a graduate from the University of Michigan, where she earned an MSW, an MA in Sociology and a PhD in Social Work and Sociology.

As a researcher, Lincoln grapples with issues that are locally, nationally and internationally meaningful. Her research lies in improving clinical and community-based treatment of persons with mental health disorders and chronic health conditions and is supported by a number of different agencies within the National Institutes of Health, including the National Institute on Aging, the National Institute of Child Health and Human Development, and the National Institute of Mental Health. The goal of her research is to identify intervention points and strategies for limiting further deterioration of health and mental health of black Americans by examining social determinants. Specifically, her research focuses on the social environment, psychosocial, sociocultural and health behavioral factors in the etiology of mental health disparities while illuminating the role of stress, social networks and health behaviors as they relate to psychiatric disorders and health outcomes.

#### **CHERYL PHILLIPS**

Cheryl Phillips, M.D. is the Senior VP for Advocacy and Public Policy at LeadingAge in Washington, D.C, a national association of over 6,000 not-for-profit aging services provider organizations. Prior to this role she was Chief Medical Officer of On Lok Lifeways, the originator of the PACE (Program of All-Inclusive care for the Elderly) model based in San Francisco, CA. She has also served as the Medical Director for Senior Services and Chronic Disease Management, for the Sutter Health System, a network of doctors, hospitals and other health providers in Northern California. As a fellowship-trained geriatrician her clinical practice focused on nursing homes and the long term care continuum. In addition to being a hands-on medical director of multiple nursing homes in California, she oversaw the network development and quality oversight for Sutter's Sacramento-Sierra region post-acute care.

Dr. Phillips is the past president of the American Geriatrics Society, the organization representing health care professionals committed to improving the health of America's seniors; and is also past president of the American Medical Directors Association, the physician organization for long-term care. She serves on multiple national boards and advisory groups for chronic care including the CMS Quality Assurance and Process Improvement (QAPI) Technical Expert Panel in Long Term Care, the National Quality Forum MAP Coordinating Committee, and has provided multiple testimonies to the U.S. Senate Special Committee on Aging. She served as a primary care health policy fellow under Secretary Tommy Thompson, and was appointed by the Governor as a California Commissioner on Aging and appointed to the Olmstead Advisory Committee for California. Currently, Dr. Phillips is the immediate past chair

of Advancing Excellence, the campaign for quality improvement in nursing homes. Bachelor of Science: University of the Pacific, Stockton, CA, 1980 Doctor of Medicine: Loma Linda University School of Medicine, Loma Linda, CA, 1985 Medical residency, chief residency, and geriatric fellowship, University of California, Davis, 1989

#### **SARAH STEENHAUSEN**

Sarah Steenhausen is the Senior Policy Advisor for The SCAN Foundation. She provides counsel and guidance regarding state-level initiatives and policy opportunities as well as recommendations for raising awareness and educating state policymakers on issues impacting California's seniors.

Ms. Steenhausen joined The SCAN Foundation after serving as assistant secretary for Long Term Care at the California Health and Human Services Agency. In this capacity, she directed efforts of the state Olmstead Advisory Committee and the Alzheimer's Advisory Committee, and served as primary advisor to the secretary on aging and long term care legislative and budget measures. Previously, Ms. Steenhausen worked as the assistant director for Strategic Planning at the California Department of Developmental Services.

Ms. Steenhausen's legislative experience includes serving as Consultant to the Senate Subcommittee on Aging and Long Term Care and as consultant to the Senate Health and Human Services Committee. She holds a Master's of Science in gerontology from the USC Davis School of Gerontology and a Bachelor of Arts in history from Connecticut College in New London, Connecticut.

#### **FERNANDO TORRES-GIL**

Fernando M. Torres-Gil is a Professor of Social Welfare and Public Policy at UCLA, Director of the UCLA Center for Policy Research on Aging and an Adjunct Professor of Gerontology at USC. He also has served as Acting Dean and Associate Dean at the UCLA School of Public Affairs, and most recently Chair of the Social Welfare Department. He has written six books and over 100 publications, including *The New Aging: Politics and Change in America* (1992) and *Aging, Health and Longevity in the Mexican-Origin Population* (2012). His academic contributions have earned him membership in the prestigious Academies of Public Administration, Gerontology and Social Insurance. His research spans the important topics of health and long-term care, disability, entitlement reform, and the politics of aging.

Professor Torres-Gil is more than an academic. He has an impressive portfolio of public service and national and international recognition as a leading spokesperson on demographics, aging, and public policy. He earned his first presidential appointment in 1978 when President Jimmy Carter appointed him to the Federal Council on Aging. He was selected as a White House Fellow and served under Joseph Califano, then Secretary of the U.S. Department of Health, Education, and Welfare (HEW), and continued as a Special Assistant to the subsequent Secretary of HEW, Patricia Harris. He was appointed (with Senate Confirmation) by President Bill Clinton as the first-ever U.S. Assistant Secretary on Aging in the U.S. Department of Health and Human Services (DHHS). As the Clinton Administration's chief advocate on aging, Dr. Torres-Gil played a key role in promoting the importance of the issues of aging, long-term care and disability, community services for the elderly, and baby boomer preparation for retirement. He served under HHS Secretary Donna Shalala, managing the Administration on Aging and organizing the 1995 White House Conference on Aging.

In 2010 President Barack Obama appointed him as Vice Chair of the National Council on Disability, an independent federal agency that reports to the Congress and White House on

federal matters related to disability policy. During his public service in Washington, D.C., he also served as Staff Director of the U.S. House Select Committee on Aging under his mentor, Congressman Edward R. Roybal. In 2013, he received the coveted John W. Gardner Legacy of Leadership Award from the White House Fellows Foundation and Association.

He earned his A.A. in Political Science at Hartnell Community College (1968), a B.A. with honors in Political Science from San Jose State University (1970), and an M.S.W. (1972) and Ph.D. (1976) in Social Policy, Planning and Research from the Heller Graduate School in Social Policy and Management at Brandeis University.

#### **LAURA TREJO**

As the General Manager of the Department of Aging, Laura Trejo is responsible for the overall administration of the Los Angeles Department of Aging which serves one of the largest concentrations of older persons in the U.S. Ms. Trejo is technical and policy advisor to the Mayor and City Council and represents the City of Los Angeles before the public, community and private groups on matters affecting senior citizen affairs. She is the first Latina appointed to the level of General Manager for the City of Los Angeles.

Ms. Trejo is a founding Co-Director/Investigator of the Los Angeles Community Academic Partnership for Research in Aging (LA CAPRA), a partnership between UCLA and the City of Los Angeles Department of Aging. For over 25 years she has dedicated her work to serving older adults and their family caregivers. She has consulted and trained extensively throughout the United States and worked with individual countries and international organizations on the development of programs for the elderly and their family caregivers.

In 2011, Ms. Trejo was appointed to the National Alzheimer's Advisory Council tasked with helping shape the nation's comprehensive plan to address Alzheimer's disease. In addition, she currently serves on the Board of Directors of the National Council on Aging, California Association of Area Agencies on Aging, California Elder Mental Health and Aging Coalition, and National Health Foundation.

Ms. Trejo's work and commitment to excellence have earned high praise and recognition, including the Robert Wood Johnson Foundation Community Health Leadership Award, considered the nation's highest honor in community health, and the American Society on Aging's awards for Excellence in Training and Education, and Leadership award in Mental Health and Aging. In 2012, Ms. Trejo was named by Los Angeles Magazine among the "50 Most Influential Women" and received the USC Roybal Institute's Community Partnership Award. In their calendar series of "Women Who Dare," the United States Library of Congress recognized Ms. Trejo's accomplishments as a force for social change.

Ms. Trejo is a gerontologist with a Master of Science in Gerontology, Master of Public Administration and Graduate Certificate in Long Term Care Administration all from the University of Southern California.

#### **STEVEN P. WALLACE**

Steven P. Wallace, PhD, is professor and Chair of the Department of Community Health Sciences at the UCLA Fielding School of Public Health and associate director at the UCLA Center for Health Policy Research (Center). Wallace is a leading scholar in the U.S. in the area of aging in communities of color. He has published research on access to long-term care by diverse elderly groups, disparities in the consequences of health policy changes on racial/ethnic minority elderly, and the politics of aging. His interest in reaching a policy and key stakeholder audience has led him to also publish several dozen policy briefs and reports at the Center. Those

briefs and his other research have received broad media coverage, including articles and stories in the New York Times, LA Times, U.S. News and World Report, National Public Radio, and Fox News. He has testified a number of times at state legislative hearings and in other forums.

He is currently PI on research supported by The SCAN Foundation that includes a project examining the current levels of coordination between long term care services and supports (LTSS) and acute medical care as many dual eligible seniors (Medicare-Medicaid) transition into managed care, as well as the patterns of those dual eligibles in obtaining information and view of continuity of care which are key aspects of that transition. He also has a project examining how to identify dignity-driven decision making among older adults with advanced stage illnesses, one synthesizing the evidence on community interventions that promote clinical preventive services use, and a project to develop and disseminate an alternative to the federal poverty line that better indicates the basic economic needs of older adults (the Elder Index). Wallace is Director of the Coordinating Center for the NIH/NIA-funded Resource Centers on Minority Aging Research. He is a fellow of the Gerontological Society of America and received his doctorate in sociology from the University of California, San Francisco.

#### **KATE WILBER**

The Mary Pickford Foundation Professor of Gerontology at University of Southern California, Dr. Wilbur holds a joint appointment as Professor of Health Services Administration in the USC Price School of Public Policy.

Dr. Wilber's research, which includes over 100 publications, has focused on improving the quality of life of people with chronic physical and mental health conditions, by exploring ways to improve the formal health and long term care delivery system. Her research focuses on four major areas:

- 1) Improving the structure, delivery, and outcomes of health and long-term services and supports
- 2) Economic security, financial planning, and decision making support in later life
- 3) Strategies to reduce elder abuse, neglect, and exploitation
- 4) Maximizing quality of life in older age through disease prevention, wellness, and empowerment.

Dr. Wilber is a Fellow of the Gerontological Society of America and a Fellow of the Association for Gerontology in Higher Education. She is a past Commissioner for the American Bar Association Commission on Law and Aging and past Director of the California Center for Long-Term Care Integration. She serves on the California Olmstead Advisory Committee, the Medical and Scientific Advisory Council of the Los Angeles Alzheimer's Association, and the Board of Directors of St. Barnabas Senior Services.

## **Listing of Individuals Interviewed on Critical Policy Issues**

## **Listing of Individuals Interviewed on Critical Policy Issues**

Interviews Conducted by: Patty Berg, Principal Consultant and  
Sarah Steenhausen, The SCAN Foundation

### HOUSING

Rebecca Shutte, Chief, LTSS Operations Branch, Long-Term Division, CHHS Agency

### WELLNESS

Viviana Criado, Executive Director, California Elder Mental Health Aging Coalition

Laura Trejo, Director, Area Agency on Aging of Los Angeles

Raja Mitry, Anti-Stigma Project Consultant

### CAREGIVING

Kathy Kelly, Executive Director, National Center on Caregiving

Michelle Nevins, Executive Director, Del Oro Caregiver Resource Center

### TRANSITIONAL CARE

Victoria Jump, Director, Ventura County Area Agency on Aging

Barbara Hanna, Executive Director, Home and Health Care Management

Ellen Schmeding, Director, Area Agency on Aging of San Diego

Eileen Koons, Director, Senior Care Network at Huntington Hospital

Michele Haddock, Director, Area Agency on Aging, Riverside

Anne Hinton, Director, San Francisco Area Agency on Aging

June Simmons, President, Partners In Care, Los Angeles

Ed Walsh, California Commission on Aging

### LONG-TERM SERVICES AND SUPPORTS

Sarah Steenhausen, Senior Policy Advisor, The SCAN Foundation

Gretchen Alkema, Vice President of Policy and Communications, The SCAN Foundation

Peter Hansel, Executive Director, Of CalPACE

Denise Likar, Executive Director, Scan Health Plan

Lydia Missaelides, Executive Director, California Association of Adult Day Services

Maya Altman, CEO, Health Plan of San Mateo

Charlene Harrington, Professor Emerita, School of Nursing, UCSF

Karen Keesler, Executive Director, California Association of Public Authorities

### ELDER JUSTICE/ABUSE

Lisa Nerenberg, Chair, California Elder Justice Coalition

Carol Sewell, Analyst, California Commission on Aging

### ALZHEIMER'S DISEASE AND DEMENTIA

Susan DeMarios, State Policy Consultant, California council of the Alzheimer's Association

Debra Cherry, Executive Vice President, Alzheimer's Association

#### LONG-TERM CARE FINANCING

Bonnie Burns, Training and Policy Specialist, California Health Advocates

#### CALIFORNIA COORDINATED INITIATIVE (CCI)

Kevin Prindiville, Executive Director, National Senior Citizens Law Center

Amber Cutler, Staff Attorney, National Senior Citizens Law Center

#### AGING/GENERIC ISSUES

Gary Passmore, Vice President and Legislative Advocate, Congress of California Seniors

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#### TRANSPORTATION AND MOBILITY

Letters emailed on 8/20/14 requesting written information to:

Susan Shaheen, UC Berkeley Transportation Sustainability Research Center

Dan Kammen, Tim Lipman (UC Berkeley)

Clay Kempf, Director, Santa Cruz Area Agency on Aging

#### EMPLOYMENT AND RETIREMENT

Letters emailed on 8/20/14 requesting written information to:

Carroll Estes, School of Nursing and Committee to Preserve Social Security

Marissa Clark, California Committee on Employment of Persons with Disabilities

Anne Price, Program Director, Insight Center for community Economic Development

## **Senate Office on Research: Demographics and Workforce**

**POPULATION PROJECTIONS FOR CALIFORNIANS 60 AND OLDER, 2010 to 2060**

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- Table, California Population Projections by Age Group, 2010 to 2060
- Table, California Population Projections FOR WOMEN by Age Group, 2010 to 2060
- Table, California Population Projections FOR MEN by Age Group, 2010 to 2060

Page 3:

- Bar Chart, California Population Projections by Age Group, 2010 to 2060

Page 4:

- Pie Charts, California Population Projections by Age Group, 2010 to 2060

Page 5:

- Table, California Population Projections for Women and Men Ages 60 and Older, 2010 to 2060
- Bar Chart, California Population Projections for Women and Men Ages 60 and Older, 2010 to 2060

Page 6:

- Table, California Population Projections by Race/Ethnicity and Percentage of Total Population of Racial/Ethnic Groups Made up of Individuals Ages 60 and Older, 2010 to 2060

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- Bar Chart, California Population Projections for Individuals Ages 60 and Older, by Race and Ethnicity, 2010 to 2060

Page 8:

- Bar Chart, Percentage of Total California Population of Racial/Ethnic Groups Made Up of Individuals Ages 60 or Older, 2010 to 2060

**SOURCE:** *State of California, Department of Finance, Report P-3: State and County Population Projections by Race/Ethnicity, Detailed Age, and Gender, 2010-2060.* Sacramento, California, January 2013.

### California Population Projections by Age Group, 2010 to 2060

Year	Total state population	60-64 as percent of total population	65-74 as percent of total population	75-84 as percent of total population	85+ as percent of total population	60+ as percent of total population
2010	37,309,382	1,854,741	2,293,371	1,371,838	606,333	6,126,283
2020	40,643,643	2,427,563	3,619,206	1,709,680	723,827	8,480,276
2030	44,279,354	2,447,481	4,558,398	2,817,675	993,496	10,817,050
2040	47,690,186	2,486,615	4,554,899	3,665,671	1,734,742	12,441,926
2050	50,365,074	2,733,808	4,890,318	3,759,252	2,484,620	13,867,999
2060	52,693,583	2,890,345	5,396,075	4,130,297	2,851,396	15,268,112

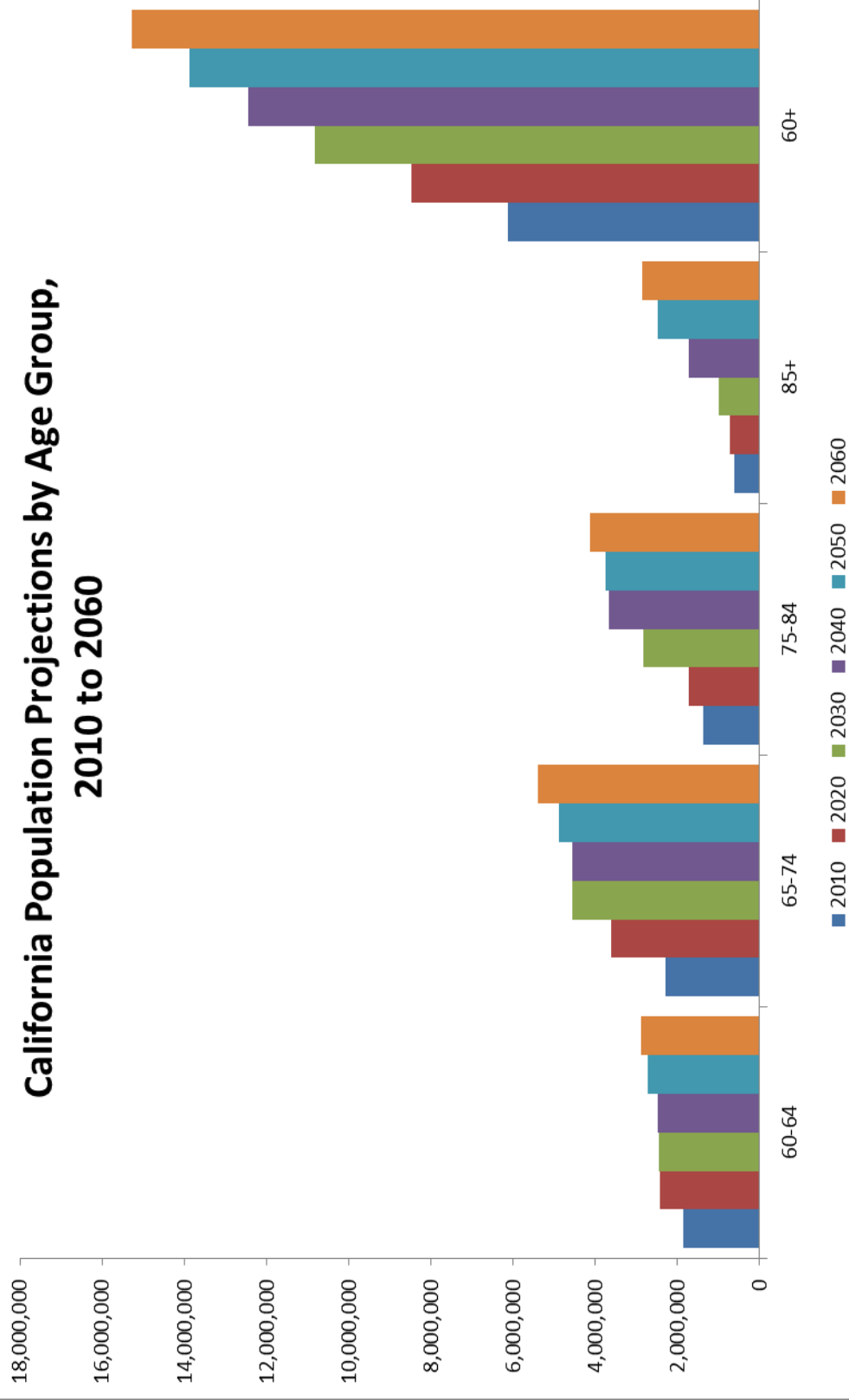
### California Population Projections FOR WOMEN by Age Group, 2010 to 2060

Year	Total state population	60-64 as percent of total population	65-74 as percent of total population	75-84 as percent of total population	85+ as percent of total population	60+ as percent of total population
2010	18,766,222	964,918	1,230,854	787,673	393,442	3,376,887
2020	20,381,518	1,248,907	1,921,516	970,851	461,986	4,603,259
2030	22,212,996	1,256,509	2,394,722	1,579,588	623,808	5,854,628
2040	23,957,732	1,279,608	2,400,671	2,030,252	1,073,045	6,783,575
2050	25,292,020	1,385,689	2,555,181	2,083,043	1,520,743	7,544,655
2060	26,418,569	1,483,626	2,793,970	2,260,199	1,744,976	8,282,770

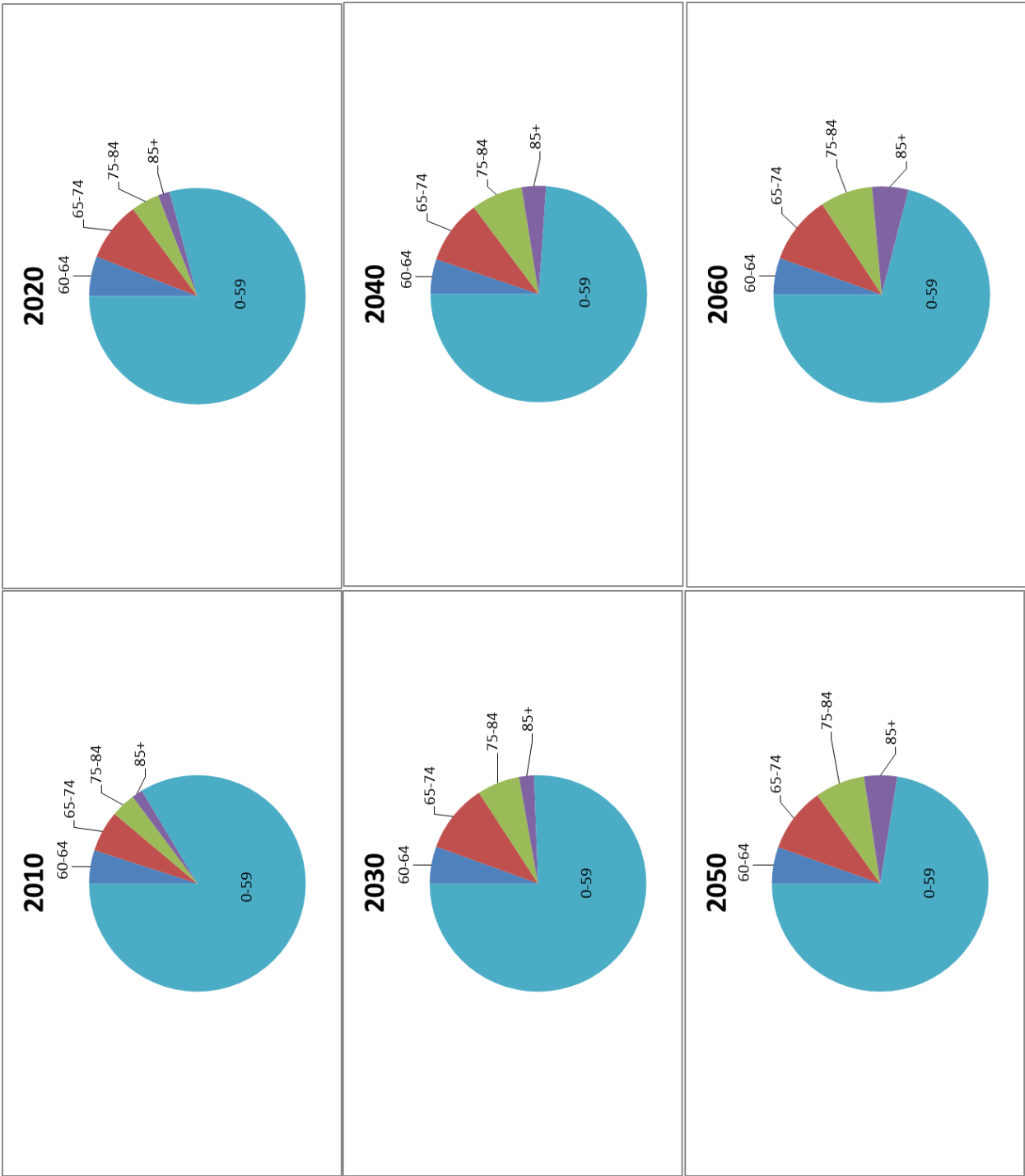
### California Population Projections FOR MEN by Age Group, 2010 to 2060

Year	Total state population	60-64 as percent of total population	65-74 as percent of total population	75-84 as percent of total population	85+ as percent of total population	60+ as percent of total population
2010	18,543,160	889,823	1,062,517	584,165	212,891	2,749,396
2020	20,262,125	1,178,656	1,697,690	738,829	261,841	3,877,016
2030	22,066,358	1,190,972	2,163,676	1,238,087	369,688	4,962,423
2040	23,732,454	1,207,007	2,154,228	1,635,419	661,697	5,658,351
2050	25,073,054	1,348,119	2,335,137	1,676,210	963,878	6,323,344
2060	26,275,014	1,406,719	2,602,105	1,870,098	1,106,420	6,985,342

# California Population Projections by Age Group, 2010 to 2060

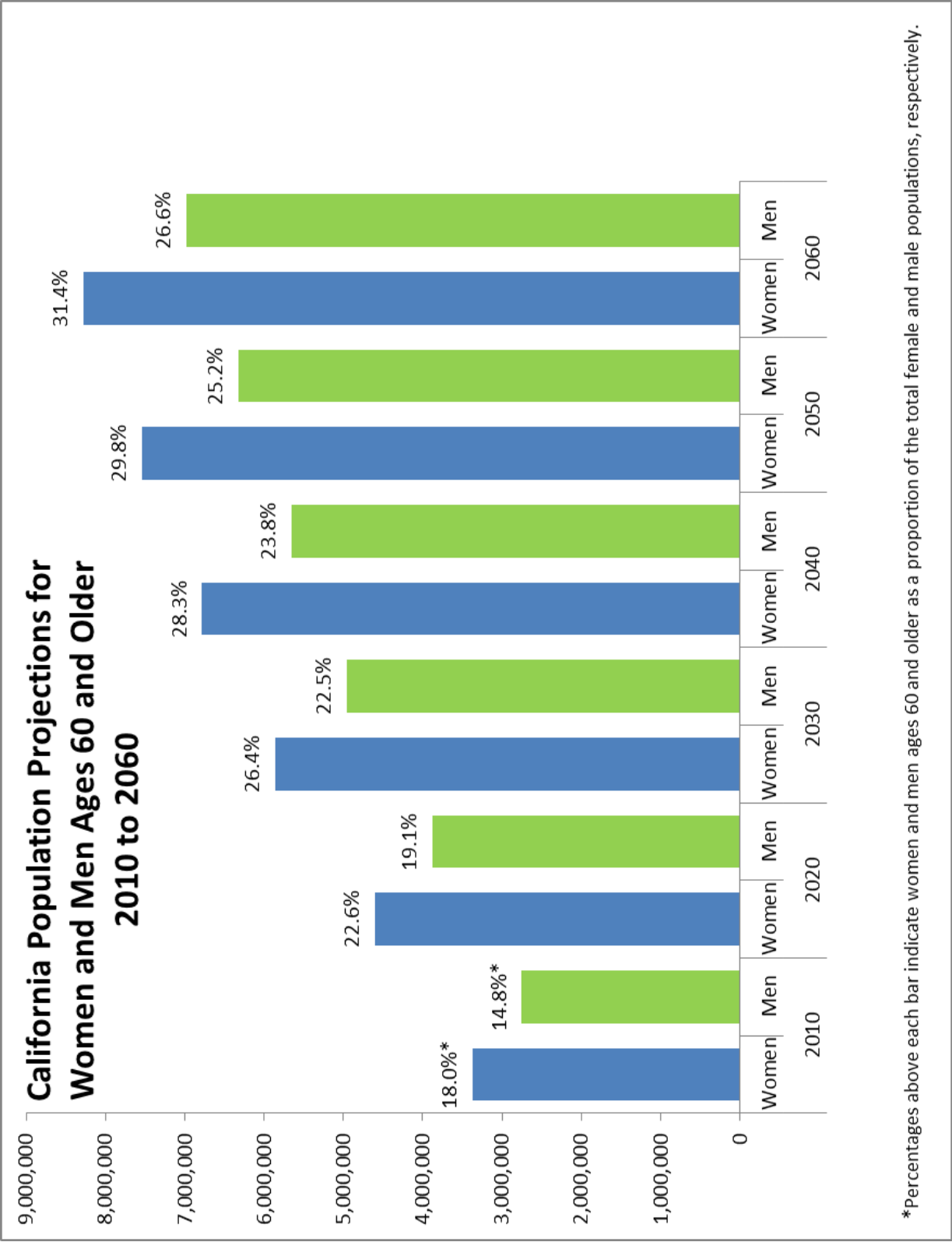


California Population Projections by Age Group, 2010 to 2060



California Population Projections for Women and Men Ages 60 and Older, 2010 to 2060

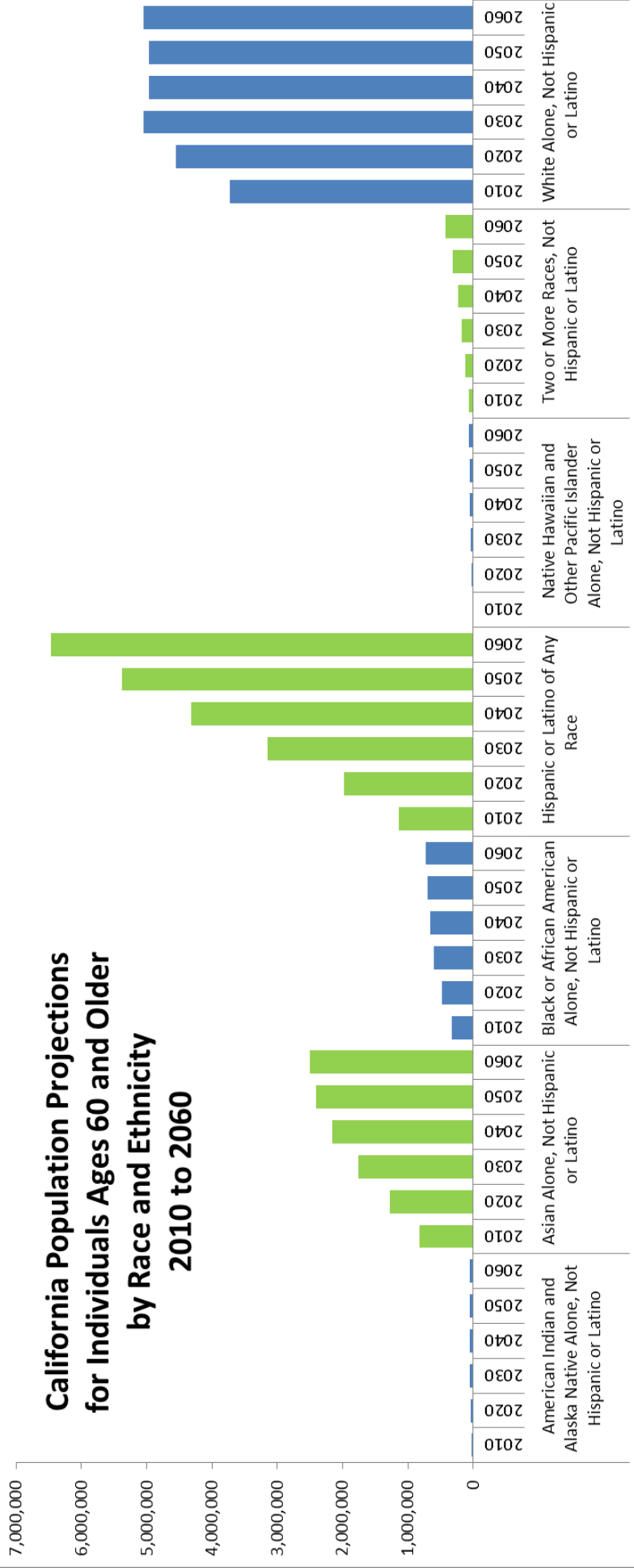
2010		2020		2030		2040		2050		2060	
Women	Men	Women	Men	Women	Men	Women	Men	Women	Men	Women	Men
3,376,887	2,749,396	4,603,259	3,877,016	5,854,628	4,962,423	6,783,575	5,658,351	7,544,655	6,323,344	8,282,770	6,985,342



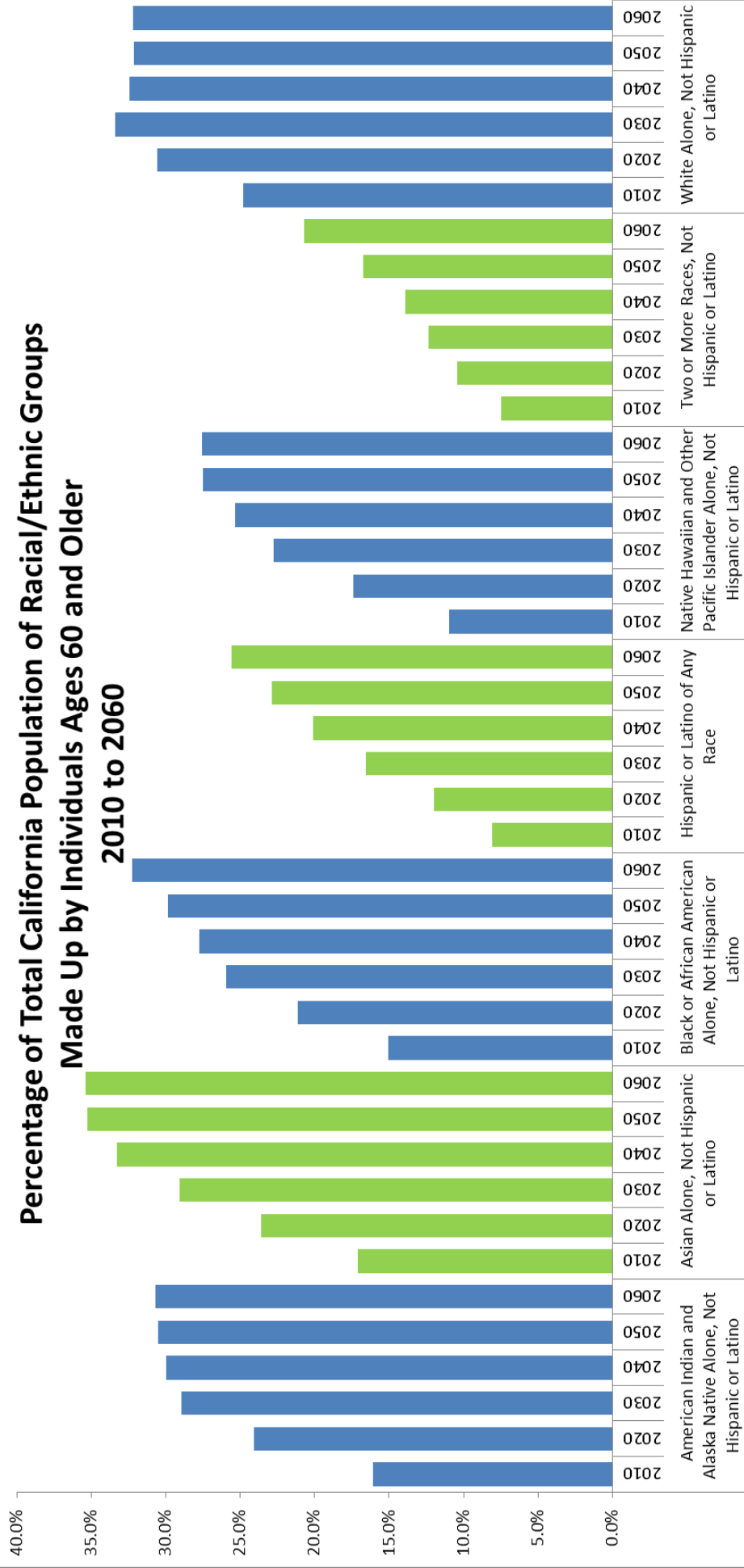
**California Population Projections by Race/Ethnicity and Percentage of Total Population of Racial/Ethnic Groups Made up by Individuals Ages 60 and Older, 2010 to 2060**

American Indian and Alaska Native Alone, Not Hispanic or Latino			Hispanic or Latino of Any Race			White Alone, Not Hispanic or Latino				
	2010	26,176	16.1%		1,134,992	8.1%		2010	3,727,051	24.8%
	2020	42,244	24.1%		1,984,254	12.0%		2020	4,547,314	30.6%
	2030	52,790	29.0%		3,143,652	16.5%		2030	5,047,896	33.4%
	2040	55,885	30.0%		4,313,233	20.1%		2040	4,971,046	32.4%
	2050	57,043	30.5%		5,374,952	22.9%		2050	4,969,688	32.1%
	2060	56,871	30.7%		6,461,320	25.6%		2060	5,042,655	32.2%
Asian Alone, Not Hispanic or Latino			Native Hawaiian and Other Pacific Islander Alone, Not Hispanic or Latino							
	2010	825,902	17.1%		14,393	11.0%				
	2020	1,280,336	23.6%		26,374	17.4%				
	2030	1,751,054	29.0%		37,922	22.8%				
	2040	2,161,415	33.3%		47,174	25.3%				
	2050	2,401,384	35.3%		55,417	27.5%				
	2060	2,502,520	35.4%		58,132	27.5%				
Black or African American Alone, Not Hispanic or Latino			Two or More Races, Not Hispanic or Latino							
	2010	329,096	15.0%		68,673	7.5%				
	2020	477,385	21.1%		122,369	10.4%				
	2030	606,680	25.9%		177,056	12.4%				
	2040	661,583	27.7%		231,589	13.9%				
	2050	700,741	29.8%		308,772	16.7%				
	2060	730,585	32.2%		416,029	20.7%				

# California Population Projections for Individuals Ages 60 and Older by Race and Ethnicity 2010 to 2060



# Percentage of Total California Population of Racial/Ethnic Groups Made Up by Individuals Ages 60 and Older 2010 to 2060



## **ADDITIONAL DATA ON CALIFORNIANS 60 AND OLDER**

- Page 2:
- Table, Poverty Status of Older Californians: Estimates
  - Table, Poverty Status of Older Californians: Percentages
  - Bar Chart, Percentage of Older Californians Living Below the Federal Poverty Level (FPL), by Age Group
- Page 3:
- Table, Distribution of Older Californians Across Household Income Brackets, by Age Group: Estimates
  - Table, Distribution of Older Californians Across Household Income Brackets, by Age Group: Percentages
- Page 4:
- Table, Health Insurance Status by Age Group: Estimates
  - Bar Chart, Older Californians' Health Insurance Status: Percentage by Age Group
- Page 5:
- Table, Older Californians With At Least One Disability, by Age Group: Estimates
  - Bar Chart, Older Californians With At Least One Disability: Percentage by Age Group
- Page 6:
- Table, Reported Disability Type by Age Group: Estimates
  - Table, Reported Disability Type by Age Group: Percentages (of Total Age Group Population)

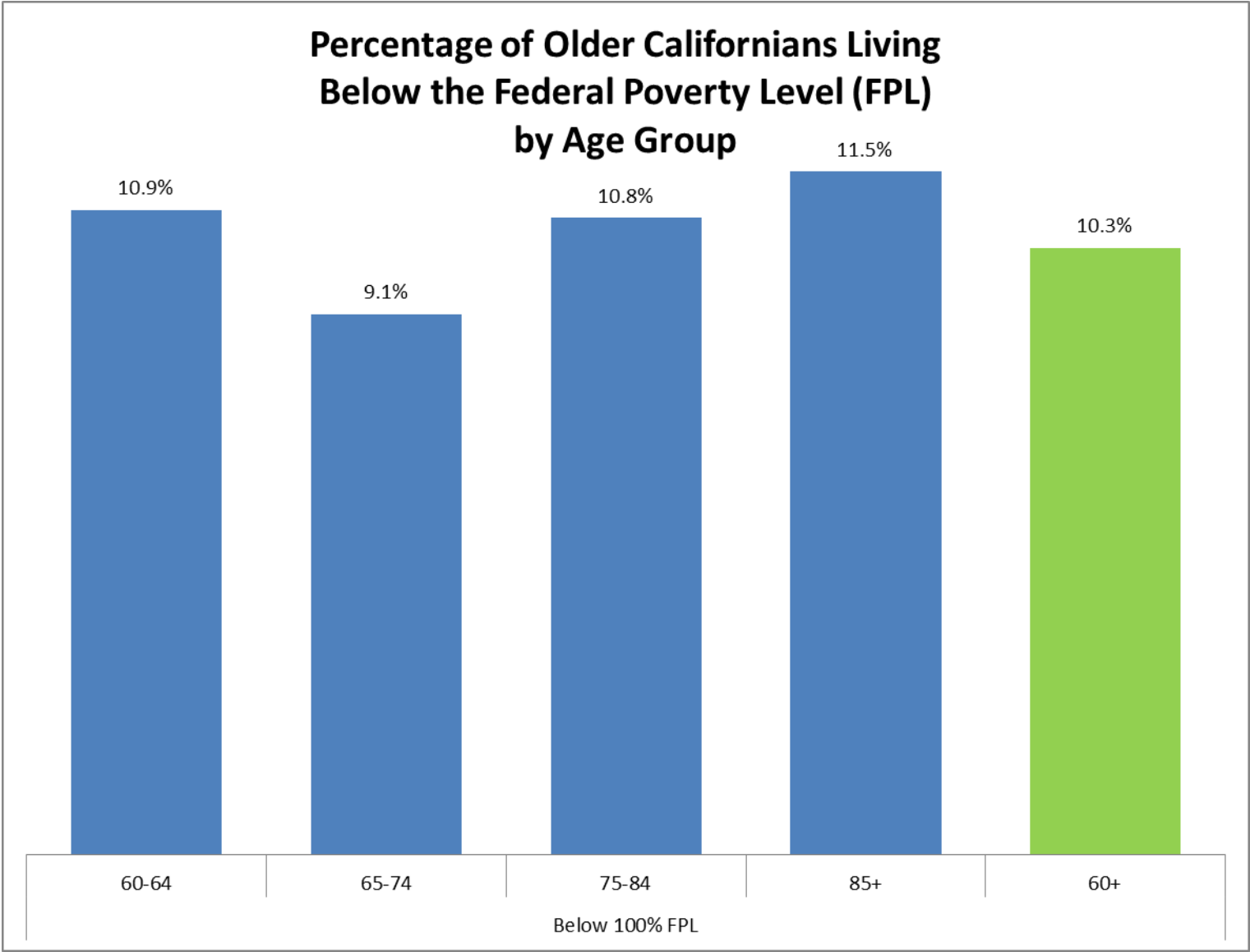
**SOURCE:** *U.S. Census Bureau, 2010-2012 American Community Survey (3-Year), Public Use Microdata Sample, Special Tabulation, extracted by California State Census Data Center, Demographic Research Unit, Department of Finance,*  
<http://www.dof.ca.gov/research/demographic/> .

Poverty Status of Older Californians: Estimates

	60-64	65-74	75-84	85+	60+
Below 100% FPL	209,271	217,705	146,619	67,770	641,365
At or Above 100% FPL	1,711,569	2,166,516	1,215,557	519,533	5,613,175
Total	1,920,840	2,384,221	1,362,176	587,303	6,254,540

Poverty Status of Older Californians: Percentages

	60-64	65-74	75-84	85+	60+
Below 100% FPL	10.9%	9.1%	10.8%	11.5%	10.3%
At or Above 100% FPL	89.1%	90.9%	89.2%	88.5%	89.7%



*Please note: the universe for the above poverty status data is persons, ages 60+, for whom poverty status has been determined.*

### Distribution of Older Californians Across Household Income Brackets, by Age Group: Estimates

Household Income	60-64	65-74	75-84	85+	60+
No Income or Loss	20,004	14,716	9,572	4,934	49,226
\$1 to \$10,000	57,167	68,362	50,980	25,021	201,530
\$10,000 to \$19,999	144,785	247,566	211,475	102,440	706,266
\$20,000 to \$29,999	143,371	228,151	178,221	87,315	637,058
\$30,000 to \$39,999	139,170	219,738	154,185	67,752	580,845
\$40,000 to \$49,999	137,005	207,240	127,239	51,095	522,579
\$50,000 to \$74,999	330,549	425,044	230,525	85,463	1,071,581
\$75,000 to \$99,999	258,032	302,669	138,152	47,910	746,763
\$100,000 to \$149,999	332,478	337,180	132,812	51,824	854,294
\$150,000 to \$199,999	157,318	144,653	54,277	20,536	376,784
\$200,000+	187,333	177,508	64,803	27,125	456,769
Total	1,907,212	2,372,827	1,352,241	571,415	6,203,695

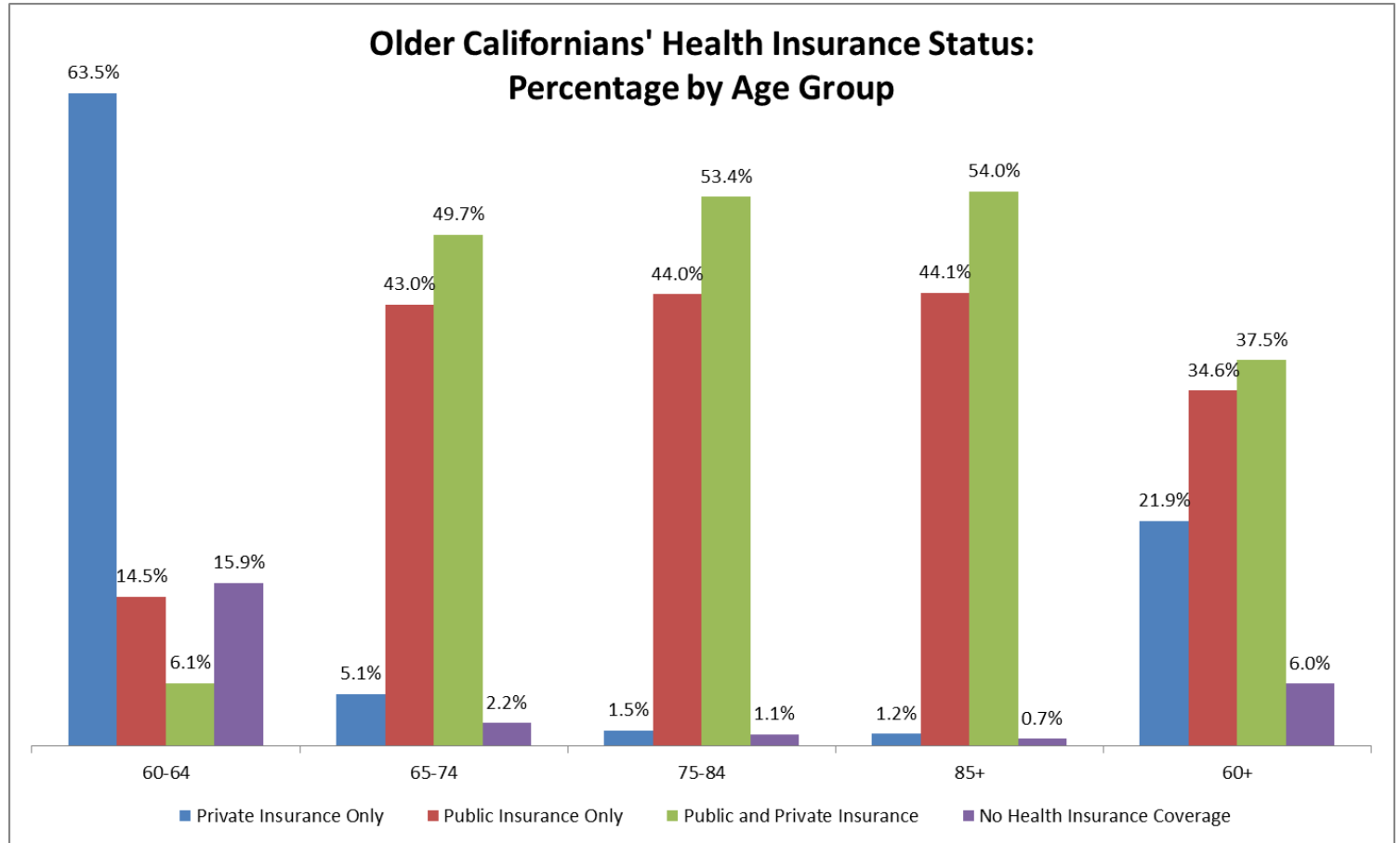
### Distribution of Older Californians Across Household Income Brackets, by Age Group: Percentages

Household Income	60-64	65-74	75-84	85+	60+
No Income or Loss	1.0%	0.6%	0.7%	0.9%	0.8%
\$1 to \$10,000	3.0%	2.9%	3.8%	4.4%	3.2%
\$10,000 to \$19,999	7.6%	10.4%	15.6%	17.9%	11.4%
\$20,000 to \$29,999	7.5%	9.6%	13.2%	15.3%	10.3%
\$30,000 to \$39,999	7.3%	9.3%	11.4%	11.9%	9.4%
\$40,000 to \$49,999	7.2%	8.7%	9.4%	8.9%	8.4%
\$50,000 to \$74,999	17.3%	17.9%	17.0%	15.0%	17.3%
\$75,000 to \$99,999	13.5%	12.8%	10.2%	8.4%	12.0%
\$100,000 to \$149,999	17.4%	14.2%	9.8%	9.1%	13.8%
\$150,000 to \$199,999	8.2%	6.1%	4.0%	3.6%	6.1%
\$200,000+	9.8%	7.5%	4.8%	4.7%	7.4%

*Please note: the universe for the above income data is persons, ages 60+, living in households.*

### Health Insurance Status by Age Group: Estimates

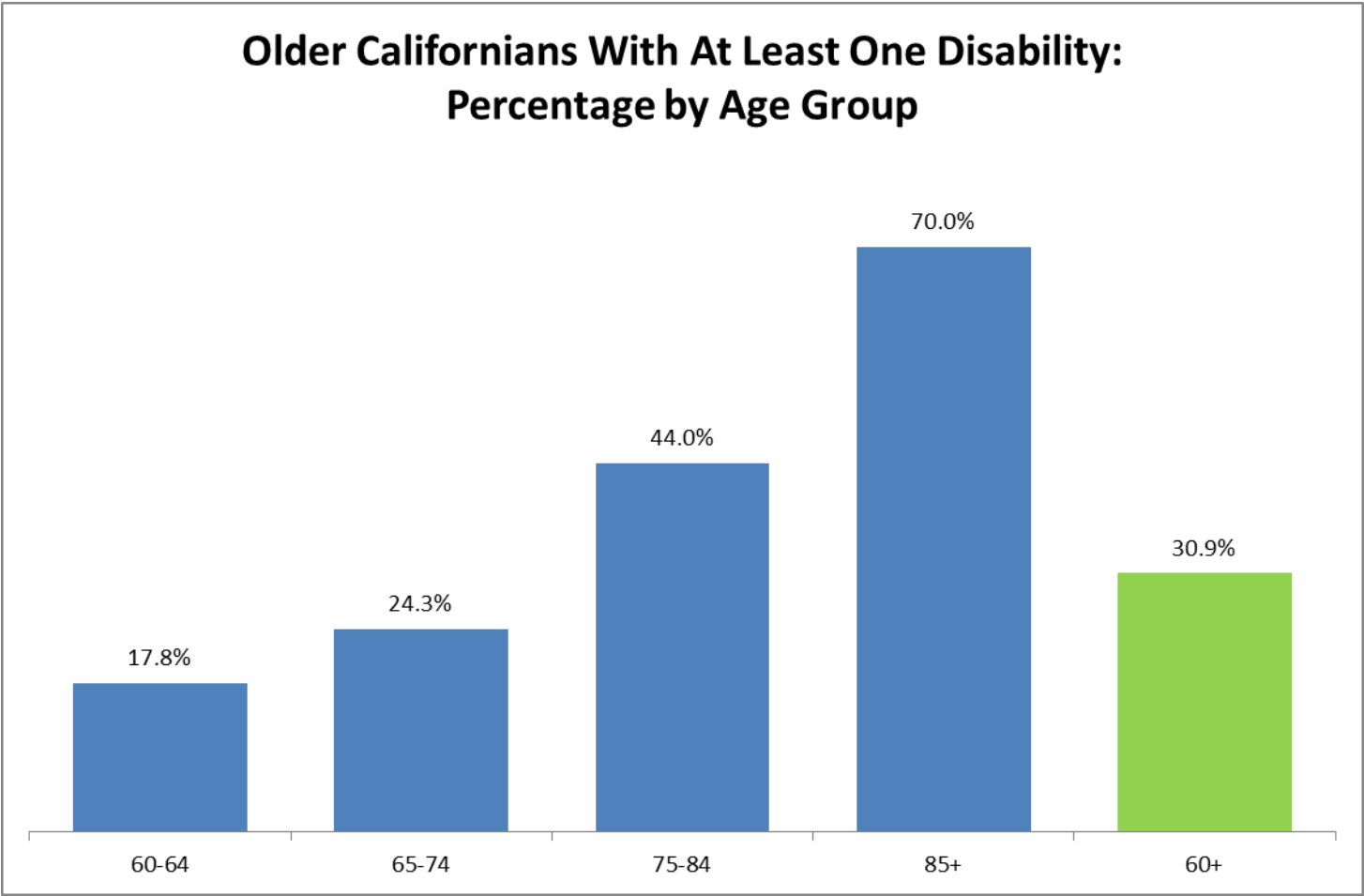
Health Insurance Status	60-64	65-74	75-84	85+	60+
Private Insurance Only	1,219,616	120,647	20,612	7,080	1,367,955
Public Insurance Only	279,230	1,024,169	598,703	259,014	2,161,116
Public and Private Insurance	116,940	1,185,791	727,619	316,951	2,347,301
No Health Insurance Coverage	304,957	53,627	15,242	4,258	378,084
Total	1,920,743	2,384,234	1,362,176	587,303	6,254,456



*Please note: the universe for the above health insurance data is the civilian, noninstitutionalized population ages 60+.*

Older Californians With At Least One Disability, by Age Group: Estimates

	60-64	65-74	75-84	85+	60+
With Disability	342,696	579,165	599,972	410,950	1,932,783
No Disability	1,578,047	1,805,069	762,204	176,353	4,321,673
Total	1,920,743	2,384,234	1,362,176	587,303	6,254,456



*Please note: the universe for the above disability-related data is the civilian, noninstitutionalized population ages 60+.*

**Reported Disability Type by Age Group: Estimates**

	<b>60-64</b>	<b>65-74</b>	<b>75-84</b>	<b>85+</b>	<b>60+</b>
Hearing Disability	86,144	188,845	239,844	205,057	719,890
Vision Disability	54,938	93,223	107,058	94,844	350,063
Cognitive Disability	102,361	135,872	166,135	158,129	562,497
Ambulatory Disability	217,064	363,736	381,250	290,925	1,252,975
Self-Care Disability	71,227	125,424	164,886	166,363	527,900
Independent Living Disability	120,128	218,665	297,589	280,943	917,325
Total	651,862	1,125,765	1,356,762	1,196,261	4,330,650

**Reported Disability Type by Age Group: Percentages (of Total Age Group Population)**

	<b>60-64</b>	<b>65-74</b>	<b>75-84</b>	<b>85+</b>	<b>60+</b>
Hearing Disability	4.5%	7.9%	17.6%	34.9%	11.5%
Vision Disability	2.9%	3.9%	7.9%	16.1%	5.6%
Cognitive Disability	5.3%	5.7%	12.2%	26.9%	9.0%
Ambulatory Disability	11.3%	15.3%	28.0%	49.5%	20.0%
Self-Care Disability	3.7%	5.3%	12.1%	28.3%	8.4%
Independent Living Disability	6.3%	9.2%	21.8%	47.8%	14.7%

*Please note: the universe for the above disability-related data is the civilian, noninstitutionalized population ages 60+.*

**CALIFORNIA HEALTH INTERVIEW SURVEY:  
SELECT DATA ON CALIFORNIANS 60 AND OLDER**

Page 2:

- Table, Would you say that in general your health is excellent, very good, good, fair, or poor?: Estimates
- Table, Would you say that in general your health is excellent, very good, good, fair, or poor?: Percentages
- Bar Chart, Self-Reported Health Status by Age Group

Page 3:

- Table, Was there ever a time during the past 12 months when you felt that you might need to see a professional because of problems with your mental health, emotions, nerves, or your use of alcohol or drugs?: Estimates
- Table, Was there ever a time during the past 12 months when you felt that you might need to see a professional because of problems with your mental health, emotions, nerves, or your use of alcohol or drugs?: Percentages
- Bar Chart, Percentage of Individuals Within Age Group Reporting the Need for Help for Emotional/Mental Health Problems or Use of Alcohol/Drug

Page 4:

- Table, During the past 12 months, how many times have you seen a medical doctor?: Estimates
- Table, During the past 12 months, how many times have you seen a medical doctor?: Percentages

Page 5:

- Bar Chart, Number of Doctor Visits in the Past Year by Age Group

SOURCE: *Estimates are from the 2011-2012 California Health Interview Survey.*

<http://healthpolicy.ucla.edu/chis/Pages/default.aspx>

*Please note:*

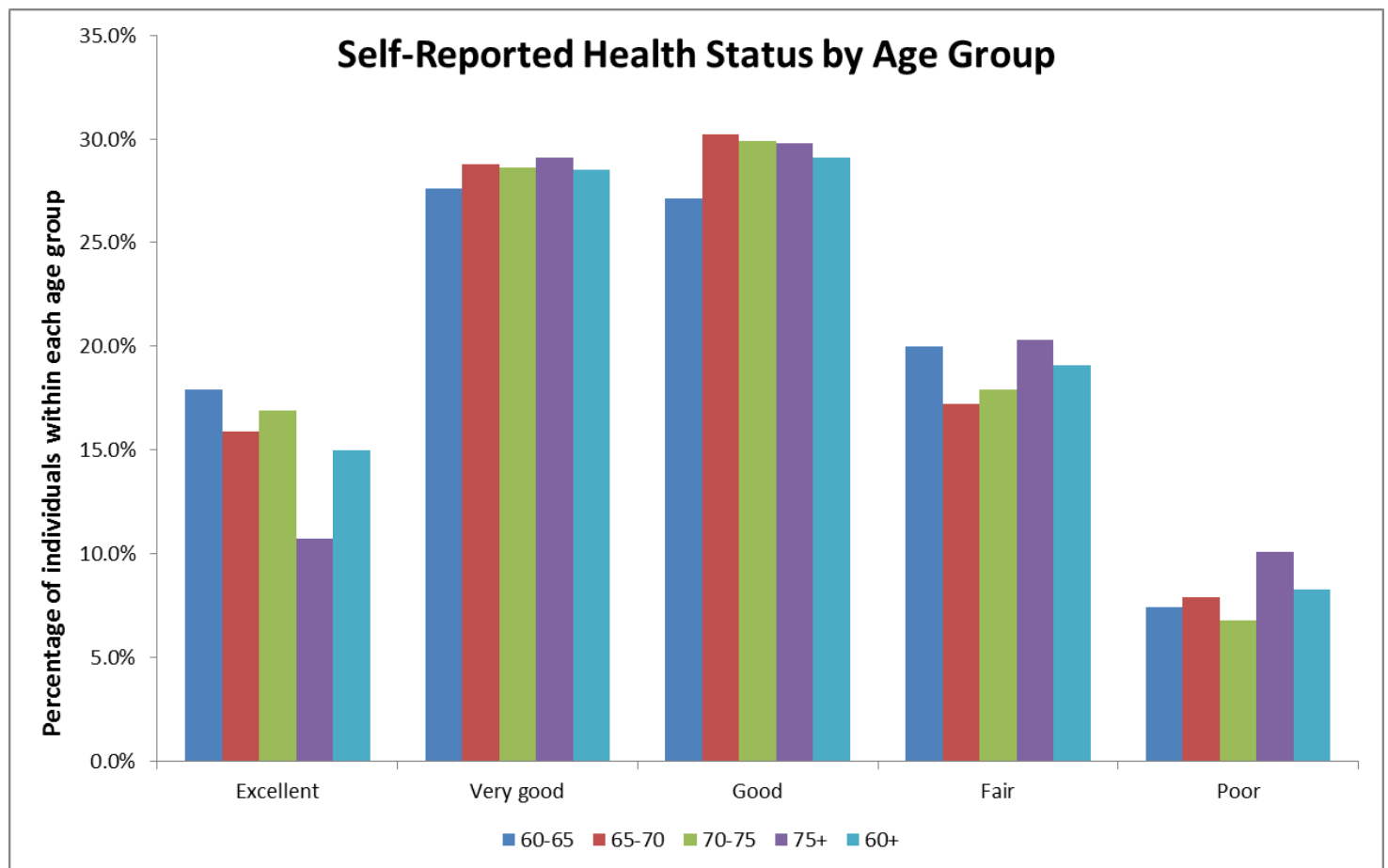
- CHIS interviews are conducted via phone calls to households.
- CHIS estimates are reported alongside confidence intervals at the 95% confidence level; these intervals are not listed in the following tables and charts, but are available.

**Would you say that in general your health is excellent, very good, good, fair, or poor?: Estimates**

Health status	60-64	65-69	70-74	75+	60+
Excellent	346,000	219,000	174,000	214,000	952,000
Very good	531,000	397,000	294,000	580,000	1,802,000
Good	522,000	417,000	308,000	595,000	1,842,000
Fair	385,000	237,000	184,000	405,000	1,210,000
Poor	143,000	109,000	70,000	202,000	524,000
TOTAL	1,926,000	1,379,000	1,029,000	1,995,000	6,330,000

**Would you say that in general your health is excellent, very good, good, fair, or poor?: Percentages**

Health status	60-65	65-70	70-75	75+	60+
Excellent	17.9%	15.9%	16.9%	10.7%	15.0%
Very good	27.6%	28.8%	28.6%	29.1%	28.5%
Good	27.1%	30.2%	29.9%	29.8%	29.1%
Fair	20.0%	17.2%	17.9%	20.3%	19.1%
Poor	7.4%	7.9%	6.8%	10.1%	8.3%
TOTAL	100.0%	100.0%	100.0%	100.0%	100.0%



**Was there ever a time during the past 12 months when you felt that you might need to see a professional because of problems with your mental health, emotions, nerves, or your use of alcohol or drugs?:**

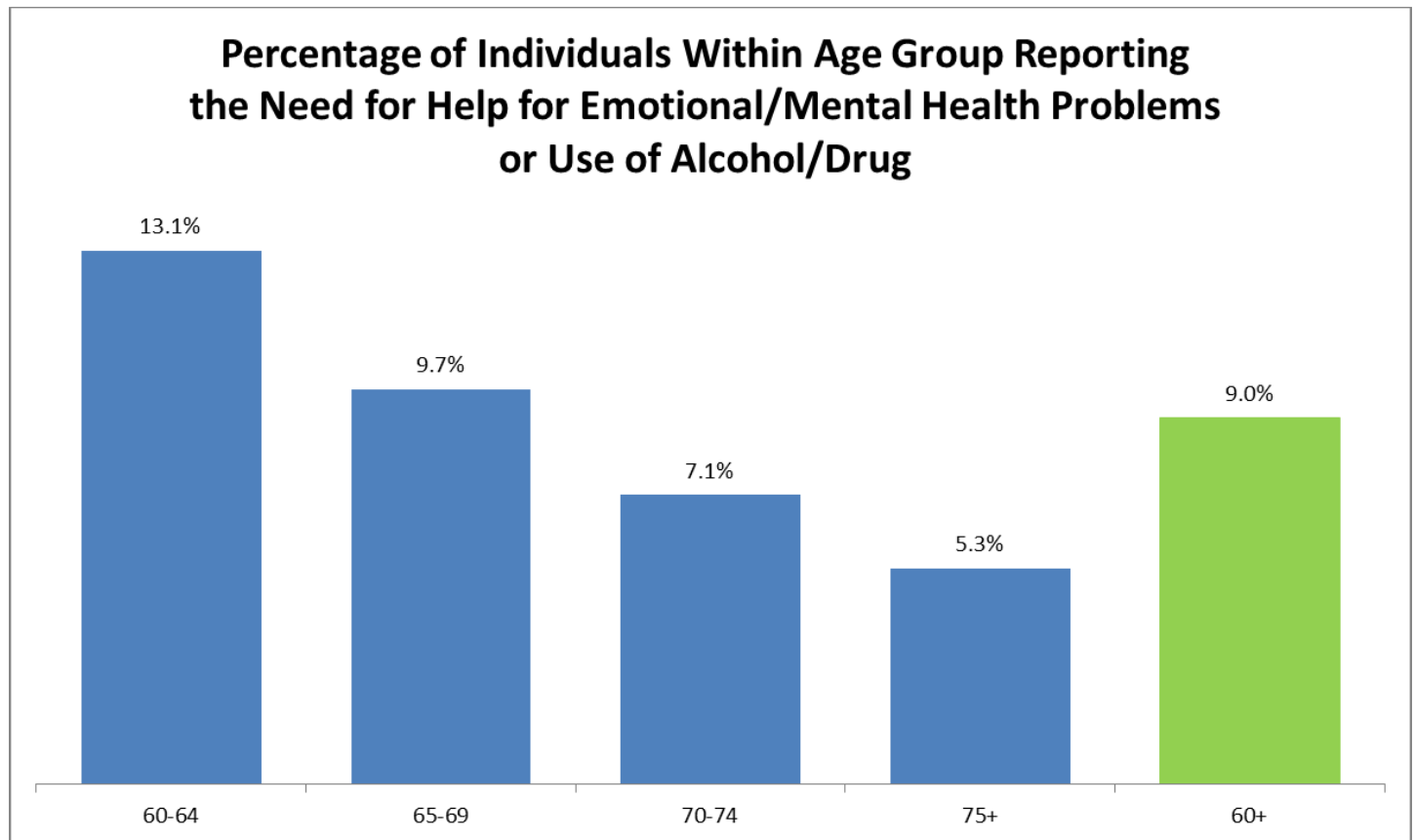
**Estimates**

	<b>60-64</b>	<b>65-69</b>	<b>70-74</b>	<b>75+</b>	<b>60+</b>
<b>Needed help</b>	253,000	134,000	72,000	102,000	561,000
<b>Did not need help</b>	1,673,000	1,241,000	946,000	1,819,000	5,678,000
<b>TOTAL</b>	1,925,000	1,374,000	1,018,000	1,921,000	6,239,000

**Was there ever a time during the past 12 months when you felt that you might need to see a professional because of problems with your mental health, emotions, nerves, or your use of alcohol or drugs?:**

**Percentages**

	<b>60-64</b>	<b>65-69</b>	<b>70-74</b>	<b>75+</b>	<b>60+</b>
<b>Needed help</b>	13.1%	9.7%	7.1%	5.3%	9.0%
<b>Did not need help</b>	86.9%	90.3%	92.9%	94.7%	91.0%
<b>TOTAL</b>	100.0%	100.0%	100.0%	100.0%	100.0%

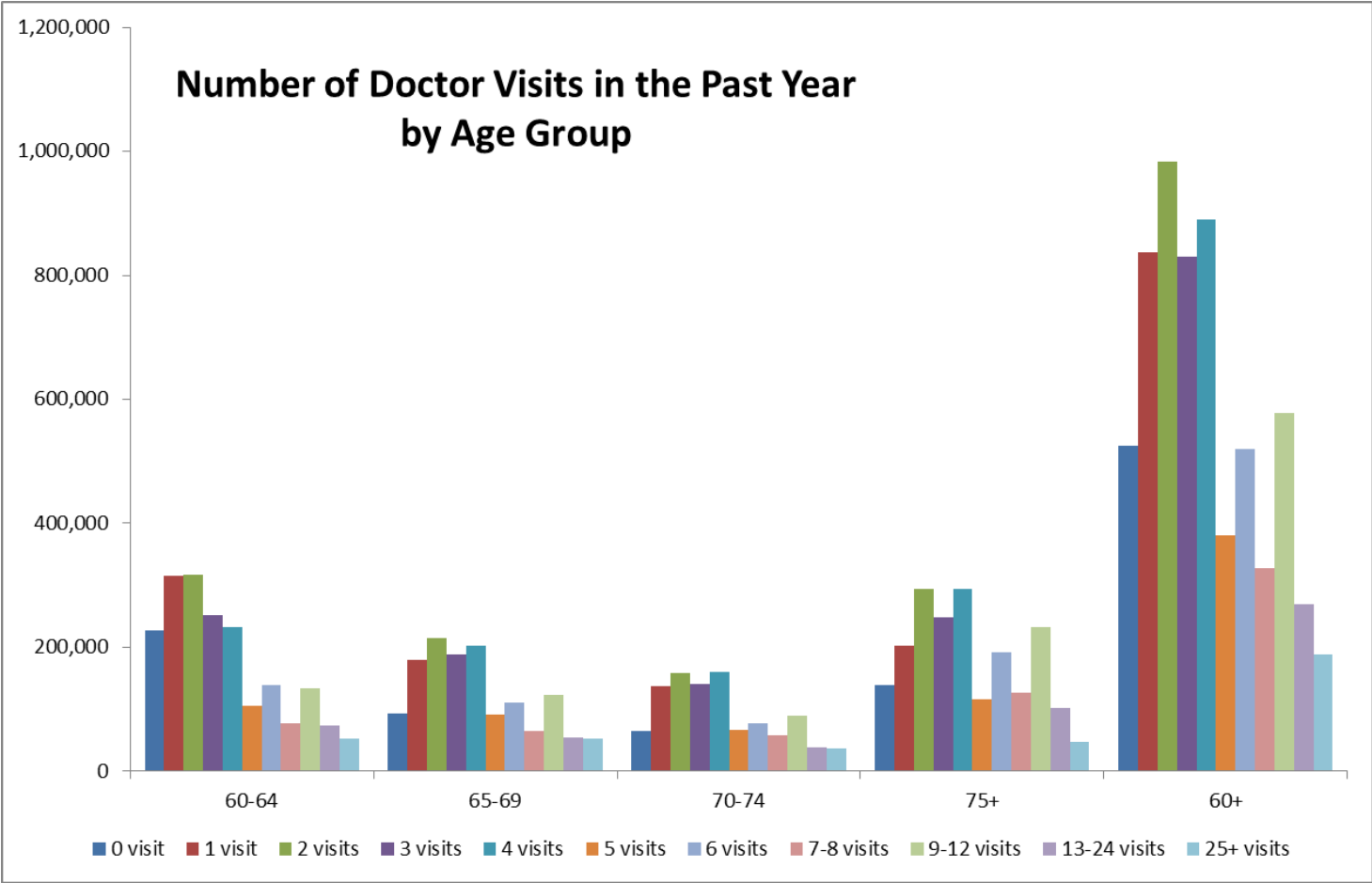


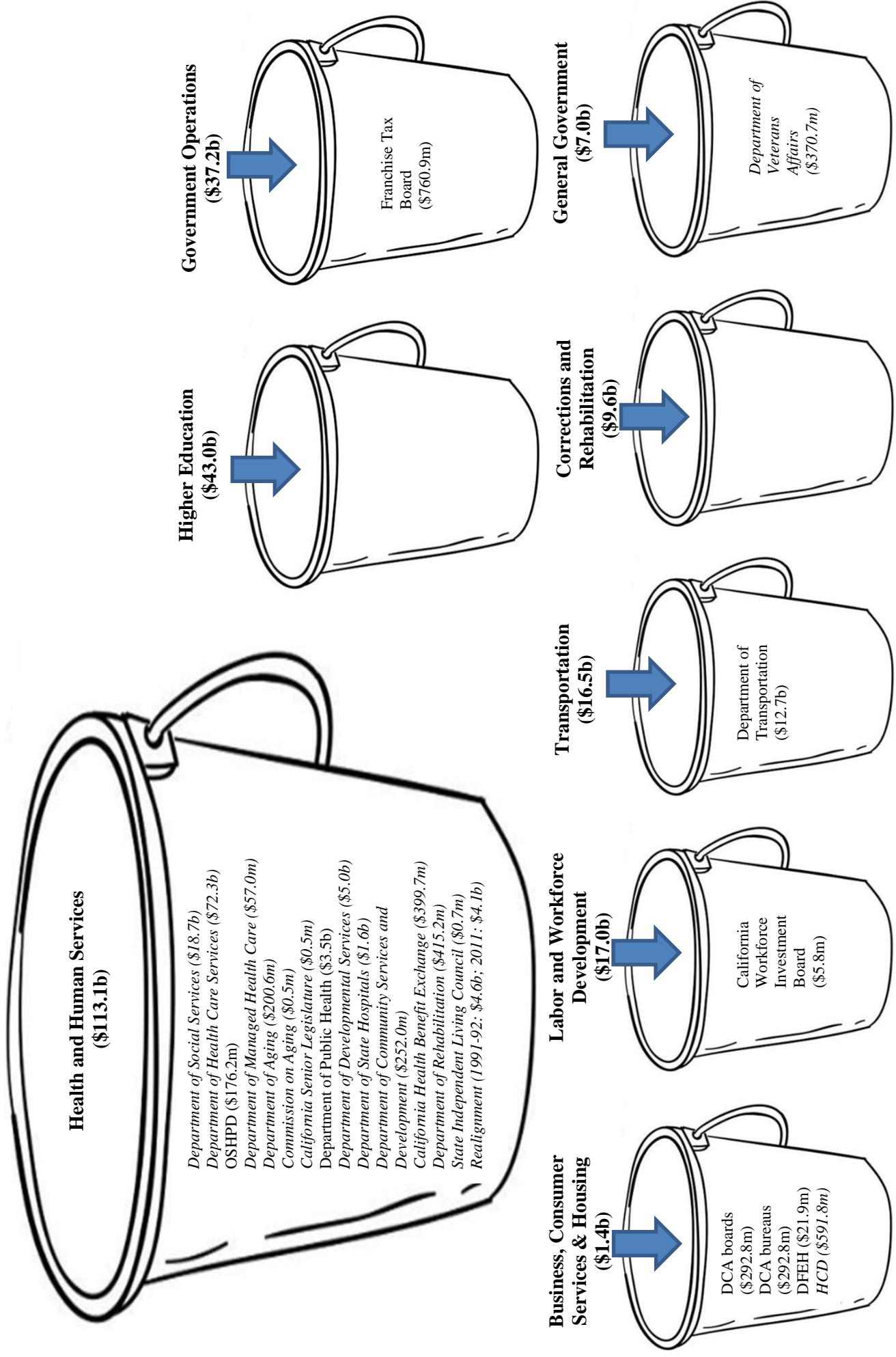
**During the past 12 months, how many times have you seen a medical doctor?: Estimates**

Number of doctor visits in past year	60-64	65-69	70-74	75+	60+
0 visit	227,000	94,000	65,000	139,000	525,000
1 visit	316,000	180,000	138,000	203,000	837,000
2 visits	317,000	214,000	158,000	294,000	983,000
3 visits	252,000	189,000	140,000	249,000	830,000
4 visits	232,000	203,000	160,000	295,000	890,000
5 visits	105,000	92,000	67,000	117,000	380,000
6 visits	139,000	111,000	78,000	192,000	520,000
7-8 visits	78,000	65,000	58,000	126,000	328,000
9-12 visits	133,000	123,000	90,000	232,000	578,000
13-24 visits	74,000	55,000	39,000	102,000	270,000
25+ visits	53,000	53,000	36,000	47,000	189,000
<b>TOTAL</b>	1,926,000	1,379,000	1,029,000	1,995,000	6,330,000

**During the past 12 months, how many times have you seen a medical doctor?: Percentages Within Age Groups**

Number of doctor visits in past year	60-64	65-69	70-74	75+	60+
0 visit	11.8%	6.8%	6.3%	7.0%	8.3%
1 visit	16.4%	13.1%	13.5%	10.2%	13.2%
2 visits	16.5%	15.5%	15.4%	14.7%	15.5%
3 visits	13.1%	13.7%	13.6%	12.5%	13.1%
4 visits	12.0%	14.7%	15.5%	14.8%	14.1%
5 visits	5.4%	6.6%	6.5%	5.9%	6.0%
6 visits	7.2%	8.1%	7.6%	9.6%	8.2%
7-8 visits	4.1%	4.7%	5.7%	6.3%	5.2%
9-12 visits	6.9%	8.9%	8.7%	11.6%	9.1%
13-24 visits	3.9%	4.0%	3.8%	5.1%	4.3%
25+ visits	2.8%	3.8%	3.5%	2.4%	3.0%





## California State and Federal Spending in Agencies and Departments That Provide Aging and Long-Term Care Services, 2013–14

The graphic above provides an update of figures presented in a 2011 policy brief by the SCAN Foundation (see page 3 of [http://thescanfoundation.org/sites/thescanfoundation.org/files/TSF\\_Policy\\_Brief\\_5\\_5.pdf](http://thescanfoundation.org/sites/thescanfoundation.org/files/TSF_Policy_Brief_5_5.pdf)). The amounts used for this update are the estimated 2013–14 expenditures from the Governor’s Budget 2014–15, Proposed Budget Detail and associated “Entire Budgets.” (For example, for the Health and Human Services Agency, see <http://www.ebudget.ca.gov/2014-15/StateAgencyBudgets/4000/agency.html> and <http://www.ebudget.ca.gov/2014-15/pdf/GovernorsBudget/4000.pdf>).

Please note that the amounts listed *are not* limited to spending on aging and long-term care; instead, they are the total budgets for those departments and agencies that, either directly or indirectly, spend some funds on programs and/or services for older Californians. The 2011 SCAN Foundation policy brief (referenced above) noted that “California’s existing LTSS system was created one program at a time, resulting in a highly fragmented arrangement of services that focuses little on the individual’s holistic needs but instead on the particulars of what each department or program provides and from where funding originates...” and that the various agency and department budgets illustrated in the brief (and updated here) show “...the fiscal and administrative complexity that drives much of the service fragmentation experienced by California’s older adults, people with disabilities, and their caregivers.”

Per the original graphic: In the figure above, *italics* represent entities with a direct association with aging and long-term care programs or populations—one in which the entity administers or oversees a program that directly serves older adults and people with disabilities. Non-italics represent entities with an indirect association—one in which the entity facilitates the provision of aging and long-term care services but is not involved in direct service through administration or oversight.

### *Abbreviations used:*

OSHPD = Office of Statewide Health Planning and Development

DCA = Department of Consumer Affairs

DFEH = Department of Fair Employment and Housing

HCD = Department of Housing and Community Development

# **Facts & Citations**

## **Healthcare Workforce Serving Aging Californians**

### **- Needs & Capacity -**

*Draft – October 20, 2014*

This document includes facts on the changing healthcare workforce serving California's aging population. Understanding the health care needs of and the projected demand for services by the aging population can help inform decisions about California's future workforce.

## **HEALTHCARE NEEDS OF AGING PATIENTS**

A high-quality, professional staff – both licensed and unlicensed – is important to supporting the quality of healthcare and the quality of life that older Californians prefer and deserve...<sup>1</sup>

### Quality Care

- Experts have found that vulnerable elderly patients receive about 50-60 percent of recommended care. One expert at UCLA observed that one-third of the patients received the care they needed for dementia, falls, bladder incontinence, and depression.<sup>2, 3</sup>
- An AARP survey reflected a significant proportion of older adults experience problems with their medical care, including a medical error (23 percent), poor communication (20 percent), readmission (15 percent), and lack of follow up (6 percent). As baby boomers age, the need for healthcare professionals trained in geriatrics will be in high demand.<sup>4</sup>
- Poor quality care can result in hospitalizations, nursing home admissions, and the inability to live independently at home.<sup>5</sup>

### Preventive Care

Preventive health services are valuable for maintaining the quality of life and wellness of older adults. Healthcare providers can play an important role in educating patients about what they can do to prevent the complications of aging, and to achieve the highest possible quality of life.

- Early diagnosis and effective management of chronic conditions can enable older adults to enjoy their later years as functional, active, independent members of their communities.<sup>6</sup> Yet, preventive

services have been shown to be underused, especially among certain racial and ethnic groups.<sup>7 8 9</sup>

- A key finding by a RAND study was that “preventive care for older adults suffers the most, while indicated diagnostic and treatment procedures are provided most frequently.”<sup>10</sup>

## Care Coordination

With increasing age, Californians are more likely to live with chronic illness and disability. Managing chronic conditions requires coordination across multiple providers, settings and a wide range of social supports to maintain health and functioning.

- In 2008, 92.2 percent of Americans over 65 reported having one or more chronic disease. With the increase in longevity and high rates of obesity this number is likely to increase.<sup>11</sup>
- More than two-thirds of older Americans have multiple chronic conditions, and treatment for those with chronic disease accounts for 66percent of the country’s health care budget.<sup>12</sup>
- Complex needs can overwhelm physicians’ informal or implicit coordinating functions, leading to the need for a care team to explicitly and proactively coordinate care.<sup>13</sup>

## Integrated Medical and Human Services to Enhance Quality of Life

- A researcher at UCLA found that the care of chronic geriatric conditions is better when it's done in interdisciplinary and inter-professional teams.<sup>14 15</sup>
- In *Dying in America*, a consensus report from the Institute of Medicine (IOM), a committee of experts found that improving the quality and availability of medical and social services for patients and their families not only enhances quality of life through the end of life, but may also contribute to a more sustainable and affordable care system.
- Many geriatric experts assert that if the wasteful medical spending on the last stage of life could be redirected, it could pay for all the social supports and services needed by today’s fragile elders and their families.<sup>16</sup>
- Studies indicate that social work services decrease health care costs, increase quality of life for older adults, and enhance the effective use of health care services among older adults.<sup>17</sup>

- Research has shown that fragile older people could avoid a quick return to the hospital if they are managed by teams of nurses, social workers, physicians and therapists, together with their own family members. Research has also shown that hospital readmissions, which cost \$17 billion a year, could be reduced by 20 percent — \$3.5 billion — or more.<sup>18</sup>
- According to a recent study by AARP, 87 percent of adults over 65 want to stay in their current home and community as they age.
- States that invest in support services show lower rates of growth in long-term care expenditures.<sup>19</sup>

### Specialty Care

- Demand for specialists is projected to grow at the same rate as the portion of the population with chronic conditions.<sup>20</sup>

## **DEMANDS ON WORKFORCE**

The aging population and the way care is delivered have a substantial effect on the demand for services. In addition, the workforce must adapt to inevitable changes including advancing technology, change in disease patterns, an aging workforce and new incentives for payment.

- **Aging Population.** The number of people in California 65 and older will double over the next twenty years while the rest of the population increases only by 10 percent.
- **Chronic conditions.** Leading causes of death for all age groups are shifting from infectious diseases and acute illnesses to chronic diseases and degenerative illnesses.<sup>21</sup> Research published in *JAMA Internal Medicine* found that, despite a longer life expectancy, boomers had higher rates of hypertension, high cholesterol, diabetes and obesity than their parents. In fact, about 80 percent of older adults require care for chronic conditions such as hypertension, arthritis, and heart disease.<sup>22</sup>
- **Retiring Workforce.** Nearly 30 percent of California's physicians are over age 60, the largest proportion for any state.<sup>23</sup>
- **Technology.** Technology use by patients and providers alike will continue to shape care options for consumer demand and service delivery.
- **Consumer engagement.** Aging baby boomers are anticipated to be assertive purchasers of healthcare, demanding consumer preference and accessibility.
- **Insurance expansion.** As a result of the ACA and the state's expansion of Medi-Cal, California has 3.6 million newly-insured patients who seek a

source for primary care and may exacerbate the maldistribution of providers.<sup>24</sup>

- **New practice and payment models.** New care models such as medical homes and accountable care organizations allow reimbursement for time spent on social and functional needs allowing practitioners to address treatment differently.<sup>25</sup>
- **Delivery system changes.** Financial incentives are transforming from a pay for service transaction model to a pay for value and shifting priorities from episodic acute care to comprehensive, coordinated care across the continuum.
- **Diversity.** By the end of 2060, there will be more elderly Hispanics over age 65 (5.1 million) than Whites (4.1 million). Asians in this age group will number 2.1 million.<sup>26</sup>
- **Shrinking number of family caregivers.** The ratio of seniors (65 and older) per 100 working adults (25 to 64 years old) is projected to increase from 21 seniors in 2010 to 36 seniors in 2030, a 70 percent increase in just 20 years. The impact of the increase is amplified because it follows four decades of no change in the senior ratio.<sup>27</sup>

## **TRANSFORMATIONS & TRENDS IN THE WORKFORCE**

There are inevitable and overarching changes that will increase and expand the demand for healthcare services in California.

**Diversity.** As the state's population becomes more culturally diverse, the health care workforce roles and responsibilities must respond to a new array of service delivery models and to the increasingly complex and diverse needs of older clients.

- Between 2014 and 2025, California's Latino and Asian populations age 65+ are projected to grow by 85 percent and 66 percent, respectively. In 2025, statewide, nearly 50 percent of California's total population age 65 and over will be nonwhite, compared with about 40 percent today.<sup>28</sup>
- The changing composition of patients and their health care needs reinforces the state's long-standing goal of diversifying its health workforce and supporting culturally-competent care as interventions necessary to reduce disparities, improve access and support healthy outcomes.<sup>29, 30</sup>
- California's population is not reflected in its health professions.<sup>31</sup> The general labor force is 38 percent Latino, 13 percent Asian, and 6 percent African-American.<sup>32</sup> Latinos make up 8 percent of nurses and 5 percent of physicians.<sup>33</sup>

- In 2010, more than one-quarter of Californians aged five years and older lived in a household where Spanish was the predominant language spoken at home; this is twice the number of households nationally.<sup>34</sup>

**Technology.** Technological innovations pose a number of benefits and challenges for patients and providers. Innovators are finding opportunities to improve the health care system's performance.

- Specifically, according to a 2012 survey by Deloitte, many consumers are interested in using innovative technologies that could enable self-monitoring, facilitate interactions and information exchange with doctors, and support treatment adherence if those technologies were to become available to them.<sup>35</sup>
- The broad use of technology can serve as a "workforce multiplier and facilitator of interprofessional collaboration", increasing the capacity of primary care.<sup>36</sup>
- Telemedicine will have an impact on the effectiveness and the capacity of primary care services. A study, published online recently in the journal *Telemedicine and e-Health*, found many benefits using telemedicine to provide care for chronic diseases. Results showed reductions in services, hospital re-admissions, length of hospital stay, costs and some reduction in mortality.<sup>37</sup>

**Primary Care.** If patterns of use and delivery of care remain relatively unchanged between 2013 and 2025, the demand for primary care physicians (including geriatricians) is projected to grow by approximately 14 percent. Health care marketplace and political stakeholders agree that patient-centered, coordinated, team-based primary care is critical to achieving a high-value health care system. [38](#)<sup>39</sup>

- The implementation of federal reforms require that new practice and payment models such as medical homes and accountable care organizations rely on primary care clinicians to better manage care.
- Changing the delivery system towards patient-centered teams to better coordinate the care for older patients is an opportunity to make a dramatic impact on cost and quality.<sup>40</sup>

## **CAPACITY OF CURRENT WORKFORCE**

### **Forecasting Workforce Needs**

Given the uncertainty of what the healthcare system will look like over the next decades, workforce projection models have limitations based on the lack of existing data and sensitivity to changing delivery care patterns.<sup>41</sup>

- The former director of the UCSF Center for Healthcare Workforce, suggests that focusing solely on historical provider ratios misses the opportunity presented by health reform to think creatively about how services are arranged and provided.<sup>42</sup> Furthermore, as a professor and renowned health care economist from Princeton testified to the U.S. Senate in 2013, there is no ideal physician-to-population ratio.<sup>43</sup>
- If healthcare workforce tasks are delegated safely, projections about the adequacy of the future physician may be exaggerated.<sup>44</sup>

### **Capacity of Health Professions**

- According to employment projections, California will need to add nearly half a million health care workers by 2020.<sup>45</sup>
- Some propose that the capacity to meet patient demand for primary care be expanded by “reallocating clinical responsibilities – with the help of current technologies – to nonphysician team members and to patients themselves” and that “physicians often complain that they are responsible for tasks that team members with far less training could perform.”<sup>46</sup>

### **Primary Care Physicians**

- National debates continue the conversation about an adequate physician workforce.<sup>47</sup>
- The Association of American Medical Colleges (AAMC) estimation is that, “if current trends continue, the nation will have a shortage of 91,000 physicians and surgeons by 2020”.<sup>48</sup>
- California currently has 1 primary care physician to 1483, greater than the national average of 1:1463.<sup>49</sup> California’s supply of physicians from 1993 to 2013 increased by 60 percent, more than double the pace of the state’s population, but some regions such as the San Joaquin Valley still face doctor shortages, according to the California HealthCare Foundation.<sup>50</sup>

- The total number of physicians in California did not accurately reflect their availability to provide care. About 20percent of all physicians devoted less than 20 hours a week to patient care.<sup>51</sup>
- Utilizing method population ratios and maintaining the status quo of utilization, projections estimate that California will require an additional 8,243 primary care physicians by 2030 -- a 32percent increase over the state's 2010 population of 25,153 practicing primary care physicians.<sup>52</sup>
- The CEO of the Accreditation Council on Graduate Medical Education has stated that projecting a need for physicians is tied to how the delivery system is unfolding. "There are several different directional pointers coming from the provider and payer sectors. Policy makers, and we as educators, are limited in how far we can go to shape the physician workforce or teach new skills until potential changes in the delivery system like the emergence of a primary care-led physician sector are clear."<sup>53</sup>
- Many experts argue that producing more doctors will not close the demand-capacity gap, but will exacerbate health spending and overlook the opportunity to improve efficiency with expanded use of nurse practitioners, physician assistants, and others teaming with doctors.<sup>54, 55</sup>
- In fact, the Academy of Medical Colleges notes that "the physician workforce is only one part of an increasingly complex health care system in which the final goal is a healthier society. The link between number and type of physicians, as well as the content of their education, and the health status of the populations they serve has yet to be completely understood. Further investigation regarding the impact of the physician workforce on health will better inform workforce planning."<sup>56</sup>
- According to AARP, primary care doctors are in such demand now that they can choose not to accept Medicare.<sup>57</sup> They are also aging and retiring. California has the nation's second-oldest physician workforce, with 32 percent older than 60. The U.S. average is 28 percent.
- Still, as demand increases for primary care, only about four percent of American medical graduates are choosing careers in primary care.<sup>58</sup>
- The current generation of workaholic physicians is being replaced by Gen Xers and millennials who demand a 35-hour work week.<sup>59</sup>

## **Osteopathic Medicine**

- Osteopathic doctors (O.D.) obtain skills that are comparable to that of a traditional medical doctor (M.D.).<sup>60</sup> ODs are licensed to practice and prescribe medicine and perform surgery in all 50 states.<sup>61</sup>
- Osteopathic schools offer the same academic subjects, two years of rotation and residencies as traditional medical schools. One in five medical students in the United States is enrolled in an osteopathic medical school. Of the nation's medical school graduates, 22 percent are from osteopathic schools.<sup>62</sup>
- About 60 percent of D.O. graduates enter primary care fields like internal medicine, pediatrics and family medicine, compared with about 30 percent of M.D.s.<sup>63</sup>
- More than 4,800 new osteopathic physicians enter the workforce each year and the number is increasing.<sup>64</sup> As of 2012, there were more than 82,500 ODs in the United States. By 2020, the number of osteopathic medical physicians will be over 100,000, say expert predictions, according to the American Medical Association.<sup>65</sup>

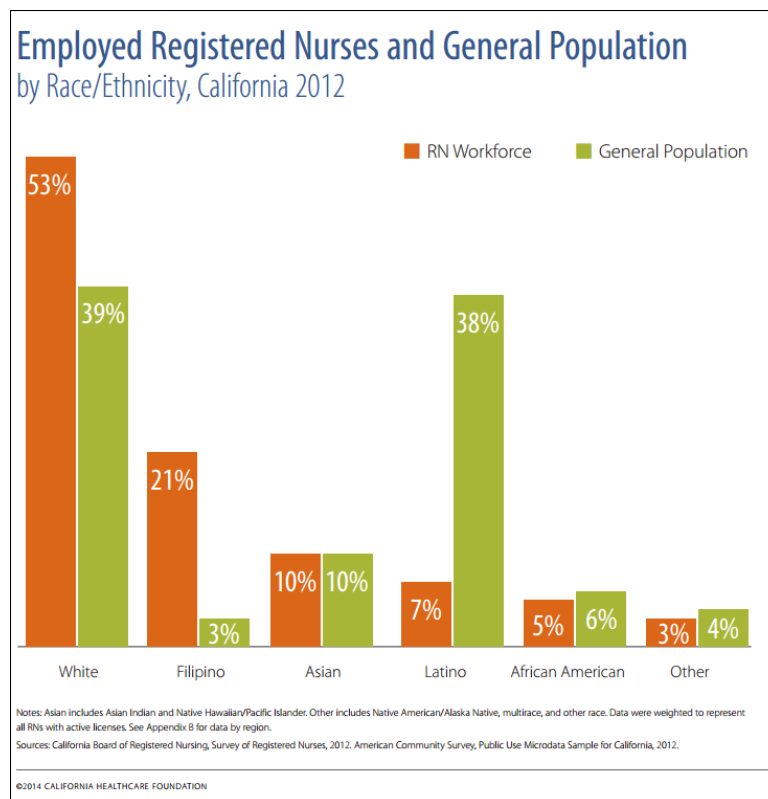
## **Geriatricians**

- While much of the practice of geriatric medicine is similar to the practice of internal medicine or family medicine, the unique needs of older adults transferring to or living in home or skilled nursing, are not always recognized by physicians who do not specialize in that area.<sup>66</sup>
- There are about 7,000 geriatricians in the country to deal with the aging boomer generation over the next 10 years. More than 20,000 will be needed, according to the American Geriatrics Society, a professional and advocacy group.<sup>67</sup> As of 2011, there were 739 geriatricians in California (1:5968 older adults). California is projected to need an additional 2813 geriatricians between now and 2030.<sup>68</sup>

## **Registered Nurses**

- "Nurses provide the front line health care for older adults in a wide variety of settings, including primary care offices, hospitals, and, 6 percent are employed in skilled/rehabilitative nursing."<sup>69</sup>
- "The primary drivers of increased RN demand – the aging of the nursing workforce and needs of the general population – remain strong."<sup>70</sup>

- Over the past 15 years the number of RNs has steadily increased in California, although the RNs-per-capita ratio has remained significantly lower than the national average.<sup>71</sup>
- Less than one percent of all registered nurses are certified as gerontological and the vast majority of schools of nursing had no faculty members who were certified in gerontological nursing by the American Nurses Credentialing Center.<sup>72,73</sup>
- 2010 and 2012 surveys of registered nurses reflected the recession as a cause for an overall decrease in employed RNs, particularly among nurses under 40 years old while employment rates of nurses age 50 years and older increased. The Board of Registered Nurses (BRN) survey concluded that more nurses are delaying retirement.<sup>74</sup>
- Overall, California's RN supply is forecasted to match demand reasonably well over the next two decades if RN graduations remain stable and state-to-state migration patterns do not change significantly.<sup>75</sup>
- The nursing workforce has grown more diverse but, as reflected in the chart below, underrepresents the state's population of Latinos, while Filipinos and Whites were significantly overrepresented.



## **Nurse Practitioners**

- A nurse practitioner (NP) is an advanced practice registered nurse who has completed advanced coursework and, in California, must possess a master's degree in nursing.<sup>76</sup>
- NPs will play an important role in meeting the demand for primary care. In 2010, 69percent of NPs working in California reported that their principal nursing position was primary care.<sup>77</sup>
- NPs can perform about 80-90 percent of the services physicians provide. There are many studies that show patient outcomes from NPs in primary care are comparable to those of MDs.<sup>78</sup>
- From 2004 to 2013, the number of nurse practitioners in California increased by 45 percent.<sup>79</sup>

## **Pharmacists**

- The use of an interdisciplinary team with geriatric competency is necessary to best manage the complex and challenging healthcare of older adults, including drug therapies.
- California's supply of pharmacists grew 15percent between 2001 and 2012, while the supply of pharmacy technicians increased 70percent.<sup>80</sup> (CHCF March 2014)
- "Less than half of pharmacy schools have a distinct course in geriatrics despite the fact that per capita prescription drug use by people 65 and older is triple that of younger individuals." <sup>81, 82</sup>

## **Direct-Care Workers**

Direct care workers are the "the linchpin of the formal health care delivery system for older adults."<sup>83</sup> They help care for older adults and individuals with disabilities by providing assistance with activities of daily living (such as eating, bathing, going to the bathroom, dressing, etc.) and certain health care and rehabilitation services. They often have the most contact with the patients and can most directly influence their quality of life.<sup>84</sup>

- Direct-care workers fall into three main categories tracked by the U.S. Bureau of Labor Statistics (BLS): Nursing Assistants (usually known as Certified Nursing Assistants or CNAs), Home Health Aides, and Personal Care Aides.<sup>85</sup>

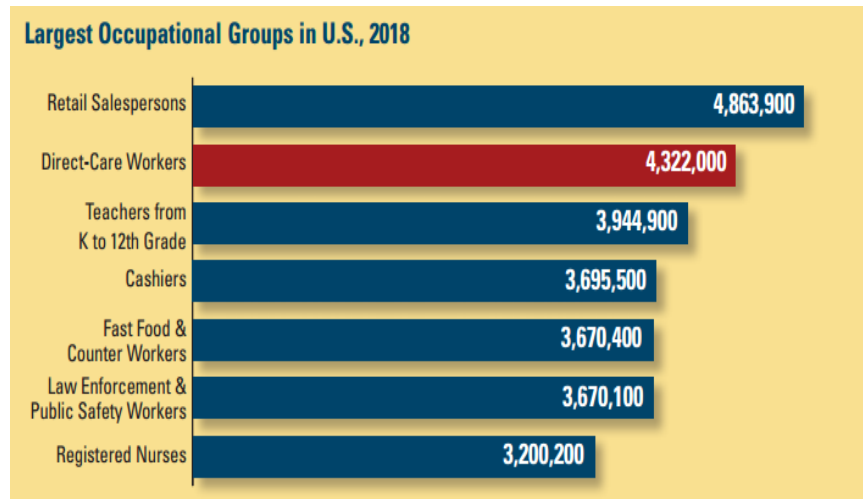
- In California, direct-care workers provide an estimated 70 to 80 percent of the paid hands-on care for older adults or those living with disabilities or other chronic conditions.<sup>86</sup>
- While direct-care workers are employed in a range of settings (from homes to nursing facilities, hospitals, group homes, assisted living facilities and non-residential day programs), most are in homes and community-based jobs.<sup>87</sup>

## Demand

- Nearly 90 percent of people over age 65 want to stay in their home for as long as possible. According to AARP, many will reject institutional care and continue to live in the community even if they have one or more disabilities.<sup>88</sup>
- A growing number of direct care workers (some estimate one-quarter) work directly for consumers and their families rather than being employed through an agency.<sup>89</sup>

## Job Growth

- Direct care workers constitute one of the largest and fastest-growing workforces in the country, playing a vital role in job creation and economic growth, particularly in low-income communities.<sup>90</sup>
- Two subsets of direct workers, personal and home care workers, are the fastest-growing job categories in the nation.
- In 2008, over 3 million direct-care workers were employed. In 2018, more than 4 million are expected to be employed and likely to outnumber facility workers by nearly two to one. Projected need is 5 million in 2020.<sup>91</sup>
- In fact, as shown in the chart below, in 2018, the direct-care workforce will reach historic proportions, exceeding teachers, law- enforcement and public safety workers, and registered nurses. According to the BLS Employment Projections Program, because many are directly employed by private households or were self-employed, figures are probably low.<sup>92</sup>



Paraprofessional Healthcare Institute (PHI), 2011<sup>93</sup>

## Work Environment for Direct Care Workers

- “Direct Care Workers are among the most poorly compensated of all U.S. workers. About 45 percent of direct-care workers live in households earning below 200 percent of the federal poverty level income. Nearly half of all direct-care workers live in households that receive one or more public benefits such as food stamps; Medicaid; or housing, child care, or energy assistance.”<sup>94</sup>
- Only about half of CNAs and HHAs participate in their employers’ health insurance plan. Almost 20percent of workers are uninsured. Some workers rely on Medicaid or another government program that pays for medical care.<sup>95</sup>
- Experts note that by improving direct care workers' work environment and training, this workforce sector can be stabilized and professionalized to ensure it meets the growing demands of California’s older population. It is also an opportunity to support one of the U.S. fastest-growing job categories in the middle class and strengthen our economy instead of swelling the ranks of the working poor.<sup>96</sup>

## Social Workers

While social workers do not provide medical care, they provide a continuum of services, from communicating with family members, accessing community resources and evaluating services and programs to acting as advocates for their clients.<sup>97</sup>

- "Social work has a significant role to play in supporting older adults with dementia, Alzheimer's disease, chronic illness, mental illness and to those who have experienced elder abuse. Social workers also address barriers to continued productivity and active aging through counseling, substance abuse treatment, caregiver support and addressing pervasive ageism in society."<sup>98</sup>
- Although 75 percent of social workers report working with older adults, only four percent of social workers report receiving geriatrics training and only 24 percent of Bachelors of Social Work programs offer a certificate in aging or gerontology.<sup>99</sup>
- While the social work labor force itself is aging, with almost one-third older than 55, by 2020, estimates are that 60,000 to 70,000 geriatric social workers will be needed.<sup>100</sup>
- In its 2008 report, *Retooling for an Aging America: Building the Health Care Workforce*, the IOM reaffirmed the growing need for gerontological social work and the low level of interest among social workers, especially those at the master's level, in working with older adults--despite several initiatives to promote education and training in gerontological social work.<sup>101</sup>
- National Association of Social Worker's (NASW) study found that social workers serving older adults face greater challenges than other social workers—including lower pay, higher caseloads, a greater proportion of tasks below their skill levels, and a lack of peer networks and agency support—thereby hindering their satisfaction and retention in the field. In the report's conclusion, NASW highlighted the recruitment and retention of social workers, especially those interested in working with older adults, as the primary challenge facing the profession.<sup>102</sup>

## WORKFORCE DEVELOPMENT

*"The impending crisis, which has been foreseen for decades, is now upon us. The nation needs to act now to prepare the health care workforce to meet the care needs of older adults." Institute of Medicine (2008)*

### Overall job growth

It is estimated that California will have to add 450,000 jobs to its health workforce over the next decade.<sup>103</sup> Yet, many experts agree that "there is a worsening shortage of competent, paid workers who are able to meet the needs of older adults." It is suggested that efforts to address the shortage first acknowledge the unique circumstances affecting these workers: "nontraditional

market forces, low compensation and prestige, limited career opportunities, and inadequate preparation for evolving roles and responsibilities".<sup>104</sup>

In California, the occupations with the highest projected demand in health care and social assistance careers are: registered nurses; personal care aides; home health aides; medical assistants; and nursing aides, orderlies and attendants. Employment in these top five occupations is projected to increase by 146,000 workers.<sup>105</sup>

- "While physicians and other highly trained clinicians are critical to health care delivery .... about 40 percent of all health care jobs that need to be filled over the next decade will require some college but less than a bachelor's degree." <sup>106</sup> These include home health aides, nursing aides, personal care aides, licensed practical and vocational nurses, medical assistants, registered nurses, physical therapist assistants/aides, diagnostic medical sonographers, occupational therapy assistants/aides, and dental hygienists.<sup>107</sup>
- "Because healthcare offers large numbers of jobs for workers with less than a bachelor's degree, these jobs are important for efforts to support upward social mobility, since they can serve as entry points into the labor force for workers with lower levels of education and potentially open up career ladders."<sup>108</sup>
- "The diverse nature of the pre-baccalaureate healthcare workforce can be a significant asset to healthcare providers. Pre-baccalaureate workers in these occupations are disproportionately people of color; five occupations have higher shares of blacks, Asians and Hispanics than the average of pre-baccalaureate workers across all occupations."<sup>109</sup>

**Geriatrics Training.** The breadth and depth of geriatrics education and training for health care professionals remains inadequate to prepare them for the health care needs of the future. <sup>110</sup> A few examples:

- Medical students can graduate from medical school with just one month of geriatrics rotation and less than 3 percent of students in medical schools choose to take geriatrics electives.<sup>111</sup>
- Less than one percent of all registered nurses are certified as gerontological and the vast majority of schools of nursing had no faculty members who were certified in gerontological nursing by the American Nurses Credentialing Center. <sup>112 113</sup>
- Only 5 percent of all social workers have taken classes in aging.

- According to academic experts, “of the programs that are out in the community operating under the Older Americans Act funding, delivering services through senior centers, 60 percent don’t have even one staff member who has taken a single course on an aging topic.”<sup>114</sup>
- There have been repeated calls to expand and improve training for many types of health care workers, including technicians and support staff (Institute of Medicine 2008). The IOM report cites “lack of faculty, lack of funding, lack of time in already-busy curricula, and the lack of recognition of the importance of geriatrics training” as the main barriers to the appropriate levels of training.<sup>115</sup>
- A professor of Gerontology points to the perception of aging services, “There’s an issue of ageism which creates negative stereotypes. A lot of physicians, who don’t know that much about aging, assume every complaint from an older person is simply because they are getting older. We need to educate physicians, including internists who are not specializing in geriatrics about what is really just age related and what’s a disease, what’s correctable and what’s preventable.”<sup>116</sup>
- Opportunities to study gerontology and geriatrics in California exist in the Community Colleges, the California State Universities, the University of California, and in Private Universities.<sup>117</sup>

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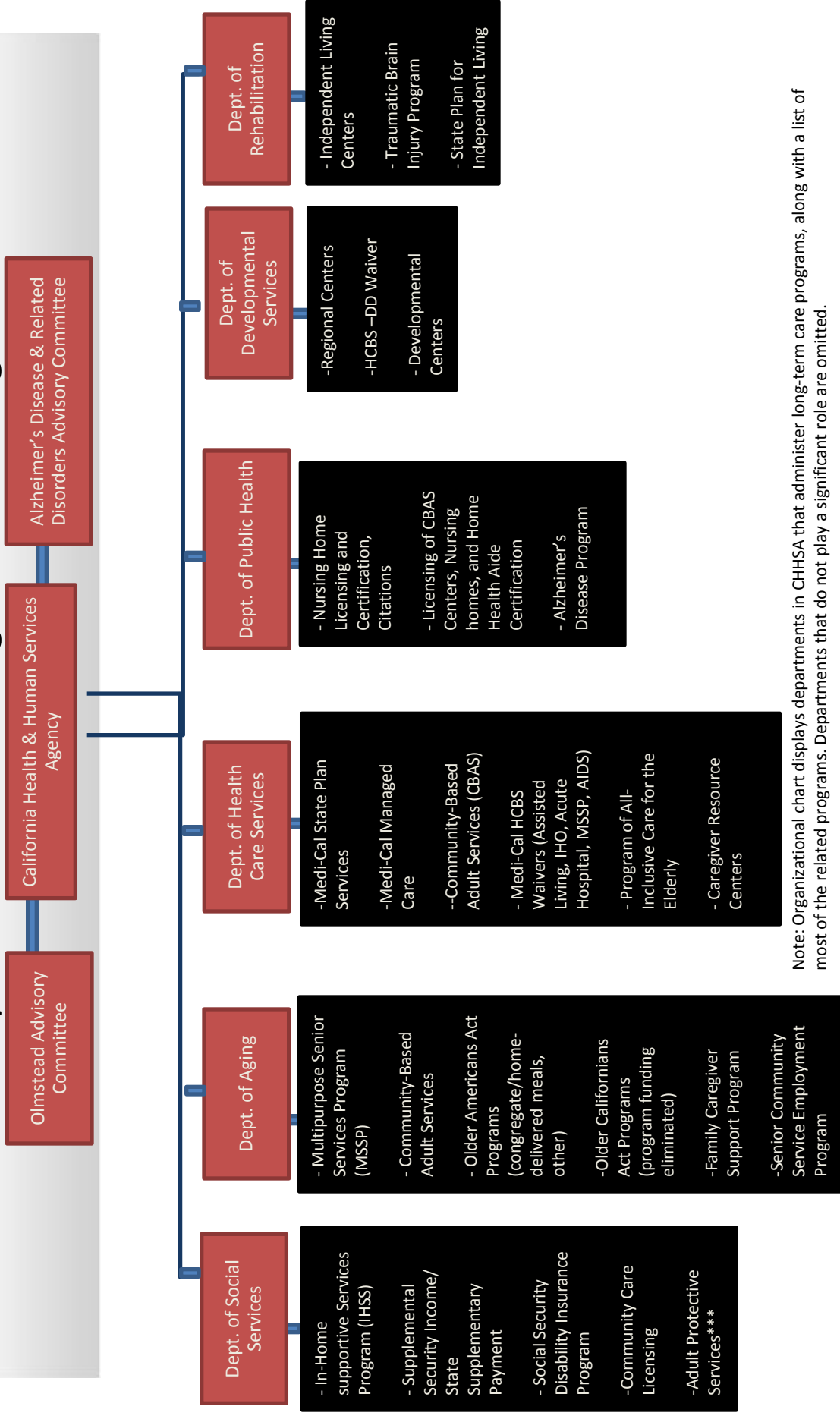
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# **California's Departments and Programs for Long-Term Care, and Program Compendium**

# California's Departments and Programs for Long-Term Care



Note: Organizational chart displays departments in CHSA that administer long-term care programs, along with a list of most of the related programs. Departments that do not play a significant role are omitted.

\*\*\* Per Budget Act of 2011, funding for the APS program has been realigned to the counties.

## Long Term Services and Supports

### Program Compendium

March 7, 2014

Federal Agencies and Departments Supporting California's Long-Term Services and Supports System	
<i>U.S. Department of Health and Human Services (DHHS)</i>	DHHS is the primary federal agency responsible for health and human services, including long-term care services. Within DHHS are the Centers for Medicare and Medicaid Services and the Administration on Aging, the two primary agencies that have direct responsibilities related to long-term care. Several other agencies and departments are involved in long-term care including the Health Resources and Services Administration, the Department of Labor, and the Department of Housing and Urban Development.
<i>Centers for Medicare and Medicaid Services (CMS)</i>	CMS administers the Medicare program and the federal portion of the Medicaid program. In addition, CMS coordinates state licensing and certification of health facilities, including long-term care facilities.
<i>Administration on Aging (AoA)</i>	The AoA administers the federal Older Americans Act (OAA), which provides funding for an array of community services including congregate and home-delivered meal programs for persons 60 and over through mandatory state units on aging that, in turn, allocate the funds to local Area Agencies on Aging.
California State Agency/Departments Supporting California's Long-Term Services and Supports System	
<i>California Health and Human Services Agency (CHHS)</i>	CHHS oversees departments that provide a range of health care services, long-term care services, social services, mental health services, alcohol and drug treatment services, income assistance and public health services, including the Department of Health Care Services (DHCS), the Department of Aging (CDA), the Department of Rehabilitation (DOR), the Department of Mental Health (DMH), the Department of Social Services (DSS), the Department of Public Health (DPH), and the Department of Developmental Services (DDS).
<i>Department of Health Care Services (DHCS)</i>	DHCS is responsible for administering Medi-Cal, California's Medicaid program that provides health care services for low-income individuals including families with children, seniors, persons with disabilities, foster care, pregnant women, and low income people with specific diseases such as tuberculosis, breast cancer or HIV/AIDS. Medi-Cal is financed by the state and federal government and is the largest funding source for long-term care services in the state. Medi-Cal covers institutional long-term care as well as home and community-based services (HCBS) through Medi-Cal "Optional" State Plan services, and Medi-Cal waivers.
<i>California Department of Aging (CDA)</i>	CDA administers programs that serve older adults, adults with disabilities, and family caregivers. CDA contracts with a network of 33 Area Agencies on Aging, which directly manage a wide array of federal and state-funded services that help older adults find employment; support older adults and adults with disabilities in the community; promote healthy aging and community involvement; and provide caregiver support. CDA also administers the Multipurpose Senior Services Program(MSSP) and certifies Adult Day Health Care centers/Community-Based Adult Services(CBAS), under an interagency agreement with DHCS.

<b>California Department of Rehabilitation (DOR)</b>	DOR works in partnership with consumers and other stakeholders to provide services and advocacy resulting in employment, independent living, and equality for individuals with disabilities.
<b>California Department of Social Services (CDSS)</b>	CDSS provides oversight, policy, and systems functions for programs providing services to the aged, blind and disabled for programs including In-Home Supportive Services (IHSS – see Medi-Cal state plan description) and Adult Protective Services (APS). In addition, CDSS' Community Care Licensing Division provides oversight and enforcement for more than 85,000 licensed residential facilities statewide serving such clients as children, parents and the elderly.
<b>California Department of Public Health (CDPH)</b>	CDPH is responsible for licensing and certification of health care facilities and nursing homes, as well as a variety of other public health programs, including the Alzheimer's Disease Program that provides services to persons with Alzheimer's disease and related disorders and their families through the Alzheimer's Disease Research Centers of California and research funding to scientists engaged in the study of Alzheimer's disease and related disorders through the Alzheimer's Disease Research Fund.
<b>California Department of Developmental Services (DDS)</b>	DDS provides services and supports to individuals with developmental disabilities including mental retardation, cerebral palsy, epilepsy, autism and related conditions. Services are provided through state-operated developmental centers and community facilities, and contracts with 21 nonprofit regional centers. The regional centers provide access to the services and supports available to individuals with developmental disabilities and their families.
<b>California Business, Transportation and Housing Agency</b>	The Business, Transportation and Housing Agency oversees several departments that impact the long-term care service system, including the California Housing Finance Agency, the California Department of Transportation, and the Department of Housing and Community Development.
<b>California Health and Human Services Agency Program Initiatives</b>	
<b>Olmstead Advisory Committee</b>	The Olmstead Advisory Committee, comprised of advocates, consumers and other stakeholders, advises on issues related to the state's implementation of the U.S. Supreme Court's Olmstead decision. <sup>1</sup>
<b>Alzheimer's Disease and Related Disorders Advisory Cmte. (ADRDAC)</b>	The ADRDAC provides ongoing advice and assistance to the Administration and the Legislature on the program needs and priorities of individuals affected by Alzheimer's disease or related disorders.
<b>California Aging and Disability Resource Connections (Cal-ADRCs)</b>	The Cal-ADRC model assists individuals with disabilities and/or chronic conditions in accessing health care, medical care, social supports, and other LTSS. ADRCs offer enhanced information and referral, long-term care options counseling (one-on-one decision support across all networks), short-term service coordination (when there is an urgent need for support until a longer term arrangement can be made), and access to information.

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<sup>1</sup> In 1999, the U.S. Supreme Court ruled in the case of *Olmstead v. L.C.*,<sup>1</sup> finding that the unnecessary institutionalization of people with disabilities is a violation of the Americans with Disabilities Act of 1990 (ADA).

California Department of Health Care Services (DHCS) Programs/Services	
<b>Medi-Cal State Plan</b>	<p>The Medi-Cal State Plan describes the nature and scope of California's Medi-Cal program. As required under Section 1902 of the Social Security Act (Act), the Plan is developed by California and approved by the federal Center for Medicare and Medicaid Services (CMS). The Plan is California's agreement that it will conform to the requirements of the Act and the official issuances of CMS. The State Plan includes the many provisions required by the Act, such as:</p> <ul style="list-style-type: none"> <li>• Methods of Administration</li> <li>• Eligibility</li> <li>• Services Covered</li> <li>• Quality Control</li> <li>• Fiscal Reimbursements.</li> </ul>
<b>Medi-Cal "Optional" HCBS State Plan Services</b>	<p>Optional benefits and services are those that the state chooses to provide under the Medi-Cal Program. In most cases, these optional benefits are not required by federal law. Each state offers a different set of optional benefits to its recipients. California's optional State Plan services include the In Home Supportive Services program (IHSS), Home Health Agency services<sup>2</sup>, and Targeted Case Management<sup>3</sup>.</p>
<b>Medi-Cal Waivers</b>	<p>Medi-Cal waivers are programs under Medi-Cal that provide additional services to specific groups of individuals, limit services to specific geographic areas of the state, as well as medical coverage to individuals who may not otherwise be eligible under Medicaid rules. DHCS must obtain approval from the federal government to administer Medi-Cal waivers. Requests for new waivers usually require prior State Legislative authorization. The proposed changes must not cost the federal government more than the expected Medicaid costs for the traditional Medicaid population under the same time period. The three types of waivers include the Research and Demonstration 1115 Waiver, 1915 (b) Waiver and the 1915 (c) Home and Community-Based Services Waiver, as follows. <u>Research and Demonstration 1115 Waiver</u>: 1115 waivers are intended to demonstrate and evaluate a policy or approach that has not been demonstrated on a widespread basis. <u>1915 (b) Waiver</u>: 1915 (b) waivers give allow states to mandatorily enroll beneficiaries into managed care programs, or creating a "carveout" delivery system for specialty care. 1915(b) waivers do not have to be operated statewide. <u>1915 (c) Home and Community-Based Services Waiver</u>: HCBS waivers allow states to offer a variety of services to consumers, including a combination of both traditional medical services as well as non-medical services.</p>

<sup>2</sup> HHA services are covered benefits under both the Medi-Cal State Plan and various 1915(c) HCBS waiver programs. Under the state plan, intermittent HHA services can cover short-term assistance with wound care, therapies, and medication monitoring, for example. Under HCBS waivers, HHA and independent nurse provider services can cover shift nursing for long-term, chronic conditions.

<sup>3</sup> Medi-Cal provides funding for case management services to help individuals obtain services covered under the Medi-Cal State Plan, such as home health, IHSS, and durable medical equipment, as well as through other public and private providers, such as emergency food and housing. Covered TCM activities also include assessment, services/support planning, and monitoring services and supports. In California, TCM is offered through local governmental agencies that provide services directly or by contracting with non-governmental entities or the University of California.

California's 1915 (c) HCBS waivers include the following:

- Assisted Living Waiver (ALW): The ALW provides home and community-based services in two settings: Residential Care Facilities for the Elderly or in publicly subsidized housing, with services provided by a Home Health Agency. Eligibility is limited to Medi-Cal beneficiaries over the age of 21. Services include, but are not limited to: assistance with activities of daily living; health related services including skilled nursing; transportation; recreational activities; and housekeeping.
- The Home and Community-Based Services Waiver for the Developmentally Disabled (HCBS-DD): The HCBS-DD Waiver provides home- and community-based services to persons with developmental disabilities who are Regional Center consumers and reside in the community as an alternative to institutionalization. This waiver is administered by the California Department of Developmental Services.
- Multipurpose Senior Services Program (MSSP): MSSP provides care management, adult day care, housing assistance, chore and personal care services (if the individual has used the allocated IHSS service hours), protective supervision, respite, transportation, meal services, social services and communication services for Medi-Cal eligible individuals over the age of 65 who meet clinical qualifications for nursing facility admissions. This waiver is administered by the Department of Aging.
- Nursing Facility/Acute Hospital (NF/AH) Waiver<sup>4</sup>: The NF/AH waiver provides community-based alternatives to Medi-Cal eligible individuals who would otherwise be receiving care in either an acute hospital, adult or pediatric subacute facility, nursing facility, or distinct-part nursing facility. There is no age limit for waiver services. The waiver is available to individuals who are currently residing in an institution but wish to transition to his/her home and community, as well as to individuals who reside in the community, but are at-risk for being institutionalized within the next 30 days.
- In-Home Operations (IHO) Waiver: The IHO waiver offers services only to Medi-Cal beneficiaries who were enrolled in an IHO HCBS waiver prior to January 1, 2002, and have physician-ordered direct care services in excess of that available through the NF/AH waiver.

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<sup>4</sup> The NF/AH waiver was previously known as the "NF A/B Waiver" and was renamed the NF/AH Waiver effective January 1, 2007. The NF/AH waiver combines the following three prior Home and Community-Based Waivers: (1) NF A/B waiver; (2) Nursing Facility Subacute (NF SA) waiver; and the In-Home Medical Care (IHMC) waiver.

## Department of Health Care Services, Program/Services Continued

<b>Community-Based Adult Services (CBAS) (Formerly Adult Day Health Care/ADHC)</b>	Community-Based Adult Services (CBAS) programs are licensed community-based day care programs providing a variety of health, therapeutic, and social services. This program replaces the Adult Day Health Care program (ADHC) program. Under an interagency agreement, CBAS is administered between the Department of Health Care Services, the Department of Public Health (CDPH), and the California Department of Aging (CDA). CDPH licenses CBAS as ADHC centers; CDA certifies them for participation in Medi-Cal. Each CBAS center has a multidisciplinary team of health professionals who conduct a comprehensive assessment of each potential participant to determine and plan services needed to meet the individual's health and social needs. Services include professional nursing services; physical, occupational and speech therapies; mental health services; therapeutic activities; social services; personal care; hot meals and nutritional counseling; and transportation to and from the participant's residence. CBAS seeks to restore or maintain optimal capacity for self-care to frail elderly persons and other adults with physical or mental disabilities and to delay or prevent institutionalization. In 30 of California's 58 counties, CBAS is provided as a Medi-Cal managed care benefit. In the remaining rural managed care counties, CBAS remains a fee-for-service benefit.
<b>California Community Transitions</b>	In January 2007, DHCS was awarded funding by CMS to implement a Money Follows the Person Rebalancing Demonstration called "California Community Transitions" (CCT). CCT allows eligible Medi-Cal beneficiaries who have been receiving services in nursing or other inpatient health care facilities for 90 days or longer to transition to a community setting, if that is their preference.
<b>Caregiver Resource Centers (CRC)</b>	CRCs provide information and referral, short-term counseling, respite care, education, training and support to families and caregivers of persons with Alzheimer's disease, stroke, Parkinson's disease, and other disorders at eleven centers throughout the state.
<b>Program for All-Inclusive Care for the Elderly (PACE)</b>	<p>PACE provides medical and supportive services to individuals who are age 55 or older, and who are certified to need nursing home care, but who are able to live safely in the community at the time of enrollment. The program is available in limited areas of the state, with services including:</p> <ul style="list-style-type: none"> <li>• Medical care provided by a PACE physician familiar with the history, needs and preferences of each participant</li> <li>• Adult day care that offers nursing; physical, occupational and recreational therapies; meals; nutritional counseling; social work and personal care</li> <li>• Home health care and personal care in the home</li> <li>• Prescription drugs</li> <li>• Social services</li> <li>• Medical specialty services</li> <li>• Hospital and nursing home care, when necessary</li> </ul> <p>An interdisciplinary team assesses participants' needs, develops care plans, and delivers all services (including acute care services and when necessary, nursing facility services). PACE provides social and medical services primarily in a Community Based Adult Services (CBAS) center, supplemented by in-home and referral services in accordance with the participant's needs. The PACE service package includes all Medicare and Medi-Cal covered services, and other services.</p>

California Department of Aging (CDA) Programs/Services	
<b>Community-Based Adult Services (CBAS) (formerly ADHC)</b>	See program description under the Department of Health Care Services. Under an interagency agreement, CBAS is administered between the Department of Health Care Services, the Department of Public Health (CDPH), and the Department of Aging (CDA). CDPH licenses CBAS as ADHC centers and CDA certifies them for participation in the Medi-Cal Program.
<b>Multipurpose Senior Services Program (MSSP)</b>	CDA is responsible for program administration of the MSSP waiver (see program description under DHCS Medi-Cal Waiver).
<b>Nutrition Services</b>	<p>CDA administers nutrition services funded by the federal Older Americans Act and state General Fund dollars through the network of Area Agencies on Aging and their service providers. The programs serve a broad population, with preference given to those in greatest economic or social need. Nutrition services are offered in two settings: congregate and home delivered meals, as follows:</p> <ul style="list-style-type: none"> <li>• <u>Title III C-1: Congregate Nutrition Services</u> provide meals in a group setting. Services also include nutrition and health promotion education, and opportunities for socialization. People eligible for Title III C-1 nutrition services are 60 years of age or older, individuals with a handicap or disability who meet specific criteria, spouses of eligible participants regardless of age, and volunteers who provide needed services during meal hours.</li> <li>• <u>Title III C-2: Home Delivered Meal Services</u> are available to people, age 60 or older, who are homebound by reason of illness, incapacity, or disability, or who are otherwise isolated. Most home-delivered meal programs provide clients with a hot meal five days a week delivered by staff or volunteer drivers.</li> </ul>
<b>Senior Community Service Employment Program (SCSEP)</b>	The SCSEP provides part-time work-based training opportunities at local community service agencies for older workers who have poor employment prospects and assists with the transition of individuals to private or other employment opportunities in the community. The program provides a variety of supportive services to the individual such as personal and job-related counseling, job training, and job referral. Individuals who participate in the program must be residents of California, be at least 55 years of age, and have an income that does not exceed 125 percent of the federal poverty level.
<b>The Long-Term Care Ombudsman Program</b>	The Long-Term Care Ombudsman Program investigates and endeavors to resolve complaints made by, or on behalf of, residents in long-term care facilities including nursing homes, residential care facilities for the elderly, and assisted living facilities. The goal of the Long-Term Care Ombudsman Program is to advocate for the rights of all residents of long-term care facilities.
<b>Health Insurance Counseling and Advocacy Program (HICAP)</b>	HICAP offers consumer counseling on Medicare, Medicare supplement policies, Health Maintenance Organizations (HMOs) and long-term care insurance. Local HICAP offices provide free community education and confidential individual counseling statewide.

<b>Family Caregiver Support Program (FCSP)</b>	The FSCP was established under Title III-E of the federal Older Americans Act Amendments of 2000. Provided through contract with the 33 Area Agencies on Aging, services include caregiving information, access to services and supports, temporary respite care <sup>5</sup> and other support.
<b>Alzheimer's Day Care Resource Centers (ADCRC)<sup>6</sup></b>	The Alzheimer's Day Care Resource Centers (ADCRC) is authorized under the Older Californians Act; however, there are no longer any General Fund dollars supporting this program. To this end, the local Area Agencies on Aging determine whether and to what extent to fund the program. ADCRCs provide care for persons with Alzheimer's disease and other dementia. The centers provide services that support the physical and psychosocial needs of persons with Alzheimer's disease or related dementia. Individual care plans are developed for each program participant with activities scheduled in accordance with these plans to maintain the highest level of functioning.
<b>Brown Bag Program<sup>5</sup></b>	The Brown Bag Program is authorized under the Older Californians Act; however, there are no longer any General Fund dollars supporting this program. The local Area Agencies on Aging determine whether and to what extent to fund the program. The Brown Bag Program provides surplus and donated fruits, vegetables and other food products to low income individuals 60 years of age and older.
<b>Foster Grandparent Program<sup>5</sup></b>	The Foster Grandparent Program is an intergenerational volunteer program that provides aid to children and youth with special and exceptional needs.
<b>Linkages<sup>5</sup></b>	To this end, the local Area Agencies on Aging determine whether and to what extent to fund the program. Linkages serves frail elderly adults and adults with disabilities, age 18 years and older, providing comprehensive care management for individuals who are not eligible for other care management programs.
<b>Senior Companion<sup>5</sup></b>	The Senior Companion program was established as part of the Older Californians Act; however, there are no longer any General Fund dollars supporting this program. To this end, the local Area Agencies on Aging determine whether and to what extent to fund the program. Under this program, volunteers serve frail older adults and adults with disabilities by providing respite for caregivers, companionship, assistance with simple chores, assistance with grocery shopping and meal preparation, transportation and other services.

<sup>5</sup> Temporary respite care and support services are offered to a grandparent/older relative caregiver of a child, or to a family caregiver of an older care receiver (60 years of age or older) that has been determined to be functionally impaired due to having two or more limitations in activities of daily living or a cognitive impairment requiring substantial supervision.

<sup>6</sup> These programs no longer receive any General Fund support, but remain authorized in statute as part of the Older Californians Act. The local Area Agencies on Aging determine whether and to what extent to fund the programs.

<b>California Department of Rehabilitation (DOR) LTC Programs/Services<sup>7</sup></b>	
<b>Independent Living Centers (ILC)</b>	ILCs are consumer controlled, community based, cross disability, nonresidential private nonprofit agencies designed and operated within local communities by individuals with disabilities. ILCs provide independent living services that seek to maximize a person's ability to live independently in the environment of their own choosing. All ILCs provide six core services: housing referrals; information and referral; peer counseling; personal assistant services; independent living skills training; and, individual and systems change advocacy. DOR oversees the state's network of 29 ILCs, providing technical assistance and financial support. ILCs serve any individuals with disabilities, regardless of age.
<b>Traumatic Brain Injury (TBI) Program</b>	The TBI program provides community reintegration, service coordination, family and community education, vocational supportive services and service coordination services to persons suffering from TBI at seven sites in California.
<b>Vocational Rehabilitation Services</b>	DOR contracts with providers for a range of vocational rehabilitation services including employment services, rehabilitation technology, independence development, and personal support services.
<b>California Department of Social Services (CDSS) Programs/Services<sup>7</sup></b>	
<b>In-Home Supportive Services (IHSS)</b>	IHSS is a federal, state, and locally-funded program that provides in-home assistance to low-income adults who are over 65 years of age, blind, or disabled, and to children who are blind or disabled. Qualified recipients receive assistance with daily tasks, including bathing, dressing, cooking, cleaning, grooming, and feeding. The IHSS program plays a significant role in helping people remain at home and avoid institutionalization, and serves as a model of self-directed services. County social workers assess individuals using a standardized assessment to determine the need and then authorize service hours per month, based on a functional index score (FIS) of 1 to 5 (1=lowest need; 5=highest need). The consumer directs his/her services by deciding how, when, and in what manner IHSS services will be provided. IHSS is administered at the state level by the state Department of Social Services (through an interagency agreement with the Department of Health Care Services), and at the local level through county human services offices.
<b>Adult Protective Services (APS)</b>	APS assists seniors (65 years and older) and dependent adults (disabled 18-64 year-olds) who are unable to meet their own needs, or are victims of abuse, neglect, or exploitation. County APS agencies investigate reports of physical, emotional, or financial abuse or neglect of seniors and dependent adults who live in multiple settings by family members or other known associates. APS staff evaluate abuse cases and arrange for services such as advocacy, counseling, money management, out-of-home placement, or conservatorship. Reports of abuse that occur in a nursing home, a board and care home, a residential facility for the elderly, or at a long term care facility by provider staff are

<sup>7</sup> The programs highlighted reflect only those provided by the department with direct relevance to home and community-based services. The Department operates a number of other programs and services in addition to those highlighted.

	the responsibility of the Ombudsman's office, under the California Department of Aging's Ombudsman program..
<b>Community Care Licensing (CCL)</b>	The CCL program provides oversight and enforcement of the licensed facilities including Residential Care Facilities for the Elderly (RCFE) and Continuing Care Retirement Communities (CCRC). RCFEs provide care, supervision, and assistance with activities of daily living to persons 60 years of age and over, as well as persons under 60 with compatible needs. RCFEs include assisted living facilities, retirement homes, and board and care homes. These facilities range from very small (six beds or less) to very large (over 100 beds). CCRCs are licensed RCFEs that provide a long-term continuing care contract for housing, residential services, and nursing care, usually in one location, and usually for a resident's lifetime.
<b>California Department of Public Health (CDPH) LTC Programs/Services<sup>8</sup></b>	
<b>Licensing and Certification of Nursing Facilities</b>	CDPH is responsible for licensing and certification of health care facilities, and nursing homes. In addition, CDPH is responsible for licensing CBAS centers (technically licensed as ADHC centers).
<b>Alzheimer's Disease Program</b>	The Alzheimer's Disease Program provides services to persons and families afflicted with Alzheimer's disease and related disorders through the Alzheimer's Disease Research Centers of California.
<b>California Department of Developmental Services (DSS) Programs/Services</b>	
<b>HCBS-DD Waiver</b>	DDS administers the Home and Community-Based Services Waiver for the Developmentally Disabled (HCBS-DD), which provides home- and community-based services to persons with developmental disabilities who are Regional Center consumers and reside in the community as an alternative to institutionalization.
<b>Developmental Centers</b>	The Department of Developmental Services operates developmental centers that are licensed and certified as Nursing Facility (NF), Intermediate Care Facility/Mentally Retarded (ICF/MR), and acute care hospitals. These facilities provide services and supports for individuals in need of a secure environment or who have special medical and/or behavioral program needs. Admission to one of these facilities requires either a formal determination that the individual meets stringent admission criteria or a court order.
<b>Regional Centers</b>	The regional center delivery system provides access to comprehensive services in the community by coordinating outreach, intake and assessment, preventive services, and case management/service coordination. In addition, regional centers develop, maintain, monitor, and fund a wide range of services and supports.

<sup>8</sup> The programs highlighted reflect only those provided by the department with direct relevance to HCBS LTC services. The Department operates a number of other programs and services in addition to those highlighted.

## **Background Articles**

- a. America's Long-Term Care Crisis: Challenges in Financing and Delivery**
- b. Policy Brief on AARP Scorecard**
- c. Transforming California's System of Care for Older Adults and People With Disabilities: A Look at the State's Administrative and Fiscal Organization**



## Health Program

*Health Project*

# America's Long-Term Care Crisis:

Challenges in Financing and Delivery

April 2014



BIPARTISAN POLICY CENTER



## Health Program

### *Health Project*

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#### ABOUT BPC

Founded in 2007 by former Senate Majority Leaders Howard Baker, Tom Daschle, Bob Dole, and George Mitchell, the Bipartisan Policy Center (BPC) is a non-profit organization that drives principled solutions through rigorous analysis, reasoned negotiation, and respectful dialogue. With projects in multiple issue areas, BPC combines politically balanced policymaking with strong, proactive advocacy and outreach.

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#### LONG-TERM CARE INITIATIVE

In December 2013, BPC launched a Long-Term Care Initiative under the leadership of former Senate Majority Leaders Tom Daschle (D-SD) and Bill Frist (R-TN), former Congressional Budget Office Director Dr. Alice Rivlin, and former Wisconsin Governor and Secretary of the U.S. Department of Health and Human Services Tommy Thompson. BPC's Long-Term Care Initiative seeks to raise awareness about the importance of finding a sustainable means of financing and delivering long-term services and supports, and, in late 2014, will propose a series of bipartisan policy options to improve the quality and efficiency of publicly and privately financed long-term care.

#### AUTHORS

This paper was produced by BPC staff, in collaboration with a distinguished group of senior advisors and experts, for the Long-Term Care Initiative. BPC would like to thank Sheila Burke, Chris Jennings, and Tim Westmoreland for providing substantial feedback, support, and direction, and acknowledge BPC staffers Katherine Hayes, Leah Ralph, Brian Collins, Katie Golden, and Kelly Isom for their role in researching and drafting the final paper.

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# Introduction

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In December 2013, the Bipartisan Policy Center (BPC) launched a Long-Term Care Initiative under the leadership of the BPC Health Project leaders, former U.S. Senate Majority Leaders Tom Daschle (D-SD) and Bill Frist (R-TN), as well as former Congressional Budget Office Director Alice Rivlin and former Wisconsin Governor and Secretary of the U.S. Department of Health and Human Services Tommy Thompson. The Long-Term Care Initiative will propose a series of bipartisan policy options in late 2014 to assist in the effort to build consensus on how to finance and deliver long-term care—referred to in this paper as long-term services and supports (LTSS)—at a time of political discord and fiscal constraints. The initiative seeks to raise awareness about the importance of the issue, bringing it to the attention of the public, as well as to policymakers, and making a strong case for action. This paper sets the stage for BPC’s recommendations by identifying the major challenges and key questions in the financing and delivery of LTSS for both seniors and individuals under age 65.

BPC leaders recognized the challenges associated with the cost and availability of LTSS while crafting BPC’s 2013 report, *A Bipartisan Rx for Patient-Centered Care and System-Wide Cost Containment*. That report called for an enhanced Medicare system in which incentives encourage both patients and providers to improve care and secure better health outcomes through reforms that would facilitate a transition away from volume-driven fee-for-service medicine and toward more organized systems of care. The report also recommended better integration of Medicare and Medicaid services for people who are dually eligible for both programs, but deferred developing specific policy recommendations to improve the financing and delivery of LTSS until a more focused set of policy options could be produced.

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*In late 2014, BPC’s Long-Term Care Initiative will propose a series of bipartisan policy options to improve the quality and efficiency of publicly and privately financed LTSS at a time of political discord and fiscal constraints.*

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The number of Americans estimated to need LTSS is expected to more than double, from 12 million in 2010 to 27 million in 2050<sup>1</sup>, while the costs of LTSS grow from 1.3 to 3 percent of GDP<sup>2</sup> and families increasingly struggle to prepare for and afford necessary care. While there is considerable consensus on how LTSS should be delivered—preferably at home and in the community rather than in institutions—there is a deep divide on how to finance LTSS. BPC’s leaders will seek to advance the discussion around LTSS by utilizing the considerable work that has already been done. BPC will draw on the thoughtful work of the 2013 Commission on Long-Term Care,<sup>3</sup> and from lessons learned during the 2010 Community

Living Assistance Services and Supports (CLASS) Act debates—and its ultimately unsuccessful implementation in 2011 and 2012.

The financing and delivery of LTSS is an issue with a long and complex history. Public programs spend well over \$100 billion annually on LTSS, and unpaid caregivers, such as family members and friends, contribute services that are worth more than \$450 billion annually.<sup>4</sup> How we deliver and pay for LTSS is important to many stakeholders, including those needing services (both over and under 65 years of age), their family members and friends, paid caregivers, providers, private insurers, states, and the federal government. Over the past 25 years, a number of proposals have been offered at the federal level to address the financing and delivery of LTSS; some were comprehensive, such as the Pepper Commission Report and the CLASS Act, and others suggested incremental changes in the regulation and tax treatment of private insurance, or provided new state options and demonstrations to expand the availability of home and community-based care through the Medicaid program.

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*CBO projects that public and private spending on LTSS for the elderly will grow from 1.3 percent of GDP in 2010 to 3 percent of GDP in 2050.<sup>5</sup>*

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Designing a comprehensive and sustainable system of financing LTSS is a challenging task for many reasons. Challenges include significant diversity in populations needing LTSS, which in turn results in tremendous variation in the level of assistance and types of services required. Significantly, the majority of services are delivered by family members and other unpaid caregivers, often at both personal and financial sacrifice; however, policymakers on both sides of the aisle have historically been unwilling to suggest that the role of the federal government should supplant those services with new federal benefits.

In the delivery of LTSS, there is significant agreement that the current bias toward institutional care under Medicaid should be eliminated. For decades, the Medicaid statute has structurally favored institutional care over home- and community-based care even though beneficiaries have a wide range of needs. Since the early 1980s, many states have taken steps to provide home- and community-based services (HCBS) through waivers for low-income Medicaid-eligible individuals. Likewise, over time, private long-term care insurance has shifted to include coverage of HCBS. Movement toward HCBS was spurred, in part, by the passage of the Americans with Disabilities Act (ADA) and the Supreme Court's 1999 decision in *Olmstead v. L.C.*,<sup>6</sup> which requires states to make reasonable accommodations to provide services to individuals with disabilities in the most integrated setting appropriate to their needs. Since that time, states have used waivers to adopt innovative approaches to the delivery of LTSS at home and in the community, although in recent years, new state options have also been made available. Despite this effort, there continues to be tremendous variation in the availability of HCBS among states.

In this paper, BPC seeks to: (1) identify the most pressing problems associated with the current system of providing LTSS in the United States; (2) identify the barriers to finding a sustainable means of financing and delivering LTSS; and (3) outline some of the more critical policy questions that will guide BPC’s work in the coming months. Given the disparate populations in need of LTSS, and the challenges both in terms of politics and budgets, a solution to financing LTSS will likely require a series of policy options—including public and private options as well as long-term and short-term options—and will require legislative and regulatory changes. In the coming months, BPC leaders, staff, and senior advisors will reach out to experts, stakeholders, and policymakers and, later this year, present bipartisan policy approaches that we hope will move the dialogue forward. Importantly, as in *A Bipartisan Rx*, BPC will also work with economists and actuaries to estimate costs and savings associated with these policy solutions. We believe that developing a realistic, politically viable set of policy options is not only achievable, but is also imperative to relieve the pressure on persons who need LTSS, their families and caregivers, and local, state, and federal governments.

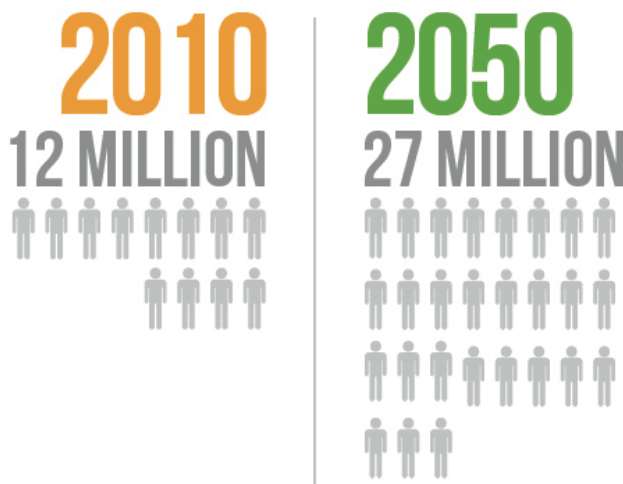
# Background

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## Demographic Challenges

An estimated 12 million Americans are currently in need of LTSS<sup>7</sup>—defined as institutional or home-based assistance with activities of daily living (ADLs) such as bathing, dressing, or medication management—including both seniors and persons under age 65 living with physical or cognitive limitations. In the next two decades, the U.S. health care system will face a tidal wave of aging baby boomers. This, among many other factors, will create an unsustainable demand for LTSS in the coming years. Fewer family caregivers, increasingly

THE NUMBER OF AMERICANS NEEDING LTSS  
IS EXPECTED TO MORE THAN DOUBLE BY 2050



limited personal financial resources, and growing strains on federal, state, and family budgets will further complicate efforts to organize and finance services. Although there is tremendous variation in what is, or will be, needed, fully 70 percent of people who reach the age of 65 will require some form of LTSS at some point in their lives.<sup>8</sup> As mentioned above, the number of Americans needing LTSS at any one time is expected to more than double from 12 million today to 27 million by 2050.<sup>9</sup> Indeed, the demand for LTSS will substantially outpace the rate of growth in the U.S. economy over the next decade and drive significant growth in Medicaid spending.

## Political and Fiscal Challenges

Potential solutions for the nation's long-term care challenges will be viewed by policymakers in the context of the current political and fiscal environments, which include significant concerns about the long-term cost of major entitlement programs and long-term public debt. The Office of the Actuary of the Centers for Medicare and Medicaid Services (CMS) estimates that Medicaid spending on LTSS will grow by an average of 6 percent annually from 2012 to 2021, far faster than GDP.<sup>10</sup> Notably, the CMS actuaries expect that the baby-boom generation, when they begin to exceed the age of 85 in the 2030s, will start to drive even faster growth in Medicaid LTSS spending. The Congressional Budget Office projects that public and private spending on LTSS for the elderly will grow from 1.3 percent of GDP

in 2010 to 3 percent of GDP in 2050, assuming that the prevalence of obesity and functional limitations does not change.<sup>11</sup> If the growth of government spending continues to outpace taxes and other revenues, public debt is on course to grow to levels that are unprecedented in U.S. history. Without changes in policy, the nation faces challenging trade-offs between spending to meet our commitments to older and low-income Americans and investments in the nation's future prosperity. Against this background, policymakers seeking to address the challenge of financing and delivering LTSS for an aging population will be looking for reforms that will reduce the rate of growth in spending over the long term through greater efficiency in public programs for those who need them and an increased reliance on privately funded solutions to constrain the need for publicly funded LTSS.

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*In the next two decades, an aging population, fewer family caregivers, increasingly limited personal financial resources, and growing strains on federal, state, and family budgets will create an unsustainable demand for LTSS.*

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Over the years, there have been numerous comprehensive proposals to address the financing of long-term care. However, stumbling blocks have included cost and the partisan divide over the appropriate role of the federal government in the financing of LTSS, particularly for higher-income individuals. As evidenced by the Commission on Long-Term Care report, some believe that LTSS should be provided through a social insurance program such as Medicare, while others believe that the financing of LTSS should be a combination of personal responsibility, through savings and the purchase of private insurance, and a safety-net program, such as Medicaid for those who do not have the resources to pay for LTSS.

Current federal fiscal challenges, combined with partisanship in Congress, make it an especially difficult environment in which to enact comprehensive financing reform of LTSS. That said, given the long-term challenges facing families, states, and the federal government, it is important that policymakers begin to lay the groundwork for action before millions of baby boomers begin to need assistance. Failure to do so will undoubtedly overwhelm the existing structure, which requires those in need of LTSS to rely on individual family resources, family caregivers, and, once private resources are exhausted, the Medicaid program. As such, the looming financing implications for the Medicaid program—and the need for Democrats and Republicans to come together to enact solutions—cannot be overstated.

# BPC's Approach

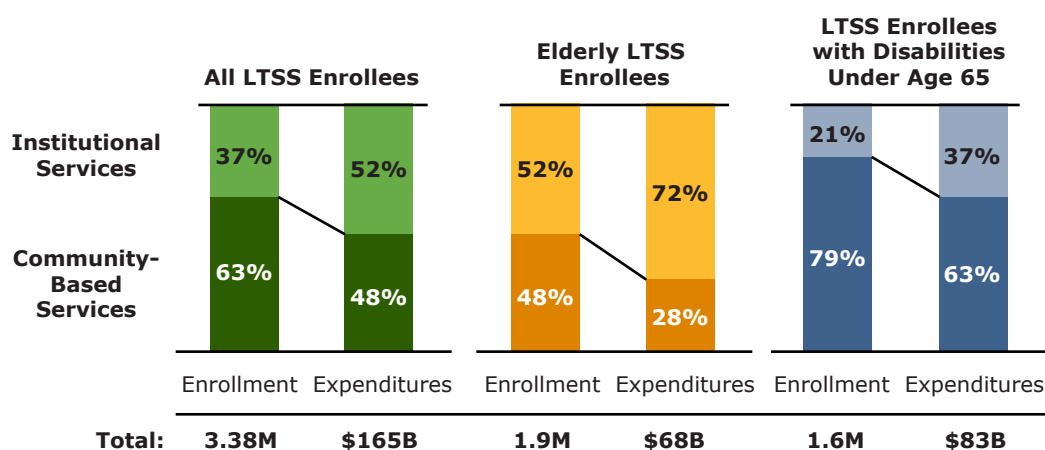
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While some may believe that a true social insurance option financed through a broad-based tax, similar to the Medicare program, may be the most efficient and equitable means of financing LTSS, the current political and fiscal environment make that solution infeasible for the foreseeable future. As outlined below, BPC's initiative seeks input from experts and stakeholders on how best to craft a series of solutions that include both publicly funded programs, such as Medicaid, and private insurance products. BPC has identified a series of issues with the current system as well as questions that will be explored in the coming months. While BPC does not expect to answer all of the questions raised here, this framework serves as a critical starting point. Further, these issues are not meant to be comprehensive, and BPC welcomes additional questions and guidance from stakeholders and policymakers.

## Medicaid

The Medicaid program provides both acute care services and LTSS for a broad range of individuals, including children, pregnant women, and people eligible for cash assistance such as Supplemental Security Income (SSI) and Temporary Assistance for Needy Families (TANF). Under the ACA, and at state option, Medicaid programs may also cover adults without dependent children with incomes below 133 percent of the federal poverty level,<sup>12</sup> as well as certain other low-income populations. The amount and type of income and assets subject to eligibility requirements vary by state. For example, assets typically counted for eligibility include checking and savings accounts, stocks and bonds, real property other than primary residence and motor vehicles other than primary vehicle. Assets not counted for eligibility include primary residence, household belongings, one motor vehicle, life insurance with a face value under \$1,500, up to \$1,500 in funds set aside for burial, and assets held in certain kinds of trusts.<sup>13</sup> Services are based on "medical necessity," so not all Medicaid-eligible individuals receive LTSS. Although eligibility generally varies by state, Medicaid programs may provide an institutional level of care for individuals with incomes up to 300 percent of SSI income levels.<sup>14</sup> Institutional care includes nursing homes, intermediate care facilities for individuals with mental retardation (ICFs/MR), and other residential facilities.

## Distribution of Enrollment and Spending Among Medicaid LTSS Beneficiaries, by Population, 2009



Source: The Kaiser Commission on Medicaid and the Uninsured and Urban Institute estimates based on data from FY 2009 MSIS. Because 2009 data was unavailable, 2008 data was used for Pennsylvania, Utah, and Wisconsin.

Medicaid programs also continue to increase the availability of services in HCBS settings through a variety of waivers and demonstration programs. Experts have suggested that better coordination of services for those with chronic conditions who are eligible for both Medicare and Medicaid could reduce health care expenditures financed under the Medicare program, thus permitting health plans or affiliated provider groups, such as patient-centered medical homes or primary care case management, to use savings to finance improved coordination and availability of LTSS under the Medicaid program. Potential health care savings, however, vary widely from state to state. We look forward to seeing the early results of these demonstrations. We also seek guidance on how the Medicaid program could be improved to provide limited LTSS to individuals whose incomes are above Medicaid-eligibility levels in order to prevent spending down into Medicaid, or to improve existing programs designed to prevent working individuals with disabilities from relinquishing their jobs in order to receive services.

- Presuming that there is agreement that a new public insurance structure is not currently fiscally and politically viable, is there a role for public insurance, apart from the Medicaid program, for those who do not have access to private resources or private long-term care insurance? If so, what is it and how would it be structured in a politically and economically viable fashion?
- What is the appropriate division of responsibility between state and federal programs?
- How could the current delivery system be improved to better coordinate care and improve patient-centeredness and efficiency?

- Should health care services and LTSS be integrated? If so, for all populations, or only for those with chronic health conditions?
- Should integration of health care services and LTSS be left to individuals and families to decide?
- What lessons can be learned from the long history of waivers and demonstration programs?
- What can be learned from other programs and plans such as the Program of All-Inclusive Care for the Elderly (PACE) and Medicare Advantage Special Needs Plans?
- Should states be expected to better coordinate care for Medicaid-covered LTSS? If so, what is the federal role in promoting better coordination?
- What are the pros and cons of proposals that would turn LTSS delivery over to state governments with limits on federal funding, such as a block grant or per capita cap?
- How can lessons learned from public programs be applied to private LTC insurance?

## Private Long-Term Care Insurance Market

No one would argue that the private long-term care insurance (LTCI) market, as currently structured, is a viable solution to address the needs of the diverse population in need of LTSS. Among other financial challenges, such as the current low-interest-rate environment, LTCI has struggled to find a viable risk pool. As with traditional health insurance coverage, the current voluntary system for private long-term care insurance has encountered adverse selection, driving up premium costs, and resulting in strict medical underwriting by insurers. The Affordable Care Act (ACA) addressed medical underwriting in the health insurance market by requiring individuals without other qualified coverage to purchase coverage or pay an assessment to assure a viable risk pool. While a potential policy approach for LTC, BPC does not believe that guaranteed issue paired with a requirement to purchase coverage is a solution that can be pursued in the post-ACA political environment. Likewise, recent experience with the enactment and repeal of the CLASS Act might suggest that a voluntary public option would have little support among policymakers in the current environment. However, a reformed private long-term care insurance market can be part of the solution in financing LTSS, and BPC seeks input on how to restructure the market.

- What is the role of the private long-term care insurance market?
- What reforms should be enacted to encourage carriers to remain in the market and encourage additional carriers to enter?
- How should products be structured to achieve this goal?

- Should products be structured and regulated similar to Medigap, with limited choices, or should the market be left flexible to address purchaser choice and market innovation?
- How should products be made available to individuals? Through the current system of brokers and sales representatives, through employers, through retirement (IRA, 401[k], etc.) account servicers, through health insurance exchanges, or through other options?
- Should LTC insurers be expected to better manage services, similar to health insurers, as opposed to paying claims or establishing per-diem payments?
- Could a non-insurer provider-sponsored model work for LTSS, and if so, how could solvency issues be assured?
- Are additional consumer protections needed, and if so, what would they include?
- What impact has existing consumer protections had on product design, availability, and affordability?
- In a political environment that is trending toward fewer deductions and preferential tax treatment, can or should the current structure of state regulation with certain federal minimum standards for tax-preferred policies be maintained?
- Would a voluntary structure work if framed to be similar to employer-sponsored retirement-savings options and disability insurance (i.e., auto-enrollment with an opt-out)?
- If so, how would one address the issue of affordability for those who cannot afford coverage?
- Could some form of reinsurance improve the viability of the LTCI market, in general, and the viability of policies with catastrophic (lifetime) coverage, in particular?
- How could reforms that increase the role of private LTCI in financing LTSS reduce the incidence of spending down to Medicaid eligibility for individuals and families and reduce public spending on Medicaid?

## Individual Role in Financing Long-Term Services and Supports

Individual and family contributions to the cost of LTSS are difficult to estimate accurately. The majority of LTSS is provided by unpaid family members and friends, creating a fundamental challenge with designing public approaches to financing LTSS. Historically, one reason that policymakers have been reluctant to address LTSS is a concern that any solution that calls for greater involvement of government programs would supplant—rather than supplement—private spending, adding significantly to federal costs.

At the same time, experts recognize the economic cost in lost productivity as family caregivers are called upon to provide care to family members, or when working-age individuals with disabilities opt not to work because an increase in income would jeopardize eligibility for LTSS. Given the cost of financing LTSS, and the lack of private savings relative to the cost of care, most experts would agree that none but the highest-income individuals could pay for LTSS solely out-of-pocket. This is especially true for working adults who may need personal assistance or adaptive technology, those who need LTSS for an extended period of time, or those who are living on Social Security and retirement savings. Yet given current fiscal and political challenges, we recognize that some level of personal responsibility is needed from those who have adequate resources. Unfortunately, personal savings for retirement needs of all kinds, including general living expenses and out-of-pocket health care expenses, are lacking among most Americans. In 2005, only one-third of Americans age 65 and over had at least \$70,000 in assets (excluding a home), which is about the cost of a one-year stay in a nursing home.<sup>15</sup> Further, 65 percent of Americans over 40 have done little to no planning for living expenses in retirement.<sup>16</sup> While some people will experience catastrophic LTSS costs that would be impossible for most Americans to realistically meet with savings, many, if not a majority, of retirees should be able to meet some LTSS costs out-of-pocket. For example, in a cohort of 65-year-olds, 42 percent will ultimately have no spending on LTSS and 30 percent will ultimately spend something, but less than \$25,000.<sup>17</sup>

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*In 2005, only one-third of Americans age 65 and over had at least \$70,000 in assets, which is about the cost of a one-year stay in a nursing home. Sixty-five percent of Americans over 40 have done little to no planning for living expenses in retirement.<sup>18,19</sup>*

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If Americans had more savings for retirement, the nation would be better able to handle the costs of less-intensive LTSS. To address this challenge, BPC's Economic Policy Project will launch a Personal Savings and Financial Security Initiative (PSFSI), which will explore potential policy solutions and recommendations for increasing private savings over the next year. BPC's Long-Term Care Initiative will collaborate with PSFSI, where appropriate, on proposals that could improve both retirement savings and families' preparedness for LTSS expenses.

- If problems associated with stability and affordability in the private long-term care insurance market could be addressed, would it be reasonable to expect that more individuals could afford to pay private long-term care insurance premiums?
- A number of tax benefits currently exist to encourage personal savings and the purchase of private long-term care insurance. In light of tax reforms, will these tax benefits continue, and if so, how could these and other incentives be better targeted?

- What is the best means of empowering and encouraging individuals to make arrangements to self-finance LTSS? To what extent is an educational component needed to inform the public of this impending need?
- How can the nation best support family caregivers without supplanting private spending?
- Can technology play a role in reducing costs by allowing individuals to remain at home and in the community?

## Delivery System Reform

Historically, states and the federal government have limited utilization of Medicaid-funded LTSS by restricting eligibility for services and by providing care primarily in institutional settings. As a result, fewer people are eligible for services, and those who are eligible receive them in the most costly settings. Over the past decades, states have used waivers and state plan options to make care available at home and in other settings, such as small group homes, but the structure of waivers and the costs of expansion have resulted in a slower transition from institutional to home and community-based settings. While the Deficit Reduction Act of 2005 and the ACA made more options available, the full potential of these options has not been realized, in part because of limited resources. Policymakers have learned much about the importance of delivery system reform in recent years with respect to the delivery of acute care services. Likewise, a handful of states have been leaders in the integration of health and long-term care services in improving patient care, while others have been more focused on assuring efficient utilization of services. While this is related to Medicaid, BPC will explore whether individuals with private insurance and Medicare coverage might buy-in to an integrated delivery system for LTSS. For example, a Medicare beneficiary may choose to utilize the provider network in place for an individual who receives both acute care and LTSS as an individual dually eligible for Medicare and Medicaid.

- How critical is delivery system reform to the financing of LTSS, particularly for those who receive care through Medicaid?
- What lessons learned about care coordination and integration of services can be applied to the private insurance market?
- Should there be better coordination and integration of acute health care delivery system reforms in Medicare with LTSS? If so, what services and how?

# Background on LTSS

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## What are Long-Term Services and Supports?

LTSS includes a broad range of health-related and social services that assist individuals who have limitations in their ability to perform self-care due to a physical, cognitive, developmental, or other chronic health condition that is expected to continue for an extended period of time (usually 90 days or more).<sup>20</sup> These services include assistance with activities of daily living (ADLs), such as bathing, dressing, eating, transferring, and walking,<sup>21</sup> and instrumental activities of daily living (IADLs), such as meal preparation, money management, house cleaning, medication management, and transportation.<sup>22</sup> Importantly, LTSS does not include medical or nursing services needed to manage an individual's underlying health condition. Defining ADLs and IADLs, and determining the number of functional limitations in performing these tasks, has important policy implications, because it determines eligibility for LTSS benefits in both public and private insurance programs.<sup>23</sup> Federal and state LTSS programs—and often private long-term care insurance—typically base eligibility and benefits on needing assistance with two or more ADLs; this population is roughly 3.2 million people.<sup>24</sup> This compares with a more broadly defined LTSS population of 12 million who need assistance with one or more ADLs or IADLs.<sup>25</sup>

## Who Needs Long-Term Services and Supports?

Individuals who use LTSS may have very different needs depending on age, health status, employment status, and the presence of intellectual and/or developmental disabilities.<sup>26</sup> For example, a senior citizen with Alzheimer's disease may need constant supervision and assistance with ADLs, while an adult with physical disabilities may only require personal care assistance to permit them to work. Of the 12 million Americans in need of LTSS, approximately 50 percent are adults over age 65, 47 percent are adults between the ages of 19 and 65, and 3 percent are children under the age of 18.<sup>27</sup>

Some individuals who utilize LTSS may have very few health care needs. For example, a young person with developmental disabilities may have no more than routine interactions with the health care system, such as the occasional office visit. Others who need LTSS have significant coexisting health conditions that may require extensive use of the health care system, or a significant medical event may have triggered the need for LTSS. This is particularly common among older Americans who use LTSS.<sup>28</sup> For these individuals, better coordination among LTSS providers and health care providers may improve quality and lower costs. Some programs already attempt to better integrate health care and LTSS payment and delivery, such as PACE and State Demonstrations to Integrate Care for Dual Eligible Individuals, both run by the CMS Medicare-Medicaid Coordination Office in

partnership with states.<sup>29</sup> Today, this kind of integration is rare, mainly occurs where explicit funding exists for LTSS through Medicaid, and is especially unusual for services funded by private LTC insurance. Proposals to improve the financing and delivery of LTSS must address the need to integrate LTSS with health care services across settings and include solutions that are targeted to the varying needs—and the disparate nature—of different populations.

## Where are Long-Term Services and Supports Delivered?

LTSS are generally provided in three types of settings—nursing care facilities, home care, and residential facilities<sup>30</sup>—and are often divided into two broad categories: institutional and HCBS. HCBS are defined as those services delivered outside of an institutional setting, which could include the beneficiary’s home, a caregiver’s home, or an assisted living facility.<sup>31</sup>

While the majority of LTSS has been, and continues to be, unpaid and delivered in the home, paid LTSS has historically focused on institutional care. State Medicaid programs are required to cover nursing-facility services, while coverage for HCBS remains optional, creating a bias toward institutional care. Originally, Medicaid and private insurance paid exclusively for nursing home care. Coverage has significantly shifted away from institutional care in favor of HCBS in recent years; today, roughly half of LTSS Medicaid spending is for HCBS, and at least one major private LTC insurance issuer has also seen claims shift toward HCBS.<sup>32</sup> Several authorities allow states to offer HCBS through Medicaid waivers or state plan options. There have been several statutory changes in the last 30 years to provide increased federal incentives, and flexibility, to states to broaden beneficiary access to HCBS.<sup>33,34</sup> Now only about 1.5 million of the nation’s LTSS recipients live in nursing homes.<sup>35</sup> This shift has had the most impact on the under-65 Medicaid LTSS population, of which nearly 80 percent are using community-based services (among the over-65 population, it’s less than 50 percent).<sup>36</sup> While this is a notable, and laudable, shift, much remains to be done in the movement to de-institutionalize LTSS.

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*The financing and delivery of LTSS are highly fragmented, lacking in coordination across services and providers, and is often provided in ways that can be inefficient, expensive, and not meeting the needs of the patient.*

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LTSS is highly fragmented, lacking in coordination across services and providers, and often provided in ways that can be inefficient, expensive, and not meeting the needs of—or ensuring the best outcome for—the patient.<sup>37</sup> The planning and organization of LTSS is often handled separately from health care planning, so that when a patient is transitioning from acute or post-acute care to an LTC setting, few incentives are in place for health care

providers to integrate LTSS in their plan for a patient. Access to services is also often determined by the funding stream, creating an approach to LTSS that is provider- or setting-focused, rather than patient-focused.<sup>38</sup> A number of initiatives to test new payment and delivery models could assist in integrating health care and long-term care services by building in the necessary financial incentives to achieve patient-centered health outcomes and a seamless continuum of care.

## Who Provides Long-Term Services and Supports?

The LTSS workforce includes, but is not limited to, nursing home and assisted living administrators, physicians, nurses, social workers, physical and occupational therapists, aides, and ancillary staff who may be employees of home health agencies, nursing homes, or assisted living facilities.<sup>39,40</sup> However, a majority of LTSS is provided by informal caregivers, such as friends or family members, providing assistance on an unpaid basis to a person in the home with functional limitations. In 2009, about 66 million Americans provided unpaid care to family members and friends, almost one-third of the U.S. adult population.<sup>41</sup> Caregiving often causes financial, physical, and emotional hardship; caregivers have little to no training for the duties they are expected to perform and have little access to information or support in navigating the LTSS system.<sup>42</sup> Caregivers who are also employed cost U.S. employers up to \$34 billion annually in lost productivity from reduced hours, absenteeism, and workday distractions.<sup>43</sup>

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*In 2009, about 66 million Americans provided unpaid care to family members and friends, almost one-third of the U.S. adult population.*

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Families pay a high price, too. Although not included in formal cost estimates for LTSS, a range of studies estimate the value of informal caregiver services—costs to families and businesses—at hundreds of billions of dollars.<sup>44</sup> Informal caregiving was estimated to be valued upwards of \$450 billion in unpaid services in 2009.<sup>45</sup> One survey found the average annual out-of-pocket expense for caregiving families is \$5,531, more than 10 percent of the median household income in 2007.<sup>46</sup> Informal caregivers also often forgo income-generating opportunities, further complicating efforts to save for their own retirement and any future LTSS needs.

LTSS faces a range of workforce challenges, including an emerging “care gap,” particularly as the population in need of LTSS continues to grow with an aging baby-boomer population. Declining birth rates in the last 50 years means there will be fewer family members to care for aging parents or relatives in the coming years.<sup>47</sup> Over the next 20 years, the caregiver support ratio is projected to drop from seven (in 2010) potential caregivers for every person over 80 to four (in 2030),<sup>48</sup> and demand for direct-care workers—nursing, home health, and personal care aides—is expected to increase by 48 percent in the next decade.<sup>49</sup>

Historically, policymakers have raised the concern that approaches to financing LTSS would ultimately have the effect of supplanting—rather than supplementing—the assistance

provided by unpaid family members and other caregivers, adding exponentially to the cost of LTC. Ultimately, any policy approach to address challenges in LTC workforce and delivery must consider how to build upon and strengthen, rather than replace, existing family caregiver support. Further, policymakers must consider ways to optimize the LTC workforce to ensure safe, high-quality care at the lowest cost.

## Who Pays for Long-Term Services and Supports?

Complexity in the delivery of LTSS is mirrored by complexity in the financing system. LTSS is financed through a range of public and private sources, including Medicaid and a variety of smaller public programs, private long-term care insurance, and personal savings. Public spending on LTSS is well over \$100 billion annually, most of which is Medicaid spending; in 2012, private LTCI paid for about \$7 billion of LTSS, and out-of-pocket spending by individuals and families accounted for tens of billions more.<sup>50</sup> Exact numbers on LTSS spending, whether private or public, are unknown due to limitations in the available data; for now, policymakers must rely on estimates. LTSS spending is hard to gauge because LTSS providers (such as skilled nursing facilities and home health providers) also deliver post-acute care (rehabilitative) services, and this spending is commingled with LTSS spending in much of the available data. However, it is clear that Medicaid is by far the major LTSS payer, paying for two-thirds or more, with private savings and private LTCI rounding out the rest. Private LTCI likely accounts for less than 5 percent of total spending on LTSS.

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*Public spending on LTSS is well over \$100 billion annually, most of which is Medicaid spending; in 2012, private LTCI paid for about \$7 billion of LTSS, and out-of-pocket spending by individuals and families accounted for tens of billions more.*<sup>51</sup>

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There are public sources other than Medicaid that pay for LTSS, but they often limit assistance to small, specific populations and cover only limited services. For example, the Older Americans Act, directed by the Administration on Aging, offers LTSS to older individuals who are low-income, minority, have limited English proficiency, live in rural areas, and are at risk for institutional placement.<sup>52</sup> The Veterans Health Administration covers some LTSS benefits for veterans, but coverage varies considerably based on location, income, availability, and disability.<sup>53</sup>

### **PUBLIC FINANCING**

#### **Medicare**

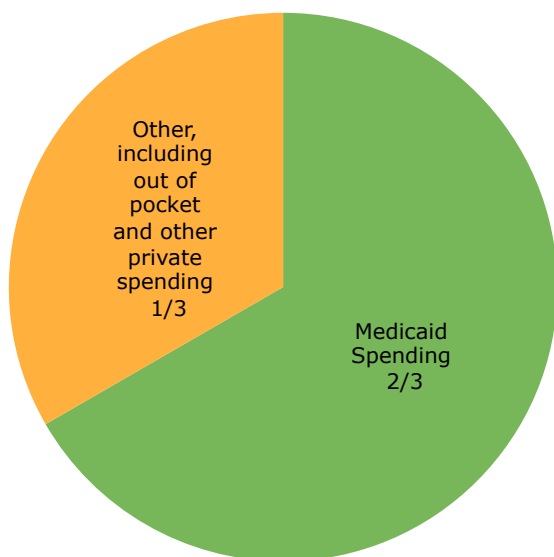
Medicare does not cover long-term services and supports. Benefits are limited to acute care health services—including, among other acute services, hospital stays, post-acute care, and physician visits—and prescription drugs for the elderly and certain individuals with disabilities.<sup>54</sup> As a result, Medicare only covers skilled nursing facility (SNF) care or rehabilitation services following a three-day hospital inpatient stay, within 30 days of

hospitalization, and only for up to 100 days per benefit period.<sup>55</sup> Medicare also covers medically necessary, intermittent home health services (60 days per episode) and physical, speech, or occupational-therapy services, as well as medical supplies and durable medical equipment such as wheelchairs, hospital beds, oxygen, and walkers.<sup>56</sup> After rehabilitation is complete, if the beneficiary's functional status indicates that personal care services are needed on a long-term basis, the continued use of skilled services would not be covered by Medicare.

## Medicaid

Medicaid is the primary LTSS payer, generating two-thirds or more of the total payments for LTSS.<sup>57</sup> In 2011, the CMS Office of the Actuary estimated Medicaid LTSS spending at \$114 billion, while an analysis by Mathematica Policy Research arrived at an estimate of \$136 billion.<sup>58</sup> LTSS accounts for at least one-quarter, and possibly almost a third, of total Medicaid spending (\$432 billion in 2011);<sup>59</sup> however, only a small fraction (6.7 percent or 4.2 million in 2009) of Medicaid beneficiaries received LTSS and/or post-acute care.<sup>60</sup> Eligibility for the elderly and persons with disabilities is subject to categorical and financial eligibility standards. In most states, Medicaid-eligible individuals who qualify for cash assistance under the SSI program (i.e., have incomes below 74 percent of the federal poverty level and meet other requirements relating to resources and level of disability) are eligible for the full range of Medicaid services.<sup>61</sup>

### Medicaid Pays for the Vast Majority of LTSS Spending



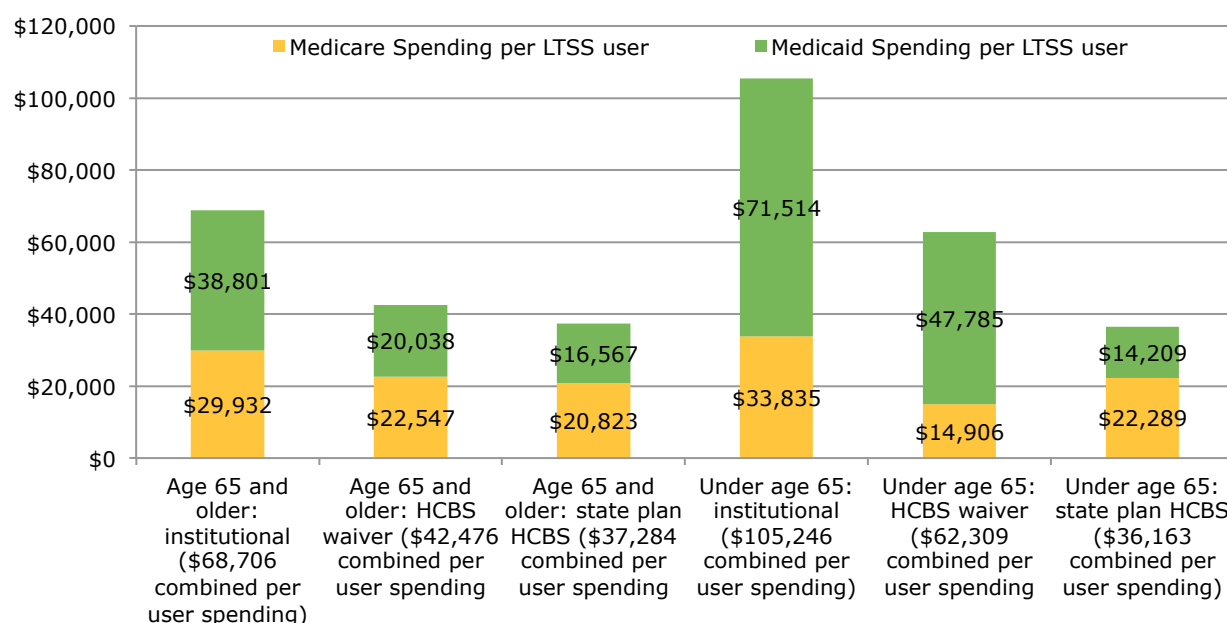
*Source: BPC Analysis, informed by the National Health Policy Forum's National Spending for Long-Term Services and Supports and the Centers for Medicare and Medicaid Services' 2012 Actuarial Report on the Financial Outlook for Medicaid. See Technical Appendix for more on BPC's analysis of national spending on LTSS.*

When an individual has too much income to qualify for Medicaid under the SSI pathway, but faces catastrophic LTSS and health care costs that he or she cannot meet, it is possible to qualify for Medicaid through a "spend down" process.<sup>62</sup> Most individuals over the age of 65 who qualify for Medicaid do so by spending down.<sup>63</sup> The details of this process vary by state, but individuals typically must exhaust almost all of their savings (an exception allows Medicaid beneficiaries to keep a home, within certain limits) and spend a substantial portion of their income on health care and LTSS expenses before they can qualify. Once a person has qualified for Medicaid coverage of LTSS, they could be required to contribute most of their remaining income to the cost of services used. There are exceptions to protect spouses who live in the community, and beneficiaries who are receiving HCBS,

who need to cover basic living and home-maintenance expenses.

For dual-eligible individuals (those eligible for both Medicare and Medicaid), Medicare covers the cost of acute and post-acute care services, such as short-term stays in skilled nursing facilities or inpatient rehabilitation facilities following hospitalizations. Medicaid pays for medically necessary acute care services covered by the state—but not covered by Medicare—as well as LTSS. It is important to note that only institutional LTSS coverage is universal in Medicaid. Coverage of HCBS remains optional for states; some do not cover it at all, and many restrict HCBS coverage to certain regions and/or a subset of Medicaid beneficiaries.

### Per User Medicare and Medicaid Spending on Fee-For-Service Full-Benefit Dual-Eligible Medicaid LTSS Users By Age, 2009



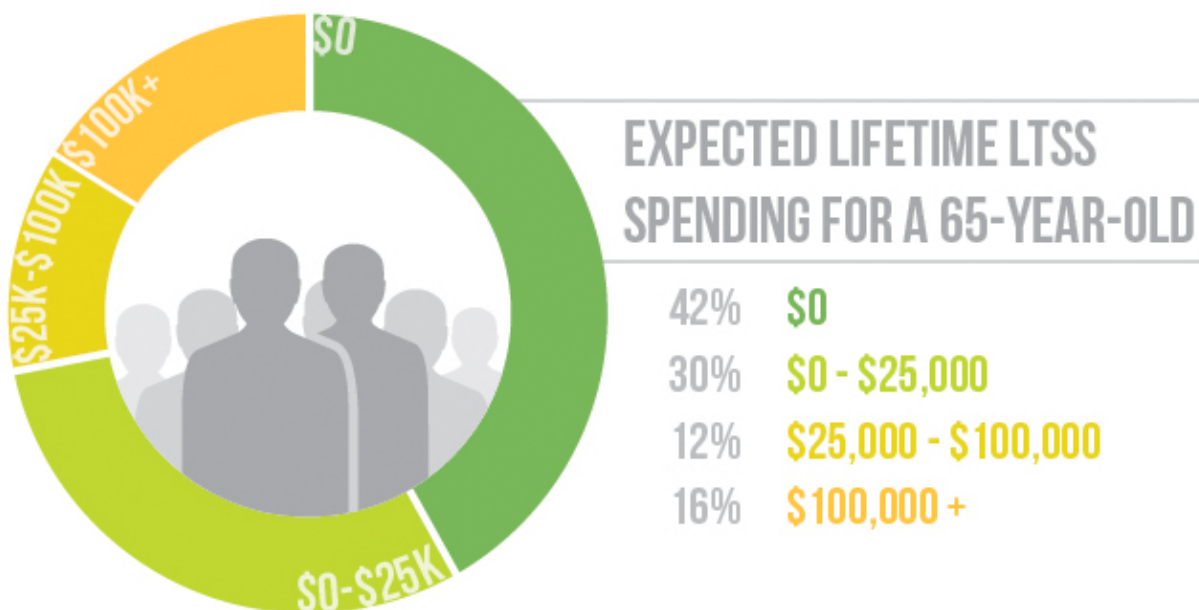
Source: Medicare Payment Advisory Commission (MedPAC) and Medicaid and CHIP Payment and Access Commission (MACPAC). *Data Book: Beneficiaries Dually Eligible for Medicare and Medicaid*. Dec 2013. P. 61. Available at: [http://www.medpac.gov/documents/Dec13\\_Duals\\_DataBook.pdf](http://www.medpac.gov/documents/Dec13_Duals_DataBook.pdf)

## PRIVATE FINANCING

### Private LTC Insurance

Long-term services and supports are expensive, especially when they are needed for long periods of time.<sup>64</sup> Of a cohort of 65-year-old Americans, a large portion (42 percent) will have no spending on LTSS for the rest of their lives, either because they will not need LTSS or they will rely on unpaid assistance from family and friends. A small group (16 percent) will ultimately use more than \$100,000 in services, with the rest spending more than zero but less than \$100,000.<sup>65</sup> Because a small number of people will have substantial needs that are unlikely to be met solely through personal savings, insurance would seem to be an

ideal mechanism to finance these needs. Yet, the private LTCI market has struggled in recent years and currently plays a minor role in the financing of LTSS.<sup>66</sup> After several years of strong growth in private LTCI coverage in the late 1990s and early 2000s, the number of insured lives has been virtually unchanged since 2005, and sales of individual-market policies have dropped by two-thirds from their peak in 2002.<sup>67</sup> Growth has focused on the group market, while the individual market (two-thirds of the total) has declined.<sup>68</sup> About 8.2 million lives are covered by private LTCI,<sup>69</sup> representing fewer than 6 percent of Americans over the age of 40.<sup>70</sup> Of those over 65 with annual incomes above \$20,000, only 16 percent carry private LTCI.<sup>71</sup> In 2012, LTCI policyholders paid more than \$11 billion in premiums.<sup>72</sup> Cash payments to policyholders (or LTSS providers) from private LTCI claims totaled about \$7 billion in 2012,<sup>73</sup> funding less than 5 percent of total spending on LTSS.<sup>74</sup>



Private LTCI is typically purchased when the buyer is middle-aged and, if needed, used in very old age. The policy parameters are fixed at purchase, as are the premiums, which are set based on age at purchase and are intended to remain level after purchase (they can and often do increase in certain circumstances described below). Private LTCI works somewhat like a high-deductible health plan. But rather than a dollar-amount deductible, the policyholder is responsible for paying the cost of all LTSS used during an initial elimination period, which is usually for 30, 60, or 90 days. After the elimination period has expired, the LTCI policy covers all costs up to a daily benefit amount for a maximum period (usually three to five years). Inflation protection is an option for all private LTCI policies, and it was included in 74 percent of policies sold in 2010.<sup>75</sup> Since it is not uncommon for decades to pass between when policies are purchased and when they are used, inflation protection is an important feature to ensure that the benefit will keep up with the rising cost of LTSS, but some do not include it because it adds significantly to the premium.<sup>76</sup> Partnership programs,

which are offered by most states, allow holders of private LTCI policies to shield additional assets from spend-down requirements, should they exhaust their private policies and need assistance from Medicaid.<sup>77</sup> The average LTCI policy purchased in 2010 had a premium of \$2,283 and would cover almost five years of nursing home care at \$153 per day after a 90-day elimination period.<sup>78</sup> The average age of purchasers in 2010 was 59 years.<sup>79</sup> Even if such a policy had been purchased with a 5 percent annual inflation adjustment, it would still be about \$50 per day short of covering the national median daily rate for a private room in a nursing home in 2013.<sup>80</sup>

Other private funding options include hybrid insurance products (a combination of life insurance and LTCI or an annuity and LTCI), personal savings (including savings in tax-advantaged accounts, such as 401(k)s, Individual Retirement Accounts, and Health Savings Accounts), and home equity, which can be used to pay for LTSS through the sale of a residence or a reverse mortgage. Hybrid products—which combine LTSS benefits with life insurance, an annuity, or both—are a newer option and are less common than traditional LTCI. Hybrid products may be more attractive to consumers than traditional LTCI policies, because there is a guaranteed cash payout at some point. For example, in a hybrid annuity/LTCI policy, if LTSS benefits are never utilized, the policyholder will still receive regular annuity payments. Additionally, premiums can never go up<sup>81</sup> and there is favorable tax treatment under the Pension Protection Act of 2006.<sup>82</sup> This law states that payouts used for LTSS are not taxable; whereas, payouts from life insurance or annuity products are sometimes considered taxable income.<sup>83</sup>

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*About 8.2 million lives are covered by private LTCI,<sup>84</sup> representing fewer than 6 percent of Americans over the age of 40.<sup>85</sup> Of those over 65 with annual incomes above \$20,000, only 16 percent carry private LTCI.<sup>86</sup>*

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While many policymakers hoped that private LTCI products would cover a growing portion of Americans, provide greater financial protection for the middle class, and reduce the burden on public programs and family members, a variety of challenges have kept this product from assuming a larger role. These challenges include high costs, adverse selection, and insufficient planning on the part of many individuals and families for potential costs during retirement, including LTSS needs. Insurers have been exiting the market (from more than 100 issuers in 2002 to about a dozen now in the individual market, and fewer than eight currently issuing new coverage in the group market).<sup>87,88</sup> Those remaining have been increasing premiums, if justified and approved by state insurance regulators, when claims are higher than expected, investment returns are lower than expected, and fewer subscribers let their policies lapse than expected.<sup>89</sup> These increases have made it challenging for some elderly policyholders to maintain coverage. Sales and underwriting costs are high, which reduces the value of the product for the price paid.

Private LTCI is also vulnerable to adverse selection. Even though the product is underwritten, buyers will always know more about their potential future health status than insurers. As such, people who are more likely to need LTSS are more likely to buy insurance, which results in higher premiums and discourages those of average or lower-than-average risk of needing LTSS from purchasing coverage.<sup>90,91</sup> Finding more viable risk pools for LTCI is a major challenge that must be met in order for the product to play a larger role in LTSS financing. More effective risk pools could help to address adverse selection, high sales and administrative costs, and the propensity of Americans to avoid planning for potential living needs in old age.

Even without adverse selection, it is not clear that consumer demand for private LTCI would be strong. Most Americans are not especially interested in or motivated to purchase private LTCI. Many do not plan for LTSS costs, and, as noted above, 65 percent of Americans over 40 have done little to no planning for any sort of living expenses for when they are older.<sup>92</sup> Many think that they won't need LTSS (70 percent of those over 65 will need some LTSS, whether paid or unpaid, but just over half say that they are at risk of needing LTSS), and most of those who do realize they are at risk of needing LTSS think that someone else will bear the cost.<sup>93</sup> For those who are interested in LTCI or on the fence, high premiums and underwriting discourage or prevent many from purchasing coverage. Some assume that Medicare will cover LTSS; it doesn't. As discussed above, Medicaid will pay for LTSS, but only for people who have very low incomes and assets to begin with or who have spent down most income and non-housing assets on LTSS.

### Personal Savings

Personal savings is an important source of financing for LTSS. But, because these services can be very expensive, savings cannot be the only source of payment for most people who need LTSS. Savings are also a complement to private LTCI. Since LTCI is typically purchased at working age, when incomes are typically higher, policyholders must be able to continue to afford premium payments during their retirement years, as well as pay for out-of-pocket LTSS costs during the policy-elimination period, should the need for LTSS arise. Personal savings for retirement are one way of meeting these costs. However, around half of Americans have insufficient savings for general living needs in retirement, let alone enough to cover potential costs related to LTSS.<sup>94</sup> Increased savings for retirement could make private LTCI more viable, helping more Americans afford premiums and related out-of-pocket costs.

For LTCI purchased in 2010, the average buyer was 59 years old at purchase and the average annual premium was \$2,283 (the parameters of the average policy are described earlier).<sup>95</sup> In that same year, the median household income of Americans age 65 and up was \$31,408.<sup>96</sup> In such a household, the average private LTCI premium for two persons would consume almost 15 percent of household income. It is unlikely that median income for retirement-age Americans would increase enough in the next few years to significantly change this analysis. Clearly, this is a major expense, which savings could help to meet.

The larger problem is that most Americans do not have sufficient savings to preserve their standard of living in retirement, let alone to pay for LTSS. Only about half of Americans participate in some kind of a workplace retirement plan, such as a defined benefit pension or defined contribution account, like a 401(k).<sup>97</sup> Those between the ages of 55 and 64 who do participate in an employer-based retirement plan have a median defined contribution account balance of \$100,000.<sup>98</sup> The National Retirement Risk Index, which incorporates factors other than retirement accounts (such as home equity and Social Security) into an assessment of national retirement preparedness, estimates that 53 percent of households are at risk of not being able to maintain their standard of living when they are no longer working.<sup>99</sup> Individuals who are unprepared for retirement in general are not likely to take steps to prepare for potential costs related to LTSS needs.<sup>100</sup>

# Conclusion and Next Steps

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The financing and delivery of LTSS is a complex issue, and policymakers have struggled for decades to improve the quality and delivery of these services in a cost-effective way. As the demand for LTSS more than doubles over the next 35 years, current funding sources will quickly become unsustainable and this population growth will only exacerbate the fragmented way in which these services are delivered. Due to both the diversity of the LTSS population and the current political environment, it is extremely unlikely that a single solution will adequately address these challenges. For this reason, BPC's Long-Term Care Initiative plans to produce a set of recommendations that weave together the approaches of publicly funded programs, such as Medicaid, with private insurance products to control costs, while also improving the efficiency and quality of LTSS. Senator Daschle, Senator Frist, Dr. Rivlin, and Governor Thompson plan to build upon the considerable work being done in this area, particularly by the recent Commission on Long-Term Care, and welcome comments and guidance from stakeholders and policymakers as the initiative progresses.

# Technical Appendix: Development of BPC Estimates of National LTSS Spending

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National spending on LTSS is difficult to estimate because the available data sources generally commingle LTSS and post-acute care (PAC) spending. PAC includes rehabilitative services that are used on a short-term basis after an acute medical issue.<sup>101</sup> An example of PAC would be rehabilitative services delivered by a skilled nursing facility (SNF) or a home health agency (HHA) for a few weeks after knee-replacement surgery. Medically-necessary PAC is covered by Medicare and private health insurance. LTSS, as described in the report, includes services to assist individuals with functional limitations with ADLs and IADLs on a long-term basis. In many cases, for PAC and LTSS, the same kinds of services are delivered by the same providers (SNFs and HHAs). As such, economic data that focuses on providers, such as the National Health Expenditure Accounts (NHEA), mix this spending together. This creates major challenges for estimating LTSS spending, for which there are not perfect solutions.

The federal Commission on Long-Term Care relied on a National Health Policy Forum (NHPF) analysis of NHEA data for LTSS spending estimates.<sup>102</sup> The NHEA data is not segmented by service type (PAC vs. LTSS), but it is segmented by payer, such as Medicare, Medicaid, and out-of-pocket, among other categories. Because Medicare does not pay for LTSS, payments to SNFs and HHAs that originate from Medicare are assumed to be for PAC and can be eliminated from the analysis; using this methodology, NHPF estimated total LTSS spending of \$210.9 billion for 2011. The advantage to this approach is that it is a broad measure that is likely to capture most LTSS spending (with the exception of assisted-living and certain social services, which are not included). The disadvantage is that the \$210.9 billion estimate also includes a substantial amount of PAC spending from private insurance, Medicaid, and out-of-pocket.

For this white paper, BPC used an alternative approach to estimate LTSS spending, examining data from major LTSS payers in order to exclude as much PAC as possible. Essentially, the BPC approach trades precision for accuracy.

## Medicaid and Other Public Spending

Medicaid is clearly the largest LTSS payer, and data on program spending is available to the public. The CMS Actuary reported that federal and state outlays for LTSS under the Medicaid program totaled \$114.3 billion in fiscal year (FY) 2011.<sup>103</sup> A study from Mathematica Policy Research estimated 2011 Medicaid spending on LTSS to be \$136.2 billion.<sup>104</sup> Both amounts include an unknown amount of PAC. However, the amount of PAC spending included is likely relatively low for two reasons. First, for dual-eligibles, Medicare is paying for any PAC services. Second, about half of Medicaid beneficiaries are enrolled in managed-care plans; capitated payments to these plans, which pay for any PAC needed by their beneficiaries, are accounted for separately and are not included in the \$114.3 billion figure. The CMS estimate (\$114.3 billion) does not include LTSS paid for by managed-care plans. The vast majority of capitation payments are for acute care, but some states provide at least some LTSS through capitated plans. The Mathematica estimate includes some data on Medicaid managed-care spending on LTSS, which was collected through a survey. The CMS and Mathematica estimates use different definitions of LTSS in other respects, as well. While they differ, they provide a realistic “ballpark” sense of Medicaid spending on LTSS; it is probably well over \$100 billion annually.

There are other public programs that pay for LTSS, such as Veterans Affairs and Older Americans Act programs. These are included in NHPF’s \$9.7 billion total for Other Public Spending, based on NHEA data.

## Private Spending: LTCI and Out-of-Pocket

Private spending on LTSS is even more difficult to estimate than public spending. The NHPF analysis of NHEA data shows a total of almost \$70 billion out-of-pocket and other private (including insurance) spending on LTSS in 2011 (not including assisted living), but this figure includes a substantial amount of PAC spending. Additionally, some spending that originated from private LTCI is reported as out-of-pocket because it is common for LTCI to pay policyholders directly, who then in turn pay LTSS providers. This figure also leaves out spending on assisted living, and probably does not include a substantial amount of gray-market home care, but it likely includes all nursing-home out-of-pocket spending, which is the most expensive form of LTSS. Because we have no sense of how much of the \$70 billion figure is for out-of-pocket and health insurance payments for PAC, the true out-of-pocket LTSS spending figure (not including assisted living) is likely somewhere well above zero and well below \$70 billion. Hence, a precise estimate is not possible; the best we can say is that tens of billions are likely spent out-of-pocket on LTSS annually, excluding assisted living.

The situation is different for private LTCI. While LTCI issuers do not report the exact amount of cash paid to policyholders and LTSS providers each year based on claims, the data available can be used to estimate annual cash payments from claims. At the request of BPC, LifePlans reviewed data collected by the National Association of Insurance Commissioners and estimated that private LTCI paid out about \$7 billion on claims in 2012.

# Endnotes

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- <sup>1</sup> Department of Health and Human Services (2003) *The Future Supply of Long-Term Care Workers in relation to The Aging Baby Boom Generation*, Report to Congress. Available at: <http://aspe.hhs.gov/daltcp/reports/ltcwork.htm#section1>.
- <sup>2</sup> Congressional Budget Office (2013) *Rising Demand for Long-Term Services and Supports for Elderly People*. June, p. 33. Available at: <http://www.cbo.gov/publication/44363>. Note: In this analysis, the Congressional Budget Office includes Medicare spending for post-acute care in its LTSS spending statistics. In BPC estimates of LTSS spending elsewhere in the report, we have attempted to exclude spending on post-acute care, to the extent possible.
- <sup>3</sup> Available at: <http://ltccommission.org/>.
- <sup>4</sup> See Technical Appendix for BPC's analysis of public LTSS spending. For an estimate of the economic value of unpaid LTSS, see: L. Feinberg, S. Reinhard, A. Houser, R. Choula (2011) *Valuing the Invaluable: 2011 Update: The Growing Contributions and Costs of Family Caregiving*. AARP Public Policy Institute.
- <sup>5</sup> Congressional Budget Office (2013) *Rising Demand for Long-Term Services and Supports for Elderly People*. June, p. 33. Available at: <http://www.cbo.gov/publication/44363>. Note: In this analysis, the Congressional Budget Office includes Medicare spending for post-acute care in its LTSS spending statistics. In BPC estimates of LTSS spending elsewhere in the report, we have attempted to exclude spending on post-acute care, to the extent possible.
- <sup>6</sup> 527 U.S. 581 (1999). In *Olmstead*, the Supreme Court overturned a decision by the state of Georgia that denied requests by plaintiffs with intellectual disabilities to be moved from a state hospital to an available community-based setting. The Court held that such "unjustified isolation" violated Title II of the American's with Disabilities Act, which prohibits discrimination based on disability by public entities, such as states and local governments.
- <sup>7</sup> Kaye, H.S., C. Harrington, and M.P. LaPlante (2010) "Long-term care: Who gets it, who provides it, who pays, and how much?" *Health Affairs* 29(1): 11-21.
- <sup>8</sup> Stevenson, D.G., M. Cohen, E.J. Tell, and B. Burwell (2010) "The Complementarity of Public and Private Long-Term Care Coverage." *Health Affairs* 29(1):98.
- <sup>9</sup> Department of Health and Human Services (2003) *The Future Supply of Long-Term Care Workers in relation to The Aging Baby Boom Generation*, Report to Congress. Available at: <http://aspe.hhs.gov/daltcp/reports/ltcwork.htm#section1>.
- <sup>10</sup> Office of the Actuary, Centers for Medicare and Medicaid Services (2012) *2012 Actuarial Report on the Financial Outlook for Medicaid*, p. 27. Available at: <http://medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Financing-and-Reimbursement/Downloads/medicaid-actuarial-report-2012.pdf>.
- <sup>11</sup> Congressional Budget Office (2013) *Rising Demand for Long-Term Services and Supports for Elderly People*. June, p. 33. Available at: <http://www.cbo.gov/publication/44363>. Note: In this analysis, the Congressional Budget Office includes Medicare spending for post-acute care in its LTSS spending statistics. In BPC estimates of LTSS spending elsewhere in the report, we have attempted to exclude spending on post-acute care, to the extent possible.
- <sup>12</sup> In 2014, 133 percent of the federal poverty level is \$15,521 for an individual and \$20,921 for a couple.
- <sup>13</sup> Department of Health and Human Services. Available at: [www.longtermcare.gov](http://www.longtermcare.gov)
- <sup>14</sup> In 2014, 300 percent of the maximum annual SSI benefit is \$25,956 for an individual and \$38,952 for a couple.
- <sup>15</sup> Commission on Long-Term Care (2013) *Report to Congress*. September 30, p. 25.
- <sup>16</sup> Commission on Long-Term Care (2013) *Report to Congress*. September 30, p. 26.
- <sup>17</sup> Commission on Long-Term Care (2013) *Report to Congress*. September 30, p. 23-24.
- <sup>18</sup> Commission on Long-Term Care (2013) *Report to Congress*. September 30, p. 25.
- <sup>19</sup> Commission on Long-Term Care (2013) *Report to Congress*. September 30, p. 26.
- <sup>20</sup> Alkema, G.E. (2013) *Current Issues and Potential Solutions for Addressing America's Long-Term Care Financing Crisis*. The SCAN Foundation, March.
- <sup>21</sup> Index of ADLs. S. Katz, et al. (1970) "Progress in the development of the index of ADL." *The Gerontologist* 10: 20-30.
- <sup>22</sup> Index of IADLs. M. Lawton and E. Brody (1969) "Assessment of older people: self-maintaining and instrumental activities of daily living." *The Gerontologist* 9: 179-186.

- <sup>23</sup> Colello, K.J., J. Mulvey, and S.R. Talaga (2013) *Long-Term Services and Supports: Overview and Financing*. Congressional Research Service, April 4.
- <sup>24</sup> Kaye, H.S., C. Harrington, and M.P. LaPlante (2010) "Long-term care: Who gets it, who provides it, who pays, and how much?" *Health Affairs* 29(1): 14.
- <sup>25</sup> Stevenson, D.G., M. Cohen, E.J. Tell, and B. Burwell (2010) "The Complementarity of Public and Private Long-Term Care Coverage." *Health Affairs* 29(1): 98.
- <sup>26</sup> Commission on Long-Term Care (2013) *Report to Congress*. September 30, p. 22-23.
- <sup>27</sup> Kaye, H.S., C. Harrington, and M.P. LaPlante (2010) "Long-term care: Who gets it, who provides it, who pays, and how much?" *Health Affairs* 29(1):11-21.
- <sup>28</sup> Commission on Long-Term Care (2013) *Report to Congress*. September 30, p. 14-15.
- <sup>29</sup> Commission on Long-Term Care (2013) *Report to Congress*. September 30, p. 17.
- <sup>30</sup> Colello, K.J., J. Mulvey, and S.R. Talaga (2013) *Long-Term Services and Supports: Overview and Financing*. Congressional Research Service. April 4.
- <sup>31</sup> Available at: <https://www.federalregister.gov/articles/2014/01/16/2014-00487/medicaid-program-state-plan-home-and-community-based-services-5-year-period-for-waivers-provider#h-9>.
- <sup>32</sup> Colello, K.J., J. Mulvey, and S.R. Talaga (2013) *Long-Term Services and Supports: Overview and Financing*. Congressional Research Service. April 4; claims data provided by Genworth.
- <sup>33</sup> Colello, K.J., J. Mulvey, and S.R. Talaga (2013) *Long-Term Services and Supports: Overview and Financing*. Congressional Research Service. April 4.
- <sup>34</sup> Waiver and state plan authority for HCBS are authorized through Title XIX of the Social Security Act and include 1915(c) home- and community-based waivers, 1915(i) state plan home- and community-based services, 1915(j) state plan self-directed personal-assistance services, and 1915(k) Community First Choice.
- <sup>35</sup> Kaye, H.S., C. Harrington, and M.P. LaPlante (2010) "Long-term care: Who gets it, who provides it, who pays, and how much?" *Health Affairs* 29(1):19.
- <sup>36</sup> Rowland, D. (2013) Testimony to the Commission on Long-Term Care. August 1. (Commission report p. 10.)
- <sup>37</sup> Commission on Long-Term Care (2013) *Report to Congress*. September 30, p. 36.
- <sup>38</sup> Commission on Long-Term Care (2013) *Report to Congress*. September 30, p. 35.
- <sup>39</sup> Institute of Medicine and National Research Council (2013) *Financing long-term services and supports for individuals with disabilities and older adults: Workshop summary*. Washington, DC: The National Academies Press.
- <sup>40</sup> Eldercare Workforce Alliance (2014) *Geriatrics Workforce Shortage: A Looming Crisis for Our Families*. Washington, DC: Eldercare Workforce Alliance. Available at: <http://www.eldercareworkforce.org/research/issue-briefs/research:geriatrics-workforce-shortage-a-looming-crisis-for-our-families/>.
- <sup>41</sup> National Alliance for Caregiving and AARP (2009) "Caregiving in the U.S. 2009." November.. Available at: [http://www.caregiving.org/data/Caregiving\\_in\\_the\\_US\\_2009\\_full\\_report.pdf](http://www.caregiving.org/data/Caregiving_in_the_US_2009_full_report.pdf).
- <sup>42</sup> Commission on Long-Term Care (2013) *Report to Congress*. September 30, p. 49.
- <sup>43</sup> MetLife Mature Market Institute and National Alliance for Caregiving (2006) *The MetLife Caregiving Cost Study: Productivity Losses to U.S. Business*, July, p. 4. Available at: [http://www.caregiving.org/data/Caregiver\\_percent20Cost\\_percent20Study.pdf](http://www.caregiving.org/data/Caregiver_percent20Cost_percent20Study.pdf).
- <sup>44</sup> Institute of Medicine and National Research Council (2013) *Financing long-term services and supports for individuals with disabilities and older adults: Workshop summary*. Washington, DC: The National Academies Press.
- <sup>45</sup> Feinberg, L., S. Reinhard, A. Houser, R. Choula (2011) *Valuing the Invaluable: 2011 Update: The Growing Contributions and Costs of Family Caregiving*. AARP Public Policy Institute.
- <sup>46</sup> Evercare and National Alliance for Caregiving (2007) *Family Caregivers: What They Spend, What They Sacrifice; The Personal Financial Toll of Caring for a Loved One*. Minnetonka, MN: Evercare, and Bethesda, MD: NAC. See also: IOM p. 3-5 and Feinberg, p. 6.
- <sup>47</sup> Commission on Long-Term Care (2013) *Report to Congress*. September 30, p. 49.
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# Raising Expectations: California's 2014 Long-Term Services and Supports Scorecard Results

*California is a leading state in an imperfect national LTSS system. Much work remains to be done to improve affordability, quality, and coordination of services within the state's system so people can access needed services to support independence and quality of life.*

Long-term services and supports (LTSS) should be affordable, high-quality, and well-coordinated in order to support older adults and people with disabilities in the setting of their choice. The 2<sup>nd</sup> [\*State Scorecard on Long-Term Services and Supports \(Scorecard\)\*](#), produced by the AARP Public Policy Institute\*, examines state system performance using five identified dimensions of a high-performing LTSS system. This brief describes [California's results](#), identifying areas for improvement as well as policy opportunities to transform and improve the state's system of care.

## **California's Scorecard Performance**

This new *Scorecard* shows that California still ranks higher than most states, coming in 9<sup>th</sup> overall, yet has areas for substantial improvement. Below are California's rankings on the five dimensions.<sup>1</sup>

**Affordability & Access:** Most Californians cannot afford the high cost of LTSS, which limits access to services. In California, the cost of home care is 82% of median household income, while nursing home care is 241% of median household income. Private long-term care insurance alone will not solve the problem. Only 5% of Californians over 40 have this coverage due to the difficulties in qualifying for coverage and high cost for most working families.<sup>1</sup>

**Choice:** The state can do a better job of ensuring people have choices regarding where they receive LTSS. Californians overwhelmingly prefer to remain in the community, meaning that affordable access to home- and community-based services (HCBS) is essential to creating more choice. While California spends more Medi-Cal funding on HCBS than institutional care (56% of all Medi-Cal LTSS dollars going to the community), the state still lags far behind New Mexico as the top-ranked state, which has 65% of Medicaid LTSS dollars going to the community.<sup>1</sup>

**Quality:** California must ensure high quality of care for people needing LTSS and it is failing on some basic measures. For example, the rate of pressure sores among California's nursing home residents is double that of Hawaii, the best-performing state.<sup>1</sup>

\**Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Disabilities, and Family Caregivers* was produced by the AARP Public Policy Institute with support from The SCAN Foundation and The Commonwealth Fund.

**TABLE 1** Characteristics of a High-Performing LTSS System & California's Rank, 2014<sup>1</sup>

CHARACTERISTIC	DEFINITION	CA'S RANK
<b>Overall Rank</b>		<b>9</b>
Affordability & Access	LTSS is easy to find and affordable.	14
Choice of Setting & Provider	Individuals have choice and control over where they receive services and who provides them.	2
Quality of Life/Quality of Care	LTSS maximizes positive outcomes while respecting the individual and their personal preferences.	24
Support for Family Caregivers	The needs of family caregivers are assessed and addressed.	24
Effective Transitions	Health care and LTSS integrate effectively, minimizing disruptive transitions between care settings.	22

Note: The Scorecard ranking is in relation to performance of other states. Methodology for the ranking can be found at [www.longterm\\_scorecard.org](http://www.longterm_scorecard.org).

**Family Caregiver Support:** Nearly six million unpaid caregivers - often family and friends - provide LTSS in the state, valued at \$47 billion annually.<sup>2</sup> California ranks 3<sup>rd</sup> in legal and system support for caregivers, yet there are significant opportunities for improvement.<sup>1</sup> Right now, California offers 12 weeks/year of job protected leave (minimum established by the federal Family Medical Leave Act) while the District of Columbia (top-ranked) provides 16 weeks family leave and 16 weeks of medical leave every two years.<sup>3</sup>

**Effective Transitions:** California can create more opportunities to safely transition individuals from institutional settings to the community. Eleven percent of California nursing home residents have low-care needs as compared to 1% in Maine, the top-ranked state. This finding suggests that more Californians could have their needs met in a community setting, which would improve their quality of life and potentially reduce costs.<sup>1</sup> If California performed like Maine, 10,727 more people would reside in the community instead of an institutional setting.<sup>4</sup>

## **Policy Recommendations**

The *Scorecard* provides insight into California's LTSS system, and offers a starting point for meaningful dialogue around ways to improve this system. While the *Scorecard* does not tell the entire story of California's performance, it does demonstrate the need for an organized system of care that better coordinates services. Building off these new *Scorecard* results, the following policy recommendations can drive change toward improved system performance and quality of life for Californians in need of LTSS.

**Continue Action on Universal Assessment:** The California Departments of Health Care Services, Social Services, and Aging are working with stakeholders to develop and pilot a universal assessment tool for individuals needing LTSS. We recommend continued action on developing and implementing

this tool as the cornerstone of an organized system of care that is more responsive to individuals' needs, values, and preferences. The Universal Assessment tool should also include caregiver-specific questions so that providers can better understand and support the needs of unpaid family caregivers who often shoulder the primary care coordination responsibility for their loved ones.

The main system outcomes of a well-developed and implemented universal assessment are threefold: 1) reliable and person-centered information to facilitate better care coordination; 2) consistent information available to evaluate population level needs; and 3) widespread data to inform the development of HCBS quality measures.

*While this new Scorecard does not measure all elements of LTSS performance, it does identify priority areas that will be critical for broad system transformation in California.*

**Elevate the Value of Care Coordination:** Care coordination is a critical component of the state's [Coordinated Care Initiative](#) (CCI). Clear guidelines and strong accountability standards will ensure that services are person-centered, provided in a timely manner, and in the setting of choice. Through effective care coordination, older adults and their families should receive information about their options and could make more appropriate choices, connect with HCBS, and be better equipped to avoid unnecessary institutionalization.

**Create a Bill of Rights for Dually Eligible Californians:** Dual eligibles – low-income individuals who use both Medicare and Medi-Cal – are among the most vulnerable population in the state. As the state implements the [Cal MediConnect](#) demonstration as part of the CCI, the Legislature should clearly identify what low-income older adults and people with disabilities can expect to experience in these new models of care. A “Duals Bill of Rights” would communicate what people should expect from this new system and clarify accountability of health plans and providers so that people can access the services they need.

**Bolster Support for California's Unpaid Caregivers:** Building from recommendations by the federal Long-Term Care Commission, California should develop a state strategy to support unpaid family caregivers and inform them about available resources. In addition, employment-related policies could be reconsidered to better support California's unpaid family caregivers in the workforce. Such policies could include increasing the length of protected leave, and expanding the California Family Rights Act to include care for grandparents, siblings, and in-laws to match the Family Paid Leave benefit.<sup>5,6</sup>

**Improve Affordability:** Working families need tools that will enable them to plan and pay for their future care needs. The Bipartisan Policy Center kicked off their [Long-Term Care Initiative](#) this spring and will deliver specific policy recommendations in late 2014. Stakeholders should examine the recommendations and continue advocating for state and federal policy makers to seek active solutions to financing future LTSS needs.

## California's Evolving LTSS Landscape: Placing Scorecard Results in Context

California is in the midst of a major system transformation. Most significant in this transformation is the movement towards a managed care delivery system to integrate all aspects of care for older adults and people with disabilities, as evidenced by the CCI. While the CCI is being implemented in eight select counties, it will influence change and set a new service delivery paradigm that will impact the entire LTSS system landscape. An organized service delivery system, as envisioned in the CCI, has the potential to better identify individuals' needs and provide accountability to meet those needs. However, health care and LTSS leadership at the state and federal level must ensure that people's core needs are at the center of the system. While the *Scorecard* yields the only comparative analysis of people's experiences in LTSS systems across all 50 states, these findings do not capture every aspect of system performance. In many areas, there are no quality measures due to lack of data and information. Therefore, the *Scorecard* is a critical step in initiating a conversation about system performance, areas for opportunity, and the importance of continued system transformation in California.

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# Transforming California's System of Care for Older Adults and People with Disabilities: A Look at the State's Administrative and Fiscal Organization

**This brief describes the existing fiscal and administrative fragmentation in California's system of long-term services and supports (LTSS), consequences of such fragmentation, and recommendations to better align programs and services toward a more efficient, person-centered system of care.**

## Introduction

California, like other states, assists older adults and people with disabilities through a wide array of programs and services financed through several state agencies, and within them, numerous departments and programs. California's existing LTSS system was created one program at a time, resulting in a highly fragmented arrangement of services that focuses little on the individual's holistic needs but instead on the particulars of what each department or program provides and from where funding originates. There are no incentives nor infrastructure to support a more integrated approach to service delivery in which available resources are organized under a single administrative structure and individual need drives resource allocation. Instead, individuals needing assistance and their caregivers struggle to navigate a complex labyrinth of agencies and regulatory structures in order to access the totality of necessary supports and services, leading to difficulty accessing the right services at the right time and in the right place.

In public and private sector organizational design, form often

follows funding. To better understand how California's fragmented system of care functions today, this policy brief outlines the funding allocations for the main departments and agencies that have either direct or indirect action on improving the lives of older adults and people with disabilities.

## Background

California's operating budget is comprised of General Fund (GF), federal matching funds, as well as state bond funds and other special funds including taxes, licenses, and fees designated by law for specific government activities. GF spending for fiscal year 2010-2011 was \$93.5 billion across the state's 10 major agencies, general government operations, and servicing California's debt.<sup>1,2</sup> Activities of three agencies and one department within general government operations described below directly impact the welfare of older adults and people with disabilities, meaning that the agency or departments contained within the agency administer or oversee programs/services that directly serve this population. This cluster comprises over 40 percent of total GF

**“California’s existing LTSS system was created one program at a time, resulting in a highly fragmented arrangement of services that focuses little on the individual’s holistic needs but instead on the particulars of what each department or program provides and from where funding originates.”**

expenditures for 2010-11.

- **California Health and Human Services Agency (\$26.9 billion GF):** This agency oversees Medi-Cal (California’s Medicaid program), LTSS including an array of home- and community-based services (HCBS) programs, and the licensing of many of the LTSS providers through seven departments within the agency.
- **Business, Transportation and Housing Agency (\$0.10 billion GF):** In this agency, the Department of Housing and Community Development allocates resources toward low-income housing and housing with supportive services for older adults and people with disabilities. In addition The Department of Transportation (CalTrans) oversees funding of critical transportation services for older adults and people with disabilities.
- **Corrections and Rehabilitation (\$9.1 billion GF):** This agency is directly responsible for the health and welfare of its populations, which include prisoners across the age range who have health and/or functional needs.
- **General Government Operations (\$2.7 billion GF):** Within the state budget, the Department of Veterans Affairs operates within general government and state operations; this department administers special benefits and services for California veterans and their caregivers.

In addition, three other agencies indirectly impact the welfare of these individuals and their caregivers. Here, the agency or associated departments facilitate the provision of programs and services for older adults and

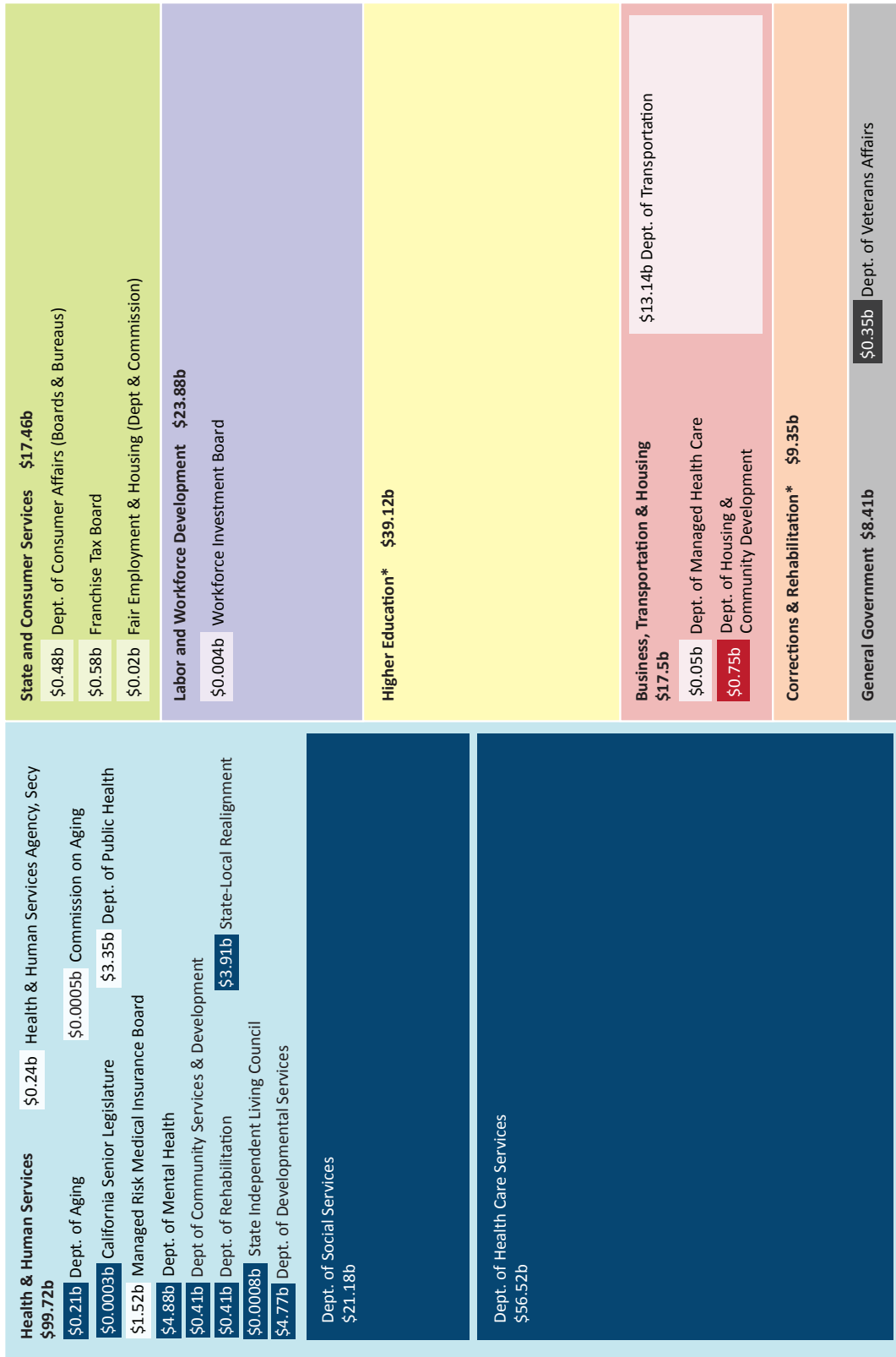
people with disabilities but are not involved in direct administration or oversight of these programs or services. The three agencies below comprise 12 percent of the total GF expenditures for 2010-11.

- **Higher Education (\$10.7 billion GF):** This agency is responsible for the provision of post-secondary education in the state, which includes education and training for a variety of workers providing health-related services. For example, the state community college system trains the direct-care workforce that provides services to older adults and people with disabilities in the home and in institutions.
- **Labor and Workforce Development (\$0.04 billion GF):** The Workforce Investment Board inside this agency provides guidance setting workforce policy for the state, including the health care workforce.
- **State and Consumer Services (\$0.59 billion GF):** The Department of Fair Employment and Housing inside this agency protects Californians from employment and housing discrimination, including protections for older adults and people with disabilities.

## California’s Budget Building Blocks

Considering the six agencies and general government operations that have either direct or indirect touch to services and supports for older adults and people with disabilities and their caregivers, Figure 1 details these “budget building blocks” graphically. Each building block represents one of the state’s major agencies and is sized to reflect the relative proportion of

Figure 1. California's Budget Building Blocks: A Closer Look at State and Federal Spending on Aging and Long-Term Care



**Note:** Dollar amounts reflect FY 2010-11 State and Federal spending for California agencies and departments that, based on a review by The SCAN Foundation, have either a direct or indirect association with aging and long-term care programs or populations. The darker shaded boxes represent entities with a direct association with aging and long-term care programs or populations—one in which the entity administers or oversees a program that directly serves older adults and people with disabilities. The lighter shaded boxes represent entities with an indirect association—one in which the entity facilitates the provision of aging and long-term care services but is not involved in direct service through administration or oversight. The percentages represent the proportion of total spending for each entity that comes from the State General Fund. Spending amounts do not include General Fund expenditures applied to debt service.

\*Neither Higher Education nor Corrections & Rehabilitation have a department or program with a specific budget line item that indicates a direct or indirect relationship with aging/long-term care programs or populations. Higher Education funds programs that train the workforce that serves aging/long-term care populations reflecting an indirect relationship; Corrections & Rehabilitation provides health and supportive services to older prisoners and prisoners with physical disabilities, thus reflecting a direct relationship with aging/long-term care programs/populations.

**Source:** The SCAN Foundation's analysis based on: Department of Finance, "Governor's Budget 2011-12, Proposed Budget Detail" (Available at: <http://www.ebudget.ca.gov/agencies/.html>).

total spending among these agencies and operations from all sources (GF, federal dollars, and other funding sources) in fiscal year 2010-2011. For example, California Health and Human Services (CHHS) is by far the largest agency detailed with total spending of \$99.7 billion in the 2010-11 budget, with general government operations as the smallest building block representing \$8.4 billion in total spending.

The next layer of detail shows that within each of the building blocks are a number of departments, commissions, and boards with specific line items in the California budget that make up the landscape of programs, services, and regulatory structures serving older adults and people with disabilities for that agency. These smaller boxes, sized relative to the total budget amount, are also assigned a primary designation of having either a direct or indirect impact to service provision. The darkest shades of the blocks reflect those departments, commissions, and boards with a direct touch to older adults and people with disabilities and the lighter shaded boxes reflect those with an indirect touch.

#### **An Example: California Health and Human Services Agency (CHHS)**

CHHS contains 14 separate budget line items that have either a direct or indirect relationship to services for older adults and people with disabilities. The largest share is held by the Department of Health Care Services at \$56.5 billion, followed by the Department of Social Services at \$21.2 billion. As noted by their darker shade of blue, most of the budget line items have a direct relationship to services for older adults and people with disabilities.

## **Impact of Fiscal and Administrative Complexity**

A quick look at Figure 1 illustrates the fiscal and administrative complexity that drives much of the service fragmentation experienced by California's older adults, people with disabilities, and their caregivers. However, the state budget is not established in isolation given that many LTSS programs and services exist through federal policies, regulations, and associated funding streams. The federal government requires states to follow particular rules and regulations in return for sustainable funding for these programs and services, which ultimately impacts the organization of services at the state level (the "form follows funding" paradigm). In addition, California is a relatively decentralized state whereby counties operate with some level of autonomy even under the auspice of federal and state laws and regulations that drive how services are funded and administered at the local level.

California's current constellation of LTSS was developed one program at a time over many years through a mixture of federal mandates (e.g., Medi-Cal coverage for nursing home care) and state innovation (e.g., the In-Home Supportive Services program). As such, LTSS programs were implemented and funded in a variety of departments that operate independently of each other – not by design but by historical circumstance. California is not alone in this regard as most states operate and budget separately for each program or service including nursing homes, personal care services, Medicaid HCBS waivers, Administration on Aging programs, and other state-funded programs. The

**“The complexity and lack of coordination across the variety of LTSS programs leads to operational inefficiency at the state level and potentially inappropriate use of available services and supports at the person and provider level.”**

result is a complex, diffuse, loosely connected network of services and supports that is difficult for older adults, persons with disabilities and their caregivers as well as local service providers to navigate when seeking assistance for those in need. The complexity and lack of coordination across the variety of LTSS programs leads to operational inefficiency at the state level and potentially inappropriate use of available services and supports at the person and provider level.

## Recommendations to Transform California's System of Care

In a perfect world, the system of LTSS would center on the needs and preferences of individuals who have met functional and financial eligibility criteria and resource allocation would be aligned with their needs and preferences. People would gain streamlined access to services through a clear and simplified assessment process. Clinical, functional, and demographic information gained through the assessment would be available to providers to create the most appropriate plan of care with the individual and their loved ones and determine how best to execute that plan of care with appropriate quality controls. Information gained through the assessment would be located in a central repository and analyzed regularly to ensure the needs of those served were being met in a person-centered, efficient, and high quality manner and to plan for future use of scarce public resources. This entire process would be centrally housed in as few administrative structures as possible with the financial alignment driving collaborative engagement both within the state and between the state, counties, and federal government.

Achieving this vision may seem too big of a task given the variety of policy, budgetary, and political challenges the state is currently facing. However, California can take decisive steps toward achieving this vision through the fiscal and administrative re-organization of those building blocks that have the greatest role in serving older adults and people with disabilities. The list below includes recommendations for the state, federal government, and the interaction between the state and county governments.

- Promote Administrative and Fiscal Re-Organization at the State Level
  - Create a LTSS global budget. Where finances cannot be aligned, better align the information about who uses which services across agencies/departments, what their needs are, and identify opportunities to minimize duplication of services.
  - Better organize the administration of publicly-financed LTSS. At a minimum, combine relevant programs, services, and regulatory structures in CHHS that impact LTSS into a single department. Where alignment under one roof is not feasible, create intentional alignments through better intra- and inter-departmental communication and flow of information.
  - Establish a core set of questions that all programs using an assessment process to determine eligibility and level of need must use. This will enable the needs of individuals who receive services from different programs to be evaluated in a uniform way. Analysis of this information will shed light on both the functional levels of individuals across programs and population-level understanding of service use to monitor quality and support future planning.

**“In this time of substantial fiscal challenge and constraint in California, now is the opportunity to break down these silos so that we have a more efficient, effective and person-centered network of care.”**

- Improve the flow of information across programs and between counties and the state – build an integrated information system that across programs using uniform assessment, and support policy making that is close to “real time.”
- Realign the financing requirements for IHSS back to the state level.
  - The In-Home Supportive Services (IHSS) program creates a fiscal disincentive to provide HCBS for eligible individuals who might require a nursing home level of care. Counties currently pay 17.5 percent of the cost of IHSS, while the state pays 32.5 percent, and the federal government pays 50 percent share-of-cost.\* For nursing facility services, the state pays 50 percent of the costs, the federal government pays the other 50 percent, and counties have no share of cost. Therefore, counties have no fiscal incentive to enroll functionally limited individuals in IHSS (a community-based service) if they are eligible for a nursing home level of care.
  - Realigning this critical community-based service back to the state would pave the way for greater centralization of all LTSS, both fiscally and administratively.
- Explore opportunities put forth by the federal government to streamline the landscape of LTSS funded through Medicaid waivers.
  - Currently, California operates seven HCBS waivers that serve older adults and people with disabilities through four

departments in CHHS. Each waiver has its own funding stream and implementation requirements to which state staff and the providers who ultimately deliver services must adhere. Each waiver also operates independently and without overlap due to existing restrictions on individuals being enrolled in more than one waived service.<sup>3</sup> Existing waivers are targeted to support specific vulnerable populations to live in the community who would otherwise require care in an institution. As a result, each waiver may serve a different population, lending to the existing fragmentation in service provision across the state. Recently, the Centers for Medicare and Medicaid Services (CMS) released a proposed rule to revise the regulations on Medicaid HCBS waivers under Section 1915(c) of the Social Security Act, which would allow a state to combine multiple target groups into a single waiver.<sup>4</sup> With this opportunity, California could design a more person-centered approach to delivering waiver services and create a more efficient system that eliminates a portion of the existing system fragmentation simultaneously.

## Conclusion

In summary, what this brief, and in particular, the budget building blocks graphic (Figure 1) demonstrate is how fragmented and siloed services are for vulnerable older adults and for people with disabilities in California. Most importantly, for that vulnerable

\* As part of the American Recovery and Reinvestment Act, the state is receiving an enhanced federal matching rate with the federal government paying 61.59 percent, and the remaining 38.41 percent is split in the same proportion between the state and counties. This enhanced match will terminate on June 30, 2011.

individual and their caregivers, there is no person, program, or entity that is fully responsible for assessing needs and coordinating across all the programs and services that may be available to them. In this time of substantial fiscal challenge and constraint in California, now is the opportunity to break down these silos so that we have a more efficient, effective and person-centered network of care.

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## **Common Aging Acronyms**

## **COMMON AGING ACRONYMS**

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<b>AAA</b>	Area Agency on Aging
<b>AARP</b>	American Association of Retired Persons
<b>ACA</b>	Affordable Care Act (Also known as Patient Protection & Affordable Care Act)
<b>ACL</b>	Administration for Community Living (federal)
<b>ADA</b>	Americans With Disabilities Act of 1990
<b>ADHC</b>	Adult Day Health Care (Now known as Community Based Adult Services - CBAS)
<b>ADL</b>	Activities of Daily Living
<b>ADRC</b>	Aging & Disability Resource Center (In California this program is known as Aging & Disability Resource Connection)
<b>AoA</b>	Administration on Aging (AoA is a program of the Administration for Community Living)
<b>APS</b>	Adult Protective Services
<b>ASA</b>	American Society on Aging
<b>AL</b>	Assisted Living
<b>B&amp;C</b>	Board and Care
<b>CAADS</b>	California Association of Adult Day Services
<b>CBAS</b>	Community Based Adult Services (Formerly known as Adult Day Health Care)
<b>CCI</b>	Coordinated Care Initiative
<b>CCLTSS</b>	California Collaborative for Long Term Services and Supports

<b>C4A</b>	California Association of Area Agencies on Aging
<b>CCRC</b>	Continuing Care Retirement Community
<b>CNCS</b>	Corporation for National and Community Service
<b>CMS</b>	Centers for Medicare & Medicaid Services
<b>CCoA</b>	California Commission on Aging
<b>CCS</b>	Congress of California Seniors
<b>CDA</b>	California Department of Aging
<b>CEJC</b>	California Elder Justice Coalition
<b>CSL</b>	California Senior Legislature
<b>DE</b>	Dual Eligible Persons are those eligible for both Medicare and Medi-Cal
<b>DEDP</b>	Dual Eligible Demonstration Project (Now known as Cal Medi-connect)
<b>EESI</b>	Elder Economic Security Index
<b>HCFA</b>	Health Care Financing Administration
<b>HICAP</b>	Health Insurance Counseling and Advocacy Program.
<b>HUD</b>	Department of Housing and Urban Development (federal)
<b>I &amp; A</b>	Information and Assistance
<b>IFF</b>	Intrastate Funding Formula
<b>IHSS</b>	In-Home Support Services
<b>LTC</b>	Long-Term Care (Now known as Long-Term Services and Supports)
<b>LTSS</b>	Long-Term Services and Supports
<b>MOW</b>	Meals on Wheels (Also known as home delivered meals)

<b>MSSP</b>	Multipurpose Senior Services Project
<b>N4A</b>	National Association of Area Agencies on Aging
<b>NASUAD</b>	National Association of States United for Aging and Disabilities
<b>NCOA</b>	National Council on the Aging
<b>OAA</b>	Older Americans Act of 1965
<b>OCA</b>	Older Californians Act
<b>PACE</b>	Program of All-Inclusive Care
<b>PSA</b>	Planning and Service Area
<b>RCFE</b>	Residential Care Facilities for the Elderly
<b>RSVP</b>	Retired and Senior Volunteer Program
<b>SILC</b>	California State Independent Living Council
<b>SNF</b>	Skilled Nursing Facility
<b>SSA</b>	Social Security Act
<b>TACC</b>	Triple-A Council of California
<b>WHCoA</b>	White House Conference on Aging (Last held 2005)

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