Executive Summary

California's long-term care system is broken. The state has no reliable means of gauging what clients need, what benefits they receive, which services are used by whom, how much each service costs the state, and which programs work the best and are the most cost-effective in keeping people in their homes. There is virtually no coordination or communication between programs and staff responsible for long-term care services. There is no integrated management or coordination of financing, service delivery or assessment of long-term care client needs or of providers. These fundamental structural flaws leave the system unable to effectively or efficiently deal with current needs and make it woefully unprepared for the "silver tsunami" of seniors who will lack services in the years to come. Furthermore, California lacks a single leader within the Health and Human Services Agency accountable for managing and modernizing long-term care in the state, which creates significant challenges to any attempt to systematically harness the dozens of long-term care programs and the many billions of dollars spent on them. Evidence of the system's failure include the following:

- Consumer confusion and difficulty in accessing needed services results in over-utilization of unnecessary and costly care, such as emergency room visits or longer-than-required nursing home stays. The process of transitioning clients from institutional to community-based care is inconsistent.
- Lack of integrated service delivery causes duplication of state, county and non-profit effort and resources, such as the multiple and duplicative assessments conducted on a single client.
- Lack of care coordination, planning and management inhibit clients' ability to find the right care at the right time in the right place.
- State-level leadership, vision and prioritization of long-term care services and system improvement are lacking.
- Focused oversight and accountability of program efficiency and outcomes are absent.
- The state administrative structure is fragmented, which isolates programs, a problem reinforced by rigid funding rules and a lack

of data that could be used for better decision-making and program planning.

- Budget cuts make delivering a full range of services difficult for state and county providers.

The lack of information about the state's long-term care programs means that the state, at any given moment, cannot say how much money California spends on long-term care for the aged and the disabled. The most recent estimate is $7 billion for the state's share, from the 2005-06 budget year, a figure aggregated by the Legislative Analyst's Office. With federal and state contributions, total spending was $13.7 billion for the period. Absent a way to assess the state's long-term care programs as a whole, the state lacks the ability to identify cost-drivers and address them in the context of other program options that may be available.

Spending on individual programs has grown rapidly in recent years, most noticeably in the In-Home Supportive Services (IHSS) program. This entitlement program must be integrated into the broader menu of long-term care options, to reduce overlap, to ensure that enough qualified caregivers and providers are available, and to improve the state's ability prioritize services so that resources are directed to those most in need. Growth in participation across programs is projected to accelerate with the retirement of the Baby Boom generation. As the first group of the Baby Boom generation turn 65 this year, the number of Californians ages 65 and older is projected to nearly double over the next two decades, to 8.84 million in 2030 from 4.64 million in 2010. The need to make better use of existing funding through more consolidated and streamlined management becomes only more critical as ongoing budget shortfalls require government to become leaner and more efficient. The addition of legal requirements, most significantly the *Olmstead v. L.C.* decision by the U.S. Supreme Court in 1999, impose greater obligations on the state to keep people out of institutions and, instead, integrated into the community, requiring that the state do even more to keep people in their homes and transition them back home after being hospitalized.

California once was a pioneer in alternative care for seniors and people with disabilities, but it has failed to integrate long-term care programs at the state level. At the local level, innovative counties have worked to provide a more seamless system of care at the local level despite the state's siloed departmental structure. During its study, the Commission saw several promising local approaches to this kind of more integrated method, whether through an actual consolidation of programs, as in San Diego County, or through creative coordination of county health and social services programs that includes expansion of the county-organized managed care plan, as in San Mateo County.

County efforts to integrate services into a cohesive system of care are impeded by the state's fragmented bureaucracy. As funding streams for county programs originate in different state programs, county officials must go through layers of state program staff in order to make changes to local long-term care services, including changes needed simply to integrate services. Most long-term care services already are provided at the local level, but controlled or monitored at the state level. Governor Brown's realignment plan proposed in his January 2011 budget, though not yet applicable to long-term care, is a reminder that successful realignment requires integrated strategies at both the state and local levels so that counties can have the support and flexibility they need to best deliver services to seniors and people with disabilities. This report recommends changes that should be made to the current system as well as incorporated into any realignment plan, which necessarily will require a consolidation of long-term care activities at the state level.

Care Coordination

As the state braces for the oncoming wave of aging Baby Boomers alongside the recurring budget cuts, California's long-term care system must be streamlined and managed in a way that maximizes all resources. Federal, state, local, non-profit, community, and individual assets must be aligned in order to provide the best care at the most economical cost. The linchpin to this alignment is "care coordination" – a mechanism to ensure that a senior or person with disabilities receives the right care at the right time in the right setting – a goal that tends to keep people in their homes and communities and out of costly institutions. Care coordination means creating a true continuum of long-term care services, one that is easy to understand and accessible to the client. It should be well-organized at the local level, either through county programs or contracted non-profit groups.

In California, services are provided piecemeal, with different eligibility criteria and separate assessments for each program; there is no coordinated management of care or even data about a client's care or condition in a central database system that can be used by more than one program. Clients have no path or system to follow to understand their care options, while state leaders have no overall understanding of client population needs, service utilization, the cost of available options, or even which programs produce the best outcomes or are the most cost-effective. Funding and policy decisions, including changes and cuts made to In-Home Supportive Services, for example, are made lacking a full understanding of consequences to the system as a whole.

The state has neither the tools necessary to manage the system nor the ability to coordinate care – an absolute necessity – for the vast majority of beneficiaries in California's publicly funded long-term care programs.

The Commission has long recognized the need for streamlined management and coordination of long-term care programs and in 1996 recommended the consolidation of long-term care services into one department. The Commission also has advocated for greater flexibility and control over service delivery at the local level for decades, with much of this work synthesized into recommendations for an agency-wide restructuring in the Commission's 2004 report: *Real Lives, Real Reforms: Improving Health and Human Services*.

A true continuum of care would start with a client receiving a single assessment of needs as well as a determination of eligibility for a range of services, and then include help in finding the appropriate services, which may change over time. County programs and other local long-term care programs, with their close contact to clients, providers and community groups, are best situated to ensure the care coordination that is necessary for both quality care and for finding the most cost-effective solution to a client's needs. As the Commission heard during its study process, beneficiaries generally choose to receive services in the more cost-effective manner because people largely prefer to stay in their own homes, a far cheaper option for the state than nursing home care.

Coordinating care around the client's needs serves multiple goals, such as improving the quality and accessibility of care for a senior or person with disabilities by connecting them to the appropriate services they need, helping keep people in their homes and out of institutions, decreasing state costs by reducing duplication of assessments and services and reserving nursing home and other institutional options for those whose needs cannot be served in any other way, and providing a vehicle for gathering and sharing information across departments. Systematic care coordination means helping seniors and people with disabilities receive the most appropriate care in a timely way in the most appropriate setting. Done well, it can make for a more satisfied client and a more effective service provider, as well as provide the state with tools that would enhance its ability to understand and manage the system as a whole.

Leadership, Vision and Action

California's long-term care services are administered in programs scattered across seven state departments: Aging, Social Services, Health Care Services, Public Health, Mental Health, Developmental Services and

Rehabilitation. This fragmented organizational structure and lack of a specific leader or entity responsible for long-term care in California leaves the state with a leadership vacuum that complicates any effort to take on comprehensive long-term care reform. The leadership gap also thwarts local efforts to improve the system, as forward-thinking counties seeking to integrate their programs try to obtain state approval for changes find themselves stymied in dealing with the different departments and are left with no one at the state who can facilitate their efforts at the local level.

The state must gain an understanding of how the system looks currently and how it should be improved. Most important to this task is a leader who can take action and follow through in implementing a statewide strategy. A state long-term care leader within the Health and Human Services Agency should create a vision for long-term care in California, have the authority to make decisions and provide direction to department heads regarding long-term care programs, manage efforts to improve the system, and be accountable for outcomes. The long-term care leader would report directly to the Health and Human Services Agency Secretary and would be a liaison and advocate on long-term care vis-à-vis counties, non-profit organizations, state departments, federal agencies and the California Legislature.

Despite the state-level fragmentation and lack of leadership, the Health and Human Services Agency has implemented several key initiatives to advance long-term care in California, such as the California Community Choices project aimed at increasing consumer access to home and community-based long-term care services, Money-Follows-the-person/California Community Transitions program to transition people from nursing facilities to home and a comprehensive analysis of data across multiple home and community-based programs, to name a few. The state has tremendous expertise and experience in the ranks of its program staff whose value can be leveraged through better coordination and leadership.

In the meantime, local jurisdictions such as San Diego, San Francisco and San Mateo are weaving together their long-term care services, despite many state and federal rules that impede true integration. These counties need an ally at the state level who can help them navigate and amend state rules and seek greater federal flexibility that will allow them to reform their systems locally.

These efforts are promising, but need a leader at the state level to ensure they reach their potential and are advanced within a specific and broader vision for long-term care. Equally important: Long-term care reform needs the support of the state Legislature, both in policy and budget development, but in oversight as well.

State Organization

The structure of California's state long-term care programs does not support a system designed around the needs of the person who requires and is eligible to receive care. Nor does it allow for a systematic assessment of expenditures and outcomes. Rather, the system is designed around funding streams tied to state and federal laws that often are unrelated to each other, and programs that were established independently over time in many different departments. The fragmentation of programs reaches from the state down to the county level. California must consolidate its long-term care programs in one place to ensure that it can effectively oversee the management, integration and coordination of locally-delivered services around the consumer.

Since the Commission's 1996 recommendation to consolidate long-term care programs, the *Olmstead* decision mandated that people with disabilities be served in the most community-integrated (non-institutional) setting possible.

Multiple advisory committees and workgroups also recommended consolidation and have presented options for how a new structure could be designed. A key goal of consolidation of long-term care programs under one leader should be to centralize budgeting authority, a starting point for better management as well as greater accountability. The state of Washington's former Assistant Secretary for State Aging and Adult Services Administration, Charles Reed, told the Commission that global budgeting is fundamental if true system reform is to occur as it gives the state the macro-level ability to move funds from one program to another based on patterns of use and emerging needs, as well as the micro-level authority to match care to an individual's needs.

A consolidated structure also allows for data collection that helps policy-makers and program administrators understand the health status of beneficiaries and their needs, service use and trends – all of which are essential when making budget decisions about which programs to cut or how to prioritize spending on the most needy beneficiaries. Consolidation also would improve the state's ability to identify population and cost trends and, given an array of program options, steer scarce funding to the programs that produce the best outcomes. Currently, California departments may be reluctant to share data with other departments, which makes it difficult to collect information that will help policy-makers understand the state's overall distribution of services and resources.

Consolidation also would create the conditions for extending more flexibility and control to local jurisdictions to deliver services along a true continuum of long-term care – with or without realignment.

The state's ultimate goal should be a county-based system in which local decision-makers design the most cost-effective continuum of long-term services that reflect their communities' specific needs. Counties would be equipped with a uniform assessment tool that could detail a client's needs and condition as well as determine eligibility for a range of programs. The evolution necessarily would consolidate and reduce existing state administration of programs and departments serving long-term care consumers.

Recommendation 1: California needs a streamlined and consolidated organizational structure at the state level.

- The Governor and Legislature should consolidate all long-term care programs and funding into a single long-term care entity within the Health and Human Services Agency, led by a long-term care leader reporting directly to the Agency Secretary.
- The long-term care department should retain state-level global budget authority for all long-term care programs and services.
- The long-term care department should serve as the single point of state-level contact to provide leadership to local jurisdictions in sharing and encouraging best practices and to ensure oversight of locally-delivered long-term care services.

Recommendation 2: California must develop a strategy for how to create a seamless continuum of long-term care services.

- The long-term care leader should lead the creation of a vision and strategy for the future of long-term care in California.
- The strategy should incorporate information gathered in the California Community Choices project data warehouse study, the California Medicaid Research Institute/SCAN Foundation study, and other data as it becomes available in order to understand the state's current long-term care programs, determine how to move forward and measure the results of future actions.
- The visioning and strategy-building process must include stakeholders.
- The vision should design a continuum of care that wraps around the individual senior or person with disabilities, gives local jurisdictions the flexibility needed to provide the right care in the right place at the right time, holds these jurisdictions accountable for results and

fosters a culture that regards seniors and people with disabilities as community assets.

- The strategy should list specific actions that will be taken to achieve the vision.

Recommendation 3: California needs a champion to lead development of a coordinated continuum of long-term care services for seniors and people with disabilities.

- The long-term care leader must have the authority and expertise to pull together long-term care data and programs from multiple state departments, initiate better coordination, create the conditions for greater innovation and facilitate integration of long-term care programs at the local level.
- The long-term care leader should annually report to the legislative policy committees about the current status of long-term care in California, the level of state spending across long-term care programs, the progress of improving the continuum of services, and the next steps that must be taken to continue to enhance the coordination and delivery of services.
- The state Health and Human Services Agency should develop the following tools to create a seamless and coordinated continuum of long-term care services:
  - ✓ A single and uniform assessment tool to better manage a client's long-term care needs across programs over time.
  - ✓ Information technology that enables the integration of services virtually, facilitates consumer case management, collects data and provides information to the county and the state to allow for effective management of the system.
- Local jurisdictions must become the single point-of-entry for long-term care services and should have the flexibility to assess needs, coordinate care, connect clients to the services they need and for which they qualify, and be able to help clients transition from program to program as needed.
- The state should provide local jurisdictions the right incentives, flexible funding and program support needed to ensure that local jurisdictions have the framework and resources needed to meet client needs.