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Policy Brief Number 2

Framework for Discussion: A Review of Long-Term Care Programs in California

Deborah Reidy Kelch, M.P.P.A.

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I. Introduction

Many people think of nursing home care for a disabled elderly person when they hear the term "long-term care." Long-term care (LTC) actually includes a wide range of services provided to people of all ages with physical and mental disabilities.

The majority of long-term care assistance continues to be provided informally by family members and friends. The U.S General Accounting office found that approximately 64 percent of all older persons with a disability rely exclusively on unpaid care from family or other informal caregivers; even among elderly persons with severe limitations in their ability to perform daily activities, about 41 percent relied entirely on unpaid care.[1] Nearly one out of every four households (23 percent or 22.4 million households nationally) is involved in caregiving for individuals aged 50 or over.[2] Most people - nearly 79 percent - who need LTC live at home or in community settings, not in institutions.[3] In recent decades, nursing home utilization rates nationally and in California actually declined, especially among persons 75 years of age and older.[4]

The overwhelming preference of older adults and persons with disabilities is to remain in their own homes and communities. When families are not available, or are stretched to the limit in helping to care for their loved ones with disabilities and multiple chronic illnesses, health and social support services can help people stay at home and avoid institutional placement. Over the last two decades, California has done a good job of creating an array of innovative community service programs – including licensed adult day care programs, in-home care programs, and programs to help individuals and families manage their care.

However, these proven programs have yet to be reproduced on a comprehensive statewide basis or fully funded to adequately serve every community in the state. Some programs were developed as so-called "alternatives" to nursing homes, and receive funding only through state and federal waivers or exceptions. Public funding of long-term care continues to emphasize institutional placement, with the largest share of government funding in the form of Medi-Cal reimbursement for nursing homes.

Moreover, most Californians are completely unaware of the services and programs that are available to help them meet their LTC needs and assist them in caring for elderly and disabled loved ones. In many California communities, individuals and families looking for long-term care assistance are left to pull together the services they need on their own. To do so, they must find and connect with multiple agencies. They may endure repeated assessments of their physical, mental and social status. They may be asked to complete multiple financial and program eligibility forms. In many cases, they will find limited or no services available. (See box – Unraveling the Bureaucracy, on page 6.)

Evaluating a Fragmented System

It is not clear if the funds allocated for long-term care are always used in the most responsive and cost-effective manner. There is no real system or consistent organization at the state or local level. Publicly funded services are offered through numerous State and local agencies, each with different programs, eligibility criteria, target populations and funding sources. The State lacks good information across programs and departments on the services being provided, the individuals being served or the results of the services delivered. There is little accountability.

Stakeholders confront conflicting and overlapping State and federal laws, entrenched bureaucracies and fragmented policymaking. The system has seemed resistant to fundamental improvements. Multiple academic analyses and reports, repeated legislatively mandated studies outlining options for improved system integration, and numerous task forces, summits and public hearings have produced little more than hand wringing about the system deficiencies, and a series of short-lived "jump starts" toward reform.

Much of the progress in LTC coordination and collaboration has occurred at the local level where government and private agencies work together to make services more "user-friendly." In many communities, they are working together, despite the categorical approach of state and federal funding and program administration.

Much of the progress made in long-term care coordination and collaboration has occurred at the local level where government and private agencies work together to make services more "user-friendly" … despite the categorical approach of state and federal funding and program administration.

At the same time, California, like the rest of the country, is facing exponential growth in the population that most uses long-term care services, older adults. The number of Californians over 60 will nearly double from 4.9 million in 2000 to 9 million in 2020.[5] The oldest old age group, those 85 and over, and most likely to need long-term care support, is increasing at an even faster rate, with an overall increase of 143 percent expected during the period from 1990 to 2020.

California is ill prepared to meet the needs of the growing numbers of seniors and others who will need long-term care services. There are not enough services. There has been too little planning. The oversight agencies, regulations and requirements often frustrate the ability of providers to meet the individualized needs of their clients. As California faces the combined challenges of a growing demand for services, and increasing constraints on government financing, long-term care policy is at a critical juncture.

This policy brief is intended to provide a framework for discussion on the future of long-term care services in California. It identifies the agencies involved, highlights some recent trends and policy developments and offers some policy options. It does not include a complete inventory of all long-term care programs, current activities and statutory requirements. The goal is to initiate and inform a conversation among stakeholders and policymakers about how to create a more responsive, efficient and consumer-oriented long-term care system.

II. Background

This section provides an overview of long-term care and a profile of those who need long-term care assistance and support.

What is Long-Term Care?

Long-term care is generally distinct from basic medical care, health maintenance and preventive health services. Rather than focusing on diagnosing, curing or treating illness, long-term care services are aimed at helping individuals with limited self-care abilities reach and maintain their highest functioning level. To that end, long-term care may include medical, rehabilitative, social, personal, supportive and housing assistance services.

Long-term care services are delivered by a variety of providers (health professionals, trained workers, family and friends) in a number of different settings (licensed health facilities, community settings and individual homes) for persons of all ages with disabilities who need ongoing care and assistance because of chronic conditions. [6]

Long-term care services fall along a continuum, ranging from limited assistance at home to full-time institutional placement. Out-of-home 24-hour care options include licensed nursing facilities, commonly referred to as nursing homes, as well as licensed residential facilities, which may also be called residential care, community care facilities, assisted living or board and care. Home and community-based services, generally less than 24-hours, are provided in an individual's home or other community setting and may include:

- Personal care, homemaker and chore assistance (In-Home Supportive Services);
- Home health and hospice services;
- Adult day programs, offering a spectrum of therapeutic services, meals and transportation;
- Home-delivered meals;
- Transportation assistance;
- Respite care, substitute care to relieve family caregivers, in the home, community day programs or short-stays in 24-hour facilities; and

- Care planning and care coordination, including assessment by professionals and linkage to appropriate community programs and services.

Who Needs Long Term Care?

The population in need of long-term care is extremely diverse, requiring a wide range of services and delivery options. Individuals generally need long-term care assistance if they have difficulty independently performing daily activities of living such as eating, bathing, and toileting and may also need help with "instrumental activities of daily living" such as meal preparation, shopping, and taking medications.

The need for assistance may result from physical or mental disability, developmental disability, chronic illness, severe injury, or any decrease in mobility or cognitive functioning. Individuals may need long-term care because of a mental impairment, such as Alzheimer's Disease, that necessitates supervision to avoid harm to themselves or others, or may require assistance with daily tasks such as taking medications.

The long-term care population is often divided into three distinct groups: frail elderly persons, non-elderly adults with disabilities and children with developmental and other disabling conditions requiring long-term care services.[7]

An estimated 1.2 million Californians not in institutions may be in need of long-term care assistance.

Since chronic illnesses and other physical and mental impairments increase with age, older adults use a high proportion of long-term care services.[8] Approximately 84 percent of the 108,000 residents of California nursing homes in 2000 were age 65 and over.[9] The most recent figures available from the national Survey of Income and Program Participation (SIPP) revealed that approximately 16 percent of non-institutionalized persons 65 and over need personal assistance with activities of daily living or instrumental activities of daily living.[10] In 2000, that would be an estimated 576,000 older Californians.[11] Among individuals 80 and over, sometimes referred to as the frail elderly, the number needing personal assistance rose to 33 percent.

There are also a significant number of adults under 65 and children who may need long-term care services. The SIPP showed that approximately 2 percent of those between the ages of 15 and 64 needed personal assistance with activities of daily living or instrumental activities of daily living.[12] In 2000, that would be an estimated 450,000 Californians. The same survey found that approximately 6 percent of children 6-14 needed similar personal assistance, or approximately 106,000 California children. In addition, approximately 4 percent of children

under 5 (99,479 California children) have a developmental delay and/or or difficulty in their basic activities, such as running and playing.

Based on these estimates, an estimated 1.2 million Californians not in institutions may be in need of long-term care support and assistance.

III. Long-Term Care Agencies and Organizations

Long-term care services are funded, administered and regulated by multiple federal, state and local agencies. Each program has distinct eligibility requirements, financing mechanisms and statutory mandates. This section provides an overview of the agencies and departments at each level and their respective responsibilities.

Federal Agencies Involved in Long-Term Care

The *U.S. Department of Health and Human Services (DHHS)* is the principle federal agency responsible for health and human services, including long-term care services, and is the largest grant-making agency of the federal government. Within DHHS, two agencies have responsibilities related to long-term care.

Administration on Aging (AoA) administers the federal Older Americans Act (OAA), which provides funding for an array of community services for persons 60 and over through mandatory state units on aging that, in turn, allocate the funds to local area agencies on aging. AoA also administers the new National Family Caregiver Support Program discussed in more detail in Section IV.

Centers for Medicare and Medicaid Services (CMS) administer the Medicare and Medicaid programs – federal programs that pay for health care services for eligible persons. *Medicare* provides health coverage for persons 65 and over and some persons with disabilities, regardless of income. Medicare generally does not cover long-term care services, except for limited nursing homes, limited home health and hospice. *Medicaid* (Medi-Cal in California) is the largest source of funding for long-term care services, providing coverage for low-income persons and those who become eligible after spending down their resources paying for long-term care. States have significant discretion on the benefits covered and may also apply for federal waivers to use Medicaid funds in nontraditional ways to serve individuals outside of institutions. CMS also coordinates state licensing and certification of health facilities, including long-term care facilities.

Unraveling the Bureaucracy… How the Consumer Experiences It

Here is just one scenario of what a person might experience, *based on actual calls made in one large California county in February 2003*.

Mrs. Jones is an 80-year old widow who lives alone in her home of 40 years. She has been able to take care of herself, but is getting frailer. Her one adult daughter lives two hours away by car. Mrs. Jones takes 6 medications every day. She is receiving SSI/SSP, Medi-Cal and Medicare.

Mrs. Jones' 76-year old neighbor finds her, weak and disoriented. She calls 911 and Mrs. Jones is hospitalized. The doctors find she has a toxic build-up of one of her medications. After a few days, she is stable and ready to be released. The whole experience has left Mrs. Jones a bit weaker and she seems to tire more easily. She can get around, but everyone wonders if she will be safe at home. Mrs. Jones pleads to be able to go home. The doctor's office contacts a local home health agency to schedule a follow-up visit and the daughter agrees to come every evening after work. The neighbor agrees to stop by a few times a day.

The home health agency calls the day after Mrs. Jones is released and sets a time to come the next day. A nurse will assess her condition, and under federal Medicare rules, set a care plan for brief home nursing visits. When the daughter arrives the first night, she finds her mother has not eaten. Mrs. Jones says she was too tired and did not want to bother the neighbor. After searching the local phone book, the daughter finds a Senior Citizens Information and Referral (I & R) number in the white pages.

The I & R worker gives the daughter phone numbers for 4 local agencies. The local Meals on Wheels program delivers hot meals to people 60 and over. When the daughter calls, she finds there is currently a 2-year waiting list for meals. She is told when her mother nears the top of the list; they will do a telephone assessment. The county In-Home Supportive Services (IHSS) program could help with light housekeeping, meals and personal services. When the daughter calls, she is told there is a waiting list and it may take several months for a social worker to come out and assess Mrs. Jones' disability status and eligibility. To help with transportation to medical appointments and other errands, she calls the local dial-a-ride program. The transportation agency tells her that she must make reservations 2 days in advance and cannot combine trips for a medical appointment, to get prescriptions or to run another errand.

Mrs. Jones' daughter finds out that the state will pay the full cost of nursing home care under the Medi-Cal program, if she can find a Medi-Cal bed. She also knows her mother would be devastated to leave her home and is not really bedridden. If Mrs. Jones went to a board and care, or assisted living facility, the SSI/SSP grant would go up. After several calls, the daughter cannot find a facility that will accept the SSI/SSP grant. The daughter drives four hour round trip several times a week to check on her mother. She is getting increasingly tired and stressed. Her boss is frustrated with all the time she spends on the phone. She does not know what to do.

What it Means. If Mrs. Jones had been fortunate to be in a community without such long waiting lists, she might have received services from at least five different agencies paid for by different federal, state and local funding streams. Each would have independently assessed her status and collected information about her that would be entered in different data systems, or left uncollected in a handwritten file. If Mrs. Jones had a little bit higher income, she would not even be eligible for some of the programs above.

Now imagine Mrs. Jones has no adult children or other available family members.

State Agencies Involved in Long-Term Care

The *California Health and Human Services Agency (CHHSA)* administers state and federal health and social services through 15 boards and departments. The CHHSA has statutory responsibility to convene and organize the newly created Long-Term Care Council, an interdepartmental council charged with improving coordination and integration of long-term care programs across CHHSA. Long-term care services and programs fall under the jurisdiction of the CHHSA and are administered by the multiple state departments listed below.

CHHSA agencies most involved in long-term care service delivery are the California Department of Aging, the California Department of Health Services and the California Department of Social Services. The Legislature has designated CDA, the smallest of the three in terms of funding and staffing, with the statutory responsibility to improve and enhance the coordination and development of home and community-based services for the frail elderly and functionally impaired adults. The new LTC Council is recognition, in part, that effective coordination and system improvement will necessarily involve collaboration and planning by all of the affected agencies, not just the CDA.

California Department of Aging (CDA) is the designated state agency on aging and administers Older Americans Act (OAA) funds through local area agencies on aging (AAAs). Federal law requires the designation of a state unit on aging and local AAAs to administer OAA programs. OAA-funded LTC services include senior meals programs, including home-delivered meals; supportive services, such as transportation, case management, handyman, chore and personal care services; and the long-term care ombudsman programs that investigate and resolve complaints made by or for residents of nursing facilities and residential care facilities. In addition to OAA funds, CDA has state-level responsibility for a number of local long-term care programs and services for the elderly and adults with disabilities, including specialized day care and case management programs, and the new Family Caregiver Support Program.

California Department of Health Services (DHS) has multiple responsibilities related to long-term care.

- **Medi-Cal.** DHS administers the Medicaid program (Medi-Cal in California) and fulfills the federal requirement to have one single state agency responsible for Medicaid programs. Medi-Cal is the largest funding source for long-term care services. Medi-Cal covers LTC services for eligible low-income persons and those who have exhausted financial resources paying for LTC. Medi-Cal covers nursing home care, in-home supportive services, limited home health, hospice, and adult day health services. In addition, the state has five federal Medicaid waivers to provide home and community-based services as alternatives to institutional placement for specific target populations on Medi-Cal.

- **LTC Facility Licensure**. DHS also licenses and certifies (approves for participation in Medicare and Medi-Cal) long-term care facilities including nursing and intermediate care facilities, home health agencies and adult day health care facilities.
- **Office of Long-Term Care**. The Office of Long-Term Care is responsible to provide leadership and a public focal point for long term care projects within the DHS, and administers several special long-term care programs and initiatives. These programs include the LTC Integration Pilot Projects, the Program of All Inclusive Care for the Elderly (PACE) and the Social HMO program, which are discussed in Section IV.
- **Alzheimer's Research and Support Services**. The Alzheimer's Disease Program within DHS administers ten Alzheimer's Disease Research Centers at university medical centers throughout California. In addition to research, the centers provide comprehensive assessments and evaluations of persons with memory loss, family conferences and support groups, information and referral services and training and education.

California Department of Social Services (CDSS) has four program areas related to long-term care.

- **IHSS.** CDSS administers through county welfare departments the In-Home Supportive Services Program (IHSS), which provides personal care and homemaker services to low-income persons with disabilities in their home setting. IHSS is primarily funded with Medi-Cal funds but the state maintains a "residual" state-funded program that allows recipients to select a family member as caregiver, which is not allowable under federal Medicaid rules.
- **Community Care Facility Licensure**. The Community Care Licensing (CCL) program regulates community and residential care facilities, including residential care facilities for the elderly (RCFEs) and social model adult day care programs. In addition, CCL has primary responsibility for oversight of Continuing Care Retirement Communities (CCRCs). CCRCs are licensed RCFEs offering long-term contracts, sometimes referred to as life care contracts, that represent a promise to provide services for a year or more.
- **SSI/SSP Out-of-Home Care**. CDSS administers the Supplementary Security Income/State Supplemental Program (SSI/SSP), which provides cash assistance to low-income aged, blind and disabled persons. California also participates in the optional program to provide a somewhat higher grant level for SSI/SSP recipients who reside in a licensed community care facility or RCFE (referred to as the non-medical out-of-home care program).
- **Adult Protective Services (APS)**. CDSS administers through county welfare departments the Adult Protective Services (APS) program, which provides assistance to elderly and dependent adults who are victims of abuse or neglect.

Several other state agencies are involved in long-term care service delivery to meet specialized service needs or provide services to specialized populations.

Department of Developmental Services (DDS) provides services and supports for over 155,000 children and adults with developmental disabilities. These services are provided through state-operated developmental centers and contracts with twenty-one nonprofit agencies known as regional centers. The five state-run developmental centers are licensed as acute care hospitals, with licensed nursing and intermediate care facility units, and provide services to individuals who require programs, training, care, treatment and supervision in a structured health facility setting on a 24-hour basis. In general, to be eligible for DDS services, individuals must have a developmental disability that began before their 18th birthday and is expected to continue indefinitely.

Department of Mental Health (DMH) administers local mental health services through county mental health departments, and operates four state hospitals for the mentally ill. DMH also funds and administers the 11 non-profit Caregiver Resource Centers, which provide a wide range of regionally-based services to support and assist families and caregivers who care for adults with cognitive impairments (e.g., Alzheimer's disease, stroke, traumatic brain injury).

Department of Rehabilitation (DOR) is charged with assisting Californians with disabilities obtain and retain employment and maximize their ability to live independently. DOR funds the 29 Independent Living Centers (ILCs),* which are nonprofit, consumer-directed, local agencies that assist indivduals with disabilities to live independently in the community.

Office of Statewide Health Planning and Development (OSHPD) does not operate direct service programs but collects and disperses financial, utilization and patient discharge data from hospitals, home health agencies, clinics, and nursing homes. OSHPD also administers the Cal-Mortgage loan insurance program for nonprofit health facilities and enforces California Building Code standards for hospitals and long-term care facilities.

Local Agencies Involved in Long-Term Care

At the local level, multiple agencies implement state and federal laws and administer long-term care programs.

Area Agencies on Aging (AAAs) are the designated local agencies that administer OAA funds in 33 local Planning and Services Areas (PSAs) – some are county agencies, some are joint powers agencies and some counties contract with nonprofit agencies to serve as the AAA. Area agencies receive

* California was home to the first Independent Living Center in the early 1970s, and there are currently ILCs in virtually every state and territory.

federal, state, and local funds to contract with community organizations for services or to provide the services directly. In addition to OAA funds, AAAs receive state funds to contract for specific long-term care services and programs such as the Linkages care management program and Alzheimer's Day Care Resource Centers.

County welfare departments administer the IHSS and APS programs and determine eligibility for Medi-Cal. In approximately one-third of PSAs in California, the AAA and the county welfare departments are integrated as a single county agency.

County health and mental health departments administer services and programs that may provide long-term care assistance to disabled and elderly persons. For example, some counties have public health nurse case management and home visiting programs, which include services to homebound disabled persons.

Regional centers for the developmentally disabled are nonprofit, private corporations, with 21 offices throughout California, serving as a local resource to help find and access the services available to individuals with developmental disabilities and their families.

Independent Living Centers (ILCs) are consumer controlled, community based, private, nonprofit agencies designed and operated within each local community by individuals with disabilities. Independent living services work to maximize a person's ability to live independently in the environment of their own choosing. ILCs offer information and referral services, housing assistance, skills training, peer counseling, advocacy and advocacy training and other services geared toward empowering individuals with disabilities to live active, independent lives.

California has made some progress in developing a more comprehensive set of services that allow individuals to remain at home.

Nonprofit agencies and other providers deliver an array of long-term care services in local communities, either independently or under contract with specific state and local agencies.

Appendix A provides an overview of long-term care services and programs.

IV. Policy Trends and Developments

Although the bulk of funds spent for long-term care continue to be spent on nursing homes, California has made some progress in developing a more comprehensive set of services that allow individuals to remain at home. In recent years, policymakers have shown greater interest in exploring options for improved service delivery and increasing funding for home and community-based services. At the same time, policymakers continue to focus on quality of care issues and effective regulation of care providers, particularly nursing home care providers. This section provides an overview of some of the most recent LTC policy developments.

Planning and System Development

Since the mid 1990s, the California Legislature has mandated several planning and system review activities to improve integration and collaboration among long-term care agencies at the state and local levels. Developments in recent years include:

Planning for System Integration: Options for A New LTC Structure. In a comprehensive 1996 report on California's LTC system, the independent Little Hoover Commission found that long-term care oversight in California is "not conducive to a coordinated continuum of care and fails to focus state efforts on consumer-centered, least-restrictive, best-value services."[13] The Commission recommended the consolidation of LTC programs into a single department. The Commission cited the opportunity to streamline program administration and reduce consumer confusion, while moving toward a more effective and coordinated system with common tools and centralized information and referral.

The Legislature followed-up by requiring the CHHSA to develop an inventory of long-term care programs; options for the integration of key programs administered by different state departments; options for integrating licensure functions for long-term care facilities, including skilled nursing and residential care facilities; and a timetable for implementation of these options (AB 1215 - Mazzoni, Chapter 269, Statutes of 1997). The subsequent report to the Legislature in 1999 identified three options to improve administration of LTC programs: (1) partial consolidation of LTC services, such as Medi-Cal and waiver programs; (2) comprehensive consolidation of the major state programs serving older adults and people with disabilities; and (3) an agency level coordinating body including directors of state departments involved in LTC service delivery.[14]

Mandating State-Level Coordination: the Long-Term Care Council. In 1999, the Legislature mandated that all directors of CHHSA departments with responsibilities related to long-term care meet at least quarterly in a public forum (AB 452 -Mazzoni, Chapter 895 of 1999). The CHHSA implemented the bill by

forming the LTC Council, which is comprised of the department directors and their key staff. The Council is charged with promoting coordinated LTC planning and policy development, developing strategies to improve consumer information on state long-term care programs and reviewing and making recommendations related to budget changes in LTC programs. The Council is also required to report to the Legislature annually on its progress and released progress reports in 2001 and 2002.

The Council established five working groups, including departmental representatives and key external stakeholders: (1) Consumer Information, (2) Coordinating Community LTC Services, (3) NF Assessment and Transition Pilot, (4) Facility and Services Licensure, and (5) LTC Data. Each of the work groups met and involved external stakeholders in developing recommendations to the Council. The work group reports are still pending Council review and action.

Planning for the Age Wave: the Strategic Plan on Aging. In 1999, the Legislature mandated that the CHHSA develop a strategic plan on aging by July 2003 (SB 910 - Vasconcellos, Chapter 948, Statutes of 1999). The legislation required the University of California to conduct a survey of existing resources and to identify demographic trends and potential service gaps. The UC completed its report in early 2001. The project, and the UC analysis, focus exclusively on older Californians across a broad spectrum of issues including economic well-being, work and retirement, housing, transportation, health status, mental health status, long-term care, residential care, family caregiving and successful aging.[15] The CHHSA is currently in the process of convening stakeholders to assist in completion of the final report, but is struggling to identify staff and resources that will support development of the actual strategic plan.

Planning for Mental Health Services: the Alzheimer's Strategic Plan. In 2001, the Legislature required the CHHSA to develop, through an interagency process, by January 2003, a strategic plan for improving access to mental health services for persons with Alzheimer's and related dementias (SB 639 - Ortiz, Chapter 692, Statutes of 2001). The CHHSA conducted a structured survey of stakeholders by phone and e-mail to identify key issues and held four task force meetings involving stakeholders in the report's preparation. The report, which reportedly includes history and background on existing programs, barriers facing Alzheimer's patients and families and recommendations to overcome those barriers, is currently pending final approval in the Administration.

Planning for Legal Compliance: The Olmstead Planning Process. In 1999, the United States Supreme Court, in *Olmstead v. L.C*., *119 S.Ct. 2176 (1999)* ruled that unnecessary segregation of people with disabilities into institutions is a form of discrimination in violation of the Americans with Disabilities Act (ADA). This landmark ruling touched off a wave of state and federal activity to determine the impact on state long-term care programs and services. Olmstead requires that people with disabilities receive services in community settings rather than

The Olmstead Decision – The New Paradigm of Patient Choice

The Olmstead legal case *[Olmstead v. L.C., 119 S.Ct. 2176 (1999)]* was initiated by two Georgia women who are disabled by mental retardation and mental illness. At the time that the suit was brought, both plaintiffs lived in state-run institutions, despite the fact that their treatment professionals had determined that they could be appropriately served in a community setting. The plaintiffs asserted that continued institutionalization was a violation of their right to live in the most integrated setting appropriate under the Americans with Disabilities Act (ADA).

The Olmstead decision was based on interpretation of Title II of the ADA, and its implementing regulation, which oblige states to administer their services, programs and activities "in the most integrated setting appropriate to the needs of qualified individuals with disabilities." The Court stated directly that: "Unjustified isolation… is properly regarded as discrimination based on disability." And further that, "institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life and "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contracts, work options, economic independence, educational advancement, and cultural enrichment."

Source: *Olmstead Update No: 2. Letter to State Medicaid Directors*. Centers for Medicare and Medicaid Services. July 25, 2000. Available on-line at http://www.cms.hhs.gov.

institutions when: (1) the person prefers or does not oppose community services, (2) professionals determine that community services could be appropriately provided, and (3) the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others who are receiving state-supported disability services.[16]

The LTC Council conducted public forums related to Olmstead planning in 2000 and concluded that a written plan should be prepared. The 2002-03 state Budget required the Council to develop a plan by April 2003. Recently enacted state legislation also requires the Council to assess the availability and the gaps in home- and community-based services as part of the planning process (SB 953 – Vasconcellos, Chapter 541, Statutes of 2002). Issues the Council is focusing on for Olmstead planning purposes include: relevant program waiting lists, existing assessments that identify consumer service needs and effective consumer information and assistance programs to ensure that individuals understand their options and the community services available to them.

Infrastructure and Program Development

California has been gradually developing innovative programs focused on keeping individuals out of institutional settings and, until the state budget crisis, had provided funding for additional programs and services after a long period of status quo funding.

At the same time, the lack of integration and collaboration at the state level is mirrored in many local communities where diverse agencies administer state and federal long-term care services and funding. Several recent initiatives have attempted to improve and resolve these conflicts in local service delivery.

This section highlights some of the most recent innovations, initiatives and program expansions in California.

Empowering Area Agencies on Aging. In 1996, the Mello-Granlund Older Californians Act (OCA) updated California's enabling legislation for aging programs and affirmed the statewide goal of strengthening and expanding home and community-based services (AB 2800 (Granlund), Chapter 1097, Statutes of 1996).

Among other things, the new OCA transferred program management of key aging programs to the local area agencies on aging. Prior to passage of AB 2800, CDA directly funded and contracted with programs in local communities, often without coordinating their activities with the local AAA. According to the legislative history of AB 2800, local management of the programs was expected to enhance development of home and community-based services by giving the AAAs more flexibility, local control and involvement in the development of such programs in their local communities.

In 1998-99, following the restructuring of programs administered by the CDA, the state budget allocated additional funding to ensure that CDA-administered long-term care and supportive programs were available in each of the 33 planning and service areas (AAAs) in California.

The Aging with Dignity Initiative. In 2000, the Governor's Aging with Dignity Initiative included expansion of home and community-based services, as well as increased funding and quality improvement strategies for nursing homes. Additional details can be found in the section on Quality and Accountability. The initiative included:

- **Long-term care Innovation Grants.** Allocated **$**14.2 million in one-time funding for "innovative models" of long-term care service delivery and activity. The project permitted diverse applicants, both public and private agencies, to come forward with their unique and potentially promising ideas for innovation in

LTC. The CDA awarded and administered grants through the end of state fiscal year 2001-02. Grants awarded, included, for example:

- Planning grants in select local communities to support integration and coordination activities;
- Transportation planning grants;
- Model program development, including a rural PACE project (see section on Medicaid waiver programs for information on PACE);
- Local needs assessments;
- Support for a county-based interactive web site to provide consumers and other stakeholders with information on community services; and
- Funding for specially equipped "Info-Vans" in 33 communities to bring materials and media to neighborhood sites to provide older people and their families with community service information.

The program evaluation found that the grants enhanced local collaborations and partnerships and introduced new, replicable service strategies for meeting the needs of functionally impaired persons and older adults.[17] As of this writing, many of the projects were able to continue to some degree with local or other grant funding.

The LTC Integration Pilot Projects. Legislation in 1995 required DHS to establish a pilot project in up to five sites to integrate the delivery and funding of long-term care services, and to evaluate the results (AB 1040 -Bates, Chapter 875, Statutes of 1995). When sites are operational, they will receive a monthly capitation, or single monthly payment, for each individual, to provide services. The projects will be responsible to control utilization of services and will be "at-risk" if costs exceed the budget.

AB 1040 set minimum requirements for integration of specific long-term care programs, but gave priority to proposals combining the administration and funding for acute and long-term care services for disabled adults and seniors on Medi-Cal, not just long-term care services. Interested counties must ultimately develop a proposal detailing the program governance structure, service package and delivery system, risk-sharing arrangements with subcontractors, data reporting and quality assurance mechanisms. Counties must demonstrate that the proposal is collaborative among local health and social services agencies and include consumer input. If selected to participate, counties would submit a detailed administrative action plan.

Since the original enabling legislation, there have been several legislative interventions to assist with implementation.[18] In 1997, DHS announced a revised implementation strategy allowing counties to incrementally phase in integration activities. In 1999, the Legislature provided $1.15 million for $50,000 planning grants and $150,000 implementation grants to assist applicants with

Emerging Trends and Promising Practices in Community-Based Long-Term Care

States are using a variety of strategies to expand home and community-based services. State efforts are driven by an interest in reducing costly institutional placements and by changing consumer preferences and demographic trends. These factors have led states to focus in two key areas: empowering consumers in choosing their own care and more effectively supporting the families that are already providing the majority of long-term care. A few examples of these new program trends are highlighted below.

Family Support: Respite care programs – Families are the backbone of the long-term care system and without them many more individuals would enter institutions, often at government expense. In recognition of this, many states have increased their respite care programs. Respite care – such as adult day care, short stay programs in nursing homes and attendant care in private homes – provides a temporary break from caregiving responsibilities. As just one illustration, the Lifespan Respite programs in Oklahoma, Oregon, Nebraska and Wisconsin involve assessing and identifying local needs, recruiting respite providers, providing respite services and administering training programs for caregivers.

Consumer-Directed Care: the Cash and Counseling Demonstration. There is a growing movement to give beneficiaries more choice and control in arranging for the personal assistance they require. Consumer-directed care is based on the principle that individuals who are disabled, or their chosen advocates—not funders or providers of services—should have primary responsibility for decisions regarding the assistance they receive. Most consumer–directed programs operate under existing Medicaid requirements.

The Cash and Counseling Demonstration, co-sponsored by Robert Wood Johnson and the federal DHHS, allocates a monthly allowance or budget to participants based on what Medicaid would pay to vendors for the services. Individuals can choose to manage the funds themselves or have the funds managed for them. Using their cash benefit, consumers choose who provides these very personal and essential services (help with bathing, eating, dressing, etc.), as well as when and how they are provided. For example, consumers may hire a friend or relative, who knows their preferences, to help them on evenings or weekends when agency services may be unavailable. Consumers are also able to use their benefit to buy other services that may increase their independence (e.g. transportation, home modifications, assistive devices). Counseling and bookkeeping are offered to help consumers manage their services.

The three demonstration states -- Arkansas, Florida, and New Jersey -- are offering the cash option to elders (over 65 years old) and adults with disabilities (ages 18-64). Children with developmental disabilities are also included in Florida. Arkansas and New Jersey are cashing out services from the Medicaid optional personal care benefit, while Florida is including services from the state's Home and Community -Based Services waiver. The project is not accepting new states but negotiations are underway to make the model a permanent Medicaid optional program.

Source: Fox-Grage, W., Donna Folkemer, Brian Burwell, and Kevin Horahan. *Promising Practices in Community-Based Long-Term Care. Issue Brief*. Forum for State Health Policy Leadership. National Conference of State Legislatures. 2001.

planning activities. Additional funding established the Center for Long Term Care Integration to provide technical assistance with data analysis and other development activities. Some level of project funding has been provided in the state budget every year through 2002-03.

The lack of integration and collaboration at the state level is mirrored in many local communities where diverse agencies administer state and federal long-term care services and funding.

Participating counties have engaged in significant local planning and capacity building. Emerging models include partnerships with Medi-Cal County Organized Health Systems (COHS), local HMOs and other counties. Participating counties have held local planning meetings, public forums and stakeholder meetings. Individual counties are considering innovative approaches such as implementing universal assessment and intake forms and procedures.

According to the Assembly Committee on Aging and Long-term Care, however, counties are several years away from providing services as envisioned under the program. Some counties concluded that significantly larger infusions of development funding would be necessary to overcome challenges associated with capitation, governance, and obtaining appropriate waivers.[19] Others concluded that the program as envisioned is not appropriate for their county, but are still interested in addressing the integration issues that originally prompted the creation of the pilots. The Committee sponsored legislation in 2002 requiring DHS to develop at least one alternative model to the LTC Integration projects. (AB 3054- Committee on Aging and Long-Term Care, Chapter 537, Statutes of 2002.)

The National Family Caregiver Support Program (NFCSP). The NFCSP is a new federally funded Older Americans Act program (Title III-E) established in 2000, administered through state units on aging and local AAAs. AAAs receive funds to support caregivers who are the primary support system for spouses, parents, older relatives and friends. As is the case with all OAA programs, AAAs may provide services directly or through contracts with community providers. The programs offer caregivers: information about available services; assistance in gaining access to services; individual counseling; support groups; training to help them in making decisions and solving problems relating to their caregiving roles; and supplemental services to complement the care they are providing. The NFCSP also recognizes the needs of grandparents caring for grandchildren, caregivers of those 18 and under with mental retardation or developmental difficulties, and the diverse needs of Native Americans.

The NFCSP represents a “paradigm shift” for AAAs because the focus is explicitly on the caregiver as the client rather than the person with disabilities or

functional impairments.[20] The program represents learning and system development opportunities in this regard. The NFCSP is also a relatively limited funding source, with specific federal statutory limitations. The federal program rules may limit the ability of communities to develop innovative approaches not envisioned by the federal government.

Medicaid waivers and optional comprehensive care programs. Many of California's most innovative long-term care programs were developed as Medicaid waiver programs or as new optional Medicaid services.

- **Multipurpose Senior Services Project (MSSP).** Under a federal Medicaid Home and Community-Based, Long-Term Care Services Waiver, the MSSP program provides comprehensive case management to frail elderly persons to help them remain at home. The program began in 1977, but grew from 22 sites serving 6,000 clients in 1996 to 41 sites with the funding to serve more than 11,000 clients every month in 2001-02. Each site receives a fixed dollar payment based on a formula that ensures the federal government that the program is cost neutral in comparison to nursing home care, and uses the funds to purchase both social and health care services for older persons who wish to remain in the community. Persons over the age of 65, currently Medi-Cal eligible and certifiable for nursing facility placement based on Medi-Cal placement criteria, are eligible for MSSP.

- **Program of All Inclusive Care for the Elderly (PACE).** PACE is the national program replicating the successful On Lok Senior Health Services model program in San Francisco, a Medicare/Medi-Cal managed care program. The On Lok program began as one of the first adult day health care centers in the country in the early 1970s, and eventually grew to a comprehensive program providing complete community-based acute and chronic care services to frail elderly participants.

  The PACE model is a capitation arrangement, where the program assumes full risk for the costs of both acute and long-term care services in exchange for flat rate payments from Medicare and Medi-Cal. The model relies on a multi-disciplinary team approach to assess participant needs, develop care plans, and monitor services provided. PACE programs enroll only persons over age 55 years who are frail enough to meet state eligibility standards for nursing home care. Participants join voluntarily and agree to receive all services through PACE while enrolled.

  PACE was initially a Medicaid waiver program but the Balanced Budget Act of 1997 authorized PACE as a permanent Medicare program and as a state optional Medicaid program. There are 25 PACE sites nationally, and 4 programs in California, including the original On Lok program.

- **Social HMO.** The Social HMO expands comprehensive HMO benefits to include community-based, long-term care and some nursing home care. The Social HMO demonstration project began in 1982, and currently includes four sites nationwide. In California, the SCAN Health Plan, a Knox-Keene licensed health care service plan, was one of the original SHMO contractors. A second-wave of SHMOs was developed envisioning a somewhat revised program. While Contra Costa County initially considered participation in SHMO II, SCAN remains the only SHMO in California.

SCAN employs a staff of geriatric social workers who can design and implement a service plan for individual members. The plan may include such benefits as respite care, adult day care, in-home nursing care, home-delivered meals, homemaker services and personal care assistance. The additional benefits above standard HMO benefits are intended to keep people in the community who would otherwise be placed in skilled nursing facilities.

Quality and Accountability

California has struggled for decades to operate effective licensing programs for institutional care, and some community-based programs, hoping to ensure patient and resident safety and protection. In addition, policymakers are increasingly faced with the challenge of providing adequate reimbursement and quality oversight in alternative long-term care settings. This section highlights recent developments related to licensure of some programs. Appendix A includes additional information about licensed long-term care programs.

Nursing Home Regulation. Nursing homes in California are licensed by the DHS and subject to complex state and federal requirements, inspections and enforcement. The requirements have continued to increase in recent decades, but many still believe that nursing home quality can be improved. The general public perception of the nursing home model continues to be negative.

The number of nursing home beds in California has remained relatively static over the last decade, even though the numbers of persons needing long-term care assistance has increased. California has one of the lowest Medicaid nursing home reimbursement rates, which pays for the care of nearly 65 percent of nursing home residents.[21]

The most recent round of "nursing home reform" yielded additional protections, stiffer enforcement and also some new approaches to improving nursing home quality. Recent changes include:

- **Aging with Dignity Initiative**. Enacts major elements of the Initiative, including increased fines and penalties for regulatory violations, more timely inspections, and the first–ever cash incentive awards for facilities meeting high

quality care standards. (AB 1731 – Vasconcellos, Shelley, Chapter 451 of 2000)

- **Nursing Home Staffing Ratios**. Requires DHS to develop by August 2003 separate staffing ratios for nurses and direct caregivers in licensed nursing facilities, and to review the standards every five years. Implementation would be subject to the budget. Current statutory staffing ratios are formula-driven and combine nurse aides (direct caregivers) and licensed nurses. Also requires DHS to implement "facility-specific" Medi-Cal rates for long-term care facilities by August 2004. (AB 1075 – Shelley, Chapter 684 of 2001)

- **Centralized Consumer Response Unit**. Requires DHS to establish a centralized consumer response unit to provide consumer education and information and to initiate onsite investigations in the case of complaints that appear to have a reasonable basis. (AB 828 – Cohn, Chapter 680 of 2001)

- **Patient Transfer Protections**. Strengthens requirements on facilities transferring nursing facility residents by requiring comprehensive resident assessments prior to notice of transfer and revised requirements related to mandatory relocation plans. (SB 339 – Ortiz, Chapter 554 of 2002)

- **Temporary Nursing Agencies**. Increased regulatory requirements applicable to employment agencies that provide temporary licensed nursing staff or certified nurse assistants in licensed long-term care facilities. (AB 1643 – Negrete-McLeod, Chapter 326 of 2001)

- **Nursing Home Administrators**. Transferred the authority for licensure and regulation of nursing home administrators from the Department of Consumer Affairs (DCA) to the DHS. Also included provisions to enhance the ability of the industry to hire, train, and develop quality nursing home administrators. (AB 1409 – Chan, Chapter 687 of 2001)

- **In-Home Supportive Services Wages and Benefits.** Funding to increase wages to IHSS workers and extend health benefits to the providers for the first time.

- **Caregiver Training and Enhancement.** Allocation of federal Workforce Investment funds to support training for potential caregivers in nursing homes and IHSS programs. Increased Medi-Cal funding for nursing homes targeted to increase wages for facility employees.

- **Nursing Home Quality Improvement.** Legislative and regulatory initiatives to strengthen enforcement of standards in nursing facilities (discussed in more detail in the section on Quality and Accountability.

Assisted Living (Residential Care Facilities). A fast-growing option in the continuum of 24-hour care for persons needing long-term care assistance is the "assisted living" model. In California, assisted living facilities -- facilities offering an array of residential, non-medical care and support services -- are licensed by the California Department of Social Services (CDSS) as Residential Care Facilities for the Elderly (RCFEs), Adult Residential and Residential Care Facilities for the Chronically Ill. These categories include residential care programs that take many forms, including assisted-living, board and care homes, adult congregate care and small family homes. The different facility types have similar but not identical statutory requirements, with the RCFE model having more specific provisions related to the care and supervision of elderly residents.

Facilities vary in size, from small facilities with fewer than six beds, to facilities with more than 100 beds. The majority of facilities have fewer than 16 beds,[22] but given the increasing numbers of very large facilities, the majority of residents live in large facilities. By law, no more than 2 people can occupy a room and the market trend is toward more private rooms or private apartments with private baths.

While the number of nursing home beds in California has stayed relatively static, the number of RCFEs has more than doubled.[23] As consumer preferences have moved toward the assisted living model, the regulatory climate has also changed to allow individual's with higher care needs to live in and remain in these non-medical facilities.

In general, facilities must petition the CDSS and obtain individual waivers for specific residents who have special conditions, but CDSS is in the process of preparing regulations that would generally authorize many of the conditions now covered by waivers, as long as specific staffing and service requirements are met. There are currently no specific staffing requirements for residential care facilities. When there are changes in the types of residents and services permitted, the statute or regulation typically calls for increased training for administrators and/or facility staff, mostly in the form of required continuing education classes. Some of the recent changes include:

- Allowing RCFEs to obtain a waiver to care for a terminally ill person under hospice care;

- Specifying allowable health-related conditions facilities can manage, such as catheter care, and the requirements facilities must meet to care for residents with the conditions; and

- Allowing facilities to advertise and promote themselves as offering specialized dementia care, with regulations currently in process to address necessary safeguards.

Adult Day Care Programs. Adult day care facilities are licensed either as adult day health care (ADHC) facilities by the Department of Health Services (DHS) or as adult day care facilities by the CDSS.

ADHCs are subject to oversight by both DHS and CDA. ADHCs are licensed as health facilities by the DHS and provide comprehensive health, rehabilitative and social services to frail elderly and disabled persons who are at the institutional level of care or at-risk of institutionalization. ADHC is Medi-Cal reimbursable and ADHCs are certified for Medi-Cal participation by the CDA.

Adult day programs are licensed by CDSS as non-medical facilities, sometimes referred to as "social model" day care, and must meet the requirements of a less rigorous regulatory framework. The specialized Alzheimer's Day Care Resource Centers (ADCRCs) are licensed under this program and receive state grant funds through the local AAAs.

As in the residential continuum, adult day care programs confront the continuing issues of meeting patient needs within the restrictions of two very different licensing models. Although the state licensing framework envisions two options: a health facility model and a distinct social or non-medical model, participant needs are much more complex since chronic health conditions typically underlie their need for support and assistance.

Assisted Living Medicaid Benefit. The DHS is currently tasked to develop a Medicaid waiver to allow for reimbursement of personal care services and other supportive services offered in the assisted living model (AB 499 – Aroner, Chapter 557, Statutes of 2000). DHS has issued an RFP for an external consultant to assist in the design and fiscal analysis of the waiver project. The assisted living waiver approach is somewhat limited by the federal Medicaid requirement that states show budget neutrality.

Financing and Fiscal Constraint

As of this writing, California is facing a multi-billion dollar funding crisis, with the potential to dramatically alter the level and type of services available in most areas of state spending, including long-term care. The magnitude of the looming deficit is prompting re-examination of programs, funding and administrative responsibility. The fiscal crisis also threatens to unravel many of the recent gains in funding and availability of home and community-based services. In addition, the proposed cuts in Medi-Cal provider rates would affect long-term care programs such as nursing homes and adult day health care services.

Long-Term Care Realignment. As part of a comprehensive realignment proposal for health and human services programs, the 2003-04 Governor's Budget proposes to transfer fiscal responsibility for the two largest long-term care programs – IHSS and Medi-Cal nursing home stays -- to the county level, along

with dedicated revenues to support the programs. The Governor proposes to retain state level oversight of the two programs. The proposal included the potential for counties to be able to transfer funds among realignment programs, so they can "meet their financial obligation" under the IHSS program. As of this writing, there are few details on the proposal and many unanswered questions.

Program Reductions. The Governor proposed mid-year 2002-03, as well as budget year reductions and program eliminations that affect an array of long-term care programs and would reduce the availability of home and community-based services. Many of the proposed reductions would undo the recent increases that resulted in additional home and community-based programs in underserved communities. In addition, wage increases for nursing home and IHSS workers would be rolled back under the Governor's proposals.

V. Policy Considerations

Policymakers now confront increasing demand for LTC services; especially programs and services that help individuals remain independent at home. At the same time, government revenues are shrinking. This section highlights some of the broader policy concerns and potential conflicts that accompany these converging trends.

Managing government resources. Just as the demand for long-term care services can be expected to grow dramatically as the number of older persons continues to increase, government at all levels is facing serious fiscal challenges. Political support for home and community-based services has been increasing because of the high costs of institutional long-term care services and voter preferences. At the same time, some are also concerned that making more options available could lead to new demands for services, and in the process, drive up long-term care costs. How can government develop a comprehensive array of long-term care services, including the full compliment of home and community-based services, while effectively managing available resources?

Maximizing Personal Choice and Independence. Individuals with disabilities and their families often need assistance in identifying the best services, and the most appropriate level of care, to meet their needs. Multiple assessment and case management programs have been developed out of this recognized need to help families and individuals with disabilities navigate the complex service systems. These programs can help to overcome the confusion that the fragmented and complex delivery system presents. At the same time, assessment and "case management" programs focus, to some degree, on external judgment of what services are needed, rather than relying primarily on the personal choice of the individual and their families. The terminology in the field already is evolving in recognition of this tension, as "case management" programs become "care coordination" services. However, federal and state funding streams often set out the design of the programs and the services that can be provided, with narrow

eligibility rules. These restrictions can limit the ability of individuals to make their own choices and direct their own care. How can government develop targeted programs that serve those most in need? How can agencies provide information resources to help families access appropriate services and at the same time facilitate maximum personal choice and independence for those needing services?

Balancing Individual Choice with Safety and Protection. In its review of long-term care programs in 1996, the Little Hoover Commission highlighted the inherent conflict as government seeks to establish rules and standards for quality and patient protection. There is a growing consumer movement for individuals to "age in place," to continue to reside in familiar surroundings – in a senior housing complex, even though it may not have any on-site support services; at home under the care of family members; in a residential setting without the accouterments of a health facility. In many of these cases, however, the choice a person makes could be less than "safe." There may be insufficient supervision. The facilities may not be designed to offer proper support or safe conditions. From a purely protection viewpoint, it may make sense for them to move to an alternative setting. How can government balance the need to ensure basic health and safety with the legitimate interest in respecting individual choice and autonomy?

How can government balance health and safety with individual choice and autonomy?

Encouraging and Supporting Innovation. Licensed facilities and other government-recognized programs confront an enormous diversity in resident and client needs. At the same time, government funding streams and licensure laws establish narrow service categories, eligibility criteria and regulatory requirements. Funding streams flow to specific government defined programs with strict eligibility. Rigid standards and clear rules may be easier to regulate and monitor and can help to control program expenditures. However, these well-intentioned quality standards limit the ability of programs and providers to effectively develop programs that can be responsive to the diverse needs of clients. How can government establish clear standards and accountability for programs and funding, while also permitting sufficient flexibility to make sure that programs can and do respond to changing client needs?

VI. Policy Options

This section includes a series of policy options presented as alternatives that policymakers may wish to consider.

Planning and System Development

Consolidate key long-term care programs into one state agency. Given the serious fiscal crisis facing the state, and the continued overlap and duplication among state agencies dealing with long-term care programs, the time may be right to establish a Department of Adult Services that combines the CDA, adult programs at CDSS, such as IHSS, and other related programs, such as Independent Living Centers. The single state agency requirement of the federal Medicaid program has historically stalled efforts to include the DHS long-term care programs. This may continue to prevent complete integration of all of the key LTC programs. There is, however, sufficient value in consolidating many even if not all programs into one department. Such a proposal could retain the LTC Council to ensure coordination among remaining programs and departments but could also position a larger, more consolidated department to take the lead in the development of the home and community-based long-term care system. Diverse programs with distinct histories and philosophies could learn from each other in creating a new culture of long-term care service delivery and development that is more reflective of the emerging needs of a changing population of individuals with disabilities needing care and services.

Maximize the LTC Council. The newly established LTC Council should be the focus for LTC planning and program development, effective oversight and accountability for the delivery of LTC programs in the state. Planning requirements, research studies, and reporting requirements related to long-term care services should be coordinated through the Council. All proposals for streamlining, budget reductions and re-organization should be evaluated and coordinated by the Council. The Legislature should look to the Council to provide leadership, oversight, accountability and coordinated information on California's LTC programs.

Enhance Legislative Coordination and Oversight. To some extent, the Legislature has also mirrored a fragmented approach to LTC policy development, segregating legislation and oversight by department, committee of jurisdiction or budgetary funding source. Legislation is often developed and adopted as single issue, single interest bills. In addition, policy activity moves from one legislative session to the next, with limited focus or opportunity for oversight and holding agencies accountable for effective implementation of legislative mandates. The Legislature might consider more joint legislative committee hearings, including hearings focused on oversight and agency accountability. In addition, the

Legislature could require annual presentation and review of a long-term care budget facilitating oversight and analysis of the system as a whole.

Infrastructure and Program Development

Prioritize direct services and home and community-based care. Given the state's financial crisis, it is more important than ever to explicitly and clearly prioritize funding and support for programs that provide direct care and support to elderly and disabled persons, and their caregivers. The highest priority should be home and community-based services. This will mean tough choices and potentially devastating short-term impacts on administrative capacity in state agencies. Given the choice between services and bureaucracy, services should come first.

Promote, facilitate and support innovations at the local level. Even though there must be ongoing state activities to improve coordination and consolidation of programs, in the meantime, local communities must be free to be creative and to find new ways of working together. As long as there are basic assurances that funds will be used for the purpose of long-term care support, California should simplify funding and regulatory requirements to allow local agencies to consolidate funding streams. They must be able to overcome duplicate requirements and conflicting eligibility criteria to meet community needs. The LTC Innovation Grant program was a unique example of tapping the experience, knowledge and diversity of local agencies and providers through a more open-ended grant program that did not predefine the programs and services that could be funded.

Any strategy to shift responsibilities, funding or accountability among agencies or levels of government must include basic protections to reduce or eliminate service disruption and to ensure quality.

Explicitly support policies and programs for caregivers. While existing programs may effectively help families in caring for a disabled loved one, the new NFCSP has really highlighted the distinction of focusing on the caregiver as the client. Future policy development must more effectively take into account the needs of caregivers and families and affirmatively support them as the backbone of the long-term care system.

Quality and Accountability

Streamline and Consolidate State Licensing programs. In order to develop the most effective range of LTC options, and ensure the basic health and safety of residents and participants, a consolidated licensing program might reduce or eliminate the artificial distinctions between medical and non-medical services and

programs. To accomplish this, licensing programs within DHS and DSS could be consolidated. The LTC Council work group on this topic recommended state-level consolidation of the licensing programs, but the report has not been reviewed or acted on by the Council. In addition, the balance must be found in protecting consumer interests without over regulating or discouraging innovation. For example, allowing individuals with higher care needs to stay in lower levels of care may be responsive to consumer preferences, but government has an obligation to ensure that basic protections and adequate supervision are also in place.

Ensure Minimum Quality and Service Standards. Although flexibility and openness can facilitate innovation, minimum quality and service standards are also paramount. Any strategy to shift responsibilities, funding or accountability among agencies or levels of government must include protections to reduce or eliminate service disruption or poor service quality for recipients. Facilities charged with the care of frail and vulnerable residents, providing medical or non-medical care, must have adequately trained staff and resources to ensure resident safety.

Financing and Fiscal Constraint

Maximize the Use of Federal Funds. California should continue existing federal waiver programs in LTC and identify all opportunities to expand available federal resources for LTC through additional Medicaid waivers and or added Medicaid optional benefits, such as the assisted living benefit.

Increase revenues available for LTC programs. As the state weathers an unprecedented fiscal crisis, there will be ongoing discussions about the need and the advisability of increasing revenues to meet the demands for state services. One element of the discussion will be perceived public support for key programs and for the proposed revenue increases. In June 2002, AARP reported the results of a scientifically conducted opinion research poll showing that nine in ten Californians rate the need to maintain current health and long-term care services very high.[24] At least two-thirds of those surveyed supported an increase in tobacco taxes and temporarily restoring the 10 and 11 percent income tax brackets to support health and long-term care services.

VII. Conclusion

California has made progress in recent years in developing and expanding the array of long-term care options available, with increasing emphasis on home and community-based services. At the same time, the current service system continues to be disjointed and overly complex, often serving the needs of the bureaucracies rather than the needs of consumers.

Long-term care policy is really at a critical juncture, facing significant increasing demand for services at the very same time that governments are experiencing fiscal constraints of a magnitude that is nearly unimaginable. Now more than ever is the time for critical review of where we have been and where we need to be going in long-term care policy in California. Now is the time to examine existing funding and administrative structures to ensure efficiency and competency, with the goal of providing the LTC services older adults and persons with disabilities, and their families, need and deserve.

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Appendix A
Overview of Long-Term Care Programs and Options

TYPE OF SERVICE	DESCRIPTION	PROGRAMS	POPULATION SERVED	STATE AGENCIES INVOLVED
Nursing Homes	Licensed health facilities providing 24-hour nursing services	Skilled nursing facilities Intermediate care facilities Skilled nursing units in licensed hospitals Developmental centers State hospitals and veteran's homes	Elderly and disabled persons needing 24-hour nursing supervision	Department of Health Services (DHS) – Licensure, certification and Medi-Cal payments Department of Developmental Services (DDS) – Operation of developmental centers and oversight of facilities for the developmentally disabled California Department of Aging (CDA) – Oversees local long-term care ombudsmen programs that investigate complaints of abuse
Assisted living Nonmedical out-of-home care	Licensed nonmedical facilities providing 24-hour care and supervision	Adult Residential Care Facilities Residential Care Facilities for the Chronically Ill Residential Care Facilities for the Elderly (RCFEs) May also be called board and care homes, community care facilities	Persons who need (or anticipate that they may need in the future) 24-hour care and supervision, such as personal care, medication assistance, meals, etc.	California Department of Social Services (CDSS) – Licenses facilities and administers the SSI/SSP cash grant for residential care CDA – Oversees local long-term care ombudsmen that investigate complaints of abuse DDS – Provides services to eligible residents in community care facilities
Adult day care programs	Licensed facilities offering a range of health, therapeutic and social services, depending on the facility type and licensure, on a less than 24-hour basis.	Adult day health care Adult day care Alzheimer's Day Care Resource Centers	Elderly and disabled adults with various levels of physical and mental impairment and service needs	CDA – Provides oversight and funding to adult day programs through AAAs DHS – Licensure, certification and Medi-Cal payments for adult day health care CDSS – Licenses adult day programs without a substantial health component

Appendix A
Overview of Long-Term Care Programs and Options

TYPE OF SERVICE	DESCRIPTION	PROGRAMS	POPULATION SERVED	STATE AGENCIES INVOLVED
Personal care or chore services in the home	Assistance in the home setting with personal care and other daily activities	In-Home Supportive Services (IHSS) OAA Home-delivered meals OAA Title III-B Home health agency personal care	Disabled persons needing assistance to remain in their homes OAA programs limited to persons 60 and over	CDA – Provides funding for chore services through AAAs CDSS – Administers the IHSS program through county welfare departments DHS – Coordinates Medi-Cal funding for IHSS and licenses home health agencies
Home health care	Health-related long-term care services in the home, including skilled nursing, therapy and medication assistance	Licensed public and private home health agencies	Individuals with time-limited nursing care needs	DHS – Administers Medi-Cal program and licenses home health agencies Centers for Medicare and Medicaid Services (CMS) – (federal) Medicare covers limited home health services
Hospice	Support services for individuals with a terminal illness, emphasizing pain management, symptom relief and family support	Hospitals, skilled nursing facilities, home health agencies and other providers offering the hospice model of services and support Typically certified as hospice providers by Medicare and Medi-Cal	Terminally ill persons	DHS – Administers Medi-Cal program and licenses home health agencies Medicare program covers hospice services for eligible recipients
Respite Care	Substitute care for disabled individuals to relieve the primary caregiver	Respite can result from a number of existing programs, including short stays in 24-hour facilities, participation in day programs, or in-home personal care assistance Purchase of service program (CDA) OAA supportive services Caregiver Resource Centers	Families and other informal caregivers of disabled persons OAA funds limited to services in support of persons 60 and over	CDA – Administers through AAAs purchase of service funds to provide respite care to caregivers of elderly and disabled adults Department of Mental Health (DMH) – Funds and oversees the Caregiver Resource Centers

Appendix A
Overview of Long-Term Care Programs and Options

TYPE OF SERVICE	DESCRIPTION	PROGRAMS	POPULATION SERVED	STATE AGENCIES INVOLVED
Case Management / Care Planning	Working with individuals and families to help assess service needs; develop care plans; and identify, authorize, coordinate and/or arrange for services	Linkages - information and case management programs Multipurpose Senior Services Program (MSSP) OAA Case Management and Information and Assistance programs and the Family Caregiver Support Program Regional Centers for the Developmentally Disabled Independent Living Centers Caregiver Resource Centers	Elderly and disabled persons and their families, depending on the program design and criteria	CDA – Administers through AAAs the OAA funded programs and Linkages, MSSP and the Family Caregiver Support program DHS – Coordinates funding of the federal Medicaid waivers for MSSP DDS – Funds and oversees the regional center system Department of Rehabilitation – Funds and oversees Independent Living Centers DMH – Funds and oversees the Caregiver Resource Centers
Comprehensive Integrated Services	Organized programs to coordinate and integrate an array of health and long-term care services to keep at-risk individuals at home in the community	MSSP Program of All Inclusive Care for the Elderly (PACE) Social HMOs	Limited to elderly persons who are Medi-Cal and/or Medicare eligible	CDA – Administers through AAAs the MSSP local programs DHS – Coordinates funding of the federal Medicaid waivers for MSSP and other waiver programs, and oversees the PACE and Social HMO projects through the Office of Long Term Care