Introduction, Purpose and Scope

California has been dealing with a large structural fiscal deficit. The dimensions of the revenue decline grew during the course of the study. The Governor’s January 9, 2009 budget message on the 2009–2010 budget stated that California faces the most challenging budget in its history. The combined effect of the structural deficit and the dramatic decline in revenues due to the international economic crisis have produced a two-year deficit of $65 billion—over half of the state’s projected 2009–2010 revenues.

This report was prepared based on information obtained primarily in 2008. Continuing revenue shortfalls and increasing program caseloads significantly alter the environment on which the report and recommendations were developed. Since the report was submitted for review to state agency staff and members of the Finance Subcommittee of the Project’s Advisory Committee, multiple spending reductions were proposed by the Administration and enacted by the Legislature.

The Amended Budget for FY 2009–2010 eliminates or reduces IHSS services to individuals with the lowest needs. Domestic and related services including housekeeping, meal preparation, food shopping and errands are eliminated for individuals whose needs are assessed at a functional index (FI) rank of 1, 2 or 3. The neediest individuals (with scores of 4 and 5) will continue to receive domestic and related services. This reduction will affect an estimated 97,000 IHSS participants.

The enacted budget for FY 2009–2010 eliminates all IHSS services to an estimated 36,000 recipients with functional index (FI) scores of 1.99 or below. The budget also reduces the State Supplementary Payment (SSP) payment standards to the levels that were in effect in 1983, which is the minimum level permitted by federal law.

Because of the ongoing nature of California’s budget-balancing efforts and reduction implementation, it was not possible to update the program descriptions and expenditures. When the impact of the budget changes is known, we suggest that state officials and stakeholders review the recommendations in the context of the current programs and establish a strategic planning process to guide future policy and funding decisions.

It is clear that California’s revenue outlook will not sustain the level of services currently offered to its residents. The long-term care system needs to change. The institutional bias and complex administrative structure limit opportunities to reduce the growth rate for long-term care spending. While recommendations included in the report require an initial investment, we believe that they will reduce the rate of long-term care spending growth over time. A recent study by Kaye et al. (2009)\(^1\) found that states with well-established HCBS programs had much lower rates of spending growth compared to those with low HCBS spending. High rates of HCBS reduced spending for institutional care. The authors reported a lag of several years before

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\(^1\) Kaye, H., LaPlante, M. & Harrington, C. (January, 2009), *Do Noninstitutional Long-Term Care Services Reduce Medicaid Spending?* Health Affairs, Vol. 28, No. 1 pp. 262-272. An abstract of the article can be found at, retrieved on 1-11-09: [http://content.healthaffairs.org/cgi/content/abstract/28/1/262](http://content.healthaffairs.org/cgi/content/abstract/28/1/262).
institutional spending appeared to decline. California is considered an “expanding HCBS state” for services to older adults and individuals with disabilities and must continue to invest in HCBS to become a well-established HCBS state for individuals with developmental disabilities. The data used for the study do not include spending for targeted case management and personal care services covered by the In-Home Supportive Services Program for individuals with developmental disabilities.

**California Community Choices**

The California Health and Human Services Agency (CHHS) received a Systems Transformation Grant from the Centers for Medicare & Medicaid Services (CMS) in 2006. The grant supports the California Community Choices project (http://communitychoices.info), which is dedicated to increasing consumer access to home and community-based long-term care services and diverting persons with disabilities and older adults from unnecessary institutionalization through development of California’s long-term care services and supports infrastructure. The Choices project includes a financing study of the state’s long-term services and supports that examines the laws, regulations, policies and payment methodologies related to long-term care financing in California. The study was initiated to improve the state’s understanding of the financial and structural barriers to increasing consumer access to home and community-based services and to provide recommendations that enable the state to more effectively manage the funding for long-term care supports that promote community living options.

The study was conducted by Robert Mollica, Senior Program Director at the National Academy for State Health Policy, and Leslie Hendrickson, Hendrickson Development.

**Methodology**

The project team obtained information about long-term care services and programs from interviews with state officials and stakeholders, public forums and a review of statutes, regulations, documents and data provided by state officials. During three site visits, we interviewed staff from CHHS, the Departments of Health Care Services, Aging, Social Services, Developmental Disabilities and Mental Health, as well as staff in the Department of Finance and the Legislative Analyst’s Office.

The Community Choices Project has an advisory committee and three subcommittees. The Financing Subcommittee provided guidance and feedback on the study during discussions at quarterly meetings and regular conference calls.

The study focused primarily on state and federal funding sources of long-term care services including IHSS, Medi-Cal home and community-based services waiver programs, ADHC, developmental services and nursing facilities. The report does not include services funded by the Older Americans Act and briefly describes services from the Department of Mental Health.

We reviewed multiple studies and materials. The reports are included in Appendix A. For example, the reports included studies such as the May 2004 *Planning for an Aging California Population: Preparing for the “Aging Baby Boomers,”* which was prepared by a Strategic
Planning Advisory Committee formed by Assemblywoman Patty Berg. The focus of this report was broader than long-term care and identified a range of issues in health care, housing, transportation, employment, finance and retirement, wellness, workforce, financial abuse and long-term supports. Concerning long-term supports, the report concluded that California needed “policies and funding streams that promote non-institutional caregiving and creative community-based long-term care arrangements.” The report identified guiding principles and a series of key questions that need to be addressed but did not describe a plan for addressing them.

**Organization of the Report**

The report is organized by section.

- **Section 1** presents an overview of long-term care services in California.
- **Section 2** provides demographic data and estimates of the number of persons with disabilities in California.
- **Section 3** describes program trends and includes descriptions of each home and community-based services program, caseload trends, expenditure data and other information.
- **Section 4** describes services for persons with developmental disabilities.
- **Section 5** discusses mental health services.
- **Section 6** presents nursing facility supply and utilization information. It also compares historical spending for institutional care and home and community-based services.
- **Section 7** describes nursing facility reimbursement and rate setting issues.
- **Section 8** analyzes HCBS rate setting issues, cost avoidance and cost-effectiveness.
- **Section 9** reviews fiscal incentives.
- **Section 10** discusses community transition initiatives.
- **Section 11** presents stakeholder feedback obtained through forums and an electronic survey.
- **Section 12** presents the findings from the report.
- **Section 13** describes the recommendations.

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Section 1: Overview

Long-term care covers institutional, residential, community and in-home services for persons of all ages with functional, cognitive or developmental disabilities. Medicaid is the primary payer for long-term care. Over 10 million persons in the U.S., about 5% of the total adult population, need assistance with activities of daily living (ADLs) such as bathing, dressing, eating, toileting and mobility and instrumental activities of daily living (IADLs) such as meal preparation, housekeeping, laundry, shopping, money management and transportation. 58% of those who receive services are age 65 or older and 42% are age 64 and younger. Medicaid paid for 40% of all long-term care expenditures in 2006. In 2007, Medicaid spent $101 billion on long-term care for institutional and community services and spending for Home and Community-Based Services (HCBS) to older adults by programs funded totally by state general revenues added another $1.2 billion.

California has an array of programs and services for individuals with disabilities. The programs are located in multiple agencies, use different delivery systems and challenge consumers, family members, advocates and providers seeking to access and coordinate services. Previous reports on long-term care programs consistently concluded that programs operate in separate “silos” which create “fragmentation” and barriers to obtaining information and access to services, and that needed program services are not available statewide.

California spends more than $10 billion annually on long-term care and the majority of the funds pay for services in the community. The state provides extensive funding for home and community-based services. Over half of Medi-Cal long-term services spending pays for home and community-based services compared to the national average of 39%. Beneficiaries that receive long-term care services incur high costs. Persons with disabilities and older adults comprise 24% of all Medicaid enrollees, yet they account for 70% of Medicaid expenditures. Nationally, long-term care services account for 75% of the total expenditures and acute care services—physician, lab, x-ray, inpatient care and therapies—account for 25% of the total expenditures for persons using long-term care. Yet the programs that cover the services for adults with physical disabilities and older adults appear to function independently, with separate delivery systems and management structures. Responsibilities for setting policy and managing programs are spread across multiple agencies.

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6 The comparison of California institutional vs. home and community spending is presented later in the report. See the section titled Nursing Home Trends.
The California Department of Aging (CDA) manages the Multipurpose Senior Services Program (MSSP), certifies Adult Day Health Care (ADHC) providers, contracts for Aging and Disability Resource Connection (ADRC) programs and manages the Older Americans Act and the Older Californians Act programs.

The Department of Social Services (DSS) manages the In-Home Supportive Services (IHSS) Program, the nation’s largest program providing supportive personal care services in residential settings.

The Department of Health Care Services (DHCS) manages nursing facility policy, three 1915(c) Waiver programs: nursing facility/acute hospital (NF/AH), In-Home Operations (IHO) and Assisted Living Waiver (ALW), plus the ADHC Program, the Program of All-Inclusive Care for the Elderly (PACE) and the Money Follows the Person (MFP) Rebalancing Demonstration.

The Department of Public Health manages the Acquired Immune Deficiency Syndrome (AIDS) Waiver program and licenses nursing facilities, intermediate care facility services for the developmentally disabled (ICF-DD) and ADHC Centers.

The Department of Rehabilitation (DOR) contracts with Independent Living Centers (ILCs) for nursing facility transition, and The Department of Developmental Services (DDS) manages institutional and community services for persons with developmental disabilities.

Unlike services for persons with developmental disabilities, programs for older adults and individuals with physical disabilities are administered by multiple organizations at the local or regional level. The absence of a consolidated organization (or single entry point), a unified database, and management structure means that consumers often cannot contact a single entity to receive information about their options, assess their service needs and access the appropriate service(s). Instead, consumers must contact different organizations for each program.
The California Community Choices project and the CDA are developing ADRCs to address the fragmentation. ADRCs provide information about the range of programs, services and eligibility requirements to help consumers make informed decisions. Where an ADRC also administers long-term care programs, access to community services is expedited.

Based in local communities, ADRCs will develop and implement consumer-centered, coordinated entry points to the long-term care support system for older adults, persons with disabilities and caregivers. They will support health and long-term care professionals and service providers who need information about available services and supports.

Four new regional ADRCs were operational in 2008. The first two, in Orange and Riverside counties, were awarded contracts under the Community Choices Project. Two additional ADRCs (one serving five north central rural counties and the other serving San Francisco County) were launched in Spring 2008 with funding from CDA. The two original ADRCs are located in San Diego and Del Norte counties, funded by CDA.

**Strategic Plan**

California does not have a strategic plan for long-term care that crosses state agencies. The DHCS developed a department-wide strategic and implementation plan in 2008 that includes long-term care components. The plan describes the following California Health and Human Services Agency (CHHS) goal that guides DHCS’ role: “disabled and aged Californians will have the opportunity to live in their own homes and communities (rather than institutional settings) in the most integrated setting possible.” The plan describes DHCS core values that include:

- We provide community-based care alternatives to promote choice.
- We develop and implement care options to address the continuum of care needs from home care through hospital and skilled nursing care and adult day health care. We respect individuals’ autonomy and self-determination.

The plan’s goals and objectives are broad and apply to the full range of DHCS services and activities. The implementation plan includes seven actions designed to provide care in settings that promote community integration. The actions cover programs for which DHCS is responsible.

The plan proposed to:

- Provide HCBS through waivers and demonstration projects, allowing individuals to remain in their homes and promoting community integration
  - Establish additional sites for PACE

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9 Available at: [http://www.dhcs.ca.gov/Pages/DHCSStrategicPlanandImplementationPlan.aspx](http://www.dhcs.ca.gov/Pages/DHCSStrategicPlanandImplementationPlan.aspx).
- Maintain and evaluate operations for the AIDS Waiver
- Maximize the effectiveness of the NF/AH Waiver by ensuring ongoing state budget neutrality requirements are met and federal flexibilities (i.e. the Deficit Reduction Act HCBS State Plan Option) are maximized
- Develop a 1915(c) Self-Directed Services Waiver for individuals with developmental disabilities
- Maintain waiver operations for the MSSP
- Maintain waiver operations for the IHSS Plus Program and assess the feasibility of converting the waiver to a 1915(j) HCBS State Plan Option
- Fully implement the Assisted Living Waiver Pilot Project in the three selected counties
- Restructure the ADHC Benefit to comply with federal policy
  - Ensure provision of health care services to former consumers of Agnews Developmental Center who have moved into community homes (in collaboration with DDS, Bay Area regional centers and three Medi-Cal managed care health plans)
- In collaboration with the City and County of San Francisco, develop a program to provide community-living support benefits to Medi-Cal beneficiaries who reside in San Francisco
- Implement the MFP Rebalancing Demonstration
- Develop and implement the California Pathways Real Choice Systems Change Grant to develop and field test an assessment and transition protocol (known as the Preference Interview Tool) for nursing facility residents who choose to transition to community placement
- Provide oversight, monitoring and technical assistance to schools that provide assessments and direct health services to special education students